

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 to take part in our study, we would like you to understand why the research is being done, and what it would involve.

What is the study about?

Physical activity refers to all movement. Ways to be active include walking, cycling, sports and active recreation. Jobs or household chores which require physical movement also count as physical activity.

Some people struggle to do physical activity, and we would like to know what we can do to help young people be active after they have had a sarcoma.

We would like to speak with you about your views and experiences of physical activity.

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

Why have I been invited?

You have been invited as you:

- are aged between 10-24 years old
- have in the past received treatment for a sarcoma
- are 2-15 years from the end of your treatment

Do I have to take part in the study?

No. It is up to you whether you want to take part or not. If you do not want to be involved, this will not affect any of the care you receive from your healthcare team.

What will I be asked to do if take part?

You will be asked to speak with Liz, a researcher from Newcastle University.

Liz will ask you about:



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

There will be no right or wrong answers, we are just interested in your own views and experiences.

This discussion (“interview”) will take around 60 minutes, or as long as you like. Interviews will be audio-recorded.

You can choose how you would like to talk to Liz and whether it is:



- at your home, Newcastle University, another place of your choice



- on the phone



- or via video-conferencing (e.g., Zoom)

As a thank you for your time, you will be offered a £20 high street shopping voucher and reimbursement for any travel costs.



What if I decide I don't want to be involved anymore?

You are free to withdraw from the study at any time, even in the middle of an interview. If you decide to withdraw, you do not have to give any explanation for your decision. However, any information you 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).



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 I would like to take part?

You can contact Liz by:



Phoning 07350 434251



Texting or WhatsApping: 07350 434251



Emailing: liz.pharoah@newcastle.ac.uk; or scan this QR code to send an email



If you prefer, you can also ask someone in your 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 I give 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 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 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 safety or the safety of others.

Audio-recordings will be deleted when the transcripts have been analysed. The anonymous transcript of your interview would be analysed together with the interviews from other 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 you 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 will be securely stored (on a secure cloud server used by Newcastle University) and destroyed after we have completed the analysis and sent you 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 of taking part?

Personally, you may find it rewarding or interesting to contribute to, and learn more about, research. You may also get satisfaction from knowing that you are contributing to research which could help better understand the needs of young people who have been treated for a sarcoma.

Are there any disadvantages of taking part?

We do not expect there to be any harm from you taking part. You will not be expected to talk about anything you are not comfortable with. If there is anything you feel uncomfortable sharing with the researchers, then you are free not to answer. You can also take a break or stop entirely at any point during the interview.

If you find talking about your health upsetting, or the interview raises questions for you, we will provide you with details of who you can contact for help after the interview.

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 you.

Privacy notice - how will we use information about you?

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

This information will include your:

- 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 are will not be able to see your name or contact details. Your data (e.g., transcript of your interview) will have a study ID number on it, instead of your 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 you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your 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 you. If you agree to take part in this study, you will have the option to take part in future research using your 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 information

- at 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