Description of final workshop to set research priorities for Bipolar

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1. Introduction and context for this report

This report describes the process and outcomes of the final prioritisation workshop of the Bipolar research Priority Setting Partnership. A report of the overall process is being prepared for publication in a scientific journal.

This report will be available on the James Lind Alliance (JLA) Bipolar research Priority Setting Partnership (PSP) website (http://www.ouh.nhs.uk/bipolar) and the JLA website (http://www.jla.nihr.ac.uk).

We would like to take this opportunity to thank everyone who participated at every stage of the process. Many of you contributed questions, and indicated your priorities online, and a few of you gave up a day of your time to take part in the final workshop.

2. Background to the Priority Setting Partnership

The initial Partnership objectives set out in the overall Partnership Protocol were:

- to work with patients**,** carers, family members and clinicians to identify uncertainties about bipolar causes, diagnosis, treatment, care, prevention and prognosis;
- to agree by consensus a prioritised list of those uncertainties for research;
- to publicise the results of the PSP and process;
- to take the results to research commissioning bodies to be considered for funding.

3. Developing the shortlist of research questions for discussion and prioritisation at the workshop

The partnership followed an established route for gathering and prioritising research questions, as described in the JLA Guidebook http://www.jlaguidebook.org/

Essentially, this involved gathering research questions through an initial survey, grouping them, and removing those that were out of scope[1]. An interim prioritisation survey then considered 71 questions, creating a list of 35 in rank order that was taken to the final workshop to identify the top ten questions. This is outlined in the diagram below which was used as a "Timeline" slide at the final workshop.

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[1] The Protocol document defined the scope as causes, diagnosis, treatment, care, prevention and prognosis of bipolar

Timeline
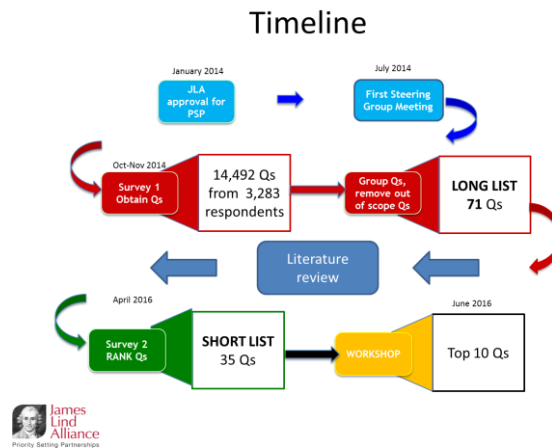
4. Workshop

4.1 Workshop participants

Three key groups of people were invited: people with a diagnosis of, or who thought they may have, bipolar; family members/ carers of people with bipolar; health professionals working with people with bipolar. A large number of people who had participated in the second survey had asked to be kept informed, and we contacted them to seek expressions of interest in participating in the final workshop.

We had planned to accept respondents on a first come first served basis within each group, to a maximum of 10 per group. In the event, all carer/family member respondents were accepted, and additional effort made to recruit health professionals through Steering Group contacts. By contrast, the number of people with a diagnosis of bipolar who wanted to attend was greater than our capacity to accept, and far greater than that experienced for other final workshops administered by the JLA "hub" at the NIHR Oxford Biomedical Research Centre (BRC). Having accepted the first 5-6 on a first come first served basis, it became clear that this group would need balancing in order to achieve a mix of gender and experience (according to year of diagnosis). The final 2-3 attendees from this group were drawn from among the group of earlier respondents where they were still available, and as cancellations were received we approached more local respondents – still from the earlier respondents where they were available – on the grounds that they would not need support in arranging travel etc. as the date of the workshop grew near.

As a result, on the day we had 8 people with a diagnosis of bipolar (as evidenced by the year of diagnosis they provided in advance of the meeting); a representative from Bipolar UK; 9 family members/ carers; and 9 health care professionals (1 GP, 3 psychotherapists and 5 psychiatrists). Some of the participants were also Steering Group members, in keeping with JLA practice.

