PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	HRE2017-0087
Project Title:	Development of clinical guidelines for perinatal obsessive-compulsive disorder using expert consensus
Principal Investigators:	Dr Rebecca Anderson, Senior Lecturer – Clinical Psychology School of Psychology & Speech Pathology, Faculty of Health Sciences Professor Clare Rees School of Psychology & Speech Pathology, Faculty of Health Sciences
Student researcher:	Ms Melissa Mulcahy, PhD (Clinical Psychology) Candidate School of Psychology & Speech Pathology, Faculty of Health Sciences
Version Number:	1.0
Version Date:	16/07/2017

What is the Project About?

- In recent years, there has been a considerable amount of research published on depression and anxiety in the perinatal period (defined, for the purpose of this research, as the period from pregnancy through to 6-months post-childbirth).
- As a result of this, both professional and community awareness of perinatal depression and anxiety has increased, and this has improved access to effective treatment/ support for these conditions.
- Emerging research shows that OCD may be one of the most common mental health disorders in the perinatal period (i.e. 'perinatal OCD').
- Despite the availability of clinical guidelines for perinatal depression and anxiety, there are currently no expert-developed clinical guidelines that are specific to, and based on the unique concerns of, individuals with perinatal OCD, to guide clinicians who work with new/expecting parents with this condition.
- This gap may mean that many individuals with perinatal OCD are not identified and offered appropriate treatment.
- We are doing this study to collect the views of a range of experts with professional or personal experience of perinatal OCD. These views will be used to develop and publish a set of professional clinical guidelines for perinatal OCD.
- We hope that these guidelines will become an important resource that will help clinicians to better assess, treat, and support people with, perinatal OCD.

Who is doing the Research?

- Ms Melissa Mulcahy, a PhD student in Clinical Psychology, is conducting this research project under the supervision of Dr Rebecca Anderson and Professor Clare Rees from the School of Psychology and Speech Pathology at Curtin University.

- The results of this research project will be used by Ms Mulcahy to obtain a Doctor of Philosophy (PhD) degree in Clinical Psychology at Curtin University and is funded by the University.
- There will be no costs to you and you will not be paid for participating in this project.

Why am I being asked to take part and what will I have to do?

- You have been approached about this study because we believe you may have professional or personal experience relevant to the condition we are studying.
- We are looking for people with relevant expertise to be a part of one of two expert panels that will assist us in developing a set of formal clinical guidelines on the assessment and treatment of perinatal OCD.
- Specifically we are looking for the following three groups of people:
    - Professionals (i.e. mental health clinicians and researchers) who have:
        - At least 5 years relevant experience in working with individuals with perinatal mental health problems, including assessing and treating OCD; and/or
        - Who have authored at least three peer-reviewed academic publications on perinatal OCD;
    - Parents who have personally experienced perinatal OCD are currently in recovery; and
    - People who have cared for a significant other (e.g. adult child or partner) who currently or previously has had perinatal OCD.
- If you are in one of these groups, we invite you to complete this survey to express your interest to take part in this important study to improve clinical practice with perinatal OCD.

What will I have to do?

- If you choose to participate, you can click the next button at the bottom of this page to go the expression of interest form. You will be asked to tell us about which of the groups listed above you belong to (i.e. mental health professional/researcher, parent with first hand experience of perinatal OCD, or carer of a loved one with perinatal OCD), and we will ask you a short series of questions about your professional experience (e.g. how many individuals with perinatal OCD you have treated) or personal experience (e.g. what treatment you received for perinatal OCD) so we can see whether you would be a good fit for our panel.
- At the end of the survey, you will be asked to provide a current email address so we can contact you when we start the study.
- After we have recruited enough people to start our study, we will email all of our panellists and ask them to complete **a series of four (4) online surveys** to provide us with their expert views on the assessment, treatment, and management of perinatal OCD, and help us decide what information we will include in our clinical guidelines. Surveys may include open-ended questions (‘*what should professionals consider when treating new/expecting parents with OCD?*) and rating questions (i.e. where panellists rate the extent to which they believe a certain recommendation is helpful or unhelpful). Panellists may also be asked to read relevant information (e.g. about perinatal OCD) and consider this information when responding to the surveys.
- Panellists will have **3 weeks** to complete each survey. Surveys do not need to be completed in one sitting – you can close it and return to it at another time. Panellists must **complete at least 50% of each survey** by the end of the survey closing date to stay in the study.
- At the end of each survey round, panellists will be given individualised feedback on the results of the survey. They will be told which recommendations have been accepted or rejected by the

panels for inclusion in the guidelines. To be accepted, a recommendation must be endorsed by at least 80% of both panels (with the exception of recommendations that relate to specialised medical or psychological treatments). Each panellist will be emailed feedback about how their responses/views compared to the overall responses of the panel. Some recommendations may need to be reviewed by the panels a second time. When this happens, panellists will be asked to review their response in light of the group feedback and to consider whether they would like to change their response. This process will continue until a decision has been made about all of the recommendations that have been proposed for the guidelines (up to a maximum of 3 survey rounds will be held).

