



ACI NSW Agency
for Clinical
Innovation

Overview: What are PROMs and PREMs?

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Overview

1. Using patient experience to develop Integrated Care
2. Introduction to PROMs and PREMs
3. State-wide approach
4. Pilot
5. System and process options/ requirements, including IT

Betty's Story

Betty, aged 82, has a chronic illness



Key themes:

- Poor case management, care co-ordination and communication
- Multiple clinicians and appointments
- Too difficult to get to GP and there is no one to come to the house

Reference: ARCHI Patient Story Library

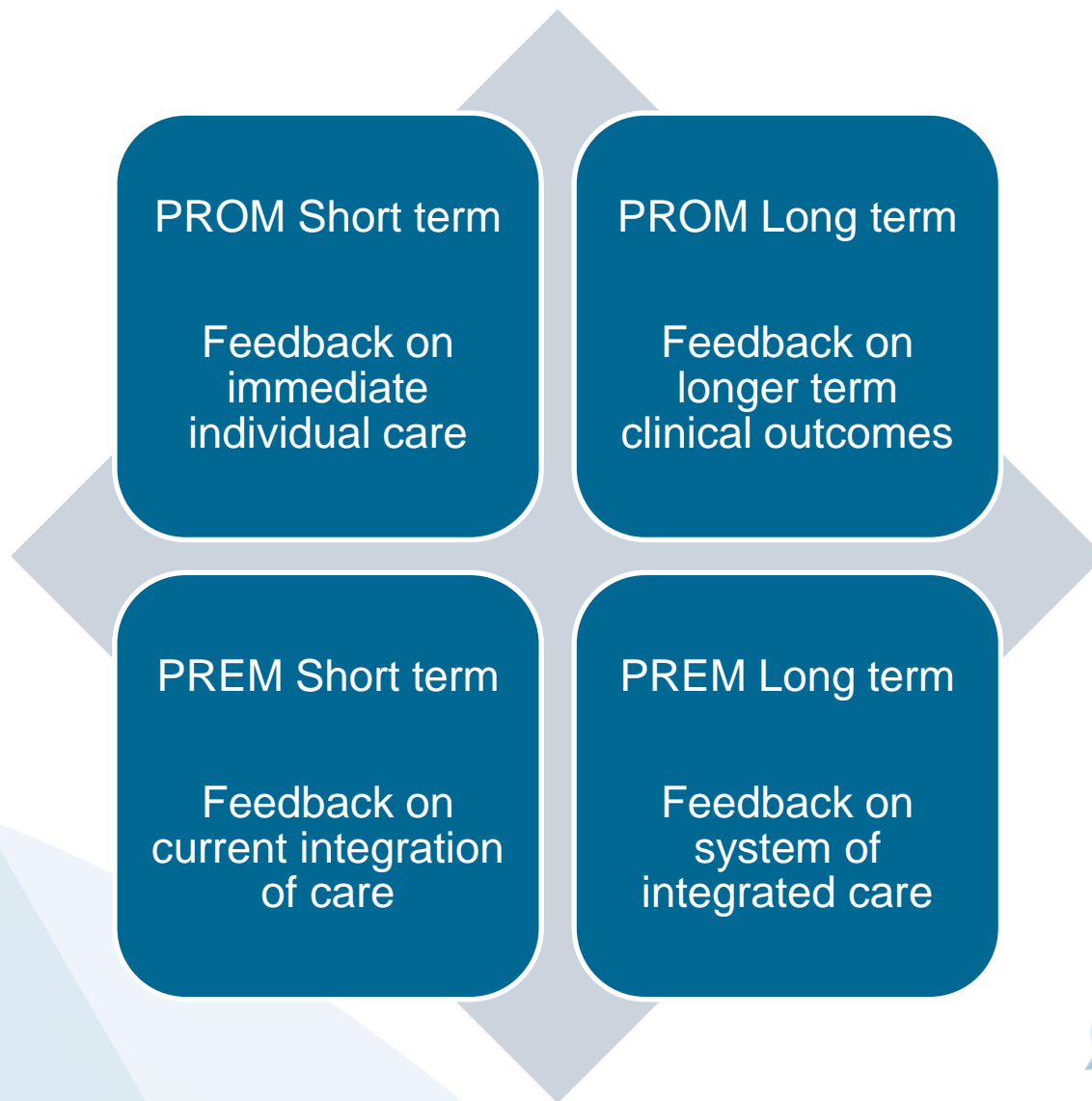
[http://www.archi.net.au/resources/patientexperience/library2/betty.](http://www.archi.net.au/resources/patientexperience/library2/betty)

