Peer support Opportunities and challenges

Insight summary



Introduction

On 10th December 2020 National Voices brought together a group of individuals and organisations involved in peer support to discuss the opportunities ahead of peer support. The session brought together organisations working in different contexts and different communities – local and national, across mental and physical health, and with communities who shared characteristics and some who shared conditions.

This followed two sessions bringing organisations together to share learning around peer support, in the context of the rapid adaptation that had occurred as a result of the Covid-19 pandemic. Learning from these sessions has been shared in a blog and learning pack.

The focus of the session was on identifying opportunities to work together to advance an agenda around improving access to peer support for all those who could benefit from it.



Context

Peer support helps us make sense of our experiences and puts us in touch with people who share them, and through whom we can see the next few steps in front of us, even in the most difficult circumstances. There is a strong and growing evidence base around its impact which demonstrates that peer support is effective.

In Spring 2019, National Voices launched the <u>Peer Support Hub</u>, which it hosts on behalf of the wider community involved in peer support. The Hub brings together resources and learning from across this community.

In recent years the formal health system has recognised the potential of peer support to help people who are managing ill-health, long-term conditions and living with disabilities. Peer Support has been recognised as a core component of Universal Personalised Care (UPC), which was put at the heart of the NHS Long Term Plan, published in January 2019.

<u>Implementing the Comprehensive Model</u> sets out how peer support fits within the UPC model. It says that peer support should be offered to everyone with a long-term condition:

"Everyone should (..) have access to a range of support options including peer support and community based resources to help build knowledge, skills and confidence to manage their health and wellbeing."

Peer support is part of supported self-management. The <u>supported</u> <u>self management model</u> is about:

"Increasing the knowledge, skills and confidence (patient activation) a person has in managing their own health and care through systematically putting in place interventions such as health coaching, self-management education and peer support."

It also recognises that peer support can play a role in reducing health inequalities:

"Peer support and strategic co-production can also help to support people from different cultural backgrounds."

Implementing the Comprehensive Model makes clear that commissioners should work with the Voluntary Community and Social Enterprise (VCSE) sector to develop models for commissioning peer support.

The Covid-19 pandemic has only intensified the case for action on peer support. As a result of the pandemic there are sobering conversations going on across the health system. We know that 2021 may be more challenging than 2020 with the impacts of Covid-19 and of the wider pandemic continuing to be felt alongside pressures due to "postponed" treatments during the pandemic, and an ongoing reduction in capacity. The backlog of treatment will impact the health system for a long time. So now, more than ever, we will need peer support that can hold people while they experience waits – helping people keep their lives together.



Opportunities and challenges for peer support across the health system

The growing need for more people to be supported to manage their conditions without formal health services, alongside the existing recognition of the strength of peer support in enabling people to do this, creates a fresh **opportunity to make the case** for peer support and to improve access to it.

We heard from colleagues at NHS England and Improvement about their plans to support progress on peer support working with citizens, clinicians and commissioners to convey its benefits for people, communities and health and social care systems. NHSE&I recognised the need to balance the desire to develop a coherent message around peer support with the need to enable diversity in peer support, and to ensure that commissioning models foster agility and adaptability while maintaining the core values of peer support.

However, while NHSE&I can put in place the structures and guidance to encourage and support better access to peer support, the change will happen in places – driven by local NHS structures including providers and commissioners. So action will be needed at a number of levels.



Where we are

A key challenge in working together on peer support is the reality that the "starting point" for peer support provision is different for different conditions, in different parts of country and for different groups.

There are significant differences in:

- The models of peer support commonly in use
- The accessibility of peer support how much is available and how easily it is to access (e.g. whether people receive information about peer support at the point of diagnosis)
- The funding of different peer support models
- The extent of the links between peer support and the formal health system

While the Universal Personalised Care commitment suggests that peer support should be available to everyone who needs support in managing a long-term condition, in some cases this aspiration is further away than in others.

