The background is a vibrant, abstract composition of various colors and patterns. It includes a teal shape with white wavy lines, a yellow shape with white wavy lines, a dark blue shape with white dots, a pink shape with white dots, a yellow shape with white plus signs, and a dark blue shape with white dots. There are also several white wavy lines scattered throughout the design.

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

Dr Danielle Shaw, BCUHB

Shaw, D., Connolly, J.F., & Piggan, L. (2025). Available from,
[https://www.tandfonline.com/doi/full/10.1080/08870446.2025.
2553866](https://www.tandfonline.com/doi/full/10.1080/08870446.2025.2553866)

Aims of today



TO PROVIDE AN OVERVIEW OF THE
PROJECT IN RESEARCH TERMS



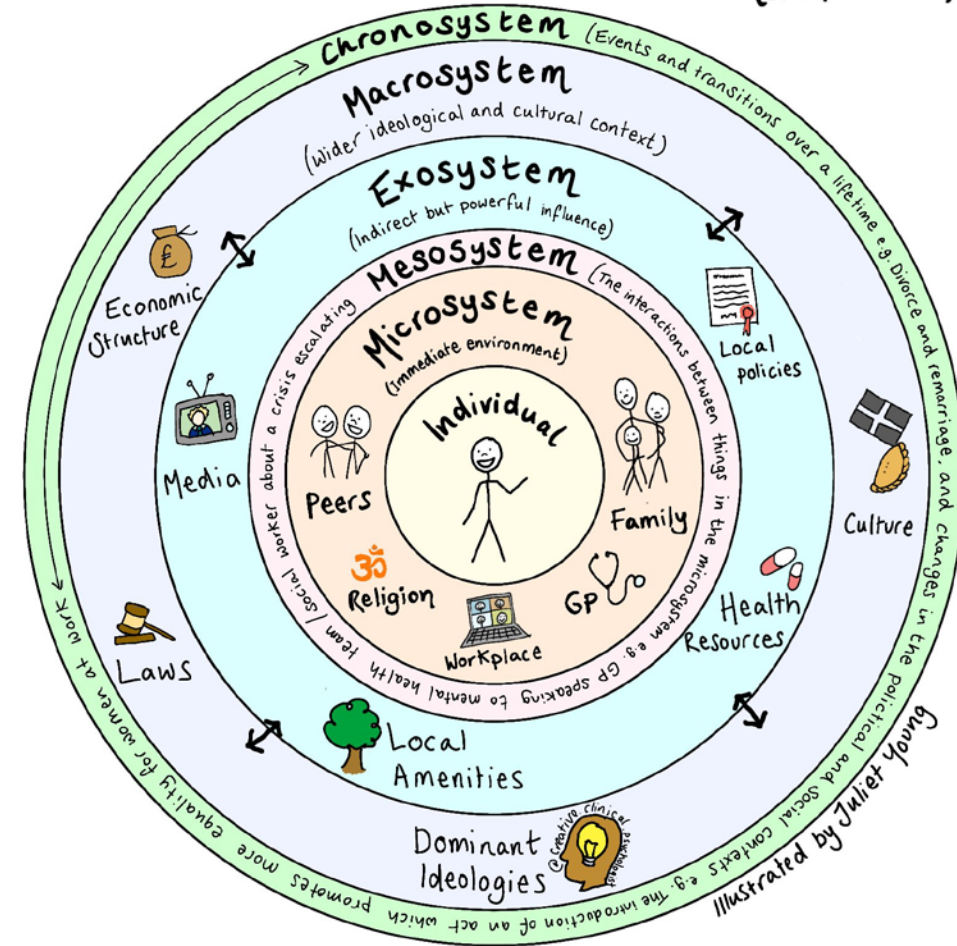
TO ALIGN FINDINGS TO PRACTICE
AND SERVICE DEVELOPMENT

Background

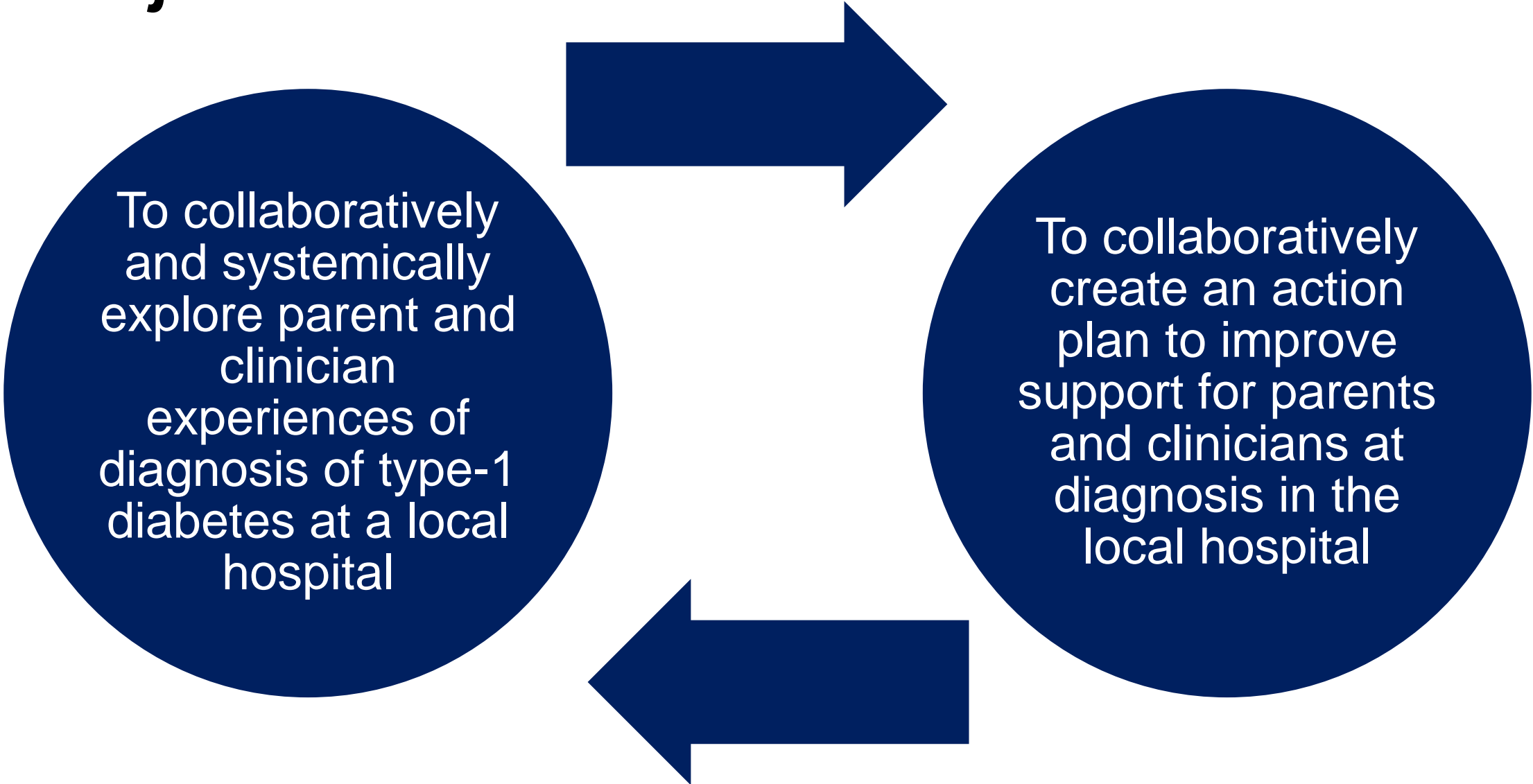
- A local diabetes team expressed a desire to look at diagnosis process at the hospital
- Diagnosis of paediatric type-1 diabetes (T1D) is an emotional and practical adjustment for families (Simpson et al., 2021; Sousa et al., 2022)
- Diagnosis of paediatric T1D requires health professionals to balance sharing life-altering information, transfer extensive medical knowledge, and beginning of longer-term patient/professional relationship (Baile et al., 2000; Davies et al., 2017; Tranberg & Brodin, 2023; Wolfe et al., 2014)

