The organisation & delivery of diabetes services in the UK: a scoping exercise.

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The Report

1 Introduction

Diabetes is one of the most important diseases confronting the United Kingdom's (UK) health care system. Diabetes is already an extremely costly disease and as its prevalence increases those costs will rise further. Diabetes is an inherently complex area of care organisation, encompassing: an expanding range of clinical interventions; a large workforce of professionals and support workers; and a wide range of different services and care contexts. Diabetes has proven to be a very innovative area of health care delivery, influencing more general developments in chronic disease management (CDM), such as care pathways and patient centred models. The overall challenge to the organisation and delivery of diabetes services is to manage rapid innovation and extraordinary levels of demand within a complex care setting. Central to this challenge is the need to develop effective models of self-care support. There are also concerns about the quality of the patient care experience with significant variations in the level of care provision both regionally and in specific clinical services. These variations are linked to health inequalities, with some populations not accessing services effectively (black minority ethnic (BME) groups, people with mental health problems, older people, travellers, prisoners and other marginalised groups).

Therefore, understanding how best to organise diabetes services is vital if the health system is going to manage the expansion in both the demand for and cost of diabetes care. This scoping report provides an overview of current developments in the organisation and delivery of diabetes services in the UK, identifying the available evidence and gaps in the knowledge base for care organisation in diabetes.

1.1 Background

There are currently 2.3 million people with diabetes in England. The Public Health Observatory, Brent PCT, ScHARR (PBS) Diabetes Prevalence Model predicts that the prevalence of diabetes within England will increase from 4.9% to 6.5% by 2025 (Yorkshire and Humber Public Health Observatory (YHPHO), 2008). The age of onset for diabetes is reducing as people develop diabetes risk factors such as obesity, at a younger age (Information Centre, 2006). Koopman et al, (2005) in examination of the National Health and Nutrition Examination Survey (NHANES) data set comparing data from the early nineties to 2000 reported a reduction in the average age of diagnosis from 52.0 to 46.0 years. This places an enormous burden on diabetes care services and health care costs (Wanless 2002). There is a pressure on the health care system to find efficient and effective models for service delivery in diabetes to: prevent diabetes, reduce the complications of diabetes (heart, kidney, eye, neurological, and foot disease), reduce mortality, and improve patients' quality of life (Diabetes UK (DUK), 2006).There is also increasing recognition that the general health care (independent of diabetes specific care) provided to people with diabetes needs to be improved (Health Care Commission, 2006).

Diabetes care has been one of the most innovative areas of chronic CDM. Diabetes health professionals were quick to recognise that successful care outcomes are largely contingent on patient self-care. Key areas of service development in diabetes have included:

- Systematic models of patient assessment (register, recall, review).
- Specialist treatment protocols.
- Continuous care models (patient journeys/pathways).
- Patient centred education models.
- Models for inter-professional working.
- Models for service integration.
- Models of patient participation both formal and informal.

The NSF for diabetes provided a platform to generalise many of these developments across the NHS with specific service outcomes (Department of Health (DoH), 2002). This framework together with other guidance and recommendations from scientific (e.g. NICE, UKPDS), professional (e.g. Joint British Societies), government (NHS Diabetes) and patient bodies (Diabetes UK (DUK)) shapes the nature of diabetes services (National Diabetes Support Team, 2006). Diabetes services are also shaped by local diabetes networks within services. These collaborative networks have a long history in diabetes having evolved in some areas from local diabetes advisory groups into sophisticated clinical and service networks with strong patient involvement (National Diabetes Support Team, 2007). Another recent innovation has been the development of the UK Diabetes Research Network (UKDRN).

Service developments have also been influenced by significant changes in care organisation, in particularl the shift toward a primary care led model for most Type 2 diabetes management. The introduction of the Quality Outcomes Framework (QOF) has impacted on the way diabetes is managed in primary care (DoH, 2004). Other innovations have been the introduction of GPs with specialist interest (GPwSI) in diabetes and intermediate care teams (Hadley-Brown, 2004). There is more service development on the horizon with the likely introduction of polyclinics (Darzi, 2007). Diabetes services are continually evolving, through either: 'home grown' models developed within small teams and then extended through the diabetes networks; or ‘mass produced’ developments with guidelines or practices being recommended more strategically.

However, despite these advances there are still many problems confronting diabetes care provision (Roberts, 2006, Health Commission, 2006). Diabetes is a complex disease requiring multiple therapeutic interventions across the patient journey from pre-diabetes to end-stage care. Technological innovation in diabetes is rapid demanding a highly skilled and responsive workforce (National Diabetes Support Team, 2007). Diabetes care is dependent on a high level of inter-professional working and operates between a wide range of specialist and general care providers, which can create problems with integration and care continuity. Diabetes management needs to be patient centred because of the high self-care component, but supporting self-care behaviours is challenging for many groups of patients with diabetes (adolescents, young people, the older frail and those with mental health problems) (DoH, 2007). Another central dilemma is the strain placed on service provision by the rising levels of diabetes. The ABCD and DUK (2006) survey of diabetes specialist services highlighted that while services had grown since the NSF in 2000, there were variations in the quality and range of care provided and certain aspects of care such as psychological support were extremely underprovided. These findings echo earlier assessments of the quality of diabetes which showed large variations in diabetes care (Audit Commission, 2000). This variability in care provision is also evident in primary care (Gulliford et al, 2007). One recent study of the impact of QOF on diabetes showed a higher proportion of exceptions (patients excluded from the quality assessment) in patients from lower socio-economic backgrounds (Sigfrid et al, 2006). There also problems with accessibility particularly in some minority ethnic groups (Mold et al, 2008).

A research advisory report (RAC) on diabetes from the DoH and MRC (2002) highlighted the lack of health services research in diabetes. Given the multiple issues identified above, it is imperative that service delivery and organisation in diabetes is supported by a strong evidence base. Diabetes needs treatments but it also needs sophisticated methods of organisation if it is to deliver the benefits of those treatments to patients. This scoping exercise identifies and explores current knowledge and research into service developments in diabetes to provide a platform to guide and extend the range of health service research in diabetes. The scoping exercise has focussed on the organisation and delivery of self-care support (including patient education) and models of diabetes care organisation.

2 Method

The aim of the scoping exercise was to provide an overview of current issues and developments in the organisation and delivery of diabetes services in the UK. The objectives of the scoping exercise were, to:

- Provide an overview of current knowledge and research on diabetes care organisation and delivery.
- Identify gaps in current knowledge and evidence, together with stakeholders views of those gaps.
- Consider specific areas: models of education; workforce; high risk populations; special populations.
- Produce a synthesis of evidence and give examples.
- Detail stakeholder concerns.
- Recommend further research and type of approach.

Four integrated methods were used for the scoping:

- Literature review and synthesis;
- Patient participation event;
- E-survey of professionals and patients.
- Confirmatory conference.

Collectively these methods generated the theoretical perspectives, empirical evidence and stakeholder views that provided the material for the scoping synthesis.

2.1 Literature review

The aim of the literature review was to provide an overview of current theory, empirical evidence and areas of development in the organisation and delivery of diabetes care.

2.1.1 Identification and retrieval of items

Focussed literature searches were undertaken in following areas:

- Patient education;
- Self-care support (including tele-care);
- National service developments in diabetes;

- Diabetes care for people with severe mental illness.

A blended approach for identifying material was used incorporating: formal protocol searching; snowballing techniques; and the knowledge of team members.

Protocol searches (using index terms and synonyms) were conducted in the following databases: Medline and Cochrane Library (see Appendix 1 for search protocol). Secondary references and citations of key papers were also used to identify material.

Grey literature was identified from multiple sources including: Diabetes UK; NHS Diabetes; DoH publications; YHPHO; Care Quality Commission; King's Fund Diabetes Leadership Course; Race for Health; the electronic Library for Diabetes, DoH Diabetes; the Information Centre for Health and Social Care; and the NHS London website. These searches were further supplemented by prior materials held by members of the scoping team.

2.1.2 Types of materials - inclusion criteria

The material identified by the searches was examined for inclusion. The aim was to include a representative range of material to provide a general summary of current knowledge and identify key examples of developments in care organisation and delivery. The wide focus of the scoping did not permit a comprehensive inclusion of all the identified material. Therefore, inclusion was related to whether the material added an additional area of knowledge to that which had already been identified. Where existing reviews were available these were used to enhance the coverage of the broad areas of activity identified. The formal literature was divided into those providing an empirical assessment of an area of care organisation and those offering a theoretical or analytical perspective on care organisation.

The specific inclusion criteria were that the review item: had relevance to the identified topic areas (patient education, self-care support and care systems); had relevance to UK health care; and was produced after 2002 when the previous DoH MRC review was undertaken (unless it had been overlooked by the previous review).

2.1.3 Data extraction

The process of data extraction varied for the different types of material. The data extracted from the empirical studies and systematic reviews included: description of study type and target population; details of the intervention (service development) including any underpinning theory; and evidence of benefit (metabolic outcomes; self-care impact; psychological outcomes; and service outcomes). The ideas and models identified from the theoretical papers were incorporated directly into the synthesis. The material from the grey literature was used to produce: a summary and description of the service development; identify the underpinning theory or concept and where available any evidence of an evaluation.

2.1.4 Synthesis

The extracted content from each review was organised within a tabulative synthesis. The type or focus of each intervention or development was categorised. The reviews where then integrated thematically within a narrative synthesis to provide a broad summary of the collected material (Forbes and Griffiths, 2002).

2.2 Patient participation event

The aim of the participation event was to get stakeholder perspectives on current care organisation and delivery in diabetes and to identify ways in which diabetes care could be better provided. This element of the scoping was led by the patient participation team of DUK. The event addressed three topic areas with specific questions:

Topic 1- Self-care support:

- What do people with diabetes think about the way self-care support is delivered to them in their day to day care experiences?
- What do people with diabetes think is helpful in supporting them in adopting positive self-care behaviours?
- What do people with diabetes think about the current educational support that is available to them?
- What do people with diabetes think about electronic media to support them (telephone, e-mail, internet, smart gadgets)?

Topic 2- Organisation of care:

- Where do people with diabetes prefer to receive their care?
- What is important to people with diabetes about where they receive their care?
- What is important to people with diabetes in relation to accessing services and support from health professionals (timing, availability)?
- What is important to people with diabetes in relation to the information they receive?
- What do people with diabetes believe to be the most important factors that determine the quality of the care they receive?

Topic 3- Patient participation/involvement:

- What factors do people with diabetes think make them feel more involved in the way care is provided to them?
- How can people with diabetes become more involved in the way care is organised and delivered?

2.2.1 Recruitment

The recruitment strategy was designed to ensure that a diverse range of people with diabetes participated. A variety of strategies were used to promote the event:

- Advertised on the Diabetes UK website, Gumtree, various online forums.
- Advertised in the Birmingham Mail and the Gujarat Samachar (a national newspaper for the Gujarati community).

• Advertised in GP surgeries, Diabetes Clinics, local Pharmacies and leisure centres throughout the UK.

• Engaged with a range of community organisations to encourage their members/beneficiaries to attend.

Potential participants were given clear information on the objectives (the topics and questions detailed above) for the event, our expectations of participants and the time they needed to commit.

2.2.2 Data collection

The day was run as a facilitated workshop built around group work with table top discussions focused on the above topics. There was also a graffiti board to allow participants to write down their thoughts. Facilitators on the tables wrote down the participants' ideas on flip chart paper. General feedback was given after each topic to encourage cross-fertilisation of ideas.

2.2.3 Data Analysis

The flip charts were collected and the responses where then analysed thematically to give summaries of the main points raised around each of the topic areas.

2.3 E-survey

The E-survey was designed to provide an assessment of care organisation and delivery in England and to generate ideas about how diabetes care could be improved. Two surveys were designed one for patients and one for professionals. The surveys were divided into sections covering the following topics:

- Diabetes education: access, quality, and areas that could be improved.
- Self-care support: methods of self-care support; areas where self-care support could be improved; and the potential of a national diabetes telephone support line.
- Care organisation: care integration; diabetes networks; intermediate care; poly-clinics; care satisfaction; governance methods; and methods for addressing inequalities.

The professional survey had an additional section asking them to identify priorities for health services research. The questionnaire also contained questions about the availability and access to self-care support for specific populations such as: BME groups; people with severe mental illness; older people; and transient populations.

2.3.1 Recruitment

The E-survey was cascaded through a variety of channels. The professional questionnaire was cascaded through: personal contacts of the scoping team (individuals and networks); people who identified their interest during an initial promotional event at Diabetes UK annual professional conference (APC); and via the website and regional networks of NHS Diabetes. The patient E-survey was marketed by Diabetes UK both via their website and through patient participation networks. The covering letter sent with the E-survey requested that respondents passed the e-survey on to others.

2.3.2 Data collection

The data were collected using an E-survey constructed in Survey-Monkey, following the topic areas outlined above (see appendix 2). The content of the questionnaires was moderated by: the scoping team; the project steering group; and NHS Diabetes. A brief pilot (n=10) was undertaken and the questionnaire was amended. The questionnaire contained pre-selected (dichotomous options and short ordinal scales) and free text options.

2.3.3 Data analysis

The E-survey generated both numerical data and text. The numerical data were extracted from Survey-Monkey and used to provide descriptive statistics and summaries of responses. The open question responses were subject to a content analysis and organised thematically.

2.4 Confirmatory conference

The confirmatory conference followed a similar method as outlined for the patient participation event. Participants were grouped onto four tables (patients; health professionals; researchers; and Diabetes UK and NHS Diabetes representatives) for discussion. Participants were given a brief synopsis of the findings in the areas of: patient education; self-care support; care organisation; and future priorities for health services research. For each area the participants were asked to list: anything the scoping had missed; anything the scoping should omit or has low relevance; the priorities for the organisation and delivery of care in each area; next steps for development; and any additional comments. The lists were summarised into tables and the key findings were presented in the overall synthesis.

2.5 Synthesis

The key findings from the three main data sources (literature, participatory conference and E-survey) where organised into thematic headings. Each theme was discussed to identify: what was known about the area; current and potential developments; and potential areas for research. The final iteration was to identify potential organisational and delivery models across the themes. These models were constructed to help provide a conceptual platform for future inquiry and service development.

2.6 Project governance

The project was overseen by a project steering group. The steering was comprised of a senior diabetologist, the research leads from DUK and NHS Diabetes, together with member of the scoping team. One of the main tasks of the steering group was to provide guidance on the range of the scoping. From an initial event held at the DUK annual professional conference (APC) it was apparent that the proposed coverage of the original scope was too broad. Therefore, one area was removed from the scoping (the management of high risk populations) and others were incorporated as cross-cutting themes (workforce development and patient participation). It was also not possible to give an in-depth consideration of all the specialist groups of patients: pregnant women; older people; children and adolescents; and people with mental health and/or intellectual impairment, although a focussed review of care organisation for people with severe mental illness was undertaken. Therefore, further scoping is recommended to address these topics in more depth.

3 Findings (scoping)

The findings of the scoping review are presented as follows:

- Literature review.
- Participative conference.
- E-survey.
- Synthesis.

3.1 Literature Review

The protocol searches generated 15,305 hits (see Appendix 1) on Medline and 330 papers were identified for review, 159 of which have been included. There were two main groups of papers: those detailing empirical work (n=88) or systematic reviews of empirical work, and more theoretical reviews (n=71). The details of the empirical studies are presented in Appendix 3. The theoretical papers have been used within the synthesis to inform the models developed therein.

The grey literature review identified 36 educational and self-care support programmes (full details of these initiatives are reported in Appendix 4). These initiatives included: Type 1 structured education programmes (n=6); Type 2 structured education programmes (n= 8); culturally adapted education (n= 9); generic and blended self-care support models (n=10); and supplemental or follow-up education (n=1). The grey literature also identified 16 examples of care organisation and delivery models operating in the UK (see Appendix 4 for details).

The product of the extracted literature (formal and grey) has fed directly into the synthesis presented in section 3.4. Therefore, this section provides a broad summary of the literature, identifying current trends in diabetes education/self-care support and diabetes care organisation.

3.1.1 Education and self-care support

Type 1 education - The majority of the Type 1 education identified in the literature review was related to structured education programmes. There is evidence from multiple sources that these programmes lead to benefits in glycaemic control, quality of life and psychological well-being. In terms of the current nationally provided programmes, the most robustly evaluated programme is the Dose Adjustment For Normal Eating (DAFNE) programme. The main trial data for the programme reported a sustained reduction (at 12 months) in HbA1c of 0.5% (Amiel et al, 2003). In a recent overview of the programme, Heller (2009), citing data from ongoing monitoring of the DAFNE programme, reported evidence of sustained (if slightly diminished) benefits in glycaemic control, psychological well-being and quality of life. There is also some evidence of economic benefit from the DAFNE programme, which reportedly saves £2,200 every ten patient years (Shearer et al, 2004), although fuller economic modelling is required to substantiate this claim. Heller (2009) also identified some areas in which more knowledge is required in terms of structured education, including: how to ensure the programmes are more accessible (exploring patient, professional and service issues); a greater insight into the mechanisms that facilitate or impede self-care behaviour (this would include consideration of patients' characteristics as predictors of successful self-care); and consideration of why group delivery seems to be more beneficial than one-to-one delivery.

While DAFNE has now been adopted by 80 centres across the UK, it is not the only structured education programme. The Bournemouth Type 1 Intensive Education (BERTIE) is another programme that has been adopted by over 40 centres in the UK. There is, however, some variation between these programmes. BERTIE has a slightly lower duration at 28 hours (one day per week over four weeks) compared to 38 hours for DAFNE (over five days in a one-week block). The variation in the amount (or intensity) of time spent on these interventions may be important. One study by George et al (2007) of a shorter, two-and-a-half-day programme (BITES) based on the DAFNE model and spread over a longer time frame (six weeks) did not find any clinical benefit, although patients in the trial (n=104) had a better starting level of glycaemic control relative to the main DAFNE trial. Other programmes included: the Torbay Insulin and Food Adjustment course, based on BERTIE, but with built in follow-up at 3, 6 and 12 months; the Whittington Insulin Dosing For Active Living (WINDFAL); and Juggling Insulin for Goals Success and Well-being (JIGSAW), which has a similar time input to BERTIE.

Another area of variation is the extent to which the delivery of the intervention is quality assured. The DAFNE programme is subject to peer review, performance monitoring and standardised data collection, but it is not clear to what extent other programmes are subject to similar scrutiny. However, while standardisation is important in ensuring consistent delivery of a model that has proven benefit, it may limit flexibility in adapting the delivery of the programme to meet the needs of different patient groups.

Not all the Type 1 programmes identified were structured. Skills for Life, a Bristol based programme, was driven more by what participants wanted (including relaxation, stress management and family issues) and was facilitated by a specialist nurse, psychologist and dietician. The Diabetes Education through Adult Learning (DEAL) programme provides both Type 1 and Type 2 education. It is designed to be delivered flexibly and incorporates both one-to-one and group sessions. It also follows something of a modular style with a basic (foundational) module, an ongoing module, a specialist intensification module (carbohydrate counting and insulin adjustment) and a flexible (fill the gaps) module.

Therefore, some key areas for future inquiry should include: comparisons of different modes of delivery (individual and group, and different arrangements in terms of the timing of delivery); accessibility; the need for follow-up or booster sessions; and the organisation of education (the degree of flexibility and the use of a more modular approach). In addition, no data were found relating to the inclusivity of these different programmes. It would be useful to know what proportion of patients, out of those invited, attend, complete and benefit from these programmes.

Type 2 education - Following the pattern in Type 1 education, there has been a shift towards group-based structured education programmes based on adult learning principles. One of the main examples of this is the Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) programme (Davies et al 2008 and Skinner et al, 2006). This model incorporates an empowerment strategy (based on social learning theory) with a heavy emphasis on patient involvement within a structured programme. The findings of a large cluster RCT showed enhanced psychological well-being, weight loss and smoking cessation. While the glycaemic control improved in the DESMOND group, the benefit was no different to that of the control group. The DESMOND findings are slightly at odds with other studies. The findings of the systematic reviews of Type 2 education largely suggest a modest benefit (overall up to 1% reduction HbA1c) in glycaemic control, with the strongest benefit coming from more intensive longer-term models (with regular and continuous follow-ups). The updated Health Technology Assessment (HTA) review by Loveman et al (2008) showed improved clinical effects for educational interventions, compared to the previous HTA review (which found small effects and emphasised the importance of medicines review as part of the education package). The Deakin et al (2007) review focused on group education. It reported a slightly stronger benefit and, overall, group interventions seemed to have an advantage over individual sessions. A finding confirmed in a recent head-to-head comparison of group and individual education by Kulzer et al (2007), found that group sessions were more effective on metabolic outcomes.

Other studies have shown that a more intensive follow-up can improve outcomes. Keers et al (2005) followed a similar model of education to that of DESMOND, but with longer sessions (ten days of group sessions with six to nine patients) and follow-up (individual support for ten weeks, plus OPD follow-up at six and 12 weeks and one year. Mannucci et al (2004) tested a long-term educational follow-up with an emphasis on developing mutual support (two-hour sessions every month), which showed an advantage of 0.5% HbA1c compared to conventional management – although these were both single centre studies with much weaker designs than the cluster RCT model adopted by DESMOND. In addition, no data were given on the costs of these longer-term, more intensive, follow-up strategies or on patient experience or preference (these programmes are demanding in terms of commitment and attendance so they may not suit all patients).

Another UK programme of Type 2 education is X-PERT, which has demonstrated glycaemic benefits, together with weight loss and self-care performance at 14 months, although, again, it was a single centre trial conducted by the designer of the programme (Deakin et al, 2006). The principle difference to the DESMOND study was in the target population – DESMOND targeted the newly diagnosed whereas X-PERT targeted both newly diagnosed and established patients. It is more challenging to show significant changes in the newly diagnosed as the differences in potential benefit are smaller and the controls also benefit from the introduction of initial medical therapies that may distract from the impact of the education. Therefore, the inclusion of some patients with established disease may have contributed to the greater effects observed in X-PERT study compared to DESMOND. Furthermore, DESMOND is only six hours over one day or two half days and X-PERT is 14 hours over six weeks. In addition X-PERT – while following a structured format with an underpinning (empowerment) similiar to DESMOND – is designed to allow flexibility so that it can be adapted to he needs of the participants and/or those of different cultural groups. Key issues here are: duration and frequency of delivery; the nature of the target population; and the level of flexibility within the structured delivery.

Multiple component models of education have also been tried. In the study by Sturt et al (2009), for example, patients were subject to an individual intervention that comprised the following: a face to face introduction (15 minutes); a 230-page manual packed with factual and self-directed learning material; audio tapes; and telephone follow-up. The results showed no metabolic advantage. The failure of this intervention may be related both to the content of the intervention and the way it was delivered. In group learning people progress together and learn from each other, whereas performance in individual learning is ultimately predicated on the motivation of the individual. It may also be that there was a lack of flexibility in the content and delivery of the intervention, so it failed to address important aspects of self-care to the individual.

Collectively these findings suggest that the potential benefit of Type 2 education may be related to the choice of method (group or individual), the relative starting point of the patients (those with poorer control demonstrate stronger effects), the integration of medical care, the level of flexibility and tailoring, and the length of follow-up. These elements are well illustrated by Krish et al's study (2008) of shared group medical consultations, where a high risk group (HbA1c > 9%) were targeted and offered group interactive sessions, plus a medicines review with a resultant 1.8% reduction in HbA1c. The benefits of a long-term, more intensive, follow-up are well illustrated by Trento et al (2004). In this Italian programme, at five years the intervention had a 1.8% lower HbA1c than the control, although the study was small (n=121) and one centred. However, there are no data on the economic viability of these models and hence further studies are required to examine these different organisational elements for education.

***Tele-care* -** There has been a great deal of innovation and development in the use of tele-care intervention to support self-care in diabetes. Some key areas of development include the use of tele-health to: enhance care-management initiatives (such as the 'chronic care model'); facilitate peer support and interaction; allow patients better access to their clinical information; enable information exchange (bi-directional – patients submit data and receive feedback); provide direct patient contact/communication; deliver psychological interventions; automate clinical data retrieval; facilitate patients' self-assessment of self-care performance and knowledge;

enable goal setting and evaluation; and provide access to further general diabetes resources and information.

In a recent systematic review Jackson et al (2006) categorised tele-interventions into three groups and evaluated their effect sizes on glycaemic control: internet (none to small effect); telephone (none to large effect); and computer (none to large effect). There were large variations in the interventions, quality of studies and effects. Hence, there is still the need to conduct far more robust studies to ensure that these types of technologies are used to best clinical effect. An as yet unpublished meta-analysis of studies being undertaken by review team Wu et al (2007) suggests that the effect on glycaemic control may be influenced by a number of factors, including: the selection of patients with poorer control for more intensive follow-up and intervention (professional interactive); and the inclusion of a psychological element to the treatment protocol.

Tele-care can be used to provide either relatively simple care support or more complex programmes. In terms of simple intervention, Krishna et al (2009), in a review of mobile phones in health care, found three studies that showed improved attendance at hospital out-patient appointments when patients were sent a text message or mobile reminder 72 hours prior to the appointment.

Tele-health is also being used to support more comprehensive packages of care. In one example the technologies are being used to enable delivery of Wagner's 'chronic care model' focussing on: self-management; support for patients; delivery system design; clinical information systems; and clinical decision support (Ralston et al, 2009). The model incorporated: e-mail communication; transmission of self-monitoring; interactive medical records; and systems for prompting and reminding patients. The intervention provided individualised care management modelled to specific patient targets. There was a significant reduction in HbA1c (0.7%), although no benefit in lipids or BP compared to controls. A further point was the frequency of contact afforded by the system. Weekly (high frequency) contact was used to keep patients moving to target (see later note on optimal treatment trajectory).

Another US-based initiative is the the Joslin Vision Network, which uses retinal photographs as a visual manifestation of diabetes. These images are shared with patients to create a platform for shared care planning and decision making. A large retrospective cohort analysis suggests some clinical benefits of this model with sustained glycaemic and metabolic improvements (Fonda et al, 2007).

It may also be that optimal benefits from tele-care are achieved when they are integrated with an existing model of care. Sweet Talk, for example, targets young Type 1 patients and sends tailored text messages, including a weekly reminder of the goal set in clinic, and a daily message providing tips, information or reminders to reinforce this goal. However, the intervention was only effective when combined with an intensive insulin model, although as the design lacked an intensive only group comparison it could be that most of the observed effect was contributed by the intensification (Franklyn et al, 2006).

Tele-care may enhance the capacity of the care system in terms of decision support as shown in a 12-month observational study by Albisser et al (2001), that divided mainly Type 2 patients (n=978) into standard education, standard education plus self-management training and standard education plus computer-generated feedback (based on a complex algorithm that determines treatment factoring fasting glucose, weight, optimal glucose target and patient characteristics). It found that the computer-managed patients achieved a similar clinically significant reduction in HbA1c (1.1%), but without increased weight gain and at a lower cost. One of the explanations given for this apparent benefit was the speed at which decision making is made (increasing efficiency). However, it is stressed that this is only an observational study.

Therefore, it may be that to get maximum benefit from tele-care technologies they need to be implemented following a clear theoretical and/or organisational model. They perhaps should also be embedded within or used to augment established care models such as intensification programmes (Piette, 2007). The interactive and feedback elements of the intervention may also be important areas for further development.

A further application of tele-care may be in the delivery of psychological therapies. In one study a telephone intervention of motivational telephone calls in six languages improved the uptake of retinal screening by 74%, compared to printed education and reminders (Walker et al, 2008). However, another recent study (Dale et al, 2009) reported no benefit in peer-delivered, motivational interviewing over the telephone.

No studies directly addressed whether tele-methods exclude some populations (lower socio-economic status, those with sensory impairment or older people). However, some studies did target older adults specifically and no problems were reported on the uptake and utility of these technologies in that population (Shea et al, 2009), although this needs further exploration. The preference for different types of tele-care support may vary between populations. Sarkar et al (2007) observed that those with poor literacy prefer telephone support to computers. Grant et al (2005) found that among primary care-based diabetes populations the older and less educated were not as likely to use the internet. Variations between genders in internet use have also been reported, with young men often wanting factual questions addressed, whereas girls prefer the social interaction opportunity provided by the internet (Ravert et al, 2004).

Improving Diabetes Efforts Across Language and Literacy (IDEALL) project uses tele-care to deliver care to hard-to-reach groups. In one application of the programme they monitor for adverse diabetes events (hypo and so on) to pre-empt any escalation in problems. The intervention was either triggered by irregularities in patient patterns or by patient-voiced concerns. The system is based on patients uploading data (blood glucose levels), which is centrally monitored and co-ordinated (Sarkar et al, 2007).

Finally, there were a number of studies reporting on the patient experience of tele-care: Piette, (2000); Zrebiec and Jacobson (2001); Sarkar (2007); Armstrong et al (2007); and Trief et al (2008). Benefits were perceived to be: the opportunity to monitor health outcomes; to have supportive contact; to receive reminders; to have greater access to specialists; and to get consistent messages. The reported patients' preferences included: preferring a real person, supplementing rather than replacing face to face; providing simple, rather than complex, support; the need for interaction; giving feedback this way; enhancing communication with health professionals; interactions being held at a convenient time for patients; personalised messages and support; peer-to-peer support; up-to-date information; and an easily accessible system.

Topic centred education - There were some examples of education that targeted specific diabetes problems rather than providing more general education: weight loss (Huisman et al, 2009), lifestyle topics (Kirk et al, 2007); and foot care (Valk et al, 2001). While there is only limited evidence of benefit from these more focussed initiatives, it may be useful to consider whether there is a place for more specific educational interventions – particularly given the complexity of some topics and the possibility that patients may wish to have more in-depth knowledge of some areas.

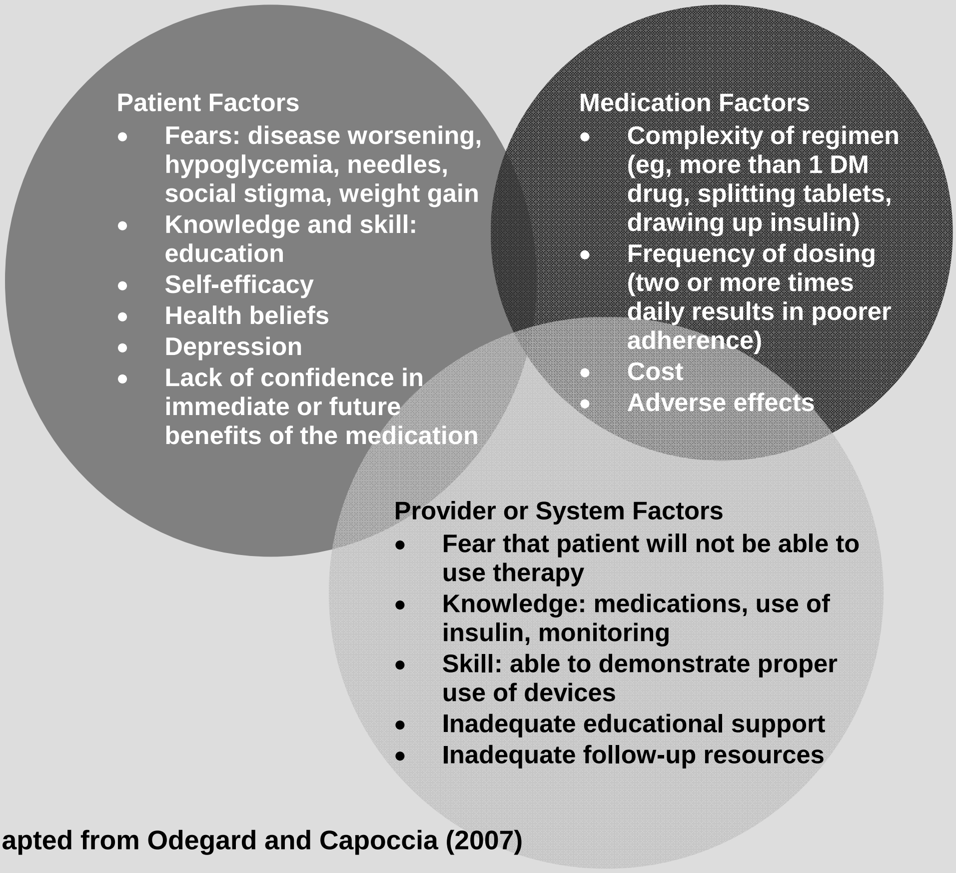
Psychological and patient empowerment models - Many current self-care support models are based on an underlying psychological construct, including: social learning theory; common sense theory of illness; commitment therapy (mindfulness); and health belief model, and espouse the adoption of empowerment model. However, the evidence base for these models is not conclusive. One systematic review reported that empowerment interventions had very mixed effects, with better effects being found where patients were given some preparation (training) in how to respond to a more empowering consultation (van Dam et al, 2003). This variability suggests that optimal empowerment models have yet to be determined (Graffy et al, 2009).

A current national initiative being co-ordinated by the Health Foundation is Co-creating Health. It involves training health professionals and patients to be better collaborators in care planning. Psychological techniques – many drawn from the principles of motivational interviewing (exploring ambivalence, encouraging self-efficacy and developing an empathetic style of communication) – are used to foster a more collaborative spirit of communication. There is an ongoing evaluation of this project that includes a diabetes focus. The evaluation focuses on the experience of care rather than the clinical effects of this shift in care provision.

Adherence/compliance interventions - The systematic review (n=2) evidence suggests that despite a wide range of interventions no single intervention is effective in producing sustained adherence or clinical benefit. This is a product both of limited efficacy and poor study design (Odegard and Capoccia, 2007 and Wens et al, 2007). The recent review of reviews from Graffy et al (2009) reported that education, reminders, nurse-led telephone interventions and pharmacist reviews have limited impact on adherence to medication. Health literacy may be an important consideration in adherence. Methods to improve patient interaction and dialogue over medicine choice are being developed. For example, Breslin et al (2008) are currently testing a series of cards that support patients in making informed choices about medications through considering their effect on: weight; hypo and hyperglycaemia; frequency of drug taking; side effects; and drug taking requirements (timing and monitoring).

While there is a limited evidence base for adherence interventions, the review did indentify some material describing factors that may explain why people do not follow self-care recommendations. Odegard and Capoccia (2007), focussing on factors that contribute to poor compliance with medical therapies, identified three groups of factors: those that are internal to the patient; those that are related to the therapy; and those that are related to the provider (the health professional) and care system (see Figure 3.3.1).

Figure 3.1 Factors That Contribute to Poor Compliance with Medical Therapies



Patient Factors

- **Fears: disease worsening, hypoglycemia, needles, social stigma, weight gain**
- **Knowledge and skill: education**
- **Self-efficacy**
- **Health beliefs**
- **Depression**
- **Lack of confidence in immediate or future benefits of the medication**

Medication Factors

- **Complexity of regimen (eg, more than 1 DM drug, splitting tablets, drawing up insulin)**
- **Frequency of dosing (two or more times daily results in poorer adherence)**
- **Cost**
- **Adverse effects**

Provider or System Factors

- **Fear that patient will not be able to use therapy**
- **Knowledge: medications, use of insulin, monitoring**
- **Skill: able to demonstrate proper use of devices**
- **Inadequate educational support**
- **Inadequate follow-up resources**

Adapted from Odegard and Capoccia (2007)

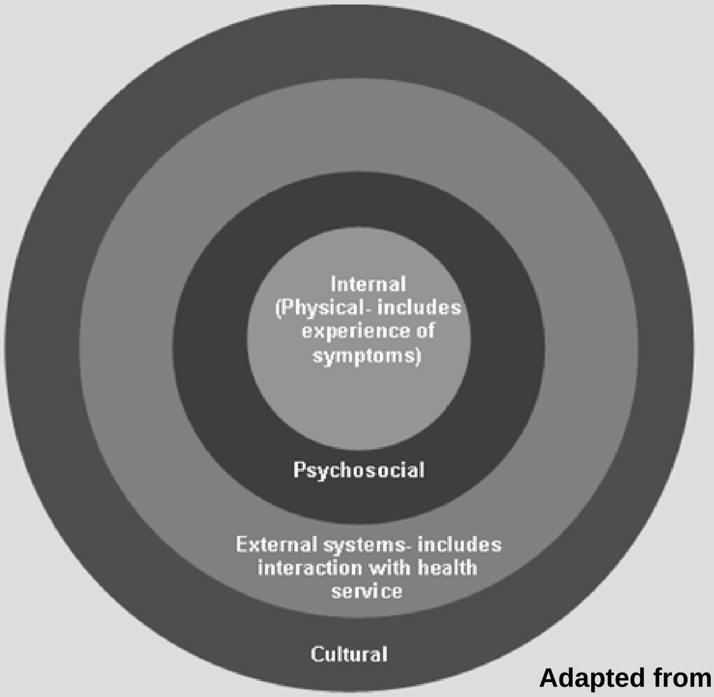
A survey of people with diabetes (n=446) by Vijan et al (2004), which focussed on factors contributing to compliance with dietary advice, included the following: difficulty reducing portion sizes; level of family support; confusion over what to eat; food-related emotional issues; perceptions of food as a dichotomy (ie, good food and bad food); difficulty during holidays and special occasions; too rigid a schedule; communication with health professionals; food cravings; and compensating for real or perceived hypoglycaemia.

A systematic review of psychological factors in diabetes self-care, by Fisher et al (2007), identified multiple issues that included general psychological orientations and specific psychological problems. Problems associated with poor metabolic control included: external locus of control; delayed intellectual and emotional development; impulsive and avoidant coping styles, number of life events; depression; motivational issues; and specific problems such as eating disorders. It also identified family level factors – such as poor communication, low socioeconomic status, low financial resources, and family stress – that may compromise adherence. Factors associated with good metabolic control included: internal locus of control; rational and problem-focussed coping styles; support from friends; a positive orientation; and making use of past experience to guide self-care.

Socio-cultural factors have also been identified as being important. In a recent qualitative study (focus groups) of Bangladeshi people (plus religious leaders and health professionals), Grace et al (2008) reported that religious and cultural factors precluded the adoption of positive lifestyle behaviours to prevent diabetes. These factors were given greater weight by people over the knowledge that these behaviours were important for their health. Participants also identified structural factors, such as a lack of time and money, together with language and educational barriers. The authors point out, however, that the participants in the study were older first generation migrants and these perspectives were unlikely to be consistent with younger second and third generation members of the Bangladeshi community. Recognising diversity within groups is important, not only because care initiatives need to be flexible even within ethnic groups, but also because structural inequalities may also contribute to adherence to effective self-care behaviours. Such structural inequalities are independent of ethnicity and impact across a wide range of social discriminants, including, among others: low socio-economic status (as well as education); gender (obesity); and old age (Karter et al, 2000; Gulliford et al, 2003; and Smith 2007). However, in many BME populations the issues of cultural and social disadvantage are often compounded. Therefore, the dynamics of the inequity in self-care behaviour are likely to be complex. While some factors are intrinsic to the characteristics of the group (poor literacy or health belief) others are extrinsic (structural), such as the accessibility (affordability) of self-care support provided and the extent to which the self-care support reflects the needs of the group.

Therefore, strategies to support self-care need to address a wide range of factors both related to the individual and to their social context. Glasgow et al (2001), in another systematic review of the impact of psychosocial factors on self-care, suggested a multi-levelled model locating the different determinants of self-care performance (see Figure 3.3.2).

Figure 3.3.2 Psychosocial Factors and Self-care



Adapted from Glasgow et al (2001)

While any one intervention may not address all these factors, it is important to consider the potential impact these factors may have in the context of the self-care support provided. Glasgow et al (2001) advocated practical assessment and intervention with models that are flexible within variant socio-cultural environments.

Feedback mechanisms - feedback is important in helping patients and clinicians make informed decisions about self-care. However, as yet there would not seem to be a clearly effective model for providing feedback. Self-monitoring of blood glucose (SMBG) remains the most common mechanism and is vital in effective Type 1 care, although in Type 2 care the evidence seems to consistently show that universal SMBG is not associated with clinical benefit and is costly (Farmer et al, 2009). In the most recent trial Farmer et al (2009) found that even when patients were given additional training in interpreting and acting on results the findings remained equivocal, although the qualitative data suggests that for some patients SMBG may be motivating and enhance positive self-care behaviours.

There may be something in the way the feedback is organised visually and how the risk is contextualised within remedial self-care behavioural options or plans. Chapin et al reported 1% improvement in HbA1c compared to controls in using a graph that linked the patients' HbA1c trend with their daily SMBG values and specific health care behaviours. Interestingly, they adopted a shaded schema (light to dark grey) rather than a coloured model (green, amber and red) to illustrate the risk level, as the latter was deemed to be to fear invoking.

In a small RCT (n=52) with limited follow-up Allen et al (2008) reported a significant reduction in HbA1c and increases in physical activity, by showing patients with Type 2 diabetes Continuous Glucose Monitoring (CGM) readings to illustrate the effects (benefits) of exercise. Furthermore, Azar and Gabay (2009) reviewed the use of uploadable clinical data and found the effect stronger in Type 2 patients, suggesting that Type 2 patients may benefit from a different model of feedback.

Tele-care systems using personal digital assistant (PDA) type technologies are also being developed to give feedback. Sevik et al (2008) tested a PDA model alongside an empowerment-based structured education module. The patient interacts with the PDA by recording data on meals and activities, the PDA calculates calorific allowances by keeping a running tally and breakdown of dietary constituents (fat, carbohydrate and so on) and gives daily targets for different food elements to maintain a balance of energy intake from different food groups. The model is based on the principle of giving positive feedback.

There are other tele-care models that link feedback to patients’ care plans more directly. In their review of tele-interventions Verhoeven et al (2007) concluded that these technologies need to emphasise the interactive feedback components. In a model described by Grant et al (2006), patients can access a web portal to see their clinical data prior to consultations and set an agenda with the physician before the visit.

Peer and social interventions - A systematic review by van Dam et al (2005) examining a range of highly heterogeneous social interventions targeting Type 2 patients (group visits to physician; peer group and peer counsellor; internet peer support and internet personal coach; spouses, family and friends participating in education; and social support group sessions) reported some benefits for mental health and quality of life, but no clear metabolic or clinical benefit. A more specific peer role is that of the peer educator, a role akin to that of the expert patient model. Nettles and Belton (2009) provided an overview of the peer educator role and suggested its principle benefits were in mediating the cultural gap between the health system and the person. They recommended that peer educators need properly recognised training and that they might best be located within a diabetes service (although it is probably important that they remain native to the group rather than the professionals).

However, Funnell (2009) has cautioned against a rapid adoption of peer educators, suggesting that little is known about how peer educators mediate behaviour change and whether they result in sustained change. This point was reinforced by a recent UK-based RCT evaluating a peer adviser intervention, which showed improvements in patient knowledge but not in glycaemic control (Baksi et al, 2008 and Baksi, 2009).

The lead author of that study has called for a more in-depth exploration of how best to integrate, train and support peer educators and advocates (Baksi, 2009).

Socio-culturally adapted interventions - Two systematic reviews included in the scoping identified a very diverse range of interventions: tailored clinic appointments; culturally-adapted education; link workers; use of non-written materials, such as flashcards; medication reviews with bilingual workers; self-help groups; specialist professionals (dieticians, diabetes nurses, podiatrists and psychologists) providing tailored care; and tailored lifestyle interventions. The meta-analysis undertaken in the Hawthorne et al (2009) review suggested that the benefits of these interventions tended to diminish with time. The Khunti et al (2008) review reported high levels of heterogeneity in the interventions and study designs.

Only two studies reported close to a clinically significant improvement in glycaemic control (0.5% HbA1c). These interventions were a programme of structured education delivered by a link worker (using flashcards) and a culturally-specific model of educational support. However, follow-up was limited to six and three months respectively. Therefore, there is a need to identify both more effective interventions and more systematic evaluation strategies. The grey literature contained many examples of culturally-adapted interventions, including initiatives that involved lay educators and outreach workers, delivered diabetes in a specific way (ie, using traditional story telling), and addressed issues of particular relevance to that population (such as Ramadan and fasting).

Psychological interventions - A recent review by Peyrot and Rubin (2007) identified three main types of psychological intervention: behaviour change interventions; emotive support interventions; and treatments for specific psychological problems (such as depression). Reviews of psychological treatments in general (largely behavioural interventions) both Type 1 and Type 2 diabetes have only shown a limited benefit, however, many studies are of a poor quality (Winkley et al, 2006 and Ismail et al, 2004).

There has been a shift away from more general behavioural approaches towards specific interventions such as cognitive behavioural therapy (CBT) and motivational interviewing (MI) – although treatment fidelity is still variable. Martins and McNeil (2009) reviewed the motivational interviewing studies in diabetes (n=9 diabetes studies 4 T2DM and 5 T1DM) and found no evidence of sustained clinical benefit. In terms of CBT, again studies produce conflicting results (Weinger et al, 2002 and Snoek, 2008).

