

# Participant Information Statement – 45 and Up COVID Insights

## What is this research project about?

The COVID pandemic is evolving and changing. The purpose of this research project is to explore emerging questions in relation to COVID to understand its impact on Australians. You are invited to take part in a series of four to five short surveys, which will provide a close to real time snapshot of health and wellbeing during the COVID pandemic. The information collected will allow researchers and decision makers to analyse the effects of the pandemic and Australia's prevention strategies, including how different groups of people are impacted by COVID. This will support improved delivery of health services and programs.

## Who is conducting this research?

The research project is being led by Dr Martin McNamara and Dr Kerrin Bleicher from the Sax Institute. The Sax Institute owns and manages the 45 and Up Study. This research is funded through a research grant from NSW Health.

## Why have I been invited to participate in *45 and Up COVID Insights*?

You have been invited to participate in this research project because you are a participant in the 45 and Up Study and have given your permission to be invited to other research projects. You may also have previously indicated your interest in contributing to COVID research in a recent 45 and Up Study questionnaire.

## What does participation in *45 and Up COVID Insights* involve?

To complete the survey series, you need to have access to a computer, laptop, tablet or mobile phone that is connected to the internet. After you provide consent you will be linked to the first online survey. Each survey will take less than 10 minutes to complete. You will be asked questions about changes in your health and wellbeing, lifestyle activities, experience accessing health care, economic/financial changes, and other factors impacted by the COVID pandemic. Each survey will be open for up to four weeks and you will be sent up to two reminders to complete the survey before it closes.

## What information will be collected about me?

The information you give in this series of short surveys may be combined with your answers from previous 45 and Up Study questionnaires. Your answers may also be linked to information about you and your health from other records that you allowed the 45 and Up Study to access when you first consented to take part in the Study. These records include health service use (e.g. hospital admissions, and Medicare data and prescriptions, screening services), specific illnesses (e.g. cancer and other notifiable diseases) etc. All projects that link to other health data require separate ethics committee approval and are listed on our website. For a full list of linked information sources and current research projects, please call 1300 45 11 45 or visit [www.saxinstitute.org.au/our-work/45-up-study](http://www.saxinstitute.org.au/our-work/45-up-study).

## What if I don't want to take part in *45 and Up COVID Insights*?

This research project is additional to the main 45 and Up Study, and participation is voluntary. It is completely up to you whether you decide to take part. If you decide not to participate, it will not affect your involvement in the main 45 and Up Study, your relationships with the researchers or the Sax Institute. Information collected by this research project will become part of the 45 and Up Study in the future.

## Confidentiality and consent

On the registration page you will be asked to select a box stating you provide consent. In doing this you authorise the 45 and Up team to deliver the survey to you by text message or email and use the data you provide for ethics approved research. All information will be treated confidentially and stored securely according to ethical, legal and government regulations. Any identifiable information that is collected about you in connection with this research project will remain confidential, will only be disclosed with your permission, or except as required by law. Results of this research project will be published or presented in such a way that you cannot be identified. A summary of the key findings will be included on the 45 and Up Study website after the research project is completed. You may also hear about results in the general media.

The 45 and Up Study is bound by Commonwealth and State privacy legislation and guidelines: Privacy Act 1988 (Cth), Health Records and Information Privacy Act 2002 (NSW); and the NSW Health Privacy Manual for Health Information. The 45 and Up Study has strict procedures and systems to safeguard confidentiality. The Study is also bound by strict scientific ethical accountability to the University of New South Wales Human Research Ethics Committee.

## How is my information stored?

Your personally identifying information (e.g. your name, phone number, email address) is always kept confidential. This information is separated from your answers, so your privacy is always maintained when researchers analyse the data.

Data collected will be stored electronically on secure servers and will only be accessible to authorised personnel via a password controlled system. These data will be kept on a password protected computer for the duration of the 45 and Up Study plus a period of seven years. Access to the data collected will only be available to researchers who have the required ethics approvals in place and will be provided through a secure controlled system. All safety measures are in place to ensure that the confidentiality of participant information is maintained, including the separation of identifying information, the use of unique research project numbers and adherence to strict guidelines regarding data transfer, storage and access.

## **How are research project outcomes reported?**

All results arising from this project will be reported in such a way that no participant can be individually identified. Summary findings may be reported in the media and in research publications and will be used to inform improvements in health and healthcare.

## **Are there risks to me in taking part in *45 and Up COVID Insights*?**

This research is expected to be very low risk, however you may feel that some of the questions we ask about your experiences during COVID are stressful or upsetting. If you become upset or distressed because of your participation in the research project, a number of free, contactable support services are included below.

There is a risk to your privacy when text messages or emails are received, or if you leave your web browser open on a shared computer, as people around you may happen to know about your participation. This can be minimised by ensuring your phone, computer or other device has a secure passcode lock, closing your web browser after use, and ensuring the message preview function is disabled on your smart phone.

## **What happens if I suffer injury or complications because of *45 and Up COVID Insights*?**

If you suffer any distress or psychological or physical injury because of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

## Will I benefit from 45 and Up COVID Insights?

We cannot guarantee or promise that you will receive any direct benefits from this research; however, possible benefits may include improvement in health policies and health care based on findings from the research project.

## Will taking part in *45 and Up COVID Insights* cost me anything and will I be paid?

Participation in *45 and Up COVID Insights* will not cost you anything and you will not receive any payment for your involvement in the research.

## What if I want to withdraw from *45 and Up COVID Insights*?

If you do not want to join this research project, you can simply ignore any invitation or reminders you may receive. You will continue to be a member of the 45 and Up Study. If you wish to withdraw from *45 and Up COVID Insights* once it has started, you can do so at any time without having to give a reason by contacting us. If you withdraw from *45 and Up COVID Insights*, data already collected will be retained to ensure that the results of the research project can be measured properly. You should be aware that data collected up to the time you withdraw will form part of the research project results.

**Contact us:** If you would like any further information concerning this project, or have any questions or comments, please call the Study Infoline 1300 45 11 45 or email [45andUp@saxinstitute.org.au](mailto:45andUp@saxinstitute.org.au)

## Who should I contact if I have concerns or complaints about *45 and Up COVID Insights*?

*45 and Up COVID Insights* has been approved by The University of New South Wales Human Research Ethics Committee (Committee A). Any person with concerns or complaints about the conduct of this research project should contact the Ethics Coordinator who is the person nominated to receive complaints from research participants:

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
HC Reference Number	HC200597 (quote this reference with any correspondence)

## Support Services Contact Details

If at any stage during the research project, you become distressed or require additional support from someone not involved in the research please call:

Organisation	Phone number	Web address
<p><b>Lifeline Australia</b></p> <p>Immediate mental health and crisis support open 24/7 (phone) 7pm-midnight AEST (online chat)</p>	13 11 14	<a href="http://www.lifeline.org.au">www.lifeline.org.au</a>
<p><b>Beyond Blue</b></p> <p>Mental health support available 24/7 (phone) 3pm-midnight AEST (online chat)</p>	1300 224 636	<a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a>
<p><b>National Alcohol and Other Drug 24-hour hotline</b></p> <p>For information and local alcohol and drug support services</p>	1800 250 015	

Thank you for taking the time to read this information and about *45 and Up COVID Insights*. If you wish to take part, please complete the online consent form which will take you to the survey.