

Unusual partnerships and new ways of working in diabetes

Jane Pennington

Diabetes self-management is a process of learning and enabling people to act upon knowledge and skills. This article describes a partnership between people with diabetes, health professionals, designers and academics that was formed to create better methods for the self-management of diabetes. One initiative to arise from the project – ‘Agenda Cards’ – is considered in detail.

In 2004 a team at the Design Council (the RED team) became interested in investigating the possibilities of creating better methods for the self-management of long-term conditions (*Table 1* provides details of the Design Council). One of the subject areas chosen was diabetes.

Investigating these possibilities was an ambitious brief and one that led the Design Council to look for an innovative and successful diabetes specialist team within a health network which acknowledged that it was struggling with the inexorable rise in people with newly diagnosed diabetes. The overriding remit was to work intensively with people with diabetes, carers and health professionals to apply robust design principles in creating new workable solutions to improve care provision.

The Design Council chose Bolton Primary Care Trust (PCT) as its partner site (specifically the diabetes network, which includes people with diabetes and health professionals). In Bolton there is the PCT and a Hospitals NHS Trust, which means that close links between primary care and acute care are possible.

David Fillingham, Chief Executive of the Hospitals NHS Trust, had been instrumental in early discussions with the Design Council

and remains highly supportive of the project. Further work related to this project is ongoing in the acute sector, aimed at developing appropriate applications in this area.

Diabetes in Bolton

There are over 12000 people with diabetes in the Borough of Bolton; approximately 30 people are diagnosed with diabetes each week (data from the local diabetes register). The central issue in diabetes care provision, the author believes, is how best to support people in self-managing their condition. Despite Bolton's track record in providing excellent care and innovative practice, in the past there have been failings in supporting everyone effectively.

The design project

The major challenge for the design team was to apply the design principle of ‘focusing on the user’, in this case the person with diabetes. The desire was to think outside traditional biomedical, dietetic, nursing-related and other ‘NHS-type’ approaches and try to gain a deeper understanding of why some people with diabetes have such difficulties in making lifestyle changes and undertaking appropriate self-management in order to live healthy lives

Article points

1. In 2004 a team at the Design Council became interested in investigating the possibilities of creating better methods for the self-management of diabetes.
2. The design team formed a partnership with the Bolton Diabetes Network, which later grew to incorporate academic input and financial backing from a pharmaceutical company.
3. One initiative to arise from the design project was ‘Agenda Cards’, which are designed to help people with diabetes to articulate their own agenda in meaningful ways.

Key words

- Design
- Communication
- Agenda Cards

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Page points

1. The design team defined a 'double diamond' method to develop a prototype. This involved opening up the problem and seeking solutions in two phases: a 'shallow dive' phase; and a combined idea generation and 'deep dive' phase.
2. Having gained a huge amount of information and some clarity of thinking, the design team and the Bolton Diabetes Network looked towards defining some new characteristics of a service that could start to address some of the issues raised.

without complications. A team with a range of design skills – relating to products, interaction and service – carried out the initial work in collaboration with health professionals and some people with diabetes.

The design team defined a 'double diamond' method to develop a prototype. This involved opening up the problem and seeking solutions in two phases: a 'shallow dive' phase; and a combined idea generation and 'deep dive' phase (*Figure 1* illustrates the technique; *Table 2* gives details of the 'shallow dive' and 'deep dive' components).

This work was unlike a pilot, which is used to fine-tune a pre-existing model. Prototyping involves exploring different ways of building a service, being open to new information as it arises, taking risks and getting the failures in early.

Issues arising from the initial work

The design team spent considerable time with people with diabetes in their homes (these people were identified using the diabetes centre database). Informal interviews were conducted, as were extended conversations. The design team accompanied people with diabetes on shopping trips to local supermarkets to gain insights into the real-life problems of trying to get it right.

People with diabetes participating in the project were encouraged to become involved in a number of 'disclosure' exercises, including mapping their 'emotional temperature' over the duration of their diabetes since diagnosis. The design team spent many hours and even days

with people with diabetes in order to gain the deepest possible understanding of the issues.

From this work, profile types of people with diabetes were suggested. Following detailed analysis with members of the design team, people with diabetes and health professionals, common profile types decided upon were:

- the 'knowing struggler'
- the 'determinedly naive'
- the 'able knower'
- the 'new to diabetes'.

New thinking

Having gained a huge amount of information and some clarity of thinking, the design team and the Bolton Diabetes Network looked towards defining some new characteristics of a service that could start to address some of the issues raised. The following phrases reflect new ideas about service provision.

