

**Bipolar Disorder Priority Setting Partnership
Fourth Steering Group Meeting – Thursday January 22nd 2015
Joint Research Office, Churchill Hospital, Oxford**

Present

- **Anonymous Patient representative**, by 'phone
- **Mary-Jane Attenburrow (MJA)** Senior Clinical Research Fellow, Department of Psychiatry, University of Oxford
- **Alison Cranage (AC)**, MQ
- **CHAIR – David Crowe (DC)**, James Lind Alliance Adviser
- **Suzanne Hudson (SH)**, Chief Executive, Bipolar UK, by 'phone
- **Tom Hughes (TH)**, Consultant Psychiatrist, Leeds & York Partnership NHS FT
- **Rachel Marshall (RM)**, Patient's family representative, by 'phone
- **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

Apologies

- **Rachel Churchill (RC)**, Editor, Cochrane Depression, Anxiety and Neurosis Group (CCDAN), Bristol University
- **Ian Hulatt (IH)**, Mental Health Adviser, Royal College of Nursing
- **Cynthia Joyce (CJ)**, Chief Executive, MQ
- **Sophie Petit- Zeman (SPZ)**, Director of Patient Involvement, Oxford BRC
- **Margaret Edwards (ME)**, Chief Executive, SANE
- **Bev Thornton (BT)**, Patient representative
- **Diana Rose (DR)**, Head of Section, The Service User Research Enterprise (SURE)
- **Edmund Brooks (EB)**, Patient's family representative
- **Amanda Hawkins (AH)**, Chair, British Association for Counselling & Psychotherapy (BACP)

Minutes

	Actions
<p>1. Welcome, Apologies and Minutes of last meeting</p> <ul style="list-style-type: none"> • Apologies were noted. Tom reported that Bev has decided to withdraw due to a mix of other commitments and lack of opportunity to date to provide the perspective of a service user. • It was agreed that it was a shame that Bev could not continue as we are just reaching the phase where there is more opportunity to express views. Bev may wish to join with the next stages of the process without sitting on the Steering Group (SG). Also, she may wish to still be listed as an SG member on the Protocol as she was instrumental in the early stages. The SG was unanimous in thanking her for her involvement. • The SG decided not to seek a replacement at this stage as it could delay moving forward. • The Notes of the November 17th teleconference were agreed. 	<p>1. DC to write and thank Bev and ask about the Protocol</p>
<p>2. Data overview</p> <ul style="list-style-type: none"> • Tom explained that Poppy has not yet had much time to get to grips with the data as she has just joined in the role of Data Manager. He presented an overview of 	

demographics and a sense of the data as well as an introduction to the Health Research Classification System (HRCS).

- The relatively small number of professional responses was discussed, and the SG noted that there is a tendency for this to be lower than patient/ carer responses in most PSPs. In particular, very few GPs responded – again this is fairly typical across PSPs.
- A few points were noted, some of which might be teased out of the data later:
 - Respondents aged 61+ are missing, which might be a reflection of the online methodology and/ or of the impact of the condition on that age group. The SG were encouraged by the number of younger respondents as diagnosis can take so long, and thought this might be a function of the question including those that “might have” bipolar, as well as the use of social media.
 - Age at onset is not easily analysable as it was a free text field and there were a number of discursive responses and a lot of missing data.
 - The spread of those “in contact with” primary and secondary care appears representative.
 - The relatively high number of those hospitalised is concerning as it is higher than studies tend to show, and may just be a more accurate picture of people with bipolar.
- Overall ethnic response is white, which might reflect who we reached or might be a function of fewer non-white ethnicities accessing secondary care.
- More than 2000 respondents wish to be kept informed as we go forward.
- Tom had a quick look at around 1000 questions to gain a sense of the data across the different areas of causes, diagnosis, treatment, care and support and prognosis. From this it seems clear that saturation has been achieved, that there are many identical questions as well as very similar ones, and some questions will need to be moved to a different group although the majority are in the correct theme.
- The SG anticipate that many questions will have been addressed by existing research - it is likely that the answers are out there somewhere but people don't know where/ how to access them.
- In his overview of the HRCS taxonomy Tom noted that many of the sections would not apply, and that although there are Mental Health categories Bipolar is not included. Of the existing categories, that on Electro Convulsive Therapy is likely to prove the most contentious in terms of psychological vs physical therapy.
- In terms of time needed to analyse the data, Poppy reported that she is in the early stages of cleaning i.e. removing incomplete lines, splitting questions out into single rows and allocating a unique i.d to each. She has found she can work with 200 per day and anticipates that this will speed up, whilst recognising that it is likely to take longer overall than anticipated – Alison agreed from her experience with the Depression PSP.
- It was agreed to aim for the beginning of March to complete the cleaning phase, including the removal of duplicates, with Poppy feeding back on progress in 1-2 weeks' time.

