

The 45 and Up Study Policy on Email Contact with Participants

1. Purpose

- 1.1 The purpose of this policy is to outline requirements of the 45 and Up Study for Mass Emails sent to Participants.

2. Principles

- 2.1 The 45 and Up Study relies on the ongoing goodwill of participants to continue to have their health followed over time. To maintain this goodwill, it is essential that the 45 and Up Study ensures all communications with participants meet the highest ethical, scientific and quality standards.
- 2.2 The privacy of Participants is to be protected.
- 2.3 Participants are not to be subjected to any undue burden as a result of their participation in the 45 and Up Study.

3. Policy

Consent

- 3.1 The 45 and Up study will not send unsolicited Mass Emails. Only participants who have given the 45 and Up Study their express consent to contact them via email, and have not otherwise withdrawn their consent, will be sent Mass Emails by the 45 and Up Study.
- 3.2 Consent to be contacted by Mass Email will be deemed to have been given by a Participant where that Participant has provided an email address:
 - a.) at baseline; or
 - b.) in response to a request by the 45 and Up Study for updated contact details;
or
 - c.) in the course of a sub-study, on the understanding that the email address will be provided to the 45 and Up Study; or
 - d.) by any other means, where the Participant expressly states that the 45 and Up Study may direct future communications with the Participant to that email address;and consent has not otherwise been withdrawn.
- 3.3 Consent to be contacted by Mass Email is not deemed to have been given by a Participant where that Participant initiates email contact with the 45 and Up Study, but does not expressly state that the 45 and Up Study may direct future communications with the Participant to that email address. In such circumstances the email address

will only be used for the purpose of responding to the Participant's contact.

Use of Participant Email Addresses

3.4 Mass Emails may be sent to Participants for the purpose of health-related research.

Emails sent for the purpose of health-related research include, but are not limited to, emails:

- a.) requesting updated contact details from Participants; or
- b.) inviting Participants to participate in a Sub-Study; or
- c.) inviting Participants to complete a follow-up questionnaire; or
- d.) providing Participants with the annual participants' newsletter

3.5 The 45 and Up Study, without exception, will not sell Participant email addresses to a third party, or otherwise use Participant email addresses in a manner adverse to Participant privacy.

3.6 Subject to paragraph 3.5, the 45 and Up Study, at its discretion, may on its own behalf or on behalf of a third party, use Participant email addresses for a purpose other than health-related research, if that purpose is:

- a.) not in conflict with the principles defined in section 2 of this Policy; and
- b.) in accordance with the *Sax Institute Advertising and Ethics in Communication Policy*; and
- c.) within the scope of the consent given by the Participant to be contacted; and
- d.) approved by the 45 and Up Study Internal Management Committee.

Use of Participant Email Addresses by Partners and Supporters

3.7 Use of Participant email addresses by Partners and Supporters will be at the discretion of the 45 and Up Study, and in accordance with the relevant Partnership and Funding Agreement and this Policy.

3.8 Partners and Supporters will not be given access to Participant email addresses. Any email contact with participants will be undertaken by the 45 and Up Study, on behalf of the relevant Partner or Supporter.

3.9 For the avoidance of doubt, no term in any Partnership and Funding Agreement made between the Sax Institute and a 45 and Up Study Partner or Supporter is affected by this Policy. In so far as this Policy conflicts with any term of a Partnership and Funding Agreement, the term of the Partnership and Funding Agreement will prevail.

Requirements for Mass Emails

3.10 Mass Emails sent by the 45 and Up Study to Participants must:

- a.) contain a functional unsubscribe facility
- b.) include accurate sender information

Unsubscribe facility

3.11 The message should include the following statement:

If you do not wish to receive further emails from the 45 and Up Study, click unsubscribe below, or call the 45 and Up Study Helpline on 1300 45 11 45

3.12 Where emails are sent using an external mass mailing system, the 'unsubscribe' link will link to the unsubscribe facility of the mass mailing system.

