

Person-centred care insights

Welcome to the seventh edition of Person-centred care insights. We are pleased to have received such a broad variety of submissions for this issue – the most we have ever had! In fact, we received so much content that we will issue another newsletter in early 2026.

Each submission offers a unique glimpse into how person-centred care is delivered across different health services and settings.

In this edition:

- Showcases programs that support inclusive healthcare for people with disabilities
- Local updates and innovations
- New resources
- Events and news
- Publications

Inclusion of a program in this issue does not imply an endorsement from the Commission, but we hope you'll find these stories inspiring and insightful.

Disability feature

Disability education awareness via lived experience

Western Health

To bridge communication and knowledge gaps in health care, Western Health has partnered with people with lived experience to co-design a Disability Awareness Training Package. The program includes an online module and in-person sessions facilitated by Lived Experience Advisors (LEAs), who share authentic insights into effective communication with people with disabilities.

Kate, one of Western Health's inspiring LEAs, lives with Down Syndrome and uses her lived experience to educate staff on how to communicate respectfully and effectively. Her presentation, 'Doing My Own Thing: My Experience, Day-to-Day Life of People with Down Syndrome', provides practical insights into the challenges and successes of people with disabilities. Similarly, Darcy, who lives with Autism and Intellectual Disability, and his father Jonathan, demonstrate how assistive tools like iPads and picture cards enhance daily communication.

This initiative has led to a positive cultural shift within Western Health, with over 700 clinicians trained in the last 15 months. Staff report valuing the real-life insights, practical examples, and clear communication strategies shared by LEAs.

Top tips and lessons learned

- Partnering with people with lived experience ensures training is authentic and impactful.
- Real stories foster empathy and understanding.
- Inclusion of people with disability in planning and delivery builds a more compassionate healthcare culture.

Contact

vishma.gautam@wh.org.au if you'd like to know more.



Excellence in practice: voices for better care podcast

National Centre of Excellence in Intellectual Disability Health

Excellence in Practice: Voices for Better Care is a podcast for healthcare professionals who want to improve their practice when working with people with intellectual disability. In each episode, hosts Ricky Kremer and Raylene Griffiths speak with experts, healthcare professionals, and people with lived experience. They share real stories and practical advice to help you build your skills and confidence.

The latest episode 'Improving Mental Health Care for People with Intellectual Disability' explores how people with intellectual disability often face additional barriers when it comes to identifying that there is a problem, getting support, and accessing effective treatment for mental health.

Visit <https://nceidh.org.au/resources#PODCAST> to find out more and access the Podcast.

GeneEQUAL

University of New South Wales (UNSW)

GeneEQUAL is an inclusive research project working with people with intellectual disability to improve health care. The team works together to create accessible resources about genetic health care. These include Easy Read documents, videos, information booklets, journal articles and the GeneEQUAL toolkit.

The video resources show how genetic health care can be respectful, accessible and inclusive. The examples are scalable to suit a range of clinical settings to improve person-centred care everywhere.



[GeneEQUAL](#) works on three key learning principles to support inclusive, person-centred and respectful genetic healthcare for people with intellectual disability:

1. Make reasonable adjustments.
2. Ensure genetic health care is person-centred.
3. Practice trauma-informed care.

Top tips and lessons learned

- Health care should be respectful, accessible and inclusive.

Visit <https://geneequal.com> or contact geneequal@unsw.edu.au to find out more.

Local updates and innovations













Redesign of John Hunter Hospital patient and visitor information

John Hunter Hospital

The John Hunter Hospital (JHH) Inpatient Admission Paperwork Project successfully addressed inconsistencies in admission information provided to patients.

An improved resource for admissions was developed, trialled, and implemented through co-design process with staff and consumer representatives. Patients and staff report the new admission information provides greater clarity, consistency, and usability, demonstrating that collaborative approaches can deliver sustainable improvements in patient experience and hospital processes.

