

**Bipolar Disorder Priority Setting Partnership  
Seventh Steering Group Meeting – Monday October 12<sup>th</sup> 2015  
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
- **Cynthia Joyce (CJ)**, Chief Executive, MQ
- **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

- **Anonymous Patient representative**

**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)
- **Rachel Churchill (RC)**, Editor, Cochrane Depression, Anxiety and Neurosis Group (CCDAN), Bristol University
- **Jennifer Rendell (JR)**, Research Fellow, Department of Psychiatry, University of Oxford
- **Jenn Tuft (JT)**, Depression PSP Project Manager, MQ
- **Mohini Morris**, Patient's family representative

**Minutes**

**1. Welcome and overview of the meeting**

- David welcomed everyone and noted apologies.
- He reported that, as agreed at the last meeting, Suzanne had liaised with Bipolar UK service users to find a new patient's family representative as Rachel Marshall had to step down. Although she can't be present today, Mohini was welcomed to the Steering Group in her absence.
- The Minutes of the June meeting were reviewed and accepted
- One outstanding action is: **(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;** on which the following action depends: **(4) SPZ and CJ to consider the practicalities of possible payment routes and implications.**

**Actions brought forward from March: (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 reported that Leeds have reduced their administration overhead and the resulting deficit is projected at circa £2.5k, which MQ and the Oxford BRC have agreed in principle to share.
- David flagged that the interim workshop will not be needed in such a way as to incur costs; and that the administration costs will be revised following discussions at JLA regarding Adviser fees.

**Action 1: PSP will review budget position on an ongoing basis, particularly in light of data requirements going forward and possible contingency funding**

## 3. Other ways of using data

- Following discussion in June about the possible loss of the richness in the stories provided in the survey, David had consulted with other JLA Advisers and provided some examples of how data had been used in different ways. For example, the Anaesthesia PSP planned a second publication addressing “what matters to patients” (using quotations) following the same concerns; and the Palliative Care PSP is analysing the data separately to produce a series of reports addressing different themes for dissemination in a targeted manner.
- Discussion acknowledged that service delivery is emerging as a key issue, and that a paper on this would be powerful, and considered the following issues and concerns: that the data had been collected for the usual PSP purposes, and that it is not possible to go back and ask everyone who contributed for permission to use for a different purpose; whether ethics would be required to mine the data for other purposes; that use of quotes would require permission even if anonymised; that the purpose, budget and timeline require that we continue with the priority work; that there should be feedback to the JLA that this challenge should be considered at the outset of a PSP so it can be factored in as necessary.
- Diana said that she would be willing to write a grant proposal, to include re-contacting people where possible to seek permission to use the data. Suzanne flagged concerns about re-contacting people, many of whom took part via Bipolar UK and highlighted that information governance issues would need to be clearly addressed in such a proposal and communications would need to come from the PSP. It was noted that we only have contact details for those who asked to be kept updated, which is a large number of people.
- Sophie highlighted that the data controller in this case is the OUH Trust as the survey was hosted via them. In order to seek their advice, we would need a clear plan.
- It was agreed that: **(2) Diana would draft an outline for post-PSP work for the Steering Group to review with a view to then seeking advice from the OUH information governance team. (3) Tom has developed a fuller protocol document for the PSP which he will share with Diana. (4) The data can inform all PSP outputs and publications.**

#### 4. Progress of working with the data

- David informed the group that Poppy will be leaving in November, which of course has implications for the data management going forward.
- Tom gave an overview of progress in each of the 8 HRCS categories. David, Sandra, Mary-Jane, Jennifer, our anonymous patient representative and some students in Leeds have all helped to categorise the data. There is still some work to do in Cats 4, 5 and 7, and some final checking to do in Cats 1, 2, 3, 6 and 8. The aim is to arrive at the longlist of indicative questions, where same/ similar questions have been combined; plus a list of out of scope questions.
- **Action 5: It was agreed that Poppy would concentrate on finalising Cat 7 by the end of October, with subsequent help from our anonymous patient representative if needed by mid-November. She will send collective data information to Data group in advance of departing**

#### 5. Next steps

- The next step is to review Cats 1, 3, and 5 in small groups after lunch in order to get a sense check of the indicative questions that have been worked up to date and whether they have captured all the original submissions that sit within them; and of the out of scope questions.
- Discussion considered how much the Steering Group would be involved going forward. It was agreed that, rather than ask the group to check a random sample, it would be better for the data group to seek second opinions on problematic questions. This would have to be according to members' availability at the time due to a range of other commitments.
- It was requested that those categories that need finalising be returned to Poppy by mid-November.
- The implications of Poppy's leaving were discussed. The budget for the role runs until the end of January, and as Poppy will leave mid-November this will leave a window of about 12 weeks. The first task is likely to be managing the process of reducing the possible 300-450 indicative questions to a longlist to go out for interim voting. Enquiries are under way for a replacement.
- **Action 6: it was agreed that David would update the role description and circulate to the Steering Group in the first instance for members to distribute.**
- Following review of the timeline it was agreed that there should be a Steering Group meeting in early/mid-December with the key task being to create the longlist of questions and agree the interim voting process.

#### 6. Group work

- **Small groups reviewed the work to date on indicative and out of scope questions in categories 1, 3 and 5. On the whole, things were felt to be going well – there may need to be a few slight revisions in some cat 1 questions, with some in cat 5 needing to be reallocated or combined. In cat 3 it was felt that questions P1, P2 and P3 could be combined to one umbrella question with examples given.**

### Action 7: Poppy

- The out of scope questions should be reviewed again when all the indicative questions have been formed to double check if they actually do fit anywhere. Action 8: Poppy/Tom
- Discussion considered that: care is needed to ensure that original submissions are not over-interpreted; indicative questions are usually quite broad, with signposts allowing researchers to pick up on the specifics held within.

## 7. MQs Bipolar Conference, Nov 9/10

- Tom will be presenting on the PSP at the MQ Bipolar conference.
- Action 9: It was agreed that Cynthia would circulate the Agenda for the meeting, and Tom would focus on the methodology/ JLA process, and the responses in a general sense, but things are not yet at a stage where he can report on findings

## 8. AOB/ Dates of next meetings

- The Steering Group thanked Poppy for all her work and wished her well in her future ventures.
- Monday December 14<sup>th</sup>, 11:00-15:00 at the Cochrane Editorial Unit, London