

## Invited review

# Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes: a systematic review

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## What is known?

- People from ethnic minority groups with diabetes have poorer access to healthcare services.
- People from ethnic minority groups with diabetes have poorer reported self-management of diabetes.
- Culturally adapted programmes may improve outcomes – glycaemic control and service uptake – for patients from ethnic minority groups.

## What the study adds

- A broad and systematic review of studies using mixed methods points to persistent barriers in patient access and self-management of diabetes, particularly for ethnic minority groups with low literacy.
- A 'whole systems' approach, targeted at patient, professional and organisational levels, is required to improve patient self-management.
- A multidimensional model of 'access', incorporating broader sociocultural factors, is more instructive than a focus on service utilisation alone.

## Aims

The aims of the review are to synthesise and evaluate evidence relating to barriers and facilitators in accessing

## Abstract

A higher risk of diabetes mellitus in South Asian and Black African populations combined with lower reported access and self-management-related health outcomes informed the aims of this study. Our aims were to synthesise and evaluate evidence relating to patient self-management and access to healthcare services for ethnic minority groups living with diabetes. A comprehensive search strategy was developed capturing a full range of study types from 1995–2010, including relevant hand-searched literature pre-dating 1995. Systematic database searches of MEDLINE, Cochrane, DARE, HTA and NHSEED, the British Nursing Index, CAB abstracts, EMBASE, Global Health, Health Management Information Consortium and PsychInfo were conducted, yielding 21 288 abstracts. Following search strategy refinement and the application of review eligibility criteria; 11 randomised controlled trials (RCTs), 18 qualitative studies and 18 quantitative studies were evaluated and principal results extracted. Results suggest that self-management practices are in need of targeted intervention in terms of patients' knowledge and understanding of their illness, inadequacy of information and language and communication difficulties arising from cultural differences. Access to health-care is similarly hindered by a lack of cultural sensitivity in service provision and under use of clinic-based interpreters and community-based services. Recommendations for practice and subsequent intervention primarily rest at the service level but key barriers at patient and provider levels are also identified.

**Keywords:** access to health-care, diabetes, ethnic minorities, self-management

healthcare services and optimising self-management by ethnic minority groups living with diabetes. The review incorporates studies of mixed methods and key findings, which will contribute towards the development and

implementation of an intervention to improve care for ethnic minority groups.

## Background

Diabetes mellitus (type 1 and 2) represents different types of conditions but is broadly characterised by insulin sensitivity and impaired glucose control (Deshpande *et al.* 2008); it requires adequate long-term management to prevent further microvascular complications (damage to kidney, eye and nervous system) and macrovascular complications including cardiovascular disease (Zaninotto *et al.* 2007).

Whilst the precise prevalence of diabetes remains unknown, most estimates suggest between 3.5 and 5% of the UK population will have diagnosed type 2 diabetes; this is projected to rise by 47% by 2025 and increases to a prevalence of 10% for South Asian and Black Caribbean groups and up to 5% for Black African populations (NCCC 2008).

The prevalence including undiagnosed diabetes is estimated to be far higher, particularly in ethnic minority groups with type 2 diabetes. For instance, an overview of studies incorporating South Asian populations indicates a four- to six-fold higher elevated prevalence in these groups compared to Europeans (Khunti *et al.* 2009), and a recent population-level study incorporating both South Asian and Black African groups found a four- to five-fold elevated risk compared to a white reference group (Hippisley-Cox *et al.* 2009). Whilst this evidence suggests that the reasons for higher prevalence by ethnicity are multifactorial and partly physiological in basis, aetiological factors beyond service access and self-management lie beyond the scope of this review.

Diabetes and associated complications place an illness burden on patients and carers, which disproportionately affects those from ethnic minority backgrounds. Improving access to health-care is, therefore, a crucial component of addressing health inequalities for these groups, particularly in terms of vascular health outcomes. In addition, the resource burden on the healthcare service is substantial at around 10% of the NHS annual budget or nine billion pounds (Great British Pounds) per annum (Khunti *et al.* 2009).

## Patient self-management

Given the chronic nature of diabetes and the causal link between type 2 and lifestyle factors, recent national clinical guidelines emphasise the importance of prevention as well as structured and constant education from the point of diagnosis (DoH 2001, NCCC 2008). However, effective education is only one component of patients' broader self-

management – which requires a whole systems approach of improved evidence-based practice at patient, professional and service or system levels (Kennedy *et al.* 2007). The application of this whole systems approach is closely aligned with the NHS agenda of promoting patient involvement and self-management in long-term conditions (DoH 2010a) but also relates to wider service-level improvements, particularly access to health-care (Kennedy & Rogers 2001). For this review, the term *self-management* encompasses self-care behaviours and is used broadly to refer 'to a range of activities undertaken by individuals or others in their social network aimed at managing illness or promoting maximum health potential' (De Friese 1989 In Kennedy & Rogers 2001).

To promote effective patient self-management, many interventions have been developed and evaluated, some with positive outcomes. In a meta-analysis of 14 interventions incorporating Black African patients, glycaemic control, quality of care and complication rates were improved for ethnic minorities beyond those of white control groups (Peek *et al.* 2007). Similarly, a meta-analysis of 14 randomised controlled trials (RCTs) of mixed ethnic groups found significant improvements in glycaemic control up to 6 months; improved knowledge scores up to 12 months and improved cholesterol at 12 months compared to non-intervention groups (Hawthorne *et al.* 2008). Whilst the former, comprehensive review (Peek *et al.* 2007) found no statistically significant effect for cultural adaptation as an intervention feature, the more recent review (Hawthorne *et al.* 2008) incorporating a wider range of ethnic diversity and an exclusively RCT evidence base highlights the efficacy of adapting programmes to cultural needs. Similarly, a recent review found that didactic teaching was an ineffective means of patient education (Glazier *et al.* 2006). Overall, effective interventions tended to be of high intensity, culturally adapted in design, community or lay-led, involve one-to-one sessions, regular assessments and feedback, use treatment algorithms and incorporate behaviour related tasks (Glazier *et al.* 2006). Whilst these review studies indicate possible ways to improve patient self-management, further research is needed to strengthen the evidence base for how patient self-management can be optimised for ethnic minority groups affected by diabetes – particularly, with reference to studies of different designs.

## Access to health-care

Definitions of 'access' in research literature vary from the narrow, such as service entry (Aday & Anderson 1981), to the multidimensional. Dimensions of access include availability, acceptability, affordability and accommodation (Penchansky & William Thomas 1981); service uptake, process of care and quality of care (Szczepura 2004); and

availability and utilisation modified by financial, organisational and social/cultural barriers (Gulliford *et al.* 2009).

Poor access to health-care amongst ethnic minority groups may contribute significantly to increased morbidity and poorer health outcomes (Rhodes & Nocon 2003, Szczepura 2004). In terms of interventions, a recent review examining the role of patient-provider race concordance suggests that whilst evidence is contradictory, matched race did not improve access for minorities in terms of healthcare utilisation, communication, preference, satisfaction or perception of respect (Meghani *et al.* 2009). It seems that the performance of providers is best improved through multi-faceted interventions incorporating: post-graduate education, peer review, audit and feedback and structured recall of patients (Mira Renders *et al.* 2000), with an additional need for cultural adaptation.

However, less is known about how the specific dimensions of access effect health outcomes for patients of ethnic minority background with diabetes. The means to improve access for these patients lies beyond health service entry or utilisation alone to include broader socio-cultural factors. As such, a multidimensional model of access is adopted here to incorporate the range of barriers and facilitators influencing access to health-care.

