

Information Sheet for Interviews

	Hello, my name is Charlotte Nutting • I am a research student. I study at Sheffield Hallam University in England and at La Trobe University in Australia. • I am a registered Learning Disability Nurse and Social Worker in England. • I live in England but will spend time in England and Australia to complete this research project. • Information in this sheet is about the research project.
	The easy read name of the research project is: • ‘What is Radiotherapy like for people with Learning Disabilities who have cancer, and the family members, paid carers and professionals who support them?’ • ‘Radiotherapy’ is a treatment that is used to treat cancer. It uses strong x-rays to kill cancer cells.
	About the research project: • I will interview people with Learning Disabilities who have or have had cancer to find out about: • how they were involved in making the decision to have or not have Radiotherapy treatment. • their experiences of Radiotherapy treatment. • how they were supported after Radiotherapy treatment.



- **I will also interview paid carers, family members and professionals who have supported a person who has a Learning Disability to find out about:**
- their experiences supporting people who have Learning Disabilities and cancer with Radiotherapy.
- A member of your family or a paid carer may be interviewed. If you decide to take part in an interview, I will need your consent (agreement) to interview your family member or paid carer.



Why is the research project important?

- **The interviews will help me:**
- develop a framework about the factors that lead to positive Radiotherapy experiences for people with Learning Disabilities, and the people who support them.



Why have you asked me to take part?

- You are invited to take part in an interview if you:
- live in England, **AND**
- have a Learning Disability, **AND**
- have or have had cancer, **AND**
- have had Radiotherapy in the last five years **OR** you were offered Radiotherapy in the last five years but decided not to have it.



Before you decide if you would like to be interviewed, it is important you understand how and why the interviews are taking place:

- Please read the information in this sheet.
- You might want to talk about the information with someone who supports you.



Do I have to take part in an interview?

- **No. You can decide if you would like to be interviewed.**
- **If you would like to be interviewed, you will be asked to give your consent.** This means agreeing to be interviewed for the research project.
- If you take part in an interview but change your mind, you can tell me up to ten days after the interview without giving a reason. If you change your mind and tell me, I will not use your interview information.



What will happen if I agree to be interviewed?

- **I will interview you:**
 - in your home **OR**
 - in a private room in community building close to your home **OR**
 - using Zoom or Microsoft Teams which you can access for free using a smartphone, computer, or laptop.
- **You can choose how and where you would like to be interviewed.** You can also tell me what time and days would be best for you. You will need a support person in the place where the interview takes place **OR** have a person you can call after the interview in case you need support.
- **We will plan a time and date for your interview.** If you want me to interview you using Zoom or Microsoft Teams, I will email you an invite. You will use the invite link to join the interview.





- **Before we start the interview, we will talk through a Consent Form so I can ask if you agree to be interviewed.**
- **I will then interview you.** I will ask questions about you, about having cancer and about Radiotherapy decision making, treatment and support. There are no right or wrong answers to the questions. You do not need to answer all the questions I ask. **The interview will last up to 60 minutes.**
- The things you say in the interview will be confidential. But I may have to tell the Chief Researcher for the project if you say something in the interview that causes me concern about your safety and/or the safety of others.
- As part of the interview you may choose to show me or share documents about your Radiography experience. For example, a patient information leaflet. If you share a document, we will make sure it does not have your name or any information that could identify you.



How will I use the interview information?

