

WORLD CLASS END OF LIFE CARE PROGRAM Nepean Palliative Care Unit Aboriginal Engagement Report

March 2024

On 20 February 2024, the project team sought feedback from Aboriginal community representatives about the design of the new Palliative Care Unit at Nepean Hospital.

Summary

This report outlines the findings of two Aboriginal Engagement Consumer Focus Groups held informing the patient experience and design of the new dedicated Palliative Care Unit at Nepean Hospital. Consumer input will be considered by the Project Team through the planning and design process for the new facility.

The Aboriginal Health Unit worked with the project team to invite community members and staff.

Two one-hour sessions were held on 20 February 2024 with 15 attendees in total. Sessions were held in the afternoon and evening. Each session had approximately 6-8 participants to facilitate opportunities for thoughtful discussion.

Participants were provided information about the project and the purpose of the consumer focus group, which was to inform the design and patient experience in the new facilities.



- The patient and family experience
- Culturally appropriate spaces
- Bedrooms and internal spaces
- Outdoor areas.

Facilitating the sessions were the following staff:

- 1. Rachel Scobie, Director Aboriginal Health, LHD
- 2. Darryl Hamilton, Aboriginal services coordinator, LHD
- 3. Belinda Berryman, Communication and Engagement Manager, HI
- Linda Ora, Palliative Care Project Manager and Clinical Nurse Consultant, LHD
- 5. Pia Lambert, Clinical Nurse Consultant, LHD
- 6. Leonie Weisbrodt, Redevelopment Program Manager, LHD
- 7. Nicole Pierre, Senior Officer, Communications and Engagement, HI
- 8. Rebecca Cooper, Project Officer, Nepean Redevelopment, LHD
- 9. Julia Sutcliff, Architect, BVN
- 10. Firas Al-Timimi, Project Manager, Capital Insights



The groups were asked a combination of the below questions as prompts:

- What is one of the biggest challenges faced by Aboriginal people when accessing palliative care?
- How can our design support families and carers?
- How do we make the outdoor and indoor spaces feel welcoming and safe for Aboriginal people
- What kind of cultural practices do we need to support in the new unit?

Open discussions were facilitated by Rachel Scobie and Belinda Berryman.

The groups also provided feedback to two case studies describing potential Aboriginal patient journeys and experiences within the future palliative care unit.

Facilitators wrote responses on post-its which were then collated underneath headings of patient/family experience, cultural spaces, bedrooms and internal spaces, and outdoor areas.

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

Patient and family experience

Participants said the Palliative Care Unit should be 'homely' rather than appearing too clinical. They also requested patient rooms and communal areas that were big enough to cater for larger families.

Families also want unrestricted 24/7 access to the unit. It is not uncommon among Aboriginal and Torres Strait Islander people to have one person nominated as the main family leader who liaises with health staff on behalf of the family.

Members suggested a brochure on how to access the unit as well as having someone to greet at the reception. They also requested to have a direct phone number to the Unit to call after hours.



The groups agreed there was not a one-size-fits-all approach in dealing with Aboriginal people in Palliative Care. They asked for nurses to have cultural training and that the attitude of staff and building trust was important. They also asked for more Aboriginal doctors and nurses employed in the Palliative Care Unit.

There was also an understanding of being able to conduct practices respectfully without hindering the experience for other non-Aboriginal patients with consideration to CALD patients.

Members said they did not want to be rushed after death and preferred the mortuary to be in the same building as the Palliative Care Unit.

Key points discussed

- · Décor homely feel
- Being 'up high' (on Level 7) is okay, as long as there is connection with outside such as 'views of the sky'
- 'Not one-size-fits all' approach when dealing with Aboriginal people
- Creating a safe and comfortable environment
- Embracing diversity in the area
- · Ability to cater for larger crowds
- · Having easy access to loved ones after death
- The nursing staff play an important part attitudes, cultural training, building trust
- Privacy, adaptability
- · Value of Aboriginal health workers in the unit
- 24/7 access
- Reception and greeting
- Not wanting to deal with racism. Wanting to be welcomed rather than scrutinised when entering the unit after hours as an Aboriginal person
- Identify family leader main person to liaise with staff on behalf of the family. Families rely on elders as much as parents
- Brochure on how to access the Unit
- Art therapy, aromatherapy
- Memory making
- · Ability to bring in and share food
- Support for a 'Jolly trolley' (alcoholic beverages) ability to have smoking or vaping outside
- Resources on dealing with grief. Flexibility and time to grieve

Culturally appropriate spaces

The participants said that gathering spaces were important and that smoking ceremonies should be able to be conducted in a space that is both safe and respectful to other patients.

