

Service evaluation of hand-held records to improve diabetes self-care

Clair Haylock, Janet Ramjeet

Article points

1. Government policy, supported by Diabetes UK, recommends the use of hand-held records for people with diabetes.
2. In a local pilot scheme, more than half of people with type 2 diabetes failed to bring their hand-held records to review appointments.
3. A service evaluation found that people used hand-held records as a resource at home and that spousal support increased their use at review appointments.

Key words

- Hand-held records
- Primary care
- Self-management
- Service evaluation
- Social support

Clair Haylock is Advanced Nurse Practitioner and Clinical Lead for Diabetes at St Stephens Gate Medical Practice, Norwich; Janet Ramjeet is Lecturer in the School of Nursing Sciences, University of East Anglia, Norwich.

Government policy currently recommends the use of hand-held records for people with diabetes. However, evidence suggests that less than half of people with type 2 diabetes actually bring their hand-held records to review appointments. In conducting a service evaluation at a local healthcare centre, the authors of this article examine the use of hand-held records in people with newly diagnosed type 2 diabetes and propose standards to encourage the use of this service and improve diabetes self-care.

Type 2 diabetes is a chronic, progressive and potentially life-threatening condition arising from persistent hyperglycaemia and is identified by the Department of Health as a long-term condition (Levene, 2003; Department of Health, 2008).

The National Service Framework for diabetes, supported by Diabetes UK, recommends that all people with diabetes are offered a hand-held record to help facilitate self-care and empowerment (Department of Health, 2001; Diabetes UK, 2003). Hand-held records are designed to encourage people with diabetes to take responsibility for their own health. This is based on the premise that if they have the ability to self-manage their diabetes, then they are more likely to have improved glycaemic control and less likely to develop the long-term complications associated with the condition (Thomas et al, 2006; Nield et al, 2007).

In another study, Ko and colleagues performed a systematic review that examined the use of hand-held records amongst people with chronic diseases, including diabetes (Ko et al, 2010). They concluded that there was insufficient evidence to support the claim that hand-held records improve clinical outcomes or satisfaction in people with chronic diseases. The results of the study also indicated that, as the use of hand-held records was low amongst participants, outcomes should be viewed with caution. There appears to be a lack of qualitative studies to explore the perception of hand-held records amongst people with diabetes. In an effort to establish local evidence on hand-held record adherence, the authors of this article assess the perspective of people with newly diagnosed type 2 diabetes on the effectiveness of hand-held records by using interviews and qualitative analysis.

This service evaluation was issued by a primary care trust (PCT). The authors were involved in piloting the use of hand-held records, which included a range of diabetes information, such as dietary advice and foot care. Agreed targets to help people with type 2 diabetes self-manage their condition were also recorded. Participants were able to share the information held within their hand-held records with any person, whether lay or professional. Initially, it was expected that participants would bring the hand-held records to review appointments with the DSNs. However, it was observed that over 50% of the participants failed to do so. Therefore, it appeared that this service required an evaluation to assess the usage of hand-held records and define a clear standard.

In a previous local evaluation, a questionnaire was developed, which had a poor response rate of approximately 10%. Hence, other methods needed to be explored to provide a clearer "picture" of why people with diabetes fail to bring their hand-held records to review appointments.

It was proposed that the service evaluation would include semi-structured face-to-face interviews in order to obtain information that would help in identifying clear standards that could be tailored to the individual.

If the scheme was to be extended (as was originally planned), to all people with newly diagnosed with type 2 diabetes in the local PCT, this would have had significant implications for the allocation of resources and their cost effectiveness.

Study design

The specific aims of this study were to:

- Ascertain whether people with type 2 diabetes issued with hand-held records brought them to their review appointments.
- Identify how people with type 2 diabetes used their hand-held records.
- Assess the overall level of satisfaction with hand-held records.

Recruitment process

The recruitment process was achieved via purposive sampling, as there were insufficient resources to recruit participants from other

healthcare centres (Punch, 2006). Therefore, the selection of participants was limited to patients at St Stephens Gate Medical Practice in Norwich. A total of 41 people were identified as having been issued with hand-held records from May 2009 until the start of the evaluation process in November 2010. Over a 2-week period, individuals with a diabetes review appointment were invited to participate in the evaluation. Two patients failed to attend their review appointments and thus did not take part. A total of 12 patients attended their review appointments, all of whom agreed to participate in the evaluation.

