Flinders University | Research Centre for Palliative Care, Death & Dying

Facilitating innovation based on patient reported experience of care quality – implementing the LEAHP Bundle

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WHY

What helps us achieve this care experience?

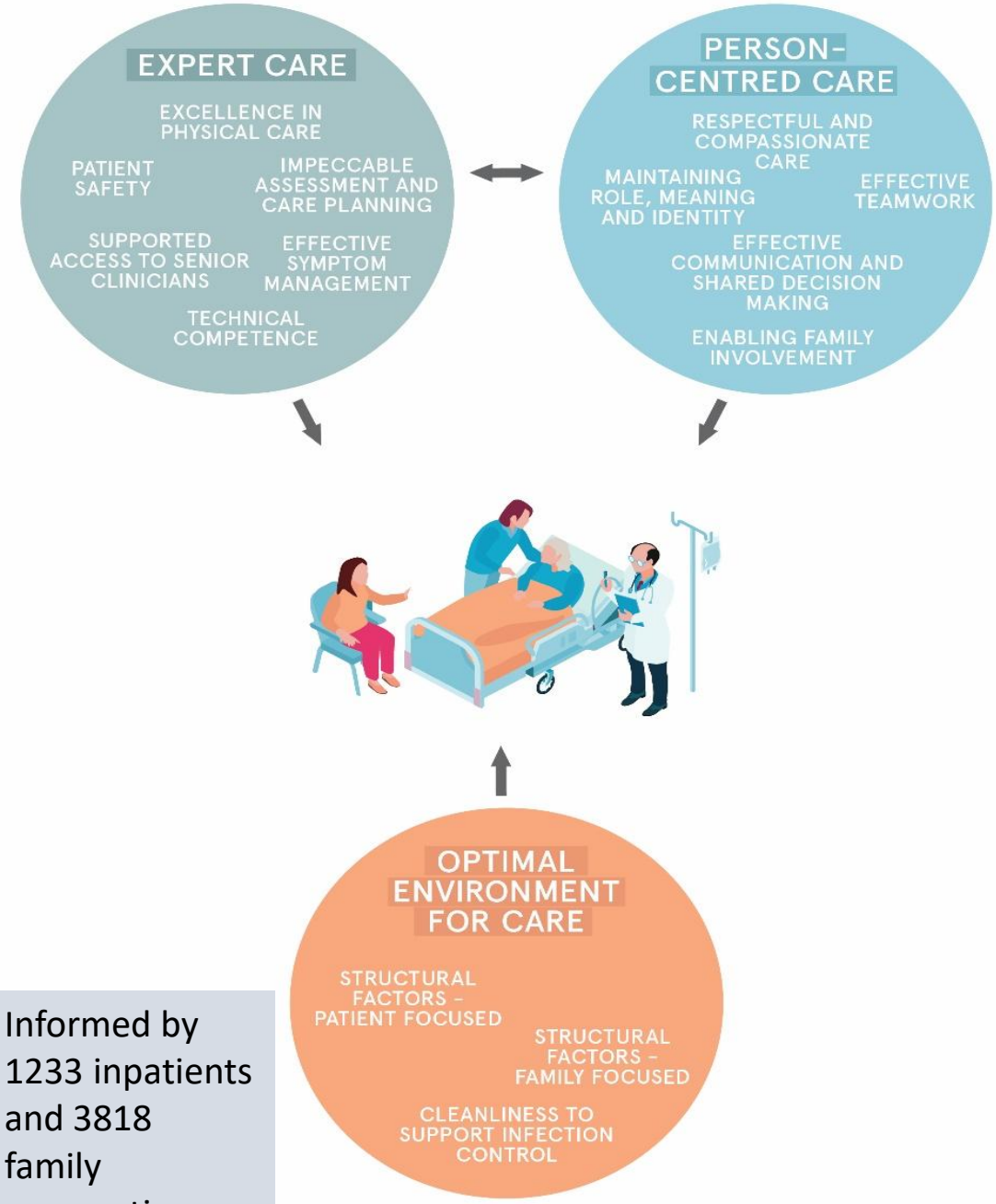
I just felt that there was a deep empathy and there was just a compassion that was palpable, so it didn't feel that it stepped over the professional boundaries at all. It was still within those boundaries, but it was very gentle and very life-giving for the families. And obviously, the character of the individuals involved in creating that safe soft space was just outstanding, you know? And we were very blessed to be carried, because that's essentially what we were, we were carried by these beautiful people through just an absolutely horrendous experience.

(Family 8, 52yr female carer for father with malignancy and bereaved family for daughter with non-malignant illness)

Image generated in Co-Pilot_12.05.26

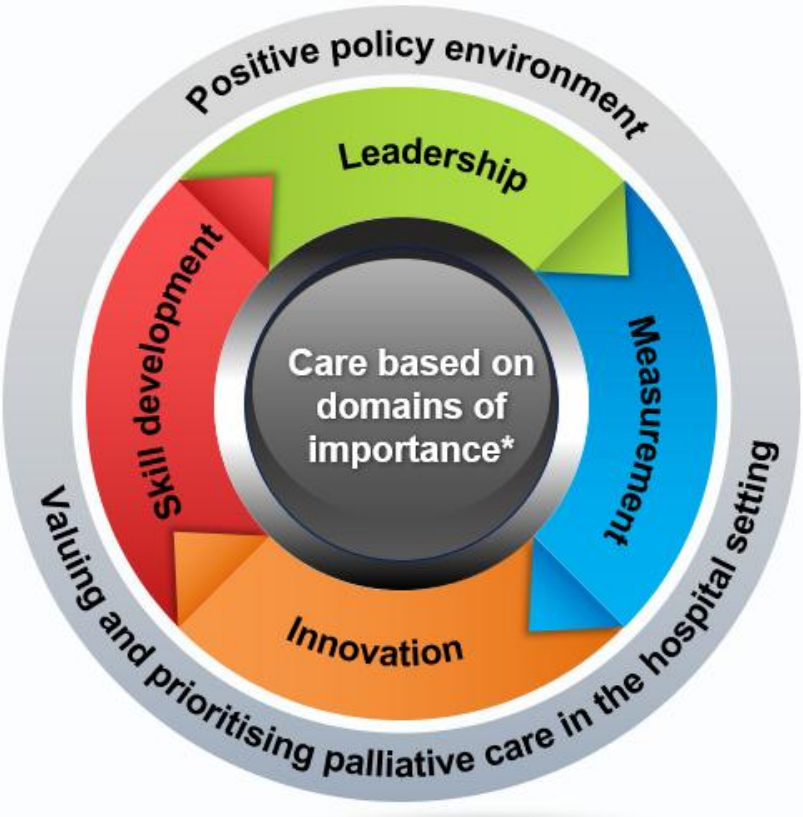
Optimising palliative care within the hospital setting

1. established the evidence base for what constitutes safe and high-quality inpatient care from perspectives of patients with palliative care needs and their families
2. established drivers to support improvement within the Australian hospital context
3. systematically reviewed published patient reported experience measures (PREM) that align with areas that matter most for patients with palliative care needs, and their families
4. worked to identify and pilot a preferred PREM (from patient, consumer and clinician perspectives) for use when informing improvement work for inpatient palliative care
5. Developed and pilot tested an improvement bundle (LEAHP) that included collection and feedback of PREM data and facilitation to empower ward-based quality improvements for inpatients with advanced serious illness.



Informed by 1233 inpatients and 3818 family perspectives

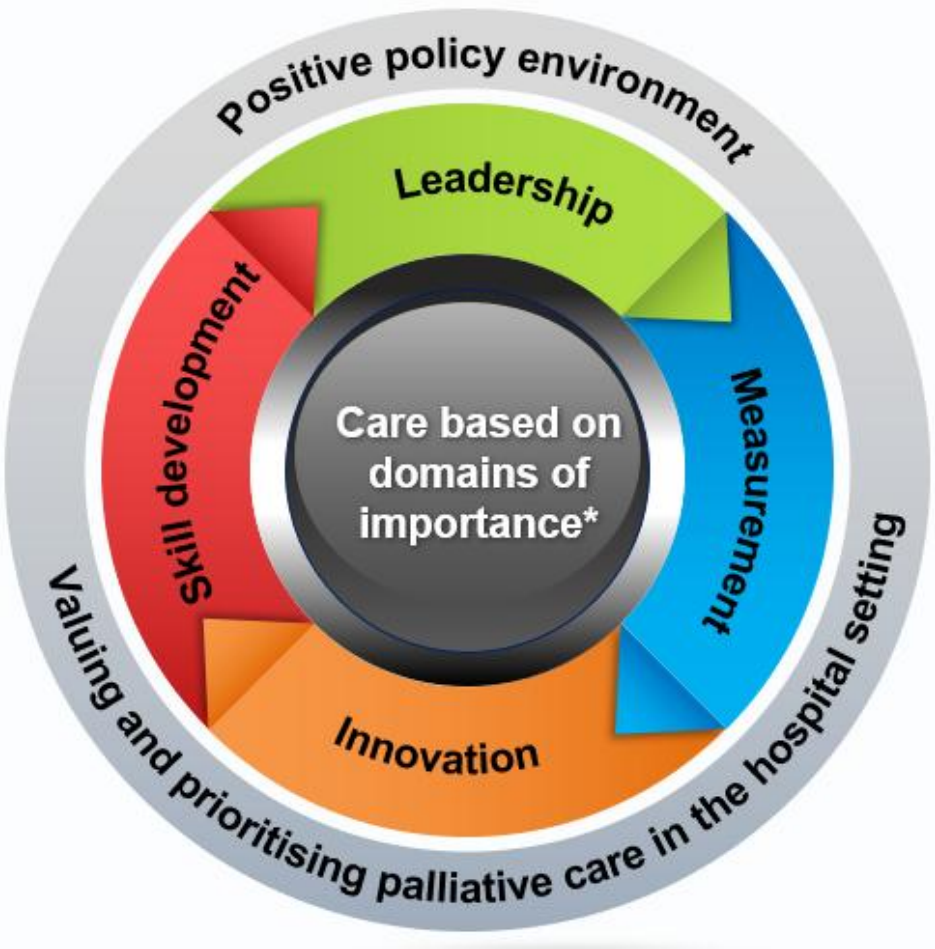
What enables patients and families to feel safe and well cared for?

