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Title: Top ten research priorities relating to stroke nursing: a rigorous approach to establish a national nurse-led research agenda

Running head: Top ten stroke nursing research priorities

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IMPACT STATEMENT

Worldwide 16.9 million people have a stroke every year. Currently, between 2-12% of the total research expenditure is directed into stroke research in Europe and the USA, therefore it is ethically and morally right that these resources are directed at what is agreed to be of greatest importance.

The aim of this study was to clarify which research questions are of greatest priority to stroke nursing. The top 10 stroke nursing research priorities, which are valued by patients and carers, will now be used to inform the prioritisation and funding of future stroke research undertaken by nurses.

ABSTRACT

Aim: To determine the top 10 research priorities specific to stroke nursing.

Background: It is important that stroke nurses build their research capability and capacity. This project built on a previous James Lind Alliance prioritisation project, which established the shared stroke research priorities of stroke survivors, carers and health professionals.

Design: Research priority setting project using James Lind Alliance methods; a survey for interim prioritisation and a consensus meeting for final priority setting.

Methods: Between September and December 2014 stroke nurses were invited to select their top 10 priorities from a previously established list of 226 unique unanswered questions. These data were used to generate a list of shared research priorities (interim priority-setting stage). A purposefully selected group of stroke nurses attended a final consensus meeting (April 2015) to determine the top 10 research priorities.

Results: During the interim prioritisation stage, 97 stroke nurses identified 28 shared priority treatment uncertainties. At the final consensus meeting, 27 stroke nurses reached agreement on the top 10 stroke nursing research priorities. Five of the top 10 questions relate to stroke specific impairments and 5 relate to rehabilitation and long-term consequences of stroke.

Conclusions: The research agenda for stroke nursing has now been clearly defined, facilitating nurses to undertake research which is of importance to stroke survivors and carers, and central to supporting optimal recovery and quality of life after stroke.

SUMMARY STATEMENT

What is already known about this topic:

- The top 10 research priorities relating to life after stroke were defined following a comprehensive, rigorous method involving stroke survivors, carers and health professionals.
- Evidence suggests that the top 10 stroke research priorities are informing research agendas, policy and funding nationally and internationally.
- The top 10 stroke research priorities did not provide specific direction to any one clinical or research grouping, including stroke nursing.

Key findings:

- The top 10 research priorities specific to stroke nursing have been identified.
- The stroke nursing research priorities relate to specific stroke related impairments, such as the management of fatigue and incontinence, and nursing strategies such as goal setting and self-management techniques.
- Two of the top 10 stroke nursing research priorities are included in the World Stroke Organisation recommendations (improving cognition and coming to terms with the long-term consequences of stroke).

Implications for practice and/or policy:

- Will ensure the stroke nursing research strategy is focused on research priorities agreed by stroke nurses.
- Will encourage more nurse-led stroke research, which is relevant to what nurses do and is valued by stroke patients and carers.
- Will increase co-ordinated and unified multi-national stroke nursing research programmes.
- Nurses and nurse-orientated research organisations should now establish collaborative activities to address the top 10 stroke nursing research priorities.

Key words: Stroke; Nursing; Patient and carer involvement; Research priorities; Research agenda;
Policy; Funding; Impact

INTRODUCTION

Stroke is a leading cause of death and disability, affecting 16.9 million people worldwide with their first-ever stroke per year (Feigin et al. 2014). About half of the 33 million stroke survivors will have a moderate to severe stroke-related disability, including significant physical, cognitive, and/or emotional deficits that require continued care and support (Di Carlo 2009, Feigin et al. 2014). This has a huge impact on health services and the economy; for example the combined health-related costs to the wider economies of Australia, Europe, China, UK and the USA exceeds £90 billion per year (Di Carlo 2009, Saka et al. 2009, Lui et al. 2011, Australian Institute of Health and Welfare 2013). However over the last 20 years, there have been significant efforts to reduce stroke incidence and mortality as well as increase the number of nurses that are knowledgeable about and interested in stroke (Kirkvold 2010).

Increasing the scope and reach of clinical nursing research is supported by governments, nursing professional regulatory bodies, and an international network of bodies including health care providers, academia and patients groups (European Science Foundation 2011, O’Byrne & Smith 2011, Chan et al.2013, Shaffer et al. 2014, Sun & Larson 2015, Wang et al. 2016). There have also been calls for clinical researchers and patient groups to work together to identify priorities for research (Liberati et al. 2011). The National Institute for Health Research in the UK (NIHR, 2014) and Patient Centered Outcomes Research Institute in the USA (PCORI, 2016) advocate the importance of public involvement, which means that patients and the public are actively participating in health care research in a strategic and meaningful way, not just contributing to data. Therefore, nurses should incorporate the views of patients and the public when prioritising research activities, ensuring that studies remain patient-centred and clinically relevant (INVOLVE 2015). In order to help stroke nurses build their research capability and capacity we undertook a project to identify the research priorities that are perceived to be of greatest importance to nursing and relevant to life after stroke.

Background

The role of the stroke nurse has been explored in the UK (Burton 2000, O'Connor 2000, Pound & Ebrahim 2000, Booth et al. 2001, Booth et al. 2009), Canada (Burton et al. 2009), Norway (Kirkvold 1997), Sweden and China (Booth et al. 2009). Research has been described as a crucial component of their role (Burton et al. 2009). However, nurses often do not have the time, research skills, confidence, and/or support from colleagues and managers to be able to undertake research themselves (Woodward et al. 2007, Edwards et al. 2009). Nurses also report difficulties in securing sufficient research funding compared with their medical colleagues resulting in smaller-scale descriptive studies that have limited influence on clinical practice (McKevitt et al. 2004; Halberg et al. 2006). This has resulted in calls for nursing research to be more "implementation focused" to ensure that it can be transferred more readily into practice (Halberg et al. 2009, Richard & Borglin 2011). It is also recommended that nursing research be clearly articulated and focused in order to develop meaningful research agendas (European Science Foundation 2011).

