

# Supporting a curriculum for delivering Type 2 diabetes patient self-management education: a patient-needs assessment

Sturt, J. , Hearnshaw , H. , Barlow, J.H. and Hainsworth, J.

**Published version deposited in CURVE February 2012**

**Original citation & hyperlink:**

Sturt, J. , Hearnshaw , H. , Barlow, J.H. and Hainsworth, J. (2005) Supporting a curriculum for delivering Type 2 diabetes patient self-management education: a patient-needs assessment. Primary Health Care Research & Development, volume 6 (4): 291-299.

<http://dx.doi.org/10.1191/1463423605pc253oa>

**Publisher statement:** Published by Cambridge University Press © All rights reserved.

**Copyright © and Moral Rights are retained by the author(s) and/ or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This item cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder(s). The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.**

**CURVE is the Institutional Repository for Coventry University**

<http://curve.coventry.ac.uk/open>

# Supporting a curriculum for delivering Type 2 diabetes patient self-management education: a patient-needs assessment

**Jackie Sturt** Warwick Diabetes Care, Centre for Primary Health Care Studies, University of Warwick, Coventry, England, UK, **Hilary Hearnshaw** Warwick Diabetes Care, University of Warwick, Coventry, England, UK, **Julie Barlow** Interdisciplinary Research Centre for Health, Coventry University, Coventry, England, UK and **Jenny Hainsworth** Interdisciplinary Research Centre for Health, Coventry University, Coventry, England, UK

The National Institute for Clinical Excellence (NICE) guideline for diabetes patient education offers little to inform National Health Services (NHS) Trusts in the curriculum design of self-management education programmes. The study aim was to conduct a patient-needs assessment of the educational curriculum content and support needs for Type 2 diabetes self-management. Different stages of the condition were chosen to identify whether needs remained constant or changed with time and experience. Six focus groups were convened for people who had recently received a new diagnosis or changed therapy. Twenty-three participants were recruited from primary care and the media in the UK. The educational curriculum support needs comprised: access to care and support, continuity of health care professional, lay support, high-quality care and support, and a positive cognitive appraisal of experiences. Needs were broadly similar irrespective of the new change situation. The current emphasis on lay support concurs with a proportion of the needs of our study participants. Motivational communications with patients need to be prioritized to enable patients to address therapeutic goals.

**Key words:** needs assessment; patient education curriculum; self-management; Type 2 diabetes

## Introduction

In the UK it is recognized that the predominant disease pattern to be embraced in the twenty-first century is one of the long-term conditions rather than acute disease (Department of Health (DoH), 2001). In response, the late 1990s witnessed the introduction of an NHS agenda aimed at improving the self-management abilities of people living with long-term conditions. Randomized controlled trials (Lewin *et al.*, 1992; Lorig *et al.*, 1993; 1999; Barlow

*et al.*, 2000) indicate physical and physiological health gains for people engaging in self-management programmes. The Expert Patient report (DoH, 2001) and the Diabetes National Service Framework (NSF) (DoH, 2002) recommended self-management education whereby people engage in active partnership and decision making in relation to disease management, and in doing so establish the need for educationally supported patients. These policy priorities remain in the long-term conditions NSF (DoH, 2005) which continues to place emphasis on patient-centred care and partnership, and attention to the educational and informational needs of people, particularly at diagnosis. Furthermore, Primary Care Trusts (PCTs) are required to implement self-management programmes for key long-term conditions, of which diabetes is one, by 2007

---

Address for correspondence: Dr Jackie Sturt, Warwick Diabetes Care, Centre for Primary Health Care Studies, University of Warwick, Coventry, CV4 7AL, England, UK. Email: jackie.sturt@warwick.ac.uk

