The development and evaluation of a community-based rehabilitation intervention for people with schizophrenia in Ethiopia

Laura Asher

TABLE OF CONTENTS (VOLUME II)

Appendix A (Chapter 4: Systematic review)

Appendix A (i): Medline search strategy

Note minor amendments were made to conduct the search in other databases

A: Schizophrenia

1. Psychotic disorders/
2. Exp Schizophrenia/
3. Exp Psychotic affective disorders/
4. (Schizophreni* or psychosis or psychoses or psychotic or schizoaffective or Schizophreniform).tw
5. Or/1-4

B: Community-based psychosocial intervention

Psychotherapy

6. exp Psychotherapy/
7. exp Counseling/
8. Schizophrenic psychology/
9. (Psychotherapy or counselling or counseling or therapy or interpersonal therapy or cognitive behavio?ral therapy or art therapy or music therapy or brief intervention or cognitive retraining or cognitive rehabilitation).tw

Psycho-education

10. Health Education/
11. Patient Education as Topic/
12. (psychoeducation* or psycho-education*).tw
13. (Patient* or caregiver* or care-giver* or carer* or family or families) adj3 (education or advice or information or training or support or intervention or livelihood).tw

Family

14. Caregivers/
15. Family relations/
16. ((family or families or carer or caregiver or care-giver) adj3 burden).tw

Adherence

17. exp Patient Compliance/
18. patient adj3 (compliance or concordance or adherence).tw
19. (antipsychotic* or anti-psychotic* or medication*) adj3 (compliance or concordance or adherence or non-compliance or non-concordance or non-adherence).tw
20. (Adherence or compliance or medication) adj3 (support or therapy or education or training or advice or information or intervention).tw

Rehabilitation

21. exp Rehabilitation/ or Rehabilitation Nursing/ or exp Rehabilitation Centers/
22. Social Adjustment/
23. Cooperative behaviour/
24. Interpersonal relations/
25. Social inclusion.tw
26. (community based rehabilitation or community-based rehabilitation or CBR).tw
27. (rehabilitat* adj3 (home based or home-based or communit*)).tw
28. (Communit* adj3 (vocational training or apprenticeship* or employment placement service* or support network* or self-employ* or supported employ* or social service* or social work*)).tw
29. (Communit* adj3 (personal assistance or personal assistant* or individual support* or disabled people* organi?ation*)).tw
30. (Communit* adj3 (empower* or awareness campaign* or self-advocacy or self-help group* or support group* or women* group* or development group*)).tw
31. (Communit* adj3 inclusi* adj3 (health or education or hous* or social or justice or empower*)).tw
32. Rehabilitation adj3 (vocational or social or personal).tw

33. Training adj3 (Life skill* or social skill* or personal skill* or interpersonal skill* or interpersonal).tw
34. Psychosocial or psycho-social or social or psychological or psychiatric or PSR or vocational or occupational adj3 (intervention* or support or rehabilitation).tw
35. Sustainable livelihood* or livelihood* adj3 (intervention or support).tw
36. Recovery or recovery model or recovery approach or social recovery.tw

Health promotion

37. Health promotion/
38. Health adj3 (promotion or advice or information or training or support).tw

Support group

39. social support/
40. Self-Help Groups/
41. (Social or peer* or peer-led or peer led or self help or self-help or community or cooperative or co-operative) adj3 (group or support or support group).tw

Collaborative/ primary/ community-based care

42. care adj3 (Collaborative or community or community-based).tw
43. (outreach adj3 (service* or care or intervention* or program*)).tw
44. Exp Primary Health Care/
45. Community health services/
46. Home Care Services/
47. Home nursing/
48. Community health nursing/
49. Community networks/ or community mental health services/
50. patient care team/
51. nursing, team/
52. exp social work/
53. community health centers/
54. community mental health centers/
55. community health workers/
56. Outpatients/
57. Ambulatory care facilities/ or outpatient clinics, hospital/
58. Ambulatory care/
59. allied health personnel/
60. nurses aides/
61. psychiatric aides/
62. (nonspecialist* or non-specialist* or allied health or nurse led or community health or village health adj3 (worker* or personnel or team*)).tw
63. or/6-62

C: Low and middle-income countries

64. developing countries/
65. (Africa or Asia or Caribbean or West Indies or South America or Latin America or Central America).hw,kf,ti,ab,cp
66. (Afghanistan or Albania or Algeria or Angola or Antigua or Barbuda or Argentina or Armenia or Armenian or Aruba or Azerbaijan or Bahrain or Bangladesh or Barbados or Benin or Byelarus or Byelorussian or Belarus or Belorussian or Belorussia or Belize or Bhutan or Bolivia or Bosnia or Herzegovina or Hercegovina or Botswana or Brazil or Bulgaria or Burkina Faso or Burkina Fasso or Upper Volta or Burundi or Urundi or Cambodia or Khmer Republic or Kampuchea or Cameroon or Cameroons or Cameron or Camerons or Cape Verde or Central African Republic or Chad or Chile or China or Colombia or Comoros or Comoro Islands or Comores or Mayotte or Congo or Zaire or Costa Rica or Cote Ivoire or Ivory Coast or Croatia or Cuba or Cyprus or Czechoslovakia or Czech Republic or Slovakia or Slovak Republic or Djibouti or French Somaliland or Dominica or Dominican Republic or East Timor or East Timur or Timor Leste or Ecuador or Egypt or United Arab Republic or El Salvador or Eritrea or Estonia or Ethiopia or Fiji or Gabon or Gabonese Republic or Gambia or Gaza or Georgia Republic or Georgian Republic or Ghana or Gold Coast or Greece or Grenada or Guatemala or Guinea or Guam or Guiana or Guyana or Haiti or Honduras or Hungary or India or Maldives or Indonesia or Iran or Iraq or Isle

of Man or Jamaica or Jordan or Kazakhstan or Kazakh or Kenya or Kiribati or Korea or Kosovo or Kyrgyzstan or Kirghizia or Kyrgyz Republic or Kirghiz or Kirgizstan or Lao PDR or Laos or Latvia or Lebanon or Lesotho or Basutoland or Liberia or Libya or Lithuania or Macedonia or Madagascar or Malagasy Republic or Malaysia or Malaya or Malay or Sabah or Sarawak or Malawi or Nyasaland or Mali or Malta or Marshall Islands or Mauritania or Mauritius or Agalega Islands or Mexico or Micronesia or Middle East or Moldova or Moldovia or Moldovian or Mongolia or Montenegro or Morocco or Ifni or Mozambique or Myanmar or Myanma or Burma or Namibia or Nepal or Netherlands Antilles or New Caledonia or Nicaragua or Niger or Nigeria or Northern Mariana Islands or Oman or Muscat or Pakistan or Palau or Palestine or Panama or Paraguay or Peru or Philippines or Philipines or Phillipines or Phillippines or Poland or Portugal or Puerto Rico or Romania or Rumania or Roumania or Russia or Russian or Rwanda or Ruanda or Saint Kitts or St Kitts or Nevis or Saint Lucia or St Lucia or Saint Vincent or St Vincent or Grenadines or Samoa or Samoan Islands or Navigator Island or Navigator Islands or Sao Tome or Saudi Arabia or Senegal or Serbia or Montenegro or Seychelles or Sierra Leone or Slovenia or Sri Lanka or Ceylon or Solomon Islands or Somalia or Sudan or Suriname or Surinam or Swaziland or Syria or Tajikistan or Tadzhikistan or Tadjikistan or Tadzhik or Tanzania or Thailand or Togo or Togolese Republic or Tonga or Trinidad or Tobago or Tunisia or Turkey or Turkmenistan or Turkmen or Uganda or Ukraine or Uruguay or USSR or Soviet Union or Union of Soviet Socialist Republics or Uzbekistan or Uzbek or Vanuatu or New Hebrides or Venezuela or Vietnam or Viet Nam or West Bank or Yemen or Yugoslavia or Zambia or Zimbabwe or Rhodesia).hw,kf,ti,ab,cp

67. ((developing or less* developed or under developed or underdeveloped or middle income or low* income or underserved or under served or deprived or poor*) adj (countr* or nation? or population? or world)).ti,ab
68. ((developing or less* developed or under developed or underdeveloped or middle income or low* income) adj (economy or economies)).ti,ab
69. (low* adj (gdp or gnp or gross domestic or gross national)).ti,ab
70. (low adj3 middle adj3 countr*).ti,ab.
71. (lmic or lmics or third world or lami countr*).ti,ab.
72. transitional countr*.ti,ab.
73. Or/64-72 (4137)

D: Controlled study

74. randomized controlled trial.pt
75. controlled clinical trial.pt.
76. multicenter study.pt.
77. (randomised or randomized or randomly).ti,ab
78. placebo.ti,ab
79. trial.ti,ab
80. groups.ti,ab.
81. intervention.ti,ab.
82. evaluat*.ti,ab
83. control*.ti,ab.
84. effect?.ti,ab.
85. impact.ti,ab
86. (time series or time points).ti,ab.
87. ((pretest or pre test) and (posttest or post test)).ti,ab.
88. (quasi experiment* or quasiexperiment*).ti,ab
89. ((multicentre or multicentre or multi centre or multi center) adj study).ti,ab.
90. Or/ 74-89

5 and 63 and 73 and 90

Appendix A (ii): Reasons for exclusion of full texts

Reference	Reason for exclusion
Arslan 2014	Non-eligible intervention (health facility only)
Bio 2011	Non-eligible intervention (work placement only)
Barretto 2009	Non-eligible intervention (health facility only)
Dikec 2016	Non-eligible intervention (health facility only)
Farooq 2011	Non-eligible intervention (health facility only)
Gohar 2013	Non-eligible intervention (health facility only)
Guo 2010	Non-eligible intervention (health facility only)
Hasan 2015	Non-eligible intervention (telephone contact / health facility only)
Idaiani 2015	Non-eligible methodology (historical/ retrospective cohort)
Kooalee 2010	Non-eligible intervention (health facility only)
Kulhara 2009	Non-eligible intervention (health facility only)
Kumar 2008	Non-eligible intervention (health facility only)
Li 2015	Non-eligible intervention (health facility only)
Maneesakorn 2007	Non-eligible intervention (health facility only)
Naeem 2015	Non-eligible intervention (health facility only)
Padma Sari 2014	Non-eligible intervention (health facility only)
Pan 2011	Non-eligible intervention (health facility only)
Paranthaman 2010	Non-eligible intervention (health facility only)
Pontes 2013	Non-eligible intervention (health facility only)
Prost 2013	Non-eligible intervention (health facility only)
Razali 2015	Non-eligible methodology (historical/ retrospective cohort)
Sharif 2012	Non-eligible intervention (health facility only)
Tao 2012	Non-eligible intervention (health facility only- day centre)
Tas 2012	Non-eligible intervention (health facility only)
Valencia 2013	Non-eligible intervention (health facility only)
Valencia 2012	Non-eligible intervention (health facility only)
Valencia 2007	Non-eligible intervention (health facility only)
Valencia 2010	Non-eligible intervention (health facility only)
Wang 2013a	Non-eligible intervention (health facility only)
Wang 2013b	Non-eligible intervention (health facility only)
Xiang 2006	Non-eligible intervention (health facility only)
Xiang 2007	Non-eligible intervention (health facility only)
Xiong 1994	Non-eligible intervention (health facility only)
Yildiz 2004	Non-eligible intervention (health facility only)
Yildirim 2015	Non-eligible intervention (health facility only)
Zhang 1993	Non-eligible intervention (health facility only)
Zhang 1998	Non-eligible intervention (health facility only)
Zhang 2014	Non-eligible intervention (health facility only)
Zhou 2014	Non-eligible intervention (health facility only)
Zhou 2015	Non-eligible intervention (health facility only- day centre)
Zimmer 2007	Non-eligible intervention (health facility only)

Appendix A (iii) Additional meta-analyses

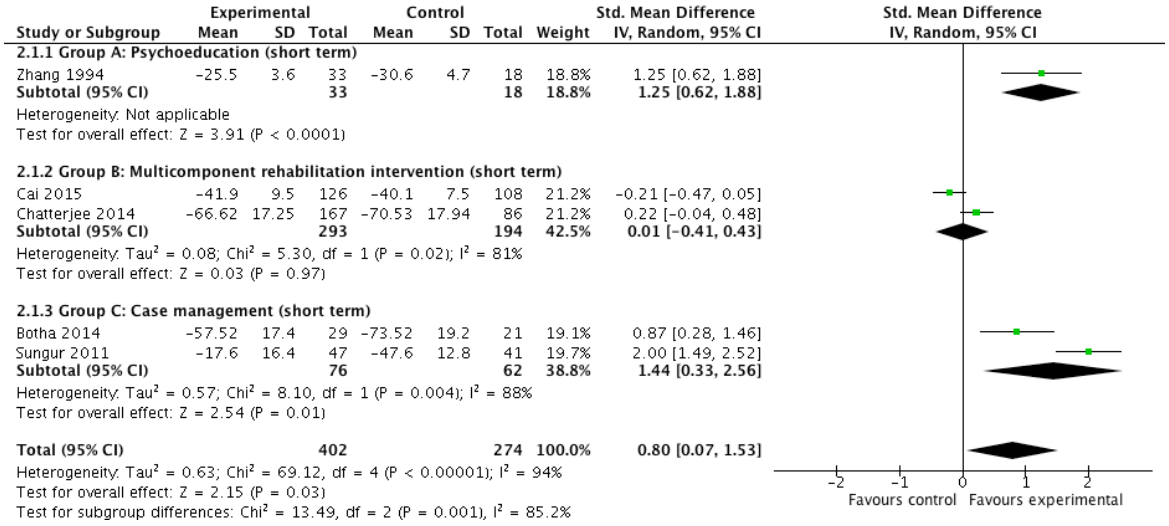

Figure 1 Community-based psychosocial intervention versus usual care: impact on symptom severity (short term and high quality studies)

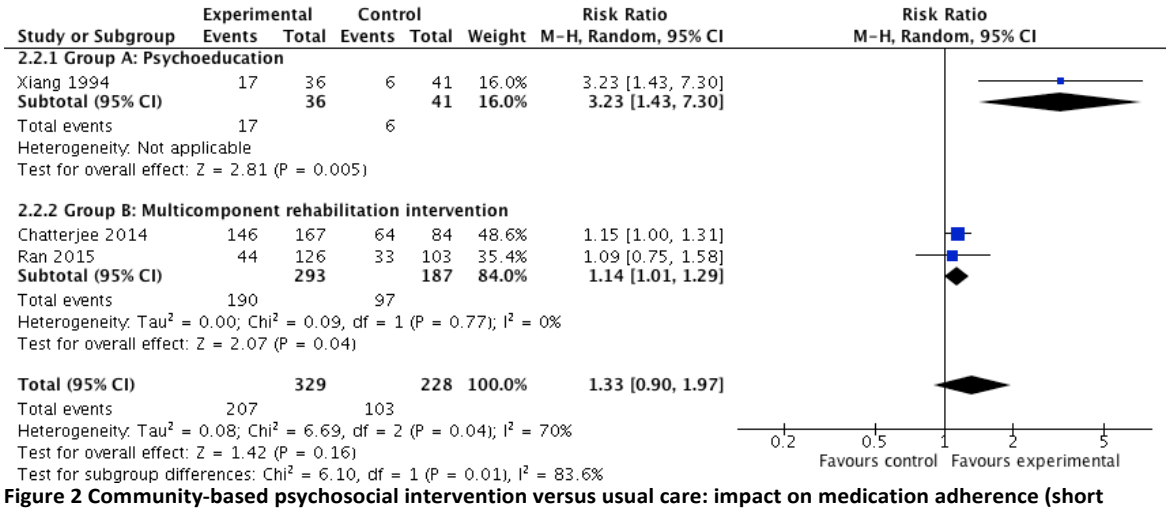

Figure 2 Community-based psychosocial intervention versus usual care: impact on medication adherence (short term and high quality studies)

Appendix B (Chapter 5: Intervention development)

Appendix B (i): Ethical approval for intervention development work

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Observational / Interventions Research Ethics Committee

Mary De Silva
Senior Lecturer
DPH / EPH
LSHTM

16 May 2013

Dear Dr. De Silva,

Study Title: **Formative study for a cluster-randomized trial: RISE (Rehabilitation In the community for people with Schizophrenia in Ethiopia)**
LSHTM ethics ref: **6408**

Thank you for your application of 8 April 2013 for the above research, which has now been considered by the Observational Committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

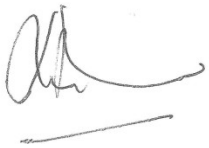
The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
LSHTM ethics application	n/a	7/04/2013
Protocol including Information Sheet & Consent Form	1.4	15/03/ 2013

After ethical review

Any subsequent changes to the application must be submitted to the Committee via an E2 amendment form. All studies are also required to notify the ethics committee of any serious adverse events which occur during the project via form E4. At the end of the study, please notify the committee via form E5.

Yours sincerely,



Professor John DH Porter
Chair
ethics@lshtm.ac.uk
http://intra.lshtm.ac.uk/management/committees/ethics/

Appendix B (ii): Intervention development information sheets and consent forms

INFORMATION SHEET FOR PARTICIPANTS

IRB Reference Number: 084/11/Psy

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Formative study for PRIME (Programme for Improving Mental healthcare)

We would like to invite you to participate in this original research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. This study is being conducted by Addis Ababa University.

Aims of the research

This study is looking at the acceptability and feasibility of a community-based rehabilitation programme for people with schizophrenia and their families.

Who are we recruiting?

We are including people with schizophrenia, their families or main caregivers, workers currently delivering CBR and their supervisors, health extension workers and their supervisors, traditional healers, community leaders, health administrators and policy makers.

What will happen if you agree to take part?

In-depth interviews

You will be invited to participate in a one-to-one interview. The interviews will usually be held at your workplace or home, or another place that is convenient for you. You will be asked some questions about your perceptions about the acceptability, feasibility and effectiveness of CBR for schizophrenia. The interview will last up to one hour. With your agreement, we will audio-tape the interview.

Discussion group

The discussion groups will be located at a central location within your town of residence/work. There will be between 6 and 10 people in the group, as far as possible with a similar background to you; for example, there will be separate groups for caregivers of people with schizophrenia, CBR workers and Health Extension Workers. The group will be asked some questions about their experiences and perceptions regarding community-based rehabiltiation for people with schizophrenia. You will be invited to contribute your opinion as part of the discussion, although there is no obligation for you to speak during the group discussion. The discussion will take between 1 and 2 hours. If all participants give agreement then we will tape-record the discussions and interview. You will be given refreshments and reimbursed for your transport costs and time.

Risks of being in the study

We don't expect that the discussion will cause you any difficulties. On rare occasions, people might be upset by the questions that are being asked. If you are distressed by the questions then you do not have to answer the question or you can leave the group at any time.

Possible benefits

Information obtained through these discussions will be instrumental in developing a CBR programme for people with schizophrenia in Ethiopia. We hope this will improve the care of people with schizophrenia in Ethiopia and other similar countries.

Once the overall study is completed, we will let you know what we found, either by inviting you to a meeting, giving you a leaflet or publicising our findings in the district.

What we will do with your data

If you take part in the tape-recorded discussion, we will make sure that the tapes do not include your name or identifying information. If notes are taken instead of tape-recording, these notes will not include your name or identifying information. The tapes and notes will be kept in a locked cupboard. Once the interview tapes have been written down, and the data has been analysed, the tapes will be cleared. Nobody except the project co-ordinators and project data managers will know that the information belongs to you. We will keep the questionnaires in a locked cupboard. After the end of this study, the information you tell us may be used by other researchers, but they will not be able to identify you in any way.

Main researchers:

Dr Abebaw Fekadu, Dr Charlotte Hanlon and Dr Laura Asher. You can contact us on telephone number 0112756434 from Monday to Friday during working hours.

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time and without giving a reason.

If this study has harmed you in any way you can contact the Institutional Review Board, Addis Ababa University, using the details below for further advice and information:

- Institutional Review Board, School of Medicine, Addis Ababa University
  Telephone number: 0115-5538734

- You may withdraw your data from the project at any time up until it is transcribed for use in the final report.
- If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of study: Formative study for Programme for Improving Mental healthcare (PRIME)

Addis Ababa University Research Ethics Committee Ref: 084/11/Psy

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

- I understand that if I decide at any time during the research that I no longer wish to participate, or for my child to participate, in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up until they are published.
- I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the national data protection rules.
- If I am selected to be interviewed in more detail then I consent to that interview being audio-taped.
- The information you have submitted will be published as a report. Please note that confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.
- I agree that the research team may use anonymized data for future research.

Participant's Statement:

I _____
agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed **Date**

Witness Statement (in event that participant is not literate):

I _____
agree that the research project named above has been explained to _____ (participant) to her satisfaction and that she agrees to take part in the study. Both the notes written above and the Information Sheet about the project have been read to her, and she understands what the research study involves.

Signed **Date**

Investigator's Statement:

I _____
Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.
Signed **Date**

Appendix B (iii): Intervention development qualitative topic guides

RISE Topic guide for IDIs/FGDs with participants and caregivers

Researchers from Addis Ababa University are looking at ways to improve the care of people with mental illness. In particular they want to develop community-based rehabilitation to help people to recover from their illness and get back to their usual activities. Community-based rehabilitation would be delivered in the kebele to people with mental illness and their family by specially trained community health workers. People who received community-based rehabilitation would also continue to attend their health centre or hospital outpatient clinic to get their medication. We are interested in your views on these ideas.

1. **Unmet needs**

   Are there any areas where additional support or treatment for you/ your family member's mental health problems could help you or your family member more?

   Probes

   Have you had any problems with your home life?

   Have you had any difficulties doing the jobs you need to do? E.g. housework or farming?

   Have you had any problems getting back to your usual life? E.g. getting involved in social or community activities or going to church

   Do you/ your family member need help accessing medication?

   Do you/ your family member need help remembering to take medications?

2. **Experience of restraint**

   Have you/your relative had any experience of being chained or tied up?

   Probes

   How long were you/ your relative chained for?

   Who was involved in chaining you/ your relative?

   Do you know the reason why you/ your relative were chained?

3. **Components of Community based rehabilitation**

   Community-based rehabilitation could have a few different components. We are interested in which components would be the most useful to you. I will now briefly explain what each component would involve. For each one, I will ask you the following questions:

   -Do you think this component would be useful? If not, why not?

   -Can you think of any difficulties or problems with this component?

   a. **Information:** About what mental illness is and medicines used to treat it
   b. **Self-management:** Receiving suggestions for how to cope with some of the symptoms of mental illness e.g. talking alone, and how to recognise when the illness is getting worse and what to do
   c. **Support with medications**: getting support to take medication regularly, for example getting into a routine, noticing side effects
   d. **Support for family members:** how to look after their relative and how to reduce violence against them, how to cope better
   e. **Health promotion**: getting advice on how to improve physical health, reduce stress and anger
   f. **Improving independence:** getting help with self- care e.g. washing and dressing and contributing to household tasks
   g. **Improving social skills:** getting training on how to hold a conversation

h. **Livelihood support:** Help with accessing microfinance. And/or help with getting support from Edir (e.g. financial or practical support).
i. **Stigma reduction**: ways to deal with stigma around mental illness, for example how deal with negative comments
j. **Support group:** participating in a group with people with mental illness and their families to share experiences and support each other. Possibly through creating a Mahaber group.
k. **Help with accessing healthcare:** for physical, reproductive and mental health. This might include help with getting free medications and having a CBR worker accompany you/ your relative to health care appointments.
l. **Help with accessing literacy groups**

4. Community mobilisation

a. Which community leaders, if any, do you think could be involved in community-based rehabilitation?

Probes/examples
Traditional healers, Religious healers, Religious leaders, Kebele leaders, Edir leaders

b. In what way could they be involved?

Probes/examples
These leaders receive information about mental illness.
These leaders are asked to encourage social participation by the person with mental illness.
These leaders support or encourage taking anti-psychotic medications alongside traditional or religious healing.
These leaders encourage reduction in use of violence and restraint by members of the community.

5. Delivery of community-based rehabilitation

a. What, if any, are your previous experiences with home-based care, including health extension workers?
b. What would you expect a community-based rehabilitation worker to be like?

Probes
What would you prefer in terms of their age/ gender/ skills/ manner ?
c. How long would you like each session to be?
d. How often would you like the sessions to take place?
e. Where would you prefer the sessions to take place?

Probes
Which would be preferable: home visits, health post, health centre or other location?
What are the reasons for your choice?

6. Barriers

Can you think of any reasons why you would be unwilling or unable to take part in community-based rehabilitation?

Probes
Would being visited by a community-based rehabilitation worker bring unwanted attention to you?
Would you have enough time to take part?
Would you/ your family member be well enough to take part?

Topic guide for FGD with existing community-based rehabilitation workers/ health extension workers and IDI with supervisor

Researchers from Addis Ababa University are looking at ways to improve the care of people with psychosis. In particular they want to develop community-based rehabilitation to help people to recover from their illness and get back to their usual activities. Community-based rehabilitation would be delivered in the kebele to people with psychosis and their family by specially trained community-based rehabilitation workers. As someone who has experience of delivering community-based rehabilitation to people with other types of disabilities, we are interested in your views on these ideas.

1. Do you feel that you know enough about severe mental illness / psychosis'?

   Probes
   Have you received any training in this area?
   Do you feel that you know enough about the symptoms?
   Do you feel that you know enough about the treatments?

2. **Experience of restraint**
   Are you aware of the practice of people with mental illness being chained or tied up?
   Probes
   Who is involved in chaining the person?
   Why do you think people are chained?

3. How would you feel about working with people with psychosis and their families?

   Probes
   Have you any experience of working with this group?
   Are there any reasons why you would not want to work with this group? [If prompting is needed add the following example] For example fear for personal safety?
   Do you think people with psychosis and their families need more support than they receive at present?

4. Community-based rehabilitation for people with psychosis could have a few different components. We are interested in which components would be the most feasible and useful to families. I will now briefly explain what each component would involve. For each one I would like you to think about these three questions:

   -How useful do you think these components would be?
   -How feasible do you think it would be to deliver them?
   -Can you think of any difficulties or problems with delivering any of these components?

   a. **Information:** About what mental illness is and medicines used to treat it
   b. **Self-management:** Giving suggestions for how to cope with some of the symptoms of mental illness e.g. talking alone, and how to recognise when the illness is getting worse
   c. **Support with medications**: Giving support to take medication regularly, for example getting into a routine, noticing side effects
   d. **Support for family members:** how to look after their relative and how to reduce violence against them, how to cope better
   e. **Health promotion**: Giving advice on how to improve physical health, reduce stress and anger
   f. **Improving independence:** Giving help with self- care e.g. washing and dressing and contributing to household tasks

g. **Improving social skills:** Giving training on how to hold a conversation
h. **Livelihood support:** helping to access microfinance. And/or helping to get support from Edir (e.g. financial or practical support).
i. **Stigma reduction**: ways to deal with stigma around mental illness, for example how deal with negative comments
j. **Support group:** Setting up a group with people with mental illness and their families to share experiences and support each other
k. **Help with accessing healthcare:** for physical, reproductive and mental health. This might include helping to get free medications and the CBR worker accompanying the person with mental illness to health care appointments.
l. **Help with accessing literacy groups**

5. What kind of workload would a community-based rehabilitation worker be able to take on?

Probes
How many families with someone with mental illness would a community-based rehabilitation worker be able to work with at any one time? Would 10 be about right?
How many kebeles should they cover? Would 3 be about right?
Would they also need to (or want to) work with people with physical disabilities?
How would you feel about working with health centre staff to decide the best rehabilitation plan for people with psychosis?

6. What kind of training do you think those delivering community-based rehabilitation for psychosis for the first time would need?

Probes
How much 'classroom' teaching do you think would be needed? Would 3-4 weeks be about right?
What methods of teaching would be useful?
How much 'on the job' training do you think would be needed? Would 4-5 weeks be about right?
Would it be useful to shadow an experienced community-based rehabilitation worker?

7. What kind of supervision do you think those delivering community-based rehabilitation for psychosis would need?

Probes
How often would it be necessary to meet with a supervisor?
Would group discussions with other community-based rehabilitation workers be helpful?

8. Can you think of any problems with delivering community-based rehabilitation for people psychosis?

9. FOR HEALTH EXTENSION WORKERS ONLY:
How could health extension workers work together with the community-based rehabilitation workers?

Probes
How much time could you dedicate to supporting community-based rehabilitation workers for psychosis?
How many families would you be able to support at any one time?
Would you also need to (or want to) support people with physical disabilities?

Topic guide for FGD primary care staff

We are a group of researchers from Addis Ababa University looking at ways to improve the care of people with psychosis. In particular we want to develop community-based rehabilitation to help people to recover from their illness and get back to their usual activities. Community-based rehabilitation would be delivered in the kebele to people with psychosis and their family by specially trained community-based rehabilitation workers. We would also expect community-based rehabilitation workers to work with primary care staff to ensure each patient is receiving the most appropriate care. Over the next few months you will be trained to treat people with psychosis with medication. We are interested in your views on how, in addition to this, you could be linked to the community-based rehabilitation intervention.

1. How do you feel about being trained to treat people with psychosis?

   Probes
   Do you have any concerns about having enough training/ supervision?
   Do you think you will be able to meet all the needs of people with psychosis?

2. In what ways do you work with or support the health extension programme at present?

3. **Experience of restraint**
   Are you aware of the practice of people with mental illness being chained or tied up?
   Probes
   Who is involved in chaining the person?
   Why do you think people are chained?

4. Community-based rehabilitation for people with psychosis could have a few different components. I will now briefly explain what each component would involve.

a. **Information:** About what mental illness is and medicines used to treat it
b. **Self-management:** Giving suggestions for how to cope with some of the symptoms of mental illness e.g. talking alone, and how to recognise when the illness is getting worse
c. **Support with medications**: Giving support to take medication regularly, for example getting into a routine, noticing side effects
d. **Support for family members:** how to look after their relative and how to reduce violence against them, how to cope better
e. **Health promotion**: Giving advice on how to improve physical health, reduce stress and anger
f. **Improving independence:** Giving help with self- care e.g. washing and dressing and contributing to household tasks
g. **Improving social skills:** Giving training on how to hold a conversation
h. **Livelihood support:** helping to access microfinance. And/or helping to get support from Edir (e.g. financial or practical support).
i. **Stigma reduction**: ways to deal with stigma around mental illness, for example how deal with negative comments
j. **Support group:** Setting up a group with people with mental illness and their families to share experiences and support each other
k. **Help with accessing healthcare:** for physical, reproductive and mental health. This might include helping to get free medications and the CBR worker accompanying the person with mental illness to health care appointments.
l. **Help with accessing literacy groups**

We are hoping that primary care staff would be involved in the following components:
a. Information
b. Self-management
c. Support with medications
k. Help with accessing healthcare

Do you think primary care staff could support the delivery of each of these components?
In what way could they be involved?
Can you think of any difficulties or problems with primary care staff supporting community-based rehabilitation workers to deliver of these components?

5. How would community-based rehabilitation for psychosis fit into your work at the health centre?

   Probes
   Do you think you would have time to discuss the rehabilitation needs of people with schizophrenia?
   Do you think you will have the skills to jointly develop treatment and rehabilitation plans with community-based rehabilitation workers for people with psychosis?
   In what ways could the health extension programme support the work of specialist community-based rehabilitation workers?

6. Do you think you would need any additional training and supervision to work with community-based rehabilitation workers for psychosis?

7. Can you think of any problems with primary care staff being linked to a community-based rehabilitation programme for people with psychosis?

Topic guide for IDI with traditional healer

We are a group of researchers from Addis Ababa University looking at ways to improve the care of people with psychosis. In particular we want to develop community-based rehabilitation to help people to recover from their illness and get back to their usual activities. Community-based rehabilitation would be delivered in the kebele to people with psychosis and their family by specially trained community-based rehabilitation workers. An important role of the community-based rehabilitation workers will be to make links with the community, including traditional healers.

1. In what ways to you treat or support people with psychosis/ mental illness or their families?

2. A. How many of the people with psychosis / mental illness in your kebele do you think you have treated, or are aware of?

   B. Do you also look after people in other kebeles?

3. **Experience of restraint**
   Are you aware of the practice of people with mental illness being chained or tied up?
   Probes
   Who is involved in chaining the person?
   Why do you think people are chained?

4. What links, if any, do you have with the health extension workers or other health workers?

   Probes
   Do you have any contact with them?
   Do you discuss individual patients?
   Do you help with health education?

5. Would you be willing to receive information and education from the community –based rehabilitation worker about psychosis/ severe mental illness? If not, why not?

   Probes
   Would traditional healers have time?
   Some of the information given by community based rehabilitation workers will include Western or medical explanations for mental illness (e.g. that it is a brain disesase)- will this be compatible with traditional explanations?

6. Community-based rehabilitation for people with psychosis could have a few different components. I will now briefly explain what each component would involve. For each one I would like you to tell me if you think traditional healers could be involved, and if so, in what way.

a. **Information:** About what mental illness is and medicines used to treat it
b. **Self-management:** Giving suggestions for how to cope with some of the symptoms of mental illness e.g. talking alone, and how to recognise when the illness is getting worse
c. **Support with medications**: Giving support to take medication regularly, for example getting into a routine, noticing side effects
d. **Support for family members:** how to look after their relative and how to reduce violence against them, how to cope better
e. **Health promotion**: Giving advice on how to improve physical health, reduce stress and anger
f. **Improving independence:** Giving help with self- care e.g. washing and dressing and contributing to household tasks

g. **Improving social skills:** Giving training on how to hold a conversation
h. **Livelihood support:** helping to access microfinance. And/or helping to get support from Edir (e.g. financial or practical support).
i. **Stigma reduction**: ways to deal with stigma around mental illness, for example how deal with negative comments
j. **Support group:** Setting up a group with people with mental illness and their families to share experiences and support each other
k. **Help with accessing healthcare:** for physical, reproductive and mental health. This might include helping to get free medications and the CBR worker accompanying the person with mental illness to health care appointments.
l. **Help with accessing literacy groups**

7. Can you think of any difficulties or problems with traditional healers being involved in community-based rehabilitation?

   Probes
   Would traditional healers be concerned that they would have fewer earnings as people with mental illness would no longer consult them?
   Would traditional healers have time to be involved?
   Some of the information given by community based rehabilitation workers will include Western or medical explanations for mental illness (e.g. that it is a brain disesase)- will this be compatible with traditional explanations?

Topic guide for IDI with Edir/kebele leader

We are a group of researchers from Addis Ababa University looking at ways to improve the care of people with psychosis. In particular we want to develop community-based rehabilitation to help people to recover from their illness and get back to their usual activities. Community-based rehabilitation would be delivered in the kebele to people with psychosis and their family by specially trained community-based rehabilitation workers. An important role of the community-based rehabilitation workers will be to make links with the community, including Edir leaders.

1. Are you aware of any people with psychosis/ severe mental illness in your kebele?

2. If so, do you think people with psychosis/ severe mental illness and their family members are generally involved in community life in your kebele?

   Probes
   Do they attend kebele meetings?
   Do they attend church/ mosque?
   Do they attend social gatherings?

3. **Experience of restraint**
   Are you aware of the practice of people with mental illness being chained or tied up?
   Probes
   Who is involved in chaining the person?
   Why do you think people are chained?

4. If you are aware of any people with psychosis/ severe mental illness in your kebele, are any of them or their family members involved in your Edir group?

5. Can you think of any reasons why people with psychosis/ severe mental illness or their family members would find it difficult to be part of an Edir group?

   Probes
   Could any of these reasons be true:
   -They are not able to financially contribute
   -They do not have time
   -Other members of the group do not wish them to join

6. Would you be willing to receive information and education from the community –based rehabilitation worker about psychosis/ severe mental illness? If not, why not?

   Probes
   Would you have time?
   Some of the information given by community based rehabilitation workers will include Western or medical explanations for mental illness (e.g. that it is a brain disesase)- will this be compatible with traditional explanations?

7. Community-based rehabilitation for people with psychosis could have a few different components. I will now briefly explain what each component would involve.

a. **Information:** About what mental illness is and medicines used to treat it
b. **Self-management:** Giving suggestions for how to cope with some of the symptoms of mental illness e.g. talking alone, and how to recognise when the illness is getting worse

c. **Support with medications**: Giving support to take medication regularly, for example getting into a routine, noticing side effects
d. **Support for family members:** how to look after their relative and how to reduce violence against them, how to cope better
e. **Health promotion**: Giving advice on how to improve physical health, reduce stress and anger
f. **Improving independence:** Giving help with self- care e.g. washing and dressing and contributing to household tasks
g. **Improving social skills:** Giving training on how to hold a conversation
h. **Livelihood support:** helping to access microfinance. And/or helping to get support from Edir (e.g. financial or practical support).
i. **Stigma reduction**: ways to deal with stigma around mental illness, for example how deal with negative comments
j. **Support group:** Setting up a group with people with mental illness and their families to share experiences and support each other
k. **Help with accessing healthcare:** for physical, reproductive and mental health. This might include helping to get free medications and the CBR worker accompanying the person with mental illness to health care appointments.
l. **Help with accessing literacy groups**

8. In what ways do you think Edir leaders can help the community-based rehabilitation process?

   Probes
   Could they be involved in educating community members about psychosis/ mental illness?
   Could they ensure the Edir group is willing to accept people with psychosis/ mental illness and their families, if they are not already doing so?
   Could they help to mobilise financial support for people with psychosis/ mental illness and their families?
   Could they help to mobilise social support for people with psychosis/ mental illness and their families?

9. Can you think of any difficulties or problems with Edir leaders being involved in community-based rehabilitation?

   Probes
   Would Edir leaders have time to be involved?
   Would Edir leaders consider it their responsibility or in their interest to be involved?
   Some of the information given by community based rehabilitation workers will include Western or medical explanations for mental illness (e.g. that it is a brain disease)- will this be compatible with traditional explanation

Appendix C (Chapter 6: RISE materials)

Appendix C (i): RISE intervention delivery forms

Form 1: Initial assessment form			
Individual		**Date**	
CBR worker		**Supervisor**	
Others present			
Start time		**Finish time**	

Information given		
Introductions between CBR worker, individual and family (tick)	**Yes**	
	No	
Introduction to CBR aims, structure and content (tick)	**Yes**	
	No	
Discussed confidentiality (tick)	**Yes**	
	No	

Family members	
Name of primary caregiver	
Relationship of primary caregiver to individual	
Other family members involved in looking after the individual	1. 2. 3. 4. 5.

Home environment			
People living at home (who is there, relationship to individual, ages)	Name	Relationship	Age
Type of home (size, type, number of rooms, condition of house)			
Position of home (distance from road, distance from health centre, public transport, problems with access during rainy season)			
Land and income (do they own land, do they have any other income)			

Illness		
Current mental health e.g. are they unwell or stable?		
How many months/years ago did individual become unwell?		
How many months/years ago did the individual first seek help and from who?		
If the individual is taking anti-psychotic medication, what is the name, dose and timing?		
List any other medications		
Needs		
Is the individual currently accessing the health centre for mental health? (tick)	**Yes**	
	Sometimes	
	No	
Reasons for not accessing and immediate actions		
Is the individual currently accessing anti-psychotic medication? (tick)	**Yes**	
	Sometimes	
	No	
Reasons for not accessing and immediate actions		
Is the individual currently chained or tied up? (tick)	**Yes**	
	Sometimes	
	No	
Reasons for chaining and immediate actions		
Other urgent needs		
Immediate actions		
Initial impressions of challenges, opportunities and recommendations		
Visits		
Convenient time/day for visits		
Next home visit time and day		
Planned location of visits (tick)	**Home**	
	Health post	
Contact details		

Form 2: Health Centre Contact Form			
Individual		**Date**	
CBR worker		**Nurse/ health officer**	
Others present			
Health centre			

CBR review (tick)	**Review I**		
	Review II		
	Review III		
	Review IV		
	None		
If not for a CBR Review, what is the reason for accompanying the individual to the health centre?			
Summary of issues discussed			
Plan			
Checked with individual and family for understanding (tick)	**Yes**		
	No		
Additional explanations or actions with family			

Form 3: Review Summary Form			
Individual			
CBR worker		**Supervisor**	

Review I

Task	Date completed
Initial assessment	
Needs assessment	
Goal setting for Phase I	
Risk assessment completed by supervisor	
Accompany to Health Centre	

Review II

Task	Date completed
Needs assessment	
Goal setting for Phase II	
Risk assessment completed by supervisor	
Accompany to Health Centre	
Invite to Family Support Group	

Review III

Task	Date completed
Needs assessment	
Goal setting for Phase III	
Risk assessment completed by supervisor	
Accompany to Health Centre	

Review IV

Task	Date completed
Continuing Care Assessment	
Accompany to Health Centre	

Form 4: Needs Assessment Form			
Individual		**Date**	
CBR worker		**Supervisor**	
Others present			
Start time		**Finish time**	
Review (Tick)			
Review I		**Review II**	
Review III			

Need	**Not a problem**	**Partially met need**	**Unmet need**	**Comments**
PHASE 1				
Individual and caregiver have been informed about schizophrenia and its treatment				
Individual is able to access medication				
Individual is able to access health centre for mental health				
Crisis management plan is in place				
Individual is not chained or restrained				
PHASE 2/3				
Medication				
Individual is willing to take medication				
Individual remembers to take medication				
Individual feels side effects are manageable				
Symptoms				
Individual feels hallucinations and delusions are manageable				
Individual feels problems with motivation and thinking clearly are manageable				
Physical health				
Individual can access services for physical/sexual /reproductive health				
Individual has strategies to deal with stress and anger				
Individual has healthy behaviours (not smoking or drinking alcohol)				
Individual has good physical health e.g. is not malnourished				
Social life				
Individual participates in community life				
Individual participates in religious activities if they are important to the individual				
Individual is able to interact socially with neighbours and friends				

Need	Not a problem	Partially met need	Unmet need	Comments
Family life				
Individual has ability to look after children				
Individual can carry out usual family role				
Individual has good relationship with family members				
Caregiver can cope				
Daily functioning				
Individual has good self-care				
Individual has ability to do household tasks				
Empowerment				
Individual has good self-esteem				
Individual does not feel discriminated against				
Individual is not victim of physical/ sexual/ emotional abuse				
Work				
Individual participates in livelihood activities				
Literacy				
Individual has basic literacy skills				
PHASE 3				
Individual has relapse prevention plan in place				

Form 5: Phase I Goal setting Form			
Individual		**Date**	
CBR worker		**Supervisor**	
Others present			
Start time		**Finish time**	

Goal	Comments and timeframe	Prioritisation	Module	Community mobilisation tasks to address goal
Individual and caregiver have been educated about schizophrenia and treatment			Understanding schizophrenia	
Individual is able to access medication and attend health centre for mental health			Improving access to health services	
Crisis management plan is in place			Preparing for a crisis	
Individual is not chained or restrained			Dealing with human rights problems	
Personal goal				
Additional goals				

Form 6: Phase II and III Goal Setting Form			
Individual		**Date**	
CBR worker		**Supervisor**	
Others present			
Start time		**Finish time**	
Review (tick)			
Review II		**Review III**	

Goal	Goal selected ? (tick)	Comments and timeframe	Prioritisation	Indicated module	Community mobilisation tasks
PHASE 1					
Individual and caregiver have been informed about schizophrenia and treatment				Understanding schizophrenia	
Individual is able to access medication and attend health centre for mental health				Improving access to health services	
Crisis management plan is in place				Preparing for a crisis	
Individual is not chained or restrained				Dealing with human rights problems	
PHASES 2/3					
Medication					
Individual is willing to take medication				Supporting individuals to take their medication	
Individual has strategies to remember to take medication				Supporting individuals to take their medication	
Individual feels side effects are improving				Supporting individuals to take their medication	
Symptoms					
Individual feels hallucinations and delusions are improving				Supporting individuals to take their medication Dealing with distressing symptoms	
Individual feels problems with motivation and thinking clearly are improving				Supporting individuals to take their medication OPTIONAL: Dealing with distressing symptoms	

Physical health					
Individual is able to access health services for physical, sexual and reproductive health needs				Improving access to health services	
Individual has strategies to deal with stress and anger				Dealing with stress and anger	
Individual has information to make decisions about healthy behaviours e.g. not smoking or drinking				Improving physical health	
Individual has good physical, sexual and reproductive health				Improving physical health	
Individual is not malnourished				Improving physical health Dealing with human rights problems	
Social life					
Individual participates in community life				Taking part in community life	
Individual participates in religious activities if they are important to the individual				Taking part in community life	
Individual is able to interact socially with neighbours and friends				Taking part in community life	
Family life					
Individual has improving ability to look after children				Improving the family environment	
Individual has improving ability to carry out family role				Improving the family environment	
Individual has improving relationship with family members				Improving the family environment	
Caregiver has improved ability to cope				Improving the family environment	
Day to day functioning					
Individual has improving self-care				Improving day to day functioning	
Individual has improving ability to do household tasks				Improving day to day functioning	
Empowerment					
Individual has improving self-esteem				Dealing with stigma and discrimination	
Individual has constructive ways of dealing with stigma and discrimination				Dealing with stigma and discrimination	

Individual is not the victim of physical, sexual or emotional abuse				Dealing with human rights problems	
Work					
Individual has improving participation in livelihood activities				Getting back to work	
Literacy					
Individual has improving literacy skills				Improving literacy	
Relapse					
Individual has relapse prevention plan					
Personal goal					

Form 7: Risk Assessment Form			
Individual		**Date**	
CBR worker		**Supervisor**	
Start time		**Finish time**	
Review (tick)			
Review I		**Review II**	
Review III			

Risk	**Is the individual at risk?**		**Circumstances leading to risk**	**Immediate actions (tick when completed)**		**Preventative actions**
Suicide	Yes			Facilitate access to health centre		
	No					
Chaining	Yes			Facilitate access to health centre		
	No					
Physical Abuse	Yes			Facilitate access to health centre		
	No			If immediate risk of serious harm, call police		
Emotional Abuse	Yes			Facilitate access to health centre		
	No					
Sexual Abuse	Yes			Facilitate access to health centre		
	No			If immediate risk of serious harm, call police		
Neglect	Yes			Facilitate access to health centre		
	No					
Risk to children	Yes			Facilitate access to health centre		
	No			If immediate risk of serious harm, call police		
Imprisonment	Yes					
	No					
Environmental risk	Yes					
	No					

Form 8: Rehabilitation plan			
Individual		**Caregiver**	
CBR worker		**Supervisor**	
Kebele		**Phone**	
Date			

Summary of illness (see Initial Assessment Form)
Main problems and needs (see Needs Assessment Form)

Phase 1 Goals (see Phase 1 Goal Setting Form)

Goal	Date goal set	Date achieved	Reason for not achieving goal
Individual and caregiver have been educated about schizophrenia			
Individual is able to access medication			
Individual is able to attend health centre for mental health			
Crisis management plan is in place			
Individual is not chained or restrained			

Phase 2 Goals (see Phase 2 Goal Setting Form)

Goal	Date goal set	Date achieved	Reason for not achieving goal

Phase 3 Goals (see Phase 3 Goal Setting Form)

Goal	Date goal set	Date achieved	Reason for not achieving goal

Form 9: Continuing Care Assessment Form			
Individual		**Date**	
CBR worker		**Supervisor**	
Others present			
Start time		**Finish time**	

1. Summary of unmet needs identified in Reviews II and III
2. Summary of modules delivered
3. Challenges faced during CBR
4. Summary of goals achieved
5. Summary of ongoing unmet needs
6. Overall plan for the future
7. Plan for relapse prevention
8. Plan for accessing health services
9. Plan for supporting to take medication
10. Key persons involved in plan and their roles
11. Other comments

Form 10.0: Kebele Logbook cover sheet			
CBR worker		**Supervisor**	
Kebele			

Name of individuals and caregivers in kebele

Individual	Caregiver

Form 10.1: Kebele Logbook (Task 1: Health Extension Worker Contact)			
CBR worker		**Supervisor**	
Kebele			

Health Extension Worker name	
Contact details	
Initial meeting date	
Health Extension Worker name	
Contact details	
Initial meeting date	

Discussion point	**Tick when discussed**	**Comments**
Exchange contact details		
Explain CBR and your role		
Explain how HEW may be involved		
Awareness of people with schizophrenia in kebele, house location, and willingness to introduce		
Key community leaders and willingness to introduce		
Key community resources		
Previous community awareness raising about mental illness		

Form 10.2: Kebele Logbook (Task 2: Identify community leaders)			
CBR worker		**Supervisor**	
Kebele			

S.N.	Name	Role (e.g. Edir leader, religious leader)	Contact details	Date of introduction
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				

Form 10.3: Kebele Logbook (Task 3: Identify community resources)			
CBR worker		**Supervisor**	
Kebele		**Date started**	

S.N.	Name (e.g. St Mary's)	Type of resource (e.g. Church)	Key contact/s (e.g. name and number of priest)
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			

Form 10.4: Kebele Logbook (Task 4: Previous community awareness raising about mental illness)

CBR worker		**Supervisor**	
Kebele		**Date form completed**	

S.N.	Type (e.g. community conversation)	Lead by	Date	Comments
1				
2				
3				
4				
5				
6				
7				

Form 10.5: Kebele Logbook (Task 5: Initial meetings with community leaders)

CBR worker		**Supervisor**	
Kebele			

Date			
Location			
Community leaders present			
SN	**Name**	**Role**	**Contact details**
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			

Topic	**Tick**	**Comments**
Reason for CBR and your role		
Authorization to CBR programme		
Outline of CBR activities (home visits and community mobilisation)		
Best place for community awareness raising		
Extra information on community resources		
Initial information about paid employment opportunities		
Information about schizophrenia, including possibility of recovery with medication		
Importance of community support		
Other issues raised		
Actions agreed		
Date and time of subsequent meeting/s, if arranged		

Form 10.6: Kebele Logbook (Task 6: Community awareness raising event/s)

CBR worker		**Supervisor**	
Kebele			

Date		
Location		
Number of participants		
Topic	**Tick when discussed**	**Comments**
Introduce self and role		
Basic explanation of schizophrenia		
Causes of schizophrenia		
Possibility of recovery		
Importance of medication		
Need for community support		
Importance of treating people with schizophrenia well and as equals		
Importance of helping people to get treatment so they don't need to be chained		
Other issues raised		
Actions agreed		
Date and time of subsequent meeting if arranged		

Form 10.7: Kebele Logbook (Task 7: Potential employment opportunities)			
CBR worker		**Supervisor**	
Kebele			

S.N.	Name of potential employer	Type of employment	Contact details	Date identified
1				
2				
3				
4				
5				
6				
7				
8				
9				

Form 10.8: Kebele Logbook (Tasks 8 to 12: Individual meetings with community leaders)

CBR worker		**Supervisor**	
Kebele			

Date	
Name of community leader	
Role in community	
Individual discussed	
Support or input agreed	
Details of next meeting if arranged	

Date	
Name of community leader	
Role in community	
Individual discussed	
Support or input agreed	
Details of next meeting if arranged	

Date	
Name of community leader	
Role in community	
Individual discussed	
Support or input agreed	
Details of next meeting if arranged	

Form 10.9: Kebele Logbook (Task 13: Demonstrate progress of individuals to community)

CBR worker		**Supervisor**	
Kebele			

Name of individual		
Contact details		
How was individual identified?		
Discussed and agreed with supervisor that meeting is unlikely to bring stigma or discrimination to individual (tick)		
Consent from individual (tick)		
Discussed expectations with individual (tick)		
Individual given appropriate compensation for time/travel (tick)		

Date of meeting	
Setting of meeting (e.g. edir)	
Number of participants	
Summary of information given by individual	
Comments	

Form 10.6: Kebele Logbook (Task 6: Community awareness raising event/s)

CBR worker		**Supervisor**	
Kebele			

Date		
Location		
Number of participants		
Had community awareness raising previously been conducted with this group?	**Yes** **No**	
Topic	**Tick when discussed**	**Comments**
Introduce self and role		
Basic explanation of schizophrenia		
Causes of schizophrenia		
Possibility of recovery		
Importance of medication		
Need for community support		
Importance of treating people with schizophrenia well and as equals		
Importance of helping people to get treatment so they don't need to be chained		
Other issues raised		
Actions agreed		
Date and time of subsequent meeting if arranged		

Form 10.11: Kebele Logbook (Task 15: Arranging employment opportunities)			
CBR worker		**Supervisor**	
Kebele			

S.N.	Individual	Name of employer	Type of employment	Date arranged	Outcome
1					
2					
3					
4					
5					
6					
7					
8					
9					

Form 11: Home visit Form					
Individual		CBR worker		Date	
Start time		Finish time			
Phase (tick)					
Phase I		Phase II		Phase III	

Participants			
Who was present at the home visit? (tick)	Individual		
	Main caregiver		
	Supervisor		
	Other		
	If other, who?		
General			
Mental health and symptoms (tick)	Worse		
	Same		
	Better		
Your comments on the individual's mental health status			
Issues or questions raised relating to previous visit			
Other issues discussed			
Goal (write in →)			
Module/s underway this home visit to achieve goal	1. 2.		
Community mobilisation tasks and other tasks underway or planned to achieve goal	1. 2.		
Issues and problems			
Progress on goal by end of home visit (Tick)	Not achieved		
	Partly achieved		
	Achieved		
Goal (write in →)			
Module/s underway this home visit to achieve goal	1. 2.		
Community mobilisation tasks and other tasks underway or planned to achieve goal	1. 2.		
Issues and problems			
Progress on goal by end of home visit (Tick)	Not achieved		
	Partly achieved		
	Achieved		
Goal (write in →)			
Module/s underway this home visit to achieve goal	1. 2.		
Community mobiilsation tasks and other tasks underway or planned to achieve goal	1. 2.		
Issues and problems			

Progress on goal by end of home visit (Tick)	**Not achieved**			
	Partly achieved			
	Achieved			
Medication				
Issues with medication				
Actions to deal with medication issues				
Physical health and substance abuse				
Issues with physical health or substance use				
Risks				
Is the individual chained? (tick)	**Yes**		**No**	
If yes, actions to deal with chaining				
Is there suicide risk? (tick)	**Yes**		**No**	
If yes, actions to deal with suicide risk				
Other risks and actions taken				
Follow up				
Task for individual/ caregiver to complete before next session				
Time and date of next home visit				
Module for next visit				
Issues to discuss with supervisor				
Referrals e.g. to health centre				
Supervisor review				
Date reviewed with supervisor				
Actions suggested by supervisor				
Supervisor signature				

Form 12: Visit summary Form			
Individual		**Participant ID**	
Participant ID		**CBR worker ID**	
Supervisor		**Supervisor ID**	

Phase	**Date of contact**	**Time spent with contact person/s (in minutes)**	**If applicable, time spent to travel to meet the contact person (one way journey, in minutes)**	**Mode of transport** 1: Walking 2: Public transport 3: Project vehicle 4: Other 5: Not applicable	**Cost of travel (one way, in Birr)**	**Type of contact** 1: Face to face at home 2: Face to face at health centre 3: Telephone contact 4: Other 5: No contact made	**Contact person/s** 1: Individual 2: Primary caregiver 3: Other family member(s) 4: Community member(s) 5: Supervisor 6: Other 7: No contact made	**Activities conducted** 1: Initial assessment 2: Needs assessment 3: Goal setting 4: Risk assessment 5: Accompanying to health centre 6: Community mobilisation task 7: Module (indicate which one/s) 8: Other 9: No contact made 10: Face to face supervision 11: Group supervision 13: Top up training 15: Engagement

Form 13: CBR worker timetable			
CBR worker		**Supervisor**	
Start date			

	Monday	Tuesday	Wednesday	Thursday	Friday
AM					
PM					
	Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**
AM					
PM					

Form 14: Health Centre Referral form

INSTRUCTIONS TO PATIENT:

1. TAKE THIS FORM WITH YOU TO THE HEALTH CENTRE AND SHOW IT TO THE NURSE OR CLINICAL OFFICER

2. GIVE THIS FORM BACK TO THE CBR WORKER ONCE YOU HAVE BEEN SEEN AT THE HEALTH CENTRE

Section A: For completion by the CBR worker	
Name of patient	
Date	
Kebele	
Health centre referred to	
Reason for referral	
Community-based rehabilitation worker name and contact details	

Section B: For completion by the health officer or nurse at the health centre	
Date	
Name of nurse or clinical officer	
Health centre	
Plan	

Form 15: Checklist for problems taking medication			
Individual		**CBR worker**	
Others present			
Date			

Tick all of the factors that are contributing towards problems taking medication

	Is it a problem?	
	Yes	**No**
Individual factors		
Insufficient support from family		
Shame or stigma		
Belief that medication will not help		
Belief that medication only required in short term		
Informed by holy water priest or attendant or traditional healer not to take		
Illness factors		
Not aware of illness that needs treating		
Low motivation		
Low concentration and attention		
Khat or alcohol		
Treatment factors		
Side effects		
Not enough food for increased appetite		
Poor relationship with nurse or health officer		
Complicated schedule		
Practical factors		
Cannot afford medication		
Cannot afford travel to health centre		
Too unwell to go to health centre		
Medication not available at health centre		

Form 16: Day to day functioning progress form			
Individual		**Date**	
CBR worker		**Supervisor**	

Day to functioning area	Is this a problem? (tick)		If yes, details	Aim	Progress and date
Cleaning teeth	Yes				
	No				
Washing	Yes				
	No				
Dressing	Yes				
	No				
Grooming	Yes				
	No				
Personal hygiene and sanitation	Yes				
	No				
Eating and meal times	Yes				
	No				

Form 17: Checklist for Early Warning signs			
Individual		**CBR worker**	
Others present			
Date			

Early Warning Sign	Tick if previously experienced	Description
Feeling tense and nervous		
Having trouble sitting still, having to keep moving		
High levels of energy and activity		
Having problems sleeping		
Getting into conflicts		
Worrying about physical health a lot		
Sad most of the time		
Changing from happy to sad very quickly		
Afraid that something bad is going to happen		
Having trouble remembering things or concentrating		
Eating less than usual		
Talking alone		
Wandering out of house		
Thinking that people are talking about him or her		
No interest in doing things		
No interest in self care		
Thoughts are coming too fast		
Cannot understand what is going on		
Religious thoughts are suddenly more intense		
Stops taking medication		
Doesn't want to go to health centre		
Increased substance use		
Other		

Form 18: Relapse management plan			
Individual		**CBR worker**	
Others present			
Date			

1. What are the individual's early warning signs (see Early Warning Signs Checklist)
2. What are the individual's stressful triggers
3. Plan of action for dealing with relapse
a. Who can support the individual and what can they do?
Family **Friends** **Community members** **Health services**
b. What can the individual do to help themselves?

Form 19: Family support group details form			
Kebele		**CBR worker**	

Group members			
Name	**Role (caregiver, person with schizophrenia)**	**Contact number**	**Date joined**

Group leader			
Name	**Role (CBR worker, caregiver)**	**Contact number**	**Date started as leader**

Introductory topics		
Topic	**Tick when discussed**	**Date**
Confidentiality		
Need to respect others opinions		
Aiming for group to run by itself		
Timing of meetings		
Location of meetings		
Tea/coffee fund		

Meeting arrangements
Timing and frequency of meetings
Location of meetings
Tea/coffee arrangements

Reason for NOT conducting family support group (tick)	
Participant/s not willing	
Participant/s dropped out of CBR	
Insufficient participants in kebele	
Other	
Specify other	

Form 20: Family support group meeting form			
Kebele		**CBR worker**	
Meeting Date		**Leader**	

Attendance	
Name	**Role (caregiver, person with schizophrenia)**

Discussion
Summary
Agreed topic for next meeting

Form 21: Supervision record form			
CBR worker		**Supervisor**	
Date		**Individual**	
Supervision type (tick)			
Face to face discussion		**Observed home visit**	
Phone contact		**Group discussion**	

1. Summary of issues discussed
2. Follow up made on actions from previous supervision
3. New actions to complete

Form 22: Crisis management plan			
Individual		**CBR worker**	
Others present			
Date			

1. What types of crisis are likely?
2. Who to ask for help and contact details
3. Crisis management plan

Form 23: Group supervision attendance form			
Date		**Supervisor**	

CBR worker Name	Health centre	Presented case or issue (tick)

Form 24: CBR worker safety assessment form

CBR worker		**Supervisor**	
Date		**Individual**	

Section 1: Risk rating

Problem	Possible impact of problem (rate from 1 to 5*)	Likelihood of this being a problem (rate from 1 to 5*)	Risk score**
Remoteness			
Severity of illness			
History of violence			
Co-morbid substance abuse			
Family issues e.g. unpredictable family member			
Overall risk score ***			

***Scoring**

Impact		Likelihood	
1	Low	1	Remote
2	Moderate	2	Unlikely
3	Significant	3	Possible
4	Major	4	Likely
5	Catastrophic	5	Certain

** Calculate risk score by multiplying Impact score by Likelihood score

*** Calculate overall risk score by adding all risk scores and dividing by 5

Section 2: Other safety concerns identified by supervisor or CBR worker

Section 3: Determine risk category

Score (tick)	
Low risk (≤ 5)	
Medium risk (6 to 10)	
High risk (11 and above) **AND/ OR** high level of concern by supervisor or CBR worker	

Section 4: Implement steps to ensure CBR worker safety

For homes that are classified as **high risk:**

- Repeat the safety assessment every 2 to 4 weeks
- Inform the trial coordinator of the assessment outcome
- The CBR worker should only make joint visits with the supervisor until the risk assessment has reduced to medium or low

For homes that are classified as **medium risk:**

- Repeat the safety assessment every 4 weeks
- The CBR worker should call the supervisor before and after every home visit

For homes that are classified as **low risk:**

- Repeat the safety assessment at the beginning of the next phase

Form 25: Supervisor incident form			
CBR worker		**Supervisor**	
Date		**Individual**	

Information received by supervisor	
Date informed by CBR worker	
Information received from CBR worker	
General assessment	
Who participated in assessment (e.g. individual, family members)	1. 2. 3. 4.
Is the individual unwell or stable?	
Summary of incident and recent events	
Immediate risks (if suicide risk or suicide attempt also fill in Form 26 Suicide Risk Assessment Form)	
Current suicidality from Suicide Risk Assessment, if applicable	
Plan (including recommendation by psychiatric nurse, if applicable)	

THE FOLLOWING SERIOUS ADVERSE EVENTS SHOULD BE REPORTED IMMEDIATELY TO THE TRIAL COORDINATOR		
Serious adverse events (tick if occurred)		**Date trial coordinator informed**
Suicide attempt		
Suicide		
Death by other cause		
Hospitalization for medical emergency		

Form 26: Supervisor suicide risk assessment form (MINI)			
CBR worker		**Supervisor**	
Date		**Individual**	

Suicide risk assessment				
	In the last one month did you….			
1	Suffer any accident? This includes taking too much of your medication accidentally	Yes	1	**0**
		No	0	
1A	Plan or intend to hurt yourself in any accident either actively or passively (e.g. by not avoiding a risk)?	Yes	1	**0**
		No	0	
1B	Intend to die as a result of any accident?	Yes	1	**0**
		No	0	
2	Feel hopeless?	Yes	1	**1**
		No	0	
3	Think that you would be better of dead or wish you were dead?	Yes	1	**1**
		No	0	
4	Think about hurting or injuring yourself or have mental images of harming yourself with at least some intent or awareness that you might die as a result?	Yes	1	**4**
		No	0	
4A	How many times?	[ ] [ ] times		-
5	Think about suicide (killing yourself)?	Yes	1	**6**
		No	0	
5A	How many times?	Occasionally	1	-
		Often	2	
		Very often	3	
5B	What was the intensity of this thought?	Mild	1	-
		Moderate	2	
		Severe	3	
6	In the last one month, did you feel unable to control these impulses?	Yes	1	**8**
		No	0	
7	Have a suicide plan or method in mind? (e.g. how, when or where?)	Yes	1	**8**
		No	0	
8	Intend to follow through on a suicide plan?	Yes	1	**8**
		No	0	
9	Intend to die as a result of a suicidal act?	Yes	1	**8**
		No	0	
10	Take any active steps to prepare to injure yourself or to prepare for a suicide attempt in which you expected or intended to die?	Yes	1	**9**
		No	0	
10A	How many times?	[ ] [ ] times		-
11	Injure yourself on purpose without intending to kill yourself?	Yes	1	**4**
		No	0	
12	In the last month, did you attempt suicide (to kill yourself)? *A suicide attempt means you did something where you could possibly be injured, with at least a slight intent to die.*	Yes	1	**9**
		No	0	
12A	How many times?	[ ] [ ] times		-
12B	Did you hope to be rescued or survive?	Yes	1	-
		No	0	

12C	Did you expect or intend to die?		Yes	1	-
			No	0	
13	Did you ever make a suicide attempt (try to kill yourself)?		Yes	1	**4**
			No	0	
14	**Is at least 1 of the above (except 1) coded YES?** **If yes, add the total points for the answers B1-B13 circled YES (in shaded column)**		**TOTAL SCORE**		
15	**Current suicidality**	**Score 1-8**	**Low**	**1**	
		Score 9-16	**Moderate**	**2**	
		Score ≥17	**High**	**3**	

DISCUSS THE RESULT OF THE ASSESSMENT WITH THE PSYCHIATRIC NURSE

Form 27: Psychiatric nurse incident form					
Psychiatric nurse		**Supervisor**		**CBR worker**	
Date		**Individual**			

Information received by psychiatric nurse	
Date informed of situation	
Who informed psychiatric nurse of situation	
Information received about situation	
General assessment	
Who participated in assessment (e.g. individual, family members)	
Clinical picture	
Summary of recent events	
Immediate risks	
Plan	

THE FOLLOWING SERIOUS ADVERSE EVENTS SHOULD BE REPORTED IMMEDIATELY TO THE TRIAL COORDINATOR		
Serious adverse events (tick if occurred)		**Date trial coordinator informed**
Suicide attempt		
Suicide		
Death by other cause		
Hospitalization for medical emergency		

Form 28: Supervisor visit summary form			
Supervisor		**CBR worker**	
Supervisor ID		**CBR worker ID**	

Phase	**Date of contact**	**Time spent with contact person/s (in minutes)**	**Time spent to travel to meet the contact person (one way journey, in minutes)**	**Mode of transport** 1: Walking 2: Public transport 3: Project vehicle 4: Other 5: not applicable	**Cost of travel (one way, in birr)**	**Type of contact** 1: Face to face at home 2: Face to face at health centre 3: Telephone contact 4: Other 5: No contact made 6: Face to face at community venue	**Contact person/s** 1: Individual 2: Primary caregiver 3: Other family 4: Community member 5: CBR worker 6: Other 7: No contact made 8: Health centre staff	**Activities conducted** 4: Risk assessment 5: Accompanying to health centre 6: Community mobilisation task 8: Other (specify) 9: No contact made 10: Individual (face to face) supervision 11: Group supervision 12: Unannounced observed visit 13: Top up training 14: CBR worker safety assessment 15: Engagement

Form 29: Top up training attendance form			
Date		**Supervisor**	

CBR worker Name	Health centre

Topics covered

Form 30: Health Extension Worker Referral form					
Individual		**CBR worker**		**Date**	
Phase (tick)					
Phase I		**Phase II**		**Phase III**	

Name of health extension worker	
Contact number	
Reason for referral	
Outcome/ plan	

Appendix C (ii): RISE training manual for CBR workers

RISE

Rehabilitation+Intervention+for+people+with+Schizophrenia+in+Ethiopia

Manual for community-based rehabilitation workers

Version 1.0

Contents

Introduction to the CBR manual

What is community-based rehabilitation (CBR) for schizophrenia?

Schizophrenia is a long-term illness, which can lead to severe disability in the individual, especially if the community does not accept them. The illness can also place a heavy burden on the family. People with schizophrenia usually need a period of rehabilitation and family support. Rehabilitation is where people are helped to regain skills and to return to their usual life activities.

Community-based rehabilitation is a way to help people with disabilities to be included in the life of their communities. It addresses all areas of a person's life including health, inclusion in social life and activities of the community, livelihood and work, education and empowerment. Empowerment means that the individual has the ability to make decisions about their own life. The focus is always on the needs and wishes of the individual. As a CBR worker you will work with individuals with schizophrenia, their families and their communities to help the individual to get back to their usual activities and be accepted fully into society.

Who is this manual for?

This manual is for community-based rehabilitation workers, who will be working with people with schizophrenia.

How to use this manual

This manual is designed to help you:

Understand what schizophrenia is and the problems it causes

→ this is covered in Section A

Learn how to help people schizophrenia and their families through CBR

→ this is covered in Section B

Know how you will be supported to deliver CBR

→ this is covered in Section C

Throughout the manual you will follow the experiences of Yosef and Sara, people with schizophrenia, and their families. Yosef and Sara are not real people, but their stories include situations and events that real people with schizophrenia have experienced.

RISE

SECTION A: Understand what schizophrenia is and the problems it causes

1 What is mental illness?

1.1 What does the mind do?

The mind does the following tasks:

- Perceiving: this means sight, hearing, smell, taste and touch
- Thinking: this means memory, judgement and decision-making
- Feeling: this means emotions such as sadness and happiness
- Behaviour: this means how we act

1.2 What is mental health?

Mental health means the mind is working well and we are productive, we have good relationships with others and we are able to cope well when problems happen.

1.3 What is mental illness?

Mental illness is any illness experienced by a person that affects their emotions, thoughts or behaviour, and has a negative effect on their life or the lives of their family.

1.4 What is disability?

Disability is where people have difficulty doing their normal activities and being part of their community. Many people with mental illness experience disability.

1.5 Why do people sometimes become mentally ill?

Like in other parts of the body, the mind can have problems and not work perfectly all the time. Mental illnesses are caused by problems with the way the mind works, especially when we are affected by stresses of life. Mental illness can cause problems with the four tasks of the mind: perceiving, thinking, feeling and behaviour.

1.6 Can people with mental illness recover?

It is important to remember that all people with mental illness have the possibility of recovery. Recovery does not always mean that the illness will be cured completely. Instead it means that things have improved, and disability is reduced, in a way that is important to the individual. In order to make sure individuals have the possibility to recover, it is important to always focus on their own needs and wishes.

1.7 What types of mental illness are there?

There are two main groups of mental illnesses: severe mental illness and common mental illness. Severe mental illness includes schizophrenia or psychosis. Common mental illness includes anxiety, depression and alcohol problems. Severe mental illness is usually more serious and disabling than common mental illness. Individuals may have more than one than one type of mental illness. For example, people with schizophrenia may also have an alcohol problem. In this manual you will learn lots more about people with schizophrenia, and how you can support them through CBR.

1.8 How can we recognise mental illness?

When people have mental illness they often behave in certain ways that helps us to recognise that the illness is there.

Psychosis or schizophrenia

Someone who has ANY of the following:	**May have:**
• Talks alone, says meaningless words or speaks in a strange language, talks very fast	**Psychosis or schizophrenia or 'severe mental illness'**
• Is often very restless; has mood swings from very happy or irritable to feeling very sad	
• Has false beliefs or suspicions, e.g. that someone is trying to harm them, or that they have special powers	
• Shows self-neglect (e.g. dirty, untidy appearance)	
• Is hearing voices or seeing things that are not there	
• Neglects or has difficulties in carrying out usual work, school performance, domestic or social activities	
• Behaves strangely e.g. running out of the house, running naked	

Seizures

Someone who has ANY of the following:	May have:
• Suddenly falls down and has sharp, shaky body movements (seizures)	**Epilepsy**
• During the seizure, he or she:	
– loses consciousness or does not respond normally	
–has stiff body, arms and legs	
–may bite their own tongue, injure themselves, and wet or soil their clothes	
• After the seizure: the person may feel very tired, sleepy, confused, and complain of headache, muscle aches	

Excessive sadness or worry

Someone who has ANY of the following:	May have:
• Complains of many physical symptoms but no physical cause has been found (e.g. headache, burning sensations, aches and pains)	**Depression or anxiety**
• Has low energy; is always tired; has sleep problems or does not want to eat	
• Always seems sad or anxious or irritable; feels hopeless or helpless or guilty	
• Has low interest or pleasure in activities that used to be enjoyable	
• Worries or thinks about day-to-day problems too much	
• Is not able or motivated to do their usual job, housework or social activities	
• Has been thinking of harming themselves, e.g. ending their life	

Alcohol problems

Someone who has ANY of the following:	May have:
• Often appears to be affected by alcohol (e.g. smells of alcohol, looks intoxicated, staggers when walking, slurred speech)	**Alcohol use disorder**
• Because of alcohol, often injures themselves, e.g. from falling down, fights, or walking in traffic	
• Has physical symptoms from excessive alcohol use (e.g. can't sleep, very tired, can't eat, vomits, complains of bad stomach, diarrhoea)	
• Has financial difficulties or crime-related or domestic problems	
• Has difficulties in carrying out usual work, school, domestic or social activities; does not attend or often arrives late	

Khat problems

Someone who has ANY of the following:	May have:
• Often appears drug-affected (e.g. low energy or agitated, fidgeting, slurred speech, suspicious, may see or hear things that are not real)	***Khat* or other drug use disorder**
• Shows signs of drug use, e.g. skin infection, unkempt appearance, burned lips, bad or worn teeth, has *dukak* (unpleasant dreams)	
• Has financial difficulties or crime-related legal or domestic problems	
• Has difficulties in carrying out their usual work, school, domestic or social activities; does not attend or often arrives late	

Problems with forgetfulness

An older person who has ANY of the following:	May have:
• Can't tell the time of day, or forgets where they are, forgets the names of objects or may not recognise familiar people	**Dementia**
• Gets lost when outside the home	
• Has difficult or embarrassing behaviour	
• Often loses emotional control, is easily upset, irritable or tearful	
• Lack of attention to personal hygiene, incontinence	
• Has difficulties in carrying out their usual work, domestic or social	

activities	

Child mental health problems

A child who has ANY of the following:	**May have:**
• Is usually kept in the house , and may be tied up or chained	**A childhood mental health or a developmental problem**
• People say the child behaves badly (e.g. is naughty, aggressive)	
• People say the child behaves oddly, or is possessed or cursed	
• Does not speak or respond like other children of the same age	
• Has problems dressing, feeding or washing themselves or using latrine at the usual age	
• Is always playing on their own, rocking, flapping their hands, or other odd behaviour	
• Is often being bullied or teased by other children	
• Is having problems at school or is often sent home by teachers	

1.9 What should we do when we recognise someone has mental illness?

You will learn what to do when you recognise someone with a mental illness other than schizophrenia in Chapter 38.

1.10 Summary

- Mental illnesses are caused by problems in the mind, which happen when people have lots of life difficulties and stresses
- Mental illness cause disability, which is when people find it difficult to do their usual activities
- Everyone with mental illness has a chance of recovery (getting better)
- There are different types of mental illness which have different signs

2 What is schizophrenia?

2.1 What kind of illness is schizophrenia?

Schizophrenia is a type of mental illness. People with schizophrenia have problems with the way their mind works in the following areas:

- Perceiving: To people with schizophrenia things that are not real might seem as if they are real
- Thinking: People with schizophrenia have confused or strange thinking. They believe things that are not true.
- Feeling: People with schizophrenia have fewer emotions or stronger emotions than usual
- Behaviour: People with schizophrenia may behave in a strange way.

2.2 What are the symptoms of schizophrenia?

There are four groups of symptoms of schizophrenia.

1. Hallucinations and delusions

Hallucinations are when a person experiences something that is not really happening. They may hear sounds that are not really there, for example a voice telling them to do something. They may see things, feel things or smell things that are not really there.

Delusions are when a person believes something that is not really true. For example, they may believe that they have special powers. Or they may believe that people are trying to poison their food.

Hallucinations and delusions may make people behave in a strange way. For example, they may talk to themselves, say meaningless words, speak in a strange language or speak very fast. They may also have mood swings, from very happy or irritable to feeling very sad.

2. Problems with motivation

People with schizophrenia often have low levels of motivation. They often do things slower, including thinking, talking and moving. They may feel they have no energy to do anything. They may not bother washing or dressing properly. They may not be interested in talking to other people. They may not show any emotions.

3. Problems with thinking clearly

People with schizophrenia often have problems concentrating on a task, or remembering things. This means it is difficult to follow a conversation or do household tasks such as cooking.

4. Lack of awareness of illness

Often people with schizophrenia do understand or believe that they are unwell. They may not realise that they are behaving strangely.

Yosef's story

Yosef is a 24 year old man who lives in a rural kebele with his mother, Addis, father, Solomon and younger siblings. About five years ago he was working hard on his family's farm. He had friends in village who he went to the alcohol shops with, or drank coffee. He wasn't wealthy but was seen as successful in the kebele. He always went to the kebele meetings and contributed to Edir. His mother hoped he would get married soon.

About five years ago Yosef began to behave in a strange way. People in the kebele noticed that he talked to himself and laughed to himself. He confided in his mother that Saint Mary was communicating with him and told him that he had to do special tasks. Sometimes he ran away for several days. He began to believe that the neighbours hated him and were trying to ruin his crops. Sometimes he shouted at the neighbours and threatened them.

As time has gone on, he has stopped talking about his strange beliefs most of the time and he no longer runs away. But he is still not back to his usual self. He has stopped working on the farm and spends the days by himself. He stopped washing and dressing properly. Things don't seem to be improving for Yosef. Every few months he becomes much more unwell again. When this happens he seems to be very distressed and shouts at the neighbours again.

2.3 What causes schizophrenia?

There is not one thing that causes schizophrenia and you cannot catch schizophrenia from someone else. **Schizophrenia is usually caused by a combination of vulnerability and life stress**. Protective factors can stop schizophrenia from developing or getting worse even when vulnerability and life stress are there. We don't always know why a person gets schizophrenia.

Vulnerability

Vulnerability means things that happen before a person is born or early in life. It includes:

- A person's mother having problems during her pregnancy, for example an infection.
- Having a difficult birth during which the baby is injured.
- Having a head injury.
- Using khat from an early age.
- Being abused during childhood.
- When someone has schizophrenia in the family most of the family members will not develop schizophrenia, but there is more chance of it happening.

Life stress

Life stress means events or circumstances in a person's life that put a lot of pressure on them. They might lead them to feel angry, anxious or sad. These might include:

- Being disappointed about a big thing. For example, a relationship or in work.
- Moving to an area where they don't know anyone
- Family conflict
- Illness
- Bereavement
- Having children

None of these things alone mean that a person will get schizophrenia. It only happens when the person has at least one type of vulnerability and at least one type of life stress.

Preventative factors

Preventative factors are things that help to stop a person becoming unwell with schizophrenia, or stop it from getting worse. They include:

- Good social support
- Good coping strategies
- Regular anti-psychotic medication

Yosef's story

Yosef's family believe that his problems are due to being possessed by spirits. His problems all seemed to start when he became very disappointed that he did not marry the woman he expected to. In the years before Yosef's problems started life had been stressful for the family. Some of his younger siblings had died and there had been a poor harvest a few years in a row.

2.4 What beliefs do people have about schizophrenia?

People with schizophrenia, their families and other people in the community may have beliefs about what causes schizophrenia which are different from the explanation given here. In Ethiopia the most common beliefs are that schizophrenia is caused by spirit possession, evil eye or possession by the devil. The same person may even have lots of different ideas about what causes it. Having different beliefs is not always a bad thing by itself. Having different beliefs becomes a problem when it results in:

- People with schizophrenia not getting treatment that works, for example not being taken to the health centre or hospital to get medication
- People with schizophrenia being treated badly, for example being beaten to exorcise the devil

2.5 How long does schizophrenia last?

Schizophrenia can either last a short time (even one episode), but usually lasts longer, even for many years. There are two main ways that people can be affected to schizophrenia:

- **Short-term, more severe illness**: During this phase the person can be very disturbed. They often have problems with hallucinations and delusions. This may lead the person to behave strangely. They may speak and think in a strange way, and may become angry. It is usually during this phase that the family of the person try and get help, for example by going to holy water or the hospital. The acute phase usually lasts from weeks to months.

- **Long-term, established illness**: During this phase the person may stop behaving strangely, but they still have problems with motivation and with thinking clearly. They may have problems with doing usual activities, such as getting dressed or doing farm work. They may find it difficult to talk to other people or socialise. This phase can last for months, years or can be life-long.

Most people with schizophrenia have a short-term, more severe illness at the beginning. What happens next varies a lot from person to person.

- A few people do not have any more severe illness. They may or may not have some less severe illness.
- Most people with schizophrenia have repeated episodes of more severe illness. These are known as relapses. In between they usually have some less severe illness.
- A few people stay unwell with more severe illness all the time

2.6 Can people recover from schizophrenia?

The important thing to remember is that everyone with schizophrenia has a chance to get better and to recover. Even if an individual does not get rid of all their symptoms, they have a good chance of getting back to their normal activities. Recovery can mean different things to different people. It doesn't usually mean that an individual is 'cured' of schizophrenia. Instead it means that things have improved in a way that is important to that person. Getting lots of support, taking medication and not using alcohol or khat make it more likely this will happen.

Even if a person with schizophrenia is feeling much better, they may suddenly become unwell again with a relapse. Relapses may happen due to not taking medication, physical illness, life stress or for no particular reason. The signs that a relapse is coming include problems with sleep, being isolated from people, being angry or anxious and stopping medication. In Chapter 30 you will learn how to prevent and manage relapses. Having a relapse doesn't mean they will be unwell forever and it is important for the individual and family not to give up hope that things will improve.

2.7 How is schizophrenia diagnosed?

There is no test for schizophrenia. The doctor or nurse decides whether someone has schizophrenia or not by listening to their problems and how long they have lasted.

2.8 How common is schizophrenia?

Schizophrenia is not a very common disease. In a kebele of 5000 people, there might be around 10 people with severe schizophrenia.

2.9 How do we give information about schizophrenia?

You will learn how to give information about schizophrenia in Chapter 16.

2.10 Summary

- People with schizophrenia have hallucinations, delusions, problems with motivation, problems with thinking clearly, and usually do not understand that they are unwell
- Schizophrenia is caused by a combination of vulnerability (early events) and life stress
- People with schizophrenia can have periods of short term, severe illness and long-term less severe illness
- All people with schizophrenia have the chance of recovery (getting back to usual activities)
- Schizophrenia is not very common

3 Medication for schizophrenia

3.1 What is anti-psychotic medication?

Taking regular anti-psychotic medication is an important part of treatment for all people with schizophrenia.