Staying Safe in Hospital

 Prevent Falls	 Prevent Blood Clots	 Prevent Infection
Use your usual walking aids. Press your buzzer if you need help.	Wear hospital stockings (if advised). Drink fluids as recommended. Take medicines as directed.	Wash hands before meals and after using the toilet. Use bedside hand gel (ask staff if missing). Remind staff and visitors to clean their hands.
		
 Your Medicines	 Prevent Pressure Injuries	 Identification
Tell staff about allergies. Ask about possible side effects.	Move regularly, even while in bed. Tell staff if you feel sore or uncomfortable.	Check your details are correct: name, address, date of birth, GP, emergency contact, allergies.
		

Top tips and lessons learned

- Strong consumer involvement from the outset ensured the resource met patient needs.
- The scoping exercise revealed more duplication than expected, highlighting the importance of mapping current state early.
- Lack of governance over previous resources had created inconsistency and risk, reinforcing the value of establishing a formal approval and review pathway.
- Staff engagement across multiple services ensured broad support but required careful coordination.

View the [JHH Patient and Visitor Information guide](#).

Empowering families in end-of-life care: a case study of community-based drainage management

Northern Sydney Home Nursing Service - Northern Sydney Local Health District

Sandy, aged 57, lived with a rare recurring ovarian tumour for over 15 years, requiring complex care including daily peritoneal drainage. Determined to maintain her quality of life, Sandy was supported at home by the community nurses of the Northern Sydney Home Nursing Service (NSHNS). To help Sandy regain independence and visit her cherished holiday home, a step-by-step aseptic protocol was developed to support her husband to safely manage her drainage.

With dedicated training from the palliative care clinical nurse consultant, Sandy's husband became confident with the procedure and understanding her signs and symptoms. As a result Sandy was able to travel and enjoy meaningful time with family.

Sandy passed away in early 2025, but her legacy lives on; a new carer education package was designed to support others in similar situations, giving patients greater autonomy and flexibility.

Sandy's daughter reflected, 'Mum felt free again. The care and compassion shown made all the difference.'

Top tips and lessons learned

- Carer education enables sustainable support: a new carer training package now offers others the same opportunity for carer assisted home-based treatment.
- Empowering carers enhances patient autonomy: training Sandy's husband to manage her daily treatment enabled her to travel and maintain a sense of normality.
- Person-centred planning supports quality of life: care was tailored to Sandy's personal goals, including spending time at her holiday home.
- Collaborative home-based care is effective: the partnership between specialist nurses and family carers demonstrated safe, compassionate care outside hospital settings.
- Emotional wellbeing matters: supporting patients in familiar, meaningful environments contributes to dignity and comfort at end of life.

Contact Shayne.Larimore@health.nsw.gov.au if you'd like to find out more about the carer education package

New peer mentor program supports head and neck cancer patients in their recovery

Peter MacCallum Cancer Centre

Peter MacCallum (Peter Mac) is piloting a one-to-one peer navigation program in partnership with Northern Health.

Trained volunteer peer mentors who have lived cancer experience are available to support patients with head and neck or upper gastrointestinal cancer at Peter Mac. Bicultural peer mentors are also available to provide in-language support for people from Indian and Chinese community groups.



Quote from a mentee

Having a mentor was a huge help to me. I was supported and felt less alone and isolated. I had someone who had survived and was thriving. Your mentor has been there and survived it and this lived experience is invaluable.



Quote from a peer mentor

Becoming a peer mentor gave me a sense of purpose in my recovery and helped me with my mental health. The most rewarding part of this program is being able to help someone go from the fear of dealing with cancer and the uncertainty, to resilience, hope and a positive recovery.

Visit www.petermac.org/peermentorprogram or contact peermentorprogram@petermac.org to find out more.