There have also been some initial small studies using group CBT that show some promise (Amsberg, 2008). One study suggested that a combination of interventions may be more powerful with MI and CBT in combination having a greater impact on glycaemic control in Type 1 diabetes than MI alone, although the CBT intervention was far more intensive than the MI at 12 sessions compared to four (Ismail et al, 2008).

Given the strong evidence that psychological issues have an influence on diabetes outcomes and self-care performance, it is important that further studies are conducted to identify optimal models for interventions targeting both psychological problems (morbidity) and self-care behaviours. In terms of organising psychological interventions the areas these questions should include are: how best to identify patients who need psychological intervention; group compared to individual delivery; who should deliver interventions (nurses or psychologists); and how can access to interventions be enhanced. Finding ways to enhance access to psychological care is a major challenge given the recent DUK report 'Minding the Gap' (2008) that highlights large national variations in the quality and range of psychological support available to people with diabetes.

The grey literature search did identify a national initiative to improve access to psychological therapies (IAPT). One project within this initiative focused on people with Type 1 diabetes and involved screening people for depression and anxiety. While response was low (20% n= 200) many respondents were directed towards the psychological care pathway within the project. The project also involved training health professionals to better recognise common psychological problems and their management within the project pathway. No data were provided on the outcome of treatment or its impact on diabetes care outcomes.

Educational tools - The review identified some examples of the development and use of novel educational tools to support self-care. These tools were designed to encourage greater participation in learning or compensate for problems with health literacy and included: the use of visual aids (maps and games) and multi-media models, such as audio and video tapes (Garret et al, 2005 and Sturt et al, 2008). However, no specific data on the benefits of these tools were found. Simulators have also been developed to help patients and their carers experiment with glucose management to gain skills in understanding how their insulin, diet and activity interact (Nordfelt et al, 2007; Hedbrant et al, 2007; and Lehmann, 2006). One novel initiative used a diabetes Tamagotchi as a simulator (Loke et al, 2001). Again there are no data that show whether these approaches benefit patients.

3.1.2 Care organisation and delivery

Chronic Care Model - The Chronic Care Model (CCM) is a whole systems model developed in North America to address the complexities of chronic disease management (CDM) and reduce health care (insurance) costs. The CCM has been very influential in shaping the organisation of diabetes care. The CCM is a multi-component model comprising: clinical information systems (registries, reminders and performance feedback), practice redesign (developing different models of care delivery such as case management), decision support (practice guidelines and professional education), and self-management support (patient education and training patients in goal-setting and how to get the best from their care) (Bodenheimer et al, 2002). The model is essentially a whole systems design, which aims to ensure an evolving care provision that is responsive to patients and maximises the impact of the available resources.

The register, recall and review elements are now fairly standard practice in CDM and provide an important platform for examining overall care delivery, particularly in primary care. Si and Bailie (2008) undertook a systematic review of the chronic care model and overall they reported clinically important benefits on glycaemic (average reduction of 0.5% HbA1c compared to controls) and metabolic control. Models that included system design (team functioning, patient care planning and follow-up, co-ordination between primary care and specialist services) and/or a self-care support element showed the strongest benefit. One recent national initiative that draws on this model is the Year of Care (see notes below).

Case management, disease management and care planning - There are a number of different interrelated (and increasingly integrated) models for managing and organising individualised care initiatives. Disease management models include: the identification of patient group; guidelines or performance standards for care; management of identified people; and information systems for tracking and monitoring. Case management models include: identification of eligible patients; assessment; development of an individual care plan; implementation of the care plan; and monitoring of outcomes. Disease management models tend to be used for patients with established mild to moderate disease as a means of secondary prevention, whereas case management models tend to be deployed for patients with more complex multifaceted problems or groups with identified poor control. A systematic review by Norris et al (2002) of both disease and case management found that both models had an overall clinically beneficial impact on glycaemic control (reductions of around 0.5% HbA1c). However, authors point out that the interventions were generally multifaceted and it was difficult to determine which components made a difference.

A recent national initiative, the Year of Care, integrates care planning with population level analysis, service development, commissioning and evaluation. This model involves more than care planning and draws on features of the CCM (described above) by embedding care planning in the context of local resources. The focus on local needs is aimed at addressing inequalities in care and ensuring a socio-culturally adapted approach. While there are no data yet on the overall impact of this model one of the pilot sites, Tower Hamlets, has reported a far greater level of participation in diabetes education, largely by tailoring the needs of that education to the local population. The model is essentially a whole systems approach with the needs assessment and evaluation of the embedded initiatives driving commissioning and service development. This model is a shift away from approaches that emphasise process level recording (annual checks) towards a model that shapes the resource available, enabling responses to self-care needs based on an agreed care plan.

Integration of care - Care integration is a multifaceted and multidimensional phenomenon. The CCM and many of the case management models described above are examples of care integration. Vertical integration is an organisational model that links many of these approaches together. Vertically-integrated models aim to improve efficiency of care delivery by recognising that patients with differing levels of severity or disease progression will need different approaches to their care. One of the most widely adopted, vertically integrated models is that of the US health provider Kaiser Permanente (Ham et al, 2004). The model proposes three vertically-integrated levels: Level 1, Self-care Support (70% to 80% of patients), which focuses on screening, education and patient empowerment; Level 2, Assisted Care (15% of patients), which focuses on high risk patients needing active disease management; and Level 3, Intensive (or case) Management (5% of patients), which focuses on patients with complex needs, often accompanied by multiple pathology. Health promotion is important at each level. Primary prevention and case finding are also important elements in vertically-integrated systems. The evidence for the impact of these integrated models is largely contained in the summaries already provided for the chronic care models and case management (Si and Bailie, 2008 and Norris et al, 2002) and generally suggests a small to modest improvement in glycaemic and metabolic control.

Two variations of the vertically-integrated model were identified in the grey literature, both with very similar characteristics. It is likely that one informed the development of the other as both are London initiatives (Gelding et al, 2005 and Health Care for London, 2009). In these models it was the care system that was organised in a vertically integrated model rather than the patient population, although, by default, the patient population is to some extent also organised vertically. In the first example patients in primary care were organised into three levels based on the competency of the general practice managing their care: level 1 – all patients with diabetes in the practice; level 2 – care for all patients with Type 2 on a diet or tablets; and level 3 – care for most uncomplicated patients, including insulin treated patients. The intermediate care team then plays a pivotal role in supporting level 1 practices to deliver general care and helping level 2 practices manage insulin therapy. The final level is the specialist diabetes care, which is responsible for: pregnant women; children and adolescents; patients with Type 1 diabetes; patients with renal, vascular or neuropathic complications; and patients with difficult glycaemic control. In the second example this model has been simplified into four tiers: 1) essential care; 2) enhanced essential care; 3) specialist care; and 4) hospital-based care. Tiers 1 and 2 are delivered in primary care, tier 3 in specialist care and tier 4 in secondary or tertiary centres.

In addition to vertical models there are also horizontal models of integration. In these models, services work together across the care population. One example of this type of integration, found in the grey literature, was the Single Point of Access (SPA) project developed in Brent. The SPA acted as an interface between primary and secondary care services. The SPA comprised: a single referral form for services, such as the dietician and patient education; a multidisciplinary rapid access clinic; and rapid tele-support.

Initiatives for specific socio-cultural populations - There is some linkage here with an early section on socio-cultural adaptations for education and self-care. The review identified a number of potential organisational developments: outreach work (working with communities); tailoring services to the needs of the population; the provision of communication support; encouraging community members to train as nurses and dieticians; developing structured education models that reflect needs of different populations; and developing peer educators' roles from within community. The evidence base for these developments is largely anecdotal (Parliamentary Best Practice Consensus Group, 2009). One UK RCT (cluster trials across 21 practices) reported only a slight improvement in BP compared to controls with an intervention designed to improve care to Asian populations in primary care, and comprised: GP, diabetes specialist nurse and culturally sympathetic link worker; four-hour session with practice nurse, supported by link workers and diabetes-specialist nurse; and a prescribing algorithm (Bellary et al, 2008).

The majority of interventions currently focus on minority ethnic groups with few addressing the needs of the socially disadvantaged or those with low health literacy more generally. In two systematic reviews of interventions to address health disparities in diabetes (Peek et al, 2007 and Glazier et al, 2006) the studies generally addressed minority ethnic groups and identified culturally-tailored interventions as the having the most impact.

A related area of activity is community-wide initiatives. These initiatives may not be diabetes specific, but they do contain features that either directly benefit people with diabetes or promote wider strategies to increase positive lifestyle behaviours that indirectly impact on diabetes. One such initiative is the Altogether Better project in Yorkshire and Humberside where £6.8 million is being invested to stimulate community-wide activities to enhance health and social well-being. One discrete component of this initiative is to support 'diabetes champions' – people from within the local population who can help improve local services by understanding the needs of people in the community. The diabetes community support worker initiative in Northumberland follows a similar model, in which a local person with diabetes facilitates community participation through support groups, organising open days and by providing a link with statutory services. The Health Trainers initiative also follows a similar model, although this is not a diabetes-specific programme. Another such initiative is Race for Health, which targets black and minority ethnic groups and involves outreach work to identify diabetes, general strategies to promote awareness of diabetes and access to care through social marketing initiatives (ie, through local radio and media). There are no data on how beneficial these models are in improving diabetes care or outcomes.

Informatics - Informatics (the flow of information to and from patients, professionals, carers and other services) has the potential to radically reshape diabetes care. Unfortunately informatic initiatives often seem dogged by high costs and technical difficulties. One of the biggest UK initiatives has been the Tayside project. This project is in fact more than an informatic project as it has whole-systems features too. The informatic systems provide a common information gateway for all members of the multi-disciplinary clinical team, enabling information to be shared to support patients. The information exchange increases communication between health care professionals and their patients. It provides information resources, including an online diabetes handbook that contains locally adopted protocols and evidence-based guidelines for the management of all aspects of diabetes. There is a built in clinical audit tool giving instant feedback to clinicians. The project also co-ordinates electronic eye screening, develops patient education and provides professional diabetes education. A retrospective audit of the project by Greene et al (2009) reported improved care processes, but a limited (if growing) impact on clinical outcomes. More complex processes required some system redesign before change was observed. Improvements were greater for Type 2 than Type 1 patients.

A national programme for the management of information to improve clinical care is being provided through the National Diabetes Information Service. This initiative aims to use data that are available to highlight short falls in care, spur service development and monitor clinical performance. There are a number of discrete projects within this umbrella initiative, including:

Diabetes E - a model that uses information as part of a quality assurance assessment identifying areas of strength and weakness within local primary care provision. An action plan, developed to address weaknesses and some qualitative data from the 70% of PCTs that have signed up to the service, suggests improved performance and increased motivation among health professionals.

Diabetes Health Intelligence (Yorkshire and Humber Public Health Observatory) - in addition to general prevalence monitoring they provide diabetes community health profiles. These profiles combine data on population characteristics, QOF performance and health care costs (eg, prescribing) to allow PCTs to identify their performance in relation to other areas and the efficiency of their care.

Therefore, there are some interesting developments in informatics both in relation to patient care and in terms of managing clinical performance. The impact of these developments on clinical care and on overall service efficiency and performance needs further study. The message from the Tayside initiative may be that improvements take time to bed in and that the introduction of these technologies should be iterative and undergo refinement to achieve maximum benefit.

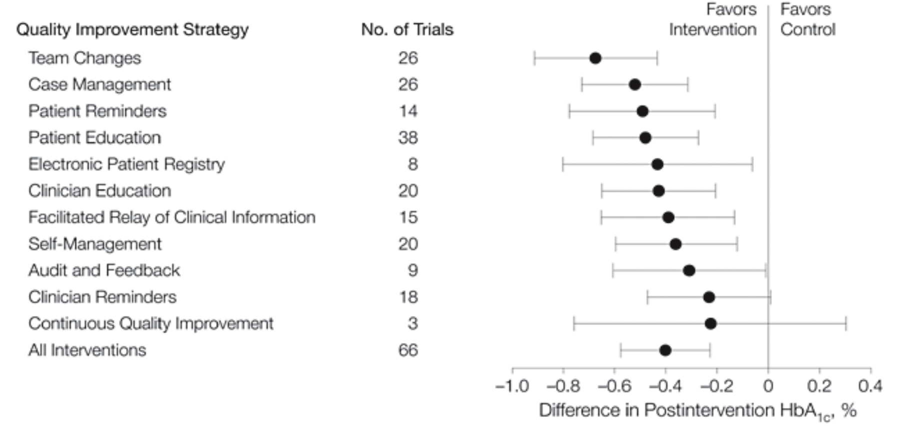
***Commissioning models* -** There were very few accounts of commissioning found in the literature review in addition to the already mentioned Year of Care model. The Health Care for London Diabetes Guide (2009) does make some particular recommendations for effective care planning:

- Systematic approach based on local diabetes data.
- Involve patients.
- Focus on patient centred care pathways.
- Identify strategies to address organisational boundaries.
- Focus on clinical and service performance.
- Introduce local commissioning networks with representation across primary and secondary care providers and service users.

This latter recommendation may be important in improving care integration between organisations. The guide also suggests that the local networks should have a governance role in ensuring that the commissioned services deliver care that is of a good quality and is effective. This model is similar to the 'diabetes without walls initiative' which is a collaboration between professional bodies, people with diabetes, commissioners and other stakeholders. The aim is to produce guidance to underpin the commissioning of fully integrated multidisciplinary diabetes care across primary, community and secondary care (DoH, 2010). One other initiative is the Commissioning for Quality and Innovation (CQUIN) project, which is not diabetes specific, but has been used in Doncaster PCT to change the commissioning model for diabetes. The model brings stakeholders together to agree quality indicators focussed on the needs of the local population and these indicators are then reviewed to inform future commissioning and remuneration. There are no data on the impact that different commissioning models have on diabetes care outcomes.

Finally, there has been one more general systematic review examining a range of different system level interventions (Shojania et al, 2006). The review incorporated a meta-analysis, which is summarised in Figure 3.3.3. The point estimate suggested a reduction in HbA1c of 0.4%, with stronger effects being observed for team changes (expanded role nurse/pharmacist or new MDT) and case management. While the findings of this review again highlight the complex heterogeneous nature of organisational interventions, it does suggest that there are some clinical benefits to be gained.

Figure 3.3.3 Meta-analysis of system interventions (mainly non-



***Shojania, K. G. et al. JAMA 2006;296:427-440*.**

3.2 Participative Conference

There were 38 participants in the conference (29 Type 2, 5 Type 1 and 3 carers). The mean age was 59 years (SD14) with a range of 22 to 78 years. There were 21 white British, 14 Asian and 2 black British participants (see table 3.2.1). The key findings of the conference are presented below following the structure of the questions posed to the participants (a full account of the conference is presented in Appendix 5).

Table 3.2.1 Conference participants

Type of diabetes	***n=***	***%***
Type 2 diabetes	29	78
Type 1 diabetes	5	13
Carer/friend/relative	3	9
Age (mean and SD)	59	(SD14)
Ethnicity	***n=***	***%***
White British	21	57
Asian	14	38
Black British	2	5

3.2.1 Factors important in the organisation of care

Patients were asked to discuss the following: what they liked and disliked about the way their care was organised; the place of care; access to care; and the organisation of informational support and patient support. In terms of likes and dislikes, participants privileged the quality of relationships with health professionals and information. When asked where they prefer to receive their care there was a common desire for ease of access, but a degree of divergence over the physical detail. While the advantages of some form of ‘one-stop’ model were expressed, there was concern that this might lead to a breakdown in continuity if the same professionals were not always available. For these reasons many patients emphasised the importance of the care provided by their local GP and practice nurse.

In terms of accessing services, it was not only the ability to find care that was important, but the quality of that care. In relation to information support there was an emphasis on the need for diversity of provision, good quality input at diagnosis and the need for ongoing support. The involvement of people with diabetes delivering support to each other was also identified. When participants were asked more specifically about patient involvement they emphasised the need for more shared decision making. They felt that having more information about diabetes and the choices available to them would be empowering and help them feel more involved in their care. The participants identified the following factors as being important (see data extracts in Example 3.1):

Relational care

- The quality of the relationship they have with the health professional.
- The length of time professionals take to listen to and talk with the patient.
- Involvement of the patient in care, including choice.

Accessibility of care

- Access to health professionals who are familiar with their care.
- Ease of access to services (available locally).
- Rapid access when needs arise.
- Access to specialist services (podiatry and dietetics).
- Diversity of provision to enable choice and preference.

Example 3.1 Selected Data Excerpts Regarding Care Organisation

Likes and dislikes

- ***“One thing I like about my care is I am able to contact my nurse at hospital any time if I need to and she is the only one who provides useful information such as monitors and dietary questions.”***
- ***“Lack of access to particular information, ie, diet and general effect on well-being.”***

Place of care

- ***“All under one roof and more likely to have up-to-date information.”***
- ***“See the same person who knows your medical history.”***
- ***“I prefer to go to the hospital as lots of GP practices are out of date and don’t give you enough information.”***
- ***“[I prefer] the GP as it is very close.”***

Accessing care

- ***“I would like more time from my GP and DSN – time to listen to them and also time for them to listen to me.”..***
- ***“Access to podiatrists – can’t get an appointment.”***
- ***“Getting an appointment quickly when needed and being seen on time.”***

Information

- ***“When newly diagnosed you need to be given an overview – what is diabetes.”***
- ***“Information would be better given out in stages rather than absolutely everything at diagnosis and then nothing further.”***

Ongoing self-care support

- The need for regular review.
- The need for patients have choice over care and therapies.
- The need for a co-ordinated patient centred care plan that is transported between care settings.

Information resources

- The quality of the information provided.
- The accessibility and timeliness of the information provided.
- Good information at diagnosis.
- Continuous information beyond diagnosis and ongoing provision of information.

- Information should be provided via a variety of media (not just leaflets).

Care integration

- Consistency and continuity of support between health professionals.
- Integration between primary and specialist care.
- Integration in transition from child to adult care.

Patient-led care

- Patient support groups.
- Individual sessions with someone who has diabetes.
- A local advisory group with strong patient representation.

Culturally sensitive care

- Providing care that is sensitive to the needs of different ethnic and minority populations.

3.2.2 Important factors for self-care support

Patients were asked to discuss the current support they receive, what they think might enhance the current support provided and their views on tele-care support. Overall participants felt that support was either not available or inadequate, particular gaps were highlighted for minority groups and in the lack of care planning. In terms of educational support participants found it hard to comment as they were generally unaware of what was available and had not experienced it. There were concerns that professionals need up-to-date knowledge to provide effective and consistent support. Strong themes in the responses were the need for greater access and diversity in provision, although there was also a desire for a greater standardisation on the availability of care.

In terms of tele-care support, the pros were the opportunity to access resources easily and get more rapid feedback. The cons were that it might compromise privacy, may be difficult for people with visual disability and should not compromise personal contact. There was also interest in patient led initiatives such as patient forums. The participants identified the following factors as being important (see data extracts in Example 3.2):

Access to self-care provision

- Need for a clear and consistent national patient educational model that is available to all.
- The education that is available needs to be promoted.
- Specialist education with dietician.
- Access to technologies to support self-care (ie, test strips).

- Provision (specifically tele-care) needs to be adapted for people with disabilities.

Diversity of self-care provision

- Choice between group and individual models.
- Provision that reflects different groups within population, such as younger and older patients.
- Choices of basic to more advanced provision.
- Culturally-specific provision.
- Provision for family and carers.
- Provision available in a variety of media (included tele-care).

Quality of self-care provision

- Professionals need up-to-date knowledge and skills to deliver educational support consistently.

Organisation of self-care provision

- Need for stepped model with basic education leading to more advanced.
- Regular updates.

Telecare (e-health) key messages

- Methods to give control to patients over appointments.
- Rapid contact and feedback.
- Need to accommodate disability and cultural diversity.
- Need to develop and promote patient forums.
- Platform for electronic record (with patient access).

Example 3.2 Selected Data Excerpts Regarding Self-care Support

Current provision

- ***"You only get support if you go out and find it or ask for it."***
- ***"We are left to our own resources especially if English is not your first language."***
- ***"No one has been offered an individual care plan or discussed self-management"***

How support can be enhanced

- ***"Basic education is needed before a structured approach."***
- ***"I kept hearing about this 'DAFNE' but wasn't told anything more – I assumed t was the name of one of the nurses."***
- ***"The courses are not always suitable for all ages. For older people a one-to-one may be better."***
- ***"Different education programmes are needed for different cultures."***
- ***"Better information – internet, leaflets, telephone and appointments."***
- ***"Education courses, easy access to courses and refresher courses."***

Tele-care

- ***"E-correspondence quicker."***
- ***"Web- chat – video conference."***
- ***"Privacy is important."***
- ***"Access needs to be rapid and quality assured – not like NHS direct."***
- ***"Personal contact still important."***

3.3 E-survey

The e-survey generated 423 professional responses (see Table 3.3.1) and 495 patient responses (see Table 3.3.2). The majority of professional respondents were either dieticians or diabetes nurses. There was a wide regional dispersal of respondents, although there was a preponderance of respondents from the London region.

The patient respondents were predominantly Type 2 patients, although the proportion is lower than the expected disease distribution. The respondents were divided between those with a disease duration of less than five years and those greater than five years. Respondents were aged between 20 and 70 years old with the largest number being aged between 40 to 60 years (n=251, 61%). Out of the respondents, 98% were of white ethnicity (n= 471) with only eight Asian and four black respondents. In terms of the geographical dispersal, there was a good distribution of respondents across England with a small number from Scotland and Wales (see Chart 3.3.1).

Table 3.3.1 Survey Respondents – Professionals

Professionals	***n=***	***%***
Dietician	140	37.6
Diabetes nurse	119	32.0
Consultant diabetes doctor	27	7.3
Psychologist	15	4.0
Diabetes doctor	10	2.7
Podiatrist	9	2.4
GP	8	2.2
Practice nurse	7	1.9
Educator	7	1.9
Health services manager	5	1.3
Representative of a patient organisation	3	1
Scientist/researcher	2	0.5
Pharmacist	1	0.3
Psychiatrist	1	0.3
Other	18	5
Geographical Dispersal		
East Midlands	27	6.6
East England	34	8.3
London	90	21.8
North East	20	4.9
North West	47	11.4
South Central	15	3.6
South East Coast	33	8.0
South West	33	8.0
West Midlands	25	6.1
Yorkshire and The Humber	60	14.6
Other	28	6.8

Table 3.3.2 Survey Respondents – Patients

Type of diabetes	***n=***	***%***
Type 2 diabetes	283	59
Type 1 diabetes	155	31
Carer/friend/relative	42	9
Other	5	1
Duration of diabetes		
< 1 year	70	15
1 to 2 years	90	20
3 to 5 years	73	16
5 to 10 years	96	21
10 to 20 years	60	13
20 to 30 years	35	7
> 30 years	38	8

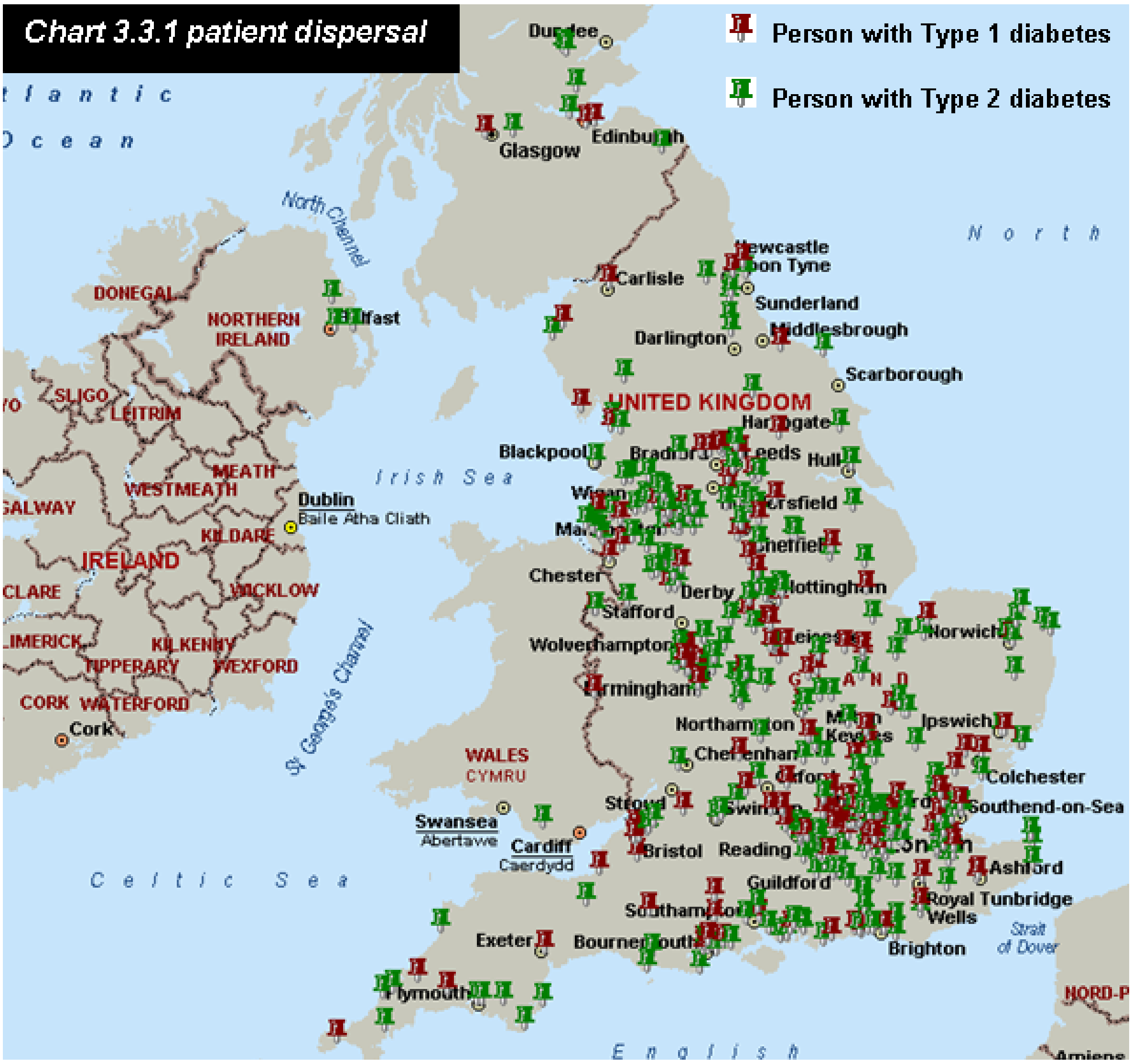


Chart 3.3.1 patient dispersal

3.3.1 Diabetes education

Patients and professionals were asked to give their opinions on the formal diabetes education available in their local areas. In terms of the overall rating as to how good diabetes education was, the responses indicated that professionals had a more positive view than patients (see Table 3.3.3). Professionals generally viewed the education provided as good to excellent or adequate to excellent for both Type 1 and Type 2, whereas the patients perceived the education as poor to adequate.

Table 3.3.3 Patient and Professional Diabetes Education

	Professional				***Patients***	
	Type 1		***Type 2***			
	n=	***%***	***n=***	***%***	***n=***	***%***
Excellent	61	20	52	17	61	13
Good	**127**	**41**	**116**	**37**	122	27
Adequate	64	21	74	24	**147**	**32**
Poor	52	17	53	17	127	28

A similar discrepancy emerged in relation to the availability of education. The majority of professionals stated that structured education was available to all or most Type 1 and Type 2 patients, 50% (n=156) and 52% (n=162) respectively. However, less than one-third of patient respondents (n=138, 29%) had been offered any formal education and even fewer, around one-quarter (n=119, 25%), had attended a formal education session. More encouragingly, the majority (n=84, 67%) of those that did attend found it beneficial. Furthermore, 60% (n=271) of patient respondents said that they had never or rarely been offered any ongoing educational support. This concurs with the professional report with less than one-fifth of professionals (n= 57, 18%) stating that booster or follow-up sessions were routinely provided in their area of care.

In terms of who provides education, the majority of patients identified the diabetes nurse (n=188, 42%), followed by Diabetes UK (n=52, 13%), practice nurse (n=42, 11%), diabetes doctor (n=40, 10%), GP (n=29, 7%) and dietician (n=9, 2%). The professional respondents reported that the formal education provided in their areas was based on a curriculum (n=255, 82%) and delivered by trained educators (n=252, 82%), although a smaller proportion reported that the clinical or patient impact of the education was assessed (n=193, 64%).

How could diabetes education be improved?

Patients and professionals were both asked the open question of what one thing would most improve the educational provision in their area. The patient responses are presented in Table 3.3.4. The responses are wide ranging with some reflecting the lack of educational provision, as detailed above, with a call for more education to be available. Greater access is also deemed important with more options so that people can choose educational models that suit them. There is also a suggestion that people with diabetes should be more involved in delivering education – the peer supporter role. As with the participative conference, there is a strong emphasis on the need for high quality up-to-date education provided by health professionals with the skills and knowledge to deliver it effectively and empathetically. Finally, there is the need for education to be continuous with a request for more follow-up booster sessions and more advanced courses for patients who have been through the baseline educational provision.

Table 3.3.4 How to Improve Education – Patients (n=344 responses)
Need More Education – Not Receiving Support
• Need to provide education. • Need promote courses so people know what is available. • Making clear to patients what the benefits are of the programme. • More structured courses (like DAFNE and DESMOND).
Quality, Access and Timeliness
• An individual point of contact (a guide to what is available). • More frequent contact and regular structured follow-up (booster) sessions. • Better availability of education (including a telephone and online support). • Education provided by someone with a high level of expertise. • Advanced provision in addition to basic education. • The need for personalised education (within individual care plan). • Consistency in the advice provided. • More up-to-date information following new developments (evidence-base).
Diversity in Provision
• Variety of media (written, audio-visual and online). • More choice over educational options.
Need to Improve Provision in Primary Care
• Better training for GPs and practice nurses in delivering education. • More education provided in local GP surgeries.
Sensitivity to Different Groups
• Age-specific education (younger people). • Education for family and carers.
More Training for Health Professionals
• Health professionals need to be more empathic and facilitative. • Better quality educators.
Peer Educators and Support
• Greater use of people with diabetes to support education. • Meeting with other people with diabetes to exchange ideas. • Young people with diabetes to meet in a more social and fun way.
Technology to Support Education
• Easier access to blood glucose testing.

The professional response is detailed in Table 3.3.5. In addition to extra resources there was an emphasis on improving the quality of the local provision by making the programmes more flexible to the needs of the local population. This included courses being available outside of normal working hours and held closer to where the patient is. Booster or follow-up sessions were also identified.

Table 3.3.5 How to improved education- professionals

More resources	**n =**
• Workforce (general) more:	28
➢ Qualified educators	19
➢ Nurses	5
➢ Dieticians	9
➢ Admin staff	11
• Resources for training	14
• Greater financial investment	16
• Facilities/venues	14
• IT resources	1
Quality of programmes	**n =**
1. Identified local gaps (currently no provision)	
• Provide type 1 education programme	6
• Provide type 2 education programme	4
• Provide paediatric education programme	2
• Provide more T2 education on insulin	2
• Reinstate courses that have been cut	1
2. Improve existing local programmes- access and equity	
• More flexible timing- evening/ weekend courses	19
• Increase number of courses/ reduce waiting time	18
• Better links with GPs to ensure they promote education & refer	16
• Booster/refresher/follow up sessions	13
• Location of education: community, closer to patients' homes	10
• Offer education as routine rather than requiring referral	8
• More choices of courses- not just groups, courses for those with particular needs	5
• More programmes in other languages, use of interpreters, health advocates	5
• Extend MDT (include psychiatry, psychology and podiatry)	5
• Extend T2 education programme (e.g. beyond newly diagnosed)	7
• Improve consistency of provision / audit / QA	4
• Extend T1 education programme	3
• Support groups/ peer support	2
• Community outreach to hard-to-reach groups	1
Policy, strategy, commissioning	
• Proper commissioning and investment in service (as opposed to short term)	14
• Education included in diabetes pathway	3
• Integrated service / co-ordination between hospitals for best use of resources	3
• Develop affordable programme to offer commissioners	1
Publicity, promotion of education programmes	
• Publicity, marketing, advertising to patients, the public	10
• Increasing HCPs' and commissioners' understanding of importance of education and what is available	9
Increase take up of education by patients	
• Give incentives to attend (financial, free lunch)	2
• Research into reasons for non-attendance	1

Table 3.3.6 Reasons People Do Not Attend Type 1 Education

	n=
People with work, family or education commitments.	34
Younger people.	24
Language and literacy problems.	21
Patients managed by GPs.	16
BME groups.	15
Lack of PCT funding or support.	13
People with disabilities.	13
Social or educational deprivation (travellers or asylum seekers).	9
Patient motivation.	8
People at a distance from education (rural communities).	6
Older or housebound people.	6
Financial constraints – time to attend cost of travel.	3
Diagnosed > five years.	2
People who dislike groups.	2

The health professional respondents were also asked to identify reasons why people may not attend structured group education. The responses are summarised in Tables 3.3.6 and 3.3.7 for Type 1 and Type 2 diabetes respectively.

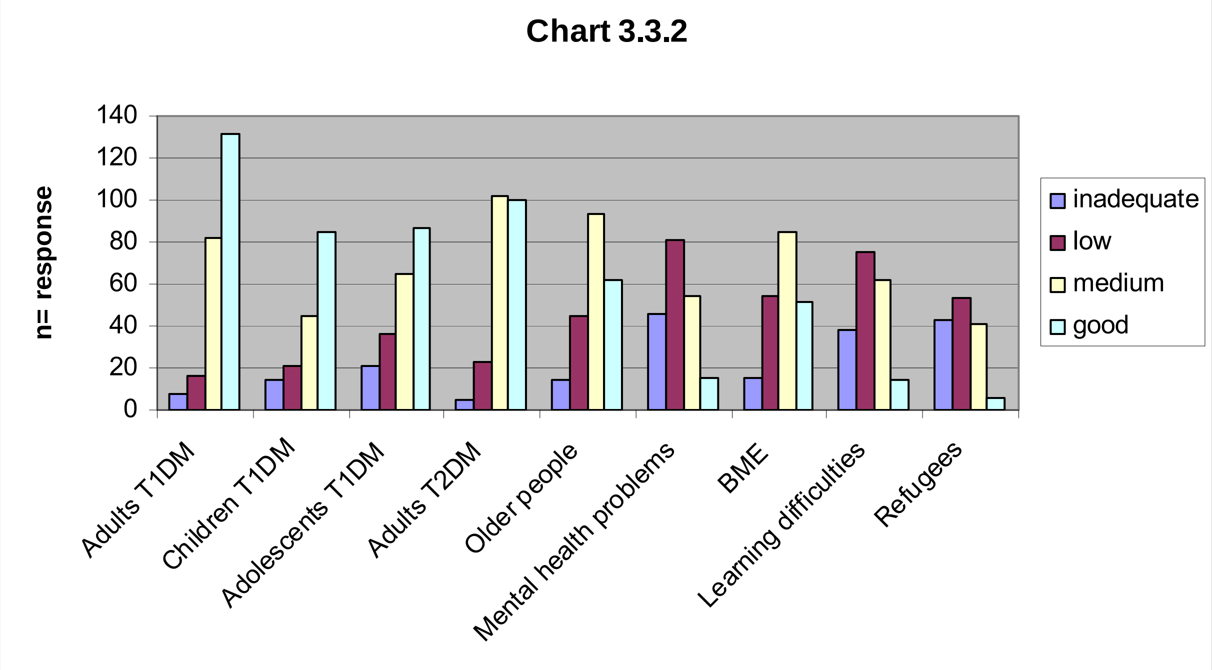
Table 3.3.7 Reasons People Do Not Attend Type 2 Education

	n=
Language or literacy problems.	27
People with work commitments.	26
BME groups.	23
Disabilities (mental, learning, sensory and physical).	17
Older or housebound people and those in institutional care.	15
People with established diabetes (as opposed to newly diagnosed).	11
Socio-economic deprivation.	10
Patient motivation.	10
Those who have difficulties with transport or travel to the venue.	9
Lack of referral from GPs.	9
Younger adults.	6
People who dislike or can't tolerate groups.	4
Lack of PCT funding.	4

3.3.1 Diabetes Self-care support

Patients and professionals were asked questions relating the availability and quality of self-care support in their local areas.

The professionals were asked to identify the overall quality of self-care provided to people with diabetes in relation to different groups (see Chart 3.3.2). The responses indicate that while the quality is viewed positively for adults with Type 1 diabetes, this perception diminishes for Type 2 patients. Self-care is deemed to be of significantly lower quality for people with mental health problems, learning difficulties and for refugees and transient populations.



The professionals were also asked to identify strategies that might improve the quality of care for these different groups of patients. These responses are summarised in categories by sub-group in Table 3.3.8. One of the underlying themes within these data is the need for more flexible and adaptable models of self-care. The suggested models emphasise the need for approaches that: are sensitive to variations, in terms of the populations needs; enable better access (up-take); and shift the focus of delivery to where the population is. There is also an emphasis for groups, such as those with mental health and learning difficulties, to do more cross-boundary working, increasing professionals' knowledge of physical care for those in mental health settings and vice versa for those in physical care settings.

In relation to the type of support for self-care the most common activities reported by the professional respondents were face-to-face and group sessions plus printed material (see Table 3.3.9). Tele-contacts such as e-mail and telephone are also quite common strategies. All these strategies were generally rated as moderately or very helpful, with group sessions being viewed as the most helpful followed by face-to-face, patient support groups, telephone and e-mail.

Table 3.3.8 How to Improve Self-care Support for Different Groups.
Adults (n=12)
• Specialist provision for hard to reach groups and communities. • Increased training to enable more patient-centred care. • More peer support.
Children T1 (n=15)

- Increase resources (staff with expertise) – DSNs specialising in children and adolescents.
- Bring care back to specialist setting.
- Set up structured education for families.
- Increase dieticians.
- Commissioning specific services.

Adolescents T1 (n=19)

- More staff in community.
- More resources – take services to patients and increase relevance.
- DSN for adolescents – providing support sessions specifically for this group.
- Different format of education for adolescents – holiday camps and fun weekends.
- Transitional interventions.
- Group work in settings chosen by the patients.

Older People (n=13)

- More staff.
- Develop and commission adequate programmes.
- Alternative education programmes tailored to needs of older people.
- Community nurses to be trained to deliver care to housebound and residential care patients.
- Community based DSNs and dieticians.
- Better links between primary and secondary care.
- Closer liaison residential and nursing homes.
- Education sessions for staff in residential and nursing homes.

BME (n=15)

- More appropriate resources – take service to patients.
- Commissioning of specific services.
- Engage community leaders in design of education programmes.
- More BME involvement.
- Training for HCPs in using interpreters.
- More accessible education in appropriate languages.
- Expert patients from same ethnicity.
- Education in local meeting places, such as place of worship.
- A liaison or link health care worker for ethnic groups.

Refugee/Transient (n=41)

- Resources that accommodate language and cultural variation.
- Increase skills of HCPs in managing refugee populations.
- Access to pool of trainers or specialist support workers (with languages).
- Delivering services in the community-flexible mobile clinics.
- Culturally sensitive patient education programmes.
- Joint working with other agencies.
- Better knowledge of needs of refugee populations.

MH Problems (n=44)

- Diabetes training and education for carers and HCPs who work with this population.
- Increase psychologist and psychotherapist input.
- Specialist diabetes HCPs with MH training.
- More appropriate education delivered in a variety of settings (eg, day centres).
- More joint working and greater integration between MH and diabetes services.
- Commissioning integrated services and programmes.
- Support teams to identify and meet local needs.
-

Learning Difficulties (n=36)

As for mental health plus:

- Dedicated specialist staff and suitable literature.
- Better training for HCPs in managing this population.
- Integrated care with learning disability teams.

Table 3.3.9 Types of Self-care Support Provided

		***n*=**
Face-to-face sessions	91.9%	227
Group sessions	86.2%	213
Printed material	86.2%	213
Telephone follow-up sessions	68.0%	168
Patient support groups	57.5%	142
E-mail interaction	49.4%	122
Interactive monitoring (eg, downloading BG)	41.3%	102
Audio-visual material	19.8%	49
Text messaging	16.2%	40
Interactive web area	5.7%	14

Patients were asked to identify if they had experienced a particular form of support, how helpful it was (Table 3.3.10). Overall, patients generally perceive all the different methods as helpful, although face-to-face stands out as the most positively rated. These data would suggest that patients are generally tolerant of a wide range of supportive strategies, although less than one-third of respondents had experience of them, with exceptions of face-to-face and printed material, which most had experienced. Text messaging was deemed unhelpful by over a third of respondents.

Table 3.3.10 Patient Assessment on Helpfulness of Self-care Support Methods

	Unhelpful		***Some help***		***Moderately***		***Very helpful***	
Face-to-face sessions	14	4%	54	15%	60	17%	**234**	**64%**
Group sessions	15	9%	44	26%	47	28%	**59**	**37%**
E-mail interaction	14	9%	38	24%	51	29%	**61**	**38%**
Telephone follow-up sessions	22	13%	25	15%	49	28%	**77**	**45%**
Text messaging	**45**	**37%**	38	31%	23	19%	15	12%
Interactive web area	18	13%	26	18%	38	27%	**60**	**42%**
Audio-visual material	13	9%	34	25%	**46**	**34%**	42	31%
Patient support groups	13	8%	35	23%	33	22%	**70**	**46%**
Printed material	15	6%	56	22%	84	33%	**98**	**49%**

In terms of patient involvement in care 30% (n=73) of professional respondents reported that care was rarely patient led and only 27% (n=64) of respondents reported that shared care planning occurred most of the time. The patient responses were that 35% (n=139) felt care decisions were made jointly with the health professional most of the time, with 27% (n=107) indicating that this was true some of the time and the remainder indicating that this rarely or never happened. Overall 65% (n=266) indicated that they were involved in their care most of the time.

How can self-care support be improved?

Professional respondents were asked to identify how the quality and capacity of self-care support could be improved in the face of increasing demand. The responses are detailed in Table 3.3.11.

Table 3.3.11 How to Improve the Quality and Capacity of Self-care Support

Quality

- Standardised education and self-care models.

"Standardised packages of care and improved access to ongoing, lifelong structured education."

- Quality assurance and peer review.

"National criteria for QA, minimum standards and standard curriculum."

- Better training and accreditation.

"Ensuring educators are accredited delivering a national recognised programme."

"Ensure competency-based training for people who are supporting those with diabetes."

- Care planning skills or goal setting.

"Work with patients to identify where they are on their journey with diabetes and prioritise goals through care planning, along with greater awareness of and access to education."

- Psychological support.

"All professionals working with diabetic patients should be aware of psychological issues regarding illness and treatment regimes. They should be able to address initial queries, provide basic psychological care and know when to pass on to someone with more specialist knowledge."

- More time in individual consultation.

"Forty-five minutes for a newly-diagnosed diabetic rather than 30 minutes to give time for assessment and advice giving."

- Incentive and reward scheme (performance management).

"Some sort of reward system."

Capacity

- Training more NHS staff.

"Training professionals in educational rather than medical model."

- Patient involvement and peer support.

"More lay tutors and training more expert patient groups."

- Telephone support and IT applications – e-health strategies.

"Support line, podcasts, hospital websites, interactive forums, visual information in clinic."

- National networks and awareness campaigns.

"Expand and integrate local networks."

- Organisational and system issues.

"Improve the efficiency of teams."

A national diabetes support line staffed by specialist nurses

Both patients and professionals were asked to comment on whether a national diabetes telephone support network should be set up.

The professional response was mixed with 31% (n=79) in favour, 21% (n=52) against and 48% (n=122) unsure. The pros that were identified included: useful additional resource if part of a wider support strategy (should not replace personal care by local team); patients having difficulty using local services would find it useful; provision should be immediate access to advice out of hours; increases patient choice; accurate up-to-date information and advice provided; take some pressure off local services; easy way to offer support to many people; and that it works – there is evidence of this from areas that have tried this type of service (plus the Novo and DUK examples).

The cons identified were: impersonal; no therapeutic relationship; loss of continuity; no access to patients' treatment information, history or test results, limiting the usefulness of advice; response limited to general enquiries and provision of basic advice and support; difficulty ensuring local follow-up; difficulty integrating centralised service with diversity of local services; risk of patients receiving contradictory advice; not appropriate for some groups (those with low health literacy or learning difficulties); no evidence service is beneficial; NHS Direct not well liked; local diabetes hotline not used; and not enough appropriately trained staff. Table 3.3.12 provides a summary of the key recommendations made by respondents if national tele-support were to be considered.

