What makes for a ‘good’ or ‘bad’ paediatric diabetes service from the viewpoint of children, young people, carers and clinicians? A synthesis of qualitative findings

Katherine Curtis-Tyler, Lisa Arai, Terence Stephenson, Helen Roberts

ABSTRACT

Background There is mounting evidence that experience of care is a crucial part of the pathway for successful management of long-term conditions.

Design and objectives To carry out (1) a systematic mapping of qualitative evidence to inform selection of studies for the second stage of the review; and (2) a narrative synthesis addressing the question, What makes for a ‘good’ or a ‘bad’ paediatric diabetes service from the viewpoint of children, young people, carers and clinicians?

Results The initial mapping identified 38 papers. From these, the findings of 20 diabetes-focused papers on the views on care of ≥650 children, parents and clinicians were synthesised. Only five studies included children under 11 years. Children and young people across all age groups valued positive, non-judgemental and relationship-based care that engaged with their social, as well as physical, health. Parents valued provision responsive to the circumstances of family life and coordinated across services. Clinicians wanting to engage with families beyond a child’s immediate physical health described finding this hard to achieve in practice.

Limitations Socioeconomic status and ethnicity were poorly reported in the included studies.

Conclusions In dealing with diabetes, and engaging with social health in a way valued by children, parents and clinicians, not only structural change, such as more time for consultation, but new skills for reworking relations in the consultation may be required.

INTRODUCTION

The progressive shift in the involvement of patients, users and citizens from the periphery of practice to a more central position has been mirrored in research and dedicated research funding.1 That said ‘involvement work’ is frequently tokenistic. Methodological and quality development has not always progressed in a stepwise manner with many small studies of ‘user views’. These may have a particular value for localised services, but there are ethical, practical, financial and methodological reasons for building on what is already known from published research rather than generating new primary studies.

The 2012 report of England’s Chief Medical Officer suggests that children’s diabetes services may underappreciate the evidence that the pathogenesis of complications starts from the time of diagnosis.5 Data indicate that only 5.8% of all children and young people with diabetes receive the care needed to reduce risk of complications,6 and English outcomes appear poor when compared internationally.7 While the evidence on ‘good’ and ‘poor’ experiences by patients, carers and staff is only one part of the picture in addressing poor outcomes, there is mounting evidence that these experiences are a crucial part of pathways to successful management of long-term conditions.

METHODS

This study entailed a secondary analysis of qualitative data—a cost-effective and time-efficient way to...
access a wider sample than one could reach in a primary study. Our search terms were designed to identify studies relevant to the English health service. These data enable us to understand from the point of view of key actors on what factors enable treatment and social health to ‘work’ (or get in the way of it working). A rapid review—one with restrictions on breadth to support timely findings—was carried out. The size of the body of literature required a focused approach with a targeted search.8

Systematic assessment of evidence

A systematic evidence assessment is one that maps the range and depth of available evidence on a given question, which can then inform the selection of studies for subsequent synthesis.9 The first stage of our review comprised systematic assessment of evidence on views and experiences of paediatric healthcare across chronic illnesses on the basis of the question, What makes for a ‘good’ or a ‘bad’ paediatric chronic illness healthcare service from the viewpoint of children, young people, carers and clinicians? A preliminary sample of 350 citations from scoping searches was discussed by the qualitative review team to inform inclusion criteria for the mapping (see table 1).

A focused approach to database searching is required in a systematic way as described in the following sections.

### Table 1

| Criteria | Rationale |
|----------|-----------|
| Inclusion criteria | Date of publication—since long-term care in England and Wales has changed considerably over time, we considered the past 10 years to be an appropriate cut-off in terms of health technologies, systems for delivery and policy interests |
| | Country—studies carried out in England or Wales |
| | Differences in the organisation of healthcare and the wider social context, across Europe and North America (and increasingly other parts of the UK) mean that comparative work within the UK and more broadly may be an important area for a more extensive piece of work |
| Focus—views/experiences of service provision for children, young people or young adults (CYP) with long-term conditions; these may include multidisciplinary configurations of services, eg inclusive education; mental healthcare for CYP whose primary condition is not mental health; care by staff outside clinical settings; views on ‘non-adherence’ |
| Participants—children, young people or young adults (authors’ definition) with a long-term condition, their carers, clinicians or support staff who work with children with long-term conditions |
| Design—primary or secondary studies collecting qualitative data and using qualitative methods for analysis* |
| Date—published 2004 onwards |
| Country—carried out in England or Wales (author institutions used as proxy if not directly reported) |
| We kept on file otherwise eligible work from elsewhere in UK and Europe |
| Exclusion criteria | Practical grounds of volume control in a rapid review |
| | Opinion pieces and best practice reviews with no methods section |
| | Unavailable online |
| | Without abstracts—(records of these studies were retained for possible future work) |
| | Surveys |
| | Studies to inform the development of a quantitative tool or instrument |
| | Studies exploring: views of provision for children in general; palliative care; screening for genetically inherited conditions; mental health provision for CYP with a primary mental health diagnosis (but records retained for future work); experiences of research participation |

