National Standards for Peer Support in HIV

Production

The Standards were developed by a Steering Group of people living with HIV, representatives of NGOs who provide peer support for people living with HIV and of the British HIV Association (BHIVA), National HIV Nurses Association (NHIVNA) and Children's HIV Association (CHIVA). Targeted consultation was undertaken with groups of people living with HIV in London and Liverpool, the youth group leaders of the CHIVA Summer Camp, and with individuals from across the sector. From August to September 2016 the standards were then out for open consultation through e-forums including UK-CAB and NGOs across the UK.

Acknowledgments

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POSITIVELY UK

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Foreword

Garry Brough

UK Community Advisory Board Chair

At a time when we are seeing shrinking funding for HIV services in both the voluntary sector and the NHS, high quality peer support needs more than ever to be able to demonstrate its effectiveness. Previous models of care, such as buddying and ongoing support groups were crucial in their time, but are no longer as appropriate or sustainable in this new era of a long life with HIV.

21st Century support must empower people to live well with HIV by promoting self-management strategies which allow them to make better health and life choices for themselves. Structured and targeted peer support is uniquely positioned to help achieve these aims and standards such as these provide the framework and guidance to allow services and individuals to demonstrate their effectiveness to clinicians and commissioners.

As someone who has lived with HIV for over 25 years, I have accessed, delivered and now train others to deliver peer support. Aside from the outstanding clinical care which has allowed me to live this long with HIV, peer support has been the defining factor in me being able to live well with HIV. Within the great diversity of the HIV community, the benefit from any one of us reaching out, sharing our lived experience and helping another person living with HIV is undeniable, and the interaction enriches both sides.

As Chair of the UK Community Advisory Board (UK-CAB), the national network of HIV treatment advocates, I wholeheartedly welcome and endorse these standards. I hope that they act as a benchmark and reference point for a new era of joined up care that is so needed, not just in HIV, but in our ability to manage any and all health conditions.

"I now see myself as someone who can support others"

Peer Support trainee

Professor Chloe Orkin

British HIV Association Chair & Consultant Barts Health NHS Trust

The cascade of care for HIV provided in the UK is widely recognised as one of the best in the world. A key challenge to maintaining and improving our world-class care is retaining people in care. Unfortunately, significant stigma is still attached to an HIV diagnosis in many communities which can make acceptance of an HIV diagnosis more difficult.

As a Consultant working in HIV our unit is fortunate enough to benefit immensely from the help of peer supporters and the work they do is pivotal in retaining people in care and supporting our offer of life-saving Anti-Retroviral treatments. Their role is instrumental in delivering that elusive but all-important fourth "90" – quality of life.

Benchmarks such as these Standards are very helpful to ensure quality peer support wherever it is accessed. These standards create a baseline from which peer support can further develop in future. The British HIV Association (BHIVA) Standards of Care for People Living with HIV (2013), state explicitly that HIV services should maximise opportunities to engage peer supporters with HIV. We endorse and strongly support these excellent and important National Standards for Peer Support.

"I don't know what magic happens in peer support, but I know whenever one of my patients sees a peer support worker, magic happens"

HIV Clinician

Table of Contents

"If there was no peer support we would be in a horrible place, everyone would be stigmatized and the epidemic would increase"

Children's HIV Association (CHIVA) Youth Committee member

Introduction

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.

Peers can be people with similar health conditions, and/or from similar communities or backgrounds, including people with shared identities based on their sexuality, gender, ethnicity or other characteristics.

Peer support creates opportunities for both parties to grow and achieve a sense of control and empowerment. It can be formal or informal, and can range from friends sharing, to people within groups supporting each other, to a befriending service.

Peer support is a reciprocal relationship, benefitting both those providing and receiving the support. Benefits can include creating collective strategies to maintain health, building resilience and self-esteem and aiding advocacy and collective action.

Structured peer support is delivered by trained peer staff or volunteers, in both one-to-one or in group settings. Trained peer supporters can model positive and healthy 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.

Why do we Need Standards in Peer Support?

At the International AIDS Conference in 2014, UN AIDS set the 90-90-90 targets of 90% of people living with HIV knowing their HIV status, 90% on treatment and 90% having an undetectable viral load[i]. While the UK has made great progress in achieving these goals, there is growing demand to a fourth '90' target of people living with HIV experiencing good quality of life. To achieve this, we must provide the right means of support.

The UK has some of the best clinical support and clinical outcomes in the world. However, quality of life goes beyond clinical outcomes[ii], encompassing physical, mental, emotional, social and spiritual well-being[iii]. These standards are established and agreed by people living with HIV, in the strong belief that those living with the condition are best placed to understand what is needed. This involvement of people living with HIV indeed underpins the peer support approach.

Through these standards we aim to create a benchmark for the HIV community, health and social care providers and decision makers to ensure consistency in approach and promote good practice in the delivery of peer support.

Context

At the time these standards were produced there were over 100,000 people living with HIV in the UK[iv]. An estimated 15% of those living with HIV are as yet undiagnosed, therefore numbers accessing care and support will continue to increase over the coming years.

There is both a growing demand for peer support from communities living with HIV and recognition within the NHS of the role of peer support in supporting clinical outcomes and improving health and well-being.

Consultations with people living with HIV such as *The Manifesto of People Living with HIV* (Positively UK, 2015) and *Positive Person Manifesto* (HIV Scotland, 2016) have all

clearly stated the centrality of peer support for people living with HIV to manage their health and well-being.

The importance of peer support in providing high quality and effective healthcare is acknowledged in three major documents:

The *NHS 5-Year Forward View* recognises the role of community led initiatives such as peer support in enabling people to "manage their own health – staying healthy, making informed choices of treatment, managing conditions and avoiding complications"[(v)]. The Forward View also recognises the need to strengthen partnerships between the NHS and the voluntary sector.

In the *British HIV Association (BHIVA) Standards of Care for People Living with HIV (2013)*, Standard 9 states that HIV services should maximise opportunities to engage peer supporters living with HIV – including paid staff living with HIV – in service delivery, and thereby optimise peer-led self-management.

Both the *NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Adults)*[(vi)] and the *NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Children*)[(vii)] identify the need for people living with HIV to access peer-to-peer support to promote emotional well-being, treatment management, behaviour change and self-management.

