Final Evaluation of the Positive Voices Project

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BACKGROUND

Brief overview of the project

Brigstowe's Positive Voices service started in July 2016 and is in its final stages. It was funded grants from The National Lottery Community Fund and The Henry Smith Charity. The Positive Voices project is a service for positive people, delivered by and with positive people, and comprised of the following three services:

- **Peer Support -** one-to-one peer support where people who have either been recently diagnosed who diagnosed longer & struggling with an aspect of their diagnosis to receive mentoring support from a peer who is also living with HIV
- **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.

In addition, in response partly to the mid-term evaluation that was conducted, **"Transition" workshops** were designed for mentees coming to the end of their peer-mentoring and one conducted, and **training for mentors specifically relating to support disclosure of HIV status** was added.

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 completed a mid-way point evaluation, which aimed to monitor impact, gather learning, investigate challenges and successes, and make recommendations[1]. This final evaluation aims to explore how the outcomes were met and provide future recommendations. Throughout this evaluation, information and text are drawn from the mid-point evaluation. This final evaluation was undertaken by an independent researcher, who has

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[1] The mid-term report is available on Brigstowe's website at https://www.brigstowe.org/wp-content/uploads/2019/07/Postive-Voices-Mid-Term-Evaluation.pdf, completed by Dr Emer Brangan. This final evaluation builds on the previously completed mid-term evaluation. Information is draw directly from that mid-term report to provide context and findings. Elements of this report are quoted throughout this final evaluation.

experience in HIV related research and delivery of mental health and psychosocial support services to people living with HIV.

Broader Context of Positive Voices and the Final Evaluation

Bristol became a Fast-track city in 2019, committing to reach the UNAIDS 95-95-95 target (95% of people with HIV diagnosed, 95% of those on treatment, and 95% of those achieving viral suppression) and zero HIV related stigma and discrimination by 2030. This comes at a time when the City Council has also recently taken over the sexual health agenda, which has moved over from the NHS. Public Health experts within the city's council commission various statutory services across this specialist sector of sexual health, which includes HIV testing and prevention services. HIV support services are partly funded by local authority Adult Social Care commissioning. However, it must be made clear that the local authorities do not have sufficient budget to fully fund HIV support work and rely on local organisations sourcing other funding to complete this work. Moreover, funding cuts have led to a significant reduction in support and closure of other HIV specific agencies.

The Positive Voices project began in 2016. During the project, a number of changes have been seen within local landscape. In late 2019, Bristol became a Fast Track City. Although in recent years, although the number of new cases of HIV diagnosed in the city has seen a decrease, the city remains a "high prevalence area" according to the latest HIV Needs Assessments. Furthermore, Public Health officials report that there are still many people diagnosed late. They also state that "There is still lots of stigma associated with HIV, so there are clear areas we want to improve in". A recent local needs assessment carried out by the city council partners revealed several key issues for the city:

- Insufficient HIV testing
- High rate of undiagnosed cases and late diagnosis
- Persistent stigma
- A lack of understanding of HIV among both healthcare professionals and the general population
- Uneven provision of support services, with a lack of services addressing mental health and support for healthy living

(von Hawrylak, Copping, & McNally, 2020).

Finally, the COVID-19 pandemic was recognised in the UK in March 2020, leading to lockdown and an urgent need to restructure services away from face-to-face support. It was also at this time that that data collection for this evaluation took place, leading to a smaller sample size and understandable reduced engagement from NHS services and other local partners.

METHODS

Ethical approval for the evaluation was gained from the University of the West of England (UWE), Bristol. Informed consent was given by all participants, and anonymised data was provided by Brigstowe.

Data were provided by Brigstowe:

- Qualitative feedback from the attendees at the Recently Diagnosed Workshops
- Feedback ratings for the HIV Awareness Training workshops
- Feedback forms for people using Positive Voices services, completed before / during / after use of the services. 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. Changes in scores were calculated by Brigstowe, and those reporting positive changes were totalled.
- Report of activities undertaken in response to the mid-term evaluation recommendations

The mid-point evaluation had already examined the communication and advertising of the project; therefore this was not covered in this evaluation.

Interview and focus group participants were all recruited via Brigstowe. A focus-group was carried out with mentees, and interviews with mentors, staff at Brigstowe working on the project, NHS HIV clinic staff and public health staff at Bristol City Council. Three mentees and three mentors took part in the study, including males and females and people identifying as heterosexual and LGBTQ+. To ensure anonymity, no further details about those who took part are provided. Anonymised quotes are provided in the report, with any identifiable details either altered or removed. Gendered pronouns are typically replaced with they/their – used to denote both a single individual and multiple people without revealing sex/gender. At some points, no quotes are used to avoid potential identification of the speaker, however the comments relate to the data provided.

The interviews and focus groups used a topic guide, based on what was developed for the mid-point evaluation. This guide provided prompts, however when Dr Martin conducted the interviews/focus group, additional relevant topics that arose during the conversations were explored, particularly where they focused on perceived strengths, weaknesses or developments of the project. The topic guide covered areas of how people became involved with the project, their overall experience with the project (services used, perceived needs and impacts), how Positive Voices fits within other services, perceived future need for similar services, and specific questions relating to the Transitions Workshop for mentees at the end of the peer-mentoring and the Disclosure Training workshop for mentors.

Analysis

Simple descriptive analysis of the feedback forms was conducted. Free text data from feedback forms, and interview data were analysed using thematic analysis (Braun & Clarke, 2006). Two interviews and the focus group were audio-recoded, however owing to technical difficulties the other interviews were not, however extensive notes including verbatim quotes were taken during these interviews, to allow analysis. Audio-recorded interviews were transcribed prior to analysis. Analysis was predominately inductive, with themes developed from the data, with some deductive themes specified in advance. These pre-specified themes were “Getting involved with Positive Voices”, “How mentoring is used”, and “Awareness training opportunities and challenges”, relating to the interview schedule and seeking to explore these specific issues of relevance to the evaluation.

PEER SUPPORT

The Peer Support element of Positive voices provides one to one peer support for people either newly diagnosed or struggling with their diagnosis. Peer mentors (hereafter "mentors") are volunteers living with HIV, trained and managed by the project staff at Brigstowe.

Outcomes data

Data from mentees who had completed the process and those attending the Recently Diagnosed Workshop were reported together. Increased self-confidence was reported by 85 people, with increased sense of purpose in 61, and increased mood in 66. This supports the achievement of outcome 1 "The emotional and mental wellbeing for individuals living with HIV will be improved". More close relationships were reported by 71 people, with greater integration into the community reported by 79 and better knowledge and confidence about accessing services in 61. This supports achievement of outcome 2 "Social inclusion for individuals living with HIV will be improved". Increased confidence around disclosure was reported by 70 people, reported increased engagement in medical treatment by 59, and increased understanding and knowledge of HIV related issues in 72. This supports the achievement of outcome 3 "People living with HIV will be able to manage their diagnosis as a long-term condition".

Specific individual evaluations of being a mentee were also provided. Participants reported personal changes relating to greater confidence, re-engagement with life by starting a new job, acceptance of diagnosis, being able restart medication and go back to clinic appointments, reduced stress, and the positive experience of being able to talk to someone who understands their situation. Scores from 1-5 (5 being strongly agree) were gained from 16 mentees who had completed their mentoring. The mean scores are given below for each question, showing very high satisfaction.

Item	**Mean score**
Mentor was approachable and helpful	4.8
Mentor support to achieve personal goals	4.8
Mentor kept to agreed appointment times	4.8
Mentor reliable in completing agreed actions	4.8
Pleased with the service	4.9
Mentor had good understanding of HIV and the experiences of people living with it	4.9

The experience of being a mentor

Some mentors had joined the project specifically to be mentors and others had previously been in the programme as mentees, either within Positive Voices or in other organisations:

> *"As a mentee, years ago, it was great. It was the only place I could go to and talk openly to someone, without fear, and it was a safe space to cry or to say how I was feeling…and it was this experience that led me to be a Mentor with Brigstowe" (Mentor).*

The process of becoming a mentor involves an interview, training, being matched with a mentee, doing the mentoring, and receiving supervision. Mentors described this as “very professionally ran”. One mentor with previous experience in support roles described what attracted them to the role

> *“The way that it [peer mentoring] was set up, so that it was clear it wasn’t just something being done ad hoc and it wasn’t sort of buddying, which I had had…that is sort of a different type of level of involvement. The way that peer mentor was structured meant it was something that I was interested in doing and I thought it would genuinely help people.” (Mentor).*

The interview process was described as

> *“Very friendly…they wanted to know me and to know where I was, emotionally, to know if I had support outside of Brigstowe like friends or whatever things like that to know that I had support if I needed it after perhaps a mentee who was struggling and you need support”. (Mentor).*

This focus on the emotional wellbeing of mentors was appreciated by them. Supporting people who are supporting others is vital, particularly when working with volunteer mentors (Harris & Larsen, 2007).

