

Diabetes Risk Factor Survey

The *Diabetes Risk Factor Survey* is for participants in the 45 and Up Study. The survey is part of a larger study of access to best practice primary health care for older Australians with diabetes.

The *Diabetes Risk Factor Survey* aims to identify how Australians manage risk factors for diabetes and cardiovascular disease and how these impact on their health and wellbeing.

The *Diabetes Risk Factor Survey* is funded by a National Health and Medical Research Council project grant.

The 45 and Up Study is managed by

saxinstitute

In partnership with



NSW HEALTH



How can I get more information?

If you would like to know more about the *Diabetes Risk Factor Survey* or the 45 and Up Study please visit our website, www.45andUp.org.au or call the 45 and Up Study Infoline on **1300 45 11 45**.

You can also write to:
Professor Emily Banks
Scientific Director
The 45 and Up Study
GPO Box 5289
Sydney NSW 2001

If you have a concern or complaint about the conduct of the 45 and Up Study, you can contact:

Ethics Secretariat
The University of NSW
Sydney NSW 2052
Tel: (02) 9385 4234
Email: ethics.sec@unsw.edu.au

If you have a concern or complaint about the conduct of the *Diabetes Risk Factor Survey*, you can contact:

Ethics Administration
NSW Population and Health Services Research Ethics Committee
Tel: (02) 8374 5615
Fax: (02) 8374 3500
Email: ethics@cancerinstitute.org.au



Diabetes Risk Factor Survey

Information for Participants



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Who is conducting the *Diabetes Risk Factor Survey*?

The *Diabetes Risk Factor Survey* is being undertaken by a team of researchers led by Associate Professor Elizabeth Comino from the Centre for Primary Health Care and Equity, University of NSW.

To ensure confidentiality, the 45 and Up Study Coordinating Centre at the Sax Institute is inviting 45 and Up Study participants to take part in the *Diabetes Risk Factor Survey*.

What does the *Diabetes Risk Factor Survey* involve?

Participation in the *Diabetes Risk Factor Survey* involves completion of a questionnaire about your health.

The questionnaire will seek information about cardiovascular disease and diabetes, and your use of health services for preventive and treatment purposes and management of these conditions if you have them.

We also ask you to give permission to link information we collect from you in the *Diabetes Risk Factor Survey* with information you have already provided to the 45 and Up Study.

How much time will my participation take?

The questionnaire will take about 20 to 30 minutes to complete.

How do I accept the invitation to participate?

If you choose to take part in the *Diabetes Risk Factor Survey*, we ask you to complete the confidential questionnaire enclosed with this information leaflet and to sign the consent form on the last page of the questionnaire which will allow the 45 and Up Study to release the information to the researchers. You can return the questionnaire to the 45 and Up Study in the reply paid envelope provided for your convenience.

Participants who complete the questionnaire and sign the attached consent form will be included in a prize draw for one of four \$50 store vouchers.

How will my information be used?

Your information will be used only for approved research projects, to investigate factors affecting the health of Australians in mid to later life.

All research projects must demonstrate that they are in the public interest and have the potential to provide important information to improve health.

The information collected by the *Diabetes Risk Factor Survey* will be linked to the health information you have already given to the 45 and Up Study and to information from your health and other records that you allowed the 45 and Up Study to access. These include NSW hospital records, cancer records, Medicare and other records (call **1300 45 11 45** or see www.45andUp.org.au for more information).

How do I know my information will be treated confidentially?

The 45 and Up Study is bound by Commonwealth and State privacy legislation and guidelines, including the Health Records and Information Privacy Act and the NSW Health Privacy Manual. The 45 and Up Study also has strict procedures and systems to safeguard confidentiality.

Your identifying details (such as name and address) will be removed from the information you give to *Diabetes Risk Factor Survey* as soon as possible and stored separately. De-identified data will be stored at the University of NSW and destroyed 7 years after the research is complete.

When the researchers talk about the study they will only use summary data. No information will be released in a way that would allow you or any other individual or household to be identified, except as is compelled by law.

The conduct of the 45 and Up Study is overseen by the University of NSW Human Research Ethics Committee and the conduct of the *Diabetes Risk Factor Survey* is overseen by the NSW Population and Health Services Research Ethics Committee and the University of NSW Human Research Ethics Committee.

By agreeing to be a part of the *Diabetes Risk Factor Survey*, you agree to the 45 and Up Study providing your completed questionnaire to the *Diabetes Risk Factor Survey* researchers.

Will I benefit from the *Diabetes Risk Factor Survey*?

The *Diabetes Risk Factor Survey* aims to improve understanding of how Australians manage risk factors for diabetes and cardiovascular disease and how these impact on their health and wellbeing, however it may not directly benefit you at this time.

Will anyone else know the results?

All information provided by participants in the *Diabetes Risk Factor Survey* will be kept strictly confidential. The results from the *Diabetes Risk Factor Survey* will be published in scientific journals and presented at scientific meetings. We will also include the results of the survey on the 45 and Up Study website (www.45andUp.org.au). The results of this project will also be included in the 45 and Up Study's participant newsletter.

All results will only be presented in a combined and summarised format and could not identify or be linked to any individual or household.

Can I tell other people about the 45 and Up Study and the *Diabetes Risk Factor Survey*?

Yes, do talk about the survey. Please note, however, that the *Diabetes Risk Factor Survey* was only sent to people who have already joined the 45 and Up Study.

What if I don't want to take part?

Participation in the *Diabetes Risk Factor Survey* is entirely your choice. If you do not wish to participate, you need take no further action.

Can I withdraw from the *Diabetes Risk Factor Survey*?

Participation in the *Diabetes Risk Factor Survey* is completely voluntary. You do not have to take part if you don't want to and, if you do take part, you can withdraw at any time by calling the 45 and Up Study Infoline on 1300 45 11 45. You can decide not to participate in the *Diabetes Risk Factor Survey* or you can withdraw from it and still remain in the 45 and Up Study.