

Positive Voices project: Mid-term evaluation report

Independent researcher: Emer Brangan, Population Health Sciences, Bristol Medical School,
University of Bristol Emer.brangan@bristol.ac.uk

Brigstowe lead: Lauren Tittle, Positive Voices manager

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1. Executive summary: Main findings and recommendations

This evaluation presents the mid-way findings of Brigstowe's Positive Voices project. The project was set up to provide the following three services commencing in July 2016:-

One-to-one Peer Support - a new and unique local service providing peer support for people who are recently diagnosed or struggling to come to terms with their diagnosis.

Recently Diagnosed Workshops: a series of workshops to bring together newly diagnosed individuals providing information to promote wellbeing and acceptance of their diagnosis.

HIV Awareness Training: training sessions delivered to professionals covering how HIV is transmitted, prevented and managed through medication. The training also covers the stigma and discrimination that still exists and the impact this can have on people living with HIV.

The evaluation was undertaken by an Independent Researcher and then reviewed by the Positive Voices Manager, and Brigstowe's CEO, as well as people living with HIV (PLWHIV). Evidence gathered included both quantitative and qualitative data.

The project's key findings

- The social support from a peer is a very powerful form of support, breaking down barriers of stigma, and assisting PLWHIV to manage their diagnosis
- The involvement of PLWHIV has an invaluable impact for the Positive Voices services, and Brigstowe as an organisation

The following recommendations are made for future improvements

- Continue to consult on service design and delivery with PLWHIV, and maintain constant dialogue on equitable inclusion of PLWHIV
- Improve engagement with under-represented groups, particularly in terms of recruiting more diverse volunteer mentors in terms of sexuality, gender and ethnicity
- Ensure areas such as confidentiality, maintaining boundaries, and preparation for ending the mentoring relationship are focused on during the peer mentor core training, and highlighted throughout supervision to ensure a safe mentoring relationship is maintained promoting independence of the mentee and to ease potential difficulties of the ending of a mentoring relationship.
- Ensure there is space for mentors and mentees to reflect on challenges of mentoring, and any issues which mentoring may not be able to resolve, and how these could be addressed
- Consider developing a follow up for mentees who have completed the mentoring relationship i.e. ad hoc mentoring when needed/peer support group
- Review Recently Diagnosed Workshop's content with PLWHIV
- Consider delivering HIV Awareness training to community groups - not just professionals.

2. Background and aims

Brigstowe's Positive Voices services, which started in July 2016, is now mid-way through its five-year funding grant from the Big Lottery (Reaching Communities). The Positive Voices project is a service for people living with HIV, by and with people living with HIV, and includes the following three services:

- **Peer Support** - one to one peer support for people either newly diagnosed or struggling with their diagnosis.
- **Recently Diagnosed Workshops** – a series of interactive information sessions providing information & addressing the needs of people recently diagnosed. Sessions are led by both people living with HIV & professionals.
- **HIV Awareness Training** – Training sessions delivered to professionals and community groups to increase knowledge around HIV, combat stigma and ignorance & thereby improve the lives of people living with HIV.

The intended outcomes of the Positive Voices project were defined as follows:

Outcome 1	The emotional and mental wellbeing for individuals living with HIV will be improved.
Outcome 2	Social inclusion for individuals living with HIV will be improved.
Outcome 3	People living with HIV will be abler to manage their diagnosis as a long term condition.
Outcome 4	Social cohesion will be improved by increasing professional's HIV expertise, and reducing stigma within community organisations.

As part of the project funding proposal, Brigstowe undertook to evaluate the project at the mid-way point, however the funder set no formal requirements for the format of the evaluation. With the above intended outcomes as a backdrop, the following objectives for the mid-term evaluation were proposed by Brigstowe:

- Monitor the project's impact on clients, volunteers, Brigstowe as an organisation, as well partner organizations.
- Gather learning for project improvement & produce recommendations
- Investigate the challenges & successes of the project so far
- Outline unexpected learning
- Explore what needs to be developed to make the service more sustainable in the future

3. Methods

3.1 Data sources

Brigstowe carry out a yearly self-assessment of the delivery of Positive Voices project activities against targets, and budget/resource aspects as part of their annual reporting to the Big Lottery. Alongside this, the researcher used a range of sources of data to explore the perspectives and experiences of the people who have been involved in, or affected by, the project. The remainder of this section describes the methods for this latter part of the work.

Feedback forms

Brigstowe has used feedback forms to collect self-reported outcomes in nine domains (see results for details) from mentees and participants in recently diagnosed workshops. Data from these forms includes participants' responses on a five-point scale (from 'Very Good' to 'Very Poor') to a range of questions, as well as free text responses to additional questions (form available as a separate document). Brigstowe anonymised all feedback form data before sharing it with the researcher.

Interviews

Semi-structured qualitative interviews were used to explore in depth people's perspectives on, and experiences of, the Positive Voices project. Alongside the views of those using Positive Voices services, we sought to include views of those delivering/supporting/organising/referring to/otherwise interacting with the services. We sought to include participants with a range of demographic characteristics (e.g. ethnicity, gender identity, length of time since diagnosis).

Interviews were carried out by the independent researcher, either by telephone or face to face, according to the participant's preference, and at a mutually convenient time/location. With participants' consent, interviews were audio recorded (using a password-protected encrypted voice recorder) to provide a full record for later analysis.

The interviews used a topic guide to ensure topics identified in advance as being of interest to the evaluation were addressed, but interviews also allowed participants to introduce additional topics which they identified as relevant. Topic guides are flexible documents – they are not followed rigidly, but used as prompts/reminders during interviews. Topic guides also evolve as data collection progresses – for example adding questions on additional topics which have been identified via earlier interviews / analysis.

Interview recruitment and sampling

Information about the evaluation, and an invitation to participate in an interview, was provided to potential participants by Brigstowe. Potential participants had the opportunity to contact Brigstowe and/or researcher to discuss the invitation. Those who decided to take part in an interview could choose to contact the researcher directly to make arrangements, or if they preferred, gave Brigstowe permission to pass their contact details to the researcher to follow up. No contact details / identifiable personal information was shared with the researcher without explicit consent, and the researcher did not disclose to Brigstowe which invitees went on to participate in the evaluation. At the time of the interview, a consent agreement was completed by the researcher and the participant. (The interview information sheet and consent agreement are available as separate documents).

Sampling for interviews was primarily purposive – with the objective of including people with a range of experiences and perspectives on the services. However, in order to ensure participation was inclusive / relevant views were not excluded, open invitations were also issued where appropriate distribution methods existed – for example relevant mailing lists and the Brigstowe newsletter.

Confidentiality and attribution of quotes

Usual practice is for quotes from participants to be reported using a unique code or pseudonym for that participant, along with an indication of the participant's role. This is intended to help the reader to understand where the speaker is 'coming from', while also allowing them to assess whether a

range of views have been represented. Several participants in this evaluation had multiple roles - for example being involved in more than one service, or involvement from more than one perspective e.g. as both a service user and volunteer. To avoid increasing the risk of identifying any person with a combination of roles, unique codes have not been used in this report. Quotes are attributed by giving the relevant role description for the context (e.g. 'Mentor' when a participant is speaking about their experience of mentoring). A letter code is then used to distinguish different speakers within each role at points where this may be helpful (e.g. Mentor A, Mentor B etc.).

3.2 Analysis

Self-reported outcome data (ordinal scale responses in feedback forms)

Self-reported outcomes are collated by Brigstowe for annual reporting. Results for the first two years of the project are included below. These figures come from calculating the percentage of people who reported a positive change on the five-point scale (from 'very poor' to 'very good') for each domain. Eight of the domains reported were assessed using a single question each. In the case of the domain 'engaging in medical treatment', there were three questions: Adherence to medication, Attendance at medical appointments, and Ability/confidence to discuss health with health professionals. We have collated these by counting an overall positive change for those participants who reported a positive change in response to at least two of these three questions.

While these outcomes are collected before and after accessing the services, many other factors may also be influencing these domains, particularly over the longer time period of the mentoring service. Thus, while we believe that the services have been influential in the positive changes reported (and the data reported in the qualitative analysis strongly supports this view), we cannot attribute these changes to the services alone.

Qualitative data (Interviews and free text responses in feedback forms)

An individual summary for each interview was produced working from the audio recordings, with key sections of the interview transcribed verbatim (word for word) and included in these summaries.

The interview summaries, as well as the free-text data from the feedback forms, were analysed using a method called thematic analysis (Braun & Clarke, 2006). To assist with this process, the data were imported into QSR NVivo 11 – a software package which can be used to assist with organising and 'coding' data (a systematic method of applying labels to segments of data).

Analysis was both 'deductive' (looking systematically at the data to find material relevant to specific questions / themes identified in advance as being of interest e.g. the intended outcomes of the Positive Voices project), and 'inductive' (building upwards from the data e.g. by looking systematically across the data, it may be possible to develop themes of relevance / importance which were not identified in advance).

Authorship of findings

Brigstowe provided the descriptions of the services which begin each of the relevant sections, the description of the Positive Voices Coordinator's role, and the 'Shared learning' summary, and also provided the summaries of self-reported outcome data from feedback forms. Qualitative data was analysed and written up independently by the researcher. The executive summary and recommendations sections were produced collaboratively by Brigstowe and the researcher.

4. Results

4.1 Introduction

Self-reported outcome data

Feedback from self-reported outcomes data was available for 44 mentees and 23 participants in recently diagnosed workshops during the first two years of the project.

- 89% reported an increase in confidence and self-esteem
- 78% reported an increase in sense of purpose in life.
- 89% reported an improvement in their mood.
- 67% reported better knowledge of available services and confidence to access if required.
- 78% reported more close supportive relationships (reduction in isolation).
- 80% reported feeling more integrated and contributing to their local community.
- 47% reported an increase in confidence around disclosure decisions.
- 57% reported an increase in engaging with medical treatment
- 82% reported an increase in understanding and knowledge of HIV and related issues.

Feedback forms thus indicated that least progress was being reported for 'increase in engaging medical treatment' sense of purpose in life', and 'confidence around disclosure decisions. Brigstowe will continue to work with PLWHIV to identify ways in which the Positive Voices services can support these domains.

Feedback form outcome data was available for 343 HIV awareness training participants from the first two years of the project:

- 93% have reported a positive change in attitude on issues around HIV
- 86% report an increase in knowledge and understanding on HIV issues.

Qualitative data

Fifteen qualitative interviews were conducted with a range of stakeholders in the Positive Voices project - including people who had used the services (peer mentoring, recently diagnosed workshops, HIV awareness training), been involved as volunteers or staff, or as members of partner organisations. Some participants had multiple roles – for example having been involved in more than one service, as a service user and/or volunteer. Interviews were conducted face to face (8) or by telephone (7) between September 2018 and January 2019, and had an average duration of 43 minutes (range 14 to 75 minutes). Six participants were female, and nine participants were living with HIV. In the interests of confidentiality, further details of interviewees are not included here.

Results are organised below under six main headings, beginning with a brief section to provide some context for the services. The next three sections present results relating specifically to each of the three Positive Voices project services – 'Peer mentoring', 'Recently diagnosed workshops', and 'HIV awareness training'. Finally, there are two sections dealing with cross-cutting themes – 'The Positive Voices project: Making it work' and 'Positive people at the centre of HIV services'.

4.2 Putting the Positive Voices services in context

The idea of peer support, which is at the heart of the Positive Voices project, came from people living with HIV. While not taken up when first put forward, it was an idea which would not go away. Over the last five years, with the support of Positively UK and the Big Lottery (Reaching Communities), Brigstowe has been in a position to bring these long-desired services into being. They continue to develop and evolve.

Participants in this evaluation noted the availability of high standards of clinical care in Bristol, but emphasised the importance of other support alongside this:

“When you’re... diagnosed, you’ve got all of these clinicians who are being – they’re brilliant in their job. But at the same time they’re not getting what you’re going through really.” (Person living with HIV)

“It’s not as simple as somebody just taking a pill, or two or three pills, every day. There’s a lot of psychological stuff that goes along with that” (Person working in HIV sector)

“The place I was in – it was pretty dark.” (Person living with HIV)

“An HIV diagnosis is so alienating ...you literally think like you’ve got HIV tattooed on your forehead. And it taps into so many things. Like into your sex life, your self-esteem, your future, what other people think about you, living well - there’s so many things” (Person working in HIV sector)

“It’s different how we react, but the background is the same – it’s the same reason...You just feel powerless....and that’s how you react – you don’t want to talk. You shut down, you keep quiet.” (Peer support volunteer)

Participants had however observed a widespread loss of funding and services across the HIV sector, with the improvements in pharmaceutical treatment sometimes used to justify cuts. The sections below describe participants’ views and experiences of how Positive Voices services have been operating in this environment, along with their ideas for the future.