Table 3.3.12 Professional Recommendations for National Tele-support

- To be of high quality.
- Give advice consistent with that offered by local diabetes team.
- Available 24/7.
- Easily accessible.
- Given wide publicity.
- Knowledgeable about local pathways and provision.
- To arrange personal support if necessary.
- Safeguard confidentiality.
- Have robust protocols and guidelines.
- To be closely monitored.
- Feedback given to local care team.
- Provision of advice in languages other than English.
- Specialised support for children, adolescents and adults.
- Inclusion of e-mail and text options.

The patient response was more positive with 55% (n=231) in favour, 16% (n=69) against and 29% (n=123) unsure. The pros identified were: positive experience of Diabetes UK helpline, which some suggested should be NHS funded; it would be an improvement on NHS Direct's current provision; rapid access to advice 24/7 (many reported difficulty in accessing local service); being able to talk to someone for reassurance; being able to access a specialist; it would supplement (but not replace) existing services; it would be helpful for particular groups and problems (eg, newly-diagnosed patients); improvement of internet accessibility; help give advice during acute situations, like sickness; resolution of diet queries; provision of a more interactive resource (better than written material or internet); and could avoid unnecessary use of services.

The perceived cons were: people prefer face-to-face contact; difficult if language barrier or disability such as deafness; service already provided by Diabetes UK or local services; preference for a professional with knowledge of medical history; loss of continuity; expertise not guaranteed and advice potentially too general; would not be cost-effective; primary care should provide this type of support; and danger if co-morbidities present may put patient at risk. Table 3.3.13 provides a summary of the key recommendations made by patient respondents if a national tele-support were to be considered.

Table 3.3.13 Patient Recommendations for National tele-support
• Be aware of patients’ personal circumstances and medical history. • Be non-judgmental. • Be advertised effectively. • Be available most of the time or 24/7. • Be staffed by people who understand living with diabetes as well as having good clinical knowledge (including patient advisors). • No use of pre-recorded messages or script reading like the call centre model. • Be free of charge.

Finally, professionals were asked to identify any current novel or innovative practices they had introduced. Over 60 different examples were given and these are summarised with examples in Table 3.3.14. While many of these are examples of the current national initiatives identified from the grey literature (such as Year of Care) they would also seem to be examples of entrepreneurial activity in the development of self-care support systems.

Table 3.3.14 Innovative and Novel Self-care Practices
Year of Care Care planning training initiative (within Year of Care).
Co-creating Health The Health Foundation’s Co-Creating Health project is looking at Type 2 diabetes. The project has three arms to support: patient self-management education, clinican education (to support self-management) and service redesign.
Peer Support Not novel, but our education group participants have set up their own internet forum. We plan to initiate a social evening for all group participants and hope the group with continue this themselves (with some support if the group request it).
Lay Educators Peer advisor in diabetes programme. Patients undertake a 12-week intensive diabetes education course. Diabetologists, nurses, dieticians, podiatrists, and psychologists are all involved with educating the patients registered on the course. At the end of 12 weeks they undertake a written (MCQ) and oral exam. The successful candidates receive a certificate stating they are qualified peer advisors in diabetes (expert patient).
BME Groups Joint Working with Islamic scholars to provide advice for fasting during Ramadan – agreed healthy messages disseminated through the mosques by the scholars.
Young people Separate transitional clinics.We offer the three age bands an annual education clinic with a rolling programme of topics. Any families struggling with management or in need of additional education are always helped as appropriate.
Telephone Support Birmingham OwnHealth.
Introducing Recognised Education Programmes

DAFNE, which has also been used by people with Type 2 diabetes in the form of FIT, a form of DAFNE as taught by Prof Kinga Howorka in Vienna. Commissioning DESMOND (and DAFNE) on an industrial scale with excellent uptake. Planned introduction of patient-centred care planning using systematic approach.
Psychological Models Skills for life: psycho-educational programme for adult T1. I use mindfulness-based cognitive therapy (essentially teaching meditation in a group) with diabetic people.
EPP Expert patient programme.
Telemedicine Beginning to look at tele-medicine link.
Websites and Web Programmes We have developed a website to support care planning and group self-management education. DAFNE online.
Patient Information Patient and professional panel working on patient information leaflets through e-mail contact.
Refreshers and Boosters Living with diabetes group – helps patients to revisit insulin dose adjustment and refresh patients on their diabetes care.

3.3.2 Diabetes care organisation

Professionals and patients were asked questions relating to the quality of the care they provided/experienced and how care organisation could be improved.

Professional responses

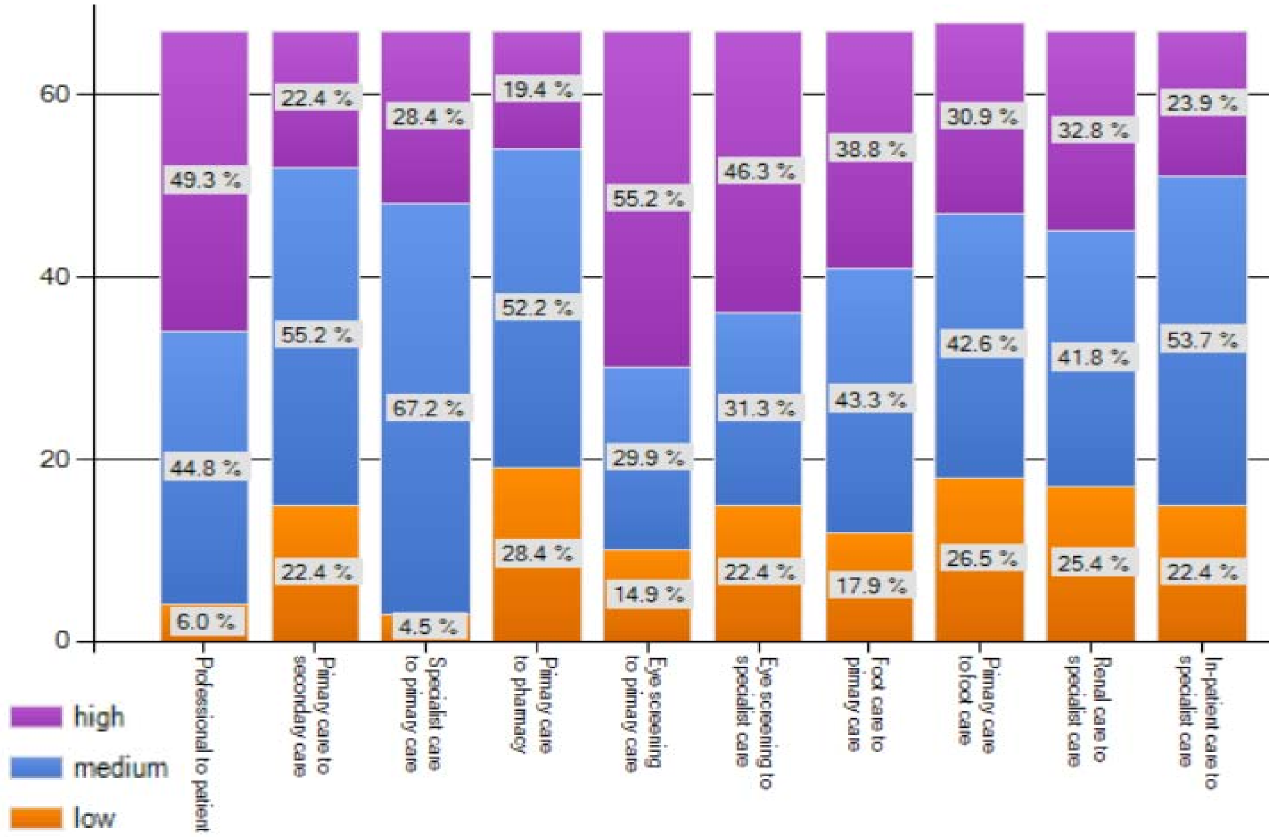
Professional views on care integration, 27% (n=59), reported a high level of integration between primary and secondary (specialist diabetes services), the majority though was a medium level of integration (53% n=117) with about one-fifth reporting a low level of integration (21% n=46). Key barriers to service integration included: poor communication; organisational weaknesses (poor leadership, financial conflicts of interest and poor quality commissioning); a general mistrust between primary and secondary care; a fragmented workforce; and a lack of integrated care models and pathways. The professionals also made suggestions as to how integration might improve with an emphasis on greater communication, integration of information and shared working, unifying working practices, and servicing of service goals, and even services, themselves (see Table 3.3.15).

Table 3.3.15 Professionals' Views on How to Improve Integration *(n = frequency)*

Communication	**103**
• Communication in general (often just 'communication' or 'good communication').	50
• Joint meetings and more personal contact.	35
• IT systems – "*linked computer systems with same software".*	8
• Information exchange/referrals/records – "*concise care plans*"; "*retinopathy screening is in primary care and we never get the results*".	10
Organisational Arrangements	**52**
• Joint working arrangements such as joint clinics and patient review.	12
• Roles that cross boundaries (DSN working across primary and secondary care).	21
• Diabetes networks.	8
• Co-location – *"being under the same roof".*	6
• Shared management/single team.	3
• Leadership.	2
Strategy/Model of Care	**21**
• Shared goals and objectives *"focused on the needs of the patient not meaningless targets and tick box remuneration".*	9
• Defined pathways *"with no bureaucratic barriers*".	5
• Shared guidelines and protocol development – common philosophy of patient care.	5
• Roles well defined and clarity.	2
Staff Education/Knowledge	**20**
• Better education and training, understanding of roles and services.	20
Commissioning/Funding	**18**
• Services for diabetes should be commissioned as one service across acute and community.	18
Attitudes/Relationships	**12**
• Includes trust, respect and willingness to work together.	12

In relation to the integration of information (see Chart 3.3) areas of strength seem to be patient/professional, and eye screening and foot care – although the pattern was somewhat dichotomous in relation to some areas, including eye screening with around one-quarter of respondents feeling the level of integration was low. It is also noteworthy that less than one-quarter of respondents rated the integration of information between primary and secondary care as high. There was also a high level of 'do not knows' (around two-thirds of respondents) to this item suggesting either a high degree of uncertainty about integration or a problem of item clarity.

Chart 3.3 Level of Information Integration



Participants were asked whether certain elements of care organisation were being incorporated into their areas (see Table 3.3.16). Respondents also gave examples and these are summarised below.

Table 3.3.16 Care Organisation – Professionals

	Yes		***No***		***Unsure***	
	n=		n=		n=	
Plans for integrating information?	105	48.6%	41	19.0%	70	32.4%
Is there an intermediate care team in your area?	86	39.6%	79	36.4%	52	24.0%
Are there any (diabetes) polyclinics in your area?	28	12.7%	132	59.7%	61	27.6%
Is there a diabetes network in your area?	137	62.6%	30	13.7%	52	23.7%
Is a regular diabetes care report produced in your area?	70	33.0%	55	25.9%	87	41.0%
Are inequalities examined or addressed in your area?	60	28.0%	36	16.8%	118	55.1%

1. Information integration - The two main vehicles for information integration identified by respondents were clinical networks and information technology. The clinical networks are involved in streamlining and integrating care pathways to ensure that there is common perspective on the patient's management that is in relation to the flow of information. However, there seems to be some frustration at the rate of development and level of impact that these networks are having.

"There has been discussion about common pathways etc and care plans, but after two years these seem to have stalled."

Information technology, particularly integrated IT systems, are being used in some areas. There a few mentions of the TPP SystmOne Diabetes module. This module enables the sharing of records, with the patient's consent, for 24-hour access to a continuous health care record.

"Diabetes Specialist Team pilot site for SystmOne (over 505 of local surgeries already using SystmOne) so should facilitate greater improvement in patient record-sharing."

Other systems included RIO and EMISWeb. There were also examples given of patient-held records, care plans and copying clinic letters to patients as a ways of integrating information to patient care.

"Letters copied to patients routinely; Desmond action plans; action planning – patients participate in putting it together and take a copy."

2. Intermediate care teams - Common functions identified for diabetes intermediate care teams were:

Providing patient care and education.

Managing complex patients.

Supporting GPs/primary care.

Providing education and training for health care staff.

'Troubleshooting' in the community.

Insulin initiation.

"We take referrals of complex patients and housebound from: secondary care; GPs; and retinal screening and podiatry. We help practices set up and run diabetes clinics. We provide structured education for patients. We provide education in diabetes to HCPs through telephone advice, courses and teaching sessions."

"Diabetes Centre. Providing a GPwSI service and DSN and diabetes dietician to people discharged from secondary care or for those with poorly controlled diabetes that the GPs are not sure how to deal with."

"There are two PCTs in our area. One has an up and running intermediate care service, which is DSN led with consultant supervision, providing an annual review and follow-up clinic and insulin initiation for patients referred from GPs. The other is getting a similar service off the ground."

The membership of intermediate care teams seems to be variable with DSNs being the most common members with dieticians, GPs with specialist interest in diabetes and diabetologists also being mentioned.

3. Polyclinics - This is clearly a more novel area of development with no additional information provided.

4. Diabetes network - Common functions identified for diabetes intermediate care teams were:

- Strategic direction, leadership.
- Policy development, setting priorities and ensuring equity.
- Leading service developments and redesign.
- Forum to link clinicians, provider trusts and commissioners.
- Performance review, quality monitoring and research.
- Development, implementation protocols, guidelines, standards and pathways.
- Co-ordination across services and integration between primary and secondary care.
- Clinical governance.
- Support for staff in diabetes service.
- Sharing good practice.
- Develop education for patients.

Diabetes networks have different emphases. The traditional role of the network has been for communicating and sharing information between services and professionals with some project work such as guideline development. However, networks are now being promoted as having a more direct role in clinical care (governance), with a remit to ensure care is delivered to a good standard.

"To monitor and direct the work of local groups commissioned across west Norfolk involved in improving the health of people at risk of and those with diabetes. Particular regard should be paid to equity, accessibility, quality of care and relevant objectives and milestones."

"The network is a focus for discussing the diabetes service in the PCT and some aspects of secondary care. It provides a forum where professionals from primary and secondary care come together with the commissioner."

5. Local report of diabetes care - The responses suggest that this is a very sporadic activity. Some areas seem to produce regular detailed reports of clinical issues and performance, whereas in other areas there may be some local audit.

"Biannual report of service provision and outcomes."

"Report of how our area is achieving the NSF standards."

"An annual audit is presented. A report of the service philosophy and how that is translated into care has just been presented by the lead diabetologist."

6. Addressing inequalities - There were very few open responses in relation to inequalities. Most responses simply indicated that addressing inequality was a routine part of PCT or service management.

"Ongoing continuous attempts made at improving ethnic minority uptake of services."

"Workstreams have been set up as task and finish groups to address care inequalities recently."

Some highlighted specific systematic approaches to reviewing equity, such as a health equity audit.

"Pacesetters project (Department of Health and PCT) to look at inequalities in accessing care."

Others implied non-systematic, ad hoc approaches, such as questionnaires, one-off reviews, or from frontline clinicians.

"Usually depends on them being flagged up by clinicians."

"Undertaken within diabetes teams, but not at macro level with all interested parties, which inhibits the care planning and progress pathways."

"Our team will address them if one of our clients is affected, but not sure if this happens in other areas."

Some responses (n=4) said inequalities were examined but not addressed. One respondent mentioned identifying poorly performing GP practices to give additional help to improve equality of access/service quality.

"A diabetes intervention team, is going in to the lowest 13 performing practices."

Patient responses

Most patients had their care delivered in primary care by their GP and practice nurses, with the remainder receiving care at a specialist centre or by a diabetes community team. Only 19% of respondents thought that the communication between the hospital team and their GP was good. Information provision was viewed more positively, with 40% indicating that information they wanted was available when they needed it, although for the majority information was only available some of the time (see table)

Table 3.3.17 patient response

Place of care	***n=***	***%***
GP-led care	248	69
Specialist diabetes centre	129	32
Diabetes community team	16	4
Communication between GP & Hospital		
Good	70	19
Adequate	160	43
Poor	139	38
Aware of local diabetes network		
Yes	105	25
No	314	75
Information needed is available		
Most of the time	157	40
Some of the time	214	58
None of the time	8	2

The patients completed the patient satisfaction questionnaire CSQ_8 (0 – no satisfaction, to 100 – extremely satisfied). The overall mean score was 54 (SD29) indicating a moderate level of satisfaction with their diabetes service. The response to the individual items (each relates to the diabetes service) is summarised in Table.

Table 3.3.18 Patient satisfaction with care-CSQ_8 items.

	Very satisfied		***Mainly satisfied***		***A bit dissatisfied***		***Very dissatisfied***	
	n=	***%***	***n=***	***%***	***n=***	***%***	***n=***	***%***
Quality of service	69	17	128	30	136	33	82	20
The service they wanted	65	16	156	37	117	28	77	19
Service met their needs	51	12	181	44	142	35	38	9
The amount of help	70	17	142	34	117	28	84	20
Overall satisfaction	78	19	142	35	120	29	71	17
	Definitely		***Generally***		***Not really***		***Not at all***	
Recommend care to others	95	23	143	35	108	27	60	15
Helped with their problems	91	22	159	39	142	35	78	19
Desire to continue with current service	130	32	122	30	97	24	55	13

How can diabetes care be better organised?

The patient respondents identified the one thing they felt would most significantly improve the care they received. Their responses are summarised categorically below in Table 3.3.17 (see Appendix 6 for the full response set). The two reoccurring themes in responses were more frequent or regular contact with services and access to specialist care – and often the two were linked.

Table 3.3.19 Patient Views on How Care Could be Better Organised

More Contact With/Communication from Services

I would appreciate a diabetes service rather than annual visits to GPs' clinics.

More contact after you have reported a problem – no one comes back to find out if the problem has been resolved.

Access to Specialists

Access to trained diabetes specialists.

Better Access to Services/More Flexibility

Have specialised diabetes Type 2 centre provided until late.

More flexible appointment days and times at clinic – it only runs on a Wednesday afternoon.

Better Co-ordination of Care

Integrate eye checks into diabetes centre and give access to eye photos to diabetes doctors/nurses.

Better communication between the services.

Continuity of Care

I would like to have the same doctor each time I visit the diabetes clinic so that I would feel more comfortable and I would know them.

Consistency of Advice

Consistency – not as many different messages as "specialists" you see.

Single Point of Contact

Better access to information, peer support, one point of contact for accessing information.

More Personalised Care/Listening to me/Care Planning

More interest in me as a person with diabetes rather than another diabetic.

Recognition of the amount of work I have done to understand how the disease affects me so advice specifically tailored rather than general.

Empowering Patients

Being allowed to track my BGL would help me keep control of things. At the moment I feel it's the medics in control and not me, I'm not really included in the decision making.

Improve Care Quality/Staffing Levels

More DSNs so more clinics can be run.

Improve the quality of advice given to Type 2s – in particular regarding testing and carbohydrate management.

More Resources for Services

Funding for insulin pumps.

Change Professional Attitudes

Stop the old boys' network regarding pumps and the interpretation of NICE guidelines.

Peer Support

Need local self-help groups.

More support locally for Type 1 diabetics through a peer support group, but administered so it doesn't become a burden on those involved to make the arrangements. Access to good quality venue.

User Involvement in Services

More user involvement.

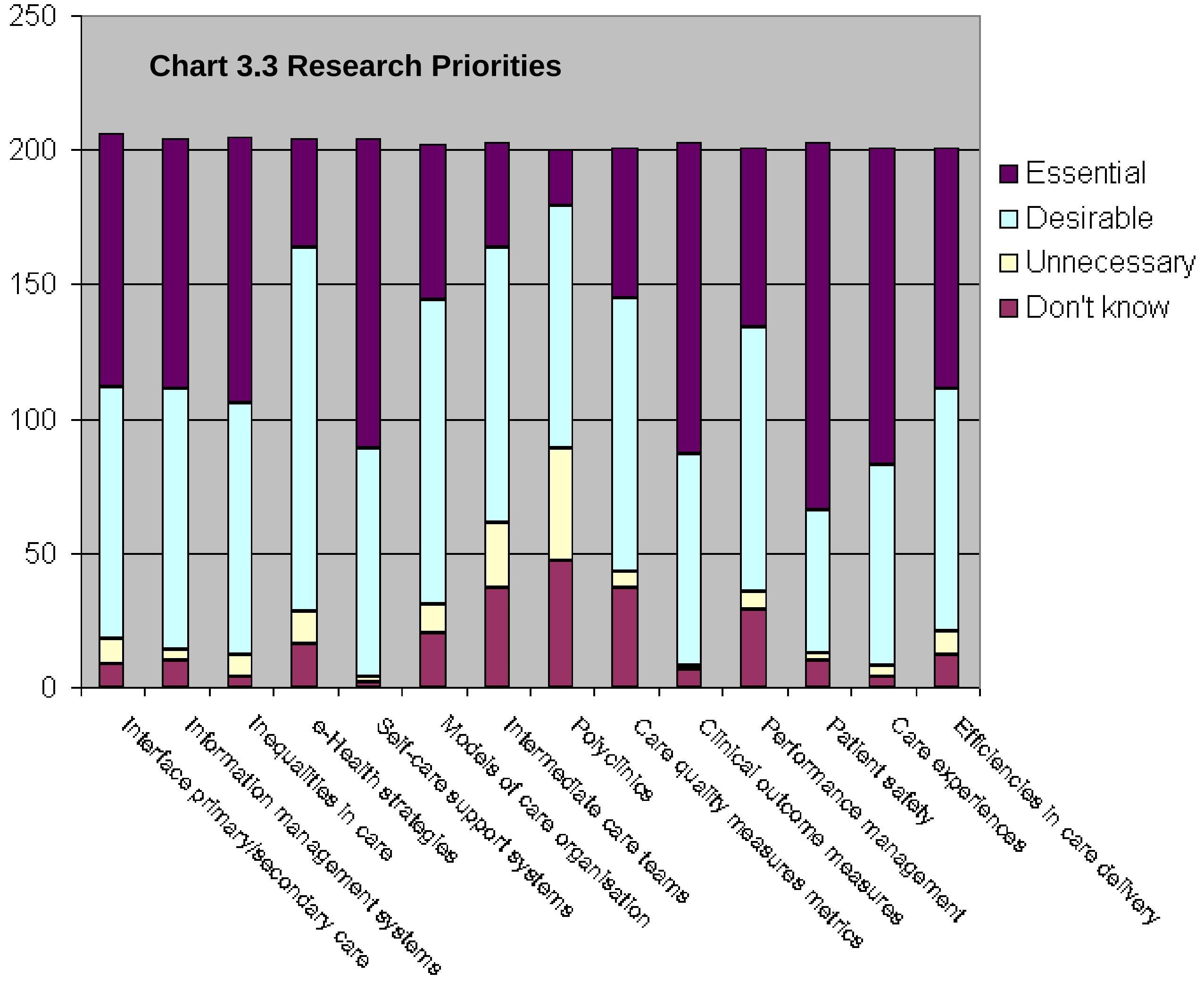
I should be asked what I would like.

Tele-health Support

I would love to be able to access my blood test online. I can access my results online for the renal clinic, but not diabetes.

3.3.3 Priorities for health services research

Professional respondents were asked to indicate priorities for future health services research. Overall 88% of respondents (n=190) regarded research into the way diabetes care is organised as being a high priority. All the pre-selected areas were rated as important, the highest ranked areas were: patient safety; the care experience; clinical outcome measures; self-care support systems; and inequalities in care (see Chart 3.3)



The open response question identifying research priorities was completed by 133 respondents, the response is summarised in Table 3.3.18.

Table 3.3.20 Diabetes Delivery and Organisation Questions, Themes and Examples
Patient's Perspectives and Experiences
What does the patient think? How can their care be improved? *Any that addresses patient need rather than what we would like as staff?* *Are patients satisfied with the diabetes care they are receiving?* *What are the issues (from patient perspective) that stop patients from accessing care?*
Self-care
Why do some patients not control their diabetes, why don't they take their meds? *How does the current model of care support self-management?* *Would a model of diabetes self-care, introduced at diagnosis, improve the patient's perception of the role of the diabetes health care professional and service delivery?*
Workforce, Professional Roles and Who Should Deliver Care
"Is the current intellectual resource in primary care sufficient to maintain and improve clinical outcomes in Type 2 diabetes."
Assessing Quality of Service Delivery
How are we doing and how can we do better? *Is care planning happening? (In the way it was intended.)* *After all the resources that have been poured into primary care, how far down the line are we for them managing a large proportion of non-complicated cases.*
Overcoming Current Organisational Problems
Ensuring integration between primary and secondary care. *Why does choose and book not work in diabetes care settings?* *How to get over the politics and get issues on the management agenda.* *Sharing of information.*
Prevention/Upstream Focus
How to deal with the 'pre diabetes' group to avoid or reduce chance DM developing. *Public perception of how dangerous or serious they believe their diabetes to be.*
Efficiency/Cost effectiveness
How can we make sure that money is spent on frontline health care professionals and not on managers or private companies set up to deliver diabetes care. *How to deliver an ever bigger service within limited resources.*
Models of Care, or Elements of Models
Are outcome measures better with integrated care compared to the present care in silos? *What will benefit the majority of patients and how it can be implemented?* *What is the optimal frequency of review for structured education?*
Accessibility
Is the right education accessible to all? *How can we be more accessible and patient friendly.*
Broader Measures of Quality and Outcomes
HbA1c is only the tip of the iceberg, focus should be individual quality of life. How well is it being done? Not only in terms of HbA1c and other biomed measures, but also in terms of patient experience and PROMs local performance and outcome measures as a one-size-fits-all national model not always appropriate.
Commissioning/Funding
What is the best way to organise (structure) and commission a range of services for people with diabetes in a given area?
Tackling Inequalities
How do we engage with patients with poor health literacy? *How do we address inequalities?*
Psychological Care
"Need for research into quality and benefit of psychological care for patients."

3.4 Diabetes Care Organisation and Delivery – Synthesis

The synthesis brings together the three data sets to identify the main priorities and issues for research into the organisation and delivery of diabetes care. The synthesis is divided into three sections:

- Patient education.
- Self-care support.
- Care organisation and delivery.

The input from the confirmatory conference is also presented, together with recommendations for further inquiry.

3.4.1 Patient education

Organising patient education (key themes):

- **Structure versus flexibility -** The literature review identified a range of structured educational programmes. These programmes follow a set curriculum and in some cases are delivered to a quality assured standard. The advantage of this model (particularly in Type 1 diabetes) is that it has a proven level of effectiveness. The disadvantage (particularly expressed in data from the e-survey) is that such models may only focus on specific sets of topics and are delivered in a way that may not suit all patients. Patients seem to want more choice and diversity in the education that is provided with more flexible models of delivery. Flexibility is also an internal dynamic with some programmes being more patient led in terms of content. The question here may be that more internally structured programmes (with a set curriculum) are better at impacting on a specific self-care practice, while more flexible models are better at impacting on more general areas of adjustment or in care planning models where patients need to contextualise their learning to their needs.

- **Accessibility and appropriateness –** The uptake of educational programmes is determined by the availability of education and its perceived benefit to the patient. There is still a high level of variation in the amount of education that is available. The lack of education can vary from no education at all to failure to provide education suited to the needs of different groups of patients at different points in their journeys. For example, in some areas programmes for Type 2 patients are targeted at the newly diagnosed and not those with the established disease. There is also the assumption that one episode of structured education will have an enduring effect or indeed that the same model of education is suited to all, so provision may need to be organised along a pathway that reflects where the patient is in relation to their adjustment to diabetes and their self-care needs. The findings of the e-survey do suggest some improvement in the availability of education compared to those of the diabetes survey from the Healthcare Commission (2006), which reported that only 11% of respondents had participated in a course to help manage their diabetes.

Another important factor in determining uptake is the way education is provided or offered to patients. Recurrent issues in the survey, and in the participative conference, were related to the failure to provide education that suited different people's work and life arrangements. There may be a need to provide people with a greater degree of choice by diversifying the provision (eg, making education available at evenings and weekends or offering an online alternative). In some DESMOND programmes up-take can be as low as 15% and even in areas that do provide flexible delivery it may only reach 30%. Given the emphasis within current guidelines on expanding participation in structured education, there is a need to consider how these programmes can be made more acceptable (desirable) to patients. Indeed while there has been an emphasis on internal quality for programme delivery there is perhaps a need to examine the impact of these programmes on the target population rather than on those that participate. This problem may also have a distorting effect on the evidence base for these programmes as it was observed that the number of eligible patients not participating in studies was not insignificant: 33% (n=184) in DESMOND (Davies et al, 2009) and even as high as 82% in some trials (Sturt et al, 2008).

- **Linkage to care system -** This theme is related to the above theme as it addresses the need for education to be built into routine care rather than an appendage only available for those who happen to be referred. This suggests the need for more specific clinical guidance and for systems to ensure that frontline professionals are adequately aware of what is needed and where it can be provided – a care pathway for education. It may also be useful to consider whether patient education should be better integrated into diabetes registers, such that it will be easier to observe the level of patients' exposure to education both individually and at the population level.

- **Integration with clinical care -** A consistent finding in the literature is that educational interventions have the strongest effect when integrated with clinical care initiatives (ie, therapy manipulation). Hence it may be important when designing an educational programme to make explicit the connectivity between the education, the therapy and the clinical outcome. The DAFNE model is a good illustration of this as there is a strong connectivity between the focus of the education (the development of self-care

> skills for insulin adjustment) and the potential clinical effect (improved glycaemic control with minimal hypoglycaemia). Rutten (2005) suggested that education needs to be wholly integrated with therapy to have much effect. A current trial (the ADDITION study) may provide some insight into this idea (Echouffo-Tcheugui et al, 2009). Like the DESM0ND trial it is targeting new onset Type 2 patients (although in this study they are actively screened for). Those in the treatment arm will have their diabetes treatment optimised through guidelines and target-led multi-factorial treatment alongside their educational materials. Therefore, the combination of screening, early intervention and multiple therapies within a structured educational model may be the way forward for Type 2 diabetes.

However, there may be instances where the education is not focussed on a specific clinical target and may focus on other areas such as adjustment or self-efficacy, with more diffuse clinical outcomes. In either situation the logic of the effect should be modelled (see later notes on self-care outcomes). The issue of the relationship between the education and the area of outcome is also an issue for evidence summaries, such as systematic reviews and meta-analyses. Many of the systematic reviews identified in the scoping commented on the heterogeneity of the interventions and methods and yet proceeded to incorporate these studies to summarise effects. It may be helpful if such reviews modelled the effect pathway for the interventions to organise the interpretation of the observed effects.

Targeting groups with poorer control (or providing different programmes for different needs) - Another common theme was that stronger benefits for education were often observed when the participants started with poorer control. While this is in part artefact (there is greater scope for relative improvement in subjects with poor control), there may be a need to systematise the education such that it can be targeted at groups where the greatest benefit will be observed. To execute such a model it would again be necessary to integrate the educational initiative into the wider system of care. This would enable a more standardised and targeted approach to the identification of patients.

Targeted to different groups and communities (socio-culturally adapted interventions) - this theme was evident in all the data sources, it encompasses elements of both organisation and delivery. The literature revealed multiple models of culturally adapted care, largely focusing on black and minority ethnic (BME) groups. However, only a few have a shown a significant clinical impact. In the e-survey language, ethnicity and literacy problems were all highlighted as issues in education provision. Health literacy may be a key concept here in trying to develop educational models that can accommodate different levels of health literacy and increase it in different populations. Therefore, finding effective ways to organise diabetes education in a way that facilitates maximum benefit to different populations is an important area for development. There was a very good example of this in the grey literature where one of the pilot sites in the Year of Care project (Tower Hamlets), which has a large Bangladeshi population, demonstrated a significant increase in the uptake of education by better tailoring their education to the local population. Given the inherent variation between populations, developing specific educational models for each population may not necessarily be the way forward. What might be more beneficial is the development of a model (a process) to allow the identification of the needs of different populations, together with a range of tailoring strategies.

Delivering patient education (key themes):

- **Follow-up ongoing learning (at diagnosis and beyond) -** This was a strong theme in the patient participation event and e-survey. This seems to suggest that both professionals and patients recognise that education needs to be ongoing if its benefits are to be sustained. In addition the data from the literature review suggested that long-term programmes have a more sustained beneficial effect. However, there are no economic data on such programmes and no models of this type have yet been developed nationally.
- **Responsive to needs -** Patients in the participation event and the e-survey feel that educational programmes need to be more responsive to their needs. There are two components to this – firstly, timeliness (having education available when it is needed) and secondly, responsiveness (education that reflects what the patient needs and how it relates to their care plan). In relation to the latter component some patients felt that the current education was too basic and that they would prefer some more advanced sessions. In the Turin long-term follow-up model (Trento et al, 2004), where patients have sustained a benefit for five years of a 1.8% reduction in HbA1c, patients were given some choice over the content of the follow-up sessions once they had a foundational input.
- **Quality of delivery -** Patients perceive the benefit of the education they receive to be related to the quality of the person providing the education. They have suggested that professionals have better training in the delivery of education. The professional respondents concurred with this point of view and also called for an expansion of quality assured educational programmes to ensure an acceptable and consistent level of delivery. The evidence from the literature in Type 1 education shows that quality assured programmes seem to have an advantage in clinical benefit, although this could be a product of more intensive data monitoring (ie, more is known about the effect rather than it necessarily being more beneficial). The skill

of the educator may also moderate the fidelity and impact of the intervention. Skinner et al (2008) noted variations in the amount that the professional talked and changes in patient illness beliefs, finding that the less the educators talk, the more patients report change in illness beliefs. Hence developing training for diabetes professionals and examining different models of governance and quality assurance for diabetes education might enhance the delivery of patient education.

- **Length and frequency of sessions -** As with the issue of follow-up there are variations in the duration and intensity of programmes. The literature review gave conflicting accounts of how the amount of time dedicated to the education influenced the outcome. Reducing the amount of input in Type 1 diabetes reduced the impact of the education (BITES compared to DAFNE). In Type 2 diabetes, a pilot intervention of five sessions of two hours, plus follow-up at three months (Bastiaens et al, 2009), showed similar outcomes to DESMOND evaluation – which was based on two half-day sessions. Therefore, there must be a trade off at some point between the amount of education provided within the programme and its cost for benefit value (more may not necessarily achieve more). There is also the issue of providing sufficient flexibility. As previously highlighted attendance at formal programmes is quite low and it may be that some patients would find committing to longer programmes more problematic (particularly as participation is outwith statutory sick leave provision). Further inquiry into patient preferences might give some insight into how this problem can be overcome.
- **General diabetes education and topic centred education (weight loss and foot care) -** While most of the programmes identified in the literature review provided general education there were some examples of more topic-specific targeted initiatives. The value of these approaches is unproven, but it may be that specialist modules could be explored further on topics such as foot care or hypoglycaemia. There may also be some connectivity with wider non-diabetes-specific initiatives, such as obesity programmes.

Technology (key themes):

- **Empowerment (adult learning) psychological models -** Empowerment models of education have proliferated in recent years following the growing recognition of the importance of psychological factors (eg, motivation) and adult learning principles in enabling patients to adapt to life with diabetes. These models promote the inter-related concepts of self-efficacy and patient empowerment. Marks et al (2005), in a review of self-efficacy enhancing interventions, identified the following characteristics as being important: multi-levelled and based on adult learning (mutual inquiry, problem solving and negotiation); ongoing with the focus on long-term gain; building of patients' sense of mastery; provision of

> role models with successful coping and behaviours; giving positive feedback; involvement of family and significant others; and accurately reflecting and understanding patients' issues. The empowering element is the communication style, the mechanism through which the above characteristics are delivered, with the key principles being: acknowledge the expertise of the patient; avoid judgement and criticism; focus on the patient's agenda; use open questions; provide information in relation to identified need; and encourage expression of emotions (Rodgers, 2005). In a qualitative study exploring how patients (n=24) changed following an empowering educational intervention, Booker et al (2008) reported that being empowered increased patients' confidence (self-belief) and range of skills in being able to meet their self-care needs – and it changed their relationship with health professionals (more active engagement).

However, not all patients may necessarily want or benefit from education based on an empowerment model. In a study examining concordance among older patients with Type 2 diabetes, it was reported that some older people prefer to be told what to do rather than be involved in decision making. There is also evidence from qualitative studies that reasons people do not take their medicines have little to do with how well informed or supported they are by the health professional or health care system and more to do with a general resistance to pill taking (Pound et al, 2005). People respond differently to diabetes. In another qualitative study, following up 173 Type 2 patients over time, people who were either more compliant or active in managing their diabetes had better glycaemic control that those who were disheartened by their diabetes (Veg et al 2007). In a commentary on the DESMOND study Davies et al (2008) made the following observations: that patients enjoyed the groups despite an overall general antithesis to groups, and that, again, different groups of people with different levels of adjustment of diabetes may need different models of care. The qualitative study of DESMOND by Okleford et al (2008) identified four distinctive characteristics in participants that may impact on their responsiveness to the education:

- The resisters.
- Identity resisters, consequence accepters.
- Identity accepters.
- Consequence resisters and accepters.

Such factors would seem to emphasise the need to develop a front-end assessment that can help professionals and patients select the education and self-care strategies that would be most suited to them. These data also suggest that some patients may need a pre-educational intervention to ensure that their chances of benefiting from the programme are maximised.

In the study of Kinmouth et al (1998) we also learned that pursuing empowerment without adequately attending to clinical need can lead to a worsening of the patient's metabolic health. Therefore, when developing an educational programme it may be important to: consider the choices that are given to patients in relation to the style or format of the education; to consider and assess the underlying psychological orientation of the patient to identify a model of education that will work best for them; and ensure that the programme will connect the patient to effective clinical strategies (either self-care or professionally delivered) that will impact positively on the patient's metabolic health. Future studies need to address these issues in their design and extend the theoretical modelling of their programme prior to testing, as programmes are still being progressed to trial without adequate proof of concept.

- **Role of peer educators -** Peer educators are increasingly being used in chronic disease education. The data from the participatory conference and e-surveys suggest that patient-delivered education is something that patients would value. However, the literature review found that there is not any evidence of a beneficial clinical effect for peer educators, although they may improve psychological outcomes. Therefore, more knowledge regarding the benefits of using peer educators is required. Those benefits might relate to improving access to education and culturally sensitising education, rather than a direct clinical effect.

- **Educational tools (health literacy - visual aids, maps and games) -** There was not a great deal of information identified on the use of these alternative educational tools to help people explore issues and experiences relating to diabetes and setting care plans. However, the whole field of health literacy, including methods of assessment and development, might be important in diabetes education – particularly in hard to reach populations. Multimodal (media) presentation might be important. Wolf et al (2009), for example, have produced a Diabetes Literacy and Numeracy Education Toolkit that delivers multimodal presentation.

- **Tele-care strategies -** Technology, including the internet, has expanded the range of delivery strategies for diabetes education. Diabetes UK has, for example, developed a distance learning package called Living with Diabetes to supplement group education sessions. It gives patients a chance to focus on certain aspects of self-care. At the end the patients take an MCQ and the results are fed back to the professional, which enables them to identify strengths and weaknesses and provide additional supplemental education. Other tele-care strategies are addressed in the self-care support section.

Points from the consensus conference:

The key points raised in relation to education at the consensus conference are summarised below.

Was anything missed by scoping?

- The only omission identified by participants was data on cost-effectiveness. While some data on cost-effectiveness is available this reflects the general lack of information on cost-effectiveness.

What are the priorities for the organisation and delivery of patient education?

- Better referral processes.
- Reduce variation in provision nationally.
- Improve flexibility to target different groups with different needs.
- Improve integration with clinical care.
- Establish educational pathway with structured courses that are available throughout the patient journey.
- Link goal setting and behaviour change strategies into educational programmes.
- Individualise flexible programmes that offer choices.
- Improve access to patients (times and days, and so on).
- Incentivise participation.
- Appropriate marketing for target audience.
- Self-referral.
- Use of e-learning and IT enabling patients to get results and self-manage.

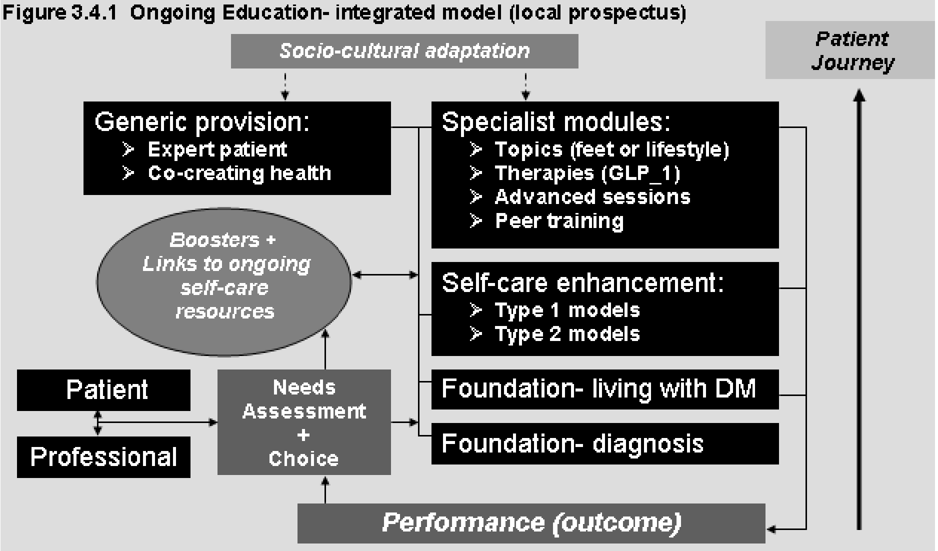
The majority of these points concur with those identified via the main scoping data sources.

Theoretical summary (models of care):

Having identified these themes for patient education, patterns emerge that enable some linkage of these constructs to form potential service models. The first model is illustrated in Figure 3.4.1. It describes a progressive approach to education commencing with a foundational module and followed by an ongoing curriculum of more targeted self-care enhancing modules. The foundational modules may attend to more general diabetes questions, such as: "what is it?", "how does it affect me?", and "what can I do?" The self-care enhancing modules will then provide education and training to target more specific elements of self-care. In Type 1 diabetes this would, for example, include carb counting and insulin adjustment. In

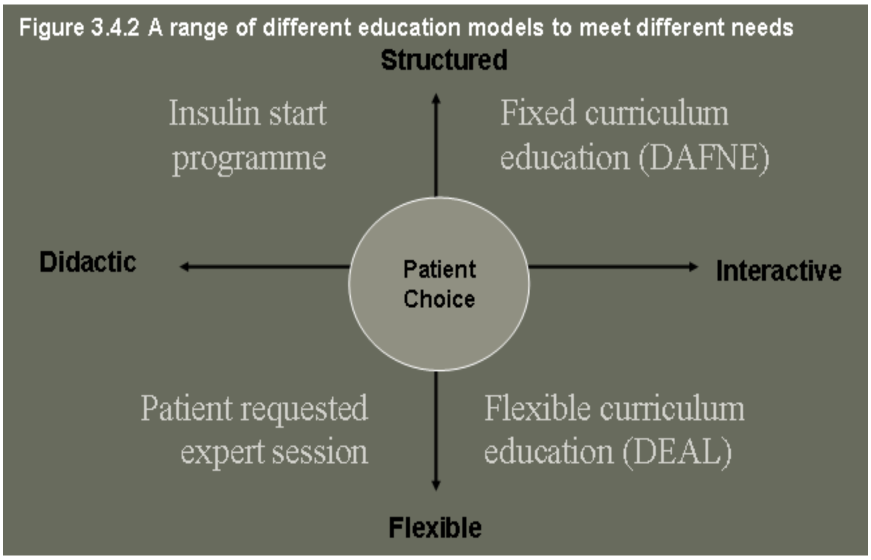
Type 2 diabetes the focus might be on developing an individual care plan that addresses lifestyle and the adoption of clinical care into their daily routine. The outcome foci for each level of education will be different. For the foundational programme, the focus will be on knowledge and adjustment; and in the self-care modules the focus will be on clinical targets. The patient journey arrow indicates that the programme should be ongoing with regular boosters and links to wider self-care resources.

Figure 3.4.1 Ongoing Education- integrated model (local prospectus)



The second model also highlights the need for choice and diversity in educational provision (see Figure 3.4.2). While currently there are a variety of different models available, it is unclear how these models are organised into to an overall programme of education. The model illustrates the variation in the curricula's degree of flexibility. More flexible curricula could be suited to general programmes that need to start from where the participants are in terms of their self-care needs. More structured curricula may be better suited to addressing specific self-care practices, ensuring that all participants of the programme reach an optimal level of self-care practice.

