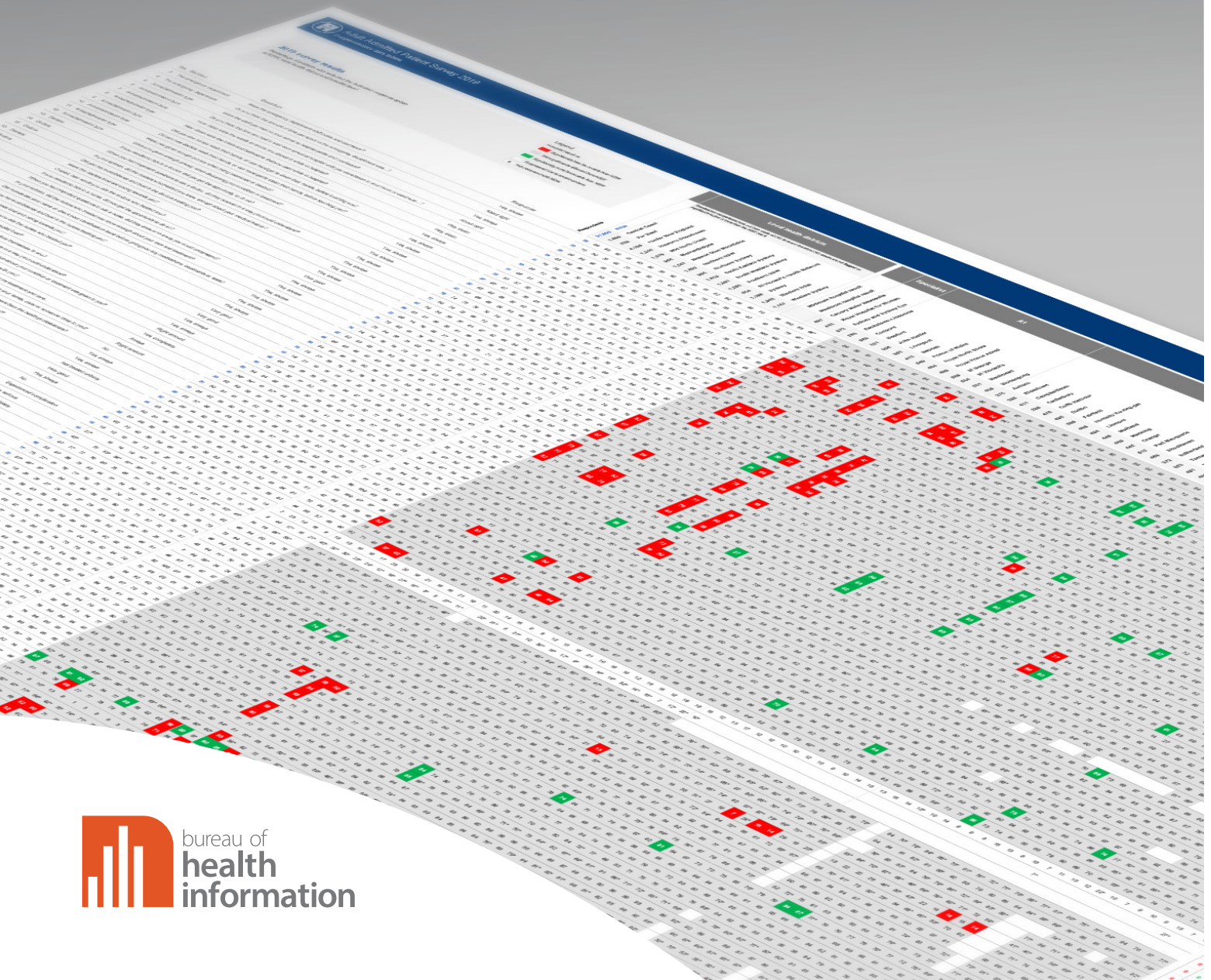


Guide for researchers

Accessing NSW Patient Survey Program data



Overview

The Bureau of Health Information (BHI) runs the NSW Patient Survey Program on behalf of NSW Health. The program is a rich source of data with feedback collected over more than 10 years from more than 650,000 patients about their experiences of care with NSW public healthcare services.

Opportunities are available to access this data on the BHI website, and by special request, to allow researchers to develop new and original insights that contribute to NSW Health's work to improve patients' experiences and outcomes.

This guide provides information for researchers about the NSW Patient Survey Program data asset including what information is available, how it can support valuable research that informs the management of health services, and how to apply for access to the data in different formats.