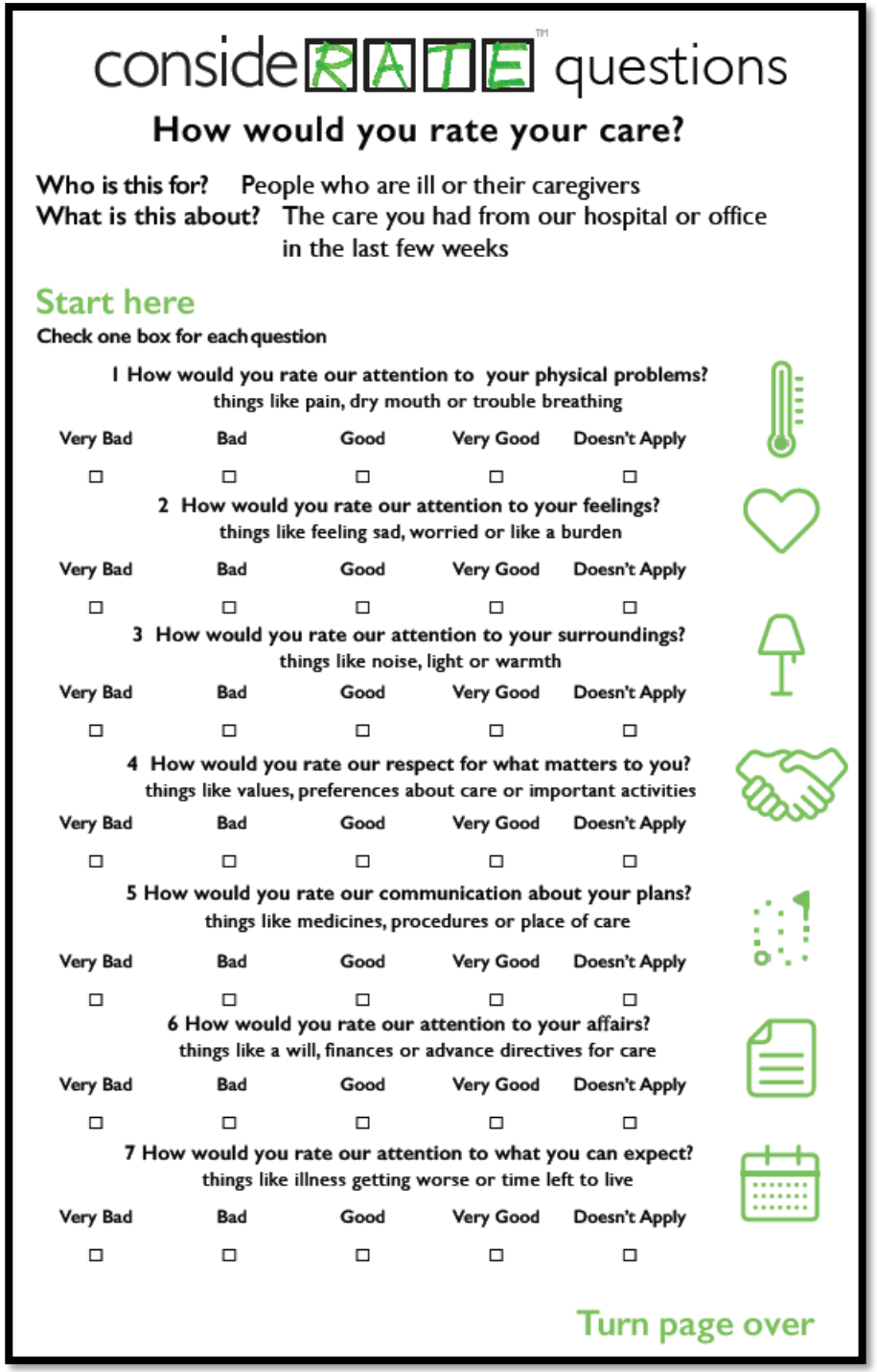


References:

- Virdun, C., Luckett, T., Davidson, P. M., Lorenz, K., & Phillips, J. (2021). Generating key practice points that enable optimal palliative care in acute hospitals: results from the OPAL project's mid-point meta-inference. International Journal of Nursing Studies Advances, 100035.

- Virdun C, Luckett T, Davidson P & Phillips, J. (2024) Strengthening palliative care in the hospital setting: A co-design study. BMJ Supportive and Palliative Care, 14(e1), e798-e806.





considerRATE™ questions

How would you rate your care?

Who is this for? People who are ill or their caregivers
What is this about? The care you had from our hospital or office in the last few weeks

Start here

Check one box for each question

1 How would you rate our attention to your physical problems?
things like pain, dry mouth or trouble breathing

Very Bad	Bad	Good	Very Good	Doesn't Apply
☐	☐	☐	☐	☐

2 How would you rate our attention to your feelings?
things like feeling sad, worried or like a burden

Very Bad	Bad	Good	Very Good	Doesn't Apply
☐	☐	☐	☐	☐

3 How would you rate our attention to your surroundings?
things like noise, light or warmth

Very Bad	Bad	Good	Very Good	Doesn't Apply
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4 How would you rate our respect for what matters to you?
things like values, preferences about care or important activities

Very Bad	Bad	Good	Very Good	Doesn't Apply
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5 How would you rate our communication about your plans?
things like medicines, procedures or place of care

Very Bad	Bad	Good	Very Good	Doesn't Apply
☐	☐	☐	☐	☐

6 How would you rate our attention to your affairs?
things like a will, finances or advance directives for care

Very Bad	Bad	Good	Very Good	Doesn't Apply
☐	☐	☐	☐	☐

7 How would you rate our attention to what you can expect?
things like illness getting worse or time left to live

Very Bad	Bad	Good	Very Good	Doesn't Apply
☐	☐	☐	☐	☐

Turn page over

Reference for considerRATE:

- Saunders, C. H., Durand, M. A., Scalia, P., Kirkland, K. B., MacMartin, M. A., Barnato, A. E., ... & Elwyn, G. (2021). User-centered design of the considerRATE questions, a measure of people's experiences when they are seriously ill. Journal of Pain and Symptom Management, 61(3), 555-565.