There is no doubt that the nurses' role in caring for stroke patients, who experience a wide range of impairments and are looked after across multiple care environments, is diffuse and complex (Booth et al. 2005). Additionally, the multidisciplinary nature of stroke care makes it difficult to discern the specific role of the nurse within traditional professional boundaries (Seneviratne et al. 2009). There are also differences in working patterns and organisational structures between nurses and other health professionals, which also emphasise the importance of determining the impact that nurses have in specific areas of stroke care and their effects on patients' outcomes. However skilled nursing care has been recognised as a core component of organised inpatient care for people with stroke, for which there is an established evidence base (Stroke Unit Trialists' Collaboration 2013, Langhorne & Pollock 2002). Further, there is now increasing evidence that nurse-led intervention studies are feasible and relevant to clinical practice (Larson et al. 2005, Middleton et al. 2011, Thomas et al.

2014). For example one nurse-led trial, “Quality in Acute Stroke Care” (QASC), found that treatment protocols for fever, hyperglycaemia and swallowing problems significantly reduce death and dependency after stroke (Middleton et al. 2011). This trial clearly highlights the importance of growing nursing evidence-based practice through high-quality research to influence better outcomes after stroke.

We have previously reported that stroke nurses have broad research interests relating to the practical management of stroke patients and carers, optimal stroke care environments and self-development (Rowat et al. 2009). However, this study did not consider the views of patients and carers and some of the priority research questions identified by nurses already had an evidence base (Rowat et al. 2009). In the UK, the James Lind Alliance (JLA) has been established to ascertain unanswered research questions related to “treatment uncertainties” that are identified and prioritised by clinicians, patients and carers (Partridge & Scadding 2004). The JLA method uses a pragmatic and efficient approach to research prioritisation that includes 5 key stages (Cowan & Oliver 2013). A key objective of a JLA priority setting project is to generate a definitive list of research uncertainties that are attained through consensus with all stakeholders. Ultimately, the final list of research priorities (i.e. top 10) should reflect what matters most to those affected by a healthcare condition and should be used to inform future research agendas as well as provide focus for research funding.

In 2010, Pollock et al. (2012, 2014) undertook a JLA priority setting project to identify research priorities relating to life after stroke. Using rigorous transparent methods, 226 unanswered research questions were identified and top 10 priorities agreed, with equal involvement of stroke survivors, carers and health professional (Pollock et al. 2013). Anecdotal evidence suggests that these top 10 stroke research priorities are now informing stroke research activities with commissioned and researcher-led research funding supporting related projects. However, a recognised limitation of

these top 10 research priorities is that they reflect research “topics” rather than clearly defined research questions (Pollock et al. 2014). Furthermore, these topic do not provide specific direction to any one clinical or research grouping, such as nursing, despite the fact that the list of 226 unanswered research questions contains many questions that are arguably of direct relevance to stroke nursing. We therefore aimed to reach consensus on the top 10 research questions specific to stroke nursing, building on the rigorous data collected during the previously completed JLA life after stroke prioritisation project (Pollock et al. 2012, 2014).

THE STUDY

Aim

We aimed to reach consensus on the top 10 nursing research priorities relating to life after stroke.

Design

Standard methods developed for priority setting were followed, involving five key stages as per the JLA guidebook recommendations (Figure 1) (Cowan & Oliver 2013). For this project, we took data collected in 2010-2012 from the previously completed JLA life after stroke prioritisation project for stages 1 to 3 as outlined in detail by Pollock et al (2012, 2014). We then used this previously collected data to complete stages 4 and 5 of the priority setting process generating data and insight into research priorities specifically relating to stroke nursing.

Priority setting methods@ stage 1-3 (previously completed)

Briefly, the methods for the previously completed stages (fully reported in Pollock et al. 2014) comprised the following:

Priority setting partnership (stage 1): The life after stroke partnership was established in February 2010, and managed by a steering group comprising a stroke survivor, caregiver, nurse, physician, allied health professional and representatives from key national stroke charities/patient organisations and from the JLA. The steering group defined the scope of this partnership and developed a protocol detailing the methods to be used.

Gather treatment uncertainties (stage 2): A survey was used to identify 548 treatment uncertainties from 15 stroke groups/clubs (183/548), 22 individual stroke survivors (77/548), 4 individual carers (21/548), 4 health professional groups/meetings (37/548), 61 individual health professionals (198/548) and 3 guideline/research recommendations (32/548).

Checking treatment uncertainties (stage 3): All 548 treatment uncertainties were checked for existence of research evidence: 162/548 were excluded as they were not questions about the effect of treatment; the remaining 386 were merged into 228 'indicative' questions. Two were removed as they were already addressed by research. This left 226 unique unanswered research questions (treatment uncertainties) relating to life after stroke.

Priority setting methods: stage 4-5 (completed for this project)

The 226 unique unanswered questions were used in this project, to complete a stage of interim prioritisation (stage 4) and a final consensus meeting (stage 5), in order to reach consensus on the shared top 10 research priorities relevant to stroke nursing. The participants were recruited specifically for this project and the data collected was unique, focusing specifically on stroke nursing.

Participants

The study included stroke nurses, including registered, unregistered and student nurses, who are members of the Scottish Stroke Nurses Forum (SSNF). All 431 SSNF members were given an opportunity to take part in the interim prioritisation stage. Nurses who attended the SSNF annual conference (25/09/2014) were given a brief presentation on the project and were then given dedicated time to complete and submit their responses at the conference if they wished to participate. In addition the questionnaire was also sent by post or email to all SSNF members in November 2014.