Training and supervision were both positively evaluated by the mentors:

> *“The training course it was great…it gave us so much information about things perhaps we didn’t know, and it was people like me doing the course too. We did the boundaries thing and all those kinds of things and how to better listen, what kind of signs to look for when we are with someone, how to signpost people if we needed because at the end of the day we are not counsellors or anything, we are just normal people in the same kind of situation. How to get the most out of them, how to ask open questions.” (Mentor)*

> *“I was able to face pretty much everything that I have had to face up to now.” (Mentor)*

The training was seen as highly comprehensive and mentors described how it covered everything they needed to know, without them needing to have any background in support work and principles such as active listening or boundaries. It built confidence and left people feeling “motivated and ready” to work with their first mentee. Brigstowe staff, people living with HIV and NHS HIV clinic staff all take part in delivering the mentor training, and this composition was positively received.

The only additional content suggested being an emphasis on helping mentors to think about how to tailor support to specific clients, for example tailoring content and information by feeling confident to select freely from what they had learnt, rather than feel there was a specific script. However, mentors also described naturally reaching this point as they gained experience and learning through supervision.

Supervision was highly positively rated. “We have monthly supervision, as peer supervision, and it’s confirmation doing it ok. It’s amazing” (Mentor).

Clearly, offering support to others can have an impact on the supporter. All mentors interviewed described the training and supervision as excellent, and all described feeling well supported. They also talked about the positive impacts for themselves, particularly increased self-confidence and sense of purpose:

> *"Everybody grows, they just grow into being a more confident person" (Mentor).*

> *"I get out as much, possibly different things, as much as mentees do. It's not a thing where I go there and give something, I maybe give my support and experiences, but I get a lot of things from them. I am more confident now, I am happy with my diagnosis now. I do see sometimes it is hard, but in all honesty, I wouldn't have it any other way." (Mentor).*

How mentoring is used

By the NHS HIV clinic: NHS HIV clinic staff see Brigstowe mentoring as an option in their referral pathway, often directly referring their patients to Brigstowe or recommending patients get in touch. Peer mentors are present in the clinic (see below) and this is very positively received by the NHS staff. The clinical staff often mention mentoring and Brigstowe support to their patients, encouraging them to take up the opportunity to meet a peer mentor at clinic or to contact Brigstowe. This was seen as useful, with a formal referral pathway (writing a letter) also a useful tool

> *"We offer, people might decline it initially, perhaps through fear of talking to someone, or who it might be…but I think sometimes plugging away at it, planting the seed and offering to make the referral and make that connection for them so it is not always on their, up to them then…we can do it for them…that Brigstowe will contact them then, so it takes away that anxiety and pressure." (HIV clinic staff).*

The project then provides an additional source of support NHS staff can refer to, and which can potentially take some pressure off them. For the NHS, this project has "been really helpful, and the feedback we get is really positive, we see people's confidence grow". There was an enthusiasm to increase the availability of peer mentors in clinic, and a suggestion for Brigstowe to work with the NHS HIV Team and training of the mentors to consider how to increase peer mentors confidence in approaching people, to reduce the burden of that first contact from the potential service users.

The relationship between the NHS clinic and Brigstowe's peer mentoring is particular worthy of further discussion. Brigstowe staff described that they have worked hard to have a good relationship with the NHS staff, and now "we have clinic mentors, peer mentors up at the clinic, who have been welcomed and used by the clinicians". It is likely that many non-statutory services who could potentially have a symbiotically beneficial relationship with NHS services could learn much from Brigstowe's success in this area.

Referrals from the HIV clinic could potentially benefit from further work. Both NHS and Brigstowe staff noted it was at times difficult to know who to refer, and of course some people choose not to be referred despite a strong "professional" view that they could benefit. Further work with the clinicians to train them on who to consider referring to Brigstowe might be useful. It was reported that peer mentors do attend the HIV clinic team meetings and guidelines have been written for the clinicians. Closer working with the HIV clinic team's psychologist might augment referral appropriateness and quality. Encouraging peer mentors to approach clinicians to explain who they are and what they do has been successful, and further work encouraging and reminding clinicians about the benefits of engaging their patients with peer mentoring should continue. Being clear to clinicians about the scope of peer-support may continue to be useful. Referrals for people who don't appear "bad enough" could likely be usefully discussed with the patient, and clinicians may be usefully supported to think about alternative referral pathways for those with complex mental health support needs.

By mentees: Peer mentoring was seen as special and offering something quite different from other support, such as buddying or NHS services.

> *"THT had a thing called the buddy system where you would go the cinema or whatever and you didn't know if they were positive or not, it was up to them to disclose, but it was like someone to have there. … A lot of that is gone [other services], so there was kind of like a big gap, so when they said about the mentoring for me I thought it would be really really positive to have another positive man or woman just so I could spend some time with, just that bit of identification because I don't have any friends who are HIV positive and it does go deep to having that identification" (Mentee).*

Mentors reflected on the uniqueness of peer-mentoring. The long-term support (for six months) is rarely available in other services and mentors and mentees both described needing this time to build a relationship and create change. The structure of the relationship was also important:

> *"It sits in a kind of…space between completely unstructured, untrained buddying and something much more structured and professional like a form of listening therapy. So they get a bit of benefit of both, which can be difficult if what they want or need is sort of a very pure version of the other. We have got someone mentee who want to go on a day trip, and we can't do that. And other mentees who what they really want is a therapist, and we can't do that. But sitting in that in between space it takes some of the pressure of so it is not as formal as sort of going to see a therapist." (Mentor)*

The above quote also illustrates the extent to which mentors had taken on board training relating to boundaries and the scope of their role.

Mentoring was used differently by different individuals, however there was a unifying factor of being able to talk:

> *"People are getting a wide range of things out of this, clearly they are getting the benefit of speaking to someone and spending time with someone who is HIV positive, which despite what I had imagined before I had started, there are quite a significant number of cases where their mentor is the only other HIV positive person that they have a connection with." (Mentor)*

For NHS HIV clinic staff, the opportunity to talk to a peer mentor, either at the clinic or as part of the peer mentoring scheme, was extremely important.

> *"That realisation they are not alone, someone else has been there…and someone you can speak to again in the future, get support from and just to take away that fear and that anxiety of feeling like it is purely on your own shoulders. It is reassuring." (HIV clinic staff)*

Brigstowe staff reflected that the way mentoring is used may be changing and is always driven by the individual involved.

> *"At its core it gives that opportunity to have a conversation with someone who understands it…when people share their diagnosis with someone they have to support that person through what is happening to them, that doesn't happen here. It's a very non-judgmental space, and it's removed from that stigma. If there wasn't stigma, there would be less need for it. It's also about information and going through a big change in your life having someone separate who you can just talk to about how you feel, work out how you feel about it. You just want to talk a bit or rant a bit. So much more important because there is still stigma" (Brigstowe staff)*

Having the opportunity to talk openly was greatly valued and perceived as not being available elsewhere in the same frank way. Here the mentees describe being able to talk about their medication:

> *"It feels nice to talk about what it's like taking your meds! You don't get it, like when you go to the doctor even if you do get chance to talk about it, they are just like why aren't you taking your meds and it's like because I have lots of other shit going on and sometimes I forget. (another mentee says "Yes, I couldn't be bothered, I was tired, I was depressed, I wanted to punish myself") (another mentee says "and they just say 'just keep taking your meds'") but yeah I know, but sometimes I don't want to because I just feel like shit, but the doctors don't care about that". (Mentees)*

Mentoring was perceived as being goal orientated, but also as offering space and release:

> *"The mentoring alleviates it [stigma], it doesn't go away but you get that comfort". (Mentee)*
>
> *"It's like even though it [peer mentoring session] is even once a week, you know that you have got a safety net to come, even though it's building up, building up, you've got that week's visit." (Mentee)*
>
> *"Alleviates a bit of pressure, even it's just for an hour or two, then you go back to your life". (Mentee)*

Mentors talked about using "achievable goals", sharing knowledge, and working to increase their mentee's confidence, both specifically to ask questions and request support at the HIV clinic, but also more generally to do things they valued.

The experience of being listened to, without judgement, was named by all as important to the process. Mentors also talked about the importance of having structure and how regular meetings in themselves provide support by giving a shape to the week: “helps them navigate, from having someone on a weekly basis, setting goals so you have structure” (mentor).

Content of discussions within mentoring sessions was highly varied.