LEAHP
LISTEN, EMPOWER AND
ACT TO IMPROVE HOSPITAL
PALLIATIVE CARE

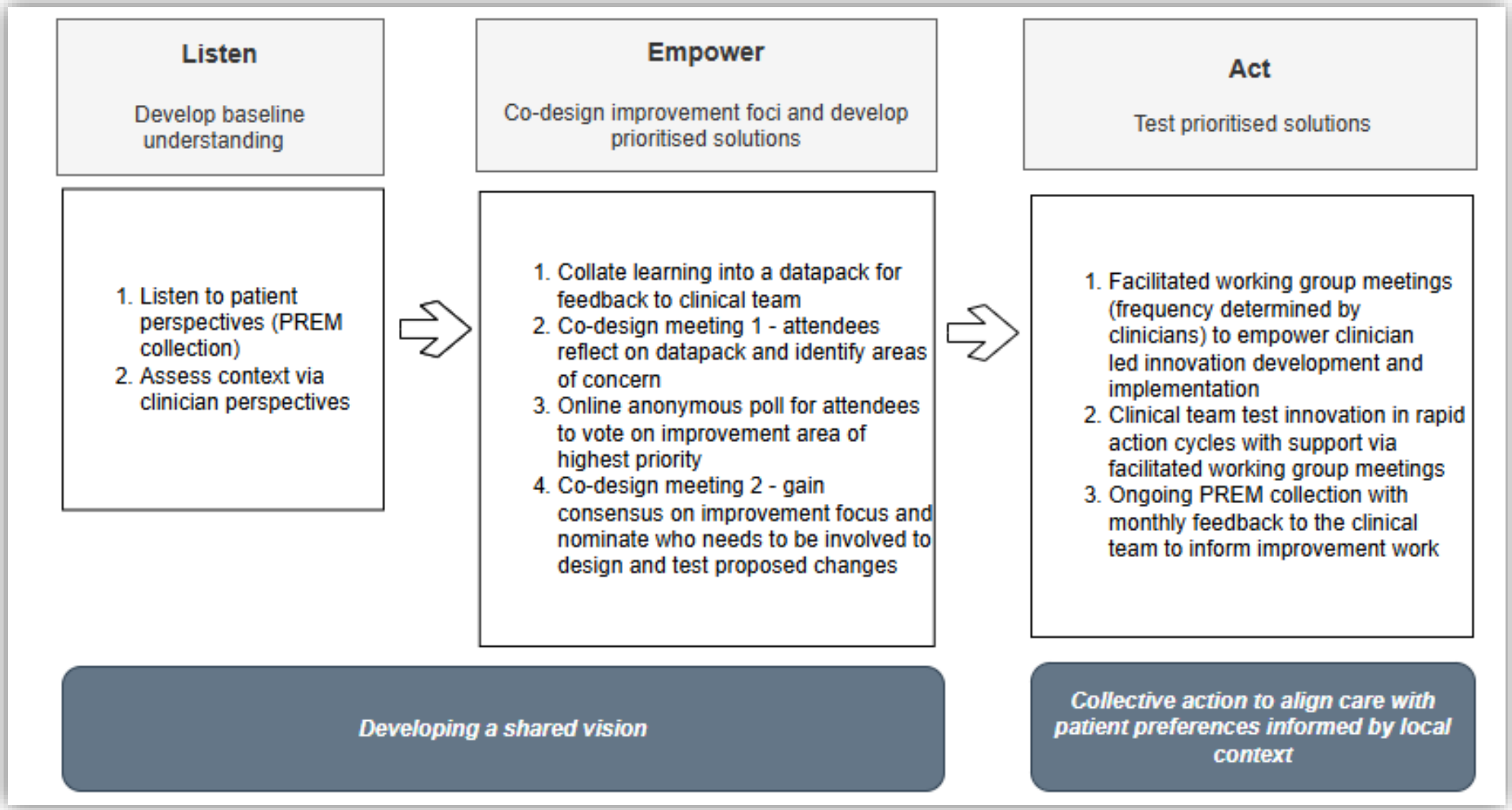
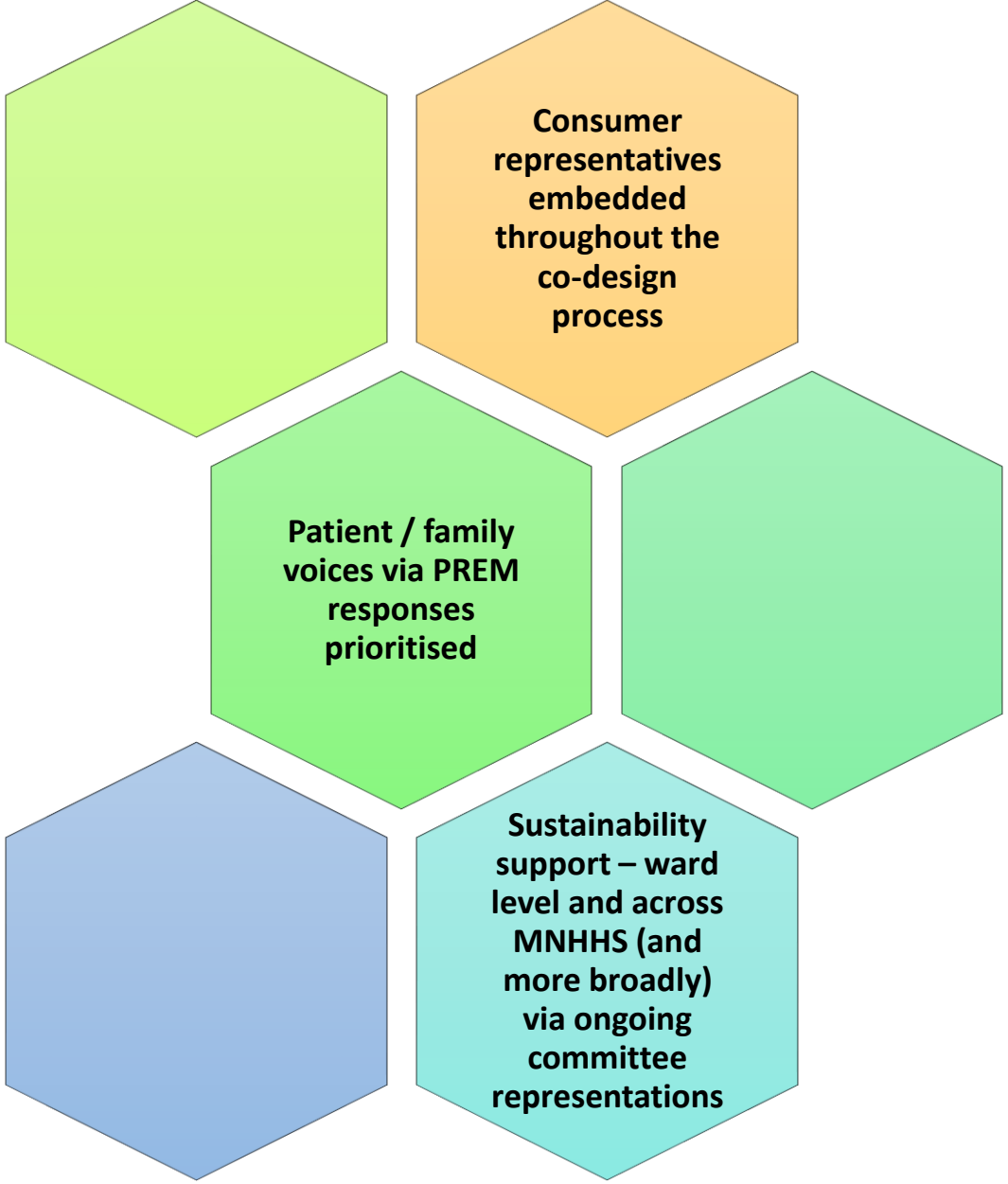


Figure – An overview of the intervention, the 'LEAHP bundle' (Listen, Empower and Act to improve Hospital Palliative care), outlining the phases, activities and proposed mechanisms of change

What happened across the study?

Phase	Planned ward activities	WARD 1	WARD 3
LISTEN	• Baseline PREM collection • Interviews with multidisciplinary clinicians to understand barriers and enablers • Context survey with nursing team • Executive interviews	• 40 PREMs collected • 33 clinician interviews (16 nurses, 7 doctors, 10 allied health professionals) • 25 surveys completed • 4 interviews completed	• 40 PREMs collected • 29 clinician interviews (12 nurses, 9 doctors, 8 allied health professionals) • 16 surveys completed • 3 interviews completed
EMPOWER	• PREM review by key stakeholder group for each ward • Prioritise key areas of improvement based on patient reported quality of care.	• Meeting #1 20 attendees (15 clinicians, 1 consumer representative, 4 researchers) • Prioritisation survey 19/20 responded • Meeting #2 19 attendees (13 clinicians, 2 consumer representatives, 4 researchers)	• Meeting #1 14 attendees (8 clinicians, 2 consumer representatives, 4 researchers) • Prioritisation survey 23/30 responded • Meeting #2 10 attendees (5 clinicians, 2 consumer representatives, 1 researcher)
ACT	• Regular multidisciplinary ward-based working groups to discuss prioritised improvement area(s) and address them using iterative rapid action cycles • Ongoing PREM collection with monthly data feedback to maintain focus on patient reported experience of care quality.	• 24 x 30-minute working group meetings, average attendees 7, included allied health professionals for initial few meetings but then medical and nursing • 259 PREMs collected, fortnightly review of Q7 (run chart) with associated free text responses provided to working group • Intervention implementation commenced within Period 3 (leaflet provision to patients – see Table 3)	• 25 x 30-minutes working group meetings, average attendees 6, medical and nursing • 184 PREMs collected, monthly feedback of graphs and free text for all questions reported to working group and Nurse Unit Manager, and distributed in hard copy to ward nurses. Updated free text data denoted by green font for speed of review • Intervention implementation commenced within Period 1 (screening all new admissions and considering outcomes within care planning – see Table 3)

Consumers leading the way in quality of care appraisal to inform improvement



Innovations

If you are unsure about anything, please ask your care team, as they are here to help. Please use this space to write down questions (or circle the question prompts in this booklet if helpful):

_____

_____

_____

_____

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_____

Talking about your health problems can create some anxiety but learning about them and remaining aware of them is a good step for your wellbeing. We are here to support you throughout this time, please let us know any questions you have.

How do I provide feedback?

