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. 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 further small-scale primary studies. This has been well-recognised in trials on the quantitative side, with increased use of meta-analyses and systematic reviews to build an evidence base. Although there have been positive exceptions, over the last decade the synthesis of qualitative work in child health research has remained underdeveloped.

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. The size of the body of literature required a focused approach with a targeted search. A rapid review

### 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. 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 rapid review. Ovid Medline, Ovid Nursing Fulltext Plus and Social Policy and Practice (incorporating ChildData) were selected as likely to offer optimum coverage of both clinical and social science literature. Free-text search strings using synonyms for ‘child’, ‘views’ and ‘long-term care’ were developed and piloted. The final search strings are set out in online supplementary appendix 1.

The publications pages of selected children’s voluntary sector websites were hand-searched, along with the reference lists of key clinical and policy guidelines (see online supplementary appendix 2).

Electronic records were screened on title and abstract, and those remaining after application of inclusion and exclusion criteria were screened on full text. Where eligibility was unclear, *For a discussion of the characteristics of qualitative approaches, see Spencer et al.* [10]

Table 1 Eligibility for the systematic evidence mapping of long-term care studies in paediatrics

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Rationale</th>
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</thead>
<tbody>
<tr>
<td><strong>Inclusion criteria</strong></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. 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.</td>
</tr>
<tr>
<td><strong>Exclusion criteria</strong></td>
<td>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.</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>
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<tr>
<td>Unavailable online</td>
<td></td>
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<tr>
<td>Without abstracts—records of these studies were retained for possible future work.</td>
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<tr>
<td>Surveys</td>
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<tr>
<td>Studies to inform the development of a quantitative tool or instrument</td>
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<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>
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</table>

Table 2 Eligibility criteria for synthesis by source

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Rationale for inclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Papers from systematic mapping</strong></td>
<td>There was sufficient evidence to support a diabetes-specific focus matching the related primary study. 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>Primary studies</td>
<td>Papers from reviews in systematic mapping: resolves difficulties around synthesising first-order and second-order data.</td>
</tr>
<tr>
<td>Diabetes focus or where data on diabetes provision could be disaggregated</td>
<td>Scottish papers kept on file from mapping: a useful resource for future comparisons between different parts of UK.</td>
</tr>
<tr>
<td>Additional material</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>Peer-reviewed journal paper</td>
<td>Hand-searches of reference lists of studies included in the synthesis: standard practice.</td>
</tr>
<tr>
<td>Primary research</td>
<td></td>
</tr>
<tr>
<td>Qualitative findings children, young people or young adults (caregivers/clinicians’ views of provision)</td>
<td></td>
</tr>
<tr>
<td>Sole diabetes focus</td>
<td></td>
</tr>
<tr>
<td>Published 2004 onwards</td>
<td></td>
</tr>
<tr>
<td>Carried out in England, Wales or Scotland</td>
<td></td>
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</tbody>
</table>
records were discussed with other members of the team to reach agreement.

Narrative synthesis
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, tailored 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 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 hypo-glycaemia 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
<table>
<thead>
<tr>
<th>Focus</th>
<th>Studies (papers in the same row report the same study)</th>
<th>Participants n ≥650</th>
<th>Family members/carers</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>CYP</td>
<td>Mixed condition studies (minimum number of CYP with diabetes)*</td>
<td>Mixed condition studies (minimum carers with CYP with diabetes) *</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diabetes studies</td>
<td>Diabetes studies</td>
<td>Diabetes studies</td>
</tr>
<tr>
<td>Information, education and support resources</td>
<td>Eiser et al16</td>
<td>27</td>
<td>18</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Waller et al17 Knowles et al18</td>
<td>24</td>
<td>29</td>
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<td></td>
<td>Waller et al19</td>
<td>48</td>
<td>48</td>
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<td></td>
<td>Christie et al20</td>
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<td></td>
<td>Hummelinck and Pollock 21‡</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Kirk et al22§</td>
<td>18 (2)</td>
<td>27 (3)</td>
<td>36 (6)</td>
</tr>
<tr>
<td></td>
<td>Williams et al23§</td>
<td>46 (16)</td>
<td>31 (6) mostly mothers</td>
<td>11 (1)</td>
</tr>
<tr>
<td>Transition</td>
<td>Allen et al24</td>
<td>46</td>
<td>39 mothers</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Price et al25</td>
<td>11</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>Coping in school</td>
<td>Boden et al26</td>
<td></td>
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<td>5</td>
</tr>
<tr>
<td></td>
<td>Marshall et al27</td>
<td></td>
<td></td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>Nevbould et al28§</td>
<td>69 (26)</td>
<td>69 (26)</td>
<td></td>
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<tr>
<td></td>
<td>Smith et al29§</td>
<td>27 (2)</td>
<td>27 (2)</td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>Dovey-Pearce et al30‡</td>
<td>19</td>
<td></td>
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<tr>
<td></td>
<td>Greene31‡</td>
<td>5</td>
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<tr>
<td></td>
<td>Curtis-Tyler32‡</td>
<td>17</td>
<td></td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Brierley et al33</td>
<td></td>
<td></td>
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<tr>
<td>Home management from diagnosis</td>
<td>Lowes et al34</td>
<td></td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Total participants</td>
<td>197 (46)</td>
<td>236 (38)</td>
<td>126 (7)</td>
<td></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 only15; for CYP generally where sample size was reported by method of data collection only;16 and for carers where the number of parents participating in each family was not described12 27 15.†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*

<table>
<thead>
<tr>
<th>‘Bad’ care</th>
<th>‘Good’ care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children’s and young people’s concern with maintaining social health</strong></td>
<td><strong>Think about it. [Intensive therapy] could make us as normal as a normal person without diabetes.” (Boy, 12 years, Waller et al, p.286)</strong>*</td>
</tr>
<tr>
<td>“[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, p.286)***</td>
<td>“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, p.542)***</td>
</tr>
<tr>
<td>“The wish for secrecy had resulted in some people refusing to take medicines [at school],” (Smith et al, 2014, p.541)***</td>
<td>“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, 2014, p.143)***</td>
</tr>
<tr>
<td>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)***</td>
<td>“Mothers and fathers valued service responsiveness and coordination of care… 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, 2014, p.53)***</td>
</tr>
<tr>
<td>“… whereas carers viewed formal education favourably, young people were less enthusiastic.” (Allen et al, 2014, p.144)***</td>
<td>“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, 2014, p.859)***</td>
</tr>
</tbody>
</table>

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

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*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, 2014, p.53)***

“[The doctor] used to talk to me like I was a baby and [to my mum as though I wasn’t there.” (Dowey-Pearce et al, 2014, p.414)***

“Some children he looked after the medication but he let me look after mine” (Parent, young person with diabetes, Smith et al, 2014, p.541)***

“Children and young people want clinicians who know them well… I think that’s an issue and the more you’re involved the more they know you and there’s a rapport.” (Dowey-Pearce et al, 2014, 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 doing it.” (Price et al, 2014, p.859)***

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*Children and young people want clinicians who know them well*

“[You’re talking to humans… people, and people kind of forget that.” (Price et al, 2014, p.858)***

“I have this one doctor that kept telling me that it was my fault…” (Mother of 10 year old with diabetes, Williams et al, 2014, p.994)***

“… 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, 2014, p.859)***

“I think you need positive reinforcement that you can carry on doing what you need to do.” (Greene, 2014, p.52)***

“You need to be offered the opportunity to learn about the process, the trial and error…” (Greene, 2014, 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, 2014, 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, 2014, p.859)***

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*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 “face or something” (Eiser et al, 2016, p.225)***

“… 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, 2014, p.859)***

“I think you need positive reinforcement that you can carry on doing what you need to do.” (Price et al, 2014, p.859)***

“I need you to be offered the opportunity to learn about the process, the trial and error…” (Greene, 2014, 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, 2014, 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, 2014, p.859)***

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*Mothers and fathers 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… I pushed and pushed and pushed for it.” (Mother of 9-year-old boy with diabetes; Williams et al, 2014, p.153)***

“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, 2012, 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, 2014, 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, 2014, 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 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 ≥650 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’ broader 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 a resource for those researching this area.

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,34 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 health-care professionals and the family.

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Contributors HR, TS and Linda Haines framed the original research question, which was further developed by KCT and LA. KCT developed electronic search strings, carried out searches and synthesis, and drafted methods and findings. LA carried out policy document searches and primary, exploratory data synthesis. All contributed to the development of eligibility criteria, worked on drafts of the paper and approved the final version of this article.

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REFERENCES


Appendix 1: Search strategy for Ovid Medline, Ovid Nursing and Social Policy and Practice

1 child*.ti,ab.
2 pediatric*.ti,ab.
3 paediatric*.ti,ab.
4 adolescent*.ti,ab.
5 young people*.ti,ab.
6 teenage*.ti,ab.
7 long-term.ti,ab.
8 chronic*.ti,ab.
9 asthma*.ti,ab.
10 eczema.ti,ab.
11 dermatolog*.ti,ab.
12 haematolog*.ti,ab.
13 SCD.ti,ab.
14 sickle cell.ti,ab.
15 thalassaemia.ti,ab.
16 diabet*.ti,ab.
17 view*.ti,ab.
18 opinion*.ti,ab.
19 perception*.ti,ab.
20 qualitative.ti,ab.
21 ethnograph*.ti,ab.
22 phenomenolog*.ti,ab.
23 1 or 2 or 3 or 4 or 5 or 6
24 17 or 18 or 19 or 20 or 21 or 22
25 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
26 23 and 24 and 25
27 limit 26 to yr="2004 -Current"
Appendix 2: websites and policy documents

POLICY DOCUMENTS (reference lists handsearched)
NICE guidance https://www.nice.org.uk/guidance

The search of NICE guidance took place at a time when the website was undergoing changes. Were we to re-run searches, we would use the population filter at https://www.nice.org.uk/Guidance/Population-groups/Children-and-young-people. Our wide searches also captured adult guidance but we have deleted from this version those where references to children were not substantial.


NICE (2009) Recognition and Assessment of Coeliac Disease and the Care of Children and Adults http://www.nice.org.uk/guidance/cg86


NICE (2005) Improving Outcomes in Children and Young People with Cancer http://www.nice.org.uk/guidance/cscyp

National Service Frameworks

- Department of Health (2010). *National Service Framework for Children, Young People and Maternity Services - Type 1 diabetes in childhood and adolescence*

Department of Health

- Department of Health (2006) *Transition: getting it right for young people: Improving the transition of young people with long term conditions from children’s to adult health services*
- Department of Health (2007) *Making every young person with diabetes matter*
- Department of Health (2009). *Healthy lives, brighter futures: The strategy for children and young people’s health*
- Department of Health (2010). *Getting it right for children and young people- overcoming cultural barriers in the NHS so as to meet their needs (Kennedy Review)*
- Department of Health (2012). *Our Children Deserve Better: Prevention Pays*
- Department of Health (2013). *Children and young people’s health outcomes forum – report of the long-term conditions, disability and palliative care subgroup*

Other

- BMA (2013). *Growing up in the UK: ensuring a healthy future*
- Royal College of Paediatrics and Child Health (2009). *Growing up with diabetes: children and young people with diabetes in England*
- CQC (2014). *Teenagers with complex health needs lack support as they approach adulthood*
- Royal College of Paediatrics and Child Health (2009). *Modelling the future III Safe and sustainable integrated health services for infants, children and young people*
- King’s Fund (2013). *Delivering better services for people with long-term conditions- Building the house of care*
- King’s Fund (2014). *Improving care for long term conditions*

WEBSITES

National Children’s Bureau [www.ncb.org.uk](http://www.ncb.org.uk) searched using terms ‘chronic’, long-term’ and ‘diabetes’; hand-searched publications/other resources pages; from this, we retrieved one study which met our inclusion criteria (Kirk et al 2012)

The Children’s HIV organisation [www.chiva.org.uk](http://www.chiva.org.uk) handsearched resource page


NICE Evidence [https://www.evidence.nhs.uk/](https://www.evidence.nhs.uk/) was searched using terms: ‘children’ AND ‘chronic’ AND ‘experience’ AND ‘qualitative’ AND ‘care’. The first ten hits were ordered in terms of relevance and titles read, and yielded one study which met our inclusion criteria (Williams et al 2011).
GOOGLE UK https://www.google.co.uk/ search using search terms: ‘Sickle Cell’, ‘Thalassaemia’, ‘Cystic Fibrosis’, ‘Duchenne’ (conditions not covered above) limited search to first two pages of each condition only.
Appendix 3: Flow chart of processes of mapping

Electronic records identified n = 8297 (Medline n = 6842; Ovid Nursing Plus n = 934; Social Policy and Practice n = 521)

Limited to publication 2004 – June 2014: n = 4730 (Medline n = 3849; Ovid Nursing Plus n = 609; Social Policy and Practice n = 272)

Combined electronic records after duplicates removed n = 4043

Records excluded on title and abstract n = 4005 (European / UK other n = 35; Provision for CYP with primary mental health diagnosis n = 5; No abstract n = 5; Other criteria n = 3960)

Electronic records full text screen n = 38

Records excluded on full text screening n = 4: (Not England or Wales n = 2; Not views of services n = 1; Not available online n = 1)

Additional eligible records identified through policy documents n = 4

Studies eligible for systematic mapping n = 38
### 1. Edgecombe et al 2010

**Uncontrolled severe asthma**  
**Aim:** to understand [YP’s] experience of living with uncontrolled severe asthma  
**Rationale** – despite ‘a prescription of corticosteroids and bronchodilators [yp] still experience symptoms... likely to be related both to asthma severity and developmental characteristics of adol such as risk-taking behaviour. These adol face additional diffs in achieving the normal psychological and social developmental tasks of adol such as gaining identity, independence and autonomy. [Understanding their views] will enable us to propose ways of improving clinical management’ p985

**Methods**  
- Design - qualitative  
  - Recruitment via paed respiratory clinics  
- Selection self selecting from all in sample frame, then purposive (not clear)  
- Data collection – in-depth semi-structured interviews  
- Data analysis  
  - Reliability + double coding/discussion; explicit theory of adolescence  
  - Validity + taped interviews, flexible questions, clarity re confidentiality, negative case analysis  
  - Interviewed by med student in clinic; asked them to fill out QoL measure as well;  
  - conclusions don’t match aims  
  - no engagement with critiques of developmentalist approaches

**Sample characteristics**  
- Participants /sample size  
- Location  
- Children’s age range  
- Gender  
- SES  
- Ethnicity

**Findings**  
- YP disliked - frequent changes of medicines - find confusing (authors feels may account for some ‘unintentional non-adherence’)  
- YP ambivalent about paed models of care  
- Disliked being with young children and parents’ presence if they had confidential concerns to discuss  
- Though relied on parents to report symptoms, remember what was agreed and ‘translate’ medical terms and many were nervous of attending on their own, one felt doctor wouldn’t want to see her alone anyway.  
- CONC ‘this group has poor adherence... underlying this are incorrect beliefs about medicines in terms of their purpose and adverse effects, failure to remember treatment, lack of motivation or competing priorities... these issues may in part reflect the less than ideal relationship that this study suggests adolescents have with their health professionals... many did not take responsibility for interacting with HCP...”

### 2. Lyte et al 2007

**Asthma**  
**Aims:** present an overview of paed asthma management in a UK primary care trust with respect to organisation and perceptions of stakeholder, parents and CYP needs.  
**Rationale** – fragmentation of care over prim, secondary, school and community services

**Methods**  
- Design Case study  
  - Recruitment via GP surgeries in one PCT  
- Selection purposive on GP structuring of system of care and level of interest in paed asthma  
- Data collection Interviews, observations of review appts and asthma related documentation  
- Data analysis Framework Reliability  
  - double coding

**Participants**  
- 18 CYP  
- 16 parents  
- 14 prac nurses  
- 14 GP

**Location**  
- practices in ‘one PCT’ with wide range of different levels of deprivation  
- Children’s age N/K

**Findings**  
- Improving practice nurse care will require  
  - a pro-active recall system to ensure regular reviews inc assessment, revising management plans and health promotion/education;  
  - developing PN understanding of paediatric work beyond a focus on communicating with children to the wider complexities of work across families so that children don’t feel left out of consultations and families feel their needs are being met (perhaps support not just on asthma from the asthma clinical nurse specialists (CNSs) but also on family centred care (FCC).  
- CONC – responsibility for management needs to be
### 3. Newbould, Francis and Smith ADC 2007

**Aim:** to examine experiences and concerns of YP and their parents re management of medicines at school

**Rationale** – ‘despite guidance from government and creation of school policies, difficulties surrounding medication and condition management in schools are still prevalent’ p1078

<table>
<thead>
<tr>
<th>Source</th>
<th>Design</th>
<th>Recruitment</th>
<th>Selection</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Reliability</th>
<th>Validity</th>
<th>Participants</th>
<th>Location</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not explicit</td>
<td>GP surgeries</td>
<td>random surgeries, N/K how CYP selected</td>
<td>face to face semi structured interviews at home</td>
<td>established qualitative analytical procedures</td>
<td>+</td>
<td>+</td>
<td>69 YP (43 asthma; 26 diabetes) and parents</td>
<td>‘contrasting areas’ in SE Eng</td>
<td>Gender 39 boys, 30 girls</td>
<td>SES only 11 parents</td>
<td>YP need support from HCP around - access to their medicines - policies could be a hindrance eg having to keep inhalers elsewhere (’I’d have to walk all the way to the office’) - other structures eg snacks being forbidden, timing of school lunches, nowhere private to do injections - teachers being disbelieving and unsympathetic (parents also felt this, and that teachers lacked knowledge). Parents need support around concerns about: - medicines being stored away from the classroom which could make access diff in a crisis; - teachers undermining regimen eg not wanting child to test blood sugar levels; -liaison with teachers a much greater challenge in secondary school cos of having more than one teacher CONC protocols in schools should be tailored to YP needs and indiv conditions, devised in partnership with YP, parents and school. Authors note guidance on medicines in schools (DH, 2004 NSF) doesn’t clarify teachers’ position if they must help yp with a medical difficulty.</td>
</tr>
</tbody>
</table>

