

## Consumer, staff and community engagement to inform design and patient experience

### Summary

Westmead is one of five hospitals to build either new or redeveloped Supportive and Palliative Care units as part of the \$93 million funding allocation from the NSW Government. This report outlines the findings of consumer staff and community engagement, between March and July 2024 to inform the patient experience and design.

Key themes which emerged during engagement included the importance of flexibility for families with easy parking and after-hours access, and a place for carers or family members to comfortably stay, gathering spaces and places where children and pets can visit. A place that is welcoming, quiet, calm and homely.

Discussions on patient rooms focused on preferences for single spacious rooms with amenities like carer day beds, seating space for visitors, and spaces for personal items.

Participants also emphasised the need for privacy for families, and homely décor to create a comforting environment. Communal areas such as a communal kitchen, quiet rooms, and family-friendly areas and spaces for children were also discussed. Artwork was recognised as healing as well as providing a symbol of cultural safety and inclusion.

The importance of the overall patient experience was frequently raised, including personalised care, compassionate staff, and support for families throughout the supportive and palliative care journey.

Participants also noted the importance of outdoor areas and the ability to bring beds outside to experience the fresh air.

The engagement outcomes captured in this report have periodically been provided to the design team to consider as part of the concept and schematic design process.

The design process has also been informed by supportive & palliative care research undertaken in late 2023 by Western Sydney Local Health District regarding the specific experiences and needs of Aboriginal and multicultural consumers when experiencing supportive and palliative care in Western Sydney.

The project team will continue to engage with consumers, staff and the community to inform the detailed design of the project.

### Engagement

#### August – December 2023: Project User Groups - design

**Summary:** Two consumers attended four project user group sessions to inform early design. The topics discussed included patient rooms, entry design, views from rooms, communal area, multi-faith room, volunteer spaces and storage, veranda design, outdoor areas, landscaping, clinical areas, lighting, floor treatments, position of the daybed/carers overnight bed.

**Outcomes:** the feedback from the consumers was communicated directly to the project managers and architects during the meetings to be considered in the design process.

## March 2024: Consumer visit and meeting to inform location and concept plans for the new unit

Summary: 5 consumer representatives along with four Western Sydney Local Health District supportive and palliative care specialists were presented with preliminary concepts and design principles and then undertook a site walk to inform the location of the new unit. The following was discussed:

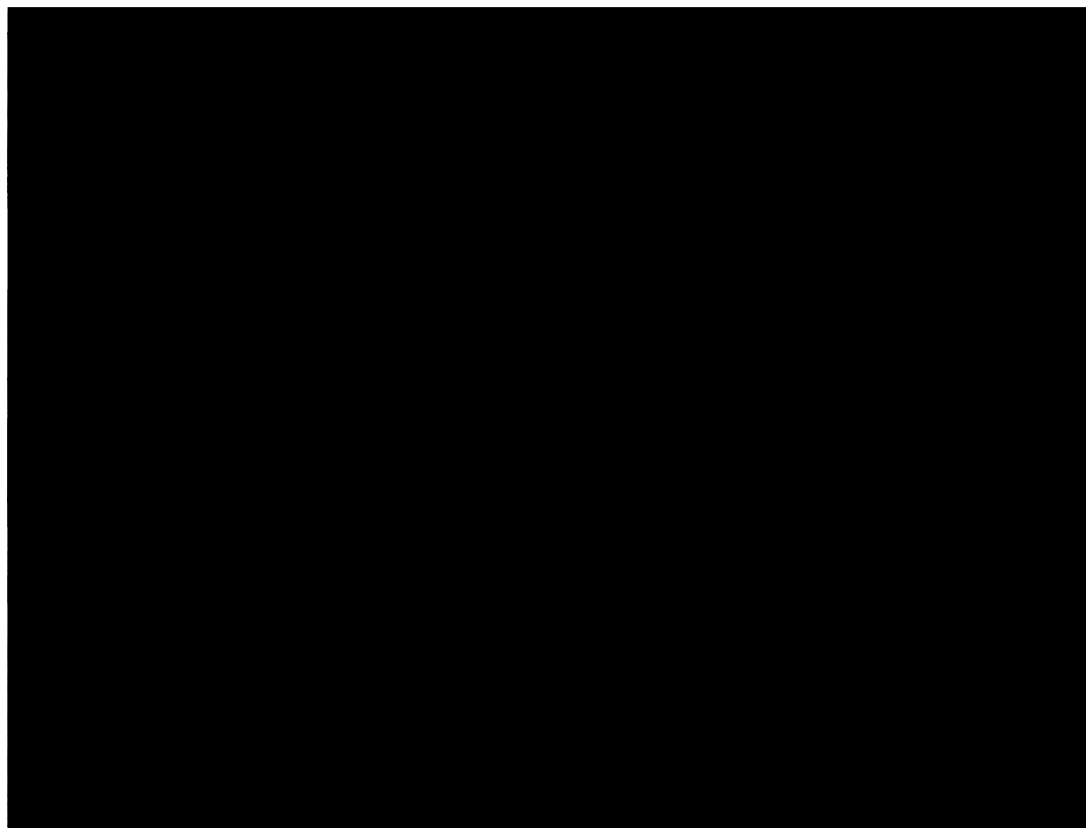
- Arrival experience
- Connection to the outdoors
- Room size
- Room fit-out
- Quiet comfort
- Timeframe for delivery
- Funding
- Arts program
- Consultation process.

Specific outcomes, feedback and comments:

- Strong support for the project.
- The connection to the outdoors and the importance of a garden was strongly supported.
- It was noted that bathrooms should be separate and seamless from the rooms.
- Consumers supported the room layout which places the overnight carer bed in the area away from the door. This design ensures that clinical staff can attend to the patient at night without disturbing the carer.
- Personal fridges were supported.
- Support for carers beds. *As consumer reps we've been involved in other developments so we know the carer beds are a must. Issues like shelving, somewhere to put your toothbrush, is really important as well, otherwise it feels like you're in a camping area. Those little things can be quite important to people to be able to do the normal stuff of life.*
- It's important to minimise noise from the nurses' station.
- The location was supported noting patients will have a view and have gardens.
- Support for how swiftly planning has occurred.

## May 2024: Youth Council Consultation

Summary: We spoke to a group of 12 members of the WSLHD Youth Council, aged 16-25, about the design plans for the new unit and sought feedback.



