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## Stroke Clinicians' Priorities for Stroke Research

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### ABSTRACT

**Purpose:** The purpose of this study was to identify research questions perceived as important by clinicians who treat stroke survivors in New South Wales (NSW), Australia. **Methods:** A cross-sectional, 3-round Delphi survey method was used. Participants invited to respond in Round I included stroke researchers (n=26); Rounds II and III included stroke clinicians (n=470) identified from NSW Health Stroke Services and/or NSW Rural Stroke Service databases. Participants in Round I were asked to identify stroke research questions of the highest priority; participants in Rounds II and III then rated these research questions on both importance and feasibility using a 5-point Likert scale. **Results:** Responses were received from 14 expert stroke researchers during Round I (54%), 38 stroke clinicians (8%) in Round II, and 56 stroke clinicians (12%) in Round III. Research topics rated as "very important" were interventions that target life-long rehabilitation, best methods for providing post-discharge rehabilitation, and delivery of physical rehabilitation. **Conclusions:** Clinicians who provide day-to-day stroke care perceive that the effectiveness of rehabilitation interventions and delivery require investigation as a key priority.

### INTRODUCTION

Stroke is among the leading causes of death in western countries and accounts for around half of all those hospitalized for acute neurological conditions annually.<sup>1</sup> Among those who survive a stroke, 50% are alive more than five years after the event; thus, the burden of stroke is ongoing.<sup>2</sup> Stroke and its subsequent disabilities place a large burden on the family, the community, and the health care system. Research into prevention, acute care, rehabilitation, and life after stroke is important. However, there are some areas of research deemed more important from the perspective of clinicians specialising in stroke rehabilitation.

Clinical decisions often have to be made in situations where there is insufficient high-quality evidence, and this has led to an increased demand for clinically relevant research. While many individual research questions are identified at the conclusion of studies, there is no published prioritisation that provides guidance on the relative importance and ranking of potential research questions. This is necessary in order to direct the limited research funds available for stroke services. Understanding research

priorities will equip policy makers and funding bodies with the necessary information to make a decision among projects and enable clinicians to participate in evidence-based research on stroke rehabilitation.

The aim of this study was to identify the research priorities of clinicians working in stroke rehabilitation. In order to overcome difficulties of face-to-face discussions, we used the Delphi method.<sup>3</sup> Using this method, there is an assumption that research questions endorsed by clinicians who treat stroke survivors will have professional and social relevance. Furthermore, translation of research into practice is likely to be more effective if the research has high clinical relevance. The Delphi method has been used elsewhere successfully to identify and prioritise research budget allocations and to determine research priorities for children with cerebral palsy.<sup>4,5</sup>

## **METHODS**

A cross-sectional study design was used. The primary data collection method was an electronic survey using the Delphi method.<sup>3,6</sup> The Delphi method uses a series of questionnaires that are completed anonymously; results from Round I generate questions for subsequent rounds. The Delphi method is efficient in time and cost, with multiple rounds enabling participants to consider the opinions of other experts, because individual participant's feedback in one round contributes to emerging consensus in the subsequent rounds.<sup>7</sup> The consensus-building nature of the process combines the rigor of traditional surveys and the collaborative methods used during focus groups.

Three iterations of the Delphi process were used to collect data in order to balance the likelihood for consensus, cost, and response rate.<sup>8,9</sup> The study was conducted with the understanding and the consent of participants; approval for this study was granted by a university Ethics Committee.

### **Round I**

In Round I, a panel of stroke research "experts" were sent an open-response email questionnaire. As findings were expected to contribute directly to the research agenda in New South Wales, Australia, three stroke experts from each clinical discipline were selected according to the following process. Ideally, professionals with the greatest publication track record in stroke, residing in New South Wales, Australia, were selected. If a discipline was not filled based on this criterion, then professionals residing in New South Wales, Australia, who had published any research in the area of stroke were selected. Then, Australian professionals with the highest number of journal articles published in the area of stroke were selected. If a discipline was still not filled, then professionals who were a contributing author to the Australian National Stroke Foundation (NSF) National Clinical Guidelines were selected.<sup>10,11</sup> Finally, for a discipline where the criteria yielded no researchers, the relevant interest groups were contacted, and peers recommended experts for inclusion. Where more than the required number was located, participants were chosen using a computer-generated random allocation procedure. The author that carried out this process (NL) was excluded from completing the Round I survey.