The right language – reducing pain and anxiety through hypnotic communication

South Australia Medical Imaging (SAMI)

South Australia Medical Imaging (SAMI) Clinical Nurse Sarah Goh and Radiologist Clinical Professor Christen Barras are leading a new approach to patient care, using hypnotic communication to reduce fear, pain and anxiety during medical imaging procedures. Both Sarah and Christen recently completed training in Clinical Hypnotherapy with the South Australian Society of Hypnosis – the first in Australia in their respective fields to do so.

Sarah, drawing on 20 years of anaesthetic nursing experience, has shown how simple changes in language can ease patient distress and reduce the need for sedation; replacing phrases like 'sharp scratch' with positive, calming cues. Christen is exploring how Clinical Hypnosis can assist claustrophobic patients undergoing MRI scans, and the research potential for expanded Clinical Hypnosis applications in clinical care.

Together, their work highlights how the right words can profoundly shape patient experience and outcomes.

Contact health.documentationsamedicalimaging@sa.gov.au to find out more.

The 5 Ways Café: an example of person-centred care in mental health

Northern Health

5 Ways Café is a peer-led support group, created and run by people with lived experience of mental health challenges. The café runs at two different community mental health sites of Merri-bek (Coburg) and Hume (Broadmeadows). Each week participants meet in an open and welcoming environment to check in, share experiences, discuss wellbeing topics, and finish with a light game. This structure encourages safety, reflection, and genuine connection.

The café supports person-centred care by valuing each person's story and giving everyone an equal voice. It focuses on partnership, respect, and empowerment rather than hierarchy. Participants are encouraged to express themselves openly, learn from others, and explore practical ways to support their own recovery. By building belonging, hope, and understanding, 5 Ways Café helps people feel seen as individuals rather than defined by their illness, embracing the true spirit of person-centred care.



Consumer story – how lived experience remains key to recovery

After years of isolation, Jan* joined our peer-led 5 Ways Café feeling unsure that anyone could ever understand her. In this space, Jan discovered people who spoke 'her language' – the language of lived experience. For the first time, she reported feeling truly heard and was able to offer empathy to others in return. Jan built friendships she never expected and began to see herself not as a patient but as a person among equals. Through laughter and honest conversation, she found hope again and realised that mental illness was not the end of her story but a path of self-empowerment that she could learn to walk. In her words 'I feel human again.'

*Name has been changed to protect privacy

Top tips and lessons learned

- Genuine human connection is powerful.
- Lived experience brings unique understanding and empathy.
- Helping people see themselves beyond diagnosis restores identity.
- Empathy and shared stories rebuild hope and self-belief.
- Co-created, peer-led spaces empower people to take part in their own recovery.

Contact Christopher.Ferguson@nh.org.au to find out more.

Beyond the birth: a collaborative approach to support mums in the fourth trimester

Western NSW Local Health District and NSW Ministry of Health

The Kindlab initiative: Honouring the Fourth Trimester is a consumer-led collaboration between the NSW Ministry of Health (funded through the 2023 NSW Health Kindlab program), Western NSW Local Health District, the Agency for Clinical Innovation, and maternity consumers and clinicians in Orange.

The project aims to raise awareness of the fourth trimester (the first three months after birth) and support mothers through individualised postnatal planning using the co-designed 'Beyond the Birth' booklet.

Consumers, community members, and health professionals came together in a one-day workshop to shape the booklet, ensuring it reflects real experiences and needs. It is now being piloted through Orange Health Service's Midwifery Group Practice Program for six months. Feedback from women, midwives, and child and family health nurses will help evaluate its effectiveness.

This project is a great example of what is possible when consumers and health organisations work together - creating tools that support women not just at birth, but beyond.

