“It’s Just a Virus”

CHIVA - Freedom 2 Be 2015
Interim Evaluation Report
December 2015

Irina Lut & Michael Evangeli
# Table of Contents

**Executive Summary**.................................................................................................................. 3  
**Introduction**................................................................................................................................... 4  
   **F2B 2015 Overview** .................................................................................................................... 5  
   **Camp attendees and Staff** ......................................................................................................... 7  
   **Activities**................................................................................................................................... 8  
**Methodology**................................................................................................................................. 9  
   **Design**...................................................................................................................................... 9  
   **Ethics**......................................................................................................................................... 10  
   **Sampling**................................................................................................................................... 10  
   **Procedure**.................................................................................................................................. 10  
**Evaluation Materials Development**............................................................................................. 11  
   **Questionnaires** ......................................................................................................................... 11  
   **Surveys and Interviews** ............................................................................................................... 13  
**Analysis plan**................................................................................................................................. 14  
**Findings**......................................................................................................................................... 14  
   **Overall feedback** ....................................................................................................................... 14  
**Pre-Camp expectations** .................................................................................................................. 15  
   **Camp experience and outcomes** ............................................................................................... 16  
   **Camp logistics** .......................................................................................................................... 16  
   **Relationships between Camp attendees and between Camp attendees and staff** ................ 18  
   **Staff experience** ....................................................................................................................... 21  
   **Workshops** .............................................................................................................................. 22  
   **Creative Activities** ................................................................................................................... 28  
   **Sharing one’s status/HIV disclosure** ......................................................................................... 29  
   **Self-Report measures** ............................................................................................................... 31  
   **Post-Camp Accounts** ................................................................................................................ 32  
   **Psychological changes after camp** ......................................................................................... 32  
   **Behavioural changes after Camp** ......................................................................................... 34  
**Discussion**..................................................................................................................................... 36  
**Evaluation Strengths and Limitations**......................................................................................... 39  
**Next phase of the evaluation** ......................................................................................................... 39  
........................................................................................................................................................ 40  
**Acknowledgements**..................................................................................................................... 40  
**References**..................................................................................................................................... 40
Executive Summary

One of the most common phrases heard from Camp attendees and Camp staff at Freedom 2 Be 2015 was, “It's just a virus.” This phrase embodies the essence of Camp - to increase knowledge about HIV and confidence in how to live well with the condition, whilst creating a space where individuals are not defined solely by their HIV status. This interim report described the key elements of the 2015 Camp, how the initial evaluation of its impact was conducted, and preliminary findings. The interim evaluation consisted of two sub-studies: a quantitative repeated measures design with pre and post-Camp time-points (n=67), and semi-structured interviews and surveys with Camp attendees (interviews, n=11; surveys, n=64), and staff (interviews, n=6; surveys, n=29).

The findings suggest that Camp was experienced very positively by Camp attendees and staff. The opportunity to meet and share with other HIV positive young people was commonly reported in positive terms, as was the lowering of the age range to 12-16 years. HIV disclosure/issues associated with sharing one's HIV status was a major theme throughout Camp. Self-report measures suggest improvements in pro HIV disclosure and pro HIV communication beliefs at the end of Camp compared with before. Positive changes were also seen in self-perception and HIV knowledge. There was little evidence of change in HIV stigma or quality of life. Camp attendees reported increased self-confidence and ongoing communication with their peers after the end of Camp. Camp attendees also reported improved medication adherence, although changes in medication beliefs and attitudes were not seen in self-report measures.

Nine recommendations are offered regarding workshop development and planning, camp logistics and pre/post-Camp support for young people and families.
Introduction

Since 2010, the Children’s HIV Association (CHIVA) has run a week long yearly residential summer camp for young people living with HIV in the UK called “Freedom 2 Be” (F2B). Previously, the Camp was available for young people aged 13-17 living with HIV from the UK and Ireland. The age range for the 2015 Camp was reduced to 12-16 year olds. The goals of the Camp are to facilitate peer friendships, increase knowledge and understanding of living with HIV, and improve confidence and self-esteem.

There is evidence in other chronic conditions of increased youth self-esteem after attending residential interventions (Odar, Canter, & Roberts, 2013). There is limited published literature on evaluating residential interventions for young people living with HIV (Gillard, Witt, & Watts, 2011; Pearson, Johnson, Simpson, & Gallagher, 1997) with only qualitative methods used and no follow-up of outcomes. The 2015 evaluation of F2B involved a more extensive use of both quantitative and qualitative data, over pre, post and six-month follow-up time points.

The aims of the overall evaluation were to:

• Measure any changes in psychological, behavioural and clinical outcomes from before F2B to after the intervention.
• Capture the experience and perceived impact of the Camp for young people (Camp attendees), Camp staff, clinic staff and parents.

This interim report only focusses on the pre- and post-Camp data points, a subset of the complete data.
F2B 2015 Overview

The 2015 Camp ran from 4th to 8th August at the grounds of the All Nations Christian College in Hertfordshire. Camp attendees from around the UK spent five days participating in workshops and creative activities as well as enjoying free time with each other. Tables 1 to 5 show the Camp programme.

<table>
<thead>
<tr>
<th>TUESDAY</th>
<th>ACTIVITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 pm onwards</td>
<td>Young people arrive; Registration - Collect packed lunch; Room allocation; Medication check in; Phone check in; Collect T shirt; Meet key worker; Badge making; Decorate T shirt (name); Human Bingo/games led by Camp Leaders</td>
</tr>
<tr>
<td>15:00</td>
<td>Whole camp meeting; Instructions for orienteering</td>
</tr>
<tr>
<td>15:30</td>
<td>Orienteering/Treasure Hunt in key worker groups</td>
</tr>
<tr>
<td>16:45</td>
<td>Evaluation with key workers; Ice breakers</td>
</tr>
<tr>
<td>17:45</td>
<td>BONFIRE/BBQ</td>
</tr>
<tr>
<td>After dinner</td>
<td>Volleyball; Football; Rounders; ‘Get to know you’ games led by Camp Leaders and Key Workers</td>
</tr>
<tr>
<td>22:00</td>
<td>House meetings</td>
</tr>
</tbody>
</table>

