

45 and Up Study Participant Information Sheet

45 and Up Health Compass

July 2022

This research project is in addition to the main 45 and Up Study. Participation is voluntary. Participation in this project does not change your involvement in the main 45 and Up Study. Information collected by this research project will become part of the 45 and Up Study in future.

What is this research project about?

The pandemic has changed many of the ways in which we live, work, and interact. There have also been changes in the way healthcare is organised and delivered, such as virtual healthcare and health monitoring devices. As we navigate this transition period it is important to understand how these changes impact on health and wellbeing and how different parts of the community are affected.

The 45 and Up Health Compass project is being conducted by the Sax Institute's 45 and Up Study. It is a series of very short surveys which should take no more than 10-15 minutes each. You will be sent no more than three surveys per year over the next three years.

The results from each survey will aid planning and decision making and support research to improve healthy ageing and good health care.

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. NSW Health have commissioned this research project.

Why have I been invited to participate in 45 and Up Health Compass?

You have been invited to participate in this research project because you are a participant in the 45 and Up Study. As a 45 and Up Study participant you have given your permission to be invited to other research projects. You may also have recently completed the 45 and Up COVID Insights research project.

What does participation in 45 and Up Health Compass 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 between 10 and 15 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 that may be impacted as we transition out of the 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.

I am not sure if I will be able to complete all the surveys over the next three years, can I still take part?

That is fine, you do not have to complete all the surveys. You can choose not to fill in future surveys or you contact the 45 and Up Study if you prefer not to receive more surveys. Any surveys you choose to complete will help our research. However, as the research project aims to track how things change over the next three years, completing more surveys will help build a more comprehensive picture of the different impacts.

What information will be collected about me?

As with all 45 and Up surveys, all the information you provide is anonymised for research, meaning you cannot be personally identified. 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 information sources and current research projects, please call 1300 45 11 45 or visit www.saxinstitute.org.au/our-work/45-up-study.

How will my information be used?

Information you provide via the surveys will be aggregated with responses from other participants to protect your identity. Key results will be reported back to health decision makers and researchers to help inform healthcare decisions, policies, programs and planning. The information you provide in the surveys will become part of the 45 and Up Study and may be used in other ethically approved health or medical research studies in the future. Your data will be stored securely and will be deidentified, meaning information cannot be identified as coming from you.

What if I don't want to take part in 45 and Up Health Compass?

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 you cannot 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 Health Compass?

This research is expected to be very low risk, however you may feel that some of the questions we ask about your experiences 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 Health Compass?

If you suffer any distress or psychological or physical injury because of this research project, you should contact the 45 and Up Study Team as soon as possible. You will be assisted with arranging appropriate support.

Will I benefit from joining 45 and Up Health Compass?

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 Health Compass cost me anything and will I be paid?

Participation in this research project 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 Health Compass?

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 Health Compass once it has started, you can do so at any time without having to give a reason by contacting us. If you withdraw, 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**

Who should I contact if I have concerns or complaints 45 and Up Health Compass?

45 and Up Health Compass 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:

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| Position | Human Research Ethics Coordinator |
| Telephone | + 61 2 9385 6222 |
| Email | humanethics@unsw.edu.au |
| Reference | HC220272 (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 | Contact details |
|---|---|
| Lifeline Australia Immediate mental health and crisis support open 24/7 (phone) 7pm-midnight AEST (online chat) | Ph. 13 11 14 www.lifeline.org.au |
| Beyond Blue Mental health support available 24/7 (phone) 3pm-midnight AEST (online chat) | Ph 1300 224 636 www.beyondblue.org.au |
| National Alcohol and Other Drug 24-hour hotline For information and local alcohol and drug support services | 1800 250 015 |

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

About the 45 and Up Study

The 45 and Up Study is the largest general population program of health-related research ever conducted in Australia. More than 267,000 people aged 45 and over are participating in the Study, and they are being followed over time through routine follow-up questionnaires and linkage to health and other records.

The 45 and Up Study has been approved by the University of New South Wales Research Ethics Committee. Study participants have also given permission to be invited to participate in further research projects. Each of these research projects has been through a stringent review process prior to approval. Participation in these research projects is optional.

Study governance

The 45 and Up Study is owned and managed by the Sax Institute in collaboration with major partner Cancer Council NSW; and partners: the Heart Foundation; NSW Ministry of Health; NSW Department of Communities and Justice; and Australian Red Cross Lifeblood.

About the Sax Institute

The Sax Institute is an independent, not-for-profit organisation that improves health and wellbeing by driving better use of evidence in policies, programs and services.

The Institute is a registered charity that works with governments, health organisations, research organisations and a network of experts nationwide to analyse policy problems and find the best evidence-based solutions.

Contact the Sax Institute about the 45 and Up Study

For any questions, comments, or complaints about the 45 and Up Study or this research project, to withdraw consent for participation or for further communication, please contact us:

Telephone: 1300 45 11 45 (toll-free Study Infoline)

Email: 45andUp@saxinstitute.org.au

In writing to:

Dr Martin McNamara, Chief Investigator, 45 and Up Study, GPO Box 5289, Sydney NSW 2001

Confidentiality

The 45 and Up Study, and any research projects associated with it, are bound by Commonwealth and State privacy legislation and guidelines: the 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 in place to safeguard participant confidentiality. The Study is also bound by strict scientific ethical accountability to the University of New South Wales:

Ethics Secretariat,

University of New South Wales,
Sydney NSW 2052

Telephone: (02) 9385 6222

Email: humanethics@unsw.edu.au

Thank you. We could not conduct the 45 and Up Study without the generosity of our participants. We are immensely grateful to all of you.

This information sheet is for you to keep.