

## **PARTICIPANT INFORMATION SHEET FOR FAMILY MEMBERS**

### **NAME OF THE RESEARCH STUDY**

'An investigation of the process of Radiotherapy as perceived by people with a Learning Disability who have cancer, their family members, paid carers, and the professionals that support them: A Constructivist Grounded Theory Study'.

IRAS ID 324949



### **AN INVITATION**

My name is Charlotte Nutting. I am a PhD student at Sheffield Hallam University (England) and La Trobe University (Australia). I am a registered Learning Disability Nurse and Social Worker in England. I would like to invite you to take part in an interview for the above-named study which I am conducting.

### **ABOUT THE RESEARCH STUDY**

The aim of the study is to explore multiple stakeholder perspectives and processes involved in Radiotherapy decision making, treatment and post-treatment support in England and Australia for people with Learning Disabilities who have cancer.

The study will explore:

- how people with Learning Disabilities are currently involved in treatment decision making when Radiotherapy is advised, and how they are supported by family members, paid carers, and health care, social care and medical professionals.
- the Radiotherapy experiences of people with Learning Disabilities, and the perceptions of family members, paid carers, and health care, social care and medical professionals who support them.
- how people with Learning Disabilities are currently supported when they have completed Radiotherapy, and the role of family members, paid carers, and health care, social care and medical professionals.
- factors that would optimise the process of Radiotherapy decision making, treatment and post-treatment support involving people with Learning Disabilities who have cancer.

The study objective is to develop a framework to optimise Radiotherapy decision making, treatment and post-treatment support involving people with Learning Disabilities who have cancer, as the basis for the development of practice guidelines.

Before deciding whether to get involved, it is important you understand how and why the interviews are taking place. Please read the information in this document and contact me if you have any questions. Thank you.

### **WHY HAVE YOU ASKED ME TO TAKE PART?**

You are invited to take part in an interview if you are a family member who has supported an adult who has a Learning Disability and cancer with Radiotherapy decision making, and/or treatment, and/or post-treatment support in England in the last five years.

### **DO I HAVE TO TAKE PART?**

No. You can decide whether you would like to take part in an interview. If you would like to take part, you will be asked to formally consent to an interview on the day the interview is scheduled. If the person you support would also like to take part in an interview, I would ask for their consent so I can interview you. If you take part in an interview but change your mind about being part of the study, you can withdraw up to ten days after the interview without giving a reason and I will not use your interview data.

### **HOW WILL YOU USE THE INTERVIEW INFORMATION?**

I will recruit and interview approximately 10 family members, paid carers, and social care professionals, 15 people who have a Learning Disability and cancer, and 10 healthcare and medical professionals. Interview data will be analysed and findings from the study will be used to develop a framework to optimise Radiotherapy decision making, treatment and post-treatment support in England and Australia involving people with Learning Disabilities who have cancer.

Study findings will be published in an international academic journal and will be presented at Oncology and Learning Disability conferences. Additionally, an accessible report will be made available via the Down's Syndrome Association and Learning Disability England. Study findings will also be presented to healthcare and social care students at Sheffield Hallam University and La Trobe University, and medical students at La Trobe University.

Your name or any other information that could identify you and others will not be used in the journal article, report or presentations. A selection of non-identifying quotes from interviews will be used to illustrate and illuminate what interview participants said. I will use pseudonyms instead of participants' real names in all the study documents, and you can choose your pseudonym.

### **WHAT WILL HAPPEN IF I TAKE PART?**

Interviews can be conducted in your home, in a private space in a community venue that you are comfortable and familiar with, or virtually using Zoom or Microsoft Teams. Zoom and Microsoft Teams are online video conferencing applications which can be accessed free using a smartphone, a computer, or a laptop. You can decide whether you would like to be interviewed in person or virtually. If you'd prefer a virtual interview, you can decide whether we use Zoom or Microsoft Teams. Likewise, you can choose a time and date that is convenient for you.

We will plan a time and date for your interview. If you choose a virtual interview, I will email you a Zoom or Microsoft Teams link so you can join the virtual interview from your smartphone, computer or laptop. You will need to be in a quite private space for a virtual interview. I will also be in a quite private space during virtual interviews.

Before we start the interview, I will talk through the Consent Form with you to formally seek your consent to participate in an interview. If the interview is in person, we will fill out a Consent Form. If the interview is virtual, I will talk through the Consent Form with you which will be audio recorded using an encrypted device and transcribed using Zoom or Microsoft Teams.

I will then interview you which will involve asking you questions about Radiotherapy decision making, treatment and post-treatment support involving your family member. There are no right or wrong answers to the questions, and you do not need to answer all the questions I ask. As part of the interview you may decide to show me or share anonymised documents that you feel are relevant to Radiography involving people with Learning Disabilities, for example, a patient information leaflet. The interview will last up to 60 minutes.

Confidentiality may be breached if during an interview a participant disclosed or implied a Safeguarding concern. In this instance, I would contact the study's Chief Investigator after the interview and follow Sheffield Hallam University's Vulnerable Participants and Safeguarding guidance.

