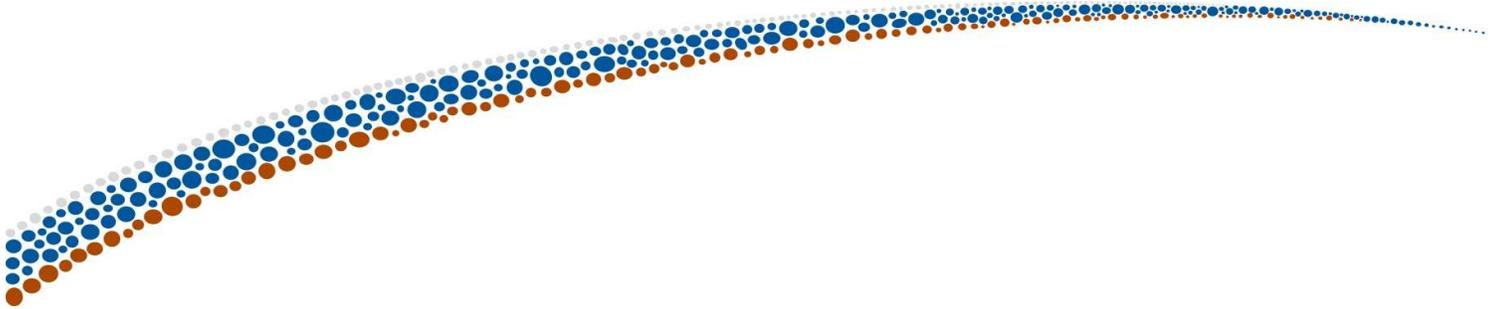


Aboriginal people living long, well and healthy lives

Aboriginal Patient Experience

Review and recommendations for improvement



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Enquiries should be directed to:

Aboriginal Health Policy Directorate
Public and Aboriginal Health Division
Department of Health Western Australia
189 Royal Street
EAST PERTH WA 6004

Phone: (08) 9222 2478

Email: Aboriginal.Health@health.wa.gov.au

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1. Background

There is now strong evidence to show that better patient satisfaction and experience is associated with improved health outcomes and clinical effectiveness. Improvements in patient safety, adherence to recommended medication and treatments, preventative care including screening and immunisation, reduced length of stay and reduced costs per case, have all been linked to positive patient satisfaction and experience¹.

Although similar, patient satisfaction and patient experience are different measures. Patient satisfaction is a subjective measure from the patients perspective of their experience, whereas patient experience, although still from the patient's point of view, is a more objective measure of the patient's interactions with the health service and whether or not things occurred, such as, being adequately informed of their treatment. Most health services combine the two measures in to the one survey tool and both measures are an important part of providing health services with information to assist in quality improvement initiatives. For the purposes of this paper the term 'patient experience' will be used to describe both patient satisfaction and experience.

Patients are uniquely positioned to provide insightful comments about their care and healthcare management. Furthermore, they are the only common link between healthcare services by which to document the overall care experience. Patient experience data can therefore inform healthcare providers of problems in the care process, which could involve the coordination of care, the care environment or the provision of treatment¹.

Acknowledging and utilising patients experiences of their care is critical to providing and improving health care². For health services measuring patient experience it is crucial to monitor quality of care, identify opportunities for quality improvement, measure impact of changes in service delivery, provide feedback to clinicians, inform strategic decision making, manage the expectations of patients, enable public accountability and benchmark and compare the performance of hospitals over time and with their peers². Patient experience data can be used to constantly adapt and refine services and processes to better meet patients' needs³.

¹ Doyle C, Lennox L, Bell D 2013, 'A systematic review of evidence on the links between patient experience and clinical safety and effectiveness', *BMJ Open*, vol. 3, no. 1, viewed April 2018, <http://bmjopen.bmj.com/content/3/1/e001570>

² Health Foundation 2013, *Measuring patient experience: evidence scan*, Health Foundation, London, viewed April 2018, <https://www.health.org.uk/publication/measuring-patient-experience>

³ Harrison R, Walton M, Manias E 2015, *Patients' Experiences In Australian Hospitals*, Evidence Check brokered by Sax Institute for the Australian Commission on Safety and Quality in Health Care, Sydney.



Sourced: <https://home.kpmg.com/au/en/home/insights/2017/05/patient-experience-recalibrating-health-care-success.html>

The Department of Health (DOH) has identified patient experience as a core component of an optimal health system, improving the health of populations and reducing the per capita costs of care^{4,5}.

While a number of mainstream patient experience tools exist, little is known about Aboriginal patients' experiences of health care. Given that Aboriginal patients are over represented in the hospital system and face significant disparities in health outcomes, measuring their experience is not only an important element of improving their health outcomes, but can also be a measure of the cultural competency and safety of the health service^{6,7}.

2. Purpose

The purpose of this paper is to:

- outline the rationale for measuring patient experience in the health sector more broadly and for Aboriginal patients specifically
- describe the policy context surrounding patient experience nationally and in Western Australia
- examine existing survey tools and look at the outcomes for Aboriginal patients in the WA health system
- identify the limitations and areas for improvement for the capture of Aboriginal specific data
- explore the possibilities of including measures of racism and racial bias in the health system
- provide recommendations for improvements in data collection of Aboriginal patient's experiences.

⁴ Quality Improvement and Change Management Unit 2017, *You Matter: A Guideline to support engagement with consumers, carers, communities and clinicians in health*, Western Australian Department of Health, Perth.

⁵ Quality Improvement and Change Management Unit 2017, *A great patient experience*, Western Australian Department of Health, Perth.

⁶ Aboriginal Health Policy Directorate 2015, *WA Aboriginal Health and Wellbeing Framework 2015-2030*, Western Australian Department of Health, Perth.

⁷ Aboriginal Health Policy Directorate 2017, *Implementation Guide for the WA Aboriginal Health and Wellbeing Framework 2015-2030*, Western Australian Department of Health, Perth.

3. Policy context

3.1 National

3.1.1 Australian Commission of Safety and Quality in Health Care

The Australian Commission of Safety and Quality in Health Care (the Commission), National Safety and Quality Health Service (NSQHS) Standards, now formally incorporates patient experience outcomes into the accreditation framework. Standard 2: Partnering with Consumers, states that systems are to be designed and used to support patients, carers, families and consumers to be partners in healthcare planning, design, measurement and evaluation of care⁸.

Underpinning the NSQHS Standards are six Aboriginal specific actions, as outlined in the *NSQHS Standards User Guide for Aboriginal and Torres Strait Islander Health*, which include the need for Aboriginal consumer partnerships and participation in their healthcare:

- Action 1.21: Improving cultural competency
 - Use continuous quality improvement processes to improve the cultural safety of the health service organisation.
 - Seek community feedback through mechanisms such as yarning circles, surveys or feedback from community representatives on the cultural safety of the organisation.
- Action 1.33: Creating a welcoming environment
 - An increased feeling of safety and engagement with the health service organisation.
- Action 2.13: Working in partnership
 - The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs⁹.