Top tips and lessons learned

- Include more voices: future workshops could use local connections to make sure the guide reflects the needs of all women in the community.
- Test and refine: testing the booklet across different maternity services in Orange, including the public antenatal clinic and high-risk service, could further determine its effectiveness.
- Support midwives: to avoid adding extra workload, the guide can be built into existing conversations. Training will help midwives see it as a women-led resource that supports, rather than adds to, their care.
- Co-design builds ownership: involving women, families, and clinicians in the design of the booklet created a strong sense of shared purpose and ownership of the final guide.
- Simple tools can make a big impact: a clear, easy-to-use resource helps start important conversations and encourages women to start their own postnatal planning.
- Partnerships strengthen outcomes: collaboration between health services, agencies, and community members helps align resources and capacity

Contact MOH-PatientExperience@health.nsw.gov.au if to find out more.



Not just a meal: co-cooking for cultural connection at Western Health

Western Health

Hospital food is vital to patient recovery, yet little research explores meal preferences and experiences of culturally and linguistically diverse (CALD) patients. At Western Health in Victoria, where around 40% of inpatients identify as CALD and over 150 cultural backgrounds are represented, the hospital menu had remained largely Anglo-European.

The 'Not Just a Meal' project brought staff and community together to explore cultural and comfort foods that could enrich the hospital menu and improve patient experience. Using a co-design approach, staff and consumers co-cooked meals in a community kitchen, ensuring authenticity of the recipes being developed.

This collaborative process shifted the approach from working for patients, to working with them, resulting in a cultural food bank and a blueprint for ongoing inclusive menu design. Hospital chefs and consumers co-cooking side by side is a novel and creative consumer centred tool for recipe development in the Australian tertiary hospital.

Top tips and lessons learned

- Collaborative, creative activities can reveal different types of knowledge compared to traditional interview or observational research methods.
- Co-design and co-cooking created a connectedness between staff and the community through a shared sense of purpose.
- Consumer led research has added depth and authenticity to menu changes.
- Food is not just a meal, it is a vital part of patient care and can play a significant role in providing comfort, support and joy when patients are unwell.



The program has been promoted on ABC's '[The Conversation Hour](#)' and through Western Health's [Instagram](#).

Contact vanessa.carter@wh.org.au to find out more.

New resources

Centring consumer voices through patient-reported measures

NSW Agency for Clinical Innovation (NSW Health)

Explore [a new video collection](#) from the NSW Agency for Clinical Innovation, highlighting how patient-reported measures (PRMs) are helping to shape care that is more person-centred, culturally safe and responsive.

- The *PRMs Spotlight* Series features stories from patients and clinicians, including Barbara and Ray, highlighting how PRMs support shared decision-making and person-centred care.
- The *Yarning About PRMs* series amplifies Aboriginal voices, showing how PRMs can foster cultural safety and self-determination through genuine partnership and co-design.



These videos are designed to support education, onboarding and implementation of PRMs across NSW Health. [Watch the videos here](#).

Top tips and lessons learned

- PRMs are more than data, they're a mechanism for listening, learning and transforming care.

Learn more about the [NSW Agency for Clinical Innovation PRMs Program](#) or contact ACI-PRM@health.nsw.gov.au.

Partnering with Consumers and Carers in Research: Researcher Toolkit

Canberra Health Service

The Canberra Health Service (CHS) '[Partnering with Consumers and Carers in Research: Researcher Toolkit](#)' has now been officially endorsed and is available to download.

This practical toolkit supports CHS researchers to partner meaningfully with consumers and carers across all stages of clinical trials and health research. A companion 'Partnering with Consumers and Carers in Research: Consumer and Carer Research Partner Toolkit' is being finalised in collaboration with local consumer and carer organisations and community members.

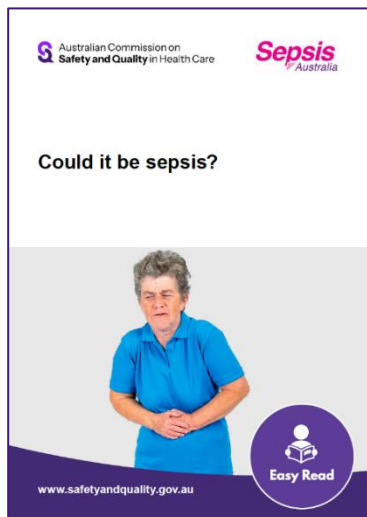
Partnering with consumers and carers leads to safer, more relevant, and more ethical research, based on the needs and experiences of our community. The toolkit is a key component in CHS's preparation for accreditation under the National Clinical Trials Governance Framework, developed by the Australian Commission on Safety and Quality in Health Care.