NSW Patient Survey Program

BHI is a board-governed statutory health corporation providing the community, healthcare professionals and policymakers with independent information about the performance of the NSW healthcare system. We do this to ensure the results are accessible and available to the public to enhance transparency, and to system managers and healthcare professionals to help inform improvements in healthcare.

BHI gives patients a voice through the NSW Patient Survey Program – the largest statewide patient survey program in Australia and NSW Health’s principal source of robust and representative information about patients’ self-reported experiences and outcomes of healthcare.

Patients provide feedback through core surveys for adult admitted and emergency department patients while additional surveys run periodically in areas such as virtual care, outpatient cancer clinics, rural and regional facilities and the Aboriginal Patient Experience Survey Program. The majority of respondents provide consent to link their questionnaire responses to other health information datasets, creating a unique data asset.

A high quality data asset

BHI implements high standards of data collection, management and governance to provide objective, accurate and robust patient survey data, including:

- Evidence-based questionnaires
 - Robust question set development process including literature reviews, cognitive testing, periodic reviews of reliability, core questions and special-purpose modules for priority policy directions and new evidence.
 - Standard questions related to key areas of patient experience and self-reported outcomes focusing on what matters most to patients and providing information of most use to support improvements to healthcare services. Questions are asked across key domains of patient experience including:



- Inviting patients to provide free-text comments about the best part of their care and what can be improved.
- Implementation of special questionnaire modules that provide insights on topics such as experiences with ambulance services, elective surgery and virtual care after discharge.
- Inclusion of survey questions that support cohort studies related to, for example, age, education status, presence and type of long-term health condition, Aboriginality and language spoken at home.

- Methodology
 - Recruitment via mail with two reminders; mail and online response options; response rates from 20–40% depending on the survey and topic; BHI calculates all survey weights to support representative results.
 - Robust data management and governance processes.
 - Rigorous sampling methodologies to ensure representative results that support reporting of descriptive results and advanced analyses.
 - Stratified sampling and census surveys of selected patient cohorts such as Aboriginal people, and patients from linguistically diverse communities.

Research opportunities

BHI is increasing access to the unique NSW Patient Survey Program data asset in line with our purpose, enabling researchers to derive greater value from patients' feedback by undertaking further analyses and producing additional insights that can inform improvements in patients' experiences and outcomes.

Patient experience is a key component of safe, high-quality care and is embedded in NSW Health's strategic objective to ensure patients and carers have positive experiences and outcomes that matter. NSW Patient Survey Program data can unlock the answers to many research questions of high clinical and policy relevance, such as:

- Is patient experience improving, in what areas, and for whom?
- What are the drivers of positive patient experience? How do these vary for different cohorts or services?
- What is the association between patient experiences and outcomes? How does this vary for different cohorts or services?
- How are vulnerable populations experiencing the health system, and how is this related to clinical and health system outcomes?

Opportunities exist for researchers to use this data to produce original insights that contribute to improving patients' experiences and outcomes – a key NSW Health system priority. Research using this data will be shared with key NSW Health teams and agencies to inform those improvement efforts.

A range of research projects are already in train or published.