*WSLHD youth consumer council*

A summary of findings is overpage

Topic	Consumer comment	Project comment
Artwork	<p>Space to display personal pictures is important.</p> <p>If there are existing hooks in the walls, patients can bring their own artwork, swap it around or choose from an art library.</p> <p>It would be good if you could paint on the walls or have a chalkboard.</p> <p><i>Comment: I've been to some units where there's really beautiful Aboriginal art and it was blue and really calming, there were softer floral artworks as well. Artworks really add to the place and make you feel much more comfortable.</i></p> <p><i>Comment: Artworks really add to the place and makes you feel a lot more comfortable.</i></p>	Project team will advise design team.
Beds	<p>Hospital beds look institutional. Can the unit have beds that look more domestic?</p> <p>It would be good to have bed drapes or quilts that cover the wheels so it looks more homelike.</p>	Noted. The project team will liaise with the Youth Council when furniture selections are more progressed.
Veranda privacy	<p>The veranda area needs more privacy between patients.</p> <p>Could have drapes or folding screens/collapsible walls between patients on the veranda – like on cruise ships.</p> <p><i>Comment: If you're going to have a view of something that's natural you probably don't want a lot of people around you. That can have an impact on the family. It looks like everyone is right next to each other.</i></p>	The project team advised that the garden views are early concepts but the feedback and suggestions will be provided to the design team.
Gardens	<p>Community garden.</p> <p>Outdoor café area or bar-style seating area (like a tiki bar) would be nice.</p> <p><i>Comment: It would be good if they could have a community garden where they could grow veggies and flowers.</i></p>	Noted.
BBQ community can get together	Need a BBQ area in the garden	Noted. Area for a BBQ or outdoor family gathering has been discussed.
Aboriginal Gathering Place	Plan for gathering place	The project advised that an Aboriginal cultural element will be included in the design so Aboriginal people feel welcome.
Shade	<p>Looks like there is not enough shade especially as trees will be new.</p> <p>Need mature trees and shade.</p>	The project team explained that it sometimes takes a while for a garden to be established. Need for shade and desire for mature trees will be advised to the design team.

Water features	<p>Wishing well or pond should be considered</p> <p>Pond would be good idea - can be self-sustaining and low maintenance</p>	<p>Noted. The project advised that water features require maintenance, and this is a consideration. However, need for water features will be considered.</p>
Pets	<p>Important to be able to see pets and bring them into the unit.</p> <p>Pets are very therapeutic, and people want to see their pet.</p>	<p>Noted and this is considered in the plan. There is allowance for pets to visit as this area is quite different from other patient areas.</p>
Kitchenette	<p>Will there be a kitchenette in each room?</p> <p>Fridge is needed.</p> <p>Why not a sink?</p> <p><i>Comment: My grandfather is in a place like this at the moment, but he really likes making tea. Especially when people come, he likes to make tea for them. We had to sneak a kettle into his room. If there was an instant hot water system that would be a bit better so they can make themselves a cup of tea.</i></p>	<p>Project advised that there are patient, carer, and social zones.</p> <p>Bathrooms are nested.</p> <p>Medical panels are discreet.</p> <p>Furniture will be soft and homelike.</p> <p>Bar fridge will be provided in each room.</p> <p>Sink/kitchenette in the rooms is not possible due to infection control, hygiene, and cleaning.</p> <p>Kitchen facilities are in the social zone.</p>
Patient TV	<p>Would be good to provide Netflix and streaming services.</p>	<p>Project advised that Bring Your Own Device has been considered for the new unit.</p> <p>Streaming and TV services will be advised closer to the time.</p> <p>At Auburn TV services for palliative care are free and that will be considered.</p>
Dimmable lighting	<p>Was supported by the group</p>	
Technology	<p>Rooms need speakers so music can be played on a low volume for ambience.</p> <p><i>Comment: A lot of people listen to white noise when they sleep or rain sounds so speakers would be cool if that's possible.</i></p> <p><i>Comment: I'm assuming the target group is older people but it would be good to have a console like a Nintendo in the lounge area if there are families and they want to play games.</i></p>	<p>Noted.</p> <p>Play/recreation area being explored as part of design for children and young people who are visiting.</p>
Quiet space	<p>Are quiet spaces available?</p> <p>Is there an alternative quiet space if the multifaith room is being used? Multifaith room is still public space.</p>	<p>Multifaith room available</p> <p>Quiet garden designated</p> <p>Other multipurpose interview, consultation and meeting spaces are flexible if the multifaith room is in use.</p> <p>Staff will usually be able to find a quiet space when needed.</p>
Library	<p>Will there be a library?</p>	<p>Open shelving area available in the social zone that could be used as a library.</p>

Floor covering	Carpet would be better for a homelike atmosphere. Should consider rugs or other soft floor covering.	Noted – will be considered as part of selecting furniture and fittings.
Storage	Storage needed for personal items.	Ample storage areas have been briefed.
Nurse call	Is nurse call/assistance available? Do they need to have portable alarms?	Nurse call will be available like a normal hospital bed. Wearable alarms are not usually provided as Nursing staff check on patients regularly.
Meeting areas	Meeting and staff areas need to have the safe soft and calm design aesthetic	No images available at this stage but interview/consultation and meeting rooms will have the same colour palette and welcoming ambience.
Vases	Need lots of vases because you never find one when you need one.	Have discussed space for volunteers' storage for gardening. Will brief to design team.
Diversional therapy	Would be good to have activities like crafts for people to do. <i>Comment: It creates a sense of community because when you're with people all the time you may want to talk and it provides a chance to socialise.</i>	Noted. Will advise service team.
Social area	Social area looks too small. If you have more than one family in there, they wouldn't fit.	Noted. Project team will be able to provide more detailed plans at next session to help everyone understands the dimensions.
Multifaith room	If someone passes away in the unit can the multifaith room be used as a grieving space?	Yes – the project team advised that this is the intention. Other multi-purpose rooms can also be used. We discussed the different grief responses of different cultures, and how the unit is designed to accommodate the needs of diverse communities.
Location	Where will the unit be built?	The project advised it will go on a rooftop area and the location will be announced in mid 2024.

## May 2024: Consumer and staff survey

Summary: In early 2024 an online staff survey was published and promoted to help inform the design of the palliative care unit expansion at Westmead Hospital and improve the patient and carer experience. The survey closed on 31 May 2024.

13 responses were received. 10 of the 13 respondents had first-hand experience as a palliative patient or a carer/ family member of a palliative patient. 6 of the 13 respondents work at WSLHD, in NSW Health or another health service provider. 5 respondents were between 50 and 75 years, 3 were 31-50 years, 3 were 18-30 years, 1 over 75 and 1 under 18.