We heard reflections from colleagues working in a range of fields including people affected by stroke, people using neo-natal support, and people with dementia – around the state of peer support.

A few things were clear:

- Few peer support groups receive funding from the NHS, and there is no single model for commissioning peer support – some organisations have contracts with CCGs, others with health providers and others fund peer support themselves.
- Funding can be disjointed and hard to access and this takes up time and resources in building relationships, identifying opportunities and making applications.
- Peer support groups value their independence of the formal health system, but would like to create clearer pathways for individuals. At present referrals can be reliant on individual clinicians.
- Some models of peer support are very informal, and need to remain so.
- People find support from peers in a wide range of group and individual settings, including groups centred around activities and interests.
- Peer support organisations are not always involved in the development of pathways for the conditions on which they work, and discussions with health system leaders sometimes only involve a narrow group of organisations, failing to reflect the diversity of views.



Hopes and fears for peer support

In discussions we considered our hopes and fears for progress on peer support, recognising the opportunity created by the pandemic and the NHS commitment to peer support make progress, but also the risks of unintended consequences.

Our hopes

We hoped

- To maintain and build upon the new partnerships and greater openness to the role of peer support that had been fostered during the pandemic
- To build more trusting relationships between peer support and the health system – to enable referrals, funding and partnership working
- To identify long-term sustainable funding for the full diversity of peer support models – including group / one-to-one; peer led / professionalised – with action to address gaps in:
 - Culturally sensitive peer support
 - Peer support for rare diseases
 - Physical as well as mental health conditions
- For recognition of the history, ethos and diversity of peer support, and of its value
- For opportunities to educate the community and health professionals about peer support

Our fears

We feared:

- The imposition of a one-size-fits-all model of peer support
- That links with the health system would lead to a regulatory approach that impedes peer support
- That professionals would crowd out peer-led support
- That a lack of funding would lead to demand outstripping supply and create a "gatekeeping" ethos which would be contrary to the values of peer support
- That we would miss opportunities, by:
 - Reverting to how things were before the pandemic
 - Failing to address key issues such as race



Extending access:

A case study: Positively UK



We heard from Positively UK about their work to build up peer support for people with HIV. While Positively UK are clear that there is still a long way to go to ensure that everyone with HIV who wants to access peer support can do so, there has been progress in building peer support into the NHS offer and linking this to a wider network of groups in the community.

1996

Effective treatment meant the challenge was recovery & living well. Also, engaging with healthcare and becoming expert patients. Support groups were being defunded.

2012

<u>Positively UK</u> pilot integration of Peer Navigators at Homerton Hospital. Peer case workers provide outreach at other clinics

2002

First paid Peer Worker in an HIV clinic – starting to build the case for the difference peer support makes, particularly at point of diagnosis.

2015

Launch of four year Project 100 to train peer mentors nationally and deliver National standards for HIV peer support and NVQ Level 2 qualifications in mentoring and treatment literacy.

2016

NHSE/NESTA Realising The

Value report shows costs

savings of peer support.

2013

British HIV Association (BHIVA) recommend peer support within HIV service delivery as part of their national Standards of Care

2018

Updated BHIVA <u>Standards of Care</u> include targets and auditable outcomes for peer support in 6 of 8 standards.

2019

Work with NHS London to integrate peer support into Chelsea & Westminster HIV clinics. Peer Support workers have direct access to patient records so can proactively contact newly diagnosed.

1980s

1990s

1980/90s: Peer support was to manage illness, death and grief.

Strong, collaborative doctor/patient relationships due to poor prognosis.

2000s

2000s: Making the case to bring peer support to one place people with HIV all went – HIV clinics. Creation of Patient Networks.

2010s

Research (e.g. <u>REACH</u>) highlights need for psycho-social support to reduce "lost to follow-up".

NV Report on peer support. <u>5-Year Forward View</u> says peer support essential to future of NHS.