> *“If newly diagnosed, meet someone else who isn’t clinical and just be able to talk openly…meeting someone who is also positive and they can share their story and support you, particularly newly diagnosed people, helps them to move forwards a lot faster.” (Mentor)*

> *“For some people, the diagnosis is just the beginning, that unravels so much more… [other difficulties, other life events, relationships with people and their reactions, self-stigma built back up again].” (Mentor).*

> *“If long-term diagnosed, sometimes feel like later on that they possibly would benefit from having a mentor because they had sort of felt that they had dealt with everything and then realise at a later point that they haven’t…or dealt with certain parts and then get to a point where they realise there is something else … e.g. self-esteem, self-stigma, disclosure..” (Mentor)*

The mentoring is designed to focus on HIV related issues, and this was made clear in training for mentors and in discussion with mentees at the start of the process. However, one mentor described the limitations of this

> *“They remind us regularly, that we are here to support people with their HIV. But for me I am concerned that the messaging might slightly get in the way of… but my instinct would be that if somebody is coming to access a mentoring service, there will be some people that it’s just a specifically related to the HIV, but actually more likely, and it feels like it from the people talking about their experiences, that actually these are going to be individuals who actually have a much wider range of issues and needs in their life of which HIV is one, but those wider issues are what are driving the behaviour or mental health or other issues that are affecting them in relation to their HIV.” (Mentor)*

This mentor went on to describe how it may be important to continue to advise mentees of the need to focus on HIV related issues in their work, however to explore with mentors in more detail a holistic way of thinking about the person’s wellbeing and thinking about how issues may connect back to HIV, for example

> *“You can give someone all sorts of dosette boxes and alarms and medication apps, but if their mental health is the reason why they are not taking their medication on a regular basis, they are not going to take their medication until they get some support around that.” (Mentor)*

One issue that arose in discussions with all respondents was that of mental health needs. Public health staff explained how they viewed the likely needs that mentoring may reach:

> “Mental health issues are one of the biggest issues, they do have access to clinical psychology, it’s not just like mental health issues like depression or anxiety, but also just understanding how it is to live with HIV – and they provide an invaluable service there”.

It is well acknowledged in the research literature that people living with HIV may be more likely to experience depression, anxiety and some other mental health problems (Chaudhury, Bakhla, & Saini, 2016; Harding et al., 2012; Nanni, Caruso, Mitchell, Meggiolaro, & Grassi, 2014). The scope of peer-mentoring is clearly not to provide psychological therapy, but to provide support and potential signposting.

Mentors and mentees described knowing others or they themselves having mental health challenges, including suicidality, substance misuse, depression, and anxiety including social anxiety. The mentees talked about their view of themselves, particularly at time of diagnosis but extending into the present

> *“I was sat feeling really down, thinking I have missed out, not by my choice…I have missed out on a lot of life because I got into the depths of despair with it all, like with drinking and self-harm and I just don’t feel good enough, I feel dirty (another mentee says “yeah me too, dirty”), and damaged goods, (another mentee says “yes, yes, it was bad before, but then, I have this now”), it cements it.” (Mentees)*

Given the context of mental health services in the UK and Bristol specifically, it is likely that some mentees will approach peer-mentoring with some mental health needs. Mentors described feeling adequately trained to manage these issues. Brigstowe staff reported taking this into account when assessing people for engagement in peer-mentoring, with onward referrals and careful consideration of suitability for the program. Closer links could be developed with the mental health services in Bristol, not only to train them in relation to HIV, but also to potentially gain some expertise in how these services are accessed.

Impact of mentoring: For Brigstowe, the aims of peer support, including peer mentoring, were clear:

> *“For people living with HIV to be able to manage their condition better, not just medically but mentally as well, and being connected, and having a support system in place, for you to be able to connect with when you are having a difficult time. And when you know someone is more active in managing their health, they are less reliant on services. Once they are feeling like their self-esteem and self-confidence are back, they can get on with their, get a job, get a partner…and it also transfers to our mentors who have become way more skilled and have connected with their colleagues.” (Brigstowe staff).*

Through the comments made about their usage and experience of mentoring, it was clear that mentors and mentees alike were reaching these outcomes.

The importance and impact of mentoring was felt very strongly. A mentor said

> *"The peer mentoring should definitely continue. It's an escape for many people. If it wasn't there, if I think of the people I have supported, their lives would be awful honestly, they wouldn't have the knowledge, they lived with fear 24/7…I think it would be terrible as many people can't access the knowledge or have a space to think. Their mental health would be, well, I don't know." (Mentor)*

This point was made even more strongly in this discussion between mentors ("-" indicates start of another person talking).

> *"I think this is invaluable…*
>
> *- I think without this, there'd be a lot…*
>
> *-more suicides -yeah, there'd be more uncomfortable, this is it, this is saving lives…*
>
> *-it's the last place I have got to go, where they are cutting more and more services". (Mentees)*

Additional developments to how mentoring is delivered and used

Owing to their significant expertise in designing and delivering peer-mentoring programmes, as evidenced by the strength of their work, they have also become involved in running groups for people with diabetes.

> *"We also run peer support for people living with type 2 diabetes, yes there can be some stigma related to that, perhaps sometimes people get a bit of blame about their eating habits and things like that, but a core element of peer support is about talking to another person who is not a professional and sharing how they manage their health in real terms as a real person and how you can adapt your lifestyle and do behavioural change, it's not just taking medication, it's all long-term health conditions. And all things, someone who has had a breakdown in a relationship the best person to speak to is someone who has been through that." (Brigstowe staff).*

An additional outcome them from the Positive Voices project is an opportunity to share transdiagnostic expertise in developing peer support programmes. There is potential for further expansion of services, and potential to offer training and consultation to researchers, clinicians and voluntary organisations seeking to offer their own peer support.

Getting involved with Peer Mentoring

Mentors became involved with the project in a variety of ways, some through friends who were already engaged with Brigstowe, and others through adverts at the clinic. Additionally, there are those who were mentees who are now mentors, "completing the circle" (mentor).

Mentees engaged in diverse ways also. The adverts at clinic had prompted some to seek mentoring out specifically, others had been signposted from other agencies or by friends, or were already using Brigstowe's other support services. Some mentees were already aware of Brigstowe or other HIV services. The methodology is inadequate to ascertain for certain, however there appears to be greater awareness of Brigstowe within the gay male community, likely simply mirroring a greater awareness of HIV amongst this group, linked to a higher prevalence amongst men who have sex with men (Nash et al., 2018). One mentee explained "I didn't know anything about Brigstowe…but HIV wasn't in my world. None of my friends knew about HIV, I didn't have any friends who knew about it, we didn't discuss it". Some mentees had engaged with Brigstowe for several years prior to becoming involved with the Positive Voices project, whilst others joined specifically for that purpose. A sustainable service is key: several mentees talked about "dipping in and out of Brigstowe's services" and feeling "they are always there when you need them", allowing people to access and use peer mentoring when they felt ready.

An initiative to place a mentor at the HIV clinics was universally talked about as a success and useful thing, to be extended if possible. One mentor described "They will have seen the clinician or the nurse or whoever, who signposted them to the clinic peer mentor and if you are there they will come to see you, and they say 'you are the first person I've spoken to about this', but this is not the case at all, but there is something about when they talk to us, about feeling heard". This initiative in turn opens up the opportunity for people to then come into peer mentoring services more formally. Mentors, mentees and clinic staff all named the importance of being able to meet someone from the peer mentoring scheme, to put a face to it, in order to help people feel confident to access the service. Additionally, although people may not require or engage with mentoring immediately, it was felt that meeting a mentor at the clinic helped to "plant the seed" (mentor) in the person's mind, so that they may know where to come for help in the future if needed or ready.

The mentoring journey

Referral and assessment:

Brigstowe staff described the process of referral and assessment. Referral could be self, by a colleague at Brigstowe who already knows the person, or from the NHS HIV clinic. The peer support co-ordinator (then makes telephone contact with the potential mentee and conducts an assessment:

> *"Find out why came to the service, what they want, what support they already have got…try to get to know them enough to feel confident enough to match with a mentor." (Brigstowe staff)*

The assessment involves a consideration of risk, and particularly considers mental health. The description of the assessment process given made it clear that scope of the service is kept in mind, seeking to ensure that peer mentoring is appropriate for the mentee, content of support is something mentors would be suited to offer, and that the mentee is likely to be able to engage in the process (for example, an unmanaged addiction problem may prompt the PSC to refer the client to addiction services, however a person who is managing an addiction and could therefore engage in peer mentoring would be considered to be a mentee).

> *"Usually when people speak to me they do delve into quite personal things sometimes, it is quite common that they share a lot…so if they are really struggling with their mental health I'd want to make sure that the service is the right thing for them, that they really want help with their mental health rather than their HIV." (Brigstowe staff).*

Brigstowe provided information there have been no adverse events relating to risk to self or others.

