Q Evidence

This challenge area focusses on the evidence of impact of peer support. It covers the methodologies and metrics used to assess the effectiveness of peer support services and the case, both financial and social, for developing and implementing peer support.

Key Questions

- How should the impact of peer support be assessed?
- What metrics would be useful when evaluating the impact of peer support?
- How can the evidence of the impact of peer support be better communicated?
- How do we create a case for alternative evaluation methods when it comes to peer support?

Key Challenges

Identified from desk research (please see suggested reading list for references)

Known but not used

1. There is a wide range of evidence which demonstrates the benefits and effectiveness of peer support, including:

a Physical and mental health and wellbeing: Peer support can lead to significant improvements in health and wellbeing for people with long-term physical and mental health conditions. The benefits included increased knowledge, skills and confidence to manage their health and care; improved physical wellbeing; adherence to medication; quality of life and social functioning as well as improved health and clinical outcomes for some conditions.

b Wider social value: Peer support can lead to wider benefits such as improved employment outcomes and reduced social isolation. Modelling based on the benefits of peer support and self-management education for people with certain conditions suggests wider savings of around £20,800 per person or £22 million per year in an average CCG area, although many of these savings will not accrue to the health and care system.

c Economic benefit: Findings from evaluations of several individual peer support services suggest that people receiving peer support use fewer health services, however more work is needed to understand whether this is due to peer support or wider factors. Economic modelling for the Realising the Value programme suggests that implementing peer support and self-management approaches for a proportion of people with certain long-term conditions could equate to net savings of £2000 per person per year, achievable within the first year of implementation.

2. Despite this evidence, the benefits of peer support are not acknowledged by all. There is a need to understand how this can be communicated better and whether alternative methodologies are required to more effectively capture the positive impact of peer support.

Knowledge and evidence gaps

1. Different arguments for peer support require different evidence bases, such as a business case or ethical stand-point.
2. The diversity and lack of consistent evidence can make it challenging to create a business case for investing in peer support.
3. Some conditions have stronger evidence bases that others, e.g. more evidence for effectiveness of peer support in relation to mental health than HIV.
4. Lack of evidence or localised evidence showing the cost effectiveness of peer support and the impact on service use.
5. Need to better understand what works best for whom and in what circumstance – variety of peer support services make it hard to identify which elements are most effective for which people e.g. understanding whether volunteers or paid peer support workers are more effective or whether structured or ad hoc services are more effective.
6. Need to understand the long term impacts of peer support.

Quality and quantity of evidence

1. Randomised control trials and systematic reviews are considered the highest quality methods of collecting evidence but may not be best suited to understand the impact of complex peer support programmes or initiatives.
2. Better evaluation techniques are needed to understand key factors in succesful implementation of peer support.
3. Most peer support is delivered by voluntary and community sector organisations but they often don't have capabiliy and resources to run robust evaluations and communicate impact of their work.
4. It is a challenge to compare evaluations of peer support due to wide range of peer support services covering different groups with different objectives and approaches as well as inconsistent methodologies.
5. Peer support is often part of wider approaches to improve care for people living with particular conditions so it can be difficult to ascertain what contribution peer support makes to achieving the reported benefits.
6. There are no consistent measures or framework for measurement.

Quotes and Insights

Identified from interviews with people involved in peer support

Evaluation Metrics

"What we've tried to do is think about the currency that we can work with. . . The great thing about the patient activation measure (PAM) is that it's been validated across much more 'hard' metrics like blood results, biomarkers or adherence to medications. Those have very strong both clinical and health economic outcomes that are taken seriously. So we've jumped on the PAM and we're doing studies now looking at before and after measures from people who have had three months, never having had access to peer support before, with that specific purpose of taking it into the realm of quantifiable value."

"The powers that be would like to see a reduction in access of statutory provider services. It is about people feeling more empowered and going to the GP less."

"There isn't an embedded way of evaluating peer support in the organisation. . . It's something that we need to get better at, but there is that... worry that any data collection in a peer relationship... transforms that peer relationship."

"[PAM takes] a very clinical approach to measuring outcomes. . . I think they are probably the best out of a bad bunch, at the moment. I think there isn't anything that is going to quite capture the impacts that we experience as practitioners."

"The metrics around improvement in wellbeing have showed an increase in wellbeing but we feel it's quite limited really. We've got some qualitative questions in there as well as part of that process and they're much more rewarding."

"Given that peer support is often quite local and quite small scale, how do we support people who are implementing it in practice to have the capability and ability and the right frameworks to evaluate and be building the evidence from what they're doing in practice?"