### Summary of findings

**Question: Is there anything you would like to tell us about your previous experience that would help us to create a better design for our new unit?**

In order of importance the following items were noted as positive experiences with previous palliative care units:

Feedback	No.	Models of care	Design elements	Furniture, fixtures and fittings (Including ICT)	Other
Outdoor spaces and the ability to bring beds outside	3		•		
Flexibility to allow for needs of family members, for example staying in the patient's room and being able to come and go, bedding/recliners and flexible visiting hours	3	•	•	•	
Engaging, homely and peaceful, natural light and views	3		•		
Fridge/microwave availability to prepare food, a dining area and kitchenette	2		•	•	
Ability to access greenery	2		•		
Carer facilities are important including relaxing spaces	2		•		
Rooms big enough for patients, staff and visitors	1		•		
Access to prayer room on same level	1		•		
Single rooms	1		•		
Access to wheelchairs as required	1	•		•	
Easy access to the service to avoid long walks, and provision of easy wayfinding	1		•		•
Close to home					•

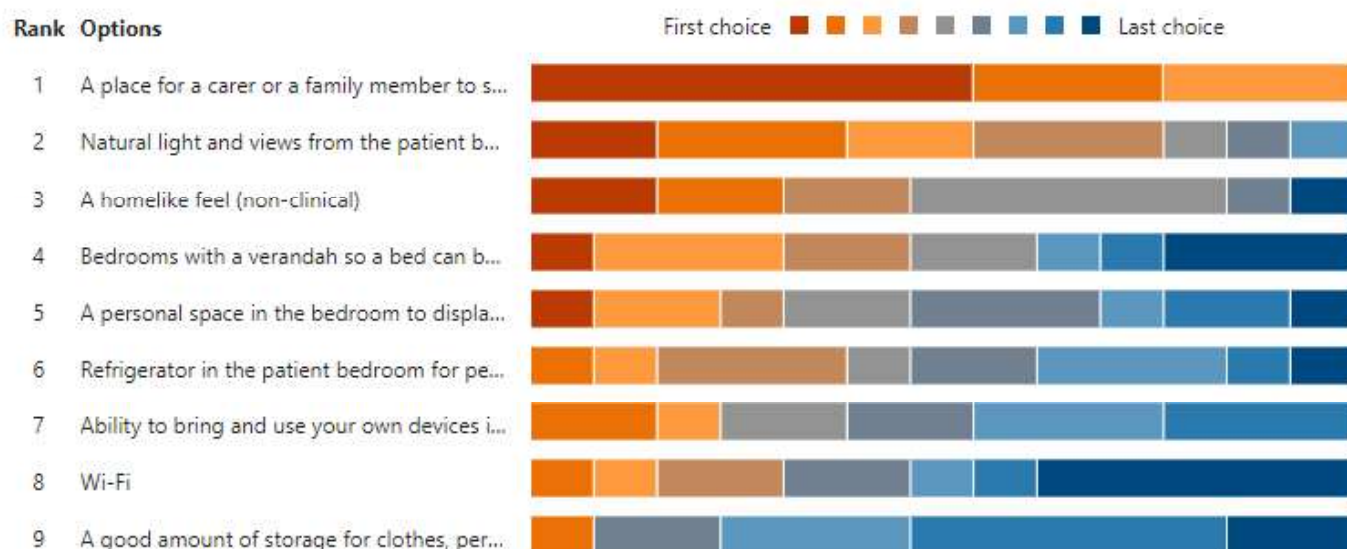
**Question: This question is about patient bedrooms. Please tell us what's important to you by ranking the following options most important to least important.**

The criteria, in order of importance is listed below.

Feedback	Models of care	Arts in health	Design elements	Furniture, fixtures and fittings (Including ICT)
A place for a carer or family member to stay overnight in the patient's bedroom (carer bed)			•	•
Natural light and views from the patient bedrooms			•	
A home like feel (non-clinical)	•	•	•	•
Bedrooms with a verandah so a bed can be moved outside			•	•
A personal space in the bedroom to display a patient's belongings and meaningful items			•	•
Refrigerator in the patient bedroom for personal food items			•	•
Ability to bring and use your own devices including convenient power points for charging devices while you are using them			•	
Wi-fi				•
A good amount of storage for clothes, personal items and carer belongings			•	•



The table below provides further details on criteria preferences.

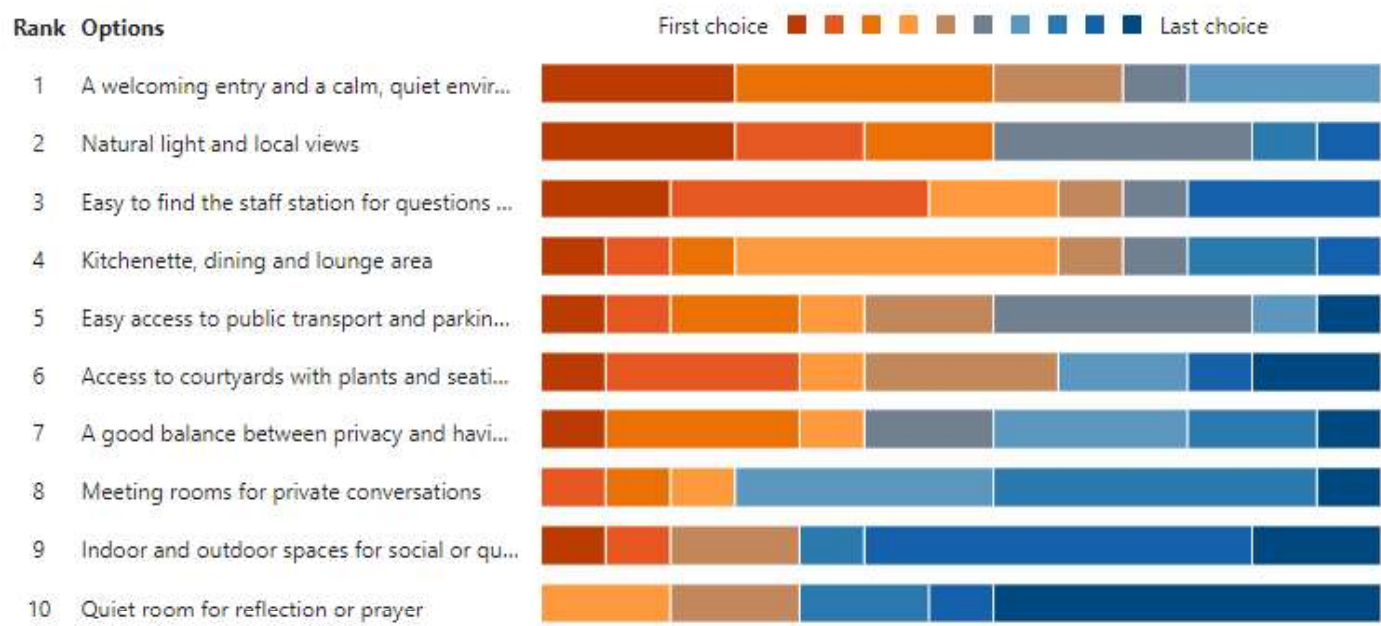


**Question:** This question is about the plan for the new unit. Please tell us what's important to you by ranking the following options most important to least important.