## Methods

### The review question

Following the rigour of systematic review methodology, our review questions were developed a priori to reduce the field of evidence and identify and extract relevant data (Dixon-Woods *et al.* 2006). First, which factors – barriers and facilitators – influence patients of ethnic minorities to access healthcare services for diabetes? Second, which factors – barriers and facilitators – influence patients of ethnic minorities to optimise self-management of diabetes?

The review focused on either South Asian or Black African-Caribbean populations to correspond with the ethnic minority populations of our local study sites and larger research programme. The review questions were addressed simultaneously in our search strategy given their overlapping nature and the similarity of key terms. Considering the multidimensional nature of access and the risk of over-seeing publications relating to but not specifically stating access issues, a broad and exploratory review strategy was developed. A range of study designs were accepted to reflect an inclusive review methodology (Dixon-Woods *et al.* 2000). These included RCTs, cross-sectional, case-control and cohort studies eliciting quantitative survey data and qualitative observational or qualitative studies including relevant grey literature.

### Eligibility criteria

Study eligibility criteria are detailed later (Table 1) and include all published reports in developed countries reporting either barriers or facilitators to access or self-management for South Asian and Black African and Caribbean groups. Few limits were placed on type of study design for inclusion purposes. As few RCTs had planned subgroup analysis, studies incorporating white groups and varying proportions of ethnic minority groups were included. Studies involving mixed cohorts of ethnic groups or white only cohorts were also eligible for inclusion where they were captured by our search terms and addressed the main review aims. Studies drawing on provider and clinician participants were also included where they related to review aims.

The healthcare systems of developing countries were considered too dissimilar to inform UK service development. The 'South Asian' population encompassed Indian, Pakistani and Bangladeshi groups and reflects the major ethnic minority group composition of the UK. Since self-management and patient-led access received the greatest emphasis in the mid-1990s, the systematic search used 1995 as the inclusion threshold. However, seminal articles prior to 1995 were also included where they addressed review aims and were selected via hand-searching. This earlier literature was included to appreciate the origin of access and self-management in their contemporary use and to capture any additional key articles.

### Databases

In 2009, the core search strategy was developed in line with patient population, intervention, comparison, outcomes strategy (PICO) and following consultation with a subject specialist librarian (Table 2). This was primarily MEDLINE based and involved an analysis of Medical Subject Headings (MeSH) terms and free text words but subsequent search strategies in other databases were added to maximise sensitivity. An extensive range of electronic databases were searched from 1995–2009: MEDLINE, evidence-based review databases including Cochrane, DARE, HTA and NHSEED, the British Nursing Index, CAB abstracts, EMBASE, Global Health, Health Management Information Consortium and PsychInfo. In addition, we searched evidence pre-dating 1995–1999 by hand-searching salient journals including Diabetic Medicine and Ethnicity and Health and scanning the reference lists of key articles and reviews. This was also repeated in 2010 to capture recent publications of relevance. The search results were imported into Reference Manager to store the citations and track the abstract and article review process.

**Table 1** Eligibility criteria

	Quality	Coverage	Topic	Population	Study type
Inclusion	Articles passing screening criteria of evaluation tools	Developed countries (United States and Europe)	Articles identifying specific barriers or facilitators to access	Patient: South Asian, Black African, Black Caribbean	Articles 1995–2010
			Articles identifying specific barriers or facilitators to self-management, including interventions	White, Mixed (of those specified) Provider/clinician responsible for diabetes care	Articles reporting primary data with explicit methods and some rigour
Exclusion	Articles failing to meet screening criteria of evaluation tools	Less developed countries	Not specifically related to either access or self-management	Ethnic minorities other than those specified	Articles prior to 1995 (except grey literature)
			Not specifically related to diabetes	Study populations unrepresentative of UK (e.g. US Hispanics, Native Indian, Caribbean)	Method articles, e.g. instrument development, validation work Review articles (secondary evidence)
			Exclusively based on clinical management or outcomes Where US private medical insurance is influential	Exclusively children Non-human	Avoidance of publication bias: same study reported 3 > times Discussion articles reporting no empirical data Non-English articles

**Table 2** Search terms

Illness	1. exp diabetes mellitus/2. diabet\$.tw./3. NIDDM.mp. [mp=tj,ab,hw,tc,id,tx,kw,ct,ot,sh,bt,tn,dm,mf,nm]/4. exp kidney disease/5. exp ne. phropathy/6.CKD.tw./7. exp chronic kidney disease/8. (end stage adj failure)/9. or/1-8.tw
Ethnicities	10. Exp ethnic\$/11. afro\$.tw./12. caribbean.tw./13caribbean.tw./14. pakistani.tw./15. mirpuri.tw./16. punjabi.tw./17. urdu.tw./18. gujarati.tw./19. bangladeshi.tw./20. bengali.tw./21. sylheti.tw./22. BME.tw. 23. or/10-22
Themes	24. Self-care.tw. 25. Self-management.tw. 26. Care preferences.tw. 27.exp information needs/28.Needs assessment.tw. 29. Prefer\$.tw. 30. Access\$.tw. 31. Barrier\$.tw. 32. Language\$.tw. 33. Gender\$.tw. 34. Cultural\$.tw. 35. relig\$.tw. 36.exp awareness/37. exp belief\$/38. Health care services.tw. 39. Patient centred.tw. 40.exp primary care/41.exp GP/42. Doctor.tw. 43. Family practice.tw. 44. Exp nurse/45.exp outreach/46. Link worker.tw. 47. DSN.tw. 48. general practitioner.tw. 49.exp secondary care/50. Exp Tertiary care/51.exp specialist\$.tw. 52. Specialit\$.tw. 53. or/23-52 and/9,23,53

### Study selection

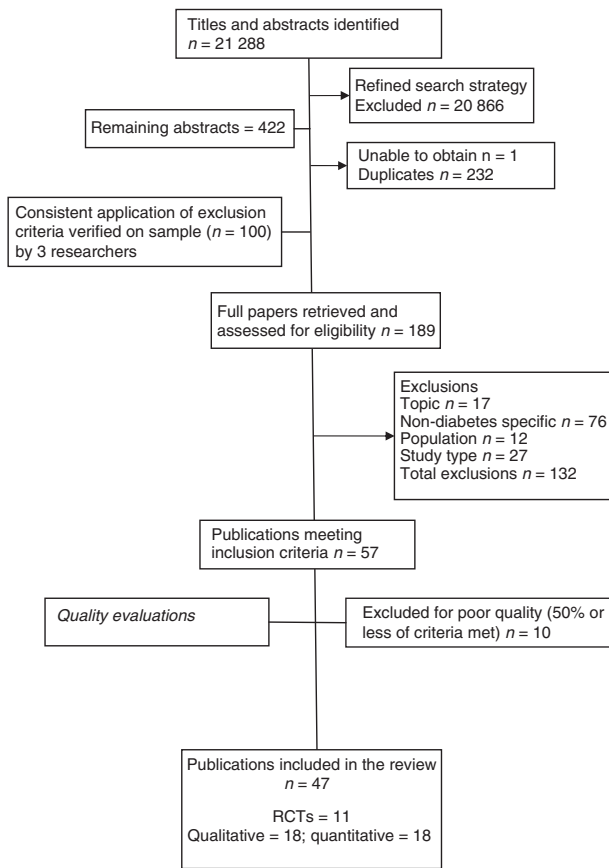
Initial search results produced an overly broad and expansive number of abstracts, so the search strategy was refined. Both steps are reported in Figure 1 since refinement involved using the same search terms but with less reliance on related terms, i.e. the 'explode' function; text word searches (.tw) and use of OR also

narrowed relevant hits. A lead researcher screened abstracts to improve the match of evidence to the review aims. To check that eligibility criteria were applied consistently, three reviewers (CW, SL and RA) then assessed a sample of one hundred abstracts independently, and any ambiguities were resolved through dialogue until consensus was reached. Following full retrieval of selected articles, six researchers (CW, SL, RA, KK, SW and KB) from a range of disciplinary backgrounds including nursing, nutritional science, psychology and social science, assessed articles for eligibility and where studies were included ( $n = 47$ ), evaluated articles using quality assessment tools.