Intended Audience

These standards are for:

- People living with HIV both providing and accessing peer support

- Organisations developing and providing peer support programmes, to inform the design of projects and ensure good practice

- Health and Social care staff interacting with peer support, including those bringing peer support into clinical settings

- Commissioners establishing standards for the services they purchase, to inform service specifications and ongoing monitoring of those services

- Policy makers, to recognise the benefits of peer support and embed quality peer support into service design from inception

About Peer Support

History of Peer Support in HIV

In the 1980's, when little was known about HIV and discrimination was widespread, small groups were formed by individuals who risked much in order to give and get support, to share knowledge and to lobby for treatment and appropriate care. HIV services owe their existence to these activists and those who campaigned alongside them. From these small beginnings emerged activism on treatment availability and prices, community advocacy, and the movements to combat stigma and influence service delivery. The expert patient initiative, the availability of information written by people living with HIV and policy lobbying organisations were soon to follow.

HIV peer support, like the disabled people's movement, has a political dimension in challenging discrimination, advocating for particular and appropriate services and access to treatment. It has altered the weighting in the doctor-patient relationship, into something at best approaching equality, or at least, being consultative. HIV activists welcomed the *Human Rights Act* and searched it for its application to HIV, to challenge areas where rights were seen as being infringed, and successfully campaigned to have HIV accepted as fitting the social model of disability.

Peer support in HIV has served to create a community for people who have experienced a disconnection from their wider community through secrecy and stigma.[viii]

Peer Support in Other Settings

There is a long history of the successful use of peer support in different settings such as education, mental health, and physical health – with the aim of improving and managing long term medical conditions, dealing with discrimination, and making changes in behaviour. Examples include:

- Education: peer support in professional teaching schemes[ix]
- Schools: peer support in schools to combat bullying[x]
- Peer support in long term medical conditions: diabetes[xi]
- BHIVA Standards of Care for People Living with HIV: peer support is quoted as part of treatment and care standards

The implementation of peer support standards exists in mental health, diabetes and the National Council of Voluntary Organisations' (NCVO) *Approved Provider Standard*, the national quality standard for mentoring and befriending projects[xii].

Principles and Values

It is common for people with shared interests and experiences to share advice and knowledge, this is an informal type of peer support, and a form of exchange familiar to us all. So peer support can readily take place when people living with HIV meet socially or for any other non-HIV focused activity, such as a walking group or choir.

All peer support relies on making your own experience and strategies freely available to others. It is voluntary and reflects Mauss's[xiii] theory of reciprocity and gift exchange in which giving, receiving and reciprocating gifts builds social bonds and interdependence between individuals who are giving and receiving.

Peer support starts with where you are and who you are, at its best it is non-judgemental in action, and as such, has similarities with the core conditions of Carl Roger's *Person Centred Therapy*, that an attitude of empathy, congruence (i.e. match/compatibility) and acceptance of a client are the most important factors in successful therapy.

The core conditions are explained as:

Match/compatibility: to be yourself without a façade, valuing the person for who they are
Empathy: being willing to understand issues from another's point of view
Acceptance: not judging or being critical

In action, peer support is the shift from 'we can help you' to 'together we can do it', making the sharing and empathy authentic. Those with shared experiences may also have strategies that professionals are unaware of, hence peer support offers something in addition to, but not something alternative to, professional support. By definition, peers are equals, so peer support should provide all players with equal opportunity to share and exchange.

In keeping to the 'together we can do it' approach, peer support is vital in helping people rebuild a sense of belonging after a disconnecting experience. The sharing of experiences can lead to other types of support, practical learning, education, advocacy and involvement

Successful peer support enhances the individual's own concept of self, their ability to make solutions and regain their strength in order to manage their situation. There is evidence that peer support promotes feeling more empowered and valued, increases confidence and self-esteem, and gives a more positive sense of identity[xiv]. Evidence also shows that peer support makes behaviour change more likely[xv].

HIV and Peer Support

For these standards, the primary element is peer support by and for those living with HIV. Interventions or groups led by people who do not have HIV are not viewed as peer support – with the exception of peer spaces for children and young people living with HIV, that may be coordinated by adults who are not living with HIV.

"When peer support is offered it helps reduce the cost of services, reduces physical and mental ill health and lessens social isolation"

Person living with HIV

Benefits of Peer Support

Successful medication for managing HIV is not a cure, and peer support remains important in maintaining health and well-being, overcoming stigma and promoting adherence and self-management. Reports by Positively UK[xvi] and by LASS[xvii] indicate peer support results in improved well-being, confidence and management of HIV.

The evidence around the benefits of peer support is still growing. Recent analysis of peer support and person centred approaches to health, carried out as part of *Realising The Value* – an NHS England funded initiative to provide a stronger understanding of the value of community, person centred interventions to health and well-being – places the benefits of peer support in three main areas:

Benefits to the Health and Well-being of the Individual

This include clinical outcomes, better adherence and understanding of health conditions leading to improved experiences of healthcare. Peer support has also been found to improve physical and emotional well-being by increasing confidence and supporting feelings of being in control of your own health, feeling less lonely and better connected to others in a similar situation.

Financial Benefits

Peer support has been found to create economic benefits by reducing pressure on other health and social care services. According to Realising the Value's economic modelling, provision of peer support can save up to £2,100 per-person per-year to the health system. Furthermore, by reducing anxiety and depression, improving self-management and individual well-being, peer support has the potential of contributing up to £20,800 per-person per-year in terms of wider social support[xviii].

Wider Social and Community benefits

Peer support has also been found to have an impact in strengthening communities, creating social connections, contributing to public health and prevention. It can play an important role as well in enabling people to go back to work, education and volunteering and thus reducing pressure on other public services.

The Format of the Standards

The format of the standards is similar to that used in the *BHIVA Standards of Care for People Living with HI*V[xix]:

Each standard is headed by a **Standard Title**, followed by:

Rationale/Why: the reason for having the standard, within this we will spell out what the standard means for three main audiences:
- People living with HIV accessing peer support
- People who provide peer support
- Health, social care and HIV service providers

Competencies and Skills: setting out what skills are needed by the person providing peer support and/or the providers to perform and deliver the standard. Core competencies describe the knowledge, skills and attitudes that need to be developed in order for peer supporters to fulfil their role.

Expected Outcomes: setting out what differences we can expect as a result of the work to deliver the standard. This is not a prescriptive list and it is recognized that services targeted towards certain groups or within certain settings will define their own outcomes.

Auditable Indicators: setting out means for demonstrating how the standards have been implemented and how quality is being maintained.

