

Guide to Peer Support Services in HIV Clinics



POSITIVELY UK

This booklet is intended to provide guidance and information to HIV Clinical Services on potential ways to integrate peer-led support within their services and care pathways. It provides:

- information on peer support and how to talk about it with patients
- guidance on how to set up peer support programmes in-house or in partnership with local voluntary sector organisations
- a suggested working agreement on the roles and responsibilities in the provision of peer-led clinical outreach
- a list of BHIVA's recommendations for peer support and collaboration with the voluntary sector, taken directly from their 2018 Standards of Care

Writing group

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Foreword

Supporting and providing peer support services is at the core of Positively UK's work and ethos. I know in my role as an HIV clinician that providing person centred care is strengthened so much by having the real, lived experience peer support workers provide within HIV services. We know that HIV related stigma still exists, and that receiving an HIV diagnosis can be frightening and isolating. We know also, that ageing with HIV may, for some, be difficult, and adapting to living with a chronic condition, sometimes with social, financial, and psychological burdens in addition to medical comorbidities and managing complex pathways and medicines can become overwhelming.

Having peer support services embedded within HIV clinics, in addition to the support provided by healthcare workers, means that people needing extra help can speak to someone who understands these issues, has often lived or is living through them themselves, and can provide a trusted and listening ear. The offer of peer support is an essential part of providing holistic HIV care, helping to improve medical outcomes but also helping people to enjoy a better quality of life, and to feel less alone.

It is with great pride and pleasure I write the foreword to this guide – pride that Positively UK works tirelessly to develop, support, and embed peer support workers into HIV clinical services, and pleasure knowing that the care and wellbeing of those affected by HIV is enhanced so dramatically by those in these essential roles.

Tristan Barber
Chair, Board of Trustees
Positively UK

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What is peer support?

Peer support is a relationship in which people see each other as equal partners and where the focus is on mutual learning and growth. At the roots of peer support there is a hope and a belief that through sharing and support we can transform our lives and the lives of our communities for the better.

How: Peer support can happen one-on-one or in groups. Peer support can happen in-person, on the phone, over text, over email or through the internet. Peers can help by sharing information, providing mutual social support and inspire to feel more confident.

When: Peer support can be helpful when coping with an HIV diagnosis, starting or changing treatment, sharing HIV status with others, dealing with external or internalised stigma, improving sexual and reproductive health or dealing with life challenges. Peer support is valuable in any moment of change in life, such as starting a new relationship, when planning to have a baby, or going through the menopause.

The role of the HIV clinic: HIV clinics are best placed to link people with HIV to peer support services, as clinics are in regular contact with people with HIV and can be aware of any physical, mental or social challenge that could be improved by a peer approach. The clinic is also a trusted environment for most people living with HIV.

Strengths of peer support approach

- Fundamentally designed to promote inclusion and empowerment
- Based on authentic empathy and validation
- Often perceived by people with HIV as a credible information source
- Accessible and flexible
- Seeing others who are contending with the same adversity and making progress in their lives can be inspiring and encouraging
- May facilitate greater openness and honesty due to equality among members
- Can foster a sense of community and purpose
- Can help to reduce pressure on healthcare providers' time
- May foster openness about HIV status and capacity of being involved in decision making, including policy making (locally, regionally, globally), etc.

How to explain/offer peer support

We recommend not simply making an offer of 'peer support' to patients, since many will not understand what this means. Instead, we suggest that healthcare providers ask:

"Would you like to speak to a member of the team who is actually living with HIV? They can provide a personal perspective on some of the challenges or anxieties you might have and can answer a whole range of questions beyond just the medical aspects"

Positively UK

Who we are and what we do?

Founded by two women living with HIV in London in 1987 to address the lack of services for women living with HIV, Positively UK continues to deliver a range of in-house and virtual peer support services, delivered in groups or face to face.

We also partner with a large number of London NHS Trusts to provide direct peer support outreach within HIV clinics. This ensures that peer support is available at the point of contact within the clinical service, so that people who might have anxieties about attending an external HIV organisation can be met without delay and can be encouraged to access other voluntary sector services.

Our Mission

To share support and solutions within HIV and across the health and social care sectors so that people living with HIV receive effective care and support, in order to achieve the best health and quality of life.

Our Vision

Everyone living with HIV has access to effective peer support to increase their knowledge, confidence, and connections, to improve their health and quality of life.

Our ambition

We want all people living with HIV to have access to peer-led support by 2025.

How we have developed our work with clinics

The 2013 version of the BHIVA Standards of Care included the following quality statement on peer support:

HIV services should seek to optimise the involvement of skilled peer workers with HIV in service delivery, thus optimising integral peer-to-peer self-management support. These skilled peer workers should have a recruitment and training process and have access to appropriate supervision and professional development

To this end, Positively UK developed Project 100 - an accredited training programme for peer mentors, which we delivered nationally over four years, training over 700 people living with HIV. Project 100 also developed a range of recommendations and protocols for the National Standards in HIV Peer Support, to guide and support both voluntary sector and clinical services in integrating effective peer support. .

This booklet provides suggestions and recommendations on how to set up peer support programmes within the HIV clinic and examples of how this has been achieved. It includes our standard agreement for providing outreach within HIV clinics, where the clinic plans to work with a local voluntary sector organization to create and manage a clinic outreach programme.