Figure 3.4.2 A range of different education models to meet different needs



There may also still be a place for more didactic models where patients request such a session or when specific skills or knowledge-based training is required. There is currently a bias in the evidence towards the novel and the new, particularly structured models and the use of an underpinning psychological mode of delivery. While comparisons to standard care models (routine clinic follow-up and traditional educational) are evident as comparators in the literature review, there is little detail available on the benefits of more traditional models. The assumption has been that traditional modes of education are generally unfit for purpose in modern diabetes care, however, this is an assumption that has yet to be fully tested. Patient choice may be central to understanding what types of educational resources need to be in place to support people with diabetes.

The final model relates to the need to make explicit how the education connects (integrates) with clinical care, self-care and the targeted diabetes outcomes (see Figure 3.4.3). This model is important as the data suggest that for education to have an optimal impact it needs to work in tandem with clinical care. The model distinguishes between the curriculum content (the desired learning outcomes) and the mode of delivery (the learning platform and methods of education). Choosing the mode of delivery will depend on the type of content being delivered and the desired outcomes of the programme. The model also highlights the psychological dimension of self-care – such that interventions seeking to manipulate self-care may incorporate a psychological component (underpinning theory and methods) to enhance delivery. However, the evidence to date suggests that while the psychological component may work to improve disorder adjustment and psychological well-being (desirable), in isolation of a strong platform of clinical care this may not result in better metabolic outcomes. In designing educational interventions the pathways for the different components to the target outcomes should be made explicit (see later notes on self-care outcomes). Testing these pathways may also be important at the pilot and proof of concept stages. The MRC complex evaluation framework may be helpful in guiding the methods for this (MRC, 2008).

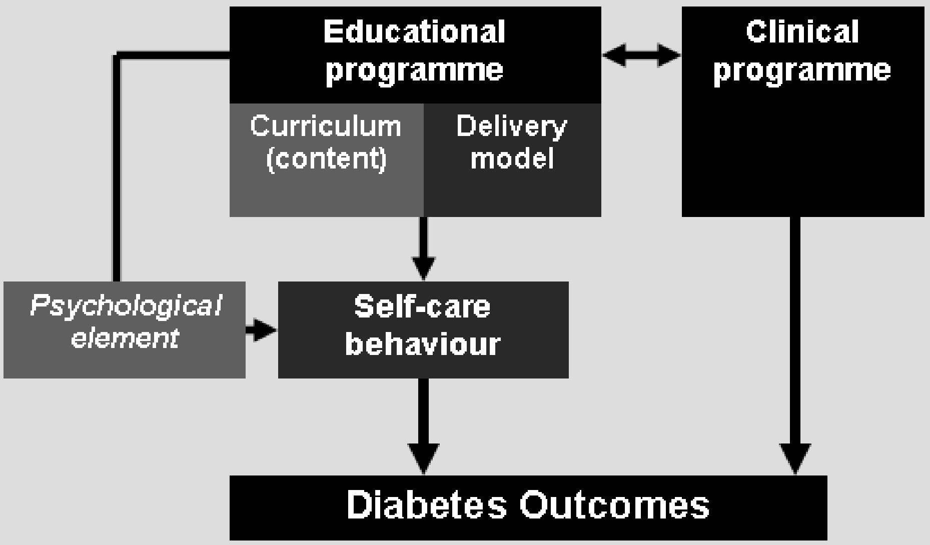


Figure 3.4.4 Integration between care system, self-care support and education.

3.4.2 Self-care support

Organising self-care support (key themes):

- **Access -** As with patient education a consistent theme across the data sets was the need to improve and extend access. The main concern from patients is in their ability to access high quality support when they need it. As with patient education patients also want more choice over the type of self-care support they can access. The patient experiences again suggest there are large variations in different areas and care settings across the level of self-care support.

- **Continuing ongoing support -** The regulation of support was identified by both professionals and patients as being important. The literature review identified no studies that have examined the optimal method for follow-up. However, as outlined in the education section, the studies that have showed the most sustained patient benefit have included regular follow-ups as part of the self-care support programme. There were some examples where the ongoing support included a review of personal targets, such that if patients did not achieve targets further advice or therapy adjustment was offered. Tele-care interventions have been used to deliver this type of support with varying levels of impact on clinical outcomes. Those that have the strongest benefit are those that target people who are not achieving their treatment aims with specialist professional support (Young et al, 2005).

- **Choice and diversity -** Being able to choose a model of self-care support was again a consistent theme expressed by patients. Choice may also encourage patients to engage more with their care. In a systematic review of self-care behaviour support Fisher et al (2007) highlighted one study of adolescents which showed that giving the adolescent a choice of multiple daily injections (MDI) or a continuous subcutaneous insulin infusion (CSII) was associated with improved adherence and control, compared to when they were simply allocated a therapy. Therefore, studying the impact of patient preference on adherence to care and clinical outcomes could be a useful area of inquiry.

- **Quality of care -** Participants in the patient conference and e-survey indicated variations in quality between groups of patients. There is a perception that self-care support is generally better for Type 1 patients than for Type 2 patients. The scoping review did not identify a reason for this perception, although it could be that Type 2 self-care support is more variable because it is delivered in primary care. The e-survey and conference data indicate that the most important determinant of quality seems to be the skill and knowledge of the health professional providing the support. Further, insight into what patients believe to be important in care quality is gained by considering their recommendations for the national helpline, which in addition to the expertise of the professional, included the need for a non-judgemental approach and continuity of information. The professionals also identified a number of ways to improve quality, including: greater training and accreditation of professionals; the introduction of standardised models that can be quality assured; and the use of an incentive model to drive up the standard of delivery.

- **Adaptation of support for different populations -** The review identified some examples of practices aimed at adapting self-care to meet the needs of different populations. In addition to the points identified in the education section, self-care support systems have to operate in often quite complex socio-cultural settings. Hence, more studies are required both to explore the nature of these inequalities in self-care support and how they might be more effectively addressed. Such studies need to think more widely than BME populations and should consider any groups where there are disadvantages in access to self-care support or where health outcomes are poor.

- **Workforce development -** Patient and professional participants in the scoping have suggested that health professionals need to be trained in delivering self-care support to improve the quality of that support. There are two different, but related dimensions required of that training: firstly, ensuring that the health professional has the appropriate knowledge and expertise to advise patients; and secondly, ensuring that the health professional has appropriate skills to communicate with and support patients in acquiring self-care skills. In relation to the latter this may include techniques in supporting behaviour change (eg, motivational interviewing) and skills in developing a shared care plan for the patient. However, without a clear evidence base for or clear models of self-care support delivery, the extent to which this can be realised may be limited. It may be better to first of all establish best practice models for self-care support and then train health professionals to deliver those models. Such an approach would be similar to that adopted by the DAFNE programme where the person delivering the programme is trained, accredited and quality assured. The Co-creating Health project is one current initiative that might help inform the development of training models for health professionals.

Delivering self-care support (key themes):

- **Tele-care -** Tele-care has become ubiquitous in chronic disease management with a rapidly expanding range of technologies (internet, telephone and text messaging) being promoted on the basis that they can: improve access; improve follow-up; increase interactivity; be more flexible (increasing patient choice); and help improve care efficiency, particularly in dealing with a large volume of patients (Piette, 2007). Tele-care is often integrated with wider e-health initiatives, including health informatics and computerised record systems. However, the materials identified in the scoping review suggest something of a mixed picture in relation to the application of tele-care in diabetes, the key issues being: the extent to which the model interfaces with the overall care system; how much the intervention enhances patient control (the danger is that patients will be monitored and managed by others rather than develop their own competence); whether they expand or limit care provision (eg, too hard to reach communities); the level of complexity with many interventions having a multi-modal delivery; the extent to which patient preferences are incorporated into the intervention; the extent to which the model of tele-care facilitates information flows; the use of the technology to allow patient networking; and the impact of the technology on the speed of decision making (optimising care more rapidly). A consistent message from patients both in the participation event and in the e-survey was that tele-care should be 'supplemental to rather a substitution for face-to-face care'.

In addition to these issues there are also limited data on the costs and benefits of tele-care interventions. The overall data suggest generally small effects on metabolic outcomes, although the studies are usually small and based on the application/technology rather than an explicit theoretical model of care delivery. In terms of costs some data suggest that programmes which are largely technology rather than person based are cheaper compared to normal care (Jansa et al, 2006); other data show that more intensive models with active care management have higher costs (Moreneo et al, 2009).

Involving patients in the development of these technologies would seem to be an essential element for any potential intervention. While tele-care models can be used to enhance patient control and decision making, there is a tendency with some interventions (particularly those where patient data are centrally managed) for professionals to take control. There may be a danger here in that one of the key lessons of the DCCT was that professional-centred measures increased risks such as hypoglycaemia. A recent pilot of a monitoring model, using a mobile phone to transmit blood glucose values so that professionals could direct the patient in bolus and correction doses, found very slight benefit (Rossi et al, 2009). The 'big brother' potential of these interventions may be an area that needs to be explored further with patients. In another pilot study patients had to transmit their BP readings two or more times per day (Logan et al, 2007). If the results deviated from the target they would receive a message such as: "Your BP is above your goal, did you take your medication?" While the study showed improved BP control, it is not clear whether patients found the level of intervention too intrusive. The literature review also showed there was a relatively high attrition rate with many interventions, again suggesting that patient choice is important.

Finally, it is important to note that some tele-care provision, particularly when provided over the internet, is not subject to quality assurance or governance procedures. A recent stock take of current online patient resources undertaken by Bull et al (2005) identified over 80 sites and examined them in terms of their interactivity, use of theory-based interventions, provision of social support and evidence-based care. They found that very few sites provided a sophisticated resource to support people with diabetes. Giménez-Pérez et al (2004) found similar results with most sites failing to communicate evidence-based care. Therefore, it may be useful to explore how people with diabetes use the internet to support their self-care practices and what resources they currently use.

- **Feedback mechanisms -** The literature review identified a number of different strategies for helping patients understand how well their diabetes was being managed. These models included feeding back data and risk assessment. Graffy et al (2009), in a recent review of reviews considering self-care support in diabetes, indicated that decision aids (communicating risk) can encourage action planning. Some of the more sophisticated models identified in the literature review integrated self-care performance with patient data collection and general glycaemic trends (HbA1c). The use of eye screening images has also been used to provide a more specific level of feedback. While these models show some promise there is a need to establish the impact of such models in different groups of patients. Therefore, research involving patients to help determine different models for giving feedback, which relates the information to self-care strategies, might be a useful way forward – connecting the feedback to effect and possible action.

- **Care planning models -** The literature review showed that care planning models have been beneficial in the context of wider programmes of case management. One potentially very important national initiative is the Year of Care project in which care planning is used to drive service development and inform commissioning, a model that follows many of the principles of the Chronic Care Model. However, the extent to which care planning is being used to support diabetes care is unclear. The methods or models being used to undertake care planning are also unclear. While the patient survey data suggested that the majority of patients felt involved in their care it was not clear whether this meant that they were engaged in planning their care or whether they had a care plan. A recommendation from the participatory conference was the need for care plans to be transferable between care settings. The professional respondents to the e-survey recommended better training for health professionals in care planning and goal setting with patients. Therefore, in developing models of care planning it may be useful to identify: how these are developed (content determination); how they are recorded (the physical manifestation of the plan); how they are communicated to patients, across care setting and between professionals; and how they impact on self-care and clinical outcomes. Clearly the patient perspective on the process of care planning is very important.

- **Patient led care -** Patient led care relates to the emphasis placed on allowing the patient to determine the direction of their care. While empowerment models are increasingly being adopted there is no strong evidence to show that such an approach improves metabolic health. The Graffy et al (2009) review of reviews indicated that empowerment models had little impact on self-care behaviours or clinical outcomes, but did: increase symptom resolution, emotional well-being and patient centeredness, and reduce anxiety. The patient survey and participatory conference data suggested that a large number of patients prefer this model of care, although as highlighted in the literature review not all patients want this type of care delivery. The e-survey also showed that while the majority of participants felt involved in care decision making there was still a large minority who did not feel involved in their care. One issue that may be important in determining the way patients are involved in their care is the preparation that both patients and professionals have for this style of consultation. The data from the Co-creating Health initiative might provide some insight into whether training health professionals and patients in a common framework for consultations enhances care delivery. However, even if such a connection is established this does not necessarily mean it will result in improved clinical outcomes. Therefore, further studies are required to help determine the relationship between consultation styles (patient involvement models) and clinical benefit. As highlighted previously, the extent to which the consultation model integrates with clinical care delivery may be important in mediating this relationship.

- **Patient-delivered care -** Patient-delivered care relates to the use of patients in a more formal capacity to deliver health care. Patients in the e-survey and participatory conference felt that expanding the role of peer support within the health care system would be beneficial. The data from the literature review, however, showed that peer educator roles have not shown a significant clinical benefit. This lack of effect may be due to the quality of the studies and the difficulty of assessing the impact of the role that is often used to target hard to reach populations. Therefore, it might be important to consider whether peer educators or patient advocates have a mediating role or a clinical role. If it is the former then the impact of the peer input would be on enhancing the care experience and sensitising delivery to the socio-cultural context, rather than on clinical outcomes. However, the role should ideally deliver on both these aspects. More study is required of how peer supporter and educators can be used to best effect in diabetes care delivery.

Technology (key themes):

- **Adherence -** While the literature review did not identify any adherence treatments with clear benefit, there was good amount of material on the reasons why people did not adhere. A complex range of factors were presented operating at the patient, professional, care delivery and socio-cultural levels. Therefore, there are a range of potential targets for interventions. Another area that may be worthy of examination is psychological assessment. Given that many of the factors that seem important to adherence are psychological in origin, developing a screening tool to identify any specific psychological problems (depression or cognitive impairment) or their general psychological orientation (locus of control, self-esteem, self-efficacy or health literacy) might help identify those who may need more support with adherence.

- **Psychological interventions -** Psychological interventions require further development if their potential is to be realised. As Graffy et al (2009) concluded in their review of reviews, psychological treatments such as MI and CBT and treating morbidity (depression) have only demonstrated a modest impact on metabolic control. There are two issues to consider: firstly, the need to develop interventions that have a good clinical effect (both in treating underlying psychological problems and on diabetes outcomes); and secondly, to develop delivery strategies that ensure they are accessible to all who would benefit. In terms of the latter there are many issues to consider, including: who delivers the intervention (nurses or psychologists); the training provided to the professionals delivering psychological interventions; and the location of services (primary and/or secondary care).

- Multi-component (complex) models interventions - A theme identified in the literature review was that many self-care interventions have multiple components. This complexity is inherent to providing more tailored programmes that work at multiple levels to give: knowledge and skills; enhance self-efficacy; and manage psychological problems. There is also the added complexity of the model of delivery: frequency of contact, type of contact and the use of different media. In addition there is a need to integrate care with clinical care and the need to tailor interventions to the individual. Further complexity is introduced when issues such as feedback and reward are considered as identifying the benefits of positive self-care to the patient (Knight, 2006). This complexity makes it difficult to determine the beneficial effects of different components of an intervention. Therefore, making clear and/or testing the underpinning theory for the intervention is crucial in developing these multi-component interventions – again the MRC (2008) complex evaluation framework provides a useful template for designing studies.

Points from the consensus conference:

Was anything missed by scoping?

- Psychological health outcomes (eg, anxiety and depression) and its relationship with readiness for self-care. We have a section below on outcome measures, including psychological measures.
- School children and diabetes support for educational staff. This area was not covered by the scoping.
- Co-morbidities, what about the other long-term conditions not just diabetes. This area is covered within vertically-integrated care models, but needs further consideration.
- Relevance of social support and ability to self-care. This area has been addressed in different elements of the scoping.

What are the priorities for the organisation and delivery of self-care support?

- Workforce development.
- Systems to make known what is available and how care can be accessed.
- Socio-culturally adapted care.
- Partnership relationship between patient and professional.
- Named health care professional for each patient.
- Longer clinical appointments, especially at diagnosis.
- Self-care support ongoing from diagnosis.
- Patient questionnaire before appointments to identify patient concerns.
- Patient led flexibility support.
- Assessment of care planning models – and not just diabetes.
- Group support so that joint learning can take place.
- Peer educators.
- Up-to-date information and refresher education.
- Time – length of appointments in relation to illness trajectory.
- Inform patients about the structure of their care, such as the timing and purpose of their visit.

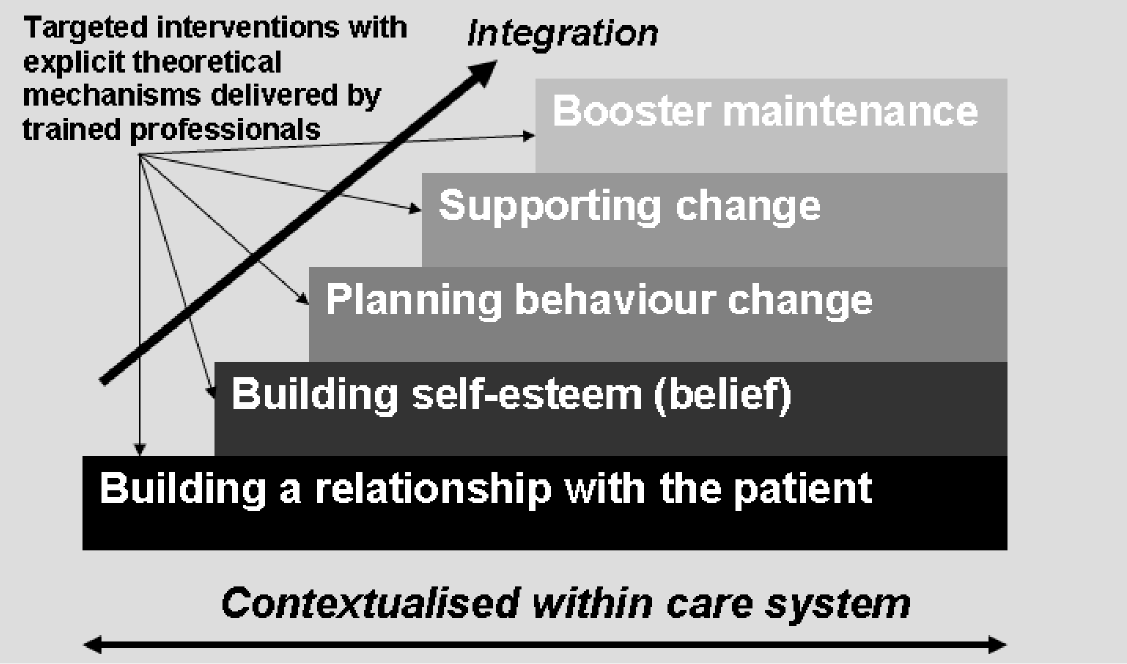
- Focus on self-management through all health professional training.
- E-learning opportunities on NHS website that allows response with advice.
- Consult with patient and families about what is needed.

Theoretical summary (models of care):

The collective materials suggest a number of potential models to inform future inquiry into the delivery of self-care support in diabetes. The first two models relate to the underpinning complexity of self-care and the steps required in making sustained behaviour change. The scoping materials suggest that the support people are given needs to be targeted to their needs. It has also been suggested that different people may be sensitive to different types of intervention and that choice may be a determinant of how effective an intervention is.

The first model emphasises the need for an ongoing model of care that is built into the care system and patient pathway (see Figure 3.4.5). The example given focuses on behaviour change, however, similar models could be constructed for knowledge and skills acquisition or other self-care activities.

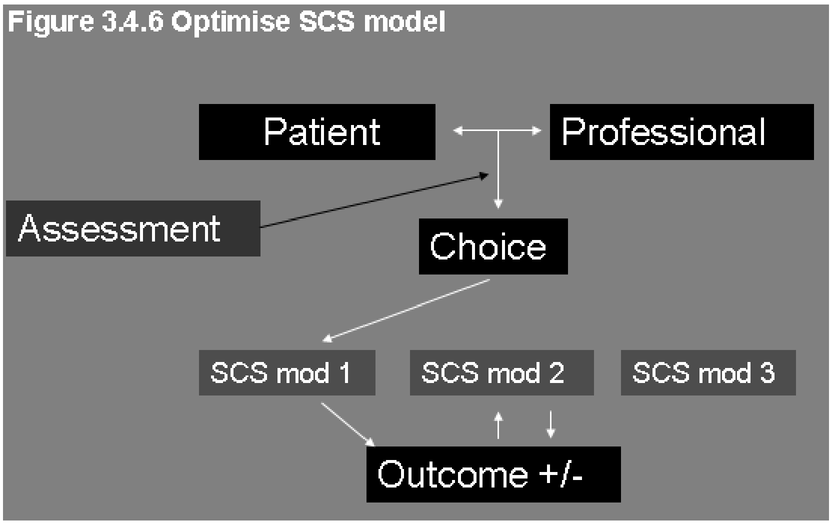
Figure 3.4.5 On-going self-care targeting and maintaining behaviour change



Patients may require different levels or types of intervention as they develop their self-care practice (see later notes on outcomes). At present while many interventions have multiple components it is not clear what their specific targets are. Multiple interventions could be part of a package or interactive programme of care with each intervention explicitly targeting a specific facet of self-care development. In the Co-creating Health programme, for example, there are tools to identify where a patient might be in terms of their self-care performance and techniques (interventions) in order to facilitate the development of self-care relative to where the patient is. Motivational interviewing follows a more sophisticated, but similar model. The first block identified in the model, 'building a relationship with the patient', reflects the patients' views that relational care is important; it is also a prerequisite for effective psychological care.

The second model focuses on tailoring interventions (see Figure 3.4.6). There are three interrelated elements to this model: assessment, choice and modulation to outcome. The first element might include psychological assessment (as detailed under the adherence theme) to help determine the patient's orientation to a particular model of self-care. The assessment could also be used to develop an individual patient care plan with details of the expected (realistic and negotiated) outcome. The second element involves the patient choosing a different self-care support strategy or strategies to help them meet their objectives (such as group education, e-mail or telephone follow-up, written advice or guidance and sessions of motivational interviewing).

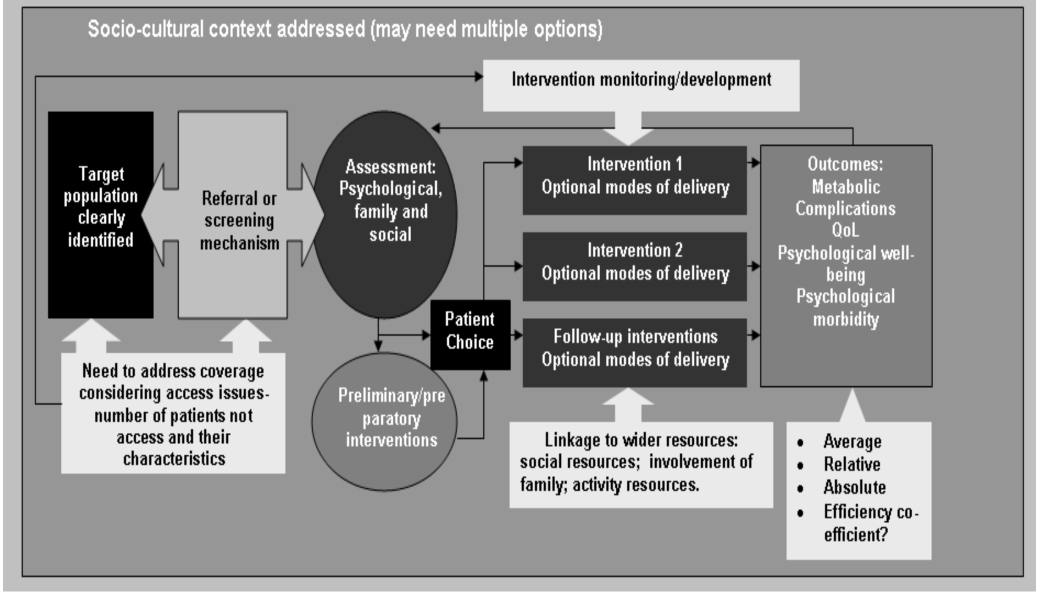
Figure 3.4.6 Optimise SCS model



Fisher and Glasgow (2007) have advocated that giving patients choice and control may be related to better engagement in care as well as ensuring more efficient care. In the third element the impact of the self-care strategy is reviewed on the objectives and then the patient is given further choices. The most important point with this model is that the care moves to the outcome rather than providing fixed care that may or may not deliver the outcome. A further consideration here would be that if the outcome is not achieved it suggests either a failure in the care system (so a different intervention may be required) or that the wrong outcome has been selected (reassessment required to identify underlying issues). The emphasis in this model is on care efficiency, such that patients do not continue to receive a model of care that is not delivering a benefit. It is stressed that these models are presented to give a conceptual perspective on self-care rather than, as suggested, clinical methods.

The third model is more complex and brings together some of the wider elements of self-care and education in diabetes. The model provides a framework against which to examine the current organisation and delivery of self-care support (see Figure 3.4.7). The model emphasises the need to define the target population such that it is possible to assess the overall utility and equity of the self-care programme. If the self-care intervention is only being utilised or accessed by a small proportion of the overall population this may mean that either the mechanisms for referral or the recruitment system have failed, or the intervention is unsuited to all in the target population. In examining the current organisation of self-care, the scoping project has tried to examine the extent to which populations are defined and how participation (or lack of it) is managed. Clearly some form of minimum coverage would be important in preventing inequalities, together with a function for adjusting interventions or mode of delivery to ensure greater inclusivity. Currently many of the programmes offered do not provide this assessment and the data from clinical trials suggest high levels of non-participation. The model also suggests that, given the multiple psychosocial factors impeding self-care, an assessment function within the delivery system may be important in identifying modifiable issues, such as depression or psychological perceptions that might impede the effect of the main self-care interventions (as highlighted in the previous models). The scope did not find any national programmes that manage patients’ eligibility or assess patients prior to entry – and most programmes were being delivered as a one-size-fits-all model. While some models such as the more flexible programmes may compensate for this internally, it could still mean that patients are exposed to programmes that may not be suited to their needs.

Figure 3.4.7 Model of self-care



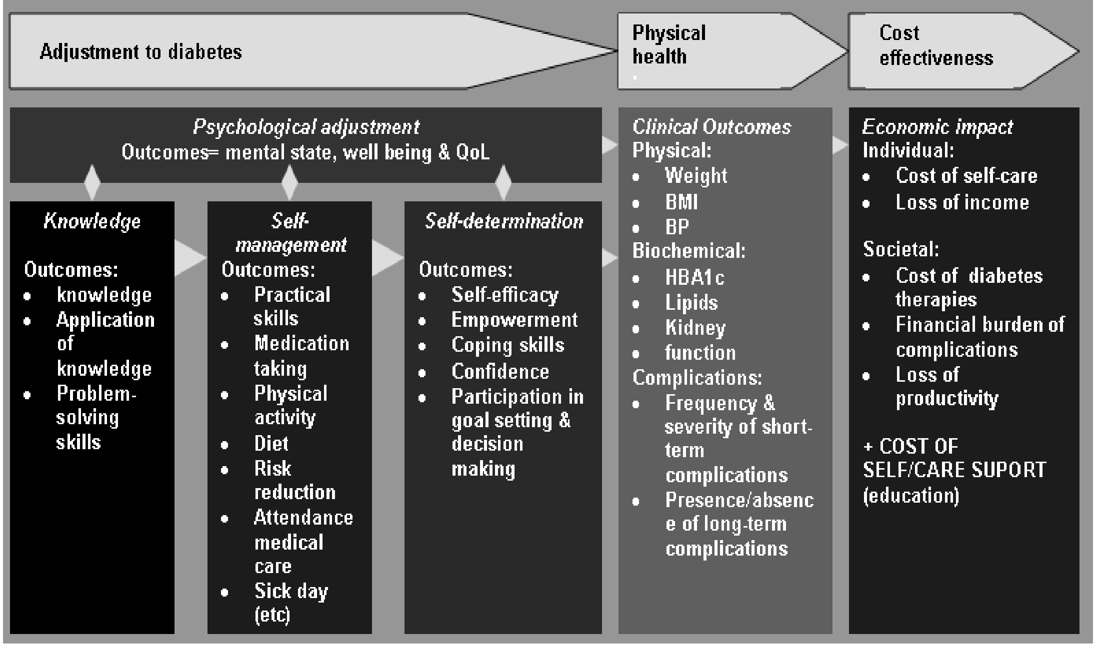
The model again highlights the issue of patient choice in relation to the type of intervention. While patient choice has been emphasised as part of the empowerment approach, it may be interesting to consider the extent to which current self-care support interventions give patients the choice over style and mode of support they receive. In terms of the interventions themselves the scope has explored both the nature of the interventions (content and underpinning theory) and their location in the care system. In relation to the latter consideration is given to the availability of options for patients and the provision of follow-up or booster sessions. The collected materials within the scoping suggest that follow-up or boosters are ad hoc and not routinely built into self-care programmes. There is also the question as to whether the self-care interventions link with wider resources to help patients adopt and maintain self-care behaviours, in particular the involvement of family and access to exercise and health foods. The extent to which programmes address the wide range of socio-cultural and psychological factors influencing self-care performance is also important. There may be a tension between the provision of structured quality assured models of education and those that are flexible and adapted to the local context. Initiatives such as the Year of Care may provide a blueprint as to how self-care programmes can develop self-care resources and assimilate to the needs of divergent populations within the context of a standardised approach.

Finally, the model highlights the importance of outcome assessment (both clinical and patient centred), the scope has also considered the way the outcomes are interpreted: average benefit (mean overall reduction); relative benefit (clinically significant improvements); absolute benefits (number of patients achieving a clinically important outcome or adverse outcomes avoided). In terms of cost-benefit modelling the addition of a care efficiency metric considering net benefits in relation to the numbers treated against clinically significant outcomes and care costs, might help inform commissioning decisions. The ultimate test here would be to consider the outcomes on an intention-to-treat basis, taking the target population outcome as a whole. The final element detailed the question of how (or whether) outcomes were fed back into the self-care delivery. In essence to what extent the self-care interventions are titrated against performance. This could occur at the individual as well as the population level. At the individual level this may require shifting the patient between self-care support interventions until an optimal model is identified. At the population level this might involve altering the referral mechanism, the assessment process, or the intervention (method or mode of delivery) to reflect the socio-cultural context or any heterogeneity of needs within the population.

Self-care/educational outcomes:

Establishing the benefit of the educational or self-care intervention is important both clinically for the patient and in assessing the overall impact of the intervention for the target population. Colagiuri and Elgenmann (2009) have developed a framework for self-care outcomes as part of a consensus process. The model they developed mapped the different outcomes to a process of self-care. This model is important because it expresses outcomes along a continuum of self-care development rather than simply as a unified assessment of performance. The scoping has adapted this model from the original, which placed psychological adjustment in a linear model. In the adapted version psychological adjustment runs in parallel to the different steps in self-care development (see Figure 3.4.8). Colagiuri and Elgenmann (2009) used the term self-determination rather than empowerment as this is the action state the patient experiences rather than the process of enabling that state.

Figure 3.4.8 Educational Outcomes (adapted from Colagiuri and Eigenmann, 2009)



In a separate paper Elgenmann reviewed the available instruments to measure the variables clustered under the 'adjustment to diabetes' arrow in the model. Disappointingly they only identified three instruments that adequately met most or all or their criteria for validity, reliability and sensitivity to change. Two of these measured psychological issues in diabetes self-care: the Problem Areas in Diabetes (PAID) and the Appraisal of Diabetes Scale (ADS). The other, the Summary of Diabetes Self-Care Activities (SDSCA) scale, measures a range of diabetes self-care activities.

While further work is required to substantiate the benefits of this model, measuring different elements of the process would seem to be worthwhile both in determining relative as well as absolute benefit. This relative gain may have particular utility in determining clinical progression. The issue of measurement on these topics should be subject to the same level of diligence that is applied to clinical measures. Further research could consider the development of a composite or integrated measure based on knowledge, skill, determination and actual behaviour. Such an instrument would help identify a patient's ability in the context of their psychological orientation to a given behaviour.

However, given the cost of self-care and educational programmes it is important that they demonstrate a beneficial clinical effect (proxy or end point). While many studies report benefits in self-care performance they do not provide data on whether these translate into clinical benefits (Garret et al, 2005; Thoolen et al, 2007; and Klug et al, 2008). It may be that interventions should be grouped into behaviour enhancing interventions (primary outcome behaviour change) and self-care programmes (primary outcome clinical benefit). The length of follow-up is clearly important – it could be that benefits decay soon after the intervention ends or that it takes time for the benefit to accumulate. Clarke (2008), in a wide-ranging review of self-management education, suggests that measuring long-term impact of education is important, after finding that the effects of self-care interventions are often short-term. This reinforces the need to consider both the longevity of the effect, plus optimal strategies for boosting the self-care behaviour.

Patient-reported outcome measures (PROMS) have been identified as an important area of outcome development. Therefore, indentifying the different patient-related factors for diabetes is important. The Diabetes Attitudes Wishes and Needs (DAWN) and Monitoring Individual Needs in Diabetes (MIND) studies have provided some evidence as to what these factors might include: self-care; patient distress; quality of professional patient relationship; and continuity of care (Funnell, 2006). Glasgow et al (2008) identified four domains of care based on the findings of the DAWN study and the seven areas of self-care identified by the American Association of Diabetes Educators. The four domains are: health behaviours, quality of life, self-management goals (collaboratively set, specific goals or action plans for diabetes management) and patient centred care (patient engagement in care, shared decision making, and consideration of patient preferences, background and environment).

To facilitate a more global assessment of the patient experience Glasgow et al (2005) have developed the Patient Assessment of Chronic Illness Care, this instrument is designed to assess the patient experience of the Chronic Care Model. The instrument contains subscales relating to: patient activation (actions that solicit patient input and involvement in decision making); delivery system and decision support (actions that organise care and provide information to patients to enhance their understanding of care; goal setting and tailoring (acquiring information for and setting up of specific collaborative goals); problem solving/contextual (considering potential barriers and the patient’s social and cultural environment in making treatment plans); and follow-up/co-ordination (arranging care that extends and reinforces office-based treatment, and making proactive contact with patients to assess, progress and co-ordinate care). The instrument does seem to demonstrate some sensitivity to self-care with the exception of medication adherence (Schmittdiel et al, 2007).

Therefore, while there are some developments taking place, self-care outcome measures for diabetes are generally limited. Given that one of the impediments to interpreting whether self-care and educational interventions are worthwhile is inconsistent measurement, it is important that a common and consistent framework for measurement is adopted both for research and to help determine clinical performance – for the individual patient and for the care system as a whole.

3.4.3 Care systems

Organising and delivering diabetes care (key themes):

- **Access -** As with education and self-care, access was deemed important by patients. Overall, patients simply want to be able to access good quality care when they need it. Therefore, in enhancing care access it may be as important to focus on any shortcomings in the type and range of care currently provided as it is to develop new systems. Potential developments suggested by participants to improve access might include one-stop shops (single-point of contact) and rapid access clinics. However, it may also be useful to consider how well the care available to people is communicated and organised, such that both patients and healthy professionals know what is on offer by following clearly-defined care pathways.

- **Integration -** The scoping identified two interrelated elements of integration. The first element was service integration. The findings from the e-survey and patient conference both indicated that service integration was weak, particularly between primary and secondary care. There are, however, some new models being developed that may provide a template for planning more integrated care systems. For example, the NHS London guide provides a clear plan as to how services might be better integrated, as expressed in a vertically-integrated model and through the adoption of care pathways common to different services. Therefore, studies of both the effect of care integration and of models for integration are important to determine the relationship between integration and care efficiency and effectiveness.

  The second element is care integration, developing a coherent plan of care for the patient. In terms of care integration patients experience a number of breakdowns, particularly in relation to the continuity of the information and advice they are given. Participants in the confirmatory conference also highlighted the issue of co-morbidities as these have the potential to further complicate care management. Patients want to access consistent care and specific suggestions included transferable (portable) care plans and records, and stronger relational care with a named lead care co-ordinator (case manager). However, while continuity of care has been shown to vary between clinical settings and is associated with greater care satisfaction it does not seem to impact on metabolic outcomes (Guliford et al 2006 and Guliford et al, 2007). Hence, further inquiry into the impact of relational care and care continuity are required. In terms of interventions or programmes that might improve care integration, the scoping identified a number of potential areas of inquiry, including: case management or care co-ordinator roles; care plans (including transferable care plans); and mechanisms for integrating the information exchange between patients, professionals and other care systems.

Other models addressing care integration included whole system initiatives, based to some extent on the Chronic Care Model, such as the Year of Care. These models seek to integrate care both through care planning and system development (correcting obstacles to care and introducing new resources based on needs). Further inquiry is also needed in relation to intermediate care teams and polyclinics. While no data on the impact of either intermediate care teams or polyclinics were found by the scoping review they both have the potential to make a strong impact on care integration, efficiency and quality. The data from the e-survey suggest that intermediate care teams not only deliver care to complex patients in the community, but they also play a role in educating other professionals and drive up care quality.

The final area of integration identified by the scoping was the area of care pathways. Care pathways are multiple within diabetes and have been used to define complex processes to more specific clinical activities. They can be designed nationally, regionally and locally. Therefore, it will be useful to consider the impact of pathways on clinical services and care outcomes.

- **Inequalities -** The scoping findings suggest that there are still large variations in diabetes care and that the needs of some populations remain unattended to. There is currently a DoH initiative called Good Diabetes Care for All: Tackling Health Inequalities and this will hopefully provide some practical methods for addressing inequalities. More systematic models for monitoring and profiling care outcomes are being used to highlight inequalities locally and nationally. The Yorkshire and Humber Public Health Observatory, for example, identifies performance in the context of local demographic and socio-cultural variants. However, systems that are dependent on QOF data are potentially limited due to the high levels of exclusions in disadvantaged groups and poor ethnicity recording. The findings of the scoping suggest that inequalities drivers are multi-dimensional and can be: intrinsic to the population group (health literacy cultural practices); internal to the care system (built-in barriers); and external (reflecting wider socio-cultural variations in health and structural inequalities).

There are some specific groups that have particular disadvantages: people with severe mental illnesses and/or learning disabilities; older people; the homeless; and refugees/asylum seekers. While the scoping has failed to look in-depth at all these populations, a report on the issues facing people with severe mental illness has been produced as attached in appendix 7. This report indentifies some of the drivers for inequalities in this group which include: intrinsic factors (a reluctance to engage with services, impaired judgment, and difficulty communicating health needs and following prescribed treatment); and service factors (barriers in accessing NHS services – particularly in primary care, diagnostic overshadowing – a focus on mental health rather physical health, patchy provision of services and poor integration of specialist services). Clearly, this topic warrants a far more in-depth assessment than has been provided by this scoping and there is a need to find both common and individual solutions to care inequality for these different populations.

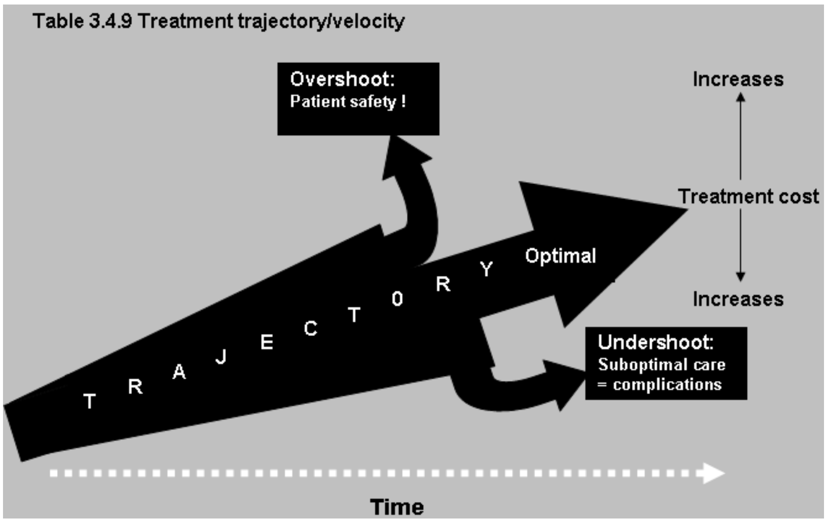
Another initiative focussing on inequalities is the national Pacesetters Programme. This programme involves tailored service redesign or development to focus on the needs of specific populations, see Example 3.1 for details of some of the projects.

Example 3.1 Pacesetter Projects

- Kings College Hospital NHS Foundation Trust
  Developing lifestyle intervention programmes – using psychological (motivational interviewing) and educational theory (empowerment theory) to prevent and reduce Type 2 diabetes with high risk ethnic groups.
- Hastings and Rotherham PCT
  Improving the health outcomes for older diabetic people through developing

- **Efficiency -** The participants in the e-survey identified a number of strategies for improving care efficiency with key areas for development being: more and better training for health professionals; better incentives for health care professionals and providers; greater use of tele-care and informatics; better integration (reducing barriers to care – 'streamlining'); greater use of patients to support care delivery; and the use of local diabetes networks to oversee performance.

It may also be possible to achieve more by adopting more sophisticated models for targeting clinical care. At present there are many patients locked into care models that consume resources, but which do not achieve any benefit for the patient. An interesting concept identified in the literature review was that of treatment trajectory or 'velocity to goal' as Azar and Gabay (2009) termed it. The concept being that there is an optimal time frame to achieving a clinical outcome. If patients are undertreated and therapies are not escalated then the risk of complications increases, and there may also be a lack of momentum for patient care. For example, a patient visiting a diabetes out-patient clinic may have visits at 3, 6 or even 12 monthly intervals at which decisions are made that could have been executed over much shorter periods of time (such as titrating or changing medicines). Conversely there is the danger, as highlighted by the recent ACCORD study and in a subsequent study of UK GP data (Currie et al, 2010), that overly aggressive management of glycaemic control may increase adverse patient outcomes and care costs. In this case the patient's care is overshot (see Figure 3.4.9).



Underpinning this model is the need for a more analytical approach to care that considers patient movement and performance within the care system. If a patient remains static in terms of clinical parameters is it because the system is maintaining them or is it because the system is inappropriate or ineffective in addressing the needs of that patient? As the demand for diabetes care increases, the capacity for systems to 'carry' patients for whom there are no clear clinical benefits is possibly unsustainable. Therefore, it is important to identify these patients and consider alternative systems of care – as has been emphasised in previous sections of the scoping. An important area of inquiry may be in developing informatic systems, which can quickly highlight such inefficiencies so that patients can be streamed into optimal care environments. Such systems could also identify patient movement, spotting those patients who seem to be deteriorating earlier to enable prompt intervention. Clearly there is an important area for further inquiry as we have very limited data on how diabetes care systems can be made more efficient in the context of the NHS.

One area where there are more data is in relation to QOF. QOF data are now being used to fuel numerous performance monitoring tools and 'dash-boards' that aim to identify strengths and weaknesses in care delivery (at the practice and PCT levels). While there are data to show improved clinical performance following the introduction of QOF (Guliford et al, 2007), there are some important limitations in using QOF as an efficiency incentiviser.

Firstly, there is the practice of exempting people from QOF. This exemption reporting may distort inequalities in care. Sigfrid et al (2006) reported that exemption reporting was 25% higher in practices in the lowest quintile of deprivation. In a very thorough analysis of the effect of both exemptions and missing cases on QOF in 147 practices from across the UK, Calvet et al (2009) found that the current diagnostic case definition for QOF does not capture up to 66% of people with Type 1 diabetes and up to 33% of people with Type 2 diabetes. The effect of these omissions is to overestimate the improvements observed since the introduction of QOF on the targets of HbA1c ≤7.5 and ≤10% by up to 15%. The NHS London Guide has called for a maximum level of 3% for exemptions. Secondly, there may be a diminished return with QOF. Campbell et al (2009) in a study of QOF data in 42 practices found that prior to QOF care performance was improving at an average rate of 1.8% per annum. Following the introduction of QOF, while there was an initial improvement in performance this rate of acceleration was not maintained and fell back to the pre-introduction level. Therefore, it may be useful to study the impact of different types of incentive models on practice performance.

Ting et al (2009) have advocated the use of integrated organisational quality models to improve service efficiency, they include: Plan Do Study Act (PDSA) rapid continuous audit cycles; Six Sigma and Lean Thinking, to eliminate waste based on concepts of *muda* (over production), *mura* (inconsistencies) and *muri* (capacity of system to meet the demand); and the Malcolm Baldrige Model for Performance Excellence, which considers leadership, strategic planning, customer focus, measurement and knowledge management, workforce focus, process management and results. Therefore, more work needs to be undertaken to examine whether these, or other organisational models, can help deliver greater care efficiency in diabetes.

One current study that may promote a better understanding of what factors contribute to care efficiency, at least for primary care, is that of Eccles et al (2009). This study is examining factors in 100 practices in the UK that contribute to good clinical outcomes. The factors include: care organisation; individual clinician factors and team functioning. It is hoped that will collect and report on service cost data too.