### 4. Forsey et al 2013

**Leukaemia**

**Aim:** How might doctors and nurses accounts of managing the emotional care of parents of children with leukaemia inform training and policy

**Rationale** – guidelines encourage HCP to discuss patients’ personal/emotional experiences’ the evidence suggests they are not doing this – ‘there seems to be a gap between policy and practice’ p260

<table>
<thead>
<tr>
<th>Source</th>
<th>Design</th>
<th>Recruitment</th>
<th>Selection</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Reliability</th>
<th>Validity</th>
<th>Participants</th>
<th>Location</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘qualitative interviews’</td>
<td>via 6 oncology /haematology treatment centres in UK</td>
<td>Purposive across centrality of role in child's care; equal across centres and by profession and both community and hospital nurses</td>
<td>Audio-recorded qualitative interviews at 2 time points</td>
<td>Constant comparative</td>
<td>+</td>
<td>+</td>
<td>30 doctors and nurses</td>
<td>UK wide</td>
<td>Gender mainly male doctors and women nurses</td>
<td>SES doc/nurses</td>
<td>Doctors thought their best contribution to emotional support is to focus on potential for cure in order ‘to keep the family together so they can function tomorrow’; and not try to elicit parents’ concerns or fears (seen as nurses’ work) they are at ‘the right place at the right time’ eg home visits, night shifts, when there is a more ‘relaxed environment.’). Felt it best to use their ‘authority’ as doctors to prevent an ‘inappropriate’ ‘emotional’, relationship as they may need to challenge parents in children’s best interests eg re adherence. Nurses thought they should develop emotional relationships, share details of their lives and offer emotional support on demand (they can phone you up’); though could feel guilty about not having capacity to provide high levels of both emotional and physical care and feel overwhelming/stressful when families too emotionally dependent. CONC: we need to know parents perspectives but perhaps guidelines which require an emotional as well as instrumental approach by doctors may need revision</td>
</tr>
</tbody>
</table>

### 5. Lowe et al 2008

**Haem/Oncology**

**Aim:** to examine families’ views on care in a paed haematology/ oncology day care unit

<table>
<thead>
<tr>
<th>Source</th>
<th>Design</th>
<th>Recruitment</th>
<th>Selection</th>
<th>P’pants</th>
<th>Location</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Focus</td>
<td>gys</td>
<td>via unit</td>
<td>16 parents</td>
<td></td>
<td>Parents disliked: - when play specialist diff to access as ‘too stretched’ - toys ‘dirty’, physical environment ‘cramped, inhuman, frightening… like a cattle market’ p3164 - long waits for chemo, consultations and prescriptions - both in local and primary treatment centres), though explanations could help. - systems for prioritising patients for general anaesthetic were debated as some felt this should be in order of arrival, others that those receiving steroid</td>
</tr>
</tbody>
</table>
Rationale – with increasing ‘pressure on inpatient beds in primary treatment centres’, greater number of CYP care now is shared between the primary treatment centre and their local hospital which ‘is not problematic if…services are designed to meet families’ needs and where there is a seamless service’ btw the two. The patient journey thru the unit was mapped from HCP perspectives but it was felt ‘the voice of children and families’ was missing. p 3161

for acute lym leukemia (or within 6 mths of completion)

Data collection: focus grp of 3-5 people

Data analysis thematic

Reliability
+ researchers discussed each other’s analysis with one another
- Validity
+ taped; notes; - groups took place ‘off the ward’

London
SES n/k
Ethnicity n/k

treatment get priority (great hunger)
- some felt rushed in such a busy environment and lacked confidence or time to ask questions
- unfamiliar faces eg rotation of junior doctors
- problems with liaison between local hospitals and primary treatment centres
- local hospitals relied on them to pick up things that get missed, and they didn’t necessarily have the knowledge of protocols to do that.

Parents valued:
- help learning procedures/routines of the unit at the same time as having to deal with disbelief at diagnosis - liked when staff went out of their way to familiarise them/ do introductions, and the CNS role in connecting home to hospital
- also wanted someone available who felt more approachable such as an experienced parent volunteering; an info board with outline of routines – and, before their child transferred from inpatient care, a visit with introductions to the day care unit;
- toys and play specialists crucial to their child’s experience
- information overload at time of diagnosis so needed pros to ‘continually build on and scaffold info’; they especially valued written info
- roles and mechanisms to support liaison between local hospital and this prim treatment centre eg new CNS role; the ‘family-held shared care record’ which held contact details of hospitals, treatments/side effects, and advice eg on anaesthetics, infections, schooling, home life and links to other info

CONC – environment and communication were the main problems and CNS role was felt to ‘make a qualitative difference’

6. Allen et al 2011

Diabetes (transition)

Aim: to explore the experiences of YP and their carers during transition from child to adult diabetes services

Rationale – YP life transitions are not linear, no longer move from ‘a state of dependence to independence’, and care transition take place at time of multiple other life transitions, plus difficulties in control from physiological change

Design Longitudinal qual case studies in 5 different diabetes services

Recruitment via ‘service providers’

Selection ‘appropriately placed service providers’ and purposive selection of yp by gender and position in process of transfer

Data collection 3 x semi-structured interviews with yp and with mothers over 12-18mths (other party occasionally present during interview)

Data analysis thematic

Reliability
+ Identifies ideas from Strauss’ account of illness trajectory as underpinning understanding of yp’s accounts; data management software used
- Validity
+ flexible approach to interviews; full transcription, most interviews at home
- Authors report diffs recruiting yp

Participants 46 CYP and 39 mothers

Location N/K (UK)

Children’s age 13-22 yrs

Gender 23 girls; 23 boys

SES n/K

Ethnicity N/K

Problem - health professionals seem to encourage a shift to lone consultation faster than yp and their parents choose when this is left up to them - and at a time when mothers feel yp’s needs are very high (because of multiple other shifts and transitions at this time of their lives)

Some mothers felt shifts to lone consultation lead to discontinuities of information and undermine their ability to continue to support their child into young adulthood...

Good care would reflect how the lives of YP are characterised by interdependencies... authors feel there is a need to develop service structures that recognise the continuing role played by mothers in the diabetes care of young adults eg in a few services a written report of the consultation was provided to parents of yp under 16 years who had moved to lone consulting (authors note that 16 years and over there are issues with confidentiality in this approach); in other services parents attended for part of the consultation; in another, the DSN made clear she would engage with parents as well (the most didn’t contact her, perhaps believing they won’t be welcome).

CONC The ‘individualised focus of adult services does not reflect the realities of yp’s lives’ p999


Diabetes (transition)

Aims: To

Design case study

Recruitment: via diabetes services in England in the Directory of Diabetes Care

Selection: at service level, purposive by transition arrangements; yp by gender and

P‘pants 38 HCP; 46 YP and 39 carers in case studies; 82 YP and carers surveyed

Users wanted (nearly verbatim) transition care that is -

a) Relational - ‘an ongoing therapeutic relationship with one or more providers [who] understand the fabric of individual’s lives’ esp so, for example, ‘deteriorating control is understood in the context of individual’s care trajectory rather than as non-compliance’ p143; ‘consultation style and interpersonal skills were highly consequential for the exp of yp’ p 144

b) Longitudinal - ‘uninterrupted relationships with providers over time, consistent with need’

These in turn are supported if care has the following 2 characteristics:
8. Curtis-Tyler 2012

**Diabetes**

To explore experiences of children 10 years or younger living with T1D with a view to identifying levers and barriers to children's contribution to their clinical care

**Rationale** – patients' views are important in identifying the best options for care tho achieving this in practice has proved difficult

| Design | In-depth qual
Design Qual synthesis |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment:</td>
<td>2 outpatient clinics</td>
</tr>
<tr>
<td>Selection:</td>
<td>ch under 11 yrs, self-selecting</td>
</tr>
<tr>
<td>Data collection – home visits, discussion groups, observation in clinic</td>
<td></td>
</tr>
<tr>
<td>Data analysis constant comparative</td>
<td></td>
</tr>
<tr>
<td>Reliability + explicit about understandings of children/childhood; data management software -</td>
<td></td>
</tr>
<tr>
<td>Validity + home visits; taped, full transcription, negative case analysis -</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>17 children</td>
</tr>
<tr>
<td>Location:</td>
<td>Large multicultural city</td>
</tr>
<tr>
<td>Sample size</td>
<td>17 Children's age 4-10</td>
</tr>
<tr>
<td>Gender</td>
<td>8 girls, 9 boys</td>
</tr>
<tr>
<td>SES</td>
<td>NK</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>6 Somali; 5 White british/english 1 Lithuanian, 2 Arabic, 2 African, 1 Bengali British</td>
</tr>
</tbody>
</table>

**Problem:** in contrast to their sense of being key players in their day to day care at home, children felt their position in clinic was peripheral, that they had nothing useful to contribute. They were excluded from discussions of illness, they and parents had little control over the timing, pace and direction of interaction, the tightly focussed question and answer format was at odds with discursive approaches favoured at home, and a biomedical model of illness fragmented experiences into physiological, social and emotional components. Conc - if clinicians want to hear from children they will need to provide a convincing rationale so questions are not perceived as a test; engage w/ children's strong experiential understandings of their condition by framing questions in terms of activities and sensations, and try to redress generational prof/lay imbalance of power by demonstrating respect and attention. However if the mainly physiological focus of consultations acts to protect families from prof surveillance, it may prove difficult to shift.

9. Curtis-Tyler 2011

**Asthma/diabetes**

Aim to identify from a synthesis of studies

<table>
<thead>
<tr>
<th>Design</th>
<th>Qual synthesis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment/Sources:</td>
<td>8 health and social care databases, ref list searches, consultation with first authors/field experts</td>
</tr>
<tr>
<td>Selection:</td>
<td>qual studies of ch (10 yrs and older)</td>
</tr>
<tr>
<td>Participants</td>
<td>14 papers</td>
</tr>
<tr>
<td>Location</td>
<td>both UK/USA</td>
</tr>
<tr>
<td>Sample size</td>
<td>Children's age 10 years or younger</td>
</tr>
<tr>
<td>Gender/SES</td>
<td>N/K (review)</td>
</tr>
</tbody>
</table>

**PROB:** One study observed younger children especially seemed to be excluded from discussion of their illness in clinic. Across studies children reported difficulties managing asthma or diabetes at school because of lack of access to...
on children’s experiences of living with asthma or diabetes, levers and barriers to patient-centred care with children Rationale – gap in the evidence about how to achieve children’s involvement in clinical care younger) experiences of living with asthma or diab Data collection N/A Data analysis / synthesis: narrative synthesis Reliability + data management software used; understandings of childhood explicit - Validity + study findings presented in context of QA of methods -

| 10. Dovey-Pearce et al 2005 Diabetes | Design Qual Recruitment via specialist diab service Selection self-selecting from pop of 16-25 yrs olds w T1 or T2 using secondary care Exclusions diagnosed less than 6 mths, Learning disabilities (also apparently autism) Data collection semi structured interviews and, having had feedback, focus gp discussion of findings Data analysis framework Reliability + explicit theory of adolescence Validity + taped and full transcription; schedule amended twice; double coding - no engagement with critiques of developmentalist approaches | Participants 19 young adults with diabetes Location NE Eng Children’s age 16-25yrs Gender 11 girls, 8 boys SES/Ethnicity N/K | YP disliked: At diagnosis - information overload, wards with much older adults, insensitive staff Secondary care - not knowing which clinician they would see in clinic, having to repeatedly share same information, not being involved in consultations, overly directive or conflicting advice with little relevance to individual situation, insensitive personal questions/giving bad news, breaches of confidentiality, feeling unable to ask questions/rushed, having to suppress distress; formality, lack of civility, poor communication between services and age inappropriate communication: ‘I'll just sit and listen... and go home. I think, what’s the point’ 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’ P409 ‘[The doctor] used to talk to me like I was a baby [and] to my mum as though I wasn’t there’ p 414 YP could feel passive recipients eg re move to adult care ‘manhandled as a piece of meat with no respect’; that because of their age they don’t deserve as much time/attention as older people, that they are culpable for not controlling their condition ‘for the future’, or that information they are given isn’t actually relevant to someone their age. Disliked activities shared with others with diabetes; YP would like: Some thought age-banded clinics could be helpful Interactions with staff seemed to be YP overriding concern (over for example, travel or clinic times), positive ones characterised by consistency, civility, rapport, listening, involvement in the consultation, choices, non-judgemental approach, encouraging feedback, facilitating coping skills and access to specialist information, whole person care facilitated by the MDT and age appropriate shifts in consultation style. CONC – ‘Bringing together a yp with a chronic condition who is still experimenting, exploring and keeping some of their options open with a healthcare system that expects engagement, partnership and adherence that will last a lifetime is an unlikely marriage... developmental tasks of adulthood [include] taking responsibility for self-care ... yp need to be supported to acquire the requisite skills, knowledge and motivation needed to be committed partners in their healthcare’ p417 ‘key requirements [are] staff consistency and civility, and navigable clinic structures... relevant information and support p417 |

| 11. Eiser et al 2013 Diabetes | Design MRC guidelines for devp a complex intervention Recruitment via young adult clinic (16-21 yrs) Selection self selecting Data collection interviews w staff, YP and carers on views of care; audit of medical records | Participants 13 staff, 27 YP, 18 parents Location Sheffield Children’s age 16-21yrs | Staff described difficulties communicating with YP and using different approaches with yp which yp reported as inconsistent. YP disliked - abstract information which didn’t take account of their lifestyle. - an emphasis on hba1c at the expense of their concerns |
Rationale – poor success of previous interventions, complex nature of care and impact on well-being and wider life; challenge of adjusting to life-threatening illness at this life stage, dependence on wider family/social support, rising incidence and link bwn early control and morbidities

and survey of YP self reported anxiety, depression + diab related distress; searches for existing evidence on how to improve diab health in young adults

Data analysis n/k
Reliability + -
Validity + -

Gender/SES/ Ethnicity n/k
around how to integrate self care into their daily lives.
Parents disliked
- feeling sidelined and described family conflict about changing responsibilities for care within the family.
 Authors report developing a 5 day goal-setting training course for yp (based on DAFNE) with follow up from key workers and a half day for parents; a 4 session parent education course on family communication about diabetes for parents; and agreeing to hold a multi-disciplinary meeting before clinic “to agree care priorities” for each patient in order to inform a more consistent approach

Diabetes (schools)
To examine the role of nurses in supporting children in school and EY settings (esp in context of intensification of regimens)
Rationale – ‘there is little about how to optimise the quality of ch’s diab care while in school’ p 872

Design Qual
Recruitment via RCN, YP diabetes community regional diabetes network, Community Ch’s Nursing networks, professional networks and Diabetes Research Nurses (Scotland)
Selection purposive
Data collection focus groups which informed follow up indiv phone interviews
Data analysis constant comparison
Reliability + double coding and discussion -
Validity + -

P/pants 47 acute and commun- ity nurses (8 gps, 8 phone interview) all having some patients using intensive therapy
Location UK
Gender / SES/Ethni city n/k
Nurses dislike:
- Legal and policy framework - ambiguous and inadequate: As there is no legal duty for school staff to administer medicines, unclear about what could be required of schools - DH ‘best practice guidance’ not legally binding, endorse inclusive education but specify parents have primary responsibility for children’s health; nurses felt they could point Heads to necessity of ‘reasonable adjustments’ under Equality Act 2010 but didn’t know how to enforce this as; Ofsted inspections may not be timed when needed. So nurse negotiated arrangements on a case by case basis, dependant on goodwill – and report school co-operation as unpredictable, depending on the head teacher personal views; they said teachers worried about child protection procedures, litigation, health and safety and physical contact – ‘teachers can’t even touch children even if they get a cut knee’ p 873 ‘i can’t be in a room if a child is going to be half undressed’ p873.
- How teachers could be scared by hearing from frightened parents at diagnosis; they could lack basic understanding, confusing T1 with T2.
- Lack of suitable locations for injecting and testing.
- Secondary schools were more problematic, sometimes just seeing their responsibility to provide a place for care, and having different teachers and different places all thru the day could make care complex compared to primary which were easier to deal with cos smaller organisations and children with same teacher in same place all day.
- Case load - Some tried to do update visits annually though with increased caseloads this was difficult; some felt school nurses could do more though others felt they hadn’t capacity either.
- Lack of evidence Despite guidance from RCN and Diab UK, they perceived a gap in the evid base on how to work with schools to best support children; they felt they learned to negotiate support for CYP by experience only and all this could lead to variations in practice eg even wide variations in amount of time different nurses spent supporting schools.
CONC need more evidence about how HCP can influence schools
13. Lowes et al 2004
Diab
To explore parents’ experiences of having a child diagnosed with T1D, managed at home, over the first year
Home m/ment: discharge 1-3 hr after diagnosis, DSN visit 2x daily first few days (2-3 hrs each), out of hrs phone access diabetes team
Rationale – evidence suggests home management safe and cost effective though concerns are expressed about parents coping at time of diagnosis of responsibility; p853