(DoH, 2001). The National Institute for Clinical Excellence (NICE) guideline for diabetes patient education (NICE, 2003) prioritizes group education and the utilization of good principles of adult education, but offers little in the way of curriculum content and support processes to inform NHS providers in the design of patient education programmes. The patient education and self-management randomized controlled trial literature (e.g., Lewin *et al.*, 1992; Lorig *et al.*, 1999), including a Type 2 diabetes systematic review (Norris *et al.*, 2001), provides some good evidence regarding the effectiveness of particular educational approaches to patient self-management. Lacking in the literature, however, has been a needs assessment, articulated by patients, of their educational and support requirements for effective self-management to take place. A literature review was conducted of Medline, Cochrane, Cinahl, PsychLit and NRR, prior to the commencement of this study in 2001. The search term of diabetes in conjunction with combinations of the following terms: knowledge, patient information, information needs, education, educational needs and patient education were used. This search revealed no research papers that identified informational or educational needs as described by people with either Type 1 or Type 2 diabetes. Whilst the literature presents patient identified curricula (e.g., Duchin and Brown, 1990; Colagiuri *et al.*, 1995), the content is prioritized from a set of health professional determined subject areas. For example, Colagiuri *et al.* (1995) set out to establish whether educational priorities set by patients resulted in an increase in knowledge level and found that it did not. Although patients were asked to set their own priorities, it was from a list of possible options predetermined by health professionals and should not be considered as an adequate needs assessment exercise. This literature base led Peel *et al.* (2004) to conclude that needs assessment research for long-term conditions on patient information and service provision has predominantly used research tools which constrain the participant into a predetermined format, further limiting the articulation of need by the people who experience it. If the informed partnerships, advocated by the diabetes NSF (DoH, 2002) are to be established between patients and health care professionals, the patient perspective of what their self-management support needs are need to be identified.

The majority of people living with Type 2 diabetes access education, information and support through primary care (Audit Commission, 2000). In addition around 100 000 people receive further information and support through Diabetes UK ([www.diabetes.org.uk](http://www.diabetes.org.uk)). The research aim was to identify, from the patient's perspective, the diabetes self-management educational and support needs from statutory and voluntary, formal and informal agencies. The progression of Type 2 diabetes usually follows a treatment regime pattern of dietary-controlled to oral medication through to insulin therapy. The critical time-points of diagnosis or change in therapy were chosen to identify whether needs changed with circumstances and experience, or remained similar irrespective of the change situation. The study identified both curriculum content (Sturt *et al.*, 2005) and curriculum support needs, this paper presents the curriculum support needs of people living with a new diagnosis of Type 2 diabetes or a new change in therapy. The result of this study will be of value to those involved in developing, delivering and evaluating patient education, and self-management programmes for Type 2 diabetes.

## Patients and methods

### Research design

This qualitative study was designed to enable participants to spend time considering responses to the questions on their needs and to ensure that the researchers could attribute correct meanings to the ideas and requirements expressed by the participants. Focus group enquiry was chosen as an established research method (Kitzinger, 1994; Barlow *et al.*, 1999) offering data generated by interaction between facilitator and participants and between participants. The method allows ideas and perspectives to be both stimulated and clarified between individuals who share a common experience. Participant homogeneity in relation to the overall research themes enables rapid focus to be achieved, as there is a little need for explanatory processes. Six focus groups were organized according to the participants' relationship to a new change situation (i.e., 2 × new diagnosis/2 × new oral therapy/2 × insulin initiation). The Warwick Diabetes Care (WDC) User Group, a lay advisory group, informed the development of patient information, consent processes, recruitment and data analysis.

**Table 1** Characteristics of the sample ( $n = 23$ )

<i>Recruitment (%)</i>	
Local press	18 (78)
Primary care	5 (22)
Socioeconomic group III (non-manual) and above (%)	17 (74)
<i>Gender (%)</i>	
Male	16 (70)
Female	7 (30)
<i>Ethnicity (%)</i>	
White	22 (96)
Asian British	1 (4)
<i>Age (%)</i>	
Over 50 years	16 (70)
50 years and under	7 (30)
Comorbidity (%)	12 (52)
New diagnosis in last year (%)	10 (44)
Initiated oral therapy in last year (%)	6 (26)
Initiated insulin in last year (%)	7 (30)

Ethical approval was granted by the local research ethics committees.

