



## HIV Peer Support

### Developing Standards for Australia

Adrian Ogier | AGM – 25 October 2019

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## History of development

- Chris and Bill
- 2018
- July 2019

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## The steering group

- Chris Howard
- Graham Brown
- Sara Graham
- Richard Keene
- Katy Roy
- Aaron Cogle

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# Tools we are using



Practice Guidelines  
in Peer Health Navigation for  
People Living with HIV

CATIE

Canadian Standards

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**RECOMMENDATION 1:** Conduct a local needs assessment that includes input from people with HIV, clients and service providers to determine the breadth of client needs. A needs assessment will help agencies to tailor peer health navigation programs and determine which roles a peer health navigator can take on to meet the needs of clients. (Type of evidence: practice)

**RECOMMENDATION 2:** Define a clear peer health navigator scope of practice and draft job descriptions that reflect the roles and responsibilities within the scope of practice. Job descriptions should also clearly outline the goals of the program and qualifications and experience that are necessary and preferred. Determine and communicate the roles and responsibilities that are outside the scope of practice of peer health navigators. Ensure job descriptions are clear and straight-forward. (Type of evidence: research and practice)

**RECOMMENDATION 3:** Involve peer health navigators in the intake and assessment of clients' needs as part of an interdisciplinary team. Using their lived experience to build trust over time, the navigator's role is to help clients identify and assess their strengths and challenges and help them develop a plan to achieve their health and wellness goals. This assessment should take into account all aspects of clients' lives. (Type of evidence: research and practice)

**RECOMMENDATION 4:** Peer health navigators use advocacy skills to ensure the client's voice is heard during healthcare appointments and in the community. Navigators also have a role in raising systemic issues that impact client care. (Type of evidence: research and practice)

**RECOMMENDATION 5:** Peer health navigators provide practical assistance to clients such as help with transportation, housing, financial assistance, child/elder care, and other services that can facilitate optimal engagement in healthcare and achievement of health and wellness goals. (Type of evidence: research and practice)

**RECOMMENDATION 6:** Peer health navigators provide support to clients before and after appointments with healthcare providers, help clients to understand the purpose of a particular medical appointment or specialist, help prepare clients with questions, and provide an explanation of the visit in plain language. Peer navigators can also provide accompaniment to appointments and advocacy during appointments. (Type of evidence: research and practice)

**RECOMMENDATION 7:** Peer health navigators play a role in providing emotional, cultural and social support to clients and their families (as appropriate) based on a common understanding of the experience of living with HIV. (Type of evidence: research and practice)

**RECOMMENDATION 8:** Peer health navigators provide culturally safe and trauma-informed education, information, care and support to clients and their families (as appropriate), based on a holistic model that includes the physical, emotional, spiritual and mental needs of clients and their families. Navigators share accurate information using language familiar to clients and their families, where appropriate. Health promotion

**VIGNETTE** A local community-based agency currently provides case management for people with HIV. The agency is expanding to develop and deliver a peer health navigation program. In reviewing Practice Guidelines in Peer Health Navigation for People Living with HIV, a consultant working with the agency to develop the program recommends that they consider how GIPA/MEPA principles are currently incorporated into the agency's work, and how they will be integrated into a peer navigation program.

The agency's leadership reflects on how it has engaged people with HIV in its work so far.

The agency admits that it has not done enough to work within a GIPA/MEPA framework. They understand that the GIPA/MEPA principles aim to realize the rights and responsibilities of people with HIV, including the right to self-determination and participation in the decision-making process. Therefore, they engage people with HIV who are currently using services within their organization but they also reach out to other organizations to help actively link them to people with HIV from other organizations. A large group of diverse people with HIV from the community are brought together to help determine how they want their voices heard within the development of this program. Based on these consultations, multiple sessions are held to provide space for input into the development and delivery of the program and an ongoing committee is struck to ensure continued input into the delivery of the program. In the end, many of these people with HIV become peer health navigators within the newly developed program.

**Assess agency readiness to ensure agency culture is inclusive**

**RECOMMENDATION 3:** Assess agency readiness to ensure agency culture is inclusive of peer health navigators. (Type of evidence: practice)

**Evidence**

This recommendation emerged from the practice expertise of the working group.