Speak to your team

V1 Effective: March 2023 Review: March 2024

Royal Brisbane and Women's Hospital

Ward 6AS Cancer Care

Ensuring you have the information you need

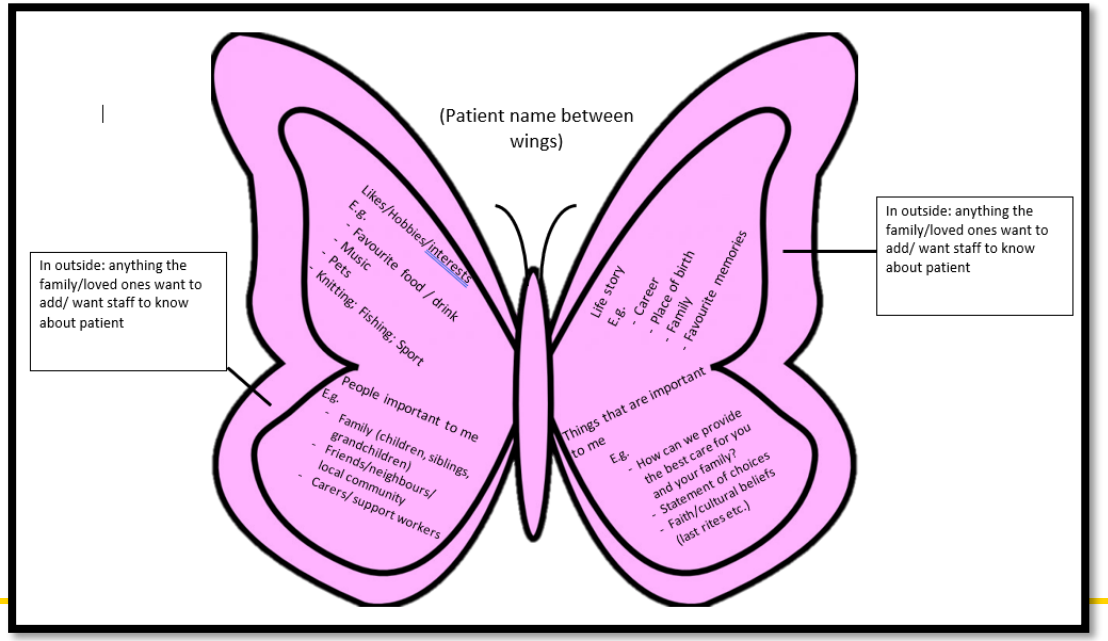
If you have any questions about this brochure, the Nurse Unit Manager of this service is:
Tracy Glynn

Ensuring you have the information you need

- We ask some patients with cancer on this ward whether they would like to talk to their doctors about their illness.
- Would you like to talk about what you might expect over the time ahead, things like your illness getting worse or time left to live? Your family is welcome to attend.
- This conversation could happen during your hospital admission or at your next outpatient visit. Please ask us more about this if you would like to, so we can make sure the doctors are aware and organise a time to talk with you and your family.
- We are here to support and care for you, so please let us know any concerns or worries you have – we want to make sure you have the information you need.

Questions some patients have found useful to ask:

- How quickly will my illness progress?
- What can I expect in the future?
- How will my pain and other symptoms be controlled in the future and by whom?
- How long am I likely to live?
- What can I expect to be able to do?
- How do I get my affairs in order and write a will?
- Who can I talk to about the medical care that I want in the future? Can I refuse treatment?
- Should I meet the palliative care team and what do they do?
- What supports are available for myself and my family?
- What support is available to help me stay in my home as much as possible?
- What activities may help me to enjoy life more e.g., massage, meditation?
- **Have you told your doctors about what is important to you? Things like attending a special event, holiday, anything else…This is important so we can try to make this happen.**



Innovations

TRIAL – PREM-QUAL Project

Queensland Government

Royal Brisbane and Women's Hospital

CRITERIA FOR SCREENING AND TRIAGING TO APPROPRIATE END OF LIFE CARE

(Affix patient identification label here)

URN:

Family Name:

Given Names:

Address:

Date of Birth: Sex: ☐ M ☐ F ☐ I

Screening date: / / Time: : Hospital admission date: / /

Components from Criteria for screening and triaging to appropriate alternative care (CriSTAL)[1]	Tick if yes
Age ≥65 *(1 point)*	☐
Eligible for admission via Emergency Department (ED) or at least 1 night in the ED *(1 point)*	☐
Nursing home resident / or in supported accommodation *(either: max 1 point)*	☐
Rockwood / Clinical Frailty Score (CFS) ≥ 5 ☐ Yes *(1 point if Yes)* ☐ No CFS score	☐
Deterioration criteria on admission (tick as many as relevant—max 1 point if ≥ 2 criteria) *(max 1 point if it meets ≥2 Rapid response team (RRT) criteria)*	
1. Decreased Level of consciousness (LOC): Glasgow Coma Score change >2 or Alert, Verbal, Painful, Unresponsive (AVPU) =P or =U	☐
2. Respiratory rate <5 or >30 or Oxygen Saturation <90%	☐
3. Hypoglycaemia: Blood glucose level (BGL) 1.0 - 4.0 mmol/L	☐
4. Repeat or prolonged seizures (single episode >5 minutes or >2 episodes in 24 hours)	☐
5. Low urinary output (<15 ml/hour or <0.5 ml/kg/hour)	☐
Risk factors/predictors (tick as many as relevant—max 7 points)	
History of active disease:	
1. Advanced malignancy	☐
2. Chronic kidney disease	☐
3. Chronic heart failure	☐
4. Chronic obstructive pulmonary disease	☐
5. New cerebrovascular disease	☐
6. Myocardial infarction ☐ New ☐ Pre-existing ☐ New and pre-existing	☐
7. Moderate/severe liver disease	☐
Evidence of cognitive impairment *(tick as many as relevant—max 1 point if ≥ 1 mental health condition)* ☐ Dementia ☐ Long term mental disorder ☐ Behavioural Alterations ☐ Mental disability from stroke	☐
Proteinuria on a spot urine sample: ++ or >30 mg albumin/g creatinine ☐ Yes *(1 point)* ☐ No ☐ Unknown	☐
Abnormal electrocardiogram (ECG) (atrial fibrillation, ventricular tachycardia, other abnormal rhythm or >5 ectopics/min, changes to Q or ST waves) *(tick as many as relevant—max 1 point if ≥ 1 abnormality)* ☐ Acute abnormality ☐ Chronic abnormality ☐ Both chronic and acute	☐
Previous hospitalisation for at least one night in past year *(only 1 point if ≥1 hospital admission)* ☐ Yes - total number of hospitalisations in the past year ☐ No ☐ Unknown	☐
Intensive care unit (ICU) admission at previous hospitalisation in the past year *(only 1 point if >1 ICU admission)* ☐ Yes ☐ No ICU admission at all ☐ Unknown	☐
Fall in the past 3 months *(1 point)*	☐
Polypharmacy (6 or more medications) before admission *(1 point if ≥6 medications)*	☐
Total CriSTAL score (out of a maximum of 19)	

Treating consultant:

Clinician name: Designation:

Signature: Date: / /

Please complete page 2 if CriSTAL score ≥6* or 'of concern' per clinician judgement

Page 1 of 2

DO NOT WRITE IN THIS BINDING MARGIN

All clinical form creation and amendments must be conducted through Health Information Services

Do not reproduce by photocopying

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Queensland Government

Royal Brisbane and Women's Hospital

CRITERIA FOR SCREENING AND TRIAGING TO APPROPRIATE END OF LIFE CARE

(Affix patient identification label h

URN:

Family Name:

Given Names:

Address:

Date of Birth: Sex: ☐ M

Care planning for a patient with a CriSTAL score ≥6*

**This score is strongly indicative of risk of death (i.e. >50% risk) within 4 months (validated in people a*

Consultant informed of CriSTAL score and elected to defer care planning questions, pending or

☐ Yes - review again within 5 days

☐ No - complete care planning questions

Care planning questions	Action required / Comments
Is the patient and family aware of the poor prognosis? ☐ Yes ☐ No	
Have Goals of Care been established with this patient and/or family? ☐ Yes ☐ No	
Are any of the following Advance Care Planning (ACP) documents in place? Please check ieMR ACP Tracker	
Acute Resuscitation Plan (ARP) ☐ Yes ☐ No	
Enduring Power of Attorney (EPOA) ☐ Yes ☐ No	
Statement of Choices (SOC) ☐ Yes ☐ No	
Advance Health Directive (AHD) ☐ Yes ☐ No	
Is a family meeting needed? ☐ Yes ☐ No	
Would this patient/family benefit from referral to specialist palliative care? ☐ Yes ☐ No If appropriate, please complete MR C 6049 - Palliative Care Service Referral	

Clinician name: Designation:

Signature: Date: / / Time: :

[1] Cardona M, Lewis ET, Kristensen MR, et al. Predictive validity of the CriSTAL tool for short-term mortality in older people presenting at Emergency Departments: a prospective study. Eur Geriatr Med. 2018;9(6):891-901. doi: 10.1007/s41999-018-0123-6

Page 2 of 2

If you are unsure about anything, please ask your care team, as they are here to help. Please use this space to write down questions (or circle the question prompts in this booklet if helpful):

Talking about your health problems can create some anxiety but learning about them and remaining aware of them is a good step for your wellbeing. We are here to support you throughout your healthcare journey, please let us know any questions you have.

How do I provide feedback?

Speak to your team

Ask one of your nurses

Royal Brisbane and Women's Hospital

Your Respiratory Care

Ensuring you have the information and supports you and your family need

If you have any questions about this brochure, please discuss these with one of your Respiratory Care team members.

Ensuring you have the information you need

- We ask patients living with respiratory illness and receiving care in our service, whether they would like to talk to their doctors about aspects of their illness not previously discussed.
- Would you like to talk about what you might expect over the time ahead, things like your illness getting worse or time left to live? Your family is welcome to attend.
- This conversation could happen during a hospital admission or at your next outpatient / clinic visit. Please ask us more about this if you would like to, so we can make sure the doctors are aware and organise a time to talk with you and your family.
- You might also need assistance in drawing up an advance health directive or appointing an enduring health power of attorney.
- We are here to support and care for you, so please let us know any concerns or worries you have – we want to make sure you have the information you need.

