





Presented by: Jess Wheeler

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Led by: Timothy Barrett & Julian Hamilton-Shield

Improving outcomes for children and young people with diabetes from diverse backgrounds: how the **'Burden of Treatment Theory'** can help us understand the needs of diverse populations

The Diversity in Diabetes Study - qualitative interviews



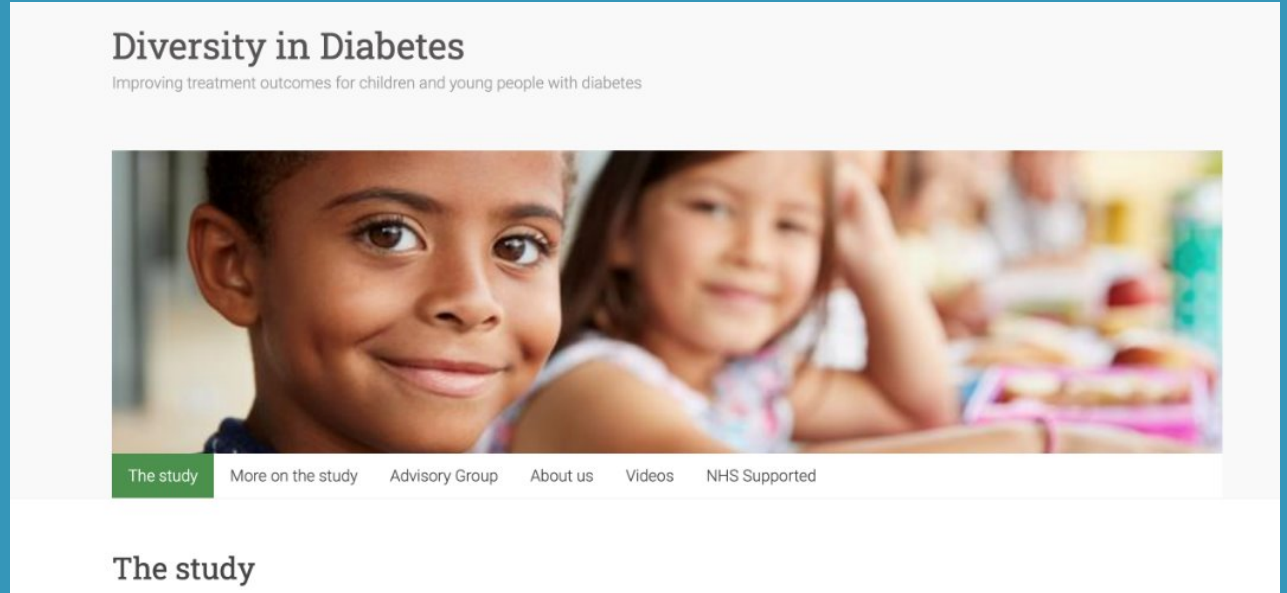


Background



What's the research about?

Can we work together with diverse* children, young people and families living with childhood diabetes **to develop an intervention that improves blood glucose control and reduces risk of long-term complications?**



<https://www.diversityindiabetes.org.uk>

***Diverse** – we focused on children living with diabetes from UK minority families (e.g. Black British, Black African, South Asian, British Pakistani, British Caribbean) and families living in multiply deprived places. **Why diverse?** Compelling evidence-based reasons for this focus.



**Why diversity?
Why an intervention?
What's the evidence base?**

**National Paediatric Diabetes
Audit 2021/22**
National report 2021/22: Care
processes and outcomes –
extended analysis
<https://www.rcpch.ac.uk>

