The Childhood Illness Perception (ChIP Study):
Understanding public perceptions of childhood cancer

Information sheet for parents / carers with childhood cancer experience
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Title of Study: The Childhood Illness Perception (ChIP) Study: understanding the public perception of childhood cancer

Name of Investigators: Dr Shaarna Shanmugavadivel (Chief Investigator), Jo-Fen Liu, Ashley Gamble, Dr Angela Polanco, Professor David Walker, Dr Shalini Ojha, Professor Kavita Vedhara.
Introduction

We would like to invite you to take part in the Childhood Illness Perception (ChIP) study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. One of our research team will go through the information sheet with you and answer any questions you have. Please take time to read the following information carefully and discuss it with family members, friends or health professionals if you wish to.

We encourage you to ask us if there is anything that is not clear, or if you would like more information. Please take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

We would like to understand what the public know and believe about illnesses in babies and children, and in particular what they know and believe about cancer in children aged 0-18. We also want to understand where they find information about childhood illnesses, and who they go to for help or advice.

In order to do this, we want to talk to a small number of parents in a group setting that we call a focus group.

Why have I been invited to take part?

You have been invited to take part because you are a parent or carer of a child under 18 with childhood cancer or a bereaved parent or carer with childhood cancer experience. We want to hear your thoughts on childhood illness and the ways in which you find information about childhood illnesses and who you approach to help.

Do I have to take part?

It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you to answer any questions you may have. If you agree to participate, we will ask you to...
sign a consent form and will give you a copy to keep. However, you would still be free to withdraw from the study at any time, without giving a reason, by simply letting the research team know.

What will happen if I choose to take part?

If you decide to take part, we will ask you to join us for a focus group where there will be a discussion about the topic of childhood illnesses. There is no need for you to prepare anything beforehand. The focus group will last approximately 2 hours and will be face-to-face in Nottingham, although we may hold the meeting online if circumstances change due to the pandemic.

We will need to record the discussion. This is so we can listen back to your answers later to help us understand them better and help us recognise any themes between the answers you and other participants gave. We will also transcribe the recording into a written transcript so that we can easily read over the conversation.

If you are happy to take part, you will be asked to sign a consent form to confirm that you understand what is involved when taking part in this study. You will be given a copy of this information sheet and the consent form to keep.

What is a focus group?

A focus group is group discussion where the participants discuss a particular topic. It typically lasts between 1.5 and 2 hours and the group consists of between 6-8 participants. The person leading the focus group is called the moderator and they will ask some pre-prepared questions for you to discuss as part of the group. There will also be an observer present who takes notes.

What are the benefits of taking part?

There are no direct benefits for you taking part in the study. However, the information we get from this study will help us to shape the messaging for a new public awareness campaign which will empower parents with knowledge of childhood cancer symptoms. This will help ensure that children are diagnosed at the earliest possible opportunity.
Will my time/travel costs be reimbursed?

To thank you for taking the time to participate in the focus group, we will compensate you with a £30 voucher. We will also cover travel and food expenses for attending the focus group.

What are the possible disadvantages and risks of taking part?

You may be asked to talk about some of your own experiences of illnesses in your child that can be upsetting or difficult. If you do feel upset or worried, please talk to your research team who will direct you to support.

One possible risk is of participants disclosing personal information of another participant that they have heard in the focus group once the study is over. In order to reduce any potential risks, the researchers will remind participants to respect each other’s privacy and not repeat anything that has been discussed before the start of the study.

What happens to the study data?

We will keep all the information you give strictly confidential. This means that we will not let anyone else other than the researchers see the answers you gave. To help ensure your privacy, only first names will be used during the actual discussion, if at all. Once the focus group is over, the audio recording will be uploaded onto the University Automated Transcription Service (ATS). This is a fast and secure way to translate English-language audio files to text files and complies with General Data Protection Regulation (GDPR). Your data files are deleted from the ATS as soon as the transcription is complete.

The ATS will use a participant study identification number for you instead of your first name (e.g. P1). We will save all the recordings of the meetings and research data using that participant study identification number so that none of the written data will have your real name or identifiers. Your name and any information about you will not be disclosed outside the study centre.

The information will be secured electronically at the University of

The data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty to confidentiality to you as a research participant and we will do our best to meet this duty. All research data and records will be stored for a minimum of 7 years after publication or public release of the work of the research.

We would like your permission to use direct quotes (which will be anonymised) in research publications. We would like everyone who takes part in the focus group to feel it is a safe space to contribute their opinions and experiences. It is important that you keep what other participants say confidential and do not share this information outside of the focus group.

Although what you say to us is confidential, should you disclose anything to us that we feel puts you, your child or anyone else at risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I do not want to carry on with the study?

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason. Any personal data will be destroyed. If you withdraw from the study, we will no longer collect any information about you or from you but we will keep the anonymous research data that has already been collected and stored as we are not allowed to tamper with study records. This information may have already been used in some analyses and may still be used in the final study analyses.

Who will know that I have taken part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations (GDPR). Any audio digital recordings and electronic data will be anonymised as detailed above. 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 any paper information (such as your consent form, contact details and any research questionnaires) would be stored safely in lockable cabinets in a swipe-card secured building and would only be accessed by the research team.

Under UK Data Protection laws the University is the Data Controller who is legally responsible for the data security, and the Chief Investigator of this study (named above) is the Data Custodian who 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/

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

Due to the professional responsibilities of some University staff, if you mention something during the focus group which may require reporting, the research team will discuss it with you and decide on a course of action.

**What will happen to the results of the research?**

The results of this study will be written up as a part of one of the researcher’s PhD thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. It will also be submitted for publication in peer reviewed scientific journals to form an evidence base for healthcare professionals nationally and internationally. You will not be identified in any report or publication. It is hoped that the results will be used to guide further awareness campaigns to improve the time to diagnosis for children and young people with cancer in the future.

All published results of this study will be available for you to view on the Children’s Cancer and Leukaemia Group (CCLG) website (www.cclg.org.uk).
What will happen if I do not want to carry on with the study?

Your agreement to participate is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you decide you no longer want to take part in the study, we will keep the information that we have already obtained as we are not allowed to modify study records and this information may still be used in the final study analyses.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given xxx by the Faculty of Medicine and Health Sciences Ethics Committee.

Who is organising and funding the research?

The study is being organised by researchers at the University of Nottingham, together with the Children’s Cancer and Leukaemia Group (CCLG). The study is funded by The National Institute of Health Research (NIHR).

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher Dr Shaarna Shanmugavadivel, who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how he/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 08-0422.
You are encouraged to ask any questions you wish before, during or after the focus group.

If you would like to discuss the study further or would like more information, please feel free to contact us by email or telephone:

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General information and useful links regarding participation in clinical research is provided by the People in Research website: www.peopleinresearch.org/?o=1192