Cancer and Palliative
Care Outcomes Centre

Harnessing patient’s with palliative care needs, and their carers’ feedback to drive improvement work within the Australian hospital setting

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CRICOS No.00213J

The Queensland University of Technology (QUT) acknowledges the Turrbal and Yugara, as the First Nations owners of the lands where QUT now stands. We pay respect to their Elders, lores, customs and creation spirits. We recognise that these lands have always been places of teaching, research and learning.

QUT acknowledges the important role Aboriginal and Torres Strait Islander people play within the QUT community.

Introductions and acknowledgments

PHD Supervision panel

1. **Professor Jane Phillips**
   Professor Palliative Care Nursing and Head, School of Nursing.
   Faculty of Health, Queensland University of Technology
2. **Dr Tim Luckett**
   Senior Lecturer, Faculty of Health, University of Technology Sydney
3. **Professor Patricia Davidson**
   Vice-Chancellor, University of Wollongong
4. **Professor Karl Lorenz**
   General practitioner and palliative care physician, and Section Chief of the VA Palo Alto-Stanford Palliative Care Program; Professor of Medicine at Stanford University School of Medicine

Throughout my PHD

- Consumer representatives – *University of Technology Sydney (IMPACCT) and NSW Translational Cancer Research Network*
- Participating hospitals across NSW
- Clinicians who assisted screening and recruitment
- Patients and family members / carers who participated in the interviews
- Clinicians, policy makers and researchers who assisted throughout in multiple ways – co-design, email interviews, peer review

Throughout my post-doctoral work

- Cancer care services and internal medicine services at the Royal Brisbane and Women's Hospital – including clinicians and patients / carers
- Consumer representatives, Metro North Hospital and Health Service

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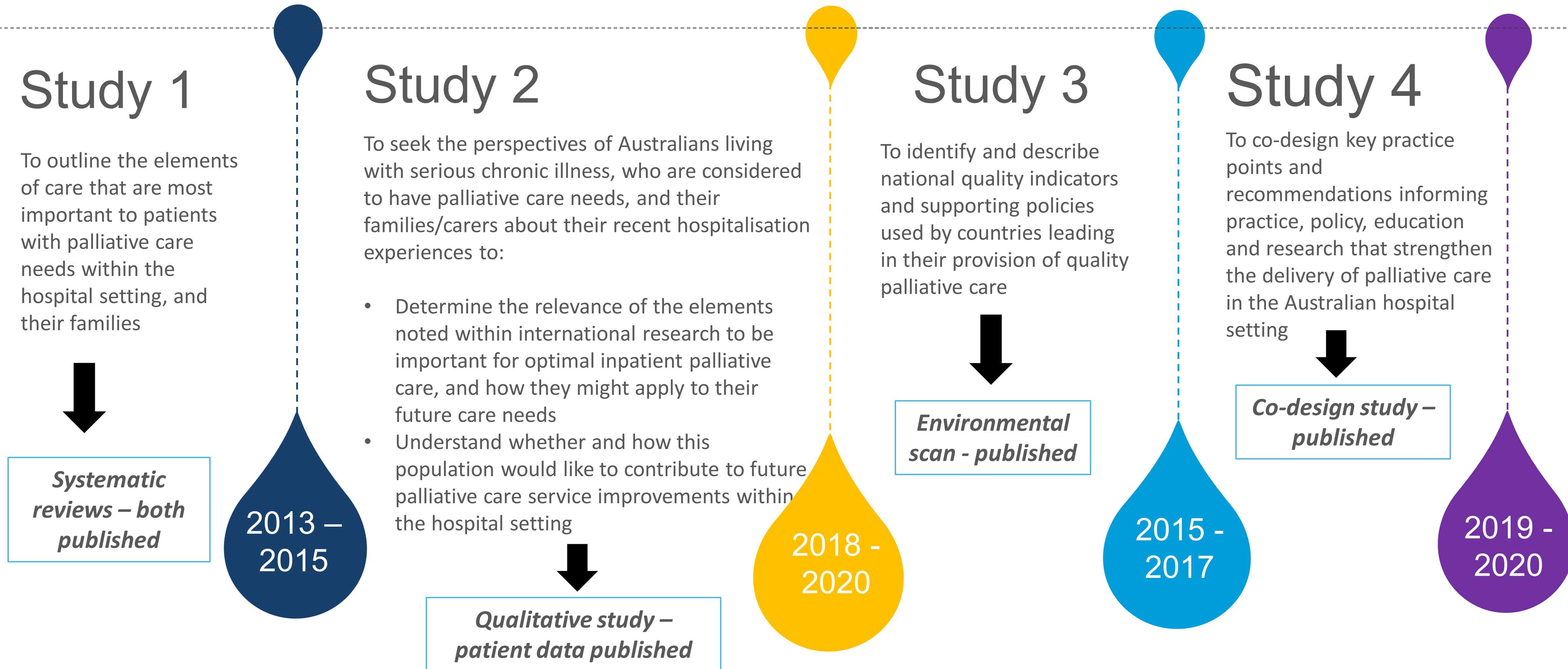
Optimising care for People with palliative care needs, and their families, in the Australian hospitaL setting – the OPAL Project



A mixed methods project privileging both quantitative and qualitative data throughout