NPDA National report 2021/22: Care processes and outcomes

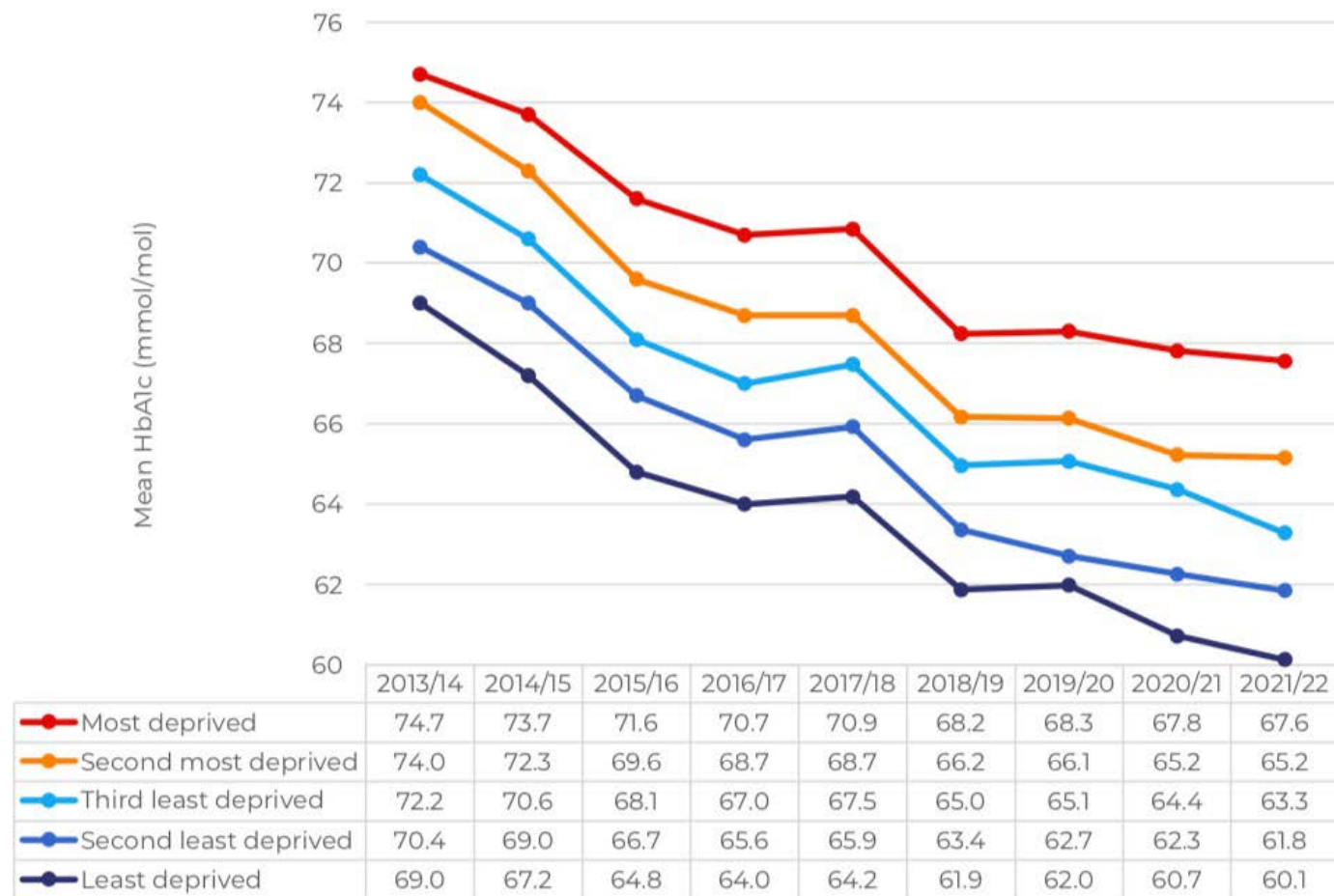


Figure 31: Mean HbA1c for children and young people with Type 1 diabetes by deprivation quintile, 2013/14 to 2021/22