The criteria, in order of importance is listed below.

Feedback	Design elements	Furniture, fixtures and fittings (Including ICT)	Other
A welcoming entry and a calm, quiet environment on the ward	•		
Natural light and local views Easy to find the staff station for questions or help	•		
Kitchenette, dining and lounge area	•	•	
Easy access to public transport and parking			•
Access to courtyards with plants and seating areas	•		
A good balance between privacy and having access to communal indoor and outdoor spaces	•		
Meeting rooms for private conversations	•		
Indoor and outdoor spaces for social or quiet activities	•		
Quiet room for reflection or prayer	•		

The table below provides further details on criteria preferences.



**Question: Calm and soothing colours which reflect the natural environment have been suggested for the new unit. The includes soft greens and neutral colour. What do you think of this plan?**

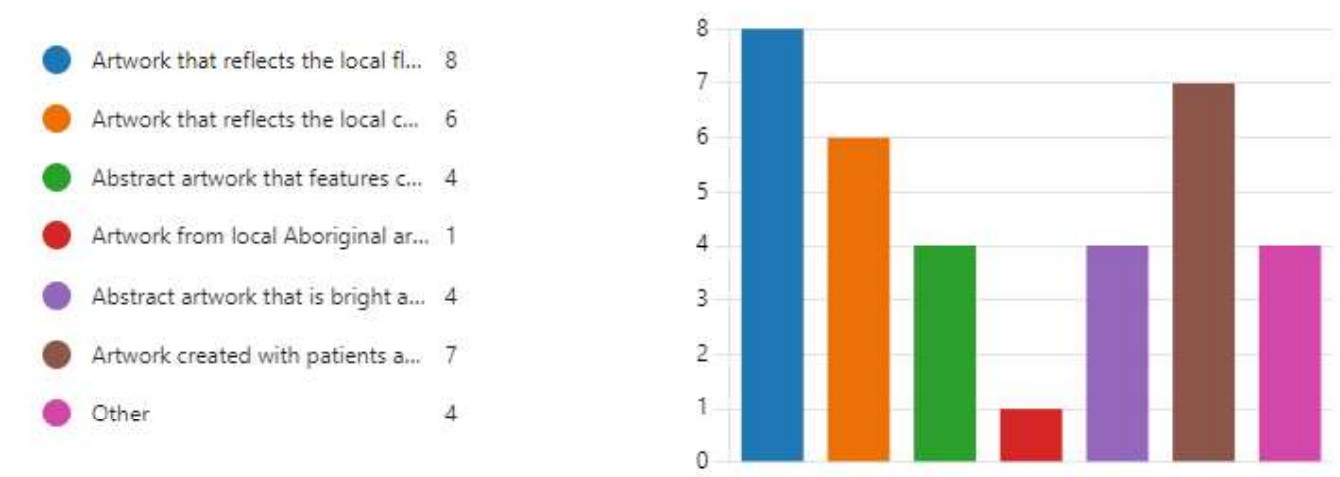
All respondents agreed with this colour palate suggested.

**Question: Integrating art into the new Supportive and Palliative Care Unit will help create a welcoming and uplifting space. What theme of artwork do you think the hospital should feature in this space?**

The criteria, in order of preference is listed below.

- Artwork that reflects the local flora and fauna
- Artwork created with patients and families
- Artwork that reflects the local community – friendly faces and recognisable landmarks
- Abstract artwork that features calming, muted colours
- Abstract artwork that is bright and colourful
- Artwork from local Aboriginal artists
- Other

The graph below provides further details on these preferences.



**Question: Do you have any other ideas for how we could make the unit more comfortable and inviting?**

Key themes arising include:

Feedback	Models of care	Design elements	Other
Spaces for family time, accommodating for children and adults, including a TV and other entertainment, for example card games, soft music and spaces to reflect		<div></div>	
Private spaces for phone calls and important family discussions		<div></div>	
Avoiding through traffic from other wards		<div></div>	
Views and access to a verandah (such as at Mount Druitt)		<div></div>	
Supply of linen such as blankets			<div></div>
Visitors such as musicians, massage therapists and counselling service	<div></div>		
Accessibility and wayfinding		<div></div>	
Interpreters, as required	<div></div>		
Orientation and introduction including where to find things	<div></div>		

**Question: Describe what a great palliative care service looks and feels like to you as a patient, family member, carer or visitor**

Key themes arising include:

Feedback	Models of care	Design elements	Furniture, fixtures and fittings (Including ICT)	Other
Attentive, friendly, calm and caring staff, access to staff and quantity of staff	•			
Continuity of care between outpatient appointments, community services and inpatient care as much as possible	•			
Clear communication with carers and patients	•			
Calming, friendly, professional (but non-clinical) and accommodating environment that is a nice place to visit and make connections. A place that also supports families		•		
Meal service for patients, apart from the cafes				•
Reducing the need to travel by integrating with other hospital services in the same location				•
A unit where patients can stay if needed and be cared for allowing families to concentrate on time with their loved one	•	•		
Respect for the speciality of palliative care and appreciation of staff, including the care for families. Recognition that the unit requires its own space, rather than being in other wards	•	•		
Access to the outdoors, such as wheeling the bed onto the verandah		•		
Bringing home comforts including pets, and a space for personal things like family photos		•		
Soft colours and comfortable chairs for long periods of sitting			•	
Ability for carers to stay overnight with patients and not feel rushed	•	•		

Family spaces that are welcoming and offer privacy		•		
Support for technology, for example to call loved ones far away. Good wi-fi, BYOD and access to an ipad		•		

