

LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



**Mapping the Treatment Gap:**  
**A mixed methods exploration of barriers to  
treatment-seeking for depression in rural India**

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**Thesis submitted in accordance with the requirements for the degree of  
Doctor of Philosophy of the University of London**

**October 2018**

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**Funded by the Bloomsbury Colleges**

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<b>Funders</b>	The Bloomsbury Colleges group (PhD studentship)  British Council and Department of Biotechnology, India (Newton Bhabha PhD Placement)

## Acknowledgements

I am enormously grateful for the support that I have received in completing this work over the past three years. I am particularly thankful to my primary supervisor, Sujit Rathod, whose detailed and patient feedback has been invaluable in completing the project. I would also like to thank Mary de Silva, for the opportunity and encouragement to pursue this project. I am indebted to my wider supervisory team – Rahul Shidhaye, Shino Shiode and Vikram Patel – who have been extremely generous in sharing their expertise. In addition, I have benefitted greatly from the guidance of Chris Grundy and Mirja Koschorke on the GIS and qualitative elements of this project, respectively.

This research project used data from the Programme for Improving Mental health Care (PRIME). PRIME is a Research Programme Consortium led by the Centre for Public Mental Health at the University of Cape Town (South Africa), and funded by the UK government's Department for International Development (DfID). PRIME collaborators in India include Sangath, the Public Health Foundation of India, and Madhya Pradesh State Ministry of Health. International partners include the Centre for Global Mental Health (London School of Hygiene & Tropical Medicine, and Kings Health Partners, UK), BasicNeeds, and the World Health Organisation (WHO). The PRIME programme was funded by UK aid from the UK Government. Needless to say, the views expressed in this project do not necessarily reflect the UK Government's official policies.

This research would not have been possible without the generous support of the PRIME India team, who kindly hosted me in Bhopal and allowed me to learn from their work. In particular, I owe thanks to Ritu Shrivastava, Vaibhav Murhar, Narendra Verma, Kamlesh Sharma, Bhagwant Chilhate, and Shalini Ahuja, who all assisted in making my field work possible. I am thankful to Abhishek Singh, Azaz Khan, Shital Muke and Rahul Shastri, for the thoughtful discussions that have informed my understanding of this topic. I am also grateful to Crick Lund and the wider PRIME team, for all of the support that they provided.

I am extremely grateful for the funding I received from the Bloomsbury Colleges group, without which this research would not have been possible. I was also fortunate to receive funding for fieldwork and travel costs from the British Council and the Indian Government's Department of Biotechnology, through the Newton Bhabha scheme, as well as from the London School of Hygiene & Tropical Medicine.

A few other individuals whose support and advice I have appreciated during the course of this project; Jane Falconer and Deirdre Beecher for advice on search strategies, Georgina Miguel-Esponda and Dzmitry Krupchanka for their diligent work to ensure the rigour of my systematic review, Grace Ryan and Richard Clarke for upgrading feedback, Chris Jarvis and Samantha Wilkinson for statistics advice, James O'Brien for GIS trouble-shooting, Alex Cohen for critical feedback and guidance, and Craig Morgan for his patience and flexibility during the final stages of completing the thesis.

I owe massive thanks to many friends, family, office-mates, and of course to my partner, Mark, for all of their emotional support during the PhD process. Without your encouragement, solidarity, and willingness to laugh both at and with me during stressful periods, I would never have made it to the end.

Most importantly, however, I am entirely indebted to the participants who gave up their time for this research, and whose voices should be at the centre of the debate around how best to improve their lives.

## **Declaration**

I, Tessa Roberts, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

I have read and understood the School's definition of plagiarism and cheating given in the Research Degrees Handbook. I have acknowledged all results and quotations from the published or unpublished work of other people.

I declare that no copy editing and/or proof reading services were availed by me in the preparation of this thesis. I have exercised reasonable care to ensure that the work is original and does not to the best of my knowledge break any UK law or infringe any third party's copyright or other intellectual property right.

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## **Abstract**

### **Background**

Depression is a major contributor to the global burden of disease. However, only 1 in 4 of those affected in low- and middle-income countries (LMIC), and just 13% in India, seek treatment. This project investigated factors that impede treatment-seeking for depression.

### **Methods**

I undertook a global systematic review of factors associated with treatment-seeking for common mental disorders. I tested the association between travel distance to the nearest public mental health service and likelihood of seeking treatment for depression in rural India, and described treatment-seeking behaviour, using data from a population-based survey. Finally, I used qualitative methods to explore barriers to treatment-seeking for depression among affected individuals and their families.

### **Results**

Systematic review results showed that treatment-seeking is more consistently related to “need” factors, such as disability and chronicity, than “enabling” factors, such as income. However, evidence from LMIC was lacking. The hypothesised association between distance to services and treatment-seeking was not supported. Most adults with probable depression had some recent contact with health services, most often in the private sector, for reasons other than depression symptoms. Use of traditional services was low. Adults who were unmarried, had not discussed their depression symptoms, and had milder symptoms, were less likely to seek treatment for depression. Low demand for depression treatment arose because participants viewed depression symptoms as a response to their circumstances, not as medical issues.

### **Conclusions**

The burden of depression is unlikely to be reduced by decreasing travel distance to services without ensuring that interventions are aligned with local priorities. These priorities include action on the social determinants of health and improving the quality of general health

care. Private practitioners must be considered in future research and service planning in India. The treatment gap does not adequately capture the needs of people with depression as they perceive them.

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## **Acronyms, Abbreviations and Definitions**

CHC – Community Health Centre

CMD – Common Mental Disorders

DMHP – District Mental Health Programme

GIS – Geographic Information Systems

HIC – High-Income Countries (as per World Bank classifications)

LMIC – Low- and Middle-Income Countries (as per World Bank classifications)

MHCP – Mental Health Care Plan

mhGAP –Mental Health Gap Action Programme

MNS disorders – Mental, Neurological and Substance use disorders

NGO – Non-Governmental Organisation

NMHP – National Mental Health Programme

PHFI – Public Health Foundation of India

PHQ-9 – Patient Health Questionnaire (9-item)

PRIME – Programme to Improve Mental Health Care

SES – Socio-Economic Status

WHO – World Health Organization

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# 1. Introduction

In this chapter I explain the concept of the treatment gap for mental disorders and its significance for global mental health policy. I then explain the focus on depressive disorders in the current research project, in light of their public health impact and their prominence in current debates around scaling up mental health services. I set out two conceptual frameworks with which to analyse the treatment gap, and show how these relate to current strategies to expand access to care worldwide, as well as indicating areas where more evidence is needed. I summarise the aims and key findings of the Programme for Improving Mental Health Care (PRIME) in India, within which this project is nested, before going on to describe the setting in which these research questions are explored. Finally, I present a summary of the knowledge gap to be addressed, and the corresponding aims, objectives and methods of the current research project.

## 1.1 Background

### 1.1.1 The mental health “treatment gap” in Global Mental Health

The concept of a “treatment gap” for mental disorders has proven highly influential in framing the agenda for Global Mental Health research and policy. Global Mental Health is a growing movement and field of research that applies the principles of Global Health (improving health and equity in health for all people worldwide) to mental health, with the aim of reducing the burden of mental disorders (1-3). A recurrent theme within this field is that there is a vast “treatment gap” for mental disorders, defined as the proportion of people with a disorder who do not receive treatment for their condition (4). According to World Mental Health Survey data, 35.5% to 50.3% of serious cases in developed countries and 76.3% to 85.4% in less-developed countries received no treatment in the past 12 months (5). Evidence of this large disparity, between those in need of treatment and those who receive it, has been used to advocate for the scaling up of mental health services, particularly in low-resource settings where access to care is most limited (6), and is cited by the World Health Organization (WHO) as a central justification for high profile initiatives to expand access to mental health care worldwide (7-10). Understanding why this gap exists, and the characteristics of those who fail to receive treatment, is essential to inform strategies to reduce the treatment gap and thus reduce the burden of mental disorders.

### 1.1.2 Depression and common mental disorders (CMD)

The current research project will focus on depression, given its significance for public health and the high priority accorded to it within the Global Health agenda (9, 11). According to the most recent Global Health Estimates from the WHO, depression is the most prevalent mental disorder and the single largest contributor to global disability, affecting 4.4% of the population worldwide and accounting for 7.5% of all years lived with disability in 2015 (12). It is closely associated with social and economic disadvantage (13), disability (14), discrimination and social exclusion (15), and poor physical health, including worse outcomes for comorbid chronic conditions such as diabetes and tuberculosis (16). People affected by depressive disorders experience significantly higher rates of premature mortality compared to the general population (17, 18) including increased risk of suicide (17, 19, 20), which is now one of the top twenty causes of death worldwide and the second leading cause of death in people aged 15 to 29 globally (21). The treatment gap for depression is estimated to be 46% in developed countries and 75% in developing countries (22).

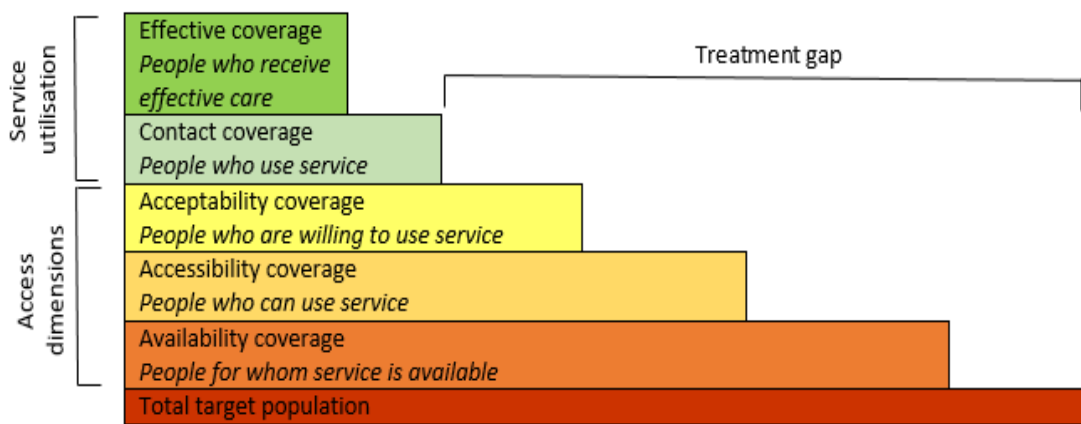
Although the focus of this project is depression, it should be noted that depression frequently co-occurs with anxiety disorders, which share risk factors and overlap in their treatment (23-26). Many people with depression are therefore likely to also experience anxiety symptoms, especially in primary care and community settings. In some sections I refer to evidence about common mental disorders (CMD) which encompasses both depression and anxiety.

### 1.1.3 Conceptualising the treatment gap: Access and coverage

The issue of the treatment gap can be understood as a problem of access to mental health care, and therefore analysed using existing frameworks of access to health care. Access to care refers to the ability or willingness of the population to enter into the health care system, which Penchansky and Thomas define as the “fit between the patient and the health care system” (27). They propose that access is conceptualised as a multidimensional construct, comprising the following elements; availability, accessibility, affordability, accommodation and acceptability. Availability refers to the supply of resources relative to the population’s needs, while accessibility describes the ease with which service users can physically reach services. The latter three dimensions – affordability, accommodation and

acceptability – denote how well services meet users’ needs in terms of cost, organisation (e.g. opening hours, appointment systems) and cultural fit, respectively. Subsequent authors have found it expedient to combine some of these dimensions, since they are closely linked (28).

This framework provides a useful starting point for analysing barriers to access to care, and has influenced models of “coverage” for mental health services (29, 30) (see figure 1 below). De Silva and colleagues define contact coverage as the proportion of people with a disorder who come into contact with health services for their condition – i.e. the inverse of the treatment gap – while effective coverage refers to receipt of treatment that leads to health benefits. Thus, this model posits that the treatment gap can be attributed to either limited availability, accessibility or acceptability of mental health services for the target population, or some combination of these barriers.



**Figure 1.** Levels of coverage for mental health services, adapted from De Silva et al. (2014)

#### 1.1.4 Closing the treatment gap

There are efforts underway around the globe to improve the availability, accessibility and acceptability of services in order to close the treatment gap. For example, in 2008, the WHO launched the Mental Health Gap Action Programme (mhGAP), which calls for packages of interventions for mental disorders to be integrated into primary health care (9), building on a growing body of evidence for cost-effective interventions that can be delivered by non-specialist health workers in low-resource settings (7). Integrating mental health into primary health care has many potential benefits, including overcoming the



severe lack of specialist human resources for mental health in many countries (31), and enabling the delivery of holistic treatment for both mental and physical health services in the same location (8). Another frequently cited advantage of this strategy is the reduction of distance and travelling time between the population and the site of care, thereby enhancing geographic accessibility and enabling more of those affected to access services (8, 9). As part of the WHO's mhGAP programme, an intervention guide for non-specialist health workers was developed to guide treatment of priority disorders in primary care, based on a systematic evidence review (32), although there is ongoing debate around the extent to which these guidelines are culturally appropriate and responsive to local needs across diverse settings (33-38).

#### 1.1.5 Andersen's socio-behavioural model of health service utilisation

While the coverage model set out by De Silva and colleagues provides a starting point for analysing the treatment gap in terms of access to care at the population level, it is not a complete model for analysing health service utilisation within a population. It offers little detail on how service characteristics interact with population characteristics, leading to health care inequities. Furthermore, the gap between acceptability coverage and contact coverage in the figure above implies that some people for whom services are available, accessible and acceptable nonetheless do not use them, which requires further explanation.

Attempts to systematically investigate the factors that influence service utilisation in high-income countries (HIC) frequently draw on an alternative model developed by Andersen and colleagues (39-42) (henceforth "the Andersen model"), which – in addition to the access barriers described above – incorporates two other categories of factors. The first category refers to *need* for health care (encompassing both subjective measures of perceived need and levels of need as evaluated by health professionals or standardised measures). The second category refers to personal characteristics that affect one's attitude or *predisposition* to use health services, including both demographic factors and beliefs or attitudes (see figure 2). In this model, access barriers roughly correspond to Andersen et al.'s conception of "enabling factors", which can be seen as structural barriers to entry into the health system, but it is recognised that individual resources affect whether services are affordable or accessible as well as health service characteristics. The latest version of this model, including both individual factors and contextual factors, is shown below (43).

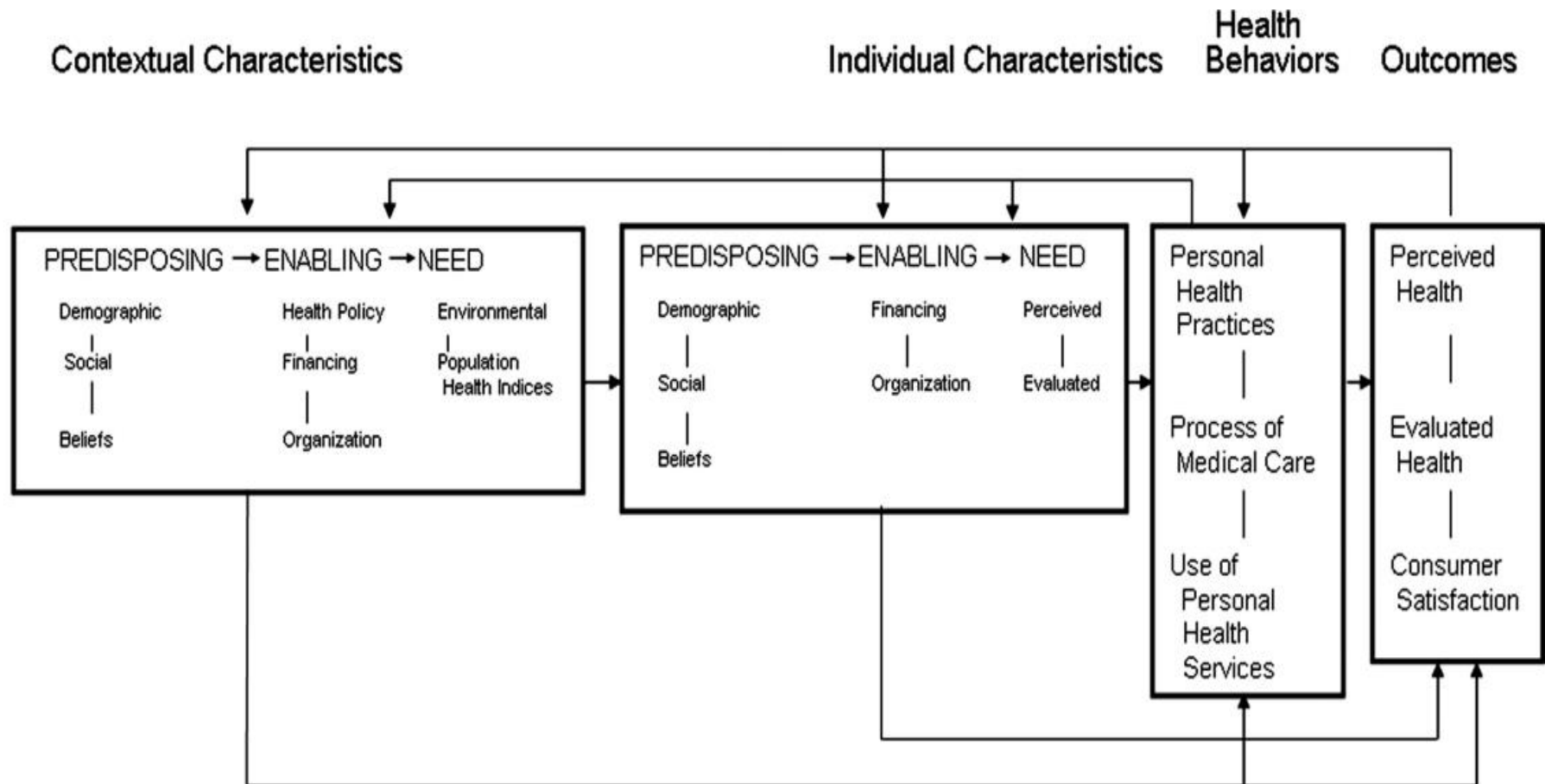


Figure 2. Andersen behavioural model of health service utilisation (2008)

The Andersen model has been applied extensively to the analysis of health service utilisation across service types and conditions, including mental disorders, although to date the majority of this research has been conducted in HIC (44). This framework complements De Silva's coverage model by showing how individual and community characteristics interact with health service characteristics, and incorporates the major elements of other influential models (e.g. (28)).

The Andersen model has been critiqued from a variety of theoretical perspectives (41), and it is not the intention of the current project to comprehensively test the model in order to support or reject it. It will, however, be used as an organising framework for investigating factors that facilitate or hinder the use of health services for depression since this facilitates comparisons between studies, which can help to infer transferability of research findings across settings.

Use of health services in Andersen's model includes both initial contact with services (analogous to contact coverage) and adherence or minimally adequate treatment (equivalent to effective coverage). Factors affecting each of these outcomes may differ, and it has been suggested that contact with services is influenced predominantly by population characteristics while the nature of treatment received depends more on health service characteristics (45). Since the treatment gap is concerned with whether or not individuals with depression reach services, the primary focus of the current project will be on barriers to contact with services, rather than on adherence or treatment quality.

#### 1.1.6 Geographic accessibility

Geographic accessibility features as a key dimension of access in the coverage model presented above, and represents an enabling factor (referred to as the "organisation" of services) in the Andersen model. According these frameworks, one would therefore expect increased geographic accessibility of services – for example, by establishing services located in rural clinics, where previously they were only available in urban hospitals – to lead to increased contact coverage.

In support of this idea, Jarvis' Law – the rule that mental health service utilisation declines with distance from services, also known as "distance decay" – has been documented in Western mental health services since the mid nineteenth century (46-50). However, previous research has found that the strength of distance decay varies by context and

severity of diagnosis, and is absent in some settings due to stigma and perceived service quality (51). Since this evidence largely originates from high-income countries, the importance of geographic accessibility as a barrier to mental health service utilisation in low- and middle-income countries (LMIC) is not known.

Furthermore, it is clear from the frameworks above that geographic accessibility is far from the only determinant of service utilisation. From a policy perspective, the relevant question is not whether Jarvis' Law holds, but how much it influences service utilisation for mental disorders after accounting for other relevant factors, and the distances that people are willing and able to travel for services within a given context. Health service planners with limited resources may face a choice between decentralising services to cover a wider area, or investing in other priorities such as increasing opening hours, improving quality, or organising public health campaigns to combat stigma and increase demand for services. The extent to which variation in utilisation rates is attributable to geographic accessibility versus other factors will affect decisions about the most effective use of resources.

#### 1.1.7 Treatment-seeking and the measurement of contact coverage

Contact coverage and the treatment gap can be measured in one of two ways, depending on data availability. Where health service records are relatively complete and comprehensive, routine patient data can be used to estimate the number of people who consulted a health care provider in connection with a given health condition, or who received a particular diagnosis or treatment type. Where such data are not available, cross-sectional surveys may collect self-reported data on consulting health providers for symptoms of a particular disorder within a specified period (29, 52). Given the limitations of health information systems in many LMIC, contact coverage is in practice frequently measured in terms of treatment-seeking for a particular set of symptoms (e.g. (4, 5, 52-55)), as defined by individuals themselves rather than by health service records.

For the purposes of the current project, I will also concentrate on treatment-seeking for symptoms of depression, as reported by the target community, rather than on the health system's response to those who seek care. The implications of this definition of contact coverage will be discussed in chapter 7.

### 1.1.8 Non-geographic factors affecting treatment-seeking

As the frameworks above clearly indicate, geographic accessibility is not the only factor of potential relevance to the treatment gap for mental disorders, but there are significant gaps in our knowledge from LMIC. In the World Mental Health Surveys (WMHS), which included 121,899 participants in 24 countries, participants who met criteria for a mental disorder but who did not report seeking treatment for their condition were asked why they did not seek treatment. The most frequently-reported barrier to service use was lack of perceived need for treatment (61.5%), followed by preferring to handle the problem alone (reported by 63.8% of those who perceived a need for treatment) (56), which contrasts with the health systems factors implicated in the coverage model by De Silva and colleagues. Stigma and low “mental health literacy” (defined as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (57)) have both been proposed to explain the low demand for services (e.g. (58-60)). However, the vast majority of evidence on these topics originates from HIC, often with non-representative samples (61-63). In the WMHS studies, symptom severity and demographic factors were found to be associated with treatment-seeking while income was generally not (5). This evidence leaves several questions unanswered about the role of service availability, geographic accessibility, beliefs and attitudes towards mental health and health services, perceived need for care, and variations by context and disorder type. More comprehensive studies of the factors that influence treatment-seeking for different disorder types, particularly in LMIC, are essential to inform service planning and policy in order to reduce the treatment gap.

## **1.2 Setting**

### 1.2.1 PRIME

The Programme for Improving Mental Health Care (PRIME) is a five-country study to generate evidence on the implementation of district-level mental healthcare plans (MHCP) for target disorders in Ethiopia, India, Nepal, South Africa and Uganda, building on the principle of integration of mental health care through existing primary care platforms (64). In India, a MHCP was developed for the district of Sehore, which targets depressive, alcohol use and psychotic disorders in primary care using mhGAP guidelines (see appendix A for

details). After piloting and preparatory work, it was implemented and evaluated in one sub-district of Sehore, beginning in 2013, in partnership with the Ministry of Health of the Government of Madhya Pradesh, the Public Health Foundation of India (PHFI), and Sangath (a Goa-based NGO) (65). This plan was intended to build on the resources provided through the District Mental Health Programme (described below). Following this research programme, the Government of Madhya Pradesh has committed to scaling up mental health services across all 51 districts in the state (66, 67).

### 1.2.3 Depression in India

In India, 5% of the total burden of disease is estimated to be attributable to unipolar depressive disorders, representing the leading cause of burden amongst mental, neurological and substance use disorders (68). Despite its substantial burden and potentially severe consequences, the “treatment gap” for depression in India is large, with only an estimated 13% of affected adults receiving treatment (69). This gap is often linked to the severe shortage of skilled human resources for mental health in the country, with just 3,500 psychiatrists serving a population of over 1.3 billion (70, 71). Compounding this lack of mental health specialists are extreme geographic inequities, with the majority of human resources concentrated in institutions in urban areas (72, 73) despite 66% of India’s population residing in rural areas (74).

### 1.2.4 Mental health policy, plans and legislation in India

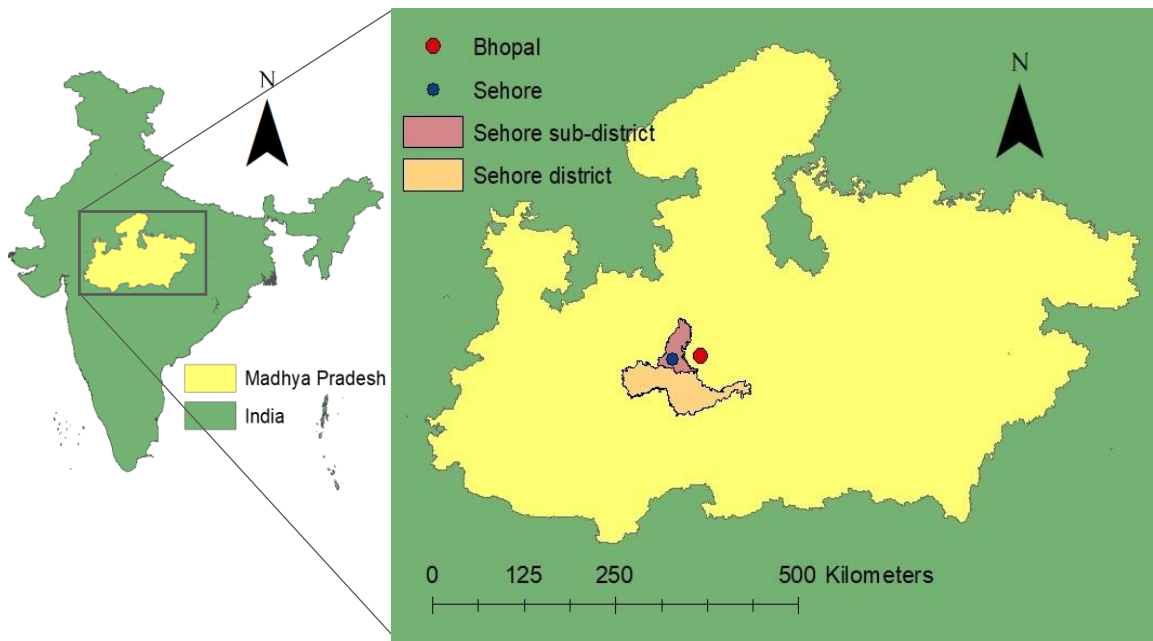
India has a long history of community psychiatry, including initiatives to integrate mental health into general health care. India has had a National Mental Health Program (NMHP) since 1982, which aims – amongst other goals – to provide basic mental health services through the existing primary healthcare system, and has been implemented in the form of the District Mental Health Program (DMHP) in 127 out of 626 districts (75). However, despite being re-designed along with significant increases in funding in 2001, evaluations of the DMHP show that it has been largely unsuccessful in practice (76, 77).

India’s Ministry of Health and Family Welfare released a new mental health policy in October 2014 (78), which is supported by the Mental Health Plan 365 (79), and a new Mental Healthcare Act was passed in 2016 (80). The Act establishes access to government-funded community mental healthcare as a human right, and state governments will be expected to integrate mental health services into general health care at all levels, including

primary health care, in line with the latest policy and plan. The most recent figures available on India's mental health spending from the WHO Mental Health Atlas are from 2011, in which it was reported that the central government spends 0.06% of its health budget on mental health (70).

#### 1.2.5 Sehore District, Madhya Pradesh

Sehore district is located in the state of Madhya Pradesh, in central India. The state has high rates of poverty, with 31.7% living below the poverty line (81), and poor health on most indicators (82, 83). Sehore has a largely rural population (81%) totalling 1.3 million. In 2011, the overall literacy rate was 70%, with a significant gender imbalance (males 81%, females 58%) (84). The population is 89% Hindu and 11% Muslim, and 88% of residents have completed primary education or less (85).



**Figure 3.** Map showing the location of Madhya Pradesh, Sehore district and Sehore sub-district, including the state capital (Bhopal) and the district capital (Sehore)

Sehore is one of the 126 districts (out of 626) across India where the District Mental Health Programme is in operation. The district has two mental health professionals; one psychiatrist and one clinical psychologist (86).

The Mental Health Care Plan was implemented in one sub-district of Sehore, consisting of the tehsils or blocks of Sehore and Shampur (henceforth referred to as "Sehore sub-

district”). This area is home to a population of 427,432 people, dispersed across 1536km<sup>2</sup>, who work primarily in agriculture (84). Sehore sub-district has three community health centres (CHCs), which were chosen as the setting for integration of mental health services due to their levels of staffing and infrastructure (65).



**Figure 4.** A Community Health Centre where depression treatment was delivered as part of the MHCP

#### 1.2.6 Geography and health service utilisation in India

In India, distance to facilities has been cited as a key determinant for access to health care for maternal health and general health needs, particularly affecting disadvantaged groups such as scheduled tribes and women (87-92). However, the effect of geographic accessibility of services has not yet been investigated in the context of mental health care.

#### 1.2.7 PRIME evaluation

A range of methods were employed to evaluate the MHCP, providing a rich source of high quality data that are rarely available in low-resource settings (52). Of particular interest for investigating service utilisation is the repeated community survey, which included 3,220 individuals in the first round and 2,968 in the second (henceforth “PRIME community survey”), to measure the treatment gap for priority mental disorders before and after



implementation of the MHCP. The first round took place in May-June 2013 and January-March 2014 while the second was conducted between October and November 2016.

Participants were selected by systematic random sampling, using voting lists as a sampling frame (which are reportedly highly complete in India (93)). In the first round, voting lists were selected by simple random sampling, after stratifying by urban and rural areas, whilst in the second round all voting lists from areas within the MHCP implementation area were chosen. The questionnaire included demographic characteristics; socioeconomic status measures; depressive symptoms; alcohol use disorder symptoms; disability; mental health literacy; help-seeking; barriers to care; inpatient and outpatient service utilisation; and medication use (see appendix B for full questionnaire). In the second round, additional questions were added to the community survey to capture information relevant to geographic access, including the location of services used. Data were collected by trained local research workers, and captured using the Mobenzi Researcher app (94) installed on an Android tablet device, which also recorded the geographic coordinates of the household.

#### 1.2.8 Availability of services and contact coverage

In the baseline community survey, 17.7% screened positive for depression and 13.1% had sought treatment for their symptoms (95). Despite the increased availability of services through the MHCP by the follow-up round of the survey, no increase in contact coverage for depression was found (96). This is an important finding in the context of efforts to reduce the treatment gap, and raises urgent questions about which barriers account for the persistent low levels of treatment-seeking.

### ***1.3 Knowledge gap to be addressed***

Due to the resources needed to conduct large-scale population-based surveys, the majority of research on depression in India has been conducted with facility-based studies (97-101), which by definition are not inclusive of affected people who do not seek health care. The PRIME community surveys provide detailed data on people affected by depressive disorders, including both those who were and were not in contact with services.

Population level measures of service coverage and the treatment gap may obscure important health care inequities between groups (102), requiring a more detailed enquiry into variations in treatment-seeking by population characteristics. Identifying the extent to which modifiable factors are associated with treatment-seeking is essential to inform ongoing efforts to expand access to care in rural India. This research will therefore examine both geographic and non-geographic variation in service utilisation for depression and explore the decision process around treatment-seeking for these symptoms. This will enhance understanding of barriers to service utilisation for depression in Sehore, and lead to recommendations for increasing service utilisation by those who could benefit, as well as generating hypotheses to be tested in LMIC more generally.

#### **1.4 Aims, Objectives and Methods**

This mixed methods research project investigated the effects of geographic and non-geographic factors on health service utilisation for depression in a rural Indian context, to inform efforts to expand access to mental health care in similar settings, using the Andersen socio-behavioural model as an organising framework.

It has been argued that epidemiological and qualitative research often proceed in parallel in analyses of the use of health care in LMIC, without integration, and that combining these methods is necessary to enable a full understanding of health service utilisation (103). Mixed methods designs offer both the advantages of generalisability and hypothesis-testing afforded by quantitative analyses, as well as the depth of explanatory data and contextualisation provided by qualitative analyses (104). This project used a sequential explanatory design (105), with the aim of using the qualitative study methods to explain and interpret findings from the quantitative studies.

Table 1 summarises the aims, objectives and summary of methods employed. First, I reviewed the international evidence on factors associated with health service utilisation for CMD. Second, I tested the hypothesis that greater geographic accessibility of depression services – measured in terms of travel distance from the residence of adults with probable depression to the nearest public health facility offering depression treatment – is associated with an increased likelihood of seeking treatment for depression, in Sehore, Madhya Pradesh. Third, I compared two measures of distance to health services, as a

sensitivity analysis to complement the second study, but which has methodological importance for research into geographic access to health care in low-resource settings. Fourth, I described treatment-seeking by adults with probable depression in Sehore, and considered its association with other factors from the Andersen model in order to generate hypotheses about the influence of these factors on treatment-seeking for depression. Finally, I used qualitative methods to explore why and how these factors influence treatment-seeking behaviour among adults in Sehore.

Each of these aims is written up in the form of one academic article, which includes full methods for each section.

**Table 1.** Aims, objectives and methods for the research contained in this thesis.

<b>Aim</b>	<b>Objectives</b>	<b>Methods</b>
1. To review current evidence on factors associated with the use of health services for common mental disorders (CMD).	<p>1. To identify factors associated with health service utilisation for CMD among adults in the general population, and to assess the quality and consistency of evidence supporting an association between each of these factors and health service utilisation for CMD.</p> <p>2. To compare the evidence for these associations from high-income countries compared to that from low- and middle-income countries.</p>	Systematic review of factors associated with adult health service utilisation for CMD, using Andersen's behavioural model to categorise findings.
2. To estimate the increase in health service utilisation for depression associated with increasing proximity to services.	<p>1. To compare travel distance by road from the households of individuals with depression to the nearest public depression treatment provider, before and after implementation of the MHCP.</p> <p>2. To measure the association between travel distance to the nearest public depression treatment provider and the probability of treatment-seeking for probable depression in rural India.</p> <p>3. To assess whether this association varies by gender, caste, age, symptom severity, disability, socio-economic status (as measured by housing type, employment status, and education level), perceived need for healthcare</p>	Network analysis using Geographic Information Systems (GIS), followed by construction of multivariable regression models of the association between travel distance and health service utilisation for depression.

	and exposure to mental health communications.	
3. To evaluate whether Euclidean (straight-line) distances and village centroid coordinates can be used as an acceptable proxy for network measures of distance using individually geocoded household coordinates.	<p>1. To measure the inaccuracy in distance to health services in rural India introduced by using Euclidean measures as compared to network measures of distance.</p> <p>2. To measure the error associated with measuring distance to health services from village centroids as compared to individually geocoded household locations, using both Euclidean and network measures, in rural India.</p> <p>3. To estimate and compare the association between distance to health services and health service utilisation for depression, using survey data from rural India, when using Euclidean versus network measures.</p>	Distance measures generated using Geographic Information Systems (GIS) and compared using Wilcoxon signed-ranks test, Spearman's rank correlation, percentage of facilities identified as closest, and difference in odds ratios and 95% confidence intervals for association between these measures and treatment-seeking for depression.
4. To describe health care use and treatment-seeking for depression symptoms in Sehore.	<p>1. To estimate the proportion of adults with probable depression who consult different types of treatment providers, (a) for depression symptoms, and (b) for any reason, and to compare the latter with general health care use by adults without probable depression.</p> <p>2. To measure the prevalence of self-reported barriers to treatment-seeking for depression, among adults with probable depression.</p> <p>3. To estimate the change in probability of treatment-seeking for symptoms of depression associated with need, predisposing and enabling factors.</p>	Secondary analysis of survey data, analysed using weighted percentages, Chi squared tests, prevalence ratios and univariable regression analyses.
5. To explore how families affected by depression in Sehore decide whether to seek help for depression.	1. To identify and describe barriers to treatment-seeking for depression as perceived by individuals affected by depression and their family members.	Semi-structured key-informant interviews with adults with probable depression and their family members.

## **1.5 Role of the candidate**

### 1.5.1 Overall design and planning

I conceived the overall concept, framed the research questions and designed each of the studies presented in this thesis, with technical support and advice from Sujit Rathod. I led the design, analysis and write-up of all of the articles written for journal publications. I also wrote the grant application that was successful in securing funding for field work from the British Council Newton Fund, and prepared the ethical applications associated with my research project.

### 1.5.2 Systematic review

I conceived the idea for the systematic review (chapter 2), designed the search strategy and inclusion criteria, carried out the literature searches, screened the resulting studies, designed the quality appraisal criteria, appraised the quality of the literature, extracted the relevant data, analysed the included studies and wrote the review. Since this was a collaborative paper, other co-authors provided contributions to the work. Georgina Miguel Esponda and Dzmitry Krupchanka screened a subset of the included articles. This work was published in BMC Psychiatry in August 2018 (Roberts, T., Esponda, G.M., Krupchanka, D., Shidhaye, R., Patel, V. and Rathod, S., 2018. Factors associated with health service utilisation for common mental disorders: a systematic review. *BMC psychiatry*, 18(1), p.262. <https://doi.org/10.1186/s12888-018-1837-1>).

### 1.5.3 Quantitative and geographical data collection and analysis

The quantitative work that forms this PhD thesis made use of a dataset generated by PRIME. Although I was not responsible for the original design of this survey, as the first round was conducted prior to the start of my PhD, in the second round I added items to the questionnaire, observed training and data collection during my field trips to the study site, and was responsible for monitoring data during this round of data collection. I spent five months based with the Public Health Foundation of India, spanning the period of the preparation and data collection for the second round of the community survey (during which time I was also able to prepare the qualitative study, below). I was also heavily involved in the geographic component of data collection for round 2, providing regular

feedback to the field team on GPS data collection progress and problem-solving to overcome technical challenges in capturing coordinates.

I carried out all of the work to check household coordinates against village coordinates, convert road data from Open Street Map into a functional GIS network, and link these data with the PRIME dataset. I also designed and carried out the statistical analyses. Shino Shiode and Chris Grundy provided guidance on the GIS components of the analysis.

#### 1.5.4 Qualitative study

For the qualitative component of this PhD, I conceived the idea for the study, designed the topic guide, created the sampling strategy (drawing on data from the PRIME community survey), and wrote the study protocol. I led the back-translation and piloting process for the topic guide, and worked closely with a research assistant at Sangath, Ritu Shrivastava, to collect the data and adapt the topic guide in response to emergent themes. I observed all interviews and took field notes throughout data collection. Transcription and translation were done by local staff. I carried out the analysis, with assistance from Ritu Shrivastava who double-coded the transcripts. Mirja Korschorke gave guidance on the design of the study and analysis of the data.

### **1.6 Ethical clearance**

Ethical approval for the research included in this thesis was granted by the LSHTM Observational Ethics Committee (London, United Kingdom) and Sangath Institutional Review Board (Goa, India) (appendix C). The original community survey was approved by the World Health Organization Research Ethics Review Committee (Geneva, Switzerland) and the Sangath Institutional Review Board (Goa, India).

## RESEARCH PAPER COVER SHEET

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<b>Student</b>	Tessa Roberts
<b>Principal Supervisor</b>	Sujit Rathod
<b>Thesis Title</b>	Mapping the Treatment Gap: A mixed methods exploration of barriers to treatment-seeking for depression in rural India

***If the Research Paper has previously been published please complete Section B, if not please move to Section C***

### **SECTION B – Paper already published**

Where was the work published?	BMC Psychiatry		
When was the work published?	22nd August 2018		
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**Student Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Supervisor Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_



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Yours sincerely,

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## **2. Factors associated with health service utilisation for common mental disorders: A systematic review**

### **2.1 Abstract**

#### **Background**

There is a large treatment gap for common mental disorders (CMD), with wide variation by world region. This review identifies factors associated with formal health service utilisation for CMD in the general adult population, and compares evidence from high-income countries (HIC) with that from low-and-middle-income countries (LMIC).

#### **Methods**

We searched MEDLINE, PsycINFO, EMBASE and Scopus in May 2016. Eligibility criteria were: published in English, in peer-reviewed journals; using population-based samples; employing standardised CMD measures; measuring use of formal health services for mental health reasons by people with CMD; testing the association between this outcome and any other factor(s). Risk of bias was assessed using the adapted Mixed Methods Appraisal Tool. We synthesised the results using “best fit framework synthesis”, with reference to the Andersen socio-behavioural model.

#### **Results**

52 studies met inclusion criteria. 46 (88%) were from HIC.

*Predisposing factors:* There was evidence linking increased likelihood of service use with female gender; Caucasian ethnicity; higher education levels; and being unmarried; although this was not consistent across all studies.

*Need factors:* There was consistent evidence of an association between service utilisation and self-evaluated health status; duration of symptoms; disability; comorbidity; and panic symptoms. Associations with symptom severity were frequently but less consistently reported.

*Enabling factors:* The evidence did not support an association with income or rural residence. Inconsistent evidence was found for associations between unemployment or having health insurance and use of services.

There was a lack of research from LMIC and on contextual level factors.

### **Conclusion**

In HIC, failure to seek treatment for CMD is associated with less disabling symptoms and lack of perceived need for healthcare, consistent with suggestions that “treatment gap” statistics over-estimate unmet need for care as perceived by the target population. Economic factors and urban/rural residence appear to have little effect on treatment-seeking rates. Strategies to address potential healthcare inequities for men, ethnic minorities, the young and the elderly in HIC require further evaluation. The generalisability of these findings beyond HIC is limited. Future research should examine factors associated with health service utilisation for CMD in LMIC, and the effect of health systems and neighbourhood factors.

**PROSPERO registration number:** 42016046551

## ***2.2. Background***

Common mental disorders (CMD) comprise depressive disorders and anxiety disorders, according to the World Health Organization’s definition (12), and are a leading cause of disability worldwide (106, 107). Depressive disorders include major depressive disorder and dysthymia, while anxiety disorders include generalised anxiety disorder (GAD), panic disorder, phobias, social anxiety disorder, obsessive-compulsive disorder (OCD) and post-traumatic stress disorder (PTSD). More than 300 million people were estimated to suffer from depression

in 2015 (4.4% of the global population), with almost as many affected by anxiety disorders, although there is substantial comorbidity between the two (12).

Despite evidence of effective treatments for CMD (108), there is a large “treatment gap” for CMD globally, with only 42-44% of those affected worldwide seeking treatment for these symptoms from any medical or professional service provider, including specialists and non-specialists, in the public or private sectors (4). This proportion has been shown to be much lower in low- and middle-income countries, with estimates of as little as 5% seeking treatment, even when traditional providers are also included (5, 109, 110).

Within the Global Mental Health literature, these statistics have been used to call for the scaling up of mental health services in order to reduce the treatment gap (6, 9, 29, 64, 111, 112), on the assumption that meeting clinical criteria for CMD indicates – or acts as a proxy for – a need for treatment.

Access to health services has been conceptualised as the “fit between the patient and the health care system” (27). Donabedian (1973) defines access as “a group of factors that intervene between capacity to provide services and actual provision or consumption of services” (113). Identifying those factors that are associated with seeking treatment for CMD can help us to better understand the reasons for the treatment gap, and inform service planning to expand access to care.

The Andersen behavioural model of health service utilisation (114) provides a useful framework to inform analyses of factors that influence health service utilisation. The Andersen model is a sociological model of health service utilisation that has been extensively applied (41, 44). This model proposes that the use of health services is affected by:

- (a) one’s *predisposition* to seek help from health services when needed (a product of socio-demographic characteristics, attitudes and beliefs);
- (b) one’s *need* for care (both objective measures and subjective perceptions of one’s health needs); and

(c) the structural or *enabling* factors that facilitate or impede service utilisation (such as financial situation, health insurance and social support).

In later iterations of the model it was recognised that these predisposing, enabling and need factors can operate at both the individual level and the contextual level (115, 116).

A substantial body of evidence exists on the factors that influence health service utilization for health conditions such as HIV treatment and maternal health care (117-119), and more recently, depression (120). However, the latter review included treatment-seeking by adolescents and by specific sub-groups of the population, and as such its results may not be generalisable to the general adult population. Furthermore, since depressive and anxiety disorders are closely related and frequently co-occur (24, 26), with many individuals experiencing mixed anxiety-depression disorders (23), we believe that it is more appropriate when studying non-clinical populations to consider the larger construct of CMD rather than separating these disorders, as has been argued elsewhere (25, 121, 122). To date, there has been no comprehensive review of the factors associated with health service utilisation for symptoms of CMDs in the general adult population.

The aim of this review is to investigate factors associated with the use of health services for CMD symptoms, in observational, population-based studies.

Specific objectives are:

- (1) To identify factors associated with health service utilisation for CMD among adults in the general population, and to assess the quality and consistency of evidence supporting an association between each factor and health service utilisation for CMD.
- (2) To evaluate the evidence for these associations from high-income countries (HIC) compared to that from low- or middle-income countries (LMIC).

## **2.3 Methods**

The protocol for this study was registered with PROSPERO (registration number 42016046551) (123). Results are presented according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (see appendix D).

### 2.3.1 Information sources and search strategy

We searched four databases; MEDLINE, PsycINFO, EMBASE and Scopus. We combined two key concepts (CMD and health service utilisation) using keywords and subject headings in the respective databases. Results were retrieved on 5th May 2016. The search strategy can be found in appendix D. We supplemented the database search by hand searching and reference searches. We only included articles published in English.

### 2.3.2 Eligibility criteria

Since the population of interest is the general adult population, we included only population-based studies, defined as community-based epidemiological studies that are representative of the adult population. We excluded studies that focused only on specific sub-populations such as veterans, students, or prisoners, whose experiences may not be representative of the wider population and warrant separate reviews.

The primary outcome measure of interest was any contact with formal health services – including private, public, generalist and specialist – for mental health reasons (also referred to as “treatment-seeking”) by adults aged 18 and above with CMD. Reflecting the definition of the treatment gap, we focussed specifically on use of services as a binary outcome – i.e. any versus no use – rather than volume of treatment received or quality of care.

To be eligible for inclusion, the study must have tested the association between treatment seeking and any other factors. We therefore included only quantitative studies, published in peer-reviewed journals, and excluded narrative reviews and commentaries. We included only studies in which the analyses were restricted to those individuals who either met diagnostic criteria or screened positive for CMD using a standardised instrument.



For the purposes of this article, CMD is defined as those ICD-10 (International Classification of Diseases - 10th Revision) disorders measured by the Clinical Interview Schedule - Revised (124) – often considered the gold standard for measuring CMD (125, 126) – namely, depressive disorders, generalised anxiety disorder, panic disorder, phobias, obsessive compulsive disorder, and mixed anxiety-depression disorder.

We excluded papers that measured only intentions to seek help, or perceived barriers to care, since multiple studies have found that these are not closely associated with behaviour (127-131).

No restrictions were placed on geographic area or date of publication. Table 1 provides full details of the inclusion criteria applied.

**Table 1. Inclusion and exclusion criteria applied.**

	<b>Include</b>	<b>Exclude</b>
<b>Participants</b>	<ul style="list-style-type: none"> <li>- Population-based studies, in which participants are randomly sampled from a sampling frame that can be reasonably expected to include the majority of the adult population</li> <li>- Studies in which CMD is measured and analyses are restricted to those who “screen positive” for CMD.*</li> </ul> <p>* Defined as:</p> <ul style="list-style-type: none"> <li>Depression</li> <li>generalised anxiety disorder (GAD)</li> <li>panic disorder</li> <li>phobias</li> <li>obsessive compulsive disorder (OCD)</li> <li>CMD not otherwise specified</li> </ul>	<ul style="list-style-type: none"> <li>- Any studies including people aged under 18 (unless these are presented separately in analyses)</li> <li>- Studies with exclusion criteria that would rule out a large proportion of the adult population (e.g. over-55s only, people of a particular minority ethnic group only, women who have recently given birth)</li> <li>- Studies in which participants do not live in community settings (e.g. prisoners, inpatients, residents of elderly care homes) or are defined by their occupation (e.g. doctors, police officers, students)</li> <li>- Studies in which all participants have used health services for mental health reasons</li> <li>- Studies that combine people with CMD and those with other conditions and do not report results separately in analyses</li> <li>- Ecological level studies in which CMD is not controlled at the individual level</li> </ul>

		<p>(i.e. it's not possible to tell whether the people using services are the same individuals who have CMD)</p> <ul style="list-style-type: none"> <li>- Studies that apply overly restrictive exclusion criteria for participants, e.g. focussed solely on individuals with a specific comorbid condition, or restricted to only specific ethnic groups</li> </ul>
<b>Design</b>	<ul style="list-style-type: none"> <li>- Observational</li> <li>- Quantitative or qualitative comparison of treatment-seekers and non-treatment-seekers</li> <li>- Cross-sectional or longitudinal</li> <li>- Articles published in peer-reviewed journals only</li> </ul>	<ul style="list-style-type: none"> <li>- Reviews/commentaries/opinion pieces</li> <li>- Conference abstracts/dissertations/book chapters</li> <li>- Case studies that lack quantitative evaluation</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>- Studies reporting on the use/non-use (as a binary variable) of formal, face-to-face health services (either specialist or non-specialist, public or private) for mental health reasons</li> <li>- Timeframe in which service use is measured must be clearly defined (e.g. past 12 months)</li> </ul>	<ul style="list-style-type: none"> <li>- Studies reporting on general health care use (i.e. including for reasons other than mental health problems)</li> <li>- Studies examining use of only one specific treatment type (e.g. antidepressant use only, counselling only)</li> <li>- Studies reporting on volume of treatment (i.e. number of visits to a treatment provider), adherence to treatment or quality of treatment</li> <li>- Studies reporting on rates of detection or referral</li> <li>- Studies reporting on theoretical access rather than actual use (e.g. insurance coverage, being registered with a clinic)</li> <li>- Studies reporting on the use of online or telephone-based services</li> <li>- Studies examining the use of informal care (e.g. friends/family/religious support) or complementary/alternative treatments (i.e. those provided outside of the formal health sector)</li> <li>- Studies reporting on <u>willingness</u> or <u>intentions</u> to use services, or recommendations for service use in case of experiencing CMD symptoms, with no measure of actual behaviour</li> <li>- Studies that report participation in screening as the outcome rather than active treatment-seeking or uptake of services post-screening</li> </ul>

<b>Associated factors</b>	- Any factors that are associated with the outcome of interest, including (but not limited to): demographic factors health status (e.g. severity/disability/comorbid conditions etc.) distance/transport to services insurance coverage interventions specific symptoms behavioural/personality factors neighbourhood characteristics characteristics of the healthcare provider health systems factors stigma/attitudes towards services	- Studies reporting on the magnitude of the treatment gap, without any factors associated with treatment-seeking - Studies that report predictors of service type (e.g. generalist vs. specialist, pharmacological vs. psychological) rather than any vs. no use - Studies reporting barriers and facilitators to the use of health services, without examining the association between these barriers and actual treatment-seeking behaviour
<b>Dates</b>	Any year of publication	
<b>Region</b>	Any country or region	

### 2.3.3 Study selection

The first author completed title and abstract screening for all references retrieved.

Subsequently two researchers (GME and DK) independently screened a random sample of 10% of the references, and inter-rater reliability was calculated at 94%. Full texts were retrieved for all studies included after the title/abstract screening. The first author screened all full texts, while the second author (GME) screened a purposive sample of 10%. At both stages, disagreements were resolved through discussion.

We assessed the quality of the relevant evidence extracted from the included studies using the Mixed-Method Appraisal Tool (MMAT) (132), which has been shown to be quick and reliable to apply (133). Table 2 sets out the criteria used. Extracted evidence for the purposes of this review was rated as poor, fair, good or excellent if 0-1, 2, 3 or 4 of these criteria were met, respectively. These ratings are not intended to reflect the study quality in relation to its own primary aims, but only of the quality of the evidence that related to this review.

**Table 2.** Operationalisation of quality appraisal criteria, based on the Mixed-Method Appraisal Tool (MMAT)

<b>Criterion</b>	<b>Definition</b>	<b>Example</b>
Appropriate sampling strategy	Population-based sample using a sampling frame that can reasonably be assumed to include the majority of the non-institutionalised adult population. (Justification of sample size was not included in this criterion since none of the included studies justified their sample size with reference to the research questions addressed in this review.)	<p><i>Meets criterion:</i> Simple random sample of households chosen from a government list of residential addresses, then one resident aged <math>\geq 18</math> randomly chosen to participate.</p> <p><i>Doesn't meet criterion:</i> Males and females sampled through separate means (males at compulsory conscription, females at enrolment on the electoral register).</p>
Sample representative of target population	Sample representative of non-institutionalised adult population, with minimal exclusion criteria applied.	<p><i>Meets criterion:</i> All adults eligible in urban area where study was conducted. Sample representative of urban residents with regard to major socio-demographic factors tested.</p> <p><i>Doesn't meet criterion:</i> Participants excluded due to age, ethnicity, chronicity of symptoms, comorbid conditions etc.</p>
Appropriate measures used	Validated measure of CMD (either screening tool or diagnostic instrument), timeframe for health service utilisation limited and specified.	<p><i>Meets criterion:</i> CIDI, AUDADIS-IV, CIS-R, SPIKE, PHQ-9, GAD-7, DIS, Burnam depression screener 12 month help-seeking from health services for MH reasons</p> <p><i>Doesn't meet criterion:</i> Self-defined depression/anxiety, prior receipt of diagnosis</p>

		Lifetime use of health services (due to limited accuracy of recall)
Acceptable response rate	>60% response rate for cross-sectional studies  >60% response rate and <30% attrition rate for longitudinal studies	<i>Meets criterion:</i> >60% response rate across all study sites, or across all major groups compared <i>Doesn't meet criterion:</i> <60% response rate overall, in some study sites, or for one gender

### 2.3.4 Data extraction and synthesis

The following data were extracted for all papers that were included in the full text search: study title, authors, publication date and journal; country; study design; population; CMD measure; outcome (i.e. health service utilisation) measure; and factors associated with the outcome (including null associations). An association was regarded as detected when it was associated with the outcome in the most fully-adjusted model presented, with a p-value of <0.05. The corresponding authors were contacted for clarification in case of any ambiguities.

Due to the number of different factors investigated, and heterogeneity in the measures used, it was not feasible to attempt a meta-analysis of the effect of each factor. Instead, the “best fit” framework synthesis method (134) was used to compare the fit of the data with an existing model of factors affecting health service utilisation. This technique was originally developed for the synthesis of qualitative research, but has since been applied to reviews of quantitative and mixed methods studies (135, 136).

The first author extracted the data from each of the included papers and coded these deductively using the Andersen framework described above (114). Any data that did not fit any of the headings in the Andersen model headings were to be coded separately under a new theme in a subsequent inductive phase.

To avoid bias in the synthesis and interpretation of results due to pre-conceived ideas about which factors are associated with treatment-seeking, we created *a priori* definitions with which

to categorise the associations found for each factor. These definitions (summarised in table 3) were created for the purposes of the current review, and are intended to be conservative.

No prior studies were found to guide the operationalisation of these definitions, and therefore the cut-off points chosen are necessarily arbitrary. However, we have tried to be entirely transparent in how these have been applied, and present the full findings and quality ratings in the appendices provided so the reader can examine how the evidence relates to the conclusions drawn.

**Table 3.** Definitions used to grade consistency of evidence when synthesising findings from included studies

Evidence level	Criteria
Good evidence of an association	≥75% of studies that investigated this factor report an association, of which ≥2 (using different datasets) are of good/excellent quality
Good evidence of no association	<25% of studies that investigated this factor report an association, of which ≥2 (using different datasets) are of good/excellent quality
Inconsistent evidence	25%-75% of studies that investigated this factor report an association, of which ≥2 (using different datasets) are of good/excellent quality
Poor quality evidence only	<2 studies of good/excellent quality (using different datasets) investigated the association between this factor and treatment-seeking for CMD
Not examined	No studies investigated the association between this factor and treatment-seeking for CMD

## 2.4 Results

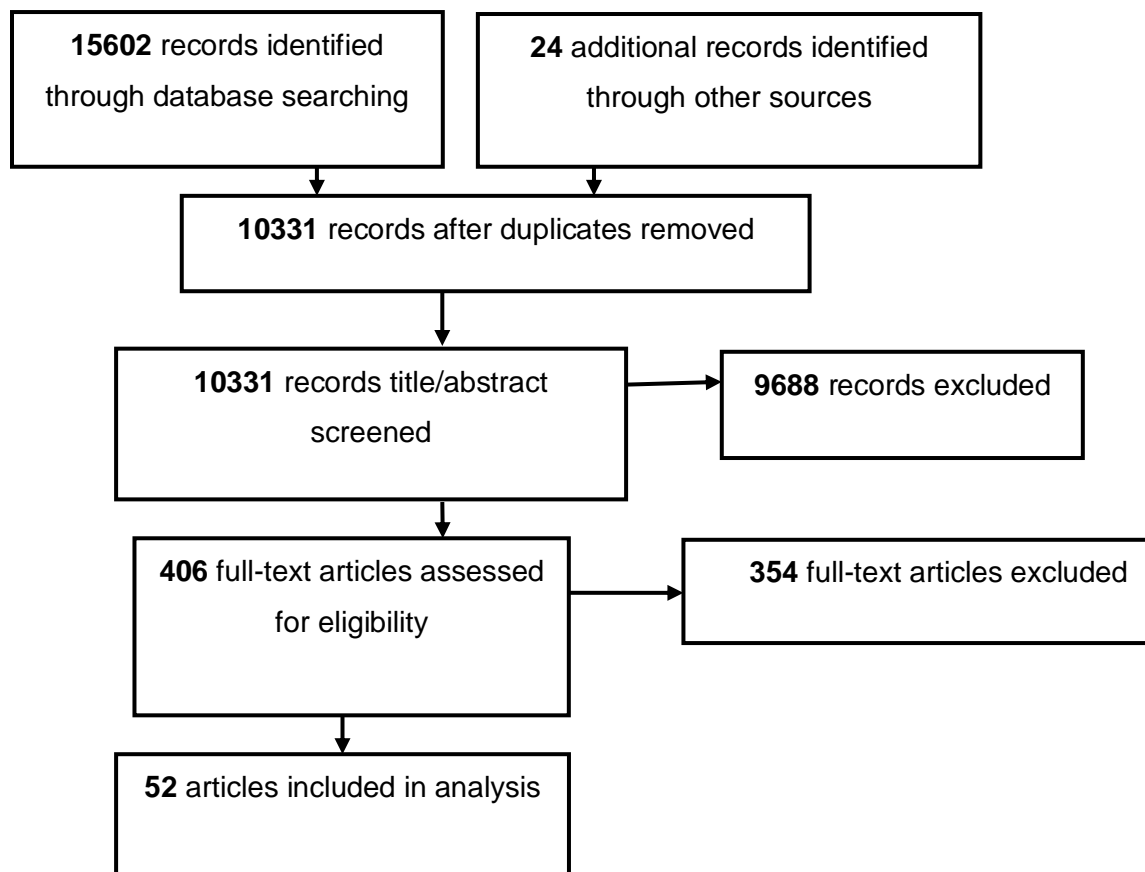
### 2.4.1 Search results

Figure 1 summarises the search process. After removing duplicates, 10,331 papers were retrieved. Fifty-two papers were found to meet the criteria at the full text screening stage. Of these, eleven were cohort studies while forty-one were cross-sectional.

