Appendix 6: Synthesis data extraction table

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

Multiple papers on same study marked with the same superscript number

Study Condition, population or service Aims/ question Rationale	**Methods** Design Recruitment Selection Exclusion Data collection Data analysis **Reliability + -** eg theories clear; data management software; team discussion of coding/dble coding; methods reporting; discussion of changes in context **Validity + -** eg taping; pilots; participants at ease; triangulation; thick description	**Sample characteristics** Participants /sample size Location Children's age range Gender SES Ethnicity	Findings **which contribute to synthesis question of what makes 'good' or 'bad' LTC** (close to original text)

Allen et al 2011[1] **T1D** (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 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	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…' p999 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; p 998 - 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 (tho 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

Allen et al 2012[1] **Diabetes** (transition)	**Design case study** **Recruitment:** via diabetes services in England in the Directory of Diabetes Care **Selection: at service**	**P'pants** 38 HCP (details n/k); 46 YP T1D and 39	Users wanted (nearly verbatim) transition care that is - 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

Aims: To id mechan-isms that help smooth transition , service compon-ents thru which these can be achieved and their interrela-tions Rationale – gap btw g'lines and 'evidence to inform service commis-sioning' p141	**level,** purposive by transition arrangements; yp by gender and transition arrangements **Data collection:** interviews with HCP with 'selected observations'; 46 case studies with yp and families comprising 3 interviews over a year/18mths including discussion of medical record; survey with 82 YP and carers; costs analysis **Data analysis of interviews with HCP and families not reported** **Reliability** **+** - **Validity** **+** flexible schedules to take into account emerging analysis; taped interviews - not clear if 'selected observations' means during HCP interviews or of something else; difficulties recruiting CYP - Authors report difficulties recruiting	carers in case studies; 82 YP and carers surveyed **Location** English diabetes services **Gender/ SES/ Ethnicity** N/K	b) *Longitudinal* – Both yp and carers wanted 'uninterrupted relationships with providers over time, consistent with need' These in turn are supported if care has the following 2 characteristics: c) *Flexible* – see for example f) Staff and carers enthusiastic about structured education, YP not. YP wanted one-stop shop info/education events at same time as clinics, and not keen on peer based support: 'staff aspired to develop [the formal education] component of the service. However, whereas carers viewed formal education favourably yp were less enthusiastic. Most were reluctant to attend events beyond routine clinic appts and few expressed a desire for peer-based support' p144. Authors conclude service funding arrangement should facilitate young adults' needs for higher levels of on-going support d) *Management continuity* – through a common purpose and treatment plan: either mothers or cyp report that the usual mechanism of 'formal written communication' between teams 'tends to be exclusively clinical and experiences of transition are deeply embedded in psychosocial understanding which I s why relations/longitudinal continuity are so important' p 143. Mothers described doing a lot of work ensuring this tho found this difficult where they no longer attended appt with yp after transfer; one service improved management continuity via appointment of a 'transition nurse' to span both services Users also wanted (not disaggregated) *e)Cultural continuity* - Seamless progression from child to adult service culture – Not clear who this is from, but services led by clinicians with a commitment to adolescent health were felt to have high cultural continuity – so clinical leadership is essential to getting continuity here *f)Developmental continuity*- Care that proactively supports yp to develop physically, psychologically and socially (usually info round 'risk issues' like alcohol, pregnancy, drugs etc) : yp and carers felt services with graduated transfer could work flexibly in relation to yp's needs (which they valued) - rather than all at once as tended to happen in models with discrete one-step transfer which tended to put more emphasis on 'preparedness to leave children's services' at the expense of yp setting 'the pace of their own development' p 144 *g)Informational continuity* – Feedback from YP and carers suggests provision of info to prepare for new service arrangements must be especially high where a) and b) are lacking, eg where there is a complete rather than graduated transfer to new clinicians; and also to explain the rationale for joint adult/paed clinics which yp report confusing Authors found services with high levels of a) and b) (eg small, co-located teams or where clinicians don't change) needed only informal, low cost informational and management continuity mechanisms, whereas services with low a) + b) needed to invest in more formal mechanisms to support transfer, eg good written information CONC- Authors highlight synergy with other evidence on the importance of acknowledging young people's 'life situation' and problems with 'the neglect of carers' p146; 'while the progression to lone consulting was a key developmental milestone for young people, many mothers felt cut off from the process' p146:

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 **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 bio-medical 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.