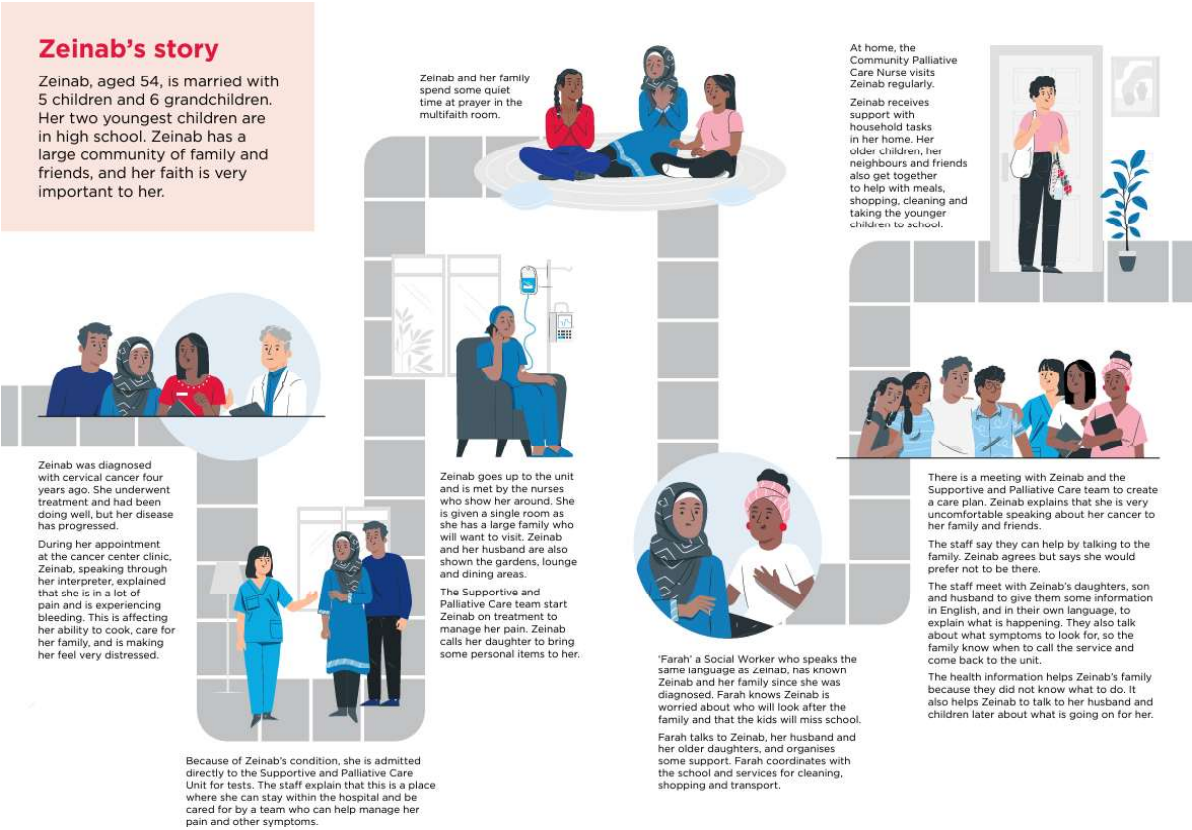
**Question: Is there anything you would like to suggest or make a comment about?**

Key themes arising include:

Feedback	Models of care	Arts in health	Design elements	Furniture, fixtures and fittings (Including ICT)	Other
Artwork make a space feel less clinical, for example, the mural on the wall in respiratory		•			
Many families inside and outside of the room can make it difficult for other families. Creating a respectful environment is important			•		
Support for the project and need recognised for a dedicated unit					•
Provision of all single rooms			•		
Access to a garden			•		
Private spaces on the verandah.			•		
Parking for family members visiting regularly and parking validation at all hours					•
Ease of afterhours access					•
Wayfinding, noting Westmead can be hard to navigate for new people			•		

June 2024: Consumer journey maps – youth, Aboriginal and multicultural consumers

Summary: In mid-2024 draft supportive & palliative care journey maps were developed for consultation with Aboriginal, multicultural and specialist stakeholders. The journey maps detail the journey of three people, with different experiences, through supportive & palliative care. The journey maps are used to inform patient experience and aid in consultation.





**Owen's story**

Owen is 21. He loves sport, has a supportive family, is studying engineering at university, and has a long-term girlfriend, Emily. He was diagnosed with leukemia 12 months ago and had intensive chemotherapy and a bone marrow transplant.



During a routine cancer care outpatient appointment, tests show Owen has an infection. He is admitted to a general ward and given antibiotics, but he develops a fever, and his blood tests show his condition is deteriorating.



Owen's condition worsens. Owen's haematologist has a family conference with Owen and his parents to explain that no further treatment is possible. Owen is referred to the Supportive and Palliative Care team. The team will work with Owen and his family, as well as the haematology team, to maximise his quality of life, while planning for his end-of-life care.



Owen needs to stay in hospital, but he wants to see his girlfriend, Emily, sister, mates and extended family. He moves to the Supportive and Palliative Care Unit where Emily and his immediate family can take turns staying overnight with him. Emily and his family bring in books and photos for Owen's room and display his favourite football club jersey and trophies.



Owen's friends spend time with him in his room, in the gardens and in the lounge area where they can watch TV and play games, but they don't know how ill he is. It's hard for Owen to share the news with his friends. Emily and Owen's parents speak to a clinical psychologist about being overwhelmed. The psychologist provides them with information, counselling, and support.

Owen wants to go home for a few days to see his dog and his mates. The unit organises to send Owen home and they set up a bed and equipment at the house.

Owen's family and mates come around to watch the footy and have a celebration. They share lots of memories, take photos and record video messages from him. He has lots of time with Emily, his family, and his dog.



Six weeks later, the family has another follow-up visit. They ask to be referred to a bereavement counsellor. In a few months, they are invited back to the unit for a memorial service.



Owen's parents call and say he wants to come back to the Supportive and Palliative Care Unit a day early as they are finding it hard at home. He returns to the unit and dies a few days later. Specialist nurses follow up the next day with a visit to the family.

John's story

John is a proud Aboriginal man. He is 57 and has very poor health. He has a chronic condition which makes him short of breath. Due to past trauma, he distrusts the medical system and has found it too hard to come to hospital or a clinic, so he does not have a treatment plan. He knows he is very sick and will not recover from his conditions.

John's treatment starts. The Aboriginal Palliative Care Officer from Supportive and Palliative Care comes to talk to John as well as the doctors, nurses and social worker.

John likes the environment, especially when his kids and extended family come to visit. They sit in the garden in a gathering place that includes Aboriginal cultural elements.