3.1.2 Australian Hospital Patient Experience Question Set

The Commission has developed a set of core questions to measure patients' experiences in hospital at the request of the Australian Health Ministers Advisory Council (AHMAC) in 2015. The questions were tested with 1,500 patients across Tasmania, South Australia, Victoria and New South Wales, however Aboriginal patients were not specifically included in the pilot. The questions were endorsed by the Australian Health Ministers' Advisory Council (AHMAC) in November 2017.

The Australian Hospital Patient Experience Question Set (AHPEQS) is a set of 12 questions that are designed for hospitals and day procedure services to use when asking patients what they observed and felt about their care⁸. Through the use of a consistent set of questions nationally, the Commission aims to promote national comparability and more effective tracking of improvements over time.

⁸ Australian Commission on Safety and Quality in Health Care (ACSQHC) 2017, *National Safety and Quality Health Service Standards*, ACSQHC, Sydney.

⁹ Australian Commission on Safety and Quality in Health Care (ACSQHC) 2017, *National Safety and Quality Health Service Standards User Guide for Aboriginal and Torres Strait Islander Health*, ACSQHC, Sydney.

The AHPEQS are in the form of a statement worded from the patients' perspective with a selection of possible responses (mainly frequency based). The questions assess the patients' experience in the following areas:

- view and concerns were listened to
- responsiveness to needs
- felt cared for
- involved in decision making
- kept informed
- clear communication between staff and the patient and also between staff
- pain management
- patient safety
- harm and distress
- overall quality of care⁸.

There are no questions relating to cultural safety or respect or experiences of racial discrimination.

The Commission is now working to (a) develop a user guide to assist in the implementation of the questions, and (b) establish a methodology that would allow nationally consistent measurement of patients' experiences across jurisdictions in the future.

DOH, Patient Safety and Clinical Quality, is planning a trial of the AHPEQS within a pilot Health Service Provider (HSP) in anticipation that they will be included in the national performance framework. The pilot program is proposed to be a joint project with Epidemiology and Aboriginal Health policy Directorate (AHPD). AHPD will provide a cultural lens to the evaluation of the AHPEQS pilot and the method of data collection to determine if the AHPEQS is fit for purpose for Aboriginal patients.

3.1.3 Patient Reported Outcome Measures

Patient Reported Outcome Measures (PROMs) are questionnaires completed by the patient that ask for their assessment of how the healthcare they received has affected their quality of life, daily functioning, symptom severity and other dimensions of health which only patients can know¹⁰.

Evidence to support the use of PROMs to inform quality improvement is growing internationally. The evidence is strongest for their use in understanding variation in clinical practice, as they can help in determining the relative effectiveness of different treatments and interventions¹¹. However, they are not currently embedded in routine measurement at a regional, jurisdictional or national level in Australia.

3.2 Western Australia

In conjunction with a commitment to implement the NSQHS Standards, the Director General, DOH, has also endorsed positive patient experience as a priority for the WA health

¹⁰ Thompson C, Sansoni J, Morris D, Capell J, Williams K 2016, *Patient reported outcome measures: an environmental scan of the Australian healthcare sector*, Australian Commission on Safety and Quality in Health Care, Sydney.

¹¹ Williams K, Sansoni J, Morris D, Grootemaat P, Thompson C 2016, *Patient reported outcome measures: Literature review*, Australian Commission on Safety and Quality in Health Care, Sydney.

system¹². The DOH, *A great patient experience*, document states that patient experience is the extent to which care delivered by a health service meets the physical and emotional needs of the patient, their family and carers, and takes into consideration the diversity of backgrounds and needs⁵.

A great patient experience document proposes that a great patient experience can best be described as:

- patient-centred, respectful, culturally sensitive care that is adaptable to an individual patient's needs and preferences
- care that is provided in a compassionate manner where confidentiality and privacy are maintained where possible
- clear and meaningful information provided to ensure informed decisions are made
- collaboration with the healthcare team allows the delivery of the highest possible quality care occurs, with family and carers input where applicable⁵.

Further supporting the WA health system commitment to provide positive patient experiences is the *You Matter - A guideline to support engagement with consumers, carers, communities and clinicians in health* (You Matter Guidelines). These guidelines provide high level recommendations for HSP to better engage with consumers⁴. The You Matter Guidelines include specific strategies for better engagement with Aboriginal communities:

Demonstrate cultural respect	Respect identity, culture and values. Observe community priorities and protocols, men's and women's information, language, interpreters and story-telling. Aboriginal people view the person as living and being in a relationship with the family, community, the land and the spiritual beings. A holistic viewpoint is important. Develop initiatives to prevent and reduce systemic racism. Provide cultural awareness training for health service staff.
Consult with community leaders	Aboriginal leadership can be invisible to those outside it. Show respect and try to identify and build relationships with community Elders and leaders.
Involve the Aboriginal Community Controlled Health Services (ACCHSs)	The ACCHSs across WA provide important links with Aboriginal community members.
Involve specialised health service staff	Aboriginal Health Strategy teams, Aboriginal Liaison Officers and Aboriginal Health Workers are important in improving community and consumer engagement at the health service level.

3.2.1 WA Aboriginal Health and Wellbeing Framework 2015-2030

Under the *WA Aboriginal Health and Wellbeing Framework 2015-2030* (the Framework), Strategic Direction 3: A culturally respectful and non-discriminatory health system, recognises racism as a key social determinant of health for Aboriginal people. The Framework states that health care, whether government or community provided, needs to be free of racism and discrimination⁶. One of the recommended strategies outlined in the

¹² Department of Health 2012, *OD 0410/12 - Implementation of the Australian Health Service Safety and Quality Accreditation Scheme and the National Safety and Quality Health Service Standards in Western Australia*, Western Australian Department of Health, Perth.

Implementation Guide for the Framework is to ‘develop and use statewide measures and systems to monitor and report on Aboriginal people’s experience of health services’⁷.

3.2.2 Health Service Performance Report

Patient satisfaction is currently included in the Health Service Performance Reporting (HSPR) under Performance Indicator (PI) E2-1: Patient satisfaction with hospital service¹³. There are four subcategories for the PI:

- a) Adult inpatients
- b) Adult outpatients
- c) Paediatric inpatients
- d) Paediatric outpatients.

HSPs are required to achieve a score of 80 or higher to be considered ‘performing’¹³.