Matching: Mentors and mentees are matched up, following an assessment of the mentees by project staff. Mentors and mentees all generally described this as a very thorough and positive experience, and were clear on the importance placed by project staff on ensuring a “good match”. One mentee described they were matched with a mentor they felt was not able to fully understand or work with their current needs and degree of comfort with disclosure of HIV. This is an issue likely to be particularly important for those more recently diagnosed: adjustment to HIV is an ongoing process, with denial, acceptance, and readiness to be “open” about HIV status something that changes as develops as a person lives with their diagnosis (Flowers, Davis, Larkin, Church, & Marriott, 2011; Martin, Russell, & Seeley, 2014). Mentees may respond by withdrawing from the service. Although the respondent described the project staff as highly responsive and understanding, there is also the risk of recipients of voluntary services not wanting to say anything negative, owing to a sense of gratitude or reduced confidence or perceived power. It must be repeated however that this negative experience was in the minority and when the person discussed it with Brigstowe, it was resolved rapidly.

Meeting***:*** Mentors and mentees did not offer specific issues relating to meeting up, with the exception of a mentee who felt their match with the mentor was difficult after their first meeting. Further questioning led to positive evaluations of this being “easy”. Sometimes meetings had specific goals, e.g. to go to a specific place to meet a goal of getting out more. Other times, meetings were simply an opportunity to chat and feel understood.

“You know when you want to talk about your meds or you just like want to talk about, like the hospital visits, because they are not like quick visits, or little things like that, you know like when you are just feeling tired, because you can tell close friends but they don’t understand, they can make all the right noises and stuff but I don’t think they really get it.” (Mentee).

For some, contact extended to text-support outside of meetings. Where this was the case, boundaries had been set as to what mentees could expect in terms of when they might hear back and the type of support. Mentors described talking about this in supervision, focusing on how to maintain appropriate boundaries.

Ending and after mentoring: One mentor put it “after peer mentoring, people want more”. For mentees, the feeling was universally that something else was needed. For some, this need was quite intense “And when it [peer mentoring] ends, it’s like the rug is pulled out from under you” (mentee).

Ending mentoring, like beginning it, was a process. For one mentee, this was particularly clear:

> *“Although it was really useful at the time, when I know something is coming to an end you just kind of like start to close back up again and I felt like I needed to continue engaging with other people who are HIV positive”. (Mentee)*

This quote also illustrated how mentoring ending led this person to seek engagement with other positive people as another support source. This vital element of being empowered to seek further social support is perhaps a key outcome of mentoring, and relates to Positive Voices project outcomes 2 and 3: Social inclusion for individuals living with HIV will be improved; and people living with HIV will be abler to manage their diagnosis as a long term condition.

A mentee echoed the need for continued support going forward after mentoring:

> *"They said to me about a group going forward after mentoring, I was like yes, because when you have finished your mentoring and things are all resolved, well not all resolved…but for me to have this out, because I achieved so much, I was so proud of myself, and the encouragement from everybody, it's just amazing." (Mentee)"*

Ongoing contact with people living with HIV and support from peers was talked about as a way of maintaining positive momentum in life and tackling social isolation.

The mentees had attended a pilot "Transitions" workshop. They all evaluated this extremely positively, had enjoyed the opportunity to reflect on their successes and changes made during their mentoring, and were empowered to make plans themselves to make contacts. They reflected back very strongly that it would be essential to continue to offer and develop these workshops, with an emphasis on a need to be flexible in content and being led by the mentees themselves. Ideas for how to continue support post mentoring are provided below, however it is important to note that the "Transitions" workshop provided a useful "end-point" to mentoring and a clear opportunity to reflect on progress, which was appreciated by mentees. As such, it is recommended that these workshops continue.

Several ideas were suggested for how to address the challenges and concerns about ending mentoring:

1) Limited meetings over three months – different mentor, check in with how coping, continuing with goals, then explore what people need to then move forward on their own – particularly important where people might not want to be in a group or who are worried about being in a group and being recognised
2) Mentees set up own monthly meeting, safe space, "feel that they could chat openly" – then is run by volunteer mentor and a group member (ex-mentee). Mentees described this idea with enthusiasm, noting that having ongoing group sessions with other positive people would be supportive and fun, in a safe environment where they felt they would not have to hide their HIV status. The pressure of feeling they had to hide part of themselves (see later section) was described by all mentees, therefore a continued peer group is of enormous importance to encourage social interaction. Mentees were keen to volunteer to run this, sharing the organising and timetabling to ensure for meetings there would always be someone there. Brigstowe staff supported peer-led approaches "Ultimately wouldn't it be great for this not to have a staff member there, for it to be ran by a peer mentor, who could be paid to do that." Funding would be essential to ensure sustainability and to respect the time offered by volunteers. Mentees described a potential rota system whereby meetings could be led informally by different graduate-mentees and a final session with a mentor could include popping into this end of mentoring group.
   One mentee made a clear analogy:

> *"Like NCT [group for people expecting babies which consists of formal sessions and then typically self-sustaining contact within the group for emotional and*

> *practical support] for HIV, you know like the mothers have all got the kids in common but they don't have to talk about that, like we have all got HIV in common, that connection, but we just want to have a laugh and talk about something different too" (Mentee)*

3) WhatsApp group and text messaging as an informal way for people who have completed mentoring to stay in touch and organise their own social events or have supportive chats. This was suggested by the mentees.

Managing the mentoring process

When the project began, it was led by the Positive Voices Services manager. Following recommendations in the mid-term evaluation, a peer support co-ordinator (PSC) was employed. This has allowed development in engaging external agencies in awareness training, writing policy for police on blood-borne viruses, and developing peer support for people living with other conditions. The PSC post is essential to provide the dedicated time to train the mentors, assess mentees, and offer additional training and supervision. This specific time to run the peer mentoring scheme is essential, to the success of the scheme and to allow the services manager time to engage in strategic development.

The time and resource to manage the mentors is essential and effective. Brigstowe staff reported

> *"It means proper things are put in place, policies, training, support for peer mentors. …Our retention for peer mentors is high, they don't want to leave, which is great. We ask a lot, the initial training is three days, then more, and ongoing stuff. You don't get that unless volunteers feel valued, and it's really a community" (Brigstowe staff).*

There is a potential role here for Brigstowe to offer other agencies consultancy expertise on how they achieve this retention and buy-in, and these comments underscore the importance of a funded co-ordinator to offer an operational service.

Given there are currently seventeen mentors engaged in the program, and both capacity (in terms of suitable volunteers) and demand (in terms of people requiring mentoring or training from mentors), greater funding for a full-time will be essential to maintain and grow this service to achieve maximum impact. Brigstowe staff have clear ideas about future development, with possibilities to broaden new referrals by visiting other organisations, LGBT groups, drug and alcohol services, student groups, and mental health charities. Here, training could also be offered about HIV. Additionally, regions around Bristol (e.g. Swindon) where there are fewer services for people with HIV, could be served by the scheme.

Progress against mid-term evaluation recommendations

The mid-term evaluation made several recommendations relating to peer mentoring. These are listed, with Brigstowe's reported actions.

1. 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. **Actions taken**: Brigstowe were able to broaden their recruitment and added seven new mentors. This includes four females, three people of colour and two heterosexual men.
2. Consider ways of providing follow-up support with people who have completed the mentoring. **Actions taken:** A consultation exercise with previous mentees took place, leading to an initial "Transitions" workshop to offer discussion of the experience of ending mentoring and plans for future support groups. More detail is presented on this issue elsewhere in the report. This trial workshop was positively received.
3. 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. **Actions taken:** Assessment of mentees is used to identify their needs and confirming the boundaries of the relationship with mentor and mentee. In addition, mentors are advised to continually revisit the needs, aims and boundaries of the work, and signpost on if necessary. Furthermore, mentors described in the interviews that supervision arrangements supported to be conscious of boundaries and aims throughout their work.
4. Consider, in partnership with mentors, how joint supervision is working, and if necessary, make changes. **Actions taken**: The project co-ordinator continues to work to create safe spaces for discussion during supervision and encourages mentors to use this. Furthermore, the use of senior mentors provides another avenue, as these senior mentors model good use of supervision and help create a safe and open atmosphere in the meetings. Data provided through the interviews with mentors supported this. Mentors described benefitting from supervision "hugely", not only in the discussion of issues they were keen to bring up, but also from listening more generally to the experiences of others and planning how to use this in the future.
5. Explore how to make the first meeting between mentee & mentor easier. **Action taken:** Brigstowe report a number of actions. The co-ordinator now regularly checks with mentees that it is there choice if and how to proceed with mentoring. Mentors have completed a profile to help the co-ordinator to ensure a better match, and this has received positive feedback from mentees. Information about the mentors is shared with the mentees in advance, which again has received positive feedback from mentees.