3.2 Why is it important to take anti-psychotic medication?

Taking anti-psychotic medication improves the chances of recovery. Anti-psychotic medication is good at reducing the following symptoms of schizophrenia:

- Hallucinations (seeing or hearing things that aren't really there)
- Delusions (believing things that aren't true)

Anti-psychotic medication is less helpful for the following symptoms of schizophrenia:

- Problems with motivation, including showing emotions
- Problems with thinking clearly, including concentrating and being organised

3.3 When is anti-psychotic medication needed?

- When a person with schizophrenia is unwell, anti-psychotic medication is needed to reduce the symptoms
- Even when the person has become better and has no symptoms, medication is still needed to prevent relapse (i.e. prevent the person becoming unwell again).
- Antipsychotic medication works best when taken regularly but it can be difficult for patients to keep taking medication.

3.4 What types of anti-psychotic medication are there?

Anti-psychotic medications are available in tablet and injection forms (see Table 1). Injections are normally given when the person with schizophrenia has difficulty remembering to take their tablets or has experienced lots of relapses (when the severe illness comes back).

Table 1 Medications for schizophrenia

Name of medication	Brand name	Type of drug	How often it should be taken
Haloperidol	Haloperidol	Tablet	Once or twice a day
Chlorpromazine	CPZ	Tablet	Once or twice a day
Fluphenazine	Modecate	Injection	Fortnightly to monthly

3.5 What side effects do anti-psychotic medications have?

Medication can sometimes cause problems (side effects) as well as help (See Table 2). The side-effects from anti-psychotic medication are common so it is important that you know how to recognise them. Despite these problems, for most people their quality of life is better when taking the medication compared to when not taking it.

Table 2 Side effects of anti-psychotic medications

Common
The person feels restless and cannot sit still
The head, neck or body becomes stuck in an unusual position because of muscle stiffness
The hands shake
The person moves very slowly
The person is sleepy during the day
The mouth is dry
A lot of saliva is produced
Constipation
The person feels dizzy when they stand up too quickly from lying down or sitting.
The person wants to eat more than usual
Unusual movements of the head, neck, arms or legs
Less common
Seizures
Suddenly developing stiff muscles, fever, and confusion
Sexual problems
Skin rash
The person cannot pass urine

3.6 Can pregnant and breastfeeding women take anti-psychotic medication?

Depending on the woman, pregnant and breastfeeding women may need to stop or reduce anti-psychotic medication.

3.7 How do we help people with schizophrenia to take their medication?

You will learn how to help people with schizophrenia to take their medication regularly in Chapter 20, including how you can help with side effects.

Yosef's story

After several years of being unwell, Yosef's parents took him to the local health centre as they had heard he might be able to get help there. Here a nurse diagnosed him with schizophrenia. The nurse gave him anti-psychotic medication, called haloperidol. He was told to take the medication twice a day. Yosef found that taking the medication stopped the voice of Saint Mary in his head. His parents noticed that he stopped shouting at the neighbours and running away. However the medication also gave Yosef some problems. He is often very tired and drowsy and his hands often shake.

3.8 Summary

- Anti-psychotic medication is needed to help people with schizophrenia to recover
- It is important to take medication when the individual is unwell, and to carry on taking the medication when the individual is well (to stop the illness coming back)
- Anti-psychotic medication can be given in tablets or injections
- Anti-psychotic medication can cause side-effects

4 Disabilities related to schizophrenia

4.1 What is disability?

Disability is when a person cannot do the activities that we would normally expect them to do, given their age and social circumstances. Disability can include:

- Problems with the body, for example blindness
- Problems with doing physical activities, for example walking
- Problems doing usual work and social activities, for example going to market.

4.2 What causes disabilities?

Disabilities in people with schizophrenia are caused by **a combination of the social environment in which the person lives and the illness itself.** For example,

- An individual may not be allowed to vote at the kebele meeting because of stigma and discrimination in the community (see Chapter 6).
- A person who doesn't have any family may not work because they are not being encouraged to do so.
- Problems with self-care may result from lack of motivation, a symptom of the illness.

4.3 What limitations do people with schizophrenia have?

People with schizophrenia usually experience many types of disability. These include:

1. Problems with self-care

This includes problems with washing, dressing, brushing hair and eating at the right time.

2. Problems doing household tasks

This includes problems with cooking, washing clothes, chopping wood or fetching water.

3. Problems with social interactions and participating in community life

This includes problems with having conversations with people and problems attending church, funerals or Edir meetings.

4. Problems in working

This includes problems doing farm work, trading or business.

5. Problems in looking after children

This includes problems giving children love, feeding and clothing them.

6. Problems with marital relationships

This includes not getting on well and arguing a lot.

4.4 What is the impact of having disabilities?

Disability may be more upsetting to the individual than the symptoms themselves. For example, finding it difficult to drink coffee with others may be more distressing than simply hearing voices. Disabilities may result in problems with money. For example, having problems with farm work is likely to mean the individual has less money. Disabilities may also have a big impact on the rest of the family. For example if a mother with schizophrenia finds it difficult to look after her children, other family members may need to help out. These family members may then have trouble looking after their own farm properly (see Chapter 5).

Yosef's story

Yosef does not often wash or dress himself. He no longer helps on the family's farm. He does not contribute to Edir anymore, instead he relies on his parent's contributions. He doesn't have any friends any more and does not go to Church.

4.5 How do we assess disabilities?

You will learn how to assess what kinds of disabilities people with schizophrenia have as part of the Needs Assessment (see Chapter 12).

4.6 How do we work with individuals to improve their situation?

The aim of rehabilitation is to work with individuals to improve their situation so they are less disabled and can get back to their usual activities. Rehabilitation should be an empowering process. This means the needs and wishes of the individual are at the centre of the work. Rehabilitation isn't about 'doing things' to or for people who are disabled. It is about working together to improve their life and work towards recovery. Recovery can mean different things to different people. It doesn't usually mean that an individual is 'cured' of schizophrenia. Instead it means that things have improved in a way that is important to that person. You will see that all of CBR is focused towards rehabilitation.

4.7 Summary

- Disability is when an individual cannot do the activities we would normally expect
- Disability is caused by a combination of the social environment and the illness
- People with schizophrenia can have problems with: self-care, household tasks, participating in community life, working, looking after children and marital relationships
- Rehabilitation involves work with the individual to reduce disability.

5 Impact of schizophrenia on the family

As well as having a big impact on the individual, when a person has schizophrenia it also has a big effect on the whole family. This is because the family are usually their main carers. These are some of the effects the illness can have on the family.

5.1 Coming to terms with the illness

Not many families immediately know or believe that their relative has a mental illness. When the individual is very unwell, the family members may be scared by what is happening. When the episode is over, everyone wants to forget this painful time and focus on the future. Families may also look for other answers, hoping that the symptoms were caused by a physical problem or stressful events that can be removed.

5.2 Stigma and discrimination

Even when families know that their relative has a mental illness, they may not want to talk with others about it, because they fear other people's reactions or might be embarrassed. Other people in the community may suggest that there is something wrong with the family to cause the illness. The family may not want to invite anyone to the home. Or they may be anxious about leaving the individual at home alone. People with schizophrenia often find it difficult to get married. This is sometimes because of the stigma towards them, which may continue even if they become well. This puts an extra burden on the parents. See Chapter for more about stigma and discrimination.

5.3 Heavy responsibility of caring

Family members may spend a lot of their time looking after the person with schizophrenia. It is often female caregivers, either the individual's mother or wife, who take on most of the responsibilities. Their household routine may be disrupted and it may be difficult to attend social gatherings such as weddings. Sometimes caregivers, for example brothers and sisters, even decide not to marry so that they can take care of a person with schizophrenia. In the end the family may become isolated from the community. Some families may feel they do not get enough support from wider family members and the community. Families may be concerned that the individual will run away, harm their neighbours' property, or other people or get hurt themselves. This

may mean that, as a last resort, families chain or tie up the individual to protect them and other people. All of these issues mean the family members often become stressed, full of worry and exhausted.

5.4 Economic impact

People with schizophrenia usually need to take medication everyday for many months or years. The cost of this, along with the cost of seeing a nurse or doctor, and cost of transport to the health centre or hospital, means the family has to spend a lot of money on the individual. The person with schizophrenia may find it difficult to do their own farm work, day to day labouring or business. This means that the other family members have more work to do, and, there may be less money coming into the family. Also the family members may be able to do less work themselves, because they are carers.

5.5 Family conflict

Family members may not understand the illness and blame the individual for their bad behaviour and for not working. They may become frustrated and angry that the individual is not getting better. Conflict in families tends to make schizophrenia worse, and it is important to try to reduce this. The individual themselves may feel bad about all the money spent by the family on treatment.

Yosef's story

The living condition of Yosef's whole family has got worse because Yosef cannot work. Addis is often scared to leave Yosef alone in case he runs away again. This makes it difficult for her to do her usual work like going to market. His parents can't go to funerals or weddings unless he is asleep. They do not have any visitors at the house because they are ashamed of Yosef. They feel that nobody in the community helps them. Sometimes the whole family has arguments about Yosef. They argue about why he is not getting any better.

5.6 How do we help the families of people with schizophrenia?

The whole of CBR aims to improve the situation of families, by helping individuals with schizophrenia get back to their usual activities. In particular, you will learn how to improve the family environment in Chapter 25.

5.7 Summary

- There may be extra costs to the family of a person with schizophrenia and they may have problems doing usual activities
- The family may experience stigma
- There may be conflict within the family

6 Stigma and discrimination

6.1 What is stigma?

Stigma is when people automatically think bad things about a person just because they have a mental illness. Stigma from other people towards people with schizophrenia consists of three problems.

- The problem of knowledge. This is called ignorance.
- The problem of attitudes. This is called prejudice.
- The problem of behaviour. This is called discrimination.

All these types of stigma can be found in family members, community members and health workers. Stigma from the person with schizophrenia towards him or herself, because they start to believe the negative things that other people say, is called self-stigma. Stigma and discrimination is also experienced by other people, for example people with physical disabilities, albinism, HIV or epilepsy.

6.2 What types of stigma do people with schizophrenia experience?

Ignorance

Most people in the community and some health workers do not have a good understanding of schizophrenia. This means they can have some of the following false beliefs:

- Nobody recovers from schizophrenia
- There is no treatment for schizophrenia
- People with schizophrenia are violent and dangerous
- People with schizophrenia are lazy and you cannot trust them
- Schizophrenia is the result of spirit possession
- Schizophrenia is the result of a weak character
- Everything people with schizophrenia say is nonsense
- People with schizophrenia cannot make decisions about their own lives

Prejudice

Prejudice is when people feel emotions such as anxiety, anger, hostility or disgust towards people with schizophrenia, as well as having ignorant thoughts. For example,

a neighbour may feel scared whilst talking to a person with schizophrenia, even if the person is not acting in an aggressive way.

Discrimination

Discrimination is when people behave differently towards people with schizophrenia, because of their ignorance and prejudice. This can mean that individuals are not able to do the activities that they used to when they were well. People with schizophrenia may continue to be discriminated against even though they have recovered. They often feel that discrimination is more distressing than the symptoms of the illness.

Here are some examples of discrimination which people with schizophrenia experience:

- Community members do not greet the individual in the neighbourhood
- Community members call the individual rude names, laugh or gossip about them
- Friends do not want to talk or drink coffee with the individual
- Community members do not listen to the individual when they try to contribute at community meetings, such as kebele meetings or edir meetings
- The individual cannot get a job or cannot be involved in a microfinance group because employers or group members think they are lazy and unreliable
- The individual finds it difficult to get married
- The family asks the individual to hide when relatives visit the house
- Family members may tie up the person with schizophrenia. This is usually done because the person is very unwell and the family cannot control them. However sometimes it is done because the family believes the individual is possessed by spirits or the devil.

Self-stigma

Some people with schizophrenia start to believe the negative attitudes that others have towards them. This can result in:

- Low self-esteem
- Feeling critical towards themselves
- Feeling hopeless
- Depression

- Being isolated

People with schizophrenia may stop themselves doing activities because they expect people to be rude to them, laugh at them, or treat them differently.

6.3 What types of stigma do families experience?

The family members of people with schizophrenia commonly experience stigma too. The whole family may be treated with less respect or people may avoid them. They may also be blamed for the illness in the individual.

Yosef's story

Sometimes people laugh and gossip about Yosef when he goes outside. Sometimes children throw stones at him. Yosef doesn't have any friends anymore. His family doesn't think he will ever get married now he has become ill. Once when he was feeling better he went to a kebele meeting and tried to add to the discussion. The other people there didn't say anything bad to him, but they ignored him. This made Yosef feel bad and he didn't go the meeting again. He has started to believe other people and thinks he is worthless.

6.4 How do we reduce experiences of stigma?

You will learn how CBR can reduce experiences of stigma and discrimination in Chapter 28.

6.5 Summary

- Stigma includes problems of knowledge (ignorance), attitudes (prejudice) and behaviour (discrimination).
- Many people with schizophrenia, and also their families, experience stigma
- Experiences of stigma may include: being laughed at or called names, being excluded from community activities or work, and being kept hidden or tied up

7 Human rights

7.1 What are human rights?

The term 'human rights' describes the belief that all people have basic rights, including the right to life, freedom of speech, belief and freedom from fear. The Ethiopian constitution states that human rights and freedom are in our human nature (Ethiopian constitution, chapter 10, No 1). All people have human rights, regardless of age, sex, ethnicity or religion. These rights enable a person to live their life with worth and dignity. The Ethiopian Constitution states that human rights should not be violated.

7.2 What human rights do people with mental illness have?

People with mental health problems have equal rights like any other Ethiopian citizen; they have the same need for respect and care. The following rights apply to people with mental illness, just like all other people:

- They should not be chained, suffer, or be locked up at home because of their illness
- They should not be held by police just because they are ill
- They have the right to have a family of their own, get married and have children;
- They have the right to work
- They have basic rights for food, clothing, housing and medical services; they should not be left to starve, or be homeless.
- They should not be abused, disrespected or called bad names, or beaten to drive out bad sprits.

It is quite common for people with mental illness to be denied their human rights.

Yosef's story

When Yosef becomes very unwell his parents sometimes chain him to the wall of their house. They do this because they are worried he will run away and hurt someone, or get eaten by hyenas or drown in the river.

7.3 How do we deal with human rights problems in people with schizophrenia?

In Chapter 19 you will learn how to help protect the human rights of individuals.

7.4 Summary

- All people have the same Human rights including the right to life, freedom of speech, belief and freedom from fear.
- It is quite common for people with schizophrenia to be denied their human rights

8 The importance of the community

8.1 What is the community?

Everybody lives within a community of some kind. When we say community we mean:

- A group of people living in the same place, for example the kebele
- A feeling of shared attitudes and interests

For people with schizophrenia their community might include:

- Their friends, neighbours and relatives
- Community members that live in the same kebele, even if they do not know them
- Community leaders such as kebele leaders, priests or the headteacher

There are many community resources in every kebele. These include:

- Churches and mosques, including priests
- Edir groups
- Religious groups such as mahaber, tsewa and lika
- Primary school
- Women's Associations and Youth Associations
- Kebele administration
- Markets
- Traditional healers, for example tanqway or herbalists, and holy water sites and holy water priests

8.2 What problems do people with schizophrenia have in community life?

People with schizophrenia often find they have problems accessing the community resources and doing their usual community activities (see Chapter 26). These might include:

- Not socialising with friends and neighbours, for example drinking coffee
- Not attending church or mosque
- Not participating in religious groups such as mahaber
- Not participating in Edir
- Not attending community groups such as the Women's or Youth Association

8.3 What role does the community have in the life of the person with schizophrenia?

Positive influences

The community can have a positive or supportive influence on the person with schizophrenia, such as:

- Making the individual feel welcome when they participate in community activities
- Helping the individual and family with food or other practical support when they are having a particularly difficult time
- Giving emotional support to the family, for example listening to their problems
- Organising community activities that the person with schizophrenia may wish to be part of. This includes government schemes, such as adult literacy groups, and local groups, such as Edir.
- Helping the family in transporting the individual to the health centre or hospital

Negative influences

The community can also have a negative influence on the person with schizophrenia. The community may make it even more difficult for the individual to participate in their usual activities. This is usually due to stigma and discrimination. See Chapter 6 for more detail.

8.4 What is the role of the community in CBR?

CBR aims to increase the positive influences of the community, and reduce the negative influences. It also aims to help people with schizophrenia to access the community resources. The community also has an important role in making sure the positive changes that have been made during CBR are continued after the CBR worker has left (see Chapter 31). The community also benefits through CBR. Once the individual is back to doing their usual activities, they are likely to be a more productive and active community member.

Yosef's story

Yosef used to be an active member of his kebele. The kebele chairperson thinks the community has been affected by his illness, and if Yosef could get better the community would benefit.

8.5 Summary

- People with schizophrenia often have problems taking part in community life
- The community can have a positive or negative influence on the person with schizophrenia
- The aim of CBR is to increase the positive influences and reduce the negative influences of the community.
- CBR helps individuals to become more productive and active, so the community also benefits

SECTION B: Learn how to help people with schizophrenia and their families through CBR

9 Overview of CBR delivery

9.1 What is community-based rehabilitation?

Community-based rehabilitation is a way to help people with disabilities to be included in the life of their communities. It aims to improve the quality of all areas of a person's life. The focus is always on the needs and wishes of the individual. CBR benefits the family, by reducing the burden upon them. It also benefits the whole community, by helping the individual to be a more active and productive community member. Sometimes it takes a long time to see the positive impacts of CBR, so it is important that everyone involved is patient and stays positive.

9.2 What are the principles of CBR?

1. Use a holistic approach

CBR addresses all aspects of the person's life including:

- Social
- Livelihood
- Health
- Education
- Empowerment (a person's ability to make decision about their own life)

These are all areas where the individual might be having problems and where CBR can make a positive change.

2. Work with the family and the community.

The family are the main carers for people with schizophrenia and the aim is to hand over care to family at the end of your involvement. The community also has an important role in the individual's life. Working with the community is required to maximise the impact of the family work and to ensure the positive impact of CBR stays after you have gone.

3. Encourage respect for human rights

All of CBR, whether work with the individual, family or community, should encourage respect for the human rights of the individual. Treating people with schizophrenia with dignity and respect is empowering and will make it more likely they will get back to their usual activities.

4. Link to existing services

Where possible, should involve linking the individual to existing services, for example the government run adult literacy scheme.

9.3 Who is involved in CBR?

The person with schizophrenia

The person with schizophrenia should always be at the centre of CBR. By always focusing on their concerns, needs and wishes you will be more likely to help them to recover in a way that is important to them. In this manual we will usually refer to the person with schizophrenia as 'the individual'.

Primary caregiver

The primary caregiver is the main person who looks after the person with schizophrenia. This may be a spouse, parent, sibling or other relative. The primary caregiver should be your main point of contact within the family. They should also be present at all home visits. They will have been identified before you start the CBR.

Other family members

At your first visit you should find out which other members are involved in the care of the person with schizophrenia. This may include a spouse, parent, sibling, child or grandparent. Depending on the individual circumstances, other family members may be involved in many of the home visits or only a few. The manual will tell you when it is particularly useful to involve other family members. In this manual we will often refer to the primary caregiver and other family members as 'the family'.

You, the CBR worker

You will arrange and lead all the home visits to the family and do all of the community work.

Your supervisor

You will be supported by your supervisor. Your supervisor will come with you at certain home visits, for example for the needs assessment and goal setting. You will also meet regularly with them to discuss the progress of each individual (see Chapter 34).

Health Centre staff

You will be linked to one health centre, where all the people with schizophrenia you are working with will receive their medical care. You will need to go with the individual to the health centre every few months, around the time of each CBR Review. There are

several situations when you should send the individual for a review at the health centre (see Chapter 37).

Trial psychiatric nurse

In certain circumstances you or your supervisor may need to contact the psychiatric nurse. This will usually be when a serious event has occurred, such as the individual attempting suicide. There is more detail on when to contact the psychiatric nurse in Chapter 35.

Community leaders

Community leaders will be invited to attend awareness-raising meetings. You may also need to have individual meetings with certain community leaders to help with parts of CBR.

Community members

Community members will be invited to attend public awareness raising events.

9.4 Where and when does CBR take place?

Most of CBR takes place through home visits, where you will meet with the individual and family. These visits will usually last between 30 and 90 minutes. In some cases the individual or family may not feel comfortable for you to visit them at home. At the first visit you should offer to see them at the health post instead, if they wish. Wherever you meet the individual, the caregiver or another family member should always be present or nearby. How often you make the home visits are depends on the phase. You will learn about the Phases in section 9.7. We suggest the following:

Phase I: Every week

Phase II: Every 15 days

Phase III: Every month

The community work will take place at different places in the kebele. For example, you may meet the kebele leader at the kebele office.

9.5 How long does CBR last?

You will work with each individual for 12 months. Even if the individual becomes much better whilst you are working with them, you should still continue to visit them during the 12-month period. This will help them to keep well and develop more skills.

9.6 How do we start CBR (initial visit)?

Your supervisor will give you the name and contact details of the individuals you will be working with. You will arrange the first home visit by phone or in person. You can ask the Health Extension Worker to help you to find the home of the individual. Over the first one or two visits you should give the following information:

- Introduce yourself
- Describe the structure and purpose of CBR (see section 9.1 and 9.7). Explain that you are not able to offer money, a loan or a job.
- Describe the modules you might cover (see section 9.7)
- Discuss confidentiality (see Chapter 10, section 10.6)
- Explain that the caregiver or another family member should be present or nearby when you do the visits

You should also gather the following information:

- Ask why they decided to participate in CBR
- Ask how long they have been unwell and when they first sought help
- Ask if they are generally well or unwell at the moment. Ask what problems the illness is causing at the moment e.g. behaving strangely, being unmotivated.
- Relationship of primary caregiver to individual
- Other family members who will also be involved in CBR. In particular think about which family member/s have most power and influence. This may be an older, male relative.
- Home environment including who lives in the home, the type and condition of the home, position of the home and any issues with access, and income and land owned by the family.
- Preferred location of visits (home or health post)
- If the individual is currently chained
- If the individual is currently accessing the health centre
- If the individual is currently accessing medication
- Contact details of the primary caregiver
- Urgent needs which need addressing immediately, before the next home visit. For example, the individual is suicidal or seriously ill with a physical health problem.

- The particular strengths, opportunities and challenges for that family.

You should record this information on the Initial Assessment form (Form 1).

9.7 What are the phases of CBR?

This CBR is divided into three phases. At each phase you will be helping the individual in different ways. This is because as time passes people with schizophrenia will usually have some improvement, so their needs will change. At the beginning of each Phase you will conduct a CBR Review together with your supervisor. The key areas for each phase are described below and summarised in Table 3.

Phase I

During Phase I the aim is to get to know the individual and family and to develop a trusting relationship with them. You will complete the four Phase I modules with all individuals. These modules are important for all people with schizophrenia as they address basic needs:

- Understanding schizophrenia
- Improving access to health services
- Dealing with human rights issues, when they arise
- Preparing for a crisis

CBR Review I, at the beginning of Phase I, helps to decide which order to address these modules. The length of Phase I depends on the particular circumstances of the individual. It may last for around 2 months, but it may be much shorter or much longer.

Phase II

Aside from the basic needs addressed in Phase I, people with schizophrenia have very different disabilities and needs. In CBR Review II, at the beginning of Phase II, you will therefore do a Needs Assessment. This helps you to decide which areas to focus on. The Needs Assessment is described in Chapter 12. On the basis of the Needs Assessment and the wishes of the individual and family, you will set goals to work towards during Phase II. Goal Setting is described in Chapter 13. To make sure we are taking actions to achieve these goals, you will then deliver a series of linked Modules. The exact modules that you deliver to the individual will depend on which problems have been identified in the Needs Assessment. Depending on the needs of the individual Phase II may include the following modules:

- Supporting individuals to take medication
- Improving day to day functioning
- Improving the family environment
- Managing stress and anger
- Taking part in community life
- Getting back to work
- Dealing with stigma and discrimination
- Dealing with distressing symptoms
- Improving literacy
- Improving physical health

In Phase II you will also set up a Family Support Group in each kebele. All caregivers, and in some cases people with schizophrenia, are invited to these Groups (see Chapter 32). The length of Phase II depends on the particular circumstances of the individual. It may last for around 3 to 6 months, but it may be much shorter or much longer.

Phase III

The new focus in Phase III is prevention of relapse (stopping the illness returning). Therefore the Module that we cover with everyone in Phase III is:

- Taking control of your health

However, individuals will still have different needs, and these are likely to have changed over time since Phase II. In CBR Review III at the beginning of Phase III you will therefore do another Needs Assessment. Depending on the needs of the individual, and the goals that are set, Phase III may include any of the Phase II modules. The Family Support Groups should continue through Phase III. The length of Phase III depends on the particular circumstances of the individual. It may last for around 3 to 6 months, but it may be much shorter or much longer.

Table 1 Overview of RISE CBR intervention

Phase	Home visits			Community mobilisation	Family support group
	CBR Review	**Goals**	**Modules**		
1	CBR Review 1: • Initial Assessment • Needs Assessment • Goal setting for Phase 1 • Rehabilitation plan • Risk Assessment • Accompany to health centre	Individual and caregiver have been informed of what schizophrenia is, available treatments, and the potential for recovery	*Understanding schizophrenia*	Task 1: Meet with health extension worker/s Task 2: Identify key community leaders Task 3: Identify key community resources Task 4: Ascertain what community mobilisation relating to mental illness has already taken place or is planned Task 5: Meet with key community leaders Task 6: Community awareness-raising events Task 7: Identify potential employment opportunities in the sub-district	
		Individual is able to access medication	*Improving access to health services*		
		Individual is able to attend health centre for mental health as indicated by clinical status			
		Crisis management plan is in place	*Preparing for a crisis*		
		Person with schizophrenia is not chained or restrained	*Dealing with human rights issues*		
2	CBR Review 2: • Needs Assessment • Goal setting for Phase 2 • Risk Assessment • Update rehabilitation plan • Invite to Family Support Group • Accompany to health centre	Individual is willing to take medication	*Supporting individuals to take medication*	Task 8: Individual meetings with sub-district leaders Task 9: Individual meetings with Edir leaders Task 10: Individual meetings with religious leaders Task 11: Individual meetings with traditional healer/ holy water priest/ attendant Task 12: Demonstrate progress of client/s to community leaders/ wider community Task 13: Community awareness raising consolidation Task 14: Facilitate employment opportunities in the sub-district Task 15: Individual meetings with literacy group leader	Family support group active
		Individual has strategies to remember to take medication			
		Individual feels side effects are improving			
		Individual feels symptoms are improving	*Dealing with distressing symptoms*		
		Individual is able to access health services for physical and sexual health needs and contraception when required	*Improving access to health services*		
		Individual has strategies to deal with stress and anger	*Managing stress and anger*		
		Individual has information to make decisions about health-related behaviours	*Improving physical health*		
		Individual has good physical, sexual and reproductive health			
		Individual is not malnourished			
		Individual has restored participation in livelihood activities, including farm work	*Getting back to work*		

Table 6.2 continued					
2		Individual participates in community life	*Taking part in community life*		
		Individual participates in religious activities if they are important to the individual			
		Person with schizophrenia is able to interact socially with neighbours and friends			
		Individual has improving ability to do parenting activities	*Improving the family environment*		
		Individual has improved relationship with family members			
		Caregiver has improved ability to cope			
		Individual has improving self-care	*Improving day to day functioning*		
		Individual has improving ability to do household tasks			
		Individual has improving self-esteem	*Dealing with stigma and discrimination*		
		Individual does not feel discriminated against			
		Individual is not the victim of physical, sexual or emotional abuse	*Dealing with human rights issues*		
		Individual has basic literacy skills	*Improving literacy*		
3	CBR Review 3: • Needs Assessment • Goal setting for Phase 3 • Risk Assessment • Update rehabilitation Plan • Accompany to health centre CBR Review 4: • Continuing Care Assessment	Individual has relapse prevention plan	*Taking control of your health*	Any Phase 2 Community Mobilisation task	Support group active
		Any Phase 2 goal	Any Phase 2 module		

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9.8 What are the CBR Reviews?

The CBR Reviews are a chance for you to discuss the individual's progress with the individual, the family and your supervisor. They take place at the beginning of each Phase. What you cover in the CBR Review depends on the Phase. Just before or around the time of each CBR Review you should go with the individual to the health centre. By doing this you will get more information about the progress the individual is making and any problems they are having. Every time you accompany an individual to the health centre you should record it on the Health Centre Contact Form (Form 2). Each CBR Review will usually take more than one home visit to complete. You should complete the CBR Review Form (Form 3) to ensure you have done everything for that CBR Review.

CBR Review I: Beginning of Phase I

Initial Assessment (see section 9.6 and Form 1)

Needs Assessment (see Chapter 12 and Form 4)

Accompany to health centre (see Form 2)

Prioritise Phase I Goals (see Section 13.5 and Form 5)

Risk Assessment (see Chapter 14 and Form 7)

Rehabilitation Plan (see Form 8)

CBR Review II: Beginning of Phase II

Needs Assessment (see Chapter 12 and Form 4)

Goal setting for Phase II (see Section 13.5 and Form 6)

Risk Assessment

Accompany to health centre

Invite to Family Support Group (see Chapter 32)

Rehabilitation Plan

CBR Review III: Beginning of Phase III

Needs Assessment

Goal setting for Phase III (see Section 13.5 and Form 6)

Risk Assessment

Accompany to health centre

Rehabilitation Plan

CBR Review IV: At 10-11 months

Continuing Care Assessment (see Section 9.12 and Form 9)

Accompany to health centre

Yosef's story

Berhan is a CBR worker who is asked to look after Yosef and his family. She records her first visit to Yosef on the Initial Assessment Form. At the next visit she conducts the Needs Assessment to get to know his situation better. As part of CBR Review I, Berhan also goes to the health centre with Yosef and Addis a few days later and sits in whilst Yosef sees the nurse. This helps her to understand his illness. She records the information on the Health Centre Contact Form.

9.9 What community work is involved?

In every kebele, you need to conduct the same core tasks to make links with the community (community engagement tasks). These should be completed around the time when the individuals are in Phase I:

- Task 1: Meet with health extension worker/s
- Task 2: Identify key community leaders
- Task 3: Identify key community resources
- Task 4: Find out what community work relating to mental illness has already taken place or is planned
- Task 5: Meetings with key community leaders
- Task 6: Community awareness-raising event/s
- Task 7: Identify potential employment opportunities in the kebele

Depending on the needs of the people with schizophrenia, you may also need to conduct the following tasks when the individuals are in Phases II and III:

- Task 8: Individual meeting with Kebele leaders
- Task 9: Individual meeting with Edir leaders
- Task 10: Individual meeting with religious leaders
- Task 11: Individual meeting with traditional healer/ holy water priest/ attendant
- Task 12: Individual meeting with literacy group leader
- Task 13: Demonstrate progress of client/s to community leaders/ wider community
- Task 14: Community awareness raising consolidation
- Task 15: Facilitate employment opportunities in the kebele

The community engagement work should be recorded in the Kebele Logbook (Form 10)

9.10 How do you deliver CBR?

CBR Manual

The rest of the manual will tell you how to deliver each module of CBR. Each chapter in the manual covers a different module. In each chapter you will find the following questions are answered:

- What is the problem?
- Why does this problem happen?
- Why is it important to help with this problem?
- How can we help?

Chapter 31 also tells you how to conduct the Community Engagement tasks.

Step-by-step guide

There is a short step-by-step guide to delivering each module. These are designed to take on the home visits to remind you of the main things to say and do for the module.

Structure of home visits

Each home visit should cover the following

- Check their general health and symptoms
- Check and record progress relating to ongoing goals
- Problem solving for ongoing goals
- Deliver module/s: selected on the basis of the remaining goals
- Check whether they are taking medication regularly
- Do brief risk assessment (see Chapter 14)
- Tasks to complete before the next session
- Plan date and content of next session

Recording home visits

All home visits should be recorded on the Home Visit Form (Form 11). You should also complete the Visit Summary Form (Form 12), which asks for information about the practical aspects of your visit, for example how long it took you to get there.

Completing modules

You can take use more than one home visit to complete a module. Sometimes, you may also cover more than one module in one home visit.

Workload

You should usually do two tasks every day. For example two home visits, or one home visit and one meeting with community leaders. See Form 13 for an example of how your timetable might look.

9.11 How do you end CBR (continuing care assessment)?

At around 10 or 11 months you should conduct CBR Review IV. At this CBR Review you should discuss the fact that CBR will soon end with the individual and family. You should look back to the Goal Setting Forms from each Phase and discuss the progress that has been made on each goal. This should be a positive exercise, which focuses on the individual's strengths and achievements. It should not be a chance to make the individual feel that they have failed. Around this time you should also attend the health centre with the individual. Together with your supervisor you should complete the Continuing Care Assessment (see Form 9). The aim is to identify ongoing needs and to formulate an ongoing plan to address these needs once you have left. You should prepare the individual and family for the possibility that old problems will come back or that new problems may appear. Reassure them that the health centre staff will continue to look after the individual. At the final session the Continuing Care Plan should be reviewed with the individual and their caregiver. They may feel angry or upset that the home visits are ending. Remind them that they have learnt to deal with their own problems whilst you have been working with them.

9.12 What do you do if CBR is not wanted?

Rarely the individual and/or family may wish to stop participating in CBR before the end of 12 months. This may make you feel shocked, upset or rejected. However we should not force anyone to be involved in CBR if they do not want to be. Here are some ways to deal with the situation:

- Accept what the family says and don't try to argue with them
- Check what the family is unhappy with and try to change it. For example, offer to meet them at the health post instead of at home.
- Consider inviting an individual who has received or is receiving CBR to discuss the benefits of participating with the individual and family.

- Always discuss the situation with your supervisor
- Leave your contact details with the family. Say you are happy to continue whenever they are ready.
- Try to arrange a final session to say goodbye and do some final work- for example reminding them what to do in an emergency situation.

9.13 Summary

- CBR aims to improve the lives of people with schizophrenia and involve them in community life. The principles are: employ a holistic approach, work with the family and the community, encourage respect for human rights and link to existing services.
- The following people are involved in CBR: the person with schizophrenia, the caregiver and family, the CBR worker, the CBR supervisor, the health centre staff, the psychiatric nurse, the community leader and community members.
- CBR lasts 12 months for each individual and takes place through home visits and meetings in the community
- CBR has 3 phases. In Phase I the aim is to build a relationship with the individual and cover the same Modules with everyone: Understanding Schizophrenia, Improving access to health services, Dealing with human rights issues, Preparing for a crisis.
- In Phases II and III the Modules differ between individuals depending on their needs. They might include: support with taking medication, improving daily functioning, improving the family environment, getting back to work and community life, Dealing with stigma and distressing symptoms, improving physical health and literacy.
- The Community Engagement Work involves: Identifying community resources, engaging with the health extension worker and community leaders, doing community awareness-raising and arranging employment opportunities.
- You will set up a Family Support Group for families to provide mutual support
- The CBR manual and Step by Step Guide tell you how to deliver CBR

10 Communication skills and problem solving

10.1 Why do we need communication skills?

A lot of CBR takes place in the family home through discussions between you and the person with schizophrenia and their family. For these discussions to go well and be useful you will need certain skills in listening and communicating. Although it may sometimes be more difficult to communicate clearly with a person who has schizophrenia, it is important that you always treat the person as a responsible and respected individual.

10.2 How to communicate well with families

1. Be friendly and understanding

It is important to be warm and friendly towards the individuals and family. Try to put yourself in the place of the person you are talking to and feel what he or she could be feeling at the moment, for example frustration or anger. The process will help you to understand better the situation of the person. You can also let the person know that their feelings are common and expected for someone in their situation. This is different from expressing pity where you only express the fact that you feel bad for the person. This does not make the person feel that he or she is being genuinely understood. Some ways to be understanding include: “I can understand how the way people have been treating you makes you feel angry” and “You seem to feel upset today.”

2. Be non-judgemental

You should accept the person for who he or she is irrespective of religion and ethnic group. The person has the right to his or her own views and feelings. Even when you do not agree you should not judge the person negatively.

3. Be respectful

Be aware of the person’s age, gender and culture. You should make them feel respected.

4. Be patient

The individual and the family may take a lot of time to understand information or to change their behaviour.

5. Encourage trust

Respond sensitively if the individual or family tell you private or distressing information (for example, regarding sexual violence), and reassure them that you will not discuss this with other members of the community.

10.3 What skills can you use when communicating?

1. Show the person that you are listening to them

Listen carefully to what the person with schizophrenia is saying. If you show the person that you are listening they are more likely to feel comfortable to say how they feel. You can do this by:

- Keeping appropriate eye contact with the person
- Use body language. Make encouraging facial expressions and gestures. Sit facing the person with your arms unfolded.
- Don't keep checking your watch or phone.
- Keep your phone on silent mode. Don't answer it unless it is your supervisor. Don't read or respond to text messages.
- Keep your voice gentle. Speak slowly and clearly.
- Don't interrupt the person or ignore what they are saying

2. Use questioning skills

'Open ended' questions can be useful in getting the person to talk. They are questions that cannot be answered in a few words or sentences. For example, "*Could you tell me more about that?"* and *"How did you feel when that happened?"* Try not to put your own view into the question. For example, "Don't you think it would be helpful if you got back to work?" This may sounds judgemental and threatening. Instead you could say, "*What do you think would be helpful for you?"*

3. Be observant

You should be observant of the body language that the individual uses. For example, if the person has a smile on her face but has her fists clenched or twisting her

fingers vigorously this may indicate a build-up of tension.

4. Use encouragement

Use word to encourage the person to carry on talking, for example "um", "really" or "ah ha". Nod your head and smile at the person. Sometimes just the repetition of a word leads to the person giving further details. If the person says "My life is a mess" you could reply *"A mess?".* This encourages the person to say what she means. You can also repeat back the person's story in your own words. This is useful to make sure you have understood correctly, and to encourage the person to talk about the problem in detail.

5. Notice the feelings of the person

It can be useful to notice the feelings of the person and show them what you have noticed. This helps them to feel understood. You might notice feelings through what the person says or how they act. For example, if the person says "I was so angry that I felt like hitting him", you could reply "You *must have been really angry".* Or if the person is biting her lips, you could say "*You seem very worried today*".

6. Notice the positive things

Noticing the positive things and how the individual is improving will help to improve their self- esteem. For example *"You say you are unhappy about your daughter-in law being rude to you... but it is good to hear that you have been enjoying time playing with your grandson."* However, try not to be unrealistic or to give false hope for things that definitely won't happen.

10.4 What approaches are <u>not</u> helpful when working with families?

- Telling the person what to think or do or making decisions for them, without asking them about their experiences or ideas
- Making judgements on whether the person is 'good' or 'bad'
- Blaming the person if they have difficulty changing their behaviour
- Making promises that you cannot keep
- Pretending to understand what they mean when you don't
- Not responding when the person tells you something sad or difficult

- Telling the person about your personal experiences

10.5 Problem solving

Sometimes people with schizophrenia and their caregivers find their problems overwhelming. Worrying or thinking too much about their problems can make them feel stress (see Chapter 23). This stress may even make the illness worse or cause a relapse (see Section 2.4). You can use **problem solving** to help individuals find ways around their problems. You can use this method for different types of problems, for example dealing with stigma and discrimination (see Chapter 28) or planning how to get back to farm work (see Chapter 27). People with schizophrenia may have many worries or problems. Try to focus on one at a time. Pick the one that relates to the module you are covering, or the one which is most important to the individual at that time. Once you have decided which problem you are going to focus on, follow these steps:

1. Describe the problem

- Discuss together what the problem is
- Try to describe it in the clearest way

2. Think of possible solutions

- Together, list as many solutions as possible to solving the problem. Sometimes you may need your supervisor's help to think about possible solutions.
- Try not to think about whether these are good or bad suggestions

3. Discuss the possible solutions

- Discuss each possible solution in turn
- For each one, now decide together whether it is a good suggestion or not useful
- For each of the good suggestions, discuss together the good and bad things about it.

4. Decide on a solution

- Decide which of the possible solutions is the best. Always check the individual is happy with this solution.
- Discuss the step by step actions which are needed to carry out the solution.
- Think about who will be involved and what their roles will be

5. Carry out the solution

- Support the individual and family to carry out the solution as you have discussed
- Check on their progress at later sessions

10.6 Confidentiality

Information that you gather during your work must be kept secret from other people, even from the patient's relatives, unless:

- The patient gives permission for you to discuss it with them
- It is essential that you tell other people in order to protect the person. For example, if you are worried the person is at risk of suicide (see Chapter 14).

The places where you talk to people with schizophrenia and their caregivers should be arranged in such a way that no-one can listen to your private discussions. Explain that you won't tell other people about the things that they tell you unless it is necessary for helping them. This will help in building trust between you and the individuals you work with.

10.7 Summary

- Good communication between you and the individual and family is essential for CBR
- When working with families you should be: understanding, non-judgemental, respectful, patient and encourage trust
- The skills you can use include: listening and questioning skills, being observant, using encouragement, noticing feelings and noticing positive things.
- You can use Problem Solving to help individuals find practical ways around their problems

11 Creating a trusting relationship

11.1 What is a trusting relationship?

A trusting relationship means that there is a bond between you, the individual and family. It means the individual and family speak freely and share their ideas and concerns.

11.2 Why is it important to have a trusting relationship?

It is very important to have a trusting relationship with the individual and family. This will help the CBR in the following ways:

- The individual and family members are more likely to tell you the information you need to help them. For example, worries about money or family conflict.
- They are more likely to listen to the information you give them
- They are more likely to try the activities which you suggest
- They are more likely to take their medication regularly
- They are more likely to keep returning to the health centre
- They have a way of expressing their emotions
- They are more likely to be hopeful that things can improve

11.3 How to form a trusting relationship

1. Introduce yourself

When you first meet the individual and family, introduce yourself. Introduce yourself to any new family members you meet at later sessions.

2. Learn about the family

Try to learn as much as possible about the individual and their family before you meet them. Find out from the health centre staff or Health Extension Worker how long the individual has been unwell and what problems they have had. When you meet the family, try to understand who is involved in the care of the individual and who has power and influence. You may need to work with this family member/s to change how the family treats the individual.

3. Focus on the problems that are important to the individual

Listen to what the individual wants to change and help them to achieve it (see Chapter 13).

4. Keep each session focused on the individual

Near the beginning of each session, ask the individual "What would make this a helpful visit?" or "What would you like to see different after our meeting?" It is not usually helpful to refer to your own experiences.

5. Get detailed information from the individual

Try to get as much information as possible about the current situation, and any difficulties they have. For example, an individual may be drinking a lot of alcohol. On asking him for the reasons for drinking, he may say this is due to frequent quarrels at home. You can then discuss how to reduce the quarrels, instead of drinking to deal with the problem.

6. Listen to ideas, beliefs and concerns

Listen to the ideas and beliefs of the individual without judging them or telling them they are wrong. For example, the individual may find it helpful to make regular visits to holy water. If this is not causing harm you should support them to continue, even if you do not believe that holy water can cure the illness. You should listen to their concerns. For example, even if they have worries about side effects that you think aren't important, you should not simply dismiss them.

7. Treat the individual with dignity and respect

Make the individual the centre of your attention at all times. Treat them with the respect you would with any other person, during the sessions and if you meet them in the kebele. Don't use stigmatizing words like 'mental'. Use non-stigmatizing words like problem and illness. These actions will help to improve the self-esteem of the individual. They also help to reduce stigma and discrimination from the family and community towards the individual.

8. Stay neutral during family discussions

There may be disagreements within the family on the best way to do things. Try to stay neutral.

9. Keep clear boundaries

You are aiming for a close working relationship with the individual and family. However, it is not appropriate for them to intrude on your personal life. The family should not visit you at home. However, it is fine to greet the family if you see them outside their home.

11.4 Challenges with forming a trusting relationship

Due to their illness people with schizophrenia sometimes find it more difficult to form a relationship or bond with other people. You should always keep trying. But this is part of the reason why it is important to also make a good relationship with the family.

11.5 Summary

- Creating a trusting relationship between you, the individual and the family makes it more likely that CBR will be helpful.
- You can form a trusting relationship by: finding out about the family, keeping the sessions focused on the individual and treating them with dignity and respect, listening to beliefs and concerns, and staying neutral during family discussions.

12 Needs Assessment

12.1 What is the Needs Assessment?

People with schizophrenia have many different sorts of problems. Some problems will be more important for particular individuals and families. Many of these problems can be helped through CBR. The Needs Assessment is an organised way of finding out what problems each individual and family are facing.

12.2 Why do we do the needs assessment?

- The Needs Assessment tells us what problems the individual and family have, and which are the most important problems at that time. This helps us decide what improvements the person with schizophrenia and their family would like to work towards first. This is called Goal Setting (see Chapter 13). This helps us to decide which Modules of CBR to start with, and which to leave until later.
- Doing the Needs Assessment will help the individual and family understand that you are interested in their problems. This will help build a trusting relationship (see Chapter 11).
- It is also useful to look back at the Needs Assessment at the end each Phase. Then we can see whether the problems that the family had at the beginning are still there, and what still needs to be done.

12.3 Who is involved in the needs assessment?

The Needs Assessment should always involve you, your supervisor, the individual and the primary caregiver. You may include other members of the family who are involved in the individual's care. Around the time of the Needs Assessment, you should accompany the individual to the health centre for a review by the nurse or health officer. By observing what the nurse or health officer says you will get extra information about the needs of the individual. There may be different views about what the most important needs are. For example, the individual may feel the most urgent need is to get back to farm work. The family may feel that the symptoms need to be under better control first. At this stage it is important to get all the points of view. In Chapter 13 you will learn how to set goals for the individual together with the family.

12.4 When is the needs assessment done?

The Needs Assessment is done three times during CBR, at CBR Reviews I, II and III.

12.5 How do we do the needs assessment?

You will use a detailed checklist to assess whether there are problems in the areas where people with schizophrenia usually have difficulties.

Using the Needs Assessment form

The Needs Assessment Form (Form 4) covers the following areas:

- Understanding schizophrenia
- Accessing health services
- Preparing for a crisis
- Human rights issues
- Symptoms
- Taking medication
- Social life
- Family life
- Daily functioning
- Work
- Empowerment
- Literacy

You should go through each potential need in turn and ask the individual and family whether they have any problems in this area. For example to assess social life you could say, *"Sometimes people with schizophrenia have problems doing the activities in the community that they used to do, or that other people their age do. For example, being part of an Edir group, going to kebele meetings or being part of a mahaber group. Have you had any problems with doing these sorts of activities?"*

Using observations

You and the supervisor can also use your own observations about what the problems are. For example, you may notice that the individual is very drowsy (which might be a side effect of medication), or that a family member often shouts at the individual.

Recording the needs assessment

Mark on the assessment form whether each possible need is:

- Not a problem for this person (everyone agrees there are no problems). For example, an individual remembers to take their medication every day without being reminded.
- A partially met need (there are a few small problems). For example, an individual occasionally does not go to church, even though they would like to.
- An unmet need (there are problems). For example the individual does not do any of the farm work that they used to do.

For each need write some comments about what you have been told and what you have observed. Include:

- Detailed information on the need. For example, what type of work the individual would like to do or what self-care tasks are most difficult.
- How long this has been a problem. For example, the individual may have had difficulty socialising for a long time, but there may be new medication side effects.
- How important this need is for the individual. This will help later when goal setting.
- If this is the second Needs Assessment, record what progress has been made since the previous needs assessment.

Assessing personal needs

In addition to the checklist you should also ask the individual and family to tell you about any other problems or needs that have not been covered. These are known as 'personal needs' and you should record them on the needs assessment form.

Yosef's story

At Review II, Berhan does the Needs Assessment with Yosef and his family. Haile, her supervisor, is also there. She records everything on the Needs Assessment Form.

12.6 Tips for completing the needs assessment

- Some individuals and family members may start by saying that they have no problems. It is important to gently continue asking for difficulties. You may need to come back to sections on the checklist. Sometimes you will need more than one home visit to complete the needs assessment.

- When you ask each question, think about what is likely to be usual for that individual. For example, if young women do not usually attend the kebele meetings, then it may not be appropriate to ask about problems with this.
- It is likely that the individual and family will ask you questions about the illness whilst you are doing the needs assessment. You should be ready to answer some questions, but remind them there will be a chance to discuss these things in more detail later.

12.7 What do we do with the information from the needs assessment?

In Phase I, we do the Needs Assessment to help to get to know the individual and the family. In Phases II and III we use the information for Goal Setting (see Chapter 13).

12.8 Summary

- We do a Needs Assessment to understand what problems the individual has and to decide which parts of CBR to start with
- We conduct the needs assessment by asking questions to the individual and family, making observations, and attending the health centre with the individual
- On the Needs Assessment Form you should record whether each possible need is not a problem for this person, an unmet or partially met need.

13 Goal Setting

13.1 What is Goal Setting?

Goal setting is about deciding together which needs to address and in which order. It should be a positive process, not one that makes the individual feel helpless or a failure.

13.2 Why do we need to do Goal Setting?

Goal setting is important so that the individual, family, you and your supervisor all know what you are working towards. This can help individuals to recover more quickly. Goal setting makes sure that the CBR Modules that you do with each individual are the right ones for him or her. Goal setting also gives a sense of achievement and progress when a goal is achieved.

13.3 Who is involved in Goal Setting?

Goal setting should always involve you, your supervisor, the individual and the primary caregiver. You may involve other members of the family who are involved in the individual's care.

13.4 When do we do Goal Setting?

We do Goal Setting as part of the CBR Reviews at the beginning of each Phase. Goal Setting should always come after the Needs Assessment.

13.5 How do we do Goal Setting?

Phase I

Phase I is about making sure all individuals have their basic needs met. Even though you might have found out about lots of different problems on the Needs Assessment, during Phase I you should focus on basic needs. The potential goals for Phase I are therefore :

- Individual and caregiver have been informed of what schizophrenia is, available treatments, and the potential for recovery
- Individual is able to access medication
- Individual is able to attend health centre for mental health as indicated by clinical status

- Crisis management plan is in place
- Individual is not chained or restrained

Not all individuals will have problems with these basic needs, so not everyone will need to set a goal around all of them. The order in which you address the Phase I goals will also depend on the situation of the individual. For example if an individual is currently chained, you should usually address the goal 'Person with schizophrenia is not chained or restrained' first, before going on to the other goals. You should work together with the individual, family and your supervisor to decide the best order to address the goals. On the Phase I Goal Setting form (Form 5), you should make notes about the most important goals to address first. Add a timeframe for how long you expect it to take to achieve the goal. In addition to these core goals you should also ask the individual if they would like to set a personal goal. You should fill in the Rehabilitation Plan (Form 8) to summarise the information from the Initial Assessment and Goal Setting. This form should be filled in using simple language that the family can understand.

Yosef's story

At Review I, Berhan does Goal Setting with Yosef and his family. Haile, her supervisor, is also there. She records everything on the Goal Setting Form.

Phase II

In Phase II, all the goals are based on the particular needs of the individual and family. This means they will differ from individual to individual. To set the Phase II goals you should go through the list of needs that you marked as 'Partially met' or 'Unmet met' on the Needs Assessment you complete as part of CBR Review II. The number of goals for Phase II will vary between individuals but will normally be around 4 to 8. The decision about which goals to focus on should be made together with the individual, family, you and your supervisor. You should also decide which goals to focus on first, and how long you expect it will take to achieve each goal. You can continue working on Phase I goals if you feel ongoing work is needed to maintain the situation. You should encourage discussion about the following:

- Which goals are most important to the individual and why?
- Which goals are most important to the family why?

- Which goals need to be achieved first before other goals can be achieved? For example, the individual may have problems remembering to take their medication. As they still have many symptoms this may be the reason why they also have difficulties with self-care and social life. You may agree that it is important for the person to start taking their medication regularly, before moving on to addressing self-care.
- Which goals are realistic?

On the Phase II Goal Setting form (Form G), you should tick off the goals you have chosen, and make notes about the most important goals to address first. Include information on why the family wants to focus on those goals first. You should add details on what you hope to achieve. For example, if the goal is 'Individual has good self-care' you could add the particular tasks you are trying to improve, such as getting washed. At any time you may be working towards several goals at once. You should also discuss the personal goal set in Phase I, and either continue working towards this or set a new personal goal. Record any personal goals on the form. Once again, you should summarise the information from goal setting by updating the Rehabilitation Plan (Form 8).

Yosef's story

At Review II, Berhan does Goal Setting with Yosef and his family. Haile, her supervisor, is also there. She records everything on the Goal Setting Form.

Phase III

Setting and prioritising goals in Phase III should follow the same process as Phase II. In addition, all individuals should have the following goal:

- Individual has relapse prevention plan in place

On the Phase III Goal Setting form (Form 6), you should tick off the goals you have chosen, and make notes about the most important goals to address first. Summarise the information on the Rehabilitation Plan (Form 8).

13.6 What do we do with the information from Goal Setting?

Each goal has a specific Module connected to it. If an individual is working towards a goal, then you should complete the connected Module at some point during the Phase.

Phase I

In Phase I everyone should complete the same Modules, even if they haven't set a specific goal relating to the module. These modules are:

- Understanding schizophrenia
- Improving access to health services
- Addressing human rights issues
- Preparing for a crisis

However the order of the Modules should be decided depending on the situation of the individual. The Initial Assessment will help you to decide this. How long you spend on each Module will also depend on the individual. For example, if an individual has a good understanding of schizophrenia, is not chained or tied up, and regularly access health services, they may only need one or two home visits to complete all these Modules. Or you may need to spend many more home visits with someone who does not access health services and who is currently suffering severe symptoms.

Phases II and III

Once you have decided which goals to focus on in Phases II or III, and in which order, you should then note and discuss which modules are needed to achieve these goals. This should be easy, as each goal has a recommended module linked to it. These are listed on the Phase II and III Goal Setting forms. On the forms you can also write other actions that you think might help to achieve the goal, but which aren't in the module. As in Phase I the length of time to complete each Module will vary between individuals.

13.7 How do we know if goals are achieved?

You should always be thinking about which goals the individual is working on at the moment. At each home visit you will check and record the progress of each of the current goals using the Home Visit Form (Form 11). On this form for each goal you record:

- The module/s you are currently working on which relate to that goal
- Any community engagement work or other actions underway which relate to that goal
- Any issues or problems relating to the goal
- Whether the goal is achieved, partially achieved or not achieved by the end of the home visit.

You should ask the individual and family whether they feel the goal has been achieved. You will also meet with your supervisor every two weeks to discuss the progress of each individual (see Chapter 34). At these meetings you should discuss whether each of the goals you are working on has been achieved yet. There is not a fixed time when any of the goals should be achieved by. In your discussions with the family you should focus on the positive things. Try not to make the individual feel they have failed if it takes a long time to achieve the goal. Once a goal is achieved tick it off on the Goal Setting Form.

Yosef's story
At each visit Berhan fills in a home visit form, which keeps track of the goals Yosef is working towards.

13.8 When do we move to the next phase?

Moving from Phase I to Phase II

Once all the Phase I goals have been achieved, you should arrange CBR Review II with the individual, family, you and your supervisor. If the individual is not ready for CBR Review II by about 2 months, you and your supervisor will review the situation together. There may be one or more goal that you, your supervisor, the individual and family agree may never be achieved despite the best efforts of you all. If this happens, with the permission of your supervisor, the individual can move onto Phase II without having achieved that goal. You should however still continue to support the individual to achieve the goal during Phase II. It is not necessary to have achieved the personal goal before moving onto Phase II. Your supervisor will be monitoring the progress of each individual.

Moving from Phase II to Phase III

Once all the Phase II goals have been achieved, you should arrange CBR Review III with the individual, family, you and your supervisor. If the individual is not ready to move to Phase III by about 8 months, you and your supervisor will review the situation together. If there is a goal that you agree may never be achieved, you can move onto Phase III without having achieved that goal.

13.9 Tips for Goal Setting

- Remember to choose realistic goals with the individual and family. For example, if the individual is still unwell at the beginning of Phase II, it may be better to choose 'Taking medication' instead of 'Getting back to work' as a goal at this stage.
- Remind the individual that just because a goal has not been chosen at this stage does not mean it will never be addressed. You can add goals later, for example in Phase III.
- If a particular goal has not been achieved yet, keep focusing on the progress made.
- Remember that if you, your supervisor, the individual and family agree that a goal may never be achieved, it is acceptable to move onto the next Phase anyway.

13.10 Summary

- We do Goal Setting to decide which needs to address and in which order, and to follow the progress of the individual
- In Phase I the Goals are the same for everyone. You should decide the order to address them by discussing with the family and recording on the Phase I Goal Setting Form
- In Phases II and III the Goals are different for each individual. You should choose 4 to 8

  goals to focus on in each Phase and record them on the Phase II or III Goal Setting Form
- The goals you choose will tell you which Modules to deliver

14 Risk assessment

14.1 What risks do people with schizophrenia face?

Suicide

People with schizophrenia are about ten times more likely to commit suicide (kill themselves) than other people. Suicide is therefore quite a common cause of death in people with schizophrenia. The most common ways people commit suicide in rural Ethiopia are hanging, drowning and swallowing pesticides or chemicals.

Attempted suicide

Attempted suicide is where someone tries to kill themselves but does not succeed. This is a serious warning sign that the person needs urgent help. Suicide attempts are much more common than suicide, where people succeed in killing themselves. Young women are most likely to attempt suicide in Ethiopia. People who have attempted suicide are more likely to commit suicide later.

Chaining and tying up

People with schizophrenia are quite commonly tied up or chained up from time to time. This may take place at the family home, or sometimes at a holy water site or traditional healer's home. The person may be tied up for a period of days to weeks, or sometimes months to years. See Chapter 7.

Physical abuse

People with schizophrenia may be beaten by family members. Sometimes they are beaten by holy water priests or attendants or traditional healers as part of the treatment. See Chapter 7.

Emotional abuse

People with schizophrenia may be treated badly even without being physically abused. For example, they may be shouted at or treated in an undignified way. This may take place within the home or outside.

Sexual violence

People with schizophrenia are particularly vulnerable to sexual violence, for example rape. This may happen within or outside the family home.

Neglect

Sometimes people with schizophrenia are not given enough food, or don't wear any clothes. Sometimes they are homeless and have no shelter. See Chapter 7.

Risks to children

Children who live in a household where a person has schizophrenia may be vulnerable to neglect or abuse. This may happen because a parent (either with the illness or a caregiver) is unable to look after the child properly due to burden on the family due to the illness.

Environmental risks

Sometimes people with schizophrenia are not able to look after themselves as well as normal. This can result in them being hit by cars, falling off buildings or being attacked by wild animals.

Imprisonment

Some people with schizophrenia get involved with the police, particularly if they are behaving in a disruptive way, and may end up imprisoned in a jail.

14.2 Why do we need to assess risk in people with schizophrenia?

Once we know the risks individuals are facing we can take action to try to reduce the risk. In some cases we may save an individual's life. In other cases, we may improve their situation so they have a better quality of life and find it easier to get back to usual activities. It is not true that asking about suicidal ideas introduces the idea in the person's mind. Instead, asking whether the person has experienced suicidal ideas is the only way to identify risk and provide the necessary help to prevent suicide.

14.3 How do we assess risk in people with schizophrenia?

In your work with individuals and families you may become aware that the individual is at risk in different ways, just by listening to them and observing their situation. Below you will find some specific things that will help you know that the individual is at risk. In addition, at every home visit you should sensitively ask questions to check for suicide risk and chaining or restraint. At each CBR Review your supervisor will do a full risk assessment by asking questions to the individual and family. You should also be present and contribute where you can. It may feel very sensitive to ask about these topics. You can start by saying, "I need to ask you some questions which might be difficult or sensitive. Before we start I want to let you know that these are routine question that we ask to everyone."

Suicide

You should ask some questions to assess suicide risk at every home visit. One way to start asking about this is: "*How do you feel about life at the moment?"* If the individual does not say anything very negative, you can carry on with the home visit as usual. If the individual says that they are feeling very negative, or things are going very badly, you should ask some more questions, such as *"I can see you are going through a very difficult period. In your situation, some people might feel that it is not worth carrying on with life. Have you ever felt like that since I last saw you?"*

Or you can use other ways of asking the question, for example,

"Have you felt it would be better if you did not wake up in the morning?"

"Have you felt it is not worth carrying on with life?"

"Have you felt that your problems in life are too difficult to be solved and that you would be better off dead?"

If the individual says yes to any of these questions you should ask them, *"Have you made any plans for harming yourself?"* This will help you know how serious the risk is. The following things may also indicate the individual is at risk of suicide:

- Any reference to death or dying, in verbal or written expression or a strong focus on an individual who committed suicide
- Not being willing to discuss the topic and seeming distressed
- Any statements that "life is not worth living"
- Impulsive and potentially dangerous behaviour. For example drinking alcohol or using khat.

If the individual tells you they have thought about suicide, listen carefully and respond sensitively using your communication skills (Chapter 10).

Chaining

You should assess for chaining at every home visit. It may be obvious that the individual is chained or you may notice wounds or sores on the individual. If it is not obvious you can check by asking: "Since I last saw have you been chained or restrained at home, at a holy water site, or by a traditional healer or by anyone else?"

Physical, emotional or sexual abuse inside or outside the home

You may notice signs of physical injury such as bruises or cuts. You may notice that a family member treats the individual in an abusive way.

Neglect and not eating or drinking

You may notice the individual looks very thin or malnourished, or that they are not wearing any clothes.

14.4 How do we respond when we find there are risks?

Record any risks you find on the Home Visit Form. Follow these steps.

1. Find out if there were any particular circumstances or factors leading to the risk.
2. Discuss with your supervisor, the family and individual immediate actions that would be helpful.
3. Follow the flow chart (Chapter 35) for the situation. It will tell you the specific steps you need to take. The steps for suicide risk and chaining are also given below (section 14.5).
4. Discuss with your supervisor, the family and individual steps to reduce the risk in future.
5. Follow up at every visit to check these steps have been taken, and if there have been any further problems.

14.5 How do we deal with suicide risk?

In addition to the general steps (Section 14.4), if you identify a risk of suicide you should always follow these steps:

- Check the individual is taking their medication and if not encourage them to do so
- Facilitate access to the health centre as soon as possible for a review. Fill in a Health Centre Referral Form (Form 14).
- Inform your supervisor immediately, if they are not already aware.
- If the individual does not attended the health centre after one day, make a joint home visit with your supervisor.
- At this home visit you and your supervisor should discuss with the family and the individual (if possible) the reasons why they have not attended.
- Try to address these reasons, for example:
    - Reiterate the importance of receiving treatment for improving symptoms

  - Mobilise community leaders to help the individual travel to the health centre
  - Also see Chapter 17 Accessing Health Services
- Your supervisor will do a more in-depth assessment of suicide risk
- Your supervisor will then give discuss the risk assessment with the Psychiatric Nurse
- If the individual still has not attended the health centre within 2 days, and the Trial Psychiatric Nurse thinks the individual is at high risk they will then do a home visit to review the situation and improve the treatment.

14.6 How do we deal with risk of chaining or restraint?

In addition to the general steps (14.4), if you identify an individual who is chained you should follow these steps (see Chapter 19 for more detail):

- Tell your supervisor immediately.
- Check the individual is taking their medication and if not encourage them to do so
- Facilitate immediate access to the health centre for a clinical review. Fill in a Health Centre Referral Form (Form U).
- If the individual is still chained and they have not attended the health centre after one week, make a joint home visit with your supervisor.
- At this home visit you and your supervisor should discuss with the family and the individual (if possible) the reasons why they have not attended.
- Try to address these reasons
- If the individual is still chained and they have not attended the health centre after one week, you should inform the Trial Psychiatric Nurse. They may do a home visit to review the situation and improve the treatment.

14.7 Summary

- We assess risks to find out what risks an individual faces, so we can take action to protect them
- Your supervisor will do a full risk assessment at every CBR Review. You should ask sensitive questions about suicide risk and chaining at every home visit

- When a risk is identified there are certain steps you should follow. Usually this is referring to the health centre and informing your supervisor, if they are not aware yet.

15 Being aware of the caregiver's needs

15.1 What problems do caregivers have?

As we learnt in Chapter 5, when someone has schizophrenia this can put a burden on the whole family. Often the burden falls on one person in particular. This may be the spouse, parent or child. It is often, but not always, a female caregiver who takes most of the responsibility. Female caregivers may be less likely to get support from other family members or people in the community. Sometime the stress on this person is so great that they become unwell themselves. The caregiver may develop distress, depression or anxiety. Some of the signs of this are when the caregiver:

- Complains of many physical symptoms but no physical cause has been found (e.g. headache, burning sensations, aches and pains)
- Has low energy; is always tired; has sleep problems or does not want to eat
- Always seems sad or anxious or irritable; feels hopeless or helpless or guilty
- Has low interest or pleasure in activities that used to be enjoyable
- Worries or thinks about day-to-day problems too much
- Is not able or motivated to do their usual job, housework or social activities
- Has been thinking of harming themselves, e.g. ending their life

15.2 Why is it important to think about the caregivers needs?

Caregivers have the right to be healthy, just like people with schizophrenia. Also, if the caregiver becomes unwell they will not be able to look after the person with schizophrenia very well.

15.3 How should we stay aware of the caregiver's needs?

Unlike for the person with schizophrenia, you do not need to do a full needs assessment with the caregiver. However, at every home visit you should think about how the caregiver seems to be getting on. Caregivers who are female, elderly, isolated or suffering from a physical illness are more likely to suffer from the stress of caregiving. Look out for any of the signs that they are distressed or depressed (section 15.1). If you notice any of these signs take these steps:

- If possible, try to talk to the caregiver by themselves, without the individual present. If you do this, you may need to explain to the individual that you are not

talking about them behind their back. Explain that you just want to check how the caregiver is doing.

- Ask the caregiver how they feel they are coping and listen to their experiences. Ask if they have anybody they can turn to for support, for example a relative or neighbour.
- Tell them it is sometimes useful to discuss their problems with somebody else. Just by doing this, things can feel easier.
- If they are not already doing so, encourage them to join the Family Support Group (Chapter 32)
- If possible, involve the other members of the family. Speak to them and share your concerns about the stress on the caregiver. Discuss how they can take some of the responsibilities
- If you are very worried about the caregiver, you should suggest that they go to the health centre for a review with the nurse or health officer. You should also tell your supervisor.

Yosef's story

Berhan notices that Addis sometimes seems sad and distressed. She often sounds hopeless about Yosef's situation. Addis agrees to talk to Berhan alone. They both reassure Yosef that they are not talking about him behind his back. Addis tells her problems to Berhan. She admits she often feels unhappy and stressed. Addis agrees to share her problems with her cousin, who she trusts. Addis is also interested in joining the Family Support Group when it gets set up.

15.4 Summary

- Caregivers can become unwell through the stress of looking after a person with schizophrenia. It is often female caregivers who take on more responsibility.
- They may have physical symptoms, low energy, be very worried, or consider harming themselves
- Ask the caregiver how they are coping. If you are concerned try to ensure they get more support, for example from friends and family.

16 Module: Understanding schizophrenia

16.1 What problems do people with schizophrenia and their families have with understanding schizophrenia?

Many people with schizophrenia and their families do not know very much about the illness. Some common beliefs, which are not true, include:

- No one with schizophrenia will improve or get well
- Medication can completely cure the illness
- Schizophrenia is caused by spirit possession or evil eye

Most of these incorrect beliefs are not harmful by themselves. However, some can be unhelpful. For example, if the individual and family believe the illness will never improve, they may make less effort to support the person. On the other hand, if they believe the medication will completely cure the illness, they may be disappointed when it takes a while to see improvements. The individual may then stop taking the medication altogether.

16.2 Why do people with schizophrenia and their families have problems with understanding schizophrenia?

People with schizophrenia and their families may have little understanding of schizophrenia because there was no information available to them. Even if they have been to the health centre, the nurse or health officer may not have had time to give the information properly.

People may find traditional beliefs make sense and that traditional practices are helpful.

16.3 Why is it important to give information about schizophrenia?

People with schizophrenia and their families have a right to have information about their illness. However, this does not mean we should force them to believe all of the information they are given. People can have lots of different beliefs at once. Having a certain belief, such as that the illness is caused by the devil, does not always stop people taking certain actions, for example taking medication.

If people have more information about schizophrenia, they may feel more positive about their illness and that things may improve. With this attitude, the individual and family may be more likely to take active steps to help recovery, including participating

in CBR more fully. The more active steps individuals and families make, the more likely they are to get back to their usual activities.

16.4 How do we give information about schizophrenia?

1. Use these principles for giving information

Giving information about schizophrenia is an ongoing process. You will need to remind the individual and family about information you have already given them. Also, the issues the person faces, and therefore the information they need, will change as time goes on. It is likely that you will involve other family members apart from the individual and the primary caregiver when you give information about schizophrenia. Who you involve should be decided between you, the individual and the caregiver. Try to include those family members that have power and influence within the family, along with those who are helping to look after the individual. Here are some general tips on giving information about schizophrenia:

- Give the individual and family time to **ask questions** and pause after each section
- **Encourage** the family to tell you if they disagree with the information
- Be prepared to **discuss and clarify** the information with the family.
- Avoid **over-loading** the family with too much information or medical terms.
- Use **examples** from what you know about the individual
- **Listen** and understand the family's view of the illness.
- Be **sensitive** to any distressing experiences of the family members
- Tell the family if you do not know the answers to their questions. Before the next session, make sure you find out the answer by talking to your supervisor or looking up the information in this manual.

2. Explain why you are doing this module

Tell them why would like to give them information about schizophrenia

3. Assess understanding about schizophrenia

- To begin with, ask whether they think something is wrong with the individual or not.
- If so, ask them what do they think that is wrong with him/her? They are unlikely to report problems with "hallucinations" or "delusions". They may instead report

the effect of hallucinations or delusions on the individual's behavior. For example, that he or she laughs and talks to himself, says things that do not make sense, is not doing well in work or school, or does not want to spend time with other people.

- Ask if they know what illness the individual has. They may not have been told the diagnosis, or if they have, they may not understand the details.
- Find out about their knowledge about medications. Do they know why medicines are given? What is the relationship between the medications and the symptoms? What are the side effects of the medication?
- Ask if they think medication can make them better or worse.
- Ask what they think about how long the illness lasts. Some families expect the illness to be cured with medication. They may not be aware that there may be many episodes.
- Finally, ask what they think about the causes of the illness. Most family members will not consider mind problems as being the main cause. They may wonder if they are being punished for something they did wrong, and therefore feel guilty, angry or responsible. Some family members may think that "evil spirits" cause it. Parents may wonder if it has been inherited and may blame the other spouse if they have a relative with a mental illness.

4. Give information about typical symptoms of schizophrenia

- Explain each symptom group in turn (hallucinations and delusions, problems with motivation, problems with thinking clearly and not understanding they are unwell)
- Use examples from the individual's behaviour to help explain
- Tell the family that each individual has a different symptom pattern and will have different symptoms at different times. This is important, as family members may not listen to you when you describe symptoms that the individual does not have.
- Emphasize that the hallucinations and delusions cannot be easily understood. They are thoughts, ideas, and voices that go in inside the individual's head. The family can only see their effects through the individual's behavior.
- Emphasize that the symptoms are real to the individual and they cannot control

them. For example, they cannot help but answer the voices they hear.

- Emphasize that problems of motivation and problems with thinking clearly cannot be easily overcome by the individual.

5. The causes of schizophrenia

- Explain that both stress and vulnerability are usually needed for a person to develop schizophrenia, but sometimes we don't know why a person develops the illness. Give examples of stress and vulnerability. When discussing vulnerability, do not emphasise that having a close family member with schizophrenia increases the risk, as this may be stigmatising. Instead, focus on difficult early life experiences.
- Families usually have their own beliefs about the cause of the illness. You should listen to these ideas. It is possible to have more than one belief about the cause.
- Family members may think they caused or could have prevented the illness in some way. These ideas make the family feel guilty and depressed. You should reassure the family that they did not cause the illness.
- If the family asks you, you can tell them that their children will most likely NOT develop the illness too.

6. Course of schizophrenia

- Inform them that there are good chances individual can recover from an episode and have a near normal life.
- Also tell them that the illness may come back (relapse), even once they have started to feel better. Describe some of the signs that a relapse is coming (e.g. problems with sleep, feeling angry or anxious). To try and stop this happening they should continue medication all the time. However sometimes things out of the individual's control will happen e.g. physical illness or life stress, which may trigger the illness to come back. If the illness does come back it is important not to give up hope.

7. How common is schizophrenia

- Tell them about 10 people have schizophrenia in an average kebele. You don't need to give them the exact number for the kebele they live in.

8. Medication

- **What are the medicines for**

Tell them medication reduces symptoms, prevents relapse and improves the chances of recovery.

- **How do they work**

Tell them the medication works by improving the way the mind works and prevents it from getting sick again. The result of this will be fewer hallucinations and delusions.

- **What is the name of the medication that has been prescribed?**
- **What are the common side effects**
- **Regular medication**

Discuss with the family and emphasize the need for taking medication regularly. There is a separate module for support with taking medication (Chapter 20).

- **Continuing medication**

Emphasize that medication will need to be taken for a long period of one to two years or even forever. The duration of the treatment depends on how well the individual is recovering and not on how long the illness was there before the treatment started.

- **Address concerns**

Some families think that the medications are addictive if used for a long time. The family may then decide that the individual should learn to cope without the medication. This view is not correct. Be clear that the medicines are not addictive.

9. Stress-vulnerability model

- Explain that both reducing stress and taking medication can help reduce relapses and help the person to recover
- Explain that other parts of CBR can help reduce stress, for example improving the family environment, reducing stigma and discrimination

Yosef's story

Berhan explains what the symptoms of schizophrenia are, referring back to Yosef's problems. She explains the causes of schizophrenia and the importance of medication. Addis is still sure that Yosef's illness was caused by spirit possession, but she can also see that the medication is useful. Addis does not try to change Addis' beliefs about spirit possession. Yosef's family have lots of questions so it takes two visits to cover all the information.

Follow up

- Be prepared to remind the family of the information at later home visits
- Look up or ask your supervisor any questions that you did not know the answer to. Give the individual and family the information at the next home visit

16.5 Summary

- Many people with schizophrenia and their families do not know much about the illness
- If people with schizophrenia know more about their illness they are more likely to take positive steps towards recovery
- You should give the following information about schizophrenia: typical symptoms, causes, course, how common it is, medication (names, side effects, importance of taking regularly and continuing once well) and the stress-vulnerability model.

17 Module: Improving access to health services

17.1 What problems do people with schizophrenia have accessing health services?

There are three levels of health services that are available for people with schizophrenia.

1. Health centre

Nurses and health officers in Sodo woreda are trained to look after people with schizophrenia. Nearly all the medical care for individuals takes place in health centres

2. Butajira Outpatient Clinic

Psychiatric nurses at Butajira have expert knowledge about schizophrenia. Sometimes health centre staff will send individuals here when they are very unwell.

3. Ammanuel Hospital in Addis Ababa

Psychiatrists (doctors with expert knowledge on mental illness) look after people with schizophrenia at Ammanuel Hospital. Rarely, an individual will be sent here when they are very unwell.

Problems accessing health services

Sometimes people with schizophrenia have difficulty getting to the health centre or hospital to get the treatment they need. This may mean that even though the individual is willing to see the nurse or health officer and to take the medication, they are not able to.

17.2 Why do people with schizophrenia have problems accessing health services?

There are various reasons why people with schizophrenia have problems accessing health services. These include:

- The family cannot afford the medication
- The family cannot afford to travel to the health centre
- There is nobody to go with the individual
- It is difficult to take the individual to the health centre because they are unwell or it is far.
- The medication is not always available at the health centre
- The individual is chained up at home

17.3 Why do we need to improve access to health services?

Getting access to the health centre is essential for recovery from schizophrenia. At the health centre the individual is reviewed by a nurse or health officer who will:

- Check overall progress
- Prescribe the medication or give the injection. People with schizophrenia need to take their medication regularly in order to feel better and get back to usual activities (see Chapter 20)
- Check for and try to improve side effects
- Change the dose of the medication if it is not enough or too much
- Refer them to Butajira outpatient clinic if they cannot meet all individual's needs

How often people with schizophrenia need to attend the health centre depends on how bad their illness is at that time. Usually they need to see a nurse or health officer and collect their medication every 1-3 months.

17.4 How can we improve access to health services for people with schizophrenia?

1. Inform the family what health services are available

2. Explain why you are doing this module

Explain the importance of accessing health services.

3. Assess problems with accessing health services

Find out what the current arrangements for accessing medication. Then assess any reasons why the individual has problems accessing health services, or might do in the future. Use the potential reasons above (Section 17.2) as a starting point. If the individual is able to access services but does not want to, you may need to complete Module: Supporting Individuals to Take Medication (Chapter 20).

4. Use problem solving to improve access to health services

You should then discuss each reason or problem in turn with the individual and caregiver. Encourage them to think of ideas for how to get around the problem using the problem solving approach (Section 10.5). Discuss the approaches they have already tried. Build on their ideas and then suggest some of your own if everything has not been covered. Some or all of the following methods can be used.

a. Explore accessing free medication

A certificate for free medication can be given by the kebele administration to the 'poorest of the poor'. Only 5 in every 1000 families can receive this certificate, therefore not all people with schizophrenia will be eligible. However, if you think that the family is amongst the poorest in the kebele and they do not already have the certificate, you should take some action. First of all encourage the family to approach the kebele leaders and request this certificate for themselves. Discuss with the caregivers the kind of things they might say. If this is unsuccessful, you should approach the kebele leader yourself and request that the family receives the certificate. See Task 8 in the Community Engagement chapter.

b. Make travelling to the health centre easier

Discuss potential sources of help for travelling to the health centre. This may include extended family members, neighbours or community leaders. They may be able to give money for the transport costs, or help to accompany the individual, along with family members, on the journey. If the family is unable to find additional support themselves, you could meet with a community leader and ask for their help. See Tasks 8, 9 and 10 in the Community Engagement chapter. You are not normally expected to accompany the individual to the health centre yourself, except for around the time of the CBR Reviews.

c. Address financial problems

Poverty is a long-term problem, which may to be difficult to improve over the course of receiving CBR. However, financial problems may be addressed to some extent by getting the person with schizophrenia back to work (See Chapter 27).

5. Discuss delivering medication to the individual's home

You should only discuss this if the individual or family suggests it. You or the Health Extension Worker taking the medicine from the health centre to the individual's home should be a last resort when all the other relevant methods have been tried. The reason for this is that it is not an empowering or sustainable way to ensure the person

takes medication. For delivery to the home to be considered, the individual should be very unwell and not attending the health centre. Discuss this with your supervisor.

6. Monitor whether the individual attends the health centre

Each individual should go to the health centre every 1 to 3 months. You should be aware of all the appointments they have, and check if they have attended. If they have missed an appointment, even if you are not due for a home visit, you should make a home visit to check for any problems and remind them to attend.

7. Make a plan

At the end of the discussion, make sure that everybody knows what input they are expected to have.

Follow up

Remember to check what progress has been made by the next home visit.
If you agreed to do so, discuss free medication certificate with kebele leader or support travelling to the health centre with community leader/s.

Yosef's story

Addis tells Berhan that sometimes they can't get to health centre because Yosef is too unwell to walk there. This makes things worse as then he can't get the medication. They agree that to get over this problem they need help to get to the health centre. They discuss who could help. Addis agrees to ask her uncles and cousins to help walk or carry Yosef to main road. They will then get a gari using small amount of money borrowed from uncle

17.5 Summary

- Some individuals do not access health services due to money or transport problems
- It is important to access the health centre to get treatment, as this will improve the chance of recovery
- Ways to improve access include: exploring the possibility of free medication, making travel to the health centre easier, and improving financial problems.

18 Module: Preparing for a crisis

18.1 What kinds of crises do people with schizophrenia have?

As we learnt in Chapter 14, people with schizophrenia are vulnerable to many sorts of risks. A crisis is when dangerous or worrying incidents happen as a result of these risks. Some common types of crisis include:

- The individual talks about or tries to commit suicide
- The individual is the victim of physical, emotional or sexual abuse
- The individual behaves in a dangerous way. For example they consume poisonous fluid thinking it wouldn't hurt them, or they jump off a roof.
- The individual thinks the family or health worker is trying to harm them and tries to protect themselves in an aggressive way.
- The individual does not want to eat or drink

The individual may feel scared and alone. The family may not know how the best way to look after the individual, and may find it difficult to cope.

18.2 Why do people with schizophrenia have crises?

Many types of crisis happen due to the illness. For example, behaving in an unpredictable way or thinking others are trying to harm them may be due to hallucinations or delusions (experiencing or believing things that aren't true). These are all likely to be worse when the individual is having a relapse (when the illness gets much worse). Other types of crisis are due to stigma or other external factors. For example, being beaten at the holy water. Although these things can happen at any time, they are also more likely to happen when the individual is very unwell.

18.3 Why is it important to prepare for a crisis?

In Chapter 14 you learnt how you should respond when you identify the individual is at risk. We also need to give families advice on how to deal with a crisis when one occurs. It is good to give the family skills to do this because they are the main carers, and they need to know how to cope when you are no longer visiting them. Being well prepared for a crisis helps to avoid a serious or undesirable outcome, for example the individual hurting themselves or someone else, or being chained up.

18.4 How do we help individuals and families to prepare for a crisis?

Principles

It is good to start preparing for a crisis when the individual is well enough to take part in the discussions. This gives the individual more control over the situation. Be aware that talking about future or past crises may be upsetting for the individual and family.

1. Discuss what kinds of crisis are likely

Ask the individual and family to think of crises that have already happened or might happen in the future. Use the examples in Section 18.1 to help them to think about it. Discuss how they will know if a crisis is happening e.g. the individual stops taking medication or becomes angry or upset.

2. Explain why you are doing this module

Explain why you would like to help them to prepare for a crisis.