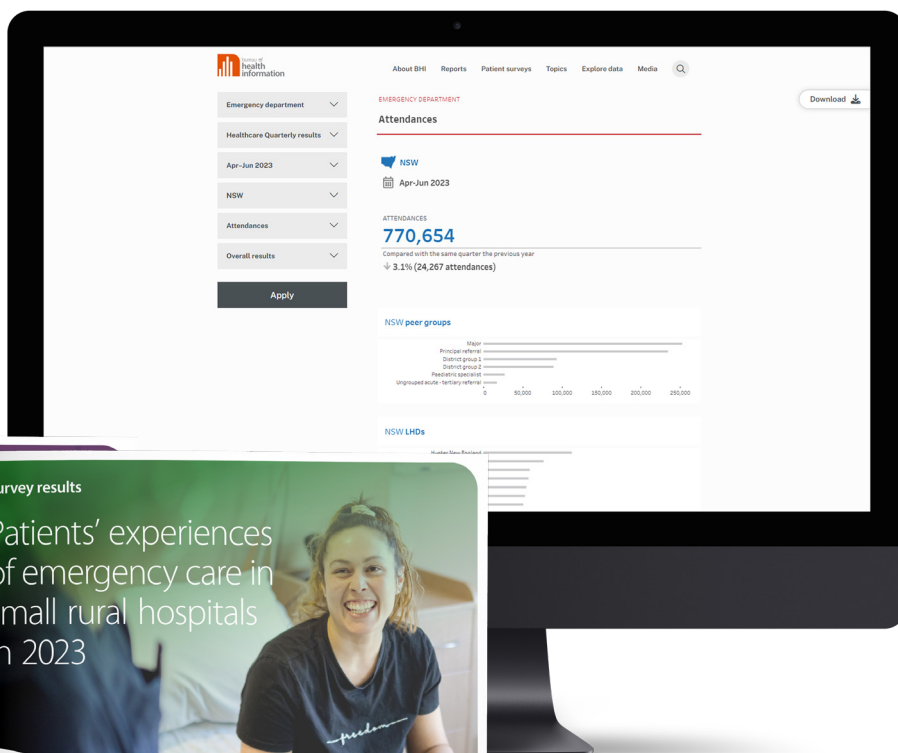
How to get started

What information is already available to you

BHI makes extensive healthcare performance information available publicly on its website to enhance transparency and accountability. Resources include:

- **BHI Data Portal**
 - Find and compare survey results, including trends, for NSW, individual hospitals and local health districts, and selected patient groups.
- Survey results reports
 - An overview of results for each release, focus on NSW level with some hospital variation.
- Supplementary data tables
 - Detailed results for the most positive survey response option and additional information such as respondent numbers and rates, and demographics, for NSW and by local health district (LHD) and hospital.
- Technical Supplements
 - Describing the sampling frame, cohorts, survey weights and levels of analyses (e.g. NSW, LHD and hospital).
- Questionnaires
 - Including Development Reports describing survey development.

BHI Survey results reports and Data Portal



Requesting access to other data formats

BHI recognises that researchers may require patient survey data in different formats (e.g. Excel spreadsheets) than those currently available on the website to support in-depth research. BHI is working progressively to make the data available through increased access to unit record survey data and an open data project.

Currently, data can be requested in different formats via a **BHI Patient Survey Data Request** form.

In reviewing requests, BHI may request further information or set up a meeting to discuss the proposed analyses. BHI assesses all applications according to the **Five Safes Risk Management Framework**, which includes confirmation that the proposed analyses align with the purpose of the data collection. If approved, you will be invited to sign a data sharing agreement and confidentiality undertaking prior to access being provided.

Please ensure that before submitting a data request you have familiarised yourself with the **Patient survey results** information already available on the BHI website, including the **BHI Data Portal**, and established that NSW Patient Survey Program data could be used to help support your research, including its value in informing improvements to NSW healthcare services.

For more information regarding data requests, see the frequently asked questions on the next page.

Frequently asked questions

Data requests

1. What approvals are required?

Once a data request has been accepted, approval to access the data will be provided by the NSW Patient Survey Program data custodian. Researchers should also contact their institution's human research ethics committee (HREC) to confirm their requirements regarding ethics approval.

2. What data are available?

Quantitative and qualitative data from any NSW Patient Survey Program survey that has completed data collection, data quality processing and reporting can be requested for analyses that align with the purposes of the data collection.

3. Where do I access and work on the data?

BHI uses the Secure Unified Research Environment (SURE), managed by the Sax Institute, to enable access to the data for research. To use the SURE platform, you will be required to complete training prior to accessing the facility. The SURE researcher training program covers the responsibilities of a user, information security and statistical disclosure control.

4. Is there a fee?

BHI does not charge a fee for access to data. However, there are fees associated with the use of SURE.

5. What support or resources are available to help researchers understand and use the data?

Technical documentation and metadata are available within SURE. This includes procedural documentation outlining how to use SURE and BHI's requirements around publications. Technical supplements describing how the survey was conducted, and sample questionnaires, are available within SURE and on BHI's website. BHI also invites researchers to attend a workshop that covers how BHI manages and analyses the survey responses.

6. Is linked data available?

Yes, NSW Patient Survey Program data can and has been linked to other datasets. BHI is actively working on creating a linked data asset, with the first tranche of linked data at concurrent episode level expected to be available via SURE soon. The Centre for Health Record Linkage (CHeReL) also enables linkage to many datasets for individual projects.

It is advisable to gain experience of using survey data in its own right, in order to effectively and accurately analyse linked data. Projects that work first with the survey data, and then progress to linked data, are encouraged.

7. Can I partner with BHI on research projects?

BHI has limited capacity to participate in projects, however where possible we will provide subject matter expertise and link researchers with other NSW Health entities or research groups undertaking similar work.

8. Can BHI provide funding?

No, you will need to secure funding for your research.

9. I have further questions, who do I contact?

For further enquiries, please contact
BHI-Enq@health.nsw.gov.au