Design qual longitudinal
Recruitment via paed unit of 5 Wales hospital
Selection self selecting from pop of parents of newly diagnosed and clinically well (optimum blood glucose level) children Mar 98- Oct 99
Data collection 3 interviews w/19 parents near diagnosis, 4mths later and a year later; 4 parents single interview at 4 months; 12 parents at 1 year only
Data analysis thematic
Reliability + -
Validity + interviewed at home, ch not present, 30-90 mins, iterative schedule, taped, full transcription; analysis discussed with participants and other researchers; divergent case analysis - Interviewer DSN for 70% children in study
Participants 38 parents of ch with T1D median age 38 yrs with children median age 9 Location 5 Wales Sample size Children’s age Gender SES range of occupations from cleaning to journalism, teaching, engineering Ethnicity white English speaking Other information 2 single parent families
Parents alarmed by speed of referral to secondary care after GP diagnosis (authors conclude ‘even while awaiting confirmation of diagnosis, they needed info’ about the condition and process of diagnosis)
All parents wanted to avoid child being hospitalised but 25% initially concerned about going home after diagnosis; most experienced information overload and described prioritising so as to absorb in small chunks, though a small number found the drip feed approach scary – fear of ‘what was to come’
Parents liked:
Accessibility to phone advice- very reassuring - within a week half of parents felt more confident about coping and all were pleased their child had not been hospitalised
3 mothers reported acute distress in the second month, grief at diagnosis. 60% of parents felt home management had helped in introducing diabetes as a manageable condition rather than an illness [this sounds like something framed by the interviewer not participants]; all did their utmost to optimise control ‘if we’re not vigilant now we could store up problems for him later’ p532; and inexplicable lack of control engendered feelings of confusion and fear.
A year later 68% felt diabetes was part of daily life and all but one parents felt they were coping most of the time, the hypos at night were a big fear, having to plan everything ahead so closely, and one mum reported having given up working outside the home. 39% parents felt it important diabetes was not allowed to become too intrusive in children’s lives. A fifth felt home management at diagnosis had helped build their confidence in making the changes to their lives required by the condition.
CONC – findings don’t support concerns that this model plays down the seriousness of the condition (see for example Scott and Donnelly 2001)

Diabetes (trans)
To evaluate a transition model and explore elementsYP find important.
Rationale - Adolescence is a time of ‘role confusion’ where the yp struggles with ideas and feelings about how they might fit into society… need time and space to … experiment with a variety of behaviours… diabetes may inhibit [this] or conversely lead them to explore risk-taking behaviour involving their diabetes…
developmental tasks of adolescence [include] accepting own body, adopting appropriate social roles, developing close peer relationships, preparing for occupational roles [and] intimate relationships, achieving emotional independence from parents, establishing personal values and ethics, striving for social responsibility;’ p853

Design qual Recruitment: via young adult clinic
Selection yp who transitioned from paed and had had a first apt in young adult clinic within 3 months;
Data collection structured interviews (2 YP interviewed again a year later)
Data analysis framework
Reliability + explicit theory adolescence -
Validity + unattributed quotations (no demo of diversity of responses) - no
P’ pants 11 YP Location N/K (author based in Tyneside) Sample size Children’s age 16-18 yrs Gender/ SES/ Ethnicity N/K
YP disliked:
- A stark change in clinicians’ interaction: ‘there shouldn’t be that much of a difference but it seems as though you’re a kid and the next day you’re an adult and that was it… no like in between bit’
- Info on drugs and alcohol too late - should be earlier, at 12 years and incremental and preferably written so ‘I’ll sit and learn it myself’ rather than having to discuss
- Staff working to a ‘set agenda’ which could make them consider not attending ‘I would rather just not go… [than] listen about me blood sugars and los[ing] weight’ p852.
They wanted
Good relationships with staff (much more important than, for example, the physical environment); above all, having a sense of partnership, collaboration and being recognised as individuals (including having choice about when to move from paed care) -
They advised ‘get to know the patient on a personal level before you can kind of tailor the advice for them’ and ‘you’re talking to humans… people, and people kind of forget that’.
Only one yp was apprehensive, the others didn’t have particular memories of how they felt before transfer perhaps reassured by the fact that paed clinicians run the y adult clinic in the same hospital as the paed clinic
YP had meetings with clinicians about their impending transition separate from their regular clinic visits (on same day) but experienced these as ‘a standard part of their overall healthcare experience’ so could have been done in routine appointments.
CONC – yp did not identify key elements of the pathway but rather highlighted the quality of their interaction with HCP as central to their experiences. Authors call for pro training, and: ‘it is clear that [didactic] interactions that do not take into account a yp’s needs or views can be frustrating… from an understanding of where adolescents are in their life stage development it can be argued that taking such an approach becomes more crucial than ever… pros need to understand adol as a life stage with all its biological and psychosocial changes*, as well as communicate effectively with yp on an individual basis’
15. Brooks et al 2013
**Complex LTC**
**Aim:** In light of recent policy to identify and map the model of service in operation and explore user/carer/HCP experiences of it
**Rationale – exploring how much policy ideals have influenced practice**

<table>
<thead>
<tr>
<th>Design</th>
<th>Participants 14</th>
</tr>
</thead>
<tbody>
<tr>
<td>case study</td>
<td>parents (inc 1 father); 2 girls; 18 staff (interviews) plus ‘a wide range of individuals eg community paed, nurses, therapists, and teachers’ (data collection not clear)</td>
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</table>

| Recruitment | Apart from needing respite care, parents main concern was communication – a lack of coordination across services sometimes resulting in conflicting advice from different pros, or an ‘information gap’ between hospitals and community services eg community paed not having details of acute admission and discharge – and fast-tracked admission to A&E for this group was not working either, took as much time as usual admission cos of A&E not having the right file. Participants highlighted the need for a designated lead, or case manager |
| Trust, postal invite or via Trust sup |
| not explicit but probably families with a child receiving care for complex needs (defined as a long-term condition requiring care from more than one agency DCSF 2008); not sure how staff selected other than they had ‘have sig input into children and families’ care within the study locality’ |

| Selection | b) parents felt they didn’t have info they needed about child’s condition nor about services to support them; felt they had to learn a particular style of communication to be heard by professionals: assertive and demanding as opposed to ‘a supportive dialogue’. Pros felt they wanted to support parents learning how to develop these skills though parents felt they did not respect their position as ‘expert parents’, their knowledge and expertise gained over the years, and they were not sufficiently involved in decision-making esp when changes were made to the care regime, for instance in hospital. CONC, as Sloper et al 2003 found, that multi-agency planning is needed to ensure co-ordination of services, assessments and appointments and there should a single key worker to liaise with and assist the family consistently. |
| not explicit but probably families with a child receiving care for complex needs (defined as a long-term condition requiring care from more than one agency DCSF 2008); not sure how staff selected other than they had ‘have sig input into children and families’ care within the study locality’ |

| Data collection | Data analysis in depth thematic |
| local/rational doc and policy review, in-depth qual interviews and focus groups | + double coding |

| Reliability | + mainly home family interviews, except support grp who chose focus grp approach, pros at place of work, pilots, taped, full transcription |
| Validity | - |

**Complex needs**
To explore appreciatively examples of best multi-agency working to determine what works well, why and what best practice in future should be
**Rationale – policy-practice gap between ‘regulatory ideal’ of ‘partnership/sealess care’ and evidence services are not experienced that way**

| Design | Participants 20 |
| Appreciative enquiry | mothers, 7 fathers; 1 child; 41 professionals |

| Recruitment | Participants felt things work well when... |
| not clear, though mentions snowballing staff | 1. The child and family are central to information and decision making |

| Selection | 2. Everyone involved in the child’s care works closely together and shares a common vision to ensure that, from the start, the child’s needs are met, prioritized and planned for holistically |
| Purposive (families diff geog areas; staff as many different agencies Data collection appreciative interviews; nominal group workshops based on statements from interviews, consensus workshops Data analysis interviews thematically; Reliability + - Validity + taped interviews, full transcription | 3. Everyone involved in the child’s care understands and respects each other’s role, expertise and the contribution that they can each make and then works (engages) appropriately with the family |

| Location | 4. Everyone involved in the child’s care and the systems they work within are accessible, available, flexible and responsive |
| Cumbria and Lancashire SES /Ethnicity n/k | 5. Communication is timely, accessible, shared and appropriate |

| Ethnicity | 6. The family has the time to be a family and their need for psychological and emotional space is respected |
| reports lack of ethnic diversity | 7. People involved in working with children with complex needs have the support and freedom to be innovative and to work collaboratively across and within organizations |

| Papers | 8. Parents have the opportunity to be linked with other parents in similar circumstances to facilitate mutual support and sharing of experiences |
| 8 | 9. Information collected about the child is streamlined and centrally accessible to reduce the family’s burden of repeating information about their child/children |

| In PICU, parents disliked | 10. Parents are given choice, throughout the child’s life-journey, to have a person who could act as a coordinator of care and who has in-depth knowledge of them and their child |
2007 Ventilated children
To identify the present state of knowledge about these needs and experiences.
Rationale - HCP increasingly caring for long term ventilated (LTV) children and their families, planning and delivering complex multi-disc healthcare packages. To do this effectively HCP must understand the needs and experiences of children and families.

Sources: Allied Complementary Medicine, BNI, RCN Journals, CINAHL, hand searching journals
Selection: studies 15 yrs old or more recent in English that explored experiences of LTV children and their families
Data analysis thematic Reliability +
Validity +

- small scale qualitative studies
- Location 6 UK, 2 USA
- Children’s age /Gender /SES/ Ethnicity N/K

- Delays in discharge while funding/arrangements made for provision at home eg purchase of equipment, new housing if necessary, recruitment and training of carers (authors say lack of ‘central agreement for funding LTV packages mean PCTs deal with each case individually – changed since then?)
- Discharge badly co-ordinated across agencies, managed by nurses lacking time and/or training to do this effectively, feeling meetings have taken place without their inclusion
- Feeling unwanted while awaiting discharge as aware child potentially blocking bed needed for acutely ill child and that prolonged stays are damaging for their child psychologically and negatively affects behaviour
- Long travel btw unit and home where the rest of the family are living and having to relate to their child under the constant gaze of HCP

And if alert YP distressed by
- witnessing trauma of distressed relatives
- seeing other children leave the unit
- restrictions and routines of the unit/loss of control and loss of ‘normal’ activities like schooling and going out to see friends which can only be done with lots of planning

At home parents and yp experienced considerable stress and financial burden. For parents struggled with
- having to plan with great precision to ensure smooth running of household as well as strict adherence to routines to avoid hospital admission and all the disruption associated - and not being able to have holidays because of equipment/ amount of planning needed
- uncertainty of living with a child with life limiting condition and constant observation of child to detect deterioration
- having carers constantly present (though some were coping without carers and negative impact on their view of themselves as parents because of having to carry out painful/distressing nursing procedures
YP (views reported in 2 studies only) struggled with
- lack of freedom to do ‘normal’ activities such as going out or seeing friends and lack of control over their lives leading to behavioural/psychological problems (especially for 2 boys who lived in a residential home rather than with their families for whom lack of privacy from staff was a particular concern)

Parents and YP want
- YP to live at home, integrated into society as much as possible
- Parents – it was usually mothers who was the primary carer – wanted time with their child doing ‘normal’ parenting activities, perceived differently from nursing activities such as suctioning

CONC – LTV children spend an extra 9 months in hospital awaiting discharge once medically stable: services need to provide more co-ordinated approach to planning and delivering care eg 2005 LTV Care pathway details best practice

18. Maddox and Pontin 2013
L/T ventilated children
To describe carers experiences of caring for CYP and families in their own homes
Rationale – anecdotal exp of ‘support issues’ and ‘carer-parent

Design qualitative abductive design
Recruitment ‘service providers’
Selection purposive to identify carers with experiences of caring for ventilated children day and night in children’s own homes and end of life care
Data collection diaries, semi-structured interviews, researcher reflexive notes
Data analysis ‘hermeneutic cycle of data construction, analysis and critique’
Reliability + use of researcher reflexive notes; data management software used for diary data

P’pants 3 paid carers
Location W
England
Gender women
SES n/k
Ethnicity n/k

Paid carers worried about
a) caring for children with parents there as differences in their way of doing things could be interpreted as doing something wrong - any challenges from parents were felt to be an ‘assault on their personal integrity’ / ability though equally they said they defer to parents as experts if they are unclear what to do
b) maintaining boundaries eg being expected to administer medicines, which legally they can’t, not even calpol, do housework, mind siblings, advice on school behaviour or act as counsellor
c) their training was rushed, uneven/patchy
d) feeling sad when children die (also happy times, respect and hospitality from parents too though)
e) lack of support mechanisms for ‘minor’ incidents esp as previously available phone support from managers was withdrawn – lack of supervision at night - carers liked support sessions intro’d as part of team meetings

CONC inc a suggestion to include parents in carers training in order to build their confidence in working with them; and for access to registered nursing support by phone out of hours.
<table>
<thead>
<tr>
<th>Relationship' strain</th>
<th>Validity +</th>
<th>- sample size small without esp thick description</th>
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<tbody>
<tr>
<td>Selection purposive – parents (by gender); children: by gender, time using ventilator, age, ethnicity, living at home/hospital/LAC</td>
<td>Data collection interview with topic guide, some draw/play techniques or computers with children</td>
<td>Data analysis Framework Reliability + data management software; joint analysis and discussion w/other researchers - Validity + taped recorded or note-taking where this was refused (n=3); audit trail of researcher decision-making; prolonged engagement in the field; play based approaches -</td>
</tr>
<tr>
<td>Participants 35 ventilator-dependent children, and 50 mothers and 17 fathers of 53 v/d children</td>
<td>Location UK</td>
<td>Children's age 6-18</td>
</tr>
<tr>
<td>Gender NK as gender totals include some children who weren't interviewed (parents were)</td>
<td>SES Ethnicity 12 ‘ethnic minority’ parents or children</td>
<td>Other information 3 LAC, most children had communication difficulties such as speech affected by ventilator, 7 needed carer to help communicate</td>
</tr>
<tr>
<td>Exclusions ‘children under 6 years... because the main purpose of the study was to ascertain children’s own perceptions’,</td>
<td>Home healthcare services were not designed to bring about the desired social outcomes that children identified eg social inclusion by being able to get out and about and take holidays, and have a good social life; and children seemed most disadvantaged when parents did not have the resources (such as transport) to compensate for this in ways that could support their child’s social inclusion.</td>
<td>CONC Flexible, high quality child-focused homecare is likely to improve children’s outcomes.</td>
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<tr>
<td>Selection: qual studies focussing on experiences of CYP less than 18 yrs with chronic health condition or neurodisability during inpatient stay</td>
<td>Exclusions: intensive care and outpatient experiences Data analysis : thematic Reliability + double coding - Validity + -</td>
<td>Participants 8 papers on exps of CYP and parents and staff Location 5 UK, 2 Ireland, 1 Canada Children’s age 3-17 Gender n/k SES n/k Ethnicity n/k</td>
</tr>
<tr>
<td>Parents disliked - nurses’ routinely underestimating children’s levels of understanding - lack of info on CYP condition and treatment - unclear division of care with staff, since nurses tendency to defer to them as experts in their child’s care could shake their confidence in the clinical team. CYP were frightened when - procedures were not explained or when children were excluded from decisions - use of medical jargon could be a problem - could find ward routines restrictive eg waking/sleeping times also concerns about missing school work and friends and family Nurses found it difficult - to judge children’s capacity for involvement in decisions - had no framework for doing this - found parents wanting to ‘protect’ children could lead to their being excluded from discussions - especially difficult to involve children with high levels of knowledge about their condition. Children described experiences as positive when - procedures were explained to them including potential pain, tho fun and jokes to add levity were appreciated. - they were asked about their views and involved in decisions - described this as reducing anxiety and making them feel more respected - there was camaraderie amongst other ‘regular’ inpatients and -positive, friendly, honest interaction with staff (central to their views on care. CONC open discussion of roles and responsibilities during the inpatient stay may clarify boundaries btw staff/parents/child’s care. CYP experiences may not be ‘optimal’ and improving staff communication skills is important to address this.</td>
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<thead>
<tr>
<th>21. Santer et al 2012 Eczema</th>
<th>Design qual interview study</th>
<th>Recruitment via primary care invites, 10% agreed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants 31 carers of children 5yr or younger with eczema from 28 families (21)</td>
<td>Parents disliked - feeling unsupported, frustrated with both medical care (14 in primary, 5 dermatology nurse, 9 dermatology/allergy clinic) and treatments. - feeling their child's suffering was not 'taken seriously', - experienced messages about a ‘trial and error’ prescribing approach and</td>
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Carers of eczema + its m/ment
Rationale is to explore parental views of treatment as poor adherence is a ‘major cause of treatment failure’ - sometimes because of poor understanding of topical preparations. ‘A first step in addressing adherence is to understand beliefs about condition/care.

