



Overview

A new Priority Setting Partnership (PSP) has been launched to give everyone affected by bipolar the opportunity to help decide priorities for future research into causes, diagnosis, treatment, care and prognosis.

The survey has been developed by the members of the PSP, including charities, research funders, clinicians and service users.

People with bipolar experience periods of depressed mood and periods of elevated ('high') or irritable mood, and sometimes a mixture of these. The depressed and 'high' or irritable moods are more severe than normal sadness, happiness or irritability and last from days to weeks or months. Many people experience general mood instability in-between the more obvious periods of depressed, high, irritable or mixed moods. The depression phase is often experienced first and commonly in the late teens and early adult life.

Your participation will help to identify unanswered questions about bipolar at a time when new technologies and approaches to understanding bipolar are becoming available. These advances expand the scope of research making it more important than ever that future research priorities are set by people with personal or professional experience of bipolar.

The survey will be open until late November 2014, and is available to complete online or as a paper version. Please contact The James Lind Alliance Project Manager on 01865 223298 or BipolarPSP@ouh.nhs.uk if you would like a paper copy.

This is your chance to make your views known.

Please complete this survey if you: have been diagnosed with bipolar; think you might have bipolar; are a carer, relative, friend or colleague of a person with bipolar or someone who might have bipolar; are a health or social care professional; or are part of an organisation representing people with bipolar, their carers and relatives.

To help you, an example is given for each kind of question. We will convert the questions we receive into a format that can be answered by research.

By participating in this survey you are agreeing to allow us to publish the questions you identify in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs – www.library.nhs.uk/duets). Your name and details will not be published.

Please complete the survey on the following pages and return it to us at the address shown at the end.



Questions you would like to see answered by future research

Please write your questions in the relevant boxes below. You can submit as many or as few as you like in each box. If you need more space, please use an extra blank page, and group and label your additional questions using the headings below.

1. What questions do you have about the causes of bipolar?

Example: Can drinking too much trigger bipolar?

2. What questions do you have about diagnosis?

Example: How good are questionnaires, completed by someone who might have bipolar, at identifying those who do have bipolar and those who don't?

3. What questions do you have about treatments?

Example: Is exercise helpful in managing bipolar?

4. What questions do you have about care and support?

Example: How long should someone with bipolar stay in contact with their psychiatrist or Community Mental Health Team following diagnosis of bipolar?

5. What questions do you have about prognosis (the probable course and outcome of bipolar)?

Example: Is bipolar a lifelong illness?



6. Do you have any other questions you would like to see answered?

Example: My older brother has bipolar. Is there anything I can do so that I don't get it too?

Some questions about you

It would be really helpful to know a little more about you, so we would be grateful if you could answer the questions in this section. If there are particular questions that you would prefer not to answer, then just leave them blank.

1. Which of these best describes you? (Please tick all that apply)

- I have been diagnosed with bipolar (now go to Question 2)
- I think I might have bipolar (now go to Question 2)
- I am a carer, relative, friend or colleague of a person with bipolar (now go to Question 2)
- I am a carer, relative or friend or colleague of someone who might have bipolar (now go to Question 2)
- I am a health or social care professional (now go to Question 3)
- I am part of an organisation representing people with bipolar, their carers and relatives (now go to Question 3)
- Other (please specify, then go to Question 2):

2. You only need to answer these questions if you are answering as a person with, or who might have, bipolar or a carer relative or friend or colleague of a person with, or who might have, bipolar.

Are you [or the person you support] in contact with your/ their GP or GP practice nurse for your/ their bipolar? Yes / No

Are you [or the person you support] in contact with a secondary care mental health service [Community Mental Health Team, psychiatrist or psychologist]? Yes / No

Have you [or the person you support] ever been hospitalised for bipolar? Yes/ No

At what age did you [or the person you support] first experience symptoms of bipolar?



If you are answering as a carer, relative, friend or colleague of a person with (or who may have) bipolar, please tell us what your relationship is to that person:

- Parent
- Child
- Sibling
- Friend
- Colleague
- Other (please explain):

Now please go to Question 4

3. You only need to answer this question if you are answering as a clinician or health / social care professional. (Please tick ONE)

In which area do you primarily work?

- Primary care
- Secondary care

What is your profession?

- | | |
|--|--|
| <input type="radio"/> Clinical Psychologist | <input type="radio"/> Pharmacist |
| <input type="radio"/> General Practitioner | <input type="radio"/> Primary Care Practice Nurse |
| <input type="radio"/> Health Service Manager | <input type="radio"/> Psychiatrist |
| <input type="radio"/> Health Support Worker | <input type="radio"/> Social Worker |
| <input type="radio"/> Health Visitor | <input type="radio"/> Talking treatment therapist other than Clinical Psychologist |
| <input type="radio"/> Mental Health Nurse | <input type="radio"/> Other- please describe: |
| <input type="radio"/> Midwife | |
| <input type="radio"/> Occupational Therapist | |

Now please go to Question 4

4. More about you

What is your gender?

- Female
- Male

What is your ethnic group?

- | | |
|--|---|
| <input type="radio"/> Asian/ Asian British | <input type="radio"/> White |
| <input type="radio"/> Black/ African/ Caribbean/ Black British | <input type="radio"/> Prefer not to say |
| <input type="radio"/> Mixed/ multiple ethnicity | <input type="radio"/> Other ethnic group: |

It would help us to know your age – please tell us the year you were born (e.g. 1961):



Next steps

Would you like to be invited to take part in the next stage of the project, which is to vote for the questions you think are most important of all those submitted? You will be able to vote even if you haven't submitted any questions or taken part in the survey. Yes/ No

If you answered 'yes', please provide details for your preferred method of contact, which will be kept confidential and securely, in accordance with the Data Protection Act.

Name	E-mail address	Postal address

Thank you for completing this survey.

These are our contact details:

James Lind Alliance Project Manager/ Hub Co-ordinator
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