Research & research position

Ecological Systems Theory (Bronfenbrenner, 1979)



Objective



To collaboratively and systemically explore parent and clinician experiences of diagnosis of type-1 diabetes at a local hospital

To collaboratively create an action plan to improve support for parents and clinicians at diagnosis in the local hospital

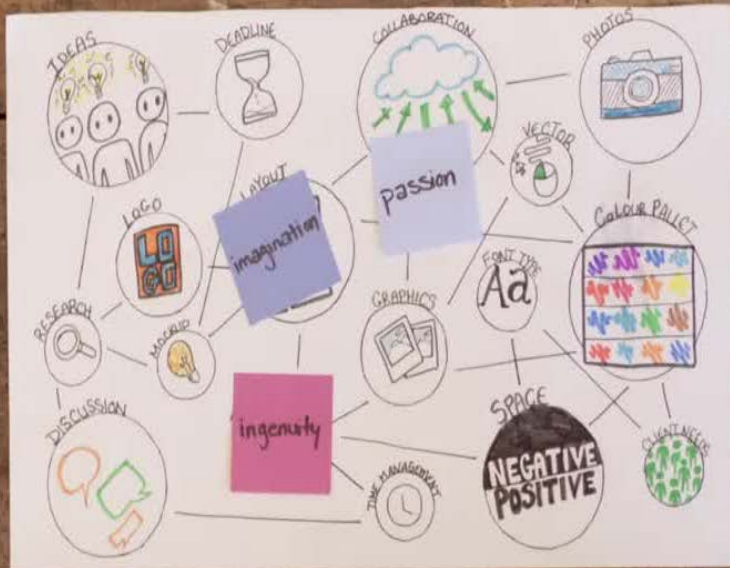
Study design

- Underlying principles (Abma et al., 2018; p8):
 - 1) Maximising participation
 - 2) Enabling people to take action
 - 3) Adding local value

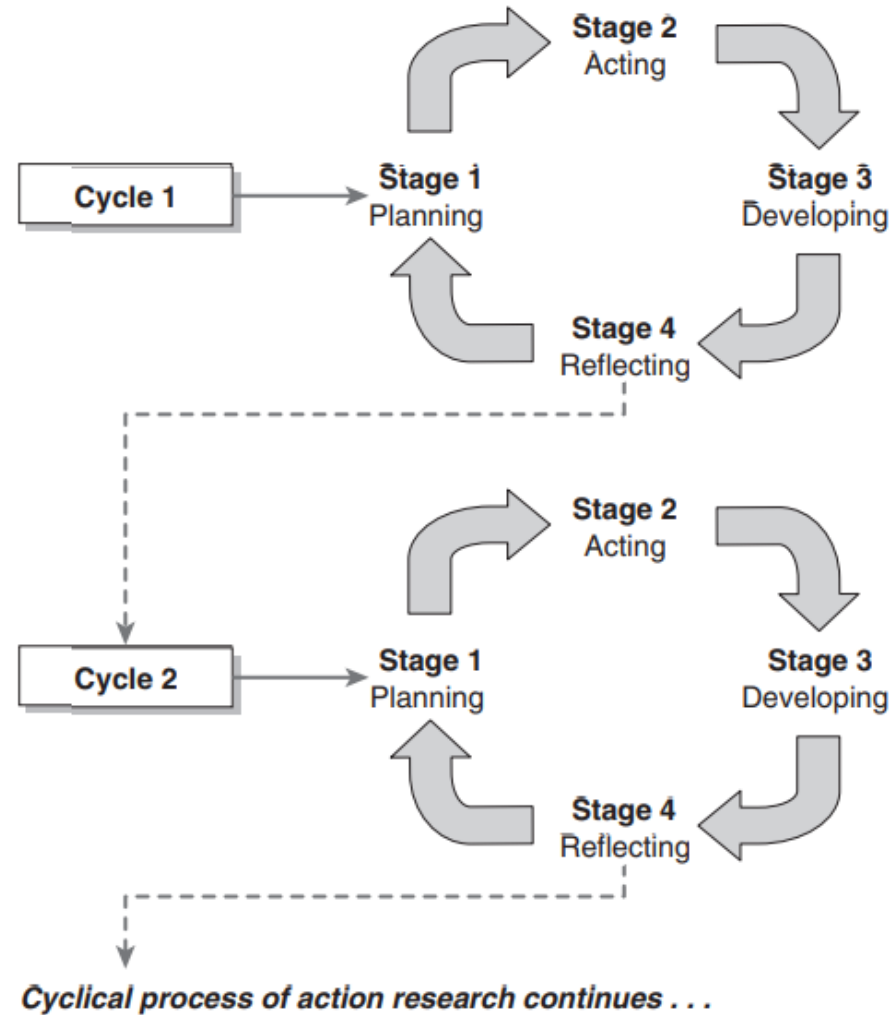
- Participatory action research:

*“Learning to look at the world through a different lens, one that sees the world in relational terms”
(Abma et al., 2018; p19)*

- Method encapsulates broader NHS values & principles



PAR cycle (Mertler, 2019)

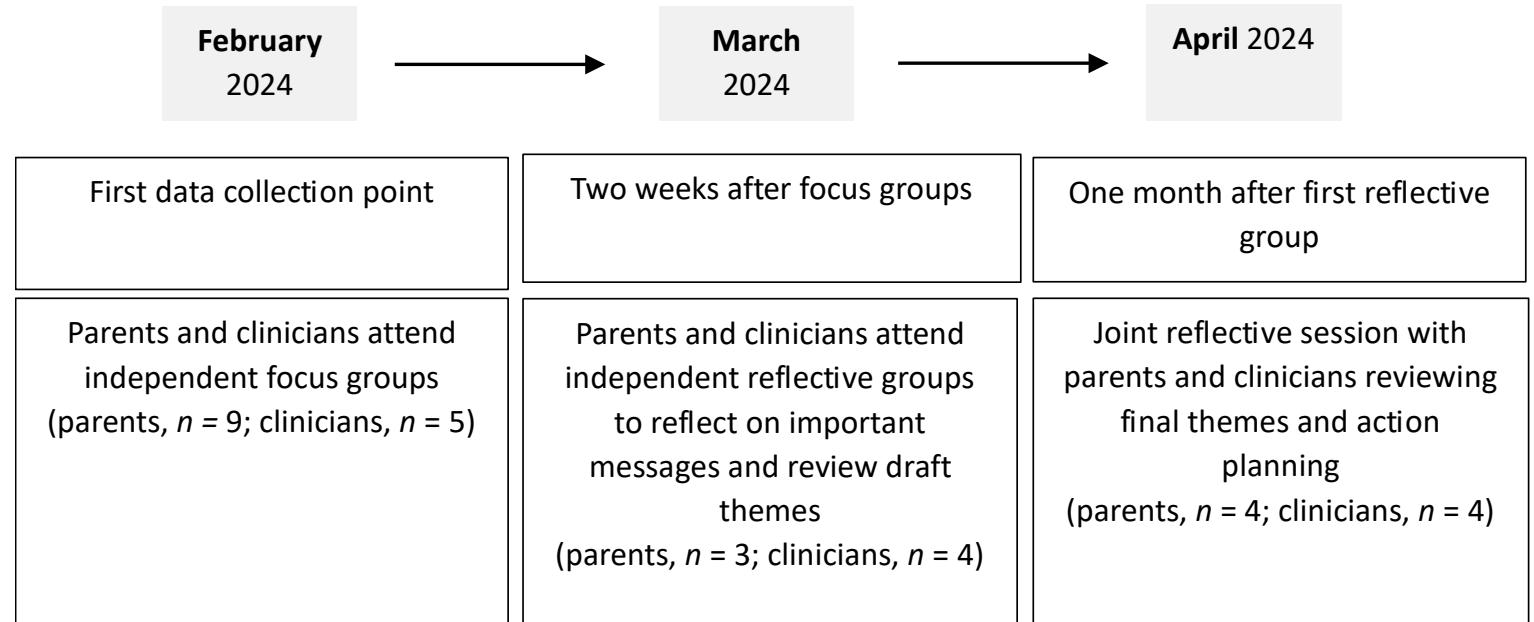


An illustration on the left side of the slide shows a team of ten people, represented by black silhouettes, climbing a green mountain peak. They are connected by a red rope. The person at the top of the peak is holding a red flag. The background is a light pink gradient.