RECENTLY DIAGNOSED WORKSHOPS

These are 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. 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

The workshops were initially run once a year, suiting the number of recently diagnosed people in the first two years of the project. Bristol has however seen a decline in number of new diagnoses. This caused some questioning about the future of these workshops, however as discussed in the section on “Timing”, the need for support relating to diagnosis at any time point is evidenced and there remains a need for this type of support. Around 10-12 people attend each group.

For those who have been recently diagnosed, the idea of attending a group may be very overwhelming. As such, significant resource is required to support these groups.

> *“It’s very labour intensive to get people to join up. People are very nervous…. So it’s lots of check ins, encouraging people to come, supporting them to get into the room, delivered by positive volunteers and some clinicians. They all bring their own thing…. and it develops as we go along – timing, time of the day etc. We have positive members deliver it as much as possible.” (Brigstowe staff)*

Several attendees at these workshops go on to make use of the mentoring system.

By April 2020, four of these workshops had taken place, with a total of 46 people attending. The workshops are delivered by the manager of the Positive Voices project, and four people living with HIV working, with input from a HIV clinic specialist nurse and a worker from Terrence Higgins Trust. Of interest, for the March 2020 workshop, two of the people living with HIV who co-delivered the workshop had previously been attendees at a Recently Diagnosed Workshop who then felt motivated and ready to move onto delivering the content to new participants.

Mentees and mentors described the impact of diagnosis on them:

> *“I remember going up to the clinic, wearing my red ribbon like I always did, and I took it off that day and I have never worn one since because for me it’s like the mark, put an X on me…and that’s still present now.” (Mentee).*

It was striking the extent to which point of diagnosis was clearly remembered by all, although the information and days and weeks that followed were not necessarily clear.

The mid-term evaluation found a clear theme of the importance of meeting with other people living with HIV during these workshops “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”. Participants at these workshops included people from a range of backgrounds and communities.

Reactions to the material presented were highly positive. The mid-term evaluation found that 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, identified at mid-term evaluation. These findings were echoed in the data provided for this final evaluation, with information about insurance also being referenced as particularly useful and the challenge of discussing HIV status was mentioned as an area for possible inclusion. It is important to note that Brigstowe developed a training workshop on disclosure for peer mentors to help them support mentees with this issue.

For this final evaluation, it was not possible to discuss factors impacting access to workshops. General issues relating to reaching out to communities are explored in the findings from the focus groups and interviews. The mid-term evaluation made the following recommendations:

1) Trial these workshops to be around over two full days
2) Continue to develop content to ensure relevant and comprehensive to meet what people living with HIV ask for

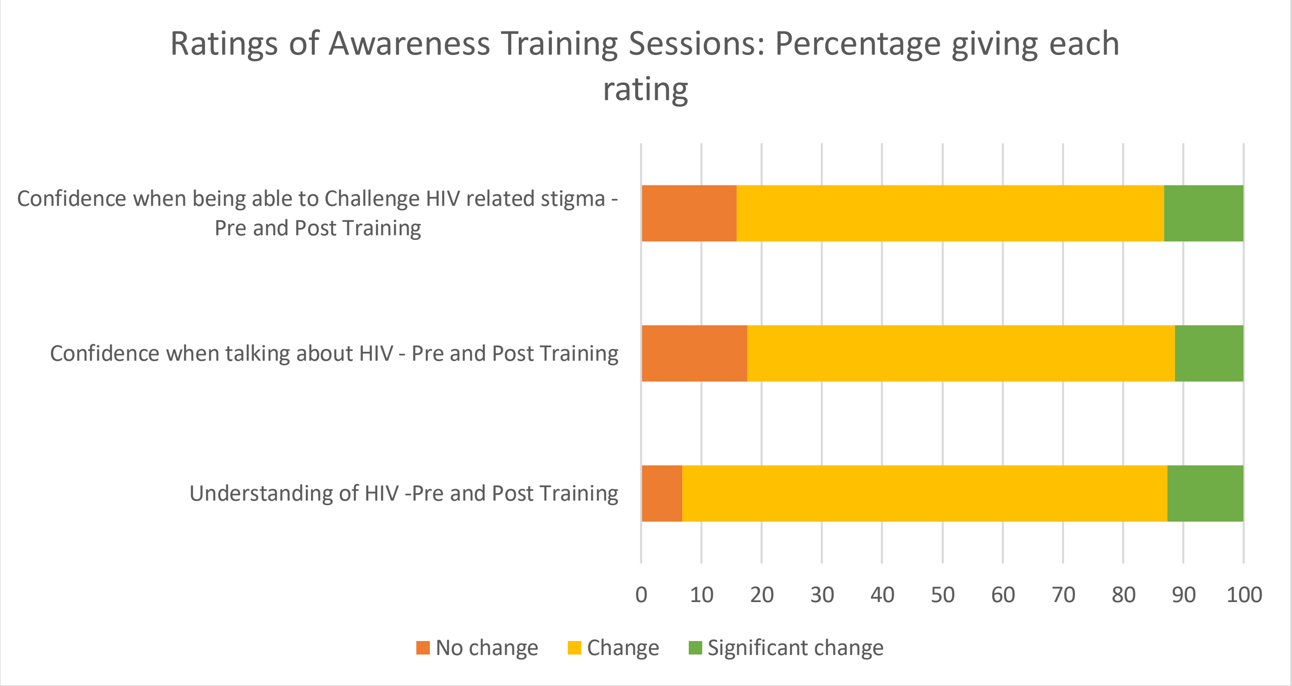
In response, Brigstowe ran sessions over two full days, which was very positively received. They also explored with people living with HIV the potential inclusion of disclosure role-plays. These were due to be ran in March 2020, but delayed owing to the COVID-19 pandemic. The approach of ongoing consultation with service users and responsive development of content is a significant strength of the Positive Voices project and should be a feature of future work.

HIV AWARENESS TRAINING

Relating predominately to Positive Voices' fourth planned outcome "Social cohesion will be improved by increasing professional's HIV expertise, and reducing stigma within community organisations", awareness training forms part of the project. The HIV epidemic began in 1981 and despite the 39 years of activism, awareness campaigns, research and advances in treatment, there remains a lack of awareness of HIV. Brigstowe has delivered 32 training sessions, reaching 19 different audiences and 847 individuals. Organisations include mental health providers, health and social care university students, other charities, the police, prisons and the Bristol city council. Full details are presented in Appendix 1.

Participants rated training as highly positive. Data were not collected from all attendees, owing to practical restraints. Figure 1 provides a summary of all data collected. No negative changes were reported. When rating the "how effective was the Positive Speaker (person living with HIV) at raising individual awareness of the issues?", 97% rated them as "very effective" (on a scale of not effective, effective, very effective). It is clear that outcome 4 has been successfully addressed by: "Outcome 4: Social cohesion will be improved by increasing professional's HIV expertise", with marginally less progress relating to reach to community organisations.

Figure 1 Ratings of Awareness sessions over project life



Training was not only highly rated on the scale used but also in the positive comments received about the level of high-quality information provided, comprehensive coverage of this information, and style of delivery. Brigstowe reported they have received repeat requests for training. The inclusion of people living with HIV telling their own stories was highly praised by those receiving training.

The need for training was described particularly strongly by the interviewed mentees and public health staff. The mentees talked about a lack of knowledge, both in the public and for some HIV positive people who did not know about it until their own diagnosis. Public health staff commented "It's a preventable disease and in this day and age we shouldn't be discriminating and people should be aware…and I think there could be more done on a health promotion point of view in terms of raising the awareness of HIV and U=U campaigns"[2].

In terms of where a lack of knowledge about HIV is perceived, mentees and mentors both talked about "everyone" needing training. Public health staff also pointed out there is a "lack of understanding amongst health care professionals, we have about 1000 people who are positive so that's not many", emphasising that some health care professionals may very rarely work with someone with HIV and therefore have limited/out of date knowledge. A mentor described that there is a need to "get information and positive information out…they don't know, you go to your GP and we still hear bad stuff". A need for public awareness was also discussed by mentees and mentors. A

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[2] "U=U" refers to the fact that when someone with HIV has an undetectable viral load, it is not possible for them to transmit HIV through sex, therefore "Undetectable = Untransmittable". This campaign has been growing since around 2019. For more, see Calabrese et al, (2019) Provides should discuss U=U with all patients living with HIV. The Lancet HIV. 6(4)e211-213

mentor felt progress had been made “It is changing, a big change with U=U, at events…people being more open, and each year that is growing, so all the events we do, they open it out”, however when the mentees discussed this issue, they raised a strong need for broad-brush community efforts.