Summary of recommendations 15

Practice Guidelines in Peer Health Navigation for People Living with HIV

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## Tools we are using



**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 (NHVNA) 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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Elisabeth Crafer – Developer & Producer  
Ginger Grange – Layout & Design  
Silvia Petrelli – Steering Group Chair

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## Introduction

The active engagement and participation of people living with HIV (PLHIV) is recognised as central to any effective response to HIV.<sup>1</sup> This engagement of communities of PLHIV is underpinned by investments in peer-based programs.<sup>2</sup>

PLHIV Peer-led programs may include peer activities ranging from peer service delivery (such as peer support), to peer health promotion (such as PLHIV peer developed and implemented campaigns or community development), to peer leadership (such as PLHIV peers taking leadership roles in their community, their sector, or participating in policy and law reform).<sup>3</sup>

### 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 belief that through sharing and support we can transform our lives and the lives of others in our communities for the better.

Peers can be people with similar health conditions, from similar communities, or with shared identities based on sexuality, gender, or cultural background.

Peer support creates opportunities for both parties to grow and achieve a sense of control and empowerment. Peer support can be formal or informal and can range from friends sharing, to people within groups supporting each other, to paid workers providing a goal-oriented 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.

<sup>1</sup>UNAIDS. The greater involvement of people living with HIV (GIPA). Policy brief. Geneva: UNAIDS, 2007.

<sup>2</sup>Brown, G., O'Donnell, D., Crooks, L., & Lake, R. (2014). Mobilisation, politics, investment and constantly adapting: Lessons from the Australian health promoter response to HIV. Health Promotion Journal of Australia, 29(1), 1-6.

<sup>3</sup>UNAIDS. The greater involvement of people living with HIV (GIPA). Policy brief. Geneva: UNAIDS, 2007.

<sup>4</sup>Brown, G., O'Donnell, D., Crooks, L., & Lake, R. (2014). Mobilisation, politics, investment and constantly adapting: Lessons from the Australian health promoter response to HIV. Health Promotion Journal of Australia, 29(1), 1-6.

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# Content

## About Peer Support

### About peer support

#### History of peer support in HIV

The central role of community and peer-led responses has been a key characteristic of the Australian partnership response to HIV since the beginning of the epidemics.<sup>1</sup>

In the 1980s, when little was known about HIV and discrimination was widespread, gay and HIV positive activists set up AIDS Councils and PLHIV organisations around Australia. And-Hit was from within these community organisations that HIV-peer support projects emerged—where defined these peer-based programs emerged—led and conducted by people from these communities, including PLHIV, and operated through organisations established and governed by their communities. Critical within these responses was the role of PLHIV specific peer-based programs - including peer support, health promotion, and community mobilisation as well as leadership and advocacy within policy.<sup>2</sup> Run by PLHIV, these projects provided one-on-one and group support, shared knowledge and lobbied for better treatment and appropriate care.

HIV services owe their existence to these activists and those who campaigned alongside them. From these small beginnings emerged action 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 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.

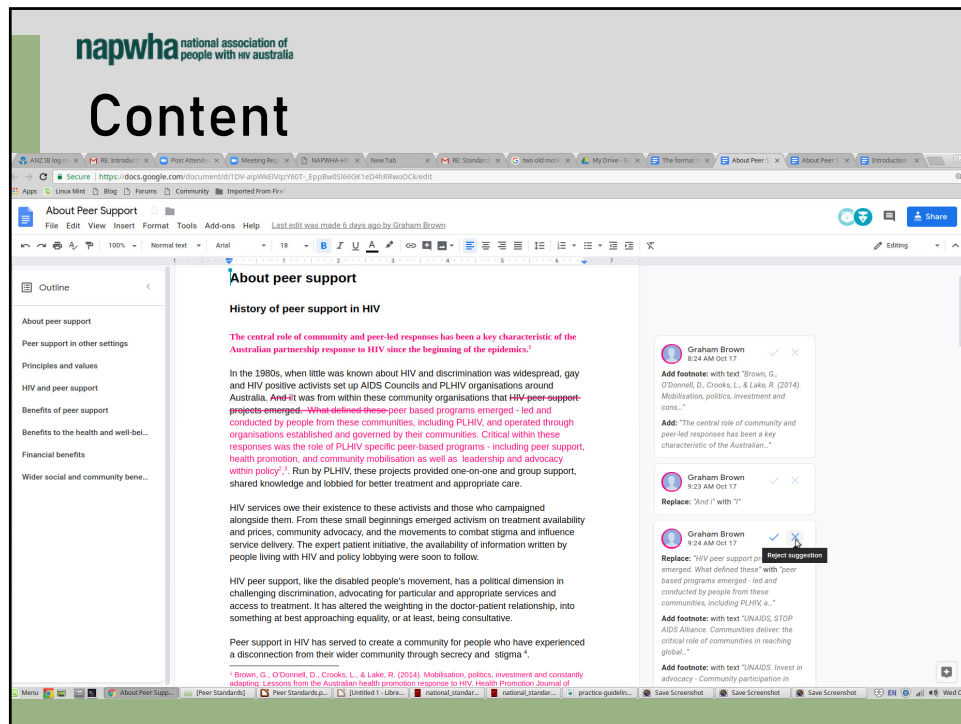
Peer support in HIV has served to create a community for people who have experienced a disconnection from their wider community through secrecy and stigma.<sup>3</sup>

<sup>1</sup>Brown, G., O'Donnell, D., Crooks, L., & Lake, R. (2014). Mobilisation, politics, investment and constantly adapting: Lessons from the Australian health promoter response to HIV. Health Promotion Journal of Australia, 29(1), 1-6.

