Improving the quality of life for families with young children who are prescribed a regular medicine

Contents

1. Introduction

Medicines are the most common treatment used by the NHS. Using a medicine has a significant impact on a patient and their family. Using a medicine means that you need to take the right medicine, at the right time, at the right dose, and follow any other instructions. It is also possible that despite using a medicine correctly, that it may still cause harm in the form of a side effect. Studies show that having a negative experience when using a medicine leads to poor adherence and worse outcomes.

Using medicines in younger children is even more of a challenge for families. There are many reasons for this. For instance, doses need to be accurately measured, calculations are needed to check the dose, GPs may be unwilling to issue prescriptions started by specialists, and liquid medicines usually have poor taste. Up to a third of children will refuse to take medicines. Therefore, parents often have to hide medicines in food, use bribes or even use physical force to get their children to take them. There are also some parents that despite their best intentions, will not follow the directions correctly, potentially harming their child. Recent studies suggest about 1 in 10 children are not given a medicine correctly at home.

The funds applied for will be used to conduct PPI that is needed to develop a NIHR ICA CDRF application for the lead applicant. PPI will be used in two stages; the first to develop the research question and the second to review the draft research proposal. The former will take the form of a focus group, and the second will be another focus group, or a panel, depending on whether we are able to retain participants from the first group.

As an aside to this PPI activity for this CDRF application, we will also use this experience to try and set up a regular PPI group for parents as part of a wider Children’s Hospital forum. Parents of young children, particularly those born prematurely, have difficulty contributing to patient and public involvement activity. We are setting up a neonatal research team, called Leeds NERDs (NEonatal Research Dream team). The group is multidisciplinary with representation from medical, nursing, pharmacy and clinical trials. Our goal is to promote research activity and promote parental involvement in research on our neonatal unit.

2. Aim

The aim of our PPI work will be to facilitate the development of an NIHR ICA CDRF application for submission in Spring 2020.

The first session will aim to discover and explore the impact that medicines have on families at home. Research has shown that parents are rarely involved with research development. However we believe they will be the most suitable group to give advice on this research proposal. The session will be facilitated by the neonatal research team and the patient experience officer here in Leeds Children’s Hospital. During and after the first focus group we will summarise the discussion and evaluate whether the research question is appropriate or whether it needs to be revised.

The second session will also be in the form of a focus group. Participants from the first group will be invited back. A summary will be provided from the first session before the second group for participants to review. The aim of the second group will be to evaluate the findings of the first session and then review the draft research proposal. The draft research proposal will be developed after the first session and circulated before the second session.

3. Method

3.1 Recruitment

We aimed to recruit 6 to 8 participants for our focus group. This would be enough to stimulate discussion, but we also anticipate that this is an emotive topic and participants are likely to have many views to express.

As there are currently no parent PPI groups within Leeds Children's Hospital, we advertised in multiple places to ensure we recruit enough participants. An A5 flyer was written (see Appendix 7: Advert used for recruit) to summarise the key information for the groups. This included; an introduction to the facilitator, background as to why we are researching this topic, aims of the session and session details (dates, time, location). Participants will be recruited from a number of sources:

- Social media (Leeds Children's Hospital twitter, Leeds Neonatal Unit Facebook parent groups and Leeds Children's Hospital Facebook group)
- Neonatal unit annual celebration event at Leeds City Museum
- Advertise in through outpatient clinics
- Veteran parents will be asked to circulate information through their networks
- Specialist Nurses (e.g. neonatal surgery) were asked to forward advert to parents they felt might be interested

We were able to recruit 9 families over a 1 month period using this method.

3.2 Description of Activity

The focus groups ran at Leeds Children's Hospital on the 22nd of October 2019. Parents who were recruited were happy to attend the seminar room on the neonatal unit. Parents were asked beforehand if this was suitable. This was mainly because the parents were familiar with the venue and how to get there. The venue also had baby changing facilities, breastfeeding rooms and toys for children to play with. The group was facilitator by the lead applicant and Fiona Metcalfe (Lead Nurse for Neonatal Surgery).

The lead applicant produced a slideshow to ensure the group stayed on topic and kept to time (see Appendix 2: Slides use during session). The group started with a brief talk about the reason we are running the group and how it should work. The group were asked to answer the following questions in 3 sections.

1. Talk about your experience of having to give medicines at home. What problems did you have? Was everything fine? What went well? How did you feel about taking responsibility for giving medicines?

2. Talk about the effect of any problems (or things that went well)? How did it make you feel? What was the effect on your child? What did you do to resolve the problem? Did you visit the GP, or hospital to sort it out? Did you search for information (e.g. internet, friend, social media)?

3. Talk about what could have helped? What would you do different a second time? What did you learn that was helpful? Who did you find that was helpful?

We used post-IT® notes to write thoughts on first. Then each parent was asked in turn to go discuss them one of them. We repeated this until either there were no more comments or we had ran out of time. This made it so everyone had a chance to speak. The final section was a summary of what we are planning to do next. We asked if parents wished to remain involved in the project going.

Finally, feedback was collected before the session was ended. The forms can be found in Appendix 5: Feedback for facilitator and Appendix 6: Feedback for NIHR.

