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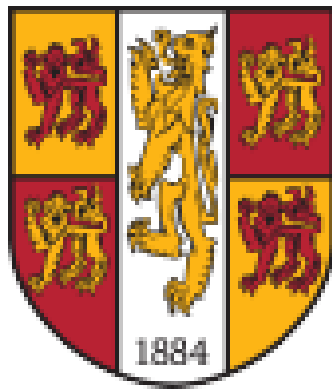
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**A systemic exploration of type-1 diabetes in childhood:
Experiences of parents, clinicians, and school staff**



PRIFYSGOL
BANGOR
UNIVERSITY

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June 2024

Submitted in partial fulfilment for the degree of Doctorate in Clinical
Psychology

Declaration

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references.

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

Danielle Shaw

24.06.2024

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Thesis abstract

A systemic exploration of type-1 diabetes in childhood: Experiences of parents, clinicians and school staff

This thesis systemically explored experiences of type-1 diabetes (T1D) in childhood from the perspectives of parents, clinicians, and school staff. Chapter one is a systematic review of school staff experiences of supporting children with T1D. School staff identified the importance of having good formal support from planning and processes to enable them to provide support to children. This included communication processes and collaboration between health, education, and families. Many school staff struggled with the medical knowledge and responsibility that T1D required from them. They had different motivations for agreeing to undertake the responsibility, one of which being a drive for inclusivity of all children within education. The review identified the important role that school staff can facilitate in providing normalisation and inclusivity that promotes the psychosocial wellbeing of children with T1D.

Chapter two presents findings from an empirical study exploring parent and clinician experiences of T1D diagnosis at a large UK hospital. It utilised a participatory action research approach to collaboratively identify important themes and an action plan to improve the process of diagnosis at the hospital. The study identified that there were key systemic difficulties experienced by both parents and clinicians. Those systemic difficulties were associated with increasing distress for parents. The action plan sought to identify solutions to the problems with the hope of improving experiences and support for parents and clinicians in the future.

The final chapter combines the findings from chapter one and two to consider contributions to theory, research, and practice. The considerable overlap between

findings from both studies provides support for further systemic exploration in this area. This chapter concludes with personal reflections by the author on the research process.

Chapter 1 – Systematic Review

A systematic review and thematic synthesis of the experiences of school staff in supporting children and young people with type 1 diabetes

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Abstract

Objectives: A systematic review of qualitative research exploring school staff experiences of supporting children and young people with type-1 diabetes (T1D). To gain a deeper understanding of the factors that may be influencing support for children and young people with T1D at school from the perspective of school staff.

Materials and methods: Studies were identified for inclusion from a systematic search of five databases (PsycINFO, CINAHL, Web of Science, Social Sciences Premium Collection and PubMed). A total of 1,677 unique records were retrieved and screened. Further records were identified from reference searches. Data from relevant studies was extracted and a thematic synthesis was completed.

Results: Twelve studies were identified, reporting the views and experiences of 429 school staff in eight countries. The synthesis resulted in three analytic themes: (1) the practical foundations of support (2) building competence and confidence, and (3) shaping the wider school culture and community.

Conclusion: The factors that influence care of children with T1D at school include systemic, relational, and psychological factors. School staff need to be supported by formal planning and processes for them to feel safe to undertake the necessary practical, psychological and social support for children with T1D.

Introduction

Type 1 diabetes (T1D) is one of the most common long-term health conditions in children and young people with a significant increase in diagnosis in the last 10 years (Ng & Soni, 2023). The day-to-day management of T1D is complex, requiring insulin therapy, blood glucose monitoring, carbohydrate counting and insulin dosage calculations, and lifestyle management (National Institute for Health and Care Excellence [NICE], 2015). Furthermore, there have been recent rapid advances in technology supporting management of T1D, including continuous blood glucose monitors and insulin pump therapy (Zimmerman et al., 2019). These advances have largely been beneficial in relation to the burden of diabetes; however, they have come with their own drawbacks, which are often over-looked (Kilvert & Fox, 2023).

Children and young people spend a significant amount of time at school and understanding how to support the complex management of T1D within this setting is important. International clinical guidance recommends that children and young people with diabetes be supported with reasonable accommodations and support from school personnel with management, as needed (Lawrence et al., 2022). Support needed may differ across primary and secondary provision and the international guidance highlights that school staff should be trained to ensure this is age and developmentally appropriate. Cross-culturally, this guidance has been implemented differently. In the UK, this requirement to make reasonable adjustments is underpinned by the Equality Act 2010. In England and Wales, there is government guidance to support schools in meeting children and young people's medical needs at school stating arrangements must be made to minimise disruption to education (Department for Education, 2015; Welsh Government, 2018). Given the responsibilities placed on the school and school personnel in supporting children and

young people with T1D, it is important to understand their experiences, including facilitators of and barriers to providing support. Importantly, in the UK in existing guidance the role of school staff in providing support is voluntary and so a critical part of minimising disruption to education of children and young people is consideration of arrangements that enable them to feel willing and able to undertake this role.

Recent qualitative systematic reviews of children and parent experiences suggest that there are wider systemic, relational, and psychological factors that enable effective management of diabetes and other long-term health conditions at school. A recent review by Spencer and colleagues (2022) highlighted themes of identity, normality and difference, autonomy, relationships with peers, and relationships with staff. Runions and colleagues (2019) identified similar themes in relation to the risk of children and young people with long-term health conditions developing mental health difficulties. In broader systematic reviews of the experiences of parents of children with T1D, they have consistently identified difficulties gaining appropriate support from schools and high expectations placed on them, including responsibility for the education of the school and broad expectations in relation to their availability (Kimbell et al., 2022; Simpson et al., 2021).

A previous mixed-methods systematic review explored the effectiveness of interventions, facilitators, and barriers to achieving optimal self-care for children and young people with T1D in educational settings (Edwards et al. 2014). The review was broad and included both intervention studies and studies exploring perspectives of parents, children, and school staff. The findings suggested that effective interventions focused on additional targeted help and support for children with management, educational interventions for school staff, and health system

interventions to facilitate communication with diabetes professionals (e.g. tele-medicine). The overarching narrative synthesis suggested that the focus of these interventions matched with the views of children, parents, and school staff in relation to support that would be helpful. However, research quality was generally found to be low with a need for more robust evaluations. The authors also noted that there was a lack of focus on psychological interventions, despite views suggesting that adaptation / coping with T1D and relationships with peers were areas of concern. Specifically, in relation to the views of school staff, much of the research at the time of the review was quantitative and limited to analysis of survey data. The methodology and nature of the research available at that time impacted the depth of the narrative synthesis, which largely focused on the practical aspects of diabetes management. Given the increasing numbers of children and young people with T1D and the significant changes in technology over the last 10 years impacting the level of support required, an updated systematic review exploring school staff experiences is likely to be timely.

There has been a substantial amount of cross-cultural research since Edwards et al.'s (2014) review, further exploring the knowledge, attitudes, and perspectives of school staff in providing the necessary support to children and young people with T1D. Quantitative research utilising survey approaches have highlighted that the level of education and knowledge about diabetes varies across different countries and much of this research has called for increased education for school staff on T1D to improve support for children and young people (Al-Bunyan et al., 2021; Alzahrani, 2019; Carral San Laureano et al., 2018; Chatzistougianni et al., 2020; Gutzweiler et al., 2020; Luque-Vara et al. 2021; Nannsen et al., 2023; Perme et al. 2022; Statiri et al., 2022; Tannous et al., 2012).

However, research evaluating educational interventions for school staff suggest that they might not be sufficient on their own to improve support for children and young people with T1D at school. Research by Gokce and colleagues (2020) investigated the impact of a longitudinal diabetes education programme with school staff in Turkey. The programme supported 75% of school staff to increase their knowledge in diabetes; however, only 50% felt more confident in supporting children and young people as a result. Similarly, Lee and colleagues (2023) found that for school nurses supporting children and young people with T1D, it was their understanding of the psychosocial impacts of diabetes that most influenced increased self-efficacy in providing care, and not their self-efficacy in diabetes education. Broader systemic and psychological factors that have been identified as important within this research are relationships with parents and behaviour / disease acceptance (Brentari et al. 2023).

The current systematic review sought to update the previous systematic review by Edwards and colleagues (2014) and complement recent systematic reviews on the perspectives of parents and children (Kimbell et al., 2022; Runions et al., 2019; Spencer et al., 2022; Simpson et al., 2021). The focus will be on the qualitative evidence of school staff experiences to provide an opportunity to gain a deeper understanding of the more complex systemic and psychological factors that may be influencing support for children and young people with T1D at school from this perspective.

Current Review

The aim of this systematic review and thematic synthesis was to synthesise empirical qualitative literature to answer the following question: *What are the experiences of school staff in supporting children and young people with T1D?*

Methods

Search strategy

In January 2024, papers were identified for inclusion from a systematic search of five databases (PsycINFO, CINAHL, Web of Science, Social Sciences Premium Collection and PubMed). A search strategy (Table 1) was developed utilising the PICO approach (Population, phenomenon of Interest, and Context; Aromataris & Munn, 2020). Searches were limited to papers published from 2012 onwards to identify research published since the previous systematic review. In addition, reference searches were completed of included papers for additional potentially relevant studies. The protocol was registered on PROSPERO (Record ID: 505587). References were managed using RefWorks (2024). Reporting followed the guidelines for Enhancing Transparency of Reporting the Synthesis of Qualitative Research (ENTREQ, Tong et al., 2012) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, Moher et al., 2009)

Table 1*Search terms presented within the PICO framework*

Population	Phenomenon of Interest	Context
School staff	Experiences	Supporting children and young people with type 1 diabetes
Teacher*	Experience*	
School*	Perspective*	
School staff	Views	
Teaching assistant	Attitude*	Type 1 diabetes
Learning support assistant	Feeling*	Diabetes type 1
School nurs*	Perception*	Diabet*
School personnel		Diabetes mellitus
Coaches		Diabetes mellitus type 1
School support staff		Type 1 diabetes mellitus
Pastoral school staff		T1D
Nursery workers		Early diabetes mellitus
Nursery staff		Juvenile diabetes
Daycare staff		
Daycare workers		
School health professional*		
School counsellor*		
Settings		
Nursery		
Pre school		
Daycare		
Kindergarten		
Kindergarden		
Secondary school		
Middle school		
High school		
Elementary school		

**Indicates various word endings*

Study selection and screening

Studies were included if they were peer-reviewed papers published in English reporting: (1) primary research using qualitative methodologies; and (2) investigating the experiences of school staff supporting children and young people with T1D in an educational setting. The perspective of any school staff working in any education or daycare context that supported children and young people aged up to 18 years old was considered relevant. Studies were excluded if they reported non-primary research

(e.g. reviews), focused on quantitative data, or were with post-18 educational staff / settings.

Mixed-methods research was included if qualitative data were significantly represented within analysis and could be extracted. Mixed-population studies were included if school staff views were significantly represented within analysis and it was possible to extract those views.

De-duplication was completed electronically by RefWorks and checked manually. Title and abstracts were then screened by the first author. Full texts were retrieved for any papers that appeared to meet the eligibility criteria. Full text papers were then screened against the eligibility criteria by both the first and second authors.

Data extraction and quality assessment

Data extraction of the included studies' characteristics was supported by the creation of a data extraction table in Microsoft Excel. This included author(s), year of publication, country, study aims, participants, study design, and qualitative methodology of analysis. Data extraction of qualitative data was completed by hand by the first author.

Quality appraisals of the papers meeting eligibility criteria were completed independently by both the first and second author using the Mixed Method Appraisal Tool (MMAT, Hong et al., 2018). Any discrepancies in screening or scoring were resolved via discussion.

Data analysis and synthesis

A three-stage thematic synthesis was completed following Thomas and Harden's (2008) approach:

- 1.) Line-by-line coding of text according to meaning and content;
- 2.) Descriptive themes created by reviewing similarities and differences between codes and grouping them to capture shared meaning;
- 3.) Generating higher order analytical themes based on the patterns and relationships between the descriptive themes and directly linked to the review questions.

Following Thomas and Harden (2008) guidance, detailed data extraction tables are included before the synthesis to preserve the context and complexity of the original research and improve the transparency of the synthesis. The coding and synthesis of data was completed independently by the first author (Appendix 1, coding extract). To reduce bias and enhance rigour, the descriptive themes were reviewed and discussed with the second author to consider any changes and agree on final analytic themes.

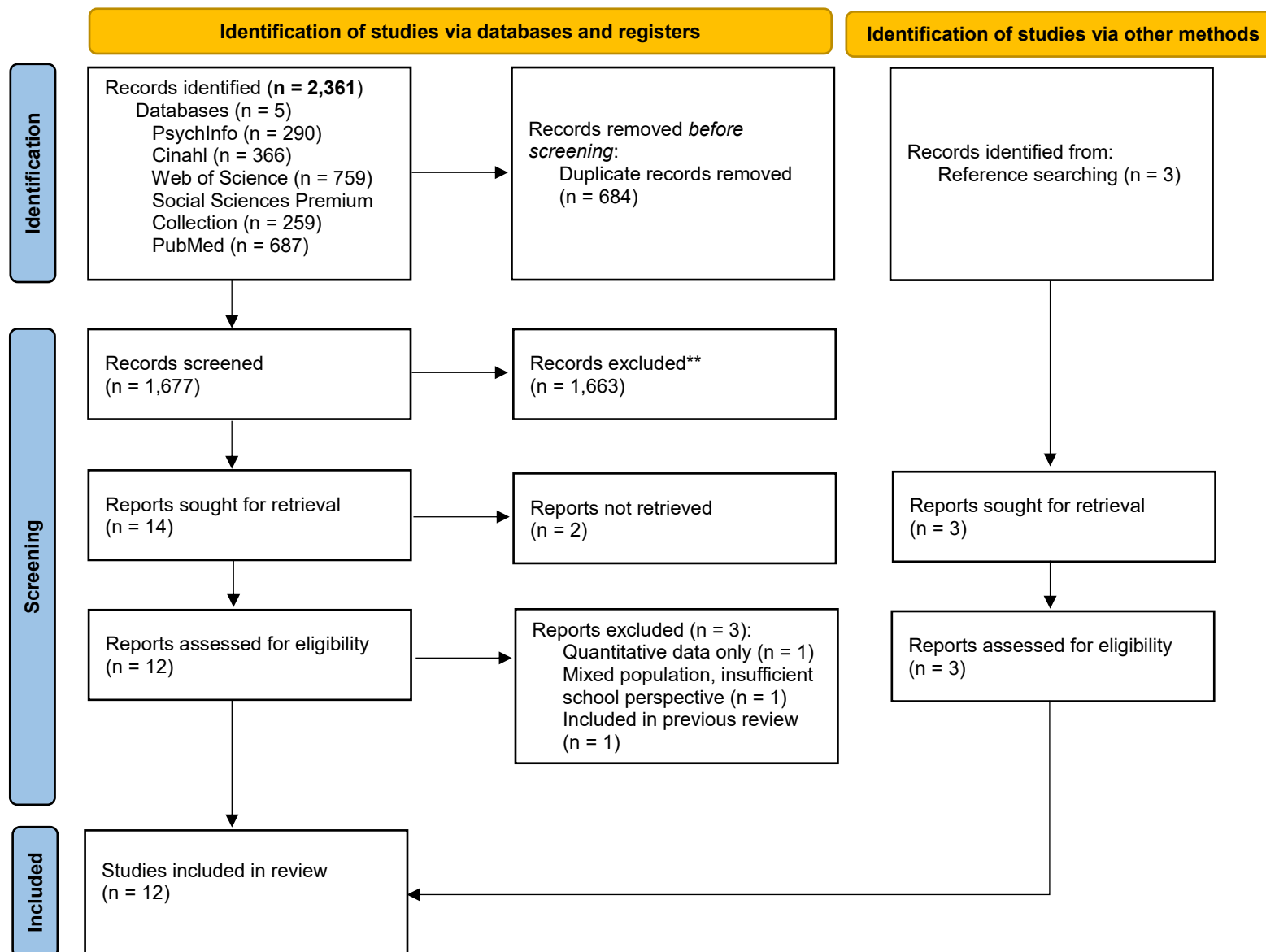
Results

The search identified 2,361 records, 1,677 unique records (after de-duplication). Of these, 1,663 papers were excluded after titles and abstracts were screened. Retrieval of full texts was attempted for 14 papers, two papers could not be retrieved electronically and more in-depth analysis of abstracts suggested that they were unlikely to contain substantial school staff perspectives. Full text reviews of 12 papers were completed and led to exclusion of another three papers that did

not meet eligibility criteria. Screening of references of the included papers identified a further three papers and a full text review was also completed of these papers (Figure 1, PRISMA flowchart of study selection process)

Figure 1

PRISMA flowchart of study selection process



Study characteristics

The 12 included studies reported the views and experiences of 429 school staff in eight countries: Australia (Fried et al. 2020; Marks et al, 2019), Sweden (Holstrom et al., 2018), Hungary (Hovarth et al., 2023), Denmark (Johansen et al., 2022), Spain (Junco et al., 2022), United Kingdom (MacMillan et al., 2015; Marshall 2018), United States (March et al., 2020; Schaumleffel & Brown, 2020; Williams et al., 2019), and Taiwan (Wang & Volker, 2012).

Eight papers reported the views and experiences of school staff only. This included four papers reporting exclusively on experiences of school nurses (March et al., 2020; Schaumleffel & Brown, 2020; Williams et al., 2019; Wang & Volker, 2012), two papers reporting experiences of teachers (Hovarth et al., 2023; Marks et al., 2019) and two papers reporting experiences of mixed school personnel (Holstrom et al., 2018; Johansen et al., 2022). The remaining four papers included mixed participants with parents and/or young people's views also included (Fried et al., 2020; Junco et al., 2022; MacMillan et al., 2015; Marshall 2018).

The majority of studies used interviews as part of their study design ($n = 8$) (Fried et al., 2020; Holstrom et al., 2018; Johansen et al., 2022; Junco et al., 2022; March et al., 2020; Marks et al., 2019; Marshall 2018; Wang & Volker, 2012). Two studies employed both interviews and focus groups (Hovarth et al., 2023; MacMillan et al., 2015), one study used only focus groups (Schaumleffel & Brown, 2020) and one utilised a survey design with a substantial qualitative element (Williams et al., 2019).

The most commonly cited method of qualitative data analysis was Braun and Clarke's (2006) methodology for thematic analysis ($n = 4$; Fried et al., 2020; Hovarth et al., 2023; MacMillan et al., 2015; March et al., 2020).

Table 2*Characteristics of studies included in the qualitative synthesis*

Author, country	Participants	Study aims	Study design	Data analysis
Fried et al. (2020) (Australia)	26 staff members from 10 schools identified by principal as significantly involved with T1D support <i>(Mixed population: young people (6) and parents (3))</i>	Description of how schools engaging in best practice for supporting psychosocial wellbeing and T1D management provide support	Interviews <i>Invited to speak freely about experiences. Some prompts focused on role, what support is provided (by staff, other, organisation), and difficulties</i>	Thematic analysis (Braun & Clarke, 2006)
Holstrom et al. (2018) (Sweden)	24 school personnel (teachers, principals & school nurses); experience with CYP aged 6-18 years old Preschool (<i>n</i> = 6) Grade 1-9 (<i>n</i> = 10) High school (<i>n</i> = 8) Teachers (<i>n</i> = 11) PE Teachers (<i>n</i> = 2) Principals (<i>n</i> = 5) School nurses (<i>n</i> = 6)	Description of experiences	Interviews <i>Open question regarding: experience with subsequent questions around (1) organisation of care (2) cooperation with others (3) difficulties</i>	Inductive qualitative content analysis (Graneheim & Lundman, 2004)
Hovarth et al. (2023) (Hungary)	30 kindergarten and school teachers	Exploration of attitudes & interpretation of role	Interviews (20); focus groups (3) <i>Interview structured around five subjects: (1) experience</i>	Thematic analysis (Braun & Clarke, 2006) Inductive and deductive analysis, including use of

			<i>with diabetes (2) knowledge of diabetes (3) options for care within their school (4) solutions to difficulties in care for T1D in school (5) Anything additional</i>	theoretical framework of attitudes (three components: cognitive, affective & behavioural) (Rosenberg & Hovland, 1960)
Johansen et al (2022) (Denmark)	121 municipal employees Public administration employees (e.g. Special Educational Consultant, School Counsellor, Psychological advisor) (<i>n</i> = 61) Municipal health service employee (e.g. School nurse) (<i>n</i> = 37) Institutional employees (e.g. School principal, social workers, kindergarten manager) (<i>n</i> = 23)	Challenges and potentials in school management of diabetes	Interviews <i>Interviews focused on three themes: (1) Framework and organisational structures, including communication and cooperation between departments (2) Experiences focusing on actual case experiences (3) Future perspectives of challenges and potentials</i>	Qualitative content analysis (Vaismoradi et al., 2013)
Junco et al. (2022) (Spain)	Qualitative: 11 teachers (pre-primary, primary, compulsory secondary and further education <i>(Mixed population: parents (15))</i>	Description of care needs and how far needs are met	Mixed methods: Inventory of Negative Attitudes (652) and semi-structured interviews (11 teachers) <i>Two broad areas: (1) what are care needs (2) how are they covered</i>	Categorical thematic analysis

MacMillan et al. (2015) (Scotland)	37 teachers (primary and secondary) <i>(Mixed population: young people (16), parents (16) and diabetes professionals (9))</i>	Barriers and facilitators to PE at school	Interviews and focus groups <i>Areas covered (1) knowledge of diabetes (2) effect of influential figures on behaviour and role in changing behaviour (3) current support characteristics (4) ideas for future support</i>	Thematic analysis (Braun & Clarke, 2006)
March et al. (2020) (USA)	40 school nurses (elementary and middle school, children aged 5-13 years old)	Experiences working with diabetes devices and health care system	Interviews <i>Two main areas of focus (1) experiences, practices and attitudes towards new technology, including challenges and advantages (2) communication between school nurses and health care system</i>	Iterative thematic analysis (Braun & Clarke, 2006) <i>Continued data collection until thematic saturation achieved</i>
Marks et al. (2019) (Australia)	11 primary school teachers	Description of experiences of teachers in providing support, including facilitators and implications	Interviews <i>Three broad questions (1) Experiences (2) Challenges (3) Impact on role as a teacher</i>	Narrative analysis (Polkinghorne, 1996)
Marshall (2018) (UK)	People involved in supporting children with T1D at school: PDSN (1); parents (2); teachers (2) TA (1) Headteacher (1)	Influences, perspectives and interactions	Interviews <i>Topic guide includes: (1) take me through a typical day (2) who was involved at each point? (3) reasonable</i>	Case study, cross case analysis (van de Ven & Poole, 2000)

	Deputy head-teacher (1) Lunch coordinator (1) cook (1) nutritionist (1) school nurse (1) First aider (1) Special needs coordinator (1)		<i>adjustments (4) communication between home, school, and the diabetes team (5) what do you think you do well? (6) what difficulties can be experienced and how are they overcome?</i>	
Schaumleffel & Brown (2020) (USA)	29 school nurses	Experiences of providing care to T1D students, including barriers and recommendations	Focus groups <i>Interview guide included questions on experiences, barriers, communication, training, and recommendations</i>	Narrative analysis and phenomenological analysis (Davidsen, 2013)
Wang & Volker (2012) (Taiwan)	5 school nurses (elementary and junior high)	Understanding lived experiences	Interviews <i>Broad main question: "what is your experience of caring for students with T1D?"</i>	Husserlian phenomenological approach (Colaizzi, 1978)
Williams et al. (2019) (USA)	84 school nurses (supporting children aged 5-18 years old)	Exploring barriers to providing care to children with T1D	Quantitative and qualitative survey <i>Quantitative and qualitative; Four open-ended qualitative questions (1) what do you find most challenging in caring for children with T1D? (2) what changes would you suggest for the care of a child with T1D in the school system? (3) what</i>	Unclear

else would you like to tell me? (4) based on your educational needs, please provide suggestions for future program topics and formats

Note, abbreviations:

T1D, Type-1 diabetes

PDSN, Paediatric Diabetes Specialist Nurse

Quality assessment

Using the MMAT (Hong et al., 2018), it was assessed by both the first and second author that all studies had clear research questions and collected data that enabled them to address the research question. Overall, the majority of studies utilised qualitative methods only and were of good quality according to the MMAT criteria. Only three studies did not provide sufficient information to assess whether findings were adequately derived from the data (Junco et al., 2022; Schaumleffel & Brown, 2020; Williams et al., 2019). This related to there being insufficient details shared relating to the data analysis method. Two of those studies were mixed methods studies.