Participants

- Parents:
 - Nine parents consented to take part in the study, representing seven families
 - 6 mothers and 3 fathers
 - Children were diagnosed between the ages of 1-9 years old
- Clinicians:
 - Five clinicians from the diabetes team
 - Consultant Paediatrician, two Paediatric Diabetes Specialist Nurses, a dietitian and a psychologist
 - Two ward staff professionals expressed interest in participating but could not on day of focus group due to competing demands

PAR data collection and analysis process



Findings



The limits and pressures on clinicians and the system



Parents' emotional lens at diagnosis



The power of knowledge



Difficulties with communication and transparency



Conditions for learning, adjusting and forming relationships



Sharing experiences and gaining support

Themes

Theme	Theme summary	Example quote
The limits and pressures on clinicians and the system	This included competing demands, wider ward staff changes and hospital pressures	<i>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)</i>
Parents' emotional lens at diagnosis	The emotional experience was prevalent throughout all discussions and there was an emotional journey during diagnosis	<i>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)</i>

Themes

The power of knowledge

The majority of parents had low pre-existing knowledge of T1D and this impacted their experience of diagnosis. This was also a factor that clinicians were mindful of. Varied ward staff knowledge and the impact of this was discussed by both groups.

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)

[Impact of high ward staff T1D knowledge and 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)

Themes

Difficulties with communication and transparency

For parents, pre-diagnosis information varied and communication at the hospital was not always clear. Clinicians reflected on some of the systemic difficulties with communication in a busy hospital setting. Both groups thought that increased communication and transparency about the initial treatment, including length of stay and items required on discharge, would be helpful.

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)

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)

Themes

Conditions for learning, adjusting and forming relationships

This related to the conditions in the hospital and included conversations around the length of the hospital stay, the suitability of the food, the availability of equipment to support learning (e.g. weighing scales), and it not being reflective of their day-to-day lives.

One thing that was an issue was that the weighing of the food, there was only one weighing scale... '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)