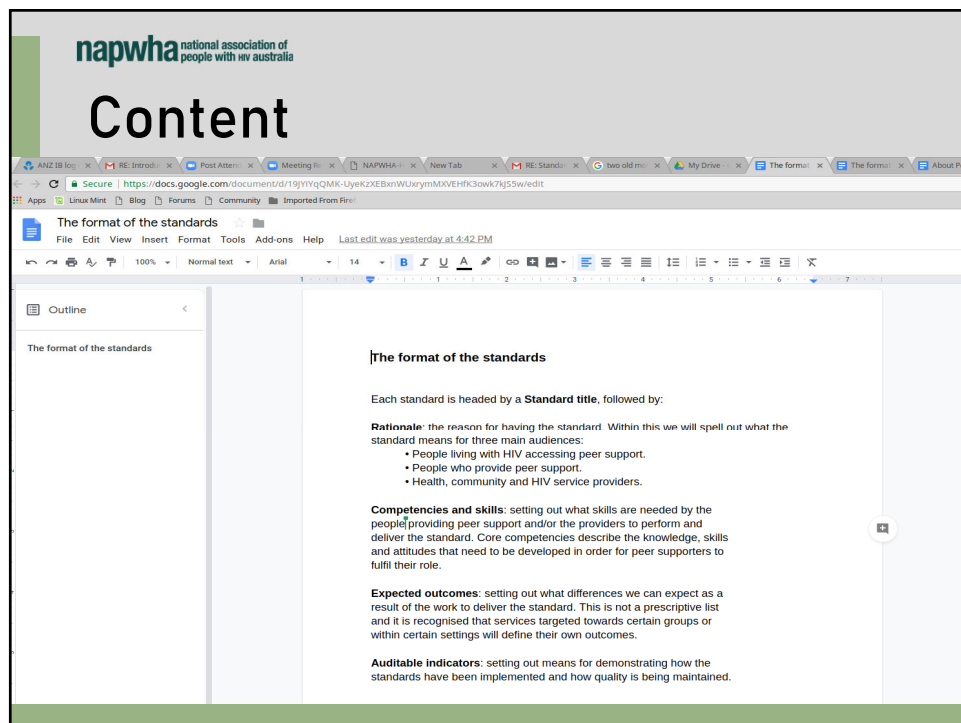
<sup>2</sup>Brown, G., O'Donnell, D., Crooks, L., & Lake, R. (2014). Mobilisation, politics, investment and constantly adapting: Lessons from the Australian health promoter response to HIV. Health Promotion Journal of Australia, 29(1), 1-6.

<sup>3</sup>UNAIDS. The greater involvement of people living with HIV (GIPA). Policy brief. Geneva: UNAIDS, 2007.