*For a discussion of the characteristics of qualitative approaches, see Spencer et al.10

### Table 2

| Criteria | Rationale for inclusion |
|----------|-------------------------|
| Papers from systematic mapping | There was sufficient evidence to support a diabetes-specific focus matching the related primary study. |
| Primary studies | Reviews were excluded from the synthesis in order to avoid synthesising first-order and second-order data (primary studies from eligible reviews were included) |
| Diabetes focus or where data on diabetes provision could be disaggregated | Papers from reviews in systematic mapping: resolves difficulties around synthesising first-order and second-order data |
| Additional material | Scottish papers kept on file from mapping: a useful resource for future comparisons between different parts of UK |
| Peer-reviewed journal paper | Papers without abstracts kept on file from systematic mapping: as Paediatric Diabetes does not use abstracts, it was important to include papers without abstracts in the synthesis |
| Primary research | Hand-searches of reference lists of studies included in the synthesis: standard practice |
| Qualitative findings children, young people or young adults (caregivers/clinicians’ views of provision) | |
| Sole diabetes focus | |
| Published 2004 onwards | |
| Carried out in England, Wales or Scotland | |
experiences of children and young people with type 1 diabetes, included other conditions. While most papers reported on the success in attempts to involve those less likely to use services.15

Methods and data extracted from each are set out in online supplementary appendix 6. All items were sufficient evidence to support a diabetes-specific focus, with additional material systematically identified from papers kept on file from the evidence mapping, and hand-searching reference lists of eligible studies (see table 2).

Papers were quality assessed.2 Data were synthesised using a narrative approach, in which methods of analysis are brought to bear to explore homogeneity and heterogeneity across studies descriptively, rather than statistically.11 Processes of the synthesis are set out in table 3.

RESULTS
The initial evidence mapping identified 38 papers reporting 36 studies (see online supplementary appendix 3 for flow chart). Study methods and data extracted on children’s, parents’ and staff views of long-term care are tabulated in online supplementary appendix 4. Also, 5 papers with no abstract and 35 European and Scottish papers were retained on file (see online supplementary appendix 5).

After application of synthesis eligibility criteria, and systematic identification of additional diabetes-related papers (see figure 1), 20 papers describing 18 studies were included in the synthesis. Methods and data extracted from each are set out in online supplementary appendix 6. All items were sufficiently strong to merit inclusion in the synthesis. Study authors reported recruiting via health providers or related voluntary agencies. Several reported recruitment difficulties12–14 and one reported little success in attempts to involve those less likely to use services.15

A summary of papers by focus and participant group is set out in table 4. Most had a sole diabetes focus (n=16); five also included other conditions. While most papers reported on the experiences of children and young people with type 1 diabetes, in five the diabetes type was not clear (table 4).

Children and young people
The synthesis drew on the views of 197 children and young people with diabetes across 8 studies (10 papers) with a sole condition focus, and at least 46 (possibly more) with diabetes from 4 studies with a mixed condition focus (table 4). While children and young people with diabetes were the most frequently consulted group, two studies with relatively large samples of parents and no children means that overall more parents than children are included in the synthesis (table 4).