Mixed methods studies were generally of lower quality than the qualitative only studies (Junco et al., 2022; Williams et al., 2019). This was largely due to the quantitative data within the studies being assessed as being of lower quality than the qualitative data. The mixed method studies also did not show good integration of the quantitative and qualitative data. Due to only the qualitative data being of interest to the current synthesis, this did not impact the overall quality of the data utilised.

Table 3

Mixed Methods Appraisal Tool assessment

Study	Screening Questions		Qualitative					Quantitative Descriptive					Mixed Methods				
	S1	S2	1.1	1.2	1.3	1.4	1.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5
Fried et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Holstrom et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Hovarth et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Johansen et al (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Junco et al. (2022)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	No	Can't tell	Yes	Yes	Yes	No	No	No
MacMillan et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
March et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Marks et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Marshall (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Schaumleffel & Brown (2020)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes										
Wang & Volker (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes										
Williams et al. (2019)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Can't tell	Yes	Yes	Yes	No	No	Can't tell

Synthesis findings

The synthesis resulted in three analytic themes: the practical foundations of support, building competence and confidence, and shaping the wider school culture and community. Within those three analytic themes, there were six descriptive subthemes (Table 4). Themes were consistently present across the majority of included studies (Table 5).

Table 4

Analytic themes, descriptive themes and illustrative quotes

Analytic themes	Descriptive themes	Illustrative quotes
<i>The practical foundations of support</i>	Underpinning formal support is important	I've had cases where I had to tell the parents: "It's hard to tell you this, but we don't have the staff to do these tasks, so you'll have to contact the social administration to get compensation for lost earnings, until we can get it under control (Johansen et al. 2022)
	Communication and collaboration	I wish I had more support from parents. I call, leave messages, and send emails and still they fail to respond. I have arranged appointments and the parent doesn't show up. We need support when trying to provide the best care to their child and we need the parents to support us (Williams et al., 2019)
<i>Building competence and confidence</i>	Diabetes knowledge and experience	It was positive to meet the diabetes nurse who really explained what diabetes means but when I got back to school and faced reality in the classroom I felt I knew nothing... I really needed to learn more... I googled... asked parents, asked the school nurse (Holmstrom et al., 2018)
	It's a big responsibility	I feel much more confident with it [diabetes] because it's not just me, there's more of us and we understand it so much better. I certainly don't feel anxious about it (Marshall, 2018)

	Staff attitudes, beliefs and feelings	[Staff members] are scared of diabetes because [a student] had left the school in an ambulance quite a few times (Fried et al., 2020)
<i>Shaping the wider school culture and community</i>	Normalisation and inclusivity	I just want her to have the education that she needs and she can't have that unless she has the insulin because the medical part of her is there permanently. So, someone or everyone has to adjust so that this child can get to school and learn, that's how I look at it (Marks et al., 2019)

Table 5*Themes present in included studies*

Author	Underpinning formal support is important	Communication and collaboration	Diabetes knowledge and experience	It's a big responsibility	Staff attitudes, beliefs and feelings	Normalisation and inclusivity
Fried et al. (2020)	x	x	x	x	x	x
Holstrom et al. (2018)	x	x	x	x	x	x
Hovarth et al. (2023)		x	x	x	x	x
Johansen et al (2022)	x	x	x	x	x	x
Junco et al. (2022)	x	x	x	x	x	
MacMillan et al. (2015)	x	x	x	x	x	x
March et al. (2020)	x	x	x	x		x
Marks et al. (2019)		x	x	x	x	x
Marshall (2018)		x		x	x	x
Schaumleffel & Brown (2020)	x	x		x		x
Wang & Volker (2012)		x	x	x	x	x
Williams et al. (2019)		x				x

x = present; blank = not present

The Practical Foundations of Support. This analytic theme represents the formal support and ongoing commitment to collaboration that was repeatedly illustrated as necessary to effective care for children and young people with T1D at school. Without this bedrock, individual staff competence and confidence and a positive wider school culture was more difficult to facilitate.

Underpinning Formal Support is Important. This theme was present in seven of the included studies (Table 4). School staff discussed the importance of formal planning in enabling them to support children and young people with T1D. Formal planning was broad and included medical plans, medical alerts to staff, specific physical education plans, updates on use of T1D technology, communication plans, emergency plans, excursion plans, and allocation of roles/responsibilities (Fried et al, 2020; Holmstrom et al., 2018; Johansen et al., 2022; MacMillan et al., 2015; March et al., 2020).

Staff reflected on the extensive benefits of this formal planning to supporting children and young people. This included supporting transitions within the school, facilitating good day-to-day support, supporting staff who feel uncertain or stressed about diabetes management, establishing trust and interaction between everyone supporting the child, and increasing the felt sense of safety and security of young people and their parents (Fried et al, 2020; Holmstrom et al., 2018; Johansen et al., 2022; MacMillan et al., 2015). However, there were also obstacles at this organisational formal planning level. This included lack of time for planning, a lack of time provided for staff to attend trainings, and variation in resources allocated for additional support staff (Fried et al., 2020; Holmstrom et al., 2018; Johansen et al., 2022; Junco et al., 2022; MacMillan et al., 2015; Schmaeffael & Brown 2020). In

some cases, these obstacles impacted inclusivity as support was not there to enable young people to attend school safely.

Communication and Collaboration. The need for communication and collaboration to support caring for children with T1D between health, education, and parents was discussed by participants in all studies (Table 4). Many school staff emphasised that communication and collaboration with parents was pivotal in ensuring continuous effective care of children. Staff talked about the essentialness of regular communication with parents and the helpfulness of parents being available to provide support and guidance (Fried et al., 2020; Holmstrom et al., 2018; Hovarth et al., 2023; MacMillan et al., 2015; March et al., 2020; Marks et al., 2019). They were also described as having a facilitating role in the communication between health and education (Johansen et al., 2022). However, staff also shared challenges in relation to communicating with parents. This included managing the increased level of communication with parents that was required and difficulties when parents were unavailable or unsupportive (Johansen et al., 2022; March et al., 2020; Schaumleffel & Brown 2020; Wang & Volker, 2012; Williams et al., 2019).

Many of the school staff in studies also reflected on the higher level of communication and collaboration needed between health and education (Johansen et al., 2022; March et al., 2020; Marks et al., 2019; Schaumleffel & Brown 2020; Wang & Volker, 2012; Williams et al., 2019). There were some positive experiences of healthcare providers reported, for example, ensuring schools were up-to-date and being available when they had questions (March et al., 2020). However, for the most part, school staff reported challenges in the availability of healthcare providers and a desire for a “more holistic approach” between health and education (Johansen et al.,

2022; March et al., 2020; Marks et al., 2019; Schaumleffel & Brown 2020; Wang & Volker, 2012; Williams et al., 2019).

Building Competence and Confidence. This analytical theme was associated with the competence and confidence held by the staff themselves and the factors that influenced this. Diabetes knowledge and experience, the nature of the responsibility, and staff attitude, beliefs and feelings all interacted to form an overall picture of competence and confidence. Low T1D knowledge and experience connected to staff being unwilling and fearful to take on the responsibility associated with supporting care. However, sharing responsibility and learning was frequently reported as an alleviator of staff concerns.

Diabetes Knowledge and Experience. Diabetes knowledge and experience was discussed by staff in nine of the included studies (Table 4). Studies reported variation in staff knowledge, with correct and incorrect knowledge demonstrated (Fried et al., 2020; Hovarth et al., 2023; Junco et al., 2022; MacMillan et al., 2015; Wang & Volker 2012). There was also variation in the level of training provided and who provided that training. Some participants had received no formal training (Junco et al., 2022; MacMillan et al., 2015). One study with both primary and secondary teachers found a variation between education provided to primary and secondary, with primary schools more likely to have received training (Holstrom et al., 2023). It was common for staff to not feel competent in supporting children and young people with T1D and to express a desire for more training (Fried et al., 2020; Hovarth et al., 2023; Junco et al., 2022; MacMillan et al., 2015; Wang & Volker 2012). In relation to who provided the training, there were some references to training being offered by

healthcare providers, sales representative from diabetes-specific device companies, or diabetes-specific third sector organisations (Holstrom et al., 2018; March et al., 2020; Marks et al., 2019). However, some staff shared having to learn independently or described a reliance on parents providing education to the school (Johansen et al., 2022; Marks et al., 2019).

Alongside variation in access to training, there was evidence of a gap between theoretical and practical knowledge (Holstrom et al., 2018; Johansen et al., 2022; March et al., 2020; Wang & Volker, 2012). This led to staff turning to various additional resources to build their knowledge and understanding, including online resources (Holstrom et al., 2018; March et al., 2020). Some staff accepted the expectation that they would complete their own learning around T1D. However, others did not think it should be their role to independently gain this knowledge. This hesitancy was more common in school nurse participants (Johansen et al. 2022; Wang & Volker, 2012). There was also acknowledgement of the importance and role of more experiential, person-centred learning, and a “learn as you go process” (Marks et al., 2019, p246) (Fried et al., 2020; Holmstrom et al., 2018; Hovarth et al., 2023; MacMillan et al., 2015; Marshall, 2018; Wang & Volker, 2012). Staff shared examples of learning how T1D specifically impacted the individual young people they supported (Fried et al., 2020; Holmstrom et al., 2018; Hovarth et al., 2023; Marshall, 2018). Some participants also talked about a changing of roles and a shared learning experience, in which they needed to learn alongside children and young people (Holmstrom et al., 2018; Wang & Volker, 2012).

It's a Big Responsibility. The nature and level of responsibility associated with supporting children and young people with T1D was discussed in eleven of the

included studies (Table 4). The high level and medical nature of responsibility associated with T1D led to some teachers refusing to support children and young people with their T1D management needs (Johansen et al., 2022; Junco et al., 2022; Wang & Volker, 2012). Unfortunately, this refusal led to children and young people with T1D experiencing exclusion. For some, refusal to accept responsibility was connected to unclear responsibility and liability in relation to mistakes.

There were some individual factors that made school staff more open to undertaking the responsibility. This included level of teaching experience, personal experience with diabetes, and holding generic first aid experience (Marks et al., 2019). However, the largest facilitator within the studies for school staff feeling open and confident to support care of T1D was more sharing of responsibility (Fried et al., 2020; Holmstrom et al., 2018; Hovarth et al., 2023; MacMillan et al., 2015; March et al., 2020; Marks et al., 2019; Marshall, 2018; Wang & Volker, 2012). The level of responsibility sharing varied; it included whole school approaches, collaboration across various school staff, between a teacher and teaching assistant, between the teacher and child, or between the teacher and parents.

In relation to sharing responsibility with the child or young person, staff shared that realising how much they were able to undertake themselves provided them with reassurance (Fried et al., 2020; Hovarth et al., 2023; Wang & Volker). Generally, responsibility varied with the age of the child and with the length of diagnosis, as the child began to be able to have more independence with managing T1D (Fried et al., 2020; MacMillan et al., 2015). Supporting the child's responsibility and independence was seen by some staff as an important part of supporting their overall psychosocial wellbeing and adjustment (Fried et al. 2020).

Staff Attitudes, Beliefs, and Feelings. This theme was present in nine of the included studies (Table 4). School staff attitudes, beliefs, and feelings towards T1D varied within and across the studies, with some staff being willing and open to supporting children and young people with T1D and others being reticent. There were some personal factors that facilitated staff openness to undertaking support, including being open to learning, previous experience with T1D, and being willing to ask for help (Marshall, 2018). However, it was more common that school staff had wider motivations underlying their willingness to undertake the role of supporting children and young people with T1D. These motivations included a desire to promote inclusivity, the relationship with the child/family, and empathy for the child/family (Marks et al., 2019; Wang & Volker, 2012).

Many participants found supporting children and young people with T1D difficult, uncomfortable, and stressful (Fried et al., 2020; Holmstrom et al., 2018; Hovarth et al., 2023; Johansen et al., 2022; Junco et al., 2022; MacMillan et al., 2015; Marks et al., 2019; Marshall, 2018; Wang & Volker, 2012). There were various reasons underlying school staff struggles with T1D. They included fear of the disease, the potential serious consequences of mistakes, the 'felt' personal responsibility for mistakes, the unclear legal liability, the medical nature of the support necessary (e.g. providing injections/administering insulin), the extent of the support, the competing pressures on teachers, and high expectations placed on them by the school and parents.

Within some studies, teachers discomfort with supporting T1D care of children and young people led to them disputing it was part of their role and, in some cases, refusing to take responsibility (Johansen et al., 2022; Junco et al., 2022; March et al., 2020; Marks et al., 2019; Marshall, 2018). For some participants,

discomfort/uncertainty decreased over time and with experience (Marks et al., 2019; Wang & Volker, 2012). However, for others, mistakes stayed with them as they had been confronted with the risks involved in care (Holmstrom et al., 2018; Marks et al., 2019).

Shaping the Wider School Culture and Community. The final analytic theme represents that within the included studies there was repeatedly something more than the sum of formal support and the staff approach. The positive culmination of the presence of those two themes that was frequently referenced in studies related to wider school culture and a whole-school approach to supporting children and young people with T1D.

Normalisation and Inclusivity. Staff in eleven of the included studies discussed the importance of normalisation and inclusion in their experiences of supporting children and young people with T1D (Table 4). This was important at both a whole school/organisational level and an individual level. On an organisational level, staff discussed policies of inclusion and acceptance, associated with strong beliefs that no child should be excluded (Fried et al., 2020; Holstrom et al., 2018; Hovarth et al., 2023; Junco et al., 2022; MacMillan et al., 2015; Wang & Volker, 2012). Some staff spoke about how the presence of a child with T1D positively impacted the school culture, as an emphasis on healthy living and acceptance became a regular theme (Hovarth et al., 2023). This led to one principal stating that, “what's good for youth with T1DM is good for all” (Holmstrom et al., 2018). In contrast, there were some views within the research that separation of children with T1D would make care easier (e.g. separate institutions or activities; Hovarth et al. 2023). This segregation

view was often connected to staff uncertainty around supporting children with T1D. It often extended to an individual level where staff would discourage participation in activities (MacMillan et al., 2015).

On an individual level, it was reflected that normalisation and inclusion was important in relation to ensuring children and young people were still able to access opportunities and that this directly connected to their psychosocial wellbeing (Fried et al., 2020; Wang & Volker, 2012). For staff, there was a balance between minimising differences whilst also providing acceptance and normalisation of the challenges of living with T1D (Fried et al., 2020; Wang & Volker, 2012). There were also reflections that normalisation and inclusion might look different for different children dependent on their preferences and that young peoples' drive to be 'normal' can sometimes negatively impact their adherence to T1D care (MacMillan et al., 2015; Wang & Volker, 2012; Williams et al., 2019).

In terms of wider inclusivity, some studies highlighted the role and various functions of peers (Fried et al., 2020; MacMillan et al., 2015; Wang & Volker, 2012). School staff shared examples of peers of children and young people learning about T1D alongside the child and their potential to be part of a wider whole school approach in supporting the child/young person (Fried et al., 2020; MacMillan et al., 2015; Wang & Volker, 2012). It was also felt important by staff that children were surrounded by peers who thought of diabetes as "no big deal" (MacMillan et al., 2015). There was acknowledgement that the involvement of peers was about 'more than' just T1D management; it was also important for the psychosocial wellbeing of children and young people in ensuring they do not feel isolated by their condition (Fried et al., 2020; MacMillan et al., 2015).

Discussion

The current review thematically synthesised the experiences of school staff in supporting children and young people with T1D from 12 studies across eight countries. There was a significant amount of coherence across the three analytic themes and six descriptive themes presented. The themes illustrated how the experiences of school staff played out across multiple layers, from organisational formal support, staff competence and confidence, to the broader school community and culture. It is clear from the findings that good support for children with T1D at school does not occur in a vacuum.

The current review builds on a previous systematic review by Edwards and colleagues (2014), providing a more in-depth narrative synthesis specific to the experiences of school staff. In line with their findings, education for staff and interventions to support facilitation of communication between schools and diabetes professionals are still indicated. However, in line with recent systematic reviews synthesising other perspectives, the experiences of school staff within this review suggest that the factors that contribute to good care of children and young people with T1D at school go beyond practical management to include systemic, relational, and psychological considerations (Runions et al., 2019; Spencer et al., 2022). In addition, the review provides important insight into the underlying reasons for the difficulties experienced by parents in getting support from schools (Kimbell et al., 2022; Simpson et al., 2021). Importantly, it also provides some direction as to possible solutions.

In relation to the need for education on T1D for school staff, the findings show variation in both knowledge and the provision of training. This supports quantitative research, which has consistently reflected this picture (Al-Bunyan et al., 2021;

Alzahrani, 2019; Carral San Laureano et al., 2018; Chatzistougianni et al., 2020; Gutzweiler et al., 2020; Luque-Vara et al. 2021; Nannsen et al., 2023; Perme et al. 2022; Statiri et al., 2022; Tannous et al., 2012). However, one of the key review findings in relation to knowledge was that there was a gap between theoretical and practical knowledge that required experiential learning. Therefore, recommendations from quantitative research calling for increased education on T1D for school staff is unlikely to be sufficient on its own to improve experiences for children and young people. Instead, it is suggested that improving school staff experiences may translate into improved care for children and young people.

This review recommends that support for schools includes recognition of the need for experiential learning and consideration as to how to best support self-efficacy and mastery (Bandura, 1977; Kolb, 1984). These key learning features are required to bridge the gap between theory and practice. Increased scaffolding from healthcare professionals during early stages of school support may be helpful. Similarly, school communities of practice, whereby schools with more experience in supporting children and young people with T1D may mentor those that are less experienced, may be a helpful avenue to explore.

Alongside improving competence and confidence of school staff, awareness needs to be raised in relation to the broader systemic and relational factors that are important for effective care for children and young people with T1D at school. First and foremost, this needs to come from a foundation of formal support that provides the basis for staff to feel safe to take on responsibility and build their competence and confidence in practice. In England and Wales, there is guidance for schools on this support (Department for Education, 2015; Welsh Government, 2018). However, there is variation in relation to legislative recourse for when support for children and

young people is not in place (e.g. Wales does not currently have legislative support for recourse). Unfortunately, a recent inquiry by the Welsh Parliament's Children, Young People and Education Committee has highlighted that children and young people with T1D are not getting the support they need to fully participate in education (Welsh Parliament, 2024). The inquiry report emphasised an overall lack of awareness of the medical management needs of children and young people with T1D and a continued need for more training and support to schools. The cross-cultural findings in this review are consistent with this locally identified need (summarised above). However, the review findings suggest that *shared responsibility* is a critical factor in supporting both staff and children and young people. Specifically acknowledging and embedding this across all formal planning and provision of training would be very beneficial. The foundation of formal support needs to be complemented by ongoing collaboration and communication between the school, health professionals, and parents. However, care needs to be taken to ensure that unreasonably high expectations are not placed on parents by the school and health services, which can have an impact on their psychological wellbeing (Kimbell et al., 2022; Simpson et al., 2021).

In ensuring that the school has the formal foundation that supports staff to build competence and confidence, the goal of ensuring that children and young people are not disadvantaged or excluded from education is more likely to be achieved. The findings suggest that schools have a crucial role in modelling inclusion and normalisation and activities that can enable a wider positive school culture and community. Activities may include enabling children and young people to be involved in extracurricular activities, informing the child's peers about the condition (explaining diabetes and its treatment), modelling how peers should treat the child with T1D, and

sensitising the peers of the child (encouraging them to be more empathic; Hovarth et al., 2023). These intentional activities should not detract from the importance of informal day-to-day relational support from both staff and peers. This informal support contributes to normalisation and inclusion and is supportive of the psychosocial wellbeing of children and young people with T1D and school staff.

In this review, a decision was made to broadly explore school staff experiences of supporting T1D as opposed to focusing solely on teachers. A benefit of this chosen approach was that it captured and highlighted the wider school community approach that was discussed as important within the studies. However, a limitation is that there was not scope to fully explore the nuances of the different school staff roles and experiences. This may be something that it is possible to explore in future research, provided there is sufficient primary data including the different professions. In addition, although the wide cultural representation across the studies is a benefit, a limitation of that diversity is that there is significant variation between the countries in relation to policy and healthcare provision that has not been explored in detail here. That variation undoubtedly impacts families' and school staff experiences. For in-depth consideration of the different provision and impact in different countries the primary research studies remain the best source of information.

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Chapter 2 – Empirical Paper

A participatory-action research exploration of parent and clinician experiences of type-1 diabetes diagnosis

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Abstract

Objectives: To systemically explore parent and clinician experiences of type-1 diabetes (T1D) diagnosis at a large UK hospital. To utilise those experiences to collaboratively create an action plan to improve support for parents and clinicians.