<table>
<thead>
<tr>
<th>Selection/Parents of ch with eczema under 5 years</th>
<th>Data collection</th>
<th>qual interviews mainly at home</th>
<th>Data analysis</th>
<th>constant comparative Reliability</th>
<th>+ used software to manage data; dbi coded and discussed;</th>
<th>Validity</th>
<th>+ taped, interviews at home; full transcription; neg case analysis;</th>
</tr>
</thead>
<tbody>
<tr>
<td>mothers, 1 father, 3 both</td>
<td>Location</td>
<td>Hampshire + Dorset</td>
<td>Sample size</td>
<td>Children’s age</td>
<td>Gender</td>
<td>SES recruitment from ‘varying sociodemographic areas’; included 8 professionals and 8 admin/retail</td>
<td>Ethnicity</td>
</tr>
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Assurance that their child would ‘grow out of it’ as a further ‘fobbing off’, or dismissal (a few were also confused about the information they’d been given on topical corticosteroids).
- frustrated with doctors focus on ‘control’ (national guidelines) whereas they wanted cure, eg through allergy testing.
- felt judged by their HCP as a parent, and felt upset and angry about this. ‘They’re looking at it and they’re like ‘IT’s very dry’. IT’s a stupid question ‘Are you moisturising?’ Well yes I am. Why would I want my child to go through that... they are quick to criticise when they are not really helping me’
- ambivalent about eczema treatments, mainly topical corticosteroids but also emollients – ‘I would prefer not to guinea pig them and ‘let’s see if this cream works’ p 263
- not understanding advice or receiving conflicting advice from different healthcare providers
Parents interested in
- dietary exclusions as a potential cure - many were trying out changes without discussion with a HCP, tho often felt unsure about these – tho perceived healthcare professionals as uninterested in this. CONC – ‘experiences of conflicting or not understanding advice may have delayed the process of gaining control... for some’ p265

<table>
<thead>
<tr>
<th>22. Lewis et al 2010</th>
<th>Epilepsy</th>
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<tbody>
<tr>
<td>To id what is effective in delivering information to YP 13-19 years with epilepsy and their parents, describe their experiences of info exchange and to id factors influencing positive and negative healthcare communication</td>
<td></td>
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<tr>
<td>Rational – current philosophies in selfcare.. focus on yp becoming experts in their own care by the time they transition to adult services. Adults whose epilepsy began in c/hood have id/d important gaps in communication during their early years.’ P2</td>
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<table>
<thead>
<tr>
<th>Design</th>
<th>Systematic mixed methods review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment/sources</td>
<td>DARE, ASSIA, Medline, Cinahl, Cochrane Epilepsy Specialised Register and Cochrane Central register of controlled trials; handsearches of key journals; 10 authors contacted for additional information – ‘some’ responded</td>
</tr>
<tr>
<td>Selection</td>
<td>studies of the knowledge, use of information, info needs and experiences of yp 13-19 with epilepsy and their parents in healthcare published in English or translations available</td>
</tr>
<tr>
<td>Excluded</td>
<td>studies of age group wider than 13-19 where data from this age group could not be extracted separately</td>
</tr>
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<table>
<thead>
<tr>
<th>Data collection</th>
<th>Data analysis adapted guidance from Thomas and Harden 2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reliability</td>
<td>+ used Ley’s cognitive hypothesis model of communication to inform interpretation of findings; used software data management</td>
</tr>
<tr>
<td>Validity</td>
<td>+ -</td>
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<thead>
<tr>
<th>Participants</th>
<th>10 qual, 5 intervention studies, 4 quant non-intervention, Location: Country of included studies not reported</th>
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<tr>
<th>Participants</th>
<th>What YP wanted</th>
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<tbody>
<tr>
<td>13-15yrs yp wanted info on about practicalities of living w/epil ‘here and now’ eg not about causes</td>
<td></td>
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<tr>
<td>Older yp wanted to know about implications for future education, employment, marriage, children</td>
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<tr>
<td>All wanted to know if being tired, sleeping/concentration/memory problems were related to epilepsy or medicines</td>
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<tr>
<td>They wanted individualised structured education on demand thru out their teenage years</td>
<td></td>
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<tr>
<td>Somewhere quiet to talk with a prof with the right communication skills</td>
<td></td>
</tr>
<tr>
<td>Barriers to YP getting this HCP focus on medical information (including at diagnosis) rather that practicalities of living with epilepsy: yp thought they are only interested in medical management</td>
<td></td>
</tr>
<tr>
<td>Felt excluded from discussions in clinic (directed at parent, and jargon difficult to follow so they stopped listening, adopted a passive role</td>
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<tr>
<td>YP felt having to repeat the same information to high turn over of different health pros depletes sense of partnership too</td>
<td></td>
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<tr>
<td>Doctors’ high status and limited time in consultations, seeing different staff each time made discussing sensitive issues difficult</td>
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<tr>
<td>YP feared asking questions feeling they would be judged eg not following the regimen, or assumed to be involved “risky” behaviours such as drinking or having sex.</td>
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<tr>
<td>YP felt HCP knew they had ‘emotional issues’ but ‘pretended not to be aware of it to avoid discussion as they did not know how to deal with it’ (NB cross ref with paper on doctors focus on ‘control’ (national guidelines) whereas they wanted cure, eg through allergy testing.</td>
<td></td>
</tr>
<tr>
<td>Authors: ‘YP made improbable lin… for some’ p265</td>
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*Note: The data table and structured format are for illustrative purposes and may not reflect the exact format of the original text.*
23. Hummelinck et al 2006

**Chronic illness generally**

To explore the complexity of parents’ information needs and how current information provision is evaluated.

**Rationale**

- gap between policy/rights agenda emphasis on providing comprehensive information and patient dissatisfaction with this (‘despite widespread dissemination of info materials’)

| Design | qual<br>Recruitment | 45 invitations via paed dept of district general hospital<br>Selection | convenience from parents living with ch 0-16 yrs with chronic condition and at least 1 drug administered daily for minimum of 1 week<br>Data collection | semi structured interviews<br>Data analysis | thematic Reliability +<br>Validity + taped (or full notes) and full transcription - not clear where interview or who conducted<br>Participants | 27 parents of 20 families<br>Location | Midlands<br>Sample size | Children’s age median 6-10yrs<br>Gender | 12 boys 9 girls<br>SES/ Ethnicity | n/k<br>Other information | median time since diagnosis 2-4 years; conditions including asthma, diabetes, CF, epilepsy (including with special needs), eczema, cancers

**Parents disliked**

- having to absorb lot of info at diagnosis and many felt overloaded (especially where condition managed across multi-disciplinary teams eg CF)
- feeling confused by jargon or frightened because they could not find answers to their anxieties.
- Conditions managed in primary care (eg asthma) tended to be characterised by concerns about lack of information.
- not knowing how to frame questions as they didn’t know what to ask, what they needed to know until they were in an unfamiliar or critical situation
- feeling most professional communication and info provision inadequate – some described actively seeking out information but one coping strategy was actively resisting information for fear of its negative impact.

In retrospect, parents said they wanted to know
- Explanation for illness
- Understand management (treatment, mechanism of drug action, possible side effects) and possible outcomes
- And practicalities of this in terms of daily care psychological and medical eg medicines supply issues, insurance cover, improving acceptability to children, available support systems/reliable info sources
- Prognosis and potential complications – to prepare for these

Later information needs were shaped by parents feelings of confidence in dealing with the condition and administering treatment, possibly linked to length of time since diagnosis and stage of child’s illness – so confidence displaced need for further formal education.

CONC – ‘individual info needs varied... [also] resisting or avoiding information could be used as a positive coping strategy in some situations’ (if parents felt overwhelmed). Parents felt information ‘inadequately tailored to their individual current or anticipated needs’ p233

24. Kirk et al 2012

**Self care support**

To determine CYp/carers/HCP perceptions of the effectiveness of different models of self care support and id factors that support/inhibit self care at individual and organisational level; and explore how models integrate with self care support provided by other organisations NB ‘the self in this context is a combination of child and adult carers’ p1975

**Rationale**

- ‘self-care support... in the context of a LTC [is] largely associated with particular interventions [rather than routine care] such as education or skills training [so] constructed largely in terms of the individual patient rather than structural constraints’ p1975 Cites evidence of yp/parents valuing ‘group based self-care for the opportunity they provide to interact with others’ and that ‘e-health methods’ of support have also been found useable and acceptable.

But ‘flexibility in provision is needed to

| Design | case studies of 6 different models of self-care support<br>Recruitment | 70 self care support projects identified in previous research<br>Selection | purposive of projects to reflect diff ways of providing support, condition specific models and general; purposive to maximise variation of children’s ages, support by different types of workers (voluntary, HCP) and to try include those who had dropped out<br>Data collection | semi structured phone interviews (except where requested otherwise), observation of self care support activities; relevant documents reviewed<br>Data analysis | Framework Reliability +
| P’pants | 26 YP, 31 carers, 36 self care support providers from projects such as support groups (inc online and lay led), residential camps, statutory secondary health care – diabetes team<br>Location | UK<br>Children’s age / Gender / |

**Organisational inhibitors of self care or access to self care support (why do authors conflate these?)**

- Parents identified primary schools - esp for ch with asthma not allowed to keep their inhalers with them (undermined what they’d been encouraged to do at asthma camp) or when schools did not action plans agreed for management.
- YP identified schools as exacerbating their feelings of difference from peers
- NHS routine referral to support projects generally reported poor (except to NHS led ones)

**Individual level facilitators of self care support or access to self care projects**

- YP said mothers played central role in encouraging them to attend self care projects and mothers/yp said yp would have to feel ‘ready’ to attend
- Both reported enjoying a ‘safe place where feeling and experiences could be expressed’ (at odds with other evidence)
- Parents wanted to learn about the condition and management strategies and promote children’s independence and described feeling that they’d got this
- YP described learning how to manage feelings, improve communication with HCP and teachers,
enable individuals to access a range of different types of support from both formal and informal self-care resources as well as support that takes account of social-economic and cultural contexts' p1975. Interventions need to be directed at HCP and systems as well as patients evidence these can improve CYP health status and reduce health service use.

| - Validity | SES / Ethnicity N/K | and self-confidence and they liked when activities were enjoyable CONC – 'promoting self-care support or an individual child/family basis by HCP and maintaining personal involvement appears to be important factors in encouraging yp to access self-care support' p1985. |
| - Authors were unsuccessful in recruiting any project ‘drop-outs’; - little report of any differences/tension in experiences across diff groups eg YP / carers |

<table>
<thead>
<tr>
<th>Design</th>
<th>Action research</th>
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<tbody>
<tr>
<td>Recruitment</td>
<td>CCN service Selection: not clear though all CCNs may have participated in develop/piloting templates of high/med/low nursing ‘input’; purposive sampling for interview on location, length of experience</td>
</tr>
<tr>
<td>Data collection</td>
<td>in-depth interviews; doc analysis of caseload data, fieldnotes, analytical memos used to develop interview schedules</td>
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<td>Data analysis</td>
<td>thematic</td>
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<tr>
<td>Reliability</td>
<td>+ data management software - ‘family nursing model’ not described (tho in other paper this is linked to family systems theory and continuity of care</td>
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<tr>
<td>+ taped and transcribed; iterative schedule and analysis - interviewed ‘at the university’; relation between aim/finding/conc rather loose and tensions between explicit organisational ethos and nurses’ views not flagged.</td>
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<tr>
<th>25. Pontin and Lewis 2008a</th>
<th>Community children’s nursing (CCNs)</th>
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<tr>
<td>Rationale – the dependency scoring case allocation method in CCN is not working because all children [with life-limiting, life threatening and chronic conditions in the community] on a given CCN caseload will score as highly dependent… so CCNs cannot use the system to differentiate between those children in order to manage their caseload to meet client need’ Authors say also there is ‘insufficient robust data to discriminate between ongoing workload trends and minor self-limiting events’ p27</td>
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<tr>
<th>26. Pontin and Lewis 2008b</th>
<th>CCN</th>
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<td>Rationale – the nursing service has ‘an explicit rationale to maintaining continuity of care and carer which is challenged by the context of delivery’; nurses in a particular CCN service wanted to find ways to ensure efficiency and equity of service delivery and wanted</td>
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<th>Design</th>
<th>Qual action research</th>
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<tr>
<td>Recruitment</td>
<td>CCN service across several PCTs Selection: purposive sampling for interview on location, length of experience</td>
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<th>Participants 6</th>
<th>CCN</th>
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<tr>
<td>Location</td>
<td>Urban and rural Other information</td>
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<tr>
<td>CCN serving</td>
<td>‘diverse population’</td>
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| CCNs reported the development of both formal and informal (written and oral) protocols to manage their workload including: - an aim to support families to have a ‘usual’ family life - anticipating issues early to avoid negative consequences - getting to know families well (not a straightforward ‘linear’ process) before they could advocate for them across other services – discouraging families from being ‘too dependent’ on nursing care or one CCN In this paper authors say ‘[CCNs] recognise their actions could engender service dependency’ p30 Perhaps unsurprisingly families are reported reluctant to ‘ring for help regardless of the situation’ p31. CCNs valued establishing strong relationships with families as this helped if/when children were dying They tried to ensure they always had a clear purpose for visits ‘they monitor their actions and justify them… to themselves and the ‘unseen other’ through their records’p31 However, ‘despite CCN attempts to ensure purposeful visits.. clients have the ability to shift the initial premise of the visit to meet their own needs... CCNs construct daily plans of action [but] the smooth sequencing of these plans is a risk if clients change the visit purpose [so] CCNs prioritise/revise them on a visit-by-visit basis’p32 CONC - Authors refer several times to nurses concerns that their work in the home is ‘invisible’ to commissioners (see Byrne 2003), and their need for this to be made ‘extant’ |

| CCNs | reported meeting family needs thru interagency working to accommodate developments eg when mother becomes pregnant and unable to lift. CNNs share out clients including by geographical location, or who has known them the longest. Meaningful working relationships with families are ‘highly rewarding’ but can be stressful, not least because of the ‘amount of information and local knowledge’ CNN must ‘take on’ to support families. Having responsibility for named clients across the job share facilitates information exchange, Junior colleagues were allocated some named clients too tho senior nurses retained overall responsibility for them. CONC – ‘findings show how nurses maintain continuity of care in a particular model of |
27. Shepherd 2014

**YP with LTC**

To highlight the emotional impact of being in the hospital for young people, and to explore the impact of the care by younger student nurses on promoting a sense of ‘normalcy’ for them.

**Rationale**

- Students nurses may be especially suited to ‘engage in caring interactions with yp in hospital’ because of ‘their age and similar stage of development’ and they are experiencing a similar ‘lifeworld’.
- Reviews show ‘one of the main concerns for yp is striving for normalcy and the need for HCP to focus on their wellness not their illness’.

**Design**

- Heideggerian phenomenology
- Nursing students via via author institution; not clear re YP, pos outpatients?

**Selection**

- Under 20 yrs at start of ‘programme’ who had ‘experienced the phenomenon’ –caring for a yp in hosp? YP over 12 yrs with exp of at least 3 hosp admissions and using trust outpatients

**Data collection**

- Unstructured interviews

**Data analysis**

- Interpretative phenomenology
- No discussion of conceptual framework, ‘lifeworld’ is central concept but not clarified

**Participants**

- 11 17-18 yr old student nurses, including one young man; 9 13-18 yrs YP in hospital with chronic condition (3 boys)

**Location**

- Not stated but author is at Greenwich university

**Ethnicity**

- n/k

**YP wanted care that relieved their boredom, made them forget their illness for a while and provides a sense of normalcy eg [she] knows the same places where everyone goes’.

**CONC** ‘in order for the care giving to be supportive and therapeutic the carer must be tuned into the person’s ontological concerns… because the students are experiencing a similar lifeworld… they are seen as being able to engage in ontic care giving’.

---

28. Swallow et al 2013

**Chronic kidney disease (CKD)**

Explore social interaction between multidisc teams (MDT) and parents, how they negotiate care roles by a) developing a descriptive profile of MDT and their parent-education activities; b) explore pros/acs of strategies during these activities; c) get a focused understanding of prof/parent interactions as parents embark on new interventions at home

**Rationale**

- ‘Rationale – increased prevalence of CKD, parent-led care at home is deemed best practice but non-maintenance of regimen or failure of det complications has emotional, psycial and financial costs for families (financial/policy implications for services). There is little evidence on factors important in parent-prof interactions when parents are mastering the skill to incorporate care into day to day parenting roles… studying the way parents and profs communicate will help profs determine how to individualise parent support from early in the trajectory. Current evidence suggests ‘unresolved tensions’ and ‘lack of negotiation around healthcare decisions’ Conceptual framework from ‘Communities of practice and activity theory’: in which learning is by doing, individuals must work out how to engage with one another (eg

**Design**

- Multi-method
- Via kidney units

**Selection**

- MDT members identified by unit PI; self-selected to interview; case studies purposively sampled by CYP age, sex, ethnicity, type of care, and profs involved in this care identified via snowballing

**Data collection**

- Initial survey; then qual grp (indiv interviews if staff couldn’t make grp); then 6 month ethnographic case studies involving:
  - Observation prof/parent interactions at home sharing care
  - Individual interviews with HCP and parents
  - Case note reviews

**Data analysis**

- Framework
  - Dbl coding;
  - Validity
  - Researchers repeatedly explicit not ‘judging’ or ‘testing’ HCP or parents’ practice; ‘incorporated reflexivity into data management process by regularly considering whether analysis might have been compromised in favour of

**Participants**

- 115 prof interviews (7 indiv interviews) with psychologists, dieticians, doctors, nurses, play spec, pharmacists, therapists, soc workers; 6 observational case studies involving 6 children, 6 mothers, 4 fathers, 2 grandparents, 28 prof, 86 observations, 41 interviews, selected case note and documentary reviews

**Location**

- 12 british children’s kidney units
- CYP age 5 mths-15 yrs
- Gender CYP: 2 boys
- SES: N/K
- Ethnicity CYP: 1 St Asian, 5 White Brit

**Other info**

- Parents were learning how to insert NG tubes, gastrostomy feeds, home dialysis, monitoring diet/fluids, clinical observations,

**HCP say they negotiate care roles by**

- Using tacit knowledge to gauge parents learning needs, how to pitch communication (‘it’s intuition’)
- Set goals for optimum management with needs and preferences of children and parents – and used a ‘staged’ approach to conveying specialist clinical knowledge

- Check out and refine info with other member of the MDT inc common assessments of parents levels of understanding
- Use common tools such as words, metaphors, diagrams, stories, routines, dolls or concepts to explain to parents ‘How the kidney does a lot of work and is made of a whole lot of little factories’ Doctor p8
- As part of this draw on parents expert knowledge of and relationship with their child

**CONC** – did not observe any tensions; profs may find it hard to make explicit tacit knowledge about how they assess parents’
Design not explicit Recruitment respiratory, endocrine, rheumatology and gastro, and adolescent outpatients in major London teaching hospital

Data collection face to face semi structured interviews (at clinic)

Data analysis constant comparative Reliability + - Validity + taped and verbatim transcription -

Participants 27 YP and parents (n=n/K)

Location London

Children's age 6-19 yrs

Gender 17 girls

SES 'small number' attending private schools

Ethnicity N/K tho authors report clinics serve diverse populations

Other information 11 adol medicine, 7 endocrine, 5 rheumatology, 3 respiratory, 1 gastroenterology; 19 YP had regular dosing and 'prn' (as needed)

YP and parents described problems with

- No private place for administration
- No advice available when feeling unwell
- No reminders to take medicines for yp
- No help with administration
- Staff having poor knowledge and awareness of yp needs

They wanted better support, esp with prn medicines eg analgesics including:

- access to medicine as needed (and promptly), without drawing attention to yourself
- somewhere private to administer (half of yp wanted to keep condition secret)
- if necessary a designated first aider to oversee, inc on trips (or remind when needed)
- individual teachers assistance eg to catch up with work after hospital admission
- flexible application of protocols (eg 'he let me look after my medicine’

CONC – Schools should address separately the needs of yp with prn medicines from those with routine regimen; individually assess yp’s needs (some need privacy others don’t); make sure staff training is in place to address the marked variability in support YP experienced

Prescribers should use medicines with one or two doses daily where possible

30. Soanes and Timmins 2004 Transition LTC To examine the attitudes and needs of adult care? Rationale is to examine whether existing organisational structures militate against successful transition.

