

Saying 'I do' to engagement



Debbie Hicks

Practice-based commissioning has helped us identify important diabetes health needs in our local areas. However, without the correct context, this could turn the communities we work with into little more than statistics. The *Health and Social Care Act* (2001) places a duty on NHS Trusts, PCTs and Strategic Health Authorities to make arrangements to involve and consult service users in service planning and operation, as well as in the development of proposals for changes. This statutory duty means the public must be involved in the following.

- Ongoing service planning (not just when a major change is proposed).
- Development of a proposal (not just in the consideration of a proposal).
- Decisions about general service delivery (not just major changes).

The *National Service Framework for Diabetes: Delivery Strategy* (DoH, 2003) advocated putting user involvement at the heart of the planning for diabetes services. The benefits of user involvement are significant. It sends out good messages that the Trust takes its public involvement agenda seriously; genuine user involvement legitimises the whole process of developing health policies and can increase the support for, and trust in, decisions made. Additionally, real involvement is likely to reduce complaints, as the service is more responsive, but, most importantly, it can improve services, as finding out what priorities people with diabetes have can lead to better targeting of resources and planning.

People with diabetes can offer valuable insights into their own experience of, and perspectives on, living with the condition. They can assess services on how well or poorly care is delivered in a way that can complement and sometimes challenge the perception of healthcare professionals. Such involvement can be seen in three different contexts (Diabetes UK, 2005).

- *Partnerships*: The views of users and professionals contribute equally to an initiative. Users contribute when making decisions and recommendations for change and also in evaluating the effects of implementation.
- *Consultation*: User views are taken into account but final decisions and recommendations are

made by healthcare professionals.

- *Informing*: Users are given information about initiatives carried out by, and decisions taken by, health professionals.

From frameworks to action

In my own experience, while working in Hull and in my current post in Enfield, North London, I have been involved with user representative groups both affiliated and non-affiliated with Diabetes UK. I strongly believe it is crucial to engage with the users of our diabetes services to understand if the services we provide are actually meeting the needs of our patients. However, in my 17 years in diabetes nursing, I have struggled with the frustration of how best to engage with such a diverse multicultural and social mix.

Diabetes UK suggests there should be at least two user representatives on any given planning group, where he or she should represent the views of their wider reference group (Diabetes UK, 2005). Most network or planning meetings I have been involved in have been undertaken during normal working hours, 09:00–17:00 Monday–Friday. This somewhat precludes any user representative who is in full-time paid employment from attending. Furthermore, *do* any Trusts within the UK provide expenses for users to attend meetings? Not in my experience. *And* the NSF suggests that user champion posts are a paid position, but *do* any Trusts have these? In my experience, these conditions result in the majority of user champions being retired individuals, meaning that the views provided are from a biased sampling group.

Enfield has three very different localities in terms of ethnic and socio-economic factors. We have an active Diabetes UK group who meet on a monthly basis. While this group is widely advertised throughout the district, the attendance to this group usually averages 20–30 people each month, hardly representative of the 14 000 people living in Enfield with diabetes. So, how do we engage with the wider diabetes population? How do we find out what our patients really think of the existing services?

When faced with this problem, the Enfield PCT diabetes nursing team decided to seek out

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our community leaders to facilitate focus groups within specific ethnic groups. We have had one meeting with our Asian women's group and are looking to plan our first meeting with our local African–Caribbean group. We feel that we need to build relationships with specific groups to ensure that their cultural needs are being included in future service development.

Diabetes UK and London Metropolitan University have produced four tools to support user involvement that will shortly be available from the NDST website (www.diabetes.nhs.uk). The titles are as follows;

- *Involving service users in diabetes services: Self assessment checklist for NHS services.*
- *User involvement and diabetes services. Toolkit for primary care trusts.*
- *Making a difference: How can you help improve diabetes services?*
- *Involving the uninvolved: A guide to user involvement in improving diabetes.*

Prepare to be engaged

From April 2008, the Government plans to replace Patient Forums with Local Involvement Networks (LINks). LINks are being introduced to help strengthen the system that enables communities to influence the care they receive. The Government aims to give LINks power to hold local health and social services to account. The legislation includes specific obligations commissioners and service providers will have to their LINK. For example, providing a LINK with information or allowing a LINK representative to view a service.

Backed by certain powers, LINks will provide everyone in the community – from individuals to voluntary groups – with the chance to say what they think about local health and social care services, such as what is working and what is not. Additionally, they will give people the chance to influence how services are planned and run and provide the opportunity for feedback to services to facilitate improvement.

Local communities are already beginning to get ready for LINks. Each local authority with a social services remit has received £10 000 to assist the planning of their LINK. Since the start of 2007, a number of places across England have been testing

how LINks might work in practice. They provide the following advice (DoH, 2007).

- Engaging your local community via existing community groups can help increase access to local stakeholders, particularly seldom-heard communities.
- Information gathering through face-to-face methods can be more effective than using questionnaires. The information gathered is of a better quality and provides an opportunity to explain LINks to members of the community.
- Members of the public can find some of the jargon used by health and socialcare professionals off-putting. Keep it simple and use plain English. Members of the public particularly dislike the use of acronyms and abbreviations.
- Consider carefully how to structure your initial stakeholder event: a market-place format with participants walking from one stall to another has been reported to be popular. Other approaches might include group problem-solving exercises to stimulate debate, or allowing people to use different media, such as film and photography, to express their views.
- Make it convenient for people to get involved. For example, in rural areas, provide ways for people to share their views without having to travel far.

With such work, it should be possible for us to engage in useful two-way dialogue with those that use our services.

It would be excellent to hear from anyone who has managed to engage their service users in a mutually productive way – perhaps via an article – that could help others struggling with the same problems to set up similar projects. ■

Diabetes UK (2005) *Guidance for Primary Care Trusts (PCTs) and Diabetes Networks. User Involvement & the Diabetes National Service Framework (NSF)*. Diabetes UK, London

DoH (2003) *National Service Framework for Diabetes: Delivery Strategy*. DoH, London

DoH (2007) *Getting ready for LINks. Local Involvement Networks Bulletin. 6: Gateway ref: 8753* Available at: <http://www.nhscentreforinvolvement.nhs.uk/docs/6th%2020070928%20Links%20Bulletin.pdf> (accessed 15.10.2007)

Health and Social Care Act. Chapter 15 (2001) HMSO, London