Freedom To Be (F2B) summer camp: outcome evaluation

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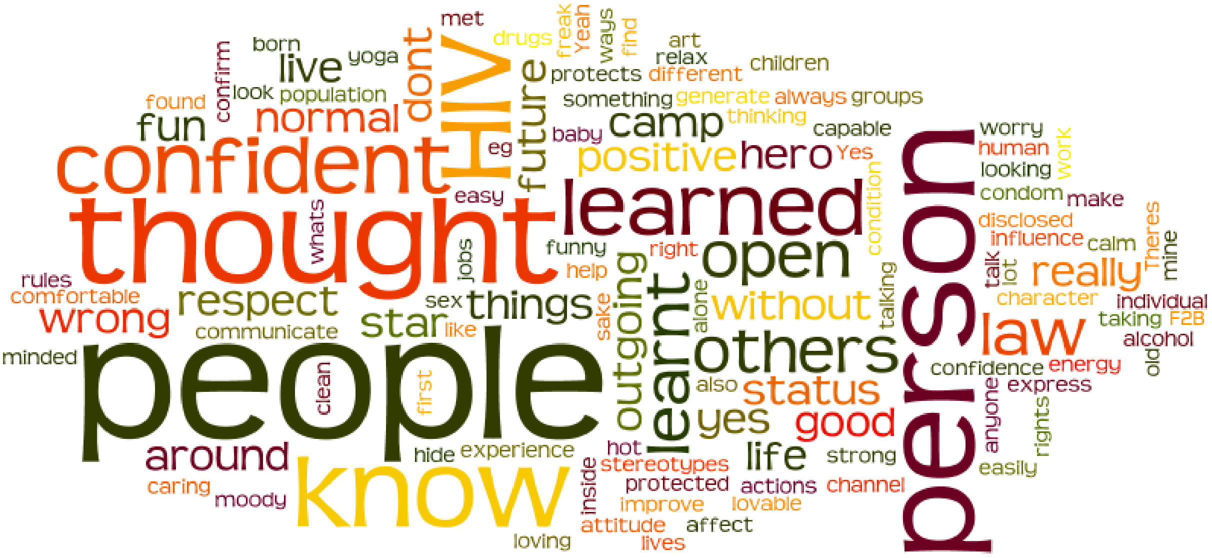

Elton John AIDS Foundation

CHILDREN'S CHIVA HIV ASSOCIATION

Sigma RESEARCH

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The word cloud on the front cover of this report represents the most common words appearing in responses when young people were asked, *Have you learned anything new about yourself at F2B*?

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Executive summary

Sigma Research was commissioned by the Children's HIV Association (CHIVA) to undertake an outcome evaluation of a pilot residential summer camp intervention for young people with HIV, called Freedom To Be (F2B). The evaluation consisted of three different data collection phases, with young camp attendees invited to voluntarily complete each of three linked questionnaires: one before camp, one the final day before leaving camp, and one three months after camp. From a total of 79 camp attendees, participation rates were reasonably high, with 55 young people taking part in phase 1, 58 in phase 2, and 39 in the final follow-up phase.

The aims of camp were to ensure that young people:

- had a positive experience at camp,
- improved their knowledge about living well with HIV,
- experienced less social isolation,
- maintained ongoing contact with other young people with HIV after camp, and
- benefitted from their interaction with adult camp leaders and volunteers with HIV.

Prior to camp

The phase 1 questionnaire was designed to assess what kind of informal support young people with HIV attending camp felt they had, and what outcomes they desired most from attending F2B.

Three-quarters of those taking part lived with at least one other person who had HIV.While many said that everyone at home knew about their status, it was also just as common for young people to say that not everyone at home knew. When it came to their friendship networks, it was very common for participants to say that none of their friends knew they had HIV. The majority of young people said they knew other young people with HIV, most of whom they had met at clinics or HIV groups, although fewer than half reported that they talked to these friends about their HIV. Young people were more likely to report discussing HIV with their doctor (71%) than with parents or carers (65%), siblings (10%) or friends who did not have HIV (2%).

At this stage of the evaluation, participants described the impact of HIV in their lives in overwhelmingly negative terms, focussing on the secrecy and stigma that HIV imposes on them, the difficulties presented by having to take medication in secret, and the concerns and fears that they felt HIV represented for their future, and that of others around them.

> *It keeps you from having a full relationship with someone because you have to keep a massive part of you away from them. (16 year old)*

At camp

Almost every young participant completing the second phase survey (98%) said they had learned more about key HIV topics while they were at F2B. More than half of all participants learned more about sex (55%), their rights (52%) and talking to others (52%) during their time at F2B. It was also very common for young people to say they learned about HIV and the law (47%), family life (45%) their own futures (45%) and HIV medications (43%) while at camp. Where it was possible to compare individuals' responses to a similar question from phase 1, the majority (71%) had met some if not most of the information needs they had identified before camp. When asked what they had learned about themselves while at camp, most participants talked about their new-found confidence, and the ease with which they had learned to talk about HIV.

> *I'm more capable of doing something than I thought I was. (16 year old)*

When asked about socialising with other young people with HIV while at F2B, the vast majority (93%) felt that this had been an important component of the experience, and almost the same proportion (90%) planned to keep in touch with people they had met. A number of participants mentioned how much they valued the involvement of adults with HIV in facilitating the camp, and when asked directly if that was important to them, almost four-fifths (79%) agreed that it was.

The elements of camp that were of greatest value to those who took part were (in order): making new friends with HIV, taking part in new activities, learning more about HIV and being in a fun and open atmosphere. What young people liked least about camp were the sleeping and waking routines, discomfort with various elements of the venue (including both beds and food), and some ways in which the activities themselves were organised, with a considerable proportion saying that they would have liked to have had more free time.

F2B was regarded by almost all participants as an exceptionally positive, esteem-boosting, beneficial experience, and this perception was maintained if not increased when young people were contacted three months later.

Three month follow-up

When asked about who knew about their HIV, more than one third of phase 3 participants reported an increase in the proportion of their friends who knew they had HIV.

A central goal of F2B was to reduce individuals' experience of social isolation by increasing ongoing contact with other young people with HIV who had attended camp. Almost all of those taking part in the follow up survey (97%) remained in contact with numerous friends made at camp. Social networking sites, mobile phones and instant messaging were the primary means of maintaining this contact.

When a similar question was asked before and after camp about the range of people they talk to about HIV, two-thirds reported an increase of openness in the following categories: friends with HIV, parents and other family members, and friends without HIV, as well as partners.

When asked before and after camp if there was still one person that they really wished they could talk to about HIV, there was little change in the extent or type of responses given, so it would appear that camp may have had little demonstrable impact on those most challenging discussions.

Arguably the most compelling information of all comes from some of the open-ended responses about participants' overarching impressions of camp, and what participants recalled learning there.

> *How to tell people – that helped me tell my boyfriend. (15 year old)*

The overwhelming majority of the responses, even three months on from the event, were full of praise and gratitude for a life-changing, or at the very least, beneficial intervention.