NPDA National report 2021/22: Care processes and outcomes

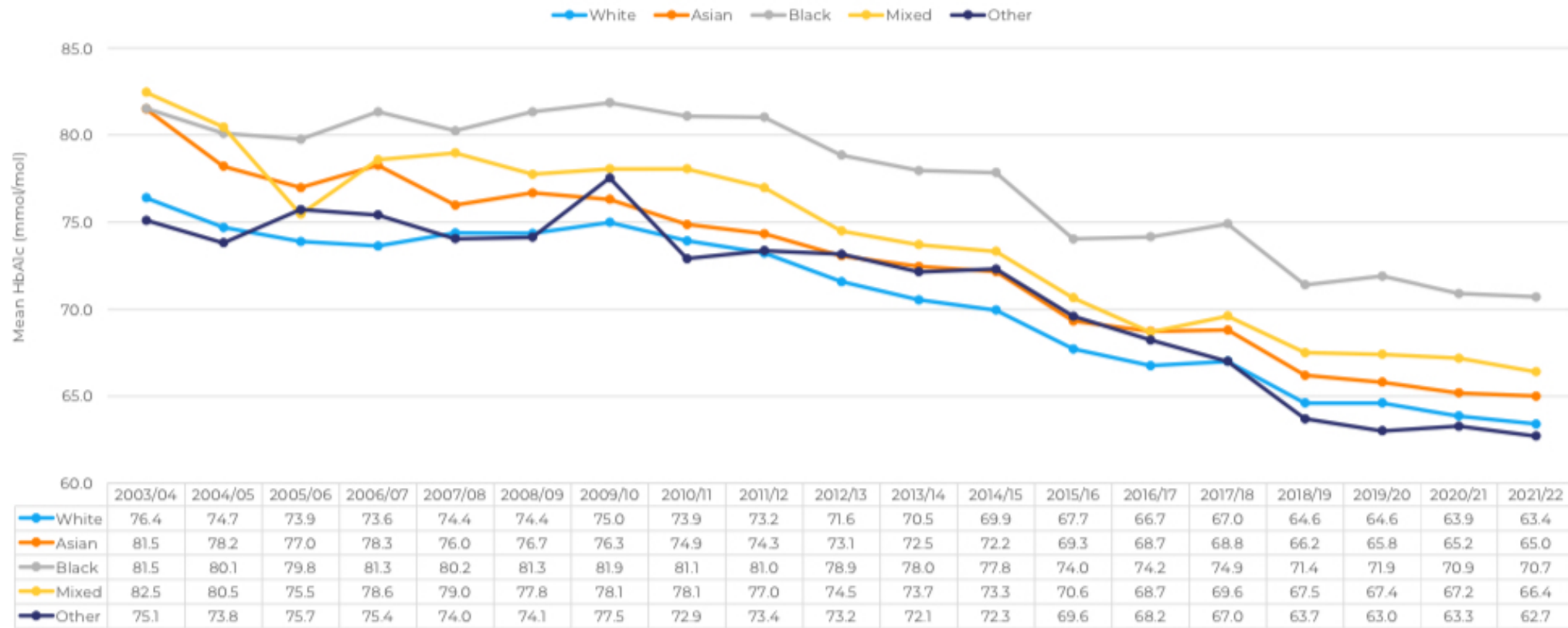


Figure 29: Mean HbA1c for children and young people with Type 1 diabetes in England and Wales by ethnic group, 2003/04 to 2021/22

Too little research has directly asked diverse minority children, young people and families living in the UK with childhood diabetes to describe their lives, experiences and to tell their stories.

The Diversity in Diabetes Study set out to visit and talk with diverse minority children, young people and families living with childhood diabetes:

- to hear their voices and stories and to try to understand and learn about their own lived experience with childhood diabetes
- to work together to develop an intervention package, to attend to the treatment outcome gap, and lead to better HbA1c outcomes.





Methods



The interview study design

How we did it, in brief



Children's diabetes clinical teams

Clinical team approach children/young people aged 5-19 and/or their carers during routine visits.

Complete 'consent to contact'...



Research team

Contacts by phone. Arranges interviews in person, visits participants at home (or online, if preferred). Explains study, completes full consent.

Audio-record semi-structured in-depth interview with parent, child or young person separately or together.

60-90 minute interview



The study design – Analysis

Phase 1. Inductive Thematic Analysis – coding, interpreting, constructing themes – Victoria Clarke, Virginia Braun

Critical realist philosophical perspective - Roy Bhaskar/ Margaret Archer

***key is being able to connect experiential accounts, stories, meanings - to causal mechanisms we can use to develop an intervention.**