### Quality assessment

A separate Critical Appraisal Skills Programme (PHRU 2006) tool was used for qualitative studies and RCT studies. For quantitative studies other than RCTs, the DARE York Manual (Centre for Reviews and Dissemination 2002) was also used. The evaluation tools were selected by consulting project researchers and methodologists experienced in the use of evaluation tools. Discrete tools were selected to reflect the different types of evidence arising from different study types. As the tools varied in question number, a consistent scoring system was developed to quantify categorical and open-ended responses to the evaluation questions and to allow for some indication of quality across study type. Having met standard screening questions, the tools were marked with the





**Figure 1** Adapted QUOROM flowchart of review process and study selection.

following scores; in the quantitative survey tool, seven marks were available for design and conduct, four marks for analysis, four for interpretation and five for overall quality; in the RCT tool, one mark for a positive indication, zero for a negative or neutral indication; and in the qualitative tool, one mark for a positive indication, zero for a negative indication and two marks for overall quality. Aggregate scores are expressed as % of evaluation criteria met (Table 3).

A small proportion of studies were excluded where either initial screening criteria or at least 50% of quality

**Table 3** Quality scores

	Number of Studies meeting quality criteria			Total
	Excluded	Included		
Study type	<50%	50–75%	75–100%	
Randomised controlled trials	3	4	7	11
Quantitative	1	13	5	18
Qualitative	4	14	4	18

criteria were unmet. Articles not meeting screening criteria were excluded because they could not be adequately evaluated using the selected tools, whereas excluding those under 50% enabled us to preserve the quality of review evidence and strengthened the basis for future intervention design. Results of the evaluation and eligibility exercise were tracked in an SPSS version 15 database with identification codes for each article matched to the Reference Manager database.

### Data extraction and synthesis

Extraction of results was conducted by a lead researcher who recorded the following details on standardised extraction tables: publication details, sample size and population details, illness type, setting and country, study aims, method, quality score, main results and recommendations for practice. A reduced and concise form of the extracted table is reported in Table 4. Synthesis was achieved using content analysis of main research findings grouped by study type. This was conducted for the first review aim relating to self-management then for the second review aim relating to access to health-care.

### Results

Result summaries are based on the extraction of key findings and are reported by study type (Table 4). Aggregate scores for study evaluations are reported in Table 3. The type of evidence by study design is acknowledged throughout the summaries. In synthesising the results, studies receiving higher quality scores were given no additional weighting.

### Access to services

#### Process of care

Providers are central to understanding the process of care delivered to patients in terms of their identity, perceptions, ability to communicate and role in organisational systems. However, there is evidence of a lack of shared understanding between patient and provider. In a survey comparing patient-provider perceptions of diabetes and impact on self-care, differential perceptions were reported for all ethnic groups but were at their greatest and predictive of self-care behaviour in African patients alone (Tang *et al.* 2008). Whilst factors at patient and organisational levels also influence shared understanding, evidence from both a large-scale survey (Sarkar *et al.* 2008) and numerous exploratory studies suggest that providers' lack of cultural understanding and effective communication may be a barrier to improving access.

**Table 4** Results

Author and date	Sample size, population	Illness type, setting, country	Aims	Key findings/outcomes
Interview studies				
Lawton <i>et al.</i> (2007)	32 White 32 Indian and Pakistani	Diabetes type 2 GP practices and hospital clinics Scotland	Contextualise accounts of illness	Pakistani and Indian respondents tended to externalise responsibility for developing the disease. White respondents tended to emphasise the role of their own lifestyle choices and personal failings. Indian and Pakistani respondents reported not having access to the correct kinds of food or medication, and language a barrier in some cases
Lawton <i>et al.</i> (2006)	23 Pakistani 9 Indian	Diabetes type 2 GP practices Scotland	Explore barriers to physical activity	Patients are generally aware of the need to undertake physical activity but few put this into practice. Practical considerations such as lack of time were interwoven with cultural norms and social expectations. Health promoters need to work with the community and their cultural norms
Lawton <i>et al.</i> (2005)	23 Pakistani 9 Indian	Diabetes type 2 GP practices Scotland	Explore perceptions and experiences of taking OHAs	Participants reported complex and ambivalent views about OHAs, which is reflected in some hesitant attitudes towards 'Western' drugs. HCPs were seen as trustworthy and authoritative professionals
Fagerli <i>et al.</i> (2007)	16 Pakistani	Diabetes type 2 GP and Hospital Norway	Explore patient expectations of health consultations and their views of professionals' style and communication	Consultation style: empathy and care valued, authoritarian style not favoured. Low trust and different role expectations between patients and health professionals attributable to class, education and ethnicity
Fagerli <i>et al.</i> (2005a,b)	15 Pakistani	Diabetes type 2 Norway	Explore patient experiences and behaviours towards dietary advice	Patients aimed to practice dietary advice but experienced many constraints. Patients found tensions between medical advice and cultural lay knowledge
Fagerli <i>et al.</i> (2005a,b)	*6 GPs 6 Dieticians	General population Primary Care and Hospital Services Norway	Explore professionals experience of cross- cultural consultations	Professionals considered themselves to be patient-centred, particularly in supporting empathy and equality, but found patients favoured a more authoritarian approach; their own efforts to be patient-centred at times led to either unintended authoritarianism or vague 'diffuse' communication
Stone <i>et al.</i> (2008)	*13 lay educators 9 interpreters	Diabetes type 2 Community England	Investigate the training and use of lay educators and interpreters in the delivery of Desmond	An education program for English speakers can feasibly be adapted for South Asian groups; pictorial resources are particularly effective. Lay people from the community require specific training, (particularly on the higher rates of the condition in South Asian groups) in order to facilitate sessions
Kerr (2007)	South Asian <i>sample size not reported</i>	Diabetes type 2 Pharmacist Scotland	Examine the effect of culturally sensitive education, including medication review and dietary advice on diabetic control	Post-6 education program at 6 months, improved patient knowledge of diabetes, particularly of 'hypoglycaemia' and 'hyperglycaemia'. Clinical Outcomes: 1% reduction of HbA1c (associated with reduced risk of micro-vascular complications) and 2.5 kg weight reduction
Stone <i>et al.</i> (2006)	12 African and Caribbean	Diabetes type 2 Community England	Identify cultural issues appropriate to the education of newly diagnosed patients	Separate sessions for these groups not favoured due to English as common language. Community locations and 'relevant' content favoured. Natural remedies to treat diabetes discussed and the desire for people to understand reasons why they are at a greater risk Education style: pictorial and non-didactic teaching preferred. Need for more information relating to portion control, method of cooking and managing social dining

Table 4 (Continued)

