



What our patients tell us they want 'Desert Island Discs'

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1. Background: VR Ready

ViRtual REality to AiD recoverY post-ICU

Critical illness has long-term consequences. Support through recovery is inadequate with regional variation and no standardised pathways.

Funding from Health and Care Research Wales (Research for Patient and Public Benefit)

Phase 1: Map the recovery pathway of ICU survivors; including identification of critical components underpinning effective recovery and facilitators and barriers affecting these.

Phase 2: Co-produce a VR mediated intervention to aid recovery

Phase 3: Determine feasibility and acceptability of the intervention

2. Method: Phase1: Focus Groups

Timeline

- Participants shared their journey to recovery
- What were the biggest challenges?
- Explored common factors

Brokered dialogue

- Is there anything you would like us to ask the staff group?
- What would be helpful for them to understand?

Desert Island Discs

- 2 priorities/activities to support recovery, 2 to support rehabilitation
- 1 piece of wisdom, 1 luxury item & 1 piece of music

3. Results: Patient Experience

"I can remember thinking I couldn't talk, I couldn't breathe, but I could think."

"I was too weak, the muscle wastage. I couldn't really move my arms at all. I described myself as an adult baby. I was unable to talk, communicate. I was unable to move. I was unable to eat solids, I had the NG tube. I was bathed in bed; I was toileted and cleaned in bed. I could do nothing for myself."

"I didn't want to exist. I didn't want to be trapped in this body. I was in so much pain. The reality of everything just hit and you're saying, what's just happened?"

"I feel like you had £1500, £2000 a day of NHS money thrown at you and then you go back to the wards for a few weeks and suddenly you're sent home and go, what the hell just happened?"

"There was no entertainment really to motivate your mind."

"There was a very much a feeling of abandonment and that's not a criticism of the hospital or that team at all. That's more about the NHS and the system we have."

"There's times when I've not wanted to exist in this body because I can't do what I want to do."

"I've been passed around from service to service for being too complex."

4. Phase1: Priorities for Recovery

- "Having a long-term goal"
- "Having things to look forward to"
- "A diary to track progress"
- "Sleep, prioritise sleep"
- "Friends and times of enjoyment"
- "Physiotherapy"
- "Music"
- "Family and friends"
- "Kindle/books, something to keep the mind active"
- "Pet therapy"

5. Phase1: Priorities for Rehabilitation

- "Be tactical, be in the moment."
- "Celebrate the wins"
- "Keep positive"
- "Walking a little bit further every day"
- "Walking aid"
- "Sensory fidget box"
- "Abdominal recovery programme"
- "... a poster on the wall each day with my exercises and stuff."
- "Resistance material for physio"
- "Decide plan together"

6. Luxury Items & Music



7. Brokered Dialogue (Patients/Staff)

1. Why did you keep going? Why didn't you pull the plug?

"It's still kind of an art as well as a science."

2. Remember the person in the bed is a human being first and a patient second

"Really valid. We need to dissociate a little bit when patients are very unwell as a protective mechanism, otherwise you'd probably go home every day and cry."

"We hear you. We care. The reason we get up every day and come to work is to help you."

3. Are there specific things that would make you feel more human?

"The fact that staff are listening and asking these questions shows they care."

4. You may not feel we understand what you're going through but we are trying. How can we make it better?

- "What helped me was having a rapport with my nurses and physios and being able to tell them how I felt."
- "Reviewing progress at the end of the day"
- "Pacing of information and how it's given. Can't process it all in one go."
- "Recognise it can be embarrassing, maintaining dignity."

8. Summary – to aid recovery

Key Themes

Pacing
Everyone is different
Be kind to yourself
Trust in staff
Goal setting
Self-motivation
Expect ups and downs

What Helps?

Recognised as a person
Reassurance
Visual displays
Psych follow-up
Therapist contact after ICU
Patient stories

The rich data gained from these focus groups was used to co-develop a virtuality reality intervention (phase 2) including mindfulness, motivation, exploration experiences, information and breathing exercises. This is now being piloted (phase 3).

Acknowledgements

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