

Parents' Information Sheet

Title: FamilyTalk

You and your family are invited to take part in a research study about your experiences of living and coping with familial adenomatous polyposis.

What is the study about? The study aims to find out more about families' experiences of living and coping with familial adenomatous polyposis and how it is discussed and information shared amongst family members including the children, young people and their parents or guardians.

What would I have to do? If you agree to take part, trained researchers will interview you and your children on a single occasion at a mutually convenient time and location, which could be your own home if you wish. Your children will be encouraged to use drawings and creative images (if they wish to) to explore their experiences. The interviews will last approximately 30 – 90 minutes and will be taped using a tape-recorder.

Which family members are to be interviewed? You as parents / guardians will be interviewed together; we would also like to talk to any of your children aged 12 – 18 years of age including children who might have been diagnosed with or are at risk from developing familial adenomatous polyposis and their unaffected brothers and sisters (siblings). We can conduct the interview with you as a family group or as individuals, whichever you and your children prefer.

Information leaflets are included for each member of your family who is interested in taking part. We would ask that you read and discuss them with your children, if possible please. We advise that you should only take part if you feel confident that you and your children feel able to openly discuss familial adenomatous polyposis with each other.

Why have I been contacted about this research study? The recruitment leaflet has been distributed via the Genetics Interest Group (GIG) to all groups and charities who provide care and support for families affected by familial adenomatous polyposis. Your details and information have not been passed on to any other organisation.

What are the benefits? There are no specific benefits to you or your family personally. However we hope that the results of these interviews will provide information to assist the education of health professionals to enable them to provide more information and support to families and provide better services in the future.

What are the risks? The interviews will cover sensitive information asking you and your children about their experiences of living and coping with familial adenomatous polyposis. Whilst our questions are designed to ask about your children's experiences without providing them with any new information, some children may raise questions with the researchers that they had not previously spoken about with you as the parent or guardian. When you contact us to express a firm interest about taking part we will discuss with you in more detail how we will handle these situations in the unlikely event that they arise.

What if my family or I do not want to take part? There is no obligation to take part in the research. You and any family member can decline to take part or withdraw from the study at any time without giving a reason and it will not affect your future treatment or care. If only one or two members of the family wish to take part we would still like those people to do so.

What happens to the information? The information is carefully studied. It will be kept strictly confidential. Each person taking part will be given a number, which will be used to identify the results from the interview so that those participating will be anonymous to everyone except

the researcher. The researcher will treat all information received confidentially and once the interview has been analysed the audiotape recording will be erased.

Who else is taking part? About 40 families will be interviewed through the duration of the project

What if something goes wrong? All of our questions are designed to not cause any distress to you or your family, however we will be discussing sensitive issues and there may be some rare circumstances that we are unaware of. In the unusual circumstances that a child is upset we will stop the interview and contact an adult family member. If a parent is upset we will discuss their wishes regarding stopping or taking a break.

It is unlikely for anything to go wrong but if the interview raises any questions, you should discuss them with your family doctor (GP), clinical geneticist, genetic counsellor or paediatrician. We will write to your GP to let them know you are taking part in the study before the interview takes place. Please note no information or details from the interview will be passed onto to your GP unless you or a family member requests it.

What happens at the end of the study? The information we learn from the findings will be published. But no individuals or families will be identifiable from the findings we publish. If we use quotes these will be completely anonymised. If you wish, the researchers will provide you with an overview of the results of the research once it has been completed.

What if my family, or I have more questions or do not understand something? Please contact our research assistant Gill Plumridge who will be happy to answer your questions, on 0121 415 8740 or email g.plumridge@bham.ac.uk . We appreciate you may have a number of questions you wish to ask before you agree to take part and welcome you contacting us to discuss them before making any decisions.

What should I do if my family and I decide to take part? Please complete the consent form on the attached letter and post it in the envelope supplied (You do not require a postage stamp) or you are welcome to ring or email Gill Plumridge (research assistant). She will contact you within the next two weeks to send out an information pack for you and each of your children who wish to take part. Gill will talk to you about how you answer any questions your children may have about the genetic condition in your family , and discuss with you how you will handle any questions that might arise as a result of the research. She will also discuss with you and your family a mutually convenient time and venue for the interviews, which could possibly be your own home if you prefer. We will provide travel expenses for you if you do have to travel to a venue

What happens if I, or a member of my family, change our minds during the research study? Just explain to the researcher that you no longer wish to take part and the interview will be stopped and the recording erased. You are not obliged to give a reason and your care and treatment will not be affected in the future.

Knowing more about the researchers: There are three members to the research team who will do the interviews, all of whom are experienced interviewers and have worked previously with families. Two are also qualified nurses and all of the researchers have gone through police checks and vetting procedures to ensure the safety of your family members.

Contact details: For further information about the research please contact the research assistant Gill Plumridge, School of Health Sciences, 52 Pritchatts Rd, University of Birmingham B15 2TT. Telephone 0121 415 8740 or email g.plumridge@bham.ac.uk

Please note: correspondence via email will be to arrange interview times and venue details with you. We will not use email to request or send you any personal information.

Who has reviewed this study? This study was given a favourable ethical opinion by the Liverpool Paediatric Research Ethics Committee.

What if I have concerns or a complaint?

If you have any concerns about this research and would like to discuss them further, please contact a lead researcher for the project

Dr Alison Metcalfe, School of Health Sciences, 52 Pritchatts Rd., University of Birmingham, Birmingham B15 2TT
Phone 0121 414 2666
Email. a.m.metcalfe@bham.ac.uk

Or if you prefer to speak to an independent adviser to the project please contact:
Ms Anna Allford (previously Lane), Genetics Interest Group, Unit 4D, Leroy House, 436 Essex Road, London N1 3QP.
Phone 020 7704 3141
Email. anna@gig.org.uk