A purposefully selected group of nurses were selected to attend a final consensus meeting to determine the top 10 nursing research priorities on the 28/04/2015. Characteristics considered within the sampling framework included position (e.g. non-registered nurse, staff nurse, charge nurse, stroke nurse specialist), care setting (e.g. acute stroke unit, rehabilitation unit, community), years working in stroke care, and geographical location.

Data Collection and Analyses

Interim Prioritisation (stage 4): We used methods based on those used and previously reported by Pollock et al (2012, 2014). Stroke nurses were asked to rank the top 10 questions that they considered a priority to stroke nursing from the summary document including the 226 unique unanswered research questions. Firstly, these data were entered in an excel spreadsheet to determine the ranked order of the unanswered research questions independent of the ranking applied by individual respondents. Second, we determined the combined rank order that reflected the top 10 ranking applied by individual nurses. Finally, we explored the ranked order of research questions based on both these methods to compile a list of shared priorities representing the views of stroke nurses. The JLA guidelines advise an arbitrary cut-off of between 25-30 shared research questions, which is based on the overall combined interim ranked scores, so the number of research questions are focused and manageable for review at the final consensus meeting (Caron-Flinterman 2005, Cowan 2010).

Final Priority Setting (stage 5): An information leaflet and the list of shared priorities identified during the interim prioritisation (stage 4) process were sent to participants 1 week prior to the final consensus meeting. In preparation for the meeting participants were asked to rank in order of priority the importance of these questions in relation to stroke nursing. The JLA recommends an adapted “nominal group” approach to agree the top 10 research priorities (Cowan & Oliver, 2013).

The first phase of this meeting involves dividing participants into smaller groups balanced according to position, base and experience. Each group was supported by an experienced facilitator who was involved in the previous JLA life after stroke prioritisation project, but was independent of this priority setting project specific to stroke nursing. The facilitators aimed to provide guidance on setting group ‘rules’ to ensure equitable participation of all group members. Each group was asked

to rank a series of cards with one of research questions printed clearly on the front in order of importance. The facilitator supported this process by first getting participants to sort the cards into piles of “high”, “medium” and “low” importance, and then ranking the order of the questions within each of these piles. Participants were informed that the wording of the questions could not be changed at this stage, but that changes would be considered during the second phase of the consensus meeting. The facilitator noted any key discussion points on the cards. The ranked order from each of the 3 groups was then summed to give a total ‘score’ for each research question.

For the second phase of the meeting, the participants were brought together to discuss the combined ranked results within a plenary session to reach a consensus on the top 10. Again adopting the methods previously described by Pollock et al (2012, 2014), the questions were written on cards and were laid out in priority order in a central place in the room. In order to establish the reasons for differences in the rankings applied by the different groups, participants were invited to discuss those research questions that were placed in the top 10 by one or more of the 3 groups, but not placed in the combined ranking top 10. The participants then discussed and moved the priority order of cards until there was unanimous agreement on the placement of the Top 10 research priorities.

Ethical considerations

A university research and integrity Committee approved the study. All SSNF members were given oral and/or written explanations of the study before written consent was sought to take part in interim prioritisation or the final consensus stages of the study.

Rigour

The JLA methods have been developed to ensure transparency, accountability and fairness (Chalmers et al. 2013). We therefore built on a previous research priority setting project that used

JLA methods to ensure that there was rigour in establishing meaningful and equitable involvement of patients, carers and clinicians views (Pollock et al. 2012, 2014). However, this method also allows for a certain amount of flexibility in order to take account of the similarities and differences between individual responses from priority-setting partners, in this case to identify specific gaps in stroke nursing practice (Arulkumaran et al. 2015). This study also strived to gain equal representation from all levels of nurses working across different care settings with stroke patients throughout Scotland to establish research priorities from a wider group of nurses, which may not be reflected in the shared top ten relating to life after stroke of health professionals, stroke survivors and carers (Pollock et al. 2012, 2014).

RESULTS

Interim prioritisation (stage 4)

Ninety-seven stroke nurses (Table 1) selected their 10 personal highest priorities from the list of 226. Individual nurses selected 190 (84%) of the 226 research questions. Exploration of the combined ranked order of research questions identified that 23 of the 226 research questions were ranked by at least 10 respondents. However when the applied rank order was considered a further 5 questions fell within the top 25 shared priorities. Therefore it was agreed to include these 28 shared priorities (Table 2), which included research questions related to: stroke prevention (n=2), cognition, mood or communication (n=6); acute, rehabilitation, and long term/care (n=17); and stroke care settings (n=3).

Final priority setting (stage 5)

Twenty-seven nurses (Table 1) attended a final consensus meeting, representing 10 of the 14 NHS boards in Scotland. There were no significant differences in nursing position, care setting and years working in stroke between nurses who took part in the interim prioritisation and final priority setting stages (all $p > 0.1$, Chi-square/Fisher Exact Tests).

During the first phase of the consensus meeting, the participants worked in 3 independent groups (n=9 per group) to agree a group priority ranking of the 28 shared research questions and combined scores and ranks are displayed in Table 2. Eleven of the 28 questions were not placed in the top 10 by any of the 3 independent groups; these 11 questions were not discussed any further, leaving 17 questions that were discussed during the full group plenary session. Three of these questions were placed in the top 10 by all 3 independent groups and were ranked as 1-3 in the agreed top 10, based on the combined group score. Seven of the remaining 13 questions were placed in the top 10 by 2 of the 3 independent groups, but two of these questions were merged into 1 question and were ranked 4-8 in the agreed top 10. The remaining 7 research questions were placed in the top 10 by

only 1 of the 3 independent groups; following substantial discussion two of these questions were ranked as agreed priority 9 and 10. The 4 remaining questions were not placed in the top 10, but 3 were considered to be covered by questions already in the top 10 (Table 2). The wording of four of the agreed top 10 questions was amended; in three cases (qs: 2, 6, 10) this was to more clearly define the focus of the question; and in one case (q: 6) this was done to merge three questions into one.