Author and date	Sample size, population	Illness type, setting, country	Aims	Key findings/outcomes
Rankin & Bhopal (2001)	334 South Asian	Diabetes and Heart Disease Community England	Assess understanding of heart disease and diabetes in the community	Two thirds of patients reported not knowing enough about the conditions to take preventative measures; knowledge levels were lowest for Bangladeshi people. 6/16 patients with diabetes could not identify any associated risk factors
Brown <i>et al.</i> (2007)	16 African-Caribbean GP practices Self-help groups	Diabetes type 2 England	Understand how health beliefs influence self-management	Poor knowledge and understanding of diabetes. Some mistrust of medical advice and preference for natural remedies and disliking of insulin therapies. General support for health care professionals with some pointing to inadequacy of NHS in caring for Black patients. Patient explanations of diabetes influenced by friends, family and own life history
Greenhalgh <i>et al.</i> (1998)	40 Bangladeshi 8 White 2 Afro-Caribbean	GP practices Diabetes type 1 and 2 England	Explore experiences, attitudes and belief systems underlying diabetes management	Patients reported strong willingness to understand and explain the onset and experience of their illness with limited evidence of fatalism Lay sources of information were major influence on behaviour. Some issues common to all groups but Bangladeshi 's tended to prefer a larger body image
Cortis (2004)	*30 RGNs	Mixed illnesses Adult acute, critical and rehabilitation care settings England	Investigate the experiences of registered nurses caring for hospitalized Pakistani patients	Professionals found relationship between culture, patient care and nursing practice difficult to explain. Deficits related to understanding Pakistani culture (religious and dietary needs, gender matching issues), poor communication with patients, and under- use of an interpreting service
Hawthorne <i>et al.</i> (2007)	20 Bangladeshi	Non-specific illness GP registered Wales	Explore community experiences prior to a culturally appropriate diabetes education program	Poor awareness of core primary care services. Views of primary care professionals are valued Access problems related to (1) family structure and behaviour, and (2) health beliefs, experiences and opinions of the local healthcare services. Appointment difficulties arose from co-coordinating the availability of a man to accompany wives and children to clinic. A family translator had also to be available, particularly for elderly patients. Medication compliance may also be affected by limited language and communication skills
Bissell <i>et al.</i> (2004)	21 Pakistani	Diabetes type 2 Primary and Secondary Care England	Identify patients' views and experiences in the context of concordance (mutual working together of patient and practitioner)	Integrating the diabetic regimen: majority reported disruption to daily pattern of living though appreciated importance of dietary change, exercise and blood/urine monitoring. Lack of material resources were a major barrier, also accommodating family and work commitments with regimen. Majority reported positive experiences of healthcare interactions. Some frustration and self-blame experienced in trying to comply and feeling of being misunderstood. The principal of concordance was not recognised by patients, rather the doctor represented authority or expertise
Rhodes & Nocon (2003)	12 Bangladeshi	Diabetes type 1 and 2 GP Practices England	Examine the experiences of patients accessing diabetes services and the role of communication	Patients rely on family to provide interpretation at clinics and this was preferred for privacy, support and mutual understanding. Evidence of poor quality of care attributed to professional attitudes and practices (e.g. mechanistic nursing, inter-personal skills)

**Table 4** (Continued)

Author and date	Sample size, population	Illness type, setting, country	Aims	Key findings/outcomes
Greenhalgh <i>et al.</i> (2005)	13 Bangladeshi 11 Gujarati, Persian, Somalian Turkish, Arabic, Chinese	Diabetes type 2 Community England	Develop and refine a complex intervention through bilingual health advocates	Diabetes education groups using a 'sharing stories' or case history method, led by bilingual professionals, were accepted well by both service-users and staff
Thomas <i>et al.</i> (2008)	15 White and Asian	Diabetes type 2 (at risk of chronic kidney disease) GP Practices England	Develop a self-management package for patients with diabetes at risk of kidney damage	Some understanding of kidney disease as a risk factor but not generally understood as a possible consequence of inadequately controlled diabetes or as linked to high blood pressure Only a few patients identified possible ways to slow progression of kidney disease Poor understanding of how to control diabetes due to perceived inconsistent or partial advice from professionals
<b>RCTs</b>				
Baradaran <i>et al.</i> (2006)	85 Pakistani 33 Indian 27 White	Diabetes type 2 GP Practices Day Care Centres (Multi-site, 18 sessions) Scotland	Develop culturally appropriate educational program and measure post-intervention improvements	At baseline, Indian and Pakistani patients held poorer knowledge and understanding of diabetes Post-intervention patients' showed greater appreciation of the seriousness of diabetes and the value of diabetic control. In ethnic groups, the only post-intervention change was perceived seriousness. Knowledge, practice or attitudes towards complications were not associated with changes beyond those of the control group and no significant differences reported between groups
Hawthorne & Tomlinson (1997)	201 Pakistani	Diabetes type 2 Diabetes Centre, General Practice (Follow up at 6 months) England	Evaluate effect of pictorial education on patients knowledge, attitudes and self-care behaviour	Pre to post improvements in intervention group for nutritional knowledge, complication knowledge, self-care behaviour and glycaemic control at 6 months. Most attitudinal measures were constant. Eating socially (with others) remained a challenge
Hawthorne (2001)	105 Pakistani female	Diabetes type 2 Diabetes Centre (Follow up at 6 months) England	Effect of culturally appropriate health education on glycaemic control and knowledge of diabetes	Female Pakistani patients with diabetes have poorer glycaemic control than male counterparts The majority of female patients receiving 1-1 educational (pictorial) intervention improved their knowledge of diabetes at 6 months. Illiterate women scored less well on knowledge indicators and post-intervention showed no improvement in glycaemic control
Keyserling <i>et al.</i> (2002)	200 African-American females	Diabetes type 2 Primary Care Clinics and Community Health Centres. (Multi-site 1 year intensive, 3 arms Follow-up at 6 and 12 months) US	Determine effect of culturally appropriate clinic and community-based intervention on physical activity	Statistically significant differences found between groups receiving clinic, community and minimal follow-up and those receiving minimal intervention and clinic only. A combined community and clinic intervention is associated with moderate improvement in the exercise levels of African American women with type 2 diabetes. Patient reported effectiveness of intervention appeared high



Table 4 (Continued)