Table 1 Camp schedule – Day 1
### WEDNESDAY

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00</td>
<td>BREAKFAST</td>
</tr>
<tr>
<td>8:45</td>
<td>Key worker time</td>
</tr>
<tr>
<td>9:00</td>
<td>Whole camp briefing</td>
</tr>
<tr>
<td>9:30-12:30</td>
<td>3x General HIV info workshops</td>
</tr>
<tr>
<td>14.00-17.00</td>
<td>3x Creative activities workshops – Art; Performance Poetry; Drama</td>
</tr>
<tr>
<td>12:45 - 13:45</td>
<td>LUNCH</td>
</tr>
<tr>
<td>17:45</td>
<td>DINNER</td>
</tr>
<tr>
<td>19:15</td>
<td>Sexual health workshops</td>
</tr>
<tr>
<td>20:30</td>
<td>Dance session; Football; Volleyball; Rounders match; Cards/table tennis; Pampering room (nails/hair)</td>
</tr>
<tr>
<td>22:00</td>
<td>House meetings</td>
</tr>
</tbody>
</table>

#### Table 2: Camp schedule - Day 2

### THURSDAY

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00</td>
<td>BREAKFAST</td>
</tr>
<tr>
<td>8:45</td>
<td>Key worker time</td>
</tr>
<tr>
<td>9:00</td>
<td>Whole camp briefing</td>
</tr>
<tr>
<td>9:30 – 16.00</td>
<td>White Water rafting trip</td>
</tr>
<tr>
<td>17:45</td>
<td>DINNER</td>
</tr>
<tr>
<td>19:00</td>
<td>Whole camp briefing - Star of the Day; Movie night</td>
</tr>
<tr>
<td>20:30</td>
<td>House meetings</td>
</tr>
</tbody>
</table>

#### Table 3: Camp schedule - Day 3

### FRIDAY

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00</td>
<td>BREAKFAST</td>
</tr>
<tr>
<td>8:45</td>
<td>Key worker time</td>
</tr>
<tr>
<td>9:30</td>
<td>Whole camp briefing</td>
</tr>
<tr>
<td>10:00-12:15</td>
<td>3x workshops on Experiences growing up with HIV</td>
</tr>
<tr>
<td>14.00-16.15</td>
<td>Creative activities - Music; Drama; Football; Yoga and well being</td>
</tr>
<tr>
<td>12:30 - 13:30</td>
<td>LUNCH</td>
</tr>
<tr>
<td>16:30</td>
<td>Whole camp briefing – Star of the Day and departure day information; Show of Wednesday and Friday creative work</td>
</tr>
<tr>
<td>17:30 - 18:30</td>
<td>DINNER</td>
</tr>
<tr>
<td>20:00 - 22:30</td>
<td>Party in canteen</td>
</tr>
<tr>
<td>23:00</td>
<td>House meeting</td>
</tr>
</tbody>
</table>

#### Table 4: Camp schedule - Day 4
SATURDAY

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>From 8:00</td>
<td>BREAKFAST</td>
</tr>
<tr>
<td>9:30</td>
<td>Whole camp briefing in the canteen; Key worker final meeting and evaluation; Phone collection; Medication collection</td>
</tr>
<tr>
<td>11:00</td>
<td>Closing ceremony</td>
</tr>
<tr>
<td>12:30 - 13:30</td>
<td>COLLECT PACKED LUNCH</td>
</tr>
<tr>
<td>PM</td>
<td>Young people leave</td>
</tr>
</tbody>
</table>

Table 5 Camp schedule - Day 5

Camp attendees and Staff

77 people attended as Camp attendees: 34 (44%) male, 43 (56%) female. 48 (62%) had never attended Camp before (47/101 (47%) in 2014). Figure 1 shows the distribution of age by gender.

![Camp attendee age and gender](image)

Figure 1 Camp attendee age distribution by gender

The Camp attendees all lived in the UK, with 40 (52%) born in Africa, 32 (42%) born in Europe and 5 (6%) born in other countries. Region of HIV care is presented in Figure 2.
Camp staff consisted of 31 adults: 20 Key Workers and 11 Camp Leaders. Key workers were adult volunteers, from a range of professional backgrounds. Many also live with HIV (n=13) and a number also previously attended camp as participants (n=7). Each key worker was responsible for supporting a small group of camp participants throughout the week. Camp Leaders were young adults with HIV aged 18-24, most of whom had attended camp as a participant previously. They have practical responsibilities throughout the week to help with the overall organization of camp, and also peer mentoring roles with the camp participants.

Activities

The HIV workshops were run by CHIVA staff and visiting facilitators. Visiting facilitators include individuals working with support and advocacy organisations within the HIV community. The workshops were interactive, using games and tasks to facilitate engagement and focus:

- The information workshop aimed to give Camp attendees a strong knowledge base about HIV, including information about transmission, and their rights as HIV-positive individuals. Camp attendees were split into morning and afternoon sessions according to age (older and younger Camp attendees) but all were presented with the same information. During the sessions with older Camp attendees, facilitators allowed for additional flexibility and encouraged participants to guide the conversation towards subject matter that was more important to them.
• The experience workshop began by questioning what Camp attendees find important in life before prompting them to consider how HIV affected this. Role-plays of HIV disclosure scenarios were used, with advice on how to approach telling other people about their status.

• The sexual health workshop was run predominantly by CHIVA staff and a key worker. This aimed to give Camp attendees the opportunity to ask questions anonymously about sexual health (on slips of paper dropped into a box) and how this relates to their HIV status. There was an open discussion session during which the facilitator tried to answer each question before the group explored the topic further, sometimes sharing their own experiences. At the end of the workshop there was a condom demonstration and young people were given the chance to try putting condoms on bananas. Participants were split by gender and further into two groups according to age so that topics were relevant to the majority of people attending.

Camp attendees also participated in music, poetry, yoga, football, drama and art workshops. These were facilitated either by key workers or visiting adults, and supported by camp leaders. All activities were compulsory and camp attendees could not switch sessions once they had signed up.

