

BETTER CARE, BETTER OUTCOMES

CONSUMER EXPERIENCES OF PERSON-CENTRED CARE IN NSW HOSPITALS



A report by:
Health Consumers NSW & the
Physical Disability Council of NSW
September 2022

HEALTH
CONSUMERS
NSW

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physical disability
council of nsw



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Health Consumers NSW

Suite F/LG Floor, 280 Pitt Street
Gadigal Land
Sydney, NSW 2000, Australia
Phone: +61 2 9986 1082
Web: www.hcnsw.org.au

Health Consumers NSW is supported by NSW Health

Physical Disability Council of NSW

St Helen's Community Centre
Gadigal Land
3/184 Glebe Point Road
Glebe NSW 2037, Australia
Phone: +61 2 9552 1606
Web: www.pdcnsw.org.au

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TABLE OF CONTENTS

- 04** Who We Are
- 06** Executive Summary
- 09** What is Person-Centred Care?
- 10** How patient-centred care supports value-based healthcare
- 11** Recommendations
- 12** Project Background
- 12** What we did
- 22** Where to from here?
- 23** References

ANNEXURES

- 24** Annexure A – Text responses to barriers to communication
- 26** Annexure B – Survey questions
- 28** Annexure C – Example of newsletter sent to HCNSW and PDCN members

WHO WE ARE

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live-in metropolitan, rural and regional areas of NSW.

Our core function is to influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- ✓ To educate, inform and assist people with physical disabilities in NSW about the range of services, structure, and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- ✓ To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e., self-advocate).
- ✓ To educate and inform stakeholders (i.e., about the needs of people with a physical disability) so that they can achieve and maintain full participation, equality of opportunity and equality of citizenship.


Health Consumers NSW (HCNSW) represents the interests of people who use health services (patients, carers, and their families) in NSW. We are a membership-based, independent, registered charity, that promotes the active involvement of health consumers in the design and governance of health services in NSW. We do this through creating meaningful partnerships between consumers, the health sector, policy-makers, and researchers.

HCNSW believes that all perspectives are important and necessary to create better health outcomes for people and that consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff.

We work to ensure that health consumers are involved in the design and delivery of health care in NSW.

HCNSW's mission: Consumers shaping health in NSW.

- ✓ We promote the best quality, appropriate health outcomes for consumers of health care services.
- ✓ We believe that all perspectives are important and necessary to create better health outcomes for people.
- ✓ Consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff.
- ✓ We work to ensure that health consumers are involved in the design and delivery of health care in NSW.



PATIENT CENTRED CARE IS HEALTHCARE THAT IS
RESPECTFUL OF, AND RESPONSIVE TO, THE
PREFERENCES, NEEDS AND VALUES OF PATIENTS
AND CONSUMERS.

THE WIDELY ACCEPTED DIMENSIONS OF PATIENT-
CENTRED CARE ARE RESPECT, EMOTIONAL SUPPORT,
PHYSICAL COMFORT, INFORMATION AND
COMMUNICATION, CONTINUITY AND TRANSITION,
CARE COORDINATION, INVOLVEMENT OF FAMILIES
AND CARERS AND ACCESS TO CARE.

Australian Commission on Safety and Quality in Health
Care, *Patient-Centred Care: Improving quality and safety
through partnerships with patients and consumers*¹



EXECUTIVE SUMMARY

Person (or patient) centred care (PCC) is a holistic approach to health care, which acknowledges the patient as an individual, and is responsive to their preferences, needs and values.

Person-centred care involves the collaboration of health care, providers, patients, and carers across all health-related decision making. Core to this is a respect for the choices of the patient, which may be influenced by a variety of factors outside traditional medical decision making, including psychological, social, and cultural factors.²

Person centred care is a key component of the Australian National Safety and Quality Health Service Standards³ and has been incorporated as a primary approach in the delivery of hospital health care services across NSW since the early 2000's. As consumer advocacy organisations, we are strong proponents for person-centred care as mechanism to ensure that patients receive health care that is both respectful and responsive to their unique care needs.

In August 2021, we ran a one-month online consumer survey to try to understand people's experience of communication difficulties in hospitals. We asked if patients felt that there were appropriate levels of communication between patients and health care staff what consumers thought the barriers were to good communication, and what was needed to improve communication. We received 182 survey responses from a diverse cohort of individuals including people with physical disability, people living with chronic disease, especially for Aboriginal and Torres Strait Islander people, and people from culturally and linguistically diverse (CALD) backgrounds, carers, and older persons.

The results are concerning.

Just under half of the participants (49%) routinely understood their diagnosis, the treatments available, and what these treatments might involve for them...

Just under half of the participants (49%) routinely understood their diagnosis, the treatments available, and what these treatments might involve for them, 36% of participants stated that they always had to repeat specific care requirements to hospital staff, for example, disability accessibility requirements, and an alarming 5.7% of participants reported never being asked to provide permission before things were either done directly to them, for example wound dressing changes, or directly in relation to them, e.g. moving assistive aids. The more complex a patient's care needs were, the higher the probability that they would not receive care aligning with person-centred care principles.

Overall, this project identified deficiencies across 4 dimensions of person-centred care:



Information sharing



Dignity & respect



Participation



Care provision

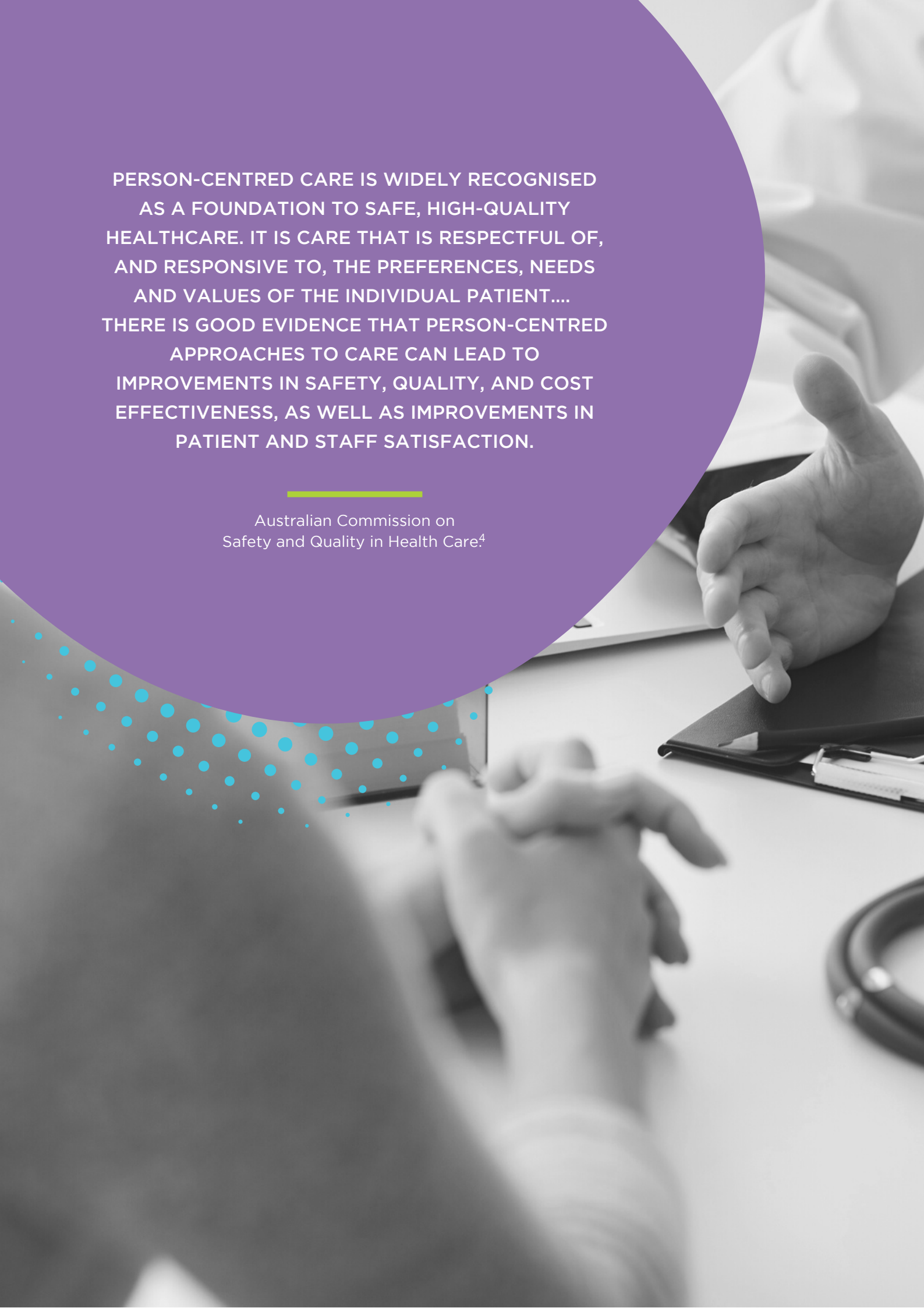
So, where do we go from here?

Our survey provides a snapshot of what, we believe, is a much larger issue in realising best practice person-centred care in hospitals. It indicates that more can be done to realise person-centred care, especially for patients with complex health care needs. It also confirms anecdotal reports about care that both PDCN and HCNSW have heard from our members.

We recognise that we are producing this report in extraordinary times. At the time that this project was conducted, the entirety of the NSW health system was grappling with the Covid19 pandemic – and still is. We cannot underestimate the potential impact that this may have had on the capacity for hospital staff to follow person-centred care processes and procedures, but at the same time, we need to acknowledge that Covid19 will be with us for some time yet and at some point, we will all need to adjust to 'Covid normal'.

Further research is required to gain a more comprehensive understanding of the challenges that can exist within hospital environments, particularly from the perspective of health care workers. A better understanding of health consumers' *positive* experiences of communicating their needs is also needed. In the meantime, we have made several recommendations on ways to enhance the health-care experiences of patients from a consumer perspective.

PDCN and HCNSW welcome the opportunity to work with hospitals, LHDs and the NSW Ministry of Health to both continue research across this important area, and to assist in co-designing solutions.



PERSON-CENTRED CARE IS WIDELY RECOGNISED
AS A FOUNDATION TO SAFE, HIGH-QUALITY
HEALTHCARE. IT IS CARE THAT IS RESPECTFUL OF,
AND RESPONSIVE TO, THE PREFERENCES, NEEDS
AND VALUES OF THE INDIVIDUAL PATIENT....
THERE IS GOOD EVIDENCE THAT PERSON-CENTRED
APPROACHES TO CARE CAN LEAD TO
IMPROVEMENTS IN SAFETY, QUALITY, AND COST
EFFECTIVENESS, AS WELL AS IMPROVEMENTS IN
PATIENT AND STAFF SATISFACTION.

Australian Commission on
Safety and Quality in Health Care.⁴

WHAT IS PERSON-CENTRED CARE?

Both in Australia and overseas, person-centred care is acknowledged as a key pillar for achieving high quality healthcare.⁵ The NSW Clinical Excellence Commission, for example, refers to person centred care as *'the foundation of a high reliability healthcare system'*.⁶

Person-centred care (PCC) involves the practice of caring for patients in a manner that is responsive to their preferences, needs and values.⁷ It acknowledges that there are many elements which shape an individual's views and decision-making across their health care journey, including psychological, social, and cultural factors.⁸

Person-centred care also acknowledges that every patient and their family is unique and what may work for one family, may not work for another.⁹ It is about recognising that each patient and their family should be provided care that is specific to their need as individuals across all aspects of their clinical care, and that healthcare professionals have a responsibility to understand and respond to these needs.¹⁰

Key concepts to PCC include:



Dignity & respect

Patients, their families, and other support persons are listened to, and their choices and perspectives are respected. The patient's beliefs and cultural background are respected and incorporated into the patient's care plan. Patients and their families are recognised as experts in the patient's health, care, and treatment.



Information sharing

Patients, their families, and other support persons are provided with accurate, objective, and timely information in a way that enables them to participate in decision making and make informed decisions.



Participation

Health care staff facilitate patients and their families being involved in care and decision-making to the level that they choose.



Collaboration

Patients, their families, and healthcare professionals work together across the design, delivery, and evaluation of all aspects of patient care – from policy and program development to facility design.¹¹

Person-centred health care has been acknowledged as being highly beneficial both to patients and the broader community. PPC has also been linked to significantly improved clinical outcomes. PPC was formally incorporated into the Australian health care system in 2008, as a component of the Australian Charter of Healthcare Rights.

