

**Bipolar Disorder Priority Setting Partnership
Ninth Steering Group Meeting – Monday February 1st 2016
Cochrane Editorial Unit, London**

Present

- **Mary-Jane Attenburrow (MJA)** Senior Clinical Research Fellow, Department of Psychiatry, University of Oxford
- **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
- **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
- **Kristina Staley (KS)**, Bipolar PSP Data Manager
- **Jen Tuft**, MQ for Cynthia Joyce

Apologies

- **Anonymous** Patient representative
- **Rachel Churchill (RC)**, Editor, Cochrane Depression, Anxiety and Neurosis Group (CCDAN), Bristol University
- **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 **Mohini Morris**, Patient's family representative
- **Sophie Petit- Zeman (SPZ)** , Director of Patient Involvement, Oxford BRC &
- **Diana Rose (DR)**, Head of Section, The Service User Research Enterprise (SURE)

Minutes

1. Welcome and overview of the meeting

- David welcomed everyone and apologies were noted.
- Picking up on actions from the last meeting:
 - David reported that he had been in touch with those organisations that had not been represented at Steering Group meetings since the early stages. It was agreed that, where a reply is not received, they will be removed from the circulation list.
 - Regarding payment for involvement, David reported that he had consulted with the JLA on this, and that there are a variety of approaches across PSPs. Expenses should always be covered, and, where possible, it is good to pay for time, using INVOLVE guidance on rates. Some PSPs provide gift tokens as a thank you.
 - Regarding benefits and pension credits – people should be referred to the INVOLVE benefits helpline which is still ongoing.
 - It was agreed that payment for time at the Final Workshop cannot be offered, or tokens, as we do not have the budget. However, expenses have been budgeted for – it should be made clear whether these will be available on the day or whether people will have to fill in forms and claim back that way.
 - A reporting strategy is still required; in which regard, the PSP website will not remain in the same way once the project has closed, but an archive site will be set up.
- The Minutes of the last meeting were agreed.

2. Budget update

- The updated budget provided by Leeds & York Partnership NHS FT was reviewed. The deficit currently projected is £5.5k which includes all the data management time to date; however, there will be Oxford costs to add since these were last provided to Leeds, plus costs of 2 more Steering Group meetings to add, and some teleconferences as well additional data management to the end of the PSP.
- Jen shared the report from the Depression – Ask the right Questions PSP which prompted discussion as to whether the Bipolar PSP should adopt a similar approach. The costs could be £4-£6k, which have not been budgeted and could take about 3 weeks of someone's time. Also, open access journal publications can cost circa £1300. If a more detailed report is also needed, this would incur extra time/ costs.
- Ensuing discussion considered whether there should also be a launch event for the report, which would incur further costs.
- The meeting concluded that a similar brochure would be nice to have, as would a launch event. Oct 6th is Bipolar Wednesday, which is when the first survey was launched so this would be a good date to aim for as the Final Workshop is likely to be in June.
- Discussion also concluded:
Actions: 1. a dissemination plan and communications strategy are required; 2. Kristina to gather the necessary information to draft the detailed report; 3. Jen to provide the pdf of the Depression brochure to use as a template, and check whether she can support the production from her experience to date; 4. David to raise the potential additional costs at the forthcoming teleconference with the PSP funders.

3. Data update

- Kristina talked through the paper she had provided on some of the issues she had encountered in preparing the data to this point:
 - Differences in coding between the Master spreadsheet she had inherited and the Master Word document which required additional time to resolve;
 - 600 questions that appeared not to have been coded or allocated to out of scope, some of which could be allocated to existing indicative questions and some creating new ones;
 - There were, in total, 6 categories of respondent – it was agreed that people with or who thought they might have bipolar could be merged, as could carers/ friends etc of people with or who might have. This reduces the categories to 4, including health/ social care professionals and organisations representing people with bipolar;
 - The way the survey was constructed allowed people to self-classify in more than one category; a number of professionals also classified themselves as service users. If they classified themselves as both a service user and a carer or health professional, they were counted more than once.
 - Some professionals were not directly related to working with people with bipolar e.g. podiatrists, again, this was a result of the way the survey was constructed. Also, of the 189 professionals a high percentage did not declare their specialisation.
- **Discussion concluded that the interim survey should be constructed in such a way as to be more explicit about the type of health/ social care professionals i.e. working with people with bipolar; and also limit to one classification e.g. service user, carer or professional.**
- Sandra flagged that the total number of respondents that Kristina had as 2744 was considerably lower than the total number who actually submitted the survey. This may be due to the fact that a number of entries were incomplete. **Action: 5. Sandra to check back in files and correspondence**
- Kristina presented the questions: total no of questions = 14,489; out of scope = 3324; single questions = 325; indicative = 71, covering 10,840 original submissions.

