

## **Palliative Care Nurses Association Conference June 2026**

### **Voices that matter: Consumer Insights into Systems Improvements**

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On behalf of EPC's Consumer Advisory Committee



# COMMUNITY PALLIATIVE CARE UNDER PRESSURE

Our community can't wait.

DEMAND RISING 

## DEMAND IS GROWING



**+40%**  
more people  
by 2040



More complex  
needs



**70-80%**  
prefer to  
die at home



## THE GAP KEEPS WIDENING



Too many people waiting  
or missing out on care.

## RESOURCES ARE LIMITED



Workforce  
shortages



High  
caseloads



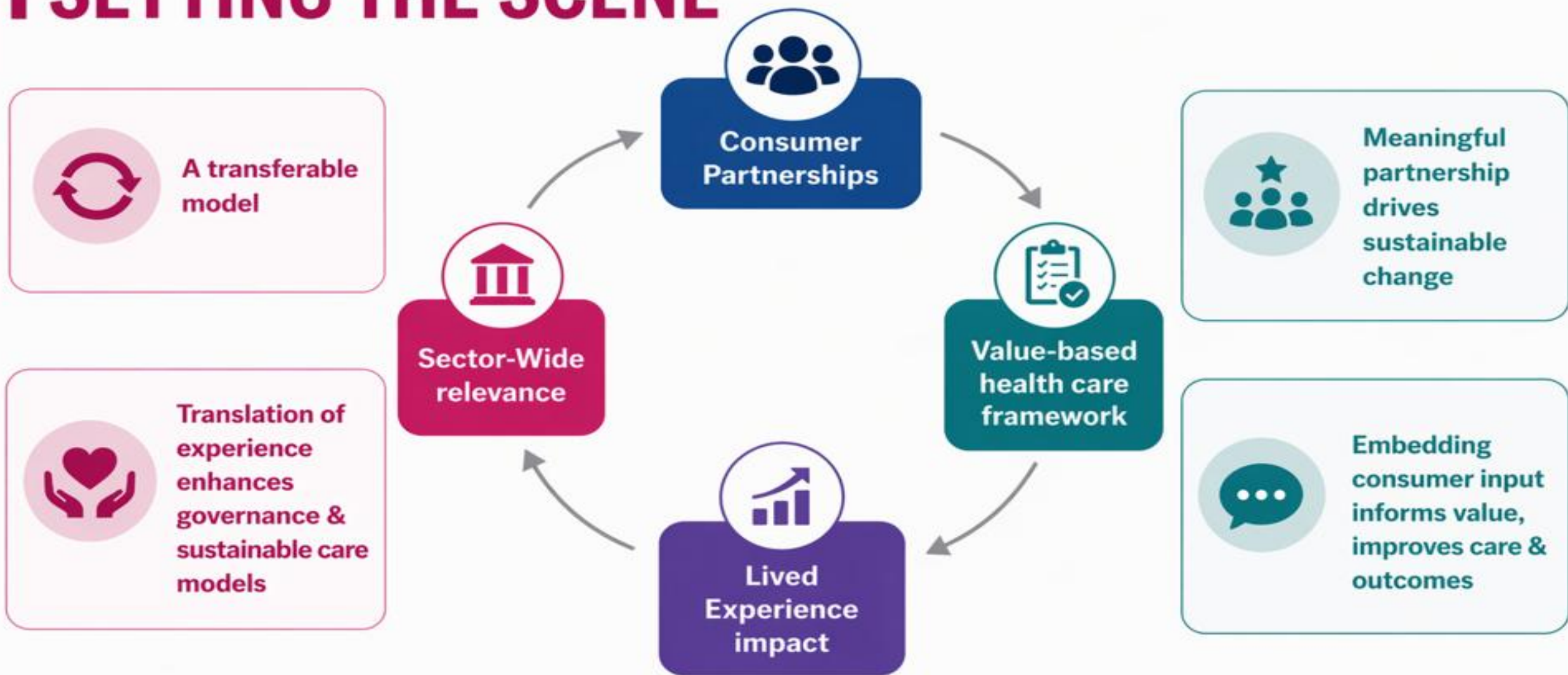
Insufficient  
funding



Travel & spread  
across large areas



# VOICES THAT MATTER: SETTING THE SCENE



# Value Based Palliative Care – Why?

## THE VALUE OF VALUE-BASED PALLIATIVE CARE



### Outcome-focused care

VBHC redefines success based on outcomes that matter to clients relative to resources used.



