

Training case study 13

Preparing people for involvement in research using the Patient Learning Journey model

Summary

The Pressure Ulcer Research Service User Network (PURSUN UK) at the University of Leeds used the Patient Learning Journey model to prepare service users for involvement in research. This approach was used to support a new service user network, with the aim of developing patient and public involvement (PPI) in a previously poorly understood area of healthcare research.

What was the aim of the training?

There were previously no service user/carer groups or indeed charities with a specific focus on pressure ulcers. The Pressure Ulcer Programme of Research (PURPOSE) team at Leeds Clinical Trials Research Unit (CTRU) identified a need to develop PPI in their own studies as well as in the field more generally. They appointed Delia Muir as part time PPI officer to facilitate training to meet this need. Workshops based on the Patient Learning Journey model were chosen as preparation for new network members.

Who was the target audience?

The PPI Officer brought together a group of six service users with some personal experience of the prevention or treatment of pressure ulcers, some of whom had experience as carers.

What did the training involve?

The Patient Learning Journey model involved facilitated

workshops where people were encouraged to tell their stories and reflect upon their personal experiences, expertise and skills as a group. Bringing people together to tell their own stories can facilitate group bonding as they recognise the common themes within their different experiences. It also provided an opportunity for people to vent their feelings about negative experiences in a safe environment, before meeting with professionals.

The next stage was to work with people to identify the learning points from their experiences and think about ways of communicating these learning points to professionals, in a constructive way. People were also encouraged to think about how much personal experience they felt comfortable disclosing when they came to meet professionals in a research context and what type of research activities they may be best suited to. Participants were encouraged to recognise the value of their experience and skills.

Further training with the network has been carried out on an informal basis, as at present there is little funding available to organise it more formally. The PPI officer also helps people to access local training and development opportunities where possible. As the group is widely spread geographically, they may be able to make use of local opportunities through universities or the National Institute for Health Research (NIHR).

What were the outcomes?

Network members who accessed the Patient Learning Journey workshops have gone on to be involved in research in a variety of ways. This has included: being a co-applicant on a funding application, being part of steering committees and project teams and speaking at conferences. The PURPOSE team has taken a flexible, 'asset-based' approach to involvement, which allows network members to take on varying roles depending on their skills, needs and the level of commitment they feel able

to give.

Who developed and delivered the training? Were members of the public involved?

The Patient Learning Journey model was developed by colleagues at the Leeds Institute of Medical Education (see Morris et al 2009) looking at involving patients in the education and training of health professionals. This team includes people with a service user / carer background. People who have completed the training themselves can train to co-facilitate future workshops. The training was adapted and delivered by Delia Muir, the PPI Officer.

How do you support participants after the training?

When an opportunity for involvement arises, the PPI Officer is available to meet service users before they meet researchers, to talk through the project with them and help them to think about the contribution they could make. The PPI officer also meets researchers to help them to think about ways of involving people in their work in a supported and meaningful way, which may include organising and facilitating meetings and events. One example of this was a public engagement day to aid service user involvement in the interpretation of data. This involved using role play and videos as well as looking at the written material arising from the research.

The PURSUN UK network also aims to provide an environment where peer support is possible. The Patient Learning Journey workshops aimed to facilitate this as they helped the network members get to know each other.

When is this training most useful? Who is it most useful for?

The Patient Learning Journey model was originally developed to prepare patients or service users for involvement in the education and training of professionals. However it is a model that can be easily transferred to other areas of public or

service user involvement. It is particularly useful in situations where you are bringing together patients or service users who have not previously been involved, whether in research or in training and education.

Learning points

- Start where people are at, know your group and help them to assess their own needs and skills; start with them and their stories rather than what professionals think they need to know.
- When thinking about training, it is vital to work with researchers as well as service users: both groups need to be prepared for collaboration if it is to be a partnership. Researchers need to appreciate that service users may not engage with the research in the same way that they do.
- For people to contribute in a meaningful way, it is important that research activities are fully accessible; the way that you involve people is part of helping them to feel supported. You need to meet people halfway.

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Reference:

Morris P, Dalton E, McGoverin A and Symons J (2009) Preparing for patient-centred practice: developing the patient voice in health professional learning. In: Bradbury H, Frost N, Kilminster S, Zukas M, Beyond Reflective Practice. Oxford: Routledge.

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