



DEVELOPMENT OF GUIDELINES FOR CARERS OF A PERSON WITH BIPOLAR DISORDER

INFORMATION SHEET

What is the aim of this project?

Families, partners and close friends are often confronted with the bipolar disorder of someone they care for without having much information about helpful things they can do to provide appropriate support, deal with the illness and its challenges, and maintain their own wellbeing. This project aims to develop a basic resource that is readily available to family members, partners and close friends who want information, not only about the illness and its treatment but also about practical ways that they can help to lighten the burden of illness on themselves, the person with bipolar disorder and their relationships. The guidelines will also contribute to pamphlets, training programs and web-based or face to face interventions to benefit carers, people with bipolar disorder and their families.

The guidelines will be developed by combining information from the existing literature with the opinions and consensus of experienced carers, consumers and clinicians. Participants will be invited to rate statements about what might be helpful and to make additional comments and suggestions. Thus, the guidelines will aim to be practically useful to carers and to have a beneficial impact on the everyday life of people dealing with bipolar disorder.

Who is conducting the research?

The research is being conducted by ORYGEN Research Centre, Department of Psychiatry, at the University of Melbourne. It has received approval from the Human Research Ethics Committee. It will form part of a PhD research project conducted by Lesley Berk under the supervision of Professor Anthony Jorm, director of the Mental Health Literacy Program.

How is the research being funded?

The research project is funded by a scholarship provided by the National Health and Medical Research Council.

What will the research involve?

You are invited to be an expert panel member to help develop the carer guidelines. If you agree to participate, you will be asked to:

1. Complete a questionnaire on the Internet (or a paper version if you prefer) which asks you to rate whether certain information and actions should be included in the carer guidelines to best support a family member, partner or close friend with bipolar disorder to manage their illness and to maintain the carer's own wellbeing. In addition, you can add your comments and suggestions for dealing with specific challenges related to the illness.
2. You may be asked to rate the statements again after you have seen a summary of the ratings given by other panel members, as the aim of this part of the project is to achieve consensus about what is helpful to include in the guidelines. You can choose to either retain or change your original ratings. Depending on the level of consensus

achieved, a few rounds of this process may be required. We do not anticipate that more than three rounds will be required.

3. You will have the opportunity to provide any final comments on a draft of the guidelines which will contribute to the final guidelines.

Please note that the expert panel will never meet face-to-face. All tasks will be completed individually in your own time. We anticipate that the first questionnaire will take between 30-60 minutes to complete and subsequent rounds will require less time. We estimate the total time commitment, *including* the possibility of three different rounds to reach consensus, to be between one to two hours. However, the total time may vary depending on the individual participant and the number of rounds required.

What if I change my mind?

Participation in this project is voluntary. Return of the first questionnaire will imply your consent to participate. If you change your mind about participating, you are free to withdraw from the project at any time and you may also withdraw your data if you wish.

Who is being asked to participate?

We are inviting people to participate as panel members if they have expertise in bipolar disorder or carer and family issues. The panel members will be drawn from Australia, New Zealand, UK, Ireland, USA, Canada and Europe and will be 18 years or older and fluent in English. There are three categories of panel members:

1. Clinicians who have professional experience in the area.
2. Consumers with bipolar I or II disorder who have experience managing the illness.
3. Carers (family members, partners or close friends) who have experience in dealing with bipolar disorder

What about privacy?

Any data we collect from you will be stored in a secure file and protected by password. As we are only interested in the consensus views of the panel, your personal responses and identity will not be disclosed to others. Instead, we will present all participants results in statistical summary form. In accordance with University policy, the data file will be kept for at least 5 years after publication. The data file will be deleted if there is not continuing interest in the data.

Are there any risks?

We do not think this study will have any adverse effects and consider that participation may be a positive experience as participants are sharing their knowledge and opinions to assist in developing guidelines to help others. If completing the questionnaire causes you any distress you can let us know by responding to the enquiry about distress at the end of the questionnaire. We will contact you to discuss this at the first opportunity or you can contact us directly on the email or phone numbers provided at the end of the questionnaire.

What are the benefits?

The guidelines are aimed at helping the person who is the primary source of emotional and/or practical assistance, to provide appropriate support to the person with bipolar disorder and to maintain their own wellbeing. They may have positive benefits in helping both carers and consumers to deal with mood swings and their consequences, to minimize relapse, enhance positive communication and to live well. The guidelines will have international relevance and be easily accessible to the public. Copies of the guidelines and published articles resulting from the project will be sent to panel members and organizations that provided assistance with the project. The guidelines could provide the basis for a number of other supportive resources ranging from pamphlets and basic training courses to interventions geared to the specialised needs of certain carers dealing with bipolar disorder.

How can I get further information?

If you would like further information before deciding to participate, please contact Lesley Berk by email: lberk@unimelb.edu.au, or by phone: +61-402 518 843.

What if I have concerns about the project?

If you have concerns about the *scientific aspects of the study*, please contact the coordinator of the project, Lesley Berk by email: lberk@unimelb.edu.au, or by phone: +61-402 518 843 or Professor Tony Jorm by email: ajorm@unimelb.edu.au, or by phone: +61-3-9342 3747.

If you have concerns about the *ethics of the study*, please contact the Executive Officer, Human Research Ethics, The University of Melbourne, phone: +61-3-8344 2073, fax: +61-3-9347 6739.