How to use evidence to bring about change

"They [other changes] didn't happen because I got them to happen. They happened because they're now part of the contract. So, the GP surgery works to contract, and it's interested in getting paid. . . that's the big driver."

"They might see the value, and they might say that they think peer support is a good idea. But when it comes to service design and staffing structures, and the real strategic thinking that builds a mental health service, peer support isn't really included."

"It is about a paradigm shift. . . If a few people are willing to take some brave steps, and give peer support a chance. Like if we were able to run a ward, just with peer workers. . . to prove the value, that might be a way forward."

"We can only really get so far with understanding and the value. But actually, arguably, and probably slightly controversially, that in itself is actually quite valueless, if people on the ground aren't actually able to access the support.'

Key words: *Metrics* | *Diversity* | *Communication* | *Impact* | *Methodology* | *Quality* | *Quantity* | *Business Case*

Q Buy-in & Culture

This challenge area focuses on the perspectives of peer support services, from the points of view of the public, health care professionals and the wider health and care system and how this affects buy-in. It covers cultural, social and ethical barriers to utilising peer support services.

Key Questions

- How can peer support be aligned with health and care services to improve buy-in?
- Do commissioners recognise the value of peer support? What would they need to support this
- How can peer support workers and health care professionals be informed of the value of peer support to promote integration?
- Would formalising peer support increase buy-in from health care professionals?
- Are there cultural barriers, for example religious or racial differences in communities, which affects buy-in from individuals who may benefit from peer support?

Key Challenges

Identified from desk research (please see suggested reading list for references)

Buy-in from commissioners

1. Peer support work could fall into the field of prevention – there tends to be an imbalance on funds spent on treatment versus prevention.
2. Peer support services need to align with local and national priorities to improve buy-in.
3. Whether peer support fits with the organisational culture and other approaches being used to manage conditions - does it clash with a predominant medical model?
7. Lack of governance and protocols can inhibit referrals. However, there is a challenge around 'professionalising peer support' which can be seen negatively.
8. Opinion of health care professionals on the value of peer support workers: some evidence suggests health care professionals think professional-led services may be more effective.

Buy-in from health care professionals

1. Potential for health care professionals to feel that their roles are being threatened.
2. Clarity around whether peer support is focussing on the specifics of condition management or enhancing motivation and providing encouragement.
3. Challenges around integration of peer support into the health and care setting.
4. Lack of interaction between peer support workers and health care professionals.
5. Concerns of health care professionals on: the spread of misinformation; mishandling of patients; and the disruption of relationships with their patients.
6. Unclear or complicated referral processes mean health care professionals are less likely to refer to peer support workers.

Buy-in from patients and the public

1. Potential conflict between peer support interventions and the social/cultural expectations of the roles of the individual and their families.
2. If medical language or jargon is used, such as in marketing materials, it can reduce buy-in.
3. It can be hard to recruit and retain peer support workers, especially if they are working on a voluntary basis.
4. Fear and anxiety around attending a peer support first session.
5. Integration of peer support requires effort and promotion, not just policies.
6. Need to engage with sceptics of peer support.

Quotes and Insights

Identified from interviews with people involved in peer support

Commissioning

"We're also suffering a little bit I think from the change in relationship between commissioners and the voluntary and commuity sector over the last few years where we've become the funders of things and created a marketplace with the voluntary and community sector, and that's changed our relationship."

"In terms of commissioning, if we had peer-led commissioners, if we had commissioners who'd listen to people and what they want, I think we would have a different kind of health service."

Challenges of embedding peer support in medical cultures

"Part of the problem we're trying to solve here is to break what we see as a dependency cycle. We think, to break that cycle, we need to recognise and honour the independency that everybody's got, to some extent, even though they might have lost some of it over the years, and encourage people to be more independent."

"I think sometimes the peer support workers question the value of what they're doing. I think because we work in a service that is all about fixing and doing things. A peer support worker is about being and learning, and then it's difficult if you've got a very different approach, to see the value of that in the face of a whole service that's working in a contrasting way."

"I think it's very mixed. I think some people really see that it's the way forward and the values that underpin the approach are really fundamental human things. I think that there's other staff who are a bit wary of it, and not sure it's coming from. And I think because there are so many cuts at the moment, there's that cynicism of 'well is this just a way of cost saving' and 'they're going to replace me' and that kind of thing."