Box 1 shows the unanimous consensus on the Top 10 shared research priorities. These included 5 research questions related to care of stroke symptoms/impairments (qs: 1-4, 8) and 5 related to rehabilitation and long/term consequences of stroke (qs: 5-7, 9-10).

DISCUSSION

This national priority-setting project identified the top research questions for stroke nurses, and will inform future nurse-led research. Five of the research questions in the top 10 were related to specific stroke impairments (qs: 1-4, 8). Four of these relate to neuropsychological impairments, including fatigue, cognition, and altered mood/emotions, which are often persistent and impact on quality of life and long-term outcomes (Donnellan et al. 2010, Duncan et al. 2012, Cumming et al. 2014, Wu et al. 2015). Further research into continence management after stroke (q 3) is also supported by recent research that demonstrates the difficulties of implementing effective continence interventions (Booth et al. 2009, Thomas et al. 2014). Similarly, research priorities including cognition and post-stroke incontinence are high on stroke research agendas set by health professionals in Europe (Quinn et al. 2009) and the USA (Miller et al. 2010), whereas fatigue is a recognised research priority identified by stroke patients in Australia (Sangvatanakul et al. 2010). The remaining 5 top 10 research questions relate to specific rehabilitation and longer-term care strategies, including social aspects on coming to terms with long-term consequences of stroke and care settings for younger stroke survivors (qs: 5-7, 9-10). Some of these questions are aligned to the national and international guidelines for stroke, which advocate specialist rehabilitation services, person centred approaches and supported self-management strategies (Department of Health 2007, Stroke Foundation of Australia 2010, Scottish Government 2014). It is important to acknowledge that this project was not designed to identify treatment uncertainties related to specific aspects of stroke assessment, investigation, immediate management, surgical/pharmacological interventions or stroke services that are also included in stroke guidelines (Department of Health 2007, Stroke Foundation of Australia 2010, Stroke Foundation of New Zealand 2010, Scottish Government 2014, European Stroke Organisation 2016) and other top 10 stroke research priorities (Wolfe et al 2010). However there is evidence that updates in the future will involve patient and carers research priorities (Lindsay et al, 2015).

It is recognised that there is an urgent need to reduce the waste of research findings and resources (Chalmers et al. 2014). A strength of the current study is that we used an efficient and cost-effective approach to establish the top 10 research priorities specific to stroke nursing, which were identified from the wider list of 226 “unanswered treatment uncertainties” co-developed through consultation with stroke survivors, caregivers and health professionals. Importantly, the results of 3 of the top 10 nursing priorities were also reflected in the previously-derived shared top ten by Pollock et al (2012, 2014) (qs: 1-2, 6); and two are also included in recently published World Stroke Organisation (WSO) recommendations (qs: 2, 6) (Sacco et al, 2015). This overlap clearly highlights the importance of nurses in addressing shared research priorities. Predictably, some of the top-10 research priorities set by nurses are different to those set by the wider health professional groups, stroke survivors and carers. Indeed the wider group included top 10 research priorities that were specific to recovery related to aphasia, arm function, balance, gait and mobility (Pollock et al.2012, 2014). Although these areas are relevant to daily practice in caring for patients with stroke, nurses may not have felt they were directly applicable to their area of expertise. This is an important finding as it may have implications for future nurse-led research and the development of nursing research agendas to enable increased capacity and capability of stroke nursing research.

It was important the top 10 questions retain the original wording in order to reflect the shared views of stroke survivors, carers and health professionals (Partridge & Scadding 2004). In this study, the wording of 4 questions was amended slightly either to focus the question (qs: 2, 9-10) or to merge three questions from the shared 28 questions into one top 10 question (q: 6). However, the top 10 stroke nursing questions may include a wide-range of interventions related to the specific topic of research. Therefore, the specific challenge for stroke nurses will be to focus the research questions to allow them to be taken forward as feasible research projects. We recommend that nurses identify and scrutinise the current stroke evidence from systematic reviews, for example using the Database of Research in Stroke (DORIS 2015), to help clarify specific nursing interventions and/or

comparators as well as relevant outcomes for each of the questions. Therefore, to ensure that the ethos of patient and public involvement is maintained, it is imperative that stroke survivors and families should be consulted at all stages of the research process in developing and conducting the research (INVOLVE 2015, Cowan & Oliver 2013).

Strengths and limitations

Although this study used a nationally recognised pragmatic and efficient approach by building on the previously completed prioritisation project (Pollock et al. 2014), there were concerns that there would be no new questions identified and that some included questions may no longer be considered “uncertainties.” However, the previous study was fairly recent (2010-2012) and 84% of the research questions from the wider list of 226 were included in individuals’ top 10 in the interim stage, suggesting that that the majority were still considered to be relevant and important to stroke nursing. Second, it could be argued that patients and carers should also have been included in stages 4 and 5 in the current priority-setting project. However, it was not our aim to repeat the JLA top 10 relating to life after stroke established by the wider group (Pollock et al, 2012, 2013). Rather the purpose of this study was to determine the similarities and differences reported in the stroke nurses’ top 10 in order to establish the gaps in their knowledge based on the wider list of 226 questions, which are also applicable to stroke survivors’ and carers’ experiences of life after stroke. Third, within our current study, there were disproportionately more stroke nurses in specialist roles (37%-44%) who had more than 10 years’ experience (58%-59%) and took part in either interim prioritisation or the final consensus meeting, which may not reflect the wider group of stroke nurses. However, this study also successfully included the views of stroke nurses who worked across different care settings in a range of different positions, including non-registered nurses, across Scotland. Likewise the configuration of stroke nursing staff working in acute, rehabilitation and community settings is similar to that of other western healthcare systems (Booth et al. 2009). Finally, by targeting SSNF members we aimed to encourage completion of the questionnaire, which

in mitigation can be complex and time-consuming as participants were required to identify 10 out of 226 questions. While only 23% of SSNF members completed the interim stage, this is similar to the proportion of participants included in previous priority setting projects (Eleftheriadou et al. 2011, Pollock et al. 2014, Morris et al. 2015).

