

# MINIMEDs: Parent Advisory Group – January 2024 Meeting - Report

## Background

The MINIMEDs project is investigating how we can reduce the harm experienced by families from the use of prescribed medicines at home. The project has a significant engagement and involvement element which is fully funded through the NIHR doctoral fellowship grant.

The MINIMEDs doctoral fellowship public/patient involvement and engagement plan includes the formation and 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

A face-to-face meeting was organised on the 27<sup>th</sup> January 2024. Leeds City Museum was used who were able to provide a function room of suitable size which was also family/child friendly. PAG members were consulted about the venue and date/time which they deemed to be suitable. Families were recruited through existing contacts, inperson events (e.g. world prematurity day at St James' Hospital) and online forums (neonatal facebook groups, twitter).

Advice from play workers was sought and used to help plan the event including activities for children and the consideration for the venue environment (e.g. use of soft play mats). 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 3 father/mother dyads, 2 mothers and 5 children (totaling 13 participants in total). To help run the event 1 nurse attended to help with facilitation, and 2 play workers attended to run activities for the children.



Photo of event

The first half of the meeting was a presentation by Stephen about what the MINIMEDs project was hoping to achieve, what patient/public engagement activity was, and what opportunities would be provided during the MINIMEDs project.

The second half of the meeting was an engagement activity designed to collect the views and opinions of the advisory group on several topics. These included:

- What the MINIMEDs project should do
- Why families wanted to be involved in the project
- Various practicalities of the group (e.g. communication methods, payment methods)

The written feedback from the members can be found in Appendix 2, and photographs of the engagement exercise can be found in Appendix 3.

## Conclusion

The event met its primary objective which was to test whether running a face-to-face group for families would be feasible. The attendance of families along with the feedback forms supports this view.

As a result of the engagement activity, the following action points have been identified:

- Setup a WhatsApp group for announcement and organising activities for the PAG
- Continue to use Amazon vouchers as payment for PAG meetings
- Try to allocate PAG members to the tasks they have expressed an interest in
- Undertake facilitator training to improve the group discussions at the PAG meetings
- Provide 'quiet time' during the meeting to facilitate reflection and thinking
- Provide food/refreshments for individuals with allergies
- To set a date for June/July for next meeting guided by a poll using the Whatsapp group

## Appendix 1. Agenda

### Welcome

- Name badges, sign-in (consent to photograph etc.), health and safety, amenities

### **Introduction for me and to the project, ground rules for inclusivity/respect/safe space/etc. (5-10 minutes)**

1. Thank you (1<sup>st</sup> and most important objective was to run the meeting!)
2. Ground rules, confidentiality, honesty, openness
3. About me (pharmacist, 11 years in childrens services, got this funding)
4. The project/'administration errors'(to me signals a disconnect between what professionals think happens, and what actually happens) / work as done&resilience

### **A chance for everyone to introduce themselves (will depend on group size, 15 mins)**

1. Who you are, what is important to you, why you want to be involved, why did you attend, anything you want to learn or perhaps just hear to listen?

### **Overview of opportunities for involvement and engagement (5-10 minutes)**

The idea is to get as many people as we can from today to stay engaged throughout the project

1. General things: Images for project (website etc.) Communication Website / social media
2. Literature review: for next meeting will bring 'findings' from the review and get the group to check my findings
3. Interview study: ethics application, design,
4. Training: foundation in patient experience

### **A brief 'consultation exercise'/'stakeholder engagement' about how the group should work, communication methods, meeting dates/times, virtual/hybrid/f2f, how would people like to be paid (10 minutes)**

- Questions:
  - communication methods (email, WhatsApp, text messages)
  - How often should I contact you before stopping (1 / 2 / 3 / +3)
  - meeting dates/times (Saturdays at end of June/July)
  - Virtual/hybrid/f2f
  - how would people like to be paid (bank transfers / vouchers)
  - What parts of the project would you be willing to be involved in (
  - Would people be interested to have a 'piggy back' project‘

**Feedback forms and EDI forms (5 minutes)**

**End of event, socialising, tidy up**

## Appendix 2. Summary of feedback forms

### **MINIMEDS: Parent/Public Advisory Group**

### **Feedback Form – January 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**

10 feedback forms received.

#### **1. Meeting Relevance:**

[ 9 / 90% ] The agenda was clear and relevant to the purpose of the meeting.