"The staff are a bit wary… they're not sure what level of lived experience, how vulnerable they are. The peer support workers were saying they feel they've got to earn the trust of the staff, because the staff are so protective of the young people they're supporting, they don't want anything unsafe to come near them."

Patients and the public

"We know it's something that people really value, so whenever groups of patients or people with different experiences are asked about what helps to keep them healthy and well and what works best, they always put peer support right up there on the top."

"A lot of the people that we work with have quite high levels of anxiety, and particularly social anxiety. I think the idea of sitting in a traditional AA style group can feel a bit daunting, and can feel like a bit of a step. I don't think peer support groups are normally like that, but I think that is the image that people sometimes have."

"The beginning is the moment of realisation that things aren't right, and then to have that [peer support] as part of your system means it's there with you forever, however long that is, if it's a few day or a few years."

Policy makers

"I think the system probably sees it as good. I think it probably sees it as something that should happen organically and doesn't need funding, and could sometimes be a substitute for actual care."

"I think increasingly the policy documents, policy rhetoric is acknowledging it. I think they really struggle at that level to convert it into any kind of action… I'm not convinced that at the most senior levels of organisation that they really do buy into it and get it."

Key words: *Engagement* | *Framing* | *Resistance* | *Language* | *Promotion* | *Integration* | *Alignment* | *Culture*

Q Workforce

This challenge area covers workforce challenges linked to peer support, from both the viewpoints of the peer support worker and other health care professionals. It covers workforce training and support as well as integration into the wider health and social care sector.

Key Questions

- How should peer support workers be selected, trained and supported?
- How do peer support workers fit within existing clinical practice boundaries?
- How do you retain the values and principles which make peer support different within a statutory setting?
- How do you educate health care professionals on the role of peer support?

Key Challenges

Identified from desk research (please see suggested reading list for references)

For the peer support worker

1. The transition from the role as a service user to a peer support worker. Peer support workers may have previously been patients – the shift from client to colleague may be difficult. Individuals may be returning to clinical settings and interacting with old contacts in a different way.
2. Risk of peer support workers relapsing and struggling to perform professional duties.
3. How to draw the line between being a peer support worker and a friend.
4. Finding a balance between sharing experiences and self-preservation.
5. Challenges around a lack of a clear definition for a peer support worker and the formality of the role.
6. Lack of training or inconsistencies with peer support worker training and accreditation
7. Although, peer support workers face criticisms around 'professionalising the role'
8. Ensuring peer support workers understand professional boundaries such as privacy and confidentiality.
9. Peer support workers note feeling a lack of value, power and recognition.
10. It is a mentally challenging role – peer support workers will need considerable support.
11. Important to consider the background of peer support workers – this may be their first paid employment after periods off-work and so they may require additional support

For the health care professional

1. There can be a lack of understanding and acceptance of the role of peer support workers by health care professionals.
2. Sometimes struggle to relinquish power to peer support workers.
3. Health care professionals can sometimes view peer support workers as 'cheap labour' to bridge gaps in professional care and support.
4. There is a risk of community, peer-led informal approaches being absorbed by more formal services – challenges around whether peer support workers and health care professionals can complement each other.
5. Health care professionals need peer support workers to subscribe to certain NHS staff policies such as risk assessment and control and restraint training which are required to fit in with the predominant medical model.

Quotes and Insights

Identified from interviews with people involved in peer support

On the value and challenges of working with peer support workers

"The fact that the people who are working as peer workers are no longer a drain on society – they are no longer drawing benefits; they're working in roles where some of them have been unemployed for 20 years. So not only are they helping other people, but actually it's a huge benefit to society."

"We try and make sure every peer has some form of peer supervision, whether that's one-to-one or group, and then we... try and create a culture where people know that they can just come and knock on our door, or drop us an email... so they've got that extra support."

"Whether they want to or not, a peer support worker, when they're employed in an NHS mental health system is subject to the rules and regulations of that system... and that compromises peer support... it's something that frightens me on a personal level, that it is being co-opted."

"A peer support worker is a paid employee. They have a lot of power. There's no getting around that. I can read somebody's notes – they can't read mine. I can help them with benefits – they can't help me with mine. There is a hierarchy there."

"A peer is someone of equal status and sometimes you might have peer support when somebody's a worker and does that change the relationship? So I think there are some issues around a power relationship."

"I can see people really benefit from training, even if they've got a really good understanding of peer support... I think there's something about the training just being in a place where peers come together, and experiencing that together, in that group as well, which is quite a powerful way of learning."