- **Teamwork -** The literature review identified a meta-analysis of organisational intervention, which suggested that interventions involving team changes and/or team working models (n= 26 RCTs) had shown the greatest overall benefit of all the interventions included in the review. This is perhaps unremarkable as diabetes is a complex disease that demands effective inter-professional collaboration. Therefore, while we know that team working is important we need to know more about what constitutes an effective team configuration (membership, roles and skills) in different diabetes settings (primary, secondary and tertiary care). Given the increasing interest in formal patient participation in care delivery, it may also be interesting to consider the role of the patient as a team member.

- **Patient involvement -** Patient involvement has been a consistent theme throughout the scoping review. While patients are clearly having more involvement in determining their care through patient participation models (as detailed previously) there is less information over the involvement of patients in organising and developing care services. There could be a number of models for this, including: direct patient participation; the service consulting an outside patient group; the commissioning of services devolved to the patient led group; patient consultation events (targeting particular developments); and patient monitoring, evaluation and feedback to inform service development. There are clearly differences in these models between the level of time and commitment required from patients and how formal (powerful) their involvement is. Further questions to consider are: how meaningful is the patient involvement; how are representative patients identified and recruited; and what training (if any) should patients be given to help them participate. There are also patient champion schemes operating in the NHS and these should also be examined to see how they help influence and shape services.

- **Workforce development and deployment -** A limitation of the scoping has been a lack of detail in relation to workforce issues. Nevertheless, a number of key areas emerged (particularly from the e-survey) in relation to the workforce: the need to develop optimal skill sets for professionals working in diabetes (at different levels), with the necessary educational and training programmes to ensure professionals acquire and regularly update those skills (accreditation); identifying optimal staffing resources for defined diabetes care systems (minimum standard); specific training for professionals to be better educators and to develop enhanced consultation/care-planning skills; impact of incentives on workforce performance; and to expand the diabetes workforce. There is some work underway exploring the link between staffing levels and diabetes care, one recent cross-sectional study in primary care reported an association between nursing levels in general practice and QOF process and outcome measures, with higher nurse to patient thresholds being associated with better outcomes (Griffiths et al, 2010).

- **Informatics -** Informatics has been highlighted as a potentially very important element of diabetes care as a means of improving: patient engagement and feedback; the flow of information; performance monitoring and quality assurance; and service redesign. However, there are many problems to be overcome before informatics can be used to best effect to improve diabetes care in the NHS. A recent Westminster Health Forum seminar on diabetes made the following points about current IT systems: they do not link all stakeholders or cross all organisational boundaries, impeding information sharing;

they often exclude patients; they need to be better equipped to identify people with diabetes (especially in the context of in-patient care); and they also need to be able to identify patients with poor or worsening control to ensure timely intervention. The review also noted that in Tayside, where one of the most developed diabetes informatics projects in the UK has been undertaken, there has only been a limited (if growing) beneficial impact on clinical outcomes.

- **Commissioning models -** The scoping review has not identified any detailed or clear commissioning models. Participants in the e-survey suggested that commissioning might improve care delivery if the service was commissioned as a whole, rather than through the current separate, and in some ways conflicting, mechanisms (eg, between primary and community care; and between primary and secondary care). Questions that might be addressed include: who should be responsible for commissioning care; what is the optimal length of time for the commissioning cycle (ie, some cycles may require more long-term commissioning); how might patients be included in the commissioning process; how can the commissioning model deal with supply and demand; and how can the commissioning process be better integrated with measures of performance and governance.
- **Patient safety -** Patient safety was another area that was not addressed in detail by the scoping review, although it was given the highest priority for further research by the participants in the peer review. Diabetes is a technologically rich area of care with many potential areas of patient risk. There are also multiple diabetes-specific preventable adverse events, such as hypoglycaemia, diabetes emergencies and acute foot problems. Hence, finding methods for reporting and collating adverse events would assist in identifying any potential hazards and their underlying causes in the care system.

Points from the consensus conference:

Was anything missed by the scoping?

- Care pathways - While the review identified some material on care pathways the participants in the confirmatory conference felt that more focus should have been given to the impact of pathway on the organisation and delivery of care. They also suggested that care pathways need to consider co-morbidities and the integration of diabetes into more general long-term-conditions (LTCs) care.

What are the priorities for the organisation and delivery of diabetes care?

- Intermediate care teams and clinics.
- Integration with other LTCs to ensure more efficient use and greater availability of resources such as psychology.

- Stronger implementation of care pathways.

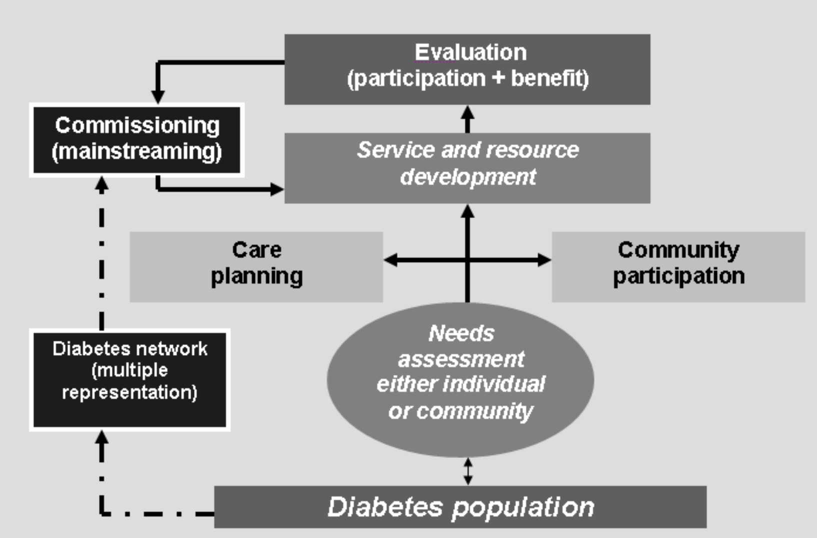
- Linking the complex range of services and structures important in diabetes into a clear model of care for patients and health professionals.
- Find methods to improve quality, efficiency and productivity.
- Find methods to reduce health inequalities.
- Structured screening for diagnosis (with risk factors) for early diagnosis.
- Reduction in duplication of care so that a diabetes team follows one pathway across primary and secondary – team approach.
- Increase the role of patients and service users in developing diabetes services.
- Develop strong diabetes networks along with remit for governance and commissioning.
- Local needs assessment, consultation and care pathways to be developed.

Theoretical summary (models of care):

Many of the models identified in the previous sections already contain many elements of care organisation. In this final section of the synthesis three additional models are presented that relay some of the underpinning constructs identified in the scoping in relation to care organisation and delivery.

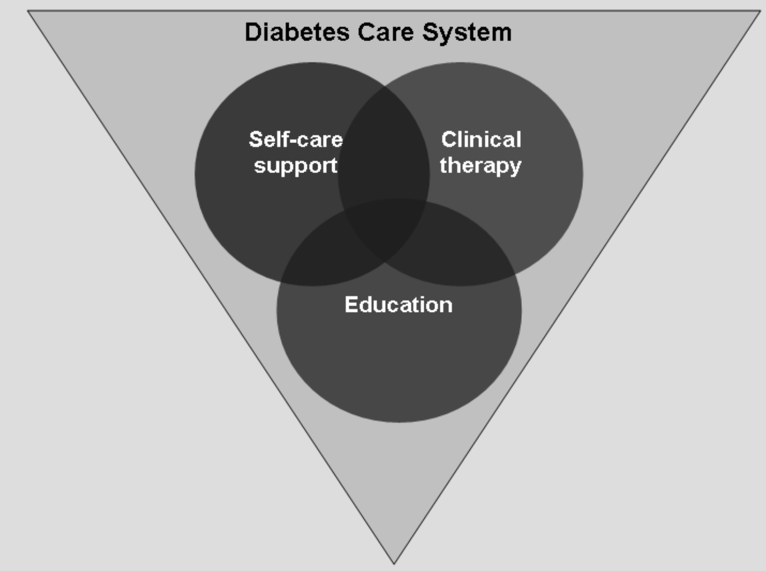
The first model details the core elements of the whole systems approach: defining the local/target population; identifying the needs of the local/target population (through the analysis of individual care plans or by involving the population in care to identify their priorities and needs); developing services to be more responsive to needs; and evaluation both in terms of inclusivity (the proportion of the population who participated) and benefit. Such a model, as with the Year of Care example given in the review, could be used to inform care commissioning. There may also be a role for a governing body (possibly the diabetes network with wide representation) to oversee the direction of the model, inform on the priorities and monitor performance. The danger of this model could be that it may lead to further variations in care delivery across the UK. The implementation of the model will depend on the ability of local services to deliver it. Hence some form of support with local delivery and national governance would be necessary to ensure that services progressed to an accepted minimum standard. This would also help ensure the transference of ideas and good practice models between different areas.

Figure 3.4.10 Whole-systems models



The second model (Figure 3.4.11) emphasises the inter-relationship between the different elements of care within the system. As has been emphasised, earlier effective education and self-care support is dependent on effective clinical therapies.

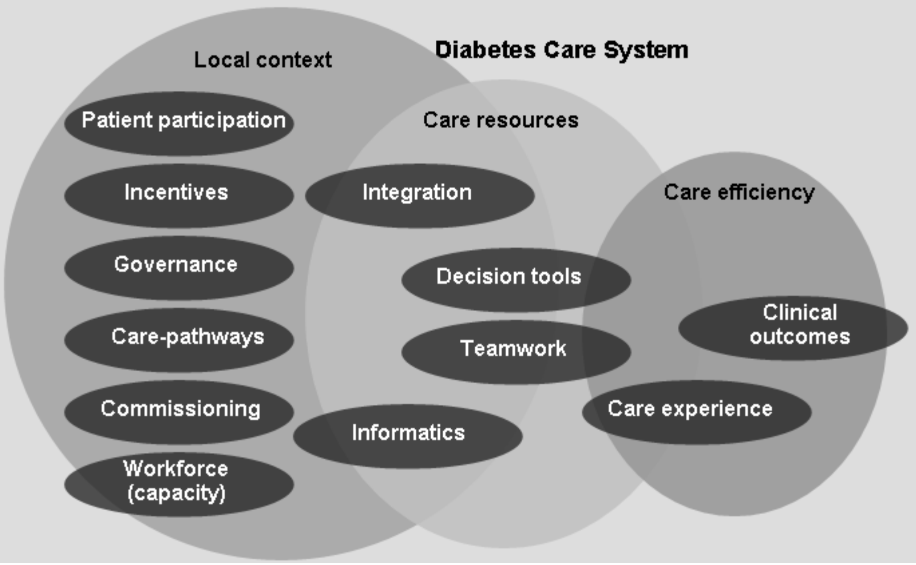
Figure 3.4.11 Integration between care system, self-care support and education.



Not only are the benefits of patient education dependent on their integration with clinical therapies. In a review undertaken by Naik et al (2007) examining the use of co-interventions in 41 RCTs for blood pressure treatment in Type 2 diabetes, there were many examples of how the effect of therapy was moderated by the model of care delivery. They observed that common co-interventions were care treatment protocols, including: the use of consensual and clearly stated blood pressure goals; frequent visits in which blood pressure levels were measured and compared with predefined goals; and modifications to the treatment based on a detailed action plan. Therefore, the achievement of an optimal treatment effect may be dependent not only the active agents within the medicine, but also on the ability of the care system to deliver the therapy in an optimal way (this arguably should be modelled on the protocol for the trial).

The final model of the synthesis tries to outline some of the organisational factors that might influence the shape and impact of the diabetes care provided (Figure 3.4.12).

Figure 3.4.12 Care system regulators



The model identifies some organisational factors identified in scoping that shape care delivery, organised to the left of the model. These factors will be in part determined by, and will need to address, the local context of the care setting. The local context includes: the characteristics and needs of the local diabetes population; the level of service demand; and the local infrastructure. In the middle of the model are some of the factors that mediate the actual delivery care. These factors will be determined by the care resources available to the system (eg, education and self-care support provision, health technologies and supportive services). Informatics and integration are positioned a little in between the organisational and delivery factors as they both have an organisational and delivery function. The untested hypothesis within the model is that these organisational and delivery factors will determine the efficiency and effectiveness of the care provided.

The model is not meant to be linear nor is it inclusive. The relationship between these different levels will be multidirectional and the associations between them will vary significantly. There will also be many additional confounding and modulating factors. Nevertheless, the model provides a perspective (a starting point) on some of the factors that need to be considered in developing a better understanding on how diabetes care is organised and delivered.

4 Conclusion & Recommendations

The scoping has presented a wide ranging account of diabetes care organisation and delivery. In this final section of the report consideration is given to the next steps for health services research in diabetes. Outlined below are some of the areas of research that need to be considered, together with some ideas as to how that research might be conducted.

4.1 Recommendations for patient education and self-care.

In terms of the organisation and delivery of patient education and self-care support the biggest priority is to find better ways of integrating self-care within the care system. There is a need for education and support to be on-going following an explicit education/self-care care pathway. There is need to develop a wider range of educational models both structured and flexible to meet different self-care needs. The relationship between the content and focus of the education and self-care activity needs to be explicitly modelled to the intended outcome. Outcomes need to be adopted developmentally to follow the progress of the patient in stages as they develop self-care mastery. Further work is required to determine the optimal intensity/duration and follow-up of education. Patient choice and selection may be important areas to consider in building a package of self-care support. Screening and assessing for psychological characteristics, psychological morbidity and health literacy may mean that self-care resources are applied more effectively and efficiently. There is a need to further develop methods for meeting the needs of different populations. The role of peer educators needs further exploration. Quality assurance methods need to be expanded to ensure the consistent delivery of education and self-care. Educational exposure should be part of routine clinical data recording. A recognised programme of professional education is needed to ensure that the workforce is able to deliver effective self-care support. While tele-care and E-health initiatives have the potential to increase access to self-care support, they need to be developed following more explicit theoretical models and their impact on the patient experience needs further study. Care planning models are being developed and further study is required to determine which approaches are most effective. Studies to identify the best methods for recording and communicating care-plans are also required. Further work is required to establish the role and contribution of psychological interventions in self-care support delivery. The interface between the self-care delivery model (e.g. patient empowerment) and the application of clinical therapies needs to be carefully observed within an integrated approach. Finally, outcome assessment needs to be developed both in terms of the measures that are available and in the way data are interpreted. Outcomes need to be considered in the context of target population (the number needed to treat for benefit) if current inequalities and variations in provision are to be recognised and addressed.

4.1.1 Areas for further inquiry

The following areas for further inquiry are suggested based on the above summary of the scoping synthesis:

- Development of assessment technologies to profile self-care needs and issues.
- Evaluation of care-planning approaches.
- Exploration and evaluation of peer support (forma and informal).
- Exploration and evaluation of models for delivering self-care to hard to reach communities.
- Exploration and evaluation of patient experience/preference for e-Health and tele-care models.
- Exploration of different care delivery styles in self-care support (models of communication and empowerment).
- Exploration and evaluation of the impact of patient choice in self-care support systems on patient and clinical outcomes.
- Evaluation of frequency of educational follow-up (boosters) and long-term clinical outcomes.
- Exploration of methods and standards for quality assurance and clinical performance indicators for education programmes in diabetes.
- Exploration of the training and education needs of health professional as patient educators.
- Exploration of the training and education needs of health professional in communication and psychological models of care delivery.
- Exploration of different models for organising psychological support in diabetes services.
- Evaluation of the impact of psychological interventions on care planning, process and outcome.
- Evaluation of technologies to support patient adherence.
- Exploration of the factors that contribute to non-attendance of group education and the development of alternative models.
- Exploration and evaluation of different feedback methods- models to enable patients to develop positive relationship to their diabetes in away that allows to respond proactively to their metabolic needs.

- Exploration and evaluation of social needs and interventions (family, peers, networks).
- Development and standardisation of patient centred outcome measures.

4.2 Recommendations for care organisation and delivery.

In terms of the organisation and delivery of diabetes care the scoping has identified a number of areas were further development is required. Work is required to ensure that diabetes care pathways are clearly defined and are accessible to all patients. New models of service/care integration have been proposed and these need to be evaluated to determine their impact on care efficiency and quality. Systems are being developed that identify variations in performance and inequities in care outcomes. These systems need to be developed further to enable more routine monitoring of performance and to enable remedial intervention where inequalities are identified. Informatics need to be developed to help improve care efficiency with models to help identify patient performance and progression to care outcomes being a priority area. Innovations such as virtual clinics and polyclinics need to be evaluated. The role and impact of intermediate care teams needs to be explored. The workforce needs better training in using information to promote care development. Further work on the impact of incentives is required both at the organisational and individual levels. There is a need to explore the involvement of patients in care system administration, service development, commissioning and in terms of governance, to determine good practice models. There is a need to define minimum skills sets for the diabetes workforce and to explore different models for the training and accreditation of the workforce. The impact of different commissioning models (e.g. the teams without walls initiative) needs to be assessed. There is need to identify models that will identify patient safety issues (early warnings) and develop interventions that will improve patient safety. In the recent NSF update report it was highlighted that between 2003 to 2009 the National Patient Safety Agency (NPSA) recorded over 13,000 incident reports relating to insulin (DoH, 2010). The integration between diabetes and other long-term-conditions care programmes and pathways needs further exploration. The role, function and impact of diabetes networks as potential drivers for local diabetes care needs to be explored. The impact of whole-systems models or care delivery need to be evaluated further. Models for teamwork in different clinical contexts need to be identified. There is a need to identify and evaluate different decision support tools and processes to ensure that best practice is identified and translated into patient care.

4.2.1 Areas for further inquiry

The following areas for further inquiry are suggested based on the above summary of the scoping synthesis:

- Explore and evaluate the impact of organisational innovations in terms of context and place of care such as polyclinics and virtual clinics.
- Evaluate the impact of inter-personal factors and continuity on care outcomes, quality and satisfaction.
- Explore and evaluate the impact of patient involvement in decision making on patient and clinical outcomes.
- Explore the factors that influence titration (trajectory/velocity) in achieving safest and most optimal progression of therapy.
- Explore and develop a diabetes specialist help-line (local, regional and national).
- Evaluate whole systems models with integrated care planning and commissioning (such as Year of Care).
- Explore the use of health informatics and information and their impact on decision making, care efficiency, commissioning and clinical/patient outcomes.
- Explore different models of diabetes networks (advisors or a policing agency, involvement of patients) in relation to the efficiency and effectiveness of the local care provision.
- Explore the factors related to care accessibility.
- Evaluate models for indentifying care inequalities and interventions to tackle inequalities in different care systems.
- Explore the role and function of intermediate care teams and their impact on clinical performance (the work of others- via education) and clinical outcomes- cost effectiveness.
- Explore and evaluate models of integration between primary and specialist care (such as the vertically integrated model proposed in the NHS London guide).

4.3 Key recommendations.

While the previous sections set out some detailed areas for further inquiry reflecting the output of the scoping review, it is also important to identify some key priorities to help patients, service providers and commissioners and researchers improve diabetes care delivery. Following an examination of the detailed recommendations as a whole, the following four key areas are suggested as priorities for improving care delivery and organisation in diabetes:

- The development of integrated models of individual and population level assessment to identify individual care needs and to develop care provision.

- The development of more effective and efficient (overall benefit for target population) models of on-going self-care support (including education) that respond to patient preference.
- The development of better systems to provide information on clinical performance and care efficiency to enhance care delivery.
- The development of commissioning models that reinforce greater integration and efficiency in care organisation and delivery (including inequalities of care).

4.4 Health services research in diabetes.

The topics outlined in this report will demand a wide range of different research approaches and expertise. Questions prefixed 'explore' will require observational studies both qualitative and quantitative. Questions prefixed 'evaluation' may require more complex models of evaluation, particularly as many of the interventions identified in the scoping exercise were multi-component or systems based. There is also a need for longer term studies following-up the impact of interventions and organisational developments. Some more specific areas to consider are:

- Secondary analyses- some of the research priorities identified above would benefit from a secondary analysis of current studies prior to further inquiry. However, it has been noted that a number of the systematic reviews and meta-analyses that have been undertaken do not adequately model the interventions to identify their core elements prior to inclusion. The result of this failure is the inclusion of studies that are superficially related but are testing quite different things. Therefore, as with complex interventions carefully theoretical modelling should be incorporated into these reviews.
- Complex evaluation- the current MRC guidance for complex evaluation will provide a useful reference for those inquiries that have multiple components. For example, educational and self-care interventions that include a psychological model or intervention and/or are delivered using a tele-care approach.
- Studies of organisation- methods for the study of organisations will be important in addressing questions of service development, integration, teamwork and efficiency.
- Epidemiological studies- long term cohort studies can provide very powerful evidence of the effects of different aspects of care organisation and delivery. It will be useful to consider how these studies might be set up both to enable exploratory analyses of the factors that might influence care performance and inquiries designed to test the impact of different organisation and delivery models.
- Cluster RCTs- when wide distribution of an intervention is proposed a cluster RCT would be a good method for estimating the real world effect

of the intervention (including the multiple organisational factors that will moderate the effect of the intervention).

- Economic analysis- the scoping exercise found very limited data on cost-effectiveness and clearly given the potential expansion of diabetes care cost-benefit must be a very important element in any evaluative studies.

Given the complex areas highlighted by the scoping exercise and the need to develop robust methods to study those areas, it is recommended that a group of experts should be convened to develop a health service research strategy for diabetes. Such a strategy will be important if the care systems for diabetes are going to be development to meet the challenge of diabetes. The strategy group should include potential research funders to encourage the development of more co-ordinated programmes.

4.5 Limitations of scoping.

The most significant limitation of the scoping was that given its broad focus and limited resources providing detailed perspectives on specific diabetes populations was not possible (with exception of severe mental illness). The most notable omissions were the care of children, adolescents, older people and pregnancy. It is recommended that the care organisation and delivery for these groups should be scoped separately. It is also acknowledged that while the scoping was designed to provide a broad assessment of national activity in diabetes care and organisation, their will be some developments that have been overlooked. More specific limitations include:

- Literature review- there was insufficient time to undertake detailed critical appraisal of items. Therefore, it was not possible to rate the quality of the evidence presented in detail.
- Patient participation event- with only 38 participants there is clearly significant potential for bias in what is likely to be a self-selecting group of patients.
- E-survey- the patient response was biased to the white population with a lack of participation from BME groups. In the professional survey participation was biased to diabetes specialist nurses and dieticians. The professional survey was also limited by poor item response for some questions.
- Confirmatory conference- participation at this event was lower than intended, despite very active promotion.

Despite these limitations it is hoped the scoping will provide a useful reference point for health services research into the organisation and delivery of diabetes care.

4.6 Conclusion.

This scoping exercise has shown the importance of care organisation and delivery in diabetes. It has also highlighted that there are still many inequalities and variations in the delivery of diabetes care nationally. In addition, the overall evidence-base for care organisation and delivery is patchy and fragmented. There are many studies and reviews of complex multi-component interventions that generally lack prior theory and modelling. Furthermore, very few of the studies included in the scoping were undertaken in the UK.

However, the scoping has identified many innovations in care organisation and delivery. Despite the limitations of the evidence-base the scoping has highlighted some interventions and service developments where benefits might be realised. The stakeholder participants have also provided a rich vein of ideas as to how diabetes care organisation and delivery could be improved. The scoping has integrated these different ideas and service developments to generate theoretical models. The models detail both actual and potential relationships between the different components of the care system. The models provide conceptual templates for:

- Ongoing integrated patient education;
- Determining different types of patient education;
- Integrating self-care and patient education into the care system;
- Staging self-care interventions;
- Assessment, choice and an iterative approach to self-care support;
- An integrated model of self-care support (target population, initiation method, assessment, patient choice, performance monitoring and efficiency).
- Self-care and educational outcome progression;
- Care trajectory;
- Whole-systems approaches;
- Factors that regulate the care system.

These innovations, ideas and models now need to be studied to enable the diabetes care system to advance and improve its quality and efficiency. To achieve this there needs to a national strategy for health services research in diabetes and funds to enable the delivery of that strategy. This investment is essential if the diabetes care system is going to manage the rising demand for care it will face over the coming decades.

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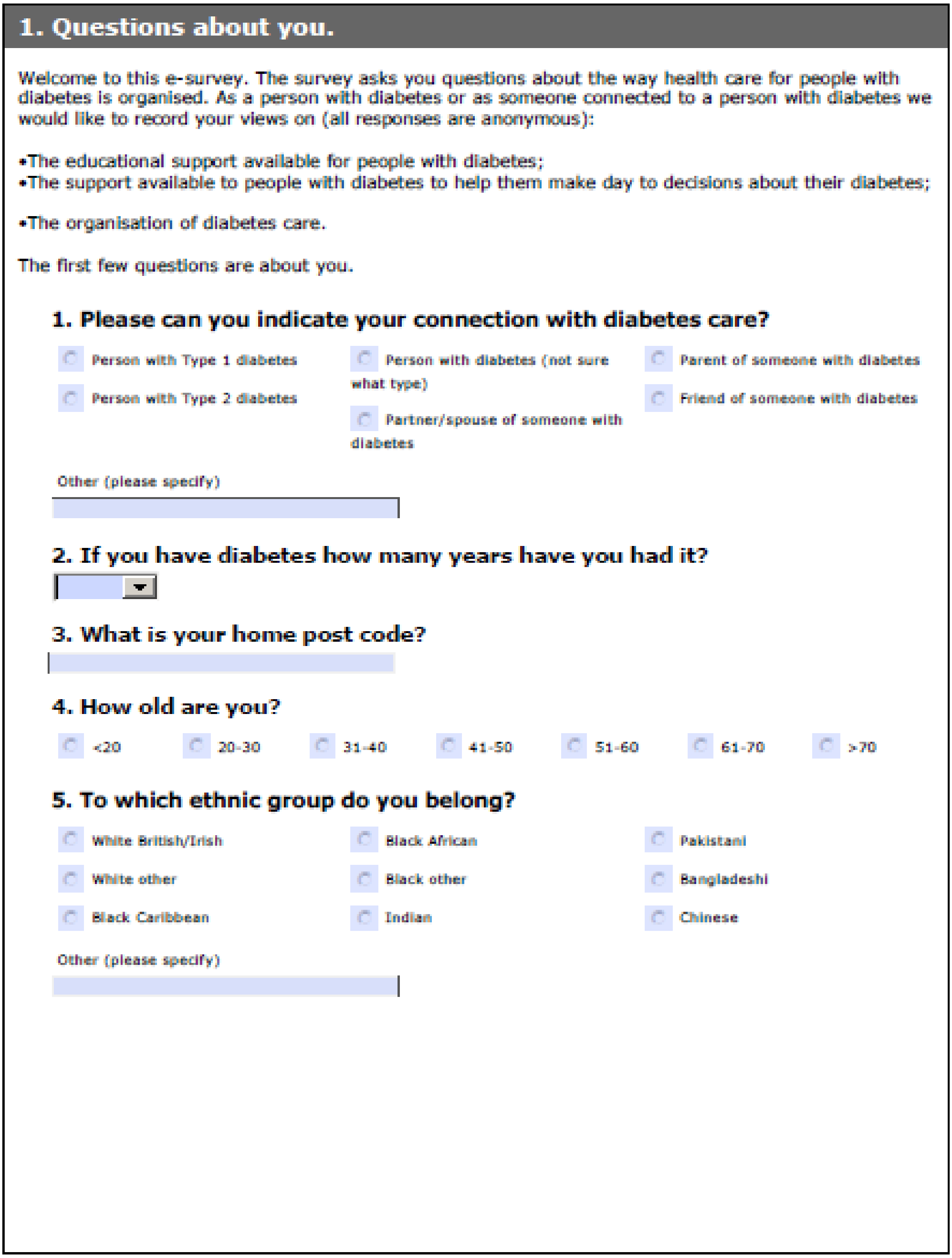
Appendix 1 Search Protocol

Topic and Search Terms (number of abstracts and tiles)	
Self care and education	***Hits***
patient education.mp. or Patient Education as Topic/	62866
Patient Education as Topic/ or structured education.mp. or Self Care/	69346
group education.mp.	379
self care.mp. or Self Care/	20786
psychoeducation.mp.	653
Interview, Psychological/ or motivational interview.mp.	9352
motivational interview$.mp.	731
Cognitive Therapy/ or CBT.mp.	10581
health promotion.mp. or Health Promotion/	41894
structured education.mp.	97
DAFNE.mp.	32
DESMOND.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	59
35 or 45 or 41 or 36 or 44 or 39 or 38 or 42 or 43 or 34 or 37 or 40	137276
Combined (and) with diabetes (limited 2000-present)	**5771**
E-health (telecare)	
1."Diffusion of Innovation"/ or Telemedicine/ or Medical Informatics/ or Internet/ or e-health.mp. or Medical Records Systems, Computerized/	63347
2. telecare.mp.	214
3. computer.mp. or Computers/	377608
4 web-based.mp. or Online Systems/ or Computer Communication Networks/	22375
1 or 2 or 3 or 4	427102
Combined (and) with diabetes (limited 2000-present)	**3828**
Care systems and organisation	
1. "Delivery of Health Care"/ or care system.mp.	64288
2. Total Quality Management/ or Managed Care Programs/ or care organisation.mp.	32768
3. Case Management/ or care management.mp.	10869
4. Informatics/ or informatics.mp. or Medical Informatics/	11298
5. "Delivery of Health Care"/ or Disease Management/ or chronic care model.mp. or Self Care/ or Models, Organizational/	84426
1 or 2 or 3 or 4 or 5	144497
Combined (and) with diabetes (limited 2000-present)	**5706**

Appendix 2 E-survey



1. Questions about you.

Welcome to this e-survey. The survey asks you questions about the way health care for people with diabetes is organised. As a person with diabetes or as someone connected to a person with diabetes we would like to record your views on (all responses are anonymous):

•The educational support available for people with diabetes;
•The support available to people with diabetes to help them make day to decisions about their diabetes;

•The organisation of diabetes care.

The first few questions are about you.

1. Please can you indicate your connection with diabetes care?

○ Person with Type 1 diabetes
○ Person with Type 2 diabetes
○ Person with diabetes (not sure what type)
○ Partner/spouse of someone with diabetes
○ Parent of someone with diabetes
○ Friend of someone with diabetes

Other (please specify)

2. If you have diabetes how many years have you had it?

3. What is your home post code?

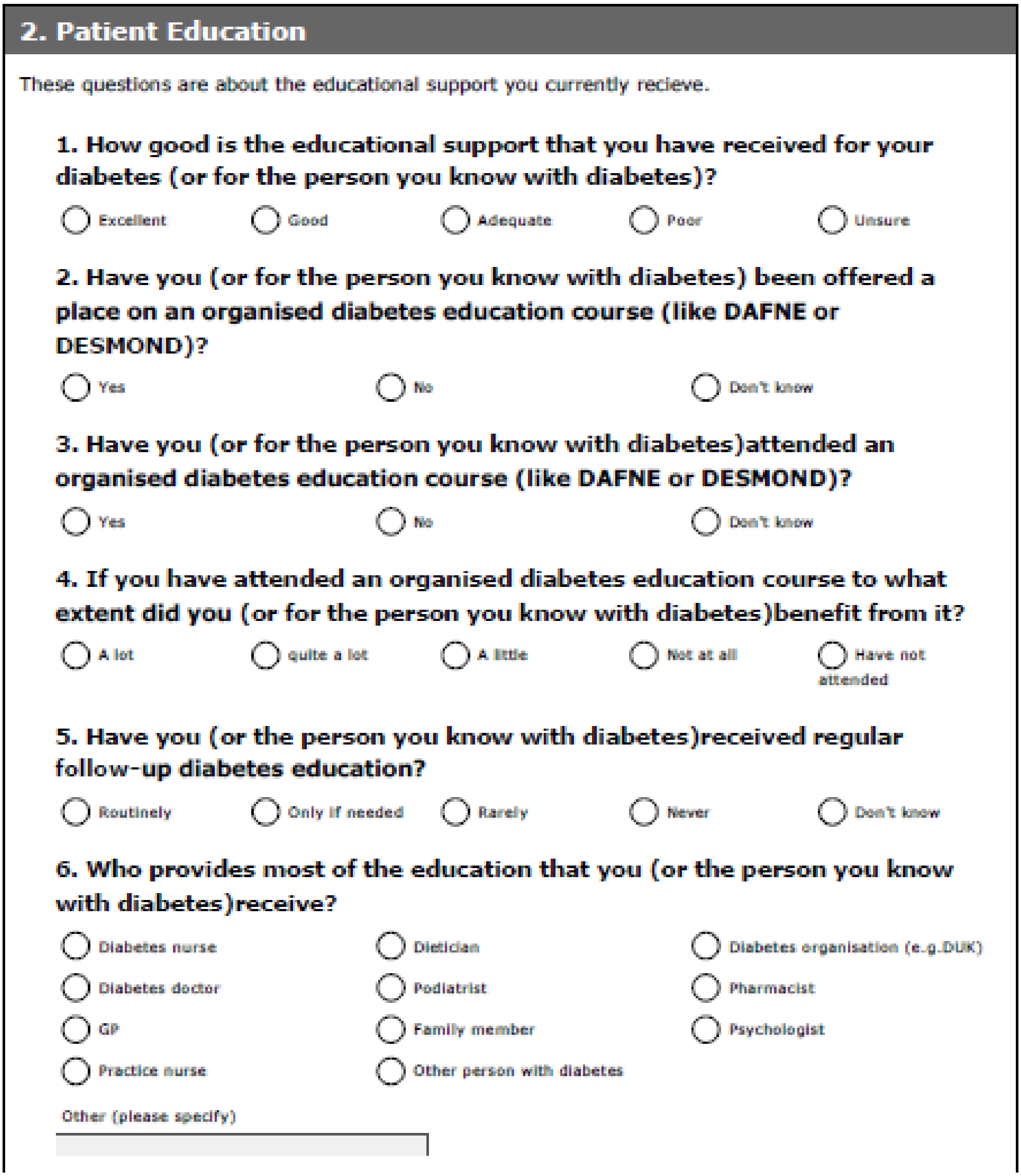
4. How old are you?

○ <20 ○ 20-30 ○ 31-40 ○ 41-50 ○ 51-60 ○ 61-70 ○ >70

5. To which ethnic group do you belong?

○ White British/Irish
○ White other
○ Black Caribbean
○ Black African
○ Black other
○ Indian
○ Pakistani
○ Bangladeshi
○ Chinese

Other (please specify)



2. Patient Education

These questions are about the educational support you currently recieve.

1. How good is the educational support that you have received for your diabetes (or for the person you know with diabetes)?

○ Excellent ○ Good ○ Adequate ○ Poor ○ Unsure

2. Have you (or for the person you know with diabetes) been offered a place on an organised diabetes education course (like DAFNE or DESMOND)?

○ Yes ○ No ○ Don't know

3. Have you (or for the person you know with diabetes)attended an organised diabetes education course (like DAFNE or DESMOND)?

○ Yes ○ No ○ Don't know

4. If you have attended an organised diabetes education course to what extent did you (or for the person you know with diabetes)benefit from it?

○ A lot ○ quite a lot ○ A little ○ Not at all ○ Have not attended

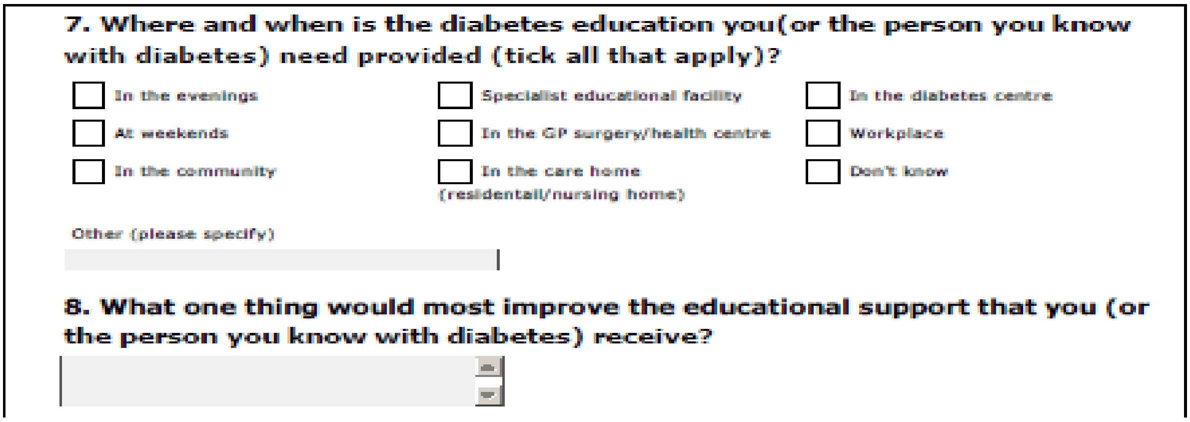
5. Have you (or the person you know with diabetes)received regular follow-up diabetes education?

○ Routinely ○ Only if needed ○ Rarely ○ Never ○ Don't know

6. Who provides most of the education that you (or the person you know with diabetes)receive?

○ Diabetes nurse
○ Diabetes doctor
○ GP
○ Practice nurse
○ Dietician
○ Podiatrist
○ Family member
○ Other person with diabetes
○ Diabetes organisation (e.g.DUK)
○ Pharmacist
○ Psychologist

Other (please specify)

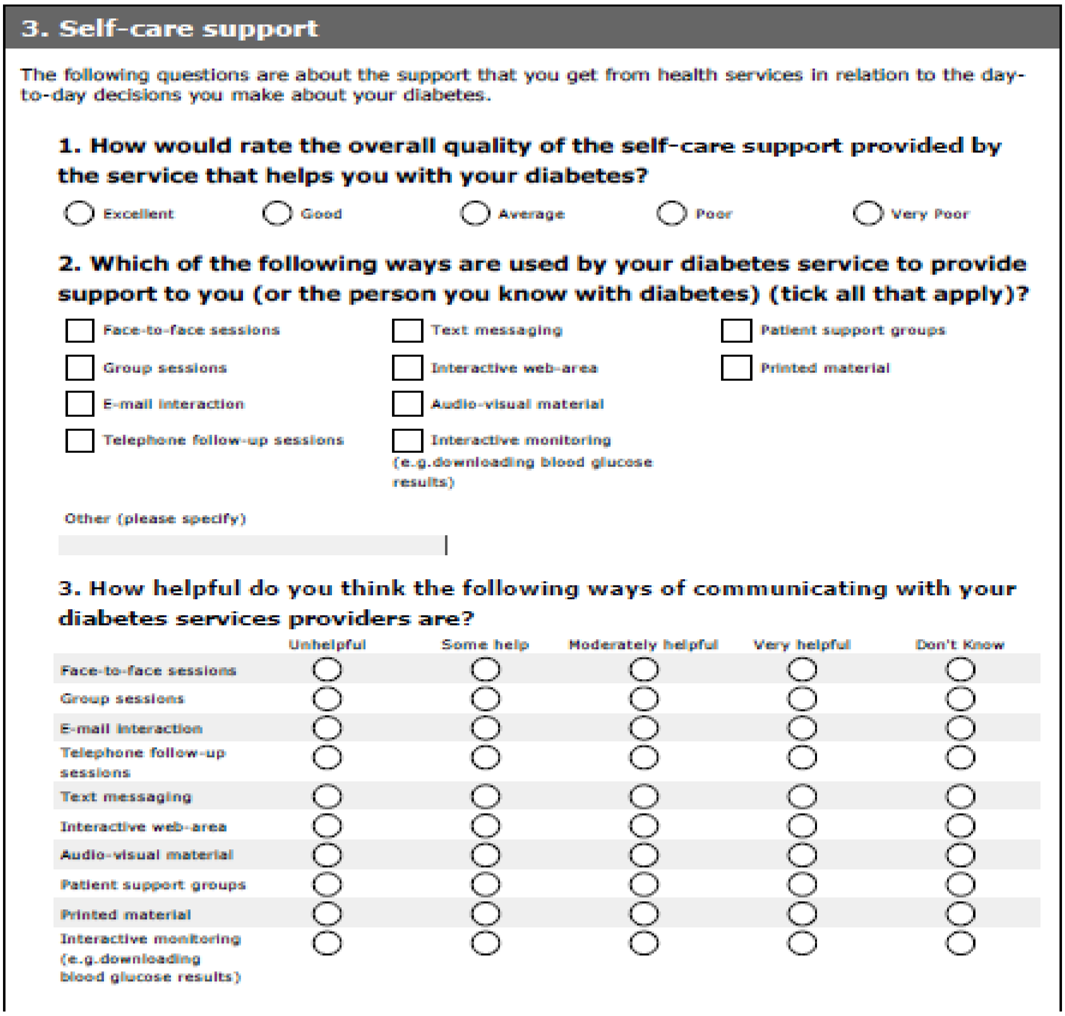


7. Where and when is the diabetes education you(or the person you know with diabetes) need provided (tick all that apply)?

☐ In the evenings
☐ At weekends
☐ In the community
☐ Specialist educational facility
☐ In the GP surgery/health centre
☐ In the care home (residentail/nursing home)
☐ In the diabetes centre
☐ Workplace
☐ Don't know

Other (please specify)

8. What one thing would most improve the educational support that you (or the person you know with diabetes) receive?



3. Self-care support

The following questions are about the support that you get from health services in relation to the day-to-day decisions you make about your diabetes.

1. How would rate the overall quality of the self-care support provided by the service that helps you with your diabetes?

○ Excellent ○ Good ○ Average ○ Poor ○ Very Poor

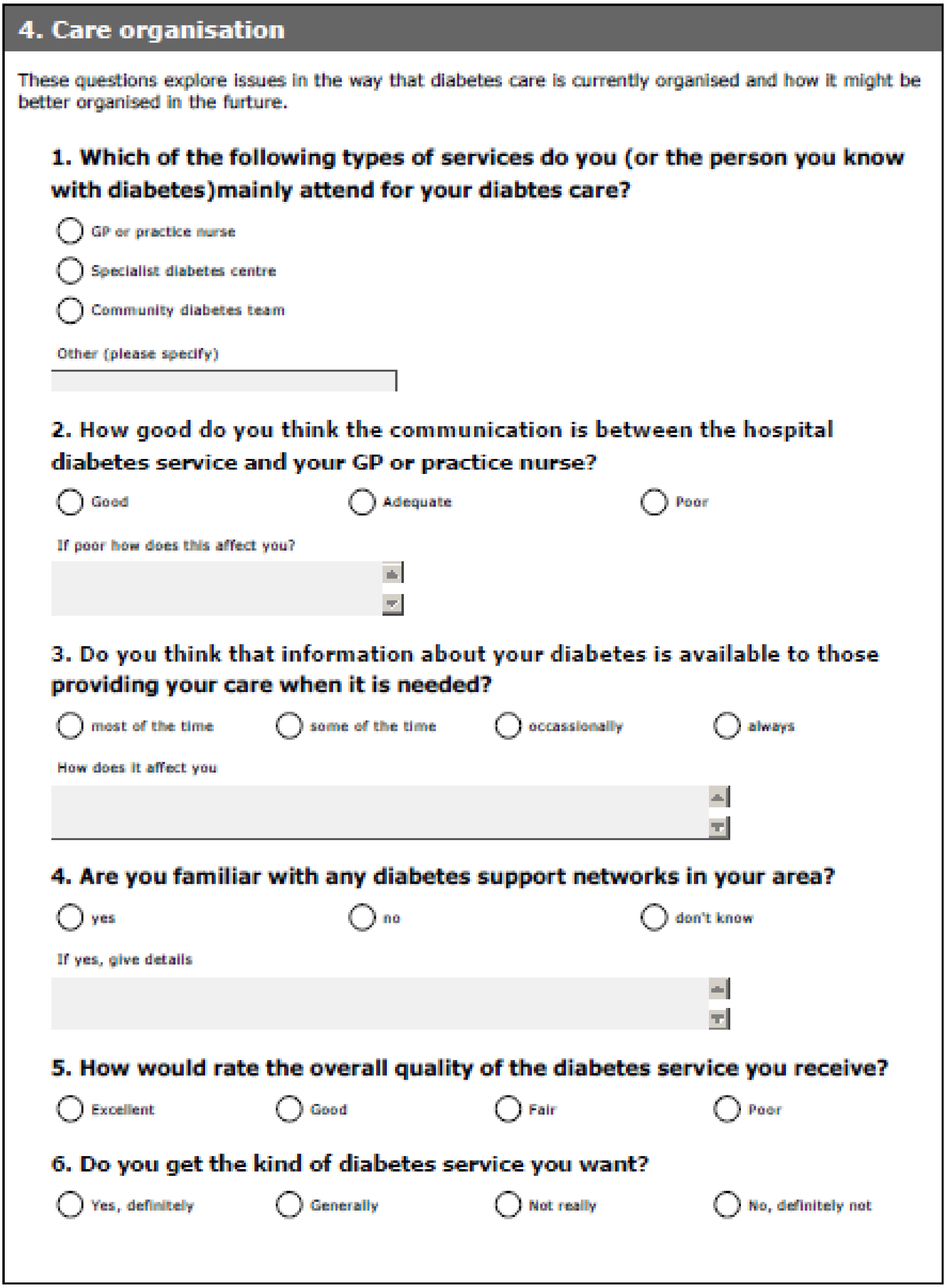
2. Which of the following ways are used by your diabetes service to provide support to you (or the person you know with diabetes) (tick all that apply)?