**Methodology**

**Design**

The elements of the evaluation reported here consisted of two sub-studies:

1. A quantitative repeated measures design with two time-points, pre-intervention and post-intervention, using self-report measures (n=67).
2. Workshop evaluations, post intervention surveys, and post intervention qualitative interviews. These included:
   a. Intervention workshop surveys
   b. Post-intervention:
      i. Staff surveys (n=29) and interviews (n=6),
      ii. Camp attendee surveys (n=64) and interviews (n=11).
Ethics

This study received ethical approval from Royal Holloway University of London Psychology Department Ethics Committee. The Health Research Authority confirmed that NHS ethics would not be required. A proposal to use data from the Collaborative HIV Paediatric Study (CHIPS) was successfully submitted, with participant identifiers allowing anonymous linkage of data for each individual (initials and dates of birth). All paper evaluation materials were kept securely at Royal Holloway University of London. Interviews were recorded and kept secure on an encrypted USB until they were transcribed and deleted. These word documents were saved with coded file names and any identifiable information within them was removed.

Sampling

All Camp attendees with parental and Camp attendee consent to take part (67/77, 87%) were invited to complete the self-report measures and the post-Camp surveys. All staff was invited to complete the post-Camp survey. For the Camp attendee interviews, sampling occurred in two stages. Firstly Camp attendees were selected using random sampling stratified by age. Of the initial 12 people that were approached, two did not want to participate and one had not consented to taking part in the evaluation. The remaining interviewees were subsequently selected using convenience sampling to ensure that the target sample was reached. We aimed for a representative sample of males and females of all ages that lived in different regions. We used stratified sampling by role to approach staff members for interviews. All who were approached agreed to participate.

Procedure

Parent consent (opt out) for Camp attendee participation was sought before Camp. If parental consent was obtained, key workers presented information sheets, allowed time for questions and sought written Camp attendee assent/consent during a session on the first day of Camp. Camp attendees were given one hour to fill in the self-report measures. One the last day of Camp a second session was allocated for completion of the post-intervention self-report measures. Post-camp surveys were also distributed to both Camp attendees and staff members on the last day of Camp. In addition,
throughout Camp, Camp attendees were asked to fill out workshop evaluations at the end of each session.

During the last few days of Camp, those young people and staff members selected to be approached were invited for interviews. Interviews were scheduled to take place either at a hospital clinic or at a known support organisation approximately six weeks after the end of Camp. These were conducted by IL in a private room with the interviewee.

**Evaluation Materials Development**

**Questionnaires**
A mixture of pre-existing measures (where available) and questionnaires developed for this evaluation were used. For the latter measures, individual questions were sourced from published research, generated by the research team and piloted with members of CHIVA and the CHIVA Youth Committee.

**HIV knowledge**
A 19-item measure was developed to cover general HIV knowledge, transmission, medication and reproduction information. Items were either new or sourced and adapted from other measures (e.g., Aaro et al. 2011; Carey and Schroder 2002). Young people ticked whether the statement was ‘true’, ‘false’ or ‘don’t know’. Items included, “A woman can transmit HIV to her child through her breast milk” (T) and “HIV medication can reduce the amount of virus in the body.” (T). The measure had a minimum score of 0 and a maximum score of 19.

**Antiretroviral (ART) adherence**
This 13-item measure was developed to cover the following areas: ART information, motivation and behavioural skills. An additional item assessed doses missed in the last 3 days. Items were sourced from LifeWindows Project 2006 including; “I am confident I can take my HIV medication whatever else I’m doing” and, “I get frustrated taking my HIV medication because I have to plan my life around them.” The response options were on a 5-point likert scale ranging from “strongly disagree” to “strongly agree”. The minimum score was 13 and the maximum score 65.
HIV disclosure/sharing

This 18-item measure was developed to assess attitudes towards sharing one’s status, normative disclosure beliefs, disclosure affect and disclosure self-efficacy. This measure included items from pre-existing measures (e.g., Semple 1999, Murphy 2011). The minimum score was 18 with a maximum score of 90. Additional items assessed the young person’s intention to share their status with others over the next 6 months and the extent of HIV disclosure in the previous 6 months. For each item, participants were asked. “How much do you agree with the following statement about telling people who do not know your status that you are HIV positive”. Examples of items included, “It will affect my relationship with them” and “I am confident that I can choose the right time and place to share my HIV status with others.” The response options were on a 5-point likert scale from “strongly disagree” to “strongly agree”.

HIV communication

This 7-item questionnaire assessed thoughts and feelings about communicating about HIV with people whom were already aware of the young person’s HIV status (outside of one’s care team). The minimum score was 7 and the maximum score was 35. Additional items assessed intention to communicate about HIV, and the extent of recent HIV communication. Young people were asked, “How much do you agree with the following statements on talking about your HIV with people who know that you are HIV positive?” Examples of items included, “It makes me feel better” and “I am confident that I can talk to people about my HIV if I need to.” The response options were on a 5-point likert scale from “strongly disagree” to “strongly agree”.

HIV stigma

Seven questions were derived from an existing measure of HIV stigma for HIV-positive children (Wiklander et al, 2013). The questions assessed HIV disclosure concerns, concerns with public attitudes about HIV and personalized stigma. An example item was, “I have lost friends by telling them I have HIV”. The minimum score was 7 with a maximum score of 28. The response options were on a 4-point likert scale from “strongly disagree” to “strongly agree”.

12
Quality of Life
Sixteen items from The KIDSCREEN quality of life measures were used (Ravens-Sieberer et al. 2005, 2010). These were the KIDSCREEN-10 index (minimum score 10, maximum score 50), a general health question (1-5) from this same index as well as the five self-perception items from the KIDSCREEN – 52 (minimum score 5, maximum score 25). Examples items included, “Have you been happy with the way you are?” and “Have your parent(s) treated you fairly?” The response options for the general health item were on a 5-point likert scale from “excellent” to “poor”. The response options for the KIDSCREEN-10 index and the self-perception items were on a 5-point likert scale from “never” to “always”.

Surveys and Interviews
Questions were generated by the research team, sourced from previous F2B evaluations, and an evaluation of a residential camp for HIV positive youth in the United States (Gillard et al., 2011). Piloting was conducted with CHIVA staff and the CHIVA Youth Committee.

