

Patients as partners in developing self management solutions: Co-design Case Study

Peer Support Framework –
Brighton and Hove CCG

Co-design Case Study: Peer Support Framework in Brighton and Hove CCG

NHS Brighton & Hove Clinical Commissioning Group (CCG) already had an interest in improving self-care and self-management provision which pre-dated the Patients in Control (PiC) programme. The CCG had quite an active personalisation programme and a patient-centred approach in place with cancer survivors, but wanted to broaden the scope into other conditions. PiC was therefore a natural progression.

Gathering patient/carer insight

There had been a good response from patients and carers in Brighton and Hove (sixty five people) to the PiC online survey, which gave insight into how people managed their long term health condition, and what would enable them to take more control. Thirty three people had expressed an interest in doing further participation work. Emotional support, education and training and increased access to non-medical options were important aspects of self-management which had been identified within the survey as a high priority for health care condition management. Commissioners felt that all these could potentially be addressed by a peer support model. This view was further supported by feedback which Brighton and Hove CCG had received regarding their proposed Patient and Public Participation Strategy. This was an ideal opportunity to explore peer support in more depth, using a co-design approach.

Building local understanding

Although Brighton and Hove already had peer supporters and expert patients in the community, the CCG wanted to develop a structure so that the services could be used as more of a resource. It wanted a comprehensive peer support model to reflect the needs of patients and carers in the community, which was rooted in the voluntary and community sector, with strong links to primary care. These approaches to patient-centred peer support could then be shared across the city, and be included in on-going work to improve personalisation and self-management for services that treat people with chronic and complex health conditions – from mental health to cancer. The CCG had many commissioning pathways e.g. diabetes, COPD and dementia in which they had voluntary organisation support, but PiC provided a different approach in which the focus was to get **user support** to encourage self-management. This view was endorsed by one of the participants - “the old way of commissioning” relied on getting feedback from patients to use as evidence in a business case, but not to seek their opinion on how to tackle particular issues (which the PiC approach does). Moreover it enabled commissioners to look at the **quality** experience of patients and users.

The aims of the sessions were:

- To explore the needs of patients and carers living with long term conditions in relation to peer support
- To establish the potential impact of effective peer support on the lives of those who access it
- To understand what ‘good’ peer support looks like, and what peer support should not be like

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- To establish the principles of good peer support, and what types of peer support are required
- To explore how best to provide access to and information about peer support, identifying enablers and the means of ensuring people know about and use it.

Working with patients as partners in co-design

Patients who had previously expressed an interest in participating further were invited to apply. Respondents were screened to ensure a mix of gender and ages, and that both physical and mental long term conditions were represented.

Three meetings were held at monthly intervals with patients, carers and CCG representatives. The commissioner who led on personalisation was present from the outset, and the patient participation manager and a pathways commissioning manager were involved throughout the process.

This contrasts with the approach in other areas where CCG representatives joined the last session only.

“We sometimes put off doing this work and engaging with patient groups because it can be time consuming, but actually it’s very rewarding and a way of getting quality feedback.”

*Neil Francis – project manager,
Brighton and Hove CCG*

Reflections from participants after the programme indicated that the approach used in Brighton & Hove was very successful and that positive CCG ownership was a key factor behind the success.

Developing the peer support framework

One significant aspect of working with patients and carers was that they had a much broader view of what constituted peer support, which may not have been considered by the CCG alone. There was a clear focus on supporting patients with long-term conditions from a much more holistic perspective, taking into account the whole person’s wellbeing and not just their strictly defined medical needs. This emphasis on the whole person was intrinsic to the peer support models explored and was welcomed by patients and carers and by the CCG commissioner, recognising that health is a wider issue not limited to medical intervention.

There was also an understanding from all parties that the PiC outcomes had the potential to lead to changes in the CCG’s commissioning approach.

The group considered and agreed the key outcomes of peer support as being:

- Social interaction
- Emotional support
- Information and knowledge
- Empathy and exchange of ideas
- Empowerment and sense of purpose

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It established a set of principles to use as a starting point for a draft *framework* for peer support delivery and development for primary care providers in Brighton and Hove, and recommended some actions and priorities for the commissioner to take back to the CCG.

Outcomes and benefits

The co-design approach was of mutual benefit:

“There was clear ownership from the CCG and it wasn’t tokenistic. It didn’t feel like ‘this is a PiC programme run by an area team somewhere’, it felt like this was our commissioners wanting to know what was going.”

Carer – Brighton and Hove

Feedback from patients’ and carers’ indicate that it was a positive experience. It provided them with a degree of personal support – sharing experiences with others made participants feel less isolated and fostered a sense of empathy and greater understanding of the issues of others. They appreciated the acknowledgement that they were the experts in their condition, and that their knowledge and expertise was valued. The participants were also able to take away some practical benefits from sessions, such as information about local activities and

the support networks. Participants felt empowered.

For commissioners, it provided a sense of reality and enabled them to develop a good understanding of the current situation before turning their attention to providing solutions. It looked for solutions from an end-user perspective, putting patients and carers at the centre of commissioning. This was felt to be pivotal to increasing the likelihood of people using self-care and self-management tools.

In relation to peer support, co-design helped the CCG to develop a deeper understanding of the needs of patients and carers across a wide range of conditions, and made commissioners realise that peer support need not be condition-specific because there was more commonality across conditions than previously recognised.

“The co-design approach provided really deep understanding from a user point of view.”

*Neil Francis – project manager,
Brighton and Hove CCG*

The programme provided new and richer patient and carer feedback, specifically around how care needs to be more joined up throughout the care pathway.

The commissioner acknowledged that the CCG must be prepared to invest time for co-design, but indicated strongly that the insights identified and the quality of the information gathered through this approach justified that investment.

As a result of the co-design sessions, the CCG is now working on the following **three specific outcomes**:

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1. Embed the principle of approaching different groups more widely. This will require changing the culture around commissioning;
2. Consider setting up a central resource to hold information about peer networks and user-led engagement, that patients can access;
3. Raise awareness and signpost information more consistently. The CCG will continue working with primary care and voluntary sector organisations to help develop community navigation to point people towards various support provisions across the city, but there is a sense that this needs to join-up better. Ideally navigators would link with primary care – but they need also to connect with social, community and secondary health care services.

Learning from the project

By having both patients and commissioners in the room at the same time, commissioners could respond immediately to any queries that were raised and helped to keep the proposals within the remit of the CCG. It made sure the voices of patients and carers were at the centre of decision-making about future commissioning priorities. The commissioner felt that the value of co-design could have been realised even further with additional input from the clinical teams, and in hindsight would have invited input from GP leads for at least part of the process.

For the co-design sessions to be productive, patients and carers stressed the importance of creating a 'safe' environment based on mutual trust and respect. Commissioners should not drive the agenda and must be willing to listen, working collaboratively with patients and carers. The use of an independent facilitator was seen as crucial in keeping the group on track and putting the patients and carers at ease but in control, ensuring that participants were able to contribute equally.

CCG engagement was seen by participants as crucial to the success of the co-design approach - its willingness to listen, to be innovative and to learn, as well as being open to challenge and not defensive.

Using co-design in the future

Following the completion of this stage of the project, the CCG representatives have said they are very likely to use a co-design approach in the future, and are already thinking about it for some work with carers, and will also be setting up co-design sessions with patients who have digestive conditions (IBS). They suggested that GPs who direct commissioning could benefit from being involved in co-design sessions in the future - although they do engage with patients in their surgery, co-design interactions would give them another lens through which to understand the benefits of services to users.

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