Thirty-two (62%) of these studies reported data from North America, nine (16%) from Europe, two (4%) from Australasia, three (6%) from Africa, one (2%) from Asia, two (4%) from Latin America and three (6%) used international data from across world regions.

The study sizes varied considerably, from 56 participants to 18,972 participants with elevated levels of CMD symptoms.

In terms of quality, evidence from one study was rated as poor, evidence from 16 was classified as fair, evidence from 20 was classified as good, and evidence from 15 studies was rated excellent. The full characteristics of the included studies are presented in appendix D.



**Figure 1.** PRISMA flowchart

#### 2.4.2 Factors associated with health service utilisation for CMD

Table 4 shows the number of studies that investigated each of the factors in the Andersen model.

Compared to other factors, we identified the highest number of studies on the association between socio-demographic factors (classified according to the Andersen model as “predisposing” factors) and treatment-seeking for CMD. We also found a large number of studies that investigated association between treatment-seeking and symptom severity, symptom profile and comorbidity (termed “need” factors in the Andersen model). Fewer of the included studies examined enabling factors such as insurance, household wealth and social support. There was a lack of published evidence on some factors implicated by the Andersen model, such as psychological factors (e.g. beliefs and attitudes, classified as “predisposing” factors) and health systems factors (e.g. the availability and accessibility of services).

Almost all of the factors identified were individual rather than contextual level factors. No factors were identified that could not be accommodated by the model.

A summary of findings for each factor group is presented below. For more detailed results see appendix D.



**Table 4. Synthesis of associations found between factors in Andersen model and treatment seeking for CMD**

Type	Factor	Summary of associations found	Evidence level	No. of studies	Relationship	No. of good quality studies	No. of longitudinal studies	Total sample size	Total number of studies from each region	No. of studies from LMIC	
<b>Predisposing factors</b>											
Demographic	Age	Hill-shaped relationship commonly reported, with highest use by middle-aged individuals and lower use by the young and the elderly	Inconsistent	25	Hill-shaped	9	3	33,779	10 1 1	N. America Australasia L. America	1
					Positive/Consistent with hill-shape	2	2	3,162	1 1 2	Africa L. America Europe	2
					Mixed	0	1	1,926	2	Europe	0
					Null	4	0	6,501	2 2 2	Africa N. America Europe	2
	Age of onset	Older age of onset associated with service use in some studies	Inconsistent	3	Positive	2	1	14,640	2	N. America	0
					Other	0	1	1572	1	Europe	0
	Gender	Female gender generally associated with greater service utilisation	Inconsistent	29	Positive (women)	9	5	28,201	10 1 1 1	N. America L. America Africa Europe	1
					Other/mixed	4	2	29,838	3 2 1	N. America Africa Europe	2
					Null	5	2	6,380	1 1 2 1 4	Africa Asia N. America Australasia Europe	1
					Negative (women)	1	0	531	1	L. America	1

<b>Social structure</b>	Ethnicity	Caucasian ethnicity commonly associated with greater use than other ethnic groups	Inconsistent	23	Positive (white)	7	2	60,534	11	N. America L. America	1
					Positive compared to some ethnicities only	2	0	17,299	3	N. America	0
					Mixed	4	1	36,558	5	N. America South Africa	1
					Null	2	1	2,658	2	N. America Australasia	0
	Immigration status	No clear pattern found	Inconsistent	6	Negative (born abroad)	0	1	2026	1	Europe	0
					Null	2	1	15,056	2	N. America Australasia	0
					Mixed	0	0	7,687	2	N. America	0
	Marital Status	Being married associated with lower service use in some studies	Inconsistent	18	Negative (married)	5	2	10,367	5	N. America Europe Australasia	0
					Null	5	1	17,493	1	L. America Africa N. America Europe	3
					Positive (married)	1	1	337	1	N. America	0
					Mixed	2	1	13,590	1	N. America Europe	0
					Null	1	1	13,590	1	N. America Europe	0
Education	Higher levels of education associated with greater service use in some studies	Inconsistent	20	Positive (higher)	6	4	31,441	6	N. America Europe L. America Africa	2	
				Null	7	1	11,377	5	N. America Europe Australasia Africa	1	
				Mixed	0	1	2,130	1	N. America Europe	0	
<b>Personality</b>	Conscientiousness	No clear pattern found	Poor	1	Positive	0	1	354	1	Europe	0
	Mastery	No clear pattern found	Poor	1	Mixed	0	1	903	1	Europe	0
	Neuroticism	No clear pattern found	Inconsistent	2	Positive	1	1	2,005	1	Australasia	0
					Null	1	1	102	2	Europe	0

Health beliefs	Prior use of services	Prior use associated with greater use	Good	5	Positive	2	2	14,163	4	N. America	0
					Null	0	0	56	1	Asia	1
	Stigma	No clear pattern found	Poor	2	Null	0	0	102	1	Europe	0
					Mixed	1	0	56	1	Asia	1
	Mental Health Literacy	Not investigated		0	N/A	0	0	0			0
<b>Enabling factors</b>											
Assets	Income/ wealth	Most studies did not find any association	Good – no association	11	Null	5	0	7,623	3	N. America	3
									3	Africa	
									1	Europe	
					Positive	1	0	7,209	1	N. America	1
								1	1	Asia	
					Mixed	1	0	2,510	2	N. America	0
	Employment	Being employed associated with lower use in some studies	Inconsistent	8	Negative (being employed)	2	2	3,452	2	N. America	0
								2	2	Europe	
					Null	3	0	3,059	2	Africa	2
									1	Europe	
									1	Australasia	
	Social support	Greater social support linked to use in some studies	Poor	5	Positive	0	1	661	1	Europe	1
								1	1	Africa	
					Null	1	1	1,275	2	N. America	0
									1	Europe	
	Insurance	Having health insurance associated with use in some studies	Inconsistent	7	Positive	2	1	10,393	4	N. America	0
					Null	1	0	956	2	N. America	0
					Mixed	0	0	558	1	N. America	0
<b>Need factors</b>											
Perceived	Self-rated health/perceived need for care	Better self-rated health (/lower perceive need for care) associated	Good	8	Negative	2	2	2,738	2	N. America	0
									1	Europe	
					Mixed or indirect	2	0	2,865	3	N. America	0
					Null	0	1	491	1	N. America	1
									1	Asia	

		with lower service use													
Evaluated	Symptom severity	Greater severity commonly associated with service use	Inconsistent	16	Positive	5	5	23,165	7	N. America	0				
									2	Europe					
									1	Australasia					
					Mixed	1	0	298	1	Europe	0				
					Null	3	1	4,052	2	N. America	1				
									2	Europe					
									1	Asia					
		Chronicity/duration	Longer duration associated with service use	Good	3	Positive	3	0	8,603	2	N. America	0			
	1									Europe					
		Disability	Greater impairment associated with service use	Good	8	Positive	3	1	4,794	1	N. America	0			
	3									Europe					
													1	Australasia	
						Mixed/borderline	0	1	2,199	2	N. America	0			
										1	Europe				
		Comorbid conditions – total	No clear pattern found	Poor	4	Null	1	1	7,565	1	N. America	1			
	1									Europe					
										1	L. America				
		Non-psychiatric chronic conditions	No clear pattern found	Inconsistent	14	Positive	3	2	17,455	3	N. America	1			
	1									Europe	(combined HIC/LMIC)				
													1	International	
									Negative	1	0	220	1	Europe	0
									Mixed	1	0	7,460	1	N. America	1
									1	Africa					
					Null	5	1	4,567	3	Europe	0				
									2	N. America					
									1	Australasia					
	Psychiatric comorbidities (general)	Comorbid mental disorders (in general) associated with service use	Good	6	Positive	5	3	6,295	3	N. America	0				
															2
									1	Australasia					
	Comorbid SUD	No clear pattern found	Inconsistent	8	Positive	3	1	24,189	3	N. America	0				
												2	N. America	0	
					Negative	1	1	1,156							

				Mixed	0	1	1,572	1	Europe	0	
				Null	2	1	20,445	2	N. America	0	
Comorbid mood/anxiety disorders	Comorbid mood/anxiety disorders associated with service use	Good	6	Positive	5	4	26,714	3	N. America	0	
				Null	1	0	102	1	Europe	0	
Other comorbid mental disorders	No clear pattern found	Inconsistent	3	Mixed	3	1	8,719	3	N. America	0	
Panic symptoms	Panic symptoms associated with service use	Good	6	Positive	5	2	26,350	4	N. America	0	
				Negative	0	0	558	1	N. America	0	
Suicidality	No clear pattern found	Inconsistent	3	Positive	2	0	1,646	1	N. America	0	
				Null	1	1	2,864	1	Europe	0	
Somatisation	No evidence of any association	Good – no	2	Null	2	1	1,566	2	N. America	0	
Other CMD symptoms	No clear pattern found	Inconsistent	5	Mixed	2	1	15,941	3	N. America	0	
Adverse childhood events	No clear pattern found	Poor	4	Positive	0	2	1,926	2	Europe	0	
				Mixed	1	1	1,201	2	Europe	0	
<b>Contextual factors</b>											
Place of residence	Urban/rural residence	No evidence of any association	Good – no	7	Null	6	1	16,677	3	N. America	1
									2	Europe	1
Country	No clear pattern found	Inconsistent	3	Mixed	2	0	4,111	1	N. America/Europe	0	
				Null	0	0	751	1	N. America	0	
Region (within-country)	No clear pattern found	Inconsistent	3	Positive	1	1	7,620	1	N. America	1	
				Null	1	0	7,153	1	L. America	0	

<b>Health service factors</b>	Service availability (perceived)	No clear pattern found	Poor	1	Positive	0	1	435	1	N. America	0
	Service accessibility	No clear pattern found	Poor	1	Null	0	0	56	1	Asia	1
	Regular source of care	No clear pattern found	Poor	2	Mixed	1	0	436	2	N. America	0
	Organisation of services (gatekeeper)	No clear pattern found	Poor	1	Negative	1	0	1498	1	N. America	0
	Service capacity/waiting times/opening hours	Not investigated		0	N/A	0	0	0			0
	Resources available	Not investigated		0	N/A	0	0	0			0
	Healthcare policy	Not investigated		0	N/A	0	0	0			0
	Quality of care	Not investigated		0	N/A	0	0	0			0
<b>Social factors</b>	Neighbourhood norms	Not investigated		0	N/A	0	0	0			0

#### 2.4.2.1 Predisposing factors

### **Overall synthesis of findings on predisposing factors**

As shown in table 5, while several trends were identified, no predisposing factors were consistently found to be associated with seeking treatment.

### **Factor-by-factor synthesis of evidence from included studies**

#### *General trends across studies:*

Having sought mental health treatment previously was generally associated with increased likelihood of seeking treatment (137-139). The relationship between age and health service utilisation for CMD was commonly found to be hill-shaped, with middle-aged respondents most likely to seek treatment (140-159). Female gender was frequently found to be associated with increased treatment-seeking (137, 138, 140-146, 148-153, 155, 156, 158-168), as was being Caucasian, which represented the majority ethnic group in the context of most of the included studies (137, 138, 140-142, 144, 146, 148-151, 155, 159, 161, 169-178). Several studies reported that higher education levels were associated with health service utilisation for CMD, although this was not found across all studies (137, 138, 140-142, 144, 146, 148-156, 159, 161, 167, 168). Being married was negatively associated with treatment-seeking, though it was unclear whether this is due to greater use of services by the never married or by those who are separated or divorced (137, 138, 140-142, 146, 148-150, 153, 155-159, 161, 164).

#### *Findings related to other predisposing factors:*

There was mixed evidence with regard to immigration status (137, 139, 159, 164, 173, 179), change in marital status (137, 138, 162), and personality factors (142, 152, 157, 165). There was limited published evidence available on age of onset, from just three studies, but the findings generally indicated increased likelihood of seeking treatment with later onset (137, 162, 168). There was also a lack of published evidence on the effect of stigma or other beliefs and attitudes (157, 158).

#### 2.4.2.2 *Need factors*

##### **Overall synthesis of findings on need factors**

Need factors were most consistently associated with the use of health services for CMD symptoms across studies, as seen in table 5.

##### **Factor-by-factor synthesis of evidence from included studies**

###### *Consistent findings:*

Five factors were consistently found to be associated with treatment-seeking across studies. These were self-evaluated health status or healthcare needs (141, 144, 158, 159, 161, 165, 174, 177); duration or chronicity of symptoms (140, 157, 162); disability or functioning (139, 142, 154, 156, 159, 164, 165, 167); comorbid mental disorders (137, 140-143, 145, 150, 156, 157, 161, 162, 164, 167, 168, 180-182); and panic symptoms (137, 142, 143, 162, 182).

###### *General trends across studies:*

Symptom severity was generally reported to be associated with an increased likelihood of seeking treatment (141, 142, 144, 145, 149, 150, 152, 156, 158, 162, 164, 165, 167, 169, 170, 176).

###### *Findings related to other need factors:*

There was mixed evidence for an association with suicidality or specific CMD symptoms (137, 138, 142, 143, 150, 154, 157, 162, 167, 168, 176, 182, 183), substance use and non-psychiatric conditions (138, 140-142, 144, 145, 148, 154, 156, 157, 159, 162, 164-166, 184-186) and adverse childhood events (152, 165, 167, 168).

#### 2.4.2.3 *Enabling factors*

##### **Overall synthesis of findings on enabling factors**

As indicated in table 5, there was inconsistent evidence for an association between treatment-seeking for CMD and enabling factors.



## **Factor-by-factor synthesis of evidence from included studies**

### *Consistent findings:*

The studies included here did not support an association between wealth or income and the use of health services for CMD symptoms (138, 146, 149, 151, 153, 155, 156, 158, 159, 166).

### *General trends across studies:*

Some studies indicated a positive association between treatment-seeking and being in employment although this was not found across all studies (141, 142, 149, 153, 156, 164, 166, 167). Having health insurance was frequently, but not consistently, reported to be associated with health service utilisation for CMD (138, 140, 141, 144, 151, 154, 159).

### *Findings related to other enabling factors:*

There was mixed evidence with regard to social support (141, 152, 157, 159, 166), and limited published evidence available on the effect of having a regular source of care (138, 139).

### *2.4.2.4 Contextual level factors*

#### **Overall synthesis of findings on contextual factors**

Overall, limited published evidence was found testing the association between contextual level factors and health service utilisation for CMD.

### *Consistent findings:*

The studies included here suggest that living in a rural area is not associated with lower rates of treatment-seeking (140, 142, 145, 146, 148, 156, 167).

### *Findings related to other contextual factors:*

Few studies compared treatment-seeking between countries or by geographic region within countries, and those that did reported inconsistent findings (140, 148, 150, 169, 187, 188). There was a dearth of published evidence on the association between the health care environment and utilisation of services for CMD, with just one study on the effect of

managed care (144), one on perceived availability of services (141), and one on perceived accessibility of services (158).

#### 2.4.3 Comparison of evidence from LMIC and HIC

There was a clear discrepancy in the quantity of research identified between high-income and low-and-middle-income countries, with just six of the included studies originating from LMIC and one international study that included data from both HIC and LMIC (184). Five of the LMIC-only studies were from middle-income countries; two from South Africa (155, 166), and one from Brazil (148), Mexico (160) and China (158). The only study from a low-income country was from Ethiopia (153).

Evidence from three out of six LMIC studies was rated as good or excellent. On average LMIC studies were smaller than HIC studies, with a mean of 1742 participants with high CMD symptoms, compared to 3374 for HICs.

The LMIC studies identified predominantly reported on the effect of predisposing factors, such as age, gender, and education levels, and on measures of income or wealth.

There was insufficient published evidence from LMIC to compare the factors associated with treatment-seeking for CMD between HIC and LMIC.

#### 2.4.4 Methodological limitations of included studies

The majority of studies used secondary datasets, which limited the choice of variables to those that are typically collected as part of multi-purpose epidemiological surveys. The frequent use of cross-sectional data also limits our ability to disentangle the direction of causation when associations are found. The majority of studies used multivariate logistic regression models for analysis. The use of hierarchical models, or structural equation modelling that explicitly recognises the potential interactions between some of these factors, may have led to differing conclusions. Although several studies cited the Andersen model to justify their choice of variables, there seems to be little agreement as to how the model should be operationalised and much heterogeneity in the measures used, making it difficult to compare the results across studies. In particular, agreement is needed on how

variables indicating level of “need for care” should be measured in the context of CMD, so that it is possible to control for this consistently when investigating whether the use of health services is equitable. Finally, many of the included studies did not correct for multiple testing when investigating multiple associations simultaneously, and as such their findings should be viewed as hypothesis-generating rather than hypothesis-testing.

## **2.5 Discussion**

### 2.5.1 Principal findings

This review furthers our understanding of the treatment gap for CMD by summarising patterns of treatment-seeking. Need factors were most consistently found to be associated with treatment-seeking for CMD symptoms. Enabling factors were not found to be consistently associated with treatment seeking for CMD. The evidence on predisposing factors was inconsistent, although there was weak evidence for an association with demographic factors, specifically age, gender, ethnicity, education level and marital status. Finally, the current results suggest that urban or rural residence is not associated with treatment-seeking.

With regard to the second objective, there was insufficient published evidence from LMIC to draw any firm conclusions about whether the factors associated with health service utilisation for CMD differ from high-income countries.

### 2.5.2 Strengths and weaknesses

This review has several strengths: It employed a broad search strategy, informed by previous reviews (117-119), since the literature on this topic spans several disciplines with varying terminology. It followed an a priori protocol, had screening verified at multiple stages by a second researcher, and employed a widely recognised theoretical framework to analyse the results. Compared to the most recent review in this area (120), we searched a larger number of databases in order to make the review as comprehensive as possible.

This review adds to previous research by considering the wider category of CMD rather than a single diagnostic category, which several researchers have argued is a more appropriate grouping for community and primary care settings (23, 25, 26, 121, 122). It was

also deliberately more liberal in terms of its definition of CMD symptoms, since it is generally accepted that CMD symptoms are better conceptualised as a spectrum rather than a dichotomy between those who meet diagnostic criteria and those who do not (24). Since conducting full diagnostic interviews in large population studies is often not feasible, it was hoped that this broader definition would lead to the inclusion of studies from a wider range of settings.

Other related reviews have been restricted to young adults (189) or to one country only (190). While the results reported here are broadly consistent with the findings of these reviews, this study extends previous research by (a) comparing results across settings; (b) including only population-based studies to ensure the generalisability of findings; (c) examining a set of symptoms that typically present together in community settings, making the results a stronger basis for informing interventions at the population level; and (d) separating service utilisation by adults from that of children or adolescents, since in many countries services are delivered separately for these two groups, and decisions regarding treatment-seeking may follow different paths for minors (defined here as those aged under 18).

However, the current review nonetheless has several limitations that must be acknowledged. One is that it was not possible to assess the power of each study to detect an association, meaning that in studies where no association was found with a given factor, this cannot be interpreted with confidence to indicate a lack of association rather than a lack of statistical power. Secondly, it is possible that some studies in which this was not the primary research question may have been erroneously excluded if associations with treatment-seeking were not reported in the title or abstract of the paper. This is more likely to be the case when no associations are found, leading to potential selection bias. For reasons of feasibility, the search was restricted to studies published in English.

We were not able to present data on the amount of variance explained by the factors included in the studies reviewed, since this was not reported in the majority of these studies. Nor was it possible to discuss the confounding factors controlled for in every analysis, due to the large number of studies included. To definitively assess the causal effect of any one factor on treatment-seeking for CMD a meta-analysis of that specific

association would be recommended; this was not the purpose of the current review, which set out to summarise associations, not to make causal claims.

The inclusion of multiple measures of CMD symptoms also means that these will not be exactly comparable across studies. Furthermore, when the quality of studies was assessed, we considered the measure of CMD used and the measure of treatment-seeking from the formal health sector; however, due to the number of factors investigated it was not possible to assess the appropriateness of measures used for each of these factors. Finally, as mentioned in the methods section, although the consistency of evidence for each factor was graded according to pre-defined criteria, other ways of operationalising levels of evidence are possible, which could lead to more or less conservative conclusions. Full details of all studies and the criteria applied are presented in the appendices.

### 2.5.3 Comparison with previous literature

Our findings are consistent with previous research pointing to need factors as the strongest determinants of health service utilisation for mental disorders (191-194). This is also consistent with the finding from the World Mental Health Surveys (WMHS) – which included both LMICs and HICs and measured substance use disorders and bipolar disorder as well as CMD – that low perceived need was the most common reason cited for not seeking treatment (56).

The same associations with female gender, middle age, higher levels of education, and being unmarried were found in the WMHS (110).

The fact that the evidence included in the current study did not support an association with economic factors was surprising, given the evidence that socio-economic factors affect the type of provider contacted (154, 159, 168), the quality of care received (154), adherence (195-199) and response to treatment (200, 201). However, a recent analysis of WMHS data by Evans-Lacko et al. (2017) found that differences in treatment rates in the WMHS by socio-economic status were predominantly accounted for by education rather than income (202).

Thus our findings on treatment-seeking for CMD are largely in keeping with the largest international study of mental disorders and service utilisation to date. The WMHS did not investigate rural/urban residence, or any of the other factors included in the Andersen model besides those listed above.

#### 2.5.4 Implications

Need factors, reflecting the extent to which CMD symptoms interfere with people's lives and whether outside help is needed, appear to be central to explaining treatment-seeking behaviour. This suggests that many of those who do not seek care from formal health services for their CMD symptoms fail to do so not because of limited supply, but because of lack of demand for services.

Whether meeting criteria for a disorder is a good indication of a "need for health services" is an ongoing debate in the context of mental health care (203). The limited demand for interventions for CMD, compared to the number of people who meet criteria for CMD, can be conceptualised as a lack of education or awareness about mental health issues, indicating a need for information, education and communication campaigns. On the other hand, it may be an indication that current diagnostic categories are overly broad, and include a large number of people who do not require formal medical care. Patel (2014) has argued that current prevalence estimates should not be regarded as the number of individuals in need of care, since a large proportion of these individuals do not require formal interventions through the health system (122). Measures of functioning or quality of life may represent better indicators of "need for care" than meeting diagnostic criteria (it is notable that the latter concept was not investigated by any of the studies included here).

Patel's argument that increasing the supply of mental health services will not alone make a substantial impact on the treatment gap for mental disorders is supported by the current findings that; (a) lack of perceived need is a major determinant of failure to seek help from health services, and (b) that enabling factors do not appear to be a major determinant of treatment-seeking (discussed below). Many individuals with less disabling symptoms are likely to view informal support – such as social interventions in the community, or advice on self-care, listed at the bottom of the World Health Organization (WHO) Service Organization Pyramid (204) – as more appropriate for their needs. As such, encouraging

these individuals to seek care through the health system may not be the best use of resources.

The lack of evidence for an association between enabling factors and health service utilisation, even in settings with weak public health systems, such as South Africa, and without universal health coverage, like the USA, was surprising. Of course, absence of evidence is not proof of a lack of association, especially given that the studies included here were not explicitly powered to detect this relationship. There is also the potential for information bias, given the sensitivity of financial topics, since most studies used self-reported data.

However, the hypothesis that economic factors do not play a major role in determining whether people with CMD initially seek care from health services is backed up by findings from Evans-Lacko et al. (2017) (202), as well as Andrews et al. (2001), who found no association at the ecological level with health spending or out-of-pocket costs (202, 205). Furthermore, Andrade et al. (2014) found that attitudinal barriers (most commonly, wanting to handle the problem alone) were reported much more often than structural barriers (which are linked to enabling factors), with the exception of severe cases. It is possible that the inclusion in this review of individuals with milder conditions, for whom low perceived need primarily inhibits treatment-seeking, might be obscuring the real impact of enabling factors such as cost and travel distance on the sub-group with severe CMD, who are most in need of care. Future research could usefully examine the extent to which supply side factors such as the availability, affordability and accessibility of care affect service utilisation by those with the most severe needs.

If equitable access to health care is defined as equal utilisation by those with equal need for care (206), then there is some evidence pointing to the need to target underserved groups such as men, ethnic minority groups, the elderly and young adults, at least in HIC. However, the extent to which need factors such as symptom severity and disability were controlled in these analyses varied between studies, so we cannot definitively rule out the possibility that these differences can be explained by variability in need for treatment.

Attempts to address these inequities have been made in HIC through strategies such as enhancing cultural competence in mental health services (207) and targeting underserved

groups through social marketing (208), with some success (209, 210). Evaluations of these interventions typically measure adherence/attrition, patient satisfaction or attitudes towards seeking care rather than treatment-seeking behaviour, so their effectiveness in reducing mental health care inequities is still to be determined.

Regarding geographic location, some studies indicate that this may affect the type of provider chosen and the quality of care received (145, 211). It is possible that the initial decision of whether or not to seek treatment is made independently of location of residence, but the subsequent decision of where to seek treatment, and the health system's response, is influenced by geography. This warrants further investigation (see "Unanswered questions and future research", below).

Finally, although it was not the topic of this review, there was some evidence to suggest that the factors associated with health service utilisation for CMD may vary between the specialist and generalist sectors (155, 168, 178), which has been highlighted in other studies (191, 202). This warrants further investigation as it has important implications for service planning. Thornicroft and Tansella (2013) advocate a stepped care model of mental health services, with the majority of services delivered through primary care in low-resource settings (212). However, it remains to be investigated which balance leads to the most equitable use of services for CMD, and whether some groups are more likely to seek treatment through primary care in LMIC.

#### 2.5.5 Unanswered questions and future research

This review identified three major gaps in our knowledge: Firstly, a lack of research from LMIC; secondly, a dearth of research on contextual factors, particularly health systems factors; and thirdly, an absence of studies that are explicitly powered to test associations between the factor of interest and treatment-seeking for CMD.

The first of these gaps directly relates to the second objective of this review. Although we have drawn some tentative conclusions above, the generalisability of these findings to LMIC is questionable at best, since nearly 90% of the studies identified were from high-income countries. In contrast, 85% of the world's population is expected to live in LMIC by 2030 (213), making this an extremely important omission.



Not only was there a noticeable lack of population-based studies from LMIC, but those studies that were identified were less consistent in their findings than those from HICs. This may be in part due to the reduced statistical power of studies from areas where treatment rates are low, meaning that larger sample sizes are needed to detect an association. More research is urgently needed in LMIC – especially in those countries for which no population-based studies were identified – to determine whether the same factors are associated with treatment-seeking for CMD in non-Western settings, using large enough samples to detect an association.

Secondly, there was also a notable lack of published evidence on several contextual factors, in particular health systems factors that are likely to affect treatment-seeking. This includes the availability of services, the geographical accessibility of those services, and characteristics of services such as opening times, which are central to several models of access to health care (27, 28, 214). This is a crucial gap, as such evidence could usefully inform service planning to expand access to care.

The extent to which distance affects treatment-seeking has particular relevance to debates around decentralisation and integration of mental health care (51). Facility-based studies have pointed to distance and travel time as a potentially important determinant of health service utilisation (49, 215-218), which contrasts with the lack of evidence supporting an association with urban/rural residence found in this review. However, these studies cannot disentangle geographic differences in prevalence from differences in treatment seeking behaviour. Furthermore, unless they assess the use of *all* health facilities in a given area – both public and private – it is not clear if distance affects whether affected individuals seek any care, or if it merely influences the choice of provider among those who do decide to seek treatment. This review showed that there is a lack of population-based data on the influence of geographic accessibility on the uptake of health services for CMD, with the exception of crude comparisons of rural and urban areas, for which no association was found with treatment-seeking.

Finally, none of the studies included here justified their sample size with regard to the relationship between treatment-seeking and the factors investigated. It is therefore possible that the lack of associations identified in some of the studies included here are the

result of under-powered studies, rather than a genuine lack of association. To build the evidence base in this area and confirm the hypotheses generated by the current review, future studies should ensure that they have sufficient statistical power to detect an association with the factors investigated.

## **2.6 Conclusion**

This review found that the set of factors most consistently associated with formal health service utilisation for CMD among the adult population were need factors, with inconsistent evidence of an association with predisposing factors – specifically demographic factors – and little evidence to support an association with enabling factors. Health system factors, such as the availability and accessibility of services, are under-researched in population-based studies. Research in low and middle-income countries is urgently needed to enhance our understanding of treatment-seeking for CMD in order to inform efforts to expand access to effective interventions and increase health service utilisation for CMD by those with greatest need for care.

## RESEARCH PAPER COVER SHEET

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***PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.***

### SECTION A – Student Details

<b>Student</b>	Tessa Roberts
<b>Principal Supervisor</b>	Sujit Rathod
<b>Thesis Title</b>	Mapping the Treatment Gap: A mixed methods exploration of barriers to treatment-seeking for depression in rural India

***If the Research Paper has previously been published please complete Section B, if not please move to Section C***

### **SECTION B – Paper already published**

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

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**SECTION C – Prepared for publication, but not yet published**

Where is the work intended to be published?	Social Psychiatry and Psychiatric Epidemiology
Please list the paper's authors in the intended authorship order:	Tessa Roberts, Shino Shiode, Chris Grundy, Vikram Patel, Rahul Shidhaye, Sujit D Rathod
Stage of publication	<b>Not yet submitted</b>

**SECTION D – Multi-authored work**

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I was the lead author, and was responsible for the study design, linkage of PRIME data with publicly available geographic data, data analysis, and the writing of the manuscript. RS, SS, and VP advised on the design of the study and the presentation of the results, and offered feedback on the draft manuscript. CG advised on the geographic component of the analysis, including identifying and extracting road network data. As final author, SR provided guidance throughout the process of study design, analysis, and writing, and also gave detailed comments and feedback on earlier drafts.
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**Student Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Supervisor Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

### **3. Distance to health services and treatment-seeking for depressive symptoms in rural India: a repeated cross-sectional study**

#### **3.1 Abstract**

##### **Purpose**

Research from high-income countries has implicated travel distance to mental health services as an important factor influencing treatment-seeking for mental disorders. This study aimed to test the extent to which travel distance to the nearest depression treatment provider is associated with treatment-seeking for depression in rural India.

##### **Methods**

We used data from a population-based survey of adults with probable depression (n=568), and calculated travel distance from households to the nearest public depression treatment provider with network analysis using GIS. We tested the association between travel distance to the nearest public depression treatment provider and 12 month self-reported use of services for depression.

##### **Results**

We found no association between travel distance and the probability of seeking treatment for depression (OR 1.00, 95% CI 0.98-1.02, p=0.78). Those living in the immediate vicinity of public depression treatment providers were just as unlikely to seek treatment as those living 20km or more away by road. There was evidence of interaction effects by age, caste, exposure to mental health communications, and employment status, but these effect sizes were generally small.

##### **Conclusion**

Geographic accessibility – as measured by travel distance – is not the primary barrier to seeking treatment for depression in rural India. Reducing travel distance to public mental health services will not of itself reduce the depression treatment gap for depression, at least in this setting, and decisions about the best platform to deliver mental health services should not be made on this basis.

## **3.2 Background**

### 3.2.1 Depression treatment gap

According to the World Health Organization (WHO), depression affects over 300 million people globally (12), or 4.4% of the world's population, but less than half of those affected receive treatment (4). Depressive disorders are closely linked with social and economic disadvantage (13), cause significant disability (14), and increase the risk of premature mortality (17, 219-223) including suicide (17, 19).

India currently has one of the highest suicide rates in the world (224). 1 in 20 people meets criteria for depression (69), which accounts for 5% of the total burden of disease (68). However, fewer than 15% of people with depression in India report seeking treatment (69). This “treatment gap” is likely to be unevenly distributed across the country; while 66% of India's population lives in rural areas (74), 75% of India's psychiatrists work in urban areas (225).

### 3.2.2 Access to care and geographic accessibility

To understand the treatment gap, De Silva and colleagues (29) proposed a framework of access to mental health care, based on the work of Tanahashi et al. (30). This framework postulates that, to be used by the target population, services must to be: (a) available; (b) accessible; and (c) acceptable.

The geographic accessibility of services also features in the models of access to health care put forward by Penchansky and Thomas, Peters et al., and Aday and Andersen (27, 28, 40), and can be manipulated through service planning strategies such as decentralisation. The phenomenon that treatment-seeking declines with distance from mental health services has been named “Jarvis’ Law” (226).

### 3.2.3 Gaps in the literature

A recent systematic review (227) identified a lack of evidence from low- and middle-income countries (LMIC) on factors that influence treatment-seeking for common mental disorders (CMD), including depression and anxiety. It also highlighted a dearth of population-based studies of the impact of geographic accessibility on treatment-seeking for CMD.

One study from Zambia replicated findings from high-income countries that rates of treatment-seeking for mental disorders decline with distance from facilities (228), while another from South Africa found that the prevalence of depression increased with distance from health services, which the authors attributed to reduced mental health service use (229).

Within India, greater distance to facilities is known to reduce treatment-seeking for general and maternal health care needs, particularly affecting disadvantaged groups such as scheduled tribes and women (87-92), but to our knowledge, no studies have tested this association for mental disorders in an Indian context.

### 3.2.4 PRIME

Through the Programme to Improve Mental Health Care (PRIME) (64), a mental health care plan (MHCP) was developed and implemented in 2014 in Sehore sub-district, in partnership with the Ministry of Health for Madhya Pradesh (65). The MHCP aims to increase contact coverage (defined as the proportion of those with a given disorder who seek treatment) for priority mental disorders, including depression, by integrating mental health care into community health centres (CHCs). This study is nested within the PRIME programme in Sehore sub-district.

We hypothesised that greater proximity to depression services would be associated with increased likelihood of seeking treatment for depression.

### 3.2.5 Objectives

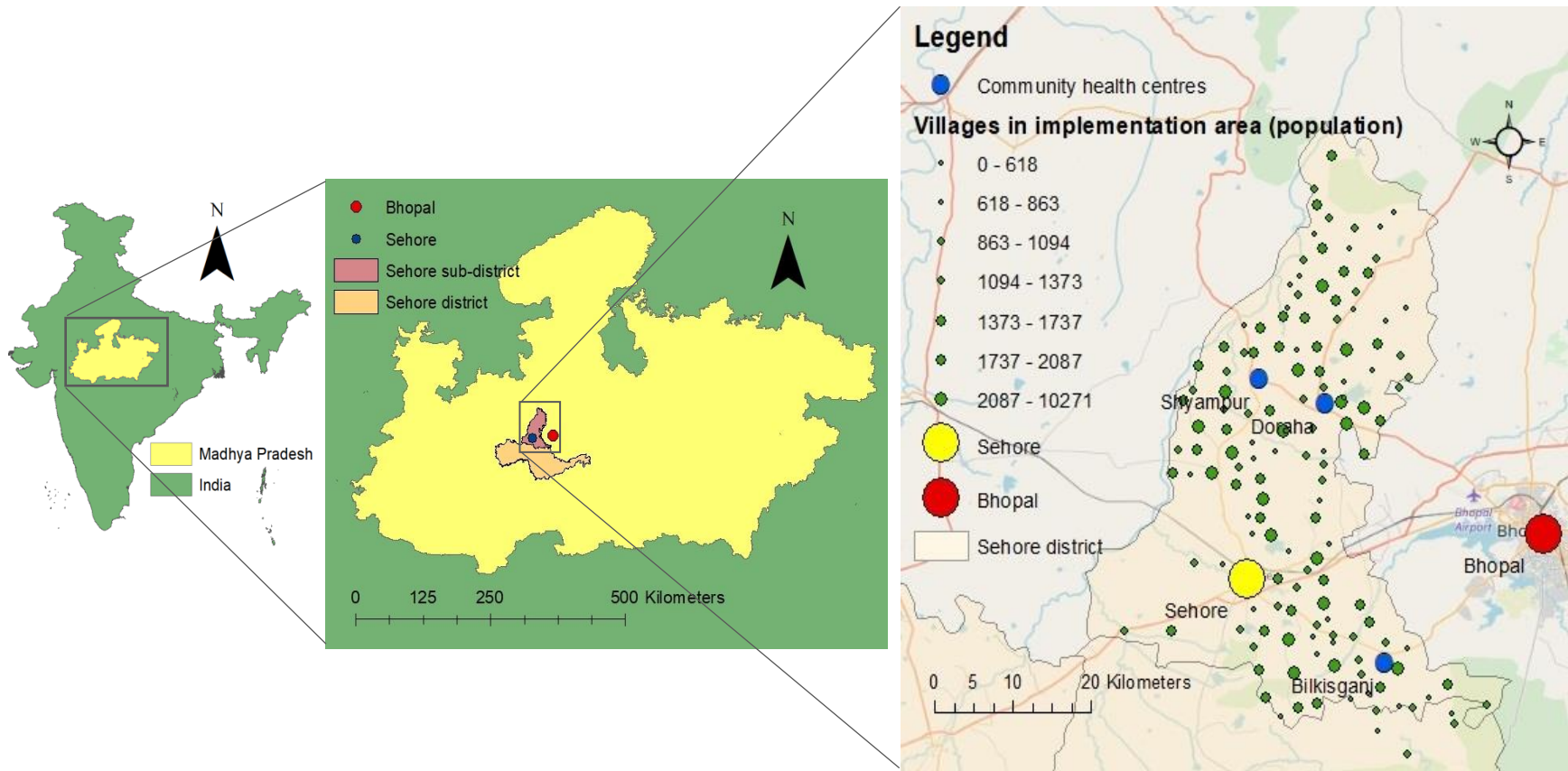
This study aims to:

- (1) Compare travel distance by road from the households of individuals with depression to the nearest public depression treatment provider, before and after implementation of the MHCP.
- (2) Measure the association between travel distance to the nearest public depression treatment provider and the probability of treatment-seeking for probable depression in rural India.
- (3) Assess whether this association varies by gender, caste, age, symptom severity, disability, socio-economic status (as measured by housing type, employment status, and education level), perceived need for healthcare and exposure to mental health communications.

## **3.3 Methods**

### 3.3.1 Setting





**Figure 1.** Location of Sehore sub-district and villages in the Mental Health Care Plan (MHCP) implementation area

The sub-district of Sehore, in Sehore district, Madhya Pradesh (see figure 1) is 74% rural, with a population of 427,432, and covers an area equivalent to greater London (84). According to 2011 census data, fewer than 4% of the population own a car, 34% own scooters/motorcycles, and 50% own bicycles (84), with lower proportions among rural residents. A 2011 situational analysis reported that there were two mental health specialist providers in the public sector, serving a district population of 1.3 million (230).

The study area (86), MHCP (65), and evaluation plan (52) have been described in detail elsewhere. Under the MHCP, psychological interventions for depression were delivered by case managers and pharmacological treatments prescribed for severe cases by medical officers at CHCs. Some community awareness activities were conducted to encourage service uptake, such as community meetings and film screenings in villages. Case managers also conducted proactive case finding in the community and screened patients in CHCs. The term “implementation area” refers to those villages where MHCP activities were fully implemented (see figure 1).

### 3.3.2 Data collection

As part of the PRIME evaluation plan, we carried out a population-based community study with two survey rounds, with the primary aim of measuring change in contact coverage for depression and alcohol use disorders before and after implementation of the MHCP. The data collection methods and sampling strategy have been described in detail elsewhere (52, 55). Data collection for the first round took place prior to MHCP implementation, in two waves (May-June 2013 and January-March 2014), and the second round after MHCP implementation (October-December 2016). The target population was adults (aged 18 and above). Additional inclusion criteria were fluency in spoken Hindi, residency in the selected household, willingness to provide informed consent, and absence of cognitive impairments that would preclude informed consent or ability to participate.

This secondary analysis of the survey data considered adults with probable depression who reside within the MHCP implementation area. Across both rounds, 6201 adults were recruited and 6134 (98.9%) consented to participate. Of these, 4,297 resided within the implementation area and 568 of these had probable depression (289 in round 1, 279 in round 2).

Questionnaires were administered orally, in Hindi, by trained local fieldworkers. Fieldworkers recorded participant responses using a questionnaire application programmed on Android tablet devices, which also recorded the interview location's GPS coordinates.

### 3.3.3 Measures

The screening tools, socio-demographic questions and measure of treatment-seeking (used to calculate contact coverage) have been described in detail elsewhere (55). In brief, we measured current depression symptoms using the Patient Health Questionnaire, 9-item version (PHQ-9), using the standard cut-off point of  $\geq 10$  to screen positive (231). In an international meta-analysis, the PHQ-9 was found to have a pooled sensitivity of 0.77 (95% CI 0.66–0.85) and specificity of 0.85 (95% CI 0.79–0.90) to detect major depressive disorder when applying this criterion (232).

The main outcome variable of interest was treatment-seeking by adults with probable depression, which we measured by asking: "Did you seek any treatment for these problems at any time in the past 12 months?" Participants who responded affirmatively were asked to specify from whom they had sought treatment. These were divided into formal providers – including generalist and specialist health workers, in the public or private sector – and complementary providers, comprising traditional and alternative healers. The new cadre of health workers (case managers), who were available in round 2 only, were included in the category of formal providers. In round 2 we also asked in which town or village the visit took place.

Additionally, we collected data on socio-demographic characteristics, disability (using the 12-item WHO-DAS 2.0, complex scoring method (233)), stigma (using the Internalized Stigma of Mental Illness (ISMI) measure, aggregated with a simple sum scoring method (234)), perceived need for health care (binary), and exposure to any mental health communications in the past 12 months (binary) (see (55) for more detail).

#### *Geographic measures*

Household coordinates were missing for 62.8% of round 1 data and 17.6% of round 2 data. In these cases, we substituted coordinates for the village centre, downloaded from India Place Finder (235). These are based on geographic information from the 2001 Census of

India, which we cross-referenced with mean GPS coordinates for households in the village. For households with GPS coordinates, the mean difference between the households and their respective village centres was 935 metres (SD = 746m).

The primary distance measure used was the shortest distance by road to the nearest public depression treatment provider (referred to here as “travel distance”), calculated using network analysis tools in ArcGIS 10.5 (236). This has been recommended as the most accurate measure of geographic accessibility in contexts where most travel is vehicular (237), as in 77.8% of recent health care visits reported by sample participants. We defined the nearest public depression treatment provider as the nearest of: Sehore city or Bhopal city only (in rounds 1 and 2), plus any of the three CHCs (in round 2). We used Open Street Maps (238) road network data to calculate travel distance to the nearest facility, after cleaning the network data to ensure connectivity. Since many households were located some distance from the nearest road in the network, we added straight line distances to the nearest road to create an estimate of total travel distance.

#### 3.3.4 Analysis strategy

We first described the socio-demographic characteristics of the sub-sample, stratified by travel distance (0<5km, 5<10km, 10<20km, ≥20km).

We then compared the median travel distance from probable cases to a public depression treatment provider by round using the Mann-Whitney test.

Next we sought to estimate the change in odds for treatment-seeking for depression associated with travel distance (in kilometres) to the nearest public depression treatment provider. We considered the following covariates as potential confounders in a logistic regression model, based on previous literature and knowledge of the local context; age, education level, gender, marital status, economic status (using housing type and employment status as proxy measures), symptom severity, disability, perceived need for health care, survey round, and 12-month exposure to mental health communications. We excluded covariates from the final model after checking for collinearity with variance inflation factors and a correlation matrix of all variables.

All regression analyses were repeated using two alternative outcome definitions – (a) any depression treatment, and (b) treatment from the formal health sector only – to check whether the inclusion of complementary providers altered any association found.

Next we used the final regression model to test for interactions by the following characteristics. Gender and caste were chosen based on previous literature from India on general health service use, suggesting that distance disproportionately affects women and disadvantaged castes, and we therefore hypothesised that the effect size would be larger in these groups. Current PHQ-9 scores were of interest due to the international literature on mental health service use, which suggests that distance is more likely to deter those with milder symptoms. We therefore hypothesised that the effect size would be smaller for those with more severe symptoms. Education, employment, land ownership and housing type were included as proxy measures for socio-economic status (SES), since we expected that distance would be a greater barrier to treatment-seeking for lower SES groups than for higher SES groups, and as such we hypothesised that the effect size would be larger in those with less education, those with lower incomes or no employment, no land, and poorer housing. Finally, perceived need for health care was included because some models of health service utilisation imply that enabling factors such as distance affect health service use only in the context of perceived need for health care. Stratum-specific effects are presented when a Wald test for all interaction terms had  $p < 0.10$ .

With the exception of counts, all figures were adjusted for the multi-stage sampling design, accounting for village-level clustering and weighting the data to reflect the probability of selection. Stata 14.2 (239) was used to conduct all analyses.

### 3.3.5 Ethics

All participants were provided with an information sheet in Hindi, which was read aloud to them by fieldworkers if required. After any questions were answered, they indicated informed consent with either a signature or thumb print. The original study was reviewed by the institutional review boards of Sangath, Goa, India; the World Health Organization, Geneva, Switzerland; and the University of Cape Town, Cape Town, South Africa. Ethical approval for this secondary analysis of data from the PRIME programme was provided by London School of Hygiene & Tropical Medicine, London, UK (LSHTM Ethics Ref: 10439).

### 3.4 Results

#### 3.4.1 Sample characteristics, by distance

Table 1 shows the characteristics of all adults with probable depression, stratified by travel distance. 69.6% of participants living less than 5km from the nearest depression treatment provider were female, compared to 49.9% of those living more than 20km away ( $p=0.08$ ). As shown in the table, the following sample characteristics varied by travel distance to the nearest facility: employment status; land ownership; and religion.

**Table 1. Demographic and health-related characteristics of adults with probable depression by travel distance to the nearest public health facility offering depression services, Sehore sub-district, Madhya Pradesh, India, 2013-2016.**

	0-5km (n=59, 8.5%)	5-10km (n=121, 18.7%)	10-20km (n=150, 24.5%)	20km- 123km (n=238, 48.3%)	Total (n=568)	P-value
<i>Gender, %</i>						
Female	69.6	60.5	51.0	49.9	53.8	0.08
<i>Age groups (years), %</i>						
18-29	22.0	20.8	17.5	15.5	17.5	0.85
30-49	41.0	42.5	45.1	44.7	44.1	
50-90	37.1	36.7	37.4	39.9	38.4	
<i>Educational attainment, %</i>						
Less than primary	79.9	77.0	70.7	73.7	74.1	0.20
Primary	18.6	21.2	22.2	23.6	22.4	
Secondary or more	1.5	1.8	7.1	2.7	3.5	
<i>Employment status, %</i>						
Unemployed	0.0	2.0	5.1	5.4	4.2	<0.01
Productive non-income	60.3	52.9	33.0	31.8	38.5	
Low income	30.7	39.0	54.1	59.6	51.9	
High income	9.1	6.1	7.8	3.2	5.4	
<i>Religion, %</i>						
Hindu	70.3	92.4	97.2	93.3	92.1	<0.01
Muslim	29.7	7.6	2.8	6.7	7.9	
<i>Caste, %</i>						
Scheduled Caste	19.2	16.0	14.6	15.9	15.8	0.88
Scheduled Tribe	3.3	5.0	6.2	3.0	4.2	
Other Backwards Caste	64.8	69.0	68.9	73.8	71.0	
General	12.7	10.0	10.4	7.4	9.1	
<i>Marital status, %</i>						

Single	10.6	8.1	3.5	6.5	6.4	0.28
Married	69.3	84.5	87.8	79.6	81.7	
Widow(er)	18.6	7.4	7.4	12.1	10.6	
Separated/Divorced	1.5	0.0	1.2	1.8	1.3	
<i>Housing quality, %</i>						
Lowest level ( <i>kuccha</i> )	62.0	53.9	57.0	46.1	51.6	0.25
Mixed ( <i>semi-pucca</i> )	13.2	17.7	17.9	13.2	15.2	
Highest level ( <i>pucca</i> )	24.8	28.3	25.1	40.7	33.2	
<i>Owns land, %</i>						
Yes	15.2	22.1	30.6	37.2	30.9	0.02
<i>Depression symptom severity (total PHQ-9 score), %</i>						
Moderate (10-14)	95.4	80.8	75.4	75.0	77.9	0.27
Moderately severe (15-19)	4.6	19.2	20.3	23.1	20.1	
Severe ( $\geq 20$ )	0.0	0.0	4.3	1.9	2.0	
<i>Survey round</i>						
Round 1 (before MHCP implementation)	17.7	34.5	58.9	87.9	64.8	0.0001
Round 2 (after MHCP implementation)	82.3	65.5	41.1	12.1	35.2	

*P-values are calculated using Chi Squared. Counts are unadjusted for sampling design, percentages are adjusted for sampling design.*

*The productive non-income group consisted of students and housewives.*

#### 3.4.2 Objective 1: Travel distance by survey round

Implementation of the MHCP in CHCs in Sehore sub-district reduced the median travel distance for probable cases to a public depression treatment provider from 26.9km in round 1 (25<sup>th</sup> and 75<sup>th</sup> percentiles: 16.0km, 36.2km; skewness 2.40) to 9.7km in the second round (25<sup>th</sup> and 75<sup>th</sup> percentiles: 6.5km, 16.8km; skewness 4.29), (Mann-Whitney  $p < 0.0001$ ).

#### 3.4.3 Objective 2: Travel distance and treatment-seeking for depressive symptoms

As reported by Shidhaye and colleagues (96), of the 568 people with probable depression in both rounds, 75 (13.9%) sought treatment for these symptoms.

As seen in table 2, there was no evidence of an association between the odds of treatment-seeking and the distance to a public depression treatment provider, either in unadjusted or adjusted models, with any provider or only formal providers.

**Table 2. Travel distance to nearest public depression treatment provider and odds of seeking treatment for adults with probable depression (n=568) in Sehore sub-district, Madhya Pradesh, India, 2013-2017.**

	<b>Unadjusted OR (95% CI)</b>	<b>P</b>	<b>Adjusted OR (95% CI)</b>	<b>P</b>
Use of any services for depression	1.01 (1.00-1.01)	0.16	1.00 (0.98-1.02)	0.78
<i>Use of formal services for depression</i>	1.00 (0.99-1.01)	0.73	0.99 (0.97-1.02)	0.69

*Odds ratios, 95% CIs and P-values calculated using logistic regression.*

*Formal services include specialist doctors, generalist doctors, other mental health professionals (psychologists, counsellors, mental health nurses), other generalist health workers (social workers, community health workers, nurses, ANMs, ASHAs, AWWs), case managers. Excludes ojha/guni/dev maharaj, traditional healers, herbalists, spiritualists, or other providers.*

*Adjusted models include the following covariates: education level, marital status, symptom severity, gender, land ownership, employment, round, exposure to mental health communications, age group.*

#### 3.4.4 Objective 3: Treatment-seeking and travel distance among sub-groups

Table 3 shows the association between travel distance and treatment-seeking by sub-group (only those factors for which Wald P-values for interaction terms < 0.10; see full table in appendix E). There was evidence of interaction effects with caste, employment status, and perceived need for health care, but no evidence of any interaction (Wald P-values for interaction terms > 0.10) for the relationship between distance and treatment-seeking by the following sub-groups; gender, education level, housing type, land ownership or symptom severity.

The effect sizes by caste and perceived need for health care were small and in the opposite direction from expected; e.g. for every 1km increase in travel distance to the nearest treatment provider, individuals from scheduled castes had 4% higher odds of seeking treatment. However, there was a more substantial effect of travel distance for the unemployed sub-group, with a 27% reduction in the odds of seeking treatment for every 1km increase in travel distance.



**Table 3. Sub-group analysis for distance to depression treatment provider and odds of treatment-seeking for adults with probable depression (n=568) in Sehore sub-district, Madhya Pradesh, India, 2013-2017.**

	Adjusted OR (95% CI)	Stratum-specific P-value	Wald P-value for interaction terms
<i>Caste</i>			0.02
Scheduled castes	1.04 (1.01-1.06)	<0.01	
Scheduled tribes	0.98 (0.90-1.06)	0.54	
Other backward castes	0.98 (0.96-1.01)	0.15	
General castes	1.00 (0.97-1.04)	0.87	
<i>Employment status</i>			0.03
Unemployed	0.73 (0.60-0.90)	<0.01	
Productive no income	1.00 (0.98-1.02)	0.95	
Low income	1.01 (0.99-1.02)	0.59	
High income	0.98 (0.91-1.05)	0.55	
<i>Perceived need for health care</i>			0.02
Health care needed	0.99 (0.97-1.01)	0.32	
Health care not needed	1.02 (1.00-1.03)	0.06	

*Odds ratios, P-values and confidence intervals were calculated with logistic regression. Besides the interaction term, each model was adjusted for education level, marital status, symptom severity, gender, land ownership, employment, round, exposure to mental health communications, and age group.*

### **3.5 Discussion**

#### 3.5.1 Principal findings

Travel distance to the nearest public depression treatment provider was significantly reduced after the implementation of the MHCP, but the proportion of people with probable depression who sought treatment remained low regardless of distance to services. To our knowledge, this is the first study from India to examine the association between travel distance and treatment-seeking for mental disorders. Almost all previous research on this topic has been conducted in high-income countries (HIC), so this study extends our knowledge by examining whether the same relationships are observed globally.

The lack of evidence for an association between travel distance and treatment-seeking was surprising, given the literature from HIC on “Jarvis’ law” in mental health care (215-217,

240-243). The narrow range of the confidence intervals indicates that this null finding is not due to lack of statistical power.

### 3.5.2 Implications

Both international and Indian mental health policies advocate the integration of mental health services into primary care (8, 9, 78), partly on the basis that this improves the geographic accessibility of services. For example, a 2008 WHO report states that “when mental health is integrated into primary care, people can access mental health services closer to their homes... for the vast majority of people, primary care is far more geographically accessible than specialized mental health services” (9). However, the current study found that those living in the immediate vicinity of public mental health services were equally as unlikely to seek care as those facing a journey of 20km or more.

One interpretation of this finding is that increasing the supply of services is insufficient to increase contact coverage in areas where demand for these services is very low, even for those with minimal geographic barriers to reaching services. Interventions to increase demand are therefore necessary. In contrast with PRIME, evaluations of the Vidarbha Stress and Health Program (VISHRAM), another depression treatment programme in central India, reported a six-fold increase in contact coverage from pre- to post-implementation (244). One of the major differences between the two programmes was the emphasis in VISHRAM on village-level interventions to increase demand for mental health services.

The current findings provide reason to re-examine the assumption that reducing travel distance will reduce the treatment gap for depression. Either geographic accessibility does not act a barrier to treatment-seeking in the case of depression in this setting, or travel distance is not a good measure of accessibility in this context. It is still possible, however, that travel distance affects adherence to treatment, as found by Fortney and colleagues in the USA (245).

### 3.5.3 Mechanisms and methodological differences

There are several potential explanations for the difference in findings compared to previous studies, explored below.

#### *Threshold effects*

Research from HIC has pointed to a “zone of indifference”, beyond which distance ceases to affect rates of mental health service use (215, 243). It is plausible that, in areas with high poverty rates and limited transport access, the majority of the population resides in the “zone of indifference”. However, we found no evidence of such threshold effects (11.3% of people with probable depression living in villages or towns where public depression treatment was available sought help, compared to 13.7% of those living elsewhere,  $p=0.40$ ).

#### *Population-based vs. facility-based samples*

Unlike most previous research on this topic, this study used a population-based sample rather than identifying cases through health services. Facility-based studies cannot disentangle geographic differences in prevalence from differences in treatment-seeking behaviour. Furthermore, unless they assess the use of every potential provider, it is not clear if distance affects whether affected individuals seek care, or merely the choice of provider.

A two-stage model of treatment-seeking could account for the difference in findings, in which the decision to seek help is distinct from the choice of provider, as proposed by Dear (246). In rural USA, Fortney and colleagues (141) found that the affordability and availability of services had a far greater impact on choice of provider than on the decision to seek treatment. The hypothesis that travel distance affects choice of provider but not overall treatment-seeking rates is consistent with the increase in depression consultations with generalist providers after services were integrated into CHCs, despite the lack of change in overall contact coverage (96). This model could be confirmed by examining distance decay effects from facility-based data in the same area.

