

The 45 and Up Study: fostering population health research in NSW

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Excellent, forward-looking population health research requires good ideas, skilled people and high quality infrastructure. The *45 and Up Study* was developed to enhance population health research in New South Wales (NSW).¹ Since its inception in 2003, it has grown to become the largest cohort study of its kind in the Southern Hemisphere, with more than 50 research projects underway using *45 and Up Study* data. It is a collaborative research resource managed by The Sax Institute in collaboration with major partner the Cancer Council NSW and partners: the National Heart Foundation of Australia (NSW Division); NSW Health; *beyondblue: the national depression initiative*; Ageing, Disability and Home Care, Department of Human Services NSW; and UnitingCare Ageing.

A shared large-scale data resource, with extensive data linkage

The *45 and Up Study* is a large-scale cohort study that includes 266 848 NSW men and women aged 45 years and over. From February 2006 to December 2009, participants sampled from the Medicare Australia enrolment database joined the study by completing a baseline questionnaire and giving signed consent for follow-up through repeat questionnaires and linkage of their data to multiple health-related databases,¹ including data on hospitalisations, cancer registrations, deaths, medications, primary health care and aged care. Researchers can also use the *45 and Up Study* as a framework for more detailed data collection and intervention studies, known as sub-studies. Following a period of exclusive use by study investigators, sub-study data are contributed to the central *45 and Up Study* pool of data.

At the time of writing, the *45 and Up Study* and linkage resources available to researchers consist of:

- baseline questionnaire data (questionnaires can be viewed at www.45andUp.org.au)

- linked data on health and service use
- sub-study data, as they become available.

Additional large-scale data will be added over time, including a 5-year follow-up questionnaire for the whole cohort, detailed data on social and economic factors requested from the first 100 000 participants, and enhanced data collection relating to diet.

Researchers apply to use the data from the study through the *45 and Up Study* Coordinating Centre, supported by an independent Access Committee. Projects that are in the public interest, meet the appropriate scientific quality and feasibility standards, and have approval from relevant data custodians and human research ethics committees, are given access to data. The charges to research groups depend on the complexity and scale of each project and whether or not their institution has paid for an ongoing licence to access data from the *45 and Up Study*.

How does the 45 and Up Study foster better population health research in NSW?

The *45 and Up Study* represents a pooling of resources to facilitate research. It fosters better population health research in NSW by:

- **Encouraging large-scale research.** Large-scale cohort studies provide prospective data on a wide range of exposures in relation to a wide range of outcomes and are recognised internationally as a sound basis for high quality research.
- **Reducing the need for primary data collection.** The *45 and Up Study* improves the efficiency and timeliness of research by allowing researchers to focus on data analysis, interpretation and writing up, rather than data collection and securing funding for data collection.
- **Improving the targeting of new data collection.** Researchers can use the *45 and Up Study* as a sampling frame for identifying participants with specific characteristics who can be recruited into sub-studies.
- **Providing a focus for collaboration.** The high profile of the study and its strong communication with a large network of collaborating researchers means that it acts as a focus for forming new research collaborations, and attracting new researchers from a wide range of disciplines.
- **Increasing the competitiveness of funding applications from NSW.** The study improves the competitiveness of grant applications from NSW, since they

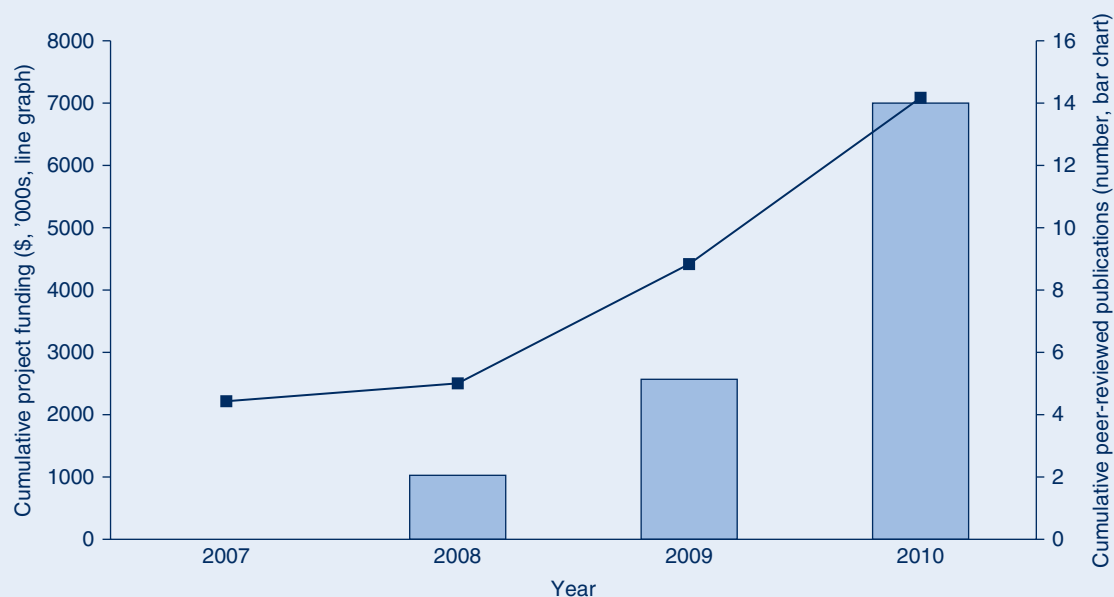


Figure 1. The *45 and Up Study*: cumulative funding for projects and peer-reviewed publications. Source: The Sax Institute, 2010.

can build on the existing infrastructure and can achieve more substantial outcomes more quickly and at reduced cost, compared to projects requiring extensive *de novo* data collection.

- **Providing data that is of direct relevance to health services provision and hence policy agencies.** The study has ongoing linkage to key health datasets through the Centre for Health Record Linkage, as well as the potential for ad hoc linkages to other service data. This presents opportunities for enhancing routinely collected health service data, and health services research, through the addition of rich person-specific information on key confounding and mediating factors such as socioeconomic status and risk behaviours.
- **Providing research infrastructure that is sustainable and grows in value over time.** The research value of the study will increase exponentially as additional events accrue and additional data are collected.

Research to date in the *45 and Up Study*

More than 70 projects have been approved to use *45 and Up Study* data and over 50 are underway, spanning a wide range of disciplines, health conditions and research

groups (see www.45andUp.org.au for details). Seven sub-studies collecting additional data on participants are underway. At June 2010, the *45 and Up Study* had cost a total of around \$7 million to establish and run. In addition to this, over \$7 million in project-specific funding has been received to date for research using *45 and Up Study* data (Figure 1). Despite completion of data entry as recently as early 2010, a total of 14 peer-reviewed papers are either published or in press (Figure 1). These papers provide insights into: breast-feeding and diabetes; sleep and health; early retirement due to illness; cancer screening; and obesity.

Conclusion

The *45 and Up Study* provides infrastructure for a wide range of public health research projects in NSW. Many of these projects and collaborations would not have been possible in the absence of this large-scale infrastructure.

Reference

1. 45 and Up Study Collaborators. Cohort profile: the 45 and Up Study. *Int J Epidemiol* 2008; 37(5): 941–7. doi:10.1093/ije/dym184