Data for this indicator is sourced from the Patient Evaluation of Health Services (PEHS) program (see section [4.1 Patient Evaluation of Health Services](#) for further detail). PI E2-1 is the mean score of the patients ‘Overall indicator of satisfaction: weighted by ranked issues of importance’. This score is calculated firstly by patients ranking the seven domains of the PEHS in order of what is most to least important to them. Secondly, the patients’ response to the questions under each of the domains and an average score out of 100 is calculated. The score is then weighted based on the ranking of importance that the patient gave the domain¹⁴. This allows for the results to reflect the different values that patient sub-groups may place on the different domains.

3.2.3 Clinical Senate: The Patient will see you now – Thinking beyond accreditation to focus on patient experience

In December 2015, the Clinical Senate of Western Australia met to debate the topic “*The Patient will see you now- Thinking beyond accreditation to focus on the patient experience*”.

The Senate resulted in a number of recommendations to the Director General, DOH, including that consideration be given to adopting an additional patient experience tool for particular subgroups of patients and carers such as Aboriginal people¹⁵.

In January 2017 a progress update of the recommendations for the WA health system was published. Although many of the recommendations regarding mainstream patient experience tools, processes and performance measures had been completed or were in progress, no system wide work has been carried out to develop a separate tool for subgroup patients.

3.2.4 Health Service Providers

The majority of HSPs have developed policy documents that outline the importance of capturing and improving consumer engagement and feedback, these include:

¹³ Information and System Performance Directorate, 2017, *Health Service Performance Report – Performance Indicator Definitions Manual*, Western Australian Department of Health, Perth.

¹⁴ Epidemiology Branch, 2017, *Patient Evaluation of Health Services – WA State Adult Admitted Patients Analysis by Aboriginal Status 2016/17*, Western Australian Department of Health, Perth.

¹⁵ Department of Health, Clinical Senate 2015, *The Patient will see you now – Thinking beyond accreditation to focus on patient experience: Final Report*, Western Australian Department of Health, Perth.

- *Aboriginal Community and Consumer Engagement Framework*, released in 2017 by South Metropolitan Health Service (SMHS)
- *Your experience matters to us*, currently undergoing the final consultation phase by North Metropolitan Health Service (NMHS)
- *WACHS Consumer and Care Engagement Policy*, released in 2017 by the WA Country Health Service (WACHS)
- *Consumer and Carer Participation Policy*, released July 2016 by East Metropolitan Health Service (EMHS).

4. Patient experience survey tools currently in use in the WA health system

4.1 Patient Evaluation of Health Services

The Patient Evaluation of Health Services (PEHS) survey is the only system-wide measure of patient experience in use across WA and has been conducted by DOH since 1997. It is run continuously from July to June each financial year. The standard adult inpatient group includes those aged 16-74 years who stayed in hospital for 0-34 nights. The different surveys included in the program are; adult inpatients (aged between 16-74 years), paediatric inpatients (aged between 0-15 years), adult emergency department patients, maternity inpatients, adult outpatients (aged between 16-74 years and paediatric outpatients (aged between 0-15 years)¹⁴. The WA PEHS is part of the WA Health Annual Performance Management Framework.

4.1.1 Method of collection

Interviews are conducted by an external contractor using the computer assisted telephone interview system. The maximum time from the patient being discharged to them completing the survey is 5-6 weeks¹⁴.

4.1.2 Eligibility Criteria

A separation must meet the following criteria to be included in the sample frame:

- aged between 16 and 74 years on the date of discharge
- length of stay between 0-34 nights
- admitted client
- Acute Care Episode
- Australian Health Care Agreement funding source
- no interpreter service required
- no psychiatric care days
- discharged home
- a residential or postal address with WA postcode
- a contact number¹⁴.

4.1.3 Domains covered

Patients are first asked to rank seven aspects or domains of health care from most to least important. The rankings are used to weight the scale score so that the patient's determination of importance guides the results. Patients are then asked specific questions

about their experience and satisfaction during their hospital stay. Responses from these questions are used to calculate the mean scale scores for each domain.

The seven domains that are covered are:

- Time and care
- Needs met
- Access
- Informed of condition and treatment
- Involvement in treatment
- Consistency in treatment
- Residential aspects of hospital stay¹⁴.

4.1.4 Outputs

Reports are created for each hospital site, HSP and region in WA. Information is also publicly reported in the DOH Annual Report. The reports include:

- Overview of response rates, importance and satisfaction, mean scale scores and the scale scores for the main domains and subscales. They include a comparison of the current year's results with previous years, a comparison to other hospitals in their peer group, e.g. other tertiary hospitals, and a comparison between WACHS and metropolitan hospitals.
- Frequency tables (results for each question asked). Total responses will vary for each question as some questions are only asked of patients staying 0-1 night and some of patients staying 2-34 nights. The questions are grouped into the seven major scales of satisfaction and an outcome scale. The scale scores represent the mean (average) rating or response category of the questions that make up a particular scale. This average is then converted to a score out of 100.
- In addition two other scores are provided, these are:
 - Overall Indicator of Satisfaction: the average of the scales weighted by their importance as ranked by the respondents. This is the score used in the HSPR.
 - Outcome Scale: the patient rated outcome of their hospital stay (i.e. the impact of the stay on their physical health and wellbeing)¹⁴.

4.1.5 Administration

The PEHS contract for the whole of the WA health system is managed by the Epidemiology Division, DOH.

4.1.6 Aboriginal specific data

It is possible to separate the PEHS results by Aboriginal status based on the information recorded in the patient administration system although reporting would be limited to sites or health services with sufficient sample size to allow disaggregation of results by this variable.

4. 2 Patient Opinion

Patient Opinion (PO) is an online forum where clients of WA health services can comment on their treatment. PO was developed in Scotland for a disability service, was adapted by QLD Health and was adopted by WA and was trialled in WACHS in 2016. The Minister made PO an Election Commitment and it has since been adopted by all HSPs through individual contracts with the provider.

The PO tool is designed to be an alternative avenue for patients to make comments regarding a health service other than a formal complaint/feedback avenue.

4.2.1 Method

The PO tool is run by a private web provider and is monitored so that any individual names are removed from the comments. It is an online forum but comments can also be made over the phone to a PO representative who will write it out on behalf of the client to ensure that people with low literacy levels and/or disability can have their story told.

4.2.2 Domains covered

The PO tool looks at the whole of the patient's journey and therefore can include events outside the HSP, for example, contact with primary health care services or private organisations.

4.2.3 Outputs

HSPs get full reports but DoH does not have access to these. Aside from the details of the person's story the reports include the following information:

- The HSP, hospital and department that the comment relates to
- No. stories told
- No. of staff registered to follow feedback
- Category 0-5 of comment (based on how urgently the comment need to be addressed and by whom)
- No. responses
- No. responses that lead to change/action
- Patient satisfaction (optional feedback)
- Time the comment was responded to (currently the only available measurement of performance).