- **When I write about or talk about the project, I will use some of the words from people's interviews.**
- **I will not use your name or information that could identify you or others when I write or talk about the project.** I will use made-up names instead of real names. This means only me, you and any people you tell will know you have been interviewed. You can choose the made-up name if you want to.
- **I will write an easy read report about the things I find out about Radiotherapy involving people with Learning Disabilities who have cancer.** If you agree

	to be interviewed, you can let me know if you would like a copy of the report. • The report will be shared with Learning Disability England and the Down's Syndrome Association. • I will also write an article that will be printed in a magazine and available online. This will be read by healthcare, social care and medical professionals. • I will make a presentation at a conference. I will also talk to healthcare, social care and medical staff and students at my two universities about the project.
	Will the things I say be recorded? • Yes, I will use a voice recorder to record what we talk about in the interview. If we use Zoom or Microsoft Teams, the interview will also be recorded and made into a written document. I will tell you before I start recording and will ask for your consent.
	What will happen after the interview? • The voice recording will be saved in the secure project folder on Sheffield Hallam University's computer network. The voice recording will be deleted from the voice recorder. • If the interview is in person, the interview will be typed up. If we use Zoom or Microsoft Teams, I will check the written recording of the interview. Your name and any information that could identify you will not be used. I will use a made-up name in the interview document, and this will be saved in the secure project folder. • If you choose to share a document with me, I will save this in the secure project folder. I will make sure the document does not contain your name or any information that could identify you.



- I may contact you up to six months after your interview and invite you to take part in a second, shorter interview.
- You can decide if you would like to take part in a second interview about Radiotherapy. The second interview will last up to 30 minutes and can be in person or using Zoom or Microsoft Teams. If you decide to take part in a second interview, we will fill out a Consent Form.



What will I get out of it?

- You might like the opportunity to talk about your experiences.



Are there any risks in being interviewed?

- You may or may not become upset when you talk about having cancer and Radiotherapy. In case you become upset you would need:
- a support person in the place where your interview takes place. You can decide if the person sits with you during your interview. **OR**
- to be able to telephone a support person after your interview if you feel upset. With the support person consent, I will also telephone them at the end of your interview if you are upset or if you did not turn up for your interview.

A support person can be someone like a family member or a carer.

- If you feel upset during the interview we can stop at any time, and you can decide whether you would like to carry on or not.



How long will the project last?

- The project will take about a year and a half to complete.
- Your interview will last up to 60 minutes.

	You may be asked to take part in a second interview that will last up to 30 minutes. You can choose if you want to take part in a second interview.
	What will happen to the interview information when the project has finished? - I will securely delete voice recordings of interviews and contact details. - The project folder that contains the typed interviews that will not include real names, the consent forms and recording will be placed in a secure archive facility at Sheffield Hallam University. All research documents will be securely destroyed 10 years after the end of the project.
	Which organisations have approved the project? To ensure that people who are interviewed are treated fairly, and their rights respected, the research project has been reviewed and approved by the London - Camberwell St Giles Research Ethics Committee with reference number 23/L0/0736. The ethics number for the project is IRAS ID 324949.
	Who can I speak to if I have any questions? - If you have any questions about the interview or the research project or you would like to find out more, you can contact me. - Or you can ask a person who supports you to contact me. Charlotte Nutting: My email is: c.nutting@shu.ac.uk My phone number is: 0114 225 5989
Thank you for reading about the research project	

 Sheffield Hallam University	Which organisation is responsible for looking after your information and keeping it safe? • Sheffield Hallam University are the research project sponsor. • Sheffield Hallam University undertakes research as part of its function for the community under its legal status. Data protection allows Sheffield Hallam University 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: bit.ly/3IkPvLD and bit.ly/3JQ3Xoe
	Who can I speak to if I have a concern or am worried about the project? You or someone who supports you can contact the people below if you have any concerns about the project. Email the Data Protection Officer at Sheffield Hallam University if you: • have a question about how your data is used by the University. • would like to report a data security breach, for example, if you think your personal data has been lost or disclosed inappropriately. • would like to complain about how Sheffield Hallam University has used your personal data. Email: DPO@shu.ac.uk Email the Head of Research Ethics, Dr Mayur Ranchordas if you have concerns with how the research was undertaken or how you were treated. Email: m.ranchordas@shu.ac.uk You can telephone 0114 225 5555 or write to Sheffield Hallam University, Howard Street, Sheffield, S1 1WB.