3. Decide who to ask for help

Ask the individual and family to decide three people to call for support in a crisis. Tell them to keep their phone numbers in more than one place so they don't lose them. The people might include:

- A relative
- A neighbour
- A community or religious leader
- The CBR worker. Remind them that this won't be possible once CBR has finished

4. Make a crisis plan

Decide together what actions the family should take when there is a crisis. This might include the following:

a) Try to make sure the individual is taking the medication

b) Take the individual to the health centre for a review. Tell the family to make sure they are clear about what the plan is and what to do next. Tell the family to inform you or the health centre staff about violent behaviour, discussion about death or

suicide and any beliefs that other people are trying to harm them

c) Contact the relative/neighbour/leader. Just bringing someone else into the home to assess the situation may be useful. They may also help with getting to the health centre if this is difficult.

d) Remove access to weapons and potentially poisonous materials

e) Make the environment safe and comforting. Give the individual lots of space.

f) Remove all access to alcohol and khat.

g) Encourage the individual to put strong feelings and energy into safe activities they enjoy, such as listening to the radio

h) Suggest the individual tries relaxation techniques (See Section 23.4)

5. Discuss how the family should treat the individual during a crisis

- Use a calm, positive but firm tone of voice.
- Use simple language
- Give the individual extra time to respond and to calm down
- Reduce expectations about work or household tasks

6. Discuss what actions are not usually helpful

- The family should try not to argue with the individual. This will only make the person confused and frustrated. Instead the family should be loving. The family shouldn't disagree with delusions. It's ok to tell the person they don't see things the same way and leave it at that.
- The family should not accept violence from the individual. The individual should be clearly told that this behaviour is unacceptable.
- They family should not be violent towards the individual and should try to avoid restraining them.

7. Make a plan to deal with the current crisis, if there is one

Follow up

Yosef's story

Yosef and Addis agree that the most likely crisis is that Yosef will become unwell and run away, like has happened in the past. They agree that if a crisis happens Solomon (Yosef's father) will ask their uncle for help. They might also ask the local priest, whose opinion they respect. Berhan writes down the crisis plan. The family cannot read but they appreciate Berhan having the plan written down. This means they can look back at it later with Berhan.

Yosef's Crisis Management Plan

- *Check if Yosef is taking the medication. Gently encourage him to start taking it again if he has stopped.*
- *Go to the health centre for a review, with the help of the uncle.*
- *Tell the local priest if Yosef has run away, in case he can help to find him and bring him home.*
- *If Yosef is still at home, make sure he has some space to himself.*
- *Make sure there is no alcohol or khat in the house.*

If there is currently a crisis, make sure you follow up on what has happened and whether the steps helped at the next home visit.

18.5 Summary

- It is common for people with schizophrenia to have crises such as dangerous behaviour or thinking about suicide
- It is important to prepare for a crisis to avoid serious outcomes such as getting hurt or being chained
- Ways to prepare for a crisis include: deciding who to ask for support, making a crisis plan, and thinking about ways to treat the individual during the crisis.

19 Module: Dealing with human rights problems

19.1 What human rights problems do people with schizophrenia experience?

All people, including all people with schizophrenia, have the same human rights. Quite commonly people with schizophrenia are denied their human rights. We have already learnt about some human rights problems in Chapter 7, and in Chapter 14 as they are also types of risks and crises. The human rights problems experienced by people with schizophrenia include:

- **Chaining and restraint**
- **Neglect**
- **Physical abuse**
- **Sexual violence**
- **Not accessing health services**

Many people with schizophrenia find it difficult to access health services either for their mental illness or for physical health problems (see Chapter 17). On some occasions people with schizophrenia are actually excluded from getting the same level of health care as people who do not have mental illness.

- **Not being able to work or get married**

Sometimes people with schizophrenia cannot do usual life activities such as working or getting married because they are too unwell. Just as often, individuals find it difficult to do these things due to stigma and discrimination (see Chapter 6).

19.2 Why do people with schizophrenia experience human rights problems?

- **Due to being unwell and the family not having enough support**

People with schizophrenia may get mentally unwell from time to time. This can happen because they are not accessing treatment or because the medication is not sufficient to help them. During these times, if the family has little support they may feel they have no choice but to restrain the individual. Usually, they are trying to protect their family member from running away and being harmed in an accident, or by other people. Often they are also concerned that the individual may harm other people or damage property. When a person is unwell with schizophrenia and the family does not have enough support it also becomes more difficult for the family to look after them properly. It becomes difficult to keep the individual fed and clothed. It

can then become more difficult to get them to the health centre, which makes all the problems worse.

- **Not taking medication**

When a person with schizophrenia is not taking their medication, the family may resort to secretly giving the medication (for example mixed into food), tying up or physically forcing the individual to make them take their medication. The person may also be tied up in order to make the journey to the health centre or hospital.

- **Stigma and discrimination**

Many people don't know very much about schizophrenia. They may believe that people with schizophrenia are always violent, or that they are possessed by the devil. These kinds of beliefs can lead people to treat those with schizophrenia badly, such as by beating them or keeping them tied up even when they are well (See Chapter 6).

- **Traditional and religious healing**

Most traditional and religious healing does not harm people with schizophrenia. However, sometimes when a person refuses to take holy water, they may be beaten or tied up so that they can be forced to take the water or bathe in it. Also, some traditional healing practices include physical abuse such as branding, beating and fumigation. All of these things make schizophrenia worse, and are an abuse of human rights.

- **No health services available**

Often the reason why people do not get medical care for schizophrenia is because there is none available locally, or it is too far or too expensive for them to use.

19.3 Why is it important to reduce human rights problems in people with schizophrenia?

People with schizophrenia have the same human rights as all people, so we should ensure they are protected. Reducing human rights issues is also an important way to help the rehabilitation. Whilst they are tied up, individuals cannot begin to undertake usual life activities like washing and dressing, drinking coffee and doing farm work. Treating people with schizophrenia with dignity and respect will improve their self-esteem and confidence and make it more likely they will get back to their usual activities. This in turn reduces the burden on the family.

19.4 How can we reduce human rights problems in people with schizophrenia?

Principles

One of the main aims of CBR is to reduce human rights problems. CBR can do this by:

- Improving access to health services for physical and mental health (see Chapter 17)
- Improving understanding about schizophrenia and changing negative and incorrect beliefs amongst the family (see Chapter 16) and community (see Chapter 31)
- Improving self-care (Chapter 24) and nutrition (see Chapter 21)
- Improving the family environment (see Chapter 25) therefore reducing the likelihood of emotional and physical abuse.

There are also specific steps we can take to reduce human rights problems. Remember that discussing human rights problems may be upsetting for the individual and family. Be sensitive to this and be ready to take a break from the discussions if necessary.

1. Explain why you are doing this module

Explain what human rights are, and that people with schizophrenia have the same rights as other people. Explain why it is important to protect the human rights of people with schizophrenia.

- The individual cannot begin to get back to usual activities whilst tied up
- Treating the individual in a dignified way will improve self-esteem and make it more likely they will do usual activities again

2. Assess human rights problems

You should begin by discussing what human rights issues the individual has faced in the past, or present or may face in the future. You should also refer back to the risk assessment, where human rights issues may have been identified (see Chapter 14).

3. Educate the family about chaining and physical abuse

Advise the family that chaining is not desirable, even if this hasn't happened to the individual. Use the reasons given above (see Section 19.3) for why it should be avoided.

4. Use problem solving to reduce human rights problems

You should then discuss each human rights issue in turn with the individual and caregiver. Encourage them to think of ideas for how to avoid the issue in future using the problem solving approach (see Section 10.5). Discuss the approaches they have already tried. Build on their ideas and then suggest some of your own if everything has not been covered. Some or all of the following methods can be used.

a. Help individuals to take their medication and reduce relapse

Use the strategies in Chapters 20 and 30 to support individuals to take medication and reduce relapse. These will help avoid situations where the individual becomes unwell and the family turn to chaining.

b. Help families to deal with violence and crises

Giving the family strategies to deal with violence from the person with schizophrenia, and other crises situations, will help them to avoid resorting to chaining. See Chapter 18.

c. Educate community members and community leaders

Part of the awareness- raising for community members and community leaders should be that restraint should not be used except in an emergency (see Tasks 5 and 6 in the Community Engagement chapter 31). Ask the family if there is any particular individual who would benefit from education about chaining or physical abuse.

d. Educating holy water priests, attendants and traditional healers

Holy water priests and attendants and traditional healers may be involved in your general community awareness raising. If not, and you feel there are particular problems with priests or attendants you have identified, you may need to undertake specific meetings with these individuals. Ask the family if there is any particular individual who would benefit from education about chaining or physical abuse. The aim is to encourage them to avoid chaining or physical abuse during their healing practices. See Task 11 in Community Engagement Chapter 31.

5. What to do if someone is chained (see also Chapter 14)

If an individual is chained whilst you are working with the family follow these steps:

- Tell your supervisor immediately.

- Facilitate access to the health centre for a clinical review. Ask the family to take the individual as soon as possible.
- If the individual is still chained and they have not attended the health centre after one week, make a joint home visit with your supervisor.
- At this home visit you and your supervisor should discuss with the family and the individual (if possible) the reasons why they have not attended.
- Try to address these reasons, for example:
    - Repeat the importance of receiving treatment for improving symptoms
    - Mobilise community leaders to help the individual travel to the health centre
    - Also see Chapter 17
- If the individual is still chained and they have not attended the health centre after one week, you should inform the Trial Psychiatric Nurse.

Unchaining

Do not tell the family to unchain the individual without support from your supervisor and the health centre. The decision to unchain should be made by the family, preferably in discussions with the health centre.

6. Reducing harm from chaining when it occurs

Despite the best efforts of you, the family and the individual, sometimes the individual may become so unwell that the family still feels the best option is to tie up the individual. You should inform your supervisor and facilitate the individual to attend the health centre for a review. You should not encourage chaining, however you can offer the following advice to the family to ensure that chaining is as safe and dignified as possible when it does occur.

- Make sure the individual is in a sheltered position not exposed to the sun and rain.
- Make sure the individual has some clothing and/or blankets to keep warm
- Make sure the individual is offered regular food and water. Help and encouragement should be given to eat and drink.
- If possible, allow the individual to be unchained every day to walk around

- Change the position of the chains/ restraint as often as possible, to ensure the individual is not always sitting or lying in the same position
- Check regularly for wounds or sores caused by the chains/restraint, or by lying in the same position for a long time. Carefully wash any wounds or sores with clean water. Change the position of the chains to allow the wounds to heal.
- Continue interacting with the individual and involving them in conversation
- If the individual becomes physically unwell, take them to the health centre

7. What to do when other human rights abuses occur

- **Neglect.** See Chapter 35.
- **Physical abuse.** See Chapter 35.
- **Sexual violence.** See Chapter 35.
- **Not accessing health services.** Complete Module: Improving Access to Health Services (Chapter 17).
- **Not being able to work or get married.** Consider completing Modules: Getting back to work (Chapter 27), Taking part in community life (Chapter 26) or Dealing with Stigma and Discrimination (Chapter 28) depending on the situation.

8. Make a plan

At the end of the discussion, make sure that everybody knows what input they are expected to have before the next session.

Follow up

Check what progress has been made relating to human rights problems at the next home visit.

Yosef's story

In the past when Yosef was very unwell Addis and Solomon felt it was necessary to chain Yosef to the house. The kebele chairperson also told them it was their responsibility to this, to protect other people and property in the kebele. Yosef and Addis find it upsetting to talk about him being chained up. Berhan tells the family that she understands that they were only trying to help Yosef and protect other people when they chained him up in the past. However, it is important to try to prevent this happening in the future. The family agree that the main way to avoid chaining is to ensure Yosef takes his medication regularly. They agree that in the future they will complete the Module: Supporting individuals to take medication. Solomon and Addis feel they cannot have any influence on the kebele chairperson. Berhan agrees to discuss the issue with him. Berhan also gives the family advice on how to chain Yosef in a way which is as dignified as safe as possible, in case they ever need to do it as a last resort.

19.5 Summary

- Quite commonly people with schizophrenia are denied their human rights, for example they are chained or physically abused.
- Respecting the human rights of people with schizophrenia is empowering and makes it more likely they will get back to usual activities.
- You can reduce human rights problems by: educating the family, supporting adherence, helping families to deal with crises, and educating community leaders and traditional healers.
- There are ways to reduce the harm from chaining when it does occur.

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20 Module: Supporting individuals to take their medication

20.1 What problems do people with schizophrenia have in taking their medication?

Some people with schizophrenia refuse to take any treatment from the beginning. More commonly, people start the medication but then stop taking it regularly, or stop it altogether, over a period of time.

20.2 Why do some people with schizophrenia not take their medication?

Individual factors

- Insufficient support from the family
- The individual feels shame or stigma from taking the medication, especially if they no longer have symptoms and wish to be seen as well
- The individual and/or their family believe that the illness is due to spirit possession or other causes, and that medication will not help this.
- The individual and/or their family understand that medication helps to relieve symptoms in the short term but do not understand the importance of medication to prevent the illness coming back.
- Holy water priests or attendants or traditional healers tell the individual that it is not needed, or even harmful, to take medication whilst receiving traditional treatment

Illness factors

- People with schizophrenia may not understand that they have an illness that needs treatment. Because of their illness, they may even believe that the treatment is being given to them to harm them.
- People with schizophrenia often have low levels of motivation
- People with schizophrenia often have low levels of attention and concentration
- The person may also be using khat or alcohol. This may make them less organised or less interested in taking medication.

Treatment factors

- The medication causes unpleasant side effects in the person with schizophrenia
- The person with schizophrenia does not have enough food to cope with feeling more hungry than usual as a result of the side effects of the medication

- The person with schizophrenia does not have a good, trusting relationship with the nurse or doctor prescribing the medication
- The medication has to be taken on a complicated schedule so the person with schizophrenia forgets to take the medication.
- The medication does not completely cure the illness so the individual does not see the point in taking it.

Practical factors (see Chapter 17)

- The family cannot afford the medication
- The family cannot afford to travel to the health centre
- It is difficult to take the individual to the health centre because they are unwell and/ or it is too far.
- There is no one free to take the individual to the health centre.
- The medication is not always available at the health centre

20.3 Why is it important to take medication regularly?

It is important to take medication regularly to treat the illness so that the person with schizophrenia starts feeling better. When individuals take medication they are much more likely to be able to get back to usual activities like farm work and housework. Once taking the medication, it also is much less likely that the individual will be so unwell that the family needs to restrain them up. It is very important to continue to take medication, even after the person with schizophrenia is feeling well again. This is to prevent the illness from coming back. If the illness comes back the individual may stop being able to work and socialise again. Even though there are some disadvantages to taking medication, for example the side effects, most people with schizophrenia feel on balance that life is better when taking the medication.

20.4 How can we support people with schizophrenia to take their medication?

Principles

- There is not one single approach to helping people to take their medication. Often a range of methods is needed for each individual.
- Which methods you use depends on their social and personal circumstances

- When somebody does not take his or her medication, it is usually not a problem that can be quickly 'solved'. This means ongoing input is needed, usually for the duration of receiving CBR.

1. Revise the information about medication

Revise the following information about medication.

- What is anti-psychotic medication
- Side effects of anti-psychotic medication

2. Explain why you are doing the module

Explain why it is important to take medication regularly and why is it important to continue taking medication when feeling well.

3. Assessing problems with taking medication

Find out what the current arrangements are for taking medication. When do they take it? Does anyone remind them? Then assess the reasons why the individual has problems taking the medication, or might have problems in the future. Ask what their attitude towards medication is. Have they found it useful? The Checklist for problems taking medication (Form 15) should be used. This covers the reasons in Section 20.2.

4. Problem solving to improve taking medication regularly

You should then discuss each reason or problem in turn with the individual and caregiver. Encourage them to think of ideas for how to get around the problem using the problem solving approach (Section 10.5). Discuss the approaches they have already tried. Build on their ideas and then suggest some or all of the ones below, if they have not been covered:

a. Involve the family

The individual's immediate family are the most important people to help them take medication regularly. You should:

- Try to understand the family member's viewpoint and attitudes towards medicines

- Involve them in understanding the reasons for not taking medicines and deciding the best methods to improve the situation
- Provide them with information on the benefits and side effects of medicines.
- Involve members of the extended family (uncles, aunts, cousins, etc) who live outside the home. They may have a significant role to play in ensuring individuals take medication regularly. Find out who the important individuals are and consider meeting with them to gain their support.
- Get the family to use positive feedback
- Give the family skills to deal amicably with situations where the family members and the individual have different views on adherence (see Chapter 25)
- Consider asking the family to observe the individual every time they take the medication. However this may not help the individual to feel independent, so try this only if this the other ideas do not work.

b. Reinforce information about medication

Give or revise information about medications, their benefits and side effects. You may need to give information to other family members as well as the individual and caregiver.

c. Address side effects

Discuss concerns about side effects. There are some side effects you can help with and others that need to be reviewed at the health centre (see Table 4).

Table 4 How to help with side effects

What happens?	How you can help
The mouth is very dry	Try putting a clove in the mouth or sipping water
A lot of saliva is produced	Advise them to put a cloth next to their mouth at night
Constipation	Advise them to drink lots of water and eat high fibre foods e.g. lentils and vegetables
The person feels dizzy when they go from lying down or sitting to standing	Advise person to get up slowly and wiggle fingers and toes before getting up
The person wants to eat more than usual	Advise that the individual probably does not need more food, this is just a side effect of the medication. Try eating small amounts regularly and including more bulky food e.g. vegetables. Refer to health centre- for change of dose or possibly medication.
The person feels restless and cannot sit still.	Refer to health centre
The head, neck or body becomes stuck in an unusual position.	Refer to health centre
The hands shake	Refer to health centre
The person moves very slowly and feels their muscles are very stiff	Refer to health centre
The person is very drowsy	Refer to the health centre- the amount of medication may need to be changed, or the time of day they take it. Drowsiness may reduce when the person gets used to the medication
Writhing movements of the head, neck, arms or legs.	Refer to health centre
Seizures	Refer to health centre
Sexual problems	Refer to health centre
Skin rash	Refer to health centre
The person cannot pass urine	Refer to health centre
Suddenly developing stiff muscles, fever, and confusion	Take to hospital immediately

d. Get a daily routine

Build medication into the daily routine. Suggest the person with schizophrenia always takes the medication after doing a daily task e.g. getting washed in the morning or having breakfast.

e. Use positive feedback

People with schizophrenia have problems with motivation. They need frequent and consistent feedback and appreciation from family members and you for continuing to take the medication. To begin, the family can reward the individual taking his medication with clear signs of appreciation (by telling them they are doing well or cooking his favourite dish). Make it clear that this is linked to the fact that the individual has been taking the medicines.

f. Improve relationship with the nurse

When you attend the health centre with the individual around the time of each CBR Review, one of your roles is to help improve the communication and relationship with the nurse. If there is any obvious misunderstanding during the consultation, try to clarify this at the time. You can also help the individual to raise any issues, for example that the medication schedule is too complicated. After the consultation, check the individual and the caregiver understood everything and fill in any gaps.

g. Arrange a medication review at the health centre

Taking the medication once daily is likely to be easier to remember. If the individual feels that the schedule is too complicated, they can discuss this with the nurse at the health centre. Having the injection instead of tablets usually makes it more likely the individual will take the medication, as they don't have to remember every day. On the other hand some people with schizophrenia are less willing to have injections than to take tablets. It is not your decision to change to injections. However, if other methods have been tried but are not successful, and the individual is willing to try injections, you can encourage him or her to speak to the nurse about this at the health centre.

h. Engage with traditional and religious healers

Try to find out who the healer is. You may have already made contact with them during your initial community engagement (see Task 5 in Community Engagement Chapter 31). With the permission of the family, try to arrange a meeting with the healer. Give them information about schizophrenia, including that medication can help to reduce symptoms and prevent the illness from returning. Tell them that the

individual does not need to stop receiving holy water or traditional practices, but that they can use medication alongside it (see Task 11 in Community Engagement Chapter 31).

i. Explore accessing free medication

See Chapter 17.

j. Make travelling to the health centre easier

See Chapter 17.

k. Address financial problems

See Chapter 17.

Table 5 can be used as a guide for which methods to use:

Table 5 Approaches for supporting individuals to take medication

Problem	**Approach/s**
Insufficient family support	Involve the family
Shame or stigma	Give information Involve the family
Differing beliefs	Give information Involve the family
Lack of understanding about preventing relapse	Give information Involve the family
Discouraged to take medication at holy water	Give information Engage with traditional and religious healers Involve the family
Lack of awareness (due to illness)	Give information Involve the family
Lack of motivation and/ or concentration	Positive feedback Daily routine Involve the family Medication review at health centre
Khat or alcohol use	Referral to health centre Positive feedback when khat or alcohol is avoided Get a daily routine Involve the family
Side effects	Address side effects
Insufficient food for increased appetite	Small regular meals including vegetables
Poor relationship/communication with nurse	Improve relationship with nurse
Complicated medication schedule	Medication review at health centre
Cannot afford medication	Explore free medication

	Address economic problems
Cannot afford travel to health centre	Make travelling to the health centre easier Address economic problems
Practical issues travelling to health centre	Make travelling to the health centre easier

5. Difficult situations

What to do when the individual refuses to take the medication

If the individual refuses to take the medication then you should try all the approaches above. However, sometimes the individual will continue to refuse. If this happens you should not force them to take it, but should refer them to the health centre for a review.

Giving the individual medication without their knowledge

The caregivers may have previously given the medication without the knowledge of the person with schizophrenia, for example by mixing it in food or tea. The family may also suggest this as a method for dealing with them not taking the medication in the future. This is a difficult situation as the individual's basic right to decide what treatment they receive is not respected. It also means that if the individual gets better they do not realise that it is due to the medication. This makes it even less likely they will take the medication out of choice later on. In addition, if the individual finds out later on that they were being given the medication in secret, they may find it difficult to trust people. This might make the illness worse.

On the other hand, it is usually understandable when families take this step, if they feel there is no other way to get the person to take the medication, and therefore get well. You should not encourage the family to give the individual medication without their knowledge. If this is done or suggested, you should explain to the family why this method should be avoided if possible, without appearing to be judgemental. Your role is then to ensure that all the other methods for helping the individual to take medication are used first. Tell your supervisor if you are aware if it is happening.

Forcing individuals to take medication

The caregivers may have previously used physical force to get the person with schizophrenia to take the medication, for example, by tying up the individual and

forcing the medication into his or her mouth. Others may suggest this as a method for future use.

You should encourage families never to force individuals to take medication in this way. As well as being disempowering, it may make the person more agitated, or they even get harmed. Tell your supervisor if you are aware if it is happening.

6. Make a plan

At the end of the discussion, make sure that everybody knows what input they are expected to have. Set some specific tasks for the individual and family to complete by the next home visit. For example:

- The person with schizophrenia agrees to take the medication with breakfast everyday
- The caregiver agrees to remind the individual to take medication with breakfast, observe whether they take it or not and to give encouragement if he or she takes it
- The CBR worker agrees to meet with the holy water priest and attendant and give information about the importance of taking medication whilst receiving holy water

Yosef's story

Yosef says even when he is well he often has problems remembering to take his medication. The medication makes him feel tired, drool saliva and makes his hands shake. Sometimes Yosef goes to holy water. The holy water attendants tell him he shouldn't use medication at the same time as this will mean the holy water will not work.

Addis and Yosef agree that Yosef needs the family's help to remember to take the medication. They agree Addis will remind him and watch him take it at breakfast every day. When he takes it she and Solomon will give lots of encouragement. Berhan advises Yosef to try putting a cloth next to his mouth at night, to help with the drooling. She also asks him to go to the health centre in case the amount of medication can be reduced, or he can take it at night. Berhan agrees to discuss the importance of continuing medication with the holy water priest and attendant. She discusses this with her supervisor, Haile, and they go together to the holy water site. It takes Berhan and the family two home visits to discuss medication and create the plan.

7. Monitoring medication

You should assess whether medication is being taken at some point during every home visit, even if you are not currently working through this module. Ask both the individual and the caregiver if there have been any problems. Use problem solving to address any problems, or complete or repeat this module. Record issues with medication on the Home Visit Form (Form 11).

Follow up

Remember to check what progress has been made at the next home visit. If relevant, refer to the health centre, or meet with community leader, kebele leader or traditional or religious healer.

20.5 Summary

- Many people with schizophrenia have problems taking their medication due to: individual reasons (for example, not enough family support), illness factors (for example, not being organised), treatment factors (for example, side effects) and systemic factors (for example, cannot afford travel to health centre)
- Taking medication is important for getting well and staying well
- Ways to help individuals take medication include: involve family, give information, get a daily routine, use positive feedback, educate traditional healers, arrange medication review at the health centre and address side effects.

21 Module: Improving physical health

21.1 What problems with physical health do people with schizophrenia have?

- **Usual health problems**

People with schizophrenia experience the same physical health problems as other people. For example, they may get malaria, a cough or a broken bone from an accident. However, people with schizophrenia are less likely than other people to get medical help for any physical health problems they have.

- **Other disabilities**

People with schizophrenia are just as likely to have other disabilities as other people. For example they may be blind or have problems walking due to childhood polio or an accident.

- **Being underweight or underweight**

In Ethiopia, people with schizophrenia are commonly underweight. Much less commonly in Ethiopia, people with schizophrenia may become overweight.

- **Reproductive health and sexual health problems, need for family planning and antenatal care**

Like anyone else, people with schizophrenia have sexual relationships. Women with schizophrenia may also be sexually exploited. They therefore need access to advice about safe sex, family planning and antenatal care just like other people.

- **Chewing khat, drinking alcohol or smoking**
- **Physical injuries**

People with schizophrenia may develop wounds and sores from being beaten or being chained up. Their muscles may stop working properly if they are chained up for a long time.

- **Heart disease and diabetes**

People with schizophrenia are more likely to get heart disease and diabetes (high blood sugar levels) than other people.

21.2 Why do people with schizophrenia have problems with physical health?

There are a number of reasons why people with schizophrenia have more physical health problems than other people.

- **Difficulty accessing the health centre**

It may be difficult for families to take the individual with schizophrenia to the health centre, either because they have difficult behaviour or because they are tied up.

- **Difficulty paying for health care**

Families may have problems paying for health care, particularly if the individual is so unwell that they or the caregiver have difficulty working.

- **Side effects of medication**

Medication can cause problems such as gaining weight and sexual problems. Sometimes people do unhealthy behaviours, such as chewing khat or drinking alcohol, to try to reduce the side effects of medication.

- **Not enough food**

People with schizophrenia may become underweight because the family is poor and they do not have enough food.

- **Stigma and discrimination**

Sometimes the family or community believes the individual does not need or deserve the same nutrition or physical healthcare as other people. Sometimes health workers don't take people with schizophrenia seriously and dismiss their physical complaints.

- **Individual not willing or able to eat regularly**

Sometimes due to the illness the individual does not want to eat or doesn't find time to eat

- **Being inactive**

Many people with schizophrenia become inactive. This can be one reason for weight gain.

- **Trying to escape problems or socialise**

People with schizophrenia may drink alcohol, chew khat or smoke to try to escape their problems and socialise.

21.3 Why is it important to improve physical health in people with schizophrenia?

People with schizophrenia are much more likely to die young than other people. This is partly due to people with schizophrenia committing suicide. However, it is mainly due to physical health problems such as infections and malnutrition. Having physical health problems may stop people recovering from schizophrenia. When people have physical health problems it may be more difficult to get to the health centre for anti-psychotic medication, or to return to farm work. It is therefore important to try to improve

physical health in people with schizophrenia. Chewing khat can result in decay of the teeth, heart problems, cancer, anxiety and depression. Both khat and alcohol make the symptoms of schizophrenia worse and make it harder to recover. It is therefore important to support people to stop using khat and alcohol.

21.4 How can we improve physical health in people with schizophrenia?

1. Explain why you are doing this module

Explain to the individual and family what physical health problems are common in people with schizophrenia. Give reasons why people with schizophrenia have these problems.

2. Assess physical health problems

Assess what physical health problems or unhealthy behaviours the individual has or might have in the future.

3. Problem solving to improve physical health

You should then discuss each problem in turn with the individual and caregiver. Encourage them to think of ideas for how to get around the problem using the problem solving approach (see Chapter 10). Discuss the approaches they have already tried. Build on their ideas and then suggest some or all of the ones below, if they have not been covered:

a. Ensure access to health care

Ensure that the individual is accessing the health centre or hospital for physical health problems when they arise, for example infections or accidents. See Chapter 17.

b. Avoid alcohol, cigarettes and khat

Encourage the individual not to drink alcohol, smoke or chew khat. Explain that this will probably make the illness worse. Ask the family to try to avoid giving the individual money for alcohol, khat or cigarettes, if possible. Discuss with the individual whether they need help to cut down or stop.

c. Get help for problems with alcohol or khat

If the individual has serious problems with alcohol or khat use, then you should refer them to the health centre. A person has a serious problem if:

- They often appear to be affected by alcohol or khat. For example, smells of alcohol, looks intoxicated, staggers when walking, slurred speech.
- Because of alcohol, they often injure themselves, for example from falling down, fights, or walking in traffic
- They have physical symptoms from excessive alcohol use. For example can't sleep, very tired, can't eat, nauseated by food smells, vomits, complains of a bad stomach, diarrhoea, headaches.
- They show signs of drug use. For example, skin infection, unkempt appearance, dry mouth, burned lips, bad or worn teeth, complains of *dukak* (vivid unpleasant dreams)

d. Encourage a healthy diet

Encourage the individual to eat a healthy diet as much as possible. Be aware that many families will have very limited choice about what they eat. A healthy diet consists of a mixture of:

- Cereals, such as teff (injera), barley and wheat
- Pulses, such as lentils
- Fruits
- Vegetables
- Small amounts of milk, cheese and yogurt
- Small amounts of meat

Make sure the person with schizophrenia eats the same amount and type of food as the rest of the family (See Chapter 24). If you are concerned the person is very underweight you should refer them to the health centre.

e. Encourage appropriate physical activity

Encourage the individual to do some physical activity as it is not good for them to sit at home all day. Most people can do this as part of their day-to-day activities, for example going to fetch water. However, people with schizophrenia should not do excessive exercise as this may contribute towards them becoming underweight.

f. Refer to the health centre for problems with side effects of medication

You should refer back to the health centre if the individual side effects which are affecting the individuals' physical health. For example, problems with menstrual periods.

g. Refer to the health centre for malnutrition

Refer the individual to the health centre, and facilitate them to attend, if they appear very underweight or malnourished (see Chapter 14).

h. Attend to physical injuries

If the individual has any wounds or sores make sure these are washed with clean water. If you are worried about the wound, for example if it is not healing, refer the individual to the health centre. If the individual has problems moving their arms or legs properly because they have been chained up for a long time you should refer them to the health centre. You may be asked to help them exercise their arms and legs.

i. Attend to physical disabilities

If the individual has a physical disability discuss with your supervisor the best way to support them.

j. Ensure access to the health extension programme

The Health Extension Worker should make routine visits to the household to cover contraception, protection against HIV, sanitation, malaria prevention and antenatal care. If the individual asks for help with any of these issues, or if you know that the Health Extension Worker has not made routine visits to the household, contact the Health Extension Worker. Ask her to make a routine visit to the individual to discuss these issues.

4. Make a plan

At the end of the discussion, make sure that everybody knows what input they are expected to have. Set some specific tasks for the individual and family to complete.

Follow up

Make sure you refer to the health centre or health extension worker if this is relevant. If you do make a referral make sure that the individual attends for the initial visit and any follow up that is needed. At later visits ask about progress with healthy behaviours. If there are physical disabilities, discuss with your supervisor.

Yosef's story

Berhan observes that Yosef is quite underweight. Yosef says sometimes he is too tired to eat. Berhan tells Addis about the different parts of a healthy diet. Addis explains that often they cannot grow or afford to buy different types of grains and vegetables and they rarely eat meat. Berhan tells Addis she understands they have limited choices. They agree that Yosef needs more support and encouragement at meal times. Berhan discusses the issue with Haile. They agree that Yosef does not need to go to the health centre at the moment, but if he loses more weight this will be necessary.

21.5 Summary

- People with schizophrenia have physical health problems such as being underweight and using khat and alcohol
- Physical health problems may be dangerous, and make it more difficult to get well
- We can improve physical health by: ensuring access to health centre and health extension worker, and giving advice about diet, exercise, alcohol and khat.

22 Module: Dealing with distressing symptoms

22.1 What distressing symptoms do people with schizophrenia have?

As we discussed in Chapter 2 people with schizophrenia can have four groups of symptoms:

a. Hallucinations (seeing or hearing things that aren't really there) and delusions (believing things that aren't true)
b. Problems with motivation
c. Problems with thinking clearly
d. Person not being aware that they have an illness

All of these symptoms can be very distressing for individuals. The extent to which they are distressing varies from person to person.

22.2 Why do people with schizophrenia have distressing symptoms?

Distressing symptoms are part of the illness of schizophrenia. Medication usually helps to reduce hallucinations and delusions, but sometimes they can continue even when an individual is taking the medication regularly. It is common for problems with motivation and problems with thinking clearly to continue even when an individual is taking their medication regularly.

22.3 Why is it important to reduce distressing symptoms?

As well as being distressing for the individual, these symptoms can be disabling. See Chapter 4. Having symptoms can make getting back to usual activities more difficult.

22.4 How can we help to reduce distressing symptoms?

Principles

At all times, the focus should be on **empowering** the individual to take charge of managing their own illness. The general approach to reducing symptoms is:

- Supporting the individual to take medication (see Chapter 20)
- Reducing **stress** by improving the environment, for example dealing with human rights problems (See Chapter 19), or improving coping strategies (see Chapter 23)

However, people with schizophrenia often continue to experience distressing symptoms despite taking these steps. It is therefore important to have specific ways to help to cope with them. To do this, follow these steps.

1. Revise information about symptoms

Revise what kinds of symptoms people with schizophrenia experience, relating them to the symptoms the individual has

2. Explain why you are doing this module

Explain why it is important to reduce distressing symptoms. Emphasise that this is a chance for the individual to feel better. Highlight that problems with motivation and thinking clearly can be difficult to overcome.

3. Assess symptoms

Find out which is the most distressing symptom and focus on that first. Discuss the following issues relating to that symptom:

- How often it happens
- How it affects the person
- What makes it worse, for example having an argument with parents
- What makes it better, for example talking to a brother or sister

4. Suggest potential coping strategies

a. Hallucinations

- *Change the level of activity*
  Try relaxation (see Chapter 23), or taking a walk
- *Do a distracting activity*
  Talk to family members or neighbours, listen to the radio or sing a song or hum
- *Talk to yourself in a positive way*
  For example, 'I can cope with this'
- *Ignore the hallucination as much as possible*

b. Delusions

- Suggest that the individual checks their ideas of reality with someone they trust, for example the caregiver

- If the individual discusses their delusions with the caregiver, the caregiver should listen to them. The caregiver should not try to argue or reason with them.

c. Problems with motivation

- Remind the family that the person is not lazy or useless, but has an illness that makes it difficult to find the energy or will power to do their usual activities.
- Encourage the individual to have a regular routine, e.g. getting up at a regular time, eating when others eat (see Section 24.4 for more detail)
- Encourage the family to involve the individual in social and community activities, for example attending church (see Chapter 26)
- Encourage the individual and family to think about the future with hope. Ask them to think about the progress that the individual has already made.

d. Problems with thinking clearly

- When the person with schizophrenia is doing something, for example preparing food or having a conversation, try to reduce distractions. For example turn off the radio and reduce background conversations.
- Try activities that improve concentration, for example weaving or praying
- Remind the family to give the individual lots of time to do small tasks and not to become impatient.
- Practice activities many times until they become easier

5. Discuss coping strategies that are unlikely to be helpful.

These include: Angrily telling the voices to go away; Drinking alcohol or chewing khat; Sleeping a lot; Avoiding contact with other people and Stopping medication.

6. Make a plan

Help the individual to select a coping strategy or strategies, involving the caregiver in the discussion. You can also use a problem solving approach (see Section 10.5). Ask the individual to practice the coping strategy they have chosen a few times. Ask to them to think about times when it is possible or not possible to use the strategy.

Follow up

Follow up progress every time you see the individual. Ask whether it is helping or not. If it is not helping, make changes to the strategy or try a different strategy.

Sara's story

Sara is a young woman who became unwell with schizophrenia one year ago. She can still hear voices that command her to do things. Sometimes she believes she has special powers to read other people's minds. Her husband, Alemu, usually tells Sara that she is stupid or mad when she talks about this. These problems are a bit better since she started taking the medication, but they have never completely gone away. Berhan asks Sara to describe these problems and to tell her how often they happen. Sara tells Berhan that the problems get worse when she doesn't take the medication and when she gets stressed. After some discussion, Sara agrees to try listening to the radio when the voices next become very bad. Alemu agrees that it doesn't seem to help when he insults Sara or tells her off when she talks about her special powers. Alemu agrees to try not to do this in future. Berhan asks Sara and Alemu to try these ideas and that they will discuss how it went at the next home visit.

22.5 Summary

- Many people with schizophrenia find their symptoms distressing, even when they are taking medication regularly.
- Having distressing symptoms can make it more difficult to get back to usual activities
- We can try to reduce distressing symptoms by supporting individuals to take medication, and reducing life stress.
- We can also suggest coping strategies such as: doing a distracting activity (for hallucinations), discussing ideas with a trusted person (for delusions), having a regular routine (for motivation problems) and reducing background noise (for problems thinking clearly)

23 Module: Managing stress and anger

23.1 What problems do people with schizophrenia have with stress and anger?

Stress is what people experience when they feel overwhelmed by the things happening in life. It makes people feel tense and anxious and that they cannot cope with the difficulties they face. We all experience stress in our daily lives. However when someone has schizophrenia this will increase the stress of the individual and their family members. Stress can have many effects on people, including changes in the body, emotions, and behaviour. In particular stress can sometimes cause people with schizophrenia to become angry. Anger can sometimes cause an individual to harm other people or themselves or damage property.

23.2 Why do people with schizophrenia have problems with stress and anger?

Different people find different things stressful. Stress can be caused by:

- Important life events that happen suddenly, for example a death in the family,
- Ongoing difficult situations, for example financial problems or family conflict. These things may be more common when someone in the family has schizophrenia.

23.3 Why is it important to reduce problems with stress?

Stress, along with **vulnerability**, is one of the factors that determines how severe the illness is and how many relapses there are (see Section 2.3). Learning to manage stress is therefore important for the wellbeing of the individual and to help them to recover. Anger can cause relationship problems within the family. If a person with schizophrenia becomes aggressive, the family may feel it necessary to tie them up in order to protect other people and the individual. In order to prevent this happening it is important to learn how to prevent and deal with anger.

23.4 How can we help to reduce problems with stress and anger?

Principles

Problems with stress and anger can be reduced by:

- Preventing stress and anger happening in the first place
- Giving ways to deal with stress and anger when it does happen

1. Give information about stress and anger

Explain what stress and anger are and why they happen

2. Explain why you are doing this module

Explain why it is important to reduce stress and anger

3. Assess problems with stress

Discuss what situations were stressful in the past or might be stressful in the future.

4. Discuss ways to prevent stress

Discuss how the individual can avoid feeling stressed in the future. Use the individual and families' ideas and suggest the following if they have not been covered:

a. Avoid or try to change situations that were stressful in the past

If a situation was stressful before, it is likely to cause problems for the person when they are in the same situation again. Suggest to the individual that they avoid these if possible. For example if the individual finds it difficult to attend a wedding, they could avoid going to the ceremony. Or suggest that they change the situation to make it less stressful. For example, they could meet the bride and groom at a different time.

b. Have regular activities

Stress can be reduced if the person has the right balance of activity and rest. People with schizophrenia usually find it helpful to have some structure to the day. Try to involve the individual in meaningful activities, such as housework, farm work or drinking coffee with others. See also Chapter 24.

c. Have a healthy lifestyle

Eating enough nutritious food, getting enough sleep, doing exercise and not drinking alcohol or using khat can all help to reduce stress. See also Chapter 21.

d. Have reasonable expectations

Having high expectations of the individual can be stressful for him or her. Encourage the family to have reasonable expectations and for realistic goals to be set.

e. Try not to be critical

It is important not be critical of the individual and for them not to be critical of

themselves. Encouragement should be given for any task that the individual does and any small changes should be acknowledged. Think of positive things about the person and remind them of these when they are feeling negative. Ask the family to do the same.

5. Discuss ways to deal with stress

Discuss how the individual deals with stress when it does happen- is it helpful? Use the individual and families' ideas and suggest the following if they have not been covered:

a. Allow the individual to discuss their feelings

Letting the person talk about their feelings often provides some immediate relief and can keep stress from building up. Stress may be an early warning sign of a relapse. If the person with schizophrenia can tell you or a relative when he/she is feeling stressed, the relapse may be prevented. See Chapter 30.

b. Allow the family to discuss the situation

Discuss the situation with the family and try to find possible solutions to the problem causing the stress. Use the problem solving approach (see Section 10.5).

c. Use relaxation techniques

Relaxation techniques can help in reducing stress and sleeping well. You can teach both the individual and family these techniques. It is best to practice every day.

Controlled Breathing

- Explain that when we become stressed our breathing rate often speeds up. Slowing down our breathing can help us to feel more comfortable.
- Show the individual and family how to breathe in for 4 counts, hold for 2 counts and breathe out for 6 counts. You can close your eyes if you wish.
- Practice this exercise in the session for 5 or 10 minutes.
- Ask for feedback from the client and family about how they found the experience and discuss any difficulties.
- Discuss that learning a slow breathing technique is more difficult than it first seems, and requires a lot of practice. You could also suggest some ways

of making the process easier, for example:

- Initially, only practice the breathing exercise when you're not feeling stressed
- Explain that some people describe feeling more stressed when they first begin using controlled breathing. It is important to carry on with the technique, because this feeling of stress will decrease with practice
- Practice in a comfortable environment. Lying down is easier than sitting in a chair. Choose a quiet dimly lit room, and try to practice at a time when they will not be disturbed
- The breathing pattern may be hard for some people so you might need to adjust it (e.g. breathe in for 3 counts, hold for 1 and breathe out for 5, or breathe in for 3 counts, hold for 1 and breathe out for 3 counts)

Muscle relaxation

The aim of this form of relaxation technique is to help the person relax by releasing muscle tension with each outward breath. It builds on the controlled breathing technique described above. This is what you should say:

"Focus on your breathing…Just focus on each breath, in and out...As you breathe in, tense the muscles in your feet as tight as you can. As you breathe out relax your feet and let go of the tension"

You then go through each specific areas of the body in turn, continuing with the ankles and working upwards. Repeat the instruction to tense the particular area as you breathe in and release any tension as you breathe out. Continue this exercise for 10-15 minutes.

d. Religion

For many people religion gives comfort and direction to their lives. Religious beliefs, prayer and attending church or mosque can help people cope with stress. Also, religious groups, for example *mahaber*, can be a source of social support, which can reduce feelings of isolation and stress.

e. Encourage the individual to talk about themselves in a positive way

Encourage the person with schizophrenia to stop talking to themselves in a negative way, for example "This is awful". Encourage them to try talking to

themselves in a positive way, for example "This is a challenge but I can handle it" or "I am going to do the best I can".

f. Keep a sense of humour

Many people with schizophrenia have a good sense of humour. When a stressful situation happens, try to say something that will make the individual smile, to avoid them being totally overwhelmed by the situation.

g. Exercise

Physical activity has a positive effect on reducing stress, lifting mood and improving sleep patterns. People with schizophrenia should try to do some light physical activity every day, for example walking. However they should not do strenuous activities or exercise for long periods as this may contribute to weight loss (see Section 21.2).

6. Discuss unhelpful ways to deal with stress

These include: smoking, drinking alcohol, chewing khat, not spending time with other people, being very busy and getting angry with other people.

7. Discuss problems with anger

Discuss what situations have made the individual feel angry or what might do in the future.

8. Discuss ways to prevent anger

Some ways to prevent anger include:

- Try to understand what makes the individual angry and try to address this problem
- Prevent and deal with stress (see above)
- Develop self-confidence in the individual (see Chapter 28)
- Make sure the individual is accessing the health centre and taking their medication
- Try to avoid drinking alcohol or using khat; these can reduce people's anger control.

9. Discuss ways to deal with anger when it happens

Suggest the individual tries some or all of the following techniques when they feel angry:

- Leave the situation which is causing him or her to feel angry as soon as possible
- Notice the fact that he or she is angry. Stop doing whatever they were doing and either walk around or sit calmly for a few minutes.
- Release the stress in a way in which there is least possible harm to self, others, and the environment, for example punching a pillow.
- Do relaxation techniques, for example controlled breathing.
- If possible do something distracting, like watering the kitchen garden
- Talk to someone about what is making them feel angry.

If he or she became aggressive, after the situation has passed, suggest that individual: Apologises to anyone involved and tries to tidy up or fix anything that was disturbed

10. Make a plan

Help the individual to select strategies for preventing with and dealing with stress and anger. Involve the caregiver in the discussion.

Follow up

Remember to review which of these ways to deal with stress or anger were helpful, and which were not. Suggest to the individual and family to focus on the helpful ones in future.

23.5 Summary

- Everyone experiences stress sometimes, but it is more common in people with schizophrenia. Stress can lead to anger.
- Stress can make symptoms worse and make relapse more likely
- Ways to prevent stress include: avoid stressful situations, healthy lifestyle, have reasonable expectations
- Ways to deal with stress include: relaxation, religion and talking about problems
- Ways to prevent and deal with anger include: developing self-confidence, leaving the situation that is making them angry, and releasing the anger in a way that is not harmful

24 Module: Improving day to day functioning

24.1 What problems do people with schizophrenia have with day-to-day functioning?

People with schizophrenia may spend the day doing nothing in particular. This can be distressing for family members and they may see the person as being 'lazy'. People with schizophrenia may also have problems doing specific tasks. They may have problems with self-care, including: Cleaning teeth, Washing their body and hair, Eating food in a proper manner, Washing hands before and after eating, Cutting nails and Using the toilet properly.

They may also have problems with household tasks, including: Preparing food, Preparing coffee, Cleaning the cooking and serving utensils, Fetching water, Going to the mill house to get grain ground, Washing clothes, Cleaning the animal area, Preparing local beverages, for example tella, for the household, fencing and repairing the house.

24.2 Why do people with schizophrenia have problems with day to day functioning?

People with schizophrenia may have problems doing these tasks for a variety of reasons:

- The illness gives them problems with motivation
- The illness gives them problems with thinking clearly
- Medication side effects, such as drowsiness or shaking hands, make some tasks difficult
- The family does not let them do tasks, for example preparing the coffee, because they are worried they will do it wrong.

24.3 Why is it important to improve day to day functioning?

- Keep the person engaged in useful tasks
- Improve memory, attention and concentration
- Distract from troublesome symptoms like hallucinations and delusions.
- Improve their self-confidence
- Reduce stigma towards them

- Improve social interactions

24.4 How to improve problems with day to day functioning?

Principles

- Establish what is normal for the household. For example, check how often other family members get washed, and whether soap is used.
- Establish what is normal for the individual. For example, check whether fetching water was expected of them when they were well.
- Set realistic goals and aim for gradual improvement. The individual will need more time than usual to do the tasks
- Involve the family at every stage of the process. The aim is for them to be able to support the individual to do the task when you are not there.
- The individual will often know how to do the task, but may have problems remembering or being motivated to do it. Focus on getting the individual back into a routine.
- Ask the family members to give encouragement when any of the tasks are done
- You may notice that there are problems with hygiene and sanitation within the household that are not only related to the individuals' illness. If this is the case you could direct some of your advice, for example about the importance of washing, towards other family members too. You can also consider asking the health extension worker to visit to discuss sanitation, if they have not already done so.

1. Explain why you are doing this module

Explain to the individual and family that problems with day to day functioning are common in people with schizophrenia. Give some of the reasons why people have problems and why it is important to improve the situation.

2. Assess for problems with self care

Ask what problems the individual has with day to day functioning, using the Day to Day functioning Progress Form (Form 16). Ask the individual why they are having difficulty. Focus on the tasks where there is a problem.

3. Give advice on how to improve each self care task

For each task:

- Discuss why it is important to do the task. Say it is healthy to keep your teeth and body clean. Also it will make it easier to socialise with friends and family.
- Check what the family normally does and what is expected of the individual
- Agree a time when the individual will do the task e.g. clean teeth straight after waking
- If the individual is very disorganised you may need to talk through, or demonstrate, the stages in the task. If appropriate, ask the individual to have a go at doing the task
- To begin with the caregiver may need to watch the individual doing the task

Tasks may include:

a. **Cleaning teeth**
b. **Washing**
c. **Grooming e.g. braiding hair, cutting nails.** The family should supervise the first few attempts at cutting nails to ensure that he/she cuts it safely and neatly.
d. **Using the toilet, washing hands and menstrual hygiene.** This is a sensitive issue and you must be careful when you discuss this topic so as not to offend the individual or the family. Discuss the disposal and washing of soiled clothes.
e. **Dressing and taking care of clothes.** E.g. not wearing too few or too many clothes**.**
f. **Healthy eating habits.** Ensure the individual is being involved in mealtimes with the rest of the family. Discuss the important things to do and not do whilst eating e.g.
    - Wash hands before eating
    - Only eat with the right hand
    - Do not lick fingers
    - Do not reach across other people
    - Wash hands after eating

4. Assess for problems with household tasks

Ask what household tasks the individual finds difficult. Refer back to any problems highlighted in the needs assessment. Try to understand from the individual why they are not doing the task.

5. Give advice on how to improve household tasks

For each household task where there is a problem, go through the following steps

- Discuss what is expected of the individual
- Talk through, or demonstrate, the stages in the task
- If appropriate, ask the individual to have a go at doing the task

The household tasks might include:

- Tidying the sleeping area, and folding the blanket
- Keeping the room tidy. They should be encouraged to pick up fallen items and replace them. They should clean the floor if something has been spilt.
- Sweep the room every day.
- Cleaning and cutting vegetables
- Fetching the water
- Preparing coffee
- Lighting the fire

6. Encouragement and positive feedback

For each self-care and household task, ask the family to encourage the individual to do the task and give them positive feedback when it is done. Tell the family the individual will need more time than usual and will need breaks whilst doing the tasks.

7. Creating a daily routine

Once the individual has some ability to do the individual tasks, you should help them to get into a daily routine. The daily routine should be a **combination of work, rest, leisure, self-care and sleep**. The following is an example of a daily routine.

12:00: Wakeup, attend to toilet, wash face, brush hair

12:15: Tidy bed

12:30: Say prayers

1:00: Eat breakfast

1:15: Wash plate and glass, tidy table

1:30: Milk the cows and feed them

2:30: Fetch water

3:30: Rest or tea/coffee break

4:00: Household activities like cooking, tidying rooms

6:30: Lunch

6:45: Wash plate, glass and tidy table

7:00: Rest

8:00: Wash clothes

9:00: Weaving cloth

10:00: Tea/coffee and converse with family, friends or neighbours

11:00: Feed the cows

12:00: Household tasks like cooking

2:00: Eat dinner

2:30: Wash plate and glass and tidy table

3:00: Listening radio or talking with family members

4:00: Sleep

You can make a similar routine for the person you are working with after considering their age, sex, needs and wishes. Give the individual guidance on how to do all the tasks. Ask the caregiver to be involved and encourage the person stick to the routine as far as possible. It is usually helpful to write it down for future reference, even if the individual and family cannot read.

8. Give advice on managing money

- The family may need to help the individual to recognize the types of coins and notes.
- Family members should encourage the person to purchase things required for the family by initially giving the exact amount to be spent. Later, the person should be encouraged to pay the appropriate amount, collect the correct balance and return home with the items.

9. Make a plan

Decide which task the individual and family will try before the next session. Agree what each person's role is. If there are many tasks that are currently difficult, focus on the ones that are a priority for the individual and family e.g. getting dressed.

Follow up

Remember to review progress at the next home visits, referring to the Day to Day Functioning progress Form.

Yosef's story

Yosef and Addis tell Berhan that Yosef does not wash and sometimes doesn't dress properly. Berhan discusses with Yosef the importance of washing and dressing properly. Yosef agrees this might be stopping him making friends again. With Addis' help, Berhan breaks down the steps of washing and dressing into simple steps. They agree that Addis will prompt him to do these steps every morning, and will give him lots of praise if he does them by himself. Together they think of a daily routine that Yosef will try to follow. Berhan doesn't write it down as the family cannot read, but they agree to try and remember it.

24.5 Summary

- People with schizophrenia often have problems with day to day functioning, such as washing themselves or tidying the house
- Problems are due to the illness, the medication and low expectations of the family
- We can improve day to day functioning by breaking down tasks into small steps, asking the family to give lots of encouragement, and making a daily routine

25 Module: Improving the family environment

25.1 What problems do people with schizophrenia have with the family environment?

Problems within the family are common when a person has schizophrenia. There may be many arguments or even violence between family members. Sometimes the family are very critical of the person with schizophrenia. Or certain family members may be involved in everything that the individual does because they are worried they cannot do it alone. This means neither one has time to themselves. All these problems sometimes mean that the family becomes less good at caring for the individual. It can also be very stressful for the caregiver, who may find it difficult to cope. Looking after children can be stressful and tiring for any parent, but especially when the parent has schizophrenia. They may feel they are not able to look after the children properly.

25.2 Why do people with schizophrenia have problems with the family environment?

The family are the main carers when a person has schizophrenia. This can put a lot of stress on the family. The individual may have disruptive behaviours, which are difficult to control. They may also not be working, which puts extra strain on the family. The costs of treatment may also be a source of stress. The family may not understand why the individual cannot work and has not recovered. All these problems can mean the family environment becomes stressful and unpleasant (See Chapter 5). Parents with schizophrenia may have problems looking after their children because they have many symptoms or because of side effects of the medication (for example drowsiness).

25.3 Why is it important to improve the family environment?

When there are problems with the family environment it usually takes longer for the person with schizophrenia to recover. It is therefore important to help the family to support the individual better. Also, improving the family environment means the family has less stress and worry. It is empowering for the individual to start looking after their children again. Doing this might improve their self-esteem and make them feel happy that they are participating in family life. It is also better for the children's development if the parents give proper love and care to the children.

25.4 How can we help to improve the family environment?

Principles

Before you can start improving the family environment it is important to have a good relationship with the family (see Chapter 11). Be aware of the fact that discussing the family environment may be upsetting for the individual and family.

1. Explain why you are doing this module

Explain why it is important for the person with schizophrenia to have a good family environment.

2. Understand problems in the family environment

Discuss with the individual and family what problems there are in the family environment. For example whether there are often disagreements or conflict. You should also check the latest needs assessment.

3. Consider how well the caregiver is coping

See Chapter 15 for how to support the caregiver if they are not coping well.

4. Give advice on how to improve the family environment.

Try and cover all the following points with the family. Relate the points to the specific issues the family has raised.

a. Have appropriate expectations

Once the worst symptoms have gone, the family may expect the person with schizophrenia to get back to their usual activities straight away. The family often feels disappointed when the individual is unable to do so. The individual may inactive, unmotivated and may need to sleep more than usual. Or they may be restless and unable to concentrate on small tasks. Give the family the following advice:

- Encourage them to have realistic expectations of what the individual can do.
- Encourage them to view the individual as having a serious physical illness, which requires a long time for resting. However they can eventually recover.
- Discourage them from thinking the individual is just being lazy.

- Encourage them to compare the individual's current behavior with how it was a month or more ago. This helps the family members to see the positive changes.

b. Set limits

Tell the family that just because the individual is ill, the family does not need to do whatever they ask. Instead, help them to set limits on the unacceptable behaviors.

- Help them to decide which behaviors are intolerable (for example violence) and which are irritating but tolerable (for example, not eating in the correct way). When the intolerable behavior occurs, they must immediately let the individual know that this is not acceptable. The aim is to stop a pattern of behaviors from starting.
- Advise the family not to discuss with the individual the reasons for setting the limit or how they feel about it. Tell them to only state that the behavior is unacceptable, without explaining why.
- Advise the family that the individual should be encouraged to behave in a way that is usual for their age. For example, an adult should not have tantrums.
- Tell the family that it will be difficult at first to set limits. It may take a number of weeks. Encourage them not to give up trying.
- Tell the family that they should not ignore behaviors such as suicidal threats or violence. See Chapter 18 for how to address these situations.
- When the individual behaves well, advise the family to reward them. This can be through giving food, allowing them to do a favourite activity, or through smiling, patting and praising them. Ask the family to think about which reward is the most useful.
- When the individual does not behave well, the family should stop rewarding him or her. If possible, the individual should be taken away from the others for a short period and returned when the individual is behaving well again. For example, when the individual disturbs others by shouting, then he or she should be taken to another room and not spoken to until he stops it. However it may be difficult to do this when the individual is very unwell.

c. Reduce stress

Remind the family that the individual should not be put under a lot of stress. Use the stress-vulnerability model to help explain (see Section 2.3).

- Tell the family to try and reduce arguments and nagging behaviours (e.g. constantly commenting negatively about what the person is doing).
- Tell the family not to be very critical of the individual or hostile towards them.
- Advise family members against talking about complex and emotional topics whilst the individual is there, for example discussing problems with money.
- Advise them that being very enthusiastic or showing lots of concern can be upsetting for the individual. Ask them to try and reduce these behaviours.
- Advise them that if the individual wants to be alone the family should allow it. They do not need to be involved in everything the individual does.

d. Improve communication

- People with schizophrenia often do not reply straight away when they are spoken to. Advise the family members to avoid speaking on the individual's behalf when this occurs. Advise them to wait for the individual to respond.
- Advise the family to avoid detailed conversations, which the individual may find confusing.

e. Get the family routine back to normal

Discuss with the family the problems that come when the individual is the centre of their lives. Tell them that since schizophrenia is a long-term illness, after some time they may become too stressed to be able to look after the individual. They may also develop problems of their own. As far as possible, encourage them to start again the daily routines that they had before the illness. Advise them to think about the needs of other family members, for example children or siblings.

f. Strengthen social networks

Sometimes family members think that they should not worry other people with their problems. They may also worry about the reactions of others.

- Discuss with the family the benefits of discussing their problems with others

like relatives, friends, neighbours, religious or community groups. This may help to reduce their distress. It also helps them to think of new and better solutions to their problems.

- Tell the family members that they will not be able to care for the individual for a long time unless they look after themselves as well.

g. Treat the individual with respect

Discuss the importance of respecting the individual as an adult who can make decision for themselves

5. Discuss unhelpful coping strategies

Sometimes family members do things that are not helpful or may even make the family environment worse. These include:

- The family may try to persuade the individual that their unusual ideas are not true. This may lead to arguments and angry responses from both sides.
- Even when it is clear that the individual does not make sense, family members may try to find a meaningful message in what the person is saying.
- Sometimes the family members ignore the symptoms and pretend the illness is not important. This is unhelpful when the symptoms are very bad.
- Family members may constantly supervise the individual, as they are not sure what they will do next. This makes the family member feel more in control. However, it is difficult for the family to maintain this constant supervision for a long time.
- The needs of other family members are ignored because the needs of the individual are so great. This may mean that other family members feel uncared for and problems with family relationships happen.

6. Give advice on how to improve parenting

- When the individual is well, encourage them to spend time with the children and to take on their usual parenting tasks. For example, helping the children to dress and wash.
- Discuss with the family how they can support the individual to get back to these activities. Ask the family to give encouragement when the individual does the activities.

- If you are concerned about the safety of the child, inform your supervisor (see Chapter 14 and Chapter 35).

7. Make a plan

Ask the family to consider what specific things they will try to do differently.

Follow up

Check how for progress at the next home visit. Ask what the family tried, and how easy or difficult this was. Ask the individual and family if the family environment feels any different.

Yosef's story

Yosef and Addis agree that there are lots of arguments within the household. They usually argue about the fact that Yosef is still not working, even though in some ways he is better. Yosef also complains that he never has any time alone.

Berhan helps them to discuss this together in a calm way. She suggests that the family need to have realistic expectations of Yosef and that it might take a long time for him to get back to his previous work. Addis agrees that she will try not to nag Yosef. They discuss that it might be useful for Yosef to spend more time alone during the day, at least whilst he is feeling well.

25.5 Summary

- Sometimes there are problems with in the family when a person has schizophrenia. These include the family being too critical or over-involved in the individual, or there being lots of conflict
- Problems in the family environment worsen illness and cause stress for caregivers
- Ways to improve the family environment include: setting limits, having appropriate expectations, reducing stress, improving communication and getting the family routine and social life back to normal
- Ways to improve parenting include: when they are well encourage the individual to spend time with the children and ask the family to support the individual with this

26 Module: Taking part in community life

26.1 What problems do people with schizophrenia have taking part in community life?

It is common for people with schizophrenia to have problems doing the usual activities in the community. People may have problems with:

- Attending weddings and funerals
- Drinking coffee with friends and neighbours
- Visiting relatives
- Taking part in Edir meetings
- Participating in the practical activities of Edir
- Participating in kebele meetings
- Attending church or mosque
- Participating in religious groups, such as mahaber or lika
- Going to market
- Participating in other community organisations, such as the Women's association

26.2 Why do people with schizophrenia have problems taking part in community life?

- The illness makes them unmotivated to go outside
- The illness gives them problems with social skills, such as difficulties starting a conversation or taking turns to speak
- Medication side effects, such as drowsiness, make it difficult to get the energy to walk somewhere and socialise.
- The family does not let the individual attend community events because they are worried they will behave strangely or do something embarrassing
- Community members may have stigmatising attitudes towards people with schizophrenia. This means they may ignore the individual, not allow them to participate in activities, not respect their opinion or even shout names at them.

26.3 Why is it important to take part in community life?

- To feel part of the community
- Improve their sense of well-being

- Improve their self-confidence
- Reduce stigma towards them
- Reduced burden on the family
- Keep the person engaged in useful tasks
- Distract from distressing symptoms like hallucinations and delusions.

26.4 What can we do to help people with schizophrenia take part in community life?

Principles

- Focus on the areas where there are problems, and which are important to the individual to change
- Establish what is normal for the household and the individual
- Involve the family at every stage of the process. The aim is for them to be able to support the individual to do the activities when you are not there.

1. Explain why you are doing this module

Explain to the individual and family that problems taking part in community life are common in people with schizophrenia. Give reasons why people with schizophrenia have these problems.

2. Discuss what problems the individual has

Discuss what problems the individual has had taking part in community life

3. Identify the activities the individual wants to do

Find out which community activities the individual would like to do but is having difficulty with at the moment. You should refer back to the latest needs assessment.

4. Identify barriers and suggest ways to overcome them

You should discuss with the individual and their caregiver why they think they are having problems taking part in these community activities. Look at the section 26.2 for suggestions. The most appropriate approach for helping individuals to take part in community life will depend on the types of barriers. You should also use the problem

solving approach to help you (see Section 10.5). You can suggest some or all of the following:

a. Improve social skills

- Ask the individual and family member to think about what social skills they need to do the community activities they would like to be involved in. These might include:
    - Greeting others
    - Listening to others
    - Asking for information
    - Expressing an opinion, for example about their own treatment.
    - Saying sorry when this is needed
    - Eating with others in a polite way

Now discuss with the individual and caregiver which things the individual has problems with. Focus on these things.

- Ask the individual to practice these skills with you. For example,
    - Ask them to show you how they would greet a neighbour they met at church.
    - Ask them to show you how they would ask the price of somethings, for example cabbage at the market
- Give encouragement, including smiles and praise, when the individual shows they can do the skill
- Ask the individual to try the skills in a real life situation

b. Invite neighbours or relative for coffee

Suggest that the family invite neighbours or relatives to the home to drink coffee. This can be a chance to practice talking to familiar people in a familiar environment.

c. Family member accompanies the person to community activities

Suggest that a family member goes with the individual to the community activity for the first few times. This will give the individual more motivation and confidence. The family member may be worried that the individual will behave in an embarrassing way. Suggest that they start with activities that are close to the house and involve fewer people. For example it may be less stressful to go to the grain mill together, than to attend a funeral with many guests.

d. Engage with community leaders

With the help of the individual and the caregiver, identify key people within the community who may be able to help the individual to get back to usual activities. Consider:

- Religious leaders, who may be able to help the person go to church, mosque or a religious group (mahaber or lika)
- Edir leaders, who may be able to help the person contribute to Edir and participate in the Edir activities
- Leaders of Youth Association, Women's Association or kebele leaders, who may be able to help the person attend meetings and contribute to kebele affairs

If you have not already done so, it may be appropriate for you to meet with the leader to give them information about schizophrenia and to see how they can help. See Tasks 8, 9 and 10 in Community Engagement Chapter 31. Alternatively the caregiver may be willing to approach the leader independently.

e. Use approaches from other modules

Some of the approaches from other modules may also contribute towards helping individuals to take part in community life, for example:

- Community-awareness raising (see Chapter 31), which aims to reduce stigma and discrimination towards people with schizophrenia
- Improving adherence and improving side effects (see Chapter 20)
- Giving the individual strategies to deal with stigmatising attitudes (see Chapter 28)
- Improving the attitude of the family towards the individual (see Chapter 25)
- Dealing with distressing symptoms such as hallucinations, lack of motivation and problems with organisation (see Chapter 22)

f. Acting as a role model

The way you behave in the kebele can have a big impact on other people's attitudes. When you see the individual outside whilst not in a home visit, greet them, as you would do anyone else. Showing the community that the individual is just like other people may be one way to reduce stigma.

You can use Table 6 as a guide for which approach to use in which circumstances:

Table 6 Approaches to support individuals to take part in community life

Problem	Approach
Lack of motivation	• Family member accompanies • Invite neighbours or relatives • *Dealing with distressing symptoms*
Medication side effects	• *Address side effects*
Problems with holding a conversation	• Practice social skills • Invite neighbours or relatives
The family does not let the individual attend community events	• *Improving the family environment* • Invite neighbours or relatives
Stigma and discrimination from community	• Engage with community leaders • Acting as a role model • *Dealing with stigma and discrimination* • *Community awareness raising*

5. Make a plan

Discuss with the individual which specific community activity to focus on first, and agree the steps to start participating again. Make sure everyone knows what their role is.

Follow up

Make sure you follow up progress on participating in community activities at the next home visit. Discuss what strategies were tried and which ones helped. Practice social skills again if you agree this may help. If relevant, make contact with community leader to facilitate engagement in community activities

Sara's story

Since she became unwell Sara has had problems visiting her sisters in the neighbouring kebele. This is something she used to enjoy a lot. Often she doesn't go because she doesn't have the energy to leave the house. She is also worried that she doesn't have anything to say. Berhan discusses with Sara and Alemu, Sara's husband, how they can change the situation. Sara suggests that she could invite her sisters to visit her first of all as this will require less energy. Then if this goes well, Alemu can try to support her to visit them. Berhan helps Sara to practice how to greet people and how to start a conversation. They all agree to try and invite the sisters within the next two weeks, which is when Berhan will visit again.

26.5 Summary

- Many people with schizophrenia have problems taking part in community life such as attending church or funerals.
- Helping individuals take part in community life is good for improving self confidence, reducing stigma, and reducing the burden on the family
- Ways to help individuals take part in community life: improve social skills, invite neighbours for coffee, family member accompanies, and engaging community leaders

27 Module: Getting back to work

27.1 What problems do people with schizophrenia have with work?

When we talk about work, it might mean different things depending on the individual and whether they are a man or a woman. Work can include:

- Farm work on the family farm
- Daily labouring on other people's farms
- Household work e.g. fetching wood, fetching water and preparing food
- Paid employment for example in a shop
- Trading at market

Many people with schizophrenia have problems with work. They may find they can work for shorter periods or only on simple tasks. Some individuals find it difficult to work at all.

27.2 Why do people with schizophrenia have problems with work?

- They are unwell and have lots of symptoms
- The illness makes it difficult to concentrate and be organised. For example, handling money at market may become difficult.
- Medication side effects, such as drowsiness and shaking hands, make it difficult to work, particularly if it involves physical labour
- The illness gives them problems with social skills
- The family does not let the individual do their usual work tasks as they are concerned they will do it wrong
- Community members may have stigmatising attitudes towards people with schizophrenia. This means it may be difficult to get paid work, for example daily labouring, within the community.
- They are restrained at home so cannot work.
- In between periods of being well and able to work, the individual has relapses, during which time it is not possible. This can make the individual seem unreliable.
- Whilst they were unwell they may have lost their farmland or cattle. This may be because they had to sell them to get money for medication or because they were unable to work. Or the land or cattle may have been given to another family member to look after.

- The illness makes them unmotivated.

27.3 Why is it important to get people with schizophrenia back to work?

- Helps to improve the economic status of the family
- Improves self-esteem and confidence
- Helps to stop the individual from thinking about their symptoms
- Reduces isolation and improves social skills
- If the person can work alone, this means the caregiver does not have to stay with them, and they can do their own usual activities
- Improves relationship with family

27.4 How can we help people with schizophrenia to get back to work?

Principles

- Focus on the areas where there are problems
- Establish what is normal for the individual
- Go slowly and steadily; they shouldn't take on too much work too soon.
- Involve the family at every stage of the process. The aim is for them to be able to support the individual to work when you are not there.

1. Explain why you are doing this module

2. Discuss what problems the individual has had with work

Discuss what problems the individual has had with work and why they have had them.

3. Identify the work the individual wants to do

Establish what was work was normally done by the individual before they became unwell. If they used to do several types of work, for example going to market, looking after the household and doing farm work, discuss with the individual and family which type of work to start with. It is usually sensible to start with the simplest type of work.

4. Consider what preparation is needed

This will depend on the type of work and the wishes of the individual and family. If the individual needs to engage with people outside the family during work, for example

daily labouring, their needs may be different. It might be necessary to ensure they have good self-care, improved social skills and the symptoms are under control. If the person plans only to work on the family farm, it might be less important to achieve these things prior to doing work.

5. Try specific tasks

- Once you have decided the type of work, ask the family to select one specific task within this. For example, if the focus is on farm work the first task selected might be looking after the cattle. Ask the family and individual to select a task that is:
    - Something the individual used to do, or is expected to do
    - Something which the individual feels ready to try
- With the family, break down the specific task into individual steps. For example, the steps involved in looking after the cattle are:
    - Untying the cattle
    - Taking them to the field
    - Watching them whilst they graze
- Ask the individual to try doing the task with a family member present. They should decide in advance which of the individual steps the family member will do, and which the individual will do. They should gradually work towards the individual doing all steps. Even if the individual makes a mistake the family should give encouragement to continue.
- Discuss that the individual will probably only be able to work for short periods at the beginning. They may need to lots of rests whilst doing work.
- Once the individual is able to do some of or the entire specific task, choose another task together and repeat steps a to c again.

6. Encourage independent working

As the individual becomes more confident and able to complete the specific tasks, the family members should encourage them to work independently.

7. Consider asking community members or an NGO for their input

In some cases you may need the help of community leaders and other community members. Any meetings with other community members should be done with the permission of the individual and family.

- In your initial meetings with community leaders you should have found out the potential for daily labouring and other paid employment opportunities within the kebele (see Task 7 in Community Engagement Chapter 31). If you found there were any opportunities, you should now discuss them with the individual and family. Follow Task 15 in Chapter 31 for how to follow up these opportunities.
- If they lost their farmland or cattle whilst unwell, you may also need to ask a community leader for input.
- Discuss with your supervisor if there is a local NGO who can offer some livelihood support or skill development.

8. Identifying barriers

You should discuss with the individual and their caregiver why they think they have had problems doing the work so far, and what potential problems might arise if they try to do the work now. Look at the Section 27.2 for some suggestions. You can also use a problem solving approach (see Section 10.5). Try to address these barriers alongside trying the specific tasks (step 4). This will increase the chances of the person being able to work.

Table 7 Approaches to support individuals to get back to work

Barrier	Approach
Unwell and lots of symptoms	• *Module: Supporting individuals to take medication*
Lacks confidence	• *Encouragement and support from you and family*
Problems with motivation	• *Module: Dealing with distressing symptoms*
Problems with organisation	• *Module: Dealing with distressing symptoms*
Medication side effects	• *Module: Supporting individuals to take medication*
Problems with holding a conversation	• *Practice social skills (Module: Taking part in community life)*
The family does not let the individual work	• *Module: Improving the family environment*
Stigma and discrimination from community	• *Engage with community leaders* • *Module: Dealing with stigma and discrimination* • *Community awareness raising* • *Acting as a role model*
Relapse	• *Module: Taking control of your illness*
Farm land has been taken by kebele administration	• *Engage with community leaders*
Farm land has been taken by other family	• *Identify who has decision-making power within family and discuss with them the benefits of individual starting to work on or look after own land or cattle again* • *Module: Improving the family environment*
Farmland lost due to poverty	• *Engage with community leaders* • *Engage with NGO*

9. Difficult situations

The individual or family may ask you for financial help, for a loan or for a job. If this happens you should explain that unfortunately you are not able to provide any of these things to them or indeed to any of the people you are working with. Tell you supervisor if the individual or family continue to ask you about this, and consider discussing together.

10. Make a plan

Make sure everyone knows what steps they will take before the next home visit.

Follow up

Once you have started helping the individual to get back to work it is important that you follow this up every time you see them.

- Check what progress has been made with specific tasks.
- Check what progress has been made overall. For example, how much of the day does the individual spend doing farm work? How does this compare to when they were very unwell? How does this compare to when they were well?
- Check for any problems. In particular whether the work is too stressful or the individual feels they are not being given enough responsibility. Try to change the plan to fit better with the individual's needs.
- Check the progress with any links made with community members
- Review any barriers that are still present and try to address them using the suggestions above.

Yosef's story

Yosef no longer does any farm work. Before he became unwell he did all the necessary tasks. He says the reason he doesn't do the work is because he usually feels tired and unmotivated, and the work seems overwhelming. Yosef and his family agree Yosef is ready to start trying to work again as his symptoms are quite well controlled. They agree he will start by helping his father to thresh the wheat. Before he starts they discuss the specific steps involved, and agree that Yosef should only work for a short time initially, before having a rest.

27.5 Summary

- Many people with schizophrenia have problems with work. This may be due to the illness, medication side effects and stigma
- Getting back to work is important as it helps to improve confidence and social skills, bring money into the family and reduce stigma
- To help the individual get back to work: decide what preparation is needed then try specific tasks broken down into steps.
- Consider working with community leaders to help find work within the community

28 Module: Dealing with stigma and discrimination

28.1 What problems do people with schizophrenia have with stigma and discrimination?

In Chapter 6 you learnt about the problems that people with schizophrenia have with stigma and discrimination.

28.2 Why do people with schizophrenia have problems with stigma and discrimination?

Stigma can be found in family members, community members and health workers. A person may also start to believe the stigmatising things that people say – that is called self-stigma.

28.3 Why is it important to reduce experiences of stigma and discrimination?

Stigma and discrimination can mean that individuals find it more difficult to return to the activities that they used to do when they were well. People with schizophrenia may continue to be discriminated against even though they have recovered. It can be upsetting to feel separate and different from family, neighbours and community. People with schizophrenia often feel that stigma and discrimination is even more distressing than the symptoms of the illness. It is therefore important to reduce stigma and discrimination. Individuals may get back to usual activities faster if these problems are addressed.

28.4 How can we reduce experiences of stigma and discrimination?

1. Explain what stigma and discrimination is

Explain what you mean by stigma and discrimination

2. Explain why you are doing this module

Explain why it is important to reduce experiences of stigma and discrimination.

3. Discuss experiences of negative comments and discrimination

First of all, discuss what experiences of stigma and discrimination the individual has had. Discuss what happened and how it made them feel about themselves. If the

individual has trouble thinking of any experiences, you can you use Section 6.2 to prompt them. Remember this might be upsetting for the individual and family.

4. Encourage the individual to think about themselves in a positive way

Discuss with the individual that even if we cannot control the way other people see them, they should still see themselves as a valuable person. Tell the individual that the illness is not the only important thing about them, and that they can recover and have a meaningful life.

5. Discuss how to deal with negative comments and discrimination

a. Discuss how the individual dealt with the situation at the time. For example, what they did when someone called them an insulting name. Discuss whether the way they responded was useful or not.
b. Discuss other ways the individual could respond. For example, it may be useful to practice explaining the illness to others. You could suggest that the individual tries saying, “I have an illness like other illnesses. I am taking the medication, which makes me better “ or “This illness could have happened to anyone.”

6. Discuss which ways of responding would not be useful.

For example, getting into a fight.

7. Discuss the caregiver’s experiences stigma and discrimination.

You can repeat these steps with the caregiver.

8. Discuss what other approaches may reduce stigma

There are many parts of CBR that help to reduce stigma and discrimination. These include:

a. Give information about schizophrenia to the person with schizophrenia and their family (see Chapter 16). In particular, focus on the possibility of positive outcomes.
b. Awareness-raising amongst community members and community leaders (see Chapter 31). Once people have more information they are less likely to have negative attitudes towards people with schizophrenia.

c. Supporting individuals to improve self-care, to get back to their usual activities within the community and to get back to farm work or employment (see Chapter 26 and 27). When people in the community see the individual doing usual activities again, this will help to reduce their ignorance and prejudice towards people with schizophrenia.

d. Supporting access to treatment and support taking medications will hopefully improve symptoms (see Chapters 17 and 20). This makes it more likely the family and community will treat the individual as normal, and also shows people that schizophrenia is treatable.

e. If the individual or their family is worried that home visits by you may bring negative attention to the household, suggest you hold the sessions elsewhere, for example at the health post.

f. Set up a Family Support Group so that the person and their family can share their experiences, including ways to deal with stigma. The groups can also be a way to improve self-esteem (see Chapter 32).

g. Encourage the family to accept the person's illness and treat the individual in a dignified way (see Chapters 19 and 25)

h. Treat the individual with respect and dignity yourself (see Chapter 11).

9. Make a plan

Agree what actions the individual and family will take before the next session

Follow up

At the next session check if there have been any new experiences of stigma or discrimination and if so how the individual dealt with it. Ask whether the strategies were useful. Discuss how to change the strategy for next time it happens.

Sara's story

Sometimes children in the kebele shout at Sara that she is mad. They laugh at her and sometimes throw stones. Sara finds this very upsetting and it makes her want to stay at home all the time. When it happens usually she ignores the children, which is quite helpful. However, she tells Berhan that she would feel more confident to go outside if she had some way of responding. Sara and Berhan practice helpful things that Sara can say in a calm way to the children next time. They agree that it is not helpful to throw stones back. Alemu agrees that it is also not helpful when he calls Sara names. Sara and Alemu agree to try these ideas before they next see Berhan in one month's time. Berhan tells Sara that she is doing awareness-raising in the kebele, which hopefully will improve the attitudes of community members, including the children.

28.5 Summary

- Stigma and discrimination is a common experience for people with schizophrenia
- It is important to reduce stigma because it is a barrier to returning to usual activities
- Ways to reduce stigma include: helping the family and community to understand schizophrenia better, supporting individuals to get back to usual activities and giving them strategies to deal with negative comments

29 Module: Improving literacy

29.1 What problems do people with schizophrenia have with literacy?

Like many people in rural Ethiopia, often people with schizophrenia are not able to read and write. This is more common in women.

29.2 Why do people with schizophrenia have problems with literacy?

People with schizophrenia may have more problems with literacy than other people if they had to leave school early due to the illness. People with schizophrenia may also find it more difficult to access the adult literacy training that is available in every kebele. This may be because of:

- Being too unwell to take part
- Having problems with motivation or problems thinking clearly
- Stigma and discrimination meaning people with schizophrenia are excluded simply because of their illness.

29.3 Why is it important to improve literacy?

Improving literacy in people with schizophrenia may have the following benefits:

- Improve self-esteem and confidence
- Provides a meaningful activity, which may distract from symptoms and side effects
- Helps to get back to usual activities for which it helps to read and write, for example participating in kebele or edir activities, or conducting business

29.4 How can we help to improve literacy in people with schizophrenia?

Principles

It is not your role to teach the individual to read and write. Instead you should help them to access existing facilities using the following steps. Before you undertake this module, confirm that there is adult literacy training or a school (if the individual is school age) in the kebele that is accepting students. Discuss with the co-ordinator or headteacher whether there is any reason why an eligible person with schizophrenia could not attend, if they wished to. See Task 15 in Community Engagement chapter. If there is a facility available, continue the following steps.

1. Explain why you are doing this module

Explain why it may be important for some people with schizophrenia to improve literacy

2. Find out the level of literacy of the individual

- How many years did they go to school for?
- How long ago were they at school?
- Can they write their name?
- Can they read shop signs?

3. Confirm the individual is interested

Confirm that they are interested in learning to read and write.

4. Arrange attendance at facility

Ask the individual and family member to approach the literacy group or school to arrange attendance. If the individual and family are not willing or able to make the initial link, arrange a meeting with the co-ordinator or headteacher yourself. Discuss the potential benefits for the group/ school and for the individual.

5. Help the individual to attend

Facilitate the individual to attend the group/school if this has been arranged. For example, discuss with the family who will take them to the facility. It may be possible for a family member to sit in the group initially.

Follow up

Follow up progress each time you see the individual. Ask the following questions:

- Has the individual attended the group/school?
- Were there any problems? If so try to use a problem solving approach.
- Is the individual noticing any benefits?

29.5 Summary

- Many people in rural Ethiopia are unable to read and write, but this may be more common in people with schizophrenia
- Learning to read and write may help with confidence, and getting back to work or community activities
- You should not teach the individual to read and write but you can help them to access existing services

30 Module: Taking control of your health

30.1 What problems do people with schizophrenia have with relapse?

Most people with schizophrenia have an 'up and down' course of the illness. This means sometimes they feel well and have no symptoms, while at other times they experience a return of symptoms. When symptoms return in a way that is problematic and distressing, this is known as a relapse.

30.2 Why do people with schizophrenia have relapses?

Different people experience relapses due to particular reasons and the time between relapses also varies a lots. Most often relapses develop gradually over a period of a few weeks. But some people experience a relapse very quickly, in a matter of days. Not taking medication makes it more likely that a relapse will happen. Some stressful situations can trigger a relapse, including:

- Illness or death in the family
- Change in daily routine or living arrangement
- Argument or relationship problem with family member or neighbour
- New responsibilities, for example due to family illness or relatives visiting
- Physical illness
- Khat or alcohol use

What are the early warning signs of relapse?

During the time before the relapse, there are changes in the person with schizophrenia that are called *'early warning signs'*. These warning signs are often unique to each person. The person with schizophrenia and family members can often identify them since they have seen this happen a few times. These early signs of a relapse are important to recognize and respond to, since this can be a time when something can be done to stop the person from suffering the serious consequences of a relapse. The most common early warning signs are:

- **Tension and nervousness**

Individuals may report feeling anxious, nervous or tense about small things that they would not usually worry about. People feel worried, walk around the house excessively, and are unable to rest by sitting in one place for long.

- **Sleep disturbances**

Many people with schizophrenia experience changes in their sleeping habits. They either have difficulty in sleeping or start sleeping more than normal.