Post Camp surveys for YP and staff
The post-Camp surveys measured overall experiences at Camp and asked both Camp attendees and Staff about what they enjoyed most and least about their week as well as how Camp could be improved. Camp attendees and staff were also asked to rate administrative and organizational aspects of camp such as the food or the balance between activities and free time. These responses were scored on 4-point likert scales from “poor” to “excellent” with the additional option of “n/a”.

Workshop evaluations
Surveys at the end of each workshop consisted of four questions, which aimed to elicit feedback on what was learned and how enjoyable the workshop was.

Post Camp qualitative interviews for YP and staff
Semi-structured interview guides were developed to assess experiences of the Camp. Care was taken to avoid leading and closed questions.
Demographic information
We collected information from Camp attendees on their initials, date of birth, country of birth, current HIV care hospital, how long they had known their status, what support services they accessed, and previous Camp attendance.

Analysis plan
Paired t-tests were used to compare pre and post time points for the self-report measures, where parametric assumptions were met. For the workshop and post-camp surveys, qualitative answers were grouped by themes and frequencies were calculated. Content analysis was used for the interview data with verbatim quotes extracted to exemplify key themes.

Findings

Overall feedback
The overwhelming feedback about the Camp from surveys and interviews was positive.

“Well I don’t want to change anything about camp, that’s the thing. Camp is such a lovely thing to do and it’s a unique experience.” [Camp attendee]
“I don’t know I just loved to be open and not care what people knew about me at all. Like if someone knows my most important secret then anything else they know about me, I don’t really mind so it was just good to have people who were the same as me or who were similar.” [Camp attendee]

“There was a spirit of unity overall.” [Staff]

“It’s more structured and I think the location is a lot better for camp and also the workshops were done a lot better than they were last year.” [Camp attendee]

Pre-Camp expectations

During interviews, Camp attendees were asked what they expected of Camp and how this compared to their experience. All of the Camp attendees interviewed believed that Camp would be a fun or interesting experience. Others expressed initial worries.

“Going there I was really nervous, I don’t know why. I can’t name it but I didn’t know what it would be like to meet people, Especially at the train station waiting, I felt just scared to walk over to them.” [Camp attendee]

This fear quickly dissipated upon arrival.

“So to meet these people for the first time, I was terrified [...] but that’s when that shift happened, it was just that first night, I felt more at ease.” [Camp attendee]

“[it] made me a bit scared and then when I went to Camp it was different because everyone had it and I didn’t know that everyone was going to have it but everyone had it and everyone was talking about it and that made me confident” [Camp attendee]
Camp experience and outcomes

Camp logistics

Six of the Camp attendee interviewees thought that Camp should be extended in length:

“I think people wanted more time with each other because the last 2 to 3 days was getting better and everyone started talking and making more friends and stuff and at the end, everyone didn’t want to go back.” [Camp attendee]

“It would bring people a lot closer. It would just bring tightness within Camp, no matter how far someone lives, there’ll just be like I can call them and see what’s happening. It would be like, unity.” [Camp attendee]

Another main area of focus in the interviews was the new age-range for Camp. Most interviewees were very positive about the change.

“I was quite excited to be back and there was also kind of a different atmosphere because it was now 12-16 year olds and obviously the whole time I’d been doing it with 13-17. [...] When I heard the reasoning behind it, then I thought that was good. [...] Like at first I was kind of like oh that’s a bit young but then if somebody's told at 10 and then don’t go to camp until 13... that’s 3 years to kind of deal with something on your own.” [Staff]

“Even though I was kind of disappointed that there were no 17 year olds, still I think the younger kids bring something to it. Cause like the 17 year olds, there’s too much drama but with the younger kids, they’re not really there for drama. They’re just there for fun. They were funny the kids.... It’s a nice dynamic.” [Camp attendee]

“It was fun to be with them (younger Camp attendees). I like them and I have friends from the younger people but in terms of what they want to know and in terms of what we want to know, it’s like a different thing.” [Camp attendee]
Staff also commented on the fact that the demographics of both attendees and staff had changed for the better.

“I think this year’s been the most diverse actually.” [Staff]

“A lot of the key workers in the beginning were gay white men and a lot of the young people were from a Black or Black Afro-Caribbean origin so you had these two different groups of people who haven’t really got an awful lot in common apart from their HIV status.” [Staff]

“I think for the first time this year there was more, more benefit in having that representation across the board.” [Staff]

The nature of the accommodation was frequently commented on. Generally, Camp attendees preferred only sharing their room with one or two other young people, but there were some differences of opinion.

“While you’re busy doing the workshops you don’t really have the chance to talk to somebody but when you’re in a room at night and like when I was up you could talk and say talk about stuff.” [Camp attendee]

“We were always like quite a lot of people in one room so it makes you talk and you’re sort of forced to talk to people but this time it didn’t feel like it cause I was in a room with one person and so I was just like, I didn’t really talk to anyone.” [Camp attendee]

“I think it was better that the location changed because you have rooms with 2 or 3 people and that was a lot better than rooms with, last year my room was 16 people.” [Camp attendee]

It was commonly expressed that free time was beneficial to promoting open communication and sharing.
“Being able to talk about it and just normalizing it is incredibly empowering and I think one of the things that probably gets overlooked is that a lot of probably the more beneficial conversations that take place are probably in the bedrooms at night when they're just chatting with their friends.” [Staff]

Camp attendees expressed the desire to have more time in the evening to talk to their friends.

“It would have been nice to have more evening time to just chat and chill outside with the fire and fairy lights.” [Camp attendee]

“It's sort of that's the times when we wanted to hang out was the evenings and we got to but we also had house meetings and very little time, free time.” [Camp attendee]

**Relationships between Camp attendees and between Camp attendees and staff**

In post-Camp Camp attendee surveys the most common answer to the question “*What was the best thing about the Camp?*” shown in Figure 3 was meeting people, more specifically people who are like them.
Camp attendees reflected on the benefit of being with other HIV positive peers.