Conclusions

These top 10 research priorities provide a clear direction for future stroke nursing research that is important to patients, carers and nurses. To ensure awareness of project outcomes and implications for future research agendas the results have been sent directly to: stroke research networks; health care providers; government working groups with a remit in stroke; and charities and organisations with a responsibility in public involvement of stroke care and funding. The results are also being disseminated widely at national and international conferences, patient involvement groups/clubs and via social media. The top-10 nursing research questions are also being used to inform our national stroke nursing research agenda in order to support stroke nurses and nurse-orientated organisations to establish collaborative activities to address these stroke nursing priorities as soon as possible. It is also reassuring that 2 of the top 10 nursing stroke research priorities are included in the WSO research priorities (Sacco et al. 2015) as this will help to foster international collaboration and co-operation to develop programmes of stroke nursing research more globally. Perhaps one of the greatest challenges is to ensure that the “treatment uncertainties” related to life after stroke secures research funding. To date the Life after Stroke priority setting project (Pollock et al. 2012, 2014) has been commended to the extent to which it has explored different methods of engagement, identifying a wide range of research uncertainties that are successfully influencing the activities of researchers and funders (Crowe et al. 2015). Overall, our aim is to encourage more nurse-led research that will facilitate the attainment of high professional standards in order to provide optimal nursing care to stroke patients and their families.

REFERENCES

- Arulkumaran N., Reay H. & Brett S.J. on behalf of the JLA Intensive Care Research Priority Setting Partnership. (2015) Research priorities by professional background – a detailed analysis of the James Lind Alliance Priority Partnership [Online]. *Journal of the Intensive Care Society*, doi: 10.1177/1751143715609954.
- Australian Institute of Health and Welfare. (2013) *Stroke and its management in Australia: an update*. Cardiovascular disease series no 37. Cat. No. CVD 61. Canberra: AIHW.
- Booth J. (2001) Observing washing and dressing of stroke patients: nursing intervention compared with occupational therapists. What is the difference? *Journal of Advanced Nursing* **33**, 98-105
- Booth J., Hillier V.F., Waters K. & Davidson I (2005) Effects of stroke rehabilitation education programme for nurses. *Journal of Advanced Nursing* **49**, 465-473.
- Booth J., Kumlien S., Zang Y., Gustafsson B. & Tolson D. (2009) Rehabilitation nurses practices in relation to urinary incontinence following stroke: a cross cultural comparison. *Journal of Clinical Nursing* **18**, 1049-1058.
- Burton C. (2000) A description of the nurses role in stroke rehabilitation. *Journal of Advance Nursing* **32**, 174-181.
- Burton C.R., Fisher A. & Green T.L., (2009) The organisational context of nursing care in stroke units: a case study approach. *International Journal of Nursing Studies* **46**(1), 85-94.
- Caron-Flinterman F. (2005) *A new voice in science – patient participation in decision making on biomedical research*. Vrije Universiteit, Amsterdam.
- Chalmers I., Atkinson P., Fenton M., Firkins L., Crowe S. & Cowan S. (2013) Tackling treatment uncertainties together: the evolution of the James Lind Initiative: 2003-2013. *Journal of the Royal Society of Medicine* **106**(12), 482-491.

Chalmers I., Bracken M.B., Djulbegovic B., Garattini S., Grant J., Gulmezoglu A.M., Howells D.W., Ioannidis J.P.A. & Oliver S. (2014) How to increase value and reduce waste when research priorities are set [Online]. *Lancet* pii: S0140-6736(15)00307-4. doi: 10.1016/S0140-6736(15)00307-4.

Chan R.J., Dunning T., Mills J., Yates P. & Zeitz K. (2013) Nursing research: the Australian College of Nursing position statement [Online]. *Collegian* doi: <http://dx.doi.org/10.1016/j.colegn.2015.01.003>.

Cowan K. & Oliver S. (2013) *The James Lind Alliance Guidebook: version 5* [Online]. Retrieved from <http://www.jlguidebook.org/pdfguidebook/guidebook.pdf> on 15 October 2015.

Cowan K. (2010) The James Lind Alliance – tackling treatment uncertainties together. *Journal of Ambulatory Care Management* **33**(3), 241-248.

Crowe S., Fenton M., Hall M., Cowan K. & Chalmers I. (2015) Patients', Clinicians' and the research communities priorities for treatment research: there is an important mismatch [Online]. *Research Involvement and Engagement* **1**, 2. doi: 10.1186/s40900-015-0003-x.

Cumming T.B., Brodtmann A., Darby D. & Bernhardt J. (2014) The importance of cognition to quality of life after stroke. *Journal of Psychosomatic Research* **77**, 374-379.

Di Carlo A. (2009) Human and economic burden of stroke. *Age and Ageing* **38**(1), 4-5.

Department of Health. (2007) *National Stroke Strategy* [Online]. Retrieved from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081059.pdf on 22 March 2016

Donnellan C., Hickey A., Hevey D. & O'Neill D.O. (2010) Effect of mood symptoms on recovery one year after stroke. *International Journal of Geriatric Psychiatry* **25**, 1288-1295.

DORIS. (2015) *Database of Research in Stroke* [Online]. Retrieved from <http://www.askdoris.org> on 22 March 2016.

Duncan F., Wu S. & Mead G. (2012) Frequency and natural history of fatigue after stroke: a systematic review of longitudinal studies. *Journal of Psychosomatic Research* **73**, 18-27.

Edwards N., Webber J., Mill J., Kahwa E. & Roelofs S. (2009) Building capacity for nurse-led research. *International Journal of Nursing Studies* **56**, 88-94.