The Workshop was observed by 5 people – 2 researchers from the NIHR Evaluation, Trials and Studies Co-ordinating Centre (NETSCC); one member of MQ, the mental health charity who helped to fund the PSP; a new JLA Adviser; and a member of the Steering Group who, as an academic, was not eligible to participate.

4.2 Methods

Prior to the workshop, all participants were asked to provide short biographies, complete a declaration of competing interests for bipolar research, and review and rank the shortlist of questions.

The workshop commenced with a presentation that provided:
- an overview of the JLA and a description of the workshop format, with information about the principles involved (e.g. respectful listening, need for compromise) and the outcomes required (i.e. the 35 questions in rank order, agreed by consensus); (David Crowe, JLA Adviser);
- information on the need for research in bipolar, and the process followed by the Bipolar PSP (Tom Hughes/ Jennifer Rendell, PSP co-leads, together with a patient representative on the Steering Group).

First Phase
Following the presentation, participants were asked to work together in small groups which included a mix of people with a diagnosis of bipolar, carers/ family members, and health professionals. Each group had a facilitator who asked them to report their top and bottom 3 priorities from the list that they had been asked to rank before the workshop. Participants were also invited to reflect on any other priorities they felt strongly about, whether positively or negatively. Their views were captured on a flipchart and used to inform the second phase.

Second Phase
First round: Each group had a set of cards with each of the 35 questions displayed on the front, with information about each question's rank in the interim prioritising survey by each group (person with bipolar, carer, professional, other) given on the reverse for reference. Facilitators laid out these cards to reflect as well as possible the priorities identified in the first phase. When the groups reconvened, they considered the order of the questions, discussing the relative importance of those where there was disagreement of ranking, with a view to agreeing a rank order of 1-35.

Facilitators for each group aimed to ensure that no one dominated the discussion or exerted undue influence on the group, ensuring that all members participated in the discussion, whilst keeping the group on task and to time.

Groups were encouraged to agree the final ranking, and over the lunch period the rank order of each question from each of the 4 groups was entered into an Excel spreadsheet, the total ranking calculated, and the results sorted to provide the rank order for the next round of discussion.

The whole group reconvened and was provided with an overview of where there was consensus or differences between groups.

Second round: The four small groups from the morning were changed in the afternoon session to create new combinations of participants. This time the groups appraised and discussed the new aggregate ranking from the first round of priority setting. Similar processes were used as in the first round, but the focus was on having a clear agreement of the top ten, as well as a complete 1 - 35 rank of questions.

Final Phase
During the refreshment break the JLA team collated the results from the second round of ranking, and the top 15 were laid out on the floor for the whole group to see. The debate was then opened up for everyone to contribute.

There was a good discussion about the nature and balance of this list:

- overall consensus was strong about the final top ten;
- a question was raised by a participant as to whether the question at position 4 should stay in the top ten (T17: What are the best ways to manage suicide risk?). This was voted on by the workshop participants and it was agreed that the question should stay in the top ten at number 4, but the question changed to be more specific about suicide in relation to bipolar (27 people participated in the vote).
- There was also consensus about the merging of 2 questions: D1: Why does it take so long to get a diagnosis of bipolar disorder, especially when patients are aware of experiencing symptoms? and D10: How can the time it takes to get a diagnosis of bipolar be shortened?

The NIHR has a topic identification process that adds another layer of patient involvement and interrogates the background data, so this is not the end of the story in terms of the questions: no questions are lost – all will be available via the JLA website.

4.3 The final Top 10

The wording in red reflects the final discussions described above. The full list of questions ranked 1-35 is available at Appendix 1.

1	What causes bipolar?
2	How can treatments be tailored to individuals?
3	What is the most effective combination of self-management approaches, therapy and medication?
4	What are the best ways to manage suicide risk among people with bipolar?
5	What could be done for people who do not get better with treatment?
6	What are the best ways to manage the side-effects of medication (including weight gain, problems with thinking and memory, and emotional numbness)?
7	Why does it take so long to get a diagnosis of bipolar disorder, and how could time to diagnosis be shortened?
8	Which are the best medications for treating episodes and for prevention of relapse in bipolar?
9	How effective are talking therapies such as counselling, dynamic psychotherapy and CBT?
10	Can medications with fewer side-effects be developed?

