Consumer Focus Group sessions and community survey to inform design and patient experience

Summary

Nepean Hospital is one of five hospitals to build a new or redeveloped Palliative Care unit as part of the $93 million funding allocation from the NSW Government.

This report outlines the findings of two Consumer Focus Groups, which were held on 15 November and 6 December 2023 to inform the patient experience and design of the new dedicated palliative care unit at Nepean Hospital. It also includes findings from an online survey, open from 19 April to 9 May 2024, to help inform the detail design of the new palliative care unit.

Based on the community engagement sessions, several key themes emerged to inform the design and patient experience of the Nepean Palliative Care Unit project.

Firstly, regarding access, participants highlighted the importance of integrating the PCU with other services, unrestricted access for families, and clear understanding of the journey into and out of palliative care. Additionally, better communication and proximity to aged care were highlighted, along with improved transport and access to staff and information at all hours.

Secondly, discussions on patient rooms focused on preferences for single rooms with amenities like carer day beds, seating space for visitors, and personal fridges. Participants also emphasised the need for controllable temperature and lighting, privacy, and homely décor to create a comforting environment.

In terms of communal areas, attendees desired a variety of spaces including a communal kitchen, quiet rooms, and family-friendly areas. They highlighted the importance of distinguishing between quiet and social spaces, as well as incorporating natural elements and artwork to create a soothing atmosphere. The provision of amenities like outdoor dining areas and children's play areas was also highlighted.

The importance of the overall patient experience was frequently raised, including personalised care, compassionate staff, and support for families throughout the palliative care journey. Participants stressed the need for after-death support, access to therapy options, and effective communication, especially for culturally and linguistically diverse communities.

Miscellaneous points raised included the role of GPs in palliative care coordination, the importance of timely and compassionate information delivery, and the need for resources and support services. Additionally, survey findings emphasised the significance of creating a homelike environment, providing spaces for reflection and prayer, and incorporating natural elements and calming colours into the design.

Overall, the community engagement sessions highlighted a holistic approach to palliative care, focusing on creating supportive environments that prioritise patient comfort, family support, and cultural inclusivity.

Key feedback from each activity:

As part of consumer engagement, the project team invited everyone who had registered their interest to participate in the Nepean Palliative Care Unit project.

Two two-hour sessions were held with approximately 14 community attendees per session.

Facilitating the sessions were the following staff:

1. Linda Ora – Palliative Care Project Officer and Clinical Nurse Consultant
2. Pia Lambert, Clinical Nurse Consultant
3. Belinda Berryman, Communication and Engagement Manager, HI
4. Leonie Weisbrodt, Redevelopment Program Manager
5. Nicole Pierre, Senior Officer, Communications and Engagement, HI
6. Rebecca Cooper, Project Officer, Nepean Redevelopment

As part of the first session, the group were given background about the project and the purpose of the consumer focus group, which was to inform the design and patient experience in the new facilities as well as inform the broader Palliative Care model of care for the Nepean Blue Mountains Local Health District.

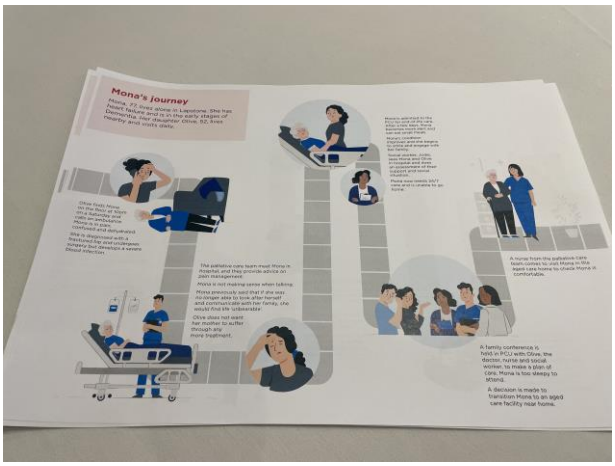
The first session was centred around three case studies describing different patient journeys and experiences within the future palliative care unit.

