

## BEING ACTIVE AFTER SARCOMA

*Understanding how we can support young people to be physically active after sarcoma*

You are being invited to take part in our study

Before you decide whether you would be happy for your child to take part in our study, we would like you to understand why the research is being done, and what it would involve for you and your child.

We have also included information sheet for your child, we would really appreciate it if you took the time to talk with your child about the study.

### What is the study about?

We are doing a study about physical activity after having a sarcoma.

Physical activity refers to all movement. Ways to be active include walking, running around, going for a bike ride, swimming and playing a sport. Household chores which require physical movement, such as vacuuming, also count as physical activity.

Some young people who have had a sarcoma struggle to do physical activity. We would like to speak with your child about their views and experiences of physical activity.

We would like to talk to them regardless of how physically active they are.

### Why has my child been invited to take part?

Your child been invited as they:

- are aged between 10-15 years old
- have in the past received treatment for a sarcoma
- are 2-15 years from the end of your treatment


### Does my child have to take part in the study?

No, it is voluntary. If you do not want your child to be involved, or your child does not want to take part, that is ok. This will not affect any of the care your child receives from their healthcare team.

## What will my child be asked to do if they take part?

Your child will be asked to speak with a researcher, Liz from Newcastle University. For younger children, this could be at your home or another place of your choosing. For older children (e.g., those aged 15 years old) it may be possible for them to speak to Liz online (e.g., on Zoom). Please discuss with Liz what you and your child would prefer.

### Liz will ask your child about:

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- their views and experiences of physical activity
  - their views on things which make it harder for you to be active, or which perhaps make it easier for you
  - their views on the information and advice that is given about physical activity to young people who have had sarcoma

There will be no wrong or right answers - we are just interested in your child's views and experiences.

Before the interview, both you and your child will be asked if you are happy to proceed. You will be asked if you would like to be present during the interview. We will also ask your child's preference.

This discussion ("interview") with Liz will take around 45-60 minutes, depending on the age of your child and their wishes.

If your child agrees, the interview will be recorded.

**As a thank you for their time, your child will be offered a £20 shopping voucher.**

## What if my child decides they don't want to be involved anymore?

Your child is free to withdraw from the study at any time, even in the middle of an interview. If they decide to withdraw, they/you do not have to give any explanation for their decision. However, any information they provide us up until that point may still be used in the study.

## Who is organising and conducting the study?

The study researchers are from Newcastle University. Newcastle University is also the sponsor for this study.



Dr Morven Brown is the study lead for Newcastle University (telephone 0191 208 2282; email [morven.brown@newcastle.ac.uk](mailto:morven.brown@newcastle.ac.uk)).



Liz Pharoah is the Newcastle University researcher for the study. She is working with the healthcare professionals in the NHS Trusts and will be carrying out the interviews.



## How can I get more information or let someone know that my child would like to take part?

You can contact Liz by:



**Phoning:** 07350 434251



**Texting or WhatsApping:** 07350 434251



**Emailing:** [liz.pharoah@newcastle.ac.uk](mailto:liz.pharoah@newcastle.ac.uk); or scan this QR code to send an email



If you prefer, you can also ask someone in your child's hospital team to pass your contact details on to us, and we will contact you.

For more information about the study please see our website:  
<https://research.ncl.ac.uk/beingactive/>

Or scan the QR code to take you directly to the study website:



## What happens with the information my child gives to you?



Audio-recordings of interviews will be stored in a secure location and only the researchers will have access to them. The recordings will be transcribed either by research staff at Newcastle University or by an external company that we work with. These transcripts will be anonymised - that means they will not contain your/your child's name or personal details, and no-one will be able to identify you, or anyone else, from anything that you have said. We will also not tell your healthcare team anything that you/your child has said to us.



Confidentiality can only be broken without consent in very exceptional circumstances. These circumstances are only if the researcher has seen or is told something that raises concerns about your child's safety or the safety of others.

Audio-recordings will be deleted when the transcripts have been analysed. The anonymous transcript of your child's interview will be analysed together with the interviews from other young people taking part in the study. The anonymised transcripts will be held for a maximum of 10 years after the end of the study.

All information collected about your child will be kept strictly confidential and we will only collect and keep information necessary for the study. This information, as well as the audio-recording and transcripts will be stored using a study ID number, and not under your name.



Your personal details (e.g., name, email address) will be securely stored (on a secure cloud server used by Newcastle University) and destroyed after we have completed the analysis and sent you/your child a summary of the study findings (if you would like to receive this).



## What will happen with the results of the study?

The results will help us to understand how young people who have had a sarcoma think and feel about physical activity, and how they can be better supported.

The results will be presented at conferences, published in a medical journal (no-one will be able to identify you in any of these presentations or reports).

We may also use the anonymous transcripts in student projects, or share them with researchers working with us. However, you will not be identifiable in anything we share.

## What are the benefits or risks of taking part?

Taking part will enable your child to share their views on being active after their illness, and let us know how we can help.

We do not expect there to be any harm from your child taking part. However, if your child finds taking part in the study upsetting and wishes to talk to someone, you will be asked to contact your child's healthcare team.

## What if I have concerns or want to make a complaint about the study?

If at any time, you are concerned about any aspect of this study, you should speak to the researcher directly, or contact the study lead using the details provided in this leaflet.



If you were approached to take part in the study by your cancer team, you may contact one of your doctors or nurses to discuss this and you may also complain formally about the study, through the Patient Advice and Liaison Services (PALS). Free Phone 0800 032 0202, website: <http://www.pals.nhs.uk/>

## Who has approved and funded this study?



This study has been approved by an NHS Research Ethics Committee (REC reference: 24/PR/1188).

The study has been funded by a grant from Sarcoma UK.



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

**Please read on if you would like further details on how we will use the information about your child.**

## Privacy notice - how will we use information about you?

We (Newcastle University – the Sponsor for the study) will need to use information from your child’s medical records for this research project.

This information will include your child’s:

- name
- date of birth
- contact details
- diagnosis
- date of diagnosis
- treatment received (e.g., chemotherapy, radiotherapy, surgery)
- date of end of treatment

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you/your child are will not be able to see your child’s name or contact details. Your child’s data (e.g., transcript of their interview) will have a study ID number on it, instead of their name.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child took part in the study.

## What are your choices about how your information is used?

Your child can stop being part of the study at any time, without giving a reason, but we will keep information about them that we already have. We need to manage your child’s records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about your child. If your child agrees to take part in this study, they will have the option to take part in future research using their data saved from this study.

## Where can you find out more about how your information is used?

You can find out more about how we use your child’s information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- by asking one of the research team
- by emailing the Data Protection Officer for Newcastle University at [rec-man@newcastle.ac.uk](mailto:rec-man@newcastle.ac.uk)