

**Bipolar Disorder Priority Setting Partnership
Second Steering Group Meeting – Wednesday 10th September 2014, 11:00 - 14:00**

Venue:

Conference Room, Victoria Charity Centre, 11 Belgrave Road, London, SW1V 1RB

Present

- **Mary-Jane Attenburrow (MJA)** Senior Clinical Research Fellow, Department of Psychiatry, University of Oxford
- **Edmund Brooks (EB)**, Patient's family representative
- **Alison Cranage (AC)**, MQ
- **CHAIR – David Crowe (DC)**, James Lind Alliance Adviser
- **Amanda Hawkins (AH)**, Chair, British Association for Counselling & Psychotherapy (BACP)
- **Suzanne Hudson (SH)**, Chief Executive, Bipolar UK
- **Tom Hughes (TH)**, Consultant Psychiatrist, Leeds & York Partnership NHS FT
- **Rachel Marshall (RM)**, Patient's family representative
- **Lucy Pike (LP)**, Communications Officer, Bipolar UK
- **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

By 'phone:

- **Rachel Churchill (RC)**, Editor, Cochrane Depression, Anxiety and Neurosis Group (CCDAN), Bristol University
- **Anonymous Patient representative**

Apologies

- **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
- **Diana Rose (DR)**, Head of Section, The Service User Research Enterprise (SURE)
- **Bev Thornton (BT)**, Patient representative

Minutes

	Actions
<p>1. Welcome and Minutes of last meeting</p> <ul style="list-style-type: none"> • DC welcomed everyone, noted apologies, and introductions were made as some people had not been present at the first meeting. • The Minutes of the previous meeting in July were reviewed. No matters arising were necessary as the Agenda covered them all. The Minutes were accepted. 	
<p>2. Website</p> <ul style="list-style-type: none"> • DC brought the site up on the screen. SR explained the constraints of the corporate site, including fixed font - the site has awards for visual accessibility, and AH confirmed that it was very accessible from that perspective. It was noted that the 	

site has a font change option for size and colour.

- A few textual changes were noted, and typos etc highlighted, and SR will work with the webmaster on these.
- The banner image was reviewed. SR explained that it is a holding image pending the final choice. The Steering Group (SG) advised that they would like a similar image but with wider age and ethnic representation.
- It was suggested adding mixed state within the section on bipolar.
- SR noted that a “News” page will be added when there is some news to upload, and that a button to link to the survey will go on the front page when the survey is ready.
- The SG asked if the navigation could go along the top rather than the side. SR thinks not but will check.
- AC confirmed that the content looks similar to that of the Depression PSP site.

1. SR to arrange text changes, and enquire about navigation change

2. SR/DC to identify potential alternative banner images

3. DC to provide SR with amended News item

3. Survey

- Unfortunately it wasn’t possible to access the first draft in Survey Monkey. Hard copies of the text version were distributed for review. SG members had accessed the online version prior to the meeting so discussion went ahead.
- TH/JR explained that they had taken the same format as the Depression PSP.
- Discussion concluded that the following amendments were required:
 - Ensuring that the overview is visible on the Survey Monkey front page for those accessing it directly and not via the website;
 - Reordering of examples to reflect Causes, Diagnosis, Treatment, Care/ Support, and other;
 - Ensuring that the response boxes for questions are organised in the same manner, with people being able to enter as many questions as they wish under each heading, or none;
 - Being able to skip from one response box/ page to the next;
 - Noting that the respondents do not have to exactly formulate research questions as this is part of the PSP process;
 - Add to the list of descriptions something like “I am a person who is concerned about having bipolar” + “I am a carer etc of someone who is concerned...”;
 - Amend “I am a person with bipolar” to something like “I have a diagnosis and am a person with bipolar”;
 - Reorder the survey so that the section following “About you” is for non-professionals, and the professional section comes at the end;
 - Remove the question which asks about medication;
 - Reorder the questions for non-professionals so that the GP question is first, then the hospital question, then the secondary care question;
 - Add a question for non-professionals who are relatives etc, asking their relationship to the person with bipolar e.g. daughter, parent using a tick box selection plus a free text for “other”;
 - Check best practice guidance regarding Gender and Ethnicity – Transgender may need to be added; the list of Ethnicities in the Survey Monkey is longer than that in the text document;
 - Change Age Range to Year of Birth with a free text box.