It is recognised as Standard 2 of the National Safety and Quality Health Service Standards (second edition) – *Partnering with Consumers*,¹² and person-centred care provisions are embedded in both the Nursing and Midwifery Board of Australia's Professional Practice Framework¹³ and the Medical Board of Australia's Code of Conduct for Doctors in Australia.¹⁴

HOW PATIENT-CENTRED CARE SUPPORTS VALUE-BASED HEALTHCARE

Values-based healthcare is about getting the best outcomes for patients at the best value to the health care system.¹⁵ Person-centred care is an essential tool towards realising value-based healthcare since it is both highly effective in achieving positive patient outcomes and reducing overall time and cost expenditures.

A non-exhaustive list of the benefits of PPC¹⁶ in line with the quadruple aims of value-based healthcare - *health outcomes that matter to patients, experiences of receiving care, experiences of providing care and effectiveness and efficiency of care* - are provided below:

Value-based Care priorities	Benefits of PPC
Health Care Outcomes that matter to patients	<ul style="list-style-type: none"> • Empowers patients and their families • Supports family care giving and decision-making • Improved community perceptions of healthcare and health care institutions • Builds on individual and family strength
Experiences of receiving care	<ul style="list-style-type: none"> • Fosters patient independence • Improves patient enablement • Reduces the risk of experiencing an adverse health event • Respects patient's values, beliefs, and cultural backgrounds • Improves trust between patient and care provider
Experiences of providing care	<ul style="list-style-type: none"> • Increased staff morale • Greater job satisfaction • Enhanced professional relationships with patients and their families
Effectiveness and efficiency of care	<ul style="list-style-type: none"> • Reduced mortality rates • Decreased hospital stays • Reduced rates of readmission • Greater treatment regime compliance • Improved delivery of preventative care services • Decreased risk of healthcare acquired infections

RECOMMENDATIONS

1

Existing structures and mechanisms for co-design with health consumers and hospital staff to facilitate best practice person centred care need to be strengthened.

2

Hospital staff should be trained (or potentially re-trained) on how to apply the fundamentals of person-centred care across all care practices. Training should be provided to hospital staff who are not traditionally acknowledged as being involved in the care of patients, e.g., cleaners, staff providing meals.

3

Patients should be made aware of the principles of person-centred care and what to expect in terms of standard of care within a hospital context. A culture of seeking constructive feedback should be encouraged amongst staff and multiple avenues provided for patients to give feedback across their healthcare journey. This should include the capacity to provide anonymous feedback and use of independent feedback processes such as Patient Opinion.

4

Staff to patient ratios must be increased. Staff workloads should be adjusted to include time to understand their patients' preferences, needs and values and to involve patients and carers in decision-making.

5

Mechanisms need to be developed to ensure that care information is not lost during transition points including shift changes, transfers between care settings (such as from residential services to hospitals, between hospitals), and discharge.

6

Hospitals need timely access to resources which facilitate communication with patients, e.g., access to translators and assistive technology.

7

Hospitals should employ targeted staff recruitment strategies to enhance generalised staff knowledge across a variety of values, languages, and cultures.

8

Hospitals need to create an embedded role for carers, both in the provision of patient health information and as a resource in providing specialised care for complex needs patients.

9

Further research should be done to understand the challenges hospital staff experience in providing patient-centred care, with a view to addressing these challenges.

PROJECT BACKGROUND

20% of patients reported that they had received contradictory information about their condition or treatment from health professionals.

Both HCNSW and PDCN, as state advocacy peak bodies, regularly consult across our memberships on a range of issues, including health.

Substantive anecdotal information from both our memberships on this issue, prompted us to investigate both the prevalence of communication difficulties between patients and healthcare providers within NSW hospitals and to explore any processes or practices patients saw as barriers to effective communication.

WHAT WE DID

PDCN and HCNSW recognise that patient experience data shows that most people have a positive experience of hospitals in NSW. Adult admitted patient survey data from 2020 shows that 95% of patients rated the care they received in hospital as 'very good' or 'good' (71% and 24% respectively). 82% of people felt that things were always explained to them in a way they understood. Only 55% were always involved as much as they wanted to be in making decisions about their care while in hospital. 13% of people said they did not receive enough information about their condition or treatment and, worryingly, 20% of patients reported that they had received contradictory information about their condition or treatment from health professionals.

The data from the Adult Admitted Patient Survey suggested that there is a significant minority of people who felt excluded from decision making around their own care, and who did not receive enough information about their care and management when they left hospitals. We wanted to have a better understanding of these people's experiences.

PDCN and HCNSW conducted an online survey across August-September 2021. The survey was promoted broadly across both organisations' membership and their online member engagement platform. The survey was also promoted across the ageing and disability sectors via emails, newsletters, and social media. The invitation to participate in the survey is included in Annexure C.

Participants were invited to share their experience of poor communication in hospital. We deliberately asked for people to share their poor experiences so we could document difficulties health consumers are currently experiencing, find out if there are groups of consumers who report more difficulties than others, identify the areas health consumers felt were the "pain points" in the system, and also to find out from consumers *themselves* to identify possible solutions to the difficulties they experienced. The survey used a person-centred approach consisting of 14 questions. Participants also had the opportunity to describe specific care experiences, positive or negative, via a free-form text box and could nominate themselves to be contacted for a follow up interview.

