

Being active after childhood cancer

We would like your help to develop new ways in which we can support young people who have had cancer or a brain tumour to be more physically active

- **Before you decide if you would be happy to help us with our study, we would like you to understand why the research is being done, what we hope to achieve and what you would be invited to do if you joined us.**

WHAT IS THE STUDY ABOUT?

- Physical activity is very beneficial for our health and wellbeing.
- In the UK it is recommended that young people aged 5-18 years old should try to do 60 minutes of physical activity every day. For adults aged 19 years and over it is recommended that they try and do at least 150 minutes of moderate intensity activity (e.g. brisk walking, cycling) or 75 minutes of vigorous intensity activity (e.g. running, sport, taking the stairs) a week; as well as this, they should do strength building activities (e.g. yoga, gym) on at least 2 days.
- However, we know that young people who have had a cancer or a brain tumour often struggle to keep physically active. Several studies have shown that many of these young people are often less active than other young people who have not had cancer or a brain tumour.
- We have already spoken, in detail, to approximately 30 young people who have had cancer or a brain tumour, and 20 of their parents. We asked the young people how they felt about physical activity and whether it was something they were interested in doing. We also asked them to talk about the reasons they struggled to do physical activity, and what things they felt helped, or would help, to keep them active.
- The people who took part in our study gave us lots of really useful and interesting information.

We now want to use this information to try and find ways in which we can encourage and help survivors of childhood cancer and brain tumours to be more physically active.

We would like your help with this.

WHY HAVE I BEEN INVITED TO TAKE PART?

- You are being invited to take part either because you are a young person who has had a cancer or a brain tumour, or you are a parent of a child who was affected.
- We are also inviting healthcare professionals to work with us in this part of our research.



SO WHAT IS THE STUDY AIMING TO DO?

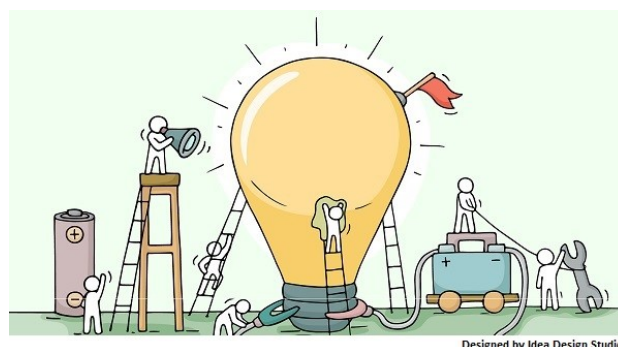
- The study aims to develop a physical activity “intervention” for young people who have had a cancer or a brain tumour. By physical activity intervention, we mean something which we can provide for young people to help encourage and support them to engage in regular physical activity which will be beneficial for their health.
- Without involving people like you, we won't know what type of ‘intervention’ young people who have had cancer or a brain tumour, and their parents, would be interested in and would be mostly likely to use.
- With your help we will be able to find out the best way we can talk to young people and their parents about physical activity and how best to encourage them to be active. We will also be able to find out whether they think the intervention should involve a healthcare professional (e.g. doctor or nurse or someone else), and what the intervention might involve (e.g. whether they would like something they can access on their smartphone, tablet or computer).

WHAT DOES TAKING PART IN THE STUDY INVOLVE?

There are 3 ways in which you could be involved in the study:

- 1. Take part in a workshop with other people and the research team**
- 2. Take part in a one-to-one or small group interview with the researcher**
- 3. Take part in an online group**

- However you decide you would like to take part, we want it to be an informal, fun, interactive and creative experience. We will all work together to brainstorm, share and build on ideas about what may help young people who have had cancer or a brain tumour to be more active.



- During the study, we will ask for your views. To help you think about the issues, we will share with you what we have found out so far in our research. We will also provide some options and ideas of possible interventions and ask you to comment on them e.g. do you think they could work? are they interesting? would you use them? what are they missing? how could they be better?
- There will be no right or wrong answers—we just want to know the views and ideas of different people.
- More information on these workshops, interviews and online groups is over the page.



WHAT DOES TAKING PART IN THE STUDY INVOLVE?

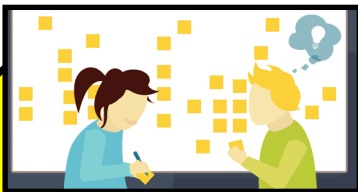
- Below we describe the 3 ways you could be involved in the study.
- You are welcome to take part in one or more of the options. These will run until December 2020.
- For each option, you may be sent some information for you to look at and think about before-hand.
- You will not be expected to contribute to all parts of the activities or discussions, unless you feel comfortable and happy doing so.

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Workshops



- We will hold a series of small workshops. If we are able to hold face-to-face workshops, they will be held in Newcastle and Leeds in a city centre location. If face-to-face workshops are not possible, they will be held online. We may ask to audio and video record parts of these workshops, or ask to take photographs. You will be asked if you are happy for us to do this.
- Each workshop may include survivors, parents, healthcare professionals and researchers. If you are a survivor, you will be asked whether you would prefer to go to a workshop just for young people.
- These workshops may last around 2 hours. However, if you become tired, and have to leave early, that's ok. We will arrange the workshops for a date and time which suits most people.
- **We will provide food and drinks and you will receive £30 for your time.**



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Interviews

- We will offer one-to-one or small group (of 2-3 people) interviews.
- Again, these could be face-to-face, online or over the phone.
- These may last around one hour and we will ask to audio-record what is said.
- **You will receive a £20 voucher for taking part in an interview.**

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Online groups



- We will be setting up online groups using platforms such as WhatsApp and Facebook.
- These groups will be closed groups so only the members of the groups can see what is posted.
- We will post images, videos, and questions online and will ask people for their views. People will also be welcomed to post and share their own ideas.
- **You will receive a £20 voucher for contributing to one of these groups.**



DO I HAVE TO TAKE PART?