The authors sent a letter inviting participants to take part in this evaluation, asking if they could answer some questions on the diabetes service provided by the healthcare centre, without specific mention of hand-held records to avoid influencing the behaviour of the participants.

Interviews

The interviews were audio-recorded and took place in the healthcare centre immediately following each participant's review appointment.

Semi-structured questions were devised to reflect the aims of the evaluation, mainly to obtain the participants' views about the quality and usage of hand-held records. A study by Bowling proposed that the use of semi-structured questions in qualitative interviews, focusing on a given topic, will produce credible data. It also suggested that rich qualitative data generated from patient interviews can highlight the patient's priorities for health services (Bowling, 2009). The interview consisted of six questions (*Box 1*). Demographic data were also collected (*Table 1*).

Ethical considerations

As this service evaluation was simply aiming to obtain the views on an existing service, the local research coordinator verified that it did not require formal ethical approval. However, ethical issues were carefully considered, including the recruitment of participants. In each interview, the purpose of the study was explained and reassurance was given that it would have no effect on the management of their condition.

Page points

1. The aims of the study were to determine how often hand-held records were brought to review appointments, as well as the effectiveness and satisfaction in using them.
2. A total of 12 participants were recruited for the study via purposive sampling.
3. The participants were interviewed using six semi-structured questions.

Box 1. Questions for study participants regarding hand-held records.

- What did or did not prompt you to bring your hand-held record to this review appointment?
- Are you using it away from your review appointments?
 - (a) If yes: How do you use it? Do you read it? Do you fill it in?
 - (b) If no: Why don't you use it?
- Tell me, are you satisfied with the hand held record? Do you find it useful?
- Do you have suggestions for improvements in the future?

Table 1. Demographic information for study participants.

	40–59 years old	>60 years old	Total
Male (single)	3	3	6
Male (married)	2	2	4
Female (single)	0	2	2
Female (married)	0	0	0
Total	5	7	12

The confidentiality of the interviews was maintained and participants were advised not to identify themselves or others during the process. Recordings and transcriptions of the interviews were anonymised, using numbers as identifiers.

Plan for analysis of the data

Thematic analysis was used as a means of identifying, analysing and reporting patterns within the data (Braun and Clarke, 2006). Once the data had been collected and transcribed, repeated readings of the data were undertaken. The next phase of thematic analysis was the generation of initial codes. Coding was performed manually for the entire data-set using written notes, searching for as many potential themes as possible. The sorting of the codes into potential themes was then undertaken. Braun and Clarke (2006) suggest it may be helpful to use visual representation to sort the different codes into themes. Therefore, a diagram was used to assist with this process (Figure 1).

Each key theme was re-visited and the codes were explored to ensure that they formed a logical pattern. Once satisfied that the key themes adequately represented the coded data, further exploration was undertaken to identify the essence of each theme and analyse the data associated with these themes.

Working independently, the authors defined and named the themes using the initial thematic map. The final themes and sub-themes were agreed and produced (Figure 2).

Results

Participants

Of the 12 participants, there were 10 males (82%) and two females (18%). Two-thirds of the participants reported not bringing their hand-held records to their review appointment.

Qualitative analysis results

The initial codes were generated from the data produced from the evaluation questions. A thematic map was developed on the use of the hand-held record (Figure 1). The three main themes identified were:

- Hand-held record (for appointment use).
- Home-held record.
- Satisfaction with hand-held record.

Hand-held record

The first theme identified was the use of a hand-held record as a “tool” to be taken to diabetes review appointments. There appeared to be several factors involved in the decision not to bring the hand-held records to appointments; “stressors” unrelated to diabetes were the primary reason.

Major stressors

Major stressors could include the death of a close relative; for example, a participant struggling to manage the documentation said:

“I don't know where it [hand-held record] is, I have so much paper stuff, there is myself, my son, my daughter and her husband living at home then I've got all my mum's paper work [mother recently deceased].”

Minor stressors

Minor stressors include the other priorities of participants, leading them to forget to bring their hand-held record. For instance, a participant said:

“I get up sharp and I come out of the door and when it's time to go, I go, and half the time, I am in too much of a hurry I forget myself!”

