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,1 Lisa Arai,2 Terence Stephenson,3 Helen Roberts3

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. 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. Data indicate that only 5.8% of all children and young people with diabetes receive the care needed to reduce risk of complications, and English outcomes appear poor when compared internationally. 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.8 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** Eligibility for the systematic evidence mapping of long-term care studies in paediatrics

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inclusion criteria</strong></td>
<td></td>
</tr>
<tr>
<td>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’</td>
<td>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</td>
</tr>
<tr>
<td>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</td>
<td>Country—studies 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 the UK and Europe</td>
</tr>
<tr>
<td>Design—primary or secondary studies collecting qualitative data and using qualitative methods for analysis*</td>
<td></td>
</tr>
<tr>
<td><strong>Exclusion criteria</strong></td>
<td></td>
</tr>
<tr>
<td>Opinion pieces and best practice reviews with no methods section</td>
<td>Practical grounds of volume control in a rapid review</td>
</tr>
<tr>
<td>Unavailable online</td>
<td></td>
</tr>
<tr>
<td>Without abstracts—records of these studies were retained for possible future work</td>
<td></td>
</tr>
<tr>
<td>Surveys</td>
<td></td>
</tr>
<tr>
<td>Studies to inform the development of a quantitative tool or instrument</td>
<td></td>
</tr>
<tr>
<td>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</td>
<td></td>
</tr>
</tbody>
</table>

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

**Table 2** Eligibility criteria for synthesis by source

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Rationale for inclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Papers from systematic mapping</td>
<td></td>
</tr>
<tr>
<td>Primary studies</td>
<td>There was sufficient evidence to support a diabetes-specific focus matching the related primary study.</td>
</tr>
<tr>
<td>Diabetes focus or where data on diabetes provision could be disaggregated</td>
<td>Reviews were excluded from the synthesis in order to avoid synthesising first-order and second-order data (primary studies from eligible reviews were included)</td>
</tr>
<tr>
<td>Additional material</td>
<td></td>
</tr>
<tr>
<td>Peer-reviewed journal paper</td>
<td>Papers from reviews in systematic mapping: resolves difficulties around synthesising first-order and second-order data</td>
</tr>
<tr>
<td>Primary research</td>
<td>Scottish papers kept on file from mapping: a useful resource for future comparisons between different parts of the UK</td>
</tr>
<tr>
<td>Qualitative findings children, young people or young adults (caregivers/clinicians’ views of provision</td>
<td>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</td>
</tr>
<tr>
<td>Sole diabetes focus</td>
<td>Hand-searches of reference lists of studies included in the synthesis: standard practice</td>
</tr>
<tr>
<td>Published 2004 onwards</td>
<td></td>
</tr>
<tr>
<td>Carried out in England, Wales or Scotland</td>
<td></td>
</tr>
</tbody>
</table>
The evidence mapping was discussed within the review team and with colleagues working in this field to inform a decision on eligibility and sources for the second stage of the review. It was agreed there was 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. 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. 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 difficulties and one reported little success in attempts to involve those less likely to use services.

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). This may be why ‘extra’ provision (eg, support groups or training courses) received a relatively lukewarm response from young people. It may also underpin the difficulties some authors report with study recruitment. 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).

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).

Authors highlighted the role of targeted information and education, for example, in mitigating anxiety at transition and helping young people to learn the intricacies of intensive therapy or to make choices ‘fully appreciating the complexities of one’s disease’ (p.151). While young people also valued timely provision of practical, tailor-made resources, 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.

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. Though authors’ interest in transition from paediatric to adult services 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. Authors of studies with younger children described their ‘extraordinary maturity and...’

**Table 3 Processes of narrative synthesis**

<table>
<thead>
<tr>
<th>Preliminary synthesis</th>
<th>Exploration of relationships within and between studies</th>
<th>Exploration of robustness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data on views of diabetes care tabulated by theme from a subsample of papers</td>
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</tr>
<tr>
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<td>From this, core themes identified for each group, using constant comparison of data within groups to identify patterns of similarity and difference.</td>
<td>Discussion across the research team to resolve differences</td>
</tr>
<tr>
<td>Creation of a conceptual map summarising emerging themes</td>
<td>Data clustered by group and theme to explore similarities and differences in priorities and experiences across participant groups</td>
<td>Content analysis of numbers of studies, participants in each group and range of aspects of care explored for each</td>
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</tr>
</tbody>
</table>

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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.15–19 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 17–19 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 31

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

<table>
<thead>
<tr>
<th>Focus</th>
<th>Participants n ≥650</th>
<th>CYP</th>
<th>Family members/carers</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Diab</td>
<td>Mixed condition</td>
<td>Diabetes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>es</td>
<td>studies (minimum number of</td>
<td>studies (minimum number of</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>CYP with diabetes)*</td>
<td>carers with</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>CYP with diabetes)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>and support resources</td>
<td>Waller et al[^7]</td>
<td>24</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Waller et al[^8]</td>
<td>48</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Christie et al[^9]</td>
<td></td>
<td>64 mostly mothers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hummelinck and Pollock[^10]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition</td>
<td>Kirk et al[^11]</td>
<td>18</td>
<td>(2)</td>
<td>27 (3)</td>
</tr>
<tr>
<td></td>
<td>Williams et al[^12]</td>
<td>46</td>
<td>(16)</td>
<td>31 (6) mostly mothers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Allen et al[^13]</td>
<td>46</td>
<td>39 mothers</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Price et al[^14]</td>
<td>11</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>Coping in school</td>
<td>Boden et al[^15]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Marshall et al[^16]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nevbould et al[^17]</td>
<td>69</td>
<td>(26)</td>
<td>69 (26)</td>
</tr>
<tr>
<td></td>
<td>Smith et al[^18]</td>
<td>27</td>
<td>(2)</td>
<td>27 (2)</td>
</tr>
<tr>
<td>General</td>
<td>Dovey-Pearce et al[^19]</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Greene[^20]</td>
<td>5</td>
<td></td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Curtis-Tyler[^21]</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home management</td>
<td>Brierley et al[^22]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>from diagnosis</td>
<td>Lowes et al[^23]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total participants</td>
<td>197 (46)</td>
<td>236</td>
<td>(38)</td>
<td>126 (7)</td>
</tr>
</tbody>
</table>