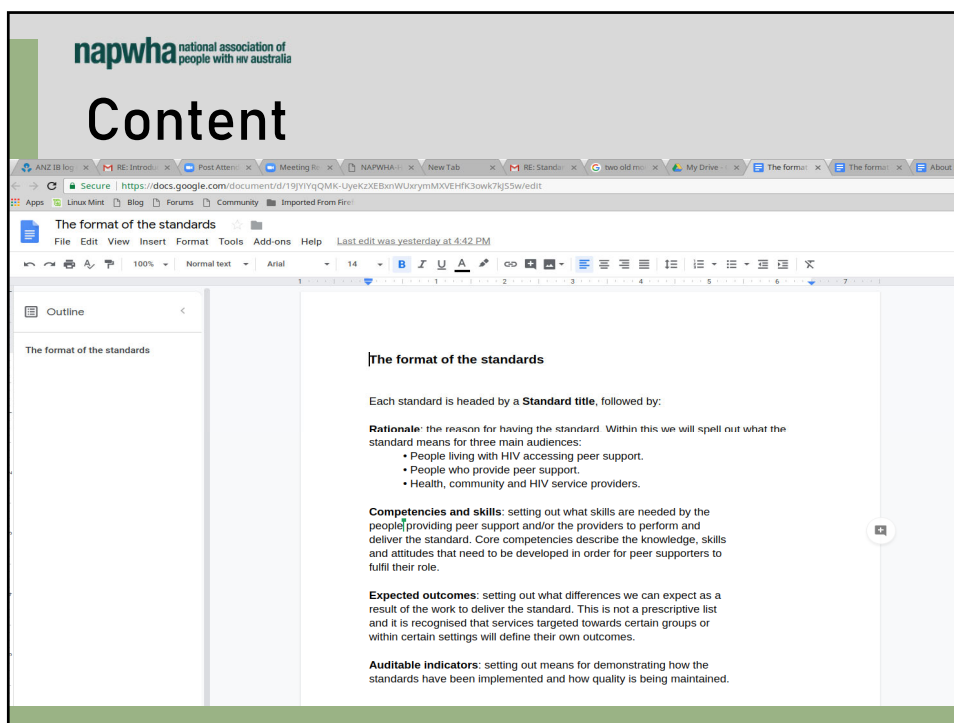
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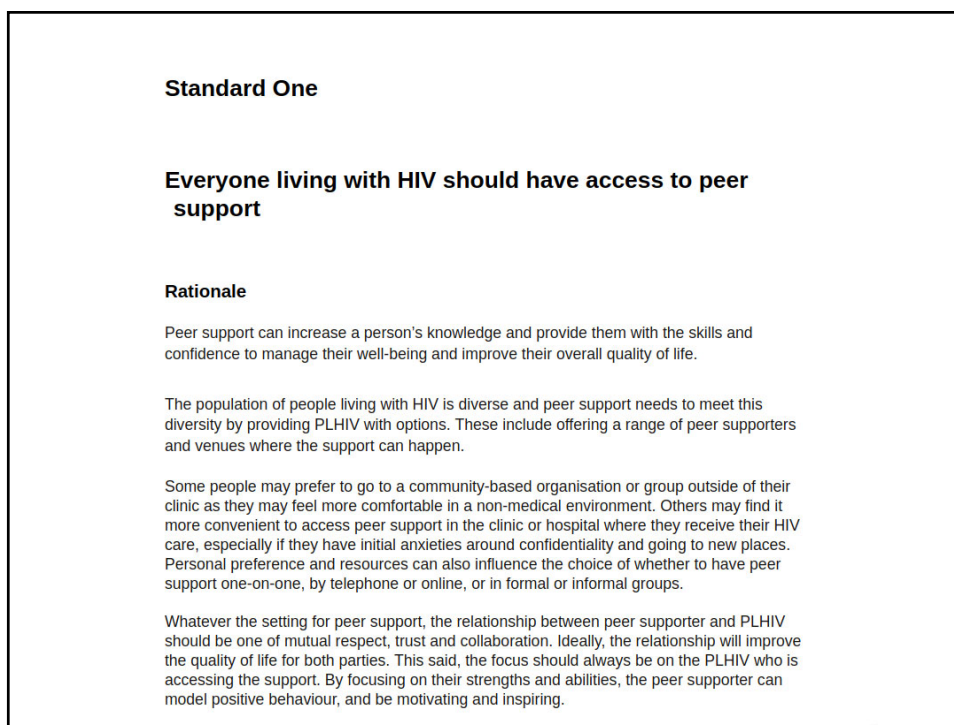
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The skills, insights and experience of people providing peer support should be valued by colleagues in community and health services. This includes being paid for their services, or when volunteering to be regarded with a high level of respect.

#### **What this means for health, community and HIV service providers**

Providers need to be aware that there are key times when referring to peer support may be of particular benefit and these include:

- At the time of diagnosis.
- When starting or changing treatment.
- At the diagnosis of a comorbidity or major illness.
- When reengaging in HIV care or at risk of disengaging from care.
- At the commencement or end of a relationship.
- When planning a family.
- When pregnancy is confirmed.
- When moving from child to adult clinical care.
- On entering aged care.
- At any other significant life event.

Peer support should be part of the clinical pathway. Effective peer support complements clinical services, and as such works best when the peer supporter is acknowledged and valued as part of the care team; acting as a bridge between the individual and the clinical

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#### **Competencies and skills**

People providing peer support will need to demonstrate an understanding of the following:

- The diverse needs of people living with HIV including those of specific groups, how to tailor support accordingly and when it is appropriate to refer a PLHIV onto another peer supporter.
- Confidentiality and the ability to explain its principles within the context of peer support.
- The importance of safeguarding those accessing peer support as well as those providing it.
- Collaboration with other agencies and the ability to refer appropriately.
- Scope of practice and when to refer to another health care professional.
- The importance of professional boundaries protecting the peer supporter and PLHIV.
- The different forms of peer support e.g. one-on-one and group settings, and how each contributes to supporting people living with HIV.
- The unique role of the peer supporter to identify important trends and issues and the ability to relate these to colleagues as well as the broader sector in order to enhance and [improve health](#) and community services.