Each case study was read out to the group to initiate a 25-minute discussion in smaller groups of about 6 (with 1-2 facilitators on a table). Facilitators wrote responses on post-its which were then collated underneath headings of design, experience, access or miscellaneous.

A summary of the key topics discussed for each theme is included in this report.

A second session was held which sought further design feedback on outdoor spaces, quiet spaces, patient rooms and communal areas. Each person was given a mood board with concept designs on each of those areas to assist in prompting group discussions on the spaces. Responses were written on post-its and combined under sub-headings.

Workshop 1 - Access



In terms of access, participants said the PCU should be integrated with other services and there was a preference for people to not have to walk through the Emergency Department to get to the unit.

Families and close ones also wanted unrestricted access to the unit. They also wanted to have access to staff at all hours and to have a clear understanding of the journey into and out of palliative care.

A couple of points came up on aged care specifically better communication on the aged care package, better choices and proximity to aged care and the ability to fast-track to aged care.

Quotes: "Palliative Care needs a core group, a coordinator for the person. Staff come and go and we have to repeat our story over and over again." | "There needs to be integration with aged care – there's a lot of red tape to get into

aged care." | "Needs to be easy access - you need to be able to get in 24/7 past security" | "Palliative Care needs to cover the gaps and coordinate the care."

Key points discussed (Access)

- Integration of PCU with other services
- Ambulance and advanced care directive
- Having one person to be a point of call
- Clearer journey into and out of care
- More gradual transition from clinic to palliative care
- Access to discharge criteria
- Aged care - better communication on aged care package, better choices and proximity to aged care
- Unrestricted access for families
- Food delivery straight to the ward
- Better transport
- Access at all hours to staff and information.

Workshop 1 and 2 - In-patient bedrooms

Patient rooms

Participants gave detailed descriptions of how they envisaged the unit's patient rooms. Single rooms were preferred. Yet, people understood that some patients wanted to be in a room with others especially if they did not have any family members or friends visiting them.

The main points for patient rooms included carer day beds, cuddle beds, seating space (to fit at least six visitors), an ensuite, personal fridge to store food from home and food for carers, dining table and chairs in shared spaces, an easy to set up entertainment system, lockers, multiple power points and equipment to set up video calls with family.

People wanted controllable temperature and lighting (including soft lighting), soundproofing, bright and pastel colour schemes, shelves, as well as artwork depicting rural and beach scenes. They also requested that medical equipment to be hidden to make the space feel less clinical and more homely. Soft furnishings including natural timbers and 'home like' décor were requested.

Quotes: "It's inconvenient to share the bathroom, especially at the end of life - you don't want to share with other people." | "I would have loved a cuddle bed when my husband was sick." | "Procedures can be such an upheaval for the patient. Need to bring them to the patient."

Key points discussed (Patient Rooms)

- Plenty of seating space
- Use of carpet as it is homelike and dampens clinical noise. They said wood-like lino would also be fine
- Wi-Fi, entertainment system and TV, multiple power points
- Single rooms and double rooms, carer day beds (need to accompany more than one a night), bar fridge in room
- Windows that open so the patient can feel a breeze

- Bathtub for aromatherapy, wheelchair accessible bathroom, large ensuites
- In room dining options e.g., small table and chairs.
- Hooks and display boards on walls to personalise the space, shelves, home-like linen and decor
- Co-location of acute and end of life care.
- Bar fridge in room
- Wind chimes, pot plants
- Bifold doors, venetian blinds to avoid the standard patient curtain
- Storage, lockers for carer and patient
- Built-in benches proposed for multifunction purposes e.g., Seating, laying down, inbuilt storage
- Dimmable lighting, controllable temperature
- Portable fans and cots
- Wheelchair accessible bathroom, large ensuites
- Ability to put request for privacy card on patient door

Workshop 2 - Communal areas

An equipped communal kitchen was discussed including the provision of basic groceries, a sandwich press, well equipped vending machine, hot water, ice machine, multiple fridges and a freezer.