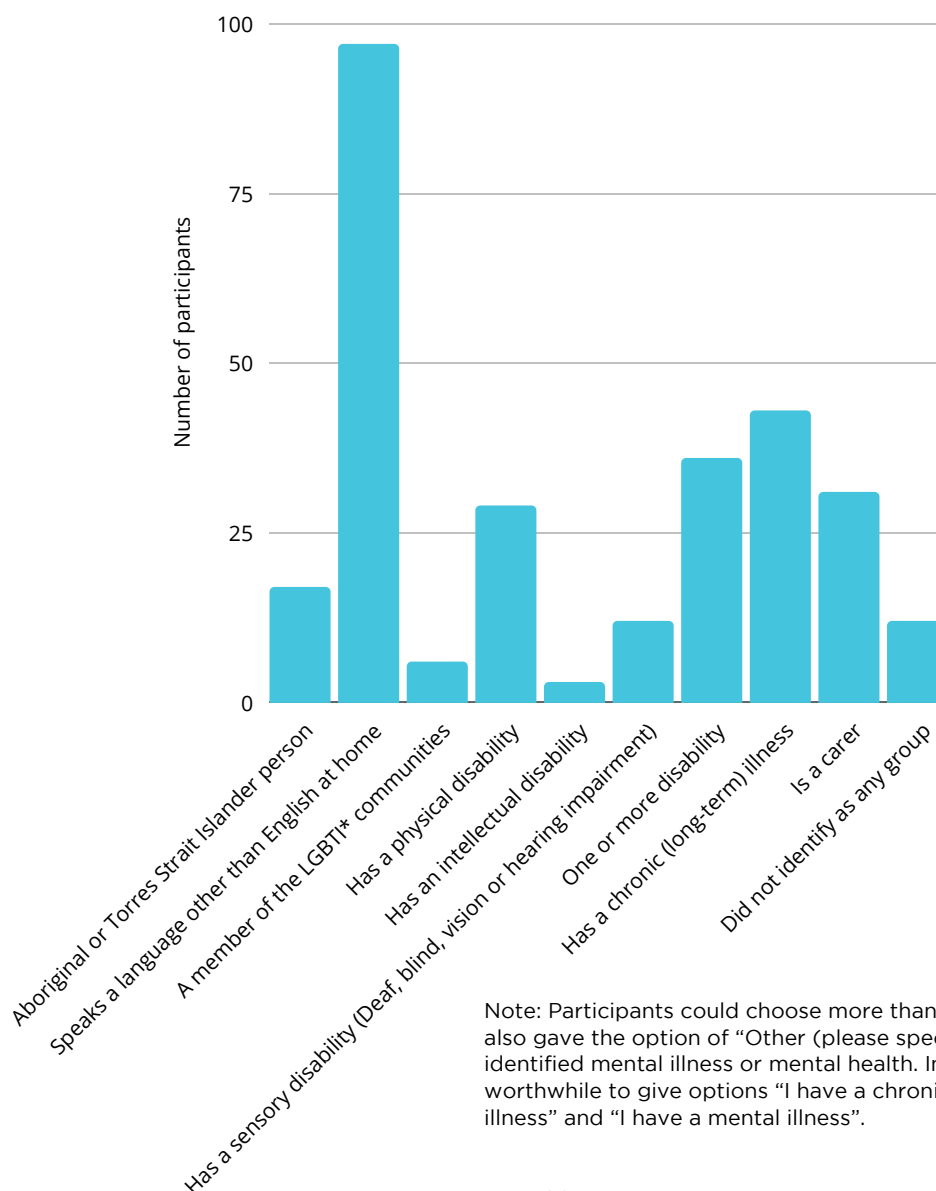
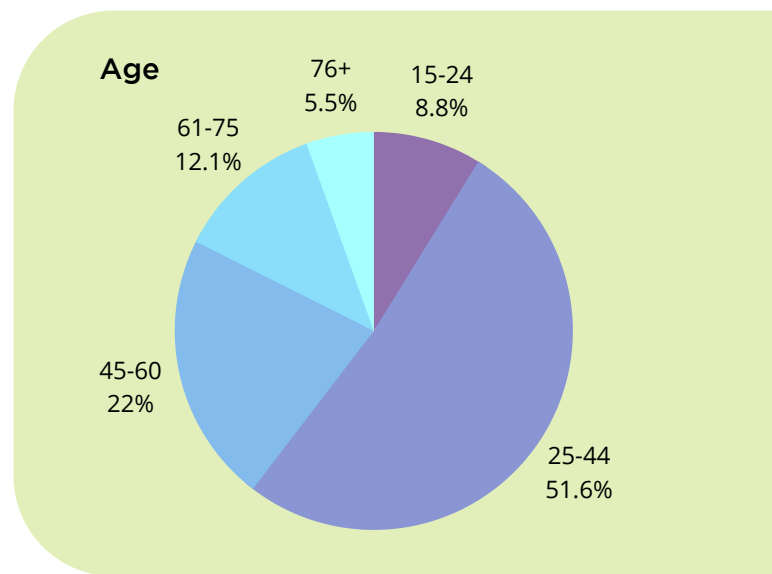
We received 182 valid survey responses, including 81 care experiences described by participants.¹⁷ 17% of the responses were from carers, who were completing the survey on behalf of someone they cared for.

DEMOGRAPHICS

More than half of the survey participants were between the ages of 25-44.

Half of participants (50%) were from a capital city, with the next highest cohort being from a large regional city or town (36%). 14% of participants came from non-urban areas, i.e., rural, or remote areas.

We had a strong representation across minority cohorts. A massive 53% of participants identified as CALD. This is significantly higher than the proportion of CALD identifying people as a subset of the population of NSW (26.5%).¹⁸



ATSI participants were also well above the population average at 9.3% of all survey participants (2016 census statistics indicate 2.9% of the NSW population as ATSI identifying). Participants identifying as LGBTI+ came in at 3%.

Collectively just under a quarter of participants identified as having a disability (physical, intellectual, or sensory). Chronic illness, as distinct from disability, made up close to another quarter of respondents (23%). As expected, several participants self-identified as having one or more disabilities (20%).

The options used to capture the demographics of participants did not expressly allow for mental illness or mental health. Four respondents identified as having mental illness or mental health in the option of 'Other' (please specify).

We were keen to know if a frequency of hospital visits had an impact across care, and asked participants how many times they had attended hospital in the last 12 months.

Most participants (57%) attended hospital once or less over the past 12 months, while close to a quarter of participants reported attending hospital between 2-5 times.

13% of participants attended hospital between 6-10 times in the past year and 4.5% attended hospital 11 times or more.

PATIENT CARE EXPERIENCES

Many participants would not be aware of the concept of PPC. To address this, we asked participants to provide information on their usual experiences across various scenarios that we would expect that a participant might experience while a hospital patient.

These scenarios included receiving a diagnosis, being told what needed to be done to treat them, and why, providing information to health care staff on specific care needs and receiving medical care/treatment.

These scenarios provided insight across several core principles of PPC:

- a) Being informed (aligns with **information and communication**)
- b) Being listened to (aligns with **information and communication/respect**)
- c) Respect for bodily autonomy (aligns with **information and communication/respect**)
- d) Receiving appropriate care (aligns with **emotional support/respect/physical comfort/access to care and involvement of families and carers**)

Participants were asked to reflect on their **usual experience** as a hospital patient.