Children and young people’s accounts indicate an overriding concern with minimising the threat of the illness and regimen to their social health by protecting their ‘sameness’ to non-diabetic peers (table 5).12 13 15 17 26–30 This may be why ‘extra’ provision (eg, support groups or training courses) (table 5) received a relatively lukewarm response from young people.14 16 17 20 28 It may also underpin the difficulties some authors report with study recruitment.12–14 Children and young people sought highly individualised and collaborative care, which was generally felt to be forthcoming only in the context of ongoing, personal relationships with specific clinicians who know them well (table 5).16 16 22 28 29

Children and young people assessed the quality of their relationships with professionals in terms of the style and content of interaction; they sought positive exchanges in which clinicians demonstrated confidence in their capacities and character, and where there were opportunities to make choices and set the agenda for discussion (table 5).12 16 22 28 29

Authors highlighted the role of targeted information and education, for example, in mitigating anxiety at transition14 and helping young people to learn the intricacies of intensive therapy16–19 or to make choices ‘fully appreciating the complexities of one’s disease’ (p.151).12 While young people also valued timely provision of practical, tailored resources,12 13 15–17 22 28 29 they suggested this is not always easy to achieve, and likely to be an adjunct to, not a replacement for, the individualised advice from relationships with clinicians who know them well.14 22 28 29

A minority of studies included the views of children under 11 years (n=5). Like teenagers, they described wanting to be ‘normal’ in relation to peers as a priority. At odds with their sense of being a key player in their care at home, they could feel sidelined both in clinic and when trying to look after their diabetes at school.12 15 26 27 30 Though authors’ interest in transition from paediatric to adult services13 14 22 23 may account for the focus on teenagers in the majority of studies retrieved, it chimes with these reports of a tendency for views of younger children to be excluded at clinic level.12 30 Authors of studies with younger children describe their ‘extraordinary maturity and

We use the phrase ‘social health’ rather than ‘well-being’ or ‘psychosocial health’ to reflect young people’s reported views that discussions of the social impact of their care should not be split off from their regular encounters with the doctors and nurses into additional ‘support’ or psychological provision, crucial though these may be for some.
adaptability’, expertise in their care arising out of their day-to-day experiences of living with illness and their willingness to discuss this when approached by an adult demonstrating confidence in their capabilities and character (ref. 12, p.153, ref. 30).

Mothers, fathers, carers and families
At least 236 family members were consulted across six diabetes studies, and at least 38 more across mixed condition studies, again mainly about information, education and additional support resources (table 4). Unsurprisingly, a central theme was the need to protect children’s immediate safety—and, where possible, minimise the impact of care on daily life.15 17–19 21 26 27 32 Perhaps as a function of studies in which they were invited to participate, parents focused on how provision supported or inhibited achieving these ends, for example, in schools, during transition or via timely information/education.12–15 17 18 20 21 26 27 32 Like children and young people they valued ‘uninterrupted relationships’,13 14 but as one part of a wider concern with responsiveness of, and coordination across services as a whole (table 5). As described above, children and young people’s views on care in schools tended to focus on threats to their social well-being as much as physical health;12 15 17 26–30 whereas nurses flagged hypoglycaemia and the absence of a statutory framework on teachers’ responsibilities.24 25 In terms of transition, feedback across groups pointed to the need for approaches that ‘more closely match the reality of families’ lives and changing interdependencies’, accommodating differences across and within families.12–14

Clinicians
Authors provided information on the backgrounds of about half of the 133 professionals involved with diabetes provision: most were nurses; support staff were not reported to have been consulted (see online supplementary appendix 6). Clinicians reported a range of aims for care.12 16 23 31 For some, “quality of life [was] paramount”;31 elsewhere “the absolute importance of achieving satisfactory glycaemic control as the goal against which current and future health and behaviour are measured.”23 31 Authors of included studies described clinicians as differing in their understandings of the proper scope and style for consultation. Some “focused on the medical aspects of diabetes and the need for discipline, with much less emphasis on the social and interpersonal consequences”31 while others aimed to understand “the wants and needs of the individual”31 and “appreciate where they are coming from”.23

Clinicians reported awareness of their need for continuity. The diabetes team in one study agreed to appoint ‘key workers’ for young people across their transition clinics.31 However, they feared the education needs of early career colleagues might compromise this;14 31 and that ‘workload and time pressure’ could lead to them falling “back on relating to an individual in