While as part of Aboriginal cultural there is a preference for connection to the land, some did suggest that the location on Level 7 did provide an important connection to sky and the moon. Being able to engage the senses by having outdoor space to feel the elements was also important.



Multiple participants also suggested having a room for family and friends to gather in before entering the in-patient room.

In terms of décor, rooms themed with native flowers were raised as well as having signage with Aboriginal language. Signs in an outdoor area showing the distance of different Aboriginal countries from Nepean Hospital was also brought up and widely agreed by the group.

Art and music therapy were also suggested including a place to play didgeridoos and clapping sticks as well as weaving and rock painting.

A memorial statue or installation was raised to recognise those who have passed as well as a dedicated area for remembrance ceremonies incorporating sand.

Key points discussed

- Gathering spaces are important, cater for big families (50-200 people)
- Smoking ceremonies ability to conduct in a safe space but also being respectful to other patients
- · A room to gather prior to entering the in-patient room
- Pastoral care offering
- Connection to the sky is important
- Give Aboriginal people the space to adapt and be safe
- · Feel the sun and breeze, ability to touch nature
- Spaces to share food
- · Native-themed rooms in terms of décor
- The healing power of storytelling
- Place to play cultural music didgeridoos
- · Write names of loved ones on rocks
- Signage on distance of different Aboriginal countries from Nepean
- Using Aboriginal language signage
- Statue to recognise those who have passed, place for remembrance ceremony
- · Using sand for cultural spaces

Bedrooms and internal spaces

Participants said open spaces which were also flexible for multiple purposes were important.

In the bedrooms, participants wanted the ability to personalise their space, have day beds, and plenty of space for visitors. They also requested speakers that could play calming natural sound of active rivers and birds. Being able to conceal clinical equipment in the design on patient rooms was also raised.

A couple of people said Mount Druitt Hospital's Palliative Care Unit should be used as inspiration for the look and feel of the new unit, while another woman said she also liked Bear Cottage.

In terms of décor, participants suggested artwork and colour schemes inspired by nature and the Blue Mountains.

Participants also requested a virtually enabled Palliative Care Unit with the ability to do video conferences and phone casting on televisions.

Key points discussed

- Open spaces important
- Home like décor indoor and outdoor Mt Druitt PCU and Bear Cottage being a point of reference
- Flexible spaces
- Being able to personalise space
- Interiors inspired by nature, flowers and the Blue Mountains
- · Bringing the outside in
- Access to sounds in system music, river sounds and birds sounds
- Bird feeders
- Connectivity to outside world easy to see night sky, peaceful setting

- · Kid friendly area, wall games
- · Extended family space and room
- · Virtually enabled PCU, webcam to cast phone, teleconference facilities, space for television
- · Hiding clinical services in design
- Day bed for carers

Outdoor areas

The group requested an outdoor area which used natural materials and mobile planter boxes to help personalise verandahs outside patient rooms. For plants, natives, medicinal plants, Wattle, and Eucalyptus leaves were preferred.

A water feature, sensory garden, fish tanks and an outdoor mural inspired by nature were suggested.

To ensure the outdoor areas can be used in a range of weather conditions, a shade sail with digitally printed artwork was suggested. Participants also recommended naming the outdoor area or garden an Aboriginal name and working with Muru Mittigar to help with the landscaping.



Key points discussed (Outdoor spaces)

- Using natural materials outside
- Native medicinal plants, Eucalyptus leaves/tea tree, Wattle. Plants that attract birds
- Personalising planter boxes
- · Water feature, sound of water
- · Sensory garden. Garden of reflection, rain roof
- Nature-themed mural
- Fish tanks with native fish
- · Digitally printed sunshade
- Give the garden an Aboriginal name. Bring Muru Mittigar for landscaping. Workshops on using Aboriginal plants
- Feeling elements water, rain, sky
- · How to cater for those who are afraid of heights