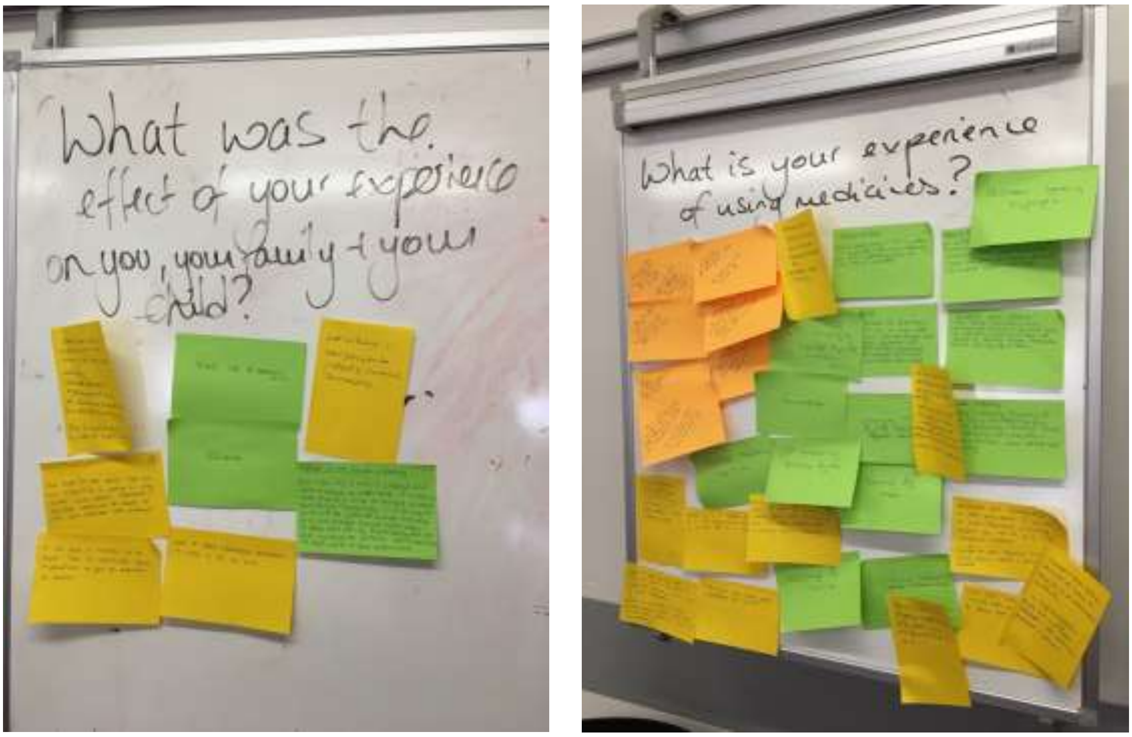
Photo of focus group

Photo of focus group

3.3 Contribution made by the PPI group

The output from the session can be found in Appendix 3: Summary of comments made by participants. The parents felt that it was a very important topic to research. They highlighted that there wasn't much help at the moment and there was a lot of negative outcomes from their experiences. They also highlighted safety issues that the applicant had not considered. For example, that a parent might be allergic to one of their child's medicines.

The main outcomes has been that the feedback has focussed the project on medication safety. This has helped to narrow the research question and ensure it is relevant to current priorities for families, and the wider NHS. Many of the problems and issues described by parents were to do with not using medicines correctly. A lot of these were as a result of systems and processes in healthcare, rather than individual capabilities. There were a lot of common themes, which add strength to the application that this is causing problems for a wide variety of parents caring for sick newborns at home.



Post IT® notes used by parents to answer the questions

The information shared by the families was used to help write the plain English summary for the NIHR ICA CDRF application. A copy of this can be found in Appendix 11: Plain English Summary on NIHR ICA CDRF application for lead applicant.

3.4 Follow-up PPI activity

It was the aim of this PPI activity to conduct a second focus group to review the NIHR ICA CDRF application for the lead applicant. This was schedule to be conducted on the

4. Feedback

Feedback was collected from multiple sources, and evaluated after the session.

4.1 Participants on the PPI activity

Written feedback was collected from the participants at the end of the session. This was to evaluated the activities conducted in the session. The form supplied by the NIHR Y&H Research Design service was used, see Appendix 6: Feedback for NIHR. A summary of the responses has been included in the appendix.

4.2 Evaluation of the lead applicant as a facilitator

The lead applicant's abilities to facilitate the PPI activity was evaluated. A written feedback form was used which can be found in Appendix 5: Feedback for facilitator.

The lead applicant had a follow up "de-brief" with the Lead Nurse for Neonatal Surgery, who helped facilitate the group. The following points summarised the discussion:

- Group were very engaged, shared experience with each other
- Stuck to time well
- Got information which was relevant
- Good recruitment, a mix of experience and time since discharge
- Outcomes should be presented at directorate meeting

There were some points to consider for future groups:

- Use of icebreaker/familiarisation period before group starts
- Different venue
- Longer session
- Extra categories of comments:- changes to medication
- Investigate charities who have access to different venue in Leeds City Centre or rooms within LTHT

4.3 Difficulties encountered

A few problems were encountered which were highlighted in the feedback.

Session too short - a difficult balance, as we had some working parents who were only allowed to be at the session for 1 hour. We overran slightly for those parents who could stay, but it was also important for those parents to contribute to all aspects of the PPI activity. In future, we are planning to run 2x 1 hour activities back to back, with a short break in between. This will allow parents to either come to both or just one activity as time allows.

Room was noisy - the location was good, but not appropriate to use again. A door outside kept banging as it was the main entrance into the unit. We are exploring using alternative venues either in the Children's Hospital or Leeds City Centre. The availability of facilities such as toilets and changing facilities was appreciated by parents.

Families who couldn't attend - we had three parents who could not attend as their children were poorly. We did recruit 8 parents in total, we were conscious not to oversubscribe. We collected comments via facebook for those that couldn't attend. We will recruit up to 12 next time, with plans to split the group into 2 groups of 6 if all attend.

Lack of representation of fathers - we have involvement from one Dad so far on the project. Due to working patterns, this is a difficult group to access. We can try to recruit more through the Children's Hospital events, such as the Graduation Party, which run on weekends. As mums are usually the main carer for a child, we are still getting good feedback with regards to our planned research activity.

4.4 Summary of feedback

The feedback we received was very positive. We were pleased that we were able to set up, recruit and run a focus group from scratch. The group was also a difficult to reach group (families with young children who have health needs), which are usually underrepresented in PPI groups.

We had positive feedback that we weren't expecting, such as families saying the appreciated having a forum to discuss issues and problems with families who and experience the same things. This is helpful to demonstrate the importance of the group and how participants can benefit from PPI activity too. This will help us to plan and fund the group in the future.

5. Impact and dissemination of findings

The PPI activity has already been used in a variety of ways.

5.1 NIHR Academy Conference - November 2019

A plain English summary of the planned research proposal was submitted and accepted to the NIHR Academy Conference in Leeds on the 19th and 20th of November. A copy can be found in Appendix 9: Poster for NIHR Conference using feedback from group. The poster was well received and won a poster prize.

5.2 Specialist Pharmacy Service Webinar _ December 2019

The applicant delivered a 1 hour webinar on the topic of "medication safety at home" on the 12th of December 2019. The Specialist Pharmacist Service (SPS) is a group of predominantly pharmacists who act as medication safety officers across organisations in the NHS. These included primary care, CCGs and secondary care.