Agencies can be registered as a 'watcher' and have access to stories but not reports. Currently the majority of 'watchers' are governing bodies such as the Health Consumers' Council and the Director General, DOH.

Consideration has been given to including PO measures as a performance indicator for HSPs in the HSPR, however the PO tool was primarily designed to be an internal improvement tool and is not set up to collect valid and reliable performance data. The time in which comments are responded to is currently the only data captured that could potentially be used as a performance indicator. Alternatively, an independent third party (e.g. Health Consumers' Council) could report on the PO tool at a state level to provide a monitory function.

4.2.4 Administration

Contracts to subscribe to PO are individually negotiated by each HSP. A working group with representatives from each HSP exists to discuss any issues and/or improvements to the PO system so that it best meets the need of the HSPs.

4.2.5 Aboriginal specific data

Aboriginal status is not requested/ recorded as part of the methodology. Aboriginality is flagged by the monitors of PO based on the content of the stories but is not specifically requested information.

4.3 Press Ganey

Press Ganey is a multi-national company that provides a suite of patient experience surveys to a number of hospitals within the WA health system, including Royal Perth, Bentley, Fiona Stanley, Sir Charles Gairdner and Osborne Park. There are a range of surveys for inpatients, day surgery, emergency department, outpatient, mental health, inpatient rehabilitation and maternity¹⁶.

4.3.1 Method of collection

The survey is paper based and is mailed out to randomly selected patients two weeks after they have been discharged. There is also an option for people to provide their responses online¹⁶.

Press Ganey offers an option for a 'point of care' survey that is taken via a tablet or smart phone while the patient is still in hospital, but this option is not currently utilised by any WA hospitals or HSPs¹⁶.

4.3.2 Domains covered

Randomly selected patients receive surveys in the mail with reply paid envelope. The survey has approximately 76 questions and covers the following domains:

- admission
- room
- meals
- nursing care
- doctor care
- tests and therapy
- visitors and family
- discharge
- personal issues
- consistency of care
- overall rating of hospital
- understanding of care given¹⁶.

¹⁶ Health Consumers' Council, *Press Ganey – What's It All About?*, viewed March 2018, <http://www.hconc.org.au/press-ganey-whats-it-all-about/>

4.3.3 Outputs

Outcomes are reported by the medical specialist area where the patient received treatment. Quarterly reports are produced for each site as well as HSPs overall corporate reports, these allow for comparative analysis by unit and specialities with ranking against peer groups.

Benchmarking

Health Services are compared against the Press Ganey “All Systems Database Peer Group”. This database contains groups of other national and international public and private hospitals using the same validated regional surveys. This is regardless of the size of the facility or whether it is public or private. Individual facilities will remain in the regional database for comparison for a period of up to ten years, even if they have not conducted another survey within this timeframe¹⁶. It is important to note that not all groups of hospitals use all surveys (i.e. some groups may survey inpatients, but not ED).

Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) is a patient experience survey that is required by CMS (the centres for Medicare and Medicaid services) for all hospitals in the United States. For the HCAHPS questions in the Press Ganey surveys, HSP hospitals are compared to international facilities participating in HCAHPS during the three preceding months¹⁶.

4.3.4 Administration

Contracts are individually negotiated by each HSP and the cost of the contract will vary depending of the number of surveys utilised by a hospital, i.e. for how many departments, and the size of the hospital.

4.3.5 Aboriginal specific data

Aboriginal patients included in the survey sample are randomly selected via the Patient Administration Systems, but the survey results are reported via medical specialist area and there is no option to separate responses based on Aboriginality.

4.4 Pilot programs

4.4.1 Your Experience Service Survey

At the national level, there has been strong interest in the development of a standardised, national measure of consumer experiences in mental healthcare to better support quality improvements, service evaluation and benchmarking between services¹⁷.

In 2010, the Australian Government Department of Health funded the National Consumer Experiences of Care project, to develop a survey for use in public mental health services¹⁷. The project resulted in the development of the Your Experience of Service (YES) survey instrument. The YES survey aims to help mental health services and consumers to work

¹⁷ Australian Institute of Health and Welfare, ‘Mental Health services in Australia’, *Your Experience of Service survey instrument*, viewed April 2018, <https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/national-mental-health-committees/mental-health-information-strategy-standing-commit/your-experience-of-service-survey-instrument>

together to build better services. The WA Mental Health Commission will pilot the YES survey in WA public mental health services in 2018-19¹⁷.

4.4.2 Culturally and Linguistically Diverse (CaLD) survey

The Public Health and Ambulatory Care Division of NMHS has developed a Culturally and Linguistically Diverse (CaLD) patient survey. The survey was adapted from the Press Ganey survey but is significantly shorter with only 29 questions. If funding is continued it is planned to have the questions voice recorded for those patients that might have difficulty reading English or who may have a disability. There was also the option of having the written version of the questions translated into one of 14 different languages.

The survey was piloted with 25 patients that had been admitted to Sir Charles Gairdner Hospital (SCGH) or Osborne Park Hospital (OPH). Interviews were conducted in person at the patient's home with their responses recorded into the online platform by the interviewer. No Aboriginal patients were included in the pilot group and the survey does not include any questions relating to the person's culture, cultural safety or experiences of racism.

If approved for further use, it is proposed that the CaLD survey will be administered to CaLD identified patients while still in the hospital setting before discharged.

4.5 Complaints and Compliments Systems

The complaints and compliments systems are web based recording and reporting systems for consumer comments, compliments and complaints. This mechanism is utilised by all of the health services and services report back on a monthly basis both locally and to the relevant HSP.

5. Aboriginal patient experiences compared to non-Aboriginal patients

5.1 WA health system

5.1.1 Patient Evaluation of Health Services (PEHS)

The PEHS is currently the only WA health system patient experience tool that can compare feedback between Aboriginal and non-Aboriginal patients. WACHS have previously requested reports which show a breakdown of responses by Aboriginal status, and for the purposes of this paper, a report of patient experience in 2016-17 across WA with breakdown by Aboriginal status was requested and produced. The report showed that there are a number of areas where Aboriginal patients rated their experience significantly lower than non-Aboriginal patients¹⁴.

Response rate

Table 1 below shows that there is a significant difference in the Raw Response Rate for Aboriginal patients (37.04%) compared to non-Aboriginal patients (73.54%)¹⁴. This difference was predominantly due to not being able to make contact with Aboriginal patients (over 56% of the sample group) and is not reflective of their willingness to participate in the survey (94.06%)¹⁴.

