

# About the study

Cancer treatment can be a frustrating and sometimes overwhelming experience; with harsh treatments, constant appointments, and painful side effects upturning lives and making those receiving care feel powerless.

I think that there's room to make things better for those in South Wales undergoing cancer care — especially through thoughtfully-designed technology. I'm determined to discover these potential improvements with the direct involvement of those actively involved in the cancer care process.

So, as part of my PhD at Swansea University, I want to understand what cancer care receivers currently go through in South Wales and work with them to consider areas which could be improved as well as potential applications of technology which would enable more person-centred cancer care. Note: this study isn't associated with NHS Wales or the Welsh Government.

## Purpose

In this study, I want to find out:

- what the receivers of cancer treatment experience on the treatment pathway
- their perceptions of this pathway
- what good quality-of-life looks like to somebody in this situation
- how they might consider introducing technology to make things better

## About you

I've reached out to you because you're a member of a cancer community in South Wales, and you've had or have a form of cancer (or are very close to someone who does).

Your lived experience and opinions are extremely valuable in understanding what it's like to have cancer treatment in South Wales, and I would appreciate your time, perspective, and input as part of this study.

## What will happen?

If you choose to take part in the study, I will invite you to come along to a workshop hosted by myself at Swansea University. We'll be in a private, accessible room and I'll provide plenty of free hot & cold drinks and snacks in regular coffee breaks. There will be several people with cancer care experience at the workshop from one or more cancer communities, and I will guide everybody as a group through some activities that will help me learn about yourself, your experiences, and your opinions.

We'll go through an introduction and quick ice-breaker, then I'll hand out some paper materials and ask everybody to make a timeline of their cancer treatment pathway to help us visualise everybody's different experiences.

Then, I'll ask some questions about how you feel about your experience and we'll explore how everybody perceived their pathway. We'll discuss how you felt and where things could have been done better. We'll have a conversation about what's most important to everybody in terms of a good treatment pathway

and together we'll try to imagine how we could perhaps use technology to put this at the centre of cancer treatment.

It's important to note that your participation will remain voluntary throughout the study, and you can take a break or stop taking part at any time before or during the study.

## Why take part?

Cancer care professionals and researchers have realised that the best way to achieve the highest quality care is through truly understanding, involving, and empathising with those receiving care. They also realise that to successfully change the way that they practice cancer care, they'll need to utilise the potential of person-centred technological innovation.

By taking part in this study, you'll be paving the way for future cancer treatment improvements in South Wales and beyond. Your perspectives will guide the design of cutting-edge technology prototypes that seek to make sure that those undergoing treatment in the future can do so without some of the burdens currently faced, whilst empowering those individuals with more control over their treatment.

As a thank you for taking part, I will also be providing a **£25 gift card of your choice**. I'll hand these out at the start of the session.

## When not to take part

This study will require you to talk about your personal cancer journey, what you experienced, and how you feel about it. This might be too sensitive or painful for some to talk about, so please do consider if you'd be okay with this.

Of course, everything you say will be kept in confidence and you won't be named as part of the study. You don't have to answer any questions or prompts that you don't feel comfortable with, and there are no right or wrong answers — this study is all about understanding your unique perspective of this difficult experience with a hope to make it easier for others in the future.

You can ask me or my supervisor Simon any questions you might have at any time and in full confidence (see the contact details at the back of this document). And, you can withdraw from the study at any point, even after signing the consent form.

## FAQs

### **How will I get to Swansea to take part in the study?**

I will cover all costs involved in travelling to and from the study, whether you're coming by car, bus, or train. I can also book this for you, if needed – just let me know!

### **How will you handle my personal information?**

Your personal information (name, contact details, association to a support group) will be kept strictly confidential and used only for the purposes of facilitating the study and in follow-up communication from myself. It will be processed in line with the Data Protection Act 2018, with further information available on the University's website (link: [pch.wales/dataprotection](http://pch.wales/dataprotection)).

### **How will you ensure my anonymity?**

The data I obtain as part of this study will be anonymised after each workshop session to ensure your responses can not be used to identify you. I will not reveal your participation to other organisations and this study is not associated with

NHS Wales. I ask that you do not disclose any personal or identifiable information shared by other participants in the studies to anybody in the interests of preserving each other's privacy and anonymity.

### **Can you support my accessibility requirements?**

Of course! The building is fully accessible with accessible facilities, and I can support any other particular accessibility requirements. Just get in touch with me beforehand and let me know what you need.

### **Can my carer/support worker/trusted family member attend along with me?**

Of course! Just get in touch with me beforehand and let me know who's coming for room capacity requirements. They will also need to read this information document in full and sign a consent form.

### **How do I take part in the study?**

Thank you for wanting to take part! To do so, get in touch with me via email or phone (my contact details are on the next page). You'll need to complete a '[Your consent](#)' form, as will anybody who is accompanying you.

If you need another copy of this information document or the '[Your consent](#)' form then get in touch with me and I can send another one over.

## Contact details

Get in touch with me at any time if you have any issues, questions, or complaints:



Matt Hall

✉ [m.c.hall@swansea.ac.uk](mailto:m.c.hall@swansea.ac.uk)

☎ 07903 454150

My academic supervisor can also be contacted with any questions you might have:

**Dr. Simon Robinson**

[s.n.w.robinson@swansea.ac.uk](mailto:s.n.w.robinson@swansea.ac.uk)

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Any complaints regarding myself or the study should be sent to:

[researchintegrity@swansea.ac.uk](mailto:researchintegrity@swansea.ac.uk)