- **'One size doesn't fit all'**. Individual empowerment remains a central challenge to care provision.
- **'New rooms, new views'**. Traditional care environments are not necessarily the most conducive places for new types of service which allow a focus on motivational psychology.
- **'Round the houses'**. Health provision is most often centred on the person with diabetes and health professional. Yet diabetes care (if it is not lacking) is critically focused on the immediate circle of the person with diabetes – partner, children, neighbours and friends. Other areas of health care recognise and use self-help groups, lay carers and other means of informal support. Diabetes services have yet to make full use of these.
- **'Stepping stones'**. Diabetes self-management is a process of learning and enabling people to act upon knowledge and skills. Structured education programmes with feedback and critically defined roles for teachers and participants are essential.
- **'Freedom to experiment'**. The NHS is set up to deliver standardised services which are segmented by clinically defined diseases. This naturally creates problems for people with multiple pathologies. There is also a tension between a system that provides standardised

Table 1. The Design Council (www.design-council.org.uk [accessed 10.08.2006]).

- The Design Council is the national, strategic body for design.
- Created in 1944, it is an executive non-departmental public body, largely funded by grant-in-aid from the Department of Trade and Industry.
- Its purpose is to strengthen and support the UK economy and society by inspiring and enabling the best use of design.
- Its vision is that UK management is the best user of design in the world, supported by the most capable and skilled design professionals.

Table 2. Descriptions of the ‘shallow dive’ and ‘deep dive’ components of the design project.

Shallow dive

This included a 2-day visit to Bolton and involved discussions with patients, carers and health professionals in order to gauge the dimensions of the problem. People with diabetes were observed to see how they managed their condition in the context of their daily lives, how they felt about it and how they interacted with professional services.

Deep dive

This included involving the original participants in prototyping ideas for a new kind of people-centred diabetes service. New tools, new roles for participants and a platform to bring them all together were developed.

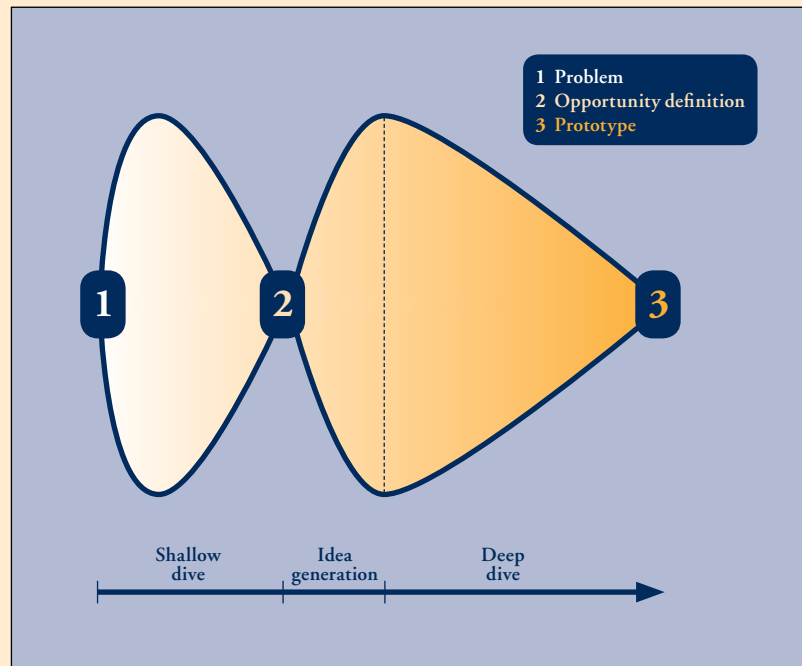


Figure 1. The ‘double-diamond’ method for design projects: from problem to prototype.

services and front-line staff who are trying to provide the best in evidence-based care using holistic approaches. Health professionals should aspire to new structures that provide safe environments for ongoing innovation.

An innovation resulting from the project: Agenda Cards

A question raised was how different types of people with diabetes (such as the ‘able knower’) can create strategies for change within their everyday lives. One key issue here was the nature of dialogue in problem diagnosis. The design team during its observations of clinical practice had noticed that some diabetes professionals appeared uncomfortable with discussing diabetes in lay terms. There appeared to be two vocabularies being used: one that is naturally used by people with diabetes; and one used by professionals that is technical and jargon based.

Using a highly interactive exchange-of-ideas session, the design team noted that it had acquired a mass of statements from people with diabetes (written on Post-it® notes and placed on a display board) that were authentic and credible, including:

- ‘I’m frightened of diabetes’
- ‘I want to get on top of this’
- ‘I’d like to help others with diabetes’.

As the discussions progressed the notion of a pack of cards (similar to a deck of playing cards) with statements on them – which people with diabetes could use to facilitate dialogue with clinicians and others – was proposed. People with diabetes, carers and health professionals readily accepted this notion. The underlying philosophy was that people with diabetes would be able to articulate their own agenda in meaningful ways. This would be without inhibitions and it could help health professionals to have a deeper understanding of the person with diabetes as an individual and his or her current issues.

