

Participant Information Sheet

Database of people interested in participating in studies on depression.



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Approved by the Auckland Health Research Ethics Committee. Reference number AH23223

You are invited to put your name on our database so that we can contact you about participating in future mental health/depression related studies. Whether or not you put your name on the database is your choice. If you don't want to put your name down it won't affect any care you receive or your relationship with the named investigators. If you do put your name on the database, this does not commit you to participating in any research, and you can ask to be removed from the database at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are creating a database, what your participation would involve, what the benefits and risks to you might be, and what would happen in the case we decide to close the database. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you would like to join the database. Before you decide you may want to talk about the database with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to be put on the database, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

VOLUNTEERING TO BE ON THE DATABASE AND WITHDRAWING

It is completely up to you whether you would like to be put on this database or not. Similarly, if you decide to be put on the database and are contacted about being in a future study, it is entirely your decision as to whether you would like to participate in that study or not. You are free to decline, or to withdraw from the database at any practicable time, without experiencing any disadvantage.

WHAT IS THE PURPOSE OF THE DATABASE?

The purpose of creating this database is to give people who are interested in participating in studies involving mental health a place to formally express their interest, as well as providing researchers a list of interested people to recruit from. Currently the researchers are particularly

looking for people with depression as they have several studies on depression starting in the coming years.

HOW IS THE DATABASE DESIGNED?

There is no limit to how many people can sign up to the database, or to their geographical location. However, in-person studies will be conducted in Auckland. The database will hopefully be used for many studies to come, and thus, there is no specific end date. The database will be used for contacting participants to ask if they would like to participate in studies involving, but not limited to, drug trials, interventions, surveys and longitudinal studies. Participants can restrict which type of studies they would like to be contacted for.

Being on the database does not mean you will be contacted about every study the research team does. Any study you are contacted about you will have the opportunity to separately consent to being a part of. You will be free at that stage to consent or decline to participate in that study without it affecting your details being in the database.

WHO CAN BE ADDED TO THE DATABASE?

Anybody over the age of 18, who provides informed consent, can be added to the database.

WHAT WILL BEING ON THE DATABASE INVOLVE?

Once a participant has given their informed consent they will be asked to fill out a brief questionnaire about their basic demographics, what type of studies they are interested in participating in, and their mental and physical health. These questions may be sensitive but are not designed to cause embarrassment.

Participants may then be contacted about any future studies they may fit the inclusion criteria for.

At least once a year participants will be contacted via email to find out if they are still interested in being on the database, to update their information if necessary, and to be updated on general information about the database.

Participation in this database is expected to take only 10-20 minutes a year. This time does not include time spent participating in any studies that you are involved in because of the database.

WHAT ARE THE POSSIBLE RISKS OF BEING ON THIS DATABASE?

There are few risks to collecting and storing this information as it will be held only on secure University servers.

WHAT ARE THE POSSIBLE BENEFITS OF BEING ON THIS DATABASE?

Being on this database will possibly provide participants with depression the chance to try new treatments should they meet subsequent trial eligibility criteria. It will provide participants without depression the opportunity to help advance current knowledge on depression and possibly, in the future, other mental health issues.

WILL BEING ON THE DATABASE COST ME ANYTHING?

There are no costs involved with being on this database.

WHAT WILL HAPPEN TO MY INFORMATION?

Identifiable Information

Identifiable information is any data that could identify you (e.g. your name, date of birth, or address). Only AP Suresh Muthukumaraswamy, Dr Joanne Lin, Dr Nicholas Hoeh, Dr Amy Chan, AP Frederick Sundram, Dr Rachael Sumner and Stephanie Glover will have access to your identifiable information, as well as future members for the research group. Names of members will be updated on a yearly basis.

Future Research Using Your Information.

If you agree, your information will be used to contact you for participating in future research related to depression and participation is optional.

Security and Storage of Your Information.

Your identifiable information is held on a secure University of Auckland managed REDCap account for the database's duration. REDCap is a secure web application for building and managing online surveys and databases. At the conclusion of the database all data will be deleted. All storage will comply with the Privacy Act 2020.

Rights to Access Your Information.

You have the right to request access to your information held by the research team. You also have the right to request that any information you disagree with is corrected.

If you have any questions about the collection and use of information about you, you should contact ANRGDatabase@auckland.ac.nz

Rights to Withdraw Your Information.

You may withdraw your consent for the collection and use of your information at any time, by emailing ANRGDatabase@auckland.ac.nz

If you withdraw your consent, your database participation will end. We will delete any information that we hold about you and will stop contacting you.

WHAT HAPPENS AFTER THE DATABASE CLOSURES OR IF I CHANGE MY MIND?

If you wish to withdraw from the database please contact ANRGDatabase@auckland.ac.nz and any data collected will be deleted. When the database closes all information will be deleted.

WHO IS FUNDING THE DATABASE?

Currently there is no funding for the database.

WHO HAS APPROVED THE DATABASE?

Establishment of this database has been approved by the Auckland Health Research Ethics Committee

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the database at any stage, you can contact the research team on: ANRGDatabase@auckland.ac.nz

If you have any questions or complaints about the database, you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 486 8920 ext 3204

AHREC Chair contact details: For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 ext 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

Approved by the Auckland Health Research Ethics Committee on 23/12/21 for six years.
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