GCU Glasgow Caledonian University

CHIEF SCIENTIST OFFICE

Nursing, Midwifery and Allied Health Professions Research Unit

Final report

Stroke survivor, carer and health professional research priorities relating to life after stroke

The James Lind Alliance (JLA) aims to ensure meaningful patient involvement in research priority setting.

A JLA priority setting partnership was established to identify research priorities relating to life after stroke.

This partnership has identified the Top 10 research priorities relating to life after stroke using a rigorous and person-centred approach.

These Top 10 research priorities have been identified and agreed by stroke survivors, carers and health professionals involved in stroke care.

The partnership believes that the Top 10 shared priorities will be invaluable in informing funding of future stroke research.

31st January 2012

DORIS database of research in stroke

Chest Heart & Stroke Scotland

The STROKE Association

Contents

Life after Stroke - Top 10 research priorities

1. What are the best ways to improve cognition after 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)
2. What are the best ways of helping people come to terms with the long term consequences of stroke?
3. What are the best ways to help people recover from aphasia?
4. What are the best treatments for arm recovery and function? (Including visual feedback, virtual reality, bilateral training, repetitive task training, imagery/mental practice, splinting, electromechanical and robot-assisted arm training and botulinum toxin).
5. What are the best ways to treat visual problems after stroke?
6. What are the best ways to manage and/or prevent fatigue?
7. What are the best treatments to improve balance, gait and mobility? (Including physiotherapy, gait rehabilitation, visual and auditory feedback, electrical stimulation, different types of ankle foot orthoses and electromechanical assisted gait training)
8. How can stroke survivors and families be helped to cope with speech problems?
9. What are the best ways to improve confidence after stroke, including stroke clubs/groups, offering support, one-to-one input and re-skilling?
10. Are exercise and fitness programmes beneficial at improving function and quality of life and avoiding subsequent stroke?

Summary of methods and results

INTRODUCTION & AIM

The *James Lind Alliance (JLA)* aims to ensure meaningful patient involvement in research priority setting. We established a JLA priority setting partnership to identify research priorities relating to life after stroke.

(Download the protocol for the priority setting project: http://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/

METHODS

(see Figure 1 for key stages within methods)

Gathering treatment uncertainties.

Treatment uncertainties were gathered from stroke survivors, carers and health professionals throughout Scotland through

(i) visiting stroke clubs in 11 NHS Scotland areas;

(ii) information stands at national stroke meetings;

(iii) posting information to stroke charities' mailing lists;

(iv) emailing health professional groups;

(v) searching clinical guidelines, systematic reviews and published research recommendations.

(Download the information leaflet about gathering treatment uncertainties: http://www.askdoris.org/D_JLA.asp)

(View an audio presentation about gathering treatment uncertainties: http://www.authorstream.com/Presentation/AskDORIS2009-691625-jla-presentation-november-2009/)

Checking treatment uncertainties.

Similar treatment uncertainties were merged, reformatted into 'indicative questions' using a standard structure, and checked to ensure that they are not already answered with research evidence.

When checking to ensure that treatment uncertainties were not already answered with research evidence we used the JLA definition of a treatment uncertainty: "a question about the effects of a healthcare intervention (including prevention, testing and rehabilitation) for

which there is no up-to-date, reliable systematic reviews of research evidence or for which there is up-to-date systematic reviews of research evidence confirming that uncertainty exists." . If there was a Cochrane review relevant to the treatment uncertainty we viewed the implications for research. If further research was recommended then this was classed as a true uncertainty. If there were no relevant Cochrane reviews we searched the Centre for Reviews and Dissemination database (http://www.crd.york.ac.uk/crdweb/SearchPage.asp) and repeated the above process as per Cochrane reviews. If there was (i) no published systematic review, (ii) a published review with a search more than 2 years out of date, (iii) a published review which identifies the need for further primary research then it was assumed that further research was necessary and the question was a true uncertainty. Each uncertainty was also checked against evidence synthesised with the SIGN stroke rehabilitation guidelines (http://www.sign.ac.uk/guidelines/fulltext/118/index.html) .

Interim prioritisation.

The list of treatment uncertainties was sent to stroke survivors, carers and health professionals who identified their top 10 priorities. The results from individual respondents were merged and a prioritised list of treatment uncertainties determined.

Final prioritisation.

The shared top 24 treatment uncertainties were discussed at a consensus meeting of stroke survivors, carers and health professionals. The Top 10 research priorities for life after stroke were agreed.

RESULTS

Gathering treatment uncertainties.

548 treatment uncertainties were gathered. These came from 15 stroke groups/clubs, 22 individual stroke survivors, 4 health professional groups/meetings, 61 individual health professionals and 3 guidelines / research recommendations.

Checking treatment uncertainties.

After merging similar questions, removing questions already answered by research and questions which were not about the effects of treatment, 226 unique research questions remained.

(Download the 226 unique research questions: http://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/)

Interim prioritisation.

97 respondents (42 stroke survivors / carers, 55 health professionals) selected their personal top 10 from the list of 226. We found substantial disagreement between the 'top' questions of stroke survivors / carers and health professionals. We identified the top questions of stroke survivors / carers AND the top questions from health professionals (we did this based on both number of votes and assigned scores). We merged these questions, resulting in a combined Top 24 treatment uncertainties.

(Download the 24 combined Top 24 treatment uncertainties: http://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/)

Final prioritisation.

28 people (16 stroke survivors / carers and 12 health professionals) attended a final consensus meeting on November 16th 2011. The group agreed on a shared Top 10 research priorities relating to life after stroke.

(Download the information leaflet for consensus meeting participants: http://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/)

(Download the agenda for the consensus meeting: http://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/)

(View the Top 10 shared research priorities relating to life after stroke: http://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/)

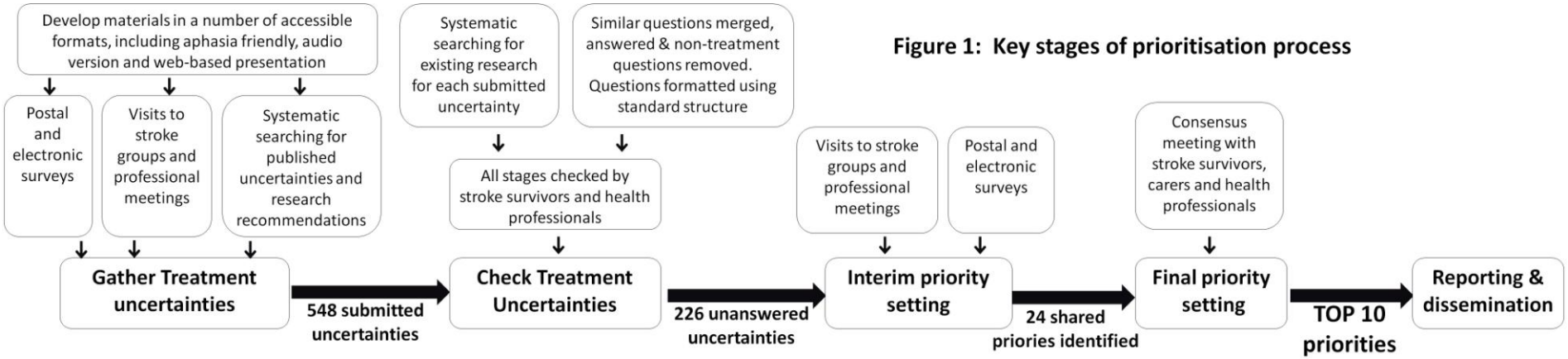

Figure 1: Key stages of prioritisation process

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For further project details:

www.askDORIS.org

http://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/