"In simple terms peer support saves lives and health care funds"

HIV Peer Support Standards Steering Group memeber

Standard 1

Everyone living with HIV should have access to peer support

Rationale/Why

Peer support can improve people's knowledge, skills and confidence to manage their well-being and overall quality of life[xx].

The population of people living with HIV is diverse and peer support needs to meet this diversity. Recognising that peer support starts with where an individual is in their life, it makes sense to offer peer support in settings and ways that are appropriate to the individual at that time[xxi].

Peer support may happen in a number of settings: some people may prefer to go to a charity or group outside of their clinic, as they may feel more comfortable in a non-medical environment that doesn't remind them of illness. Others may find it more convenient, to access peer support in hospital where they receive their HIV care, as it saves time, and it can feel safer – especially if they have initial anxieties around confidentiality and going to new places. Personal preference and resources can also influence the choice of whether to have peer support face-to-face, by telephone or online, or in formal or informal groups.

Whatever the setting for peer support – whether it be between peers within a group, provided online, or in a structured one-to-one setting between the person providing peer support and their peer – the relationship should be one of mutual respect, trust and collaboration. The relationship ought to be geared towards achieving and maintaining meaning and purpose in life for all parties, it should create opportunities for both parties to grow and achieve a sense of control and empowerment. Through focusing on

strengths and abilities, peer supporters can model positive behaviour, and be motivating and inspiring.

Having clear principles of good practice suitable to each setting of peer support will ensure effective support and a safe and comfortable environment for peers. Good practice principles should cover expectations in a peer support relationship such as:
- Confidentiality and what is confidential and what is not
- Acceptable length of the group, meeting or conversation
- Clarity on when and how to make contact
- Time between contacts
- Personal privacy and sharing lived experience
- Hours available for support and whether there is a policy of drop-in, open access or if appointments are needed

What this Means for People Living with HIV Accessing Peer Support

Everyone should have access to peer support that is timely, easy to access and meets their needs.

What this Means for People Providing Peer Support

They should be able to provide support in a range of settings and using approaches that can benefit everyone and be most effective.

People providing support in different settings need to be clear on how they can effectively listen and empathise in different contexts. They need to be aware of when and how it is appropriate to share their life experiences, and how doing so will be beneficial for the person they are supporting.

What this Means for Health, Social Care and HIV Service Providers

Health and social care providers need to be aware that there are key times and events when peer support can be of particular benefit, and referrals should be made:
  • At time of diagnosis / when informed of their diagnosis
  • Starting treatment
  • Changing treatment
  • Major illness and/or diagnosis of co-morbidity
  • Starting/ending relationships
  • Planning a family
  • Pregnancy
  • Moving from child to adult clinical care
  • Key life events of aging such as the menopause, reaching the age of 50 etc
  • Any major life changes
  • For support around home testing toolkits

Peer support should be embedded in clinical and social services and be part of the clinical pathway. Effective peer support complements clinical services, and as such it works best when there is a good team relationship. Where possible the peer supporter should be part of the team able to act as a bridge between the individual and the clinical staff, but remaining independent of the establishment.

To ensure an inclusive working environment there will need to be a clear description of the peer supporter's role and responsibilities and to have a senior team member responsible for peer support. In a clinic or social care setting agreements will need to be established on the responsibilities of the person providing peer support with regard to governance, communication with the team, feedback, sharing of information and the role of advocacy.

Competencies and Skills

People providing peer support will have to demonstrate:
- Understanding of the needs of people living with HIV
- Understanding of the needs of specific groups living with HIV and how to tailor services accordingly
- Understanding of confidentiality
- Understanding of safeguarding for people accessing support and those providing support
- Ability to collaborate with other agencies
- Understanding of different forms of peer support e.g. one-to-one, group settings, and how they will contribute to supporting people living with HIV

Outcomes for People Living with HIV Accessing Peer Support

Outcomes should be tailored to the needs of service users and expectations of the service but may include:
- Knowledge and understanding of HIV treatments
- Improved adherence to medications
- Ability to manage their own health
- Ability to speak openly with healthcare professionals
- Building supportive and fulfilling relationships
- Ability to talk about HIV and other issues
- Confidence in their choices of sexual relationships
- Improved engagement with their community whether that be faith group, workplace, or local community
- Resilience, including the ability to cope and to manage without a peer supporter at the end of relationship
- Feeling optimistic about the future
- Taking up training, education, employment or personal development opportunities

Auditable Indicators for Health, Social Care and HIV Service Providers

HIV Service Providers
A range of interventions in place to meet the needs of people living with HIV such as:
- Face-to-face, online, group support, workshops
- Services tailored to specific communities e.g. gay & bisexual men, women, African communities
- Procedures and policies in place for safeguarding and confidentiality

HIV Clinics
- 90% of those newly diagnosed offered peer support or signposted to peer support at their first clinic appointment
- 90% of those living with HIV offered peer support or signposted to peer support when facing a significant life event
- Procedures and policies in place for safeguarding and confidentiality
- Agreed pathway from the clinic to peer support which can be tiered depending upon resources:
  - Signposting and information given to patients
  - Referral pathways and sharing of data in place between the clinic and agency providing peer support
  - Peer support integrated and delivered within the clinical setting

Standard 2

People who provide peer support will be living with HIV and have access to training, support and personal development

Rationale/Why

Peer support works best when facilitated by trained peers drawn from the community they support[xxii].

The breadth of knowledge and skills involved in providing peer support (see *Core Competencies* below) means it is important that those providing peer support have access to structured training, and are linked to professional qualifications, where appropriate and possible.

A structured process to recruit, train and retain peer supporters will ensure high quality peer support. Training should provide techniques to protect the person providing peer support from being overwhelmed by another person's pain or life complexities. All peer supporters should be *Disclosure and Barring Service (DBS)* checked and have the appropriate training to work with vulnerable adults (see *Standard 4* for working with children and young people).

Peer support needs to be properly resourced and managed, whether that be within a patient group or organisation. It needs to ensure a safe environment for both those providing and those receiving peer support, including organisational procedures like risk assessments and policies on lone working etc.

Organisations or groups offering peer support should be committed to providing peer supporters with regular structured support, supervision and time for reflection with others, as well as training updates. Supervisors need to look at ways to enable the people they supervise to self-care and have clear strategies on how to maintain their own physical and emotional health.

What this Means for People Living with HIV Accessing Peer Support

People can access peer support in the knowledge that those providing support are trained, will treat them with respect, uphold their confidentiality and deliver effective support.