☐ Face-to-face sessions
☐ Group sessions
☐ E-mail interaction
☐ Telephone follow-up sessions
☐ Text messaging
☐ Interactive web-area
☐ Audio-visual material
☐ Interactive monitoring (e.g.downloading blood glucose results)
☐ Patient support groups
☐ Printed material

Other (please specify)

3. How helpful do you think the following ways of communicating with your diabetes services providers are?

	Unhelpful	Some help	Moderately helpful	Very helpful	Don't Know
Face-to-face sessions	○	○	○	○	○
Group sessions	○	○	○	○	○
E-mail interaction	○	○	○	○	○
Telephone follow-up sessions	○	○	○	○	○
Text messaging	○	○	○	○	○
Interactive web-area	○	○	○	○	○
Audio-visual material	○	○	○	○	○
Patient support groups	○	○	○	○	○
Printed material	○	○	○	○	○
Interactive monitoring (e.g.downloading blood glucose results)	○	○	○	○	○



4. Care organisation

These questions explore issues in the way that diabetes care is currently organised and how it might be better organised in the furture.

1. Which of the following types of services do you (or the person you know with diabetes)mainly attend for your diabtes care?

○ GP or practice nurse
○ Specialist diabetes centre
○ Community diabetes team

Other (please specify)

2. How good do you think the communication is between the hospital diabetes service and your GP or practice nurse?

○ Good ○ Adequate ○ Poor

If poor how does this affect you?

3. Do you think that information about your diabetes is available to those providing your care when it is needed?

○ most of the time ○ some of the time ○ occassionally ○ always

How does it affect you

4. Are you familiar with any diabetes support networks in your area?

○ yes ○ no ○ don't know

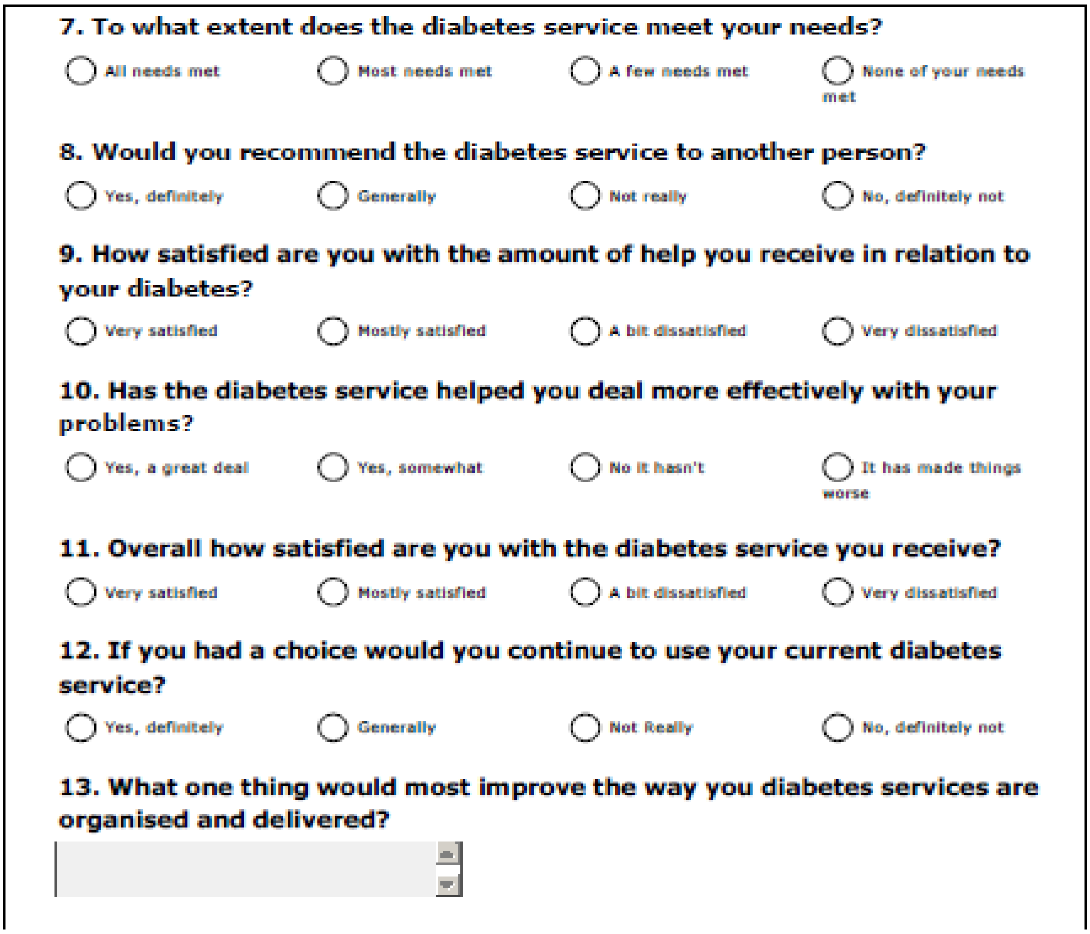
If yes, give details

5. How would rate the overall quality of the diabetes service you receive?

○ Excellent ○ Good ○ Fair ○ Poor

6. Do you get the kind of diabetes service you want?

○ Yes, definitely ○ Generally ○ Not really ○ No, definitely not



7. To what extent does the diabetes service meet your needs?

○ All needs met ○ Most needs met ○ A few needs met ○ None of your needs met

8. Would you recommend the diabetes service to another person?

○ Yes, definitely ○ Generally ○ Not really ○ No, definitely not

9. How satisfied are you with the amount of help you receive in relation to your diabetes?

○ Very satisfied ○ Mostly satisfied ○ A bit dissatisfied ○ Very dissatisfied

10. Has the diabetes service helped you deal more effectively with your problems?

○ Yes, a great deal ○ Yes, somewhat ○ No it hasn't ○ It has made things worse

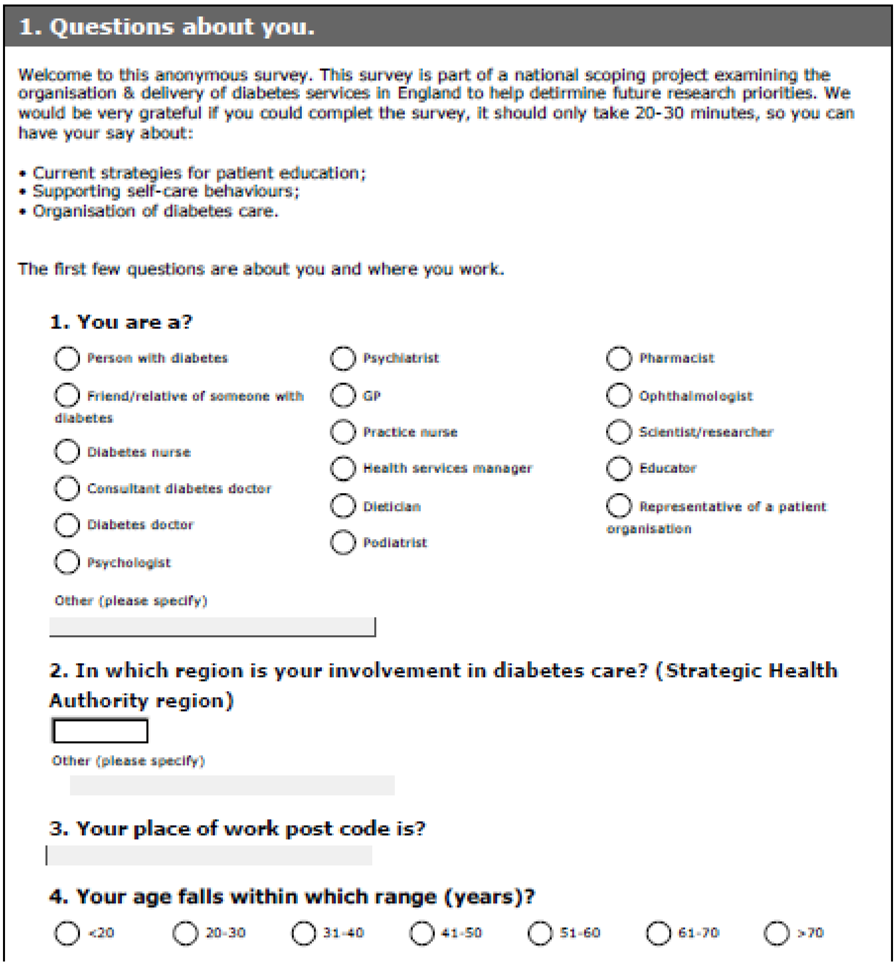
11. Overall how satisfied are you with the diabetes service you receive?

○ Very satisfied ○ Mostly satisfied ○ A bit dissatisfied ○ Very dissatisfied

12. If you had a choice would you continue to use your current diabetes service?

○ Yes, definitely ○ Generally ○ Not Really ○ No, definitely not

13. What one thing would most improve the way you diabetes services are organised and delivered?



1. Questions about you.

Welcome to this anonymous survey. This survey is part of a national scoping project examining the organisation & delivery of diabetes services in England to help detirmine future research priorities. We would be very grateful if you could complet the survey, it should only take 20-30 minutes, so you can have your say about:

- Current strategies for patient education;
- Supporting self-care behaviours;
- Organisation of diabetes care.

The first few questions are about you and where you work.

1. You are a?

○ Person with diabetes
○ Friend/relative of someone with diabetes
○ Diabetes nurse
○ Consultant diabetes doctor
○ Diabetes doctor
○ Psychologist
○ Psychiatrist
○ GP
○ Practice nurse
○ Health services manager
○ Dietician
○ Podiatrist
○ Pharmacist
○ Ophthalmologist
○ Scientist/researcher
○ Educator
○ Representative of a patient organisation

Other (please specify)

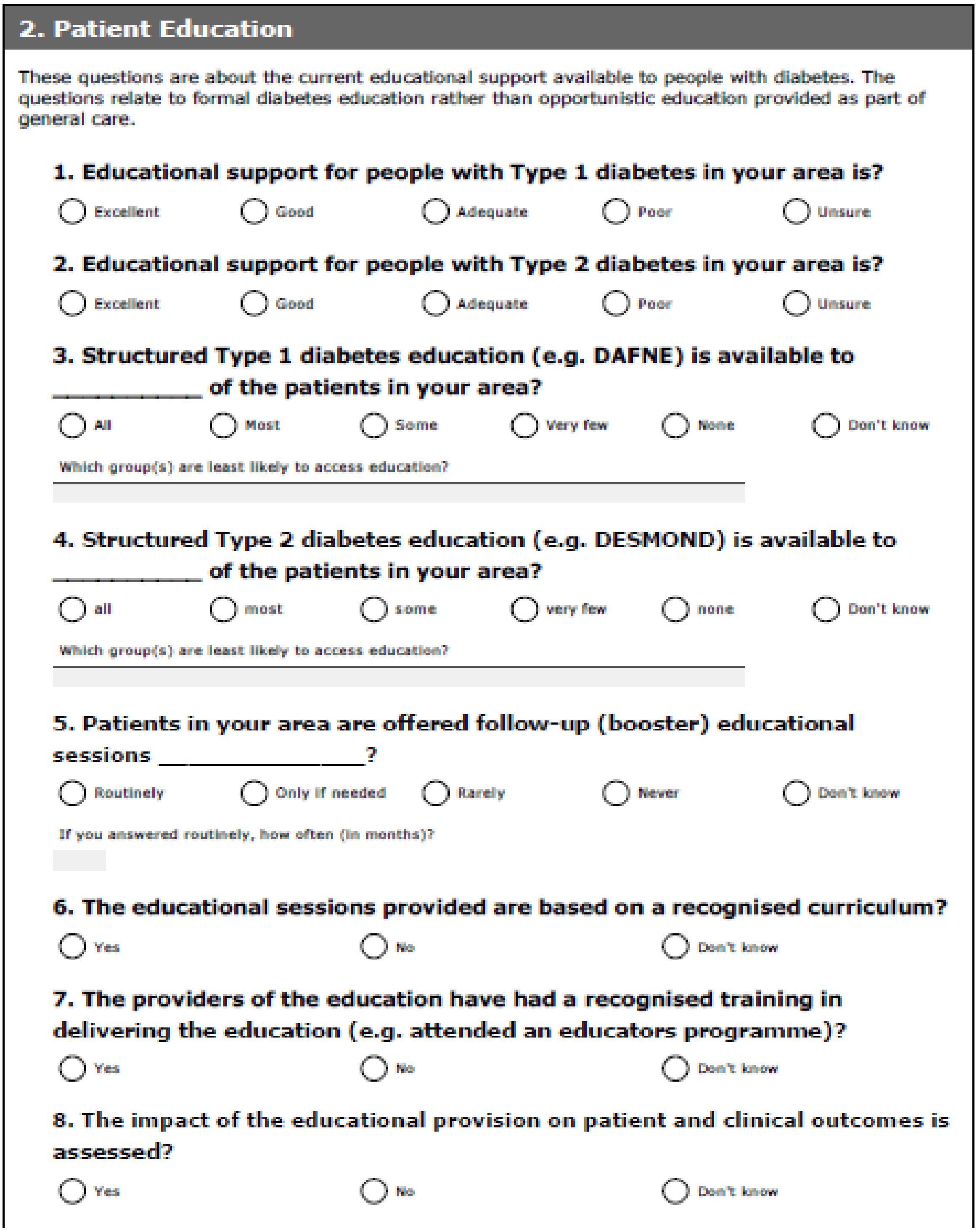
2. In which region is your involvement in diabetes care? (Strategic Health Authority region)

Other (please specify)

3. Your place of work post code is?

4. Your age falls within which range (years)?

○ <20 ○ 20-30 ○ 31-40 ○ 41-50 ○ 51-60 ○ 61-70 ○ >70



2. Patient Education

These questions are about the current educational support available to people with diabetes. The questions relate to formal diabetes education rather than opportunistic education provided as part of general care.

1. Educational support for people with Type 1 diabetes in your area is?

○ Excellent ○ Good ○ Adequate ○ Poor ○ Unsure

2. Educational support for people with Type 2 diabetes in your area is?

○ Excellent ○ Good ○ Adequate ○ Poor ○ Unsure

3. Structured Type 1 diabetes education (e.g. DAFNE) is available to ___________ of the patients in your area?

○ All ○ Most ○ Some ○ Very few ○ None ○ Don't know

Which group(s) are least likely to access education?

4. Structured Type 2 diabetes education (e.g. DESMOND) is available to ___________ of the patients in your area?

○ all ○ most ○ some ○ very few ○ none ○ Don't know

Which group(s) are least likely to access education?

5. Patients in your area are offered follow-up (booster) educational sessions _______________?

○ Routinely ○ Only if needed ○ Rarely ○ Never ○ Don't know

If you answered routinely, how often (in months)?

6. The educational sessions provided are based on a recognised curriculum?

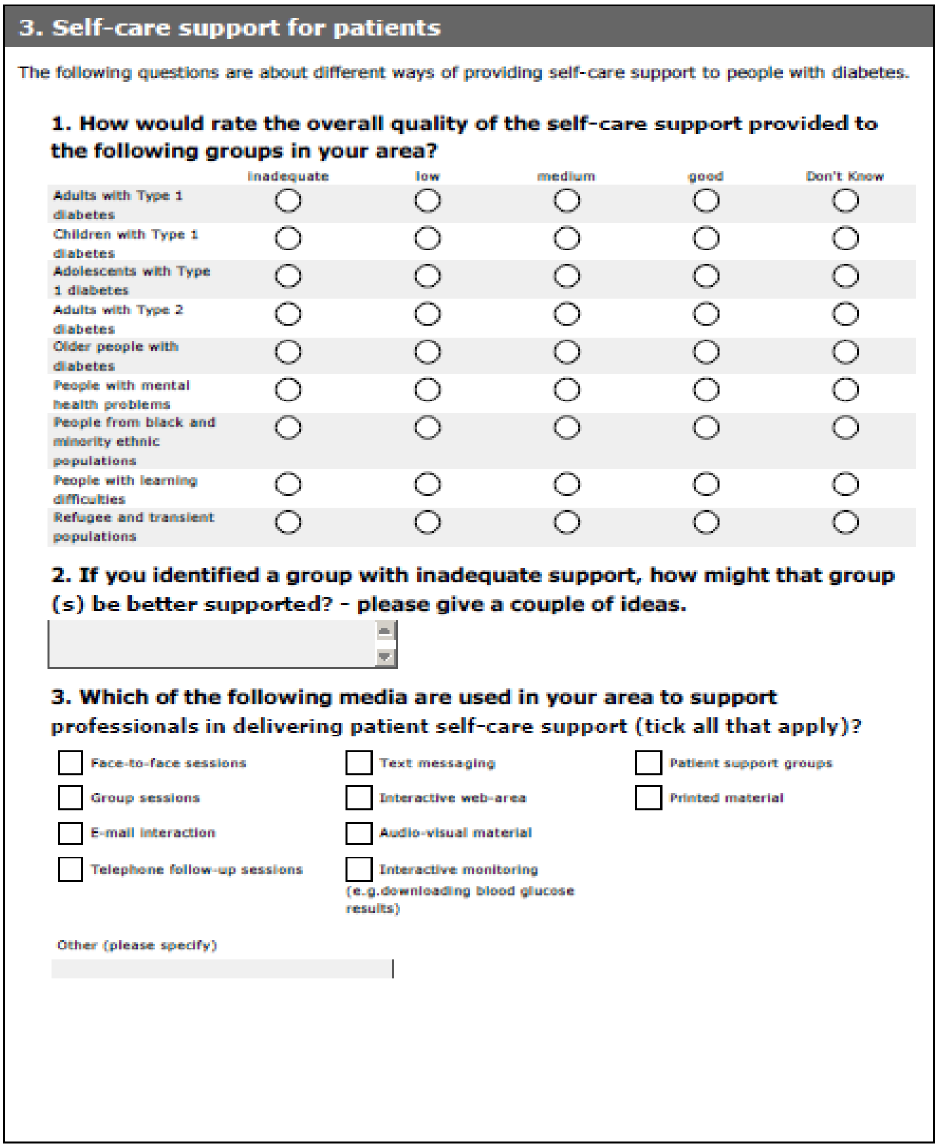
○ Yes ○ No ○ Don't know

7. The providers of the education have had a recognised training in delivering the education (e.g. attended an educators programme)?

○ Yes ○ No ○ Don't know

8. The impact of the educational provision on patient and clinical outcomes is assessed?

○ Yes ○ No ○ Don't know



3. Self-care support for patients

The following questions are about different ways of providing self-care support to people with diabetes.

1. How would rate the overall quality of the self-care support provided to the following groups in your area?

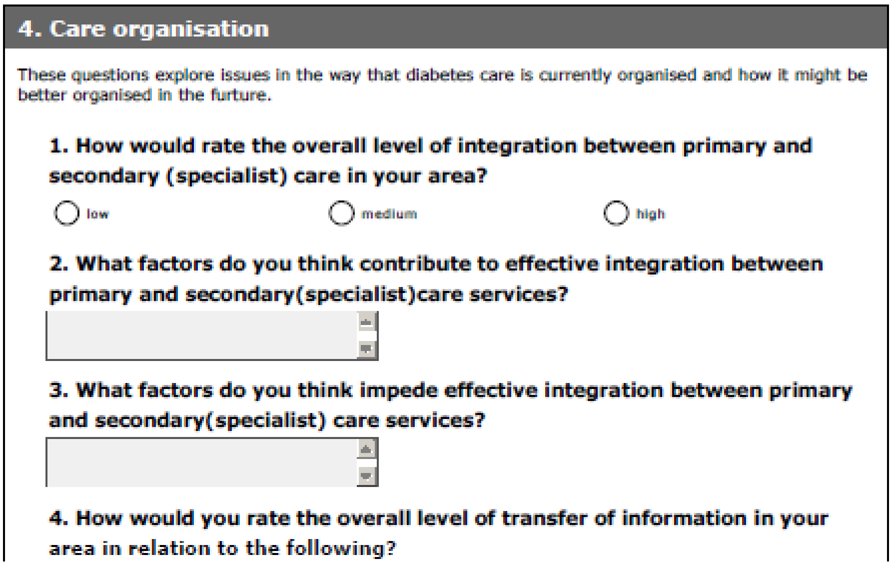
	inadequate	low	medium	good	Don't Know
Adults with Type 1 diabetes	○	○	○	○	○
Children with Type 1 diabetes	○	○	○	○	○
Adolescents with Type 1 diabetes	○	○	○	○	○
Adults with Type 2 diabetes	○	○	○	○	○
Older people with diabetes	○	○	○	○	○
People with mental health problems	○	○	○	○	○
People from black and minority ethnic populations	○	○	○	○	○
People with learning difficulties	○	○	○	○	○
Refugee and transient populations	○	○	○	○	○

2. If you identified a group with inadequate support, how might that group (s) be better supported? - please give a couple of ideas.

3. Which of the following media are used in your area to support professionals in delivering patient self-care support (tick all that apply)?

- ☐ Face-to-face sessions
- ☐ Group sessions
- ☐ E-mail interaction
- ☐ Telephone follow-up sessions
- ☐ Text messaging
- ☐ Interactive web-area
- ☐ Audio-visual material
- ☐ Interactive monitoring (e.g.downloading blood glucose results)
- ☐ Patient support groups
- ☐ Printed material

Other (please specify)



4. Care organisation

These questions explore issues in the way that diabetes care is currently organised and how it might be better organised in the furture.

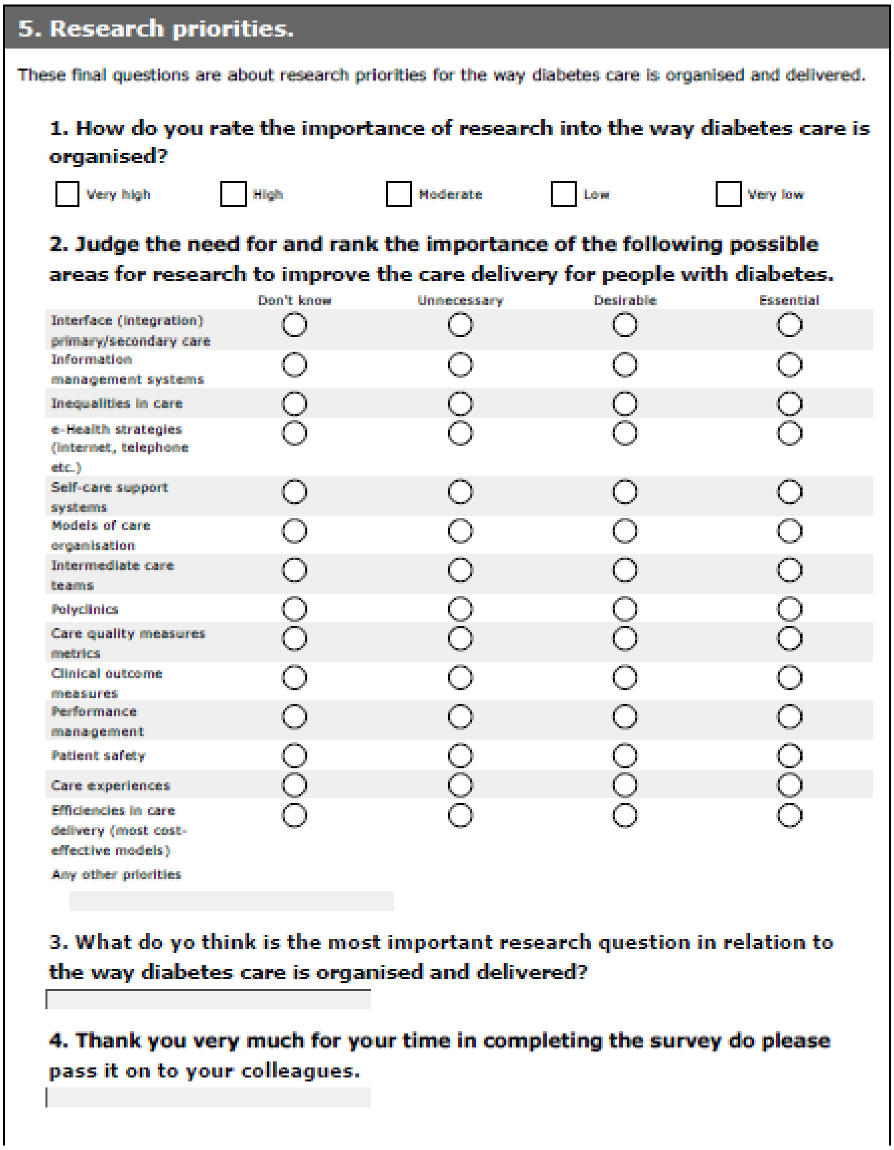
1. How would rate the overall level of integration between primary and secondary (specialist) care in your area?

○ low ○ medium ○ high

2. What factors do you think contribute to effective integration between primary and secondary(specialist)care services?

3. What factors do you think impede effective integration between primary and secondary(specialist) care services?

4. How would you rate the overall level of transfer of information in your area in relation to the following?



5. Research priorities.

These final questions are about research priorities for the way diabetes care is organised and delivered.

1. How do you rate the importance of research into the way diabetes care is organised?

☐ Very high ☐ High ☐ Moderate ☐ Low ☐ Very low

2. Judge the need for and rank the importance of the following possible areas for research to improve the care delivery for people with diabetes.

	Don't know	Unnecessary	Desirable	Essential
Interface (integration) primary/secondary care	○	○	○	○
Information management systems	○	○	○	○
Inequalities in care	○	○	○	○
e-Health strategies (internet, telephone etc.)	○	○	○	○
Self-care support systems	○	○	○	○
Models of care organisation	○	○	○	○
Intermediate care teams	○	○	○	○
Polyclinics	○	○	○	○
Care quality measures metrics	○	○	○	○
Clinical outcome measures	○	○	○	○
Performance management	○	○	○	○
Patient safety	○	○	○	○
Care experiences	○	○	○	○
Efficiencies in care delivery (most cost-effective models)	○	○	○	○

Any other priorities

3. What do yo think is the most important research question in relation to the way diabetes care is organised and delivered?

4. Thank you very much for your time in completing the survey do please pass it on to your colleagues.

Appendix 3 Literature Review

Overviews and systematic reviews of general educational/self care interventions

Description	Interventions	Evaluation
Odegard and Capoccia (2007) systematic review of intervention to improve compliance therapy	• Electronic medication devices • Telephone reminders • Behavioural therapy • Psychotherapy • Pharmacist education • Nurse education • Monitoring medication use	RCTs (moderate to weak design) showing minimal to small benefits on glycaemic control, stronger effects on patient behaviours including compliance.
Wens et al (2007) systematic review of educational interventions aimed at improving adherence to medical treatment recommendations.	Both individual and group interventions reviewed: • Individual included: pharmacist led interventions (pill count, Micro-Electro-Mechanical Systems (MEMS), comprehensive care, treatment adjustments or prescription refill reminders). • Group education varying levels some psychologist-led. • Telecare- weekly nurse-led or automated reminder calls.	Poor quality studies heterogeneous outcome measures and difficulties in evaluating different aspects of the interventions meant that no conclusions were drawn- need for more studies.
van Dam (2005) systematic review of social support interventions in T2DM (6 RCTs)	Systematic review • Group visits to physician • Peer group and peer counsellor • Internet peer support • Internet personal coach • Spouses, family and friends participants in education • Social support group sessions following diabetic education	Outcomes suggest some benefits of social support on psychological well-being and quality of life. But findings inconsistent and interventions very heterogeneous. Gender difference have been highlighted with women benefiting more from social support compared to men.
Loveman et al (2008) HTA systematic review (update) Education T2DM (13 clinical trials)	All interventions were structured education programmes they were divided into two groups: • Educational interventions on a range of topics related to diabetes	Overall structured education achieved a benefit of around 1% reduction in HbA1c. The study with the strongest effect was relatively small (n=121)

	self-management. • Intervention was focused on one or two aspects of self-management alone (e.g. diet and/or exercise).	and it was a long-term programme. At 5 years there were advantages for HbA1c (1.8% better than control), plus modest benefits in BMI and lipids (Trento, et al 2004).
Mujika Zabaleta and Forbes (2008) Review of structured-group education for Type 2 diabetes. 3 poor quality RCTs.	Interventions varied in size of groups, frequency and duration: • Groups of 4–6 for 90–120 minutes weekly for 1 month • Groups of 8 for 90–120 minutes weekly for 1 month • Groups of 19-20 for 120 minutes for 6 months	No clinically important benefit reported in glycaemic control or other diabetes outcomes.
Valk et al (2001) Cochrane review of education to prevent foot complications- 9 RCTs.	Interventions included: • Group diabetes education • Group foot care education • Patient education kit, videotapes and daily foot care sheets • Individual patient education and podiatric care visits • Education tailored to individual needs • Education targeting both people with diabetes and doctors	Only two studies reported end point data, one showed 30% reduction in ulceration and amputation rates in high risk patients after 12 months. The intervention targeting both professionals and patients reported a 40% reduction in serious foot ulceration, but no significant effect overall on foot ulceration.
Kirk et al (2007) Review of TTM in relation to physical activity in T2DM	Interventions to promote physical activity based on self-efficacy and TTM, focussing on: • Decisional balance • Experiential processes (exploring desire need and resources for change) • Behavioural processes (working on goals and acquiring resources for change).	Evidence outlined based on 'review' (not clear how valid) of studies most of which showed a self-efficacy model based on TTM and motivational enhancement improves physical activity and glycaemic control (at least in the short term).
Deakin et al (2005) Cochrane review of group education for Type 2 diabetes. 11 studies (n= 1532)	Group based interventions variations in duration, number of participants, curriculum and underpinning theory (not always explicit). In most studies the comparisons was with usual care (n=7), with 3 to waiting lists and 1 to an individual intervention.	The evaluation is impeded by heterogeneity, overall: a reduction of glycated haemoglobin is reported 0.8 to 1.9% (although variations in length of reporting and size of effect); a reduction in weight of 1.6kg; an improved self-care knowledge; an improved BP; and reduced diabetes medicines.
Clarke (2008) not systematic but wide	Key areas of review:	

ranging review of self-management education including large number of systematic review findings (n=11).	• Self management education: lower quality studies > effect sizes; longer duration of programme = ↑ SCB; knowledge and skill effect maintained longer term (to at least 1 year), weight loss not sustained past 12 months; metabolic control peaked at between 1 and 6 followed by declined, the opposite trend occurred with psychological outcomes; effect sizes smaller for age > 40. • Adolescent education: glycaemic control average effect size of 0.08 after removing studies with large effect. Improvements in psychosocial outcomes were larger (mean effect size 0.37). • NICE evidence suggests that DAFNE reduces costs over 10 years by £536. • Community based peer support- US evaluations have shown reductions in symptoms, physician visits, and costs relative to patients receiving usual care. UK evaluations on-going of projects such as expert patient programme. E-health (interactive computer) Cochrane systematic review included some diabetes results indicated probable positive effect on self-efficacy.	
van Dam et al (2003) systematic review of professional-patient interaction (n=8 RCTs, although only 4 really about empowering consultations).	Interventions: 1. GPs and PNs trained in empowering consultations and shared goal setting (3 RCTs). 2. Patients given 30 minute session to help them respond to empowering session before consultation controls had standard diabetes education same length of time before consultation.	Outcomes: 1. Patient satisfaction improved in one study unchanged in others; metabolic control deteriorated in one study remained the same in another and improved in one; little change in self-care behaviour; 2. At 9 months improved patient satisfaction, perceived health, and diabetes control (mean HbA1c down 1.2% more in treatment group).
Si and Bailie (2008)systematic review of Chronic Care Model in diabetes (n= 69 studies 43 RCTs)	Intervention components: • Organizational goals and resources for chronic illness care: quality improvement strategies; incentives. • Community linkages. • Self-management support. • Decision support. • Delivery system design: team functioning, patient care planning and follow-up, co-ordination between primary care and specialist services. • Clinical information systems.	An average or around 0.5% reduction in HbA1c interventions that addressed delivery system design reported had greatest impact, followed by those employing a self-management component. Interventions involving decision support or clinical information systems reported relatively

		smaller effect sizes.
Graffy et al (2009) Review of systematic reviews (n=22) focussing on the components of care planning.	Care planning heterogeneous activity comprising: • Individual patient story- the focus here was on patient professional communication (empathy eliciting patient agenda), the reviews reported ↑ symptom resolution, ↑ emotional well-being, ↑ patient centeredness, ↓ anxiety. However, impact on SCB or clinical outcomes weak and mixed. • Case management from a professional perspective- finding and treating those at risk has shown benefit in monitoring and in glycaemic control. • Interactive computer interventions- slight improvement in glycaemic control and SCB • Promoting feels of self-efficacy and mastery might be important in SCB but no compelling evidence. • Psychological interventions MI, CBT and treating morbidity (depression) some impact on HbA1c. • Decision aids communicating risk in a way the patient can relate to might encourage action planning. • Neither education, reminders, nurse-led telephone interventions or pharmacist reviews had much impact on adherence to medication.	

Specific Educational interventions		
Description	**Interventions**	**Evaluation**
Amiel et al (UK) (2002) RCT (n=169) Comparing structured education (DAFNE) with those on waiting list for	• Group based structured education programme, based on adult learning principles 5 day course. • Patients thought how to adjust insulin doses to match energy intake and expenditure.	Significant positive impact on glycaemic control (1% advantage over controls), without additional hypoglycaemia. Benefit in

DAFNE (6 month FU).		diabetes control. Benefit at 12 months in QoL. No other metabolic benefits.
Davies et al (2008), Skinner et al (2006) (UK) Cluster RCT in 207 practices in 13 health districts, (n=824) to evaluate DESMOND Type 2 structured education programme.	DESMOND is a structured education programme delivered over two half days, based on the following principles: • Individual choices are important • Patients need support/resources to make good choices • Common-sense model of Illness = how the person constructs diabetes will influence how they behave in response to it. • Social learning theory = emphasises self-efficacy (mastery) • Learning occurs in the sphere of the patients own experience (zone of proximal development)- adult learning principles	Improved glycaemic control 1.5%, however not significantly greater than control group. Psychological well-being (depression) better and patients in the intervention group greater weight loss and smoking cessation.
Breslin et al (2008) (US) Development of decision making tool to support medicines choices with patients.	• Series of cards to support patients making informed choices about medications considering effects on: weight; hypo and hyper glycaemia; frequency of drug taking; side-effects; and drug taking requirements (timing and monitoring).	Study developed and field tested cards. They stimulated wider conversation with patients about their medicines choices. A trial is planned to assess impact on compliance.
Keers et al (2005) (EU) before and after study with a reference group and economic analysis of multidisciplinary intensive diabetes education programme (MIDEP) (n=230)	MIDEP, similar principles to DESMOND- empowerment model, adult learning, patient centred targets, but more intensive: • 10 days of group sessions (6-9 patients) + individual support for 10-weeks + follow-up OPD at 6 and 12 weeks and 1 year. • MDT = DSN, endocrinologist, dietician, social worker, psychologist, physio, OT and an activity therapist.	Improved glycaemic control (medium effect 0.3 = 0.5% hbA1c, NNT = 3 for every 0.5% reduction) and psychological well-being (PAID) and reduced overall costs- despite intensive nature of intervention, although reduction equivocal. .
Cooper et al (2008) (UK) RCT waiting list design (similar to DAFNE study) those on waiting list act as control (n=89)	LAY (look after yourself) model based on 2-hour sessions weekly for 8 weeks, incorporating: • Adult learning • Skills training • Use of visual media to stimulate discussion in relation to: living with diabetes, changing behaviour, and preventing complications.	The study found now sustained (12 month) benefit in glycaemic control, although there were benefits in self-monitoring and attitudes to diabetes.

Garret et al (2005) RCT (n=462) evaluating a group based patient led education module. (US)	• Intervention based on Bandura incorporated a learning map consisting of two 3-ft · 4-ft tabletop visual posters (the “Learning Map visual”), activity cards, and a facilitator’s guide. • One poster was used to help patients explore the nature of diabetes the second helped them conceptualise their potential journey.	No data on impact on glycaemic control, although all the primary outcomes superior in the intervention group: knowledge, feeling of control, and self-care behaviour.
Mannucci et al (2004) Case control study (no-randomisation) comparing interactive education with usual care (routine clinic appointments)	Interactive Educational and Support Group (IESG) was designed as a semi-structured, long-term, open, group education programme. • Monthly evening sessions of 2 hrs held by diabetologist who did not give direct advice but facilitated group decision making.	Participants (self-selecting) saw a mean fall of 0.7% in HbA1c compared to falls of 0.2 and 0.3% controls and non-attendees, respectively.
Farmer et al (2009) RCT of SMBG Type 2 DM (n=453) (UK) – clinical and economic analysis.	Interventions: • 3-monthly HbA1c • 1 + self-testing with patient training focused on clinician interpretation of results. • 2+; additional training of patients in interpretation and application of the results to enhance motivation and maintain adherence to a healthy lifestyle	No clinical or statistically significant difference between the control or either of the intervention groups. Qualitative data (n=40) suggested that patients feel SMBG: increases awareness of diabetes and link between symptoms and BG; gives reassurance about health status; promotes link between behaviour and diabetes; increases adherence; improves interaction with clinicians. Economic= SBGM associated with higher costs and lower quality of life.
Sturt et al (2008) Cluster RCT 45 practices (UK)- (n=245) Type 2 education.	Intervention= structured 1:1 education, based on empowerment self-efficacy model delivered by practice nurses (educated with a 2 day course): • 15-min face-to-face consultation with patients to introduce the 12-week Diabetes Manual programme. • Manual = 230-page workbook topics included diabetes facts/ metabolism/goal setting and evaluation/exercise/ nutrition/blood glucose monitoring/weight loss/smoking	No statistical or clinical difference in any metabolic outcomes. Slight improvement in diabetes related psychological problems (PAID) and self-care behaviour/knowledge- although completion of these measures was low.

	cessation/tests/ complications/medication/stress, anxiety and depression/ cholesterol/quizzes to self-evaluate /other peoples' stories/self-assessment to encourage personal evaluation of behaviour change. • Audio tapes (factual and relaxation) • Telephone follow-up calls from PN.	
Kulzer et al (2007) RCT (n=181) T2DM (EU)	Interventions 3 treatment modalities: • Didactic session 4X 90 minutes • Patient-led motivation group sessions 12 X 90 minutes • As above except half of sessions face-to-face.	Significant clinical benefits at 15 months of group model compared to didactic sessions. This studies suggests that group education works better than more individual models.
Chapin et al (2003) RCT (n=127)T2DM (US)	Intervention was a feedback model- patients were given a spreadsheet of their HbA1c trend with an explanation of risk and action points to improve control. The chart was graded in terms of risk level and relationship of HbA1c to average BG level.	The intervention group had a mean improvement in HBA1c of 1% compared to 0.2% in the control.
Schillinger et al (2009) RCT (n= 339) (US)	Intervention designed to target specifically hard to reach populations: • Automated calls with nurse follow-up (weekly calls 39 weeks) • Monthly group medical sessions (90 minutes for 9 months) • Usual care routine OPD	Improvements in both treatments for self-efficacy and self-care management. Neither treatment showed significant impact on metabolic outcomes, although the impact was stronger in the automated calls with nurse follow-up group.
Barratt et al (2007) RCT (n=53) T2DM (UK)	Intensive dietician intervention to prevent weight gain for new to insulin T2DM, intervention X6 individual sessions (30 minutes) over 1/12, elements: • Individual food/activity plan/targets • Emotional and psychological factors • Food knowledge (labels etc.) • Progress review- feedback • Supportive resources (weight watches etc)	Intervention maintained starting weight while control gained significantly (5kg) at 6 months following insulin initiation. Both groups achieved similar improvement in glycaemic control. The authors note that less than a fifth of control subjects saw a dietician after insulin initiation- suggests need for more systematic models.
Allen et al (2008) RCT (n=52) T2DM (US)	Intervention based on feedback related to CGM to promote more physical activity. Both groups received 90 min of diabetes	Self-efficacy and physical activity greater in the intervention group. The study also

	education with a follow-up phone call 4 weeks later. Intervention group also received counselling based on self-efficacy theory, five steps: five steps: • Review CGMS graphs with each participant • Outline benefits of physical activity • Assess confidence in changing physical activity • Prescribe physical activity program • Discuss normal responses to a physical activity program.	reported a significant improvement in glycaemic control in the intervention group with 0.7% advantage in change over the 8 week intervention, no data on long-term follow-up.
Gregg et al (2007) RCT(n=81) T2DM area of deprivation (US)	Psycho-education intervention: • One session (one day) of diabetes education with (intervention) or without (control) acceptance and commitment therapy- this therapy promotes mindfulness regarding difficult thoughts and feelings about diabetes, exploration of personal values related to diabetes, and a focus on the ability to act positively.	Improved glycaemic control at 3 months with 0.5% greater reduction compared to control. Plus improved self-management, acceptance and understanding.
Adolfsson et al (2006) RCT (n= 101) T2DM, 12 month follow-up (EU)	Intervention compared to usual care: • Empowerment based model of education based on adult learning principles, 4 to 5 two and half hour group sessions. Groups led by patients facilitated by specialist nurses and physicians. Patients set own agenda and set their own goals.	At 1-year follow-up, the level of confidence in diabetes knowledge was significantly higher in the intervention group than in the control group ($p < 0.05$). No significant differences were found in self-efficacy, satisfaction with daily life, BMI and HbA1c between the intervention and control group.
George et al (n=104) RCT (UK) T1(DM)	BITES trail, brief intervention based on psychological theories of self-regulation and social learning- empowerment model following principles of adult learning: conceptualization (in the classroom), observation (classroom and home), experimentation leading to expertise (home), and reflection (classroom and at home after the intervention), format: • 2.5 days spread over 6 weeks (compared to 5 days for DAFNE) • Carb. counting and insulin adjustment	No improvement in glycaemic control or reduction in hypos, explanations suggested as: comparison with patients on MDI already; lower baseline HbA1c compared to DAFNE or Düsseldorf studies. The short delivery over a longer period of time diluted

Deakin et al (2006) RCT T2DM (n= 314)	Group-based (14 hours in 6 weeks) empowering education model (X-PERT) involving patient-led activities to explore issues and benefits: • Exercise, dietary components. • Supermarket tour- sourcing foods. • Explore complications. • Weekly goal setting for duration of course. • A patient manual- diabetes handbook.	Benefits observed at 14 months 0.7% advantage in intervention group compared to control in HbA1c. Slight benefit in weight (not clinically significant). Other benefits included: reduced requirement for diabetes medication, increased consumption of fruit and vegetables, enjoyment of food, knowledge of diabetes, self-empowerment, self-management skills and treatment satisfaction
Huisman (2009) RCT Weight loss in T2DM (n=31)	Compared general education with a multifaceted psychologist-led intervention comprising: • Individual motivational interview (1hr) • 6 2-hr group meetings + two 2-hr booster sessions within 1 • year, led by a health psychologist, • workbook with homework assignments • use of a pedometer.	No differences in weight at 3 or 6 months.