- **Feeling sad and angry**

Individuals may feel sad all the time. This can lead the person feeling hopeless and having suicidal ideas. Family member may notice that the person is talking less, hardly smiles, looks worried and is often tearful.

- **Becoming isolated from others**

Many people will become withdrawn and less interested in talking to people. This is often noticed first by family members as the person becomes quieter, does not meet guests, and avoids going out of the house. There can be many reasons for the social isolation. Some people feel tense and anxious if they have to talk to someone, while others can start feeling suspicious of people and decide the best way to deal with it is by reducing social interactions.

- **Difficulty in concentration:**

Individuals may find it more difficult to concentrate and pay attention to something for a period of time. This leads to difficulty in following a conversation, cooking a meal, or remembering to get things from a shop.

- **Reducing or stopping medicines**

Sometimes the person with schizophrenia does not realize that they are going to have a relapse. Because of this they may decide to reduce or stop the medication. They may also refuse to go to the health centre or refuse to see you.

- **Change in appetite**

Before a relapse people often change their eating habits. Usually there is a loss of appetite. This can sometimes lead to a loss of weight and to a general sense of tiredness and lack of energy. Less commonly, people may start wanting a lot of food several times a day.

- **Unique signs of relapse**

Quite often, family members will be able to describe particular signs of a relapse that are unique to the individual and tend to occur only in such situations.

30.3 Why is it important to prevent relapse?

During a relapse, most people are too unwell to do farm work, housework or other usual activities. Even after the symptoms stop, it can take a few weeks or months for

the person to return to the previous level of functioning. Some people may even feel that they want to commit suicide during this time due to constantly hearing voice telling them negative things or because they have developed depression. Others can become very suspicious and frightened. This is also the time when some people become irritated and easily angry; rarely, there can be a risk of harm from the person to others in the family or community. The family may feel they have no choice but to tie up the person with schizophrenia. After a relapse the individual may also have a sense of failure ('This happened in spite of trying so hard to stay well'). They may also feel more stigma and discrimination from their family, neighbours and community. Having a serious relapse is a setback for everyone and preventing this from happening is one of the most important goals of CBR.

30.4 How can we prevent relapse?

Principles

Relapse prevention involves helping the person with schizophrenia and the family to recognize the early signs of a relapse and putting in place a plan to deal with the situation. It is a joint effort involving you, the person with schizophrenia and the family. The focus should be on helping the individual to take control of their own health. The aims of relapse prevention are:

- To prevent a relapse from happening. Unfortunately this is not always possible.
- To minimize the severity of the relapse so that the time to recovery is shortened.

To prevent relapse we should do two main things:

- Firstly, we should support individuals to take medication.
- Secondly, we should try and reduce life stress by helping individuals to cope better with their problems.

Before undertaking this module, decide who to involve. The person with schizophrenia must always be involved, as well as the primary caregiver and any other key family members who the person trusts and is comfortable with. The group should be between 3 and 5 people and will usually involve parents, spouses and in some cases adult children or more distant relatives. Gather the group together to carry out the following steps:

1. Explain why you are doing this module

Give information about what relapse is, what problems it causes and why it is important to prevent it.

2. Discuss the problems of relapse

Discuss what happened during the most recent relapse, for example which symptoms were most prominent and what usual tasks the person could no longer do. All members of the group should be encouraged to join the discussion.

3. Discuss the early warning signs

Explain what early warning signs are and ask the group whether they usually notice any. Use the Early Warning signs Checklist (Form 17) to make sure you haven't missed any. Agree on 3 to 5 important signs for the individual.

4. Discuss stressful triggers

Explain that relapse can be caused by certain stressful situations. Ask the group whether they can remember any which came before the person's relapse. Explain that it is useful to think about these so they can be avoided in the future, where possible.

5. Discuss the relapse management plan

Explain that the purpose of the plan is to decide in advance how you will all respond to early warning signs. Having a plan may help us to prevent a serious relapse, or help it to resolve quicker. The plan should be made jointly with the group members. In particular the wishes of the person with schizophrenia should be sought and included in the plan. They should feel they have some control over what happens to them during the relapse. Record the plan on the Relapse Management Form (Form 18). Each member should be clear on what their role is. If appropriate, give a copy of the plan to each member of the group. The detailed parts of the plan will be different for each individual. However for most families the following elements should be included.

a. Family meeting

If early warning signs are noticed by the person with schizophrenia or family members, a family meeting should be held. Concerns should be discussed openly and a plan is agreed on. This process should help everyone, including the person with schizophrenia, to participate as equals in trying to improve the situation. This process also helps the person with schizophrenia and family take on responsibility for managing the illness and improve their sense of control.

b. Review whether the individual is taking medication regularly

Not taking medication is often an important factor in a relapse. Find out the person's reasons for stopping the medicine. Take the steps in the adherence support chapter to ensure the individual starts the medication again as soon as possible.

c. Clinical review

Arrange for a review at the health centre as soon as possible. Inform the person with schizophrenia and family when the appointment is. Check if there are any major barriers to attending the health centre and try to resolve them. If you feel they are unlikely to attend, you might need to accompany the person to the health centre. After the review, check if everyone has understood the advice from the nurse.

d. Reduce stress

Identify any obvious stressful situation that the person has experienced recently. If possible try to remove or reduce the stress. Suggest stress management activities, particularly those that have been useful in the past (see Chapter 23).

e. Reduce alcohol or khat

Using alcohol or khat may make the relapse worse**.** You and the family should help the person to reduce or stop using alcohol or khat. For example, by removing any bottles from the house, providing less money to buy it and by reinforcing any steps taken by him to reduce alcohol use.

f. Activate social and practical support

Identify relatives, friends and community leaders who may be able to provide social and practical support. In particular, the caregiver may need more support during a

relapse. For example, neighbours may be able to help with the farm work whilst the person is unwell.

g. Monitor the situation

Your role is to closely monitor the situation. At each visit check whether the early warning signs have improved.

6. Make the plan

Ensure each member is clear on what his or her role in the plan is.

Follow up

It is a good idea to review the plan every 6 months, to ensure that everyone involved remembers the issues clearly and any updates can be made.

30.5 Summary

- When symptoms return in a way that is problematic and distressing, this is known as a relapse. Relapses are a common part of the illness
- Relapses may be triggered by stressful events
- You should help the family to develop recognise the early warning signs and know the likely stressful triggers
- You should help the family to make a relapse prevention plan which usually includes: family meeting, check medication, review at the health centre and reduce stress

31 Community engagement

31.1 Why is it important to do community engagement work?

The community can have a powerful impact- both positive and negative- on the experiences of the person with schizophrenia. CBR aims to increase the positive influences of the community, and reduce the negative influences. There are many community resources in every kebele (see Chapter 8). It is your role to ensure that the person can do the same community activities as other people of their age and gender. The community also has an important role in making sure the positive changes made during CBR are continued after you have left.

31.2 What community engagement work do we do?

Phase I

During Phase I you should do the following tasks in each kebele where you are working. You should do these tasks at the same time as you are doing the home visits to each individual you work with. You don't need to do these tasks in the order set out below; lots of the tasks will overlap.

Task 1: Meet with health extension worker/s (HEW)

How?

- Get the HEW contact details from the health centre and arrange a meeting. You may need to spend between 2 hours and a whole day with the HEW.
- Check whether the HEW is aware of the people with schizophrenia to whom you have been allocated. If they are, ask if they are willing to show you where they live. Ask what they know about them and what problems they are aware of.
- Ask them who the important community leaders are (see Task 2) and if the HEW would be willing to make initial introductions
- Ask what the important community resources are (see Task 3)
- Explain what your role will be in terms of home visits and community engagement
- Explain how you would like them to be involved: support the messages you will give about reducing stigma and discrimination and the importance of accessing treatment; do their usual home visit and offer the care they usually provide to people with schizophrenia e.g. family planning.

- Give your contact details in case they have any questions

Task 2: Identify important community leaders e.g. kebele leader/s, Edir leaders, religious leaders, traditional healers, women's association leader.

How?

- First ask the HEW to help you. If they do not have the information use: Health Centre of District Health Bureau (DHB) records; church/mosque; other community leaders
- Get the names/address/telephone number

Task 3: Identify key community resources e.g. churches/mosque, Edir, adult literacy group, schools, Mahaber/tsewa/lika groups, informal social networks, women/youth associations, NGOs

How?

- Ask the HEWs, kebele leader and community leaders
- If they do not have the information use: Health Centre or DHB records and church/mosque

Task 4: Ascertain what community work relating to mental illness has already taken place or is planned e.g. community conversations, engagement/training of traditional headers

How?

- Ask the HEWs
- This will help you to plan meetings with community leaders (Task 7) and community awareness raising (Task 6)

Task 5: Meetings with important community leaders

How?

- Ask the HEWs to introduce you to community leaders if possible
- Meet with and introduce yourself to 5-10 important community leaders from across all sectors.

- Invite these community leaders to a meeting, either in one group or small groups depending on the local circumstances. Discuss with your supervisor.
- The meeting may take up to 2 hours.
- At the meeting, cover the following:
    - Purpose of CBR programme (briefly describe severe mental illness; the possibly of recovering; importance of medication; the need for help with rehabilitation too; get more productive community member at the end, benefits whole community),
    - Authorisation given to CBR programme (links to district health bureau and Addis Ababa University)
    - Give outline of CBR activities, including home visits and types of modules
    - Give outline of community engagement activities (community awareness raising events, further individual meetings with community leaders according to needs of individuals)
    - Give outline of how you want the community leaders to be involved (help arrange community awareness-raising events; general support e.g. encouraging individual to keep using medication; encourage inclusion in Edir tasks for the person with schizophrenia; encouraging inclusion in kebele meetings; making sure people are not excluded from church)
    - Give outline of how you want general community members to be involved (general support; encourage general social inclusion)
    - Ask what is the best place for a community awareness-raising event
    - Ask about community resources (See Task 3)
    - Gather information on potential paid employment in the kebele e.g. farm labouring (see Task 7)
    - Arrange a subsequent meeting if the community leader/s would like more time to discuss

Task 6: Community awareness-raising event/s

How?

- Utilise the place suggested by the community leaders e.g. kebele or Edir meeting

- Pre-arrange the date, start time and the amount of time you have to speak. The meeting may take 30 minutes to 2 hours depending on where it is held and the topics you cover
- You may wish to arrange 2 or 3 meetings to give you time to cover all the topics. This is a suggestion for how to divide up the topics.
- Meeting 1 topics
    - Introduce yourself and explain that you are working in the kebele to try and support people with schizophrenia
    - Describe how schizophrenia is a mind disease that can improve with medication
    - People develop schizophrenia due to stressful events that happen in life.
- Meeting 2 topics
    - Explain that with time and support people with schizophrenia can get back to usual activities, such as work and socialising
    - People with schizophrenia can get medication at the health centre. This will make them better.
- Meeting 3 topics
    - To get better people with schizophrenia need the support of people in the community
    - It is important not to treat people with schizophrenia differently, for example with disrespect, calling them names, or ignoring them just because they have this illness.
    - This kind of behaviour will stop them from getting back to their usual activities
    - It is also important not to beat people with schizophrenia. This will not help them get better.
    - Getting medication will reduce the need for individuals to be chained. We should avoid chaining if possible, and instead help people with schizophrenia get treatment.
- Explain the information simply and clearly
- Listen carefully to the responses from those attending. Be respectful of any differences in beliefs or differing opinions.
- Thank attendees for their time.

Task 7: Identify potential employment opportunities in the kebele

How?

- Identify potential paid employment opportunities e.g. farm labouring by consulting: community leaders, the person with schizophrenia and HEWs. This may be on a one-off or ongoing basis.
- Arrange a meeting with the potential employer
- Discuss potential benefits for the employer, community, individual and caregiver of offering paid employment
- Address any concerns the potential employer has

Phases II and III

In Phases II and III you may or may not need to conduct the following activities depending on:

- Needs of individual and caregivers. It is indicated in the modules when a Community Engagement task is likely to be useful.
- Available community resources, which you identified in Task 3.
- What the person or their family is willing or able to do themselves (therefore not requiring your input).
- You should always discuss with your supervisor which ones to undertake.

Task 8: Individual meetings with Kebele leaders

In what circumstances?

- If the individual is not receiving free medication but may be eligible AND/OR
- If the individual and/or caregiver is not engaged in kebele activities but would like to be, and family have been unsuccessful in getting involved without your help

How?

- Arrange meeting with Kebele leader
- Discuss the possibility of letter supporting free medication AND/OR
- Discuss the fact that the individual or caregiver finds it difficult to participate in kebele activities
- Discuss the benefits of them participating e.g. contribute to development of kebele
- Discuss how to facilitate their increased participation

Task 9: Individual meetings with Edir leaders

In what circumstances?

- If the individual or caregiver is not engaged in Edir activities but would like to be, and family have been unsuccessful in getting involved without your help AND/OR
- The health extension worker or community leaders suggest that the Edir group could give financial or practical support to the individual and family

How?

- Arrange meeting with Edir leader
- Discuss the fact that the individual or caregiver finds it difficult to participate in Edir activities
- Discuss the benefits of them participating e.g contribute to Edir work, reduce work of others.
- Discuss how to help them participate more AND/OR
- Discuss that in a crisis situation the individual may come to Edir for financial or practical support

Task 10: Individual meetings with religious leader

In what circumstances?

- The individual, caregiver or HEW identifies religious leader as important source of support AND/OR
- The individual has had difficulties attending church or religious groups, and family have been unsuccessful in getting involved without your help AND/OR
- The individual, caregiver or HEW identifies priest as currently giving incorrect or conflicting messages about treatment, including medication

How?

- Arrange meeting with religious leader
- Discuss how the religious leader can support the individual and caregiver e.g. reinforce importance of accessing care, not chaining unless absolutely necessary AND/OR
- Give information about the importance of taking medication for recovery. Be respectful and do not disagree with their beliefs AND/OR

- Discuss the fact that the individual or caregiver finds it difficult to participate in church/mosque/religious groups
- Discuss the benefits of them participating
- Discuss next steps for involving them, if possible e.g. priest is welcoming to individual; priest makes adaptations or special arrangements to encourage individual to attend.

Task 11 Individual meetings with traditional healer / holy water attendant

In what circumstances?

The individual, caregiver or HEW identifies traditional healer or holy water attendant as important source of reinforcement or currently gives incorrect messages about treatment

How?

- Arrange meeting with traditional healer or holy water priest or attendant
- Discuss how the traditional healer or holy water attendant can support the individual and caregiver e.g. reinforce importance of taking medication whilst at holy water
- Be respectful and do not disagree with their beliefs

Task 12 Individual meetings with literacy group leader or headteacher

In what circumstances?

If the individual or caregiver is not engaged in literacy group or school (and is school age) but would like to be, and family have been unsuccessful in arranging this without your help.

How?

- Arrange meeting with literacy group leader
- Discuss the fact that the individual or caregiver would like to participate in the literacy group
- Discuss the benefits of them participating
- Discuss next steps for involving them, if possible

Task 13 Demonstrate progress of individuals to community leaders/ wider community

In what circumstances?

- Person with schizophrenia who is recovered and has good functioning is available and willing to speak to general community AND
- There is a suitable place in a community setting where this individual can speak AND
- You and your supervisor assess that the community has a good level of awareness and speaking to community members is unlikely to bring additional stigma and discrimination to the individual.

How?

- Work with supervisor to identify person with schizophrenia who is suitable for this task, either through RISE or the Butajira study
- Discuss expectations with the individual e.g. any fears about stigma
- Take consent from the individual
- Arrange with community leader for individual to speak at public meeting e.g. Family Support Group meeting, kebele meeting, Edir meeting.
- Ensure the individual receives compensation for their time, transport etc. Discuss with your supervisor

Task 14 Community awareness raising consolidation

In what circumstances?

Community leaders are willing to receive further community awareness raising activities

How?

Repeat Task 6 in the same or different community meetings

Task 15 Facilitate employment opportunities in the kebele

- Arrange joint meeting with the individual, caregiver and employer previously identified as able to offer employment
- If the employment goes ahead, keep in regular contact with the employer to discuss progress and concerns.

31.3 How do we deal with difficult situations?

When meeting with community and religious leaders you may find they have different beliefs about schizophrenia, for example that it is caused by spirit possession or evil eye, or that holy water will not work if the individual takes medication. You should not tell them their beliefs are wrong. You may find it useful to say there may be many different reasons why someone becomes unwell with schizophrenia, and often we don't know the cause. Also remember that you are not suggesting that people should stop going to holy water, unless they are being harmed there. You should be working towards the individual using medication and holy water at the same time.

Occasionally, community leaders may not be interested to meet with you. If this happens you should work on building your relationship gradually, instead of insisting that they work with you. You could try asking others for help building the relationship, such as the HEW, or another community leader who is more interested in CBR. If you are having lots of problems with community engagement work you should discuss this with your supervisor and make a plan together for how to improve the situation.

31.4 How do we document the community engagement work?

For each kebele you are working in you will have a separate Kebele Logbook (see Form 10). In the Logbook you will record information all the community engagement work you undertake.

31.5 How do we monitor the progress of the community engagement work?

You will discuss at the community engagement work in each kebele at your Face-to-Face Discussions with your supervisor, and also at the Group Supervision sessions.

31.6 Summary

- It is important to do community engagement work to try to increase the positive influences of the community on the individual, and to reduce the negative influences.
- In Phase I you should: meet with the health extension worker, identify important community leaders and resources, find out what mental health awareness raising has already taken place, meet with the community leaders, do a community awareness-raising event, and find out about potential employment opportunities.

- In Phases II and III you may or may not need to do the following steps, depending on the needs of the individual: individual meetings with the kebele leader, religious leader, Edir leader, Traditional healer and holy water priest or literacy group leader; demonstrate the progress of individuals to the community; and facilitate employment opportunities
- You should document the community engagement work in the Kebele Logbook
- Your supervisor will monitor the progress of community engagement work at your supervision meetings

32 Family support groups

32.1 What are family support groups?

Family support groups are where the caregivers of people with schizophrenia who live in the same kebele meet regularly. Sometimes people with schizophrenia themselves are also part of the groups. The aim is to share experiences and information and provide one another with support. The type of support is usually emotional support, but can sometimes be practical.

32.2 Why are family support groups important?

Caregivers of people with schizophrenia are often isolated from other people in the community. They may feel alone with their problems and that no one understands what they are going through. Many caregivers, and sometimes also people with schizophrenia, find it useful to discuss their experiences with other people in the same situation. This can:

- Be empowering as it helps caregivers and people with schizophrenia feel they are able to help themselves
- Reduce feelings of isolation by seeing other people in the same position
- Help to work through problems, such as difficulties returning to farm work, by sharing ideas
- Reduce stress by talking about problems
- Help to give ideas about how to deal with stigma and discrimination
- Improve confidence and self-esteem
- Improve social skills by having a chance to meet with others in a safe setting

Family support groups may also continue after you have stopped doing CBR in the kebele. This may help the positive effects of CBR to continue after you have left.

32.3 How to we set up family support groups?

Who can participate in the family support groups?

There should usually be one family support group in each kebele. The caregivers of all the individuals you are working with and any other key family member should be invited to join. In addition, you will be asked to invite the caregivers of any other people with schizophrenia in the kebele, but who are not participating in CBR. Your

supervisor will give you information about these individuals. You will not be asked to provide any other components of CBR (for example, home visits) to these additional individuals. Family support groups may vary a lot in size. In some kebeles they may be very small, for example 3 members. Family members are more likely to benefit if the group is not too big e.g. more than 10 people (althought you can be flexible depending on the needs of the families). In some kebeles there may be a network or group of caregivers already. If so you should try to build on this rather than starting a new group. People with schizophrenia who are unwell or very disabled will usually find it difficult to participate in the group. However some individuals may find it useful to be involved, especially when they are getting better. Discuss with your supervisor, the family and the individual, if possible, about whether they should be involved. If they are too unwell at the beginning, this should be reviewed as time goes on.

When do we start the family support groups?

You will invite caregivers to participate in the family support group around the time that the families you are working with are moving from Phase I to Phase II. This will usually be about 2 months after you start working in the kebele, but this may vary. The reason for starting around Phase II is that you are more likely to have a good relationship with the family by then, and you should have addressed the most important problems. However you should invite all families to participate at the same time, even if some of them haven't reached Phase II yet. As well as inviting the families you are already working with, you should invite the other people with schizophrenia living in the kebele at around this time.

How do we invite families to participate?

You could say something similar to this to invite individuals and families to join:

''We are planning to start a family support group in your kebele which will allow you to meet with people having similar problems as you are experiencing. This will give you opportunity to express your difficulties, gain support by sharing personal experiences and will help to learn different ways of tackling your problems. We will not be able to provide any loans, but we still hope the group will be helpful. Will you be interested to be a part of the group?''

32.4 How do we organise the family support groups?

Where will the family support groups be held?

The family support group should take place within the kebele, usually in the health post. They could also take place in one of the families' homes, if this is suggested by members of the group. The location should be easily accessible on foot for all the members.

How often will the family support groups meet?

How often the group meets should be decided together with the group members at one of the first meetings. It should usually be about every month. Once decided, the group members should agree to try and attend all the meetings.

When will the meetings be held?

When the group meets should be decided together with the group. It is usually helpful to meet at the same time each month, for example at early on the 1st Saturday each month.

How long will the family support group meetings last?

The meetings might last 60 to 90 minutes, but this should be decided by the group members.

Will we provide coffee or tea at the meetings?

You will not be given any money to buy coffee or tea for the group. However the group may decide to each contribute a small amount each month to buy coffee or tea.

How do we record the details of the Family Support Group?

You should record the details of each family support group on the Family Support Group Details Form (Form 19).

32.5 What do we do in the family support group meetings?

Who leads the meetings?

In the beginning you should be responsible for leading the meeting. After several meetings have taken place you should try to identify a group leader who can take over after you have left. The group should decide together who the leader will be. Different group members can be the leader at different time.

What is the structure of the meetings?

Whoever is leading the group- you or a group member- is responsible for keeping the structure of the meetings. Meetings should normally follow these steps:

- Welcome all members, and introduce new members to the rest of the group
- Remind the group what topic you will discuss at this meeting
- Asking group members to share their experiences, concerns and ideas on the topic
- At the end summarising the main points which were raised in the discussion
- Agree which topic you will discuss at the next meeting and confirm the time, date and place of the meeting

Very small groups may be more informal and not necessarily follow these steps.

What do we discuss in the meetings?

The group members should decide what you discuss in the meetings, but you can give suggestions. It is usually a good idea to keep to one or two topics at each meeting. Decide together which topic you will discuss next week. Topics might include:

- Sharing problems with taking medication and how to overcome them.
- Sharing experiences of negative comments or other types of discrimination from community members, and how to deal with these situations
- Discussing how to improve participation in community life. Caregivers or people with schizophrenia from different families may agree to go together to social events

What should the basic rules of the meetings be?

At one of the first meetings you should agree on the basic rules, using the ideas from the group. These should normally include:

- Everything discussed in the group should be confidential
- Everyone should listen to the other group members and share their own experiences
- No one should make judgements or criticise the other members
- Everyone must respect the other member's situation. What is right for one person does not have to be right for the others.

How do we document the meetings?

The group leader should record who attends and what was discussed on the Family Support Group Meeting Form (Form 20).

What should we do if the group asks for a loan or equipment?

The group members may ask you for financial help, for a loan, for stationary or other equipment or for training. If this happens you should encourage the group to think of how they can use their own strengths, skills and resources. Explain that unfortunately you are not able to provide any of these things to them or indeed to any of the groups you are working with. Tell your supervisor if the group continue to ask you about this, and consider discussing together.

32.6 How do we make sure the family support groups carry on after we have left?

From the beginning of the support group meetings you should be thinking about how to make sure they carry on after you have left the kebele. Here are some ways to do this:

- Make sure the group discusses topics that are important to the members. If they are benefitting from the group it is more likely to continue.
- Tell the group that you will support them in the beginning but that you hope they will run it by themselves later on, once they are ready.
- Find a group leader from within the group after the first few sessions.
- Be prepared for the group to take a long time to get started and to run by itself.

32.7 Summary

- Family support groups are where caregivers of individuals, and sometimes people with schizophrenia themselves, provide support to one another
- They are empowering for the participants, and reduce feelings of stress and isolation
- The groups should have 5-10 members and should meet about every 15 days.
- You should lead the group initially then later a group member should lead. You should try to ensure the group carries on after you have left
- Discussion topics can include: sharing problems, sharing experiences, improving participation in community life

SECTION C: Know how you will be supported to deliver CBR

33 CBR worker wellbeing

33.1 What problems with wellbeing might CBR field workers have?

Working with people with mental illness is often rewarding but you may sometimes find it stressful. Stress isn't always bad, but it can cause problems. These problems include:

- Worrying all the time
- Sleeping badly
- Being irritable
- Drinking too much alcohol or chewing *khat*
- Not wanting to be with people
- Physical health problems (high blood pressure, peptic ulcer disease)
- Conflicts with your work colleagues over small things
- Problems with relationships at home
- Developing depression or an anxiety disorder

33.2 Why might CBR field workers have problems with wellbeing?

Here are some of the reasons why you might have problems with your wellbeing:

- You feel you have too much to do
- You are worried about your personal safety.
- You feel there are high expectations from others or the individuals aren't making enough progress
- You have to make difficult decisions
- You don't have enough support
- Working with people with many problems, you may take on their worries as your own

33.3 Why is it important for CBR workers to look after themselves?

It is very important for you to look after yourself. It will be difficult to help the people you are working with if you are not looking after yourself and feeling well. You might feel that admitting you feel stressed or unhappy is a sign of weakness or lack of commitment to your work. This is not true.

33.4 How can you maintain your wellbeing?

1. Reducing stress

Here are some ideas to make sure stress doesn't cause problems for you:

- Don't work all the time – in your rest times, meet up with family and friends, do things you enjoy and try to relax
- Eat adequately
- Try to maintain a routine
- Discuss work problems with another person, for example your spouse or a friend
- Don't be afraid to ask for more support.
- Try the relaxation techniques in Chapter 23.

2. Discuss your work

You should have lots of opportunity to discuss how your work is going, and any problems you are facing (see Chapter 34). These include:

- Meeting with your supervisor once every two weeks
- Monthly group supervision with other CBR workers
- You can call your supervisor at any time if you are facing difficulties.

Remember that it might take a long time to see positive changes in the individuals you are working with. Try to stay positive and think about the small changes which have happened since you started.

3. Seek help

There are two situations where you should look for help STRAIGHT AWAY:

- **Suicidal feelings.** If you feel so hopeless that you are thinking that life is not worth living, or even thinking about ending your life it is very important to discuss these feelings with someone you trust.
- **Problems with alcohol or khat.** If you are concerned that you have a problem with alcohol or khat or your friends or relatives tell you they are concerned, you should try to get help.

To get help you can also talk to your supervisor or go to the health centre.

4. Keep safe

The following steps are designed to ensure you feel safe whilst at work:

- Your supervisor should accompany you on first two home visits to each individual
- For each individual, your supervisor will undertake a CBR worker safety assessment of the risk to you and the supervisor
- You should always carry a mobile phone. You will be provided with credit.
- You should ensure that there is a family member present at all home visits. This should be emphasised to the caregiver during your first visits.
- If there is a high risk to your safety, your supervisor will accompany you on the home visits
- If there is a medium risk to your safety, you should call your supervisor at the beginning and the end of each visit

5. Know how to deal with a violent or aggressive person

- Be aware of the signs that someone is going to become violent. These include:
    - Talking louder or becoming threatening
    - Fists opening and closing
    - Breathing fast
    - Fidgeting
    - Tapping, punching or slapping tables, walls or the floor
- Be aware if the individual smells of alcohol, is losing their balance or has slurred speech. This might mean the individual is drunk and is more likely to be violent
- Think about your own feelings. If you feel scared you should stop the home visit and leave the house.
- Make sure that both you and the individual can reach the door of the house easily.
- Speak in a clear and calm voice. Do not shout to try and calm the individual.
- Let the individual know that you want to help them.
- Don’t tell them that they can’t really hear voices or that their beliefs are wrong.
- Do not threaten the individual or correct their swearing. This will only make it worse.

- If the individual has a weapon, reassure them that you are here to help them and there is no need for a weapon. If they refuse to put down or hand over the weapon, you should stop the home visit and leave the house.
- If the individual becomes violent tell him to calm down by firm reassurance. If this is not possible you should stop the home visit and leave the house.
- After the incident call your supervisor to tell them what has happened and agree together any steps you need to take now.

33.5 Summary

- Whilst working as a CBR worker you may sometimes feel stressed or unhappy
- This may happen if you feel you do not have enough support or you are worried about your safety or have other problems in your life to deal with
- It is important for you to stay well so that you can help the individuals you are working with properly
- Ways to stay well and happy include: reducing stress, discussing your work with others, seeking help if you need to, keeping safe and knowing how to deal with a violent person

34 Supervision

34.1 What is supervision?

Supervision is where somebody else supports you in your work and gives advice on how to improve the way you are working.

34.2 Why is supervision important?

It is important that you are supervised for the following reasons:

- To make sure that all the right steps are taken for each individual, for example that referrals to the health centre are made at the right time.
- To make sure all the individuals receiving CBR are supported in a similar way. Even though each individual will receive a different version of CBR, depending on their needs and goals, there are some things that should be the same for everybody. These include your relationship with the individual and how well you document their progress.
- To make sure all the kebeles have similar community engagement, for example community awareness raising.
- To make sure gaps in your knowledge are identified, so that you can receive extra training and support if you need it.
- To make sure you are safe and well whilst delivering CBR

34.3 Who is involved in supervision

You and the other CBR workers

You and the other CBR workers will get lots of experience with working with people with schizophrenia whilst delivering CBR. You will probably find it useful to share these experiences and hear about how others have overcome difficulties.

Your supervisor

Your supervisor will be your main source of supervision. They have experience in supervising CBR workers.

The trial co-ordinator

The trial co-ordinator will supervise your field supervisor. You will not have very much contact with the Trial Co-ordinator.

34.4 How will you be supervised?

There are four ways in which you will be supervised.

1. Face to face discussion

Who? You and your supervisor

When? Every 15 days at a pre-arranged meeting

Where? At the health centre or a health post

What?

- Using the most recent Home Visit Forms (Form 11) and the logbooks you will discuss the progress of each individual you are working with, including:
    - General health and symptoms
    - Whether they are taking medication
    - Whether any risks have been identified, particularly suicide risk
    - Modules you are working on and modules you have completed
    - Progress on current goals
    - Any problems or difficulties achieving the goals
    - Practical issues
    - Safety issues
- You will record any actions that your supervisor suggests on the most recent Home Visit Form. You will need to make sure you use these suggestions in your next home visit. At the next Face to Face Discussion your supervisor will check whether you used the suggestions.
- Using your kebele logbooks you will discuss the progress of the community engagement, including:
    - Community engagement activities carried out and planned
    - Any problems with community engagement
- You will discuss your timetable for the next fortnight. Both you and your supervisor will then have a record of which individuals you plan to visit, and what community engagement activities you plan to do, on each day. See Form 13.
- Your supervisor will identify any training needs that you have and update your knowledge or skills if needed. You should record this part of your discussion on the Supervision Record Form (Form 21).
- You will arrange your next supervision meeting and any joint home visits which are needed

2. Phone contact

Who? You and your supervisor

When? Whenever you need advice or support

Where? By mobile phone

What?

- You can call your supervisor at any time to discuss problems or questions which arise during your work
- There are certain situations where you should always call your supervisor. These include:
    - Individual is at risk of suicide, chaining, neglect, physical or emotional abuse inside or outside the home, or sexual violence (see Chapter 14 and Chapter 35)
    - You have made an urgent referral for the individual to attend the health centre (see Chapter 36)
- You will record any suggestions that your supervisor makes on the most recent Home Visit Form, if it relates to an individual, or on the Supervision Record Form if it relates to your own training needs. You will need to make sure you use these suggestions in your next home visit.

3. Unannounced observed home visits

Who? You and your supervisor

When? About every month, but you will not know the time or day in advance

Where? At an individual's home

What?

- You will carry out the home visit as normal, but your supervisor will also come to the home and observe you working. They will be looking at:
    - How good your relationship is with the individual and family
    - How well you listen and explain things to the individual and family
    - Whether you do modules or tasks which seem right for the individual at that time
    - How well you write down what happened during the home visit

- After the home visit, usually at the health post or health centre, the supervisor will tell you how well they think you are working. They will always give you some positive feedback, as well as telling you about any problems.
- You will discuss together how you can improve things if there are any problems. Your supervisor may give you more training if you need it.
- You will record any suggestions that your supervisor makes on the current Home Visit Form if it relates to the individual, or on a Supervision Record Form if it relates to your own training needs. You will need to make sure you use these suggestions in your next home visit.

4. Group supervision

Who? You, all the other CBR workers and both field supervisors

When? Every month

Where? At a health centre

What?

- Prior to the meeting you should try to think of one or two specific problems or issues that you have faced that you would like some support with. These might be related to:
    - Issues with delivering the modules e.g. the best way to give advice about self care
    - Issues with working with people with schizophrenia e.g. How to react when an individual is unwell and hallucinating
    - Issues with community engagement work e.g. how to work with an obstructive community elder
    - Practical issues e.g. how to use public transport to get to a particular location
    - Your own well being e.g. how to balance work and home life
- During the session the supervisor will facilitate the discussion. They will ask one of you to briefly present your problem or question. The other CBRWs will then have a chance to ask you questions to make sure everyone understands what your issue is.

- The supervisor will then ask for ideas and advice from you and the other CBR workers for how to overcome the problem. It may be useful for other CBR workers to describe how they responded to a similar situation.
- You will record any suggestions that the group makes on a Supervision Record Form. You will need to make sure you use these suggestions, for example at your next home visit.
- The supervisor will then ask the next CBR worker to present their problem. In each session around half of the CBR workers will have chance to present their issue.
- The supervisors will also update your knowledge or skills based on issues that come up during the group discussion, or which they have noticed from face to face discussions or observed home visits.

34.5 Summary

- It is important that you are supervised to make sure all the right things are being done for each individual; to make sure your skills are up to date and that you are safe
- Every 15 days you will have a Face to Face Discussion with your supervisor to discuss each individual and kebele you are looking after, your timetable, and any training needs
- You can call your supervisor at any time for support. You should also call them when you identify certain risks or if you have made a referral to the health centre
- Your supervisor will make an unannounced home visit about once a month
- You will have a Group Supervision session every month to discuss issues with other CBR workers and share ideas.
- You should record any supervision on the most recent Home Visit Form or a Supervision Record Form

35 Dealing with difficult situations

35.1 What difficult situations might you come across?

As you learnt in Chapter 14, people with schizophrenia are vulnerable to many types of risks. These include: suicide attempt or suicide risk, chaining, neglect, physical abuse outside the home, physical or emotional abuse inside the home and sexual violence.

Other difficult situations you might come across include:

- The individual commits suicide or dies from another cause
- The individual is admitted to hospital due to a serious side effect from the anti-psychotic medication, or due to any other serious medical emergency
- The individual is violent or aggressive towards you or others

35.1 Why is it important to know how to deal with difficult situations?

It is important that you know how to deal with difficult situations so that the individual can get the best care and support available as soon as possible. This will lead to a better outcome for the individual, family and the community.

35.1 How should you deal with difficult situations?

In this section there is a summary of what you should do for each difficult situation. Your priorities when dealing with difficult situations are always to ensure your own safety and the safety of the individual. Whenever you send the individual to the health centre, write on the Health Centre Referral Form (Form 14) the reason for the referral and ask the individual or caregiver to show the form to the nurse or health officer. Keep a copy of the form for the participant logbook. You should only call the police if you strongly believe the individual is in immediate danger of being seriously hurt by someone.

KEY

Solid arrow: always continue to the next step

Dashed arrow: continue to the next step if the red writing is true in this situation

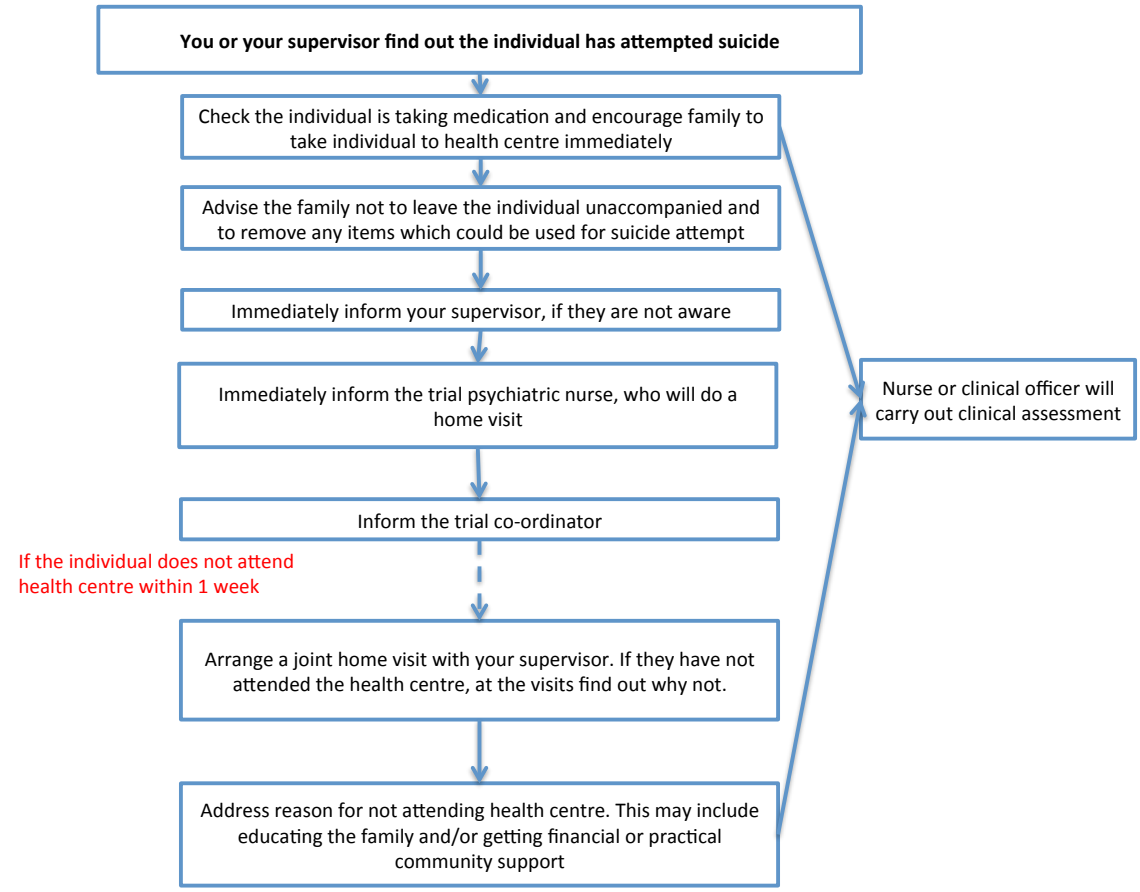


Figure 1 Attempted suicide flow chart

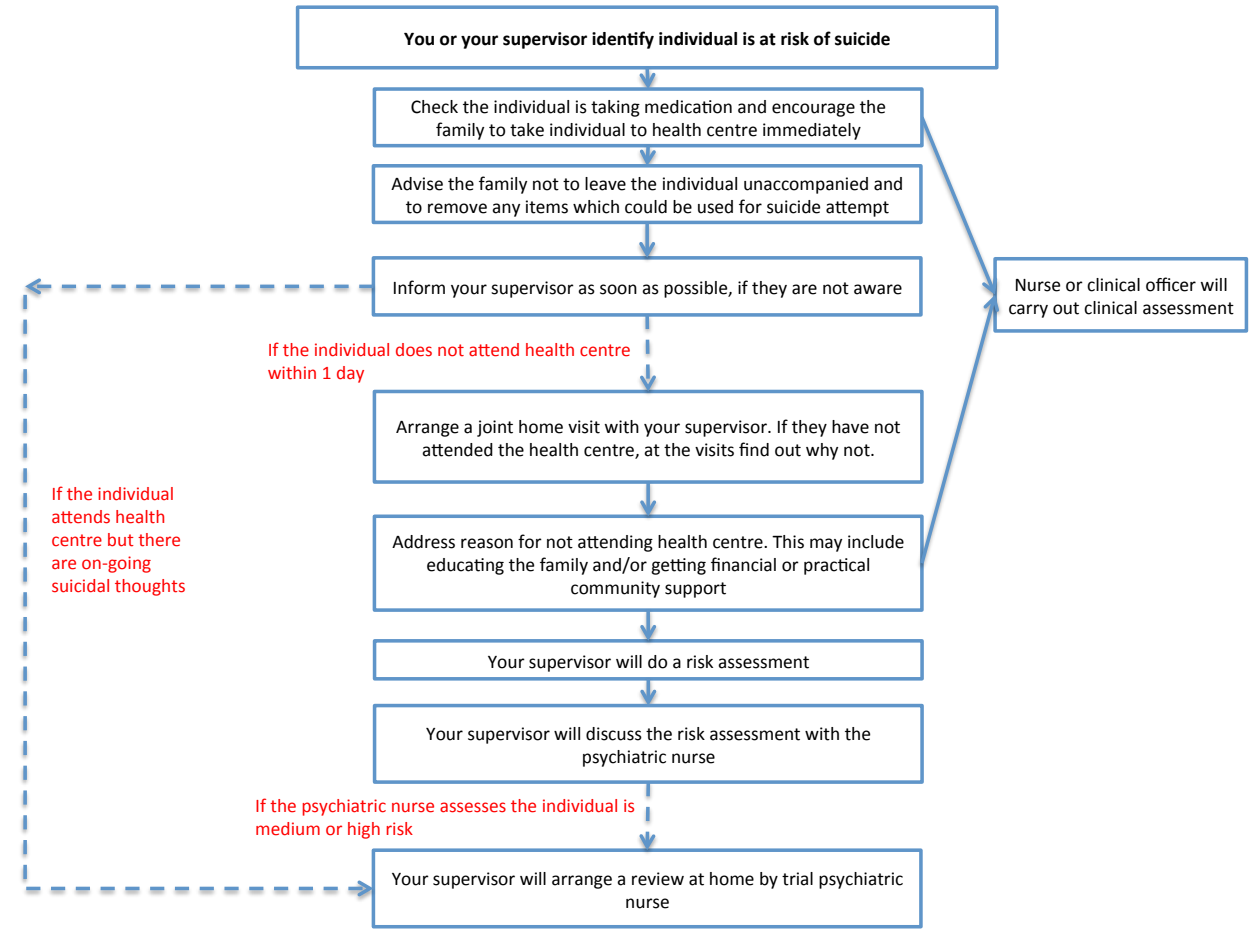


Figure 2 Risk of suicide flow chart

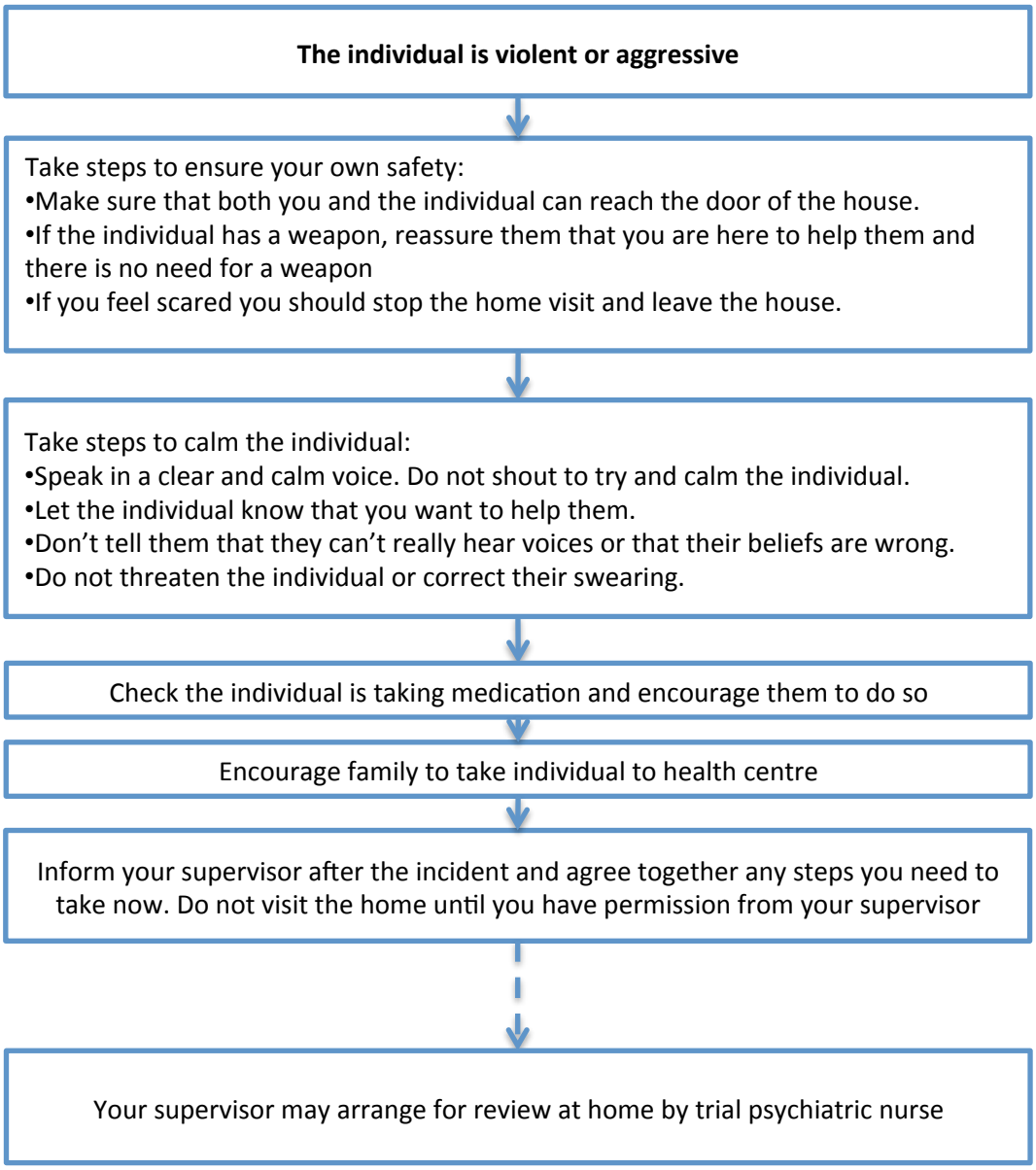


Figure 3 VIolent or aggressive individual flow chart

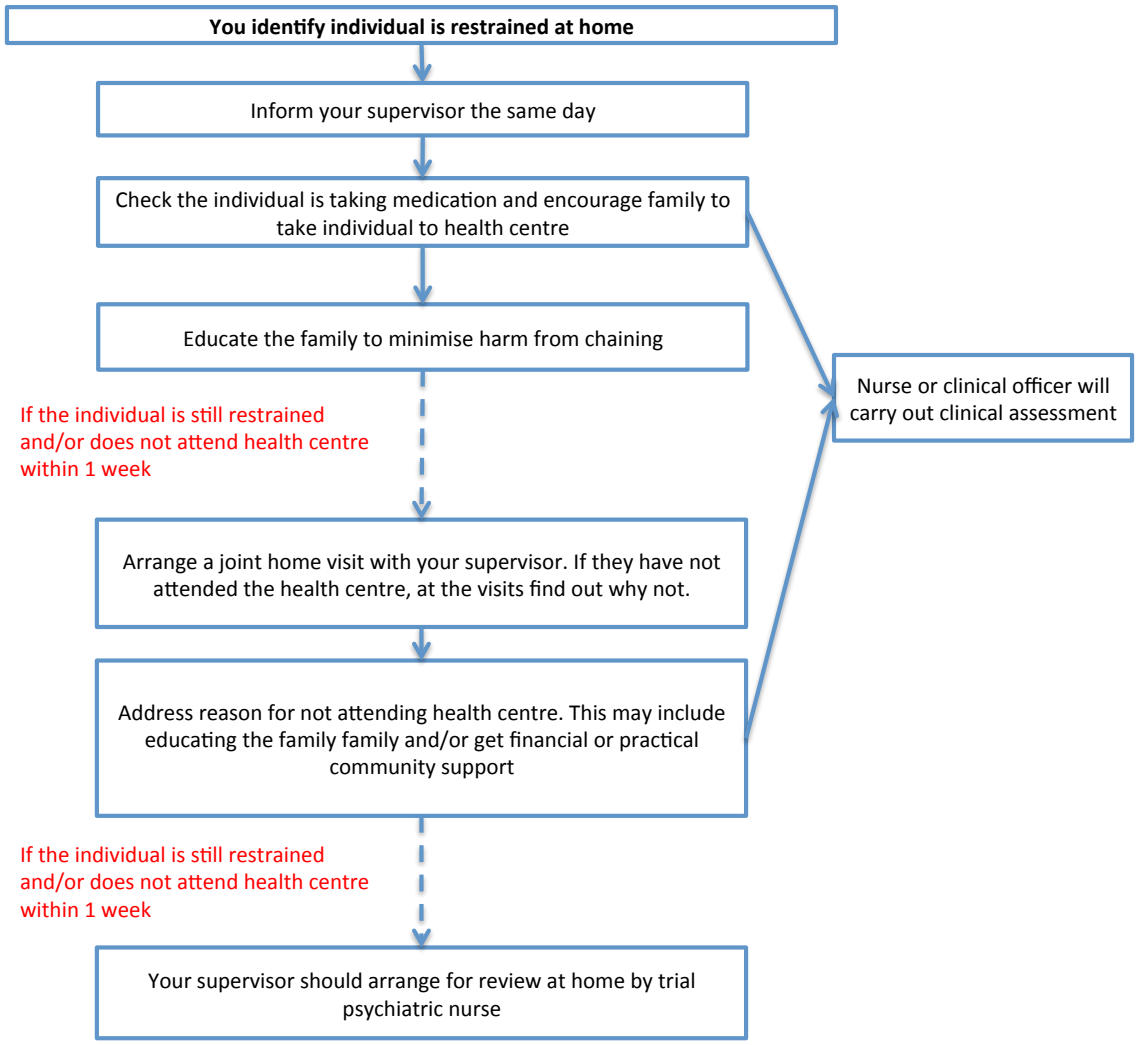


Figure 4 Restrained or chained individual flow chart

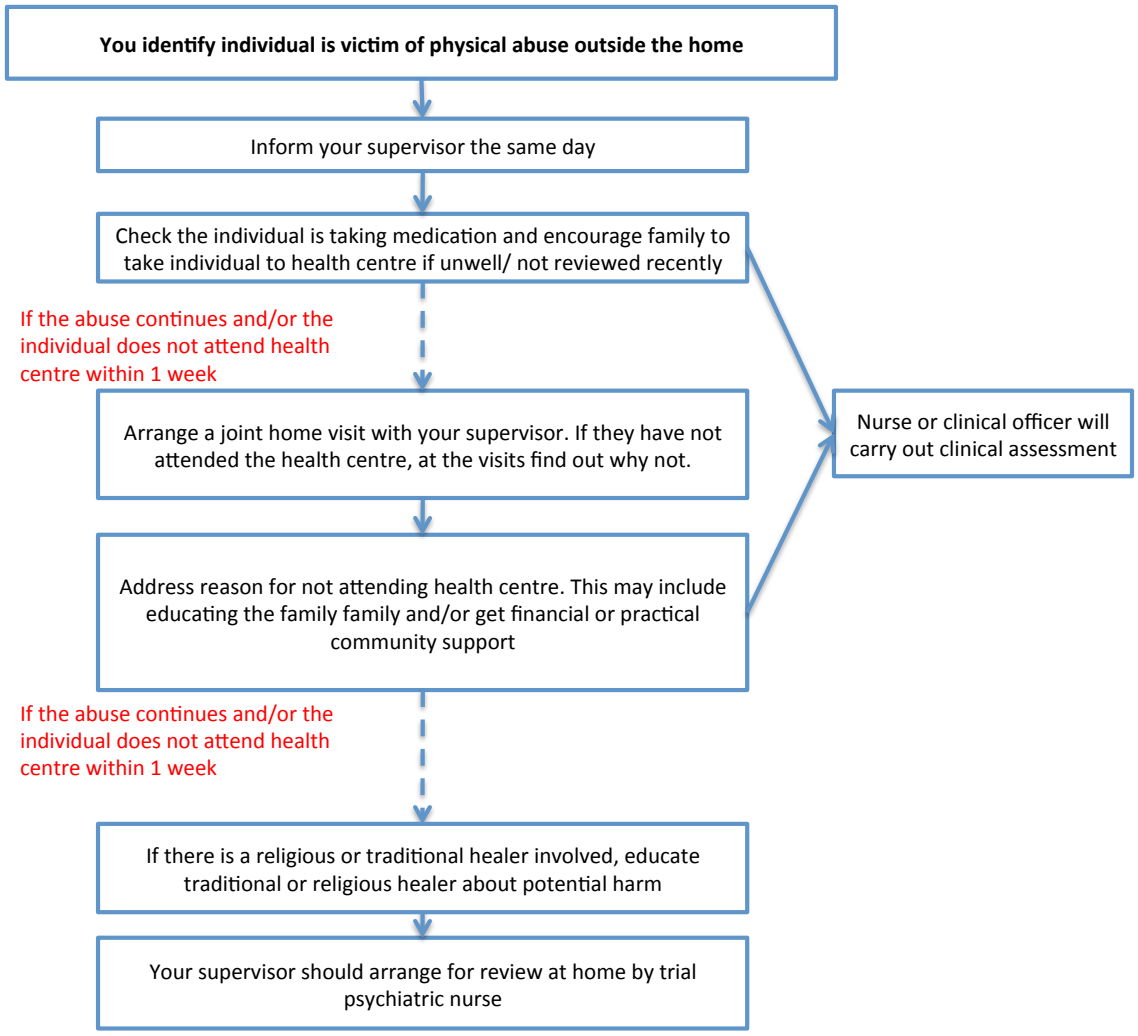


Figure 5 Physical abuse outside the home flow chart

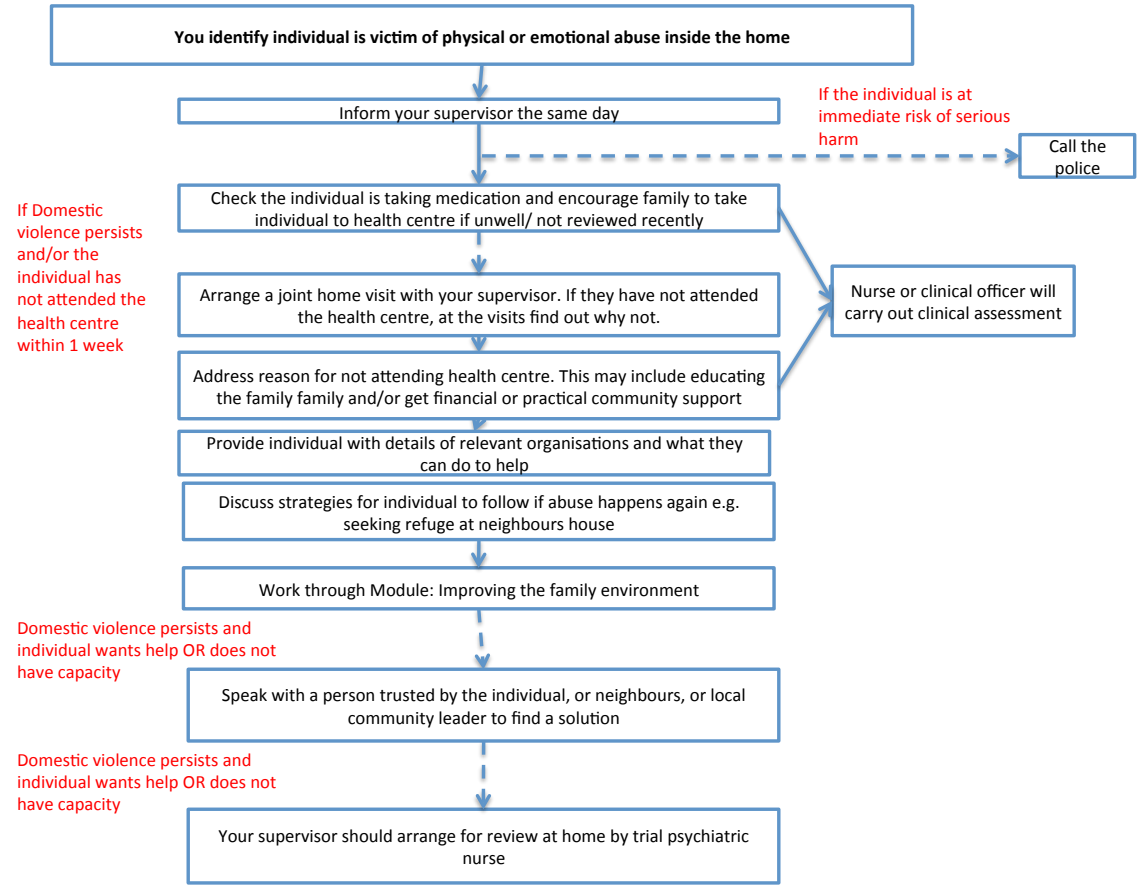


Figure 6 Physical or emotional abuse inside the home flow chart

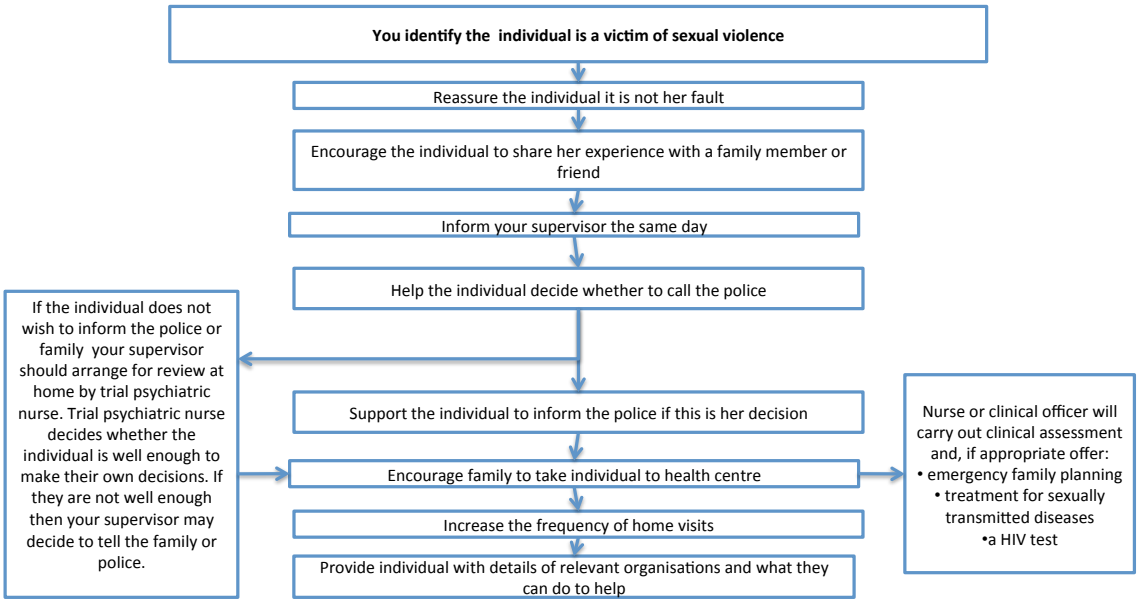


Figure 7 Sexual violence flow chart

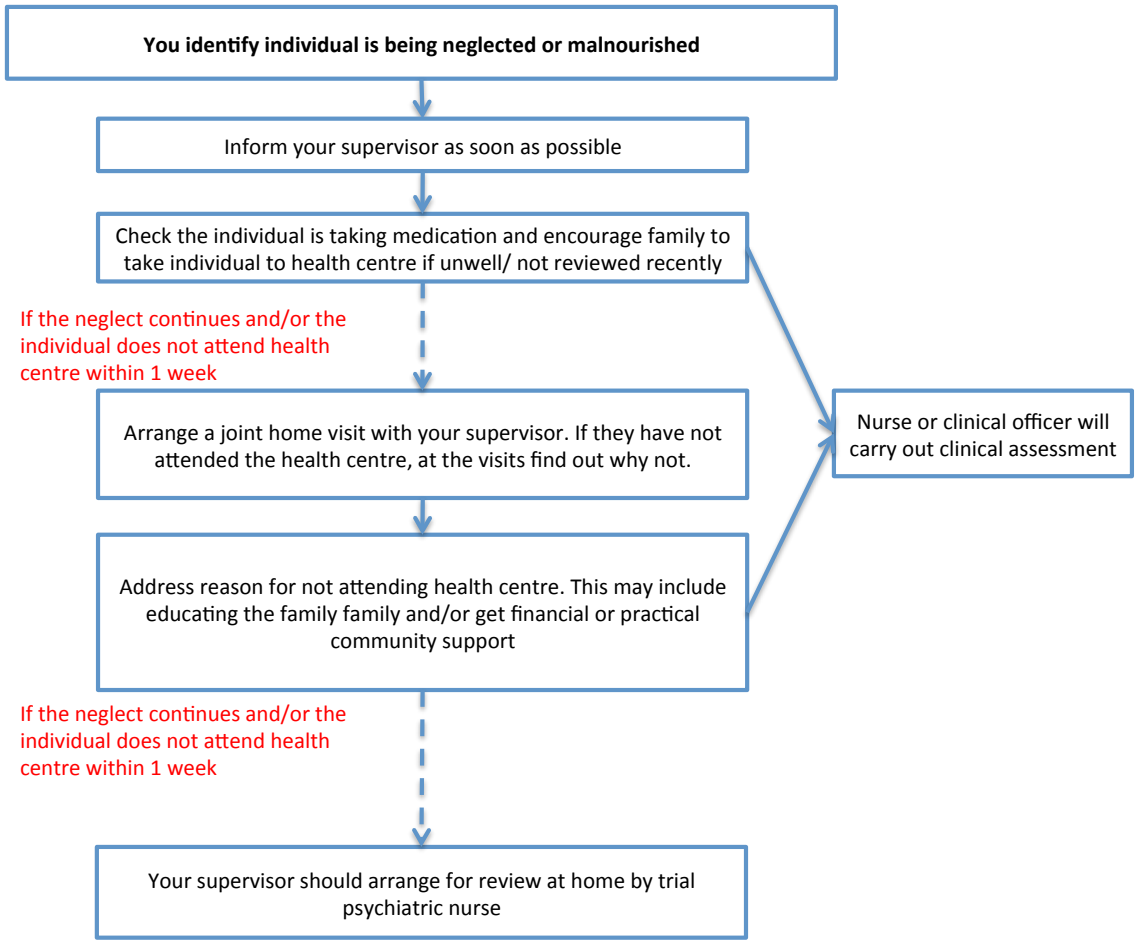


Figure 8 Neglected or malnourished flow chart

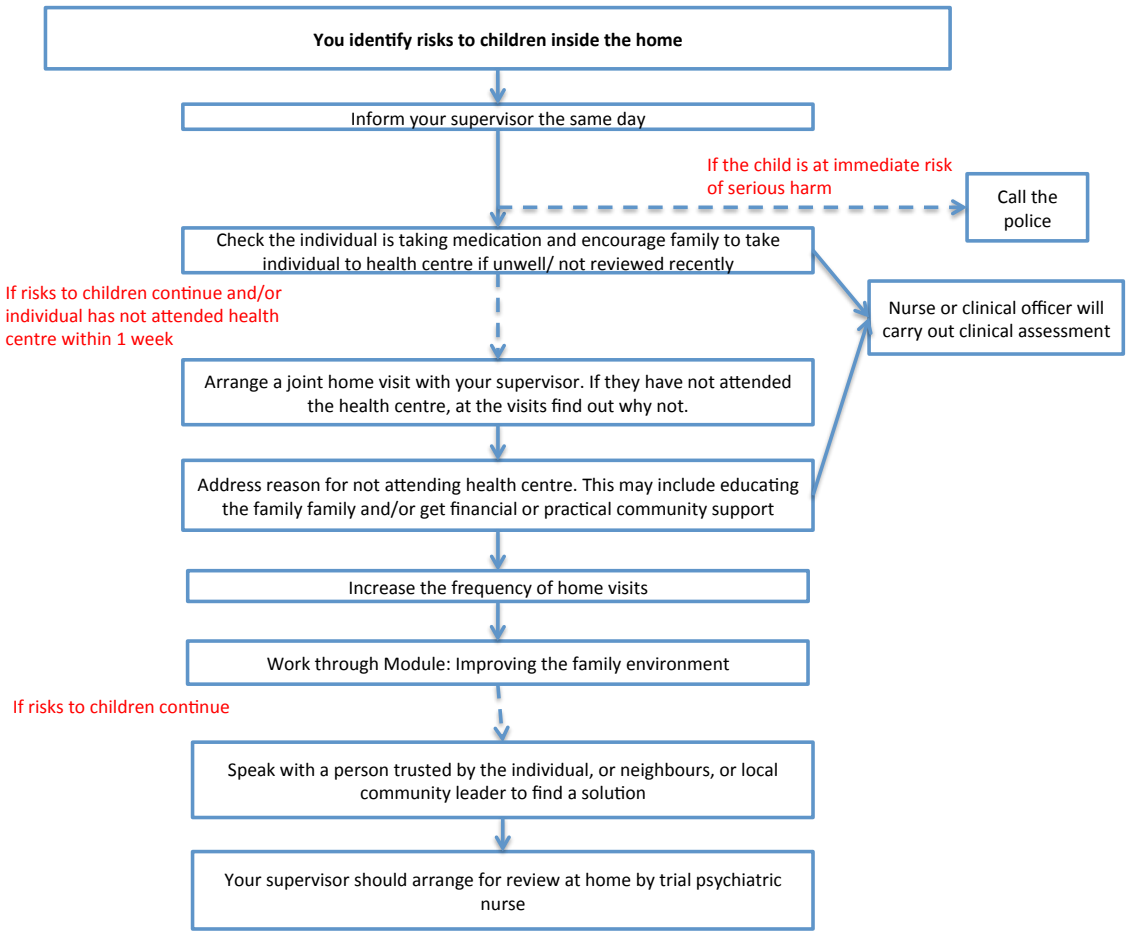


Figure 9 Risks to children flow chart

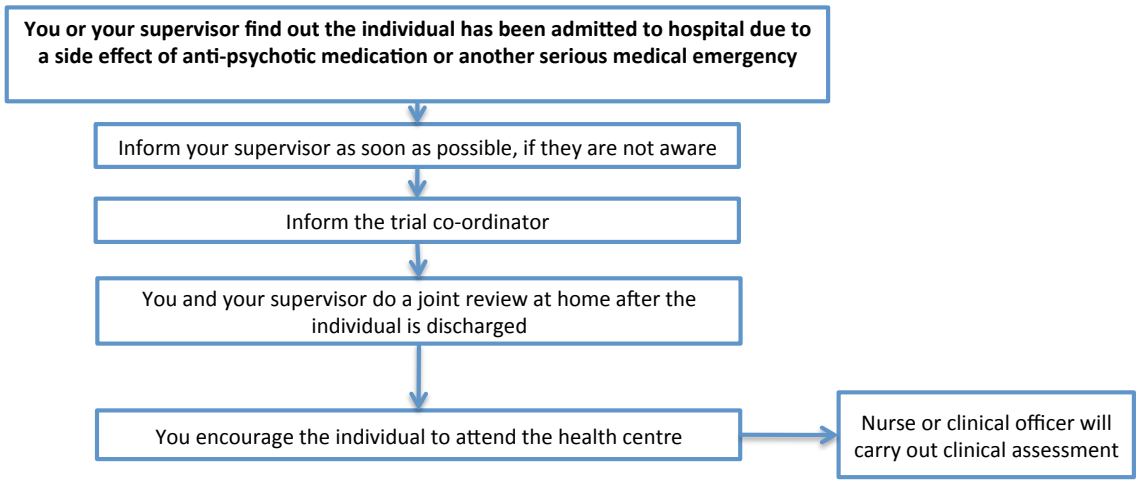


Figure 10 Hospitalisation flow chart

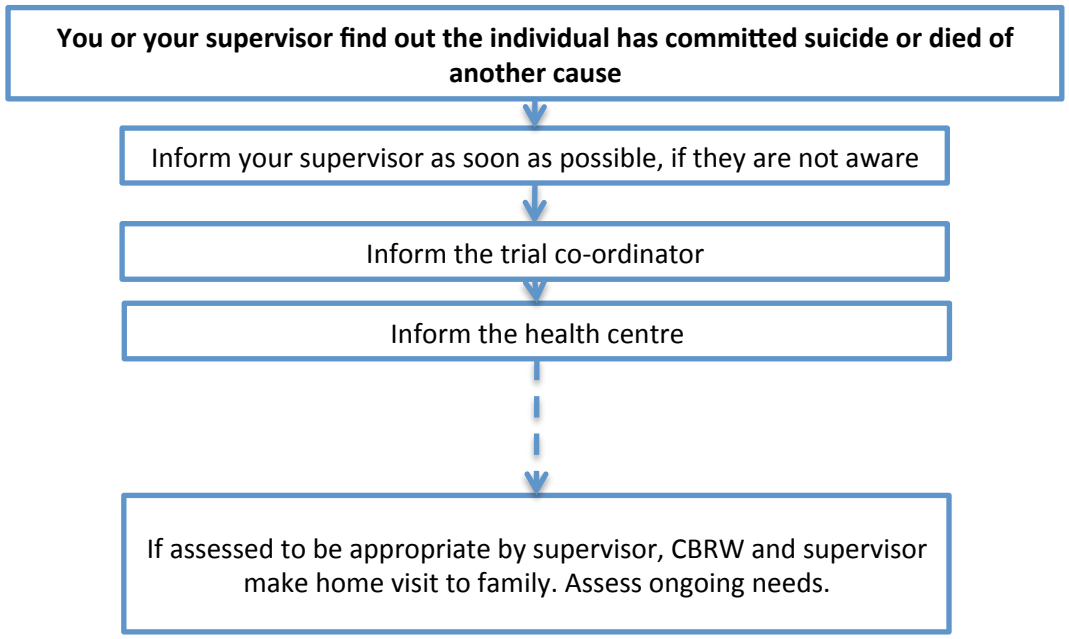


Figure 11 Suicide or death from other cause flow chart

35.4 Summary

- It is important you know how to deal with difficult situations to make sure the individual gets the best care possible
- There is a set of actions you should take for each difficult situation

36 Links to health services

36.1 What are links to health services?

Links to health services are any communication that you have with:

- The health centre
- The health extension workers

36.2 Why is it important to have links to health services?

All the individuals you are working with have access to medical care for schizophrenia at the health centre. It is part of your role to ensure that the individual attends the health centre regularly, as this will help them to recover (see Chapter 17). There are some situations that are too complicated for you to deal with, for which you should send the individual to the health centre. There are other types of work, for example giving advice about family planning, which you have not been trained for, so you should involve the health extension worker. Keeping links with health services will ensure the individual can get the best possible care.

36.3 How do you keep links to health services?

Introduce yourself at the health centre

At the beginning of the CBR programme you and your supervisor will introduce yourself to the health centre head and the nurses and clinical officers. They will already be aware of the CBR programme but you can remind them of your role.

Regular appointments at the health centre

Each individual should go to the health centre every 1 to 3 months. You should be aware of all the appointments they have, and check if they have attended. If they have missed an appointment, even if you are not due for a home visit, you should make a home visit to check for any problems and remind them to attend.

Special situations

You should send the individual to the health centre in any of the following situations:

- You think the individual is at risk of committing suicide (See Chapter 14 and 35)
- You are worried that the individual is not eating or drinking (See Chapter 35)

- You are worried that children may be at risk of harm from the individual (See Chapter 35)
- The individual has harmed someone else or you are worried this is going to happen
- The individual has a relapse i.e. is very unwell with symptoms of schizophrenia (Chapter 30)
- The individual become pregnant. You should also inform the psychiatric nurse.
- The individual has a new physical health problem or physical injury (Chapter 21)
- The individual has a serious problem with alcohol or khat (Chapter 21)
- The individual has serious side-effects of the anti-psychotic medication (see Chapter 20 for description of side effects).
- You would like the nurse to review the medication schedule or consider the injection (Chapter 20)

You should tell your supervisor if any of these situations happen. Advise the family to take the individual to the health centre as soon as possible and give them support in making the journey. This may include finding other community members who can help the family (see Chapter 31). Record on the home visit form that you have referred to the health centre. Write on the Health Centre Referral Form (Form 14) the reason for the referral and ask the individual or caregiver to show the form to the nurse or health officer. Keep a copy of the form for the participant logbook. You can go to the health centre with the individual. If you accompany the individual you should complete a Health Centre Contact Form (see Form 2). Once they have returned from the health centre you should continue to deliver CBR as normal. If you find that the caregiver is very distressed you can suggest they go to the health centre (see Chapter 15).

Health Extension Programme

The health extension workers should be continuing to provide their usual care to the individuals you are working with. You should ask the health extension worker to visit the individual if they need support with contraception, sanitation advice, or malaria prevention, and they have not received a home visit. Health extension workers are not expected to assist with CBR, for example help with self-care.

36.4 Summary

- It is important to have links with the health centre and health extension worker to ensure the individual has the best care possible.
- You should send the individual to the health centre when: they are at risk of committing suicide, they are not eating or drinking, they have harmed someone else, they are very unwell with schizophrenia, they are pregnant, they have a physical health problem or they have serious side effects of anti-psychotic medication.
- You should ask the HEW to visit if they have not delivered their usual care to the individual
- If an individual misses a routine appointment at the health centre you should remind them to attend

37 Good documentation

37.1 What is good documentation?

Good documentation means that you write things down, for example about a home visit, in a way that:

- You are able to look back and remember what happened.
- Other people, for example your supervisor, can understand what happened without having to ask you
- The individual and family can read what you have written and they think it is a good description of what happened during the visit

37.2 Why is it important to have good documentation?

When you are doing CBR with many families at the same time it may be difficult to remember the details of what happened every time you see a family. By keeping a good record of each individual's progress, you will be much better at helping them each time you see them. It will also be easier for your supervisor to check that you are looking after individuals in the right way, and give you advice on how to improve the way that you are working. The individual and family you are working with may ask to see what you have written. It is fine for you to show them.

37.3 What do we need to document?

For each individual you are looking after you will keep an individual logbook. This will include the following forms:

- Initial contact form (Form 1)
- Health Centre Contact Form (Form 2)
- CBR Review Form (Form 3)
- Needs Assessment Form (Form 4)
- Goals setting Forms (Forms 5 and 6)
- Risk assessment Form (Form 7)
- Rehabilitation plan (Form 8)
- Continuing Care Form (Form 9)
- Home visit forms for each visit (Form 11)
- Visit Summary Forms (Form 12)

- Health Centre Referral Form (Form 14)
- Medication checklist (Form 15)
- Day to Day functioning Progress Form (Form 16)
- Early Warning signs checklist (Form 17)
- Relapse Management Plan (Form 18)
- Supervision Record Forms (Form 21)

For each kebele you are working in you will keep a kebele logbook (Form I). You have learnt about what information to record in these logbooks in other sections of the manual.

37.4 How do we make sure we have good documentation?

These are the things you can do to make sure you have good documentation:

- Write in a clear and legible way
- Write in Amharic
- Write down enough detail so that you and someone else will be able to understand it later
- Make sure you would be happy for the individual and family to read whatever you write down.
- Use a pen instead of a pencil
- Keep all your logbooks with you at all times when you are working in the field. At other times keep them in a safe place.
- Keep your logbooks dry and clean
- Your supervisor will check your documentation every so often and will give advice on how to improve it if necessary

37.5 Summary

- Good documentation is where you record things in a way it is easy to understand later
- It is important to make sure you and your supervisor can easily follow the progress of individuals
- You will keep an logbook for each individual and each kebele
- You can ensure good documentation by: writing clearly, keeping logbooks dry and clean, writing in pen and writing enough detail

38 How to deal with other people with problems

38.1 What other problems might you come across?

During your CBR work you may come across people, apart from the individuals you are working with, who have problems. These might include:

- People with schizophrenia who have been offered care at the health centre but who you have not been asked to look after. They might live in a kebele where you are working, or another kebele where you are not working.
- People who you think may have schizophrenia but who are not receiving care at the health centre
- People with other sorts of mental health problems, for example alcohol problems in adults, or developmental delay in children
- People with other sorts of disabilities, for example blindness or problems walking due to polio
- Community members or community leaders may ask you to do community engagement work in another kebele

38.2 Why might you come across other people with problems?

In most kebeles there will be people with schizophrenia who are receiving care at the health centre but who you have not been asked to look after. The reasons for this will be:

- They are generally more well or less disabled so do not need the extra support of CBR
- They were offered CBR but they did not want to participate
- There is another reason why they could not receive CBR, for example there was no caregiver able to participate, or they have plans to leave the kebele soon.

You may be asked by the individual, family or community members to offer CBR or extra support to these individuals. It may be difficult for people to understand why you are giving extra support to some people with schizophrenia but not others.

You will become good at recognising schizophrenia, and you may notice the symptoms in people who have not been diagnosed by a nurse at the health centre. Or community members might tell you about individuals who are chained up because they are unwell.

When you are working within the kebele you might also notice other sorts of problems, for example physical disabilities, just by observing the people you meet. The family you are working with might tell you about problems with other family members. Community leaders or other community members may see you as a source of support and may tell you about problems that other people have, even if you don't ask them to.

Community members or community leaders from kebeles which have not been allocated to receive CBR may ask you to do community engagement work in their kebele. They may have seen or heard about you doing this work in the kebeles where you are working.

38.3 Why is it important to know what to do if you come across other people with problems?

In this CBR programme your role is to support the people with schizophrenia that you have been asked to look after. However, it is important that you know what to do if you come across people with other problems. This is to make sure that these people get any care and support that is available. It will also help the individual, family and community to trust you more if you know what to do when you come across people with other problems.

38.4 What should you do if you come across people with other problems?

What you should do when you come across other people with problems depends on the type of problem. But the general rule is to ask someone else to help, rather than helping the person yourself.

1. People with schizophrenia who have been offered care at the health centre but whom you have not been asked to look after

- Suggest that they visit the health centre if they have not been recently
- Explain that unfortunately you cannot offer home visits to them and that this is out of your control.
- Ask the Health Extension Worker to support the individual, for example encouraging them to attend the health centre.

- If the individual lives in kebele where you are working (i.e. in a kebele allocated to receive CBR), consider inviting them to the Family Support Group, if this has already started.
- If the individual lives in kebele where you are not working (i.e. in a kebele not allocated to receive CBR), it is important that you do **not** invite them to the Family Support Group.
- Inform your supervisor of your discussions

2. People who you think may have schizophrenia but whom have not yet been offered care at the health centre

- Suggest to the individual and family to take the individual to the health centre
- Ask the Health Extension Worker to also encourage them to attend the health centre and to follow up on their progress.
- Inform the health centre that you have asked the individual to attend
- Inform your supervisor

3. People with other sorts of mental health problems

- Suggest to the individual and family to take the individual to the health centre
- Ask the Health Extension Worker to encourage them to attend the health centre and to follow up on their progress.
- Inform the health centre that you have asked the individual to attend
- Inform your supervisor

4. People with other sorts of disabilities

- Suggest to the individual and family to take the individual to the health centre
- Ask the Health Extension Worker to encourage them to attend the health centre
- Inform the health centre that you have asked the individual to attend
- Inform your supervisor
- Refer the individual to any relevant NGOs

5. Community members or community leaders who want you to do community engagement work in another kebele

- It is very important that you do NOT do any community engagement work in kebeles where you are not already working (i.e in kebeles not allocated to CBR).
- Explain that unfortunately you cannot offer community engagement work in their kebele and that this is out of your control.
- Explain that medical care for people with schizophrenia is available at the health centre and that anyone with schizophrenia who is not already doing so should seek help there.
- Give them the number of the trial co-ordinator in case they wish to discuss this further
- Inform your supervisor of your discussions.