Questions some patients have found useful to ask:

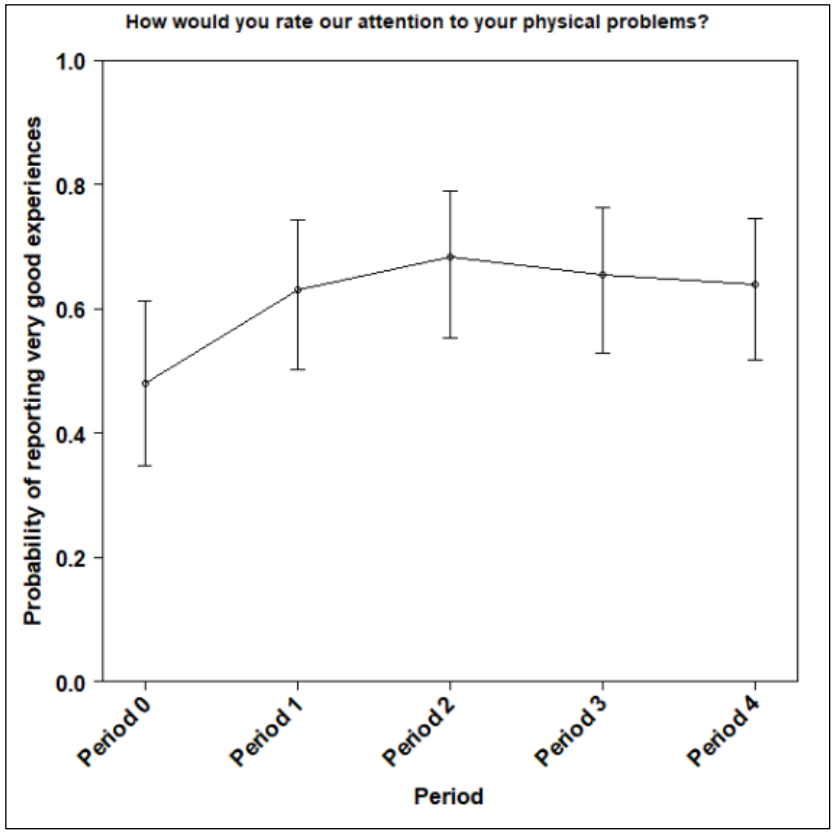
- How will my symptoms (e.g. breathlessness, fatigue, anxiety) be controlled in the future and by whom?
- How quickly will my illness progress?
- Should I start using supplemental oxygen?
- What can I expect in the future?
- How long am I likely to live?
- What can I expect to be able to do or not do?
- How do I get my affairs in order and write a will?
- Who can I talk to about the medical care that I want in the future? Can I refuse treatment?
- Should I meet the palliative care team and what do they do?
- What supports are available for myself and my family?
- What support is available to help me stay in my home as much as possible?
- What activities may help me to enjoy life more e.g., massage, meditation?
- **Have you told your doctors about what is important to you? Things like attending a special event, holiday, anything else…This is important so we can try to make this happen.**

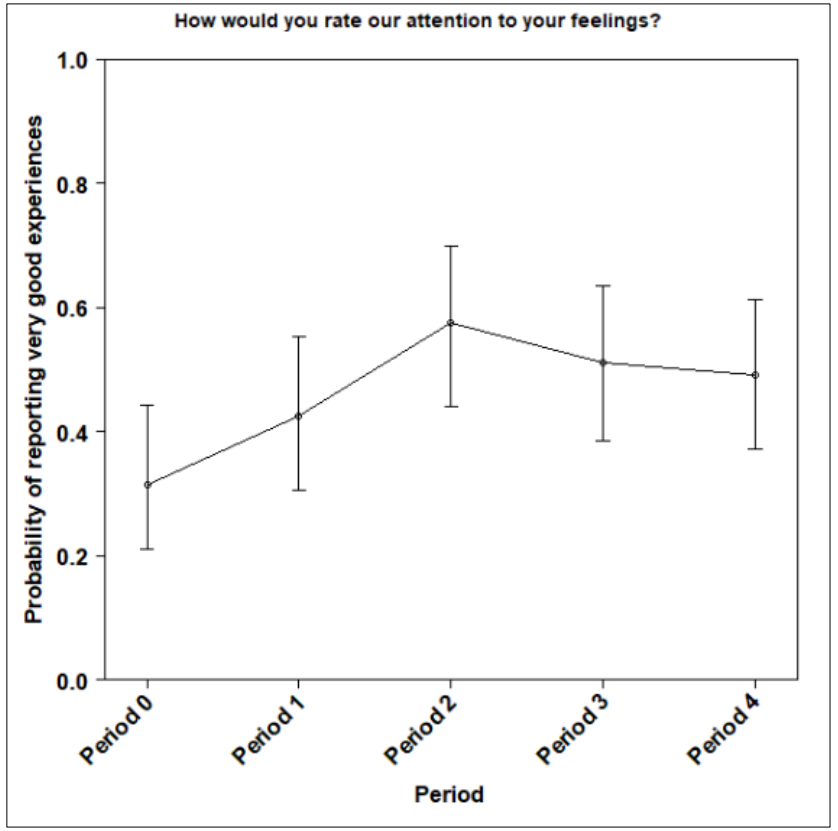
CRICOS No. 0014A

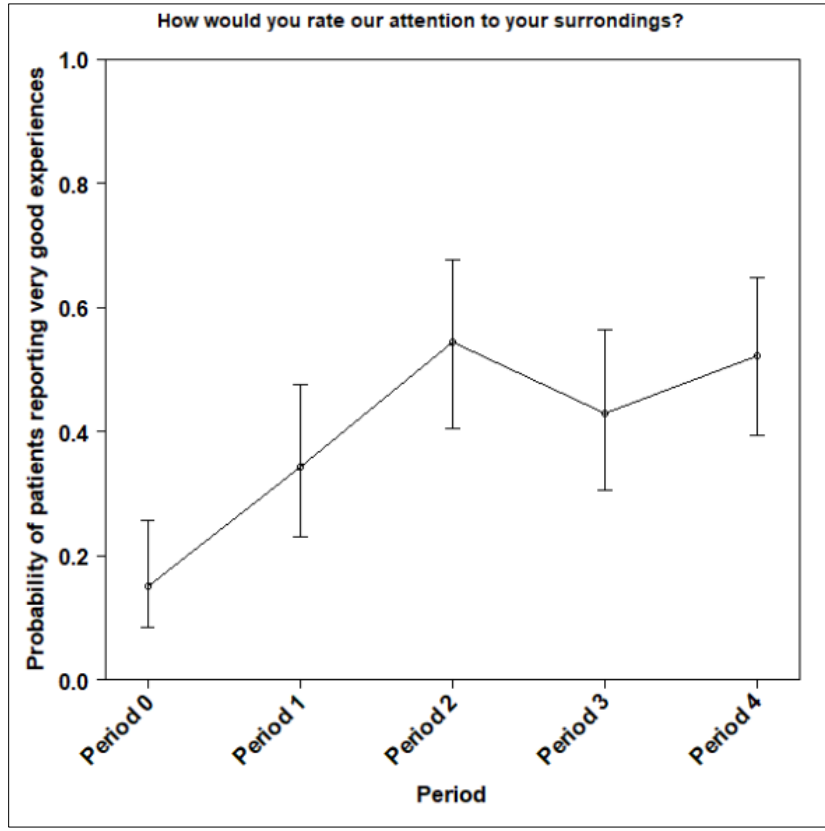
Did patient experience improve over time for patients screened to have palliative care needs?

What did we learn?

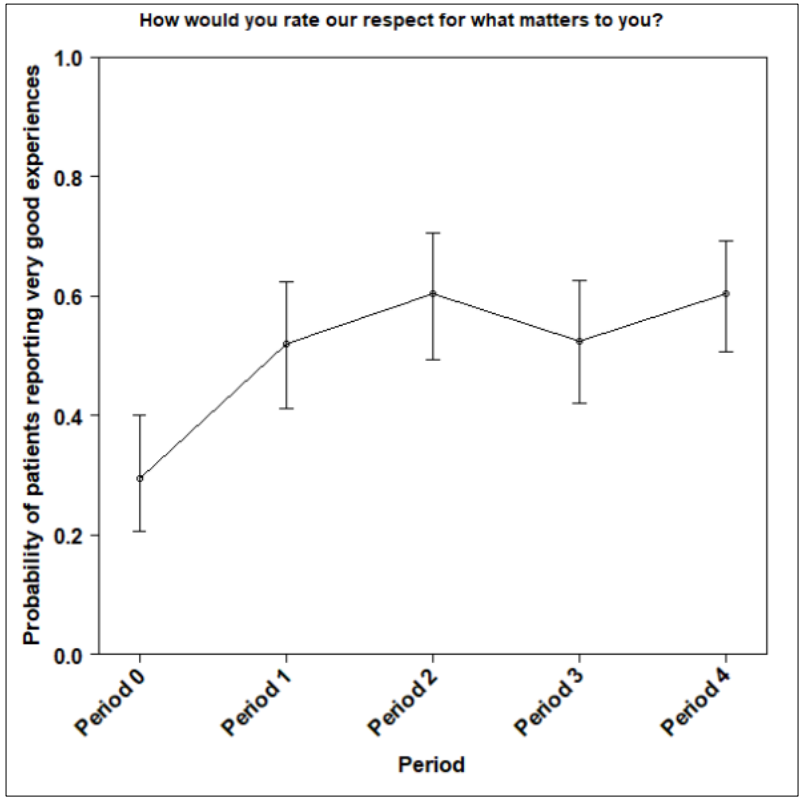
- When clinical teams are supported to reflect and act on meaningful patient reported experience data, this improves patient experience of care quality at the ward level (statistically significant for 6 of the 7 questions within the PREM used)