Design qualitative Recruitment: via large, teaching hospital youth club

Selection: Purposive by age (14-18) likelihood of having personal experience of transition, and long-term illness

Data collection half hour semi-structured interviews in youth club

Data analysis ‘coded for content… then codes refined’

Reliability + -

Validity + full transcription, taped, flexible schedule

- authors acknowledge generalizability limited; NB bias of recruitment via hosp youth club.

Participants 7 YP with LTC

Location N/K

Children’s age 14-17 yrs

Gender 2 girls

SES / Ethnicity n/k

Other information 4 with diabetes, 2 chronic renal failure and 1 cancer

YP want

- informal approaches which make them feel comfortable ‘i like knowing everyone… be able to chat with them. The hospital is a sort of second home’ p 104

Some felt paed services attractive for their informality whereas others found them condescending and no longer appropriate to their needs

- transition to be gradual with lots of preparation ‘a year or two in advance’ when they are ready, not coerced ie flexible, individualised process and supported by nurses and youth workers

- didn’t want family involved for long

YP felt info on drugs and alcohol was poor in paed services

CONC – services must review the types of info available, consider a ‘buddy’ system, evaluate the use of an informal day or residential weekend to facilitate transition, use factors other than age as indicators of readiness to transfer.

31. Taylor, Gibson, Franck 2008 Living with LTC during Design SR Sources: Medine, Cinahl, PubMed, PsychINFO

20 studies, Location N/K; CYP age: 10-19

Gender /SES/

RE care and treatment, YP disliked

- clash between treatment and priorities in wider life, felt especially in middle adol when authors feel they are taking more responsibility from parents, though as they got older are reported to take control by developing their own routine

- lack of support in schools from staff who imposed unnecessary restrictions, didn’t know enough about their condition and made it hard for yp to maintain their valued sense of
adolescence
To identify, describe and critique lit on ‘the adolescent lived experience of chronic illness’ Rationale – living with illness can ‘disrupt adolescent development’ p3085 but little is known about how YP perceive this

Selection: qual studies with yp 10-19 yrs in English on experiences of living with illness
Data analysis thematic
Reliability + explicit theory of adolescence - Validity + studies were QA’d - no engagement with critiques of developmental psychology

Ethnicity N/K
Other info Cancer, renal, diab, CF, IBD, L/T ventilate, SCD, Disability, Asthma, Epilepsy, Depression, Cerebral palsy, Treacher Collins

sameness with peers
- only in 3 studies did YP make reference to the care team: ‘felt devalued if they felt judged’ - not feeling respected would make them feel like stopping treatment YP liked
- feeling understood, supported and respected by their care team
- needed to know about their illness
CONC – authors suggest implications for practice as follows:
- the importance to yp of developing and maintaining friendships: encourage friends to visit during hospitalisation; ‘ensuring early socialisation experiences are optimised’
- Importance of family: ‘teaching parents coping skills early after diagnosis’; ‘teaching parents ways of coping with a teenager’
- Attitude to treatment: ensure info about the illness is available in a developmentally appropriate form
- Experiences of school: ensuring liaison during periods of hospitalisation; educating teachers about the condition and importance of promoting normality
- Reln with HCP: Involve yp in decision-making and engage yp in discussion rather than their parents

32. Hutchinson, Hall 2007
Rheumatology service
To understand young women’s experiences of learning about their illness and preferred learning options - to inform a decision about whether the expert patient programme would be a useful ‘educational tool’ – later: ‘to determine the knowledge of yp ... regarding their... illness’ p522
Rationale – Authors explain use of new drugs with side effects and how ‘education’ is needed to ‘optimise concordance’
‘To facilitate empowered understanding... nurses must first understand the care situation as viewed by those most closely involved’ p522 especially as ‘imparting knowledge to yp is challenging as they may rely on others to take responsibility for knowledge about their illness... this study arose from recognition of this challenge within one CYP rheumatology unit

Design Multiple case study
Recruitment yp’s rheumatology service in a UK hospital
Selection random selection of eligible yp, (eligibility criteria not clear)
Data collection semi struc interviews in own home
Data analysis Colaizzi’s 7 stage process
Reliability + - Validity + choice of interview venue; 2 others analysed data as well
- ‘when yp lacked knowledge potentially leading to harm... time for discussion was made after the interview’ p525 – was the interviewer their CSN? - Clinical view of care: patients must be ‘specially trained’ in order to ‘effectively support others with the same illness in managing self-care’; policy has ‘outlined plans for the enhancement of the patient role in care’ p522

Participants 6 y women 16-19 years
Location UK
Sample size SES/Ethnicity N/K

‘All participants had read around their illness and the desire to learn was unanimously evident’ p527
YP liked
- When a doctor arranged for her to meet with another girl with lupus (contrary to yp with diab)
- Pos’y (when pressed) more info on progression, duration of treatment and knowledge of famous people with arthritis – and possibly counselling might be helpful
- Effective communication about their illness from clinicians - found useful information on their illness from GP, consultant, leaflets in clinic,

Authors conclude the need for ‘tailored services’ and ‘the potential for expert patient schemes’ p530.

33. Taylor, Franck, Dhawan, Gibson 2010
Liver transplant
To explore in the depth the subjective aspects of yp’s quality of life after transplant, where yp’s

Design Recruitment via liver transplant centre
Selection: purposive by age and chronic/acute/metabolic liver disease
Data collection semi structured

Participants 14
Location N/K (UK)
Children’s age 12-18
Gender/ SES /

CYP (over 14 yrs – those younger didn’t comment on HCP, author thinks pos because they are not included in consultations) found difficult
- feeling local hospital staff had little understanding or experience of liver transplantation
- The journey to the tertiary centre
- Feeling information from doctors was inconsistent
perception of their quality of life is understood as arising out of clinical factors relating to the transplant combined with factors relating to the young person. Rationale – quality of care will be judged in the UK on patients views of their experiences and outcomes from care (DH2008). A step toward involving yp in service provision is ‘to understand their illness experience’.

| Design IPA | Recruitment: 16 families identified via a national register of yp with JHD willing to be contacted about research; 2 families known to the researcher | Participants 12 carers in 10 families with CYP with JHD, 8 mothers, 4 fathers (may be guardians rather than biolog parents) | Parents disliked professional support that Blamed them for child’s challenging behaviour eg parenting skills ‘this psychiatrist just tore us to shreds’ (child was misdiagnosed with dyspraxia initially) Not listening, not believing eg receiving little support before confirmed diagnosis, having to fight to have their view heard, feeling judged eg ‘we did end up in a big meeting… the court martial’ … we had to stand in front of all these people… and they asked us question after question’ Inflexibility eg dentist who expected boy with JHD to be able to sit still with his mouth open – gave impression he didn’t believe diagnosis; school unreasonable expectations I’ve given up going to parents evenings. I find them so depressing’ p48 Inconsistency / instability cos of high turnover of staff working with the family – difficult for children who find coping with change difficult Parents liked support from profs that was Active listening and believing Demonstrating that they understood families concerns (rather than questioning ‘what do you mean’) Being open and honest eg about not knowing much about the condition Consistent – eg social worker ‘he stuck in there, he stayed the course’ Flexibility – being willing to ‘try anything’ rather than there being fixed to one way of doing things’ – ‘open-minded to new ways of approaching a problem’ p47 CONC – reiterate findings |
| Data collection | semi struc interviews: 8 with one parent, 2 with both parents, Data analysis thematic Reliability + - Validity + taped, full transcription, interviews at home - | Data collection partial, | |
| Ethnicity N/K | Other information Time since transplant was 10mths to 14.5 years | (eg around drinking alcohol) and advice not proactive - Feeling torn between familiarity and continuity in paed services and wanting to transition to adult where they felt there might be better provision of ‘adult-type’ information eg sex (only raised by 17-18 yrs YP as the centre had no planned transition pathway) CYP wanted - Information about the transplant in a context with which they could identify… otherwise info just increased anxiety |

34. Brewer, Smith, Eatough, Stanley, Glendinning, Quarrell 2007 Juvenile Huntington

Aims: to investigate the social and health care needs of those affected by JHD Rationale – social support is seen as ‘desirable’ though some ‘research highlights more negative aspects of some social interactions [as] a stressor rather than supportive’ it would be useful to investigate which particular well-intentioned interactions are satisfying for individuals and which have the opposite effect p42’ Mothers are often sole carers as HD from fathers

35. Williams et al 2011 To identify:
- Types and characteristics of children’s health info resources available; and how they are used
- Preferences about type of info/ format; diffs between CYP and families on these and diversity of
### Health Information Needs

- **Issues around when it is appropriate for CYP to be making choices about their care (at what developmental stage); and how this is negotiated between CYP and families and HCP.**

### Rationale - Info is central to empowering CYP to have choice, make decisions, and learning to self-care in age-appropriate ways. But we know little about the types/delivery formats which support and empower CYP/families decisions and choices in self-care.

### Design Focus Group Discussion

- **Recruitment:** via ‘participating hospitals’
- **Selection:** initially random invitations, then purposive selection from positive response to max variation by gender, SES, ethnicity, age, severity and duration of condition
- **Data collection:** focus groups
- **Data analysis:** IPA, constant comparative analysis

### P/pants

- **YP 12-30yrs and their parents (n=53)**
- **Location:** N Eng, S Eng, Midlands
- **Gender:** YP 67% y women, SES n/k
- **Ethnicity:** YP 83% white, Other information 83% urban residence; median duration disease 5 yrs

### Participants wanted transitional care to be

- centred on regular individualised assessments of yp’s disease status, developmental level, life event and personal aspirations
- co-ordinated by a multi-disciplinary team with specialist JIA knowledge and strong interagency links esp with GPs and schools, and earlier referrals (not clear if this means to adult services or something else) and greater signposting of information (?) with a named key worker/co-ordinator as first point of access in a crisis
- consent for students to observe consultation sought in waiting room beforehand, and that they are present only part of consultation
- more flexible appts to minimise missing school/work – drop-in might minimise DNA information on functional ability, treatments, psychological health, social and parental issues (eg impact on family and minimising impact on valued activities), education, vocation (appropriate career choices), independent living inc benefits, housing/driving, skills for independence, sexual relationships inc disclosure, sexual health/contraception, parenting, genetic risk (parents wanted to gate-keep yp access to info on side effects, but yp didn’t want either prof or parents to act as gatekeepers to any info)
- communication that is honest, realistic and jargon-free
- for YP: HCP who make effort to ‘lessen the inequalities between them by making the environment less formal, asking about non-medical aspects of their lives and sharing personal information’; who sought their consent and respected their decisions (tho they were unclear about their rights to accept/refuse treatment); who supported their confidence in their ability to advocate for themselves in lone consultations begin prep for transfer early by learning to have lone consultations and so feeling in control and independent
- transition arrangements where they could stay with their same health care team
- YP wanted flexibility about time of transfer determined by individual readiness and shared decisions-making but parents felt it should be done by the time yp were 18, though if they had a crisis often wanted to return to paed

### Participants did not like

- strangers in consultations (students) esp if they just observed and didn’t contribute: implied consultation for HCP not yp; felt invasion of privacy and threat to confidentiality - yp said they were asked for consent and found difficult to refuse

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<table>
<thead>
<tr>
<th>36. Shaw Southwood, McDonagh 2004 JIA transition</th>
<th>Design Focus Group Discussion</th>
<th>Recruitment via ‘participating hospitals’</th>
<th>Selection: initially random invitations, then purposive selection from positive response to max variation by gender, SES, ethnicity, age, severity and duration of condition</th>
<th>Data collection: focus groups</th>
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of yp’s views may result in policies and practices that have little meaning for those that they are intended to benefit’ p770

| Findings at conclusion of group for amendment, comment, prioritisation, taping, full transcription; non-directive facilitation; negative case analysis - differentiation btw grps needs to be clear eg YP/carers | - their experiences of transition which were sudden and ill-prepared – felt ‘abandoned’ esp those who had to change consultant or who had strong reln with paed staff
- YP feeling their adulthood not recognised by staff who’d known them as children and who remained responsible for their care into adult services
- perceived low levels of expertise, empathy and resources in adult services (eg no longer qualified for hydrotherapy) compared to paed (and high numbers of old people)
- delays in transfer, discontinued care and cancelled appts because of poor co-ordination
- yp did not like managing consultations alone or found it difficult if they relied on parents to transport to refuse them coming into consultation
- Parents feared yp would not know how to ‘use the consultation to their best advantage’ and though they recognised the importance of yp learning to attend alone felt ch didn’t always give a true representation of their health status
CONC – authors feel because YP concerns with confidentiality, good information and staff friendliness chime with concerns of ‘healthier’ yp, they are likely to be generalizable over other conditions. |

37. Kirk 2008
What are CYP w complex needs experiences of moving from child to adult services and moving from parental care to self-care. Rationale - We have evidence on parents exp of transition but little of CYP not least because they ‘are a relatively new gp of children... surviving to adulthood’ p568; key elements of effective transition are known (multi-agency, person-centred planning, co-ordination of services, and continuity, involvement of CYP and families and dedicated transition support). But, there is little evidence on which to build service models

<table>
<thead>
<tr>
<th>Design not explicit Recruitment via CCN Selection purposive by age, and medical technology Data collection face to face in-depth interviews at home Data analysis grounded theory Reliability + Validity flexible interviews at home; full transcription, taped -</th>
<th>Participants 28 YP with complex healthcare needs or where CYP did not use verbal or alternative communication, parents were key informants (n=9) Location NW England Children’s age 8-19 yrs Gender/SES/Ethnicity N/K</th>
</tr>
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</table>
| YP need transition care that Acknowledges multiple concurrent transitions in ‘life’ (childhood to adulthood) at same time as organizational/illness transitions. YP disliked how service transition was hard because of
- poor information and involvement in planning and lack of formalised processes to support this
- sudden unexpected change, and worry about continuity of support packages into adult services and whether specialist expertise would be available at all. While learning responsibility for managing therapies and devices was evolving, individually negotiated, responsibility for decision-making and liaising with services could be acquired suddenly on transfer to adult services and not as part of an integrated self-care transition process.
- having to adjust in adult care to a different (less ‘cosseted’) culture, more ‘depersonalised’ environment and way of working and loss of relationships with familiar, trusted HCP. ‘They had to adjust to their involvement in decision-making being encouraged’ p569 CONC – individualised person-centred assessment and planning is especially important for yp with complex conditions at multi-agency and specialist care level as many have conditions and support needs unfamiliar to adult care providers eg costly/complex home support packages. ‘CYP were not well prepared during their time in children’s services for becoming increasingly involved in decision making and in consultations with HCP... access to support from independent advocates may be appropriate’ p574. |

38. Miles et al 2004
To explore YP experience of transition from paed to adult HIV care.
‘the general complicating factors during transition such as lifetime changes in schooling, employment, leaving home, new social opportunities, and developing independence can be further complicated

<table>
<thead>
<tr>
<th>Design not explicit Recruitment via adult HIV outpatients Mortimer Market Centre Selection YP who had transitioned from GOS paed unit to the MMC Data collection single semi</th>
<th>Participants 7 YP aged 16-22 Location central London provider Children’s age Gender 5 men, 2 women SES n/k Ethnicity 4 ‘UK born’, 3 ‘African’ Other information Transitioned with past 2 years when 16-</th>
</tr>
</thead>
</table>
| YP liked
- existing established process beneficial especially intro to adult service early on in transition prep period
- sense of independence, shift in responsibility to themselves and general satisfaction in being treated as an adult. Some yp had concerns about
- co-ordination of haemophilia and HIV care (haemophilia adult care in different building)
- fear of adult services eg being judged about origin of HIV; or seeing adults with HIV illness would remind them of the increased likelihood of illness with age
- YP who’d been more involved in planning their paed care...
<table>
<thead>
<tr>
<th>Research</th>
<th>Title</th>
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</table>


Miles K¹, Edwards S, Clapson M. AIDS Care. 2004 Apr;16(3):305-14. Transition from paediatric to adult services: experiences of HIV-positive adolescents..


Shepherd JM. Younger children’s nursing students are uniquely placed to provide emotional care for young people in hospital and promote for them a sense of normalcy. Nurse Educ.Today 2014;34(6):1034-1039.


Williams. Children’s Health Information Matters: Researching the practice of and requirements for age appropriate health information for children and young people http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1718-145_V01.pdf
Appendix 5

Records with no abstract kept on file from systematic mapping (n=5)


Spencer J, Cooper H, Milton B. Qualitative studies of type 1 diabetes in adolescence: a systematic literature review. Pediatric Diabetes 2009.11(5)364-75


UK-other/European records kept on file from systematic mapping (n = 35)


Jönsson, L., Hallström, I., & Lundqvist, A. (2010). A multi-disciplinary education process related to the discharging of children from hospital when the child has been diagnosed with type 1 diabetes--a qualitative study. BMC Pediatrics, 10, 36-36.


