

**Bipolar Disorder Priority Setting Partnership
Fifth Steering Group Meeting – Monday March 23rd 2015
Cochrane Editorial Unit, London**

Present

- **Mary-Jane Attenburrow (MJA)** Senior Clinical Research Fellow, Department of Psychiatry, University of Oxford
- **Rachel Churchill (RC)**, Editor, Cochrane Depression, Anxiety and Neurosis Group (CCDAN), Bristol University
- **CHAIR – David Crowe (DC)**, James Lind Alliance Adviser
- **Suzanne Hudson (SH)**, Chief Executive, Bipolar UK
- **Tom Hughes (TH)**, Consultant Psychiatrist, Leeds & York Partnership NHS FT
- **Cynthia Joyce (CJ)**, Chief Executive, MQ
- **Rachel Marshall (RM)**, Patient's family representative
- **Sophie Petit- Zeman (SPZ)** , Director of Patient Involvement, Oxford BRC &U

- **Sandra Regan (SR)**, James Lind Alliance Project Manager and Hub Co-ordinator, NIHR Oxford Biomedical Research Centre
- **Diana Rose (DR)**, Head of Section, The Service User Research Enterprise (SURE)
- **Poppy Siddell (PS)**, Bipolar PSP Data Manager

Apologies

- **Anonymous Patient representative**
- **Ian Hulatt (IH)**, Mental Health Adviser, Royal College of Nursing
- **Edmund Brooks (EB)**, Patient's family representative
- **Amanda Hawkins (AH)**, Chair, British Association for Counselling & Psychotherapy (BACP)
- **Jennifer Rendell (JR)**, Research Fellow, Department of Psychiatry, University of Oxford

Minutes

1. Welcome, Apologies and Minutes of last meeting

- David welcomed everyone, introductions were made, and the Minutes of the January meeting accepted.

Action: brought forward from 22/1/15 - SR to chase up biogs etc and arrange website update

2. Review of PSP scope and HRCS Categorisation

- David reminded the SG of the agreed scope of the PSP, and of the Health Research Classification System (HRCS) framework for categorising the data.
- With circa 14,500 questions to categorise, discussion concluded that weighting may be needed where there are important questions that don't show prevalence and this will need looking at later on.
- It was agreed that questions about primary prevention would be within scope.

3. Results of the survey

- Poppy explained that categorisation of the data is ongoing, and presented a sample of some 40 questions representing a range of respondents and categories from her work to date on 4000/5000 of the questions.
- Discussion of the data process highlighted that once categorised, groupings of questions will emerge which may be brought together in a broader more research-friendly question, with PICO formatting not taking place until after the checking of the evidence base prior to the Final Workshop.
- The SG worked on an exercise aimed at providing a steer and ground rules for Poppy going forward.

In sub-groups, working with different sub-sets of the sample, they considered whether questions were in the right category, whether they were in or out of scope, and whether there were similar questions that might be grouped together.

- Following the exercise it was agreed that: members of the SG who have time will provide a steer by e-mail on any grey areas as Poppy moves forward with the data; the respondent groups need to be tracked against the questions (i.e. as questions are merged/changed etc, we need to keep track of how many times each amalgamated question was asked by which group); a feedback/communications strategy will be needed regarding “out of scope” and “known unknowns” – we can learn from the depression PSP on this.
- There was a discussion about how well using the HRCS categories, and the general JLA process at this stage, reflect the lived experience of the people concerned – i.e. the sense of “losing the spirit” in the process - and the question was raised of whether there’s another way to approach the data. It was felt that although the data is being touched at least 3 times (which is quite resource intensive), alternative approaches such as NVIVO might be worth exploring, in part to see whether “the process loses the spirit”. Whilst it was agreed that NVIVO or other tools are not practicable for this PSP at this stage, these questions will be considered within the OxJLA hub and/or taken back to NETSCC as part of JLA development, along with the broader issue of how PSPs may need to adapt to such large numbers of submitted questions – see last point.
- PSPs prior to publication of the HRCS in 2009 must have taken an alternative approach. The Oxford BRC has a report comparing the 3 methods of collecting data from patients/ carers used by the PSP on Hip and Knee Replacement for Osteoarthritis.
- Another discussion considered the implications of the success of the survey for resources, whether there are strategies that could be considered prior to getting started, what the learnings are for the JLA, and where the saturation point might be within the circa 14,500 questions.