> *Because when i came back home i felt good that i did because at the camp it was like everyone was just the same as me and basically i had to accept that i have HIV. it actually lifted me up instead of me stay[ing] scared of what was going to happen through my future. (14 year old)*

Young people were happy to have gained new friends, to have spent time in a welcoming, open and understanding atmosphere that encouraged confidence-building, and to have many of their questions about living with HIV answered.

1 F2B: a summer camp for young people with HIV

1.1 Organisers

The Children's HIV Association (CHIVA) is a registered charity that started as a network for those working in health and social care that are supporting children and families living with HIV in the UK. More recently, it has progressed into running a number of national projects to meet the needs of children, young people and families living with or affected by HIV (more details are available at www.chiva.org.uk).

1.2 HIV among young people in the UK

Clinical monitoring of all new HIV diagnoses among children undertaken by the Collaborative HIV Paediatric Study (CHIPS) www.chipscohort.ac.ukindicates that there are currently more than 1200 children and young people accessing paediatric HIV care in the UK & Northern Ireland and the Republic of Ireland. Of these, nearly four-fifths are of black African ethnicity, and more than half live in London. HIV remains a highly stigmatised illness, and teenagers are very aware of the discrimination they may face if their HIV status is disclosed at school, at college or to their peers. For this reason, it is common for only a few members of a young person's family to know about their HIV diagnosis, and no one else. Sometimes, other people living in the same home will be unaware of a young person's diagnosis. Such secrecy can contribute to high levels of anxiety and feelings of social isolation.

1.3 Rationale and organisation of camp

CHIVA had organised smaller weekend residential breaks for young people with HIV in the past, and wanted more young people to benefit from a larger residential programme lasting longer than just one weekend. For this reason, they piloted a residential summer camp in 2010 for young people with HIV. Key aims of the summer camp included: reducing social isolation, increasing confidence, and improving knowledge about HIV-related topics.

Those attending the camp gained an opportunity to develop sustained peer relationships with other young people who have diagnosed HIV. The organisers hoped that such contact would contribute to improved well-being and self-esteem. Improved esteem was a central goal, as they felt that it could lead on to improved self-care, including increased medication adherence, better educational attainment and improved aspirations.

The pilot summer camp, called *Freedom to Be (F2B)*took place on 15th-19th August 2010 at a school campus in the South East of England. More than 100 young peoplebetween the ages of 13 and 17 who knew about their HIV diagnosis were offered places at camp, and ultimately 79 young people attended. In addition to those who self-referred, camp referrals were made by young people's HIV health and social care providers, and close links with care providers were maintained before and after camp. All places were free with all running costs, transport and associated costs provided by the Elton John AIDS Foundation and Pfizer Pharmaceuticals.

F2B provided a balance between structured workshops covering issues related to living with HIV, as well as sporting, creative and leadership activities designed to develop confidence and overcome fears (listed on the following page). The time away was carefully structured to ensure that all involved were safe and had a positive, sociable and supportive experience.

CHIVAestablished a Steering Group to advise on the planning and the content of the camp.The F2B Steering Group consisted of invited professionals including: paediatric HIV clinicians, mental and sexual health professionals, representatives of HIV voluntary organisations, CHIVA and Sigma Research. In addition to the Steering Group, the CHIVA Youth Committee whichconsists of eight young people with diagnosed HIV, also advised

CHIVA on planning the content and structure of F2B. Camp activities and workshops were led by invited experts, while pastoral care, practical facilitation and day and night supervision were all provided by a team of volunteers. Five paid CHIVA staff were responsible for planning decisions as well as the supervision of volunteers and camp attendees.

CHIVA maintained core responsibility for planning and governance over camp activities, including:

- Final decision-making on camp location, duration, content and structure.
- Advertising for adult volunteers, camp leaders and attendees at camp.
- Final decision-making on camp attendees, based on a brief application form submitted electronically.
- Screening, recruitment and training of over 30 of adult volunteers, many of whom live openly with diagnosed HIV.
- Screening, recruitment and training of approximately 10 camp leaders, aged 18-25 who themselves had diagnosed HIV (those trained received OCN Level 2 accreditation in youth work).
- Responsibility for safety and regulatory matters including CRB checks.
- Management and oversight of camp, and coordination of those delivering workshops and activity sessions.

Camp workshops / activities

Legal and rights based issues
Having children
Dealing with parents
Understanding HIV medication
Drink, drugs and HIV
HIV basics
Sexual health / avoiding transmission
Feelings
Disclosure
Confidence-building
Camp newsletter committee
Youth committee
Relaxation
Yoga
Massage
Creative writing
Football
Tennis
Swimming
Natural sculpture
Dance
Drama
Rap
Singing
Film-making
Fashion design

The evaluation methodology, implementation and reporting has been undertaken by Sigma Research, and was commissioned and project managed by CHIVA. The Steering Group and the Youth Committee had input into the planning of the evaluation process, and were given the opportunity to comment on an earlier draft of this report.

1.4 Report structure

This evaluation report seeks to give insight into the value of participation in the camp, as well as offering constructive feedback from participants on the ways in which camp might be improved if it happens again in the future.

Chapter 2 describes how the evaluation was undertaken, the range of methods used, and the decisions made to protect the confidentiality and security of respondents' information at all stages of the evaluation process. Chapter 3 offers a description of all those who answered questions about their demographic details when taking part in the first phase of the evaluation, so it gives a general profile of the young people taking part. Chapters 4, 5 and 6 each describe the results from the questions asked in each of the three phases of research (before camp, at camp and three months after camp). Chapter 6 also describes change analysis undertaken on the data across the different phases, and makes a set of recommendations for future interventions of this type.

2 Evaluating the experience

The evaluation instruments were designed to provide insight into the extent to which the following aims were met for F2B participants:

- Positive experience at camp
- Improved knowledge about living well with HIV
- Reduced social isolation
- Ongoing contact with other young people with HIV
- Beneficial interaction with adult camp leaders and volunteers who have HIV

Guidance on the content and wording of information sheets, questionnaires and interview topic guides was sought from the Steering Group, and from the Youth Committee. Members of the Youth Committee assisted in the piloting of all written materials associated with this evaluation.

After being accepted to attend F2B, camp participants were invited to complete a brief survey including a quantitative assessment of social and health related needs and some qualitative items regarding their hopes and fears about attending F2B (Phase 1). Camp attendees were then invited to complete a follow-up questionnaire on the final day of camp (Phase 2) and a final questionnaire three months later (Phase 3).

2.1 Pre-camp survey (phase 1)

Phase 1 consisted of an online survey (including mainly quantitative, but some qualitative items) which each young person accepted into camp was encouraged to complete.

Where participants expressed a preference, they were sent a paper copy of the exact same survey in the post, to be returned directly to Sigma Research via Freepost. The data collected in this phase provides a baseline of need for each individual, and for the group as a whole.

This data set wasanonymised and collated to be shared as interim data with the camp organisers. Taking attendees' concerns and desires into account at the formative stage helped organisers confirm their plans to meet the needs of those attending.

2.2 At-camp survey (phase 2)

The Phase 2 survey was completed on paper on the final day of F2B. Camp Leaders and Key Worker volunteers helped to ensure that the young people in their cohort were allowed adequate time and private space to ensure confidential completion. The Phase 2 survey elicited reflections on attendees' experience of the camp (what they did, how they found it, what they learned, and the extent to which their hopes and expectations were met).

