

The patient voice



Working with the patient voice: developing teaching resources for interprofessional education

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Service users and carers are increasingly involved in the education and training of health and social care professionals.¹⁻³ There are very different (sometimes muddled and contradictory) views about this, which merits much more discussion (and research).⁴ In particular, we need more critical analysis of the underpinning assumptions. Whilst

recognising these debates and problems exist, our purpose here is to explain some ways in which we have involved patients, carers and professionals in developing interprofessional education (IPE) teaching resources, and how we have tried to address some consequent difficulties. We begin with a brief explanation of our IPE projects, and then

use three examples to show how we have developed our approach.

IPE PROJECTS AT LEEDS

There are two large IPE projects in which patients are involved in both development and teaching: both projects are based on clinical scenarios.

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1. Work-based IPE workshops for all final-year health and social care students from four local universities. Workshops include: asking difficult questions; breaking bad news; learning disabilities; living with diabetes; stroke; post-natal depression. They are intended to: develop the participants' understanding about each other's professional roles; enhance team-working and develop communication skills; and include specific content.
2. First-year medical students take a compulsory module on team-working. Students critically evaluate, through discussion, small-group work and a placement visit, the role of the multidisciplinary team involved in diagnosis, treatment and management of a chronically ill virtual patient living in a virtual online community.

The development of these projects has been informed by a series of action research projects, which showed that the success of IPE workshops is determined by the clinical realism and relevance of the content.⁵ This realism has been established and maintained by including the perspectives of patients and carers, as well as different health care professionals, at all stages of development and delivery of the projects.

WHO IS INVOLVED AND HOW?

Service users, carers and providers, together with university and practice-based professionals, are all involved. The simulated patients (SPs) are service users and carers already involved in medical education. The roles they take on as an SP may not necessarily be the same as their 'patient' role; therefore, in these projects, SPs and patients are not exclusive categories (Figure 1).

SERVICE USER AND PROVIDER INVOLVEMENT

Our primary aim in developing teaching resources, particularly clinical scenarios, is to maintain clinical realism and relevance. To do this we need to involve not only service users and carers, but also different professionals and voluntary sector service providers and groups. This is for two reasons. First, clinical realism is not solely dependent on patient perspectives but also depends on the perspectives of relevant professionals and services. Second, both IPE projects are intended to develop understanding about multidisciplinary team (MDT) working; therefore, the perspectives of service providers are as important as the perspectives of patients.

Practically, it is important to select content for which there is not only suitable local expertise

but also sufficient services and resources to enable all students to have placements and undertake independent research. Therefore, we have built on links with individuals and local community groups established by our Patient Voice and Community-based teaching teams,^{6,7} to identify appropriate service users, carers and providers.

Service users, carers and providers have commented on and developed content, suggested new contacts, hosted students at relevant meetings, provided digital stories (via Health Talk Online,⁸ and Pilgrim Projects,⁹), trained SPs, acted as SPs and co-facilitated workshops (Box 1). We recognise that the views and perceptions of patients and carers vary, as do those in any group. Therefore, we do not consider that any one scenario is representative of a particular condition or problem, merely that it is realistic and not stereotypical.

The following three examples show different aspects of our approach to involvement.

Post-natal depression

This scenario was the first we developed with service-user, carer and professional involvement. It involves a single mother, with two children, who has post-natal depression. It was developed in a series of workshops that included staff working in health visiting, midwifery and mental health, together with SPs who had personal experience of mental

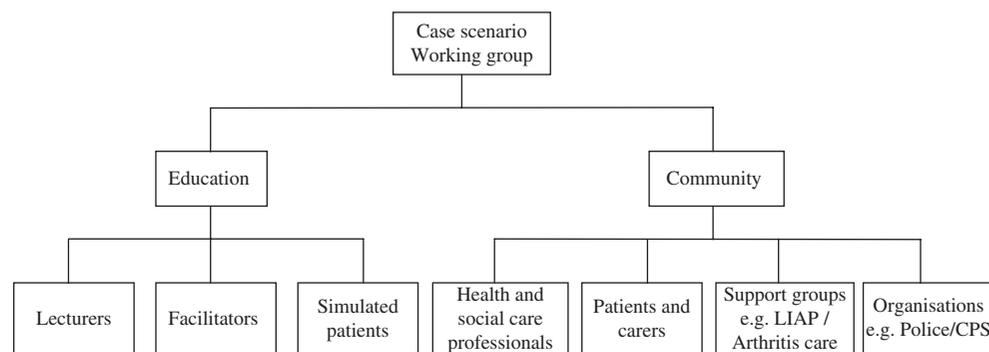


Figure 1. Stakeholders involved in developing resources.

health problems: one had her own experience of post-natal depression. The development of this first case scenario demonstrated how professionals also have their own histories, which may include being a patient or carer, and they chose whether or not to declare their own experiences when professional and personal boundaries collided.