Materials and methods: A participatory action research framework was utilised to support collaboration between researcher, parents, and clinicians. Data was collected via semi-structured focus groups. Data was analysed using thematic analysis and refinement of themes/findings was supported through reflective groups with participants.

Results: Six themes were identified from parents and clinicians experiences: (1) The limits and pressures on clinicians and the system (2) Parents' emotional lens at diagnosis; (3) The power of knowledge (4) Difficulties with communication and transparency (5) Conditions for learning, adjusting, and forming relationships (6) Sharing experiences & gaining support. An action plan was created to address the needs identified.

Conclusion: The task of diagnosis of T1D in childhood is complex and requires sharing/processing life-altering news and transferring large amounts of information. There is a connection between systemic difficulties (e.g. staff knowledge and communication) and parental distress at diagnosis. Collaboration between clinicians and patients was helpful in identifying actionable improvements to a complex process and system.

Introduction

Type 1 diabetes (T1D) is one of the most common long-term conditions diagnosed in childhood. In England and Wales, there are approximately 32,276 children and young people with T1D (Royal College of Paediatrics & Child Health, 2024). The incidence of new diagnoses has been steadily increasing year-on-year, with 4,390 children diagnosed in 2022 (National Health Service [NHS] data; NHS, 2023). Once diagnosed, T1D requires the use of daily intensive insulin therapy, self-administered via injections or insulin pump. For families to undertake this task, there is guidance via an extensive education programme covering insulin delivery, dosage adjustments, blood glucose monitoring, managing illness with T1D, the impact of diet and exercise, and detecting hypoglycaemia, hyperglycaemia, and ketosis (National Institute for Health and Care Institute [NICE], 2015; Olinder et al., 2022). Generally, delivering this education is the responsibility of a specialist paediatric diabetes team and, dependent on age, parents are most likely to take responsibility for learning about and overseeing ongoing care.

There are some geographical differences in initial diagnosis and management for children with T1D; practices vary from minimal hospitalisation combined with homecare to longer hospital stays (Clar et al., 2007). This often depends on the child's medical condition at presentation; for example, if children present in an emergency. Research has found no difference in relation to metabolic control of T1D between hospital or home treatment; however, there are benefits reported by parents of homecare connected to the ability to learn in the framework of their day-to-day lives (Lowes et al., 2004; Gregory et al., 2019).

Generally, research has considered parents' experiences of T1D diagnosis within the wider context of adapting to life with T1D. This research has found that distress for children and parents at the point of T1D diagnosis and during initial adjustment is common; the period immediately post-discharge has been considered the most difficult, with younger children and their parents often struggling more (Heilporn et al., 2019; Jonsson et al. 2015; Simms & Monaghan, 2016; Simpson et al., 2021; Sousa et al., 2022). Common experiences for parents at diagnosis include shock, overwhelm, grief, sadness, anger, hopelessness, devastation, guilt, and stress/anxiety (Heilporn et al., 2019; Holstrom Rising & Soderberg, 2023; Kingod & Grabowski, 2020; Lowes et al., 2004; Rankin et al., 2014a; Simpson et al., 2021; Sousa et al., 2022; Theofilou & Vlastos, 2023; Tong et al., 2022). Most parents report little prior knowledge of T1D, and the unexpectedness of the diagnosis adds to feelings of overwhelm (Holstrom Rising & Soderberg, 2023; Lowes et al., 2004; Rankin et al., 2014a).

The combination of high emotions and low T1D knowledge is likely connected to further widespread reports that parents struggle with the high volume of information shared at the hospital following diagnosis (Heilporn et al., 2019; Holmstrom Rising & Soderberg, 2023; Kimbell et al., 2021; Kingod & Grabowski, 2020; Rankin et al., 2014a). One study, specifically exploring parent support needs at diagnosis, found that parents wanted more emotional reassurance from professionals before being expected to absorb complex information (Rankin et al., 2014a). Theoretically, this would likely be beneficial to both the emotional processing of the diagnosis and the learning required, as strong emotional reactions are linked to a difficulty in information recall (Schwabe & Wolf, 2010). Irrespective of emotional content, patient recall of medical information is a huge challenge; it is proposed that

between 40-80% of information is immediately forgotten (Kessels, 2003; Ley, 1988; Townshend et al., 2023). For a condition like T1D, the impact of emotions on information recall is particularly pertinent given the requirement of that information for effective management of the condition on discharge from hospital.

On transitioning home, parents have reported low self-confidence, high uncertainty, difficulties recalling information in stressful situations (e.g. night hyper- and hypoglycaemia), and need for more information to prepare for day-to-day challenges (Heilporn et al., 2019; Holstrom Rising & Soderberg, 2023; Kimbell et al., 2021; Kingod & Grabowski, 2020; Rankin et al., 2014a; Sousa et al., 2022; Tong et al., 2022). In another study, exploring education needs, parents gave their opinion on preferred educational stages via a card-sorting task (Marker et al., 2021). The parents' shared they would have preferred education extended over the first 12-months from diagnosis covering broader, longer-term needs. For example, parents suggested a basic education refresher at six months alongside support for communicating with others, managing diabetes distress and burnout. For T1D longer-term, the mismatch between parental needs and the focus of information/knowledge sharing of clinicians has created disconnect, with parents consequently leaning more towards peer-support (Kimbell et al., 2021; Kingod & Grabowski, 2020). Research also suggests that while parents adjust to the practical management of T1D over time, psychological adaption can be more difficult (Bowes et al., 2009; Holstrom Rising & Soderberg, 2023; Kimbell et al., 2021; Kingod & Grabowski, 2020; Marker et al., 2021; Simpson et al., 2021; Sousa et al., 2022; Tong et al., 2022; Watt, 2017).

The psychological impact of T1D on parents should be of central consideration in paediatric diabetes teams at diagnosis and beyond. Longer-term

parental distress has been connected to lower child wellbeing, lower child quality of life, and poorer management of the condition (Whittemore, 2012). This could be considered in the context of ecological systems theories of child development, which posit that a child's development and wellbeing is influenced by a series of interconnected environmental systems around them (from the family system to wider society) (Bronfenbrenner, 1979). From this perspective, focusing on improving the systems around the child will ultimately benefit the child at the centre. Alongside parents, the health system and health professionals are another key influence on child wellbeing during the T1D diagnosis process.

Sharing a new diagnosis has often been considered within the frame of 'breaking bad news' or 'sharing life-altering information' (Berger & Miller, 2022; Buckman, 1984; Wolfe et al., 2014). Several general communication models have been developed to support doctors sharing difficult diagnoses (Baile et al., 2000; Narayanan et al., 2010; Rabow & McPhee, 1999), with a small number of attempts to create paediatric and condition-specific models (Boyd et al., 2001; Cunningham et al., 1984; Macdonnell et al., 2015; Wolfe et al., 2014). In these later examples, key adaptations included training focused on parent stories and more team reflection spaces (pre- and post-diagnosis). However, 'event' specific models of sharing life-altering news can be viewed as somewhat reductive by not recognising longer-term processes. This is particularly important in communicating paediatric T1D diagnosis as longer-term patient/health professional care relationships are necessary.

Research has identified challenges related to clinicians' ability to confidently and competently share life-altering information with patients (Bousquet et al., 2015; Monden et al., 2016; Studer et al., 2017). These challenges have included lack of time, difficult internal communication between health professionals, difficulties

managing the emotional content of the communication (including own emotions, as well as those of patients) and lack of training. As technical 'skills-based' difficulties only account for part of this process, there has been a move towards understanding the experience in more relational terms. These models of best practice incorporate relational processes by placing mindfulness of connection and the emotional relationship at the heart of effective patient/professional communication (Davies et al., 2017; Tranberg & Brodin, 2023). Interestingly, some evidence suggests that an increased focus on addressing emotions through 'affective' communication, as opposed to technical communication, can increase patient recall of information (van Osch et al., 2014). However, the research concludes that to support clinicians to share information in this way requires a shift in the way training is provided (Davies et al., 2017; Tranberg & Brodin, 2023). This would include more focus on human-to-human interaction and time/support to reflect on clinicians' own needs in that task. To date, there has been no research exploring clinician experiences of sharing paediatric T1D diagnoses, which is a significant gap in the literature. The complex task in paediatric T1D diagnosis requiring professionals to be cognisant of the 'event' of sharing life-altering news, the transfer of extensive medical information, and requirement for longer-term patient/professional care relationships makes this an area of research important to improving practice.

Current study

The complex tasks of sharing/processing life-altering news and transferring/learning extensive medical information in paediatric T1D diagnosis creates challenges for both parents and clinicians. The current study sought to

expand on existing research by systemically exploring for the first time both parent and clinician experiences of T1D diabetes diagnosis at a large UK hospital in Wales. These perspectives were selected to represent the key systems influencing child wellbeing and initial adjustment during T1D diagnosis. It utilised a participatory action research (PAR) framework with the objective of identifying whether and how this process could be improved to better support parents and clinicians. The PAR methodology involves collaboration between researcher and participants through systematically combining academic-research knowledge with local, lived experience-led knowledge to support understanding of a situation to inform action or change (Koch & Kralik, 2006; Raynor, 2019). This is a research approach that strongly aligns with NHS values and healthcare principles of person-centred/family-centred care (Shen et al., 2017). The process encourages understanding and action that is historically, culturally, and contextually situated (Baum et al., 2006), improving the relevance of research to practice (Shen et al., 2017). The study culminated with an action plan specifically for the hospital involved that was collaboratively developed and owned by participants.

Methodology

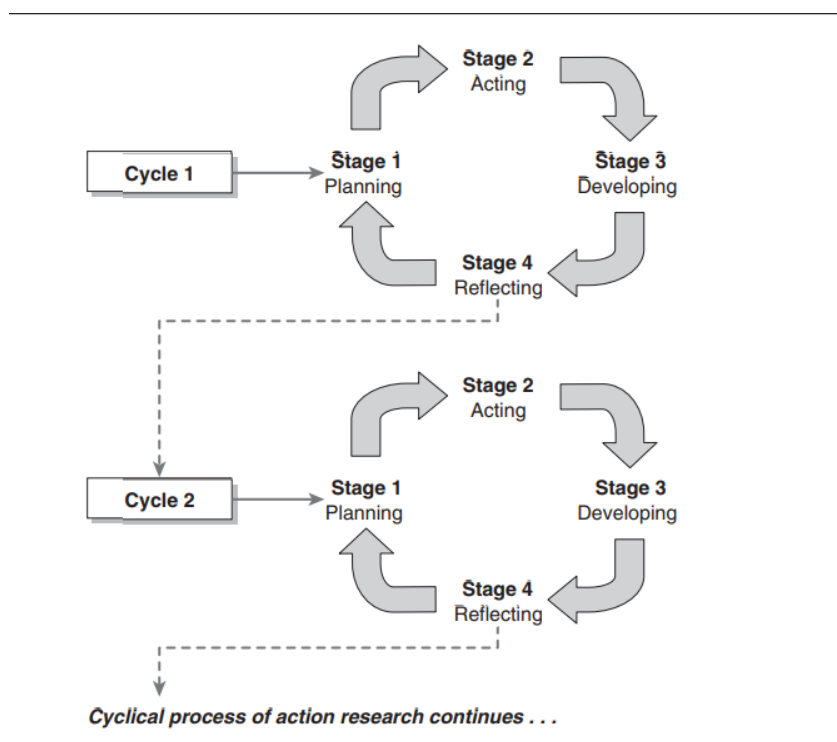
Design

The study design was guided by the underlying principles of PAR: (1) maximising participation (2) enabling people to take action (3) adding local value (Abma et al., 2018; p.8). A fundamental tenet of PAR is that it commences with interest from a group or community (Stringer, 1996, 1999); it recognises the importance of trust and reciprocity to the research process, and it is seen as

beneficial for the researcher to be, or become, part of the community/group they are researching (Lenette, 2022). The initial idea for the research question came from potential participants whilst the first author was on a clinical placement with the local child health psychology service. The first author therefore had existing relationships with the clinicians and some parents.

The PAR process is a reflective cycle with data collection and analysis determining action (Baum et al., 2006; Mertler, 2019). Participants are collaboratively involved throughout that cycle and, ultimately, take some ownership, often referred to as 'co-researchers' (Lenette, 2022). Further details of participant involvement in this study's reflective cycle will be elucidated within the relevant sections. The PAR cycle is iterative and this study represents the first 'planning' part of the PAR cycle of change (Figure 1).

Figure 1: Process of action research (taken from Mertler, 2019, p29)



The positioning and values of the researcher are important influences within PAR. The researcher/first author holds a pragmatic epistemological approach, respecting that there are many different ways to view the world and no single point of view can provide a complete understanding (Morgan, 2014). Central to the pragmatic epistemology is the importance of human experience, it takes a process-based approach to knowledge strongly connecting research/inquiry and action (*ibid.* Morgan, 2014). Utilising human experience as a starting point, knowledge from this standpoint is viewed as inherently contextual, emotional, and social. This positioning influenced the research design decision to utilise PAR and to incorporate multiple perspectives/experiences. For the researcher/first author, this multiple perspective approach is further influenced by an underpinning philosophy of a participatory worldview, "learning to look at the world through a different lens, one that sees the world in relational terms" (Abma et al., 2018; p.19).

Participants

Following ethical approval (Bangor University sponsorship, Research Ethics Committee, and local health board research and development; Appendices 2-4) parents were recruited by postal invitation including full bilingual participant information and consent form (Welsh and English) (Appendices 5-7). All parents contacted had children who were recently diagnosed (previous three years, 2021-2023) at one local UK hospital when their child was under the age of 12 years (parents contacted, $n = 25$). Parents of younger children were chosen due to this being the first 'peak' in diagnosis of childhood T1D, the higher responsibility for management placed on parents of younger children, and the time period being

associated with greater parental distress at diagnosis (Jonsson et al., 2015; Patton et al., 2022).

Parents confirmed interest in participating either by emailing the primary first author or through contact with the diabetes team. Parents had the opportunity to ask questions to complete the informed consent process. Nine parents were recruited and represented seven families/children (with two sets of parents attending together). Participants included mothers and fathers, with higher representation of mothers. Two families had a family history of diabetes. There was higher representation of parents of children diagnosed between the ages of 1-5 years old (Table 1).

Table 1

Parent participant characteristics

Parent	Child age at diagnosis	Family history of diabetes
Parent 1, mother	5 years old	No
Parent 2, mother*	5 years old	No
Parent 3, father*	5 years old	No
Parent 4, mother	9 years old	No
Parent 5, father	4 years old	Yes
Parent 6, mother*	5 years old	Yes
Parent 7, father*	5 years old	Yes
Parent 8, mother	8 years old	No
Parent 9, mother	1 year old	No

**Mother and father of one child*

Clinicians were recruited via email with an invitation to participate in the research with full bilingual participant information and consent form attached (Welsh and English) (Appendices 8-9). Clinicians confirmed interest by replying to the email. Clinicians were provided with the opportunity to ask questions to complete the informed consent process. Five clinicians were recruited. All were health professionals involved in T1D diagnosis and represented all roles within the multi-disciplinary diabetes team. This included a consultant paediatrician, two specialist diabetes nurses, one dietician, and a clinical psychologist. Two further professionals initially expressed interest in participating and would have represented staff involved with diabetes diagnosis on the paediatric ward. Unfortunately, they were unable to attend the focus group on the day due to clinical demands.

Data collection

Research using PAR is not method-specific and can use a range of methods to achieve its aims (MacDonald 2012). Semi-structured focus groups with parents and clinicians were utilised for data collection (focus group schedules, appendices 10-11). Focus groups were utilised (as opposed to individual interviews) to support the collaborative and relational objective of a PAR approach. The focus group schedule was shared with potential participants/co-researchers at the design stage and feedback was gained. Data were collected in two focus groups, one with parents and one with clinicians. Focus groups were completed face-to-face in February 2024 in the hospital. The groups were facilitated in English only due to the principal investigator not being able to speak Welsh and all participants either being first language English or bilingual. This may have precluded some Welsh speakers from taking part and / or precluded participating Welsh speakers to contribute in their

preferred language. Focus groups lasted approximately one hour and were audio recorded and transcribed in full by the first author.

Data analysis

Data were analysed using the process for reflexive thematic analysis (Braun & Clarke, 2006). This approach was chosen due to its flexible epistemological approach and accessibility for collaboration with non-academic participants. Analysis was completed by the first author and refined in collaboration with all co-researchers, including co-authors and participants (Table 2, data analysis process activities). Two reflective groups with participants supported the data analysis and creation of the proposed action plan (Figure 2, timeline; Appendices 12-14 for PowerPoint presentations used to support the reflective groups). Involvement of the co-authors and participants in analysis provided checks on the first authors interpretation of data, providing support for the quality and rigour of the analysis. The third author was independent to the local hospital and service to provide an outside perspective on analysis to further support research rigour.

It was intended that the participant reflective groups would include both parents and clinicians together; however, due to a limited timeframe and constraints on both families and clinician timetables, it was not possible to do this for the first session and separate reflection spaces were held (parents, $n = 3$; clinicians, $n = 4$). The final session was attended by parents and clinicians together (parents, $n = 4$; clinicians, $n = 4$). Participants who could not attend reflective sessions provided feedback on reasons for not attending, including work commitments ($n = 3$), holiday ($n = 1$), other medical appointments ($n = 1$), and child illness ($n = 1$).

Figure 2

Timeline of collaborative activities with participants

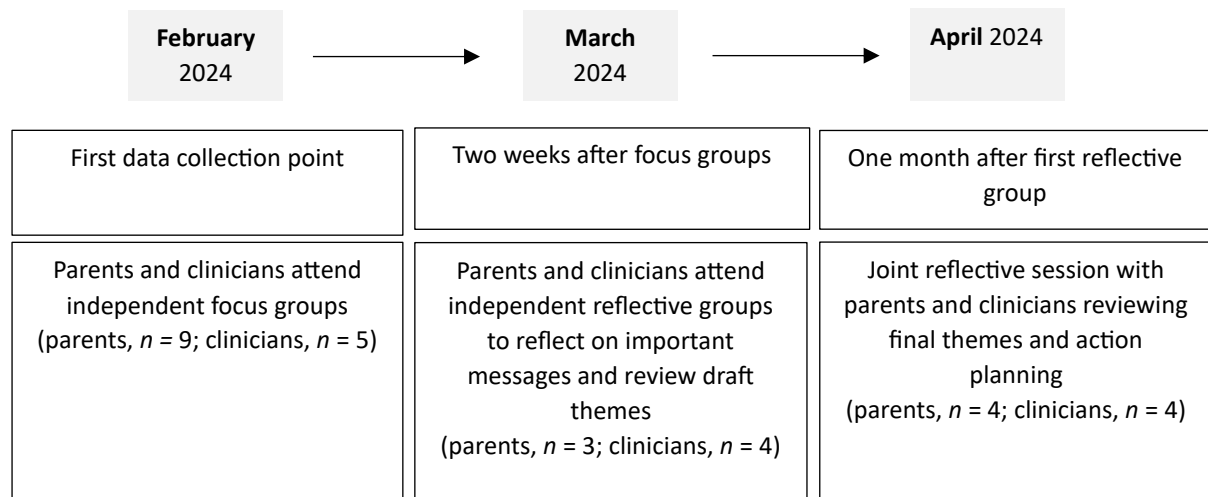


Table 2

Data analysis process (Braun & Clarke, 2006)

Stage of process	Activities that supported analysis
Stage 1: Familiarisation	<ol style="list-style-type: none">1. Transcribing the focus groups2. Two additional complete read-throughs of the transcribed focus groups3. A reflective log was started prior to the focus groups and maintained throughout the research process. This supported all stages of analysis. During familiarisation stage, this included, noting initial ideas of what was in the data and any potential interesting patterns that were returned to at later stages of analysis
Stage 2: Generating initial codes	<ol style="list-style-type: none">1. Inductive analysis was applied, with initial codes derived from the transcripts2. Transcripts of parent and clinician focus groups were analysed separately3. Line-by-line coding was completed on the transcripts within Microsoft Word through use of the comments function. Codes began to descriptively capture the meaning participants had made of their experiences of diagnosis (Appendix 15, coding extract)
Stage 3: Searching for themes	<ol style="list-style-type: none">1. Codes and connected data from transcripts were extracted into a Microsoft Excel spreadsheet2. Initial codes and data from parent and clinician focus groups were extracted separately3. Searching for themes involved refining and organising codes within Microsoft Excel to collate codes that seemed related or had similar meaning. This process resulted in initial potential themes4. Potential themes were reflective of ideas that had been repeated by several participants at several different points within the data (i.e. decided based on frequency)

Stage 4: Reviewing themes

1. Feedback and reflection on potential themes was completed with co-authors and some collaborative changes were made to the descriptive labels of themes
2. The first reflective sessions with participants were held at this stage of analysis (2-weeks after the focus groups)
3. Participants were first asked to reflect on what they felt were the most important themes or messages from the focus group. This was done to provide an opportunity for an unbiased check of the researchers' own interpretations
4. The potential themes were then presented to the participants and they were able to provide further feedback on whether they felt those had captured what they felt was important

Stage 5: Defining and naming themes

1. At this stage, there was reflection between the first author and co-authors as to whether data and themes for each group remain separate or be combined. Due to the overlap between the themes of both groups, and to present the data as a relational/interactional process, the decision was made to synthesise the data/themes, whilst respecting any individual themes as the lens through which each group viewed the process
2. Data and themes were synthesised and decisions made about what to prioritise in the final combined themes. These decisions were driven by participants' reflections on the most important aspects of the focus group conversations
3. A second reflective group was held with participants to present the refined themes and create an action plan
4. Further meetings with second and third authors provided opportunities to reflect on the overall story of the data and what was important about the themes and why

Stage 6: Producing the report

1. Write-up of the report provided further opportunity to refine presentation of the themes and clarify the story of the data
 2. Feedback from second and third authors on the drafts of the report provided further opportunity for reflection and clarification of meaning
-

Results

Analysis resulted in six themes, two independent and four shared.

Independent themes were those generated from data from primarily one group (i.e. parents or clinicians) and shared themes were those generated from substantial data from both groups (Table 3). Independent themes are described first as they represent the unique perspectives/influences of each group within the process of diagnosis. All themes were highlighted within discussions with participants in the first reflective groups around most important messages (Appendix 14, Reflective Session 2; PowerPoint, slide 4 [table showing most important messages from perspective of participants]).

