PARTICIPANT INFORMATION SHEET: Survey

Project Title: Understanding the Wellbeing and Support Needs of Partners of Parents with Bipolar (PPB)

We would like to invite you to take part in a survey exploring the needs and experiences of partners of parents with bipolar. Before you decide whether you'd like to take part, we want to explain why we are doing this research and what it will involve. Please read the following information and discuss with others if you wish. You may download this sheet and print it off to read at your own convenience, or we can post it to you. Please ask us if there is anything that's unclear, or if you'd like further information after reading the information sheet (contact details at the end).

What is the project all about?

The overall project aims to work with people who are partners of parents with bipolar to explore their needs and experiences of support. The whole project involves an online survey, interviews, and co-design workshops to develop support for social care workers and people caring for a partner with bipolar. This part of the project is the survey.

What is the survey about?

The survey is about your relationship with your partner and your child(ren), your caring responsibilities, and your own mental health. This survey has been developed by partners of parents with bipolar together with researchers including academics, clinicians and social care workers. It is designed to be simple and straightforward to complete whilst having enough detail to provide a picture of your experiences and what you would like to change.

Who is the survey for?

We are inviting 150 people who:

- live with a partner who has bipolar,
- have at least one child aged up to 18 years,
- live with the child,
- live in the UK.

Participants will also need access to a computer, tablet, or mobile phone, as well as internet access to take part. If you want to take part but have issues with the cost of internet access, please let us know as we may be able to help with this.

Why have you been approached?

You have been approached because you have indicated that the partner you live with has bipolar and we think that you could make a valuable contribution to this research project. Sharing your experiences with us will help us to understand more about the needs of partners of parents with bipolar.

Do you have to take part?

No. Taking part is completely voluntary – it is up to you.

What will happen if you take part?

If you decide you would like to take part, you will first need to register your interest on the project's information website here: [insert link]. We'll ask you to give us a few different ways to contact you (email, phone number, and postal address).

You will then be invited to have an initial phone call with a member of the research team. This will involve a brief chat to check that you are eligible to take part in the survey and should take no longer than 5 minutes. After the call, you will be provided with a copy of this information sheet for you to keep and you will be emailed a unique link to the consent form and the online survey. Please take as long as you need to read them, you are welcome to also ask us any questions.

The survey should take around 30 minutes to complete. After you complete the survey, you will be emailed a £20 Love2Shop voucher code as a thank-you for taking part. The survey will be open for a period of one year and will close on (Closing date will be inserted in line with the recruitment timeline). You may access and complete the survey at any point from when you receive the unique survey link up until the closing date.

At the end of the survey, you will have the option to indicate whether you would like to take part in a follow-up online interview, an online co-design workshop, or both. If you choose to provide consent to be contacted, we will get in touch with you separately at a later date.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. Lancaster University is the sponsor of this research. Lancaster University is responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

- NHS Trusts
- Clinical Trials Units
- Universities

We will keep all information about you safe and secure by:

- Collecting your survey responses through REDCAP (Research Electronic Data Capture), which is a secure survey software designed to be used in research.
- Storing your information in password-protected databases.
- Anonymising your data before it is analysed.

International Transfers

Your data will not be shared outside the UK.

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for a maximum of 10 years. The study data will then be fully anonymised and securely archived or destroyed.

Use of data for future research

Some of the information you provide in this survey may be valuable for other research projects in the future. With your consent, anonymised data from this survey may be stored and used for future research studies and may be shared with other researchers for academic purposes, only with approval from the Chief Investigator. This will not include any information that could identify you.

You can choose whether to allow your data to be used for future research when you complete the consent form. Choosing not to allow your data to be used for future research will not affect your participation in the survey.

What are your choices about how your information is used?

- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- our leaflet: Lancaster University: www.lancaster.ac.uk/research/data-protection. York Clinical Trials Unit: https://www.york.ac.uk/records-management/dp/your-info/generalprivacynotice/.
- by asking one of the research team
- by sending an email to Lancaster University Information Governance Manager: information-governance@lancaster.ac.uk, or
- by ringing us on 01524 65201 and asking for the Information Governance Manager.

How can you withdraw from the survey?

If you leave the survey incomplete (without telling us you are withdrawing), you will be sent reminder emails to complete the survey 1, 2 and 3 weeks after you last edited the survey. If you want to stop receiving email reminders and/or withdraw completely, you must email us at ppbstudy@lancaster.ac.uk.

If you have not completed the survey by the end of the study period, and we do not hear from you with a request to withdraw, we will assume you have withdrawn and remove your data from the analysis.

If you decide to withdraw after completing the survey, please email the research team at ppbstudy@lancaster.ac.uk and include the unique email address you used to access the survey. Please note that if the data has already been anonymised, withdrawal may not be possible.