The questionnaire asked respondents to list not more than five clinical research questions or issues where insufficient research existed to guide practice or where uncertainties existed about the value or outcome of a particular practice. One reminder was sent to non-respondents after six weeks.

Research questions or issues provided by Round I respondents were used to develop a structured questionnaire for use in Rounds II and III. Questions were categorised jointly by two authors (NL & LA) and assigned on the basis of agreement. Guidelines provided by Lazarsfeld were followed for coding unstructured answers and research questions were classified under the headings developed by The National Stroke Foundation in the Clinical Guidelines for Acute Stroke Management and Clinical Guidelines for Stroke Rehabilitation and Recovery.<sup>10-12</sup> This process generated a set of mutually exclusive research questions for the Round II questionnaire.

### **Round II**

In Round II, stroke clinicians (n=470) were sent a questionnaire with closed questions by email. Stroke clinicians were identified from New South Wales Health Stroke Services and/or Rural Stroke Service databases. Health professionals were grouped according to their discipline as specified by the Clinical Guidelines for Acute Stroke Management: (1) doctors: neurologists, rehabilitation specialists, geriatricians; (2) nurses; (3) allied health: physiotherapists, occupational therapists, speech pathologists, dieticians, social workers.<sup>11</sup>

For each question, clinicians were asked to rate the importance and feasibility of conducting a research study to answer the question in a clinical setting (Figure 1). A 5-point Likert scale was used to categorise responses for both importance and feasibility of research questions from "very important/feasible" (+2) to most "unimportant/not feasible" (-2).<sup>13</sup> Clear definitions of

importance and feasibility were provided to clinician raters to standardise the use of the categories and minimise variation in understanding about the rating scales. Respondents could choose to comment in a free text section at the end of each questionnaire in Round II. One reminder was sent to non-respondents 6 weeks after Round II questionnaires were first dispatched. The highest-rated research questions during Round II were used to develop the questionnaire for use in Round III.

**Figure 1. Closed questionnaire used during Rounds II and III with examples of research questions and definitions of response categories.**

	IMPORTANCE						FEASIBILITY					
	No opinion	Very Important +2	Important +1	Neutral 0	Un-important -1	Most Un-important -2	No opinion	Definitely Feasible +2	Probably Feasible +1	May or May not be feasible 0	Probably Unfeasible -1	Definitely Unfeasible -2
Does having a research strategy and incorporating of research into routine clinical practice increase the research infrastructure for stroke?												
What is the impact of community education on prevention of stroke?												
Does changing the way we deliver physical rehabilitation (eg. using workstations, groups, classes) increase the amount of practice?												

#### IMPORTANCE

Very important - most relevant question; first-order priority; has direct bearing on most patients. must be resolved, dealt with or answered.

Important - a relevant question; second-order priority; significant impact, but not until other questions are answered.

Neutral/slightly important - may be relevant; third-order priority; unsure whether or not this would have an impact.

Unimportant - insignificant question; low priority; has little impact.

Most unimportant - no priority; no relevance; no measurable effect; should be dropped off as a question to consider.

#### FEASIBILITY

Definitely feasible - can be implemented; definitely within available resources; no major roadblocks; will be acceptable to other clinicians and general public

Probably feasible - some indication that this could be implemented; available resources would have to be supplemented; some roadblocks; some indication that this may be acceptable to other clinicians and general public

May or may not be feasible - indeterminable development of effort needed to implement; increase in available resources would be necessary; roadblocks; some indication that this may not be acceptable to other clinicians or general public

Probably unfeasible - some indication that this cannot be implemented; existing infrastructure inadequate; large scale increase in available resources would be needed; major roadblocks; not acceptable to a large proportion of other clinicians nor general public.

