

Developing a decision aid for Hodgkin lymphoma survivors considering having a lung cancer screening test

Participant Information Sheet (PIS)

You are being invited to take part in a research study.

The aim of the study is to see what people think of an information booklet we have developed. The information booklet is to help people treated for Hodgkin lymphoma to decide whether to have a lung cancer screening test.

This study is part of a researchers PhD degree.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➤ Who will conduct the research?

Dr Rachel Broadbent is conducting this research. She is affiliated with The University of Manchester (Division of Cancer Sciences) and works at The Christie NHS Foundation Trust.

➤ What is the purpose of the research?

We have written an information booklet to invite people treated for Hodgkin lymphoma to have a lung cancer screening test. The aim of the booklet is to provide information about the test which helps people make a decision whether to have it or not. The purpose of the study is to find out if the information in the booklet can be understood by Hodgkin lymphoma survivors

and is acceptable to them. We hope that around 70 other people will take part in the study.

➤ **Will the outcomes of the research be published?**

The results of the study will be published as in a thesis and in a journal.

We do not plan to contact participant to tell them about the findings.

➤ **Who has reviewed the research project?**

The study has been reviewed by The University of Manchester Proportionate Research Ethics Committee.

➤ **Who is funding the research project?**

- The Christie Charity
- The NIHR Patient Safety and Translational Research Centre
- The NIHR Biomedical Research Centre.

What would my involvement be?

➤ **What would I be asked to do if I took part?**

Complete an online survey

Read an information booklet and complete a survey, all online. There will be some questions about yourself such as your age, gender, ethnicity and your level of education.

This should take 30-40 minutes.

AND / OR

Take part in an online focus group

Take part in an online focus group using Zoom. There will be up to 10 other Hodgkin lymphoma survivors, one researcher and one lymphoma nurse specialist on the call. The focus group will take 30-40 minutes. It will be audio recorded, but videos will not be recorded. You will be sent the booklet to read before the focus group, then the focus group will be asked what they think about it.

The main disadvantage is that this will take up some of your time.

Some people might find it upsetting to think about cancer. We will direct you to resources for more support and information.

This study does not involve any treatments and we will not be accessing your medical records or contacting your GP.

➤ **Will I be compensated for taking part?**

After completing the online survey or taking part in the focus group you will be given a £30 voucher to spend at a number of UK high street stores.

If you participate in *both* the survey and the focus group, you will receive two £30 vouchers, one for each activity. Voucher/s will be sent to you by email.

➤ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part.

If you want to take part, click the survey link in the advert. If you want more information first, contact Dr Rachel Broadbent by email:

Rachel.broadbent-2@postgrad.manchester.ac.uk

If you do decide to take part you can keep this information sheet.

If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

Data Protection and Confidentiality

➤ **What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically we will need to collect:

For the focus group only:

- Your name (for the focus group only)

For the survey and the focus group:

- gender
- age
- ethnicity
- level of education.
- Your email address (optional but required to send you the £30 voucher)

The audio recording of the focus group will be voice only (no images).

➤ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

➤ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).

• **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

For the focus group only:

- You will need to provide your name on the consent form. Your consent form will be securely stored for 5 years.

For the survey and the focus group:

To claim your £30 voucher, you will need to provide your email address. Your email address will be linked to a random study ID number only known to the research team (known as pseudonymised).

Only the study team at The University of Manchester will have access to your study ID and email address, but they will anonymise it as soon as possible. Only the research team will have access to the key that links this ID number to your personal information (email address). This information will be stored securely on University of Manchester computers.

Your email address and study ID number will only be stored until you have been sent your £30 voucher. After that, your data you provided in the survey will be anonymised and kept for a period of 5 years.

We will not share any of your personal data with any other organisations.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

The audio recording of the focus group will be transcribed by an external University of Manchester approved supplier. The audio recording will not contain any information that could identify you. Only the researchers will have access to the transcripts.

What if I have a complaint?

If you have a complaint that you wish to direct to members of the research team, please contact:

Dr Kim Linton:

Email: kim.linton@manchester.ac.uk

Phone number: 0161 4463753

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#) Tel 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researcher:

Dr Rachel Broadbent

Rachel.broadbent-2@manchester.ac.uk

To get more information or support:

1. Speak to your GP
2. Seek advice and support from Lymphoma Action- they are aware of this study
 - via their website <http://lymphoma-action.org.uk>
 - or their free helpline 0808 808 5555 Monday to Friday 10am-3pm

- a live chat option is available via the 'Contact Us' section of the website
- 3. Cancer Research UK www.cancerresearchuk.org
- 4. Macmillian Cancer Support
www.macmillian.org.uk