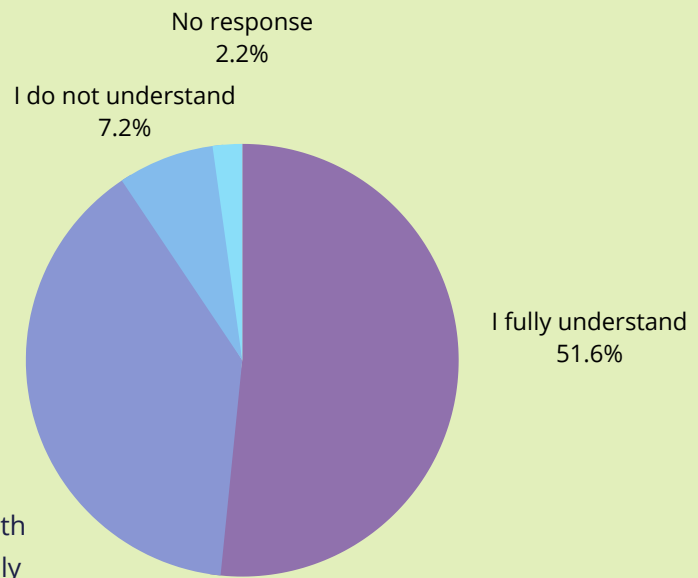
BEING INFORMED

These questions focused on:

- Being given a diagnosis (or a suspected diagnosis)
- Being told why certain care/treatment activities are necessary and what this care or treatment would involve

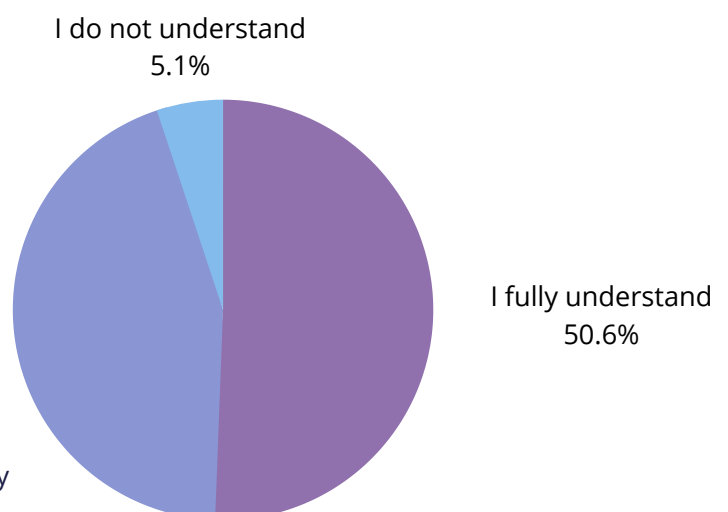
Understanding diagnoses or suspected diagnoses*

*This is based on valid data received.



Close to half of all participants (46%) reported that they usually either had no idea what health care staff thought was wrong with them or only partially understood this information.

Understanding reasons given for treatment and treatment processes



50.6% percent of participants advised that they understood when health care practitioners explained what treatments were necessary and these treatments would involve. 44.3% of participants partially understood this information and 5.1% of participants routinely did not understand this information at all.

BEING LISTENED TO

We also wanted to know whether participants felt that they were routinely listened to by health care staff. Listening to the thoughts and views of patients, and accepting patients and carers as experts in care, are fundamental to realising PCC.

We asked if participants had to repeat care information and whether they had experience of receiving inappropriate care due to not being listened to.

36% of participants stated that they always had to repeat specific care requirements to hospital staff, for example, dietary needs, interpreter usage or assistive technology requirements. 42% of participants reported that they sometimes had to repeat information about their care requirements and only 18.4% reported no issues in terms of communicating their care needs.

Participants who identified as having physical disability were overrepresented in always needing to repeat specific care requirements (61% of this cohort).

42% of survey participants reported that they believed that they had received inappropriate care as a hospital patient because they could not communicate effectively with health care providers.

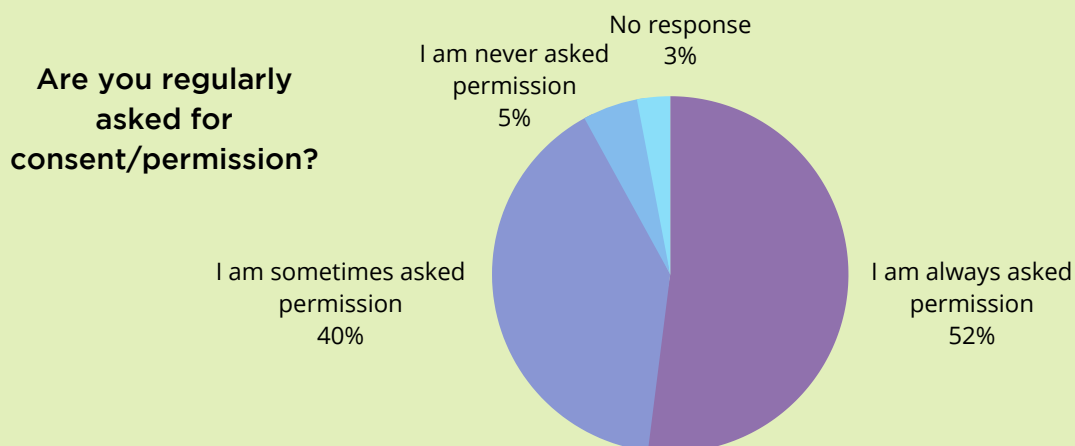
Again, participants with physical disability were overrepresented in this category. Just under 70% of participants with physical disability had experienced inappropriate care due to some type of communication barrier.

BEING RESPECTED

Participants were asked if they were routinely requested to provide consent before activities were done, either to them directly (bodily autonomy) or in relation to them, for example, relocation of assistive aids. This was to try to gauge the extent to which health care professionals had a culture of seeking permission for day-to-day care activities to occur.

Only 52% of participants reported always being asked to provide consent for minor activities. 40% of participants reported sometimes being asked to provide consent and 5% of participants reported never being asked, even when intimate activities were done directly to them, e.g., wounds being dressed, taking blood pressure.

The cohort least likely to be asked to provide consent before minor activities were done were those with physical disability, with only 35% of this cohort reporting always being asked.



BARRIERS TO BEST PRACTICE PERSON-CENTRED CARE

We asked participants what they saw as the major barriers to communication as a key driver of person-centred care.

Participants were asked to select from several options. Participants could select multiple options from the list and there was also an option to provide a unique response (Other: please specify).

