

# 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, carers and health 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 long-term 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 the 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 with 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.

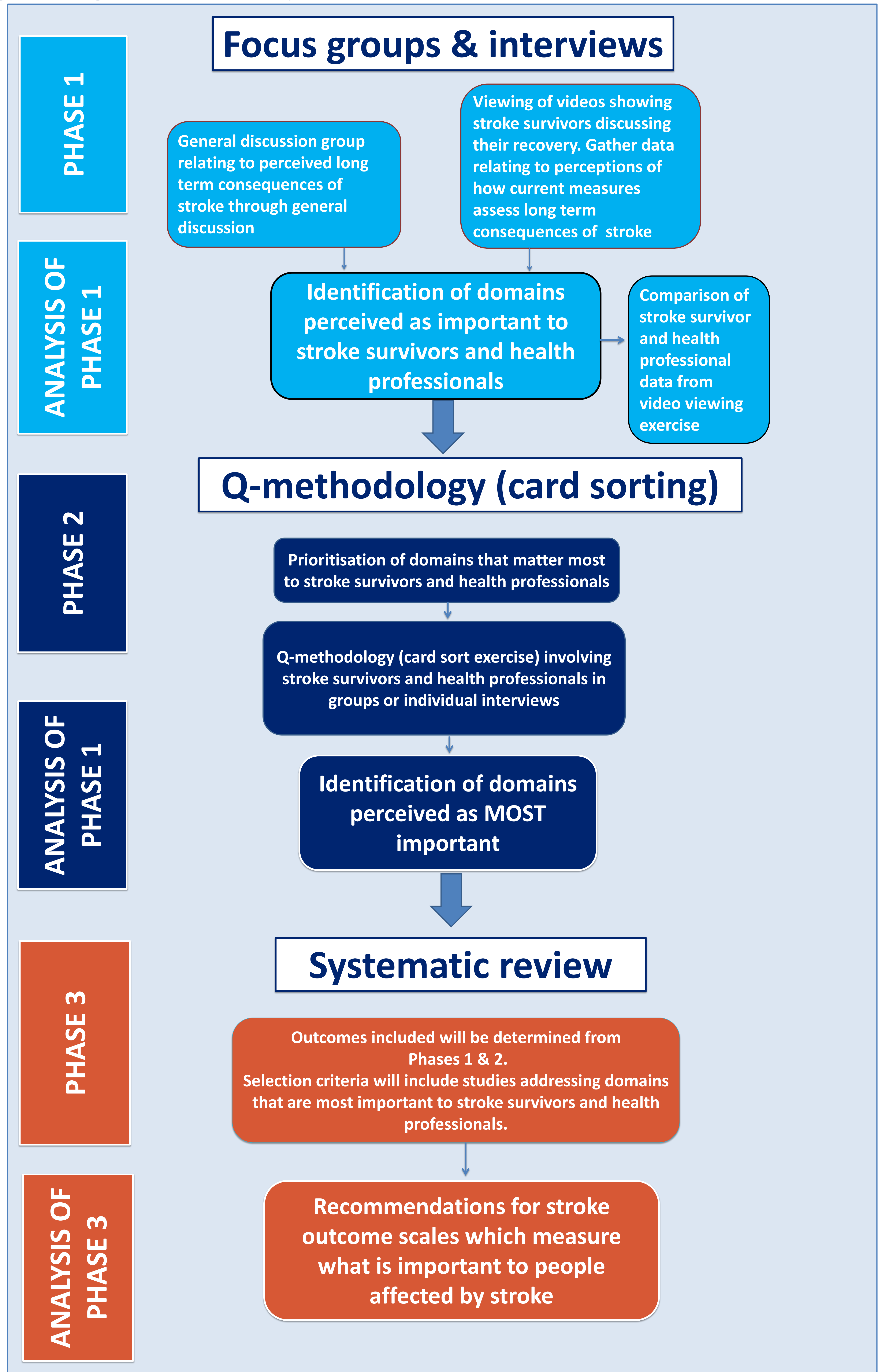


Figure 1 showing the 3 planned phases of the project

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