		Bengali British	

Dovey-Pearce et al 2005 Diabetes 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	**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	**Participants** 19 young adults with diabetes (disease type not specified); **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

Eiser et al 2013 **Diabetes** To use MRC guidelines on complex interventions to develop an intervention to improve physical and psychological health among yp with T1D 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	**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 +** -	**Participants** 13 staff (details n/k), 27 YP T1D, 18 parents **Location** Sheffield **Children's age** 16-21yrs **Gender/ SES/ Ethnicity** n/k	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

Marshall et al 2013 **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 community nurses (8 gps, 8 phone interview) all having some patients using intensive therapy **Location** UK **Gender / SES/Ethnicity** 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 tho with increased caseloads this was difficult; some felt school nurses could do more tho others felt they hadn't capacity - 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

Lowes et al 2004 **Diabetes** 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	**Design** qual longitudinal **Recruitment** via paed unit of S 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** S 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 aren't 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 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. CONC – findings don't support concerns that this model plays down the seriousness of the condition (see for example Scott and Donnelly 2001)

Price et al 2011 **Diabetes** (transition)	**Design** qual **Recruitment:** via	**P' pants** 11 YP	YP disliked: - A stark change in clinicians' interaction: 'there shouldn't be that much of a

To evaluate a transition model and explore elements YP 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	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)	T1D **Location** N/K (author based in Tyneside) **Sample size** **Children’s age** 16-18 yrs **Gender/ SES/ Ethnicity** N/K	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 prof 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… profs 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’

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 hand-over 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	**Design** ‘interviews [and] analysis using a qualitative Framework approach’ p1939 **Recruitment:** paediatric and young adult clinic **Selection** all clinicians working in these clinics **Data collection** semi structured interview **Data analysis** framework **Reliability +** researchers discussed development of coding framework - **Validity +** questions developed out	**P’ pants** 5 dieticians; 1 psychologist; 1 endocrinologist; 1 paediatrician; 1 DSM **Location** N/K (author based in Tyneside) **Sample size** 9	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’ p494; 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 orgnanisations.’ 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 is 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

		conditions including asthma, diabetes, CF, epilepsy (including with special needs),eczema, cancers	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

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.	years in f/t education (postal invite) **Data collection** face to face semi structured interviews (at clinic) **Data analysis** constant comparative **Reliability + -** **Validity +** taped and verbatim transcription; interviews co-ordinated with consultation timings - interview at clinic	**Gender** 17 girls 10 boys **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)	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 u p 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

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 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*

ental 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	**hesis:** mixed-method evidence integration. **Reliability:** **+** interview data analysis well described on p. 113; + facilitated by discussion; + use of coding frameworks; +and use of software +use of theoretical frameworks; **Validity** + clear methods reporting + extensive discussion of findings/implications - difficulties recruiting CYP - total sample sizes not clear, only reported by type of data collection eg 41 CYP in focus groups, 46 CYP interviewed, not clear to what extent these are different young people		*going to enjoy … coming* (Mother of 17 year old male with Diabetes) p155 *'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 life-style 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.

Boden et al 2012 **Diabetes** (school)	**Design** Qualitative **Recruitment** via schools in trust area identified as having child with diabetes;	**Participants** 22 primary staff (heads, teachers, TAs) from 13	Staff anxious especially about - injecting and testing (eg compared to asthma where no needles) - 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

Aim: to examine concerns of primary school staff caring for children w/ diabetes in and relate these to views of local HCP Rationale – if the care of ch with diabetes is to be improved' we need to know teachers views/experiences	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 -	schools; 5 HCP ('in a range of posts from the local trust') **Location** Coventry and Warwickshire **SES** (teachers including some heads, TAs, not clear which health profs) **Ethnicity** 'multi-ethnic' area	were over-protective in ways that prevented children managing their condition more independently Some felt specific diabetes training might reduce their anxiety and improve confidence (this could include dieticians meeting with dinner ladies and playground assistants) - or having a teacher with particular experience appointed a 'diabetes expert' to advise others HCP concerned - some schools 'purposely withdraw themselves from external sources of help and advice' in order to avoid having to take on responsibility for children with diabetes - teachers inability to spot hypos and react in time - flexibility of primary school timetable making in diff for children and parents to plan regimen in school - overprotective parents who expected staff to do everything - communication books between teachers, parents and HCP were felt by HCP and teachers as possible way forward to improve communication (and 'evidence' should something go wrong, by teachers) - HCP also flagged importance of access to psychology services for children and family as part of diabetes routine care. - one HCP felt that schools should rethink policies which restricted children's access to their medical supplies. CONC Improved access to info on diabetes, staff training and better communication btw schools, HCP and parents are all important.