Author and date	Sample size, population	Illness type, setting, country	Aims	Key findings/outcomes
Ziemer <i>et al.</i> (2003)	648 African-American	Diabetes type 2 Diabetes Centre (Equivalence, Clinic based dietary instruction and nutritional therapy, follow-up up to 6 months) US	Compare effect of a simple meal plan with a traditional 'exchange-based' meal plan in reducing HbA1c levels	Glycaemic control improved similarly in both those receiving the simple healthy food choices plan and those receiving the exchange-based meal plan; no significant differences were found on other clinical outcomes
Griffiths <i>et al.</i> (2005)	439 Bangladeshi	Chronic Illness including diabetes ( $n = 139$ ) GP Practices (2 arms, follow-up at 4 months) England	Effectiveness of culturally adapted, lay-led self-management program	Intervention group receiving an Expert Patient Program: the Chronic Disease Self-Management Program (CDSMP) reported improved self-efficacy, self-management behaviour and lower depression scores at 4 months; improvements were higher for those attending regularly. No statistically significant differences relating to communication or health-care use
Vyas <i>et al.</i> (2003)	211 South Asian	Diabetes type 2 General Practices (Multi-site, 2 arms, 1 year follow-up) England	Investigate whether secondary-primary care partnership education improves understanding of diabetes care	Patients reported diabetes as burdensome on social and working life. No significant differences in knowledge, awareness or self management scores in intervention group
Bellary <i>et al.</i> (2008)	1486 South Asian	Diabetes type 2 General Practices Cluster Trial England	Effectiveness of a culturally sensitive enhanced care package for improvement of cardiovascular risk factors	No significant differences reported between groups or improvement in glycaemic control. At baseline, CV risks high and clinical indicators far below recommended guidelines. Overall CVD improvements at 2 year follow-up associated with increased statin and anti-hypertensive medication following the Quality and Outcomes Framework
Young <i>et al.</i> (2005)	591 Caucasian	Diabetes type 2 GP Practices (2 arms, variable follow-up to 1 year) England	Determine whether Pro-Active Call Centre Treatment Support improves glycaemic control	Intervention group improved their HbA1c by 0.31%. At baseline, patients with HbA1c of <7% reported no change: those of >7% reported post-intervention improvements of 0.49%
Long <i>et al.</i> (2005)	394 White	Diabetes type 2 GP Practices (2 arms) England	Assess patient acceptability and satisfaction with telephone support	65% of patients found usual care acceptable. Post-intervention satisfaction was high: >90% strongly agreed or agreed on acceptability of tele-care. Patients valued: the 'personal' service and rapport with the tele-carer, help with problem-solving and reported greater confidence, self-control and well-being
New <i>et al.</i> (2003)	1407 White	Diabetes type 1 and 2 Primary: GP and hospital-based care (2 arms, follow-up at 4–6 weeks) England	Determine the effectiveness of specialist nurse-led clinics for hyper tension and hyper lipidemia	Borderline difference in effect between usual care and intervention. Interventions associated with significant improvement in patients achieving targets at 1 year (more so for hyperlipidemia than hypertension) and reduced mortality (based on small number of cases)
Survey and quantitative designs				
Khanam & Costarelli (2008)	25 Bangladeshi, female	Overweight and Obese Community England	Investigate attitudes towards health and exercise and explore ways to increase physical activity	Some did not perceive themselves as overweight. Majority held poor knowledge about diabetes and only willing to exercise at gym following GP referral. Majority preference was for swimming; followed by slow walking, running was least preferred

**Table 4** (Continued)

Author and date	Sample size, population	Illness type, setting, country	Aims	Key findings/outcomes
Mainous <i>et al.</i> (2006)	2523 South Asian	Diabetes type 1 and 2 Hypertension Community England	Examine language skills and prevalence of undetected diabetes and hypertension at population level	Adjusted regression suggest that for Bangladeshi people, poorer English language is significantly associated with undetected elevated blood glucose and for Pakistani people, elevated blood pressure. Foreign-born South Asians had a higher diagnosed diabetes prevalence (2.5%) than UK-born South Asians (0.8%)
Sedgwick <i>et al.</i> (2003)	799 White; 163 African; 522 Caribbean; 415 other	Diabetes type 2 GP Practices UK	Evaluate whether Black African and Black Caribbean people gain equitable access to diabetes care compared with white	Adjusting for healthcare need, Caribbean groups reported higher healthcare utilisation on 4/9 variables; African groups were only higher for 2/9. Remaining utilisation variables were equivalent for all groups
Piette <i>et al.</i> (1999)	252 mixed ethnicity, low-income	Diabetes type 1 and 2 Hospital clinics US	Examine acceptability of ATDM (automated telephone disease management) to low-income patients	High completion rates of bi-weekly check-ups (69%) were associated with healthier patients No other socio-economic indicators were associated with completion rates or responsiveness Self-monitored blood glucose (SMBG) was well reported (in 74% of assessments) and negatively associated with lower income, non-white ethnicity and pre-high school education. Higher SMBG accompanied by frequent reporting of poor control, hypo symptoms, foot problems and poor general health
Hawthorne & Tomlinson (1999)	201 Pakistani	Diabetes type 2 GP and Secondary Care UK	Study factors influencing knowledge and self-management of diabetes	Deficits in applying diabetes knowledge to daily life, particularly in relation to persistent hyperglycaemia. Females had poorer practical knowledge and glycaemic control. Poorer ability with problem scenarios associated with illiteracy
Brooks <i>et al.</i> (2000)	277 South Asian	Acute Secondary care UK	Explore verbal communication between healthcare providers and Urdu or Punjabi speaking inpatients	Half of participants were aware of the interpreting service; those who were, found it useful Where interpreting not used, family, members of staff and visitors assisted Patients recommended more interpreters linked to wards, a 24-hour service, more Asian clinicians on wards and raising awareness of the service in general
Tang <i>et al.</i> (2008)	273 Black African and White *71 providers	Diabetes type 1 and 2 Community healthcare system US	Compare patient-provider differences in perceptions between ethnic groups and examine self-care behaviours	A greater number of patient-provider differences in perceptions of African patients on several items. Semantic differential scores were associated with five self-care behaviours for African patients (healthy diet, physical activity, blood glucose monitoring, insulin use and medication), but only two for white patients (healthy diet and physical activity). Providers' semantic differential scores predicted self-care behaviour for African patients only
Margerison (2004)	*40 GP Practices	Diabetes type 1 and 2 GP UK	Review current provision of diabetes services in primary care	Around half of practices had systematic routes for diabetes care whilst half delivered care on an ad hoc basis. Room for considerable improvement in maintaining practice registers and identifying patients with diabetes (pre implementation of QoF). Staff recruitment and retention problems persist in PCT

Table 4 (Continued)

Author and date	Sample size, population	Illness type, setting, country	Aims	Key findings/outcomes
Glasgow <i>et al.</i> (2007)	506 mixed ethnicity	Diabetes type 2 Depression Multi-centre US	Assess relationships between diabetes problem-solving skills, patient characteristics and depression levels	Problem-solving skills significantly associated with co-morbidities, complications, self-management behaviour, blood glucose (dietary association), lipids (exercise association) and psychosocial functioning (distress). Greater co-morbidities and complications associated with lower physical activity problem-solving. Variability in problem-solving not determined by race or ethnicity
Hawthorne (1990)	40 Asian 31 White	Diabetes type 2 Secondary care UK	Evaluate the care received by Asian patients in a hospital clinic	High up-take (90%) of patient education. Asian patients held lower knowledge of diabetic complications, glucose monitoring and the value of check-ups: they also rated the clinic more negatively in terms of waiting times and staff communication) Poorer glycaemic control reported in Asian than white patients (based on $n = 50$ )
Ryan <i>et al.</i> (2008)	524 mixed ethnicity	Diabetes type 1 and 2 Population study US	Investigate whether self-reported racial and gender discrimination are associated with poorer diabetes management.	Adjusting for patient-provider race and gender concordance; self-reported ethnic discrimination was associated with approx 50% lower probability of receiving an A1C test, foot exam or blood pressure test. Self-reported gender discrimination associated with 22% lower probability of haemoglobin test. No other associations were significant
Ledda <i>et al.</i> (1997)	27 African	Diabetes type 2 Foot care clinic US	Develop, evaluate and pilot a self-care, home-based program for the prevention of foot problems	Majority of African American patients found a home-care program incorporating an induction session, instruction booklet and large hand held mirror beneficial for foot care regime. Hand-held mirror reported as the most beneficial. Younger patients (40–60) preferred African adapted materials. Older patients (60+) favoured multi-ethnic materials
Welch <i>et al.</i> (2006)	6433 African White, Native US, Other	Diabetes type 1 and 2 Secondary (managed care) US	Evaluate the impact of a diabetes management program	African and Hispanics reported more frequent annual visits compared to whites (statistically significant). At program follow-up (1 year), African and Hispanics had lower utilisation rates of preventive services than white patients. Ethnic differences in self-management behaviours (self glucose testing) at baseline were reversed at follow-up in terms of glucose control with Africans self-testing more frequently
Sarkar <i>et al.</i> (2008)	265 African 264 White 267 Hispanic	Diabetes type 1 and 2 Multi-centre US	Identify interest in different types of self-management support and assess factors associated with patient preference	69% interested in telephone support; 55% in group medical visits, 42% in Internet. African patients more interested in all types than white patients. Patients with literacy problems and non-English speakers more likely to be interested in telephone support. 40% reported that communication with professionals could be improved; those who did so were more interested in self-management in general
Bhopal <i>et al.</i> (2002)	684 South Asians 825 European	Coronary heart disease Diabetes type 1 and 2 Population UK	Test the hypothesis that worse SES is associated with glucose intolerance	Europeans had highest socio-economic position. Socio-economic heterogeneity within South Asian groups: Indians advantaged compared to Pakistani and Bangladeshi groups. Interactions between socio-economic position and ethnicity: 71/84 SES variables predicted health outcomes for Europeans in predicted direction with 25 of statistical significance; 58/84 for South Asians with 12 of statistical significance

