Information and consent form for participants over 18 years of age participating in mental health clinical or research activities

Researcher in Charge of the Research Project
Stephanie Lloyd, PhD, Professor, Department of Anthropology, Université Laval

Funding Agency
Canadian Institutes of Health Research (CIHR 2019-2024), grant number 419621

Introduction

We are seeking your participation in a research project. Before agreeing to participate in this research project, please take time to read and understand the following information. This document explains the purpose of the research, its procedures, benefits, risks, and drawbacks. This form may contain terms that you don't understand. We invite you to pose any questions you may have to the person presenting this document. You may ask them to explain any words or information that is not clear.

Nature and Objectives of the Research

The purpose of this study is to examine understandings of mental illness and risk of mental illness, as well as emerging scientific models of suicide risk. In particular, it explores how people understand mental illness in regard to their participation in clinical and developmental studies, mental health care, and community organizations. This project uses ethnographic research methods, which are an important means used to describe people's perceptions and experiences of mental illness to better understand different points of view. Interviews with key informants are an integral part of this type of research.

Participants in this research project are recruited because of: their participation in clinical and developmental studies and mental health care as a family member; as an adult patient with lived experience of mental illness; or as peer-helper for people with mental health conditions. We are interested in your personal experiences and what you have learned: for instance, whether it has changed, or not, the way you understand your own experience, or a family member's, of mental health and illness.

To achieve this goal, we are conducting 30 interviews with people such as yourself. The interviews follow a conversational format and will be guided by a set of open questions. This style of interview orients the topics covered, but also offers participants flexibility in their responses as well as the opportunity to discuss topics that they find particularly relevant.

This project was approved by the Research Ethic Committee of Université Laval
(Approval # 2019-341 A-2 / 11-11-2022)

Nature of Participation

Your participation in this research consists of answering questions during a semi-structured individual interview. The interviewer will ask questions that give you the opportunity to take the conversation in the directions that are the most important to you. The interview will take about 60-90 minutes. The interview will be held in person if possible and will be carried out at the time and place of your choice. The interview may also be conducted over the phone or using an online platform (e.g., Zoom or Teams). With your agreement, the interview will be audio recorded and stored in an audio bank for transcription. Its content will focus on your perceptions, experiences, ways of understanding mental health, and beliefs about the origins of your health condition or that of a family member. The interview will address, in particular:

- your perceptions and experiences with mental illness;
- your general background and personal attitudes and beliefs;
- the role of your life experiences and other factors;
- your response to and personal experience of your participation in mental health studies, care, and support.

Benefits, Risks or Possible Disadvantages of your Participation

Participating in this research gives you the opportunity to reflect on and confidentially discuss your perceptions of and experiences with mental illness. It is possible that you may feel embarrassed or confused about how to answer some questions. Because of the sensitive nature of the subject under study, it is possible that telling your own story may give rise to uncomfortable reflections or memories. If this happens, do not hesitate to inform the person conducting the interview. This person can tell you the name of a resource that can help you if needed. Available resources include emergency support and counselling resources such as Lifeline Australia (13 11 14) and Kids Helpline (1800 55 1800), with further information available at https://www.blackdoginstitute.org.au/emergency-help/ or https://headspace.org.au/emergency-assistance/. You have the right not to answer any question. At any time, you can end the interview without any justification or negative consequences.

Sharing Sensitive Information

Any information shared that raises serious concerns about safety, injury, and/or harm to self or to others will be automatically disclosed to the experts in charge of the study and/or mental health care with which you are affiliated and to the researcher in charge of this research project (Stephanie Lloyd).

Voluntary Participation and Right of Withdrawal

Your participation in this research project is voluntary. You are, therefore, free to refuse to participate. You can also terminate your participation without negative consequences or prejudice and without having to justify your decision. If you decide to end your participation, it is important to inform the researcher whose contact details are included in this document.

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Confidentiality

In research projects, researchers are required to ensure confidentiality of participants. In this regard, the following measures will be applied:

During research:

- the participant's name and all those mentioned during the meeting will be replaced by a code;
- only the researcher will have access to the list of names and codes, which will be kept separate from research material, data, and consent forms;
- all research material, including consent forms and records, will be kept in a locked file in a locked room;
- the data in digital format will be stored in encrypted files whose access will be protected by the use of a password and to which only the research team will have access.

When disseminating the results:

- the names of the participants will not appear in any report and will be removed from publications to minimize the chances of being identified;
- the results of the research will be published in scientific journals, and no participant will be identifiable or recognizable.

After the end of the research:

- all material and data will be stored in a databank to be created under the supervision of a research professor at Université Laval (Stephanie Lloyd). This databank was created in order to trace and understand the evolution of scientific, medical, and non-scientific conceptions of mental illness and suicide risk. One of its functions is to collect and store data that will be used to carry out other research projects such as theses, dissertations, and publications related to the theme of the study. The data of participants who do not consent to have their information stored in the databank will be destroyed in 2031 at the latest.

Project Funding

The researcher in charge of this research project received a grant from a funding agency to carry out this research project.

Compensation

You will receive an amount of $50 to compensate for the costs and inconveniences incurred in your participation in this study.

Compensation for Harm and Rights of the Research Subject

By agreeing to participate in this project, you do not waive any of your rights or release the researcher or institution from their civil and professional liability.

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Surveillance of the Ethical Aspects of the Research Project

The Research Ethics Board of Université Laval has approved this research project and follow its progress. In addition, they must approve any revisions and modifications to the information and consent form and the research protocol.

Acknowledgment

Your collaboration is appreciated and enables us to carry out this study. We would like to thank you for the time and attention you devote as a result of your participation.

Signatures

I, the undersigned, _____freely agree to participate in the research entitled: Situating Suicide Risk: An inquiry into the production of lives and afterlives of neurobiological vulnerability.

I read the form and understood the purpose, nature, advantages, risks, and disadvantages of the research project. I am satisfied with the explanations, clarifications, and answers that the researcher provided to me, if any, regarding my participation in this project.

_____ _____

Signature of participant Date

Audio recording

Do you agree to the audio recording of the interview and its storage in an audio bank to facilitate transcription and analysis?

Yes ☐ No ☐

I explained the purpose, nature, benefits, risks, and drawbacks of the research projects to the participant. I responded, to the best of my knowledge, to the questions asked and verified the participant's understanding.

_____ _____

Signature of researcher or representative Date

Additional information

If you have any questions about the research, the implications of your participation, or wish to withdraw from the project, please contact the lead investigator, Stephanie Lloyd, at the following email address stephanie.lloyd@ant.ulaval.ca or at the following phone number : (418) 656-2131 ext. 407663.

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Title of research: Situating Suicide Risk: An inquiry into the production of lives and afterlives of neurobiological vulnerability

Complaints or Criticisms

Any complaint or criticism of this research project may be addressed to the Office of the Ombudsman of Université Laval:
Pavillon Alphonse-Desjardins, office 3320
2325, rue de l'Université
Université Laval
Québec (Québec) G1V 0A6
Informations – Secretariat: (418) 656-3081
Toll free: 1-866-323-2271
Email: info@ombudsman.ulaval.ca

Copy to participant / copy to researcher

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