### Study recruitment and population

People living with Type 2 diabetes were recruited through the local press and primary care in both urban and rural areas of the West Midlands. Media recruitment resulted from a press release to a local daily purchased newspaper asking for people's views on what information and support the NHS should provide for people with diabetes. Forty-four people responded to the press release and 41 subsequently confirmed appointments to attend one of the focus groups. Five participants responded from the primary care recruitment (Table 1). Participant eligibility was new diagnosis of Type 2 diabetes or a new change of therapy to oral medication or insulin, within the previous 12 months.

Once recruitment and consent procedures were completed, the six focus groups, facilitated by J.S., J.H. and H.H. were held on the university campus. Participants were offered an afternoon or an evening focus group and were reimbursed for out-of-pocket expenses. The discussion schedule was derived from the lay-led self-management literature (e.g., Lorig, 1993; 1999; Barlow *et al.*, 2000) and with close reference to the research aims (Table 2). The schedule was pilot tested with the first focus group of six people with a new diagnosis, resulting in a more flexible approach to the introduction of topics

**Table 2** Focus group schedule

1. Types of information, education and support required as a consequence of diagnosis/change in therapy.
2. At what points in time were different pieces of information, education and support required?
3. In what ways were/are self-management needs being met?
4. How have they contributed to meeting their own self-management needs?
5. How are health information and services used?
6. How do they manage their own diabetes and general health needs?
7. What types of services should be developed to meet their self-management needs?
8. Attitudes surrounding lay-led and professional-led support and services.
9. What do they think health professionals think they need?

according to the generation of ideas and perspectives during the subsequent focus group discussions.

Focus groups lasted between 75 and 90 min and were audiorecorded. Upon completion of the focus group, participants were asked to reaffirm consent to the data being used in the study. Any concerns about content were discussed and negotiation took place in order to delete a particular contribution whilst retaining the essence of the discussion. Following verbatim transcription, the data were analysed using Nvivo software. Three of the six transcripts were concurrently analysed by J.S. and J.H. using thematic generation with close reference to the research aims. Coding differences were discussed and consensus reached concerning the overriding themes. Once inter-rater reliability was established, J.S. analysed the remainder of the data. Three members of the WDC User Group also subsequently analysed the same three transcripts to identify any subtleties within the data accessible to those who could relate to the participants' experiences.

### Results

The educational curriculum support for patient self-management education required by this study population comprised the following components:

- Access to care and support
- Continuity of health care provider
- Lay support

- High-quality care and support
- Positive cognitive appraisal of experiences.

### Access to care and support

Access to care and support referred to the patients' need for somewhere to field their questions as and when they arose. It referred to the provision of some or all of the following: sustained access in person, or over the telephone, to a health care professional, as and when needs arose; the systematic provision of information; educational materials and lay support:

It's just that once you're on it (medication) ... everybody sort of, they tend to disappear. ... But sometimes you just wish you were given a little bit more help or they kept in contact maybe a bit more. I mean I have to make the first move, my nurse is very good and she'll see me at any time but I'd never, she'd never dream of making an appointment or ringing me up and saying how's it going. If I don't contact them they won't contact me.

(Female taking oral medication 4)

The importance of having somewhere to field questions could in many cases be satisfied in the form of written material, particularly to reinforce new information:

So I would say that what we need is written information, that we can refer back to because at the club (lay meeting) all sorts of things were being discussed ... for instance, one of the things they said was five pieces of fruit and veg, not a problem, until I went to prepare a meal and I thought oh now have I got to have five pieces of vegetables on that plate or it can be three pieces of vegetables and two bits of fruit, I know it sounds silly but...

(Female with a new diagnosis 1)

### Continuity of health care provider

This was an important aspect in the development of trusting relationships viewed as essential for supporting a curriculum for self-management education. Continuity of health care provider limited the possibility of receiving conflicting advice and offered the opportunities for sustainable and

trusting relationships, it was particularly important to participants with a recent diagnosis:

In terms of support I think continuity should be important as well, that you're getting the same people week in week out rather than going to different people and getting different advice because I think that will confuse people.

(Male with a new diagnosis 1)

Diabetes care offering combinations of access arrangements (e.g., dedicated telephone support and written information) were felt to be important. Good care packages prioritized continuity as an essential component.