### Palliative care outcomes

Key outcomes include symptom relief, quality of life, preferred place of care, and experience for clients and carers.



### Shared language and purpose

VBHC provides a common language for all stakeholders to discuss quality, equity, and sustainability.



### Ethical resource use

Linking outcomes to resource use supports ethical and transparent decision-making amidst limited resources.

# Consumer Voice – How has this added value?

## EMBEDDING CONSUMER VOICE AS STRATEGY



### Consumer advisory committee role

Transforming lived experience into strategic insights influencing policy and models of care.



### Impact on care and governance

Consumer input shaping quality activities, digital initiatives and governance, and reduces unwarranted variation in care.



### Cultural shift in healthcare

Embedding consumer voice shifts culture → consultation to shared stewardship of care systems.



# Consumer led change

## SYSTEMS LEVEL – IMPACT OF CONSUMER LED CHANGE



### Consent redesign

Consumer input improves consent processes to be clear, respectful and aligned with what matters most to people.



### Health & Death Literacy

Consumer-led education builds understanding and confidence to support informed decisions and better care experiences.



### Handover improvements

Consumer insights reduce gaps in information transfer and improve continuity and safety in care.



### Consumer voices embedded

Consumer voices embedded in governance and decision-making shapes systems that work better for everyone.

# From Voice to Value - Consumer Contribution Tracker

|   | A  | B                | C                           | D         | E                                          | F                                                                                                                                          | H                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | I                       | J         | K        | L                          | M                                                                                                                     |
|---|----|------------------|-----------------------------|-----------|--------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------|-----------|----------|----------------------------|-----------------------------------------------------------------------------------------------------------------------|
|   | No | Date Idea Raised | Forum                       | NS Action | Action Type                                | Action Item                                                                                                                                | Consumer Suggestion                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Staff Responsib         | Date Due  | Status   | Measure of Success         | Consumer/ staff Comments                                                                                              |
| 1 | 11 | 21/05/2024       | Consumer Advisory Committee | NS2.01    | Workshop                                   | <b>Development of Person Centred Value Based Healthcare Strategic Plan</b>                                                                 | <p>Strategic Planning Workshop- discussion and feedback:</p> <ul style="list-style-type: none"> <li>• Committee of Management have approved the Value Based Health Care Framework (VBHC).</li> <li>• Models of Care need to align for increasing demand.</li> <li>• Trajectories of key illnesses, 40% of our clients have presentations other than Cancer. Discussion around how many clients are on Home Care Packages and how this is managed.</li> <li>• VBHC and the different client trajectories.</li> <li>• VBHC emphasizes the value as a primary driver for the values of client as well as value for service</li> <li>• Value and outcome to the individual is core – noted that Patient Reported Outcome Measures are utilised.</li> <li>• Need for flexibility with our service delivery and offerings.</li> <li>• The framework is centred around Consumer &amp; Workforce Engagement &amp; Co-design.</li> <li>• Stigma associated with Palliative Care and a lack of understanding of what the services are. Hopefully this will create awareness and clients / carers will be more informed.</li> <li>• The definition of early intervention and what does that mean to the Community i.e. early support/ participation/access.</li> <li>• Consider different documents and language use for different audiences. E.g. inward facing vs outward facing documents and information.</li> <li>• Principle 8 In the VBHC Exec Summary - suggestion that patient come before resource utilisation.