

## Participant Information Sheet for Parents/Carers- Interviews



**Chief Investigator:** Dr Anna Selby

**Ethics/IRAS number:** 332076

### Prescription Alerts for Reliever Inhalers in Children (PARC) Project

Thank you for taking part in the PARC project with your child. You are now being invited to take part in an interview to find out what you thought of your child's asthma/wheeze check-up. To help you decide whether you would like to take part or not, it is important that you understand why we would like to talk to you and what the interview will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information. You may like to discuss it with others, but it is up to you to decide whether you take part. If you are happy to take part, you will be asked to sign a consent form.

#### What is the interview about?

The aim of the interview is to find out what you thought about the asthma/wheeze check-up your child had as part of the PARC project. We would like to know whether you have any suggestions for how we could improve the check-ups. Your thoughts and ideas will also help us to improve asthma/wheeze check-ups for children in future.

#### What will the interview involve?

The research team will contact you to arrange a suitable time for the interview. If you choose to take part, the interview will be done via video call, on the phone or in person depending on your preference. It will be led by a member of the research team with training in doing interviews. The interview will last about 30 minutes, and no longer than one hour depending on how much feedback you have. Depending on your child's age, they may wish to join you for the interview or have a chat separately with the research team. With your permission, we will record the interview (audio and video) and then write it up. You may turn your camera off if you wish. The recording will be stored securely and deleted as soon as it has been written up. Once it has been written up, it will be anonymised.

#### Are there any benefits in my taking part?

Being involved in research can be a rewarding experience. By sharing your views about the check-up your child had, you will have the chance to influence how asthma/wheeze check-ups for children and young people are carried out in future. This will help to improve the care of children with asthma/wheeze. You will also receive a £10 voucher to thank you for your participation.

## Are there any disadvantages to me taking part?

Taking part in the interview will involve giving up some of your time. Your participation is entirely voluntary, and you can stop the interview at any time. You will be reimbursed for any travel costs associated with attending the interview.

## What data will be collected?

You and your child's name and contact details will be collected. Personal data including your child's gender and ethnicity will also be collected. This information will help to ensure that we interview a wide range of people. Your child's personal data and the typed-up interview will be stored separately and will only be linked by your child's project ID number. This means that all interview data will be anonymous when stored.

## Will my participation be confidential?

Your participation and the information you tell us during your interview will be kept strictly confidential. Sometimes, individuals from regulatory authorities require access to the information we collect to check we are carrying out the project correctly. These people have a duty to keep information about you and your child strictly confidential.

## Do I have to take part and what happens if I change my mind?

It is entirely up to you whether you take part or not. You have a right to change your mind at any time and do not need to give a reason. This will not affect your child's clinical care or involvement in the rest of the project.

## What will happen to the results of the project?

The findings of the project will be written up and may be published in scientific journals/presented at research conferences. They will be used to help decide whether prescription alerts for reliever inhalers should be used by health professionals looking after children with asthma. They may also influence how asthma check-ups for children are carried out.

## Who is organising and funding the project?

The project is funded by the NIHR Research for Patient Benefit programme. University Hospitals Southampton NHS Foundation Trust (UHS) is the project sponsor.

## Who has reviewed the project?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee (REC). The purpose of the REC is to protect your child's safety, rights, wellbeing and dignity. This project has been reviewed and given a favourable opinion by the West of Scotland Research Ethics Service. The reference number is 24/WS/0004 (IRAS 332076).

## What happens if there is a problem?

If you have a concern about any aspect of this project, you should contact a member of the project team who will do their best to answer your questions (contact details below). If you remain unhappy or have a complaint about any aspect of this project, please contact the Patient Advice Liaison Service (PALS) at UHS.

UHS has appropriate insurance in place in the unlikely event that you or your child suffer any harm as a direct consequence of your child's participation in the project. NHS indemnity operates in respect of the clinical treatment provided.

## Contact Details

If you have any questions about this project/would like more information, please contact a member of the research team (led by Dr Anna Selby and Professor Graham Roberts).

Email: [parc@uhs.nhs.uk](mailto:parc@uhs.nhs.uk)

Phone: 07584 613936



Thank you for reading this information sheet.

## Data Protection Privacy Notice

### How will the research team use information about my child?

We will need to use information that you, your child and your child's GP have given us about you and your child for this research project. This information will include you and your child's name, age, gender, ethnicity and contact details.

This information will be held securely at the University Hospitals Southampton NHS Foundation Trust (UHS)/University of Southampton. It will be used to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a project ID number. We will keep all information about you and your child safe and secure. Once we have finished the project, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you or child took part in the project.

### Where can I find out more about how my/my child's information will be used?

You can find out more about how we use your child's information:

- At [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/) and [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- By contacting the research team (details above)
- By contacting UHS's Data Protection Officer ([dataprotection@uhs.nhs.uk](mailto:dataprotection@uhs.nhs.uk))

### What are my choices about how my/my child's information is used?

You and your child can stop being part of the project at any time, without giving a reason. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you or your child.

For the purposes of data protection law, the University Hospitals Southampton NHS Foundation Trust (UHS) is the 'Data Controller' for this project, which means that UHS is responsible for looking after your information and using it properly. UHS will keep identifiable information about you/your child for up to 15 years after the project has finished. After this, any link between you and your information will be removed. To safeguard your rights, we will use the minimum personal data necessary to achieve our research project objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. UHS will not do anything with your personal data that you would not reasonably expect.