#### **Outcomes for PLHIV accessing peer support**

Outcomes should be tailored to the needs of the service user, but may include:

- Enhanced knowledge of HIV and understanding the virus.
- Enhanced knowledge of HIV treatments and how they work.

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- Increased ability to self-manage their health.
- Increased confidence to speak openly with healthcare professionals.
- Enhanced skills to build supportive and fulfilling relationships.
- Increased knowledge about their rights and responsibilities as they relate to HIV.
- The ability to talk about HIV and other issues.
- The confidence required to make choices within sexual relationships.
- The confidence to manage disclosure of HIV status.
- Improved engagement with a personal/peer network, faith group, workplace, or local community.
- Resilience, including the ability to manage without a peer supporter.
- Optimism about the future.
- The confidence to take up training, education, employment or personal development opportunities.
- Improved quality of life indicators.

#### **Auditable indicators for health, community and HIV service providers**

##### **HIV service providers**

A range of interventions are in place to meet the needs of PLHIV such as:

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## **Standard Two**

### **People who provide peer support should be living with HIV and have access to training, supervision and personal development**

#### **Rationale**

Peer support works best when facilitated by trained individuals drawn from the communities they support. Lived experience is a particularly invaluable tool when supporting other PLHIV. An HIV positive peer supporter is able to relate first-hand to the shock of an HIV diagnosis, the sting of HIV stigma, the complexities around treatment and the difficulty of disclosure. What's more, revealing their experience with an issue often helps alleviate the tension for those receiving support and can provide perspective.

Organisations or groups offering peer support should be committed to providing peer supporters with structured training and regular updates, support including regular supervision with peer supervisors where possible, time for reflection with other peers and opportunities that facilitate personal and professional growth.

Structured training, supervision and support will ensure high quality services, safety for peer supporters and their clients, and retention of the peer support workforce.

#### **Training**

Peer supporters should have access to a suite of structured and regular training opportunities to develop their skills and knowledge.

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### Standard Three

#### Peer Support will include robust monitoring and evaluation processes

##### Rationale

Monitoring and evaluation is a vital way of measuring the impact of services and programs. Monitoring and evaluation assists in:

- Identifying the impact of peer support services on target populations.
- Identifying what is working well and what might need improving.
- Measuring the effectiveness of services and providing evidence in meeting contractual requirements.
- Measuring quality and consistency of support provided.
- Collating peer insights into the evolving experience of PLHIV and their peer, community and health service needs.

Bodies who provide funding often require monitoring and evaluation of services and programs. Contracts will often specify performance indicators, which may include a combination of outputs, quality and outcomes measures. Data collected will be a combination of qualitative and quantitative data.

- Outputs focus on measurements that may include the number and types of activities provided i.e. the number and type of clients seen, the number of workshops delivered.

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### Standard Four

#### Peer support should be tailored for key populations

##### Rationale

The PLHIV population in Australia is made up of affected communities who group-identify in ways other than by HIV positive status.

Many of these sub-populations are from communities who already feel marginalised by broader society. HIV adds another burden that in many cases is not easily discussed within those communities. It is ideal, therefore, for peer support to be tailored and provided in a way suited to an individual who presents with a unique set of issues and/or who identifies with an affected community.

Empathy comes from others who share similar backgrounds and experience; therefore the ideal peer supporter will often be one drawn from the same community and the most appropriate peer support group will consist of other PLHIV who share similar cultural, sexual and gender issues.

While this may not be possible for all individuals or groups - particularly when services are limited - it is important for any organisation offering peer support to identify key affected communities within their jurisdiction and provide peer support training that includes specific sensitivity training on these populations.

Fortunately, the principles of peer support should resonate with any individual regardless of their background. Often the identity of the peer supporter is not important. For reasons of confidentiality, a PLHIV seeking support may in fact prefer to be supported by someone outside of their community. A well-trained and supervised peer supporter should be able to offer appropriate and sensitive support to any PLHIV. And while doing so, they will be looking for ways to link the PLHIV with other supportive

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## 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 provide 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](http://lass.org.uk)

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

CHIVA Youth Committee member

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## Future steps

- Examples of HIV peer support in action
- Steering group meeting
- Forewords
- Editing and proofing
- Design and production

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