### Lay support

Lay support was considered beneficial to some participants in enabling them to compare their problems, solutions and care packages with others. Lay support that particularly focused upon diabetes experiences and different approaches to management at the personal level, were valued:

Somebody who lives near to me and I know slightly, we have a mutual friend, the mutual friend knew that we were both in the same position and put us in touch and she's somebody I get on with well ... she's a similar age, similar circumstances and it was quite helpful. ... It's been interesting to sort of compare notes in a very low key way and I think we might go for walks together.

(Female with a new diagnosis 3)

Formal lay experiences with limited discussion opportunities (e.g., with invited speakers) were considered less useful.

### High-quality care

Having access to information leaflets or walk-in clinics only partially addressed the needs of participants who were well versed in assessing the quality of services they had experienced. Trustworthy care was felt to be the essential component of quality care. Trust was established in a number of ways with regard to both the health professional care received or the literature accessed through a variety of sources.

### Quality in health professional consultations

Specialist support from a dedicated clinic was more widely trusted than information and care delivered by a generalist. Primary care diabetes clinics, where the participant had supplementary information about the GP or nurse running the clinic, were viewed positively:

My doctor has an interest in diabetes ... has a clinic within the practice, and is closely involved at the post-graduate centre at (the local hospital) and those sort of activities. And he knows the consultants ... he obviously doesn't know everything, nobody does. But I think because there is, err, special interest, perhaps he's better informed than some.

(Male taking insulin 5)

Trust in the information giver had an impact on the value participants placed on a particular prescription or piece of advice. Some knowledge of the recency of the health professionals' diabetes training and their involvement in local diabetes networks made the advice more authoritative and the participants felt more confident in incorporating the advice into their self-management regime.

### Quality of written information

All participants reported that written information had been available to them upon diagnosis, the majority of whom had received leaflets from health care professionals regarding recommended dietary changes and about diabetes in general. A proportion had received information published by Diabetes UK. Written information was identified as an important part of the diabetes care package:

If there was a folder there for every new person who was diagnosed and every leaflet currently in use is in that folder and say right go home and read this I think people would read it. You'd think straight away well there's more to this, it's not just a word. I think you should be given a little bit of support like that, a one off package right from day one, and I think that would make you more aware.

(Male with a new diagnosis 4)

The quality of information received by participants varied widely and whilst their experiences differed, participants were in general agreement

upon the mark of trustworthy literature-based information:

- Evidence of publication date/using current organization name (e.g., Diabetes UK rather than its previous name of British Diabetic Association/current name of department or trust issuing the information).
- Personalized/Targeted/Systematic (e.g., leaflets specific to sub-populations including age profile and/or stage of diabetes).
- Original copy, rather than photocopy.
- Evidence that the health professional places value on the document.

### Positive cognitive appraisal of experiences

Participants' cognitive appraisal of their experiences provided insights into their emotional needs during periods of transition.

#### *Communications with health professionals*

Early emotional reactions to diagnosis and changes in therapy (e.g., anger, defiance, optimism and confidence) facilitated or hindered participants' initiation and maintenance of self-management behaviours:

For a couple of weeks you're in a shock that you've got diabetes. It's diabetes, overweight, exercise all in one breath and off you go out of the door ... and I thought, coming out, feeling thanks a lot, where's the pub, sort of thing, I need a drink, I need a chip butty or something.

(Female taking oral medication 4)

Participants perceived health professionals as often displaying de-motivating attitudes. They reported that consultations would benefit from being proactively motivational rather than responsive, to enable people to move forward in addressing therapeutic goals.

#### *Social comparison with peers*

Several participants reported that the focus group was the first time they had discussed the management of their diabetes with someone else living with diabetes. This type of lay support was considered valuable, especially if it was structured in

ways that would enable them to make comparisons between themselves and others about patterns of control, medication doses, type of care received, food choices and information sources:

There was a group of people talking about their diabetes ... I didn't altogether go with that, because quite a number of them were telling you all their personal life. ... I wasn't really interested, not being rude, but I wasn't interested in their personal life. ... I was interested in their experience from the diabetes point of view ... I did pick up a little bit of information.