The resource includes guidance, examples, and planning tools to support effective consumer and carer research partnerships from early planning to sharing results.

There is significant interest and willingness to partner with consumers and carers in hospital-based research. However, the need for practical resources like a toolkit is important to move from theory to practice.

View and download the [Partnering with Consumers and Carers in Research: Researcher Toolkit](#). One-on-one support is also available. Contact CHS.research@act.gov.au.

New resources from the Commission



Sepsis Easy Read

The Commission released a new [Easy Read resource about sepsis](#) as part of our activities to mark International Day of People with Disability on 3 December.

Developed as part of the National Sepsis Program, it aims to support people with intellectual disability and cognitive impairment to understand the signs and symptoms of sepsis, and know what to do if they are worried about sepsis.

The Easy Read resource provides accessible health information to support early recognition and response, resulting in improved patient care. The resource is also digitally accessible for screen readers.

View [The Easy Read](#) or learn more about [the National Sepsis Program](#)

MedicineInsight – Supporting COPD care through data-driven insights

MedicineInsight continues to empower general practices with meaningful data to improve person-centred care. The [GP Snapshot: Chronic Obstructive Pulmonary Disease \(COPD\) Pharmacological Management](#) was released in November 2025, followed by the customised Practice Report and GP Report for participating practices and GPs.

These resources offer valuable insights, providing practice-level data as well as aggregate trends across all participating MedicineInsight practices. Aligned with best practice guidelines, both reports include actionable recommendations to support safer, more effective COPD management. By translating data into practical quality improvements, MedicineInsight helps clinicians deliver care that is both evidence-based and tailored to individual patient needs.



Join the MedicineInsight program and be part of a national effort to enhance quality care through data-driven decision-making. [Find out more about the MedicineInsight program.](#)

The PaRIS Survey – giving patients a voice

The Australian Commission on Safety and Quality in Health Care has released the Australian results of the OECD Patient-Reported Indicator Surveys (PaRIS) initiative. The PaRIS Survey is an international study of the care experiences and health outcomes of people living with chronic conditions in primary care settings.

The aim of the PaRIS Survey is to fill a critical gap in primary care by providing insights into areas that matter most to people, and to strengthen the measurement of care experiences and health outcomes through standardised indicators that enable cross-country comparisons.

The PaRIS Survey asked patients about their experiences of health care in five areas: confidence to self-manage, coordination of care, person-centred care, quality of care, and trust in the health system. It also asked about their health outcomes in five areas: physical health, mental health, social functioning, wellbeing, and general health.

Read the [PaRIS Survey - Australian National Report 2025](https://safetyandquality.gov.au/paris-survey).



Top tips or lessons learned

- Positive care experiences are linked to better health outcomes.
- The GP-patient relationship is critical for better care, with longer GP relationships resulting in better health outcomes and trust in the health system.
- Patients with an established GP relationship also reported better experiences with care coordination.
- A patient's experience with person-centred care was influenced not only by the number of chronic conditions but also by the combination of conditions they were living with.
- A patient's mental health is a critical factor to consider in the management of multiple chronic conditions and its impact on the patient's social life.
- Patients' experiences of person-centred care improved when GPs provided a tailored care plan, discussed a patient's specific health goals, provided written care instructions, recorded self-management goals in medical records, and involved loved ones and carers in care decisions.