2.3 Post-camp survey (phase 3)

The final survey was designed to assess the extent to which the learning and peer support established in the camp was carried forward into everyday life.

F2B participants were contacted by CHIVA in late November 2010 to respond (online or on paper, depending on their previous preference) to a range of questions about the impact that F2B had on their physical, social and emotional well-being, and what they thought of camp in general. Some questions asked in phase 1 were repeated in phase 3 in order to assess change. Data from each individual was linked through the use of an individual identification code, described in greater detail in section 2.5.

Those taking part in this final phase were asked how many F2B participants they were still in contact with three months after camp, and how contact has been maintained. Finally, they wereasked if they would recommend F2B to other young people with HIV.

Due to a limited number of phase 3 responses, the lead researcher (working out of the CHIVA Projects offices for this purpose) undertook a number of brief interviews by telephone with young people who had not completed the final survey within a fortnight. These consisted of simply asking all the items in the questionnaire verbatim, with the researcher writing down each response.

2.4 Ethics and confidentiality

This evaluation project was approved by the Faculty Research Ethics Committee of the Faculty of Humanities and Social Sciences at the University of Portsmouth.

Consent to participate in research

Prior to invitation to participate in the pre-camp survey, an information sheet describing the evaluation for parents/carers and for participants was included in the F2B acceptance pack. Those aged 16 and over were able to consent fully for themselves, whereas those under 16 were asked for their consent, as well as their parent/carers'. Where relevant written consent was not given, Sigma Research ensured that data was not collected from those young people.

The consent form asked young people (and parents / carers where necessary) to provide their name, the date and a signature to confirm their consent to take part. Participants were informed that they could opt out of participating in any phase of the evaluation process.

Ethical issues

We endeavoured to ensure that participation in the evaluation activities did not harm or distress the young participants in any way, and that the activities were appropriate for all of those taking part. All questionnaires and project documentation were vetted and commented upon by members of the Steering Group and Youth Committee in order to ensure that the language used was appropriate, and that informed consent was assured. This process also helped to ensure that questions were directly connected to the aims of the evaluation.

Participation in the evaluation was entirely voluntary, and this was made clear to young people and their parents/carers. Participants were reminded of Sigma Research's contact details throughout the process, and they were invited to contact Sigma with questions about the process, to ask to see the data they have already submitted to us, and to have it withdrawn if they so choose. No participant or their carer chose to do so.

The lead researcher was CRB-checked prior to undertaking this evaluation, and no other members of the Sigma Research team had direct access to either the participants, or their contact details.

2.5 Data management and analysis

Unique identification codes

On the consent form, participants created their own anonymised unique identifier by answering the following questions:

1. What is the **day** of your date of birth?
2. What are the **last two** letters of your first name?
3. **How many letters** are there in your **name** when you add them up without the spaces?

These three pieces of information were combined to create a 6 character code unique to each individual participant. These same three questions were asked during every phase of the research, enabling us to link respondents' answers and experiences over time.

For the duration of the project, CHIVA maintained a list of the unique identifier codes comprised of these three sets of information, alongside participant names and contact details. CHIVA securely stored all signed participant consent forms. At no point in this evaluation did Sigma Research hold the names or personal contact details of any F2B participant. Where it was necessary to cross-check identification codes with names and contact details (for instance, to chase up responses or to identify individual participants who entered varying ID code information), this was manually undertaken by a Sigma researcher at the CHIVA offices.

All written communication (emails and letters) related to this evaluation was addressed directly to those who had consented to participate, and was undertaken by CHIVA project staff. Toward the end of phase 3, the contact database was used to telephone those who had not completed the final survey within a fortnight. This was undertaken by the lead Sigma researcher in the CHIVA office with a CHIVA staff member present.

At all times, young people's answers to survey questions were kept separate from their names and contact details, and no staff member at CHIVA had any direct access to the evaluation data.

Data handling

The online survey was designed and hosted using www.demographix.com, an online internet survey instrument. The design of the online survey allowed data to be captured and viewed as soon as a participant pressed 'submit' at the end. Monitoring of survey uptake (both online and paper versions) was continued throughout the data collection phases before and after camp, and at both phases 1 and 3, those who had not responded were prompted again to participate.

Quantitative data was then managed and analysed using SPSS 16.0. Given the small sample size, a complex comparative statistical analysiswas not feasible. As a result, the quantitative analyses reported in the following chapters relate only to the frequencies of various responses.Where unique ID codes connected one individual's responses across the various phases of data collection, it was also possible to identify changes in their experiences and outlook.

Participants were also given the opportunity to complete some answers in their own words. Identification of key themes in those responses utilising a framework approach to thematic analysis was undertaken by the lead Sigma researcher, with some assistance from a CHIVA volunteer with a background in social science research. Coding and cross-checking of these themes was undertaken across the qualitative items in all three data sets.

3 Sample description

In the pre-camp survey (phase 1), young people were asked a few basic questions about themselves. Given that not all camp attendees participated in the evaluation, this is not an exact reflection of the characteristics of those who took part in the camp itself. A total of 55 completed pre-camp surveys are included in this sample, meaning that more than two-thirds of all 79 camp attendees took part. Where participantswould have been expected to give at least one answer to a closed question and did not, this data is described as 'missing'. Where percentage values do not total to exactly 100%, this is because of the effects of rounding the figures for presentation in this report.

In phase 1, the vast majority of respondents completed the survey on paper (n=44), with only a small proportion completing the online version of the survey (n=11).

3.1 Gender

When asked about their gender, 20 participants said they were male, and 35 said they were female. This means that there were twice as many young women (64%) as young men (36%) taking part in this evaluation. This trend also reflects the fact that there were considerably more girls/young women attending camp than boys/young men. This in itself is likely to be a reflection on increased intervention uptake among girls and young women than their male counterparts, given that there are relatively equal proportions of male and female children reported in paediatric care through the CHIPS monitoring cohort.

3.2 Age

The following table shows participants' age at the time they completed the pre-camp questionnaire.

Age (n=54, 1 missing)	**Number**	**Percent**
13 years old	10	18%
14 years old	10	18%
15 years old	11	20%
16 years old	17	31%
17 years old	6	11%

F2B only accepted people between the ages of 13 and 17. There was a good balance between older and younger camp participants taking part in the evaluation.

3.3 Ethnicity

Participants were asked, *What is your ethnic background?,* and were offered one of the five options below.

Ethnicity (n=55)	**Number**	**Percent**
Asian	2	4%
Black	44	80%
Mixed	6	11%
White	3	6%
Other	0	0%

Almost all of those who described themselves as mixed went on to describe having both black and white ethnicities. Given that the vast majority of those attending camp were members of black and minority ethnic populations (mainly Black African), the ethnicity of this sample is broadly reflective of those attending camp, and of the population of children with HIV as a whole.

3.4 Residence

Participants were asked the open-ended question, *Where do you live? (give the name of your city or town)*. Their responses were then categorised as belonging to one of 10 regions in England. Although there were a small number of young people attending camp from other countries (Ireland, Northern Ireland, Scotland and Wales), none participated in this phase of the evaluation.