Actions:

1. **PS to track demographics of contributors against questions**
2. **SG to develop strategies for communicating on “out of scope” and “known unknowns”**
3. **DC to check if other PSPs have developed categorisation from the data rather than using a pre-set classification**
4. **DC/SR to investigate feasibility of using NVIVO or other for future PSPs**
5. **PS/TH to bring next phase of data for checking at June SG, consulting SG by e-mail in between with any grey areas**
6. **SR to circulate link to the BRC Report that compared 3 different methods of collecting uncertainties in the PSP on Hip and Knee Replacement for Osteoarthritis**

4. Next steps

- The Bipolar questions submitted to the Depression PSP will be provided by MQ once their new Project Officer starts, in order to ensure compliance with the promise made that questions would not be wasted. It may be necessary to try and cross-reference the respondent IP addresses between the two surveys in order to see whether the same people have already been included.
- Discussion of the forthcoming activity on checking the evidence base concluded that: we can’t estimate timing or duration as we don’t yet know how many questions will be involved and when they will be ready; it’s likely to be a bigger task than anticipated based on Depression PSP experience; there may be some resource from Jennifer’s Systematic Review Group in Oxford depending on timing; in part, the magnitude of the task depends on the scope/ quality of the sources included; it might be possible to employ someone but that depends on the magnitude of the task.
- It was agreed that the success of the survey means that the timing of the process needs adjusting. The revised aim is for a Final Workshop late 2015/ early 2016. There are resource implications in respect of Poppy and David which need exploring. The data will be reviewed in 2 months with the intention of seeing it in depth at the June SG meeting.

Actions:

7. CJ to provide Bipolar uncertainties from Depression PSP when new project manager starts in April
8. RC/CJ to explore magnitude of evidence checking activity and cost/ feasibility of employing someone
9. DC to revise overall timeline in light of decision to adjust timing in keeping with the success of the survey, with Final Workshop being late 2015/ early 2016
10. June SG to review status of data, with teleconference in advance
11. TH/PS to discuss possibility of extending PS contract
12. Budgetary implications of extending PS & DC time to be considered

5. Mailing list for other studies

- It was agreed that it would not be feasible to ask people who took part in the Bipolar PSP to self-select to a mailing list to be informed about subsequent studies due to the issues around information governance.
- This prompted a discussion about how to keep people involved/ informed going forward, especially after the PSP concludes on the subject of funding of priorities. The Oxford BRC JLA hub website could provide one place for such information. A reporting and publication strategy is needed. There are cost implications for open access journals.

Actions:

13. Try to protect £1300 for open access publication fees
14. SG to develop publication/ reporting strategy, and consider keeping people informed beyond the life of the PSP by, for example, keeping a page current on the OUH site even once SGs have disbanded

6. JLA Evaluation Symposium

- Tom explained that he had received an invitation to attend the JLA Evaluation Symposium on June 23rd, together with a patient/ family representative from the SG. Diana is available but said she would prefer not to attend if anyone else is keen. Rachel M may be available. David will check with our Anonymous patient representative.

Actions:

15. RM to check if she can attend
16. DC to see if Anonymous representative can attend

7. AOB

- The issue of patient representation on the SG following Bev's resignation was revisited. Rachel M highlighted that she too will be less able to input later in the year. It was agreed that 2 new representatives should be sought and Diana offered to engage with the potential recruits to help manage expectations. Suzanne is happy to help.
- Suzanne flagged that Bipolar UK is receiving a lot of enquiries about the progress of the PSP and an alternative update to the Newsletter is needed.

Actions:

16. DC/SR to consider approach to recruiting 2 new SG members
17. DC/ SR to provide update for partners to use other than recent Newsletter

8. Dates of next meetings

Teleconference to be arranged for 2 weeks prior to June 17th 1130-1530, London – venue TBA

Actions:

18. RM checking if CEU available; SR holding Victoria Centre (cost implication)