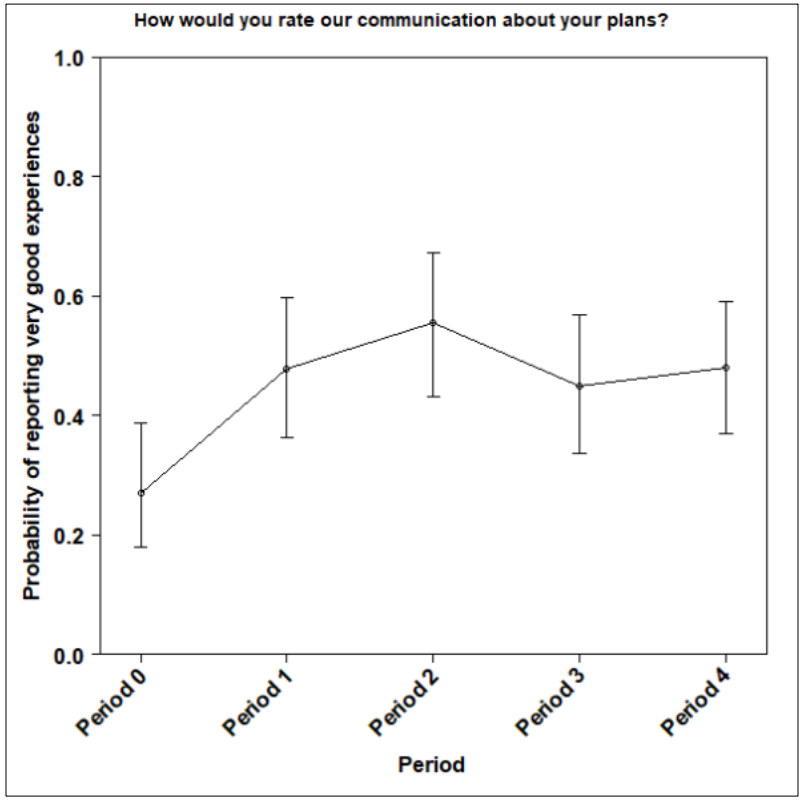


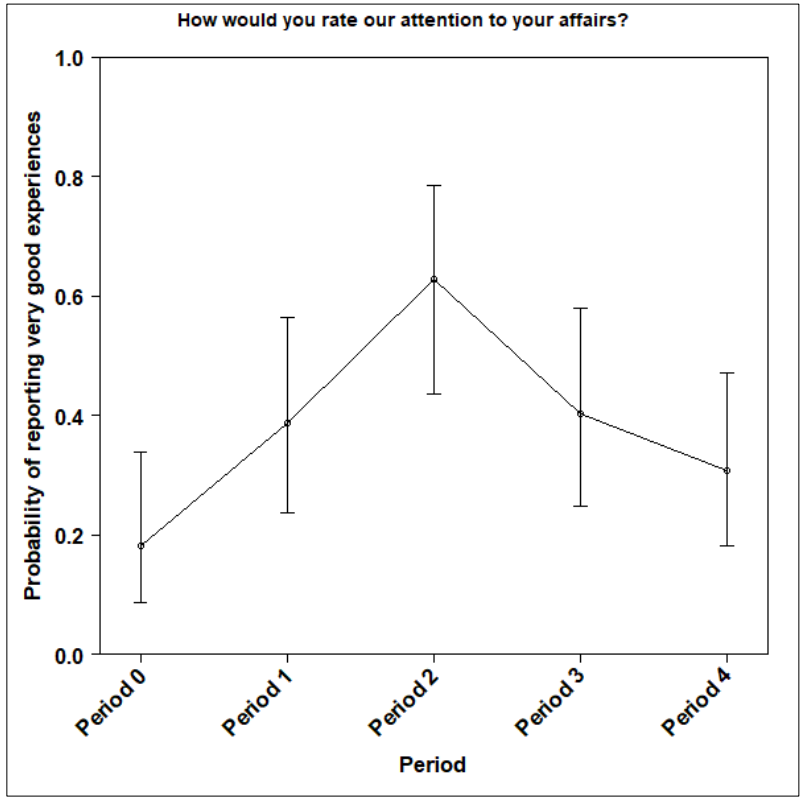




What did we learn?







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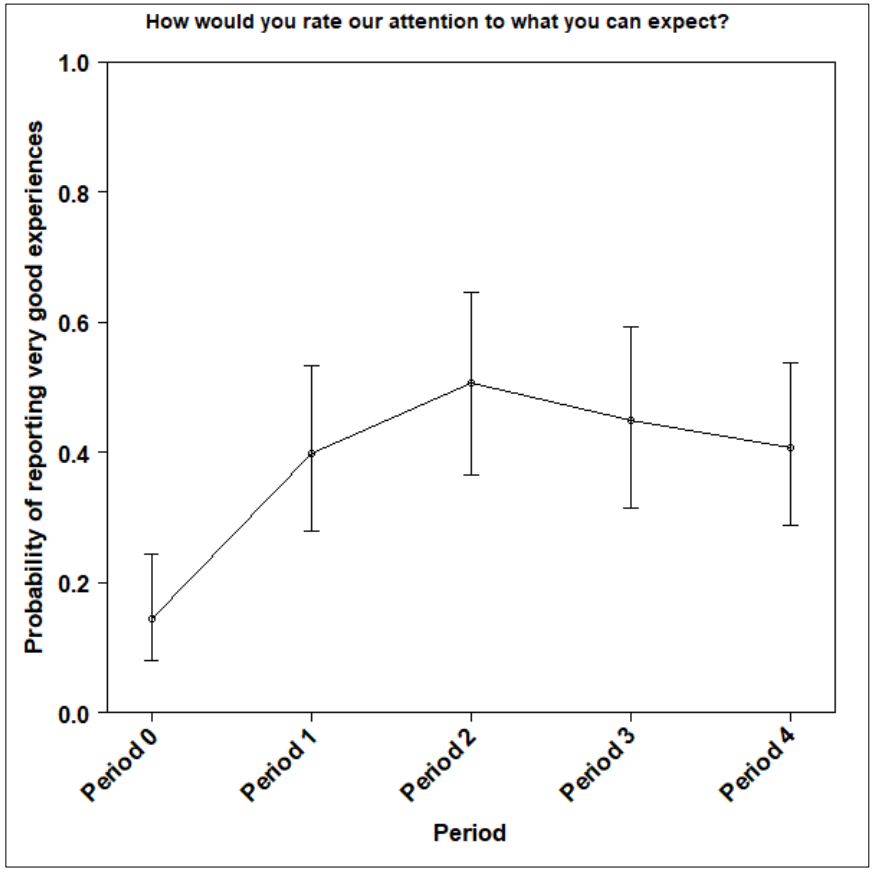

consideRATE questions

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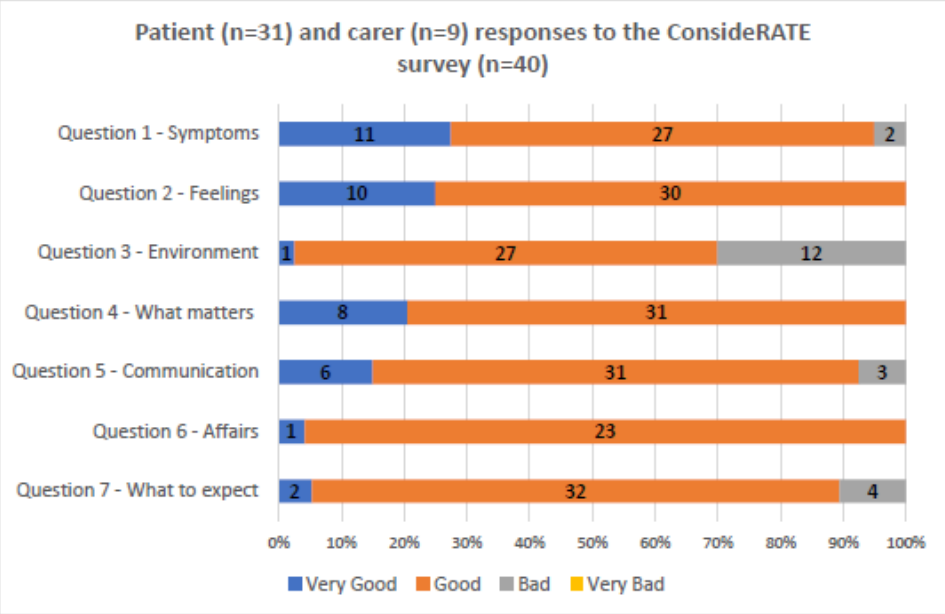
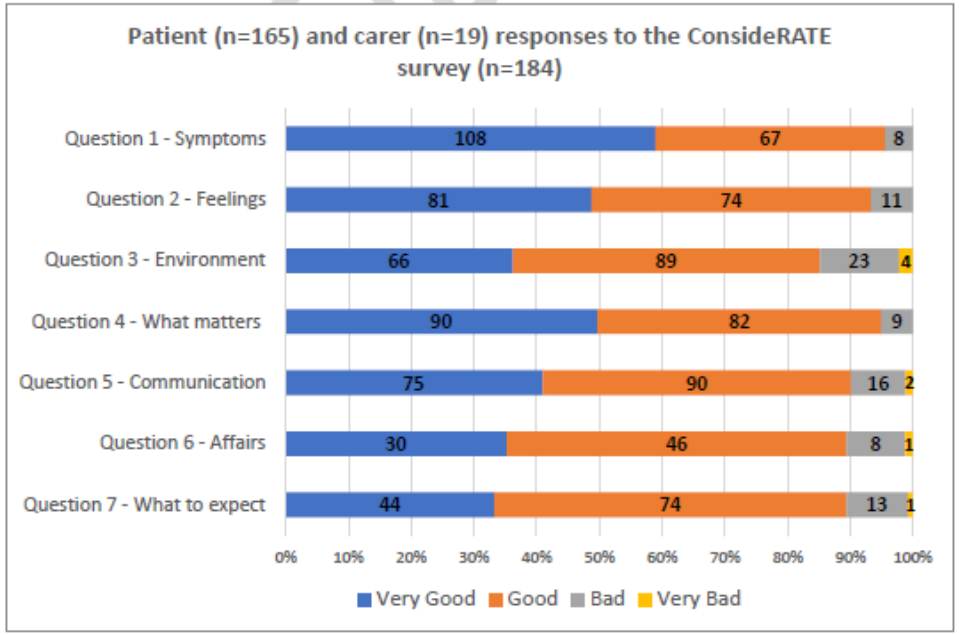
Phase 1 data: September – November 2022