**Table 4** (Continued)

Author and date	Sample size, population	Illness type, setting, country	Aims	Key findings/outcomes
Ettner <i>et al.</i> (2008)	11 927 White and Black African	Diabetes type 1 and 2 Multi-centre US	Examine associations between SES and extra time spent on self-care (foot-care)	Around a third of patients spent no additional time on foot-care or exercise; over half of patients spent no additional time on shopping/exercise. Ethnic minorities, the socio-economically disadvantaged and less educated spent a little extra time on foot-care. Black Africans spent around three minutes per week additional time on foot-care than whites
David & Kendrick (2004)	839 White and South Asian	Diabetes type 1 and 2 GP Practices ( <i>n</i> = 8) UK	Examine differences in processes of care between ethnic groups and place of delivery	Trend suggests that adjusting for age, gender, residence, practice and treatment, South Asian groups were less likely to have blood pressure or serum creatinine measured. Overall, those receiving shared care (GP and hospital-based) had more frequent health care checks and superior record of and process of care indicators. Differences in processes of care by ethnic group persisted
Karlson & Nazroo (2002)	582 Caribbean, 973 Indian, 848 Pakistani and Bangladeshi, 104 Chinese	General population UK	Explore associations between racism, social class and health among ethnic minorities	Experience of racial discrimination (either violence, institutional discrimination or socioeconomic disadvantage) has an independent effect on health (a higher incidence of self-reported 'poor' ratings)

CKD, chronic kidney disease; CVD, cardiovascular disease; HCPs, health care professionals; OHA, oral hypoglycaemic agents; RCT, randomised controlled trial; RGN, registered general nurse; SES, socioeconomic status; SMBG, self monitored blood glucose; QoF, Quality and Outcomes Framework. \*Provider participants. Provider: clinician, lay educator, interpreter or manager.

In terms of nursing, this may be due to a poor understanding of Pakistani culture and underuse of available interpreting services (Cortis 2004) or to professional attitudes, inadequate interpersonal skills or mechanistic care (Rhodes & Nocon 2003). In medical consultations, perceptions of physicians as expert or authority figures, expecting compliance makes some Pakistani patients feel misunderstood (Bissell *et al.* 2004).

Discrepancies between patient and provider views of their role also extend beyond ethnic differences to include both class and education (Fagerli *et al.* 2007). Overall, whilst some providers may intend to be patient-centred, this is not always effectively communicated to patients (Fagerli *et al.* 2005a,b), and the use of bi-lingual providers, where appropriate, is recommended to improve communication (Rhodes & Nocon 2003, Greenhalgh *et al.* 2005) along with the need to adapt services to cultural need.

#### Health service utilisation

A review of primary care diabetes services points to room for considerable improvement in maintaining practice registers and structuring care pathways for all patients at national level (Margerison 2004). Evidence relating to differences in healthcare utilisation by ethnic

group is contradictory. Results from large, multi-ethnic surveys, controlling for healthcare need, suggest that African patients have more frequent annual check-ups in secondary care but lower use of preventative services (Welch *et al.* 2006), whilst Caribbean and Black African patients have reported higher utilisation than white patients in primary care settings (Sedgwick *et al.* 2003). However, utilisation of service is only one dimension of access to health-care.

#### Quality of care

Whilst quality of care is widely identified as a dimension of access, the evidence base for quality of care outcomes is limited. In one small multi-ethnic survey, Asian patients rated a secondary care clinic more negatively, particularly in terms of waiting times, staff communication and value of check-ups (Hawthorne 1990).

#### Adequacy of information

As with self-management, the adequacy of information in terms of improving access to services is problematic in terms of cultural relevance and format, particularly for speakers of other languages. However, some caution should be taken in culturally adapting materials. An exploratory study reported that African patients over

sixty preferred multi-ethnic materials whilst younger patients preferred materials adapted to specifically African culture (Ledda *et al.* 1997). Further research is needed to explore the role of patient preference in terms of cultural adaptation of information.

#### *Access interventions*

Patients receiving shared care may have more frequent health-care checks but results for clinical monitoring are poorer for South Asian groups compared to white, and patient non-attendance remains a problem (David & Kendrick 2004). Trials designed to improve general cardiovascular outcomes for vulnerable populations include an enhanced care programme incorporating additional time with a specialist nurse, practice nurse and link worker; statistically significant improvements at 2 years were, however, only associated with increased use of statin and anti-hypertensive medication in primary care (Bellary *et al.* 2008). A further trial found that a nurse-led intervention with follow-up at 4–6 weeks was associated with a small significant improvement in hypertension treatment targets compared to the usual annual review led by a diabetologist (New *et al.* 2003).

Interventions incorporating community-based care may lead to positive outcomes. For instance, in an intensive intervention targeted at African–American women, a combined community and clinic intervention was associated with a significant, albeit moderate improvement in exercise levels (Keyserling *et al.* 2002). The use of telephone support or tele-care has also been trialled. The use of pro-active call centre treatment support (PACCTS) in a predominantly white sample was found to improve HbA1c results with clinical significance and be highly acceptable to patients (Long *et al.* 2005) but was of minimal cost-effectiveness compared to usual care alone (Young *et al.* 2005). In US settings, results similarly suggest general acceptability of tele-care but point to the persistent challenge of lower rates of blood glucose self-monitoring in non-white and socio-economically disadvantaged groups. There is additional evidence from a large multi-ethnic-based survey that non-English-speaking patients and those with lower literacy skills may be more amenable to telephone or internet support, possibly as a result of perceived poor communication with professionals (Sarkar *et al.* 2008). Exploratory research also suggests that community-based education is preferred by patients of African or Caribbean ethnicity (Stone *et al.* 2006).

#### *Health service accommodation*

In terms of service accommodation, Urdu and Punjabi patients support greater availability of interpreting services on a 24-hour basis and greater use of interpreters by clinicians (Brooks *et al.* 2000). In contrast, a study of

twelve Bangladeshi patients found that family interpreters were preferred because of the benefits of shared understanding and privacy (Rhodes & Nocon 2003). This may, however, cause difficulties in arranging appointments if a family member, usually a man, is expected to be available for clinic visits with the patient (Hawthorne *et al.* 2007).

#### *Role of socioeconomic status*

In addition to factors relating to the patient, provider and organisational levels, three population studies highlight the influence of socioeconomic status and perceived discrimination on health status. There is marked heterogeneity within South Asian groups showing the relative disadvantage of Pakistani and Bangladeshi groups, and significant interactions between disadvantage, ethnicity and health status, including glucose intolerance (Bhopal *et al.* 2002). There is further evidence that patients who report ethnic discrimination in their lives have a higher incidence of poor health (David & Kendrick 2004) and a far lower probability of receiving clinical monitoring tests (Ryan *et al.* 2008).