"Six months ago all that person could do was cry, now look at them, chairing this meeting"

Peer supporter

What this Means for People Providing Peer Support

People living with HIV providing peer support should:
- Understand and subscribe to the basic philosophy and principles of peer support
- Be trained in providing effective peer support and how to adapt their approach to meet the needs of different people and different situations
- Understand the differences between peer support, counselling and psychological interventions
- Have an awareness of their own limits and abilities in supporting people who may be in distress, who present with mental health issues that require clinical support, and/or require legal advice or practical support beyond the peer supporter's remit
- Be able to self-care and manage their own well-being
- Adhere to the policies and practices of the parent group or organisation providing peer support
- Be committed to attending regular supervision
- Be committed to attending updates and regular further training
- Understand the roles and responsibilities of HIV health and social care professionals and collaborate to better support individuals

What this Means for Health, Social Care and HIV Service Providers

The clinical or social care team will be confident in the abilities and knowledge of the person providing peer support, that supervision and updating is part of service delivery and that the structure of the peer support being provided has a clear and well evidenced basis.

Peer support training should provide clarity on roles and responsibilities, boundaries and governance for peer support in clinical and social care settings.

"They had the struggle, we don't"

CHIVA Youth Committee member

Competencies and Skills

Core competencies peer supporters should be able to demonstrate are:
- Basic knowledge and understanding of HIV and treatments
- Insight into well-being and self-management strategies
- Ability to not over identify with a presented issue
- Ability to demonstrate practical knowledge of sexual health
- Ability to recognise diversity and know how to work with this
- Ability to ensure safety for all parties
- Effective listening and communication skills
- Understanding of confidentiality
- Understanding of safeguarding for vulnerable adults
- Understanding of monitoring and ability to maintain accurate records

Secondary competencies and skills could include:
- Ability to communicate information around reproductive health needs and choices
- A clear knowledge base around safer sex and risk reduction
- Knowledge of current approaches to drug and alcohol issues and use
- Ability to signpost to further support services or information
- Understanding of evaluation and recording the impact of support

Outcomes for People Living with HIV Accessing Peer Support

- Increased confidence and feelings of self-worth
- Increased resilience and personal strength
- Acceptance of their HIV diagnosis
- Access to mutual support
- Improved well-being
- Uptake of training and skill opportunities
- Increased problem solving skills
- Improved stress management skills
- Increased knowledge around HIV, sexual health and related conditions
- Increased skills and opportunities to join committees and advisory boards and other networks e.g. UK-CAB
- Increased skills and opportunities to campaign or advocate, to 'make a difference'
- Ability to set up patient groups
- Engagement with the HIV community, getting a 'sense of belonging'
- A sense of meaning and purpose
- Increased awareness and self-reflection: including when to seek support

Auditable Indicators for Health, Social Care and HIV Service Providers

- All people providing peer support, whether paid staff or volunteers, have attended and completed relevant training
- Peer support training covers the core competencies set out above
- Peer support training is recognised and accredited by a secondary organisation; where possible training is linked to a professional qualification
- A schedule for supervision of peer supporters is agreed and provided
- All people providing peer support attend an agreed numbers of supervision sessions per year
- All people providing peer support have access to and complete an agreed programme of professional development per year

Standard 3

Peer Support will include robust monitoring, measuring and evaluation processes

Rationale/Why

Monitoring and evaluation is a vital way of measuring the impact of any service. It helps demonstrate the difference the service has made. It also highlights what works well and what doesn't work well[xxiii]. Monitoring and evaluation is required by those who fund services, for example, NHS contracts set out requirements for service targets, outcomes and quality improvements[xxiv]. The Charity Commission strongly advises not-for-profit agencies to undertake monitoring and evaluation to demonstrate their effectiveness[xxv].

Monitoring and evaluation will identify the impact of peer support, both what is working well and what needs improving.

Doing so should also ensure the quality and consistency of the support provided.

Robust processes should ensure the active participation of people accessing peer support in measuring progress towards meeting their goals and the effectiveness of peer interventions.

Evaluation of the service and the people providing peer support will help make for a dynamic and flexible service. In the current environment where resources are scarce, data analysis can provide evidence based information for funding successful and cost effective services.

What this Means for People Living with HIV Accessing Peer Support

Using a monitoring system will provide opportunities for people accessing services to participate in measuring their own achievements.

It should provide access to clear and accurate records of the support sessions they have accessed and a record of their journey through the support service.

People living with HIV will have opportunities to contribute to the shape and content of their services.

What this Means for People Providing Peer Support

- Monitoring shows successes and areas needing more work, making for more effective peer support
- Accurate referrals as a result of having records to analyse
- A good evidence base to inform advocacy, including research gaps and the need for policy change
- Allocating time for record keeping, administrative work and debriefing sessions after a peer support meeting

What this Means for Health, Social Care and HIV Service Providers

- Accurate data and evidence for planning and delivering services
- Access to evidence for commissioning services
- Data for planning and informing research programmes
- Accurate referrals to health and social care professionals
- Monitoring and evaluation systems and tools appropriate to the service

Competencies and Skills

People providing peer support should have:
- An understanding of why monitoring and evaluation are important, both for individuals and organisations
- An understanding of confidentiality
- An ability to record peer support interventions accurately e.g. who, what, when, why, and actions taken

Health, social care and service providers should have:
- An ability to collect and analyse information
- An understanding of quantitative and qualitative data
- An ability to use information to demonstrate the effectiveness of services, identify areas for improvement and plan for the future

Outcomes for People Living with HIV Accessing Peer Support

The purpose of this standard is in gathering data and demonstrating the outcomes for *Standards 1, 2* and *4*.

Auditable Indicators for Health, Social Care and HIV Service Providers

- There will be an agreed monitoring system in place for capturing, at a minimum, basic data on who is accessing the service
- There will be an agreed method of evaluation to measure the impact of services upon health and well-being
- Monitoring and evaluation will be used to make changes and improvements to the service
- There will be established systems in place to provide people accessing support to access their records, in line with legal requirements

Standard 4

Children and young people living with HIV will have access to child and youth centred peer support

Rationale/Why

Children and young people have rights to be supported in their health and well-being. These rights are articulated in the *United Nations Convention on the Rights of the Child (UNCRC)*, to which the UK government is a signatory[xxvi] [xxvii].

As with adults, peer support for children and young people living with HIV can have a positive effect on emotional and physical well-being and provide a bridge to health and social care services.