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** "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 swop 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

Greene 2009 **What HCP can do – a view from YP with diabetes** **Aim:**	**Design** qualitative **Recruitment** via IDF youth ambassadors and DAWN youth ambassadors **Selection** purposive (criteria not	**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

To indicate acceptability and feasible methods for promoting patient-centred care Rationale 'A key outcome of DAWN Youth…is 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 t/selves' p50	explained) **Data collection** 45 – 75 min phone interviews **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' p 50 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 - Criteria for purposive sampling not reported	Scotland but 'ambassadors' are international **SES/Ethnicity –** not known	yp'p51 eg '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' p 53; '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

Waller 2005[2] **Aim:** to seek the views of CYP with T1D and their parents regarding the acceptability of a new programme (for intensive insulin therapy ie DAFNE structured education course) and practical	**Design** 'a focus group analysis' **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 **Data collection** 8 focus groups at clinic building	**P'pants** 24 children T1D and 29 parents **Gender** 12 boys; 12 girls; 8 fathers, 21 mothers **Age 11-16 yrs** mean 13.5 yrs **Locatio**	Parents liked - The intensive therapy would 'allow more freedom and spontaneity' p 286 and is 'just normal' 'more flexibility all round' eg late nights, lie ins, not having to do snacks – focussed on QoL, didn't mention benefits to glycaemic control or long-term health, in fact on that basis 'if your child's got good HbA1c anyway would you want to interfere with it' p286 (authors: 'somewhat laissez-faire attitude')! - YP liked skills learning from group work (see below) but mum emphasised ''she thought 'she's not the only one' - Parents wanted education that was fun, with time off from diabetes and 'practically based', with IT based ref material for follow up which they thought children would be more likely to engage with - Agreed with children education course during school hours okay – as long as not during exams - Thought an older teenager with experience should be present to motivate children – also a separate less intense course for children - Both parents and CYP 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

aspects around design and delivery. 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	**Data analysis** emergent themes summarised **Reliability +** double coding and analysis checked with group moderators **Validity** **+** taped and full transcription; during group, key ideas recorded on a flip chart; 2 moderators - Group held at clinic building	**n** Sheffield **SES/Ethnicity n/k**	better than family groups 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 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 communication with medical staff was difficult - 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 CONC – authors say parents were worried about children’s capacity to cope

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 ‘its 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

unless it is introduced in parallel with structured educqtion' p927	data management; analysis processes unclear - Collecting quant including biomedical eg HbA1c, height and weight, QoL		

Knowles et al 2006[2] Aim: 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 Rationale - Evidence-based structured education is recommended for all people with diabetes tailored to meet their personal needs and learning styles p 322	**Design** 'a focus group evaluation' **Recruitment via** diab 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 **Data collection** focus groups with 2 moderators **Data analysis** n/k **Reliability + -** **Validity +** taped and transcribed - Details of methods not included but this is a summary of more detailed paper Waller et al 2005	**P'pants** 24 children T1D and 29 parents **Gender** 12 boys; 12 girls; 8 fathers, 21 mothers **Age 11-16 yrs** mean 13.5 yrs **Location** Sheffield **SES/Ethnicity n/k**	Parents' anxieties included children's ability to cope especially in school, and concerns that greater dietary freedom would lead to less healthy food choices. They liked potential to improve QoL, despite increased testing and injections CYP views not differentiated from parents.

Brierley et al 2012 **Aim: '**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. **Rationale** – 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	**Design** **Recruitment** via diabetes team **Selection** self selection (3 non-responses) **Data collection** in depth semi-structured interviews **Data analysis** constant comparative, themes emerging from data **Reliability +** double coding; data management software; explicit about theories of adolescence - **Validity** **+** interviewer independent researcher	**P'pants** 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 **Location** Sheffield **SES** as above **Ethnicity** n/k	Staff liked - 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' Staff saw as problematic - Emotional burden , feelings of helplessness and personal inadequacy, not knowing how much to divulge about possible future consequences of suboptimal care - feeling yp unlikely to 'open up': they tell you what you want to hear' - 'given workload and time pressure staff fell back on relating to an individual in terms of their social and cultural background, education or motivation… some used pejorative terms to categorise patients into 'good' (those who achieve adequate HbA1c) and 'bad' (those who do not) p 679 - 'A major distinction was made between those who favoured a patient-centred or more traditional approach 'different philosophies' p679. The former placed emphasis on the wants and needs of the individual with quality of life considered paramount, assuming goals to be achieved by offering praise rather than punishment. The latter emphasised the absolute importance of achieving satisfactory glycaemic control as the goal against which current and future health and behaviour are measured.. the consultation focused on the medical aspects of diabetes and the need for discipline, with much less emphasis on the social and interpersonal consequences.'p679 - Authors suggest transition team more authoritarian and paed 'more caring' - Differences in approach were accepted but 'not openly discussed [so] there was uncertainty about how other members of the team approached patients. To compensate many staff

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