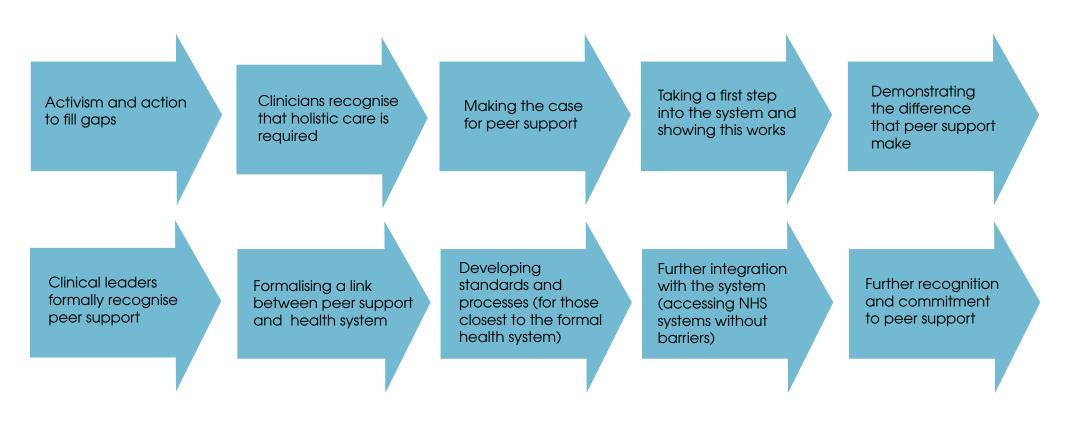
While some HIV peer support has been professionalised there is still a lot of informal support – those closer to the system link to third sector and more informal groups.

20208

Improving access to peer support: steps taken



We reflected on what Positively UK's experiences suggested about the processes that might support progress on peer support. While this pathway won't be suitable or desirable for every other peer support groups, we found it helpful to identify the different stages they have been through on their journey and to reflect on their potential relevance in driving the progress we individually and collectively want to see.



Next steps

Thinking about the opportunities ahead, the different starting points for different organisations and individuals working in the peer support area, and the learning from organisations like Positively UK, we considered the key **assets** we shared in driving forward work on peer support. These are:

- A network of organisations and individuals that wants to share learning and work together
- Existing frameworks, guidance and measures that have been developed in particular areas, but which could be adapted and shared.
- A significant and growing evidence base around quality peer support and its impact, held within organisations such as a Self Help UK and on the Peer Support Hub.
- Lived experience that health system partners need and want to understand.
- A window of opportunity to make the case for peer support with the NHS.

We identified the following potential areas of collective action:

Developing clearer shared messages around the nature and value of peer support, for example by:

- Defining the principles and standards of what good looks like and help more people get this.
- Creating a powerful narrative that the NHS can hear especially by amplifying experience and voice.
- Capturing the full benefits of peer support including to families and communities.
- Sharing stories.

Developing an offer to support the NHS, which could include:

- Guidance and support for commissioners and providers on how to work with the ecosystem of peer support
- Promoting understanding of the strength of diversity in peer support – defining different models so commissioners can understand them
- Educating health professionals and people so they can understand peer support

Establishing some key principles to protect the core values of peer support from being eroded, for example by:

- Holding fast to the core values and ways of working that matter to those in the field
- Being clear where peer support cannot "fit" the NHS model; nor can it become part of the NHS (it is of the community)
- Recognising that some services should be kept away from clinical settings
- Not allowing professionals to take over hold fast to what peer-led groups are for

Building our community of practice, for example by:

- Working together to share learning and build understanding
- Building the diversity of the network, and avoiding excluding people – for example, by using language that some groups don't recognise e.g. "conditions"



Next steps

In the remaining stages of this project we will have further discussions with stakeholders to map out how we could resource these areas of activity in future.

If you have ideas about how to do this, or are aware of opportunities in this area, do get in touch with us at

info@nationalvoices.org.uk



National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users,

carers, their families and the voluntary organisations that work for them.

We have more than 160 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.



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