Distinguishing between quiet spaces and family/ kid friendly spaces was important. There was also a request for different zones including a sunroom, break out spaces, rooms for video conferencing/meetings, a communal library/reading room, and therapy rooms for art and music therapy.

Bring the outdoors in, using natural light and plants in a protected sunroom or dining was also important.

In terms of décor, some suggested it being styled like a hotel lobby and there were requests for rotating artwork in digital or physical form.

There was also a preference for no televisions in the main communal room but the option to have one in a separate TV room. A concierge with a volunteer was also discussed.

In terms of equipment, people requested communal fridges, sandwich press, kettle, coffee machine, and microwave. People wanted the ability to cook, heat up food, and order food delivery. Yet the cooking of food was less of a priority because it omits unpleasant odours.

Most liked the idea of having a separate bathroom and laundry for carers.

Other common room requests in the unit included a procedure room, quiet spaces, a multifaith room, a study, library, patient lounge area, therapy rooms (art therapy/music therapy) and a mothers' room.

There was also requests for a room to conduct bereavement activities including memory making and legacy resources for family and children.

The design's impact on children was also discussed. People wanted toys and activities for children, a kids' play area, a childcare worker, kids' books that dealt with topics of death as well as specific bereavement support for children.

People raised the importance of noise attenuation and having private rooms for calls, conferences, and 'work from hospital' options.

The discussion also focused on having a space in the communal area that has pamphlets and booklets about the support services available, such as financial and social work resources, funeral preparation and memory making etc.

Quotes: "Some people have very large families together and others need a quiet room so we need a social room and a quiet room some cultures would have their whole tribe there."

Key points discussed (Communal areas)

- Communal kitchen with basic groceries in kitchen e.g., toast, tea, coffee, hot chocolate, bread.
- For children - Kids play area, childcare worker, kids' books on death/dying, iPads for children.
- Family rooms - social room and quiet rooms to cater for different cultures, family sleeping rooms.
- Bathroom facilities - Separate bathroom to patient bathroom.
- Rooms/spaces - Multiple quiet rooms including interview room with soft furnishing, comfortable chairs, 'home like' décor, procedure room in the palliative care unit, solitary/quiet spaces, patient lounge area.
- Newspapers, magazines, home like décor, social room and quiet room to cater for different families.
- Access to a café and retail shop/s, beauty care.
- Wheelchair access and smoking areas.
- Break out zones.
- Video conferencing rooms
- Communal library and reading room.
- Therapy room – music, art therapy, piano access
- Art works – rotating art works, mix of digital and physical.
- Plant walls

Workshop 2 - Outdoor spaces

The group requested an outdoor area which was weatherproof and could be used all year round. They asked for an outdoor space which was equipped with picnic tables, a barbecue, a shade sail, lighting at night, a garden and a child-safe water feature.

In terms of plants, the majority said they were okay with a mixture of artificial and natural plants with a preference for local natural plants. Using plants sufficient in height for privacy between patient rooms in outdoor spaces was also raised.

Others also raised having modular outdoor seating, pet access/zone, a reflection garden, and outdoor play area for children including hopscotch and maze.

People asked for outdoor power points so that equipment could be wheeled outside, as well as outdoor buzzers.

In terms of design, there was a preference for curved over sharp edges. Garden beds and murals showing Aboriginal art and calm scenery including the ocean and natural landscapes were discussed.
Quotes: "Outdoor areas need picnic tables and shade sail - something you can use in all weather."

Key points discussed (Outdoor spaces)

- Plants – mix of natural and artificial, preference for local plants, succulents
- Sensory garden
- Reflection garden
- Water feature
- Children's play area outside
- Patch of real grass, astro turf okay, glass for rails should be avoided due to heat.
- Pet access
- Retractable shades, modular outdoor seating
- Flexible outdoor spaces to meet changing needs of patients and families.
- Outdoor spaces appropriate for Aboriginal patients and families e.g., place for smoking ceremonies
- Outdoor dining tables, outdoor fans
- Fairy lights, good lighting at night
- Dedicated outdoor courtyards, that can fit the patient's bed and seating for up to three people.
- To maintain privacy and comfort for patients, ensure the private courtyards are used for quiet reflection and if the family wants to chat, they should go with the patient to a communal outdoor area.
- Café style tables and comfortable seating
- High hedges/plants for privacy
- A storage area to add outdoor furniture where needed and cushions to tailor your space and needs.
- Access to different services outside e.g., Gases, power points for equipment
- Outdoor murals
- Bifold doors

Workshop 1 - Experience

Participants spoke of the importance of personalised care and having access to family support services such as social workers right from the start as well as access to a grief counsellor if required.