A description of the session is here:
https://www.sps.nhs.uk/meetings/musn-monthly-webinar-medication-safety-at-home-key-findings-from-a-parent-focus-group/

A copy of the slides can be found here:
https://www.sps.nhs.uk/wp-content/uploads/2019/11/SPS-Webinar-DECEMBER-2019-Stephen-Morris-HANDOUTs.pdf

5.3 Twitter - October 2019

The group was advertised using twitter and was a popular post.

Stephen Morris

A massive thank you 👏 to our 5 parents, 3 children and 1 grandparent who participated in the 1st @LeedsNERDs focus group today. Very interesting to listen to their stories and journeys. Their voice will be at the centre of my academic journey. (Parents ok for photos 2bshared)

10:35 AM - 22 Oct 2019

Stephen Morris
A massive thank you 👏 to our 5 parents, 3 children and 1 grandparent who participated in the 1st @LeedsNERDs focus group today. Very interesting to listen to their stories and journeys. Their voice will be at the centre of my academic journey. (Parents ok for photos 2bshared)
pic.twitter.com/a1iAHcXw9e

Impressions	4,083
Total engagements	337
Media engagements	222
Profile clicks	47
Likes	26
Detail expands	21
Retweets	9
Link clicks	9
Replies	3

5.3 E-mail newsletter for parents - January 2020

I sent a newsletter out via email in January 2020. A copy can be found in Appendix 10: Follow up e-mail newsletter to parents. This was to keep the parents and families updated of the progress of the project, and also to show how they had impacted and changed my research project.

6. Plan for future PPI work

The lead applicant will ask participants if they are willing to conduct further work with regards to developing his CDRF application and subsequent research projects within the CDRF. This would include further development of the research question, the selection of research methodologies, reviewing materials related to those projects (e.g. plain language summarise, consent forms) and assistance with gaining ethics approval. The CDRF application would specify the involvement of PPI during any projects conducted as part of the CDRF and be costed for appropriately.

The first work package of the CDRF is likely to involve a qualitative component. Therefore it will be vital to form a panel of patient and public participants to help advice on how these should be conducted. It would be helpful to include participants from this initial work who will have experience of the work undertaken as part of the application.

We will be mindful that if participants are parents then they may have competing demands on their time. We will aim to get all the information we need during these sessions, but if any parents volunteer for additional work then we will discuss with them what they feel capable of doing.

The lead applicant will disseminate a summary of the findings and outcomes of the focus groups to participants. In accordance with NHS ethics guidance, due to the nature of conducting work with carers of NHS patients, the events will be publicised but not their content, using different media outlets (e.g. twitter account, facebook parents groups, printed newsletter for outpatient clinics). The lead applicant will advertise his own twitter account for his research activities (@sjm_85) and also the neonatal PPI group (@LeedsNERDs) for updates regarding the CDRF application.

Parents will also be asked if they would be willing to form a virtual network for PPI activity in the future. This in particular will be helpful for ensuring maximum impact of the CDRF output by utilising PPI for dissemination of any findings.

Appendix 1: Detailed breakdown of how the funding was spent

Session 1: October 2019

Gift vouchers
5 parents were offered £10 gift voucher and accepted = £50

Travel Expenses

Travel was offered but not taken up.

1 parent travelled by free travel pass

2 worked in Leeds city centre and did not travel

2 refused to claim

Refreshments

Cakes - £4.50

Fruit, milk and bottled water - £5.35

Stationary

Post It Notes - 2 x Large note multipacks - 2x £7.99

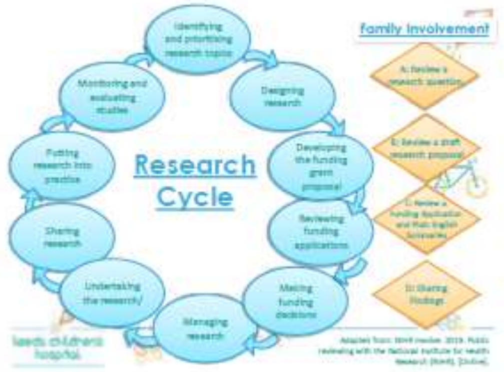
Total = £75.83

Appendix 2: Slides use during session

Neonatal
Research
Dream Team

Focus Group – 22nd October

Why are we here?



Research Cycle

- Identifying and prioritising research topics
- Designing research
- Developing the funding grant proposal
- Reviewing funding applications
- Making funding decisions
- Managing research
- Undertaking the research/
- Sharing research
- Putting research into practice
- Monitoring and evaluating studies

Family Involvement

- A: Review a research question
- B: Review a draft research proposal
- C: Review a funding application and Plain English Summaries
- D: Sharing findings

Adapted from: NIHR involve. 2019. Public reviewing with the National Institute for Health Research (NIHR). [Online].

Why are we here?

Photos from twitter: Sarah Knowles @sl_know Chris Bedford @chrisjbedford

- Please say if you do not wish to be photographed, or audio record (to help me write the report!)

Photos from pxhere: Under creative commons license

Discuss your experience of giving medicines at home?

- What did you experience?
- What was the effect of that experience?
- What could we do to improve that experience?

Is this a good topic to research?

Time	Activity	Duration
11:00	Introduction	10 minutes
11:10	What did you experience about medicines at home?	15 minutes
11:25	What was the effect of these experiences on you, your child and your family?	15 minutes
11:40	What would you do differently, or what could we do to improve your experience?	10 minutes
11:50	Feedback + Expenses	10 minutes

What was your experience of using medicines at home?

Measuring doses
Mistakes
Medicines from the pharmacy
Prescriptions from the GP
Keeping track of everything
Information
Support
My child won't take it!
Side effects
Wasted medicines

What was the effect on you, your child and your family?

Scared
Worried
Felt better
Felt worse
In control
Blood tests
Upset
Frustrated
GP Visits
Hospital Visits

What would you do differently?

More education
Better education
More counselling
Less medicines
More medicines
Medication review
More information
Support from hospital
Support from GP
Support from Pharmacy

What next?

- Write up focus group
  - I'll send to group
- Write up research proposal
  - Speak to university
- Bring proposal back to focus group
- Apply for PhD fellowship
- Form Steering Committee
  - More involvement, possible meet every quarter, or milestones in project

Feedback and Expenses

- Up to £15 on travel
  - Car: 40p per mile
  - Use googlemaps for mileage

Photos from pxhere: Under creative commons license

Appendix 3: Summary of comments made by participants

Colour Code

Blue - Written on post IT note

Green - Sent remotely via facebook (from parent who was unable to attend)

Orange - Spoken from audio recording

Question 1: What is your experience of using medicines at home?