Integrated Care



- AKA: person-centred, co-ordinated care (UK)
- Aims:
 - Keep people healthy at home for longer
 - Improve people's experience of care
 - Identify 'unmet' need
 - Improve 'navigability' of the health system
- Enablers:
 - Patient Reported Outcome Measures (PROMs)
 - Real time patient feedback facilitated by Patient Reported Experience Measures (PREMs)

Original scope – PROM and real time patient feedback...



Now
PROM
and
PREM

Patient Experience

- Purpose: allows patients to provide **direct feedback** on their care to **drive improvement** in services.
- Qualitative and quantitative approaches
 - Surveys: paper and electronic e.g. PETs
 - Focus Groups
 - Patient story/ journey
 - Observation



Patient Journey Approach

1. Identify **common stages** in patient experiences.
2. Track an individuals' **ideal health pathway** and identify “push” and “pull” factors regarding access to health care.
3. Identify and monitor **which services** and health professionals **people engage** with, their experience of these services and health outcomes.
4. **Involve patients** in articulating and mapping their own ideal health outcomes and pathways.

PROMs Patient Reported Outcome Measures

- Capture a person's perception of their health
- Validated generic & disease specific tools
- Measure:
 - Symptoms
 - Distress/ Anxiety
 - Unmet need

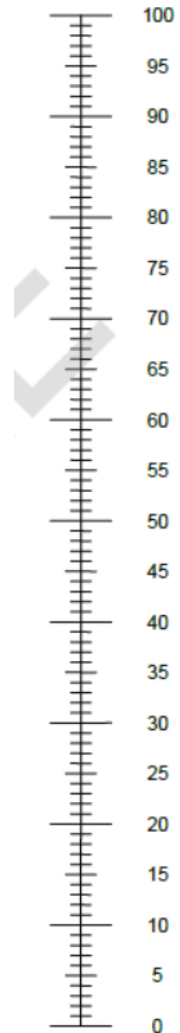


PROMs Examples

- Quality of life e.g. EQ-5D, AQoL
- Symptoms e.g. pain (NPRS), fatigue (FSS)
- Distress e.g. depression (K10, PHQ-2), anxiety (GAD7)
- Functional ability e.g. WHODAS 2.0, ODI
- Self-reported health status e.g. SF-36
- Self-efficacy e.g. GSE

EQ-5D: We would like to know how good or bad your health is today.

The best health
you can imagine



The worst health
you can imagine

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PREMs Patient Reported Experience Measures

- Capture a person's perception of their experience with health care or service.
- Various indicators included in validated surveys/ questionnaires e.g. CAHPS (US)
- Newer attempts to measure integrated care e.g. Singer, Picker Institute Europe

