We would like to invite you to take part in the ‘Childhood cancer diagnosis’ 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 would like you to ask us if there is anything that is not clear. Take time to decide whether or not you wish to take part. You are welcome to keep this leaflet. Thank you for reading this.

What is the purpose of the study?
To make sure that children with a diagnosis of cancer have the best possible treatment and outcomes, we need to understand more about what happens before they reach their diagnosis.
In order to do this, we want to know what symptoms they experience, who they go to see with these symptoms and how long it takes from noticing their first symptoms to seeing the oncology team.

Why have I been invited to take part?
You are being invited to help us with this research because your doctors have diagnosed you with a type of childhood cancer.

We are inviting all children in the United Kingdom with a new diagnosis of cancer to take part. We want to understand what symptoms children have, how they get their diagnosis (e.g. GP or A&E) and the time it takes from first symptoms to seeing the oncology team.

Do I have to take part?
No. It is up to you.

If you decide to help us, we will ask you for your agreement, and your parents or carer will be asked to sign a form to say that they also agree to you taking part. You are free to change your mind at any time during the research without giving a reason. This will not affect the care you receive from your doctor.

What will happen if I choose to take part?
You do not need to do anything if you decide to take part.

You and your parents/carers have already given us the information we need, when you first met your oncology doctors. These questions are normally asked to all children at this time and your doctors have already noted down the answers on a form for us.
If you choose to take part in this study, the form will be passed on to us (the research team) so that we can look at the answers.

**What are the benefits of taking part?**

We cannot promise the research will help you, but the information we get might allow us and other researchers to identify any areas where the pathway to diagnosis of cancer can be improved. Any change made as a result of this information will hopefully improve other children and young peoples’ experiences of diagnosis in the future.

**What are the possible disadvantages and risks of taking part?**

There are no specific risks or disadvantages if you take part.

**What happens when the research study stops?**

Your treatment and care will continue as normal.

**What if there is a problem?**

We take any complaint you may have very seriously. Any complaint about the way you have been treated during the study will be investigated fully.

**Will anyone else know about me taking part?**

Your information will be treated in the strictest confidence. Only doctors and researchers who need to know or have the right to know will see your details. Wherever possible, we will remove your name and address before we send out information.
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. The study is funded by The National Institute of Health Research (NIHR).

Who has reviewed the study?
This study has been reviewed and given favourable opinion by Yorkshire & The Humber - Leeds West Research Ethics Committee.

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

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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