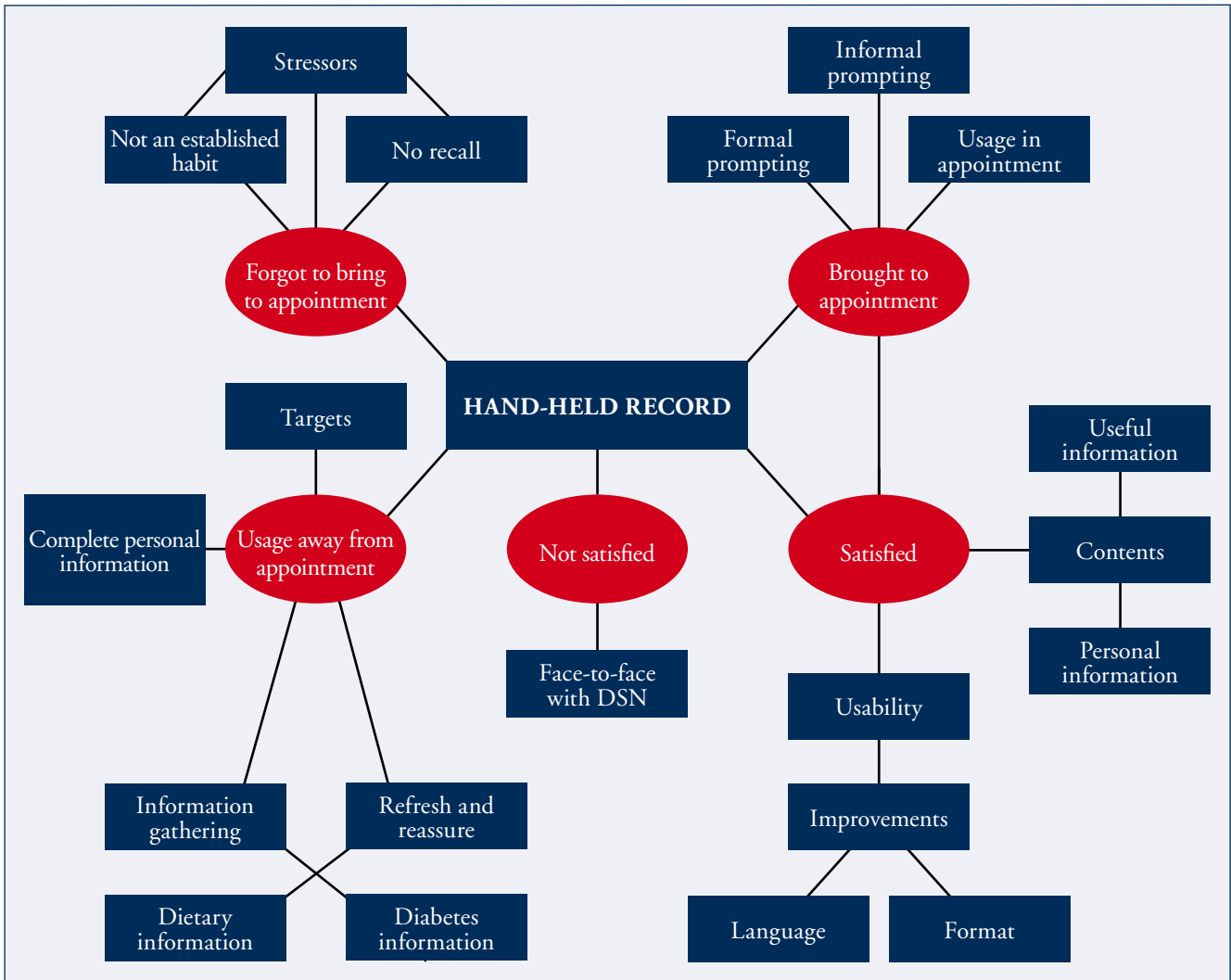


Figure 1. Initial thematic map, showing the initial codes (blue) and the five main key themes (red).