#### *Disorder type*

Most previous studies on distance have included people with any psychiatric diagnosis. However, in those that have compared different disorders, the impact of distance in HIC seemed to be greater for those with common mental disorders, such as depression, than

for those with severe mental disorders such as psychosis (215) so the lack of an association remains surprising.

#### *Over-utilisation*

Using Australian data, Davey & Giles (1979) argued that distance decay effects may reflect over-utilisation of services by those in the vicinity of health services without a clinical need for care, rather than under-utilisation by those living further afield (217). Since the current analysis was restricted to people with probable depression, treatment-seeking by those without clinical need was largely excluded. In Canada, Joseph & Boeckh (1981) have also shown that distance decay primarily affects those with milder symptoms (247), so it is possible that distance decay effects are less relevant in settings where the subjective threshold for treatment-seeking is higher.

#### *Use of private health care*

Indian mental health policy focusses primarily on public health services (78), as the PRIME programme has done (65, 230), to reduce financial barriers to care. However, private practitioners are ubiquitous in the current setting, and are likely to represent the default source of health care used for many of the target population (248, 249)) which may be one reason why the location of public facilities is of little relevance to decisions around treatment-seeking. Greater attention to private providers may be warranted in future research.

#### 3.5.4 Sub-group differences

The results of the sub-group analyses should be viewed with caution, since the number of tests performed increases the likelihood of chance findings. With the exception of the unemployed group, the effect sizes found were extremely small, suggesting that travel distance is not a major determinant of treatment-seeking even in these groups. Unemployed adults may be more sensitive to travel as an obstacle to treatment-seeking than the rest of the population. However, this group represents only 4.2% of individuals with probable depression.

### 3.5.5 Strengths

A particular strength of the study is the use of a community-based sample, rather than including only those who came into contact with health services. The sample size compares favourably with international studies of treatment-seeking for depression (227) and to previous India-based studies of treatment-seeking for mental disorders (250-255). We chose network analysis using road networks as the most rigorous method of calculating travel distance (256-258), although Euclidean (straight line) distances were sufficiently strongly correlated to provide a reasonable proxy measure ( $R^2=0.77$ ,  $p<0.001$ ). We also conducted sensitivity analyses to check whether limiting the outcome to the use of formal health services only affected the results.

### 3.5.6 Limitations

The measure of geographic accessibility used was an estimate of travel distance, which may be considered a proxy for travel time. We lacked data on access to transportation to be able to convert distance estimates to travel time estimates, which may be of greater relevance to treatment-seeking decisions. It is therefore possible that travel distance is a poor indicator of geographic accessibility in this context, if journey times vary by season, mode of transport and road conditions. Future research could build on these findings by generating more nuanced estimates of travel time and cost for all potential users of mental health care to compare the predictive value of alternative measures of geographic accessibility.

The cross-sectional nature of the data means that some potential confounding factors or effect modifiers may have changed since the depressive episode in question; in particular symptom severity and perceived need for health care. It is possible that differential misclassification occurred if longer journeys led to greater recollection of treatment-seeking. Another limitation of the study is the use of self-reported outcome data, which can be subject to recall bias (259), although some HIC studies have found that this affects binary measures of contact coverage less than measures of volume or frequency of health care utilisation (260, 261).

### **3.6 Conclusion**

The current study identified no association between travel distance to the nearest public depression treatment provider and treatment-seeking for probable depression, except for the small sub-group of unemployed adults. Low geographic accessibility does not explain the overall low contact coverage, as rates of treatment-seeking are equally low for those living within a short distance of services. This contrasts with research from high-income countries where travel distance has been shown to be an important predictor of treatment-seeking. Decentralising mental services to reduce travel distance will not of itself reduce the treatment gap for depression, at least in rural India. Policymakers and service planners should therefore not base decisions about the best platform through which to deliver mental health services on these grounds. Future research should examine alternative measures of geographic accessibility and identify other factors that influence treatment-seeking for depression.

# RESEARCH PAPER COVER SHEET

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## **SECTION A – Student Details**

<b>Student</b>	Tessa Roberts
<b>Principal Supervisor</b>	Sujit Rathod
<b>Thesis Title</b>	Mapping the Treatment Gap: A mixed methods exploration of barriers to treatment-seeking for depression in rural India

***If the Research Paper has previously been published please complete Section B, if not please move to Section C***

## **SECTION B – Paper already published**

Where was the work published?			
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Where is the work intended to be published?	Health & Place
Please list the paper's authors in the intended authorship order:	Tessa Roberts, Shino Shiode, Vikram Patel, Rahul Shidhaye, Sujit D Rathod, Chris Grundy
Stage of publication	<b>Not yet submitted</b>

**SECTION D – Multi-authored work**

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I was the lead author, and was responsible for the study design, data analysis, and the writing of the manuscript. RS and VP advised on the design of the study and the presentation of the results, and offered feedback on the draft manuscript. As final author, SR provided guidance throughout the process of study design, analysis, and writing, and also gave detailed comments and feedback on earlier drafts.
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**Student Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Supervisor Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_



## 4. A comparison of methods for measuring distance to health services in rural India

### 4.1 Abstract

Geographic accessibility of health services is a potential barrier to health care utilisation and can be measured in multiple ways. We compared two measures in rural India, to determine if straight-line distance can be used as an adequate proxy for travel distance in this setting, and assessed the impact of using village centroids in place of household coordinates.

We used Geographic Information Systems to map geocoded data from a population-based community survey in one district of Madhya Pradesh, India. We calculated travel distance by road from households and village centroids to the nearest public health facility using network analysis and compared this with Euclidean (straight-line) distance, using Spearman's rank correlation coefficients, absolute differences, and the percentage of the same facilities identified as closest. We also used logistic regression to model the association of each measure with the use of health services for depression among adults with probable depression.

Network and Euclidean distance measures were strongly correlated with each other ( $r_s = 0.90$ ,  $p < 0.0001$ ), and identified the same facilities as closest in 86% of cases. Measures calculated from village centroids rather than household coordinates identified the same closest facility in 95% of cases using Euclidean methods and 96% using network methods, and the median difference in distance to services was 0.04km (IQR: -0.56–1.12km) using Euclidean methods and 1.38km (IQR: 0.17–3.17km) using network methods. Neither Euclidean nor network measures showed an association with the use of health services for depression, with similar 95% confidence intervals (0.99-1.04 versus 0.97-1.10).

Euclidean and network measures of distance to health services produced comparable results, demonstrating that Euclidean distance can be reasonably used as a proxy for geographic accessibility of services in settings where the terrain is flat and the distances of interest are large (median > 7.5km). Using village centroid coordinates has little impact for analyses of health service utilisation when village areas are small. The resources required to

obtain and use road network data and collect household-level coordinates need to be considered in light of the context and requirements of the study.

## **4.2 Background**

Geographic accessibility of health services is one of several dimensions of access to health care (27). Geographic accessibility refers to the relationship between the location of health services and the location of potential patients, and is measured in terms of the ease with which patients can travel to the site of care (258). This concept is posited as a barrier or facilitator of health service utilisation in most widely-used models of healthcare access (28, 30, 40).

Associations between geographic access to health services and rates of health care utilisation can be found across health domains (262, 263). In the context of mental health care, the World Health Organization recommends decentralising services and integrating mental health treatment into primary health facilities – rather than secondary or tertiary facilities – in order to improve the geographic accessibility of services by reducing the distance between the facilities where services are delivered and the target population (8, 9, 264).

Geographic access to health care can be operationalised in a variety of ways, and the measures used in low- and middle-income countries (LMIC) are often limited by data availability (265, 266). The simplest individual level measure is Euclidean distance, defined as the straight-line distance between two points; in this case a patient’s residence and the nearest health facility. When data are available, more sophisticated strategies include finding the distance along the shortest route in a road network (termed “network distance” in this report); estimating travel time based on distance, expected travel speed and factors such as public transport availability; and raster models that can incorporate elevation and type of terrain (237). (Raster models are based on grids in which every pixel is assigned a value, in contrast with the vector models used in the current report, which are defined by points that are connected by lines or paths in a network.) Such measures can be calculated using Geographic Information Systems (GIS) and require geocoded data including the locations of health care providers and locations of residence of the target community.

While calculating Euclidean distance is relatively simple and computationally feasible, more nuanced measures such as network distance require additional data, skills, and processing capacity (267). Therefore, an important question is whether Euclidean distances are a reasonable proxy measure for geographic access to health services as measured by more sophisticated approaches. If this is the case it would substantially reduce the time, data requirements, and level of training required to conduct geographic research on health care access, thus facilitating research on this topic in LMIC (257).

Furthermore, obtaining individual coordinates for residential addresses is both resource-intensive, and introduces potential ethical issues related to anonymity (268). Where household coordinates are unavailable or incomplete, aggregate measures can be substituted, based on the coordinates for the village centroid or census tract centroid, which can be easily obtained from maps or satellite data and do not compromise study participants' privacy. The magnitude of error introduced will depend on the size of the villages or census tracts, and must be interpreted relative to the distances between these and health services.

Several studies from high-income countries (HIC) have compared the accuracy of simple Euclidean measures with more sophisticated approaches, using both individual coordinates and aggregate measures such as census tract centroids (256, 258, 269-273). These studies show that distance measures that incorporate travel route tend to be significantly longer than Euclidean measures, especially in rural areas. Euclidean distances are therefore likely to overestimate the proportion of people with adequate geographic access to care when operationalised as living within a given travel distance of a facility. However, these studies also report high levels of correlation between alternative measures, suggesting that using Euclidean distances and local area centroid coordinates in place of household coordinates and more nuanced distance measures would have minimal effects on analyses of the association between distance to services and service uptake or health outcomes.

Few comparisons of geographic access measures have been conducted in LMIC (274-276). In a study from Kenya, negligible differences were found between network and Euclidean measures, although a more sophisticated model that incorporated competition between health facilities had greater accuracy in terms of predicting which health service participants would use (274). In Brazil, network distances were found to be significantly longer than Euclidean distances, but the correlation between the two measures was not

reported, nor was the proportion of facilities identified as closest (276). In Ethiopia, in a mountainous area in which most participants travelled on foot, Euclidean distance was not found to be an adequate proxy for actual travel distance to services (measured by following study participants' exact routes to services and measuring the distance travelled using GPS trackers) since the latter measure was strongly associated with child mortality while Euclidean distance was not (275). In contrast, in a relatively flat area of rural Ghana, the difference between alternative measures was found to be negligible for the purposes of analysing geographic access to health services (257), suggesting that the appropriate measure may depend on the topology of the research context. Comparisons of measures across a wider range of settings are needed to establish the conditions under which Euclidean distances and village or census tract centroid coordinates are appropriate.

To our knowledge this issue has not yet been investigated in south Asia, in order to inform geographic research on health service utilisation in this area. This study aimed to compare alternative measures of distance to establish whether Euclidean distance and village centroid coordinates can be used as proxy measures for travel distance measured using network analysis from individual households.

The objectives of this study are to:

- (1) Measure the inaccuracy in distance to health services in rural India introduced by using Euclidean measures as compared to network measures of distance, in terms of the absolute difference, relative difference, and correlation between the two measures, and the proportion of cases in which the same health facility was identified as closest;
- (2) Measure the error associated with measuring distance to health services from village centroids as compared to individually geocoded household locations, using both Euclidean and network measures, in rural India;
- (3) Estimate and compare the association between distance to health services and health service utilisation for depression (i.e. whether or not adults with depression used health services for these symptoms in the past 12 months, as a binary outcome variable), using survey data from rural India, when using Euclidean versus network measures.

### **4.3 Methods**

#### 4.3.1 Setting

The sub-district of Sehore, in Sehore district, Madhya Pradesh is 74% rural, covers an area of approximately 1625 km<sup>2</sup> (83), and has a population of 427,432, who are served by 3 community health centres and one district hospital (230). According to 2011 census data, fewer than 4% of the sub-district population own a car, 34% own scooters/motorcycles, and 50% own bicycles (84). However, data collected as part of the current survey (described below) indicated that 62.6% of those who had used health services in the past 3 months had travelled by private vehicle.

Data on road types was not available at the sub-district level, but across the full district of Sehore, 34% of roads (in terms of total distance covered) are national, state or district highways, 15.5% are rural roads, and 50.5% are “kuccha” roads (unpaved dirt tracks) (277). The difference in elevation between the highest and lowest points of the district is approximately 150 metres.

A mental health care plan was implemented in this area between 2014 and 2016, in which treatment for priority disorders was integrated into primary care (64, 65). The programme implementation area has been described in detail elsewhere (86). No data was available on the current state of roads in the district.

#### 4.3.2 Study procedures

A population-based community survey with two rounds was carried out as part of the evaluation of the mental health care plan, with the primary aim of estimating contact coverage for depression and alcohol use disorders (i.e. the proportion of adults with these disorders who sought treatment) (52, 55). The target population was adult (aged 18 and above) residents of Sehore sub-district. The data collection methods and sampling strategy have been described in detail elsewhere (52, 55, 95). In brief, villages were selected at random from 2011 census data and participants were recruited from electoral registers within these villages through systematic random sampling.

A research assistant orally administered a structured questionnaire to participants using a tablet device. Data collection took place in May 2013-March 2014 (n=3,220), and October-

December 2016 (n=2,968). The current analyses are restricted to the 4,297 individuals who resided within the final implementation area.

#### 4.3.3 Data collection

Structured interviews were conducted in Hindi by trained research workers, which asked about depression symptoms and health care use, and collected GPS coordinates.

Depression was measured using the Patient Health Questionnaire, 9-item version (PHQ-9) (278), using the standard cut-off point of  $\geq 10$  to screen positive (232). Probable depression was defined as screening positive on the PHQ-9. Treatment-seeking for depression was measured by asking: "Did you seek any treatment for these problems at any time in the past 12 months?"

Household coordinates were collected on the Android tablet device used for questionnaire administration using Mobenzi software (94) and were available for 2,891 participants (67.3%); 528 from round 1 (18.3%) and 2,363 from round 2 (81.7%).

GPS coordinates for village centroids were downloaded from India Place Finder (235), which uses geographic information from the 2001 Census of India. Village centroid coordinates were available for all participants. We cross-referenced these against coordinates for households in the same village from our sample, and in the few cases where these were clearly inaccurate we replaced these based on the mean latitude and longitude for households within this village from our sample.

GPS coordinates for nearest government health facility were extracted from maps of the area. We defined the nearest public health service as the nearest Community Health Centre or District Hospital, which is the most accessible level of the government health system at which general health services are offered (279).

We collected road network data from Open Street Maps (238), after cleaning these data to create a fully connected network for analysis of shortest-path routes.

#### 4.3.4 Distance Measures

We calculated Euclidean distances from participants' households, when household coordinates were available, to the nearest public health facility using the Near tools in ArcGIS software, version 10.5 (236).

Network distance from participants to their nearest health centre was calculated using the network analyst tools in ArcGIS software. The network distance was operationalised as the shortest distance from participants' place of residence to the nearest public health facility along roads compiled from Open Street Maps. We included a straight line distance from the household to the nearest road.

We also calculated Euclidean and network distances from participants' respective village centroids, for comparison, using the same approach as above.

#### 4.3.5 Analyses

In order to measure the extent to which using Euclidean measures leads to inaccuracy as compared to network measures of distance to health services (aim 1), we first report the median distance and inter-quartile range from all households with GPS coordinates to their nearest public health service, using Euclidean and network distance measures, and compare the difference between the two measures using a Wilcoxon signed-ranks test. Non-parametric methods were chosen due to the skewed distribution of the data. We then report the correlation between Euclidean and network distances using Spearman's rank correlation coefficients, which provides a non-parametric measure of rank correlation ( $r_s=0$  indicates no correlation, whereas  $r_s=1$  indicates a perfect monotonic relationship in which observations are ranked identically according to both measures, from highest to lowest geographic access). We also used ArcGIS to identify the closest public health facility to each household using Euclidean versus network distance measures, and report the percentage agreement in facilities identified as closest.

To measure the error introduced by substituting village centroid coordinates for household coordinates (aim 2), we first calculated the mean difference (measured in metres of Euclidean distance) between village and household coordinates, for all households with GPS coordinates. We then tested whether the same facilities were identified as closest when using village and household coordinates, using each distance measure, and finally compared total distance to the nearest health service (first using Euclidean methods, then using network methods) when using village versus household coordinates, using medians and Spearman's rank correlation coefficients.

Finally, we estimated and compared the association between distance to public health services and health service utilisation for depression, among adults with probable

depression, using Euclidean and network distance measures (aim 3). To do so we calculated the odds ratio of the association between distance (in kilometres) to the nearest public health facility and self-reported treatment-seeking for depression, using logistic regression, using Euclidean and network measures of distance, and compared the effect size and confidence intervals. We repeated this using both household coordinates and village coordinates (restricting the analysis to those with household GPS coordinates, for comparability, n=338). The complex sampling design was adjusted for in these analyses using the survey commands in Stata.

Stata/IC 15.1 (239) and ArcGIS 10.5 (236) were used to conduct the analyses.

#### 4.3.6 Ethics

Ethical approval for the original survey was granted by the World Health Organization Research Ethics Review Committee and the Sangath Institutional Review Board in India. Ethical approval for this secondary analysis of data was granted by the London School of Hygiene & Tropical Medicine (10439).

## **4.4 Results**

46.1% of the sample were female while 53.9% were male. The mean age was 40.3 years. The sample characteristics are described in detail elsewhere (55, 95, 96).

### 4.4.1 Objective 1: Comparison of network versus Euclidean distance measures

The median Euclidean distance was 7.5km (inter-quartile range: 4.5-11.1km) while the median network distance was 8.2km (IQR: 4.0-15.2km). The Wilcoxon signed-ranks test indicated that network distances were significantly longer than Euclidean distances ( $Z=-25.10$ ,  $p<0.0001$ ).

We assessed the correlation between the two measures, comparing those with GPS coordinates only. Spearman rank results show that Network distance and Euclidean distance were strongly correlated, and that the same households were generally ranked as having higher or lower geographic access regardless of the measure used ( $r_s=0.90$ ,  $p<0.0001$ ).



When comparing Euclidean and network distances, the same facility was identified as closest for 86% of participants.

#### 4.4.2 Objective 2: Use of village coordinates versus household coordinates

For households with GPS coordinates, the mean Euclidean difference between household coordinates and their respective village centres was 935 metres (SD 746m).

When we substituted village coordinates for household coordinates, the same facility was identified as closest in 95% of cases when using Euclidean methods, and 96% cases when using the network approach. The correlation between the two Euclidean and network distances (using village versus household coordinates) and the median difference between the total distance to the nearest public health facility is shown in table 1. There was strong correlation between distances measured from households as compared to village coordinates, when using both Euclidean and network distances. Distances from village centroids tended to be larger than from household coordinates when using network measures.

**Table 1.** Distance from adult residents to the nearest public health facility when using village coordinates versus household coordinates, in Sehore District, Madhya Pradesh, India, 2013-2016.

Distance measure	Spearman's Rho (P value)	Median difference, km (IQR)
Euclidean	0.80 (<0.0001)	0.04 (-0.56-1.12)
Network	0.92 (<0.0001)	1.38 (0.17-3.17)

#### 4.4.3 Objective 3: Effect of distance measures on analyses of treatment-seeking for depression

The odds ratios and 95% confidence intervals for the association between distance and likelihood of treatment-seeking for depression, using either network or Euclidean distance, and household or village centroid coordinates, are shown in table 2. These analyses are restricted to adults with probable depression for whom household coordinates were available (n=338). There were negligible differences between odds ratios and only small differences in 95% confidence intervals depending on the measure used.

**Table 2.** Treatment-seeking for depression by adults with probable depression and distance to nearest public health facility, using Euclidean and network distance measures, in Sehore District, Madhya Pradesh, India, 2013-2016.

<b>Distance measure</b>	<b>OR (95% CI)</b>	<b>p-value</b>
Network distance, km - from households	1.01 (0.99-1.04)	0.35
Network distance, km - from village centroids	1.02 (1.00-1.05)	0.09
Euclidean distance, km - from households	1.04 (0.97-1.11)	0.25
Euclidean distance, km - from village centroids	1.04 (0.98-1.10)	0.21

*ORs and P values adjusted for sampling design.*

## **4.5 Discussion**

### 4.5.1 Principal findings and implications

Network distance measures give consistently larger estimates of distance to the nearest facility than Euclidean measures. However, network and Euclidean measures are strongly correlated; identify the same facilities as closest in the majority of cases; generally identify the same households as having greatest and most limited geographic access to care; and produced virtually identical results when analysing the impact of geographic access on treatment-seeking for depression. This supports the proposal that Euclidean distance can be used as a reasonable proxy measure for analyses of the association of geographic access with health service utilisation within this context and in comparable settings (257).

The results also showed that when village centroid coordinates were substituted for household coordinates the same facilities were identified as closest, and the difference in estimates of distance to services was small, relative to the overall distance to services. Substituting village coordinates for household coordinates in cases of missing data therefore appears to be a reasonable strategy in this context, and the additional resources

and ethical implications of collecting individual household locations may not be warranted by the relatively small increase in accuracy.

Salient features of the study setting are that the terrain is largely flat with no major travel barriers such as lakes or mountains, the median Euclidean distance between households and their nearest health facility was over 7.5km, and the mean distance between households and village centroids was less than 1km. In settings in which the relevant distances are smaller, differences in estimates of the magnitude reported here may be more important and therefore more fine-grained measurement may be necessary. Equally, in areas where villages are larger or households within villages are more dispersed, the error associated with using village centroids will be correspondingly larger. Finally, previous studies have indicated that Euclidean distances do not provide a valid proxy for travel distance in areas where there are major barriers to travel, such as mountainous areas or lakes (275). Hence, the appropriate measure should be chosen on the basis of both the research questions and the study setting.

#### 4.5.2 Limitations

There is no universally accepted “gold standard” measure of distance to health services (262), so in the current study we compared a simple measure (Euclidean distance) to a more sophisticated measure (network distance), on the assumption that the latter provides a more accurate estimate. This was nonetheless an imperfect measure, for several reasons.

Firstly, it is based on certain assumptions about actual travel routes: (a) We assumed that participants would consult their nearest public health facility and take the shortest route by road to get there. (b) Some households were located away from the nearest road in our network, since this network did not contain all small dirt tracks, so we assumed that participants travelled in a straight line from their household to the nearest section of road, which may be an under-estimate of participants’ actual travel distance in some cases. If these assumptions are inaccurate, then it is possible that both Euclidean and network distances provide invalid estimates of actual travel distance. More complex models would therefore be required to assess geographic access to health care, incorporating factors such as competition between health facilities, facility characteristics, and local influences on route choice, such as road quality and the availability of public transport (e.g. (274)).

Similarly, we were not able to estimate travel time, which might provide a more accurate measure of geographic access to services (267). We lacked data on access to transportation for individual participants, in order to predict whether participants were likely to walk, take public transport, or use private vehicles, and use these to adjust travel routes and convert these into travel time estimates. Since 62.6% of those who had used health services in the past 3 months had used private vehicles to travel to services, and 77.8% used either public transport or private vehicles, the assumption that all participants travelled by road will have been appropriate for the majority of participants, but not all.

We also lacked the data to distinguish between “pucca” roads (all-weather metalled roads) and “kuccha” roads (mud roads, that may be more susceptible to seasonal changes) in the analysis, nor did we have data on the current state of maintenance or deterioration of the roads, which may vary within the study area. The time and cost implications of travelling the same distance on different road types may vary, as travel speed is likely to be lower on roads that are in poor condition. If detailed travel time estimates are necessary in future geographic analyses in this area, researchers should consider developing a more detailed road network that incorporates these details, in order to estimate travel times that factor in such data. However, collecting these data and ensuring that they are up-to-date is likely to be resource-intensive.

Finally, since private providers are extremely numerous and largely unregulated in this setting (73, 248), no reliable database exists to enable us to include these (or traditional providers) in the current analysis. We chose to focus on public health facilities since current efforts within this area to improve geographic access to mental health care do so through the platform of the public sector (65) so it is the impact of their geographic accessibility to the population that is primarily of interest in evaluating their effect on service utilisation rates. Given that the median distance to the nearest private provider is likely to be substantially shorter than the median distance to the nearest public health facility (248), errors of the size reported here would be potentially more problematic for analyses that incorporated all providers.

#### 4.5.3 Future research

It would be useful to track a sample of participants’ actual travel routes using GPS devices, to assess whether the assumptions made in the network model used as a “gold standard” here – that participants travel in an approximately straight line to the nearest road and

then take the shortest distance by road from there to the nearest public health facility – approximate actual travel routes with a reasonable level of accuracy. Ethnographic research would also be valuable to inform “gold standard” travel models, by identifying local factors that influence transport mode, travel route and choice of health care facility.

Finally, the comparison conducted here should be repeated across a range of contexts to determine the circumstances under which more sophisticated measures are required.

#### 4.5.4 Recommendations

Without repeating these analyses across a range of settings, it is not possible to establish exact parameters for when Euclidean distances and village centroid coordinates can be used to estimate travel distance to health services with a reasonable level of accuracy. However, based on the current findings and prior research, we tentatively suggest that this simple, low-resource approach provides a reasonable level of accuracy for analyses of the association between geographic access to care and health service utilisation when all of the following conditions are fulfilled:

1. The terrain is flat and the study area contains no major travel barriers (e.g. lakes).
2. The distances of interest are relatively large (median > 7.5km).
3. Village sizes are small in area (mean distance to village centroid < 1km).

Future research should refine these criteria based on further evidence to establish more precise boundaries. When interpreting Euclidean distance estimates, it should be borne in mind that these are likely to be an under-estimate of actual travel distance, and that the exact magnitude of this under-estimate is likely to vary by setting.

## **4.6 Conclusion**

In relatively flat settings such as rural Madhya Pradesh, and where the distances of interest for research purposes are relatively large (median > 7.5km), Euclidean distances represent a reasonable proxy for travel distance for analysing associations between distance to services and service utilisation. Substituting village centroid coordinates when individual household coordinates are not available is a justifiable strategy in this setting, in which villages are small in area. Researchers should consider using more sophisticated methods if the

distances of interest are smaller, or if the terrain is mountainous or includes other major travel barriers. When estimating the proportion of the population within a given distance of health services, it should be recognised that Euclidean distances under-estimate actual travel distance.

## RESEARCH PAPER COVER SHEET

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***PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.***

### SECTION A – Student Details

<b>Student</b>	Tessa Roberts
<b>Principal Supervisor</b>	Sujit Rathod
<b>Thesis Title</b>	Mapping the Treatment Gap: A mixed methods exploration of barriers to treatment-seeking for depression in rural India

***If the Research Paper has previously been published please complete Section B, if not please move to Section C***

### **SECTION B – Paper already published**

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

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**SECTION C – Prepared for publication, but not yet published**

Where is the work intended to be published?	Indian Journal of Psychiatry
Please list the paper's authors in the intended authorship order:	Tessa Roberts, Rahul Shidhaye, Vikram Patel, Sujit D Rathod
Stage of publication	<b>Not yet submitted</b>

**SECTION D – Multi-authored work**

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I was the lead author, and was responsible for the study design, data analysis, and the writing of the manuscript. RS and VP advised on the design of the study and the presentation of the results, and offered feedback on the draft manuscript. As final author, SR provided guidance throughout the process of study design, analysis, and writing, and also gave detailed comments and feedback on earlier drafts.
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**Student Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Supervisor Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_



## **5. Health care use and treatment-seeking for depression symptoms in rural India: A descriptive cross-sectional analysis**

### **5.1 Abstract**

There is a large “treatment gap” for depression worldwide, including in India. This paper aims to describe health care use and treatment-seeking for depression in rural India.

This study is a secondary analysis of data from a cross-sectional community survey carried out in rural Madhya Pradesh in two rounds, between May 2013 and December 2016. We examine the proportion of individuals with probable depression who sought treatment in different sectors, for depression symptoms and for any reason, and compare the latter with health service use by non-depressed individuals. We also show the frequency with which barriers to health care utilisation are reported by adults with probable depression, and test for differences in the proportion of adults who sought treatment for depression by predisposing, enabling and need factors.

86% reported seeking no treatment for depression. However, 66% of adults with probable depression had used health services for any reason in the past 3 months, compared to 46% of those without depression ( $p < 0.0001$ ). Private providers were most frequently consulted by adults with probable depression (32%), while only 19% consulted traditional providers. Structural barriers to health care use such as cost and distance to services were frequently reported (54% and 52%, respectively) but were not associated with treatment-seeking for depression. The following factors were found to be positively associated with seeking treatment for depression: higher symptom severity; reporting lack of energy, lack of interest/pleasure, low self-esteem, or slow movements or restlessness on more than 7 days in the past 2 weeks; being married; having discussed depression symptoms; and reporting problems with medication availability and supply as a barrier to health care.

The majority of adults with probable depression actively seek health care, but not specifically for depression symptoms, indicating the need to improve detection of depression during consultations about other complaints. Private providers should be included in programmes to improve the detection and treatment of depression. Unmarried

individuals may experience greater difficulties in accessing care in this setting. Further research should test the hypotheses generated in this descriptive study, in which the evidence did not support differences in treatment-seeking for depression by socio-economic, demographic or attitudinal factors.

## **5.2 Background**

Depressive disorders are largely untreated despite accounting for an enormous burden of disease. The 2010 Global Burden of Disease study found that depression was the second leading cause of disability worldwide (280). However, in developed countries only 54.3% of people with a 12 month major depressive episode report visiting any service provider for mental health reasons in the past year, and just 25.2% in low- and middle-income countries (LMIC) (22). Fewer than half of those who sought help received minimally adequate treatment according to evidence-based guidelines (281).

The reasons for low demand for services in LMIC are poorly understood. The World Health Organization (WHO) advocates integrating evidence-based interventions into primary care to increase the availability and accessibility of services (8) as a strategy to reduce the gap. Yet in the World Mental Health Surveys, only 34.6% of people with depression in LMIC regarded themselves as needing treatment (281), suggesting that the treatment gap cannot be explained solely in terms of limited availability of mental health services.

Few data are available to inform strategies to promote treatment-seeking in LMIC, such as India, where the treatment gap for depression is over 85% (69). Two recent systematic reviews on treatment-seeking for common mental disorders showed that “need factors”, such as greater symptom severity, chronicity, and disability, are positively associated with the likelihood of seeking treatment, and that women, the middle-aged, those with higher levels of education, and people of Caucasian ethnicity are more likely to seek treatment in high-income countries (120, 227). They also showed that factors such as income, employment, and place of residence were generally not associated with treatment-seeking. However, there was a relative lack of evidence from LMIC, and few data were available

with which to evaluate factors such as beliefs, attitudes, social support or health systems characteristics, which are hypothesised to be important to treatment decisions (227).

In India, data on treatment-seeking for depression are scarce. In 2016, a systematic review of “contact coverage” (72) (i.e. the proportion of adults with depression who sought treatment for depression (29)) found only one population-based study of treatment-seeking from India. This study reported that rural residents were less likely to seek treatment than urban residents, with no clear association with wealth (282). However, the researchers used receipt of a depression diagnosis as its outcome measure, which conflates treatment-seeking with health care providers’ ability to detect and diagnose depression. Other Indian studies have reported on the use of general health services by people with depression, but without distinguishing between treatment sought for depression and for other health problems (251, 283, 284). As such, very little evidence is available from India to inform efforts to reduce the treatment gap for depression.

Evidence-based strategies for reducing the treatment gap can only be devised if service planners have access to information on who seeks treatment, under what circumstances, and from where, some of which may differ between settings. This study is a descriptive analysis of treatment-seeking for depression by adults in Sehore sub-district, Madhya Pradesh, with the following specific objectives:

- (1) To estimate the proportion of adults with probable depression who consult different types of treatment providers, (a) for depression symptoms and (b) for any reason, and to compare the latter with general health care use by people without probable depression;
- (2) To measure the prevalence of self-reported barriers to using health services among adults with probable depression;
- (3) To estimate the change in probability of treatment-seeking for symptoms of depression associated with need, predisposing and enabling factors.

### **5.3 Methods**

### 5.3.1 Setting

Sehore sub-district is a predominantly rural area in Madhya Pradesh, with a population of 427,432 (84). 31.7% live below the poverty line and agriculture is the mainstay of the local economy (81). General health indicators are below the national average (83), literacy rates are 81% for males and 58% for females (84), and 88% of residents have completed only primary education or less (85).

The PRIME programme (Programme for Improving Mental Health Care) aimed to implement and evaluate district-level Mental Health Care Plans (MHCP) (64). The MHCP for Sehore focussed on depression, psychosis and alcohol use disorders and was implemented through community health centres between August 2014 and October 2016 (65).

Prior to implementation of the MHCP, outpatient and inpatient services were provided through Sehore District Hospital, by one psychiatrist and one clinical psychologist who are employed under the District Mental Health Programme and provide their services on alternate days, with periodic “outreach camps” (86). No psychotropic medication or psychosocial interventions were available in primary care facilities, there were no psychiatric social workers or psychiatric nurses, and primary care workers were largely untrained in identifying and treating mental disorders. After the plan was implemented, depression treatment was available at three Community Health Centres with psychological interventions delivered by case managers and pharmacological treatments prescribed for severe cases by medical officers. Community awareness activities were conducted to encourage service uptake, such as community meetings and proactive case finding in the community by the case managers. They also screened patients in Community Health Centres. The study area (86), Mental Health Care Plan (55), and PRIME evaluation plan (52) have been described in more detail elsewhere. The term “implementation area” will be used to refer to those villages where MHCP activities were fully implemented.

### 5.3.2 Sample

This report is a secondary analysis of data from a repeated, population-based, cross-sectional community survey carried out with the primary aim of estimating the change in treatment-seeking among adults with probable depression, before and after implementation of the MHCP. This secondary analysis focuses on characterising treatment-seeking patterns for adults with probable depression in both rounds.

The study design, sampling plan, and data collection have been described in detail elsewhere (52, 55). Briefly, data collection for the first round took place prior to Mental Health Care Plan implementation, in two waves (May-June 2013 and January-March 2014), and the second round after implementation of the plan (October-December 2016). The target population was adults (aged 18 and above) residing within the implementation area, with participants selected from voter lists through systematic random sampling. Inclusion criteria were fluency in spoken Hindi, residency in the selected household, willingness to provide informed consent, and absence of cognitive impairments that would preclude informed consent or ability to participate.

Across both rounds, 6,203 adults were recruited, 6,134 (98.9%) consented to participate, and 4,297 resided within catchment areas of the de facto implementation area, where treatment was made available in the Community Health Centres. Of the 4,297, 568 adults (289 in round 1, 279 in round 2) screened positive for depression and comprise the primary sub-sample for this secondary analysis. For the purposes of the current analyses, data from both rounds were pooled to increase statistical power. In order to compare use of health services by adults with and without depression, for this analysis we also included the 3,531 community survey participants who resided within the implementation, did not screen positive for depression, and who did not report equivalent symptoms within the past 12 months. The sample size was calculated for the parent study based on the numbers required to detect a difference in contact coverage between rounds (the proportion of people with depression and alcohol use disorders who sought treatment for their condition), as described elsewhere (55).

### 5.3.3 Data collection

Interviews were administered orally, in Hindi, by trained local fieldworkers who recorded participant responses using a questionnaire application programmed on Android tablets. The structured questionnaire included sections on socio-demographic details, health care use, barriers to using health services, depression symptoms, treatment-seeking for depression, alcohol use and related treatment, disability, internalised stigma related to depression and alcohol use, suicidal ideation and behaviours, and mental health knowledge and attitudes.

#### 5.3.4 Study measures

The PHQ-9 consists of 9 items on depression symptoms which are summed to generate a symptom score (278). We used a cut-off point of  $\geq 10$  to indicate probable depression (231, 285) which has previously been validated in India (125, 286). Participants were also asked if they had experienced equivalent symptoms for any 2 week period in the past 12 months.

Barriers to the use of health services were based on the Study on Global Ageing and Adult Health (SAGE) (287). We added one question in round 2 on distance to health services. These barriers were not specific to depression.

We chose factors to investigate based the Andersen socio-behavioural model (41, 114), which groups factors associated with health service utilisation into; (a) need factors, which include both objective and subjective assessments of health status, (b) predisposing factors, covering both demographic characteristics and attitudinal factors such as health beliefs, and (c) enabling factors, which refers to structural determinants such as financial situation, transport and social support.

Predisposing factors included gender, religion, education, age, caste, marital status and internalised stigma (measured using questions from the Internalized Stigma of Mental Illness (ISMI) scale (288)). Enabling factors included land ownership, housing type, employment status, discussing depression symptoms with someone, and reporting cost and travel barriers to health care. Need factors included symptom severity, disability (measured using the 12-item World Health Organization Disability Assessment Schedule (WHODAS 2.0)(233)), perceived need for health care, probable alcohol use disorder (measured using the Alcohol Use Disorders Identification Test (AUDIT) with a cut-off of  $\geq 8$  (289-292)), suicidal thoughts (measured using the Composite International Diagnostic Interview (CIDI) suicidality module (293)), and PHQ-9 item-specific symptoms of depression.

Treatment-seeking was measured after completing the PHQ-9 questionnaire by asking “Did you seek any treatment for these problems at any time in the past 12 months?”. Thus, in this report, “treatment-seeking for depression” refers to seeking treatment for the symptoms listed in the PHQ-9. Participants who answered affirmatively were asked to specify the type of provider consulted. In the section on health care utilisation, participants were asked “In the last three months, have you visited any health facility or provider for

any health problem?”, and in which sector. Details of all measures used, and how these were treated in the analysis, are presented in appendix F.

### 5.3.5 Analysis

First, we describe the sociodemographic and clinical characteristics of the sub-sample of adults with probable depression, using unweighted counts and weighted percentages to account for the sampling design.

To estimate proportion of adults with probable depression who consult different types of treatment providers for depression symptoms and for general healthcare, we present the frequency of self-reported treatment-seeking for depression symptoms and general health care use, using weighted percentages and unweighted counts. We also present the frequency of general health care use by adults without depression (excluding those who reported depression symptoms over the past 12 months) and compare these proportions using Chi squared tests.

We next measure the prevalence of self-reported barriers to health service use by adults with probable depression, by presenting percentages on the frequency with which each barrier was reported, again using weighted percentages and unweighted counts.

To assess the association between perceived need, predisposing and enabling factors and treatment-seeking for depression, we present the proportion of adults with probable depression who sought treatment for depression by each characteristic, along with prevalence ratios and 95% confidence intervals, and tested the association between each variable with the outcome of treatment-seeking for depression using univariable log-linear regression analyses. For brevity, we present only the results for factors where this association reached a significance level of  $p < 0.05$ , but a full table is included in appendix F. Since these analyses were intended to be descriptive and hypothesis-generating, rather than causal and hypothesis-testing, we did not conduct multivariable analyses to control for potential confounders. In order to interpret the findings on the effect of discussing depression symptoms (presumed to be a proxy measure for social support), we also examined participants' self-reports on who they discussed symptoms with, but the numbers in each group were too small to treat as separate variables.

All analyses were conducted using Stata/IC 15.1 (239). Frequencies are reported as observed, while percentages, regression coefficients, 95% confidence intervals, and P-values are design adjusted.

#### 5.3.6 Ethics

In the parent study, with adults who were selected from the electoral roll, researchers explained the purpose of the survey, read out the contents of study information sheets, and answered potential participants' questions. Informed consent was indicated with either a signature or a thumbprint. All screen-positive participants who were not receiving treatment were referred to the nearest public health facility where depression treatment was available.

The parent study was approved by the World Health Organization Research Ethics Review Committee (Geneva, Switzerland) and the Sangath Institutional Review Board (Goa, India). The London School of Hygiene & Tropical Medicine Observational Ethics Committee (London, United Kingdom) approved this secondary analysis (10439).

### **5.4 Results**

#### 5.4.1 Sample characteristics

The socio-demographic and mental health characteristics of participants with and without probable depression are described in table 1. Among those with probable depression, the mean age was 45.4 years, there were approximately equal proportions of men and women (53.8% female), and most participants were Hindu (92.1%), married (81.7%), and had not completed primary education (74.1%). The majority of participants with probable depression had moderate symptoms (77.9%). Tiredness or lack of energy was the most frequently reported symptom (reported by 79.2% on more than 7 days in the past 2 weeks), followed by feeling depressed or hopeless (63.3%).

The non-depressed group included more males, more people with secondary education, fewer unemployed people, and the mean age was lower (39.6 years).



**Table 1.** Socio demographic and mental health characteristics of adults with and without probable depression in Sehore sub-district, India, 2013-2016

Characteristic	Adults with probable depression, N (%)	Adults without probable depression, N (%)
Gender		
<i>Female</i>	321 (53.8)	1,589 (43.9)
<i>Male</i>	247 (46.2)	1,942 (56.1)
Age group, years		
18-29	98 (17.5)	1,138 (32.8)
30-49	248 (44.1)	1,514 (43.0)
50-90	222 (38.4)	879 (24.2)
Education level completed		
<i>Less than primary</i>	419 (74.1)	2,017 (56.8)
<i>Primary</i>	129 (22.4)	1,124 (32.8)
<i>Secondary or more</i>	20 (3.5)	390 (10.5)
Employment status		
<i>Unemployed</i>	20 (4.2)	53 (1.7)
<i>Productive non-income</i>	241 (38.5)	1,401 (34.0)
<i>Low income</i>	277 (51.9)	1,785 (52.4)
<i>High income</i>	30 (5.4)	289 (7.9)
Religion		
<i>Hindu</i>	525 (92.1)	3,180 (89.8)
<i>Muslim</i>	43 (7.9)	350 (10.2)
<i>Christian</i>	0 (0)	1 (0.0)
Caste		
<i>Scheduled Caste</i>	101 (15.8)	516 (14.2)
<i>Scheduled Tribe</i>	25 (4.2)	140 (4.0)
<i>Other Backwards Caste</i>	393 (71.0)	2,503 (71.1)
<i>General</i>	49 (9.1)	372 (10.7)
Marital status		
<i>Single</i>	32 (6.4)	375 (10.9)
<i>Married</i>	461 (81.7)	2,953 (83.9)
<i>Widowed / Separated / Divorced</i>	75 (11.9)	213 (5.3)
Current depression severity (PHQ-9 score)		
<i>Moderate (10-14)</i>	450 (77.9)	0 (0.0)
<i>Moderately severe (15-19)</i>	107 (20.1)	0 (0.0)
<i>Severe (≥20)</i>	11 (2.0)	0 (0.0)

Depression-related symptoms reported on more than 7 days in past 2 weeks		
<i>Tiredness / lack of energy</i>	450 (79.2)	842 (23.3)
<i>Feeling depressed or hopeless</i>	371 (63.3)	255 (7.5)
<i>Sleep problems</i>	333 (58.1)	347 (9.8)
<i>Lack of interest or pleasure</i>	289 (53.3)	175 (5.5)
<i>Appetite problems</i>	293 (49.9)	282 (8.2)
<i>Lack of concentration</i>	229 (40.3)	155 (4.5)
<i>Low self-esteem / feeling like a failure</i>	123 (22.5)	38 (1.2)
<i>Slow movements / restlessness</i>	119 (22.2)	47 (1.3)
<i>Thoughts of death / self-harm</i>	37 (7.4)	3 (0.0)

Counts reported as observed, percentages are design adjusted.

#### 5.4.2 Objective 1: Use of health services and treatment-seeking for depression

Table 2 shows the health care used for any reason in the past 3 months by adults with and without probable depression.

65.6% of adults with probable depression had used health services for some reason in the past three months. Of these, 48.4% consulted the private sector while 29.8% consulted public providers and 29.3% consulted traditional providers. Those with probable depression were more likely to have used health services in the past 3 months than those without depression (65.6% vs. 45.7%,  $p < 0.0001$ ).

**Table 2.** Health care used in the past 3 months for any reason by adults with and without probable depression in Sehore sub-district, 2013-2016

	By those with probable depression, N (%) (n=568)	By those without probable depression, N (%) (n=3,531)	P-value
Private health care provider	165 (32.0)	638 (19.0)	<0.0001
Public health care provider	108 (19.6)	408 (11.5)	<0.0001
Traditional service provider	119 (19.2)	675 (18.2)	0.60
Mental health specialist	1 (0.3)	0 (0)	0.02
Other	3 (0.6)	5 (0.2)	0.06
None	205 (34.4)	1,909 (54.3)	<0.0001

Counts reported as observed, percentages are design adjusted.

Table 3 shows treatment sought specifically for depression symptoms in the past 12 months by adults with probable depression.

13.9% of adults with probable depression sought treatment for depression symptoms, and of these, 61.3% did so from generalist providers, compared to 22.1% who consulted specialists and 16.7% who consulted traditional service providers.

**Table 3.** Health care used in the past 12 months for depression symptoms by adults with probable depression in Sehore sub-district, 2013-2016.

	<b>By those with probable depression, N (%) (n=568)</b>
Generalist health worker (including case managers employed under the mental health care plan)	48 (8.5)
Specialist mental health worker	13 (3.1)
Traditional service provider	14 (2.3)
None	493 (86.1)

*Counts reported as observed, percentages are design adjusted.*

*Total exceeds 100% because some participants visited more than one sector.*

#### 5.4.3 Objective 2: Barriers to health care use

Table 4 presents self-reported barriers to health care use by adults with probable depression. Cost and distance barriers were the most commonly reported barriers, with each reported by more than half of the sample who were asked about these (54.3% and 52.3%, respectively). The third most commonly reported barrier was the belief that health services were not needed (31.3%).

**Table 4.** Self-reported barriers to health care use among adults with probable depression in Sehore sub-district, 2013-2016

<b>Barrier</b>	<b>Number of adults with probable depression who reported barrier (%)</b>
Fees are not affordable	302 (54.3)
Services are too far away	145*(52.3)
Services not currently needed	172 (31.3)
Dislike taking medications	178 (30.9)
Care received is not good enough	148 (26.2)
Care providers do not understand my health problems	135 (23.4)
They don't have medicines I need	95 (17.3)

They frequently run out of medicines	81 (15.9)
Other reason	56 (11.2)
Seeking some kinds of treatment can make me or my family feel embarrassed	38 (8.1)

*All percentages are adjusted for the complex sampling strategy.*

*\*only measured in follow up round, so denominator was 279.*

#### 5.4.4 Objective 3: Factors associated with treatment-seeking for depression symptoms

Table 5 shows those associations between need, predisposing and enabling factors and treatment-seeking among all adults with probable depression that evidence suggestive of an association ( $P < 0.05$ ). See appendix F for the full set of results.

Among the “need factors”, the following were positively associated with treatment-seeking: symptom severity (39.5% of those with severe symptoms sought treatment compared to 11.5% of those with moderate symptoms), and reporting four specific symptoms on the PHQ-9 on 7 or more days in the past 2 weeks; tiredness or lack of energy, lack of interest or pleasure, low self-esteem or feeling like a failure, and slow movements or restlessness.

Under “predisposing factors”, 5.9% of unmarried people (single, separated or widowed) sought help for depression compared to 15.7% of those who were married.

Among “enabling factors”, 29.4% of those who discussed symptoms sought help compared to 3.9% of those who did not. Spouses were the most common person who symptoms were discussed with (67.5%; data not presented). There was a positive association between treatment-seeking for depression and reporting that “services frequently run out of medications” and “services don’t have the medications I need” as barriers.

**Table 5.** Association between need, predisposing and enabling factors and treatment-seeking for depression among adults with probable depression in Sehore sub-district, 2013-2016

	Total seeking treatment (n)	Prevalence of treatment-seeking, % (95% CI)	Prevalence ratio (95% CI)	p-value
<b>Need factors</b>				
Symptom severity (total current PHQ score)				
10-14	50/450	11.5 (8.5-15.5)	1	<0.01
15-19	20/107	20.7 (13.2-30.8)	1.79 (1.11-2.88)	
≥20	5/11	39.5 (12.8-74.5)	3.42 (1.33-8.81)	
Tiredness/lack of energy				
< 7 days in past 2 weeks	10/118	7.3 (3.8-13.5)	1	0.03
≥ 7 days in past 2 weeks	65/450	15.7 (11.7-20.6)	2.14 (1.08-4.24)	
Lack of interest or pleasure				
< 7 days in past 2 weeks	26/279	9.7 (6.3-14.7)	1	0.01
≥ 7 days in past 2 weeks	49/289	17.6 (13.2-23.2)	1.82 (1.16-2.85)	
Low self-esteem / feeling like a failure				
< 7 days in past 2 weeks	51/445	11.5 (8.5-15.3)	1	<0.01
≥ 7 days in past 2 weeks	24/123	22.4 (15.2-31.9)	1.96 (1.28-3.00)	
Slow movements / restlessness				
< 7 days in past 2 weeks	51/449	12.2 (8.9-16.5)	1	0.01
≥ 7 days in past 2 weeks	24/119	20.1 (14.4-29.3)	1.65 (1.13-2.39)	
<b>Predisposing factors</b>				
Marital status				
Single / separated / widowed	7/107	5.9 (2.7-12.2)	1	0.02
Married	68/461	15.7 (11.9-20.6)	2.67 (1.19-5.99)	
<b>Enabling factors</b>				
Spoken to someone about these problems				
No	13/352	3.9 (2.2-7.0)	1	<0.001
Yes	62/216	29.4 (23.1-36.5)	7.50 (4.11-13.68)	
Services don't have medications I need				
No	55/473	11.9 (8.7-16.2)	1	0.01
Yes	20/95	24.4 (15.9-35.6)	1.99 (1.19-3.32)	
Services frequently run out of medications				
No	56/487	11.9 (8.4-16.7)	1	0.01
Yes	19/81	23.6 (16.3-33.0)	2.05 (1.23-3.39)	

Counts reported as observed. Prevalence ratios, percentages and P-values are design adjusted.

This table presents data for only those factors for which there was evidence suggestive of an association with treatment-seeking for depression ( $P < 0.05$ ). See appendix F for full set of findings.

## **5.5 Discussion**

### 5.5.1 Principal findings

Although few people sought treatment specifically for depression symptoms, almost two thirds of adults with probable depression had recent contact with health services, which was significantly higher than by adults without probable depression. The private sector was most frequently consulted, while traditional services were used least, indicating that private health services are an important platform through which individuals with depression could theoretically be identified and treated. Structural barriers to using health services such as cost and distance are felt to be major barriers to the use of health care, but the current evidence suggests that reporting these barriers is unrelated to treatment-seeking for depression. These findings suggest the potential importance of social support and marriage in seeking treatment for depression in this context.

### 5.5.2 Implications for service planning and future research

#### *Use of health services for non-depression reasons*

Adults with high levels of depression symptoms are likely to be in contact with health services, but their primary complaints are rarely the depression symptoms listed in the PHQ-9. This echoes previous findings from India that depressed individuals frequently present to health services with somatic symptoms (99, 251, 283, 294, 295). Therefore, the most important challenge from a public health perspective appears not to be to persuade depressed individuals to visit services, but rather to enable health workers to recognise their mental health needs during consultations about other complaints. In other words, the relevant “treatment gap” is not between those who do and do not consult health services, but between those who receive effective treatment and those who do not. Health workers should be trained and supervised to distinguish psychosomatic symptoms from other health problems that are comorbid with depression, and provide appropriate care.

#### *Use of the private sector*

Importantly, however, we found that adults with depression are more likely to consult private than public health care providers, highlighting the importance of engaging private providers in initiatives to improve depression care. In the state of Madhya Pradesh, 76% of qualified medics and 72% of qualified paramedical staff are employed in the private sector (248). India has one of the most privatised health systems in the world (249), with around 80% of outpatient care provided in the private sector (296, 297). High rates of private health care use have been linked to the underfunding and poor performance of the public health sector (249), and public perceptions that public services are of poor quality (298).

Interventions delivered through the public health system have little chance of reducing the treatment gap in a context where the majority of health care consultations take place elsewhere. The current landscape of the Indian health system is not reflected in the Global Mental Health literature, where traditional services are often discussed (299-305), but private providers are rarely mentioned, despite evidence that they frequently dispense psychotropic medications in India (306). The MANAS trial in Goa demonstrated the feasibility of training and supervising private providers to strengthen their ability to detect and treat depressive disorders (307); this strategy should be evaluated in other regions of India.

#### *Use of traditional services*

We also found that only a small proportion of treatment sought by people with probable depression was in the traditional sector. The report of the 2015-16 National Mental Health Survey of India posits preference for traditional services as a major barrier to the use of formal treatment (69), based on qualitative interviews with health professionals and community leaders, but presents no quantitative data on service use. Common mental disorders were not distinguished from severe mental illness in these interviews, so it is possible that the difference between our results and the perceptions of these stakeholders arose because traditional providers play an important role in treating people with psychotic disorders but not depression. Our estimates are backed up by a recent national survey showing that the use of traditional healers is low relative to the use of allopathic care for all health conditions, even in rural areas (308). This suggests that engaging with or influencing the use of traditional services should not be a major policy focus in improving care for depression in this context.

#### *Detecting depression: Symptomatology and help-seeking*

In terms of improving detection of depression in health services, health workers should be aware that tiredness or lack of energy is the most common symptom reported by depressed people in this population, followed by depressed mood or hopelessness. Those experiencing lack of energy are more likely to present to health services with depression symptoms than those with depressed mood, potentially because the former symptom is seen as a more legitimate medical complaint than emotional symptoms (309). Future research should test the predictive value of brief questions using local idioms of distress, as in recent research in Nepal (310), to find the most efficient way of detecting depression among primary care attendees who present with somatic symptoms, during short consultations (311).

#### *Who seeks health care for depression symptoms?*

An important unanswered question remains about why people with probable depression do not seek health care for depression symptoms specifically. Our findings on factors associated with treatment-seeking for depression symptoms should be interpreted with caution, since these were descriptive rather than hypothesis-testing: The results show which groups seek treatment rather than establishing causal relationships between these factors. However, some intriguing hypotheses were generated that deserve further investigation, to avoid wasting resources on ineffective strategies to reduce the treatment gap.

Firstly, we found no evidence that those with lower levels of self-stigma, exposure to mental health communications, or indicators of higher mental health literacy were more likely to seek treatment for depression. This contrasts with the conclusions of previous Indian studies, which have implicated these factors as barriers to treatment-seeking (284, 312). This may be because in the current study research workers referred to specific symptoms of depression, rather than to mental illness or psychiatric treatment, and some evidence suggests that symptoms of common mental disorders are not associated with mental illness in India (295). Service planners should exercise caution before investing resources in anti-stigma or awareness campaigns without further evidence of their effectiveness in stimulating treatment-seeking for depression (62).

Secondly, while a majority of participants felt that cost and distance barriers are important, in line with previous research (284, 312, 313), those who reported these barriers were no less likely to seek treatment for depression. We also found little evidence to support



differences in treatment-seeking by socio-economic status. While structural factors may operate as barriers to general health care use, these findings suggest that lack of treatment-seeking for depression symptoms is not linked to economic and practical constraints, but rather to the nature and severity of symptoms. This requires further investigation, both to explicitly test these hypotheses using quantitative data and to qualitatively explore why enabling factors are not associated with treatment-seeking.

Thirdly, the evidence did not support an association between treatment-seeking and disability or perceived need for health care, which is at odds with international evidence (227). In light of the high rates of general health service use, this may be because people with depression consider themselves to have other health problems, and attribute their disability and associated need for health care to these non-depression symptoms. Future research should assess the overall health needs of adults with depression and investigate the effect of comorbid conditions on help-seeking behaviour.

Intriguingly, the gender differences often reported in studies from high-income countries were not replicated in this setting, and we found the opposite association between marital status and treatment-seeking from that which is typically reported elsewhere (5, 120, 227). This demonstrates the importance of local data in identifying vulnerable groups for service planning, and provides suggestive evidence that processes believed to inhibit treatment-seeking in other cultural contexts – such as masculine ideals of self-sufficiency (314, 315) – may not apply in the same way to Indian populations.

Finally, participants who reported limited availability or irregular supply of medications were counter-intuitively more likely to seek treatment for depression than those who did not report these barriers. This may result from retrospective measurement of these factors, since negative experiences of health care affect attitudes towards services (316).

Longitudinal studies are needed to establish causal relationships between attitudes to services and help-seeking behaviour, and test the impact of negative experiences of health care on subsequent attitudes and treatment-seeking behaviour.

Future research should test the hypotheses generated here while controlling for confounding factors, and investigate factors for which data were not available including contextual influences such as social norms. Qualitative research is important to identify factors that the community perceives to be important, and to better understand why so

few adults with probable depression consider treatment to be necessary for these symptoms specifically.

#### 5.5.4 Strengths and limitations

To our knowledge, this study is the most comprehensive population-based study to explore patterns of treatment-seeking for depression in India. The current study used a large, representative community-based sample, to show which groups should be targeted in order to reduce the treatment gap for depression. Given the dearth of research on this topic from LMIC, the current findings may provide useful insights for service planning and policy, and generate hypotheses about barriers to treatment-seeking for further testing.

Since this was a secondary analysis of data collected for another primary purpose, however, we were limited by the measures used. More detailed, mental health-specific measures of barriers to care exist that were not employed due to interview length considerations, such as the Barriers to Access to Care Evaluation scale (BACE) (317). This limits the extent to which our results can be compared to recent studies from other settings (e.g. (318)), which could help to distinguish context-specific from more universal barriers. The measures used to indicate economic status are also imperfect proxies, meaning that we cannot be sure from our findings that poverty does not inhibit treatment-seeking for depression, despite the lack of association found here. Equally, the sample size was determined with reference to the primary aim of the parent study, and as such some of the current analyses may have been under-powered to detect an association, particularly for rare characteristics such as unemployment and suicidal thoughts.

Participants' mental health status was determined using a screening tool, not full diagnostic interviews, so the sample is likely to include some false positives, especially given the low positive predictive value of the PHQ-9 reported in Goa (125). Furthermore, since these data were generated through a cross-sectional survey, symptom severity, level of disability and attitudes towards health services were measured only at the time of the interview despite being subject to change over time, whereas treatment-seeking was measured retrospectively over the past 12 months.

