

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.

Dissemination: Dissemination via a one-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 admitted 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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Table of Contents Patients39 Rights And Professional Practice

1. Understanding the eBook Patients39 Rights And Professional Practice
 - The Rise of Digital Reading Patients39 Rights And Professional Practice
 - Advantages of eBooks Over Traditional Books
2. Identifying Patients39 Rights And Professional Practice
 - Exploring Different Genres
 - Considering Fiction vs. Non-Fiction
 - Determining Your Reading Goals
3. Choosing the Right eBook Platform
 - Popular eBook Platforms
 - Features to Look for in an Patients39 Rights And Professional Practice
 - User-Friendly Interface
4. Exploring eBook Recommendations from Patients39 Rights And Professional Practice
 - Personalized Recommendations
 - Patients39 Rights And Professional Practice User Reviews and Ratings
 - Patients39 Rights And Professional Practice and Bestseller Lists
5. Accessing Patients39 Rights And Professional Practice Free and Paid eBooks

- Patients39 Rights And Professional Practice Public Domain eBooks
- Patients39 Rights And Professional Practice eBook Subscription Services
- Patients39 Rights And Professional Practice Budget-Friendly Options
- 6. Navigating Patients39 Rights And Professional Practice eBook Formats
 - ePub, PDF, MOBI, and More
 - Patients39 Rights And Professional Practice Compatibility with Devices
 - Patients39 Rights And Professional Practice Enhanced eBook Features
- 7. Enhancing Your Reading Experience
 - Adjustable Fonts and Text Sizes of Patients39 Rights And Professional Practice
 - Highlighting and Note-Taking Patients39 Rights And Professional Practice
 - Interactive Elements Patients39 Rights And Professional Practice
- 8. Staying Engaged with Patients39 Rights And Professional Practice
 - Joining Online Reading Communities
 - Participating in Virtual Book Clubs
 - Following Authors and Publishers Patients39 Rights And Professional Practice
- 9. Balancing eBooks and Physical Books Patients39 Rights And Professional Practice
 - Benefits of a Digital Library
 - Creating a Diverse Reading Collection Patients39 Rights And Professional Practice
- 10. Overcoming Reading Challenges
 - Dealing with Digital Eye Strain
 - Minimizing Distractions
 - Managing Screen Time
- 11. Cultivating a Reading Routine Patients39 Rights And Professional Practice
 - Setting Reading Goals Patients39 Rights And Professional Practice
 - Carving Out Dedicated Reading Time
- 12. Sourcing Reliable Information of Patients39 Rights And Professional Practice
 - Fact-Checking eBook Content of Patients39 Rights And Professional Practice
 - Distinguishing Credible Sources
- 13. Promoting Lifelong Learning
 - Utilizing eBooks for Skill Development

- Exploring Educational eBooks

14. Embracing eBook Trends

- Integration of Multimedia Elements
- Interactive and Gamified eBooks

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