Figure 1  Flow chart of selection of studies for synthesis.
Table 4  Papers in synthesis by focus and participants

| Focus                        | Participants ≥650 | Family members/carers | Professionals |
|------------------------------|-------------------|------------------------|---------------|
|                              | Studies (papers in the same row report the same study) | Diabetes studies (minimum number of CYP with diabetes)* | Diabetes studies (minimum carers with CYP with diabetes) * | Diabetes studies (minimum professionals with responsibility for diabetes)* |
| Information, education and support resources | Eiser et al. | 27 | 18 | 13 |
|                               | et al.          | 24 | 29 | 27 (3) |
|                               | Christie et al. | 48 | 48 | 31 (6) mostly mothers |
|                               | Hummelink and Pollock | 64 mostly mothers |
|                               | Kirk et al. | 18 (2) | 27 (3) |
|                               | Williams et al. | 46 (16) | 31 (6) mostly mothers |
| Transition                    | Allen et al. | 46 | 39 mothers | 38 |
|                               | Price et al. | 11 | 9 |
| Coping in school              | Boden et al. | 11 | 5 |
|                               | Marshall et al. | 47 |
|                               | Nevbould et al. | 69 (26) | 69 (26) |
|                               | Smith et al. | 27 (2) | 27 (2) |
| General                       | Dovey-Pearce et al. | 19 |
|                               | Greene | 5 |
|                               | Curtis-Tyler et al. | 17 |
|                               | Brierley et al. | 14 |
| Home management from diagnosis| Lowes et al. | 38 |
| Total participants            | 197 (46) | 236 (38) | 126 (7) |

*Figures show minimum possible totals for children, young people or young adults (CYP) with diabetes where sample size was reported by source of recruitment only; for CYP generally where sample size was reported by method of data collection only; and for carers where the number of parents participating in each family was not described.

†Includes type 2 diabetes.
‡Participants’ diabetes type unclear.
§Includes children under 11 years.
Table 5  Children’s, young people’s and parents’ priorities for care*

