

Bipolar Priority Setting Partnership
First Steering Group Meeting - Thursday 3rd July 2014, 11:00 - 14:00
Seminar Room 2, West Wing Teaching Suite, John Radcliffe Hospital, Oxford

Participants

Present

CHAIR - David Crowe (DC), *James Lind Alliance Adviser,*

Tom Hughes (TH), *Consultant Psychiatrist, Leeds & York Partnership NHS FT*

Dr Jennifer Rendell (JR), *Research Fellow, University of Oxford*

Amanda Hawkins (AH), *Chair, BACP*

Suzanne Hudson (SH), *Chief Executive, Bipolar UK*

Cynthia Joyce (CJ), *Chief Executive, MQ*

Professor Diana Rose (DR), *Head of Section, SURE*

Edmund Brooks (EB), *Patient representative*

Bev Thornton (BT), *Patient representative*

Beccy Maeso (BM), *JLA Senior Programme Manager, External Relations - **Observer***

Hilary Cullen (HC), *Oxford BRC, PSP Coordinator*

By teleconference

Sophie Petit- Zeman (SP-Z), *Director of Patient Involvement, Oxford BRC*

Dr Rachel Churchill (RC), *Reader, University of Bristol and University of York and Coordinating Editor Cochrane DAN Group*

Rachel Marshall (RM), *Patient representative*

Apologies

Mary-Jane Attenburrow (M-JH), *Consultant Psychiatrist, Oxford*

Margaret Edwards (ME), *Director of Strategy and Communications, SANE*

Ian Hulatt (IH), *Mental Health Adviser RCN*

1. Welcome and introductions - DC

Initial introductions were made of all those present. Arrangements had been made for teleconference for those who were not able to join the meeting in person.

Difficulties with connection resulted in those joining the meeting by phone introduce themselves, and then left the meeting.

2. Introduction to the JLA process - DC / SP-Z

Sophie Petit-Zeman (SP-Z) (by phone) gave an overview of her role in developing the James Lind Alliance (JLA) PSPs in Oxford, as Director of Patient Involvement at the Oxford NIHR Biomedical Research Centre. She also talked about other ways in which the work of PSPs can take forward understanding in areas of health care. This included occasions where 'uncertainties' received in surveys, when reviewed, are found to have already been resolved by research. This may indicate an issue around professional education or dissemination of best practice. A PSP may also identify issues that are not to do with treatments as such, but diagnosis, prognosis etc and discussion are ongoing with UK DUETS about whether there is scope to develop a further database to house them. The Biomedical Research Centre and

Unit in Oxford are also working on the wider issues of patient involvement and relationships with industry and will also thus explore how best to take forward JLA-identified priorities to industry for funding.

The OUH NHS Trust web site is also hosting a number of Priority Setting Partnerships, one of which will be the Bipolar PSP website.

David Crowe (DC) advised that the JLA has facilitated about 20 PSPs over the last 10 years, with the experience across many different areas of health care. There is a Depression PSP currently under way, with the survey already launched. Some members of that Depression Steering Group are also on the Bipolar PSP Steering Group, which will provide the opportunity for learning to be shared.

Beccy Maeso (BM) who is attending this meeting as observer, gave a brief overview of the work of the National Institute of Health Research. NIHR supports the ethos of the JLA to facilitate patients and clinicians to work together in equal partnership to agree priorities in research. This is done by directly funding some PSPs, appointing JLA Advisers to work with each PSP and assisting in fundraising for PSPs where appropriate. The NIHR will consider the longer list of uncertainties collated by PSPs for promoting to potential research funders.

3. Background to the project – TH / JR

Tom Hughes (TH) explained the background to this PSP and his involvement in it. In his work as a clinician he had identified the need to include patients in a clinical study, and had recognised that patients needed to be involved in the whole process of clinical research. This led to finding out about the work of the JLA, recognising the need for expertise in literature searches and linking in with Oxford clinicians also interested in developing the PSP.

Cynthia Joyce (CJ) applauded the fact that the impetus for this PSP had come from clinicians.

Jennifer Rendell (JR) gave a presentation outlining the range of issues around bipolar disorder that may be addressed in the survey. These included: a variety of therapies, the physical and mental health interactions, diagnostic tools used by clinicians, remote monitoring of patient general, mental and physical health, genetic involvement (including the work of the bipolar genetics network) and the possibility of affecting treatments.

A discussion was held on the name of this PSP:

SH and EB said that they were not comfortable with the term 'bipolar disorder' being used.

TH acknowledged that the PSP needs to use a phrase / term that the SG were comfortable with.

DR suggested 'Living with bipolar'.

Action Point 1: HC

*PSP to be called
'Bipolar Priority
Setting Partnership'
and the term
'Bipolar' to be used*

CJ (and others) noted that there had been changes over the past few years in terms used, with 'bipolar disorder' previously was known as 'manic depression' DR noted that 'bipolar disorder' was not 'a fact' but rather 'a hypothesis' AH pointed out that terms used in some areas of health care were changed as a result of the response from patients/public, citing the example of "visually impaired" no longer being considered an appropriate term, and now changed to "(people with) sight loss".

on the web site with a sentence underneath giving fuller explanation: this will be discussed further at September meeting

4. Review and discussion of draft protocol

DC referred to the draft protocol forwarded to all prior to the meeting, and asked that the meeting discuss issues around the protocol on: who are we looking to involve in the PSP, what issues will within the scope of PSP and what the Steering Group need to consider around publicity for the PSP survey.

A wide ranging discussion with all the Steering Group followed, and the following points were among those raised:

BM noted that the survey questionnaire was very critical, with the option of preparing the survey with open questions and more directed questions.