4.3 Positive voices services: Peer mentoring

The peer mentor service enables people who are either recently diagnosed or diagnosed for longer & struggling with an aspect of their diagnosis to meet with a trained volunteer mentor who is also living with HIV. The mentor & mentee meet with each other once a week in the community to share experiences, give advice, goal set together as well as to provide information based around the mentees' diagnosis. The mentoring relationship is time limited to promote independence so a mentoring relationship can last up to a maximum of 6 months.

For the first 2 years of the project Brigstowe has trained 22 people, with 19 going on to become volunteer mentors in the Positive Voices Project; 44 people have accessed the service as mentees.

Overall impact of mentoring

Participants involved in the peer support service – mentees, mentors, and staff – were unanimous in reporting the profound positive impacts of mentoring. Some challenges were discussed and potential changes or improvements were suggested - these are addressed in the sections which follow.

Mentees spoke both of what they had learned, and how mentoring had changed them. Learning ranged from increased understanding of the virus and treatment, to discovering the possibility of a life lived well as a positive person. Mentees spoke of having accepted themselves and their diagnosis, and regained their confidence, as a result of mentoring:

"He helped me to sort of accept myself, and accept it more." (Mentee G)

"...after I started meeting her things changed. I became so confident. We talked so many things in life, and she taught me other things that I didn't even know about HIV....I've kept up going out. Before I couldn't just go in a café and sit down and have a cup of tea or – I love my latte. But now I can go. I still go to that same café and sit down and have my latte and then go back home. And I still try to be so healthy, because she's taught me so many things as well – being positive, that I'm not the only one who is positive. Yeah, she taught me a lot." (Mentee H)

"I got involved with that programme as a mentee. Which was, well fantastic – it was the start to everything that then happened after that... we finished early because we both agreed that there wasn't much more to be done. I'd regained confidence and – my mentor was lovely...[Positive Voices services] were pretty spot on. It was above and beyond anything that I expected" (Mentee J)

"I think it made a massive difference to me....and I'm quite lucky because I've got a really good support structure in terms of friendships, I've got friends that I can tell and there would be no issue. And it was still really helpful to me. So imagine somebody who is really going through a crisis and doesn't have that support – it must be really important to them" (Mentee I)

"...after the mentoring I changed like 200%.....I started recognising myself as being enough, as who I am. Like I feel whole, like complete...it was really really an unbelievable experience that I had....I didn't believe that this could help. It was incredible..... You click ...so there's no way to turn back....after that I am never questioning myself like 'oh my god I'm never going to find a boyfriend' or 'if I challenge my friend'. After that... I really don't care. I know exactly how it works. I have inside information about myself, about HIV, about people living with HIV. I can raise some flags, when I have to raise some flags. This was - because of Brigstowe, there was this project, to help me" (Mentee F)

Mentees, as well as participants who were staff at Brigstowe or partner organisations, said that the mentoring had been a building block which supported how they were able to engage in other areas of their lives. People described being more able to engage with other support services, including clinical care, and being ready to return to voluntary or paid work.

"We have a patient who we've had for years, who was always really worried about confidentiality, wasn't really engaged in anything. And we'd often offer referrals to different services. The peer mentor was there that day, and my colleague introduced them. And then, I think the next appointment ..the patient turned up and said it was the best thing that could ever have happened, and they've now got involved in services and much more – and happier. So that's just one example of the impact that having that kind of service has had." (HIV Specialist clinician)

One mentee described how having mentoring had reduced the strain placed on his other sources of support – in particular his partner:

"I've got a partner who isn't positive, and I was really aware that I didn't want to put all my issues – it would strain our relationship if I didn't sort of seek help elsewhere as well. He had a lot going on with my diagnosis as well." (Mentee I)

Comments in written feedback forms reflected similar themes of increased understanding, acceptance, and confidence; with several forms mentioning how mentees had been able to strengthen other relationships, apply for jobs, and engage with other services as a result.

Mentors also reported very positive experiences of volunteering in this role, finding it therapeutic for themselves, and extremely rewarding to be able to help another person through a difficult time in their life:

"It's the most satisfying experience I have had since I've been positive. It's absolutely wonderful..... It's given me more confidence, much more confidence. It's therapeutic for me as well. And what I find quite refreshing, is having an arena to talk about those things – supervision.....It's enabled me to understand, that what I was feeling, throughout the years, is not unique to me. That was really important. And that there are ways around it, and that I can help people get around it – if they want help, that is." (Mentor A)

"It's that thing of stopping somebody going through that horrible place that you were in. That you can actually do something to help a person not go through quite such a mucky time of it as you did...It's really nice to see people move on...in the six months you see them - change and develop and move on" (Mentor B)

"It's continued to help my self-knowledge and growth, and professionalism. And it's continued to address issues that I've still got....So during this whole process.... I have really come to terms with lots and lots of those key issues. Gradually. I mean you can do the course and tick it all off, but to actually assimilate and feel those changes and those viewpoints – that you know are right, but you just don't feel it just yet. But I do, I'm getting there. So it's continually helping, actually, being involved. For everyone – I've heard other mentors say that, so I'm not the only one." (Mentor C)

"You're in somebody's life for a little snapshot – six months....but that time stays with them. And the transformation of some of the mentees is quite miraculous.....I think I get as much out of it as the mentees do – it's incredibly rewarding" (Mentor D)

Mentoring was not a panacea – comments from both mentors and mentees recognised that some mentoring relationships did not work, and that there were some issues which had not been resolvable even within mentoring relationships which did work very well:

“The mentoring has changed me in so many other things but in that one - I haven’t gone anywhere to cook for anybody. I live on my own, I just stay at home.” (Mentee H)

“People want to please, as well. They want to come through their three months with you and say ‘yes, you’ve done a good job.’ I’d prefer it if they said ‘It didn’t work for me’. That would be really valuable.....I don’t think it’s a three month thing and then you leave. It’s a progression. It’s a start, mentoring. So I don’t see success coming right at the start” (Mentor A)

Matching and mentor identity

The process of matching a mentee to a mentor was the responsibility of a designated member of Brigstowe staff, and was described as requiring good knowledge of both mentors and mentees. For mentors this included knowledge of their personalities, life experiences, and interests, as well as demographic characteristics. As part of the recruitment process all mentors were asked about willingness to mentor different types of people, and Brigstowe staff reported that thus far there had been no instances of an available mentor declining a mentee.

For mentees, the Brigstowe staff member might have some existing knowledge of the individual – for example through any previous interactions with Brigstowe, but for all mentees the process included a purposeful hour and a half assessment. Mentees were asked about their preferences regarding different potential mentor characteristics or experience, and to rate the importance of different factors to them:

“And ask them ‘is it important to meet with somebody who is a listener or a talker? Does it matter if you talk to a woman or’ – ask those kinds of questions....and then they think it’s like Tinder [laughs] – it’s definitely not Tinder!” (Brigstowe staff member)

The Brigstowe staff member responsible for matching drew on this knowledge of those involved – taking into account timing (e.g. availability of potential mentors), alongside shared experiences (e.g. disclosing to children), hobbies/interests, and demographics (e.g. gender, sexuality, age). For demographics the objective was not necessarily for these to be similar, but for the fit to be best for that mentee. For example, some mentees expressed a preference for a mentor of a similar age or cultural background, whereas others specifically requested a mentor with different demographic characteristics to themselves:

“We talked through the type of person I’d want. So I wanted someone a similar age to me, I wanted another gay man because I wanted it to be someone who I could relate to.” (Mentee I)

“If it was someone my age, I don’t think it was going to work for me. Because I’m [age] but I have a really old soul. I’m not like the usual [age] guy, that in their 20s was partying.” (Mentee F)

However ‘personality’ was central to the match:

“Ultimately it comes down to personality. It has to. So, I know the mentors really well, I know their personalities. The mentees – I have an hour and a half assessment. I just try, as much as I can.” (Brigstowe staff member)

“We got on really well actually. Really well...There’s a lot of things in common... Politics and things like that where we had a pretty similar frame of mind. Which was really good.” (Mentee G)

The Brigstowe staff member carrying out the matching process at the time all of the matches for participants in this evaluation were made, had built up this knowledge of mentors over time through extensive engagement with them as individuals, and intimate involvement in training and ongoing support and supervision. The personal skill of the Brigstowe staff member who had been responsible for matching participants in this evaluation in carrying out this task was rated highly:

"We're very very carefully matched by a very very skilful person." (Mentor D)

"She's got lots of un-obvious skills.... I think the key thing that she does is match up a mentor with a potential mentee....and that's really key, so key. And in order to do that job well you need to know all of the mentors super well. Not just that they've all been trained to a certain standard but...what type of people they are, what kind of personality they've got. What kind of person would be great to relate to them, and for them to use their strengths to the best of their ability...So that is one way that [manager] looks after us, if you like, and makes it successful. They're not all successful, but the percentages are very high." (Mentor C)

"To be honest, I think some of that is either you can do or you can't. I think you've got to be quite a shrewd person to identify certain aspects, and you've got to know your base [of mentors] well." (Mentor B)

Mentees also described very positive experiences of the outcome of the matching process:

"Definitely the right decision. It was the perfect person to pair. I felt like a lot of thought went into it, which was really nice, and quite important actually." (Mentee I)

"It was brilliant the way she did it...she said 'there is this person that I think is going to match with you' and then she put us together....And then to have a male figure, to me at that time he was kind of a Dad to me. Like a father that I never had. And the fact that I was talking with a man, that I always have problems with straight guys – manly guys. He's gay, but he was older, with his own life. There is all this life experience, his background....someone my age won't bring me all the weight that I need to – in order to grow." (Mentee F)

Not all mentoring matches proved successful, and Brigstowe relied on mentors to alert them to any indications of problems:

"Sometimes personalities just don't fit and I get it all wrong. Doesn't happen often....I have always said to the mentor – and I think we have quite an open dialogue – that they can come to me if they think it just isn't going to work – and that has happened, and that's great, and that's fine....Quite often the mentee will be feeling the same but they won't have said anything, because they're the service user" (Brigstowe staff member)

If a mentoring match did not seem to be working, Brigstowe offered further/alternative support to the mentee if appropriate. For example, one match had been made which Brigstowe staff knew might not be a good fit, but the mentee involved wished to access the service as soon as possible, thus potential mentors were limited by who was available quickly. The mentee subsequently began to disengage from the service, suggesting that they no longer wished to use it. However when Brigstowe offered an alternative mentor – the one who had been identified initially as the best match, but who had not been available at that time, and who the mentee had already met in a different capacity - the mentee responded very positively.

Mentors reported having been matched successfully with different types of people, and those who had experience of a less successful match had found this acceptable/manageable .

At the time of the evaluation work, was under way at Brigstowe to train another member of staff to be able to carry out matching. Brigstowe staff noted that the introduction of the senior mentors' role (see below) had an unintended consequence in that senior mentors had taken over much of the daily interaction with mentors from Brigstowe staff. This left Brigstowe staff with less opportunity to get to know mentors well, and less visibility of what was going on in their lives. Another limitation on matching was that, while participants reported diversity amongst the mentors who were available, there were limitations based on the demographics of the people who put themselves forward. Some mentors noted that this was not always representative of the range of people living with HIV:

"In terms of demographics, it would be great if there were more women obviously – just because it's more balanced.....there's also a really growing population, or of infection, with older heterosexuals as well, which is an interesting demographic, because we don't have any straight – heterosexual – men on the team. So that's not that representative. But you kind of get what you've got. That's not to say that you can't mentor a straight white woman if you're a gay black man....It would be nice if we had a choice – we would bolster the numbers of women and heterosexual men. But of course because of the stigma, they're much less likely to even be on the horizon." (Mentor C)

Beginning mentoring

Participants who were mentees generally reported having found it straightforward to make the decision to accept the mentoring service when it was offered to them by Brigstowe.

"It was a bit of a 'Oh, OK then' moment, because I never knew that existed. And I thought well it'd be great to actually talk to somebody in the same position, cos there's only I think, two people who know that I am in my private life. And it would be nice to have someone else to talk to that actually had it. So that - people who were understanding if you know what I mean." (Mentee G)

One participant had been initially uncertain, but after talking the idea over with people he was close to, decided it was the right thing to do:

"I was hesitant about the whole sort of 'meet up with a random person and talk about stuff'. I find that a bit – especially talking about something so personal. So my natural inclination is to back away from that." (Mentee I)

Participants described having been introduced to their potential mentor at a meeting at the Brigstowe offices which also included a Brigstowe staff facilitator. After introductions had been made, the mentor and mentee were left on their own together to begin getting to know each other. A number of participants described the experience of this first meeting between mentor and mentee as "a bit awkward", and one feedback comment suggested that Brigstowe consider offering some conversational prompts to help people get started.