Table 3

Overview of themes

Theme	Perspective
1. The limits and pressures on clinicians and the system ^b	Clinician
2. Parents' emotional lens at diagnosis ^a	Parents
3. The power of knowledge ^a	Shared
4. Difficulties with communication and transparency ^{a, b}	Shared
5. Conditions for learning, adjusting, and forming relationships ^{a, b}	Shared
6. Sharing experiences & gaining support ^{a, b}	Shared

^a *Highlighted as important by parents in first reflective session*

^b *Highlighted as important by clinicians in first reflective session*

Limits and pressures on clinicians and the system

This theme, represented primarily by clinicians, highlighted that diagnosis took place within a system that had limitations and pressures. There was very little discussion about the limits and pressures on the system in the parent group, aside from one parent reflecting this was not at the front of their mind during diagnosis. Some of these limits and pressures were within the specialist diabetes team, others were within the wider hospital system. Clinicians discussed competing demands on their time due to other parts of their role, which limited flexibility within the process of diagnosis.

We do try and prioritise [diagnosis] because if you don't get it right with newly diagnosed then... but then we may have to cancel numerous calls that we may have got on our calendar on that couple of days and then some you can't"
(Clinician 3)

Clinicians shared that competing demands on their time created a felt pressure to communicate the required information to parents that was sometimes in conflict with parents' readiness to receive that information. Clinicians repeatedly highlighted that every family and diagnosis was different in relation to needs and readiness, connected to the need for person-centred care. The mandatory need to transfer information to allow for diabetes management at home appeared to make person-centred care more difficult.

Sometimes, there's a pressure on us, like we have to go and give them this information but actually, if you think of yourself and someone giving you information... I probably would have switched off after a few minutes. So you

have to not think of what you need to deliver but actually what they can absorb in that time (Clinician 5)

Staff changes and hospital pressures resulted in difficulties ensuring general doctors and ward staff were up to date with T1D knowledge and able to feel confident and competent supporting diagnosis. Some participants reflected that having a specialist diabetes team could 'disempower' or 'deskill' ward staff, which contributed to the challenge of ensuring effective holistic support after diagnosis. It was also suggested that there was an element of avoidance or discomfort from general doctors and ward staff towards T1D. Clinicians noted misinformation about T1D being given on the wards and suggested that the nature of diabetes care, including the potential for making mistakes, impacted ward staff confidence and competence.

So I think we have really tried to make sure that all the ward staff are up to date, but that's quite difficult because it's quite a big change over [of staff].... We are trying to educate the staff but it's difficult to get more staff to come to education sessions because they're busy at the moment (Clinician 2)

When you've got specialist nurses you have to be careful because you're not taking the whole role of it. You can actually make people deskilled on the ward. So your job is actually to make sure that you empower those people and this is what we're doing with training sessions (Clinician 3)

A lot of staff on the ward actually really don't like or feel comfortable dealing with diabetes... Probably a lot of fear around it, like making mistakes (Clinician 1)

Parents' emotional lens at diagnosis

This theme, represented primarily by parents, reflected the overarching emotional recollections of experiences of T1D diagnosis. Clinicians expressed empathy for parents and the psychological challenges of coping with a T1D diagnosis. However, for parents, the prevalence and intensity of emotions reported during this phase became a lens through which everything else at diagnosis was seen. There was a clear emotional 'journey' as parents shared emotions from different phases of the diagnosis, from the lead-up, when first hearing the news, and after diagnosis (Table 4). These emotions made processing the new T1D information more difficult.

Table 4*Parent emotions at different stages of diagnosis*

Stage of diagnosis	Feelings	Supporting quotes
<i>Lead up to diagnosis</i>	<ul style="list-style-type: none"> • Fear / dread • Felt sense that “something is not right” 	<p>It was so scary, but you have no idea (Parent 9)</p> <p>...[there] was a bit of a build-up and then you [towards other parent] kind of thought: ‘God, I hope it’s not diabetes’ (Parent 3)</p> <p>So, now that I’ve got children, I was paranoid. I was checking their bloods.... I was checking while she was sleeping (Parent 6, with family history of T1D)</p>
<i>At diagnosis</i>	<ul style="list-style-type: none"> • Emotional overwhelm • Grief • Shock • Guilt/responsibility • Relief 	<p>Oh God, nothing. My head was just blank (Parent 4)</p> <p>You’re in this grief, shock, panic... erm, completely out of your depth zone... (Parent 2)</p> <p>Mine was relief for my diagnosis (Parent 8)</p>
<i>After diagnosis</i>	<ul style="list-style-type: none"> • Grief/sadness • Guilt/ responsibility • Isolation/ loneliness • Fear / dread • Gratitude • Hope 	<p>I couldn’t listen to anything they were saying. They were trying to get me to watch videos... And I just couldn’t...I just started crying at every tiny little thing (Parent 1)</p> <p>In the beginning, though, you think it’s the end of the world and to really miles ahead thinking, ‘he’s not going to be able to do this, and this, and that’ (Parent 9)</p> <p>Because I’ll see her in the bath and she has got the Omnipod on one side of her back and the Dexcom on the other side of her back. And she’s the only one in her class and you send her in there and I’ve sort of given that to her for the rest of her life, unfortunately (Parent 5, with family history of T1D)</p>

So, you've been monitoring for it. I feel that paranoia. I've pushed it onto the other two (Parent 2 [fear for other children])

I just felt like I was completely on my own. Nobody understood it. No one to talk to. It was very isolating (Parent 9)

So someone said to me you'd pick diabetes before a lot of things. And you think to yourself, it could be worse (Parent 7)

On the lead-up to diagnosis, the predominant feeling was fear. For those with no knowledge or history of diabetes, this appeared to be driven by having “*no idea*” what was going on. In contrast, for those with knowledge or history, fear was driven by experiences/expectations of the realities of life with diabetes.

At diagnosis, the primary experience shared was an emotional overwhelm and shock. Parents shared feeling guilty or responsible for the diabetes. For parents with low knowledge of diabetes, this guilt came from thoughts of “What have I done?” (Parent 1) that were sometimes linked to confusing type 1 and type 2 diabetes: “I thought it's my fault, I'm her mum. It's me that buys the shopping and feeds her” (Parent 4). In contrast, parents with a history of diabetes felt a personal responsibility due to the role of genetics. For other parents, after suspecting something was wrong and searching for the reason, they experienced relief.

After diagnosis, there was a continuity of feelings of fear and guilt as parents continued to process the news. Some of this fear was connected to the learning necessary for ongoing management of diabetes; one parent shared that discharge from hospital was “like being sent home with a new-born again” (Parent 9). Parents also discussed fears of their other children getting diabetes. The emotional overwhelm and guilt at this stage linked to experiences of grief and sadness, with parents grieving the life they had expected for their child in the face of the new reality of diabetes. This left some feeling isolated. In contrast, one parent experienced gratitude for the diagnosis of diabetes in comparison to other possibilities. There was also evidence of hope within parents' discussions of the future, especially connected to changes in technology.

The power of knowledge

The influence of knowledge and information was a key theme for parents and clinicians. In the reflective sessions, parents highlighted this theme as one of core importance as it extended beyond the initial diagnosis phase and had a pervasive impact on life with T1D. Parents and clinicians talked about the influence of pre-existing knowledge about T1D diabetes and about the impact of high versus low T1D knowledge of general doctors and staff on the wards.

Low knowledge for parents and staff resulted in delayed pathways to diagnosis, more myths/misinformation, and increased distress. For parents, pre-existing T1D knowledge was generally low. Out of the nine parents in the group, six had low prior medical knowledge and no family history of diabetes.

You don't really know what you're looking for. I mean you know the word diabetes exist and you know that people can get it (Parent 1)

I knew nothing. To me old people had diabetes, my chubby sister, do you know what I mean? (Parent 8)

Low pre-existing knowledge affected routes to diagnosis, with a more delayed pathway more commonly reported. This appeared to be due to two main factors; parents not having full awareness of the possibility of T1D emerging in very early childhood, and the potential to easily miss symptoms due to similarities with more common childhood issues.

Yeah, my [child] was diagnosed at 18 months old...I had no idea that was a thing... So young and to me, he was just unwell, like for a few weeks, he was wetting through, like you say, he was extra thirsty, but because obviously he's not talking, how am I able to know?... I just thought he was poorly and

there's not really much awareness. I hear a lot about Type 2, but nothing on Type 1 really and about the ages (Parent 9)

[Child] was five at the time and we just thought it was a growth spurt or hormones or, I don't know, just being a Rascal or whatever. Yeah, not sleeping and then the not sleeping became the issue... So then the moods tilted and then the behaviour tipped and it all just became a complete... bag of crap that you just didn't know how to go forward or backwards (Parent 2)

For clinicians, parents' pre-existing knowledge of diabetes had an impact on how they engaged with the information shared at diagnosis. Where parents had less knowledge, clinicians felt there was often a need to correct 'myths' or misinformation as "most people, when you speak to them think it's because they've eaten lots of sugar and things" (Clinician 2).

Both parents and clinicians highlighted the role that T1D knowledge of general doctors and ward staff had on diagnosis. Where there was less knowledge held by ward staff this, at best, added to the uncertainty for parents and influenced their confidence. At worst, there were examples of parents having to correct staff in management early on in their own learning about T1D. For clinicians, lower knowledge, incorrect advice, and mistakes created confusion to unravel and impacted trust.

And, then when it's about 10:00 o'clock at night and you're thinking, 'oh, I'll ask the nurse when she comes in a minute', and she comes and she doesn't know... They do apologise...but I'm thinking, 'if she doesn't know, I've got no hope! [Laughter] And they're sending me home with this kid!' (Parent 4)

[On realising ward staff had made a mistake] And I was the one that had to ring the bell and say, 'no, I've been doing the sums here as well'. And that was only our second day there (Parent 6)

So.. you know misunderstandings, like we've had people being told that they need a snack before they go to bed and that's old fashioned. Or...you can only have a correction at mealtime (Clinician 2)

Parents having high pre-existing T1D knowledge reduced the time to diagnosis. Parents with family histories of diabetes shared that they had been relatively quick to recognise early signs in their children, seeking medical attention sooner than parents with no prior T1D knowledge. This can be seen as a benefit to preexisting knowledge of T1D. However, clinicians also suggested that it could be a limitation, with these parents potentially being less open to learning as they may "feel they know everything already" (Clinician 2).

For doctors and ward staff, high T1D knowledge was reported by parents and clinicians to have had a positive impact on the initial diagnosis phase. For parents, this empowered them with the knowledge they needed to take on the responsibility of ongoing care. Within discussions, parents reflected the desire to have more 'in the moment' information about the practical management of T1D from ward staff. This desire made ward staff knowledge pivotal in their experiences of T1D diagnosis. Clinicians similarly iterated that positive early experiences with ward staff could make a big difference to early adjustment.

[The nurse that] had a three month secondment [with the diabetes team]...that was a game changer for [child], for me, because every question I asked, she actually knew the background information (Parent 2)

[After weekend of ward staff and parents doing injections and carbohydrate counting together] We came on Monday and it was just like, you know, you feel like it's a walk in the park... they were just at a better place really....That was really positive (Clinician 3)

Difficulties with communication and transparency

For parents, pre-diagnosis information varied. Only one parent was given an indication by their General Practitioner (GP) that their child may have diabetes. Parents reported that little to no information was provided by GPs. Several parents reported being sent to the hospital with no verbal communication of concerns – some taking only a sealed letter. This experience of difficulties with communication and lack of transparency increased parental fear.

I didn't understand, but that really frightened me. They were like, “you have to take him to hospital right away”. And there was this letter, and I was saying to myself... ‘you open it’ (Parent 1)

There was also often delay in diagnosis at the hospital and insufficient information shared with parents about the ongoing investigations. One parent had not been told that their child had diabetes before treatment started. Overall, this led to parents suggesting that improving communication and transparency throughout would be helpful.

No one actually told us she was diabetic... They didn't tell me anything. We were then moved to the ward and I was like “something's up”... We went to sleep... About two in the morning and they were like, “we're giving her an injection now”,

and I was like, “oh, iawn [okay], okay”. And then Doctor X came in the morning
(Parent 6)

I just wish they'd say, 'OK, we thought it was that and it was that. And it was, or
it wasn't that' (Parent 8)

Yeah, being transparent about what they're looking at... what's the possibility...
They don't share everything with you. I guess there's limitations, but you
know... (Parent 3)

Clinicians also discussed difficulties in communication. Clinicians assumed that
parents would have had prior communication or a suspicion about T1D before
reaching the hospital. Transparent and open communication from the GP about
concerns was seen as potentially helpful to parents prior to confirmation by the
hospital. At the hospital, the number of staff involved on the ward meant it was often
difficult to track what information had already been provided and by whom.

[In response to whether there was a set process for communicating a diagnosis]
No, because it depends at what point they come in... We can't control what
GPs say. I don't think it's a bad thing for them to have the heads up that that's
what they suspect. But ED [emergency department] could be literally anyone
and there wouldn't be a way we could do that. I mean, once they've got on the
ward... they have probably heard it or guessed it or almost definitely heard it
before any doctor comes along to officially say (Clinician 1)

You know, it's difficult here in that...a nurse does your obs [observations], and
then an SHO [senior house officer] and they'll often clock first and then a reg
[registrar] will come round after and then they'll speak. And so you're seen by
quite a few people, it takes quite a long time. ...And then maybe me

[consultant], if I come to them next and they've got all this information to untangle, have they been given the right information? ...but how much have parents been told already? It's not always clear from the notes (Clinician 2)

One parent had a child who had been admitted to hospital as an emergency. The parent and clinicians shared that this impacted communication as the emergency took priority.

[In an emergency] those parents are told diabetes but you can't talk to them very much because you're dealing with a child who is really acutely unwell, so that that's really hard as well (Clinician 2)

[During emergency admission] And because obviously they're just doing their job and they didn't have time to sort of tell me. I had no idea. I just knew he was really, really poorly (Parent 9)

Parents also reported a lack of communication or clarity about the ongoing process of diagnosis and initial treatment, including length of stay. Clinicians also discussed this uncertainty in the initial hospital treatment phase of diagnosis and expressed that they felt more communication/clarity about this could be beneficial.

But if you'd known it was going to be a week, it would be easier to plan than saying you'll have to stay in for the night... because we went home and got him stuff for the night.. sorted out care of the little baby at home [for one night] (Parent 1)

If one of my kids suddenly had [diabetes] and I came in on a Friday... I would be like, what's happening in the next week? I'd like to know, at some point on Monday, you'll be seen by the team and... you'll be in for, it depends, but usually on average it's about five working days, but it may be longer,

depending on how you're coping and how it is... I'd need that I think (Clinician 2)

In addition, parents shared that there was a delay in communicating what practical items would be needed to manage T1D after discharge, with one parent only finding out on the day of discharge that they would need a mobile phone for monitoring. A suggestion was made that being given early practical information about necessary equipment and resources would be helpful.

We didn't know we needed a phone for her with the monitor because they only told us... [P6: A few hours before]... It was very rushed... [It would be good to be told] 'She's diabetic, you might need whatever' (Parent 7)

You almost need a list of [P9: What to get]... Cream for her skin to get the [sensor for glucose monitoring] off... start thinking about the phone and the phone contract. Start thinking about these kind of things (Parent 2)

The conditions for learning, adjustment, and forming relationships

Clinicians and parents both discussed the initial time in hospital after diagnosis and whether the environment provided the conditions for learning, adjustment, and forming relationships between parents and healthcare professionals. Clinicians repeatedly emphasised that a positive early diagnosis experience led to better future engagement with the team and management of T1D. This was expressed in terms of ensuring information was transferred effectively, but more so, to clinicians, it was about the beginning of the care relationship. Clinicians saw this as a strength within diagnosis.

I think if we get this relationship right with them in the beginning, it just makes things so much easier, doesn't it? And it's the ones that don't want to come back because they've had bad experiences, it's keeping them coming back to us, which is important, isn't it? (Clinician 2)

I think we build up a good rapport with them, don't we? (Clinician 4)

Due to the geographical dispersion of the local area, clinicians recognised that they did not have the same flexibility as other areas to utilise home visits. To clinicians, this meant that the initial hospital stay was crucial to initiating that relationship and early care. There were some disagreements as to the 'ideal' length of that stay. Clinicians had agreed a general guideline of five days; however, it was suggested that this was too short to account for systemic challenges, allow parents time to process the news, and to transfer the knowledge required for self-management. This was connected to a feeling that parents primarily required *"time and compassion...it can be very, very overwhelming"* (Clinician 1).

I've always been quite strongly of the view that they should stay minimum of two weeks to make sure they see everybody... I've always being worried that we send people out too quick with a great big bag of equipment and a load of leaflets (Clinician 1)

Clinicians and parents shared experiences and concerns that the ward environment may not be the best setting for supporting a positive diagnosis experience.

And I find that I feel quite guilty, that they're stuck in a bay with potentially a load of other noisy, sick kids. They probably haven't slept well for a few days..

If we're only giving them this amount [of diabetes education] every day ... And I know it takes time to give but it must be really hard (Clinician 2)

And you're sat there all day, all night. And I'm 53, nearly, and it's knackered for me. I'm tired and I'm sat there with this ill child... and you think, this is boring, tell me [the information] (Parent 8)

In further discussions about the suitability of the ward environment, both groups noted additional barriers to early learning and adjustment. Firstly, parents reported that the food provided during admission was carbohydrate heavy (all toast, chips etc.), which made it more difficult to initially stabilise blood sugars, was not reflective of their diet at home, or good modelling of the recommended diet for supporting management of T1D. Secondly, parents shared that there was difficulty accessing the weighing scales on the ward to support carbohydrate counting, resulting in them not being able to complete carbohydrate counting with staff on the ward and in food being cold by the time children were allowed to eat. Finally, clinicians reflected on the sedentary nature of a long hospital stay making T1D management more difficult and not reflective of their normal day-to-day needs.

I mean, it's like the food he was given for that five days was a horrific Type 1 diet. You know, it was all like white bread, pasta, sugary puddings, like Rice Krispies (Parent 1)

One thing that was an issue was that the weighing of the food, there was only one weighing scale. [P9: Yeah. That little thing? And it would be cold by the time...]... 'Ohh, no, it's not that you can't eat that because of diabetes, it's because we can't get into the kitchen' [parent mimicking explaining delay to child] (Parent 2)

And it's hard working out their insulin requirements, if they're not active, lying down all the time (Clinician 4)

One potential solution reflected on by clinicians within the focus group for improving initial experiences of diagnosis was previous experiences of facilitating 'leave' from the ward. These discussions centred on how this may support early more positive adjustment to T1D and improve the relationship with hospital staff.

Like just some fresh air. A change of scene. And yeah, I think that actually helps a little bit with the trust as well, because I think a lot of them do feel like they're being judged (Clinician 1)

I remember someone asking, when I first started, to go to a Halloween party, and I remember being really sceptical about it. And I remember the consultants agreeing to [the party]... because he [consultant] just wanted it to be, you know, normal. And I was like, 'ohh... a Halloween party where you're just gonna be exposed to all of these things'. But, do you know what? They were allowed to go and it was a positive experience (Clinician 3)

Sharing experiences and gaining support

Both parents and clinicians talked about needing more space to connect with others who had shared experiences as a way of gaining support. Parents felt that a lot of the support wanted and needed after diagnosis could be provided by other parents, including through support groups: "Yeah, they should have a support group... It's good to meet other people, isn't it, that are going through similar?" (Parent 9).

However, there was also recognition that adjustment to T1D was difficult for parents, who did not always feel able to seek support for themselves. Some parents thought this could be helped by more direct acknowledgement by health professionals to encourage them to seek additional support when needed, including more information about the availability of support from clinical psychology. One suggestion to support this was to provide more structure to how early psychological support was offered.

Yeah, because you as a parent feel... your emotion and everything... but... it's not me, it's my child and you think, 'I can't be selfish. It's not me that's going through it'. But you need someone there as well (Parent 4)

And I don't think people understand what it's [psychology] there for either. I mean because you know you're gonna have help with a dietitian, help with a nurse... and then they say simply that [the team can] support psychologically kind of thing. But, what? But, if it's explained, you know for you to adjust, for the child to adjust, for the family to adjust and, 'ohh yeah', suppose that makes sense because it's a big change.. it's just labelled as the psychological support and you're going to think, 'why do I need that?' (Parent 3)

[Talking about structure/timing of psychological input] I think definitely there should be a bog standard three months down the line and again every month there after until patient or the family or whoever it is says, actually, 'I don't need this service' (Parent 2)

Clinicians also reflected on the pressures T1D management put on parents and their role in acknowledging, normalising, and validating experiences to improve

support. There was a suggestion that the demands of T1D management was only increasing with new technology.

I think some parents have like, some trauma from the diagnosis, you know. I was speaking to one parent this morning that has two children with diabetes. And she said, 'I know they're doing absolutely hopeless. But, I hate having two children with diabetes. I don't want my children to have diabetes'. So you know, we can look at the data we say, 'oh, they're not doing this and not doing that' and actually judge them. Actually, if I was in that situation, I would be useless for my children and I might not be doing much better than they're doing....So, I think we need to maybe think that actually the parents might be really struggling (Clinician 5)

You know what I think sometimes about the pressures, and I know why we've got Psychology in our team... we've obviously gone from giving injections to all of this [technology for monitoring] (Clinician 3)

Clinicians also felt that more space to connect and reflect with each other, and others involved in diagnosis, would support the team and help facilitate learning to improve practice. Clinicians thought this would be helpful on a broad level and also on a case-by-case basis for each diagnosis.

