

# Reflecting on the '45 and Up Study' after 15 years: learnings, impact and future opportunities from a large-scale cohort study

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## The inspiration behind the 45 and Up Study

This special edition of *Public Health Research & Practice* (PHRP) is being published in memory of Professor Dame Valerie Beral AC (1946–2022). Dame Valerie, for many years the Director of the Cancer Epidemiology Unit at the University of Oxford, UK, was an internationally recognised leader in epidemiology and women's health. Dame Valerie, an Australian, maintained many links with the Australian research community over the years, and was a driving force behind the Sax Institute's establishment of the 45 and Up Study. The design of the Study greatly benefited from insights and lessons learned from the extraordinary ongoing Million Women's Study<sup>1</sup>, which she established and led in the UK. Dame Valerie was also part of the editorial team that developed the approach for this special edition of PHRP.

The 45 and Up Study (the Study) is Australia's largest ongoing study of health and ageing. Conceived in 2004, the Study went on to recruit over 250 000 participants in Australia's most populous state, New South Wales (NSW), from 2005 to 2009.<sup>2,3</sup> At the time it was established, the ambition was to create a locally relevant platform to enable timely research to answer key health and social challenges. As a longitudinal study, following participants over time via ongoing surveys and linkage of routinely collected data, it also provides an avenue to understand factors underlying health and wellbeing in mid-adulthood through to older ages among the people of NSW.

A recent Sax Institute review of the outputs of the Study in several key areas demonstrates the success in achieving that initial ambition. More than 500 research publications have been identified that have used Study data across a broad portfolio of crucial topics – from chronic disease to mental health and wellbeing, through to the impact of the physical environment on health.<sup>4</sup> More than 800 researchers have accessed and used the Study data to support their work, and over 30 policy agencies have either directly used the data from the Study or cited it in their work.<sup>5</sup>

## The impact of the 45 and Up Study

The papers in this [special edition](#) of PHRP summarise the impact of the Study in several key areas, including physical activity, cardiovascular disease, healthy ageing and cancer. They also discuss how rapid surveys were conducted to gather data on participants' experiences and wellbeing during the coronavirus disease 2019 (COVID-19) pandemic and the potential for the Study to make substantial contributions to genomics and precision medicine.

The importance of physical activity to overall health and wellbeing has long been established. [Bauman et al.](#) outline the varied portfolio of research on physical activity that has been conducted via the Study.<sup>6</sup> They report methodological and other challenges, but also cite the potential of the Study to further uncover the relationship between physical activity and long-term health outcomes as more data are collected in coming years. The opportunity outlined by Bauman et al. to utilise the Study to better understand the impact of policies directed towards increasing rates of physical activity in the community is particularly important.<sup>6</sup>

The research review by [Byles](#) describes the value of the Study as a method to track key life transitions and better understand health issues that emerge at different ages.<sup>7</sup> It is a resource that provides the opportunity to make important comparisons of the experiences and health outcomes of participants at similar ages across different time periods. As a result, the Study provides a mechanism to understand the influence of changes in service delivery, policy and social and cultural factors on health and wellbeing outcomes.

[Paige et al.](#) describe some of the factors that have made the Study such a powerful research tool.<sup>8</sup> They emphasise four key attributes – the collaborative nature of the resource; its large scale; the incorporation of high quality self-reported data; and linkage to routinely collected administrative data. They illustrate the power of the resource by outlining case studies of research that has demonstrated underlying education-linked inequalities in the incidence and mortality of cardiovascular disease, and of mortality risks in smokers in the Australian context. These findings that have contributed to policy-setting and national and international monitoring and reporting.

The emergence of the COVID-19 pandemic led to the research sector being required to move swiftly to produce new insights and evidence to support decision making; in the context of the pandemic, such agility was highly valued. [Dawson et al.](#) describe the approach undertaken in the Study to recruit a subsample of participants to complete regular surveys at key stages of the pandemic.<sup>9</sup> The iterative design of this survey series, with extensive stakeholder involvement and co-production, produced important and timely insights into the behaviours and

wellbeing of participants to support the response to the pandemic.

[Weber et al.](#) provide an overview of the value of the 45 and Up Study to cancer research, in bringing together survey and administrative data.<sup>10</sup> They use the example of lung cancer as a case study to illustrate the power of the Study to address important questions in cancer risk and prevention; cancer screening; pathways to diagnosis and uptake of treatment; and costs of cancer treatment. In the case of lung cancer, the Study data has been used to provide local evidence on the continuing impact of smoking in Australia and to validate – in an Australian cohort – an international tool for classifying the risk of future development of lung cancer. This tool could, in the future, be used to assess eligibility for a potential lung cancer screening program in Australia, an initiative with significant potential to improve cancer control. Data from the cohort has also been used to estimate the excess health service costs associated with lung and other cancers, and to understand how pathways to diagnosis and patterns of cancer care vary in population subgroups.<sup>10</sup>

## Future directions

There has been much interest in the potential for genomics and precision medicine to deliver optimised, targeted approaches to improving health and wellbeing. [Armanasco et al.](#) discuss the ethical and practical challenges related to biospecimen collection, but also elucidate the potential of the Study to act as a platform for the creation of an important population-based collection of biological samples.<sup>11</sup> They discuss the need for other longitudinal studies to contribute to a diverse national resource. Ultimately, they emphasise the synergistic relationship between biospecimen collections and prospective cohort studies, and the power of the combined resource to push the boundaries of current knowledge.

The papers in this edition of the journal showcase the breadth and depth of research undertaken with 45 and Up Study data. New opportunities will continue to emerge. Mobilising the data from the Study to measure the effects of policy change, service redesign and the piloting of new interventions holds considerable promise. There is also growing interest in applying machine learning and artificial intelligence methods to the Study data. As the cohort ages, there will continue to be opportunities to better understand the epidemiology of chronic disease and optimal strategies for prevention and management.

This themed edition of PHRP – with its look back over the important insights gained from Australia's largest cohort study – is a fitting tribute to one of the Study's original founders. Professor Dame Valerie Beral will be greatly missed by all in the Australian public health research community, but the central role of the 45 and Up

Study to population health research will become one of her legacies.

## Acknowledgements

This editorial is part of a special issue of PHRP reflecting on the 45 and Up Study, which is published in memory of world-renowned epidemiologist Dame Valerie Beral (1946–2022), who played a vital role in establishing and supporting the Study.

The 45 and Up Study is managed by the Sax Institute in collaboration with partners Cancer Council NSW, the Heart Foundation and NSW Ministry of Health. We acknowledge and thank all the participants of the Study.

KC has used 45 and Up Study data in various research projects. She is co-principal investigator of the 'Compass' trial of cervical screening run by the Australian Centre for Prevention of Cervical Cancer, a government-funded, not-for-profit charity. The trial receives infrastructure support from the Australian Government and the Centre has received equipment and a funding contribution from Roche Molecular Diagnostics, US. KC is also co-principal investigator on the Elimination of Cervical Cancer in the Western Pacific program, which has received support from the Minderoo Foundation and Frazer Family Foundation and equipment donations from Cepheid Inc.

## Peer review and provenance

Internally reviewed, invited.

## Competing interests

MM is Chief Investigator of the 45 and Up Study and a Guest Editor of this issue. He was not involved in review of this paper.

## Author contributions

Dame Valerie Beral and MM conceptualised the focus of the manuscript. MM and KC were responsible for design and drafting the paper and both authors edited and approved the final manuscript.

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