

# Peer support in HIV care

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While very much an upcoming health support strategy, peer support has been a mainstay of HIV care since the initial days of the epidemic, over 30 years ago. Faced with a climate of fear, ignorance and judgement about the condition, there were few places for people living with GRID (gay-related immune deficiency, as it was then) to get any kind of support. The gay community took up the challenge to look after its own when few others would, setting up organisations such as Body Positive and Terrence Higgins Trust to provide support and share what little information there was available. With few solutions to the myriad problems and opportunistic infections, medical staff tried to deal with symptoms and illnesses as they arose, while patients shared their difficulties, experiences and potential solutions (however unconventional) with each other.

As the epidemic grew and broadened, new peer-led organisations such as Positively Women, Mainliners, the AIDS Treatment Project and the UK Coalition of People Living with HIV (UKC) started providing targeted support. Shunned by wider society, turning to one another for help and support was the only realistic option and much of the focus of that support was to make those difficult last years of life more bearable. The main focus was to help people to step out of their isolation into a welcoming space where they could meet others who were going through the same difficulties.

While the advent of effective HIV medication in 1996 [1] transformed a terminal condition into a manageable lifelong infection, it also meant that those who funded support services no longer saw as great a need for them and, one by one, many smaller local charities either closed or merged with larger organisations. Opportunities for people to meet and support each other on a daily basis diminished, but weekly support groups and newly diagnosed courses still found pockets of funding to provide peer support.

In the face of rapidly disappearing peer support services, some patients developed programmes within the HIV clinics where they accessed care, encouraged by forward-thinking consultants such as Martin Fisher and Ian Williams, who used a more collaborative approach in addressing patient need than had previously been the case within a traditional 'Doctor knows best' health service. 'Patient involvement' and 'patient-centred care', new millennium buzzwords, had been at the heart of HIV clinical care for years; the Lawson Unit in Brighton and Bloomsbury Clinic in London now boasted in-house Patient Representatives providing peer support and signposting to external

support services, making for a genuinely holistic model of care that considered a patient's physical, mental and social wellbeing. Gone was a model of palliative support that helped people die with dignity, and instead emerged a solution-focused support mechanism to help people live well and longer with HIV.

At the same time that effective medication was becoming available, Stanford University were piloting their 'Positive Self-Management Program', an HIV-specific training to support patients in increasing their skills and effectiveness around managing pain, symptoms, medication and isolation, as well as exploring wellbeing through exercise and nutrition, communication with friends, family and medical teams, and making plans and setting goals for the future. The pilot study [2,3] demonstrated effectiveness in improving both physical symptoms and medication adherence. This was rolled out in the UK during the early 2000s via a number of HIV organisations and proved extremely popular with participants, who often went on to become facilitators themselves. Again, the benefit of having someone living with HIV providing information and tools to improve health and self-management strategies paid dividends in ensuring people felt understood and were not alone in their diagnosis.

Positively Women developed a volunteer peer support training programme for women living with HIV in the early 2000s and demonstrated how volunteers with HIV benefited from providing peer support within an HIV setting in terms of building skills and confidence (which was presented as an abstract at the XIII International AIDS Conference in Durban, South Africa, in July 2000). The training was designed to prepare women for all aspects of the role and based on the model used by the Landmark HIV Centre in Brixton, which sadly closed in 2001.

Positively Women were moving from a more unstructured befriending model of peer support, where the peer relationships had no end date, to a peer mentoring model, where support could be targeted over a significant period in the person's life:

*A voluntary, mutually beneficial and purposeful relationship in which an individual gives time to support another to enable them to make changes in their life. (Mentoring and Befriending Foundation [4])*

Opt-out HIV testing in pregnancy increased the number of women being diagnosed in pregnancy, and choice and effective treatment meant that more

were choosing to have children after diagnosis. Positively Women developed its Mentor Mother Programme, which included an additional two-day training package on top of the core peer support training to provide targeted support over this particular time: diagnosis; starting treatment as prevention; adherence in pregnancy; birth options; testing of baby after delivery; breastfeeding; and maternal treatment options after delivery.