*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[^27][^15]; for CYP generally where sample size was reported by method of data collection only[^16][^12] and for carers where the number of parents participating in each family was not described[^15][^20][^17].

[^6]: Includes type 1 diabetes.
[^7]: Participants’ diabetes type unclear.
[^8]: Includes children under 11 years.
**Table 5  Children’s, young people’s and parents’ priorities for care**

<table>
<thead>
<tr>
<th>'Bad' care</th>
<th>'Good' care</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;[Re-injecting at school] I wouldn’t want everyone else looking at me like I’ve got half a face or something.&quot;  (Boy with diabetes, 12 years, Waller et al,12 p.286)</td>
<td>&quot;Think about it. [Intensive therapy] could make us as normal as a normal person without diabetes.&quot;  (Boy, 12 years, Waller et al,12 p.286)</td>
</tr>
<tr>
<td>&quot;The wish for secrecy had resulted in some people refusing to take medicines [at school].&quot;  (Smith et al,27 p.541)</td>
<td>&quot;She doesn’t like being questioned a lot… especially about her diabetes…&quot;  (Parent, young person, Smith et al,27 p.541)</td>
</tr>
<tr>
<td>My daughter feels that having diabetes does not mean she has to hang out with others who also have diabetes.&quot;  (Christie et al,25 p.391)</td>
<td>&quot;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.&quot;  (Young person, Smith, et al,22 p.542)</td>
</tr>
</tbody>
</table>

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)

"[Children and young people and parents want] any episodes of deterioration in control understood in the context of the individual’s care trajectory rather than as non-compliance."  (Allen et al,14 p.143)

Children and young people want clinicians who know them well

"I 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,26 p.409)

"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,28 p.54)

Children and young people want to set the agenda and have choices

"You’re talking to humans… people, and people kind of forget that."  (Price et al,25 p.858)

"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)

"I think you need positive reinforcement that you can carry on doing what you need to do."  (Greene,29 p.52)

"I only had him for a few appointments but he… he was fine with it. For me he seemed to be there and with others they really want to know about you."  (Greene,28 p.54)

"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)

Children and young people want clinicians who know them well

"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,28 p.54)

"You need to be offered the opportunity to learn about the process, the trial and error…"  (Greene,28 p.52)

"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,28 p.54)

Children and young people want clinicians who know them well

"[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,26 p.414)

"[Children and young people and parents want] any episodes of deterioration in control understood in the context of the individual’s care trajectory rather than as non-compliance."  (Allen et al,14 p.143)

Children and young people want clinicians who know them well

"Some clinicians are happy hearing about the… more human side of life. Others behave like the godfather of medical things. Its more abstract and it’s harder to speak about your personal interactions…"  (Price et al,22 p.858)

"I think you need positive reinforcement that you can carry on doing what you need to do."  (Price et al,22 p.859)

"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)

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"[Children and young people and parents want] any episodes of deterioration in control understood in the context of the individual’s care trajectory rather than as non-compliance."  (Allen et al,14 p.143)

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"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)

"I only had him for a few appointments but he… he was fine with it. For me he seemed to be there and with others they really want to know about you."  (Greene,28 p.54)

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"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)

"[Children and young people and parents want] any episodes of deterioration in control understood in the context of the individual’s care trajectory rather than as non-compliance."  (Allen et al,14 p.143)

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"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,28 p.54)

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"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,28 p.54)

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d | 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.  

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 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 comorbidity—all factors that affect the ‘how’ as well as the ‘what’ in service delivery. While recruiting those less engaged with services can be challenging,12 with a few exceptions,12 13 papers include little discussion of these biases. This means we may have failed to capture the views of those at greatest risk and with most to tell us. Finally, all authors of included studies were from healthcare organisations or were health science academics, so the focus of papers (eg, on educational interventions) may be influenced by (and may themselves influence) current concerns in clinical settings. Strengths of the paper include a cost-effective and relatively speedy study in an area where there is policy commitment to change; researchers sharing research tasks for reliability, comparing notes and discussing within a team of social scientists and clinicians. The appendices provide a resource for those researching this area.

**CONCLUSION**

Implementation may require not only structural change, such as more time for consultation, but new skills for reworking relations in a context where children know their physiological outcomes are necessarily judged.30 Clinicians may need skills in negotiating children’s and parents’ sometimes differing priorities for care, and ensuring pressing parental concerns about children’s physical health do not squeeze out opportunities for children to contribute.34 Since holistic care opens up a much larger part of children and families’ lives to professional scrutiny,30 relationship building will be increasingly important in a National Health Service with patients at the centre, and with social and physical health informing interaction between healthcare professionals and the family.

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