There are estimated to be 2,427 young people aged 15-24 and 315 children below the aged of 15 living with HIV the UK[xxviii]. The cohort of children and young people living with HIV is distributed across the UK, leaving many experiencing social isolation or attending clinical services that are not specifically HIV centred. The majority – approximately 1,383 – acquired HIV through perinatal transmission, with over 700 young people, predominantly gay & bisexual men, acquiring HIV through sexual transmission. All require access to age-appropriate peer support yet all will experience variances in availability and quality of support on offer including HIV and mental health services.

There are specific requirements for children and young people in accessing support. If the person is under 16 parental/guardian consent will be required. Safeguarding of vulnerable children and young people from manipulation, violence, abuse and exploitation has to be ensured. It is possible that support for children and young people may involve a health or social care professional who does not have HIV. At all times clear boundaries and relationship/group agreements will need to be in place[xxix]. Peer support services need to have rigorous boundaries to protect all parties from the risk of negative peer pressure[xxx].

For those born with HIV there is a high value to sharing their experience and journey with others born with HIV. The lived experience of a young person born with HIV and one who has acquired HIV through sexual contact or injecting drug use, is very different and this should be an important consideration when making a peer support link. Parents of children born with HIV may be reluctant to let their children take up opportunities for peer support, in order to keep their own, as well as their children's HIV status confidential. "Stay safe, don't tell" – a common message from parents and guardians of children with HIV – limits opportunities for young peoples' peer exchanges. Although health and social care professionals may have close relationships with the young people they are treating, there comes a time when teenagers are striking out into sex and relationships and may no longer wish to share this stage of their lives with their health care professionals.

Support from older adults may be helpful, but attitudes and HIV treatments have changed dramatically in a short period of time, creating a gulf between the experiences of younger people and older adults living with HIV.

What this Means for Children and Young People Living with HIV

Young people have the right to be heard, respected and valued as a young person living with HIV, and to access support:
- When diagnosed with HIV, or when told of their diagnosis if born with HIV
- In a safe environment with appropriate safeguarding
- Providing information relevant to the person's age
- Addressing HIV and family dynamics, including bereavement issues and caring responsibilities for other family members
- Addressing sexual and reproductive health and rights
- Addressing issues such as bullying and negative peer pressure
- Providing information around HIV, treatments and transmission
- Available at key points of transition for children and young people e.g. from paediatric to adult health care services, from school to further education or employment

What this Means for People Providing Peer Support

- Appropriate training addressing the needs of young people
- Opportunities to develop specific support skills to work with children and young people[xxxi]

What this Means for Health, Social Care and HIV Service Providers

Peer support should be embedded in clinical and social services and be part of the clinical pathway for young people living with HIV. Since often young people living with HIV may not have any opportunity to talk about HIV at home, pro-actively integrating peer support into clinical services can be critical in enabling young people to access it.

The young person offering peer support should be well-incorporated in the clinical team so that they can act as a bridge between the young individual and the clinical staff, and can also receive assistance and support for themselves from the clinical team if needed. At the same time, it is also important that the young person offering peer support can retain a certain level of independence from the establishment, and build a relationship based on trust and mutual understanding with the young people they support in the clinic.

Competencies and Skills

People providing peer support to children and young people need to be able to demonstrate core competencies and skills specific to children and young people, in addition to those listed previously.

Children and Young People Specific Competencies:
• Ability to provide youth/child centred support
• Knowledge of how HIV affects family dynamics
• Ability to signpost to appropriate youth services
• Good knowledge of safeguarding issues and legal requirements for vulnerable children and young people
• Knowledge of treatment issues for children and young people

General Core Competencies:
• Basic knowledge and understanding of HIV and treatments
• Insight into well-being and self-management strategies
• Ability to not over identify with a presented issue
• Ability to demonstrate practical knowledge of sexual health

• Ability to recognise diversity and know how to work with this
• Ability to ensure safety for all parties
• Effective listening and communication skills
• Understanding of confidentiality
• Understanding of safeguarding for vulnerable people
• Understanding of monitoring and ability to maintain accurate records

Secondary competencies and skills could include:
• Ability to communicate information around reproductive health needs and choices
• A clear knowledge base around safer sex and risk reduction
• Knowledge of current approaches to drug and alcohol issues and use
• Ability to signpost to further support services or information
• Understanding of evaluation and recording the impact of support

Outcomes for Children and Young People Living with HIV

While approaches for children and young people will be different, the outcomes are the same as for adults, with improvements in:
• Knowledge and understanding of HIV treatments
• Adherence to medications
• Ability to manage their own health
• Ability to speak openly with healthcare professionals
• Building supportive and fulfilling relationships
• Ability to talk about HIV and other issues
• Confidence in their choices of sexual relationships

• Engagement with their community whether that be faith group, school/workplace, or local community
• Resilience, including the ability to cope and to manage without a peer supporter at the end of relationship
• Feeling optimistic about the future
• Taking up training, education, employment or personal development opportunities

Auditable Indicators for Health, Social Care and HIV Service Providers

HIV Service Providers
- Young people living with HIV will have access to youth centred peer support
- Procedures and policies in place for safeguarding and confidentiality

HIV Clinics
- 90% of young people who are born with HIV to be offered peer support or signposted to peer support when they are told that they have HIV.
- 90% of young people offered peer support or signposted to peer support when they are newly diagnosed with HIV
- 90% of young people living with HIV offered peer support or signposted to peer support when facing a significant life event and when making the transition from paediatric to adult care
- Procedures and policies in place for safeguarding and confidentiality
- Agreed pathway from the clinic to peer support which can be tiered depending upon resources:
  - Signposting and information given to patients
  - Referral pathways and sharing of data in place between the clinic and agency providing peer support
  - Peer support integrated and delivered within the clinical setting

"Peer Support has been my manual on how to live well with HIV"

Person living with HIV

Appendix I – Putting Peer Support into Practice

The *National Standards for Peer Support in HIV* outline the core principles behind effective peer support, but are in no way prescriptive. It is recognised that good peer support can be provided in a variety of ways. This Appendix aims to provides practical examples of peer support in action; each model of peer support is linked to the relevant standard.

Standard 1: Everyone living with HIV should have access to peer support

LASS: Women's Programme

The Leicester AIDS Support Services (LASS) Women's Programme aims to improve positive women's quality of life by:
- increasing their knowledge and understanding of HIV and its treatments
- providing peer support and reducing social isolation
- boosting women's confidence
- offering qualifications and skills-building to move women into education or the workplace

It also aims to shape local services by building relationships with care providers to influence the way that women living with HIV are supported in clinical settings.