The study design – Burden of Treatment Theory Analysis (BoTT)*



**Phase 2 – applying a BoTT lens to
inductive thematic data analysis...**

- Deductive**
- Does a new picture of what is
going on pop out in 3D clarity?**



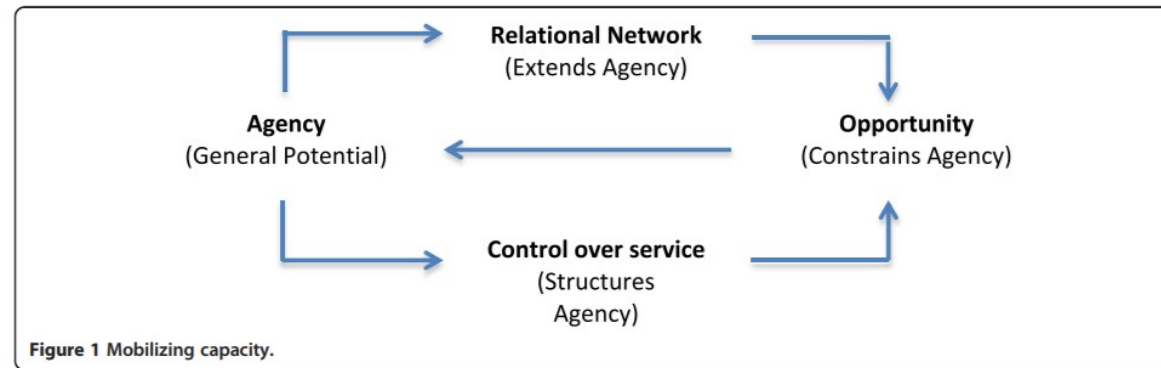
Burden of Treatment Theory

What is the BoTT?

May, C. R., Eton, D. T., Boehmer, et al. (2014). Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC health services research*, 14, 1-11.

But it's also an abstract conceptual model...

...to understanding at a general level (across all patient groups) how capacity for action interacts with the work that stems from healthcare (across all healthcare systems) ...a structural model that focuses on the work that patients and their networks do.



Does it apply? Can it be helpful? Is it relevant to the lives and experiences of diverse minority children, young people and families living with diabetes in the UK?



Results

Interviews = 43

Participants = 69

Age of CYPD	
< 10 years	9
10-15 years	25
16-19 years	9
UK minority heritage or white (IMD 1 or 2)	
Black British /Black African	14
British Asian /South Asian /Pakistani	11
British Caribbean	4
Brazilian	1
Mixed heritage	3
White (IMD score 1 or 2)	10
Gender of CYPD	
Male	15
Female	28
Gender of parents	
Male	7
Female	19
IMD score (CYPD postcode)	
1 or 2 (two most deprived deciles)	30
Interview with	
Child or young person only	11
Child or young person plus parent	21
Parent(s) only	10

Results– who took part

Participants





Results

Thematic analysis

Internal barriers – the level of the individual

Relational barriers – the level of the local community/family support network

Clinical barriers – the level of the diabetes health service and relationships within the clinical

Internal barriers: Fed up, not prioritising diabetes, wanting to forget



Parent: “She’ll go out and she knows what she’s doing, she’s very smart. But I think there’s like a sort of a denial thing where sometimes she just might be out with her friends and you know, it’s just like oh yeah, I’m not that bothered and just decides to put it to the back of [her] head...”

Young person: “I don’t *just decide*...but I do forget a lot.”

Young person: “And I hate having it, so I don’t talk about it...I have to take the injection and because I don’t like needles, at first I don’t like the medicine I have to take. At first I was scared of the injection... and then because I had to take it often, it was really annoying....”

Relational barriers: Assertiveness, understanding, community support and appropriate adaptations



I was checking my blood sugar and the teacher was like a supply teacher, and he was really, really annoyed at me 'cause I had my head on the desk and... I wasn't doing anything and I'd done all my work. I don't know why he was mad at me, but he was like really angry at me and then I was checking my blood sugar and he got super mad..... And then the teacher came up to me and he was asking me – he was telling me that I was supposed to be in isolation and then I told him that the teacher thought I was on my phone and then he just took it off me...

Clinical barriers: diabetes team relationships, communication about diabetes management, HbA1c and clinical support options



They [Diabetes Consultants] feel very condescending, even now, they feel very condescending like I know nothing and I feel like it always felt like that, so having a consultant who treated me as an equal really helped me understand it.