| 'Bad' care | 'Good' care |
|-----------|------------|
| **Children’s and young people’s concern with maintaining social health** | **Think about it. [Intensive therapy] could make us as normal as a normal person without diabetes.” (Boy, 12 years, Waller et al, 13 p.286) |
| “(Re-injecting at school) I wouldn’t want everyone else looking at me like I’ve got half a face or something.” (Boy with diabetes, 12 years, Waller et al,13 p.286) | “I want to Iceland on a school trip but it was fine… My form tutor… was fine with it. For some children he looked after the medication but he let me look after mine.” (Young person, Smith et al, 14 p.542) |
| “The wish for secrecy had resulted in some people refusing to take medicines” (Smith et al,27 p.541) | “…whereas carers viewed formal education favourably, young people were less enthusiastic.” (Allen et al, 14 p.144) |
| My daughter feels that having diabetes does not mean she has to hang out with others who also have diabetes.” (Christie et al, p.391) | “Children [and young people] wanted] an ongoing therapeutic relationship… in which HCPs understand the fabric of individuals’ lives.” (Allen et al, 14 p.143) |
| “… whereas carers viewed formal education favourably, young people were less enthusiastic.” (Allen et al, 14 p.144) | “Children and young people want clinicians who know them well” (Greene, 29 p.54) |
| **Children and young people want clinicians who know them well** | **Children and young people want clinicians who know them well** |
| “I think what’s really stressful is that a lot of people don’t see the same health professionals each time… it makes you not want to go [to clinic because] it doesn’t really matter if you go or not because if you see a new doctor you can’t use his advice because he doesn’t know what to advise you about, because he doesn’t know you.” (Greene, 29 p.53) | “I went to Iceland on a school trip but it was fine… My form tutor… was fine with it. For some children he looked after the medication but he let me look after mine.” (Young person, Smith et al, 14 p.542) |
| “She said you should do this and that and she was reading from a text book [but] it’s in a text book and it might not exactly apply to me. I might do all that and end up coming into hospital.” (Dovey-Pearce et al,29 p.409) | “You have to get to know the patient on a personal level before you can kind of tailor advice for them.” (Price et al, 22 p.858) |
| “Sometimes the endocrinologists lose track of the practical side… they say ok, put some more insulin in your body, without even bothering to ask why they’re high.” (Greene, 29 p.54) | “… and with others they really want to know about you. “(Greene, 29 p.54) |
| **Children and young people’s strong preferences about clinicians’ style of interaction** | **Children and young people’s strong preferences about clinicians’ style of interaction** |
| “You’re talking to humans… people, and people kind of forget that.”(Price et al, 22 p.858) | “I only had him for a few appointments but he’s so down to earth and treated us like an adult.” (Price et al, 22 p.859) |
| “I have this one doctor that kept telling me that it was my fault…that’s stayed with me, the guilt… you feel like giving up.” (Greene, 29 p.54) | “You need to be offered the opportunity to learn about the process, the trial and error…” (Greene, 29 p.52) |
| “Going to the doctor is a bit like going for a test. You either pass or fail and you’re relieved when it’s over…” (Greene, 29 p.54) | “Clinicians give different impressions. With some you feel they don’t really want you to be there and with others they really want to know about you.” (Greene, 29 p.54) |
| “[The doctor] used to talk to me like I was a baby [and] to my mum as though I wasn’t there.” (Dovey-Pearce et al, 29 p.414) | “I only had him for a few appointments but he’s so down to earth and treated us like an adult.” (Price et al, 22 p.859) |
| “(At home) children saw themselves as active, reliable contributors to care alongside mothers… in clinic [they] felt peripheral.” (Curtis-Tyler, 10 p.1306–7) | “…” I was going to stop going altogether to appointments… and I enjoyed going after meeting him ‘cos of the way he treat us.” (Price et al, 22 p.859) |
| **Children and young people want opportunities to set the agenda and have choices** | **Children and young people want opportunities to set the agenda and have choices** |
| “Some clinicians are happy hearing about the… more human side of life. Others behave like the godfather of medical things. Its more abstract and its harder to speak about your situation.” (Greene, 29 p.54) | “I think you need positive reinforcement that you can carry on doing what you need to do.” (Greene, 29 p.52) |
| “[Doctors are] often more focused on your doses or how many times you test your blood sugars, and that’s not really what I come for.” (Greene, 29 p.54) | “You need to be offered the opportunity to learn about the process, the trial and error…” (Greene, 29 p.52) |
| “[Young people] did not understand why there was an emphasis on HbA1c at the expense of issues of concern to them such as how to integrate self-care into their daily lives.” (Eiser et al, 16 p.225) | “Clinicians give different impressions. With some you feel they don’t really want you to be there and with others they really want to know about you.” (Greene, 29 p.54) |
| **Children and young people want to have opportunities to set the agenda and have choices** | **Children and young people want to have opportunities to set the agenda and have choices** |
| “Young people wanted staff to be less abstract when giving information and take into account their individual lifestyle.” (Eiser et al, 16 p.225) | “I only had him for a few appointments but he’s so down to earth and treated us like an adult.” (Price et al, 22 p.859) |
| “You need to be offered the opportunity to learn… how you cope with sports, relationships, exams, family problems which the specialty doesn’t always understand.” (Greene, 29 p.52) | “…” I was going to stop going altogether to appointments… and I enjoyed going after meeting him ‘cos of the way he treat us.” (Price et al, 22 p.859) |
| “Those that promoted a sense of partnership and collaboration in the consultation were most highly regarded, while those that tended to be based around a ‘set agenda’ were not… while the physical environment and other elements did matter these results suggest the centrality of personal interactions.” (Price et al, 22 p.857–8) | “…” I was going to stop going altogether to appointments… and I enjoyed going after meeting him ‘cos of the way he treat us.” (Price et al, 22 p.859) |
| “I thought the paediatric consultants were brilliant at talking to him… ‘It’s up to you’ and then look at him.” (Mother of 12-year-old boy with diabetes, Williams et al, 14 p.160) | “…” I was going to stop going altogether to appointments… and I enjoyed going after meeting him ‘cos of the way he treat us.” (Price et al, 22 p.859) |

* Quotations are selected to illustrate the range of issues raised. See online supplementary appendix 6 for all data extracted across studies. Italicised quotations are direct speech quoted in the study, and roman text is reported by the study author.

