



MS Priority Setting Partnership Steering Group Meeting

Friday 1st March 2013

Rose room, MS National Centre, 372 Edgware Road, London, NW2 6ND

11.00am – 3:00pm

Members:

Chair: Sally Crowe, James Lind Alliance

Karen Chong, Roger Bastow

Grace Hazlett, UK MS Specialist Nurses Association

Waqar Rashid, Association of British Neurologists

Richard Warner, Specialist MS Nurse, Gloucestershire Neurology Service

Ed Holloway, Susan Kohlhaas, Mital Patel, Research Team, MS Society

Ann Daly, Independent Information Specialist

Apologies for absence: Neil Kemsley, Nick Rijke, Gwen Covey-Crump, Paul Bull

Minutes

1) Welcome

The chair welcomed everyone to the third MS PSP steering group meeting. Apologies were noted as above.

2) Action points from previous meeting

- Minutes from the previous meeting were agreed
- No action points were outstanding

3) Extension of MS PSP

- Sally and Ed opened discussions by recapping a short discussion the steering group (SG) had during the February conference call in which it was proposed the SG extend the MS PSP

- We had a great response to the survey to gather research uncertainties and generated a large data-set
- In order to do a quality exercise on sorting and formatting questions and to allow for external participation in interim prioritisation the timetable needs to be extended
- Mital presented a revised timetable, based on this timetable the final workshop will take place on 12 July 2013 and survey to prioritise uncertainties will take place from beginning of April till end of May
- Following a brief discussion the steering group agreed to extend the MS PSP but noted they did not want the exercise to go beyond July

Action Point: SG to confirm date of final workshop in their diaries as Friday 12 July 2013.

4) Interim prioritisation

- The SG discussed the process of interim prioritisation:
 - Interim prioritisation will be external and another survey will be launched in April
 - The survey will be available online and as a hardcopy
 - This survey will be open to people affected by MS and healthcare professionals
- The long list has yet to be finalised but the sorting and formatting exercise will likely result in 80-90 uncertainties
- The SG made it clear that their function is to maintain the integrity of the long list and not to prioritise the list prior to external prioritisation
- The steering group proposed the survey asks responders to carry out the following:
 - Rank research categories: diagnosis, prognosis, treatment, and prevention
 - Rate individual research questions (likert scale)
- The SG were encouraged to use their networks to promote the voting survey and in a similar way to their efforts to promote the survey to gather research questions

Action point: MP to develop a draft survey and guidance for SG to comment on at next teleconference

Action point: MP to add an agenda item to look at voting pattern of responders

Action point: MP to provide text for SG to use to promote the voting survey

5) Scoping participants for final workshop

- Ed opened discussions by encouraging the SG to use an open and fair process of choosing people to take part in the final workshop
- SG will need to ensure workshop participants represent a range of MS perspectives and experiences and to balance people affected by MS and healthcare professionals
- The workshops will involve approx 30-40 individuals. 5-6 will be observers and the rest will be participating and voting on the shortlist
- People who can vote: people with MS, carers, family members and professionals with a clinical connection to MS. This includes members of SG

- The SG agreed to do an open call for workshop participants. Individuals interested to take part will need to complete a request form, which will ask the same demographic questions as the first survey
- SG will be presented with a summary of the requests and choose proportions of each responder group to take part. Participants will then be randomly selected
- Sally also ran through the process that will be used during the workshop to reach the top 10 (<http://www.jlaguidebook.org/jla-guidebook.asp?val=44>)

Action point: MP to draft information sheet and request form for workshop and circulate to SG

Action point: MP to email workshop invite to responders of the first survey

Action point: EH to find a facilitator from MS Society

6) Update on survey respondents

- Mital presented a paper summarising demographics of respondents of the first survey
- SG were happy with the range of people taking part in the MS PSP

Action Point: Mital to circulate summary paper

7) Overview of question sorting and formatting

- Ann presented the process of sorting and formatting questions
 - Questions were grouped using the Health Research Classification System
 - Questions outside of the scope were checked by SG
 - A quality check was carried out on a random selection of question to look at formatting and questions considered at aetiology

Action Point: Mital to circulate PowerPoint

8) Exercise – generating indicative questions for the ‘long list’

- In pairs, SG members produced indicative questions summarising grouped questions

Action Point: SC, AD and MP to collate indicative questions

Action Point: AD to work through unique questions and group, where appropriate, into indicative questions

Action Point: MP to circulate draft long list and organise a steering group to finalise long list

9) Next meeting

Next SG meeting: Friday 26 April 2013, MSNC