> *“I would like them to do a campaign and put more adverts…on the telly, doctor surgeries…but not scare posters, just facts and information, you know knowledge to make people more comfortable…like HIV AIDS and gravestones and stuff.” (Mentee)*

> *“You see adverts on the TV now about ladies incontinence and stuff….they are done nicely…and like Canesten and stuff…I’ve got some Viagra…why not that for HIV…but I think we are living through the trauma of what they created in the 80s, in needs to be bigger to smash that out.” (Mentee)*

There remains some work to be done. Training was delivered to professionals rather than community groups and it remains vital to engage with a range of local communities to truly increase HIV awareness. Furthermore, there is greater need within the health service and other third sector providers. Brigstowe described that owing to staff capacity, it was challenging to deliver more sessions. It will be vital to expand the pool of trainers, including people living with HIV where possible, and perhaps consider development of online training and video materials.

Public health staff commented on the possibility here to be more strategic in the training work, with suggestions for targeting whole organisations, as well as the smaller number of people from an organisation who will make it to face-to-face training sessions. For example, they suggested “Trying to reduce stigma around workplaces, rather than just working with a few individuals, working with the City Council to look at what they do with workplaces”. Positive voices could usefully offer this training, but also write policies, education materials and guidelines for managers and staff.

One specific audience for further training was suggested from public health experts. “Working with dentists, thinking about how they can influence that type of work and having positive HIV charters in workplaces and skilling them up, with that peer support element of people going in there talking about their experiences and getting people to understand what it is like to live with HIV services”.

At more strategic level still, public health staff talked about how “It’s trying to make sure they are in the right places to have those influential discussions, like getting into One City [an inter-agency city-wide vision, with boards focusing on different challenges such as inequalities] led meetings with the HIV issue”. One City meetings are also attended business and local leaders, representing a potential opportunity to create strategic plans to address HIV awareness. People living with HIV could play a key role in this, acting as advocates and providing their expert input and knowledge, attending high level meetings to provide their insights and contribute to planning efforts.

The mid-term evaluation made recommendations for the awareness training: 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. Specifically, consider delivering sessions to community organisations; train fundraiser and communications managers to deliver the training and shadow training delivered by people living with HIV prior to themselves delivering sessions. Plans were made for all of these actions to take place, with the fundraiser and communications manager having undergone some training and planned to deliver training to police groups.

Of note, the “U=U” message (that an undetectable viral load means HIV is untransmissible through sex), which is a common component of modern HIV awareness training sessions, was not perceived in a straightforward way by the mentees. Mentors talked about being able to share this important and positive message, and it is included in the Recently Diagnosed Workshop. Mentees described a sense of disbelief and repeatedly emphasised the “what ifs”: what if I have a “blip” in my viral load, what if I forget my tablets.

> *“It’s like the U=U, it’s great but it is still a responsibility, you can only do U=U if you are taking your meds, so there is another responsibility.” (Mentee)*

> *“I was like, Oh my god, finally, like after all these years it’s ok to have sex without too much guilt, but that was short lived. I have read too much into it and I’ve gone but yeah, then I’m still responsible that I’ve taking my meds and if I’ve with another person who is positive have they taken their meds, you are still responsible.” (Mentee).*

This then represented an additional sense of pressure, to be undetectable constantly. Previous research has documented the sometimes onerous sense of responsibility that can arise from U=U type messaging (Young, Davis, Flowers, & McDaid, 2019). It remains important then to explore how useful this message is within mentoring for each individual. Furthermore, mentees all described the ongoing challenge of medication adherence, and times when low mood or life events might interfere with adherence.

DISCLOSURE WORKSHOP

Mentees discussed the challenges of disclosure, and highlighted how this may be a particular challenge for non-white, people with strong religious beliefs, and / or heterosexual people – suggesting that within these communities knowledge of HIV may be lower and stigma higher than in the gay community, for example. Disclosure is seen as an individual’s choice, however it was also seen as stressful by mentees. Mentors also were aware of the importance of this issue: “It’s a major issue for the people I have mentored” (mentor).

Disclosure of HIV status tends to be higher for heterosexual people, people of non-white ethnicity, with more recent diagnosis, and without a stable partner; and has been found to be associated for men who have sex with men with depression, anxiety, and poorer adherence to HIV medication, and (Daskalopoulou et al., 2017). It is a complex process, rather than a single event or discussion (Smith, Cook, & Rohleder, 2017), and can be experienced as highly stressful owing to concerns about stigma and rejection (Dibb, 2018). The mid-term evaluation made the following recommendation:

“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.” Specifically this included recommendations to consult with mentors to help identify ideas; design and deliver workshops for mentors to support mentees; and incorporate disclosure into the Recently Diagnosed Workshops. Brigstowe has reported their work in these areas. Consultation with mentors for how best to address this is ongoing. Training workshops for mentors have been designed and one workshop has been delivered to date. Ongoing revision of the content of the Recently Diagnosed workshops is developing further disclosure content.

Mentors who attended the disclosure workshop described this as providing “good tools” to support discussion with mentees. They felt the workshop covered important content of helping people think through how to actually do it in reality. The workshop and materials were well received

> *“We did like the pros and cons of disclosure, and it was so clear that the positives weighted so much more than the negatives. But to hear what other people think, that I hadn’t thought about, it was very enriching”(Mentor)*

One issue to consider further was named by a mentor who talked about what to do when people live in communities where their reality is very much that they cannot disclose. The mentor raised the importance of being clear that although disclosure is seen generally as positive, there are situations where mentors need to be sensitive, and provide a message that “You are free when you tell someone, but you don’t have to” (Mentor). Indeed, for some, disclosure may have significant negative experiences and one mentor reflected that this was covered in the training when supporting mentees to consider pros and cons of disclosure. The finding here is of the importance of offering training that avoids a normative expectation that disclosure is *always* positive, and that this is emphasised.

ADDITIONAL FINDINGS FROM THE FOCUS GROUPS AND INTERVIEWS

Stigma and fragmentation

Mentees and mentors alike talked about the impact of stigma, as did the Public Health staff. Some remarked on how Brigstowe seek to fight stigma, both through the training done as part of this project and through other actions like booking HIV events to take place in public spaces.

One mentee described their view of HIV stigma.

> *“HIV diagnosis, there is so much stigma. Like there is stigma attached to alcohol and drug abuse, but like they are common, and you add HIV to it and it’s like where do I go with all of that…. I didn’t have to be anyone else, it felt like I could just be with another person.” (Mentee).*

Here the idea of having to “be” someone else is evidenced. This was discussed in detail by the mentees, who described a sense of having to break oneself up into different bits, that you can show some of in different places. Another mentee put it: “It’s almost like a game of poker isn’t it, because you are not quite sure how to do it, who you are playing with”. (Mentee). In contrast, when using Brigstowe services and peer-mentoring in particular, they felt this was not necessary: they could bring their whole selves.

HIV services are increasingly facing mainstreaming, whereby specialised services may be reduced as people living with HIV are encouraged to access services open to all. Whilst this approach is useful for provision of long-term condition support in many way (National Aids Trust, 2016), the description from mentees of feeling fragmented raises a potential concern here. Mentees spoke about feeling stress at having to keep their diagnosis secret, at having to hide a part of themselves owing to stigma: “When you are in places that aren’t HIV specific, it creates a thing where you don’t want to talk about all of you" (mentee). The Positive Voices project, particularly the peer-mentoring, offered a service where people can receive support about living with their condition in a way where disclosure feels safe and, vitally, people feel able to be themselves. Other services, such as generic mental health befriending or mainstream mental health support workers would not offer this.

Isolation

Related to stigma for many, but not exclusively, was the theme of isolation.

> *"It was thinking about my own experience….I had positive friends when I was diagnosed … that made me sort of realise how invaluable that was in that point of time for me really, how well it set me up to cope going forward, and realising that probably isn't the case for some people. …but some people are so isolated when they become positive." (Mentor)*

Mentees variously described feeling isolated because they were part of heterosexual communities where HIV simply was not talked about, and mentors echoed this by also describing working with people who were part of faith or cultural groups where HIV remains highly stigmatised and not spoken about.

> *"You have been told you have got this [HIV] and I thought god I'm going to die, my life is over, and I couldn't tell anybody, I still haven't told [only told my family]. You feel very lonely and isolated don't you and you have got to be very guarded when you meet people and you are talking, you have to think yeah but you don't know and you have to be careful, it's very tiring and sometimes like even now I stop seeing certain people because I feel I can't trust them and I don't trust myself not to say something and then they find out." (Mentee)*

In sharp contrast to experiences of isolation, were the experiences of the peer mentoring relationship.