### **WILL THE THINGS I SAY BE RECORDED?**

Yes, the interview will be audio recorded using an encrypted device. Virtual interviews will also be transcribed using Zoom or Microsoft Teams. The audio recorder and the Zoom or Microsoft Teams transcription function will not be turned on without you knowing and without your consent.

### **WHAT WILL HAPPEN AFTER THE INTERVIEW?**

The audio recording will be downloaded from the encrypted device to the site file in the secure study folder on Sheffield Hallam University's network. The audio recording will then be deleted from the encrypted device. The Zoom or Microsoft Teams transcript of the interview will be saved as a Word document in the secure study folder on Sheffield Hallam University's network. The transcript will be checked for accuracy against the audio recording. All names and any identifying information will be removed from the transcript. Any anonymised documents you choose to share will also be saved in the secure study folder on Sheffield Hallam University's network. The transcript and any documents shared will then be analysed.

In the six months following your interview I may contact you to invite you to participate in a shorter second interview. The follow-up interview will provide an opportunity to explore categories and concepts that have emerged in the study to date relative to Radiotherapy involving your family member. The second interview will last up to 30 minutes and can be in person or virtual using Zoom or Microsoft Teams. You can decide whether you would like to take part in a second interview, and a separate Consent Form would be completed.

### **ARE THERE ANY RISKS IN BEING INTERVIEWED?**

We do not anticipate any risks to being interviewed. However, if you did find aspects of the interview topic upsetting, we can stop at any time, and you can decide whether you would like to continue the interview or

not. If you feel upset after the interview, you might choose to seek support from a member of your support network.

### WHAT WILL I GET OUT OF IT?

You may welcome the opportunity to talk about and reflect on your experience and involvement supporting your family member with Radiotherapy decision making, treatment and/or post-treatment support. Additionally, your contribution will support the development of a framework to optimise Radiotherapy decision making, treatment and post-treatment support in England and Australia involving people with Learning Disabilities who have cancer.

### HOW LONG WILL THE PROJECT LAST?

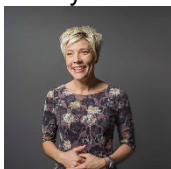
The project will take up to eighteen months to complete. Your interview will last up to 60 minutes and may be followed by a second interview that will last up to 30 minutes and will be within six months of the first interview.

### WHAT WILL HAPPEN TO THE INTERVIEW INFORMATION WHEN THE PROJECT HAS FINISHED?

We will securely destroy the audio interview recording and your contact details. The site file; containing pseudonymised transcripts and audio recordings of consent, will be placed in a long-term, secure archive facility at Sheffield Hallam University. All research study documents will be destroyed ten years after the end of the study.

### WHO CAN I SPEAK TO IF I HAVE ANY QUESTIONS?

If you have any questions about the interview or the research study, you can contact me. Please also contact me if you would like to take part in an interview:



**Charlotte Nutting:**

Email: [c.nutting@shu.ac.uk](mailto:c.nutting@shu.ac.uk)

Telephone: +44 (0) 114 225 5989

### WHICH ORGANISATION IS RESPONSIBLE FOR LOOKING AFTER YOUR INFORMATION AND KEEPING IT SAFE?

Sheffield Hallam University are the research study sponsor. Sheffield Hallam University undertakes research as part of its function for the community under its legal status. Data protection allows us to use personal data for research with appropriate safeguards in place under the legal basis of public tasks that are in the public interest. A full statement of your rights can be found at: [www.shu.ac.uk/about-this-website/privacy-policy/privacy-notice-for-research](http://www.shu.ac.uk/about-this-website/privacy-policy/privacy-notice-for-research) and: [www.shu.ac.uk/research/excellence/ethics-and-integrity](http://www.shu.ac.uk/research/excellence/ethics-and-integrity)

### WHICH ORGANISATIONS HAVE APPROVED THIS PROJECT?

To ensure that participants are treated appropriately, and their rights respected, the research study has been reviewed and approved by the London – Camberwell St Giles Research Ethics Committee with reference number 23/LO/0736.

### WHO CAN I SPEAK TO IF I HAVE A CONCERN OR AM WORRIED ABOUT THE PROJECT?

You contact the people below if you have any concerns about the project:

<p><b>Email the Data Protection Officer (<a href="mailto:DPO@shu.ac.uk">DPO@shu.ac.uk</a>) if:</b></p> <ul style="list-style-type: none"><li>• you have a question about how your data is used by the University</li><li>• you would like to report a data security breach (e.g. if you think your personal data has been lost or disclosed inappropriately)</li><li>• you would like to complain about how the University has used your personal data</li></ul>	<p><b>Email the Head of Research Ethics, Dr Mayur Ranchordas (<a href="mailto:m.ranchordas@shu.ac.uk">m.ranchordas@shu.ac.uk</a>) if:</b></p> <ul style="list-style-type: none"><li>• you have concerns with how the research was undertaken or how you were treated</li></ul>
<p><b>Or you can telephone +44 (0) 114 225 5555 or write:</b> Sheffield Hallam University, Howard Street, Sheffield, South Yorkshire, United Kingdom, S1 1WB</p>	

**THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET AND CONSIDERING WHETHER YOU WOULD LIKE TO TAKE PART IN THE STUDY.**