Difficulty getting medicines, items needed to give medicines or prescriptions/appointments	“problem getting syringes” “GP reducing quantity of milk” “GP changing provider of milk” “running out, and GPs can’t get your prescription on time.” “sodium chloride difficult to get hold of initially until doctors at GP knew about it and got a regular supply” “ring hospital as gp wasn’t able to get prescription milk due to a manufacturers problem, so had to ask advise on what to do and what is the next step” “ordering prescriptions and also getting a doctors appointment” Reusing syringes, we didn’t know we had to reuse them and was throwing them away, assuming more would be given to us. Prescriptions from pharmacy are difficult to get at home ie joules phosphate Eurithomising (I know that’s spelt wrong) has 7 days, prescriptions need to be for a few in powder form so we can make it up. People don’t want to be picking up prescriptions week by week. Milk...prescribed tiny amounts. Once was prescribed 200ml formula. Olivia was on 130ml per feed. It’s just so I inconvenient when you are learning so much with a

	new baby I was standing in the pharmacy, and they said "we can't get hold of this sodium chloride liquid". I was exhausted, I said, "it's just salt isn't it? Just tell me how much to put in some water and I'll make it myself".
Difficulty getting child to take medicines	"wouldn't take sodium chloride at home so had to find alternative methods" "in hospital there are NG/NJ tubes available, so you know how much is given" "tried own methods of administering (mixing with breast milk in a teat) as reflux was a problem at first" "mixing medication into fluid/food so that daughter does not know." "When he was first discharged, he was on quite a lot of different medications all at the same time. And, again, to try and promote this growth, he was on a large volume of milk, which his little tummy just didn't like taking." "The amount of times he would have a big lot in one go, then he'd bring it all back up again, which was just too much for him to take. That was an interesting learning curve for once we came out of hospital." "but when you're at home, there's no NG tube, there's no NJ tube, so you're like, right, got this syringe of salt, how am I going to get it in?"
Clinicians unsure of how to manage difficult or specialist patients	"nervousness from non-neonatal staff to offer any advice or guidance as most medicines (including calpol) say not to give to premature babies" "mixed advice from health visitors and consultants regarding vitamins" "recording of why certain medicines given at home e.g. a pharmacist called asking about an antibiotics but this had actually been a previous reflux medication" "seemed to be an element of we'd be ok with medications and decisions as we had been in a while" "felt more like I was in charge and told to adjust to

	child's needs. If something works stick to it, if not its changed at next appointment. The direction I would like to go to is to be given an answer and stick to it, not change around meds every so often as it can be frustrating for me and my daughter. Relatives not supportive as don't want to feel responsible." "We've found with a few medicines that we've been asked by the health visitor or doctor about what we should or shouldn't be doing" "she struggles to take her medication, and they so, oh just change doses, or change doing this, it's not really an answer, it's all up in the air really. They say base it on how her body works, but I don't know how her body works"
Difficulty using medicines	"crushing tablets, or using other alternative" "adding or removing frequency of dose along with measuring doses can be frustrating. 1 sachet of movicol does not always work, may need 2. Whereas lactulose 1 dose worked more efficiently." "daughter won't take it. Has tasted medication when first started taking it so won't have her medication unless it is mixed into something. Always refuses medication straight from syringe or spoon" "changing ratio of med which affects volume" "funny dosages" "movicol and mixing in 73.5mL water can't be precise unless have measuring cup which is specifically used for mixing movicol mediation." "trouble blocking NG tube" "if hospital, doctors change the measurements and you forget and give the wrong dose" What do you do if you are on meds that require a fridge and you are out and about for the day?
Difficulty with timing of doses, organising timings	"1st time round at one point [Patient] was on 24 doses of medication per day. Some every 6 hours, some every

	8 hours, some every 12 + 24 hours…..and then feed etc. Almost felt as though every day was a military procedure, writing a list and setting alarms” “had to keep diary and lots of notes at start, therefore at times it made [breastfeeding] difficult keeping track of reflux medications. Balance of recording is tough because trying to make home less clinical bt needed to keep track for medicines” “remembering times to give medication due to hectic life styles. What if you miss a dosage? What would happen?” - [ ] Working out a routine is hard. Is it best to do the meds as and when? Do them for the day? What if you are out and about? It’s all just trial and error with some guessing. No ideas or direction are given before you head home. “Time just, disappears, you change nappy [looks at watch], where have two hours gone? Just disappeared…”
Issues with transfer between hospital and home	“link from hospital through to GP took ages to sort out measurements and doses etc. constantly double checking” “had to call neonatal outreach to check a lot at first” - [ ] We were used to meds been changed on weight of baby but then that stops once in the community and it’s hard to get your head round when every gram vs ml is important in hospital
Adverse drug reactions	“allergies, e.g. if parents are allergic to the ingredients in the medicine” “No-one told me that my son’s vitamins contained peanut oil. I have a serious allergy to nuts. Once we got home I had a rash all over my hands and arms. It took me weeks to figure that his medicine was causing this. “every time he had this medicine, I were itching like mad, and I thought this was a bit weird” “I do follow that [the instructions], I have a specific beaker that I use, that I measure it out and mix it. Side effect wise, I don’t know if that is making it work less efficiently. Sometime I will give 2 sachets and then she

	complains of tummy ache".
Wasting of medicine	- [ ] Size of bottle in community is crazy...sytron 1litre, use once a day and has 3 month life-waste of nhs money
Difficult measuring doses	After several washes, the markings on the syringes start to wear off. There are times where you have to estimate the dose. My child was on roughly one and a half capsules of loperamide. It never dissolves well in water. I realised that the smaller part of the capsules was about half the total size, so I'd just measure using the half.

Question 2: What are the effects of giving medicines at home?