Themes

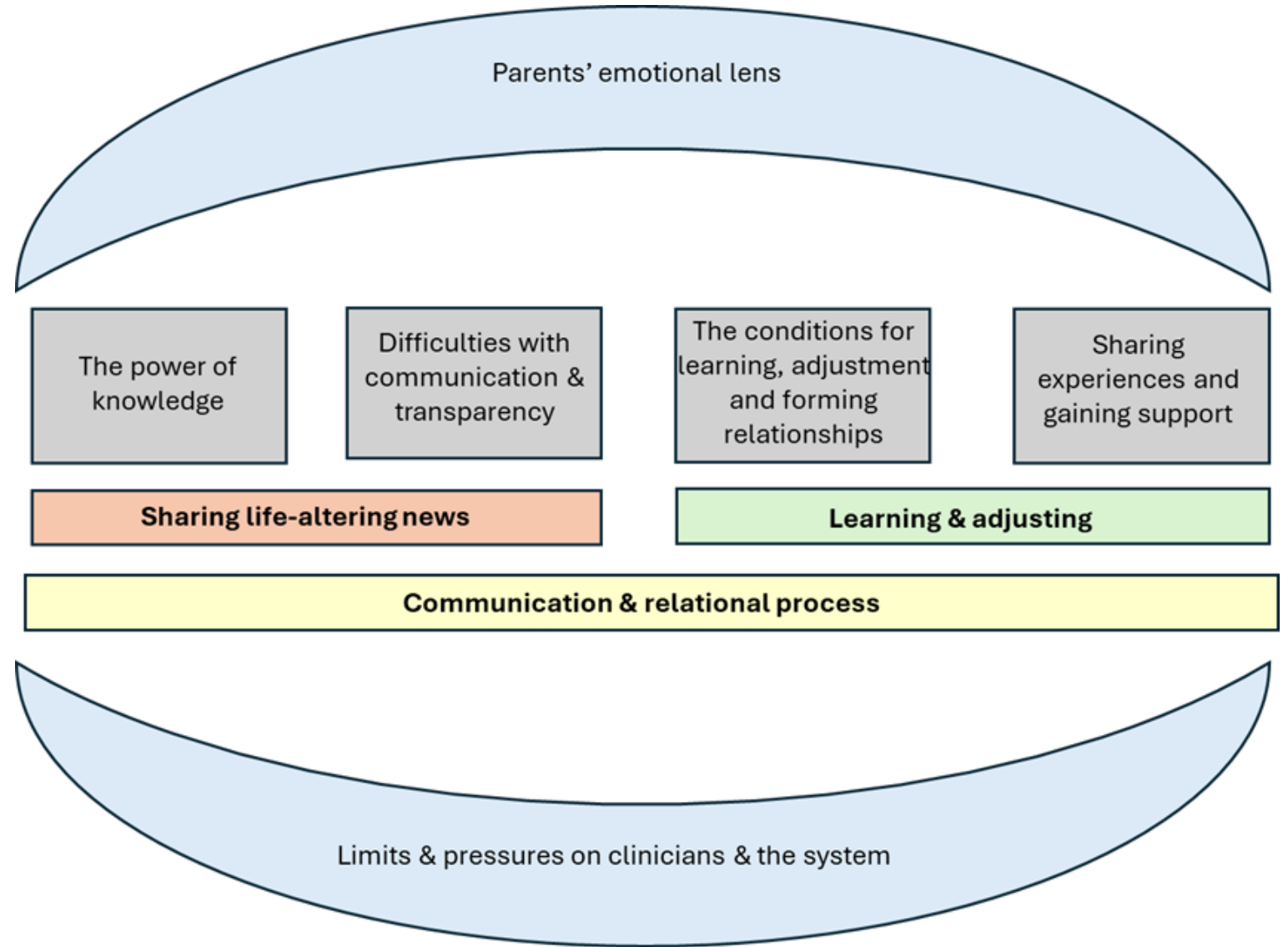
Sharing experiences and gaining support

Both parents and clinicians spoke about needing more space to share with others who had shared experiences as way of gaining support. Parents expressed barriers to accessing support for themselves and clinicians reflected on needing to remind themselves of their role in facilitating this support.

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)