Women have the programme tailored to their specific support needs. They are asked about the areas of their life that they find difficult or that they need help with through the use of a spider diagram, where women rank on a scale of 1 to 10 their confidence around eight areas (see page 30 for an example).

Topics of the workshops are identified by positive women and are often facilitated by women in the programme. LASS ensures the sustainability of the programme by training participants to become trainers themselves, and by working with local clinicians to help steer the project and influence commissioners.

The programme has received very positive feedback. LASS has been successful in helping several women move into employment and apply for college. Women report that their increased knowledge around HIV and the emotional impacts of peer support make them more confident to advocate on their own behalf. More and more women are being trained to lead various elements of the programme.

The programme has also led to concrete policy change: the formation of strong relationships with local health care professionals.

lass.org.uk

"The journey to get psychological help was a bad one"

CHIVA Youth Committee member

Homerton University Hospital: Peer Navigator Service

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 the skills of those patients 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 Case Work Manager from Positively UK work as a team providing formal line management, running team meetings, and supervision. Both organisations then take a lead in areas according to their respective expertise or governance:

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 a phone, computer and meeting rooms, as required
- Oversight of the day-to-day work

Positively UK's leads on:
- Training of Peer Navigators
- Group supervision which is 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

Lessons from the project evaluation were:
- *A Clinical Champion:* identify someone in the clinical team who will champion the project, supporting their colleagues in understanding and utilising the service

- *Contractual considerations:* ensure compliance with both the host organisation and clinic's needs; for instance, there may be additional training around safeguarding or data protection to ensure the peer support team meet the NHS Trust's requirements

- *Training and development:* the Peer Navigator service provided an opportunity to support people back into work, as part of this a personal development plan should be developed including areas such as time management and IT skills. Opportunities for training can also be maximised by providing access to training at both the NHS Trust and host organisation

- *Targeted approach:* targeting peer interventions from the outset can help in bringing the project online e.g. offering a referral to the peer support service for all newly diagnosed patients

- *Integration:* maximise opportunities for the peer service to be integrated into clinical practice including peer workers attending inter-disciplinary meetings to provide presentations on their work

- *Two-way communication:* implement systems to feed back to clinical staff the outcome of peer interventions, this can be verbally or updating notes on the clinic's data management system that can be viewed by the clinical team

Terrence Higgins Trust: myHIV

myHIV is Terrence Higgins Trust's innovative online service; it is the UK's largest online community for people living with HIV with over 11,000 members accessing self-management tools, information and online support, including online advice, counselling and peer support. Since its launch in January 2011 myHIV has helped people manage their own diagnosis and increase their knowledge of the condition in order to live well.

At the heart of myHIV is the community forum with more than 3,800 members. This peer-led space allows people from across the UK to have conversations with each other and share their own stories. The most popular forum topics include receiving an HIV diagnosis, treatment, relationships, staying healthy and living with co-morbidities. During the evenings, an online peer support volunteer team of peer mentors chat with forum members, answering questions using their own lived experiences and signposting them to services from both Terrence Higgins Trust and other HIV or sexual health organisations. The forum is a positive space and members love to share their good news as well as their problems, for example finding out their viral load is 'undetectable' for the first time.

Volunteers deliver peer support in an informal group chat space, but also engage with the people they support one-to-one via private messages should they want to speak in confidence about their issue. Unlike the majority of face-to-face services myHIV's online peer support is a drop-in service, and people with HIV who need peer support can come and go as often as they like at a time that is convenient to them. The majority of people accessing the support are newly diagnosed or have reached a milestone in their diagnosis, perhaps starting treatment for the first

time or when they meet a new partner. Many others simply want to be able to speak to others with the condition they share.

People providing and receiving peer support discuss situations and problems together just as they would in other peer support environments, and together they look at what actions can be undertaken. The peer support volunteers build a rapport and relationships with a number of different people in the forum by responding to topics in various different threads and there is a real sense of community with members all helping to support each other as their own confidence grows. Some people accessing the forum prefer to speak to particular peer volunteers, whilst others are happy to talk to whoever is available. The peer volunteers provide support on a rota basis for one to two hours a week and this is published for forum members to see.

Volunteers providing peer support receive training and supervision from Terrence Higgins Trust and adhere to the charity's policies regarding safeguarding and boundaries etc. Peer volunteers are not expected to assist clients in a crisis situation or advise them about complex medical needs but have access to on-call support and are trained to sign-post to applicable services, for example A&E, HIV clinicians or specialist nurses, GPs, or other organisations such as Samaritans.

myHIV is able to help anyone living with HIV in the UK. The services is accessed by a range of people, from those living in low prevalence areas that may not have access to face-to-face support services, to people who are unable to contact local groups for personal reasons.

tht.org.uk/myhiv

Standard 2: People who provide peer support will be living with HIV and have access to training, support and personal development

Positively UK: Project 100

The aim of Project 100 is that 100% people living with HIV have access to high quality HIV peer support at any time after diagnosis wherever they are in the UK, through training and developing a national network of volunteer peer mentors. This is done by:

- Training 1000 people living with HIV across the UK to become Open College Network accredited peer mentors (NVQ Level 2) over four years
- Partnering with organisations, clinics and individuals across the UK to support the development of local programmes for peer support and mentoring, through capacity building
- Evaluation of peer support by the New Economics Foundation

The centre of the programme is the *Project 100 Core Peer Mentor Training* which is a three day course delivered by Project 100 trainers. These three days are broken down into sections, skills and topics. It all comes together to provide a strong and wide skills-base for all peer mentors.

Training is accredited through the Open College Network, leading to a Level 2 Qualification in Peer Mentoring and addresses how to provide one-to-one support, outreach to clinics, follow-up assessments and organising and facilitating groups. The programme has achieved the Mentoring and Befriending Foundation *Approved Provider Standard*.

The three days of training includes:

Day One	Day Two	Day Three
Defining mentoring and the skills and qualities needed to be an effective peer mentor	Communication skills, including talking about HIV	The mentoring relationship, including starting off and ending
Boundaries, self-disclosure, confidentiality, safeguarding and limitations	HIV transmission and treatment	Action planning, problem solving and goal setting
	How our experiences influence the way we mentor	
	Using outcome measurements for monitoring progress in a mentoring relationship	

Project 100 also has an online aspect to its learning, and people are creating their own support networks through this tool.

positivelyuk.org/project-100

Intentional Peer Support (IPS)

"Peer support is about social change"

Intentional Peer Support (IPS) relationships are viewed as partnerships that invite and inspire both parties to learn and grow, rather than as one person needing to 'help' another.

