Consumer experiences and their perspective on quality palliative care in WA

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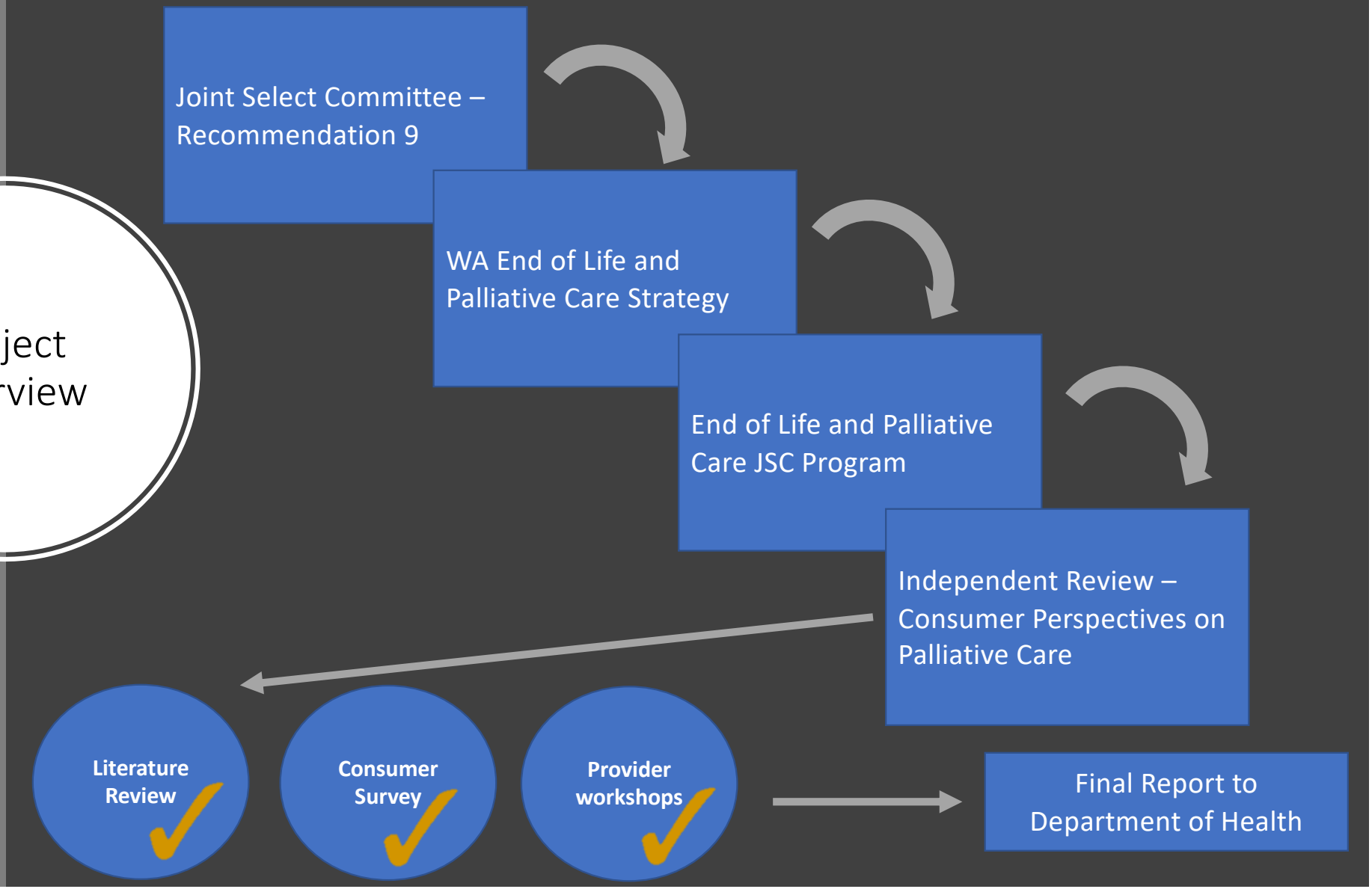
Project Overview



Literature Review

-Consumer experience of palliative care is poorly investigated.

-Consumer contribution to service and policy design is limited and selective.

-There is no compelling evidence that points to a preferred organisational model for any setting.

-Any palliative care strategy that reduces hospitalisation is likely to be cost-effective.

-Case management is a feature common to most effective models of palliative care provision.

-The evidence for benefit of extending a palliative approach to all at end of life is strong.

-Very few models have explored collaboration and integration of formal health services with informal networks of care.

Most current models fall short because their integration is limited to formal health services and consumers are involved as clients to be consulted rather than partners in the co-design of services.

Palliative and End of Life Care in 2019 in Western Australia

14,676 deaths per year in WA

↓

65% were predictable deaths and amendable to palliative/EOL care (n=9,539)

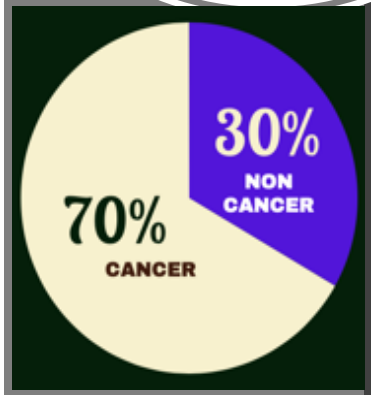
↓

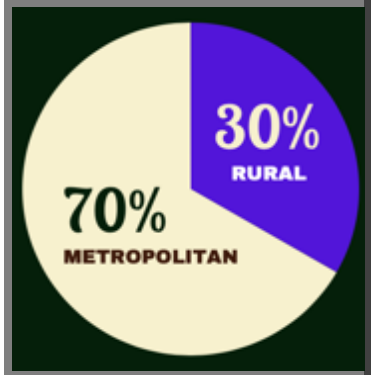
40% of the predictable deaths actually received palliative/EOL care (n=3,816)

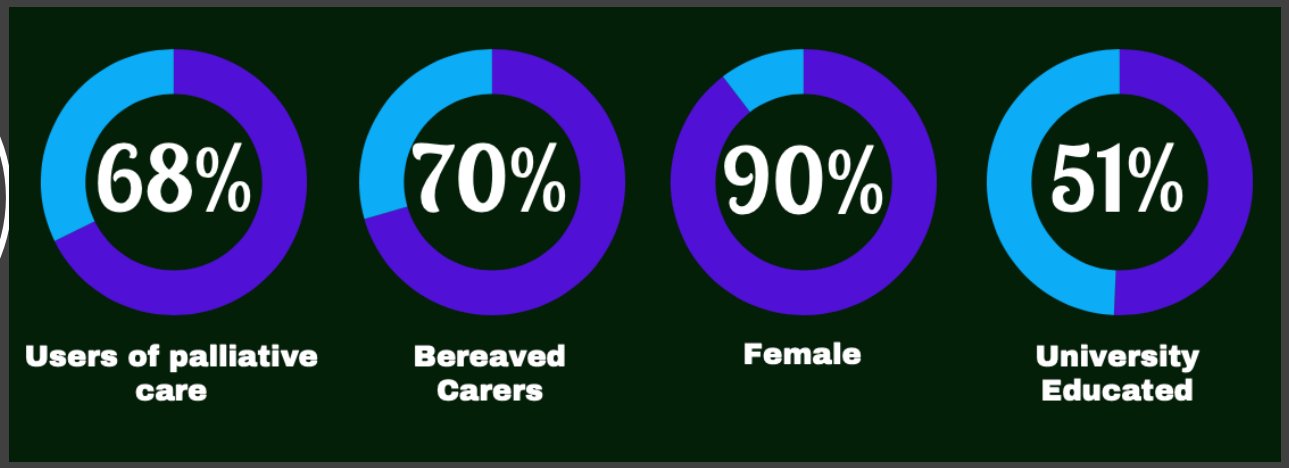
60% of the predictable deaths did not receive palliative/EOL care (n=5,723)

