

MINIMEDs: Parent Advisory Group – June 2024 Meeting - Report

Background

The MINIMEDs project is exploring how to improve the support given to parents and carers so that they can give medicines safely to their children. The project is now 6 months underway. The literature review is ongoing and qualitative work is progressing through planning and approval stages.

The MINIMEDs doctoral fellowship public/patient involvement and engagement plan includes a regular meeting (6 monthly) of a public/parent advisory group (PAG). The role of this group is to provide advice, support and guidance for the PhD student and project.

Methods

The PAG met on the 29th June 2024. The same setup was used from the meeting in January 2024 which received positive feedback from attendees. A small function room in Leeds City Museum was booked. The room included a small craft table and soft floor play mats for young people. A play worker also attended to provide activities for any children. The PAG members were consulted to choose a date/time using the MINIMEDs PAG WhatsApp group.

Advice from PAG members was sought and used to help plan the event which included activities. Feedback from the previous meeting was also reviewed. In particular, the planned agenda included space to encourage group discussion and feedback of discussions, which was felt to be lacking at the first event.

The agenda for the meeting can be found in Appendix 1. A risk assessment was completed as per University of Leeds guidance for external events and the university safeguarding guidance was also followed.

Results

In total, 5 families attended the event. They comprised of 1 father/mother dyad, 5 mothers and 5 children (totaling 11 participants in total). To help run the event a play worker organised activities for the children



Photo of event

Discussion of resilience theory

The first half of the meeting was a guided discussion using the following prompts:

- What does the term resilience mean to me?
- How have I experienced resilience?

Participants were asked to write down their interpretation of resilience on a post-it note, and then discuss in pairs their experiences of resilience. Each pair was then asked to feedback their discussion to the group. A brief discussion was then had between the whole group.

The researcher took some notes about this, but no specific details and summarised this in bullet points. The group was in agreement the resilience was a good concept to 'standardise' experience and found it useful to relate to each other's experiences.

What does resilience mean to me?

Being able to cope and adapt to a situation with minimal impact on one's self. To not let the situation overwhelm you. Mental and physical resilience. Mentally strong, can draw the physical. Impacts both emotion and physical state.

Withstand / overcome challenges or difficulties.

Strong - Versatile to change relevant

To keep going - looking how to change / improve things.

Being able to cope even when things aren't as we had planned.

how you can cope/fight against change.

Phoebe (8) said "being tough"

• versatile to change.

• ongoing 'over the journey'.

• preparing for challenges

• strength.

• being resilient to negatives "blue badge situation"

• coping strategies

• developing 'parent radar'

• by necessity

What have been my experiences of being 'resilient'?
Discussions

• going back to work.