There is also the potential for non-response bias, since only 62.5% of selected adults were located at baseline, and 76.2% at endline, due to death or migration. If those who were not located differ systematically from those who were, this would result in biased estimates.

We have no data on those who were not located, although our sample characteristics are generally comparable to the most recent census data (84).

Finally, self-reported data are always potentially open to social desirability bias, especially when using face-to-face interviews, and it is possible that this led to under-reporting of traditional service use. However, our estimates are in line with a recent national survey showing that the use of traditional healers is low relative to the use of allopathic care for both minor and major morbidity, even in rural areas (308).

## **5.6 Conclusion**

Although most participants had not sought help specifically for depression symptoms, almost two thirds reported recent contact with health services, most frequently in the private sector. Private health care providers are an important group to engage in efforts to improve detection and treatment of depression in this area, and should be included in programmes of training and supervision to reduce the treatment gap for depression. Future research should investigate why adults with probable depression seek help for other symptoms rather than for depression, and replicate the current findings on factors associated with treatment-seeking for depression symptoms.

## RESEARCH PAPER COVER SHEET

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***PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.***

### **SECTION A – Student Details**

<b>Student</b>	Tessa Roberts
<b>Principal Supervisor</b>	Sujit Rathod
<b>Thesis Title</b>	Mapping the Treatment Gap: A mixed methods exploration of barriers to treatment-seeking for depression in rural India

***If the Research Paper has previously been published please complete Section B, if not please move to Section C***

### **SECTION B – Paper already published**

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

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**SECTION C – Prepared for publication, but not yet published**

Where is the work intended to be published?	Social Science & Medicine
Please list the paper's authors in the intended authorship order:	Tessa Roberts, Ritu Shrivastava, Rahul Shidhaye, Mirja Koschorke, Vikram Patel, Sujit D Rathod
Stage of publication	<b>Not yet submitted</b>

**SECTION D – Multi-authored work**

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I was the lead author, and was responsible for the study design, development of the topic guide, checking the back-translation of the topic guide, logistics of data collection and field notes, data analysis, and the writing of the manuscript. RS (2 <sup>nd</sup> author) conducted the interviews, checked the transcription and translation, and double-coded the transcripts, as well as discussing the results to check fidelity to the original interview and providing comments on the draft manuscript. MK provided guidance on qualitative methodology and the presentation and interpretation of results. RS (3 <sup>rd</sup> author) and VP advised on the design of the study and offered feedback on the draft manuscript. As final author, SR provided guidance throughout the process of study design and writing process, and also gave detailed comments and feedback on earlier drafts.
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**Student Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Supervisor Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## **6. “Is there a medicine for these tensions?” Barriers to treatment-seeking for depressive symptoms in rural India: A qualitative study**

### **6.1 Abstract**

Fewer than 15% of adults with depression in India seek treatment for depression symptoms. This paper aims to describe self-reported barriers that contribute to this “treatment gap”, in a rural district in central India where depression treatment had recently become available in primary care facilities.

In this qualitative study we conducted in-depth interviews with 35 adults who screened positive for depression and who had not sought treatment for their condition, and 15 of their relatives. We analysed the data using the framework approach.

A key barrier to seeking health care for depression was lack of perceived need for treatment for these symptoms. Lack of perceived need for health interventions arose because participants frequently attributed depression symptoms to their socio-economic circumstances, or to the stress of physical illness, which conflicted with the biomedical approach associated with health services. It was believed that health care providers are only able to treat somatic symptoms, which were commonly reported, despite recognition of the links between psychological symptoms, social circumstances and physical health.

The community’s perceived needs do not align with a biomedical model of mental health. Meeting their needs may require a radical change in approach that acknowledges the social determinants of distress. Many adults with depression perceived themselves to have health needs besides depression, for which they did seek help, posing a challenge for health services to recognise and address participants’ biological, psychological and social needs, in collaboration with other sectors.

## **6.2 Background**

There is a large “treatment gap” for depression: According to World Mental Health Survey (WMHS) data, conducted in 24 countries worldwide, 46% of adults with depression do not seek treatment, while in developed countries this figure is estimated to be 75% (22). This treatment gap is a primary rationale behind efforts to scale up mental health services globally (6-8). Understanding the reasons why so few seek treatment is essential to inform policy responses.

Quantitative evidence suggests that demand issues are at least as important as limited supply of services, but fail to explain why demand is so low. Lack of perceived need for treatment was the most frequently reported factor (61.5%) in the WMHS (250), followed by preferring to handle the problem alone (reported by 63.8% of those who perceived a need for care). A recent systematic review of factors associated with treatment-seeking for common mental disorders found that need-related factors – such as disability level, chronicity, and self-rated health status – were most consistently associated with treatment-seeking for these conditions, whereas the evidence failed to support an association with structural or enabling factors (227). Understanding why many people with depression perceive no need for treatment, and how these issues manifest across cultures and health care environments, is essential for health authorities to take informed action to reduce the burden of depression.

In India, the treatment gap for depression is estimated to be over 85% (69), but the reasons for low levels of treatment-seeking are poorly understood. Previous studies have suggested that people with depression in India only present to services with somatic symptoms, since these are considered to fall within the remit of medical services whereas psychological or emotional symptoms are not (295, 309, 319, 320). However, the majority of in-depth qualitative research on this topic has been conducted in Goa, so it is unknown whether these findings are generalisable to elsewhere in India. Furthermore, this research has generally been conducted either with facility-based populations, or among specific sub-groups such as perinatal women, so it is not clear if the findings apply to the general adult population.

The aim of this research is to identify and describe barriers to seeking health care for depression, among a community-based sample of adults who screen positive for depression, and their relatives, in a rural district of Madhya Pradesh, central India.

## **6.3 Methods**

### 6.3.1 Setting

The current study focusses on the general adult population of Sehore sub-district, where a Mental Health Care Plan (MHCP) has recently been implemented in partnership with the state and district government as part of the Programme for Improving Mental Health Care (PRIME) (52, 64). The study area (86) and the mental health services available (65) have been described in detail elsewhere.

Briefly, Sehore sub-district is a largely rural area in Sehore district, Madhya Pradesh, where infant and maternal mortality rates are high (82), literacy levels are 81% for males and 58% for females, and 31.7% live below the poverty line (81). The majority of residents work in agriculture (84) and 88% have completed primary education or less (85).

Under the MHCP, services for depression and alcohol use disorders were integrated into primary care services starting in 2015, with treatment delivered by non-specialist health workers. As part of the evaluation of the MHCP, adults receiving treatment for depression were interviewed to understand beliefs about their condition, pathways to care, attitudes towards treatment, and experiences of the services delivered (forthcoming). However, the perspectives of the nearly 90% of those who screened positive for depression but who did not seek treatment (55, 96) – which are crucial to understanding why so few seek care – have not yet been explored.

### 6.3.2 Sample

This qualitative study was nested in the follow-up round of a population-based community survey of adults in Sehore, which aimed to measure the change in proportion of people with probable depression or alcohol use disorders who sought treatment-seeking (52, 95). Eligibility criteria for this qualitative sub-study were: being aged 18 and above, residency in the MHCP implementation area, fluency in Hindi, screening positive for depression (defined as scoring  $\geq 10$  on the PHQ-9 (231, 285)), having given permission to be re-contacted after the community survey, not having sought depression treatment in the 12 months prior to the community survey, and willingness and capacity to provide informed consent.



In this sub-study, we used purposive sampling to ensure adequate sample variability with regard to our primary sampling criteria; gender, depression symptom severity, and age. This involved intentional over-representation of individuals reporting higher levels of depression symptoms according to the PHQ-9, since previous research suggests that barriers to treatment-seeking vary by symptom severity (250). We also asked the screen-positive individual to nominate a close relative to be interviewed, as decisions are often taken at the level of the family within this cultural context (321). We chose to interview the pair separately to ensure that we heard both perspectives, rather than only that of the head of the household, and to allow for comparisons of perceived need for treatment and barriers to seeking care between the screen-positive individual and their family member. Relatives were informed that we wished to interview them about their relative's health and use of health services, but the terms "depression" and "mental illness" were not used.

We aimed to recruit at least twenty adults with probable depression and twenty relatives, but continued recruiting participants until data saturation was reached. A research assistant contacted selected participants by telephone or at home, explained the purpose of the interview, read out the contents of an information sheet and answered any questions. Participants were excluded if there was any doubt about their ability to understand this information, for example due to intellectual disabilities. Informed consent was indicated with either a signature or a thumbprint. Consent procedures for relatives and screen-positive individuals were identical. All participants who were not receiving treatment were referred to services.

### 6.3.3 Data collection

Data were collected via individual semi-structured individual interviews, conducted in Hindi by a trained research worker (the second author) between February and April 2017. Interviews lasted an average of 30 minutes. The interviewer was female, educated to Master's level in Public Health Management in India, and had prior experience conducting qualitative interviews. It would have been evident from the researcher's name, accent and style of dress that the researcher was well-educated, middle-class and unmarried. The first author – a Caucasian British female, educated to post-graduate level in the UK – was also present for all interviews. Participants had not previously met the interviewer, but efforts were made to establish rapport through general conversation, answering participants' questions about us, and the sharing of chai, before commencing the interview. Participants

understood that the motivation for the research was to inform health service planning, although the term “depression” was not used, and it was emphasised that the researchers were independent of the Ministry of Health. Participants were interviewed individually, in or near their homes or places of work. Efforts were made to ensure privacy, to the extent possible given local cultural norms.

Interviews were audio-recorded with participants’ permission and subsequently transcribed and translated into English. The accuracy of translation and transcription was checked by the second author (RS), who is fluent in both Hindi and English. Identifying details were removed from the transcripts prior to analysis. Field notes were taken on the context of interviews and body language of participants, and were reviewed during the process of analysis.

#### 6.3.4 Topic guide

We developed a topic guide based on our research questions and informed by both previous literature and preliminary findings from analysis of the community survey data. The guide covered explanatory models of depression symptoms, perceived need for care, perceptions of health services, barriers to service use, and logistics of using health services. The guide was translated into Hindi then independently back-translated to check for equivalence of meaning, and adjusted in response to piloting to ensure that the questions were comprehensible to participants. Small adjustments were made throughout the data collection process as new themes emerged, to ensure that these were fully explored. The topic guide for relatives followed the same format as for screen-positive individuals. The full topic guides can be found in appendix G.

Following the methods used in PRIME (52), the term “depression” was not used in the topic guide. Instead, we referred to the symptoms listed in the PHQ-9, which includes emotional and psychological symptoms, such as low mood and anhedonia; insomnia; appetite problems; lack of energy and concentration; and restlessness or slow movements. In this report, we use the term “depression symptoms” to refer to this cluster of symptoms.

### 6.3.5 Analysis

We first present the demographic and depression-related characteristics of the participants, and the relationship to their participating relative, using counts and percentages.

To analyse the data, we followed Gale et al.'s recommended steps for applying the framework method (322). These steps involve familiarisation with the interview data, open coding, the development of an analytical framework through iteratively grouping codes and refining categories, indexing all transcripts using the coding framework, and then charting the data into a framework matrix. The first and second author both coded the transcripts and developed the codebook through a collaborative process. Coding proceeded inductively, to allow new insights about this population. Codes were subsequently grouped into the three themes discussed in previous literature; perceived need for healthcare, attitudinal barriers, and structural barriers, following the categories used in the World Mental Health Surveys (250), which broadly mirror the categories from the Andersen socio-behavioural model of health service utilisation (need, predisposing and enabling factors) (41, 114). This facilitates comparison of these results with existing literature. We used NVivo 11 qualitative data analysis software (323) to assist with coding and generating the matrix. Data from screen-positive individuals and relatives were compared within dyads. The coding framework can be found in appendix G.

Due to the challenging logistics of contacting participants and low literacy rates, it was unfortunately not possible to return transcripts to participants for comments or to review the findings. However, the second author checked the findings against the original Hindi recordings and transcripts.

### 6.3.6 Ethics

Institutional review boards at the World Health Organization (Geneva, Switzerland), the University of Cape Town (South Africa), and Sangath (Panjim, Goa, India) provided ethical approval for the community survey. Ethical approval for this qualitative study was granted by the Sangath (Panjim, Goa, India) Institutional Review Board (TR(NSA)\_2016\_27) and the London School of Hygiene & Tropical Medicine (London, United Kingdom) Observational Ethics Committee (11912). On concluding the interviews, all participants who were still

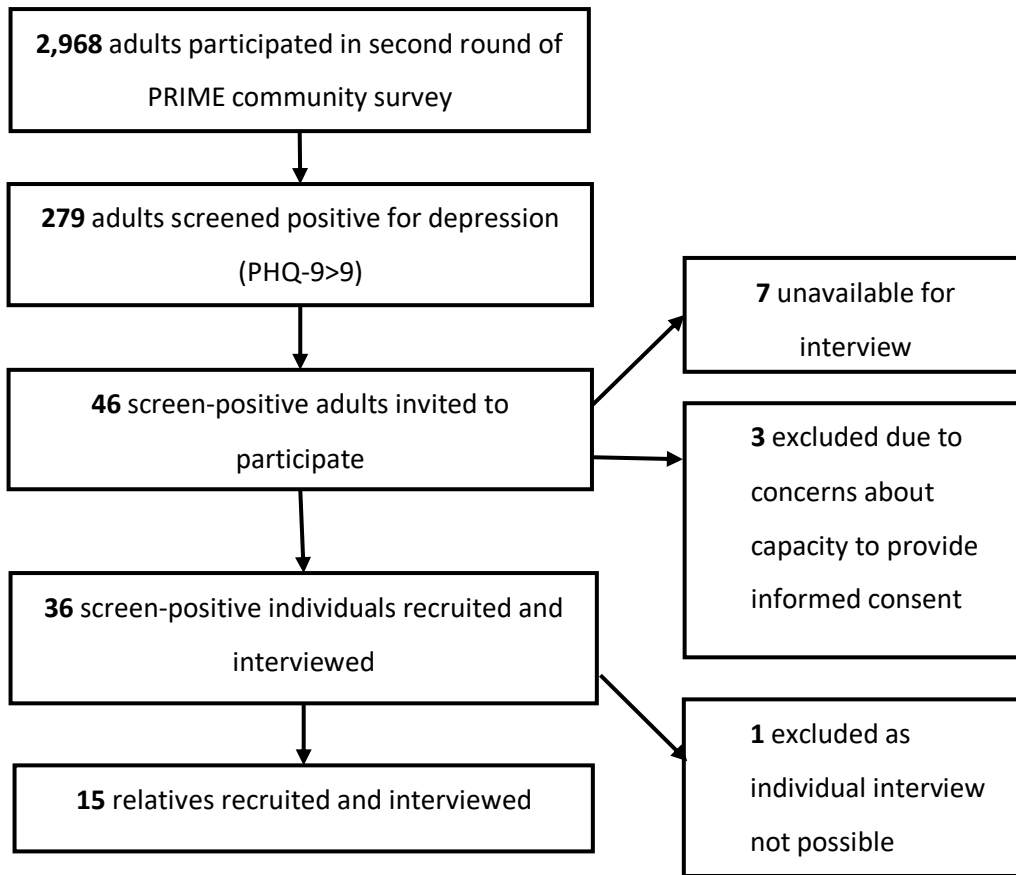
experiencing symptoms and who were not receiving treatment were referred to the nearest public health facility where depression services were available.

## **6.4 Results**

### 6.4.1 Sample characteristics

Figure 1 summarises the recruitment process. In total, we selected 46 individuals from the community survey to participate in this qualitative study. Potential participants were selected for each day of data collection and sample characteristics were monitored on an ongoing basis to ensure that the final sample included a diverse range of participants in terms of gender, age and symptom severity. Of the 46 selected, we excluded 10 (7 due to unavailability for interview, 3 because of concerns about capacity). All 36 individuals who were successfully contacted provided informed consent. One interview was excluded from analysis because it was not possible to ensure privacy, and the family repeatedly answered questions on behalf of the screen-positive individual. We were unable to recruit a family member for 20 participants due to unavailability or participants declining to nominate a relative to be interviewed. We met the target sample size of 20 screen-positive individuals, though continued to recruit until we had 35 participants and 15 relatives, at which point we judged that data saturation had been reached.

Table 1 shows the characteristics of the individuals with probable depression (n=35) and the relationships of the relatives interviewed to these individuals (n=15). Note that these characteristics are based on interviews from the PRIME community survey, whereas qualitative interviews took place up to six months later.



**Figure 1.** Recruitment flowchart

**Table 1.** Demographic and depression screening characteristics of qualitative study participants in Sehore District, India, 2017.

	Mean (SD)	N (%)
<b>Gender</b>		
Female		21 (60)
Male		14 (40)
<b>Age, years</b>	42.3 (14.5)	
18-29		7 (20)
30-49		14 (40)
50-70		14 (40)
<b>Education level completed</b>		
Less than primary		24 (69)
Primary or more		11 (31)
<b>Religion</b>		
Hindu		32 (91)
Muslim		3 (9)

<b>PHQ-9 score</b>	12.8 (2.3)	
Moderately severe (15-19)		9 (26)
Moderate (10-14)		26 (74)
<b><i>Gender of relative</i></b>		
Male		10 (67)
Female		5 (33)
<b><i>Relation to relative</i></b>		
Spouse		11 (73)
Sibling		1 (7)
Aunt/uncle		1 (7)
Son/daughter		1 (7)
Son/daughter-in-law		1 (7)

Participants often mentioned structural or attitudinal barriers to health services that were not specific to depression, such as lack of time and competing priorities. However, exploration of participants' perceived health status, their explanatory models of depression symptoms, and their perceptions of the role of health services, revealed that participants did not generally consider themselves to need formal health care for depression symptoms specifically, suggesting that they would have been unlikely to seek care for these symptoms regardless of the general barriers to health care use.

The results section will therefore primarily explore the issue of low perceived need for depression treatment, which emerged as the key barrier to seeking care for depression symptoms specifically. In what follows, we distinguish treatment-seeking for depression symptoms, understood as those symptoms listed in the PHQ-9 (278), from the use of health care for other reasons. This approach reflects the measurement of contact coverage and the treatment gap, which excludes treatment-seeking for somatic problems (4, 5, 52, 55). A summary of findings on general barriers, including factors that have been hypothesised to inhibit treatment-seeking but which were not supported by the current evidence, are presented in the supplementary material.

Findings from screen-positive individuals and their relatives are presented together, as there was substantial overlap in their reports, but we also compared findings within dyads and present the differences identified below.

#### 6.4.2 Perceived need for health care

*Participants' perceived needs are for change in their social and economic circumstances*

Participants frequently pointed to social and economic factors as the source of their depression symptoms. As such, they did not conceptualise their problem in terms of illness, and medical treatment was not regarded as a viable solution. They spoke of their symptoms in terms of worries or "tension" (stress), which were seen as a normal response to adversity, particularly poverty. For example:

"Money is the issue. We have no money in our home. If I had money then all of my tension would be ended." – 43-year-old male with moderate symptoms

"Tension of being in shabby and poor conditions. Tension of not being able to fulfil the household expenditures and children's needs. Tension of not having enough earnings... Tension of my non-working husband" – 39-year-old female with moderate symptoms

Problems related to marriage and the family were also frequently cited, which medical providers were also seen as unable to address. For instance:

"My son and I fight and argue daily... What should I say to the doctor... Can he come and stop my son from fighting with me?... I am asking you, is there a medicine for these tensions?" – 70-year-old male with moderate symptoms

"It's not any kind of disease... I have deep sorrow... I gave birth to five girls then finally we got one son but he died..." – 35-year-old female with moderate symptoms

The hardships that participants experienced, and to which they attributed their emotional state, were considerable. Nine participants described the premature deaths of close family members (excluding reports of parental deaths when participants were in adulthood), either due to illness or accidents. Participants aged sixty and above undertook manual labour in searing heat. Some female participants described alcoholic, abusive, or economically inactive husbands, who left them to bear the family's expenses alone on daily labourers' wages. Families with their own land described borrowing money to invest in agriculture, only to lose everything if the rains arrive too early or too late. There were frequent references to the stress of getting their children married (particularly daughters)

and educated (particularly sons), both of which were seen as vitally important, but were bound up with financial pressures.

The context for all of these issues was the unrelenting stress of living in poverty. When asked what kind of help participants needed to alleviate their distress, they spoke not of health services but of the need for financial support, change in their social situation, and routes out of poverty for their families. For example:

“No doctor can treat worry and your mind... The worry and stress which you have 24/7 only God or money can cure it... [The doctor] can't provide bread to your home. When your hunger will be ended then your mind will become fine...” – 63-year-old male with moderate symptoms

“The most important and huge tension for me is debt... If it [debt] will get solved then my tension will get ended.” – 36-year-old female with moderate symptoms

“Once the kids get educated they will support us. Then there won't be any issue of disputes and sorrow.” – Relative of 43-year-old male with moderate symptoms

“For me the most difficult thing is my husband... If my husband was good then there would not be any sorrow in the family.” – 39-year-old female with moderate symptoms

Several participants mentioned the existence of government welfare schemes to alleviate financial problems, such as Below Poverty Line (BPL) cards, widows' pensions, disability pensions, financial support for the elderly, insurance schemes for crop failures, development programmes to improve housing conditions, and programmes to support members of disadvantaged castes. However, many expressed frustration at being unable to access these programmes, either due to strict eligibility criteria, or to the “sarpanch” (village leader) failing to pass these benefits on those who need them. For example:

“We are Thakur by caste [general caste] so that's why we don't get any benefits” – 43-year-old male with moderate symptoms

“The government introduced so many schemes for poor people but... the sarpanch is not providing any benefit to us... He favours rich people and known people...”



Look at me, how old I am. I am very elder but they say you don't fulfil age criteria."

– 65-year-old female with moderate symptoms

*Participants' perceived needs are for effective physical health care*

At the same time, almost all participants described somatic complaints (see box 1 for a list of somatic problems mentioned) for which health care was seen as appropriate, and most participants had sought treatment for these symptoms. Many participants described pain and other somatic issues as the problem that bothered them the most, particularly when these affected their ability to work. Unlike depression symptoms, somatic symptoms were considered to be medical problems that fell within the remit of health care, irrespective of their cause.

**Box 1.** Somatic complaints reported by adults with probable depression

Limb pains, headaches, backaches, swelling, chest pain, kidney pain, vision problems, fevers, vomiting, diarrhoea, high blood pressure, fainting, urinary tract infections, vaginal discharge, abscesses, haemorrhoids, digestive problems, bowel problems, respiratory problems, nose bleeds, arthritis, allergic rashes, injuries, heart disease, kidney failure, gum pain, dental problems, strokes.

Participants had varying models of how their depression symptoms related to their somatic symptoms. Some attributed their psychological problems directly to the stress of being physically unwell. For example:

"Due to illness my mood was not good... I had tension for my illness only" – 37-year-old female with moderate symptoms

"When my body is not healthy then it makes everything unbalanced. If there is any difficulty in your body it is quite obvious it will reach to the mind" – 43-year-old male with moderate symptoms

Those who considered their depression to be caused by physical illness perceived a need for treatment for their underlying physical ailments only, and believed that their depression symptoms would disappear if these were effectively treated. For instance:

"If my pain will be cured so maybe this tension will be cured." – 54-year-old male with moderate symptoms

“If [my] hands and legs get cured then [my] tension will end” – 36-year-old female with moderate symptoms

An important source of stress for many participants was their dissatisfaction with the health care they received for their somatic complaints. Participants reported having sought treatment multiple times, sometimes at great cost, without lasting improvements in their condition. They also complained about the provision of treatment without physical check-ups to accurately diagnose and treat any physiological disorder, or to rule organic disease out. For instance:

“I am taking treatment probably from 10 years, I am still not recovered... When I don't get relief here [in the village]... I go to there and there have to pay 1000 rupees [approximately \$14 USD], and I get relief for two-six days then again it is the same” – 63-year-old male with moderate symptoms

“They don't do proper tests and investigations in government hospitals, they only write the prescription based on your verbal complaints” – 33-year-old male with moderate symptoms

*Health workers unable to treat “tension” since it is not a medical issue*

Conversely, it was also commonly believed that one's social and economic circumstances can cause physical illness, through “tension” or stress. Nonetheless, participants still reported only somatic symptoms to health care providers. These examples illustrate how participants perceived the relationship between emotions and physical health:

“If a person is happy and laughs then only his/her body and mind will be healthy. If a person is not happy... then automatically they will become like a patient.” – Relative of 54-year-old female with moderate-severe symptoms

“Once a man's heart starts getting anxiety he becomes weak in all aspects and starts getting fifty diseases... When you have no money in your pocket, one after another illness will catch you. And if we get one disease it will lead to a thousand more diseases in your body.” – 64-year-old male with moderate symptoms

“All of our things got robbed... Day and night I feel anxious and I worry for the same reason. And this anxiety and worry give rise to disease... Then I get headaches. I

can't see clearly from my eyes." – 50-year-old female with moderate-severe symptoms

Despite believing that their physical health problems had psychosocial causes, participants consulted health care providers about somatic symptoms because these were considered to be medical problems that health workers are equipped to treat. Psychological and social problems were not reported during consultations because participants believed that health professionals have neither the time nor the capacity to address the wider context of their lives. For instance:

Interviewer: "Did you tell him about your thoughts and tension?" Participant: "No, I shared nothing about this all... The doctor will not give this much time to share about all the problems." – 56-year-old female with moderate symptoms

"There is no treatment for sadness, dissatisfaction and tension. There is a treatment if you have some stomach pain or some other pain, but mind pain there is no treatment. It can't be possible, like if there is no production of wheat in my farm and I am in tension due to no production of wheat, can government give me wheat and take away my tension?" – 70-year-old male with moderate symptoms

Unless participants had somatic symptoms, therefore, participants were rarely seen to be truly ill and therefore in need of medical assistance. Thus, even those with high symptom scores were sometimes seen as insufficiently sick to warrant treatment. For example:

"We thought he will become fine on his own. Why take treatment, he is not having some severe disease" – Relative of 25-year-old male with moderate-severe symptoms

"I have a small problem... I can manage it on my own... I don't feel much difficulty because of it" – 35-year-old female with moderate-severe symptoms

Participants clearly distinguished "tension" from mental illness. Unlike depression symptoms, mental illness was associated with psychotic symptoms and regarded as a legitimate medical issue. For instance:

"My mind is fine and well. I have only [a] tension problem... In mental problems people behave strange from their mind, and tension is far different than that... For

mental people there are different doctors available which separately see only mental cases. Their medication and treatment all is different.” – 54-year-old woman with moderate-to-severe depression symptoms

“I don’t have anything like I am crazy or some mental person... I am not suffering from some episodes/craziness attack of craziness... I don’t have that illness. I have tension related to my work. And isn’t it quite normal to have tension related to work and household?” – 50-year-old woman with moderate-to-severe depression symptoms

Finally, some explained “tension” as arising from individuals’ thought patterns, rather than an inevitable response to one’s circumstances. Those who expressed this view nonetheless rejected the possibility of treatment for depression symptoms because they believed that only the individual themselves has the ability to change their thoughts. For instance:

“I think only I myself can help me... If I can make my mind not to think and do worry” – 60-year-old male with moderate symptoms

“Neither doctor understands tension nor is treatment available for tension... Medication can’t help, it will continue until one must decide to end it on [his] own... Tension is actually a person’s thinking... It is not any physical illness” – relative of 54-year-old female with moderate-severe symptoms

#### *Family members unaware of depression symptoms*

Finally, while in some families interviewees stated that everyone takes their own decisions, in others there was a clear decision-maker; usually a male relative. In such families, the decision of whether to seek treatment therefore depended on this person’s perceptions of their relative’s treatment needs. Participants often said that they did not share their feelings with other family members as there was little they could do to help and it would only give their relatives more cause for stress and worry. For example:

“If I will explain the whole of my problem then obviously they all will get tension too... What is the benefit in sharing with anyone... They won’t be able to solve my problems” – 33-year-old male with moderate symptoms

Many relatives could describe their family member's somatic complaints, but were unable to comment on their emotional state, suggesting that emotional experiences were not a common topic of conversation in many households. For instance, while these participants described issues relating to "tension", their relatives said:

"Only she can know about it... I don't know what she thinks in her mind and what she doesn't think" – relative of 43-year-old female with moderate-severe symptoms

"She only has gum pain and nothing more. As per my knowledge she has nothing... only gum pain" – relative of 36-year-old female with moderate symptoms

#### 6.4.3 Structural and attitudinal barriers to health care

Structural and attitudinal barriers were also discussed, but applied to the use of health care in general, and were conditional on perceiving some need for health care. As described above, participants often perceived a need for treatment for somatic symptoms, but rarely considered treatment necessary or appropriate for depression symptoms specifically. Findings relating to structural and attitudinal barriers are briefly summarised in appendix G, as these may be applicable to service planning if demand for treatment were to increase. They also have relevance for understanding patterns of health service use for other reasons besides depression symptoms, which is outside the scope of the current study.

### **6.5 Discussion**

#### 6.5.1 Principal findings

This study identified the main barrier to seeking treatment for depression as lack of perceived need for depression treatment. This is consistent with existing evidence from around the world, but particularly in low- and middle-income countries (227, 250, 281).

The most prominent reason for the lack of perceived need for medical intervention was the attribution of depression symptoms to "tension", or stress, which was seen as a common and understandable response to adverse life events and psychosocial stressors, including poverty, poor working conditions, chronic illness (often without effective treatment),

bereavement, family problems, and domestic abuse. Participants considered tension-related problems to be distinct from mental illness, as previously reported (295, 309, 319, 324, 325). Thus, the community largely view depression as a form of social suffering rather than a health problem, in contrast with the biomedical model associated with health services. Again, this is consistent with previous literature from India (295, 309, 320, 325-327), although it is not necessarily specific to India (328).

While participants placed varying degrees of emphasis on the biological, psychological and social aspects of health in their particular case, their accounts clearly recognise the connections between these three domains. As per the biopsychosocial model of health (329), therefore, participants did not regard their mental health as independent of their physical health or of their social context, in contrast with vertical approaches that treat depression in isolation from other issues. Nonetheless, they considered that health services were only equipped to intervene in the biological domain, not the psychological or social.

#### 6.5.2 Reflexivity

Before discussing the implications of these findings, I will first present some reflections on the interview process, to provide context.

Following local custom, participants were extremely welcoming of the research team as guests, although occasionally we encountered suspicion about us interviewing female members of the household. This may have been related to previous women's empowerment initiatives that were perceived to disrupt traditional ways of life.

Participants were inevitably curious about where we had come from and why (particularly the first author, as a conspicuous foreigner), and the second author would answer these questions before the interview.

There was a notable power imbalance, in that participants to some extent deferred to us as authority figures, due to our levels of education and our affiliation with a research institution. This was evident in the responses given to some questions; for example, when asked directly what they believed to be the cause of their symptoms, or the type of help needed, participants often stated that they were villagers with little education whereas we were educated people from the city, and supposed that we would have greater knowledge of these issues than they did. Older men – who were perhaps more used to being treated as authority figures within their communities – tended to be more willing to accept that,

despite their lack of education, they knew something that we did not. Some probing and reframing of the questions was necessary to encourage interviewees to explain their perspective.

The role of the first author during interviews was as a silent observer. We were initially concerned that this would inhibit participants from sharing their thoughts and experiences freely, but after the initial curiosity and questions were addressed, most participants appeared to either ignore my presence during the interview or in some cases directed their comments to both researchers. The second author had recently conducted qualitative interviews without such an observer as part of another study, and did not consider there to be a substantive difference in the extent to which interviewees were willing to talk openly. Translation did not occur simultaneously, and my level of Hindi is basic, so I was able to recognise some key words but not follow the conversation. However, we conducted a full debrief after each interview, to discuss the overall narrative and key themes brought up, which enabled us to collaboratively interrogate the research question in light of the latest data and review whether any concepts should be further explored in future interviews, as well as judging when saturation had been reached.

Obtaining informed consent was challenging in two ways: Firstly, although we explained that participation was entirely voluntary, due to the power imbalance described above and the cultural expectation to welcome guests, interviewees may have found it difficult to decline to participate. Reluctant participation manifested itself in some interviews in which interviewees agreed to participate but gave very little information, stating that they had no health problems and had nothing to say about health services. Secondly, despite introducing the purpose of the interview as a research study, it became clear in some interviews that participants lacked an understanding of what research was or how this differed from a clinical interview, since some interviewees requested treatment for various health problems that we were not in a position to directly offer. We found it helpful to liken research to a survey or census, with which participants were more familiar, and discovered that it was necessary to spell out not only that participation would not affect their future treatment but also to be explicit that no treatment would be directly given, although we could provide information and referrals. We explained that the information we gathered would be used to improve health services, although some participants were overtly sceptical about whether it would in fact lead to change.

Similarly, there was an ongoing process of re-interpretation as we observed participants' responses to questions. For example, it became obvious that participants found hypothetical questions confusing – for instance, when exploring the role of gender in seeking health care – so we began to frame these questions in terms of concrete help-seeking behaviour by different family members in response to actual episodes of ill health, rather than asking about what would be the case if circumstances were different.

Maintaining privacy was predictably challenging in this setting, but in most cases the challenge was not insurmountable. Families were generally surprised when we said that we wanted to speak to one person at a time but humoured us nonetheless, with the caveat that they were not far away while we conducted the interview. The format that we found most acceptable was to interview participants outside, where family members could observe us without hearing the content of the conversation. Our interest in interviewing relatives was helpful, as it allowed us to reassure family members who wished to contribute that their perspective would also be heard. Interviews were regularly interrupted by curious neighbours who would approach to listen, at which point we would pause the interview and politely explain that we were conducting a research study and needed to speak to the person alone. We would then wait for the person to leave before resuming. On some occasions, it was not possible to interview the participant out of earshot of their family members, which may have led them to withhold information that they might otherwise have shared, especially in cases where depressive symptoms were linked with domestic abuse.

### 6.5.3 Implications

#### *Community participation and social/economic interventions*

A key reason for low perceived need for depression treatment was the conceptualisation of problems in social or economic rather than medical terms, indicating that health services for depression fail to address what matters most to the community (330).

A common response to the divergent perceptions of depression between professionals and lay people is to promote psychoeducation to overcome the community's apparent ignorance or lack of "mental health literacy" (57, 331). Although greater dialogue with



communities is undoubtedly needed, a more constructive approach than attempting to align communities' perceived needs with services would involve bidirectional exchange, in which services are adapted in response to the community's values and priorities (332).

Participants described their needs in terms of addressing the modifiable social determinants of mental health, which in this context referred to greater economic security, better working conditions, accountability and quality improvements in the public health system, improvements in family relationships, and a route out of poverty through education for their children. Although primary care workers may have a role in identifying and referring individuals in need of such support, for instance through the social prescribing models being explored in high-income countries (333, 334), primary care is not necessarily the best platform through which to provide interventions such as financial protection schemes or gender-based violence interventions.

Investing in community-based social work may be a more feasible strategy for addressing some of the proximal determinants of mental disorders and amplifying the voices of those affected to ensure that services meet their needs (335). The VISHRAM project in Vidarbha demonstrates how a more community-based approach, using local models of understanding distress, can lead to increased engagement with services compared to the facility-based model used in this context (244). The Atmiyata project in Maharashtra has also demonstrated that local "community champions" can be trained to facilitate access to social benefits and build on existing social resources to support people with CMD symptoms (336).

#### *Systems strengthening and holistic care*

While recognising the limitations of primary care, it must also be noted that the majority of participants sought health care, as reported elsewhere (251, 283). They therefore perceived some need for health interventions, but were often dissatisfied with the treatment received. The World Health Organization's mhGAP guidelines include a module on medically unexplained symptoms (337), which deserves greater attention to ensure that providers are able to recognise and appropriately respond to psychosomatic symptoms.

However, it is important not to assume that all of the somatic symptoms experienced by people who screen positive for depression are psychosomatic. Primary care also has an important role in ruling out organic causes of somatic complaints and treating comorbid

health problems. Previous research on depression in India has often attributed somatic symptoms to psychological problems (101, 295, 309, 319, 325, 327), but these studies have not generally included a full clinical examination to rule out comorbid conditions. It seems likely from the range of health problems reported in the current study that many participants also experienced comorbid health problems, which should be expected given the evidence on bidirectional links between mental and physical health (16, 338). Participants' scepticism about the benefits of depression treatment without diagnosing and treating their physical complaints may well be warranted in the context of frequent comorbidities and weak standards of general health care.

Access to effective physical health care is an important modifiable social determinant of mental health (339). mhGAP guidelines recommend testing for alternative causes of symptoms and attending to comorbid conditions before commencing treatment (337), but in a context where primary care workers have around two minutes per consultation (311), accurately assessing and treating participants' physical and mental health is likely to be extremely difficult. Much literature has been devoted to the significant challenges facing India's health system, not only in terms of lack of investment but also management of public health care services and the regulation of the private sector (e.g. (297, 340)). In rural Madhya Pradesh, 67% of health care providers have no medical qualifications at all, and even qualified providers have been found to rarely give correct diagnoses, follow clinical checklists, or provide effective treatment (341). Therefore, although the majority of adults with probable depression are in contact with health services, they are nonetheless unlikely to have their physical health needs met.

Substantial systems strengthening is required to achieve minimum standards of care. Since physical and mental disorders are often inter-linked (338, 342), standards of basic care matter for depression not only because they undermine the community's faith in the public health system through which depression treatment is provided, potentially leading them to consult elsewhere, but also because poor physical health is a cause of depression. Strengthening the health system should include investing in the workforce to ensure that health care providers have sufficient time, skills and motivation to fully assess patients' health needs, developing inter-sectoral linkages as described above, and incorporating a biopsychosocial orientation into the training of all health care professionals (343).

*Closing the treatment gap*

Closing the treatment gap for priority mental disorders, including depression, is currently a central goal in the field of Global Mental Health (6, 344). The appropriateness of closing the treatment gap for depression must be considered in the knowledge that a large proportion of those who do not currently receive treatment have no desire to do so, and instead describe either social and economic interventions, or treatment for other health problems, as their primary need. This is consistent with evidence that as many as 90% of those who meet criteria for depression have mild or moderate symptoms, who are likely to benefit more from a label of “distress” and informal support, than from a diagnosis and biomedical intervention (345).

The treatment gap is typically measured in terms of treatment-seeking for mental or emotional problems (or in the case of PRIME, for depression symptoms as measured by the PHQ-9 tool). This assumes that an important distinction is whether treatment is sought for mental/emotional problems or for physical/somatic problems. However, many participants saw their health problems as inter-linked, possibly influenced by the lack of distinction between physical and mental health in traditional Indian systems of medicine (346, 347). Along with previous Indian studies (251, 283), we found that most people with probable depression have regular contact with a health provider, for issues that have biological, social and psychological components, but that they only report symptoms that fit with a biomedical viewpoint. We contend that dividing episodes of help-seeking into those that are mental health-specific or not is of questionable utility. The more important gap relates to the quality of support provided by both health and social care services to address the patients’ inter-related mental health, physical health and social needs, rather than to lack of contact with health services specifically for psychological symptoms, as the treatment gap implies (348).

#### 6.5.4 Strengths and limitations

Unlike previous studies of depression in India, this study used a community-based sample in order to explore the perspectives of those who do not seek treatment, and included relatives as well as individuals with probable depression, who may play a role in health care decisions in this context.

However, some limitations should be acknowledged: Firstly, data analysis was conducted in English, whereas the original interviews were conducted in Hindi. To counter any misunderstandings, the first author consulted extensively with the second author during

the analysis, who conducted the interviews and is fluent in Hindi. Secondly, as in any qualitative study, both researchers will have brought assumptions and prior ideas to the research based on their experience and educational backgrounds. We attempted to deliberately examine and challenge these assumptions through ongoing discussion at each stage of the research process.

Participants' mental health status was determined using a screening tool rather than a full diagnostic interview, and other health conditions were not ruled out. Given the relatively low positive predictive value of this tool when it was validated in Goa (125), it is therefore likely that the sample will have included some individuals who would not have received a depression diagnosis had their full clinical picture been taken into account. However, all participants experienced depression symptoms as measured by the PHQ-9 and therefore were well-placed to comment on why they did not seek health care for these, which was the aim of the study.

We were also unable to recruit a family member for every person included, due to unavailability or participants declining to have a relative interviewed, meaning that it was not possible to compare the individual and family perspectives for every participant. However, based on the analysis of the fifteen relative interviews, we believe that we reached saturation of themes arising from relatives' accounts. Finally, we excluded participants who had sought treatment, which would have been a useful comparison group. The views of adults who are receiving depression treatment will be explored in a separate study, however, which can be compared and contrasted with the current findings.

## **6.6 Conclusion**

The depression treatment gap in rural India is largely attributable to low perceived need for treatment for depression symptoms. This was because many participants saw their depression symptoms as inextricably linked with their social circumstances, and therefore felt that biomedical interventions could not address these issues. Participants also considered themselves to have multiple physical health needs, and prioritised somatic symptoms during consultations with health workers since these are compatible with a biomedical model. To close the gap between the community's priorities and the services offered, interventions must be informed by dialogue with the communities they serve, and recognise the social determinants of mental health in the local context. This is likely to require linkages with community-based actors outside of the health sector, in addition to

efforts to improve care for chronic conditions that co-occur with depression. Since most people with depression used health services for somatic symptoms, health care providers – including private providers – require support to assess and effectively respond to patients’ inter-related biopsychosocial needs.

## 7. Synthesis

### 7.1 *Principal findings*

This research project set out to investigate the associations between both geographic and non-geographic factors with treatment-seeking for depression in a rural Indian context, to inform efforts to expand access to mental health care in similar settings. The specific aims of the project were to:

1. Review current evidence on factors associated with service utilisation for common mental disorders (CMD) from across settings;
2. Estimate the increase in health service utilisation for depression associated with increasing proximity to services in rural Madhya Pradesh, India;
3. Compare alternative measures of geographic access to health services;
4. Describe patterns of health service utilisation and treatment-seeking for depression in rural Madhya Pradesh;
5. Explore how individuals with probable depression and their families decide whether to seek help for depression symptoms in the same context.

#### 7.1.1 Factors associated with health service utilisation for CMD globally

The global systematic review showed that “need” factors – in particular, perceived need for health care, chronicity, disability, psychiatric comorbidity and panic symptoms – are most consistently associated with treatment-seeking for depression, with less consistent evidence of variation in the probability of seeking treatment by demographic group (“predisposing” factors, including age, gender, ethnicity, education level and marital status), and little support for an association with “enabling” or structural factors, such as wealth or urban/rural residence. It also demonstrated that our current knowledge base rests almost entirely on studies from high-income countries, and as such these findings cannot be generalised globally.

#### 7.1.2 Proximity to health services and treatment-seeking for depressive symptoms in rural India

The second study tested the hypothesis that travel distance by road to the nearest public health facility offering depression treatment is inversely associated with the probability of

seeking treatment for depression, in a rural area of Madhya Pradesh, India, where depression treatment was recently integrated into primary care services. Although travel distance was significantly reduced after the implementation of the MHCP (median 26.9km versus 9.7km,  $p < 0.0001$ ), this had no effect on treatment-seeking, and the odds of treatment-seeking among adults with probable depression did not appear to change with every kilometre increase in distance to the nearest facility, even after adjusting for potential confounders (OR 1.00, 95% CI 0.98-1.02,  $p = 0.78$ ). The lack of association was unchanged when use of traditional and complementary providers was excluded (OR 0.99, 95% CI 0.97-1.02,  $p = 0.69$ ). The narrow confidence intervals for the effect estimate suggest that the null finding was not attributable to lack of statistical power, and no evidence for distance decay effects were found even when the sample was stratified by symptom severity. There was no evidence to suggest that travel distance is a major factor in explaining treatment-seeking rates among any group, except potentially for the unemployed (for whom the odds of treatment-seeking decreased by 27% for each kilometre increase), who represent only 4.2% of the population.

#### 7.1.3 Measuring distance to health services in rural India

Linked to the study above, I also tested whether Euclidean – i.e. straight-line – distances can be used as a reasonable proxy for travel distance, and whether village centroid coordinates can be substituted for household coordinates, to reduce the complexity and processing demands of conducting geographic research on access to health services. The current evidence supports the idea that these two simplifying research strategies are reasonable when estimating the association of distance with health service utilisation in settings where the terrain is relatively flat, the distances of interest are large (median  $> 7.5$ km), and villages are small in area.

#### 7.1.4 Descriptive analysis of health service use and treatment-seeking for depression in rural India

The fourth study was a descriptive analysis of health care utilisation and treatment-seeking for depression within the same population. It demonstrated that the majority of adults with probable depression (65.6%) had used health services in the past three months, which was significantly higher than for non-depressed adults (45.7%,  $p < 0.0001$ ). The private sector was the most common source of care (consulted by 50.5% of adults with probable

depression who used any health services) while traditional providers were only consulted by 19.2% of adults with probable depression. Concerns about cost and distance (reported by 54.3% and 52.3%, respectively) were the most frequently reported barriers to the use of health care among adults with probable depression, but reporting these barriers was not associated with treatment-seeking for depression.

The following factors were found to be associated with an increased likelihood of seeking treatment for depression; greater symptom severity (prevalence ratio for severe compared to moderate symptoms 3.42, 95% CI 1.33-8.81), being married (PR 2.67, 95% CI 1.19-5.99), having spoken to someone about depression symptoms (PR 7.50, 95% CI 4.11-13.68), experiencing four specific depression symptoms for more than 7 days in the past 2 weeks (tiredness/lack of energy, loss of interest/pleasure, low self-esteem/feeling like a failure, and slow movements/restlessness), and reporting problems with health services' medication supply (PR 1.99, 95% CI 1.19-3.32) and medication availability (PR 2.05, 95% CI 1.23-3.39) as barriers to health service utilisation.

#### 7.1.5 Qualitative study of treatment-seeking for depression symptoms in rural India

Finally, the qualitative results helped to explain some of the findings generated in the studies above, through semi-structured interviews with individuals who screened positive for depression and their families. Interviewees frequently described their problems in terms of stress or "tension", which they clearly distinguished from mental illness. Many perceived no need for health services for these symptoms because they understood these as a response to socio-economic challenges rather than as a medical issue. Others linked their depression symptoms with physical health conditions, often describing multiple somatic complaints, and therefore perceived a need for health care to treat what they saw as their overall or underlying medical issue, rather than for depression symptoms per se. Only somatic symptoms were considered to indicate medical problems that health workers can treat, despite acceptance of the links between the biological, psychological and social domains of health and wellbeing. Family members were important in health care decisions but were often unaware of their relative's psychological symptoms.



## 7.2 Implications



**Figure 1.** A sign for the “Mann Kaksh” (mental health room) in a Community Health Centre

Mental health services cannot achieve public health impact if they are not used by the population who they intend to serve. India has an ambitious and progressive mental health policy, supported by the new Mental Health Care Act and the National Mental Health Programme (78-80, 349, 350). Yet, the proportion of people with depressive disorders who seek treatment is estimated to be less than 15% (69), and the PRIME results showed that this proportion did not increase even when services were made available through primary care facilities (96). Understanding why this is so is crucial to achieving the aims set out in India’s policy documents.

This project addresses the issue of why people with symptoms of depression fail to seek treatment. However, given the strong overlap between depressive disorders and other common mental disorders, such as anxiety (126, 351), these findings may have relevance to CMD more generally.

In what follows I will explore the implications of the above findings for mental health policy and service planning in India. In doing so I will explore the dominant paradigm, which promotes increasing the availability and accessibility of services as a key strategy to expand

access to treatment, and the attribution of low demand to stigma and low mental health awareness (69, 349). I will argue instead that a paradigm shift is needed to align the way services are designed and delivered with the principles of person-centred care (352, 353), in order to meet the target population's needs. I will further question whether the concept of the treatment gap should be redefined or replaced with alternative measures of unmet need.

While these findings are specific to rural India, many of the issues raised may have relevance to other settings, and to conceptual models of access to mental health care and the research agenda in Global Mental Health.

### 7.2.1 Geographic accessibility of depression treatment and service use

The coverage model presented in the introduction chapter set out three key access barriers to mental health treatment; availability, accessibility and acceptability of services (29). Findings from PRIME indicated that increasing the availability of services, through the Mental Health Care Plan (MHCP), was not sufficient to increase contact coverage (96).

This research project included a particular focus on the next barrier in this model, which has thus far received little attention in the Global Mental Health literature; accessibility, operationalised in terms of distance to services. I showed that while the implementation of integrated mental health services in primary care facilities significantly reduced the average distance to the nearest public health service offering depression treatment, these distances nonetheless remained large. I hypothesised that geographic accessibility remained a major barrier to service use for depression, but the results revealed no relationship between distance and treatment-seeking. Service planners should be aware that decentralising the delivery mental health services to reduce travel distance is, of itself, unlikely to have an impact on the treatment gap for depression in this context. This is an important note of caution in a policy environment in which decentralisation of services is a major focus, partly due to considerations of geographic accessibility (8).

Several potential explanations exist for the lack of association between geographic accessibility of depression services and treatment-seeking for depression, which will be appraised based on a synthesis of the findings presented above.

Firstly, distance to services may not be the most important measure of accessibility for this population. Econometric models (e.g. (354)) assume that distance acts as an impediment to service use by increasing the cost of seeking treatment, due to transport costs and travel time. In this setting, travel distance and cost may be only weakly correlated, since participants in the qualitative study described waiting times and opening hours as more important determinants of lost wages than travel time (see appendix G).

Secondly, findings from the descriptive quantitative study showed that adults with depression generally consult the private sector when they need health care, who may be available closer to home (355), rendering distance to public services of little relevance to families' treatment decisions. Evidence from the qualitative interviews indicated that awareness of the availability of depression treatment in public services was low, and mistrust in public health services was widespread.

Thirdly, some studies have suggested that distance primarily affects provider choice, rather than the initial decision of whether or not to seek any treatment (354, 356). If this is the case – which could usefully be tested in a follow-up study to the current project – then the access barriers summarised in De Silva's coverage model (29) may be better viewed as a framework for analysing use of a particular service, rather than whether those with a given disorder use any services.

Finally, and most importantly, one reading of the Andersen model of health service utilisation is that enabling factors, including the ability to travel to services, are necessary but not sufficient for health care use, and are conditional on perceived need for care (41). The qualitative study strongly supports this interpretation, finding that the majority of people with probable depression do not consider themselves to need treatment. In the section below, I will address reasons for the low perceived need for depression treatment and discuss the implications of these.

Is geography therefore irrelevant to mental health service planning? Only if the sole ambition of public health authorities is to reduce the treatment gap. The finding that many people with probable depression endorsed distance as a barrier to health care use suggests that travel distance does matter to participants, even if it doesn't affect their likelihood of seeking treatment for depression. Changing patterns of provider choice may be an important goal if this reduces out-of-pocket expenditure, or if more effective treatment can be provided through public services than through private providers (an assumption that

requires investigation, and is counter to what was found in the MANAS trial (307)). A further location-related consideration in choosing the site of public service delivery is the potential impact of distance on treatment adherence, as suggested by evidence from other contexts (357), which merits further investigation.

#### 7.2.2 Non-geographic factors and the treatment gap for depression in India

Beyond availability and accessibility of services, the coverage model posits “acceptability” of services as the final barrier to seeking treatment (29). Since this is a very broad heading, the Andersen model provides a useful supplement to the coverage model, setting out predisposing factors that influence the acceptability of services, such as illness beliefs and attitudes towards health services, as well as demographic factors that are thought to be associated with attitudes to help-seeking (40, 114).

The Andersen model also makes explicit another category of factors, designated “need” factors, which includes both objective measures of health status and subjective perceptions of one’s health care needs. Need factors are an important addition to the access barriers in the coverage model, as they determine whether any health services are considered to be necessary, regardless of the acceptability of specific services.

As mentioned at the outset, this study used a sequential explanatory design, in which general trends were identified through quantitative research, and qualitative evidence is used to explain those trends (105). I will therefore first summarise the quantitative findings on predisposing and need factors, before examining how the qualitative evidence furthers our understanding of these results.

Evidence from the systematic review suggests that “need factors” are of particular importance to understanding the treatment gap for CMD, while “enabling” or structural factors were less relevant. The quantitative analyses of treatment-seeking in Sehore also implicated “need factors” within the context of rural India – particularly symptom severity and symptom profile – as strongly associated with treatment-seeking, while the evidence for an association with “enabling factors” such as socio-economic status, and “predisposing” factors, such as demographics, beliefs and attitudes, was less strong. The exception to this was that being married, and being able to talk about depression symptoms with someone, were strongly predictive of treatment-seeking in this population,

potentially reflecting the central role of family support in facilitating treatment-seeking in rural Indian contexts (321).

The qualitative findings showed that perceived need for depression treatment was low, due to participants' explanatory models of depression symptoms and the belief that only somatic symptoms can be treated by health care providers. These findings helped to explain the lack of an association between beliefs and attitudes towards mental health and treatment-seeking, since depression was not widely regarded as a mental illness. They also showed that although the head of household's appraisal of their relative's health needs affects health care decisions, adults with probable depression rarely disclosed their symptoms to family members due to the perception that there was nothing that they could do to help. Finally, the qualitative results demonstrated that many people with probable depression considered themselves to have other health complaints besides depression, which may explain why disability and perceived need for health care were not closely associated with treatment-seeking for depression specifically.

Viewed together, this evidence points overwhelmingly towards perceived need or demand-related factors in explaining the treatment gap. There was conspicuously less evidence of the importance of supply issues, such as the enabling factors from Andersen's model or access barriers from the coverage framework, in treatment-seeking for depression specifically. From a policy perspective, the take-home message is that increasing the supply of services is insufficient to close the treatment gap in the absence of demand.

#### *7.2.2.1 Demand and supply*

Within rural India, then, demand side issues appear to be crucial for understanding health service utilisation and the treatment gap for depression as currently conceptualised. Evidence from the systematic review (227), and from the World Mental Health Surveys (281), suggests that rural India is not unique in this regard; around the world, many people with depression do not believe they need biomedical treatment for these symptoms.

The role of demand side factors does not feature prominently in the seminal papers that have shaped the Global Mental Health campaign to scale up mental health services. The mhGAP Action Programme report, for example, includes just one sentence on demand issues, stating that barriers to uptake of mental health services include cost, lack of information, and gender, social, and cultural factors (9). The 2009 "Packages of care for

depression in LMIC” article from the influential PLOS Medicine series includes a single paragraph on the need to “increase patient or consumer demand”, blaming under-use of services on stigma and lack of awareness of mental disorders and advocating interventions to improve mental health literacy and reduce stigma, although they note that at the time there was no evidence available from LMIC that anti-stigma campaigns or awareness programmes lead to increased demand for services (358).

The current findings suggest that the issue of demand for interventions deserves far greater attention in the Global Mental Health movement, and will not easily be solved by the provision of free treatment and information. Health systems consist of a set of relations between institutions and populations (359), and while much analysis focuses on the institutional or supply side, it is a mistake to conceptualise the population only as passive beneficiaries. The evidence presented here indicates that health service research on the supply side can only provide a partial understanding of why mental health interventions fail to reach their intended beneficiaries, and that studying demand issues from the community perspective is key to understanding the treatment gap.

An obvious recommendation, then, would be that demand should be generated through campaigns aimed at improving awareness of mental disorders and mental health treatment (57, 331). Indeed there is evidence to suggest that community-level awareness-raising activities can be effective in increasing contact coverage, both from the VISHRAM programme in India (244), and from other LMIC (360). However, before recommending this it is worth pausing to consider why perceived need for depression treatment is low, and what adults with probable depression and their families currently consider their needs to be, to guide an appropriate and locally-informed approach to demand generation.

Three major factors that were implicated in low demand for health care for depression symptoms (operationalised here as symptoms included in the PHQ-9, which excludes somatic symptoms), are low perceived severity, socio-economic attributions of symptoms, and physical health attributions of symptoms, each of which I will discuss below in the context of initiatives to reduce the treatment gap for depression.

#### *7.2.2.2 Severity of depression and the need for formal treatment*

Although low symptom severity was negatively associated with treatment-seeking for depression, this may appear to be too obvious a reason for low demand to merit

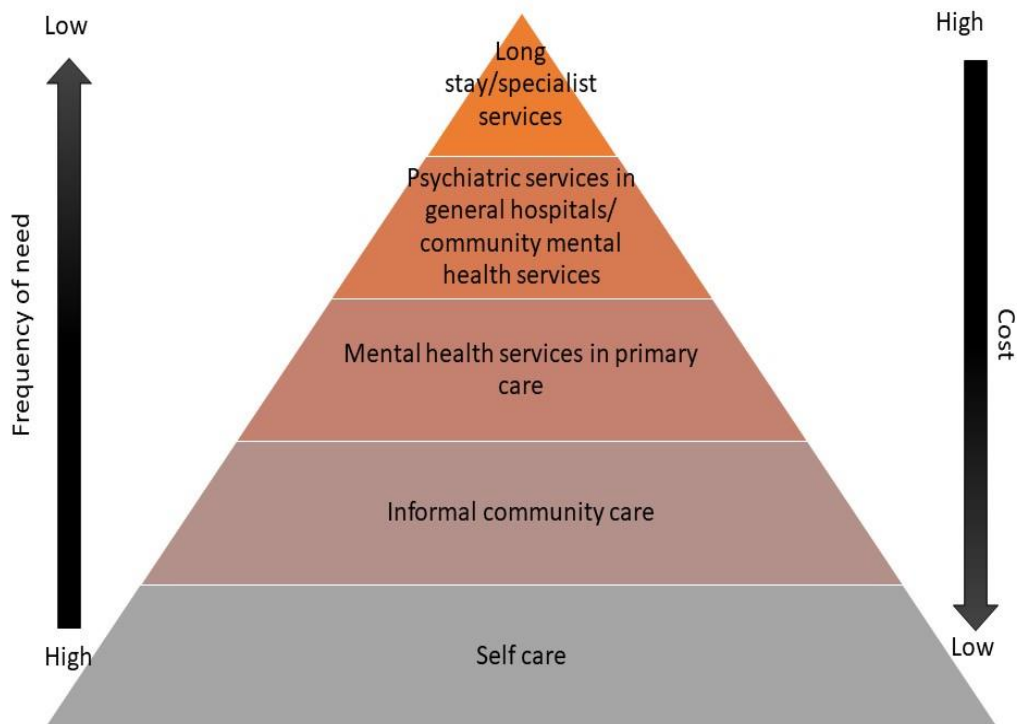
discussion. However, it has important implications for interpreting and acting on the treatment gap. Since depression symptoms are normally distributed in the population (24), it should be unsurprising that the majority of those who meet diagnostic criteria for depression have mild or moderate symptoms (361), as in the current sample, and these individuals are less likely to seek depression treatment. Before launching public awareness campaigns to increase demand for services, then, it is important to ask whether it would be beneficial for population health if all of these individuals sought depression treatment.

