Understanding the cancer care givers' perspective

A practical observation and probing discussion

Purpose

This study is about gaining an understanding of what's involved in the delivery of cancer care at Velindre, from the care givers' perspective. Through shadowing of day-to-day practice across six key areas of VCC, I want to find out:

In practical structure and organisation:

- What does cancer care involve of care givers? (people, procedures, systems)

- How and where are care receivers involved in delivery?

- How does practice change pragmatically?

In theory and motivation:

- How person-centred is cancer care, as delivered?

- What factors influence practice?

- Where do care givers consider opportunity for digital enhancement?

Prerequisites
- Professional competence
- Communication and respect between team members
- Established common values
- Commitment to the job
- Individual reflexivity

The practice environment
- Interprofessional meeting space
- Shared decision-making systems
- Good staff relationships
- Power sharing
- Adequate physical environment
- Supportive organisational systems
- Potential and support for innovation

Person-centred processes

Understanding the care receiver
- Attention to physical and environmental needs
- Emotional support, empathy, and respect

Developing the relationship
- Involvement and support for family & carers
- Involvement in decisions and respect for preferences
- Clear information, communication, and self-care

Coordinating care in the system
- Effective treatment by trusted professionals
- Continuity of care and smooth transitions
- Fast access to reliable healthcare

Above: My 'consolidated framework' for what person-centred healthcare looks like, based on the most widely accepted literature. This is what I'll be using to guide my exploration throughout the study.

What it will involve

For the most part, I'll be quietly observing each team as they go about a typical day of practice. I'd be present at the team's meetings, consultations, discussions, and general movements around Velindre. In quieter moments, I might take two minutes to talk with whomever I'm shadowing about what I've observed. I'll clarify any details I might have missed, reflect on the motivations behind decisions made, and together we'll shape an authentic analysis of the day's events. I anticipate shadowing 1-2 days of practice per team, split between various team members as appropriate. However, we'll agree on a plan of action that best suits the team before I start any shadowing.

When this is finished, I'll explore these analyses in more detail and consider the wider context within and beyond Velindre. Finally, a couple of weeks later, I'll follow-up with each team to discuss and solidify our findings to ensure that they're accurate and complete.

Canolfan Ganser Felindre
Velindre Cancer Centre

Swansea University
Prifysgol Abertawe

Contact details

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

Matt Hall
matthew.hall3@wales.nhs.uk
07903 454150

Ethics

It's important that I have the freedom to observe and inquire about all aspects of practice in this study – not just for my sake, but for the sake of bringing about meaningful and useful improvements in practice and environment at Velindre. I'm not here to audit or judge anyone at Velindre, nor will our findings from this study be used against anyone involved.

At the same time, I appreciate the need for discretion and respect – especially when this study might involve shadowing in the presence of patients. Whilst it's difficult to pre-empt every scenario I might observe in this study, I'll only gather data with the consent of those involved. Open reflection is an essential part of this study, and our findings will be mutually agreed as to minimise implication.

Ethical approval for this study was obtained from Swansea University, and operates as a service evaluation within VUNHST. More details at pch.wales/resources/s03.

About the project

For my PhD, I'm working to co-create meaningful digital enhancements with care givers and care receivers at Velindre. There's a huge need for person-centred healthcare and a renewed focus on quality-of-life in cancer care, and I believe that technology designed through real participation is a huge opportunity for achieving this – at Velindre and across Wales.

Why this study

My background is in human-centred computer science, so I hope to use this study to build my understanding of cancer care from the care giver's perspective; to learn about what's important to care givers, what's frustrating, and together consider where we might improve. At the same time, I hope that I can share my enthusiasm for thoughtfully co-created digital systems, and how they can bring tangible benefits to both care receivers and care givers at Velindre.

Right: An illustration of how this study (S03) fits in with the other key aspects of the PhD project

S01 ✓	S02 ✓	S04	Year 3
Preliminary research	Workshops with care receivers	Rapid digital prototyping	Refinement of methodologies
Literature review	**S03**	Participatory design with care givers and care receivers at VCC	Considerations for actual usage
Initial discussions and survey at VCC	**Care giver shadowing**		Synthesis & conclusion

2022 ···················· **2023** ···················· **2024** ···················· **2025**