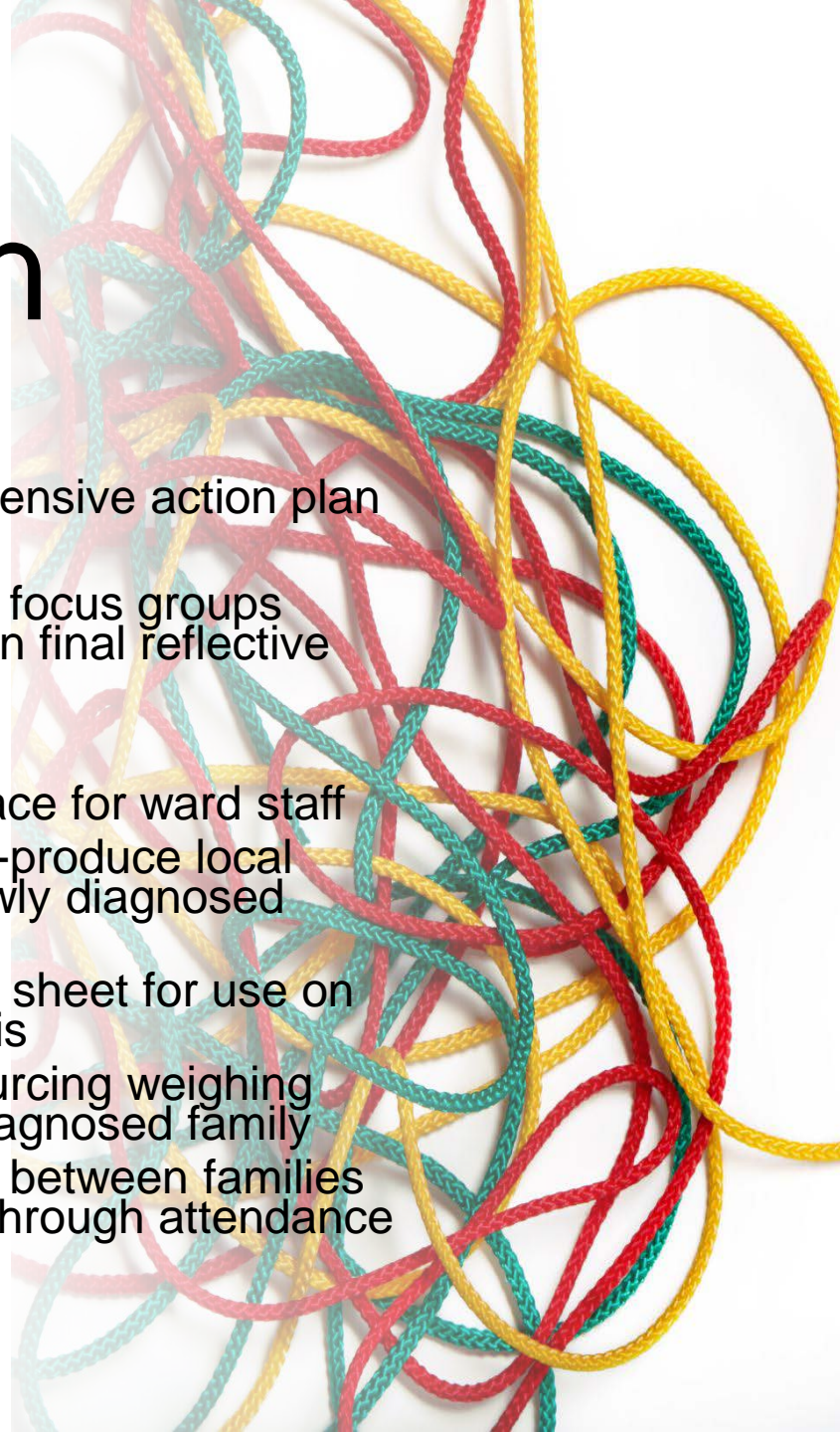
That we never get an opportunity to sit around and talk about things like this and hear from our colleagues, other professionals. And wouldn't it be nice if sometimes our staff could sometimes fit in, and just have some directive topics and how do you feel about that? That would be really useful (Clinician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

Findings



Action plan

- Based on themes a comprehensive action plan was created
- Suggested actions from both focus groups formed basis of discussions in final reflective group
- Actions included:
 - Facilitating reflective space for ward staff
 - Exploring potential to co-produce local information video for newly diagnosed families
 - Creating communication sheet for use on the ward during diagnosis
 - Exploring options for sourcing weighing scales for each newly diagnosed family
 - Continuing collaboration between families and diabetes team e.g. through attendance at team away days



Conclusions & reflections



Bringing two perspectives together highlighted the difficulties in the complex task of both sharing life-altering news ***and*** the learning task in T1D diagnosis



There was a strong connection between systemic difficulties and parental distress → focusing on improving the systems and processes at diagnosis could have a positive impact on initial parental experiences and early adjustment



Clinicians need more space to connect and reflect on practice to support them and support good practice



Both clinicians and parents appreciated the space to connect with each other and there was a continued desire to work together

Limits & future directions

Considering other perspectives in the system / interaction: *Who's story has not been told?*

Thinking about service development: *Are there other areas this process could be applied to?*

Facilitating collaboration: *Do we need to adapt methods further to facilitate 'community' engagement and attrition?*

The impact of power: *How do we break down the barriers between health care and the communities we serve?*

Feedback and questions

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