There is reason to believe that it might not be. Meta-analyses show that both pharmacological and psychological treatments are less effective for those with milder symptoms (362-364). Studies comparing primary care patients whose depression is detected with those whose depression is undetected have failed to find better outcomes, even in settings with considerably more resources than in India's public health system (365-370), leading Gilbody and colleagues to argue that morbidity can be more effectively reduced by targeting those cases that are identified – who tend to be more severe and chronic – rather than identifying more minor problems (371).

Furthermore, Jacob and others argue that psychiatric categories that were developed in the context of specialist care are a poor fit for the majority of patients seen in primary care, where adjustment problems and borderline cases are common, somatic symptoms are frequent, patients often have mixed presentations and multiple needs, and rates of spontaneous remission and placebo responses are high (25, 372-374). This poor fit between context-free psychiatric labels and the community's perceptions of their distress was evident in the current qualitative findings.

Such evidence has led prominent Global Mental Health advocates to begin calling for a paradigm shift, suggesting that only around 10% of those who meet current criteria for depression or CMD require formal health interventions (122). Resources would therefore be better invested in increasing the quality of care for the minority who both want and stand to benefit from treatment, than on encouraging the majority who have mild to moderate symptoms to seek treatment in biomedical settings. The symptoms of a large proportion of those who meet criteria for CMD but are currently untreated could be more constructively interpreted in terms of psychosocial distress, necessitating a more biopsychosocial orientation in the health and social care system in general (329), rather than specific depression interventions for this group. They should also be supported

through non-medical strategies (discussed below), as per the lowest two levels of the WHO’s “optimal mix of services for mental health” pyramid (see figure 2) (204).



**Figure 2.** WHO’s “optimal mix of services for mental health” pyramid (204)

### 7.2.2.3 The need for multidisciplinary approaches

The second major reason for low perceived need for depression treatment is the attribution of symptoms to psychosocial stressors. Again, this is important for the debate around whether we should respond to the low demand with public education campaigns to change the community’s understanding of the condition.

Social factors are largely ignored when treating people with depression through health services, despite their fundamental importance in the experience of depression by the individuals affected. The biopsychosocial model of mental health is widely accepted, including by the WHO, both to explain the aetiology of mental illness and as a framework to guide treatment (329, 375). Yet, in practice, the MHCP in Sehore focusses exclusively on the biological and psychological aspects of mental health, overlooking the social element that is central to the community’s explanatory models. As Jain and Jadhav observed a decade ago, there is a “conceptual asymmetry between official policies and common concerns of the wider population” (376). To its credit, the mhGAP intervention guide



(version 2.0) includes repeated references to the social circumstances that cause distress and depression, and exhorts practitioners to address factors such as housing, family and relationship issues, financial problems, and access to basic security and services, as a core component of care (337). Unfortunately, with average consultation times of less than two minutes (311), it is virtually impossible to envisage how these recommendations could be implemented within India's current health system.

Again, calls for psychoeducation to change the community's current understanding of depression may be misguided, as there is evidence to suggest that people facing severe psychosocial adversity are less likely to respond to treatment in the absence of a change in their circumstances. In a trial of psychological treatment for CMD in Goa, Patel and colleagues found that patients facing major current life problems were significantly more likely to continue to have high symptom scores after treatment (OR 5.62,  $p < 0.005$ ) and expressed their need for a fundamentally different kind of help (e.g. "Can you find my son a steady job? If he gets a job I will surely be fine" / "I don't have the money to buy myself medicines that the doctor has prescribed and until I get alright I cannot go back to work which means my children will have to go hungry. Tell me what can I do?") (377). In the United States, Cohen and colleagues report that antidepressant treatment is less effective for adults living in impoverished neighbourhoods, even after controlling for psychiatric comorbidity (200), with similar findings reported in other US (378) and UK studies (379). A recent review also found tentative evidence that psychological treatments for depression are less effective for those of lower socio-economic status (380).

Given the extensive evidence on the social determinants of mental health (13), it stands to reason that efforts to improve patients' mental health while the causes of depression are ongoing are unlikely to succeed. Within humanitarian contexts, the importance of securing individuals' basic needs before delivering more targeted interventions is well-recognised (381), but this same logic has not been extended to non-emergency settings. As Marmot famously asked; "why treat people and send them back to the conditions that made them sick?" (382). Although there is robust evidence for the influence of poverty-related social conditions such as food insecurity, inadequate housing, unstable income and low education levels on CMD (339, 383), healthcare systems in LMIC tend to locate resources in hospitals and clinics, leaving the social and environmental factors that affect people's health and wellbeing to non-governmental organisations (384). To quote Jain and Jadhav on previous community mental health initiatives in India; the "largely singular strategy based on

primary health care does not allow an engagement with issues of poverty, social inequity, and the cultural dilemmas of globalisation that India is facing” (376). A decade later, it appears that this critique has not been heeded by switching to more multidisciplinary strategies.

Finally, anthropological evidence – in line with the qualitative findings presented here – indicates that people experiencing ongoing adversity do not want solutions that are separated from the context of their misery. Kleinman argues that suffering is inextricably bound up with the things that matter desperately to people within their day-to-day worlds of experience, meaning that to isolate their feelings of distress from these social experiences is to deny a basic component of their humanity (385, 386). In seeking to help an individual or a community it is therefore necessary to consider depression symptoms in the context of psychosocial hardship. Calls for community participation in the design of mental health interventions appear with regularity throughout the Global Mental Health literature (e.g. (387)), but to make this more than rhetoric we must be prepared to listen to those whom services are intended to help and respond by making meaningful adaptations to the programmes delivered. In this context, it seems clear that listening to participants’ values and priorities, as advocated by the proponents of patient-centred care (352, 353), means engaging with the realities of their lives and designing interventions that address some of the prominent social determinants of mental health.

What does this mean in terms of increasing demand for depression treatment? Firstly, it suggests there may be limits to the benefits of increasing demand for services in the absence of social welfare or community development initiatives that engage with the social determinants of depression in this population. Secondly, generating demand is likely to be a far easier task if services are better aligned with the community’s perceived needs, since lack of demand arises from the perception that health services are not equipped to address the root of people’s problems.

Previous researchers on CMD in India have argued for a paradigm shift, away from the use of psychiatric diagnoses and towards an understanding of CMD as a stress-related disorder with biopsychosocial origins (295). This would be more in line with local understandings of depression as expressed here. Nonetheless, health services still remain ill-equipped to address the sources of stress (388). Using health services as the primary platform through which to address depression restricts the conceptualisation of the problem and its

solutions to the biomedical realm (376), and risks recasting collective problems as individual pathology, requiring medical interventions rather than social change (389). Primary care undoubtedly has a role in helping people with severe depression symptoms, who may need biomedical treatment instead of or in addition to social interventions. It is also essential for the treatment of comorbid health problems, and may be able to play a role in detecting and referring those with social problems. However, tackling many of the issues brought up by participants (such as financial instability and domestic abuse) will inevitably require looking beyond health facilities.

Emphasising social work as a central component of mental health care is one potential route to incorporating these concerns into practice (335). The “Atmiyata” programme in Maharashtra, India, provides a model for how community-based initiatives can incorporate interventions such as the facilitation of access to government benefits, and working with existing community resources such as women’s self-help groups and farmers’ clubs to address poverty as an important risk factor for CMD (336). Interventions for senior citizens in Goa are also being developed that explicitly recognise and act on the proximal determinants of mental health (390, 391). Community-based case managers or chronic care workers may be able to fulfil a similar function, given the overlap between support needed for people with depression and those with other chronic conditions (392). The cost of providing such social interventions is likely to be higher than existing cost estimates that are based on purely facility-based psychological or pharmacological interventions (393), but it is plausible that these costs may be offset by wider economic benefits. Greater evaluation of such interventions – including cost-effectiveness analyses – is necessary to inform efforts to incorporate social interventions into mental health strategies.

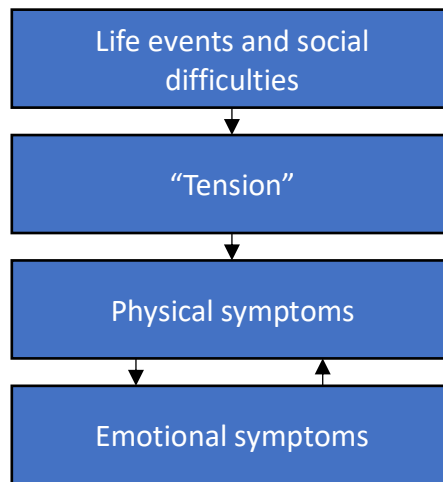
To ensure that there is demand for the services offered, community perspectives must be taken into account when designing and delivering a mental health programme, for instance through participatory action research (394) or co-production in partnership with potential service users (395). However, this may require a fundamental re-think of both the interventions to be implemented and their method of implementation, including more multidisciplinary solutions than the current emphasis on increasing the supply of mental health services through the health sector.

#### *7.2.2.4 Wider health systems issues and health service utilisation for somatic symptoms*

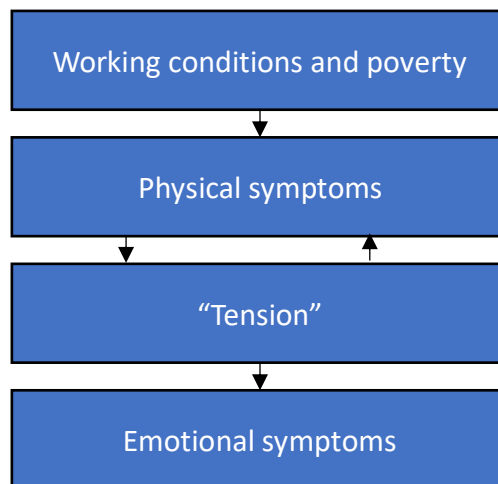
Another important finding from this project was the high proportion of participants who used general health care use for reasons other than depression symptoms, as reported elsewhere in India (251, 283). This finding changes the interpretation of the depression treatment gap, suggesting that the relevant gap is not between those who reach health services and those who do not, but between those whose needs are met or not (i.e. “effective coverage” (29)).

There are two competing interpretations of the high rates of general health service use by adults with depression, which lead to divergent recommendations on how to provide effective treatment to these individuals. The first is that people with depression are seeking help for psychosomatic problems, which need to be recognised and treated as mental health problems (100, 396). During piloting of the MHCP in Sehore, medically unexplained symptoms were the most common presentation reported, with 59% receiving this diagnosis compared to just 9% given a depression diagnosis, supporting the notion that psychological problems frequently manifest in somatic symptoms in this population (65). Under this interpretation, the most important task for policymakers and service planners is not to stimulate treatment-seeking, but to encourage disclosure of these symptoms during consultations and help health workers to recognise and treat these cases (which may need to include inter-sectoral linkages and referrals to actors beyond the health system, as described above).

The second interpretation is that people with depression experience high rates of comorbidity, which is also consistent with extensive evidence (16, 338). Kohrt and colleagues caution against assuming that all somatic symptoms among people who meet criteria for CMD are psychosomatic, based on evidence from Nepal that two thirds of typical somatic symptoms reported by people with CMD could be attributed to physiological comorbidity, and that the same symptoms were also common among those without CMD (397, 398). In contrast with participants’ explanatory models (see figures 3 and 4 for two different causal models expressed by participants in the qualitative study), health systems are largely set up to deal with individual diseases rather than multi-morbidity (399), taking a vertical approach (400), despite the growing prevalence of multi-morbidity in India (401, 402).



**Figure 3.** Conceptual model of the causal pathways of CMD (Andrew et al., 2012) (295)



**Figure 4.** An alternative conceptual model of the causal pathways of CMD

As the second conceptual model shows, many people with depression symptoms believe that they feel depressed because they are physically ill, but cannot access effective health care. In discussions of mental-physical comorbidity there is sometimes an assumption that effective physical care is already available, to which mental health treatment must be added (16), but in a context where services fail to meet basic minimum standards we cannot take the provision of quality physical health care for granted (340, 341, 403). A common complaint in the qualitative study was that government health workers fail to offer a full examination before initiating treatment, which eroded faith in these services and drove participants to use private services instead.

In line with participants' expectations, the mhGAP intervention guide states that all patients should receive a physical health assessment to rule out physical conditions as a cause of the patient's symptoms, and identify and treat comorbid conditions (337). Again, however, the enormous difficulties of achieving this vision within a weak public health system such as India's should be apparent, with minimal consultation times, staff shortages, widespread absenteeism problems and a lack of accountability in the system (297, 340). The vision set out in mhGAP-IG 2.0 is completely at odds with how rural Indian residents describe their experiences of government primary care services at present. True integration requires more than co-location of mental and physical health services (404), but providing genuinely holistic care requires more time for consultations, motivated staff, coordination between professionals, and a working health management information system to monitor patients' care, all of which require a major commitment of time and resources (65).

As many have pointed out, mental health care is only as good as the system it is integrated into (376, 405) and the challenges facing the public health system in Sehore are enormous (65, 86, 406). Recent research on syndemics – the clustering of interacting diseases within a population – reinforces the need to recognise the inter-relationships between depression, comorbid conditions, and their social context, and to develop horizontal services rather than treating mental and physical health in parallel, as independent problems (338, 342).

In summary, an exclusive focus on providing depression treatment without strengthening physical health care, which people with depression in this study often believed they needed, not only reduces engagement with services but also risks neglecting conditions that may be directly or indirectly causing depression (16, 407). In such a setting, the first priority to improve mental health must shift from trying to integrate services into a failing system, to strengthening and transforming these systems in general (408).

#### *7.2.2.5 The role of the private sector*

The private sector rarely features in the Global Mental Health literature (306), but in the evidence presented above, private providers emerged as the primary source of general health care for adults with depression. In 2004, approximately 80% of outpatient health care in India was provided by the private sector, a proportion that has been steadily increasing year on year (296). The qualitative findings indicated that poor perceived quality

of public health services is a major reason for the high rates of private health service utilisation, which is consistent with evidence from elsewhere in India (298).

Service planning must be informed by the reality of the local health care landscape (409). Whereas PRIME, like many initiatives to improve mental health care in LMIC, focusses exclusively on public health services, a growing body of evidence indicates that non-degree allopathic providers, or uncertified rural practitioners, provide the majority of health care in rural India (355, 356, 410-412) and that these providers may prescribe antidepressant medication (413). Given that these private providers are the de facto first point of contact for a large proportion of the population, but are largely unregulated and fail to meet basic standards of quality and safety (340), it is imperative that these providers receive more attention as part of efforts to improve health care in these areas, including for depression.

#### *7.2.2.6 Barriers that were not supported by current evidence*

Before concluding this section on responses to low demand for services, it is worth briefly mentioning the potential implications of some of the null findings from this project for mental health policy and service planning. In particular, the current findings did not support internalised stigma, the use of traditional services, or socio-economic factors as major barriers to treatment-seeking for depression symptoms in rural Madhya Pradesh, contrary to my expectations at the outset of the project.

Stigma is often invoked as a barrier to treatment-seeking for mental illness, and therefore merits some discussion in this context (69, 349). A recent international systematic review concluded that stigma related to mental illness has a negative impact on help-seeking (63). However, out of 18 cross-sectional studies that measured help-seeking behaviour (as opposed to attitudes or intentions), the results were mixed: Half reported positive associations while half reported negative associations, with five reaching statistical significance of which two were positive and three negative. The two prospective studies that used behavioural indicators reported a median association of almost zero ( $<-0.01$  and  $-0.07$ ). None of these studies were from India. A recent anti-stigma campaign for CMD in rural India reported low levels of stigma prior to the intervention (414), which were reduced even further after the intervention, but the study did not measure the association between stigma and help-seeking behaviour, or the effect of the anti-stigma intervention on contact coverage.

The findings presented in this project suggest that, while mental illness is stigmatised, rural Indian participants did not consider CMD to be a mental illness, mirroring findings from Goa (295). This may explain why stigma did not feature as a major barrier to treatment-seeking – at least from generalist health care settings – in either the quantitative or qualitative studies. Biomedical models of mental illness have been shown to be associated with higher levels of some aspects of stigma compared to psychosocial explanations (415-417), and so we should be wary of launching mental health awareness campaigns that encourage people to classify CMD as a mental disorder, since increased perceived need for treatment may be accompanied by increased levels of stigma. Some studies have implicated stigma as a reason for reporting somatic symptoms rather than psychological symptoms (101, 418), but our results suggest that somatic symptoms are reported because these are viewed as biomedical problems whereas psychological problems are seen as reactions to social problems, again consistent with evidence from Goa (309).

Similarly, supernatural illness explanations and a preference for traditional healing approaches have also been invoked to account for the treatment gap in India (69), but the evidence from this project provides little support for this explanation in the case of CMD. Fewer adults with probable depression reported using traditional services in the past 3 months than used either private or public services, and only 2.3% used traditional services for depression symptoms specifically over the past year. Interviewees in the qualitative study indicated that faith healing and other traditional practices were used alongside formal health care, rather than inhibiting their use, as found in other studies (419, 420). This project does not, therefore, provide evidence to support a focus on engaging traditional providers in care for depression in rural India.

Finally, we also found little evidence of socio-economic inequities in access to care, echoing recent findings from the World Mental Health Survey data (202). This may be because private providers, of varying quality and cost, are ubiquitous in India (355, 356), and thus the majority of those who decide to seek health care are able to do so from somewhere, even if that means consulting an unqualified provider. An important contributor to the high rates of private health service use is poor perceived quality of public health services, which reflects objective evaluations of general standards of care (421-426). As discussed above, this suggests an urgent need to assess and improve the quality of care provided in private health services, at the same time as accelerating efforts towards universal health care to improve access to good quality, free health care through the public sector.



### 7.2.2.7 Summary

I have argued that a major reason for not seeking depression treatment is low perceived need for health interventions for these symptoms specifically, rather than access barriers. I have also argued that, given the reasons for low perceived need, we should be cautious about responding with didactic initiatives to increase demand for services among all those who fall into the depression “treatment gap”, but should instead consider (a) targeting interventions at those with severe and distressing disorders rather than at everyone who meets criteria for a depression diagnosis, (b) investing in interventions that address the social determinants of mental health, informed by community consultation and delivered in community settings, and (c) investing in strengthening health systems to improve standards of general health care, both in the public and private sectors.

### 7.2.3 Global Mental Health and the treatment gap for depression

I started this project with a central issue from the Global Mental Health agenda – why there is such a large treatment gap for depression – before focussing in on rural India to examine these issues in a particular context. In this section I will examine the potential implications of this project for these wider debates, and what can be learned from it to inform the movement for Global Mental Health.

#### 7.2.3.1 *Why do treatment gap measures matter?*

First, a reminder of the influence of treatment gap statistics in terms of international health policy and research. In the landmark Lancet 2007 series that propelled Global Mental Health into the mainstream, the authors open their final “call to action” as follows:

“We believe that scaling-up of services for people with mental disorders is the most important priority for global mental health. Every year up to 30% of the population worldwide has some form of mental disorder, and at least two-thirds of those people receive no treatment...” (6)

This quote represents the central argument of Global Mental Health over the past 15 years: Mental disorders are highly prevalent, but although effective interventions exist, only a small proportion of cases receive treatment. This “treatment gap” narrative forms the central basis of arguments to scale up mental health services worldwide, urging

governments and other stakeholders to reduce the gap between the number of people living by mental disorders and the number receiving treatment. The same argument can be seen at the heart of other high-profile publications, such as the 2008 WHO report on integration of mental health services into primary care, and the mhGAP report, respectively:

“Despite the potential to successfully treat mental disorders, *only a small minority of those in need receive even the most basic treatment*. Integrating mental health services into primary care is the most viable way of closing the treatment gap” (8)(italics added)

“The resources that have been provided to tackle the huge burden of MNS disorders are insufficient, inequitably distributed, and inefficiently used, *which leads to a treatment gap of more than 75% in many countries with low and lower middle incomes*. In order to reduce the gap... the World Health Organization (WHO) presents the Mental Health Gap Action Programme (mhGAP).” (9)(italics added)

A Google Scholar search for “mental health” and “treatment gap” gives 6,800 results, while the article by Kohn et al. (4) that coined the term has been cited over 1200 times, demonstrating the traction that this concept has gained. Even a cursory glance at recent literature associated with the Global Mental Health movement demonstrates how pervasive the treatment gap continues to be in shaping the narrative of the central problem to be solved, with numerous high-profile articles framing their findings in terms of the treatment gap for mental disorders (e.g. (72, 244, 344, 427-429)), including those related to PRIME (64).

#### *7.2.3.2 Assumptions that underlie treatment gap measures*

As described above, the treatment gap is defined as the difference between the true prevalence of a disorder and the treated prevalence, or the percentage of individuals who require care but do not receive treatment (4). Its inverse has been labelled “contact coverage” (29) (see figure 5). In practice, as noted earlier, the numerator in these equations is typically measured in terms of treatment-seeking, either for mental or emotional problems in general, or for symptoms of a specific disorder.

<i>Treatment gap</i>	<i>Contact coverage</i>
No. of people with a disorder who <u>do not</u> receive treatment for their condition	No. of people with a disorder who <u>do</u> receive treatment for their condition
No. of people with the disorder	No. of people with the disorder

**Figure 5.** The treatment gap (4) and contact coverage (29)

Three assumptions underlie these measures as appropriate indicators of the extent of unmet need for treatment:

1. All those who meet diagnostic criteria for a disorder require treatment;
2. Treatment-seeking is equivalent to, or can be used as a reasonable proxy for, receipt of treatment;
3. People seek help either for mental health reasons or for other (physical) health reasons, and can clearly distinguish between the two.

I believe we have reason to question each of these assumptions, based on evidence from this project and other studies.

#### *7.2.3.3 The extent of “need for treatment”*

The first of these assumptions has been rigorously debated in the critical literature on Global Mental Health (e.g. (34)) and is discussed above. In the treatment gap literature, meeting diagnostic criteria for a mental disorder (i.e. the denominator in both treatment gap and contact coverage equations) is assumed to indicate a need for mental health care, leading prevalence estimates to be used as a measure of population-level need for services. Mechanic argues that prevalence figures are likely to overestimate the need for formal care, and proposed three approaches to determining need: (a) whether those affected judge that they require formal assistance, (b) levels of disability, or the extent to which symptoms interfere with functioning, and (c) demonstrated value of intervention (203).

The current findings reinforce the idea that many individuals with CMD do not consider themselves to need health interventions for depression symptoms. Some argue that this lack of demand for services is due to low mental health literacy (e.g. (331)). However, a fundamental principle of person-centred care – a concept that the WHO and HIC governments are increasingly aspiring towards (353) – is respect for the service user as the ultimate expert on their own values and priorities, rather than assuming that health care providers always know what is best for patients (352, 353). The need to listen to the communities that international aid projects are intended to serve is increasingly being recognised in the humanitarian and development sectors (430). Taking the person-centred approach seriously means acknowledging and respecting that many adults with depression do not want health care for these symptoms. Rather than attempting to re-educate the target community to align their perceived needs with the services offered, a person-centred approach would involve listening to adults affected by depression when they say that what they need is help with psychosocial stressors and improvements to their quality of life, and changing services to better meet these needs.

Regarding the objective value of intervention, we must consider that over 80% of untreated cases in the current setting had mild or moderate symptoms (PHQ-9 score of <15). These individuals are less likely to benefit from formal treatment than those with severe disorders (362-364). Many of those who meet current criteria for CMD but have mild-to-moderate disorders, therefore, do not necessarily require formal interventions through the health sector (122, 345). The denominator of the current treatment gap paradigm therefore appears to represent an overestimate of need, according to the parameters set out by Mechanic (203).

#### *7.2.3.4 Treatment-seeking versus receipt of treatment*

The second of these assumptions has not been explicitly acknowledged in the treatment gap literature. Measuring any contact with health services versus no contact with health services within a given period is a simple task, with little room for differing interpretation between providers and patients (260, 261). However, when it comes to dividing contact with health services for physical health problems from contact for mental health problems, the potential for divergence between patients' and health providers' perceptions increases.

In their widely-cited systematic review, Kohn and colleagues (2004) present treatment-seeking for mental health reasons and the receipt of any treatment for mental health

problems as equivalent (4). They initially define the treatment gap in terms of treatment receipt (any mental health treatment, not minimally adequate or effective treatment) but later state that “service utilization was defined as seeking assistance from any medical or professional service provider” (italics added). The review includes a mixture of studies in which the outcome was measured as seeking treatment for mental health reasons (e.g. (431, 432)), as well as some that measure the treatment received (e.g. (433, 434)) and others that are mixed or poorly defined. Similarly, the WHO’s 2008 report on integration of mental health services into primary care describes the treatment gap in terms of “the number of people receiving care and treatment” (italics added) (8), but goes on to cite studies that measured treatment-seeking for mental health reasons (53).

Patients’ help-seeking behaviour can certainly be theoretically distinguished from the health system’s response in providing treatment. On one hand, individuals with mental disorders may seek help for psychiatric symptoms, but not receive any mental health diagnosis or psychiatric treatment. Equally, a mental disorder may be detected by a health provider without the patient actively seeking help for these symptoms (for instance, through screening during treatment for another condition).

PRIME provides a perfect example of the disconnect between treatment-seeking and treatment receipt in practice. Many of those who received treatment as part of the MHCP had either come to health services for help with other complaints, or were identified in community settings without having sought treatment (PRIME data, unpublished). Thus, treatment receipt occurred in the absence of treatment-seeking. Conversely, before the MHCP was implemented, rates of detection and treatment of depression in primary care were both 0% (294), so of the 68 individuals in the baseline community survey who reported seeking treatment for depression, those who visited public health services presumably received no depression-related diagnosis or treatment, even when this is distinguished from minimally adequate treatment.

It seems likely that this issue is not confined to PRIME, given that patients with mental disorders who present to health services are frequently undiagnosed and untreated across settings (435, 436). On the other hand, antidepressant medication may be given out by unlicensed health care providers in response to a range of complaints (413). Self-reported treatment-seeking for mental health reasons may therefore diverge considerably from measures of treatment received. This discrepancy indicates an important flaw in the way

that the treatment gap is measured. From a public health perspective, receiving treatment is arguably a more important measure than seeking it, but this is not what many of the treatment gap statistics that are frequently cited actually measure.

#### *7.2.3.5 Treatment-seeking for mental versus physical health*

Finally, in cultures in which mental and physical health are less clearly divided than in Western settings, the third assumption may not withstand scrutiny. Dividing episodes of help-seeking into episodes that are mental health-specific or not – even solely from the patient’s perspective – can be complex, for several reasons.

Firstly, it is well-documented that many people with CMD seek help for somatic rather than psychological symptoms of CMD (100). Pereira and colleagues (319) recommended the use of somatic idioms as the defining clinical features of depression in Indian populations. Indeed, studies across a range of settings have shown that this phenomenon is not specific to Indian populations, and that somatic symptoms such as bodily aches are commonly experienced by people with CMD around the world (396, 437, 438). In PRIME (52, 55), contact coverage was measured with reference to the symptoms listed in the PHQ-9 (278), but since the PHQ-9 does not include somatic symptoms, this measure therefore excludes treatment-seeking for these core features of depression. Given that most participants in the PRIME community survey did report recent contact with health services for some reason, had the question been framed in terms of commonly experienced somatic symptoms the estimates of contact coverage would be expected to be substantially higher. The treatment gap for depression should therefore be interpreted as a measure of the extent of treatment-seeking for psychological symptoms of depression only, which represents a minority of depression-related help-seeking.

Secondly, people do not necessarily distinguish between treatment-seeking for depression symptoms and for other health problems, since it is not obvious to those without medical training which of their symptoms form part of the same underlying health issue. During qualitative interviews for the current project, it became apparent that some interviewees did not clearly delineate treatment-seeking for depression symptoms from treatment-seeking for their other health complaints, depending on the specific symptoms experienced. Discussions about seeking and receiving treatment specifically for mental health problems were often confusing, as participants switched between talking about psychological and other symptoms interchangeably. The following excerpts illustrate this

difficulty. (Note that many participants referred to their psychological problems in terms of “tension”, as previously documented (295, 320, 325).)

*Interview with a relative of a 54-year-old woman with moderate-to-severe depression symptoms:*

Interviewer: “Has she taken any treatment particularly for tension?”

Respondent: “Yes, she had taken two years ago.”

Interviewer: “Where?”

Respondent: “Here in Sehore town. She had pain in her chest, for that she had taken treatment. From that time her chest pain is lesser now.”

Interviewer: “Oh, for pain she had taken, not for tension?”

Respondent: “Yes, she had taken treatment for her symptoms at that time. She had complaints of chest pain, hands and legs pain, for these complaints she had taken treatment.”

*Interview with a 60-year-old man with moderate depression symptoms:*

Interviewer: “As you have been stating your problems like tension, anxiety and giddiness, so for these have you taken treatment from [a] doctor yet?”

Respondent: “Yes, I have taken.”

Interviewer: “Have you taken treatment for tension?”

Respondent: “Yes, I go every month and get tests done. I keep doing it 8-15 days.”

Interviewer: “For what?”

Respondent: “For checking that how much anxiety is upon me. Yesterday I had 190 degree anxiety.”

Interviewer: “Oh, blood pressure was 190.”

Respondent: “Yes, I went yesterday morning and got it done.”

*Interview with a 43-year-old women with moderate depression symptoms:*

Interviewer: "But didn't you take treatment for chest pain? And what about tension and worrying?"

Respondent: "Yes, yes, I have taken for all of these."

Interviewer: "Okay, so you have taken for these too? For tension and worrying too?"

Respondent: "Yes, yes, yes."

Interviewer: "Recently two months back?"

Respondent: "I had chest pain, I got check-ups done for chest pain, I got sonography and x-ray done so it all might have appeared in the tests."

All of the interviewees above had answered "no" to the contact coverage question used in PRIME, and yet their descriptions above provide a more complex picture.

This issue does not merely reflect a problem with the phrasing of the contact coverage measure used in PRIME. An alternative measure of the treatment gap, used in the World Mental Health Surveys (WMHS), asks participants if they have consulted any of a list of professionals "for problems with emotions, nerves, mental health, or use of alcohol or drugs" (5, 22, 54). This measure is also rendered problematic in contexts in which participants do not divide their health, and their corresponding use of health services, into neat camps of "mental/emotional" and "physical". Whereas the Cartesian division of mind and body still permeates much of Western thought, the idea that the mind affects the body and vice versa may be more widely accepted in Indian traditions (346, 347), making the distinction between mental and physical health, and the separation of treatment for each, less self-evident than it appears from a European or North American perspective.

Thirdly, concepts of mind and mental health also influence the interpretation of whether health care was sought "for mental health reasons". As described above, interviewees in the qualitative study described "tension" – the most commonly used term to refer to the experience of depression – as entirely distinct from mental illness, in line with previous research from India (295). "Tension" was described as a psychological response to stressors, whereas mental illness was generally associated with symptoms of psychotic



disorders or intellectual disabilities. Therefore, regardless of whether they had sought treatment for “tension”, these participants would not consider themselves to have sought or received treatment for a mental health problem. From this perspective, the WMHS list of “emotions, nerves, mental health, or use of alcohol or drugs” may appear to be a heterogeneous set of problems, and it is ambiguous whether “tension” would be classified as part of this group, complicating the interpretation of responses. Participants in the qualitative study were keen to differentiate their health problems from mental illness, when this was mentioned, potentially reducing their inclination to identify their help-seeking as part of this category.

As Kohrt and colleagues point out, there is huge variation in how mind and body are conceptualised in non-Western cultures (397). In our research, similar to findings from Nepal (439), mental illness was associated with the brain-mind (“dimaag”), as distinguished from the heart-mind (“man”), which is associated with emotions. Phrasing questions in terms of one or the other concept is likely to lead to major differences in responses that are not evident when translated into English. Much more transparency around which of these concepts is used in surveys is essential to avoid misinterpretation of the findings.

Finally, the issue of which problems motivate treatment-seeking can be interpreted in terms of symptomatology or aetiology. The question used in the WMHS relies on participants being able to categorise their symptoms as either psychological or physiological, but when asked whether they believed their symptoms were related to their emotions or if they had an organic cause, some participants said that only a doctor (or god) could determine this. While some talked about psychological symptoms being caused by physical illness, participants also frequently described “tension” giving rise to physical illness, which then requires biomedical treatment (as described in Chapter 6). Whether treatment for physical problems that result from stress should be classified as “problems with emotions, nerves, mental health, or use of alcohol or drugs” depends on whether this question is understood as referring to the cause of health problems, or to the nature of symptoms.

The question used to measure contact coverage in PRIME (and therefore in the current project) clearly refers to psychological symptoms of depression, rather than to mental health-related problems in general, and so is less affected by issues related to concepts of mental health and the causal attribution of symptoms than the WMHS measure. It is

nonetheless complicated by the fact that adults with probable depression do not always speak of their help-seeking as restricted to either their depression symptoms or to other symptoms, as described above, suggesting that study participants may not have understood this question in the expected way.

These reflections are based on a population from rural central India, and do not necessarily apply across settings. However, they raise a number of questions about the validity of current measures of the treatment gap, which warrant further investigation in a wider range of contexts. Considerable time and resources have been invested in validating measures of mental disorders cross-culturally, but very little has been devoted to the cross-cultural validation of contact coverage measures. At present these measures are viewed as sufficiently self-explanatory that even in high-profile studies such as the Vidarbha Stress and Health Programme (VISHRAM), the results of which were recently published in the *Lancet*, the question used to measure this was not included in the text despite constituting the primary outcome measure of interest (244).

The validity and measurement of the contact coverage concept warrants far greater attention if treatment gap statistics continue to be widely used in Global Mental Health. Measures used to evaluate treatment coverage must be locally validated in the same way as screening and diagnostic tools prior to their use in research. When there is no obvious “gold standard” against which to compare these measures, qualitative methods should be used to assess understanding of the proposed questions, and alternative measures considered when these questions prove to lack validity within the local context.

#### *7.2.3.6 Re-thinking the treatment gap*

In line with the current findings, Pathare and colleagues recently argued that the treatment gap is an inadequate measure of unmet need for care by people with mental disorders (348). They contend that the “treatment gap” implies a need for biomedical interventions for all those who meet criteria for a disorder, leading to an exclusive focus on curative clinical services, and propose replacing this with a broader term, the “mental health care gap”. This latter concept is intended to recognise unmet needs for psychosocial care (such as disability benefits and other social welfare measures) as well as the need for physical health care by people with mental illness.

The felt need for psychosocial interventions and effective physical health care were both evident from the qualitative findings presented here, as was the lack of perceived need for formal depression treatment by many, especially those with milder symptoms. In rural India, participants' understanding of health appears to be in line with a biopsychosocial model, in which the mental, physical and social are closely inter-related, with bidirectional links between these (329, 440, 441). The treatment gap narrative takes a narrower view, which conceptualises both "need for care" and "treatment" in isolation from general health status and social circumstances. According to the treatment gap paradigm, participants' needs are met only if these symptoms are directly treated, but not if the causes of mental ill health are addressed, which is what many people with depression say they want. Above, I have tried to make the case that not only do the community's perceived needs matter in terms of influencing help-seeking behaviour, and that there is a moral imperative to incorporate the community's priorities in person-centred service planning, but also that the community's views on this are, at least to some extent, supported by evidence.

The WHO defines health as a "state of complete physical, mental, and social well being" (442). Rather than addressing only one third of these interwoven aspects of health, a central challenge for Global Mental Health should be to work towards meeting people's mental, physical, and social needs, which will require collaboration with colleagues in other areas of health, as well as those engaged in social and community development work. While mental health treatment is one component necessary to achieve this goal, the treatment gap paradigm does not capture either necessary or sufficient conditions to meet the needs of people with mental disorders. In other words, not everyone within the treatment gap requires formal depression treatment, nor does the receipt of depression treatment alone signify that their needs are met. Putting into practice the biopsychosocial ideals embodied in documents such as the mhGAP-IG 2.0 (337) requires a fundamental shift in the way that "treatment" is conceived and delivered, from the current biomedical paradigm of treating single diseases towards considering whole people with interwoven social, physical, and mental health needs.

### ***7.3 Strengths and Limitations***

Despite the prominence of the treatment gap in the Global Mental Health literature and the current focus on depression and other common mental disorders in international

mental health policy (9), there is a dearth of research from LMIC using population-based samples to systematically investigate factors that influence treatment-seeking for depression (227). The studies presented here use multiple methods to further our knowledge of treatment-seeking for depression in the context of rural India, combining the advantages of generalisability from quantitative research using a large, representative sample of the population, with the depth and richness afforded by in-depth qualitative research to understand social processes in more detail. This project includes the first population-based study to empirically evaluate the contribution of geographic accessibility of health services to the treatment gap for depression in India, which has direct relevance for service planning. This project is also the first to apply the Andersen socio-behavioural model to understanding treatment-seeking for depression in India, supplementing analyses of data from a large, population-based sample with in-depth qualitative interview data that enable the examination of some of the assumptions that underlie the quantitative results. It makes an original contribution to the evidence base on the treatment gap by systematically examining reasons for the treatment gap using an established model that enables comparisons across settings; by testing methods for estimating geographic accessibility in rural India; and by critically examining the way in which the treatment gap is measured.

However, there are many limitations of this research that should be recognised, and which are discussed below.

### 7.3.1 Interpreting null findings

Publication bias could have affected the results of the systematic review, since null associations are less likely to be reported. Null associations are also more likely to have been missed if they are not reported in the title or abstract. We should therefore be cautious in assuming that the trends observed hold consistently across all studies.

Although the sample size of the quantitative studies presented here compares favourably with other studies of help-seeking for depression (227), the sample size calculations were not aimed at answering the current research questions, and some sub-group analyses will have had limited power. Greater sample size would have enhanced the ability to detect smaller effect sizes, although these are likely to be less important from a public health perspective.

### 7.3.2 Focus on public sector

Private providers were not included in the GIS study (neither formal, informal, nor traditional) reflecting PRIME's focus on public health services (64). Given the ubiquity of private providers in rural India (248, 249, 355), had it been possible to map all of the private providers in the area and includes these in the analysis, the results might have differed substantially. Developing a database of all private providers, in their various forms, and their capacity to treat depression, is a separate research project worthy of pursuing in its own right.

### 7.3.3 Geographic measures

While efforts were made to apply the most rigorous methods possible for estimating geographic accessibility, this analysis was limited to some extent by the data available. GPS data were missing for 1,406 out of 4,297 participants (32.7%), and so village coordinates were used instead. Small tracks were not included in the road networks available for the study area, and so travel distance to the nearest road was estimated based on straight line distances. Finally, data on access to different modes of transportation were not available, and therefore it was not possible to calculate estimates of travel time. However, the effect of substituting village coordinates for household coordinates was tested and found to have minimal effects on the results of the analysis, and since Euclidean (straight line) distances were found to be a reasonable proxy for travel distance, it seems unlikely that the inaccuracy introduced by estimating distance to the nearest road altered the findings.

The impact of measuring distance rather than travel time, due to lack of data on mode of transport, and the assumption that participants travel along the shortest route by road regardless of whether they walk, use private transportation, or take public transport, is unknown, however. The qualitative data demonstrate the difficulties of collecting and incorporating such data, however, since participants described how vehicle ownership does not necessarily correspond to the usual mode of transport (as sometimes this vehicle is in use by another relative, and many people borrow vehicles from other households) and varied in their mode of transport from visit to visit. When self-reported travel time for general health care (i.e. for any reason, not just depression) was compared with estimates of travel distance to the nearest public health service these were only moderately correlated, which could indicate variations in mode of transport and other factors that

affect travel time besides distance (such as traffic, weather, road conditions and whether the shortest route is taken). Alternatively, as suggested by findings from the descriptive quantitative study, this might simply reflect the fact that many people use private services and therefore are not travelling to the destination assumed in this analysis. Ethnographic research into travel for health care would be necessary to develop appropriate measures of travel time for this context.

What is clear from this analysis, however, is that existing distance measures – whether simple Euclidean distance or measures of travel distance via road using network analysis techniques with currently available data – show no association with treatment-seeking for depression when the distance in question is from households to the nearest public health facility offering depression services, and therefore the present evidence does not support the relocation of public mental health services as a sufficient strategy to reduce the treatment gap for depression in rural India.

#### 7.3.4 Non-response bias

Refusal rates in the baseline community survey were low (0.2%). However, many sampled individuals were not contactable, leading to the replacement of 2,865 individuals (out of 9,068) to reach the total sample size. Some groups who are less likely to be located, such as migrant workers, may therefore have been under-represented. Since voter lists are also only updated periodically, those who have recently reached voting age are also likely to have been excluded. The current findings therefore cannot necessarily be generalised to more mobile populations, or to young adults who have just reached the age of majority, whose needs warrant further investigation.

#### 7.3.5 Inferring causality

These analyses used cross-sectional data and therefore where associations were reported, causal relationships cannot be assumed. The same applies to the majority of research on this topic, even in high-income countries (227). There is potential for reverse causation in the case of some of factors implicated by the Andersen model, such as symptom severity and beliefs or attitudes towards health services, which may be modified as a result of seeking treatment. This research project is an important first step in building the sparse evidence base around treatment-seeking for depression in rural India with a description of

treatment-seeking patterns. Longitudinal studies are necessary to further illuminate the causal role of these factors in the treatment-seeking process.

The descriptive quantitative study also involved multiple tests, increasing the likelihood of type I errors, and as such the findings should be regarded as exploratory and hypothesis-generating, with future hypothesis-testing research needed to establish causal links between treatment-seeking and the factors implicated.

#### 7.3.6 Limitations of instruments

The PHQ-9 is a screening tool rather than a diagnostic instrument, although it has been used to assess treatment needs and outcomes in other settings (443, 444). Several authors have argued for a dimensional rather than categorical view of mental disorders (24, 445), so the criterion used should be interpreted as indicating an elevated level of symptoms within a continuous distribution, not the presence or absence of an underlying disease. However, the likely inclusion in the sample of some individuals who would not be diagnosed with major depressive disorder by a clinician (as indicated by the low positive predictive value of the PHQ-9 in the only study to have validated it in an adult population in India (125)) does affect the interpretation of the results, in that those whose symptoms are directly attributable to another condition – or to side-effects of treatment for another condition – might not be reasonably expected to seek treatment specifically for depression symptoms. For example, the interpretation of and responses to symptoms like insomnia, low mood and loss of appetite are likely to be different if these are associated with a long period of fever, or are expected side-effects of a necessary medication, compared to if these are experienced in isolation. The measure of probable depression used in PRIME and in this study does not make such distinctions. Equally, the PHQ-9 measures only current symptoms, while treatment-seeking was measured with a 12 month timeframe, thus excluding those who had experienced recent episodes but had recovered at the time of the survey.

Several other variables included in the current analysis also used imperfect instruments, particularly measures of economic status, as set out in chapter 5. Thus, these findings require replication using alternative measures. Furthermore, the measurement of perceived need for care was not specific to depression care, but rather to any health care. It would have been useful to measure perceived need for depression treatment, as well as

perceived need for any health care, in order to test the hypothesis generated in the qualitative study that this is the dominant barrier to treatment-seeking for depression.

### 7.3.7 Unmeasured variables

The data are constrained by what was measured through the PRIME community surveys, which excludes relevant contextual factors, such as local safety levels and neighbourhood level measures of health. The sub-district may also be too homogeneous with regard to some variables to show variations that might be evident at a larger scale. The effect of factors that are relatively invariant across the study area could therefore be underestimated.

The lack of measures on physical health is an important limitation of these studies, meaning that it is not possible to distinguish comorbid problems from somatic manifestations of depression. As Kohrt points out, this is also a limitation of many studies of common mental disorders in non-Western settings that is rarely explicitly acknowledged (397, 398). Understanding the range of health needs experienced by people with depression is essential to plan services that take into account the potential inter-relationships between these conditions and their treatment (338, 342).

### 7.3.8 Complexity and systems thinking

Research on health systems and public health increasingly recognises that complex adaptive systems, including health systems and communities, present particular challenges to study, based on insights from complexity science (446, 447). Such systems are characterised by features such as interconnected feedback loops, change over time, embeddedness within other systems, fuzzy boundaries, path dependency (i.e. sensitivity to initial conditions), emergent properties, inherent self-organisation, and unpredictable consequences of small changes in the system (448). The current project has arguably not fully embraced the paradigm shift advocated by systems thinking researchers. Future research using more sophisticated methods could usefully build on the current findings to examine the inter-dependency between factors implicated here and – particularly in the context of the scale-up of depression services across Madhya Pradesh – investigate the effect of any changes in depression treatment behaviour on other aspects of the system, and vice versa. For instance, qualitative findings suggested potential issues of diagnostic over-shadowing resulting from participants being assigned a depression diagnosis without



further investigation, which could potentially worsen health outcomes for other conditions that either cause depression or have overlapping symptoms, and further erode trust in public health services. Complex systems perspectives have a valuable role to play in elucidating this hypothesis and others generated by the current findings.

#### 7.3.9 Linguistic and cultural issues

Data were collected by research workers other than myself, for language reasons. There is the potential for nuance, tone and body language to be lost in translation when data are analysed, and for problems in data collection to be overlooked. To reduce this possibility, I accompanied the survey team on several occasions to observe quantitative data collection, and was present for all of the qualitative interviews. Following these interviews I took detailed field notes and discussed my observations with the local research team, who were able to clarify many of my queries and correct potential misunderstandings. I have also discussed my findings, and the themes emerging from the qualitative analysis throughout this process, with multiple members of the PRIME India team to minimise the potential for cross-cultural misinterpretation.

#### 7.3.10 Generalisability

Data used are from Sehore sub-district only, and may not necessarily be generalisable beyond this area. However, an advantage of this setting is that the area is typical of much of Hindi-speaking central India. The hypotheses generated here should be tested in other settings.

### ***7.4 Directions for future research***

Findings from this project raise several questions for mental health service planning in India and suggest avenues of research for addressing the needs of people with CMD across settings.

#### 7.4.1 Replication and testing of hypotheses on the role of geographic accessibility

Firstly, future research should replicate the finding of no association between treatment-seeking for depression and travel distance in India and in other low-resource settings. The

PRIME community surveys offer an ideal opportunity to investigate this question across diverse LMIC contexts (52, 55). Ideally such analyses would include not only public health care providers but also map the private providers within the same area. Creating a comprehensive spatial database that includes all of the sites within a catchment area where people with depression seek health care – regardless of the treatment available – and incorporating public transport networks would help to confirm the interpretation of the results presented here.

In larger populations, or where treatment-seeking rates are higher, the relationship between travel distance and provider choice among those who do seek treatment for depression could also be examined (the number of treatment-seekers was too small to examine this in the current dataset). Facility-based data from health service records, or from the PRIME Facility Detection Surveys (52, 294), could be used to triangulate these findings by demonstrating the areas served by each particular facility. A very preliminary analysis of the community survey data and PRIME facility data in India (unpublished) supports the idea that people will choose the nearest provider from among their chosen provider type (i.e. among those who visited a public primary care facility, the majority appeared to choose the nearest to their home). Preliminary analyses also suggest that distance to public health services has a small effect on the use of public health services for any reason, but not on overall health care use. This suggests that location may be a relevant factor in the second stage of a two-step decision model in which the first decision is whether to seek care and the second is from where. The hypothesis that proximity to services is associated with the choice of health care provider among those who seek treatment requires rigorous testing while controlling for confounding factors.

#### 7.4.2 Testing association between geographic accessibility and treatment adherence

This research project focussed on the aspect of health service utilisation that is reflected in measures of the treatment gap; i.e. contact coverage, measured in terms of treatment-seeking for depression symptoms (29). Effective depression treatment requires repeated contacts (337), however, and structural factors that can be overcome for a single visit to a health care facility may not be easily overcome on multiple occasions. The impact of travel distance on adherence to treatment therefore also warrants investigation. Attrition rates from MHCP services were high (96). Future research should use process data from PRIME to map patients' villages of residence in order to test the hypothesis that geographic

accessibility is associated with adherence, and examine differences in attrition by other factors from the Andersen model.

#### 7.4.3 Exploring context-specific measures of accessibility

Future geographic work in rural Indian settings would also benefit from both GPS tracking of actual travel routes and ethnographic research on the process of travelling to health services, to understand the relative contributions of travel distance and other factors to the overall time and cost involved in seeking care. The resulting factors can then be used to develop spatial models with which to measure of travel impediments in a way that is sensitive to local conditions. Such models need to recognise the potential for travel barriers to change over time, by season and as vehicle ownership gradually increases. Based on these findings, location allocation models (449) may help to inform decisions about which facilities mental health services should be integrated into to optimise the cost of travel to services for the population.

#### 7.4.4 Testing hypotheses on the role of non-geographic factors

This study also described associations between various predisposing, enabling and need factors and treatment-seeking for depression, which generated various causal hypotheses about the role of these factors in treatment decisions. For example, the hypothesis that being married facilitates treatment-seeking warrants confirmation in subsequent hypothesis-testing studies, controlling for confounding factors, particularly age. Similarly, the hypothesis that socio-economic factors are unrelated to treatment-seeking (but may influence provider choice) also requires further testing, as do the associations between treatment-seeking and gender, internalised stigma, education and beliefs and attitudes, to establish whether the lack of association with treatment-seeking in the current study was due to limitations of the measures used, or whether these are indeed irrelevant to treatment-seeking for depression in rural India.

Again, the PRIME community surveys offer an opportunity to investigate common factors and setting-specific factors that influence treatment-seeking for depression in a range of low-resource settings, including contextual factors that vary between sites. Although the MHCPs in all participating countries were based on the principle of integrating mental health into primary care using mhGAP guidelines, the resulting plans were unique to each setting. In Nepal, for example, services were delivered in the community across a smaller

geographic area, and implementation was led by an NGO with greater control over the budgets, workforce and activities, in contrast to the facility-based model used in India that was constrained by working within the public health system (64, 230), so an important research question when investigating treatment-seeking will be to disentangle programme effects from other contextual influences. Again, if the numbers seeking treatment are sufficiently large then it would also be informative for policy and service planning to examine non-geographic factors associated with provider choice, using mixed logit models that have been employed in other areas of health services research (354). It may even be possible to experimentally manipulate some of the relevant factors of interest – for example, providing compensation for travel costs and lost wages – to assess the impact of potential changes in these.

#### 7.4.5 Assessing care provided for depression in private health services

The study presented in Chapter 5 suggested high rates of use of private health services by people with depression, demonstrating the need to assess the quality of care provided in these settings. In Goa outcomes for adults with depression who were treated in the private sector were found to be comparable to outcomes in public services (307), but whether the same would be found in the far more impoverished area of rural Madhya Pradesh, where many providers are unqualified (248, 341), is unknown. Some research suggests that unlicensed private providers (or “rural medical practitioners”) regularly dispense psychopharmacological treatments (413). Future research could usefully compare the relative treatment quality and total costs (including transport, fees and lost wages) between private and public health care providers, both for depression and for other health conditions. This would provide a more in-depth understanding of why private providers are consulted so regularly, the quality of treatment provided, and potential strategies to either change this pattern of consulting or improve the safety and efficacy of treatment received. Future intervention studies should explore the feasibility of including private providers and measure depression outcomes for those who consult in different sectors.

#### 7.4.6 Assessing physical health of adults with probable depression

People with depression in the current study reported a wide range of somatic symptoms, and it was not possible to establish which of these were attributable to depression and which resulted from comorbidity. Understanding how health conditions cluster within this

population and how chronic illnesses in combination affect disability and the care received is essential for health care planning that moves away from siloed approaches towards more effectively integrated care. Future research should include clinical measures of general health status to assess the extent of comorbidity with depression in this population, which would enable service planners to develop appropriate services and to improve detection of depression in health services. These studies should also compare somatic symptoms between depressed and non-depressed individuals, to assess their specificity as markers of depression. Future intervention studies should test integrated care models for depression and comorbid chronic conditions, which have shown promise in HIC (450, 451).

#### 7.4.7 Evaluating interventions that target social determinants of mental health

The current findings also suggested a need for psychosocial interventions targeted at the social determinants of mental health, such as financial strain and domestic abuse. The hypothesis that those facing severe current psychosocial adversity are less likely to respond to formal treatment requires rigorous testing, as this has clear implications for the delivery of mental health interventions particularly in low-resource settings.

Existing local organisations and civil society initiatives to address the community's wider needs, such as farmers' cooperative and women's self-help groups, should be identified, and the feasibility of establishing referral mechanisms between these and the health sector should be assessed. The cost-effectiveness of mental health initiatives that explicitly address the social, as well as physical and psychological, needs of people with CMD should be evaluated, of which there are many examples within India (e.g. (336, 452-454)). Greater evaluation of mental health outcomes should also be included in development and social protection initiatives, such as in promising recent work on cash transfer programmes in sub-Saharan Africa (455-457) and Mexico (458), and their cost-effectiveness as interventions for depression should be evaluated, to develop the evidence base on the impact of poverty-alleviation initiatives on CMD (459).

Participatory approaches to research, including not just local leaders but also more disadvantaged community members (as the qualitative data indicated that the interests of village leaders and people with depression did not necessarily align with one another) could help to harness local knowledge and improve the alignment between interventions and community priorities (394).

Barriers to investment in social care interventions, and synergies with other policy priorities, should also be investigated through qualitative research with state government representatives and other key stakeholders, to inform advocacy strategies.

#### 7.4.8 Validating coverage measures

Finally, the validity of existing treatment gap measure requires further investigation. Ethnographic research from a wider range of settings should explore the extent to which people with depression and their families divide help-seeking into mental health-oriented and physical health-oriented episodes across a range of settings. The relevance of whether patients consider their reason for consultation to be depression-related – as distinguished from health care use for other reasons – can be tested by comparing health records with patient-reported reasons for help-seeking, to establish whether those who seek help specifically for depression symptoms are more likely to receive a depression diagnosis or treatment. Given the potential for comorbid conditions, it may also be beneficial to test whether those who report depression symptoms to health workers are less likely to be diagnosed or treated for other health problems, to generate a more nuanced understanding of the treatment gap, and indeed the “mental health care gap” (348). In India, Nepal, South Africa, Ethiopia and Uganda, it should be possible to test the question of whether patient-reported reasons for seeking-help affect the likelihood of detection of depression using data collected through PRIME (52, 294). Depression outcomes should also be measured for both those who do and do not report depression symptoms to health workers, and those who are and are not detected as depression cases by health workers, controlling for symptom severity, in order to evaluate the extent to which disclosure and recognition of depression affects health outcomes compared to those who report only somatic symptoms.

## **7.5 Dissemination**

To date, dissemination of these findings has included the following activities: The systematic review presented in Chapter 2 was published in August 2018 in BMC Psychiatry. Preliminary results were presented to the PRIME India team in April 2017, to inform the scale-up of services and future mental health work in this area. A detailed report on field work, research activities and preliminary findings was also submitted to the British Council Newton Fund, who funded my placement with the Public Health Foundation of India. A poster summarising key findings was presented at the Movement for Global Mental Health summit in Johannesburg in February 2018. It was also presented to the funders of this work at the Bloomsbury PhD Research Symposium in June 2018, and at the annual LSHTM Poster Day where it received an award for research in Epidemiology and Population Health. I published a blog based on this research for the London International Development Centre in July 2018. The synthesised findings of this project were presented to an international audience of mental health and public health professionals at the Centre for Global Mental Health Summer School 2018. Elements of this research were also included in lectures given as part of the “Design and Evaluation of Mental Health Programmes” and “Fundamentals of Global Mental Health” modules at the London School of Hygiene & Tropical Medicine. Finally, I conducted practical workshops based on the GIS methods used in this project to staff members of Sangath and the Public Health Foundation of India in Bhopal, Goa and Delhi during autumn 2016.

Future dissemination of this work will include the publication of the work presented in chapters 3 to 7 in peer-reviewed journals, and the oral presentation of these findings at relevant conferences both in India and internationally. I also intend to develop a short report and policy brief for health officials in Madhya Pradesh at the district and state levels. Unfortunately, due to the resources involved in locating participants, it is not likely to be feasible to disseminate the results to the individuals who participated in this research.