### **Self-management**

Living with diabetes requires effective patient self-management, particularly for vulnerable groups at risk of poorer glycaemic control. Studies identified multiple factors influencing patients' ability to self-manage the following: patients' knowledge and understanding of their illness, their trust in medical advice, self-management practices (including diet, exercise, body-image and social relationships) and views of treatment, medication and adherence behaviour.

#### *Knowledge and understanding*

Variability in patients' problem-solving skills appears determined by clinical factors and self-management behaviour but not by race or ethnicity (Glasgow *et al.* 2007). However, there are differences by ethnic group in terms of knowledge and understanding. South Asian patients have reportedly lower knowledge of diabetes (Hawthorne 1990). At baseline, in a comparative multi-ethnic RCT (Baradaran *et al.* 2006), Indian and Pakistani patients held poorer knowledge and understanding of diabetes than a white population. Such deficits were also reported in a trial (Hawthorne 2001) and cross-sectional survey (Hawthorne & Tomlinson 1999) involving Pakistani women with diabetes (Hawthorne 2001), and in a small study of Bangladeshi women with weight problems (Khanam & Costarelli 2008).

The cross-sectional design of many studies, whilst indicative, does not allow for reliable comparisons between groups and whilst controlled studies offer the



necessary comparative element, results are typically modest and should be interpreted with caution. For instance, in a recent RCT, Indian and Pakistani patients reported poorer baseline knowledge and understanding of diabetic control and complications than white groups but differences by group were not of statistical significance (Keyserling *et al.* 2002).

Exploratory studies highlight deficits in knowledge and understanding of diabetes, associated complications and preventative measures across all groups (Brown *et al.* 2007, Thomas *et al.* 2008), particularly for Bangladeshi (Rankin & Bhopal 2001) and African-Caribbean patients (Brown *et al.* 2007), but suggest that patients are generally willing to understand their illness (Greenhalgh *et al.* 1998). Overall, there is a clear need to raise patients' knowledge and understanding of their illness if self-management is to improve; this is particularly the case for patients of Bangladeshi and Pakistani origin and female patients with illiteracy problems within these groups. There is some suggestion from exploratory work that patient self-management strengthens over time (Hawthorne & Tomlinson 1997) but this is dependent on effective patient education and is unlikely to occur with disease progression alone.

#### *Trust in medical advice*

Results from qualitative studies suggest that patients with diabetes generally trust the medical advice they are given by professionals (Bissell *et al.* 2004, Lawton *et al.* 2005), but at times advice is perceived as inconsistent, contradictory (Thomas *et al.* 2008), or poorly adapted to the needs of Black patients (Brown *et al.* 2007). Limited evidence suggests that cultural norms and social expectations per se act as barriers to the acceptance of conventional medical advice within South Asian communities (Lawton *et al.* 2005).

#### *Self-management practices*

There is little to suggest that self-management behaviour differs substantially by ethnic group. A multi-ethnic survey found that Black Africans from socioeconomically disadvantaged backgrounds spent additional time on foot care each week (Ettner *et al.* 2008), compared to white groups, but the difference was minimal and of limited clinical significance.

However, African patients appear to practise glucose self-monitoring less frequently (Welch *et al.* 2006), indicating a particular need for targeted self-management education.

Dietary control is particularly salient in optimising self-management behaviour and is closely related to social and family functioning. The pressures associated with social dining often compromise recommended diets for ethnic minority groups with diabetes (Ziemer *et al.*

2003, New *et al.* 2003) and may persist after patients receive education intervention (Griffiths *et al.* 2005).

Exploratory studies report that diabetic dietary regimens are disruptive to patients' daily lifestyle (Bissell *et al.* 2004, Fagerli *et al.* 2007) and exist in tension with traditional South Asian diets and lay advice (Fagerli *et al.* 2005a,b). This may be a result of poorer access to healthy foods for Indian and Pakistani patients (Lawton *et al.* 2007) or attributable to lower material resources in these groups (Bissell *et al.* 2004). African and Caribbean patients reported that portion control and greater attention to cooking method rather than food types were of particular concern (Stone *et al.* 2006). Whilst the social element of dietary control is problematic for many patients (Greenhalgh *et al.* 1998), there may be distinct dynamics for those from ethnic minorities. Family, friends and life history play a central role in shaping African and Caribbean understanding of illness (Brown *et al.* 2007) and provide a strong source of knowledge and emotional support for those from South Asian backgrounds (Bissell *et al.* 2004). There is broader evidence that families frequently serve as informal interpreting services in South Asian families (Brooks *et al.* 2000, Rhodes & Nocon 2003), so act as important intermediaries in self-management behaviour; this may be particularly the case for elderly patients (Hawthorne *et al.* 2007).

Physical activity appears to present a similar self-management issue for all groups. However, an interview-based study highlighted the need for culturally tailored exercise programmes for South Asian groups (Lawton *et al.* 2006), and there is further evidence that concepts of healthy body image may differ across cultures. For instance, Bangladeshi patients have indicated a higher tolerance for larger body types (Greenhalgh *et al.* 1998) and greater reluctance to view themselves as overweight (Khanam & Costarelli 2008).

#### *Language*

Lower levels of English skills in South Asian groups are associated with a greater incidence of undiagnosed diabetes and a poorer ability to self-manage. This has been found in terms of a greater incidence of undetected elevated blood glucose in Bangladeshi patients with limited English skills (Mainous *et al.* 2006) and poor glycaemic control associated with illiteracy in Pakistani women (Hawthorne & Tomlinson 1999). Additionally, limited English language is a barrier in accessing services for many South Asian groups, but perhaps less so for African and Caribbean where English is regarded as a common language (Stone *et al.* 2006). Whilst many quantitative studies identify associations between lower English language proficiency and poorer self-management, further research is needed to understand how these factors are related, particularly in terms of patients' lived experience.

### Treatment

In terms of treatment self-management, some evidence suggests ambivalence towards oral hypoglycaemic agents amongst South Asian patients. A few patients report intentionally reducing their medication because of a fear of dependency and adverse effects (Lawton *et al.* 2005). Poor medication compliance in the Bangladeshi community has also been associated with limited language and communication (Hawthorne & Tomlinson 1997). Some use of herbal medication has been reported in South Asian cohorts (Hawthorne 1990) and in a patient focus group, African and Caribbean participants related poor acceptance of insulin therapies to a preference for natural remedies (Brown *et al.* 2007). However, there is little to suggest that these are widespread views amongst patients or substantially affect self-management behaviour.

### Self-management interventions

Interventions designed to improve patient self-management of diabetes have variously focused on the following: cultural adaptation of information particularly pictorial resources, the use of lay, community or multilingual providers and non-didactic or novel educational methods. Fewer interventions have specifically included medical review or dietary planning.

In terms of improving diabetes knowledge, an 18 session culturally adapted programme was found to yield general improvement in the perceived value of diabetic control, but for South Asian patients, the only marked improvement was perceived seriousness of diabetes with no significant improvement for knowledge, practice or attitudes towards complications (Baradaran *et al.* 2006). Similarly, a multicentre, joint care intervention between primary and secondary care providers produced no significant improvements in patient knowledge, awareness or self-management beyond those reported for patients receiving primary care alone (Lawton *et al.* 2006). A further equivalence trial comparing a simple meal plan with an exchange-based meal plan in African-American patients found no significant difference in glycaemic control at 6 months.