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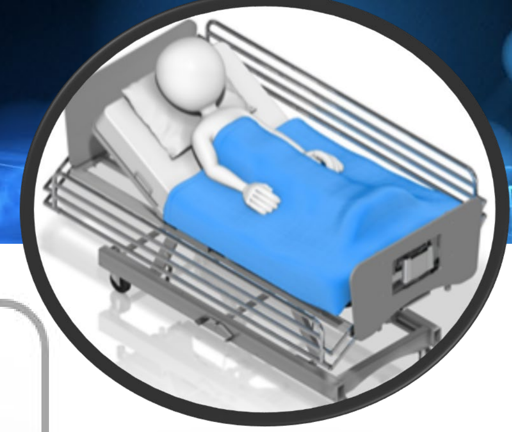


1. Excellence in physical care
2. Impeccable assessment and care planning
3. Effective symptom management
4. Technical competence
5. Patient safety
6. Supported access to senior clinicians

Expert care

Person-centred care

Optimal environment

Optimal inpatient palliative care

1. Respectful and compassionate care;
2. Effective communication and shared decision making;
3. Effective teamwork;
4. Enabling family involvement;
5. Maintaining role, meaning and identity

1. Structural factors - patient
2. Structural factors - family
3. Cleanliness to support infection control

14 domains of care broken into 68 key clinical practice points

Figure: Key domains of importance for optimal inpatient palliative care from both patient and family perspectives

Reference: 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, 3, 100035.

Key drivers to strengthen optimal palliative care in the Australian hospital setting

1. Recognising and valuing palliative care as core business and a priority for inpatient care;

2. Leadership at macro (policy), meso (hospital executive) and micro levels (ward) to develop systems and processes to enable optimal palliative care provision in accordance with consumer need;

3. Measurement to inform quality assurance and identify targets for improvement;

4. Innovation to co-design, with clinicians, administrators, other relevant experts and palliative care consumers, structures and processes that align with required patient and family-identified needs for optimal care; and

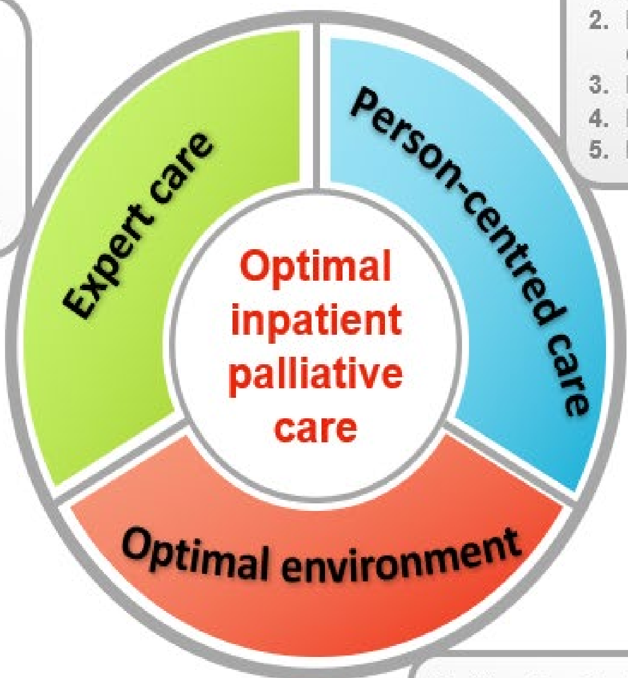
5.Targeted skill development to support clinicians and ancillary staff in their delivery of palliative care.

**Key domains of importance (n=14) for optimal inpatient palliative care from the perspectives of patients with palliative care needs and their families*

Figure: Key drivers for optimal palliative care in the Australian hospital setting

Where to from here …

1. Excellence in physical care
2. Impeccable assessment and care planning
3. Effective symptom management
4. Technical competence
5. Patient safety
6. Supported access to senior clinicians



