



Multiple Sclerosis Society

MS Priority Setting Partnership Steering Group Meeting

23rd November 2012 – MS National Centre, 372 Edgware Road, London, NW2 6ND

12.00pm – 3:00pm

Members:

Chair: Sally Crowe, James Lind Alliance

Karen Chong, Paul Bull, Roger Bastow, Gwen Covey-Crump, MS Society Members

Grace Hazlett, UK MS Specialist Nurses Association

Neil Kemsley, Chair, UK MS National Therapy Centres

Richard Nicholas, Consultant Neurologist, Imperial College Health Care NHS Trust

Nick Rijke, Ed Holloway, Doug Brown, Mital Patel, Research Team, MS Society

Ann Daly, Independent Information Specialist

Apologies for absence: Richard Warner and Waqar Rashid

1) Welcome and introductions

- The chair welcomed everyone to the second MS Priority Setting Partnership (MS PSP) steering group meetings. Apologies were noted as above.

2) Action points from previous meeting

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

3) Protocol and terms of reference

- Terms of reference and protocol for the MS PSP steering group were agreed and signed.

4) Update on survey data and discussion

- Mital presented a summary paper on the early data from the survey. The presentation outlined the demographics of those who have completed the survey

- The steering group discussed the early data and were generally happy with the range of people responding, although work needed to be done for particular groups e.g. MS specialist nurses

Action Point: MP to circulate summary paper, presentation and list of questions (in word and in excel) to the steering group (at this point the questions are confidential and for the steering groups eyes only).

Action Point: MP and SC to send the steering group an update on survey data before the Christmas break

5) Update on gathering treatment uncertainties – survey launch and further publicity work

- The survey to gather questions went live on 1st November 2012
- The group gave a brief update on the work done to publicise the survey to different people in the MS community and further work each member intended to be do:
 1. MS Society:
 - Website
 - Social media: MSS blog, Facebook and twitter
 - MSS magazines and newsletters
 - Direct email to researchers and a number of health professional organisations and networks
 - Send out reminders: newsletters, emails etc
 - Ask for Gavin Giovannoni and David Baker to feature a blog on JLA
 - Send information to MS support groups
 - Send information to vascular professional organisations
 - To approach MSRC
 - Email GPs on MSS GP database
 - Circulate information at MSS events e.g. Living with MS
 2. James Lind Alliance:
 - Website
 - Twitter
 - Newsletter
 - Contact ophthalmologists via the Vision PSP
 - Contact John Scadding, a neurologist
 3. MS National Therapy Centres:
 - Website
 - Announcement at members meeting
 - Information sheet and survey link sent to all centres for incorporation into local newsletters, websites and managers blog
 - Front page of newsletter
 - Will send fortnightly reminders

4. UK MS Specialist Nurses Association:
 - Email sent to all members
 - Discussed at the annual general meeting
 - Will send follow up emails
 5. Anne: will ask clinical librarians with an interest in neurology to distribute information
 6. Gwen: circulated information to family, friends and health professionals she knows
 7. Karen: circulated information to Ladies with lesions, Shift MS, Ladies who dine and Women against MS
 8. Paul: information in Colchester branch newsletter. Will include reminder in Jan 2013 newsletter and will highlight JLA when visiting branches
 9. Roger: circulated information to family, friends and health professionals he knows. Also has good links with local therapy centre and will encourage people to complete the survey
- The MSS blog post on Facebook resulted in people directly posting questions onto Facebook. After a brief discussion the group agreed to keep a record of these questions and decide later how these will feed into the priority setting exercise
 - Health professionals on the steering group were advised not to actively solicit patients (as defined in clinical settings) to complete the survey as this requires ethics approval.

Action Point: MP to keep a record of questions posted on Facebook

Action Point: MP to put a simple leaflet/poster together for people to distribute

6) MS Taxonomy

- Ann presented the amended taxonomy, which is now based on the Health Research Classification System (HRCS)
- Submitted questions will be allocated into the HRCS taxonomy

Action Point: MP to send AD submitted questions now for Ann to begin checking and refining questions.

7) Management of data analysis

- The group had a brief discussion about data management and agreed to table the protocol for the next meeting
- AD will be leading on data analysis of the submitted questions

- SC, MP and AD have scheduled a teleconference with Mark Fenton, from UK DEUTS, to discuss data management
- SC ran a short exercise on formatting questions into Intervention, Comparison, Patient and Outcome (ICPO) with steering group members
- Steering group members will need to support Ann in the allocation of questions in the taxonomy and with converting questions into ICPO

Action Point: MP to circulate the slides from the presentation to the steering group

8) Interim prioritisation – initial thoughts

- SC highlighted issues the steering group will need to consider for the next phase of the priority setting exercise, these included:
 1. Process to narrow down a large data set to a manageable number – will it be an internal interim or external?
 2. Unique uncertainties (questions that cannot be combined) – the group will need to decide which to include for interim prioritisation
 3. Methods of external prioritisation_- the method chosen must not be burdensome or exclude people affected by MS. Steering group members suggested either an online system where people can log in and out, a word document listing all the questions, asking people to score rather than ticking to help respondents keep track etc.
- Sally noted that other PSP's normally create a top 10 list but given the wide scope of this PSP the steering group may want to lengthen the list, or consider separate top tens for areas of MS research. The group agreed to table this once the interim prioritisation has been completed.

9) **Next meeting, final prioritisation workshop dates and actions**

- Survey closes end of January 2013
- A teleconference will likely be needed before the next steering group meeting
- Next meeting will either be in week beginning 25 Feb or March 1 2013
- Final workshop will be sometime in the week beginning 22 April 2013

Action Points:

All:

- Further comms work to publicise the survey (see item 5)

Sally:

- Amend timeline based on a workshop taking place week beginning 22 April 2013

Mital:

- Send a doodle poll for Feb/Mar steering group meeting

- Circulate to group summary paper on demographics of respondents and list of questions (in word and in excel) to the steering group (at this point the questions are confidential and for the steering groups eyes only).
- Circulate to group an update on survey data before Christmas break
- Keep a record of questions posted on Facebook
- Send AD submitted questions for Ann to begin checking and refining questions.
- Circulate to group the PICO exercise slides