This meeting was intended to offer the mentee an opportunity to decide if they wished to proceed with this mentor. One mentee had thought that this was a two-way process – that the mentor would also be deciding whether to accept or 'reject' the potential mentee. His self esteem was low at the time, so he saw this as being a possible outcome for himself, and also thought that it would have been damaging for him at that time:

"All that was a bit worrying, just in case.....if you say yes, the other person says no....When you're diagnosed and you're, like I was, pretty isolated... and to be told that 'oh no, he doesn't want to

be with you' – if you are isolated it can make it worse....If they could find a gentler way in"
(Mentee G)

Other mentees described having understood that the decision about whether to proceed with mentoring, and whether to do that with a particular mentor, as being in their own hands:

"[Brigstowe staff member] will let you decide. She will just tell you: 'it has worked for some people, I don't know whether it will work for you, but if you want to give it a go you can give it a go. And any time if you want to stop, you can stop. If you don't like that person I can give you another one'." (Mentee H)

Two participants who were mentees mentioned that after having agreed to proceed, they had initially cancelled some planned meetings with their mentor. Reasons included finding it difficult to leave the house because of depression or anxiety, or not wanting to "open up" to someone. Both reported that their mentor had responded compassionately:

"She's very good, she's a lovely person, she knows – I think that, that's her role - she knows what she's doing all the time.....She made it easy for me, and I started doing it....it just became easy."
(Mentee H)

Process of mentoring

There was a lot of overlap in how participants described the process of mentoring, however there were also variations. Meeting weekly for coffee at a time and place which worked for both of them was a common part of the process, with some mentees also mentioning contact by text.

"It was so lovely. It was more than I thought it would be. Because I thought maybe we just go there, it would be a questionnaire, or – but no, it was just a friendly conversation. She would listen." (Mentee H)

One mentee mentioned combining talking about health with going for a walk/counting their steps. Another mentee described the meetings as having initially involved talking a lot, and later bringing in more structured activities – each writing down funny things about their diagnosis which they wouldn't say to anyone else; drawing pictures expressing how they felt about their diagnosis; and putting their HIV journey down on paper:

"...to get you really thinking about things....It gave us a talking point to carry on the discussion."
(Mentee I)

In another mentoring partnership, a mentee described a more biographical progression, with early sessions having focused on his childhood and problems in his past, and then moved on to the time when he was living with HIV and the problems he was experiencing in relation to this:

"The fact that I was just expressing, the way that I had never been able to express to anyone else. Being very clear about what's going on – 'these are my difficulties, and I don't think that I'm going to be happy or - ' And actually, having someone who has the same thing as me, and him telling me 'this is going to finish...It's just a moment.'" (Mentee F)

Yet another mentee described having regular progress discussions with her mentor regarding milestones they had agreed to aim for. This process had begun right at the start of her mentoring when she had filled in an assessment form which included a section on why she was there and what she wanted from the service. She recalled that at that time she had put:

"Something along the lines of 'I don't know, but I know I need something'" (Mentee J)

Mentors discussed tailoring their approach to the individual mentee, and the importance of mentees being “*in the right place*” to begin mentoring, as mentoring had to be mentee-led. Mentors described strategies for breaking the ice with a new mentee, and choosing locations for early meetings to provide contextual subjects to keep the conversation going if necessary, while maintaining sufficient privacy:

“It’s a busy café, nobody can overhear you. And if the conversation dries up you can always talk about the boats, the river, the trees. So there’s always like a fall back to keep the conversation going – it can be very difficult” (Mentor D)

This mentor gave a detailed description of their approach to meeting their mentee:

“I don’t sort of take notes or anything else like that, I store everything in my head. As soon as I jump in the car and I’m on my way to meet a mentee, that is when I start planning or thinking about the things that I want to talk about, discuss, see how they’ve got on if any goals have been set the previous week. And then the mentoring can go on for usually a minimum of an hour, can be an hour and a half, sometimes two hours. I never ever put a time limit on it, I don’t think that’s right. You never know – somebody may be sort of keeping something – not keeping it back but.....After the meeting I then jump back in the car and sort of go over the meeting, things that I think I may or may not need to mention the next time.” (Mentor D)

Ending mentoring

Five mentees spoke about their experience of mentoring coming to an end. Three of these had found the process manageable for themselves, and linked this to the progress they had made during mentoring, and to having access to a wider support network. Two of these mentees had finished their mentoring before reaching the six-month point.

“I knew it was coming. I didn’t want to stop seeing her because she was so nice, but at the same time I didn’t want to hold her away from other people.....Someone who felt that they weren’t ready, or it was quite abrupt finishing, I can definitely see it being a struggle. For me it wasn’t because I was already seeing other groups of people, I was getting involved.” (Mentee J)

One mentee described the timing as having been based on the progress which his mentor could see they had made:

“He was like ‘OK, you are totally fine, you can go’” (Mentee F)

Another mentee described strategies which had been used to support the transition:

“We mutually decided it would be better to have them more spaced out, so the last two months we met up every other week...Because we knew it was coming to an end, so time of not seeing each other. And I think if you did it every week still it would be quite a shock – so to space it out meant it was a bit more of a slow decline rather than a sudden -” (Mentee I)

Afterwards he thought this had been the right thing to do, but it still felt “*weird*” when it stopped. They had discussed what they wanted to happen after the mentoring ended – they agreed to have a break of a few months when they were not in contact, and set a date when they could get back in touch if wanted to. He had been his mentor’s first mentee:

“We both said that it would be really strange to go through all that and then not be in contact again, so it was nice that there was a point in time when...” (Mentee I)

This mentee also thought that the end of mentoring could potentially be difficult for someone who did not have the wider support network he himself had. He had remained in contact with someone who had attended the same recently diagnosed workshop as him, and whose mentoring had now also come to an end:

"I'm someone he gets in contact with, and I don't think there is anyone really else that he talks to. And I'm fine with that, but it's just an example - he suddenly feels quite isolated I think, having had this really close stuff" (Mentee I)

Two other mentees described how they had found the end of mentoring very difficult. Both linked this to not having any other comparable sources of support. One mentee's experience had been exacerbated because support from a different organisation had ended at the same time as the mentoring.

"Basically, all my support that I had, stopped, at that point.....and I did feel quite cut off" (Mentee G)

For this mentee the end of mentoring had come as a shock – he knew at the start how many months were planned, but had not realised how much time had passed. He did not recall the subject having been discussed until very close to the end. He acknowledged that it may have been, but he might not have taken this in, because *"I had other things going on at the time."*

"I remember being shocked....he might have said next week's our last meeting. It come round so quickly, and we got on so well, when it did happen it was a bit of a shock....Maybe the wrapping up of it could be better" (Mentee G)

Another mentee described how her mentor had moved them towards the end:

"Towards the end, she was informing me, to prepare me – 'now we're towards the end, what else can we talk about; what else do you feel that I can do; what more do you want us to look at; what more do you want to know before the end?' She was so brilliant." (Mentee H)

The end was still hard, but she had managed to maintain the progress she had made during mentoring:

"I didn't want it to end. I was like 'I have a friend, that I can talk to', so. But it had to endIt has been OK. Even if I haven't found someone that I can have coffee with. But I can do my own things. I normally now come out most of the time" (Mentee H)

Both of these mentees brought up 'rules' about not contacting their mentors afterwards. They acknowledged that mentoring was intended as a professional relationship, and that it could be problematic if mentees were *"too clingy"*, but they still experienced these 'rules' as harsh:

"The ruling is that you cannot contact your mentor afterwards. And I found that difficult. Cos I mean, we got on really well. We could have been friends. But because you're not allowed to contact somebody after – it's difficult. And I can understand that there can be some people who are a bit too clingy, and don't want to let go of their mentor. I can appreciate that. But, it was, it's a bit like my life line's been cut, and I think I went downhill quite a bit." (Mentee G)

"I would want more time. I would want more – because that time, it was professional, strictly professional. But - you can't change that – she has to be professional. But sometimes I feel – she was like my friend. A friendship for six months, we are meeting every week. Then all of a sudden that friendship is cut." (Mentee H)

This view also came up in written feedback:

“Maybe not set up a time period and allow it develop further as friends or not depending on how both feel. I now only have Brigstowe staff to talk to.” (Mentee feedback form comment)

Participants who were mentors did not report personally having found the end of mentoring relationships difficult, but one mentor said the issue had come up in group meetings where mentors sometimes expressed worry about how their mentee would cope. He said that mentoring training included preparing the mentors for maintaining appropriate boundaries, and strategies for bringing mentoring to an end e.g. discussing the expected duration of mentoring; preparation over the last half to a third of the time; checking with the mentee about how it was going - whether the issues originally identified had been covered, and whether anything else had come up which needed to be addressed. The mentor acknowledged the tensions inherent in the mentoring relationship as both ‘friendship’ and ‘professional’:

“It’s a difficult one. During the mentoring you form a close friendship or whatever. But it’s not a ‘friendship’ friendship, you’re not there to make friends. You’re there to support and steer them in the right direction. You get some mentees who get it but don’t quite get it And you say ‘well it doesn’t really work like that’ and have to be sort of quite firm, and confirming that it isn’t like that.” (Mentor D)

He was concerned that if mentors and mentees did remain in contact once formal mentoring ended, it was possible that a mentor could find themselves becoming overloaded:

“The chances are that if you were to continue a friendship, it would still be a form of mentoring...we’re trained well enough to spot that and avoid it and not get snowed under with it really.” (Mentor D)

He noted that if mentors and mentees agreed that they wanted to stay in touch, it was considered appropriate to pause contact for a few months and then “drop a text” if this was still what they wanted. He thought that having had that break, people had usually moved on.

Follow up support?

Three mentees made suggestions of follow up support which could be helpful in some cases once mentoring ended. While they appreciated the other social and involvement opportunities offered by Brigstowe, they were clear that these did not meet the same needs.

“See the mentoring is different – it’s the group that is feeling most low about their HIV....if it is in one pot with someone.... stronger than you....” (Mentee H)

“From a personal point of view, once that socialisation thing had gone, there was nothing there for me. The events they do are great but they’re few and far between.” (Mentee G)

Some participants also stated that some social activities took place during the day meaning it could be difficult to attend, or noted that getting involved in campaigning did not suit everyone. They also understood that resources – including people’s time – were limited.

Two distinct potential types of follow up support were suggested. The first of these was for there to be some sort of lower frequency meeting available for people who had completed mentoring. Participants thought that a group format could work for this – for example if a particular individual’s mentor was not available to be involved in continued support, they might find others in the group with whom they could create a support network.

"It can't go on forever, but it might have been good if there was something - monthly or three-monthly get togethers or something" (Mentee G)

"Maybe once a month. It would be like a treat. We meet up as a group of those who have taken part. Just do one activity, we sit down and look back, and see the way forward. We help one another in it as well. Because I think, if we don't do that you can go back again." (Mentee H)

The other suggestion was for there to be the possibility of 'one off' mentoring meetings at a later stage – not necessarily with the same mentor. It was acknowledged that this might be a difficult model to manage. It was seen as potentially useful if a different issue came up for someone at a later stage of their diagnosis, or if they needed some support to get through a shorter low spell:

"Crisis mentoring? I can't think of a better way to put it – but when you're going through a bad patch, then there's the option of someone that you can just have a coffee with, just one off sort of thing. But how you'd manage that I don't know" (Mentee I)

Volunteer and staff participants' views were mixed – some thought that follow up support was something which Brigstowe already could or did facilitate, or that existing opportunities to get involved were sufficient. Others recognised differences between what was available currently and what had been suggested, and either saw specific follow up support as feasible, or thought that having different levels of support available at different stages would be a positive development. It appeared that, at present, any such support would need to be specially requested, rather than forming part of the service proactively being offered by Brigstowe.

Tools to support a mentoring service

A range of tools and processes were in place to support the mentoring service. When starting to set up the service, Brigstowe contacted other organisations which offered some form of mentoring or peer support, in order to collate and build on the ideas and resources they were using. Positively UK were a key partner, sharing the peer support service model they had developed, and providing training on its components to Brigstowe staff. Brigstowe were able to implement this model, adapt it for local circumstances, and to support its evolution and development over time as new needs and opportunities emerged.

Recruitment and training

Positively UK's model included a "proper recruitment process" for potential mentors, including a formal application form, a Disclosure and Barring Service (DBS) check, references, and an interview. The three-day initial training for mentors was seen in part as an extension of the recruitment process, as it was during this that it sometimes became clearer to people whether this was a role they were ready to take on at that point.