Strategic health authority area of England (n=55)	**Number**	**Percent**
North East (England)	1	2%
North West (England)	13	24%
Yorkshire and the Humber (England)	2	4%
East Midlands (England)	3	6%
West Midlands (England)	2	4%
East of England	2	4%
London (England)	23	42%
South East Coast (England)	3	6%
South Central (England)	2	4%
South West (England)	4	7%

The high representation of participants from London and from the North West reflects the geographic spread of camp attendees more broadly. Recruitment to the camp was undertaken in direct collaboration with clinical and service providers and promoted across professional networks such as CHIVA, National AIDS Trust, National Children's Bureau and HYPNet.

3.5 Household

Participants were asked, *Tell us about your home, do you live...?*, and then were offered one of the three options below.

Household composition (n=55)	**Number**	**Percent**
With family	50	91%
With foster carers	3	6%
On your own or with flatmates	2	4%

Almost all participants lived with family, however it should not be presumed that this always meant parents.

4 Pre-camp survey responses (Phase 1)

This chapter describes responses from online and paper versions of the initial survey that participants completed prior to camp. There were 55 participants in this phase of the evaluation, whose demographic characteristics were described in the previous chapter.

4.1 Diagnosis and disclosure

Participants were asked how old they were when they found out that they had HIV. It was most common for young people to say they were either 11 or 12 years old when they found out about their diagnosis. The range of answers was quite broad, with some participants reporting that they were as young as 2, or as old as 16 when they became aware that they had HIV.

Making a rough comparison between current age, and the age at which participants found out about their HIV status, it was possible to estimate how recently they had learned of their infection.

Estimated time since participants had learned of their HIV status (n=50, missing 5)	**Number**	**Percent**
Between 1 and 2 years	17	31%
Between 3 and 4 years	17	31%
More than 4 years	11	20%
Unsure	5	9%

The results indicate that there was a relatively even divide among those who had found out about their HIV more recently, and those who had known for some time. Only one-fifth of participants had known about their HIV status for more than four years.

When asked, *Who knows that you have HIV*?, participants were given the choice to identify whether *All, Some, or None* of the people in the following categories were aware of their diagnosis.

Who knows that you have HIV?	**All (n)**	**Some (n)**	**None (n)**
People you live with	25	25	2
Your friends	1	13	24
School / college staff	2	34	36
Family you don't live with	5	21	13

It was most common for participants to say that people they lived with knew about their HIV status (although just as many said that not everyone at home knew). It was far more common for young people to report that school or college staff knew about their HIV status, than having any friends who knew. It was uncommon for young people to say that all members of the extended family knew about their HIV status.

4.2 Knowing others with HIV

When participants were asked *Do you live with someone else who has HIV*?, three-quarters (n=41) responded that other people in the household shared their HIV status. When asked to describe who it was at home who also had HIV, participants most commonly mentioned their mothers (76%), followed by fathers (32%), while there were also those who identified siblings or nieces / nephews (22%). About one-third of all those with other household members with HIV said there was more than one other person at home with HIV.

When young people were asked, *Do you know any other people your age who have HIV*? most (84%) said they did, whereas 11% did not know anyone else their age with HIV, and 6% said they were not sure.

Those who answered that they did know other young people with HIV were asked how many they knew. Their responses to this are combined with those from the question above in the following table.

How many other young people with HIV they know (n=53, missing 2)	**Number**	**Percent**
None	6	11%
One	4	8%
Between 2 and 5	5	9%
Between 6 and 10	5	9%
More than 10	30	57%
Not sure if they know young people with HIV	3	6%

A follow up question asked young people to say where they had met other young people with HIV. It was most common for participants to say that they had met other young people with HIV at an HIV support group (63%) or though other CHIVA activities (41%), however others had also met through their hospital (35%). It was relatively rare to have met young people with HIV anywhere other than HIV-specific settings, but a few mentioned either meeting others when living or visiting other countries, or socially.

4.3 People to talk to

Participants were asked*Who do you talk to about living with HIV*?and were invited to tick as many of the following items that applied:

Who participants talk to about HIV (n=48, missing 7)	**Number**	**Percent**
HIV doctor	34	71%
Parents / carers / step parents	31	65%
HIV nurse	24	50%
Friends who have HIV	20	42%
HIV support staff	18	38%
Brothers / sisters	5	10%
No one	4	8%
HIV counsellor	3	6%
Other family (such as cousin, aunt, grandparent)	3	6%
Friends who do not have HIV	1	2%
Staff at my school / college	1	2%
Other	1	2%
Boyfriend / girlfriend	0	0%

Participants were most likely to report that they talked to their HIV doctor (71%), parents / carers (65%), HIV nurse (50%) friends who have HIV (42%) or HIV support staff (38%) about their own HIV diagnosis. Only a small proportion (8%) said that there was no one that they talked to about HIV.

When considering all the responses to this question cumulatively for each individual, more than a third (36%) of participants identified at least four different groups of people they were able to talk to about HIV, whereas it was more common for participants to indicate between one and three members of the categories given (44%). As noted above, a few people said they spoke with no one about it.

Participants were also asked *Is there one person in your life that you really wish you could talk to about HIV?* Just under one third of participants (31%) said there was someone they really wanted to be able to discuss it with. When asked to describe who those persons were, participants most commonly mentioned family members, with a particular focus on their mothers and or their siblings. A few others wished they could talk to their boyfriend or girlfriend about it, and one individual wanted to be able to discuss it with their HIV doctor.

4.4 HIV impact

Participants were asked*How does HIV affect your life?*and were offered the space to put down their own thoughts. Of all those taking part in this phase of the evaluation, 41 participants gave an answer to this question, ranging from a few words to several sentences in length. Thematic coding of the responses revealed a range of recurring themes including: restricted options, fears and concerns about negative outcomes, taking medication, the secrecy and stigma associated with HIV, clinical visits, coping and those who said they felt no effect. Many individuals' responses included more than one theme, and these were all included in the coding process.

A considerable number of responses (n=14) made mention of the secrecy and stigma that accompany HIV, and participants often commented on the fact that they disliked having to keep information from people who are close to them.

> *It keeps you from having a full relationship with someone because you have to keep a massive part of you away from them. (16 year old)*

In many cases, those who raised secrecy and stigma as an issue connected this with the experience of having to hide their medications from friends, particularly on school outings, or when staying over.

> *When i want to go to a party i have to think if i should bring my medz with me. Also if I am sleeping round my mates if i do bring them when should i take them...where should i keep them. If someone sees them what should isay. Another way is when i go away with my school abroad and iam away from home for several days i need to make a firm decision if i should bring them with me or skip it whileiam away. (15 year old)*

Of all the people who mentioned medications in their response (n=13), more than half said that the problem with taking medication was how to take it in front of others who were unaware of their HIV status. Other issues raised were that tablets were difficult to take, and that there was simply a lot of medication to take all the time.