John and his family yarn about how the space makes them feel welcome. John gets some relief from his symptoms and is feeling better.



John's wife Sarah convinces him to come to the hospital emergency department. Sarah is not coping and wants John to stay in hospital, but he is insisting on going home.

In emergency, John has identified as being Aboriginal, so an Aboriginal Liaison Officer comes to talk to him and Sarah.

The emergency department staff suggest that John and Sarah talk to the Supportive and Palliative Care team about a plan for his care.



The Supportive and Palliative Care team explain that there is a new unit where he can get support and help with his symptoms.

John agrees to go to the new Supportive and Palliative Care Unit, and the team sits outside with him in the garden area. He sees there are outdoor areas and spaces for family and friends to gather, and he can be supported by an Aboriginal Palliative Care Officer.

John likes the comfortable homely feel, Aboriginal artwork and native plants in the gardens. He agrees that he will stay and be supported in the new unit.

He can also leave the unit to go out during the day.



The team talks to John about his wishes for end-of-life care. John is relieved as he knows he is dying but was too upset to talk to his wife and family.

The staff help John with his end-of-life planning as well as his care. John says he wants to die at home when the time comes.

John stays in the unit for a few days while the staff organise care for him at home. The social worker arranges respite care for Sarah so she can have a break.



At home, the Aboriginal Health Community Nurse also comes to see John and Sarah.

She is well known and respected in the community, and they yarn about how John and Sarah want to be supported at home.

The Aboriginal Health Community Nurse explains that she can arrange for John to go back to the Supportive and Palliative Care Unit if his symptoms get worse again.

John says he is happy to go back when he needs to because he felt comfortable and respected, and he has the freedom to attend to his cultural practices during his stay.



July 2024: Aboriginal consultation

Summary: We spoke to a group of 7 Aboriginal consumers with lived experience of accessing supportive & palliative care services about the design plans for the new unit and sought feedback. In attendance was also 6 members of the Western Sydney Local Health District supportive and palliative care team including two Aboriginal education officers.

Outdoor inspiration and principles

INSPIRATIONS AND PRINCIPLES



Summary of findings

Topic	Consumer comments	Project comments
The Unit should feel homelike	<p>It should feel homely. An example was provided about another facility that didn't have a courtyard and felt too clinical. Even though the furniture was new. It was noted that the Unit didn't feel homely. It was lacking in warmth and felt staged.</p> <p>It was noted that Mount Druitt felt homely– it felt so comfortable and relaxed with the balcony, bush area, courtyard and fish. And the kids loved it.</p> <p>The Unit shouldn't be too fancy without being homely.</p>	<p>A homely environment is a key design principle and will continue to inform design going forward.</p>
Aboriginal artwork	<p>Aboriginal artwork in the rooms makes it feel welcoming. Artwork should be by local artists.</p> <p>The Unit could consider Aboriginal art on a wall for people to take a photo if they want to. It might be their last family photo so this should be considered.</p> <p>Stories could be interconnected. For example, the artwork could be connected through Westmead for continuity.</p>	<p>This is noted. Arts in Health is an important part of the design process which will be further explore during the next phase of design.</p> <p>The feedback about artwork continuity is noted however artwork beyond the Unit itself is outside of the scope of this project.</p>
Beds and carer furniture	<p>It was noted that in QLD bariatric beds are used that are big enough for two people.</p> <p>It was noted that beds should not be fixed, and they should be flexible.</p>	<p>The new Unit aim to have cuddle beds that can fit 2 people. The design so far has allowed enough room for this. The specification for the beds will be determined during the next phase of design.</p>

	If beds aren't big enough carers feels like they can't fit in. Bones can be sore and bodies frail.	Beds will be flexible and not fixed to the wall. The beds will be able to be moved outside each room.  Carer furniture will be considered later in the design however furniture needs to be flexible and consider space. The furniture, fixtures and equipment will be explored in more detail later in the design.
Tables	Big tables for families would be useful.	This is useful feedback to consider. We also need to recognise the need to accommodate multiple families so there will need to be flexibility in the family space set up. The furniture arrangements will be determined during the next phase of design.
Colour palette	The colour palette principles were discussed, and it was noted that colours are liked. The wood provides softness.	The colour palette is an important part of creating a homelike feel and it will continue to be refined throughout the design process.
The small things are important	Clocks showing the day and month and TVs are important. It's hard for families to come and watch family die when the room is so silent.	This is acknowledged, including the need for Wi-Fi to facetime family.
Entertainment for children	Young kids need to be considered. An example was provided of a mum with 4 kids who is also wanting to say goodbye to her dad.  Kids need a safe space where they can be entertained to allow space for properly saying goodbye. It's so important to have that opportunity.  Practical things that could be considered for kids includes canvases, colouring in, soft games, activities for kids in the rooms and the ability for kids to write messages.  It was noted that death is part of living. Kids need to be taken on the journey and will help them cope later in life. Children experience and share sadness too.	A family area will be included as part of the Unit which will consider what kids need for entertainment and to also be accommodated in their journey. There will also be Wi-Fi for BYOD.
Design of outdoor spaces	Need to be mindful of crowding outside, the Unit needs to have space for people to move in and out easily.  The outdoor divides between rooms could be higher.  Calming gardens that are homelike reduces trauma and helps people with the transition and to say goodbye.  Intensive care in Blacktown was noted as having a beautiful outdoor area.	There will be flexibility in how far people can venture outside. They will be able to stay near the room or go further out onto the veranda.  Not everyone will go out at the same time. Some people may just like the breeze with a door open and feeling of connection to the outdoors.  The outside area will be designed to provide for privacy outside of the rooms with dividers. The dividers may include plants and would need to be of a height also suitable for nursing staff to have visibility of patients.
Parking	The process for parking was queried and it was noted that elderly partners shouldn't have to walk far.	Parking arrangements will be the same as what currently exists for Westmead. Family will get a