“[We] were closer and it felt natural to be able to talk about things like that cause I’d like to bring it up with my other friends who aren’t HIV positive but they would [...] be trying to react appropriately so they’d try to react like it was a really horrible thing or it’s ok or to help but actually sometimes you just want to talk. You’re not trying to get a reaction and that’s, that’s what was much easier at Camp cause we’d just talk, we wouldn’t have to say.” [Camp attendee]

“The most useful thing about Camp, I think is sort of brings people together that think they might be alone or that feel that nobody accepts them or like they can’t be like anybody else in the world but Camp brings all those people together and sort of tells them that you’re still you and you are important, as important as everyone else and nothing about you is different really, just apart from the fact that you found out something about yourself, just like people do every day.” [Staff]

“Just happy cause I was somewhere where like I could express myself and like get away from home and school and being with the people that you can share stuff with.” [Camp attendee]
Most respondents (65%) answered that they chose to go to Camp to meet people, to see old friends or for fun.

“What I enjoyed the most was meeting new people and getting to know them and learning about my illness. Because it’s not every day that I go out and [...] get to meet a new person and especially with people that have the same illness as you. That is just, you can see how they’re doing in their life and like how you’re doing and compare it and have support and talk about it and like, it won’t be weird.”
[Camp attendee]

Several of the Camp attendees interviewed commented on relationships between Camp attendees and between Camp attendees and staff.

“Everyone fit in well together. You could like, talk to everyone, you could get the help needed, you could ask questions freely. It was really good.” [Camp attendee]

“My friends were all in the corridor and we would just stay up late and sit in the hallway talking and we could talk about anything. We could be talking about the past and all the stuff that we wouldn’t talk to our normal friends about.” [Camp attendee]

“We all just laughed. Most people that have been there a long time, we know each other and just had a laugh. Were not judging each other, just get on with friends.” [Camp attendee]

Staff also commented in a positive way about relationships between Camp attendees.

“I really like that they (Camp attendees) can be free and just be like young people like everyone else. I could see all these friendships and romances going on and you know, people getting together and sharing secrets and it was great. I don’t think it was any different to any camps I did with other children who didn’t have the same status so it was good to see that they’re just typical children.” [Staff]
“It was really nice to see them behave “normally” and to have those feelings because some of those young people, they won’t have kissed a girl or they won’t have had those feelings or felt safe enough to go and approach somebody.” [Staff]

There were many examples of Camp attendees helping each other.

“I didn’t understand some stuff so she (another Camp attendee) explained it to me.” (Camp attendee)

“I think he was missing his mum and all the other Camp attendees came and started hugging him and trying to make him do stuff.” (Staff)

Staff experience

In interviews and surveys, staff often reported positively about the relationships formed at Camp, being able to interact with Camp attendees while seeing them grow, feeling supported (e.g., in terms of training) and the continued opportunity to gain further knowledge about HIV.

“CHIVA have been really good in terms of [...] providing training for the staff that work there so that’s really really good, even from the cleaners to the kitchen staff.” [Staff]

“Even I learned something new that I didn’t really know.” [Staff]

Staff also commented positively on changes to Camp.

“The CHIVA team are really open to suggestions, they’re really adaptable to change. They’re very flexible in the moment and they’re so calm and how they organize that is incredible. They always listen to ideas and thoughts and they try things and sometimes they don’t work and sometimes they do and you can see how the camp has evolved and changed from year to year to grow into this.” [Staff]
“Every year they’ve taken on feedback and every year that has changed so that’s really positive. I always leave very inspired from camp.” [Staff]

Staff also spoke about the personal importance of their Camp role.

“It was an opportunity for me to give back because I remember being in their shoes. [...] Because I remember at that time I was at a low point in my life and attending Camp sort of brought me out of my cage a bit more and enabled me to develop the confidence. Otherwise at the time I didn’t really see much of a point in life.” [Staff]

“The way I see it is that I did go through struggles but now I’m at a place where I can handle those struggles and it’s only right for me to be like a mentor inspirational person and pass the lessons down.” [Staff]

**Workshops**

**Information Workshop**

The information workshop was experienced positively.

“It’s not something that you would usually sit down and talk about and see how other people grow, deal with it every day and what you can do or just general knowledge. It’s just like “wow, I’m not the only one.” [Camp attendee]

“I think it’s really good that the workshops are including up to date, new kind of like information and development.” [Staff]

Figure 4 shows Camp attendees’ feedback about the information workshop.
Figure 4 Information Workshop Survey

Figure 5 shows the main topics that Camp attendees answered as the most important thing they learned about during this workshop. Other than general facts about HIV, the two main topics were disclosure and the law.

Figure 5 Information Workshop Survey

The importance of discovering that HIV is a disability with associated rights was mentioned in both the post-Camp survey and interviews.
“I hadn't been interested but being this age and wanting to know about my college and work and relationships and stuff, I would be more interested in the law.” [Camp attendee]

“I found out that I have a lot more rights than I thought I did.” [Camp attendee]

One topic that Camp attendees mentioned as needing more time was medication, more specifically how different medications work and side effects.

**Experience Workshops**

Responses shown in Figure 5 indicate that Camp attendees also rated the experience workshop positively.

![How useful and enjoyable was the experience workshop?](image)

**Figure 6 Experience Workshop Survey**

In the experience workshops, often Camp attendees shared stories about their personal experiences. These appeared to resonate strongly with Camp attendees, many of them engaging with the topic by asking questions and contributing to a conversation within the group. Figure 7 shows that learning about sharing one’s status was the most frequently reported learning point from the workshop.
All of the Camp attendees interviewed stated how beneficial it was to be able to hear other people’s experiences, as well as realizing that they are not only one with HIV dealing with fears around their status being known. This sometimes appeared to affect the intention to discuss HIV with others.

“I figured out [...] it’s not going to work if you hold it all inside and actually that doesn’t help but you have to talk to somebody whether that’s an adult, a friend, a parent, you have to talk to somebody. It doesn’t work on your own.”

**Sexual Health Workshops**

The sexual health workshops were generally well received with Figure 8 showing that the majority found the workshop both useful and enjoyable.
When asked about what they learned from the workshop, the most common answer was “sex” or “safe sex” followed by “how to use condoms” (Figure 9).

