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User involvement in diabetes care: A contemporary perspective

As you have been following the healthcare policy 'plot', you will not have failed to notice the recent emphasis on involving service users in health service planning and provision. This idea was heralded in the *NHS Plan* (Department of Health [DoH], 2000) and has sprung to life through the advent of Patient and Public Involvement Forums, Patient Advice and Liaison Services, the Commission for Patient and Public Involvement in Health and further powers in health care for Overview and Scrutiny Committees of local authorities, all covered by legislation in the form of Section 11 of the *Health and Social Care Act of 2001* (The Stationary Office, 2001).

Since January 2003, the NHS has had a duty to routinely consult and involve service users and the public about the services provided and to respond to the information gathered. This development, generally known as 'user involvement' is very welcome. The chance to formally contribute in both general and specific ways to the NHS seems to have been enthusiastically received by many people; and there is to be no let-up – the Government's key priorities for the next few years include an emphasis on long-term conditions and on improving the patient experience.

User involvement

What does user involvement currently look like in the world of diabetes? For people with diabetes who, by necessity, require health care from many sources throughout their lifetime, and others also affected by it, user involvement has been welcomed. For Diabetes UK, with a mission to champion the view and role of people living with diabetes, the recent developments have added welcome grist to this mill as the policies demand that service users are represented on service planning bodies.

The User Involvement Project (UIP), funded by the DoH and run by Diabetes UK, includes providing formal training for people with diabetes who are involved as user representatives in local diabetes planning groups and networks, and

evaluating their role and its impact in the longer term. The training component of the UIP (lasting 1 day) has been rolled out via the regional offices of Diabetes UK and is supported by regional officers of the National Diabetes Support Team. So far, seven training days have been held at various locations around the UK, with between eight and 22 people at each day. Seven more days are planned for the Autumn.

Jill Rodgers and I (both partners in In Balance Healthcare UK) have designed and facilitated the days for the user involvement team at Diabetes UK and we have also collated the evaluations so far (the project has not yet been fully evaluated). This not only has been a privilege but has given some important insights into the experience of undertaking the role of the user representative and the perception of it by others. For example, it seems that the extent to which a user representative is welcomed as an equal participant onto diabetes planning or implementation groups varies considerably. At one end of the spectrum, one man found himself completing forms so he could be 'properly paid' and others reported enjoying warm relationships with service managers and providers. However, 'I feel like I'm just a bit of "Any Other Business";' said another participant of her experience at meetings and others reported feeling as though they had only been invited so that 'a box can be ticked'.

Evaluation

Overall, the reports of people undertaking the role of user representative are so far tending towards the less welcoming end of the spectrum, with people feeling as though they are being held at arm's length and viewed with some suspicion rather than as a full member of the team with an important contribution to make. It seems that a lack of confidence plays a big part in these feelings among user representatives, and the skills they develop on the training days go a long way towards people feeling more understanding of their role, and that of the NHS and health professionals, and thus they are much more confident about

dealing with situations that arise in meetings and working groups.

Much of this confidence comes from the sheer relief, usefulness and pleasure that people get from meeting and sharing their experiences with others – this is definitely the number one ‘most useful’ part of the day on the evaluations. Such feelings about sharing are a feature of so many projects where people with diabetes are brought together for whatever purpose (Anderson and Funnell, 2005; Walker et al, 2005), and might usefully be recognised as a powerful influence that can be harnessed in the pursuit of confidence and reassurance. People are encouraged to continue this sharing through a user involvement smart group set up by Diabetes UK.

Perceptions

One issue that has emerged, as a perception by others of the user representative role, is that the representatives will use their own point of view or experience rather than give a broader view. The training days have revealed that on the contrary, people are extremely concerned *not* to consider their own diabetes in the context of their role as a user representative and understand very well their role to inform themselves of views from all service users and providers.

Another perception seems to be that the user representatives are seen as ‘just patients’. In fact, people attending the training come from all walks of life and from various experiences of diabetes and bring considerable professional expertise (for example, local council administrators and self-employed business people) to their role (which is completely voluntary in all but a few cases) as well as an extremely practical and articulate perspective on what services are like at the receiving end.

The main bugbears user representatives report in working with health professionals? The amount of jargon we use and our tendency to make the representatives feel sidelined and less valuable than we ourselves are. To address these issues, the training includes information about the workings of the NHS and health professional practice, and developing skills in responding assertively to certain situations that may arise. The ideas about dealing with these and the sharing of existing strategies that emerge in the training days are practical and collaborative – in addressing the jargon

issue, examples range from a request from a user representative at each meeting they attend to keep jargon to a minimum so that they can fully participate, to a user representative working with health professionals to create a glossary of terms likely to be used so that they can refer to it when needed.

What could be a downside to user involvement? User representatives are most often operating in a voluntary capacity, which immediately puts them at an unequal footing to others. The main inequality that they see is in the timings of the meetings. Although user representatives are under no illusions that health professionals work only their contracted hours, health professionals are paid for the time they spend in meetings during office hours but volunteers are not. This means that if user representatives take time off their own work, they may not be paid at all that day. Many user representatives are regular and committed volunteers in other capacities too, so their time is often as limited as that of health professionals. While the user representatives are not resentful of this, the lack of recognition of this situation has emerged as an issue during the training days.

Another downside for health professionals might be asking the people using services what they think. This can result in some uncomfortable answers – for example, it seems that services are perceived as too often designed around the health professionals or around target achievement, rather than around the needs of the person using them.

Questions – and answers

A key question upon which the delivery of the *National Services Framework for Diabetes: Standards* (DoH, 2001) and a competent workforce is predicated is ‘what do people with diabetes need?’ (Skills for Health, 2004). This question might pose something of a challenge when reviewing diabetes services. However, the people who can help provide the answers to it are increasingly available and equipped with the skills to participate. Seeking out, welcoming and making the most of the valuable resource of the user representative could be an important step towards successfully achieving services where everyone gets the outcome they want. ■

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