		<p>swipe card. Train station and light rail access provide another way to visit.</p> <p>Parking will be right outside K Block near the unit. The ease of parking helped inform the specific location. Parking is also available on Hawkesbury Road.</p> <p>There is a volunteer buggy service available at Westmead Hospital that can be accessed by all visitors requiring additional mobility assistance.</p> <p>Parking generally is acknowledged as an issue for many people.</p>
Claustrophobia	One participant noted issues with claustrophobia and going up lifts	It was noted that stair access will be available. It will be on level 5.
Family accommodation	Queries were raised about where people from rural areas and families will stay.	<p>Several apartments have been refurbished and are now functioning within the Westmead Accommodation Complex on Darcy Road, Westmead.</p> <p>Accommodation is also available for people who need to come in from the country for treatment and their families.</p>
Cultural practices	<p>Personal examples were provided of where cultural practices i.e. women's business was accommodated and respected and where it wasn't.</p> <p>It was also noted that cultural practices may need to occur with very little time so it would be useful to have cultural items on hand i.e. gum leaves for a smoking ceremony and spaces where this can be accommodated.</p> <p>The idea of a cultural box was discussed where ceremonial items could be retrieved with little notice and a process of noting cultural practices on admission so they can be accommodated.</p> <p>It was noted that a cultural box is used in southwest Sydney.</p> <p>A specific reference to the smell and feel of gum leaves was noted as comforting and keeping water on coolamons allows the smell to flow.</p> <p>It was also noted that wattle can be controversial depending on what the local interpretation is.</p>	<p>It was noted that it is now the practice that family is consulted as part of the model of care process.</p> <p>The design will accommodate spaces where ceremonies can be performed.</p> <p>The cultural box idea has been noted for consideration during the commissioning stage.</p> <p>Native plants will be incorporated into the design of the outdoor area – this will be the next stage of design.</p>
Rooms	Sharing of rooms i.e. women co-located with men is not OK and bathrooms should also not be shared.	The new unit will have single rooms with private ensuites and one double room with shared ensuite.
Cultural symbols	Plants and flowers, trees and a flagpole are very significant for Aboriginal families. These are underlying cultural items that others wouldn't realise.	These items are noted and appreciated

Positive experiences	<p>The following was noted as contributing to positive experiences:</p> <ul style="list-style-type: none"> <li>• Accommodating the whole family</li> <li>• A kitchen that all the family can access</li> <li>• Kids are accommodated</li> <li>• Being able to all be in the room</li> <li>• Being accommodated at the facility i.e. family can shower</li> <li>• Access to the outdoors and balcony views</li> <li>• Allowances for special things for end of life i.e. food/drink, visiting pets</li> <li>• Staff keeping the family up to date and being open and caring</li> <li>• Staff that are culturally aware</li> <li>• Being able to stay with the passed relative after they pass.</li> </ul>	These items are noted and appreciated.
Personal grooming and services	<p>It would be great to have a place for grooming – barber and nails/hair. Teeth, hair and other personal care is all important.</p> <p>One participant noted that all her dad wanted was a shave.</p> <p>It was noted that touch is important. One participant noted that when her auntie was passing, she wanted fingers run through her hair.</p> <p>Some form of massage would also be good to provide. It was noted that touch is often overlooked in elderly people.</p> <p>Volunteers could come in for hand massages for example.</p>	The rooms will allow for mobile visitors to come in for personal services like this.
Podiatry	Podiatry was noted as typically being overlooked.	This is acknowledged.
Visiting hours	Current visiting hours of 8am-8pm can be problematic. It can be difficult for families, and they may have visited from off Country and need to be accommodated.	<p>It is acknowledged that sensitivity is needed and visiting arrangements should be managed on a case-by-case basis. Carers can usually stay if their loved one's condition is changing. It was acknowledged that depending on the patient's condition, patient rest period should be taken into consideration. Staff will strive to meet specific family needs where possible.</p> <p>Sorry business is very important, and we acknowledge this.</p>
Advocacy	The group noted the importance of advocacy for Aboriginal people and told personal examples of where advocacy had been so	It is agreed that advocacy very important, especially in supportive and palliative care.

	<p>important and other instances of where there was no advocacy for the family.</p> <p>An important part of this advocacy noted was to have someone who could be a conduit between clinical staff and patients and help them understand.</p> <p>It was noted that relationships are very important. Having someone in the system who is looking after you and knows you makes all the difference.</p> <p>Nicole and Carol were recognised as making a huge difference.</p>	
Negative experiences	<p>The following was noted as contributing to negative experiences (in hospital generally)</p> <ul style="list-style-type: none"> <li>• Lack of advocacy</li> <li>• Placement in the wrong ward</li> <li>• Lack of understanding/communication between patients and staff</li> <li>• Lack of recognition symptoms of dying and palliative care, palliative care intervention too late</li> <li>• Inadequate pain relief</li> <li>• Inadequate nursing for needs</li> <li>• Not feeling heard</li> <li>• Aboriginal people not being flagged in the system early enough</li> <li>• Treatments that may not be appropriate at end of life.</li> </ul>	<p>We acknowledge that there needs to be recognition of when supportive and palliative care is needed, and advocacy is important. A part of this is close and honest consultation with the family.</p> <p>Appropriate recommendations on treatment need to be advised. These are hard conversations and sometimes patients and families may wish to pursue treatment.</p> <p>The supportive and palliative care unit will create training opportunities for other staff so they can learn how to provide high quality supportive and palliative care across the system.</p>
General feedback	<p>The mob doesn't always fit into the medical model.</p> <p>An example from QLD was provided where everybody wore Aboriginal uniforms – it made people feel included and welcome. It was also noted that some people didn't like the uniforms as it made some feel excluded.</p>	<p>Thank you for this feedback.</p>