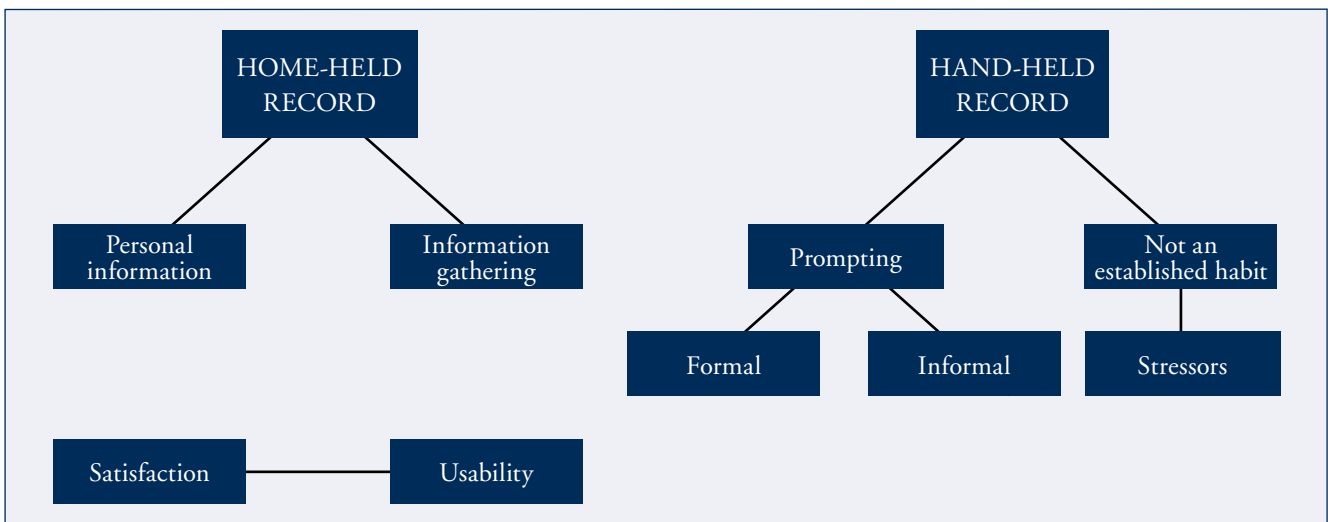


Figure 2. Final thematic map showing the three main themes.

Page points

1. The authors propose that minor stressors could have prevented individuals from taking their hand-held records to review appointments.
2. Prompting, whether informal or formal, was identified as a “trigger” for remembering to bring the hand-held record to appointments.
3. It was found that some participants used their hand-held records away from appointments, suggesting their use as “home-held records”.

It could be suggested that experiencing minor stressors on a day-to-day basis prevented individuals from developing the habit of taking their hand-held records to review appointments.

Prompting

Prompting, whether formal or informal, was also found to impact on remembering to take the hand-held records to appointments. As an example of informal prompting, one participant revealed that he was dependent on his wife prompting him:

“My wife normally reminds me to bring it. My wife, she is my little treasure: ‘do this; do that; do this; have you got this?’, ‘have you got that?’, ‘have you got your phone in your pocket?’, ‘have you got your cup?’, ‘have you put your flask in your bag?’ ‘No I haven’t, yes I have now!’”

In contrast, formal prompting in the appointment letter was acknowledged by some participants as being the “trigger” for bringing the hand-held record to their appointment. Some individuals identified a verbal cue from the DSN. For example, one participant said:

“You told me to bring it every time. Every time I come for my diabetic appointment, I bring my book.”

Despite formal prompting, however, some participants had no recollection of this request. For instance, a participant claimed:

“I remember ‘you need to give blood’ and ‘please bring a urine sample’ but, I am sorry, I don’t remember about bringing the book. Oh no, I generally forget, either I simply didn’t read the end of the letter or it has just gone completely out of my head.”

It seemed clear from this participant that some self-management behaviours had already become established habits, with the exception of bringing the hand-held record to appointments. This perhaps could be attributed to the perception of the hand-held record as an unimportant part

of their care, as the importance of this service was not emphasised by either the healthcare professional or the letter that was sent.

Home-held record

The term “home-held record” implied that the hand-held record was a tool that participants utilised away from appointments. Nearly all the participants (11 out of the 12 interviewed) said that they either currently used or had previously used their hand-held record at some point since being issued with it. The usage of the hand-held record as a “home-held record” had not been anticipated by the authors, as it was assumed that general usage was low owing to the failure to bring hand-held records to review appointments.

