

**Bipolar Disorder Priority Setting Partnership  
Sixth Steering Group Meeting – Wednesday June 17<sup>th</sup> 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

- **Jennifer Rendell (JR)**, Research Fellow, Department of Psychiatry, University of Oxford
- **Diana Rose (DR)**, Head of Section, The Service User Research Enterprise (SURE)
- **Poppy Siddell (PS)**, Bipolar PSP Data Manager
- **Jenn Tuft (JT)**, Depression PSP Project Manager, MQ

**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)

**Minutes**

**1. Welcome, Apologies and Minutes of last meeting**

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

**Actions brought forward: (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. Project/ Administrative update**

- SR reported that brief biographies of Steering Group members, where available, are now on the PSP website, together with Minutes of previous meetings that have been approved.
- SH reported that Bipolar UK are receiving a lot of enquiries about the status of the PSP. It was agreed that a News update is needed that all partners can use, and that the project timeline should also be available on the PSP website.
- TH passed round copies of the expenditure against budget to date for review. On the whole, it looks as if things are on track; however, clarification is needed as to whether the figures include the revised amounts needed for DC/PS extended time.
- Discussion was initiated on the costs of the interim process and final workshop, including payment for involvement of public members. DC clarified that the interim process is likely to be via survey and

therefore not require additional facilitation as noted in the budget; if it does require a workshop process with the Steering Group to prepare for the survey, then additional public members may be needed but not additional facilitators.

- The discussion on payment for public involvement considered that: it is best practice as a general principle; however, it was not budgeted for - JLA guidance is that it is up to each PSP, and the decisions was taken at the beginning to not provide; expenses should always be covered; potential Steering Group members had not joined because payment hadn't been offered – how could it now be added?; the end-of-PSP feedback should state that PSPs need a clear and implementable payment policy; agreeing to pay for time at one-off workshops is not the same as agreeing to pay for ongoing commitment through Steering Group membership so we may decide to offer this at that stage; what do other PSPs do?; what are the implications of offering payment both for the budget, and for the practicalities of management, given the challenges around paying such as deducting PAYE via Trust payrolls, and effects on benefits.
- **It was agreed that, before a decision can be made: it would be good to know (i) what other PSPs do and (ii) what a decision to pay for involvement at workshops might cost; also, if it is agreed to offer payment, (iii) people do not have to accept, and (iv) a workable decision about how to implement without causing problems to those who might accept would be needed.**

**Actions:** (1) SR/DC to prepare News update & circulate and then add to website together with timeline; (2) TH to clarify whether budget/ expenditure includes additional time for DC/PS; (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 ; (4) SPZ and CJ to consider the practicalities of possible payment routes and implications.

### 3. Overview and review of work to date/ Next steps

- PS reported that: all circa 14,000 questions have now been categorised using the Health Research Classification System (HRCS); some categories are very large, with around 5000 questions; more work is needed to prepare the broad indicative questions/ themes.
- TH clarified that it seems possible to work with around 350 questions per day to gather into the broad areas/ remove from scope, with additional time then needed to check and refine the broad headings further; in reality, this looks more like 100 questions per person per day to bring from raw questions to something approaching a research question.
- MJA & JR have done some work on one category, using a mix of approaches between them: JR used key word searching; MJA eyeballed around 1200 questions in 4-5 hours, creating sub-themes.
- Discussion considered that, by splitting out original submissions that were more of a personal narrative and applying the HRCS categorisation, richness of information might be lost concerning the individual stories. **It was concluded that:** (i) this is an issue to flag with the JLA regarding methodology; (ii) the workload in doing this would be even higher; (iii) following the PSP, it might be possible (as a separate project) to work with the data in a different way to mine that richness e.g. natural language processing; (iv) the dataset needs preserving somewhere to allow such future work.
- DC reported back from his discussions with colleagues at the JLA that: the volume of data acquired from this PSP and that on Depression is new territory as, on the whole, PSPs tend to have between 500 and 1200 questions. It was agreed that the learning from this experience needs to inform forthcoming PSPs – e.g. the wider the scope, the more data is likely, in which case being transparent from the outset about the amount of data that can be managed is necessary (e.g. through statement of intent to do random sampling if response is large). **It was agreed that this PSP cannot now adopt random/ statistical sampling as that was never stated at the outset – all the questions must be looked at in order to maintain integrity.**
- RC flagged that checking the evidence base against very broad themes will be highly challenging; she also highlighted that we need to be clear as to why we are going through this stage of developing indicative questions; JT pointed out that there are a number of iterations involved – from indicative questions accessible to lay users, to research friendly questions that can be checked against the