Parents felt responsibility of medicines made them a carer rather than parent	"didn't feel like a mother, more like a carer in the early days" "it did feel like it was put on us to sort it, because the health visitor was asking us, and were thinking we're not the experts."
Worries about not being able to give medicines	"felt as though I was going to be judged if I wasn't succeeding" "felt in control when he took all medication" It's daunting with a prem baby coming home without having to go to drs numerous times, everything is a struggle and nothing is given in volume so it's a constant battle "And I think I made myself and my husband get that worked up about it, has he had the medication, has he spat it out, and you tie yourself up in knots."
Conflict between parents regarding medicines	"arguments at home all because we wanted the best for out little boy" "fed up and angry"
Lack of support from family and relatives	"felt that no one could help out with babysitting or caring as they didn't know about medicines, this then continued so meant no one else supported with children."

	"alone" "anxious" "I was exhausted"
Conflict between parents and child	"she will not have it, if I bring a spoon to her mouth, she will not have it. She will run away, and go 'no mummy'." "It's frustrating because she's cranky, and she doesn't want to take her medication" "And it was battle after battle. Just trying to get some of the medications in."

Question 3: What would you do different?

Accepting of difficulties	"2nd time round I'm not getting myself tied up in knots, if she spits some out then so be it"
Developing strategies for overcoming problems	"getting the child to take it, give the most vile tasting one last then offer a drink/treat" "So, we had a lot of problems, erm, they were sort of giving the medications all at once, rather than spread out throughout the day. Because of your systems of having to mark them on the charts, for example, you would have to have his sytron, urso, and all of that all at once , and when you added up 0.3ml, 0.9ml, whatever, whatever, to him, that was a large volume. So then once we got home, we realised that actually, those can be given throughout the day, they are not time specific ones." "I'm a bit OCD, I had an excel spreadsheet, so I had the whole medicines list in times and laminated it so I could tick off each day so myself and [Dad] knew if I had or hadn't given the med, it really worked for us. Erm, but it was about putting that in place to make sure you could monitor what medicines had given or not given." "We had a similar system, when you are sleep deprived anyway, the only way of trying to remember what you have to do at what time it was, we set alarms on our phones, just to remind us."
More preparation before going home	"it was good in hospital to be shown how to administer some medications to give an element of control"
Better follow up	Too long between follow up of meds, could the come off them sooner?

Clearer instructions	"I'd like to told, you know what, do this and stick to it, and for a certain amount of time. But if they're always change it around then I don't really know"

Appendix 4: Email correspondence sent to participants

Good evening,

Thank you for volunteering to come to our focus group next week. We have had a fantastic response and we have got a full focus group (including a few children too!). We are really looking forward to seeing everyone. I am sending out a few details in advance to make sure everything runs smoothly next week.

If you have any further questions then please let me know,

Stephen
(on behalf of Leeds NERDs)

Stephen Morris
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Where and when are we meeting? (Date and Venue)

Date and time: **Tuesday 22nd October 2019 11-12pm**
Venue: L43 Seminar Room, this is immediately on the right as you walk onto L43. Myself and Fiona (Fiona Metcalfe, Lead Nurse for Neonatal Surgery) will be there so we can guide you in. As a reminder, L43 is on C Floor, Clarendon Wing, Leeds General Infirmary.

Please contact me on 07480 977620 if you are running late, **it is no problem arriving late**, but we have to start at 11am. We can catch you up on what you've missed. Also, we'll be in the room at about 10:30am so if you'd like to come early you will be welcome too, and we'll probably hang about until 1pm afterwards!

What will we be doing? (Focus Group)

I will start with a brief talk about the reason we are running the group and how it should work. I want to talk for as little time as possible so you can do most of the talking! We will use post-it notes to write your thoughts on first, then go around the room to discuss them. This makes it so everyone will get a chance to speak. We will break the session into three smaller parts.

1. We'll talk about your experience of having to give medicines at home first. What problems did you have? Was everything fine? What went well? How did you feel about taking responsibility for giving medicines?

2. Secondly we will talk about the effect of any problems (or things that went well)? How did it make you feel? What was the effect on your child? What did you do to resolve the problem? Did you visit the GP, or hospital to sort it out? Did you search for information (e.g. internet, friend, social media)?

3. Finally, we'll talk about what could have helped? What would you do different a second time? What did you learn that was helpful? Who did you find that was helpful?

I'll wrap up by saying what we are planning to do next. We would love to have everyone involved in the project going forward (e.g. during my PhD, fingers crossed it gets funded), so please have a think if you'd want to stay involved. We have had a few people who can’t come to the group because we are full. We might design a survey to get there thoughts too. It would be great to have some parents help design the survey with us.

How do I get my expenses paid and voucher? (Expenses)

You can claim up to £15 for travel expenses (including parking). You will need to provide any evidence you can (e.g. tickets). The hospital would like us to use bank transfers, I have sent the form with this email but I will have paper copies too. I’ll have the vouchers that I’ll need everyone to sign for at the end.

How do I say whether it was a good or bad session? (Feedback and Evaluation)

We need to collect feedback about the event. I'll pass around the forms at the end of the event, filling in the forms will be really appreciated and will be used to improve future events.

Why are you taking photos or recording things? (Photos and Audio Recording)

We would like to take a photo of the group to use for advertising and to raise the profile of the group. It will help us get more funding in the future. We will also take photos of the post-it notes that may be shared if we do any presentation to staff or researchers, or on social media. We will have some red/pink post it notes, **if you don’t want a comment to be shared then please write it on the red/pink post-it notes** and we’ll make sure to remove them before taking any photos.

We would also like to audio record any discussions. This is because I will need to write a report for the session. I will write about the topics that we discussed, what experiences people had (all names will be removed) and what the group wants to happen next. It will be easier for me to remember what is said if I can listen back to it! **If you don't wish to be recorded then please say so before or during the event**. The recording will be just for me, it won't be played anywhere else or used in any other way. I'll delete it once the report is written. It won’t be used for presentations.

We will ask before starting any recording and check everyone is happy with this. We will try to take written notes too, but it will be hard to listen and write at the same time! Fiona will be on hand to take notes as well.

Will food be provided? (Refreshments)

I have money to pay for some refreshments. I will get some biscuits and fruit snacks. The unit have kindly said we can use their facilities for tea and coffee. I’ll make sure we have water and squash in the room. If there is any specific dietary requirements then please let me know.

Appendix 5: Feedback for facilitator

FEEDBACK FORM

Name of Speaker	Title of Session / Presentation	Date
Stephen Morris	Leeds NERDs Focus Group "What is your experience of giving medicines at home?"	22nd October 2019

Your feedback would be greatly appreciated.