### Appendix 6: Synthesis data extraction table

<table>
<thead>
<tr>
<th>Study</th>
<th>Methods</th>
<th>Sample characteristics</th>
<th>Findings which contribute to synthesis question of what makes 'good' or 'bad' LTC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allen et al 2011&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Design Longitudinal qualitative case studies in 5 different diabetes services Recruitment via ‘service providers’ Selection ‘appropriately placed service providers’ and purposive selection of yp by gender and position in process of transfer Data collection 3 x semi-structured interviews with yp and with mothers over 12-18mths (other party occasionally present during interview) Data analysis thematic Reliability + Identifies ideas from Strauss’ account of illness trajectory as underpinning understanding of yp’s accounts; data management software used - Validity + Flexible approach to interviews; full transcription, most interviews at home - Authors report difficulties recruiting yp Participants 46 CYP T1D and 39 mothers Location N/K (UK) Children’s age 13-21 yrs Gender 23 girls; 23 boys SES n/K Ethnicity N/K</td>
<td>Participants</td>
<td>Some mothers felt shifts to lone consultation - lead to discontinuities of information – ‘even if they just sent you a quick letter saying everything was fine.’ p997 undermine their ongoing role in supporting their child into young adulthood eg ‘I’m involved when something is out of the ordinary... if she thinks it’s something a bit different to what she’s expecting then’ we’ll discuss things with her.; 997 could be esp difficult if they felt yp’s control was worse than previously when they’d played a greater role ‘it probably bothers me more than it bothers Samuel at the moment because I don’t feel that he’s taking it seriously enough or maybe I’m just being an over anxious mum’ p998 and could bring to the fore underlying feelings of overwhelming sorrow ‘I mean every change he makes it’s like [respondent becomes upset] – you never get over it, you know, that it’s never going to go away...’ p998 CYP described - the ongoing importance of mothers’ role day to day in supporting their increasingly independent management of their condition eg ‘I would double check with my mum say if I had eaten a bowl of pasta... I would say do I need four units and she would say I would give five’ p997; eg ‘in my mid-twenties... I imagine she’ll still be here, at home and I’ll still talk to her about it; p998 - the role of mothers’ continued presence in clinic to reflect this ongoing support ‘fair enough, she does help me out quite a lot so she likes to... keep up to date’ p997 Good care would reflect how the lives of yp are characterised by interdependencies... authors feel there is a need to develop service structures that recognise the continuing role played by mothers in the diabetes care of young adults eg in a few services a written report of the consultation was provided to parents of yp under 16 years who had moved to lone consulting (authors note that 16 years and over there are issues with confidentiality in this approach); in other services parents attended for part of the consultation; in another, the DSN in transition clinic was the same that parents had known from paed care which meant they still felt able to access the support they needed. In another the DSN made clear she would engage with parents as well (though most didn’t contact her, perhaps believing they won’t be welcome). CONC The ‘individualised focus of adult services does not reflect the realities of yp’s lives’ p999</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Allen et al 2012&lt;sup&gt;2&lt;/sup&gt;</th>
<th>Design case study Recruitment: via diabetes services in England in the Directory of Diabetes Care Selection: at service</th>
<th>Participants</th>
<th>46 CYP T1D and 39</th>
<th>38 HCP (details n/k);</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users wanted (nearly verbatim) transition care that is -</td>
<td>a) Relational – Both yp and carers wanted ‘an ongoing therapeutic relationship with one or more providers [who] understand the fabric of individual’s lives’ esp so, for example, ‘deteriorating control is understood in the context of individual’s care trajectory rather than as non-compliance’ p143; For yp: ‘consultation style and interpersonal skills were highly consequential’ p 144</td>
<td></td>
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</tbody>
</table>

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**Abbreviations**

CYP : children and young people  
Paed : paediatric  
T1D: type 1 diabetes  
DSN: Diabetes specialist nurse

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Multiple papers on same study marked with the same superscript number
Aims: To id mechanisms that help smooth transition, service components through which these can be achieved and their interrelations

Rationale – gap btw g’lines and ‘evidence to inform service commissioning’

p141

<table>
<thead>
<tr>
<th>Curtis-Tyler 2012</th>
<th>Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>To explore experiences of children 10 years or younger living with T1D with a view to identifying levers and barriers to children’s contribution to their clinical care</td>
<td></td>
</tr>
<tr>
<td>Rationale – patients’ views are important in identifying the best options for care tho achieving this in practice has proved difficult</td>
<td></td>
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</tbody>
</table>

Design In-depth qual Recruitment: 2 outpatient clinics Selection: ch under 11 yrs, self-selecting Data collection – home visits, discussion groups, observation in clinic Data analysis constant comparative Reliability + explicit about understandings of children/childhood; data management software - Validity + home visits; taped, full transcription, negative case analysis -

Participants 17 children T1D all 10 years or younger Location: Large multicultural city Sample size 17 Children’s age 4-11 Gender 8 girls, 9 boys SES NK Ethnicity 6 Somali; 5 White British/English, 1 Lithuanian, 2 Arabic, 2 African, 1

Problem: in contrast to their sense of being key players in their day to day care at home, children felt their position in clinic was peripheral, that they had nothing useful to contribute. They were excluded from discussions of illness, they and parents had little control over the timing, pace and direction of interaction, the tightly focussed question and answer format was at odds with discursive approaches favoured at home, and a biomedical model of illness fragmented experiences into physiological, social and emotional components.

Conc- if clinicians want to hear from children they will need to provide a convincing rationale so questions are not perceived as a test; engage w/ children’s strong experiential understandings of their condition by framing questions in terms of activities and sensations, and try to redress generational prof/lay imbalance of power by demonstrating respect and attention. However if the mainly physiological focus of consultations acts to protect families from prof surveillance, it may prove difficult to shift.
<table>
<thead>
<tr>
<th>Design Qual Recruitment via specialist diab service</th>
<th>Participants 19 young adults with diabetes (disease type not specified); Location NE England Children’s age 16-25yrs Gender: 11 girls, 8 boys SES/Ethnicity N/K</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection self-selecting from pop of 16-25 yrs olds w T1 or T2 using secondary care</td>
<td>YP disliked: At diagnosis - information overload, wards with much older adults, insensitive staff  Secondary care - not knowing which clinician they would see in clinic, having to repeatedly share same information, not being involved in consultations, overly directive or conflicting advice with little relevance to individual situation, insensitive personal questions/giving bad news, breaches of confidentiality, feeling unable to ask questions/rushed, having to suppress distress, formality, lack of civility, poor communication between services and age inappropriate communication: “I’ll just sit and listen... and go home. I think, what’s the point’ 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” P409  ‘[The doctor] used to talk to me like I was a baby [and] to my mum as though I wasn’t there’ p 414  YP could feel passive recipients eg re move to adult care ‘manhandled as a piece of meat with no respect’; that because of their age they don’t deserve as much time/attention as older people, that they are culpable for not controlling their condition ‘for the future’, or that information they are given isn’t actually relevant to someone their age. Disliked activities shared with others with diabetes; YP would like: Some thought age-banded clinics could be helpful  Interactions with staff seemed to be YP overriding concern (over for example, travel or clinic times), positive ones characterised by consistency, civility, rapport, listening, involvement in the consultation, choices, non-judgemental approach, encouraging feedback, facilitating coping skills and access to specialist information, whole person care facilitated by the MDT and age appropriate shifts in consultation style. CONC – “Bringing together a yp with a chronic condition who is still experimenting, exploring and keeping some of their options open with a healthcare system that expects engagement, partnership and adherence that will last a lifetime is an unlikely marriage... developmental tasks of adulthood [include] taking responsibility for self-care ... yp need to be supported to acquire the requisite skills, knowledge and motivation needed to be committed partners in their healthcare”’ p417  ‘key requirements [are] staff consistency and civility, and navigable clinic structures... relevant information and support p417</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dovey-Pearce et al 2005 Diabetes</th>
<th>To describe and understand considered opinions of young adults with diabetes about secondary services Rationale – YP are broadening their focus from ‘tasks of childhood (eg friendships, academic success and community conduct) to include emerging tasks of adulthood (work, intimate relationships, other future life-goals) ...they must receive developmentally appropriate support that takes into acct how their health care goals fit with their other life goals’ p410</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Design MRC guidelines for devp a complex intervention Recruitment via young adult clinic (16-21 yrs) Selection self selecting Data collection interviews w staff, YP and carers on views of care; audit of medical records and survey of YP self reported anxiety, depression + diab related distress; searches for existing evidence on how to improve diab health in young adults Data analysis n/k Reliability + - Validity + -</td>
</tr>
<tr>
<td></td>
<td>Participants 13 staff (details n/k), 27 YP T1D, 18 parents Location Sheffield Children’s age 16-21yrs Gender/ SES/Ethnicity N/K</td>
</tr>
<tr>
<td></td>
<td>Staff described difficulties communicating with YP and using different approaches with yp which yp reported as inconsistent  YP disliked - abstract information which didn’t take account of their lifestyle. - an emphasis on hba1c at the expense of their concerns around how to integrate self care into their daily lives. Parents disliked - feeling sidelined and described family conflict about changing responsibilities for care within the family. Authors report developing a 5 day goal-setting training course for yp (based on DAFNE) with follow up from key workers and a half day for parents; a 4 session parent education course on family communication about diabetes for parents; and agreeing to hold a multi-disciplinary meeting before clinic “to agree care priorities” for each patient in order to inform a more consistent approach</td>
</tr>
<tr>
<td>Marshall et al 2013</td>
<td>Diabetes (schools)</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>To examine the role of nurses in supporting children in school and EY settings (esp in context of intensification of regimens)</td>
<td>Rationale – ‘there is little about how to optimise the quality of ch’s diab care while in school’ p 872</td>
</tr>
<tr>
<td>Design</td>
<td>Qual</td>
</tr>
<tr>
<td>Recruitment</td>
<td>via RCN, YP diabetes community regional diabetes network, Community Ch’s Nursing networks, professional diabetes and Diabetes Research Nurses (Scotland)</td>
</tr>
<tr>
<td>Selection</td>
<td>purposive</td>
</tr>
<tr>
<td>Data collection</td>
<td>focus groups which informed follow up indiv phone interviews</td>
</tr>
<tr>
<td>Data analysis</td>
<td>constant comparison</td>
</tr>
<tr>
<td>Reliability</td>
<td>+ double coding and discussion</td>
</tr>
<tr>
<td>Validity</td>
<td>+ -</td>
</tr>
<tr>
<td>P/pants</td>
<td>47 acute and commun- ity nurses (8 gps, 8 phone interview) all having some patients using intensive therapy</td>
</tr>
<tr>
<td>Location</td>
<td>UK</td>
</tr>
<tr>
<td>Gender / SES/Ethni city</td>
<td>n/k</td>
</tr>
<tr>
<td>Nurses dislike:</td>
<td>- Legal and policy framework - ambiguous and inadequate: As there is no legal duty for school staff to administer medicines, unclear about what could be required of schools - DH ‘best practice guidance’ not legally binding, endorse inclusive education but specify parents have primary responsibility for children’s health; nurses felt they could point Heads to necessity of ‘reasonable adjustments’ under Equality Act 2010 but didn’t know how to enforce this as; Ofsted inspections may not be timed when needed. So nurse negotiated arrangements on a case by case basis, dependant on goodwill – and report school co-operation as unpredictable, depending on the head teacher personal views; they said teachers worried about child protection procedures, litigation, health and safety and physical contact – ‘teachers can’t even touch children even if they get a cut knee’ p 873 ‘I can’t be in a room if a child is going to be half undressed’ p873.</td>
</tr>
<tr>
<td>- How teachers could be scared by hearing from frightened parents at diagnosis; they could lack basic understanding, confusing T1 with T2.</td>
<td></td>
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<tr>
<td>- Lack of suitable locations for injecting and testing.</td>
<td></td>
</tr>
<tr>
<td>- Secondary schools were more problematic, sometimes just seeing their responsibility to provide a place for care, and having different teachers and different places all thru the day could make care complex compared to primary which were easier to deal with cos smaller organisations and children with same teacher in same place all day.</td>
<td></td>
</tr>
<tr>
<td>- Case load - Some tried to do update visits annually tho with increased caseloads this was difficult; some felt school nurses could do more tho others felt they hadn’t capacity</td>
<td></td>
</tr>
<tr>
<td>- Lack of evidence Despite guidance from RCN and Diab UK, they perceived a gap in the evid base on how to work with schools to best support children; they felt they learned to negotiate support for CYP by experience only and all this could lead to variations in practice eg even wide variations in amount of time different nurses spent supporting schools.</td>
<td></td>
</tr>
<tr>
<td>CONC need more evidence about how HCP can influence schools</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Lowes et al 2004</th>
<th>Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>To explore parents’ experiences of having a child diagnosed with T1D, managed at home, over the first year</td>
<td>Rationale – evidence suggests home management safe and cost effective though concerns are expressed about parents coping at time of diagnosis</td>
</tr>
<tr>
<td>Design</td>
<td>qual longitudinal</td>
</tr>
<tr>
<td>Recruitment</td>
<td>via paed unit of S Wales hospital</td>
</tr>
<tr>
<td>Selection</td>
<td>self selecting from pop of parents of newly diagnosed and clinically well (optimum blood glucose level) children Mar 98- Oct 99</td>
</tr>
<tr>
<td>Data collection</td>
<td>3 interviews w/19 parents near diagnosis, 4mths later and a year later; 4 parents single interview at 4 months; 12 parents at 1 year only</td>
</tr>
<tr>
<td>Data analysis</td>
<td>thematic Reliability + -</td>
</tr>
<tr>
<td>Validity</td>
<td>+ interviewed at home, ch not present, 30-90 mins, iterative schedule, taped, full transcription; analysis discussed with participants and other researchers; divergent case analysis</td>
</tr>
<tr>
<td>- Interviewer DSN for 70% children in study</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>38 parents of ch with T1D median age 38 yrs with children median age 9</td>
</tr>
<tr>
<td>Location</td>
<td>S Wales</td>
</tr>
<tr>
<td>Sample size</td>
<td>Children’s age Gender</td>
</tr>
<tr>
<td>SES range of occupations from cleaning to journalism, teaching, engineering Ethnicity white English speaking</td>
<td></td>
</tr>
<tr>
<td>Other information</td>
<td>2 single parent families</td>
</tr>
<tr>
<td>Parents alarmed by speed of referral to secondary care after GP diagnosis (authors conclude ‘even while awaiting confirmation of diagnosis, they needed info’ about the condition and process of diagnosis).</td>
<td>Parents liked:</td>
</tr>
<tr>
<td>All parents wanted to avoid child being hospitalised but 25% initially concerned about going home after diagnosis; most experienced information overload and described prioritising so as to absorb in small chunks, though a small number found the drip feed approach scary – fear of ‘what was to come’</td>
<td></td>
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<tr>
<td>Accessibility to phone advice- very reassuring - within a week half of parents felt more confident about coping and all were pleased their child had not been hospitalised</td>
<td></td>
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<tr>
<td>3 mothers reported acute distress in the second month, grief at diagnosis. 60% of parents felt home management had helped in introducing diabetes as a manageable condition rather than an illness [this sounds like something framed by the interviewer not participants]; all did their utmost to optimise control ‘if we aren’t vigilant now we could store up problems for him later’ p532; and inexplicable lack of control engendered feelings of confusion and fear.</td>
<td></td>
</tr>
<tr>
<td>A year later 68% felt diab was part of daily life and all but one parents felt they were coping most of the time, though hypos at night were a big fear, having to plan everything ahead so closely, and one mum reported having given up working outside the home. 39% parents felt it important diab was not allowed to become too intrusive in children’s lives. A fifth felt home management at diagnosis had helped build their confidence in making the changes to their lives required by the condition.</td>
<td></td>
</tr>
<tr>
<td>CONC – findings don’t support concerns that this model plays down the seriousness of the condition (see for example Scott and Donnelly 2001)</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Price et al 2011</th>
<th>Diabetes (transition)</th>
</tr>
</thead>
<tbody>
<tr>
<td>To</td>
<td>Design qual</td>
</tr>
<tr>
<td>Recruitment</td>
<td>via</td>
</tr>
<tr>
<td>P’ pants</td>
<td>11 YP</td>
</tr>
<tr>
<td>YP disliked:</td>
<td>- A stark change in clinicians’ interaction: ‘there shouldn’t be that much of a</td>
</tr>
</tbody>
</table>
Adolescence is a period of rapid physical, emotional, social, and psychological change. During this time, young people must navigate developmental tasks of adolescence (include) accepting one's body, adopting appropriate social roles, preparing for occupational roles, and developing intimate relationships. The transition from pediatric to adult care is a significant event for young people and requires careful planning and management.

### Framework

A framework was developed to facilitate the transition process. This framework included questions to guide the process, ensuring that young people and their families were involved in decision-making. The framework was designed to support the development of skills, emotional independence, and social responsibility, which are crucial for successful transition.

### Sample

**Pants**

<table>
<thead>
<tr>
<th>Design</th>
<th>P's</th>
<th>Location</th>
</tr>
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<tbody>
<tr>
<td>'Interv</td>
<td>5</td>
<td>N/K</td>
</tr>
<tr>
<td>(and) analysis using a qualitative Framework approach’</td>
<td>dieticians;</td>
<td>(author based in Tynsided)</td>
</tr>
<tr>
<td>1939</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Recruitment:</td>
<td>endocrinologist;</td>
<td>1</td>
</tr>
<tr>
<td>paediatric and</td>
<td>paediatrician;</td>
<td>1</td>
</tr>
<tr>
<td>young adult</td>
<td>1 DSM</td>
<td>1</td>
</tr>
<tr>
<td>clinic</td>
<td>Location N/K</td>
<td>Location N/K</td>
</tr>
<tr>
<td>Selection all</td>
<td>(author based in</td>
<td>Location N/K</td>
</tr>
<tr>
<td>clinic workers in</td>
<td>Tynsided)</td>
<td>Sample size 9</td>
</tr>
<tr>
<td>these clinics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data collection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>semi structured interview</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Data analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>framework</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reliability +</td>
<td></td>
<td></td>
</tr>
<tr>
<td>researchers discussed development of coding framework</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validity +</td>
<td></td>
<td></td>
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<tr>
<td>questions developed out</td>
<td></td>
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### Data

*Price et al 2010*

Diabetes (transition) a transition pathway [TP] implemented comprising 3 planning meetings in paed and a final meeting in adult care, a planning questionnaire at the start to elicit yp's concerns and a handover document to communicate key issues to the adult clinicians at transfer. The study aimed 'to examine the impact on 2 diabetes services of implementing the TP from the point of view of the professionals concerned [and to understand] the changes required at a systems level to adopt and invest fully in the new service’ p492

'Transition should be regarded as a process with ‘transfer’ to adult services as an event within it. Adolescence is a period of rapid change and health transitions are just one of a number that a young person must make as they go through puberty, change schools, and make career decisions.... Managing and preparing for the handover from paediatric to adult health

Although staff turn-over/ sickness meant clinicians couldn’t offer continuity across the transition sessions, some valued the opportunity to engage more ‘holistically’ with yp eg ‘there’s certain things you talk about in transition that aren’t normally asked in my personal consultation with them and you actually find information quite useful’ p494; ‘it’s brought up lots of questions that we should be asking teenagers before we get rid of them... we should be asking a lot of social side around them, a lot about their friends, a lot about their hobbies because we don’t really discuss that unless it comes up in clinic...we’re too busy looking at control and HbA1c’s’ p494; good communication and empathy were felt important not just in transition planning but for good care generally: ‘it sort of being able to appreciate where they are coming from’ p494, though staff identified lack of experience and skills in discussion sensitive topics such as drug/alcohol use and sexual health ‘those aren’t subjects I would naturally tend to discuss’ ‘it feels a bit uncomfortable’ p496

Others saw transition sessions as an add-on detracting from core care ‘there usually seems enough to talk about in a regular consultation because these are often young people whose control is poor and so you’re, you’re trying to find ways of um improving the diabetes control and that tends to be the thing that you concentrate on’ p495; it was felt to by some to require new skills and ways of relating ‘I think the managers need to recognise the skills development and the skills maintenance that their staff need if they’re being asked to do this work’ p494.