• trusting your gut

• having to adapt

• having the confidence to stand up for yourself

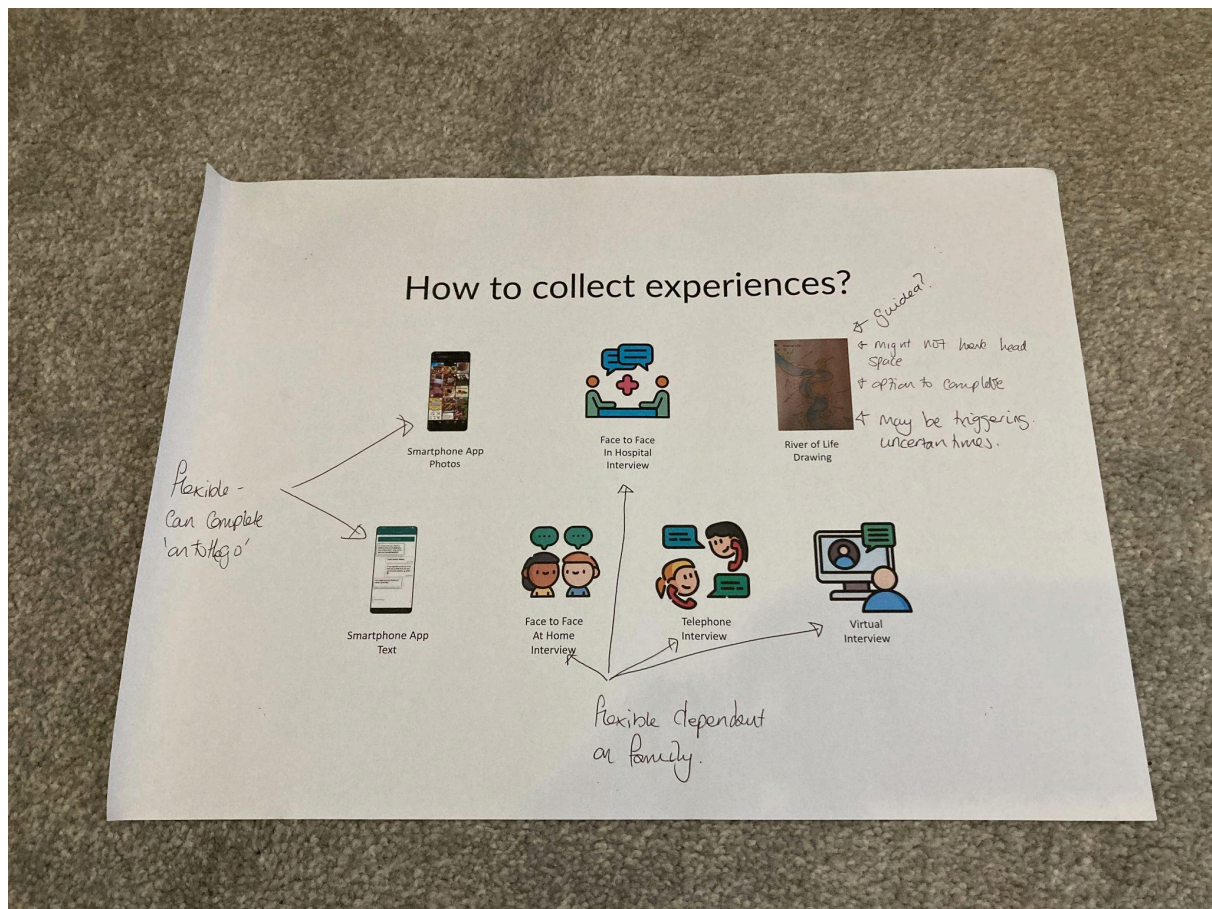
• being adaptive with minimal impact to your child.

For the second half of the meeting, participants reviewed the longitudinal qualitative study design. They were given A3 print outs of the proposal and asked to write comments on them.

Data Collection

Participants were very supportive of using a smartphone app and felt this would be acceptable to families. The possibility of voice notes was also suggested. They thought a paper diary would not be used. The participants also were supportive of using a variety of methods for interviewing depending on the needs of families (e.g. telephone calls can be made around nap times, virtual calls might not be helpful if participants are concerned about appearances).

Discussions in the meeting (and with advisors not present) have uncovered that a 'river of life' exercise is not feasible for this study. Some of the issues raised include: lack of time, lack of understanding of how to complete task, and importantly potential negative emotional impact of completing the task.



How to collect experiences?



Smartphone App
Photos

Visual powerful
+ easy for parents to
do. Low touch, low
cost, portable



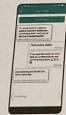
Face to Face
In Hospital
Interview

Tie in with appointments



River of Life
Drawing

This might feel over-
whelming. May need to
be near end of study,
for headspace + reflection



Smartphone App
Text

Easy to do when
Suits parents, collect
data + process at time
of convenience



Face to Face
At Home
Interview

Maybe go for
a walk with child
pushchair



Telephone
Interview

Time is to suit
parents, nap times,
lunch times



Virtual
Interview

When you feel
rubbish, last thing
you want is to
look at yourself on
a screen...