Please answer all the statements according to the following 1 to 5 scale:-
1 = Strongly Disagree (SD), 2 = Disagree (D), 3 = Neutral (N),
4 = Agree (A) and 5 = Strongly Agree (SA)

Please **circle a number** between 1 and 5 to indicate which response best fits your experience of the session.

	Average Score
CONTENT	*(Responses = 4)*
The content was at an appropriate level	5
The content was relevant to me	4.8
STRUCTURE	
There was a clear introduction to the subject	4.8
The aims and objectives were clearly stated	5
The material was well organised	4.8
There was a clear summary and conclusion	4.8
FOCUS GROUP	
The presenter appeared well informed about the subject	5
The presenter appeared enthusiastic about the subject	5
Audience participation and interaction was encouraged	5
The focus group was given at the right pace	4.4
The focus group was of a reasonable length	4.2
OVERALL	
Overall, this session was of a high quality	5

I **liked** the following things about the session:

- Clear purpose to the group, Very welcoming
- I got to meet other parents going through the same things as myself. Got to open up and speak about my sons conditions.
- Good to get together with other parents knowing that we all experience similar issues and that we aren't on our own
- Being able to give opinions and medications and how it effects child and parents

- All of the parents were engaged with the topic and willing to contribute. It was good to be able to share experiences with one another and feel that this feedback was useful to research.

The session might be **improved** by:

- A different room, found the main door banging and distracting
- Being a little bit longer
- Not completed
- Adding more parents to it, fathers who have been hands on would be good too as group was mother oriented
- We were a little stretched for time at the end, so perhaps more time for discussions or more chance to capture information in another format.

Please return your completed feedback form to the speaker at the end of today's focus group. ***Thank you!!!!!***

Appendix 6: Feedback for NIHR

NIHR | Research Design Service Yorkshire and Humber

The University of Sheffield
Regent Court
30 Regent Street
Sheffield S1 4DA

Tel: +44(0)114 222 0828
Fax: +44(0)114 272 4095
Email: rds-yh@sheffield.ac.uk

Would you be willing to provide feedback on your recent experience of being involved in the development of a research proposal?

If the answer yes, we would be grateful if you could spend a few minutes answering the following questions. The information you provide will help researchers to improve how they involve other patients, service users and carers in the future.

1. What was the name of the researcher who asked you to be involved?

- Stephen Morris (x4)

2. Please describe briefly what you were asked to do by the researcher (for example, were you asked to comment on a summary of the research idea, a recruitment letter, an information sheet, or a questionnaire?)

- Attend a focus group to discuss uses surrounding medicines
- Write our thoughts on post it notes, share ideas
- Come prepared with thoughts and examples of experiences
- Was asked to share experience with giving medication to my child at home along with how it effects day to day administration, ability to measure correctly and also share the aftermath and what can be improved in the service
- We were asked to discuss in a group our use of medications/administering medicines to our children after leaving neonatal care, including positive and negative experiences of this.

3. Did the researcher tell you how they would use your input in their grant application? Please tick the appropriate box.

Yes	100%
No	0%

4. Do you know if your contribution has made a difference to the research?

Yes	60%
No	20%
Unsure	20%

5. Did you enjoy the experience of assisting the researcher with their research?

Yes	100%
No	0%

6. Can you let us know in what ways, if any, the researcher could have improved your experience?

- A different room without banging door
- No comment
- No comment
- Researcher was very well prepared and made sure everyone in the focus group participated
- Perhaps a slightly different location to make it easier for parents bringing children. Also, coming back onto the ward may be challenging for some families who may not have returned since their child was on the unit.

7. Thinking about your experience, would you be willing to take part in similar activities in the future to help other researchers develop their ideas and their research proposals?

Yes	100%
No	0%

Appendix 7: Advert used for recruiting participants to first group

leeds children's hospital

Neonatal Research Dream Team

Funded by: NIHR | Research Design Service Yorkshire and Humber

Hi, I'm Stephen. I am a pharmacist that works at Leeds Children's Hospital. I am interested to learn more about the experience of families who give medicines at home. This is so we can improve the way we use medicines.

Medicines at Home

What is your experience of giving medicines to a child at home?

Family Focus Group: Tuesday 22nd October 2019 11am to 12noon

Location: Leeds Neonatal Unit (L43) Seminar Room (on the right as you walk on to L43), Leeds General Infirmary

(Travel costs and a £10 gift voucher will be given as a thank you for your time.)

The Project

I am about to start a project to look at the way families use long term medicines at home (treatment for longer than 1 month). What we know on this so far is:

- For some children, they will be taking lots of medicines. This is a lot of work for families. They may come up with 'life hacks' by changing their medicines so they are easier to use.
- 1 in 3 parents need to modify a medicine in some way so their child will take it (e.g. mix with food)
- 1 in 3 children will refuse to take their medicines

These changes may affect how the medicine works, making it better or worse. By learning about how families use their medicines, we can give better advice and stop any bad effects.

What is a family focus group?

The session will last for up to an hour. There will be Stephen, up to 8 other parents and a few staff from Leeds Children's Hospital. We will discuss your experiences of using medicines at home. The group will then decide if this is good research idea, or may suggest better ones.

Should I attend?

Any family can attend, but we would like to hear about medicines. So if you have used a medicine at home already, that's all you need. Please ask if you are unsure. Children are welcome but will need to be supervised.

How do I attend?

Please contact me in advance to say you want to attend.

Tel/Text: 07480 977620 Email: Stephen.morris1@nhs.net
Facebook: Leeds Neonatal Research Dream Team
Twitter: @LeedsNERDs

Appendix 8: Advert used for recruiting participants to second group

Funded by: NIHR | Research Design Service Yorkshire and Humber

Hi, we are staff from the neonatal unit at the LGI. We are setting up a group to help us with doing research at the hospital. We would love to welcome you to our next event.

Neonatal Unit Research Event

Family Focus Group

Tuesday 17th March 2020 10am to 12noon

Location: Leeds City Museum, The Denny Room, LS2 8BH
(downstairs inside the main entrance)

Tea, coffee and cake, plus a £10 gift voucher.
Also we can pay your travel costs too.

What are the projects?

We have three projects to talk about at this group:

1. Live music for families on the neonatal unit

Keri (a doctor) will talk about her project. She would like to have live music such as singers and musicians performing on the unit for families. She needs help to design a survey.