Source: Presentation by Prof Kathy Eagar, Perth, 19 August 2019

Consumer Survey (n=353) 6 surveys







- 239 Users of PC
- 114 Non-Users

- 249 Bereaved carers
- 72 current carers
- 32 patients

Family Carer

- Majority female and from Australian/English speaking background
- Around 1/3 were spouses; 1/3 daughter/son
- More than half were involved day to day hands-on whilst relative was at home

Care setting

- 109 used one setting
- 37 used two settings
- 3 used three settings
- 43% care at home; 26% hospital; 23% hospice; 8% nursing home

Most reported service provider

Home setting
Silver Chain, GP

Hospice setting
SJOG, Bethesda

Hospital setting
SCGH, FSH

Priority One: Care is accessible to everyone, everywhere

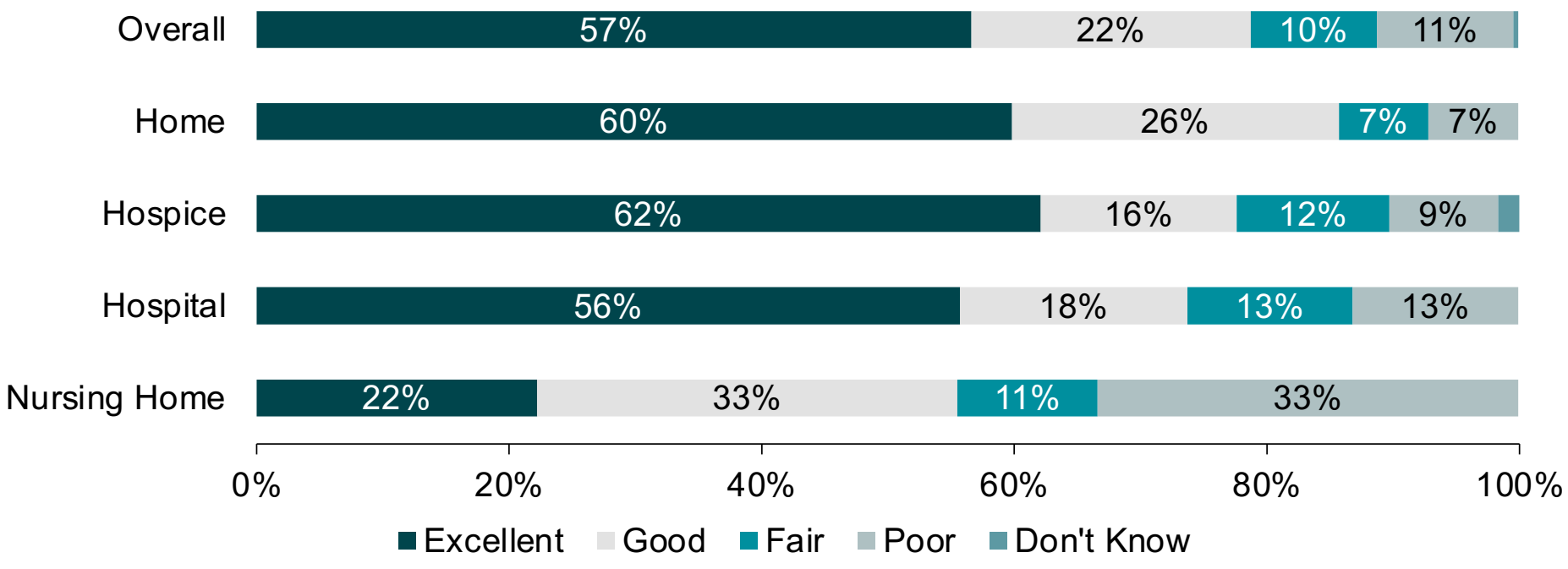
What is working well

- 78% for quality of care (home setting highest 86%).
- 84% could access care as soon as they needed.
- 76% for relief of pain
- 70 % for relief of symptoms other than pain and practical assistance.
- over 80% for EoL quality care and receiving enough help at time of death.
- Quality of care rated high and similar for both metropolitan and rural areas.

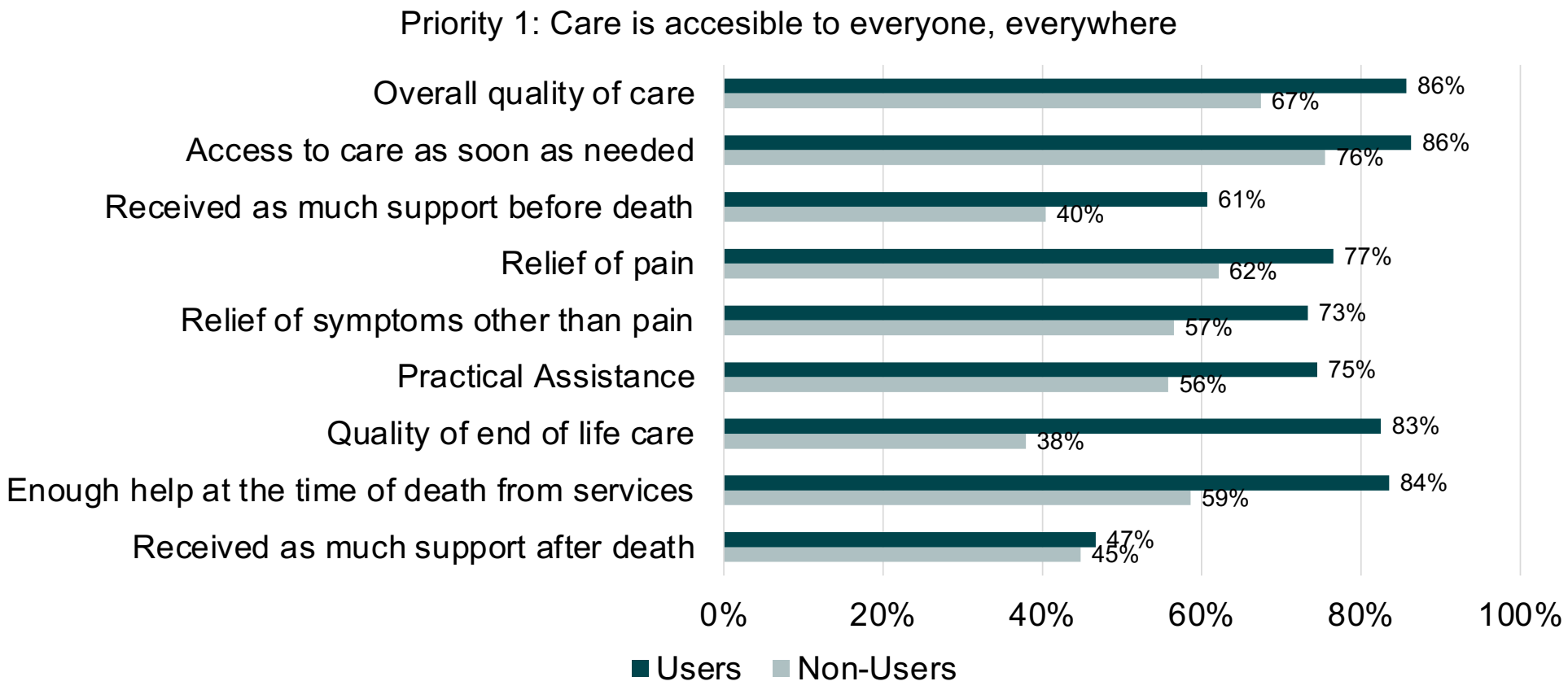
What is NOT working so well

- Only 60% reported receiving as much support as wanted before death.
- Less than 50% felt they received enough help after their relative's death.
- Nursing home indicators lower than other settings, particularly for receiving as much support as wanted (44%) and for relief of pain and other symptoms (50%).
- All indicators lower for non-cancer
- All indicators lower for non-users

