

Terms of reference for MINIMEDs Parent/Public Advisory Group

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(adapted from documents kindly shared by J Tomlinson and the University of Bradford team)

1. Introduction

This document contains the terms of reference for the Parent and Public Advisory Group (PAG) for a PhD research project " Minimising harm from medicines at home (MINIMEDS): Developing support for families who will administer prescribed medicines to infants at home".

1.2 Plain English Summary of the research project

Background

Research tells us that nine out of ten families will give a medicine incorrectly at some point. If a medicine is not given 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 being given the wrong prescribed medicine at home. I want to learn about what problems parents/carers have when giving medicines at home, why they happen and what can be done to stop it happening.

Plan

In the first part of my project, I will review the evidence to find out what we know about the problems families have with giving medicines at home. I will also look for any help for families that has been developed already.

In the second part, I will interview families and staff to learn more about what problems families have giving prescribed medicines at home, and why they happen. I will use the review, and my parent advisors, to choose what questions to ask. I will find families to interview before they go home from hospital wards that take care of infants on lots of medicines. Staff will be found in hospital and community jobs that take care of infants on medicines.

Both of these studies will help plan the final part of this project. I will bring staff and families together to decide why medicines are given incorrectly at home and what we can do to stop it happening. 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.

1.3 Roles available to PAG members

You will also be invited to contribute to:

- Review and comment on participant information leaflets designed for this research;
- Review and comment on interview questions;
- Scripting or review and comment on a plain English summary for this research project;
- Discuss any possible ethical considerations;
- Discuss ideas for recruitment of participants;
- Discuss the research methods.

Ways of working

The group will meet twice a year with communication by email in between if necessary. Each meeting will last for no longer than two hours. The place and time of the meetings will be agreed with the group members. Group members will receive a meeting agenda and associated documentation two weeks prior a meeting. Minutes of the meeting will be made by the researcher and agreed by the group members who attended the meeting. The research project is planned to run for four years. The group will

- Respect anonymity of discussion;
- Take into account all representative views;
- Determine areas of particular priority for discussion;
- Be informed of the research topics prior to the meeting;
- Be informed of the attendance of specialists / researchers prior to the meeting.

Confidentiality

It is important that members are able to speak freely of their views and experiences. When discussing any of the Group's work publicly, there will be no attribution of comments or views of an individual. At any time, a member may wish to state that the material or information offered by them is confidential and should not be shared or seen by anyone outside the group and should not be noted.

Safeguarding and Risk Assessment

All members of families are welcome to attend. For those under 18 years of age, they will need to be kept under supervision of parents/guardians at all times. Play therapy will be offered during the PAG meetings and parents/guardians are expected to supervise these activities at all times.

A Risk Assessment has been completed following guidance from the University of Leeds.

3 Expenses and payments

You will be reimbursed for your time. You will receive payment based on an hourly rate of £25/hour. You can also claim back your travel expenses, including parking if required. Refreshments will be provided during meetings.

Payment will be made through the University of Leeds and PAG members will need to provide the necessary details in order to receive a bank transfer.

4 Monitoring and feedback

PAG meetings will be monitored using guidelines from the Leeds Teaching Hospitals Trust and National Institute of Health and Social care Research.