Psychological interventions

Description	Interventions	Evaluation
Snoek et al (2008) RCT (n=86) comparing BG awareness training with CBT (EU)	• CBT six weekly group sessions. plus information sheets homework (psychologists) • BG awareness training (diabetes nurse)	No impact for either intervention on glycaemic control. However, some benefit from CBT in patients with prior depression.
Amsberg et al (2008) RCT (n=94) Group	• 8 weekly 2-hour sessions of CBT: with the exception of session 7, all were delivered in groups.	Advantage in glycaemic control in favour of

based CBT (EU)		intervention -0.5%.
Peyrot and Rubin (2007) theoretical review of behavioural and psychosocial interventions (US).	Identifies different types of intervention: • Behaviour change interventions- they construct these into the following model 1. Constructing a problem definition; 2. Collaborative goal setting; 3. Collaborative problem solving; 4. Contracting for change; 5. Continuing support. • Emotive support interventions- emphasis on the need to assess psychological issues (Identify patients who are suffering from diabetes-related distress; 2. Apply effective treatments to relieve diabetes-related distress; 3. Identify patients who are suffering from psychiatric disorders; 4. Refer patients for specialized mental health care when appropriate). • Treat Depression.	The review is more theoretical than empirical, although attempts are made to draw on evidence when available- clearly a need for better studies to confirm these ideas.
Martins and McNeil (2009) systematic review motivational interviewing	9 diabetes studies identified 4 T2DM and 5 T1DM. Controls generally quite week comparisons.	Evidence of effect mixed improvements in patient experience and in self-efficacy, however sustained change in clinical outcome not shown consistently.
Moran et al (2008) (UK) observational study of diabetes consultations (n=44)	Overall few motivational strategies used despite the high (44%) level of consultations involving lifestyle changes. Association was found between physicians' use of patient-centred and partnership strategies and patients expressing views; higher patient satisfaction; and patients asking questions. Familiarity between doctor and patient was associated with more physician recommendations, information giving and more assertive responses from the patient	
Ismail et al (2008) (UK) RCT examining CBT and MI (n=344) T1DM	• Nurse-delivered motivational enhancement therapy (4 sessions over 2 months), • Motivational enhancement therapy plus cognitive behavior therapy (12 sessions over 6 months), or usual care.	Effect stronger in MI plus CBT group -0.5% compared to -0.1% in the MI only group, although intervention was more intensive in the former.

Culturally adapted programmes		
Description	**Interventions**	**Evaluation**

Anderson-Loftin et al (US) Controlled Trial (n=97) comparing culturally tailored dietary ed. with standard model	• African American focus, low fat cooking classes (x4) using AA foods + 4 monthly professional/peer support group sessions + weekly phone calls from nurse. • Standard model= 8hr educational session	Weak trial- follow-up less than 80%. Weight reduction 1.8kgs in intervention weight gain 1.9kgs in control.
Hawthorne et al (2009) Cochrane review of Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups. 11 clinical trials included.	Educational interventions tailored to the cultural/religious beliefs and linguistic skills of the community being approached, methods of delivery included: • Link workers (four studies) • Dieticians (eight studies) • Diabetes nurses (seven studies) • Podiatrists (one study) • Psychologist (one study) • Exercise physiologists (two studies)	Meta-analysis showed slight benefits in glycaemic control at 3 and 6 months, although improvements not sustained past 12 months. Knowledge also improved but no other benefits in metabolic well-being observed.
Khunti et al (2008) systematic review of studies examining psycho-educational interventions for migrant South Asian populations T2DM 9 studies- not all RCTs (n=1004)	Interventions were individual and group based and included: • Tailored clinic appointments • Culturally adapted education • Structured education by link-worker using flashcards • Medication reviews with bi-lingual worker • Self-help groups	High levels of heterogeneity design and intervention. Only two studies reported close to a clinically significant improvement in glycaemic control (0.5% HbA1c). These interventions were the: structured education by link-worker using flashcards; and an intervention of culture-specific care including educational resources. Follow-up limited to 6 and 3 months respectively. Stronger impact found on knowledge limited account of wider metabolic outcomes (BP lipids). Suggested need for better methods and more systematic model of design to aim for a uniform approach that addressed the heterogeneity of the population.
Griffiths et al (2005) RCT (not just diabetes chronic conditions) (n=476)-	Educational intervention designed to promote self-efficacy: • Culturally adapted version of the Chronic Disease Self-management Programme, a lay-led (Bangladeshi tutors who	Only 50% completed programme. Intention-to-treat analysis showed improvement self-

high level of exclusions (>60%). Primary outcome self-efficacy (UK)	themselves had a chronic condition) programme based on Bandura's theoretical model of self-efficacy. • 6 weekly 3hr secessions + video , topics: cognitive symptom management (anger, fear); relaxation techniques; making an action plan; communication; healthy eating; problem solving.	efficacy but limited impact on self-care. If subjects attended 3 or more sessions the impact was stronger and there was also a reduction in depression scores. Cost = £123.00 per patient.

Telecare Interventions – self care

Description	Interventions	Evaluation
Dale et al (2008) RCT (n=231) T2DM	Telephone follow-up by peers delivering motivational support via telephone 6 calls over 5 months. The calls were made at a time when changes were instigated by GPs or PNs in primary care. The comparison was to DSN telephone follow-up and usual care.	At 6 months there were no statistically significant differences in self-efficacy scores, HbA1c or other secondary outcome measures, although it is noteworthy that the DSN and usual care groups achieved a clinically significant advantage in HbA1c compared to the control group.
Trief et al (2009 Longitudinal study prospective cohort no case match.	Case management via a home telemedicine unit- a web-enabled computer to upload blood glucose (BG) and blood pressure (BP) readings, to videoconference with a dietician/nurse case manager and to access education and data. Televisits were 30–60 minutes long, and occurred every 4–6 weeks.	Improvements in self-efficacy and HbA1c reported, although design does not allow comparative estimate and no actual data given on numbers achieving significant improvement.

Azar and Gabay (2009) review of RCTs examining patient uploaded data with professional feedback.	Varying degrees of automation from patients manual up-loading data to devices that automatically transmit data. Follow-up from professionals varying in intensity and frequency	Overall benefits on glycaemic control found un Type 2 patients but not in Type 1 patients. In some studies there was notable drop out suggesting that patients may not be universally suited to this type of intervention.
Jackson et al (2006) Systematic review US 26 studies from 3 Interactive behaviour change technology (IBCT) types: • internet (n=6; 3 RCTs) • telephone (n=7; 4 RCTs) • integrated computerised information (n=13, 7 RCTs)	1. Professional to patient models (automated and professional), although internet models included self-directed patient educational material. 2. The integration of clinical guidelines and algorithms to provide individual self-care/treatment advise.	Glycaemic benefits report as follows: • internet (none to small) • telephone (none to large) • computer (none to large) Some benefits reported in reduced hospital attendance and admission. Data on costs inadequate. Heterogonous studies generally of low quality.
Rossi et al (2009) pilot (pre-post test)(n=41) T1DM	Mobile phone based device to calculate CHO intake with bolusing and corrections managed to BG results by health professionals.	A non clinically or statistically significant 0.33% reduction in HbA1c.No hazards reported seems acceptable to patients.
Ralston et al (2009) T2DM (n= 83) (US)- the IDEALLTeL programme	Intervention was web-based case-management regular review (weekly) to get patient moving too targets. Followed by tailored follow-up based on patient outcomes and needs. Incorporated: e-mail communication; transmission of self-monitoring; am interactive medical records; and systems for prompting and reminding patients. The intervention was mapped to Wagner's care management model targeting: self-management; support for patients, delivery system; design, clinical information systems, and clinical decision support.	HbA1c improved by 0.7% compared to control no improvement in BP or Lipids.
Shea et al (2009) T2DM (older adults >55 years ethnic diversity) US – RCT- 5	Nurse self-care support through televisits and monitoring, adhering to diet, exercise, foot care, and medication regimes-	Found a significant sustained small reduction in HbA1c of 0.3%, BP systolic

year follow-up on the IDEATeL programme	promoting optimal therapy models.	(4.2mmHg) and lipids. Mortality was equal in both groups. However, comparison to other interventions by Moreno et al (2009) suggested that these benefits at a cost >$8,000 were not good value.
Estabrooks and Smith-Ray (2008) Controlled trial (n=77) (US)	Weight loss intervention pre-diabetes using interactive voice messaging (IVR)- counselling messages and tips. Patients have to actively choose the tip of the day either diet or physical. Counselling goals led to patient choosing new goals.	Patients in the IVR group achieved a modestly greater increase in weight loss (2.6%) compared to the control (1.6%) group.
DelliFraine and Dansky (2008) Home based tele-care included 5 RCTs	Five of the studies investigated reported changes in HbA1c levels had sample sizes ranging from 31–140. The effect size was 0.13 indicating that the meta-analysis did not support a link between tele-health and diabetes outcomes.	
Fonda et al (2007) The Joslin Vision Network cohort study- retrospective analysis.	Comprehensive diabetes package centred on eye care encompassing: • Education- linking eye to BP, glucose and importance of annual review • Eye screening- images imported into patient record and used to inform decision making. • Follow-up care plan	They reported that those in the tele-eye care programme were more likely to have reduced HbA1c through time and improved lipid profiles.
Williams et al (2007) US T2DM RCT (n= 866)	Computer programme assessed current self-management and provided tailored feedback, goal setting, with an individual action plan, including a summary of self-management. The programme highlighted issues the patient would like to discuss. Patients had designated care managers who follow-up patients with calls calls after visits. The programme incorporated the Chronic Care Model (Bodenheimer, 2002). Comparison was patient who got computer but without the interactive package.	Complex evaluation model (using SEM), while model supported improved autonomy the metabolic control associations were weak.
Logan et al (2007) US T2DM before/after (n= 33)	Blood pressure monitoring automatically telephoned in via mobile. Patients received reminders on medication and lifestyle guidance	Mean reduction in systolic BP 11 mmhg and diastolic 5 mmhg. Patients found system

	via text message + therapy modulation based on individual targets.	acceptable.
Glasgow et al (2006) T2DM US RCT (n=335)	Interactive CD-ROM with self-care programme based on Chronic Care Model (Bodenheimer, 2002) including assessment of current health behaviour, feedback, identification of benefits and barriers to change, and tailored goal-setting and action-planning + tailored follow-up letters reinforcing the patient's selected goals and feedback on clinical results. Health coaches trained in MI were also incorporated into the intervention. Comparison was to Usual care with computer supported self-care (but without the enhanced care elements).	Only 8 week follow-up given no significant improvement in glycaemic control, although slight benefit 0.3% reduction in HbA1c intervention group. There was also very modest improvement in weight and lipids.
Franklyn et al (2006) T1DM (youth) RCT (n=126) Sweet-Talk text messaging	Sweet Talk is an automated, scheduled text-messaging system Patients set their own goals and based on these goals and patients' age, sex and diabetes regimen, Sweet Talk sends tailored messages, including a weekly reminder of the goal set in clinic, and a daily message providing tips, information or reminders to reinforce this goal. In addition, patients receive occasional text 'newsletters' regarding topical diabetes issues. Factorial design 3 groups: • Usual care non-intensified insulin. • Usual care + Sweet Talk • Intensified insulin + Sweet Talk.	Majority of patients felt sweet talk had improved their diabetes. Sweet talk increased diabetes self-efficacy and adherence. However, only intensified group achieved significant improvement in HbA1c 0.8%, although mean was only 9.2%.
Jansa et al (2006) T2DM US RCT (n=40)	The use of transmitted BG results and telephone counselling (0 telephone 3 out-patient) compared to 12 OPD visits, over 12 months.	No difference in clinical outcomes, although Telecare reported to be cheaper- not full economic analysis.
Rami et al (2006) T1DM (youth) RCT-crossover design	Patients uploaded BGs daily and received advice from diabetologist.	Patients control improved during the intervention and deteriorated outside of intervention. Patients found it acceptable- no data on costs.

Heidgerken et al (2006) T1DM (youth) Case series (n=9)	Tele-based psychological intervention for troubled adolescent young T1 patients (frequent DKA poor control etc.) telephone or video conference. An initial asses net followed by 3-4 weekly contacts average number of 41 per patient.	Benefits observed were a 1% drop in HbA1c and no hospital admissions.
Tate et al (2003) Pre-diabetes (overweight adults) RCT (=92)	A basic web-support compared to an internet counselling model: • Basic web-support- (a tutorial on weight loss, a new tip and link each week, and a directory of selected Internet weight loss resources) + an e-mail reminder to submit weight and receive weight loss education. • Internet Counselling- (as above) + more detailed diet exercise reporting and any comments or questions for the therapist via a Web-diary (daily to start with. The therapist e-mailed participants 5 times each week for one month and then weekly e-mails for the remaining 11 months. Counsellor e-mails provided feedback on the self-monitoring record, reinforcement and recommendations for change.	The e-counselling group lost more weight at 12 months than the basic Internet group (−4.4kg compared to -2.0kg), and had greater decreases in percentage of initial body weight (4.8% vs 2.2%), and waist circumference (−7.2cm vs −4.4cm cm). No data on comparative costs etc.
Holbrook et al (2009) RCT T2DM (n=511) (CAN)	The intervention aimed to ensure and the most recent laboratory results were available to both provider and patient at the time of the patient’s visit. Electronic tracker also linked to patients record sending automated reminders to patients about taking medicines and attending follow-up appointments	Improvements found in composite process scores (complication screening) and outcome composite (HbA1c, lipids, BP), although only statistically significant in the latter.
Meigs (2003) RCT (cluster) T2DM (n=307) (US)	Diabetes website to manage patient information, displaying interactive patient-specific clinical data, treatment advice, and links to other web-based care resources.	Small 0.3% different in HbA1c advantage to intervention.
Glasgow et al (2002) RCT Factoral (US) T2DM (n=320)	Factoral design in which four elements of the study were tested incrementally: • Goal setting • Community resources- folder with information plus news letter encouraging participation in activities to support lifestyle. • Telephone follow-up- interactive and tailored to clinical response	Each element independently and collectively contributed a small (0.83%) improvement in glycaemic control.
Levatan et al (2002) RCT (n=150) (US)	Intervention to generate patient feedback of clinical data (HbA1c,	No differences in metabolic outcomes

	BP, weight and lipids). Clinical data were used to produce individualised poster for patient (coloured and laminated). The poster details in easy read (with explanation) current status in one column and target in the next. At the foot of the poster is a personalised action plan.	observed at 6 months, although patients in the intervention group had a 0.5% advantage over controls in reduction in HbA1c with a reduction of 1.1% compared to 0.6%.
Grant et al (2008) Cluster RCT (n=11 primary care practices, 244 patients) US	Integration of electronic care plan with medical record to facilitate agenda setting for primary care consultations: • Patient access to their clinical information linked to tailored decision support. • Online tool to identify areas requiring clinical action. • Generation of a "Diabetes Care Plan" based on patients' • responses submitted directly to medical record.	No difference in metabolic control between groups, despite improvement in medication adjustment in intervention group. Authors suggest that good baseline control may have been a factor.
Sarkar et al (2007) Observational study (n=111) (US)	Examined the use of an automated call system to detect adverse events (actual or preventable). Patient trigger follow-up calls from nurse by responding to pre-set questions or be raising a query.	The system identified adverse events in around 12% of calls. Suggesting that the model may increase patient safety by increasing the speed in detecting problems.
Grant et al (2005) US Survey n=909 patients with Type 2 DM	Examined inequalities in use of e-technology. Older and reduced socio-economic status less likely to use internet. However, low use not implicated in metabolic control. Access and use of internet not universal. Low users would not choose to use for health care purposes.	
Thomson et al (2009) Overview of Diabetes-e (UK)	Diabetes-e (not to be confused with diabetes-E) is an electronic diabetes encyclopaedia providing comprehensive education to patients, carers and health professionals. It includes: information leaflets (that can be printed during a consultation); streaming educational video and slide resource packs; self-assessment questionnaires connected to further education; and CPD for health professionals.	
Verhoeven et al (2007) Systematic review of tele-consultations and videoconferencing studies (n=39).	The selected studies suggest that both tele-consultation and videoconferencing are practical, cost-effective, and reliable ways of delivering a worthwhile health care service to diabetics. However, the diversity in study design and reported findings makes a strong conclusion premature. To further the contribution of technology to diabetes care, interactive systems should be developed that integrate monitoring and personalized feedback	

Care system		
Description	**Interventions**	**Evaluation**
Si et al (2008) Systematic review of the chronic care model in DM 69 studies (43 randomized controlled trials and 26 controlled before–after studies)	Chronic care model is a whole systems model that incorporates, the following integrated elements: the community, the health system, self-management support, delivery system design, decision support and clinical information systems. Interventions based on the model seek to provide a comprehensive package of care that is patient centred and links the patient with a range of different supportive components. It has been widely adopted in North America with some pilots in the UK.	Meta-analysis showed a mean reduction of 0.46% (95% CI 0.38, 0.54) in HbA1c, mean reduction of 2.2 (95% CI 0.9, 3.5)mmHg in systolic blood pressure, mean reduction of 1.3 (95% CI 0.6, 2.1)mmHg in diastolic blood pressure and mean reduction of 0.24 (95% CI 0.06, 0.41) mmol/L in total cholesterol. Greatest benefit found in systems deploying a self-management support component.
Parliamentary Best Practice Consensus Group (2009) report into Diabetes in the South Asian Community	A range of interventions identified: • Outreach work (working with communities) • Tailoring services to the need of the population • Communication support • Encouraging community members to train as nurses and dieticians • Developing structured education models that reflect needs of populations	Mainly anecdotal, although the best practice examples have certainly demonstrated improvements in care participation.
Bellary et al (2008) UKADS cluster RCT	Intervention: Bellary et al (2008)	Small improvements in BP no improvement

(n=21 practices n= 1486 patients) testing impact of enhanced care model for patients of South Asian origin.	• GP, diabetes specialist nurse and culturally sympathetic link-worker. • Four hour session with practice nurse, supported by link workers and diabetes-specialist nurse. • Prescribing algorithm provided. Control- usual diabetes care from practice nurse and GP plus prescribing algorithm.	in HbA1c. Economic analysis suggested intervention not cost effective.
Peek et al (2007) systematic review (n=42 studies including 22 RCTs remainder quasi-experimental) address in care inequalities in diabetes	Interventions: • culturally tailored programs; • one-on-one feedback and education • and health system interventions such as case managers and specialist nurses.	Overall 0.4% reduction in HbA1c. However effects stronger for culturally tailored programmes 0.6%,
Glazier et al (2006) Systematic review interventions (n=15 RCTs) for social disadvantaged	Interventions: • cultural tailoring of the intervention, • community educators or lay people leading the intervention, • one-on-one interventions with individualized assessment and reassessment • behaviour change interventions (high-intensity interventions)	No specific data on glycaemic effects, although they report improvements of 1% in HbA1c in a number of the included studies.
Greene et al (2009) retrospective audit evaluating the Tayside informatic project.	Tayside large quality and informatic project (reported elsewhere in the scoping). Information used to guide quality improvement initiatives, including: • guideline development and dissemination, • education, • clinical audit, • encouragement of multidisciplinary team working, • task service/ redesign.	Simple process measures improved (checking HbA1c). However, more complex process measures such as eye screening improved more slowly, and were more dependent on redesign of the care pathway. Improvement was greater for type 2 than type 1 diabetes. Significant shifts of care for type 2 diabetes into primary care were achieved, between harder to achieve without additional resources. No significant improvement in HbA1c although trend is now better, systolic BP deteriorated.

Norris et al (2002) Systematic review of Disease (n=27) and Case (n=15) Management studies	Disease management, essential elements: • the identification of patient group; • guidelines or performance standards for care, • management of identified people, • information systems for tracking and monitoring. Case management, essential elements: • identification of eligible patients; • assessment; • development of an individual care plan, • implementation of the care plan, • monitoring of • outcomes.	The disease management studies reported a Median reduction of 0.5% in HbA1c (IQR-1.35% to -0.10). The case management studies reported a Median reduction of 0.5% in HbA1c (IQR-0.7% to -0.5). Authors point out that interventions generally multifaceted and difficult to determine which components make a difference.
Borgermans et al (2008) Review of systematic reviews examining theoretical integrity of diabetes programmes (n=26 reviews).	Key observations: • the variety and relative absence of conceptual backgrounds in diabetes care programmes, • confusion over what is considered a constituent of a diabetes care program and components of the implementation strategy, • large variety in type of diabetes care programmes, settings and related goals, • heterogeneity in both interventions and quality indicators used, • no conclusive evidence on effectiveness, • no systematic results on costs.	
Gelding et al (2005) Describes service development in East London	Similar to integrated care model described in NHS London Guide based on integrated care models: Primary care: • Level 1—identify all patients with diabetes in the practice • Level 2—care for all patients with type 2 on diet or tablets • Level 3—care for most uncomplicated patients, including insulin treated Intermediate Care • Full care—for level 1 practices • Insulin commencement—for level 2 practices Specialist Care: pregnant women; children and adolescents; patients with type 1 diabetes; patients with renal, vascular or neuropathic complications; patients with difficult glycaemic control.	

Balas et al (2008) Systematic review of computer supported diabetes care	Interventions: • computerized prompting of diabetes care, • home glucose records in computer-assisted insulin dose adjustment, • and computer-assisted diabetes patient education.	Improved guideline compliance computerized prompting studies (6/8). Reduction in HabA1c with insulin dosage computers (3/4 studies). Educational programs improved diet and some impact on metabolic control.
Renders et al (2000) Systematic review of interventions to improve care quality in primary care	Interventions: • Professional education and development; • Patient interventions • Revision of health care roles • Telecommunication systems	Poor quality heterogeneous studies both in methods and outcomes. Education and recall models (using computers) can impact on care processes the impact on clinical outcomes is equivocal.
Speight et al (2009) A review of Quality of Life Measures	Review identified only 3 true QoL measures World Health Organization Quality of Life (WHOQOL) and the diabetes-specific Diabetes Quality of Life (DQOL) and Audit of Diabetes-Dependent Quality of Life (ADDQoL). The WHOQOL could for comparing diabetes and non-diabetes populations. Other instruments accurately measure health status (SF-36 and EQ-5D), treatment satisfaction (Diabetes Treatment Satisfaction Questionnaire and psychological well-being (Beck Depression Inventory (BDI), Hospital Anxiety and Depression Scale (HADS), Well-Being Questionnaire (W-BQ), Problem Areas in Diabetes (PAID)). Choosing the correct instrument is important in relation to the construct of interest. Current instruments for QoL in diabetes not ideal.	
Shojania et al (2006) systematic review and meta-analysis of system level quality improvement interventions for T2DM (66 studies 50 RCTs)	Interventions: • Team Changes- expanded role nurse/pharmacist or new MDT (number of trials= 26) • Case Management (number of trials= 26) • Patient Reminders (number of trials= 14) • Patient Education (number of trials= 38) • Electronic Patient Registry (number of trials= 8) • Clinician Education (number of trials= 20) • Facilitated Relay of Clinical Information (number of trials= 15) • Self-Management (number of trials= 20) • Audit and Feedback (number of trials= 9) • Clinician Reminders (number of trials= 18) • Continuous Quality Improvement (number of trials=3)	All interventions demonstrated a small to moderate positive effect on glycaemic control. The overall point estimate was a reduction in HbA1c of 0.4% for all interventions (adjustment assumed a HbA1c ≥ 8%) strongest benefits were with team changes and case management.

Montani et al (2001) Systematic review of computerised management models (n=17 RCTs)	Studies grouped into two types of intervention: • Day-by-day advisory systems supplying self-care and therapeutic advice to patients. • Visit-by-visit systems assisting health professionals in interpreting the blood glucose readings and make adjustments to therapy.	The effect sizes for both intervention types were small and may studies were equivocal.
Parchman et al (2007) cross-sectional audit of primary care centres(n= 30)	Study measured relationship between delivery of chronic care model (Assessment of Chronic Illness scale) to 10 year CVD risk (assessed using UKPDS risk Engine) and on glycaemic control.	Higher fidelity to the chronic care model was associated with a reduction in 10 year CVD risk. The glycaemic data were more complex while patients who exercised showed little association those who were more sedentary did improve.
Piatt et al (2006) (US) RCT comparing chronic care model (n=30) with education (n=31) and usual care groups (n=51)	CCM model was multifaceted and included: community resources; delivery system design, and decision support. Education group had one problem based learning session as did CCM group.	The CCM group achieved an 0.6% reduction in HbA1c compared to other groups. Also improvement in: cholesterol; self-monitored blood glucose; diabetes knowledge test scores; and empowerment scores.
Chodosh et al (2005) systematic review and meta-analysis of chronic disease self-management programmes (n=26 studies)	Interventions were heterogeneous and were grouped as follows: • Tailoring- individualised care plans. • Group setting- group based therapies/education • Feedback- individual review with the provider of the intervention • Psychological emphasis within model.	Pooled effect size of-0.36 (95% CI, -0.52 to -0.21) for HbA1c, equivalent to a reduction in HbA1c level of about 0.81%. Publication bias likely. No differences observed in different type of programme.
Krish et al (2008) (US) Quasi-experiment (n=42) examining impact of shared medical consultations (group consultations) T2DM.	Intervention focussed on patients with elevated CVD risk and involved a group based consultation to foster productive interactions between informed activated patients and a prepared proactive team as well as peer support. Intervention was delivered by a team comprised: diabetes doctor; diabetes nurse; a pharmacist; and a psychologist. Group sessions focussed on discussion of clinical goals and the development of strategies	Each group had up to 8 patients. At the initial visit, 83% had HbA1c levels > 9%, and 34% had Systolic BP >160 mm Hg. HbA1c fell by 1.4% (compared to control 0.3% and systolic BP 16 mm Hg.

	based on collective experience. Individuals also had their medicines moderated.	

Appendix 4 Grey literature

Type 1 education programmes

Title And Description	***Theory***	***Evaluation***	***Accessibility***	***Ref***
Dose Adjustment for Normal Eating (DAFNE) National programme of structured group education for T1 focused on self management. Groups of 6-8 patients taught to match insulin dose to food on a meal by meal basis (carb counting). 12,00 patients have been through DAFNE. Trained educators: DSNs and dieticians. Currently (March 2009) 365 trained educators and 209 DAFNE doctors working in 80 DAFNE services in the UK and Eire. Written curriculum with external peer review and auditing to ensure fidelity. **Total hours/ duration:** 38hrs over 5 consecutive days (Mon-Fri), plus 2hrs follow up in next 6 weeks	Social Learning Theory (Bandura) Therapeutic Patient Education (Assal) Experiential Learning Model (Kolb) Adult Learning Theory (Knowles)	RCT data show reductions in HbA1c, severe hypos and improved QoL. Improvements in psychological distress. Ongoing audit programme: HbA1c, lipids, incidence of severe hypoglycaemia, DKA, psychological outcomes (PAID, HADS) Audit data collated nationally and fed back to each centre. These data suggest that benefits sustained in longer term.	Local adjustment not encouraged needs to conform to standard. Data on socio-economic coverage and inclusion and attrition not available.	17
Bournemouth Type1 Intensive Education (BERTIE) For T1 patients after one year, during which they receive support, basic education and information one-to-one from DSN and attend group session with MDT once every three months. These sessions introduce principles of carb counting and dose adjustment, also offer peer support. Referral to	Social learning theory	Audit. HbA1c, PAID	Delivered in hospitals and community settings.	18, 19

BERTIE through primary and secondary care. Delivered by trained educators DSNs and dieticians. (BIDAC course) Psychologist attends to contribute to goal setting and review sessions. Over 40 centres in the UK have adopted this programme. On-line version, via DUK website. Online BDEC Diabetes Learning Programme provides background information to support BERTIE, also resource for those unable to attend sessions. **Total hours/ duration:**28hrs: 1 day/week over 4 weeks	Written curriculum	Clinical indicators measured at clinic visits Audits show over 80% of participants meet their goals; over 95% of participants feel they benefited from attending the course; average HbA1c levels fall for up to six years; many participants have less hypoglycaemia.	Literacy and numeracy problems identified. Numerous local courses are said to be based on BERTIE- these have been adapted.	
Torbay Insulin and Food Adjustment Course (TIFA) based on BERTIE (as above) with added peer support element built in. Participants invited to return after 3 months to discuss experiences and to meet participants on current course (who are at week 2) to allay fears and provide support. Also return at 6 and 12mo.	As BERTIE + Emphasis on peer support	A support group has started out of TIFA course – meets every month in local pub. Members act as resource for courses.	Not clear	20
Juggling Insulin for Goals Success and Wellbeing (JIGSAW). This programme offers more advanced skills in adjusting food, exercise and insulin to improve glycaemic control. Covers goal setting, insulin and food, hypos, stress, exercise. Delivered by MDT Part of care pathway for intensive insulin therapy. Patient led post programme support group **Total hours/ duration:** 18hrs: 3hr session each week for 4 weeks plus 1 whole day.	Self efficacy (Bandura) Written curriculum	The majority of patients stated that they felt they had achieved their goals by the end of the programme. (n=67) HbA1c – 69% improved, with a mean reduction of 0.6%. (but not followed up) Weight +0.9kgs 90% improve PAID scores	Not clear	22

		68% improve WHO well being		
Skills for Life. Local Bristol group education course for T1 developed from research with patients. Programme is co-facilitated by DSN, clinical psychologist, specialist dieticians. Topics include stress, relaxation and family. **Total hours/ duration:**24hrs over 8 weeks	Based on what people with diabetes said they wanted from a programme. Social learning theory	Not clear	Not clear	25
WINDFAL Whittington Insulin Dosing for Active Living Group education for T1 with access to rolling programme of follow up courses. Patients asked to keep food and insulin diary for week before course. Psychologist joins for two days. The session on hypoglycaemia starts off as a group discussion on signs, symptoms and treatment, moving on to the Diabetes Consultant talking about the science behind hypoglycaemia and the importance of retaining awareness, followed by a WINDFAL walk for 40 minutes, often raising some good examples & questions. The programme has a website and on-line resources for patients, **Total hours/ duration:**26 hrs 1 day/week over 4 weeks	Non-judgemental, flexible approach. Sessions are interactive and varied. Social learning theory	Not clear	Not clear	26

Type 2 education programmes

Title And Description	*Theory*	*Evaluation*	*Accessibility*	*Ref*
X-PERT Programme Local programme (started 2005) adopted widely. Social enterprise. Health professional led group based diabetes education: diet, food labelling, supermarket tour (actual or virtual), medication, games. Individuals identify their problems and solutions.	Based on principles of empowerment, discovery (adult)	Audit results 2009 (n=4480) include 97% attend at least one session and 81% four or more;	Educators are encouraged to adapt the X-PERT programme to meet	1

Group size 15-18 plus carers. Intended for people with newly-diagnosed or established T2 diabetes. Refresher sessions provided. Educators are HPs who have been trained to deliver X-PERT- nationally > 600 professionals have been trained. **Total hours/ duration:** 14hrs over 6 weeks Derivatives include: X-PERT Insulin (new) X-PERT in Urdu X-PERT self-directed learning DVDs and handbook	learning and patient centred care. Follows written curriculum	Improved clinical outcomes (HbA1c at six months at 1 year); 2.1 kg weight loss at six months and 2.4 kg at 1 year; 1 cm waist circumference reduction at 6 months and 3 cm at 1 year; Modest improvements in lipid profile at six months and 1 year. Internal and external QA	the specific cultural needs of the local population. Urdu programme follows X-PERT very closely	
Diabetes education and self-management for ongoing and newly diagnosed (DESMOND) National programme of foundational education for T2 (started 2006). Programme focuses on lifestyle factors, such as food choices, physical activity, and CVD risk factors. Participants choose a behaviour change goal to work on. Newly diagnosed module intended as the first step in an ongoing cycle of diabetes care, integrating education with clinical management. Trained educators. Nationally over 500 professionals are trained, recently introduced training for lay people. **Total hours/ duration:** 6hrs total: one full day or two half days not more than 3 weeks apart	Leventhal's common sense theory, the dual process theory, social learning theory, self-efficacy. Non-didactic approach. Written curriculum	RCT (n= 824) newly diagnosed T2; in primary care; follow up over one year. No change in HbA1C (levels were generally low); reduction in weight and triglyceride levels. Improvement in 10 year CVD risk status. Decrease in smoking and increase in physical activity. Greater understanding of illness; depression scores lower. No difference in QoL. Limitation: all behaviour self-reported.	Delivered in a community setting. Programme content suitable for a broad range of participants. New culturally appropriate resources being developed for S Asian community.	3

FOCUS Local programme for newly diagnosed T2 developed by Bournemouth and Poole PCT, influenced by **DESMOND**. Open access programme requires referral from GP. Delivered by trained HCPs. **Total hours/ duration:**6hrs total: 3 days over 3 weeks.	As DESMOND	Data no available	Runs twice weekly in two different community venues.	4
Living with Diabetes programme developed in Bristol for newly diagnosed T2. Based on ***Portsmouth*** getting started with diabetes course (led to DESMOND) Part 1 covers basic diabetes education, blood glucose monitoring, diet, exercise, goals. Part 2 covers goals, treatment and prof support. Six month follow up session facilitated by MDT Trained professional educators, including practice nurses. **Total hours/ duration:**9.5hrs over 1.5 days.	Social learning theory, dual process theory, self regulation theory, self determination theory. Written curriculum	Data no available	Offer courses in a variety of locations.	5
Basic Education for Newly Diagnosed type 2 (BEND2) This is part of the **DEAL** suite of education programmes developed in St Helens (see below). Trained educators, DSNs and dieticians	Social constructivist Written curriculum	Audit of HbA1c, BP, lipids. Satisfaction, QoL, DTSQ- before and after. Diabetes self care scores improved for blood glucose monitoring. Anxiety & depression scores fell; quality of life improved in all 4 domains and total & emotional PAID scores improved significantly.	Designed to appeal to broad demographic- but no details on uptake.	7

Total hours/ duration:12hrs: 3hrs per week over 4 weeks				
Structured Diabetes Mellitus Education Programme (SDMEP) local T2 programme developed in Barnsley. Covers basic diabetes education, diet and food choices, goal setting, services and support available, e.g. weight management, shopping tours (organised separately) Trained HCP educators **Total hours/ duration:**6hrs over 2 weeks	Social learning theory Patient centred model Adult learning Written curriculum	77% patient satisfaction	Designed to suit Barnsley community, takes patients' concerns as starting point, delivered in 4 popular locations, including evening sessions.	8
Time2Act Individualised Physical Activity Counselling Intervention – T2 diabetes. Provides people with knowledge, skills and motivation to become and stay more active. 1:1 consultation with trained HCP incorporates the following components: past and present physical activity behaviour, benefits and barriers to becoming more active, available facilities, social support, goal setting, and relapse prevention. Specific diabetes information was given on hypoglycaemia management and foot care. Workbook used to guide content in trial (possibly less person-centred than DESMOND) Intervention aims to supplement to basic diabetes education **Total hours/ duration:**0.5hr consultation initially, repeated after 6 months	Trans-theoretical model	RCT (n = 134) compared 2 methods of delivering activity intervention (consultation in person or in written form) (Kirk et al 2009) inactive people with T2 selected because they were in contemplation phase of change. Neither a physical activity consultation delivered by a person or in written form was better than standard care at increasing physical activity levels or improving health outcomes (blood pressure, BMI, waist circumference, HbA1c, cholesterol) measured at baseline, 6 and 12 months.	Data on recruitment suggested a low response 134 participants out of >1000 eligible after deducting exclusions.	13
Managing Diabetes - Making Choices (previously The Diabetes Look After Yourself (LAY) Course) Interactive group education course for T2 developed in Liverpool. Education pack produced for diabetes educators, including materials for interactive learning. Course covers diet, weight management, psychological health, change and adaptation, lifestyle choices, self care and support from health services.	Theoretically based – Adult learning, although specific theories not listed.	Quantitative and qualitative results showed that the course can empower individuals with Type 2 diabetes to develop their own strategies for self-management. The impact of these changes upon blood glucose control was significant against a control group at six	Flexible teaching programme than can be adapted to needs of the group	14

Total hours/ duration: Not clear		months, but this effect diminished at 12 months.		

Culturally adapted education programmes				
Title And Description	***Theory***	***Evaluation***	***Accessibility***	***Refs***
Aap Ki Sehat Aap Ke Haath (Your health in Your Hands) Local T2 group education programme for S Asians in Hounslow adapted from X-PERT. Delivered by a dietetic assistant fluent in speaking the main Asian languages trained to deliver the sessions in Hindi and Punjabi. Participants are recruited via Asian radio, posters, flyers, search on GPs diabetes registers **Total hours/ duration:**10hrs: 2hr session each week for 5 weeks	As for X-PERT	Audit results for one year showed improvements in clinical indicators and increased knowledge and empowerment scores. Difficulty assessing knowledge because no validated instrument in language.	Delivered in community venues accessed frequently by the community: temples, mosque, day centres.	2
Apnee Sehat (Our Health) Local project in S Warwickshire to raise awareness of diabetes and CVD in S Asian community and support behaviour change. Various initiatives, including DVD, cooking lessons, recipes for low fat- low sugar sweets, Diwali health calendar, health fair. **Total hours/ duration:** Not clear	Community based initiative.	Limited although the initiative was promoted by word of mouth suggesting some positive input.	Used Gurdwara as a focus for activities to encourage opportunistic participation.	9
Coping with Diabetes Project Hackney Lay educators recruited from local ethnic minority communities for training to deliver group education sessions. Group sessions have been run for people with diabetes, people at risk of diabetes and people with obesity,. CD and DVD in Turkish produced. Sessions take place in a variety of community settings. **Total hours/ duration:** Not clear	Adult learning theory	Non-evident	There are Turkish, Gujarati, Hindi, Vietnamese, Bengali, Somali, and Urdu language groups.	10

Ramadan focused Education and Awareness in Diabetes (READ). Local project in Brent to provide group education for Muslims with T1 and T2 diabetes about managing diabetes during Ramadan. Covers nutrition, meal planning, hydration, physical activity, medications, fasting, principles of blood glucose monitoring and recognising complications. T1 also attend later 1:1 session with DSN to discuss safety of fasting. Delivered by trained GP, DSN, dietician. Linked to local diabetes service, but not clear how it relates to other local education programmes **Total hours/ duration:** 2hrs	Not given	Evaluation compared intervention (n=57) and control group (n=66). Intervention reduced hypoglycaemic episodes ($p<0.001$) and weight gain.	Not clear how people access the groups.	11
Diabetes Storytelling Project Tower Hamlets Local project trained bilingual health advocates to work with diabetes patients and devised group course, initially for Bangladeshi community. Groups explore the experience of diabetes, concerns, medication, healthy lifestyles, learning to self test. Not restricted to people with diabetes, open access to those who wanted to attend – set up in community venues – each group had its own character. Groups begin by sharing stories. Themes are suggested for later sessions, including inviting HCPs and 'action-oriented' activities, e.g. cooking, self monitoring, shoes, exercise. Linked to local diabetes service, although initially resistance to advocates working independently rather than with HCP. **Total hours/ duration:** Groups meet for several months	Based on qualitative study showing some Bangladeshi people found stories told by another member of the community more helpful than information provided by a HCP.	Action research model to develop project Groups resistant to formal facilitation and preset agenda	Working with local groups in settings where they meet naturally to make learning more accessible	12

Maslaha DVD and website for Muslim community commissioned by Tower Hamlets PCT to increase access to services and better management of diabetes. DVD in English and Sylheti provides advice from a religious perspective on the importance of taking personal responsibility for managing one's health and medical advice. Website linked to Tower Hamlets PCT website **Total hours/ duration: Not clear**	Community based initiative.	Evaluation qualitative: resources well received by community and HCPs.	Multiple methods used to encourage participation. Based on local partnerships plus local television channels, internet cafes, community organisations and community centres.	15
Somali Storybook Diabetes Education Project. Local culturally and linguistically appropriate diabetes information and education resource developed for Somali community in S Wales. Illustrated story book in Somali and English 'Living with Diabetes Saleebaan's story'. Includes explanation of symptoms, treatment, self management, complications. Intended to be read aloud in small group led by Somali speaker with a good understanding of diabetes. Basis for further structured education **Total hours/ duration:** Can be read aloud by group and questions discussed in 1.5hr session	Based on Somali story telling tradition.	None	Resource developed specifically for disadvantaged group, some of whom are unable to read in any language.	16
Khush Dil (Happy Heart) Community Diabetes Specialist Nurse (CDSN) was developed in 2005 to improve access to diabetes services for the ethnically diverse population in Gloucester City – part of role is to provide structured group education. Provides intensive, culturally appropriate diabetes care to BME people with Type 2 diabetes with an HbA1c of greater than 8%. Weekly physical activity sessions for women.	Community based initiative.	Limited data suggesting a reduction in HbA1c And increased understanding of diabetes.	Targeting specific groups of patients.	30

Generic and Blended models

Title And Description	***Theory***	***Evaluation***	***Accessibility***	***Refs***
Diabetes Education Through Adult Learning (DEAL). Flexible programme developed in St Helens and Knowsley comprised of 6 modules for T1 and T2 (see BEND2 above) covering basic diabetes education (new diagnosis), ongoing education, a specialist intensification module (carb-counting and adjustment) and a flexible module to meet any gaps. The flexible module is one-to-one while the remainder are group based. Delivered by trained educators. Built into local care system with pathways through primary and secondary care. The programme is delivered in designated education room with a range of media and resources **Total hours/ duration:** not clear	Based on social constructivist model; adult learning theory (patient centred building on their experiences). Promotes active learning. Explicit curricula	Limited (n=24) before after study some benefits in self-care, QoL, psychological well-being (HADS, PAID) no data given on clinical outcomes or economic data.	Designed to be flexible to different populations. The one-to-one flexible module is reported as a bespoke session catering for diversity. Mainly delivered in hospital setting.	21
Co-creating Health Pilot schemes around the UK; different LTCs. Focus on changing the way clinicians and patients interact. Offers: • Skills development for clinicians: self man support and communication skills. Agenda setting, goal setting, proactive goal follow up. Patients are co-facilitators. • Self management programme for patients, group co-facilitated by patient and clinician, covering health literacy, decision making, self man skills and confidence.	Chronic care model (Wagner) Self efficacy Active patient-clinician partnership.	Programme as a whole is being evaluated Coventry university data not yet available.	Local venues for patient groups. Not sure how clinicians and patients selected to take part. Inclusiveness?	23

- Organisation development programme. **Total hours/ duration:** Clinicians: 3 half days Patients: 21 hrs 3hrs/week for 7 weeks			Are those who choose not to take part disadvantaged?	
The Diabetes Manual *one to one* self-management/structured education for T2 with workbook and audio tapes developed by Warwick university. Used by practice nurses in primary care, who also provide telephone support. Two day nurse training. Goal setting Relaxation training included, developing skills and confidence Phone calls follow up on goals **Total hours/ duration:**12 weeks One face to face session, followed by 3 10min phone calls at weeks 1, 5 and 11.	Based on the 'Heart Manual' which has been evaluated. Self efficacy theory, incorporating CBT supporting patients in behaviour change	RCT (n=245) in 48 practices. Outcomes: HbA1c, cardiovascular risk factors, diabetes-related distress measured by the PAID and Diabetes Management Self-Efficacy Scale. Outcomes were assessed at baseline and 26 weeks. No sig difference between intervention and control, although lower PAID score in intervention group. Not clear how faithfully intervention delivered by nurses .	Only 18.5% response rate to recruitment.	27
Diabetes Community Support Worker, Wansbeck Northumberland, to support User Involvement and service development and to establish patient/carer groups. Also, to work with other professionals and voluntary sector workers in the implementation of support to people with diabetes. Open day events on living with diabetes.	Community initiative	Groups have helped improve information leaflets. Links to exercise initiatives	Aim to engage people from hard to reach groups.	29

User led diabetes groups were set up in 2003. Health workers and professionals visit from time to time to offer education and support and also to get direct feedback from people who use the services they provide. Links made with different parts of diabetes services.				
Birmingham Own Health – chronic disease care (not just diabetes) offering a structured and personalised programme of support, delivered over the telephone by care managers (trained nurses employed by NHS Direct) to improve self manage and the way patients' use existing local NHS services. The service is .multi-lingual service, offering direct services in English, Punjabi, Urdu and Hindi. Patients referred by GP. It is Each care manager is dedicated to a care managers with whom they build one-to-one relationships, calling people at mutually agreed times, as often as needed. Here is a plan to introduce health monitoring devices will be introduced which people can use in their own home to record vital health measures including blood pressure, heart rate, blood oxygen levels, lung capacity and weight, and automatically share the results with their GP. **Total hours/ duration:** Regular phone contact	Model based on a 'holistic approach' and empowerment principles. Also Kaiser health care model.	Audit results only positive, no full study cited. Before and after only showed improvements in: physical activity; sodium intake; adherence with medication and average HbA1c reduction of 0.5%.	Flexible access but no data on uptake.	31

Health Trainers National scheme designed to tackle health inequalities by training local people to engage with hard to reach groups/clients to promote smoking cessation, healthy eating, exercise. Patients produce personal health plans Service provided by 90% of PCTs (2009) More than 2,500 HTs nationally. Implications Health trainers receive special training and accreditation **Total hours/ duration:** not clear	Focus on behaviour change: motivation, goal setting, self-efficacy.	Some local evaluation, although effectiveness of intervention unknown. National evaluation expected next year. Not clear on relationship with diabetes.	Explicitly targeting hard to reach groups.	32
Altogether Better Community Health Champions**.** Empowering communities and individuals to change their lives. Diverse portfolio of 16 local community-based projects, across 14 local strategic partnerships, with the aim of reducing health inequalities, by helping people eat more healthily, be more physically active, improve their mental health. Volunteer ‘community health champions’ from target communities recruited and trained to work with communities to achieve defined outcomes. **Total hours/ duration:** Not clear	Community initiative	Not available	Explicitly targeting hard to reach groups.	33