That we never get an opportunity to sit around and talk about things like this and hear from our colleagues, other professionals. And wouldn't it be nice if sometimes our staff could sometimes fit in, and just have some directive topics and how do you feel about that? That would be really useful (Clinician 1)

I mean, there's only one patient that I thought was going to die. He was really sick, but it's interesting that we didn't really have a debrief after that. Actually, it

would be quite nice just to have a cup of tea when someone's gone home. Just go, how do you think that went? (Clinician 2)

Now that's something I said that the end of the meeting under any other business, was that I feel a bit sad that we don't have more time together as a team (Clinician 4)

Action plan

The identification of the above themes allowed the creation of a collaborative action plan with participants. Some potential actions had already been identified during the focus groups and these were further refined and discussed in the second reflective group (Appendix 14, second reflective session PowerPoint). The actions are organised here around the four shared themes (Table 5

Table 5*Proposed actions*

Theme	Proposed actions
<i>The power of knowledge</i>	<ul style="list-style-type: none">• Facilitate a reflective space for general doctors and ward staff to gain their perspective on difficulties with diabetes diagnosis and T1D knowledge• Review options for funding to create a local bilingual introductory information video with parents that could be shared with new families, reviewed by staff when new diagnosis on the ward and with wider family members and school staff• Parents to review information materials shared with parents when first diagnosed
<i>Difficulties with communication & transparency</i>	<ul style="list-style-type: none">• Share the research with GPs to raise awareness of communication difficulties at initial stage• Create a communication sheet for the diabetes team to keep track of what has been shared with parents and how they are getting on (e.g. how they are adjusting/coping, areas of understanding/education that are strong or they are struggling with)• Create a 'practical necessities' list to add to information provided to parents at diagnosis• Increase communication about the early process; timeline of initial hospital stay, who they will meet, roles of diabetes team versus ward staff, and what information is required to be transferred• Consider a conversation with parents to identify a 'learning plan' to support early education (i.e. identify parts of information/learning they are more concerned about (e.g. injections versus calculations))
<i>Conditions for learning, adjusting & forming relationships</i>	<ul style="list-style-type: none">• Consider a more active offering of 'leave' from the ward to allow families a break/more stimulation and 'test' learning in real-life activities• Highlight weighing scales on the list of necessities and parents encouraged to bring them in from home to facilitate early learning and ease difficulties at mealtimes

-
- Team to review options for funding to purchase weighing scales to share with newly diagnosed families on the wards for them to use
 - Consider repetition of early education in early clinic appointments

Sharing experiences & gaining support

- Continue collaboration between the team and parents, through:
 - Confirming agreement from all parent participants that they are happy to be contacted by the team for the proposed actions
 - Provision of regular protected space within quarterly team away days to have interested parents join, connect, and reflect together (purpose to review actions here but potential for wider)
 - Further space to reflect and develop wider engagement with parents. Proposal for use of surveys as part of continual review of diagnosis experiences
 - Maintain newly established under 5s newly diagnosed group (this has been widely engaged with). Clinicians reported historic difficulties with engagement with parent support groups due to geography of area. Based on the response to under 5s group and parents highlighting peer support, review whether more specific parent support groups are more relevant than generic
 - Consider providing more information and structure to psychology support, including:
 - Repetition of role of psychology with newly diagnosed families in early clinics
 - Maintaining role of psychology, where possible, in annual reviews
 - Potential provision of annual newly diagnosed group session to provide space to reflect on the early adjustment phase and connect with other parents at a similar time-point
 - Raise and maintain clinician awareness of importance of connecting and reflecting with each other, as much as is possible
 - Consider providing more spaces for clinicians to facilitate post-diagnosis learning and debriefing, for example:
 - Informally checking-in after a diagnosis
 - A formal post-diagnosis team meeting to think about each individual diagnosis and to consider a plan for the individual needs of that family
-

Discussion

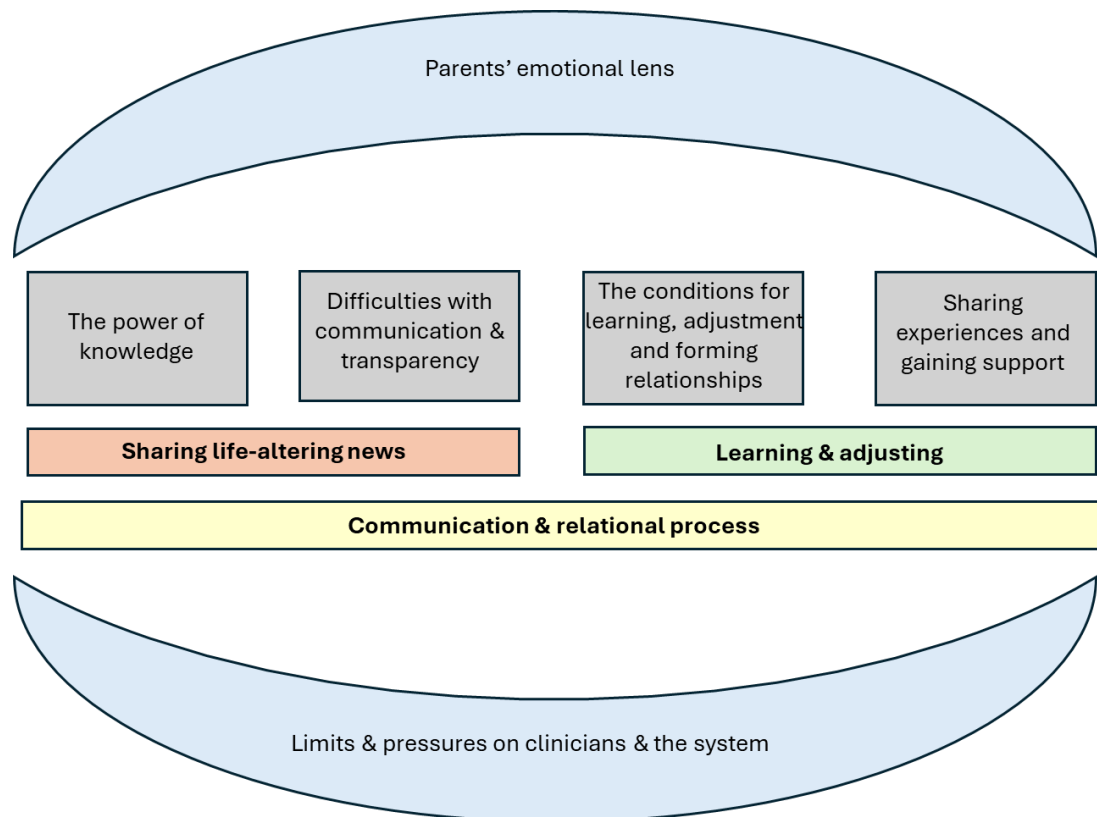
This study provides a unique contribution to our understanding of T1D diabetes diagnosis from the perspective of both parents and clinicians. This understanding has been created in collaboration with the participants, resulting in an action plan to support improvements within the local system. The study identified themes that reflected a somewhat chronological, interactional process that is entered into by those involved, with their own unique perspective and influences. These perspectives could be conceptualised as the 'lenses' through which diagnosis is viewed. The independent themes of *the limits and pressures on clinicians and the system* and *parents' emotional lens* reflect that the people involved in diagnosis are both impacted by stress in various ways. The pressure and emotions from the different perspectives then interacted and influenced the shared themes of *the power of knowledge, difficulties with communication and transparency, the conditions for learning, adjustment and forming relationships, and sharing experiences and gaining support*. There was a strong connection between systemic difficulties and parental distress. Therefore, focusing on improving the system and processes around diagnosis could have a positive impact on initial parental experiences and early adjustment.

Bringing these two perspectives together has highlighted difficulties inherent in sharing/processing life-altering information *and* facilitating the learning required to support effective T1D self-management. Arguably, T1D is unique in there being limited choice or flexibility in relation to the volume of information that must be shared in the emotionally sensitive phase after diagnosis. The challenges that have been highlighted within the findings reflect the complexity of the task and concurrent

processes that exist within this window of time. The below figure visually represents the themes and the associated processes (Figure 3).

Figure 3

Model of themes and associated processes



The study supports existing research that reports difficult emotional experiences for parents on diagnosis of T1D (Bowes et al., 2009; Commissariat et al., 2019; Kingod & Grabowski, 2020; Sousa et al., 2022). In line with previous suggestions from research, low pre-existing T1D knowledge appeared more likely to delay the pathway to diagnosis and to increase parental distress at diagnosis (Holstrom Rising & Soderberg, 2023; Lowes et al., 2004; Rankin et al., 2014a; Rankin et al., 2014b). Also highlighted in this study was that experiences of low T1D

knowledge of staff on the wards also increased distress for parents during the initial diagnosis phase. Parents with greater pre-existing knowledge due to a personal history of T1D shared similar experiences of distress but with different underpinnings (e.g. in relation to personal guilt/responsibility). Supporting greater T1D knowledge in the wider health system may reduce parental distress during diagnosis. It would also be beneficial in practice to be aware of the potential different underpinnings of distress for parents with personal/family history of T1D. Further research could investigate if this is a broader theme and how that emotional experience impacts their longer-term engagement/connection with services.

The importance of T1D knowledge, the variation in knowledge and the impact of this on diagnosis and beyond was very clear throughout conversations with participants. In the first reflective group, parents described difficulties with *“knowledge from every direction [health professionals, schools, family/friends]”*. This was identified as a lifelong burden of living with T1D and is likely related to the difficulties gaining support from others that has been highlighted in wider research on T1D (Kimbell et al., 2021; Simpson et al. 2021). Therefore, broad improvement of knowledge of T1D, such as in a public health campaign, has the potential to improve both the initial diagnosis experience and ongoing support, both of which impact parent psychological wellbeing. Connected to this, one action suggested in the second reflective groups was for the participants to create a bespoke local informational video that could have a broad systemic reach, including new parents, their related support networks (family, friends, and school), and hospital staff (Proposed Actions, Table 5).

Both parents and clinicians identified difficulties with communication and transparency. Parents highlighted that difficulties with communication and transparency increased their distress during diagnosis and so improving this is

another systemic way of containing the emotions present during this time.

Participants were able to consider solutions to improve that in their specific context, including sharing findings with GPs and creating/adapting communication sheets to keep track of information shared (Proposed Actions, Table 5). To support the sharing of key learning around this with the wider hospital staff, existing communication models could be further adapted to include factors unique to the setting and T1D that have been illustrated here (e.g. Baile et al., 2000; Narayanan et al., 2010; Rabow & McPhee, 1999).

However, the results also highlighted that communication difficulties were contextually located. Contrary to other research, clinicians did not highlight a need for additional training in communication skills or managing the emotions associated with sharing difficult information (Bousquet et al., 2015; Monden et al., 2016; Studer et al., 2017). The provision of good practice suggestions alone de-contextualises the problem by not recognising that the system often limits healthcare professionals' abilities to respond effectively. In line with the proposals to recognise the need for a more relational approach, the clinicians identified the competing demands on their time and the limited the space available for them to connect with each other and reflect on their practice as a key barrier to learning and improving care (Davies et al., 2017; Tranberg & Brodin, 2023). To support clinicians to provide mindful and person-centred care more effectively – a core value of the NHS – the system must provide appropriate space. The clinicians identified some possible avenues for them to increase connection and reflection (Proposed Actions, Table 5). However, this finding and proposed action relates only to clinicians within the specialist diabetes team. Facilitating a reflective space for general doctors and ward staff, as proposed in the action plan, could provide space to explore if this is similar for the general doctors and ward staff involved in diagnosis..

Both parents and clinicians expressed difficulties with the hospital environment in relation to early adjustment and learning, including difficulties with diet, equipment, and lack of ecological validity (i.e. not providing true-to-life learning). Research has identified a key benefit of home treatment after T1D diagnosis was the ability for families to learn in the framework of their lives (Gregory et al., 2019; Lowes et al., 2004). In the context of this research, the geography of the region prevented early home treatment. Therefore, the findings and actions highlighted the need to focus on how to make initial hospital treatment after T1D diagnosis truer to families day-to-day to enhance learning/adjustment. In the final reflective group, participants identified several possible actions that would improve the environment, including better access to weighing scales and an active offer of 'leave' from the ward (Proposed Actions, Table 5). It was a benefit of this collaborative approach that participants were able to identify together small but innovative adjustments that were realistic and relevant in the context. These smaller adjustments have the potential to have a large impact on facilitating important opportunities for learning, mastery and self-efficacy through experiential learning and feedback (Bandura, 1977; Kolb, 1984).

The final theme highlighted that both parents and clinicians wanted increased space to connect with others and that shared experience was an important way of gaining support. For clinicians, that need for connection and reflection is discussed above. Similar to previous research, parents highlighted a possible role for other parents to provide support (Kimbell et al., 2021; Rankin et al., 2014a; Simpson et al., 2021; Sousa et al., 2022). The benefit of having both parent and clinician perspectives in considering actions allowed a contextual consideration of the action of increasing parental peer support. During the second reflective group, clinicians shared with parents some concerns and limitations for professionals in facilitating that support (e.g., parents shouldering too much responsibility for other parents who

are struggling). There was also discussion related to some of the difficulties clinicians had found in running groups for parents in the specific context (e.g. large geographical area impacting attendance). However, the benefits observed during the focus group of providing a space for parents to connect and share their experiences of diagnosis encouraged clinicians to consider offering similar post-diagnosis sessions for newly diagnosed parents in the future (Proposed Actions, Table 5).

In line with a PAR approach, the results and the action plan are most relevant and applicable to the context from which they have been drawn. However, the PAR framework utilised supported working collaboratively and bringing patients and health professionals together, which could beneficially be replicated across other paediatric diabetes services or long-term health conditions. Parents of children with long-term health conditions, like T1D, often experience a perceived lack of control as a continued struggle; therefore, empowerment through engagement with participatory research may be particularly valuable (Shen et al., 2017). In the final reflective group, one parent suggested 'widening the diabetes team', considering the team to include the health professionals and all the families with children with diabetes in the service. From both parents and clinicians, they appreciated the space to connect with each other and there was a continued openness and desire to continue working together past the end of this research study.

Limitations

This study gained substantial feedback related to general doctors and ward staff. Unfortunately, no representatives of this staff group were able to participate. It would be helpful to gain their perspective and experiences of T1D diagnosis. Similarly, further exploration could include more perspectives on the diagnosis process

including children, young people, and extended family support. Parent participants only represented a sample of views and there were concerns shared by clinicians during the second reflective group that the voices of a significant proportion of parents who do not engage with services were not captured. This led to a discussion as to whether the parents who engaged with this research may be able to support the diabetes team to engage with other parents (i.e. whether parents in the study may have ideas for facilitating communication with wider parent population). There may also be scope to explore more creative engagement options to pursue this endeavour in future projects.

There were difficulties experienced during the study with attrition of parent participants to the reflective groups. This was expected and engagement in these groups were voluntary due to the recognition of the additional burden of engaging in longer research. Mindful of attrition, the principal investigator offered the parents' the choice of an online or in-person reflective group and they voiced a preference for an in-person group. There may have been a conflict here between their preference and the practicalities of in-person attendance (e.g. time for additional travel, work commitments, childcare arrangements etc.). Future engagement and studies may wish to include a protocol of multiple groups via different mediums.

In relation to the PAR methodology, the intention was to emphasise collaboration between health professionals and parents. However, there is a large power imbalance between these groups that may have created barriers in relation to the information shared by parents. The first author, in a dual role as researcher and health professional, was seen as closely allied to the clinicians. In the reflective group with parents, one parent shared that there were aspects of their care they did not feel comfortable talking about due to ongoing reliance on the local diabetes team for care. This means that not all aspects of the parental experience have been

captured. One potential theme was removed after the first reflective group as parents fed back it did not accurately represent their views on that area. This shows the limitations and benefits of this process, views were omitted but also assumptions made by the researcher were caught/corrected. The correction by participants provides hope that if PAR continued to be followed as an iterative process allowing for the building of trust, as intended, that it may have the potential to erode the barriers of conducting collaborative research in systems of substantial power imbalance.

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Chapter 3 - Contributions to theory, research, and practice

Introduction

This thesis has explored experiences of type 1 diabetes (T1D) in childhood using a systemic lens. This approach aligns with ecological systems theory, proposing that child development is influenced by the systems around the child and improving those systems ultimately benefits the child (Bronfenbrenner, 1979). The systematic review synthesised qualitative research investigating experiences of school staff supporting children and young people with T1D. The empirical paper explored the experiences of parents and clinicians of a diabetes diagnosis process. This final chapter integrates these findings to consider contributions to theory, research, and practice. The chapter concludes with personal reflections on the research process.

Thinking systemically in type-1 diabetes in childhood

Supporting broadening perspectives in research

To the author's knowledge, this is the first study to consider experiences of T1D diagnosis from the perspective of both parents and clinicians. The systemic frame of the thesis was extended by exploring school staff experiences for the systematic review. The intention of including multiple perspectives within this thesis was to expand the frame of the research; moving away from looking at a situation from one perspective to considering the interaction between multiple perspectives involved in a complex setting. There were considerable similarities between the findings of the systematic review and empirical study (Table 1, overview of study themes). Both studies highlighted the importance of formal support or context, T1D knowledge, the conditions supportive of learning (whether sharing responsibility or experiential opportunities), the role of emotions, and the importance of wider support.

Table 1*Overview of themes from Systematic Review and Empirical Study*

Systematic Review	Empirical
Underpinning formal support is important	The limits and pressures on clinicians and the system
Staff attitudes, beliefs and feelings	The emotional lens
Diabetes knowledge and experience	The power of knowledge
Communication and collaboration	Communication difficulties
It's a big responsibility	The conditions for adjustment, learning and building relationships
Normalisation and inclusivity	Sharing experiences and gaining support

The considerable similarities between the themes across the multiple perspectives is supportive of considering these perspectives as part of one overarching complex system. Adopting a systemic lens, this could be seen as the equivalent of shifting from a first order perspective to a second order perspective (Bateson, 1972). Within the T1D context, it is common for the health system to be viewed as the external 'expert' (a first order perspective). The methodology utilised in this research supported a shift to a second order perspective; positioning the health system as part of the wider system provided greater understanding and movement towards a more collaborative and relational approach. These findings support construction of research taking broader systems frames to highlight and illustrate the complexity and interaction between multiple perspectives. This second order systemic perspective is also in line with the Participatory Action Research (PAR) framework, which also places the researcher as part of the system to support participation and collaboration (Lenette, 2022). The empirical study demonstrated that utilising PAR as the research framework can be facilitative of taking a wider

perspective and consideration of utilising this approach in other complex systems could be helpful.

What would a systemic approach in practice look like?

The similarities between difficulties and potential solutions across parents, clinicians, and school staff experiences encourages more consideration of systemic practice solutions. Importantly, both papers within this thesis supported the proposition that systemic changes could have important impacts on the quality of life for children with T1D and their families. One of the key findings across both studies was the need for improved communication and collaboration. During the completion of this thesis, the proverb “it takes a village” was frequently reflected by the implications of the findings on practice and ongoing care. When considering how to expand the frame of research and practice, the question is: How do we support the village? Reupert and colleagues (2022) explored this concept in relation to supporting children and families with multiple adversities, which may include physical health difficulties. They outlined several principles to support creating a ‘village’ approach (Table 2). These could translate to providing a systemic approach to T1D care in paediatrics.

Table 2

Village approach principles (Taken from Reupert et al., 2022)

Principle	Implication for policy and practice
<i>Interdisciplinary</i>	Practitioners from various professional disciplines, including but not limited to physical health, psychology, social work, and education, are provided with the training and time to work collaboratively
<i>Coordinated</i>	Interagency support is provided to families depending on need, including but not

	limited to housing, employment, childcare and education
<i>Strengths-based</i>	Family, parenting and children's strengths and resources are identified, recorded and celebrated
<i>Prevention-focused</i>	Support aims to prevent immediate and long-term problems
<i>Developmental, lifespan approach</i>	Different support is provided to parents/caregivers and children at different times, depending on key developmental milestones.
<i>Promoting parents' agency and empowerment</i>	The views and perspectives of parents is actively sought when defining problems and solutions. Parents are partners in the planning and delivery of services.
<i>Giving children a voice</i>	Children of all ages are encouraged to present their perspectives on the issues and potential solutions to existing and future family issues
<i>Culturally sensitive</i>	Individual, familial and communal cultures are acknowledged and considered when addressing problems and solutions
<i>Feedback and evaluation</i>	Feedback and evaluation processes are built into Village-focused policies and practices

The methodology in the empirical study supported the start of a 'village' approach in the local paediatric T1D context, certainly in relation to promoting parents' agency and being contextually/culturally situated. The PAR framework also supports a continuation of feedback and evaluation processes. The research was conducted in a service that is in itself already interdisciplinary with close working relationships between physical health and psychology. The broader findings, including the systematic review, suggest that further improved communication and collaboration would be helpful in the context of paediatric T1D. In relation to a more

systemic approach being preventative of long-term problems in this context, there could be potential longer-term benefits to improving health and wellbeing of children with T1D and their families. Research has connected diagnosis of T1D in young children (aged 5-9 years) with a high incidence of at least one major life change following diagnosis (50%; Stanek et al., 2020). These included income changes, job or school changes, additional family health changes, or changes in parents' marital status. These major life changes were associated with higher stress levels, poorer parental wellbeing, and worse glycaemic control. The study concluded that families should be supported with stress management. However, the value of the qualitative research considered in this thesis suggests that difficulties with systemic support after diagnosis may play a pivotal role in these stressful life events e.g. having to change schools as there is inadequate support for T1D care or parents reducing working hours to support T1D care. Therefore, focusing on improving collaboration and systemic support could reduce systemic stressors and have implications for both family wellbeing and T1D management.

Challenges to systemic working and next steps

There are undoubtedly challenges to creating a wider collaborative/interdisciplinary systems approach. The main one being the current standard of systems working in 'siloes' (Reupert et al., 2022). Systemic theories on supporting effective communication could be helpful in this endeavour. The Coordinated Management of Meaning (CMM) is a practical communication theory that is frequently applied in the context of systemic practice and seeks to facilitate better communication to improve our social worlds (Pearce & Cronen, 1980). It rests on

three central concepts or processes that work together: coherence, coordination, and mystery (Table 3, definitions).

Table 3

Central principles of Coordinated Management of Meaning (CMM; Pearce & Cronen, 1980)

Principle	Definition
Coherence	The making and managing of meaning through story-telling; to integrate what we experience with what we know to be true
Coordination	The process of coordinating, collaborating and aligning our stories with others
Mystery	The element that we cannot control or explain

Research activity and practical next steps towards more collaborative working would be to continue creating spaces for collaborative conversations and alignment of stories/experiences. This is also very much in line with PAR objectives of creating “communicative spaces” (Kemmis, 2006). One of the practical models within CMM is the LUUUUTT model (Pearce & Pearce, 1998; Box 1). The LUUUUTT model could be used to support thinking about who needs to be present in communicative spaces through consideration of the stories unknown, untold, unheard, and untellable. This could then be combined with the PAR framework to support collaborative action based on those stories. It has already been considered that ward staff in the hospital involved in T1D diagnosis are an unknown story that would be helpful to explore. It has also been considered that there are more parents within the service that may have different stories that are currently unknown. There are undoubtedly more unknown stories that can be explored and constructed within this context including the children and young people within the service, extended family support networks and local school staff. Potentially, there are also untold, unheard, or untellable stories

from the parents and clinicians within this study. Stories were shared in the context of the hospital environment and time-limited, which may have some implications for the nature of stories shared. As collaboration and action continues, it will be important to be mindful of and explore those stories as part of the continued endeavour to support improved practice. From a broader perspective, the LUUUUTT framework could be helpful in other complex systems to identify collaborative actors and solutions.