Table 1: PEHS 2016-17 response rate Aboriginal and non-Aboriginal patients

	Group	
	Aboriginal	Non Aboriginal
	Patients	Patients
Sample	1,026	5,166
Phone not connected / business / fax / modem	580	991
Eligible sample	446	4,175
Deceased between discharge and first contact	4	15
Unable to contact after 10 attempts	8	55
Refusals	24	169
Unable to respond (unavailable / language / illness)	30	137
Completed interviews	380	3,799
Raw Response Rate	37.04%	73.54%
Eligible Sample Response Rate	85.20%	90.99%
Eligible Contacted Response Rate	87.56%	92.55%
Participation Rate	94.06%	95.74%

Demographics

There were some socio-demographic differences identified between Aboriginal and non-Aboriginal respondents, with Aboriginal respondents:

- more likely not to have private health insurance (90.4% compared with 58.3%)
- more likely to have a health care card (68.4% compared with 46.6%)
- less likely to have completed studies post year 12 (20.0% compared with 50.9%)
- more likely to be in hospital for non-elective treatment (62.9% compared with 43.2%); and younger than non-Aboriginal respondents (46.3% aged 25 to 44 years compared with 36.4%)¹⁴.

Importance of domains

Aboriginal and non-Aboriginal respondents ranked *Time and Care* as the most important aspect of health care, followed by *Needs*. However, Aboriginal respondents ranked *Access* as the third most important aspect of health care while non-Aboriginal respondents ranked *Informed* as the third most important aspect of health care. For Aboriginal patients, improvements in areas related to *Access* would therefore be most beneficial and appreciated.

Aboriginal feedback

Specific examples where Aboriginal respondents had notably lower responses compared with non-Aboriginal respondents include:

- **Access scale:**
 - Being asked if they had any cultural or religious beliefs (32.0% compared with 41.0%).
 - The time given to consider any consent form rated 'as much as needed' (89.3% compared with 95.8%).
 - Checking their understanding of the information given to them (87.3% compared with 91.9%).
- **Involvement scale:**
 - Awareness that each hospital has a complaint service (69.9% compared with 76.7%).

- Felt able to ask for a second opinion about the proposed test/treatment/procedure (80.7% compared with 85.3%).
- Felt able to refuse the proposed test/treatment/procedure (86.1% compared with 91.1%).
- **Needs scale:**
 - Always/Usually shown respect while being examined or interviewed (91.9% compared with 96.8%).
 - Always/Usually being treated with politeness and consideration (85.5% compared with 95.3%).
- **Time and Care scale:**
 - Always/Usually having confidence in doctors (85.5% compared with 92.4%).
 - Always/Usually having confidence in nursing staff (86.6% compared with 94.2%)¹⁴.

Comments

There were three comments made regarding negative experience due to being Aboriginal, and six respondents made suggestions for improvement regarding their own or others' Aboriginality.

5.1.2 Health Service Performance Report

Performance Indicator E2-1: Patient satisfaction with hospital service, is not currently reported separately for Aboriginal patients, however, based on a requested 2016-17 comparison report, the E2-1 a) Adult inpatient, the mean score for Aboriginal patients is 77.6 and 'under-performing'. This is compared to 81.8 and 'performing' for non-Aboriginal patients for the same time period. This is a statistically significant difference with a 95% confidence interval¹⁴.

5.2 National

5.2.1 Patients' experiences in Australian hospitals

The Sax Institute conducted a study on behalf of the Australian Commission on Safety and Quality in Health Care looking at patient experiences in Australian hospitals. The study searched databases and grey literature dated from 1995 to 2015 for publications relating to qualitative studies of patient experiences in Australian hospitals and day procedure centres and summarised the evidence³.

In relation to Aboriginal patients it found firstly that there is a lack of evidence but, where evidence is available, the following key findings were noted:

- Miscommunication and a lack of cultural and spiritual understanding among health professionals is an issue. For example, Aboriginal women reported not understanding the information provided by nurses about their maternity care and not having the opportunity to ask questions¹⁸.
- Lack of preparation about what to expect from the hospital and challenges of having to leave close communities to give birth are concerns.

¹⁸ Watson J, Hodson K, Johnson R, Kemp K 2002, 'The maternity experiences of indigenous women admitted to an acute care setting', *Australian Journal of Rural Health*, vol. 10, no. 3, pp. 154-160.

- The provision of hospital self-care accommodation is valued as a way to feel safe when outside of the community.
- Lack of communication and information provision in hospital led to feelings of loneliness.
- Lack of clear communication with Indigenous women who speak little English was threatening to their safety of care.
- Those that had a positive experience were proactive in asking questions and seeking information³.

‘Cultural competence’ and identifying sociocultural needs were highlighted in the negative care experiences of CaLD and Indigenous patients. This was reported as being due to staff who were neglectful, lacked caring qualities, lacked understanding of the patient’s perspective or were perceived as racist³.

5.2.2 National Aboriginal and Torres Strait Islander Social Survey 2014-15

The National Aboriginal and Torres Strait Islander Social Survey 2014-15 reported the following findings for Aboriginal Australians aged 15 years or over:

- 35 per cent experienced unfair treatment due to their race in the previous 12 months
- 14 per cent avoided situations due to past unfair treatment , and of those 13 per cent had avoided seeking health care due to past unfair treatment
- 6 per cent disagreed or strongly disagreed with the statement ‘Your doctor can be trusted’
- for those living in non-remote areas, their General Practitioner rarely or never showed respect for what was said (15%), listened to them (20%) or spent enough time with them (21%)¹⁹.

6. Limitations of existing tools for collecting Aboriginal patient’s satisfaction and experience

There is limited evidence of Aboriginal patient’s experience in the WA health system both in general and specifically relating to their cultural and race. The gap in the evidence can be attributed to a number of factors including:

- limitations in the methods of current tools to adequately reach and capture feedback from Aboriginal patients
- generic design of survey tools
- type of information that is captured
- monitoring and reporting of information once obtained.

6.1 Method

One of the biggest challenges in collecting patient experience data from Aboriginal patients is contacting the patient. The two main survey tools utilised in WA are via phone or mail

¹⁹ Australian Bureau of Statistics 2016, *National Aboriginal and Torres Strait Islander Social Survey 2014-15*, Australian Bureau of Statistics, Canberra.

which require an active phone number or a current mailing address, and this can pose challenges in contacting some Aboriginal patients.

Approximately 62 per cent of the WA Aboriginal population live in regional or remote areas where phone and internet connection can be poor and where the delivery of mail can be disrupted by distance and adverse weather such as flooding¹⁵. Many regional and remote communities also do not have individual dwelling addresses but instead have a community mailbag which can make it difficult for paper based surveys to reach an individual.

Aboriginal people are also more likely to experience financial difficulties which can result in frequent changes in address, transient accommodation or homelessness, and/or the disconnection of a phone number.