The range of options included:

- Lack of interpreters (CALD and disability related)
- Limited time to communicate
- Hospital staff unfamiliar with patients' communication technology/devices
- Inadequate health care record keeping
- Hospital staff don't ask about patient's care needs
- Patients feel uncomfortable to tell hospital staff what their needs are
- Information is not communicated over staff shift changes
- Carers are not provided with a chance to provide information for patients
- Hospital staff lack experience in communicating with people with complex communication needs



Responses were as follows:

Answer	Count	%
Inaccurate health care records	43	23.6%
Carers don't have chance to provide information for patients	45	24.7%
Hospital staff are unfamiliar with patients' communication technology /devices	53	29.1%
Hospital staff lack experience in communicating with patients with complex communication needs	61	33.5%
Patients can feel uncomfortable to tell hospital staff what their needs are	64	35.2%
Hospital staff don't ask what patients' care needs are	76	41.8%
No interpreter support	78	42.9%
Information is not communicated over staff shift changes	95	52.2%
Communication time is limited	95	52.2%

Note: Of the 45 respondents who selected the answer "Carers don't have chance to provide information for patients", 26 had not identified as carers in a previous question.

Participants were also able to contribute text responses in an 'Other (please specify)' box. These free-form responses are provided in Annexure A.

Limited communication time and information not communicated between health care staff during shift changes were equally seen as primary barriers.

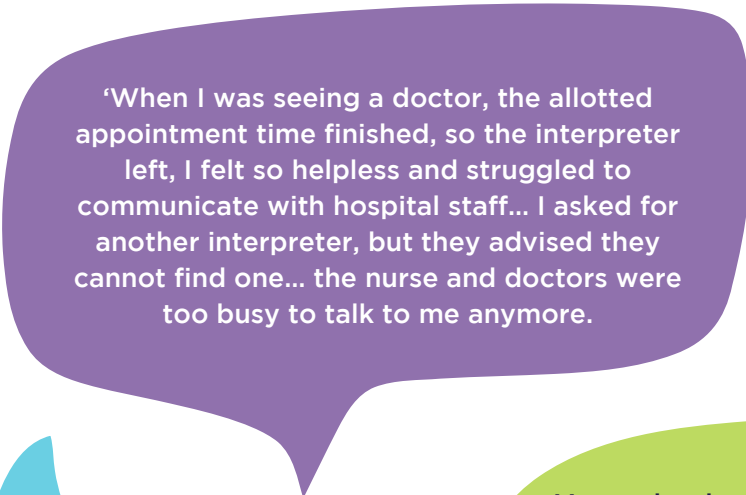
These were key themes across several of the care experiences recounted by participants:

My wife is a patient who is suffering from cancer, and her left shoulder injury is recovering, so I need to emphasize with every doctor and nurse how to make my wife safe and reduce pain. I need to repeat to three different nurses almost every day, especially when the shift is handed over in the morning and evening, I think the nurse did not clearly document the patient's condition and medication, is there any 5-10 minutes briefing every day? I'm tired of telling the nurse the same care requirements.

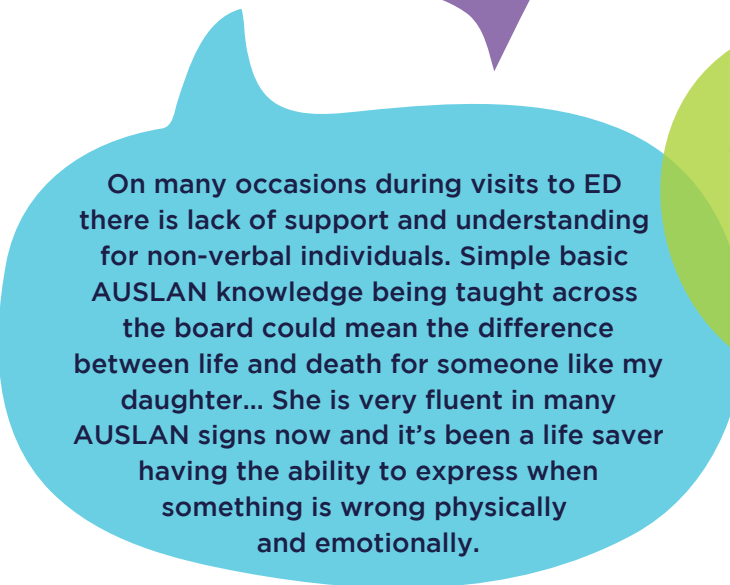
It's annoying to keep telling the different hospital staff about your own condition, repeat and repeat, and some of staff they don't know your situation, need to report it to leader and come back with different staff, you need to repeat again. It's a headache to being in hospital already [sic], and wait for so long, and keep telling make me angry [sic].

It's not necessarily a communication issue but one of resources and getting access to the support at the right time. In a busy day on a hospital ward, nurses are so busy as it is, so how can I get the physical support at the right time and for the time that I need it? What are other options? Can I utilise formal support from outside the hospital?

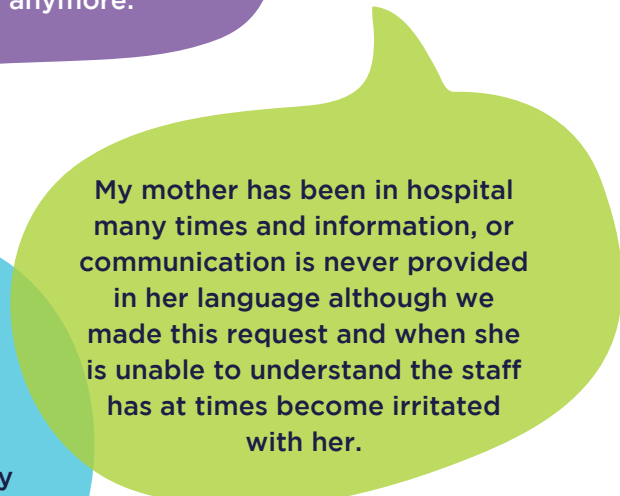
No interpreter support was also seen as a significant barrier, identified by 42.9% of participants, which was not unexpected. It is noted that interpreters could include CALD interpreters, or interpreters trained in disability specific communication, e.g., AUSLAN.



'When I was seeing a doctor, the allotted appointment time finished, so the interpreter left, I felt so helpless and struggled to communicate with hospital staff... I asked for another interpreter, but they advised they cannot find one... the nurse and doctors were too busy to talk to me anymore.