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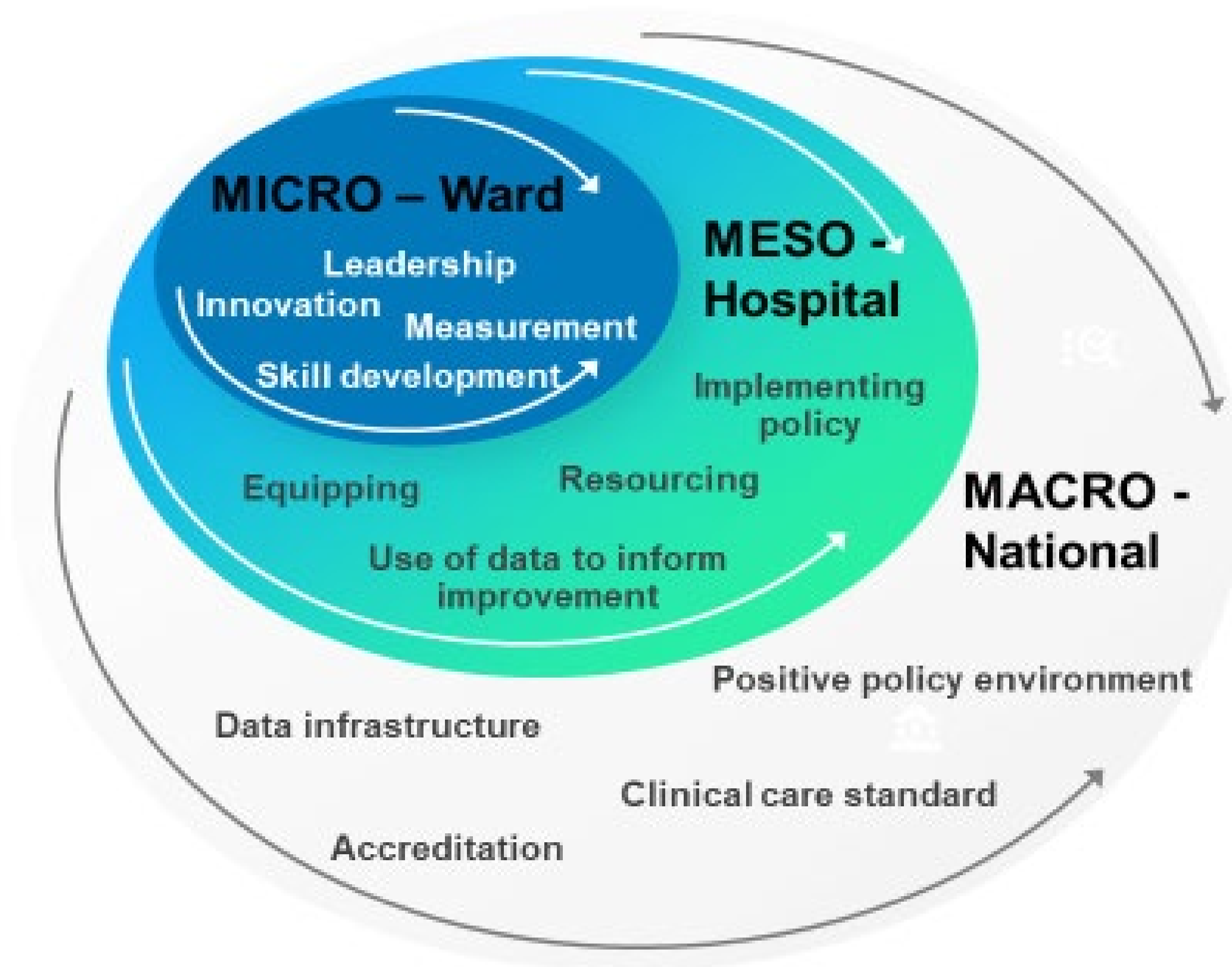
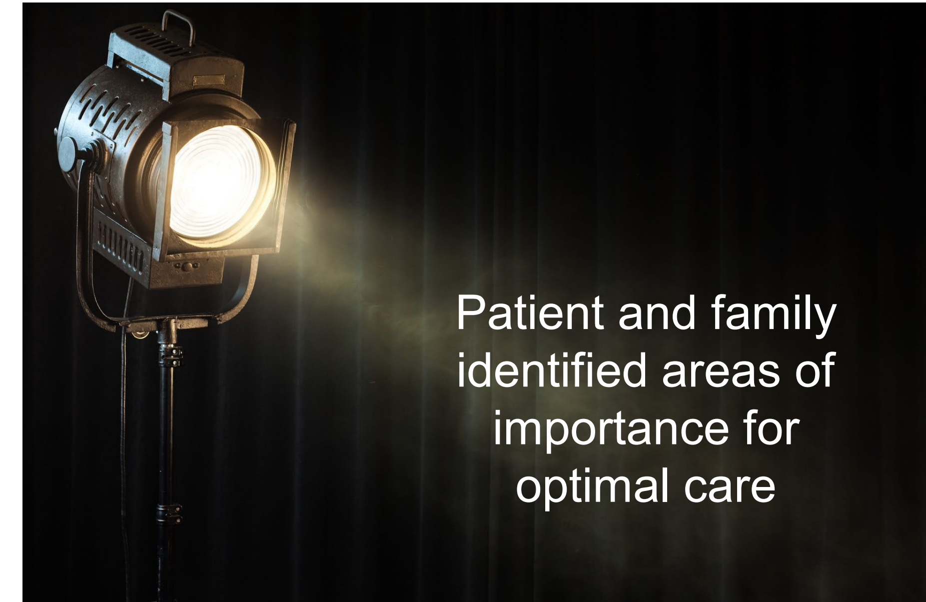


Figure: Key components of recommendations for systematic improvements in inpatient palliative care within Australian hospitals



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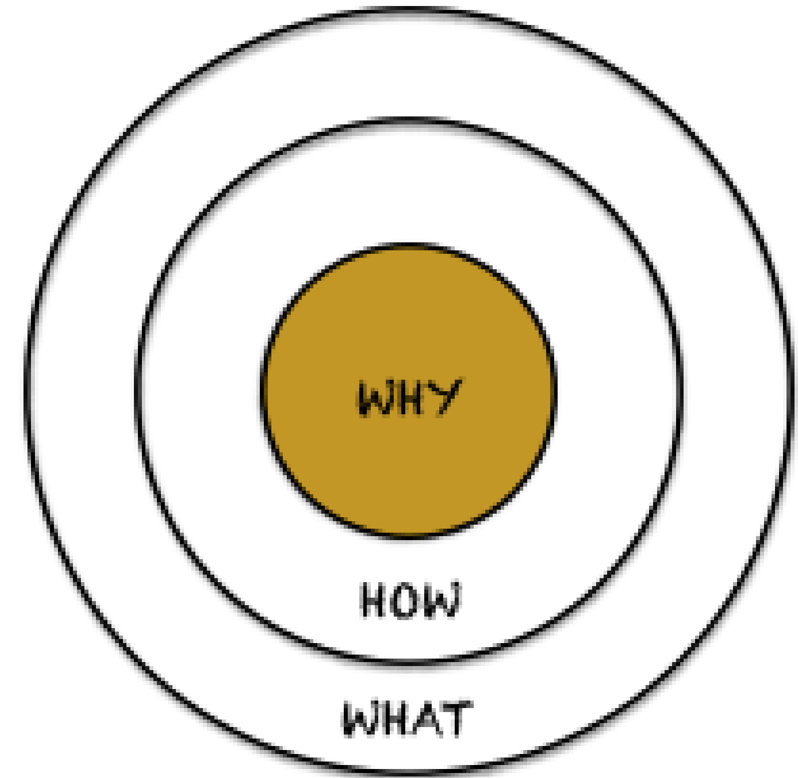
Driving change based patient's with palliative care needs, and their carers' preferences