Sustaining the TP was seen to require ‘clinic structures to be organized a little differently’ p495, especially in relation to case load and time ‘I have a number of other diabetic patients that need to be seen and transition can take up to an hour and there is also the time involved in dictating transition letters’ p495
services is important in preventing young people from dropping out of services and becoming lost to the healthcare system... evaluations of transition services have largely sought the views of young people and their carers. There has been little investigation of the impact that the development of such services makes on organisations.’ P491-2

of group discussion with potential participants; interviews recorded and transcribed - unattributed quotations (no demo of diversity of responses)

A questionnaire to elicit yp’s priorities about transition was considered useful but the ‘hand-over’ document which paed staff prepared for clinicians in adult care was rarely ready in time, considered too time consuming and with insufficient input from yp: ‘you could have the documentation more compact and have some involvement and ownership from the children’ p495

Newbould, Francis and Smith 2007

Asthma/diabetes

Aims: to examine experiences and concerns of YP and their parents re management of medicines at school

Rationale – ‘despite guidance from government and creation of school policies, difficulties surrounding medication and condition management in schools are still prevalent’ p1078

Design Not explicit

Recruitment: GP surgeries

Selection random surgeries, N/K how CYP selected

Data collection: face to face semi structured interviews at home

Data analysis established qual analytical procedures

Reliability

+ -

Validity

+ interviews at home; taped; full transcription;

- not qual sample strategy: ‘designed to obtain representative sample primary care sample of yp’

Participants 69

YP (43 asthma; 26 diabetes, disease type not specified) and parents (n = n/k)

Location ‘contrasting areas’ in SE Eng

Children’s age 8-15 yrs

Gender 39

boys, 30 girls

SES only 11

parents reported not owning home

Ethnicity: 3

parents ‘non-white’

YP need support from HCP around

- access to their medicines - policies could be a hindrance eg having to keep inhalers elsewhere (‘I’d have to walk all the way to the office’) – other structures eg snacks being forbidden, timing of school lunches, nowhere private to do injections

- teachers being disbelieving and unsympathetic (parents also felt this, and that teachers lacked knowledge).

Parents need support around concerns about:

- medicines being stored away from the classroom which could make access diff in a crisis;

- teachers undermining regimen eg not wanting child to test blood sugar levels;

-liaison with teachers a much greater challenge in secondary school cos of having more than one teacher

CONC protocols in schools should be tailored to YP needs and individual conditions, devised in partnership with YP, parents and school. Authors note guidance on medicines in schools (DH, 2004 NSF) doesn’t clarify teachers’ position if they must help yp with a medical difficulty.

Hummelinck et al 2006

Chronic illness generally

To explore the complexity of parents’ information needs and how current information provision is evaluated.

Rationale: gap between policy/rights agenda emphasis on providing comprehensive information and patient dissatisfaction with this (‘despite widespread dissemination of info materials’

Design qual

Recruitment 45

invitations via paed dept of district general hospital

Selection convenience from parents living with ch 0-16 yrs with chronic condition and at least 1 drug administered daily for minimum of 1 week

Data collection semi structured interviews

Data analysis thematic

Reliability

+ -

Validity

+ taped (or full notes) and full transcription - not clear where interview or who conducted

Participants 27 parents in

20 families (3 families with CYP with diabetes, disease type N/K)

Location W Midlands

Parents of children aged

median 6-10yrs (12 boys, 9 girls)

SES/ Ethnicity

n/k

Other information

median time since diagnosis 2-4 years;

Parents disliked

- having to absorb lot of info at diagnosis and many felt overloaded (especially where condition managed across multi-disciplinary teams)

- feeling confused by jargon or frightened because they could not find answers to their anxieties.

- Conditions managed in primary care (eg asthma) tended to be characterised by concerns about lack of information.

- not knowing how to frame questions as they didn’t know what to ask, what they needed to know until they were in an unfamiliar or critical situation

- feeling most professional communication and info provision inadequate – some described actively seeking out information but one coping strategy was actively resisting information for fear of its negative impact.

In retrospect, parents said they wanted to know

- Explanation for illness

- Understand management (treatment, mechanism of drug action, possible side effects) and possible outcomes

- And practicalities of this in terms of daily care psychological and medical eg medicines supply issues, insurance cover, improving acceptability to children, available support systems/reliable info sources

- Prognosis and potential complications – to prepare for these
| Kirk et al 2012 | Self care support | To determine CYP/carers/HCP perceptions of the effectiveness of different models of self care support and id factors that support/inhibit self care at individual and organisational level; and explore how models integrate with self care support provided by other organisations NB ‘the self in this context is a combination of child and adult carers’ p1975  
Rationale - 'self-care support... in the context of a LTC [is] largely associated with particular interventions [rather than routine care] such as education or skills training [so] constructed largely in terms of the individual patient rather than structural constraints’ p1975 Cites evidence of yp/parents valuing ‘group based self-care for the opportunity they provide to interact with others’ and that ‘e-health methods’ of support have also been found useable and acceptable. But ‘flexibility in provision is needed to enable individuals to access a range of different types of support from both formal and informal self-care resources as well as support that takes account of social-economic and cultural contexts’ p1975. Interventions need to be directed at HCP and systems as well as patients evidence these can improve CYP health status and reduce health service use. | Design | case studies of 6 different models of self-care support  
Recruitment 70 self care support projects identified in previous research  
Selection purposive of projects to reflect diff ways of providing support, condition specific models and general; purposive to maximise variation of children’s ages, support by different types of workers (voluntary, HCP) and to try include those who had dropped out.  
Data collection semi structured phone interviews (except where requested otherwise), observation of self care support activities; relevant documents reviewed  
Data analysis Framework Reliability  
+  
- Validity  
+  
- Evidence only from yp attending organised support groups  
- authors report difficulties recruiting any project ‘drop-outs’;  
- little report of any differences/tension in experiences across diff groups eg YP / carers | P’pants 26 YP (at least 2 known to have diabetes, disease type N/K), 31 carers (26 mothers, 5 fathers) 6 of CYP with diabetes; 36 self care support providers including 6 staff from statutory secondary diabetes team offering a support group for CYP  
Location UK  
Children’s age / Gender / SES / Ethnicity N/K | Organisational inhibitors of self care or access to self care support  
- Parents identified primary schools as problem when children can’t keep supplies with them (undermines regimen) and when schools did not action plans agreed for management.  
- YP identified schools as exacerbating their feelings of difference from peers  
- NHS routine referral to support projects generally reported poor (except to NHS led ones)  
Individual level facilitators of self care support or access to self care projects  
- YP said mothers played central role in encouraging them to attend self care projects and mothers/yp said yp would have to feel ‘ready’ to attend  
- Both reported enjoying a ‘safe place where feeling and experiences could be expressed’  
- Parents wanted to learn about the condition and management strategies and promote children’s independence and described feeling that they’d got this  
- YP described learning how to manage feelings, improve communication with HCP and teachers, and self-confidence and they liked when activities were enjoyable  
CONC – ‘promoting self-care support or an individual child/family basis by HCP and maintaining personal involvement appears to be important factors in encouraging yp to access self-care support’ p1985. |

| Smith, Taylor, Newbould and Keady 2008  
Medicines in school | To examine the experiences and concerns of YP with chronic illness and their parents in managing medicines in school | Design | not explicit Recruitment respiratory, endocrine, rheumatology and gastro, and adolescent outpatients in major London teaching hospital  
Selection 5-19 | Participants 27 YP (11 attending adolescent clinic and 7 endocrine, at least 2 known to have diabetes, disease type N/K), and parents (n=n/k)  
Location London  
Children’s age 5-18 yrs | [Half of yp who spoke about peer relationships] were not comfortable with others knowing about their condition. The wish for secrecy had resulted in some people refusing to take medicines...’ p541. Also problems about not being believed by staff when they needed medicines/supplies, problems getting access without drawing attention to yourself and staff having poor knowledge and awareness of their needs  
Problems also described (not disaggregated by user group) with getting advice when yp feel unwell and lack of help with administration or reminders re medicine taking, if needed, YP and parents wanted better support, esp with prn medicines eg |
Rationale – ‘CYP with chronic illness should be able to lead as normal lives as possible (DH 2004)’ but there is evidence that despite the ‘Supporting Pupils with Medical Needs’ (1996) guidance and from the NSF, CYP experience difficulties in maintaining regimens and administering medicines at school.

<table>
<thead>
<tr>
<th>Gender 17 girls 10 boys</th>
<th>analgesics including:</th>
</tr>
</thead>
<tbody>
<tr>
<td>SES ‘small number’</td>
<td>- access to medicine as needed (and promptly), without drawing attention to yourself</td>
</tr>
<tr>
<td>attending private schools</td>
<td>- somewhere private to administer (half of yp wanted to keep condition secret)</td>
</tr>
<tr>
<td>Ethnicty N/K tho authors report clinics serve diverse populations</td>
<td>- if necessary a designated first aider to oversee, inc on trips (or remind when needed)</td>
</tr>
<tr>
<td>Other information 11 adol medicine, 7 endocrine, 5 rheumatology, 3 respiratory, 1 gastroenterology; 19 YP had regular dosing and ‘prn’ (as needed)</td>
<td>- individual teachers assistance eg to catch up with work after hospital admission</td>
</tr>
</tbody>
</table>
|                         | - flexible application of protocols (eg ‘he let me look after my medicine’)
|                         | CONC – Schools should address separately the needs of yp with prn medicines from those with routine regimen; individually assess yp’s needs (some need privacy others don’t); make sure staff training is in place to address the marked variability in support XP experienced Prescribers should use medicines with one or two doses daily where possible |

**Williams et al 2011**

To identify:
- Types and characteristics of children’s health info resources available; and how they are used
- Preferenc es about type of info/ format; diffs between CYP and families on these
- Diversity of health informati on needs
- Issues around when it is appropri te for CYP to be making choices about their care (at what developm

| Design: Mixed (3 stages, including a qualitative component); Recruitment: hospital out-patient clinics, primary care and home settings, Medicines for Children Research Network (MCRN). Selection: CYP with a specified tracer condition/ long-term conditions/ acute conditions Data collection partial, scoping and illustrative review of lit; exploratory qual study inc observations, focus gps, in-depth interviews with children and key family members Data analysis/synt | Participants: 41 CYP in focus groups (CYD with T1D: 16); 46 CYD interviews (CYD with T1D: 10); 52 family members (mostly mothers, condition n/k); 11 clinicians including 1 DSN Location: not identified SES: no information Ethnicity: CYP from minority ethnic backgrounds purposively sampled (p. 112) but no other information on ethnicity of respondents |

Examples of good care in diabetes eg ‘psychosocial’ as well as ‘biomedical aspects of condition’ addressed and ‘positive relationships’ were built up over time with teenagers p 128. Though generally (including other conditions) HCP focus on gaining adherence to treatment rather than exploring causes of non-compliance... strong question and answer approach to consultations where the opportunity was not taken to explore or discuss underlying problems... ‘p125 Care could be ‘insensitive, unsympathetic, and not responsive to needs’ ‘Excellent child-centred approaches were exception rather than rule (p.126). eg ’It was me who pushed for [young person] to go... on four injections and they weren’t happy when I... I pushed and pushed and pushed for it. (Mother of 9 year old male p157), advice given to help manage her newly diagnosed son’s reaction and behaviour to developing Diabetes: ‘Oh put him on the naughty step’ - Nurse psychologist (Mother of 9 year old boy with Diabetes). P157 Exclusion of children from consultations ‘[re play] there was a tendency for children especially younger children to be distracted by toys and play and facilitation did not always focus on engaging children in consultations [during which] they were situated at the periphery and sometimes not involved at all... partnership sometimes appeared to be perceived by HCP as engaging the child in play whilst professionals and parents discussed the child... we saw a huge variation in practice and different ideas about what child and family-centred care looks like... ’ Information: ‘fully appreciating the complexities of one’s disease is in part a function of the information one is given’ p151; ‘information was almost always given verbally with little written back up’ p 125 eg re insulin ‘I only really started to find out what it did, I knew it lowered your blood sugar but I didn’t know why it did that... I was told about 6 weeks ago... now I know that it turns it into glycogen and stores it as fat so I have a bit of a better understanding of it’ 17 yr old male p151. Authors feel knowledge creates responsibility: ‘Child development also implies that children’s level of comprehension increases over time during the long-term condition trajectory, particularly if they were diagnosed quite young and excluded from information provision. We found that increasing comprehension was linked to capacity to take more responsibility. A key aspect to facilitation was that healthcare professionals were able to assess the level of comprehension and capacity’ of individual children – though information isn’t seen as only influence eg ‘healthcare professional commented that dietary behaviour in diabetes was modelled in families and therefore the family culture would need to adjust to accommodate that of a child’ p154 Authors see HCP as well as parents as crucial in ‘maximising receptivity of information by the child’ eg helpful when ‘HCP directed questions to the child in consultations rather than the ‘top and tail approach’ (addressing child in general manner at the beginning and end of the consultation):

This had to be positive and inspirational not punitive interaction: ‘... it’s like when you go to school and you find a teacher that ... you get on with and ...respect, you look up to, you learn a lot more from them, ... it’s the same with a situation like this, if you feel somebody chastising you all the time and not being positive about anything you do you ... you’re not
| Boden et al 2012 | Design | Qualitative Recruitment via schools in trust area identified as having child with diabetes; | Participants | Staff anxious especially about |
| | | | 22 primary staff (heads, teachers, TAs) from 13 | - injecting and testing (eg compared to asthma where no needles) |
| Diabetes (school) | | | | - having to be constantly monitoring child and checking following regimen |
| | | | | - where they stand legally if they are judged not to have done the right thing |
| | | | | - children’s potential to “cheat” and “manufacture hypos” and that some parents |

'Diabetes takes a normal child and puts it in a very abnormal situation, it is not normal to have to stick yourself with needles every day, prick your finger and stick to a diet ... we need to celebrate any success, even if it’s a small amount of success. DSN

‘Offering choice’ is seen as central to ‘the encouragement of independence and self-care management ‘p146 such as whether to stay in hospital or go home at diagnosis Authors feel yp with diabetes (and CF) especially struggle during teenage years: YP describes the irony of how yp take on more responsibility for their physical care just at a time when they find it especially compromising to their social health ‘being young, really young is fine because you kind of let people do what they want. And then you get to that age when you start making decisions yourself you don’t want to feel different from everyone else -- so you do the least you can.’

So for parents ‘this involves a process of stepping back to encourage responsibility... but stepping in to prevent deterioration’ and trying to stop themselves from ‘nagging’ ‘they don’t want that’ p143-5. eg: ‘I try and give her that little bit of independence but she knows she can always fall back and ask my advice. But I’m there always overlooking her from a distance.’ Mother of 11 year old girl with diabetes p 144

DSN described some parents as finding transition very hard. Another key concern for parents was the loss of the connection and rapport with children’s services, as well as the desire to stay at the children’s hospital where the adult service was deemed inappropriate for a young person. P164

Style/content and timing of information resources: CYP with diabetes in focus groups wanted real narratives and images tailored to their own age, stage of illness trajectory (those just diagnosed wanted different information from those with more experience) and individual lifestyle and interests across home and family, and school or college - not cartoons, nor on DVDs actors pretending eg ‘it shows you people injecting insulin and its real’ Girl and including ‘well known people living with the same condition as them to act as positive role models’ p116

CYP saw picture/text ratio as indicating targeted age-group: ‘it’s not like filled full of cartoons all over it, it’s got one or two pictures which is okay so you sort of know its aimed... well teenage years’ p 118. Generally younger children (below 10 years) expected more pictures and less text: ‘I wouldn’t really enjoy it because its just basically lots of text and not much pictures’ Girl p118

Although ‘the language [appropriate] for a 7 year old was not the same as for a 10 year old [and it] was also clear that age can be a factor with treatment, e.g. the size of a tablet to be swallowed’ p153, parents and HCP challenged the idea that age and maturity align since some children did their own injections at 8 while others still needed help at 15.... We found that levels of comprehension for children were highly variable’ p 151 Eg. ‘We saw that children of a relatively young age can show extraordinary maturity and adaptabilityp153

Not disaggregated by participant group: At diagnosis users wanted information on the condition and treatment plan, how to manage own treatment and self-care, who to contact if unsure/problems. In short- and medium term they wanted info on - medicines and lifestyle management in different settings; interventions to promote medication concordance and blood glucose testing; staying healthy; managing hypos. In long-term, info on transition, long-term consequences of medication/treatment concordance and need to actively manage health. Users wanted up to date information on Diabetes treatments and described purchasing additional information e.g. carbohydrate counting – titrating insulin to carb intake was a challenge for most participants. Users also flagged importance of timely info eg alcohol and Diabetes.