3.13 Where emails are sent using the internal email system of the 45 and Up Study Coordinating Centre, the 'unsubscribe' link will be the 45 and Up Study email address 45andUp@saxinstitute.org.au, or any amendment or replacement thereof.

3.14 The 45 and Up Study will ensure that all requests to unsubscribe from further email communications are:

- a.) actioned in a timely manner;
- b.) recorded in a central location, which must be routinely checked prior to sending any subsequent Mass Email communications to Participants;

in accordance with relevant 45 and Up Study procedures.

3.15 Where a Participant unsubscribes from email contact, the 45 and Up Study will not make any further email contact with that Participant, unless otherwise advised by the Participant. Email contact will include contact for :

- a.) administrative purposes, including, but not limited to, the annual participants' newsletter and requests for updated contact details; and
- b.) research purposes, including, but not limited to, invitations to participate in sub-studies and requests to complete follow-up questionnaires.

3.16 Where a Participant has unsubscribed from email contact, but subsequently initiates email contact with the 45 and Up Study, the 45 and Up Study may email that Participant for the purpose of replying to that contact, but must not use the Participant's email for unrelated communications, including Mass Emails, unless the Participant has given their express consent.

3.17 A request to unsubscribe from email contact does not affect a Participant's status regarding mail or telephone contact. Where consent has not otherwise been withdrawn, the 45 and Up Study may still contact the Participant via mail or telephone for administrative or research purposes, as defined at paragraph 3.15.

Sender Information

3.18 Mass Email messages sent to Participants must:

- a.) identify the organisation who authorised the sending of the message; and
- b.) include accurate information about how the recipient can readily contact the organisation

Applicability to Sub-Studies

3.16 In accordance with the *45 and Up Study Policy on Sub-Studies*, invitations to participate in Sub-Studies, including email invitations, must be sent by the 45 and Up Study on

behalf of the Researchers. The 45 and Up Study will be subject to the requirements outlined in this Policy when emailing invitations, on behalf of Researchers, to participate in Sub-Studies

- 3.17 Where a Participant has given their consent to participate in a Sub-Study, the Researchers may subsequently make email contact with the Participant, where:
- a.) written approval has first been obtained from the 45 and Up Study; and
 - b.) the consent obtained from the Participant permits email contact from the Researchers; and
 - c.) contact is for the purpose of the Sub-Study.
- 3.18 The requirements of this Policy will apply to Researchers seeking to send a Mass Email to Participants as part of a Sub-Study as though the Researchers were the 45 and Up Study.
- 3.19 Notwithstanding paragraph 3.18, the 45 and Up Study may impose additional requirements on the Researchers as it reasonably sees fit.

6. Definitions

In this Policy, unless the contrary intention appears:

Coordinating Centre means the Coordinating Centre of the 45 and Up Study, located at:
Level 8, UTS Building 10
ULTIMO, NSW, 2007

or the subsequent registered business address of the Sax Institute.

Mass Email means any email communication sent to more than one Participant at a time, and where the message is not unique to the recipient.

Participant means a participant of the 45 and Up Study

Partner means a natural person or legal entity that has entered into an agreement with the Sax Institute not in the true meaning of a partnership but as a significant financial contributor to the Study (financial contribution being equal to, or more than, the minimum contribution required of a Partner).

Partnership and Funding Agreement means a written agreement made between the Sax Institute and another party, to appoint that party as a Partner or Supporter of the 45 and Up Study.

Policy means the *45 and Up Study Policy on Mass Email Contact with Participants*

Researcher means any person named as an investigator in the Sub-Study Application to the 45 and Up study, or in a Sub-Study Amendment.

Study means the 45 and Up Study

Sub-Study means projects approved by the 45 and Up Study to collect additional data from Participants that is not part of follow-up or other activity of the Coordinating Centre

Supporter means a natural person or legal entity that has entered into an agreement with the Sax Institute as a financial contributor to the Study (financial contribution being less than that

required of a Partner).