Many participants (n=12) also raised a note of concern and fear about the future, in relation to a number of different issues. Some said that HIV affected them by making them feel extra cautious about not passing on HIV to others through open cuts, sex, or when planning to have children. Others expressed concern about ill health, death and possible progression from HIV to AIDS.

> *HIV can affects your life if not treated like take your meds it can end up being AIDS. (13 year old)*

In contrast to this, a sizeable minority of participants (n=8) said that HIV did not affect them. A few others mentioned that they often had to go to the clinic (n=2) or that HIV represented restrictions for them (n=3), either due to travel restrictions, or because they felt they could not stay at friends' houses due to the medication issues described above.

Only two participants mentioned moderating or coping mechanisms which sometimes made them feel less lonely, and quite strong. One said,

> *Well to tell the truth, I'm a really brave girl. (16 year old)*

Overall, the vast majority of responses to this question were about the negative impact of HIV in the lives of participants, while a smaller proportion were neutral, and only a couple focussed on means of dealing with one's status.

4.5 Considering camp

Participants were asked*What made you decide to apply to F2B*? and were invited to tick as many of the items in the list below as applied.

What made you apply to F2B? (n=55)	**Number**	**Percent**
To make new friends	34	62%
To meet other people with HIV	34	62%
It might be fun	29	53%
To learn more about HIV	23	42%
To do sports and other activities	16	29%
To be away from home for a while	15	27%
I trust CHIVA to run a good programme	14	26%
Someone else told me to	11	20%
To find a girlfriend / boyfriend	3	6%
I am not sure / don't remember	1	2%
Other	0	0%

The four most popular reasons for applying to attend camp were, to make new friends (62%), to meet other people with HIV (62%), because it might be fun (53%), and to learn more about HIV (42%).

Before they went to camp, participants were asked*Which HIV topics would you like to know more about?*and were invited to select as many of the topics in the list below as applied.

Which HIV topics would you like to know more about? (n=55)	**Number**	**Percent**
The future	30	55%
Having children	27	41%
HIV and the law	24	44%
Family life	22	40%
Your rights	22	40%
Medications	19	35%
Sex	19	35%
Positive living	19	35%
The science of HIV	18	33%
Stigma and rejection	14	26%
Talking to others	10	18%
Support services	7	13%
The clinic	5	9%
Other	4	7%

Desire for more knowledge can indicate a number of things, it can demonstrate gaps in awareness, as well as interest stimulated by existing knowledge. The converse of this can also be true – not wanting to know more can indicate that all of a person's needs are met, or that they are unaware of the topics that might be of most use to them. The format of this survey question does not allow us to determine the extent to which this is the case for any ofthese items, but the findings offered the camp organisers advance insight into which particular topics the young people most wanted to learn about.

Among those who indicated their interests, the most common responses included: the future (55%), HIV and the law (44%), having children (41%), family life (40%) and your rights (40%). The two issues that garnered the least interest were: the clinic (9%) and support services (13%). There were seven participants who did not indicate any HIV topics that they wanted to know more about.

Participants were also asked*What would you like to do at camp?*and were offered an open space in which to give an answer. Once again, this was designed to offer the organisers some advance understanding of the types of activities and outcomes the participants were seeking. Some responses contained more than one topic, and all of these were included in the thematic coding during analysis. Most commonly, participants said that they wanted to have fun, enjoy themselves and party (n=17). It was also very common for young people to say that they wanted to make friends, and meet other young people who also had HIV (n=15). A sizeable proportion (n=13) said they looked forward to taking part in activities, and several of these identified swimming and other sports. Finally, a group of participants (n=9) said that they wanted to learn new things at camp, a few of whom specifically said they wanted to learn more about HIV.

5 Survey at camp (Phase 2)

On the last day of summer camp, all participants who consented to take part in the evaluation were asked to complete the phase two survey. The questions in this survey were quite different from the ones asked in the first phase, and related directly to young people's experiences at camp in the previous few days.

Slightly more participants took part in this phase of the evaluation (n=58) than those taking part in the first phase (n=55), as there was time and space allotted to do so at camp.

5.1 Learning

Participants were asked, *What new things about HIV did you learn at F2B*? and were invited to select more than one item in the list below if this was applicable.

What new things about HIV did you learn at F2B? (n=58)	**Number**	**Percent**
Sex	32	55%
Talking to others	30	52%
Your rights	30	52%
HIV and the law	27	47%
Family life	26	45%
The future	26	45%
Medications	25	43%
Having children	19	33%
The science of HIV	17	29%
Positive living	17	29%
Stigma and rejection	13	22%
The clinic	11	19%
Support services	10	17%
Other	3	5%

More than half of all participants learned more about sex (55%), their rights (52%) and talking to others (52%) during their time at F2B. It was also very common for young people to say they learned about HIV and the law (47%), family life (45%) their own futures (45%) and HIV medications (43%) while at camp.

It was possible to undertake a comparison between which of these topics participants said they wanted to know more about before camp (in phase 1), and which answers each individual gave to this question immediately after camp (in phase 2), in order to determine the extent to which information needs were met. Almost three-quarters of those for whom such a comparison was possible (71%, n=33) had learned about some, most or all of the topics that they had wanted to know more about. Many learned about new things in areas where they had not previously identified a need, and only one participant out of all those who responded did not report learning anything new about the HIV topics listed above, while at camp.

Participants were also asked*Have you learned anything new about yourself at F2B*?, and were given an open space in which to write an answer. This may have presented young people as a greater challenge than the question above, as a smaller proportion of them gave a response (n=44).

Among those who did give an answer, the most popular theme related to having a sense of increased confidence (n=25) as a direct result of being at F2B. Many simply said that they felt more confident, while others described how they felt in more detail. For some, they felt a burden had been lifted:

> *That I can be myself without having to worry what’s wrong.(14 year old)*

Others found that being at camp had revealed capabilities of which they had been previously unaware:

> *I’m more capable of doing something than I thought I was. (16 year old)*

And there were also those whose new-found confidence was based in their discovery that HIV was an experience that could be openly shared with others.

> *That I don’t have to hide from anyone.(16 year old)*

About one quarter of those responding to this question (n=12) commented on new information they had learned, or skills they had acquired while at F2B. Many of these participants mentioned an increased awareness of legal and rights issues connected with HIV:

> *Yes, I have learned more about my rights which I didn’t know. (17 year old)*

The remainder (n=7) said that F2B had not prompted them to learn anything new about themselves.

5.2 Social ties

A number of questions were asked about social interactions during camp, including interactions with peers, camp leaders and adult volunteers.

When asked how they usually spent their social time during camp, the vast majority said they spent time making new friends (91%), and many spent time with others they already knew (59%). It was less common for participants to say they spent time at camp on their own (16%), with their Key Worker (10%), or with Camp Leaders (5%).

One of the central goals of F2B was to reduce social isolation among young people with diagnosed HIV, in large part by increasing awareness that there are many other young people who are also diagnosed. In order to assess how this was interpreted by participants, they were asked, *How important was it for you to be around other young people at F2B with HIV?*and they could choose one of the answers on a five point scale as outlined below.