Diabetes info was reported in variety of formats. Eg Trust in-house leaflets, pharmaceutical leaflets, Diabetes UK (range of age-appropriate magazines), structured educational and interactive/activity programmes. It wasn’t just written info that mattered but clinicians eg dietician , CNS – crucial in ongoing supportive and information provision role. Peer support mattered especially in meeting challenges of managing at school.

CONC - CYP health information resources need to be realistic, tailored and involve CYP in development. Written information should support verbal information and needs to be detailed but not too scientific and up-to-date.
| Aim: to examine concerns of primary school staff caring for children with diabetes in and relate these to views of local HCP | Rationale – if the care of children with diabetes is to be improved ‘we need to know teachers views/expperiences’ and HCP via trust Selection staff self selected; HCP with clinical responsibility for children in those schools. Data collection in depth, semi structure face to face interviews Data analysis structured (anticipated) and iterative thematic approach Reliability + - Validity + taped and transcribed in full; interviewer social scientist, not diabetes specialist - | Design “semi structured interviews” Recruitment via paed and adolescent clinic Selection self-selecting from parents of all CYP except those with co-morbidities and diagnosis less than 1 year Exclusions no co-morbidities or diagnosed less than 1 year Data collection semi structured phone interview Data analysis IPA (NB not IPA data collection) Reliability + - Validity + interviews piloted (not clear if any amendments) - interviews sound structured; incorporate a lot of closed questions as well as open; short - 8 minutes on phone | P’pants 64 parents (62 mothers) Location N/K (central London clinic) SES/Ethnicity n/k 81% interested; of these 1/3 wanted a CYP group; only 15% a parent group and only 11% a family group; nearly a quarter would prefer individual work; They said groups would be useful to get practical knowledge and swap ideas, share experiences with others and get more confident (and CYP more confident) about managing; and there was a strong preference to time groups to coincide with clinic visits, alternatively at weekends.. Parents said reasons for not attending would be feeling like they were already doing well, school demands, using online or other local support, feeling uncomfortable speaking in a group and CYP dislike of doing any more diabetes related activities than they absolutely have to ‘My daughter feels that having diabetes does not mean she has to hang out with others who also have diabetes’ p391 CONC – ‘there is a belief that groups are more cost effective than individual work ‘ but ‘the challenge of creating the right kinds of groups has not been resolved’; ‘Trying to get the age, gender and culture mix right can be time consuming and prevent groups from taking place’ p392 |
| Christie et al 2008 Diabetes (psychological support) | | | |
| Aim: to explore potential interest in psychological support groups in ch and adol diab service | Rationale – groups are ‘often attractive to yp’ and an opportunity for them to ‘receive a range of models and feedback about different behaviours’; this study was to explore ‘potential uptake of regular support groups’ | Design qualitative Recruitment via IDF youth ambassadors and DAWN youth ambassadors Selection purposive (criteria not specified) | P’pants 5 yp 18-26 yrs (disease type n/k) Location N/K – lead author based in At diagnosis yp reported feeling overwhelmed ‘at prospect of tackling a complex lifelong illness. All remember hearing little of what was said to them in their first meetings with health professionals. P51 ‘All remember struggling to maintain their management of diabetes brought on... by manipulation of their new status as ‘ill person’... how they learnt to play the system’ p51. HCP should know - Making healthy life choices ‘needed to be individually packaged to suit each... |
### Waller 2005

**Aim:** to seek the views of CYP with T1D and their parents regarding the acceptability of a new programme (for intensive insulin therapy i.e. DAFNE) structured education course and practical education

<table>
<thead>
<tr>
<th>Design</th>
<th>’a focus group analysis’</th>
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<tbody>
<tr>
<td>Recruitment</td>
<td>via diabetes clinic lists</td>
</tr>
<tr>
<td>Selection</td>
<td>90 x CYP 11 – 16 years, diagnosed for at least a year, English speaking</td>
</tr>
<tr>
<td>Exclusions</td>
<td>those on pump therapy or with ‘known behavioural problems’ p284</td>
</tr>
<tr>
<td>Data collection</td>
<td>8 focus groups at clinic building</td>
</tr>
<tr>
<td>P’pants</td>
<td>24 children T1D and 29 parents</td>
</tr>
<tr>
<td>Gender</td>
<td>12 boys; 12 girls; 8 fathers, 21 mothers</td>
</tr>
<tr>
<td>Age</td>
<td>11-16 yrs mean 13.5 yrs</td>
</tr>
<tr>
<td>Location</td>
<td>Scotland but ‘ambassadors’ are international</td>
</tr>
<tr>
<td>SES/Ethnicity</td>
<td>not known</td>
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yp’s findings:
- ‘you need to be given the opportunity to learn the process, the trial and error’ p52;
- ‘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’ p54 asking yp ‘instead of like my old doctor, who might say something general like you need to eat less’, she asked, where to do you think the best place to start because you can’t do it all at once’ p52
- ‘I don’t really care if I see a doctor because they often don’t tell me that much... they’re often more focussed on your doses or how many times you test your blood sugars, and that’s not really what I come for. I’m worried about the small problems that turn really big. Whereas [doctors] have difficulty seeing the patterns in how certain things you do may be affecting control. I think nurses are better at seeing that because they see you for a longer time’ p54
- Advice that doesn’t fit the yp’s needs often felt unrealistic and to be ignored ‘It’s a vicious circle, when the clinicians say you have to improve your levels it makes you more stressed
- Yp live with fear of diabetes on a daily basis: shock tactics only increase stress not management
- Continuity at clinic apt with the same HCP is crucial – ‘what’s really stressful is that it doesn’t really matter if you go [to clinic] 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’ p53
- The yp’s social network is always important (boyfriends/girlfriends not just parents) ‘HCP need to be better equipped to deal w different families. Some are illiterate or in awe of the medical profession...’ p52
- Diabetes fatigue means yp need a family member to take over part of management every so often
- Yp’s movement towards independence in life generally as well as diabetes will not be linear and can shift almost daily across different aspects of their lives: moving towards young adulthood needs to be tailored to individual needs and decisions made in partnership not something to be decided upon alone
- Awareness of ‘diabetes communities’ might help feel less isolated and cope with stigma
- Other: ‘I’m lucky I can phone my centre any day and send my pump readings down the phone and they can ring me back to discuss them’ p53; ‘if you only have 10 mins you need to use the time effectively... you have to act pretty fast and that’s difficult for most people’ p54
- A code of conduct is important between HCP, YP and members of their social network which includes details for wider family about how diabetes affects your mood or how you would like them to manage it (eg in public) and details of doses etc ‘so you parents take some of the responsibility for a while...’ p53

### Rationale

‘A patient promoting methods for acceptability...’ p50

### Methods

- Waller 2005
  - [45 – 75 min phone interviews](https://example.com)
  - **Data analysis** thematic, but no detail of processes
  - **Reliability** +
  - **Validity** + taped, field notes taken during and after; lot of direct quotation from yp
  - ‘these yp are not necessarily representative of a general population of yp with diabetes’ p50 authors say this because they have all ‘achieved relatively effective management’ but surely their having volunteered as ambassadors for the programme is an issue to - Criterias for purposive sampling not reported

#### Waller 2005

- Aims
  - To indicate acceptability and feasible methods for promoting patient-centred care
  - To facilitate [resources] that HCP can use to support yp’s self-management of their diabetes

- Research has tended to focus on the problems associated with yp’s poor management of diabetes and the challenges faced by HCP delivering services for them. Less well explored are the insights and guidance directly from the yp

- **Participants**
  - yp’s: 21 girls; 12 boys; 29 parents
  - yp’s aged 12 yrs – 16 yrs
  - yp’s diagnosed for at least a year, English speaking

- **Location**
  - Scotland but ‘ambassadors’ are international

- **Methods**
  - **Data collection** 8 focus groups at clinic building
  - **Data analysis** thematic, but no detail of processes
  - **Reliability** +
  - **Validity** + taped, field notes taken during and after; lot of direct quotation from yp
  - ‘these yp are not necessarily representative of a general population of yp with diabetes’ p50 authors say this because they have all ‘achieved relatively effective management’ but surely their having volunteered as ambassadors for the programme is an issue to - Criterias for purposive sampling not reported

- **Recruitment**
  - via diabetes clinic lists
  - Selection 90 x CYP 11 – 16 years, diagnosed for at least a year, English speaking
  - Exclusions those on pump therapy or with ‘known behavioural problems’ p284

- **Sampling**
  - purposive sampling

- **Analysis**
  - thematic, but no detail of processes

#### Data collection

- **Sampling**
  - purposive sampling

- **Analysis**
  - thematic, but no detail of processes

#### Data analysis

- **Sampling**
  - purposive sampling

- **Analysis**
  - thematic, but no detail of processes

#### Reliability

- **Sampling**
  - purposive sampling

- **Analysis**
  - thematic, but no detail of processes
<table>
<thead>
<tr>
<th>aspects around design and delivery.</th>
<th>Data analysis emergent themes summarised</th>
<th>n Sheffiel d SES/Eth nicity n/k</th>
<th>better than family groups</th>
</tr>
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<tbody>
<tr>
<td>Rationale 'There is increasing evidence that even brief periods of poor control accelerate the onset or progression of microvascular complications … Consequently educational interventions are advocated to improve knowledge, self-care and ultimately glycaemic control’ p283</td>
<td><strong>Reliability</strong> + double coding and analysis checked with group moderators <strong>Validity</strong> + taped and full transcription; during group, key ideas recorded on a flip chart; 2 moderators - Group held at clinic building</td>
<td>Parents concerns - Not about ‘physical act of injecting or testing [but] children coping when they are away from them eg the commotion in schools… and lack of understanding of diabetes as its management’ ‘teachers didn’t know for 2 years that he was diabetic even though I’d written a letter’ p286</td>
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| | | YP liked - That intensive therapy would allow them to ‘act and feel more similar to peers’ p 286 ‘this could make us as normal as a normal person without diabetes’– focussed on QoL, didn’t mention benefits to glycaemic control or long-term health - group education is good because ‘you get to talk to other people and you get to know what they do and then it makes you think I should be doing that p 286 - information /education should be interesting and enjoyable without ‘tests’ and with outside ‘fun’ activities to ‘allow time away from… diabetes’ - it should be practically based not didactic (parents agreed) - Children thought structured course should be during school time to preserve their free time and a child with experience take part to motivate them - Both groups happy to have structured education at clinic as long as there was some time away from it and the atmosphere was relaxed; and would like member of their diabetes team present - and both thought learning groups structured by generation better than family groups YP concerns - Like parents, not about ‘physical act of injecting or testing’; what matters is privacy (‘I wouldn’t want everybody looking at me like I’ve got half a face or something’ p 286) and minimising interruptions (‘… you couldn’t have your whole break’ p286) - felt information /education structured update sessions don’t teach anything new formally (though informally learned ‘by being with similar others rather than through what was taught’p287 - Jargon and recommendations directed at parents meant comm - Information overload at diagnosis ‘a massive cram of information’ p287 Not possible to disaggregate across user groups - parents and YP: ‘happy’ with current info and support from staff ‘friendly and accessible’ – could cope with longer intensive structured education as long as days structured like school day | Waller et al 2008

**Aim:** to pilot a 5 day educational programme for CYP with T1D

**Prog re carb counting and dose adjustment (intensive insulin therapy) held in 3 local secondary schools**

**Rationale – intensive therapy is recommended for all patients. However tight glycaemic control is difficult to achieve and moving to multiple daily injections does not necessarily improve control**

**Design** not explicit – mixed methods ‘pilot’

**Recruitment** via ‘3 UK diabetes centres’

**Selection from 188 x CYP 11-16 yrs with at least one year diagnosis T1D**

**Exclusions** ‘children with learning behavioural or lang diffs… since the course involves group interaction’ p928

**Data collection** semi-struc interviews

**Data analysis** ‘content analysis’ and ‘thematic analysis’

**Reliability** + selected double coding +

**Validity** + taped and transcribed

- No information on relation of interviewee with participants, any efforts to put participants at ease during interview or

**P’pants 48 11-16 CYP and their parents (n = n/k), from 55 families who took the course**

**Location** Manchester, Derby, Sheffield

**SES 12 ‘wealthy achievers’; 3 ‘urban prosperity’; 12 ‘comfortably off’ 6 ‘moderate means’ 12 ‘hard-pressed’

**Ethnicity** 47 white; 1 ‘mixed race’

Parents like

Flexible regimen ‘it’s not fun thinking the kids at school are having pudding and she can’t’ or ‘he had his first sweets in 9 years… he’d been cheating beforehand’ p929

YP want

‘anything to help me with my diab control cos I’m not good at it ’ M16

Greater independence – ‘I’m going on holiday with the school’ They like improved sugars from intensive management ‘my sugars have been a lot better’ p929

And improved independence ‘my mum used to do a lot of… my stuff… but now I can do it myself’ p929

Parents concerns

- intensive regimen will be difficult eg having to ‘read packets’

- After course some reported needles not a problem but some children could find carb counting hard ‘she’s not fantastic at maths’ and others difficulty with stabilising control; others found commitment of course too much – ‘I just had too much on’ –929

YP fears

- That intensive regimen will be difficult eg ‘more needles’

- Missing school work for course

CONC Reasons for taking part inc’d better control, skills and QoL, tho some fears round more injections/testing, management during school time, and learning to carb count and adjust insulin. Afterwards greater dietary freedom, independence and child responsibility were reported… ‘our failure to observe a fall in HbA1c levels was disappointing’ p930
<table>
<thead>
<tr>
<th>Knowles et al 2006*</th>
<th>Brierley et al 2012</th>
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<tr>
<td><strong>Aim:</strong> to adapt the adult DAFNE course to design a skills training course for children 11-16 years focussing on self-management within an intensive insulin regimen, and ensure that the course ‘meets the developmental, intellectual and social needs of children and adolescents and is delivered using educationally sound techniques’ p322</td>
<td><strong>Aim:</strong> ‘to describe staff views about challenges working with this age group (16-21 years)... the strengths and limitations of current provision and working with y adults’ NB current provision includes paed clinics with consultants, 2 DSNs, psychological support on ad hoc, transfer to transition clinics as suits but definitely by age 16. Transition clinics staffed by paed and adult consultants, with DSNs and dietician monthly at 2 hospitals in diff parts of city.</td>
</tr>
<tr>
<td><strong>Rationale</strong> - Evidence-based structured education is recommended for all people with diabetes tailored to meet their personal needs and learning styles p 322</td>
<td><strong>Rationale</strong> – yp with T1D experience difficulties achieving glucose targets. Clinic attendance can be poor, although health and self-care tend to be better among those who attend regularly... Good self-care may also be hindered by adolescent lifestyles, adoption of risk-taking behaviour, susceptibility to peer influence and inadequate communication btw y adults and their family about responsibilities for self-care... [the difficulties of] finding ways to integrate diabetes care into everyday life with</td>
</tr>
<tr>
<td><strong>Design</strong> 'a focus group evaluation’ <strong>Recruitment via</strong> diab clinic lists <strong>Selection</strong> 90 x CYP 11 – 16 years, diagnosed for at least a year, English speaking <strong>Exclusions</strong> those on pump therapy or with ‘known behavioural problems’ p284 <strong>Data collection</strong> focus groups with 2 moderators <strong>Data analysis</strong> n/k <strong>Reliability</strong> + <strong>Validity</strong> + taped and transcribed - Details of methods not included but this is a summary of more detailed paper Waller et al 2005</td>
<td><strong>Design</strong> Recruitment via diabetes team <strong>Selection</strong> self selection (3 non-responders) <strong>Data collection</strong> in depth semi-structured interviews <strong>Data analysis</strong> constant comparative, themes emerging from data <strong>Reliability</strong> + double coding; data management software; explicit about theories of adolescence - <strong>Validity</strong> + interviewer independent researcher <strong>P’pants</strong> 14 staff (8 men) from diabetes care (1 clinical lead, 4 consultants, 4 nurses, 3 dieticians, 1 registrar, 1 psychologist ); 4 worked in paed and transition; 3 in paed, 7 in transition team <strong>Location</strong> Sheffield <strong>SES/Ethnicity</strong> n/k <strong>Staff liked</strong> - Sense of helping ‘the achievement of a successful adult life’ p678 ‘I love em... they come along and joke and you hear all about the traumas in their life’</td>
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minimal intrusion... may be compounded by normative issues characteristic of development (Elkind 1967 Egotism in adolescence)’ p 677

‘Four key service indicators have been identified as contributing to adequate glycaemic control in y adults... access to specialist care, number of clinic visits, access to care from a MDT and regular phone contact (Hatherly et al 2009)

were reluctant to give clear messages as they were not sure if colleagues adopted the same approach. Time pressures in the clinic meant there was no opportunity to resolve some of these differences or work through how different approaches might be used to optimise rather than undermine care’ p679

- Lack of communication between paed and transition team ‘info accumulated by the paed team is lost in the transition process’ p679

Staff saw solution to include
- Making clinic less ‘clinical’ and more ‘user friendly’
- Supervision for staff including addressing emotional need and improving skills/knowledge for better communication with each other and yp
- Each yp to be allocated key worker ‘to ensure continuity of care’ and offer ‘greater flexibility in terms of how and when y adults were seen and better indicator of individual need for special support’ tho difficult to cover during staff illness and to cater for registrars need to gain range of experience
- ‘Individualised care for y adults tailored to their individual developmental needs and education levels [including] education about T1D and its management, bearing in mind most y adults diagnosed as children and education directed at parents’. P680

CONC – ‘[staff] understand that managing diabetes and living a ‘normal’ life are not readily compatible [and] struggle to find ways in which young adults can achieve both and disagree about whether or not it is possible at all... they differed in their views about how best ot achieve a service that more optimally met the needs of y adults but the overwhelming consensus was for greater patient-centred care.... Successful management of T1D involves not only correctly balancing insulin and blood sugar but recognition of individual lifestyle and changing needs for education.’ P680