TH: Diagnosis and treatment and a wide range of other issues could be raised, and there needed to be clarity on the web site about what issues could be raised.

CJ: for information, the first one thousand survey responses from the Depression PSP are currently being reviewed with regard to the range of issues raised. In setting up the survey there was discussion about whether to include 'example questions' or not.

AH: It would be helpful to include a space for '...and anything else that impacts on you'

There was a discussion about how the responses from the survey - submitted uncertainties / research questions - are then translated into a question that could be researched.

JR explained that this was known as a 'PICO' question which stood for 'People, Intervention, Comparator, Outcome', and indicated the elements of a question that needed to be present before research is undertaken, for example: 'is this treatment (X) better than another treatment (Y).

BM noted that an important aim of the PSP was to have funders provide funding for research, and it was therefore part of the process of the PSP to translate the questions from the survey into 'PICO' questions.

TH explained that the work to do this 'translation' is done as part of the data / survey response management that will be done by the PSP , which includes a

literature search, to be done in Oxford and Bristol, in conjunction with the Cochrane group.

The Steering Group then discussed in small groups the issues listed in the agenda, and then fed back to the whole group:

4.1 Potential missing partners?

- Royal College of GPs, Royal College of Psychiatrists to be invited to join the Steering Group.
- BPS, Health and Wellbeing Boards
- Outreach needed to PPI advocates in each NHS Trust
- Mental health support groups / for young people
- Talk to early intervention clinicians to generate awareness
- Young people at first presentation
- NSUN network
- Multiple contacts needed with each partner over the period of the PSP
- Charities: NIH, Equilibrium, Rethink, MIND
- Not all people with Bipolar are in the health care system; we will inevitably get people responding to the survey who have not been diagnosed with bipolar disorder

4.2 Scope of PSP and timeline

- On line survey
- Focus groups may be helpful (mixed opinions on this)
- Phone "apps" to be considered
- Need a 'support sheet' for local group facilitators to explain / assist
- Need an "expert" who has done lots of survey work to help guide us
- Need to think about aspects of crossover with other conditions/co-morbidity; this needs to be considered when collecting data on the survey
- Survey to include a question to identify which area of treatment / type of illness the respondent has 'treatment uncertainties' about
- The survey also needs to include space for 'any other comments'
- Part of the work of data analysis from the first survey will be to create themes/headings and a "catch all bucket"
- Other survey questions to include: what is the first language of survey respondent if not English?; diagnosis of bipolar (disorder) received or not?; how long have they had a mental health problem.

Timeline

- Pilot to be run among Steering Group for 2-3 weeks before launch of the survey

- The launch of the survey could be linked with the Mental Illness Awareness Week in October 2014. *[Dates confirmed: Mental Illness Awareness Week 5 – 11 October 2014, Bipolar Awareness Day – October 10th 2014]*

**Action Point 2:
DC / Steering Group**

Launch of survey to coincide with the Mental Health Awareness Week, and a more detailed outline of the survey and dissemination methods and partner participation will be reviewed at the September meeting

4.3 Identifying treatment uncertainties – survey approaches: individual methods and communication channels.

- Steering group members will assist with dissemination of the survey through their multiple networks
- Social media including Twitter and Facebook
- Use campaigns already running eg: MIND ‘Time to change’
- NIHR networks
- Community health - leaflets and posters at GP surgeries / other venues

4.4 Refining questions and uncertainties and Prioritisation

These were not looked at in detail at this stage of the PSP, and will be reviewed at future meetings

5. Finances

5.1 Budget & pledged contributions

- Oxford BRC - £10K
- Leeds and Yorkshire Partnership NHS Foundation Trust (LYPFT) - £15K
- Funds will be held in Leeds, monitored by Tom Hughes and countersigned by the Head of Research in the LYPFT
- CJ advised that MQ is interested in being a funding partner, but will need a formal proposal with details of the budget
- It was requested that resources and support given to the PSP ‘in kind’ from Steering Group partners will be monitored for reference, so that this can be included in overall monitoring as far as possible.

**Action Point 3:
DC / HC**

To prepare budget and formal proposal for MQ to consider further funding of the PSP; to monitor ‘in kind’ support / expenditure.

5.2 JLA Consultancy

BM advised that James Lind Alliance Advisers from previous PSPs have noted that funds raised for previous PSPs have found that the cost of the data management of PSPs has varied, and further funding may be needed, for example in setting up the final prioritisation workshop.

5.3 Admin support and information scientist / systematic reviewer

As above.

5.4 Billing procedures and Memorandum of Understanding between funding partners

Travel expense claims to be submitted to Tom Hughes for payment.

6. Communication Plan

6.1. Launch of the PSP and timing of initial press release

The PSP survey will be drafted for review in September, launched in early October, as above

6.2. Website

The web site will be hosted by the Oxford University Hospitals and draft information has been circulated at this meeting. The web site in place for the Shoulder PSP was displayed at the meeting, to show the format onto which the draft information will be entered into similar pages for the Bipolar PSP web pages.

Action Point 4: HC with support from DC, TH and JR to set up the website by end July

6.3. Communication contacts

6.4 Upcoming conferences or meetings

Bipolar Awareness Day – October 2014

Bipolar UK National conference – March 2015

7. Date and frequency of next meetings

Meetings will be held at regular intervals, future dates to be confirmed pending availability of Steering Group Members.

Next meeting:

10th September 2014, 11:00 – 14:00,
RNIB Offices, 105 Judd St, London WC1H 9NE

8. Any other business

No other business