

**Bipolar Disorder Priority Setting Partnership
Tenth Steering Group Meeting – Tuesday April 26th 2016
Cochrane Editorial Unit, London**

Present

- **Anonymous Patient representative**
- **Edmund Brooks (EB)**, Patient's family representative
- **Rachel Churchill (RC)**, Coordinating Editor, Cochrane Common Mental Disorders Group, University of York
- **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
- **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 by Skype
- **Sophie Petit- Zeman (SPZ)**, Director of Patient Involvement, Oxford BRC & BRU

Apologies

- **Mary-Jane Attenburrow (MJA)** Senior Clinical Research Fellow, Department of Psychiatry, University of Oxford
- **Ian Hulatt (IH)**, Mental Health Adviser, Royal College of Nursing
- **Amanda Hawkins (AH)**, Chair, British Association for Counselling & Psychotherapy (BACP)

Minutes

1. Welcome and overview of the meeting

- David welcomed everyone and introductions were made as this particular combination of group members had not been together before; apologies were noted.
- Picking up on actions from the last meeting, it was noted that the majority had been addressed and would either be covered under the Agenda or the results of those actions had informed the Agenda.
- The only outstanding item was Action 5, relating to the number of responses to the first survey. Sandra reported that she had checked the files and the original download from Survey Monkey contained 3283 responses. Kristina had previously reported that she was working with 2744, which means that the difference were either empty or incomplete. It was agreed that this should be made clear in the reporting. **Action 1: for inclusion in the PSP report (see item 7 below).**
- The Minutes of the last meeting were agreed.

2. Budget update

- The updated budget provided by Leeds & York Partnership NHS FT was reviewed. Since the update had been prepared, the deposit for the Final Workshop has been paid. Sandra explained that the total cost for the Final Workshop was calculated based on 40 people, and is expected to be £1667 inc. VAT where applicable. Tom was uncertain whether the current meeting was included in the forecast and will check. **Action 2: Tom**

- It was noted that the current forecast now includes an additional contribution of £10,000 from Oxford Health NHS Foundation Trust and the University of Oxford's Department of Psychiatry, which Jennifer had arranged. The list of Income/Contribution should be amended accordingly, by splitting out the £20,000 showing against Oxford University Hospitals Trust. **Action 3: Tom/ Leeds admin**
- We may need a final teleconference before the Final Workshop to tie up any loose ends on the budget: **Action 4: Tom/Jennifer/David/Sandra to liaise**
- The question arose as to whether a further Steering Group meeting would be needed – discussion of this was deferred to later in the meeting.

3. Interim survey

- Kristina gave an overview of the process she had followed to identify a top circa 30 questions, following closure of the interim survey on April 15th. There were a total of 2234 respondents, with a varying number of responses to each question. This had been anticipated at the last Steering Group meeting, so the questions had been set 5/6 to a page and the pages randomised so that if people dropped out, they would do so at different points in the list of 71 questions.
- Kristina used the output from the Early Osteoarthritis of Hip and Knee interim survey as a template, provided by Sandra. The overall rank is linked primarily to the Highly Important response. For example, question T17 (which ranks as 1) had a total of 1715 responses, of which the total of Highly Important responses was 1238, and this is shown as a percentage of 1715.
- There are 31 questions that show 50% or above on Highly Important. Where a question showed the same level of ranking based on Highly Important alone, then the level of Important was used to determine rank. E.g. questions O5 and D10 both show 56% on Highly Important, with O5 showing 29% on Important and D10 28%; therefore O5 was ranked at 16 and D10 at 17.
- Questions T21 and T1 are ranked at 30 and 31 respectively; however, they score very similarly, so it might be worth extending to a Top 31.
- Discussion arose concerning weighting of responses and the methods used by other PSPs. Kristina reported that she had conducted an online search for methodology on analysing Likert scales and found the that the advice is not to weight as we can't know what weighting the respondent gives their choices. This led to her decision to calibrate according to frequency, following the Early Osteoarthritis example. Cynthia flagged that the Depression PSP weighted according to numbers of respondents in each group.
- Kristina explained that the Highly Important responses to each question per respondent group were shown on the chart, and that she had checked to see if there were any questions that would have been ranked differently. She identified A3 (currently ranked at 37), A2 (ranked 40) and C4 (ranked 43) as being Highly Important at the level of more than 50% to one or more of the individual respondent groups. In addition, she identified H1 (ranked 39) as the only question identified as more important to Health Professionals than to patients. **Action 5: these 4 questions to be added to the top 31 to form a top 35 to take to the Final Workshop/Kristina to send to Sandra**
- Discussion concluded that it would be helpful to see a visual representation at the Final Workshop of the overlap of ranking between the different respondent groups, also showing the outliers (e.g. using a traffic light system). The Anonymous Patient Representative thought that this would be relatively easy to do and volunteered to take forward in good time. **Action 6: Anonymous Patient Representative**
- Amendments to the indicative questions prior to the interim survey affected some 11 of the categories of question, resulting in the potential need to re-code circa 3000 questions. Kristina estimated that this might take 2 days of time. As things stand therefore, three of the questions in the top 35 and 6 other questions in the longlist of 71 do not show the breakdown of original contributors