Domestic violence

This workshop shows how working with groups rather than individual 'patient' voices may be more appropriate. It was developed with an established local project developing a multi-agency approach to improving the safety of women, and their children, experiencing violence from men they know. We took a deliberate decision to work with the project rather than individual women who had experienced violence. This decision was based on research and evaluation evidence, and on theoretical perspectives about domestic violence. Domestic violence is a massive problem about which many myths and stereotypes exist,¹⁰ so we needed to ensure that we had relevant expertise and information. There are many issues for women to consider when choosing whether and how to speak about their experiences of domestic violence, and these would not necessarily be addressed by working with individual women. Again, discussions during the development of the case scenario demonstrated that professional and personal experiences are not necessarily exclusive.

Child health – living with a learning disability

This scenario concerns a teenager with autism who needs a routine operation. During the initial planning it became obvious that involving parents and teenagers with autism would pose a number of challenges. Colleagues from learning disabil-



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ity and child health teams were 'protective' of their clients, and suggested that there were ethical considerations when involving vulnerable groups and young people. Their preferred approach, which we used, was for education and practice staff to talk about their experiences of working with children with learning disabilities, in order to highlight some of the issues for the child, family, and health and social care professionals. This can be interpreted as advocacy or 'speaking for' young people: probably elements of both were present. Our decision to work with the practice staff in this way was partly pragmatic and partly because we chose to accept their professional perspectives. There were two ways in which we were able to include the 'voices' of young people and their carers. First, some members of the SP team attended a social event with a local support group to meet with parents and autistic teenagers in a relaxed environment. Second, SPs watched a series of short films (from the

National Autistic Society) featuring autistic teenagers: this obviously lacks some immediacy, but did offer a way of hearing young people speak for themselves.

SUMMARY

We consider that involving service users, carers and relevant professionals in developing teaching resources provides realism and relevance, and may enable service users and carers to offer their perspectives. However, this is a complex process, and there are many practical and ethical issues to be considered. Policy imperatives, concerns to 'put patients at the centre of care' and rhetoric all suggest that it is important to involve individuals directly. We agree with this, but also argue that there are sometimes justifiable empirical, practical and theoretical reasons why it is not always appropriate to involve individuals directly, as the above examples demonstrate. We also consider that both service user and provider perspectives are

Box 1: Service user and carer feedback

I feel that these sessions have been consistently good and this was no exception. It is evident to me that there is so much to learn from this interdisciplinary approach, and those attending have a lot of 'good practice' to share with one another.

It may have been at this session that someone said that they were very surprised when I had said out of role that I had experienced post-natal depression after post-natal psychosis, and didn't it bother me going to that place again and remembering. I said it was ok for me and I was glad to put my experience to use in clinical-type sessions.

Involvement and consultation with service users and providers recognises, respects and takes account of different perspectives and needs

Box 2. Student feedback

It has helped highlight areas of importance and how to use a patient-centred approach to treatment... Final-year physiotherapy student

Overall very good session, and is very helpful to see other professionals and how they dealt with certain circumstances Final-year physiotherapy student

[The best aspects of the course were] applying a clinical problem to a real life situation, and seeing how teams work to help the patient First-year medical student

essential to developing the relevant teaching resources (Box 2).

The voices of service users and carers have been marginalised, and one important reason for their involvement in clinical education is an attempt to redress this marginalisation. One paradox is that such involvement often involves some sort of training or development, so it is sometimes argued that such patients become 'professionalised' as they become increasingly familiar with academia and medicine. Although we recognise that this familiarity may change the patient 'voice', we believe such individuals can remain advocates for patient experiences. We also need to recognise that as educators and clinicians we often ask patients and carers to speak about their own experiences, whilst rarely acknowledging our own experiences of health care. There are many reasons for this, but we need to remember that the boundaries between patient and professional are not always as clear as is often assumed.

Nevertheless, we believe that it is important to continue to include service user and carer perspectives, together with those

of relevant professionals and service providers. This enables all participants to better recognise other perspectives, and enables students to develop better understanding of holistic care and MDT working. Such involvement can also be empowering for service users and carers. Although the nature of involvement can vary, this is acceptable providing the following conditions are met.

- Involvement and consultation with service users and providers recognises, respects and takes account of different perspectives and needs.
- Involvement may be with individuals or groups.
- Listen to all voices whilst recognising the impact of the power structures inherent in health care delivery (and in society generally).

Finally, such involvement requires a flexible and pragmatic approach!

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