

Case study: Calderdale and Huddersfield NHS Foundation Trust

Developing peer to peer support for patients suffering from chronic pain

The challenge

As part of the Co-creating Health initiative, Calderdale and Huddersfield NHS Foundation Trust runs a successful Patient Skills Programme for patients living with the long term condition of chronic pain and, more recently, chronic obstructive pulmonary disease (COPD). Participants attend a 7 week course run jointly by a health care professional and a volunteer lay tutor living with the same long term condition. Three months after completing the course participants meet for a reunion in order to discuss their progress, consolidate their learning and to conclude their attendance on the programme.

However, although many graduates from the programme acknowledged that they gained useful tools and techniques to support their self management journey, a number felt they would benefit from further peer to peer support after the course was completed. Individual feedback from patients attending our course showed that participants value the support from others who have experienced or are living with a similar long term condition. Indeed, participants emphasised the importance of positive peer support and shared experience in helping them to stay motivated and sustain the benefits from their attendance.

What we did

In September 2011, we successfully applied for funding from the People Powered Health (NESTA) organisation to explore the development of peer to peer support networks. The People Powered Health project manager worked closely with our Co-creating Health volunteer lay tutors to design the scheme.

Following informal discussions and a scoping exercise, we arranged a workshop to collectively generate ideas and gather information about the concepts of befriending and navigators. We used external facilitators from John Worth Associates to support the design and development which was run over two days at the trust's learning and development centre. This process was underpinned by six core principles for co-production:

- recognising people as assets
- building on people's capabilities
- mutuality and reciprocity
- Peer Support Networks
- blurring the distinction between producers and consumers
- facilitating rather than delivering.

As a result, the roles of befrienders (initially termed 'buddies') and navigators were defined and agreed through a co-design process:

- Befrienders were identified as people who were trained to provide ongoing support to people who had attended the Patient Skills Programme using a variety of communication methods such as contact by telephone, face to face meetings or facilitating a small group (see a more detailed description of the role below).
- Navigators were defined as people who were trained to signpost and encourage patients to access and explore self management resources. Navigators' roles depend on them using their own local knowledge of resources and directories of self care support to enable new self managers to 'navigate' their way through various information sources finding support that is individual and appropriate. Thus, navigators are active self managers who can draw on their own experience to help support new self managers.

As the existing lay tutors were committed to the existing training schedule for our Patient Skills Programme and are also involved in various tutor meetings, presentations etc, we needed to consider their work load. The team were in the process of recruiting more lay tutors from amongst people attending the Patient Skills Programme in order to grow the group and reduce the existing time commitment given by lay tutors. In keeping with the broader strategy of growing the lay tutor team, the training of existing tutors in new roles as befrienders and navigators was augmented by approaching people who had completed the Patient Skills

Programme and who had expressed an interest in being involved in the programme.

The tutor meetings were used as a means of disseminating information about the new roles and both health care professional and lay tutors were involved in identifying potential candidates from the courses. The People Powered Health manager approached these candidates and invited them to attend training.

External trainers were brought in to deliver two full days of co-designed training. The training focussed on the principles underpinning the roles of befrienders and navigators; and trainees were invited to participate in skills practice. Some time was also spent on exploring the importance of volunteers being supported by health professionals in order to create professional boundaries to protect volunteer befrienders and navigators. Nine volunteers completed the training, of whom 3 were lay tutors and 6 were recent graduates from the Patient Skills Programme.

Following the training, the People Powered Health project manager brought the group together for a debrief session and they discussed the training and their expectations for their development. As a result the training materials will be adjusted in preparation for the next cohort of volunteers.

Progress and outcomes

- The team have now established a rolling recruitment system from the Patient Skills Programme where tutors talk about different ways in which participants can become lay tutors, befrienders or navigators and participants are offered the support of existing befrienders and access to the peer-to-peer self management HELP support group. These innovations are in the process of being tested and will be extended in step with the growth of the volunteer group.
- The work undertaken has led to further interest from participants on the Patient Skills Programme in helping to take an active role to sustain the co-production approach.

- It has built on the existing system of on-going recruitment for lay tutors and has revitalised the team's understanding of sustaining the self management approach by actively encouraging and identifying new active self managers to grow the group of volunteers.
- The tutor team (health care professionals and lay tutors) are able to offer participants a range of self care support options on a collective and individual basis to suit different people's needs.
- Initial ad hoc patient feedback has been encouraging and graduates of the self management programme attending the HELP group have given positive feedback and this is echoed in the attendance figures for the group – the impact of navigators and befrienders on patient experience is still being gathered as the scheme is still being set in place.

Our learning

- The co-production approach adds real value to the design and development of the programme – health care professionals and volunteers have fed back about their enthusiasm in actively supporting the new innovations as they have been involved in the process.
- A co-production approach ensures service users are included in service improvement and service redesign.
- The workshops run over two days have had an impact on volunteers (who are people living with a long term condition) and many felt tired after a demanding schedule (for example spending time concentrating, activities such as active listening and skills practise facilitating groups etc). Future training programmes over 4 half days are being considered as a solution.
- A support network needs to be in place for new volunteers joining the group and governance arrangements need to be put in place to support volunteers – this takes time to design, develop and implement.

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- A set of co-designed principles underpinning roles and responsibilities is important to ensure expectations are transparent and clear to all.
 - A system of quality assurance is required for volunteer befrienders and navigators to ensure a standard service delivery.