**2. PS to feedback
on progress Jan
29 – Feb 5**

3. Interim process and overall timeline

- David presented an overview of the process from the JLA perspective and sought SG input on the overall timeline.
- Next stages involve grouping the questions by allocating codes from the HRCS;

combining similar questions to make “indicative” questions; checking the evidence base to see which have already been answered; and formatting the questions (where possible) to include Population, Intervention, Comparator, Outcome (PICO) – a process that many of the SG are familiar with.

- Discussion on the PICO element of the work highlighted that perhaps those that emerge as clearer PICO questions would be more suited to go forward for funding, whilst those that emerge as less clear might be better suited to inform Systematic Reviews.
- PICO activity can be taken to a very detailed level, and take a lot of time; it was felt that a more general level would be better as researchers taking questions forward for funding could do the more detailed work themselves.
- There might be the possibility for this work to inform Core Outcome Sets for Bipolar.
- The SG will need to help with this work in different ways, and to check that things are proceeding along agreed lines. This would be via e-mail, teleconferences and at face to face meetings.
- Both patient representatives are keen to be involved in the data work, and the existing data sub-group is happy to continue.
- In response to a question about UK DUETs, it was clarified that we are bound by the process as it is the required repository for the priorities. Feedback on the fit for purpose is welcome. Sandra is happy to advise Poppy as necessary – more columns can be added to the template for working purposes, but the final version to upload to DUETs must match their requirements.
- Jennifer and Rachel Churchill will lead on taking forward the checking of the evidence base. The timescale will need to depend on when this activity can occur, the available resource at the time, and the volume of questions. David will obtain guidance on the number of questions and point in the process for this activity.
- We need to keep people informed – Sandra will organise a thank you letter providing an update on number of responses and next steps, with a link to the JLA Newsletter.
- It was noted that Jennifer is away March 7th to 28th and that Easter is April 5-8.
- It was agreed that there should be face to face meetings in March and June, with data teleconferences to be arranged, whilst recognising that the timeline is emergent and may need adjusting.

4. Budget overview

- Tom gave an update on the budget and noted that: there are some items outstanding still; Oxford BRC had agreed to use the contingency funds to cover increased support from David should this be needed; in the meantime, Leeds will work with the overall funds held there.
- Sandra highlighted that the original budget included circa £4k for an interim workshop. If the interim process is virtual, then this becomes free.
- The SG noted that the central co-ordination and guidance from David is crucial and so are happy if increased support is needed.

5. Administration follow-up

- There are a number of Declarations of Interest, and Biographies/ Photos for the website outstanding. Sandra will chase up and publish what we have after 2 weeks.
- The update being sent out could also be uploaded to the NEWS section of the website.

**3. DC to check re number of questions/ when in process for PICO formatting & checking evidence base
NB. see post-meeting note below**

4. SR to create mailing list of people to keep informed and draft update to send

5. DC to circulate timeline

6. SR to chase up and arrange website update

6. AOB & Dates of next meetings

AOB

- Tom shared a request that had been made to him regarding someone observing the process with a view to comparing with another for submission within an NIHR post-doctoral fellowship. The SG would like to help, but would like to have more information about what's involved.
- Tom sought the SG's view on whether it would be appropriate to ask those that wish to be kept informed to self-select to a mailing list to receive information about other studies. Discussion took place around who could hold the data and who could access it. This should be an Agenda item at the next SG

Meetings

- Next SG Meetings – March 23rd or 19th; June 17th; in London
- Data sub-group meetings – to be arranged in between SG

David closed the meeting, thanking everyone for their input – especially those on the 'phone as the conditions were not ideal.

Post meeting note:

David has done some follow up checking on when questions are usually "PICO'd" which we talked about during the Steering group; it's usually at the long list stage when there are about 30 questions, and comes down to what we intend as a PSP to publish; if we are publishing the full 30, even with a top 10 within that, then we would need to put them into PICO format

7. TH to respond to enquirer

8. TH and MJA to make enquiries at respective Trusts

9. SR to include on March SG Agenda

10. SR to send out a doodle poll and arrange meeting rooms, ideally through PSP partners