5. What next for the priorities?

The Steering Group are meeting in July to review the outcomes from the Final Workshop and develop a plan to share, and raise awareness of, the research priorities.

This will include approaches such as presentations at conferences (e.g. the International Society for Bipolar Disorder Annual Conference), summary articles, and more detailed accounts of the process and results. These will be shared with professional publications as well as newsletters, and be available on the websites of the partner organisations, with social media used to promote them.

6. Workshop evaluation

6.1 Summary

We sought feedback about the information that was sent out prior to the workshop, how the workshop day was organised and facilitated and whether objectives were met. We asked participants to indicate their answer on a sliding scale of options (e.g. Very Helpful through to Very Unhelpful). We received 22 out of a possible 26 evaluation forms. In summary, with one exception, people found the pre-workshop information and exercise very helpful or helpful. Everyone was very satisfied or satisfied with the way the workshop was facilitated and felt able to communicate their views in the workshop. The majority were very satisfied or satisfied that the workshop objective was achieved and that their views helped shape the final list of research questions. The details of this are collated in section 6.2 below.

We also asked for comments about what went well and what could have been done differently. People took time to write constructive comments. Many thought the day was worthwhile and that the process was well managed with excellent facilitators who ensured everyone's views were heard. Words such as 'kindness', 'empathy', fantastic' and 'outstanding' were used in many of the comments.

In terms of what could be done differently, some felt we should ideally have widened the group to include younger people and a wider cross-section of society. There was a question over inclusivity and whether people who were not on the internet were excluded from the process. There were reflections that some questions were ambiguous, some overlapped too much and that putting questions into themes may have helped. It was suggested that care needs to be taken with both body and spoken language so as not to upset, exclude or patronise participants. One person felt that the group had a moral obligation to put the question about suicide into the top 10 as people with bipolar who had completed suicide could not be there to vote. Another person suggested that participants should have been paid for their time to attend the workshop as that is best practice.

6.2 Collated responses

1. **Pre-Workshop information and exercise**

How helpful was the pre-workshop pack in preparing you for the workshop? (please circle one option)

Very helpful 14	Helpful 7	Neither	Unhelpful 1	Very unhelpful

2. Workshop Facilitation

How satisfied were you with the way the James Lind Alliance team facilitated the workshop? (please circle one option)

Very satisfied 16	Satisfied 6	Neither	Dissatisfied	Very dissatisfied

3. Workshop Content

How satisfied were you that you were able to communicate your views in the workshop? (please circle one option)

Very satisfied 15	Satisfied 7	Neither	Dissatisfied	Very dissatisfied

4. Priority Setting Process

How satisfied are you that your views and preferences shaped the final list of research questions? (please circle one option)

Very satisfied 9	Satisfied 11	Neither 1	Dissatisfied 1	Very dissatisfied

5. Workshop outcome

How satisfied are you that we achieved the objective of establishing the top ten questions for research? (please circle one option)

Very satisfied	Satisfied	Neither	Dissatisfied	Very dissatisfied
11	**9**	**1**	**1**	

6. Venue

How satisfied were you with the venue for the workshop? (please circle one option)

Very satisfied	Satisfied	Neither	Dissatisfied	Very dissatisfied
16	**6**			

In order to understand the types of people who participated in the workshop please circle the following statements that relate to you – this information will be treated with the strictest confidence and is only used for our evaluation purposes.