## 8. Conclusion

The work presented in this thesis aimed to further our understanding of a central issue in Global Mental Health: Why there is a large “treatment gap” for depression, particularly in low- and middle-income settings, and specifically in rural India. The evidence presented here suggests that “need” factors, relating to demand for services, play a much larger role than is sometimes acknowledged. Increasing the supply of mental health services – including the “enabling” factors of availability and accessibility of depression treatment – is likely to be insufficient to reduce the treatment gap if the reasons for low demand are ignored. In rural India, lack of demand for services appears to arise from a mismatch between the perceived needs of individuals and families affected by depression, and the biomedical approach with which primary care services are associated. However, the majority of adults with depression do seek help for other complaints besides depression. Given the challenges currently facing the Indian public health system, meeting the needs of the target population will require extensive systems strengthening, and may require the delivery of community-based services that address the social determinants of mental health. This study suggests that investing in improving the quality of services may be more important in terms of public health impact than focussing on expanding geographic access to care. It also points to a need to consider the role of the private sector when planning mental health services, as this is the dominant source of health care in India. Finally, it suggests that treatment gap measures require further evaluation to ensure their validity as a measure of unmet need for depression treatment.



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# 10. Appendices

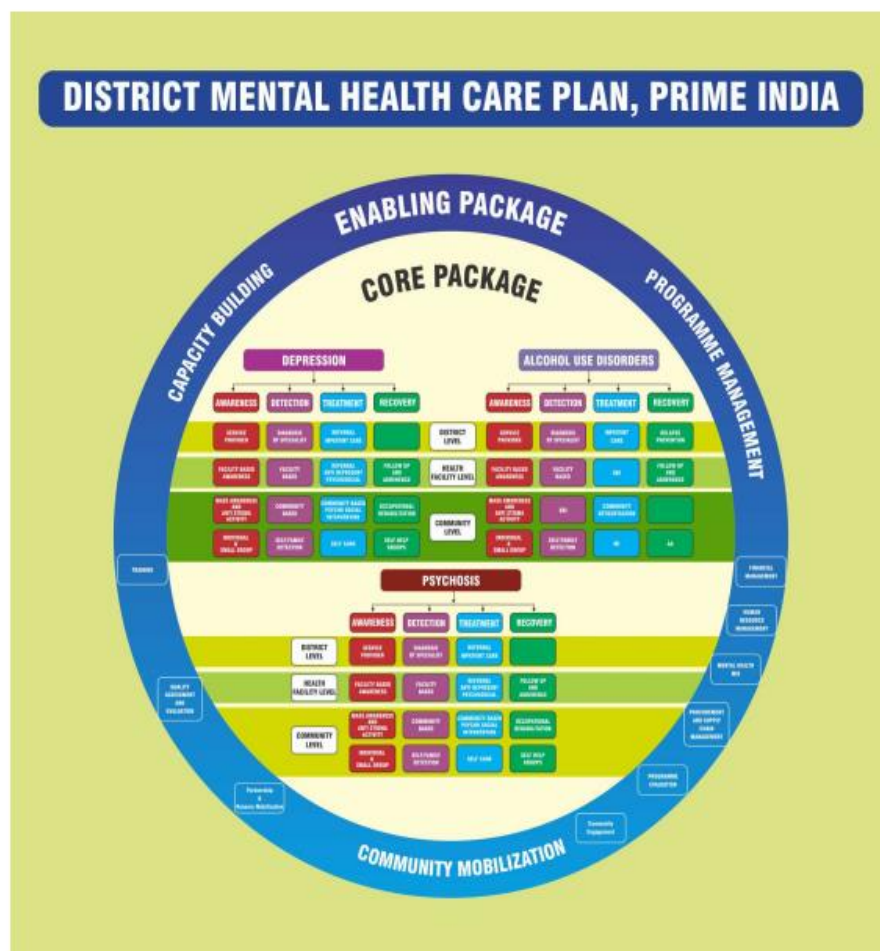
## a. PRIME India Mental Health Care Plan



**INDIA (SEHORE DISTRICT)  
MENTAL HEALTH CARE PLAN**



**PUBLIC HEALTH FOUNDATION OF INDIA**

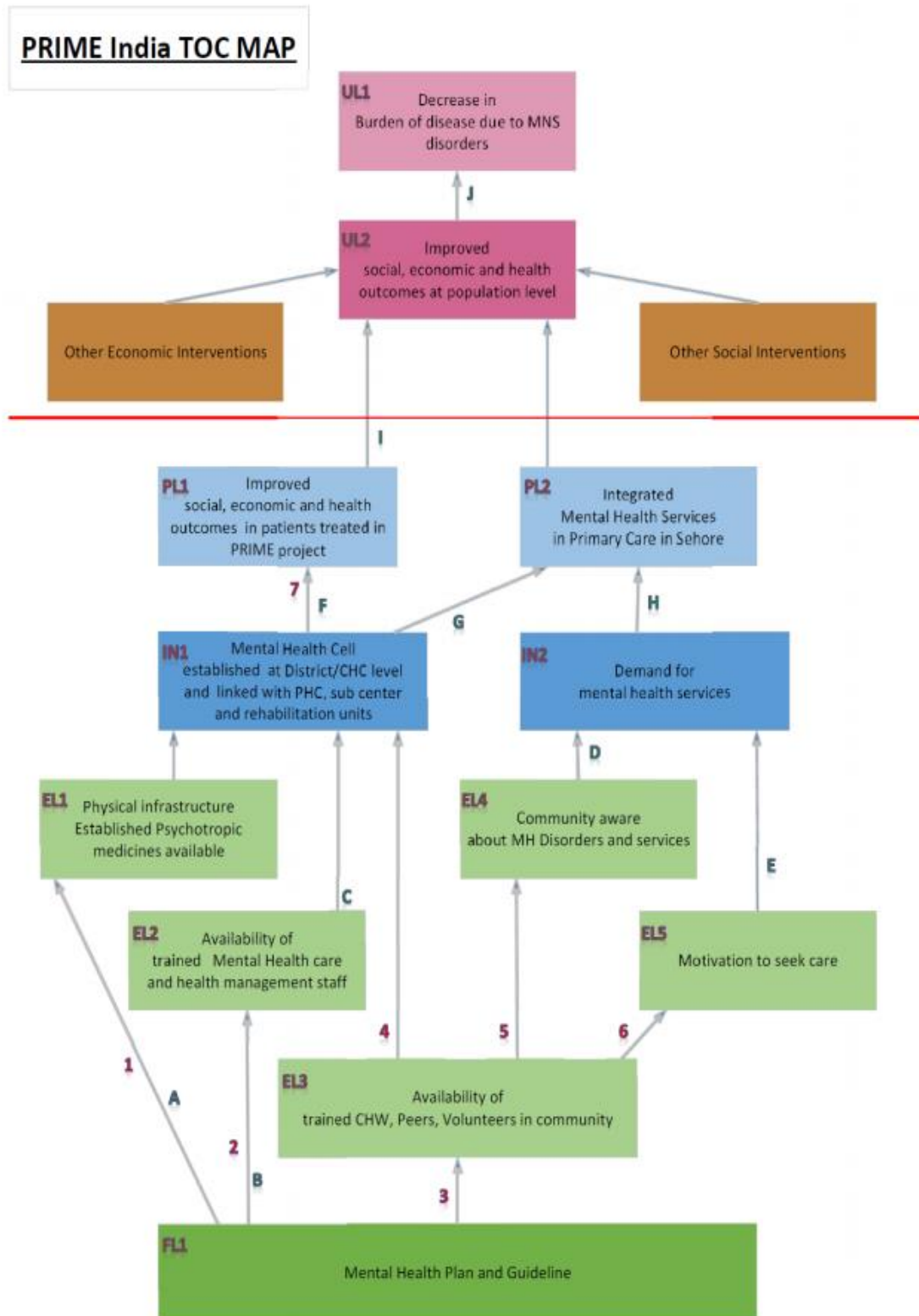


**Table 1: Mental Health Care Plan: Enabling Packages**

<b>Package</b>	<b>Component</b>	<b>Implementation Steps</b>	<b>Human Resource</b>
<b>Program Management</b>	<b>Procurement and Supply Chain Management</b>	<ul style="list-style-type: none"> <li>Timely approval of the requests from facilities</li> </ul>	District Level Administration/Chief Medical and Health Officer
		<ul style="list-style-type: none"> <li>Request for procurement of psychotropic drugs generated from CHC/District Hospital</li> <li>Maintenance of buffer stock of psychotropic drugs</li> </ul>	Facility Administration/ In-Charge Medical Officer and <i>PRIME District Coordinator</i>
	<b>Mental Health Information Systems</b>	<ul style="list-style-type: none"> <li>Compilation of data on monthly basis done at the district level</li> <li>Feedback sent to the facilities (CHC) based on the indicators</li> </ul>	District Level Administration/Health Management Information System Officer and <i>PRIME District Coordinator</i>
		<ul style="list-style-type: none"> <li>Information on key mental health service delivery indicators sent to the district on weekly basis</li> </ul>	Facility Administration/ In-Charge Medical Officer
	<b>Human Resource Management</b>	<ul style="list-style-type: none"> <li>Review of current human resource for mental health service delivery</li> <li>Engagement with potential human resource (existing/new) for mental health service delivery</li> <li>Administrative supervision and performance assessment of human resource</li> </ul>	District Level Administration/Chief Medical and Health Officer
<b>Financial Management</b>		<ul style="list-style-type: none"> <li>Set up of financial management standards as per government guidelines</li> <li>Directives for prompt utilization of funds and ensure reporting</li> <li>Provide feedback and corrective action</li> </ul>	District Level Administration/Chief Medical and Health Officer
		<ul style="list-style-type: none"> <li>Ensure timely utilization and reporting</li> </ul>	Facility Administration/ In-Charge Medical Officer
<b>Capacity Building</b>	<b>Curriculum Development</b>	<ul style="list-style-type: none"> <li>Design and contextualization of training materials</li> </ul>	<i>PRIME Intervention Coordinator</i>
	<b>Training and supervision</b>	<ul style="list-style-type: none"> <li>Conduction of training sessions for MOs and FLWs</li> <li>Supportive supervision sessions for medical officers and front line workers</li> </ul>	District Mental Health Programme Team and <i>PRIME Intervention Coordinator</i>
<b>Community Mobilization</b>	<b>Community Engagement</b>	<ul style="list-style-type: none"> <li>Engage with Community members and key stakeholders</li> <li>Formulate and ensure smooth functioning of user groups</li> </ul>	<i>PRIME Intervention Coordinator and District Coordinator</i>
	<b>Partnership building and resource mobilization</b>	<ul style="list-style-type: none"> <li>Identification and mapping of Governmental/non-governmental organizations interested in mental health programs</li> <li>Establishment of District Mental Health Consortium</li> </ul>	<i>PRIME Intervention Coordinator and District Coordinator</i>

Note: In the human resource column, plain text indicates individuals who were responsible to implement these packages during the design of MHCP while text in *italics* indicates individuals who need to play important role in implementation of these packages post pilot-implementation.

## Theory of Change map



### Interventions and Assumptions in Theory of Change map

<b>Interventions in TOC</b>
1. Procurement of Psychotropic medications and setting up a space for mental health interventions in the facilities
2. Training of medical officers/mental health managers
3. Recruitment and training of Front-line workers
4. Identification of patients with priority mental disorders, provision of mental health first aid, follow-up of patients and provision of rehabilitation services
5. Community based interventions to improve mental health literacy
6. Community based interventions to reduce stigma and improve help-seeking behavior
7. Pharmacological management of priority mental disorders and provision of psycho-social interventions

<b>Assumptions in TOC</b>
A. Budget provisions made and money is made available for setting up space and procurement of psychotropic medications
B. Political buy-in and support to endorse mental health guidelines and support its implementation
C. General health staff (MOs and FLWs) willing to provide mental health services at community and facility level
D. Improvement in mental health literacy would improve help-seeking behavior resulting in demand for services
E. Stigma reduction interventions would improve help-seeking behavior resulting in demand for services
F. Patients receive regular follow-up and are adherent to treatment and in these patients interventions lead to reduction in disease severity and disability severity
G. Mental Health Cell is accessible
H. Services offered in Mental Health Cell are acceptable and affordable

**Table 2: Mental Health Care Plan: Service delivery Packages**

Awareness	Detection	Treatment	Recovery	Human Resource
<b>Specialist/ District Hospital</b>				
<ul style="list-style-type: none"> <li>• Conduct small group meetings with individuals attending the hospital</li> <li>• Screen audio-visual interventions/films in the hospital</li> <li>• Display of posters in a designated space/corner in the hospital</li> </ul>	<ul style="list-style-type: none"> <li>• History taking, assessment and clinical diagnosis of priority disorders of individuals coming to the hospital/referred from facility</li> </ul>	<ul style="list-style-type: none"> <li>• Prescribe anti-depressants and psycho-social interventions to individuals with depression as per mhGAP guidelines</li> <li>• Management of psychosis as per mhGAP guidelines</li> <li>• Management of alcohol dependence</li> <li>• Provide psycho-education to families of individuals with depression, AUD and Psychosis</li> <li>• Facilitate referral of individuals with depression, AUD and Psychosis to higher centres for further management</li> </ul>	<ul style="list-style-type: none"> <li>• Link individuals with depression, AUD and Psychosis to CHC (if required) for further follow-up and community based rehabilitation</li> </ul>	<p>District Mental Health Team (Psychiatrist and Psychologist)</p> <p><i>Mental Health Case Manager</i></p>
<b>CHC/Sub-District Hospital</b>				
<ul style="list-style-type: none"> <li>• Conduct small group meetings with individuals attending the Facility</li> <li>• Screen audio-visual interventions/films in the Facility</li> <li>• Display of posters in a designated space/corner in the Facility</li> </ul>	<ul style="list-style-type: none"> <li>• History taking and assessment of priority disorders based on mhGAP guidelines, of individuals coming to the facility/referred by FLWs</li> </ul>	<ul style="list-style-type: none"> <li>• Prescribe anti-depressants and psycho-social interventions to individuals with mild to moderate depression as per mhGAP guidelines</li> <li>• Manage acute episode of Psychosis as per mhGAP guidelines</li> <li>• Provide brief interventions to individuals with AUD as per mhGAP guidelines</li> <li>• Provide psycho-education to families of individuals with depression, AUD and Psychosis</li> <li>• Facilitate referral of individuals with depression, AUD and Psychosis to district level for further management</li> </ul>	<ul style="list-style-type: none"> <li>• Provide follow-up care including prescription of psycho-tropic medications and psycho-social interventions to individuals referred from the District Hospital after initial consultation</li> <li>• Link individuals with depression, AUD and Psychosis to FLWs for further follow-up and community based rehabilitation</li> </ul>	<p>Medical Officers and Para-medical workers</p> <p><i>Mental Health Case Manager</i></p>



**Table 2  
(continued)**

**Community**

<ul style="list-style-type: none"> <li>• Conduct small group meetings with community members</li> <li>• Screen audio-visual interventions/films in villages</li> <li>• Display of posters at community meeting places such as Village Government Offices (Gram Panchayat) and Village Health and Nutrition Centre (Anganwadi)</li> </ul>	<ul style="list-style-type: none"> <li>• Establish contact, interact and assess individuals based on symptoms/behavioral presentations</li> </ul>	<ul style="list-style-type: none"> <li>• Provide Mental Health First Aid with emphasis on self-care strategies especially for depression</li> <li>• Provide Psycho-education to families of individuals with Psychosis and encourage referral</li> <li>• Provide brief interventions to individuals with AUD</li> <li>• Conduct risk assessment for self-harm</li> <li>• Facilitate referral to facility by accompanying the individual if possible</li> </ul>	<ul style="list-style-type: none"> <li>• Regular follow-up visits and advice on adherence support to individuals who have been prescribed drugs in the facility/advised psycho-social interventions</li> <li>• Link individuals with psychosis (clinically stabilized) to rehabilitation agencies in the community</li> <li>• Link individuals with AUD to existing self-help groups such as Alcoholic Anonymous</li> </ul>	<p>Front-line workers</p> <p><i>Mental Health Case Manager</i></p>
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Note: In the human resource column, plain text indicates individuals who were responsible to implement these packages during the design of MHCP while text in *italics* indicates individuals who need to play important role in implementation of these packages in the modified MHCP post pilot-implementation.

**b. PRIME Community Survey Questionnaire**

Questionnaire ID			QNO
[Geographic unit 1] (eg district)			G1
[Geographic unit 2] (eg catchment area)			G2
[Geographic unit 3] (eg community)			G3
Household address			HHADD
HH contact attempt 1	DD / MM / YYYY	HH : MM	CDATE1 CTIME1
Contact outcome			COU1
HH contact attempt 2	DD / MM / YYYY	HH : MM	CDATE2 CTIME2
Contact outcome			COU2
HH contact attempt 3	DD / MM / YYYY	HH : MM	CDATE3 CTIME2
Contact outcome			COU3
Name of interviewer			INTNAME
Interviewer ID			INTID
Supervisor ID			SUPID
Data entry ID			DATID

Contact outcomes: 1=Completed; 2=No household member at home or no competent respondent at home at time of visit; 3=Entire household absent for extended period of time; 4=Postponed; 5=Refused; 6=Dwelling vacant or address not a dwelling; 7=Dwelling destroyed; 8=Dwelling not found; 77=Other (specify)



Consent for first household interviewee					
Hello. My name is [NAME]					
I am working with [NAME OF ORGANIZATION], in collaboration with the [COUNTRY] and [DISTRICT] Ministries of Health.					
We are conducting a survey about health all over [NAME OF DISTRICT]. The information we collect will help the government to plan health services. Your household was selected for the survey. I would like to ask you some questions about your household. The questions usually take about X to Y minutes. All of the answers you give will be confidential and will not be shared with anyone other than members of our survey team. You don't have to be in the survey, but we hope you will agree to answer the questions since your views are important. If I ask you any question you don't want to answer, just let me know and I will go on to the next question or you can stop the interview at any time.					
In case you need more information about the survey, you may contact the person listed on this card. [Give card with contact information]					
If there are questions you don't want to answer that is fine, just tell me and we will move onto the next question. If there are any questions you want to ask me, or you need more information at any time during the interview, do not hesitate to stop the interview. I just want to check again if you have any questions?					

Written consent form here (interviewer copy), if necessary

Household composition					
Please give me the names of the persons who usually live in your household and guests of the household who stayed here last night, starting with yourself.					
HHMEM#	Name	Is [NAME] male or female	How old is [NAME] in years	How old is [NAME] in months	Eligible for survey (Y/N)
HHMEM#	Not for data entry	SEX#	AGEY#	AGEM#	ELIG#
1		M / F			Y / N
2		M / F			Y / N
3		M / F			Y / N
4		M / F			Y / N
5		M / F			Y / N
6		M / F			Y / N
7		M / F			Y / N
8		M / F			Y / N
9		M / F			Y / N

10		M / F			Y / N
11		M / F			Y / N
<p>Just to make sure that I have a complete listing, are there any other persons such as small children or infants that we have not listed? Are there any other people who may not be members of your family, such as domestic servants, lodgers, or friends who usually live here? Are there any guests or temporary visitors staying here, or anyone else who stayed here last night, who have not been listed? [Interviewers will use national DHS criteria to determine which individuals are considered household members or not]</p>					

## Individual Screening Interview

<b>Questionnaire ID</b>		
<b>Household address</b>		
<b>Household member #, name</b>		
<b>Interview contact attempt 1</b>	DD / MM / YYYY	HH : MM
<b>Contact result 1</b>		
<b>Interview contact attempt 2</b>	DD / MM / YYYY	HH : MM
<b>Contact result 2</b>		
<b>Interview contact attempt 3</b>	DD / MM / YYYY	HH : MM
<b>Contact result 3</b>		

Contact result codes: 1=Completed; 2=Not at home; 3=Postponed; 4=Refused; 5=Partly completed; 6=Incapacitated; 7=Other (specify)

<b>Consent for Interviewee</b>
<p>Hello. My name is [NAME]</p> <p>I am working with [NAME OF ORGANIZATION], in collaboration with the [COUNTRY] and [DISTRICT] Ministries of Health.</p> <p>We are conducting a survey about health all over [NAME OF DISTRICT]. The information we collect will help the government to plan health services. Your household was selected for the survey. I would like to ask you some questions about your health. The questions usually take about X to Y minutes. All of the answers you give will be confidential and will not be shared with anyone other than members of our survey team. You don't have to be in the survey, but we hope you will agree to answer the questions since your views are important. If I ask you any question you don't want to answer, just let me know and I will go on to the next question or you can stop the interview at any time.</p>

In case you need more information about the survey, you may contact the person listed on this card. [Give card with contact information]

If there are questions you don't want to answer that is fine, just tell me and we will move onto the next question. If there are any questions you want to ask me, or you need more information at any time during the interview, do not hesitate to stop the interview.

I just want to check again – do you have any questions?

Written consent form here (interviewer copy), if necessary

Basic socio-demographic information			
	[Record start time]	HH : MM	T0
	How old are you?	<input type="text"/> years	AGE
	[Interviewee sex]	Male	0
		Female	1
	What is the highest level of education you have completed?	Less than primary school	1
		Primary school	2
		Secondary school	3
		College/University	4
	What is your employment status?	Paid or self-employment	1
		Voluntary employment	2
		Unemployed	3
		Student	4
		Retired	5
		Other [Specify] <input type="text"/>	77
			EMPOT

B. Screening tools			
AUDIT and treatment			
Now I am going to ask you some questions about your use of alcoholic beverages during this past year. [Visual cues for “a drink” - Explain what is meant by “alcoholic beverages” by using local examples of beer, wine, vodka, etc. Code answers in terms of “standard drinks”]			
	How often do you have a drink containing alcohol?	Never [-> go to B9]	0
		Monthly or less	1
		2-4 times a month	2
		2-3 times a week	3
		4 or more times a week	4
	How many drinks containing alcohol do you have on a typical day when you are drinking?	1-2	0
		3-4	1
		5-6	2
		7-9	3
		10 or more	4
		Never	0
			AUD3

	How often do you have six or more drinks on one occasion?	Less than monthly	1	
		Monthly	2	
		Weekly	3	
		Daily or almost daily	4	
	[If Question B2 AND Question B3 are both scored 0 → go to B9.]			
	How often during the last year have you found that you were not able to stop drinking once you had started?	Never	0	<b>AUD4</b>
		Less than monthly	1	
		Monthly	2	
		Weekly	3	
		Daily or almost daily	4	
	How often during the last year have you failed to do what was normally expected from you because of drinking?	Never	0	<b>AUD5</b>
		Less than monthly	1	
		Monthly	2	
		Weekly	3	
		Daily or almost daily	4	
	How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?	Never	0	<b>AUD6</b>
		Less than monthly	1	
		Monthly	2	
		Weekly	3	
		Daily or almost daily	4	
	How often during the last year have you had a feeling of guilt or remorse after drinking?	Never	0	<b>AUD7</b>
		Less than monthly	1	
		Monthly	2	
		Weekly	3	
		Daily or almost daily	4	
	How often during the last year have you been unable to remember what happened the night before because you had been drinking?	Never	0	<b>AUD8</b>
		Less than monthly	1	
		Monthly	2	
		Weekly	3	
		Daily or almost daily	4	
	Have you or someone else been injured as a result of your drinking?	No	0	<b>AUD9</b>
		Yes, but not in the last year	2	
		Yes, during the last year	4	
	Has a relative or friend or a doctor or another health worker been concerned about your drinking or suggested you cut down?	No	0	<b>AUD10</b>
		Yes, but not in the last year	2	
		Yes, during the last year	4	
	Total score for B1-B10	<del>_____</del>		<b>AUDTOT</b>
	AUDIT score (=B11)	<X [→ go to B32]		
		>X [→ go to SA1]		

<b>AUD Internalized Stigma</b>	
You have mentioned that you frequently experience some problems with your drinking in the past year. I will ask you some	<b>AUDST_</b>

questions about these problems. Let me know if you agree or disagree with the following statements.			
I feel out of place in the world because of these problems	Strongly disagree	1	_ISMI01
	Disagree	2	
	Agree	3	
	Strongly agree	4	
I am embarrassed or ashamed of these problems	Strongly disagree	1	_ISMI05
	Disagree	2	
	Agree	3	
	Strongly agree	4	
I am disappointed in myself due to these problems	Strongly disagree	1	_ISMI16
	Disagree	2	
	Agree	3	
	Strongly agree	4	
These problems have spoiled my life	Strongly disagree	1	_ISMI17
	Disagree	2	
	Agree	3	
	Strongly agree	4	
Because of these problems, I need others to make most decisions for me	Strongly disagree	1	_ISMI19
	Disagree	2	
	Agree	3	
	Strongly agree	4	
I can't contribute anything to society because of these problems	Strongly disagree	1	_ISMI23
	Disagree	2	
	Agree	3	
	Strongly agree	4	
People discriminate against me due to these problems	Strongly disagree	1	_ISMI03
	Disagree	2	
	Agree	3	
	Strongly agree	4	
People often patronize me, or treat me like a child, just because of these problems	Strongly disagree	1	_ISMI15
	Disagree	2	
	Agree	3	
	Strongly agree	4	
People ignore me or take me less seriously just because of these problems	Strongly disagree	1	_ISMI22
	Disagree	2	
	Agree	3	
	Strongly agree	4	
Nobody would be interested in getting close to me because of these problems	Strongly disagree	1	_ISMI25
	Disagree	2	
	Agree	3	
	Strongly agree	4	
Others think that I can't achieve much in life because of these problems	Strongly disagree	1	_ISMI28
	Disagree	2	
	Agree	3	
	Strongly agree	4	
[→ go to B12]			

You mentioned that you frequently experience some problems with your drinking in the past 12 months. In the	No [→go to B14]	0	AUDDISC
	Yes	1	

	past 12 months, have you spoken to anyone about your concerns about your drinking?			
	To whom have you spoken? (Circle all that apply)  Anyone else?	Friend / neighbour	1	AUDDISC_ FRIEND SPOUSE OFAM EMPL REL HCWORK OTHER
		Spouse/partner	2	
		Other family member	3	
		Employer/co-worker	4	
		Religious advisor	5	
		Health care worker (e.g. traditional healer, nurse/doctor, specialist)	6	
		Other (specify)	77	
	Did you seek any treatment for your use of alcohol at any time in the past 12 months?	No [→go to B32]	0	AUDTX
		Yes	1	
		Don't know [→go to B32]	888	
	From whom did you receive professional treatment?  [Chose all that apply before continuing.  Complete both sections from B16 and B24 if necessary.]  Any others?	<i>Specialist doctor</i> : Psychiatrist [→go to B16]	1	AUDTX_ _PSY _OSPEC _GENDOC _OGEN _REL _TRAD _OTHER  AUDTXO
		<i>Specialist other</i> : Other mental health professional, e.g. psychologist / counsellor/mental health nurse [→go to B16]	2	
		<i>Generalist doctor</i> : Any other medical doctor [→go to B24]	3	
		<i>Generalist other</i> : e.g. General social worker, community health worker, nurse [→go to B24]	4	
		Religious or spiritual advisor [→go to B32]	5	
		Traditional healer, herbalist, or spiritualist [→go to B32]	6	
		Other [specify]	77	

	Generalist AUD care			
	How many visits did you make in the past 12 months to the [all		visits	AUDGVISIT

	generalists named above]?			
	How many minutes did these visits last on average?	<del> </del> minutes		AUDGMINS
	What was the nature of the treatment provided by the [all generalists named above]?	Medication	1	AUDGTX
		Counselling [→go to B28]	2	AUDGTXO
		Other [→go to B28] [specify] <del> </del>	77	
	What is the name and daily dosage of the medication(s) provided by [all generalists named above]? How long were you taking this medication?	1. <del> </del> weeks	<del> </del>	AUDGRX1 AUDGRX2 AUDGRX3
		2. <del> </del> weeks	<del> </del>	
		3. <del> </del> weeks	<del> </del>	
		4. Don't know	888	
	Did you complete the full recommended course of treatment?	No	0	AUDGDONE
		Yes	1	
		Don't know	888	
	Are you still seeing [a generalist named above]?	No	0	AUDGSTOP
		Yes	1	
	How much has the treatment helped you?	A lot	1	AUDGHELP
		Some	2	
		A little	3	
		Not at all	4	
		Don't know	888	
	How satisfied are you with the treatments and services you received from [all generalists named above] in the past 12 months?	Very satisfied	1	AUDGSAT
		Satisfied	2	
		Neither satisfied or dissatisfied	3	
		Dissatisfied	4	
		Very dissatisfied	5	
		Don't know	888	
	Did you ever go to a self-help group like Alcoholics Anonymous for help with your use of alcohol?	No [→go to B34]	0	AUDAA
		Yes	1	
		Don't know [→go to B34]	888	
	How many meetings of such a group did	<del> </del> meetings		AUDAANO
		Don't know	888	

	you attend in the past 12 months?			
--	-----------------------------------	--	--	--

Specialist AUD care				
	How many visits did you make in the past 12 months to the [all specialists named above]?	<del>8</del> visits	AUDSVISIT	
	How many minutes did these visits last on average?	<del>8</del> minutes	AUDSMINS	
	What was the nature of the treatment provided by the [all specialists named above]?	Medication [→go to B19]	1	AUDSTX
		Counselling [→go to B20]	2	
		Other [→go to B20] [specify] <del>8</del>	77	AUDSTXO
	What is the name and daily dosage of the medication(s) provided by [all specialists named above]? How long were you taking this medication?	1. <del>8</del> weeks	<del>8</del>	AUDSRX1 AUDSRX2 AUDSRX3
		2. <del>8</del> weeks	<del>8</del>	
		3. <del>8</del> weeks	<del>8</del>	
		4. Don't know	888	
	Did you complete the full recommended course of treatment?	No	0	AUDSDONE
		Yes	1	
		Don't know	888	
	Are you still seeing a specialist?	No	0	AUDSSTOP
		Yes	1	
	How much has the treatment helped you?	A lot	1	AUDSHELP
		Some	2	
		A little	3	
		Not at all	4	
		Don't know	888	
	How satisfied are you with the treatments and services you received	Very satisfied	1	AUDSSAT
		Satisfied	2	
		Neither satisfied or dissatisfied	3	



	from [all specialists named above] in the past 12 months?	Dissatisfied	4	
		Very dissatisfied	5	
		Don't know	888	
[If interviewee saw any 'generalist' in B15 → go to B24  If interviewee did not see any 'generalist' in B15 → go to B32]				

PHQ-9 and treatment				
Over the last two weeks, how often have you been bothered by any of the following problems?				
	Little interest or pleasure in doing things	Not at all	0	PHQ1
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Feeling down, depressed, or hopeless	Not at all	0	PHQ2
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Trouble falling/staying asleep, sleeping too much.	Not at all	0	PHQ3
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Feeling tired or having little energy	Not at all	0	PHQ4
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Poor appetite or overeating	Not at all	0	PHQ5
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	Not at all	0	PHQ6
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Trouble concentrating on things, such as reading the newspaper or watching television.	Not at all	0	PHQ7
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	Not at all	0	PHQ8
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
		Not at all	0	PHQ9

	Thoughts that you would be better off dead or of hurting yourself in some way.	Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Total for PHQ1-PHQ9	<del>_____</del>		PHQTOT
	Apart from these past two weeks, during the past 12 months, did you have other episodes of two weeks or more when you felt depressed or uninterested in most things, and had most of the problems we just talked about?	No [→go to B45]	0	DEPHIS
		Yes [→go to SD1]	1	
	PHQ9 score (=B43)	<X [→go to “Selection for full interview”]		
		>X [→go to SD1]		

Depression Internalized Stigma				DEPST_
You have mentioned that you frequently have been bothered with some problems recently. I will ask you some questions about these problems. Let me know if you agree or disagree with the following statements.				
	I feel out of place in the world because of these problems	Strongly disagree	1	_ISMI01
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	I am embarrassed or ashamed of these problems	Strongly disagree	1	_ISMI05
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	I am disappointed in myself due to these problems	Strongly disagree	1	_ISMI16
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	These problems have spoiled my life	Strongly disagree	1	_ISMI17
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	Because of these problems, I need others to make most decisions for me	Strongly disagree	1	_ISMI19
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	I can't contribute anything to society because of these problems	Strongly disagree	1	_ISMI23
		Disagree	2	
		Agree	3	
		Strongly agree	4	
		Strongly disagree	1	_ISMI03

	People discriminate against me due to these problems	Disagree	2	
		Agree	3	
		Strongly agree	4	
	People often patronize me, or treat me like a child, just because of these problems	Strongly disagree	1	_ISMI15
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	People ignore me or take me less seriously just because of these problems	Strongly disagree	1	_ISMI22
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	Nobody would be interested in getting close to me because of these problems	Strongly disagree	1	_ISMI25
		Disagree	2	
		Agree	3	
		Strongly agree	4	
	Others think that I can't achieve much in life because of these problems	Strongly disagree	1	_ISMI28
		Disagree	2	
		Agree	3	
		Strongly agree	4	
[→ go to B46]				

	You have mentioned that you frequently have been bothered with some problems in the past [two weeks/year], such as [having little interest in doing things / feeling down/ feeling tired etc]. In the past 12 months, have you spoken to anyone about these problems?	No [→go to B48]	0	DEPDISC
		Yes	1	
	To whom have you spoken? (Circle all that apply)  Anyone else?	Friend / neighbour	1	DEPDISC_ FRIEND SPOUSE OFAM EMPL REL HCWORK OTHER
		Spouse/partner	2	
		Other family member	3	
		Employer/co-worker	4	
		Religious or spiritual advisor	5	
		Health care worker (e.g. traditional healer, nurse/doctor, specialist)	6	
		Other (specify)	77	
B1		No [→go to B66]	0	DEPTX

	Did you seek any treatment for these problems at any time in the past 12 months?	Yes	1	
		Don't know [→go to B66]	888	
B2	From whom did you receive treatment? [Chose all that apply before continuing. Complete both sections from B50 and B58 if necessary.] Any others?	<i>Specialist doctor.</i> Psychiatrist [→go to B50]	1	DEPTX_
		<i>Specialist other.</i> Other mental health professional, eg psychologist / counselor/mental health nurse [→go to B50]	2	_PSY _OSPEC _GENDOC _OGEN _REL _TRAD _OTHER
		<i>Generalist doctor.</i> Any other medical doctor [→go to B58]	3	
		<i>Generalist other.</i> e.g. General social worker, community health worker, nurse [→go to B58]	4	
		Religious or spiritual advisor [→go to B66]	5	
		Traditional healer, herbalist, or spiritualist [→go to B66]	6	
		Other [specify] ☒ [→go to B66]	77	DEPTXO

Specialist Depression care				
	How many visits did you make in the past 12 months to the [all specialists named above]?	☒ visits	DEP SVISIT	
	How many minutes did these visits last on average?	☒ minutes	DEPSMINS	
	What was the nature of the treatment provided by the [all specialists named above]?	Medication	1 DEPSTX DEPSTXO	
		Counselling [→go to B54]	2	
		Other [→go to B54] [specify] ☒	77	
	What is the name and daily dosage of the medication(s) provided by [all specialists named above]? How long were you taking this medication? [Ask to	<b>Name</b>	<b>Dose</b>	<b>Dura tion</b>
		1.		
		2.		
		3.		
		4. Don't know		888
				DEPSRX1 DEPSRX2 DEPSRX3

	see prescriptions if literacy/recall is poor]				
	Did you complete the full recommended course of treatment?	No	0	DEPSDONE	
		Yes	1		
		Don't know	888		
	Are you still seeing [any specialist named above]?	No	0	DEPSTOP	
		Yes	1		
	How much has the treatment helped you?	A lot	1	DEPSHELP	
		Some	2		
		A little	3		
		Not at all	4		
		Don't know	888		
	How satisfied are you with the treatments and services you received from [all specialists named above] in the past 12 months?	Very satisfied	1	DEPSSAT	
		Satisfied	2		
		Neither satisfied or dissatisfied	3		
		Dissatisfied	4		
		Very dissatisfied	5		
		Don't know	888		
	[→If interviewee saw any generalist in B49 → go to B58]  [→If interviewee did not see any generalist in B49 → go to B66]				

Generalist Depression care			
	How many visits did you make in the past 12 months to the [all generalists named above]?	<del>☒</del> visits	DEPGVISIT
	How many minutes did these visits last on average?	<del>☒</del> minutes	DEPGMINS
	What was the nature of the treatment provided by the [all generalists named above]?	Medication	1
		Counselling [→go to B62]	2
		Other [→go to B62] [specify]	77
	What is the name and daily dosage of the medication(s) provided by [all generalists named above]? How long	1. <del>☒</del> weeks	<del>☒</del>
		2. <del>☒</del> weeks	<del>☒</del>
		3. <del>☒</del>	<del>☒</del>
			=DEPGRX_NAME =DEPGRX_DOSE =DEPGRX_WKS

	were you taking this medication?	weeks		
		4. Don't know	888	
	Did you complete the full recommended course of treatment?	No	0	DEPGDONE
		Yes	1	
		Don't know	888	
	Are you still seeing [a generalist named above]?	No	0	DEPGSTOP
		Yes	1	
	How much has the treatment helped you?	A lot	1	DEPGHELP
		Some	2	
		A little	3	
		Not at all	4	
		Don't know	888	
	How satisfied are you with the treatments and services you received from [all generalists named above] in the past 12 months?	Very satisfied	1	DEPGSAT
		Satisfied	2	
		Neither satisfied or dissatisfied	3	
		Dissatisfied	4	
		Very dissatisfied	5	
		Don't know	888	

Suicidal ideation and action				
	Have you thought of taking your life in the past 12 months?	No [→ go to C1]	0	SUITHINK
		Yes	1	
	Did you ever make a plan for taking your own life at any time in the past 12 months?	No [→go to C1]	0	SUIPLAN
		Yes	1	
	Have you attempted to take your own life in the past 12 months?	No [→go to C1]	0	SUIATT
		Yes	1	
	Did it require medical attention?	No	0	SUIMED
		Yes	1	
	In the past 12 months, have you spoken to anyone about thinking about or attempting to take your own life?	No [→go to C1]	0	SUIDISC
		Yes	1	
	To whom have you spoken? (Circle all that apply)	Friend / neighbour	1	SUIDISC_ _FRIEND _SPOUSE _OFAM _EMPL _REL _HCWORK _OTHER
		Spouse/partner	2	
		Other family member	3	
		Employer/co-worker	4	
		Traditional healer	5	
		Health care worker (e.g. nurse/doctor, specialist)	6	
	Anyone else?	Religious or spiritual advisor	7	

		Other (specify)	77	<b>SUIDISCO</b>
		<del>☒</del>		
	Did you receive any treatment for thinking about or attempting to take your own life?	No [→go to C1]	0	<b>SUITX</b>
		Yes	1	
		Don't know [→go to C1]	888	
	What treatment did you receive?	<del>☒</del>		<b>SUITXO</b>
		[→go to C1]		

Selection for full individual interview		
B11 (AUDIT total)	<=X	Go to next question
	>X	→Go to C1
B43 (PHQ9 total)	<=Y	Go to next question
	>Y	→Go to C1
B44 (Recent depression)	=0	Go to next question
	=1	→Go to C1
Random selection table	0	→Go to Record end time
	1	→ Go to C1
[Record end time]	HH : MM	T1

Interviewer comments	
<del> </del>	
Supervisor comments	
<del> </del>	

[Thank you script]





## Individual Full Interview


Questionnaire ID		
Household member #, name		

C. Detailed socio-demographics				
Household asset index				
I want to ask you a few questions about the characteristics of your home.				
	What is the main source of drinking water for members of your household?	Piped water	1	<b>WATER</b>
		Tube well	2	
		Water from spring	3	
		Rainwater	4	
		Tanker truck	5	
	What kind of toilet facility do members of your household usually use?	Flush toilet	1	<b>TOILET</b>
		Pit latrine	2	
		Composting toilet	3	
		Bucket toilet	4	
		Bush/field	5	
	Do you share this toilet facility with other households?	Yes	1	<b>SHARET</b>
		No	0	
	Does your household have electricity?	Yes	1	<b>ELEC</b>
		No	0	
	Does your household have a radio?	Yes	1	<b>RADIO</b>
		No	0	
	Does your household have a television?	Yes	1	<b>TV</b>
		No	0	
	Does your anybody in your household have a mobile telephone?	Yes	1	<b>MOBILE</b>
		No	0	
	Does your household have a refrigerator?	Yes	1	<b>FRIGE</b>
		No	0	
	What type of fuel does your household mainly use for cooking?	Electricity	1	<b>FUEL</b>
		Gas	2	
		Kerosene	3	
		Wood	4	
		Animal dung	5	
		No food cooked in household	6	
	Do you have a separate room which is used as a kitchen?	Yes	1	<b>KITCHEN</b>
		No	0	
	[Observe main material of floor]	Natural material	1	<b>FLOOR</b>
		Rudimentary	2	
		Finished floor	3	
		Finished walls	5	
<b>Individual characteristics</b>				

	What is your marital status?	Single	1	<b>MARIT</b>
		Married	2	
		Divorced	3	
		Widowed	4	
		Married but not living together	5	
		Cohabiting	6	
	[For female interviewees] Are you pregnant?	No	0	<b>PREG</b>
		Yes	1	
		Not applicable	66	
		Don't know	888	
	Do you have children?	No	0	<b>KIDS</b>
		Yes	1	
	How old is your youngest child?	<input type="checkbox"/> months <input type="checkbox"/> years		<b>YOUNG</b>
	What is your religion?		1	<b>RELIG</b>
			2	
			3	
		Other [Specify] <input type="checkbox"/>	77	<b>RELIGO</b>
	What is your occupation?	Home worker (e.g. housewife)	1	<b>OCC</b>
		Unskilled labourer (e.g. farmhand)	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 [Specify] <input type="checkbox"/>	77	
	Has anyone in your household, including yourself, gone hungry in the last month due to lack of resources/food?	No	0	<b>HHFOOD</b>
		Yes	1	

D. Mental health knowledge, attitudes and behaviour				
<p>I would now like to ask you some questions about mental illness. Many people understand this term to refer to persons who are behaving strangely, for example talking to themselves or becoming violent. However, mental illnesses include a very wide range of problems, including health problems related to stress and tension in one's daily life (for example which can make a person feel tired, have sleep problems, get headaches, feel worried or unhappy or suicidal). Mental illnesses also include drinking too much alcohol or taking drugs. The questions I am now going to ask you refers to any type of mental illness.</p>				
D1	Have you seen or heard any information about mental health or mental illness issues in the last year, in any of these ways? (Choose all that apply)	Newspaper	1	HOWINFO_ _NPAPER _TVNEWS _RADIO _MAG _POSTER _HCENTRE _PEOPLE _OTHER HOWINFOO
		TV	2	
		Radio	3	
		Magazine	4	
		Poster/leaflet	5	
		Health centre	6	
		People talking about it	7	
		Other (specify)	77	
				
D2	Where do people in this community first go to seek care for mental illness?	Nowhere/care is not available	0	MHTX      MHTXO
		Traditional healer	1	
		Neighbour/community member	2	
		Local clinic	3	
		Hospital	4	
		Religious or spiritual advisor	5	
		Other (specify)	77	
				
D3	If you suffered from a mental health problem would you tell your family or friends? (Choose all that apply)	No one	0	TELL
		Friends	1	
		Family	2	
	Tell me to what extent you agree or disagree with the following statements.			STIG_
D4	Mentally ill people tend to be violent.	Agree strongly	1	_ISMI02
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D5	Mentally ill people shouldn't get married.	Agree strongly	1	_ISMI06
		Agree slightly	2	

		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D6	People with mental illness cannot live a good, rewarding life.	Agree strongly	1	_ISMI10
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D7	People with severe mental health problems can fully recover.	Agree strongly	1	_MAKS05
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D8	Medication can be an effective treatment for people with mental health problems.	Agree strongly	1	_MAKS03
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D9	I would be willing to live with someone with a mental health problem.	Agree strongly	1	_RIBS05
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D10	I would be willing to work with someone with a mental health problem	Agree strongly	1	_RIBS06
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D11	I would be willing to live nearby someone with a mental health problem	Agree strongly	1	_RIBS07
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D12	I would be willing to continue a relationship with a friend who developed a mental health problem.	Agree strongly	1	_RIBS08
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D13	People with mental health problems are far less of a	Agree strongly	1	_CAMI10
		Agree slightly	2	

	danger than most people suppose.	Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D14	We need to adopt a far more tolerant attitude toward people with mental illness in our society.	Agree strongly	1	_CAMI03
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D15	People with mental health problems should not be given any responsibility.	Agree strongly	1	_CAMI12
		Agree slightly	2	
		Neither agree nor disagree	3	
		Disagree slightly	4	
		Disagree strongly	5	
		Don't know	888	
D16	Do any of the following people you know have a mental illness?  Read all options. Chose all that apply.	Family member in this household	1	KNOWMH_ _INFAM _OUTFAM _FRIEND _NEIGH _WORK _OTHER _NONE
		Family member outside this household	2	
		Friend/Acquaintance	3	
		Neighbour	4	
		Work colleague	5	
		Someone else? (specify)	77	KNOWMHO
				
		No one known	0	

E. Disability and health care use WHO Disability Assessment Schedule II
<p>The interview is about difficulties people have because of health conditions. [Hand flashcard to respondent] 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 [Point to flashcard #1].</p> <ul style="list-style-type: none"> <li>• Increased effort</li> <li>• Discomfort or pain</li> <li>• Slowness</li> <li>• Changes in the way you do the activity</li> </ul> <p>[Point to flashcard #1]. 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] Use this scale when responding. [Read scale aloud]: None, mild, moderate, severe, extreme or cannot do.</p> <p>[Flashcards #1 and #2 should remain visible to the respondent throughout the interview]</p>

	How do you rate your overall health in the past 30 days?	Very good		<b>OVERALL</b>
		Good		
		Moderate		
		Bad		
		Very bad		
[Show flashcard #2 to participant.] In the last 30 days how much difficulty did you have in:				
Standing for long periods such as 30 minutes?	None	1	<b>STAND</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
Taking care of your household responsibilities?	None	1	<b>HOUSE</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
Learning a new task, for example, learning how to get to a new place?	None	1	<b>LEARN</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
How much of a problem did you have in joining community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	None	1	<b>JOIN</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
How much have you been emotionally affected by your health problems?	None	1	<b>EMOTE</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
In the last 30 days, how much difficulty did you have in:				
Concentrating on doing something for 10 minutes?	None	1	<b>CONC</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
Walking a long distance such as a kilometre?	None	1	<b>WALK</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
Washing your whole body?	None	1	<b>WASH</b>	
	Mild	2		
	Moderate	3		
	Severe	4		
	Extreme/cannot do	5		
Getting dressed?	None	1	<b>DRESS</b>	
	Mild	2		
	Moderate	3		
	Severe	4		

		Extreme/cannot do	5	
	Dealing with people you do not know?	None	1	<b>DEAL</b>
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
	Maintaining a friendship?	None	1	<b>FRIEND</b>
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
	Your day to day work?	None	1	<b>DAY</b>
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
	Overall, how much did these difficulties interfere with your life?	None	1	<b>INTERF</b>
		Mild	2	
		Moderate	3	
		Severe	4	
		Extreme/cannot do	5	
	Overall, in the past 30 days, how many days were these difficulties present?	✍ _____ days		<b>DIFFDAYS</b>
	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		<b>UNABLE</b>
	In the past 30 days, not counting the days 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		<b>CUTBACK</b>
E1	In the last 3 months, have family members or friends had to stop or reduce usual work or activities due to the your ill health?	No [->go to F1]	0	<b>REDWRK</b>
		Yes	1	

I want you to think about the <u>two</u> most important people you know who stopped or reduced the usual activities due to your ill health in the <u>past 3 months</u> .				
E2	What is your relationship to the first person?	<input type="text"/>		HELP1_WHO
E3	How much time did this person spend assisting you? You can tell me the number of days, or the average number of hours per week, from the past three months	<input type="text"/> day		HELP1_DTIME
		<input type="text"/> hours		HELP1_HTIME
E4	What sort of work did this person give up to care for you?	Unpaid work (eg housewife)	1	HELP1_WORK    HELP1_WORKO
		Manual work (agricultural or factory worker)	2	
		Office/non-manual work (skilled worker, business, professional)	3	
		Other (specify) <input type="text"/>	77	
E5	What is your relationship to the second person?	<input type="text"/>		HELP2_WHO
E6	How much time did this person spend assisting you? You can tell me the number of days, or the average number of hours per week, from the past three months	<input type="text"/> day		HELP2_DTIME
		<input type="text"/> hours		HELP2_HTIME
E7	What sort of work did this person forgo?	Unpaid work (e.g. housewife)	1	HELP2_WORK    HELP2_WORKO
		Manual work (agricultural or factory worker)	2	
		Office/non-manual work (skilled worker, business, professional)	3	
		Other (specify) <input type="text"/>	77	




F. Health care use				
I would now like to know about your recent experiences with obtaining health care. I want to know if you needed health care recently, and if so, why you needed health care and what type of health care provider you received care from.				
Inpatient Care				
	In the last year, have you ever stayed overnight in a hospital?	No [→ go to F6]	0	HOSP
		Yes	1	
	How many times have you been admitted into hospital in the last year?	<input type="text"/>		HOSPNO
For each separate hospital admission you have had, please complete the following:				
Admission No	<b>Why were you admitted?</b> 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) 77 = other condition (specify) 888 = don't know	<b>Where was the admission?</b> 1 = charity / church-run hospital 2 = private hospital 3 = government hospital	<b>How long was the admission?</b>	<b>How much did you, your family or friends have to pay (for hospital fees, medicines, investigations)?</b>  (local currency units)
	#	IN#_WHY <input type="text"/> IN_WHYO	IN#_WHERE	IN#_LENGTH Days
			Days	
			Days	
			Days	
Outpatient Care				
Excluding inpatient care, how many times did you see any of these or other health care providers in the last 3 months?				
F1	Traditional/spiritual healer	No	0	OUT_TRAD
		Yes	1 →	visits TRADNO
F2	Community health worker / General Nurse or midwife / Pharmacist	No	0	OUT_HCW
		Yes	1 →	visits HCWNO
F3	Mental health professional, eg Psychiatrist, psychiatric nurse, counsellor, social worker)	No	0	OUT_MH
		Yes	1 →	visits MHNO
F4	General medical doctor or Specialist (non-psych) medical doctor	No	0	OUT_DOC
		Yes	1 →	visits DOCNO
F5	Other (specify) <input type="text"/>	No	0	OUT_OTH
		Yes	1 →	visits OUTO

Health care visit details											
For each separate contact or visit with these health care providers, please complete the following: (For current visit use line F11)											
Visit No.	Who did you see? 1 = traditional/spiritual healer 2 = community worker 3 = nurse / midwife 4 = pharmacist 5 = General doctor 6 = Specialist doctor 7 = Psychiatrist 8 = other mental health worker 77= other(specify) 888 = don't know	Where did it take place? 1 = your own home 2 = local health centre 3 = private office 4 = 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 (e.g. heart, diabetes) 77 = other (specify) 888 = don't know	What were the main features of the visit? (list up to three elements)			How long did it take you to travel to where you received care? (minutes)	How long did you wait for your consultation? (minutes)	How long was the consultation (excluding waiting time)? (minutes)	How much did you, your family or friends have to pay (consultation fees, travel)? (local currency units)	
				1	2	3				Fees	Travel
VISNO#	HC#_WHO HC#_WHOO	HC#_WHERE	HC#WHY HC#WHYO	HC#_F1	HC#_F2	HC#_F3	HC#_TRAVEL	HC#_WAIT	HC#_LONG	HC#_COST1	HC#_COST2
							Mins	Mins	Mins		
							Mins	Mins	Mins		
							Mins	Mins	Mins		
							Mins	Mins	Mins		
							Mins	Mins	Mins		
							Mins	Mins	Mins		

Medication use			
Please list medications you have been prescribed <u>in the last 3 months</u> : If you do not remember what medications you have been prescribed, you can show me the pills or prescriptions.			
	Generic/brand name of drug e.g. Fluoxetine/Prozac	For how many days? (max = 90 days)	Dose per day (mg)
#	RX#NAME	RX#DAYS	RX#DOSE
	A.		
	B.		
	C.		
	D.		