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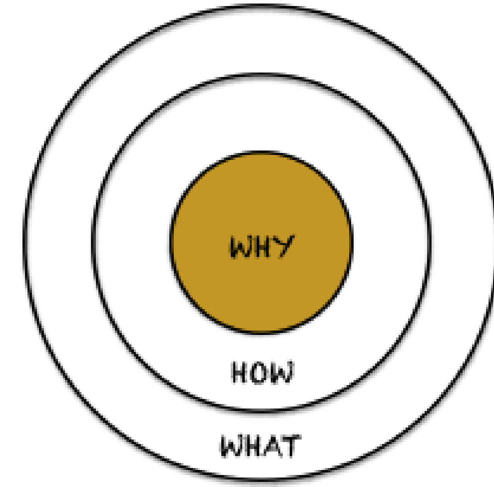
Driving change based on patient preferences



PREM tools available for palliative care appraisal – hospital focus

Aim: To identify and describe available PREMs designed for inpatients living with advanced serious illness and their carers.

Design: A systematic review with narrative synthesis.

Results: 44 PREMs with 827 items were included. Items per PREM varied from 2 to 85 (median 28; IQR 30). 534 (65%) of items were designed for carers (n= 534) 283; 34% for patients, and 10 (1%) for both. 66% of items measured person-centred care, 30% expert care, and 4% environmental aspects of care. PREMs had a median of 38% (range 0-100%) items above grade 8 reading level.

Conclusions: Whilst 44 PREMs are available for people living with advanced serious illness or their carers, a disproportionate number of items are available for some domains of care provision (e.g. communication and shared decision-making) that are important for patients and carers, compared to other areas of importance. In addition, few are suitable for people with lower levels of literacy or limited cognitive capacity due to illness.

(Note this work is underway – draft manuscript in preparation – contact us for further details)

Patient focused – n=16

PREM name, date of publication presented in chronological order, country	Purpose	No. of items	% of items above Flesch-Kincaid grade 8	Validation data available
consideRATE, 2021[22]* **USA**	A measure of serious illness experience based on what matters most to people who are seriously ill.	8	0	Yes
Palliative Care Clinical Network – Palliative Care Experience Survey,[23] 2020* **Australia**	An online survey to collect information on experiences of palliative care quality in South Australia from perspectives of patients, unpaid carers or health professionals.	14	14.3	Not reported
The Sinclair Compassion Questionnaire (SCQ), 2020[24] **Canada**	Evaluates compassion experienced by patients in the care they received from a facility.	15	33.3	Yes
Quality Care Questionnaire-Palliative Care (QCQ-PC), 2018[25] **Korea**	Evaluates four factors: communication with health care professionals; discussing value of life and goals of care; support and counselling for holistic care needs; and accessibility and continuity of care in patients receiving palliative care.	32	46.9	Yes
Victorian Palliative Care Satisfaction Instrument (VPCSI),[26] 2016* **Australia**	Assesses patient and carer satisfaction with palliative care provision from services across Victoria, Australia.	58	74.1	Not reported
Feeling Heard and Understood, 2015[27] **USA**	The Heard & Understood measure was developed for patients with advanced cancer who receive inpatient palliative care consultation, to measure the degree to which they feel heard and understood by those caring for them in the hospital environment.	2	50	No
Quality from the Patient's Perspective (QPP-PC), 2015[28] **Norway**	Measures the quality of palliative care from patients' perspectives across a variety of care contexts.	51	33.3	Yes
Patient Satisfaction Questionnaire, 2014[29] **United Kingdom**	Evaluates doctor's communication and interpersonal skills, from the perspective of patients with palliative care needs in the inpatient hospice setting.	12	33.3	No

Example of work underway

So – how might we move forward?