2. Using medicines at home

Stephen (a pharmacist) will talk about his project. He wants to interview families to find out how they use medicines at home. He needs help designing his project.

3. Video consultations for neonatal surgery clinics

Fiona (a nurse) will talk about her project. She is using live video chat (think skype or facetime) for clinic appointments. She would like help to design a project about her clinics.

What is a family focus group?

The session will last for up to 2 hours (with breaks). There will be Stephen, Keri and Fiona, up to 10 other parents, and a few staff from the hospital. You will get a chance to ask questions about our projects and tell us how we could make them better. We really want to hear your views!

Should I attend?

Any family can attend, but it would be best if you have stayed on the neonatal unit in the past. Please ask if you are unsure. Children are welcome but will need to be supervised.

How do I attend?

Please contact me in advance to say you want to attend.

Tel/Text: 07480 977620 Email: Stephen.morris1@nhs.net
Facebook: Leeds Neonatal Research Dream Team
Twitter: @LeedsNERDs

Appendix 9: Poster for NIHR Conference using feedback from group

leeds children's hospital

Stephen Morris
NIHR ICA Pre-Doctoral Fellow, University of Leeds
Clinical Pharmacist, Leeds Children's Hospital

UNIVERSITY OF LEEDS

QR code for contact details

Medication Safety at Home

Learning from the experience of families to reduce harm caused by medication at home

Background

The World Health Organisation (2017) states that the unsafe use of medication is the leading cause of preventable harm in healthcare. Children are at an even greater because:

- calculations are often needed,
- young children can't tell us about side effects,
- few medicines are designed for children.

After a hospital stay, parents have to manage their child's medicines at home. At least 1 in 10 families experience safety problems at home (Walsh, 2010). However, there are very few studies on this topic.

Patient and Public Involvement

We asked parents to share their experiences at a focus group. They confirmed that parents often have safety concerns when giving medicines. They also described new issues. These included allergic reactions, running out of syringes used for measuring, and missed doses when GPs/Pharmacies are unable to supply medication. Parents also talked about anxiety and stress caused by these issues.

Parents sharing their experiences

The reality of medication at home for many families

Aim

The aim of this project is to explore the experience of families and medication safety at Home.

The research questions for this project are:

- What medication safety issues do parents experience at home following discharge?
- How do medication safety issues effect parents and their families?
- Why do these medication safety issues occur?
- How do parents manage these safety issues at home?

Project Plan

Phase 1 – Scoping review

To find any current research and identify knowledge gaps.

Phase 2 – Qualitative study

Families will be sampled from infants who are discharged from hospital with medication. The infants will have either been born early or had surgery. Parents will be interviewed using semi-structured questioning. Thematic analysis will be used to explore their experiences.

Phase 3 – Co-designing processes to prevent harm from medication at home

Parents and professionals will design processes around hospital discharge to prevent harm.

Copyright and permission

Families photographed have given permission to the author to use photos as part of this research project.

Disclaimer

This poster presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

References

Walsh, K.E., et al. 2013. Medication errors in the home: a multisite study of children with cancer. *Pediatrics*. **131**(5), pp.1098-4275
World Health Organisation. 2017. Medication without harm. *Bulletin of the World Health Organisation*. **95**(5), pp.317-317.

FUNDED BY NIHR | National Institute for Health Research

NHS The Leeds Teaching Hospitals NHS Trust

Funding

Stephen Morris is funded by a National Institute for Health Research (NIHR), Integrated Clinical Academic Pre-Doctoral Fellowship for this research project. Patient and public involvement was funded through the NIHR Research Design Service Yorkshire and Humber Public Involvement Fund

Appendix 10: Follow up e-mail newsletter to parents

Dear all,

Firstly, I want to wish you all a happy new year and I hope 2020 brings you and your families lots of joy and happiness. Thank you to everyone for supporting the group. We have been busy following the focus group in October. We are planning bigger things for 2020! Here is an update for you.

Leeds NERDs Meetings/Focus Group

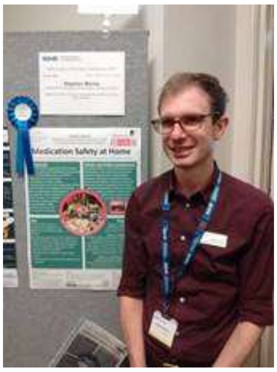
We have listened to the feedback from the last group. I am pleased to say the next meeting will be at the City Museum (across Millennium Square from the hospital). We agreed that the room we used in the hospital was too small and too noisy. The City Museum was used for the Neonatal Graduation Party last September. It's a great venue and hopefully you will think so too. **The next group we are running will be the 17th March 2020, 10am to 12noon**.

Some parents wanted a longer event. So we will aim to discuss 3 research projects at the next meeting. There will be a break in between so if you can only come for an hour, we would still love to see you. People are welcome to come and go as they wish. The topics will be; medication safety, music on the neonatal unit, and infections from nurseries. There will also be time before and after the event for chatting if parents wish.

Using medicines safely at home

I have been working on my research plan using the feedback from the focus group. I will give an update at the next focus group. It was brilliant to listen to so much talking around medicines and how you use them at home. I am hopeful we will make a strong case for this research project. This will help us get more money and support to help support families. I also won a prize when I spoke about the group at a National Institute for Health Research (NIHR) event, so thank you for all your help!

I would like to hear from any parents who would like to help me write a report on safe use of medicines at home. Please contact me if you are interested.



