

**Bipolar Disorder Priority Setting Partnership
Eighth Steering Group Meeting – Monday December 14th 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
- **Mohini Morris**, Patient's family representative
- **Sandra Regan (SR)**, James Lind Alliance Project Manager and Hub Co-ordinator, NIHR Oxford Biomedical Research Centre

- **Jennifer Rendell (JR)**, Research Fellow, Department of Psychiatry, University of Oxford
- **Diana Rose (DR)**, Head of Section, The Service User Research Enterprise (SURE)
- **Kristina Staley (KS)**, Bipolar PSP Data Manager

Apologies

- **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)
- **Cynthia Joyce (CJ)**, Chief Executive, MQ
- **Sophie Petit- Zeman (SPZ)**, Director of Patient Involvement, Oxford BRC & U
- **Anonymous Patient representative**

Minutes

1. Welcome and overview of the meeting

- David welcomed everyone to the meeting, in particular Mohini the new family representative and Kristina, the new data manager, and introductions were made.
- Apologies were noted. A discussion took place regarding the organisations who have not been represented at meetings for some considerable time, and it was agreed that they be approached to check if they will be represented going forward. **Action 1: Mary-Jane/ David**
- The Minutes of the last meeting were reviewed and accepted, with the following actions to be carried forward:
 - **From the June meeting: Action 3 – DC to establish what other PSPs do re payment for involvement, and if this happens, what the potential cost of involvement in workshops would be; and Action 4 – SPZ and CJ to consider the practicalities of possible payment routes and implications.** It was noted that INVOLVE Guidance is £150/ day and that some PSPs offer gift vouchers; discussion highlighted that there may be inequities if people are on benefits and can only accept a small percentage of the day rate and that accepting vouchers can still penalise them; Diana highlighted that the INVOLVE Benefits Helpline is due to close at the end of the year. More checking is needed.
 - **From the March meeting: Action 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 SG has disbanded.**

2. Budget update

- Tom presented the budget update. Taking account of the new situation with data management, the

project is currently looking at a deficit of circa £1000. This does not allow for any expenditure by the Oxford BRC since they last provided Leeds with an update, or for any possible input from Kristina beyond the current contract. **Action 1: Sandra to check Oxford expenditure since last update**

- It was noted that: there had previously been a commitment in principle to the BRC and MQ sharing the over spend; the costs for an interim workshop have been removed, as have the costs for one additional JLA facilitator at the Final Workshop; Kristina has done her initial allocation of 10 days, plus 0.5 day over and we will need to plan the way forward after today.

3. Progress of working with the data and discussion of challenges/ principles

- David provided a reminder of the process, and where we are at: the circa 14,000 questions from more than 3,000 respondents have been reviewed and categorised using the HRCS Activity Codes; duplicates and similar questions have been combined into thematic indicative questions, individual questions listed, and out of scope questions listed.
- We now need to review the principles applied to the out of scope and then develop criteria for creating the longlist of questions that will go out for interim voting, as well as to apply a sense check of the literature to establish whether there are any obvious questions to remove.
- The interim survey will then be designed, and a steer is needed as to the whether this should be a ranking exercise by respondents (e.g. top 3, 5 or 10) or whether they should select responses from a Likert-type scale. The results of this survey should yield the Top 30 priorities, which can then be cross-checked against the existing evidence base to establish whether they are true uncertainties. If any are removed at this stage, then subsequent priorities can be moved up.
- In response to a question, Tom clarified that the health professional response rate was about 25%.
- Kristina described the process that she had been through: she has reviewed all the categories, developed further sub-themes where needed, and combined sub-themes where appropriate. The result is 62 indicative questions + 115 individual questions + 3800 out of scope. She explained the principles that she had applied to deciding whether a question was out of scope – if it seemed to be a request for information, a health policy question, or a very general question (e.g. about raising awareness or cure) then she removed it.
- Discussion concluded that: (i) the out of scope questions should be reviewed by SG members in order to be sure that the right decision has been made; some questions may go back in under existing indicative questions, or as individual questions, or as new indicative questions; (ii) Bipolar UK would take the resulting out of scope questions and, where possible, use them to inform somehow; and (iii) the rationale for the out of scope should be available for transparency.

Action 2: Sandra to send out of scope questions to 8 SG volunteers, who will each review an allocation of circa 500 questions to see if they should be in scope. Suzanne, Mohini, Mary-Jane, Tom, Jennifer, Rachel and David to review and feedback to Sandra by the end of the first week in January for collation and passing on to Kristina. One more volunteer is needed.

Action 3: At a later date, Bipolar UK with help from Mohini will group what's left with a view to seeing how to take forward.

- Kristina highlighted some grey areas in relation to some of the indicative questions. These were discussed, with the following conclusions:
 - where there is ambiguity over the intention of language used in original submissions, they should be allocated to both possible indicative questions and this doubling-up clearly tracked;
 - interpretation has resulted in the occasional use of language in indicative questions that is not directly derived from the data (e.g. “journey” in H1), the Steering Group should therefore check all indicative questions and flag any queries so that the data can be checked for veracity; in the

case of H1, Kristina will check to see whether the phrase “balanced mood” is appropriate.