Importance of being around other young people at F2B with HIV (n=57, missing 1)	**Number**	**Percent**
Very important	41	72%
Sort of important	12	21%
Not sure	3	5%
Not really important	1	2%
Not important at all	0	0%

The majority of participants (93%) felt it was important to spend time with other young people with HIV while they were at camp.

In addition to the reduced sense of social isolation that the camp experience itself might offer, the organisers hoped that a proportion of young people would aim to maintain contact with one another once camp was over. When they were asked if they planned to keep in touch with other people who had come to F2B, again, the overwhelming majority (90%) said yes, and the rest were unsure (10%). There was no participant who left camp feeling that they did not want to keep in touch with anyone they met.

Akey feature of planning F2B included the purposeful recruitment of many adult volunteers (Key Workers) living openly with HIV, as well as Camp Leaders with HIV as a key aspect of the camp structure and experience. In order to gauge the impact this had on participants, they were asked, *How important was it for you to meet adults at F2B with HIV?*

Importance of meeting adults at F2B with HIV (n=55, missing 3)	**Number**	**Percent**
Very important	24	44%
Sort of important	19	35%
Not sure	9	16%
Not really important	1	2%
Not important at all	2	4%

Almost four-fifths of participants valued their interactions with adults living openly with HIV.

5.3 Likes, dislikes and constructive criticism

Participants were asked to *Say 3 things you liked most about F2B*, and were given a short line for each. All of those taking part in this phase of the evaluation (n=58) responded. Thematic coding was undertaken on their responses in order to determine a set of categories that fit most answers. More than four-fifths of participants (n=48) said that they liked making friends and getting to know people at camp, and this was often the first of the three responses. About two-thirds (n=37) also mentioned that they enjoyed taking part in various activities, with some mentioning activities such as dancing, performing, swimming and yoga by name. A third of people (n=19) mentioned that they had enjoyed learning about new topics in the workshops, while a similar proportion (n=19) also commented on some feature of the atmosphere created at camp that they particularly enjoyed (such as it being fun, or a place where people were made to feel comfortable and open). And finally, just under one in six participants (n=10) mentioned that they had appreciated the involvement of the adult team members, and a similar proportion (n=11) commented on their appreciation of the venue (referring either to the space or the food).

Participants were asked to *Say 3 things you liked least about F2B*, and were given a short space for each. Almost all participants (n=54) responded, and thematic coding of their responses revealed a range of response categories. Most prominently, about three quarters of participants (n=39) disliked the sleeping and waking times, with most of these saying that the venue’s strict 10 pm curfew (and 11 pm bed-time) was too early and many also saying that they were awoken too early in the morning. Under half of those responding (n=24) raised issues about the venue, either that they disliked the food, the beds, or they found the scale of the school too large to navigate easily. A similar proportion (n=23) made a comment that related in some way to the organisation of the camp, either in relation to disagreements with particular decisions (such as allocation of room-mates), the lack of free time built in to the daily schedule, or the organisation and communication of workshop and activity allocations. More than a quarter of participants (n=15) felt that camp was too brief, with some saying they would have preferred a full week – however, this should be regarded as more of a compliment than a criticism. Some also said that they disliked the content of some of the workshops or activities (n=11).

Toward the end of the survey, participants were also asked to complete the following: *If F2B happens again, the people planning it should think about...* Essentially the same topics as those described above arose again, demonstrating the strength of young people’s feelings on how the camp could be improved. Many only mentioned one topic, resulting in a decline in the overall number of responses that were coded. Responses most often related to the organisation of camp (n=24) with a particular focus on a desire for more free time, as well as a relaxation of some of the more firm rules. Just as popular were those who again mentioned that bedtime was too early (n=22). Also mentioned in these responses were a desire for camp to be longer in duration (n=14), and issues relating to the quality of food or sleeping quarters provided by the venue (n=10). Finally, there were also those who commented on workshops and activities (n=12), however in this instance, most said that they would have liked to have seen more diversity and less repetition in what was on offer.

5.4 Overarching impressions

Toward the end of the survey, participants were asked to complete the following: *My time at F2B has been...* and were given an open space in which to give a response. Almost every individual completing the survey gave a response to this question (n=57), and the results were overwhelmingly positive. These ranged from the descriptions of camp as 'fun', 'enjoyable' and 'good' (n=28) to those who were more superlative in their positive depictions of camp as 'amazing', 'fantastic', and 'great' (n=24). Some of those in this latter group were clearly moved by what they had experienced, with camp described as life-changing:

> *The best days of my life time.(16 year old)*

Some of the young people went on to describe what had made F2B enjoyable. Some talked about the value of meeting other young people with HIV, as well as the adults who were involved in making it happen (n=10).

> *An amazing time getting to know that there is a lot of people who have HIV not only me and making friends who have the same illness as me was more fun than anything else. (14 year old)*
>
> *Very good because I got to make new friends and meet new people and adults that have HIV. (17 year old)*

Other young people (n=10) added that they enjoyed camp because of the opportunity to try new activities, and the new things they learned.

> *Fun, I learned things I didn't know. (13 year old)*

There were also those whose comments were far less approving than those described above (n=5). This ranged from those whose comments included descriptions of camp as '*alright*', or *'a bit too strict' to 'sometimes boring'*. One participant said camp was,

> *Confusing, some workshops were not what I was expecting. (17 year old)*

The overwhelming impression gained from participants was that even where there were complaints about the rules, the organisation and the venue, these were overwhelmingly overridden by their experience of camp as positive and affirming experience. Some of the things that young people most valued were the opportunity to meet other young people with HIV, to acquire HIV-specific knowledge on a range of topics, and to try activities that were new to them.

6 Follow up survey (Phase 3) and indications of change

Three months after F2B took place, participants were contacted for a final time to determine how life had been for them since going to camp, and to find out which features of their experience at camp they continued to value.

A number of the questions that were asked in the Phase 1 survey were repeated in this phase in order to determine the extent of change that had been introduced into each individual's life before and after going to camp. Of course, there should be some caution exercised about attributing certain changes to F2B alone, particularly in the quantitative (tick-box) elements of these surveys, given that other factors could also have played a part in any positive and negative changes that young people will have experienced in that time period. However, we note the overall trends with interest, and in many cases, the narratives offered in the qualitative (open-ended) parts of this final survey do give considerable force to the sense that F2B had a beneficial impact on most of those taking part.

A total of 39 young people completed this final phase of the evaluation, meaning that just under a third of those who participated in earlier phases dropped off at this final stage, which is unsurprising. When comparing the demographic profiles (gender, age, ethnicity and region of residence) of those completing this final phase of research with those completing phase 1, there is little change in the make-up of this final sample.

There were more participants who completed this phase of the survey online (n=15) that those completing it online in phase 1, however, this form of participation remained low. Of the remainder, 9 young people completed a paper copy of the survey returned to Sigma via Freepost, and 14 completed the survey by telephone with a member of Sigma Research staff.

6.1 Diagnosis and disclosure

When asked, *Who knows that you have HIV*?, participants were given the choice to identify whether *All, Some, or None* of the people in the following categories were aware of their diagnosis. Not all participants gave a response for every category.