We believe that strong partnership work between the voluntary and clinical sectors is needed if we are to achieve the quality statements and auditable outcomes listed within the 2018 BHIVA Standards of Care for People Living with HIV.[1] For ease of reference, this document also includes all relevant quality statements and recommendations for peer support and partnership work with the voluntary sector that are contained within those Standards.



[1] Standards of Care for People Living with HIV, British HIV Association, 2018

Why and how to provide peer support in clinics

The case for peer support to contribute to the physical and mental health and wellbeing of people living with HIV is well documented and clinics offering peer support make for a genuinely holistic model of care. The 'At the Heart of Health: Realising the value of people and communities' Report looks at person and community-centred approaches for health and wellbeing and identifies peer support as one of five interventions that has 'significant potential to enhance the quality of life of people living with long term conditions.[2]

Peer support in clinics means that people with lived experience can supplement clinical support by providing real life examples of the benefit of effective self-management. It offers both newly diagnosed patients and those attending for ongoing care the opportunity to benefit from a joined-up approach to care, putting a person-centred approach into practice. We know that people living with HIV are twice as likely to suffer with depression and poor mental health as the general population.[3] We also know, given the stigma resulting from discrimination and ignorance around HIV, that peer support is even more important for this health condition.

Clinics can feel overwhelmed by the idea of setting up peer support as staff and resources are stretched. However, there are examples of some great peer work being undertaken in health care settings. Our general guidance aims to give you the resources you need to integrate a peer approach into your service by helping you to decide the best and most efficient way to get a peer support service up and running in your particular clinic.

How are you going to resource your peer support project?

The barrier to setting up peer support in a clinic is rarely a lack of enthusiasm. It is usually resources. Whether you want to set up the provision in house or work in partnership, you are not working from scratch because you are already part of an organisation with policies and procedures in place. It is a matter of knowing what you already have – and what you might need to implement.

[2] At the Heart of Health: Realising the value of people and communities, page 9

[3] Positively UK States of Mind: Improving Mental Wellbeing in the HIV Community – 2013, Jannsen

Setting up peer support ‘in-clinic’

If you are intending to set up peer support in your clinic, you are not the first to have done this. Therefore, one of the first and most useful things you can do is find out who else has set up a similar project already and talk to them about how they have done it.[4]

The following questions are designed to help you think about what you need to consider for your project:

What resources are available to you?

Do you have the budget to develop a staff role, or expand upon an existing role? Having a dedicated staff role is the easiest way to get a project off the ground, but it's not the only way. Some budget should be set aside for expenses should volunteering be the chosen way forwards.

Who are your champions?

Who are the people in your clinic that are really passionate about peer support and want to make it happen? It might be clinical staff, or it could also be patients who are actively engaged with the clinic and have been lobbying to develop peer support. If you have a group of people who are keen to make it happen, bring them together to help implement your project. Whether you have a dedicated staff member or are developing the service with existing resource, your champions are the people who will make it happen – because they want it to succeed.

What already exists in your Trust?

Policy and procedure – you should already have the policies and procedures you need in house. Information about policies and procedures that apply to peer support are detailed in our online resource.[5] If you do not have all the paperwork already in your clinic or more widely in your NHS Trust, you can access relevant information from our webpages and adapt for your own use.

Does your Trust have a Volunteer Service that could support you?

There may already be peer support in another department working with other types of health conditions. The Volunteer Service will already have the relevant paperwork and policies to make your job easier.

Our peer support is provided by “peer navigator” who are particularly invaluable, working with the wider team, in caring for people who have just received their diagnosis. We draw on their expertise to support adherence, and as people encounter different challenges throughout their life course. Many of our patients comment on how reassuring it is to meet a friendly face who can talk with them, drawing on their experience of living well with HIV, within the safe environment of the clinic.

Dr Iain Reeves

Consultant physician GU Medicine
Homerton Hospital

[4] Examples of other clinics includes Bloomsbury, Chelsea and Westminster, St Thomas's, Homerton and Kings in London. Lawson Unit in Brighton, Brownlee Centre in Glasgow, Sheffield Teaching Hospitals

[5] <https://positivelyuk.org/wp-content/uploads/2018/02/Structure-for-Peer-Mentor-Handbook-FS-003.pdf>

What are your mentors going to do?

Existing models of peer support in clinic are varied, and you need to decide what you want your mentors to do. The best way to execute a successful programme is to work within the constraints of your clinic, rather than be set on a certain type of mentoring that does not fit with the environment you are working in. The following types of support are not exhaustive, but all have been delivered in a clinic environment:

Peer Mentors

Usually providing one to one support in a safe space in clinic. They may be supporting newly diagnosed or ongoing patients. A feature of this type of support is that it is time bound and focusses on working with patients to set achievable goals linked to management of their HIV. A good example would be working with a patient over a number of months to help them achieve good adherence to medication. Peer Mentors may also facilitate peer support groups.

Peer Educators

Used as a form of health promotion. Peer Educators will be people living with HIV who can engage individuals and/or groups in conversations around issues of concern, seeking to promote health, enhancing knowledge and skills and ultimately, behaviour change. They may be used in clinic or supported by the clinic to engage in health promotion in the community, supported by health professionals.