IPS doesn't start with the assumption of a problem. With IPS, each of us pays attention to how we have learned to make sense of our experiences, then uses the relationship to create new ways of seeing, thinking, and doing.

IPS promotes a trauma-informed way of relating. Instead of asking "What's wrong?" we learn to ask "What happened?".

IPS examines our lives in the context of mutually accountable relationships and communities – looking beyond the mere notion of individual responsibility for change.

IPS encourages us to increasingly live and move towards what we want instead of focusing on what we need to stop or avoid doing.

During the Core Training, participants learn to:
- Seek ways to connect, become aware of disconnects, and work to reconnect
- Explore how we have "come to know what we know"
- Strive for mutuality in relationships
- Stay curious, question assumptions and own judgements and opinions
- Open up new ways of listening
- Use experience to relate and build trust
- Name and negotiate power in relationships
- Approach crisis as an opportunity to grow
- Share risk and responsibility
- Focus on the quality of relationships instead of fixing one another
- Pay attention to the impact of clinical and labelling language
- Understand how trauma affects lives
- Keep the energy in relationships moving towards what we want
- Understand peer support in the context of social change and social justice

The first step to implementing IPS is the *Core Training*. Based on Shery Mead's innovative curriculum, *'Intentional Peer Support: An Alternative Approach'*.

The five day Core Training is an extensive overview of the IPS framework and is designed to have participants practicing right away. In a highly interactive environment, participants learn the IPS tasks and principles, examine assumptions about who they are, and explore ways to create mutual relationships where power is negotiated, co-learning is possible, and support goes beyond traditional notions of 'service'.

The second step to implementing IPS is to practice *Co-Reflection*. IPS requires an ongoing commitment to learning and growth. To achieve this end, we developed co-reflection, a practice where people regularly come together to reflect on their relationships using the IPS framework. Here is an opportunity to examine relational patterns, look at assumptions, and sustain the tasks and principles.

The third step to implementing IPS is to explore *Advanced Training*. Once people complete Core Training and begin practicing IPS, lots of questions emerge – most commonly, "How do I make this stuff work in my particular environment?"

The four day Advanced Training takes IPS practice a step further. Here we learn to heighten self-reflection, work through the principles and tasks using real-life scenarios, enhance ways of building mutual connections, and sustain the practice through co-reflection.

With a focus on crisis as opportunity, we also explore how to navigate conflict and challenging scenarios, develop flexible boundaries, use pro-active crisis planning, act trauma-informed, and prepare for programme evaluation.

The Advanced Training is for graduates of Core Trainings and is customized to an organization's needs.

intentionalpeersupport.org

"I didn't believe this woman had HIV, she looked well, got up every day and went to work, was in a relationship, had a child – all the things I wanted and thought I could never have now I had HIV. She said she had been like me once, and things would be different for me too."

Young woman newly diagnosed with HIV, describing her first meeting with her peer supporter

Standard 3: Peer Support will include robust monitoring, measuring and evaluation processes

There are a range of tools available for monitoring and evaluation. The level and complexity of the information you gather and how you evaluate will depend on the project, resources and funding. As a basic rule, you should only collect data that will be used to understand who is using your services and understand how they are benefiting from the service. Examples of evaluation tools you can readily use are:

Outcome Stars

Outcome Stars are an easy-to-use tool to measure the progress someone makes during their support. Over time it also provides a picture of their journey. There are a range of outcome stars available to use and buy online. In setting up their women's project (see page 24 for more information), LASS created a blank outcome star.

Peer workers and volunteers support service users in identifying what areas they want to change in their life. The outcomes are then agreed and individual to each user. At a later time the user together with the peer worker / volunteer can repeat the assessment using the outcome star, and see where change had happened.

Example Outcome Star — LASS
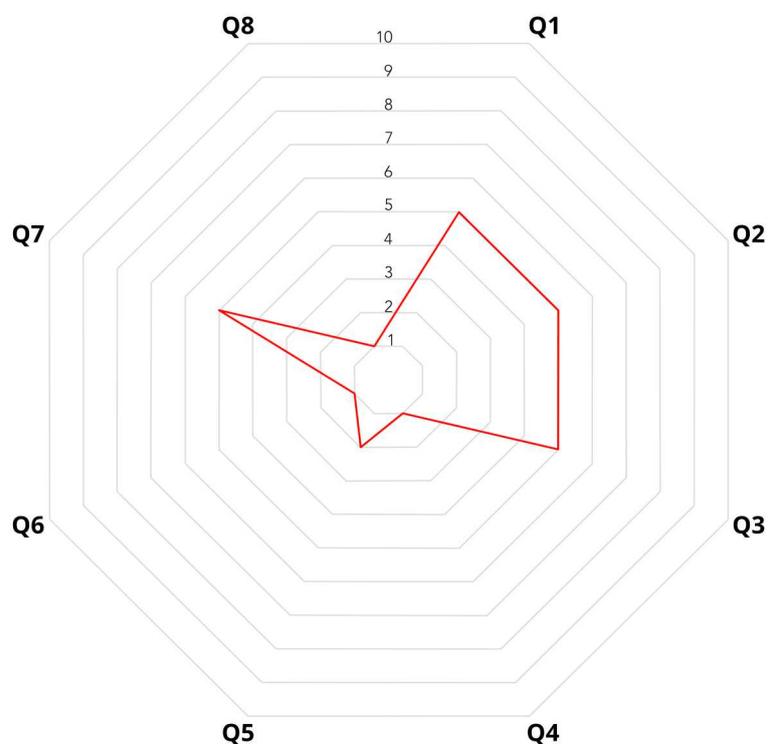
Q1: Disclosure
Q2: Relationships
Q3: College or studies
Q4: Work
Q5: Family & friends
Q6: Dentist
Q7: Medication management
Q8: Being settled (in relation to immigration)

Warwick-Edinburgh Mental Well-Being Scale

The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) was developed to support the monitoring of mental well-being in the general population. It widely recognised and used across a number of projects and services, and is acknowledged within the government's *Public Health Outcomes Framework*.