How to collect experiences?



Smartphone App
Photos

Great option as I always have
my phone on me and a picture
tells a better story in my
Opinion. In the same
way I think taking
or voice notes
would work well.
Its quick and
easy and accessible



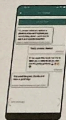
Face to Face
In Hospital
Interview

This would need to ideally be
around lunchtime when most
parents are hopefully getting a
break.



River of Life
Drawing

I like the idea and it's
creative but as discussed I
couldn't forecast our future
and probably couldn't now.



Smartphone App
Text



Face to Face
At Home
Interview

I'm an over sharer and
a talker so this would be
my preference. Would work better at home as the hospital could be stressful



Telephone
Interview

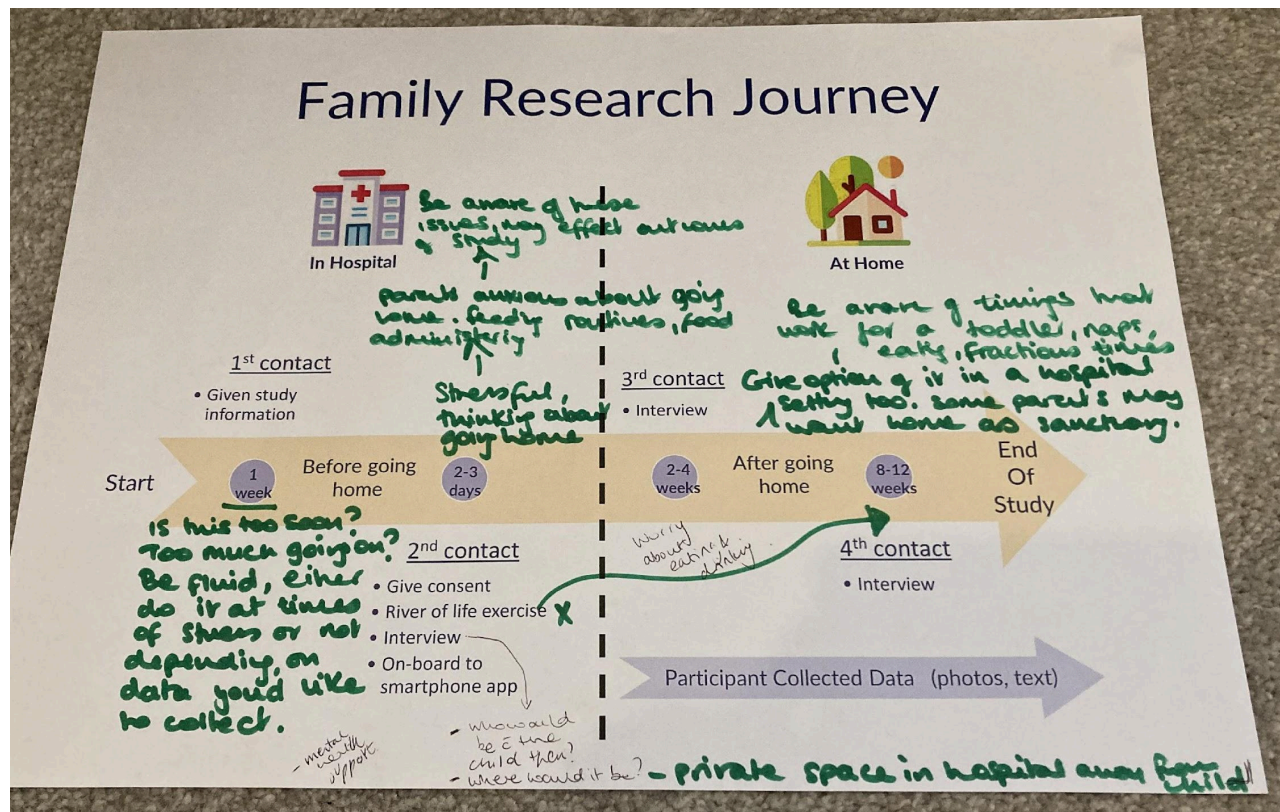


Virtual
Interview

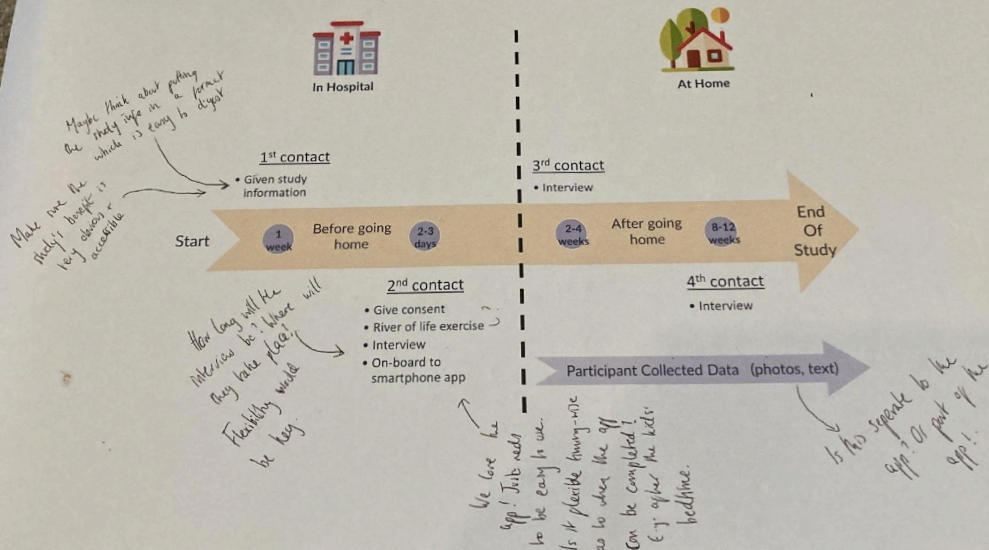
Research Design

The participants gave positive feedback about the design. They did not think it was too burdensome, if flexibility was built into the design. Three interviews that are 30 minutes of length was felt to be acceptable.

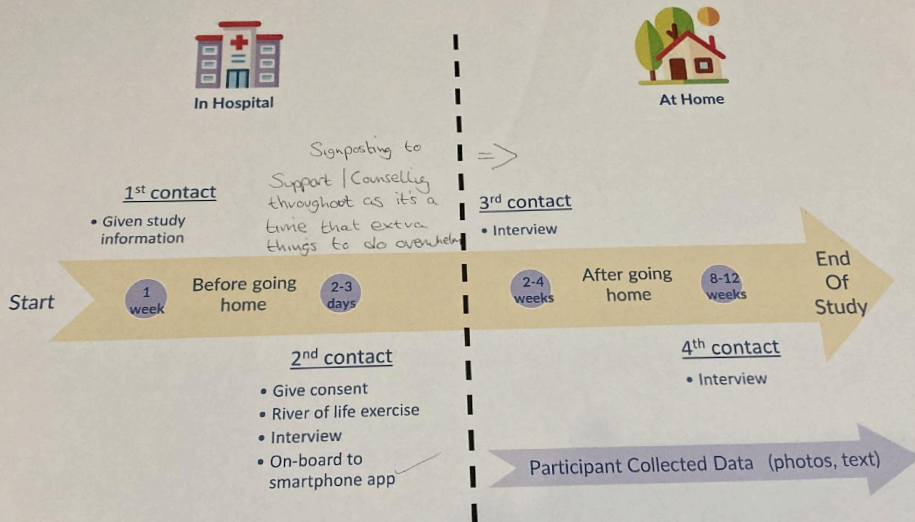
Participants highlighted that before hospital discharge is a stressful and emotional time. Participants recommend that careful consideration is given to how to support families with this to help them participate in the research.