Information gathering

As a form of information gathering, the hand-held records provided participants with a “reference library” resource where they could access information on various aspects of diabetes, including the condition of diabetes as a process. For instance, a participant said:

“I have read through certain points of it [hand-held record] to see what diabetes actually is and what is happening here. I have read through it a couple of times.”

Several participants also indicated that they had read the hand-held record as a way of gathering information specifically about dietary advice. For example, one participant said:

“I do have a look especially with the food side, in the early days I used to have a look at that and say well I can’t eat that, I can’t eat that and I mustn’t have that, you can have a bit of that.”

Personal information

The hand-held records contained results of recent investigations, including blood tests, blood pressure and agreed targets with the participants. Targets involved activities, such as weight loss, for which the recommended steps to be taken before the next review appointment were outlined. A number of participants indicated that reflecting

Page points

1. The majority of participants appeared to perceive the hand-held record as a valuable resource.
2. The authors conclude that the hand-held record provides a valuable educational and informational resource to people with type 2 diabetes.
3. The use of written information in the hand-held record complements self-management.

on their personal information was another way in which they used their hand-held record as a “home-held record”. Some individuals also indicated that they recorded their personal results and targets, indicating a perception of the hand-held record as a “living” document rather than simply an information resource.

Satisfaction

Responses to questions about satisfaction and usefulness appeared to suggest that the participants in this study perceived the hand-held record to be a valuable resource. The enquiry into satisfaction with the hand-held record revealed that most participants were satisfied with the usability of the format in which it is provided. As an example, one participant stated:

“Well that’s good, I mean the size is fine, anything smaller and it [hand-held record] would just disappear in the general jungle of life and because any bigger and you would have no where to put it. So that seems to be a fine size, as I say it’s just sat on the bookshelf and I know exactly where it is, it’s not lost or anything in my case.”

Another participant claimed that the hand-held record is self-explanatory. There was also positive feedback for the information it contained:

“There is some useful information in it [hand-held record]; I have read through some of the parts in there which were quite good diabetic records and that sort of thing, and some of the information in the front on diabetic facts.”

Discussion

This evaluation found that the majority of people with type 2 diabetes who were issued with hand-held records did not bring them to review appointments. However, it became evident that nearly all the participants of this study did use them away from their appointments. One of the main themes uncovered was that individuals used their hand-held records as “home-held records”. This supported the notion that hand-held records are “vehicles” that provide a valuable

educational and informational resource to people with diabetes. This is supported in the results of another study by Davis and Bridgford (2001), who reported that 70% (620) of participants were using the database (hand-held records) regularly. Moreover, as only 17% of those participants took their database to any appointments, it was suggested that they were also using the database (hand-held record) away from appointments, perhaps as a “home-held record”.

It appears that in this evaluation, the use of written information in the hand-held record complements self-management. It could be argued that accessing and using personal information in the ways indicated by the participants to help achieve targets, such as weight loss or steps to increase physical activity, is a form of self-management. For instance, if people with type 2 diabetes engage in weight management, their condition is likely to be better controlled, thus reducing the risk of complications and ultimately improving their quality of life (Rubin and Jarvis, 2007; Funnell et al, 2010). Therefore, the authors conclude that the hand-held record can be used to support people with type 2 diabetes to engage with self-management tasks.

Although the sample size of this study is relatively small, this evaluation demonstrates the importance of the social support (informational) from others who provided prompting, in reminding individuals to bring their hand-held records to review appointments. Further research, using a larger number of participants, could examine the viewpoints of the family and friends of the participants on the hand-held record as a means of supporting self-management. Furthermore, another study by Orvik et al (2010) regarding spousal educational needs and perceptions of health in partners with type 2 diabetes has recommended the continual need for educational programmes for the partners of people with type 2 diabetes. It could be proposed that the hand-held record is one way of providing this to both people with diabetes and their partners, and that partners should be encouraged to accompany the patient at the initial visit to the healthcare centre when the hand-held records are offered. Formal prompts for this could include a telephone call, text message or email.

“The role of spouses in prompting individuals to bring their hand-held records to review appointments appeared to reinforce the vital role families may play in supporting people with diabetes.”