Expert Patient Programme (generic and specific) EPP aims to help patients take more control of their health by learning new skills to manage LTCs. Topics covered include: pain and tiredness; coping with feelings of depression ; relaxation techniques and exercise; healthy eating; communicating with family, friends and health professionals; planning for the future; goal setting; and remaining active The course is run by two trained tutors who themselves live with a long-term condition. Run in most areas and often advertised to patients with diabetes. EPP has been run in Lancashire specifically for people withT2 diabetes, by people with diabetes who were specially trained, and evaluated. 6 sessions+ 7th on diabetes. Referral or self –referral **Total hours/ duration:** 6-week course 2-2½ hours per week.	Bandura, self-efficacy, goal setting, peer support.	Diabetes specific EPP RCT (Cade et al 2009) (n=317). High drop out rate from intervention group. No differences found: weight, body mass index (BMI), waist circumference, lipid profile and blood pressure; 3-day food diaries and questionnaires; diabetes control; and ADDQoL. Qualitative element reported disappointment with the course. It has been reported elsewhere that people with diabetes find EPP too simplistic and patronising, since many are already managing their illness effectively. More specific content seems to be preferred.	Diabetes participation unclear.	34
Peer advisers Isle of Wight centre. People with diabetes were trained to become 'peer advisers' and deliver an education programme on self management to other patients. Set up as RCT to compare peer adviser to SHP delivered programme. Little info about the intervention, although developed with patient input and said to be suitable for T1 and T2, although split for final session. Extensive training for peer advisers.	Peer support – although follows a fixed curriculum.	RCT (n=83). Good course attendance rates. Knowledge scores increased for both groups. No difference in HbA1c. Concludes Trained patients are as effective in imparting knowledge to their peers as specialist health professionals.	Not addressed.	35

Total hours/ duration: 6 weekly 1.5hr sessions Groups of 10-15 people				
Care planning approaches 'Year of Care' Individual care planning is generally seen as an extension of 'annual review' for person with diabetes. HP facilitates planning process. Appropriate information and education, matched to level of health literacy. Supporting patient to engage with care planning process and articulate priorities, needs for information, education, goals. Joint decisions and creation of an action plan. Offered a menu of options to achieve goals. Consultation is structured and plans recorded. Emphasises patient choice – but not clear what this means. Care planning training for professionals (consultation skills) Similarities to Co-creating health (above) This approach supported by diabetes structured education programmes, so patient understands their condition. The care planning is also fed into the care commissioning process. **Total hours/ duration:** Individual, annual or as frequent as necessary	Patient centred approach: active involvement of patient; patient's priorities addressed; holistic. Joint decision making Emphasises self management, behavioural change and prevention.	TBA	Represents a change in approach of key element of diabetic review – so if successful, should be available to all. Possibly difficulties for those who want less involvement in decisions and care.	36

Follow-up or supplemental education

Title And Description	***Theory***	***Evaluation***	***Accessibility***	***Ref***
Living with Diabetes (DUK + EduCare Leamington Spa) Distance learning programme designed to provide essential knowledge, skills and confidence for newly diagnosed T2 or as refresher. Aims to supplement existing structured education or as 'prescribed education', material in the form of a booklet dispatched to patient on receipt of referral from HCP. 4 modules: initial diagnosis; care and support; diet and exercise; strategy for life. MCQs on each module submitted by patient and results returned; HCP gets feedback. HCP get test results and focus on sharing and improving patient's care plan. **Total hours/ duration:** Up to 3hrs, depending on patient	Patient led self-directed learning	Piloted in West Midlands Over 50% of patients successfully completed the programme, plus another 30% completed without doing MCQs. Patient feedback +ve.	Patients can follow course when and where suits them. Literacy and language issues not addressed.	6

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Care organisation- Description of development	***Underpinning Concept***	***Evaluation***	***Ref***
Year of Care Integrated model of organising diabetes care, comprising: care planning; development of networks; integration of services; commissioning; patient involvement and needs analysis. Focus is on providing individualised care via care planning, which will influence what services are provided, rather than designing and implementing top down service model. The emphasis is on care planning (actions and self-care) rather than screening. This in response to findings that annual checks were carried out but less than half patients had a plan. 3 pilot sites tested feasibility (2007-9) and generated learning for delivery phase. Service reviews also assess local provision and expand to offer full menu of services to meet all needs, including groups with specific requirements. Key elements: • Establish care planning in routine practice. • Identify sections of the local diabetes population by potential need for services and support for self care. • Develop new and existing providers to support self care. • Systematically link individuals' needs and goals into population level commissioning. • Explore the costs and benefits of providing these services and support. Examples of developments have included the introduction of educational programmes that are tailored to the needs of the local population.	A patient centred model that shifts emphasis away from simple screening to more comprehensive care planning and service development/enhancement. It incorporates some elements of Wagner's Chronic Care model (Bodenheimer, 2002).	Not yet available but anticipated very soon. One pilot (Tower Hamlets has reported greatly increased participating in diabetes education).	1
Healthcare for London: Diabetes Guide for London London wide plan to improve the organisation of diabetes care in recognition of increasing demand and widespread inequalities in care. There are a number of themes within the plan: prevention and early detection of diabetes; patient centred models (including, care pathways, care planning and structured education); care integration (a 4 tier model is proposed integrating essential care, enhances essential care, specialist community care, and specialist hospital care); reduction of inequalities (including quality enhancement measures (staff training and diabetes networks), provision for specific groups); targeting high risk patients; and commissioning models. The report draws on other areas where care developments have been introduced, including: Bolton PCT, Leeds PCT, NHS Scotland, Cumbria, Bexley Care Trust, Enfield PCT, Tower Hamlets PCT and NHS Westminster. The plan also reference Year of Care (above) and Co-creating Health (see self-care support) as developing care planning which should be implemented as part of this model.	This is an overarching strategy for organising diabetes care to enhance care quality, improve clinical outcomes, reduce inequalities and maximise capacity.	Recommendations for clinical outcomes but no data collected to date.	2
Tayside Diabetes Managed Clinical Network This is a very wide ranging model of care and service integration that has a long history of	A network that has access to clinical performance data and	Evidence of increased use of	3

development and well developed programme of informatics- Diabetes Audit and Research in Tayside Study (DARTS), SCI-DC Diabetes Information Management System. The network has responsibilities to: • assure care Standards; • undertake service needs assessment; • give advice to local health authority; • prioritisation and development of new services, • including evaluation; • manages the informatic systems to: provide a common information gateway for all members of the multi-disciplinary clinical team, enable information to be shared to support patients on their journey of care; to enhance a high level of communication between clinical colleagues and between health care professionals and their patients; develop patient information resources; maintain an online Diabetes Handbook, which contains locally adopted protocols and evidence-based guidelines for the management of all aspects of diabetes; provide access to clinical resources (a foot risk-assessment tool and a cardiovascular risk calculator); provide a clinical audit tool giving instant feedback to clinicians; co-ordinate electronic eye screening; develop patient education; and provide professional diabetes education. There is an integrated care pathway too, with a 4 tier model similar to that proposed in the London Guide.	can act to enhance excising or develop new services in response to performance. The key element of this model is the use of informatics to provide continuous feedback (individual and service levels) together with information integration between professionals and patients.	services and strong impact on care process. Impact on clinical measures limited (see literature review).	
Co-creating health (The Health Foundation) Integrated programme of enhancing care deliver by: • Training for health professionals to support and motivate their patients to take an active role in their own health • Enabling patients to develop their knowledge and skills so they can form an effective partnership with their clinicians. • Developing new approaches to health service delivery that enable patients to take a more active role in their own health. Co-creating health follows the Chronic Care model and believes that professional-patient interactions should be characterised by collaboration based on a partnership structured around explicit, processes that help patients self-manage their condition (e.g. shared agenda setting, agenda-setting, goal-setting and goal follow-up).	A service redesign based on educating professionals and patients in methods to enhance clinical communication and care planning. The model incorporates some psychological techniques drawn from motivational interviewing.	On going evaluation being conducted by Coventry university.	4
Shared Leadership for Change (The Health Foundation) This initiative aimed to test an approach to organisational and team development that involves	Team working model based on shared leadership.	One pilot site reported improved:	5

providing high quality, tailored leadership development to teams in order to improve the quality of health and health care. The intervention involves 30 days of specialist leadership consultant input delivered over 18 months to develop shared leadership, defined as: a shared vision; a clear strategy and plans for implementation; joint accountability for progress; appropriate team processes; a recognized leader, but with shared responsibility for outcomes; lack of dependency on one or two key individuals; and well identified key stakeholders and means by which they keep in touch.		critical discuss of decision making; patient participation; capacity to make changes and set specific goals for quality.	
National Diabetes Information Service The national diabetes information service encompasses a cluster of project all aiming to use information to inform and improve diabetes care. Integrated information portal to provide easy access to diabetes information including: diabetes data directory; patient experience project; DiabetesE; the National Diabetes Audit; PBS Diabetes Prevalence Model; and the Diabetic Retinopathy Screening Programme.	Integration of different work streams aimed at using patient and service information to highlight shortfalls in care, spur service development and measure performance.	Impact not assessed, although they do co-ordinate National Diabetes Audit	6
DiabetesE DiabetesE is a web-based self-assessment quality assurance resource that measures system performance. DiabetesE uses the Health Service Performance Improvement Framework (HSPIF) a methodology that goes beyond the assessment of clinical processes and outcomes to help identify an underlying cause of any short comings. The role of DiabetesE is to drive service improvement across diabetes networks by enabling commissioners and service providers to: • Conduct a baseline review of how they are implementing the NSF • Identify priority areas for improvement • Identify ways in which improvements may be made • Develop improvement plans reflecting the goals and aspirations of the NSF • Continually reassess and review progress in implementing the NSF locally.	An online service quality assurance and service development tool following a whole system model. The model allows GPs and PCTs to benchmark there performance internally (before and after) and in reference to other practices.	70% of PCTs participated in DiabetesE. Recent report states: average scores are improving; performance related to the number of assessments performed; and some indication that motivation has improved.	7
YHPHO Yorkshire and Humber Public Health Observatory (Diabetes Health Intelligence) Provides a range of resources and data to support local work, including: • Diabetes Attributable Deaths. • Diabetes Area Classification, area level risk factors for diabetes to facilitate comparison.	The diabetes community health profile initiative provides an informatic support for diabetes decision	No formal assessment provided.	8

• PBS Diabetes Prevalence Model; • Estimates of diabetes of women of childbearing age; • Adult obesity trends and predictions; • Diabetes community health profiles. The community health profiles provide a detailed multivariate assessment of performance based on QOF data, deprivation and health spend. This identifies relative performance between practices and PCTs.	making locally. It should identify relative performance.		
Altogether Better A five year £6.8 million project based in Yorkshire and the Humber (not diabetes specific more wider public health with some focus on healthy living and diabetes self-care support). The project is multifaceted and involves Building a partnerships health, local authorities, third sector and local communities. Specific projects focusing on community health champions and mental health and employment. Facilitating a learning network aimed at sharing intelligence, experience and learning across projects. Projects address empowerment, reducing health inequalities, mental health and employment. Lifestyle and well-being projects have themes such as healthy eating and physical activity. Health champions are a key component with some focussing on better self-management for diabetes.	Community based initiative integrated in wider public health strategy. Identifying people with diabetes to work within community.	No evaluation details given.	9
Birmingham Own Health Launched in 2006, the service provides telephone support for people with LTCs referred by GPs. The service is delivered over the phone by a team of care managers – via NHS Direct. Care managers build and maintain ongoing relationships with enrolled members, providing motivation, support and knowledge to help encourage people to take actions to improve their health. Once enrolled in the service, people receive structured and personalised support over the telephone. The Care Manager helps individuals to: understand medical condition ; acquire skills and knowledge for self-care; correctly follow treatment programmes as prescribed by health professionals; and use services more appropriately and effectively. The service has multi-lingual support.	A generic tele-care support targeting people with LTCs. Adopts some of the principles outlines in Kaiser Permanente model- linked to the Working Together For Health initiative.	No evaluation details given.	10
Race for Health Race for Health is a DoH initiative (not diabetes specific) that aims to improve the health of people from black, and minority ethnic backgrounds. Some local projects have focused on diabetes or are directly relevant to them. Lambeth and Liverpool PCTs are doing work on patient profiling is important. Bristol has a diabetes facilitator working with the S Asian community with an emphasis on verbal transfer of information. Report published. In East Berkshire PCT Slough has a campaign on	Multiple projects targeting different health needs within BME groups. A sub-theme seems to be community working and taking care into the local population to	No evaluation details given.	11

early identification of diabetes ‘Action Diabetes’. Includes outreach to local Asian community, health promotion in shopping centres etc, testing, developing local specialist clinic. (see East Berkshire file).Two reports feature social marketing in campaigns to raise awareness about hypertension (Lambeth) and reducing salt consumption (Nottingham).	improve acceptability and access.		
Commissioning for Quality and Innovation (CQUIN) CQUIN is a framework that aims to improve quality and innovation in the NHS. CQUIN is linked to other performance and remuneration methods. One diabetes example is reported in Doncaster PCT were local stakeholders came together to agree a set of quality indicators with its community services provider arm and local Foundation Trust.	Developing outcomes that reflect the needs of local services and encourage more innovative models of working.	No evaluation details given.	12
Improving access to psychological therapies (IAPT) This is national non-diabetes specific initiative to improve psychological care in LTCs. One diabetes example was the Salford Pathfinder projector. This project has developed a pathway to help people with type 1 diabetes who have depression and/or an anxiety disorders access psychological care (sessional input into the community diabetes clinic).1,000 people on the type 1 diabetes register have been sent a copy of the Diabetes UK booklet on diabetes and depression, a PHQ-9 and GAD-7 and an invitation from the consultant diabetologist to have a discussion about these issues. Additionally, staff who manage people with diabetes have been trained to screen and identify common mental health problems such as depression and anxiety, and refer those patients to providers of psychological therapies	Two key functions awareness raising and screening. In addition to workforce development.	There was a 20% response rate, with direction into the IAPT service for people with moderate to severe symptoms and joint management of problems between services. .	13
Local examples **Bolton** This project involved the Design Council who developed a project to shift away from teaching patients what they should do, and instead find out from each individual what they can do, identifying what barriers there are to change, overcoming them and supporting that change into the long term. They developed agenda cards and introduced personal trainers to complement existing educational and medical resources. They have formed a group called BOND (Bolton New Deal) to help drive a new diabetes healthcare agenda for the community, and to undertake a more in-depth evaluation of the prototypes. Starting with the agenda cards, the BOND team, supported by the Design Council, has involved five GP practices, four diabetes nurses and nine patients to undertake an initial study of the proposed system. **Brent** Integrated care model. The majority of patients have continuous screening & assessment in primary	Patient participation model both care planning and service development-collective ownership.	Initial feedback suggests that using the agenda cards does not increase appointments, and helps patients to focus on the real issues, sessions are often more productive.	14

care. Primary care refers anyone that falls outside of their realms of expertise to the Single Point of Access (SPA). The SPA acts as an interface between primary care and the acute trust. One referral form is only needed for all services (e.g. Dietician, education) that can be organised by the SPA team. Patients can be seen within a week in rapid access clinics run by consultants and/or other members of the multi-disciplinary team. In addition, instant (within 24 hours) replies by telephone, email and fax for any queries that are received by SPA. Only specific group of patients are seen at the diabetes specialist centre in the acute trust (this model similar to that advocated in he NHS London Diabetes Guide) **Cumbria** Cumbria Diabetes is a new organisation within the NHS in Cumbria which will be responsible for improving, overseeing and delivering diabetes care for adults and young people across the county from the summer of 2009. The key priorities are equity, improved outcomes and an improved patient experience of diabetes care. Cumbria Diabetes aims to address these priorities by supporting people to manage their own diabetes through patient education, supporting clinical staff through training and making sure that services are available both when and where people need them. Cumbria Diabetes will be working closely with GPs to ensure that everyone has access to a high standard of diabetes care. A new Cumbria Diabetes website is being developed which will provide information to help people manage their diabetes. It will describe the diabetes care that people should expect to receive.			

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Appendix 5 Participatory Conference

This is a PDF

Appendix 6 Patient E-survey open responses

What one thing would most improve the way you diabetes services are organised and delivered?

Issues and themes here seem to be very similar to those identified in 'educational support' question. Again very varied and quite difficult to categorise.

The two most frequent themes in responses were more frequent or regular contact with services and access to specialist care –often the two were linked

More contact with / communication from services

To be seen every 6 months by someone with experience in diabetes and not just a nurse that has attended a 2 hour course on the subject.

Reminders sent out prior to appointments. A more readily available team. It would be better to speak to someone easily rather than having to wait or put it off until another occasion.

DSN is nice, but all I get is my Metformin and HbA1c.annually. If I want another Hba1c, I have to organise it myself

More frequent appointments

More appointments with the nurses - general how you coping etc

Having someone professional to ask a question about diabetes.

More contact with the patient

Better monitoring

Although my husband's type 2 diabetes is controlled by diet, I am aware his condition could get worse and there is little concern or emphasis that we need to be very careful, even at this stage, with his diet. Ideally I should like to be able to talk, face to face, with a trained diabetic nurse whenever I need to, and would suggest that for the first year my husband and I are seen together on a quarterly basis to ensure that all is going in the right direction.

I would like to have more frequent appointments and be able to see someone when I need to.

I would appreciate a diabetes service rather than annual visits to GPs' clinics

More contact after you have reported a problem-no-one comes back to find out if the problem has been resolved.

Meet to talk regularly

I would like any service as don't get one at present

More contact, more information and advice. I am still waiting to get an appointment with a nutritionist to advise on my diet since I was diagnosed

More regular consultations

Communication, communication, communication. Please let the newly diagnosed diabetic know what's available - what is expected of them- when and where clinics are held. Where the support groups are. What a pateint can expect from the G.P. practice. Advice about equipment how and where and hen these can be obtained and lots more that someone new with diabetes has no idea what's ahead of them. Communicating with patients and helping them to know what is and what is not available would be so helpful

Access to specialists

Access to trained diabetes specialists

Really believe that training and expertise needs to be elevated. We are now at the point where we know more than our local team.

Access to a specialist system and proper information on my condition

I would feel a lot happier if I knew that the GP who looks after me was an expert in diabetes - but I know this is extremely unlikely.

There would be sufficient resource for me to have HbA1c every 3 months, and foe me to not nag to have this done

They should be organised and delivered by someone who REALLY knows about diabetes.

Would like more regular meetings with diabetic nurse, dietician, podiatrist in 5 years have only seen podiatrist once.

Consistent specialist care in a specialist centre/clinic e.g. at a hospital. GPs are a lottery and lack knowledge and interest

GPs being willing to hand over your diabetes care to a diabetes centre or hospital, where the staff are specialists and you may be able to meet with other people with diabetes

Being seen by a professional who specialises in Diabetes rather than my nurse who appears to know very little or is just not interested

I would like to have access to specialised diabetes professionals instead of GP and practice nurse.

More access to diabetic nurse specialists.

Easier/more local access to trained staff

I would prefer to see a diabetes specialist rather than my GP but can't do this unless I am referred by them to the diabetes service

Simply, we need more health-care professionals in the NHS, but where chronic diseases are concerned we need more specialised health-care professionals.

Ready access to TRAINED and CERTIFIED staff via any means.

MY NURSE BEING ABLE TO SPEND MORE TIME AT MY G P PRACTICE

Ready access to an informed professional

Someone, anyone who understands insulin pumps would be good.

ATTENDANCE AT A CLINIC RATHER THAN JUST THE GP

An experienced children's diabetic nurse would be great.

The ability to drop-in for advice from someone who understands about IDDM. In primary care, I don't have confidence that they have enough clinical expertise in IDDM as opposed to NIDDM.

Other respondents also highlighted access, but in terms of flexibility of timing of clinics or timeliness of access

Better access to services / more flexibility

Have specialised diabetes type 2 centre provided until late

More flexible appointment days and times at clinic - it only runs on a Wednesday afternoon

Services available at the week end.

Prompt help in a crisis

Evening or Weekend education sessions as opposed to mid-week daytime.

A diabetic educator who you can contact at all times of the day. Someone to give advice and reassurance.

Better clinic times, so that time off school not needed

Easier to make appointments when I need an appointment not just routinely

Regular diabetes drop in sessions at the practice with our diabetic nurse

To avoid having to take a lot of time off work to attend appointments

Another frequently occurring theme was integration of services and co-ordination of care around the patient

Better coordination of care

Integrate eye checks into diabetes centre and give access to eye photos to diabetes Drs/nurses.

Better communication between the services

Better communication between hospital and GP

Centralised results. My GP doesn't even know how to print out blood test results and scolds me for asking for them!!!

Treat us as whole people instead of fragmented illnesses so that we do not have to visit several "experts" for various conditions with little or no communication between them

Availability at clinic visits of dietician, without separate appointment at another time and location

I have never been asked if I need dietician, psychologist or even podiatrist. I have my eyes checked by the hospital and my bloods when I chase the doctor for them.

Annual review annually - not delayed

If all services, i.e. podiatry, eye tests, dietician, etc and consultant were all seen on the same day at the diabetic centre, instead of being spread over the health service.

Try to prevent the friction between hospital and GP care

Getting all my annual examinations in 1 session

More co-operative working between diabetes services and other healthcare professionals looking after my many diabetic complications.

Joined up better between hospital and GP

Better communication between the Diabetologist/GP/Diabetes Nurse/Practice Nurse

The interface between the hosp and surgery could be improved.

A related theme was patient experience of continuity and consistency of care, and a few patients thought a single point of contact would be beneficial

Continuity of care

I would like to have the same doctor each time I visit the diabetes clinic so that I would feel more comfortable and I would know them

More specialist nurses! And each nurse assigned patients so they can get to know their different needs, instead of seeing whoever is available and having to re-tell them what has and hasn't worked**.**

Consistency of advice

Consistency and up to date information

Consistency - not as many different messages as "specialists" you see.

Consistency of check-ups e.g. the GP Practice check-ups tie in with the Specialist diabetes centre (Hospital) which is currently not the case.

More time to discuss my condition and how it can be managed better with clear and consistent messages being given

Single point of contact

Better access to information, peer support, one point of contact for accessing information.

For one person to be designated as the co-ordinator

Providing more personalised care, better care planning and empowering the patient were another set of themes strongly represented in responses

More personalised care / listening to me / care planning

More interest in me as a person with diabetes rather than another diabetic.

Recognition of the amount of work I have done to understand how the disease affects me so advice specifically tailored rather than general

More feed back of results to know if what I am doing is right or wrong

The flexibility for the expert to meet the diabetic and have meaningful discussions aimed at understanding the individual rather than a slot amongst throngs that addresses nothing except fills in paperwork.

Proper planning and targeting so it feels as though everyone knows where we're going and why, rather than "oh who's this? What shall we do this time?"

Professionals listening to your concerns rather than making judgements too quickly

Listening to me

To make it more personal to each individual

A structured coherent programme of support with reliable up-to-date information and individual help

Joint holistic personal health planning

Having more information given to me about my diabetes, and realistic planning and discussion at specialist appointments

Empowering patients

Being allowed to track my BGL would help me keep control of things. At the moment I feel it's the medics in control and not me, I'm not really included in the decision making.

Acceptance that, as an individual, I need to be in control of the condition and allow me the means to be so.

More information on self help e.g. how to use exercise to improve sugar levels

Being given the opportunity to become involved rather than treated as the GP's patient. I realise that this would require much more of the GP's time and does not worry me.

An interest in communicating results and ideas to me rather than to a computer as well as support rather than indifference when I strive to monitor and improve my readings

Some respondents indicated particular elements of service provision that were lacking: most frequently the need for more staff or more trained staff to run more clinics, but also including psychological support, dietetic advice, foot care etc

Improve care quality /staffing levels

More DSNs so more clinics can be run

More trained specialist diabetes nurses.

More nurses and more time at clinic to really talk

More clinics to allow more time with doctor and professionals and less time waiting for appointment

Put all your nurses on a 1 year course (yes 1 year) that is run by diabetics who have turned their own lives around by controlling the condition themselves.

Better education and better trained staff

To deal with emotional side

Improve the quality of advice given to Type 2s - in particular regarding testing and carbohydrate management.

Adequate foot care provision

Dietary advice

Dietetic and psychology support (none in this area)

Interestingly, only a few respondents included more structured education programmes

Knowledge is power. Would love to do a Desmond course and to interact with others

The remaining themes occurred much less frequently

More resources for services

Funding for insulin pumps

Give them enough money and improve communications.

Get rid of the postcode lottery for test strips etc

Change professional attitudes

Stop the old boy’s network regarding pumps and the interpretation of NICE guidelines

Acceptance that T2 is as serious as T1 and should receive the same consideration.

Stop patronising the patients who live with diabetes and know what it's like

Open minds

Friendly and approachable team.

Peer support

Need local self help groups.

More support locally for type 1 diabetics. Through a peer support group, but administered so it doesn't become a burden on those involved to make the arrangements. Access to good quality venue.

User involvement in services

More user involvement

I should be asked what I would like.

Telehealth support

Make more use of online ways of tracking blood sugar levels

I would love to be able to access my blood test on line. I can access my results on line for the renal clinic but not diabetes.

Other responses

Educate schools more, we had to move primary schools because our previous one was so bad

A glimmer of intelligence in the NHS??

"Diabetes services" is very vague and not very clear who from. As long as I get my test strips, which they begrudgingly supply, and my medication, I'm fairly happy. But I've never been counselled, advised or introduced to a support group. The most important thing is education, education and education. Unfortunately, the NHS, supporting the old plate model are not really the best people to provide advice.

The GP could see me more often to discuss diabetes and my results. The Diabetes Nurse could be better trained. I felt like I knew more about Diabetes than she did after only looking on the internet. The DESMOND training should be available everywhere and there should be a follow-up session after 6 months and then regular follow-up every couple of years.

Better support: more consultations (at present once a year), dedicated telephone number to use for support and advice, local support groups run by people with diabetes

Accessibility, co-ordination and a person centred approach. I know that's 3 things!

Appendix 7 Severe Mental Illness in Diabetes

Summary compiled by Jane Hughes.

Approach

This scoping focused on people with severe mental illness (SMI). SMI includes people with psychotic disorders, bi-polar disorders, addictions and personality disorders whose mental health problems are managed mainly by secondary or tertiary mental health h services. Literature was sought on the physical health problems of this group and provision of services, with an emphasis on finding examples of services targeted towards identifying and managing diabetes in patients with SMI and interventions to prevent cardiovascular disease.

Evidence of inequalities in health

Over the last 20 years substantial and consistent research evidence has been gathered in developed countries that compared to the general population people with SMI have worse physical health, increased mortality and reduced life expectancy. (De Hert et al 2009) The excess mortality is not caused only by suicide rates: people with SMI have an increased mortality associated with physical illness, the commonest cause of death being cardiovascular disease (CVD). A retrospective cohort study in the UK showed that people with SMI have a more than threefold risk of CHD and more than twofold risk of death from stroke. (Osborn et al 2007). Internationally, studies have consistently found an association between schizophrenia and diabetes. (Bushe, Holt 2004)

CVD risk factors

The excess cardiovascular mortality and morbidity associated with SMI is multifactorial and studies have highlighted, but not clarified, the influence of genetics, social and economic deprivation, lifestyle, the impact of the disease itself, the effects of medication, and the interaction of these factors. Studies find a high proportion of people with SMI have CVD risk factors (smoking, obesity, diabetes, hypertension, dyslipidaemia and physical inactivity) and excess CVD mortality has been attributed to this. (See table below)

Table: Estimated prevalence (%) and relative risk (RR) of modifiable cardiovascular disease risk factors in schizophrenia and bipolar disorder compared to the general population.

Modifiable risk factors	Schizophrenia		Bi-polar disorder	
Obesity	44-55%	RR 1.5-2	21-49%	RR 1-2
Smoking	50-80%	RR 2-3	54-68%	RR 2-3
Diabetes	10-15%	RR 2	8-17%	RR 1.5-2
Hypertension	19-58%	RR 2-3	35-61%	RR 2-3
Dyslipidaemia	25-69%	RR >5	23-38%	RR< 3
Metabolic Syndrome	37-63%	RR 2-3	30-49%	RR 1.5-2

Source: De Hert et al 2009

In the literature these risk factors are often described as 'modifiable', and seen as individual 'lifestyle choices' which are amenable to behavioural interventions. In this context, however, they are perhaps more realistically and usefully viewed as a result of the constellation of physical, social, economic, psychological and environmental consequences of living with and being treated for SMI. This is not to say CVD risk factors cannot be reduced in SMI groups by appropriately designed and delivered interventions.

Diabetes

Internationally, studies have found an increased incidence and prevalence of diabetes among people with schizophrenia, with estimates of prevalence around 10-15%, which is 2 to 3 times higher than in the population as a whole. A recent systematic review found that the highest quality studies indicated a two-fold risk of diabetes in people with schizophrenia, and greater prevalence of metabolic syndrome in SMI. (Osborn et al 2008) This review showed no association between SMI and hypertension. People with schizophrenia are more likely to have a family history of diabetes and to be overweight - two of the main predictors of diabetes. In addition antipsychotic medication has been implicated in increasing the risk of diabetes. (De Hert et al 2009)

Antipsychotic medication and diabetes

Weight gain is a well documented adverse side effect of antipsychotic medication, although drugs vary in their effect and there may be marked inter-individual variation in change in weight. The mechanisms leading to weight gain are not fully understood, but may involve stimulation of appetite and disruption of metabolism. Observational studies suggest that there is an increased risk of diabetes in people receiving antipsychotic medication for schizophrenia, some second generation anti-psychotic agents (SGAs) being particularly implicated, although research evidence is currently not good enough to confidently estimate the extent of diabetogenic effect. (Smith M et al 2007) The STAR study in the UK has shown that the metabolic side effects of aripiprazole treatment are less than those produced by other treatments, with health benefits for individual patients and economic benefits for the NHS. (Barnett et al 2009) The differential effects of particular drugs and variability of individual responses highlight the importance of monitoring SMI patients for diabetes and managing CVD risks.

Variation in provision and quality of health care

Internationally, studies have shown that people with SMI receive less preventive care and treatment than the general population. (Mitchell et al 2009) One of the largest UK studies of health outcomes for people with SMI found that excess deaths from CHD and stroke were not wholly explained by smoking, social deprivation or antipsychotic medication, (Osborn et al 2007) which raises questions about the quality of medical care received by this group.

Studies in the US have consistently found under diagnosis and under treatment in people with SMI, including diabetes care. For example, the CATIE schizophrenia trial screened participants at baseline and found that more than 30% of people with diabetes, 62% with hypertension and 88% with dyslipidaemia were not receiving treatment for these conditions. (Nasrallah et al 2006) Research in the UK has revealed similar inequalities in treatment. (DRC 2006) A UK multicentre primary care study investigated the quality of routine preventive care for patients with schizophrenia and asthma. Patients with schizophrenia were less likely to receive clinically important health checks such as BP and cholesterol in general practice. (Roberts et al 2007) However, a large scale UK study using electronic GP records and QOF indicators found that patients with diabetes who also had diagnoses of schizophrenia or bipolar disorder had been monitored and treated similarly to patients with diabetes who did not have SMI. (Whyte et al 2007) Since this study relied on information provided by the practices, few quality checks were possible. The data were collected in the first year of the new GMS contract (2004/5), which incentivised creating case registers and monitoring and recording a range of process and outcome indicators, when it is likely that registers were incomplete. There is also the possibility of ‘gaming’ by some practices to achieve target levels on the relevant indicators, thus making inequalities harder to detect. The study could not ascertain who had monitored and treated the patients.

Most UK studies that screened people with SMI report discovering high levels of unmet need for medical treatment or preventive care. However, most of these studies tend to be small and recruit patients from mental health services, who may be less likely to be monitored in primary care. A well-being intervention programme recruited 966 outpatients with SMI who on screening were found to have a high prevalence of obesity, hypertension, smoking, poor diet and lack of exercise. Thirty-four patients (3.5%) required urgent medical referral for potentially life-threatening conditions, including severely raised glucose and lipids, malignant hypertension and abnormal thyroid function. (Smith et al 2007). Nurses at a medication management clinic in Scotland screened 31 patients prescribed antipsychotics and also found a high prevalence of obesity, poor diet and lack of exercise. 14 referrals were made for potentially serious problems, including raised glucose and lipids, hypertension and cardiac problems. (Shuel et al 2009)

Explanations for inequalities in screening and treatment among SMI patients include:

- ***Significant barriers to accessing NHS services, particularly in primary care.*** Not all people with SMI are registered with a GP: homelessness or not having a permanent address can make it difficult. (All-party Parliamentary Group for Diabetes 2006) Patients whose behaviour is perceived as difficult or violent may be removed from practice registers, and subsequently have problems being accepted by another GP practice. (DRC 2006) Practice staff may not understand the needs of people with SMI and inflexible organisation of surgeries and appointment systems can create barriers. (DRC 2006)
- ***Reluctance to engage with services.*** Experiences of dealing with health care professionals may have undermined SMI patients’ trust and confidence. In addition, some patients report being stigmatised when using mainstream services. (DRC 2006; All-party Parliamentary Group 2006)
- ***Impaired judgment; difficulty communicating health needs and following prescribed treatment.*** SMI itself may limit patients’ ability to assess and communicate their health needs and to follow treatment. Patients with diabetes need to make informed choices about treatment options and those with SMI may need additional help to manage their illness and to achieve good glycaemic control. (All-party Parliamentary Group 2006)
- ***Diagnostic overshadowing.*** This is the tendency of health professionals to attribute any symptoms to a person’s mental health problems, rather than considering the possibility of physical illness. This may be compounded by lack of trust and communication difficulties. (DRC 2006)

- ***Lack of clarity about who is responsible for physical health care.*** 'The lack of consensus over who should take responsibility for the general healthcare needs of patients with mental illness has resulted in a continuing failure to provide appropriate services.' (De Hert 2009)
- ***Patchy provision and poor integration of specialist services.*** Patients with SMI typically rely on generalist services to meet their physical health needs. Those who have a long term conditions such as diabetes may not have access to services that can provide expert care for both illnesses, in particular to physical health care from professionals who understand the implications of SMI. A survey of provision of psychological support for people with diabetes in the UK found that only a small proportion of diabetes teams had access to expert mental health input, i.e. from mental health professionals who also had an understanding of diabetes. (DUK 2008)
- ***Rehabilitation services not focused on physical well-being.*** A number of reports have noted professionals' low expectations about people with SMI participating in health promotion activities. Recent studies paint a much more optimistic picture of the extent of participation in and the benefits of well-designed and appropriately delivered initiatives to improve physical health. (Smith et al 2007; Pendlebury et al 2007; Eldridge, Dickers 2007; The Scottish Government 2008)

Consensus on issues and need for action

In the last five years various organisations in the UK have published reports that reviewed evidence on the physical health inequalities experienced by people with SMI and called for changes in policy and practice to provide better services and improve health outcomes. One of the most hard-hitting reports on the health experiences of people with mental health problems and learning disabilities was of an investigation, including specially commissioned research, by the Disability Rights Commission (2006). This report is almost unique in exploring service users' perspectives and experiences of services. In 2008 the Royal College of Psychiatrists launched a manifesto for a three year campaign to tackle inequality in mental healthcare. (Fitch et al 2008) The same year the Scottish Government, professional bodies and the mental health third sector produced a report on improving the physical health of people with mental illness, including examples of good practice in service provision. (The Scottish Government 2008) Most recently, the European Psychiatric Association (EPA), supported by the European Association for the Study of Diabetes (EASD) and the European Society of Cardiology (ESC), have published a position statement on cardiovascular disease and diabetes in people with SMI, which includes evidence-based management guidelines, with the aim to improving screening and treatment. Diabetes UK has campaigned on SMI and diabetes, producing reports highlighting inequalities for disadvantaged groups (All-Party Parliamentary Group on Diabetes 2006) and on mental health and diabetes in Northern Ireland (Action Mental Health and Diabetes UK Northern Ireland 2006).

All these reports made recommendations for action, including a clear national policy lead and guidelines; local policies on SMI and physical health care; improved physical health screening for people with SMI in primary care; provision of services to improve the physical health of people with SMI; and better integration of mental health services and physical health services, in primary and secondary care. These are considered in turn below, highlighting particular initiatives.

National Policy

Evidence of inequalities in physical health of people with SMI and campaigns to highlight deficiencies in services prompted a national policy response that is apparent in current national guidance and recent policy initiatives. The focus has been on measures to improve access to screening and monitoring physical health of people with SMI, particularly for CVD risk factors, and to addressing physical health and well-being as part of treatment and rehabilitation. This is reflected in the current Department of Health consultation on mental health policy (DH 2009) and the guidelines issued by bodies such as NICE (NICE 2009). Screening in general practice for people with long term mental health problems is encouraged by provision of financial incentives as part of the Quality and Outcomes Framework (QOF) in the new GMS contract. However, there has been little national policy attention to how to best to deliver services for people with SMI who are also require treatment for long term conditions such as diabetes.

National guidelines

The NICE guideline on treatment and management of schizophrenia in adults has recently been updated and includes a section entitled ‘primary care and physical health’. (NICE, 2009)

‘GPs and other primary healthcare professionals should monitor the physical health of people with schizophrenia at least once a year. Focus on cardiovascular disease risk assessment as described in 'Lipid modification' (NICE clinical guideline 67) but bear in mind that people with schizophrenia are at higher risk of cardiovascular disease than the general population. A copy of the results should be sent to the care coordinator and/or psychiatrist, and put in the secondary care notes.’

The main emphasis is on screening people with schizophrenia in primary care, using practice registers to identify patients and monitoring at least once a year, focusing particularly on cardiovascular disease risk assessment and managing risk factors or providing treatment in line with current national guidance. Mental health professionals in secondary care are also given responsibility for ensuring that checks and any necessary treatment are provided in primary care. The guidelines also state that patients admitted to mental health units should receive a physical health check.

Local policies and guidelines

The effectiveness of providing physical health care for people with SMI based on improved screening in primary care remains to be assessed. Although most people with SMI receive treatment in primary care (it is estimated that between 25 and 50% of patients with SMI are ***not*** in contact with specialist mental health services), the evidence suggests that problems of access to and engagement with primary care and the variable quality of screening and subsequent treatment may mean this approach has inherent limitations unless accompanied by fundamental changes to the delivery of primary care and the skills available in the primary care team. (DRC 2007) Local policies to secure physical health care for everyone with SMI may adopt a 'belt and braces' approach to ensure all patients receive health checks and treatment for physical health problems. It seems that some mental health trusts are assuming responsibility for SMI patients they are in contact with receiving complete health care. For example, the Pennine Care Foundation NHS Trust policy (2008) follows the NICE guidelines closely, requiring all patients admitted to a mental health unit to undergo a physical health check, and care co-ordinators in mental health teams to ensure that every outpatient is registered with a GP and receives appropriate screening and regular review of LTCs. Guidelines are provided. If a patient chooses not to have a check in primary care, the policy states unequivocally that it is the responsibility of trust staff to find an alternative option. While most trusts provide staff with medication monitoring guidelines, it was not possible to ascertain how many trusts have a similarly comprehensive SMI and physical health policies.

Screening in primary care

The Quality and Outcomes Framework is used to monitor and reward activity in primary care, incentivising GPs and their practice teams to improve the identification, care and support of people with long-term severe mental health problems. Practices are recommended to carry out an annual physical health check, including monitoring CVD risk and measuring blood glucose levels.

What is not clear is what happens once patients on register have been screened. Anecdotal evidence that GPs don't refer to specialist support programmes to manage CVD risk. (Smith et al 2007)

Primary care service for psychiatric inpatients

One example was found of a GP contracted by a PCT to provide a primary care service for patients in an acute psychiatric unit, offering consultation with patients, including treatment, health promotion advice and referral to specialists if necessary, and advice to staff on managing patients' physical illnesses. The service was designed to ‘fill a gap’ in provision of physical health care for inpatients, which it appears to have achieved, but as an ad hoc solution it raises questions about wider integration of services and securing continuity of care for patients after discharge from the acute unit. (Welthagen et al 2004)

Screening mental health service users

A number of examples were found of initiatives by mental health staff (usually nurses) offering general health screening and encouraging mental health service users to participate in specially designed preventive programmes. These developments were noted in the DH consultation document *New Horizons*: ‘increasingly mental health services working with primary care offer smoking cessation support, health checks and advice on diet and exercise.’ (DH 2009) These initiatives seem to have developed alongside improved monitoring of antipsychotic medication for physical side effects, for example using the LUNSERs screening tool. (Day et al 1995)

The Mental Health in Scotland report (the Scottish Government 2008) gives an example of a joint initiative between CMHTs and primary care offering annual screening to people with SMI at ‘lifestyle clinics’ run by CMHT staff and practice nurses in GP surgeries. Referrals and follow up appointments are organised if risk factors or problems are discovered.

A further example in the same report describes a different model of screening. NHS Tayside created an integrated MDT (medical, nursing, OT, dietetics and physiotherapy input) which provides annual checks to people on antipsychotic medication at a community clinic, with an emphasis on CVD risk and identifying metabolic syndrome. The team offers advice on diet and exercise and education on medication management. Information is shared with GPs and specialists to ensure appropriate follow up.

Mental health nurses in Scotland also reported using a physical health screening tool (HIP) to assess patients and deliver targeted interventions. (Shuel et al 2009)

Well-being support programmes

Other studies report linking nurse-led screening with interventions to reduce CVD risk or improve well-being more generally. The best reported and evaluated scheme began with a pilot service in Lambeth that screened patients with SMI and offered them weight management and physical activity groups. (Ohlsen et al 2005) This was extended to seven centres in the UK. (Smith et al 2007) Nurse advisers recruited 966 patients known to local services, offering individual consultations for physical health screening and, if necessary referral to specialists, a weight management, physical activity, or healthy living group. Over 80% of participants remained in the programme for two years. Evaluation demonstrated that the programme was successful in modifying risk factors, although there was no significant change in mean weight and BMI.

Similar nurse-led local interventions are reported from other trusts in England. In Kent a physical well-being support service has been set up that provides:

- A one-to-one consultation by a nurse/occupational therapist who carries out a complete health check and reviews lifestyle and side-effect management;
- Referrals to other NHS agencies when health issues are identified requiring specialist intervention;
- Access to healthy living groups (for weight management advice, for example) and physical activity groups. (Eldridge, Dickers 2007)

A report from South Essex describes interventions that are aimed at increasing social functioning and inclusion as well as improving physical health and self-esteem, e.g. walking groups, allotment and gardening group. (Arnold et al 2008)

Specialist input and integration of services

The European Psychiatric Association recommends that 'Psychiatric centres should cooperate with diabetes centres to establish shared care of patients with mental illness and diabetes. For patients who require insulin treatment a diabetes nurse educator from a diabetes centre should be available upon request for patients in psychiatry units.'   However, it is difficult to find examples of models of integrated specialist care.

Liaison psychiatry is one way of creating a link between diabetes and psychiatric teams. The consultation-liaison model offers consultation with patients referred to the psychiatrist by the diabetes team, and regular team meetings to discuss patients and aspects of patient care that help to educate and support the team in managing mental health problems. In this model the liaison psychiatrist tends to be used to manage a wide range of mental health issues affecting diabetes patients, rather than focusing on those with SMI; it is a reactive and selective service determined by the diabetes team's perception of appropriate referral rather than the needs of patients and as such opportunities for useful collaboration may be missed; it is of no benefit to diabetes patients with SMI who are not currently receiving specialist care. The DUK survey found that such liaison psychiatry posts were relatively rare in the UK. (DUK 2008) One example is reported in the literature (Dalvi et al 2008)

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Please note there has been text change on page 18, Chapter 3, 3.1.1 Education and self –care support from:
“The principle difference to the DESMOND study was in the target population – DESMOND targeted the newly diagnosed, but X-PERT targeted established patients. It is more challenging to show significant changes in the newly diagnosed as the differences in potential benefit are smaller and the controls also benefit from the introduction of initial medical therapies that may distract from the impact of the education.”

To:
“The principle difference to the DESMOND study was in the target population – DESMOND targeted the newly diagnosed, whereas X-PERT targeted both newly diagnosed and established patients. It is more challenging to show significant changes in the newly diagnosed as the differences in potential benefit are smaller and the controls also benefit from the introduction of initial medical therapies that may distract from the impact of the education. Therefore, the inclusion of some patients with established disease may have contributed to the greater effect observed in X-PERT study compared to DESMOND.”

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Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.