</li> <li>• Request for choice in service delivery methods i.e. face to face / telehealth / phone consults – the members felt a mixed approach was appropriate depending on the client's circumstances noting it's not a one size fits all approach. Various barriers discussed in addition to what Telehealth training options are available for staff.</li> <li>• Link partnering with other Specialists particularly in early illness stages depending on the client's illness given their expertise.</li> <li>• Different modalities of capturing feedback to inform service changes i.e. Bereavement Support Sessions, Newsletters. •Various measures of care outcomes for Quality of life and EOL.</li> <li>• Capturing that we have to meet goals- clients and carers set.</li> <li>• How to build a therapeutic relationship with telehealth, noting that this would not occur at assessment, and only utilised if deemed appropriate during the stable phase.</li> <li>• Invitations for carers to complete surveys after an appropriate bereavement period.</li> <li>• Review of information for those whom English is a second language.</li> <li>• Review of greener options for care provision.</li> <li>• CAC contributions to the Allied Health and Volunteer Services Model of Care review and Renal Early Access, Surveillance and Evaluation (EASE)</li> </ul> | Innov/ Special projects | 17-Jul-24 | Complete | Successful and sustainable | CAS feedback adopted into Draft 2024-27 Strategic Plan. Revision 2025-2028                                            |
| 2 | 12 | 24/06/2024       | Chair CAC                   | NS2.01    | Client & Care Information & Website update | <b>Rights &amp; Responsibilities</b>                                                                                                       | Our staff safety is non-negotiable. Aggression or violence towards staff in any form (racial, verbal or physical) is never ok. EPC has zero tolerance for any form of violence or aggression- racial, verbal, or physical towards staff. To maintain a safe work environment for our staff, we regularly assess how our service is delivered. We may adjust our service in individual circumstances to ensure the safety of our staff.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | QRCM                    | 27-Jun-24 | Complete | Successful and sustainable | All CAS suggestions implemented on brochures and the EPC website.                                                     |
| 3 | 13 | 19/07/2024       | Chair CAC                   | NS2.01    | Consent feedback                           | <b>Consumer review of Specialist Palliative Consent Forms to ensure informed consent and meeting the Health Records Act and Australian</b> | <p>Review of Consent Forms</p> <ul style="list-style-type: none"> <li>- Adult specialist Palliative Care</li> <li>- Carer specialist Palliative Care</li> <li>- Child/ Young Adult specialty Palliative Care</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | QRCM                    | 20-Nov-24 | Complete | Successful and sustainable | All information incorporated and forwarded to the Ethics Board Committee for final approval. Staff roll out Feb 2025. |
| 4 | 14 | 11/08/2024       |                             |           | Bereavement Correspondence Review          | <b>Feedback on revised Correspondence sent to bereaved carers</b>                                                                          | Sample Feedback- My only suggestion with them is that in the Bereavement Volunteer Companion "offer a reassuring presence" might be moved to top of the list as I think it is so important. The 2 week email: perhaps tweaking wording a little - "Music therapy for children under 18", and "Comfort cushions made with clothes significant to you and your loved one". Walking with Grief brochure - there is a lot of text on each page. I suggest making the heading "Walking with Grief" a bit more prominent so the eye is drawn to that first. Apart from that the letters and brochures are all so good; clear and well-set out. The brochures use beautiful and appropriate images, the wording is very clear.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | PDVS                    | 20-Aug-25 | Complete | Successful and sustainable | All CAC members suggestions incorporated and in use by the bereavement staff and bereavement volunteers.              |
| 5 |    |                  |                             |           |                                            |                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                         |           |          |                            |                                                                                                                       |