evidence base, and back to lay-friendly again. SPZ proposed that, given the unusual volume of questions, the evidence base be checked AFTER the interim questions have been set (and before going out to interim vote) rather than earlier in the process, as is usual. **It was agreed that this be done, as it will make the task of evidence checking much more manageable, although it will have implications for the interim process i.e. the number of questions on the interim longlist, the number of iterations of evidence checking that might be needed, and the longlist using indicative language with the PICO activity coming afterwards.**

- **It was further agreed that:** (i) the existing approach be continued but refined so that a standard structure of approach is being applied; (ii) to do this, MJA/JR would draft a guiding note on their approach which TH/PS could then refine according to their experience; (iii) further help is needed – SR can give some time for a couple of months to assist, and Steering Group members can be asked to volunteer to help; (iv) the audit trail is hugely important; (v) the Steering Group will need to agree the interim longlist at the Autumn Steering Group, and then going out to vote (using a Likert scale) and staying open for 3-4 weeks, with Final workshop in February/ March 2016.

**Actions:** (5) MJA/JR to draft a data analysis framework with TH/PS and share with Steering Group by Tuesday 23<sup>rd</sup> June; (6) Steering Group members to be asked to get involved (see Item 5 on Group Work below); (7) DC to update the timeline.

#### 4. AOB (taken now as some people need to leave early)

- RM will not be available going forward, although does hope to join the Final Workshop. The Steering Group thanked her wholeheartedly for all her input to date.
- CJ informed the Steering Group that MQ is, with NIHR, co-hosting an international meeting of the Bipolar research community on November 9/10 and invites interest in getting involved with that, as well as ideas for how to inform the meeting from the PSP. Discussion concluded that, although the PSP would not be complete by then, there would certainly be something of interest to share – not least the phenomenal success of the PSP in terms of patient and carer engagement, which is highly relevant to the research agenda.
- Patient/ family member representation on the Steering Group was revisited. Having now lost 2 members, **discussion concluded that the appropriate way forward at this stage of the PSP is for SH to identify and approach potential a new patient member and a new carer** as open recruitment, whilst best practice, would divert a lot of resource from the data work. A role description/ terms of reference would be helpful.

**Actions:** (8) CJ to update the PSP closer to the international meeting, on the basis that the PSP will be able to share overall progress on data collection and prioritisation; (9) DC to provide role description to SH; (10) SH to take forward.

#### 5. Group work

- Some time was spent in small groups reviewing the themes that have been collated to date to provide feedback and guidance for PS/TH, and to check on any out of scope questions emerging and any queries.
- It was felt that, overall, the broad themes reflect the questions included within them; specific comments/ suggestions were provided to PS/TH and they were thanked for all their hard work.
- **It was agreed that:** (i) where questions might possibly sit in more than one theme, they be labelled accordingly; (ii) TH/PS would send themes to the whole Steering Group as they become ready for checking, and ask for 2 volunteers to sense check within a stated timeframe; (iii) MJA/ JR would continue to work with the Category on Diagnosis; (iv) RC would seek help with sense-checking from colleagues.

**Actions:** accordingly!

#### 8. Dates of next meetings

Monday October 12<sup>th</sup>, 11 to 3.30, at the Cochrane Editorial Unit, London