### G. SAGE

Do you feel that your use of health services is affected by any of the following factors:

G1	You do not consider that services are currently needed	No	0	SAGE_ _NEED
		Yes	1	
G2	Care providers do not understand your health problems	No	0	_UNDE R
		Yes	1	
G3	You feel that the care that you receive is not good enough	No	0	_QUAL
		Yes	1	
G4	The fees/charges that you pay towards treatment/medicines are not affordable	No	0	_COST
		Yes	1	
G5	Seeking some kinds of treatment can make you or your family feel embarrassed	No	0	_STIG
		Yes	1	
G6	You dislike taking medication	No	0	_SFX
		Yes	1	
G7	They don't have the medicines you need	No	0	_SUPPL Y
		Yes	1	
G8	They frequently run out of medicines	No	0	_NOAV AIL
		Yes	1	
G9	Other reason(s) for not using treatment services (specify 	No	0	_REAS SAGEO
		Yes	1	

[Thank you script]

[Referral script for depression]

[Referral script for AUD]

[Referral script for suicidality]

### c. Ethical approval letters

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LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



#### Observational / Interventions Research Ethics Committee

Ms Tessa Roberts  
LSHTM

8 January 2016

Dear Ms Roberts

Study Title: Spatial Analysis of Data from PRIME (Programme to Improve Mental health care)

LSHTM Ethics Ref: 10439

Thank you for responding to the Observational 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	PRIME community survey protocol	11/12/2011	1
Local Approval	LSHTM sign-off	05/04/2012	1
Protocol / Proposal	Info sheet and consent form - community survey	06/01/2013	1
Protocol / Proposal	Info sheet and consent form - cohort study	08/01/2013	1
Protocol / Proposal	Info sheet and consent form - facility detection study	08/01/2013	1
Local Approval	Sangath approval letter	21/03/2013	1
Protocol / Proposal	Community survey (India)	03/12/2013	1
Protocol / Proposal	Facility detection survey (India)	03/12/2013	1
Local Approval	WHO ethics approval	16/01/2014	1
Protocol / Proposal	PRIME cohort questionnaire	05/06/2015	1
Investigator CV	Tessa Roberts CV	05/11/2015	1
Covering Letter	Clarifications response letter	21/12/2015	1

#### After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>

Additional information is available at: [www.lshtm.ac.uk/ethics](http://www.lshtm.ac.uk/ethics)

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Observational / Interventions Research Ethics Committee

Ms Tessa Roberts  
LSHTM

8 February 2017

Dear Tessa,

Study Title: Perceived barriers to health service utilisation for depressive symptoms in a district of Madhya Pradesh

LSHTM Ethics Ref: 11912

Thank you for responding to the Observational 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
Local Approval	IRB decision letter - Tessa Roberts	23/09/2016	1
Investigator CV	Tessa Roberts CV 2016	30/09/2016	1
Protocol / Proposal	Qualitative protocol - updated 20th Nov	20/11/2016	2
Protocol / Proposal	Qualitative protocol - updated 20th Nov	20/11/2016	3
Advertisements	Recruitment procedure	29/11/2016	1
Protocol / Proposal	Qualitative protocol - updated 20th Nov	29/11/2016	4
Protocol / Proposal	Qualitative protocol - updated 30th Nov	01/12/2016	5
Information Sheet	Qualitative consent form - updated 1st Feb	01/02/2017	2
Covering Letter	Ethics response cover letter	01/02/2017	2

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexplained Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

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Additional information is available at: [www.lshtm.ac.uk/ethics](http://www.lshtm.ac.uk/ethics)

Yours sincerely,


**SANGATH INSTITUTIONAL REVIEW BOARD**

(EC Reg No: ECR/235/Ind/GA/2015)

**DECISION LETTER**

Title of Project	Perceived barriers to and facilitators of mental health service utilisation: A qualitative study
Sangath IRB Reference number	TRINSAI_2016_27
Application Type	Student Application
Name of Student/ PI	Tessa Roberts
Name of Supervisor	Bahul Shinde, Vikram Patel

**Documents Reviewed**

Document Name	Version	Date
sangath IRB application - revised	NA	26.05.2016
Information sheet and consent form	NA	03.06.2016
Draft topic guide	NA	02.06.2016
Ethics application for secondary PRIME data	NA	28.07.2016
Sangath IRB data access letter July 2016	NA	07.07.2016
Referral form	NA	28.07.2016
PRIME letter for collaboration	NA	26.07.2016
PhD ethics approval letter	NA	08.07.2016
Data management plan	NA	12.05.2016
CS interview protocol	NA	28.07.2016
Email responses	NA	28.07.2016, 09.09.2016, 16.09.2016

**DECISION**

Approved	Approved subject to suggested modifications (Does not need further committee review)
Not approved	Not approved
Can be resubmitted but will need second review	

**d. Supplementary material from Chapter 2**

PRISMA checklist

<b>Section/topic</b>	<b>#</b>	<b>Checklist item</b>	<b>Reported on page # (of submitted manuscript)</b>
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2-3
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	5-7
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	7-8
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	8
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	8-10
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	8



Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Additional file 1 (referenced p.8)
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	10
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	10-11
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	10
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	10, 11
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	11
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	12 (and Figure 1)
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment	Table 2



		(see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Not entirely applicable for observational studies of this sort but findings for each study presented in table 2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	12-17 (meta-analysis not applicable)
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	18
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	17
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	19 (see also 21-25)
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	19-21
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	21-28
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	4

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097. For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

Search strategy (Medline)

1. (depression or (depressive adj2 disorder\$)).ti,ab.
2. depressive disorder/
3. CMD.ti,ab.
4. somatoform.ti,ab.
5. (common adj2 (mental adj2 disorder\$)).ti,ab.
6. MUS.ti,ab.
7. (medically adj2 unexplained).ti,ab.
8. (pathway\* adj2 care).ti,ab.
9. barrier\$.ti,ab.
10. access\$.ti,ab.
11. ((health adj2 service\$) or healthcare or (health adj2 care)).ti,ab.
12. (access\$ adj4 ((health adj2 service\$) or healthcare or (health adj2 care))).ti,ab.
13. (barrier\$ adj4 ((health adj2 service\$) or healthcare or (health adj2 care))).ti,ab.
14. "Delivery of Health Care"/ut [Utilization]
15. Health Services/ut [Utilization]
16. coverage.ti,ab.
17. utili#ation.ti,ab.
18. (utili#ation adj4 ((health adj2 service\$) or healthcare or (health adj2 care))).ti,ab.
19. (coverage adj4 ((health adj2 service\$) or healthcare or (health adj2 care))).ti,ab.
20. "use".ti,ab.
21. ("use" adj4 ((health adj2 service\$) or healthcare or (health adj2 care))).ti,ab.
22. "Patient Acceptance of Health Care"/
23. Health Services Accessibility/
24. Help-Seeking Behavior/
25. Healthcare Disparities/
26. help?seek\$.ti,ab.
27. (service\$ adj2 contact).ti,ab.
28. 8 or 12 or 13 or 14 or 15 or 18 or 19 or 21 or 22 or 23 or 24 or 25 or 26 or 27
29. Anxiety Disorders/
30. (anxiety adj2 disorder\$).ti,ab.
31. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 29 or 30
32. 28 and 31
33. limit 32 to humans
34. limit 33 to "all adult (19 plus years)"
35. limit 34 to english language

Characteristics of included studies

Study	Country	Study design	Population	CMD measure	Outcome	Factors associated	Andersen coding	Sample size	Response rate (overall)	Sampling strategy appropriate	Sample representativeness of population	Measures appropriate	Acceptable response rate	Overall score
Alegría et al. (2008)	USA	Cross-sectional	Combined 3 nationally representative samples; one of the general adult population, 1 of the adult black population and 1 of the adult Latino and Asian population	12 month major depression or dysthymia (CID)	12 month visit to a specialist or general medical provider for mental health reasons	Ethnicity	Predisposing (ethnicity)	1,082 with depression/dysthymia	70.9%-77.7%	Strategy appropriate but no justification of sample size	Yes (when weighted)	Yes	Yes	****
Andersson et al. (2013)	South Africa	Cross-sectional	18-40 year olds (random population-based sample)	Lifetime depression (DSM-IV criteria)	Lifetime help-seeking from healthcare staff for emotional reasons	Age (18-29 less likely), comorbid TB, social support. null: sex, employment, income, comorbid HIV (p=0.07). Sex interacted with age; sex differences in older but not younger groups.	Predisposing (age, null: sex), enabling (social support, null: employment, income), need (comorbid TB, null: HIV)	307 with lifetime depression	Not reported	Strategy appropriate. Sample size justified but not clear what question they're addressing with this	Yes (representative of 18-40 year olds)	Yes (though lifetime recall questionable)	Unknown	*

Angst et al. (2010)	Switzerland	Prospective cohort	Adults with depression, bipolar, anxiety, panic, neurasthenia and insomnia (SCL-90-R), stratified subsample by severity score	Depression/anxiety (SPIKE - DSM-III or DSM-IV criteria, but including subthreshold cases)	12 month use of health services (generalist and specialist) for MH symptoms	For depression: sex, subjective distress, childhood family problems (null: work impairment, social impairment, mastery, comorbidities). For GAD/panic attacks: subjective distress, work impairment (null: sex, social impairment, mastery, childhood family problems, comorbidities). Being above threshold for diagnostic criteria not associated	For depression: predisposing (sex), need (subjective distress, childhood family problems, null: work impairment, social impairment, "mastery", comorbidities, meeting full diagnostic criteria). For GAD/panic attacks: predisposing (null: sex), need (subjective distress, work impairment, null: social impairment, mastery, childhood family problems, comorbidities, meeting full diagnostic criteria)	323 with depression, 192 with panic disorder and 388 with GAD (not necessarily meeting diagnostic criteria)	Initial response rate 62% (men; 66%, women; 58%). 62.1% retained in the study for the full 20 years (dropouts did not differ significantly on most characteristics). Refusers had lower educational levels but otherwise no socio-demographic differences.	Males and females sampled through separate means, sampling frame somewhat unclear for females (addresses provided "by the communities"). Total sample size not justified but there is reference to stratification and over-sampling of those at risk to give "a sufficient number for further analyses"	Sample representative of canton of Zurich	Yes	Borderline - women only 58%	**
Ault-Brutus (2012)	USA	Cross-sectional	Adults aged 18-54 (from nationally representative sample)	12-month mood and/or anxiety disorder (CID-I - DSM-III-R or DSM-IV criteria, depending on wave)	12 month visit to a health professional for MH reasons	Race/ethnicity - black people less likely to use services than white/Latino people (not mediated by SES, partially mediated by perceived need)	Predisposing (ethnicity), mediated by need (perceived)	2127	82.4% (wave 1), 70.9% (wave 2)	Strategy appropriate but no justification of sample size	Yes (representative of 18-54 yr-olds)	Yes	Yes	***
Ault-Brutus & Alegria (2016)	USA	Cross-sectional	White, black or Latino adults aged 18-54 (from nationally representative sample)	12 month mood/anxiety disorder (CID-I - bipolar excluded)	12 month visit to a specialist or generalist medic for MH reasons	Ethnicity not associated with perceived need, but among those with perceived need for care there were ethnic disparities - blacks and Latinos	Predisposing (ethnicity) interacts with need (perceived)	2127 with mood/anxiety disorders	82.4% and 70.9%	Strategy appropriate but no justification of sample size	Yes (representative of 18-54 year olds who are white/black/Latino)	Yes	Yes	***

						less likely to receive treatment than whites - in 2001/2003 but not 1990/1992								
Bauldry & Szaflarski (2017)	USA	Cross-sectional (part of a cohort study but current analyses used cross-sectional data)	Adult civilian, non-institutionalized population (from nationally representative sample) of European, African/Afro-Caribbean, Asian/Pacific Islander, Hispanic, or Puerto Rican background (excluded those of Canadian, Australian, Native American, or Middle Eastern origins)	12 month mood/anxiety disorder (AUDADIS-IV - DSM-IV criteria - bipolar excluded)	12 month disorder-specific health service use (not 100% clear that this excluded non-health service providers though - separate question added for cross-sectional analysis that's less specific than longitudinal questions)	In adjusted model, first generation immigrants less likely to use services for mood disorders but doesn't reach significance for anxiety disorders. Second generation immigrants no different from non-immigrants. People of African and Hispanic origin have lower odds of utilizing mental health care for either mood or anxiety disorders than people of European origin. Acculturation (identify dimension) increases treatment-seeking - still significant in adjusted model for mood but not anxiety disorders or for any disorders among people of European origin	Predisposing (immigration status, ethnicity, acculturation) interacts with need (disorder type)	3,230 (mood), 4,239 (anxiety)	89% (wave 1), 86.7% (wave 2)	Strategy appropriate but no justification of sample size	Yes (representative of main ethnic groups)	CMD measure appropriate but outcome not clearly defined	Yes	**

Boerema et al. (2016)	Netherlands	Cross-sectional	General adult population (excluding those with low level of Dutch language)	MDD (CIDI 2.1)	6 month contact with a health care professional for MH reasons	Duration of symptoms (longer - more treatment-seeking), personal stigma (less - more treatment-seeking). Null: age, partner status, severity (X2?), comorbid anxiety, comorbid physical complaints, neuroticism, loneliness, perceived stigma	Predisposing (personal stigma, null: age, marital status, neuroticism, perceived stigma), enabling (null: loneliness*), need (duration, null: comorbid anxiety, comorbid physical complaints) (*could be seen as enabling/need/predisposing)	102 with MDD	28% (of those who scored positive on K-10, response rate to K-10 not reported)	Strategy appropriate but no justification of sample size	Yes (representative of those who speak Dutch)	Yes	No	***
Bucholz & Dinwiddie (1989)	USA	Prospective cohort	Adults from community survey	Elevated symptoms of depression/dysthymia (DIS - not necessarily meeting full DSM-III criteria)	12 month discussion of depressive episode with a doctor	Comorbid psychiatric conditions (OCD/panic disorder more likely, substance abuse less likely). Mania, schizophrenia, phobia and somatisation not associated (antisocial personality disorder approached significance p=0.09)	Need (some comorbid psychiatric conditions, null: other comorbid psychiatric conditions)	218	80% at baseline, 85% follow-up	Strategy appropriate but no justification of sample size	Sample representative of St. Louis	Yes	Yes	****

Bucholz & Robins (1987)	USA	Cross-sectional (part of a cohort study but current analyses used cross-sectional data)	General adult population (includes those in institutions)	18m depression/dysthymia (DIS - DSM-III criteria)	12m discussion with a doctor about the depressive symptoms	In fully adjusted model, appetite symptoms, worsening of physical health, being female, being separated/widowed, previous use of specialty mental health services and not using ER as usual source of care were associated with treatment-seeking. Null: prior consultation with a doctor about somatic symptoms, race, education, recent change in marital status, household income, health insurance, having a usual source of care	Predisposing (gender, marital status, null: ethnicity, change in marital status), enabling (null: education, household income, health insurance, usual source of care), need (specific symptoms: appetite, worsening physical health, previous speciality service use, not using ER as usual care, null: prior contact with doc for somatic symptoms)	218 with depression/dysthymia	75% to 80% (varied by site)	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****
Burnett-Zeigler et al. (2012)	USA	Prospective cohort	Adults with 12-month major depression or dysthymia, persistent symptoms and no prior depression treatment (from nationally representative sample)	12 month depression/dysthymia (AUDADIS-IV - DSM-IV criteria)	Use of health services for MH reasons (including inpatient and emergency care) between baseline and follow-up (approx. 3 years)	Gender, substance use, race/ethnicity, marriage status, education, self-rated health, anxiety disorders	Predisposing (sex, ethnicity, marital status), enabling (education), need (substance use, self-rated health, anxiety disorders)	337	81.0% at baseline, 86.7% at follow-up	Strategy appropriate but no justification of sample size	Yes (representative of those with persistent symptoms and no prior treatment)	Yes	Yes	***

Carragher et al. (2010)	USA	Cross-sectional	Non-institutionalised adults with a lifetime diagnosis of MDD (from nationally representative sample)	Lifetime MDD (AUDADIS-IV - DSM-IV criteria)	Lifetime use of health services for depressive symptoms (includes inpatient and emergency care)	Sex, ethnicity, education, age, income, insurance, number of depressive episodes, some comorbid medical conditions (high blood pressure, arthritis), comorbid mood/anxiety disorder. Not associated: marital status, region, urbanicity, comorbid alcohol problems or personality disorder, other medical conditions (liver problems, heart/artery problems, stomach problems)	Predisposing (sex, ethnicity, age, null: marital status), enabling (education, income, insurance, null: region, urbanicity), need (number of depressive episodes, some comorbid medical conditions, comorbid mood/anxiety disorder, null: comorbid alcohol problems, personality disorder, other medical conditions)	7153	81%	Strategy appropriate but no justification of sample size	Yes	Yes (though lifetime recall questionable)	Yes	***
Chartrand et al. (2012)	USA	Prospective cohort	Adult non-institutionalized population	MDD (AUDADIS-IV - DSM-IV criteria)	Use of any health services for MH reasons since start of study (approx. 3 years)	Suicidality (behaviour and ideation) associated in univariate analyses but not adjusted model (except hospitalisation). In unadjusted analyses, gender, age, ethnicity, marital status, region, education, comorbid mental disorder and depression severity were all associated	Predisposing (unadjusted: gender, age, ethnicity, marital status), enabling (education), need (null: suicidality, except being hospitalised, unadjusted: comorbid mental disorder, severity), contextual (region)	2864 with MDD	70.20 %	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****



Chen (2012)	China	Cross-sectional	Urban residents aged 18-70 from household survey	Psychological distress (K10 $\geq$ 20)	Help seeking for emotional reasons in the previous 12 months (separated by health professionals, informal support and alternative services)	Concerns about affordability negatively associated, no association for concerns about accessibility, refusal to recognise need, lack of trust, embarrassment or stigma, symptom severity, self-rated physical health, age, gender or marital status	Predisposing (null: age, gender, marital status, stigma/embarrassment, lack of trust in professional services), enabling (affordability concerns, null: accessibility concerns), need (null: severity, recognition of need, self-rated physical health)	56 with high distress scores	51%	Strategy appropriate but no justification of sample size	Yes (representative of urban population aged 18-70 in Beijing)	Double-check K-10 properties. Screener not diagnostic tool	No	**
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Chen (2013)	USA	Cross-sectional (part of a cohort study but current analyses used cross-sectional data)	Adult non-institutionalized population (original sample included under-18s but excluded in current study)	MDE (CIDI - DSM-IV criteria)	12 month use of health services for MH reasons	Comorbid substance dependence (after adjusting for sociodemographic characteristics). Multiple comorbid SUDs associated with greater treatment-seeking	Need (comorbid SUD)	18,972 with MDE	Weighted response rates for household screening and for interviewing: 91.3% , 76.2% , respectively (2005) 90.6% , 74.2% (2006) 89.5% , 73.9% (2007) 89.0% , 74.4% (2008) 88.8% , 75.7% (2009) 88.8% , 74.7% (2010)	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****
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Demytten aere et al. (2006)	Belgium, France, Germany, Italy, the Netherlands and Spain	Cross-sectional	Community-dwelling adults (nationally representative sample)	Depression (CIDI 3.0)	12 month help-seeking from health services for MH reasons	Comorbid painful physical symptoms (reduces treatment-seeking)	Need (comorbid pain)	Weighted sample of 5489 (of whom 220 had 12 month MDE)	61.2% (but ranges from 45.9% in France to 78.6% in Spain)	Strategy appropriate, sample size justified for cross-country comparisons of treatment gap, not effect of pain	Yes	Yes	Borderline (acceptable in some countries but not others)	***
Demytten aere et al. (2008)	Belgium, France, Germany, Italy, the Netherlands and Spain	Cross-sectional	Community-dwelling adults (nationally representative sample)	Anxiety (CIDI 3.0)	12 month help-seeking from health services for MH reasons	Comorbid painful physical symptoms (increases treatment-seeking but doesn't reach stat. sig.)	Need (comorbid pain)	Weighted sample of 5489 (of whom 280 had 12 month anxiety disorder w/o comorbid mood disorder)	61.2% (but ranges from 45.9% in France to 78.6% in Spain)	Strategy appropriate, sample size justified for cross-country comparisons of treatment gap, not effect of pain	Yes	Yes	Borderline (acceptable in some countries but not others)	***
Fortney et al. (1998)	USA	Prospective cohort	Adults with current depression symptoms	Depressive disorder - major depression/dysthymia/subthreshold depression (Burnam depression screener)	6 month use of health services for depression, or in which depression was diagnosed/mentioned in notes/antidepressant prescribed (not clear whether visits for other MH reasons included or not)	Age, gender, employment status, depression severity, and psychiatric comorbidity, "Expected maximum utility of sector choice", insurance coverage and availability. Null: ethnicity, living alone, education, social support, perceived need for depression treatment, medical comorbidities	Predisposing (age, sex, null: ethnicity), enabling (employment, insurance, availability?, "expected utility of sector" Null: education, social support, living alone), need (severity, psychiatric comorbidity, null: perceived need, medical comorbidity)	435	70.5% (then 73.9% of depressed subsample)	Strategy appropriate but no justification of sample size	Representative of those with telephones and no comorbidities	Screeners only	Yes	**

Gabilondo et al. (2011)	Spain	Cross-sectional	Community-dwelling adults (from nationally representative survey)	12-month major depressive episode (CID)	12-month use of services for MH reasons - includes non-health sector providers but reported separately	Unemployment/not working due to disability, comorbid mental disorders. Null: age (doesn't reach significance), sex, education, marital status, urbanicity, income, severity, chronic general medical conditions	Predisposing (null: age, sex, marital status), enabling (employment*, null: education, urbanicity, income), need (comorbid mental disorders, disability*, null: severity, chronic physical conditions), *same measure used	247	78.60 %	Strategy appropriate, sample size justified for cross-country comparisons of treatment gap, not sub-group analyses	Yes	Yes	Yes	****
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Galbaud du Fort et al. (1999)	Canada	Cross-sectional	Adults (aged 18+) from household survey	Lifetime depressive illness (DIS)	Lifetime discussion of symptoms with a doctor or "other professional" (not defined)	Sex, age at first onset, duration of illness, bereavement, specific psychiatric symptoms and comorbid psychiatric disorders; psychomotor retardation, suicidal ideation, mania, panic disorder, drug abuse/dependence (latter reduced chances whereas others increased chances of seeking treatment). Some interactions (suicidal ideation with age at first onset, comorbid OCD and age at first onset, duration with weight loss and alcohol abuse). Null: number of depressive symptoms, number of comorbid diagnoses, specific symptoms (hypersomnia, weight gain, loss of appetite, trouble concentrating, guilt, disinterest in sex, thoughts of death*), somatisation, comorbid schizophrenic disorders or eating disorders	Predisposing (sex, age of onset), need (duration, comorbid disorders, suicidal ideation, psychomotor retardation, drug abuse). Not clear how to classify bereavement - could be seen as predisposing, enabling or need	1348	71.60 %	Strategy appropriate but sample size not justified	Yes	Outcome measure ambiguous (plus lifetime recall questionable)	Yes	***
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González et al. (2010)	USA	Cross-sectional	Combined 3 nationally representative samples; one of the general adult population, 1 of the adult black population and 1 of the adult Latino and Asian population. Current study included only Mexican, Puerto Rican, Caribbean black, African American, and non-Latino white respondents	12 month MDD (CIDI - DSM-IV criteria)	12 month use of pharmacotherapy or psychotherapy	Mexican American/African Americans less likely to receive treatment than whites (but difference not stat. sig. for Puerto Ricans or Caribbean blacks in adjusted analyses). Age also associated (35-64 yr-olds most likely to use care), and health insurance. Null: education, household income, gender (approached significance, 0.05>p<0.01)	Predisposing (ethnicity, age, null: gender), enabling (insurance, null: education, income)	1307 with MDD	72.30 %	Strategy appropriate but no justification of sample size	Yes (representative of main ethnic groups)	CMD measure appropriate but outcome excludes consultations that didn't result in treatment	Yes	**
Gwynn et al. (2008)	USA	Cross-sectional	City-dwelling non-institutionalized adults (aged 20 years or older)	12 month MDD or anxiety (CIDI - DSM-IV criteria)	12 month consultation with a MH specialist or use of pharmacotherapy	For depression: previous diagnosis, symptoms limiting ability to work, being born in the USA. For anxiety: having a regular source of medical care, symptoms limiting ability to work. Null associations not reported. Education and nativity associated with lack of diagnosis (more educated - less likely to be diagnosed, foreign-born - less likely to be diagnosed)	DEPRESSION: Predisposing (nativity, previous diagnosis*), need (work impairment) *Could be categorised as need variable. ANXIETY: enabling (regular source), need (work impairment)	145 with MDD, 73 with anxiety	55%	Strategy appropriate, sample size powered for accuracy of prevalence measure	Yes (representative of urban residents aged 20+)	CMD measure appropriate but outcome excludes consultations in generalist settings where pharmacological treatment not prescribed)	No	**

Hailemariam et al. (2012)	Ethiopia	Cross-sectional	Adults aged 18+ (from nationally representative survey)	12 month depression (WHO-CIDI - ICD-10 criteria)	12 month use of health services for depressive symptoms	Educational status. Urban-rural, age, marital status, employment status, income and gender differences didn't reach statistical significance in multivariate analyses	Predisposing (null: gender, age, marital status), enabling (education, null: urbanicity, employment, income)	4925 (449 with depression)	99%	Strategy appropriate but no justification of sample size	Yes	Yes	Yes (suspiciously high...)	****
Hamalainen et al. (2008)	Finland	Cross-sectional	Adults aged 30+ (from nationally representative sample)	Major depressive disorder or anxiety disorders (CIDI)	12 month health service use for mental health reasons	For MDD: severity, perceived disability, psychiatric comorbidity, specific symptoms (feelings of inferiority, suicide plans) and living alone. Null: sex, age, employment, education, rurality, somatic disorders, parents' psychiatric problems. For anxiety: perceived disability, psychiatric comorbidity, younger age, and parent's psychiatric problems. Null: sex, marital status, employment status, education, rural/urban residence, somatic disorders	Differences by disorder (anxiety vs. depression). For depression, need only (severity, perceived disability, psychiatric comorbidity, feelings of inferiority, suicidal plans). For anxiety, predisposing (age, parent's psychiatric problems) and need (perceived disability, psychiatric comorbidity). Null associations not clear - only amalgamated results reported and statistical tests refer to differences in service type	298	75%	Strategy appropriate but no justification of sample size	Yes (representative of adults aged 30+)	Yes	Yes	***
Hankerson et al. (2011)	USA	Cross-sectional	Non-Hispanic black and white adults (from nationally representative sample)	12 month MDD (DSM-IV criteria)	12 month receipt of any mental health treatment (includes inpatient and emergency services)	Race/ethnicity	Predisposing (race/ethnicity)	1866	81%	Strategy appropriate but no justification of sample size (though check Grant et al., 2004)	Representative of 2 main ethnic groups, excludes others	Yes	Yes	***

Issakidis & Andrews (2002)	Australia	Cross-sectional	People who reported anxiety as their principal complaint (from nationally representative sample)	Anxiety (CIDI) (restricted to those for whom anxiety was principal complaint)	12 month consultation with a health professional for MH reasons	Age, marital status, disability, neuroticism, disorder type, severity, number of comorbid mental disorders. Sex, education, employment status, ethnicity, urbanicity, and physical disorder not associated	Predisposing (age, neuroticism, marital status, null: sex, ethnicity), enabling (null: urbanicity, education, employment), need (disability, disorder type, severity, comorbid mental disorders, null: physical disorders)	2005	78.10 %	Strategy appropriate but no justification of sample size	Excludes those for whom anxiety symptoms were not principal complaint	Yes	Yes	***
Iza et al. (2013)	USA	Prospective cohort	Adults aged 18+ (from nationally representative sample)	Anxiety disorders (DSM-IV criteria)	Lifetime treatment-seeking for anxiety symptoms from doctor, psychologist, therapist, counselor "or any other service provider"	Disorder type (panic highest, phobia lowest). Associated for all disorders: age at onset, change in marital status, prior MH treatment, comorbid mood disorders. Associated for some disorders: sex (GAD only), ethnicity (black - reduced HSE for phobia), education (GAD and phobia only), marital status (never married - increased HSU for social anxiety). Null for all: nativity, SUD/SUD treatment, (all results are after adjusting for sex, race, nativity and age at onset)	Predisposing (sex, ethnicity, prior MH treatment*, age at onset, null: nativity), enabling (education, marital status), need (disorder type, comorbid mood disorders, null: SUD). *Could be classified as need factor. Note differences by disorder type	13292	86.7% (for wave 2), 70.2% (from original sample - reported elsewhere)	Strategy appropriate but no justification of sample size (though check Grant et al., 2003)	Yes	Outcome measure ambiguous (plus lifetime recall questionable)	Yes	***



Keyes et al. (2008)	USA	Cross-sectional	Non-Hispanic white or black adults aged 18+ residing in households and group quarters	Lifetime anxiety disorders (AUDADIS-IV - DSM-IV criteria) (mood and substance use disorders also measured but presented separately)	Lifetime use of health services for MH reasons	White respondents were significantly more likely than black respondents to use services in all models	Predisposing (ethnicity)	32752	81%	Strategy appropriate but no justification of sample size	Yes (representative of white and black populations)	Yes (though lifetime recall questionable)	Yes	**
Lee et al. (2011)	USA	Cross-sectional	Community-dwelling adults with lifetime major depression or anxiety disorders (from nationally representative survey)	Lifetime major depression and anxiety disorders (AUDADIS-IV - DSM-IV criteria) (other disorders measured but reported separately)	Lifetime use of services for specific disorders (12m also measured) - includes inpatient and emergency services	Race/ethnicity (after adjusting for socioeconomic and years of residency in the US) - for depression and anxiety, but different patterns for each	Predisposing (ethnicity)	6624 (depression), 7241 (anxiety disorders)	81%	Strategy appropriate but no justification of sample size	Yes	Yes (though lifetime recall questionable)	Yes	***
Lee et al. (2014)	USA	Cross-sectional	Community-based sample of adults aged 18+ (excluding Native Americans)	Lifetime depressed mood or anhedonia (AUDADIS-IV - DSM-IV criteria A)	Lifetime use of health services for mood problems	Sub-type of depression (severity but also differences between "cognitive" and "psychosomatic" types, interacts with race/ethnicity)	Need (specific symptoms, severity) - interacts with predisposing (ethnicity)	13,424 with lifetime depressed mood	81.20 %	Strategy appropriate but no justification of sample size	Yes (except Native Americans)	Yes (though lifetime recall questionable)	Yes	**
Lopes et al. (2016)	Brazil	Cross-sectional	Adults (from nationally representative sample)	Depression (PHQ-9)	Current use of health services for depression	Gender (female), race/ethnicity (white), age (30-69), region (not the North), education (higher), multimorbidities (includes both physical and mental). Null: marital	Predisposing (gender, ethnicity, age, null: marital status), enabling (education), need (comorbid MH and other), contextual (region, null: urban/rural)	4756 with depression	86.10 %	Strategy appropriate but no justification of sample size	Screening only	No	Yes	**

						status, urban/rural residence								
Mackenzie et al. (2012)	USA	Cross-sectional	Community-dwelling adults (from nationally representative survey)	Past year anxiety and mood disorders (AUDADIS-IV - DSM-IV criteria). Mood disorders includes mania, but disorders reported separately	Past year contact with a health professional for mood/anxiety disorders (includes inpatient and emergency services)	Disorder type, age (interacted slightly with disorder type), gender (interacted slightly with age), comorbid anxiety/mood disorders (interacted slightly with age)	Predisposing (age, gender), need (comorbid anxiety/mood disorders, disorder type)	9,487 with GAD, panic, phobia, social phobia, depression or dysthymia	86.7% (for wave 2), 70.2% (from original sample - reported elsewhere)	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****
Mojtabai & Olfson (2006)	USA/Canada	Cross-sectional	Adults with 12 month probable major depressive episode (from nationally representative sample)	12 month probable major depressive episode (CID-SF)	12 month contact with a health professional for mental health reasons	US/Canadian residency made no difference to use/no use (but it did to source of care), race/ethnicity was associated in both countries, severity had more association in Canada than US	Predisposing (ethnicity) enabling (null: country of residence), need (severity)	751 (304 from Canada and 447 from USA)	66% (Canada), 50% (USA)	Strategy appropriate but no justification of sample size (though see Sanmartin et al., 2004)	Yes (representative of households with telephones)	Screener only	No	**
Nakash et al. (2014)	International	Cross-sectional	Community-dwelling adults (from nationally representative surveys)	CMD (CID)	12 month use of services for MH problems (either a MH professional or general medical professional)	Cancer status (active cancer, cancer survivor, cancer-free)	Need (comorbid disorders)	14017 (active cancer; 96, cancer survivors; 355, cancer-free; 13566)	79.9% (weighted - rates varied across countries)	Strategy appropriate but no justification of sample size (though see Kessler & Ustun, 2008)	Yes	Yes	Yes on average - in some countries no (e.g. France, 45.9%)	***

Ojeda & McGuire (2006)	USA	Cross-sectional	Adults with depression/dysthymia (from nationally representative sample)	Major depression/dysthymia (CID)	12 month use of outpatient mental health or substance use services (includes emergency services)	Education, age (interacts with gender), gender, perceived health status (interacts with gender), healthcare environment (i.e. managed care with gatekeeper), race/ethnicity, - interacts with gender (minority women less likely to use services than white women, African American men less likely to use services than white men but Latino men at same rate as white men). Ethnicity still associated after adjusting for education, insurance, and health status, (and age for AAs, young Latinos less likely to use services). Mental health status (severity?) and physical comorbidity not associated	Predisposing (gender, ethnicity, age), enabling (education, health care environment), need (perceived health status, null: severity, comorbidity)	1498	64.0% (though non-responders includes those who were ineligible because they were children)	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****
Olfson & Klerman (1992)	USA	Cross-sectional	Adults	Depressive symptoms (DIS - DSM-III criteria)	6 month use of health services for MH reasons	Meeting diagnostic criteria associated with service use. Also age between 45 and 64 years, white, racial background, current unemployment, and separated or divorced marital status. Null: household income, education and gender (trends in expected directions but didn't reach significance)	Predisposing (age, ethnicity, marital status, null: gender), enabling (employment, null: income, education), need (meeting diagnostic criteria)	744 with depressive symptoms	68%-79%	Strategy appropriate but no justification of sample size	Yes (representative of communities sampled)	Yes	Yes	****

Pirkis et al. (2001)	Australia	Cross-sectional	General population (adults only, from nationally representative sample)	Anxiety disorders (CIDI) (affective disorders and SUDs also assessed, but reported separately - former included bipolar)	Use of health services for mental health reasons (timeframe not specified, includes inpatient care)	English-speaking backgrounds (note: not ability to speak English, as non-English-speakers excluded) not associated with service use	Predisposing/enabling (linguistic background)	10,641 (overall), 1026 with anxiety disorders	78%	Strategy appropriate but no justification of sample size	Yes	Timeframe of outcome not specified	Yes	***
Rafful et al. (2012)	Mexico	Cross-sectional	Urban community-dwelling residents aged 18 to 65	12 month MDE (CIDI)	12 month consultation with a medic or other professional for emotional reasons	Gender (males more likely to seek help), interacted with age - youngest women least likely to seek help	Predisposing (gender - males more, interacts with age)	531 with MDE	76.60%	Strategy appropriate but no justification of sample size	Yes (representative of urban residents aged 18-65)	Yes	Yes	***
Robinson et al. (2009)	USA	Cross-sectional	Individuals meeting criteria for an anxiety disorder in the past 12 months (from nationally representative sample)	12 month anxiety disorders (DSM-IV)	Lifetime mental health service use (includes inpatient and emergency services)	Engaging in self-medication	Predisposing? (Doesn't obviously fit into any category)	4880	81%	Strategy appropriate but no justification of sample size	Yes	Yes (though lifetime recall questionable)	Yes	***

Rost et al. (1998)	USA	Prospective cohort	Adults who screen positive for depression on the DIS, from telephone survey	"Substantial depressive symptoms" (screen-positive on DIS)	12 month treatment-seeking from a health professional for depression (self-report verified by medical/insurance records or recorded diagnosis/mention of depression in medical notes/antidepressant prescription). Inpatient treatment also measured but analysed separately	No rural-urban differences in service use (though affected number of specialty care visits). Gender, age, severity and psychiatric and physical comorbidity were associated with service use	Predisposing (gender, age), need (comorbidity, severity), enabling (null - neighbourhood level: urban/rural)	446	74% (of whom 95% were followed up)	Strategy appropriate but no justification of sample size	Yes (representative of households with telephones)	Screener only	Yes	***
Roy-Byrne et al. (2009)	USA	Cross-sectional	Adults who met criteria for a mood or anxiety disorder (from nationally representative sample)	12 month mood or anxiety disorder (CID)	12 month receipt of treatment for emotional or substance use problems (in general medical and mental health specialty sectors)	Age, gender, marital status, race/ethnicity associated, but education, income, and assets only minimally associated in multivariate analyses	Predisposing (age, gender, marital status, ethnicity), enabling (income, null: education, assets, urban-rural)	1772	70.90 %	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****

Schomerus et al. (2013)	Germany	Prospective cohort	Adults aged 20–79 with lifetime depression (from population sample)	Lifetime depression (M-CIDI)	Lifetime visit to a psychologist, psychiatrist or general practitioner for their depressive symptoms	Age, education, perceived social support, childhood abuse, conscientiousness, resilience, depression severity. Gender, extraversion, openness, agreeableness, neuroticism, and alexithymia not associated	Predisposing (age, some personality factors), enabling (education, social support), need (childhood abuse*, severity). Predisposing (null - gender, other personality factors), need (null - alexithymia**). *alternatively could be seen as predisposing factor. ** alternatively could be seen as enabling factor	354	68.8% (of whom 95.2% were invited to participate in the cohort study, of whom 65.4% agreed, of whom 5.6% were excluded due to missing data)	Strategy appropriate but no justification of sample size	Yes (representative of adults aged 20-79)	Yes (though lifetime recall questionable)	No	**
Seedat et al. (2009)	South Africa	Cross-sectional	Adults living in households or hostels (from nationally representative sample)	All disorders (CIDI 3.0) (separated for some analyses)	12 month contact with any mental health professional or general medical practitioner for MH (or substance use) reasons	Gender (p=0.05 for depression/dysthymia, p=0.77 for anxiety disorders). No socio-demographic variables associated: age, education, race, marital status, income. (There were some associations found within gender groups but these combined those with CMD and SUD)	Predisposing (gender, but only for depression not anxiety, null: age, ethnicity, marital status), enabling (null: education, income)	4351	85.50 %	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****

Starkes et al. (2005)	Canada	Cross-sectional	General population (aged 12+) from population survey	Major depression (CIDI-SF)	12 month consultation with a health professional about mental or emotional health	Age (several other variables investigated but included those under age 18) - older age associated with reduced chances of help-seeking, though only 45-64 year old group significantly lower, 65+ not statistically different from 20-44 year olds	Predisposing (age)	1,312	80% (not reported in article but found elsewhere)	Sampling strategy not specified. Sample size calculated to have sufficient (unspecified) power to estimate the numbers seeking treatment	Yes	Yes	Yes	***
Sussman et al. (1987)	USA	Cross-sectional	General population (presumably adults only), from urban household survey	Depression (DSM-III criteria using DIS) (episode in past 6 months)	Two measures; (1) 6 month disclosure of emotional/psychological problems as an outpatient/1 year disclosure as an inpatient (includes to non-health providers), (2) lifetime disclosure of depressive symptoms to a doctor or (non-specified) professional	Race/ethnicity, which interacts with severity (racial disparities greatest in those with mild symptoms)	Predisposing (ethnic group) and need (severity)	116	75%-80%, depending on the site (not reported in article but found elsewhere)	Strategy appropriate but no justification of sample size	Yes (when weighted). Includes those in institutions	Yes	Yes	****
Tempier et al. (2009)	Australia/Canada	Cross-sectional	General adult population (excludes under-18s from Canadian sample)	12 month depressive/anxiety disorders (CIDI) (also measures SUD but presented separately)	12 month use of outpatient health services for MH reasons	Country associated for comorbid anxiety/depression but not depression alone - borderline for anxiety alone (p=0.05)	Contextual enabling (country), interacts with need (disorder type)	Not specified. Total original sample size was 36816 (Canada) and 10641 (Australia) but this includes	78% (Australia), 77% (Canada)	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****

								under-18s in Canada						
Tempier et al. (2010)	Canada/France/Belgium	Cross-sectional	General adult population	12 month depressive/anxiety disorders (CIDI)	12 month contact with a health professional for MH reasons (lifetime also measured)	Overall, no statistically significant differences found for 12 month service use (although the French use psychiatrists more and Canadians use non-psychiatrist MH professionals more). Once separated by disorder, Canadians with anxiety disorders used services more than Europeans but no stat. sig. difference for MDE or combination	Contextual enabling (country), interacts with need (disorder type)	Number with disorders not specified. Total original sample size was 8071 (Canada), 389 (Belgium), 1436 (France)	77% (Canada), 51% (Belgium), 46% (France)	Strategy appropriate but no justification of sample size	Yes	Yes	No (only in Canada)	***



ten Have et al. (2004)	Netherlands	Prospective cohort	General population aged 18-64	Lifetime major or minor depression (CIDI - DSM-III-R criteria)	Lifetime use of health services for MH reasons	Associated with both primary and specialist care: Fatigue/loss of energy, feelings of worthlessness or guilt, comorbid anxiety disorder, having a parent with a psychiatric history. Associated with specialist care only: loss of interest/pleasure, weight loss/gain, insomnia/hypersomnia, reduced ability to think/concentrate, age, education, age of onset (reduces chances of treatment, while all other increase it). Associated with primary care only: comorbid SUD. Null: depressed mood, psychomotor agitation/retardation, recurrent thoughts of death, gender.	Predisposing (age and age of onset associated with specialist care only (latter negatively), null: gender), enabling (education associated with specialist care only), need (specific symptoms: fatigue, feelings of guilt/worthlessness, comorbid anxiety, parent with history of MH problems, SUD associated with primary care only, various symptoms associated with specialist care only, null: depressed mood, psychomotor agitation/retardation, recurrent thoughts of death)	1572 with lifetime major or minor depression	69.7% , 79.4 % followed up	Strategy appropriate but no justification of sample size	Yes (representative of 18-64 year-olds)	Yes (though lifetime recall questionable)	Yes	**
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Vasiliadis et al. (2007)	USA/Canada	Cross-sectional	Community-dwelling adults (aged 18+)	Probable MDE (CIDI-SF - DSM-III-R criteria)	12 month contact with a health professional for MH reasons	Health insurance (interacts with country - no effect in Canada, only in USA, though this disappeared in fully adjusted models). Disability (borderline significant? No p-value presented, 95% CI for OR: 1.0-1.7), long-term health problems that affect daily life, having a regular medical doctor, gender (female), marital status (single), education (university vs. less than high school), race (white vs. other). Null overall: income (but affects use of specialist services), perceived general health (affects use of generalist services), age, country of birth, household size. (Unmet need not associated with overall use/no use)	Predisposing (gender, marital status, ethnicity, null: age, country of birth) enabling (insurance - interacts with country, education, null: income - but affects use of specialist care, household size), need (disability borderline, chronic conditions that affect daily life, null: perceived general health - but affects use of generalist services)	287 (Canada), 451 (USA) with MDE	66% (Canada), 50% (USA)	Strategy appropriate but no justification of sample size	Yes	Screener only	No (only in Canada)	**
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Vesga-Lopez et al. (2008)	USA	Cross-sectional	General population aged 18+ (from nationally representative sample)	Generalised anxiety disorder (DSM-IV criteria)	Lifetime contact with a counselor, therapist, physician, or psychologist, inpatient admission, use of emergency services, or receipt of prescription for psychotropic medication	Gender	Predisposing (gender)	1757	81%	Strategy appropriate but no justification of sample size	Yes	Yes	Yes	****
Vigod & Levitt (2011)	Canada	Cross-sectional	General population aged 20+ (from telephone survey)	Lifetime depressive symptoms (CIDI)	Lifetime depression-specific use of health services from a physician (family physician or psychiatrist) - also looked at Lifetime psychotropic medication use, use of health services from a non-physician therapist, and psychiatric hospitalization	Seasonal depression severity score	Need (seasonality - positive association)	625	81.10 %	Not 100% clear - area stratified by latitude and then presumably sampled using PPS methods, but not specified. No discussion of sample size.	Mostly (sample not significantly different from the Ontario population with regard to educational level, marital status, and employment status, but women slightly oversampled and not clear whether rural-urban divide was representative)	Yes (though lifetime recall questionable)	Yes	**

Wallerblad et al. (2012)	Sweden	Prospective cohort	Swedish citizens aged 20–64 years from one county	Depressive/anxiety disorders (multiple diagnostic tools - DSM-IV criteria)	12 month contact with a health professional for psychological/sleeping/personal problems (includes "alternative medical treatment" - undefined)	Gender (female), age (older), marital status (single), nativity (born abroad), employment (outside the labour market), comorbid somatic illness, comorbid mental illness (both depression and anxiety), severity, disability	Predisposing (gender, age, marital status, nativity), enabling (employment), need (comorbid somatic illness, comorbid mental illness, severity, disability)	2026 with CMD	53% retention rate 83% (so overall 44%)	Strategy appropriate but no justification of sample size	Yes (representative of 20-64 year-old citizens from region surveyed)	Yes	No	**
Wang et al. (2000)	USA	Cross-sectional	Adults (from nationally representative sample)	MDD, panic disorder or GAD (CIDI-SF)	12 month use of health care for MH reasons, or self-help or religious advisor	Education level and number of comorbid conditions predicted use of generalist sector, while severity, age and MH insurance predicted use of specialist sector. Severity, comorbidity and insurance coverage predicted any treatment-seeking (including from non-health sector)	Need (disorder type)	428 (depression), 206 (panic disorder), 100 (GAD) (558 in total, presumably due to overlap in categories with comorbidities)	60.8% (70% for initial sampling stage and 86.6% for full interview)	Strategy appropriate but no justification of sample size	Yes (when weighted)	No outcome that corresponds to any health service use	Borderline	**

## Detailed results by factor

To avoid repetition in the presentation of results, when a factor is said to have been investigated, this should be understood as “investigated as a factor that is potentially associated with health service utilisation for CMD”. Any associations referred to should be understood as associations between this factor and health service utilisation for CMD, among individuals who screen positive for CMD.

### *Predisposing factors*

#### Summary

As shown in table 5, while there were some trends towards greater treatment-seeking by women, the middle-aged and individuals in the majority ethnic group, and having sought treatment for a previous episode of CMD symptoms, none of these associations was identified consistently across studies.

#### Age

Twenty-five studies investigated age. Fifteen studies were of good/excellent quality, and 18 of 25 studies reported some association. The most common relationship found was hill-shaped, with middle-aged respondents most likely to seek treatment (140-151). Three studies reported lower use by the youngest or oldest age groups (164, 166, 167), one study found a positive association with age (152), two studies reported mixed findings (160, 168) and seven studies found no evidence of an association (153-159).

#### Age of onset

Three studies tested age of onset of CMD, of which two were rated good/excellent quality. In two out of three papers a later onset was associated with increased likelihood of seeking treatment (137, 162), while Ten Have et al. (2004) reported mixed findings (168).

#### Gender

Twenty-nine studies investigated either gender or sex, of which eighteen were rated good/excellent quality, and 20 of 29 reported some association. With the exception of

Rafful et al. (2012) (160), all of the studies that reported gender differences found that women were more likely to seek help than men (138, 140, 141, 145, 146, 148, 150, 159, 161-164). Six studies reported mixed results (137, 143, 144, 155, 165, 166), while nine studies reported no evidence of an association (142, 149, 151-153, 156, 158, 167, 168).

#### Ethnicity

Twenty-three studies investigated race or ethnicity. Seventeen were of good/excellent quality, and 20 of 23 reported some association. It was commonly reported that Caucasians (the majority ethnic group in the context of most studies) were more likely to seek treatment than minority ethnic groups (140, 146, 148-150, 159, 161, 169-173). Some studies found differences between minority groups, but these were not consistent with one another (151, 174, 175). Six studies reported mixed results (137, 144, 155, 176-178) and three did not find any association (138, 141, 142).

#### Education

Twenty studies examined education level. Thirteen were rated good/excellent quality and 11 of 20 reported some association. All those that found an association reported that higher education levels were associated with a greater likelihood of seeking treatment (137, 140, 144, 148, 150, 152, 153, 159, 161). Two reported mixed results (154, 168) while nine found no evidence of an association (138, 141, 142, 146, 149, 151, 155, 156, 167).

#### Immigration status/country of birth

Six studies investigated country of origin or linguistic background. Two were classified as good/excellent quality and 3 of 6 reported some association. Three studies found no evidence of any association (137, 159, 179), one reported mixed results (173) and two studies found associations in opposite directions (139, 164).

#### Marital status

Eighteen studies investigated marital status. Fourteen were rated as good/excellent quality, and 10 of 18 reported some association. In general, being married was associated with a lower likelihood of treatment-seeking, though it is unclear from the evidence whether this was due to greater use of services by the separated or divorced group, or the never married (138, 142, 146, 149, 150, 159, 164). One study found that married individuals were more likely to seek treatment than other groups (161). Eight studies reported no evidence of an association (140, 141, 148, 153, 155-158) and one found mixed results (137).

Three studies examined a change in marital status. The findings were inconsistent (137, 138, 162).

#### Personality factors

Four studies examined personality traits. Two were of good/excellent quality. 3 of 4 reported some association. There was no clear consensus between studies as to which traits were associated with seeking treatment (142, 152, 157, 165).

#### Attitudes towards and experience of mental health services

Five studies reported on previous experiences with mental health services or expectations of mental health services. Two were rated good/excellent quality. 2 of 3 reported a positive association with having prior experience of services (137-139), one found a positive association with expected benefits of services (141), and one very small study did not find an association with trust in professional services (158).

#### Stigma

Two studies, of which one was rated good quality, examined stigma. One found an association with personal stigma but not perceived stigma (157), while the other – a very small study – found no evidence of an association (158).

#### *Enabling factors (individual level)*

##### Summary

As indicated in table 5, there was inconsistent evidence for an association between treatment-seeking for CMD and enabling factors. The studies included here suggest that income is not associated with the use of health services for CMD symptoms.

#### Income/wealth

Eleven studies assessed wealth or income. Eight were of good/excellent quality. Just one of 11 studies found a positive association with income (the measure most commonly used) (140), two found mixed results (146, 159) and a fourth reported a negative association with

concerns about affordability (158). None of the remaining studies found an association (138, 149, 151, 153, 155, 156, 166).

#### Employment

Eight studies examined employment. Four were classified as good/excellent quality. 4 of 8 studies found a negative association with being in employment (141, 149, 156, 164), while the others did not find an association (142, 153, 166, 167).

#### Social support

Five studies examined social support or related factors, of which one was rated as good/excellent quality. Two of five studies reported an association, with greater perceived social support linked to treatment seeking (152, 166), and two did not (141, 157). No association was found with household size (159).

#### Insurance

Seven studies reported on health insurance. Three were of good/excellent quality. Four studies reported a positive association between having health insurance and treatment-seeking (140, 141, 144, 151). One reported mixed results (154) and two did not find an association (138, 159).

#### Regular source of care

Two studies – of which one was rated good/excellent – investigated having a usual source of health care, with inconsistent results (138, 139).

#### *Need factors (individual level)*

##### Summary

Need factors were most consistently associated with the use of health services for CMD symptoms across studies, as seen in table 5. Chronicity or duration of symptoms, disability (particularly affecting the ability to work), comorbid mental disorders, panic symptoms, and self-rated health status or perceived need for care, were all associated with treatment-seeking, and there was a trend towards greater treatment-seeking by those with more severe symptoms.



#### Self-rated health / Perceived need for care

Eight studies examined individuals' perceptions of their own health status or need for care. Four were rated as good/excellent quality. 3 of 8 studies reported a negative association between treatment-seeking and self-rated health status or subjective distress (144, 161, 165). Two studies found indirect evidence for the role of perceived need for care in mediating or moderating the effects of ethnicity on treatment-seeking (174, 177). Two studies did not find an association (141, 158), including one longitudinal study, while another reported mixed results (159). Two out of three longitudinal studies reported a negative association.

#### Symptom severity

Sixteen studies investigated symptom severity. Eight were of good/excellent quality. 10 of 16 studies found a positive association between symptom severity and treatment-seeking (141, 142, 145, 149, 150, 152, 164, 169, 170, 176) and another found mixed results (167). Five studies did not report an association (144, 156, 158, 162, 165). Five out of six longitudinal studies found a positive association.

#### Chronicity/Duration

Three studies examined the chronicity or duration of illness, all of which were rated as good/excellent quality (140, 157, 162). All found a positive association. None used longitudinal data.

#### Disability

Eight studies investigated some measure of disability or functioning. Three were rated good/excellent quality, and 7 of 8 reported some association. Five studies reported that those with greater levels of impairment were more likely to seek treatment (139, 142, 156, 164, 167), two found mixed results (154, 165) and the final study found an association that bordered on statistical significance (159). Of two longitudinal studies, one reported a positive association.

#### Comorbid conditions - total

Four studies reported on an individual's total number of comorbid conditions, of which one was rated as good/excellent quality. 3 of 4 studies – including the only longitudinal study –

reported no evidence of an association (148, 162, 165) while Wang et al. (2000) reported mixed results (154).

#### Non-psychiatric chronic conditions

Fourteen studies investigated non-psychiatric comorbidities. Ten were of good/excellent quality. Only three of the eight studies that looked at medical comorbidities in general found a positive association (145, 159, 164), while five reported no evidence of an association (141, 142, 144, 156, 157). Two out of three longitudinal studies reported a positive association. Bucholz and Robins (1987) found an association with worsening physical health (138).

Five studies investigated specific comorbid conditions or comorbid pain, with mixed results (140, 166, 184-186).

#### Psychiatric comorbidity

Seventeen studies investigated comorbid mental and substance use disorders. Fourteen were classified as of good/excellent quality.

Of the six studies that examined comorbid mental disorders in general, all – including all three longitudinal studies – reported a positive association with treatment-seeking, (141, 142, 145, 150, 156, 167).

Six studies investigated comorbid mood or anxiety disorders. Five reported a positive association (137, 143, 161, 164, 168) while one did not (157). All four longitudinal studies found a positive association.

Eight studies examined substance use symptoms. Three found a positive association (161, 180, 181), two reported a negative association (162, 182), one reported mixed results (168) and two did not find an association (137, 140). The findings from longitudinal studies were equally mixed.

Findings with regard to other comorbid psychiatric diagnoses were inconsistent (140, 162, 182).

### Specific CMD symptoms

Thirteen studies investigated specific symptom profiles. Ten were of good/excellent quality.

Five studies reported that panic symptoms were associated with treatment-seeking (137, 142, 143, 162, 182) although one found reduced treatment-seeking by those with panic symptoms compared to those without (154). There were two longitudinal studies of which both reported a positive association.

Three studies investigated suicidality, with inconsistent results (150, 162, 167). There was one longitudinal study, which did not find an association.

There was no clear consensus on the associations between other CMD symptoms and treatment-seeking (138, 157, 168, 176, 183) and no evidence of an association with somatisation (162, 182).

### Adverse childhood events

Four studies examined adverse life events in childhood of various sorts, of which one was rated as good/high quality. Three found that adults who had experienced adversity as a child were more likely to seek treatment (152, 168) while two reported mixed results (165, 167).

As mentioned under “predisposing factors”, there were contradictory findings with regard to bereavement or change in marital status (137, 138, 162).

### *Contextual level factors*

#### Summary

Limited evidence was found for the association between contextual level factors and health service utilisation for CMD. The studies included here suggest that living in a rural area is not associated with lower rates of treatment-seeking.

Place of residence

*Urban/rural*

Seven studies examined urban or rural residence, of which 6 of 7 were classified as good/excellent quality. None found evidence of an association overall (140, 142, 145, 146, 148, 156, 167).

*Country*

Three studies, of which two were of good/excellent quality, compared treatment-seeking by country of residence. There were no consistent findings, despite the differences in health systems between the countries included (169, 187, 188).

*Within-country region*

Three studies examined differences by within-country region. 2 of 3 were rated as good/excellent quality. 2 reported an association (148, 150), while one did not find an association (140).

Health care environment

*Organisation of services*

One study, rated excellent quality, examined the effect of managed care and found that those for whom there is a gatekeeper to health services are less likely to seek treatment (144).

*Availability of services*

Only one study, rated "fair" quality, examined perceived availability of services, and found a positive association with treatment-seeking (141).

*Accessibility of services*

One study, of poor quality and a very small sample size, investigated concerns about the accessibility of health services (158). No evidence of an association was found.

**e. Supplementary material from Chapter 3**

**Table 4.** Sub-group analysis for distance to depression treatment provider and odds of treatment-seeking for adults with probable depression (n=568) in Sehore sub-district, Madhya Pradesh, India, 2013-2017.

	Adjusted OR (95% CI)	Stratum-specific P-value	Wald P-value for interaction terms
<i>Caste</i>			0.02
Scheduled castes	1.04 (1.01-1.06)	<0.01	
Scheduled tribes	0.98 (0.90-1.06)	0.54	
Other backward castes	0.98 (0.96-1.01)	0.15	
General castes	1.00 (0.97-1.04)	0.87	
<i>Employment status</i>			0.03
Unemployed	0.73 (0.60-0.90)	<0.01	
Productive no income	1.00 (0.98-1.02)	0.95	
Low income	1.01 (0.99-1.02)	0.59	
High income	0.98 (0.91-1.05)	0.55	
<i>Educational attainment</i>			0.62
Less than primary	1.00 (0.99-1.02)	0.70	
Primary or more	0.99 (0.94-1.04)	0.70	
<i>Perceived need for health care</i>			0.02
Health care needed	0.99 (0.97-1.01)	0.32	
Health care not needed	1.02 (1.00-1.03)	0.06	
<i>Housing quality</i>			0.25
Lowest level ( <i>kuccha</i> )	1.01 (0.99-1.02)	0.32	
Mixed ( <i>semi-pucca</i> )	0.97 (0.92-1.02)	0.26	
Highest level ( <i>pucca</i> )	0.99 (0.97-1.02)	0.72	
<i>Gender</i>			0.54
Male	1.00 (0.96-1.03)	0.82	
Female	1.01 (0.99-1.02)	0.37	
<i>Owns land</i>			0.49
Yes	1.00 (0.97-1.03)	0.80	
No	1.01 (0.99-1.02)	0.51	
<i>Symptom severity (total PHQ-9 score)</i>			0.48
Moderate (10-14)	1.00 (0.98-1.02)	0.98	
Moderately severe (15-19)	1.01 (0.98-1.04)	0.60	
Severe (≥20)	0.97 (0.91-1.03)	0.33	

*Odds ratios, P-values and confidence intervals were calculated with logistic regression.*

*Besides the interaction term, each model was adjusted for education level, marital status, symptom severity, gender, land ownership, employment, survey round, exposure to mental health communications, and age group.*

**f. Supplementary material from Chapter 5**

**Table 1.** Instruments used to measure barriers to health service use and factors associated with treatment-seeking for depression in PRIME community survey, Sehore sub-district, India, 2013-2016.