If you decide not to take part or withdraw at any time, this will not affect any services or care that you, your partner or your child may be receiving, or your ability to take part in future research.

What will happen to the results?

The information from this survey will help to improve the understanding of the experiences of people with partners with bipolar and hopefully lead to developing more support in the future. The survey results will also inform what questions we ask in interviews later in this project and the development of support to help social care workers better meet the needs of partners of parents with bipolar.

A summary of the results will be available at the end of the project, and if you opt in, we will email the summary to you. The findings will be presented at academic and mental health conferences and events. The findings will also be published in mental health journals and other publications, with the aim of reaching a wide audience of mental health professionals including social care workers, people with bipolar and their partners, and other researchers. You will not be personally identifiable from the published results.

What are the benefits of taking part?

There are no immediate benefits to taking part other than the opportunity to share your views on this important topic. We hope you find the information in the survey helpful and interesting to engage with and maybe reflect on what it is like being a partner of a parent with bipolar. We hope you finish the survey feeling like you've made an important contribution to research aimed at improving support for partners of parents with bipolar and their families.

Will you be paid for taking part?

As a thank you for your time, you'll receive a £20 Love2Shop voucher for completion of the survey.

What are the risks of taking part?

There are no direct risks anticipated with participating in this survey. If you do experience any distress in relation to any aspect of the research, please use the contacts listed at the end of this document.

Who has reviewed the project?

This project has been reviewed and approved by a Reference Group of partners of people with bipolar, the Health Research Authority (HRA),and the …… NHS Research Ethics Committee (REC).

Who can you contact for more information?

You can contact the research team on our email:
ppbstudy@lancaster.ac.uk

You can also contact the chief investigator of the project:
Professor Steven Jones
The Spectrum Centre for Mental Health Research
Faculty of Health and Medicine (Division of Health Research)
Lancaster University
Email: s.jones7@lancaster.ac.uk

What do you do if something goes wrong?

It is unlikely that you will be harmed by taking part in this survey. However, if you wish to raise concerns or make a complaint about any aspect of this project, and you don't wish to speak to the researcher above, then you can contact either of the following people:

Dr. Rachael Rigby
Deputy Chair for the Ethics Committee, Faculty of Health and Medicine
Lancaster University
Email: rachael.rigby@lancaster.ac.uk

Professor Mark Limmer
Head of Department: Division of Health Research
Lancaster University
Email: m.limmer@lancaster.ac.uk

Lancaster University holds appropriate indemnity cover which includes but is not limited to Public Liability, Professional Indemnity and Employers Liability Insurance. If you are harmed whilst taking part in this study as a result of negligence by Lancaster University or its staff members, you may have grounds for legal action and should obtain independent legal advice. Non-negligent harm is not covered, and any claims that arise may be referred to the insurance provider for assessment. Should you require more information on the indemnity cover that Lancaster University holds, please contact the researcher.

Thank you for taking the time to read this participant information sheet

FURTHER RESOURCES

Contact details of research team

If you have any questions or would like more information about the project, please get in contact with a member of our research team on ppbstudy@lancaster.ac.uk

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Parenting Resources

- BBC Bitesize Parent's Toolkit – includes a variety of stories, expert advice and fun activities that can help you support your child: https://www.bbc.co.uk/bitesize/parents
- The Parenting Project – provides support, counselling and mentoring for parents: https://parentingproject.org.uk/

Caring Resources

- CarersUK – provides information and support for carers: https://www.carersuk.org/

Resources for Dealing with Distress

Should you feel distressed during the survey, the following resources may be helpful for you.

- Mind – provides information, training, and support for people with mental health problems and their families: https://www.mind.org.uk/
- Rethink Mental Illness – provides information, training and support for people with mental health problems and their families: https://www.rethink.org/
- Bipolar UK – provides information and support for people with bipolar, including support groups and support lines: https://www.bipolaruk.org/
- Campaign Against Living Miserably – provides online information and telephone/online chat support to people experiencing distress: https://www.thecalmzone.net/

- The Hub of Hope – provides details of mental health support services in your area (UK only): https://hubofhope.co.uk/
- Patient Advice and Liaison Service (PALS) - provide a point of contact for patients, their families and their carers for confidential advice, support and information on health-related matters: What is PALS (Patient Advice and Liaison Service)? - NHS (www.nhs.uk)

If you need more urgent help and are already in contact with mental health services, please contact them directly. If you are not in contact with mental health services, the following might be helpful:

- Your usual GP practice
- Your local out of hours GP or Accident and Emergency. Please visit www.nhs.uk if you're unsure where to find these services
- If you are unsure of what help you need, call 111 for the NHS telephone advice service
- For someone to talk to over the phone, call Samaritans on 116 123 or email jo@samaritans.org
- If you feel there is a serious and immediate risk, please call the emergency services on 999