Peer Navigators

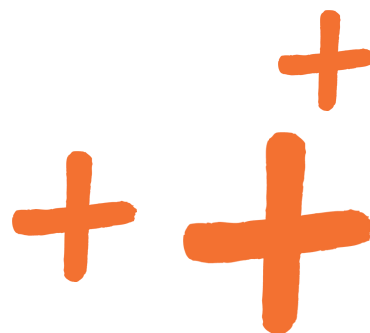
Generally based in the clinic, or sometimes a GP surgery. Peer Navigators will have a function similar to Educators and Mentors that is about behaviour change. However, a key feature of their role is signposting and helping people to access the wider range of support services and activities that are available in their community.

Peer Support Volunteer

This role title is often interchanged with Peer Mentor, but generally Peer Support Volunteers are more likely to offer less structured support, perhaps in a peer support group. They may also be carrying out quite a different volunteer role but will be identified as having lived experience and therefore able to empathise and chat with patients, offering informal peer support or befriending.

Mentor Mothers

Mothers living with HIV who use lived experiences to support others in their journey to become parents, especially around issues of conceiving, pregnancy, delivering a healthy baby, motherhood, breastfeeding and more.



To help you decide what model best suits your clinic and the type of peer work that will be carried out, you should consider practical issues, such as:

Space

For one-to-one work you need to have a room, or rooms available at varied days and times of the week. Where space is limited, consider how a peer support volunteer might operate alongside and share space with a health advisor or other staff member.

Booking system

Someone needs to be responsible for booking appointments and rooms and informing patients and peers of the arrangements. There also needs to be a way for peers and mentees to let each other know if an appointment has to be cancelled.

Access to information

You need to decide whether your peers will have access to patient information and the amount of information they will be privy to. If they will be seeing patient notes, then they may need an Honorary Contract. Some organisations will give more access to information than others, depending on the type of support and the relevance of the information shared. Whatever you decide, there needs to be the associated confidentiality and data protection policy – and training of peers to ensure patient information is protected.

Note taking

You need to decide the extent to which peers will be recording, and what they will be recording, where the information will be stored and how they will access it. If the peers are doing any work in the community, you will need to consider what information they carry with them and again, what they record and how they record it.

There are also support and development issues to consider in helping to ensure your peers are able to deliver the best service they can. You have an equal duty of care towards them and the patients they are supporting. These are some of the ongoing aspects of working with peers that you need to consider:

Training

How will you ensure that your peers are trained for the particular roles you want to develop, and how will you take care of or refer to ongoing training and support?

Support and Supervision

Who will be supporting peers and how/when will supervision be offered? If supervision is not offered in clinic through lack of resource and/or expertise, who will offer this? Who will be dealing with issues when they arise and how will difficult decisions around matters such as termination of service be made? There needs to be clear accountability in relation to line management and the reporting of any issues.

Communication

Who will be communicating with the peers and making sure that they are made to feel part of the service you are offering patients and valued for the work they are doing?

Working in partnership

Given that clinics are often busy, pressured environments, developing a model that does not impact significantly on people's existing workloads is vital to success. It may be possible to work with other organisations or services experienced in training and supporting peer volunteers. Not only can they lend their expertise, but this may lead to the potential for partnership funding and extra resource for your project.

Sometimes people I see in clinic are lost and scared and when approached by peer supporters they tell me that they feel much better as they know what to expect in regards to their health. We have increased the capacity of peer support in our clinics following extremely positive feedback from people living with HIV and colleagues who reported higher levels of engagement and acceptance of care. Our peer support colleagues are helping us (doctors and nurses) with multiple aspects of care delivery and contribute to improve how people living with HIV who attend our clinics feel and live their lives.

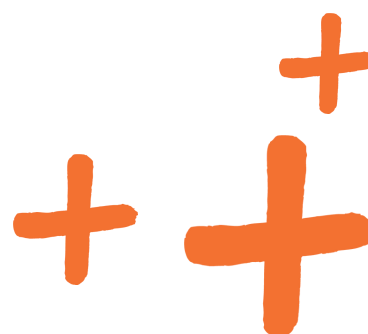
Prof Marta Boffito

Consultant physician at Chelsea & Westminster Hospital

Having peer support embedded within the clinic is especially beneficial for those who may not feel confident to access what could be perceived as an external service. This is especially true of people with high levels of internalised stigma. Many people also worry that peer support may be a little like counselling (and thus can also be associated with the stigma of mental health needs). Being able to directly introduced people to the peer support team or get them seen within an environment they feel safe in facilitates that initial engagement. I don't think the below is quick right so feel free to adapt but please do run past me if you do amend before using. Peer support is crucial to supporting wellbeing for many people with HIV. Having peer support embedded within the clinic is particularly helpful. It means people can access support directly within a space they feel safe and familiar with, and often in real time, facilitating engagement.

Prof Fiona Burns

Clinical senior lecturer, honorary consultant physician and clinical lead for HIV at the Royal Free Hospital



Case Study: Peer support for young people with HIV

St Mary's 900 Clinic and King's Hospital Caldecot Centre

Young people who have acquired HIV perinatally face many challenges, including growing up, often, in families where HIV is not talked about, internalised stigma, having lost a parent or other family members to AIDS and related grief, long term use of ARVs and more. There is evidence that often adherence to HIV treatment is a challenge in this group. [6] Within this context having access to a young peer who has had similar challenges, but has learnt strategies to deal with them, can be an important source of support.