<b>Factor</b>	<b>Instrument</b>	<b>Categories used for analysis</b>
Symptom severity and specific symptoms	Patient Health Questionnaire (PHQ-9) (278)	Total score (sum of items): None (0-4)/ Mild (5-9)/ Moderate (10-14)/ Moderately severe (15-19) /Severe ( $\geq 20$ ) Individual symptoms: $\geq 7$ days in past 2 weeks/ $< 7$ days in past 2 weeks
Disability	12-item World Health Organization Disability Assessment Schedule (WHODAS 2.0) (233)	Total score (complex scoring, divided into terciles)
Probable alcohol use disorder	Alcohol Use Disorders Identification Test (AUDIT) (289-292)	Screen-positive (AUD $\geq 8$ , AUD $< 8$ )
Suicidal thoughts	Composite International Diagnostic Interview (CIDI) suicidality module (293)	Yes/No
Barriers to healthcare use (including lack of perceived need)	Questions from the Study on global AGEing and adult health (SAGE) (287), with one question added in round 2 on distance to services	Agree or strongly agree / disagree or strongly disagree
Self-stigma	Questions from the Internalized Stigma of Mental Illness (ISMI) scale (288)	Total score: Sum of items (divided into terciles)
Land ownership	No structured instrument used	Yes/ No
Housing type	No structured instrument used	Kuccha (lowest level)/ Pucca (highest level)/ Semi-Pucca (mid-level)
Employment status	No structured instrument used	Unemployed/ Productive non-income (students and housewives)/ Low income/ High income
Discussing depression symptoms	No structured instrument used	Yes/ No If yes: Friend / Neighbour / Spouse / Parents / Siblings / Relatives / Employer or coworker / Other
Gender	No structured instrument used	Male/ Female
Religion	No structured instrument used	Hindu / Muslim / Christian / Sikh / Buddhist / Jain / Other

Education level	No structured instrument used	Less than primary school completed / Primary school or more completed
Age	No structured instrument used	18-29/ 30-49/ 50-90
Caste	No structured instrument used	General/ Scheduled caste/ Scheduled tribe/ "Other Backward Caste"
Marital status	No structured instrument used	Single/ Ever married
Health care utilization	Questions from the Client Socio-Demographic and Service Receipt Inventory (CSSRI) (460)	Any use of health care in the past 3 months (private/ public/ traditional/ other/ none)
Treatment-seeking for depression	No structured instrument used	Overall: Yes/ No Provider type: Specialist mental health workers (psychiatrists, other specialist medics, psychologists, counsellors, psychiatric nurses, other mental health professionals) / Generalist health workers (other medical doctor, social worker, community health worker, nurse, ANM, ASHA, AWW, PRIME case managers based in primary care facilities*), Complementary service providers (ojha, guni, dev maharaj, traditional healers, herbalists, spiritualists). *available in round 2 only

**Table 6.** Association between need, predisposing and enabling factors and treatment-seeking for depression among adults with probable depression in Sehore sub-district, 2013-2016 – all factors

	Total seeking treatment (n)	Prevalence of treatment-seeking, % (95% CI)	Prevalence ratio (95% CI)	p-value
<b>Need factors</b>				
Symptom severity (total current PHQ score)				
10-14	50/450	11.5 (8.5-15.5)	1	<0.01
15-19	20/107	20.7 (13.2-30.8)	1.79 (1.11-2.88)	

≥20	5/11	39.5 (12.8-74.5)	3.42 (1.33-8.81)	
Disability (total WHO-DAS score)				
Low	2/36	8.3 (1.7-31.7)	1	0.15
Medium	14/148	9.9 (4.5-20.3)	1.19 (0.23-6.21)	
High	59/384	15.9 (12.4-20.2)	1.92 (0.44-8.32)	
Perceived need for health care				
No	15/172	9.2 (4.5-18.1)	1	0.12
Yes	60/396	16.1 (12.4-20.5)	1.74 (0.86-3.54)	
Comorbid AUD				
No	69/531	13.7 (10.6-17.5)	1	0.53
Yes	6/37	17.2 (7.5-34.7)	1.25 (0.62-2.54)	
Suicidal thoughts				
No	49/421	12.7 (9.4-16.9)	1	0.21
Yes	26/147	17.2 (11.0-25.8)	1.35 (0.84-2.16)	
Sleep problems				
< 7 days in past 2 weeks	33/235	15.2 (10.5-21.4)	1	0.60
≥ 7 days in past 2 weeks	42/333	13.0 (8.6-19.3)	0.86 (0.49-1.51)	
Tiredness/lack of energy				
< 7 days in past 2 weeks	10/118	7.3 (3.8-13.5)	1	0.03
≥ 7 days in past 2 weeks	65/450	15.7 (11.7-20.6)	2.14 (1.08-4.24)	
Appetite problems				
< 7 days in past 2 weeks	37/275	14.8 (10.0-21.4)	1	0.58
≥ 7 days in past 2 weeks	38/293	13.0 (9.6-17.5)	0.88 (0.56-1.39)	
Lack of concentration				
< 7 days in past 2 weeks	43/339	13.0 (9.7-17.2)	1	0.50
≥ 7 days in past 2 weeks	32/229	15.3 (9.9-22.9)	1.18 (0.73-1.89)	
Lack of interest or pleasure				
< 7 days in past 2 weeks	26/279	9.7 (6.3-14.7)	1	0.01
≥ 7 days in past 2 weeks	49/289	17.6 (13.2-23.2)	1.82 (1.16-2.85)	
Feeling depressed or hopeless				
< 7 days in past 2 weeks	32/197	16.8 (11.7-23.5)	1	0.13
≥ 7 days in past 2 weeks	43/371	12.2 (8.9-16.7)	0.73 (0.49-1.10)	
Low self-esteem / feeling like a failure				
< 7 days in past 2 weeks	51/445	11.5 (8.5-15.3)	1	<0.01
≥ 7 days in past 2 weeks	24/123	22.4 (15.2-31.9)	1.96 (1.28-3.00)	
Slow movements / restlessness				
< 7 days in past 2 weeks	51/449	12.2 (8.9-16.5)	1	0.01
≥ 7 days in past 2 weeks	24/119	20.1 (14.4-29.3)	1.65 (1.13-2.39)	
Thoughts of death / self-harm				
< 7 days in past 2 weeks	64/531	13.0 (9.5-17.6)	1	0.11
≥ 7 days in past 2 weeks	11/37	25.3 (12.0-45.7)	1.95 (0.87-4.37)	
<b>Predisposing factors</b>				



Sex				
Male	41/247	16.1 (11.3-22.3)	1	0.22
Female	34/321	12.1 (8.4-17.1)	0.75 (0.47-1.19)	
Religion				
Hindu	68/525	14.1 (10.7-18.3)	1	0.76
Muslim	7/43	12.2 (4.8-27.9)	0.87 (0.34-2.19)	
Education level completed				
Less than primary	51/419	12.9 (9.8-16.8)	1	0.26
Primary or more	24/129	16.8 (10.5-25.9)	1.30 (0.82-2.07)	
Age				
18-29 years	9/98	9.2 (4.8-17.0)	1	0.13
30-49 years	36/248	15.1 (10.7-20.8)	1.64 (0.82-3.28)	
≥50 years	30/222	14.7 (10.2-20.8)	1.60 (0.97-2.64)	
Caste				
Scheduled caste (SC)	13/101	15.2 (8.1-26.7)	1	0.62
Scheduled tribe (ST)	3/25	16.9 (6.0-39.1)	1.11 (0.34-3.64)	
"Other backward caste" (OBC)	53/393	13.8 (9.7-19.1)	0.91 (0.44-1.85)	
General	6/49	11.6 (5.4-23.3)	0.77 (0.28-2.13)	
Marital status				
Single / separated / widowed	7/107	5.9 (2.7-12.2)	1	0.02
Married	68/461	15.7 (11.9-20.6)	2.67 (1.19-5.99)	
Heard about mental health in past 12 months				
No	22/191	12.4 (8.1-18.6)	1	0.51
Yes	53/377	14.9 (10.5-20.8)	1.20 (0.69-2.07)	
Agree that medications can be effective for mental health problems				
Yes	59/464	13.9 (10.6-18.1)	1	0.56
Don't know	8/34	19.8 (9.4-37.1)	1.43 (0.67-3.06)	
No	7/66	9.8 (4.0-21.8)	0.70 (0.32-1.56)	
Agree that people with mental health problems can recover				
Yes	53/368	15.9 (11.6-21.6)	1	0.08
Don't know	12/86	13.4 (7.4-23.0)	0.84 (0.47-1.51)	
No	10/110	9.1 (5.1-15.8)	0.57 (0.30-1.10)	
Seeking services makes me feel ashamed or embarrassed				
No	69/530	13.5 (10.1-17.9)	1	0.40
Yes	6/38	18.4 (9.3-33.3)	1.36 (0.66-2.82)	
Dislike taking medications				
No	60/390	16.1 (12.1-21.2)	1	0.09

Yes	15/178	9.0 (4.7-16.6)	0.56 (0.28-1.10)	
<b>Self-stigma</b>				
Low	24/203	12.2 (7.4-19.3)	1	0.41
Medium	23/191	14.0 (9.6-20.0)	1.15 (0.65-2.04)	
High	28/174	15.6 (10.5-22.4)	1.28 (0.71-2.30)	
<b>Enabling factors</b>				
<b>Owning land</b>				
No	46/402	12.3 (8.9-16.6)	1	0.10
Yes	29/166	17.7 (12.0-25.3)	1.44 (0.94-2.22)	
<b>House type</b>				
Kuccha	35/309	12.8 (8.8-18.1)	1	0.93
Semi-pucca	17/85	21.0 (12.6-33.0)	1.65 (0.99-2.76)	
Pucca	23/174	12.5 (7.9-19.2)	0.98 (0.55-1.75)	
<b>Employment</b>				
Unemployed	1/20	5.4 (0.8-28.5)	1	0.09
Productive non-income (student/housewife)	28/241	12.3 (8.2-18.0)	2.28 (0.34-15.08)	
Low income	42/277	15.6 (11.2-21.4)	2.89 (0.42-19.99)	
High income	4/30	15.9 (6.6-33.5)	2.96 (0.58-14.92)	
<b>Fees not affordable</b>				
No	32/266	12.7 (7.5-20.8)	1	0.60
Yes	43/302	14.9 (11.2-19.8)	1.18 (0.64-2.16)	
<b>Services too far away</b>				
No	9/134	6.8 (3.8-12.0)	1	0.24
Yes	16/145	10.5 (6.6-16.3)	1.54 (0.74-3.19)	
<b>Spoken to someone about these problems</b>				
No	13/352	3.9 (2.2-7.0)	1	<0.001
Yes	62/216	29.4 (23.1-36.5)	7.50 (4.11-13.68)	
<b>Quality of services is not good enough</b>				
No	56/420	14.2 (10.0-19.8)	1	0.82
Yes	19/148	13.2 (8.3-20.5)	0.93 (0.50-1.73)	
<b>Services don't have medications I need</b>				
No	55/473	11.9 (8.7-16.2)	1	0.01
Yes	20/95	24.4 (15.9-35.6)	1.99 (1.19-3.32)	
<b>Services frequently run out of medications</b>				
No	56/487	11.9 (8.4-16.7)	1	0.01
Yes	19/81	23.6 (16.3-33.0)	2.05 (1.23-3.39)	
<b>Providers don't understand my health problems</b>				
No	60/433	14.7 (11.0-19.4)	1	0.28
Yes	15/135	11.4 (7.3-17.3)	0.77 (0.49-1.23)	

Percentages and P-values are adjusted for the complex sampling strategy.

**g. Supplementary material from Chapter 6**

Topic guides

Question	Probes
<p><b>1. Experience of symptoms</b></p> <p>You mentioned experiencing some problems recently [give examples of DD symptoms reported in CS]. Can you tell me about these problems, in your own words?</p> <p>हाल ही में आप कुछ परेशानियाँ महसूस कर रहे थे जो यहाँ उल्लेखित हैं (CS में दर्ज लक्षणों का उदाहरण देना है), क्या आप इन परेशानियों के बारे में मुझे अपने शब्दों में बता सकते हैं। और हाल ही में आपको कुछ परेशानियाँ हो रही थी [cs में दर्ज लक्षणों का उदाहरण देना है] क्या आप इन परेशानियों के बारे में अपने शब्दों में मुझे बता सकते हैं।</p>	<ul style="list-style-type: none"> <li>- When did the problem start?</li> <li>- परेशानी कब शुरू हुई?</li> <li>- How would you describe your experience of these problems?</li> <li>- आपकी इन परेशानियों के बारे में आपके अनुभवों को कैसे बतायेगे?</li> <li>- और</li> <li>- क्या आप इन परेशानियों से संबंधित में आपके अनुभवों के बारे में बता सकते हैं</li> <li>- How severe were these feelings? Can you tell me what it felt like?</li> <li>- आपने इन परेशानियों को कितना गंभीर महसूस किया? क्या आप बता सकते हैं की आपको कैसा महसूस हुआ था.</li> <li>- और</li> <li>- क्या आप बता सकते हैं की ये परेशानियाँ कितनी गंभीर थी, और आपको कैसा महसूस हुआ था?</li> <li>- How did these problems affect your life?</li> <li>- इन परेशानियों ने आपके जीवन को कैसे प्रभावित किया है.</li> <li>- Which symptoms did you find most important or difficult to deal with?</li> <li>- कौनसे ऐसे लक्षण थे जिनसे निपटने में आपको सबसे ज्यादा कठिनाई हुई या जो सबसे ज्यादा महत्वपूर्ण थे.</li> <li>- How common do they think these problems are? Do you know anyone else who has felt like this?</li> <li>- आपके विचार से ये परेशानिया कितनी आम हैं? क्या आप ऐसे किसी व्यक्ति को जानते हैं जो आपके जैसी परेशानिया महसूस करते हैं.</li> <li>- Do you think you need help for this problem?</li> <li>- क्या आपको लगता है, आपको इस परेशानी के लिए सहायता की जरूरत है.</li> </ul>
<p><b>2. Understanding of symptoms - causes</b></p> <p>What do you think caused these problems?</p> <p>आपको क्या लगता है, आपकी इन परेशानियों का कारण क्या है?</p>	<ul style="list-style-type: none"> <li>- Can you tell me how you explain these problems?</li> <li>- क्या आप मुझे बता सकते हैं कि, आप इन परेशानियों के बारे में कैसे समझायेगे.</li> <li>- और</li> <li>- क्या आप मुझे बता सकते हैं की ये क्या(किस तरह की) परेशानियाँ हैं?</li> </ul>

<p>और आपके विचार से किन कारणों से ये परेशानियाँ हुई है?</p>	<ul style="list-style-type: none"> <li>- What did you think, when you started feeling like this?</li> <li>- आपको जबसे ये परेशानो हुई, तब आपने कैसा महसूस किया?</li> <li>- Can you tell me what was happening in your life when you got these problems?</li> <li>- क्या आप बता सकते हैं की, जब आपको ये परेशानिया हुई तब आपके जीवन में क्या हो रहा था.</li> <li>- How is your health in general?</li> <li>- सामान्य तौर पर आपका स्वास्थ्य कैसा है.(कैसा रहता है)?</li> <li>- Have you ever felt like this before?</li> <li>- क्या आपको पहले भी कभी ऐसा महसूस हुआ है?</li> <li>- Is there anything you could do to prevent this problem from happening?</li> <li>- क्या ऐसा कुछ है, जो आप इन परेशानियों को होने से रोकने के लिये कर सकते थे?</li> <li>- How did the research worker explain these problems to you when you were interviewed as part of the PRIME survey?</li> <li>- प्राइम सर्वेक्षण के अंतर्गत आपका इंटरव्यू किया गया था, तब शोधकर्ता ने आपकी परेशानियों के बारे में कैसे(क्या)समझाया था.</li> </ul>
<p><b>3. Understanding of symptoms – treatability/prognosis</b></p> <p>How long do you expect these sort of problems to last? आप क्या अपेक्षित/आशा करते है, की इस तरह की परेशानियाँ कितनी लम्बी ( समय अंतराल/ दिनों) चलती है? और आप इस परेशानियों का कितना लम्बा होना अपेक्षित करते है.</p>	<ul style="list-style-type: none"> <li>- What do you think will happen with these problems if you wait and do nothing?</li> <li>- यदि आप इंतज़ार करते है और कुछ भी नहीं करते तो आपकी इन परेशानियों के साथ क्या होगा, आपको क्या लगता है? और यदि आप इन परेशानियों के लिए इंतज़ार करते है औए कुछ भी नहीं करते है तो आपको क्या लगता है, इन परेशानियों का क्या होगा?</li> <li>- How have these problems changed since you were last interviewed about them?</li> <li>- आपकी परेशानियों के बारे में आखिरी इंटरव्यू होने के बाद, ये परेशानियाँ कितनी बदल गयी है. और आखिरी बार जब आपका इन परेशानियों के बारे में इंटरव्यू हुआ था, तब से आपकी परेशानियों में कितना परिवर्तन आया है.</li> <li>- How do you think they will change in future?</li> <li>- आपको क्या लगता है, भविष्य में इनमे कितना परिवर्तन आयेगा?</li> </ul>
<p><b>4. Social meaning of symptoms</b></p>	<ul style="list-style-type: none"> <li>- What do people say about these sort of problems?</li> </ul>

<p>How do people in your family or village react to these problems? आपके परिवार के सदस्य और गाँव के लोग इन परेशानियों पर कैसी प्रतिक्रिया देते हैं?</p>	<ul style="list-style-type: none"> <li>- इस तरह की परेशानियों के बारे में लोग क्या कहते हैं? और लोग आपकी इस परेशानी के बारे में क्या कहते हैं?</li> <li>- How do people treat you when you are having these problems?</li> <li>- लोग आपके साथ कैसा बर्ताव करते हैं, जब आपको ये परेशानिया है और आपको ये परेशानियाँ हैं, इस कारण से लोग आपको किस तरह की प्रतिक्रिया देते हैं?</li> <li>- What sort of advice do they give for these problems?</li> <li>- इन परेशानियों के लिए वो किस तरह की सलाह देते हैं?</li> <li>- How do people react when you have other health problems, like fever? In what ways is it different from how people react when you have the problems we have been talking about today?</li> <li>- आपको कोई दूसरी स्वास्थ्य परेशानी जैसे की बुखार है तब लोग कैसे प्रतिक्रिया देते हैं? और ये प्रतिक्रिया किस तरह से उन परेशानियों के लिए अलग है जिनके बारे में आज हम बात कर रहे हैं.?</li> <li>- और आज हम जिन परेशानियों के बारे में बात कर रहे हैं, उनके लिए मिलने वाली लोगों की प्रतिक्रिया और दूसरे स्वास्थ्य समस्या जैसे की, बुखार में मिलने वाली लोगों की प्रतिक्रिया में क्या अंतर है?</li> </ul>
<p><b>5. Help-seeking/coping strategies</b></p> <p>What do you do to help yourself feel better when you experience these sort of problems?  जब आपको इस तरह की परेशानियाँ अनुभव होती है तब आप खुद को अच्छा महसूस कराने की लिए क्या करते हैं और जब आपको इस तरह की परेशानियाँ होती है तो खुद की</p>	<ul style="list-style-type: none"> <li>- Can you describe anything you do to make yourself feel better when you have these problems?</li> <li>- क्या आप बता सकते हैं जब आपको परेशानियाँ होती है तो, आपको अच्छा महसूस कराने के लिए ऐसी कोई चीज़ जो आप करते हो?</li> <li>- और आपकी परेशानी में, आपको बेहतर महसूस कराने के लिए आप क्या करते हैं, कुछ उदाहरण देकर बता सकते हैं?</li> <li>- How much do these things help you? Why?</li> <li>- ये चीज़े आपको कितना मदद करती हैं? कैसे?</li> <li>- How do you feel about asking for help with these problems?</li> <li>- इन परेशानियों के लिए मदद मांगने में आपको कैसा महसूस होता है?</li> </ul>

<p>मदद आप कैसे करते हैं की आपको बेहतर महसूस हो?</p> <p>Reminder: Would it be different if the person having this problem was male/female? What would be different, and why? आपको क्या लगता है की आपका महिला/ पुरुष होना इस परेशानी को प्रभावित करता है?</p>	<p>और आपको कैसा महसूस होता है इन परेशानियों के साथ मदद मांगने के लिए?</p> <ul style="list-style-type: none"> <li>- Who do you go to for help? Why? आप मदद के लिए किसके पास जाते हैं? क्यों?</li> <li>- How easy is it to get help if you feel you need it?</li> <li>- जरूरत पड़ने पर आपको मदद मिलना कितना आसान है?</li> </ul> <p>और जब आपको मदद की जरूरत होती है तब कितने आसानी से मिल जाती है?</p> <ul style="list-style-type: none"> <li>- What stops you from going for help?</li> <li>- मदद मागने में आपको क्या रोकता है?</li> </ul> <p>और ऐसा क्या है जो आपको मदद मांगने से रोकता है?</p> <ul style="list-style-type: none"> <li>- Can you tell me a bit more about this?</li> <li>- क्या आप इसके बारे में थोडा और मुझे बता सकते हैं? क्या और भी कोई ऐसे कारन है जिसकी वजह से आप इन परेशानियों में मदद नहीं लेते हैं, सबसे जादा जरुरी क्या है</li> </ul>
<p><b>6. Attitudes towards health services generally</b></p> <p>What are health services like in your area? आपके क्षेत्र में स्वास्थ्य सेवाए किस तरह की है?</p>	<ul style="list-style-type: none"> <li>- What do you think about the quality of health services in your area?</li> <li>- आपके क्षेत्र की स्वास्थ्य सेवाओं की गुणवत्ता के बारे में आप क्या सोचते हैं?</li> <li>- How are the public and private health services different?</li> <li>- सरकारी और प्राइवेट (निजी) स्वास्थ्य सेवाए कैसे भिन्न है?</li> <li>- Which do you think is better and why?</li> <li>- आपके विचार से कौनसी ज्यादा बेहतर है? और क्यों?</li> <li>- What about traditional healers and religious healers, or any other places you can go to for health problems? Can you tell me what you think of these in your area?</li> <li>- आपकी परेशानियों के लिए आप कहाँ और जा सकते है उनके बारे में थोडा बताइए जैसे की, परंपरागत, धार्मिक उपचार, या फिर कोइ दूसरे स्थान? क्या आप मुझे बता सकते है की आपके क्षेत्र में इनके बारे में आप क्या सोचते है?</li> <li>- Who makes decisions about healthcare in your family?</li> <li>- परिवार में कौन निर्णय लेता है, की किस डॉक्टर के पास जाना चाहिए?</li> <li>- Where do you usually go if you or someone in your family is sick? Why?</li> </ul>

	<ul style="list-style-type: none"> <li>- यदि आप या आपके परिवार का कोई सदस्य बीमार होता है, सामान्य तौर पर आप कहाँ जाते हैं? क्यों?</li> <li>- How do staff treat you if you go there?</li> <li>- वहाँ का स्टाफ आपके साथ कैसा बर्ताव (कैसी प्रतिक्रिया) करता है?</li> <li>- How easy is it to use health services when you need them?</li> <li>- जरूरत पड़ने पर स्वास्थ्य सेवाओं का उपयोग करना कितना आसान है?</li> <li>- What are the things that make it more difficult? ऐसी क्या चीज़ें हैं जो इसे और कठिन बनती हैं?</li> <li>- Have you used health services since these problems started?</li> <li>- जबसे ये परेशानियाँ आपको शुरू हुई हैं, क्या आपने स्वास्थ्य सेवाओं का उपयोग किया है?</li> </ul>
<p style="text-align: center;"><b>7. Reasons for non-disclosure</b></p> <p><i>If the person has used health services recently:</i> यदि व्यक्ति ने हाल ही में स्वास्थ्य सेवाओं का उपयोग किया हो: Did you talk to the health worker about the problems that we have been talking about?</p> <p>जिन परेशानियों के बारे में हम बात कर रहे हैं उनके बारे में, क्या आपने स्वास्थ्य कार्यकर्ता से बात की है?</p> <p>और अभी जिन परेशानियों के बारे में हम बात कर रहे हैं, क्या इनके बारे में आपने स्वास्थ्य कार्यकर्ता से बात की है?</p> <p>***</p> <p><i>If the person has not used health services recently:</i> यदि व्यक्ति ने हाल में स्वास्थ्य सेवाओं का उपयोग नहीं किया है तो:</p>	<ul style="list-style-type: none"> <li>- Why/why not?</li> <li>- क्यों/ क्यों नहीं?</li> <li>- Please tell me more about this [Reflect back what they are saying to explore their response and elicit more information.]</li> <li>- इसके बारे में कृपया थोड़ा मुझे और बताइए? [पीछे देखिये, ये क्या कह रहे हैं उनकी प्रतिक्रिया के आधार पर और जानकारी निकालने की कोशिश करना है]</li> </ul>

<p>Would you tell the health worker that you have been experiencing these problems? आपको ये परेशानिया रही है, क्या आप ये स्वास्थ्य कार्यकर्ता को बतायेगे? ( यदि आप जाते तो)</p>	
<p><b>8. Awareness of mental health treatment</b></p> <p>Have you heard anything about treatment for this sort of problem? क्या आपने इस तरह की परेशानियों के लिए उपचार के बारे में कुछ सुना है?</p>	<ul style="list-style-type: none"> <li>- Have you ever heard of people being treated in health centres for this sort of problem? What have you heard about these treatments?</li> <li>- क्या आपने इस तरह की परेशानियों का स्वास्थ्य केंद्र में उपचार लेते हुए किसी को सुना है? इन उपचार के बारे में आपने क्या सुना है? और क्या आपने इस तरह की परेशानियों के लिए किसी को स्वास्थ्य केंद्र में उपचार लेते सुना है? इन उपचार के बारे में आपने क्या सुना है?</li> <li>- Have you heard that these treatments are being offered in the CHCs in Sehore?</li> <li>- क्या आपने सुना है की इस तरह के उपचार सीहोर, के सामुदायिक स्वास्थ्य केंद्र में दिए जा रहे है?</li> <li>- What have you heard about services for these problems in the Sehore CHCs?</li> <li>- सीहोर के सामुदायिक स्वास्थ्य केंद्र में इन समस्याओं की सेवाओं के बारे में आपने क्या सुना है?</li> <li>- What sort of treatment do you think would be given if you told the health worker about these problems?</li> <li>- यदि आप स्वास्थ्य कार्यकर्ता को इन समस्याओं के बारे में बताते, तो आपको क्या लगता है किस तरह का उपचार आपको दिया जाता? और आपके विचार से आपको स्वास्थ्य केंद्र में किस तरह का उपचार दिया जाता, यदि आप स्वास्थ्य कार्यकर्ता को आपकी परेशानी बताते?</li> </ul>
<p><b>9. Attitude towards mental health treatment</b></p> <p>Would you be willing to accept treatment in a health centre for these problems and why/why not? स्वास्थ्य केंद्र में आपकी परेशानियों के लिए, क्या आप उपचार स्वीकार करना चाहेगे?</p>	<ul style="list-style-type: none"> <li>- Did you plan to go to the health centre after you were interviewed? If not, why not? If yes, what happened?</li> <li>- आपका इंटरव्यू होने के बाद क्या आपने स्वास्थ्य केंद्र जाने का प्लान किया था? यदि नहीं, क्यों नहीं? यदि हाँ, क्या हुआ?</li> <li>- What sort of person do you think uses these services?</li> <li>- किस तरह के लोग, इन सेवाओं का उपयोग करते है?</li> </ul>



	<ul style="list-style-type: none"> <li>- Is there anything you would be worried about if you accepted treatment for these problems in a health centre?</li> <li>- यदि आप स्वास्थ्य केंद्र में, आपकी परेशानियों के लिए स्वास्थ्य सेवाओं को स्वीकारते हैं तो, ऐसा कुछ है जो आपको भयभीत करता है? और आपकी परेशानियों के लिए यदि आप स्वास्थ्य केंद्र की सेवाएं लेते हैं, तो ऐसे क्या कारन हो सकते हैं जिनसे आपको डर लगेगा?</li> <li>- Can you tell me about any difficulties you would face in going to the health centre for this problem?</li> <li>- इस परेशानी के लिए स्वास्थ्य केंद्र जाने में, जो कठिनाइयाँ आ सकती हैं उनके बारे में क्या आप मुझे बता सकते हैं? और क्या आप उन कठिनाइयाँ के बारे में मुझे बता सकते हैं जो इस परेशानी के लिए स्वास्थ्य केंद्र जाने में आपको होंगी?</li> <li>- How would your family respond if you used this sort of treatment? Why?</li> <li>- आपका परिवार कैसे प्रतिक्रिया देगा, यदि आप इस तरह का उपचार लेंगे? क्यों? और इस तरह का उपचार लेने पर आपका परिवार कैसे प्रतिक्रिया देगा? क्यों?</li> <li>- Do you believe these treatments could help you? Why/why not?</li> <li>- क्या आपको विश्वास है कि, ये उपचार आपकी मदद कर सकता है? क्यों? क्यों नहीं?</li> </ul>
<p><b>10. Priorities for recovery</b></p> <p>When you think about overcoming these problems and getting better, what is the most important thing for you? जब आप इन परेशानियों से छुटकारा पाने और बेहतर होने के बारे में सोचते हैं, तब आपके लिए सबसे ज्यादा महत्वपूर्ण क्या है? और आपके विचार से, आपकी परेशानियों से छुटकारा दिलाने और आपको बेहतर बनाने के लिए क्या महत्वपूर्ण है?</p>	<ul style="list-style-type: none"> <li>- Which of these matters the most for you:</li> <li>- इनमें से आपके लिए सबसे ज्यादा क्या महत्वपूर्ण है:</li> <li>- to no longer feel this way? इस तरह से अब नहीं लगे</li> <li>- to be able to do everyday tasks? रोजमर्रा के कामकाज कर सके?</li> <li>- to be able to earn money? पैसा कमा सके?</li> <li>- to be respected by people around you? आपके आसपास के लोग आपका आदर करें?</li> <li>- some other thing? या फिर कुछ और?</li> <li>- Can you tell me what difference this would make to your life?</li> <li>- क्या आप मुझे बता सकते हैं की, इससे आपके जीवन में क्या बदलाव आयेगा?</li> </ul>

	<ul style="list-style-type: none"> <li>- Do you believe that it is possible for you to overcome these problems?</li> <li>- क्या आप को विश्वास है इन परेशानियों से उभर पाना आपके लिए संभव है?</li> </ul>
<p><b>11. Ideal support/interventions</b></p> <p>What sort of support would you like for these problems? इन परेशानियों के लिए आप किस तरह का सहयोग चाहते हैं?</p>	<ul style="list-style-type: none"> <li>- What do you think could help you to feel better?</li> <li>- आपको क्या लगता है, की क्या आपको बेहतर महसूस करा सकता है?</li> <li>- Is there any things that could have prevented you from feeling this way?</li> <li>- क्या ऐसा कुछ है, जो आपको इस तरह से महसूस करने से रोक सकता है?</li> <li>- What would a perfect service for these problems be like, in your opinion?</li> <li>- आपके विचार से, इन परेशानियों के लिए सबसे उत्तम (सबसे बढ़िया) सेवाएं क्या हो सकती है (कैसी होनी चाहिए)?</li> </ul>

Question	Probes
<p><b>1. Experience of symptoms</b></p> <p>Your family member mentioned experiencing some problems recently [give examples of DD symptoms reported in CS]. Can you tell me about these problems, in your own words?</p> <p>हाल ही में आपके परिवार के सदस्य कुछ परेशानियाँ महसूस कर रहे थे जो यहाँ उल्लेखित है (CS में दर्ज लक्षणों का उदाहरण देना है), क्या आप इन परेशानियों के बारे में मुझे अपने शब्दों में बता सकते हैं.</p> <p>और हाल ही में आपको कुछ परेशानियाँ हो रही थी [cs में दर्ज लक्षणों का उदाहरण देना है] क्या आप इन परेशानियों के बारे में अपने शब्दों में मुझे बता सकते है.</p>	<ul style="list-style-type: none"> <li>- When did the problem start?</li> <li>- परेशानी कब शुरू हुई?</li> <li>- How severe do you think these problems are?</li> <li>- आपने इन परेशानियाँ को कितना गंभीर महसूस किया? क्या आप बता सकते है की आपके परिवार के सदस्य को कैसा महसूस हुआ था.</li> <li>- और</li> <li>- क्या आप बता सकते हैं की ये परेशानियाँ कितनी गंभीर थी, और आपके परिवार के सदस्य को कैसा महसूस हुआ था?</li> <li>- How did these problems affect your family member's life?</li> <li>- इन परेशानियों ने आपके परिवार के सदस्य के जीवन को कैसे प्रभावित किया है.</li> <li>- How did these problems affect your life and the lives of the rest of the family?</li> <li>- इन परेशानियों ने आपके और आपके परिवार के अन्य सदस्यों को कैसे प्रभावित किया?</li> <li>- Which symptoms did you find most important or difficult to deal with?</li> <li>- कौनसे ऐसे लक्षण थे जिनसे निपटने में आपको सबसे ज्यादा कठिनाई हुई या जो सबसे ज्यादा महत्वपूर्ण थे.</li> <li>- How common do they think these problems are? Do you know anyone else who has felt like this?</li> </ul>

	<ul style="list-style-type: none"> <li>- आपके विचार से ये परेशानिया कितनी आम हैं? क्या आप ऐसे किसी व्यक्ति को जानते हैं जो आपके जैसी परेशानिया महसूस करते हैं.</li> <li>- Do you think your family member needs help for this problem?</li> <li>- क्या आपको लगता है, आपके परिवार के सदस्य को इस परेशानी के लिए सहायता की जरूरत है.</li> </ul>
<p style="text-align: center;"><b>2. Understanding of symptoms - causes</b></p> <p>What do you think caused these problems?</p> <p>आपको क्या लगता है, आपकी इन परेशानियों का कारण क्या है? और आपके विचार से किन कारणों से ये परेशानियाँ हुई है?</p>	<ul style="list-style-type: none"> <li>- Can you tell me how you explain these problems?</li> <li>- क्या आप मुझे बता सकते हैं कि, आप इन परेशानियों के बारे में कैसे समझायेगे. और क्या आप मुझे बता सकते हैं की ये क्या(किस तरह की) परेशानियाँ है?</li> <li>- What did you think, when your family member started feeling like this?</li> <li>- आपको जबसे ये परेशानो हुई, तब आपके परिवार के सदस्य ने कैसा महसूस किया?</li> <li>- Can you tell me what was happening in their life when they got these problems?</li> <li>- क्या आप बता सकते हैं की, जब आपके परिवार के सदस्य को ये परेशानिया हुई तब उनके जीवन में क्या हो रहा था.</li> <li>- How is their health in general?</li> <li>- सामान्य तौर पर आपका स्वास्थ्य कैसा है.(कैसा रहता है)?</li> <li>- Have they ever had these problems before?</li> <li>- क्या आपके परिवार के सदस्य को पहले भी कभी ऐसा महसूस हुआ है?</li> <li>- Is there anything you could do to prevent this problem from happening?</li> <li>- क्या ऐसा कुछ है, जो आप इन परेशानियों को होने से रोकने के लिये कर सकते थे?</li> <li>- Did the research worker explain these problems to you when your family member was interviewed as part of the PRIME survey? If so, how did they explain them?</li> <li>- प्राइम सर्वेक्षण के अंतर्गत आपका इंटरव्यू किया गया था, तब शोधकर्ता ने आपके परिवार के सदस्य की परेशानियों के बारे में कैसे(क्या)समझाया था.</li> </ul>
<p style="text-align: center;"><b>3. Understanding of symptoms – treatability/prognosis</b></p> <p>How long do you expect these sort of problems to last?</p>	<ul style="list-style-type: none"> <li>- What do you think will happen with these problems if you wait and do nothing?</li> <li>- यदि आप इंतज़ार करते है और कुछ भी नहीं करते तो आपकी इन परेशानियों के साथ क्या होगा, आपको क्या लगता है? और</li> </ul>

<p>आप क्या अपेक्षित/आशा करते हैं, की इस तरह की परेशानियाँ कितनी लम्बी ( समय अंतराल/ दिनों) चलती हैं? और आप इस परेशानियों का कितना लम्बा होना अपेक्षित करते हैं.</p>	<p>यदि आप इन परेशानियों के लिए इंतज़ार करते हैं और कुछ भी नहीं करते हैं तो आपको क्या लगता है, इन परेशानियों का क्या होगा?</p> <ul style="list-style-type: none"> <li>- How have these problems changed since your family member was last interviewed about them?</li> <li>- आपकी परेशानियों के बारे में आखिरी इंटरव्यू होने के बाद, आपके परिवार के सदस्य की ये परेशानियाँ कितनी बदल गयी है.</li> </ul> <p>और आखिरी बार जब आपका इन परेशानियों के बारे में इंटरव्यू हुआ था, तब से आपकी परेशानियों में कितना परिवर्तन आया है.</p> <ul style="list-style-type: none"> <li>- How do you think they will change in future?</li> <li>- आपको क्या लगता है, भविष्य में इनमें कितना परिवर्तन आयेगा?</li> </ul>
<p><b>4. Social meaning of symptoms</b></p> <p>How do people in your family or village react to these problems? आपके परिवार के सदस्य और गाँव के लोग इन परेशानियों पर कैसी प्रतिक्रिया देते हैं?</p>	<ul style="list-style-type: none"> <li>- What do people say about these sort of problems?</li> <li>- इस तरह की परेशानियों के बारे में लोग क्या कहते हैं? और लोग आपकी इस परेशानी के बारे में क्या कहते हैं?</li> <li>- How do people treat your family member when they are having these problems?</li> <li>- लोग आपके परिवार के सदस्य के साथ कैसा बर्ताव करते हैं, जब आपको ये परेशानिया है और आपको ये परेशानियाँ हैं, इस कारण से लोग आपको किस तरह की प्रतिक्रिया देते हैं?</li> <li>- How do people treat your family when they know that you have a family member with these problems?</li> <li>- जब लोगो को पता चलता है की आपके परिवार के सदस्य को ये परेशानिया है तो, लोग आपके परिवार के साथ कैसा व्यवहार करते हैं</li> <li>- What sort of advice do they give for these problems?</li> <li>- इन परेशानियों के लिए वो किस तरह की सलाह देते हैं?</li> <li>- How do people react when a family member has other health problems, like fever? In what ways is it different from how people react when someone has the problems we have been talking about today?</li> </ul>

	<ul style="list-style-type: none"> <li>- आपके परिवार के सदस्य की कोई दूसरी स्वास्थ्य परेशानी जैसे की बुखार है तब लोग कैसे प्रतिक्रिया देते हैं? और ये प्रतिक्रिया किस तरह से उन परेशानियों के लिए अलग है जिनके बारे में आज हम बात कर रहे हैं?</li> <li>- और आज हम जिन परेशानियों के बारे में बात कर रहे हैं, उनके लिए मिलने वाली लोगों की प्रतिक्रिया और दुसरे स्वास्थ्य समस्या जैसे की, बुखार में मिलने वाली लोगों की प्रतिक्रिया में क्या अंतर है?</li> </ul>
<p><b>5. Help-seeking/coping strategies</b></p> <p>What do you do to help your family member feel better when they experience these sort of problems?</p> <p>जब आपके परिवार के सदस्य को इस तरह की परेशानियाँ अनुभव होती है तब आप उन्हें अच्छा महसूस कराने की लिए क्या करते हैं</p> <p>और जब उनको इस तरह की परेशानियाँ होती है तो उनकी मदद आप कैसे करते हैं की उनको बेहतर महसूस हो?</p> <p>Reminder: Would it be different if the person having this problem was male/female? What would be different, and why? आपको क्या लगता है की आपका महिला/ पुरुष होना इस परेशानी को प्रभावित करता है?</p>	<ul style="list-style-type: none"> <li>- Can you describe anything you do to help your family member feel better when they have these problems?</li> <li>- क्या आप बता सकते हैं जब आपके परिवार के सदस्य को ये परेशानियाँ होती है तो, आप उन्हें अच्छा महसूस कराने के लिए ऐसी कोई चीज़ जो आप करते हो?</li> <li>- और उनकी परेशानी में, उनको बेहतर महसूस कराने के लिए आप क्या करते हैं, कुछ उदाहरण देकर बता सकते हैं?</li> <li>- How much do these things help them? Why?</li> <li>- ये चीज़े उनको कितना मदद करती है? कैसे?</li> <li>- Does your family member speak to you about these problems? क्या आपके परिवार के सदस्य आपसे उनकी परेशानियों के बारे में बात करते हैं?</li> <li>- How do you feel about asking for help with these problems outside the family?</li> <li>- इन परेशानियों के लिए मदद मांगने में आपको कैसा महसूस होता है?</li> <li>- Who do you go to for help? Why? आप मदद के लिए किसके पास जाते हैं? क्यों?</li> <li>- How easy is it to get help for your family member if you feel they need it?</li> <li>- आपके परिवार के सदस्य के लिए जरूरत पड़ने पर आपको मदद मिलना कितना आसान है? और जब आपको मदद की जरूरत होती है तब कितने आसानी से मिल जाती है?</li> <li>- What stops you from going for help?</li> <li>- मदद मागने में आपको क्या रोकता है? और ऐसा क्या है जो आपको मदद मांगने से रोकता है?</li> <li>- Can you tell me a bit more about this?</li> </ul>

	<ul style="list-style-type: none"> <li>- क्या आप इसके बारे में थोड़ा और मुझे बता सकते हैं? क्या और भी कोई ऐसे कारन है जिसकी वजह से आप इन परेशानियों में मदद नहीं लेते हैं, सबसे जादा जरुरी क्या है</li> </ul>
<p><b>6. Attitudes towards health services generally</b></p> <p>What are health services like in your area? आपके क्षेत्र में स्वास्थ्य सेवाए किस तरह की है?</p>	<ul style="list-style-type: none"> <li>- What do you think about the quality of health services in your area?</li> <li>- आपके क्षेत्र की स्वास्थ्य सेवाओं की गुणवत्ता के बारे में आप क्या सोचते है?</li> <li>- How are the public and private health services different?</li> <li>- सरकारी और प्राइवेट (निजी) स्वास्थ्य सेवाए कैसे भिन्न है?</li> <li>- Which do you think is better and why?</li> <li>- आपके विचार से कौनसी ज्यादा बेहतर है? और क्यों?</li> <li>- What about traditional healers and religious healers, or any other places you can go to for health problems? Can you tell me what you think of these in your area?</li> <li>- आपकी परेशानियों के लिए आप कहाँ और जा सकते है उनके बारे में थोड़ा बताइए जैसे की, परंपरागत, धार्मिक उपचार, या फिर कोइ दूसरे स्थान? क्या आप मुझे बता सकते है की आपके क्षेत्र में इनके बारे में आप क्या सोचते है?</li> <li>- Who makes decisions about healthcare in your family?</li> <li>- परिवार में कौन निर्णय लेता है, की किस डॉक्टर के पास जाना चाहिए?</li> <li>- Where do you usually go if you or someone in your family is sick? Why?</li> <li>- यदि आप या आपके परिवार का कोई सदस्य बीमार होता है, सामान्य तौर पर आप कहाँ जाते है? क्यों?</li> <li>- How do staff treat you if you go there?</li> <li>- वहां का स्टाफ आपके साथ कैसा बर्ताव (कैसी प्रतिक्रिया) करता है?</li> <li>- How easy is it to use health services when you need them?</li> <li>- जरुरत पड़ने पर स्वास्थ्य सेवाओं का उपयोग करना कितना आसान है?</li> <li>- What are the things that make it more difficult? ऐसी क्या चीजे हैं जो इसे और कठिन बनती है?</li> <li>- Have you used health services for your family member since these problems started?</li> </ul>

	<ul style="list-style-type: none"> <li>- जबसे आपके परिवार के सदस्य को परेशानियाँ शुरू हुई है, क्या उन्होंने स्वास्थ्य सेवाओं का उपयोग किया है?</li> </ul>
<p><b>7. Reasons for non-disclosure</b></p> <p><i>If the family has used health services recently:</i> यदि परिवार ने हाल ही में स्वास्थ्य सेवाओं का उपयोग किया हो: Did you talk to the health worker about the problems that we have been talking about?</p> <p>जिन परेशानियों के बारे में हम बात कर रहे हैं उनके बारे में, क्या आपने स्वास्थ्य कार्यकर्ता से बात की है?</p> <p>और अभी जिन परेशानियों के बारे में हम बात कर रहे हैं, क्या इनके बारे में आपने स्वास्थ्य कार्यकर्ता से बात की है?</p> <p>***</p> <p><i>If the person has not used health services recently:</i> यदि व्यक्ति ने हाल में स्वास्थ्य सेवाओं का उपयोग नहीं किया है तो: Would you tell the health worker that your family member has been experiencing these problems? आपके परिवार के सदस्य को ये परेशानिया रही है, क्या आप ये स्वास्थ्य कार्यकर्ता को बतायेगे? (यदि आप जाते तो)</p>	<ul style="list-style-type: none"> <li>- Why/why not?</li> <li>- क्यों/ क्यों नहीं?</li> <li>- Please tell me more about this <i>[Reflect back what they are saying to explore their response and elicit more information.]</i></li> <li>- इसके बारे में कृपया थोड़ा मुझे और बताइए? [पीछे देखिये , ये क्या कह रहे है उनकी प्रतिक्रिया के आधार पर और जानकारी निकालने की कोशिश करना है]</li> </ul>
<p><b>8. Awareness of mental health treatment</b></p> <p>Have you heard anything about treatment for this sort of problem?</p>	<ul style="list-style-type: none"> <li>- Have you ever heard of people being treated in health centres for this sort of problem? What have you heard about these treatments?</li> <li>- क्या आपने इस तरह की परेशानियों का स्वास्थ्य केंद्र में उपचार लेते हुए किसी को सुना है? इन उपचार के बारे में आपने क्या सुना है? और</li> </ul>

<p>क्या आपने इस तरह की परेशानियों के लिए उपचार के बारे में कुछ सुना है?</p>	<p>क्या आपने इस तरह की परेशानियों के लिए किसी को स्वास्थ्य केंद्र में उपचार लेते सुना है? इन उपचार के बारे में आपने क्या सुना है?</p> <ul style="list-style-type: none"> <li>- Have you heard that these treatments are being offered in the CHCs in Sehore?</li> <li>- क्या आपने सुना है की इस तरह के उपचार सीहोर, के सामुदायिक स्वास्थ्य केंद्र में दिए जा रहे है?</li> <li>- What have you heard about services for these problems in the Sehore CHCs?</li> <li>- सीहोर के सामुदायिक स्वास्थ्य केंद्र में इन समस्याओं की सेवाओं के बारे में आपने क्या सुना है?</li> <li>- What sort of treatment do you think would be given if you told the health worker about these problems?</li> <li>- यदि आप स्वास्थ्य कार्यकर्ता को इन समस्याओं के बारे में बताते, तो आपको क्या लगता है किस तरह का उपचार आपको दिया जाता? और आपके विचार से आपको स्वास्थ्य केंद्र में किस तरह का उपचार दिया जाता, यदी आप स्वास्थ्य कार्यकर्ता को आपकी परेशानी बताते?</li> </ul>
<p><b>9. Attitude towards mental health treatment</b></p> <p>Would you be willing to accept treatment for your family member in a health centre for these problem and why/why not? स्वास्थ्य केंद्र में आपके परिवार के सदस्य की परेशानियों के लिए, क्या आप उपचार स्वीकार करना चाहेगे?</p>	<ul style="list-style-type: none"> <li>- Did you plan to go to the health centre after your family member was interviewed? If not, why not? If yes, what happened?</li> <li>- आपके परिवार के सदस्य का इंटरव्यू होने के बाद क्या आपने स्वास्थ्य केंद्र जाने का प्लान किया था? यदि नहीं, क्यों नहीं? यदि हाँ, क्या हुआ?</li> <li>- What sort of person do you think uses these services?</li> <li>- किस तरह के लोग, इन सेवाओं का उपयोग करते है?</li> <li>- Is there anything you would be worried about if your family member accepted treatment for these problems in a health centre?</li> <li>- यदि आप स्वास्थ्य केंद्र में, आपके अप्रिवार के सदस्य की परेशानियों के लिए स्वास्थ्य सेवाओं को स्वीकारते हैं तो, ऐसा कुछ है जो आपको भयभीत करता है? और उनकी परेशानियों के लिए यदि आप स्वास्थ्य केंद्र की सेवाएं लेते है, तो ऐसे क्या कारन हो सकते है जिनसे आपको डर लगेगा?</li> </ul>



	<ul style="list-style-type: none"> <li>- Can you tell me about any difficulties you would face in going to the health centre for this problem?</li> <li>- इस परेशानी के लिए स्वास्थ्य केंद्र जाने में, जो कठिनाइयाँ आ सकती हैं उनके बारे में क्या आप मुझे बता सकते हैं? और क्या आप उन कठिनाइयाँ के बारे में मुझे बता सकते हैं जो इस परेशानी के लिए स्वास्थ्य केंद्र जाने में आपको होंगी?</li> <li>- How would the rest of the family respond if you took your family member to use this sort of treatment? Why?</li> <li>- आपका परिवार कैसे प्रतिक्रिया देगा, यदि आप इस तरह का उपचार आपके परिवार के सदस्य के लिए लेंगे? क्यों? और इस तरह का उपचार लेने पर आपका परिवार कैसे प्रतिक्रिया देगा? क्यों?</li> <li>- Do you believe these treatments could help your family member? Why/why not?</li> <li>- क्या आपको विश्वास है कि, ये उपचार उनकी मदद कर सकता है? क्यों? क्यों नहीं?</li> </ul>
<p><b>10. Priorities for recovery</b></p> <p>When you think about your family member overcoming these problems and getting better, what is the most important thing for you? जब आप इन परेशानियों से छुटकारा पाने और बेहतर होने के बारे में आपके परिवार के सदस्य के बारे में सोचते हैं, तब आपके लिए सबसे ज्यादा महत्वपूर्ण क्या है? और आपके विचार से, उनकी परेशानियों से छुटकारा दिलाने और आपको बेहतर बनाने के लिए क्या महत्वपूर्ण है?</p>	<ul style="list-style-type: none"> <li>- Which of these matters the most for you:</li> <li>- इनमें से आपके लिए सबसे ज्यादा क्या महत्वपूर्ण है: - that they no longer feel this way? इस तरह से उन्हें अब नहीं लगे - that they can do everyday tasks? वे रोजमर्रा के कामकाज कर सकें? - that they can earn money? जिससे वे पैसा कमा सकें? - that they (and the family) are respected by people around you? आपके आसपास के लोग उनका आदर करें? - some other thing? या फिर कुछ और?</li> <li>- Can you tell me what difference this would make to your life?</li> <li>- क्या आप मुझे बता सकते हैं कि, इससे आपके जीवन में क्या बदलाव आयेगा?</li> <li>- Do you believe that it is possible for your family member to overcome these problems?</li> <li>- क्या आपको विश्वास है इन परेशानियों से उभर पाना आपके परिवार के सदस्य के लिए संभव है?</li> </ul>
<p><b>11. Ideal support/interventions</b></p>	<ul style="list-style-type: none"> <li>- What do you think could help your family member to feel better?</li> </ul>

<p>What sort of support would you like for these problems? इन परेशानियों के लिए आप किस तरह का सहयोग चाहते हैं?</p>	<ul style="list-style-type: none"> <li>- आपको क्या लगता है, की क्या उनको बेहतर महसूस करा सकता है?</li> <li>- Is there anything that could have prevented your family member from feeling this way?</li> <li>- क्या ऐसा कुछ है, जो आपके परिवार के सदस्य को इस तरह से महसूस करने से रोक सकता है?</li> <li>- What would a perfect service for these problems be like, in your opinion?</li> <li>- आपके विचार से, इन परेशानियों के लिए सबसे उत्तम (सबसे बढ़िया) सेवाएं क्या हो सकती हैं (कैसी होनी चाहिए)?</li> </ul>
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Coding framework

Theme	Sub-theme	Definition	Example
Structural factors	Availability and accessibility of services	Whether health services are available nearby Distance to health services Transport/travel arrangements to health services	“There is a doctor nearby in village” “There is no doctor in the village, I have to go to Sehore for treatment” “It is only 17 kilometers from here. we can go by personal vehicle”
	Affordability of services	Cost of health services Ability to pay for health services and impact on household finances	“Doctors’ fees are 200 rupees plus tests and investigations” “You can spend these 100 rupees money in household expenditure or you can get treatment done from the same money”
	Waiting times and overcrowding	Waiting time to be seen at health services Queues	“I stayed outside where they give you slip with your number on it... my number didn’t come”
	Lack of time/opening times	Ability to find time to visit health services Ability to get to health services during opening hours Logistical barriers such as childcare	“Till Holi I am busy... I can’t make it to go” “I got busy in so many jobs like some marriage came in my house so all of us got busy in that”
	Social support	Whether help from other people (family members/neighbours) is needed to visit health services Whether other people (family members/neighbours) are willing to help Whether affected individual is willing/able to share problems with family/neighbours	“There is nobody to take me to the doctor” “I need to call some relative or someone from village to accompany me” “For themselves they go for treatment. But for me nobody listens” “I can’t go out from home until he gives me the permission to go out”

		Includes gendered issue of power dynamics within family	
	Health system difficult to navigate	Admin/paperwork required such as registration, form filling, finding correct department	“There are so many procedures you have to go through, prescriptions and appointment slip...”
	Information/education	Whether individuals/families have knowledge/information on where/how to access health services Whether individuals/families have vocabulary to communicate concerns to health workers Whether doctors explain diagnosis and individuals/families able to understand this information	“We don’t have knowledge of hospital that what happens where how to access them, what services are available where” “Have you heard about it that there is a treatment available for mental problems such as stress and others? No, I have not heard.”
Attitudinal factors	Perceived quality of services	Perceptions of the quality and effectiveness of treatment at health services	“Before I shown it to there but it didn’t get well. the treatment didn’t give any relief” “Good treatment is not available there”
	Fear of hospitals/medical treatment	Worries about consequences of seeking treatment, such as being admitted for a long time or being given new diagnoses Dislike of taking medications	“Out of fear of getting identified with some disease I didn’t go” “Who knows [if] people from government will make him admitted in the hospital, then who will look after the kids?”
	Fatalism	Belief that whatever God wills will happen regardless of own actions	“If [God] sends me an invitation of death then no one can delay it or stop it. All efforts will be failed against God's wish”
	Too many problems to know where to start	Overwhelmed by number of health problems	“So many things are out there, for how many should I get treatment for, how many I should not.”

			<p>"If there is only with one problem she goes to doctor, then also doctor can understand problems... If one same person presents with 10 types of different problems how would he offer a definite treatment for all."</p> <p>"We are in so much trouble... for how many illnesses we can go for treatment."</p>
	Symptoms inhibit help-seeking	Depression symptoms prevent clear thought or proactive steps to seek help	"In that situation and anxiety it didn't come in my mind to seek treatment for it"
	Stigma	Worries about what people will think if they seek treatment for symptoms	<p>"They will think I am lying as I am looking all fine and doing labour"</p> <p>"If I share this to my relatives or anyone in the village they laugh at us"</p>
	Preference for traditional services	<p>Choice to seek help from faith healer or other complementary/alternative providers rather than allopathic services</p> <p>Belief that only complementary/alternative providers can solve problem</p> <p><i>(Do not include if CAM used in addition to allopathic services)</i></p>	"I was taken to the Kumar Kotri village, there is a place where God and Goddess live. Then I got cured from there."
Perceived need for health care	Symptoms attributed to social and economic causes	<p>Belief that problem will not be solved while social/ economic causes of problem continue</p> <p>Belief that symptoms are a normal/ common response to environment</p>	<p>"How can I show it for daily daily problems?"</p> <p>"For me the most difficult thing is my husband... He doesn't do any business or job, so obviously I will have tension... if he starts doing a job then I will not have any tension"</p>

			<p>"If we will have money we would not get this much tension."</p>
	<p>Symptoms attributed to physical ill health</p>	<p>Depression seen as secondary to another condition  No distinction drawn between depression symptoms and other symptoms  Seeking health care but reporting other complaints only, or primarily</p>	<p>"You mean even if you take treatment for tension it will not work as you have pain in hands and legs?" "Yes, it will make no difference"  "The first thing is needed the most [is] that my illness will recover, so automatically I will be able to work hence will be able to earn money. The main tension is that there must not be disease inside my body"</p>
	<p>Health workers unable to treat "tension", only physical illness</p>	<p>Belief that psychological problems can only be solved by the individual themselves and treatment not possible  Distinction between tension (not treatable) and mental illness</p>	<p>"Tension is in our hands/it depends on our own thinking, what do I need to consult it for?"  "Tension is actually a person's thinking. If person doesn't think then there is no tension... If you want from within then it will be cured."  "Worry depends on my own mind otherwise I will not have it if I will not take it."  "I don't have any mental problem... it is not like crazy people. My mind is fine and well. I have only tension problem."</p>
	<p>Problem not severe enough to need treatment</p>	<p>Symptoms not seen as serious enough to warrant treatment  Recovered without treatment / expects problem to resolve without treatment</p>	<p>"These all problems are regular problems"  "She told me that a doctor is available but it slipped from my mind to visit him. It's like when you suffer with something major you rush to hospital."</p>

			“Her condition was not very serious [at] that time, if it was one immediately rushes to hospital. But she was not in [a] bad condition.”
	Family/neighbours’ perceptions of health care needs	Opinions of family/neighbours about condition and need for health care	“Everyone told me that I don’t have as such difficulty” “Everyone says that you have made your gum removed that is why you have got weakness. Everyone and everybody says I have weakness”
Comparison of views of affected individuals and relatives/caregivers	Similarity in views	Parallels between caregiver and individual’s account of problems	
	Difference in views	Discrepancies between caregiver and individual’s account of problems	“[My period] was 15 days delayed then this tension problem started” vs. “There was nothing like tension and all” “When there is tension then I feel sleeplessness” vs. “she has no problem” “My mood was not good... I get anxiety” vs. “she had fever temperature... apart from this she had no problems”

## Structural and attitudinal barriers to health care utilisation

### **Structural barriers**

#### *Lack of information*

Participants had little awareness about the existence of treatment for depression. Although participants had been referred to public health services as part of the PRIME community survey, few had understood the referral to be specifically for depression symptoms, and instead often interpreted this as treatment for their somatic symptoms, since these were considered to be medical issues while psychological symptoms were not.

#### *Lack of time and opening hours*

Several participants cited lack of time to go to health services due to work and family commitments as a barrier to seeking care. A related issue was limited opening times, especially in public services where doctors were said to be present only for 2-3 hours in the morning, which clashed with working hours on the farms.

#### *Social support*

Participants described the wellbeing of household members as strongly intertwined and family was seen as an important source of financial and emotional support. When the head of household was neglectful or abusive, however, this presented a barrier to the use of health services, particularly for women and the elderly. It was not common to report confiding in friends or neighbours, due to fear of gossip, or believing that they cannot help, and so most interviewees shared their problems beyond the household only to request practical assistance, such as loans or transportation.

#### *Difficulties in navigating health system*

Among illiterate participants, a commonly reported barrier was difficulty in finding and accessing services, particularly in completing paperwork and finding the correct department. They described difficulty retaining instructions and needing someone to guide them through clinic procedures.



### *Perceived service quality*

Perceptions of service quality were frequently mentioned but did not appear to deter treatment-seeking overall. Instead, these issues served to affect provider choice. Many participants equated health services with private providers, due to concerns about public service quality. A common complaint was that government staff fail to conduct the necessary examinations to properly diagnose their problem.

### *Accessibility and affordability of services*

Structural barriers such as cost, transport, and losing wages to attend health services all made the process of getting care more difficult, and led to financial hardship. However, they did not generally prevent participants from seeking treatment when a health care was seen as essential (which it rarely was in the case of depression symptoms, as described above). Participants overcame these barriers with community support, for example by taking loans and borrowing vehicles from neighbours. With minor illnesses, or when unable to travel further afield, they often consulted untrained local providers (or “small doctors”) who are available closer to home, have shorter waiting times, and work more flexible hours.

## **Attitudinal barriers**

### *Multiple problems*

Some participants described feeling overwhelmed by the number of problems they experienced, leading them to ignore some symptoms and prioritise others. Some participants stated that doctors are unable to treat multiple problems simultaneously, and that they have to prioritise a single complaint per consultation. Participants pointed out that other household members also experience health problems, and families need to prioritise their use of resources rather than seek help for every issue.

### *Aversion to medical treatment*

Aversion to medical treatment acted as a barrier to using health services for a minority of participants. Pharmacological interventions were assumed to be the only form of treatment, and some were wary about side-effects, uncomfortable about taking more

medicines having already been prescribed many, or concerned that long-term or unnecessary use of medications could be harmful. Others worried about being admitted to hospital, and neglecting their family duties, or receiving additional diagnoses which they could not afford to treat.

### *Fatalism*

Several participants expressed fatalistic attitudes to their situation, referring to destiny and God's will, and in some cases implying that help-seeking is futile. Others expressed resignation to their fate in terms of transferring their hopes onto their children rather than investing resources in their own health.

### *Stigma*

Issues related to stigma were not frequently mentioned, and no participant mentioned shame or embarrassment as a reason for not seeking care. This appeared to be because depression symptoms were not considered to indicate mental illness, with mental illness exclusively associated with psychotic disorders and intellectual disabilities. Some participants reacted with offence to questions about whether their problems could be a mental health problem, suggesting that stigma would represent a barrier to the use of mental health services or psychiatric care, whereas we referred to seeking help from any source for depression symptoms. However, some participants did report refraining from discussing their feelings with neighbours due to concerns that they would not be believed to be truly ill.

### *Preference for complementary/alternative treatment*

A minority of participants mentioned consulting faith healers or traditional providers. One participant said that faith healers instruct their patients not to consult anywhere else. However, most of those who reported using alternative treatment had also used formal allopathic services, suggesting that the use of traditional healing approaches does not inhibit treatment-seeking from other providers.