



45 and Up Study e-News

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Editor: Study Director Margo Barr

Welcome to the 12th issue of the 45 and Up Study e-News, a bulletin for members of the 45 and Up Study Research Network, researchers, policy makers and others with a professional interest in Australia's largest cohort study. This is my first eNews, having joined the 45 and Up Study in May 2014. I look forward to working with you and I hope to bring my expertise in epidemiology, survey and cohort management, system development and analysis to the Study. It was great to meet many of you at the Collaborators' Meeting. Also thank you to all the researchers who contributed to the postmeeting survey.

Wave 2 data collection progress

A total 127,690 study participants, 48% of the cohort, have now been followed up (41,440 in the September 2012 follow-up; 86,250 in November 2013 follow-up) and the November 2013 follow-up data will soon be available. Another 52,644 participants have just been sent questionnaires (December 2014 follow-up) and the remainder (around 60,000) will be followed-up in February 2015. All participants will then have been followed-up at least once, with the first 100,000 being followed up twice due to participation in the Social, Economic and Environmental Factors (SEEF) Project.

Wave 3 data collection planning

Wave three will begin at the end of 2015 and planning is about to begin on the questionnaire items. Although many questions will need to be retained there is an opportunity to include additional questions and for others to be removed.

Our recent survey of collaborators' meeting attendees identified three top priorities for new questionnaire items and/or topics: medications; current depression; presence of dementia and Alzheimer's disease; attitudes towards exercise; barriers to physical activity; oral health; usual source of care; experiences of integrated care; neighbourhood walkability; travel behaviours; out-of-pocket heath expenses; more about alcohol consumption and/or issues; more nutrition items; more biospecimens; e-cigarettes; health literacy; number of siblings; type of diabetes.

Processes and fees

From 2015 the 45 and Up Study processes and fees will change. We are simplifying the application process and in order to keep abreast with the increasing costs of managing the cohort and data, the licence fees and charges will increase. This will be the first fee increase in several years. The new annual licence fee per researcher per year will be: \$8,250 +GST for the first questionnaire dataset and 50% of that for the second questionnaire dataset. The two questionnaire datasets that are currently available are baseline (more than 250,000 records) and first follow-up including SEEF (around 100,000 records).

Data preparation fees will now be \$3,800 + GST per occasion. These fees are charged to prepare data for linkage, to provide access to MBS data, to provide access to PBS data and to include geocoded data. For more information see https://www.saxinstitute.org.au/our-work/45-up-study/for-researchers/#data-costs.

Research update

A total of 70 research projects are approved and/or currently underway and 31 are completed. If your project status is different to what is listed on the website at https://www.saxinstitute.org.au/our-work/45-up-study/research-underway/ please advise us accordingly.

A total of 121 papers using the 45 and Up Study data have now been published in peer-reviewed journals. A full <u>list of publications</u> is available on our website. There were 72 research articles/conference abstracts and reports technically reviewed in 2014. As soon as we are aware of these papers being published we add them to the website. If you have recently published a paper and it is not on the list please send it to us. Your publications are very important to us. They are used by others and in our reporting to partners. If your research has influenced, or has the potential to influence, policy and/or practice, please let us know as this is vital information to share and is a significant component of our partner reporting.

The 45 and Up Study coordinating centre has recently updated the technical review guidelines to help researchers in this process. We have provided separate guidelines for articles/reports and abstracts. These are available at https://www.saxinstitute.org.au/wp-content/uploads/Guidelines-for-authors-regarding-technical-review-of-45-and-Up-Study-papers.pdf. We ask that you send your paper or abstract to us at least 30 days before submission. Every effort will be made to achieve a fast turnaround but adequate time for the technical review should be allowed before any external deadlines. In particular, this applies to papers requiring additional review by the Department of Human Services where use of the DHS data (MBS and/or PBS) forms part of the analyses.

Data updates

Researchers should soon be able to access the updated (to 2011) ABS mortality records linked to the RBDM deaths records. Currently, the NSW Ministry of Health does not have permission to provide this to other parties, either directly or through CHeReL. This has been applied for and as far as we are aware will be approved. It is expected to be available soon and it will be dated up to 2012. In the interim, CHeReL has offered to make a list of researchers with ethics approval for 'latest available ABS mortality records linked to the RBDM deaths records' and so researchers should email them and request that they are advised of the process to get that data once it becomes available. The email to contact CHeReL is cherel.mail@moh.health.nsw.gov.au

MBS and PBS data to Dec 2012 is now ready. We have received data for an additional 78 participants in the MBS data so we now have data for 99% of active participants. For the PBS data, we received data for an additional 60 participants so we now have data for over 87% of active participants.

How to contact the 45 and Up Study

The 45 and Up Study coordinating centre is located at the Sax Institute, NSW, Australia, Level 13, Building 10, 235 Jones Street Ultimo NSW 2007. For more information about the Study, to submit a project application, or to share news about achievements please contact us on 1300 45 11 45 Email 45andUp.research@saxinstitute.org.au.

Our partners

The 45 and Up Study is managed by the Sax Institute in collaboration with major partner Cancer Council NSW; and partners: the National Heart Foundation of Australia (NSW Division); NSW Ministry of Health; *beyondblue*; NSW Government Family & Community Services – Carers, Ageing and Disability Inclusion; and the Australian Red Cross Blood Service.

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