They also discussed the importance of kind, compassionate and communicative staff, with training in dealing with death.

After death, the attendees requested for family and loved ones to not be rushed and to have time to say goodbyes and pick up belongings after death. They also asked to be given bereavement support including specifically tailored support to children.

If patients are transitioning from the palliative care unit to the home, a risk assessment of the home was requested as well as access to home support regardless of age including volunteers and a dietician.

In the patient rooms, privacy and sound proofed walls were preferred. Different types of therapy including animal therapy, music therapy and art therapy were also requested.

The groups recognised that communication was key for all patients and families, including for members of the CALD communities including better access to interpreter services.

Quotes: "It can be lonely for carers." | "The doctor had to write a letter and they still wouldn't let everyone in." | Staff organised meals for me, they just started arriving. It was more to me than just food." | "Someone needs to tell the family what to expect."

Key points discussed (Experience)

- Staff - Staff to be trained to better deal with death, caring palliative care volunteers, attitude of staff is important.
- After death - Not to rush after a death, inform patient on process after death, follow up after death, time to collect personal objects, not having the pink plastic bags to put belongings in.
- Bereavement needs to be prioritised including support for children.
- Therapy – animal therapy (pets visiting), music therapy, art therapy, care for carers.
- Risk assessment of the home, access to home support including volunteers.
- Early referral to social worker and grief counsellor, having a care coordinator.
- Communication for CALD communities
- After hours support and crisis and emotional support, flexible visiting.
- Pastoral care offered.
- Access to allied health support.
- Bed moving not occurring too late.
- Volunteers to support lonely patients.
- OT and physio should be available to the patient daily.
- Ability to choose own music, ability to video call family.
- Support with transition to aged care.
- Wait periods - not having a long wait list for chronic/pain team, not having a long wait for wound care.

Miscellaneous

A few people discussed the important role of the patient's GP in the palliative care journey, specifically reducing the gap between the GP and hospital through the GP being able to access information and being informed when a patient is admitted.

Participants also noted the importance of getting all the facts in a timely manner but also ensure it is delivered with compassion with a focus on quality personalised care.

More staff training about bereavement and discussions with families to help them better understand palliative care, and advanced care directives.

Some suggested having an orientation for families and carers new to the palliative care unit, as well as having a board in the communal room with the names of the nurses on duty accompanied by their picture.

Others also suggested having a special symbol on the door of a meeting room to let people know if it is occupied.

Key quotes: "Health tends to work in silos." | "There needs to be home support regardless of age." | "Need volunteer recruitment. It stopped during COVID" | "There needs to be help with Commonwealth services like NDIS and ACAT."

Key points discussed (Miscellaneous)

- Smooth flow of information
- GPs – communication with GP about admissions and planning, reduce gap between hospital and GP, keeping GP informed, after-hours access.

- Resources – financial resources e.g., Knowing that banks can put mortgages on hold, staff resources on bereavement, resources to understand what palliative care is, aged care packages, social worker and counselling.
- Palliative care volunteers
- Person-centred care
- Palliative care training room
- Legacy work is important. Volunteers to help with video messages/memory making.
- Easy parking for visitors – reduced price if possible
- Access to a register of Nepean Justice of the Peaces' (JPs).