Stressors, both major and minor, were highlighted as a possible reason for why participants forgot to bring their hand-held records to review appointments. However, it could be suggested that the hand-held record acts as an unwelcome reminder of the condition. This reminds diabetes specialist teams that the health priorities of the individual do not always match their own (Marks et al, 2000). Thus, careful consideration of the underlying reasons for people not bringing their hand-held records needs to be taken into account. The authors propose that the training of informal supporters and amendment of information letters to reflect the importance of hand-held records will help improve the standards of this service.

A strength of this service evaluation was that it focused on examining current care by asking for the consumers' views. It set out to ascertain whether people with type 2 diabetes issued with hand-held records brought them along to review appointments, and also whether they used them and were satisfied with them. This evaluation achieved these aims. It is important to note that this evaluation was reliant on the views of those participants who attended their appointments and did not consider the non-attendees to assess whether the hand-held record was of value to them. It is clear that their contribution would have given the evaluation a broader perspective by either further supporting the evidence found or by offering different perspectives.

As the evaluation was conducted as part of a Master's degree project, it was shaped by both financial and time constraints. This resulted in the first author having to conduct the interviews, introducing a potential risk of bias in that the author may have unwittingly teased out the responses from the participants in order to confirm their own ideas (Bowling, 2009).

Having reflected on the seemingly poor quality of the literature available on the use of hand-held records in people with type 2 diabetes, it may have been more pertinent to have systematically reviewed the existing evidence on hand-held records in other chronic disease areas, such as mental health or cancer. This may have resulted in higher-quality evidence either supporting or contradicting the findings in this study.

Conclusion

This study clarified that people with type 2 diabetes do not always bring their hand-held records to review appointments, uncovering the underlying reasons for this. The role of spouses in prompting individuals to bring their records appeared to reinforce the vital role families may play in supporting people with diabetes. It was also found that individuals used their hand-held records as “home-held records”. Further work is required to investigate the quality and usage of the hand-held records. Such studies could also assess the cost-effectiveness, metabolic outcomes, technological reliability and time-related issues.

In conclusion, it is clear that satisfaction in using the hand-held record is crucial and people with diabetes need to be consulted in its development in order to achieve optimum use. ■

- Bowling A (2009) *Research Methods in Health: Investigating Health and Health Services*. Open University Press, Berkshire
- Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**: 77–101
- Davis T, Bridgford A (2001) A comprehensive patient-held record for diabetes. *Practical Diabetes International* **18**: 311–4
- Department of Health (2001) *National Service Framework for diabetes: standards*. DH, London. Available at: <http://bit.ly/hK4rOB> (accessed 03.09.12)
- Department of Health (2008) *Raising the Profile of Long Term Conditions Care: A Compendium of Information*. DH, London. Available at: <http://bit.ly/OgEuje> (accessed 03.09.12)
- Diabetes UK (2000) *Care recommendations: patient-held records*. Diabetes UK, London. Available at: <http://bit.ly/OHQ6gh> (accessed 03.09.12)
- Funnell M, Brown T, Childs B et al (2010) National standards for diabetes self-management education. *Diabetes Care* **33**(Suppl 1): S89–96
- Ko H, Turner T, Jones J, Hill C (2010) Patient-held medical records for patients with chronic disease: a systematic review. *Qual Saf Health Care* **19**: 41
- Levene S (2003) *Management of Type 2 Diabetes Mellitus in Primary Care: a practical guide*. Elsevier Science Limited, Philadelphia, USA
- Marks D, Murray M, Evans B, Willig C (2000) *Health Psychology: Theory Research and Practice*. Sage Publications, London
- Nield L, Moore H, Hooper L et al (2007) Dietary advice for treatment of type 2 diabetes mellitus in adults. *Cochrane Database Syst Rev* **3**: CD004097
- Orvik E, Ribu L, Johansen O (2010) Spouses' educational needs and perceptions of health in partner with type 2 diabetes. *European Diabetes Nursing* **2**: 63–69
- Punch K (2006) *Developing effective research proposals* (2nd edition). Sage Publications, London
- Rubin A, Jarvis S (2007) *Diabetes for Dummies*. Wiley, Glasgow
- Thomas D, Elliott E, Naughton G (2006) Exercise for type 2 diabetes mellitus. *Cochrane Database Syst Rev* **3**: CD002968