(Male taking insulin 2)

There was no consensus on whether group or individual, formal or informal formats were desirable; rather, it was the structure of the contact that would positively engage them. Lay support, facilitated from within the health care system, was felt to represent an untapped resource for supporting a curriculum for self-management education.

## Discussion and conclusions

The findings from this qualitative study offer clinicians and researchers a clearer picture of the curriculum support processes required for people to engage in self-management education programmes for Type 2 diabetes. The study had a number of limitations, however, which should be considered when assessing the relevance of this study for future research and changes in clinical practice. The participant profile of retired, white, educated men is not representative of the local population and may have occurred as a consequence of the study's overt links with the university, attracting a confident and articulated volunteer group. A second limitation concerns the poor response rate to written invitation from the GP practices. Adriaanse *et al.* (2002) suggested that people with a new diagnosis minimize the impact of a positive diagnosis when no medication is prescribed or limited follow-up is arranged by their physician. This phenomenon may have led a proportion of our newly diagnosed sample population to consider their condition too mild and decide that they were inappropriate participants. A third limitation was the number of participants in each of the focus groups. The number of participants in several of the focus

groups was smaller than anticipated, due to participant non-attendance on the day. A desirable feature of focus groups is one of participant homogeneity. The homogeneity of the groups was maintained and enabled the rapid focus to be achieved between even small numbers of participants. The homogeneity was further strengthened by the larger numbers of retired men in several of the groups, particularly the oral medication and insulin initiation groups. Had non-attendance, following the media recruitment been anticipated and alternative research methods employed, we feel that some of the data would not have emerged. Findings in relation to lay support and quality issues, in particular, would have been more likely to have remained hidden without the exchanges in experiences that prompted contributions, comparisons and provocations between participants. Media recruitment proved variably successful, whilst the team made telephone contact and confirmed appointments with 41 people, only 18 attended on the day. This needs to be anticipated in future studies where a minimum number of participants is desirable.

The results reveal five important issues for practitioners and NHS Trusts to emphasize when designing and resourcing diabetes patient education. These are access to care and support, continuity of health care provider, lay support, high-quality care and support, and positive cognitive appraisal of experiences. It is of interest to note how few differences in identified need emerged from each of the three focus group categories of new diagnosis, initiation of oral medication or insulin initiation. This aspect of our findings are somewhat a mirror of those of Peel *et al.* (2004) who sought to determine the emotional responses to diagnosis and early information provision. Their data revealed three routes to diagnosis and that irrespective of this route, the majority of their 40 interviewees wanted information to be provided at diagnosis. The findings from both these studies might suggest that researchers are looking for within group differences that ultimately have little impact on the needs of the person experiencing what could be a dramatic change (e.g., diagnosis or lifetime medication initiation) in their personal health perceptions.

The first identified need, access to care and support, encompasses both person-to-person contact and written/audio-visual material. Our findings concur with those of Peel *et al.* (2004) that information on diagnosis or upon treatment change was

an unmet need for the majority of our participants. Written material was felt to have a strong supplementary role in reinforcing information and advice offered during a consultation. The data suggest that people require health professionals to follow-up their consultations with the provision of written material containing the same factual material.

The participants in this study required continuity of health care provider. Continuity is a prescribed feature of general practice, where the majority of Type 2 diabetes care is provided, and should be less organizationally challenging for primary, rather than secondary care. An emphasis placed on access and on continuity, by NHS Trusts, could lead to creative curriculum support options in the provision of responsive facilities for users to access. Ways to achieve this might include nurse-led telephone support, an information pack serving as an ongoing reference or a lay mentoring scheme. Differences in access and continuity requirements between the new change situation groups were minimal suggesting that organizational service developments focussing upon access and continuity will be broadly appropriate for people living with Type 2 diabetes at all stages of the condition. Persistence was exercised by the research team to identify themes that differed from the norm by involving a research user group of people living with Type 2 diabetes to code transcripts. This co-analysis by lay people added robustness to the interpretations made by the researchers.