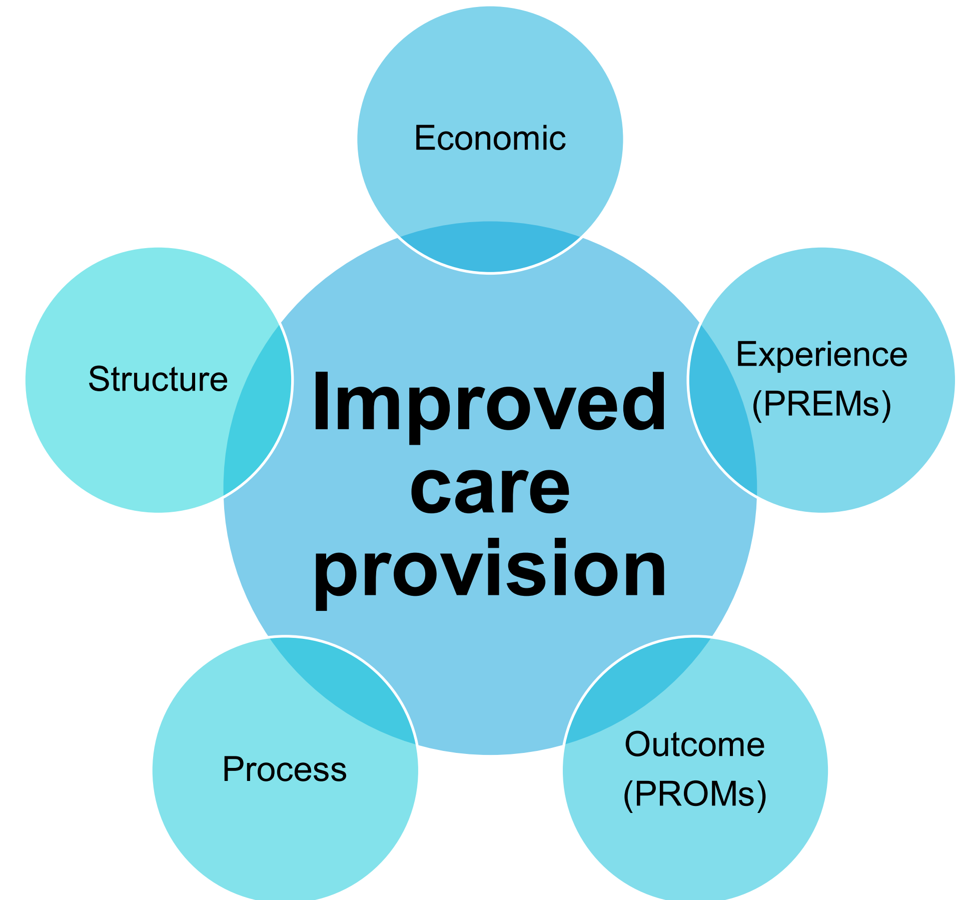
Some thoughts…

1. As a sector we need to think through the differences between key quality indicators/measures and consider which are the best fit for purpose

2. We need to look to what is already collected and see if we can leverage from this at all (Eg – environmental factors)

3. We need to consider perspectives from:
   I. patients living with palliative care needs
   II. patients imminently dying
   III. carers supporting patients
   IV. bereaved carers

4. We need to think about tools that are best suited for patients, carers and clinicians



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Driving change based on patient preferences – one example

Study 1 (completed June – Dec 2021) – focused on identifying which tool might work best within the specific context I was working within

Study 2 (underway) – testing whether this tool can support change

THE PREM-QUAL STUDY

Improving the quality of hospital care for people with serious illness through patient experience measurement and feedback informing facilitated ward-based improvement: an implementation pilot study **(The PREM-QUAL study)**

Sponsors:
- Queensland University of Technology
- Metro North Hospital and Health Service
- Queensland Health

- **Collaborator:**
- Royal Brisbane and Women's Hospital

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THE PREM-QUAL STUDY

OBJECTIVES

IDENTIFY KEY ENABLERS

To understand the key enablers (personal and contextual) for improving inpatient palliative care provision at the ward level;

TEST SOLUTIONS & SUSTAINABLE CHANGES

To co-design and pilot test pragmatic and innovative solutions to effect sustainable changes in care delivery for people with serious illness in the inpatient setting;

EVALUATE PATIENT EXPERIENCE & FEEDBACK

To evaluate the feasibility, acceptability and resource requirements of measuring patient experience data and using feedback in facilitated ward-based improvement in care for inpatients with complex and serious illness;

EXPLORE IMPACT ON SAFETY & QUALITY

To explore the potential impact of this approach on the quality and safety of inpatients with palliative care needs in alignment with the Australian commission's national guidance and accreditation standards.

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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
☐	☐	☐	☐	☐

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
☐	☐	☐	☐	☐

5 How would you rate our communication about your plans?
things like medicines, procedures or place of care

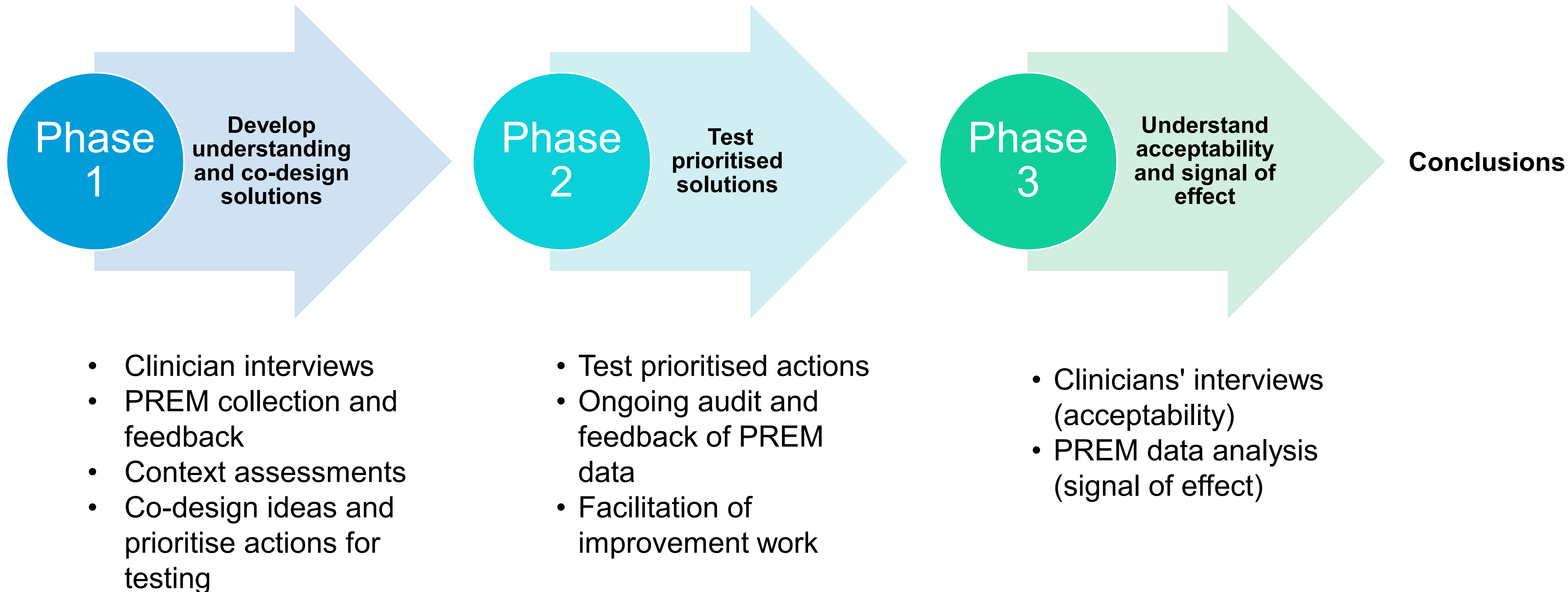
Very Bad	Bad	Good	Very Good	Doesn't Apply
☐	☐	☐	☐	☐