Overall reported quality of care per setting



Comparison with non-users- Priority 1



Priority One: Care is accessible to everyone, everywhere

- *"everyone with a life limiting illness should be seen by palliative care to start the relationship and then be available whenever they are needed" (patient, user)*

- *"The nurses were fantastic but had too many clients and the service was not coping with demand at that time." (family carer, user)*

- *"This was a critical service at one of the saddest times of our lives. But the service enabled us to care for Dad all the way through, at home, even helping us to care for his body after he passed away. It was priceless to keep him at home, in the comfort and privacy of their home …" (family carer, user)*

Priority One: Lack of access- Rural

"I was having to go into town (30min drive each way) to change Dad's Nikki pump over, leaving him without analgesia/other symptom cover for 1.5hrs each day (disconnected, drove in, refilled, drove home, reconnected). I asked the hospital coordinator if she could spare a nurse to drop a new one out (as I was informed that this would likely be a possibility) and she refused stating that she did not have the staff to provide this service. Subsequently I was in at the hospital refilling his nikki pump at the time that he passed away on the afternoon of the 19/7/20".

"There are very limited services in most rural areas. Referral may be relatively easy but actually accessing suitable services in a timely and appropriate fashion is very difficult."

Priority Two: Care is person-centred

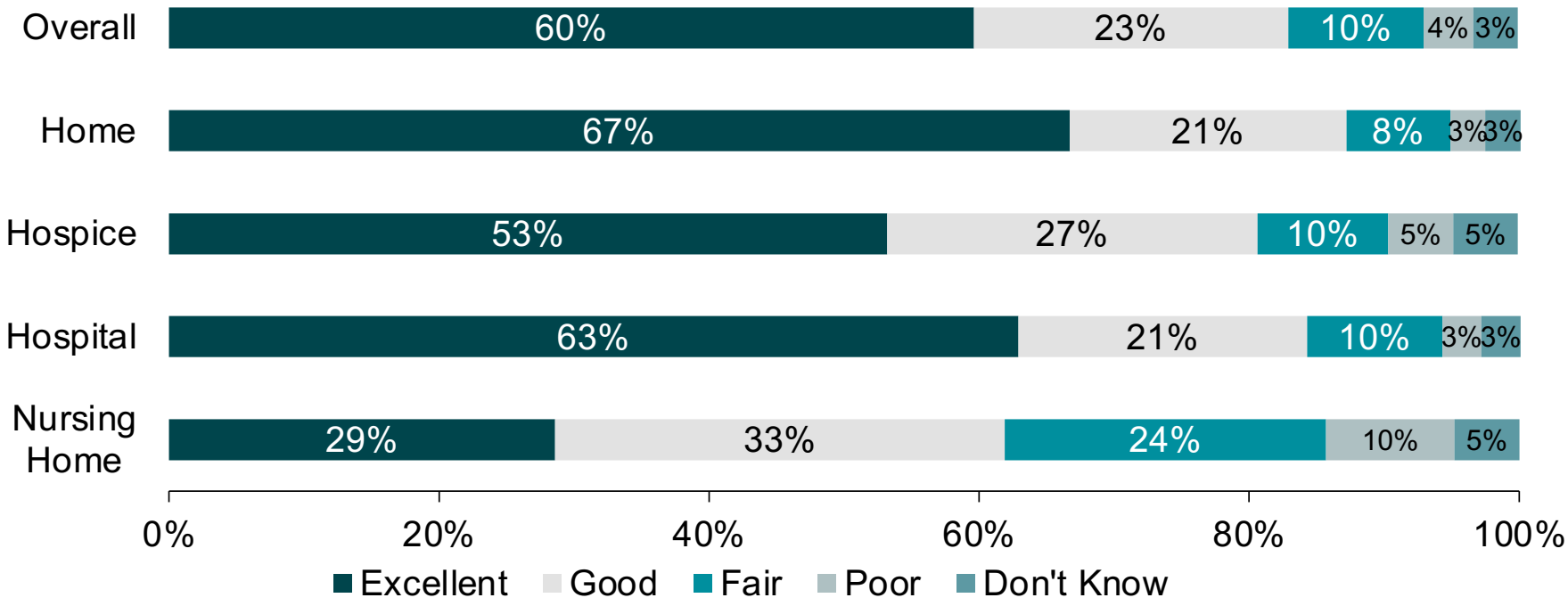
What is working well

- Above 80% for respect to values, culture, spiritual beliefs.
- 60% had one or more of EOL wishes documents.
- 70% reported that the services checked if they have any of these documents
- 80% reported their wishes were taken into account.
- 70% Patients were included in care decisions
- 80% family carers were involved in decision making at EOL.