The training for mentors, which had been developed by Positively UK, was described by more than one participant as "brilliant". Those who had been through the training unanimously reported that it had been an extremely positive experience for them:

"In fact, doing the training was my - support for me really, cos I got to meet lots of other positive people and talk about the key issues...the process of becoming a mentor is therapeutic in itself. All of the mentors on my training felt the same.....It was so positive. It really made you feel positive about being positive I suppose" (Mentor D)

"The training was insightful around people's feelings and emotions, as well as it was informative around medication and the virus....I was impressed. It takes a lot to impress me – I'm a cynical old sod" (Mentor B)

Brigstowe staff involved with the training agreed that it was a positive intervention in itself, as well as developing the skills participants would need to take on the mentoring role:

"It can be pretty tough. It's all about peer mentoring skills, communication skills, motivational interviewing, goal setting, as well as a HIV treatment update. Very reflective, with role play and all of that. And I feel like every positive person should go on this because it's really an opportunity for people to see how far they've come" (Brigstowe staff member)

The funding for Positively UK to deliver training to other organisations was coming to an end, thus for legacy purposes, the Brigstowe team had recently been trained to deliver the training to new mentors themselves. The existing Brigstowe peer mentoring team included people with teaching and training skills, which had helped the team to be able to take this on.

"The point of that training is it was delivered by positive people, and that's why it works. So it's got to be positive people....The next training will be us." (Brigstowe staff member)

Supervision and other group support

Ongoing support provided to mentors included a monthly group meeting which was intended to provide an opportunity for mentors to talk about how things were going, share support and knowledge, and discuss any issues. It was also used to provide any relevant updates on HIV knowledge, and ongoing professional development training for mentors. Participants noted that mentors were informed in advance if someone from outside the group would be coming to speak, and one volunteer highlighted the need for this to be scrupulously attended to, including details of who the visitor would be.

Participants described the meetings as a helpful catch up, and sociable as well as dealing with mentoring business. There were opportunities to 'coach' peers with less mentoring experience, and share support and updates.

One participant, who particularly valued the opportunity the supervision meeting offered for mentors to talk things through, found it problematic when that time was *"taken over"* by training. Two participants thought that mentors did not use what they thought should be the *"really safe space"* of the supervision meeting to share enough of their struggles with mentoring. Both participants thought that there was often a tendency to focus on the positive, even to the extent of being *"almost in competition with each other"*. Both participants thought that this could make things more difficult for a mentor who was struggling:

"I feel uncomfortable because I don't feel that way. I feel like I've failed, because I haven't made much movementI'd like the group meetings to reflect our practice. That's what I think it needs to do a little more. It does it, but for my liking, not enough." (Mentor)

These participants thought that this was something they could work on with support from the group leadership – giving each other *"permission"* to say mentoring did not always work, and leading each other by example in sharing their own challenges. One mentor thought it would be helpful if it was also possible to communicate to mentees that it was okay to say if and when mentoring was not working for them.

A WhatsApp group for mentors had also been created, which participants had found useful in creating a community, and avoiding the need for multiple individual messages. Participants reported this group being used to ask questions, check in with each other, share difficult experiences or updates. Mentors also had each other's phone numbers, so could call a fellow mentor when they needed to.

“...we have a WhatsApp group for the mentors. We also have each others’ phone numbers. Some of us are good at some things, some of us are good at other things....between us all we can usually answer most questions” (Mentor D)

Senior mentors

One of the local developments to the peer mentoring service model was the introduction of a new ‘senior mentor’ role. The intention was for senior mentors to take over some aspects of the work which had originally been the responsibility of the project manager – freeing up some of the manager’s time, while providing an opportunity for mentors to further develop their skills in taking on this new role.

A recruitment and training process had been created for this role, which was intended for mentors with more experience. Each mentor was matched with one of three senior mentors, who was intended to become their first point of contact and one-to-one support in their mentoring. The relationship was intended to mirror the peer mentoring one to a certain extent, with regular meetings. The role was still evolving, and suggestions for the future included further training in areas such as group management, to support senior mentors in providing leadership at group supervision meetings.

Participants had mixed views on how the new arrangements were going so far. In general there was agreement that it was successful in reducing the project manager’s workload, which was considered a good thing. Some mentors regretted the reduced contact with the project manager, and various participants reported that mentors on some occasions chose to “*by-pass*” their senior mentor. In some instances, participants reported that mentor/senior mentor pairings were not working. The process in such circumstances was considered to be for both parties to discuss the situation with Brigstowe staff, so that a solution could be sought. Participants – both mentors and senior mentors – also described positive experiences of this support arrangement:

“You know you can’t think of everything for your mentee, so you come out with an issue and he says ‘well think about this way’, or ‘ask about this’ – that is really good” (Mentor A)

“It’s just supporting them really, because I must admit the first time I was due to meet a mentee I didn’t have a clue what the hell I was going to say. I didn’t think for a minute any of the training had gone in.” (Senior mentor)

Clinic mentoring

Establishing the service

Another recent development of the peer mentoring service had been the provision of a mentoring service located within the city’s HIV outpatient service on HIV clinic days. This innovation had been a long time in the planning, with hurdles to be overcome having included finding a suitable space in the clinic for a mentor to be based, and meeting NHS governance requirements for the mentors who would be working on site.

Brigstowe staff reported that peer support in HIV clinics was only happening in a tiny number of locations nationally, and that the models elsewhere were not similar to the Bristol one. The NHS was described as being “*very risk adverse*”, and thus something so innovative took time. While numerous people locally – staff of relevant organisations alongside volunteers and service users - had been on the “*long journey*” to implement this service, there had been increased recognition nationally of the value of such initiatives:

“While this has been happening in Brigstowe, Bristol, nationally within the HIV sector, the British HIV association has recognised the importance of peer support.” (Brigstowe staff member)

This national level endorsement by a reputable body was seen as important in helping NHS organisations to be open to such services. In Bristol, the demonstrable success of the other Positive Voices services was seen as having been an influential factor, as well as the formalisation of a qualification for mentors.

“But it is an amazing thing, because they’ve been trying to do this – Brigstowe have been trying for about four years to get mentors into the clinic. So finally – they’ve now established that we’ve got a qualification and it’s a successful process – the clinic have accepted us.” (Clinic mentor S)

All participants who spoke about clinic mentoring thought that it had been a very important step to take, and that it was already evident that it was helping them to reach people who would not otherwise have accessed support. The response from clinical staff had been very positive, and all parties were keen for the service to continue.

The process in the clinic

A clinic mentoring ‘shift’ was for four hours, but volunteers would each do just one such shift a month. The clinic mentor had a private room off the clinic waiting area, so that confidential conversations could take place. Mentors used a range of strategies to engage with people in the waiting area, to let them know about the service. Clinicians also mentioned the service to patients who they thought might benefit, and if the person was interested, the clinician brought them to the mentor’s room after their clinical consultation. Brigstowe had worked with clinical staff on how to introduce the subject – for example, the term ‘peer mentor’ was unlikely to be understood:

“If you say ‘A peer mentor is here’ – well what the hell’s a peer mentor? So – ‘We’ve got somebody from Brigstowe here, who also comes to this clinic’ – that kind of thing. ‘Would you like to have a quick chat?’... ‘I think it will be useful if you do’” (Brigstowe staff member)

Mentors would allocate 45 minutes to each person who wished to access the service. This time included providing peer support – by sharing that they were also positive, having “a chat”, and telling them about support services available locally from Brigstowe and THT. If the person was interested, the mentor would refer them to the appropriate service, using a generic referral form which had been developed.

“It’s an opportunity for us to meet all these people who have bypassed Brigstowe for whatever reason and are getting on with their lives, and just say ‘do you need to revisit any of this? How are you managing? How’s it going?’ Then you let them know – basically you go to the clinic, you set up your laptop with the referral forms on, and then they start arriving at the clinic. We’re in kind of a little room to the side of the waiting area...And of course I know the [clinic] process because I’ve done it. So that’s one of the reasons they really wanted to have positive people in place...I’ve had about 20, 25 conversations and I’ve made about five referrals.” (Clinic mentor S)

Demand had varied for different clinic sessions – from nobody choosing to access the service that day, to clinic mentors having a queue of people building up toward the end of a session and struggling to get away. Clinic mentors had to be active and go and ‘say hello’ to people in the waiting room – reactions varied, from people who were completely unreceptive, to those who were very pleased to be approached:

“You don’t have to say ‘Hey, I’m positive as well’, no, we keep it subtle – you just sort of start a conversation and say ‘Oh I’ve been coming to this clinic for so many years. How do you find it?’

Have you heard of Brigstowe? I'm a volunteer. If you'd like to come and chat – about Brigstowe, about possibly getting involved or learning about the mentoring then I'm in this little room on the side', so the doctors don't have to sort of physically send them to you. You go out and kind of fish a little bit. And some of them are really willing to come and chat. And some of them are like 'thanks but I'm fine'. And others are completely vulnerable and the doctors don't really know what to do with them so they kind of walk them into your room and say 'please talk to so and so'.....that's how it's working so far but it's really early days, and we're constantly refining it." (Clinic mentor S)

"It's very intense, but it's also great fun. You never know what's going to be thrown at you which I quite like." (Clinic mentor T)

At the time of the evaluation the clinic mentoring service was taking place during clinics for people with an established diagnosis, as the clinics specially for people who were newly diagnosed were not yet considered feasible.

Rising to new challenges

Staff and volunteers involved in the clinic mentoring service noted that it meant mentors were working directly with people who were at a different stage in the process of engagement with support. With the original peer mentoring service, mentees would have completed a screening process, and been carefully matched with a mentor. The environment at the clinic was very different:

"[Clinic] mentors are seeing people who maybe aren't physically well, aren't mentally well, really different people...They were doing proper front-line stuff, which is amazing, but I learned that from having our first group supervision. I didn't really think about that." (Brigstowe staff member)

"Huge learning curve. Something that none of us were prepared for in any way, shape or form....and that is a real challenge – you've really got to think fast, and think on your feet." (Clinic mentor T)

While mentors described being able to pass anything they were not able to deal with to Brigstowe, the difference between clinic mentoring and the longer term relationship of peer mentoring could be emotionally difficult – for example because you did not have the same opportunities to see progress, or to check if the person was going to be okay:

"We haven't been trained for this, though obviously we're trained mentors, but it's kind of front-line work....and I find it quite difficult actually – because there's no comeback...You don't get to see any progress, or whether your conversation or your referral's done anything. Or they've been picked up. Or they're alright. And of course with a mentee, you get to know them over a long period of time. And you see progress, and you have goal setting and all the rest of it. But this, is very much sort of like speed dating...and the amount of issues that come pouring out in that sort of half an hour. It left me completely boggled. And I don't actually know how to deal with all of this. And that's the nature of - cos it's a new venture, there are no - we don't know what it's going to be like." (Clinic mentor S)

The unpredictability of clinic mentoring could, and did, result in a mentor meeting a sequence of people with complex needs during one session:

"...an unlucky series of very distressed vulnerable people and I felt – it was kind of a bit mind-blowing unfortunately. And I felt really out of my depth." (Clinic mentor S)

This was not something which any mentor would be expected to be able to deal with. It was agreed that it was probably an unusual set of circumstances, however it reinforced the need for additional support to be available for people taking on the clinic mentoring role. A regular group supervision session for the clinic mentors had now commenced, as those involved needed to share experiences and support each other. Mutual support around the times of clinic sessions had also been reinforced – with the option to ring another clinic mentor if not able to contact Brigstowe staff. Clinic mentors were also reminded that it was always okay to step back from the role if it became too much:

“..really important to hear that, because it takes the pressure off. And that’s just one of the techniques that [Brigstowe staff member] is very skilful at really. Very skilful.” (Clinic mentor S)

4.4 Positive Voices services: Recently diagnosed workshops

The workshop aims to provide HIV related information to people recently diagnosed to prevent crisis, along with providing the opportunity for the participants to meet & connect with other people experiencing similar situations. The workshop sessions cover:

- Stigma & self-stigma
- Treatment options & other clinical aspects of HIV management
- Disclosure, relationships and sex
- Legal rights particular in reference to employment
- Travelling abroad
- Information about HIV support and services

Brigstowe delivered two workshops in the first two years of the project, and 23 people have accessed the service.