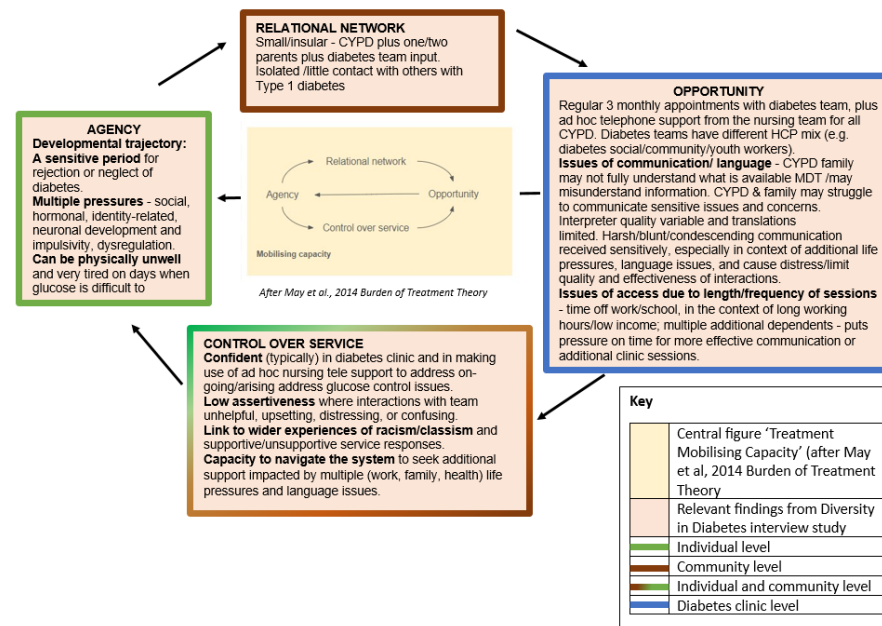
He'd (consultant) be saying your basal rates, your this, your that, your whatever and I'm like seven years old or ten years old, I didn't know what any of this means and I'd be forced to learn it quite in my face, you know? So it was never an enjoyable experience because it was like somebody was just talking to me in another language and expecting me to understand everything they were saying,....



BoTT gives makes it easier for us to see how pressures, stresses, fragilities relate to diabetes management and relevance to diverse CYPD.

Results

BoTT lens – threatened resources



Agency
Relational networks
Resilience
Relational networks



Interventions



Level	Intervention idea
Individual Level <p>- Addressing barriers to diabetes management at the level of the individual. Holistic – attending to the whole life, including inner life – and ability to balance and attend to diabetes management. CYPD and family experiences, feelings, thoughts, beliefs are the focus and how these relate to diabetes management and your whole life. Can work directly with CYPD, or for younger children with parents of CYPD.</p>	Life coach (CYPD 10 years plus) <p>- Helping to understand diabetes in the context of whole life and to prioritise and balance diabetes management effectively, while taking care of the whole person. - Addressing underlying blocks and barriers to good self-care, and developmental transitions.</p>
Community Level <p>Working to support family life life/everyday life and positive communication/relationships that impact on diabetes management. Talking through everyday concerns, identifying important issues, taking positive action. Work with CYPD and family to support communication and support in school, clinic, other services or wider community. Work as an advocate/ally, to support self-advocacy and increase the effectiveness of the support attained in everyday life.</p>	Peer support work (CYPD and families) <p>- Peer led issues, facilitated groups, sharing experiences of technology use, dealing with everyday issues, fears, experiences at school, clinic, or in family, gaining confidence in self-advocacy and articulation of concerns and issues. Also social, addressing isolation.</p>
Clinic Level <p>Working with the clinical team to address issues relevant to communication, cultural competence and sensitivity in the clinic and availability (and communication of availability) of appropriate one to one and group sessions for CYPD and families.</p>	Diabetes community/ family/ youth or social worker (CYPD and families) <p>Working with CYPD and families to understand issues and concerns. Support to attend to everyday life pressures, including family tensions. Advocacy work, helping young person and family to get appropriate adaptations, working with schools, attending to clinical relationships, housing, benefits, social network building.</p> <p>Community workers may be purposively selected and trained from same heritage community.</p>
	Additional diabetes clinic sessions (HCPs) <p>e.g. introducing new technology, increasing family confidence in new technology/technology changes. Bringing together CYPD with experience with those without; GI food; transitions.</p>
	Focus on the nature of the clinic <p>Make the clinic a positive, constructive, judgement-free space, focused on good communication, understanding. Extra time where English is an additional language or interpreters are needed. Positive, constructive, solution focused and supportive, empathetic responding.</p>



Discussion



Did the BoTT help? Yes

Did it change the interventions we had begun to see as relevant? No

But it did strengthen and deepen our understanding of why these interventions might be helpful and by zooming out, we could see more clearly some of the specific threats to our diverse minority population, in terms of development and agency, relational networks and strains, clinical practices and communication issues.



Thank you!