[ 5 / 50% ] The meeting addressed the issues I anticipated.

[ 0 ] Other (please write below): \_\_\_\_\_

#### **2. Engagement:**

[ 10 / 100% ] I was provided with enough opportunities to express my views and opinions.

[ 8 / 80% ] My contributions were acknowledged and considered.

[ 1 ] Other (please write below): \_\_\_\_\_

- As an introductory meeting it could have done with more guided introductions between members – encouraging us to share our stories and experiences of medication.

### 3. Communication:

[ 10 / 100% ] The materials and presentations were clear and easy to understand.

[ 8 / 80% ] The communication during the meeting was effective.

[ 1 ] Other (please write below): \_\_\_\_\_

- It would have been better if we had discussed our answers given on the sheets round the walls after having written/responded.

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### 4. Facilitation:

[ 10 / 100% ] The facilitator effectively guided the meeting and managed discussions.

[ 7 / 70% ] The key points and outcomes were well summarised.

[ 2 ] Other (please write below): \_\_\_\_\_

- We didn't summarise our responses at the end.
- The childcare aspects is great and made the meeting feel more relaxed / like real life!

### 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?

Average 4.8 (n=10), range (4 to 5)

#### 6. Suggestions for Improvement:

Please give us any suggestions for improving future meetings.

Please write below: \_\_\_\_\_

- Can be quite overwhelming with children running around, suggest maybe some sort of screen/video game. Find it hard to concentrate if needs more focussed work/agendas.
- Ask families to say why they want to help – opportunity to share current experiences with medicines
- It's tricky because it has been a great introductory meeting, but perhaps just not having good with my daughter's allergies if possible (nuts on the pastries)

#### 7. Additional Comments:

Please write below: \_\_\_\_\_

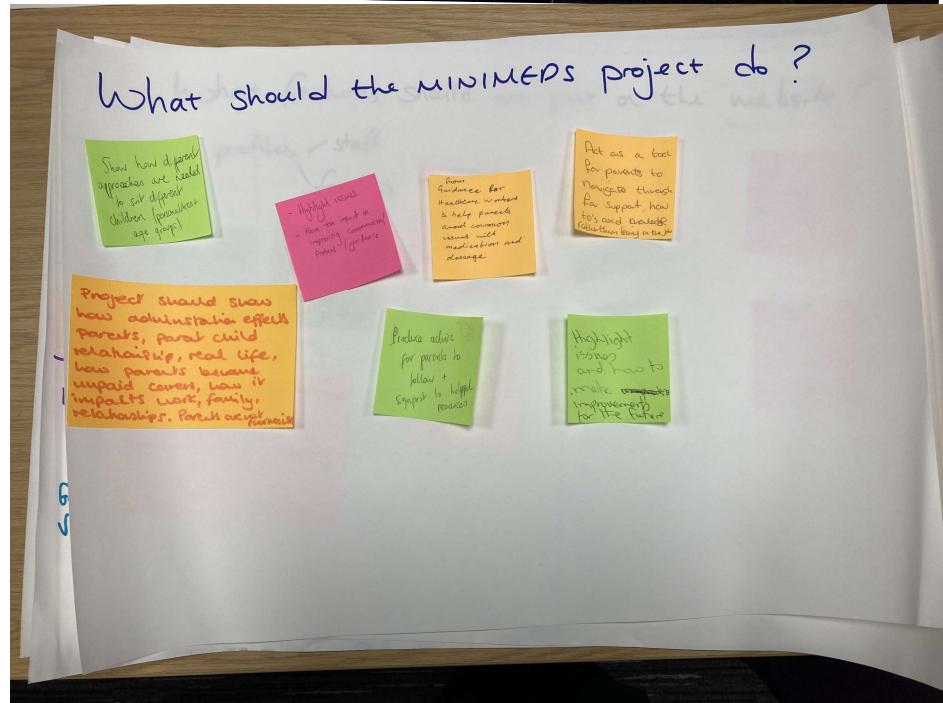
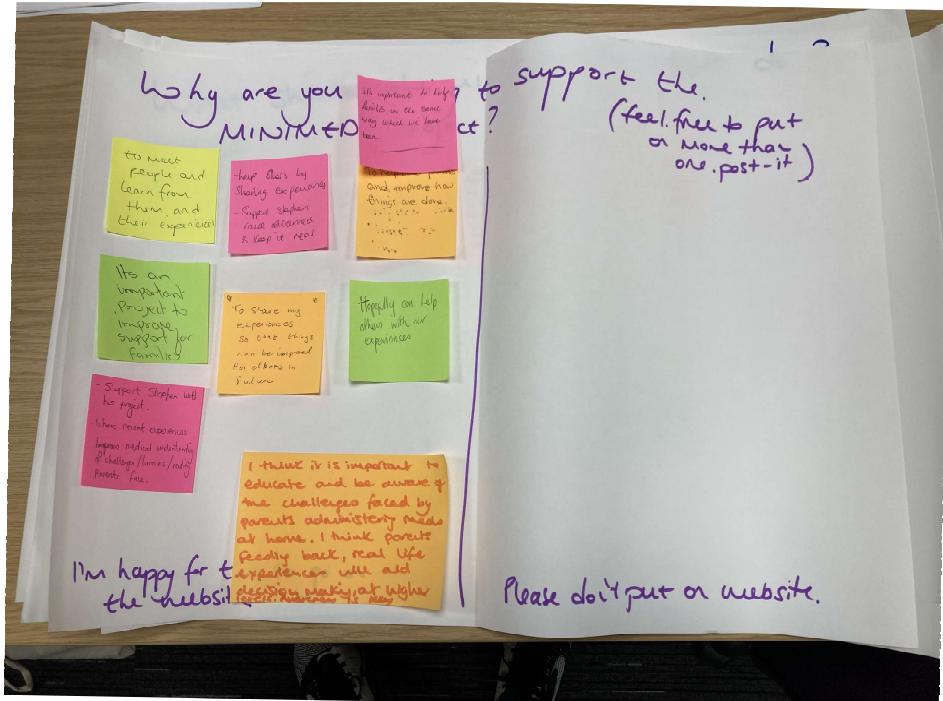
- Looking forward to being involved in the project.
- The session set the scene well. Next time would be good to include some more discussion.
- Very well organised
- It was nice and informal and nice to meet other families. Look forward to see how it progresses.
- It was a great collaborative session.