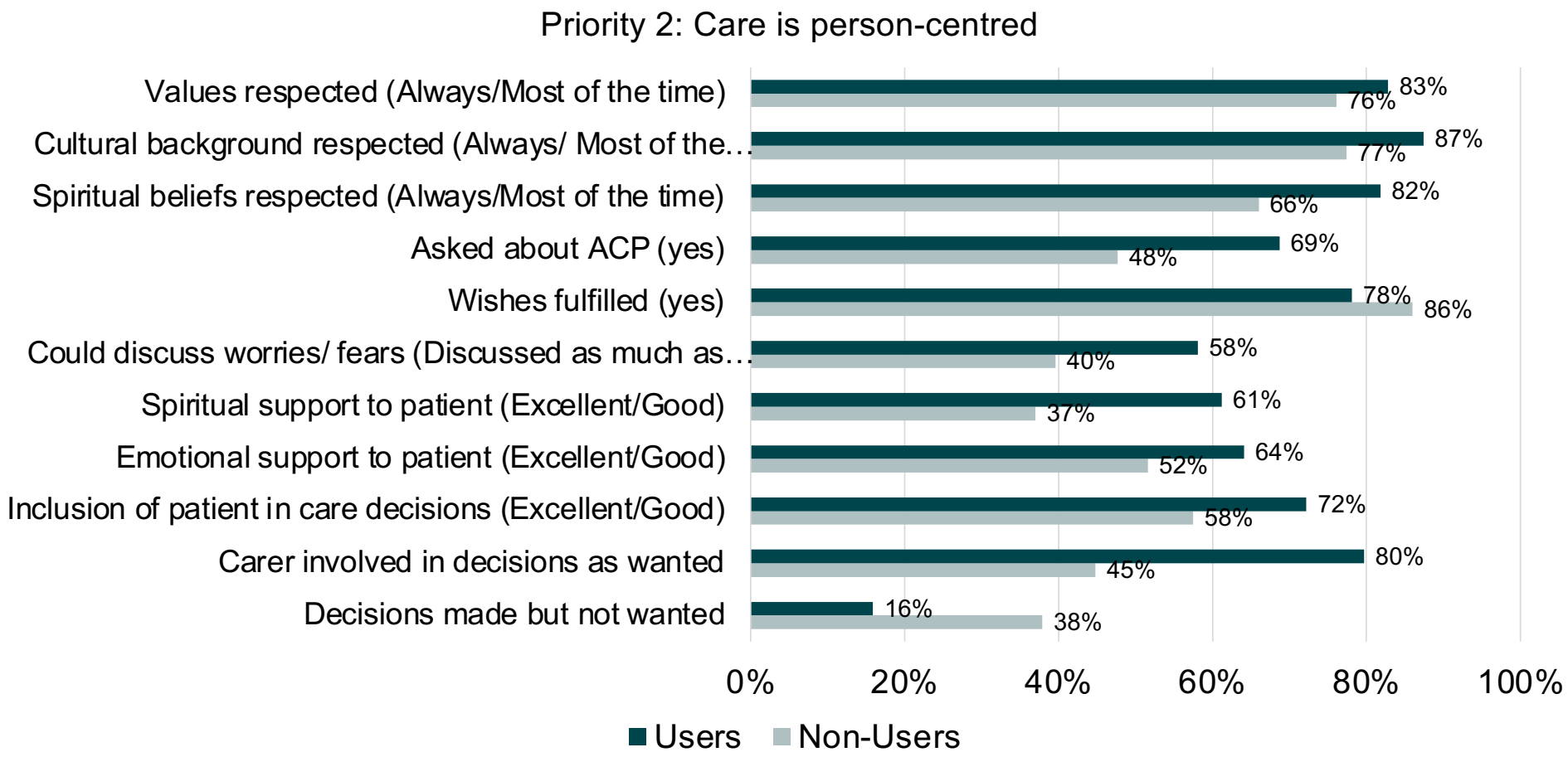
What is NOT working so well

- 60% able to discuss worries/fears as much as wanted.
- 60% rated Spiritual and emotional support to patient as excellent/good.
- Nursing home quality indicators lower than other settings.
- All indicators of non-cancer rated lower
- All indicators for non-users rated lower

Values Respected



Comparison with non-users-Priority 2



Priority Two: Care is person-centred

"my mum was essentially an experiment – she wanted to live but definitely was pushed beyond her limits in treatment and some stages of palliation" (family carer, user)

"Mum's condition was worsening every day before it became terminal. Our fears were expressed greatly with everyone, but no one seemed to act on them urgently. We were always told to wait." (family carer, user)

"Inadequate time to communicate well with one another as service providers" (service provider)

"Insufficient time for good emotional support for patients and family carers" (service provider)

Priority Three: Care is coordinated

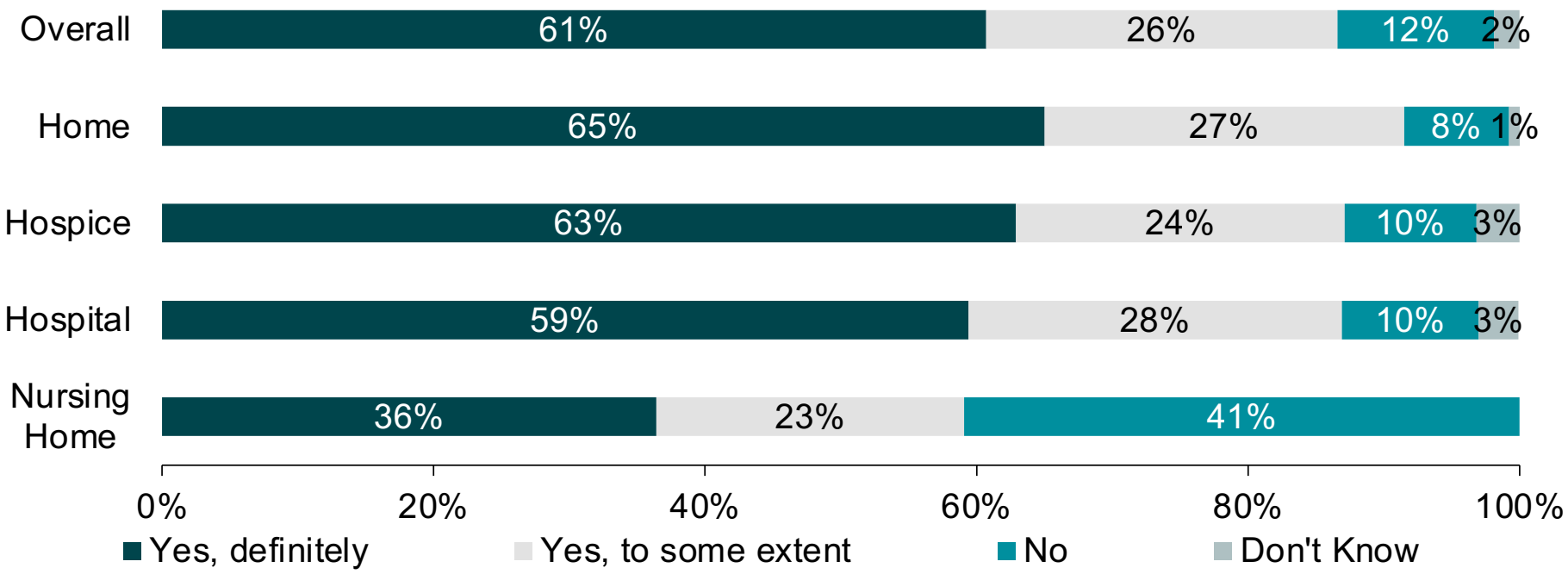
What is working well

- Staff worked well together within each setting (87%).
- 75% rated referral process as very easy/easy
- 74% rated out of hours services as ‘excellent/good’.