Workshop content and structure

“By the end of the day, you can physically see the difference. In the way they’re speaking, they’re holding themselves...almost 100%. And this real buzz. And it’s almost like ‘we just have to get these people together and they’ll be fine’. Obviously we’re steering it, but it feels a bit like magic.” (Peer support volunteer)

It was striking throughout the feedback form comments and the interviews that the most important element of the workshops was the opportunity to meet with other people living with HIV. The ability to get to know people over the course of the workshop, to hear their stories, discuss shared concerns, and understand that they were not alone in this experience was repeatedly identified in feedback as extremely helpful. One participant had found the diversity of people in the workshop he attended refreshing:

“I thought ‘oh I’m going to just walk into a room of gay men’ and it wasn’t at all. There was women there, straight men there, and they were a real mix of people, so I think it was really nice. Mainly because it gave different perspectives to stuff...just sort of removed that element of it being all about LGBT stuff.” (Workshop participant L)

Two participants mentioned that they had maintained contact with other attendees of the workshop they went to.

“That was.... brilliant. It was very informative. Everything you needed to know or wanted to know. And also it was a chance to meet other people going through the same thing or similar. And after that we created a little friend group and still keep in touch.” (Workshop participant M)

In their written comments on the workshop feedback forms, and interviews, many workshop participants reported that the workshop had covered everything they had needed from it. Topics mentioned as having been particularly interesting or valuable included: scientific information about the virus, transmission and treatment; rights and legislation; relationships and disclosure; and dealing with stigma. Nutrition or healthy living was suggested as an additional topic.

Regarding what they would like more of, comments on feedback forms coalesced around a desire for more time for group discussion, and sharing of experiences – for example in relation to disclosure to people close to them. Interest was also expressed in having more time focusing on other emotional aspects such as coming to terms with your status, and dealing with stigma; and in having additional time – perhaps at the end of sessions – to process and discuss what had been covered.

Workshop participants reported that the pace of the sessions had been right, they had been well facilitated, and that facilitators had been very responsive to questions. This included following up afterwards if they did not immediately have an answer. An added benefit of the group format was that other attendees asked useful questions which a participant themselves had not thought of:

"All my questions were answered and questions other people asked were helpful as it informed me about things I wouldn't have thought of." (Workshop feedback form comment)

"Basically I will go in and just sort of say 'what do you want to know?' and would either give people a post-it note to write the questions downor people shout out things that they might want to know. And at the beginning, we would write down all those questions or statements or whatever, and then would formulate sort of the session from that. Rather than me going in with something that I thought that I should tell them or what they should know." (Professional involved in workshop delivery)

The resource pack provided to take away was well received, with one comment expressing a preference for electronic / emailed resources. People reported that they had found the materials useful to share with others they had disclosed to, and as a reference, noting that the inclusion of links to online resources meant that they could keep up to date going forward.

Feedback form comments powerfully illustrated the impact participants felt the workshop had on them:

"Now I'm confident that I can do anything in life."

"It has made me more sure (positive) Happier with myself."

"I simply loved that feeling. Thanks a lot for helping me to set myself free."

"This 3 sessions gave me hope for the future. I feel normal now and I can do anything like everybody."

Those involved in delivering the workshop also reported very positive experiences of this, ranging from a professional who took what they learned from workshop participants back to their own practice, to peer support volunteers who loved being able to see the transformations in people which they were contributing to:

"I think they're just all relieved - that person's positive and you're positive and we can talk about it and it's fine and no one's judging anyone...and that is such a relief....So that I absolutely love, and will continue to do that. Time commitment wise it's very doable." (Peer support volunteer)

"It was absolutely brilliant. I saw myself in all the people – very upset, very 'oh my god my life is finished'....and I was able to talk about... 'Last year I was exactly this, I was upset, sad....and look at me – I'm talking freely'" (Peer support volunteer)

Supporting people to access the workshops

While some workshop participants reported having felt comfortable about attendance before coming, others fed back regarding varying degrees of anxiety at the prospect. These ranged from being *"a bit nervous"* or shy about meeting new people; to being concerned about confidentiality or anxious about who would be there. Some workshop participants were of the view that, considering the topic, a certain level of anxiety was to be expected. Some commented that they felt better once they had arrived and met people, or once the workshop had broken into smaller discussion groups. Several comments related to it being helpful to know/have spoken to someone who would be there

in advance – either other participants or facilitators. Participants noted support which had been offered by Brigstowe staff in advance of the workshop.

Workshop participants who had begun having peer mentoring before attending the workshop reported that this had made the decision to attend easier for them:

“I was seeing my mentor by then, so I was ready to meet other people” (Workshop participant M)

This participant thought it had been harder for those in the group who, by coming to the workshop, were meeting other people living with HIV for the first time. However this participant also observed Brigstowe staff working to ease this experience:

“and you could tell, it was difficult for them..... I did see [Brigstowe staff] going to meet people, bringing them in and just slowly introducing them to other people” (Workshop participant M)

Another participant, who had attended the workshop prior to mentoring, reported that the invitation had been extended in very open way, as something for him to choose freely, should he so wish. He did choose to take up this invitation but initially found it hard to engage:

“What am I doing here, this is ridiculous. I don’t want to listen to people’s stories. It’s just not for me.” (Workshop participant K)

Despite this, he returned for the second session, and experienced a moment of powerful connection with the group:

“In the end we had a moment when [facilitator] said ‘Tell me how you’re feeling, what you think about this’. And it was when I said something that was like, powerful for everyone. And in that moment I was like ‘wow. This was great’.....It was a really powerful thing... this was last year, and if you think that I’m HIV positive for ...years, and this just happened last year. That a small thing took me from a massive hole that I put myself. So it was extremely important.” (Workshop participant K)

The workshops ran as a full day on a Saturday, followed by two evening sessions in subsequent weeks. Two participants observed that not everybody had been able to attend the evening sessions of the workshop – for example if they were travelling from outside Bristol. One participant had also thought that the evening sessions felt more rushed. While agreeing that it was important to have time in between the sessions to absorb what had been covered, they suggested that running the workshop over two sequential Saturdays might avoid losing people from the group:

“On a day, towards the end, you start sort of really getting on as a group, but then that disappears” (Workshop participant L)

Other participants thought it would be helpful if more people were able to access a workshop like this as soon as possible after their diagnosis – for example if they could be offered more regularly:

“Someone who is newly diagnosed, waiting a year, to have a group like that – it’s a long time” (Person working in HIV sector)

“People today when they’re diagnosed, very often the reaction they’re having is the same as people were having 20, 25 years ago. Which is ‘oh my god I’m going to die’. Just doom and gloom and terror and anxiety. And it really doesn’t need to be like that. It’s down to lack of education. It’s down to lack of organisations like Brigstowe being around to put the information out there and to hold workshops for people who are newly diagnosed.” (Peer support volunteer)

4.5 Positive Voices services: HIV awareness training

Brigstowe's HIV Awareness Training empowers professionals with the skills and knowledge they need to work confidently with people living with, affected by or at risk of HIV. The training covers the following:

- HIV prevention and transmission.
- Clarify the definitions and differences between HIV & AIDS.
- Provide up-to-date information on treatment.
- Explore stigma and prejudice.
- Explain testing services.
- Promote best practice when working with a person living or affected by HIV.
- Inform participants of support available.

Within the first two years of Positive Voices Brigstowe has delivered 15 sessions to student social workers and clinicians, prison staff, mental health care providers, housing associations and other voluntary organisations.

Context – Experiences of poor HIV awareness

A lack of HIV awareness in wider society negatively influenced the ideas people living with HIV themselves held about HIV at the point of their diagnosis:

“Because I think when you're diagnosed with something like that, I mean, being an older gentleman, coming from like the early eighties, when AIDS was a gay disease and a killer and all that lot – you've still got that stuck in your head. When someone's got it, you're like 'oh my god they're dead'.” (Person living with HIV)

Post diagnosis, they were also affected by poor awareness displayed by others:

“Because of that stigma, I don't cook for anybody....because, my family, when they knew.... they just didn't want me to touch anything. So from that time – even if someone doesn't know me, that I'm positive, I will not cook. I don't want to touch anything of theirs.” (Person living with HIV)

As well as contributing to stigma, participants noted that poor awareness prevented people from getting tested for HIV themselves, for example if they did not perceive themselves to be at risk.

Experiences of poor HIV awareness amongst professionals delivering services to people living with HIV were particularly striking. Consequences included inappropriate disclosure of a positive person's status by a professional, and subsequent inappropriate exclusion from facilities or services. While keenly aware that what had happened was wrong, people living with HIV were sometimes reluctant to challenge such behaviour, even with support to do so, because of fear of damaging their relationship with the professionals involved:

“So I never went...I just left it as it is. Because it will make me feel so so bad.” (Person living with HIV)

Positive people, as well as professionals who had received the HIV awareness training, reported that they had not initially realised that this training was needed in their own environment. It had taken a negative incident in a work context, or the experience of the training itself, for this to become apparent to them:

“There was a bit of an incident at work which just made it really clear that people don't get the importance of what they're doing.....I think in the past, before I went through my diagnosis...I'd be

like ‘what do you need that for’ type of thing. But I think, considering that I work in healthcare - how little people know from within healthcare.” (Person living with HIV)

Health professionals were prominent amongst those who participants reported would benefit from HIV awareness training. It was also suggested, with the growing population of older people living with HIV, that training would become increasingly important in areas such as community services and care homes:

“It’s getting professionals to understand they need that.” (Peer support volunteer)

One participant discussed how the experience of his diagnosis had been exacerbated by how the health professionals involved had communicated with him.

“In hindsight, I think he was just terrified of telling me [laughs]....thinking about it later on.....I don’t know how much they get – support, to give results....I’m not sure what I’d want, but at the same time I feel he didn’t really know how to deliver the news.” (Person living with HIV)

What works about the training

There was widespread support from evaluation participants regarding the inclusion of HIV awareness training in the Positive Voices project. People working in organisations where HIV awareness training had been delivered reported that the suggestion had been welcomed by staff, and that the training itself had been well delivered and impactful:

“There were quizzes and things like that to test our knowledge, on what we knew already. Which was very useful actually – shockingly! But we started with nothing - and we came away knowing everything that we need to know, with a lot of myths busted along the way as well.” (Training participant N)

“I knew nothing before about HIV, I now feel confident talking about it thank you!” (Training feedback form comment)

There was positive feedback about how the session was timed, and the interactive nature of the training, and staff from very different backgrounds reported finding it easy to follow:

“Some of the terminology was quite difficult but it was made really manageable by the trainer.” (Training participant N)

The contribution to the HIV awareness training of the positive speaker was described by attendees as *“one of the highlights”*:

“It wouldn’t work without the service user perspective because that rounds it all up. Because that’s where you hear a story, you have empathy.” (Training participant O)

“There was a lady there who shared her experience. It was such a privilege – for her to share that with us. It really hit home.” (Training participant N)

Participants reported a range of positive impacts after the training, from reflecting on their own practice, to increased confidence in that practice; and from responding to things differently themselves, to sharing their new awareness with others:

“They loved it actually... the learning was loads...it created a really good thoughtful debate about the notion of ‘are we practicing what we’re preaching as nurses or healthcare professionals, and our own prejudices that we don’t often think about’. What’s the phrase? It made our unconscious into our conscious around working in HIV and AIDS’.....And what’s sort of really

amazing is something came up in the news about HIV, and they could all connect to that. And we all looked at each other and said we wouldn't have taken much notice of it if we hadn't done the training.... One of the nurses said she had a really powerful conversation with her teenage daughter about it....it had a knock-on effect.” (Training participant O)

“I had a lot of feedback from my colleagues about just feeling more secure in our knowledge of what to do if we're working with someone who has HIV. And particularly for me and [team names], that if we have [service users] with HIV that it's not – that it shouldn't need to be a big thing.” (Training participant N)

“I feel more able to challenge more confidently with current knowledge.” (Training feedback form comment)

Participants in organisations where training had been delivered considered it a good investment of resources on their part:

“I guess I had to put forward a case to my manager because obviously it's taking time out of the day, but because quite a few of the team leaders had come back to me and said 'actually this would be really beneficial for all of our teams', so because of that it was easier to put that idea forward...It was quite a short training as well – it was just a morning session.” (Training participant N)

One unintended benefit was that the training had been a focus which allowed people from different parts of the organisation to spend reflective time together:

“It was really nice actually because we don't often all get time out to train together.” (Training participant N)

A training participant who was a healthcare professional thought that it was essential that training for healthcare staff was delivered by an organisation with Brigstowe's level of experience in HIV, rather than someone with theoretical knowledge:

“My argument would be – they are experts at what they do, and they have the ability to answer questions very well linked to their own clinical practice, which is asked by the clinicians...So because they have lived experience of working in that environment they can offer a safer answer which is best practice. Where if it were just a teacher delivering, I think, to be honest, because it's not your bread and butter, your answers would be quite unsafe I would imagine.” (Healthcare professional)

What to consider for the future

Demand for a range of different types of services linked to HIV awareness had emerged – from the 'standard' training, to shorter or tailored talks, to working with organisations to review their policies.