You have friendly faces, it's nice to know that there's someone to speak to, you also make the waiting room nice to sit in.

Young patient at St. Mary's Hospital

Positive Futures is Positively UK's project that offers clinic based peer support to young people with HIV, and has outreach embedded at St. Mary's 900 Clinic since 2015, and King's College Hospital Caldecot Centre since 2018.

Youth peer workers are trained as peer mentors with the Project 100 programme, and have a good understanding of HIV, ARVs, confidentiality, boundaries and safeguarding.

Youth peer workers have regular access to support and supervision with an experienced line manager, external clinical supervision with a psychologist, and are embedded in a peer team of older peer caseworkers who can also advise and support them, when needed.

They are part of a community of peer support.

[6] Adherence to antiretroviral therapy in adolescents living with HIV: systematic review and meta-analysis, (2014) Sung-Hee Kim, Sarah M Gerver, Sarah Fidler, Helen Ward https://pubmed.ncbi.nlm.nih.gov/?term=Kim+SH&cauthor_id=24845154

What young people can expect from peer support

- Meeting someone who understands what they've been through and who has similar life experiences
- A safe space to talk about their issues related to HIV
- A guiding ear
- Ways to manage their well being
- Signposting to the right support groups i.e., Positively UK groups/residential/welfare & benefit support; Food Chain, THT, Body, and Soul etc.



Case study: working in partnership

Homerton Peer Navigator Project

The Peer Navigators service was developed and delivered by Homerton University Hospital in partnership with Positively UK.

The programme recruited patients from the clinic's patient cohort, developed their skills to be expert patients and provide peer support to others in the clinic, as well as help navigate their way through the complex health and social care system.

Homerton Hospital's Social Care Coordinator and the Casework Manager from Positively UK work as a team providing formal line management, running team meetings and supervision.

Both organisations take the lead in areas according to their respective expertise or governance. Interventions are reported within the Trust records as well as Positively UK's database.

Initially funded by a grant from MAC AIDS Fund, the Trust has explored a variety of approaches to joint and in-house funding in collaboration with Positively UK.

Homerton Hospital leads on:

- Honorary contracts for Peer Navigators
- Dedicated working space for Peer Navigators to meet with patients and conduct administrative work
- Access to phone, computer and meeting rooms as required
- Oversight of day-to-day work

Positively UK leads on:

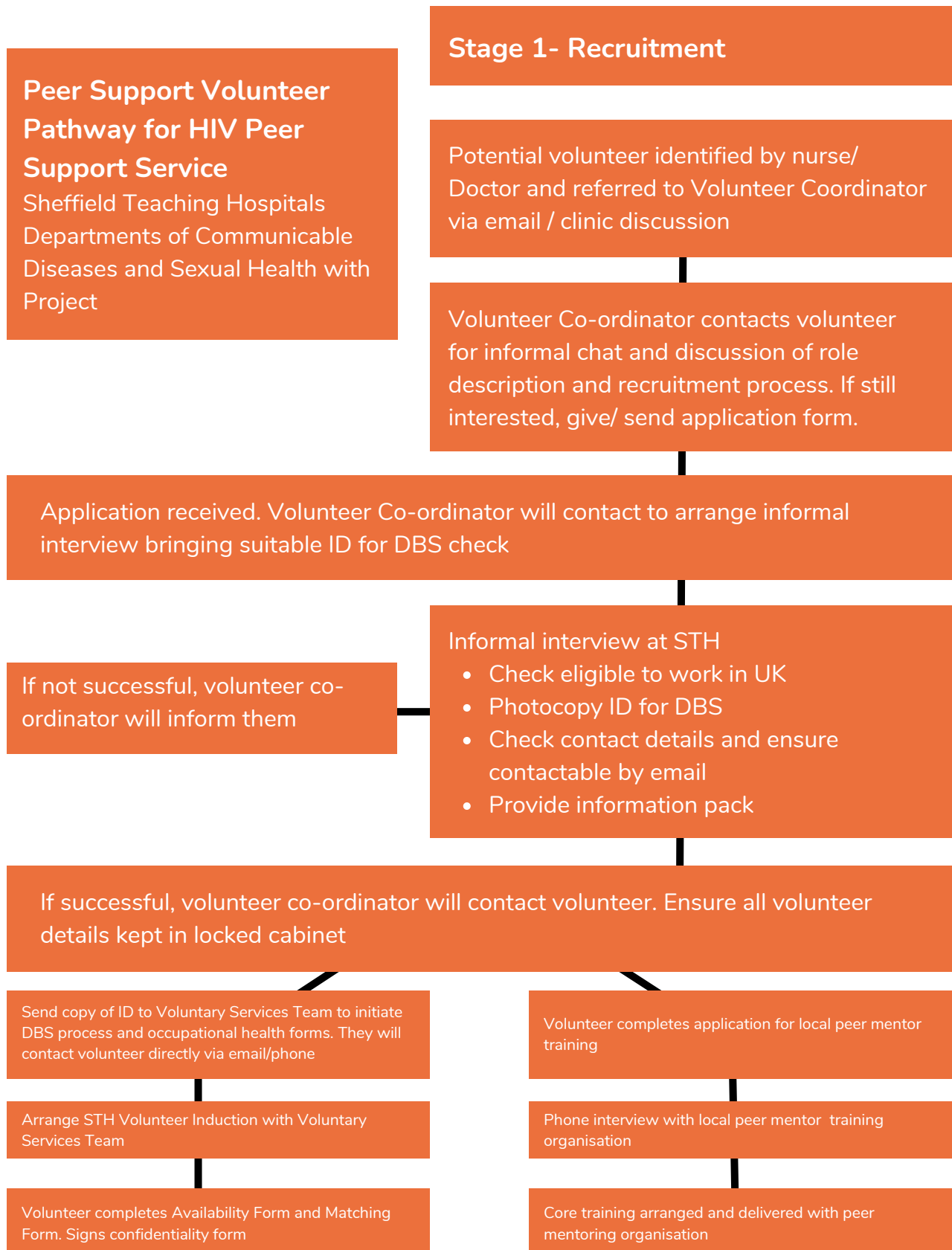
- Training of Peer Navigators
- Group supervision, attended by all case workers at Positively UK
- Being available for one-to-one meetings with Peer Navigators as required
- Supporting Peer Navigators with personal challenges in their role
- Ongoing professional development