- No, it is entirely voluntary.
- If you (or your child) are a patient at the Great North Children's Hospital or Leeds Children's Hospital and do not want to be involved, this will not affect any care you (or your child) receive, or your/their legal rights.
- If you decide to take part, and then later change your mind, that is ok. You also do not have to give a reason. However, we may still use any information you have given us up until that point.

WILL THERE BE ANY BENEFITS OR RISKS FROM ME TAKING PART?

- You may find that you develop new skills. This could be particularly useful for young people and we will be happy to give you a certificate of participation which may be useful for job and UCAS applications.
- It may also give you an opportunity to use skills you already have (e.g. art, design). However, you certainly do not need these skills to take part.
- It could give you an opportunity to meet others with a shared experience and interest.
- Personally, you may find it rewarding or interesting to contribute to, and learn more about, research.
- It is also a chance for you to share your views on physical activity and what you think would help young people.
- If you are interested, there will be opportunities for you to help us to tell people about our study, what we found and how you helped. This could be through assisting us to write social media posts, by helping us writing an article about the study, or even attending a conference with us.
- We do not expect there to be any harm from you taking part. However, if you find taking part brings up issues which you/your child finds upsetting and you wish to talk to someone, you will be asked to contact you/your child's consultant oncologist/haematologist or GP.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

- This study will help us to understand how young people can be helped to be physically active after having a cancer or brain tumour.
- The study will produce an intervention which aims to promote and support physical activity to young people who have had a cancer or a brain tumour.
- Results of the study will be published in a medical journal and presented at conferences.
- This intervention will then be tested in a future study so we can understand if what we have developed will actually help young people to be more active.

WHO HAS APPROVED AND FUNDED THIS RESEARCH?

- This study has been approved by an NHS Research Ethics Committee. The study has been funded by a grant from the Children's Cancer and Leukaemia Group, a children's cancer charity.



WILL MY TAKING PART BE KEPT CONFIDENTIAL?

- Yes, your information will be kept strictly confidential.
- If you take part in a workshop or interview it will be audio-recorded, typed up and anonymised (this means you will not be identifiable). The anonymised transcript from the workshop you take part in, will be kept on a password-protected desktop computer in a secure university building and will be stored for five years. Any information you share on an on-line group will also be confidential and will only be viewable by other members of the group. If we use any comments you have made in this group, these will be anonymised also. If we audio-record a workshop, only the researchers will have access to this.
- Your personal details will also be stored securely and will only be kept for up to 12 months after the study has ended. This is so we can send you a summary of what we find out from the study.

WHAT IF I HAVE CONCERNS OR A COMPLAINT ABOUT THE STUDY?

- If you are unhappy with any aspect of the study and you would prefer to raise your concerns with someone not involved in your child's care, you can contact the Patient Advice and Liaison Service (PALS). This service is confidential and can be contacted on: **Freephone** 0800 032 0202.
- If you wish to make a formal complaint, you can do so on any of these details:
- For Newcastle upon Tyne Hospitals NHS Foundation Trust: **Telephone:** 0191 223 1382 or 0191 223 1454 **Email:** patient.relations@nuth.nhs.uk **Address:** Patient Relations Department, The Newcastle upon Tyne Hospitals NHS Foundation Trust, The Freeman Hospital, Newcastle upon Tyne, NE7 7DN.
- For Leeds Teaching Hospitals Trust: **Telephone:** 0113 206 6261
Email: patientexperience.leedsth@nhs.net

WHAT SHOULD I DO IF I AM INTERESTED IN TAKING PART?

- **If you have any questions or are interested in taking part, please contact the researcher for the study, Morven Brown on:**

Telephone/Text/WhatsApp: 07814 736 929

Email: morven.brown@ncl.ac.uk



- **You can also access more information about the study and the research team on our website: research.ncl.ac.uk/beingactive**

Thank you for taking the time to read this information.

- If you wish to speak to someone not involved in the research team about taking part in research in general, please contact Professor Simon Bailey (Consultant Paediatric Oncologist at the Great North Children's Hospital). **Email:** simon.bailey@ncl.ac.uk or Julie Evans (Senior Research Nurse at Leeds Children's Hospital) **Tel:** 0113 392 2159.

PRIVACY NOTICE

You may have read or heard about the General Data Protection Regulation (GDPR) which came into law in the UK in May 2018. The GDPR aims to protect your personal data and because of this we need to be clear with you about how we will use your personal data, and what your rights are.

Newcastle upon Tyne Hospitals NHS Foundation Trust (NuTH) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. NuTH will keep identifiable information about you for up to 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at http://www.newcastle-hospitals.org.uk/about-us/freedom-of-information_how-we-use-information.aspx or by contacting the Data Protection Officer for NuTH via email: nuth.dpo@nhs.net.

Newcastle University will collect information from you for this research study in accordance with our instructions.

Newcastle University will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from NuTH and regulatory organisations may look at your research records to check the accuracy of the research study. Newcastle University will pass these details to NuTH along with the information collected from you (this may include anonymised transcripts of the workshop or interview you attended). The only people in NuTH who will have access to information that identifies you will be people who need to contact you about your participation in the study or to audit the data collection process.

Newcastle University will keep identifiable information about you from this study for up to 1 year after the study has finished.

When you agree to take part in a research study, the information provided by you may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you. It will not be used to make decisions about future services available to you.