Eleftheriadou V., Whitton M.E., Gawkrödger D.J., Batchelor J., Corne J., Lamb B., Erdder S., Ravenscroft J. & Thomas KS. on behalf of the vitiligo priority partnership (2011) Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership. *British Journal of Dermatology* **164**(3), 530-536.

European Science Foundation. (2016) *Researching complex interventions for nursing (REFLECTION)* [Online]. Retrieved from <http://www.esf.org/coordinating-research/research-networking-programmes/biomedical-sciences-med/current-esf-research-networking-programmes/researching-complex-interventions-for-nursing-reflection.html> on 22 March 2016.

European Stroke Organisation. (2016) *Guidelines* [Online] Retrieved from <http://www.eso-stroke.org/eso-stroke/education/guidelines.html> on 13 April 2016.

Feigin V.L., Forouzanfar M.H., Krishnamurthi R., Mensah G.A., Conner M., Bennett D.A., Moran A. E., Sacco R.L., Anderson L., Truelsen T., O'Donnell M., Venketasubramanian N., Barker-Collo S., Lawes C.M.M., Wang W., Shinohara Y., Witt. E., Ezzati M., Naghavi M. & Murray C. on behalf of the Global Burden of Diseases, Injuries and Risk Factors Study 2010 (GBD 2010) and Risk Factors Experts Group. (2014) Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet* **383**(9913), 245-254.

Halberg I. (2006) Challenges for future nursing research: providing evidence for health-care practice. *International Journal of Nursing Studies* **43**, 923-927.

Halberg I. (2009) Moving nursing research forward towards a stronger impact on health care practice? *International Journal of Nursing Studies* **46**, 407-412.

INVOLVE (2015) *Public involvement in research: values and principles framework*. INVOLVE, Eastleigh.

- Kirkvold M. (1997) The role of nursing rehabilitation of acute stroke patients: toward a unified theoretical perspective. *Advances in Nursing Science* **19**(4), 55-64.
- Kirkvold M. (2010) The role of nursing in the rehabilitation of stroke survivors: an extended theoretical account. *Advances in Nursing Science* **33**(1), E27-40.
- Langhorne P. & Pollock A. (2002) What are the components of effective stroke unit care? *Age and Ageing* **31**, 365-371.
- Larson J., Franzen-Dahlin A., Billing A., Arbin M., Murray V. & Wredling R. (2005) The impact of a nurse-led support and education programme for spouses of stroke patients: a randomised controlled trial. *Journal of Clinical Nursing* **14**(8), 995-1003.
- Liberati A. (2011) Need to realign patient-orientated and commercial and academic research. *Lancet* **378**, 1777-1778.
- Lindsay MP., Gubitz G., Bayley M., Phillips S. & Smith E.E. on behalf of the Canadian Stroke Best Practice Advisory Committee. (2014) *Canadian stroke best practice recommendations (update 2014-15)* [Online] retrieved from <http://www.strokebestpractices.ca> on 13 April 2016.
- Lui L., Wang D., Wong K.S.L. & Wang Y. (2011) Stroke and stroke care in China. *Stroke* **42**, 3651-3654.
- McKevitt C., Redfern J., Mold F. & Wolfe C. (2004) Qualitative studies of stroke: a systematic review *Stroke* **35**, 1499-1505.
- Middleton S., McElduff P., Ward J., Gimshaw J.M., Dale S., D'Este C., Drury P., Griffiths R., Wah Cheung N., Quinn C., Evans, M., Cadilhac D. & Levi C. on behalf of the QASC Trialists Group. (2011) Implementation of evidence-based treatment protocols to manage fever, hyperglycaemia, and swallowing dysfunction in acute stroke (QASC): a cluster randomised controlled trial. *Lancet* **378**(9804), 1699-1706.
- Miller E.L., Murray L., Ruchards L., Zorowitz R.D., Bakas T., Clark P & Billinger S.A. on behalf of the American Association Council on Cardiovascular Nursing and the Stroke Council. (2010)

Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patients: A scientific statement from the American Heart Association. *Stroke* **41**, 2402-2448.

Morris C., Simkiss D., Busk M., Morris M., Allard A., Denness J., Janssens A., Stimson A., Coghill J., Robinson K., Fenton M. & Cowan K. Setting research priorities to improve the health of children and young people with neurodisability: a British Academy of Childhood Disability – James Lind Alliance Priority Setting Partnership [Online]. *British Medical Journal Open* 5(1), e006233.

doi:10.1136/bmjopen-2014-006233

NHS National Institute for Health Research (2014) *Patient and public involvement in health and social care research: A handbook for researchers* [Online]. Retrieved from <http://www.nihr.ac.uk/funding/how-we-can-help-you/RDS-PPI-Handbook-2014-v8-FINAL.pdf> on 10 September 2015

O'Byrne L. & Smith S. (2011) Models to enhance research capacity and capability in nephrology nurses; a narrative review. *Journal of Nephrology Nursing* **20**(9-10), 1365-1371.

O'Connor S.E. (2000) Nursing interventions in stroke rehabilitation: a study of nurses' views of their pattern of care in stroke units. *Rehabilitation Nursing* **25**, 224-230.

Partridge N. & Scadding J. (2004) The James Lind Alliance: patients and clinicians should jointly identify priorities for clinical trials. *Lancet*, **364**, 1923-1924.

Patient Centred Outcomes Research Institute. (2016) *Shared decision making* [Online]. Retrieved from <http://www.pcori.org> on 22 March 2016.

Pollock A., St George B., Fenton M. & Firkins L. (2012) Top ten research priorities relating to life after stroke. *Lancet Neurology* **11**(3), 209.

Pollock A., St George B., Crowe S., Fenton M. & Firkins L. (2013) Development of a new model to engage patients and clinicians in setting research priorities [Online]. *Health Services Research and Policy*. doi: 10.1177/1355819613500665.