> *"Just the fact that you are talking to someone who is also positive and they have been through their own journey and they have experienced a lot, and you can, when you are sitting there talking to someone and they say 'yeah I know, I've been there'". (Mentor)*

> *"I think it's the identification… there is nothing like talking to people with the same sorts of problems, and having that identification." (Mentee).*

A mentee described the importance of that peer-to-peer set up:

> *"It's like that scenario you have a male gynaecologist saying come on Mrs, push it out, I know just how you feel, and it's just like no you don't, you don't, you haven't had a baby you haven't got a bleeding clue…so if you have someone who is positive with you, they do know how they feel because they have probably experienced something similar, even if it's just like 50%...they have gone through it." (Mentee).*

Mentoring then was directly addressing Positive Voices outcome 2, by reducing social isolation.

Timing of support

The point of diagnosis is often when support and information is offered. A mentor talked about "It's about what happens to you as a person when you get that diagnosis" when describing the impact of it. Starting new relationships, becoming single, disclosing to new people, managing medication, becoming fatigued of medication, and seeing changes in physical health and ageing with HIV are all points where people need support with ongoing processes, as described by various participants.

> *"It's something that can be suddenly impacting on your life or be fine for years and then have suffer some really bad stigma or be in the beginning of a new relationship and have to disclose and then it all comes back. HIV can be something you think hasn't really affected you, and then all of a sudden it does and they don't know how to deal with it or move forward." (Mentor)*

Additionally, information given at diagnosis may be neither processed nor currently up to date:

> *"At diagnosis, they give you all that information, but it's a shock and you don't take it in. Then people who were diagnosed years ago, they got the shock and then gone away from the information, so they are stuck with old information. They might not know about U=U. It's great when they come to Brigstowe, as then you share the knowledge and they are like "wow". …It's much broader than those who are recently diagnosed, it's anyone really." (Mentor)*

There is a clear need to offer services that are open to people beyond the stage of their diagnosis, and that are based on needs. This was also acknowledged by public health staff:

> *"it's a very good thing that people are living longer with HIV these days, and around that needs to be that psychosocial support, that came out in our needs assessment, and what physical health and mental health services they have, so it's not just newly diagnosed." (Public health staff)*

NHS HIV clinic staff also reflected the need for support to be independent of time since diagnosis:

> *"Lots of people are very settled and don't have any problems, established on treatment, and everything is fine. But some people or those people can come in and something has happened, met somebody new, or met someone in their personal lives that has set something off – then we would talk about it then. If we feel that Brigstowe can offer a service, we will offer a referral." (HIV clinic staff).*

The importance of not offering services based on time since diagnosis was expressed by one mentee, who told their story:

> *"Brigstowe deal with HIV, so I came here to learn about it. Although I was diagnosed [several years ago], I just took my tablets and that was that, I didn't want to know about it. I didn't want to care about it, I didn't want to know it was in my body, I just did my check up and got on with my life…so then I came here, and I'm learning a bit more about HIV, which is good because I want to know about it now, but they care about the whole package and I think that is important, the whole you. Whereas if you go to another group or support, they just care about that thing, not the whole of you." (Mentee).*

Rather than offering services relating to time since diagnosis, offering more, perhaps shorter workshops on different specific issues may be of appeal. Brigstowe staff described potential topics of disclosure (in addition to the existing training for mentors on how to support disclosure), women's sessions, sex and relationship issues, and mentees also talked about ongoing needs to discuss medication adherence and U=U. Delivery with or by HIV positive people is essential to maintain the uniqueness, credibility, and empowerment of people living with HIV.

Impact of HIV

> *"Years ago you would have died from it, but it seems like because we are not dying it's like we are not as important, but really, we are dying, we are dying inside in some respects. …I'm dying, I'm dying from this because I am not the person I want to me, I'm not the person I was before this, and my life, when I [got the diagnosis at specific time and date], my life ended, I died." (Mentee)*

Mentors and mentees both described the significant impact of HIV on their lives. In their narratives, it appeared to wax and wane in terms of the extent to which it featured, for example being often more extreme around the time of new or ending intimate relationships. What is important to note however is that this impact was non-trivial, and therefore the ongoing need for support is significant for some individuals.

Reaching the unreached

Recent UK data (from 2017) show that whilst over half of all new HIV diagnoses occur within men who have sex with men, 18% are heterosexual men and 24% are heterosexual women, with 38% of all heterosexual adults newly diagnosed being black African (Nash et al., 2018). Brigstowe, like many other HIV and health services, recognises it has been hard to engage with non-white communities. Late diagnosis in Bristol persists amongst some Black and Ethnic Minority populations, according to public health staff and reports. This is not unique to Bristol (Nash et al., 2018). Perceptions of the reasons for this given by the respondents include stigma, shame, discrimination, lack of knowledge and perception of the available services.

Mentors described a need to "continue to grow the awareness in those different communities and the general public" and a "need to connect with black males…maybe they need their own service or group". Strategies suggested were to continue to engage volunteers in evaluation and planning, be they individuals with HIV or simply interested members of those communities (mentors). One mentor who had worked with BAME mentees talked about the importance of recognising that some people, for example African or West Indian women, may not want to have a black mentor, owing to fear of meeting someone from their community and their status "getting out". Additionally there was a challenge perceived in "accessing some Muslim communities, for example, because sometimes people from these groups don't even get to the clinics, so they can't even know about Brigstowe" (mentor). This illustrates the importance of taking the message to the people, with ongoing efforts needed to engage with different communities across Bristol. This was seen as particularly obvious when it came to the need to spread new knowledge:

> *"U=U doesn't get filtered down to everybody, there are specific demographics where that information is delivered, received and understood. White MSM (men who have sex with men) mentors know about this and understanding this, BAME*

> *(black, Asian and minority ethnic) clients in general and even people who have been long-term diagnosed, they might have heard of it but they won't understand what that actually means." (Brigstowe staff)*

The HIV clinic staff had a more positive view, noticing that the peer mentors "are a very mixed groups – ethnicities and sexualities etc – and that is really useful when it comes to referring". They reflected that the NHS struggles to engage some communities and described again how people may avoid areas where they might meet someone from their community, "for example, they may avoid certain pharmacists". Discussions about engaging faith leaders and Imams were reported to have been had by HIV clinic staff, however progress on this appeared limited.

Community engagement and outreach work is itself a specialist endeavour that is hugely time consuming. It remains vital in relation to HIV and future projects should seek specific funding, including staff time and costs for running appropriate community engagement events, to allow this work to be done.

Public health staff also named the challenges in reaching non-white populations:

> *"We have gaps around ethnicity – black African population are over-representative in the figures but under-represented in the treatment, that is an area where there is a gap, and we need to really understand that community and how we can address the stigma amongst that community, especially amongst the churches and religious communities. We are trying to do more work with the faith leaders."*

They talked about how they and Brigstowe are engaging with the Black African voices forum and continued work to reach out to communities and their leaders was named.

Brigstowe staff described their activities in reaching out. Success has been had in recruiting a broad range of peer mentors, working together with Brigstowe's migrant asylum support service. Supporting volunteers to complete applications forms was done and this may be essential where confidence in written English or cultural ideas about who can take on a role like mentoring might otherwise preclude engagement. Stigma was named as the barrier to engagement for many

"it's people who the fear of someone finding out in their community might find out. Black African communities and Black Caribbean communities – ask about what communities they use and places where you would worry about seeing someone from that community. What comes back is that I don't want anyone from my Black Caribbean community etc etc" (Brigstowe staff)

This underscores how essential awareness arising in these communities is as a potential precursor to being able to attract more BAME people into the wider services.

In addition to ethnicity, gender can be a challenge. Brigstowe staff reflected that the lack of a childcare budget could be a barrier to women, both as mentors and mentees. This should be considered in future funding applications, to avoid deepening existing health inequalities.

Other issues

The reduction in funding and therefore the range and extent of HIV services in Bristol means there is far less choice of services. This may impact engagement with services in the existing agencies are perceived in anyway to be “for” specific groups. Some respondents raised a potential concern that Brigstowe may be seen as a LGBTQ+ organisation, which may in turn hinder engagement from people outside of that community or people who identify as LGBTQ+ but are from communities where this is not less accepted. This may relate to a lack of knowledge that means some people continue to consider HIV as a “gay disease” (as stated by one mentee). Anecdotally, the author of this report has heard a variety of ideas about how Brigstowe is seen, with some people describing it as for people from ethnic minority groups and others talking of it as an organisation that does not focus on any specific group. As such, it may be essential for Brigstowe to complete some work exploring how it is perceived, and potential strategies to address this. Given the funding landscape, agencies like Brigstowe are now necessarily needing to serve a very wide range of communities, which is a challenge to how they position themselves.