Interviewees had some differences of opinion regarding what information was most appropriate for younger Camp attendees.
“I was wondering if we are not sometimes maybe pushing them too much and not introducing stuff to them which they are not ready for.” [Staff]

“I think nothing is assumed, which I think is really good. Especially when you’re coming from a 12 year old perspective, I think that’s really important.” [Staff]

Some Camp attendees were satisfied with this workshop but others would have benefited from more time to ask further questions.

“More on sexual health and relationships, just slightly more cause, yeah as I said I wasn’t interested about it two years ago at all but I would like to know now and they didn’t offer quite as much as I was hoping for.” [Camp attendee]

Several of the older Camp attendees suggested they would have enjoyed more detail (and more new information) on topics relevant to their age group.

“If it had been my age group or older. Like if it had been 15-16-17 year olds instead of 14-15-16. That one year made a difference, I don’t know cause some of the girls wouldn’t want to talk about some things I would now. I wouldn’t have, if it was two years ago I wouldn’t have wanted to know about relationships, not really much about sex, I wouldn’t have wanted to so age group does made a difference hugely.” [Camp attendee]

“They were very informative because I was, I’m one of the older people we didn’t have... we weren’t given much more new information because we’d already learned about all this stuff before so it just basically renewing what we already knew.” [Camp attendee]

“We were with girls that were like 14 to 16, not really wanting to have children but I would still like to know.” [Camp attendee]
During interviews, one participant (a younger Camp attendee) found the content difficult:

“It was quite embarrassing. [...] I felt uncomfortable.” [Camp attendee]

Despite this they reported that they found the workshop useful.

**Creative Activities**

All of the creative activities got good feedback but the poetry and music workshops seemed to be most memorable for Camp attendees.

“It was kind of emotional in a way cause everyone was like expressing their story in music and it was really good. I was like out of all them, music was really good.” [Camp attendee]

“I like to hear things like that cause then I can repeat it when I feel like I’m breaking or like I’m not feeling good or something so memories of camp or stuff we did or things people said like, stick with me when I’m not feeling so good.” [Camp attendee]

“It’s a form of expression. [...] I did it a little bit before but the thing kind of like reintroduced me to it.” [Camp attendee]

Other workshops such as yoga and football were also well received, allowing the young people to either release energy or relax.

“[Yoga] was lovely because I do it every year and it’s just nice to relax and everything.” [Camp attendee]
Sharing one’s status/HIV disclosure

This topic of onward HIV disclosure/sharing one’s status was prevalent throughout all the interviews. Hearing about other peoples’ experience of HIV disclosure was often a key aspect of the workshops.

“As the young ... camp leaders, they became key workers and young people became camp leaders... that has been totally amazing and I saw that this year in a workshop for the first time where I think one of the most, perhaps the most successful workshop I’ve seen over 6 years occurred when one of the key workers who used to be, she started as a young person, was a camp leader, then became a key worker... most successful workshop was when she shared her experiences of disclosure. Now she wasn’t ready to do that previously, cause she’s on her own journey but you could hear a pin drop in those workshops. [...]I think that is something they need to develop more and perhaps have... because they’re respected.” [Staff]

Camp attendees often spoke about wanting to know how to deal with specific situations where sharing one’s status might be relevant. For the younger camp attendees, some of their worries about HIV disclosure related to friends asking questions about pills or situations in the school settings.

“They [Camp attendees] want to know how do you disclose to your best friend who you’re going for sleepover with tomorrow.” [Staff]

“I would want to talk about it more but what I’m scared about it if it comes up in a school subject or something like that because in my school it hasn’t come up yet but normally in other peoples’ school it has.” [Camp attendee]

For older Camp attendees, anxieties also stemmed from disclosing to a sexual partner and being unsure about timing or whether they should share their status at all:
“If I tell her before having sex with her she’d probably get angry and wouldn’t talk to me again but if I tell her after we have sex... My friend had a girlfriend and then I talked to him ... ‘why did you tell her?’ and he said ‘because we’ve been through a lot and I know stuff about her and I felt like she needed to know because I think, we’ve been together long enough.” [Camp attendee]

After the workshop, Camp attendees were sometimes more confident about how to manage situations:

“Cause I know like what to say, when to say it, who to tell and be careful. Like I wouldn’t tell someone I met today because obviously they’ll just tell people but if you knew them, like if it’s a family member or best friend, you can be, I’ll be comfortable enough to tell them.” [Camp attendee]

**Closing ceremony**

At the end of Camp, the closing ceremony brought everyone together to reflect on what they got out of Camp.

“I enjoyed the last day of when we went to the tree and stuck on our little notes because everyone read out theirs. [...] I can’t remember all the words but mine said I’m happy to be at camp and I’ve really enjoyed myself and I’ve learned a lot of things.” [Camp attendee]

One Camp attendee enjoyed the closing ceremony but felt it could be enhanced.

“I think it would be better if they did a show, like a talent show that everyone can watch and people dancing or whatever their talent is.” [Camp attendee]

**Returning to F2B**

Camp attendees spoke about their desire to return as staff members in the future, to continue educating others or to get involved in the community as a result of F2B:
“I want to make other people feel comfortable around Camp and stuff plus other key workers made me feel comfortable so I want to make other people feel comfortable when I’m around them.” [Camp attendee]

Self-Report measures

HIV Knowledge
HIV knowledge scores were skewed towards higher scores. The median score was 14 before Camp (IQR 11-15.27) and 15 after Camp (IQR 13-17). The p-value for this increase was 0.001, strong evidence that this change was not due to chance. At the post-Camp point, all items were answered correctly by 70% or more of the sample except for the following questions:

- The CD4 count measures the amount of HIV in the body (F) – 33%
- An HIV positive person whose viral load is low is likely to transmit the virus if they are having sex without a condom with an HIV negative person (F) – 50%
- Some medications for HIV need to be taken on an empty stomach (T) – 48%
- If an HIV negative person has sex without a condom with someone who has HIV and they take HIV medication afterwards, this can reduce the risk of HIV transmission (T) – 59%

ART adherence
The mean score for this measure pre-Camp was 49.22 (standard deviation (sd) 8.36) and 50.59 post-Camp (sd 7.25). The p-value for this increase is 0.15, weak evidence that this change was not due to chance. In relation to the question about how many doses of medication were missed in the three days prior to camp, only 15 Camp attendees responded. Of these 11 had no missed doses, two had one missed dose and two had missed two doses. Twenty-two Camp attendees answered the same question at the end of Camp. All 22 reported no missed doses.

