



Parent co-Designed Drug Information for parents and Guardians Taking Neonates home

Information Sheet for Healthcare Professionals - E-Survey

What is this study about?

This study aims to work with healthcare professionals (HCPs) and parents/carers to co-design resources for use in the UK and Ireland, to improve the safety of neonatal medication administration in the home environment. HCPs and parents/carers of babies will be invited to participate in electronic surveys to establish the problems or issues related to medicines following discharge and the resources currently available. Parents/carers on five neonatal units in the UK and Ireland will then be invited to participate in on-line or face to face focus groups to discuss any medicine-related problems they experienced following discharge and what type of information, educational resources or interventions they think would have been helpful to support giving medicines to their babies following discharge. A small group of these parents/carers will be invited to help co-design new targeted medicine support resources. Once the resources have been produced, a separate group of parents and HCPs will be asked to provide feedback on these resources.

Why are we doing this study?

Current practice on most neonatal units in the UK and Ireland is for nursing staff to give medicines to neonates. There have been recent moves towards parents/carers giving medicines in hospital in order to prepare them to give medicines to their baby at home. The training provided to parents/carers differs between units and may only occur immediately prior to discharge in some situations. Premature neonates are often prescribed medications which require small volumes to be administered. This can cause high levels of anxiety and concern for parents/carers as they worry about making mistakes when measuring doses. We want to develop resources which will support parents/carers giving medicines safely to their babies following discharge and reduce parental anxiety.

Why you?

You are a healthcare professional that works with neonates requiring medicines.

What will the study involve?

We would like to ask you some questions about your view on medication problems encountered by parents/carers during the transition between hospital and home and ask you to identify any existing available resources used to support this process.

The questions will be in the form of an electronic survey (e-survey) which will be emailed to you. It will take no longer than 10 minutes to complete. The e-survey will be open for 4 weeks. We will send you a reminder after 1 and 3 weeks.

Are there any risks/ benefits to taking part?

We do not expect there to be either any risks or immediate benefits to you. However, we hope that the information gathered will help design resources for parents/carers and HCPs in the future. We will not be collecting any participant identifiable information and so the e-survey will be anonymous. The information collected from the e-surveys will be analysed and used to prepare material for online focus groups with parents/carers from the five study sites which will explore the unmet needs identified and what parent/carers think are important issues resources should address/support.

Do I have to take part?

No, it is up to you if you want to participate or not. If you do not want to take part, that is not a problem. If you have any questions about taking part or would like more information please contact a member of the research team who will be happy to help.

Can I change my mind?

Yes, you can change your mind and stop completing the e-survey at any time. Once your e-survey is completed, however, you will not be able to withdraw from the study as your e-survey is anonymous and therefore we will not be able to match you to your e-survey.

Who is doing this research?

This research is being carried out through collaboration between the Paediatric Medicines Research Unit (PMRU) at Alder Hey Children's NHS Foundation Trust (FT), Liverpool Women's NHS FT, Wirral University Teaching Hospital NHS FT, Leeds General Infirmary (part of Leeds Teaching Hospitals NHS Trust), the Rotunda Hospital Dublin and the Royal College of Surgeons in Ireland.

What will happen once I have completed my e-survey?

All of the information will be analysed by the PMRU team at Alder Hey Children's NHS FT and the Royal College of Surgeons in Ireland.

We hope that this study will help us to develop resources for parents/carers to improve the safety of medication administration in the home environment. We plan to share our results in journals and conferences and at other meetings. We may use quotes from your e-survey, however you will not be identified in any report or publication, and you can have a copy of the final report, if you wish.

Once the study is finished we will create a report which summarises the results and this will be published on the PMRU website for you to read, if you wish. You can access this here: <https://alderhey.nhs.uk/research/paediatric-medicines-research-unit>

Will the information you give be kept private?

Anything you tell us will be kept confidential. We will not tell anyone outside of the study team about what you have told us unless it is completely anonymised. Data we collect will be anonymised using a unique reference number which will be allocated from, and held within, a secure network at Alder Hey Children's NHS FT. All the information about your participation in this study will be kept confidential and in accordance with the General Data Protection Regulation (GDPR).

In line with GDPR, as Alder Hey Children's NHS FT is the Sponsor for this research study and is based in the United Kingdom, they will be using information from you and in order to undertake this study and will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly. Alder Hey NHS FT will keep information about you for 10 years after the study has finished to allow the study to be reviewed by the authorities after it is finished.

Please note that no identifiable information will be collected during this study. We will ask for the hospital you work in and your role. You will not be asked for your name, except in order to be emailed the e-survey by a gatekeeper from your organisation who is not part of the research team. **All data you provide will be anonymous.**

Your rights to access, change or move your information are limited, as the Sponsor organisation need to manage this information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we have chosen to collect **no personally identifiable information**. The only people outside the immediate research team who will have access to anonymous information about you will be people who need to audit the data collection process.

You can find out more about how Alder Hey Children's NHS FT uses your information by contacting the Alder Hey Data Protection Officer on info.gov@alderhey.nhs.uk.

At the end of the study, the documentation held at Alder Hey Children's NHS FT will be stored securely for 10 years after the study finishes, within the Trusts secure network, in line with Alder Hey's data storage procedures.

Has the study been checked?

Yes. Within the UK the study has been reviewed by the Health Research Authority, a Research Ethics Committee and Alder Hey Children's NHS FT to make sure it is safe and ethical. In Ireland the study has been reviewed by The Rotunda Hospital Research Ethics Committee. The Committees are satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits, and that you have been given sufficient information on which to make an informed decision to take part or not.

Who do I ask about this?

Please contact the research team using the contact details at the end of this information leaflet.

What if something goes wrong?

If you are unhappy, or have concerns about any aspect of this study, or would like to make a complaint, you should speak to the PMRU team at Alder Hey Children's NHS FT. Please contact Dr Louise Bracken, Senior Research Pharmacist louise.bracken@alderhey.nhs.uk or on 0151 252 5570.

STUDY CONTACT DETAILS:

PADDINGToN Study Team on 0151 252 5570

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