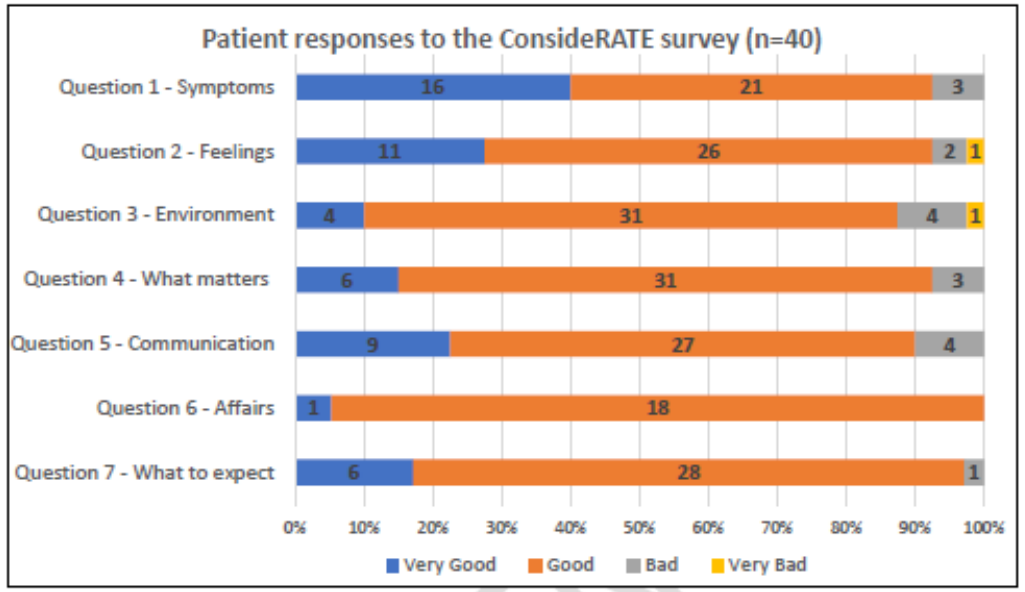
Phase 2 data: April – November 2023



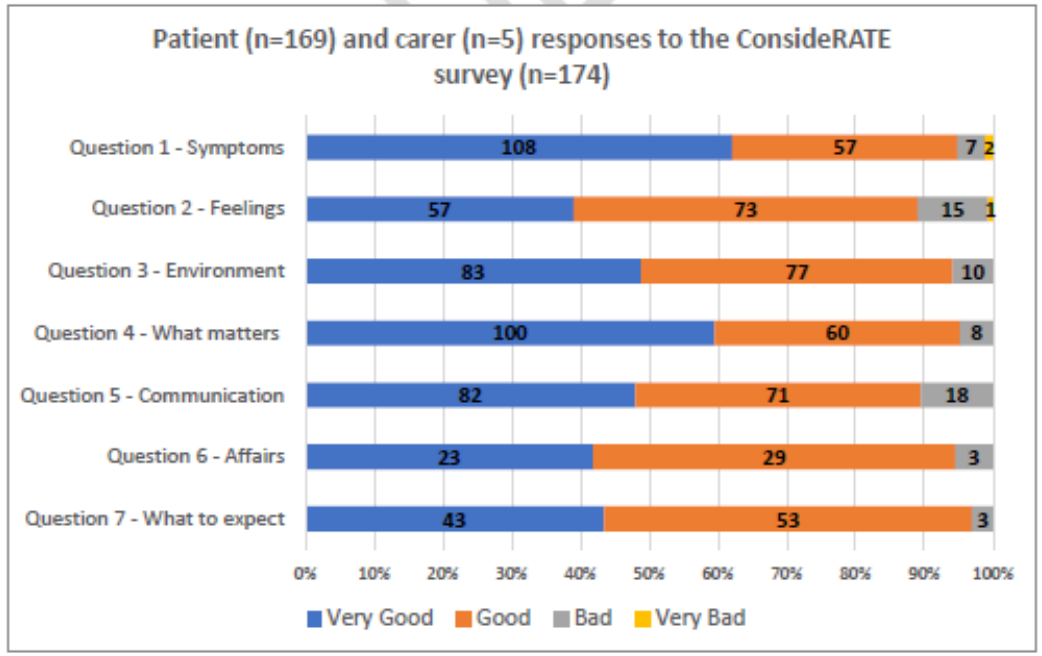
Comments for Q7: How would you rate our attention to what you can expect?

Positive feedback	Constructive feedback
• They talked about this yesterday. It was straight to the point but respectful to our wishes. I would prefer to know so that we're prepared. • The consultants say that they haven't got a silver bullet for me, they can't fix me up. I've been on trials, but they didn't work. • I've still got a lot to do with my grandkids. I've got to give it a try. • My doctors are very good at letting me know what is happening with my health. • This doesn't apply to this ward, but I have had a previous conversation in ICU just prior to coming to this ward. They thought I may have had a bowel obstruction and I said I didn't want an operation if that was the case. I don't think they were happy but it's my decision. As it turns out, I didn't have a bowel obstruction. • the doctors and nurses are always letting me know what is happening. • The doctor talked me through this conversation - it was a bit scary but it was a positive experience. I think this is very important. I felt a lot better after I verbalised what I was thinking. I want them to do what's best not only for me, but for my husband. I	• We understand that the doctors are overworked but it would have been good to see the oncologists soon after diagnosis. We have many questions that have remained unanswered for weeks. Very stressful. • We haven't talked about it this admission but I have on other occasions. My daughter is a doctor and she looks after those sorts of things. • I need to tell my doctors what I am thinking and what is important, They don't really talk about that stuff. I think I have been given extra time as it is. I can't imagine any better care. I hadn't thought about this at all until my doctor pulled me aside and said 'hey, you are very unwell and we need some guidelines in place'. Since then, I have thought more about it and I should talk to my doctor again. I want my husband to have time to say goodbye to me if that happens. His father passed 'nd he didn't make it, he was on the plane and he didn't make it. And I think that was so hard. His dad died painfully of cancer and so 11o one wanted to prolong that, but I think it would have been so much easier for my husband if he could just have said goodbye. So, I want to be resuscitated and put on life support so my husband can say goodbye. I don't want to stay on life support though. But I haven't told anyone about these thoughts, I have just been thinking about it.