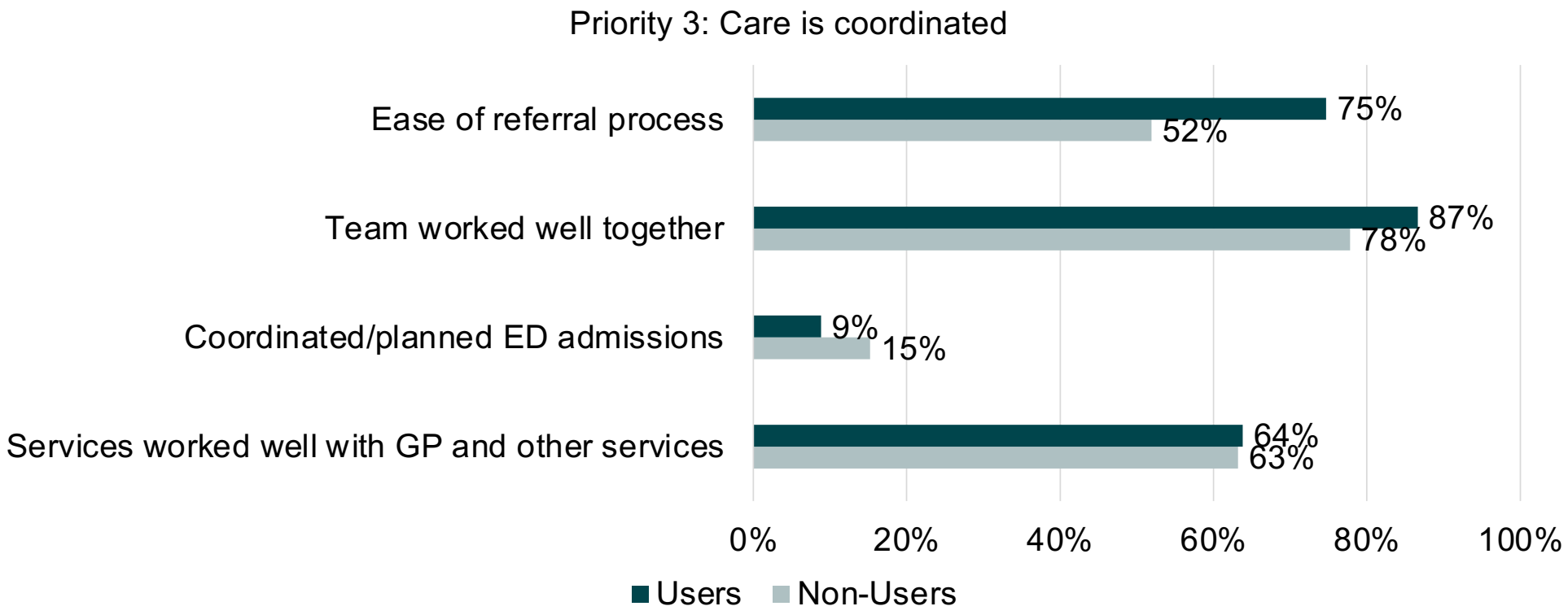
What is NOT working so well

- Services worked well with GP & external services (66% hospice; 69% hospital; 43% nursing home).
- 8-12% of ED admissions were planned or coordinated and higher for non-cancer and non-users.
- All other indicators lower for non-cancer.

Health professionals worked well together within a setting



Comparison with non-users –Priority 3



Reasons for not using palliative care services (non-Users)

- Unaware of what was available
- Satisfied with the care we received from general health and community services
- Tried but could not access them
- No-one initiated a referral to these services
- We were told it was not close enough to dying/end of life stage
- We were told it was too soon in the illness trajectory
- Unaware how it could help

Priority Three: Care is coordinated

"The GP was amazing at liaison and remained constantly in touch and available for advice and visits and assistance even when Silver Chain took over." (family carer, user)

"I was never convinced that communication between the medical service teams was all that great. It was up to me to update them and connect the dots." (family carer, user)

"Liaison, communication and coordination between doctors, [RACF], palliative and family is very poor. We are constantly seeking information, updates etc. No one provider is 'in charge' of my Dad's care". (family carer, user)

Priority Three: Lack of care coordination for non-cancer

"Our care was chaotic. No one knew who was doing what, no co ordination. Left hospital without an adequate home care plan, incorrect referrals to inappropriate services and then totally uncoordinated care within our town and our home. Much of my time was spent trying to wrangle specialists and appointments whilst trying to deal with caring for my husband in the face of his terminal illness diagnosis.

We both were in shock and had not really faced any reality of his MND diagnosis when he suffered respiratory failure in our home in the middle of the night, just days after an appointment with a respiratory specialist and only 3 months after his eventual diagnosis with MND. 3 months of stress and trauma trying to get the right care and support services in place instead of any worthwhile time together. The process not his illness exhausted us both and I believe took him before time. "

Priority Four: Family and carers are supported

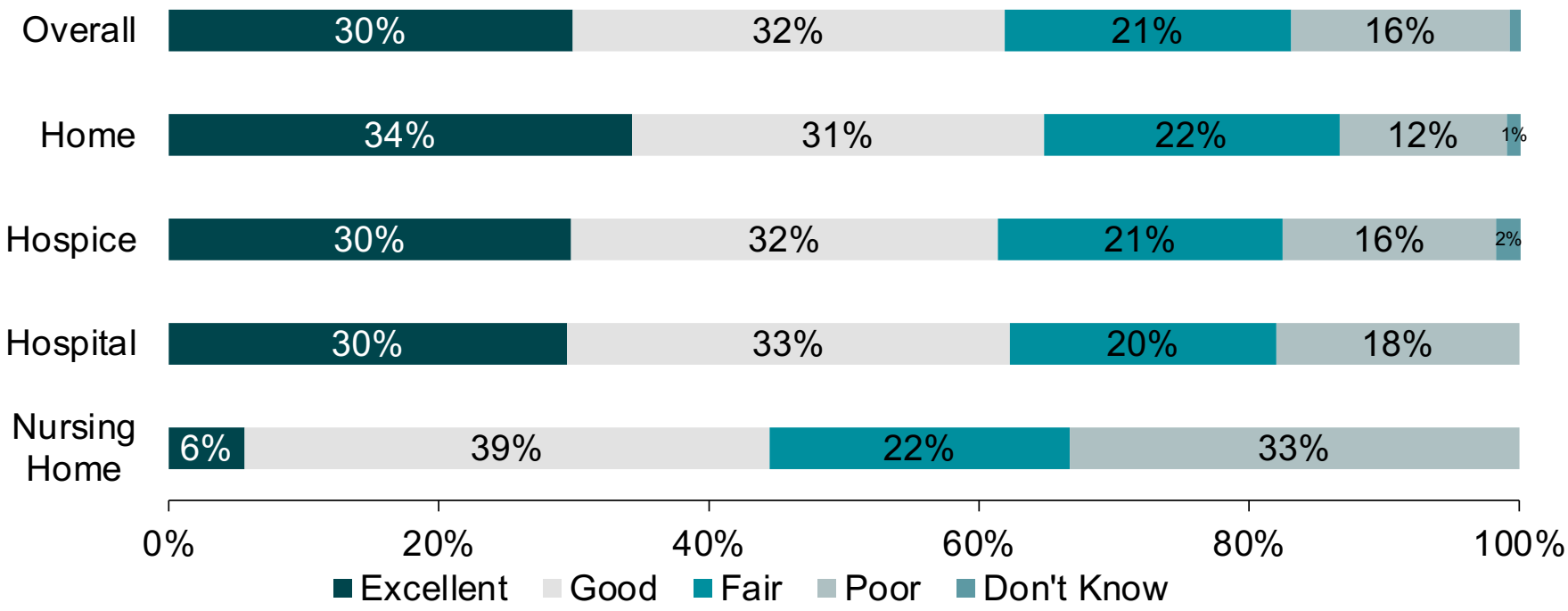
What is working well

78% of carers reported patients involved in decisions about their EOL care as much as they wanted

