

## What is the Skin Health Study?

The Skin Health Study is a new part of the 45 and Up Study that focuses on skin cancer and aims to improve our understanding of how sun, lifestyle and viruses can together cause this disease. It is a study of the common skin cancers, basal cell carcinoma (BCC) and squamous cell carcinoma (SCC).

Australia has very high rates of skin cancer. We know that most skin cancers are caused by exposure to the sun. What we don't know is why some people get them and others don't, even with the same sun exposure.

## Who is doing the Study?

The Skin Health Study is being done by researchers at Cancer Council NSW, the University of Sydney, the Australian National University and the German Cancer Research Center.

To ensure participant confidentiality, the 45 and Up Study Coordinating Centre at the Sax Institute is inviting 45 and Up Study participants to take part in the Skin Health Study. The 45 and Up Study will only give your details to the Skin Health Study if you agree to participate by signing the Consent Form.

The Skin Health Study is funded by a grant from the National Health and Medical Research Council of Australia.

## How can I get more information?

### For more information about the Skin Health Study:

**Tel:** 1800 739 459 (freecall) OR  
(02) 9334 1992 (Project Coordinator)

**Fax:** (02) 8302 3550

**Email:** [skinhealthstudy@nswcc.org.au](mailto:skinhealthstudy@nswcc.org.au)

**Mail:** Skin Health Study  
PO Box 572  
Kings Cross NSW 1340

### For more information about the 45 and Up Study:

**Web:** [www.45andUp.org.au](http://www.45andUp.org.au)

**Tel:** 1300 45 11 45

The Skin Health Study has been approved by the Cancer Council NSW Ethics Committee. If you have any concerns or complaints about it, or the way it is being conducted, you may contact the Committee:

**Mail:** The Secretary,  
Cancer Council NSW Ethics  
Committee  
PO Box 572, Kings Cross 1340

**Tel:** (02) 9334 1900



Research to improve health and wellbeing

# Skin Health Study

## Information for Participants

The 45 and Up Study is managed by the

**sax**institute

In partnership with



**Human Services**  
Ageing, Disability  
& Home Care

**NSW HEALTH**



Research to improve health and wellbeing

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## Who is being asked to join the Skin Health Study?

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You joined the 45 and Up Study in 2008 by completing a questionnaire about your health and lifestyle. We are now asking two groups of people from the 45 and Up Study to join the Skin Health Study based on information they provided:

- People who have recently been diagnosed for the first time with a basal cell carcinoma (BCC) or squamous cell carcinoma (SCC)
- People who have not had skin cancer.

The researchers will compare these 2 groups: their sun sensitivity, sun exposure, other lifestyle characteristics, number of moles, and the presence of human papillomaviruses (HPVs) on their skin. HPVs are very common viruses, with 4 out of 5 people having them at some stage of their lives. We want to see if they contribute to causing skin cancer.

## What will you ask me to do if I take part?

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Participating in the Skin Health Study is in two parts.

First, **please sign the Consent Form** and return it to us in the enclosed reply paid envelope. People who said they have had a skin cancer may also receive a Skin Cancer Record. **If you have received one, it's on the back of the Consent Form** - please also fill it in and return it and the completed Consent Form.

Second, once we have received your signed Consent Form, we will send you more information and ask you to:

- Complete a questionnaire about your hair and eye colour, freckling and moles on your skin, sun sensitivity, places you've lived, your general health, and other lifestyle aspects. This will take about 30 minutes to complete.
- Visit a local pathology centre to have a small blood sample taken (less than two tablespoons or about 30ml) and give a sample of loose skin cells swabbed from a small area of your skin. The swab causes no discomfort and has no harmful effects. The study will pay for collecting the blood and skin cells. You do not pay.

We may also wish to contact you again in the future to obtain information about any changes to your skin health. We will only contact you for the purposes of skin cancer research, and your participation would be completely voluntary. We will also ensure that we limit the number of times we contact you, so we do not over-burden you.

## What tests will be done on my samples?

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The blood sample you provide will be used:

- To test for past exposure to HPVs and other infectious agents possibly related to skin cancer (e.g. Merkel cell polyomavirus, human herpesviruses and others still to be identified)
- For future testing of DNA for changes in genes that may influence the activity of vitamin D or the risk of having a BCC or an SCC.

## Will I get the results of the tests done on my samples?

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We will not send you or your doctor the results from any tests we do on your blood sample. Knowing them would not benefit your health. We can send you a summary of the overall results of the study when they are complete. If you would like to receive this, please tick the box at the bottom of the Consent Form.

## How will the 45 and Up Study use my blood sample and questionnaire information?

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A small portion of your blood sample, your DNA, and the information from your questionnaire will also be used by the 45 and Up Study.

The 45 and Up Study will store your blood sample securely and allow it to be used over the coming decades for approved health research. It may be used by researchers to look at a wide range of factors able to be measured in blood, such as cholesterol, antibodies, and blood sugars. Research may also include investigation of genetic factors, such as the structure and function of certain genes, and how they relate to a range of illnesses and other conditions.

Information you provide in the Skin Health Study questionnaire will also be combined with the information

that you have previously given to the 45 and Up Study, including information from your health and other records that you allowed the 45 and Up Study to access (see [www.45andUp.org.au](http://www.45andUp.org.au) or call 1300 45 11 45 for more information).

## What about my privacy?

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All information and blood samples provided to the 45 and Up Study and the Skin Health Study are bound by Commonwealth and State privacy legislation and guidelines, including the Health Records and Information Privacy Act and the NSW Health Privacy Manual. The commitment of both studies to providing a high standard in handling personal information includes:

- Working with the University of NSW Human Research Ethics Committee and Cancer Council NSW Ethics Committee, which are responsible for overseeing the conduct of the 45 and Up Study and the Skin Health Study respectively
- Ensuring information is used for health research and the purposes described in this leaflet only
- Ensuring your identifying information, such as name and address, is removed and stored separately as soon as possible
- Ensuring information is not released in a way that would allow an individual or household to be identified, except as is compelled by law.

## What if I don't want to take part?

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Participation in the Skin Health Study is entirely your choice. If you do not wish to participate, you need take no further action.

## Can I withdraw from the Skin Health Study?

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If you do take part in the Skin health Study, you can withdraw at any time by calling the 45 and Up Study Infoline on 1300 45 11 45. You can withdraw from the Skin Health Study and still remain in the 45 and Up Study.