Who knows that you have HIV?	**All (n)**	**Some (n)**	**None (n)**
People you live with	19	17	2
Your friends	0	19	11
School / college staff	0	4	28
Family you don't live with	5	16	12

Given that this question was also asked in phase 1, it was possible to compare individual participants' own responses given before and after camp in order to examine the degree of change. A notable positive change reflected through comparison of individuals' responses is that among those answering this question in both phases, more than one third (35%) report an increase in the proportion of their friends who know that they have HIV, and there are no decreases in this response category. However, somewhat surprisingly,when examining responses of those who answered this question at phase 1 and phase 3, about one-fifth (19%) indicated that fewer people in their household knew about their HIV since camp, with only a couple of participants reporting an increase. On a similar comparison, almost one-quarter (24%) indicated that fewer members of their extended family now knew about their HIV, as compared to about one-sixth (14%) who indicated an increase.

These changes are not a result of different sets of participants giving different answers – as we only examined changes in answers given by those who answered these particular questions before and after camp for this question. There could be a few explanations for these unexpected patterns. It is possible that frequent changes in household and family composition mean that the question could mean different things to participants at different points in time. Another possible explanation is that young people's perceptions of who knows about their HIV could be very changeable – because they may be quite unsure of which family members know, particularly if they feel their HIV is not a matter for discussion.

In real terms, it is unlikely that many fewer household members or extended family members outside of the home would know about a young person's HIV diagnosis within a three month span, however, where there is a lack of certainty about who knows and who does not know – responses to such questions will be open to variation in both directions. Young people often commented throughout this research that HIV is often not an issue that is discussed openly at home, and it is possible that they feel little control over disclosure with family members. Perhaps this is why there is a more clear direction of travel when it comes to changes in awareness among participants' friends. Young people will have much more direct control over which of their friends know and do not know about their status, which may contribute to the large increase in reported awareness of participants' HIV status among their friends in the three months following camp. Given their increased social networks involving other young people with HIV (described below in section 6.2), this also helps to explain the increased proportion of respondents who now say they have friends who know.

6.2 Social ties

After being prompted to think about the other young people with HIV that they met at F2B, participants were asked, *How many of them have you kept in touch with since camp?* To which they were offered the response options shown in the table below.

Number of camp attendees with whom young people have remained in contact (n=39, none missing)	**Number**	**Percent**
None	1	3%
One	0	0%
Between 2, 3 or 4	6	15%
5 or more	32	82%

The overwhelming majority of participants in this phase of the evaluation (97%) had remained in contact with others from camp, and most said they kept in touch with a sizeable number of people. Following on from this question, participants who reported keeping in touch with others were asked to identify the different means through which they kept in contact, and were invited to select as many items from the list in the following table that applied.

What are the different ways you keep in touch with people you met at F2B camp? (n= 38, 1 missing)	**Number**	**Percent**
Social networking sites (such as Facebook)	34	90%
Mobile phone (calls or texts)	32	84%
Instant messaging (such as MSN)	20	53%
Meeting up in person	16	42%
Email	14	37%
Home phone	7	18%
Online video or audio calls (such as Skype)	5	13%
CHIVA's secure website	1	3%
Writing letters	1	3%
Other	1	3%

It is clear from these responses that Facebook (and other similar social networking sites) has proven to be a key resource used to maintain contact. Depending on how they are used, such sites may be useful for less personal communications such as status updates, etc, but they are not often the best means for personal, private exchanges to take place. It is therefore also interesting to note that more than four-fifths of participants (84%) interact using mobile phones, followed by just over half (53%) who say they also use instant messaging to keep in touch. The use of these more private means of contact also means there is the capacity for personal, meaningful friendships to evolve as a result of camp. Anecdotes gained from questionnaires completed by telephone indicate that at least some of those who reported meeting up in person were referring to others from F2B who they also see at regular support group meetings, so it is difficult to determine what proportion of those who said they have met up have done so independently from any ongoing organisational interventions. It is worth pointing out that CHIVA's secure website for young people only went live at the time these follow up surveys took place, which explains why it is not yet a key communication resource for this population.

6.3 People to talk to

Participants were asked, *Since F2B, who do you talk to about living with HIV*?, and were invited to tick as many of the following items that applied:

Who do you talk to about living with HIV? (n=39)	**Number**	**Percent**
Parents / carers / step parents	25	64%
Friends who have HIV	24	62%
HIV doctor	19	49%
HIV nurse	17	44%
HIV support staff	15	39%
Brothers / sisters	8	21%
Friends who do not have HIV	6	15%
HIV counsellor	6	15%
Other family (ie. cousin, aunt, grandparent)	6	15%
Boyfriend / girlfriend	4	10%
Staff at my school / college	1	3%
No one	1	3%
Other	0	0%

Examination of individual participants' responses to this same question in both the phase 1 and phase 3 surveys allows analysis of the degree of change, although for reasons discussed in more detail below, such comparisons are complicated by the time frames imposed by each of the questions. There were 26 participants who fully completed this question in each survey. And although there were a number of instances where avenues of communication were reported to have declined, there were twice as many reports of new people with whom young people were talking about HIV.

Overall, about two-thirds of those for whom data is available described someone new that they can talk to about HIV, and most of those described gaining more than one such person.

The most common categories in which participants now report having someone to talk to, whereas this was not the case prior to camp are: friends with HIV (n=8), parents (n=5), extended family (n=5), and friends without HIV (n=5). It is also very encouraging to note that three young people said they now talk to their boyfriend or girlfriend about HIV, whereas they had not prior to camp. This is particularly noteworthy, as not one participant in the pre-camp survey reported having talked with a partner about HIV.

The most common categories in which participants reported less communication about HIV three months after camp as compared to before camp are: HIV doctor (n=6), HIV support group (n=5), and HIV nurse (n=4). Given that these are service and clinic settings, it is worth considering that young people may simply not have had the opportunity or need to access such settings since camp. The question in phase 1 (*Who do you talk to about HIV?*) infers a much broader time scale, and will include those individuals to whom a young person has ever spoken about HIV, even if that has only taken place on one occasion. In contrast, the phase 3 question (*Since F2B, who do you talk to about HIV?*) automatically imposes a much more brief time-span of only three months. It is therefore unsurprising that there have been decreases in some categories, particularly those that perhaps have a more professional relationship with young people.

Just as in phase 1, participants were also asked, *Is there one person in your life that you really wish you could talk to about HIV?* Similarly to the results when this was first asked, just under one third of participants (31%) said there was someone they really wanted to be able to discuss it with. When asked to describe who those persons were, the most common responses also remained strikingly similar to those given intially. It was most common for participants to mention family members (most commonly siblings and extended family members, and also a parent in one case). Others mentioned wanting to talk with their boyfriend / girlfriend about it. Finally, one person said that they would like to be able to talk about it with their friends who are not aware of their infection.

This demonstrates that barriers to open disclosure and ongoing informal support remain for a considerable proportion of participants.

6.4 Learning

Participants were asked both before and after they went to camp, *Which HIV topics would you like to know more about?*and were invited to select as many of the topics in the list below as applied.