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
☐	☐	☐	☐	☐



- Clinician interviews
- PREM collection and feedback
- Context assessments
- Co-design ideas and prioritise actions for testing

- Test prioritised actions
- Ongoing audit and feedback of PREM data
- Facilitation of improvement work

- Clinicians' interviews (acceptability)
- PREM data analysis (signal of effect)

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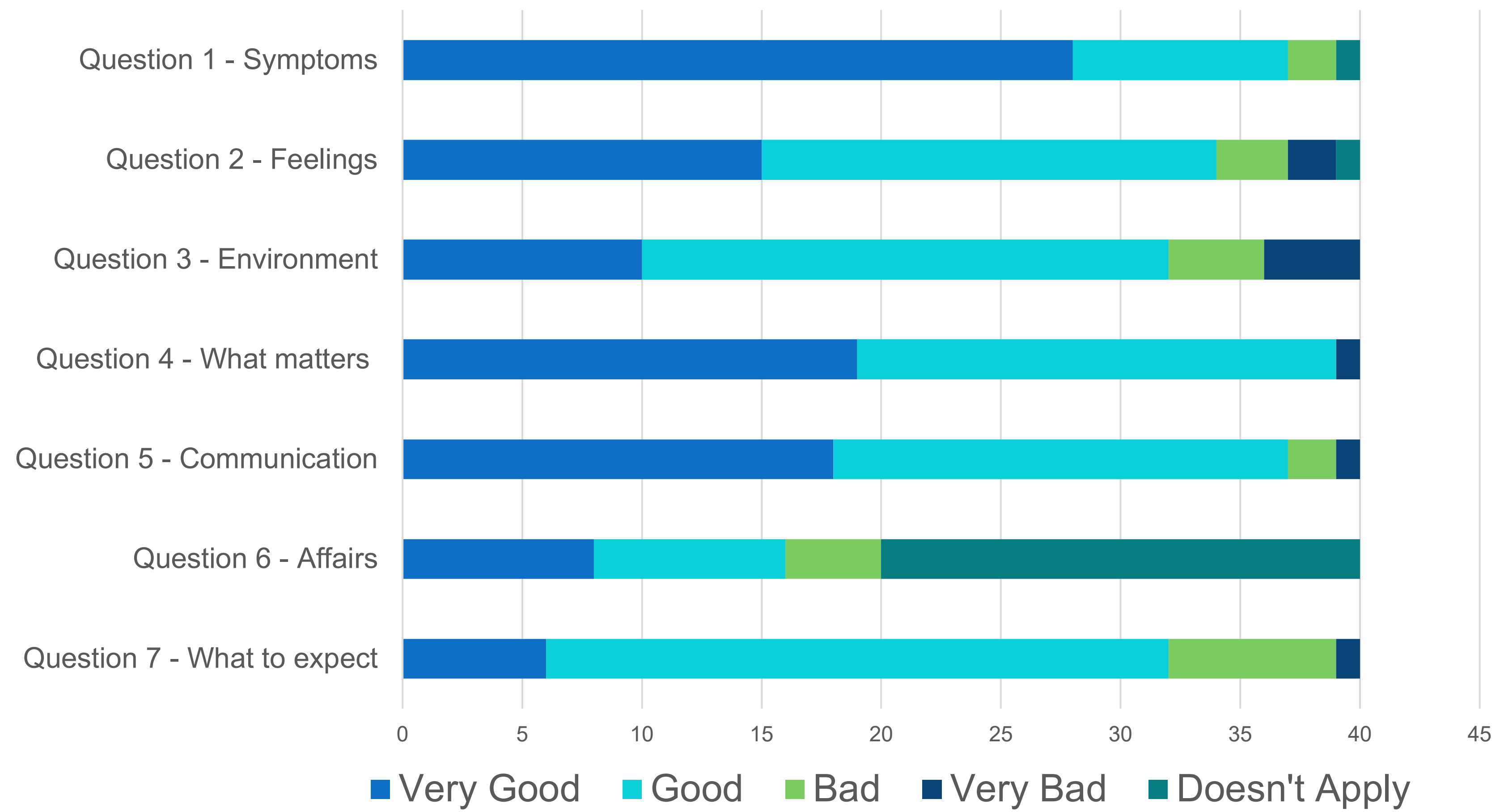
Note – this graph shows false data – provided as an example

Where is this up to?