### Patient education

In terms of information provision, the use of pictorial information, including graphics, flashcards and posters in patient education, appears effective, particularly when delivered by trained lay personnel and in one-to-one sessions (Hawthorne & Tomlinson 1997, Hawthorne 2001, Stone *et al.* 2008). In cohorts of Pakistani patients, improved knowledge on several scales and improved glycaemic control has been reported at 6 months using these methods (Hawthorne & Tomlinson 1997). This is

with the exception of female Pakistani patients with illiteracy problems, where inadequate glycaemic control has persisted following educational intervention (Hawthorne 2001). In a sample of African-Caribbean participants, pictorial information was also reported by patients as a preferred method, accompanied by a non-didactic style of teaching (Stone *et al.* 2006).

A further trial reported improved self-efficacy, self-management behaviour and psychological functioning for regular attendees of the Expert Patient Programme in Bangladeshi patients (Griffiths *et al.* 2005). Further effective methods involving South Asian groups have included a case history approach of 'sharing stories' in groups (Greenhalgh *et al.* 2005) and for African-Caribbean patients, culturally relevant programme content (Stone *et al.* 2006). There is evidence that trained lay providers with interpreting skills are best placed to facilitate self-management education programmes (Stone *et al.* 2008); though, some studies favour programmes led by bi-lingual professionals with peer facilitation (Greenhalgh *et al.* 2005). However, peer facilitation does not always feature as an essential component of self-management education. In primary care, a multicomponent intervention, incorporating dietary advice and medical review, targeted at South Asian patients and led by a multilingual community pharmacist produced positive outcomes for glycaemic control (1% reduction in HbA1c) and patient knowledge of diabetes at 6-month follow-up (Kerr 2007).

### Discussion

The questions of our review arose from a wide body of research highlighting problems in relation to patient self-management and access to services in ethnic minority people with diabetes. Indeed, the breadth of the review presented several challenges; the large number of hits necessitated a refined search strategy, decisions relating to eligibility criteria were also subject to extensive consideration to ensure both inclusiveness and relevance. The approach to be taken in synthesising such a high volume of data, incorporating mixed methods designs, was also problematic; for instance, results could have been synthesised by study type rather than thematically. However, results have been presented in a way which most directly addresses our study aims. Differences in study type have also been acknowledged throughout following a rigorous process of evaluation.

Cultural misunderstanding, language and communication problems, inadequate information, and poor awareness of services have all frequently been reported as barriers in improving health-care for patients with diabetes. Several intervention studies also made general recommendations for practice. However, this review has

considered factors which facilitate as well as hinder patient self-management and includes a range of intervention studies with applicability for all patients. It has also analysed the concept of access in its different dimensions and following a whole-systems model, evaluated a comprehensive range of evidence at three main levels of relevance.

In terms of patient self-management, there are persistent deficits in patients' knowledge and understanding of diabetes; this is particularly the case in Pakistani and Bangladeshi groups where language or literacy problems may serve as barriers to optimal self-management. Limited evidence points to less frequent self-glucose testing in Black African and Caribbean groups and poor medication compliance in ethnic minorities overall. Whilst exploratory studies suggest that trust in medical advice is generally high, some evidence suggests that advice is perceived as contradictory or inadequately adapted to Black African and Caribbean patients. Qualitative studies also highlight tensions between diabetic diets and social dining with families from South Asian and Black African and Caribbean groups appearing to have a greater influence on patients' ability to manage their diet. This suggests that self-management education which draws on a whole systems approach (Kennedy *et al.* 2007) is still required and some degree of cultural adaptation to patient need is recommended.

However, the results of self-management interventions are mixed, which is partly attributable to different study designs. Several interventions reported no significant improvements in terms of efficacy but overall intervention features associated with positive outcomes tended to be of high intensity, culturally adapted in design, use community or lay-led interpreters, non-didactic behavioural education and include visual images and graphics.

In terms of improving access to services, barriers persist in several dimensions, primarily in terms of appropriateness, process of care and quality of care; these are influenced by social and cultural barriers (Szczepura 2004). In terms of health service utilisation, care pathways for patients are clearly variable. Whilst some evidence points to lower uptake of preventative services by ethnicity, there appears little difference in utilisation by ethnic group. In terms of care processes, there appears to be poorer clinical monitoring of South Asian groups but the possible relationship with patients' utilisation practices, e.g. role of missed appointments, is largely unknown.

In general, a lack of shared understanding between patient and provider is frequently reported. This highlights the scope for further interventions at the provider level. This includes education and training aimed to improve cultural awareness and communication, making full use of interpreting services, providing bi-lin-

gual clinicians and communicating patient centeredness in consultations. The wider use of interpreting services is also to be welcomed as a fundamental accommodation issue. In terms of quality of care, limited evidence suggests that South Asian patients are less satisfied with clinics in terms of communication, waiting times and perceived value. There is stronger evidence that the adequacy of information can be improved by adapting materials to cultural need but further research on preference for information type and degree of cultural adaptation is needed. Drawing on the whole systems approach (Kennedy *et al.* 2007), there is further scope for intervention at the organisational level. Moderate improvements for all patients, regardless of ethnic group, are also associated with medical review, nurse-led follow-up, more frequent follow-up, intensive community-based interventions and telephone support.

## Conclusion

The results of this review should be interpreted in light of considerable variation in study design and outcome measures. Eligibility criteria also placed restriction on the evidence considered, and evaluations of cost-effectiveness were lacking in the results. Search terms used in relation to ethnicity may also be specific to UK populations, and some ethnic minority groups were not included in our review. The broader social context in which the whole systems approach operates is also important. Socioeconomic status intersects with ethnicity in its association with glucose intolerance and is further complicated by considerable variation of status within ethnic group. As such, future studies should take a critical approach to constructions of ethnicity in health science research (Mainous *et al.* 2006). Our review, built on existing evidence, found strong recommendations for optimising patient self-management and access in diabetes care for ethnic minorities at patient, provider and organisational levels. Principal recommendations relate to improving access at the service-level and are based on some evidence of effectiveness. These will be used to develop a future intervention and delivery of culturally competent services in local clinical sites. Several components may be suitably incorporated in the intervention including: adequate resourcing of patients' needs assessments, provision of interpreters (Hawthorne *et al.* 2007), provider training, community education programmes (Baradaran *et al.* 2006, Stone *et al.* 2006) and intense or greater frequency of follow-up (Glazier *et al.* 2006). Many recommendations can be applied to all patients regardless of ethnic minority status and include nurse-led educational delivery by managers/nurse clinicians (Peek *et al.* 2007) or nurse specialists (New *et al.* 2003), use of telephone support (Piette *et al.* 1999, Young

*et al.* 2005) and community and primary care group drop-in sessions (Rhodes & Nocon 2003). There is also further scope for strengthening relationships between primary and secondary care (Hawthorne 1990, David & Kendrick 2004).

Exploratory research points to barriers in implementing these changes, primarily professional role dilemmas (Fagerli *et al.* 2005a,b), and organisational structures resistant to either advocate led services or the targeting of resources at patients in greatest need (Greenhalgh *et al.* 2005). Whilst some studies recommend targeting resources – particularly towards ethnic populations with literacy needs (Hawthorne & Tomlinson 1999), or culturally adapting education programmes – a few studies highlight the similarity of need across patient group (Sedgwick *et al.* 2003), suggesting constancy of service provision. More research investigating the efficacy of interventions, their cost-effectiveness and patient preferences on access and self-management is needed (Ledda *et al.* 1997).

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