Children and young people valued service responsiveness and coordination of care

*It was me who pushed for [young person] to go … on four injections and they weren’t happy when I … pushed and pushed and pushed for it”. (Mother of 9-year-old boy, Williams et al, 13 p.157)

*There is a clear need to develop service structures that recognise the continuing role played by mothers in the diabetes care of young adults.” (Allen et al, 13 p.994)

*Mothers and fathers valued service responsiveness and coordination of care

“You were there when we needed you… you came round when we needed you… you were at the end of the phone at the end of the day. If I was worried I could pick the phone up. So, I was afraid of feeling very isolated, but no, I haven’t felt isolated at all. Quite the reverse actually. There has been somebody there if I’ve needed them.” (Mother 7, daughter 9 years with diabetes, first interview, Lowes, 22 p.534)

“I had a word with the school nurse and the dose has been changed. She’s stopped taking it at school now.” (Parent, young person with diabetes, Smith et al, 22 p.541)

“(One) young child (9 years) read the Tadpole Times (Diabetes UK) and found out that he could have multiple doses of insulin and he decided to negotiate with the Doctor for a change of regime: ‘He’s sort of told Dr [C] and Dr [C] was like oh okay [laughs] fine yeah and so it was a decision he made.” (Mother of 10 year old with diabetes—father also has diabetes; Williams et al, 14 p.148)
terms of their social and cultural background, education or motivation...” (ref. 31, p.679)—not the individualised approach they aspired to and young people sought.

In practice, a holistic approach could be viewed as a distraction from, rather than part of, the effort “to find ways of um improving... control”;23 “we’re too busy looking at... HbA1cs”.23 Some felt that they lacked the skills for holistic engagement, especially when this involved topics such as drug/alcohol use and sexual health, not “subjects I would naturally tend to discuss”, “it feels a bit uncomfortable”.23 Arguably, the preponderance of papers on ‘extra’ education or ‘support’ interventions (Table 4) may indicate a preference for engaging with the non-biomedical outside the consultation room. Most consultations in Williams and colleagues’ observation work focused on ‘adherence to treatment rather than exploring causes of non-compliance’.12 Unresolved professional differences about the aims of care and inconsistent styles of engagement were a source of confusion and dissatisfaction for young people.16 31

DISCUSSION
Drawing on the views of >630 children, parents and clinicians, this qualitative literature synthesis found that children and young people of all ages value positive, relationship-based approaches that engage with their social, as well as physical, health. Children, young people and parents valued care that was as sensitive to the wider context of their lives as to their bodies. Parents wanted responsive provision, particularly across services and specialties. Unsurprisingly, they wanted children to be safe, but also had concerns for their social health. Clinicians, sometimes less attuned to families’ priorities beyond physical health, were inclined to see ‘non-adherence’ in terms of a need for education. They were divided between those who espoused a focus on medical outcomes alone and those who wanted to engage with children and families’ wider priorities but felt that this was squeezed out in day-to-day practice. Quite apart from their concern for children’s well-being, healthcare professionals need their patients to do well so that their clinic performs well and is seen to do so. But a focus on medical outcomes alone does not engage with the extent to which, in the context of chronic illness, processes of care as much as disease management are problematic.

The main limitation of our study is the trade-off between a timeliness and confidence of no study missed, mitigated by transparent methods and data. There was poor reporting in included studies of socioeconomic status, ethnicity and transparent methods and data. There was poor reporting in included studies of socioeconomic status, ethnicity and transparent methods and data.

REFERENCES
1 Bedford Russell AR, Passant M, Kitt H. Engaging children and parents in service design and delivery. Arch Dis Child 2014;99:1158–62.
2 Thomas J, Sutcliffe K, Harden A, et al. Children and healthy eating: a systematic review of barriers and facilitators. London: SRU, 2004.
3 Morris C, Janssen A, Allard A, et al. Informing the NHS Outcomes Framework: evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting. Health Serv Deliv Res 2014;2: ISSN: 2050-4399.
4 Attree P. Growing up in disadvantage: a systematic review of the qualitative evidence. Child Care Health Dev 2004;30:679–89.
5 Davies SC. Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays. London: DH, 2013.
6 National Paediatric Diabetes Audit Project Board. National Paediatric Diabetes Audit 2010–11. 2012.
7 NHS Diabetes. National Paediatric Diabetes Service Improvement Delivery Plan 2013–2018. 2013.
8 Petticrew M, Roberts H. Systematic reviews in the social sciences: a practical guide. Oxford: Blackwell; 2006.
9 Caird J, Hinds K, Kwan I, et al. (2012) A systematic rapid evidence assessment of late diagnosis. London: EPPI Centre, Social Science Research Unit, Institute of Education, University of London.
10 Spencer L, Ritchie J, Lewis J, et al. Quality in Qualitative evaluation: a framework for assessing research evidence. London: Cabinet Office, 2003.
11 Arici I, Britten N, Popay J, et al. Testing methodological developments in the conduct of narrative synthesis: a demonstration review of research on the implementation of smoke alarm interventions. Evid Policy J Res Debate Pract 2007;3:361–83.
12 Williams A, Noyes J, Chandler-Oatts J, et al. Children’s Health Information Matters: Researching the practice of and requirements for age appropriate health information for children and young people. Final Report, 2011.
13 Allen D, Channon S, Lowes L, et al. Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service. Diabetic Med 2011;28:994–1000.
Allen D, Cohen D, Hood K, et al. Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study. *J Health Serv Res Policy* 2012;17:140–8.