These issues are reflected in the response rates attained in the PEHS 2016-17, with 56.5 per cent of the original sample of Aboriginal patients unreachable due to a disconnected number, compared to only 19 per cent of the non-Aboriginal patient sample group¹⁴. Once Aboriginal patients were contacted to complete the PEHS their response rate was similar to that of non-Aboriginal patients, demonstrating that there is no reluctance or unwillingness to respond. Although response rates by Aboriginal status are not available for Press Ganey surveys, it is likely that similar issues would affect the response rate of Aboriginal patients for paper-based surveys.

6.2 Design

The length and language used in the paper based Press Ganey tool could deter completion by Aboriginal patients who have trouble reading or writing in English either because English is not their first language and/or because of low literacy levels²⁰.

Keeping questionnaires short, using simple plain language and using diagrams where possible can increase the completion rate for people who have difficulties reading or writing in English²⁰. The use of culturally specific language and design in written materials, such as images of Aboriginal people and Aboriginal graphics, can also be a useful tool to increase the participation rate of Aboriginal people.

6.3 Information captured

All patient experience tools used in the WA health system are the same for Aboriginal and non-Aboriginal patients. Only PEHS includes a culturally specific question; *“Were you asked if you had any cultural or religious beliefs that might affect the way you were treated while at the hospital?”* There are no questions relating to cultural safety or experiences of racial discrimination across any of the tools.

Additionally no consultation has been conducted to see if current questions appropriately capture what is important to Aboriginal people.

6.4 Monitoring and reporting

The findings outlined in section 5. Aboriginal patient experiences compared to non-Aboriginal patient, demonstrate that Aboriginal patient experience is different to non-

²⁰ Survey Vitals 2015, *Patient Satisfaction Survey Best Practice – Increasing response Rates*, view April 2018, <https://www.surveyvitals.com/start/best-practice-increasing-response-rates>

Aboriginal patient experience. Currently it is only possible for PEHS to report Aboriginal patient experience for WACHS as budget constraints limit the sample size and consequently the metropolitan HSPs capture insufficient sample size of Aboriginal patients to produce valid and reliable results.

A 'watcher' of PO can flag a story as being from an Aboriginal person if the content of the story makes it obvious, i.e. the author states that they are Aboriginal, but this information is not used in any form of monitoring or reporting.

Without monitoring the experiences of Aboriginal patients, services are unable to identify any disparities in their experience or initiate any required quality improvements in services for Aboriginal patients².

6.5 Cost

There are significant costs and resources associated with each patient experience tool used by the WA health system. Purchasing power is further reduced through the procurement of different tools across the system and/or the same tool by different HSPs. Efficiencies could be gained by consolidating resources and procuring one tool (preferably) for use across the system.

7. Measuring racial discrimination and racial bias in the health sector

There is strong evidence that experiencing racism is detrimental to a person's health both physically and mentally. There is also evidence that experiencing racism within a health setting can contribute further to poorer health outcomes through reduced participation in screening and early intervention programs, lower rates of follow-up appointments and treatments, and less likelihood to adhere to care instructions²¹. In the WA health system there is limited data recording the prevalence and effect of racism within the health setting.

Aside from acts of overt and deliberate racism, racial bias is also a significant factor that affects the treatment of Aboriginal people in the health setting. Racial bias is often an implicit bias in which a health professional's attitudes, feelings or stereotyping based on characteristics such as race, age and appearance, affect their understanding, decisions, actions and behaviours towards other people in an unconscious manner²². These associations develop over a long time beginning at a very early age through exposure to direct and indirect messages. In addition to life experiences, the media are often the origins of implicit associations²².

In regards to measuring experiences of racism in the health setting a recent study illustrated that there are some parallels with other measures such as, a patient's feeling of emotional wellbeing and safety, feeling that they were listened to by health professionals, and feeling

²¹ Williams D R, PhD, MPH, Wyatt R, MD, MHA 2015, 'Racial Bias in Health Care and Health Challenges and Opportunities', *Journal of American Medical Association*, vol. 314, no.6, pp. 555-556.

²² Green A, Carney D, Pallin D, Ngo L, Raymond K, Lezzon L, Banaji M 2007, 'Implicit Bias among Physicians and its Prediction of Thrombolysis Decisions for Black and White Patients', *Journal of General Internal Medicine*, vol. 22, no. 9, pp. 1231- 1238, viewed April 2018, <https://link.springer.com/article/10.1007%2Fs11606-007-0258-5?LI=true>

that their opinions were respected by health professionals. Significant disparities in overall patient experience for Aboriginal and non-Aboriginal patients may also be indicative of racial bias. However, at present the WA health system has no explicit measures in place to record experiences of racism within the health setting.

7.1 Discrimination in Medical Setting Scale

In 2011 the United States National Institutes of Health conducted a study in which the Williams' Everyday Discrimination Scale (EDS) was adapted to the medical setting. The EDS is one of the most widely utilised and internationally recognised measures of racial discrimination and the study found that it could successfully be modified to the medical setting. The Discrimination in Medical Setting (DMS) Scale was tested and found to have excellent internal consistency, test reliability and discriminant validity amongst African American patients²³.

Results from interviews indicated that patients did not interpret, "people think you are being dishonest" consistently, and felt that the items, "being called names/insulted," and "being threatened/harassed" were extreme and unlikely to occur in a health care setting and so these three items were removed²³. The resulting DMS Scale consisted of seven questions:

1. You are treated with less courtesy than other people.
2. You are treated with less respect than other people.
3. You receive poorer service than others.
4. A doctor or nurse acts as if he or she thinks you are not smart.
5. A doctor or nurse acts as if he or she is afraid of you.
6. A doctor or nurse acts as if he or she is better than you.
7. You feel like a doctor or nurse is not listening to what you were saying.

Responses were assessed with a 5-point Likert scale (1-never, 2-rarely, 3-sometimes, 4-most of the time, 5-always)²³.

7.2 Self-reported racism in the healthcare setting

A study in New Zealand also looked at experiences of racial discrimination in the healthcare setting, and other settings, after previous studies showed that measures of negative patient experience were significantly more frequent for Maori and Pacific patients²⁴.

Questions that were used to assess an individuals' personal experience of racial discrimination covered 5 items: experience of an ethnically motivated (1) physical or (2) verbal attack, and unfair treatment because of ethnicity (3), by a health professional, (4) at work, or (5) when gaining housing²⁴.

Racial discrimination by a health professional was associated with lower odds of breast and cervical cancer screening among Maori women. Patients who reported experience of racial

²³ Peek M E, MD, MPH, Nunez-Smith M, MD, MPH, Drum M, PhD, Lewis T T, PhD 2011, 'Adapting the Everyday Discrimination Scale to Medical Settings: Reliability and Validity Testing in a Sample of African American Patients', *Ethnicity and Disease Journal*, vol. 21, no. 4, pp. 502-509.