## WHAT THE DATA SHOWS 2023–2025



### PROJECT COMPLETION RATE



Twenty-eight  
CAC-led projects



**93%** completion rate  
from 2023 to 2025



### VBHC DOMAINS COVERED



Initiatives spanning  
multiple domains

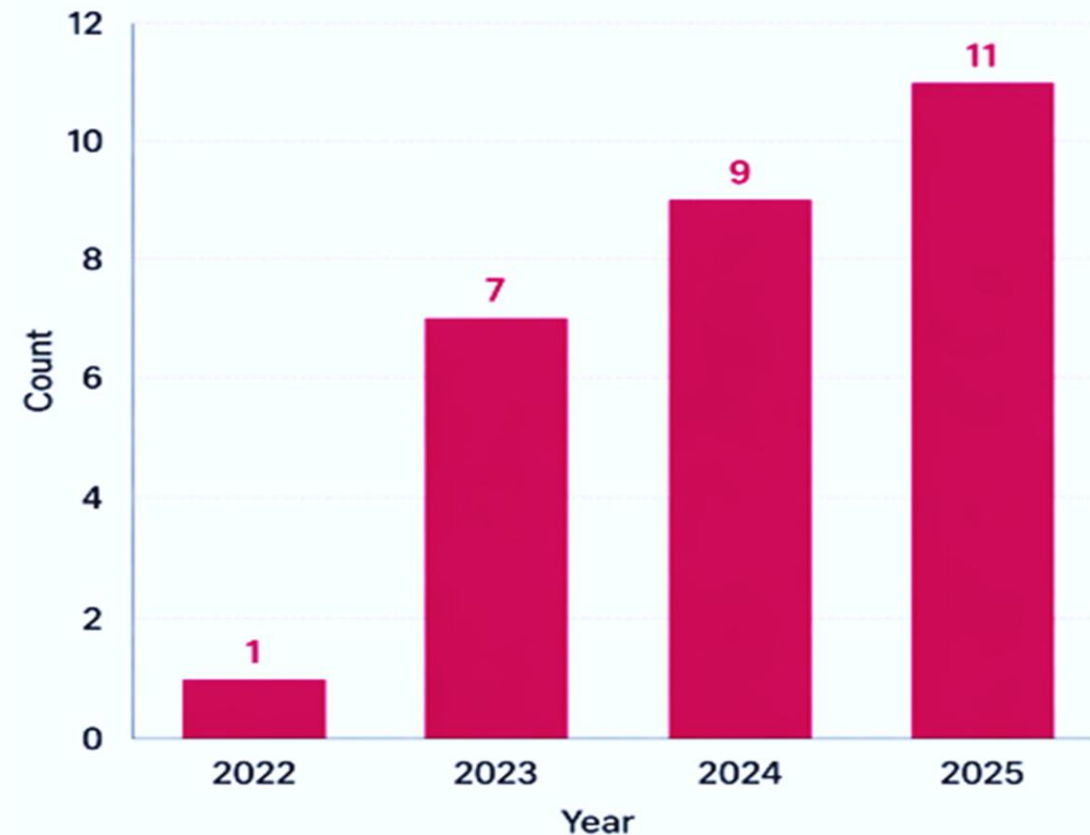


### IMPACT OF STRUCTURED CO-DESIGN



Structured co-design  
within VBHC leads to  
sustainable organisational  
change

### PROJECTS RAISED BY YEAR (ALL)



# CAC projects – mapped to VBHC framework

## VBHC DRIVING SYSTEMS CHANGE



### Culture & Capability

- Development of Health & Death Literacy Policy
- Health Literacy checklist developed for new and reviewed publications and Information
- Development of Consumer Advisor Palliative Care Dictionary



### Integrate Care Across Providers & Systems

- Day in the Life program – where various staff present to CAC on their roles to assist Consumer Advisors understand caring for the dying and their families
- GP Palliative Care Registrar pilot program
- Handover Project Review



### Future Funding Models

- Development of Person Centred Value Based Healthcare Strategic Plan



### Governance

- Define the Role Statement for Consumer Representatives
- Development of Consumer and Community Engagement Plan 2025-2028
- Consumer review of Specialist Palliative Consent Forms meeting the Health Records Act and Australian Privacy Principles
- Consumer opportunity to build CAC agendas

# CAC projects

## EXAMPLE OF PROJECTS CAPTURED IN THE TRACKER AGAINST VBHC MEASURES



### Models of Care/ Care Provision

- Review of Falls Preventions & Harm Minimisation Booklet
- Review of Feedback: Compliments, Suggestions & Complaints
- Collaboration on Information brochures – End of life care: Noisy breathing, Large Bleed, fatigue, Care plans for medication management
- Change of title for staff allied health cohort
- Feedback on correspondence sent to bereaved carers



### Data Collection & Evaluation

- Quality, Safety & Performance Scorecard
- CAC members Committee satisfaction/reflections
- PREMs Project contributions
- Understanding of Palliative Care Survey for increased awareness of services available to someone with a life limiting illness



### Measure Outcomes & Costs

- Project work in Allied Health Model of Care
- Project work Renal EASE (Early Access, Surveys and Evaluation)
- Project work Aged Care – testing the use of Virtual Visits



### Infrastructure & ICT

- Automation of preadmission processes
- Website update – Public facing Information
- Rights & Responsibilities
- Consent Video Scripting – link send to clients prior to admission



## WHY THIS MATTERS FOR PALLIATIVE CARE



**Equitable, Sustainable care**



**Client and carer values**



**Empowering nursing  
leadership in partnership**

# Meet the team



Linda Miln





Palliative care. Living well every day.