Definitely unfeasible - cannot be implemented (unworkable); basic scientific knowledge lacking; politically unacceptable; completely unacceptable to other clinicians and to the general public

### Round III

In Round III, the same stroke clinicians (n=470) were sent a revised closed questionnaire by email. Respondents could choose to comment in a free text section at the end of each questionnaire in Round III. One reminder was sent to non-respondents approximately six weeks after Round III questionnaires were first dispatched. Low initial responses to the Round III questionnaire were supplemented by asking attendees at a national clinical stroke meeting to complete a questionnaire if they had not already done so.

### Statistical Analysis

Data from Rounds II and III were presented using descriptive statistics. Median scores and interquartile ranges (IQR) were calculated for the groups' responses to each question. Priorities were ranked by median values due to the anticipated skewness of data distribution.

## RESULTS

### Round I

A total of 14 experts responded to Round I, a response rate of 54%. Table 1 shows the discipline of respondents. The 58 topics submitted by the experts in Round I were classified into categories:

- (1) Prevention and diagnosis of stroke (n=9 topics, 16%)
- (2) Organisation of care (n=28 topics, 48%); questions which aim to address a complex package of care.
- (3) Management of consequences of stroke (n=6 topics, 10%); questions which aim to assess treatments or issues that minimise the consequences of stroke.
- (4) Discharge planning, transfer of care, integrated community care (n=9 topics, 16%); questions which aim to assess treatments or issues that improve community reintegration,
- (5) Evidence based practice (n=6 topics, 10%); questions about applying research in the clinical setting.

### Round II

A total of 38 clinicians rated the 58 questions in Round II, representing a response rate of 8% from the total population. All invited clinicians were employed within clinical settings, identifying themselves as working with stroke survivors; table 1 shows the discipline of respondents. Prominent among priorities in Round II were efficacy trials questioning the optimal management in acute care, rehabilitation, and delivery of health care. Understanding the needs of carers and the best ways of supporting these carers long-term were also of high importance. Only those questions which reached a median rank of 1.0 in Round II were included in Round III.

### Round III

A total of 56 clinicians rated the 18 questions in Round III, representing a 12% response rate. Table 1 shows the discipline of respondents. No significant difference was found in the proportion of respondents for each discipline between Round II and III.

**Table 1. Number (%) of respondents according to discipline**

Discipline	Round I (researchers) N = 14	Round II (clinicians) N = 38 <sup>a</sup>	Round III (clinicians) N = 56 <sup>a</sup>
Medicine <sup>b</sup>	3 (22)	4 (10)	2 (4)
Nursing	3 (22)	8 (21)	15 (27)
Allied Health <sup>c</sup>	8 (57)	25 (66)	29 (52)

a. Proportions do not add up to 100% due to missing data

b. Medicine includes neurologists, stroke physicians, geriatricians with stroke interest and neurosurgeons

c. Allied health includes occupational therapist, physiotherapists, speech therapists and social workers

There were small shifts in the rank order of questions from Round II to Round III. Respondents continued to rank highly both the importance and feasibility of conducting efficacy trials to identify the optimal therapy and delivery methods. The highest ranked question (with lowest variability in agreement) sought an answer to whether providing ongoing rehabilitation produces better long-term outcomes in stroke survivors. This question had a median feasibility score of 1.0. The delivery model of such ongoing rehabilitation was also of high priority to clinicians; should it be delivered in a home-based, community-health centre or outpatient model? Does changing the way we deliver physical rehabilitation increase the amount of therapy that is provided (eg. using workstations, groups, classes)?