38.5 Summary

- During CBR work you may come across other people with problems, for example people with mental health problems, or people with physical disabilities
- It is important to know what to do so that these people can get the best care possible
- Generally, you should not try to look after these people yourself, but you should tell them how to get help

Appendix C (iii): RISE training programme for CBR workers

Schedule
8:45 Arrive and register
9:00 Teaching session
10.30 Coffee
11:00 Teaching session
12:30 Lunch
13:30 Teaching session
15:00 Coffee
15:30 Teaching session
17:00 End

Week 1 Monday

Introduction to Training programme - AH		
Competencies • Aware of and adheres to cultural norms in terms of dress and general behaviour. • Demonstrates good time-keeping and attendance		
Steps	**Resources**	**Timing**
1. Thank everyone for coming, welcome trainees and introduce all trainers 2. Ask the trainees to introduce themselves, giving their name and one interesting thing about themselves		20 min
3. Introduce the RISE training programme	Powerpoint 1	10 mins
4. Ask the trainees ask why they chose to participate, and if they have any expectations or concerns about the training programme. 5. For each contribution, write it on the flipchart and ask if other participants share them.	Flipchart	20 min
6. Ask the trainees to think of ground rules, which will help them to work together and participate well in the training 7. Write each contribution on the flip chart paper,	Flipchart	20 mins
8. Check all important points are covered	Powerpoint 1	
9. Tell the group about how CBR workers will be assessed and selected	Powerpoint 1	10
Total		80

Introduction to CBR - AH		
Reference: Chapter 9		
Competencies • Understands and is able to explain purpose and structure of CBR programme		
Steps	**Resources**	**Timing**
1. Teach the following: • What is disability? • What are the pillars of CBR? • What are the principles of CBR?	Powerpoint 2	15
Total		15

CBR for schizophrenia I - AH		
Reference: Chapter 9		
Competencies • Understands and is able to explain purpose and structure of CBR programme		
Steps	**Resources**	**Timing**
1. Tell the trainees: • Who is involved in CBR • Where does CBR take place? • How long does CBR last? • How do we start CBR?	Powerpoint 3	30
2. Quiz	Powerpoint 3	10

Total		40

CBR for schizophrenia II - RB		
Reference: Chapter 9		
Competencies • Understands and is able to explain purpose and structure of CBR programme		
Steps	**Resources**	**Timing**
1. Tell the trainees: • What are the CBR modules? • What are the phases of CBR?	Powerpoint 4	30
2. Quiz	Powerpoint 4	10
3. Tell the trainees: • What are the CBR Reviews?	Powerpoint 4	15
4. Quiz	Powerpoint 4	10
Total		65

Introduction to CBR for schizophrenia III - RB		
Reference: Chapter 9		
Competencies • Understands and is able to explain purpose and structure of CBR programme • Aware of procedures for ending intervention with family		
Steps	**Resources**	**Timing**
1. Tell the trainees: • What Community mobilisation work is involved? • Family Support Groups	Powerpoint 5	15
2. Quiz	Powerpoint 5	10
3. Tell the trainees • How do you deliver CBR? • How do you end CBR? • What if CBR is not wanted?	Powerpoint 5	20
4. Quiz	Powerpoint 5	5
Total		50

Overview of RISE trial - RB		
Reference:		
Competencies • Understands structure and purpose of RISE pilot and RISE trial		
Steps	**Resources**	**Timing**
1. Teach the following: • What is RISE • What is the RISE pilot? • What will the CBR workers do during the RISE pilot? • What is the RISE trial? • What will the CBR workers do during the RISE trial? • What are the important things for CBR workers to remember about the RISE trial?	Powerpoint 6	25
2. Quiz questions	Powerpoint 6	5
3. What have you learnt today? Anything surprising, shocking, interesting, useful?		15
Total		45

Week 1 Tuesday

Introduction to Mental illness		
Reference: Chapter 1		
Competencies • Has basic knowledge of mental disorders including depression, alcohol use disorder etc		
Steps	**Resources**	**Timing**
1. Teach the following: • What does the mind do?	Powerpoint 7	5
2. Ask the participants: • What is mental health? • What is mental illness? • What is disability? Write the answers on the flip chart	Flipchart	10
3. Teach the following, using the ideas from the group: • What is mental health? • What is mental illness? • What is disability?	Powerpoint 7	10
4. Ask the group: • Why do people get mental illness?	Flipchart	5
5. Teach the group: • Why do people get mental illness (using the group's ideas) • Can people with mental illness recover?	Powerpoint 7	10
6. Ask the group • What types of mental illness are there?	Flipchart	5
7. Teach the group: • What types of mental illness are there? • How can we recognise mental illness?	Powerpoint 7	20
8. In groups of the three the trainees should read the vignettes and decide which mental illness the person may have 9. Ask each group to feed back their decisions for one vignette	Handout 1	20
Total		85

Introduction to Schizophrenia I		
Reference: Chapter 2		
Competencies • Has good knowledge of schizophrenia (causes, course) and medical treatment		
Steps	**Resources**	**Timing**

1. Ask if the trainees have ever known anyone who might have had schizophrenia. Ask them to describe what problems they had and how they behaved. Write the answers on the flip chart.	Flip chart	20 min
2. Teach the following: • Symptoms of schizophrenia (using the examples from the group)	Powerpoint 8	15 min
3. Ask the trainees to read Yosef's story. Divide into groups of 3. One trainee should read the vignette. Each group should discuss what parts of the scenario show the different symptoms. 4. Ask for feedback on a different type of symptom from each group	Page xx Manual	20 min
5. Ask the trainees to individually think about how it would feel to have schizophrenia On their own each trainee should think about how it would feel to have schizophrenia, using the prompts 6. The trainees should get into pairs and discuss their own thoughts for 10 minutes	Handout 2	20 mins
7. Teach the following points: • How is schizophrenia diagnosed • How common is schizophrenia	Powerpoint 8	10 min
Total		85

Introduction to Schizophrenia II		
Reference: Chapter 2		
Competencies • Has good knowledge of schizophrenia (causes, course) and medical treatment		
Steps	**Resources**	**Timing**
1. Ask the trainees how long they think schizophrenia lasts and whether people can get better. Ask them to think about people they know with schizophrenia. Write their answers on the flip chart.	Flip chart	10 mins
2. Teach the following points: • How long does schizophrenia last • Recovery	Powerpoint 9	10
3. Ask the trainees to read Yosef's story. Divide into groups of 3. One trainee should read the vignette. Each group should discuss how long Yosef's illness is lasting 4. Ask for feedback on from each group.	Manual	20 mins
5. Ask the group what they think the causes of schizophrenia are. Write their suggestions on the flip chart	Flip chart	15 mins
6. Teach the following points: • What causes schizophrenia, using the stress vulnerability model. Try to incorporate the group's suggestions, where possible. • What different beliefs people have	Powerpoint 9	15 mins
7. Ask the trainees to read Yosef's story. Divide into groups of 3. One participant should read the vignette. Each group should discuss what might have caused Yosef's illness 8. Ask for feedback on from each group.	Manual	20 mins
Total		90

Medicines for Schizophrenia		
Reference: Chapter 3		
Competencies • Has good knowledge of schizophrenia (causes, course) and medical treatment		
Steps	**Resources**	**Timing**
1. Ask the trainees what they know about medication for schizophrenia, and how it can help. Write answers on the flip chart.	Flip chart	10 mins
2. Teach the following points: • What is anti-psychotic medication • Why it is important to take it • Names of medications	Powerpoint 10	30 mins

• Side effects		
3. Ask the trainees to read Yosef's story. Divide into groups of 3. One participant should read the vignette. Each group should discuss the good and bad things about taking medication. 4. Ask for feedback on from each group.	Manual	20 mins
5. Quiz	Powerpoint 10	10
6. What have they learnt today? Anything surprising, shocking, useful or interesting?		15
Total		85

Week 1 Wednesday

Disabilities related to schizophrenia		
Reference: Chapter 4		
Competencies • Understands the impact of schizophrenia in terms of disability,stigma,human rights and family burden		
Steps	**Resources**	**Timing**
1. Tell the group what disability means	Powerpoint 11	5 mins
2. Ask the trainees what types of disabilities might be related to schizophrenia. Write their answers on the flip chart.	Flip chart	15 mins
3. Teach the following points: • What types of disabilities people with schizophrenia have. Use the examples the group gave. • What causes disabilities	Powerpoint 11	15 mins
4. Ask the trainees to read Yosef's story. Divide into groups of 3. One participant should read the vignette. Each group should discuss what disabilities Yosef has and what might have caused them. 5. Ask for feedback on from each group.	Manual	25 mins
6. Teach the following points: • Remind what rehabilitation and recovery is	Powerpoint 11	5 mins
7. Ask the group what recovery might mean to Yosef	Flip chart	10
8. Quiz	Powerpoint 11	5
Total		80

Family impact of schizophrenia		
Reference: Chapter 5		
Competencies • Understands the impact of schizophrenia in terms of disability,stigma,human rights and family burden		
Steps	**Resources**	**Timing**
1. Ask the trainees what impact schizophrenia might have on the family. Write their answers on the flip chart.	Flip chart	20 mins
2. Teach the following points: • Impact of schizophrenia on the family. Use the group's examples	Powerpoint 12	20 mins
3. Ask the trainees to read Yosef's story in 3s. One participant should read the vignette. Each group should discuss the impact on Yosef's family and how this might impact on his recovery. 4. Ask for feedback on from each group.	Manual	20 mins
Total		60

Stigma related to schizophrenia		
Reference: Chapter 6		
Competencies • Understands the impact of schizophrenia in terms of disability,stigma,human rights and family burden		
Steps	**Resources**	**Timing**
1. Tell the group what stigma means	Powerpoint 13	10 mins
2. Ask the trainees what experiences of stigma people with schizophrenia might have. Write their answers on the flip chart.	Flip chart	20 mins
3. Teach the following point: • What experiences of stigma people with schizophrenia have. Use the examples the group gave.	Powerpoint 13	10 mins
4. Ask the trainees to read Yosef's story. Divide into groups of 3. One participant should read the vignette. Each group should discuss what experiences of stigma Yosef has, how this might make him feel and how this might impact on his recovery. 5. Ask for feedback from each group.	Manual	20 mins
6. Ask the trainees to think about their own attitudes towards people with schizophrenia, and whether this has changed.		10 mins
7. Ask the group to think about how they can act in their every day lives which will help to reduce stigma. Write the answers on the flip chart. E.g. Greet the individual as you would anyone else	Flip chart	10 mins
Total		80

Human rights issues related to schizophrenia		
Reference: Chapter 7		
Competencies • Understands the impact of schizophrenia in terms of disability,stigma,human rights and family burden		
Steps	**Resources**	**Timing**
1. Tell the group what human rights are	Powerpoint 14	10 mins
2. Ask the trainees what experiences of human rights abuses people with schizophrenia might have. Write their answers on the flip chart.	Flip chart	15 mins
3. Teach the following points: • What experiences of human rights abuses people with schizophrenia have. Use the examples the group gave.	PowerPoint 14	10 mins
4. Ask the trainees to read Yosef's story. Divide into groups of 3. One participant should read the vignette. Each group should discuss what experiences of human rights abuses Yosef has and how this might impact on his recovery. 5. Ask for feedback on from each group.	Manual	25 mins

6. Quiz	Powerpoint 14	5
Total		75

Importance of the community		
Reference: Chapter 8		
Competencies • Understands the impact of schizophrenia in terms of disability, stigma, human rights and family burden • Understands and is able to explain purpose and structure of CBR programme		
Steps	**Resources**	**Timing**
1. Tell the group • What is a community?	Powerpoint 15	5 mins
2. Ask the group what resources there are in their communities	Flip chart	5
3. Tell the group what resources can be found in communities	Powerpoint 15	5
4. Ask the group what the positive and negative influences of the community might be on a person with schizophrenia	Flip chart	10
5. Tell the group about positive and negative influences	Powerpoint 15	10
6. What have they learnt today?		15
Total		50

Week 1 Thursday

Initial visit		
Reference: Chapter 9		
Competencies • Understands and is able to explain purpose and structure of CBR programme		
Steps	**Resources**	**Timing**
1. Tell the trainees: • How to arrange the first visit • the key issues to cover and information to gather on the initial visit • How to record the initial visits • Confidentiality	Powerpoint 16	15 mins
2. Read Yosef's story and look at his Initial Visit Form in groups of 3. Ask for any comments.	Manual and Handout 3	10
3. Ask the trainees to get into pairs to do a role play of the initial visit. *One trainee should pretend to be the caregiver and one trainee should pretend to be the CBR worker. It is the first time the CBR worker has met the caregiver. Trainees should do the role play twice, taking it in turns to be the CBR worker.* 4. After each role play the person playing the caregiver should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 4	30
5. Ask each pair to make one comment about this to the rest of the group. For example, it was difficult to explain the purpose of CBR		5
Total		60

Communication skills		
Reference: Chapter 10		
Competencies • Has good listening skills • Is able to explain concepts clearly, check for understanding etc		
Steps	**Resources**	**Timing**
1. Tell the group why it is important to have good communication skills and a trusting relationship with the individual and family	Powerpoint 17	5
2. Ask the group to get into pairs to do a role play.	Handout 5	15

3. Ask the group how they knew they were being listened to, and how they felt when they weren't being listened to		
4. Tell the group • How to have good communication skills	Powerpoint 17	20
5. Watch the video of bad communication skills 6. Discuss what the CBR worker did wrong		15
7. Watch the video of good communication skills 8. Discuss what the CBR worker did well		15
9. Ask the group to get into pairs to do a role play. *One trainee should pretend to be the caregiver or person with schizophrenia and one trainee should pretend to be the CBR worker. The trainees should take it in turns to be the CBR worker.* 10. After each role play the person playing the caregiver should feedback to the person playing the CBR worker: communication skills they used, any good things they did, any thing they did less well, something they can improve on for next time.	Handout 6	30
11. Ask each pair to make one comment about this role play to the rest of the group.		10
Total		110

Problem solving and building a trusting relationship		
Reference: Chapter 10 and 11		
Competencies • Able to build trusting relationship with person with schizophrenia and their family • Able to transfer skills to caregivers in order for family to continue CBR after end of programme • Can employ a problem solving approach		
Steps	**Resources**	**Timing**
1. Explain what problem solving is and the steps involved	Powerpoint 18	15
2. In threes the trainees should do a role play. One trainee should pretend to be the caregiver, one trainee the person with schizophrenia and one trainee should pretend to be the CBR worker. ***The problem is the person with schizophrenia no longer goes to market to sell vegetables.*** After the role play the trainees playing the caregiver and person with schizophrenia should feedback to the person playing the CBR worker: communication skills they used, any good things they did, any thing they did less well, something they can improve on for next time.	Handout 7	25
3. Ask each group to make one comment about this exercise to the rest of the group.		10
4. Tell the group: • What a trusting relationship is • Why it is important to have a trusting relationship	Powerpoint 18	5
5. Ask the group for ideas on how to build a trusting relationship	Flip chart	5
6. Give your own suggestions for building a good relationship- using the group's suggestions where possible	Powerpoint 18	10
7. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		85

Needs assessment		
Reference: Chapter 12		
Competencies • Able to conduct a needs assessment for people with schizophrenia and caregivers in conjunction with supervisor		
Steps	**Resources**	**Timing**
1. Tell the trainees: • What a needs assessment is	PowerPoint 19	20 mins

• Why we do the needs assessment • When we do the needs assessments • Who is involved • How to do the needs assessment		
2. Ask the trainees: • For suggestions for how to ask about each need • Use the form to guide the discussion	Needs assessment form	15
3. Tell the trainees: • How to record the needs assessment	PowerPoint 19	5
4. Read Yosef's story and look at the Needs Assessment form in groups of 3. 5. Each group should feedback one comment on: • the most important needs for Yosef, • the most important needs for Addis, • areas which are not a problem for Yosef.	Handout 8	20
6. Tell the trainees: • Tips for the needs assessment	PowerPoint 19	5
7. In groups of three, ask the participants to read the vignettes. They should discuss together and write down which needs these statements relate to and whether these needs are met, unmet or partially met. 8. Ask each group to feed back their decisions for one vignette	Handout 9	20
9. Tell the trainees: • How to be aware of the caregivers needs	Powerpoint 19	10
Total		95

Week 1 Friday

Goal Setting I		
Reference: Chapter 13		
Competencies • Able to develop a rehabilitation plan in conjunction with supervisor • Able to assess achievement of goals on an ongoing basis		
Steps	**Resources**	**Timing**
1. Tell the group: • what goal setting is • why we do goal setting • When we do goal setting • Who is involved	PowerPoint 20	20 mins
2. Tell the group: • How to do goal setting in Phase I • How to record goal setting in Phase I • Go through the sections on the Phase 1 goal setting form	PowerPoint 20 and Phase I goal setting form	10
3. Read Yosef's story and look at the Phase I goal setting form in groups of 3. Ask theme to discuss –Which goals are prioritised –How the goals relate to information on Yosef's Initial Assessment Form 4. Ask for one comment from each group.	Handout 10	20
5. Tell the group: • How to do goal setting in Phase II and III • How to record goal setting in Phase II and III • Go through the sections on the Phase II/III goal setting form	Powerpoint 20 /Phase II/III GS form	15
6. Read Yosef's story and look at the Phase II goal setting form in groups of 3. Ask them to discuss: –Which goals are prioritised	Handout 11	20

–How the goals relate to the information on Yosef's Phase II Needs Assessment Form 7. Ask for one comment from each group.		
Total		85

Goal Setting II		
Reference: Chapter 13		
Competencies • Able to develop a rehabilitation plan in conjunction with supervisor • Able to assess achievement of goals on an ongoing basis		
Steps	**Resources**	**Timing**
1. Tell the trainees: • How we use the information from goal setting to decide which modules to do • How do we know if a goal is achieved • Introduce the Home Visit form	Powerpoint 21 and Home Visit Form	25
2. Read Yosef's story and look at the Home Visit form in groups of 3. Ask them to look at which goals have been achieved or not 3. Ask for any comments.	Handout 12	15
4. Tell the trainees: • Tips for goal setting • Moving to the next phase	Powerpoint 21	10
5. In groups of three, ask the participants to read the vignettes. They should discuss together and write down which goals are achieved, not achieved, or partially achieved and any comments they should record. 6. Ask each group to feed back their decisions for one vignette	Handout 13	25
7. Quiz	Powerpoint 21	5
8. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		95

Week 2 Monday

Introduction to RAPID Adama	**Resources**	**Timing**
		30

Needs assessment and Goal Setting Practice
Reference: Chapter 12 and 13
Competencies • Able to conduct a needs assessment for people with schizophrenia and caregivers in conjunction with supervisor • Able to develop a rehabilitation plan in conjunction with supervisor • Able to assess achievement of goals on an ongoing basis
• Trainees should accompany CBR workers on home visit/s. • If possible, the trainee should ask the parents what the current needs and goals are • The trainee should observe the visit and discuss the following points with the CBR worker: o How they conduct the visit; their behaviour with the family; the skills they use o The specific needs of the individuals and families they have visited. o What goals the individual is working towards o Using the previous needs assessment and rehabilitation plan they should discuss how needs and goals have changed over time • The trainee should write notes so they can remember and discuss what they found the following day.

Week 2 Tuesday

Needs assessment and Goal Setting Discussion		
Reference: Chapter 12 and 13		
Competencies • Able to conduct a needs assessment for people with schizophrenia and caregivers in conjunction with supervisor • Able to develop a rehabilitation plan in conjunction with supervisor • Able to assess achievement of goals on an ongoing basis		
Steps	**Resources**	**Timing**
Ask six trainees in turn to share with the group their experience in the field. Use the following prompts: • Describe the individual or family they visited e.g. What needs do they have; What goals are they working towards; How have needs and goals changed over time • Skills for working with famillies • What have they learnt • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss together	Flip chart	120

Improving Day to Day Functioning		
Reference: Chapter 24		
Competencies • Able to develop plan to enable improved self-care and improve participation in household tasks		
Steps	**Resources**	**Timing**
1. Ask the group what problems people with schizophrenia have with day to day functioning. Write the answers on the flip chart.	Flip chart	10
2. Tell the group about: • Common problems with day to day functioning, using the group's examples • Why people with schizophrenia have problems with day to day functioning • why it is important to improve problems with day to day functioning	PowerPoint 22	15
3. Describe the steps to improve problems with day to day functioning • Principles • Explain why you are doing this module • Ask for problems with self care • Give advice on how to improve self care	PowerPoint 22	15
4. In threes, one trainee should pretend to be the caregiver, one trainee the person with schizophrenia and one trainee should pretend to be the CBR worker. Take it in turns to take each role. *The CBR worker should try to explain one of the following tasks, including why it is important to do the task* • Cleaning teeth • Washing • Healthy eating *Before you start, look in the manual (pg xx) for some ideas.* After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 14	25
5. Ask each group to make one comment about the role play e.g. what they find difficult.		10
6. Describe the following steps to improve problems with daily functioning: • Ask about problems with household tasks	PowerPoint 22	15

• Give advice on improving household tasks • Encouragement and positive feedback • Creating a daily routine • Advice on managing money • Making a plan and Follow up		
Total		90

Improving Physical Health		
Reference: Chapter 21		
Competencies • Able to give advice to improve healthy behaviours • Able to assess reasons for poor physical health and use problems solving to address this		
Steps	**Resources**	**Timing**
1. Ask the group what problems people with schizophrenia have with physical health. Write the answers on the flip chart.	Flip chart	10
2. Tell the group about: • Common problems with physical health, using the group's examples • Why people with schizophrenia have problems with physical health • why it is important to improve physical health problems	PowerPoint 23	15
3. Describe the steps to improve problems with physical health • Explain why you are doing this module • Ask for problems with physical health • Problem solving to improve physical health	PowerPoint 23	5
4. Quiz (steps in problem solving)	Powerpoint 23	5
5. Possible solutions to problems	Powerpoint 23	15
6. In groups of three the trainees should discuss how they could solve the problem vignettes. *Suggest as many ways as you can think of to deal with the following problems. Decide which are not good suggestions and which are good suggestions. Select the best one.* 1. Betty is married and doesn't want more children but is not currently using contraception 2. Daniel sometimes chews khat with friends. 3. Henok drinks alcohol every day. He often smells of alcohol and sometimes vomits. 4. Solomon often gets a bad cough but hasn't been to the health centre even though it is getting worse. 5. Tigist looks very thin and underweight	Handout 15	20
7. Ask each group to feedback their suggestions for problem solving		10
8. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		95

<u>Week 2 Wednesday</u>

Improving Daily Functioning and Improving Physical Health Practice
Reference: Chapter 21 and 24
Competencies • Able to develop plan to enable improved self-care and improve participation in household tasks • Able to give advice to improve healthy behaviours • Able to assess reasons for poor physical health and use problems solving to address this
• Trainees should accompany CBR workers on home visit/s. If possible the trainees should visit clients who have had problems with daily functioning and/ or physical health (distinct from their disability) • If possible, the trainee should practice one or more of the following tasks: o Ask the parents what the problems with daily functioning are o Explain why it is important to improve daily functioning

- Give advice on how to do a specific daily functioning task e.g. cleaning teeth
- Ask the parents what the problems with physical health are
- Explain why it is important to improve physical health
- Discuss or do problem solving on how to improve physical health

- The trainee should discuss the following points with the CBR worker:
  - The specific needs of the individuals and families they have visited.
  - What goals the individual is working towards
  - How needs and goals have changed over time
- The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Week 2 Thursday

Improving daily functioning and physical health discussion		
Reference: Chapter 21 and 24		
Competencies • Able to develop plan to enable improved self-care and improve participation in household tasks • Able to give advice to improve healthy behaviours • Able to assess reasons for poor physical health and use problems solving to address this		
Steps	**Resources**	**Timing**
Ask six trainees in turn to share with the group their experience in the field. Use the following prompts: • Describe the individual or family they visited e.g. What problems with daily functioning or physical health do they have; Experience of explaining daily functioning tasks; Experience of discussing or problem solving about physical health problems; How have needs and goals changed over time • What have they learnt; how can they use the information in their own work • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss amongst themselves	Flip chart	120

Family Support Groups		
Reference: Chapter 32		
Competencies • Able to organise and facilitate support groups or befriending arrangements		
Steps	**Resources**	**Timing**
1. Tell the group what family support groups are	PowerPoint 24	5
2. Ask the group why family support groups might be important. Write the answers on the flip chart.	Flip chart	10
3. Tell the group about: • Why family support groups are important, using the trainees' ideas • How we set up family support groups • How we organise family support groups	PowerPoint 24	20
4. Ask the trainees to think about topics which might be useful to discuss		10
5. Tell the group: • Some ideas for topics	PowerPoint 24	5
6. Ask each group to think about who should lead the group and the pros and cons of each type of leader		5
7. Give ideas to the group about who should lead the group	PowerPoint 24	5
8. Ask the group to decide the basic ground rules	Flip chart	10
9. Tell the group	PowerPoint 24	10

• Some suggestions for ground rules • How we make sure the groups continue after the CBR worker has left		
Total		80

Dealing with stress and anger		
Reference: Chapter 23		
Competencies • Able to give advice for dealing with stress and anger		
Steps	**Resources**	**Timing**
1. Tell the group about: • What problems people with schizophrenia have with stress and anger • Why people with schizophrenia have problems with stress and anger	PowerPoint 25	10
2. Ask the group: • Why is it important to prevent stress and anger?	Flip chart	5
3. Tell the group: • Why is it important to prevent stress and anger?	Powerpoint 25	5
4. Ask the group for suggestions of how to deal with stress. Divide their suggestions into ways to prevent and ways to deal with it when it happens	Flip chart and pen	10
5. Describe the steps to deal with stress and anger: • Principles • Explain why you are doing this module • Assess problems with stress • Discuss stressful triggers • Discuss ways to prevent stress • Discuss ways to deal with stress	Powerpoint 25	20
6. Lead the group through the relaxation techniques		15
7. Ask the group to comment about the relaxation techniques e.g. what they find difficult. Do they think this will be easy or difficult to do with people with schizophrenia and caregivers?		5
8. Ask the group for suggestions of how to deal with anger. Divide the group into ways to prevent it and ways to deal with it when it happens.	Flip chart	10
9. Continue describing the steps to deal with stress and anger: • Discuss problems with anger • Discuss ways to prevent anger • Discuss ways to deal with anger when it happens	Powerpoint 25	10
10. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		95

Week 2 Friday

Family Support Groups Practice
Reference: Chapter 32
Competencies
• Trainees should accompany CBR workers to a parents group meeting. • They should observe the group and discuss some of the following points with the CBR worker, and group members o When the group started o Who the members are and how the members were recruited o Who leads the groups o Practical arrangements e.g. time and place, tea/coffee o What record is made of the discussions

- Aim of the group
- What topics are discussed
- Other activities of the group e.g. Is there any practical support given between group members, loans
- Who has dropped out and why
- Benefits the group members have seen
- Challenges facing the group
- Whether the group will carry on once the CBR worker has left the area

• The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Week 2 Saturday

Family support group discussion		
Reference: Chapter 32		
Competencies • Able to organise and facilitate support groups or befriending arrangements		
Steps	**Resources**	**Timing**
Ask six trainee in turn to share with the group their experience in the field. Use the following prompts: • Describe the parents group they visited; Topics discussed • Benefits and challenges of the group • How have needs and goals changed over time • What have they learnt; how they can use the information in their own work • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss amongst themselves	Flip chart	120

Community mobilisation work I		
Reference: Chapter 31		
Competencies • Able to form good relationships with community leaders and HEWs • Able to engage with community leaders to facilitate CBR • Able to maximise sustainability of programme through community involvement		
Steps	**Resources**	**Timing**
1. Remind the group of the role of the community in CBR	Powerpoint 26	5
2. Tell the group about Community Mobilisation Tasks 1 to 5	Powerpoint 26	25
3. In pairs the trainees will do a role play. They should take it in turns to be the community leader and CBR worker. They should imagine it is the first meeting the CBR worker has had in the community. <u>Scenario 1</u> *CBR worker should cover the following steps from Task 5:* o Purpose of CBR programme o Accreditation of CBR programme o Give outline of CBR activities *Community leader should raise the following points:* • The community members can support the individual well without the help of CBR. • I don't believe this medication works. The most important thing is to use holy water. <u>Scenario 2</u> *CBR worker should cover the following steps from Task 5:* o Give outline of community mobilisation activities o Give outline of how you want the community leaders to be involved o Give outline of how you want general community members to	Handout 16	30

be involved *Community leader should raise the following points:* • We community leaders are very busy and we don't have much time to be involved in some extra CBR work • The community members only believe in spirit possession, they are not interested in medical explanations for mental illness. 4. At the end the community leader should feedback things the CBR worker did well, and things that can be improved.		
5. Ask each pair to feedback one comment to the rest of the group e.g. something they found difficult about giving the explanation		10
Total		70

Community mobilisation work II		
Reference: Chapter 31		
Competencies • Able to conduct community awareness raising • Able to engage with community leaders to facilitate CBR • Able to maximise sustainability of programme through community involvement		
Steps	**Resources**	**Timing**
1. Tell the Group about community mobilisation tasks 6 and 7	Powerpoint 27	15
2. Ask the group to think about any challenges they might face in arranging or delivering the community awareness raising tasks, and how they might overcome them.	Flip chart and pen	10
3. Tell the group about Community mobilisation Tasks 8- 15	Powerpoint 27	15
4. In pairs the trainees will do a role play. They should take it in turns to be the community leader and CBR worker. <u>Scenario 1</u> *CBR worker should cover the following points:* • Person with schizophrenia finds it difficult to participate in Edir, they need some support to do this *Edir leader should cover the following points:* • Is it the business of the Edir group to get involved? • The person with schizophrenia may be disruptive and cannot be trusted to contribute regularly <u>Scenario 2</u> *CBR worker should cover the following points:* • Person with schizophrenia finds it difficult to continue taking medication whilst staying at holy water *Holy water priest should cover the following points:* • Medication may interrupt the way holy water works 5. At the end the community leader should feedback things the CBR worker did well, and things that can be improved.	Handout 17	25
6. Ask each pair to feedback one comment to the rest of the group e.g. something they found difficult		5
7. Tell the group about: • How you record and monitor community mobilisation work	Powerpoint 27 Kebele logbook	5
8. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		**100**

<u>Week 2 Sunday</u>

Taking part in community life
Reference: Chapter 26
Competencies • Able to assess reasons for reduced participation in community life and apply problem solving approach to address this

Steps	Resources	Timing
1. Ask the group what problems people with schizophrenia have with taking part in community life. Write the answers on the flip chart.	Flip chart and pen	10
2. Tell the group about: • Common problems with taking part in community life, using the group's examples • Why people with schizophrenia have problems with taking part in community life • why it is important to improve problems with taking part in community life	PowerPoint 28	10
3. Describe the steps to improve problems taking part in community life • Principles • Explain why you are doing this module • Ask for problems with taking part in community life • Agree what community activities the individual wants to do • Discuss barriers and do problem solving to decide how to overcome problems	PowerPoint 28	15
4. In threes, one trainee should pretend to be the caregiver, one trainee the person with schizophrenia and one trainee should pretend to be the CBR worker. Take it in turns to take each role. *The CBR worker should work with the person with schizophrenia to practice the following social skills:* • Greeting others • Asking for information • Expressing an opinion 5. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 18	25
6. Ask each group to make one comment about the role play e.g. what they find difficult.		10
7. In groups of three the trainees should discuss how they could solve the problem vignettes. *Suggest as many ways as you can think of to deal with the following problems. Decide which are not good suggestions and which are good suggestions. Select the best one* 1. Betty used to go to market but doesn't anymore. She says she is too tired to go. 2. Daniel used to vote at the kebele meetings but doesn't any more. Last time he went people ignored him. 3. Henok doesn't go to weddings or funerals because his parents are worried he will shout at people and be embarrassing. 4. Solomon used to contribute to Edir by making payments by himself and helping with the tasks at funerals e.g. erecting the tent. His family say he shouldn't do this now he is ill. 5. Tigist used to go to church but now she doesn't go. She doesn't have any friends in the kebele now and she is worried she will have trouble talking to people.	Handout 19	15
9. Ask each group to feedback their suggestions for solving the problems.		10
Total		100

Getting back to work		
Reference: Chapter 27		
Competencies • Able to assess reasons for reduced participation in vocational activities and apply problem solving approach to address this		
Steps	**Resources**	**Timing**

1. Tell the group • what problems people with schizophrenia have with getting back to work. Write the answers on the flip chart.	Powerpoint 29	5
2. Ask the group: • Why people with schizophrenia have problems getting back to work • why it is important to get back to work	Flip chart	10
3. Tell the group about: • Why people with schizophrenia have problems getting back to work • why it is important to get back to work	Powerpoint 29	10
4. Describe the steps to improve problems with getting back to work • Principles • Explain why you are doing this module • Ask for problems with getting back to work • Agree what work the individual wants to do • Consider what preparation is needed • Try specific work tasks • Discuss barriers and do problem solving to decide how to overcome problems	Powerpoint 29	20
5. In groups of three do a role play together. *One trainee should pretend to be the caregiver, one trainee the person with schizophrenia and one trainee should pretend to be the CBR worker. Take it in turns to take each role.* *The person with schizophrenia wants to get back to one of the following work tasks:* • Looking after animals • Trading at market • Farming crops *The CBR worker should follow the steps to support them to do this:* • *Consider what preparation is needed* • *Try specific tasks: agree a specific tasks and break it down into steps* • *Discuss how the family will support the individual to do the task* • *Discuss how community leaders can be support the individual* 6. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 20	25
7. Ask each group to make one comment about the role play e.g. what they find difficult.		10
8. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		10 mins
Total		90

Week 3 Monday

Community mobilisation Practice
Reference: Chapter 31
Competencies • Able to form good relationships with community leaders and HEWs • Able to conduct community awareness raising • Able to engage with community leaders to facilitate CBR • Able to maximise sustainability of programme through community involvement
• Trainees should accompany CBR workers to a community mobilisation activity e.g. community awareness raising, meeting with community leader/head teacher • They should observe the activity and discuss some of the following points with the CBR worker

- Previous meetings, awareness raising activities
- Skills needed to work with community leaders
- Skills needed to give information to the community
- Topic discussed
- Challenges of working with community leaders or wider community
- Benefits of community mobilisation work
- How/ whether community mobilisation work helps CBR to continue after the CBR workers have left

- The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Week 3 Tuesday

Community mobilisation discussion		
Reference: Chapter 31		
Competencies • Able to form good relationships with community leaders and HEWs • Able to conduct community awareness raising • Able to engage with community leaders to facilitate CBR • Able to maximise sustainability of programme through community involvement		
Steps	**Resources**	**Timing**
Ask each trainee in turn to share with the group their experience in the field. Use the following prompts: • Describe the community mobilisation activity they observed • Topics discussed • Benefits and challenges of the work • Skills needed for the work • What have they learnt; how can they use the information in their own work • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss amongst themselves	Flip chart	120

Week 3 Wednesday
Assessment

Week 3 Thursday

Understanding schizophrenia		
Reference: Chapter 16		
Competencies • Able to give information on schizophrenia		
Steps	**Resources**	**Timing**
1. Ask the group what misunderstandings people with schizophrenia and their families might have about schizophrenia. Write the answers on the flip chart.	Flip chart and pen	10
2. Tell the group about: • Common problems with understanding about schizophrenia, using the group's examples • Why people with schizophrenia have problems with understanding schizophrenia • why it is important to improve understanding	Powerpoint 30	15
3. Describe the steps to give information about schizophrenia • Principles • Explain why you are doing this module • Give information about symptoms, causes, course, how common, medication and stress vulnerability	Powerpoint 30	20

4. In pairs do a role play together. *One trainee should pretend to be the caregiver or person with schizophrenia and one trainee should pretend to be the CBR worker. Each trainee should play the CBR worker for 2 scenarios. The person playing the CBR worker should try to respond to the questions and comments of the other trainee.* **Scenario 1** CBR worker should: explain the symptoms of schizophrenia Person with schizophrenia should say: This doesn't apply to me, I've never had the feeling that..[add whatever examples the CBR worker has given e.g. that someone will poison my food or is chasing me.] **Scenario 2** CBR worker should explain: how long it lasts and that relapses are common, but recovery is possible. Person with schizophrenia should say: I don't think I will ever improve, things have been bad for a long time **Scenario 3** CBR worker should explain: causes of schizophrenia, including stress vulnerability ideas. Caregiver should say: Does this mean if my son has children they will also catch schizophrenia? What about my other grandchildren- will they get it? **Scenario 4** CBR should explain: the importance taking medication Caregiver should say: I agree he needs to take it when he's well but it doesn't make sense to carry on when he's better-he has side effects 5. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 21	30
6. Ask each group to make one comment about the role play e.g. what they find difficult.		10
Total		85

Preparing for a crisis		
Reference: Chapter 18		
Competencies • Able to give information on how to deal with a crisis and support development of crisis management plan		
Steps	**Resources**	**Timing**
1. Ask the group what types of crisis people with schizophrenia might have. Write the answers on the flip chart.	Flip chart and pen	10
2. Tell the group about: • Common crises amongst people with schizophrenia, using the group's examples • Why people with schizophrenia have crises • why it is important to prepare for a crisis	Powerpoint 31	15
3. Describe the steps to prepare for a crisis • Discuss what crises are likely • Explain why you are doing this module • Decide who to ask for help • Make a crisis plan	Powerpoint 31	20
4. In pairs look Yosef's story and crisis management plan together. Discuss why each part of the plan is there, and anything you would change	Yosef's story	15
5. Ask the group • what are helpful ways to treat the individual during a crisis • What are unhelpful things to do	Flip chart	10
6. Teach the group:	Powerpoint 31	10

• what are helpful ways to treat the individual during a crisis • What are unhelpful things to do		
7. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		95

Risk assessment		
Reference: Chapter 14		
Competencies • Able to conduct a risk assessment • Able to sensitively address the issue of chaining and physical abuse and take appropriate steps to address this		
Steps	**Resources**	**Timing**
1. Tell the group: • What kind of groups people with schizophrenia face • Why it is important to deal with risks • How to assess for risks	Powerpoint 32	30
2. In pairs the trainees will do a role play. They should take it in turns to be the person with schizophrenia and CBR worker. <u>Scenario 1</u> *CBR worker should cover the following points:* • Ask questions to assess suicide risk • Respond to anything the person with schizophrenia says Person with schizophrenia should cover the following points: • *Your family would have less stress without you there. You feel that you are better off dead.* • *When asked, say you have thought about swallowing pesticides* <u>Scenario 2</u> *CBR worker should cover the following points:* • Ask questions to assess suicide risk • Respond to anything the person with schizophrenia says Person with schizophrenia should cover the following points: • *In the past you have felt very bad and not wanted to carry on. Now you feel things are improving.* • *When asked, say you haven't made any plans to commit suicide* 3. At the end the person with schizophrenia should feedback things the CBR worker did well, and things that can be improved.	Handout 22	20
4. For each scenario discuss: • whether the individual is at risk of committing suicide • What was easy and what was difficult		10
5. Tell the group: • How we respond when we find there are risks	Powerpoint 32	20
6. Quiz	Powerpoint 32	10
Total		90

Dealing with human rights problems		
Reference: Chapter 19		
Competencies • Able to sensitively address the issue of chaining and physical abuse and take appropriate steps to address this		
Steps	**Resources**	**Timing**
1. Ask the group: • what human rights are • what types of human rights issues people with schizophrenia might have (revision). Write the answers on the flip chart.	Flip chart	10

2. Tell the group about: • Common human rights problems amongst people with schizophrenia, using the group's examples • Why people with schizophrenia experience human rights problems • why it is important to deal with human rights problems	Powerpoint 33	15
3. Describe the steps to improve human rights problems: • Explain why you are doing this module • Assess human rights • Educate the family about chaining and physical abuse • Use problem solving to address human rights problems	Powerpoint 33	15
4. In pairs do a role play together. *One trainee should pretend to be the caregiver or community leader and one trainee should pretend to be the CBR worker. Each trainee should play the CBR worker for 1 scenario. The person playing the CBR worker should try to respond to the questions and comments of the other trainee.* **Scenario 1** **CBR worker:** The person with schizophrenia is currently well and not chained. You know the family has chained up the individual in the past when they have become unwell. Explain to the caregiver why it is important to avoid chaining if possible. **Caregiver should say:** We are scared he will run away and get killed if we don't chain him when he is unwell. Someone will beat him up, or the hyenas will get him because he will sleep outside. **Scenario 2** **CBR worker:** You are giving information to the priest about chaining. Explain why it is important to avoid chaining if possible. **Priest should say**: He must be chained up to protect other people in the kebele and their property. People with schizophrenia are known to kill people and set fire to houses. If someone had a dangerous dog, it would be the owner's duty to keep it tied up. 5. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 23	20
6. Ask each group to make one comment about the role play e.g. what they find difficult.		10
7. Tell the group: • The steps to take if someone is chained at home (flow chart)	Powerpoint 33	5
8. Ask the group • what are ways to reduce the harm from chaining	Flip chart	5
9. Teach the group: • what are ways to reduce the harm from chaining	Powerpoint 33	5
10. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		100

Week 3 Friday

Understanding schizophrenia and dealing with a crisis practice
Reference: Chapter 16 and 18
Competencies • Able to give information on schizophrenia • Able to give information on how to deal with a crisis and support development of crisis management plan
• Trainees should sit in the outpatient clinic or accompany on home visits with a data collector or psychiatric nurse • They should observe the activity and practice some of the following tasks with the individual or

caregiver:

- Explain why it is useful to have more information about schizophrenia
- Explain one or more of the following: symptoms of schizophrenia, causes, how common it is, how it is diagnosed, the course and relapses, chance of recovery, the stress vulnerability model, medication
- Ask what kinds of crises individuals have faced in the past or what might happened in the future
- Create a crisis management plan
- Discuss some of the following points with the psychiatric nurse or data collector
  - The level of understanding about schizophrenia and how this has changed over time
  - Types of crises they have faced in the past and how they dealt with it
  - The skills the psychiatric nurse or data collector uses when talking to people with schizophrenia and caregivers
  - Challenges of providing information or preparing for crises
- The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Risk assessment and dealing with human rights issues practice
Reference: Chapter 14 and 19
Competencies • Able to conduct a risk assessment • Able to sensitively address the issue of chaining and physical abuse and take appropriate steps to address this

• Trainees should sit in the outpatient clinic or accompany on home visits with a data collector or psychiatric nurse
• They should observe the activity and practice some of the following tasks:
• Explain what human rights are and why it is important to protect them
• Assess what human rights issues an individual faces
• Explain why it is important to avoiding chaining
• Describe what to do if an individual is chained, to reduce harm
• Ask whether it would be helpful to discuss with traditional healer/ holy water priest or attendant or other community leader to reduce chaining
• Discuss some of the following points with the psychiatric nurse or data collector
  ○ Risks and human rights issues faced by the indivdiual how this has changed over time
  ○ The skills the psychiatric nurse or data collector uses when talking to people with schizophrenia and caregivers
  ○ Challenges of dealing with chaining, risks and human rights
• The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Week 4 Monday

Understanding schizophrenia and dealing with a crisis discussion		
Reference: Chapter 16 and 18		
Competencies • Able to give information on schizophrenia • Able to give information on how to deal with a crisis and development of crisis management plan		
Steps	**Resources**	**Timing**
Ask six trainees in turn to share with the group their experience in the field. Use the following prompts: • Describe the individual or family they visited e.g. What problems with understanding schizophrenia or crises do they have; How have needs and goals changed over time • Experience of explaining importance of understanding schizophrenia or preparing for a crisis; Experience of preparing a crisis management plan • What have they learnt; how can they use the information in their work • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising	Flip chart	120

Encourage the group to ask each other questions and discuss amongst themselves		

Risk assessment and dealing with human rights issues discussion		
Reference: Chapter 14 and 19		
Competencies • Able to conduct a risk assessment • Able to sensitively address the issue of chaining and physical abuse and take appropriate steps to address this		
Steps	**Resources**	**Timing**
Ask six trainees in turn to share with the group their experience in the field. Use the following prompts: • Describe the individual or family they visited e.g. What risks or human rights issues they face; How have needs and goals changed over time • Experience of explaining importance of dealing with human rights issues; explaining how to reduce harm from chaining; • What have they learnt; how can they use the information in their own work • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss amongst themselves	Flip chart	120

Improving access to health services		
Reference: Chapter 17		
Competencies • Aware of health services available for people with mental illness • Able to assess reasons for not accessing medication or attending health centre and apply problem solving approach to address this		
Steps	**Resources**	**Timing**
1. Tell the group: • what health services are available	Powerpoint 34	5
2. Ask the group: • Why do people with schizophrenia have problems accessing health services	Flip chart	10
3. Tell the group about: • Why people with schizophrenia have problems accessing health services • Why it is important to access health services	Powerpoint 34	10
4. Describe the steps to improve access to health services: • Inform the family what health services are available • Explain why you are doing this module • Assess problems accessing health services • Use problem solving to address problems accessing health services • Discuss delivering medication to the individual's home • Monitor whether the individual attends the health centre	Powerpoint 34	25
5. In groups of three the trainees should discuss how they could solve the problem vignettes. *Suggest as many ways as you can think of to deal with the following problems. Decide which are not good suggestions and which are good suggestions. Select the best one* 1. It takes 2 hours for Betty to walk to the health centre. Her sister sometimes doesn't have time to go with her. 2. Last time Daniel went to the health centre they had run out of his medication. They told him to come back in 2 weeks time. 3. Henok's family are going bankrupt. They spend all their money	Handout 24	25

on the medication for Henok. Also Henok isn't working so they have even less money than before. Henok's father suggests they stop wasting money on the medication because he is better now. 4. Solomon's family have chained him to the side of the house as he is very unwell. This means it is difficult to take him to the health centre. 5. When Tigist is unwell it is difficult to take her to the health centre because she behaves strangely and doesn't believe she should go. Her mother is worried she will run away. Her father suggests they chain her up to help to get her there.		
6. Ask each group to feedback their suggestions for solving the problems.		10
Total		85

Supporting individuals to take medication		
Reference: Chapter 20		
Competencies • Able to assess reasons for not taking medication and apply problem solving approach to address this		
Steps	**Resources**	**Timing**
1. Ask the group: • Why do people with schizophrenia have problems taking medication	Flip chart	5
2. Tell the group about: • Why people with schizophrenia have problems taking medication • Why it is important to support individuals to take medication	Powerpoint 35	10
3. Describe the steps to support individuals to take medication: • Revise the information about medication • Explain why you are doing this module • Assess problems taking medication • Use problem solving to improve taking medication regularly	Powerpoint 35	20
4. In groups of three the trainees should discuss how they could solve the problem vignettes. *Suggest as many ways as you can think of to deal with the following problems. Decide which are not good suggestions and which are good suggestions. Select the best one.* 1. Betty finds the medication makes her very tired. This puts her off taking it. 2. Daniel doesn't mind taking medication but he usually forgets to take it. 3. Henok and his family don't trust the medication. They don't see why he needs to take it when he is well. 4. Solomon is told by the holy water attendant not to take medication whilst he is using holy water, as it will stop the holy water working	Handout 25	15
5. Ask each group to feedback their suggestions for solving the problems.		10
6. Tell the trainees about: • Discuss difficult situations e.g. forcing individual to take medication • Monitor whether the individual takes medication	Powerpoint 35	5
7. In pairs do a role play together. *One trainee should pretend to be the caregiver and one trainee should pretend to be the CBR worker. Each trainee should play the CBR worker for 1 scenario. The person playing the CBR worker should try to respond to the comments of the other trainee.* **<u>Scenario 1</u>** **Caregiver:** The only way to give our son the medication is to mix it into his food without his knowing. Otherwise he won't take it.	Handout 26	15

CBR worker: explain why they should avoid this if possible and suggest what they can do instead **<u>Scenario 2</u>** **Caregiver:** When he is unwell, the only way to give our son medication is to tie him up and force it into his mouth. **CBR worker**: explain why they should avoid this if possible and suggest what they can do instead 8. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.		
9. Ask each group to make one comment about the role play e.g. what they find difficult.		5
10. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		100

Week 4 Tuesday

Improving access to health services and supporting medication practice
Reference: Chapter 17 and 20
Competencies • Aware of health services available for people with mental illness • Able to assess reasons for not accessing medication or attending health centre and apply problem solving approach to address this • Able to assess reasons for not taking medication and apply problem solving approach to address this
• Trainees should sit in the outpatient clinic or accompany on home visits with a data collector or psychiatric nurse • They should observe the activity and practice some of the following tasks with the individual or caregiver: • Explain why it is important to access the health centre and take medication • Assess problems with accessing the health centre or taking medication • Explain why it is important to avoid forcing an individual to take medication • Discuss some of the following points with the psychiatric nurse or data collector o Problems the individual has had accessing health services or taking medication and why they had those problems o How the data collector or nurse has helped to get around problems o The skills the psychiatric nurse or data collector uses when talking to people with schizophrenia and caregivers o Challenges of dealing with accessing health services and taking medication • The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Week 4 Wednesday

Improving access to health services and supporting medication discussion		
Reference: Chapter 17 and 20		
Competencies • Aware of health services available for people with mental illness • Able to assess reasons for not accessing medication or attending health centre and apply problem solving approach to address this • Able to assess reasons for not taking medication and apply problem solving approach to address this		
Steps	**Resources**	**Timing**
Ask six trainees in turn to share with the group their experience in the field. Use the following prompts: • Describe the individual or family they visited e.g. What problems they have had with accessing health services or taking medication. How have needs and goals changed over time	Flip chart	120

• Experience of explaining importance of accessing health services and taking medication • What have they learnt; how can they use the information in their own work • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss amongst themselves		

Improving the family environment		
Reference: Chapter 25		
Competencies • Able to detect distress in caregivers on an ongoing basis • Able to deliver family intervention		
Steps	**Resources**	**Timing**
1. Ask the group: • What problems do people with schizophrenia have with the family environment?	Flip chart	10
2. Tell the group about: • What problems people with schizophrenia have with the family environment • Why people with schizophrenia have problems with the family environment • Why it is important to improve the family environment	Powerpoint 36	20
3. Describe the steps to support individuals to take medication: • Explain why you are doing this module • Assess problems with the family environment • Consider how well the caregiver is coping • Give advice on how to improve the family environment • Discuss unhelpful coping strategies • Give advice on how to improve parenting	Powerpoint 36	25
4. In pairs do a role play together. *one trainee should pretend to be the caregiver, and one trainee should pretend to be the CBR worker. Each trainee should play the CBR worker for 1 scenario. The person playing the CBR worker should try to respond to the questions and comments of the other trainees.* **<u>Scenario 1</u>** The CBR worker should give the following advice to improve the family environment: • Have appropriate expectations • Set limits • Reduce stress The caregiver should say: • The best way to deal with my son's problems is to pretend he isn't ill, this way he will learn to behave normally again. Also we try to convince him that his strange ideas aren't true. • He has been ill for so long, it's time he got back to working on the farm **<u>Scenario 2</u>** The CBR worker should give the following advice to improve the family environment: • Improve communication • Get the family routine back to normal • Strengthen social networks • Treat the individual with respect The caregiver should say:	Handout 27	30

• The best way to deal with my son's problems is to constantly watch him and make sure he is not doing anything wrong. • I shouldn't worry my friends with my problems, so I don't talk to anyone about the difficulties we have 5. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.		
6. Ask each group to make one comment about the role play e.g. what they find difficult.		10
Total		95

Dealing with distressing symptoms		
Reference: Chapter 22		
Competencies • Able to give advice for dealing with distressing symptoms		
Steps	**Resources**	**Timing**
1. Ask the group: • Why each type of symptom might be distressing	Flip chart	10
2. Tell the group about: • What problems people with schizophrenia have with distressing symptoms • Why people with schizophrenia have problems with distressing symptoms • Why it is important to improve distressing symptoms	Powerpoint 37	10
3. Describe the steps to support individuals to take medication: • Revise information about symptoms • Explain why you are doing this module • Assess symptoms • Suggest potential coping strategies: o For hallucinations o For delusions o For problems with motivation o For problems with thinking clearly • Discuss unhelpful coping strategies	Powerpoint 37	25
4. In pairs do a role play together. *One trainee should pretend to be the person with schizophrenia, and one trainee should pretend to be the CBR worker. Each trainee should play the CBR worker for 1 scenario. The person playing the CBR worker should try to respond to the questions and comments of the other trainees.* **Scenario 1** The CBR worker should give the following advice: • How to cope with hallucinations • How to cope with problems with motivation The person with schizophrenia should say: I feel I can't cope with the hallucinations, there is no way I can control them. **Scenario 2** The CBR worker should give the following advice: • How to cope with delusions • How to cope with problems with thinking clearly The person with schizophrenia should say: It's best for me just to drink alcohol. This stops me from worrying that people are following me. 5. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 28	20

6. Ask each group to make one comment about the role play e.g. what they find difficult.		10
7. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		90

Week 4 Thursday

Improving the family environment and dealing with distressing symptoms practice
Reference: Chapter 22 and 25
Competencies • Able to detect distress in caregivers on an ongoing basis • Able to deliver family intervention • Able to give advice for dealing with distressing symptoms
• Trainees should sit in the outpatient clinic or accompany on home visits with a data collector or psychiatric nurse • They should observe the activity and practice some of the following tasks with the individual or caregiver: • Explain why it is important to improve the family environment • Assess problems with the family environment or distressing symptoms • Suggest methods for improving the family environment • Suggest methods for dealing with distressing symptoms • Discuss some of the following points with the psychiatric nurse or data collector o Problems the individual has had o How the data collector or nurse has helped to get around problems o The skills the psychiatric nurse or data collector uses when talking to people with schizophrenia and caregivers o Challenges of improving the family environment and dealing with distressing symptoms • The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Week 5 Friday

Improving the family environment and dealing with distressing symptoms discussion		
Reference: Chapter 22 and 25		
Competencies • Able to detect distress in caregivers on an ongoing basis • Able to deliver family intervention • Able to give advice for dealing with distressing symptoms		
Steps	**Resources**	**Timing**
Ask six trainees in turn to share with the group their experience in the field. Use the following prompts: • Describe the individual or family they visited e.g. What problems they have had. How have needs and goals changed over time • Experience of explaining importance of improving the family environment • What have they learnt; how can they use the information in their own work • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss amongst themselves	Flip chart	120

Taking control of your illness		
Reference: Chapter 30		
Competencies • Able to identify early warning signs with family and develop relapse prevention plan		
Steps	**Resources**	**Timing**

1. Tell the group about: • What problems people with schizophrenia have with relapse • Why people with schizophrenia have problems with relapse • What the early warning signs of relapse are	Powerpoint 38	20
2. Ask the group: • Why is it important to prevent relapse?	Flip chart	10
3. Tell the group: • Why is it important to prevent relapse?	Powerpoint 38	5
4. Describe the steps to prevent relapse: • Principles • Explain why you are doing this module • Discuss the early warning signs • Discuss stressful triggers • Discuss the relapse management plan	Powerpoint 38	25
5. In threes do a role play together. One trainee should be the caregiver, one the person with schizophrenia and one the CBR worker. You are creating a relapse management plan of a young man together. CBR worker: lead the process, asking for input from the caregiver and person with schizophrenia Caregiver (mother) should give this information: • Why do we have to discuss this? it is just bringing up old problems for no reason • Before my son become unwell he stops talking to us and is angry towards us. • I wish we had more support when he becomes unwell Person with schizophrenia should give this information: • Before I become unwell I can't sleep properly and I lose my appetite. • When we have a very bad harvest that usually seems to make me more ill • When I start becoming unwell I usually turn to alcohol and khat to try and improve things 6. After each role play the trainees playing the caregiver and person with schizophrenia and should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 29	25
7. Ask each group to make one comment about the role play e.g. what they find difficult.		10
Total		95

Dealing with stigma and discrimination		
Reference: Chapter 28		
Competencies • Able to identify early warning signs with family and develop relapse prevention plan • Able to give advice on dealing with stigma and discrimination		
Steps	**Resources**	**Timing**
1. Tell the group about: • What problems people with schizophrenia have with stigma and discrimination (revision) • Why people with schizophrenia have problems with stigma and discriminations	Powerpoint 39	10
2. Ask the group: • Why is it important to deal with stigma and discrimination?	Flip chart	10
3. Tell the group: • Why is it important to deal with stigma and discrimination?	Powerpoint 39	5
4. Describe the steps to deal with stigma:	Powerpoint 39	25

• Explain what stigma and discrimination is • Explain why you are doing this module • Discuss experiences of stigma and discrimination • Encourage the individual to think about themselves in a positive way • Discuss how to deal with negative comments and discrimination • Discuss which ways of responding are not helpful • Discuss the caregiver's experiences of stigma • Discuss what other approaches may reduce stigma		
5. In pairs do a role play together. *One trainee should pretend to be the person with schizophrenia, and one trainee should pretend to be the CBR worker. Each trainee should play the CBR worker for 1 scenario. The person playing the CBR worker should try to respond to the questions and comments of the other trainees.* **Scenario 1** CBR worker: Ask the individual about their experiences of stigma. Discuss ways they can deal with this in the future. Person with schizophrenia: Sometimes people shout rude names at me and say I am crazy and that I smell bad. I feel like fighting them. **Scenario 2** CBR worker: Ask the individual about their experiences of stigma. Discuss ways they can deal with this in the future. Person with schizophrenia: People ignore me and don't listen to what I say, sometimes including my family. It makes me feel like not going outside and that I don't deserve to have any friends or any opinions. 6. After each role play the trainee playing the person with schizophrenia should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 30	25
7. Ask each group to make one comment about the role play e.g. what they find difficult.		10
8. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		15 mins
Total		100

Week 5 Monday

Taking control of your health and dealing with stigma practice
Reference: Chapter 28 and 30
Competencies • Able to identify early warning signs with family and develop relapse prevention plan • Able to give advice on dealing with stigma and discrimination
• Trainees should sit in the outpatient clinic or accompany on home visits with a data collector or psychiatric nurse • They should observe the activity and practice some of the following tasks with the individual or caregiver: • Explain why it is important to prevent relapse or deal with stigma • Assess problems with relapse or stigma • Develop a relapse management plan • Suggest methods for dealing with stigma • Discuss some of the following points with the psychiatric nurse or data collector o Problems the individual has had o How the data collector or nurse has helped to get around problems o The skills the psychiatric nurse or data collector uses when talking to people with schizophrenia and caregivers o Challenges of dealing with stigma and preventing relapse • The trainee should write notes so they can remember and discuss what they did and learnt the following day.

Week 5 Tuesday

Taking control of your health and dealing with stigma discussion		
Reference: Chapter 28 and 30		
Competencies • Able to identify early warning signs with family and develop relapse prevention plan • Able to give advice on dealing with stigma and discrimination		
Steps	**Resources**	**Timing**
Ask six trainees in turn to share with the group their experience in the field. Use the following prompts: • Describe the individual or family they visited e.g. What problems they have had. How have needs and goals changed over time • Experience of explaining importance of preventing relapse or dealing with stigma • What have they learnt; how can they use the information • Anything that was confusing • Anything that was difficult or challenging • Any thing that was interesting or surprising Encourage the group to ask each other questions and discuss amongst themselves	Flip chart	120

Improving literacy		
Reference: Chapter 29		
Competencies • Able to assess literacy and basic skills suggest steps to improve them		
Steps	**Resources**	**Timing**
1. Tell the group about: • What problems people with schizophrenia have with literacy • Why people with schizophrenia have problems with literacy	PowerPoint 40	5
2. Ask the group: • Why is it important to improve literacy?	Flip chart	10
3. Tell the group: • Why is it important to improve literacy?	PowerPoint 40	5
4. Describe the steps to improve literacy: • Principles • Explain why you are doing this module • Find out the literacy level of the individual • Confirm the individual is interested • Arrange attendance at literacy group/ school • Help the individual to attend	PowerPoint 40	10
Total		30

CBR worker wellbeing		
Reference: Chapter 33		
Competencies • Has skills to maintain own wellbeing		
Steps	**Resources**	**Timing**
1. Ask the group: • what problems with wellbeing they might have • Why they might have these problems	Flip chart	10
2. Tell the group about: • what problems with wellbeing they might have • Why they might have these problems	Powerpoint 41	10
3. Ask the group: • Why is it important to deal with problems with wellbeing	Flip chart	10
4. Tell the group: • Why is it important to deal with problems with wellbeing	Powerpoint 41	5
5. Ask the group:	Flip chart	10

• How they think they can help maintain their own wellbeing		
6. Tell the group: • Suggestions for how to maintain their own wellbeing	Powerpoint 41	10
7. In pairs do a role play together. Both trainees should pretend to be CBR workers. You should take it in turns to be the one seeking help. **Scenario 1** CBR worker seeking help: The people you are working with have so many problems. You feel worried that you are never going to be able to improve things for them and that you are a failure. You have started to drink alcohol a lot at the weekends to take your mind off it. Other CBR worker: Listen to the other CBR workers problems and suggest ways to help them. **Scenario 2** CBR worker seeking help: You are worried one of the individuals you are looking after is going to attack you. Nothing like this has ever happened but people are always telling you that you are doing a dangerous job. You can't sleep at night because you are so worried about it. Other CBR worker: Listen to the other CBR workers problems and suggest ways to help them. 8. After each role play the trainee seeking help should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.	Handout 31	25
9. Ask each group to make one comment about the role play e.g. what they find difficult.		10
Total		90

Supervision		
Reference: Chapter 34		
Competencies • Aware of circumstances in which to contact supervisor for support		
Steps	**Resources**	**Timing**
1. Tell the group :what is supervision	Powerpoint 42	5
2. Ask the group: Why is it important to be supervised	Flip chart	10
3. Tell the group about: • Why is it important to be supervised	Powerpoint 42	10
4. Tell the group: • Who is involved in supervision • How they will be supervised	Powerpoint 42	30
5. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		10
Total		65

Week 5 Wednesday

Dealing with difficult situations		
Reference: Chapter 35		
Competencies • Able to sensitively address the issue of chaining and physical abuse and take appropriate steps • Aware and able to follow procedures for the following scenarios: suicidal intent, neglect, etc • Able to deal with difficult situations e.g. angry person, violent person		
Steps	**Resources**	**Timing**
1. Ask the group: • What difficult situations might you come across?	Flip chart	**5**
2. Tell the group: • What difficult situations might you come across? • Why is it important to know how to deal with difficult	Powerpoint 43	**30**

situations? • How to deal with difficult situations		
3. Quiz	Powerpoint 43	**10**
Total		45

Good documentation		
Reference: Chapter 38		
Competencies • Able to complete documentation correctly		
Steps	**Resources**	**Timing**
1. Tell the group: • What is good documentation? • Why it is important to have good documentation • What we need to document	Powerpoint 44	15
2. Ask the group: • How can we make sure we have good documentation	Flip chart	15
3. Tell the group: • How can we make sure we have good documentation	Powerpoint 44	15
Total		45

Links to health services		
Reference: Chapter 37		
Competencies • Aware of health services available for people with mental illness • Aware and able to follow procedures for the following scenarios: suicidal intent, neglect, etc		
Steps	**Resources**	**Timing**
1. Tell the group • What are links to health services?	Powerpoint 45	**5**
2. Ask the group: • Why is it important to have links to health services?	Flip chart	**5**
3. Tell the group: • Why is it important to have links to health services? • How do we keep links to health services?	Powerpoint 45	**10**
Total		20

Dealing with other problems		
Reference: Chapter 38		
Competencies • Aware and able to follow procedures for following scenarios: identification of physical disability or mental illness in community member		
Steps	**Resources**	**Timing**
1. Ask the group: • what other problems might you come across, whilst doing CBR	Flip chart	10
2. Tell the group about: • what other problems might you come across, whilst doing CBR • Why they might come across these problems • Why is it important to know what to do if you come across people with other problems	Powerpoint 46	10
3. Tell the group: • How to deal with people with other problems	Powerpoint 46	20
4. In pairs do a role play together. *One trainee should pretend to be the CBR worker, and one trainee should pretend to be the community member. Each trainee should play the CBR worker for 1 scenario. The person playing the CBR worker should try to respond to the questions and comments of the other trainees.* **<u>Scenario 1</u>** Kebele chairperson from a kebele where the CBR worker is not	Handout 32	25

working: You have heard that there are health workers giving educational talks in the kebele about mental illness. You know some people in your kebele who are unwell with mental illness and they are not treated well by the community. You want the CBR worker to come and give information to the general community. When the CBR worker says they can't give the educational talk in your kebele say this is very unfair- why should the other kebeles get special treatment? CBR worker: respond to the kebele chairperson. **Scenario 2** Neighbour of a family receiving CBR: You have heard that the CBR worker is supporting the family very well. You have a seven year old son who is different to other children his age. He can't talk and can't use the latrine by himself. You want the CBR worker to help your family. When the CBR worker says they can't give the support say this is very unfair- why should your neighbour get special treatment? CBR worker: respond to the neighbour 5. After each role play the trainee seeking help should feedback to the person playing the CBR worker: any good things they did, any thing they did less well, something they can improve on for next time.		
6. Ask each group to make one comment about the role play e.g. what they find difficult.		10
7. Ask the group what have they learnt today? Anything surprising, shocking, interesting or useful?		5 mins
Total		90

Week 5 Thursday
Assessment

Appendix C (iv): RISE assessments for CBR workers

RISE CBR worker post-training written test			
CBR worker		**Date**	

WRITTEN TEST PART ONE

1. How you would feel in each of the following situations?
Circle one answer from 1 to 4 which describes best how you would feel

		Definitely	Probably	Probably not	Definitely not
1	Would you feel afraid to have a conversation with someone who has schizophrenia?	**1**	**2**	**3**	**4**
2	Would you be upset or disturbed about working on the same job with someone who has schizophrenia?	**1**	**2**	**3**	**4**
3	Would you be able to maintain a friendship with someone who has schizophrenia?	**1**	**2**	**3**	**4**
4	Would you feel upset or disturbed about sharing a room with someone who has schizophrenia?	**1**	**2**	**3**	**4**
5	Would you feel ashamed if people knew someone in your family has been diagnosed with schizophrenia?	**1**	**2**	**3**	**4**
6	Would you marry someone with schizophrenia?	**1**	**2**	**3**	**4**

2. To the best of your knowledge, what causes schizophrenia? (List 3 possible causes)

(1) _____
(2) _____
(3) _____

3. Which of the following statements are true and which are false?
People with schizophrenia…

1	Hear voices telling them what to do	___**True**	___**False**
2	Are usually violent and dangerous	___**True**	___**False**
3	Cannot work	___**True**	___**False**
4	Can have long periods without symptoms	___**True**	___**False**
5	Usually need medication to control their symptoms	___**True**	___**False**
6	Can be successfully treated outside of the hospital in the community	___**True**	___**False**
7	Are often mentally retarded or of lower intelligence.	___**True**	___**False**
8	Usually cannot make decisions concerning their health	___**True**	___**False**
9	Sometimes have problems washing and dressing by themselves	___**True**	___**False**
10	May be seen talking to themselves or shouting in public areas	___**True**	___**False**

4. Tick one of the following statements. There is only one correct answer.

1	You are doing a home visit when the person with schizophrenia becomes very angry and shouts insults at you. They say they can hear voices. You feel very scared. Which **one** of the following steps **should** you take?	A	Correct the person's swearing	
		B	Shout back at them to make yourself heard	
		C	Insist that the voices aren't real	
		D	Stay calm and check with the family that the individual is taking their medication.	
		E	Threaten that you will stop making home visits to them if they don't calm down	
2	You notice that the mother of an individual with schizophrenia always seems sad and hopeless. Which **one** of the following steps **should** you take?	A	Encourage her to join the family support group	
		B	Tell her to stop complaining and that this will only make the individual's illness worse	
		C	Tell her neighbours that she is unhappy	
		D	Tell her that you are not there to help her, only the individual with schizophrenia	
3	A priest from a kebele that is not receiving CBR comes to see you. He says it is not fair that they are not receiving any help. Which **one** of the following is **true**	A	Only the best kebeles were chosen to receive CBR.	
		B	People with schizophrenia who live in kebeles not receiving CBR can still get help from the health centre	
		C	CBR workers are allowed to start CBR in any kebele they want	
		D	CBR workers can invite people from any kebele to participate in the family support groups.	
4	Whilst you are working as a CBR worker you feel stressed and overworked. Which **one** of the following steps **shouldn't** you take?	A	Tell your supervisor you feel overworked	
		B	Quit your job straight away without telling anyone	
		C	Try relaxation techniques	
		D	Discuss with other CBR workers if they feel the same	
		E	Tell your mother or other close relative how you are feeling	
5	An individual you are working with is chained to the side of their house. Which **one** of the following steps **shouldn't** you take?	A	Help the family to take the individual to the health centre	
		B	Tell your supervisor about the situation	
		C	Tell the family to unchain the individual straight away	
		D	Tell the family to check for wounds caused by chaining	
		E	Tell the family to keep offering food and water to the individual	
6	Which **one** of the following is **NOT** likely to be a step in a crisis management plan?	A	Check the individual is taking their medication	
		B	Suggest a small amount of khat to improve their mood	
		C	Try controlled breathing	
		D	Ask a relative or friend for help	
		E	Take the individual to the health centre for a review	
7	Which **one** of the following is **not** a principle for improving problems with day-to-day functioning?	A	Try not to involve the family. Otherwise the individual will never become independent	
		B	Find out what household tasks were done by the individual before they were unwell	
		C	Find out what is normal for the household, for example do they use soap for washing	

		D	Ask the family to give encouragement to the individual	
8	Which **one** of the following is **not** a way to improve the family environment?	A	Have appropriate expectations of the individual	
		B	Reduce stress in the household	
		C	Improve communication between family members	
		D	Get the family routine back to normal	
		E	Send the individual to stay at holy water for a few weeks	
9	Which **one** of the following is **NOT** a step in helping to improve distressing symptoms?	A	Explain why you are covering this topic	
		B	Suggest avoiding talking to other people to help reduce delusions	
		C	Assess which symptoms are most distressing to the individual	
		D	Suggest doing a distracting activity to help with hallucinations	
		E	Make a plan for what steps the individual will take	
10	Which one of the following statements about stress is **NOT** true	A	All people experience some stress in their lives	
		B	Stress can make schizophrenia worse	
		C	Drinking alcohol can help to relieve stress	
		D	Prayer and attending church or mosque can help to relieve stress	
		E	It is good to avoid or try to change situations that were stressful in the past	
11	Which **one** of the following is **NOT** way to improve problems with physical health?	A	Fast for 3 days every week	
		B	Eat a balanced diet	
		C	Ensure access to the health extension programme	
		D	Avoid alcohol	
		E	Get treatment for physical injuries	
12	Children in the kebele often shout names and throw stones at the individual you are working with. Which **one** of the following is **NOT** a good way to help with this problem?	A	Community awareness-raising meeting	
		B	Advise the individual to throw stones back at the children.	
		C	Discuss things the individual can say to the children in response	
		D	Support the individual to improve their self-care	
		E	When you see the individual outside their home, greet them as you would greet anyone else	
13	A man with schizophrenia has difficulty doing the farm work that he used to. Which one of the following is a NOT a likely reason for this?	A	His hands shake due to the medication	
		B	He has no energy due to his illness	
		C	His father gave his land away to his brother when he became unwell	
		D	He is sleepy all the time due to the medication	
		E	The illness has made him lazy	
14	A women with schizophrenia has difficulty going to church. Which one of the following is NOT a good way to help with this?	A	With the woman's permission, discuss with the priest how he can help	
		B	Ask her sister to go with her	
		C	Do a role play to practice greeting people	
		D	Go to church with her yourself every week from now on.	
15	A woman with schizophrenia wants to learn to read and write. Which one of	A	Check the literacy level of the woman	
		B	Start teaching her to read and write	

	the following is NOT a good way to help with this?		yourself	
		C	Check whether there is a literacy group in the kebele	
		D	Discuss with the co-ordinator of the literacy group if the woman is able to attend	
16	Which one of the following is NOT a reason to meet with a community leader?	A	Ask the priest to tell the individual off for not taking medication every day	
		B	Educate the primary school headteacher about schizophrenia	
		C	Ask the kebele leader to consider a certificate for free medication	
		D	Tell the Edir leader an individual wishes to contribute to Edir activities and ask for the leader's support in this	
17	Which one of the following steps should you NOT take when ending your CBR work with a family?	A	Complete the Continuing Care Form	
		B	Reassure them the individual will continue to receive care from the health centre	
		C	Focus on the things the individual hasn't been able to achieve	
		D	Remind them that they have learnt to deal with their own problems whilst you have been working with them.	
		E	Focus on the individual and families strengths and achievements	
18	Which of the following statements about family support groups are NOT true?	A	You should look for a leader amongst the group who can take over from you after a few months	
		B	The project can offer small loans to help start income generation projects	
		C	The group should decide themselves what topics they cover	
		D	What is discussed in the group is confidential	
	Total correct answers:			

WRITTEN TEST PART TWO

Write short answers to these questions

1. **What is the purpose of the needs assessment in CBR? (1 mark)**

2. **What is the purpose of goal setting in CBR? (2 marks)**
3. **Solomon has schizophrenia and was prescribed the medication CPZ by the nurse at the health centre. He was taking it in the morning and it was making him feel very sleepy. When he went to holy water, the priest told him he shouldn't take medication at the same time as holy water, otherwise the holy water wouldn't work. For these reasons Solomon has stopped taking the medication.**
   What steps would you take to help him to take the medication? (4 marks)

4. **Betty has schizophrenia and she has been chained up inside the house by her family. What steps would you take to help Betty? (5 marks)**

5. **In the kebele where you are doing CBR work you are asked by a community elder to help a child with seizures/epilepsy. What would you say to the community elder? (2 marks)**

6. **Daniel has schizophrenia and his symptoms are now under control. However he still isn't doing any work that he used to do, for example farming. His hands shake from the**

medication and his family don't trust him to do the work properly. How would you help Daniel to get back to work? (5 marks)

7. **Abraham has schizophrenia and he has a bad relationship with his family. They are always arguing. His parents are always telling him to get back to doing work and stop being lazy. Sometimes Abraham gets very angry and threatens to hit his mother. List four steps that you could take to improve the family environment (4 marks)**

8. **List four possible early warning signs for relapse of schizophrenia (4 marks)**

9. **You are going to hold a community awareness raising meeting in the kebele where you're working. List four topics that you might cover (4 marks)**

10.1	The CBR worker should always be the leader of the Family Support Group	___**True**	___**False**
10.2	If the person with schizophrenia develops shaking hands due to anti-psychotic medication the CBR worker should send them straight to Butajira Hospital	___**True**	___**False**
10.3	The CBR worker should check for the progress of goals at each home visit	___**True**	___**False**
10.4	The CBR worker should provide contraception directly to the person with schizophrenia	___**True**	___**False**
10.5	Every person with schizophrenia has feelings that people are trying to kill them, or are poisoning their food	___**True**	___**False**
10.6	The CBR worker should look for potential employment opportunities in the kebele	___**True**	___**False**
10.7	The CBR worker should do resource mapping in every kebele they are working in. For example finding out about local schools, edir groups and churches.	___**True**	___**False**
10.8	The health extension worker may help the person with schizophrenia to wash and dress	___**True**	___**False**
10.9	A priority of CBR is to give the family the skills to better care for the person with schizophrenia	___**True**	___**False**
10.10	In extreme circumstances, if the person with schizophrenia cannot afford the medication you can lend them money to get it	___**True**	___**False**
	Total correct answers		

RISE CBR worker observation by trainers			
CBR worker		**Date**	
Trainer			

When observing trainees, grade their professionalism and participation according to the following criteria. For each criteria please circle one grade.

	Very poor	Poor	Satisfactory	Good	Very good
1. Attendance	**1**	**2**	**3**	**4**	**5**
a. Attends all or nearly all sessions b. Informed training organisers if unable to attend, providing reasons					
2. Time management	**1**	**2**	**3**	**4**	**5**
a. Arrives on time to all or nearly all sessions b. Provides reasons for attending late c. Completes tasks in a timely manner					
3. Appearance	**1**	**2**	**3**	**4**	**5**
a. Dresses appropriately					
4. Participation	**1**	**2**	**3**	**4**	**5**
a. Is interested and engaged in training b. Contributes to discussions c. Asks questions to trainer d. Is polite and respectful during discussions e. Listens to the view points of other trainees f. Takes part in all role plays and makes an effort g. Does not make or receive calls or text messages during sessions					
5. Receiving feedback	**1**	**2**	**3**	**4**	**5**
a. Listens to feedback given by trainer or other trainees *b.* Takes feedback onboard e.g. Adjusts style of interviewing according to feedback					
6. Attitudes	**1**	**2**	**3**	**4**	**5**
a. Demonstrates positive attitude towards people with mental illness i.e. not stigmatising *b.* Is friendly and gets on well with other trainees *c.* Keen to learn					
7. Asking for help	**1**	**2**	**3**	**4**	**5**
a. Is aware of own limitations in skills or knowledge b. Willing and able to ask for help from other trainees or trainers when unsure					
Total score					

ASSESSMENT ROLE PLAY A: Generic communication skills

Instructions for assessor

General instructions

- After the trainee has had five minutes to read the information, remind the trainee they have 15 minutes to do the role play.
- Start recording and make a note of the time
- Tell the trainee to start the role play now
- Stop the trainee after 15 minutes

Information given to the role player/ person with schizophrenia

- *When the trainee asks you how you are say you are very worried that you are a big burden on your family*
- *If they ask for more details say :*
    - *that you find it hard to do the work you used to,*
    - *you have to pay for your medication.*
    - *you were poor even before the illness came on, now it is getting worse.*
- *When the trainee asks if you went to the health centre, say no.*
- *When they ask why say you it's too far and you didn't have money for transport.*

Information given to trainee

- *Imagine it the beginning of your visit to Haile*
- *You should start by asking Haile how he is.*
- *Respond to the things he says using your good communication skills.*
- *At some point during the discussion you should ask him if he went to his appointment at the health centre, which was supposed to be a few days ago*.

Scoring

ENACT

ASSESSMENT ROLE PLAY B: Risk assessment

Instructions for assessor/ person with schizophrenia

Scenario
This scenario involves a discussion between a CBR worker and Haile. Haile is a 21-year-old man who has schizophrenia. The CBR worker knows Haile and her family and has been working with them for a several of weeks. In the discussion the CBR worker and Haile will discuss how Haile is getting on.

General instructions

- After they have had five minutes to read the information, remind the trainee they have 10 minutes to do the role play.
- Start recording and make a note of the time
- Tell the trainee to start the role play now
- Stop the trainee after 10 minutes

During the role play

- When asked, say that you are not feeling very well. You're getting lots of voices at the moment, which are upsetting you a lot.
- If the CBR worker asks about other things, give brief replies but bring it back to how bad you are feeling.
- If the CBR worker asks you how you are feeling about life, or whether you are considering harming yourself, say you have thought about this.
- If asked, say you haven't made any specific plans to harm yourself. You can add that it would upset your family too much if you did anything like this.
- If the CBR worker does not ask you a suicide risk assessment question by half way through the role play, you should interrupt and say "sometimes things feel so bad I don't think I can carry on with life"

Information given to trainee
In this role play you do not have time to do everything that you would normally do at a home visit. Please try to do these tasks:

- Ask Haile how things are going
- Respond to anything that Haile says

After the role play, ask: What steps would you take after this visit?

Scoring: ENACT

ASSESSMENT ROLE PLAY C: Problem solving

Scenario

This scenario involves a discussion between a CBR worker and Desta, a caregiver. Desta is the mother of Betty, a 21-year-old woman who has schizophrenia. She lives with her parents. Betty is not taking regular medication and is currently unwell. The CBR worker knows Betty and her family and has been working with them for a couple of weeks. You have already set an agenda for this visit, which is to address the goal 'Individual is able to attend health centre for mental health'.

General instructions

- After they have had five minutes to read the information, remind the trainee they have 15 minutes to do the role play.
- Start recording and make a note of the time
- Tell the trainee to start the role play now
- Stop the trainee after 15 minutes

During the role play

- When asked, say it is difficult to get to the health centre when your daughter Betty is so unwell. When prompted to give more details add:
    - Because of difficulties getting to the health centre she hasn't taken medication
    - She has become more unwell recently and has stopped getting dressed properly and doesn't do anything all day.
- When asked, say you your brothers used to help you to take her to the health centre but you have fallen out with them so now you can't ask them.
- When asked for solutions to the problem first suggest that the CBR worker brings you the medication. Also say there is a priest who knows the family and who might be able to help with getting Betty to the health centre.

Information given to the trainee

In this role play you do not have time to do everything that you would normally do at a home visit. Please try to do these tasks:

- Remind Desta that you have previously agreed to discuss problems getting to the health centre
- Find out what the situation is and any problems they have had
- Use a problem solving approach to find a solution to the problems

After the role play, take about 5 minutes to ask: After the visit, what would you tell or ask the supervisor? What other steps would you take afterwards?

Scoring: ENACT

RISE CBR worker self-reported competence			
CBR worker		**Date**	
CBR worker ID			

Circle a number to show how much you agree with each statement.

