PARTICIPANT INFORMATION SHEET: Co-design Workshops

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

Lived Experience Experts version

We would like to invite you to take part in a series of two workshops, co-designing one of the outputs of the Partners of Parents with Bipolar project. Before you decide whether you'd like to take part, we want to explain why we are doing these workshops 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. We will hold separate workshops with two aims. A series of five workshops will be held to develop support for social care workers and people caring for a partner with bipolar. Up to two workshops will be held to begin developing a toolkit specifically aimed at people caring for a partner with bipolar. This part of the project is the co-design workshops to develop a carer toolkit.

What are the workshops about?

The workshops aim to bring together researchers, social care professionals, and people with experience of having a partner with bipolar, to help design better resources for social care workers and other partners and parents with bipolar. The workshops will draw on the findings from the survey and interviews which were also conducted as a part of this project, as well as your own experiences.

Who are the workshops for?

We are inviting 10 people who meet at least one of the following criteria:

- Have lived experience of being a carer of someone with bipolar.
- Is a partner of someone with bipolar

You will need access to a computer or tablet as well as internet access to take part.

Why have you been approached?

You have been approached because you have consented to being contacted to be a part of research through organisations such as Bipolar UK, Spectrum Connect, and LSCft. Taking part in the workshops will help us to begin designing a meaningful resource for carers and potentially help other people with a partner with bipolar. This work has been informed directly by feedback from the Carer Reference Group (also known as the advisory panel), which is made up of people with lived experience in the PPB study.

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 be asked to complete an online form establishing your consent to participate.

As part of the co-design group, you will attend a series of two co-design workshops. These will be 2 hours in length and will take place online. The workshops will require access to a computer, internet, and will use Zoom or Microsoft Teams software packages. You will be given access to these as part of your participation.

As part of the consent form, you will also be asked to agree to the use of anonymised quotations from the co-design workshops in publications. You will also be asked to provide your consent to a live illustrator being in attendance at the workshops to summarise discussions into an accessible visual summary. All quotations will be coded to ensure that you cannot be identified. In addition to the online consent form, you will also be asked to provide verbal consent before the start of each workshop to confirm ongoing consent. You will also be reminded of your right to withdraw before each session.

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. We also require your personal data- to organise your participation in the workshops and arrange reimbursement for taking part. People who do not need to know who you are and are not part of the research team 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. All personal data will be stored in accordance with the General Data Protection Regulation and the Data Protection Act 2018. 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 consent form through Lancaster University's secure Microsoft Forms.
- Storing your information in password-protected databases.
- Making sure that the data is only accessible to the research team members.

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 shared during the co-design workshops may be valuable for future research. The anonymised workshop data may be stored and used in future research studies and shared with other researchers for academic purposes, only with the Chief Investigator's or delegated person's approval. This will not include any information that could identify you. The data will only be shared with those who have a clear and relevant interest in improving support for partners of parents with bipolar disorder.

As the workshop data is recorded in the form of anonymised notes, it will not be possible to remove individual contributions after the workshop has taken place. For this reason, consent for the future use of anonymised workshop data is required to take part in the workshops.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have
- 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.
- 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 workshops?

You can stop taking part in the workshops by emailing us at: ppbstudy@lancaster.ac.uk.

If you change your mind about something you have shared and would like it to be excluded from the notes, please let us know during the workshops so that it can be removed at the time. As data will be recorded as anonymised field notes, it will not be possible to identify individual participants. For this reason, once the data has been collected, it cannot be withdrawn.

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 your data?

Your consent form will be hosted on Lancaster University's secure Microsoft Forms. All other project-related data will be stored on OneDrive systems at Lancaster University. Access to these platforms is password-protected, and only members of the research team will be able to access them.

Notes from the sessions will be taken by the research team and will be anonymised. Notes may also be taken by an external illustrator to inform a live illustration of one of the workshops. The research team will analyse this anonymous information, and it may be used in research outputs including reports, conference presentations, websites, and training events and materials. At the start of the study, participants will be informed of the requirement to keep workshop discussions confidential to those attending the group.

Personal information will remain confidential. The research team will only break this confidentiality and share information with other professionals if we are made aware of an immediate risk of harm to participants or others around them, for example in an emergency. If this happens the research team will contact relevant professionals, such as emergency services, to inform them of what is happening and direct support to those involved. We would always inform you if this was happening.

What will happen to the results?

Outputs of the workshops will be presented at end-of-project events, as well as at academic and mental health conferences and events. The findings may 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 may be opportunities to co-author academic papers about the co-design process. There are no other immediate benefits to taking part other than the opportunity to share your views on this important topic. We hope you find participating in the workshops helpful and interesting to engage with. We hope you finish the workshops feeling like you've made an important contribution to a project aimed at improving support for partners of parents with bipolar and their families.

Will you be paid for taking part?

You will be paid in line with NIHR guidelines for participatory research which is costed at £27.50 per hour. This can be paid either as a voucher (Love2Shop or Amazon), or as a bank transfer, depending on your preference. You will also receive an additional £5 to cover internet costs per workshop.

What are the risks of taking part?

If you are in receipt of benefits, please be aware that in the UK, payments for taking part in research may affect benefit's entitlement. Please refer to the resources at the end of this form for resources on advice on welfare benefits and participation in research.

There are no other known direct risks to taking part.

Who has reviewed the project?

This project has been reviewed and approved by a Reference Group of partners of people with bipolar and the East Midlands – Leicester South Research Ethics Committee (REC).

In what instances might we have to share information with other services?

We will only contact emergency services if an immediate and serious risk of harm to yourself or others is identified by the research team. If this happens, we are required to break confidentiality and inform the appropriate emergency services (e.g. medical, police or social services) to protect the welfare of both you and those around you, including your child/children.

Your address and phone number will be stored securely by Lancaster University. We will only hold this information whilst you are in the project. Once you have finished engaging with project activities, this data will be securely destroyed.

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 the workshops. However, if you wish to raise concerns or make a complaint about any aspect of this project, 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.

Resources on welfare benefits

Resources are available to provide advice and support to people taking part in research who are also in receipt of welfare benefits.

- Benefits Advice Service – offers free confidential advice for people whose welfare benefits may be affected by payment for involvement in research funded by the National Institute for Health Research. To access this service, first please contact the National Institute for Health Research Centre for Engagement and Dissemination on 020 88437117 or ced@nihr.ac.uk. You will then be referred to the Benefits Advice Service.

- Citizen’s advice Bureau – provides independent advice on benefits available in the UK. https://www.citizensadvice.org.uk/benefits/

- Disability Rights UK – provides online information on disability rights in the UK, including welfare rights. https://www.disabilityrightsuk.org/

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