The impact on health care professionals

"The staff are a bit wary... they're not sure what level of lived experience, how vulnerable they are. The peer support workers were saying they feel they've got to earn the trust of the staff, because the staff are so protective of the young people they're supporting, they don't want anything unsafe to come near them."

"It's about supporting the whole team, and taking the team on a journey with you... curiously questioning established structures... peer support isn't just about employing peer support workers, it's about changing the culture of the organisation."

"The main benefit of us sitting, or being seen as not entirely the system, is that people tell us stuff that they normally wouldn't tell other people. We get people opening up a lot more."

"We've got one foot out and we want to use that to be more user-friendly, more community-orientated and have much more user-generated content."

Key words: *Training* | *Value* | *Integration* | *Boundaries* | *Support* | *Acceptance* | *Integrity* | *Formalise*

Q Access

This challenge area covers barriers to accessing peer support services, including practical, emotional and cultural barriers. It covers engagement and communication as well as integration between different services.

Key Challenges

Identified from desk research (please see suggested reading list for references)

Engaging People

1. Challenges around making peer support services accessible to potential recipients e.g. making it easy for people to sign up and then supporting people to be confident to attend. There are also challenges about making health care professionals aware of how to access peer support services and making it easy for them to fit it in with their existing workload.
2. Need to better understand what individuals value when accessing peer support and what their intrinsic motivations are: these insights can be valuable when designing peer support services.
3. Diversifying peer support options: when people are offered a range of locally developed approaches to peer support, it is the sense of agency – choice and control – in deciding what peer support to access, when and why, that is associated with positive outcomes.

Raising awareness

1. Not enough is known about what peer support services are out there.
2. Need to better understand how people find out about peer support – this could be retrospective understanding or proactive planning.
3. Whether or not formal health and care services effectively signpost patients towards peer support services. Research shows that in some clinical specialities there is good signposting: For example, from the 2015 National Cancer Patient Experience survey 83% of respondents said that hospital staff gave them information about support or self-help groups for people with cancer. There is a need to understand whether levels of awareness of peer support services differs depending on clinical speciality.

Connecting, brokering and signposting

1. Challenges around connecting health and care services to peer support.
2. Leveraging the role of large national charities in order to broker peer support – they have access to large pools of potential supporters and can match people to meet specific needs and preferences.
3. Embedding peer support alongside existing services – creating a continuum of approaches to address a particular issue or condition.
4. Making sure peer support services link to local and national priorities to improve uptake.

Key Questions

- How can access to peer support services be improved?
- What communication and engagement techniques can be used to improve awareness and utilisation of peer support services?
- What motivates people to use peer support services?
- To what extent should peer support services be tailored and individualistic to improve access?
- What role should the health and care services and charities play in signposting towards peer support?
- Should – and how can – peer support services be better aligned to local and national priorities to improve access?
- How can peer support services be better connected to charities and health and care services?
- Are there cultural barriers to accessing peer services?

Quotes and Insights

Identified from interviews with people involved in peer support

Engaging People

"The evaluation that we have done... all the social demographic factors show that we are working with those below and under the spectrum of health inequalities. But, I think it is very difficult to engage them and sort of get them involved."

"I think our peer support workers are largely female, largely white as well... People are able to access peer support, but whether they would identify with that peer support worker as a peer is another matter."

"I've ended up... seeing that new technology can take what has always been around, which is peer support, to a completely different level and make it much more accessible. I think one of the problems with peer support is the accessibility of it to everyone because a lot of the people who probably need it are the most isolated."

"People still, in 2017, are very, very isolated when it comes to health information. Most people might end up on NHS choices, or they might end up on a patient organisation website, but really, I think if you're landed with a new diagnosis of cancer or rheumatoid arthritis it's still a position of total isolation."

Raising awareness

"I really pride myself with keeping up to date with these sorts of things, and knowing what is around locally. I still got it wrong today."

"It's just hard to know what's going on out there at the grassroots and I think those are the people that we need to be contacting."

Connecting, brokering and signposting

"For a clinician to signpost or refer somebody to something, unlike other people, they feel much more professionally duty bound to be really confident that that's a quality service... they want to know it is going to be around for a while."

"At the moment, we've got an interface which is stressed [GPs], perhaps not thinking of the best options. I don't see that they're the right people to be signposting. They can do it, but at the moment they're not doing it very well."

Key words: *Engagement* | *Signposting* | *Communication* | *Leverage* | *Awareness* | *Alignment* | *Motivation* | *Connection*