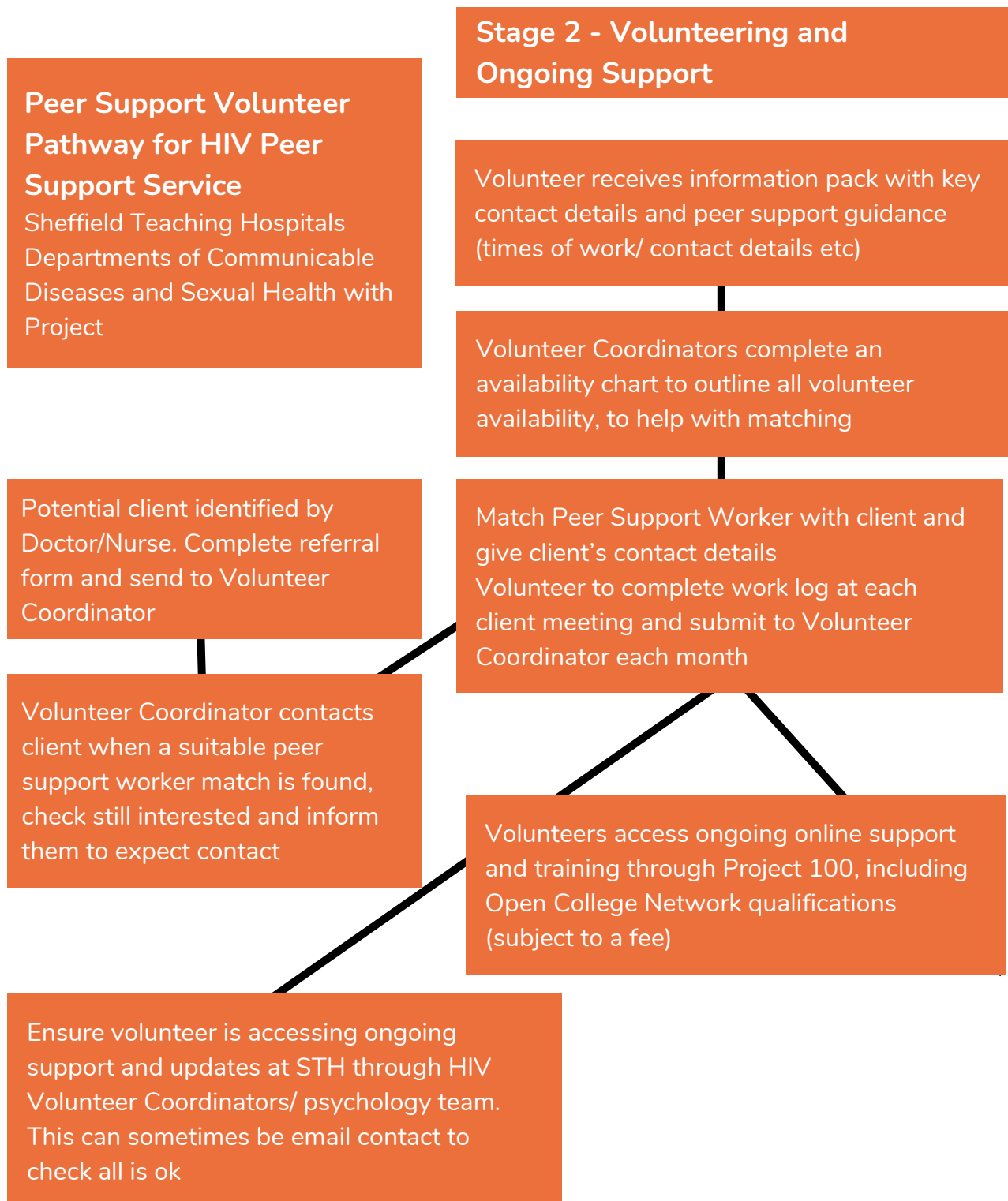
Hub and Spoke Model for Peer Mentoring

A Hub and Spoke model for providing HIV peer support services regionally:



Sheffield Teaching Hospitals (STH) recruitment and referral pathways





Suggested Service Specifications for Peer Support Outreach in HIV Clinics

HIV Clinical Partners will:

- Hold either a statutory contract, service level agreement or memorandum of understanding for paid employees providing outreach, or utilise the Trust Volunteer pathway for volunteers, to ensure that the peer support team is officially engaged with the service. Ensure that this pathway is fit for purpose and as easy to navigate as possible to facilitate the easy integration of peer support.
- Ensure that clinical staff have a clear understanding of what peer support is, what it offers and how it benefits the patients and service.
- Ensure that all relevant training and induction programmes for their service is provided to peer supporters.
- Ensure there is an appropriate confidential space available in the clinic to provide support whenever outreach is being offered.
- Have a clear appointment booking system, with time slots allowing breaks between appointments.
- Have secure, clear and straightforward patient referral pathways which work alongside the clinic's own appointment and IT systems.
- Have a designated point of contact in-house that peer supporters can report to in relation to safeguarding or other emerging issues.

- Have a clear process for recording patient notes, whether within the Trust's patient records, or by registering patients with local voluntary sector partner for tracking on their client database.
- Ensure that any breach in duty or contravention of protocols is reported directly back to either the relevant in-house line manager or volunteer coordinator at the local partner agency, depending on the status of the peer supporter.
- Be confident in referring suitable patients to become volunteers and have clear referral pathways to local voluntary sector partners for peer mentor training, or contact Positively UK to access our online training: peermentoring@positivelyuk.org

Voluntary Sector partners will:

- Provide a named line manager who can be a point of contact for both the peer supporter for any issues that might arise, as well as for the clinical team should any issue arise with any staff member or volunteer providing outreach.
- Ensure high quality peer support provision by interviewing and assessing the suitability of all outreach staff and volunteers.
- Provide appropriate basic training for peers who are providing support in clinics e.g., Peer Mentor Training, Clinic Induction Training, Mental Health First Aid Training, as well as

opportunities for ongoing learning and professional development.

- Obtain relevant references and DBS checks before allocating peer supporters to clinics (unless the Trust undertakes this as part of their usual volunteer service).
- Pass on those volunteers who are trained and ready to volunteer to the relevant Trusts in a timely and professional manner.
- Work with HIV clinics to ascertain what kind of support might work best in their service, by sharing knowledge and experience of ways of working successfully in other Trusts.
- Share any volunteer-related documentation with clinical partners, as required, such as Volunteer Handbook and relevant policies.
- Ensure that staff and volunteers have access to one-to-one supervision, along with monthly group supervision for peer supporters, with an expectation that volunteers will attend at least 6 out of 12 sessions a year.
- Maintain clear lines of communication with clinics and inform the team of any change in provision of support (e.g., In case of illness or annual leave).
- Maintain appropriate records of support interventions, whether on their own services database or that of the relevant NHS Trust and follow all relevant Information Governance and GDPR regulations.
- You can of course reference the National Standards in HIV Peer Support for any additional recommendations.



BHIVA Standards of Care for People Living with HIV 2018: Recommendations for peer support and voluntary sector partnership

“HIV service delivery must evolve to meet the challenges of increasingly constrained resources and the varying needs of a changing population of people living with HIV. HIV treatment outcomes and retention-in-care rates are among the best in the world within the current models of care in the UK, and whatever service models are implemented, maintaining, and improving these outcomes must remain the top priority for all those involved in the commissioning and delivery of care.”

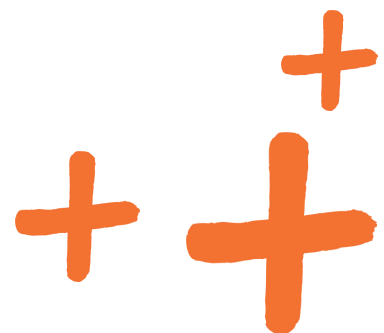
Standards which reference and make recommendations for Peer Support

Standard 2 – Person-Centred Care

2a Stigma: Appropriate peer support enables people living with HIV to develop confidence and gain information and skills from others in an easily identifiable and applicable way, which is critically important for all other aspects of self-management.

2b Self-management and Peer Support:

Peer support is a relationship in which participants see each other as equal partners and where the focus is on mutual learning and growth. Within NHS services, structured peer support is delivered by trained peer staff or volunteers, in both one-to-one and group settings. Trained peer supporters can model positive and health behaviour, and signpost to services and appropriate information. The focus is on strengths and abilities, motivating and working to achieve agreed goals and improve or maintain quality of life. Peer support is a key contributor to optimising self-management as it not only draws on community resources and expertise but allows people to contribute to communities.



Self-management and voluntary sector involvement in care also bring economic benefits to the community and to the health system.

For people living with HIV, self-management can help with at least five interconnected major areas:

- Physical health, including HIV-specific issues, comorbidities that may be influenced by HIV, life-stage health issues (such as pregnancy, ageing, puberty), and general health matters
- Health promotion and prevention of ill-health.
- Mental health and well-being, including resilience building and potentially reducing the development and/or exacerbation of emotional distress.
- Economic inclusion and well-being, including access to financial and employment support.
- Social inclusion and well-being (with peer support as a key intervention).

Self-management is an important part of comprehensive HIV care because:

- People living with HIV are best placed to know and understand their own needs.
- It allows people to take greater personal responsibility for their own health and wellbeing.
- Professional resources can be focused where they are most needed.