Participants noted that HIV awareness training could generate income for Brigstowe, and highlighted that flexibility in pricing for different organisations and scenarios would be beneficial. For example, commercial organisations might be willing to / have capacity to pay higher rates; compared to an educational organisation operating to tight budgets, and potentially wishing to incorporate training into the curriculum for different groups of students on an ongoing basis.

There was tension between the desire for Brigstowe to proactively market the training in a range of environments and ensure costs remained affordable, in order to reach more people; and limitations based on current staff capacity. Staff noted that tailoring training could be time consuming, and that this needed to be costed in.

4.6 The Positive Voices project: Making it work

Peer magic

There were a number of mechanisms contributing to the impact of the Positive Voices services. The most prominent and irreplaceable of these was the ‘peer’ factor. At times participants were able to explain aspects of why this was important, but at times it was beyond words:

“it feels a bit like magic” (Peer support volunteer)

In written feedback forms, and in interview participants’ descriptions and explanations of the importance of their contact with other people living with HIV, there were a number of recurring themes. The first of these related to not being alone; no longer feeling like the only one in this situation:

“I don’t feel like I’m the only one that is positive.” (Mentee H)

“I think it made one feel less alone and isolated.” (Workshop feedback form comment)

“Meeting other people – it’s so different. I think it’s what everyone needs who’s newly diagnosed, definitely.” (Workshop participant M)

“Even if you don’t say anything, someone else will say something I felt/experienced. So it’s nice to know I’m not alone.” (Workshop feedback form comment)

Recognising other people living with HIV’s experiences, and having them recognise yours, could transform how people felt about themselves:

“And when I sort of said some things about how I felt he would say to me ‘well that’s the medication’. It didn’t make me feel like a leper any more. It made me feel a bit more human, if you know what I mean. Somebody who actually understood where I was coming from. So it was really good.” (Mentee G)

“All of the people in the group are all feeling a bit like you’re feeling, and you can be open with them. You might not have told anybody, it’s the first time you can actually voice it – is powerful in itself. And you get a chance to tell your story, and for somebody across the room to go ‘oh yeah, that’s what happened to me’ ‘Oh that’s what I was worried about’. It’s just, it’s a brilliant thing, and I absolutely loved it.” (Peer support volunteer)

No matter how well-informed, well-intentioned, or professionally skilful a negative person was, they could not identify with a positive person’s lived experience. It could take a lot of energy to explain how you were feeling to someone who was not positive, and thus not in a position to ‘get it’ in the same way:

“Someone who, all the way through just gets it....that was what was really important to me.....talking to my friends who haven’t got HIV – it was always like explaining how you’re feeling all the time, whereas talking to my mentor.... something I said to him was ‘I just feel a bit toxic all the time’ – this was before I became undetectable. And he said ‘aw yeah I remember, I could feel my blood, like flowing’ – he just got, straight away, and there was none of that explanation. It can just get exhausting when you trying to communicate all the time. Whereas it just felt really easy all the time” (Mentee I)

Hearing other people’s stories, and sharing their experiences, could help people to feel ‘normal’ again:

"The identification I had with my mentor was invaluable, it was so refreshing to talk so openly with another woman who understood what I was going through. It made me feel normal and not like I was damaged goods." (Mentoring feedback form comment)

"When you are surrounded by HIV positive people you feel normal also. It's just not like it's an environment full of people – it's an environment full of people like you." (Workshop participant K)

"Hearing other people's stories made me feel less stupid for getting this." (Workshop feedback form comment)

Sometimes it was only possible to accept/believe something about HIV when the source of this information was another person with lived experience of HIV:

"I can't have relationship because I'm scared. No matter how much they teach us 'this is OK, this is that', I was still not comfortable. Until I had this mentor." (Mentee H)

"It's OK people explaining to you 'oh no no - it's not a disease now where you die from it'. People are saying that. But when you got that stuck in your head – you've seen people dying years ago – it's hard to accept that. And [mentor] helped me see that, you know he just educated me, and helped me to see that you know people could live – quite happily and healthily – with it." (Mentee G)

Other people living with HIV were role models for living well with HIV:

"So just meeting another person who is well - as well as one can be – it really breaks down the stigma, and the psychological impact. Which therefore – in terms of self-management, of a long-term health condition – that is what is needed. It complements the clinical side – you know all the treatment, the medicine, which a positive person needs – to stay alive. But to be able to function, in daily life – it's the psychological thing which needs to be smashed. And that peer support – that's what the peer support does" (Brigstowe staff member)

In this environment, your positive status was transformed into (or recognised/experienced as) something which gave you the power to help others:

"...after that I felt so inspired. I was like 'oh my god I want to do this for my life' The fact that you can actually – you can help someone. Just talking. And listening – it was brilliant" (Peer support volunteer)

Working collaboratively

It was evident in many participants' accounts that significant benefits were being generated through the collaborative approach to working taken by many of the organisations and individuals involved.

Brigstowe staff had contacted a range of other organisations – in the HIV sector, but also from other relevant sectors – in order to find ideas and resources for the planned Positive Voices services. These other organisations were generous in their response, providing models, templates and advice which Brigstowe could build on. There was also ongoing collaboration with other HIV sector organisations such as Positively UK and the Terrence Higgins Trust. Additional organisational links were being created via the HIV awareness training:

"Having links now with Brigstowe – if we ever did have a [service user] in the future who had HIV then we would be able to link them with support there. So it I guess broadened our networks as well....I mean I'd heard of them, but it's always good to know a bit more about their services now, and what kind of support they can offer." (Training participant N)

Collaboration with clinical services was considered crucial, and much work had been put in on all sides to strengthen these relationships. Staff from Brigstowe and the city's HIV outpatient service described their relationship as always having been good, but the work around the Positive Voices had taken this to a new level.

"...it's certainly helped the relationship between the two services as well. We feel much more like we're working together. Not that we were ever working against each other, but there wasn't always an awareness of what a service was particularly doing, and I think there is a much greater awareness now." (HIV specialist clinician)

Brigstowe had intentionally sought to engage the clinic's staff in the Positive Voices services from the outset. As described in the section on clinic mentoring above, it had taken time to be able to implement this part of the service, but the benefits of the broader engagement were striking. A clinician reported new insight into what a patient living with HIV might need from them:

"A better insight into people, particularly when they've been newly diagnosed, what they actually want to know isn't always what I think is important... For a lot of people it's just 'what's going to happen now?' And we're kind of 'you need to know about your CD4 count, your viral load, you need to know about treatments', and that can be very overwhelming. And trying to gauge from the individual what is important to them, and then sort of taking it from there. So I think it has been really useful for me" (HIV specialist clinician)

While clinic staff had previously referred people to Brigstowe for support with issues such as housing benefit, they were now actively referring to the Positive Voices services:

"Because I've been involved, and link with the rest of the team to let them know what's happening as well, we do try and refer as many people as possible to either the peer support service, or if people are interested in the newly diagnosed workshop. So there is kind of direct involvement in linking people in." (HIV specialist clinician)

Participants in the evaluation who were living with HIV reported having had clinical staff discuss Positive Voices services with them during clinical appointments. Clinical staff described how they had become more proactive in their referrals – offering to contact services on a patient's behalf, rather than simply providing them with information. A mentee who had been referred in this way had found it extremely helpful:

"It's a big shock, when you're newly diagnosed. I went to my clinic appointments....and was acting completely normal [Laughs] and as I always say 'typically English'. You know, brush everything under the carpet, put on a brave face. 'Yeah I'm fine'. But then after a few months I started hitting rock bottom. And my nurses noticed. They noticed a massive dip in my mood and everything. So they actually got in contact with Brigstowe... and asked them to contact me. [Laughs] Cos they know what I'm like – they know I probably wouldn't ask for help...I did get a call from [healthcare professional] at the time, and he said 'I'm going to contact these people - are you happy for me to do this?'" (Mentee J)

Creating spaces for support

The people involved in Positive Voices services – staff, volunteers and partners – had created spaces where support became possible. What was needed was different for different people. Two mentees spoke about the difference the offer of one-to-one support made – not feeling ready for a group environment, or having tried it and struggled:

"When I did one-to-one, it became so easy" (Mentee H)

"My first thoughts were 'yeah, amazing, this would be great!' It's different than being offered, say, counselling. I didn't have to go to – the thought of going into a big group of people say, if you were in some kind of support group – that was a bit daunting at the time. Just seeing someone face to face in a casual setting sounded much better" (Mentee J)

For others it was the group environment which had been key, as well as the move away from a clinical environment:

I was feeling blessed in that place, for everything that I saw, listened and felt. (Workshop feedback form comment)

When I was diagnosed it was lots of doctor talk. The group setting helped me understand things easier. (Workshop feedback form comment)

"It was important that people had the opportunity to meet somebody outside of the clinical setting, on kind of a neutral area, and to be able to ask questions and get information without necessarily being in a consultation or whatever. And to be able to get information about HIV that they hadn't had, or hadn't looked up, or hadn't understood." (Professional involved in workshop delivery)

Participants who had attended HIV awareness training also spoke about how the trainers had engaged attendees, and created a space where people felt able to be open about their level of HIV awareness, and take on new learning:

"Everyone got really involved, and were very open about their previous knowledge or their experience....She kept things quite light. Obviously it's quite a difficult subject. There was really good rapport between her and everybody in the group. She just really managed her audience very well." (Training participant N)

"Some of the things they do – and they probably don't realise how good they are – like some of their motivational interviewing techniques. And some of their conversations – it's probably not therapy but they are therapy-based conversations." (Training participant O)

One important aspect of creating spaces for support was how to make space for all voices - with no one voice dominating. This was raised by several interview participants, as well as in workshop feedback form comments. People noted that it might be inevitable in any group that there would be those who were more confident in expressing their opinion. People also recognised that there were benefits to having people who had a stronger voice – often this came from depth of experience and passion, and sometimes they expressed things others were unable to say:

"Even if you don't say anything, someone else will say something I felt/experienced." (Workshop feedback form comment)

However there could also be challenges - if this contributed to some others feeling less able to speak, or be heard:

"...which puts up a barrier for people who are less strong as a personality to actually come forward....There's got to be a platform for everybody." (Person living with HIV)

"We need to create a space for women to be able to chat. Because what they contribute is amazing. Within the HIV sector there has just been a recognition the last two years that the woman's voice is rarely heard." (Person working in HIV sector)

Participants thus expressed a desire to find ways to facilitate more equal contributions. This was seen as being the responsibility of whoever was leading a group, but it was a responsibility which leaders found challenging – not wanting to be put in a position of having to “*lay down the law*” to other group participants. As this issue occurs in many environments, another suggestion was to see if helpful group management strategies or structures could be adapted from those developed for other sectors.

Facilitating Access

Barriers to access

Another cross-cutting theme was how to ensure the services were accessible to those who needed them most. The first steps could be a particular challenge for people, and participants discussed barriers which they were aware of, or had experienced themselves. While organisations were working together to reach more people, participants thought that many still ‘slipped through the net’. Referrals were often not accepted, and participants were not always clear why, but were of the view that it was still helpful to offer services, and make people aware of them, in case they wished to engage in the future. Mentors spoke about how daunting it could be to walk out of a clinic with a HIV diagnosis and just leaflets or phone numbers for support:

“I would say 80% of them don’t follow it up, because it’s just a leaflet or a phone number. And when you’re newly diagnosed particularly, it’s the last thing you want to think about. It’s difficult.” (Mentor C)

A mentee described their experience of receiving their diagnosis, reporting a lack of emotional support at that time at the healthcare facility where it had happened. They had also felt overwhelmed by the type and format of the information which was communicated:

“You’re bombarded with information, I remember thinking ‘I’m not listening to you at all’... Then they give you like all these leaflets, but they’re these massive things. That’s the last thing you want to do is read through stuff like that.....I think what they need to do is get the information more succinct.....all I wanted to know was ‘these are the next steps’ sort of thing. So I think they give you too muchand just giving you the option of having support now or ‘do you want it later’ sort of thing.” (Mentee I)

A different clinic, where staff had been involved in Positive Voices services, had now changed their practice:

“One of the things we used to do, was quite often we’d give people the information and leave it up to people to contact Brigstowe or THT. I think we’re much more proactive now about you know ‘if you’re interested, we’ll contact them and they’ll contact you’. So that barrier is taken away of having to actually physically pick up the phone, or go in somewhere, which we appreciate can be really difficult for people.” (HIV specialist clinician)

Two participants reported having been referred in this way, which they had found helpful. However in one case the participant and referring clinician had different understandings of when the referral was to be made – the participant was expecting it to happen immediately, while the clinician thought the participant needed a chance to “*process stuff*” first. This had resulted in a two-week delay which the participant had found unhelpful:

“That’s two weeks of being very isolated, going through all that” (Mentee I)

Having been referred to, and contacted by, support services, another participant faced a new barrier – that of actually walking through the door of an organisation visibly associated with HIV:

"I went to see to see [other HIV support organisation]. However, because [other HIV support organisation] ... at the time, it was very clearly named, out the front. And you had to press a buzzer to get in. So I did this thing where I turned up and you know, I was feeling confident, I went to the door, I walked past the door, walked around, walked past the door again, and then I'm like 'Oh my god I can't do this, I can't do this'. And then [Brigstowe staff] got in touch with me. And they're obviously based at a community centre, and it's not all plastered outside. And it was a lot more discrete. So she came out and met me and it was much more kind of subtle and easy going for a first person.....obviously now I look back and I think 'uh, idiot, what was I doing?'"
(Mentee J)

A mentor thought that HIV services needed to give further consideration to what they could do to help people experiencing *"shame and stigma"* access their services:

"When you actually go along to something like that you're publicly affirming that you're HIV positive. Publicly doing that, to all of those people in the room. And you may not have disclosed to anyone else.... And I think those moments are not catered for when thinking about that."
(Mentor A)

Under-represented groups

Participants also discussed various population groups who they thought might face particular barriers to access, or were under-represented amongst those accessing support. Groups mentioned included older white women, heterosexual men, young people, and transgender people. A Brigstowe staff member thought it would be helpful if the task of identifying under-represented groups and leading on strategies to address these became a formal part of the role of somebody in Brigstowe.