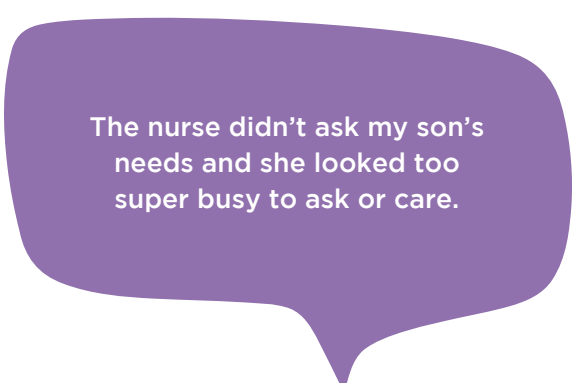


On many occasions during visits to ED there is lack of support and understanding for non-verbal individuals. Simple basic AUSLAN knowledge being taught across the board could mean the difference between life and death for someone like my daughter... She is very fluent in many AUSLAN signs now and it's been a life saver having the ability to express when something is wrong physically and emotionally.

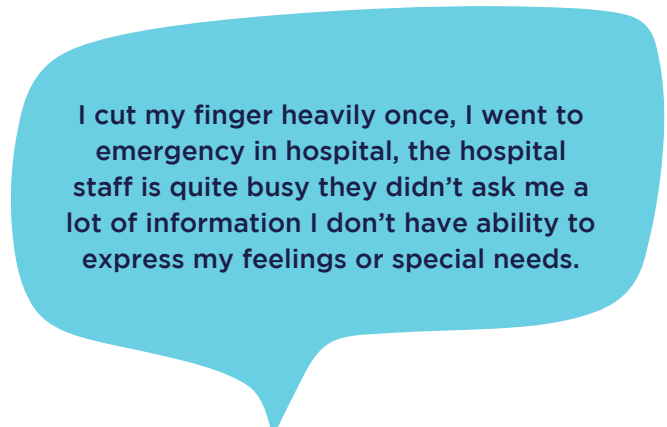


My mother has been in hospital many times and information, or communication is never provided in her language although we made this request and when she is unable to understand the staff has at times become irritated with her.

Simply not being asked about care needs was also identified as a common barrier (41.8%). Many participants indicated that they were reluctant to make specific care requests if they believed that staff were too busy.



The nurse didn't ask my son's needs and she looked too super busy to ask or care.



I cut my finger heavily once, I went to emergency in hospital, the hospital staff is quite busy they didn't ask me a lot of information I don't have ability to express my feelings or special needs.

Participant discomfort expressing their care needs to health care providers was also identified as a major impediment (35.2%). This overlaps to an extent with not being asked to explain care needs but may be indicative of the way that certain cultures express (or don't express) intimate health information.

The doctor and nurses were impatient and stressed. Many Brazilian people look for Brazilian doctors because these stressful situations exist.

I went to doctor to confirm the day that I could come back, he said 'I will send that information to your GP. But he even didn't ask any information about my GP. I don't have a GP, why can't he get in touch with me directly? Finally, I left as he was quite busy. And after two weeks I keep monitoring the wounds and self-recovered. I feel I didn't get really much support from the doctor.

Another barrier appears to be lack of experience across the health care sector in appropriate care for patients with complex care needs, including those with disabilities (selected by 33.5% of participants).

Participants advised that health care professionals could be unwilling to recognise gaps in their knowledge or listen to patient/carer expertise. Several care experiences recounted by participants with complex needs concerned with inappropriate care being given to them despite participants attempts to communicate what was necessary.

I am at risk of developing pressure injuries on my buttocks, upper back legs. I know where my skin should be checked twice daily to ensure skin integrity. I was not listened to, and my twice daily checking procedures were not followed, and I was made to feel as though I was being 'fussy', 'bossy' and a general feeling that I did not know what I was talking about. The nursing staff were prepared in their 'textbook' management of my disability and not prepared to listen to my 'lived experience'. As a result, on my return home, I discovered I had a pressure injury on the top of my right leg as a result of this area not being monitored.

I have a spinal cord injury and some years ago attended hospital with a fracture to my lower leg. [medical staff] insisted on putting it in plaster despite me telling them it was not the way to treat a fracture to an insensitive limb and asking them to phone the Spinal Cord Unit at [another hospital]. They plastered my leg and I ended up with a pressure sore on my foot from the plaster. Eventually (after a few days), they removed the plaster, and I was sent home with a "moon boot" and all was good.

I am deaf and lipread. Some doctors think it's okay to talk in front of me and not to me. I find this insulting. Another issue I have is around those with heavy accents or facial hair. I have been spoken at, and not to, about findings etc despite my repeated requests for someone to repeat what is being said to me. This resulted in me receiving treatment I was actually not supposed to have.

WHERE TO FROM HERE?

This report is a snapshot of patients' care experiences in hospital, but the information we have received is deeply concerning.

The high numbers of participants reporting care that does not accord with person-centred care principles warrants broad, in-depth investigation including consultation with health care professionals, to determine to what extent PPC is able to be practically realised and a more comprehensive understanding of the barriers that presently exist to applying PPC in the context of healthcare in NSW hospitals.

In the interim, there are various actions that could be taken to ensure that patients have better healthcare experiences – particularly when those patients have complex care needs.

Hospitals, at an organisational level need to work with health consumers in co-design to develop mechanisms to ensure that person-centred care is embedded across all aspects of operation.

Health consumers and their representative peak organisations should be engaged in developing and evaluating strategies to ensure hospitals provide best practice person-centred care to patients. It is particularly important to involve consumer groups with complex care needs.

Both patients and hospital staff need to be aware of the fundamentals of PPC. We would suggest that all hospital staff are trained (or potentially re-trained) on how to apply the fundamentals of person-centred care across their work as a rolling competency. Person centred care should be embedded in medical student training both in-house and across educational institutions such as TAFEs and universities.

Patients (and their carers) need to be made aware of PPC and how this should be reflected across the patient/health care provider relationship. Patients should have an informed expectation of the standard of care to expect within a hospital context and mechanisms to effectively communicate their views, thought and opinions, including access to communication supports or advocates. Hospitals should promote a culture where staff actively seek feedback from patients and accessible mechanisms should be provided for more formal feedback (including anonymous feedback).

PDCN and HCNSW would like to see increased staff to patient ratios, an embedded role for carers to assist in the provision of care for patients and ready access to communication tools such as interpreters or assistive technology. If in-house resources are not available, hospitals need readily accessible funding to contract services to ensure timely and effective communication with patients and carers.

We would encourage hospitals to look at targeted staff recruitment to ensure that there is diverse pool of in-house knowledge that can be called upon when developing individualised care plans. Cultural competency and inclusion training should be routine for front-line staff.