Which HIV topics would you like to know more about? (n=39)	**Number**	**Percent**
The future	21	54%
Your rights	18	46%
HIV and the law	17	44%
Family life	12	31%
Having children	15	39%
Stigma and rejection	15	39%
The science of HIV	15	39%
Talking to others	15	39%
Sex	15	39%
Medications	13	33%
Positive living	12	31%
Support services	12	31%
The clinic	4	10%
Other	3	8%

After having been to camp, this sample of participants remained most interested in finding out more about the future (54%), their rights (46%), HIV and the law (44%). There was also considerable interest in the science of HIV (39%), talking to others (39%), sex (39%), having children (39%) and dealing with stigma and rejection (39%). This does not represent vast difference from the leading topics of interest from phase 1, however, some additional topics of interest following camp include: the science of HIV, talking to others, and dealing with stigma and rejection. The topic that garnered the least interest in this phase was the clinic (10%). Those who raised other issues not on the given list said that they wanted to know more about disability benefits, being a carer for a parent with HIV, and meeting more people who have HIV. A blanket comparison between the responses given before and after camp show that the greatest change was an increased interest in information about support services (from 13% to 31%) and talking to others (from 18% to 39%).

Participants were asked, *What 3 things did you learn at F2B?*and were offered a line for each response. The majority(n=33) gave at least one response to this question, and most completed all three sections.The highest number of responses (n=25) to this question related to knowledge that young people acquired about HIV while they were at camp. This category includes those who mentioned that they learned more about '*living with HIV*' in quite general terms, as well as those who gave specific examples of improved knowledge about either the legal and regulatory features of living with HIV (n=7).

> *Different jobs you can do or not do.(14 year old)*
>
> *Your rights during sex.(14 year old)*

There were others in this category (n=7) who mentioned that they had learned about preventing the transmission of HIV to sexual partners and to future children that they may have.

> *How not to pass the virus. (17 year old)*
>
> *That i can have children with[out] affecting them. (16 year old)*

In addition to those who talked about the facts that they had learned at camp, there was a sizeable proportion who talked about the personal growth that they had experienced in the three months since being at camp. A number of participants (n=13) said that F2B had inspired a new degree of personal self-confidence.

> *Not to worry what others think. (13 year old)*
>
> *I feel more positive about my future. (15 year old)*
>
> *You can still succeed in life no matter what you have. (16 year old)*

And finally, another considerable group of participants (n=13) mentioned that camp had given them the ability to talk more openly with others about their HIV, including talking to those who are well placed to give support and information.

> *How to tell people – that helped me tell my boyfriend. (15 year old)*
>
> *If I did feel upset then I could tell one of my friends. Not to close up my feelings. (age unknown)*
>
> *To be more open with my doctor (age unknown)*

6.5 Lasting impressions of F2B

Participants were also asked, *If another young person with HIV asked you about F2B, would you say they should go?*and were given the options: *Not sure, No and Yes*. The table below shows their responses.

Would you say [others] should go? (n=39)	**Number**	**Percent**
Not sure	2	5%
No	1	3%
Yes	36	92%

Participants were also asked,*Are you glad you went to F2B?*and were given the options: *Not sure, No and Yes*. The table below shows their responses.

Are you glad you went to F2B? (n=39)	**Number**	**Percent**
Not sure	1	3%
No	0	0%
Yes	38	97%

Following on from this, young people were given the opportunity to say why they felt this way. The person who said they were unsure about being glad that they went to F2B did not choose to explain why this was the case. Almost all (n=35) of the remaining responses focussed on the beneficial impact of meeting other young people with HIV at camp. Some simply focussed in the joy of meeting people with shared experience, and increasing their friendship networks.

> *Meeting people having fun and being yourself. (age unknown)*
>
> *It was because I had fun there. I was kind of like getting to know more people. I never really got to talk to anyone before camp. (15 year old)*

Others took this opportunity to describe the inspiringand motivating effect that meeting up with peers has had on their own outlook.

> *Cause i met other people with hiv and that made me strong can be just like anyone else. (age unknown)*
>
> *Because when i came back home i felt good that i did because at the camp it was like everyone was just the same as me and basically i had to accept that i have HIV. it actually lifted me up instead of me stay scared of what was going to happen through my future. (14 year old)*
>
> *Because it made me make new friends & made me realise how important it is to take your medication & its not only 1 or 2 people who have the disease. (age unknown)*

Among those few who did not mention making friends or meeting new people, they simply focused on their overall enjoyment of camp as a key turning point in their life,

> *Because it was one of the best experiences of my life! (16 year old)*

6.6 Conclusions and recommendations

For each of the F2B objectives that this evaluation was designed to assess:

- a positive experience at camp,
- improved knowledge about living well with HIV,
- reduced social isolation,
- ongoing contact with other young people with HIV, and
- beneficial interaction with adult camp leaders and volunteers who have HIV;

these findings demonstrate that for at least three-quarters or more of those taking part there is evidence of positive change.

This does not mean there are not areas for growth and improvement suggested among the evaluation findings. Some of these are outlined in the recommendations below, which organisers and funders may want to consider if this or a similar intervention is to take place again in future.

Although there was considerable support and information need evident among those selected to attend camp, it would appear that many are already accessing at least some social interventions for young people with HIV.

- **Recommendation 1:Ensuring either greater geographic diversity, or a needs assessment undertaken as part of the recruitment process will help to ensure that this intervention targets those in greatest need.**

Despite the fact that concerns about the large size and scale of the venue was only raised by a small number of participants, this may represent physical access issues worth considering.

- **Recommendation 2: Careful consideration will need to be taken about the appropriateness of the venue for the physical needs of all those taking part.**

A considerable number of participants in the phase 2 survey raised concerns about the night time curfew required by the venue. Certainly, young people need to get enough sleep to benefit from the experience, and to remain healthy while away from home, however there was a concern expressed about the inflexibility of curfews, bed-times and waking-times, despite the spread of ages of those attending camp.

- **Recommendation 3: Organisers might like to consider how key matters such as bed-time rules are communicated and implemented in ways that may elicit better cooperation and understanding from attendees.**

Among the themes about camp organisation that were mentioned in the phase 2 data, the two most common were: a desire for more free time to socialise, and an improved system of selecting and being assigned to various workshops and activities.

- **Recommendation 4: Some attention should be paid to the scheduling of activities, both to provide space and time for socialising, as well as ensuring that all attendees have advance notice of their schedule for the day.**

As has proven the case with previous residentials organised by CHIVA, a large proportion said they wanted F2B to be longer. This will have cost as well as logistical implications, but may be worth consideration, given that many expressed this desire.

- **Recommendation 5: Assess the feasibility of running camp for a slightly longer duration.**

There is little doubt of the lasting beneficial impact that F2B has had for the majority of those who attended. It is notable that the practical concerns expressed by participants about rules and organisational issues on the final day of camp (which form the basis of many of the recommendations above) fell away from their minds as they described their overarching impressions of camp several months on. For some, F2B represented a significant milestone in their lives, a time when they grew to be more open, and more confident in themselves as young people with HIV. For many others, F2B was a time of release, escape, fun, and a chance to make many lasting friendships. Almost all those participating reported having learned more about HIV and its place in their lives, as well as having learned considerably more about themselves.