Statement	I don't agree at all	I don't agree	I slightly agree	I agree	I strongly agree
1. I know what to do if work stress is affecting me	1	2	3	4	5
2. I can do a needs assessment with a person with schizophrenia	1	2	3	4	5
3. I can do a brief risk assessment for a person with schizophrenia	1	2	3	4	5
4. I can do goal setting with a person with schizophrenia	1	2	3	4	5
5. I can keep track of goals on an ongoing basis using the Home Visit Form	1	2	3	4	5
6. I would know what to do in the following difficult situations. The individual with schizophrenia...					
a. Has aggressive or disturbed behaviour	1	2	3	4	5
b. Attempts suicide	1	2	3	4	5
c. Dies suddenly	1	2	3	4	5
d. Is sexually assaulted by a family member	1	2	3	4	5
e. Is chained or restrained at home	1	2	3	4	5
7. I feel confident doing a home visit by myself	1	2	3	4	5
8. I feel confident meeting with a community leader by myself	1	2	3	4	5
9. I can do community-awareness raising, for example run a public meeting	1	2	3	4	5
10. I know when to send the individual with schizophrenia to the health centre	1	2	3	4	5
11. I know when to contact my supervisor for support	1	2	3	4	5
12. I can use a problem solving approach with people with schizophrenia	1	2	3	4	5
13. I know what to do if a community member asks me to support someone with a physical disability	1	2	3	4	5
14. I can develop a crisis management plan	1	2	3	4	5
15. I can organise and run a family support group	1	2	3	4	5
16. I can give advice on how to improve problems with:					
a. Self care	1	2	3	4	5
b. The family environment	1	2	3	4	5
c. Physical health	1	2	3	4	5
d. Accessing health services	1	2	3	4	5
e. Taking medication	1	2	3	4	5

f. Taking part in community life	1	2	3	4	5
g. Getting back to work	1	2	3	4	5
h. Stigma and discrimination	1	2	3	4	5
i. Human rights problems	1	2	3	4	5
j. Understanding schizophrenia	1	2	3	4	5
k. Stress and anger	1	2	3	4	5
l. Literacy	1	2	3	4	5
m. Distressing symptoms	1	2	3	4	5
17. I know how to make a relapse prevention plan	1	2	3	4	5

Total score	
Mean score	
Calculated by	
Date	

Appendix C (v): ENhancing Assessment of Common Therapeutic factors (ENACT) rating scale- adapted version for Ethiopia

1. NON-VERBAL COMMUNICATION & COMMUNICATION THROUGH ACTIVE LISTENING AND WITH THE USE OF APPROPRIATE BODY LANGUAGE ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Does not make appropriate eye contact with the patient or stares; shows anger; laughs at/mocks patient; turned away from patient; repeatedly interrupts the patient conversation; ignores patient; answers mobile phone without permission
2	**DONE PARTIALLY**	Does not consistently use body language to express interest: rarely makes eye contact, expresses only limited emotion, appears artificial;
3	**DONE WELL**	Makes appropriate eye contact throughout their conversation; smiles when appropriate; sits at appropriate angle from patient, leans in to the patient to show interest; use of 'uh-huh', 'hmm' and other keys to signal interest in their conversation
2. VERBAL COMMUNICATION SKILLS: OPEN-ENDED QUESTIONS, REPEATING THE MAIN TOPIC, CLARIFYING STATEMENTS ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Uses mostly 'yes/no' questions, e.g. "do you take your medication?"
2	**DONE PARTIALLY**	Uses open-ended questions, but does not explore topics further or does not repeats the main topics for patient to reflect upon
3	**DONE WELL**	Uses Open-ended questions, repeats the main topic and clarifies statements, e.g. asks questions like "What happened? Tell me more."
3. BUILDING TRUST	**Not applicable**	
1	**NEEDS IMPROVEMENT**	Clinician does not attempt to make the patient feel comfortable by treating him with respect and dignity
2	**DONE PARTIALLY**	Clinician does not attempt to make the patient feel comfortable but treats him with respect and dignity.
3	**DONE WELL**	Clinician attempts to make the patient feel comfortable by treating him with respect and dignity.
4. FURTHER EXPLORATION, INTERPRETATION AND NORMALIZATION OF FEELINGS ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Clinician does not ask about patient's feelings **OR** clinician is judgmental/critical about patient's emotions and feelings (e.g., "You shouldn't feel that way" "You should stop thinking or feeling that."
2	**DONE PARTIALLY**	Clinician asks but does not normalize (does not explain that it is common)/validate **OR** does not explore feelings in detail with patient (Uses questions which need a Yes/No reply)
3	**DONE WELL**	Clinician explains that the patient's feelings are common and expected for a person in his/her situation
5. EMPATHY, WARMTH, & GENUINENESS ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Is critical, or hostile, of patient's concerns or complaints
2	**DONE PARTIALLY**	Clinician is not critical or hostile but does not demonstrate that he/she understands the experience of patient or does not consider him seriously.
3	**DONE WELL**	Clinician demonstrates that he/she understands the experience of patient in genuine, sincere manner
6. ASSESSING IMPACT OF PSYCHOSOCIAL PROBLEMS ON LIFE, FUNCTIONING AND DAY TO DAY ACTIVITY ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Clinician does not ask patient about the impact of stress, worry, thoughts and psychosocial problems on functioning and daily life.
2	**DONE PARTIALLY**	Clinician asks functioning and day to day activities, but does NOT relate it to psychosocial concerns
3	**DONE WELL**	Clinician explores the relationship between psychosocial problem and functioning

7. EXPLORES PATIENT'S AND SOCIAL SUPPORT NETWORK'S EXPLANATION FOR THE CAUSE OF PROBLEM (CAUSAL MODEL) ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician does not ask patient about his/her own view of the cause of his problem OR is judgmental/critical about patient's explanation (e.g. "Witchcraft doesn't cause these problems, that is an ignorant/backwards idea
2	**DONE PARTIALLY**	Clinician asks patient about his/her own view of cause of problems, but does not explore if his/her view is similar to his family or other important people in support network.
3	**DONE WELL**	Clinician asks patient about his own view of the cause of his problem **and** asks if family or significant other support network have same or different explanations

8. ASSESSING COPING MECHANISMS FOR PROBLEMS AND CHALLENGES AND PRIOR SOLUTIONS ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician does not ask patient about how patient has coped with the problem **OR** clinician is judgmental/critical about how patient has coped (e.g., "Why did you think that work?" or "That isn't helpful.")
2	**DONE PARTIALLY**	Clinician asks about coping and prior solutions, but does not provide positive feedback
3	**DONE WELL**	Clinician asks patient about how he has coped with the problem and provides positive feedback

9. ASSESSING IMPACT OF PATIENT'S RECENT STRESSFUL LIFE EVENTS ON PSYCHOSOCIAL WELLBEING ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician does not ask about current stressful situations/events
2	**DONE PARTIALLY**	Clinician asks about current stressful situations but does not see its relation with current mental health issues
3	**DONE WELL**	Clinician asks about current stressful situations and discusses connection with current mental health

10. ASSESSING, ALCOHOL OR DRUGS USE (INCLUDING MISUSE OF PRESCRIPTION DRUGS) ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician does not ask about drug and alcohol use (including misuse of prescription drugs), OR asks about drug or alcohol use in an inappropriate or insensitive way for the patient's age and sex
2	**DONE PARTIALLY**	Clinician takes partial history but does not explore positive responses about alcohol or drug use (including misuse of prescription drugs)
3	**DONE WELL**	Clinician assesses issues with alcohol or drugs (including misuse of prescription drugs) and explains relationship to patient's condition when appropriate OR clinician does not ask about drug and alcohol use but this is appropriate to age and gender of patient OR clinician asks about alcohol or drug use in close family members

11. ASSESSING APPROPRIATE INVOLVEMENT OF FAMILY MEMBER, SIGNIFICANT OTHER AND CAREGIVER ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician only talks with the patient's family and does not give the appropriate respect for the feedback of the patient and ignores patient perspective, (e.g., "You should listen to your family more.)OR (if family not present) fails to ask the patient about the involvement of the family
2	**DONE PARTIALLY**	Clinician ask about family involvement, but does not explore patient's reasons for involvement or non-involvement
3	**DONE WELL**	Clinician makes a treatment plan that considers the patient's perspective on how much they want family involvement (even if the family is not present) **and** encourages interaction between the two

12. ASSESSING COLLABORATIVE GOALS SETTING AND EXPECTATIONS OF THE PATIENT FOR RECOVERY ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician does not ask patient about his/her goals for recovery **OR** clinician just tells patient what to do without asking his/her opinion
2	**DONE PARTIALLY**	Clinician asks patient about goals for recovery but does not discuss if these are realistic or can be accomplished
3	**DONE WELL**	Clinician asks about goals regarding the treatment and discusses with patient what is and is not realistic and achievable through treatment; collaboratively clinician and patient establish treatment plan
13. PROMOTION OF REALISTIC HOPE FOR CHANGE ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician either gives no hope (e.g. you will never get better) or gives unrealistic expectations (e.g. you will be cured in a few weeks and never have problems again) for what to expect in treatment and recovery
2	**DONE PARTIALLY**	Clinician vaguely tells patient what will happen during treatment
3	**DONE WELL**	Clinician helps patient feel positive about the future **and** creates realistic expectations about what can and cannot be achieved through treatment and explains treatment checking patient understanding
14. ASSESSING THE USE OF LOCAL (ETHNOPSYCHOLOGICAL) TERMSIN CONDUCTING PSYCHOEDUCATION ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician uses technical jargon to explain about mental illness **OR** uses stigmatizing terms **OR** does not explain how treatment works
2	**DONE PARTIALLY**	Clinician uses a limited amount of technical jargon but **No** stigmatizing terms
3	**DONE WELL**	Clinician conducts psychoeducation using local terminology and phrases to explain mental health and treatment in non-stigmatizing language, in a local language where appropriate, and checks to see if patient understands
15. ASSESSING PROBLEM SOLVING SKILLS: PROBLEM FORMULATION & PRIORITIZATION, SOLUTION GENERATION, ACTION PLANNING ☐ **Not applicable**		
1	**NEEDS IMPROVEMENT**	Clinician attempts problem solving steps #2-4 (see below) but only completes 1 or 2 steps satisfactorily
2	**DONE PARTIALLY**	Clinician attempts problem solving steps #2-4 (see below) but only completes 3 steps satisfactorily
3	**DONE WELL**	Clinician helps patient to do all of the following (1) formulate and prioritize primary problem, (2) brainstorm solutions, (3) explores advantages and disadvantages, and (4) formulate action plan

16. ASKING FOR FEEDBACK AND PROVIDING ADVICE, SUGGESTIONS AND RECOMMENDATIONS ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Clinician lectures patient what to do without asking if this is acceptable and comfortable to patient,
2	**DONE PARTIALLY**	Clinician gives useful advice but does not ask for feedback from patient about the usefulness of the advice to the patient
3	**DONE WELL**	Clinician gives appropriate advice for the patient and explicitly asks for feedback about the usefulness of the advice
17. CLINICIAN EXPLAINS CONFIDENTIALITY OF THEIR DISSCUSSION ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Clinician does not address confidentiality (by explaining confidentiality or ensuring privacy) OR does not adjust conversation to setting (e.g. if other family members are present, does not take care with topics discussed)
2	**DONE PARTIALLY**	Clinician tells patient that everything is confidential with explaining harm to self or others
3	**DONE WELL**	Clinician explains that all clinician-patient discussions are confidential with the exception of harm to self and others OR ensures privacy OR adjusts conversation to setting
18. HARM TO SELF, HARM TO OTHERS, AND HARM FROM OTHERS AND COLLABORATIVE RESPONSE PLAN ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Clinician does not ask about harm to self or others or does not pick up on key signals of self harm or suicide
2	**DONE PARTIALLY**	Clinician asks about harm to self or others, but does not help patient to develop a crisis plan
3	**DONE WELL**	Clinician asks about harm to self or others and facilitates appropriate actions to assure safety
19. ASSESSES ANTI-PSYCHOTIC MEDICATION ADHERENCE (TAKING MEDICATION APPROPRIATELY) ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Does not ask about anti-psychotic medication adherence OR reprimands patient for not taking medication appropriately
2	**DONE PARTIALLY**	Asks about anti-psychotic medication adherence but does not ask him reasons for non-adherence, and/or does not explore ways to improve medication adherence
3	**DONE WELL**	Asks about anti-psychotic medication adherence, and asks him reasons for non adherence, tries to understand reasons for these and explores ways to improve the situation
20. ASSESSES FOR POTENTIAL ROLE OF COMMUNITY OR SOCIAL NETWORKS IN FINDING SOLUTIONS TO PROBLEMS ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Does not assess the role of community or social networks as potential solutions to improve patient's situation
2	**DONE PARTIALLY**	Makes suggestions about role of community or social networks as potential solutions to improve patient's situation without asking for patient input
3	**DONE WELL**	Makes appropriate suggestions and asks for feedback, about the role of strengthening community engagement or social networks as a potential solution to improve patient's situation
21. ASSESSING PHYSICAL HEALTH ISSUES ☐ Not applicable		
1	**NEEDS IMPROVEMENT**	Clinician does not ask about physical health and physical health issues
2	**DONE PARTIALLY**	Clinician takes partial history but does not explore positive responses about physical health issues
3	**DONE WELL**	Clinician assesses related physical health issues and explains relationship to patient's condition and lifestyle when appropriate

Case difficulty rating (CIRCLE)	
1	No complex issues or challenging behaviour
2	Some complex issues or some challenging behaviour
3	Very complex issues or very challenging behaviour

Appendix D (Chapter 7: RISE pilot)

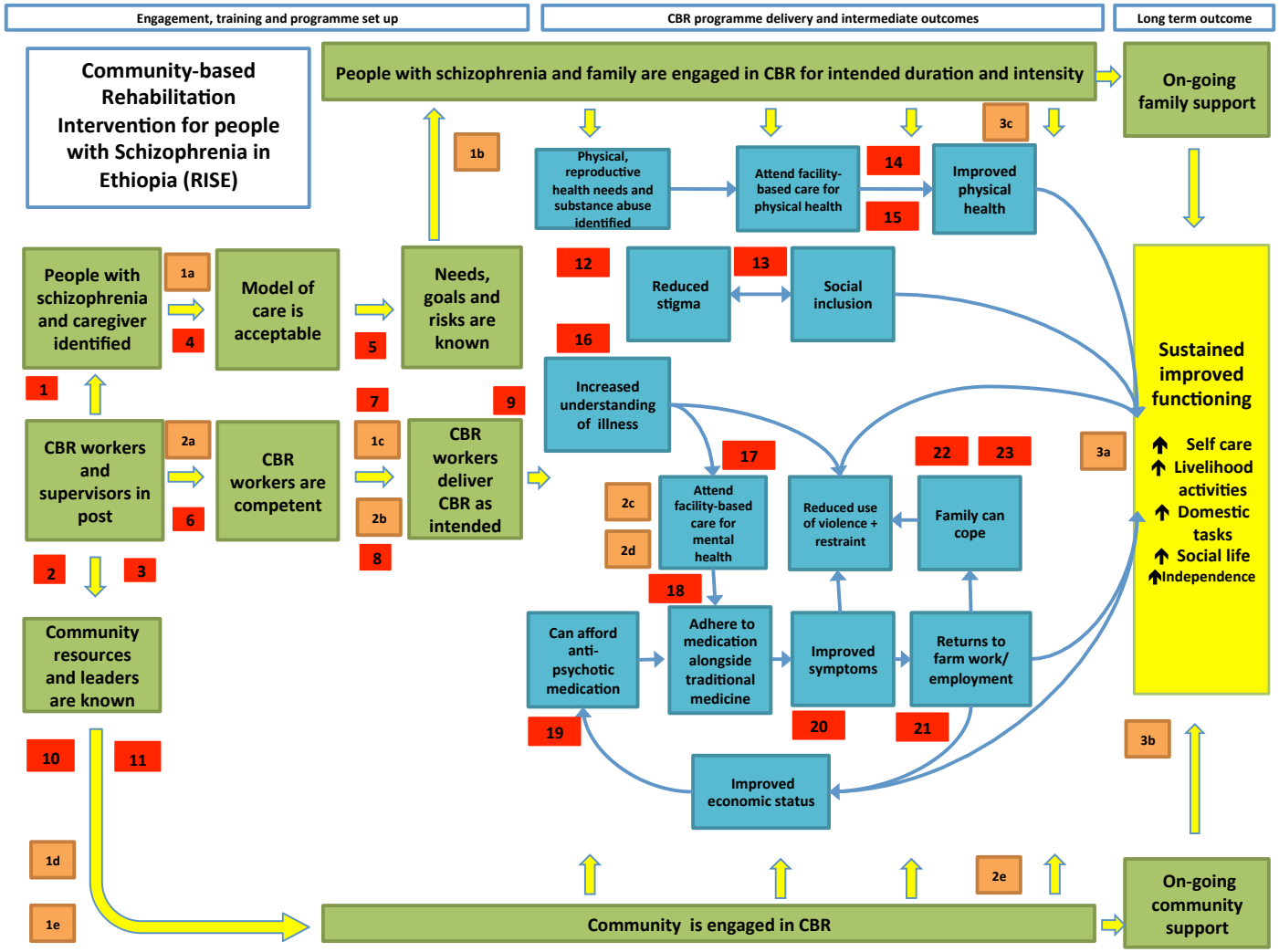
Appendix D (i): Pilot eligibility assessment form

ID. Details		*Data entry*
Date	**[ ][ ]/[ ][ ]/[ ][ ][ ][ ] G.C**	*scdate*
Patient's PRIME ID	**[ ][ ][ ][ ][ ]/[ ][ ]**	*primeid*
Assessor's ID	**[ ][ ]**	*assid*
RISE Pilot ID (complete if recruited):	**[ ][ ]**	*risepid*

1a	From the PRIME baseline data collection does the patient have a clinical diagnosis of schizophrenia, schizoaffective disorder or schizophreniform disorder?	**Yes [→ go to Q2]**	**1**	dx
		No [→ patient must not be entered in RISE pilot]	**0**	
2	Is the patient 18 years or over?	**Yes [→go to Q3]**	**1**	over18
		No [→ patient must not be entered in RISE pilot]	**0**	
3a	What is the patient's Brief Psychiatric Rating Scale-Expanded (BPRS-E) score according to the psychiatric nurse assessment?	**[→ go to Q3b]**		bprse
3b	Is the BPRS-E score 52 or greater?	**Yes [→ go to Q3c]**	**1**	bprses2
		No [→ go to Q3c]	**0**	
3c	What is the patient's converted WHO Disability assessment schedule-36 item (WHODAS-36) score according to the psychiatric nurse assessment?	**[→ go to Q4d]**		whodas
3d	Is the converted WHODAS-36 score 35 or greater?	**Yes [→ go to Q3e]**	**1**	whodas 35
		No [→ go to Q3e]	**0**	
3e	What is the patient's Clinical Global Impression (CGI) severity score according to the psychiatric nurse assessment?	[→ go to Q3f]		cgi
3f	Is the CGI severity score 4 or greater?	**Yes [→ go to Q3g]**	**1**	cgi4
		No [→ go to Q3g]	**0**	
3g	How many of the past 6 months has the patient been symptomatic, according to the Longitudinal Interval Follow-up Evaluation: DSM-IV Version (LIFE) assessment completed by the psychiatric nurse?	**[→ go to Q3h]**		life
3h	Has the patient been symptomatic for 3 or more out of the last 6 months on the LIFE?	**Yes [→ go to Q3i]**	**1**	life3
		No [→ go to Q3i]	**0**	

3i	Did you answer 'Yes' to one or more of the following questions: 3b, 3d, 3f or 3h?	**Yes [→ go to Q4]**	**1**	elig
		No [→ Patient must not be entered in RISE pilot]	**0**	
4	Has the patient been a resident in their kebele for >6 months and have no immediate plans to leave the kebele?	**Yes [→ go to Q5]**	**1**	keb6m
		No [→ Patient must not be entered in RISE pilot]	**0**	
5	Does the patient have a primary caregiver who is willing to participate in the study?	**Yes [→ Patient is eligible for RISE]**	**1**	careg
		No [→ Patient must not be entered in RISE pilot]	**0**	

Appendix D (ii) Detailed pre-pilot theory of change



Interventions

Engagement, training and programme set up activities

1 CBR worker and community leaders identify people with schizophrenia
2 CBR worker signs contract and receive salary
3 CBR worker conducts resource mapping
4 CBR worker conducts initial engagement with family
5 CBR worker conducts needs and risk assessment in conjunction with supervisor
6 CBR worker receive adequate training, including field practice
7 CBR worker receive regular supervision including peer supervision and observed CBR sessions. Supplementary training given for skill gaps.
8 Measures to ensure safety of CBR worker
9 CBR worker creates rehabilitation plan in conjunction with supervisor
10 CBR worker educates community leaders about mental health and CBR
11 CBR worker conducts individual mobilisation with community leaders and traditional healers, as required

CBR activities

12 Support dealing with stigma and discrimination
13 Facilitate access to social networks and community activities → keep
14 Advice on healthy behaviours
15 Skills for self-care
16 Psycho-education and human rights education to people with schizophrenia and caregiver
17 Supports access to health facility
18 Adherence support
19 CBR worker facilitates access to free medication
20 Crisis and relapse management plans
21 Support returning to livelihood activities
22 Family intervention
23 Family support group

Assumptions

1a People with schizophrenia and caregivers are willing and have time to participate
1b CBR can meet the needs of people with schizophrenia
1c CBR workers are willing to work with people with schizophrenia
1d Community leaders willing to support CBR
1e Traditional and religious healers are willing to support CBR

2a Non-specialists can be trained to deliver CBR for people with schizophrenia
2b CBR workers can overcome logistical challenges to deliver CBR
2c Primary care staff are supportive of CBR
2d Anti-psychotic medication is accessible
2e *Edir* support will be available and sustainable

3a CBR can improve functioning in people with schizophrenia
3b A community mobilisation approach is needed in addition to home-based care
3c Family support groups are perceived to be useful

Rationale

Link between intermediate outcomes	Rationale
CBR workers and supervisors in post→ People with schizophrenia and caregivers identified	RAPID project uses CBR workers to identify people with disability. In implementation of CBR, this is the method that would be used to identify people with schizophrenia (Expert theory of change workshop)
CBR workers and supervisors in post → Community resources and leaders are known	CBR workers should lead on resource mapping, which is an essential first step in CBR to understand available opportunities. (Expert theory of change workshop, RAPID, WHO CBR guidelines (1))
CBR workers and supervisors in	Non-specialist workers trained to deliver mental health

post →CBR workers are competent*	interventions in other settings (2-6)
People with schizophrenia and caregivers identified → Model of care is acceptable*	Initial engagement work can be carried out to ensure CBR is acceptable to participants e.g. adjusting content, building a trusting relationship (Expert theory of change workshop)
Model of care is acceptable →Needs, goals and risks are known	Greater acceptability of intervention is likely to lead to greater satisfaction with care and engagement (7). Unlikely to retain CBR workers if CBR model is not acceptable (community and expert theory of change workshops, qualitative interviews)
Needs, goals and risk are known→ People with schizophrenia and family are engaged in CBR for intended	People with schizophrenia have diverse needs so it is essential to assess them and tailor CBR accordingly (qualitative interviews). Needs assessment is part of RAPID assessment, COPSI assessment (8)
People with schizophrenia and family are engaged in CBR for intended duration and intensity → CBR conceptual framework*	Impact of CBR only achievable with proper participation in CBR (theory of change workshops)
CBR workers are competent → CBR workers deliver CBR as intended*	CBR workers will deliver CBR successfully if they have adequate supervision and training (expert theory of change workshop)- demonstrated in previous projects (2-5, 9)
Community resources and leaders are known → Community is engaged in CBR*	Being aware of who community leaders are is an essential step before engaging/educating them (Expert theory of change workshop)
Community is engaged in CBR → CBR conceptual framework*	Community mobilisation is required for the individual/family level interventions to be successful e.g. engaging in Edir, reducing stigma (theory of change workshops and qualitative interviews). Importance of engaging community is central to CBR philosophy (WHO CBR guidelines (1))
People with schizophrenia and family are engaged in CBR for intended duration and intensity → Ongoing family support	CBR should empower individual and family to continue CBR after the CBR worker has left; this is only possible with proper engagement (theory of change workshops, RAPID)
Community is engaged in CBR → Ongoing community support	Community mobilisation is key way to ensure sustainability of CBR. (theory of change workshops, RAPID, WHO CBR guidelines (1))
Increased understanding of illness→ Attends facility-based care for mental health*	Understanding of schizophrenia may be limited at baseline (10). Increased understanding of benefits of medication for recovery will lead to greater attendance. Some evidence psychoeducation can improve appointment attendance (11, 12)
Increased understanding of illness →Reduced use of violence and restraint	Understanding of schizophrenia may be limited at baseline (10). Education about causes of schizophrenia may reduce physical abuse (e.g. not beating out devil)
Attends facility-based care for mental health → Adhere to medication alongside traditional medicine	Medication available only at facility, therefore attending facility is perquisite for taking medication (theory of change workshop)
Can afford anti-psychotic medication → Adhere to medication alongside traditional medicine*	Key barrier to taking medication is inability to pay (qualitative interviews)
Adhere to medication alongside traditional medicine → Improved symptoms	Adherence associated with improved outcomes and reduced relapse in Butajira cohort (13). Evidence that adherence support leads to improved symptoms (14-16)
Improved symptoms→ Reduced use of violence and restraint	Families restrain as a last resort when the individual is unwell. Improvement in symptoms may therefore result in reduced use of restraint (qualitative interviews)
Family can cope→ Reduced use of violence and restraint	Families may be less likely to resort to restraint, even when their relative is unwell, if they have better mechanisms to deal with

	illness and caregiver burden
Improved symptoms→ Returns to farm work/ employment	Problems with negative symptoms, linked to inability to do farm work (qualitative). Improved symptoms associated with improved functioning in Butajira cohort (17)
Returns to farm work/employment→ Improved economic status	People with schizophrenia are typically young and economically active family members prior to illness. Return to farm work/ employment is likely to have substantial impact on the economic status
Improved economic status → Can afford anti-psychotic medication	Schizophrenia has an economic impact on families (through inability to work and cost of treatment)(18). Many families have difficulties paying for treatment (Qualitative interviews). Improving economic status likely to have an impact on ability to pay for treatment.
Returns to farm work/employment→ Family can cope	Part of caregiver burden is inability of people with schizophrenia to work and provide income (18). Reducing these problems is likely to reduce burden on family and increase ability to cope.
Reduced stigma → Social inclusion	Stigma described as a barrier to social inclusion (qualitative interviews). Reducing stigma may therefore improve social inclusion.
Social inclusion → Sustained improved functioning in people with schizophrenia	Social exclusion/stigma a key factor in poor functioning (qualitative interviews)
Physical, reproductive health needs and substance abuse identified→ Attends facility based care for physical health	Need to assess and identify specific issues prior to referral to health centre for assessment/treatment (experts theory of change workshop)
Attends facility based care for physical health → Improved physical health	Accessing health centre is an essential step for improving physical health
Improved physical health→ Sustained improved functioning	High rates of mortality in people with schizophrenia in Ethiopia (19). Improving physical health likely to lead to improved ability to do work and social activities
Reduced use of violence and restraint → Sustained improved functioning	Reducing chaining and restraint will allow people with schizophrenia to return to usual activities
Return to farm work/employment→ Sustained improved functioning	Ability to work is an important component of functioning
Improved economic status → Sustained improved functioning	Improved economic status likely to allow a range of activities e.g. social and community life
Ongoing community support → Sustained improved functioning	Community mobilisation is key way to ensure sustainability of CBR (RAPID, theory of change workshops, WHO CBR guidelines (1))
Ongoing family support→ Sustained improved functioning in people	Thread through CBR should be empowering individual and family to continue CBR after the CBR worker has left (RAPID, theory of change workshops)

* The rationale identified for these links prior to the pilot is listed here; in addition these item had associated assumptions, which were tested in the pilot (see Chapter 6)

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Indicators

Intermediate outcome	Indicator	Method and data source	Result
CBR workers and supervisors are in post	*10 CBR workers and two supervisors recruited*	**Process**: staff recruitment data	**Achieved**
	10 CBR workers and two supervisors retained for 12 month duration of pilot	**Process**: staff recruitment data	**Achieved**
People with schizophrenia and caregiver are identified	*2- 3 eligible and consenting participants identified in each sub-district*	**Process**: participant recruitment data	**Achieved**
Community resources and leaders are known	*Community mobilisation tasks 2 and 3 (identify community resources and leaders) completed in all sub-districts within two months*	**Process**: Kebele logbook	**Achieved**
Community is engaged in CBR	*Community mobilisation tasks 5 and 6 (meetings with community leaders and awareness raising events) completed in all sub-districts within two months*	**Process**: Kebele logbook	**Partially achieved:** Tasks 5 and 6 completed in all sub-districts by 11 weeks on average.
	Good quality engagement with community leaders	**Qualitative**: 12 month IDI with community leaders; FGD with CBR workers	**Partially achieved:** see Assumptions 1d and 1e
	≥1 individual mobilization of community leader/ member in each sub-district (tasks 8-11)	**Process**: Kebele logbook	**Acheived**
CBR model of care acceptable to CBR workers and participants	*Approximately 80% eligible participants agree to participate*	**Process**: participant recruitment data	**Achieved**
	Reported acceptability of model of care by CBR workers *and participants*	**Process**: feedback meetings **Qualitative**: 2 month IDIs with participants and FGDs with CBR workers	**Partially achieved**: see Assumptions 1a and 1c

Intermediate outcome	Indicator	Method and data source	Result
Needs, goals and risk relating to participants are known	*Needs assessment, goal setting, risk assessment and rehabilitation plan completed for each participant at beginning of Phases I, II and III*	**Process**: Participant logbooks	**Achieved** [nb not including participant that quit at 8 months]
CBR workers are competent	*All CBR workers achieve >40% on post training written test*	**Process**: End of training written tests	**Achieved**
	No CBR worker rated as 'needs improvement' on >20% ENACT items by end of training	**Process**: End of training ENACT assessments	**Achieved**
CBR workers deliver CBR as intended	*All CBR workers have minimum of 10 observed unannounced home visits*	**Process**: Supervisor logbook	**Not achieved***: 0 CBR workers have 10 visits; mean 5.4 unannounced visits (range 4-6)
	All CBR workers have minimum of 12 face to face supervision sessions	**Process**: Supervisor logbook	**Not achieved***: 3 CBR workers have 12 sessions; mean 9.7 sessions (range 6-14)
	CBR workers attend 80% group supervision sessions	**Process**: Supervisor logbook	**Partially achieved*** : 8 sessions held; 9 CBR workers attend >80% sessions
	Supervision perceived to be useful and of appropriate frequency	**Qualitative**: 2 and 12 month CBR worker FGD	**Partially achieved:** see assumption 2a
People with schizophrenia are engaged in CBR for intended duration and intensity	*All participants receive all core modules in first 2 months*	**Process**: feedback meetings and participant logbook	**Not achieved:** 3 participants (30 %) achieved within 2 months; 9 participants (90%) achieved within 3 months
	Participants undertake, on average, 90% modules indicated by goal setting	**Process**: Participant logbooks	**Achieved**
	All participants continue to receive CBR visits for 12 months	**Process**: Participant logbooks	**Not achieved:** six participants (60%) receive CBR up to 12 months
	Participants receive approximately 22 home visits over 12 months	**Process**: Participant logbooks	**Achieved**

Intermediate outcome	Indicator	Method and data source	Result
Ongoing family support	*Continuing Care Form completed for all participants by 12 months*	**Process**: Participant logbooks	**Not achieved:** completed for six participants
	Family and CBR worker *feel family are able to continue support by 12 months*	**Qualitative**: CBR worker FGD and participants IDI 12 months	**Partially achieved:** see Assumption 3a
Ongoing community support	*Reported ongoing community support at 12 months*	**Process**: feedback meetings **Qualitative**: CBR worker FGD, participants IDI, community members IDI 12 months	**Partially achieved:** see Assumption 3b
Physical, reproductive health needs and substance abuse identified	*Phase I needs assessment form completed for all patients*	**Process**: Participant logbooks	**Achieved**
People with schizophrenia attend facility for physical health	*Reported attendance to facility for physical health*	**Process**: feedback meetings **Qualitative**: CBR worker FGD, participants IDI 12 months	**Partially achieved:** see Assumption 3a
	Increased % with ≥1 visit to health facility at 12 months compared to baseline	**Quantitative:** Adapted CSRI baseline and 12 months	**Partially achieved:** 50% baseline vs. 75% endline
People with schizophrenia have improved physical health	*Perceived improvement in physical health after 12 months CBR*	**Qualitative**: CBR worker FGD, participants IDI 12 months	**Partially achieved:** see Assumption 3a
	Improved AUDIT scores at 12 months compared to baseline	**Quantitative**: AUDIT baseline and 12 months	**Achieved**
Reduced stigma against people with schizophrenia and caregivers	*Perceived reduction in stigma after 12 months CBR*	**Qualitative**: CBR worker FGD, participants IDI, community members IDI 12 months	**Partially achieved:** see Assumption 3a
	Improved DISC scores at 12 months compared to baseline	**Quantitative**: DISC baseline and 12 months	**Achieved**
Social inclusion of people with schizophrenia	*Perceived improvement in social inclusion after 12 months CBR*	**Qualitative**: CBR worker FGD, participants IDI, community members IDI 12 months	**Partially achieved:** see Assumption 3a
People with schizophrenia and caregivers understand illness	*Reported improvement in understanding*	**Qualitative**: CBR worker FGD, participants IDI 12 months	**Partially achieved:** see Assumption 3a

Intermediate outcome	Indicator	Method and data source	Result
People with schizophrenia attend facility-based care for mental health	*Increased % with ≥1 visit to health facility in last three months at 12 months compared to baseline*	**Quantitative:** Adapted CSRI baseline and 12 months	**Partially achieved:** 50% baseline vs. 75% endline
	Reported attendance to facility for mental health	**Qualitative**: CBR worker FGD, participants IDI 12 months	**Partially achieved:** see Assumption 3a
People with schizophrenia can afford anti-psychotic medication	*Medication fee waiver obtained for participants unable to afford medication*	**Process**: feedback meeting **Qualitative**: CBR worker FGD	**Not achieved:** Not obtained in any of four cases
	Reported ability to pay for anti-psychotic medication by 2 months	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Partially achieved:** see Assumption 3a
People with schizophrenia use medication alongside traditional medicine	*Reported use of medication alongside traditional medicine*	**Qualitative**: CBR worker FGD, participants IDI 12 months	**Not achieved:** See Assumption 2c
	Perceived improvement in adherence	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Partially achieved:** see Assumption 3a
People with schizophrenia have improved symptoms	*Perceived improvement in symptoms*	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Achieved**
	Improved CGI and PHQ-9 scores at 12 months compared to baseline	**Quantitative**: CGI and PHQ-9 baseline and 12 months	**Achieved**
Reduced use of violence, restraint against people with schizophrenia	*Perceived reduction in violence and use of restraint*	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Partially achieved:** see Assumption 3a
	Reduced incidence of restraint at 12 months compared to baseline	**Quantitative**: restraint questions	**Partially achieved:** 2 episodes of restraint during pilot compared to 4 prior to pilot
Family can cope	*Perceived improvement in family burden*	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Achieved**
	Improved IEQ scores at 12 months compared to baseline	**Quantitative**: IEQ baseline and 12 months	**Achieved**

Intermediate outcome	Indicator	Method and data source	Result
People with schizophrenia return to farm work/ employment	*Reported increase in farm work/ employment*	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Achieved**
Improved economic status of people with schizophrenia and family	*Perceived improvement in economic status*	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Partially achieved:** see Assumption 3a
Sustained improved functioning	*Improved WHODAS scores at 12 months compared to baseline*	**Quantitative**: WHODAS baseline and 12 months	**Achieved**
	Perceived improvement in functioning	**Qualitative**: CBR worker FGD, participants IDI 2 months	**Achieved**

Appendix D (iii): Pilot qualitative topic guides

RISE pilot initial evaluation (2 months): Topic guide for IDIs with individuals with schizophrenia/caregivers

1. **Tell me about your experience of being involved in CBR so far.**
- What were the best things
- What were the worst things

2. **How did you find the experience of being involved in CBR?**

Prompts

- What was it like being visited at home?
- How did you find the frequency of the visits?
- How did you find it when you were asked whether you had thoughts of harming themselves?
- How did you find it when you asked whether you had been chained up recently?
- What was it like being accompanied by the CBR worker to the health centre?

3. **How did you find the CBR worker?**

Prompts

- What is your relationship with the CBR worker like?
- How did you find their manner?
- What do you think about their knowledge?
- How were they at listening to you?
- How were they at explaining things?

4. **Is CBR useful for you so far?**

Prompts

- What problems and needs do you have? Does CBR address your needs? How?
- What expectations did you have of CBR when you started? Has it met your expectations? In what ways?
- How has CBR impacted on your understanding of schizophrenia?
- How has CBR impacted on your ability to access medication and the health centre?
- How has CBR impacted on how often you are chained up?
- How easy to understand was the information you received?
- How did you find the format of the information? (e.g. which is better: handouts or just hearing the information verbally?)

5. **What can we change or add to CBR to make it better for you?**

Prompts

- Have you had any problems taking part in CBR?
- If so, is there anything that can be done to make it easier for you to take part?
- Is there anything that would improve CBR?

RISE pilot initial evaluation (2 months): Topic guide for FGDs with CBR workers/ IDI with supervisor

1. What has been your experience of being a CBR worker/supervisor so far

2. How useful do you think CBR is for the participants?

Prompts

- What expectations do you think the individuals and families had of CBR?
- Do you think you will be able to meet those expectations?
- In what ways do you think your home visits are useful? Give me some examples from your experience.
- How has CBR impacted upon the individual's understanding about schizophrenia?
- How has CBR impacted upon the individuals' ability to access care?
- How has CBR impacted upon human rights issues such as chaining?

3. What challenges did you have in your work?

Prompts

- Was there anything that made it difficult for individuals and families to participate?
- Was there anything that made it difficult for you to deliver CBR?
- How did you overcome these challenges?
- Is there anything that can be done to make it easier for you to deliver CBR?
- Is there anything that can be done to make it easier for individuals and families to participate?

FOR CBR WORKERs:

4. What was it like doing CBR home visits?

Prompts

- What was it like working with a person with schizophrenia +/- intellectual disability?
- What is your relationship with the individual and family like?
- How confident do you feel in delivering CBR?
- How did you find asking about suicide risk?
- How did you find asking about chaining?
- How acceptable do you think it is to ask about these things every time?
- If you had to deal with any difficult situations, what was that like?
- What is your attitude like towards people with schizophrenia?
- Has this changed at all since you started work?

5. What was it like starting the community mobilisation work?

Prompts

- What are the positive aspects of this work so far?
- What are the negative aspects?
- Did you experience and resistance or difficulties? Tell me about those

6. How supported do you feel in delivering CBR?

Prompts

- How do you feel about your personal safety?
- How accessible is your supervisor?
- How useful are your supervision meetings? How might they be made more useful for you?

FOR CBR SUPERVISORS:

7. What was it like supervising CBR?

Prompts

- What is your relationship like with the CBR worker?
- What was it like working with a person with schizophrenia +/- intellectual disability?
- How confident do you feel in supervising CBR?
- How acceptable do you think it is to ask about suicide risk and chaining at every home visit?
- What was your role in community mobilisation work?

8. What were your experiences of managing difficult situations?

Prompts

- How do you feel about the instructions/ flow charts?
- How do you feel about the support you got for managing these situations?
- What was your experience of adverse event reporting, if this occurred?

9. How supported do you feel in supervising CBR?

Prompts

- How do you feel about your personal safety?
- How accessible is the trial coordinator/ trial manager?

RISE pilot initial evaluation (2 months): Topic guide for FGDs with health centre staff

1. What has been your experience of having contact with CBR workers so far?

2. What was it like when the CBR worker came to the health centre with the patient?

Prompts

- Did the presence of the CBR worker affect your work in any way?
- How does CBR affect the care that you can give the patient? E.g. do they help or hinder the care you provide?
- How does CBR affect your relationship with the patient and caregiver?
- What is your relationship like with the CBR worker?

3. How useful do you think CBR is for the participants?

Prompts

- How has CBR impacted upon the individual's understanding about schizophrenia?
- How has CBR impacted upon the individuals' ability to access care?
- How has CBR impacted upon human rights issues such as chaining?
- Do you notice any impact of CBR even when the CBR worker is not there?

4. What challenges do you have relating to the CBR workers?

Prompts

- Are there any difficulties you faced relating to the CBR workers?
- How did you overcome these challenges?
- Is there anything that can be done to make it easier for you to work alongside CBR workers?

RISE pilot initial evaluation (2 months): Topic guide for FGDs with community members/ leaders

1. **Are you aware of any people with mental illness living in your area?**

2. **Whose responsibility do you think it is to support people with mental illness?**

3. **Have you been involved in supporting people with mental illness in anyway?**

Please tell me about how you have been involved. If they haven't been involved before ask: How might you be involved in the future?

[Orientate the participant to what we mean by CBR. Distinguish from PRIME (care at the health centre) and health extension workers]

4. **If the participant has been involved: How has the CBR worker affected your own involvement?**
   Prompts
- Were you aware of the person/people with mental illness before the CBR worker started?
- In what way were you involved in supporting the person before the CBR worker started?
- How has the CBR worker increased or decreased your involvement?

5. **If the participant has been involved: How do you feel about being involved in supporting the person with mental illness?**

What difficulties, if any, did you have in supporting the person?

Prompts

- Do you feel happy to help?
- Has it taken your time?
- Have you used your own funds?
- Have you had any stigma towards yourself for giving this support?

6. **In what circumstances do you think the CBR should ask community leaders/ members to help support a person with mental illness?**

Prompts

- Is it appropriate in all cases or just some cases?
- What kind of support should the CBR worker look for from community leaders/ member?
  1. Financial support?
  2. Paying for medication?
  3. Fetching medication?
  4. Food?
  5. Housing?
  6. Mediation/ discussion with the family?
  7. Finding employment?
  8. Encouragement to the individual?

7. **How important or useful is support from community leaders/ members for people with mental illness?**
8. **In what ways do you think CBR has helped the person with mental illness?**
   Did it help with…

…independence?
… self care?
…doing household tasks?
…symptoms?
…accessing health services?
…taking medication?
…social and community life? For example, participating in Edir, going to church, drinking coffee with others..
…getting back to work?
...the family environment?
…physical health?
…substance abuse?

…stress and anger?
…experiences of stigma and discrimination?
…self esteem?
…caregiver burden?
…physical restraint?
…managing a crisis/ relapse?

9. In what ways has CBR changed awareness about mental illness in your community?

- Have attitudes changed?
- Has knowledge changed?
- How has this impacted on individuals with mental illness?

10. In what ways can CBR be improved?

In particular how can the involvement of community leaders/members be improved?

RISE Pilot qualitative endline interviews with participants

1. How did you feel about receiving CBR?

If you weren't happy to receive CBR please tell me why not (e.g. didn't find it useful)

2. How has CBR impacted on your life?

Prompts

Has it impacted on any of the following areas?

…independence?
… self care?
…doing household tasks?
…symptoms?
…accessing health services?
…taking medication?
…social and community life? For example, participating in Edir, going to church, drinking coffee with others..
…getting back to work?
...the family environment?
…physical health?
…substance abuse?
…stress and anger?
…experiences of stigma and discrimination?
…self esteem?
…caregiver burden?
…physical restraint?
…managing a crisis/ relapse?

3. What was the impact of CBR on your taking medication or not?

Did CBR help with any issues with:

- Medication availability?
- Medication cost?
- Side effects?
- Remembering to take it?
- Being told **not** to take it by others (e.g. relatives, holy water priest)

4. Were there any negative impacts of receiving CBR?

- Decreased time for other activities e.g. farming
- increased stigma from home visits

5. What was the role of the CBR worker in any changes over the last year?

In particular did any of the following help?

- Having home visits from the CBR worker
- Having CBR worker accompany or remind you to go to the health centre?
- Having someone you can trust to talk to
- Family support group [if applicable]
- The CBR worker giving education to the community and making links in the community

6. Aside from CBR, what other factors have helped to improve your situation?

Prompts

- Having support, e.g. from family, support from community worker, support from community
- Finding work, getting financial support
- Taking medication regularly; getting free medication
- Community having increased awareness
- Spirituality/ prayer/ help from God, holy water,
- Accepting circumstances, understanding illness/knowing what to expect,
- Improved self-esteem/ positive attitude,

7. Did anything make it difficult to participate in CBR?

Prompts

- not having enough time,
- increased stigma from home visits

8. What could have made CBR more helpful for you?

1. What would you like to see changed about the CBR programme?
2. How useful do you think the CBR programme might be for other people in your situation?

9. Are you aware of any work the CBR worker did in your kebele, aside from visiting you at home?
e.g. community awareness raising meetings, meetings with businessmen/ priest with the aim of supporting you

If yes→ Please tell me what you think about this community work
Prompts

- Do you think this community work is useful?
- Did this community work impact upon you in anyway?
- Did this community work have any negative impacts on you?

10. **How do you feel about the fact that CBR is finishing?**

1. Do you feel that CBR has given you skills/ knowledge that will continue to help you even though the CBR worker will stop coming?

2. For caregivers: **how confident/ able do you feel to look after you relative?**

RISE pilot endline: Topic guide for IDIs with CBR supervisors/ FGDs with CBR workers

1. What is your experience of being a CBR worker/supervisor – positive or negative

2. How useful do you think CBR is for the participants?

Prompts

- What expectations do you think the individuals and families had of CBR?
- Was the CBR worker able to meet those expectations? Did participants eventually understand that CBR would not be able to provide financial support or free medication?
- In what ways do you think home visits are useful? Give me some examples from your experience.

- **What is the most important ingredient of CBR in your opinion?** E.g. just having the home visits/ contact with the CBR worker? Any specific module? The community work?

3. **In the last 12 months have any changes occurred relating to the following** *[for each probe follow up with 'Tell me about the change' AND 'What was the role of CBR in the change?']:*

…independence?
… self care?
…doing household tasks?
…symptoms?
…accessing health services?
…taking medication?
…social and community life? For example, participating in Edir, going to church, drinking coffee with others..
…getting back to work?
...the family environment?
…physical health?
…substance abuse?
…stress and anger?
…experiences of stigma and discrimination?
…self esteem?
…caregiver burden?
…physical restraint?
…managing a crisis/ relapse?

- **In your opinion on which aspect of life does CBR have the greatest impact?**
- **Did CBR have the impact you expected on the participants? Were you surprised by anything? Were you disappointed by anything?**

4. What other factors, apart from just CBR, do you think had an impact on the individual

Prompts

- Having support, e.g. from family, support from community worker, support from community
- Finding work, getting financial support
- Taking medication regularly; getting free medication
- Community having increased awareness
- Spirituality/ prayer/ help from God, holy water,
- Accepting circumstances, understanding illness/knowing what to expect,
- Improved self-esteem/ positive attitude

5. What do you think will happen to the individual/ family you were working with after CBR is finished?

1. Do you think any positive effects of CBR will continue? Tell me more about this...
2. What is the role of the caregiver in continuing positive effects of CBR?
3. What is the role of the community in continuing positive effects of CBR?

6. Tell me about your experience of the community mobilisation work

Prompts

- What are the positive aspects of this work so far?
- What are the negative aspects?
- Did the CBR worker experience and resistance or difficulties? Tell me about those

- How much does community mobilisation work (including awareness raising, individual meetings with community leaders etc) have an **impact** on people with schizophrenia?
- In the manual and training there is the task to 'demonstrate the progress of people with schizophrenia to the community'. There wasn't a chance to do this in the pilot. Why do you think this wasn't possible? Can you imagine a situation where it would be possible? If not, why not? What impact do you think this could have if it was possible?
- What are the particular issues with arranging employment opportunities for people with schizophrenia? How useful is this part of CBR?
- Why was there no involvement with traditional healers- is it taboo, not relevant to participants, are they hidden?

7. What challenges did you have in your work?

Prompts

- Was there anything that made it difficult for individuals and families to participate?
- What were the reasons why people stopped CBR?
- Was there anything that made it difficult for you to supervise/deliver CBR?
- How did you overcome these challenges?
- Is there anything that can be done to make it easier for you to supervise CBR?
- Is there anything that can be done to make it easier for CBR workers to deliver CBR?
- Is there anything that can be done to make it easier for individuals and families to participate?
- Would you like to continue supervising CBR work?

FOR CBR WORKERS:

8. What was it like doing CBR home visits?

Prompts

- What is your relationship with the individual and family like? How has this changed over time?
- How confident do you feel in delivering CBR? How has this changed over time?
- If you had to deal with any difficult situations, what was that like?
- What is your attitude like towards people with schizophrenia? How has this changed over time?

9. How supported do you feel in delivering CBR?

Prompts

- How do you feel about your personal safety?
- How do you feel about the emotional burden on you?
- How accessible is your supervisor?
- How useful are your supervision meetings? How might they be made more useful for you?
- How useful are the group supervision meetings? Do you also discuss CBR with other CBR workers outside of these meetings?
- How do you deal with stress?
- How do you feel about the amount of top up training you received? How useful was it?

FOR CBR SUPERVISORS:

10. What was it like supervising CBR?

Prompts

- How is your relationship with the CBR worker? **How has it changed over time?**
- What was it like working with a person with schizophrenia +/- intellectual disability?
- How confident do you feel in supervising CBR? **How has this changed over time?**

11. What were your experiences of managing difficult situations?

Prompts

- How do you feel about the instructions/ flow charts?
- How do you feel about the support you got for managing these situations?
- What was your experience of adverse event reporting, if this occurred?
- Have your experiences or feelings changed over time in relation to managing difficult situations?

12. How supported do you feel in supervising CBR?

Prompts

- How do you feel about your personal safety?
- How accessible is the trial coordinator/ trial manager?
- How do you feel about the emotional burden on you?
- Do you ever feel stressed? How do you deal with stress?

Appendix D (iv): Ethical approval for the pilot and trial

Note the pilot and trial protocols were combined and therefore there is only one approval from each institution.

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Observational / Interventions Research Ethics Committee

Dr. Laura Asher
Research Degree Student
DPH / EPH
LSHTM

29 August 2014

Dear Dr. Asher,

Study Title: Rehabilitation Intervention for people with Schizophrenia in Ethiopia (RISE): a cluster randomised trial

LSHTM Ethics Ref: 7035

Thank you for your letter of 27 August 2014, responding to the Interventions Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Protocol / Proposal	RISE Trial protocol 28.08.13 amharic.docx	28/08/2013	1
Information Sheet	Patient Information Leaflets and consent forms 28.08.13.docx	28/08/2013	1

After ethical review

Any subsequent changes to the application must be submitted to the Committee via an Amendment form on the ethics online applications website. The Principal Investigator is reminded that all studies are also required to notify the ethics committee of any serious adverse events which occur during the project via an Adverse Event form on the ethics online applications website. An annual report form is required on the anniversary of the approval of the study and should be submitted during the lifetime of the study on the ethics online applications website. At the end of the study, please notify the committee via an End of Study form on the ethics online applications website. Ethics online applications website link: http://leo.lshtm.ac.uk

Yours sincerely,

Professor John DH Porter
Chair

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

ANNEX 3

Form AAUMF 03-008

IRB's Decision

Meeting No: 059/14 Date (D/M/Y): 16 April 2014

Protocol number: 083/13/Psy . Assigned No.....

Protocol Title: "RISE (Rehabilitation Intervention for people with the Schizophrenia in Ethiopia): a cluster randomized trial		
Principal Investigators:	Dr. Abebaw Fekadu	
Institute:	School of Medicine-College of Health Sciences, AAU	
Elements Reviewed (AAUMF 01-008) :	☑ Attached	☐ Not attached
Review of Revised Application ☐ Yes ☐ No	Date of Previous review:	
Decision of the meeting:	☑ **Approved** ☐ Approved with Recommendation ☐ Resubmission ☐ Disapproved	

I. Elements approved- 1. Protocol Version No. .....
2. Protocol Version Date.....
3. Informed consent Version No. .....
4. Informed Consent Version Date .....

II. Obligations of the PI-
1. Should comply with the standard international & national scientific and ethical guidelines
2. All amendments and changes made in protocol and consent form needs IRB approval
3. The PI should report SAE within 10 days of the event
4. End of the study, including manuscripts and thesis works should be reported to the IRB

III. **TO NERC** ☐

Institution Review Board (IRB) Approval: Period from **16 April 2014 to 15 April 2015**

Follow up report expected in

3 Months ___ 6 months ✓ 9 months_____one year____

Chairperson, IRB
Dr. Yimtubezenash W/Amanuel
Signature _____
Date: 17 April 2014

Associate Dean Director of Research and Technology Transfer
Signature _____
Date _____

ADDIS ABABA UNIVERSITY Institutional Review Board Office (IRB) College of Health Sciences

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የሳይንስና ቴክኖሎጂ ሚኒስቴር
The Federal Democratic Republic of Ethiopia
Ministry of Science and Technology

ቁጥር 3.10/048/2015
Ref. No.
ቀን Sep 7/2015
Date

To: Addis Ababa University, College of health sciences, Ethics Review Committee

Addis Ababa

Re: RISE (Rehabilitation Intervention for People with Schizophrenia in Ethiopia): a Cluster Randomized Trial

Dear Sir/Madam//Mr./Mrs./Dr,

The National Research Ethics Review Committee (NRERC) has reviewed the aforementioned project protocol in an expedited manner. We are writing to advise you that NRERC has granted

Full Approval

To the above named project, for a period of **one year (September 7, 2015- September 6, 2016).** All your most recently submitted documents have been approved for use in this study. The study should comply with the standard international and national scientific and ethical guidelines. Any change to the approved protocol or consent material must be reviewed and approved through the amendment process prior to its implementation. In addition, any adverse or unanticipated events should be reported within 24-48 hours to the NRERC. Please ensure that you submit biannual progress report once in six months and annual renewal application 30 days prior to the expiry date.

We, therefore, request you as PI and your esteemed organization to ensure the commencement and conduct of the study accordingly and wish for the successful completion of the project.

With regards,

Yohannes Sitotaw
Secretary of NRERC

CC: Dr. Abebaw Fekadu (PI)

_ NRERC chairperson

ማነጋገር ቢያስፈልግዎ
You may Contact

ፖ.ሳ.ቁ. P.O.Box 2490
አዲስ አበባ ኢትዮጵያ Addis Ababa, Ethiopia
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Web site:-http://www.most.gov.et

Appendix D (v): Pilot information sheets and consent forms

Patient Information Sheet

Study title
RISE (Rehabilitation Intervention for people with Schizophrenia in Ethiopia): pilot study

Invitation paragraph
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Schizophrenia is a severe mental illness that causes symptoms such as hearing voices and strange beliefs. Many people with schizophrenia find they have difficulty doing usual life tasks such as doing farm work, housework, getting dressed or going to church. Medication usually helps to improve some of these symptoms, but sometimes people find it difficult to always take their medication. Also, medication by itself often does not help with difficulties with life tasks. Some people with schizophrenia and their families do not understand what causes schizophrenia or the reasons for taking medication.

It has been suggested that community-based rehabilitation, alongside medication, may help to improve the lives of people with schizophrenia. Community-based rehabilitation involves a community health worker supporting people with schizophrenia and their families to understand schizophrenia, take medication regularly and get back to doing usual life tasks. We are not sure if community-based rehabilitation will work in the way we expect. We are therefore doing a study to test whether it improves the lives of people with schizophrenia and their caregivers.

Why have I been chosen?
You have been chosen to participate in this study because you have been found to have schizophrenia and your illness is particularly severe or disabling. People who meets this description in your kebele is being invited to participate, along with their caregivers. Four kebeles in Sodo district are involved in this pilot study and we expect about 22 participants (patients and caregivers) in total to be included.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. In order for you to take part, both you and your caregiver must agree to participate in the study.
You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
Length of the study
If you choose to take part, you will be involved in the study for the next 12 months, which is how long the study lasts. If you agree to take part in this study you will receive community-based rehabilitation and your usual care for schizophrenia.

Community-based rehabilitation

You will be visited at home or at the health post (in the kebele) by a community health worker. For the first two months the visits will be once a week; for around the following five months they will be once a fortnight; and for around the final five months the visits will be once a month. You will probably have about 23 sessions over the course of 12 months. Sessions will involve you and your caregiver and will usually last 30-60 minutes.

Usual treatment

You will be offered usual treatment for schizophrenia. Usual treatment involves attending the health centre to see a nurse or clinical officer in order to receive anti-psychotic medication. How often you need to attend the health centre will differ between individuals and will depend on how severe your illness is. You should have been offered usual treatment when you were found to have schizophrenia. You may or may not have taken up this treatment so far.

Interviews

You and your caregiver will be invited to attend up to three interviews in total. They will be in about 2 to 3 months, about 7 months time, and about 12 months time The interviews will be done by a researcher and will be done at your home or another convenient location for you. Each interview will last about 45 minutes for you and 45 minutes for your caregiver. Your interview will include open questions on:

- Your overall experiences of receiving community-based rehabilitation, for example whether you attended all the available sessions.
- Any problems with receiving community-based rehabilitation
- Any positive impacts of community-based rehabilitation for example whether it has helped you to get on with usual life tasks

You will also get a chance to cover any other topics which are related to receiving community-based rehabilitation and which you would like to discuss. If you agree, the interviews will be audio-recorded.

What is the intervention that is being tested?

In this study community-based rehabilitation is being tested.

The first sessions of community-based rehabilitation will involve the community health worker asking you about your particular needs and problems. Depending on your needs, the later sessions may involve the community health worker:

1. Giving information on what schizophrenia is and how it can be treated
2. Advising on how to make sure medication is taken regularly
3. Advising how to deal with negative attitudes and beliefs of friends and neighbours towards you
4. Helping you get into a routine of washing, dressing and eating
5. Supporting you to get a job or do farming work
6. Supporting you or your caregiver to be involved in local community organisations, for example *edir,* government microfinance scheme

You and/ or your caregiver may also be invited to attend a family support group with other people with schizophrenia and/ or their caregivers. In the session you would discuss the experience of having or looking after someone with schizophrenia and share ways to cope with the illness. The RISE project cannot give you any direct financial assistance or access to loans.

What are the possible disadvantages and risks of taking part?

Some people may find it difficult to find the time for the community-based rehabilitation sessions. Other people may not feel comfortable receiving a home visit from the community health worker as this may draw unwanted attention to you and your family. For this reason the community health worker will offer to hold the sessions at the health post, within the kebele. If you receive home visits you will be given advice on how to respond to neighbours' queries about the reason for these visits. Some people may also find it difficult to find the time to participate in the research interviews.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help improve the treatment of people with schizophrenia.

What happens when the research study stops?

After the study ends you will continue to be offered usual care. Community-based rehabilitation will last for 12 months and will not be offered after the study stops.

Will my taking part in the study be kept confidential?
Yes. All the information about your participation in this study will be kept confidential. If you join the study, some parts of your medical records and the data collected for the study will be looked at by authorised persons from the London School of Hygiene & Tropical Medicine and Addis Ababa University. They may also be looked at by representatives of regulatory authorities to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site. Any information about you which leaves the health centre will have your name and address removed so that you cannot be recognised from it. The nurses involved in your care at the health centre will be informed that you are participating in this study.

What will happen if I don't want to carry on with the study?
You can withdraw from community-based rehabilitation at any time. If you do so you can choose whether or not to continue attending the interviews. If you wish, the information collected in your interviews can be destroyed immediately. If you withdraw from receiving community-based rehabilitation and/ or the interviews you will still be able to receive usual care.

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to Rahel birhane by **09 13 60 43 52**. She will do her best to answer your questions**.** If you remain unhappy and wish to complain formally, you can speak to Dr. Abebaw Fekadu by using butajira project office phone number (**046 115 15 95) at working days and hours.**

The London School of Hygiene & Tropical Medicine holds insurance policies that apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation without having to prove that the School is at fault. This does not affect your legal rights to seek compensation.
If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform Rahel Birhane by 09 13 60 43 52.

What will happen to any information I give?
Information that identifies you will be stored separately and removed from all from the written records of the interviews before we analyse the data or report the findings. We will store all information about you securely, on both a computer and in a locked filing cabinet.

What will happen to the results of the research study?
The researchers intend to write a report of the results and publish them in a scientific journal. The researchers will hold a meeting in your local area to present the results of the study, which you will be invited to attend. You will not be identified in any report, publication or presentation.

Who is organising and funding the research?
The London School of Hygiene and Tropical Medicine, UK, and Addis Ababa University are organising this study. The Wellcome Trust is funding the study.

Who has reviewed the study?
This study was given a favourable ethical opinion by the Institutional Review Board at the College of Health Sciences, Addis Ababa University, and the Research Ethics Committee at the London School of Hygiene and Tropical Medicine.

For Further information
If you need further information about the study, you can call and speak to Rahel by 09 13 60 43 52.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking the time to read this sheet.

PARTICIPANT INFORMED CONSENT FORM

Full Title of Project: RISE (Rehabilitation Intervention people with Schizophrenia in Ethiopia): pilot study

Name of Principal Investigator: Dr Abebaw Fekadu
Name of Chief Investigator: Dr Mary De Silva

	Please initial box
1. I confirm that I have read and understand the subject information sheet dated November 11-2014 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from Addis Ababa University or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access my records.	
4. I agree to the health centre being informed of my participation in the study.	
5. I agree to take part in the above study.	

Name of Participant	Signature [or thumbprint]	Date
Name of Witness [if thumbprint]	Signature	Date
Name of Person taking consent (if different from Principal Investigator)	Signature	Date
Principal Investigator	Date	Signature

INFORMED CONSENT FORM FOR PARTICIPANTS UNABLE TO GIVE CONSENT THEMSELVES

Full Title of Project: RISE (Rehabilitation Intervention people with Schizophrenia in Ethiopia): pilot study

Name of Principal Investigator: Dr Abebaw Fekadu
Name of Chief Investigator: Dr Mary De Silva

	Please initial box
1. I confirm that I have read and understand the subject information sheet dated November 11- 2014 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my child/parent/spouse/…… participation is voluntary and they are free to withdraw at any time, without giving any reason, without their medical care or legal rights being affected.	
3. I understand that sections of any of their medical notes and data collected during the study, may be looked at by responsible individuals from Addis Ababa University or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access their records..	
4. I agree to their health centre being informed of their participation in the study.	
5. I agree for my child/parent/spouse/…… to take part in the above study.	

Name of Participant	Signature [or thumbprint]	Date
Name of Legal Representative	Relationship to participant	Date
Signature [or thumbprint]		
Name of Witness [if thumbprint]	Signature	Date
Name of Person taking consent	Signature	Date
Principal Investigator	Date	Signature

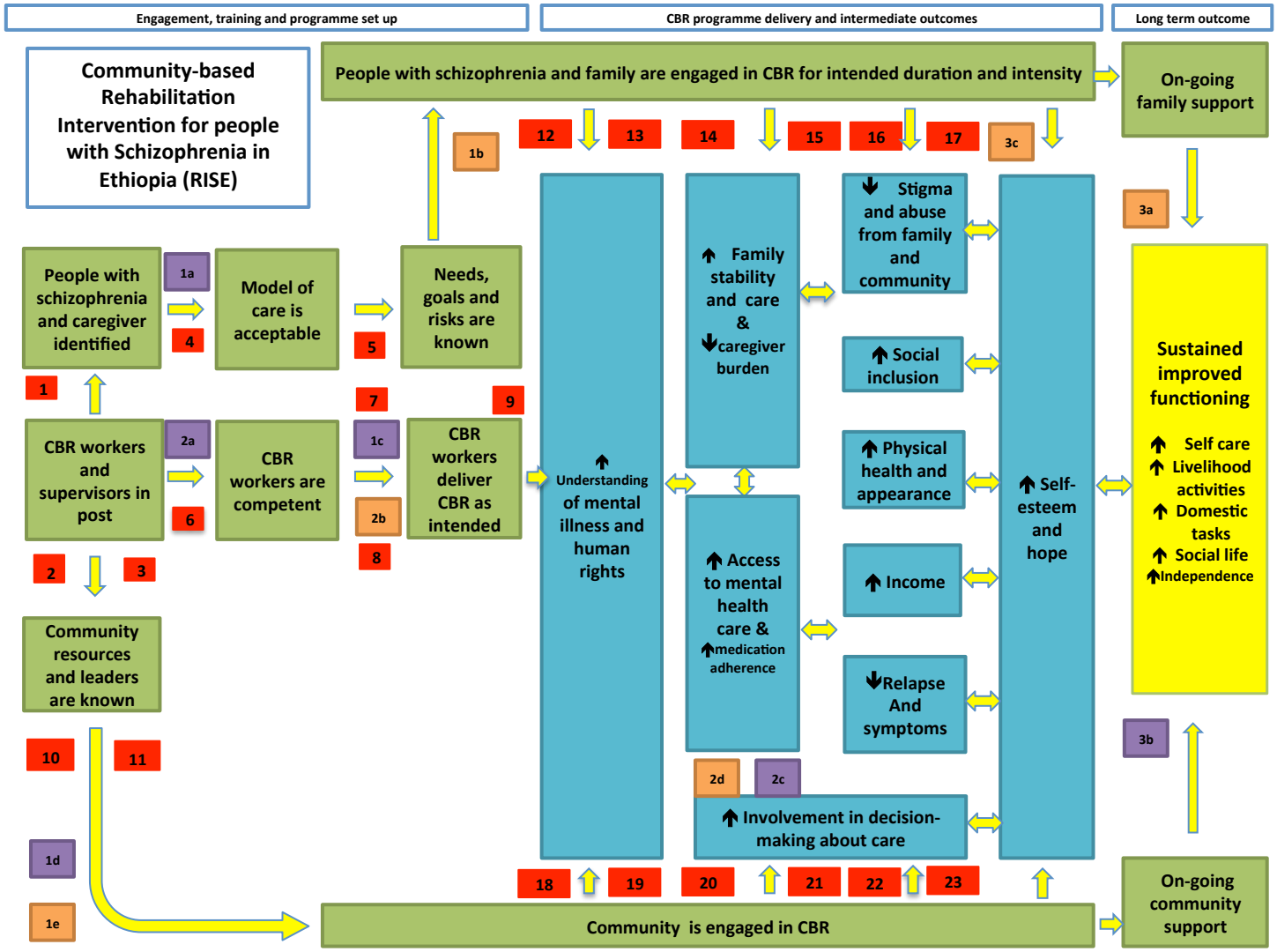
Appendix D (vi): Pilot supplementary data

CBR participant data relating to symptom severity and course type

ID	Symptom severity (BPRS-E)			Course type last 6 months (LCS)		
	0 m	6 m	12 m	0 m	6 m	12 m
1	42	14	60	Episodic	Never psychotic	Continuous
2 *	61	56	63	Continuous	Continuous	Continuous
3 *	37	44	Participant died	Continuous	Continuous	Participant died
4	50	25	24	Continuous	Never psychotic	Never psychotic
5	37	64	59	Episodic	Continuous	Continuous
6	39	24	Participant refused	Continuous	Never psychotic	Participant refused
7	55	55	24	Continuous	Never psychotic	Never psychotic
8	65	28	27	Episodic	Episodic	Never psychotic
9	63	27	24	Continuous	Never psychotic	Never psychotic
10	62	29	24	Continuous	Episodic	Never psychotic
Median (interquartile range) or %	**52.5 (39,62)**	**28.5 (25,55)**	**25.5 (24,59.5)**	**0% never psychotic**	**50% never psychotic**	**62.5% never psychotic**

** Co-morbid intellectual disability

Appendix D (vii) Detailed post-pilot theory of change



Interventions

Engagement, training and programme set up activities

1 CBR worker and community leaders identify people with schizophrenia
2 CBR worker signs contract and receive salary
3 CBR worker conducts resource mapping
4 CBR worker conducts initial engagement with family
5 CBR worker conducts needs and risk assessment in conjunction with supervisor
6 CBR worker receive adequate training, including field practice
7 CBR worker receive regular supervision including peer supervision and observed CBR sessions. Supplementary training given for skill gaps.
8 Measures to ensure safety of CBR worker
9 CBR worker creates rehabilitation plan in conjunction with supervisor
10 CBR worker educates community leaders about mental health and CBR
11 CBR worker conducts individual mobilisation with community leaders and traditional healers, as required

CBR activities

12 Support dealing with stigma and discrimination
13 Facilitate access to social networks and community activities → keep
14 Advice on healthy behaviours
15 Skills for self-care
16 Psycho-education and human rights education to people with schizophrenia and caregiver
17 Supports access to health facility
18 Adherence support
19 CBR worker facilitates access to free medication
20 Crisis and relapse management plans
21 Support returning to livelihood activities
22 Family intervention
23 Family support group

Assumptions

1b CBR can meet the needs of people with schizophrenia
1e Traditional and religious healers are willing to support CBR
2b CBR workers can overcome logistical challenges to deliver CBR
2d Anti-psychotic medication is accessible
3a CBR can improve functioning in people with schizophrenia
3c Family support groups are perceived to be useful

Rationale

Link between intermediate outcomes	Rationale
CBR workers and supervisors in post→ People with schizophrenia and caregivers identified	RAPID project uses CBR workers to identify people with disability. In implementation of CBR, this is the method that would be used to identify people with schizophrenia (Expert theory of change workshop)
CBR workers and supervisors in post → Community resources and leaders are known	CBR workers should lead on resource mapping, which is an essential first step in CBR to understand available opportunities. (Expert theory of change workshop, RAPID, WHO CBR guidelines (1)). Resource mapping successful (pilot).
CBR workers and supervisors in post →CBR workers are competent	Non-specialist workers trained to deliver mental health interventions in other settings (2-6) **Pilot finding: Non-specialists can be trained to deliver CBR for people with schizophrenia (rationale 2a)**
People with schizophrenia and caregivers identified → Model of care is acceptable	Initial engagement work can be carried out to ensure CBR is acceptable to participants e.g. adjusting content, building a trusting relationship (Expert theory of change workshop). **Pilot finding: people with schizophrenia and caregivers are willing and have time to participate (Rationale 1a)**

Model of care is acceptable →Needs, goals and risks are known	Greater acceptability of intervention is likely to lead to greater satisfaction with care and engagement (7) (theory of change workshops, qualitative interviews, pilot)
Needs, goals and risk are known→ People with schizophrenia and family are engaged in CBR for intended	People with schizophrenia have diverse needs so it is essential to assess them and tailor CBR accordingly (qualitative interviews). Needs assessment is part of RAPID assessment, COPSI assessment (8). Note: assumption not confirmed.
People with schizophrenia and family are engaged in CBR for intended duration and intensity → CBR conceptual framework*	Impact of CBR only achievable with proper participation in CBR (theory of change workshops, pilot)
CBR workers are competent → CBR workers deliver CBR as intended	CBR workers will deliver CBR successfully if they have adequate supervision and training (expert theory of change workshop)- demonstrated in previous projects (2-5, 9) **Pilot finding: CBR workers are willing to work with people with schizophrenia (rational 1c)**
Community resources and leaders are known → Community is engaged in CBR	Being aware of who community leaders are is an essential step before engaging/educating them (Expert theory of change workshop) **Pilot finding: Community leaders willing to support CBR (rationale 1d)**
Community is engaged in CBR → CBR conceptual framework	Community mobilisation is required for the individual/family level interventions to be successful e.g. engaging in Edir, reducing stigma (theory of change workshops and qualitative interviews). Importance of engaging community is central to CBR philosophy (WHO CBR guidelines (1)) **Pilot finding: A community mobilisation approach is needed in addition to home-based care (rationale 3b)**
People with schizophrenia and family are engaged in CBR for intended duration and intensity → Ongoing family support	CBR should empower individual and family to continue CBR after the CBR worker has left; this is only possible with proper engagement (theory of change workshops, RAPID, pilot)
Community is engaged in CBR → Ongoing community support	Community mobilisation is key way to ensure sustainability of CBR. (theory of change workshops, RAPID, WHO CBR guidelines (1)). Note: concerns over sustainability of community support in pilot.
Increased understanding of illness and human rights←→ Increased access to mental health care and increased medication adherence*	Understanding of schizophrenia may be limited at baseline (10). Increased understanding of benefits of medication for recovery will lead to greater attendance. Some evidence psychoeducation can improve appointment attendance (11, 12). Understanding may increase further once benefits of medication are seen.
Increased understanding of illness and human rights ←→ Increased family stability and care & decreased caregiver burden → reduced stigma/abuse	Education about causes of schizophrenia may increase appropriate supportive behaviors from family (pilot), as well as reducing physical abuse (e.g. not beating out devil). Families may be less likely to resort to restraint, even when their relative is unwell, if they have better mechanisms to deal with illness and caregiver burden
Increased family stability and care & decreased caregiver burden ←→ improved physical health and appearance	Components of more supportive approach from family may include giving their relative better quality food, including in mealtimes, taking to the health centre for physical health problems (pilot).
Increased income ←→ Increased access to mental health care and increased medication adherence	Key barrier to taking medication is inability to pay (qualitative interviews). Improving economic status likely to have an impact on ability to pay for treatment (pilot- partial). **Pilot finding: primary care staff are supportive of CBR (rationale 2c)**
Increased access to mental healthcare and increased medication adherence← →	Adherence associated with improved outcomes and reduced relapse in Butajira cohort (13) (pilot- partial). Evidence that adherence support leads to improved symptoms (14-16).

Decreased relapse and symptoms	Adherence may be sustained once changes in symptoms are seen.
Increased income→ Reduced caregiver burden	Part of caregiver burden is inability of people with schizophrenia to work and provide income (18). Reducing these problems is likely to reduce burden on family and increase ability to cope (pilot- partial).
Reduced stigma and abuse ←→ Sustained improved functioning in people with schizophrenia	Stigma may be a key factor in poor functioning. Improved functioning will lead to reduced stigma. Improved self-esteem will support both (pilot). Reducing chaining and restraint will allow people with schizophrenia to return to usual activities
Social inclusion ←→ Sustained improved functioning in people with schizophrenia	Social exclusion a key factor in poor functioning (qualitative interviews). Improved functioning will lead to greater social participation. Improved self-esteem will support both.
Improved physical health ←→ Sustained improved functioning	High rates of mortality in people with schizophrenia in Ethiopia (19). Improving physical health likely to lead to improved ability to do work and social activities. Improved functioning will lead to greater ability to self care. Improved self-esteem will support both (pilot).
Increased income ←→ Sustained improved functioning	Improved economic status likely to allow a range of activities e.g. social and community life. Improved ability to do income generating activities will lead to increased income. Improved self-esteem will support both (pilot).
Decreased relapse and symptoms ←→ Sustained improved functioning.	Problems with negative symptoms, linked to inability to do farm work (qualitative). Improved symptoms associated with improved functioning in Butajira cohort (17). Improved self-esteem will support both (pilot).
Increased understanding of illness and human rights←→ Increased involvement in decision making about care	People with schizophrenia may be more involved in treatment decisions if they and their family have a better understanding of human rights and the illness.
Increased involvement in decision making about care←→Self esteem and hope	Involvement in treatment decisions is empowering
Ongoing community support → Sustained improved functioning	Community mobilisation is key way to ensure sustainability of CBR (RAPID, theory of change workshops, WHO CBR guidelines (1))
Ongoing family support→ Sustained improved functioning in people with schizophrenia	Thread through CBR should be empowering individual and family to continue CBR after the CBR worker has left (RAPID, theory of change workshops)

* The rationale identified for these links post pilot is listed here; in addition these items had associated assumptions, which were highlighted for monitoring in the trial (see Chapter 7) NOTE: see Appendix D (ii) for references)

Appendix E (Chapter 8: Trial protocol)

Appendix E (i): SPIRIT statement

SPIRIT 2013 Checklist: Recommended items to address in a clinical trial protocol and related documents*

Section/item	Item No	Description	Page number of full protocol
Administrative information			
Title	1	Descriptive title identifying the study design, population, interventions, and, if applicable, trial acronym	1
Trial registration	2a	Trial identifier and registry name. If not yet registered, name of intended registry	3
	2b	All items from the World Health Organization Trial Registration Data Set	Throughout
Protocol version	3	Date and version identifier	1
Funding	4	Sources and types of financial, material, and other support	52
Roles and responsibilities	5a	Names, affiliations, and roles of protocol contributors	2-4
	5b	Name and contact information for the trial sponsor	4- 5
	5c	Role of study sponsor and funders, if any, in study design; collection, management, analysis, and interpretation of data; 52 writing of the report; and the decision to submit the report for publication, including whether they will have ultimate authority over any of these activities	
	5d	Composition, roles, and responsibilities of the coordinating centre, steering committee, endpoint adjudication committee, data management team, and other individuals or groups overseeing the trial, if applicable (see Item 21a for data monitoring committee)	2-4
Introduction			
Background and rationale	6a	Description of research question and justification for undertaking the trial, including summary of relevant studies (published and unpublished) examining benefits and harms for each intervention	16
	6b	Explanation for choice of comparators	16
Objectives	7	Specific objectives or hypotheses	18-19
Trial design	8	Description of trial design including type of trial (eg, parallel group, crossover, factorial, single group), allocation ratio, and 19 framework (eg, superiority, equivalence, noninferiority, exploratory)	

Methods: Participants, interventions, and outcomes

Study setting	9	Description of study settings (eg, community clinic, academic hospital) and list of countries where data will be collected. Reference to where list of study sites can be obtained	17- 18
Eligibility criteria	10	Inclusion and exclusion criteria for participants. If applicable, eligibility criteria for study centres and individuals who will perform the interventions (eg, surgeons, psychotherapists)	33- 32
Interventions	11a	Interventions for each group with sufficient detail to allow replication, including how and when they will be administered	22- 34
	11b	Criteria for discontinuing or modifying allocated interventions for a given trial participant (eg, drug dose change in response to harms, participant request, or improving/worsening disease)	33
	11c	Strategies to improve adherence to intervention protocols, and any procedures for monitoring adherence (eg, drug tablet return, laboratory tests)	43
	11d	Relevant concomitant care and interventions that are permitted or prohibited during the trial	n/a
Outcomes	12	Primary, secondary, and other outcomes, including the specific measurement variable (eg, systolic blood pressure), analysis metric (eg, change from baseline, final value, time to event), method of aggregation (eg, median, proportion), and time point for each outcome. Explanation of the clinical relevance of chosen efficacy and harm outcomes is strongly recommended	28-43, 125
Participant timeline	13	Time schedule of enrolment, interventions (including any run-ins and washouts), assessments, and visits for participants. A schematic diagram is highly recommended (see Figure)	29-32, 125
Sample size	14	Estimated number of participants needed to achieve study objectives and how it was determined, including clinical and statistical assumptions supporting any sample size calculations	46-47
Recruitment	15	Strategies for achieving adequate participant enrolment to reach target sample size	29- 32

Methods: Assignment of interventions (for controlled trials)

Allocation:

Sequence generation	16a	Method of generating the allocation sequence (eg, computer-generated random numbers), and list of any factors for stratification. To reduce predictability of a random sequence, details of any planned restriction (eg, blocking) should be provided in a separate document that is unavailable to those who enrol participants or assign interventions	33
Allocation concealment mechanism	16b	Mechanism of implementing the allocation sequence (eg, central telephone; sequentially numbered, opaque, sealed envelopes), describing any steps to conceal the sequence until interventions are assigned	33
Implementation	16c	Who will generate the allocation sequence, who will enrol participants, and who will assign participants to interventions	33

Blinding (masking)	17a	Who will be blinded after assignment to interventions (eg, trial participants, care providers, outcome assessors, data analysts), and how	48, 36
	17b	If blinded, circumstances under which unblinding is permissible, and procedure for revealing a participant's allocated intervention during the trial	n/a
Methods: Data collection, management, and analysis			
Data collection methods	18a	Plans for assessment and collection of outcome, baseline, and other trial data, including any related processes to promote data quality (eg, duplicate measurements, training of assessors) and a description of study instruments (eg, questionnaires, laboratory tests) along with their reliability and validity, if known. Reference to where data collection forms can be found, if not in the protocol	38-42, 127-163
	18b	Plans to promote participant retention and complete follow-up, including list of any outcome data to be collected for participants who discontinue or deviate from intervention protocols	43
Data management	19	Plans for data entry, coding, security, and storage, including any related processes to promote data quality (eg, double data entry; range checks for data values). Reference to where details of data management procedures can be found, if not in the protocol	46
Statistical methods	20a	Statistical methods for analysing primary and secondary outcomes. Reference to where other details of the statistical analysis plan can be found, if not in the protocol	47-49
	20b	Methods for any additional analyses (eg, subgroup and adjusted analyses)	47-49
	20c	Definition of analysis population relating to protocol non-adherence (eg, as randomised analysis), and any statistical methods to handle missing data (eg, multiple imputation)	47-49
Methods: Monitoring			
Data monitoring	21a	Composition of data monitoring committee (DMC); summary of its role and reporting structure; statement of whether it is independent from the sponsor and competing interests; and reference to where further details about its charter can be found, if not in the protocol. Alternatively, an explanation of why a DMC is not needed	52, 172-179
	21b	Description of any interim analyses and stopping guidelines, including who will have access to these interim results and make the final decision to terminate the trial	n/a
Harms	22	Plans for collecting, assessing, reporting, and managing solicited and spontaneously reported adverse events and other unintended effects of trial interventions or trial conduct	34-38
Auditing	23	Frequency and procedures for auditing trial conduct, if any, and whether the process will be independent from investigators and the sponsor	52

Ethics and dissemination

Research ethics approval	24	Plans for seeking research ethics committee/institutional review board (REC/IRB) approval	50
Protocol amendments	25	Plans for communicating important protocol modifications (eg, changes to eligibility criteria, outcomes, analyses) to relevant parties (eg, investigators, REC/IRBs, trial participants, trial registries, journals, regulators)	50
Consent or assent	26a	Who will obtain informed consent or assent from potential trial participants or authorised surrogates, and how (see Item 32)	50-51
	26b	Additional consent provisions for collection and use of participant data and biological specimens in ancillary studies, if applicable	n/a
Confidentiality	27	How personal information about potential and enrolled participants will be collected, shared, and maintained in order to protect confidentiality before, during, and after the trial	51
Declaration of interests	28	Financial and other competing interests for principal investigators for the overall trial and each study site	Signed forms for each investigator
Access to data	29	Statement of who will have access to the final trial dataset, and disclosure of contractual agreements that limit such access for investigators	46, 49
Ancillary and post-trial care	30	Provisions, if any, for ancillary and post-trial care, and for compensation to those who suffer harm from trial participation	n/a
Dissemination policy	31a	Plans for investigators and sponsor to communicate trial results to participants, healthcare professionals, the public, and other relevant groups (eg, via publication, reporting in results databases, or other data sharing arrangements), including any publication restrictions	
	31b	Authorship eligibility guidelines and any intended use of professional writers	52
	31c	Plans, if any, for granting public access to the full protocol, participant-level dataset, and statistical code	

Appendices

Informed consent materials	32	Model consent form and other related documentation given to participants and authorised surrogates	85-122
Biological specimens	33	Plans for collection, laboratory evaluation, and storage of biological specimens for genetic or molecular analysis in the current trial and for future use in ancillary studies, if applicable	n/a

Appendix E (ii): Adequacy of screening assessment form

ID. Details		*Data entry*
Date	**[ ][ ] / [ ][ ] / [ ][ ][ ][ ]**	*scdate*
Patient's PRIME ID	**[ ][ ][ ][ ][ ] / [ ][ ]**	*primeid*
Assessor's ID	**[ ][ ]**	*assid*
RISE Pilot ID (complete if recruited):	**[ ][ ]**	*risepid*

1	**Was the patient deemed eligible for the RISE pilot according to the screening procedure?**	**Yes [→ Go to Q2]**	**1**	**elig**
		No [→ Go to Q4]	**0**	
2	**In your own assessment of the patient, will they benefit from receiving CBR?**	**Yes[→ Form complete]**	**1**	**eligel**
		No [→ Go to Q3]	**0**	
3	**Give details on why the patient may not benefit from receiving CBR [→ form is complete]**			*whynotbel*
4	**In your own assessment of the patient, would they have benefited from receiving CBR?**	**Yes [→ Go to Q5]**	**0**	**noteligible**
		No [→ Form complete]	**1**	
5	**Give details on why they may benefit from receiving CBR [→ form is complete]**			*whybel*

Appendix E (iii): Trial eligibility assessment form

Date	**[ ] [ ] / [ ] [ ] / [ ] [ ] [ ] [ ] E C**	*scdate*
Patient's PRIME ID	**[ ] [ ] [ ] [ ]**	*parid*
Assessor's ID	**[ ] [ ]**	*assid*
RISE ID	**[ ] [ ] [ ] [ ] [complete if recruited to RISE trial]**	*riseid*

1	Is the patient in the PRIME cohort study or have they otherwise had facility-based care available to them for the past 6 months?	**Yes [→ go to Q2]**	**1**	*dx*
		No [→ patient must not be entered in RISE trial]	**0**	
2	Does the patient have a documented DSM-IV diagnosis of schizophrenia, schizoaffective disorder or schizophreniform disorder?	**Yes [→ go to Q3]**	**1**	*dxloc*
		No [→ patient must not be entered in RISE trial]	**0**	
3	Is the patient 18 years or over?	**Yes [→ go to Q4]**	**1**	*over18*
		No [→ patient must not be entered in RISE trial]	**0**	
4a	What is the patient's BPRS-E score? *[see Clinician Section, Section 1]*	**[→ go to Q4b]**		*bprse*
4b	Is the BPRS-E score 52 or greater?	**Yes [→ go to Q4c]**	**1**	*bprse52*
		No [→ go to Q4c]	**0**	
4c	What is the patient's converted caregiver reported WHODAS score? *[see Caregiver Section, Section 17→ convert score]*	**[→ go to Q4d]**		*whodas*
4d	Is the WHODAS score 35 or greater?	**Yes [→ go to Q4e]**	**1**	*whodas35*
		No [→ go to Q4e]	**0**	
4e	What is the patient's converted patient reported WHODAS score? *[see Patient Section, Section 1→ convert score]*	**[→ go to Q4f]**		*whodasp*
4f	Is the WHODAS score 35 or greater?	**Yes [→ go to Q4g]**	**1**	*whodasp35*
		No [→ go to Q4g]	**0**	
4g	Has the patient had continuous illness over the past 6 months, according to the LCS? *[see Clinician Section, Q401]*	**Yes [→ go to Q4h]**	**1**	*lcs*
		No [→ go to Q4h]	**0**	
4h	How many of the past 6 months has the patient been symptomatic, according to the LIFE score? *[see Clinician Section, Section 5]*	**[→ go to Q4i]**		*life*

4i	Has the patient been symptomatic for 3 or more out of the last 6 months?	**Yes [→ go to Q4j]**	**1**	*life3*
		No [→ go to Q4j]	**0**	
4j	What is the patient's CGI severity score? *[see Clinician Section, Q 201]*	**[→ go to Q4k]**		*cgi*
4k	Did the patient score 3 or greater on the CGI Severity?	**Yes [→ go to Q4l]**	**1**	*cgi3*
		No [→ go to Q4l]	**0**	
4l	Did you answer 'Yes' to one or more of the following questions: 4b, 4d, 4f, 4g, 4i or 4k?	**Yes [→ go to Q5]**	**1**	*clinicaleli g*
		No [→ Patient must not be entered in RISE trial]	**0**	
5	Has the patient been a resident in their kebele for >6 months and have no immediate plans to leave the kebele?	**Yes [→ go to Q6]**	**1**	*keb6m*
		No [→ Patient must not be entered in RISE trial]	**0**	
6	Does the patient have a primary caregiver who is willing to participate in the study?	**Yes [→ Patient is eligible for RISE; proceed to the Consent Procedure]**	**1**	*careg*
		No [→ Patient must not be entered in RISE trial]	**0**	

Appendix E (iv): Trial information sheets and consent forms

Patient Information Leaflet Version 2.0 (01.03.15)

Study title
RISE (Rehabilitation Intervention for people with Schizophrenia in Ethiopia): a cluster randomised trial

Invitation paragraph
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Schizophrenia is a severe mental illness that causes symptoms such as hearing voices and strange beliefs. Many people with schizophrenia find they have difficulty doing usual life tasks such as doing farm work, housework, getting dressed or going to church. Medication usually helps to improve some of these symptoms, but sometimes people find it difficult to always take their medication. Also, medication by itself often does not help with difficulties with life tasks. Some people with schizophrenia and their families do not understand what causes schizophrenia or the reasons for taking medication.