The WEMWBS is a series of 14 questions on different areas of mental well-being such as optimism, feelings towards others and oneself.
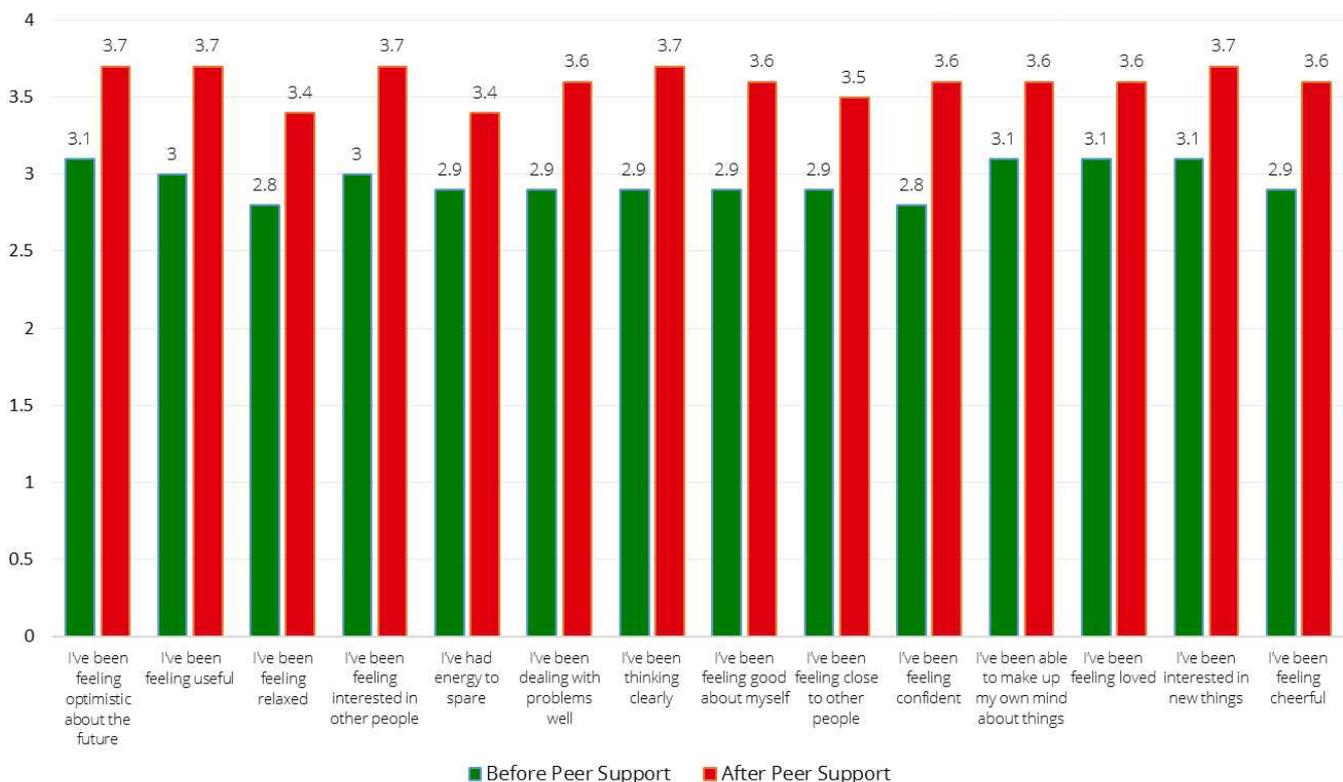
The 14 questions have scores for the scale, 1 point for 'None of the Time', and 5 points for 'All of the Time'. It can be completed at different times in a person's journey or support plan to measure progress. The tool and a user guide are available to download from the Warwick Medical School website:

*www2.warwick.ac.uk/fac/med/research/
platform/wemwbs/*

Example WEMWBS — Positively UK

The WEMWBS was used by Positively UK in a review of its services to demonstrate the role of peer support in promoting emotional well-being. Service users were asked to complete the 14 question scale twice: when first accessing Positively UK's peer support service, and a second time two weeks after accessing the service. The averaged scores of all respondants were then compared:

Bar chart comparing Before Peer Support (green) and After Peer Support (red):

Question	Before Peer Support	After Peer Support
I've been feeling optimistic about the future	3.1	3.7
I've been feeling useful	3	3.7
I've been feeling relaxed	2.8	3.4
I've been feeling interested in other people	3	3.7
I've had energy to spare	2.9	3.4
I've been dealing with problems well	2.9	3.6
I've been thinking clearly	2.9	3.7
I've been feeling good about myself	2.9	3.6
I've been feeling close to other people	2.9	3.5
I've been feeling confident	2.8	3.6
I've been able to make up my own mind about things	3.1	3.6
I've been feeling loved	3.1	3.6
I've been interested in new things	3.1	3.7
I've been feeling cheerful	2.9	3.6

31

Further Resources:

The National Council for Voluntary Organisations (NCVO) have published: *Practical Monitoring and Evaluation: A Guide for Voluntary Organisations* available from *NCVO.org.uk*

NVCO also run a number of workshops on monitoring and evaluation *ncvo.org.uk/training-and-events*

Workshops may also be available through your local voluntary sector council *navca.org.uk/members/members-directory*

"I take the person by the hand and lead them to meet the peer worker"

HIV Clinician

Standard 4: Children and young people living with HIV will have access to child and youth centred peer-support

CHIVA: Freedom To Be

The Children's HIV Association (CHIVA) is a registered charity working across the UK and Ireland to improve care for HIV positive children and their families. CHIVA provides information, guidance and support for professionals, parents and young people living with HIV and runs an annual support camp for HIV positive young people.

'Freedom To Be' is an annual residential support camp which brings together up to 100 children, aged 11-16, from across the UK and Ireland, annually in August. The camp is comprised of HIV workshops, creative and performance arts opportunities, outward bounds and recreational activities and is intended:

- To facilitate the development of peer friendships and networks in order to address the high level of social isolation experienced by this group of children
- To supplement participants' knowledge and understanding of how to live well with HIV
- To enhance participants' confidence and self-esteem through creative and arts based activities, and emotional support
- To facilitate participants' access to a broader community of people living with HIV so as to provide them with knowledge, support, guidance and inspiration

The staff team who deliver 'Freedom To Be' consist of: key workers, volunteers who support the young people attending camp; and camp leaders, volunteers aged 18-24. All camp leaders are living with HIV and most have previously attended the camp as a participant. Many key worker volunteers also live with HIV and an increasing number on the team each year have grown up with HIV.

CHIVA is committed to a model which enables the camp to be led by people who are living with HIV, many of whom will have been attendees at the camp in previous years.

chiva.org.uk

"We need someone in between"

CHIVA Youth Committee member

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