Box 1

The LUUUUTT model (Pearce & Pearce, 1998)

1. Lived stories = *What we actually did or are doing (before meaning)*
2. Unknown stories = *Information that is missing*
3. Untold stories = *What we choose not to say*
4. Unheard stories = *Stories we choose to say that are not heard*
5. Untellable stories = *Stories that are forbidden or too painful to say*
6. Storytelling = *How we are communicating the stories*
7. Stories told = *The content of the stories we tell*

Supporting learning and adjustment

Knowledge... and beyond

This thesis contributes to existing research that has indicated low T1D knowledge in parents (before diagnosis) and school staff (Al-Bunyan et al., 2021; Alzahrani, 2019; Carral San Laureano et al., 2018; Lowes et al., 2004; Rankin et al., 2014; Chatzistougianni et al., 2020; Gutzweiler et al., 2020; Holstrom Rising & Soderberg, 2023; Luque-Vara et al. 2021; Nannsen et al., 2023; Perme et al. 2022; Statiri et al., 2022; Tannous et al., 2012). Parents in the reflective groups also suggested that difficulties with T1D knowledge and the fear connected with 'getting it

wrong' created problems for them more broadly in gaining support from friends and family.

Therefore, any intervention that employs a broad systemic approach to T1D education on diagnosis would be helpful. This would include broader public health initiatives to improve T1D knowledge in wider society that could support parents at diagnosis and beyond. At diagnosis, newly diagnosed parents could then begin their journey with a greater baseline knowledge, which could reduce initial stress and support early learning (Holstrom Rising & Soderberg, 2023; Lowes et al., 2004; Rankin et al., 2014). Greater knowledge in their support networks would mean they could have greater support from their family and friends on discharge and less difficulties in terms of transitioning children back into education.

However, it is important to note that that this research has also suggested that improving T1D knowledge is only part of the solution. A large contribution of this study has been to repeatedly emphasise and demonstrate the multiple systemic needs and how those systemic changes could have impact on the wellbeing of children with T1D, their families *and* their support network (including health professionals and school staff). The need for supporting structures and processes that enable both clinicians and school staff to provide the person-centred care and support they want to provide were also highlighted. These supporting structures could also have implications for the pressure felt by clinicians and school staff (and, therefore, their wellbeing). Broader systemic support for clinicians would be to have more time to reflect and support to provide relational, person-centred care. This broader relational, person-centred care has been highlighted by parents, children, and clinicians to be central to 'good' T1D care (Curtis-Tyler et al., 2015). For school staff, formal policies, planning and sharing responsibility was highlighted as

important for school staff in feeling safe, competent, and confident in undertaking support for children with T1D at school.

Applying theoretical learning frameworks

Both studies have emphasised the difficult task in diabetes in supporting learning *and* emotionally adjusting to a new reality of living with and supporting a child with T1D. In the empirical study, there was consideration of the role of communication models for 'breaking bad news' to support clinicians in communicating T1D diagnoses. One of those models is the SPIKEs model developed by Baile and colleagues (2000). This model could be adapted to integrate some of the findings from the study and support staff to consider the specific communication needs within paediatric T1D (e.g. Table 4).

Table 4

SPIKE-T1D: A communication model to support sharing of learning (adapted from Baile et al., 2000)

SPIKE Principles	SPIKE-T1D: Hospital specific recommendations
Setting Setting up the interview (including, privacy, involving significant other, making a connection, managing time constraints)	Set up clear communication and transparency from the beginning of the process. Give clear information from start, including in GP surgery, why tests are being conducted etc.
Perception Assessing the patient's perceptions ("Before you tell, ask", enabling clinicians to check baseline and correct misinformation)	At every contact during the process, assess what family has been told so far (by GP or previous clinicians), check understanding, and correct misinformation.
Invitation Obtaining the patient's invitation (the extent of information the patient wants)	At every contact during the process, check-in with how much information and <u>what</u> information the family wants at this stage. What are their biggest concerns?

<p>Knowledge Giving knowledge and information (including, adapting communication to the level of understanding of the patient, use of non-technical terms/no jargon, avoid excessive bluntness, chunk information and regularly check understanding)</p>	<p><u>Remember</u>, the family are processing and emotions are likely to be heightened, impacting their ability to recall information. Go at the families own pace in relation to information <u>and</u> education.</p>
<p>Emotions Addressing patient's emotions with empathetic responses (including, a combination of empathic, exploratory, and validating statements)</p>	<p>Provide space for parents to share their worries. Normalise and validate their emotions. May be helpful to share emotions commonly reported by parents at T1D diagnosis.</p>
<p>Strategy and summary Strategy and summary (including, providing some plan for the future to contain uncertainty and summarising/checking understanding of conversation)</p>	<p>Set out a clear guide of what will happen during the initial admission (average length of stay, who is involved [explain difference between specialist diabetes team and ward staff], who will provide what support); provide a practical checklist of requirements created by other parents; agree a 'learning strategy' (e.g. this is what we need to share with you, where are your concerns and where shall we start?)</p>

More broadly, Bandura's (1977) theory of self-efficacy from social learning theory is particularly relevant in this context given the role of the emotions of fear and behavioural avoidance for parents, ward staff, and school staff that was identified as problematic in both studies. In the theory of self-efficacy, cognitive events are induced and altered through experiences of mastery arising from effective performance. Through effective performance, expectations of mastery increase and influence initiation and persistence of coping in difficult situations. Crucial to self-efficacy is the importance of social learning and creating a supportive environment for this process. Self-efficacy learning can come from various sources of information including performance accomplishments, vicarious experience, verbal persuasion, and physiological states (Table 5).

Table 5*Self-efficacy sources of information and modes of inducing (Bandura, 1977)*

Source of information	Modes of inducing
Performance accomplishments	<ul style="list-style-type: none"> • Participant modelling (learning from successful attempts) • Performance desensitisation • Performance exposure • Self-instructed performance
Vicarious experience	<ul style="list-style-type: none"> • Live modelling (seeing others complete without adverse consequences) • Symbolic modelling
Verbal persuasion	<ul style="list-style-type: none"> • Suggestion (suggesting someone's ability to complete tasks successfully) • Exhortation (encouragement) • Self-instruction
Physiological states	<ul style="list-style-type: none"> • Attribution (of success to self) • Relaxation, biofeedback • Symbolic desensitisation • Symbolic exposure

From the empirical study, there are several findings which support the relevance of social learning theory and self-efficacy to T1D learning and adjustment following diagnosis: (1) Parents' desire to observe live modelling by ward staff and to be supported in more performance exposure alongside staff on the ward to achieve mastery experiences; (2) Parents' having access to equipment that would facilitate early experiential learning/performance exposure and desensitisation (e.g. scales); (2) Parents' desire to have more peer support that would provide them with further live modelling and verbal encouragement in the community. For school staff in the systematic review, the findings demonstrated that there was a gap between theoretical knowledge and practical experience. Arguably, in that gap resided the staff fears and reluctance to undertake the role of supporting care for T1D driven by

low expectations of their ability to cope. The findings suggest that self-efficacy theory offers a framework for facilitating learning. Potentially, there is a role for psychology in this context in supporting physical health colleagues to embed these ideas within the learning process. For parents at diagnosis, it can be built into the initial diagnosis stage at the hospital, by utilising some of the suggestions by parents. For school staff, it suggests that single education theoretical education sessions would be more effective if combined with some practical scaffolding and shadowing.

The role of peer support

The importance of sharing experiences and peer support was highlighted by both studies within this thesis. For the systematic review, peers had a role in supporting normalisation and inclusivity. Arguably, peers could facilitate a similar role for parents; however, the focus from the empirical study was more around their role in further supporting learning and adjustment. In relation to the empirical study, there was some hesitancy and caution expressed by the clinicians in relation to peer support and the potential for this be 'burden' placed on parents. However, there is an increasing desire to increase the role of peer support in health, particular in relation to mental health and psychological wellbeing. In the context of Wales, where this research was conducted, there is support for increased peer support roles from Health Education Improvement Wales (HEIW) and Social Care Wales in their strategic mental health workforce plan and a framework and practice framework for peer support (HEIW, 2022a; 2022b). As sharing experiences and peer support was highlighted as helpful for both practical and emotional adaptation to T1D on diagnosis, there could be helpful transferable learning to the context of paediatric T1D services. In particular, the supporting structures and processes that may be helpful to place around those roles that would allay professionals concerns around

the responsibility being placed on parents. The practice framework also includes consideration of peer support workers and peer trainers. Co-facilitation of support groups with peer trainers could also be considered as part of ongoing consideration by the local service in relation to facilitation of peer support.

What next? The action research cycle

This empirical study represents the first stage of an action research cycle (Mertler, 2019). The findings of the study have already been embraced by the service and, at time of writing, there is a bid for funding to co-produce a contextually and locally situated T1D informational video with health professionals, parents, and children. This focuses on the first implication for practice in relation to improving T1D knowledge. Importantly, this will also be a project that continues collaborative working and a video that could have wide systemic reach; with the potential to share with newly diagnosed families, extended networks of support, schools, and health professionals. The service has also already received donations of weighing scales from a local supermarket to be given to families on diagnosis to support early adjustment and learning. As the actions from this phase of the research is implemented, the changes will need to be monitored by the service to evaluate whether and how they have addressed the difficulties identified by parents and clinicians as part of the empirical research.

Broader contributions: Bringing research and practice closer together in Clinical Psychology

Part of the intention of utilising the PAR methodology as part of this research has been to bring research and practice closer together. Clinical psychologists are

trained to hold the skills and knowledge for both research and practice. However, once qualified, it is uncommon for clinical psychologists to be regularly engaged in psychological research in clinical practice, with a modal research publication number of zero (Eke et al., 2012). In fact, it seems there is a divide in the profession, with clinical psychologists either becoming academics/researchers *or* clinical practitioners (Norcross et al., 2005; Norcross & Karpiak, 2012). The danger of this divide is that there is the development of a research base and evidence-based clinical practice guidelines being increasingly detached from clinical psychology practice itself. Perhaps this explains to some degree why there is some evidence of clinical psychologists having negative attitudes towards evidence-based practice, particularly the further from training/longer they are qualified (Hamill & Wiener, 2018; Santos et al., 2024).

There has also been movement away from the concept of clinical psychologists as 'scientist-practitioners' towards 'reflective-scientist-practitioners' (British Psychological Society, 2019). Within guidance, this reflects the role of clinical psychologists in developing evidence-based practice and practice-based evidence. Arguably, clinical psychologists are more often engaged in developing practice-based evidence within the services they work within and this is less frequently published. The PAR framework and cycle approach of action and reflection could support a more integrated scientist-reflective-practitioner stance. PAR provides a framework for reflective practice combined with the application of qualitative research methods standards of research rigour. This may increase the likelihood that practice-based evidence leads to publication and contributes to the evidence-base.

Another important consideration related to the divide between research and practice in clinical psychology is the allocation of time and resources provided to conduct research. The research that has identified barriers to clinical psychologists

completing research has highlighted clinical pressures as the main barrier (McHugh & Byrne, 2011). Again, PAR provides a method that may enable psychologists to view and conduct research that is embedded within their work as opposed to an additional responsibility. It also potentially encapsulates many of the factors that have been identified for successfully setting up and implementing research in clinical practice (Smith & Thew, 2017). In particular, supporting a practical research scope, gaining managerial support through connection to service development/action, and the centrality of collaboration. As a final and further practical enabler, there is rising implementation of the Clinical Associate in Psychology (CAP) programme across Wales (also supported by HEIW [2022a]). With this implementation, there could be more opportunity for clinical psychologists to have the time and space to utilise their full skill set in clinical practice.

Personal reflections

Writing this near the end of the research process, I am able to reflect that, overall, this project has enabled me to pursue research aligned with my previous experience and values. I have not followed the traditional route to clinical psychology, having also worked within law and the third sector. These experiences largely involved service-user participation and advocacy. Through this experience, I developed strong values of collaboration, systemic working, openness to learning, and creativity. I also really wanted to conduct research in a way that I may continue into clinical practice on qualification. I believe that the application of the PAR process for my empirical study and extending the systemic focus to my systematic review has resulted in a final report that represents these values at its core. I have learnt more about a research process that I believe I could continue to embed within clinical

practice. I feel proud of this work and grateful to the support I have received from my supervisors who have nurtured and supported me in developing my research voice.

It has been an interesting and valuable experience to complete a research project utilising the PAR relational lens. The importance of relationships was central to the research approach and, interestingly, was echoed in the findings in both the empirical and systematic review papers. For the empirical study, the existing relationships I held with the clinicians and some parents in the study was facilitative in setting up the research and, I believe, likely influenced the openness and commitment to participating (particularly from clinicians). From this perspective, I also felt it was helpful bringing the parents and clinicians together as part of the process and there was a desire from both sides for this increased connection and collaboration to continue in the future. Relationships were also important to me in relation to my choice of supervisors. I chose supervisors who I knew well and had already built working relationships with. This was incredibly supportive to me throughout this process. Overall, this experience has strengthened my belief that starting with relationships first is important and has strengthened my commitment to the PAR philosophy of "learning to look at the world through a different lens, one that sees the world in relational terms" (Abma et al., 2018; p.19).

Whilst my approach to this research has been driven by my values and experiences, I was drawn to this subject area through both my personal and professional experiences. As a parent, I have personally experienced huge variation in the quality of information-sharing of difficult information about myself and my child by health professionals. Professionally, I have observed this same variation, with occasions where the emotional impact of the information shared was not always appreciated or acknowledged. This gave me an interest in how we could improve communication within the health setting and if there may be a way to make

processes more inherently psychologically supportive. In relation to the systematic review, I wanted to further represent the broader systemic and relational context that a newly diagnosed child and their family sit within. I was again interested in whether there was the potential to understand and improve the wider system and process to be more psychologically informed. As findings emerged, I was frequently reminded of the proverb that “it takes a village to raise a child” and what that may look like in the context of diagnosis of T1D.

During the empirical study, I greatly resonated with the emotional experiences of the parents in the study whilst also resonating with the endeavours of the clinicians and NHS colleagues to do their best in a challenging system. At times, I found it difficult juggling these two positions and maintaining neutrality. In designing the research, I felt strongly about the benefits of bringing health professionals and patients into a space where they could communicate and connect differently. After the initial focus groups, there was a time when I was nervous about bringing the two ‘sides’ together and how to navigate the potential difficulties within the relationship. Supervision was incredibly important in considering this potential and how to navigate it. In this instance, the general agreement in the issues within the process of T1D diagnosis was helpful and, ultimately, I was encouraged by the actions that the group were able to generate when both perspectives were taken into account. However, afterwards I found myself reflecting on the potential for difficulties or conflict within these spaces and that would be in the forefront of my mind in future PAR projects. This is likely to be particularly relevant when conducting research within the context of the current NHS where the pressures and limitations on the system mean that the likelihood of people having unaired and unresolved grievances may be greater.

Alongside this, I did experience frustrations in completing research in the context of the NHS. This was mainly in the form of long and competing demands of different ethics processes (e.g. University, NHS, and local research and development). It made me appreciate some of the barriers to practising clinical psychologists completing research in this context and there were times that I vowed never to do research again. Thankfully, I managed to overcome that hurdle and was hugely supported by NHS colleagues to ensure that I was able to complete the study in a reduced timeline. As well as this practical barrier, I experienced a personal barrier in thoughts that participating in the research was a time-burden for people and this led me to being somewhat apologetic in my approach at the beginning of the process. Again, I appreciated the supervision I received relating to this in encouraging me to recognise the value of the research to the service. This encouragement was supported through experience and feedback from participants. Participants generally shared feedback that they valued that I had chosen this area to highlight and personally felt a benefit from the space to talk that the focus groups provided. On reflection, I can see parallels between a process of diagnosis that is inherently psychologically supportive and a process of practice-based research that may be the same. For me, this has fuelled intrinsic motivation to continue attempting research in practice when qualified.

At the conclusion of this study, I remain passionate about collaboration, co-production, systemic working and working within a learning culture. This research has allowed me to explore this within an NHS context in a safe space with supportive supervisors and participants (my 'co-researchers'). I have found the PAR framework supportive in uniting research and practice and I plan to continue to pursue the application of PAR as I move into qualified life. I look forward to being able to continue my learning about the research approach and explore more creative

methods of data collection and analysis that may support greater levels of collaboration. The findings of both the empirical paper and systematic review have encouraged me to continue being mindful of broader systemic and relational factors in all that I do.

However, I also move forward with a greater awareness of some of the challenges of completing participatory research from the perspective of a clinical psychologist within the NHS. There were times with parents where there was express communication and acknowledgement of the power differential between the parents, health professionals and the NHS. As a health professional, I was seen by the parents as someone who also wielded that power. In the context of the research, I struggled with this realisation as I felt like I had failed in one of the objectives of completing PAR to reduce power imbalances. I was struck that having worked hard for many years to get to a position where I could implement work like this from a position of influence, I have moved further away from the wider community and the people's voices I wanted to work with and advocate for. It seemed in that moment in the research that from an observer's perspective I had essentially 'swapped sides'. As I move forward, I am aware of the need to recognise and assimilate the fact that I now possess a significant degree of what others would observe as 'power'. This will require me to hold less tightly to the view that power equates to 'bad' and be open to the possibility that power can be wielded differently. For me, I believe that continuing to pursue collaboration and co-production will be a part of this journey. As will furthering my understanding of complementary leadership approaches, such as compassionate leadership (West, 2021).

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Appendices

Appendix 1 – Systematic Review coding extract

<p>So it is education and acceptance of everyone. That's what we have our policy on - inclusion and acceptance. Everything is normalised (Education Support Coordinator Primary School).</p> <p>And just that culture that we can do it by working with the parents rather than putting it in the too hard basket (Teacher Primary School).</p> <p>People need to know that they are not solely responsible and that the responsibility is shared across the school (Deputy Principal Primary School).</p> <p>Interpersonal support</p> <p>Disease management and academic support</p> <p>You know the camp was exhausting for all the adults involved but the fact that the kids with diabetes were included made a huge difference to them. It was like a turning point. (Education Assistant Primary School).</p> <p>Emotional support</p>	<p>Participants in schools frequently spoke about how the culture of the school played an important role in supporting students with T1D. A school culture of inclusivity supported by compassion and a "you can do it" attitude was discussed.</p> <p>To enable an inclusive culture, participants spoke about the need to share responsibility across staff and parents.</p> <p>Interpersonal support</p> <p>Disease management and academic support</p> <p>The level of staff monitoring was dependent on the age of the child, the stability of the student's BGLs and the type of activity the student was engaging in. For example, close monitoring was required for students on camp or away from their usual routine. A participant talked about how intense it was to take primary school students with T1D on camp but how important it was socially and emotionally for the child.</p> <p>Emotional support</p>	<p>More than words - normalisation + inclusivity</p> <p>Sharing responsibility / partnership / collaboration - legal liability?</p> <p>More than words</p> <p>Normalisation + inclusivity</p> <p>Flexibility / individualised approaches OR</p> <p>Sharing responsibility / supporting independence</p>
<p>So it is education and acceptance of everyone. That's what we have our policy on - inclusion and acceptance. Everything is normalised (Education Support Coordinator Primary School).</p> <p>And just that culture that we can do it by working with the parents rather than putting it in the too hard basket (Teacher Primary School).</p> <p>People need to know that they are not solely responsible and that the responsibility is shared across the school (Deputy Principal Primary School).</p> <p>Interpersonal support</p> <p>Disease management and academic support</p> <p>You know the camp was exhausting for all the adults involved but the fact that the kids with diabetes were included made a huge difference to them. It was like a turning point. (Education Assistant Primary School).</p> <p>Emotional support</p>	<p>Participants in schools frequently spoke about how the culture of the school played an important role in supporting students with T1D. A school culture of inclusivity supported by compassion and a "you can do it" attitude was discussed.</p> <p>To enable an inclusive culture, participants spoke about the need to share responsibility across staff and parents.</p> <p>Interpersonal support</p> <p>Disease management and academic support</p> <p>The level of staff monitoring was dependent on the age of the child, the stability of the student's BGLs and the type of activity the student was engaging in. For example, close monitoring was required for students on camp or away from their usual routine. A participant talked about how intense it was to take primary school students with T1D on camp but how important it was socially and emotionally for the child.</p> <p>Emotional support</p>	<p>More than words - normalisation + inclusivity</p> <p>Sharing responsibility / partnership / collaboration - legal liability?</p> <p>More than words</p> <p>Normalisation + inclusivity</p> <p>Flexibility / individualised approaches OR</p> <p>Sharing responsibility / supporting independence</p>

Appendix 2 – Research Ethics Committee (REC) favourable opinion



**Health Research
Authority**

North East - Tyne & Wear South Research Ethics Committee

NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

13 November 2023

Dr John Connolly
Senior Clinical & Health Psychologist
Betsi Cadwalader University Health Board
Ysbyty Gwynedd Hospital
Penrhos Road
Bangor
LL57 2PW

Dear Dr Connolly

Study title: Experiences of and support for parents of children with newly diagnosed type 1 diabetes
REC reference: 23/NE/0204
Protocol number: N/A
IRAS project ID: 332191

Thank you for your letter of 10/11/2023, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Appendix 3 – Health Research Authority (HRA) approval



Dr John Connolly
Senior Clinical & Health Psychologist
Betsi Cadwalader University Health Board
Ysbyty Gwynedd Hospital
Penrhos Road
Bangor
LL57 2PW

Email: approvals@hra.nhs.uk

13 November 2023

Dear Dr Connolly

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Experiences of and support for parents of children with newly diagnosed type 1 diabetes
IRAS project ID:	332191
Protocol number:	N/A
REC reference:	23/NE/0204
Sponsor	Bangor University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix 4 – Local health board research and development approval

From: Laura Longshaw (BCUHB - Research & Development) <Laura.Longshaw@wales.nhs.uk>
Sent: 12 January 2024 17:00
To: Danielle Shaw (BCUHB - Mental Health & Learning Disabilities) <Danielle.Shaw@wales.nhs.uk>; Lucy Piggin <l.piggin@bangor.ac.uk>; John Connolly (BCUHB - Paediatrics) <John.Connolly@wales.nhs.uk>; Lee Hogan (BCUHB - Substance Misuse Services) <Lee.Hogan@wales.nhs.uk>
Cc: huw.roberts@bangor.ac.uk <huw.roberts@bangor.ac.uk>
Subject: IRAS 332191 BCUHB Confirmation of Capacity and Capability

Dear John Connolly and Danielle Shaw,

Full study title: Experiences and support for parents of children with newly diagnosed Type 1 diabetes

This email confirms that Betsi Cadwaladr University Health Board (BCUHB) has the capacity and capability to deliver the above referenced study, documents reviewed are those as listed in the original HRA/HCRW approved list dated 13 November 2023 and includes Amendments 1. Please note that the current protocol is version 2.0 Nov 2023

This C&C is on condition that amendments are submitted as follows as agreed with the PI:

- Amendment to submit the minor corrections to footers and headers in the approved documents (Information Sheets)
- Amendment to the protocol to bring the recording and storage of the data (in the protocol text) in line with the HRA approved amendment 1.