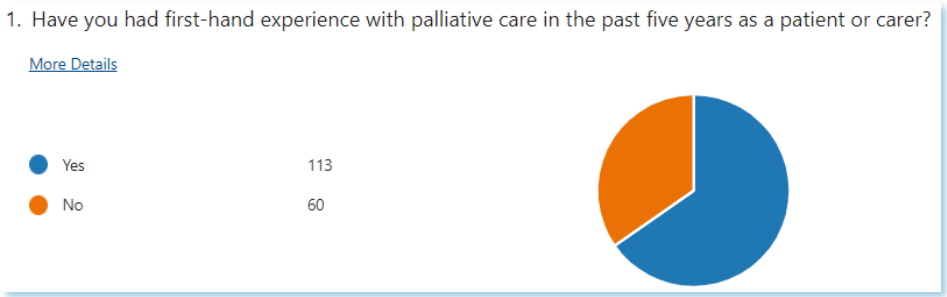
Online survey findings

From 19 April to the 9 May 2024, an online community survey was published and promoted to help inform the design of the palliative care unit expansion at Nepean Hospital and improve the patient and carer experience.

In total, 173 responses were received with 64 per cent working for NSW Health. Women made up most respondents at 90 per cent, while men made up 7 per cent. Most of those who completed the survey were from the 50-75 age group followed by the 31-50 age group.

Below is a summary of the findings to be considered in project user groups and key decision-making points for the project at Nepean Hospital.

A list of all the questions and multiple-choice answers are provided at the end of the report.
Out of the 173 responses, 64 per cent of respondents had first-hand experience as a palliative patient or a carer/ family member of a palliative patient.



Respondents who had a first-hand experience in palliative care as a carer/family member were asked to answer an open-ended question answering what the most important thing about a previous experience in palliative care was that they wanted us to consider in the design of the new unit.

Most referenced the important of having a supportive space for families to visit and stay in the unit and ensuring the unit was welcoming and offered a "home-like" experience.

Many wanted the unit to be calm, quiet and private with single patient rooms and outdoor spaces. A few mentioned the importance of having a cultural and sacred space, one of which also referenced the importance of having a cultural space to cater for large families particularly for Aboriginal and Torres Strait Islander people. Other elements mentioned included having a spaces that were pet friendly and family friendly for those with young children. If there were shared rooms, it was mentioned for patients of different genders to not be mixed.

"Making the unit inviting, home like experience. Space for family members, relaxing gardens, kitchen areas, facilities for family members to easily shower/toilet."

"A non-clinical feel with the ability to manage your own heating/cooling & lights. From my experience of my Dad passing, towards the end of his life he needed lights dimmed and as his body was unable to regulate his temperature, air con was important to have him feel comfortable."

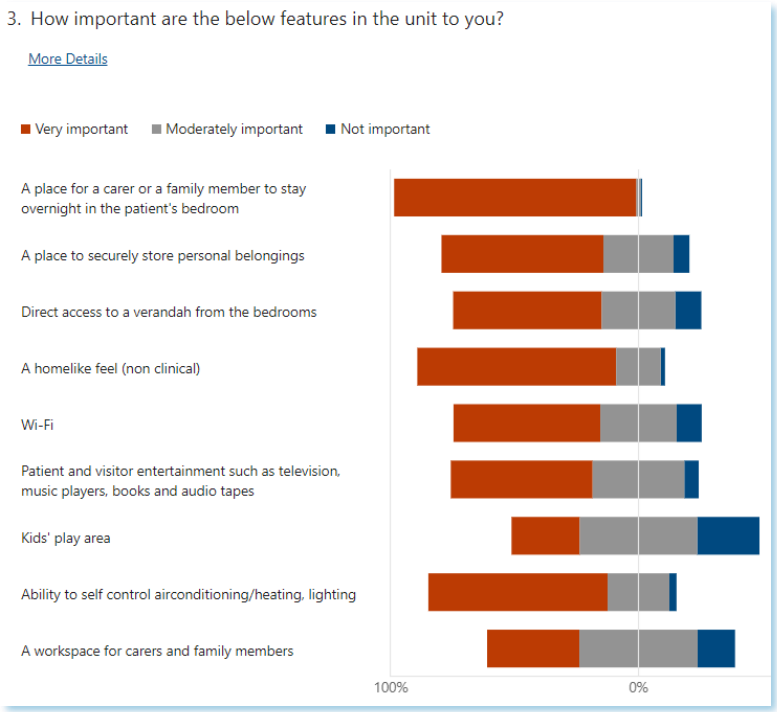
Design features based on importance

Respondents were asked how important the below features were to them with a set list of options for them to answer from very important to not important.