The peer support that Positively Women (in recent years becoming Positively UK) provided in clinics for nearly 30 years, along with the success of their Mentor Mother programme, were instrumental in Homerton Hospital developing the role of Peer Navigator within their clinic in partnership with Positively UK. The abstracts demonstrating the successful outcomes of this role won awards at both NHIVNA [5] and BHIVA [6] conferences in 2015.

The advent of the digital age has provided even greater opportunities for people to link via online forums and groups on social networking sites, such as Facebook. Terrence Higgins Trust developed its myHIV.org.uk website to include a Community Forums discussion board and chat room, staffed by peer support volunteers through the evenings, so that people could log in and talk to someone else living with HIV, wherever they were in the UK and however remote access to face-to-face services might be.

All these projects have had great success, and the expansion of the patient representative model in particular has grown to the extent that at least six London clinics now employ paid in-house patient representatives. On a wider level, however, the NHS has been slow to mandate for the provision of peer support, but in the last few years the push to include peer support as an integral part of care has gained momentum. First, in 2013, the British HIV Association (BHIVA) published their Standards of Care for People Living with HIV, which includes in Standard 9 (Self-management) the quality statements [7]:

*Self-management services including access to peer-support opportunities should be available in a choice of modalities, and should be accessible both via HIV specialist clinical services and by direct access.*

*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 structured recruitment and training process and have access to appropriate supervision and professional development.*

This was swiftly followed in 2014 by Simon Stevens' *NHSE Five Year Forward View*, which proposed the greater alignment and integration of health and social care and a focus on empowering patients and engaging communities [8]. It states:

*We will do more to support people to manage their own health – staying healthy, making informed choices of treatment, managing conditions and avoiding complications. With the help of voluntary sector partners, we will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge.*

Importantly, the document not only recognises the value of greater partnership between the NHS and voluntary sector organisations, but considers that skilled volunteers should not necessarily be unpaid:

*Too often the NHS conflates the voluntary sector with the idea of volunteering, whereas these organisations provide a rich range of activities, including information, advice, advocacy and they deliver vital services with paid expert staff... NHS employers also have the opportunity to be more creative in offering supported job opportunities to 'experts by experience'.*

However, the 'evidence base' to demonstrate the effectiveness of community-led programmes is often lacking. This is why NHS England have recently commissioned *Realising the Value* [9], a programme led by NESTA and the Health Foundation, which aims to identify the evidence and strengthen the case for investment in community-based support. There are five programme strands to *Realising the Value* (self-management education, peer support, health coaching, group activities that promote health and wellbeing, and asset-based approaches in a health and wellbeing context) [10], with Positively UK chosen as the partner site for peer support.

With the NHS recognising the value of peer support and many local authorities specifying the requirement for peer support and mentoring in their tenders for HIV services [11], the time has clearly come for programmes which deliver on the approach laid out by BHIVA in their quality statement. This is where Positively UK return to the picture, with Project 100 [12].

Funded by the Monument Trust, Project 100 aims, over the course of four years, to provide access to high-quality peer support to every person diagnosed with HIV in the UK, by training 1000 peer mentors from across the country. The volunteers may be referred via partner organisations and HIV clinics, or be self-referring individuals who wish to give something back and make a difference in the lives of others.

The training programme provides an accredited qualification in peer mentoring and ongoing supervision, training and development opportunities, so that people are supported to grow and learn in their roles while encouraging others to deal with their

various HIV-related issues. The project also includes a mandate to develop national standards for HIV peer support, alongside a robust evaluation of the benefits of the programme, in terms of both personal and financial effectiveness.

It is to be hoped, with such an increase in the skills and capacity of so many people living with HIV to offer support to each other, that the potential for NHS staff to refer non-clinical support issues on to trained mentors will relieve some of the time pressures on currently underfunded NHS services, freeing up the time of clinical staff to deal with specific medical issues.

Further information and links to express an interest in partnering with the Project can be found via Positively UK's dedicated webpages: <http://positivelyuk.org/project-100/>

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