Ward 1 – 40 PREMs collected + 33 interviews + 2 co-design meetings – now implementation phase

Ward 2 - 40 PREMs collected + 28 interviews – co-design meetings coming up

Ward 3 – Phase 1 data collection underway



Free text – positive and constructive

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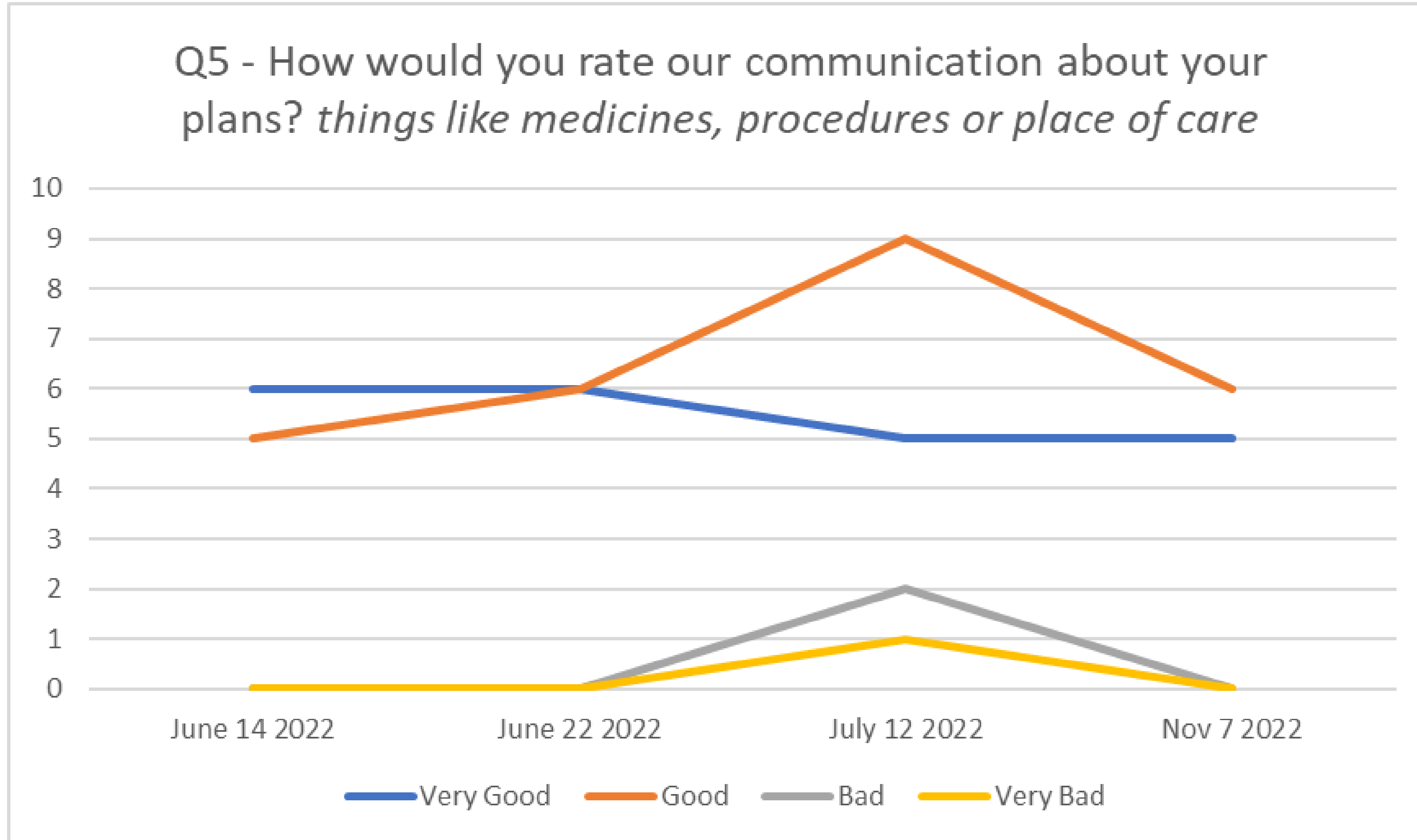
Again – this is false data used for example only

Some options for using this data to drive change – 1 question from ConsideRATE



Run chart using the following scoring system:

Very good = 6 points	Good = 4 points	Bad = 2 point	Very bad = 0 points

Again – this is false data used for example only

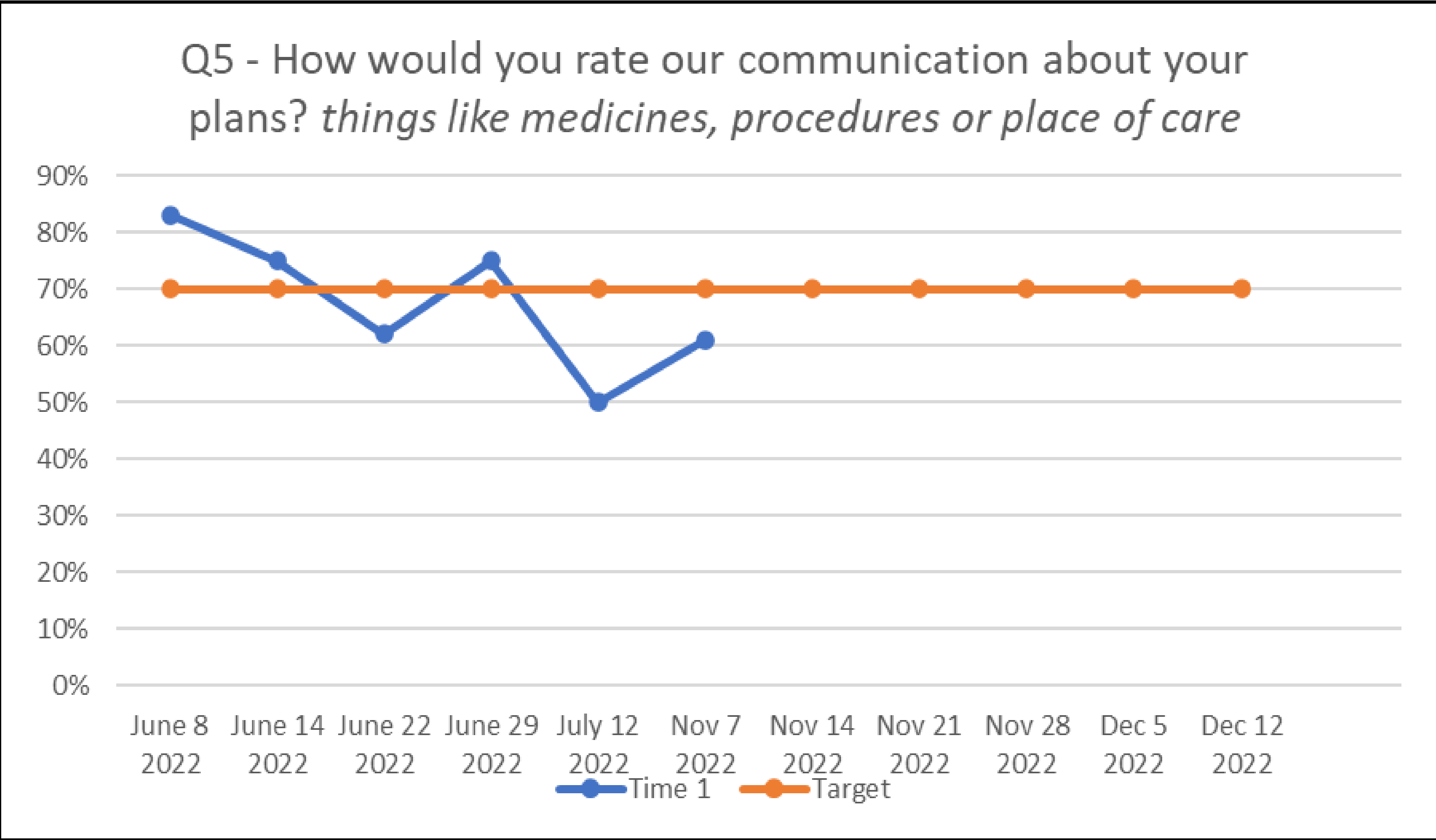


Figure: Run chart presenting results* from Question 5 of the ConsideRATE survey as a total % out of 6

* Data includes totals for each reporting period divided by number of surveys and represented as a percentage of the total of 6

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Driving change based on patient preferences – early thoughts

This is messy and hard…. But so important

Motivation – patients, families, consumer representatives, interdisciplinary team

Context – micro, meso, macro

Timing – system challenges

Resourcing – we need to be real

Pragmatism – we need to be real

Data / evidence – this is foundational

Co-design – we need innovative approaches to capture all perspectives

Communications – complex

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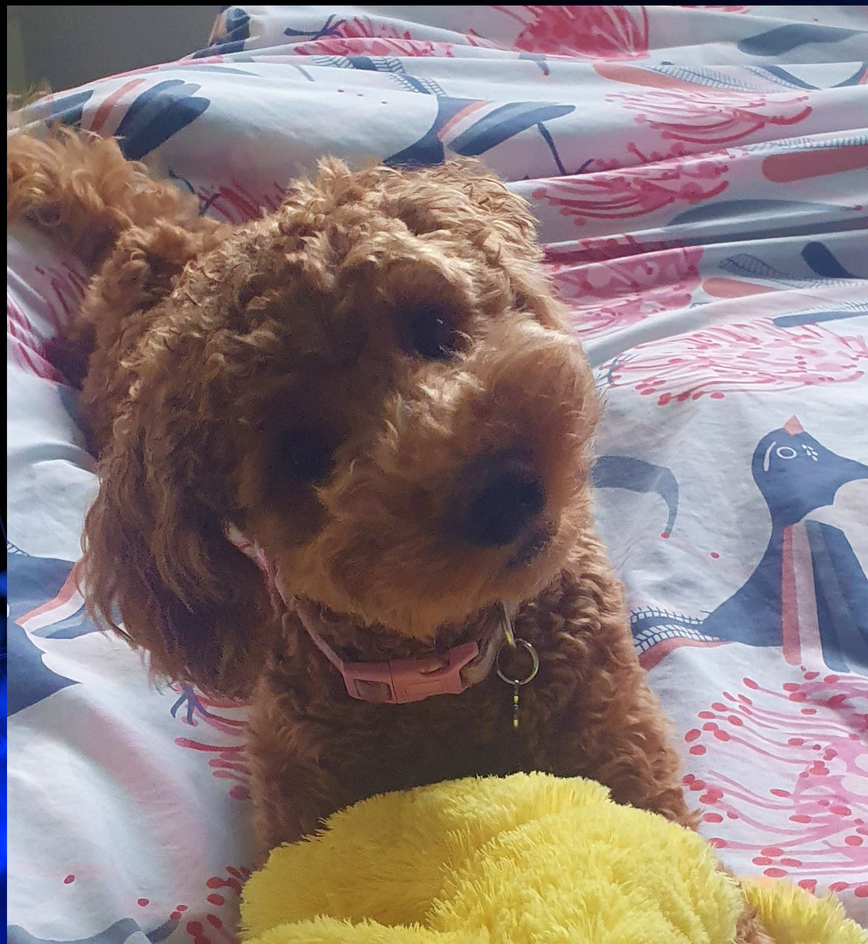

Thank you for listening

Questions / discussion

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