

Empowering teenagers to self manage their asthma

PARTICIPANT INFORMATION SHEET (participating parent/guardian)

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with others if you wish.

- **Part 1** tells you the purpose of this study and what will happen to you if you take part.
- **Part 2** gives you more detailed information about the conduct of the study.

Please take time to read the following information and discuss it with your friends, family or GP if you wish. If anything is not clear and you require more information before you decide whether or not to take part in the study, please contact the a member of the study team (details at end of information sheet)

PART ONE

What is the purpose?

The purpose of this study is to develop a more effective patient-centred, adolescent approach for managing teenagers with asthma. To this, we are approaching adolescents with asthma, their parents and their healthcare professionals to understand the challenges that these teenagers face and obtain ideas on how their care can be improved.

Asthma is one of the commonest long-term conditions in adolescents. Our previous research has shown that healthcare professionals do not always communicate effectively with this age group. This may lead to poor self-management and poorly controlled asthma. Health care professionals therefore need to take a different approach to interacting with adolescents with asthma. By developing an approach, based upon real experiences, we aim to promote the engagement of adolescents with their asthma management, this should lead help them to achieve better asthma control.

Why have I been invited?

You have been chosen because you have a child, aged between 12-17 years, with asthma.

Do I have to take part?

It is entirely up to you as to whether you take part in this research. If you decide to take part, you will be given a copy of this information sheet to keep and you will be asked to sign a consent form. You are free to withdraw from the study at any time and without having to give a reason.

What will happen to me if I take part?

You will be invited to take part in two focus groups with other parents of children with asthma. These will be audio-taped and transcribed verbatim. Fully anonymised direct quotes may be used in the presentation and/or publication of this research.

What will I have to do?

We will ask you to complete a short questionnaire to give us some background information about your child's asthma, any other illnesses and family background.

Focus groups will be arranged with other parents of children aged 12-17 years with asthma. The groups will be facilitated by a researcher and will consist of up to 8 parents.

The information obtained will help us identify what you feel works and doesn't work in the current management of your child's asthma and how you feel your child could be better supported to manage their asthma. This information will be used to help us develop an improved adolescent approach.

About three to six months later, you will be invited to a second focus group or interview. During this second contact, your feedback will be sought on the adolescent approach developed from the information obtained from the initial groups. The feedback obtained will then be used to further refine the approach.

What are the benefits of taking part?

You will have the opportunity to discuss your views about the management of your child's asthma. These views will guide the development of an adolescent asthma approach designed to empower adolescents to effectively self-manage their asthma. Reasonable travel and parking expenses will be reimbursed.

What are the possible disadvantages and risks of taking part?

It is important that all participants are able to be open and honest. In the unlikely event that information is disclosed which indicates that a participant's child may be at risk of harm, this information may need to be imparted to the participant's healthcare team. An agreement will be sought within each group to respect each other's confidentiality however confidentiality between group members cannot be guaranteed by the researcher.

This completes Part 1 of the Information Sheet. Part 2 will give you more detailed information about the conduct of the study.

PART 2

Will my taking part in the study be kept confidential?

All information that is collected about you and your child during the course of the research will be kept strictly confidential. Personal details (e.g. name) will be kept securely and separately from all other research data and accessed by the research team only. You will be allocated a code name/number on all other documentation so that at no time will any of your personal details be revealed. The procedure for handling, processing, storage and destruction of any data collected during the study are compliant with the Data Protection Act 1998 and in line with the University Hospital Southampton's NHS Foundation Trust Policy.

Any individual experiences or quotes used subsequently in reports of the study will not be attributed to the source.

Audiotapes, from which your voice could potentially be recognised, will be destroyed at the end of the study as per University of Southampton guidelines.

What will happen to the results of the research study?

The results will be used to develop an adolescent approach for the management of asthma.

The approach developed will be presented in a clinical study report, which may be used for publication and presentation at scientific meetings. You and your child will not be identifiable in any publications arising from this project.

Who is organising and funding the research?

The study is being funded by Asthma UK and is sponsored by University Hospital Southampton NHS Foundation Trust.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (see contacts for further information below). If you still have questions or concerns, you can contact Research and Development, University Hospital Southampton NHS Foundation Trust (telephone number 02381 208215). In the very unlikely event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for legal action for compensation against University Hospital Southampton NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints procedure will still be available to you.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by NRES Committee East of England- Cambridge Central.

How long do I have to decide whether my child should take part?

Your decision to participate in this study is entirely voluntary. You should take as much time as you need to decide whether to take part.

Contact for further information

Further information can be obtained from:

Research psychologist: Dr Simone Holley, Clinical & Experimental Sciences, University of Southampton, Faculty of Medicine, Southampton General Hospital. Telephone: 0238120 5227
s.l.holley@soton.ac.uk

Research nurse: Ruth Morris, Children's Asthma Research Nurse, NIHR Wellcome Trust Clinical Research Facility, 02381 204989, ruth.morris2@uhs.nhs.uk.

Chief Investigator: Prof Graham Roberts, Professor & Consultant, Paediatric Allergy and Respiratory Medicine, Clinical & Experimental Sciences & Human Development in Health, University of Southampton Faculty of Medicine & University Hospital Southampton NHS Foundation Trust. Telephone: 02381 206160.

Thank you for taking the time to read this information sheet.