The research team

- Led by two **Professors who are also Children's Diabetes Consultants**
- **Two University teams** – clinicians with clinical research interests in diabetes & researchers with expertise in qualitative research in healthcare and interviewing
- **Research partners - Diabetes UK and Alstrom UK**
- **Young People's Advisory Group** – young people with diabetes and siblings of children and young people with diabetes, and young people with experience in health research advisory work
- Supported by two children's **diabetes clinical teams** (nurses, doctors, etc. in the clinic)

Improving outcomes for children and young people with diabetes from diverse backgrounds: how the 'Burden of Treatment Theory' can help us understand the needs of diverse populations (the qualitative interview component of the Diversity in Diabetes Study)



Presented by: Jess Wheeler

Research Team: Sabi Redwood, Aidan Searle, Danielle Byrne, Sheila Greenfield, Ian Litchfield, Suma Udah, Parth Narendran, Kerry Leeson, Charlotte Austin + Advisory Group

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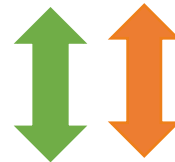
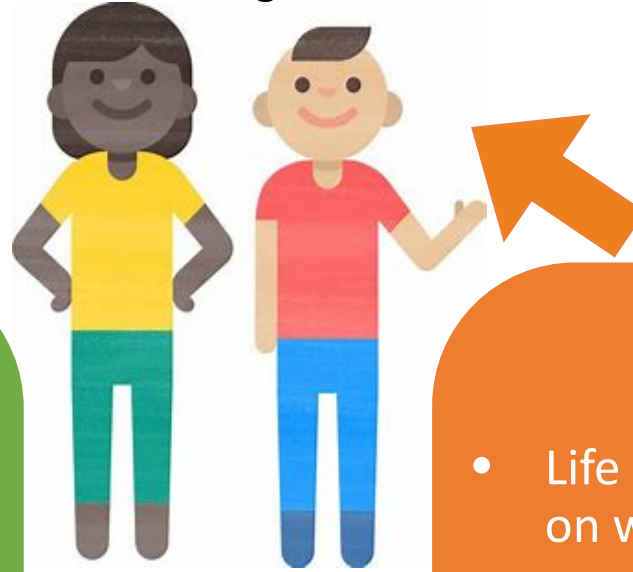
Intervention level 1: Individual

Focus: the young person with Type 1 diabetes – your experiences, feelings, thoughts, beliefs, and how these relate to your diabetes self-care and your whole life and self-care in general.

Peer support

- Peer-led issues (young people decide what want to focus on and when)
- Facilitated groups (an experienced facilitator helps to make group discussions flow comfortably)
- Or 1:1 mentoring (age / experience related)

e.g. Sharing experiences of tech use, dealing with everyday issues, fears, experiences at school, clinic, or with family/parent relationships and tensions.

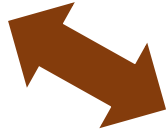


Life-coach

- Life coach to work with young person on whole life issues - feelings, experiences and the underlying blocks and barriers to good self-care.
- Helping young person to prioritise and also balance your diabetes self-care with other life concerns.
- Practising ways to manage awkward and annoying situations in protective ways.

Diabetes life-coach

- Working directly with young person (one to one)
 - Around 6-12 sessions
 - Work to re-prioritise diabetes self-care when fed-up/forgetful or in denial
 - Exploring routines, habits and rhythms of life and diabetes care
 - Addressing underlying blocks and barriers to good self-care
 - Steps to making new strategies, building new habits
- ❖ Going deeper than is usually possible in the clinic - coaching/counselling style
 - ❖ Focus on life transitions or when young people feel stuck
 - ❖ Addressing irritations and underlying issues that get in the way of managing diabetes
 - ❖ Addressing fears about the future consequences of diabetes and life impact



INTERVENTION LEVEL 2: family and school, clinic and community relationships

FOCUS: Family life/everyday life and positive communication/relationships that impact on diabetes self-care.

- Talking through everyday concerns, identifying important issues, taking positive action
- Work with young person and family to support communication and support in school, clinic, other services or wider community
- Work together to increase the effectiveness of the support you and your family get in your everyday lives.

Intervention level 2: family and school, clinic and community relationships

Focus: Family life/community life and positive communication/relationships (independent of clinic services?)

e.g. communication and support in school, clinic, other services or wider community- to enhance inter-relationships and enhance the support you and your family get in your everyday lives.