by respondent group (i.e. numbers of patients, carers, and professionals who submitted original questions). **Action 7: Sandra/ David to check with JLA whether this is still a requirement for reporting.**

- The Steering Group extended thanks to Kristina for all her work in picking up the data when she did and moving things on so well, as well as her part in the evidence-checking (see item 4 below).

4. Evidence checking

- Jennifer reminded the Steering Group that the decision taken at a previous meeting was to check the evidence for the treatment questions in the longlist of 71. With some 1800 potentially relevant Systematic Reviews to review, Jennifer and Rachel concluded that this was not achievable. Given that treatment guidelines such as those prepared by NICE do the job of checking Systematic Reviews, they decided that the best way forward was to check such guidelines. Rachel reviewed the guidance from the Canadian Network for Mood and Anxiety Treatments (CANMAT, 2013), Jennifer reviewed the NICE guidance (2015), and Kristina reviewed the Department of Veteran Affairs and Department of Defence guidelines (USA, 2010).
- They concluded that there is no clear evidence to support the removal of any of the 71 longlisted questions. Of the top 31 questions, there might be 5 questions that have some evidence but this would not answer the questions posed.
- Discussion concluded that: (i) where evidence sits against any of the top 35 questions, this be highlighted; (ii) it would be worth checking the CANMAT update and the summary of the recent British Association for Psychopharmacology (BAP) report. **Action 8: Rachel to check CANMAT/BAP;**
- **Action 9: Sandra to check the JLA Reporting requirements and liaise with Rachel regarding the nature of referencing required.**

5. Final workshop

- David described the format of the Final Workshop, using slides from a previous PSP to illustrate the scope. He explained that there is a prescribed process using nominal group technique, where small groups work to agree ranking in rounds, the scores then calculated across the groups, and the resulting rankings discussed in revised groups before being recalculated across groups and discussed in a final plenary session. The day will start with a presentation from David - as JLA Adviser – to provide some of the background, and from Tom/ Jennifer - as PSP leads – to provide the context relating to the condition and some of the key results e.g. numbers of survey respondents, interim questions. The Steering Group suggested that it would be a good idea to have a patient/ family representative also involved in the presentation. **Action 10: Tom to draft slides and Tom/Jennifer to consider asking patient representative to be involved in the initial presentation**
- The workshop will be held at Somerville College, Oxford using three rooms. With more than 2000 people expressing interest in being kept informed about the next stages of the project, discussion about numbers attending the Final Workshop considered: how many people, in total, could attend and what the breakdown across respondent groups might be; whether non-voting members of the Steering Group could attend (NB. according to JLA principles, to vote, people need to be patients, carers or clinicians); whether voting members of the Steering Group should give up a place to allow others to be present.
- The conclusions were: (i) keep to a maximum of 40 people including observers (NB. the NIHR Evaluation, Trials and Studies Co-ordinating Centre typically sends 2 observers, with a remit to

consider potential for research funding); (ii) aim for equality of representation across the patient, carer and professional groups, whilst allowing for flexibility according to the numbers of responses; (iii) invitations for expressions of interest to indicate that responses will be considered on a first come, first served basis in each respondent group (in order to minimise the administration); (iv) voting members of the Steering Group to be assumed as participating unless they opt out; (v) accommodate as many observer members of the Steering Group as possible within the overall numbers. **Action 11: Sandra to take arrangements forward.**

- Further discussion highlighted that none of the questions will be lost as they will all be published via the JLA Website, and can be included in the PSP Dissemination/ reporting strategy (see below).