Responses were analysed for the total sample of respondents and by discipline: doctor, nurse or allied health. No differences were found between the total sample and each of the disciplines and results were therefore reported for the total sample (Table

2). Research topics rated as very important were interventions that target ongoing/life-long rehabilitation, best methods for providing post-discharge rehabilitation, and delivery of physical rehabilitation. Feasibility of researching these topics was consistently rated as being "probably feasible" by responding clinicians. "Does providing ongoing rehabilitation produce better long term outcomes?" was the research question rated most important by stroke clinicians. There was little variability in how they ranked importance (noted by the small interquartile range). This question also received a median ranking of 1.0 for feasibility. Thus, not only was the topic of ongoing rehabilitation the most important research priority for clinicians, but clinicians also perceived that undertaking a clinical trial to answer this question was feasible.

**Table 2. Median (IQR) rating (-2 to 2) of research questions from Round III in rank order from highest to lowest (respondents, n=56).**

Research Question	Importance	Feasibility
Does providing ongoing rehabilitation produce better long term outcomes?	2 (0.25)	1(1)
Does the implementation of post-rehabilitation services what are accessible, affordable and continue/are ongoing, enhance function, community participation and quality of life?	2(0.5)	1(1)
Does community based rehabilitation as a service delivery model in regional/rural Australia improve outcomes after stroke?	2(1)	1(1)
Does early intensive rehabilitation (1-7 days) improve outcomes?	2(1)	1(1)
Does changing the way we deliver physical rehabilitation (eg. using workstations, groups, classes) increase the amount of practice?	2(1)	1(1)
Does fast-tracking potential stroke patients to comprehensive stroke units improve outcomes?	2(1)	1(1)
What proportion of stroke units, rehabilitation teams are routinely implementing evidence as recommended in the 2005 stroke rehabilitation and recovery guidelines?	2(1)	1(1)
What interventions best prevent shoulder subluxation and upper limb contractures?	2(1)	1(1)
What is the quality of life in post-stroke patients and their caregivers?	2(1)	1(1)
How do we implement strategies of proven effectiveness in stroke that are sustainable?	2(1)	1(1)
What are the needs of people with stroke and their families? Do these match the assumptions held about what constitutes "service delivery" and "intervention" by the health care system?	2(1)	1(1)
What model of stroke care provides best outcome for money?	1(1)	1(1)
What is the optimal management of blood pressure in acute ischaemic and haemorrhagic stroke?	1(1)	1(1)
What is effective in preventing and treating mood disorders after stroke?	1(1)	1(1)
What is the mean delay time from time of symptom onset to presentation in the emergency department over the past 12 months?	1(2)	2(1)
What is the impact of community education on prevention of stroke?	1(1)	1(2)
How can the emergency department physicians be engaged in delivering hyperacute therapies?	1(2)	1(1.25)
Do education programs targeting those with known risk factors for stroke such as hypertension, previous TIAs etc, yield greater benefit in reducing delay to attend hospital?	1(2)	1(1.5)

Notes: TIA = transient ischaemic attack

Clinicians were invited to make comments at the end of the questionnaires. Of the 14 respondents who wrote multiple comments, some expressed doubt about the value of research in general, eg, "We lack resources and infrastructure in rural Australia and it's not the most important thing to spend money on." Others indicated the overriding importance to them of specific topics, while others thought that all of the topics listed were important, making rating difficult. Some respondents found the questionnaire tedious, particularly in Round II where they had to respond to 58 questions using two rating scales. The range of topics generated was large; an earnest effort was made to group similar topics together to shorten the questionnaire in Round III. Only those questions, which reached a median rank of 1.0 in Round II, were included in Round III to reduce respondent burden.

Some of the clinicians commented on the vagueness of some questions and the specificity of others. The expression of topics represented as closely as possible the wording of questions as submitted by stroke researchers.

Finally, some respondents reported that they would have liked a summary of questions that had already been answered and which questions had either non-existent or inconclusive findings. These comments suggest that further work is required to disseminate current research findings. Although the National Stroke Foundation produces clinical practice guidelines that provide a summation of relevant research, respondents identified that these guidelines represent only a portion of the available research and do not provide an indication of studies underway.