Pollock A., St George B., Fenton M. & Firkins L. (2014) Top ten research priorities relating to life after stroke – consensus from stroke survivors, caregivers and health professionals. *International Journal of Stroke* **9**(3), 313-20.

Pound P. & Ebrahim S. (2000) Rhetoric and reality in stroke patient care. *Social Science and Medicine* **51**, 1437-1446.

Quinn T.J., Paolucci S., Sunnerhagen K.S., Sevenius J., Walker M.F., Toni D. & Lees K.R. (2009) Evidence-based stroke rehabilitation: an expanded guidance document from the European Stroke Organisation (ESO) guidelines for management of ischaemic stroke and transient ischaemic attack 2008. *Journal of Rehabilitation Medicine* **41**, 99-111.

Richard D.A & Borglin G. (2011) Complex intervention and nursing: looking through a new lens at nursing research. *International Journal of Nursing Studies* **48**, 531-533.

Rowat A., Lawrence M., Horsburgh D., Legg L., Smith L. on behalf of the Scottish Stroke Nurses Forum. (2009) Stroke research questions – a nursing perspective. *British Journal of Nursing* **18**(2), 100-104.

Sacco R.L., Sandercock P., Endres M., Feigin V., Pandian J., Shinohara Y. & Spence J.D. (2015) Review and prioritization of stroke research recommendations to address the mission of the World Stroke Organization: a call to action from WSO research committee. *International Journal of Stroke* **10**, 4-9.

Saka O., McGuire A. & Wolfe C. (2009) Cost of stroke in the United Kingdom. *Age and Ageing* **38**(1), 27-32.

Sangvatanakul P., Hilege S., Ialor E., Levi C., Hill K. & Middleton S. (2010) Setting stroke research priorities: the consumer perspective. *Journal of Vascular Nursing* **28**, 121-131.

Scottish Government. (2014) *The stroke improvement plan* [Online]. Retrieved from <http://www.gov.scot/Publications/2014/08/9114> on 10 September 2015.

Seneviratne C.C., Mather C.M., & Then K.L. (2009) Understanding nursing on an acute stroke unit: perceptions of space, time and interprofessional practice. *Journal of Advanced Nursing* **65**(9), 1872-1881.

Shaffer F.A., Davis C.R., Dutka J.T. & Richardson D.R. (2014) The future of nursing: domestic agenda, global implications. *Journal of Translational Nursing* **25**, 388-394.

Stroke Foundation of Australia (2010) Clinical guidelines for stroke management: a quick guide for nursing [Online]. Retrieved from

https://strokefoundation.com.au/~media/strokewebsite/resources/treatment/nsf_concise-guidelines_nursing_2011.ashx?la=en on 22 April 2016.

Stroke Foundation of New Zealand (2010) New Zealand clinical guidelines for stroke management [Online]. Retrieved from

<http://www.stroke.org.nz/resources/NZClinicalGuidelinesStrokeManagement2010ActiveContents.pdf> on 22 April 2016.

Stroke Unit Trialists' Collaboration. Organised inpatient (stroke unit) care for stroke. (2013) *Cochrane Database Systematic Reviews* (9):CD000197, doi: 10.1002/14651858.CD000197.pub3.

Sun C. & Larson E. (2015) Clinical nursing and midwifery research in African countries: a scoping review. *International Journal of Nursing Studies* **52**(5), 1011-1016.

Thomas L.H., French B., Burton C.R., Sutton C., Forshaw D., Dickson H., Leathley M.J., Britt D., Roe B., Cheater F.M., Booth J. & Watkins C.L. on behalf the ICONS Project Team & the ICONS Patient, Public and Carer Involvement Groups. (2014) Evaluating a systematic voiding programme for patients with urinary incontinence after stroke in secondary care using soft systems analysis and normalisation process theory: findings from ICONS case study phase. *International Journal of Nursing Studies* **51**, 1308-1320.

Wang C.C., Whitehead L. & Bayes S. (2016) Nursing education in China: meeting the global demand for quality healthcare [Online]. *International Journal of Nursing Sciences* doi: 10.1016/j.ijnss.2016.02.009.

Wolfe C., Rudd A., McKevutt C., Heuschmann P. & Kalra L. (2010) *Top ten research priorities for stroke services research – a summary of an analysis of research for National Stroke Strategy* [Online] retrieved from http://www.interactstrokesupport.org/sites/interactstrokesupport.org/files/uploads/WolfeKalraetal_0.pdf on 13 April 2016.

Woodward V., Webb C. & Prowse M. (2007) The perceptions and experiences of nurses undertaking research in the clinical setting. *Journal of Research in Nursing* **12**(3), 227-244.

Wu S., Kutlubaev M.A., Chun H.Y.Y., Cowey E., Pollock A., Macleod M.R., Dennis M., Keane E., Sharpe M. & Mead G.E. (2015) Interventions for post-stroke fatigue. *Cochrane Database of Systematic Reviews* 2015, Issue 7. Art. No.: CD007030, doi: 10.1002/14651858.CD007030.pub3.