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



### Appendix 3. Summary of engagement activities



What features should we put on the website?

e.g. profiles ✓ staff  
✓ families

friendly stories  
good  
bad

Examples from  
different  
families  
Globally  
children

Links to  
support agencies  
and relevant  
resources within  
easy, help  
families

Tips on how  
to help parents

Mario is real  
with stories/  
experiences

Profiles - staff - who we  
parent accounts  
Information on the  
project - why it's happening

Relevant useful  
links to support  
agencies

Key research/  
update - bit  
written in  
non-medical language

Stories + experiences  
- How to guides  
- Contribution/exploration  
from healthcare professionals

I would like to help with... *updated outline* *else*  
*...bake cakes*

Coming  
to  
meetings  
Gov.  
Vicki/Andy  
Sarah  
Helen

Ethics  
review.  
Gov.  
Vicki/Andy  
Sarah  
Helen  
Jenny

(or sharing)  
Making/curating  
and social  
Media, content

Gov.  
Vicki

Practice  
Interviews  
Gov. Jenny  
Vicki Maria

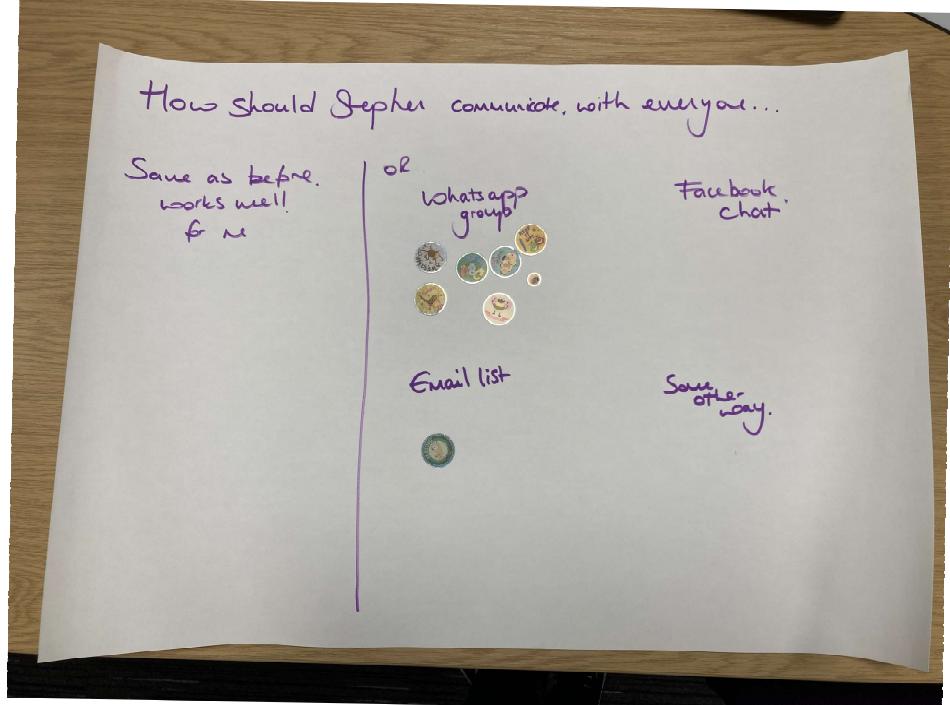
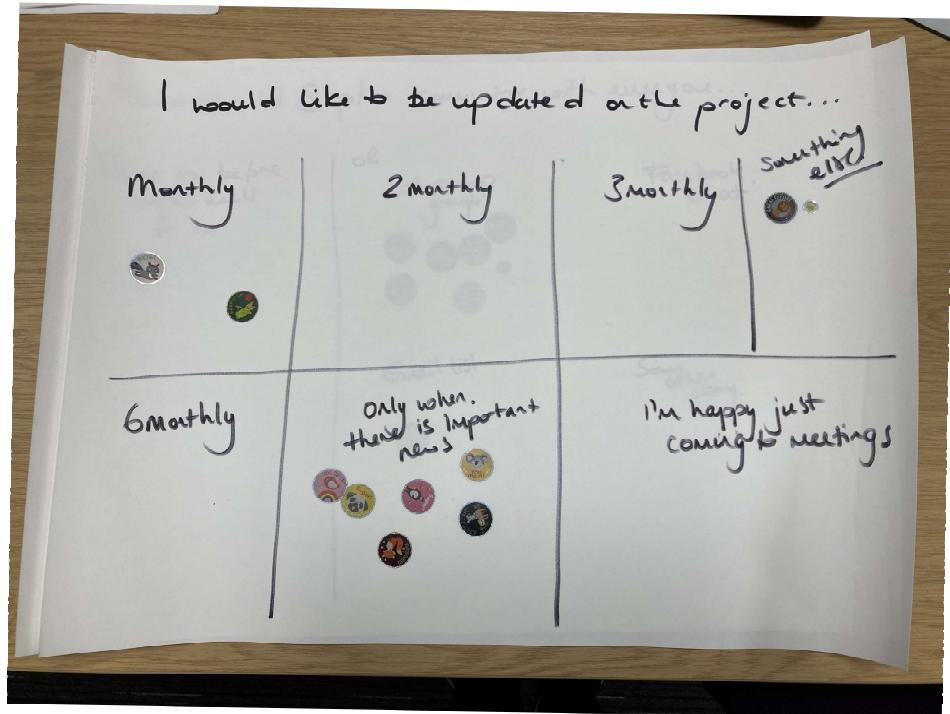
Analysing  
data.  
Gov.  
Vicki  
Jenny

Reviewing  
Steph's  
work  
Gov.  
Vicki/Andy  
Helen  
Maria  
Jenny

Talking or  
events  
Gov.  
Vicki  
Sarah  
Helen  
Jenny

Something  
else.  
...bake cakes

Not sure.



What payment method  
would work best for you?

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Amazon Voucher  
(Max. £30 per event)



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Bank Transfer.  
(£25/hour)

I would be interested in  
Sharing my experiences  
to be published in some form

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Yes.



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No.

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Not Sure.

Have you been to  
a research event  
like this before. ?

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Yes



No



Not Sure .



I would like to come to  
the next meeting.  
I could do these dates

June		
Early	Middle	Late
  		  

July		
Early	Middle	Late
 	  	 

Would you like to help  
other researchers who could  
visit after this meeting?  

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(we have the room  
until 12:30)

Yes.



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No

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Not Sure.