## DISCUSSION

In summary, the most common research priorities raised by clinicians who work in stroke care focused on rehabilitation and community care. These clinicians witness the poor outcomes obtained for many stroke survivors on a regular basis, observing how many of those with significant disability are unable to access in-patient or out-patient rehabilitation.<sup>14</sup> It is therefore not surprising that clinicians working in this environment have highlighted that research should better quantify how to maximize outcomes through rehabilitation in an effort to ensure the best possible health care is provided to all stroke survivors.

There is no simple method for assessing stroke research priorities. This survey represents one method. Findings are only as valid as the responses and opinions of the experts in the panel.<sup>15</sup> Our main limitation was the low the number of respondents to Rounds II and III. This may reflect the low priority given to research by busy clinicians, or simply that they were too busy to complete the survey. However, research shows that under ideal circumstances, groups with only four members can provide useful, well-considered data.<sup>15,16</sup> Respondents were broadly representative of stroke clinicians in New South Wales, but with some limitations. The stroke clinicians involved with the Stroke Services Network work in a multidisciplinary environment, hence the priorities identified are reflective of this shared understanding of stroke care. Further, the majority of respondents in all three rounds were allied health professionals. These professionals typically spend little time addressing stroke risk factors and secondary prevention with stroke survivors which may have contributed to the focus on long-term rehabilitation and community care questions in the final list of priorities for further research. As with all Delphi methodologies, it was accepted that sampling a different cohort of clinicians who treat stroke survivors may result in different priorities. Results from the smaller sample do, however, provide an impetus for surveying clinicians in a larger, nationally representative sample in a future study. Nevertheless, these responses represent the opinions of clinicians actively engaged in acute stroke care and rehabilitation and constitute a significant beginning to identifying what clinicians regard as important.

There were differences between the rating of importance and feasibility of different research questions. The median response for feasibility for all but one question in Round III was 1.0 ("probably feasible with some indication that this research could be implemented"). While the stroke clinicians rated the importance of many of the questions highly, feasibility may have been ranked lower because these clinicians currently face resource and time pressures which make participation in clinical research difficult. While all researchers would acknowledge that greater resourcing is likely to be necessary for research questions to be addressed in a clinical setting, it was interesting to note that the variation in response patterns was not evident as it was for rating importance. Further research would be needed to confirm the reasons behind the lower feasibility scores and whether research experience influences response patterns.

The low level of research funding and support provided at the level of clinical health services in Australia means that there is great selectivity about the direction of limited research efforts. However, the similarity of questions prioritised in this study with those found by a recent Canadian publication of research priorities point to the international nature of research problems faced by the stroke community and the value of cooperative efforts. Similar to the current study, Bayley et al.<sup>18</sup> reported that community reintegration after stroke, rehabilitation after severe stroke, and the timing and intensity of rehabilitation after mild and moderate stroke were of enormous importance to clinicians and academics alike. The agreement between studies (and across western countries) provides important information to policy makers, both in terms of disease management (health improvement) and wider socio-economic goals.

## CONCLUSION

This study focused on research priorities as identified by stroke researchers and clinicians in Australia. However, the opinions of stroke survivors and their carers are equally important. A small Australian study recently examined consumer views on research priorities for conducting studies in areas where there is currently little to no research.<sup>17</sup> Findings showed that stroke survivors and caregivers ranked recommendations under the topic heading "getting to hospital" as a high priority for research. Importantly, stroke research priorities from the consumer perspective appear to differ from those of health professionals' as published in the literature, making it important to ensure that all perspectives are considered when making funding decisions.

We conclude that the Delphi process is a viable data collection method for investigating stroke research priorities. This method is economical, productive, and generated future research questions. Stroke clinicians highlighted a need for more research about the optimal amount, quality, and content of rehabilitation. Ownership of research questions by clinicians may enable more research to be successfully integrated into the clinical setting, and ultimately lead to greater uptake of findings when complete. Finally, stroke researchers and funding bodies need to be aware of priorities highlighted by this study, while also recognising the limitations and its need to be repeated on a national sample.

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## KEY TERMS

Delphi Technique, Research Priorities, Stroke, Consensus



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