Family Research Journey



Family Research Journey



Feedback

Feedback forms were completed. A summary of these can be found in Appendix 2.

Conclusion

The meeting achieved the objectives set out. Using the concept of resilience was acknowledged by participants as acceptable and they were able to relate it to their lived experiences.

Feedback was also collected in the longitudinal research design and amendments to the design will be made as advised by the participants.

Finally, the feedback was positive and had addressed the feedback from the first meeting (e.g. a lack of opportunities to discuss experiences).

Action points

- Remove river of life from data collection methods.
- Investigate cost of adding 'voice notes' feature to smartphone app.
- Provide clear guidance about psychological/emotional support that participants may need to access.
- Review study protocol in light of all comments received

Appendix 1. Agenda

Objectives

- o Update group on project progress
- o Explore the groups understanding of resilience
- o Explore feasibility and acceptability of study design/data collection methods

Plan

Welcome

Progress Update

- o Salm case report
- o Systematic review
- o Research protocol

Recap of public involvement

- o Video (first 2 minutes only) <https://www.youtube.com/watch?v=L6tYCVefnt0>

Activity 1 - What does resilience mean to you?

- o To make sure we understand each other we need to use the same terms/language
- o Group discussion
- o Summary

Prompts...

- *Write down what you think the word means?*
- *Think of a time you have been resilient, or had to adapt to something unexpected, an example with a medicine would be good, but it could be anything. E.g.*

Activity 2 – Review research data collection methods

- o Stephen to present research design
- o Group discussion
- o Summary

Prompts...

- *What is good with this design?*
- *What could be improved or removed?*

- Use green/red post it notes to annotate diagram

Appendix 2. Summary of feedback forms

MINIMEDS: Parent/Public Advisory Group

Feedback Form – June 2024 Meeting

Thank you for your coming along to this meeting. Your feedback is really important as we try and learn how best to engage with patients, parents and the public.

Please take a few moments to share your thoughts on the meeting.

Thank you, Stephen

Tick the statements you agree with, or write in any other comments below

1. Meeting Relevance:

[6 (100%)] The agenda was clear and relevant to the purpose of the meeting.

[5 (83%)] The meeting addressed the issues I anticipated.

[] Other (please write below): _____

- o *Useful to understand the project and feed into family experiences and how to engage families in the project.*

2. Engagement:

[6 (100%)] I was provided with enough opportunities to express my views and opinions.

[4 67%] My contributions were acknowledged and considered.

[] Other (please write below): _____

- o *Stephen gave everyone opportunities to speak and acknowledged everyone's contribution*

- o I really enjoyed the group activities and discussions – they were really interesting*

3. Communication:

[6 (100%)] The materials and presentations were clear and easy to understand.

[5 (83%)] The communication during the meeting was effective.

[] Other (please write below): _____

4. Facilitation:

[6 (100%)] The facilitator effectively guided the meeting and managed discussions.

[5 (83%)] The key points and outcomes were well summarised.

[] Other (please write below): _____

5. Overall Experience:

On a scale of 1 to 5 (1 being the worst and 5 being the best), how would you rate your overall experience at the meeting?

_____5_____

- o Always feel like a welcoming environment, a safe space to share experiences*
- o Always thought there was a gap in support for parents and this is really positive for feeling heard*

6. Suggestions for Improvement:

Please give us any suggestions for improving future meetings.

Please write below: _____

- o The facilities for kids were brilliant, thank you!*
- o Really appreciate the children's playworker. It really helped me to concentrate knowing she's enjoying herself*
- o Perhaps a little more information on the study's design next time (if applicable)*

7. Additional Comments:

Please write below: _____

- Fab having the play worker for the kids
- It was a brilliant session – I really enjoyed it and it was great to chat to the other parents more :)

Thank you for your time and support with our research and engagement work.