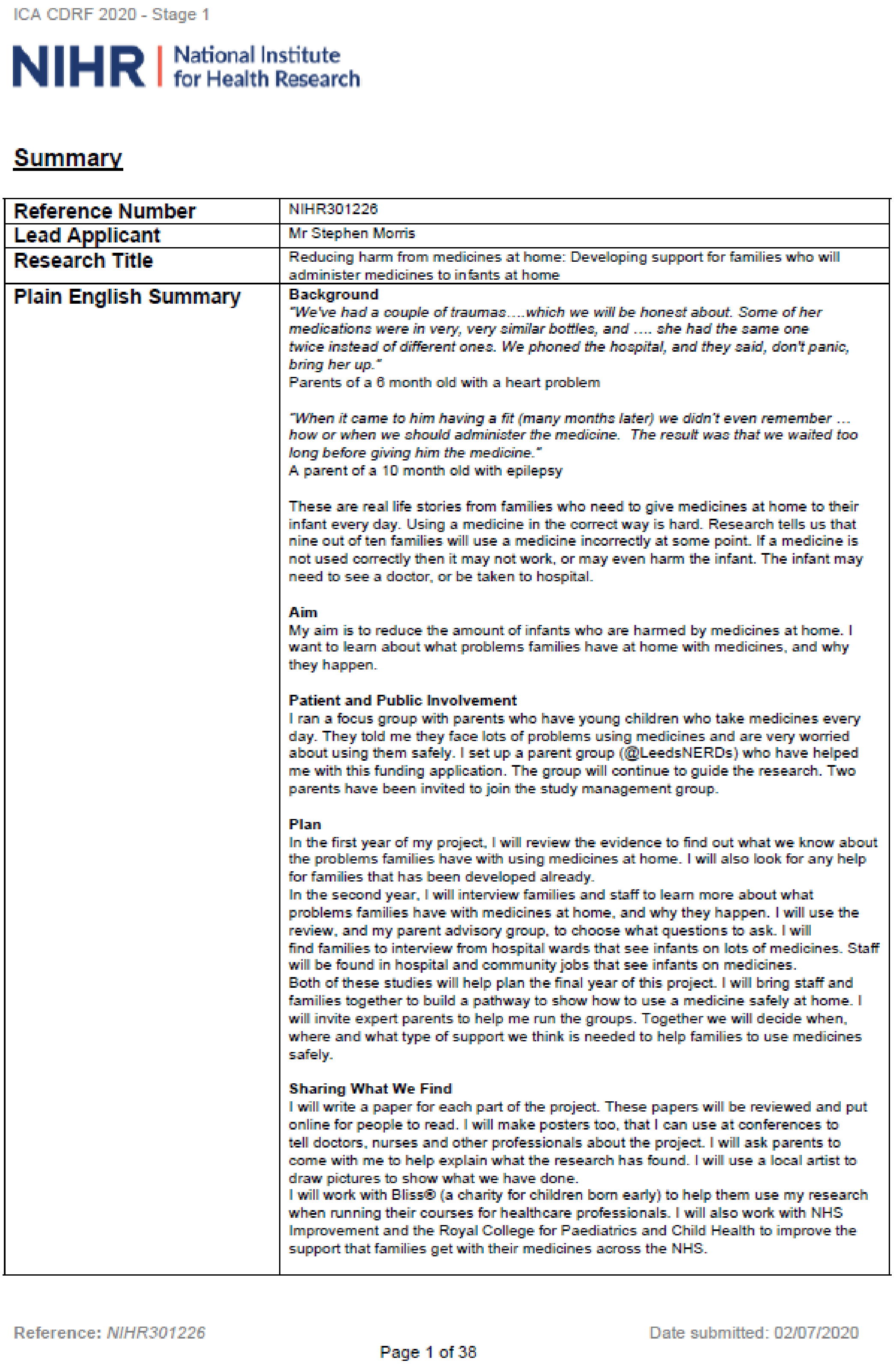
That’s all for now. Please keep an eye out for adverts for the next group over the next few weeks. We look forward to seeing you soon, thank you for helping support out work.

Stephen

Stephen Morris
Hospital days: Tuesdays and Fridays
Specialist Clinical Pharmacist - Neonates | **Leeds Teaching Hospitals NHS Trust**
NIHR ICA Predoctoral Fellow | **University of Leeds**
Pharmacy, Leeds General Infirmary, Great George St., LS1 3EX
Telephone No: 0113 3925250 I Pager: 2354 I Mobile: 07480 977620
www.leedsth.nhs.uk

leeds children’s hospital

Appendix 11: Plain English Summary on NIHR ICA CDRF application for lead applicant



ICA CDRF 2020 - Stage 1

NIHR | National Institute for Health Research

Summary

Reference Number	NIHR301226
Lead Applicant	Mr Stephen Morris
Research Title	Reducing harm from medicines at home: Developing support for families who will administer medicines to infants at home
Plain English Summary	**Background** *"We've had a couple of traumas….which we will be honest about. Some of her medications were in very, very similar bottles, and …. she had the same one twice instead of different ones. We phoned the hospital, and they said, don't panic, bring her up."* Parents of a 6 month old with a heart problem *"When it came to him having a fit (many months later) we didn't even remember … how or when we should administer the medicine. The result was that we waited too long before giving him the medicine."* A parent of a 10 month old with epilepsy These are real life stories from families who need to give medicines at home to their infant every day. Using a medicine in the correct way is hard. Research tells us that nine out of ten families will use a medicine incorrectly at some point. If a medicine is not used correctly then it may not work, or may even harm the infant. The infant may need to see a doctor, or be taken to hospital. **Aim** My aim is to reduce the amount of infants who are harmed by medicines at home. I want to learn about what problems families have at home with medicines, and why they happen. **Patient and Public Involvement** I ran a focus group with parents who have young children who take medicines every day. They told me they face lots of problems using medicines and are very worried about using them safely. I set up a parent group (@LeedsNERDs) who have helped me with this funding application. The group will continue to guide the research. Two parents have been invited to join the study management group. **Plan** In the first year of my project, I will review the evidence to find out what we know about the problems families have with using medicines at home. I will also look for any help for families that has been developed already. In the second year, I will interview families and staff to learn more about what problems families have with medicines at home, and why they happen. I will use the review, and my parent advisory group, to choose what questions to ask. I will find families to interview from hospital wards that see infants on lots of medicines. Staff will be found in hospital and community jobs that see infants on medicines. Both of these studies will help plan the final year of this project. I will bring staff and families together to build a pathway to show how to use a medicine safely at home. I will invite expert parents to help me run the groups. Together we will decide when, where and what type of support we think is needed to help families to use medicines safely. **Sharing What We Find** I will write a paper for each part of the project. These papers will be reviewed and put online for people to read. I will make posters too, that I can use at conferences to tell doctors, nurses and other professionals about the project. I will ask parents to come with me to help explain what the research has found. I will use a local artist to draw pictures to show what we have done. I will work with Bliss® (a charity for children born early) to help them use my research when running their courses for healthcare professionals. I will also work with NHS Improvement and the Royal College for Paediatrics and Child Health to improve the support that families get with their medicines across the NHS.

Reference: *NIHR301226* Date submitted: 02/07/2020

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