Multiple participants – mentors and staff from Brigstowe and partner organisations – identified Black and minority ethnic (BME) groups, including Bristol's large Somali population, as facing higher barriers in accessing both clinical and support services due to increased HIV stigma.

"There are some groups who find it difficult to engage – generally it's the groups where stigma of HIV is much much greater. For example Somali community tends to not have fabulous engagement in services, and support services, due to fear of their diagnosis being found out. That's a very difficult one to get over." (HIV specialist clinician)

While partner organisations observed that Brigstowe had sought to actively recruit volunteers from different backgrounds, within some population groups, the prospect of disclosing to someone from the 'same community' served to heighten rather than reduce fears regarding confidentiality. Despite assurances regarding confidentiality, thus far, this problem was proving intractable. One partner noted that the HIV awareness training which formed part of the Positive Voices project could potentially contribute to reducing stigma and barriers to accessing services within these groups. A Brigstowe staff member reported that the introduction of mentoring at the clinic had started to have a positive impact, with several BME patients having accepted referrals to Brigstowe. A mentor reported that a long-term survivors group which ran residential weekends had made notable progress in the proportion of people from BME backgrounds participating, and suggested that this might thus be somewhere they could learn from.

Where to reach people

Evaluation participants who had used Positive Voices services had found out about them via a clinical referral, word of mouth, or being told about them by Brigstowe staff if they were in contact with the organisation for other purposes. The increased engagement with the city's HIV outpatient

service, and particularly the clinic mentoring service, were seen as extremely helpful in starting to reach people who might otherwise not have been aware of Brigstowe's services.

A participant from a BME background thought that word-of-mouth was only a viable route within very specific groups, and would not work within their own environment:

"It is very difficult that you can know someone who is also positive...because they are not talking about it." (Person living with HIV)

A mentee with a positive experience of care via their GP (primary care doctor), suggested this as another route for referrals. Several participants suggested increasing the profile of both Brigstowe and Positive Voices services more generally, acknowledging that this work had already begun, but thought yet more could be done:

"They need to get the name of Brigstowe out there more in the general community....Get information into pubs and clubs, but not only gay pubs and clubs." (Mentor B)

However participants also noted that there were tensions inherent in increasing Brigstowe's visibility – between the value some people attached to being able to access an organisation which was less recognisably associated with HIV, and the increased access and funding opportunities which came with high profile publicity:

"They're quite good at this, but a little bit more self-promotion. It's quite tricky because you're dealing with a subject that you have to be really careful about confidentiality, so you don't want to go shouting from the rooftops. And that's why Brigstowe became very popular with people that had just been diagnosed because they didn't want to go to the [other HIV support organisation] ... they didn't want to go there because it was like, so obvious, but Brigstowe..." (Mentor C)

"For me I don't mind if there are posters that have been put there, all about Brigstowe. But some people say...if maybe I live with my family, maybe not everyone in my family knows that I am positive. If I say that I am going to Brigstowe, if they have seen that somewhere, then they will say 'Ah!' so, it's really tricky" (Mentee H)

"To play devil's advocate with it - I don't know if we would have survived if we didn't have this really big public voice" (Brigstowe staff member)

However participants in general thought that increasing Brigstowe's profile was the right thing to do, and that mitigating measures should be considered so that there were clearly signposted ways to engage with Brigstowe more discretely should this be preferred e.g. 'non-branded' entrances etc.

Sustainability

Feasibility for volunteers

Positive Voices services rely heavily on the voluntary work contributed by people living with HIV, with the peer mentoring service in particular a large commitment for people to make. Staff and volunteers emphasised the importance of a robust recruitment process, and provision of high quality training and ongoing support, to make the role feasible for those who chose to take it on. The early development stages of the project had depended heavily on the dedication and patience of volunteers:

"Previously from my volunteer management experience it's never been so service-user led... I've been wonderfully, pleasantly surprised, that first year, of the dedication of the volunteers... how

up they were for just being the pilot, trial and error, you know – we really didn't have much money. We were going into this blind. They were so supportive of me. And you know, really were patient. And really contributed really well.” (Brigstowe staff member)

As Brigstowe gained experience, they had improved and refined these processes, and there were some clear indications that this was improving feasibility of the role, and retention of volunteers.

“All of those things have meant that it's a much clearer role, and it's much easier to see your progress, and there's more people to support you through it.” (Mentor C)

Both staff and people living with HIV noted that the role was not feasible for everyone, and that feasibility could be dependent on the 'space' an individual was in at that time. Two participants who had been mentees had at some point considered a mentoring role, and concluded it was not the right time for them, although one thought that this was now changing:

“I don't think I was in the right space to support other people.” (Mentee G)

“I think Brigstowe are very careful with recruiting volunteers, and who they allow to be volunteers” (Mentor B)

Sometimes it was not possible to gauge feasibility until after going through the training, and decisions were sometimes taken at that point not to continue. Mentors and other volunteers reported satisfaction with the level of support provided, and noted that the relationship with key Brigstowe staff had been an important facilitator:

“Channels of communication, particularly through [Brigstowe staff member] are super super strong. So none of us would be worried about anything that we needed to say – we'd all say it.....she's created that relationship, that really open reflective style. Which is brilliant, because when there is an issue....then she can help to repair it.” (Mentor C)

The mentoring role was recognised as a challenging one, and this in itself, as well as other life circumstances (e.g. moving away, getting a new job, changes in physical or mental health) contributed to turn-over of mentors, with people deciding it was time to take a break, or move on.

“And of course we're all positive, and our health is completely as diverse as health in a negative population...and we're older, a lot of us. Some of the new ones are quite young, which is great.... And there are mental health issues, because we're coming from a vulnerable section of the population potentially. So sometimes people aren't well enough so they take a break... Or they try it and they just think 'actually...I can't afford the time, and I haven't got the energy to do this.' So there's quite a lot of natural wastage if you like – all for very good reasons.” (Mentor C)

The more recent development of clinic mentoring had been an extremely positive step for the service, but – as described above - it also brought new, and sometimes unforeseen, challenges for volunteers. Additional support had thus been put in place, and the role description for clinic mentors was being updated to better reflect the likely experience:

“We should have got together a bit earlier than we did...There is that support network, it just wasn't explicit, and we're learning.” (Clinic mentor)

A healthcare professional had thought that there had been reduced availability of mentors able to deliver the sessions at the clinic for a time. As clinicians had quickly come to highly value this service, they hoped that it would be possible to recruit sufficient clinic mentors to provide continuity going forward.

Despite such challenges, the overwhelming message from participants who were volunteers was that for them, the rewards of the role far outweighed these. At the time of the evaluation Brigstowe had a waiting list of people who wished to embark on the mentoring training:

“Being involved, with Brigstowe, and meeting all of these people, is very powerful, and very therapeutic. And it actually makes – well you get as much out of it as you put in....and it’s just made the biggest difference ever to the people that are involved....with that level of passion and commitment, you’re working with gold actually” (Peer support volunteer)

Feasibility for organisation offering services

Positive Voices has a full-time member of staff developing, coordinating and delivering the project, along with managing the volunteers who deliver the different services. Having an overarching coordinator is seen by Brigstowe as particularly important in terms of coordinating the peer mentoring service, to provide the infrastructure for peer mentors to deliver support safely and confidently.

Brigstowe described the coordinator’s role as not to only check that sessions are running smoothly and that everyone involved is working together towards positive outcomes, but to also provide a space for the mentors to debrief and feedback when necessary. Brigstowe believes that an open environment where mentors can share both positive and challenging experiences must be encouraged and designated by the coordinator, to ensure the service is successful for both mentee and mentor. Having this space is intended not only to ensure better retention of mentors, but also to assist mentors in their development - both in their mentoring practice and in a personal capacity.

Mentors noted that while the possibility of a mentoring service had been discussed in the past, feasibility had been a concern for HIV support organisations.

“Can’t imagine why this sort of service wasn’t done years ago, but it’s funding and everything else – policies and politics and all the rest of it.” (Mentor D)

Volunteers could see the “very tight” situation of resources in HIV support organisations, and noted that this could contribute to hesitation regarding trying new things, with safeguarding existing services given a high priority. Brigstowe staff and volunteers had received feedback from other areas of the country that the model which had evolved in Bristol was the one which was working best, and their funding had been one of the key determinants of this:

“I think there is a feeling that that is because it’s got funding behind it – because we’ve got resource to do it” (Brigstowe staff member Q)

For services such as those provided by the Positive Voices project to exist, a funded coordinator / manager role was widely considered essential. A number of participants noted that while training for mentors had been provided in many areas, only those areas where there was a paid coordination post had been able to establish a mentoring service. The amount of work required to go from having trained mentors, to having a functional mentoring service, was beyond what was feasible for a “grassroots approach”:

“Basically, you need a coordinator, and HIV services left right and centre are losing their funding... [otherwise] you then have these people who are trained up, ready to go, with this amazing training – but there is nothing for them to do.” (Brigstowe staff member P)

Several participants observed that while the individual who had been appointed in the coordinator role for Brigstowe at the start of the Positive Voices project had been a key factor in the project’s

success, it was not sustainable for services to depend so heavily on any one individual. Actions were thus being taken to try to address this:

“You can’t build something that’s sustainable around one person. It doesn’t work. So she’s doing all that she can to make sure that it’s not all on her shoulders” (Mentor C)

“Capacity just continues to be a massive challenge....Positive voices is ambitious – a really massive massive project. And just to have one member of staff working on it feels a bit tricky...there’s just not the budget.” (Brigstowe staff member Q)

A number of participants commented that the original appointee had a unique set of skills which had been valuable in establishing the services. Efforts to improve sustainability thus included identifying the different aspects involved, and making sure there were others within the organisation able to cover different parts of what had originally been a single role. The development of the senior mentor role had been an important part of this. Brigstowe staff saw the new, more delimited, peer support coordinator role as requiring someone with skills and experience in volunteer management, and a good understanding of HIV – as well as a prolonged and comprehensive handover support from the original postholder.

There was a widespread sense that while it would be very desirable to scale up the mentoring service – and there was evidence that demand for this existed - it was currently at capacity. Within the existing resources, a limit of 15 mentors at a time had been set, although 12 was considered a more feasible number. The monthly group supervision session was helpful as it reduced the number of one-to-one meetings which would otherwise be required.

“Because it’s all voluntary so - we’re carefully supervised and stuff like that. It’s really difficult for it to become a much bigger – if you increase the numbers then you’re increasing all of the logistics and it’s hard to manage. We’re kind of at capacity at the moment” (Mentor C)

While the current cohort of mentors had been in post for an unusually long duration, in the earlier stages of the project mentors on average had participated for about one year – which meant two rounds of six-month mentoring delivered each.

It was important for the coordinator to manage demand carefully – once a potential mentee was ready to engage, it was seen as important that they did not have to wait too long to be matched with a suitable mentor. A month was considered the maximum reasonable. It was not considered helpful to have an available mentor waiting too long to be allocated a mentee, however it was possible to maintain dialogue should such a situation occur.