Action 4: Kristina to check the specific instance cited and amend as necessary.

Action 5: Sandra to circulate list of indicative questions to the Steering Group for a language check, requesting feedback by the second week in January for collation and passing on to Kristina.

- Discussion about whether to combine the individual questions concerning spiritual issues concluded that they were separate questions, and should be left as such: the interim process will decide whether any of them stay in. Bipolar UK would be happy to take any that don't stay in together with the out of scope, as above.
- The Steering Group thanked Kristina for the work that she has done to bring things together in such a short time, building on Poppy and Tom's earlier work.

4. Next steps

- David highlighted 3 issues for consideration: (i) what criteria might be considered important for developing the longlist that will go for interim voting; (ii) how best can a sense check of the evidence base be conducted at this stage; (iii) what are the important factors in shaping the interim survey?
- The Steering Group considered an extract from the JLA Guidebook on **criteria for reducing the list**. Discussion concluded that, in the case of this PSP, there are 3 groups of voices to be taken account of: people who have/ might have Bipolar; healthcare professionals; and interested others. With this in mind, **it was agreed that prevalence is important, as well as whether more than one group has rated a question more highly**. Individual questions will be assessed according to whether the issue raised reflects what Steering Group members know to be concerns of groups under-represented among survey respondents, or overlap with uncertainties expressed in research or in for a such as patient helpline services.
- Kristina flagged that, although more than 14,000 questions were originally submitted, she had inherited a dataset of some 13,800 questions. It seems that some 600 original questions have not been tracked. These would need to be identified and added to the Master Database in order to inform the count of how many people in each of the 3 groups contributed to each indicative question. Jennifer highlighted a simple method for comparing spreadsheets and volunteered to take this on.

Action 6: Kristina to send the 2 relevant spreadsheets to Jennifer for checking.

Action 7: Kristina to subsequently apply the count of how many people from each group contributed to each indicative question, and to identify which group contributed each individual question, to inform the next Steering Group meeting.

Action 8: At the next Steering Group meeting, the criteria will be applied to the list.

- Discussion about sense-checking the list of indicative and individual questions against the evidence base at this time concluded that: this is not yet about a comprehensive search of the literature for every possible question held within the indicatives; only treatment-related questions will be addressed by Systematic Reviews and so only those questions will be considered at this time; the evidence base for questions relating to cause etc is not the same and a separate strategy might be needed later; Mohini has recently completed a piece of work that may be useful in this respect and she is happy to share it.

Action 9: Rachel and Jennifer to review the list and agree which questions to check at this time (if any), devise a strategy and capture the results in advance of the next Steering group on the 1st February; Mohini to share her review.

- Discussion about the shape of the interim survey concluded that a Likert-type scale would be preferable to ranking e.g. 3, 5 or 10, as the former would require people to answer as they go whilst the latter would require them to remember their earlier answers and move backwards and forwards in order to make changes.
- The interim survey will be available nationally online again, and it was agreed that it would be sensible to set a maximum number of responses.

Action 10: Sandra/ David to draft the interim survey for review at the next Steering Group meeting.

5. Feedback from MQ's Bipolar Conference, Nov 9/10

- Tom and Rachel reported back on the event which they had both attended. Tom had given an overview of the PSP to date, including demographics of respondents, which was well-received.
- David provided an overview that Jenn Tuft from MQ had sent in Cynthia's absence:
 - 2-day international conference to set research priorities on Bipolar Disorder
 - Attended by 60 experts, funding representatives and MQ staff
 - More than 20 presentations on 7 themes and over 4 hours' discussion
 - Consensus within group that top 3 salient priorities are to:
 - 1. Make better use of existing evidence, treatment options and datasets
 - 2. Develop a research platform (similar to DPUK)
 - 3. Include "high-risk" populations in studies (those who are suicidal, drug and alcohol misuse, etc.)
- Rachel flagged that it would be nice to see alignment of work in this area going forward, and highlighted that the NIHR has just put out a call for Bipolar research. It was mentioned that Sir Muir Gray has an interest in this area, and suggested that the Steering Group could write a letter to the Guardian calling for more funding.

6. Proposal for a secondary analysis of the PSP data

- As discussed at the last meeting, Diana had outlined a proposal for secondary qualitative analysis of the PSP data that could be made available by re-consenting those who provided their contact details, using software such as NVIVO. Although she felt that the work Kristina has since done begins to address the issue of bottom-up analysis rather than top-down, the Steering Group considered it could still make a useful and interesting comparison, perhaps contributing to JLA evaluation activity. Cost could be in the region of £30,000.

Action 11: David to raise at JLA Advisors meeting/ NETSCC; ALL to suggest potential funders to Diana

7. AOB/ Dates of next meetings

- The Steering Group agreed that it would be essential to have another 10 days of Kristina's time going forward. **Action 12: David to raise with funders (Oxford BRC and MQ)**
- The next meeting will also be face to face on Feb 1st from 11:00 to 15:00