6. Adviser role

- David explained that, due to other commitments, he will be leaving his role as JLA Adviser, concluding with the Final Workshop for this PSP which is, typically, the point of the process that an Adviser would step away. After this, a PSP would usually implement a dissemination plan in order to prompt funding of research to address the priorities.
- Sandra informed the Steering Group that she has been appointed as a JLA Adviser in a freelance capacity, outside of her Oxford role and could offer some support going forward. However, as neither Sandra nor Sophie were comfortable with the idea of the PSP paying her for such support, this could be accommodated within her Oxford role if agreeable.
- It was agreed that: it would be important for someone to hold things after the Final Workshop; if the whole Steering Group wished to stay involved, that would be ideal, otherwise it would need to be at least 2/3 people and not solely Sandra; there may need to be one or two meetings after the Final Workshop to take dissemination forward. **Action 12: An e-mail to be sent to all Steering Group members to ask who would like to stay involved/Sandra/David to coordinate**
- The Steering Group thanked David for all his work over the last two years.

7. Out of scope questions and Dissemination Plans

- Suzanne reported that, as previously agreed, Bipolar UK had received the list of original questions that were deemed out of scope. These fall into 10-12 broad topics, which include requests for information (some of which are addressed and need better signposting, and some which are not), and advice/ support issues. Where they fall into existing information areas covered by Bipolar UK and others, the questions will be included in Bipolar UK's resources; where they fall outside of existing areas, Bipolar UK will create new resources.
- This prompted a discussion about the timing of the launch of the PSP results, and about the form of the reporting that would take place. The conclusions were:
 - (i) there will be a generic report, with a lot of detail, which will be drawn on for a scientific paper and any and all other items yet to be agreed (e.g. a two page Newsletter, information for Clinical Commissioning Groups); the draft report that David had started to prepare will become this, with documents such as the Protocol to be appended, and a description of the interim process and the evidence-checking to be included. A description of the changes in methodology should also be included, and a section for reflections. **Action 13: David/ Sandra/ Kristina/ Rachel to work on initially, then Tom/Jennifer and then the Steering Group; in the meantime, if any SG members have any further suggestions for headings, please forward to Sandra; ultimately, the Oxford hub will forward this to the JLA**
 - (ii) it would be good to do something on Bipolar Awareness Day on Tuesday October 4th (which was the launch date of the first survey in 2014) – this would be too late to launch the official

report which should be earlier e.g. in July, however it could be used to raise awareness of the out of scope activities, as well as acting as a follow-up to the initial launch. **Post-meeting amendment: Bipolar UK will take the lead on working towards Bipolar Awareness Day activities.**

- (iii) advantage should also be taken of: (a) the International Society of Bipolar Disorder meeting in the Netherlands on July 13-16 which Tom is attending, and at which MQ will be presenting and could refer to the PSP; and (b) the Cochrane Editorial meeting in York on July 11th at which - Rachel advised - someone from the Steering Group would be welcome to present **Action 14: Cynthia/Tom/Jennifer/Rachel.**
- (iv) Tom will take the lead in drafting a scientific paper (to be submitted to e.g. The Lancet, Nature) with contributions assumed from all active Steering Group members unless they opt out **Action 15: Tom.**
- (v) there should be a face-to-face meeting in July, for those that wish to stay involved (as discussed above), to finalise the dissemination plan; Cochrane Editorial Unit agreed to host on July 7th. **Action 16: Sandra to organise, and to draft an action timeline.**

8. AOB/ Dates of next meetings

- The plan for a secondary analysis of the first survey data raised by Diana in December was revisited. David reported that NETSCC had suggested some possible funding routes e.g. the Economic and Social Research Council and the Arts Council. Tom suggested the NIHR Research for Patient Benefit programme. Sophie suggested that, if the latter is an option, then linking with the methodology of healthtalk.org could be a way forward. Healthtalk uses interviews to arrive at a set of themes, which can then be shared using video clips. This would avoid the main issue of concern i.e. approaching people who shared their contact details for the purpose of the PSP to see if they would like to opt in to having their data used for a secondary analysis. **Action 17: Diana to explore with Louise Locock possibility of working with Healthtalk and feed back to the Steering Group**
- **Action 18: David/ Sandra to feed back to JLA the Steering Group recommendation that future consent be worded to allow for secondary analysis of data.**
- **July 7th Dissemination meeting, 11-3, same venue**