A research study exploring how adults aged 65 years or older with a new diagnosis of lymphoma make decisions about their treatment

Participant Information Sheet (PIS)

Invitation

You are being invited to take part in a research study. The purpose of the study is to find out how older people who have been diagnosed with lymphoma make decisions about their treatment. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information. Ask questions if anything you read is not clear, or you would like more information.

What is the purpose of the study?

The purpose of the study is to find out how older people who have been diagnosed with lymphoma make decisions about their treatment. Understanding your experiences will help healthcare workers tailor the necessary assessments, information and support to provide the best care for older adults with lymphoma in the future.

Why have I been invited?

You have been chosen as you have recently had a new diagnosis of lymphoma, you are 65 years or older and you are receiving chemotherapy or chemotherapy has been recommended for you.

Do I have to take part?

No, you do not have to take part. Your participation in this study is entirely voluntary. If you decide not to take part or withdraw from the study, it will not affect the care you receive. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you agree to take part, more details about the study will be provided and you will be given the opportunity to ask further questions. You will then be asked to sign a consent form indicating your agreement to take part in the study.

The study involves a conversational interview either using a video platform that is available for you to use (such as Skype or Facetime) or on the telephone, lasting around 45-60 minutes. This will take place within 3 months of starting your lymphoma treatment. You will be contacted by the researcher to arrange a mutually convenient day and time for the interview to take place. If on the day of the planned interview you do not feel well enough for the interview to place, the researcher will rearrange the interview with you for a different day.

The interviews will be recorded on an audio recording device. The researcher will have a simple interview guide of questions, but the interview will be mainly led by your own experiences.

Expenses and payments?

There are no expenses or payments available to participants for this study.

What are the possible disadvantages and risks of taking part?

During the course of the research interview it is possible that unpleasant memories or feelings may arise as a result of talking about this subject area. The researcher undertaking the interviews is an experienced lymphoma nurse with skills and training to provide emotional support, should it be required. There will also be an opportunity after the interview to discuss any issues raised during the interview. You can choose to stop the interview at any time. Information about organisations that can provide ongoing support will be provided by the researcher. The researcher may also ask for your permission to contact your clinical nurse specialist to ask them to provide you with support if needed.

What are the possible benefits of taking part?

The study does not intend to benefit you individually. However, it is possible that exploring how you made your personal treatment decision may benefit you in making any future decisions about your treatment or care. In addition, the information gained from the study will help to improve the care provided to older adults with lymphoma in the future, by increasing our understanding of how treatment decisions are made.

What if there is a problem?

If you have a concern or complaint about any aspect of this study, in the first instance you should ask to speak to the researcher, Jane Gibson, who will do her best to answer your questions. If you do not wish to contact the researcher or if you remain unhappy and wish to complain formally you can do this by contacting the research supervisor, Dr Deborah Robertson. If the matter is still not resolved, please forward your concerns to the Chair of the University of Salford Health Research Ethical Approval Panel. Contact details are provided on page 4.

How will we use information about you?

We will need to use information from you and from your medical records for this research project. This information will include your

- name
- NHS number
- date of birth
- gender
- your type of lymphoma
- date of lymphoma diagnosis
- treatment start date
- contact telephone number
- contact email address (if you have an email address)

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, NHS number, date of birth or contact details. Your data will have a code number instead. 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.

To keep you or others safe, if you reveal anything during the course of the study related to criminal activity and/or something that is harmful to you or others, the researcher will have to share that information with appropriate authorities.

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 Jane Gibson
- by sending an email to D.A.F.Robertson@salford.ac.uk or
- by ringing us on 07742885479

What will happen to the results of the research study?

The results of the study will be used to educate healthcare practitioners who are involved in the care of older adults with lymphoma. This will be done at relevant health and educational meetings and conferences. The results will also be presented to relevant patient organisations such as Lymphoma Action patient charity. The research will be also submitted for publication to relevant medical and/or nursing journals. You will be asked if you would like to receive a copy of a written summary report when the study has been completed. You will not be identified in any report or publication unless you have given your consent.

Who is organising or sponsoring the research?

This is a Professional Doctorate research study being undertaken by Jane Gibson. The research is being sponsored by The University of Salford. Any reference to 'we' in this participant information sheet relates to the research sponsor.

If you would like to take part in this study

Please telephone Jane Gibson on 07742885479 or email j.gibson3@edu.salford.ac.uk

Further information and contact details

You are encouraged to ask any questions you may have about this study. If you have any questions, please speak to Jane Gibson.

Specific information about this research project, please contact

Jane Gibson, Lymphoma Nurse Clinician
The Christie NHS Foundation Trust
Wilmslow Road
Manchester
M20 4BX
Tel: 07742885479 Email: j.gibson3@edu.salford.ac.uk

If you are unhappy with the study, please contact

Dr Deborah Robertson, Research Supervisor
Mary Seacole Building
Frederick Road Campus
University of Salford
Salford
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Tel: 0161 295 4985Email: D.A.F.Robertson@salford.ac.uk

If the matter is still not resolved, please contact

Professor Andrew Clark
Chair of the Health Research Ethical Approval Panel
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