4. SR to start the amendments in the text version, and pass to TH/JR to finalise;

5. SR to work with survey developer to effect changes in Survey Monkey;

6. SH to provide copies of best practice for Gender and Ethnicity;

<p>4. Potential linked survey</p> <ul style="list-style-type: none"> • TH circulated copies of the proposed linked survey to understand a number of issues, such as the time between onset of symptoms and initial diagnosis and the relationship people have with their medication. The first part of the survey is adapted from that used in the USA 20 years ago. The second and third parts use validated questionnaires. His suggestion is that the survey could be linked to from the PSP survey, at the end so it does not detract, and participation would be voluntary. • Discussion raised concerns about ethics, information governance, impact on participation in the PSP survey/ potential for confusion, and the fact that the SG has not gone out to tender for the work and so there could be conflict of interest. • It was agreed that the survey would not be linked to the PSP survey. 	<p>7. Bring forward the linked survey to a future SG meeting, post-survey.</p>
<p>5. Launch</p> <ul style="list-style-type: none"> • DC explained that Bipolar Awareness Day is October 7th, and Mental Health Awareness day is October 10th, and it was proposed that we aim for survey launch on October 7th. • LP circulated a draft Press Release and Communications Plan. She explained that the Press Release could be used as a template by SG members. Bipolar UK will do their own Press Release and publicise via their website and their e-Newsletter to some 14,000 people. They also have a day of drop-in sessions planned for October 10th, and will have laptops set up so people can do the online survey. • The timeline was discussed. Some amendments to the survey are required, and these need to be done through the Oxford University Hospitals Trust communications team. SR hopes that these could be done within a week of receiving the final version from TH/JR, but needs to check. TH raised the issue of piloting the survey prior to launch. It was agreed that this would be nice to have if the timeline allows. Otherwise, the SG members will pilot it, as there is wide representation. • Discussion then considered the wider groups that need to be reached including GPs. AH will organise circulation via BACP Newsletter to some 42,000 members. SH suggested that the Royal College of GPs and other such organisations tend to pick up the Bipolar UK releases; MJA reported that the Oxford CLAHRC will publish in their Newsletter and on their website, as well as tweet and disseminate via the main co-ordinating centre. • RC highlighted that the Depression PSP offered a “tweet sheet”, as well as a flyer. • SH asked the SG for a nominated person to front to the media, as it shouldn’t be seen as being Bipolar UK. SR/DC volunteered SPZ in her absence, and TH volunteered. It was agreed that the two would offer a good front. 	<p>8. SR to check turnaround time with survey developer;</p> <p>9. LP to amend comms plans in light of feedback, inc “tweet sheet”, and provide to DC/SR for review and circulation to SG</p> <p>10. SR to publish on People in Research database, ask JLA/ BRC/ OUHT to tweet, and prepare a map of partners to go through</p> <p>11. SG members to provide SR with wider contacts to add to database</p> <p>12. AC to provide Depression PSP materials to SR/DC/LP/SH</p>
<p>6. Administration</p> <ul style="list-style-type: none"> • TH/JR reported that SPZ had sent a letter to the Daily Telegraph following an article about someone with bipolar. The salient elements of the letter had been omitted, 	<p>13. SR to amend Protocol and</p>

and SPZ will go back to the paper at a later stage of the process.

- Protocol – two amendments are required which SR will make in the electronic copy. Those present signed the signature page. SR will try to gather the remaining signature electronically.
- Declarations of interest, biographies and photos – It was noted that the following still need to provide all 3 to SR: MJA, AH, IH, BT. JR to provide photo.

gather remaining signatures

14. MJA, AH, IH, BT and JR to provide biogs etc as necessary

7. AOB

a) There was a brief discussion concerning **data management**.

- The start of analysis is dependent on the close date for the survey, currently anticipated as end of November. However, an extension may be required once there is a sense of how many/ who is responding. RC highlighted that the Depression PSP has 4000 responses and 8000 questions, and that whilst she, JR and TH can offer some resource in kind, it may not be possible for all the work to be done that way. The work breaks down into two areas: (a) checking the evidence base to understand which, if any, of the uncertainties contributed by respondents are already known; (b) analysing the responses, and formatting the questions. It would benefit from having a clear process outlined. AC advised that for the Depression PSP, they anticipate needing 3-4 months to analyse and review existing evidence. SH reminded the SG that the earlier decision to ask respondents to submit their questions within 5 categories is a step in the right direction, whereas the Depression survey was completely open. TH remarked that there is some money in the budget to employ someone who may, for example, be employed part-time elsewhere; however, to work on the data the person really needs an understanding of the field.
- The overall PSP timeline was considered: there is a Bipolar Conference on March 15th 2015 which could make a target date for highlighting some results, but is too soon for Final results to be available.
- AH suggested that the role could be put out to tender, perhaps via BACP, and perhaps whichever organisation won might be prepared to part-fund.
- DC proposed that the sub-group take forward the development of a data protocol etc, with support from wider SG as/ when needed. This was agreed. The sub-group have a teleconference on October 20th and will pick this discussion up then.

15. Sub-group to discuss data protocol etc at t/c Oct 20th

16. DC to send out a note to sub group in advance of the 20th October asking them for (a) what support in kind they can offer and (b) what resources they feel the project needs in terms of overall coordination of data management

b) DC took feedback on what worked well/ not so well both in terms of the meeting/ organisation, and more generally

- Some SG members felt that there was too long a gap between the last meeting and preparing for this. It was agreed that 3-weekly updates would be circulated.

17. DC (SR) to organise 3-weekly updates

8. Next meetings

- **Teleconference November 17th at 4pm**, to review survey responses
- **Face to face meeting January 28th 11:00-15:00** at RNiB in London (courtesy of AH), to review the position following start of data analysis (NB. Post meeting DC suggested 11:30 -15:30 to allow for those coming by train)

18. All to note dates