Finally, mechanisms to facilitate consistency of care across a patient's hospital journey, must be developed. Our research indicates information loss can occur during admission, across shift changes, and at the point of discharge.

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16. These benefits have been observed both in Australia and overseas.
17. There were significant numbers of survey responses generated by bots that needed to be identified and manually removed.
18. This is based on 2016 Census statistics.

ANNEXURE A

TEXT RESPONSES TO BARRIERS TO COMMUNICATION

Communications from doctors non-existent.

Cultural differences.

Professional bias, the clinicians knows better than patient.

So many different accents, I had difficulties communicating as did staff, AND importantly, with each other.

Complex medical history having to be reviewed & interpreted by different doctors on each admission.

Many hospital staff are not expected to communicate e.g., people coming into the room who wear headphones listening to music and don't respond when I ask who they are.

Lack of language aids as nurses/radiographers etc.

It's not necessarily a communication issue but one of resources and getting access to the support at the right time. In a busy day on a hospital ward, nurses are so busy as it is, so how can I get the physical support at the right time and for the time that I need it? what are other options? can I utilise formal support from outside the hospital?

Health professionals don't listen 'yeah, yeah, we'll get to that'.

There is also a lack of interest in society support people with disabilities and they are treated less human and devalued in society. People need reminding that just because you are not born with a disability it doesn't mean you could develop on or sustain barriers that affect you later in life.

I don't think they take me seriously.

Hospital staff are reluctant to listen to patient and then check with a specialist to provide appropriate care.

Non-verbal, lack capacity to push a hospital buzzer and lack of capacity to understand and make decision.

Assumptions are made and their personal opinions come over the care of the patient.

Piecemeal, broken system where the right hand doesn't know nor care what the left hand is doing.

I was over the age of 16, and they didn't want to deal with me.

Hospital staff not aware, nor educated, about my medical condition.

Patients don't want to be a nuisance by asking for help.

Dr not listening to myself as a patient no shared decision making at all.

I do not have complex communication needs. My communication needs were ignored.

There is also a lack of interest in society support people with disabilities and they are treated less human and devalued in society. People need reminding that just because you are not born with a disability it doesn't mean you could develop on or sustain barriers that affect you later in life.

Diagnosis discrimination (where staff think they know was a diagnosis is, don't believe it is real, and then discriminate based on that leading to the patient and their symptoms being dismissed). It can be very dangerous.

ANNEXURE B

SURVEY QUESTIONS

1

Are you answering these questions?

- ☐ By myself
- ☐ On behalf of someone I care for

2

What is your age?

- ☐ 15-24
- ☐ 25-44
- ☐ 45-60
- ☐ 61-75
- ☐ 76+

3

Do you live in?

- ☐ I live in a capital city
- ☐ I live in a large regional city or town
- ☐ I live in a rural area
- ☐ I live in a remote area

4

Do you identify with any of the following groups? (Please check as many as apply)

- ☐ I am an Aboriginal or Torres Strait Islander person
- ☐ I speak a language other than English at home
- ☐ I am a member of the LGBTI* communities
- ☐ I have a physical disability
- ☐ I have an intellectual disability
- ☐ I have a sensory disability (Deaf, Blind, vision or hearing impairment)
- ☐ I have a chronic (long-term) illness
- ☐ I am a carer
- ☐ Other (please specify)

5

In the last year, how often did you attend hospital?

- ☐ 1 time or less
- ☐ Between 2-5 times
- ☐ Between 6-10 times
- ☐ 11 or more times

6

Do hospital staff usually explain why they need to do certain procedures or processes in a way you can understand? (E.g. Scans, surgeries, observations, showers etc.)

- ☐ I understand a little
- ☐ I fully understand
- ☐ No, I do not understand

7

Do hospital staff usually ask your permission before doing things in your room or space? (e.g. Taking temperature, blood pressure, moving your equipment, checking wounds etc.)

- ☐ They ask my permission sometimes
- ☐ They always ask my permission
- ☐ They never ask my permission

8

Do you usually need to repeat your specific requirements related to your care? (e.g. Dietary requirements, need for interpreters, assistive technology etc.)

- ☐ Yes, sometimes
- ☐ Yes, always
- ☐ No

9

Have you, or someone you care for, received inappropriate care due to your special care requirements not being communicated?

- ☐ Yes
- ☐ No
- ☐ If yes, please tell us what happened?

10

What are the reasons you think might cause a communication gap (Tick as many apply)

- ☐ No interpreter support
- ☐ Communication time is limited
- ☐ Hospital staff are unfamiliar with patients' communication technology /devices
- ☐ Inaccurate health care records
- ☐ Hospital staff don't ask what patients' care needs are
- ☐ Patients can feel uncomfortable to tell hospital staff what their needs are
- ☐ Information is not communicated over staff shift changes
- ☐ Carers don't have chance to provide information for patients
- ☐ Hospital staff lack experience in communicating with patients with complex communication needs.
- ☐ Other (please specify)

ANNEXURE C

EXAMPLE OF NEWSLETTER SENT TO HCNSW AND PDCN MEMBERS

5 August 2020


[View this email in your browser](#)

HCNSWALERT

HEALTH CONSUMERS NSW

Survey

Have you – or someone you know – had a poor communication experience in hospital?
[Tell us and take our survey now](#)



Communication breakdown
in hospital?

We want to hear from you!

Have you – or someone you know – had a poor communication experience with hospital services? Or have you received inappropriate care in hospital? We want to know your story!

[Health Consumers NSW](#) and the [Physical Disability Council of NSW](#) are planning to develop a communication tool called Care Passport. Care Passport will allow patients to document their hospital care needs in one place to assist hospital staff to understand and respond appropriately to patients' unique care needs. We would love for you to tell us your story.

Why do we want your story?

We will use some of your stories to include them in a report. The report will show the need for Care Passport. Telling real people's stories will underscore the urgency to create something like Care Passport and make decision-makers understand. Your personal information will be de-identified and will not be able to be linked back to you.

What's in it for me?


If your story is chosen to illustrate recommendations in the report, you will receive a \$100 shopping card. And you will help policymakers better understand the need for the Care Passport in NSW.

How do I tell my story?

Simply complete our survey, which should take around six minutes. Please make sure you leave your email address so we can contact you about your story and the gift card and project outcomes.

Tell us your story here: <https://www.surveymonkey.com/r/BOYMN5H>

Please share with people and groups who may be interested!



HEALTH CONSUMERS NSW