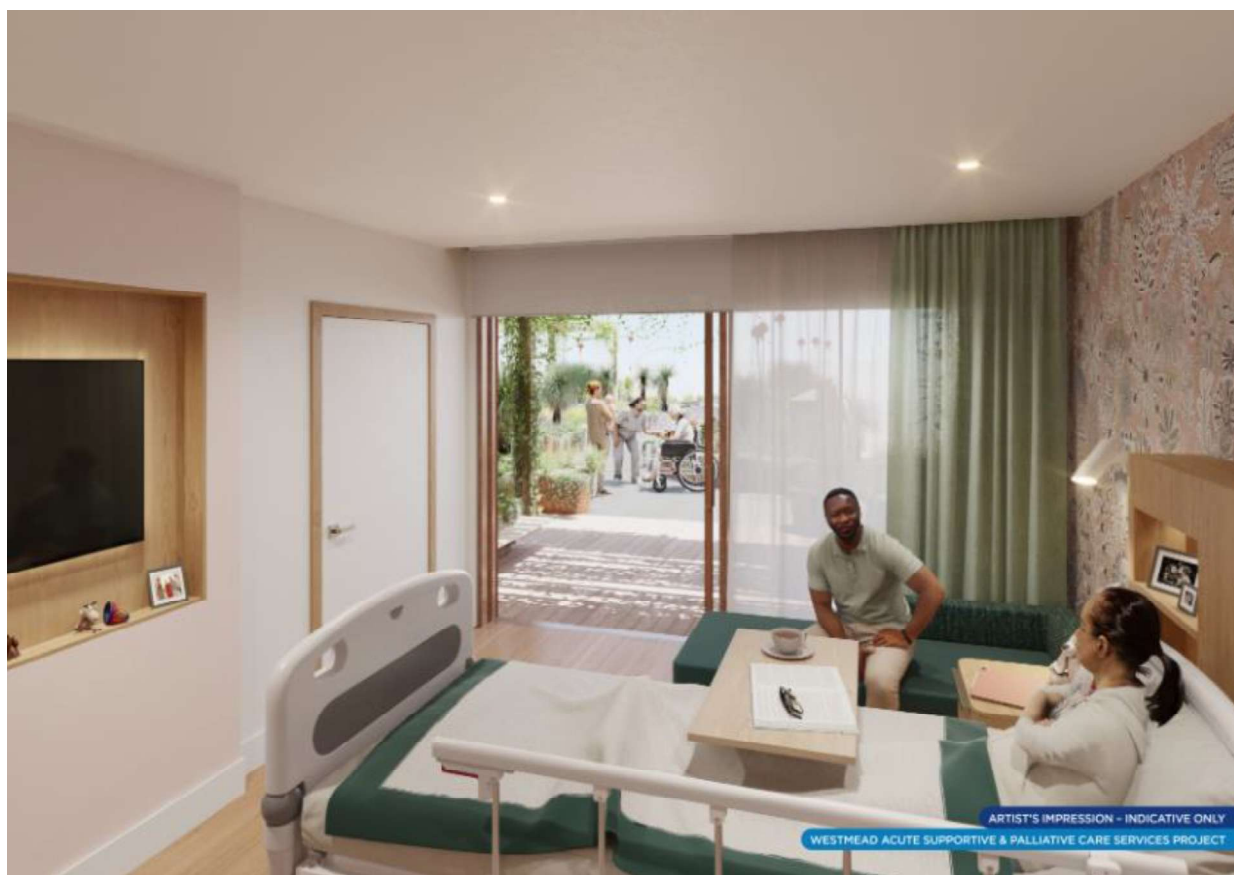
## September 2024: Media release, Western Sydney communities given first look at new Palliative Care Unit at Westmead Hospital

Summary: The community was provided with a first look at the design of the Supportive and Palliative Care Unit to be delivered at Westmead Hospital along with the site location.

The media release noted that planning and design of the unit has been informed by extensive consultation with healthcare professionals, carers, and community members, ensuring that it will provide a culturally sensitive, home-like environment with spaces for family gatherings, a multi-faith room, and veranda access from every room.

This dedicated facility will enable palliative care staff to deliver essential care and support in a setting that feels more like home, a need identified during community consultations, as well as access to outdoor areas and communal spaces.

It was noted that the next steps in the design process would focus on interiors, landscaping, fittings and equipment.



## Appendix

### October 2023 – Research undertaken by Western Sydney Local Health District

Summary: What Matters in the End, and companion report, Stories of Care, document findings from a research project funded by the NSW Ministry of Health: Understanding the End-of-Life Needs of CaLD and Aboriginal Communities in Western Sydney Local Health District.

The research was undertaken by investigators from the Western Sydney University Caring at End-of-Life Research Program in collaboration with the Western Sydney Local Health District Advisory Board and research partners.

Both reports are available online at the following links:

What Matters in the End: <https://doi.org/10.26183/cnxj-nw28>

Stories of Care at End-of-Life: <https://doi.org/10.26183/w66h-qn16>

The design of the Westmead supportive & Palliative Care Unit incorporates the insights and learnings from this research.

#### What Matters in the End

What Matters in the End details a population-based end-of-life needs analysis for people actively living with and dying from a life limiting illness in Culturally and Linguistically Diverse and Aboriginal communities in Western Sydney.

The research, funded by the NSW Ministry of Health, was designed to directly engage with communities, giving voice to those who are marginalised, vulnerable or disadvantaged. It focuses on understanding cultural needs, and the ways in which end-of-life care can be provided in culturally safe ways for the Aboriginal community, and people from Arabic, Hindi and Mandarin speaking backgrounds.

Based on the findings generated by the research, the report makes clear and achievable recommendations for service systems to better support people who are experiencing end-of-life, as well as their carers and communities. Although the research was focused on Western Sydney, its implications are much broader, with the potential to make a significant contribution to culturally attentive models of care for other communities living in urban regions of Australia.

The primary aim of the research was to understand what diverse communities need from Western Sydney Local Health District (WSLHD) end-of-life services, and what can be done to make these services culturally safe.

#### Stories of Care

Stories of Care is the culmination of a unique collaboration between researchers and photovoice participants in a multi-method research initiative investigating the end-of-life needs of culturally diverse people living in Western Sydney.

The research was undertaken by the Western Sydney University Caring at End-of-Life Research Program in collaboration with Western Sydney Local Health District. Using a COVID-adapted photovoice method, we worked with participants from the Aboriginal community and from Arabic, Mandarin and Hindi speaking backgrounds who had cared for someone at end-of-life. We asked them what they found helpful and supportive in their caring journey. This uncovered stories about what works (and doesn't) in the service system and wider community to support culturally diverse people and their families at end-of life.

Stories of Care showcases participants' photographs and narratives, giving voice and visibility to their experiences and needs. Their participation has contributed to our deeper appreciation of the relationships, values and practices that can sustain and be significant for people at end-of life; in turn, showing service providers what is needed for delivery of culturally appropriate and safe end-of-life care.

# What Matters in the End

*Understanding the End-of-Life needs of Culturally & Linguistically Diverse and Aboriginal communities in Western Sydney Local Health District*

ما يهم في النهاية ... فهم احتياجات مرحلة نهاية الحياة لدى المجتمعات المتنوعة ثقافياً ولغوياً ومجتمعات السكان الأصليين في المنطقة الصحية المحلية في غرب سيدني

आखिर में क्या मायने रखता है...वेस्टर्न सिडनी लोकल हेल्थ डिस्ट्रिक्ट (पश्चिमी सिडनी स्थानीय स्वास्थ्य डिस्ट्रिक्ट) में सांस्कृतिक और भाषाई रूप से विविध और ऐबोरीजिनल समुदायों के जीवन के अंत की आवश्यकताओं को समझना

最终什么才重要...了解西悉尼地方卫生区文化和语言多元化群体和原住民社区的临终需求

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OCTOBER 2023