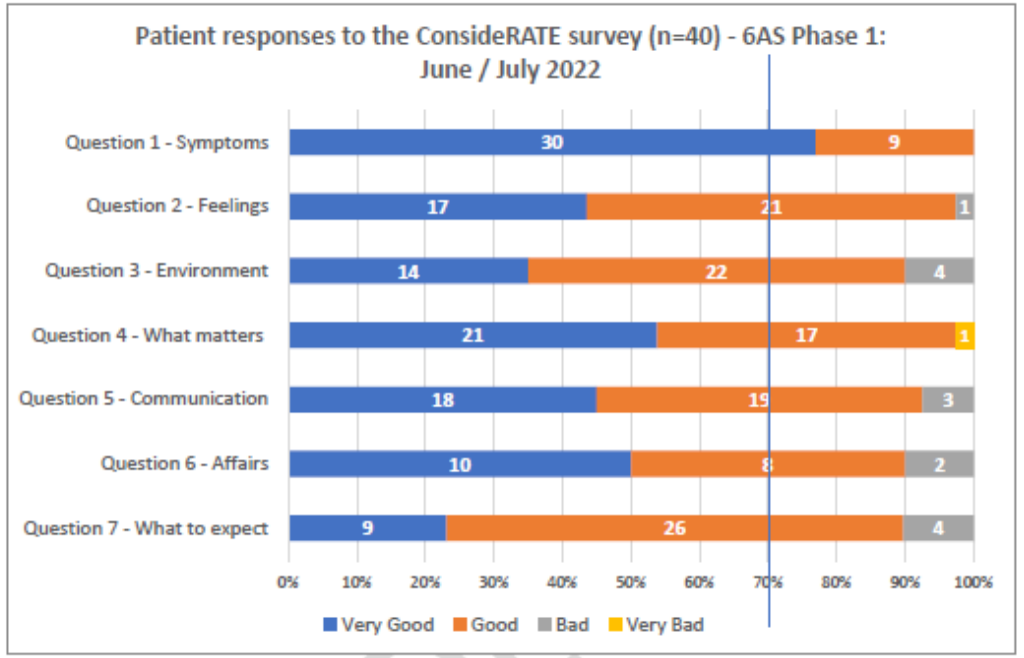
Phase 1 data: August – September 2022



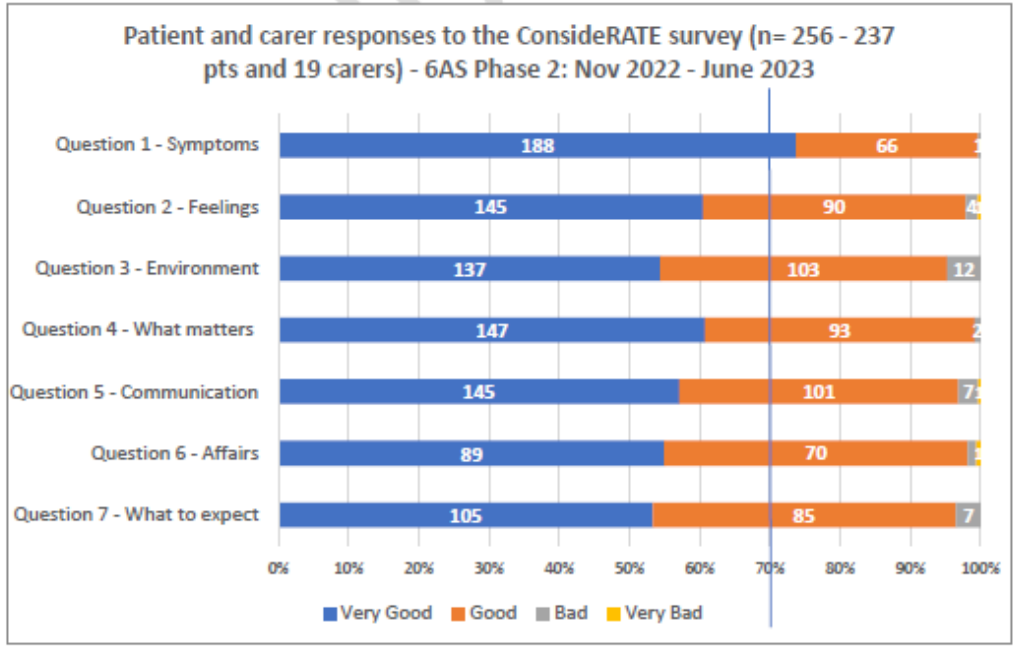
Phase 2 data: February – September 2023



Phase 1 data (n=40) – benchmark of 70% for 'very good' responses selected by working party



Phase 2 data (n=256) – benchmark of 70% for 'very good' responses selected by working party



Patient voices are valued – they drive engagement

Some examples of free text quotes provided – positive feedback:

I can't fault the staff's attention to my pain and physical needs - they have gone above and beyond.

Everyone is working together to best care for my health issues. It really is a team effort which shows you you're getting the best care.

Compassion, empathy, concern shown by all staff - they are all wonderful

The palliative care team have spoken about the future. They discussed resuscitation and told me it wouldn't help at this stage. I appreciate the honesty.

Patient voices are valued – they drive engagement

Some examples of free text quotes provided – constructive feedback:

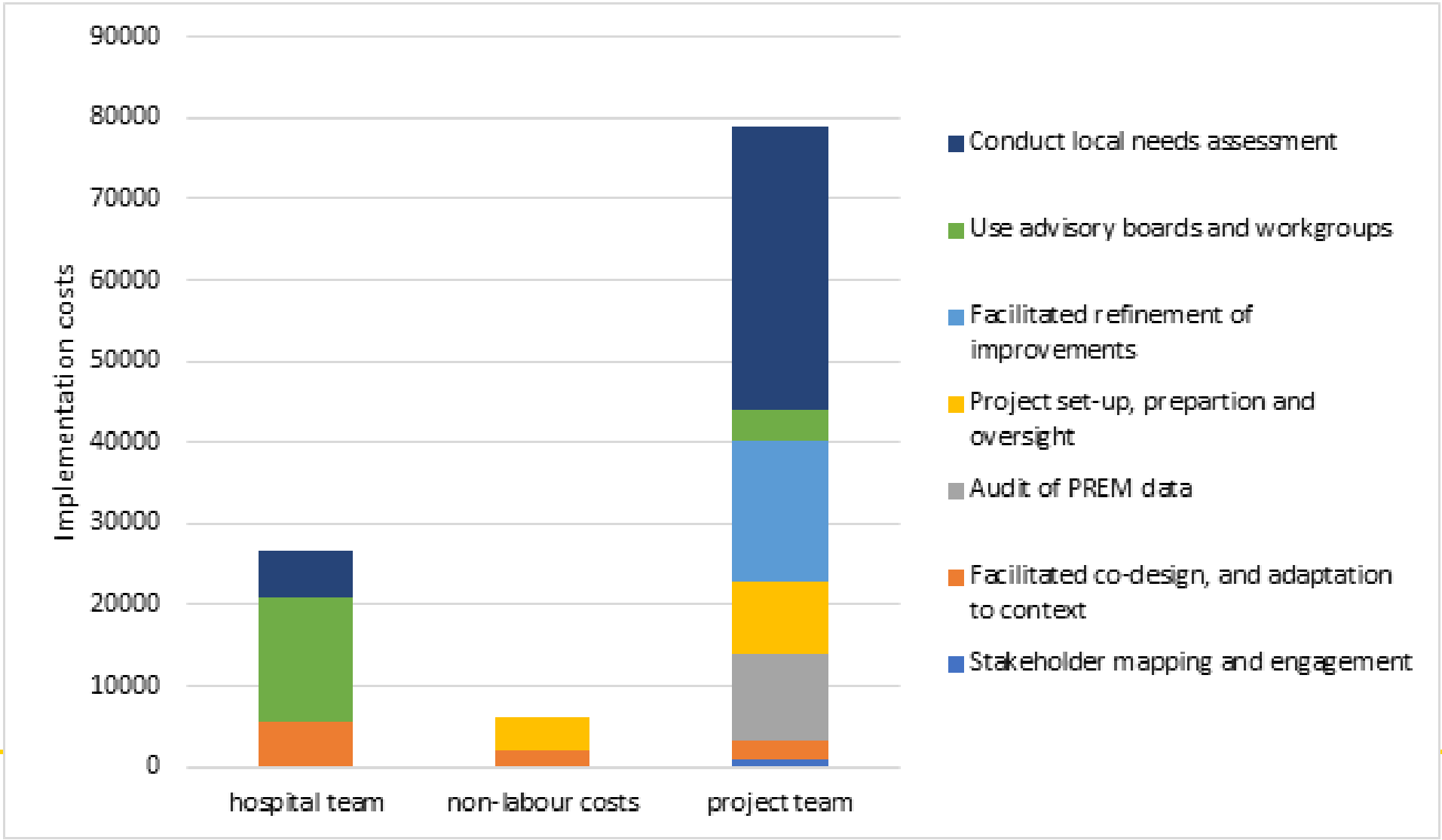
I need to tell my doctors what I am thinking and what is important, They don't really talk about that stuff. I think I have been given extra time as it is.

It is woeful because they are scared. Everybody is scared to talk about death. When you waver and ask, no one wants to talk to you. When you force the issue they will but they won't be the people to bring it up. Makes it easier if you bring it up.

I would have appreciated a talk about this when I first came into hospital and was really sick. You're thinking it but no one is saying anything. It must be very hard for them to have that sort of conversation, but I'd like them to be honest.

What did we learn?

Base case overall costs, by cost category and implementation strategy (across three wards)



Study conclusions

- Implementation of the LEAHP bundle led to improved palliative care experience within three wards in one large tertiary hospital setting.
- Improved patient experience occurred regardless of the innovation designed and tested at the local level and therefore seems to be related to the actions of developing a shared vision based on patient feedback and empowering collective action tailored to local context.
- Listening to patients and staff and empowering clinical teams to collectively reflect on patient data and lead change was crucial to study success.
- Further testing of the transferability, scalability, sustainment and costs of this intervention will help to inform ongoing systems improvement in hospital palliative care.

LEAHP
LISTEN, EMPOWER AND ACT TO IMPROVE HOSPITAL PALLIATIVE CARE

National community of practice

Contacted by 19 other clinical services from across Australia with interest in the use of PREMs and facilitation to guide change in palliative care

Established an informal national community of practice with these self-nominated services to share learnings and collaborate

Meet for 1 hour, 5 times a year via Teams – so far have held 11 meetings

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