²⁴ Harris R, MB ChB, Tobias M, MB BCh, Jeffreys M, PhD, Waldegrave K, PGDipPsych, Karlsen S, PhD, Nazroo J, PhD 2006, 'Effects of self-reported racial discrimination and deprivation on Māori health and inequalities in New Zealand: cross-sectional study', *Lancet*, vol. 367, pp. 2005-2009.

discrimination by a health care professional were significantly more likely to report that they were not always listened to carefully, that they did not always have information fully discussed with them, and that they were not always treated with dignity and respect²⁵.

8. Recommended actions to improve Aboriginal patient experience data collection in the WA health system

It is well established that capturing patient experience information can significantly contribute to improving service delivery, reducing costs and achieving better health outcomes for patients. It is also acknowledged that there is a substantial gap in patient experience information for Aboriginal patients, a priority population group, who experience significant disparities in health outcome compared to other population groups.

Improving the quantity and quality of Aboriginal patient experience information will contribute to improving health outcomes for Aboriginal people, reducing costs to the health system, and is a good measure of the cultural competency of a health service.

Aboriginal patient experience information, in particular experiences of racism in health services, is an emerging priority at both the state and national level. It is the topic of the pending 2018 WA State Clinical Senate, and has been flagged as an area for development in the most recent Indigenous Health Data Strategy.

8.1 Improve existing survey tools

The following recommended actions are specifically in relation to the PEHS program. This is because PEHS is the only existing survey tool that has the capacity to identify Aboriginal patients. In addition, PEHS is managed and administrated by DOH, the System Manager, and is therefore consistent across the WA health system. Furthermore, many HSP Press Ganey contracts are coming to an end and it is uncertain if any will be renewed.

8.1.1 Targeted approach to increase data from Aboriginal patients

A targeted approach to improve response rates and/or increase the number of Aboriginal patients would help to compensate for the significantly lower raw response rate of Aboriginal patients currently observed in PEHS. Suggested targeted approaches include:

- Prioritise Aboriginal patients for earlier contact

Contacting Aboriginal patients as soon as possible after discharge may increase the number of patients that are contactable as it is less likely that their phone number or residential address will have changed.

The possibility of getting patient feedback *before* the patient leaves the hospital, as has been proposed by the CaLD pilot survey, poses some ethical concerns as the patient may not feel comfortable, or be completely honest about their experience if they are still under the care of the hospital.

²⁵ Harris R, MB ChB, Cormack D, PhD, Tobias M, MB BCh, Yeh L, MA, MSc, Talamaivao N, MSocSci, Minster J, BSc, BA, Timutimu R, BSc. 2012, 'Self-Reported Experience of Racial Discrimination and Health Care Use in New Zealand: Results from the 2006/07 New Zealand Health Survey', *American Journal of Public Health*, vol. 102, no. 5, pp. 1012- 1019.

- Increase the number of Aboriginal patients included in sample group

Patients are randomly selected for PEHS, therefore increasing the number of Aboriginal patients that are included in the sample group, while not necessarily improving the response rate should increase the overall number of responses from Aboriginal patients. It is noted that this strategy is likely to incur a cost given the current budget allocated for PEHS.

8.1.2 Improve collection of Aboriginal status

Capturing a patient's Aboriginal status allows results to be compared with the wider community so that any disparities between population groups can be identified. Currently the PEHS program uses the demographic variables in the patient administration systems to identify patients as Aboriginal. However, there are concerns that administrative systems may underestimate the number of Aboriginal patients and a recent study in NSW illustrated that self-report Aboriginal status in patient experience surveys was a slightly more reliable measure²⁶.

Including a self-report question on Aboriginal status in the PEHS survey would allow self-reported identification status to be compared with what is captured via patient administrations systems, with the aim of potentially improving the Aboriginal status variable. Benefits of improved identification include:

- more accurate Activity Based Funding reporting
- accurate monitoring of disparities in health care and outcomes
- ensure that patients have access to Aboriginal service and receive culturally appropriate care
- accurately informing policy, service planning and delivery⁹.

8.1.3 Include measurements of racism

As discussed in section [7. Measuring racial discrimination and racial bias in the health sector](#), experiencing racism within the health setting can significantly impact on a person's health outcomes²³. In order for health services to reduce racism and better serve Aboriginal consumers, they must first be able to identify the extent of racism in services. Through the modification of some existing questions and/or the inclusion of small number of additional questions, experiences of racism within health services can be better measured.

Below are some suggestions for capturing experiences of racism however any inclusions or changes addressing racism should be done in consultation and with advice from Aboriginal consumers.

Option 1

Inclusion of one or two additional questions regarding how the patient believes they were treated and the patient's interpreted explanation for the treatment.

Example 1:

- Question: Were you treated with respect and dignity?

²⁶ Bureau of Health Information 2016, *Patient Perspectives – Hospital care for Aboriginal people*, Bureau of Health Information, Sydney.

Response options: 'All of the time', 'most of the time', 'some of the time', and 'none of the time'.

Follow-up Question (Asked only of those who did not answer 'all of the time'): What do you think is the main reason for these experiences?

1. Your Ancestry or National Origins Your Gender
2. Your Race
3. Your Age
4. Your Religion
5. Your Height
6. Your Weight
7. Some other Aspect of Your Physical Appearance
8. Your Sexual Orientation
9. Your Education or Income Level²³.

Example 2:

- Question: Have you experienced, by a health professional, racially motivated (1) physical attack, (2) verbal attack, and/or (3) unfair treatment?

Response options: 'Yes' or 'No'²⁵.

Option 2

Inclusion of the DMS Scale questions as outlined in section 7. Measuring racial discrimination and racial bias in the health sector.

8.1.4 Reporting and monitoring of Aboriginal patient experience

As outlined previously, only WACHS receive sufficient sample size of Aboriginal patients through the PEHS to produce valid and reliable results. However, an annual system-wide Aboriginal comparison report for WA, as was produced on request for this paper, would provide some insight to other HSPs and DOH of the outcomes of patient experience for Aboriginal patients specifically, as well as how this compares with non-Aboriginal patients.

In the future, if other recommendations for improvement have been successful at increasing the amount of Aboriginal patient experience data captured (see section 8.1.1 Targeted approach to increase data from Aboriginal patients), it would be valuable to include an Aboriginal specific measure for the HSPR Patient satisfaction PIs, E2-1a Adult inpatients and E2-1b Adult outpatients, as well as individual HSP reports.