The cards were named ‘Agenda Cards’ and the design team created the first version of a prototype for examination and interaction with people with diabetes, carers and health professionals. Following considerable interactions, second and third versions of the prototype were developed. The pack (in its current format) consists of 40 cards and several blanks for people to write their own statements on.

Life coaches

Another important development, which is related to use of the cards and which the author believes is unique in diabetes care in the UK,

Page points

1. The design team noticed that there appeared to be two vocabularies being used: one that is naturally used by people with diabetes; and one used by professionals that is technical and jargon based.
2. Prototyping of ‘Agenda Cards’ took place with the underlying philosophy of enabling people with diabetes to articulate their own agenda in meaningful ways.

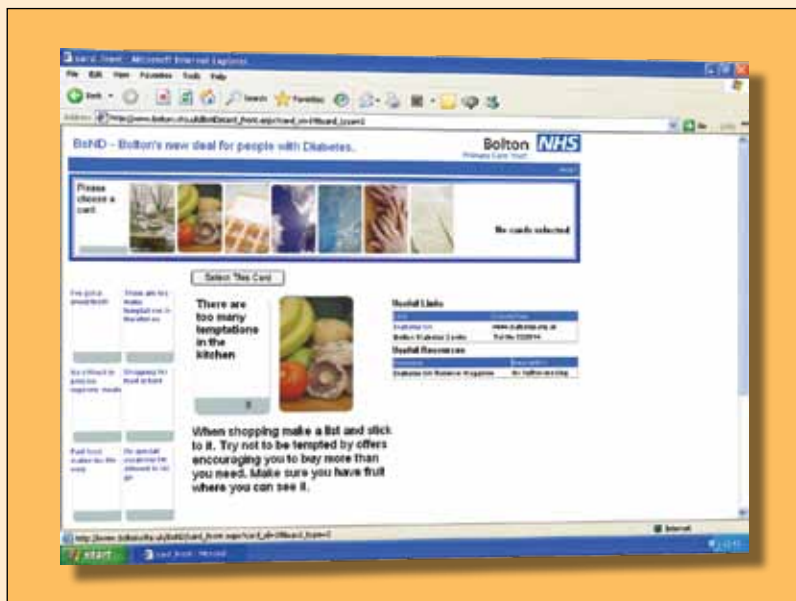


Figure 2. The on-line version of the 'Agenda Cards'.

is the use of lay life coaches. The design team developed ideas about using non-professional carers (trained in diabetes but not working as professional carers) who would support people with their diabetes-related issues, as expressed in the use of the Agenda Cards, and provide support in times of particular need, as a second level of support. Further development work is underway to develop a prototype and run a pilot for these activities later this year.

A third partner

In the author's experience, the Agenda Cards have found great favour with patients and their carers; health professionals have been a little more circumspect, but there is now a strong will among the Bolton Diabetes Network to see the cards in routine practice. Obviously such a development does not come without cost, and to see the project move into the next phase of implementation, facilitation was required. A third partner in the project was found – Eli Lilly and Company. The support the company has given relates to skilled facilitation, project planning and some financial resources.

A stakeholder group (with representatives from the Design Council, the Bolton Diabetes Network and Eli Lilly and Company) has been formed that meets regularly and undertakes short-, medium- and long-term action planning and monitoring. The project is fully supported

by the Bolton PCT management team. Following a major launch event for the project (and other educational initiatives in Bolton) in May 2006, GPs and practice nurses showed considerable interest for using the Agenda Cards in routine practice. Fifteen practices have been recruited, as have the diabetes specialist team and community dietitians.

Website

An on-line version of the Agenda Cards can be found at www.bolton.nhs.uk/BoND/card_front.aspx (accessed 10.08.2006; see Figure 2). The website will undergo considerable further development and will include a 'blog' facility.

A fourth partner

It is imperative that the project (given its importance for people with diabetes and health professionals alike) is rigorously evaluated in a research context. To ensure that this happens, a fourth partner has been involved to undertake this work. The Leeds University Business School is currently designing a research protocol and project plan to evaluate the work. The results will assess patient satisfaction, staff satisfaction, hard outcomes and a number of other objective measurements. Results will be disseminated as they become available during 2007 and 2008.

Concluding remarks

Diabetes is a condition that kills people and is the cause of considerable negative effects on quality of life for people with the condition and their carers. Communication difficulties can be a significant barrier to people with diabetes being able to make positive changes in their lives. So far, the Agenda Cards have been very well accepted by people with diabetes and health professionals. Extensive piloting and evaluation will assess the effectiveness and viability of the whole project, including Agenda Cards and lay life coaches.

The partnership method has brought together diverse groups of people – people with diabetes, health professionals, designers and academics – in an environment where skills, knowledge, experience and unmet need have informed a new way of approaching care. ■

Acknowledgement

This work was jointly conducted by the Bolton Diabetes Network and the RED team at the Design Council.