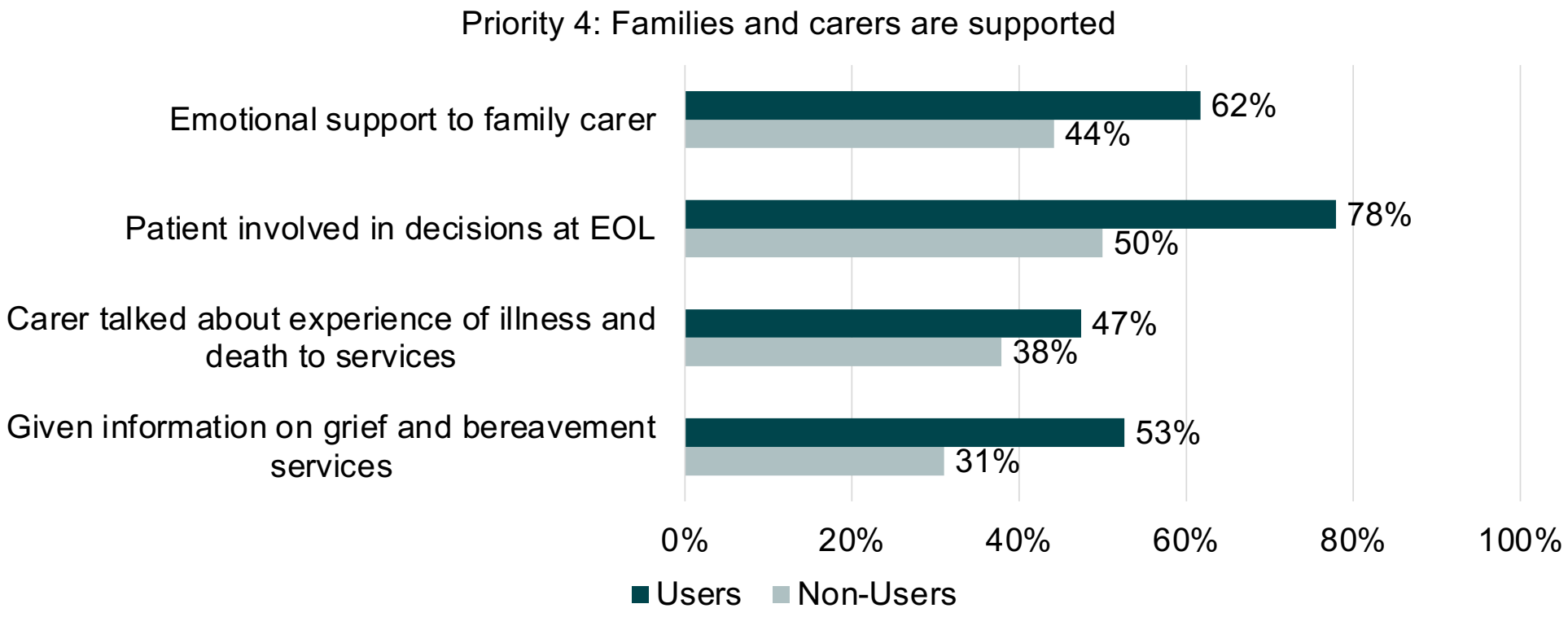
What is NOT working so well

- 62% emotional support to family carer.
- 60% information on their relative's condition.
- 47% talked to health and/or social services about their experience of relative's illness and death.
- 53% offered information about grief and bereavement services.
- 42% contacted within 3-6 weeks of the death of their relative.
- 16% contacted about 6 months after the death of their relative.
- Indicators for non-cancer rated lower.
- Indicators for non-users rated lower.

Emotional support to family carer



Comparison with non-users –Priority 4



Priority Four: Family and carers are supported

- *"a caring follow up call from palliative care would have been helpful but when it did occur months later it was done as a perfunctory task which lacked empathy and was unhelpful." (family carer, user)*

- *"I think that as soon as someone is diagnosed there should be a referral for domestic and health help at home for the carer, not wait for the family to initiate at the end of when things get too much" (family carer, non-user)*

- *"Palliative care is so important and when you've had good palliative care it makes a huge difference to your experience. Cancer patients that I've spoken with who have palliative care seem to have a much better experience than those who go without. But it's not just the patient .. the family too cope better when there's a pal care team involved. They have someone to call and they have a plan - there is support." (patient, user)*

Priority Five: All staff are prepared to care

What is working well

- 88% treated with respect/ dignity
- 89% compassion/kindness
- 91% staff competence
- 78% Able to obtain information when needed
- 86% Family dealt with in a sensitive manner

What is NOT working so well

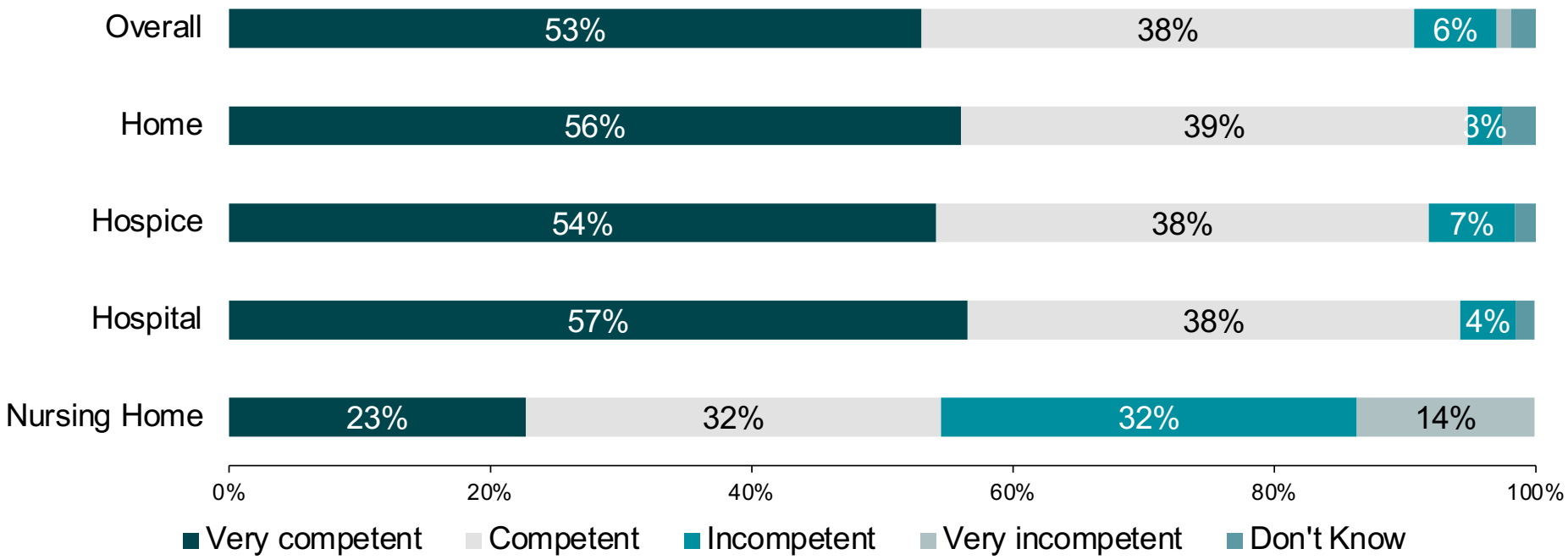
- Quality indicators lower:

-Nursing Homes

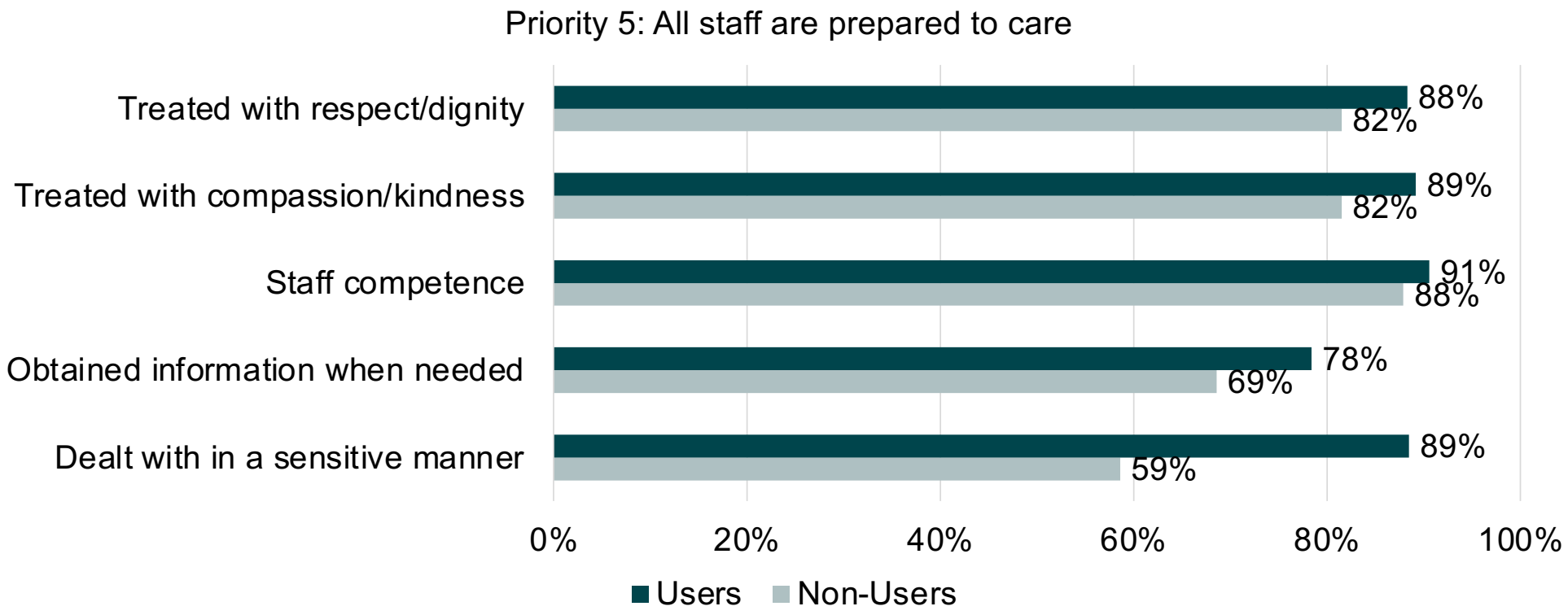
-Non-cancer

-Non-Users (mainly being dealt with in a sensitive manner- 59%)

Staff competence



Comparison with non-users - Priority 5



Priority Five: All staff are prepared to care

- *"Good knowledge and lots of compassion especially when you are having a bad day." (patient, non-user)*

- *"Junior staff tried their best but clearly no institutional culture to support education and practice of palliative care. Senior staff uneducated and seemingly unaware of own knowledge and practice inadequacies. Senior nursing staff in particular had no knowledge of principles of patient centred care, professional standards or good palliative care." (family carer, non-user)*

Priority Six: The community is aware and able to care

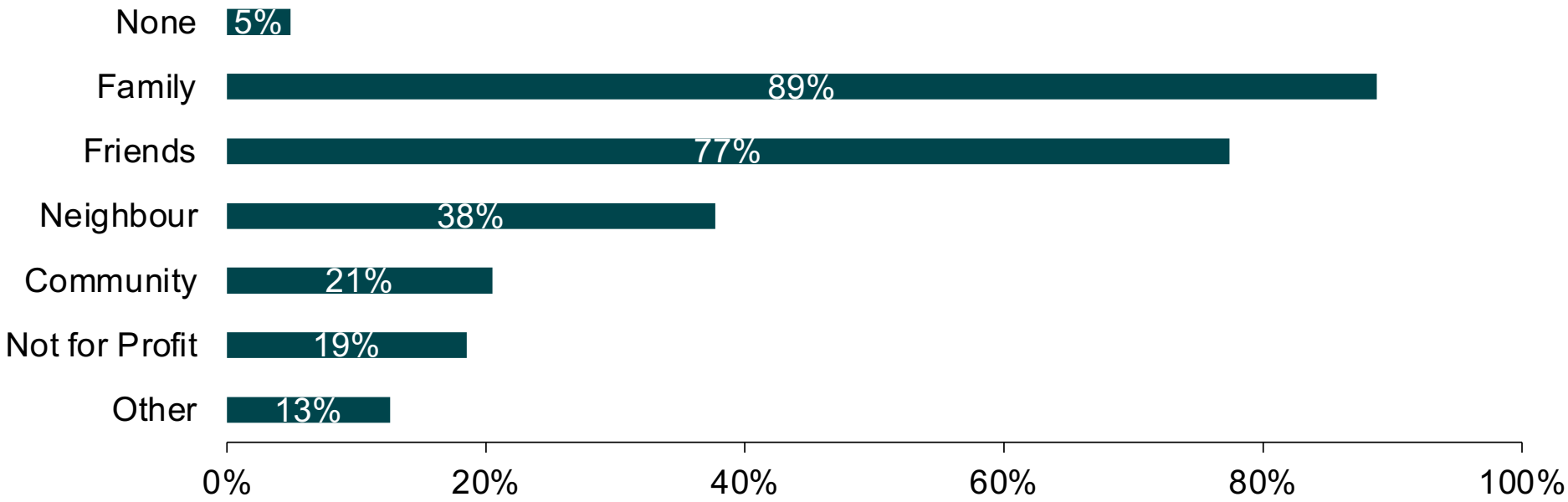
What is working well

- Informal support received before (95%) and after bereavement (93%)
- Helpfulness of informal support before (91%) and after bereavement (87%).

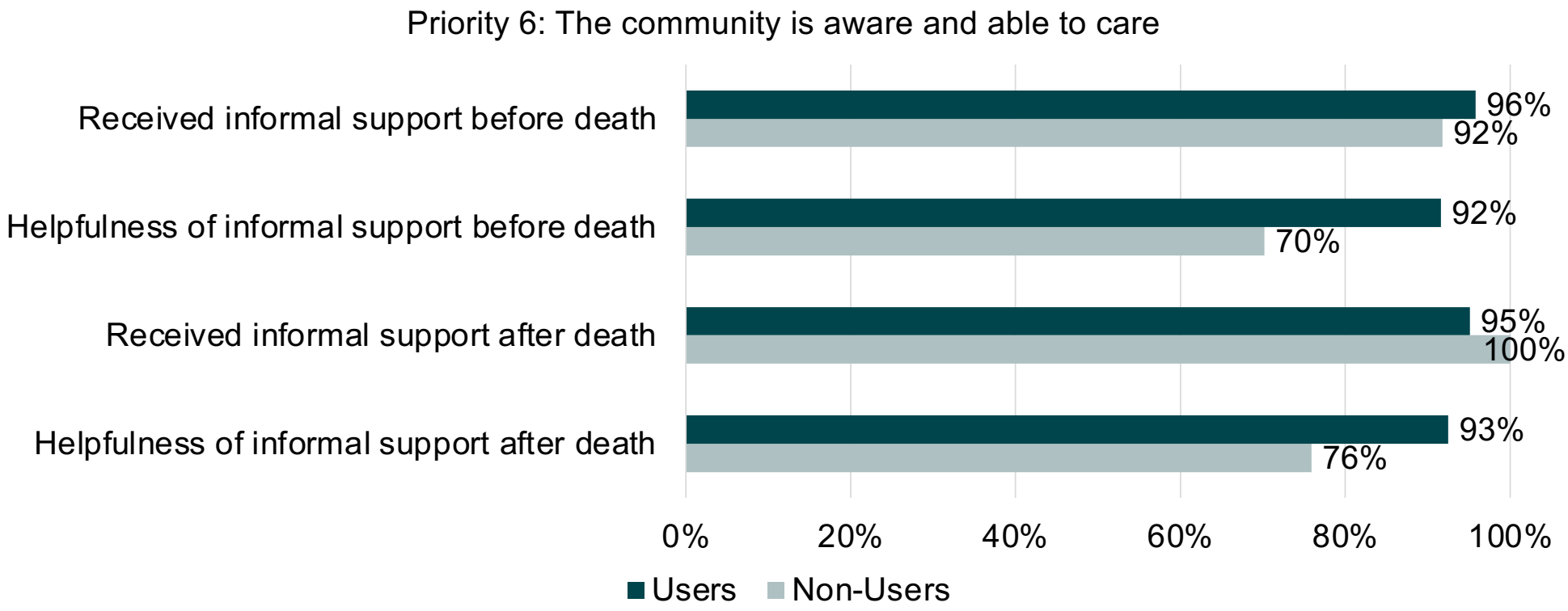
What is NOT working so well

- Non-users: lower rates of helpfulness before and after death

Sources of informal support before death



Comparison with non-users – Priority 6



Priority Six: The community is aware and able to care

"Friends and neighbours who just dropped around to help normalise my life …, lend books, bring food, help with the garden. Family who would video conference from overseas in support." (patient, non-user)