- Each survey round will take less than 60 minutes to complete including time spent reading relevant information/individual feedback before the survey.
- Once the guidelines have been compiled, panellists will be sent a copy of the draft guidelines to review and provide feedback on their accuracy in representing the views of the panels.

Are there any benefits' to being in the research project?

- There may be no direct benefit to you from participating in this research. However, sometimes people appreciate the opportunity to contribute their professional clinical experience or personal experience of perinatal OCD to research in the field.
- We hope the results of this project will add to the knowledge we have about clinical practice with perinatal OCD in order to help health professionals to better support new and expecting parents who may have or be at risk of developing this condition.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

- Throughout this study, we will be asking you to reflect on your professional experiences of working with new/expecting parents with OCD (i.e. if you are health professional) or your personal experience of living with/caring for a loved one with perinatal OCD (i.e. if you are a person with lived experience).
- While have been careful to make sure that the questions in the surveys do not cause you any distress, it is possible that you may experience some mild discomfort when doing the survey. But, if you feel anxious about any of the questions you do not need to answer them. If the survey raises any personal issues for you, we suggest that you speak to your General Practitioner or Counsellor. If they are not available, you can call *Lifeline* on **13 11 14** (Australia-wide) or contact one of the following international online services – *Imalive* (https://www.imalive.org/) or *Big White Wall* (http://www.bigwhitewall.com/).
- At the end of the survey, we will give you a list of resources where you can find relevant information on perinatal mental health, including relevant support services.
- Apart from giving up your time, we do not expect that there will be any other risks or inconveniences associated with taking part in this study.

Who will have access to my information?

- The information collected in this research will be identifiable, so that we can provide you with personal feedback on your survey responses, compared to other panellists. This means that any information we collect that can identify you will stay on the information we collect and it will be treated as confidential and used only in the project unless otherwise stated. We can let others know this information only if you say so or if the law says we need to.
- When we provide feedback to other panellists at the end of each survey round, your results will be reported in a group-level summary (i.e. the percentage of experts from each panel who

voted in each category). The other panellists will therefore not know who you are or how you voted as an individual.

- All information will be stored securely at Curtin University in Perth, Western Australia.
- The following people will have access to the information we collect in this research: the research team and, in the event of an audit or investigation, staff from the Curtin University Office of Research and Development.
- Electronic data collected from you will be password-protected and hard copy data will be in locked storage.
- The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended and then it will be destroyed.
- You have the right to access, and request correction of, your information in accordance with relevant privacy laws.
- The results of this research, including the final clinical guidelines, may be presented at conferences or published in professional journals or on the study's webpage. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?

- Yes - if you participate as a panel member in our study, we send you a detailed summary of the study's overall results when they are available. You will also be sent a copy of the final clinical guidelines for you to review and provide feedback on before they are published.
- If you do not participate as a panel member in our study, you can get a summary of the results and final guidelines by contacting us directly (see contact information below) or visiting the Facebook page (http://fb.me/perinatalstudy) for our study.
- We expect that the study results and final guidelines will be available by March 2018.
- Results will not be individual but based on all the information we collect and review from panel members as part of the research.

Do I have to take part in the research project?

- Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the study. You do not have to give us a reason; just stop the survey. If you choose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues.
- If you chose to leave the study and tell us that you would like to withdraw your expression of interest or stop participating, we will destroy the information that we have collected from you.

What happens next and who can I contact about the research?

- If you have any questions or would like further information about this study, you can contact Ms Melissa Mulcahy, PhD Candidate, or the Research Supervisor, Professor Clare Rees, by calling +61 9266 1717 or emailing melissa.mulcahy@postgrad.curtin.edu.au or c.rees@curtin.edu.au. If you are an international participant, please leave a message and we can call you back to answer your questions during business hours in your local time zone.
- On the survey page, there is a checkbox to indicate that you have understood the information and meet the study eligibility criteria provided on this page. Checking this box indicates that you agree to be in the research project, confirm your eligibility for the study, and have your information used as described. Please take your time and contact us to ask any questions you have before you decide to continue to the survey. You can also contact us if you want to have a copy of this information to keep.

- Once you have checked this box, please click the ‘next’ button to go to the start of the expression of interest form.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2017-0087). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.