Visit [Patient-Reported Indicator Survey \(PaRIS\)](https://safetyandquality.gov.au/paris-survey) to find out more or contact acsqhcigr@safetyandquality.gov.au

Events and news

Person-centred care in practice webinars

The Commission's most recent Person-centred care in practice webinar was held on 3 December as part of our activities to mark International Day of People with Disability (IDPwD). The theme for IDPwD this year was fostering disability inclusive societies for advancing social progress.

The webinar, hosted in conjunction with the National Centre of Excellence in Intellectual Disability Health (the Centre), focussed on inclusive health care for people with intellectual disability. It explored how personalised adjustments support safe, high-quality, person-centred care with presentations by:

- Dr Cathy Franklin from the newly formed Queensland Centre of Excellence in Intellectual Disability and Autism Health
- Dr Jessica Smith, clinical lead for two specialist pathways supporting adults with intellectual and developmental disabilities within the Southern Adelaide Local Health Network

Scientia Professor Julian Trollor, Director of the Centre, Ricky Kremer, Lived Experience Inclusion Lead at the Centre and Anna Flynn, Director Partnering with Consumers at the Commission joined the speakers for an engaging question and answer session following the presentations.

This recording of the webinar will be available shortly at this link: [Person-centred care in practice webinar series](#).



Recent publications

Below are some recent publications in person-centred care that you may find useful. Inclusion of publications in this section is not an endorsement or recommendation of any publication or provider.

Access to documents may depend on whether they are Open Access and/or your individual or institutional access to subscription sites/services. Material that may require a subscription is included as it is considered relevant.

1. Chauhan A, Newman B, Chin M et al. Developing best practice principles for enhancing engagement with consumers from culturally and linguistically diverse backgrounds in cancer services. *Aust Health Rev* 2025:
<https://doi.org/10.1071/AH25217>
2. Alan JJ, Laging B, Cameron P et al. Enhancing person-centred care in the final years of life: insights from emergency department visits and hospitalisations in Victorian residential aged care (2015/16 to 2022/23). *Emergency Medicine Australasia* 2025:
<https://onlinelibrary.wiley.com/doi/10.1111/1742-6723.70092>
3. Gupta P & Greenfield D. Words in action: centering the patient voice to achieve an efficient and compassionate healthcare system. *International Journal for Quality in Health Care* 2025:
<https://academic.oup.com/intqhc/article/37/4/mzaf104/8263975?searchresult=1>
4. Bureau of Health Information (AU). The Insights Series – Aboriginal people's experiences of hospital care. Sydney, Australia; Released 24 September 2025
https://www.bhi.nsw.gov.au/BHI_reports/Insights_Series/Aboriginal-peoples-experience-of-hospital-care-2019-2024 (accessed November 2025)
5. Goldman J, Rotteau L, Lo L et al. Integrating equity into incident reporting and patient concerns systems: a critical interpretive synthesis. *BMJ Quality & Safety* 2025.
<https://qualitysafety.bmj.com/content/early/2025/11/04/bmjqs-2025-019118>
6. Janerka C, Leslie GD, Gil FJ, PCC ED Triage Group. Co-design of a framework for person-centred care at emergency department triage and waiting room. *Health Expectations* 2025:
<https://onlinelibrary.wiley.com/doi/full/10.1111/hex.70442>
7. Alm AK, Hellzen O, Rising-Holmström M. Registered nurses' experience of person-centred care through digital aids in primary care setting during the COVID-19 pandemic. *Nursing Open* 2025:
<https://onlinelibrary.wiley.com/doi/full/10.1002/nop2.70134>
8. Toribio-Mateas M & Noble G. Making room for every voice: reimagining person-centred care in the neurosciences. *Health Expectations* 2025:
<https://onlinelibrary.wiley.com/doi/10.1111/hex.70350>
9. Ruseckaite R, Mudunna C, Ackerman I et al. Development of a best practice guide to optimise the reporting of patient reported measures by clinical quality registries for quality improvement purposes. *Health Services Insights* 2025:
<https://journals.sagepub.com/doi/10.1177/11786329251347343>