Community Worker

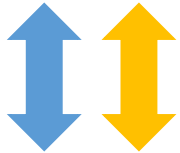
- Work with parents and child/young person to understand issues and concerns.
- Advocacy work (working with agencies to improve their understanding and to be more sensitive and supportive, and with family and young person to self-advocate).
- Supporting positive communication

Helping the young person, family and agencies to get the best support from the clinic, school, other available resources and benefits as needed.

Diabetes community worker

- An ally (should they be independent of clinic?)
- Working with family and young person and support agencies
- Focus on positive communication and advocacy/self-advocacy
- Supporting communication within family
- Supporting communication with school
- Supporting communication with clinic
- Supporting communication with other services

- ❖ Positive action to address social environment and inter-relationships to improve everyday life and experiences that impact on diabetes self-care
- ❖ Addressing barriers to diabetes self-care that are because of an unhelpful/unsupportive environment
- ❖ Addressing concerns that are not being talked about – for whatever reasons
- ❖ Help to get the support young people / families need in everyday life.



INTERVENTION LEVEL 3: The clinic

FOCUS: Clinic awareness, sensitivity and interventions offered

- what the clinic offers young person and family as part of the diabetes treatment package
- the ethos / nature of communication in the clinic

Intervention level 3: The clinic

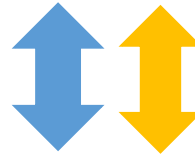
Focus: Clinic awareness, sensitivity and interventions offered

e.g. what the clinic offers as part of treatment package and the ethos of communication in the clinic

Focus on the ethos of the clinic

Work with diabetes service team to help the clinic to:

- Be a positive, judgement free, constructive space
- Increase awareness and understanding of diverse cultures, and issues of race and class, health literacy and sensitivity to different lifestyles and choices.



Additional clinical sessions/groups –

Focus on:

- Trialling new routines/tech for diabetes self-care, managing risks
- Tech awareness/latest systems
- Psychological health and well-being
- Food health, low GI diets, carbs and diet awareness updates

Additional clinical sessions/groups

- Clinic offer focused sessions outside of normal consultation?
- Group work – one session/a series of sessions with peers
- Individual 1:1
- With young person, or family/parents or both.

e.g.

- Making changes to diabetes care e.g. changing food habits, exercise, insulin or tech
- Understanding & testing boundaries for safety e.g. what can I skip and still be safe?
- Tech awareness/latest systems – pros and cons and issues for different age groups
- Psychological health and well-being – managing fears, insecurities, everyday issues and life crises. Family tensions, developmental issues, life events and major transitions.
- Food health, low GI diets, carbs and diet awareness updates
- Transition preparation e.g. secondary school, work experience, puberty, independent self-care, personal challenges, holidays.

Focus on the clinic

Work with the health team to make sure the clinic is a safe space and that the whole clinical team work towards:

- Positive, **gentle**, judgement-free, constructive, sensitive, and pro-active communication
- Have high expectations for patient's current and future health and life.
- Checks in regularly on issues, concerns, experiences, knowledge, understanding.
- Has a strong awareness of diverse local cultures, practices, and concerns and is sensitive to different lifestyles and choices.
- Does not make assumptions based on heritage/stereotypes – sees the person, asks respectfully, does not rely on assumptions.
- Understands potentially traumatising migrant experiences entering the UK.
- Understands issues of race, class, youth alienation and disempowerment.

Acknowledgements

Many thanks to all the young people and families who have participated in interviews for 'Diversity in Diabetes' Study

Interviews conducted by:

- Ms Danielle Byrne
- Dr Jess Wheeler

Research Team: www.diversityindiabetes.org.uk/about-us


Review of systematic reviews

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Developments in the design and delivery of self-management support for children and young people with diabetes: A narrative synthesis of systematic reviews

Ian Litchfield  Timothy Barrett, Julian P. Hamilton-Shield, T. H. M. Moore, Parth Narendran, Sabi Redwood, Aidan Searle, Suma Uday, Jess Wheeler, Sheila Greenfield

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Theresa H. Moore , Sarah Dawson, Jessica Wheeler, Julian Hamilton-Shield, Timothy G. Barrett, Sabi Redwood, Ian Litchfield, Sheila M. Greenfield, Aidan Searle ... [See all authors](#) 

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