98 per cent marked *a place for a carer or a family member to stay overnight in the patient's bedroom* as very important. It was followed by a *homelike feel (non-clinical)* which 80 per cent marked as very important.

72 per cent of respondents marked the *ability to self-control air conditioning/heating and lighting* as very important.

The least important was a kids' play area with 25 per cent marking it as not important.



Dedicated quiet room

Respondents were asked how they would see a dedicated quiet room for reflection or prayer being used and what should be included in the room.

Most saw this room being used by people of a range of different religions and cultural backgrounds. People requested for tissues, soft furnishings, candles, soft or adjustable lighting, carpet, stained glass windows, calming colours and art, comfortable lounge chairs, tea/coffee facilities, and a window out to a calming outlook. Some also referenced having a meditation corner with pillows and space for yoga mats. Some requested for cultural symbols to be included to make the space inclusive for everyone.

"(…) Not everyone is religious, and the spaces needs to be inclusive for everyone. Include pictures of landscapes, birds as they lead us home."

"If I had a family member dying, I would use this space to pray and have quiet reflection."

"Non denomination, respectful of culture without being intrusive."

Colour palette and art

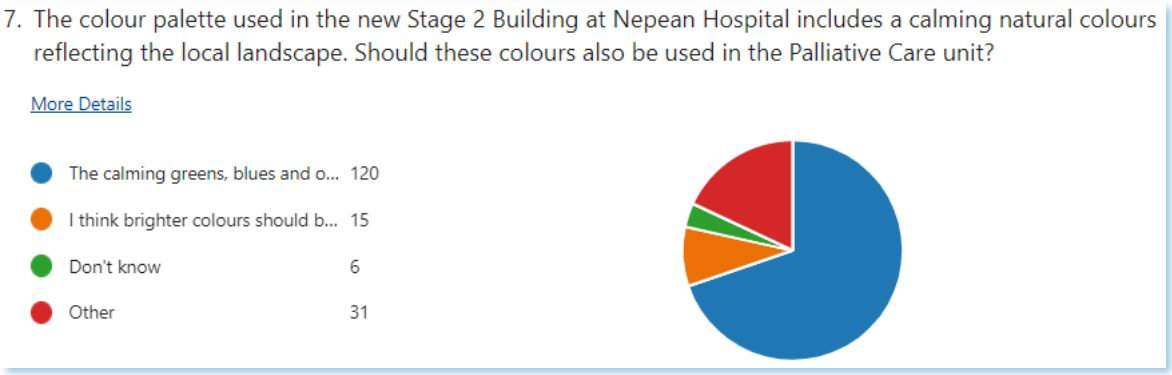
When asked on their preference of colour palette for the new palliative care unit, respondents were able to choose from four options. The most popular was calming greens, blues and oranges based on the natural environment at almost 69 per cent. About 18 per cent chose other and gave a range of responses including asking for colours that would 'age well' rather than being trendy. A couple preferred brighter colours and others preferred calming pastel colours with some saying they did not like the oranges in the first option.

"Soothing/calming pastel colours. Please don't use the normal Hospital colours that are in our Hospitals as they make it too Clinical and cold."

"I favour blues and lavenders. the bush palette is too dull."

When asked on artwork, respondents could pick up to three options from a list with the option to choose other.

There were 115 responses marked for *artwork that captures the local flora and fauna*, followed by *artwork that features calming landscapes and colours inspired by nature* with 103 responses.



Outdoor privacy

Respondents were told that in-patient rooms would have access to private and communal outdoor spaces and asked how they would like privacy to be created in the outdoor spaces with the option of picking at most 2 options. *The use of green, living foliage* was the clear preference with 129 responses, followed by *furnishing, decorative pieces eg. Water foundations, statues* with 84 responses.