Quality statements

People living with HIV should have equitable access to services that promote self-management of HIV including provision of support and information:

- About HIV, treatment, healthy living with HIV, diet and lifestyle, and optimisation of general health including rehabilitation services.
- On maximisation of entitlement to health services and support.
- To enable people to optimise their entitlement and access to financial and housing support, and to optimise their ability to maintain/gain/regain employment.

HIV services should maximise the use of peer support as set out in the National Standards for Peer Support in HIV.

Measurable and auditable outcomes

- Proportion of people reporting they feel supported to manage HIV (target: 90%).
- Proportion of services that provide, or have an agreed care pathway to, peer support and self-management services (target: 95%).

2d Wellbeing: Agencies providing HIV care have a responsibility to ensure that well-being is an issue that is considered in the design, review and provision of services and there are opportunities for referral and support that enhance well-being. Attention to and responding to issues such as homelessness, immigration experience, access to education, intimate partner, and gender-based violence, drug and alcohol use, stigma, and social exclusion within the remit of the service will assist in optimising life outcomes for people living with HIV.

Quality statements

Services should ensure that:

- Issues of well-being continue to be incorporated into clinical and care practices in transparent ways.
- A person-centred approach is taken in providing care to ensure that well-being for each person is holistic and meaningful.
- Well-being is a consideration when developing, delivering, and assessing services and policies in health and social care for people living with HIV.
- Pressure on the cost and time available to provide clinical services does not result in the erosion of well-being initiatives or considerations.
- Best practice service provision that incorporates concerns of individual and community well-being should be broadly communicated.

Measurable and auditable outcomes

Within HIV care

- Documented evidence of a local guideline for assessment for and access to support around accessing benefits and financial hardship.

Standard 3 - HIV Outpatient Care & Treatment

3a Access to and retention in care:

Recent data highlight factors that may be predictive of suboptimal engagement in care in newly diagnosed people. These include age at diagnosis, having children, recreational drug use, drug/alcohol dependency, insufficient money for basic needs and use of public transport to get to the clinic. People with mental health comorbidities and people who use drugs may also be at particular risk. Close working links between primary care, secondary care, mental health services, social care, legal services, benefit agencies, peer support and voluntary sector agencies is required in these situations to maximise wellbeing.

Quality statements

Access:

- People newly diagnosed with HIV should have the initial investigations and assessments recommended in BHIVA guidelines and be able to access psychological and peer support within 2 weeks of receiving their HIV positive result.
- People living with HIV should expect to have access to appropriately trained HIV specialist professionals for opportunities to discuss emotional, psychosocial and partner notification issues, as well as access to community support, especially when newly diagnosed with HIV.
- HIV outpatient units should have an agreed pathway to enable access to peer support.
- HIV outpatient units should have an agreed pathway to enable access to financial and housing advice and support.

Retention

- People living with HIV should expect to have access to peer and psychological support when required, particularly when facing a significant life event such as starting/changing treatment, major illness, pregnancy, and menopause.

Measurable and auditable outcomes

- Proportion of people newly diagnosed with HIV who are offered referral for peer support (target: 90%).

3b Outpatient Care

Quality Statements

- Specialist HIV outpatient services should provide easy access to multidisciplinary support, in particular: specialist nursing; sexual health services; specialist adherence support; specialist HIV pharmacy advice; dispensing services; dietetics; mental healthcare; counselling; and peer and advocacy support. There should be ready access to, or information about, services that can provide advice about social care and benefits entitlements.

3c Antiretroviral prescribing

Quality statements

- People living with HIV should have access to adherence support, which should be provided by staff with appropriate skills, when starting or switching ARVs and at any time when viral rebound or suspected low adherence occurs. There should be evidence of adherence assessment as per national guidelines.

Any patient reporting missed medication or experiencing viral load rebound should receive adherence support, noting the evidence of the contribution of psychosocial factors to adherence and the potential benefit of peer support.

Measurable and auditable outcomes

- Proportion of people with documented evidence of being offered written information and access to peer support when making treatment decisions and in reporting side effects (target: 90%).

Standard 4 - Complex HIV Care

4a. Inpatient care

Quality Statements

- Arrangements for care in specialist HIV inpatient services must ensure there is: Access to psychosocial and welfare advice and support, including peer support.

4c. Supporting people with higher levels of need:

People with multiple needs will often have a number of agencies or services involved in their care, but they may also be the least able to make best use of these services and face challenges in attending the multiple appointments that are often required. A care coordinator role has been successfully used in other conditions such as mental health and is widely advocated for people with complex needs.

Quality Statements

- Interventions should be planned with the person according to needs as well as clearly agreed priorities and aims. Peer support should be offered to all patients, but in this group, there may be particular benefits in providing

support in negotiating the health and social care system and reducing isolation.

- Where social care needs, financial difficulties, housing, or other insecurities, are identified, clinics should have as a minimum, signposting to, or information, about sources of advice and support to address these difficulties.
- HIV support services, often provided by the third sector, are of great value in supporting people with higher levels of need. Support provided by clinical and other support services must be as coordinated as possible with strong referral and communication links.

Measurable and auditable outcomes

- Proportion of services with formal arrangements for people with increased needs that are appropriate to a geographical area to ensure they have equitable access to best-quality advice relating to their rights and access to health and social care and their entitlements to public services and assistance.