HIV disclosure/sharing
The mean for this measure pre-Camp was 56.60 (sd 9.37) and post-Camp was 61.67 (sd 9.17). The p-value for this increase was less than 0.001, very strong evidence that this change was not due to chance. Sixteen Camp attendees (24%) stated that they had
disclosed to someone in the 6 months prior to camp. The mean intention to disclose at pre-Camp was 2.59 (sd 1.14). The mean for this post-camp was 2.62 (sd 1.24). This difference was not statistically significant (p=0.89).

HIV communication
The mean for this measure pre-Camp was 25.63 (sd 4.66). The post-Camp mean was 26.85 (sd 4.92). The p-value for this difference was 0.05, strong evidence that this is not due to chance. The mean score for intention to communicate about HIV pre-camp was 2.89 (sd 1.26), and for post-Camp was 2.88 (sd 1.36). This difference was not statistically significant (p=0.94). Twenty-nine Camp attendees (43%) replied that they had communicated with someone about HIV (outside of their care team) in the previous 6 months.

HIV stigma
The mean for this measure pre-Camp was 17.49 (sd 3.68). The post-Camp mean was 17.61 (sd 4.08). This difference was not statistically significant (p=0.79).

Quality of Life
The mean for the quality of life screening measure pre-Camp was 40.03 (sd 6.96). The post-Camp mean was 40.99 (sd 6.33). This increase was not statistically significant (p=0.12). The mean for the quality of life self-perception items pre-Camp was 18.50 (sd 5.04). The post-Camp mean was 19.90 (sd 4.09). There was strong evidence that this increase was not due to chance (p=0.01). The mean for quality of life general health item pre-Camp was 4.18 (sd 0.90), and post-Camp was 4.15 (sd 0.86). This increase was not statistically significant (p=0.77).

Post-Camp Accounts

Psychological changes after camp
Several changes were noted in the few weeks between the end of Camp and the interviews.

Confidence
Increased confidence was frequently reported:
“I’m glad. I was expecting it to just be like a fun time and then yeah, I’d have some more friends but it has actually changed me cause I don’t know, I’m more confident and happier in myself. Yeah, so I’m really glad it happened.” [Camp attendee]

“I think being able to see that there are other people like me going through the same sorts of things has made me feel like I’m not alone and it’s again, a confidence booster.” [Camp attendee]

“[Camp] did change a lot for me because before I was like so scared [...] scared of what people would think but [...] it’s hard not to tell someone and really talk about it but now I feel I can be open.” [Camp attendee]

Staff also reported witnessing positive change from year to year in Camp attendees.

“You saw an awful lot of those young people come back and had just grown… in their understanding of HIV, they’d grown in the way they held themselves, in their confidence, in their self-esteem. They weren’t letting HIV rule their lives. They were talking openly about it.” [Staff]

“I feel like they got a sense of belonging and not feeling alone and that they can be confident in achieving what they want to achieve.” [Staff]

**Maturity**

Camp attendees felt more responsible and mature after Camp.

“I went in on my own. Not to the hospital, in the room I went on my own.” [Camp attendee]

“My maturity of my HIV has changed. Cause I used to think it’s not a problem and I still think that but I understand it... each year I understand it a bit more and get on with my life. I’m more independent.” [Camp attendee]
Willingness to help/engage in community

Camp attendees reported a post-Camp desire to give back and get involved in volunteering and advocacy work.

“I definitely want to be involved with CHIVA charity and HIV in my life. [...] So being at Camp like, it didn’t open my eyes cause I knew it was happening already but I was more aware of [people struggling] and I’m more motivated to help.” [Camp attendee]

“I did inform [people at home] on the facts about it and I feel like if I learn something, I should give it back out to the whole world because so many people get the wrong idea of having HIV.” [Camp attendee]

Behavioural changes after Camp

Adherence

Camp attendees talked about the impact of Camp on their adherence to their medication regime.

“Every time I took them I felt like it was a reminder like that I had HIV but then at Camp it was just, it was a lot like not letting it define who you are and just being you and in life I was like “yeah I’m gonna do that” and ever since Camp I’ve been taking my medication.” [Camp attendee]

“It changed in many ways like, I felt like I’m not the only one that deals with it... they all take their medication and to live well I need to do the same even though I may not like them but they’re gonna help.” [Camp attendee]

“It’s improved quite a lot, I’ve been doing well so far so I’m happy about that and I find it much more easier. [...] cause I know more about it. Before I didn’t know what it was, just took it and just made sure.” [Camp attendee]

Staff commented on the importance of speaking about medication at Camp as a tool to promote good adherence:
“I think normalizing it, having those little conversations, they really do make a difference and in that respect you can be effective.” [Staff]

One staff member talked about how transitioning from Camp attendee to Key Worker helped him change his perspective:

“Once I was in Camp and I was held responsible to give other children pills, I just reflected on myself and said if I can do this for these other children and make sure every day that they take their pills and make sure that they see the value... it was almost like [...] I had to become that person and [...] ever since camp so I’ve just been like you know what, I can do it.” [Staff]

**Communication**

Camp attendees were asked whether they are still in contact with people they met at Camp and to describe the frequency of their communication. Camp attendees reported using multiple applications such as WhatsApp, Instagram, Snapchat and Facebook to stay in touch with friends.

“I talked to everyone! Like right now, as soon as camp finished, there was a group that was made and there were like 40 of us in it. [...] We’re so tight.” [Camp attendee]

“I’d say 20-30 cause we’re in a group chat and everyone talks.” [Camp attendee]

“[I talk to people a lot] About 20 people [...] Like every two days.” [Camp attendee]

These reports are encouraging and are in line with evidence from the post-Camp survey where 49 Camp attendees (66%) responded that they thought they would talk to others from Camp once a week or more.