Table 1: Characteristics of participants in the interim prioritisation stage (n=97) and the final consensus meeting (n= 27)

	Interim Prioritisation (n=97)	Final Consensus (n=27)	p value*
Position n (%):			p=0.292
Charge Nurse	14 (14)	4 (15)	
Staff Nurse	19 (20)	5 (19)	
Stroke specialist ^a	36 (37)	12 (44)	
Nursing Assistant	1 (1)	2 (7)	
Research	12 (12)	3 (11)	
Other/not stated ^b	15 (15)	1 (4)	
Base n (%):			p=0.373
Acute stroke unit	22 (23)	4 (15)	
Rehabilitation stroke unit	12 (12)	7 (26)	
Combined stroke unit	15 (15)	2 (7)	
Community	23 (24)	7 (26)	
Both hospital/community	7 (7)	4 (15)	
University	9 (9)	2 (7)	
Other/not stated ^b	9 (9)	1 (4)	
Experience, years:			p=0.742
≤5	22 (23)	6 (22)	
6-10	15 (15)	5 (19)	
10+	56 (58)	16 (59)	
Not stated	4 (4)	0	
NHS Health Board representation, n (%):	Not stated	10 (71)**	

^aIncludes stroke consultant, stroke nurse co-ordinators, and stroke liaison nurses

^bIncludes voluntary sector or office based positions

*Chi-square/Fisher Exact tests were used to compare the differences between nominal data

**There was no stroke nurse representative for 4 Scottish NHS Boards (Forth Valley, Orkney, Shetland & Tayside).

Table 2: Consensus on shared Top 10. Individual group prioritisation, combined group score and ranking, and key notes relating to shared top 28 research questions, as determined at Consensus Meeting.

Research question (classification used in the wider list of 226 questions)	Group 1 ranking	Group 2 ranking	Group 3 ranking	Combined group score	Combined group ranking	FINAL Agreed Top 10 (and key notes from consensus meeting)
What are the best ways to manage and/or prevent fatigue?	5	7	1	13	1	1
What are the best ways to improve cognition after stroke?	9	3	5	17	2	2
What are the best ways to manage urinary and faecal incontinence?	7	6	6	19	3=	3
What are the best ways to manage altered mood and emotion after stroke?	4	2	13	19	3=	4
What are the best ways to promote self-management and self-help after stroke?	3	1	17	21	5=	5
What are the best ways of helping stroke survivors and their families come to terms with the uncertainty of prognosis and the long term consequences of stroke? ^b	1	9	18	28	8	6
Can a goal setting approach help recovery after stroke?	13	5	3	21	5=	7
What is the impact of thrombolysis on emotion, cognition and communication?	6	4	22	32	10	8
Is a “young stroke environment” better than other stroke rehabilitation environments at improving recovery of young people after stroke? ^c	10	14	10	34	11	9
What is the optimal amount and intensity of therapy provided by nurses for patients with stroke? ^d	26	8	20	54	18	10
What is the best way of supporting family members of stroke survivors?*	11	11	4	26	7	Combined with 6
What is the best way to help people deal constructively with the uncertainty of prognosis?*	2	10	19	31	9	Combined with 6
What is the optimal staffing levels within stroke units?	20	25	2	47	15	Covered by 10
How can memory problems after stroke be improved?	14	13	8	35	12	Covered by 2
How can stroke survivors and families be helped to cope with speech problems?	15	16	9	40	13	Covered by 6
What is the best way to manage central post-stroke (neuropathic) pain?	25	12	7	44	14	Not put in top 10
Can screening programmes reduce the risk of subsequent stroke?	8	19	24	51	17	Not put in top 10
When is the best time to move someone from a major stroke unit to a smaller rehabilitation unit nearer to their home?	16	17	15	48	16	not discussed

Are specialist stroke nurses better than non-specialist nurses at improving recovery after stroke?	22	23	12	57	19=	not discussed
What is the best way of managing the long term needs of stroke survivors? (including the roles of primary care health practitioners and consultants).	19	15	23	57	19=	not discussed
Does thrombolysis have an adverse effect on cognitive abilities?	12	21	25	58	21	not discussed
Is lifestyle advice useful at promoting lifestyle improvements and reducing risk of stroke?	18	20	21	59	22	not discussed
What is the best way to provide information after stroke?	17	27	16	60	23	not discussed
What are the key components of an effective stroke unit?	27	24	14	65	24	not discussed
How often should General Practitioners check drugs and blood pressure (BP)?	28	28	11	67	25	not discussed
Has the FAST (Face-Arm-Speech-Time to call) campaign improved stroke management?	24	18	27	69	26	not discussed
Are stroke co-ordinators / liaison workers beneficial in the management of stroke?	23	22	26	71	27	not discussed
Does high morale within the stroke team service improve stroke recovery?	21	26	28	75	28	not discussed

^a Original wording of question: “What are the best ways to improve understanding (cognition) after stroke?” Wording was amended and a definition added.

^b Original wording of question: “What are the best ways of helping people come to terms with the long term consequences of stroke?” Wording was amended, and this original question combined with 2 questions*.

^c Original wording of question: “Is a ‘young stroke environment’ better than a geriatric/ stroke rehabilitation environment at improving recovery of young people after stroke?” Wording was amended to remove the terms “geriatric / stroke rehabilitation environment”. It was noted that the question ought not to imply any preference for one environment over another, but rather to highlight the need for research into the relative benefits of different types of environment.

^d Original wording of question “What is the optimal amount and intensity of therapy for patients with stroke?” The phrase “provided by nurses” was added.

Box 1: Top Ten nursing research priorities relating to life after stroke.

1. What are the best ways to manage and/or prevent fatigue?
2. What are the best ways to improve cognition* after stroke?
3. What are the best ways to manage urinary and faecal incontinence?
4. What are the best ways to manage altered mood and emotion after stroke?
5. What are the best ways to promote self-management and self-help after stroke?
6. What are the best ways of helping stroke survivors and their families come to terms with uncertainty of prognosis and the long-term consequences of stroke?
7. Can a goal setting approach help recovery after stroke?
8. What is the impact of thrombolysis on emotion, cognition and communication?
9. Is a “young stroke environment” better than other stroke rehabilitation environments at improving recovery of young people after stroke?
10. What is the optimal amount and intensity of therapy provided by nurses for patients with stroke?

**Cognition: the function of processing information and applying knowledge. Functions include processes requiring thought and intelligence, such as attention, perception, learning, memory, comprehension, judgment and decision-making (Stroke Association, 2015).*

Figure 1: Key stages of priority setting process relating to life after stroke (stages 1-3) and stroke nursing (stages 4-5)