The third emphasis of lay support endorses health policy (DoH, 2001). Although no preferred form of lay support emerged here, diabetes-focused discussion was more valued than listening to speakers or general discussions. This finding may be of interest to established patient support groups attached to NHS Trusts or charitable organizations. Whilst the current DoH (2002) and NICE (2003) educational focus is on formal group arrangements, there is scope for individual and informal roles to develop. This could enable creativity to emerge in primary care (Barlow *et al.*, 2002) for developing roles in lay support that many of our participants sought. People living with diabetes require access to other people with similar experiences for a number of purposes. Lay supporters can offer empathy, vicarious experiences (Bandura, 1977) and comparisons by which people can assess their own experiences, therapies, metabolic control and behaviours. Social comparison with peers emerged in this

study, as in other studies (Eijkelberg *et al.*, 2002), both as a mechanism through which people could cognitively appraise their own experiences of living with diabetes and of diabetes care provision, and as providing an essential component for productive learning (Barlow *et al.*, 1997). As professionals develop specialist expertise, for example GPs with special interest (DoH/Royal College of General Practitioners (RCGP), 2002), they see greater numbers of patients living with the same condition. This enables the developing specialist to make case comparisons, develop analytical and clinical skills, and refine their therapeutic thinking. In contrast, people living with diabetes self-manage their complex metabolic condition in relative isolation, often using only personal diabetes data on which to base their judgements. Structured lay support could offer similar opportunities to people living with diabetes.

Quality assessments relating to both written material and health professional consultations were routed in the absence or presence of measurable trust. Issues of quality in text-based information are paramount as the abundance of health-related information to be found in leaflets, magazines and increasingly on the Internet, offers high potential for conflicting information. The features of trustworthy health literature for our participants were similar, though not as extensive, as those advocated by the Centre for Health Information Quality ([www.hfht.org/hiquality/guidelines.htm](http://www.hfht.org/hiquality/guidelines.htm)). The data indicates, however, that the participants were experienced in making informal judgements regarding the trustworthiness of the written information they received in the absence of access to formal guidelines.

The extent, to which the health professionals had up-to-date knowledge and experience, including having undergone specialist training in diabetes, was valued highly by participants. Providing evidence of specialist training or engagement with local diabetes networks represents a challenge for health care professionals and patients alike. The development of local networks, however, is now a Diabetes NSF standard (DoH, 2002) which could facilitate the recognition of qualifications or expertise in diabetes care. The focus on quality and qualification within the data may reflect the socio-economic profile of the respondents who, typically from professional backgrounds, may value accreditation highly.

## Conclusions

The DoH's emphasis on group diabetes patient education concurs with a proportion of the needs of our study participants. Resources are required to support group and individual patient education needs in the form of trustworthy written materials. Motivational interview techniques may help health care professionals to facilitate patients in early therapeutic goal setting, providing patients with opportunities to feel less defiance and more confidence as they process the meaning of their experiences.

## Implications for practice

- Access, continuity of health care professional and quality, criteria should be addressed before delivering a diabetes patient education programme.
- At diagnosis of diabetes, the importance of self-management goals must be clearly emphasized with health care professionals communicating positively and motivationally with patients.
- Practices should consider encouraging people living with diabetes to meet and discuss their attitudes and approaches to diabetes self-management with each other.

## Implications for research

- Investigation of a wider population is required to enable the priorities for supporting a diabetes self-management educational curriculum to be determined.
- The effect of lay support on psychological and clinical outcomes should be determined.

The NSF for Diabetes (DoH, 2002) states that people with diabetes should be empowered to participate in decision making, supported in managing their diabetes and helped to adopt and maintain a healthy lifestyle. This, along with expert patient policy (DoH, 2001) offers possibilities for building responsive and imaginative services, integrating lay roles to meet some of these stated patient needs. The design of curriculum support services needs careful attention to ensure that people have the access to materials, processes and facilities to enable them to respond to the NSF agenda. The focus groups have

provided a range of views, the frequency with which views are held across a larger, and generalizable, population requires further investigation.

## Acknowledgements

We would like to thank the study participants and the Warwick Diabetes Care User Group for their advice throughout the duration of this study. We are indebted to Diabetes UK for funding this study. The views expressed here are those of the authors and not necessarily of the funding body.