Public health staff talked about how engagement with Brigstowe had informed their work to support Fast Track Cities work. This drew upon the experiences gained from the Positive Voices project. The wider impacts of the project are challenging to quantify. The ongoing active participation and growing leadership from people living with HIV within this project has likely informed how further work is being planned and has increased the skills and communication pathways for people living with HIV to service delivery and planning.

The NHS clinic staff commented on the need for more work to re-engage people who have been lost to follow-up. Whilst there are potential confidentiality challenges around this, as people would have to give consent to be contacted, the potential scope for people with HIV to usefully contact those who have dropped out of clinic attendance is huge. The use of peers in this role may allow a more frank discussion and a different type of relationship in which to talk about the challenges on remaining in HIV services. Peer mentoring could include support to re-engage with services, where patients have been successfully contacted by NHS staff and consent gained. It may be possible also to ask at an initial appointment with a patient for a priori consent to be contacted by a peer mentor should they miss two consecutive clinic appointments, for example.

Brigstowe were asked what other services they felt they could expand into. They described potentially developing work in relation to prevention, and noting how they could “start incorporating positive voices in testing”, which may help decrease fear around testing. – having our peer mentors going out and testing people.

COVID-19

During the timing of this evaluation project, the COVID-19 lockdown began. This has led to increase isolation for many people, not just those with HIV. Public health staff talked about the rapid response of Brigstowe. They named how

> *“there needs to be some consideration of how they are starting to support people who are potentially shielding or think they need to because of their HIV status, and how that peer support program develops in that new normal we have, and what that kind of digital offer can look like. …They are doing phone calls at the moment and have some access to video calls, most people choosing the phone – as in voice.”*

Several issues are contained within this, 1) education for people living with HIV about their need to (not) shield and who to contact within the NHS to establish this for the individual, 2) how to adapt support to a range of clients, some of whom may want more online support whilst others may be less familiar or able to access those technologies. Brigstowe responded rapidly to this new need and was able to do so owing to their network of mentors and the relationship that their staff, particularly the PSC, has with Brigstowe service users. They opened a new service:

“A telephone befriending service developed as art of the COVID Reponses. Our mentors put themselves forward, a couple of them did, it’s befriending, they already knew our policies,. They have been able to alleviate staff in other areas. They enrich Brigstowe, we can just start a whole new service, with their support.” (Brigstowe staff)

This telephone offer may be a useful way to offer services to those who are currently not using mentoring. For example, people from minority ethnic groups or those with childcare responsibility who may find it hard to find time to physically “meet” a person could benefit from telephone support.

SUMMARY AND FUTURE RECOMMENDATIONS

Overall, the Positive Voices project was overwhelmingly positively received. The successes of creating meaningful relationships with the NHS HIV services facilitated this, together with funding for the PSC, to enable professional management of the project. In relation to the outcomes, although some of these were not directly measured, this report find successful contribution to all planned outcomes..

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.

This is evidenced in participant ratings of change since using services, the ratings of the impact of training, and the extensive qualitative comments.

Future recommendations

1. The enormous impact on people who have used the services strongly supports the need for follow-on funding to continue to supply this service and develop it further. People living with HIV clearly articulated the absolute importance of having a place they can come to for a range of supports where they can be open about their HIV. This is eminently achieved by the peer-support approaches and these must continue to meet this ongoing need, particularly in the face of streamlined and mainstreamed services.
2. Rather than offering services relating to time since diagnosis, future workshops and events could be targeted at particular topics or needs. This may also include addressing issues relevant to mental health and broader aspects of healthy living, as the city's needs assessment revealed a need for greater service provision in these areas.
3. Delivery with or by HIV positive people is essential to maintain the uniqueness, credibility, and empowerment of people living with HIV.
4. Future specific funding should be sought to provide research and activities to engage with people from non-white ethnicities. Extensive input to support community engagement and community-led activities will be required. This is essential owing to the rates of late diagnosis in BAME communities. It is also important to consider gender and age when planning services. The 2020 Bristol City Council needs assessment notes late diagnosis as a major issue.
5. Funding should include provision for childcare, to ensure parents and most likely women are not excluded from receiving support.
6. Continue to increase the presence of peer mentors in the NHS HIV clinic, with continued training for those mentors on how best to work in the clinic and training for the NHS staff on how best to work with the mentors. More training and reminders for clinic staff on who to

discuss mentoring with as a potentially appropriate option. Closer working with the team psychologist may also support.

7. Offer consultancy advice and training to other third sector organisations, to help them mirror successes in creating strong relationships with NHS partners, and in the process of setting up and managing peer-support programmes, including training, supervision, matching processes, and support that helps achieve volunteer retention.
8. Sustainable funding is essential as people living with HIV described needing support at different times during their lives, therefore it is essential that an organisation exists to address these needs.
9. In considering the details of the peer mentoring, reflect that non-engagement with mentors may be a sign of mismatch and explore further with mentors how they might address this. Ensure that in matching, the stage of acceptance and disclosure is carefully considered and potentially communicated to the mentor to help them be sensitive to these issues. Following supervision, ensure that mentors reflect on what has been most useful and what might change their practice.
10. Several recommendations for continuing support at the end of mentoring have been made. Provision of workshops to mark an end-point and establishment of a self-sustaining group ran by graduate-mentees may be enormously helpful. WhatsApp groups or other technologies may be able to support this.
11. The success of the services clearly require adequate staffing, and the presence of the co-ordinator has allowed excellent support for mentors and mentees alike, in addition to management of other services. Future funding bids must include adequate resources to allow optimal expansion of these services, likely full-time co-ordinator staff who can also support broader engagement with other organisations to increase referrals, for example by working with LGBT groups and mental health charities.
12. Further engagement with other areas around Bristol is essential, where there are smaller numbers of people living with HIV, who are then in turn more likely to be isolated and less likely to have access to support.
13. Awareness training requires further engagement with community organisations and other NHS organisations. Persistent stigma was identified in the city’s needs assessment as a major issue. Again, this requires dedicated funding for staff time to co-ordinate. Further, it is essential to continue to expand the pool of trainers, including people living with HIV where possible, and consider development of online training and video materials. Additionally, it is suggested to develop a more strategic approach to training, to ensure entire organisations are engaged with and policy contributions continue to be made.
14. Working with Public Health colleagues, it is vital for future projects to be representative at city-wide planning and co-ordination meetings.
15. New services working with the NHS HIV clinic to support people who have been “lost to follow-up” to re-engage with services should be considered. This is particularly important to individual and public health, as non-engagement typically means uncontrolled HIV, worse health outcomes and greater risk of onward transmission.
16. Support with improving testing uptake may be explored. Insufficient testing is identified as a priority within the 2020 city needs assessment, and it may be possible to include HIV positive people in testing projects.
17. Telephone services devised in response to COVID-19 should be evaluated and potentially extended, as these may offer increased accessibility for support, not just in relation to potential ongoing “lockdown” restrictions, but also for people with child care responsibilities or mobility issues, for example.

Appendix 1

List of the people we have delivered HIV Awareness Training along with number of people who attended the sessions.

Agency/organisation	No. of participants
2016-2017	
Cygnet House – Specialist in patient mental health services for older adults	14
Bristol University MSc Student Social Workers	52
Bristol University Medical students	30
HMP Ashfield Prison Staff	70
HMP Ashfield Prisoners	70
2017-2018	
Cygnet House - Specialist in patient mental health services for older adults	12
Ashley Housing	16
Inter-professionals	11
Bristol University MSc Student Social Workers	44
Brigstowe Trustees	9
Bristol Refugee Rights/	10
Bristol University Medical students	30
Bristol City College	9
Bristol University Medical Students	32
Devon Art House	32
Avon & Somerset Police round table	18
2018-2019	
Self Help Housing	7
UWE Professional Help Practitioners CPD: Dual Diagnosis: Substance Misuse & Mental Health	12
Avon & Somerset Police Custody Suite officers x 1	30
Avon & Somerset Police Custody Suite officers x 1	30
Avon & Somerset Police Custody Suite officers x 1	30
Avon & Somerset Police Custody Suite officers x 1	30
Next Link	8
Bristol City Council legal team	12
Age UK Wiltshire	12
Age UK Bath	7
2019-2020	
Age UK ‘Age is no Protection’ campaign launch	25
British Association for sexual health and HIV (BASHH) South west conference	32
Avon & Somerset Police LGBT Network	12
Avon & Somerset Police Medics	19
Bristol University PHD Digital Health students	16

UWE Professional Mental Health Practitioners CPD: Dual Diagnosis: Substance Misuse and Mental Health	7
UWE Professional CPD : Promoting Sexual Health in Practice	17
Bristol University medical students	88

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