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COMPASS - Communicating about Parental Mental Illness: a resource for health and social care professionals to support family-centred conversations

PARTICIPANT INFORMATION SHEET FOR PEOPLE WITH LIVED CHILDHOOD EXPERIENCE OF PARENTAL MENTAL ILLNESS

Central University Research Ethics Committee Reference: MS IDREC 2514356

Introductory paragraph

You are being invited to take part in a research project. To help you decide whether you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please read all the following information and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information (our contact details are above and at the end of this sheet). The researcher leading the study (Principal Investigator) is Elizabeth Rapa. The team consists of a Clinical Psychologist (Louise Dalton), a Psychiatrist (Tina Mohindra) and a Patient and Public Involvement (PPI) Lead with lived-experience (Verity Westgate). Take time to decide whether you wish to take part.

Why is this research being conducted?

Mental health problems affect 1 in 6 adults in England. Over half of those with a mental illness are parents with many having children aged under 18 years. Honest communication about parental mental illness has been found to support children's psychological wellbeing and help families to work together. Studies have found that parents want guidance from the professionals working with them (e.g. Nurses, Psychiatrists, Social Workers) around talking to their children about the illness. However, some professionals think it would be helpful to have more training to better help parents talk to their children about mental illness. This project is developing a training resource for mental health and social care professionals to help them support parents talk to their children about mental illness.

Why have I been invited to take part?

You have been invited to take part in this study as you have had experience of a parent with mental illness during your childhood e.g. depression, anxiety, schizophrenia, bipolar disorder, psychosis. The workshop will involve up to 5 other people (called participants) who also have childhood lived experience of parental mental illness. Participants must currently be aged 18 years or over but experienced a parent's mental illness before the age of 24 years. Participants must have sufficient verbal English to be able to take part in a workshop.

Do I have to take part?

No. It is up to you to decide whether to take part. You can stop taking part in the study at any time and without giving a reason. There will be no impact on the care received by you and your family if you choose to leave the study. You can withdraw any information you have contributed to the research up until the point that the data is no longer identifiable. This is approximately within 2 weeks of taking part in the study. If you decide to withdraw from the study then any data that has already been collected will be deleted immediately.

What will I be asked to do if I take part in the research?

1. Before the workshop takes place a researcher will send you a link to an online consent form. This will be a series of statements that give you the option to tick ‘Yes’ or ‘No’. One of the statements asks if you agree for the workshop to be audio recorded using the function on Microsoft Teams. This is to make sure we accurately collect everyone’s thoughts, experiences and recommendations. There is also a question asking if you want to be video recorded by putting your camera on during the workshop. You’re welcome to join the call without turning your camera on—you can still fully take part.
2. If you need any reasonable adjustments for the workshop, please let the research team know before or at the start of the session. This could include extra time to think and respond.
3. If you decide to take part, you will be sent a link to take part in one group call (workshop). This will last up to 3 hours (including regular breaks during the session). It will take place online using Microsoft Teams.
4. During the workshop, you and up to 5 other participants will take part in a discussion facilitated by a member of the research team. Participants will be asked to keep the content of discussions confidential.
5. The workshop will explore:

- Your experience of being told (or not told) about your parent's illness
- What information you think is important to share with children at different ages or in different situations (e.g. during a hospital admission or periods of acute illness)
- What would help children and parents talk about mental illness
- What you think is important for professionals to know so they can better support parents talk to children about mental illness

6. The audio recordings will be written up (now called transcripts), removing any data which would identify any of the participants. Only the research team (the people described in the first paragraph) will have access to the recordings and the transcripts.
7. We are aware that the discussion during the workshop may bring up sensitive or difficult memories and situations. You can take a break at any time during the workshop, you can ask to stop the discussion or leave the virtual room without needing to give a reason. If you feel you need help after the session, we can talk with you and signpost you to appropriate sources of support. We will give you information about how to ask for this help at the start of the session. If anything shared during the workshop raises concerns for you, or the researchers, about someone’s safety, our safeguarding protocol will be followed.

What are the possible disadvantages and risks in taking part?

