

A James Lind Alliance top stroke survivor priority leads to a PhD fellowship exploring the long term consequences of stroke.

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Background

The shared Top 10 research priorities of stroke survivors, and health carers professionals have been identified in a James Lind Alliance Priority setting project. No 2 (and the top stroke survivor priority) was:

"How can we help people come to terms with the long term consequences of stroke?"

This study aims to explore the answers to this complex question.

What did we do?

This study consists of the 3 phases shown in Figure 1. At the start of the project we brought together an Advisory Group of longterm stroke survivors to ensure meaningful stroke survivor involvement throughout.

So far we have held 5 meetings where group members give their opinion and advice. They have also become involved in all aspects of project including design, methods, implementation and dissemination.

Our Advisory Group

Danny Gordon David Allan Margaret Baird Donna Cullinane Sandra McCallum (not in picture)



What was the impact on the project?

- ☐ Valuable stroke survivor advice on overcoming potential barriers to stroke survivor participation.
- ☐ Improved design and content of information sheets.
- ☐ Piloted and refined focus groups.
- □ A group member actually organised one of the project focus groups including bringing together participants, organising a venue and refreshments and facilitating the smooth-running of the group.
- Another member co-presented Bridget at a national stroke conference and talked about their experiences of stroke and their input into the project.

Conclusion

Involving stroke survivors in the planning of this PhD fellowship has enhanced and provided credibility to our methods. We are confident that continuing to include the stroke survivors' perspective throughout will be of benefit, and further improve the project as it progresses.

Focus groups & interviews H Viewing of videos showing **PHASE** stroke survivors discussing **General discussion group** their recovery. Gather data relating to perceived long relating to perceptions of term consequences of how current measures stroke through general assess long term discussion consequences of stroke OF **Identification of domains Comparison of** ANALYSIS ш stroke survivor perceived as important to S and health stroke survivors and health professional professionals data from video viewing exercise Q-methodology (card sorting) 2 **Prioritisation of domains that matter most** to stroke survivors and health professionals Q-methodology (card sort exercise) involving stroke survivors and health professionals in groups or individual interviews ANALYSIS **PHASE** Identification of domains perceived as MOST important Systematic review **M** Outcomes included will be determined from Phases 1 & 2. Selection criteria will include studies addressing domains that are most important to stroke survivors and health professionals.

Figure 1 showing the 3 planned phases of the project

Recommendations for stroke

outcome scales which measure

what is important to people

affected by stroke

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