It has been suggested that community-based rehabilitation, alongside medication, may help to improve the lives of people with schizophrenia. Community-based rehabilitation involves a community health worker supporting people with schizophrenia and their families to understand schizophrenia, take medication regularly and get back to doing usual life tasks. We are not sure if community-based rehabilitation will work in the way we expect. We are therefore doing a study to test whether it improves the lives of people with schizophrenia and their caregivers.

Why have I been chosen?
You have been chosen to participate in this study because you have been found to have schizophrenia and your illness is particularly severe or disabling. Everyone who meets this description in your kebele is being invited to participate, along with their caregivers. All kebeles in Sodo district are involved in the study and we expect 160 people with schizophrenia and their caregivers in total to be included.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. In order for you to take part, both you and your caregiver must agree to participate in the study. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
Length of the study
If you choose to take part, you will be involved in the study for the next 12 months, which is how long the study lasts.

Deciding which treatment you will receive
Sometimes we don't know which way of treating patients is best. To find out, we need to make comparisons between the different treatments. We will put the 54 kebeles who are involved in the study into two groups and give the participants in each kebele group a different treatment; the results

will be compared to see if one treatment is better. To try to make sure the groups are the same to start with, each kebele is put into a group by chance (randomly). The results are then compared.
You have a 50% (one in two) chance of receiving community-based rehabilitation as well as your usual treatment at the health centre. The other 50% will receive only their usual treatment at the health centre.

Community-based rehabilitation
If your kebele is selected to receive community-based rehabilitation you will be visited at home or at the health post (in the kebele) by a community health worker. For the first two months the visits will be once a week; for the following five months they will be once a fortnight; and for the final five months the visits will be once a month. You will probably have about 23 sessions over the course of 12 months. Sessions will involve you and your caregiver and will usually last 30-60 minutes.

Usual treatment
You will be offered usual treatment for schizophrenia, whether or not you are also receiving community-based rehabilitation. Usual treatment involves attending the health centre to see a nurse or clinical officer in order to receive anti-psychotic medication. How often you need to attend the health centre will differ between individuals and will depend on how severe your illness is. You were offered usual treatment when you were diagnosed with schizophrenia around 6 months ago. You may or may not have taken up this treatment so far.

Research interviews
You and your caregiver will be invited to attend two research interviews in total, whether or not you are receiving community-based rehabilitation. You have already been invited to the first one, which is in 6 months time, because you are a participant in the PRIME research study. If you agree to be part of the RISE study we would like you to attend another interview in 12 months time. The interview will be done by researchers and will be done at the health centre, your home or another convenient location for you. It will last about 90 minutes for you and 30 minutes for your caregiver. Your interview will include questions on:

- Symptoms of schizophrenia
- Difficulties with looking after yourself and doing usual life tasks
- Attitudes and beliefs of other people to you and your illness
- How often you have used health services and the amount you have spent
- How often you take your medication
- Problems with low mood and drinking alcohol
- Experiences of being tied up or being the victim of violence

What is the intervention that is being tested?
In this study community-based rehabilitation is being tested.
The first sessions of community-based rehabilitation will involve the community health worker asking you about your particular needs and problems. Depending on your needs, the later sessions may involve the community health worker:

- Giving information on what schizophrenia is and how it can be treated
- Advising on how to make sure medication is taken regularly
- Advising how to deal with negative attitudes and beliefs of friends and neighbours towards you
- Helping you get into a routine of washing, dressing and eating
- Supporting you to get a job or do farming work
- Supporting you or your caregiver to be involved in local community organisations, for example *edir,.*

You and/ or your caregiver may also be invited to attend a group session with other people with schizophrenia and/ or their caregivers. In the session you would discuss the experience of having or looking after someone with schizophrenia and share ways to cope with the illness. The RISE project cannot give you any direct financial assistance or access to loans. Remember that if you choose to take part in this study, you may or may not receive community-based rehabilitation. That depends on whether your kebele is randomly selected to receive community-based rehabilitation.

What are the possible disadvantages and risks of taking part?
Some people may find it difficult to find the time for the community-based rehabilitation sessions. Other people may not feel comfortable receiving a home visit from the community health worker as this may

draw unwanted attention to you and your family. For this reason the community health worker will offer to hold the sessions at the health post, within the kebele. If you receive home visits you will be given advice on how to respond to neighbours' queries about the reason for these visits. Some people may also find it difficult to find the time to participate in the research interviews.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get might help improve the treatment of people with schizophrenia.

What happens when the research study stops?
After the study ends you will continue to be offered usual care at the health centre. Community-based rehabilitation will last for 12 months and will not be offered after the study stops.

Will my taking part in the study be kept confidential?
Yes. All the information about your participation in this study will be kept confidential. If you join the study, some parts of your medical records and the data collected for the study will be looked at by authorised persons from the London School of Hygiene & Tropical Medicine and Addis Ababa University. They may also be looked at by representatives of regulatory authorities to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site. Any information about you which leaves the health centre will have your name and address removed so that you cannot be recognised from it. The nurses involved in your care at the health centre will be informed that you are participating in this study.

What will happen if I don't want to carry on with the study?
You can withdraw from community-based rehabilitation at any time. If you do so you can choose whether or not to continue attending the research interviews. If you wish, the information collected in your interviews can be destroyed immediately. If you withdraw from receiving community-based rehabilitation and/ or the interviews you will still be able to receive usual care.

What if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to Rahel Birhane on **09 13 60 43 52**. She is the study coordinator and she will do her best to answer your questions**.** If you remain unhappy and wish to complain formally, you can speak to Dr. Abebaw Fekadu by using the Butajira project office phone number (**046 115 15 95)** during working hours**.** The London School of Hygiene & Tropical Medicine holds insurance policies that apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation without having to prove that the School is at fault. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform Rahel Birhane.

What will happen to any information I give?
Information that identifies you will be stored separately and removed from all questionnaires before we analyse the data or report the findings. We will store all information about you securely, on both a computer and in a locked filing cabinet.

What will happen to the results of the research study?
The researchers intend to write a report of the results and publish them in a scientific journal. The researchers will hold a meeting in your local area to present the results of the study, which you will be invited to attend. You will not be identified in any report, publication or presentation.

Who is organising and funding the research?
The London School of Hygiene and Tropical Medicine, UK, and Addis Ababa University are organising this study. The Wellcome Trust is funding the study.

Who has reviewed the study?

This study was given a favourable ethical opinion by the Institutional Review Board at the College of Health Sciences, Addis Ababa University, and the Research Ethics Committee at the London School of Hygiene and Tropical Medicine.

Contact Details

If you need further information about the study, you can call and speak to the study coordinator Rahel Birhane 09 13 60 43 52.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking the time to read this sheet.

PARTICIPANT INFORMED CONSENT FORM

Full Title of Project: RISE (Rehabilitation Intervention people with Schizophrenia in Ethiopia): a cluster-randomised trial

Name of Chief Investigator: Dr Laura Asher

Name of Principal Investigator: Dr Abebaw Fekadu

	Please initial box
1. I confirm that I have read and understand the subject information sheet dated 01.03.15 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from Addis Ababa University or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access my records.	
4. I agree to the health centre being informed of my participation in the study.	
5. I agree to take part in the above study.	

Name of Participant	Signature [or thumbprint]	Date
Name of Witness [if thumbprint]	Signature	Date
Name of Person taking consent	Signature	Date

1 copy for participant; 1 copy for Principal Investigator

INFORMED CONSENT FORM FOR PARTICIPANTS UNABLE TO GIVE CONSENT THEMSELVES

Full Title of Project: RISE (Rehabilitation Intervention people with Schizophrenia in Ethiopia): a cluster-randomised trial

Name of Chief Investigator: Dr Laura Asher **Name of Principal Investigator**: Dr Abebaw Fekadu

	Please initial box
1. I confirm that I have read and understand the subject information sheet dated 01.03.15 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my child/parent/spouse/…… participation is voluntary and they are free to withdraw at any time, without giving any reason, without their medical care or legal rights being affected.	
3. I understand that sections of any of their medical notes and data collected during the study, may be looked at by responsible individuals from Addis Ababa University or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access their records..	
4. I agree to their health centre being informed of their participation in the study.	
5. I agree for my child/parent/spouse/…… to take part in the above study.	

Name of Participant	Signature [or thumbprint]	Date
Name of Legal Representative	Relationship to participant	Date
Signature [or thumbprint]		
Name of Witness [if thumbprint]	Signature	Date
Name of Person taking consent	Signature	Date

Patient Information Leaflet for eligibility check Version 2.0 (01.03.15)

Study title
RISE (Rehabilitation Intervention for people with Schizophrenia in Ethiopia)

Invitation paragraph
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
Schizophrenia is a severe mental illness that causes many problems with day-to-day life. We are looking for people who have this illness to take part in a study called RISE. In the RISE study some people with schizophrenia will receive community-based rehabilitation. Community-based rehabilitation involves a community health worker supporting people with schizophrenia and their families to understand schizophrenia, take medication regularly and get back to doing usual life tasks.
To make sure the right people are included in the study, we need to do interviews with people who have had some problems. This will help us to check whether they have schizophrenia. Any person who is found to have schizophrenia in the interview will be invited to join the RISE study.

Why have I been chosen?
You have been chosen to participate in this study because you have had some problems and you may have the illness schizophrenia.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
If you agree to take part, a nurse will do an interview with you. The interview will take about 45 minutes to 1 hour. She will ask you questions about problems you have had including symptoms and problems with day-to-day activities. If, from this interview, the nurse thinks that you may have a mental health problem called schizophrenia, then you will be invited to participate in the RISE study.

What are the possible disadvantages and risks of taking part?
We don't think there will be any major risks from you participating in the interview. You may feel that you don't have time to take part. Some people might find it difficult or upsetting to answer questions about their illness.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get might help improve the treatment of people with schizophrenia.

Will my taking part in the study be kept confidential?
Yes. All the information about your participation in this study will be kept confidential. If you take part in the interview, the data collected will be looked at by authorised persons from the London School of Hygiene & Tropical Medicine and Addis Ababa University. They may also be looked at by

representatives of regulatory authorities to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site. Any information about you which is recorded will have your name and address removed so that you cannot be recognised from it. We will store all information about you securely, on both a computer and in a locked filing cabinet.

What will happen if I don't want to carry on with the study?
You can withdraw from the interview at any time. If you wish, the information collected in your interviews can be destroyed immediately. If you withdraw from the interview you will still be able to receive usual care.

What if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to Rahel Birhane on **09 13 60 43 52**. She is the study coordinator and she will do her best to answer your questions**.** If you remain unhappy and wish to complain formally, you can speak to Dr. Abebaw Fekadu by using the Butajira project office phone number (**046 115 15 95)** during working hours**.**
The London School of Hygiene & Tropical Medicine holds insurance policies that apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation without having to prove that the School is at fault. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for a legal action.

Who is organising and funding the research?
The London School of Hygiene and Tropical Medicine, UK, and Addis Ababa University are organising this study. The Wellcome Trust is funding the study.

Who has reviewed the study?
This study was given a favourable ethical opinion by the Institutional Review Board at the College of Health Sciences, Addis Ababa University, and the Research Ethics Committee at the London School of Hygiene and Tropical Medicine.

Contact Details
If you need further information about the study, you can call and speak to the study coordinator Rahel Birhane 09 13 60 43 52.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking the time to read this sheet.

PARTICIPANT INFORMED CONSENT FORM FOR ELIGIBILITY CHECK

Full Title of Project: RISE (Rehabilitation Intervention people with Schizophrenia in Ethiopia): a cluster-randomised trial

Name of Chief Investigator: Dr Laura Asher
Name of Principal Investigator: Dr Abebaw Fekadu

	Please initial box
1. I confirm that I have read and understand the subject information sheet dated 01.03.15 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from Addis Ababa University or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access my records.	
4. I agree to the health centre being informed of my participation in the study.	
5. I agree to take part in the above study.	

Name of Participant	Signature [or thumbprint]	Date
Name of Witness [if thumbprint]	Signature	Date
Name of Person taking consent	Signature	Date

1 copy for participant; 1 copy for Principal Investigator

INFORMED CONSENT FORM FOR ELIGIBILITY CHECK- FOR PARTICIPANTS UNABLE TO GIVE CONSENT THEMSELVES

Full Title of Project: RISE (Rehabilitation Intervention people with Schizophrenia in Ethiopia): a cluster-randomised trial

Name of Chief Investigator: Dr Laura Asher **Name of Principal Investigator**: Dr Abebaw Fekadu

	Please initial box
1. I confirm that I have read and understand the subject information sheet dated 01.03.15 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my child/parent/spouse/…… participation is voluntary and they are free to withdraw at any time, without giving any reason, without their medical care or legal rights being affected.	
3. I understand that sections of any of their medical notes and data collected during the study, may be looked at by responsible individuals from Addis Ababa University or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access their records..	
4. I agree to their health centre being informed of their participation in the study.	
5. I agree for my child/parent/spouse/…… to take part in the above study.	

Name of Participant	Signature [or thumbprint]	Date
Name of Legal Representative	Relationship to participant	Date
Signature [or thumbprint]		
Name of Witness [if thumbprint]	Signature	Date
Name of Person taking consent	Signature	Date

INFORMATION SHEET FOR PARTICIPANTS QUALITATIVE STUDY version 2.2 (13.05.2015)
IRB Reference Number: 083/14/Psy
YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Study title: RISE (Rehabilitation Intervention for people with Schizophrenia in Ethiopia) qualitative study
Invitation paragraph
We would like to invite you to participate in this original research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.
This study is being conducted by Addis Ababa University.
Aims of the research
This study is looking at the acceptability, feasibility and impact of a community-based rehabilitation programme for people with schizophrenia and their families.

Who are we recruiting?
We are recruiting the following different groups of people:
- People with schizophrenia, their families or main caregivers who have been receiving community-based rehabilitation
- People with schizophrenia, their families or main caregivers who have not been receiving community-based rehabilitation, but who are part of the PRIME psychosis cohort.
- Workers currently delivering community-based rehabilitation and their supervisors
- Traditional healers and community leaders who live in kebeles where community-based rehabilitation has been delivered and who may have been involved in community-based rehabilitation
- Primary care staff (nurse and health officers) who have been involved in the care of people with schizophrenia who are receiving community-based rehabilitation

What will happen if you agree to take part?

In-depth interviews
If you are a person with schizophrenia, caregiver, community leader or community-based rehabilitation supervisor you will be invited to participate in a one-to-one interview with a researcher. The interviews will usually be held at your home, or another place that is convenient for you. Some community-based rehabiliation workers may also be asked to participate in in-depth interviews.
If you are a person with schizophrenia or family member you will be asked about the problems you have and, if you have received community-based rehabilitation, whether it helped. All groups will be asked some questions about your perceptions about the acceptability, feasibility and impact of the community-based rehabilitation for schizophrenia that you have been involved in, or that has been taking place in your kebele. The interviews will last up to one hour. With your agreement, we will audio-tape the interview.
Focus group discussion group
The discussion groups will be located at a central location within your town of residence, usually at your workplace. There will be between 5 and 10 people in the group. There will be separate groups for community-based rehabilitation workers and primary care workers. The group will be asked some questions about your experiences and perceptions regarding community-based rehabiltiation for people with schizophrenia, including how useful you think it is. You will be invited to contribute your opinion as part of the discussion, although there is no obligation for you to speak during the group discussion. The discussion will take between 1 and 2 hours. If all participants give agreement then we

will tape-record the discussions and interview. You will be given refreshments and reimbursed for your transport costs and time.

Member checking

After your interview or focus group discussion, you may also be invited to participate in another meeting. At this meeting we will feedback our ideas about what you said in the interview or group discussion, and check that we have understood the information correctly. If you agree we will audio record the meeting. The meeting will take about 1 hour.

Timing

If you are a person with schizophrenia or family member, you will be asked to participate in two interviews. The first will take place immediately, and the second will take place in about 12 months time. Community based rehabiliation workers and supervisors and will be asked to take part in up to 4 interviews or focus group discussions over the next 18 months. Community leaders and health centre staff will be asked to participate in up to 3 interviews or focus groups discussions over the next 18 months. The member checking meetings, if you are asked to take part, will take place a few weeks after your interview or discussion group.

Risks of being in the study

We don't expect that the discussion will cause you any difficulties. On rare occasions, people might be upset by the questions that are being asked. If you are distressed by the questions then you do not have to answer the question or you can leave the group at any time.

Possible benefits

Information obtained through these discussions will be instrumental in improving the community-based rehabilitation programme for people with schizophrenia in Ethiopia. We hope this will improve the care of people with schizophrenia in Ethiopia and other similar countries.

Once the overall study is completed, we will let you know what we found, either by inviting you to a meeting, giving you a leaflet or publicising our findings in the district.

What we will do with your data

If you take part in the tape-recorded discussion, we will make sure that the tapes do not include your name or identifying information. If notes are taken instead of tape-recording, these notes will not include your name or identifying information. The tapes and notes will be kept in a locked cupboard. Once the interview tapes have been written down, and the data has been analysed, the tapes will be cleared.

Nobody except the project co-ordinators and project data managers will know that the information belongs to you. We will keep the questionnaires in a locked cupboard.

After the end of this study, the information you tell us may be used by other researchers, but they will not be able to identify you in any way.

Main researchers:

Dr Abebaw Fekadu, Dr Laura Asher, Rahel Birhane and Alehegn Habtamu. You can contact us on 0112756434 from Monday to Friday during working hours.

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time and without giving a reason.

If this study has harmed you in any way you can contact the RISE trial coordinator, Rahel Birhane 0913604352. You can also contact the Institutional Review Board, Addis Ababa University, using the details below for further advice and information:

- Institutional Review Board, School of Medicine, Addis Ababa University
  Telephone number: 0115-5538734

- You may withdraw your data from the project at any time up until it is transcribed for use in the final report.
- If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

PARTICIPANT INFORMED CONSENT FORM

Full Title of Project: RISE (Rehabilitation Intervention people with Schizophrenia in Ethiopia): qualitative study

Name of Chief Investigator: Dr Laura Asher

Name of Principal Investigator: Dr Abebaw Fekadu

	Please initial box
1. I confirm that I have read and understand the subject information sheet dated 13.05.15 (version 2.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that data collected during the study may be looked at by responsible individuals from Addis Ababa University where it is relevant to my taking part in this research. I give permission for these individuals to access this data.	
4. I agree to take part in the above study.	
OPTIONAL 5. I agree for the interview to be audio-recorded.	

Name of Participant	Signature [or thumbprint]	Date
Name of Witness [if thumbprint]	Signature	Date
Name of Person taking consent	Signature	Date

1 copy for participant; 1 copy for Principal Investigator

Appendix E (v): Process data forms

RISE 12 month participant process data form		
Individual RISE ID	[ ] [ ] [ ] [ ]	**riseid**
Form completed by ID	**T** [ ] [ ]	**tid**
CBR worker ID	**W** [ ] [ ]	**wid**
Supervisor ID	**S** [ ] [ ]	**sid**
Date completed (ET)	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	**indprocessd6**

Section 1: Receipt of CBR				
101	Is the individual currently receiving CBR? (defined as at least 1 visit in the last month)	No	0	currcbr6
		Yes [→ go to Q 103]	1	
102	Why is the individual not currently receiving CBR?	Participant dropped out	1	currcbry6
		Participant died	2	
		Not stated	3	
		Other reason	4	
		Participant not willing	5	
	Specify other			currcbryo6
103	Has the individual been receiving CBR continuously for the last 12 months (defined as at least 1 visit in each 1m period)	No	0	moncbr6
		Yes [→ go to Q 105]	1	
104	Why did the individual not continuously receive CBR for the last 12 months?	Participant dropped out	1	moncbry6
		Participant died	2	
		Not stated	3	
		Other reason	4	
		Participant not willing	5	
		Cannot access participant	6	
	Specify other			moncbryo6
105	Date of last CBR home visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		lastcbr6
106	Date of initial visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		firstcbr6

Section 2: Phases and home visits				
201	Date of first Phase 1 visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		p1startd6
202	Number of home visits in Phase 1	[ ] [ ]		p1visit6
203	Has the individual completed Phase 1?	No [→ go to next section]	0	P1comp6
		Yes	1	
204	Date last Phase 1 visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		P1compd6
205	Has the individual started Phase 2?	No	1	P2start6
		Yes	2	
206	Date first Phase 2 visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		P2startd6
207	Number of home visits in Phase 2	[ ] [ ]		P2visit6
208	Has the individual completed Phase 2?	No [→ go to next section]	0	P2comp6
		Yes	1	
209	Date last Phase 2 visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		P2compd6
210	Has the individual started Phase 3?	No [→ go to next section]	1	P3start6
		Yes	2	
211	Date fist Phase 3 visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		P3startd6
212	Number of home visits in Phase 3	[ ] [ ]		P3visit6
213	Has the individual completed Phase 3?	No [→ go to next section]	0	P3comp6
		Yes	1	
214	Date last Phase 3 visit	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		P3compd6

Section 3: Goals							
	Goal	Was the goal selected? 0= No 1= Yes	Why was the goal not selected? 1= Participant refused 2= Not relevant to participant 3= Plan to start in the future 4= Not stated 5= Other	Date goal **first** selected	Was the goal achieved? 0= No 1= Yes [→data goal achieved]	Why was the goal not achieved? 1=still working towards goal 2=Agreed goal is not attainable 3=Not stated 4=Other	Date goal achieved
301	Individual and caregiver have been informed about schizophrenia and its treatment	Undsel6	undsely6 Specify other undselyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] undseld6	undach6	undachy6 Specify other undachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] undachd6
302	Individual is able to access medication and attend health centre for mental health	amedsel6	amedsely6 Specify other amedselyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] amedseld6	amedach6	amedachy6 Specify other amedachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] amedachd6
303	Crisis management plan is in place	crisel6	crisely6 Specify other criselyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] criseld6	criach6	criachy6 Specify other criachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] criachd6
304	Individual is not chained or restrained	chasel6	chasely6 Specify other chaselyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] chaseld6	chaach6	chaachy6 Specify other chaachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] chaachd6
305	Individual is willing to take medication	wmedsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] wmedseld6	wmedach6	wmedachy6 Specify other wmedachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] wmedachd6
306	Individual has strategies to remember to take medication	rmedsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] rmedseld6	rmedach6	rmedachy6 Specify other rmedachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] rmedachd6
307	Individual feels side effects are improving	sidsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] sidseld6	sidach6	sidachy6 Specify other undachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] sidachd6
308	Individual feels hallucinations/delusions are improving	symsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] symseld6	symach6	symachy6 Specify other symachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] symachd6
309	Individual feels motivation/thinking clearly are improving	motsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] motseld6	motach6	motachy6 Specify other motachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] motachd6
310	'Individual is able to attend health centre for physical health needs	paccsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] paccseld6	paccach6	paccachy6 Specify other paccachyo6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] paccachd6

311	Individual has strategies to deal with stress and anger	strsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] strseld6	strach6	strachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] strachd6
						Specify other	strachyo6
312	Individual has information about healthy behaviours	behsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] behseld6	behach6	behachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] behachd6
						Specify other	behachyo6
313	Individual has good physical, sexual and reproductive health	physel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] physeld6	phyach6	phyachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] phyachd6
						Specify other	phyachyo6
314	Individual is not malnourished	malsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] malseld6	Malach6	malachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] Malachd6
						Specify other	malachyo6
315	Individual participates in community life	comsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] comseld6	comach6	comachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] comachd6
						Specify other	comachyo6
316	Individual participates in religious activities	relsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] relseld6	relach6	relachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] relachd6
						Specify other	relachyo6
317	Individual is able to interact socially with neighbours and friends	neisel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] neiseld6	neiach6	neiachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] neiachd6
						Specify other	neiachyo6
318	Individual has improving ability to do parenting activities	parsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] parseld6	parach6	parachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] parachd6
						Specify other	parachyo6
319	Individual has improving ability to carry out family role’	rolsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] rolseld6	rolach6	rolachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] rolachd6
						Specify other	rolachyo6
320	Individual has improving relationship with family members	famsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] famseld6	famach6	famachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] famachd6
						Specify other	famachyo6
321	Caregiver has improved ability to cope	carsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] carseld6	carach6	carachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] carachd6
						Specify other	carachyo6
322	Individual has improving self-care	selsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] selseld6	selach6	selachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] selachd6
						Specify other	selachyo6
323	Individual has improving ability to do household tasks	housel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] houseld6	houach6	houachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] houachd6
						Specify other	houachyo6
324	Individual has improving self-esteem	estsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] estseld6	estach6	estachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] estachd6
						Specify other	estachyo6

325	Individual does not feel discriminated against	dissel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] disseld6	disach6	disachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] disachd6
						Specify other	disachyo6
326	Individual is not the victim of physical, sexual or emotional abuse	abusel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] abuseld6	abuach6	abuachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] abuachd6
						Specify other	abuachyo6
327	Individual has improving participation in livelihood activities	livsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] livseld6	livach6	livachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] livachd6
						Specify other	livachyo6
328	Individual has improving literacy skills	litsel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] litseld6	litach6	rolachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] rolachd6
						Specify other	rolachyo6
329	Individual has relapse management plan	relasel6		[ ][ ]/[ ][ ]/[ ][ ][ ][ ] relaseld6	relaach6	relaachy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] relaachd6
						Specify other	relaachyo6
330	Personal goal 1	per1sel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] per1seld6	per1ach6	per1achy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] per1achd6
						Specify other	per1achyo6
331	Personal goal 2	per2sel6	n/a	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] per2seld6	per2ach6	pe2achy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] per2achd6
						Specify other	per2achyo6

Section 4: Modules						
	Module	Was the module indicated? 0= No [→ go to next question] 1= Yes	Was the module started? 0= No 1= Yes [→ go to module start date]	Why was the module not started? 1= Participant refused 2= Not relevant to participant 3= Plan to start in the future 4= Not stated 5= Other	Module start date	No. home visits
401	Understanding schizophrenia	n/a	mundst6	mundsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mundstd6	mundv6
				Specify other	mundstyo6	
402	Preparing for a crisis	n/a	mcrist6	mcristy6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mcristd6	mcriv6
				Specify other	mcristyo6	
403	Dealing with human rights problems	n/a	mchast6	mchasty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mchastd6	mchav6
				Specify other	mchastyo6	
404	Improving access to health services	n/a	maccst6	maccsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] maccstd6	maccv6
				Specify other	maccstyo6	
405	Supporting individuals to take medication	mmedin6	mmedst6	mmedsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mmedstd6	mmedv6
				Specify other	mmedstyo6	
406	Dealing with distressing symptoms	msymin6	msymst6	msymsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] msymstd6	msymv6
				Specify other	mysmstyo6	
407	Dealing with stress and anger	mstrin6	mstrst6	mstrsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mstrstd6	mstrv6
				Specify other	mstrstyo6	
408	Improving physical health	mphyin6	mphyst6	mphysty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mphystd6	mphyv6
				Specify other	mphystyo6	
409	Taking part in community life	mcomin6	mcomst6	mcomsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mcomstd6	mcomv6
				Specify other	mcomstyo6	
410	Improving the family environment	mfamin6	mfamst6	mfamsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mfamstd6	mfamv6
				Specify other	mfamstyo6	
411	Improving day to day functioning	mselin6	mselst6	mselsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mselstd6	mselv6
				Specify other	mselstyo6	
412	Dealing with stigma and discrimination	mdisin6	mdisst6	mdissty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mdisstd6	mdisv6
				Specify other	mdisstyo6	
413	Getting back to work	mlivin6	mlivst6	mlivsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mlivstd6	mlivv6
				Specify other	mlivstyo6	
414	Improving literacy	mlitin6	mlitst6	maccsty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] maccstd6	maccv6
				Specify other	maccstyo6	
415	Taking control of your health	n/a	mrelast6	mrelasty6	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] mrelastd6	mrelav6
				Specify other mrelastyo6		

Section 5: Community mobilisation tasks relating to the individual			
501	Number of individual meetings with kebele leader relating to individual	[ ] [ ]	meetkeb6
502	Number of individual meetings with edir leader relating to individual	[ ] [ ]	meetedir6
503	Number of individual meetings with religious leader relating to individual	[ ] [ ]	meetrel6
504	Number of individual meetings with traditional healer relating to individual	[ ] [ ]	meettrad6
505	Number of individual meetings with holy water attendant relating to individual	[ ] [ ]	meetholy6
506	Number of individual meetings with literacy group leader or head teacher relating to individual	[ ] [ ]	meetlit6
507	Other community member engaged with		nmeetot16
508	Number of meetings with other community member	[ ] [ ]	meetot16
509	Other community member engaged with		nmeetot26
510	Number of meetings with other community member	[ ] [ ]	meetot26

Section 6: Reviews				
601	Were any components of Review 1 completed?	No	0	rev16
		Yes [→ go to Q 603]	1	
602	Why were no components of Review 1 completed?	Participant refused [→ go to Q 616]	1	rev1y6
		Not stated [→ go to Q 616]	2	
		Other [→ go to Q 616]	3	
	Specify other			rev1yo6
603	Date Review 1 started?	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev1d6
604	Was the initial assessment completed?	No [→ go to Q 606]	0	rev1i6
		Yes	1	
605	Initial assessment date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev1id6
606	Was the needs assessment completed?	No [→ go to Q 608]	0	rev1n6
		Yes	1	
607	Needs assessment date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev1nd6
608	Was the goal setting completed?	No [→ go to Q 610]	0	rev1g6
		Yes	1	
609	Goal setting date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev1gd6
610	Was the risk assessment completed?	No [→ go to Q 612]	0	rev1r6
		Yes	1	
611	Risk assessment date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev1rd6
612	Was the health centre contact form completed?	No [→ go to Q 614]	0	rev1h6
		Yes	1	
613	Health centre visit date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev1hd6
614	Was the rehabilitation plan completed?	No [→ go to Q 616]	0	rev1p6
		Yes	1	
615	Rehabilitation plan date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev1pd6
616	Were any components of Review 2 completed?	No [→ go to Q 618]	0	rev26
		Yes	1	
617	Why were no components of Review 2 completed?	Participant refused [→ Q 629]	1	rev2y6
		Participant dropped out [→ Q 629]	2	
		Phase 1 not complete [→ Q 629]	3	
		Not stated [→ Q 629]	4	
		Other [→ Q 629]	5	
		Specify other		rev2yo6
618	Date Review 2 started?	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ] [→ Q 619]		rev2d6
619	Was the needs assessment completed?	No [→ Q 621]	0	rev2n6
		Yes	1	
620	Needs assessment date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev2nd6
621	The goal setting completed?	No [→ Q 623]	0	rev2g6
		Yes	1	
622	Goal setting date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev2gd6
623	Was the risk assessment completed?	No [→ Q 625]	0	rev2r6
		Yes	1	
624	Risk assessment date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev2rd6
625	Was the health centre contact form completed?	No [→ Q 627]	0	rev2h6
		Yes	1	

626	Health centre visit date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev2hd6
627	Was the rehabilitation plan completed?	No [→ 629]	0	rev2p6
		Yes	1	
628	Were any components of Review 3 completed?	No	0	rev36
		Yes [→ Q 631]	1	
629	Why were no components of Review 3 completed?	Participant refused [→ next section]	1	rev3y6
		Participant dropped out [→ next section]	2	
		Phase 2 not complete [→ next section]	3	
		Not stated [→ next section]	4	
		Other [→ next section]	5	
		Specify other _____		rev3yo6
630	Date Review 3 started?	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev3d6
631	Was the needs assessment completed?	No [→ Q 634]	0	rev3n6
		Yes	1	
632	Needs assessment date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev3nd6
633	The goal setting completed?	No [→ Q 636]	0	rev3g6
		Yes	1	
634	Goal setting date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev3gd6
635	Was the risk assessment completed?	No [→ Q 638]	0	rev3r6
		Yes	1	
636	Risk assessment date	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev3rd6
637	Was the health centre contact form completed?	No [→ Q 640]	0	rev3h6
		Yes	1	
638	On what date was the health centre contact form completed?	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		rev3hd6
639	Was the rehabilitation plan completed?	No [→ next section]	0	rev3p6
		Yes	1	
640	Was the continuing care form completed?	No [→ next section]	0	contc6
		Yes	1	
641	Date continuing care form completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		contcd6

Section 7: Risks identified and Referrals				
701	Number of referrals to health centre	[ ] [ ]		refhc6
	For each referral indicate the primary reason for referral using this list	Medication side effects	1	
		Other medication review	2	
		Relapse/symptoms	3	
		Physical health problem	4	
		Suicide risk	5	
		Risk of neglect /malnourished	6	
		Victim of violence	7	
		Risk to children	8	
		Pregnancy/ breastfeeding	9	
		Substance abuse	10	
		Chaining/ restraint	11	
		Other	12	
702	Reason for referral 1	[ ] [ ]		refhc1y6
	Specify other reason for referral 1			refhc1yo6
703	Reason for referral 2	[ ] [ ]		refhc2y6
	Specify other reason for referral 2			refhc2yo6
704	Reason for referral 3	[ ] [ ]		refhc3y6
	Specify other reason for referral 3			refhc3yo6
705	Reason for referral 4	[ ] [ ]		refhc4y6
	Specify other reason for referral 4			refhc4yo6
706	Number of referrals to health extension worker	[ ] [ ]		refhew6
	For each referral indicate the primary reason for referral using this list	Contraception	1	
		Sanitation	2	
		Malaria prevention	3	
		Child nutrition	4	
		Vaccination	5	
		Medication adherence support	6	
		Support accessing health services	7	
		Other	8	
707	Reason for referral 1	[ ] [ ]		refhew1y6
	Specify other reason for referral 1			refhew1yo6
708	Reason for referral 2	[ ] [ ]		refhew2y6
	Specify other reason for referral 2			refhew2yo6
709	Reason for referral 3	[ ] [ ]		refhew3y6
	Specify other reason for referral 3			refhew3yo6
710	Number of referrals to trial psychiatric nurse	[ ] [ ]		refpn6
	For each referral indicate the primary reason for referral using this list	Suicide risk	1	
		Neglect/ malnourished	2	
		Chaining/restraint	3	

		Victim of violence	4	
		Unwell/relapse	5	
		Other	6	
711	Reason for referral 1	[ ] [ ]		refpn1y6
	Specify other reason for referral 1			refpn1yo6
712	Reason for referral 2	[ ] [ ]		refpn2y6
	Specify other reason for referral 2			refpn2yo6
713	Reason for referral 3	[ ] [ ]		refpn3y6
	Specify other reason for referral 3			refpn3yp6
714	Number of separate incidents relating to suicide risk	[ ] [ ]		incsuicrisk6
715	Number of separate incidents relating to suicide attempt	[ ] [ ]		incsuicatt6
716	Number of separate incidents relating to risks to children	[ ] [ ]		incchild6
717	Number of separate incidents relating to neglect/ malnutrition	[ ] [ ]		incneg6
718	Number of separate incidents relating to sexual violence	[ ] [ ]		incsexv6
719	Number of separate incidents relating to physical abuse outside the home	[ ] [ ]		incphy6
720	Number of separate incidents relating to emotional or physical abuse inside the home	[ ] [ ]		incdomv6
721	Number of separate incidents relating to individual being violent or aggressive	[ ] [ ]		incviol6

Section 8: Family support group			
801	Number times individual attended family support group	[ ] [ ]	sgind6
802	Number of times caregiver attended family support group	[ ] [ ]	sgcar6

RISE 12 month sub-district process data form		
Kebele ID	[ ] [ ] [ ]	**kid**
CBR worker ID	[ ] [ ]	**wid**
Supervisor ID	[ ] [ ]	**sid**
Investigator ID	[ ] [ ]	**tid**
Date completed (ET)	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	**kprocessd6**
Date completed (GC)	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	**kprocessdg6**
Date kebele allocated	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]	**datealloc**

Section 1: Community mobilisation tasks				
101	Was Task 1 completed (meeting with health extension worker)?	No [→ go to Q 103]	0	cet16
		Yes	1	
102	Date Task 1 started	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet1d6
103	Was Task 2 completed (community leaders identified)?	No [→ go to Q 106]	0	cet26
		Yes	1	
104	Number of community leaders identified	[ ] [ ]		cet2n6
105	Date Task 2 started	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet2d6
106	Was Task 3 completed (resource mapping)?	No [→ go to Q 109]	0	cet36
		Yes	1	
107	Number of resources identified	[ ] [ ]		cet3n6
108	Date Task 3 started	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet3d6
109	Was Task 4 completed (establish previous mental health awareness raising)?	No [→ go to Q 112]	0	cet46
		Yes	1	
110	Number of previous mental health awareness raising activities identified	[ ] [ ]		cet4n6
111	Date Task 4 completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet4d6
112	Was Task 5 completed (meeting with community leaders)?	No [→ go to Q 115]	0	cet56
		Yes	1	
113	Number of meetings with community leaders	[ ] [ ]		cet5n6
114	Date first meeting completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet5d6
115	Was Task 6 completed (community awareness raising events)?	No [→ go to Q 118]	0	cet66
		Yes	1	
116	Number of awareness raising events	[ ] [ ]		cet6n6
117	Date first event completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet6d6
118	Was Task 7 completed (identify employment opportunities)?	No [→ go to Q 121]	0	cet76
		Yes	1	
119	Number of employment opportunities identified	[ ] [ ]		cet7n6
120	Date Task 7 started	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet7d6
121	Was Task 8 completed (individual meeting	No [→ go to Q 124]	0	cet86

	with kebele leader)?	Yes	1	
122	Number of meetings with kebele leader/s	[ ] [ ]		cet8n6
123	Date Task 8 first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet8d6
124	Was Task 9 completed (individual meeting with edir leader)?	No [→ go to Q 127]	0	cet96
		Yes	1	
125	Number of meetings with edir leader/s	[ ] [ ]		cet9n6
126	Date Task 9 first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet9d6
127	Was Task 10 completed (individual meeting with religious leader)?	No [→ go to Q 130]	0	cet106
		Yes	1	
128	Number of meetings with religious leader/s	[ ] [ ]		cet10n6
129	Date Task 10 first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet10d6
130	Was Task 11 completed (individual meeting with traditional healer)?	No [→ go to Q 133]	0	cet116
		Yes	1	
131	Number of meetings with traditional healer/s	[ ] [ ]		cet11n6
132	Date Task 11 first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet11d6
133	Was Task 12 completed (individual meeting with literacy group leader/ headteacher)?	No [→ go to Q 136]	0	cet126
		Yes	1	
134	Number of meetings with literacy group leader/ headteacher	[ ] [ ]		cet12n6
135	Date Task 12 first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet12d6
136	Was individual meeting with cell leader conducted?	No [→ go to next Q]	0	cetcell6
		Yes	1	
137	Number of meetings with cell leader	[ ] [ ]		cetcelln6
138	Date cell leader meeting first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cetcelld6
139	Was individual meeting with businessman conducted?	No [→ go to next Q]	0	cetbus6
		Yes	1	
140	Number of meetings with businessman	[ ] [ ]		cetbusn6
141	Date meeting with businessman first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cetbusd6
142	Was individual meeting with government official completed?	No [→ go to next Q]	0	cetoff6
		Yes	1	
143	Number of meetings with government official	[ ] [ ]		cetoffn6
144	Date meeting with government official first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cetoffd6
145	Was meeting with community member completed?	No [→ go to next Q]	0	cetmem6
		Yes	1	
146	Number of meetings with government official	[ ] [ ]		cetmemn6

147	Date meeting with government official first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cetmemd6
148	Was meeting with Other (1) leader completed?	No [→ go to next Q]	0	cetoth16
		Yes	1	
	Specify other (1) community leader			cetoth1s6
148	Number of meetings with other (1) community leader	[ ] [ ]		cetoth1n6
150	Date meeting with other (1) leader	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cetoth1d6
151	Was meeting with Other (2) community leader completed?	No [→ go to next Q]	0	cetoth26
		Yes	1	
	Specify other (2) community leader			cetoth2s6
152	Number of meetings with other (2) community leader	[ ] [ ]		cetoth2n6
153	Date meeting with other (2) leader	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cetoth2d6
154	Was meeting with Other (3) community leader completed?	No [→ go to next Q]	0	cetoth36
		Yes	1	
	Specify other (3) community leader			cetoth3s6
155	Number of meetings with other (3) community leader	[ ] [ ]		cetoth3n6
156	Date meeting with other (3) leader	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cetoth3d6
157	Was Task 13 completed (demonstrate progress of individuals)?	No [→ go to Q 139]	0	cet136
		Yes	1	
158	Number of sessions relating to Task 13	[ ] [ ]		cet13n6
159	Date Task 13 first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet13d6
160	Was Task 14 completed (awareness raising consolidation)?	No [→ go to Q 142]	0	cet146
		Yes	1	
161	Number of awareness raising consolidation meetings held	[ ] [ ]		cet14n6
162	Date Task 14 first completed	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet14d6
163	Was Task 15 completed (facilitate employment opportunities in the kebele)?	No [→ go to next section]	0	cet156
		Yes	1	
164	Number of employment opportunities facilitated	[ ] [ ]		cet15n6
165	Date first employment opportunity facilitated	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		cet15d6

Section 2: Family support group				
201	Was a family support group started?	No	0	fsg6
		Yes [→ go to Q 203]	1	
202	Why was a family support group not started?	Participants not willing [→ form is complete]	1	fsgy6
		Participants dropped out of CBR [→form is complete]	2	
		Insufficient participants in kebele [→ form is complete]	3	
		Not stated [→form is complete]	4	
		Other [→form is complete]	5	
		Specify other		fsgyo6
203	Date family support group started	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		fsgd6
204	Number of participants at first meeting	[ ] [ ]		fsgn16
205	Number of participants at most recent meeting	[ ] [ ]		fsgn26
206	Number of meetings in the last 6 months	[ ] [ ]		fsgm6
207	Did the group involve caregivers who are RISE participants?	No	0	fsgcar6
		Yes	1	
208	Did the group involve individuals with schizophrenia who are RISE participants?	No	0	fsgind6
		Yes	1	
209	Did the group involve caregivers who are NOT RISE participants?	No	0	fsgnocar6
		Yes	1	
210	Did the group involve individuals with schizophrenia who are NOT RISE participants?	No	0	fsgnoind6
		Yes	1	
211	Did the group involve any one else other than caregivers or people with schizophrenia?	No	0	fsgoth6
		Yes	1	

RISE 12 month CBR worker process data form			
CBR worker	**W** [ ] [ ]		**wid**
Supervisor	**S** [ ] [ ]		**sid**
Form completed by ID	**T** [ ] [ ]		**tid**
Date completed (ET)	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		**cbrprocessd0**
Date completed (GC)	[ ] [ ]/ [ ] [ ]/ [ ] [ ] [ ] [ ]		**cbrprocessdg0**
Section 1			
101	**Number of face to face supervision sessions attended in the last 6 months**	[ ] [ ]	**f2ft0**
102	**Number of group supervision sessions attended in the last 6 months**	[ ] [ ]	**groupt0**
103	**Number of unannounced visits conducted in the last 6 months**	[ ] [ ]	**supt0**
104	**Number of Group top up training sessions attended in the last 6 months**	[ ] [ ]	**traint0**
105	**Trial baseline written test attitudes-item 1 (afraid)**	[ ]	**att1t0**
106	**Trial baseline written test attitudes-item 2 (work with)**	[ ]	**att2t0**
107	**Trial baseline written test attitudes-item 3 (friendship)**	[ ]	**att3t0**
108	**Trial baseline written test attitudes-item 4 (share room)**	[ ]	**att4t0**
109	**Trial baseline written test attitudes-item 5 (ashamed)**	[ ]	**att5t0**
110	**Trial baseline written test attitudes-item 6 (marry)**	[ ]	**att6t0**

CBR Structured assessment of met and unmet needs			
Individual		**CBR worker**	
Supervisor		**Date**	

Need		**To what extent was this problem in the last 2 years?**			**To what extent did CBR help to improve this problem?**			
		Not a problem (0)	A small problem (1)	A significant problem (2)	CBR did not help at all (0)	CBR helped a little (1)	CBR helped a lot (2)	
1	**Poverty**							cbrpov
2	**Lack of employment/ income generation**							cbrinc
3	**Problems paying for medication**							cbrmed
4	**Exclusion from social or community activities**							cbrsoc
5	**Conflict/ arguments within the family**							cbrfam
6	**Feeling unhappy**							cbrhap
7	**Feeling angry**							cbrang
8	**Lack of understanding about mental illness**							cbrund
9	**Drinking too much alcohol**							cbralc
10	**Poor self care**							cbrcar
11	**Not feeling good about yourself (low self esteem)**							cbrest
12	**Lack of awareness about the medication and its side effects**							cbrmedawr
13	**Problems in doing household tasks**							cbrhou
14	**Problems in accessing health facilities for physical health issues**							cbrphy
15	**Problems in communicating with the health centre staff**							cbrhcst
16	**Willingness to take medication**							Cbrmedwil
17	**Problems in accessing health centre due to its distance**							cbrhcfar
18	**Feeling weak and sleepy**							Cbrsleep
19	**Having suicidal thoughts**							Cbrsuicde
20	**Lack of awareness about relapse**							Cbrrelapse
21	**Other (Specify)**							Cbroth

Appendix E (vi): Trial qualitative topic guides

Note: additional topic guides have been created for CBR workers, supervisors, health centre staff and community members

Baseline topic guide for people with schizophrenia

1. **You have been receiving some treatment over the past few months, can you tell me about that? What was the reason for the treatment?**

(If the participant says they have no illness and/or do not need treatment→ Go to question 3).

2. **Could you tell me about when you first noticed that you were ill/ not feeling yourself?**
   - How did you feel? What problems did you face?
   - Do you have any ideas about why you became unwell/ started having problems?
   - What has happened to you since that time?
   - Did you get any treatment or support?

3. **Tell me about your life at the moment.**
   - **A. What do you do?**
     What kind of work do you do? Do you have a family?
   - **B. Can you tell me about any difficulties that you are facing at the moment?**
     Prompts
     - inability to work, lack of work, lack of money
     - stress
     - Problems with relationships
     - Symptoms
     - poor physical health,
     - inability to afford medication, medication side effects,
     - stigma, not participating in community life
   - **C. Which problem is of greatest concern?**

4. **Think back to your life 5 years ago** *(add 'before you became unwell' if the participant acknowledged their illness)*
   - Are things different now compared to in the past?
   - In what way are things different? (e.g. relationships with family, friends or neighbours; ability to work; financial situation; participation in community life; self care)
   - Were these changes related to your illness starting?
   - Were these changes related to your illness getting worse?
   - Were these changes related to your illness getting better?

5. **Now I would like to ask you about how you see your life in the future** (for example to next year or a few years time)
   - How do you hope things will be in the future?
   - What things would you like to be different? (e.g. relationships with family, friends or neighbours; role in family; marriage/ relationships; finding a job; ability to work; financial situation; increased independence, participation in community life; self care; reduced symptoms; less need to take medication; reduced side effects; reduced stigma/ discrimination)
   - Would you like things to be the same as in the past, before you became unwell? Tell me more about this.

6. **How hopeful are you that these changes are possible?**

7. **How important do you think these things would be to your family?** Tell me more about that. What differences are there between what you and your family think?

8. What could help things to be how you would like in the future?

Prompts

- Having support, e.g. from family, support from community worker, support from community
- Finding work,
- Getting financial support
- Taking medication regularly; getting free medication
- Community having increased awareness
- Spirituality/ prayer/ help from God, holy water,
- Accepting circumstances,
- Understanding illness/knowing what to expect,
- Improved self-esteem/ positive attitude/ being hopeful

9. How much could these changes be down to you?

- What do you think you can do to help yourself?
- How much might these changes be possible with the input of others?

10. What do you think might make it difficult to live life in the way you would like to?

Prompts

- Poverty, no free medication, lack of work;
- stigma/ discrimination;
- lack of support;
- medication doesn't help

Participants allocated to CBR only:

11. You have recently agreed to have visits to your home by a community based rehabilitation worker.

- What are your expectations about this intervention?'
- In what ways do you think this might help you?
- Are there any ways in which it might be unhelpful for you?

Endline topic guide for people with schizophrenia

1. **Think back over the last year. Please tell me about what has happened to you during that time.**

2. **When we spoke one year ago you said you hoped things would change in this way: [refer back to baseline interview]**

Please tell me about whether anything has changed in the way you had hoped.

3. **In the last 12 months have any changes occurred relating the following** *[for each probe follow up with 'Tell me about the change']:*

…independence?
… self care?
…doing household tasks?
…symptoms?
…accessing health services?
…taking medication?
…social and community life? For example, participating in Edir, going to church, drinking coffee with others..
…getting back to work?
...the family environment?
…physical health?
…substance abuse?
…stress and anger?
…experiences of stigma and discrimination?
…self esteem?
…caregiver burden?
…physical restraint?
…managing a crisis/ relapse?

4. **What factors helped things to change?**

Prompts

- Having support, e.g. from family, support from community worker, support from community
- Finding work, getting financial support
- Taking medication regularly; getting free medication
- Community having increased awareness
- Spirituality/ prayer/ help from God, holy water,
- Accepting circumstances, understanding illness/knowing what to expect,
- Improved self-esteem/ positive attitude,

5. **How important do you think these changes were to your family?** Tell me more about that.

What differences are there between what you and your family think?

6. **How much were these changes down to you?**
   - What did you do to help yourself?
   - How much were these changes only possible with the input of others?

7. **What made it difficult for things to change?**

Prompts

- Poverty, no free medication, lack of work;
- stigma/ discrimination;
- lack of support;
- medication doesn't help

8. **How hopeful are you that change is still possible in the future?**

9. You have been receiving some treatment over the past few months, can you tell me about that?
Were you advised to take medication? If so, did you take the medication?
How easy or difficult was it for you to take medication?
Prompts Were there any problems with:

- Medication availability?
- Medication cost?
- Side effects?
- Remembering to take it?
- Being told not to take it by others (e.g. relatives, holy water priest)

Participants allocated to CBR only:
10. How did you feel about receiving CBR?
If you weren't happy to receive CBR please tell me why not (e.g. didn't find it useful)

11. Did anything make it difficult to participate?
Prompts

- not having enough time,
- increased stigma from home visits

12. What could have made CBR more helpful for you?
What would you like to see changed about the CBR programme?
How useful do you think the CBR programme might be for other people in your situation?

13. What was the role of the CBR worker in any changes over the last year?
In particular did any of the following help?

- Having home visits from the CBR worker
- Having CBR worker accompany or remind you to go to the health centre?
- Having someone you can trust to talk to
- Family support group [if applicable]
- The CBR worker giving education and making links in the community

14. What was the impact of CBR on your taking medication or not?
Did CBR help with any issues with:

- Medication availability?
- Medication cost?
- Side effects?
- Remembering to take it?
- Being told not to take it by others (e.g. relatives, holy water priest)

15. How do you feel about the fact that CBR is finishing?
Do you feel that CBR has given you skills/ knowledge that will continue to help you even though the CBR worker will stop coming?
For caregivers: **how confident/ able do you feel to look after you relative?**

Appendix E (vii): Trial patient report form

SECTION ONE (Clinician administered)

INTERVIEW DETAILS

001a	Ethiopian Calendar Interview date (E.C.)	[ ][ ]/[ ][ ]/[ ][ ][ ][ ]		ECclinicdate6
001b	European Calendar Interview date (G.C.)	[ ][ ]/[ ][ ]/[ ][ ][ ][ ]		GCclinicdate6
002	Assessor's name			intname
003	Assessor's ID	[ ][ ]		intid
004	PRIME ID	P E [ ][ ][ ][ ]		parid
005	Interview start time	[ ][ ]:[ ][ ]		clinicst6
006	Interview finish time	[ ][ ]:[ ][ ]		clinicfi6

TO BE COMPLETED BY RISE TRIAL STAFF (not to be completed by data collector)			
Is the participant recruited to the RISE trial?	No	0	rise
	Yes	1	

SECTION 1: Symptom Severity (BPRS-E)

101	**Somatic concern** Degree of concern over present bodily health. Rate the degree to which physical health is perceived as a problem by the patient, whether complaints have a realistic basis or not. ***Somatic delusions should be rated in the severe range with or without somatic concern.*** Note: be sure to assess the degree of impairment due to somatic concerns only and not other symptoms, e.g., depression. In addition, if the individual rates 6 or 7 due to somatic delusions, then you must rate Unusual Thought Content at least 4 or above.		
	Absent	**1**	BPRSSOM6
	Very mild Occasional somatic concerns that tend to be kept to self.	**2**	
	Mild Occasional somatic concerns that tend to be voiced to others (e.g. health worker).	**3**	
	Moderate Frequent expressions of somatic concern or exaggerations of existing ills OR some preoccupation, but no impairment in functioning. Not delusional.	**4**	
	Moderately severe Frequent expressions of somatic concern or exaggerations of existing ills OR some preoccupation and moderate impairment of functioning. Not delusional.	**5**	
	Severe Preoccupation with somatic complaints with much impairment in functioning OR somatic delusions without acting on them or disclosing to others.	**6**	
	Extremely severe Preoccupation with somatic complaints with severe impairment in functioning OR somatic delusions that tend to be acted on or disclosed to others.	**7**	
102	**Anxiety** Reported apprehension, tension, fear, panic or worry. Rate only the individual's statements - not observed anxiety which is rated under Tension.		
	Absent	**1**	BPRSANX6
	Very mild Reports some discomfort due to worry OR infrequent worries that occur more than usual for most normal individuals.	**2**	
	Mild Worried frequently but can readily turn attention to other things.	**3**	
	Moderate Worried most of the time and cannot turn attention to other things easily but no impairment in functioning OR occasional anxiety with autonomic accompaniment but no impairment in functioning.	**4**	
	Moderately Severe Frequent, but not daily, periods of anxiety with autonomic accompaniment OR some areas of functioning are disrupted by anxiety or worry.	**5**	
	Severe Anxiety with autonomic accompaniment daily but not persisting throughout the day OR many areas of functioning are disrupted by anxiety or constant worry.	**6**	
	Extremely Severe Anxiety with autonomic accompaniment persisting throughout the day OR most areas of functioning are disrupted by anxiety or constant worry.	**7**	

103	**Depressive mood** Include sadness, unhappiness, anhedonia and preoccupation with depressing topics (can't attend conversations due to depression), hopeless, loss of self-esteem (dissatisfied or disgusted with self or feelings of worthlessness). Do not include vegetative symptoms, e.g., motor retardation, early waking or the amotivation that accompanies the deficit syndrome.		
	Absent	**1**	BPRSDEP6
	Very mild Occasionally feels sad, unhappy or depressed.	**2**	
	Mild Frequently feels sad or unhappy but can readily turn attention to other things.	**3**	
	Moderate Frequent periods of feeling very sad, unhappy, moderately depressed, but able to function with extra effort.	**4**	

	Moderately Severe Frequent, but not daily, periods of deep depression OR some areas of functioning are disrupted by depression.	**5**	
	Severe Deeply depressed daily but not persisting throughout the day OR many areas of functioning are disrupted by depression.	**6**	
	Extremely Severe Deeply depressed daily OR most areas of functioning are disrupted by depression.	**7**	
104	**Suicidality** Expressed desire, intent, or actions to harm or kill self		
	Absent	**1**	BPRSUIC6
	Very mild Occasional feelings of being tired of living. No overt suicidal thoughts.	**2**	
	Mild Occasional suicidal thoughts without intent or specific plan OR he/she feels they would be better off dead.	**3**	
	Moderate Suicidal thoughts frequent without intent or plan.	**4**	
	Moderately Severe Many fantasies of suicide by various methods. May seriously consider making an attempt with specific time and plan OR impulsive suicide attempt using non-lethal method or in full view of potential saviours.	**5**	
	Severe Clearly wants to kill self. Searches for appropriate means and time, OR potentially serious suicide attempt with individual knowledge of possible rescue.	**6**	
	Extremely Severe Specific suicidal plan and intent (e.g., "as soon as_____I will do it by doing X"), OR suicide attempt characterised by plan individual thought was lethal or attempt in secluded environment.	**7**	

105	**Guilt feelings** Overconcern or remorse for past behaviour. Rate only on the basis of the patient's subjective experiences of guilt as evidenced by verbal report with appropriate affect; do not infer guilt feelings from depression, anxiety, or neurotic defences. Note: if the individual rates 6 or 7 due to delusions of guilt, then you must rate Unusual Thought Content at least 4 or above, depending on level of preoccupation and impairment.		
	Absent	**1**	BPRSGUIL6
	Very mild Concerned about having failed someone, or at something, but not preoccupied. Can shift thoughts to other matters easily.	**2**	
	Mild Concerned about having failed someone, or at something, with some preoccupation. Tends to voice guilt to others.	**3**	
	Moderate Disproportionate preoccupation with guilt, having done wrong, injured others by doing or failing to do something, but can readily turn attention to other things.	**4**	
	Moderately Severe Preoccupation with guilt, having failed someone or at something, can turn attention to other things, but only with great effort. Not delusional.	**5**	
	Severe Delusional guilt OR unreasonable self-reproach very out of proportion to circumstances. Moderate preoccupation present.	**6**	
	Extremely Severe Delusional guilt OR unreasonable self-reproach grossly out of proportion to circumstances. Individual is very preoccupied with guilt and is likely to disclose to others or act on delusions.	**7**	
106	**Hostility** Animosity, contempt, belligerence, threats, arguments, tantrums, property destruction, fights, and any other expression of hostile attitudes or actions. Do not infer hostility from neurotic defences, anxiety or somatic complaints. Do not include incidents of appropriate anger or obvious self-defence.		
	Absent	**1**	BPRSHOST6
	Very mild Irritable or grumpy, but not overtly expressed.	**2**	

	Mild Argumentative or sarcastic.	**3**	
	Moderate Overtly angry on several occasions OR yelled at others excessively.	**4**	
	Moderately Severe Has threatened, slammed about or thrown things.	**5**	
	Severe Has assaulted others but with no harm likely, e.g., slapped or pushed, OR destroyed property, e.g., knocked over furniture, broken windows.	**6**	
	Extremely Severe Has attacked others with definite possibility of harming them or with actual harm, e.g., assault with hammer or weapon.	**7**	

107	**Elevated Mood** A pervasive, sustained and exaggerated feeling of well-being, cheerfulness, euphoria (implying a pathological mood), optimism that is out of proportion to the circumstances. Do not infer elation from increased activity or from grandiose statements alone.		
	Absent	**1**	BPRSELEV6
	Very mild Seems to be very happy, cheerful without much reason.	**2**	
	Mild Some unaccountable feelings of well-being that persist.	**3**	
	Moderate Reports excessive or unrealistic feelings of well-being, cheerfulness, confidence or optimism inappropriate to circumstances, some of the time. May frequently joke, smile, be giddy, or overly enthusiastic OR few instances of marked elevated mood with euphoria.	**4**	
	Moderately Severe Reports excessive or unrealistic feelings of well-being, confidence or optimism inappropriate to circumstances, much of the time. May describe feeling `on top of the world', `like everything is falling into place', or `better than ever before', OR several instances of marked elevated mood with euphoria.	**5**	
	Severe Reports many instances of marked elevated mood with euphoria OR mood definitely elevated almost constantly throughout interview and inappropriate to content.	**6**	
	Extremely Severe Individual reports being elated or appears almost intoxicated, laughing, joking, giggling, constantly euphoric, feeling invulnerable, all inappropriate to immediate circumstances.	**7**	
108	**Grandiosity** Exaggerated self-opinion, self-enhancing conviction of special abilities or powers or identity as someone rich or famous. Rate only individual's statements about himself, not his/her demeanour. Note: if the individual rates 6 or 7 due to grandiose delusions, you must rate Unusual Thought Content at least 4 or above.		
	Absent	**1**	BPRSGRAN6
	Very mild Feels great and denies obvious problems, but not unrealistic.	**2**	
	Mild Exaggerated self-opinion beyond abilities and training.	**3**	
	Moderate Inappropriate boastfulness, e.g., claims to be brilliant, insightful or gifted beyond realistic proportions, but rarely self-discloses or acts on these inflated self-concepts. Does not claim that grandiose accomplishments have actually occurred.	**4**	
	Moderately Severe Same as 4 but often self-discloses and acts on these grandiose ideas. May have doubts about the reality of the grandiose ideas. Not delusional.	**5**	
	Severe Delusional - claims to have special powers like extra-sensory perception, to have millions of dollars, invented new machines, worked at jobs when it is known that he/she was never employed in these capacities, be Jesus Christ, or the Prime Minister. Individual may not be very preoccupied.	**6**	
	Extremely Severe Delusional - same as 6 but individual seems very preoccupied and tends to disclose or act on grandiose delusions.	**7**	

109	**Suspiciousness**

	Expressed or apparent belief that other persons have acted maliciously or with discriminatory intent. Include persecution by supernatural or other non-human agencies (e.g., the devil). Note: ratings of 3 or above should also be rated under Unusual Thought Content.		
	Absent	**1**	BPRSUSP6
	Very mild Seems on guard. Reluctant to respond to `personal' questions. Reports being overly self-conscious in public.	**2**	
	Mild Describes incidents in which others have harmed or wanted to harm him/her that sound plausible. Individual feels as if others are watching, laughing or criticising him/her in public, but this occurs only occasionally or rarely. Little or no preoccupation.	**3**	
	Moderate Says other persons are talking about him/her maliciously, have negative intentions or may harm him/her. Beyond the likelihood of plausibility, but not delusional. Incidents of suspected persecution occur occasionally (<1 time per week) with some preoccupation.	**4**	
	Moderately Severe Same as 4, but incidents occur frequently, such as more than once per week. Individual is moderately preoccupied with ideas of persecution OR individual reports persecutory delusions expressed with much doubt (e.g., partial delusion).	**5**	
	Severe Delusional: speaks of political plots or others poisoning food, persecution by supernatural forces.	**6**	
	Extremely Severe Same as 6, but the beliefs are bizarre or more preoccupying. Individual tends to disclose or act on persecutory delusions.	**7**	
110	**Hallucinations** Perceptions without normal external stimulus correspondence.		
	Absent	**1**	BPRSHALL6
	Very mild While resting or going to sleep, sees visions, smells odours or hears voices, sounds or whispers when no external stimulation, but no functional impairment.	**2**	
	3 Mild While in clear consciousness, hears a voice calling name, experiences non-verbal auditory hallucinations, formless visual hallucinations or has sensory experiences in the presence of a modality relevant stimulus infrequently (e.g., 1-2 times per week) and with no functional impairment.	**3**	
	Moderate Occasional verbal, visual, gustatory, olfactory or tactile hallucinations with no functional impairment OR non-verbal auditory hallucinations/ visual illusions more than infrequently or with impairment.	**4**	
	Moderately Severe Experiences daily hallucinations OR some areas of functioning are disrupted by hallucinations.	**5**	
	Severe Experiences verbal or visual hallucinations several times a day OR many areas of functioning are disrupted by these hallucinations.	**6**	
	Extremely Severe Persistent verbal or visual hallucinations throughout the day OR most areas of functioning are disrupted by these hallucinations.	**7**	
111	**Unusual thought content** Unusual, odd, strange, or bizarre thought content. Rate the degree of unusualness, not the degree of disorganisation of speech. Delusions are patently absurd, clearly false or bizarre ideas that are expressed with full conviction. Consider the individual to have full conviction if he/she has acted as though the delusional belief was true. Ideas of reference/persecution can be differentiated from delusions in that ideas are expressed with much doubt and contain more elements of reality. Include thought insertion, withdrawal and broadcast. Include grandiose, somatic and persecutory delusions even if rated elsewhere. Note: if Somatic Concern, Guilt, Suspiciousness or Grandiosity are rated 6 or 7 due to delusions, then Unusual Thought Content must be rated 4 or above.		
	Absent	**1**	BPRSTHOU6
	Very mild Ideas of reference, ideas of persecution. Unusual beliefs in powers, spirits, or unrealistic beliefs in one's own abilities. Not strongly held. Some	**2**	

	doubt.		
	Mild Same as 2, but degree of reality distortion is more severe as indicated by highly unusual ideas or greater conviction. Content may be typical of delusions (even bizarre), but without full conviction. The delusion does not seem to have fully formed, but is considered as one possible explanation for an unusual experience	**3**	
	Moderate Delusion present but no preoccupation or functional impairment. May be an encapsulated delusion or a firmly endorsed absurd belief about past delusional circumstances.	**4**	
	Moderately Severe Full delusion(s) present with some preoccupation OR some areas of functioning disrupted by delusional thinking.	**5**	
	Severe Full delusion(s) present with much preoccupation OR many areas of functioning are disrupted by delusional thinking.	**6**	
	Extremely Severe Full delusion(s) present with almost total preoccupation OR most areas of functioning disrupted by delusional thinking.	**7**	

112	**Bizarre behavior** Reports of behaviours which are odd, unusual, or psychotically criminal. Not limited to interview period. Include inappropriate sexual behaviour and inappropriate affect.		
	Absent	**1**	BPRSBIZ6
	Very mild Slightly odd or eccentric public behaviour, e.g., occasionally giggles to self, fails to make appropriate eye contact, that does not seem to attract the attention of others OR unusual behaviour conducted in private, e.g., innocuous rituals, that would not attract the attention of others.	**2**	
	Mild Noticeably peculiar public behaviour, e.g., inappropriately loud talking, makes inappropriate eye contact, OR private behaviour that occasionally, but not always, attracts the attention of others, e.g. hoards food, conducts unusual rituals, wears gloves indoors	**3**	
	Moderate Clearly bizarre behaviour that attracts or would attract the attention or concern of others, but with no corrective intervention necessary. Behaviour occurs occasionally, e.g., fixated staring into space for several minutes, talks back to voices once, inappropriate giggling/laughter on 1-2 occasions, talking loudly to self	**4**	
	Moderately Severe Clearly bizarre behaviour that attracts or would attract the attention of others or the authorities, e.g., fixated staring in a socially disruptive way, frequent inappropriate giggling/laughter, occasionally responds to voices, or eats non-foods.	**5**	
	Severe Bizarre behaviour that attracts attention of others and intervention by authorities, e.g., directing traffic, public nudity, staring into space for long periods, carrying on a conversation with hallucinations, frequent inappropriate giggling/laughter.	**6**	
	Extremely Severe Serious crimes committed in a bizarre way that attract the attention of others and the control of authorities, e.g., sets fires and stares at flames OR almost constant bizarre behaviour, e.g., inappropriate giggling/laughter, responds only to hallucinations and cannot be engaged in interaction.	**7**	

113	**Self-care** Hygiene, appearance, or eating behaviour below usual expectations, below socially acceptable standards or life threatening.		
	Absent	**1**	BPRSCARE6
	Very mild Hygiene/appearance slightly below usual community standards, e.g., shirt out of pants, buttons unbuttoned, but no social or medical consequences.	**2**	

	Mild Hygiene/appearance occasionally below usual community standards, e.g. irregular bathing, clothing is stained, hair uncombed, occasionally skips an important meal. No social or medical consequences.	**3**	
	Moderate Hygiene/appearance is noticeably below usual community standards, e.g., fails to bathe or change clothes, clothing very soiled, hair unkempt, needs prompting, noticeable by others OR irregular eating and drinking. Minimal medical concerns and consequences.	**4**	
	Moderately Severe Several areas of hygiene/ appearance are below usual community standards OR poor grooming draws criticism by others and requires regular prompting. Eating or hydration are irregular and poor, causing some medical problems.	**5**	
	Severe Many areas of hygiene/appearance are below usual community standards, does not always bathe or change clothes even if prompted. Poor grooming has caused social ostracism at school/residence/work, or required intervention. Eating erratic and poor, may require medical intervention.	**6**	
	Extremely Severe Most areas of hygiene/ appearance/nutrition are extremely poor and easily noticed as below usual community standards OR hygiene/appearance/nutrition require urgent and immediate medical intervention.	**7**	

114	**Disorientation** Does not comprehend situations or communications, such as questions asked during the entire BPRS interview. Confusion regarding person, place, or time. Do not rate if incorrect responses are due to delusions		
	Absent	**1**	BPRSDISO6
	Very mild Seems muddled or mildly confused 1-2 times during interview. Oriented to person, place and time.	**2**	
	Mild Occasionally muddled or mildly confused 3-4 times during interview. Minor inaccuracies in person, place, or time, e.g., date off by more than 2 days, or gives wrong division of hospital or community centre.	**3**	
	Moderate Frequently confused during interview. Minor inaccuracies in person, place, or time are noted, as in 3 above. In addition, may have difficulty remembering general information, e.g., name of Prime Minister.	**4**	
	Moderately Severe Markedly confused during interview, or to person, place, or time. Significant inaccuracies are noted, e.g., date off by more than one week, or cannot give correct name of hospital. Has difficulty remembering personal information, e.g., where he/she was born or recognising familiar people.	**5**	
	Severe Disoriented as to person, place, or time, e.g., cannot give correct month and year. Disoriented in 2 out of 3 spheres.	**6**	
	Extremely Severe Grossly disoriented as to person, place, or time, e.g., cannot give name or age. Disoriented in all three spheres.	**7**	
115	**Conceptual organisation** Degree to which speech is confused, disconnected, vague or disorganised. Rate tangentiality, circumstantiality, sudden topic shifts, incoherence, derailment, blocking, neologisms, and other speech disorders. Do not rate content of speech.		
	Absent	**1**	BPRSFTD6
	Very mild Peculiar use of words or rambling but speech is comprehensible.	**2**	
	Mild Speech a bit hard to understand or make sense of due to tangentiality, circumstantiality, or sudden topic shifts.	**3**	
	Moderate Speech difficult to understand due to tangentiality, circumstantiality, idiosyncratic speech, or topic shifts on many occasions OR 1-2 instances of incoherent phrases.	**4**	
	Moderately Severe Speech difficult to understand due to circumstantiality,	**5**	

	tangentiality, neologisms, blocking or topic shifts most of the time, OR 3-5 instances of incoherent phrases.		
	Severe Speech is incomprehensible due to severe impairment most of the time. Many BPRS items cannot be rated by self-report alone.	**6**	
	Extremely Severe Speech is incomprehensible throughout interview.	**7**	

116	**Blunted affect** Restricted range in emotional expressiveness of face, voice, and gestures. Marked indifference or flatness even when discussing distressing topics. In the case of euphoric or dysphoric individuals, rate Blunted Affect if a flat quality is also clearly present.		
	Absent	**1**	BPRSBLUN6
	Very mild Emotional range is slightly subdued or reserved but displays appropriate facial expressions and tone of voice that are within normal limits.	**2**	
	Mild Emotional range overall is diminished, subdued or reserved, with few spontaneous and appropriate emotional responses. Voice is slightly monotonous.	**3**	
	Moderate Emotional range is noticeably diminished, individual doesn't show emotion, smile or react to distressing topics except infrequently. Voice tone is monotonous or noticeable decrease in spontaneous movements.	**4**	
	Moderately Severe Emotional range very diminished, individual doesn't show emotion, smile, or react to distressing topics except minimally, few gestures, facial expression does not change very often. Voice tone is monotonous much of the time.	**5**	
	Severe Very little emotional range or expression. Mechanical in speech and gestures most of the time. Unchanging facial expression. Voice tone is monotonous most of the time.	**6**	
	Extremely Severe Virtually no emotional range or expressiveness, stiff movement. Voice tone is monotonous all of the time.	**7**	
117	**Emotional withdrawal** Deficiency in individual's ability to relate emotionally during interview situation. Use your own feeling as to the presence of an `invisible barrier' between individual and interviewer. Include withdrawal apparently due to psychotic processes.		
	Absent	**1**	BPRSEMOT6
	Very mild Lack of emotional involvement shown by occasional failure to make reciprocal comments, seems preoccupied, or smiling in a stilted manner, but engages the interviewer most of the time.	**2**	
	Mild Lack of emotional involvement shown by noticeable failure to make reciprocal comments, appearing preoccupied, or lacking in warmth, but responds to interviewer when approached.	**3**	
	Moderate Individual does not elaborate responses, fails to make eye contact, doesn't seem to care if interviewer is listening, or may be preoccupied with psychotic material.	**4**	
	Moderately Severe Same as 4 but emotional contact not present most of the interview.	**5**	
	Severe Actively avoids emotional participation. Frequently unresponsive or responds with yes/no answers (not solely due to persecutory delusions). Responds with only minimal affect.	**6**	
	Extremely Severe Consistently avoids emotional participation. Unresponsive or responds with yes/no answers (not solely due to persecutory delusions). May leave during interview or just not respond at all.	**7**	

118	**Motor retardation** Reduction in energy level evidenced by slowed movements and speech, reduced body tone, decreased number of spontaneous body movements. Rate on the basis of observed behaviour of the

	individual only. Do not rate on the basis of individual's subjective impression of his own energy level. Rate regardless of medication effects.		
	Absent	**1**	BPRSMOTO6
	Very mild Slightly slowed or reduced movements or speech compared to most people.	**2**	
	Mild Noticeably slowed or reduced movements or speech compared to most people.	**3**	
	Moderate Large reduction or slowness in movements or speech.	**4**	
	Moderately Severe Seldom moves or speaks spontaneously OR very mechanical or stiff movements	**5**	
	Severe Does not move or speak unless prodded or urged.	**6**	
	Extremely Severe Frozen, catatonic.	**7**	
119	**Tension** Observable physical and motor manifestations of tension, `nervousness' and agitation. Self-reported experiences of tension should be rated under the item on anxiety. Do not rate if restlessness is solely akathisia, but do rate if akathisia is exacerbated by tension.		
	Absent	**1**	BPRSTENS6
	Very mild More fidgety than most but within normal range. A few transient signs of tension, e.g., picking at fingernails, foot wagging, scratching scalp several times or finger tapping.	**2**	
	Mild Same as 2, but with more frequent or exaggerated signs of tension.	**3**	
	Moderate Many and frequent signs of motor tension with one or more signs sometimes occurring simultaneously, e.g., wagging one's foot while wringing hands together. There are times when no signs of tension are present.	**4**	
	Moderately Severe Many and frequent signs of motor tension with one or more signs often occurring simultaneously. There are still rare times when no signs of tension are present.	**5**	
	Severe Same as 5, but signs of tension are continuous.	**6**	
	Extremely Severe Multiple motor manifestations of tension continuously present, e.g. pacing &hand wringing.	**7**	
120	**Uncooperativeness** Resistance and lack of willingness to co-operate with the interview. The uncooperativeness might result from suspiciousness. Rate only unco-operativeness in relation to the interview, not behaviours involving peers and relatives.		
	Absent	**1**	BPRSCOOP6
	Very mild Shows non-verbal signs of reluctance, but does not complain or argue.	**2**	
	Mild Gripes or tries to avoid complying, but goes ahead without argument.	**3**	
	Moderate Verbally resists but eventually complies after questions are rephrased or repeated.	**4**	
	Moderately Severe Same as 4, but some information necessary for accurate ratings is withheld.	**5**	
	Severe Refuses to co-operate with interview, but remains in interview situation.	**6**	
	Extremely Severe Same as 6, with active efforts to escape the interview	**7**	
121	**Excitement** Heightened emotional tone or increased emotional reactivity to interviewer or topics being discussed, as evidenced by increased intensity of facial expressions, voice tone, expressive gestures or increase in speech quantity and speed.		
	Absent	**1**	BPRSEXCI6
	Very mild Subtle and fleeting or questionable increase in emotional intensity. For example, at times seems keyed-up or overly alert.	**2**	
	Mild Subtle but persistent increase in emotional intensity. For example, lively use of gestures and variation in voice tone.	**3**	

	Moderate Definite but occasional increase in emotional intensity. For example, reacts to interviewer or topics that are discussed with noticeable emotional intensity. Some pressured speech.	**4**	
	Moderately Severe Definite and persistent increase in emotional intensity. For example, reacts to many stimuli, whether relevant or not, with considerable emotional intensity. Frequent pressured speech.	**5**	
	Severe Marked increase in emotional intensity. For example, reacts to most stimuli with inappropriate emotional intensity. Has difficulty settling down or staying on task. Often restless, impulsive, or speech is often pressured.	**6**	
	Extremely Severe Marked and persistent increase in emotional intensity. Reacts to all stimuli with inappropriate intensity, impulsiveness. Cannot settle down or stay on task. Very restless and impulsive most of the time. Constant pressured speech.	**7**	
122	**Distractibility** Degree to which observed sequences of speech and actions are interrupted by stimuli unrelated to the interview. Distractibility is rated when the individual shows a change in the focus of attention as characterised by a pause in speech or a marked shift in gaze. Individual's attention may be drawn to noise in adjoining room, books on a shelf, interviewer's clothing, etc. Do not rate circumstantiality, tangentiality or flight of ideas. Also, do not rate rumination with delusional material. Rate even if the distracting stimulus cannot be identified.		
	Absent	**1**	BPRSDIST6
	Very mild Generally can focus on interviewer's questions with only 1 distraction or inappropriate shift of attention of brief duration.	**2**	
	Mild Individual shifts focus of attention to matters unrelated to the interview 2-3 times.	**3**	
	Moderate Often responsive to irrelevant stimuli in the room, e.g., averts gaze from the interviewer.	**4**	
	Moderately Severe Same as above, but now distractibility clearly interferes with the flow of the interview.	**5**	
	Severe Extremely difficult to conduct interview or pursue a topic due to preoccupation with irrelevant stimuli.	**6**	
	Extremely Severe Impossible to conduct interview due to preoccupation with irrelevant stimuli.	**7**	

123	**Motor hyperactivity** Increase in energy level evidenced in more frequent movement and/or rapid speech. Do not rate if restlessness is due to akathisia.		
	Absent	**1**	BPRSHYPE6
	Very mild Some restlessness, difficulty sitting still, lively facial expressions, or somewhat talkative	**2**	
	Mild Occasionally very restless, definite increase in motor activity, lively gestures, 1-3 brief instances of pressured speech.	**3**	
	Moderate Very restless, fidgety, excessive facial expressions, or non-productive and repetitious motor movements. Much pressured speech, up to one-third of the interview.	**4**	
	Moderately Severe Frequently restless, fidgety. Many instances of excessive non-productive and repetitious motor movements. On the move most of the time. Frequent pressured speech, difficult to interrupt. Rises on 1-2 occasions to pace.	**5**	
	Severe Excessive motor activity, restlessness, fidgety, loud tapping, noisy, etc., throughout most of the interview. Speech can only be interrupted with much effort. Rises on 3-4 occasions to pace.	**6**	
	Extremely Severe Constant excessive motor activity throughout entire interview, e.g., constant pacing, constant pressured speech with no pauses,	**7**	

	individual can only be interrupted briefly and only small amounts of relevant information can be obtained		
124	**Mannerisms and posturing** Unusual and bizarre behaviour, stylised movements or acts, or any postures which are clearly uncomfortle or inappropriate. Exclude obvious manifestations of medication side effects. Do not include nervous mannerisms that are not odd or unusual.		
	Absent	**1**	BPRSPOST6
	Very mild Eccentric or odd mannerisms or activity that ordinary persons would have difficulty explaining, e.g., grimacing, picking. Observed once for a brief period.	**2**	
	Mild Same as 2, but occurring on two occasions of brief duration.	**3**	
	Moderate Mannerisms or posturing, e.g., stylised movements or acts, rocking, nodding, rubbing, or grimacing, observed on several occasions for brief periods or infrequently but very odd. For example, uncomfortable posture maintained for 5 seconds more than twice.	**4**	
	Moderately Severe Same as 4, but occurring often, or several examples of very odd mannerisms or posturing that are idiosyncratic to the individual.	**5**	
	Severe Frequent stereotyped behaviour, assumes and maintains uncomfortable or inappropriate postures, intense rocking, smearing, strange rituals or foetal posturing. Individual can interact with people and the environment for brief periods despite these behaviours.	**6**	
	Extremely Severe Same as 6, but individual cannot interact with people or the environment due to these behaviours.	**7**	

Section 2: Clinical Global Impression (CGI)

CGI Severity				
201	Considering your total clinical experience with this particular population, how mentally ill is the patient at this time?	Not assessed	0	CGI_SEVERITY6
		Normal, not at all ill	1	
		Borderline mentally ill	2	
		Mildly ill	3	
		Moderately ill	4	
		Markedly ill	5	
		Severely ill	6	
		Among the most extremely ill patients	7	
CGI Global improvement				
202	Rate total improvement whether or not, in your judgement, it is due entirely to drug treatment. Compared to his condition at admission to the project, how much has he/she changed?	Not assessed	0	cgi_improve6
		Very much improved	1	
		Much improved	2	
		Minimally improved	3	
		No change	4	
		Minimally worse	5	
		Much worse	6	
		Very much worse	7	
CGI Efficacy index				
203	Rate this item on the basis of drug effect only. Select the number which best describe the degrees of therapeutic effect and side effects and record the number in the box where the two items intersect.			cgi_drugeffect6

		Side effects			
Therapeutic effect		**None**	**Do not significantly interfere with patient's functioning**	**Significantly interferes with patient's functioning**	**Outweighs therapeutic effect**
Marked	**Vast improvement. Complete or nearly complete remission of all symptoms**	01	02	03	04
Moderate	**Decided improvement. Partial remission of symptoms**	05	06	07	08
Minimal	**Slight improvement which doesn't alter status of care of patient**	09	10	11	12
Unchanged or worse		13	14	15	16

Section 4: Illness course (Life Chart Schedule (LCS))				
To be completed utilising patient interview, medical notes and treating clinician. Period of enquiry is last six months				
401	Course type	Episodic – relapsing and remitting course [→go to Q402]	1	CRTYP6
		Continuous – no remission during this interval [→go to Q406]	2	
		Never psychotic in this period [→ go to Q409]	4	
If episodic, rate items 402 – 405				
402	Type of remissions	Mainly complete	1	TYRMSN6
		Mainly incomplete	2	
		Mixed	3	
403	Presence of negative symptoms between episodes	No	0	PRNSBE6
		Yes, usually mild	1	
		Yes, usually prominent	2	
404	Number of psychotic episodes	None	0	NPSYEP6
		1	1	
		2	2	
		3	3	
		4-9	4	
		10 or more	5	
405	Weeks of longest psychotic episode	[→ go to Q411]		WELPE6
If continuous, rate questions 6 – 8				
406	Usual severity of symptoms	Mild	1	USYMT6
		Moderate	2	
		Severe	3	
407	Presence of negative symptoms	No	0	PRNGSY6
		Yes, usually mild	1	
		Yes, usually prominent	2	
408	Fluctuations in symptoms	Minimal or none [→go to Q411]	0	FLSYM6
		Episodic exacerbations [→go to Q411]	1	
If never psychotic in this period, rate items 9 and 10				
409	Type of remissions	Mainly complete	1	TYRMSN96
		Mainly incomplete	2	
		Mixed	3	
410	Presence of negative symptoms between episodes	No	0	PRNSE6
		Yes, usually mild	1	
		Yes, usually prominent	2	
411	Source of information for Life Chart schedule	Patient	1	lcsinfo6
		Caregiver	2	
		Both	3	

SECTION 5: Medication

501	In the past 3 months, how many new or continuing medications have you been prescribed for any health condition?			rxmeds6
	[Answer the following questions for each medication seperately]			
502	What is the name of the first medication you were prescribed? If you do not remember what medications you have been prescribed, you can show me the pills or prescriptions.	Fluoxetine	1	rx1name6
		Carbemazepine	2	
		Thiamine	3	
		Diazepam	4	
		Resperidone	5	
		Trihexiphynidil	6	
		Sodium valproate	7	
		Phenytoine	8	
		Haloperidol	9	
		Fluphenazine	10	
		Phenobarbitol	11	
		Amytryptyline	12	
		Imipramine	13	
		Promethazine	14	
		Olanzapine	15	
		Phenobarbitone	16	
		Chlopromazine	17	
		Other medication	77	
503	Specify the other medication			rx1nameo6
504	For how many days was medication most recently prescribed?			rx1days6
505a	Answer if oral medication: What was the daily dosage for the medication?		MG	rx1dosage6
505b	Answer if injection: What is the monthly dose?		MG	rx1dosagei6
506a	Who prescribed the medication for you?	Nurse/midwife/ health officer	1	rx1who6
		General doctor	2	
		Specialist doctor (non-psychiatrist)	3	
		Psychiatrist	4	
		Psychiatric nurse	5	
		Other mental health worker	6	
		Other (specify)	77	
506b	Specify other			rx1whoo6
507	Did the [health care worker] give you advice and support with taking [medication]?	No	0	rx1advice6
		Yes	1	
		Don't know / Can't remember	88	
508	Did the [health care worker] talk to you about potential side effects of [medication] and what to do if you experience any of those side effects?	No	0	rx1sfx6
		Yes	1	
		Don't know / Can't remember	88	

509	What is the name of the second medication you were prescribed? If you do not remember what medications you have been prescribed, you can show me the pills or prescriptions.	Fluoxetine	1	rx2name6
		Carbemazepine	2	
		Thiamine	3	
		Diazepam	4	
		Resperidone	5	
		Trihexiphynidil	6	
		Sodium valproate	7	
		Phenytoine	8	
		Haloperidol	9	
		Fluphenazine	10	
		Phenobarbitol	11	
		Amytryptyline	12	
		Imipramine	13	
		Promethazine	14	
		Olanzapine	15	
		Phenobarbitone	16	
		Chlopromazine	17	
		Other medication	77	
510	Specify the other medication			rx2nameo6
511	For how many days was medication most recently prescribed?			rx2days6
512a	What was the daily dosage for the medication?		MG	rx2dosage6
512b	Answer if injection: What is the monthly dose?		MG	rx2dosagei6
513a	Who prescribed the medication for you?	Nurse/midwife/ health officer	1	rx2who6
		General doctor	2	
		Specialist doctor (non-psychiatrist)	3	
		Psychiatrist	4	
		Psychiatric nurse	5	
		Other mental health worker	6	
		Other (specify)	77	
513b	Specify other			rx2whoo6
514	Did the [health care worker] give you advice and support with taking [medication]?	No	0	rx2advice6
		Yes	1	
		Don't know / Can't remember	88	
515	Did the [health care worker] talk to you about potential side effects of [medication] and what to do if you experience any of those side effects?	No	0	rx2sfx6
		Yes	1	
		Don't know / Can't remember	88	
516	What is the name of the third medication you were prescribed? If you do not remember what medications you have been prescribed, you can show me the pills or prescriptions.	Fluoxetine	1	rx3name6
		Carbemazepine	2	
		Thiamine	3	
		Diazepam	4	
		Resperidone	5	
		Trihexiphynidil	6	
		Sodium valproate	7	

		Phenytoine	8	
		Haloperidol	9	
		Fluphenazine	10	
		Phenobarbitol	11	
		Amytryptyline	12	
		Imipramine	13	
		Promethazine	14	
		Olanzapine	15	
		Phenobarbitone	16	
		Chlopromazine	17	
		Other medication	77	
517	Specify the other medication			rx3nameo6
518	For how many days was medication most recently prescribed?			rx3days6
519a	What was the daily dosage for the medication?		MG	rx3dosage6
519b	Answer if injection: What is the monthly dose?		MG	rx3dosagei6
520a	Who prescribed the medication for you?	Nurse/midwife/ health officer	1	rx3who6
		General doctor	2	
		Specialist doctor (non-psychiatrist)	3	
		Psychiatrist	4	
		Psychiatric nurse	5	
		Other mental health worker	6	
		Other (specify)	77	
520b	Specify other			rx3whoo6
521	Did the [health care worker] give you advice and support with taking [medication]?	No	0	rx3advice6
		Yes	1	
		Don't know / Can't remember	88	
522	Did the [health care worker] talk to you about potential side effects of [medication] and what to do if you experience any of those side effects?	No	0	rx3sfx6
		Yes	1	
		Don't know / Can't remember	88	
523	***Main source of information for medication questions***	Patient	1	medinfo6
		Caregiver	2	
		Both	3	

Section 8: LIFE CHART				
801	Date of LIFE CHART completion – European calendar (G.C.)	[ ] [ ]/ [ ] [ ] /[ ] [ ] [ ] [ ]		lifedate6
802	Start date for LIFE CHART period– European calendar (G.C.)	[ ] [ ]/ [ ] [ ] /[ ] [ ] /[ ] [ ]		lifest6
803	End date for LIFE CHART period– European calendar (G.C.)	[ ] [ ]/ [ ] [ ] /[ ] [ ] /[ ] [ ]		lifeend6
804	Source of information for LIFE chart	Patient	1	lifeinfo6
		Caregiver	2	
		Both	3	

		April	May	June	July	August	September	October	November	December	January	February	March
Psychosis (psy[month])													
Depression (dep[month])													
Mania (man[month])													
Substance abuse	Alcohol (alc[month])												
	Khat (kha[month])												
Deliberate self harm	Any (dsh[month])												
	Severity (sev[month])												
Life events (lif[month])													
Medication	Any (med[month])												
	Adequacy (ade[month])												
	Tolerability (tol[month])												

SECTION TWO (lay interviewer administered: patient)

INTERVIEW DETAILS

001a	Ethiopian calendar Interview date (E.C.)	[ ][ ]/[ ][ ]/[ ][ ][ ][ ]		EClaydate6
001b	European Calendar Interview date (G.C.)	[ ][ ]/[ ][ ]/[ ][ ][ ][ ]		GClaydate6
002	Assessor's name			intname6
003	Assessor's ID	[ ][ ]		intid6
004	PRIME ID	P E [ ][ ][ ][ ]		parid
005	Interview start time	[ ][ ]:[ ][ ]		layst6
006	Interview finish time	[ ][ ]:[ ][ ]		layfi6

TO BE COMPLETED BY RISE TRIAL STAFF (not to be completed by data collector)			
Is the participant recruited to the RISE trial?	No	0	rise6
	Yes	1	

SECTION 1: DISABILITY (WHO DAS (DISABILITY ASSESSMENT SCHEDULE) 2.0 – 36 ITEM

Note to the interviewer**:** *ONLY PATIENT RESPONSES SHOULD BE USED TO COMPLETE THIS INSTRUMENT*

Note to the interviewer**:** *Hand flashcard 1 to respondent and explain the following*

The next few questions are about difficulties people have because of health conditions. By health condition I mean diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs.

