



University of
Nottingham

Children & Young People's Health Research



Research Priorities for Community Children's Nursing (CCN'S) in the Context of Babies, Children, and Young People (BCYP) Experiencing Complex Medical Needs and their Families

A Participant Information Sheet (PIS)

Introduction

We would like to invite you to take part in a study which involves participation in an online survey comprising a total of 60 questions. 35 questions concern research ideas to help us to establish priorities for research. As well there are 9 demographic questions and 16 questions related to work, Covid-19, and Long Covid. **The exact number of questions you will be presented with depends on your answers.** The estimated time for completion is 15 minutes. Before you decide, it is important for you to understand why the study is being undertaken and what it will involve.

Please take time to read this information carefully and discuss it with others if you wish. Please ask any relevant questions of the researcher if anything is not clear or you would like more information. Do take time to decide whether you wish to participate.

What is the purpose of the research?

There is an awareness of the impact of Long COVID on BCYP and their families and health care professional carers including CCN (Coad et al., 2023). However, to date, there has been no national study on the impact of Long COVID on BCYP in receipt of care in the community and in terms of alignment to integrated health and social care services. Research is thus needed to understand this phenomenon, to enable best care to be given and to improve health outcomes. Of interest is the impact of Long COVID in the context of BCYP experiencing complex medical needs and their families. This survey aims to identify the research priorities from the perspective of Community Nurses working with BCYP and families in community settings in England. The research aligns to the integrated Care Systems and the Long-Term NHS Plan in improving the health and/or wellbeing of BCYP health in the community. Centred on CCN working in community-led settings the identification of research priorities and subsequent research will also support the implementation of the Chief Nursing Office Research Strategy Plan.

Why have I been invited to take part?

You are eligible to take part in this research if you are a registered CCN who cares for BCYP with medically complex conditions.

The exclusion / inclusion criteria are:

Inclusion criteria

- The participants will be Community Children's Nurses CCN's who care for or who have cared for BCYP with medically complex conditions
- English proficiency
- Working in England
- Ability to provide informed consent

Exclusion criteria

- A health professional who is not a Registered Nurse and who does not care for or care for BCYP with medically complex conditions
- Working geographically beyond England

Do I have to take part?

It is up to you to decide if you want to take part in this research. We have described the research in this PIS and are happy to answer any questions you may have. If you agree to participate, we will ask you to e-sign a consent form. However, you would still be free to withdraw from the study at any time, without giving a reason, simply let the research team know.

1. What will happen to me if I take part?

This study will involve you taking part in an online survey. The survey contains 60 questions divided into two sections. It should take no longer than 15 minutes to complete the survey. In the first section we would like you to consider 33 research ideas and rate each on a 10-point scale from 1 not important at all to 10 very important according to how much of a priority you think it is for research to answer it. Next we invite you to complete two free text questions asking if you have any other research ideas. Finally, section 2 contains 9 demographic questions, and 16 questions related to work, Covid-19, and Long Covid.

2. Are there any risks in taking part?

We do not anticipate any risks involved in an online survey. There are no sensitive questions or anything about care of patients. However, it is possible that in one free text response to a survey question you may disclose sensitive information concerning Long COVID issues, health care professionals including yourselves, and/or BCYP patients and their families. If this happens and you require support, please contact the researcher on susan.tomlinson@nottingham.ac.uk or access this link [Home - Long Covid Support](#)

3. Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research, but your contribution will help the identification of research priorities regarding BCYP, and families impacted by Long COVID in community settings. An understanding of the landscape that CCN's caring for BCYP with medically complex conditions can help us to advise professionals on adaptations and or areas of concern.

4. Will my time/travel costs be reimbursed?

Participants will not receive an inconvenience allowance to participate in the online survey.

5. What happens to the data provided?

Your personal data being the consent form, demographic data and the data from the online survey will be stored confidentially. To help ensure your privacy, you will be assigned a volunteer study identification number (for example P01 for participant number 1), and it will be used instead of your name. The consent form and demographic will be saved and stored as volunteer study identification number. The files containing the consent forms and demographic data will be encrypted.

Only the research team will have access to personal and research data. All research data and records will be stored for a minimum of 7 years after publication or public release of the work.

6. What will happen if I don't want to carry on with the study?

Even after you have consented to participate in the study you change your mind about taking part. To withdraw closes your browser at any time during the completion of the survey. We will only record responses from people who proceed to the end of the survey and submit their response. Once your response is submitted, we are unable to remove your data as it is anonymous.

7. Who will know that I am taking part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. Electronic storage devices will be encrypted while transferring and saving of all sensitive data generated in the course of the research. All such data are kept on password-protected databases sitting on a restricted access computer system and would only be accessed by the research team.

Under UK Data Protection laws, the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (Professor Jane Coad) is the Data Custodian (manages access to the data).

You can find out more about how we use your personal information and to read our privacy notice at:

<https://www.nottingham.ac.uk/utilities/privacy.aspx/>

8 What will happen to the results of the research?

The research may / will be published in reputable academic journals. As well the results will be disseminated in report form to the funders and may be presented in either oral or written format at conferences.

9. Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. In this case it is the Faculty of Medical and Health Sciences Ethics Committee at the University of Nottingham.

10. Who is organising and funding the research?

Dr Joanne Cooper (PhD RN)

Head of Nursing Research (Research Transformation)

CNO Policy and Strategy Unit - Nursing Directorate

NHS England

Email: joanne.cooper31@nhs.net Website: www.england.nhs.uk

Ref Number Project 17075909

11. What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher Dr Susan Tomlinson or the Principal Investigator Professor Jane Coad, who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.

Please quote ref no: FMHS 290 0523

12. Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Dr Susan Tomlinson

School of Health Sciences

B Floor, Queens Medical Centre, Nottingham, NG7 2HA

Email: susan.tomlinson@nottingham.ac.uk