Please forward the amendment details once completed for our records.

We agree to start this study on the date you, as Sponsor, provide as the “Green light”. Please include BCU.ResearchApplications@wales.nhs.uk in the “Green Light” e-mail.

If you wish to discuss further, or have any queries, please do not hesitate to contact me.

N.B. Future submission of amendments, should be sent to our R&D generic inbox: BCU.ResearchApplications@wales.nhs.uk
Cofion, Regards

Laura Longshaw

Dirprwy Rheolwr Ymchwil a Datblygiad / Deputy Research and Development Manager
Bwrdd Iechyd Prifysgol Betsi Cadwaladr/Betsi Cadwaladr University Health Board

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Halkyn Road
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e-bost • e-mail: Laura.Longshaw@wales.nhs.uk

 *Dilynwch ni ar Twitter/Follow us on Twitter: @BetsiResearch*

<http://www.healthandcareresearchwales.org/>.



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Cymraeg

Rhybudd Ebst (2010) - Bwrdd Iechyd Prifysgol Betsi Cadwaladr

Fe'ch cyngorir i ddarllen rhybudd ebst Bwrdd Iechyd Prifysgol Betsi Cadwaladr (a'i argraffu er mwyn cyfeirio ato yn y dyfodol). Gellir dod o hyd iddo yn y lleoliad canlynol

<http://www.wales.nhs.uk/sitesplus/861/tudalen/47230>

English

Betsi Cadwaladr University Health Board - Email Notice (2010)

You are advised to read (and print for future reference) the Betsi Cadwaladr University Health Board e-mail notice which can be found at this location

<http://www.wales.nhs.uk/sitesplus/861/page/47229>

Betsi Cadwaladr University Health Board is the operational name of Betsi Cadwaladr University Local Health Board

Appendix 5 – Parent participant letter of invitation



[Address]

[Date]

Dear [Name]

Re: Invitation to participate in research study

Research study title: *Experiences of and support for parents of children with newly diagnosed diabetes*

You are being invited to take part in the above research study as a parent of a child who has recently been diagnosed with diabetes at Ysbyty Gwynedd, Bangor (within the last 3 years).

Participation would involve taking part in focus groups. Your participation is voluntary and will not affect your health care. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Therefore, we have provided you with the enclosed information ('Participant Information Sheet'). Please take time to read it carefully and discuss it with others if you wish.

The research is being completed as part of the researcher's doctorate in clinical psychology with the North Wales Clinical Psychology Programme and is sponsored by Bangor University. **If you have any questions, please use the researcher contact details provided in the information sheet. The information sheet also has details of next steps if you are interested in taking part.**

Thank you for taking time to read this letter and accompanying information.

Kind regards,

Danielle Shaw
Trainee Clinical Psychologist / Principal Investigator

Appendix 6 – Parent participant information sheet



Parent Participant Information Sheet

Study title:

Experiences of and support for parents of children with newly diagnosed type 1 diabetes.

Researchers:

Danielle Shaw, Trainee Clinical Psychologist, North Wales Clinical Psychology Programme; Dr John Connolly, Clinical & Health Psychologist, Betsi Cadwaladr University Health Board; Dr Lucy Piggin, Clinical & Health Psychologist, North Wales Clinical Psychology Programme

Invitation and brief summary

You are being invited to take part in a research study exploring the experiences of, and support for, parents of children (up to age of 11 years) who have been diagnosed with type 1 diabetes. Whether or not you decide to take part in the study is completely up to you. This information sheet is provided to help you understand why the research is being done and what taking part would involve. You are welcome to share and discuss this information with other people if you would like to do so. We are happy to answer any questions that you might have.

Who is undertaking this research?

This research is being undertaken by Danielle Shaw, Trainee Clinical Psychologist as part of the completion of the Doctorate in Clinical Psychology with the North Wales Clinical Psychology Programme. The project is sponsored by Bangor University.

Why is the study being done?

The purpose of the study is to explore parent's experiences of diagnosis in children recently diagnosed with type 1 diabetes. We are also exploring the experiences of doctors and nurses in the diabetes team of this process.

Diagnosis of a long-term health condition in childhood can be stressful and involve significant life changes. This can impact on the emotional wellbeing of both children and their parents. This study seeks to understand what diagnosis was like for parents of children diagnosed at Ysbyty Gwynedd (Bangor, North Wales) and what early support was received or would have been helpful. We will also be asking doctors involved in the process what they think works well and what could be different. This is a collaborative study, which we hope

will help us understand how we can improve support services when a child is diagnosed with type 1 diabetes.

Why have I been invited to take part?

You have been asked to take part because you are the parent of a child – under 12 years old - who was diagnosed with diabetes at Ysbyty Gwynedd in the last three years. Taking part is voluntary and you can change your mind at any stage. Your decision will not affect the diabetes care you or your child receive in any way.

What will I be asked to do if I take part?

If you decide to take part, you will be invited to join a focus group with other parents (up to a maximum of 8 parents). A separate focus group will be held with clinicians in Ysbyty Gwynedd involved in the diabetes process (e.g. Community Paediatricians, Specialist Diabetes Nurses, Ward Nurses, and Clinical Psychology; up to a maximum of 8 clinicians). Before the focus group, you will be asked to complete a brief questionnaire gathering some information about you and your child (e.g., age of your child at diagnosis, whether you have a family history of diabetes). At the focus group, you will be asked to talk about your experiences of when your child was diagnosed with diabetes including, what was helpful, unhelpful, and what further support may have been beneficial. This will last approximately one hour.

The focus groups will take place in a private room at Ysbyty Gwynedd in Bangor or at other local NHS hospital properties. The focus groups will be recorded so that the researcher has a record of the discussions. There will be a separate focus group for doctors to talk about their experiences.

After the focus group, you will be invited back for two further *optional* joint focus groups – with parents and clinicians together.

In the first of these optional groups, the researcher will share some of the key themes (ideas) that emerged during the initial focus group, and you will be invited to give some feedback. The second optional focus group will be an opportunity for the researcher to share the final themes and to think about what changes may be helpful to improve local services.

These two optional focus groups may be supported online (via videoconferencing) to enable attendance, depending on your preferences.

How will my information be used and confidentiality protected?

We will need to use information from you for this research project. This information will include your name and contact details. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- by asking one of the research team, or
- by sending an email to Anita Thomas, Data Protection Officer (anita.thomas@bangor.ac.uk)

What will happen with the results of the study?

This study will be written up as a thesis as part of the researcher's Doctorate in Clinical Psychology (Danielle Shaw). Anonymised quotes from the focus groups may be used to explain the findings and support the suggested action plan. The information will be presented from the whole group. It will not be possible to identify either you or your child in the final report.

Further sharing of the results is anticipated. The researcher may submit the anonymised report for publishing in an academic journal. The anonymised report will also be shared with professionals - including those responsible for developing services - at Ysbyty Gwynedd.

What are the possible benefits of taking part?

It is possible that you will not directly benefit from taking part in this study. However, you may find it helpful to have an opportunity to talk about your experiences and to connect with other parents who have shared similar experiences. It is hoped that this research will help services to better understand how a diagnosis of diabetes is experienced by parents and doctors. The improved understanding gained through the study may be helpful in informing service development to support parents and clinicians at diagnosis in the future.

You will receive a £25 voucher to thank you for participating in this research.

What are the potential disadvantages and risks?

We understand that the topic of this study may be sensitive for some parents, especially if they have struggled with their child's diagnosis. You do not have to answer any question that you do not want to during the focus groups. If helpful, you can request to see the questions that will be asked in advance.

If you become upset or distressed at any point during a focus group, you will be able to leave or take a break. If you feel it would be helpful to talk to someone after the focus group, the researcher can refer you to the existing health psychology provision. There is also support available through charities, such as Diabetes UK (<https://www.diabetes.org.uk/>).

It is possible that you, another parent or a clinician could make a disclosure of poor practice. In the event of a disclosure, BCUHB policies and processes would be followed. This may include use of the BCUHB reporting systems for complaints or safeguarding.

What if I want to withdraw?

You can withdraw from the study at any stage without having to give a reason – including during the initial focus group. However, once you have taken part in the first focus group, your anonymised data may still be used, even if you have no further involvement in the study. Withdrawing from the study will not affect the care that you or your child receive.

How will I find out about the results of the study?

Participants will be involved throughout the study and fully informed of the intended report findings. There is the opportunity for participants to influence the presentation of the results and discussion with the researcher about this is welcomed.

How is the research funded?

This study is being completed as part of the researcher's Doctorate in Clinical Psychology on the North Wales Clinical Psychology Programme (NWCPP) at Bangor University.

Who has reviewed the study?

This study has been reviewed and approved by [NHS Research Ethics Committee]. It has also been given sponsorship by Bangor University.

What if there is a problem?

If you have concerns about any part of this study, please speak to the researchers who will do their best to answer any questions.

If you have a complaint, please contact:

Colin Ridyard
Senior Research Governance and Policy Officer
Bangor University
c.h.ridyard@bangor.ac.uk

If you are interested in taking part:

If you would like to take part, please contact:

Danielle Shaw
Trainee Clinical Psychologist
Bangor University
dns21vvq@bangor.ac.uk

Danielle will contact you to answer any further questions, discuss dates, and complete a consent form.

Appendix 7 – Parent participant consent form

IRAS ID: 332191

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: Experiences of and support for parents of children with newly diagnosed type 1 diabetes.

Name of Researcher: Danielle Shaw, Trainee Clinical Psychologist

Name of Research Supervisors: Dr John Connolly, Clinical Psychologist

Dr Lucy Piggin, Clinical Psychologist

Please
initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I consent to an audio recording being made during the focus group and understand this will be deleted once the research is complete.

4. I am aware and understand that direct quotations said by me may be used in the thesis report or subsequent publications / presentations. However, I also understand that these will be anonymised.

5. I understand that the anonymised data collected may be used to inform local service development and / or academic publishing

6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person
seeking consent

Date

Signature

Appendix 8 – Clinician participant information sheet



Clinician Participant Information Sheet

Study title:

Experiences and support for parents of children with newly diagnosed type 1 diabetes.

Researchers:

Danielle Shaw, Trainee Clinical Psychologist, North Wales Clinical Psychology Programme; Dr John Connolly, Clinical & Health Psychologist, Betsi Cadwalader University Health Board; Dr Lucy Piggin, Clinical & Health Psychologist, North Wales Clinical Psychology Programme

Invitation and brief summary

You are being invited to take part in a research study exploring the experiences of, and support for, parents of children (up to age of 11 years) who have been diagnosed with type 1 diabetes. Whether or not you decide to take part in the study is completely up to you. This information sheet is provided to help you understand why the research is being done and what taking part would involve. You are welcome to share and discuss this information with other people if you would like to do so. We are happy to answer any questions that you might have.

Who is undertaking this research?

This research is being undertaken by Danielle Shaw, Trainee Clinical Psychologist as part of the completion of the Doctorate in Clinical Psychology with the North Wales Clinical Psychology Programme. The project is sponsored by Bangor University.

Why is the study being done?

The purpose of the study is to explore parent's experiences of diagnosis in children recently diagnosed with type 1 diabetes. We are also exploring doctors and nurses in the diabetes team their experiences of this process.

Diagnosis of a long-term health condition in childhood can be stressful and involve significant life changes. This can impact on the emotional wellbeing of both children and their parents. This study seeks to understand what diagnosis was like for parents of children diagnosed at Ysbyty Gwynedd (Bangor, North Wales) and what early support was received or would have been helpful. We will also be asking doctors involved in the process what they think works well and what could be different. This is a collaborative study, which we hope

will help us understand how we can improve support services when a child is diagnosed with type 1 diabetes.

Why have I been invited to take part?

You have been asked to take part because you are a clinician within Ysbyty Gwynedd currently involved in supporting the diagnosis process. All clinicians involved in the diagnosis process at Ysbyty Gwynedd are being invited with the aim to have representation from the different professions, including, Community Paediatricians, Specialist Diabetes Nurses, Ward Nurses, and Clinical Psychology. Taking part is voluntary and you can change your mind at any stage.

What will I be asked to do?

If you decide to take part, you will be invited to join a focus group with other clinicians (up to a maximum of 8 people). A separate focus group will be held with parents of children who have been recently diagnosed (within the last 3 years; up to a maximum of 8 parents). Before the focus group, you will be asked to complete a brief questionnaire gathering some background information, including, your job role and number of years working with children with diabetes. At the focus group, you will be asked to talk about your experiences of supporting the diabetes diagnosis process, including, what you think works well and what further support may be beneficial. This will last approximately one hour.

The focus groups will take place in a private room at Ysbyty Gwynedd in Bangor or at other local NHS hospital properties. The focus groups will be recorded so that the researcher has a record of the discussions. There will be a separate focus group for parents to talk about their experiences.

After the focus group, you will be invited back for two further *optional* joint focus groups – with parents, doctors and nurses together.

In the first of these optional groups, the researcher will share some of the key themes (ideas) that emerged during the initial focus group, and you will be invited to give some feedback. The second optional focus group will be an opportunity for the researcher to share the final themes and to think about what changes may be helpful to improve local services.

These two optional focus groups may be supported online (via videoconferencing) to enable attendance, depending on your preferences.

How will my information be used and confidentiality protected?

We will need to use information from you for this research project. This information will include your name and contact details. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- by asking one of the research team, or
- by sending an email to Anita Thomas, Data Protection Officer (anita.thomas@bangor.ac.uk)

What will happen with the results of the study?

This study will be written up as a thesis as part of the researcher's Doctorate in Clinical Psychology (Danielle Shaw). Anonymised quotes from the focus groups may be used to explain the findings and support the suggested action plan. The information will be presented from the whole group. It will not be possible to identify either you in the final report.

Further sharing of the report is anticipated. The researcher may submit the anonymised report for publishing in an academic journal. The anonymised report will also be shared with professionals - including those responsible for developing services - at Ysbyty Gwynedd

What are the possible benefits of taking part?

It is possible that you will not directly benefit from taking part in this study. It is hoped that this research will help services to better understand how a diagnosis of diabetes is experienced by parents and doctors. The improved understanding gained through the study may be helpful in informing service development to support parents and clinicians at diagnosis in the future. It also provides an opportunity for clinicians to potentially improve relationships by working together with the families they support.

What are the potential disadvantages and risks?

It is unlikely that this subject will cause any distress to clinicians involved. However, we will be discussing past experiences of providing a diagnosis to families and clinicians may have found this challenging. You do not have to answer any question that you do not want to during the focus groups. If helpful, you can request to see the questions that will be asked in advance.

If you become upset or distressed at any point during a focus group, you will be able to leave or take a break. If any distress is experienced, it is recommended that support be accessed via BCUHB Occupational Health or the Staff Support and Wellbeing Service.

It is possible that a parent or another clinician could make a disclosure of poor practice. In the event of a disclosure, BCUHB policies and processes would be followed. This may include use of the BCUHB reporting systems for complaints or safeguarding.

What if I want to withdraw?

You can withdraw from the study at any stage without having to give a reason – including during the initial focus group. However, once you have taken part in the first focus group, your anonymised data may still be used, even if you have no further involvement in the study.

How will I find out about the results of the study?

Participants will be involved throughout the study and fully informed of the intended report findings. There is the opportunity for participants to influence the presentation of the results and discussion with the researcher about this is welcomed.

How is the research funded?

This study is being completed as part of the researcher's Doctorate in Clinical Psychology on the North Wales Clinical Psychology Programme (NWCPP) at Bangor University.

Who has reviewed the study?

This study has been reviewed and approved by [NHS Research Ethics Committee]. It has also been given sponsorship by Bangor University.

What if there is a problem?

If you have concerns about any part of this study, please speak to the researchers who will do their best to answer any questions.

If you have a complaint, please contact:

Colin Ridyard
Senior Research Governance and Policy Officer
Bangor University
c.h.ridyard@bangor.ac.uk

If you are interested in taking part:

If you would like to take part, please contact:

Danielle Shaw
Trainee Clinical Psychologist
Bangor University
dns21vvq@bangor.ac.uk.

Danielle will contact you to answer any further questions, discuss dates, and complete a consent form.

Appendix 9 – Clinician consent form

IRAS ID: 332191

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: Experiences of and support for parents of children with newly diagnosed type 1 diabetes.

Name of Researcher: Danielle Shaw, Trainee Clinical Psychologist

Name of Research Supervisors: Dr John Connolly, Clinical Psychologist

Dr Lucy Piggin, Clinical Psychologist

Please
initial box

7. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

8. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected.

9. I consent to an audio recording being made during the focus group and understand this will be deleted once the research is complete.

10. I am aware and understand that direct quotations said by me may be used in the thesis report or subsequent publications / presentations. However, I also understand that these will be anonymised.

11. I understand that the anonymised data collected may be used to inform local service development and / or academic publishing

12. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature
seeking consent

Appendix 10 – Parent focus group semi-structured schedule

DRAFT semi-structured parent focus group schedule

Participants will have received a copy of the participant information sheet explaining the purpose of the research before the focus groups. They will have had the opportunity to ask questions and have signed a consent form confirming they wish to take part.

The following schedule will be used as a topic guide, however, remain flexible to facilitate discussions within the group.

1. What was the experience leading to your child's diabetes diagnosis like for you?
2. What was the diabetes diagnosis process like for you? / How were you told your child had diabetes?
3. What were your first thoughts and feelings about the diagnosis?
4. What was helpful about the diagnosis process?
 - a. Whilst in hospital?
 - b. Transition to home?
 - c. Information provided?
 - d. Support provided?
5. What could be improved about the diagnosis process?
 - a. Whilst in hospital?
 - b. Transition to home?
 - c. Information provided?
 - d. Support provided?
6. What information / support did you receive from organisations / people outside of the hospital?
7. What was helpful / unhelpful about that information / support?
8. Looking back now was there anything you needed back then that you didn't g

Appendix 11 – Clinician focus group semi-structured schedule

DRAFT clinician semi-structured focus group schedule

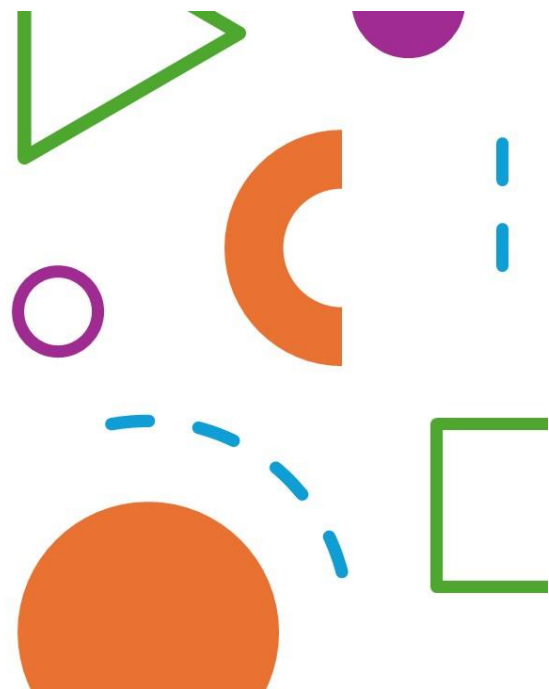
Participants will have received a copy of the participant information sheet explaining the purpose of the research before the focus groups. They will have had the opportunity to ask questions and have signed a consent form confirming they wish to take part.

The following schedule will be used as a topic guide, however, remain flexible to facilitate discussions within the group.

9. What are the different patient experiences leading to diabetes diagnosis? How do you think those experiences influence the diagnosis process?
10. What training/support have you received in communicating childhood diabetes diagnoses to parents / long-term childhood health conditions generally?
11. How do you feel about communicating diabetes diagnoses to parents?
12. What is the hardest part of delivering a diagnosis for you?
13. How are new childhood diabetes diagnoses currently communicated to parents at YG?
 - a. What do you find most difficult about the initial diagnosis period when the client is in hospital?
 - b. What do you think families need most at this point?
14. What is the process after the diagnosis is given?
15. What do you think currently works well within the diabetes diagnosis process at YG?
 - a. In hospital?
 - b. Transition to home?
 - c. Information provided?
 - d. Support provided?
16. What do you think could be improved within the diabetes diagnosis process at YG?
 - a. In hospital?
 - b. Transition to home?
 - c. Information provided?
 - d. Support provided?
17. What support do you feel you need as a clinician / team to improve the experience for parents and children?

Diabetes diagnosis: Parent reflections session

Monday 11th March 2024



Aims of today

- To make sure that write-up captures & does not lose the most important messages from perspective of those involved
- To gain your views on how those messages might (or might not) connect to each other



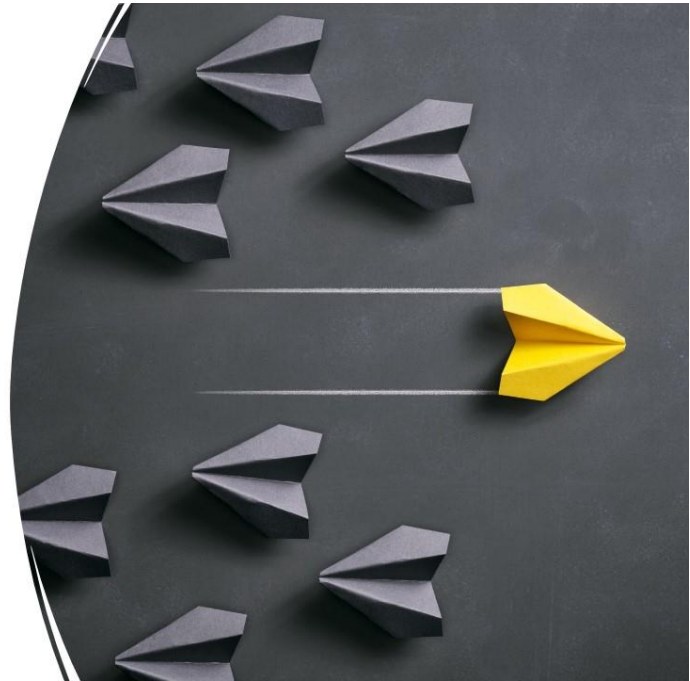
Initial thoughts and feelings

- What are your first thoughts and feelings about what the key messages or important themes were from the focus group?



A key point...

