

BMJ Open Using patients' experiences of adverse events to improve health service delivery and practice: protocol of a data linkage study of Australian adults age 45 and above

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ABSTRACT

Background: Evidence of patients' experiences is fundamental to creating effective health policy and service responses, yet is missing from our knowledge of adverse events. This protocol describes extensive research addressing this significant deficit, investigating the experiences of a large cohort of recently hospitalised patients aged 45 years and above in hospitals in New South Wales (NSW), Australia.

Methods and analysis: The 45 and Up Study is a cohort of 200 000 adults aged 45 years and above in NSW. Patients who were hospitalised between 1 January and 30 June 2014 will be identified from this cohort using data linkage and a random sample of 20 000 invited to participate. A cross-sectional survey (including qualitative and quantitative components) will capture patients' experiences in hospital and specifically of adverse events. Approximately 20% of respondents are likely to report experiencing an adverse event. Quantitative components will capture the nature and type of events as well as common features of patients' experiences. Qualitative data provide contextual knowledge of their condition and care and the impact of the event on individuals. Respondents who do not report an adverse event will report their experience in hospital and be the control group. Statistical and thematic analysis will be used to present a patient perspective of their experiences in hospital, the characteristics of patients experiencing an adverse event, experiences of information sharing after an event (open disclosure) and the other avenues of redress pursued. Interviews with key stakeholders and a thematic analysis will be used to create a map of the current practice.

Ethics and dissemination: Dissemination via a two-day workshop, peer-reviewed publications and conference presentations will enable effective clinical responses and service provision and policy responses to adverse events to be developed.

Strengths and limitations of this study

- The use of data linkage is a novel strategy that will facilitate identification of a large number of recently hospitalised patients, patient experience studies to date consistently suffer from small and unrepresentative patient samples.
- Linkage with national patient data allows us to triangulate patient reported experiences with information in their medical record for example, the health problem they presented with, how long their stay in hospital and the treatments received. This information validates the self-reported patient data.
- The 45 and Up Study cohort does not include a representative sample of culturally and linguistically diverse (CALD) participants. We address this weakness by analysing a subsample of data of CALD participants to explore whether their experiences differ from the main sample.
- The patient sample data includes those who are 45 years or older therefore is not a representative population sample. Adults aged 45 and above are more likely to be hospitalised and have more frequent contact with the health system, therefore knowledge of the experiences of this group is valuable. Data from younger patients may be explored in future work using this study as a model.

BACKGROUND

Adverse events are a significant problem

Preventable harm in hospitals due to health-care activities is one of the top six health problems in the developed world.¹ At least one in seven hospitalised patients suffer an adverse event (AE) which may require extra care or cause permanent harm or even death.² It is estimated that AEs cost the NHS in hospital care alone—at least nine dollars in every seven spent on healthcare.³ This

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