## References

- Adriaanse, M.C., Snoek, F.J., Dekker, J.M., van der Ploeg, H.M. and Heine, R.J.** 2002: Screening for Type 2 diabetes: an exploration of subjects' perceptions regarding diagnosis and procedure. *Diabetic Medicine* 19, 406–11.
- Audit Commission.** 2000: *Testing Times: a review of diabetes services in England and Wales*. London: HMSO.
- Bandura, A.** 1977: Self-efficacy theory: towards a unifying theory of behaviour change. *Psychological Review* 84, 191–215.
- Barlow, J.H., Cullen, L., Davies, S. and Williams, R.B.** 1997: The power of sharing common experiences: the "hidden" benefit of group education for people with arthritis. *British Journal of Therapy and Rehabilitation* 4, 38–41.
- Barlow, J.H., Shaw, K.L. and Harrison, K.** 1999: Consulting the experts: children's and parents' perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health Education Research* 14, 597–610.
- Barlow, J., Sturt, J. and Hearnshaw, H.** 2002: Self-management interventions for people with chronic conditions in primary care: examples from arthritis, asthma and diabetes. *Health Education Journal* 61, 365–78.
- Barlow, J.H., Turner, A. and Wright, C.C.** 2000: A randomised controlled study of the arthritis self-management programme in the UK. *Health Education Research: Theory and Practice* 15, 665–80.
- Colagiuri, R., Colagiuri, S. and Naidu, V.** 1995: Can patients set their own educational priorities? *Diabetes Research and Clinical Practice* 30, 131–36.
- Department of Health.** 2001: *The expert patient: a new approach to chronic disease management for the 21st century*. London: Department of Health.
- Department of Health.** 2002: *The National Service Framework for Diabetes Standards document*. London: Department of Health.
- Department of Health/Royal College of General Practitioners.** 2002: *Implementing a scheme for general practitioners with special interests*. London: Department of Health.
- Department of Health.** 2005: *The National Service Framework for long-term conditions*. London: Department of Health.

- Duchin, S.P. and Brown, S.A.** 1990: Patients should participate in designing diabetes educational content. *Patient Education and Counseling* 16, 255–67.
- Eijkelberg, I.M.J.G., Mur-Veeman, I.M., Spreuwenberg, C. and Koppers, R.L.W.** 2002: Patient focus groups about nurse-led shared care for the chronically ill. *Patient Education and Counseling* 47, 329–36.
- Kitzinger, J.** 1994: The methodology of focus groups: the importance of the interaction between research participants. *Sociology of Health and Illness* 16, 103–21.
- Lewin, B., Robertson, I.H., Cay, E.L., Irving, J.B. and Campbell, M.** 1992: Effects of self-help post myocardial infarction rehabilitation on psychological adjustment and use of health services. *The Lancet* 339, 1036–40.
- Lorig, K. and Holman, H.** 1993. Arthritis self-management studies: a twelve-year review. *Health Education Quarterly* 20, 17–28.
- Lorig, K., Sobel, D.S., Stewart, A.L., Brown, B.W., Bandura, A., Ritter, P., Gonzalez, V.M., Laurent, D.D. and Holman, H.R.** 1999: Evidence suggesting that a chronic disease self-management programme can improve health status whilst reducing hospitalisation: a randomised trial. *Medical Care* 37, 5–14.
- National Institute for Clinical Excellence.** 2003: Guidance on the use of patient-education models for diabetes. Technology Appraisal No 60. NHS.
- Norris, S.L., Engelgau, M.M. and Venkat Narayan, K.M.** 2001: Effectiveness of self-management training in type 2 diabetes: a systematic review of randomised controlled trials. *Diabetes Care* 24, 561–87.
- Peel, E., Parry, O., Douglas, M. and Lawton, J.** 2004: Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions to diagnosis and views about information provision. *Patient Education and Counseling* 53, 269–76.
- Sturt, J., Hearnshaw, H., Barlow, J., Hainsworth, J. and Whitlock, S.** 2005: Education for people with type 2 diabetes: what do patients want? *Journal of Diabetic Nursing* 9, 145–50.