While they were more open with people who knew about their HIV status, Camp attendees also reported challenges in telling people about the Camp upon returning home, without implying or outwardly disclosing their HIV status.
“When I went back [...] I told people about the activities that we did, I said that it was fun but they didn’t know about the virus and things, I just told them about the activities [...] then I said it was really fun and exciting but the information that I learned, it was mainly about the virus so I didn’t really share it.” [Camp attendee]

“It was difficult to tell them about my holidays and stuff but Camp made [...] it much easier to know that I could talk to people about my whole self and in the meantime I just have my own friends and I can be myself and they don’t need to know I have a secret. It made me much more confident.” [Camp attendee]

Camp attendees also described a reduction in communication over time despite a continued need for support.

“We [...] still go through issues whilst you’re not at Camp. It would be very useful if we could talk to each other after Camp as well.” [Camp attendee]

“I don’t know, it’s difficult because, it’s difficult to be in touch with people unless you’re seeing them and it’s difficult to just like, message them.” [Camp attendee]

Camp attendees suggested an online platform to stay in touch.

“Originally in the first year, we had a camp Facebook group but then people kind of [...] we used to add people to it but now it’s kind of dropped and we don’t have anyone adding anyone, which is kind of disappointing because it means there aren’t very many people talking anymore.” [Camp attendee]

**Discussion**

F2B is a complex intervention. Therefore, evaluating whether and why it is effective is challenging, particularly in the absence of a comparison intervention. Nevertheless, the findings from this interim evaluation are promising. Self-report measures showed significant improvements in pro-HIV disclosure cognitions and affect, HIV knowledge,
self-perception and pro-HIV communication beliefs. Interviews also reported positive post-Camp benefits in medication adherence and self-confidence.

The increase in HIV disclosure scores is particularly interesting, given that there was little explicit focus on sharing one's status in planned workshops and pre-Camp disclosure rates were very low. It may be that the numerous ways that HIV disclosure was discussed at camp, often outside of the context of specific workshops, explains this finding. For example, Camp attendees mentioned the increased confidence about sharing their status arising from hearing other peoples’ experience as well as receiving specific tips of how to manage disclosure situations. There was no change, however, in the intention to disclose.

**Recommendation 1: A more specific focus on enhancing motivation and skills in sharing one's status may be required for changes in intention and actual disclosure. This may require a separate workshop and more first-hand accounts of sharing.**

Increases in HIV knowledge may be explained by the lengthy HIV information workshop sessions and the fact that certain facts are repeated throughout Camp in multiple workshops. The changes may also have been contributed to by communication between Camp attendees outside of workshops. There remain, however, some aspects of HIV knowledge that may require further input given low scores at the post-Camp point.

**Recommendation 2: Ensure that those areas of HIV knowledge with continuing low post-Camp rates of correct scores are covered comprehensively.**

The positive change in HIV communication beliefs was not mirrored by changes in the intention to communicate. Levels of communication about HIV with people outside of one's care team, was low. Changes in communication levels and beliefs may be more resistant to change than other areas, as they are to some extent dependent on the perceived beliefs and behaviour of others (e.g., families).
Recommendation 3: Consider how Camp activities can be communicated with families such that HIV communication with Camp attendees can be facilitated.

Self-report measures did not show change in pro-Art adherence cognitions and affect. The lack of a significant adherence effect may have been due to a ceiling effect. Alternatively, some aspects of medication use may not have been covered in sufficient depth, as suggested by some Camp attendees.

Recommendation 4: Provide more time to cover medication issues

Camp attendee interviews reported frequent post-Camp communication between Camp attendees. This contact, if maintained, has the potential to decrease isolation, increase practical and emotional social support and enhance wellbeing. There were, however, some concerns that communication could reduce over time.

Recommendation 5: Camp attendees could benefit from the promotion of existing or new online spaces specifically for them (e.g., private Facebook groups).

The sexual health workshop was well received but there was evidence that Camp attendees would like these to be more closely tailored to their individual needs.

Recommendation 6: Consider splitting the sexual health workshop into three age groups rather than two and adapting the material accordingly

There were minimal changes in HIV stigma, although our measure did not include items on internalized stigma (beliefs about oneself as an HIV-positive person). Future research should work to create an appropriate HIV stigma scale that covers this aspect. There was also no evidence of an increase in quality of life, perhaps to be expected in sample that reported generally good quality of life and with such a brief intervention.

Regarding the experience of Camp, there were repeated Camp attendee suggestions to increase the duration of Camp to maximize its benefits.
Recommendation 7: Consideration should be given for extending the duration of Camp

Extending the duration of Camp may allow for more of a balance between activities and free time. The latter was also a common request from Camp attendees.

Recommendation 8: Allow more free time in the evenings for Camp attendees

Finally, there were some Camp attendees who reported not being fully prepared for Camp prior to arrival (e.g., not knowing whom Camp was for or what to expect).

Recommendation 9: Consider a range of ways that Camp attendees can be provided with more information about Camp prior to their arrival

Evaluation Strengths and Limitations

This evaluation used or will use mixed methods and repeated objective measures with multiple informants. The response rate was good and representative sampling methods were used as much as possible. The most significant limitation is the lack of a control group. Additionally, there was a need to develop new measures (in the absence of appropriate alternative measures) in a short period of time, restricting the possibility for extensive piloting. Statistical methods to assess the reliability and validity of measures (not reported here) have been carried out.

Next phase of the evaluation

The next phase of the evaluation will involve follow-up questionnaires for Camp attendees six months after the end of camp (February 2016). We will also conduct interviews with the 11 Camp attendees previously interviewed. These Camp attendees have already given consent for us to interview their parents. We will be conducting ten interviews with parents or carers of young people who attended Camp as well as ten interviews with clinicians involved in the medical care of Camp attendees. Finally, clinic data will be sought for the year prior to and the year after Camp to assess any changes in clinic attendance, CD4 count and viral load.
Acknowledgements

Freedom 2 Be was funded by The Monument Trust, MAC Aids Fund, The Albert Trust, Viiv Healthcare, Elton John AIDS Foundation and Children in Need. Viiv Healthcare also separately funded the evaluation of the Camp. Special thanks to the CHIVA staff for facilitating this intervention and Rosie McGuire for her work during the early stages of the evaluation planning.

References