I remind you to keep all of your health problems in mind as you answer the questions.

When I ask you about difficulties in doing an activity think about

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

Note to the interviewer**: *give the following extra information to the respondent***

When answering, I'd like you to think back over the last 30 days. I also would like you to answer these questions thinking about how much difficulty you have, on average over the past 30 days, while doing the activity as you usually do it.

Hand flashcard #2 to interviewee and read scale aloud. Then give the following additional explanations to the respondent

Use the following scale when responding.

1. None 2. Mild 3. Moderate 4. Severe 5. Extreme or cannot do.

Note to the interviewer**:** *Flashcards #1 and #2 should remain visible to the respondent throughout the interview*

Cognition

I am going to ask you some questions about communication and thinking activities.

Use the above mentioned five scales for disability assessment when responding. These are

1. None 2. Mild 3. Moderate 4. Severe 5. Extreme or cannot do.

In the past 30 days, how much difficulty did you have in:				
101.1	Concentrating on doing something for ten minutes?	None	**1**	**WHUFP6**
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
101.2	Remembering to do important things?	**None**	**1**	WHURD6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
101.3	Analysing and finding solutions to problems in day-to-day life?	**None**	**1**	WHUDA6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
101.4	Learning a new task, for example, learning how to get to a new place?	**None**	**1**	WHUNT6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
101.5	Generally understanding what people say?	**None**	**1**	WHUP6
		Mild	**2**	

		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
101.6	Starting and maintaining a conversation?	**None**	**1**	WHUCW6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	

Mobility

Now I am going to ask you problems associated with mobility

In the past 30 days, how much difficulty did you have in:				
102.1	Standing for long periods such as 30 minutes?	**None**	**1**	WHMLW6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
102.2	Standing up from sitting down?	**None**	**1**	WHMSP6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
102.3	Moving around inside your home?	**None**	**1**	WHMWP6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
102.4	Getting out of your home?	**None**	**1**	WHMOH6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
102.5	Walking a long distance such as a kilometre [or equivalent]?	**None**	**1**	WHMLP6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	

Self-care

Now, I am going to ask you problems associated with self care

In the past 30 days, how much difficulty did you have in:				
103.1	Washing your whole body?	**None**	**1**	**WHCWB6**
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
103.2	Getting dressed?	**None**	**1**	WHCWC6
		Mild	**2**	
		Moderate	**3**	

		Severe	**4**	
		Extreme or cannot do	**5**	
103.3	Eating?	**None**	**1**	WHCEP6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	
103.4	Staying by yourself for a few days?	**None**	**1**	WHCDF6
		Mild	**2**	
		Moderate	**3**	
		Severe	**4**	
		Extreme or cannot do	**5**	

Getting along

Now I am going to ask you problems associated with getting along with other people. Remember that I am going to ask only difficulties that might be encountered with this due to a health condition. This means, diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs.

Show the respondent flash card #1 and #2 and read				
In the past 30 days, how much difficulty did you have in:				
104.1	Dealing with people you do not know?	None	1	WHDFM6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
104.2	Maintaining a friendship?	None	1	WHWFR6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
104.3	Getting along with people who are close to you?	None	1	WHFRCD6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
104.4	Making new friends?	None	1	WHNFS6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
104.5	Sexual activities?	None	1	WHSCP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

Life activities

5(1). Taking care of your household responsibilities

The next questions are intended to elicit respondents' appraisal of any difficulty they encounter in maintaining the household and in caring for family members or other people they are close to. These activities are those that people do on most days; they include: cooking, cleaning, going to the market or shops and taking care of other people and protecting your property.

Show the respondent flash card #1 and #2 and read				
In the past 30 days, how much difficulty did you have in:				
105.1	Taking care of your household responsibilities?	None	1	WHHWR6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
105.2	Doing most important household tasks well?	None	1	WHVNHT6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
105.3	Getting all the household work done that you needed to do?	None	1	WHFAP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
105.4	Getting your household work done as quickly as needed?	None	1	WHSDP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	

If the respondents give above 'none' (greater than 1) for the level of difficulty within questions 105.1 – 105.4, ask the following. [→ if all the responses are none, go to 105(2)]

105.01	In the past 30 days, for how many days were you totally unable to carry out your usual house work because of any health condition?	_____ days	WHTDY6

105 (2) work/school

Now I am going to ask you about your work or school.

Show the respondent flash card #1 and #2 and read

In the past 30 days, how much difficulty did you have in:				
105.5	Your day-to-day work/school?	None	1	WHDWP6
		Mild	2	
		Moderate	3	
		Severe	4	

		Extreme or cannot do	5	
105.6	Doing your most important work/school tasks well?	None	1	WHNEG6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
105.7	Getting all the work done that you need to do?	None	1	WHFWP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
105.8	Getting your work done as quickly as needed?	None	1	WHEWP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

If the respondents give above 'none' (greater than 1) for the level of difficulty within questions 105.5 – 105.8, ask the following. [→ if all the responses are none, go to 106)]			
105.02	In the past 30 days, for how many days did you miss work for half days or more than that because of any health condition?	_____ days	WHPHD6

105.9	Did you have to work less than you are expected or less than usual?	No	1	WHILW6
		Yes	2	
105.10	Did your income decrease because of your illness?	No	1	WHIIR6
		Yes	2	

6. Participation

Now I am going to ask you about your participation in the community and the impact of your health condition on your and your families community life. Some of this problems might have stayed more than a month. However, when you give response to the following questions, please focus only on the past 30 days. I remind you again to keep all of your health problems in mind as you answer the questions

In the past 30 days				
106.1	How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way anyone else can?	None	1	WHSAPB6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
106.2	How much of a problem did you have because of barriers or hindrances in the world around you?	None	1	WHSMA6
		Mild	2	
		Moderate	3	
		Severe	4	

		Extreme or cannot do	5	
106.3	How much of a problem did you have living with dignity because of the attitudes and actions of others?	None	1	WHBALP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
106.4	How much time did you spend on your health condition, or its consequences?	None	1	WHGSWT6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
106.5	How much have you been emotionally affected by your health condition?	None	1	WHAEMN6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
106.6	How much has your health been a drain on the financial resources of you or your family?	None	1	WHIACT6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
106.7	How much of a problem did your family have because of your health problems?	None	1	WHSFUP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
106.8	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	None	1	WHENOH6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

107.1	Overall, in the past 30 days, how many days were these difficulties present?	_____ days	WHMLWD6
107.2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	_____ days	WHMLHS6
107.3	In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	_____days	WHMAPL6

108	Main source of information for WHODAS	Patient	1	whodasinfo6
		Both	3	

SECTION 2: DEPRESSION (PHQ 9 +1)

	Over the past 2 weeks, have you been bothered by any of the following problems? **Note: :-Explain to the interviewee that occasionally means (2-6 days), several days means 7-11 days and nearly every day means 12 -14 days**			
201a	Little interest or pleasure in doing daily activities?	Yes	1	PHLI6
		No [→go to Q 202a]	0	
201b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHLIIF6
		Several days	2	
		Nearly every day	3	
202a	Feeling down, depressed, or hopeless?	Yes	1	PHFS6
		No [→go to Q 203a]	0	
202b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHFSIF6
		Several days	2	
		Nearly every day	3	
203a	Trouble falling/staying asleep?	Yes	1	PHIS6
		No [→go to Q 204a]	0	
203b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHISIF6
		Several days	2	
		Nearly every day	3	
204a	Sleeping too much?	Yes	1	PHOS6
		No [→go to Q 205a]	0	
204b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHOSIF6
		Several days	2	
		Nearly every day	3	
205a	Feeling tired or having little energy?	Yes	1	PHLE6
		No [→go to Q 206a]	0	
205b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHLEIF6
		Several days	2	
		Nearly every day	3	
206a	Poor appetite?	Yes	1	PHLR6
		No [→go to Q 207a]	0	
206b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHLRIF6
		Several days	2	
		Nearly every day	3	
207a	Overeating	Yes	1	PHFH6
		No [→go to Q 208a]	0	
207b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHFHIF6
		Several days	2	
		Nearly every day	3	
208a	Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	Yes	1	PHFAIL6
		No [→go to Q 209a]	0	
208b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHFAILIF6
		Several days	2	
		Nearly every day	3	

209a	Trouble concentrating on things, such as reading the newspaper or watching television?	Yes	1	PHDC6
		No [→go to Q 210a]	0	
209b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHDCIF6
		Several days	2	
		Nearly every day	3	
210a	Moving or speaking so slowly that other people could have noticed?	Yes	1	PHDT6
		No [→go to Q 211a]	0	
210b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHDTIF6
		Several days	2	
		Nearly every day	3	
211a	Being so fidgety or restless that you have been moving around a lot more than usual that other people could have noticed?	Yes	1	PHDS6
		No [→go to Q 212a]	0	
211b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHDSIF6
		Several days	2	
		Nearly every day	3	
212a	Thoughts that you would be better off dead or of hurting yourself in some way? If the interviewee ANSWERS YES, refer him/her to THE PROJECT COORDINATOR FOR CLINICAL REVIEW	Yes	1	PHWD6
		No [→go to Q 213]	0	
212b	If yes, how frequently in the last 2 weeks?	Occasionally	1	PHWDIF6
		Several days	2	
		Nearly every day	3	
213	If the interviewee responded Yes to one of the above problems, ask the following? : How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	0	PHDR6
		Somewhat difficult	1	
		Very difficult	2	
		Extremely difficult	3	
214	In addition to what we have been discussing, in the past 12 months have you ever feel depressed and loss of interest for two weeks or more?	No	0	PHWFG6
		Yes	**1**	
215	**Source of information for PHQ-9**	Patient	1	phqinfo6
		Caregiver	**2**	
		Both	**3**	

	PHQ Score (0,1, 2 or 3)	
Item 201b		
Item 202b		
Highest score for item 203b OR Item 204b		
Item 205b		
Highest score for item 206b OR item 207b		
Item 208b		
Item 209b		
Highest score for item 210b OR Item 211b		
Item 212b		
TOTAL		phrefer6

If the TOTAL is 10 or greater→ refer him/her to THE PROJECT COORDINATOR FOR CLINICAL REVIEW

SECTION 3: SUICIDAL IDEATION AND ACTION (CIDI)

301	Have you thought of taking your life in the past 6 months?	No	0	SUITHINK6
		Yes	1	
302	Did you ever make a plan for taking your own life at any time in the past 6 months?	No	0	SUIPLAN6
		Yes	1	
303a	Have you attempted to take your own life in the past 6 months?	No [→ Go to Q305]	0	SUIATT6
		Yes	1	
303b	If you have attempted to take your own life in the past 6 months, how many times have you attempted?	[ ] [ ] times		SUIATF6
309	Source of information for Suicide ideation and action	Patient	1	suiinfo6
		Caregiver	2	
		Both	3	

SECTION 4: SERVICE UTILISATION AND COST (SAGE)

Outpatient care					
Excluding inpatient care, how many times did you see these health care providers in the last 3 months? If yes, how many times did you see him/her?					
401	Traditional healer	No	0		OUT_TRAD6
		Yes	1 →	visits	TRADNO6
402	Community health worker, Nurse or midwife, health officer, Pharmacist	No	0		OUT_HCW6
		Yes	1 →	visits	HCWNO6
403	Mental health : Psychiatrist, Psychiatric nurse, counsellor	No	0		OUT_MH6
		Yes	1 →	visits	MHNO6
404	General practitioner or Specialist (excluding Psychiatrist	No	0		OUT_DOC6
		Yes	1 →	visits	DOCNO6
405	Other (Specify)	No	0		OUT_OTH6
		Yes	1 →	visits	OTHNO6

Inpatient care				
406	In the last 6 months, have you ever stayed overnight in a hospital?	No [→ go to Q410]	0	**HOSP6**
		Yes	1	
407	How many times have you been admitted into a hospital in the last 6 months?			**HOSPNO6**

For each separate hospital admission you have had, please complete the following:

	Admission No.	Why were you admitted? 1 = infectious disease (e.g. malaria) 2 = maternal / perinatal condition 3 = acute condition (e.g. flu, cough) 4 = injury 5 = sleep problems 6 = depression or anxiety 7 = alcohol problems 8 = other mental health problems 9 = other chronic disease (e.g. heart, diabetes) 10 = psychosis 11 = epilepsy 77 = other condition (specify) 88 = don't know	Where was the admission? 1 = charity / church-run hospital 2 = private hospital 3 = government hospital 77 = other (specify)	How long was the admission? (DAYS)	How much did you, your family or friends have to pay (for hospital fees, medicines, investigations)? (birr)
	#	**IN#WHY6 IN#WHYO6**	**IN#WHERE6 IN#WHEREO6**	**IN#LENGTH6**	**IN#COST6**
408	1			days	
409	2			days	

410	***Source of information for health service utilisation and cost***	Patient	1	serviceinfo6
		Caregiver	2	
		Both	3	

	For each separate contact or visit with the outpatient health care providers in the past 3 months, ask the following													
	Visit	[Who was seen?] 1 = traditional healer / spiritualist / herbalist 2 = community health worker 3 = nurse / midwife 4 = pharmacist 5 = General doctor 6 = Specialist doctor 7 = Psychiatrist 8 = Psychiatric nurse 77= other	Where did it take place? 1 = your own home 2 = traditional healer 3 = local health centre 4 = private clinic 5 = hospital outpatient	Why did you have this visit? 1=infectious disease (e.g. malaria) 2 = maternal / perinatal condition 3 = acute condition (e.g. flu, cough) 4 = injury 5 = sleep problems 6 = depression or anxiety 7 = alcohol problems 8 = other mental health problems 9 = other chronic disease 10= psychosis 11= epilepsy 77 = other (specify)	What were the main features of the visit? (list up to three elements) 1 = assessment and/or diagnosis 2 = drug prescription (for condition listed on left) 3 = drug prescription (for other condition) 4 = psychosocial support/care 5 = follow-up visit 6 = referral to other provider 7 = Prayer/ Muslim prayer/ Holy water 77 = other (specify) **1** **2** **3**			To whom did you get a referral? 1 = traditional healer / spiritualist / herbalist 2 = community health worker 3 = nurse / midwife 4 = pharmacist 5 = General doctor 6 = Specialist doctor 7 = Psychiatrist 8 = Psychiatric nurse 77= other	How satisfied are you with the treatment you received? 1=Very satisfied 2=Satisfied 3=Neither satisfied nor dissatisfied 4=Dissatisfied 5=Very dissatisfied 888=Don't know	How long did it take you to travel to where you received care? **(MINUTES)**	After arriving, how long did you wait for your consultation to begin? **(MINUTES)**	How long was the consultation (excluding waiting time)? **((MINUTES)**	How much did you, your family or friends have to pay in consultation fees? in travel? (birr) Health care cost Travel cost
	VISNO#	**HC#WHO6 HC#WHOO6**	***HC#WHERE6***	**HC#WHY6 HC#WHYO6**	**HC#F16**	**HC#F26**	**HC#F36**	**HC#REF6**	**HC#SATIS6**	**HC#TRAVEL6**	**HC#WAIT6**	**HC#LONG6**	**HC#COST16**	**HC#COST26**
411	1													
		OTHER		OTHER	OTHER									
412	2													
		OTHER		OTHER	OTHER									
413	3													
		OTHER		OTHER	OTHER									

SECTION 5: TREATMENT GAP

	USE ONLY PATIENT RESPONSES TO COMPLETE THE SECTION ON RESTRAINT (Q549- Q568)			
549	Have you been chained, restrained or confined in the last six months?	**No [→ go to next section]**	**0**	rstrnt66
		Yes	**1**	
550	Number of times you have been chained or restrained in the last six months?			rstrntfrq6
551	Total duration of the restraint in the last six months (complete either days or months)	days		rsttdrnd6
		months		rsttdrnm6
552	Have you been chained, restrained or confined in the last one month?	**No**	**0**	rstrnt16
		Yes	**1**	
553	**Who instigated the chaining or restraint (on any occasion of restraint)?**			
553a	Traditional healer	No	**0**	rsttrad6
		Yes	**1**	
553b	Priest/ Religious healer	No	**0**	rstrel6
		Yes	**1**	
553c	Health care worker	No	**0**	rsthcw6
		Yes	**1**	
553d	Family member	No	**0**	rstfam6
		Yes	**1**	
553e	Prison staff or police	No	**0**	rstpris6
		Yes	**1**	
553f	Other community member	No	**0**	rstcom6
		Yes	**1**	
553g	Other	No	**0**	rstoth6
		Yes	**1**	
553h	Specify other			rstoths6
554	**What were the reasons for the chaining or restraint?**			
555a	To prevent you from attacking others	No	**0**	rsnatak6
		Yes	**1**	
555b	To prevent you from getting lost	No	**0**	rsnlost6
		Yes	**1**	
555c	To prevent you from having an accident	No	**0**	rsnfrac6
		Yes	**1**	
555d	To prevent you from wandering around	No	**0**	rsnwand6
		Yes	**1**	
555e	To prevent you from harming myself or committing suicide	No	**0**	rsnslfhr6
		Yes	**1**	
555f	To prevent you from disturbing the family	No	**0**	rsndstfa6
		Yes	**1**	
555g	To prevent you from disturbing neighbours	No	**0**	rsndsnei6
		Yes	**1**	
555h	To prevent you from disturbing women and children	No	**0**	rsndschil6
		Yes	**1**	
555i	To prevent you from using alcohol or khat	No	**0**	rsnsubus6
		Yes	**1**	
555j	To prevent you from behaving in a shameful or taboo way	No	**0**	rsnshame6
		Yes	**1**	

555k	To prevent you from destroying property	No	0	rsndstry6
		Yes	1	
555l	To prevent you from being exploited to carry out labouring tasks	No	0	rsnlabu6
		Yes	1	
555m	Because neighours or others suggested it	No	0	rsnadvne6
		Yes	1	
555n	In order to transport you to a health centre or hospital	No	0	rsntran6
		Yes	1	
555o	In order to force you to take the medication or receive injection	No	0	rsnmed6
		Yes	1	
555p	To punish you for doing something wrong	No	0	rsnpun6
		Yes	1	
555q	Other reason	No	0	rsno6
		Yes	1	
555r	Specify other			rsnos6
556	**Where did the restraint take place?**			
556a	At home	No	0	phome6
		Yes	1	
556b	Prison	No	0	pprison6
		Yes	1	
556c	Holy water site	No	0	pholy6
		Yes	1	
556d	Health facility	No	0	phealth6
		Yes	1	
556e	Other place	No	0	poth6
		Yes	1	
556f	Specify other			poths6
557	In your opinion was it necessary to carry out the chaining or restraint?	No	0	ness6
		Yes	1	
558	**How did you feel whilst you were being restrained?**			
558a	Angry/ frustrated	No	0	rangry6
		Yes	1	
558b	Releived	No	0	rreleiv6
		Yes	1	
558c	Demoralised	No	0	rdemoral6
		Yes	1	
558d	Fearful	No	0	rfear6
		Yes	1	
558e	Helpless	No	0	rhelp6
		Yes	1	
558f	Safe	No	0	rsafe6
		Yes	1	
558g	Other	No	0	roth6
		Yes	1	
558h	Specify other			roths6

SECTION 6: Alcohol Use Disorders Identification Test (AUDIT): Self-Report Version

Now I am going to ask you some questions about your use of alcoholic beverages. Because alcohol use can affect many areas of health (and may interfere with certain medications), it is important for us to know how much you usually drink and whether you have experienced any problems with your drinking. Please try to be as honest and as accurate as you can be. Show cards for standard drinks measures

601	In the last three months, how often do you have a drink containing alcohol?	Never [→ go to Q 609]	0	AUHO6
		Monthly or less	1	
		2-4 times a month	2	
		2-3 times a week	3	
		4 or more times a week	4	
602	In the last three months, how many drinks containing alcohol do you have on a typical day when you are drinking?	1 -2	0	AUHM6
		3-4	1	
		5-6	2	
		7-9	3	
		10 or more	4	
603	In the last three months, how often do you have six or more drinks on one occasion?	Never [skip to Questions 609 and 610 if scored 0 on Q 602 **AND** scored 1 for Q 603]	1	AUHS6
		Less than monthly	2	
		Monthly	3	
		Weekly	4	
		Daily or almost daily	5	
604	How often during the last 6 months have you found that you were not able to stop drinking once you had started?	Never	1	AUDS6
		Less than monthly	2	
		Monthly	3	
		Weekly	4	
		Daily or almost daily	5	
605	How often during the last 6 months have you failed to do what was normally expected from you because of drinking?	Never	1	AULD6
		Less than monthly	2	
		Monthly	3	
		Weekly	4	
		Daily or almost daily	5	
606	How often during the last 6 months have you needed a first drink in the morning to get yourself going after a heavy drinking session?	Never	1	AUEO6
		Less than monthly	2	
		Monthly	3	
		Weekly	4	
		Daily or almost daily	5	
607	How often during the last 6 months have you had a feeling of guilt or remorse after drinking?	Never	1	AUFG6
		Less than monthly	2	
		Monthly	3	
		Weekly	4	
		Daily or almost daily	5	
608	How often during the last 6	Never	1	AUUR6

	months have you been unable to remember what happened the night before because you had been drinking?	Less than monthly	2	
		Monthly	3	
		Weekly	4	
		Daily or almost daily	5	
609	Have you or someone else been injured as a result of your drinking?	No	1	AUID6
		Yes, but not in the last 6 months	2	
		Yes, during the last 6 months	3	
610	Has a relative or friend or a doctor or another health worker been concerned about your drinking or suggested you cut down?	No	1	AUAR6
		Yes, but not in the last 6 months	2	
		Yes, during the last 6 months	3	
611	***Main source of information for AUDIT***	Patient	1	auditinfo6
		Caregiver	2	
		Both	3	

SECTION 7: Social support (OSLO 3-item social support scale)

Please circle the option that represents your experience.				
701	How easy is it to get practical help from neighbours if you should need it ?	Very easy	1	OSAS6
		Easy	2	
		Possible	3	
		Difficult	4	
		Very difficult	5	
702	How many people are so close to you that you can count on them if you have serious personal problems (choose one option)?	None	1	OSCRS6
		1 or 2	2	
		3-5	3	
		More than 5	4	
703	How much concern do people show in what you are doing (choose one option)?	A lot of concern and interest	1	OSNPS6
		Some concern and interest	2	
		Uncertain	3	
		Little concern and interest	4	
		No concern and interest	5	
704	***Main source of information for OSS***	Patient	1	ossinfo6
		Caregiver	2	
		Both	3	

SECTION 8: Discrimination (DISC-12)

In this section, I would like to ask about times in the last 6 months when you have been treated unfairly because of mental health problems. In this section, there are 21 questions. Please give response for each.				
801	Have you been treated unfairly in making or keeping friends?	Not at all	0	DIFUR6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
802	Have you been treated unfairly by the people in your neighbourhood?	Not at all	0	DNAU6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
803	Have you been treated unfairly in dating or intimate relationships? (excluding treatment by spouse or co-habiting partner as covered by Q806)	Not at all	0	DLFUA6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
804	Have you been treated unfairly in housing? (including becoming homeless)	Not at all	0	DHRUM6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
805	Have you been treated unfairly in your education? (ask about school, college, university, on the job training, vocational courses)	Not at all	0	DECUT6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
806	Have you been treated unfairly in marriage or divorce? (including co-habiting or civil partnership. Ask about ability to find a partner or spouse, problems during the relationship, divorce settlements)	Not at all	0	DMRD6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
807	Have you been treated unfairly by your family? (ask about family of origin – parents, brothers, sisters and other relations as well as any children. Exclude treatment by spouse or co-habiting partner as covered by Q806)	Not at all	0	DFBSR6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
808	Have you been treated unfairly in finding a job? (this means finding full or part-time paid work)	Not at all	0	DGWU6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
809	Have you been treated unfairly in keeping a job?	Not at all	0	DWEU6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	

810	Have you been treated unfairly when using public transport? (ask about using free travel pass, passengers, drivers, etc)	Not at all	0	DPRTU6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
811	Have you been treated unfairly in your religious practices? (ask about attending church, other church members, church leaders)	Not at all	0	DUDBO6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
812	Have you been treated unfairly in your social life? (ask about socialising, hobbies, attending events, leisure activities)	Not at all	0	DSLPT6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
813	Have you been treated unfairly by the police? (ask about any contact with police because of mental health problems or any other reasons)	Not at all	0	DPLUT6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
814	Have you been treated unfairly when getting help for physical health problems? (ask about GP, dentist, nurses, health officers, health extension workers, and emergency treatment)	Not at all	0	DPBHP6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
815	Have you been treated unfairly by mental health staff? (ask about treatment and behaviour of staff, feeling disrespected or humiliated by contact with mental health staff)	Not at all	0	DBQM6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
816	Have you been treated unfairly in your personal safety and security? (ask about verbal abuse, physical abuse, assault)	Not at all	0	DPSRT6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
817	Have you been treated unfairly in starting a family or having children? (ask about the behaviour of health professionals, friends and family, as well as how they or their partner were treated during pregnancy or childbirth)	Not at all	0	DFCPD6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
818	Have you been treated unfairly in your role as a parent to your children? (ask about behaviour of other parents, teachers, family or mental health staff)	Not at all	0	DFRT6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
819	Have you been avoided or shunned by people who know that you have a mental health problem?	Not at all	0	DMISA6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
820	Have you been treated unfairly in getting welfare	Not at all	0	dwelf6

	benefits or disability pensions?	A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
821	Have you been treated unfairly in your levels of privacy? (ask about privacy in hospital and in community settings, eg private letters or phone calls, medical records)	Not at all	0	dpriv6
		A little	1	
		Moderately	2	
		A lot	3	
		Not applicable	4	
822	How much do you agree with the following statement: I feel that receiving treatment for mental illness/ psychosis has lead to people tending to treat me more fairly	Strongly agree	1	dtreat6
		Agree	2	
		Neither agree / disagree	3	
		Disagree	4	
		Strongly disagree	5	
823	***Main source of information for DISC***	Patient	1	discinfo6
		Caregiver	2	
		Both	3	

SECTION 11: Economic activity				
1101	What is your occupation? That is, what type of work do you do when you are working?	Home worker (e.g. housewife)	1	occup6
		Unskilled labourer (e.g. farmhand / domestic	2	
		Skilled labourer (e.g. builder)	3	
		Services / sales (e.g. shop worker)	4	
		Clerical worker (e.g. secretary)	5	
		Professional (e.g. nurse, lawyer, doctor)	6	
		Other	77	
	Specify other			occupo6
1102	What is your CURRENT employment status? That is, what is your working status?	Full- or part-time employment (salaried)	0	emp6
		Paid or self-employment (including subsistence farmer)	1	
		Voluntary employment [→go to Q1105]	2	
		Not employed (including housewife) [→go to Q1105]	3	
		Student [→go to Q1105]	4	
		Retired [→go to Q1105]	5	
		Other [→go to Q1105]	77	
	Specify other			empo6
1103	About how many days did you work in the past 4 weeks (28 days)?	Days		Econworkdys6
1104	How much do you usually earn per day/week/month/year (before taxes and other deductions)?	If days: birr [→go to Q1108]		econearnd6
		If weeks: birr [→go to Q1108]		econearnw6
		If months: birr [→go to Q1108]		econearnm6
		If years: birr [→go to Q1108]		econearny6
1105	Have you EVER worked for income / had employment?	No [→go to Q1107]	0	econever6
		Yes	1	
1106	How long ago did you LAST work for income / have employment?	Days		econunempd6
		Months		econunempm6
		Years		econunempy6
1107	Are you looking for work or intending to return to work?	No	0	return6
		Yes	1	
1108	Has anyone in your household, including yourself, been hungry in the last month due to lack of resources/food?	No	0	hhfood6
		Yes	1	

SECTION 12: Medication Adherence

USE ONLY PATIENT RESPONSES TO COMPLETE THIS QUESTION

1201	Do you ever forget to take your medication?	No	0	rxforget6
		Yes	1	
1202	Are you careless at times about taking your medication?	No	0	rxcareless6
		Yes	1	
1203	When you feel better do you sometimes stop taking your medication?	No	0	rxbetter6
		Yes	1	
1204	Sometimes if you feel worse when you take your medication, do you stop taking it?	No	0	rxworse6
		Yes	1	
1205	In the past **one month**, have you been taking your medication as prescribed by your health care worker?	All the time	1	rxmonth6
		Most of the time (> 3 of the last 4 weeks)	2	
		Sometimes (at least 2-3/4 weeks)	3	
		Took the medicine occasionally (<2 of the last 4 weeks)	4	
		Did not take any medicine at all	5	
1206	Do you ever stop taking your medication because you cannot	No	0	Rxcantafford6
		Yes	1	
1207	Do you ever stop taking your medication because it is not	No	0	Rxunavailable6
		Yes	1	
1208	In the last 12 months have you ever received anti-psychotic	No	0	Rxfree6
		Yes	1	

SECTION 13: Community interventions

	Have you received any of the following types of support in the last 6 months?	Was the support/ intervention received? 0= No 1= Yes	Who gave the support/ intervention? 1= Family 2= Health extension worker 3= NGO 4= Priest/ religious leader 5= Traditional healer 6= Community health worker e.g. Community-based rehabilitation worker 7= Commuity member 8= Health centre staff (nurse/ health officer) 9 = Other		How helpful did you find the support you received? 1=A lot 2=Some 3=A little 4=Not at all
		Received#	#who #whoo		#help
1301	Support returning to work (including farm work, daily labouring or paid employment?)				
			Specify other		
1302	Advice or support with remembering to take medication?				
			Specify other		
1303	Support with improving your self-care e.g. getting washed and dressed by yourself?				
			Specify other		
1304	Support with meeting up with other people with mental illness or their families e.g. a family support group?				
			Specify other		
1305	Support with social/ community engagement e.g. attending Edir or church				
			Specify other		
1306	Home visits by a health extension worker for issues relating to your mental health problems				
1307	Main source of information		Patient	1	comminfo6
			Caregiver	2	
			Both	3	

Physical assessment

TO BE COMPLETED BY THE NURSE

Pulse	___ ___ ___ beats / minute		pulse6
Systolic blood pressure	Systolic_____mm Hg		sbp6
Diastolic blood pressure	Diastolic_____mmHg		dbp6
Weight	___ ___ ___ .___kg		weight6
Height	___ ._____m		height6
Are there any gross physical abnormalities (e.g. swelling, skin lesion)	Yes	1	abnorm6
	No	0	
If yes, describe the abnormality			dabnorm6

Please take time to double-check that all of the forms are complete and that no questions have been missed.

Confirmation of questionnaire completion			
Name of assessor	**Signature**		**Date (EC)**
Confirmation of questionnaire data completeness and quality check			
Name	**Role**	**Signature**	**Date (EC)**

SECTION THREE (lay data collector administered: caregiver)

INTERVIEW DETAILS

1601a	Ethiopian calendar Interview date (E.C.)	**[ ][ ] / [ ][ ]/ [ ] [ ] [ ][ ]**		ECclaydate6
1601b	European Calendar Interview date (G.C.)	**[ ][ ] / [ ][ ]/ [ ] [ ] [ ][ ]**		GCclaydate6
1602	Assessor's name			cintname6
1603	Assessor's ID	**[ ] [ ]**		cintid6
1604	Is the caregiver the same individual who attended at baseline? [Consult the coordinator]	No [→ get new ID from coordinator]	0	cverify6
		Yes	1	
1605	PRIME caregiver ID	P E **[ ] [ ] [ ][ ] C**		carid
1606	PRIME patient ID	P E **[ ] [ ] [ ][ ]**		parid
1607	Interview start time	**[ ] [ ] : [ ][ ]**		clayst6
1608	Interview finish time	**[ ] [ ] : [ ][ ]**		clayfi6

TO BE COMPLETED BY RISE TRIAL STAFF (not to be completed by data collector)			
Is the participant recruited to the RISE trial?	No	0	crise6
	Yes	1	

SECTION 17: DISABILITY (WHO DAS (DISABILITY ASSESSMENT SCHEDULE) 2.0 – 36 ITEM PROXY VERSION

Note to the interviewer**:** *ONLY CAREGIVER RESPONSES SHOULD BE USED TO COMPLETE THIS INSTRUMENT*

Note to the interviewer**:** *Hand flashcard 1 to respondent and explain the following.*

This questionnaire asks about difficulties due to health conditions experienced by the person about whom you are responding in your role as friend, relative or carer.

By health condition I mean diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs.

I remind you to keep all of your health problems in mind as you answer the questions.

When I ask you about difficulties in doing an activity think about

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

Note to the interviewer: give the following extra information to the respondent

Think back over the past 30 days and, to the best of your knowledge, answer these questions thinking about how much difficulty your friend, relative or carer had while doing the following activities. (Note: the questionnaire uses the term "relative" to mean "friend", "relative" or "carer".) For each question, please circle only one response.

Hand flashcard #2 to interviewee and read scale aloud. Then give the following additional explanations to the respondent

Use the following scale when responding.

1. None 2. Mild 3. Moderate 4. Severe 5. Extreme or cannot do.

Note to the interviewer**:** *Flashcards #1 and #2 should remain visible to the respondent throughout the interview*

Cognition

I am going to ask you some questions about communication and thinking activities.

Use the above mentioned five scales for disability assessment when responding. These are

1. None 2. Mild 3. Moderate 4. Severe 5. Extreme or cannot do.

In the past 30 days, how much difficulty did your relative have in:				
1701.1	Concentrating on doing something for ten minutes?	None	1	CWHUFP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1701.2	Remembering to do important things?	None	1	CWHURD6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1701.3	Analysing and finding solutions to problems in day-to-day life?	None	1	CWHUDA6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1701.4	Learning a new task, for example, learning how to get to a new place?	None	1	CWHUNT6
		Mild	2	
		Moderate	3	
		Severe	4	

		Extreme or cannot do	5	
1701.5	Generally understanding what people say?	None	1	CWHUP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1701.6	Starting and maintaining a conversation?	None	1	CWHUCW6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

Mobility

Now I am going to ask you problems associated with mobility

In the past 30 days, how much difficulty did your relative have in:				
1702.1	Standing for long periods such as 30 minutes?	None	1	CWHMLW6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1702.2	Standing up from sitting down?	None	1	CWHMSP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1702.3	Moving around inside your home?	None	1	CWHMWP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1702.4	Getting out of your home?	None	1	CWHMOH6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1702.5	Walking a long distance such as a kilometre [or equivalent]?	None	1	CWHMLP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

Self-care

Now, I am going to ask you problems associated with self care

In the past 30 days, how much difficulty did your relative have in:				
1703.1	Washing your whole body?	None	1	CWHCWB6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

1703.2	Getting dressed?	None	1	CWHCWC6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1703.3	Eating?	None	1	CWHCEP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1703.4	Staying by yourself for a few days?	None	1	CWHCDF6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

Getting along

Now I am going to ask you problems associated with getting along with other people. Remember that I am going to ask only difficulties that might be encountered with this due to a health condition. This means, diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs.

Show the respondent flash card #1 and #2 and read				
In the past 30 days, how much difficulty did your relative have in:				
1704.1	Dealing with people you do not know?	None	1	CWHDFM6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1704.2	Maintaining a friendship?	None	1	CWHWFR6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1704.3	Getting along with people who are close to you?	None	1	CWHFRCD6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1704.4	Making new friends?	None	1	CWHNFS6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1704.5	Sexual activities?	None	1	CWHSCP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

Life activities

1705(1). Taking care of your household responsibilities

The next questions are intended to elicit respondents' appraisal of any difficulty they encounter in maintaining the household and in caring for family members or other people they are close to. These activities are those that people do on most days; they include: cooking, cleaning, going to the market or shops and taking care of other people and protecting your property.

Show the respondent flash card #1 and #2 and read				
In the past 30 days, how much difficulty did your relative have in:				
1705.1	Taking care of their household responsibilities?	None	1	CWHHWR6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
1705.2	Doing most important household tasks well?	None	1	CWHVNHT6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
1705.3	Getting all the household work done that they needed to do?	None	1	CWHFAP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
1705.4	Getting their household work done as quickly as needed?	None	1	CWHSDP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	

If the respondents give above 'none' (greater than 1) for the level of difficulty within questions 17***05.1 –*** 17***05.4, ask the following. [→ if all the responses are none, go to*** 17***05(2)]***

1705.01	In the past 30 days, for how many days were they totally unable to carry out their usual house work because of any health condition?	_____ days	CWHTDY6

1705(2) work/school

Now I am going to ask you about your relative's work or school.

Show the respondent flash card #1 and #2 and read

In the past 30 days, how much difficulty did your relative have in:				
1705.5	Their day-to-day work/school?	None	1	CWHDWP6
		Mild	2	
		Moderate	3	
		Severe	4	

		Extreme or cannot do	5	
1705.6	Doing their most important work/school tasks well?	None	1	CWHNEG6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1705.7	Getting all the work done that they need to do?	None	1	CWHFWP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1705.8	Getting their work done as quickly as needed?	None	1	CWHEWP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

If the respondents give above 'none' (greater than 1) for the level of difficulty within questions 1705.5 – 1705.8, ask the following. [→ if all the responses are none, go to 1706]			
1705.02	In the past 30 days, for how many days did your relative miss work for half days or more than that becaue of any health condition?	_____ days	CWHPHD6

1705.9	Was your relative obliged to work less than what they are expected to do or less than usual?	No	1	CWHILW6
		Yes	2	
1705.10	Has your relative's income gone down because of their illness?	No	1	CWHIIR6
		Yes	2	

6. Participation

Now I am going to ask you about your relative's participation in the community and the impact of their health condition on their and your families community life. Some of this problems might have stayed more than a month.However, when you give response to the following questions, please focus only on the past 30 days. I remind you again to keep all of their health problems in mind as you answer the questions

In the past 30 days				
1706.1	How much of a problem did your relative have joining in community activities (for example, festivities, religious or other activities) in the same way anyone else can?	None	1	CWHSAPB6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1706.2	How much of a problem did your relative have because of barriers or hindrances in the world around you?	None	1	CWHSMA6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1706.3	How much of a problem did your relative	None	1	CWHBALP6

	have living with dignity because of the attitudes and actions of others?	Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1706.4	How much time did your relative spend on your health condition, or its consequences?	None	1	CWHGSWT6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1706.5	How much has your relative been emotionally affected by their health condition?	None	1	CWHAEMN6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1706.6	How much has your relative's health been a drain on the financial resources of themselves or their family?	None	1	CWHIACT6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1706.7	How much of a problem did their family have because of your relative's health problems?	None	1	CWHSFUP6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	
1706.8	How much of a problem did your relative have in doing things by themself for relaxation or pleasure?	None	1	CWHENOH6
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme or cannot do	5	

1707.1	Overall, in the past 30 days, how many days were these difficulties present?	_____ days	CWHMLW6
1707.2	In the past 30 days, for how many days was your relative totally unable to carry out their usual activities or work because of any health condition?	_____ days	CWHMLHS6
1707.3	In the past 30 days, not counting the days that they were totally unable, for how many days did your relative cut back or reduce their usual activities or work because of any health condition?	_____days	CWHMAPL6

SECTION 18: Butajira Functioning assessment Scale- proxy version

USE ONLY INFORMATION FROM THE CAREGIVER TO COMPLETE THIS INSTRUMENT

In the past one month, how much difficulty did your relative have in accomplishing the following tasks/activities compared with most other people of their age and sex?

1801	Able to ask for or prepare and eat food when needed	None	1	ceating6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1802	Washing own body	None	1	cwashbody6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1803	Washing hands before and after eating	None	1	cwashand6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1804	Washing own clothes	None	1	cwashcloth6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1805	Cutting nails	None	1	ccutnails6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1806	Able to change clothes when it gets dirty	None	1	cchange6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1807	Able to keep oneself from danger	None	1	ckeepdan6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1808	Using the toilet properly	None	1	cusetoilet6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1809	Washing hair	None	1	cwashair6

		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1810	Working in the field	None	1	cworkfield6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
		Not applicable	6	
1811	Kitchen gardening	None	1	cgarden6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
		Not applicable	6	
1812	Looking after and attending livestock during the day	None	1	clivestock6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
		Not applicable	6	
1813	Cutting grass	None	1	ccutgrass6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
		Not applicable	6	
1814	Splitting firewood	None	1	cwood6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
		Not applicable	6	
1815	Going to market	None	1	cmarket6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1816	Travelling for one hour	None	1	ctravel6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
From 18**17 to** 18**24 is for women only**				
1817	Raising chickens	None	1	cchicken6
		Little	2	

		Moderate	3	
		A lot	4	
		Can't do task	5	
		Not applicable	6	
1818	Preparing food/ Cooking	None	1	ccooking6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1819	Cleaning house	None	1	cclean6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1820	Going to mill house to get grain ground	None	1	cgomill6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1821	Washing clothes of the household	None	1	cfamcloth6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1822	Cleaning the animal area	None	1	ccleanani6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1823	Preparing local beverages for the household (Tela/Keribu/Kinato)	None	1	cbeverage6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1824	Doing handicraft (such as "kasha", "mosob", and "dantel")	None	1	chandcraft6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
		Not applicable	6	
From 18**25 to** 18**41 is for both men and women**				
1825	Following up children's health	None	1	cchildhea6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1826	Motivating and encouraging children in their	None	1	cchildedu6

	education and other activities	Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1827	Communicating well (living in peace and agreement) with family	None	1	ccommfam6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1828	Discussing family issues with family members	None	1	cdiscfam6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1829	Helping parents or close elderly relatives	None	1	chelpeld6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1830	Maintaining social contact with relatives	None	1	ccontrel6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1831	Following up children's hygiene	None	1	cchildhyg6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1832	Advising and disciplining children	None	1	cadvchild6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1833	Communicating well (living in peace and harmony) with neighbors	None	1	ccommneig6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1834	Doing different tasks in cooperation with neighbors	None	1	ccoopneig6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1835	Going and attending when there is mourning in the neighbourhood	None	1	cmourning6
		Little	2	
		Moderate	3	

		A lot	4	
		Can't do task	5	
1836	Participating in "Idir"	None	1	cidir6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1837	Visiting postnatal women, people who are sick, prisoners and elderly	None	1	cvisiting6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1838	Participating in and preparing Mahiber/Senbete/Lika/Deremo	None	1	
		Little	2	cmahiber6
		Moderate	3	
		A lot	4	
		Can't do task	5	
1839	Attending Kebele and village meetings	None	1	cmeeting6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1840	Going to church/mosque	None	1	cchurch6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	
1841	Giving food or money for those who are in need	None	1	cgiving6
		Little	2	
		Moderate	3	
		A lot	4	
		Can't do task	5	

SECTION 19: Family Interview Schedule Section III (Stigma)
WHO Co-ordinated Multi-Centre Study on the Course and Outcome of Schizophrenia

Families can have a lot of different experiences when one of its members has psychiatric problems. Can you please tell me whether any of the following things have happened- not at all, sometimes, often or a lot over the past 6 months.

1901	You worried that your neighbours would treat you differently	Not at all	0	WSGNB6
		Sometimes	1	
		Often	2	
		A lot	3	
1902	You spent time worrying whether people would out about it	Not at all	0	WPKNP6
		Sometimes	1	
		Often	2	
		A lot	3	
1903	You sometimes felt the need to hide this fact	Not at all	0	SHPBM6
		Sometimes	1	
		Often	2	
		A lot	3	
1904	You have helped other people to understand what it is like to have a family member with psychiatric problems	Not at all	0	MIUOP6
		Sometimes	1	
		Often	2	
		A lot	3	
1905	When you met people for the first time, you made a special effort to keep this fact a secret	Not at all	0	FPMCL6
		Sometimes	1	
		Often	2	
		A lot	3	
1906	You worried that friends and neighbours would avoid you after they found out about it	Not at all	0	AKPWN6
		Sometimes	1	
		Often	2	
		A lot	3	
1907	You have found yourself explaining to others that __(name) isn't like their picture of "crazy" people	Not at all	0	GAPMN6
		Sometimes	1	
		Often	2	
		A lot	3	
1908	You worried that people would blame you for his or her problems	Not at all	0	MIPBW6
		Sometimes	1	
		Often	2	
		A lot	3	
1909	You worried that a person looking to marry would be reluctant to marry into your family	Not at all	0	BPFMNC6
		Sometimes	1	
		Often	2	
		A lot	3	
1910	You worried about taking him or her out	Not at all	0	WHPWOH6
		Sometimes	1	
		Often	2	

		A lot	3	
1911	You felt ashamed or embarrassed about it	Not at all	0	PBSFG6
		Sometimes	1	
		Often	2	
		A lot	3	
1912	You sought out people who also have a family member who has psychiatric problems	Not at all	0	OLMIFM6
		Sometimes	1	
		Often	2	
		A lot	3	
1913	You felt grief or depression because of it	Not at all	0	BPMFD6
		Sometimes	1	
		Often	2	
		A lot	3	
1914	You felt somehow it might be your fault	Not at all	0	BUSFDM6
		Sometimes	1	
		Often	2	
		A lot	3	

SECTION 20: Caregiver economic activity

THIS SECTION SHOULD BE COMPLETED WITH REFERENCE TO THE CAREGIVER

2001	What is your occupation? That is, what type of work do you do when you are working?	Home worker (e.g. housewife)	1	coccup6
		Unskilled labourer (e.g. farmhand / domestic worker, subsistence farmer)	2	
		Skilled labourer (e.g. builder)	3	
		Services / sales (e.g. shop worker)	4	
		Clerical worker (e.g. secretary)	5	
		Professional (e.g. nurse, lawyer, doctor)	6	
		Other	77	
	Specify other			coccupo6
2002	What is your CURRENT employment status? That is, what is your working status?	Full- or part-time employment (salaried)	0	cemp6
		Paid or self-employment (including subsistence farmer)	1	
		Voluntary employment [→Q2005]	2	
		Not employed (including housewife) [→go to Q2005]	3	
		Student [→go to Q2005]	4	
		Retired [→go to Q2005]	5	
		Other [→go to Q02005]	77	
	Specify other			cempo6
2003	About how many days did you work in the past 28 days)?	Days		ceconworkdys6
2004	How much do you usually earn per day/week/month/year (before taxes and other deductions)?	If days: birr [→go to Q2008]		ceconearnd6
		If weeks: birr [→go to Q2008]		ceconearnw6
		If months: birr [→go to Q2008]		ceconearnm6
		If years: birr [→go to Q2008]		ceconearny6
2005	Have you EVER worked for income / had employment?	No [→go to Q2007]	0	ceconever6
		Yes	1	
2006	How long ago did you LAST work for income / have employment?	Days		ceconunempd6
		Months		ceconunempm6
		Years		ceconunempy6
2007	Are you looking for work or	No	0	creturn6

	intending to return to work?	Yes	1	
2008	Has anyone in your household, including yourself, been hungry in the last month due to lack of resources/food?	No	0	chhfood6
		Yes	1	

SECTION 21: Caregiver work burden

2101	In the past one month, has [the patient] had to stop or reduce work or other activities because of his/her ill health?	No [→go to 2105]	0	reducework6
		Yes	1	
2102	How many days in the past one month, did [the patient] reduce work/activities? Or How many hours/ week was work or activities reduced?	Days		reduceworkd6
		Hours/week		reduceworkh6
2103	What kind of work did [the patient] stop?	Housework, that is not paid for (e.g housewife)	1	typework6
		Manual work (e.g farming)	2	
		Office worker	3	
2104	How much money was lost every day?			moneylost6
2105	In the past one month, have any friends or family of [the patient] had to stop or reduce work or other activities because of his/her ill health?	No [→go to next section]	0	frndfam_reducework6
		Yes	1	
2106	What is the relationship of this person to the patient?	Spouse/partner	2	frndfam_relation6
		Sibling	3	
		Parent/grandparent/aunt/uncle	4	
		Child, niece/nephew	5	
		Friend	6	
		Other	77	
2107	How many days in the past one month, did this caregiver] reduce work/activities? Or How many hours/ week was work or activities reduced?	Days		frndfam_reduceworkd6
		Hours/week		frndfam_reduceworkh6
2108	What kind of work did this caregiver stop?	Housework, that is not paid for (e.g housewife)	1	frndfam_typework6
		Manual work (e.g farming)	2	
		Office work	3	
2109	In the past one month, have any other friends or family of [the patient] had to stop or reduce work or other activities because of his/her ill health?	No [→go to next section]	0	ofrndfam6
		Yes	1	
2110	What is the relationship of this person to [the patient]?	Spouse/partner	2	ofrndfam_relation6
		Sibling	3	
		Parent/grandparent/aunt/uncle	4	
		Child, niece/nephew	5	
		Friend	6	

		Other	77	
2111	How many days in the past one month, did [#2110] reduce work/activities? or How many hours/ week was work or activities reduced?			ofrndfam_reduceworkd6
				ofrndfam_reduceworkh6
2112	What kind of work did [#2110] stop?	Housework, that is not paid for (e.g housewife)	1	ofrndfam_typework6
		Manual work (e.g farming)	2	
		Office worker	3	

SECTION 22: CAREGIVER DEPRESSION (PHQ 9 +1)

THIS SECTION SHOULD BE COMPLETED WITH REFERENCE TO THE CAREGIVER

	Over the past 2 weeks, have you been bothered by any of the following problems? **Note: :**-Explain to the interviewee that occasionally means (2-6 days), several days means 7-11 days and nearly every day means 12 -14 days			
2201a	Little interest or pleasure in doing daily activities?	Yes	1	CPHLI6
		No [→go to Q 2202a]	0	
2201b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHLIIF6
		Several days	2	
		Nearly every day	3	
2202a	Feeling down, depressed, or hopeless?	Yes	1	CPHFS6
		No [→go to Q 2203a]	0	
2202b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHFSIF6
		Several days	2	
		Nearly every day	3	
2203a	Trouble falling/staying asleep?	Yes	1	CPHIS6
		No [→go to Q 2204a]	0	
2203b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHISIF6
		Several days	2	
		Nearly every day	3	
2204a	Sleeping too much?	Yes	1	CPHOS6
		No [→go to Q 2205a]	0	
2204b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHOSIF6
		Several days	2	
		Nearly every day	3	
2205a	Feeling tired or having little energy?	Yes	1	CPHLE6
		No [→go to Q 2206a]	0	
2205b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHLEIF6
		Several days	2	
		Nearly every day	3	
2206a	Poor appetite?	Yes	1	CPHLR6
		No [→go to Q 2207a]	0	
2206b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHLRIF6
		Several days	2	
		Nearly every day	3	
2207a	Overeating	Yes	1	CPHFH6
		No [→go to Q 2208a]	0	
2207b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHFHIF6
		Several days	2	
		Nearly every day	3	
2208a	Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	Yes	1	CPHFAIL6
		No [→go to Q 2209a]	0	
2208b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHFAILIF6
		Several days	2	

		Nearly every day	3	
2209a	Trouble concentrating on things, such as reading the newspaper or watching television?	Yes	1	CPHDC6
		No [→go to Q 2210a]	0	
2209b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHDCIF6
		Several days	2	
		Nearly every day	3	
2210a	Moving or speaking so slowly that other people could have noticed?	Yes	1	CPHDT6
		No [→go to Q 2211a]	0	
2210b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHDTIF6
		Several days	2	
		Nearly every day	3	
2211a	Being so fidgety or restless that you have been moving around a lot more than usual that other people could have noticed?	Yes	1	CPHDS6
		No [→go to Q 2212a]	0	
2211b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHDSIF6
		Several days	2	
		Nearly every day	3	
2212a	Thoughts that you would be better off dead or of hurting yourself in some way? If the interviwee ANSWERS YES, refer him/her to THE PROJECT COORDINATOR FOR CLINICAL REVIEW	Yes	1	CPHWD6
		No [→go to Q 2213]	0	
2212b	If yes, how frequently in the last 2 weeks?	Occasionally	1	CPHWDIF6
		Several days	2	
		Nearly every day	3	
2213	If the interviewee responded Yes to one of the above problems, ask the following? : How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	0	CPHDR6
		Somewhat difficult	1	
		Very difficult	2	
		Extremely difficult	3	
2214	In addition to what we have been discussing, in the past 12 months have you ever feel depressed and loss of interest for two weeks or more?	No	0	CPHWFG6
		Yes	**1**	

	PHQ Score (0,1, 2 or 3)	
Item 2201b		
Item 2202b		
Highest score for item 2203b OR Item 2204b		
Item 2205b		
Highest score for item 2206b OR item 2207b		
Item 2208b		
Item 2209b		
Highest score for item 2210b OR Item 2211b		
Item 2212b		
TOTAL		cphrefer6

If the TOTAL is 10 or greater→ refer him/her to THE PROJECT COORDINATOR FOR CLINICAL REVIEW

SECTION 23: IEQ Caregiver

Note to the interviewer: ***explain these questions have been asked previously. We are asking again to check if anything has changed in the past 6 months.***

2301	How do you express your family's current income or life?	Very low	1	REINC_C6
		Lower	2	
		Middle	3	
		Higher	4	
		Very high	5	
2302	Marital status	Single [→ go to 2304]	1	MARIT_C6
		Married	2	
		Divorced [→ go to 2304]	3	
		Widowed [→ go to 2304]	4	
		Married but not living together	5	
2303	Your spouse's occupation [ask only if the respondent is married or his spouse is alive)	Farming	1	EMPSP_C6
		Private organization employee	2	
		Self-employed	3	
		Volunteer	4	
		House wife	5	
		Unemployed	6	
		Student	7	
		Pensioner	8	
		Government employee	9	
		Other (Specify)	77	
2304	Do you live alone or with others?	I live alone [→ to to Q2306]	1	LIVEW6
		I live with my spouse/partner and/or children	2	
		I live with my parents and/or sisters/brothers	3	
		I live with other relatives	4	
		I live with friends	5	
		Others (Specify)_____	77	
2305	How many people, including yourself, are there in your household?			HOUSEHOLD6
2306	Is your relative/ friend currently receiving help for his or her mental health problems?	I don't know	1	HELPMRF6
		No professional help	2	
		Yes, from the health centre	3	
		Yes, from a psychiatrist	4	
		Yes, in Butajira	5	
		Yes, from a psychiatric nurse	6	
		Yes, at Ammanuel hospital	7	
		Yes, as in-patient in a psychiatric hospital or a general hospital	8	
		Yes, other (please specify)	9	
2307	What is your precise relationship with	I am his/her:		RELATNFR6

	your relative/friend?	Mother/father (step, foster and adoptive parents included)	1	
		Daughter/son	2	
		Sister/brother	3	
		Other relative	4	
		Spouse, partner or girl/boy friend	5	
		Friend	6	
		Neighbor	7	
		Colleague/fellow student	8	
2308	Is you relative/friend part of your household?	No	0	PARTRF6
		Yes	1	
2309	How many days have you and your relative/friend lived together at the same address during the past 4 weeks?	None	1	LIVEDTG6
		Some days.	2	
		The full 4 weeks	3	

2310	What is your family's approximate net income?	Less than 500 birr per month	1	NINCOME6
		501 – 999 birr per month	2	
		1000-1999 birr per month	3	
		2000-2999 birr per month	4	
		2000-3499 birr per month	5	
		More than 3500 birr per month	6	
2311	What has been your average *weekly* telephone or personal contact with your relative/friend over the past 4 weeks?	Less than 1 hour per week	1	ATELECON6
		1-4 hours a week	2	
		5-8 hours a week	3	
		9-16 hours a week	4	
		17-32 hours a week	5	
		More than 32 hours a week	6	
The following questions are about the encouragement and care you have given to your relative/friend over the past 4 weeks.				
2312	How often during the past 4 weeks have you encouraged your relative/friend to take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair, etc.)?	Never	1	ENCOURD6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2313	How often during the past 4 weeks have you helped your relative/friend take proper care of him/herself (e.g. washing, bathing, brushing teeth, dressing, combing hair, etc.)?	Never	1	HELPRF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2314	How often during the past 4 weeks have you encouraged your relative/friend to eat enough?	Never	1	ENCFOUF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2315	How often over the past 4 weeks have you encouraged your relative/friend to undertake some kind of activity (e.g. go for a walk, have a chat, hobbies, and	Never	1	ENCACT6
		Sometimes	2	
		Regularly	3	
		Often	4	

	household chores)?	(Almost) always	5	
2316	How often during the past 4 weeks have you accompanied your relative/friend on some kind of outside activity, because he/she did not dare to go alone?	Never	1	ACCOATAC6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2317	How often during the past 4 weeks have you ensured that your relative/friend has taken the required medicine?	Never	1	ENSURED6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2318	How often during the past 4 weeks have you guarded your relative/friend from committing dangerous acts (i.e. setting something alight, assenting others, endangering livestock etc.)?	Never	1	GUARD6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2319	How often during the past 4 weeks have you guarded your relative/friend from self-inflicted harm (i.e. cutting him/ her, excessive medication intake, burning, suicide attempt, etc.)?	Never	1	GUARDRF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2320	How often during the past 4 weeks have you ensured that your relative/friend received sufficient sleep?	Never	1	ENSURSS6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2321	How often during the past 4 weeks have you guarded your relative/friend from drinking too much alcohol?	Never	1	GUARDDRI6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2322	How often during the past 4 weeks have you guarded your relative/friend from taking drugs like Khat?	Never	1	GUARDDRU6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2323	How often during the past 4 weeks have you carried out tasks normally done by your relative/friend (farming, household chores, financial matters, shopping, cooking, etc.)	Never	1	CARRIED6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2324	How often during the past 4 weeks have you encouraged your relative/friend to get up in the morning?	Never	1	ENCOUGET6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2325	How often during the past 4 weeks has your relative/friend disturbed your sleep?	Never	1	DISTURB6
		Sometimes	2	
		Regularly	3	
		Often	4	

		(Almost) always	5	
The following questions are about how you have got on with your relative/friend in the past 4 weeks.				
2326	How often during the past 4 weeks has the atmosphere been strained between you both, as a result of your relative/friend's behaviour?	Never	1	ATMOSHP6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2327	How often during the past 4 weeks has your relative/friend caused a quarrel?	Never	1	CAUSEQ6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2328	How often during the past 4 weeks have you been annoyed by your relative/friend's behaviour?	Never	1	ANNOYBRF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2329	How often during the past 4 weeks have you heard from others that they have been annoyed by your relative/friend's behavior?	Never	1	HEARD6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2330	How often during the past 4 weeks have you felt threatened by your relative/friend?	Never	1	FELTTHR6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2331	How often during the past 4 weeks have you thought of moving out, as a result of your relative/friend's behavior?	Never	1	MOVINGOT6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2332	How often during the past 4 weeks have you been able to pursue your own activities and interests (e.g. work, school, hobbies, sports, visits to family and friends)?	Never	1	PURSUE6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
The following questions are about the worries that may arise from your involvement with a relative/friend who has mental health problems.				
2333	How often during the past 4 weeks have you worried about your relative/friend's safety?	Never	1	WORRIEDU6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2334	How often during the past 4 weeks have you worried about the kind of help/treatment your relative/friends is receiving?	Never	1	WORIEDRF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2335	How often during the past 4 weeks have you worried about your relative/friend's general health?	Never	1	WORIEDGH6
		Sometimes	2	
		Regularly	3	

		Often	4	
		(Almost) always	5	
2336	How often during the past 4 weeks have you worried about how your relative/friend would manage financially if you were no longer able to help?	Never	1	WORIEDMF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2337	How often during the past 4 weeks have you worried about your relative/friend's future?	Never	1	WORIDRFF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2338	How often during the past 4 weeks have you worried about your own future?	Never	1	WORIDUF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2339	To what extent have your relative/friend's mental health problems been a burden to you during the past 4 weeks?	No burden at all	1	EMHBU6
		A slight burden	2	
		A fairly heavy burden	3	
		A heavy burden	4	
		A very heavy burden	5	
2340	Have you got used to your relative/friend's have mental health problems?	No	1	UMHPFR6
		A little	2	
		Fairly well	3	
		Very well	4	
		Completely	5	
2341	How often have you felt able to cope with your relative/friend's mental health problems?	Never	1	COPMHPRF6
		Sometimes	2	
		Regularly	3	
		Often	4	
		(Almost) always	5	
2342	Has your relationship with your relative/friend changed since the on set of the mental health problems?	No	1	CHNGEMHP6
		A little	2	
		Rather a lot	3	
		A lot	4	
		A great deal	5	
The following questions are about the financial cost to you and your household, as a result of your relative/friend's mental health problem.				
2343	Professional help for your relative/friends	No	0	PHRF6
		Yes	1	
2344	Damage caused by your relative/friends	No	0	DCRF6
		Yes	1	
2345	Large expenditures incurred by your relative/friend	No	0	LEIRF6
		Yes	1	
2346	Relative/friend's travel expenses	No	0	RFTE6
		Yes	1	
2347	Medicine for your relative/friends	No	0	MDNRF6
		Yes	1	
2348	Paying off debts incurred by your relative/friend	No	0	PODIRF6
		Yes	1	
2349	Other expenses (please indicate)	_____		OEXPENS6

2350	If you add up all the extra expenses that you have incurred on behalf of your relative/friend during the past 4 weeks, what is the estimated toal figure?	Less than 100 birr per month	1	UIBRFETF6
		100- 299 birr per month	2	
		300- 499 birr per month	3	
		500- 999 birr per month	4	
		1000 and above birr per month	5	
Please read the questions below and each of the four possible answers. We want to know how your health has been in general over the past four weeks. Have you recently:				
2351	Been able to concentrate on what you are doing	Better than usual	1	BACNWUD6
		Same as usual	2	
		Less than usual	3	
		Much less than usual	4	
2352	Lost much sleep over worry?	Not at all	1	LSOWORRY6
		No more than usual	2	
		Rather more than usual	3	
		Much more than usual	4	
2353	Felt that you are playing a useful part in things?	More so than usual	1	FELTPUPT6
		Same as usual	2	
		Less so than usual	3	
		Much less than usual	4	
2354	Felt capable of making decisions about things?	More than usual	1	FELTCMD6
		Same as usual	2	
		Less so than usual	3	
		Much less capable	4	
2355	Felt constantly under strain?	Not at all	1	FELTCUS6
		No more than usual	2	
		Rather more than usual	3	
		Much more than usual	4	
2356	Felt you couldn't overcome your difficulties?	Not at all	1	FELTOUD6
		No more than usual	2	
		Rather more than usual	3	
		Much more than usual	4	
2357	Been able to enjoy normal day-to-day activities?	More than usual	1	BAENDDA6
		Same as usual	2	
		Less than usual	3	
		Much less than usual	4	
2358	Been able to face up to your problems	Better than usual	1	BAFUUP6
		Same as usual	2	
		Less than usual	3	
		Much less than usual	4	
2359	Been feeling un happy or depressed	Not at all	1	BEFUHDP6
		No more than usual	2	
		Rather more than usual	3	
		Much more than usual	4	
2360	Been losing confidence in yourself?	Not at all	1	BLCONFUS6
		No more than usual	2	
		Rather more than usual	3	
		Much more than usual	4	
2361	Been thinking of yourself	Not at all	1	BTHURSF6
		No more than usual	2	
		Rather more than usual	3	
		Much more than usual	4	

2362	Been feeling reasonably happy, all things considered	More so than usual	1	BFRHATC6
		Same as usual	2	
		Less so than usual	3	
		Much less than usual	4	
2363	Are you receiving help from health centre/health post for any of these complaints?	No	0	RHHCPC6
		Yes	1	
2364	Are you receiving help from a different professional (counsellor or psychologist) for any of these complaints?	No	0	RHCHPC6
		Yes	1	
2365	Are you taking any kind of medicine for these complaints?	No	0	TALFTD6
		Yes	1	
If a father or a mother has mental health problems, this may have consequences for their children, if any. The following questions are about these consequences.				
2366	Has your relative/friend with mental health problems any children (including step/foster/adopted children)?	No (proceed to the next section)	0	HURFMHPC6
		Yes (number of children:___)	1	
2367	Has your relative/friend any children under the age of 16 years?	No (proceed to the next section)	0	HURFCUS6
		Yes (number of children:___)	1	
How often has it happened in the past 4 weeks that the child/children has/have:				
2368	Shown loss of appetite	Never	1	SHLOAP6
		Sometimes	2	
		Often	3	
		Don't know	4	
2369	Been sleepless at night	Never	1	BSLANGHT6
		Sometimes	2	
		Often	3	
		Don't know	4	
2370	Been less attentive at school	Never	1	BLATTAS6
		Sometimes	2	
		Often	3	
		Don't know	4	
		Not applicable	99	
2371	Show fear for father/mother	Never	1	SHOWFFM6
		Sometimes	2	
		Often	3	
		Don't know	4	
2372	Not attended school	Never	1	NATTSCH6
		Sometimes	2	
		Often	3	
		Don't know	4	
		Not applicable	99	
2373	Displayed difficult behavior	Never	1	DSDIBEH6
		Sometimes	2	
		Often	3	
		Don't know	4	
2374	Played less often with friend	Never	1	PLLOWF6
		Sometimes	2	
		Often	3	
		Don't know	4	
2375	Felt ashamed of mother/father	Never	1	FALTASMF6
		Sometimes	2	

		Often	3	
		Don't know	4	
2376	Had to stay with neighbors, relatives or friends	Never	1	HSWNIHRF6
		Sometimes	2	
		Often	3	
		Don't know	4	

SECTION 24: Family Interview Schedule Section II (Impact)
WHO Co-ordinated Multi-Centre Study on the Course and Outcome of Schizophrenia

Now I would like to ask some specific questions about your own involvement with____(name)___and the involvement of other family members in the last six months				
2401	Would you say that you are the family member that __(name) depends on the most?	No	0	
		Yes	1	FIDM6
2402	Overall, how much have you been involved in helping (name) when he/she has had psychiatric problems?	Not at all	0	
		A little	1	
		Some	2	
		A lot	3	FIIHP6
I would now like to ask you some questions about how (name) 's problems may have affected your life in the past or might in the future.				
2403	Have (name's) problems made it difficult for you to have the type of social life you would like to have? E.g. caused you to stay at home when you would have liked to be visiting friends	In the past:		
		Not at all	0	
		A little	1	
		Some	2	FIDPSL6
		A lot	3	
		Not applicable	9	
		In the future:		
		Not at all	0	
		A little	1	
		Some	2	FIDPSLFU6
		A lot	3	
		Not applicable	9	
2404	Have (name's) problems caused strain between you and other family members? E.g. disagreements over who should care for (name)__	In the past:		
		Not at all	0	
		A little	1	FIDFSL6
		Some	2	
		A lot	3	
		Not applicable	9	
		In the future:		
		Not at all	0	
		A little	1	FIDFSLFU6
		Some	2	
		A lot	3	
		Not applicable	9	
2405	Have (name's) problems made it difficult for you to do the type of work you would like to do?	In the past:		
		Not at all	0	FIDOC6

	E.g. turned down job opportunities or did not work because of the need to take care of (name)___	A little	1	
		Some	2	
		A lot	3	
		Not applicable	9	
		In the future:		
		Not at all	0	
		A little	1	
		Some	2	FIDOCFU6
		A lot	3	
		Not applicable	9	
2406	Have (name's) problems caused you financial difficulties? E.g. forced you to devote scarce resources to (name's) care	In the past:		
		Not at all	0	
		A little	1	
		Some	2	FICFDx6
		A lot	3	
		Not applicable	9	
		In the future:		
		Not at all	0	
		A little	1	
		Some	2	FICFDFU6
		A lot	3	
		Not applicable	9	

SECTION 25: Caregiver reported physical restraint

ONLY INFORMATION FROM THE CAREGIVER SHOULD BE USED TO COMPLETE THIS INSTRUMENT

2501	Has your relative been chained, restrained or confined in the last six months?	No [→ go to next section]	0	crstrnt66
		Yes	1	
2502	Number of times your relative has been chained or restrained in the last six months?			crstrntfrq6
2503	Total duration of the restraint in the last six months (complete either days or months)	days		crsttdrnd6
		months		crsttdrnm6
2504	Has your relative been chained, restrained or confined in the last one month?	No	0	crstrnt16
		Yes	1	
	Who instigated the chaining or restraint (on any occasion of restraint)?			
2505	Traditional healer	No	0	crsttrad6
		Yes	1	
2506	Priest/ Religious healer	No	0	crstrel6
		Yes	1	
2507	Health care worker	No	0	crsthcw6
		Yes	1	
2508	Family member	No	0	crstfam6
		Yes	1	
2509	Prison staff or police	No	0	crstpris6
		Yes	1	
2510	Other community member	No	0	crstcom6
		Yes	1	
2511	Other	No	0	crstoth6
		Yes	1	
2512	Specify other			crstoths6
	What were the reasons for the chaining or restraint?			
2513	To prevent relative attacking others	No	0	crsnatak6
		Yes	1	
2514	To prevent relative getting lost	No	0	crsnlost6
		Yes	1	
2515	To prevent relative having an accident	No	0	crsnfrac6
		Yes	1	
2516	To prevent relative wandering around	No	0	crsnwand6
		Yes	1	
2517	To prevent relative harming self or committing suicide	No	0	crsnslfhr6
		Yes	1	
2518	To prevent relative disturbing the family	No	0	crsndstfa6
		Yes	1	
2519	To prevent relative disturbing neighbours	No	0	crsndsnei6
		Yes	1	
2520	To prevent relative disturbing women and children	No	0	crsndschil6
		Yes	1	
2521	To prevent relative using alcohol or khat	No	0	crsnsubus6
		Yes	1	
2522	To prevent relative behaving in a shameful or taboo way	No	0	crsnshame6
		Yes	1	

2523	To prevent relative destroying property	No	0	crsndstry6
		Yes	1	
2524	To prevent relative being exploited to carry out labouring tasks	No	0	crsnlabu6
		Yes	1	
2525	Because neighours or others suggested it	No	0	crsnadvne6
		Yes	1	
2526	In order to transport your relative to a health centre or hospital	No	0	crsntran6
		Yes	1	
2527	In order to force your relative to take the medication or receive injection	No	0	crsnmed6
		Yes	1	
2528	To punish your relative for doing something wrong	No	0	crsnpun6
		Yes	1	
2529	Other reason	No	0	crsno6
		Yes	1	
2530	Specify other			crsnos6
	Where did the restraint take place?			
2531	At home	No	0	cphome6
		Yes	1	
2532	Prison	No	0	cpprison6
		Yes	1	
2533	Holy water site	No	0	cpholy6
		Yes	1	
2534	Health facility	No	0	chealth6
		Yes	1	
2535	Other place	No	0	cpoth6
		Yes	1	
2536	Specify other			cpoths6
2537	In your opinion was it necessary to carry out the chaining or restraint?	No	0	cness6
		Yes	1	

SECTION 26: Medication Adherence- Caregiver reported

ONLY INFORMATION FROM THE CAREGIVER SHOULD BE USED TO COMPLETE THIS INSTRUMENT

2601	Does your relative ever forget to take their medication?	No	0	crxforget6
		Yes	1	
2602	Is your relative careless at times about taking their medication?	No	0	crxcareless6
		Yes	1	
2603	When they feel better you're your relative sometimes stop taking their medication?	No	0	crxbetter6
		Yes	1	
2604	Sometimes if your relative feels worse when they take their medication, do they stop taking it?	No	0	crxworse6
		Yes	1	
2605	In the past **one month**, has your relative been taking their medication as prescribed by their health care worker?	All the time	1	crxmonth6
		Most of the time (> 3 of the last 4 weeks)	2	
		Sometimes (at least 2-3/4 weeks)	3	
		Took the medicine occasionally (<2 of the last 4 weeks)	4	
		Did not take any medicine at all	5	
2606	Has your relative ever stop taking their medication because they cannot afford to pay for it?	No	0	Crxcantafford6
		Yes	1	
2607	Has your relative ever stop taking their medication because it is not available at the health centre or	No	0	Crxunavailable6
		Yes	1	
2608	In the last 12 months has your relative ever received anti-psychotic medication for free?	No	0	Crxfree6
		Yes	1	

Please take time to double-check that all of the forms are complete and that no questions have been missed.

Confirmation of questionnaire completion			
Name of assessor	**Signature**		**Date (EC)**
Confirmation of questionnaire data completeness and quality check			
Name	**Role**	**Signature**	**Date (EC)**