Are you a: (please circle all that apply)

Service user/parent: **14**   Health professional: **6**   Carer: **4**

Researcher: **2**   Other (please describe)

Are you: (please circle one option)

Male: **11**   Female: **11**

Are you aged between: (please circle one option)

18-30 : **1**   31-45 : **4**   46-55 : **7**   56-65 : **6**   65+: **4**

Appendix 1: The final ranking of the 35 questions

Rank	Question
1	C10: What causes bipolar?
2	T12: How can treatments be tailored to individuals?
3	M3: What is the most effective combination of self-management approaches, therapy and medication?
4	T17: What are the best ways to manage suicide risk among people with bipolar?*
5	T14: What could be done for people who do not get better with treatment?
6	T5: What are the best ways to manage the side-effects of medication (including weight gain, problems with thinking and memory, and emotional numbness)?
7	D1 & D10 combined: Why does it take so long to get a diagnosis of bipolar disorder, and how could time to diagnosis be shortened?**
8	T8: Which are the best medications for treating episodes and for prevention of relapse in bipolar?
9	T11: How effective are talking therapies such as counselling, dynamic psychotherapy and CBT?
10	T4: Can medications with fewer side-effects be developed?
11	M2: Can bipolar be managed effectively without medication and if so how, and what are the long term outcomes?
12	P1: Can bipolar be prevented, and if so, how?
13	H1: What is the best and most cost effective way to provide clinical care for those with bipolar, including who should provide it?
14	M4: What can we learn about managing bipolar from the people who are managing the condition well?
15	M7: What are the most effective ways for people with bipolar to monitor their condition, and take steps to avoid or minimise the impact of a relapse?
16	D10: How can the time it takes to get a diagnosis of bipolar be shortened?**
17	T9: How effective are combinations of medication, e.g. antidepressant plus a mood-stabilising drug, in the treatment of bipolar?
18	R2: What are the risks and benefits to mother and baby of medication for bipolar (e.g. during pregnancy, childbirth and breastfeeding)?
19	T2: What are the unwanted long-term effects of medication?

20	A3: How can family members and carers best be supported to manage life with a person with bipolar?
21	T15: What are the outcomes of people with bipolar being more involved in decisions about their treatment?
22	M5: What are the most effective ways to train and support a person with bipolar so they are motivated and able to manage the condition themselves?
23	M6: What are the triggers for bipolar episodes (e.g. life events and stress) and how do these vary?
24	P2: Can bipolar be prevented in people who are at high risk because they have a family history of bipolar?
25	T18: What is the impact of more positive attitudes to bipolar amongst (a) health professionals and (b) people affected by bipolar?
26	P3: Can bipolar be prevented in later life with children/teenagers/ young adults who already have mild symptoms (depression, anxiety and mood swings)?
27	O5: What impact does bipolar have, including on education, work, relationships, parenting and quality of life?
28	M1: What precise lifestyle changes can individuals make to manage their bipolar (e.g. diet, exercise, sleep, yoga, meditation, rest, routine, sunlight, change of job, avoiding alcohol and recreational drugs)?
29	T10: Can medication such as antidepressants trigger the onset of bipolar or worsen its course?
30	A2: How can family members and carers best support people with bipolar (e.g. through education, training and practical support)?
31	O1: Is it possible to fully recover from bipolar and live a 'normal' life, or are people always affected throughout their lives?
32	T21: How effective are the forms of support for people with bipolar (professional, social, family, peer support)?
33	T3: How often should medication plans be reviewed, and should dosage change?
34	R3: What are the best ways to support parents with bipolar?
35	C4: How are children of parents with bipolar affected by their parent(s)' illness, including can they learn bipolar behaviours?

* As requested at the Final Workshop, the phrase "among people with bipolar" was added to priority number 4.

** As requested at the Final Workshop, questions D1 (Why does it take so long to get a diagnosis of bipolar disorder, especially when patients are aware of experiencing symptoms?) and D10 (How can the time it takes to get a diagnosis of bipolar be shortened?) were combined to form priority number 7 "Why does it take so long to get a diagnosis of bipolar disorder, and how could time to diagnosis be shortened?"

Appendix 2: The partners

Bipolar UK

British Association for Psychopharmacology

British Association for Counselling and Psychotherapy

Cochrane Collaboration Common Mental Disorders Group

Leeds and York Partnership NHS Foundation Trust*

MQ, Transforming Mental Health*

NIHR CLAHRC Oxford

NIHR Oxford Biomedical Research Centre*

Oxford Health NHS Foundation Trust*

Royal College of Nursing

SANE

Service User Research Enterprise (SURE)

University of Oxford Department of Psychiatry*

*Denotes funding partner