"unhelpful-Doctors and specialists who are usually unable to point one towards a needed support. How difficult would it be for doctors/specialists to at a minimum have some business cards at the counter for voluntary groups such as the prostate support groups?" (patient, non-user)

What needs to be improved?
Based on consumer survey and provider consultations

NURSING HOMES

Residential Aged Care Facilities and health care providers work in collaboration to address the lower standard of care experienced by residents and their family carers.

NON-CANCER CONDITIONS

Partnerships between specialist and generalist services and the community are needed for a more inclusive palliative approach to care to address the lower standard of care for non-cancer conditions.

Non-cancer conditions should be targeted in new models of care.

FAMILY CARER SUPPORT

To help family carers care for the ill person but also to help care for themselves. Instigate a system that assesses and addresses carer support needs, collects regular consumer feedback and co-designs service improvements.

The DOH EOLC Program to facilitate the implementation based on the evidence already provided in the WA Strategy.

GRIEF AND BEREAVEMENT SUPPORT

The principal providers of this support are family and friends, supported by a range of other primary care and community services. Community education and grief literacy are at least as important as direct services in this area.

The DOH EOLC Program and PCWA to make available a resource list, continuously updated, to health professionals and the community.

HEALTH AND DEATH LITERACY FOR CONSUMERS

Improve health literacy and death literacy of consumers around end of life and palliative care, including through promoting the uptake of tools such as Advance Care Plans, Advance Health Directives and Goals of Patient Care.

PCWA, DOH, HSPs, Primary Care – A shared responsibility

WORKFORCE/ HEALTH PROFESSIONAL EDUCATION/ TRAINING/ SUPPORT

Professionals need to share their training and consulting capabilities with each other and with informed caregivers in addition to their well-developed service provision and referral skills.

WA Health End-of-life and Palliative Care Education and Training Framework and Resource Hub is an important tool for the sector to help achieve this.

MODELS OF INTEGRATED CARE

Implement models of integrated care, including mobilizing community options/ better primary care engagement and potentially episodic care to broaden the reach of palliative care, case coordination and improved communication/ clinical handover. The role of not-for-profit organisations is vital in this space.

Proposed Model of Palliative Care and End of Life Care for WA

The preferred model is one:

- grounded in community upskilling/ knowledge,

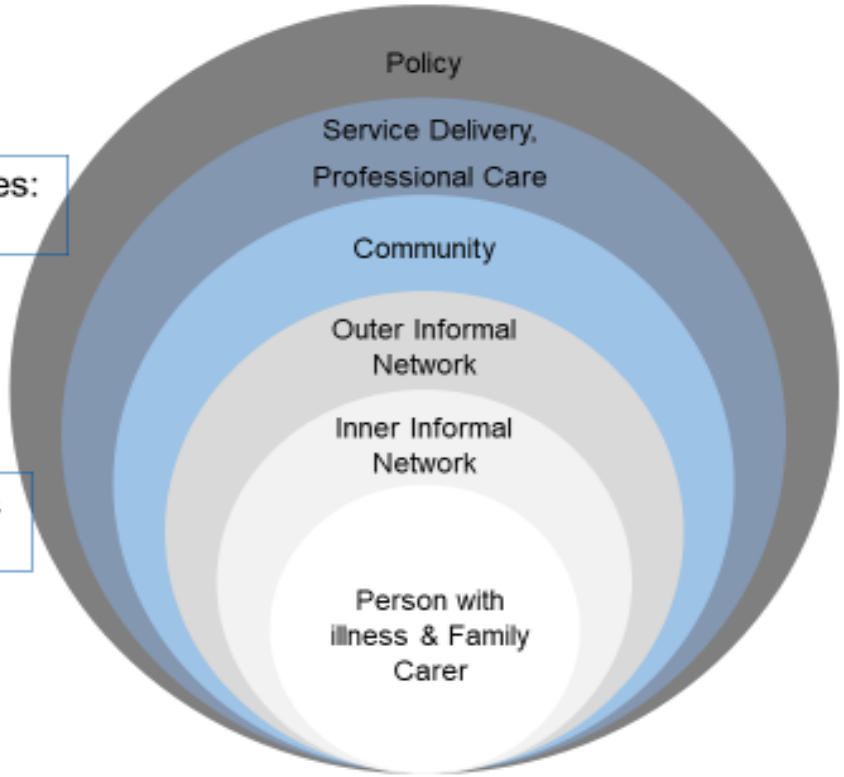
-supported consistently by generalist palliative care,

-with specialist palliative care providing ‘episodic’ care as particular needs arise during the illness journey.

Public Health Approach to Palliative & EOL Care

ENABLERS

- Digital and Assistive technologies: Telehealth, Equipment
- Advance Care Planning
- Education & Training Programs
- Compassionate Communities & Social Network Enhancement
- Not For Profit organisations & Other NGOs

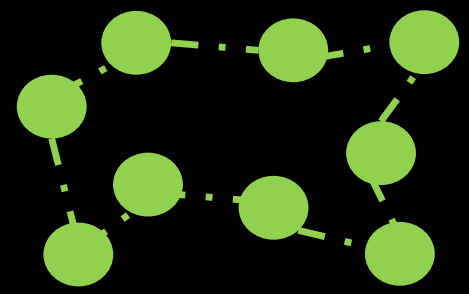


CIRCLES OF CARE

INTEGRATION OF SERVICES

- Disability Sector, NDIS
- Aged Care Sector
- Specialist Palliative Care
- Generalist Palliative Care
- Disease specific clinics
- Primary Care & Allied Health Care

HOW DO WE START TO JOIN THE DOTS?



Develop and test a public health palliative care model thorough a demonstration project. One or more trial sites (metro and rural) are needed to explore the complexities of coordination, transition and communication inherent in the model.

Demonstration Project/s

- Audit of care provided for all deaths in the selected region, drawing upon as many data sources as can be usefully linked with the project.
- Map existing end of life care assets and gaps in care provision, with particular attention to:
  - The illness journey for all deaths, particularly transitions in site and provision of care over the last year of life.
  - Patterns of formal end of life care, in particular the relationship between specialist palliative care, generalist palliative care, primary care, aged care, community care.
  - Patterns of informal end of life support, including social networks, information about the community programs and organisations that provide support, and the type of support provided.

CONCLUSION

WA Health, in commissioning this systematic exploration of consumer experience, leads the field nationally and in many respects internationally, in particular because the review was unique in seeking information about the experience of non-users

as well as users of palliative care.

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