8.1.5 Culturally appropriate promotion

Increasing public awareness of patient experience surveys and the importance of them to improve services provides motivation for patients to complete surveys and increases response rates²⁰. Promoting survey tools also gives patients advance notice that they could be contacted. If it is expected and the purpose is clearly understood, it is more likely that a patient will answer a call from the hospital or respond to a letter²⁰. Promotion can include posters within hospitals, information packs/pamphlets, and even a text message prior to contacting a patient to identify who will be calling and for what purposes.

Although HSPs already promote patient experience survey tools, the use of Aboriginal design, imagery and language on promotional materials could attract the attention of Aboriginal patients, convey targeting messages, and encourage participation if contacted.

8.2 Developing new survey tools

8.2.1 AHPEQS pilot program

Patient Safety and Clinical Quality have approached Epidemiology and AHPD to collaborate on a proposed pilot of the AHPEQS in the WA health system in 2018/19. The pilot will provide AHPD with an opportunity to evaluate the cultural appropriateness of the AHPEQS, as well as testing and assessing targeted approaches to increasing the number of Aboriginal responses to patient experience surveys (identified in section [8.1.1 Targeted approach to increase data from Aboriginal patients](#)).

8.2.2 Consultation with Aboriginal consumers

When developing any new tools to improve consumer engagement from Aboriginal patients, there needs to be consultation with Aboriginal consumers, healthcare workers and community groups⁷. Consultation ensures that information on what is most important to Aboriginal patients, which might be different to those of non-Aboriginal people, is adequately and appropriately captured in survey tools. Aboriginal people may also have different preferences, or face different life situations, that influence what the most suitable and effective method of providing feedback is for them.

8.2.3 Consolidation of resources

There is some overlap in the questions from the two main patient experience tools currently used in the WA health system, the PEHS and Press Ganey, however the results are not amalgamated nor are they directly comparable to each other. A pilot of the Commission's AHPEQS is also planned. Consolidating resources towards a single consistent patient experience tool for the whole of the WA health system could significantly increase the quantity of responses received and provide a single source of feedback that is comparable across services and time.

A more in-depth review of the information captured in each of the current and proposed tools could help identify areas of overlap and assess the feasibility of whether different survey tools could be combined into a single survey while still meeting the needs of hospitals and other stakeholders.

8.2.4 Utilising technology

As digital technologies continue to evolve and improve it provides opportunities for new and more efficient methods of capturing patient experience information. Modern technology that could be utilised and warrant further investigation than was possible for this paper. These include but are not limited to:

- The use of tablets and other devices within the hospital setting

Capturing a patient's experience while still in the hospital setting would resolve the issue of not being able to contact patients after discharge. However, consideration needs to be given to the ethical implications of patients feeling comfortable providing honest feedback while still under the care of the health service. In addition, questions on the discharge process and short-term health outcomes resulting from contact with the health service could not be measured. Results from

the pilot CaLD patient experience project conducted in SCGH and OPH may provide further information on the viability of this approach.

- Use of new or existing application software

There may be opportunity to include patient experience survey tools within the newly developed Aboriginal specific health application MAPPA (yet to be released) which aims to link Aboriginal health services and providers across the state in a singular easy to use application. Alternatively the development of a similar application to collect Aboriginal patient experiences data could be explored noting that the reliability and representativeness of the data would not be as high as more rigorous survey methodologies.

- Use of emails, text messages and online patient experience survey tools

A text message or email providing patients with a link to an online patient experience survey would be a cost effective method of contacting patients and collecting data, allowing for an increase in the number of patients being included in the sample group.

The use of emails has previously been avoided due to emails going to the person's junk mail folder and ignored. There are now steps that can be taken to help improve the chances of an email passing SPAM filters and not going to junk mail folder.

The difficulty of utilising emails is that it would require a change to hospital patient administration systems, and information collection procedures, to ensure that email addresses are captured and recorded. In addition, while an increasing number of patients are providing mobile phone numbers as their primary contact number, not all patients have access to a mobile.

Where possible however, using text messages instead of an approach letter to inform patients that they should expect a phone call, and/or to arrange a convenient time for a phone call, might improve the number of patients that answer the phone when contacted to complete the PEHS.

While online survey tools provide a cost-effective approach for data collection, they typically return much lower response rates which can affect the reliability and representativeness of the information collected. In addition the information is collected in a less timely manner than telephone interviews, which can subsequently impact on monitoring and reporting. Another challenge is the availability of internet infrastructure, which can be a particular issue in rural and remote areas of WA.

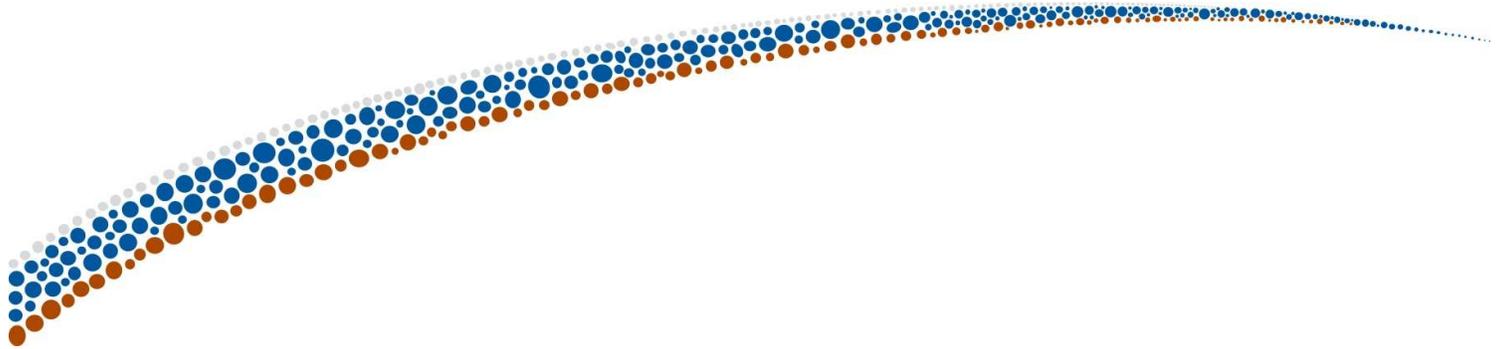
Technology can also be used to address problems that patients routinely highlight as having an impact on their experience, such as waiting times. For example, at the Children's Hospital in Melbourne, scheduling and queue management systems allow for patients to self-check in via an app when within a one kilometre radius. They are also sent a text message 10 minutes prior to their appointment allowing patients to wait in areas of the hospital which suit them, rather than spending extensive time in the waiting room²⁷.

²⁷ Hawkins K, Rawstron E 2018, *Patient experience: How do we get to extraordinary?*, KPMG, viewed April 2018, <https://home.kpmg.com/au/en/home/insights/2018/02/healthcare-patient-experience-how-do-we-get-to-extraordinary.html?>

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