Securing Funding

Brigstowe intended to apply for funding to continue the Positive voices during the fourth year of the current five-year funding. Several participants spoke of the need to diversify funding sources, with traditional sources severely affected by austerity policies. Innovative approaches taken by other organisations were mentioned – such as linking up with relevant commercial organisations based around particular themes, and offering reciprocal support such as talks or training for staff. A healthcare professional emphasised demonstrating the value which the services were delivering, and was certain that local clinicians, having witnessed that value, would do all they could to support the services to continue:

“I appreciate funding is a massive difficulty and lots of people competing for the same pot of money.....Having the clinicians onside – which they definitely are – will definitely help, so we can provide our support and say how we feel it’s helped also our services as well. Our lead clinician is

very keen on keeping up links between the services, and that it continues.” (HIV specialist clinician)

Participants were unanimous in their conviction that the Positive Voices services must continue, particularly in the context of the reduced support now available from other sources.

“Definitely it’s needed...it’s an amazing service, I can’t rate it enough.” (Person working in HIV sector)

Participants were not aware of any other source where they could have accessed comparable support.

4.7 Positive people at the centre of HIV services

Transforming the culture of Brigstowe

Some changes in the culture of Brigstowe pre-dated the Positive Voices project – being linked by participants to the arrival of new members of staff. However, the Positive Voices project was considered by Brigstowe staff to have profoundly changed the organisation, in unexpected ways which reached well beyond the Positive Voices services themselves.

These changes were multi-faceted. They began with the people living with HIV who chose to embark on the pilot of the services with Brigstowe as volunteers, and were amplified as the developing services meant that Brigstowe began to engage, in new ways, with populations of people living with HIV who had previously had little contact with the organisation:

“Of course the experience of people living with HIV is a massive range. On reflection, we were probably missing a chunk of people who were struggling with their diagnosis but still had a job and a circle of friends and stuff.” (Brigstowe staff member Q)

The potential wider impact of the project had been flagged in advance by other organisations which Brigstowe had consulted in the process of developing the Positive Voices services, but at that time, staff had not been in a position to understand what would happen:

“The benefit overall for the organisation of having something really service-user led – that’s what they all were talking about. And I didn’t get that at the time...but then really quickly, we saw the culture of Brigstowe change from that. People wanting to be more involved in lots of different ways.” (Brigstowe staff member P)

“It’s tricky to know whether it’s just about Positive Voices, but I think that over the last three or four years Brigstowe has been through a really big cultural shift. We’ve always had quite a good user involvement arm, we’ve always consulted, and listened to voices of people living with HIV. But I guess through the peer support service in particular, we started bringing people living with HIV to the centre of service delivery – which hadn’t happened before. Which was amazing. And whilst that was happening – I don’t know whether it’s fair to say that that was shifting it, or whether it’s just an organisational shift – but we started to get louder publicly too. So our public presence and public representation of positive voices started to get better.....It’s made us much more dynamic as an organisation” (Brigstowe staff member Q)

This observation by staff was reflected in interviews and feedback forms from people living with HIV, with multiple comments about volunteering with Brigstowe in a variety of ways, including using their existing professional skills and contacts:

“That thing that I’d been looking for was suddenly there” (Mentee)

One of the major changes which participants attributed to the Positive Voices services was the growth of Brigstowe’s campaigning presence. This happened in a context where other organisations well known for campaigning on HIV had been experiencing widespread loss of funding – thus there was a risk of loss of progress on this front. People involved with the Positive Voices services were seeing the changes that were possible in the lives of individual people living with HIV, and becoming more confident about their ability to make changes to society too. New volunteers arrived – wanting to help deliver Positive Voices services, but also to become active in campaigning and fund-raising, and to be actively engaged with the broader community which Brigstowe was becoming. Brigstowe staff believed that this had been a key factor in the organisation’s successful campaign the previous year to reverse a proposed cut to their funding:

“Last year, Bristol City Council were about to cut our main source of funding by 100%. 100%. And we got so much support – which we would have done anyway, we have very loyal clients – but we had support from people who were willing to be out with their status. Which we previously probably wouldn’t have had. We would have had people writing letters. But we had people who were going to [Council offices], who would attend all these things with [Mayor] and all of that. And be in the press. And I don’t think that that would have happened without positive voices, and the campaigns” (Brigstowe staff member P)

Another notable success was the work which had been undertaken in response to a stigmatising press release by the police service, in which risk of HIV was inappropriately used to justify officers’ use of spit guards. Brigstowe were now in a position to mount a response on a different scale to what would have previously been possible – meeting with the police service, challenging them to change their guidance, and delivering HIV awareness training to officers. Independently of Brigstowe, volunteers had contacted the police service to register complaints.

“The feedback from people living with HIV was that it is great to have an organisation which could do that...[before Positive Voices project].... I don’t think we’d have been as thorough. We wouldn’t have been in a position to drill down into it as much. There wouldn’t have been the potential for that real like holistic systemic change which – I mean who knows whether you can change the police force but - we’re knocking into” (Brigstowe staff member Q)

The campaigns team also now had a growing group of people living with HIV willing to do public-facing work:

“It’s about giving space to the voices of HIV positive people in the press and stuff, and a lot of peer supporters have come on with me in doing this work too. Which is awesome. So that has been a direct impact” (Brigstowe staff member Q)

This culture change had helped Brigstowe staff feel more confident when communicating publicly:

“You’re received better as an organisation if you have stuff like this – confident services.” (Brigstowe staff member Q)

Brigstowe were not the only organisation to benefit from transformative potential of the Positive Voices project – clinical services were also changing:

“Having done those sessions, I’m very mindful of how I deal with somebody who is in front of me who, it is their first appointment, where, you know, they may be scared stiff of what’s going to happen. And it’s just kind of being very careful to explain at the beginning exactly what it is that we’re going to do, and that if they have any questions that that is just as important as what I’m doing and to really try and make it a two-way process. Whereas I think before – hopefully I’ve been helpful, but maybe, because you have a proforma, have run off the proforma and that can be a bit of a barrier for a patient. So, it’s having the ability to get the information you want, and need, for the service, but also balancing that with what the patient wants and needs as well.” (HIV specialist clinician)

The weight of history

This confident new Brigstowe was evolving in a context with a long, and ongoing, history of discrimination and stigma. Positive people who had past negative experiences of this spoke about how it was a filter through which they continued to perceive how they were treated:

"There is still an element of being 'second class' – it's my term – it runs through all of my experience with HIV organisations." (Person living with HIV U)

"That is one of the worst things about HIV services...we are not given validation as whole people. We are seen as tainted. And I think Brigstowe are partially guilty of that...But they're getting better [laughs]." (Person living with HIV V)

Participants spoke about experiences of services which were not user-led, and where the idea of people living with HIV helping each other had sometimes been dismissed:

"For so long positive people were not encouraged to help themselves. It was very much we were done unto." (Mentor B)

"Very often they plan a service that you have to fit in to, rather than being responsive. Brigstowe are responsive." (Mentor A)

It was thus essential that organisations working in the HIV sector not only gave careful consideration to avoiding any form of discrimination, but explicitly, transparently and continually discussed and demonstrated the reasoning behind anything which could potentially be perceived as discrimination:

"Think about handling of people who are positive. Because I'm very tender about it." (Person living with HIV U)

Being a member of staff: When is status important?

"I guess with traditional support services you have a support worker and a client, and it's very sort of - there is a power structure within that. And I think positive voices challenges quite a lot of that." (Brigstowe staff member)

There was a sense that when it came to being a member of staff in an organisation such as Brigstowe, there were times when your HIV status was important. The views expressed on this subject were complex and diverse. Positive and negative participants were uncomfortable with the idea that staff could be put in a position of 'having' to disclose their status, but it sometimes seemed difficult to avoid. Many participants – volunteers, staff and partner organisations – wanted to see the role of peer support volunteers continuing to develop, with increasing responsibilities in management and oversight of services. But some participants expressed a desire for Brigstowe also to more actively seek to recruit paid staff who were positive.

"I think they should have more positive people working there. Because it's like....I have black friends who suffer prejudice, but I never suffer a black prejudice so - I know how they feel, but it's not my skin. And I think it's important to have positive people working there..... I never raised this to them, but I think it is something that – they could take this into consideration as well. But there is another problem – if you cannot find positive people qualified to work there. So it's not just like: 'OK we need this', it was just like - something that I think. But it doesn't mean that it's right or wrong." (Mentee)

Participants discussed what they saw as essential skills, experience and knowledge for particular roles, and when lived experience of HIV might be an advantage. One participant thought that the new peer support role was primarily about coordination rather than peer support, and thus that experience relevant to coordination was what should be prioritised. However another participant felt strongly that the coordinator should be a positive person.

Both positive and negative participants expressed views recognising both potential benefits and disadvantages of lived experience in different roles. For example, that it could potentially be more difficult to balance personal experience with professionally stepping back from that experience to *“soak in everybody’s experience.”* Both positive and negative participants spoke about fluctuation of both physical and mental health in people living with HIV – but also highlighted that this was true of any population, and that perhaps it was something which should just be addressed as it arose.

Consensus emerged around the idea that open and reflective discussions were needed on if, when, and why positive HIV status should be a required characteristic for a staff position at Brigstowe. There was widespread support for further steps to ensure people living with HIV are at the centre of Brigstowe as an organisation: what remained to be agreed was what this should look like and how it could be achieved.

5. Recommendations

- Ensure there is a proactive approach to recruiting more diverse mentors, in particular females and heterosexual men. Having a more diverse team of volunteer mentors will contribute to better representation of the wider HIV community, as well as enabling Brigstowe to increase their understanding and response to the needs of the HIV community. Furthermore, having volunteers from different communities may increase engagement, and encourage further potential volunteers from those communities. One way to try to achieve this will be to have a longer recruitment period, and advertise initially using specific adverts in the HIV clinic.
- Consider ways of providing follow-up support with people who have completed the mentoring. For example, by providing a peer support group and crisis/ad hoc mentoring when needed. Just as important is to highlight with mentors, via core training, 1-2-1 & group supervision, the need to continually promote independence with their mentees. This could include increased focus on preparing for the ending of the mentoring relationship and keeping to professional boundaries.
- Recognise the limits of mentoring i.e. Issues that pre-existed before diagnosis such as loneliness, and clarify with mentees what mentoring can help with to ensure expectations are appropriate. To support this to happen Brigstowe will focus on clearly identifying the needs of a mentee, and seek to confirm what a mentoring relationship can and cannot assist with. Mentors will then continue to revisit this during the mentoring relationship, and agree with mentees the next steps that might be helpful to go forward post mentoring.
- Consider, in partnership with mentors, how joint supervision is working, and if necessary make changes. The coordinator needs to be mindful of creating equal space for all voices within joint supervision sessions, and to encourage more of a safe space to talk about mentoring difficulties.
- Explore how to make the first meeting between mentee & mentor easier. For example, at the initial assessment with the mentee the coordinator to check that the mentee understands it is their choice if they choose to proceed or not, and identify any actions necessary to reduce any stress or barriers to the service for mentee – for example, fear of ‘rejection’ by a potential mentor. Furthermore, giving mentees their mentor’s profile (with the mentor’s consent) in advance of their first meeting so they have some information about who they are meeting may reduce anxiety as well as addressing potential power issues. The coordinator will also ensure that they contact mentees in advance of the first meeting to encourage & support the mentee to attend the first meeting.
- Review and continue to develop the Recently Diagnosed Workshop content in consultation with PLWHIV – particular people who have previously attended the workshops. Suggestions from this

evaluation include inclusion of nutrition and healthy living plus more space for discussion by participants.

- To trial the Recently Diagnosed Workshop sessions on two full days instead of one full day and two half day sessions.
- Continue to work with PLWHIV to identify ways in which the Positive Voices services can support people in relation to confidence to disclose, which feedback forms indicated was one of the domains where less progress had been achieved through accessing the services
- Consider delivering HIV awareness training to more community-based organisations - particularly in communities where PLWHIV have identified higher levels of stigma, or lower levels of HIV awareness - and not just to professionals.

Shared Learning

Over the first two years of Positive Voices, Brigstowe has had the opportunity to assist and support other organisations both within and outside of the HIV sector, nationally and locally, in terms of developing and delivering peer support which has led to good partnerships for Brigstowe. This includes Brigstowe being part of two service and project advisory groups: Project 100's (Positively UK) national project steering group; and Bristol's Golden Key peer mentoring service – offering guidance, advice and support, and over sight of the progress of the project so far. Brigstowe has also shared resources and learning with other regional HIV organisations who are developing peer support services. Brigstowe will continue to share the learning they have gained for the rest of the project.

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List of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
BME	Black and Minority Ethnic
HIV	Human Immunodeficiency Virus
PLWHIV	People Living With HIV
THT	Terrence Higgins Trust

References

Braun V & Clarke V. 2006. Using thematic analysis in psychology. *Qual Res Psych*, 3: 77-101