- The indicative questions were prepared using the criteria agreed at the previous meeting, based on the principles of prevalence and which group was asking.
- **Discussion concluded that the interim survey should: be limited to a maximum of 80 questions to allow for inclusion of any single questions that Steering Group members might wish to make a case for; present the questions in a randomised different order to avoid people consistently not answering the same questions if they sign out before completing; use the same Likert scale as Depression (importance 1-4 & Don't Know); present the question about who respondents are at the beginning, in order to maximise the chance of capturing that information.**
- It was further agreed that: there should be a new indicative question around novel treatments, one around employment/ lifestyle, and one around duration of illness; Steering Group members would check to see if any of the single questions could realistically be included in the existing indicative questions, or combined into new indicative questions, and let Kristina know by the end of the week so that she could make the changes. **Action 6: SG and Kristina**
- Kristina flagged that it would be useful to have guidance on how to approach the data work; Jen highlighted that this had been a key aspect of discussions at the JLA Evaluation Symposium last summer.

4. Overview of interim priority setting process

- David gave an overview of the interim process. Subsequent discussion concluded that:
 - there should be some context provided at the front end of the survey;
 - it should be open circa 4 weeks, launching w/c 22 Feb and open until the end of March;
 - Bipolar UK would pro-actively communicate about it;
 - more professional responses are needed – Jen will check to see if the Depression Steering Group is happy for her to promote via their contact list;
 - GPs are needed e.g. via Royal College and British Journal of GPs
 - Jen will check to see if the Depression SG is happy for her to share their interim survey template;
 - If the Final Workshop date is known, it should be added to the interim survey information;

Action 7: Sandra to draft interim survey in survey monkey

5. Next steps

- David reported that he had consulted colleagues regarding the process of **information checking**. Initially PSPs were just considering treatment uncertainties and the Cochrane Review Groups (CRG) allow checking of these.
- Rachel advised by e-mail that there could be about 18 to 1800 sources of information from the CRG. David advised that pragmatism is needed in light of the resource available. A colleague had suggested Cochrane and Mental Elf as the key sources and suggested that it might need 2-3 days of dedicated time to focus on the treatment uncertainties.
- It was agreed that: transparency is needed in relation to the fact that there is no method for checking the non-treatment uncertainties; the checking be done on the interim results that relate to treatment uncertainties prior to the final workshop; in the meantime, the longlist going to interim should be checked against the Cochrane database to get a sense of where there is information; Jennifer will discuss the approach with Rachel and develop a protocol, and Kristina can support the activity; if the evidence checking finds that some of the questions have been answered then the ranking may need adjusting prior to the Final Workshop; a strategy is also needed to check if there are trials that address a question e.g. via UKCTG, or the output from the Bipolar Research Conference **Action 8: Jennifer, Rachel & Kristina**
- In addition, Kristina will send the out of scope list to Suzanne, who will present a strategy for dealing with to the next Steering Group meeting. **Action 9: Kristina and Suzanne**
- The Final Workshop date was discussed. It was agreed that it should be either June 7th or 14th.



Suzanne reported that from Bipolar UK experience, to get folk in London to attend it needs to be a weekend or an evening. As it was impossible to find a Saturday that would work for enough of the Steering Group member diaries, and as an evening is not long enough for the format, it was suggested that we also look outside of London (Friends Meeting House, Kings College via Suzanne) e.g. Oxford or Birmingham (hotel near the NEC, Medical School). **Action 10: Sandra**

6. AOB/ Dates of next meetings

- Next SG, April 26th 11-3, same venue