Standard 5 - Sexual and Reproductive Health

Quality Statements

- The management of pregnancy, childbirth and the immediate postnatal period should be in line with current national guidelines and undertaken by a specialist multidisciplinary team (to include obstetrician, HIV specialist physician, specialist midwife, specialist HIV pharmacist and paediatrician and ideally peer support where available) with expertise in HIV and pregnancy.

Designated individuals within an organisation or network should be identified.

- People living with HIV should have access and/or referral to peer support as outlined in 'National Standards for Peer Support in HIV', particularly during pregnancy.

Standard 6 - Psychological Care

6a. Emotional Wellbeing: These Standards draw upon the 'Standards for Psychological Support for Adults Living with HIV' and the two should be read in conjunction. Key to this is the stepped-care model in which the psychological care needs of people living with HIV should be considered and managed by all health and social care providers they encounter, with self-help and peer support throughout.

A vital resource in the support of people living with HIV with stigma and illness burden is other people living with HIV. Peer activism, advocacy and support have always been a bedrock of HIV care, adapting to changing financial climates, technologies, and medical advances. It includes online and App-based information and forums, as well as face-to-face individual and group meetings. These can range from educational (e.g., newly diagnosed courses, patient networks), skills-based (e.g., mindfulness, benefits support) and informal social and recreational gatherings. Some are formally supported and hosted within NHS HIV services, while others are based within local or national charities and organisations.

Quality statements

- All people living with HIV should have access to peer and psychosocial support, and advice according to national standards. There should be agreed pathways in place for those with more serious psychological or cognitive difficulties, which ensure early detection of the problems and prompt referral to appropriate services.
- Peer support should be discussed and made available to all people living with HIV, and form part of their clinical care pathway options.

Measurable and auditable outcomes

- Proportion of all new patients with documented evidence of discussion of peer and emotional support and signposting to appropriate services as required (target: 90%)

Standard 7 - HIV Across the Life Course

7a Young Adults & Adolescents living with HIV:

Peer support enables young adults and adolescents living with HIV to meet other young people in similar circumstances, boosting confidence and self-esteem, and allows a safe space to discuss HIV. It may provide support with adherence or help escape isolation, particularly for young adults and adolescents living with HIV outside large cities where it can be accessed remotely (e.g., via Skype or facetime). Adherence to ART is poorer in adolescence when compared to children or adults. Once-daily regimens with a higher genetic barrier to resistance and fixed-dose combinations reducing pill burden should be considered, with adherence support from the multidisciplinary team including access to peer support.

Quality statements

- Young adults and adolescents living with HIV should have access to peer support, whether directly provided within clinic or through referral to external agencies.

7b Early to Middle Adulthood: Owing to the trend of earlier diagnosis and earlier ART initiation, increasing proportions of people living with HIV have experienced no or minimal HIV-related health problems. Most will be in education, training or employment and will often need services that are streamlined and allow minimum disruption to their lives. However, significant numbers of people will have heightened vulnerabilities due to one or more of a number of different factors including late diagnosis, long duration of HIV, toxicity of early ART, anxiety and depression, drug and alcohol dependency, poor housing, stigma, poverty, and immigration status. It is important that services are configured to meet the needs of people in these disparate categories and be sensitive to the fact that people move between non-complex and complex categories. In such cases, they will have enhanced care needs.

Quality Statements

- Supporting healthy lifestyles through the young to middle adult years is especially important and potentially has an important impact on health in later years. Key elements relate to smoking, drug and alcohol use, sex, diet, and exercise. These parameters should be regularly assessed, and people supported to modify behaviours that improve their health. Support will range from providing

information through to short interventions (e.g., motivational interviewing), and referral to specialist services (e.g., smoking cessation, drug and alcohol services and dietetics).

7c Older Age: Peer support may be particularly important for those diagnosed in older age, as many people will have had no previous exposure to people living with HIV or HIV-related issues. This may be crucial for engagement and retention in care. Peer support needs for those living long term and ageing with HIV will differ from other groups, as issues such as historic stigma and discrimination, community-level loss and survivor guilt may play out quite differently.

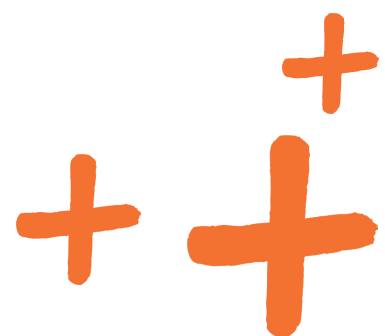
Standard 8 - Developing and maintaining excellent care

Peer-support team

Peer support can be delivered by paid staff and volunteers who are living with HIV in both one-to-one and group settings. There are many approaches to providing peer support, this can be informal or a formal structured approach such as peer mentoring. These Standards are primarily concerned with the delivery of structured support as set out in the 'National Standards of Peer Support in HIV' (2017).

Peer support works best when facilitated by trained peers from the community they support. The breadth of knowledge and skills involved in providing peer support means it is important that the people providing it should have access to structured training, linked to a professional qualification, where appropriate and possible. Core competencies should include knowledge

and understanding of HIV and treatments, ability to recognise and work with diversity, effective listening, and communication skills, understanding of confidentiality and safeguarding for vulnerable adults. Organisations or groups providing peer support should provide peer supporters with regular structured support and supervision, as well as ongoing professional development.



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