- Everything is 'up for grabs' at this stage
- Final themes are likely to be different





Initial ideas for important messages / themes

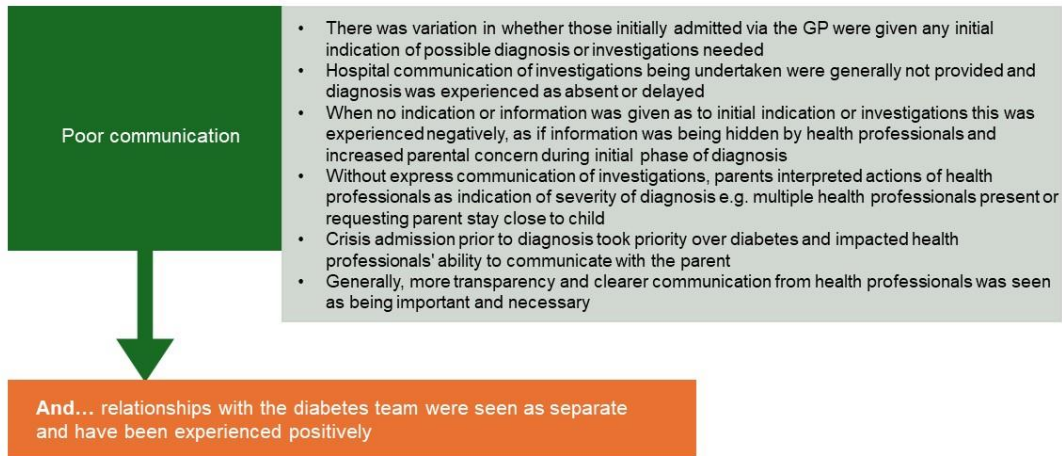
Emotions were central to the diagnosis experience

- **Before diagnosis** – uncertainty, denial, confusion / “No idea”, fear, felt sense/ “something is not right”
- **At diagnosis** – overwhelm, disbelief, shock, guilt/responsibility, searching for answers as to ‘why’, relief
- **After diagnosis** - grief/sadness, guilt/responsibility, continued uncertainty & learning, isolation/loneliness, searching for answers as to ‘why’, minimising diabetes as reassurance, gratitude, hope

The power of knowledge

- Generally, parents have low T1D knowledge pre-diagnosis
- Personal history of diabetes increases T1D knowledge before diagnosis and has a positive impact on shortening time taken before seeking diagnosis
- Personal history of diabetes/increased knowledge has a negative impact on thoughts/feelings towards diabetes
- Ward staff knowledge of diabetes varies – good ward staff knowledge of diabetes had a positive impact on diagnosis process by being able to ask questions ‘in the moment’; poor ward staff knowledge had a negative impact on diagnosis process by increasing uncertainty/fear in parents

Messages / themes continued...



Initial ideas for important messages / themes

Practical difficulties and the hospital environment

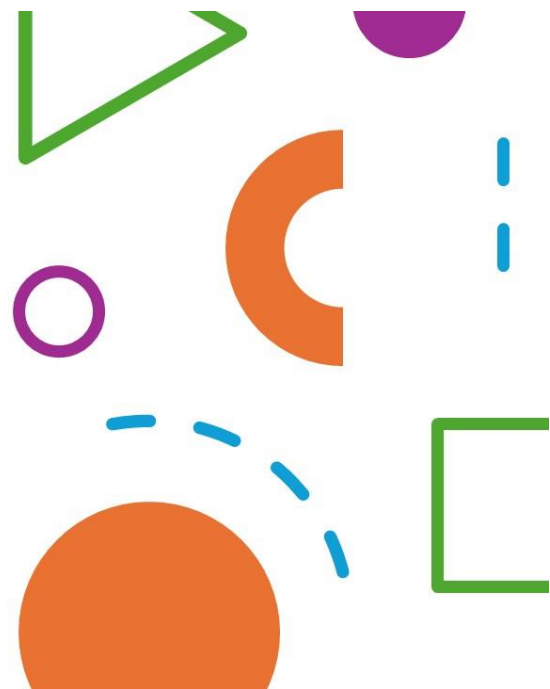
- Practical management of diabetes is difficult to grasp and constant
- Learning/adjusting to practical management of diabetes is key part of initial hospital admission e.g. injections
- The hospital environment added difficulties to learning practical management of diabetes – lack of weighing scales, food provided complex to manage with T1D (e.g. lots of complex carbohydrates)
- Information related to practical management of diabetes at home was slow to be given and caused problems e.g. delay being told needed mobile phone for monitoring
- Uncertainty around length of initial hospital stay created uncertainty and caused practical difficulties for wider parenting responsibilities e.g. childcare of other children

The role of support and validation

- Parents found support of other parents helpful for both practical and emotional support after diagnosis
- Parents thought increased support around connecting with other parents after diagnosis would be helpful e.g. support groups, peer buddies
- Parents struggle psychologically with diabetes after diagnosis
- Parents were not clear on role of psychology in diabetes / supporting parents and there were some barriers in accessing that support for themselves e.g. feeling like they are not the ones that should access support / stigma
- Parents felt that more structure around early emotional/psychological support for parents post-diagnosis would be helpful
- Parents found it difficult finding and accessing external support post-diagnosis
- External support has been experienced as mixed - Diabetes UK helpline did not have information on specific difficulties; online Facebook group has been helpful in answering questions

Diabetes diagnosis: Clinician reflections session

Monday 11th March 2024



Aims of today

- To make sure that write-up captures / does not lose the most important messages / themes from perspective of those involved
- To gain your views on how those messages / themes might connect to each other



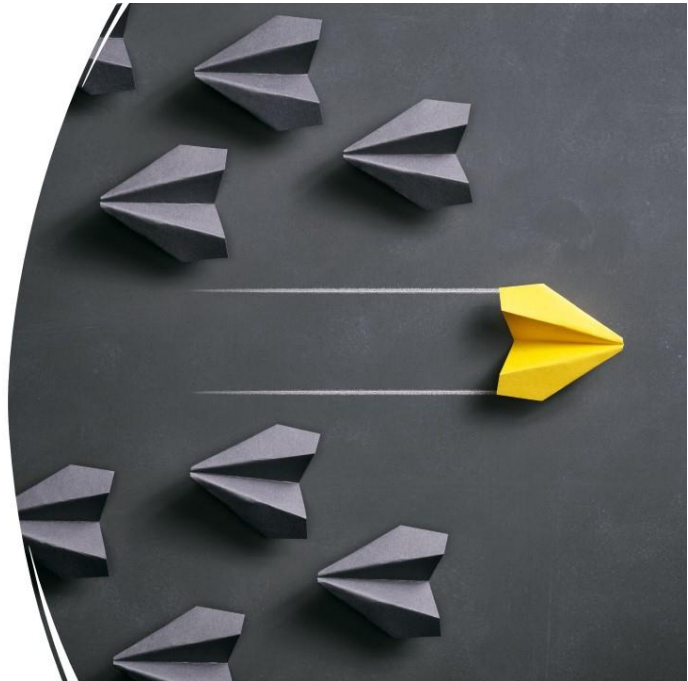
Initial thoughts and feelings

- What are your first thoughts and feelings about what the key messages or important themes were from the focus group?



A key point...

- Everything is 'up for grabs' at this stage
- Final themes are likely to be different than what / how presented today



Initial ideas for important messages / themes

Every child, family and diagnosis are different

- Different routes to diagnosis can impact the ability of parents to process information, increase length of initial admission & effect understanding of diabetes
- A child/family's background or history may influence their thoughts/emotions during diagnosis and ability/willingness to take on information (e.g. previous experience of hospitals, health, family communication and diabetes)
- Even with these factors, acceptance and adjustment to diagnosis can't be predicted
- Formulating a good understanding as an MDT of each child/family/diagnosis post-diagnosis could support person-centred ongoing care and management

The nature of the system creates limits and pressures on the diabetes process

- There are competing demands on time of diabetes team that impacts the availability of staff and, therefore, the process of diagnosis
- There is a conflict between the pressure to communicate information and the readiness of parents to receive that information
- Geographical dispersion of families makes supporting transition to home more difficult and places importance on the role of the hospital
- The interaction between a specialist team and the ward staff
- Pressure on hospital staff can make it difficult to transfer and maintain diabetes knowledge and skills
- Staff connection and reflection helpful but not always 'space'

Initial ideas for important messages / themes

Diabetes knowledge and the challenge of myths, misinformation and misunderstandings

- Parents bring with them pre-diagnosis understanding of diabetes, which can include myths, misinformation and misunderstandings
- Ward staff have different levels of knowledge and skills with diabetes that can positively impact the initial diagnosis phase or create additional confusion for parents
- Access to online information can interfere with the diagnosis process and add additional challenges to supporting parent understanding of diabetes
- Protecting against and mitigating against this challenge is a difficult and necessary task in the diagnosis process

The complexities of communication

- Multiple people involved can delay diagnosis, affect clarity of communication, and create confusion
- Communication of a diagnosis is a balance between seriousness and hope
- Difficulties in conveying the long-term and pervasive nature of diabetes
- Principles to 'breaking bad news' may support the communication of a diagnosis
- Balance between clinician need to convey information and the information the parents want

Initial ideas for important messages / themes

Making the hospital environment work for initial diagnosis

- The initial length of the hospital stay is important to ensuring 'success' of the early diagnosis phase
- Longer hospital stays cause practical problems for the ward and families
- The hospital environment does not necessarily provide optimum conditions for modelling / setting up ongoing diabetes management (e.g. food, activity, good practice in insulin administration)
- Flexibility in initial hospital stay by utilising hospital 'leave' can provide respite, support positive initial acceptance/adjustment, and increase trust between family/health professionals
- Structure and certainty in length of hospital stay may support practical difficulties for families

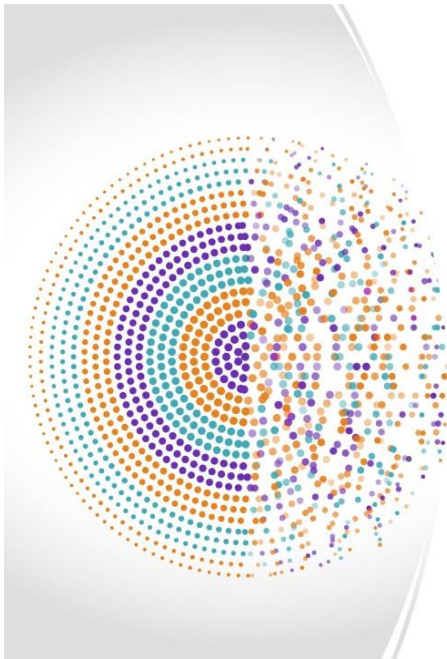
Recognising the longer-term impact of diabetes and consequences of pressure on parents

- Diabetes is life-changing and constant
- Diabetes management is hard and places a large pressure on parents
- The increasing pressure of improved diabetes care/management has increased the practical/emotional burden on parents
- It is important for parents to think about their own psychological wellbeing in the adjustment to diagnosis and the increasing pressure of diabetes care is likely going to have an impact on the need for psychological support

Final... initial ideas for important ideas / themes

- The initial diagnosis phase and the parent/clinician relationship are important for future diabetes care and management
 - 'Getting it right' at the start is important and the initial diagnosis phase the 'foundation' for ongoing care and management
 - The relationships between the diabetes team and parents are a strength and that relationship underpins good ongoing care and management
 - Importance of communicating with different family members
 - It can be difficult to 'repair' after difficult initial admissions





Diabetes diagnosis: Final reflections & possible actions

Monday 15th April 2024



Aims of today

- To review current themes now they have all been brought together
- To review possible actions that could be taken



A key point...

- Please continue to speak openly and honestly about what you feel is important
- Your views are invited and encouraged
- Changes are still very possible

Important areas you highlighted

Parents

- Problem with information/knowledge – including, general awareness of T1D (“knowledge from every direction”)
- An emotional experience
- Difficulties with communication
- Learning & adjusting in the hospital environment
- The importance of parent support - sharing stories, shared experiences & connection (in reducing isolation)

Clinicians

- Communication between health professionals – information & needs
- Need for more connection and reflection – for support & learning
- Reminder of balance between need to share information & individual (slowing down process and remembering that “one size doesn’t fit all”)
- Learning & adjustment in the hospital environment (need for time...)

Provisional themes

Theme	Key points	Perspective
1. The limits and pressures on the system	<ul style="list-style-type: none"> - Competing demands for the team - Conflict between need to transfer information & individual needs of the parents / person-centred care - General hospital staff turnover & interaction between general staff and specialist diabetes team 	Clinician
2. Emotions come first and diagnosis is viewed through their lens	<ul style="list-style-type: none"> - An emotional process and different emotions present at different phases of diagnosis - Emotional process influenced by pre-existing knowledge / family history of T1D 	Parents
3. Power of knowledge	<ul style="list-style-type: none"> - Low T1D knowledge in parents & general hospital staff influenced the time taken to diagnosis, increased myths/misinformation & increased distress - Pre-existing T1D knowledge in parents reduced time taken to diagnosis but reduced openness to learning; good T1D knowledge of general staff had large positive impact on initial diagnosis phase 	Shared

Provisional themes

Theme	Key points	Perspective
4. Poor communication & lack of transparency	<ul style="list-style-type: none"> - Initial communication of diagnosis by GPs was variable but mostly not provided - Hospital communication of the diagnosis was often delayed - Causes of hospital communication difficulties, e.g. number of people involved, lack of communication between staff - Communication of diagnosis during emergency admission - Communication of the process of diagnosis 	Shared
5. Conditions for learning, adjusting & forming relationships	<ul style="list-style-type: none"> - The importance of the diagnosis phase to later engagement with the team and T1D management - Reliance on hospital environment that may not be best setting for learning - Barriers to supporting practical, experiential learning on the ward - Possible solutions to improving the early diagnosis experience & supporting practical, experiential learning on the ward 	Shared

Provisional themes

Theme	Key points	Perspective
6. Sharing experiences & gaining support	<ul style="list-style-type: none">- Having space to connect and talk to others who had a shared experience was important to both parents and clinicians- A lot of the support parents wanted and needed after diagnosis could be provided by other parents- Support could be facilitated by clinicians through acknowledging difficulties with living with T1D and encouraging parents to share their experiences- Improved connection between staff could improve support and facilitate learning	Shared

Discussion



What do you think of these?



Have they kept what you felt was most important?



Are they missing anything?



Would you make sense of things differently?

Suggested actions from you...so far

- **Clearer and more transparent communication**
 - Within the diabetes team, a communication sheet
 - Of the diagnosis process e.g. average length of stay and who you will meet
 - Earlier communication of practical requirements of T1D management
- **Improving general doctors and ward staff T1D knowledge and skills**
- **Improving the ward stay**
 - Equipment?
 - Diet?
 - Leave?
- **Facilitating early parent support, including, peer support**
 - Newly diagnosed under 5s group (just started, may meet some need)
 - Facilitating connections with other parents, 'buddy' system
 - Increased normalisation & validation of impact of diabetes on parents, encouragement to share experiences to gain support
 - More information and structure to psychology input
- **Facilitating clinician support and learning**
 - Post-diagnosis informal debriefs
 - Post-diagnosis thinking and MDT care planning

Discussion



WHAT DO YOU THINK OF THESE?



ARE THEY REALISTIC / PRACTICAL?



WHAT OTHER ACTIONS MIGHT BE HELPFUL BASED ON OUR DISCUSSIONS SO FAR?

Further possible actions / reflections

- Providing a space and getting the views of doctors and ward staff
- Generic ward staff knowledge versus link staff approach
- Psychology input into initial communication – more involved to provide normalisation/validation about the learning process?
- Difficulties with misinformation – what about a diabetes team common Q&As sheet to be included in the initial information pack?
- Generic, low T1D knowledge in parents and general healthcare, information campaign to local GPs? Flyers related to common childhood symptoms of T1D? Link in with Public Health colleagues...
- GP communication difficulties, share research?
- Annual newly diagnosed meet-up



The future

- How might you want to share this learning further?
- How might you continue to monitor and reflect on the diagnosis process at YG?
- How might you continue to encourage or lead interest, research and actions in this area?



Final reflections

- How have you found taking part in this research?

Appendix 15 – Empirical paper coding extract

Parent transcript

P1: If you were already in DKA, we wouldn't have gone through the GP.

P9: Yeah, my son was diagnosed at 18 months old. Erm, so I had no idea even that that was a thing. **(P2:** Yeah, even at that age). So young and to me, he was just unwell, like for a few weeks, he was wetting through like you say, he was extra thirsty, but because obviously he's not talking, how am I able to know?

P1: And it's not abnormal to wee.

P9: Yeah, exactly. And then he was getting more tired and things. And anyway, it ended up in severe DKA and they said if we would have been 20 minutes later, he wouldn't have made it. It was Alder Hey, they had ketamine drills into his shins to get fluids through, like one of our consultants have said, like, it's the worst thing they've seen, it was so scary, but you have no idea, I just thought he was poorly and there's not really much awareness. I hear a lot about Type 2, but nothing on type one really and about the ages and you know you don't hear much of it, do you?

P2: You don't really know what you're looking for. I mean you know the word diabetes exist and you know that people can get it.

P9L: Yeah.

P4: And that's what I thought my daughter had cause she's a big girl, OK? She's not massive, but she is a big yeah girl. And that's what I thought she had. **(P2:** So then there's all this...) And it was when they told me in hospital she was type one and not type 2, my head just went again, then cause type two, I thought it's my fault, I'm her mum. It's me that buys the shopping and feeds her.

5

P3: Yeah, being transparent about what they're looking at, what you know what's the possibility. It's very, yeah, it kind of, they don't share everything with you. I guess there's limitations, but you know, yeah...

P7: Or just this and this and this, trying to roll out everything... or just she might have this...

P2: Or, "this ones looking more likely. Yeah, there's obviously something diabetes related or, you know, her blood sugars are high and they shouldn't be high. We need to get that under control, manage it and then we'll look at it a bit deeper".

P8: The only way I could explain it is like if you've got a dog, you go to the vet, they say, "your dog's got blah blah blah blah". That's cause it's your dog. Yeah, you go to hospital, that's your child, that's your baby. And then you want them to tell you everything bad or good, or how difficult it's going to be. But they don't. Well, why? Why does she know? She's just the nurse who lives down the road. I need to know, I wish they'd tell us everything.

Facilitator: Okay, so you want more information **(P8:** Good and bad)... in terms of investigations and...

P3: Yeah and if they don't know, you know it's understanding what they're looking at, what they're looking for.

P2: Now when you do find out, when a medical person comes to you and says, I don't really know what's going, it doesn't really fill you with a whole lot of confidence [Laughter]. It's that tightrope business you're in this grief, shock, panic... erm, completely out of your depth zone... So, I think it needs to be maybe a very consistent, vague, direct.

D9 Danielle Shaw ...
Key diabetes symptoms noticed/not noticed by parents
Reply

D9 Danielle Shaw ...
DKA/crisis route to diagnosis
Reply

D9 Danielle Shaw ...
Parental thoughts/feelings at diagnosis
Uncertainty pre-diagnosis
Diabetes can be easily missed
Reply

D9 Danielle Shaw ...
Diabetes can be easily missed
Key diabetes symptoms noticed/not noticed by parents
Low pre-diagnosis knowledge of T1D
Reply

D9 Danielle Shaw ...
Low pre-diagnosis knowledge of T1D
Reply

D9 Danielle Shaw ...
Low pre-diagnosis knowledge of T1D
Reply

D9 Danielle Shaw ...
Parental thoughts/feelings at diagnosis
Parental overwhelm at diagnosis
Reply

D9 Danielle Shaw ...
Parent desire for more clear and transparent communication of diagnosis process
Parent thoughts/feelings that there are things being hidden during process
Reply

D9 Danielle Shaw ...
Parent desire for more clear and transparent communication of diagnosis process
Belief that more clear and transparent communication of diagnosis would improve
Reply

D9 Danielle Shaw ...
Parent desire for more clear and transparent communication of diagnosis process
Parent thoughts/feelings that there are things hidden during diagnosis
Reply

D9 Danielle Shaw ...
Parent desire for more clear and transparent communication of diagnosis process
Reply

D9 Danielle Shaw ...
Parent empathy/seeking to understand reasons for the diagnosis process
Reply

Clinician transcript

C1: Time and compassion, I'd say. Well, it can be very, very overwhelming. So the diagnosis...

C5: Sometimes, there's a pressure on us, like we have to go and give them this information but actually, if you think of yourself and someone giving you information. If you're in that situation, I probably would have switched off, you know, after a few minutes. So you have to not think of what you need to deliver but actually what they what can they absorb in that time. And then if you have to only do 30 minutes that day...

C3: It's not a tick box, is it? |

C1: So there's a bit of a pressure sometimes, and this isn't a criticism because obviously it's stuff that you know, hospital, but sometimes there's a bit of a pressure from the ward for some, for some of the team to get **get** down there. You know, just they haven't seen anyone and they've been here since Friday. Well, but that might not actually be OK because there might be some loads of others, well, people will be busy doing the other stuff and, but there is a bit of a pressure there sometimes.

C3: Sometimes the education, I think we didn't see someone till Monday, they did the basic skills with the ward staff and that really worked well. And I think it was our previous dietician that did with me on the Monday, and they'd actually had time to accept that diagnosis. They've actually done some of the practical aspects of carb counting and, you know, the injections with the ward staff over the weekend. And we came on Monday and it was just like, you know, you feel like it's a walk in the park that you're just slipped in this and they were just at a better place really. You know, it doesn't suit everyone, but you know, it did work with this one. That was really positive. |

C5: So that can be a positive or also could have been negative. **[C3: Yeah, yeah]** They could have been given the wrong information. **[C1: Yeah, that's happened before].** Not actually telling them how to properly carb count. |



D5 Danielle Shaw ...
Thoughts/feelings about diagnosis
Diagnosis of diabetes is hard

Reply

D5 Danielle Shaw ...
Conflict between hospital/staff pressure and
parent readiness/ability to process
Clinician empathy/putting self in parent
.....

Reply

D5 Danielle Shaw ...
Every diagnosis and family is different

Reply

D5 Danielle Shaw ...
Diagnosis process is impacted by staff
availability

Reply

D5 Danielle Shaw ...
Every diagnosis and family are different
Positive ward staff experience in supporting
diagnosis
.....

Reply

D5 Danielle Shaw ...
Variation in ward staff knowledge and skills
Myths/misinformation/misunderstandings

Reply

Appendix 16 - Thesis word count

Thesis section	Main body*	Inclusive
Thesis abstract	-	293
Systematic review abstract	-	196
Systematic review body	5,820	9,206
Empirical abstract	-	195
Empirical body	9,250	12,560
Contributions to theory, research and practice	4,485	6,297
Title pages, contents, appendices, wordcount	-	7,734
Total word count	19,555	36,581

**excluding abstracts, tables, figures, references and appendices*