Kirk S, Beaty S, Callery P, et al. Perceptions of effective self-care support for children and young people with long-term conditions. *J Clin Nurs* 2012;21:1974–87.

Eiser C, Johnson B, Brierley S, et al. Using the Medical Research Council framework to develop a complex intervention to improve delivery of care for young people with Type 1 diabetes. *Diabetic Med* 2013;30:e223–8.

Waller H, Eiser C, Heller S, et al. Adolescents’ and their parents’ views on the acceptability and design of a new diabetes education programme: a focus group analysis. *Child Care Health Dev* 2005;31:283–9.

Knowles J, Waller H, Eiser C, et al. The development of an innovative education curriculum for 11–16 yr old children with type 1 diabetes mellitus (T1DM). *Pediatr Diabetes* 2006;7:322–8.

Field J, Waller H, Eiser C, et al. Pilot study of a novel educational programme for 11–16 year olds with type 1 diabetes mellitus: the KICK-OFF course. *Arch Dis Child* 2008;93:927–31.

Chappell M, Romano GM, Thompson R, et al. Attitudes to psychological groups in a paediatric and adolescent diabetes service—implications for service delivery. *Pediatr Diabetes* 2008;9(4 Pt 2):388–92.

Hummelinck A, Pollock K. Parents’ information needs about the treatment of their chronically ill child: a qualitative study. *Patient Educ Couns* 2006;62:228–34.

Price C, Corbett S, Lewis-Barned N, et al. Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. *Child Care Health Dev* 2011;37:852–60.

Price C, Corbett S, Dovey-Pearce G. Barriers and facilitators to implementing a transition pathway for adolescents with diabetes: a health professionals’ perspective. *Int J Child Adolesc Health* 2010;3:489–98.

Boden S, Lloyd CE, Godden C, et al. The concerns of school staff in caring for children with diabetes in primary school. *Pediatr Diabetes* 2012;13:e6–e13.

Marshall M, Gidman W, Callery P. Supporting the care of children with diabetes in school: a qualitative study of nurses in the UK. *Diabetic Med* 2013;30:871–7.

Newbould J, Francis SA, Smith F. Young people’s experiences of managing asthma and diabetes at school. *Arch Dis Child* 2007;92:1077–81.

Smith F, Taylor K, Newbould J, et al. Medicines for chronic illness at school: experiences and concerns of young people and their parents. *J Clin Pharm Ther* 2008;33:537–44.

Dovey-Pearce G, Hurrell R, May C, et al. Young adults’ (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health Soc Care Community* 2005;13(5):409–19.

Greene A. What healthcare professionals can do: a view from young people with diabetes. *Pediatr Diabetes* 2009;10(Suppl 13):50–7.

Curtis-Tyler K. Facilitating children’s contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes. *Diabetic Med* 2012;29:1303–10.

Brierley S, Eiser C, Johnson B, et al. Working with young adults with Type 1 diabetes: views of a multidisciplinary care team and implications for service delivery. *Diabetic Med* 2012;29:677–81.

Lowes L, Lyne P, Gregory J. Childhood diabetes: parents’ experience of home management and the first year following diagnosis. *Diabetic Med.* 2004;21:531–8.

Lucas Pj, Curtis-Tyler K, Arai L, et al. What works in practice? User and provider perspectives on the acceptability, affordability, implementation, and impact of a family-based intervention for child overweight and obesity delivered at scale. *BMC Public Health* 2014;14:614.

Coyne I. Children’s participation in consultations and decision-making at health service level: a review of the literature. *Int J Nurs Stud* 2008;45:1682–9.