Some of the discussions may bring up sensitive or difficult memories and situations. Participants can take a break at any time during the workshop without needing to give a reason; the team will follow up with you after the workshop to check how you are and discuss how you can access more support if needed.

Are there any benefits in taking part?

You will receive no direct benefit from taking part in this study. However, we hope the findings from the study will help professionals communicate with families about talking to children about parental mental illness. Research has found that effective communication can help children and families cope with the challenges of a mental illness.

Expenses and payments

You will receive £75 for participation. You may choose to receive this payment as a voucher or into your bank account. If you choose to receive payment into your bank account you will need to share your home address and bank account details with the team who will not store this information but will pass them onto the University of Oxford finance department.

What information will be collected and why is the collection of this information relevant for achieving the research objectives?

We are interested in the experience of how your parents, family and professionals may have talked to you about parental mental illness, what you found helpful and what you think children in similar situations need. The information you provide will help us understand what professionals need to know so that they can better help their patients talk to children about the mental illness.

The research team will collect and have access to two types of data: personal data and research data. These data will be stored on secure servers at the University of Oxford. Research data and personal data will be stored separately on the server, in different folders with restricted access. Personal data will not be stored alongside research data.

Personal data includes your contact details and consent form. These will be stored for 5 years and then will be destroyed. Your ethnicity and your parent's mental illness diagnosis is called Special Category data. This information will help us ensure our research reflects the diversity of families affected by mental illness. Your email address (for a voucher) or home address and bank details (for bank transfer) will be shared with the University of Oxford Department of Psychiatry finance team to arrange payment.

Research data includes audio and video recordings and transcripts. We would like to audio record discussions to get an accurate record of the ideas shared during the call. At this point participants could be identified as the research data will contain participants' voices. If you choose to keep your camera on during the workshop you will also be identifiable. However, these audio files will be written up (transcribed) as soon as possible (within 2 weeks) and any identifiable information such as names and places will be removed. The audio and video files will then be destroyed. The pseudonymised transcripts will be stored as a Word file. Pseudonymisation means any personal or identifying details are removed, but the message participants are trying to convey remains.

Each participant will be given a unique participant number; research data will use this number (not your name). The number for each participant will be entered onto a password protected Excel spreadsheet which links the numbers to names. This linkage Excel spreadsheet will be destroyed when it is no longer needed.

All non-identifiable research data will be stored for 3 years after publication or public release of the work of the research.

Will the research be published? Could I be identified from any publications or other research outputs?

The findings from the research will be written up in academic publications and presented at relevant conferences. Summaries will also be posted on the team's pages on the University of Oxford Department of Psychiatry's website. You will not be identifiable in any of these instances, and your details will remain strictly confidential. We will ask for your consent to use anonymised direct quotations in research outputs. This is optional and does not affect your participation in the study.

At the end of the study, you will receive a summary of the results and the impact of the research.

Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the research. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from the University's Information Compliance website at https://compliance.admin.ox.ac.uk/individual-rights.

Who is funding the research?

This study has received funding from the National Institute of Health and Care Research (NIHR) Research for Patient Benefit programme.

Who has reviewed this research?

Before this study started it was checked by a group of people known as a Research Ethics Committee to make sure that it is safe, respectful and treats people properly. This research has received favourable opinion from a subcommittee of the University of Oxford Central University Research Ethics Committee (Ethics reference: MS IDREC 2514356).

Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this research, please contact Professor Elizabeth Rapa, 01865 618 271, elizabeth.rapa@psych.ox.ac.uk, and they will do their best to answer your query. They will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on +44 (0)1865 616480.

Further Information and Contact Details

If you do feel unwell or upset while taking part in this study, below are some options for you to contact for some help:

Samaritans: Free, confidential support for people experiencing feelings of distress or despair.
Phone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk
Mind: Free advice and support to empower anyone experiencing a mental health problem.
Phone: 0300 123 3393
Website: www.mind.org.uk

Shout: Free, 24/7 mental health text support.
Text: 85258
SANE: Offers non-judgemental and compassionate emotional support.
Phone: 07984 967 708
Website: www.sane.org.uk

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

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