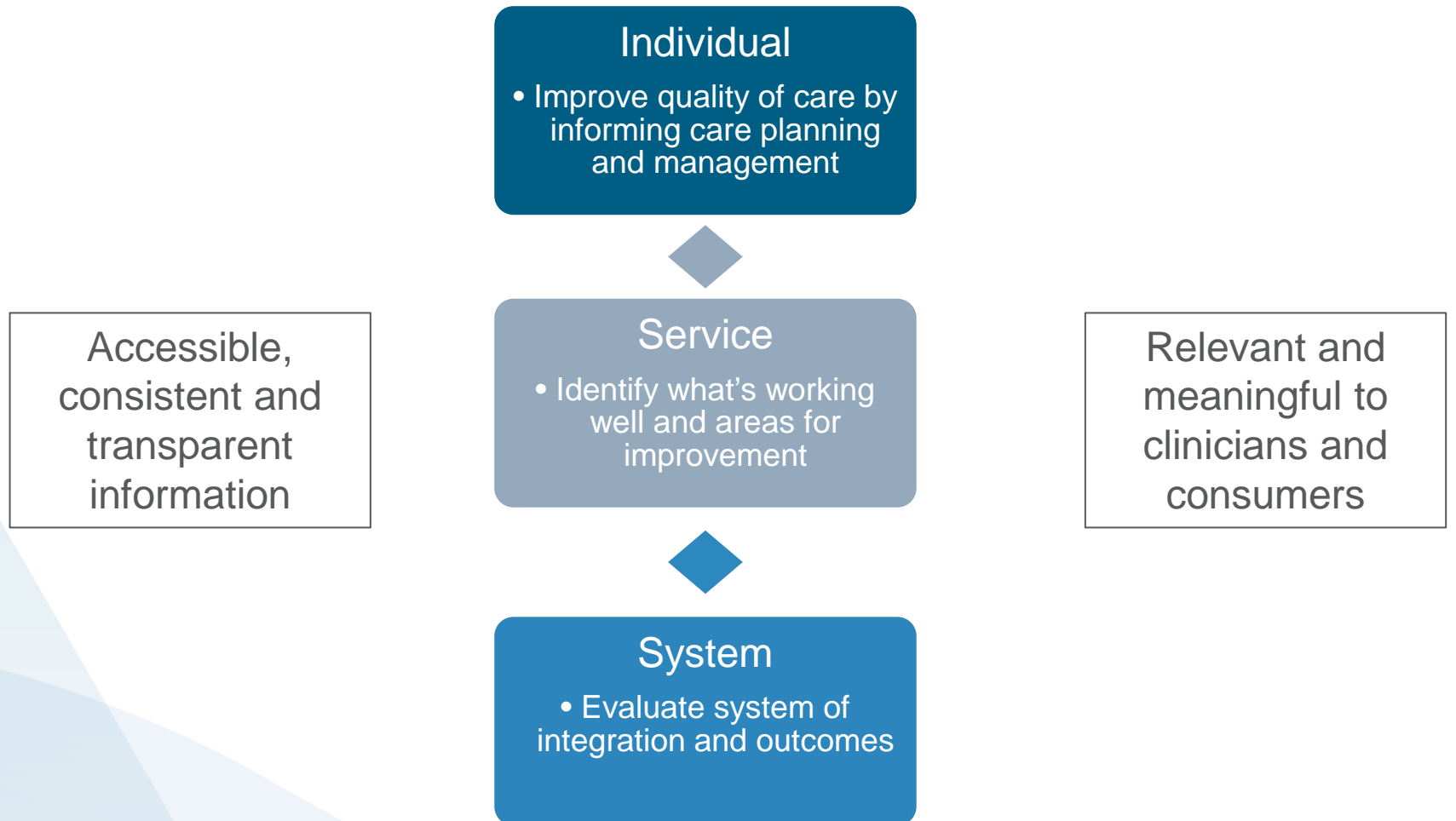


1 in 4 patients said
doctors spoke in front
of them **as if they
weren't there.**

PREMs Examples

- Time spent waiting
- Access to and ability to navigate services
- Involvement (consumer and carer) in decision-making
- Knowledge of care plan and pathways
- Quality of communication
- Support to manage long-term condition
- Would they recommend the service to family and friends

PROMs & PREMs Purpose



Advantages in practice

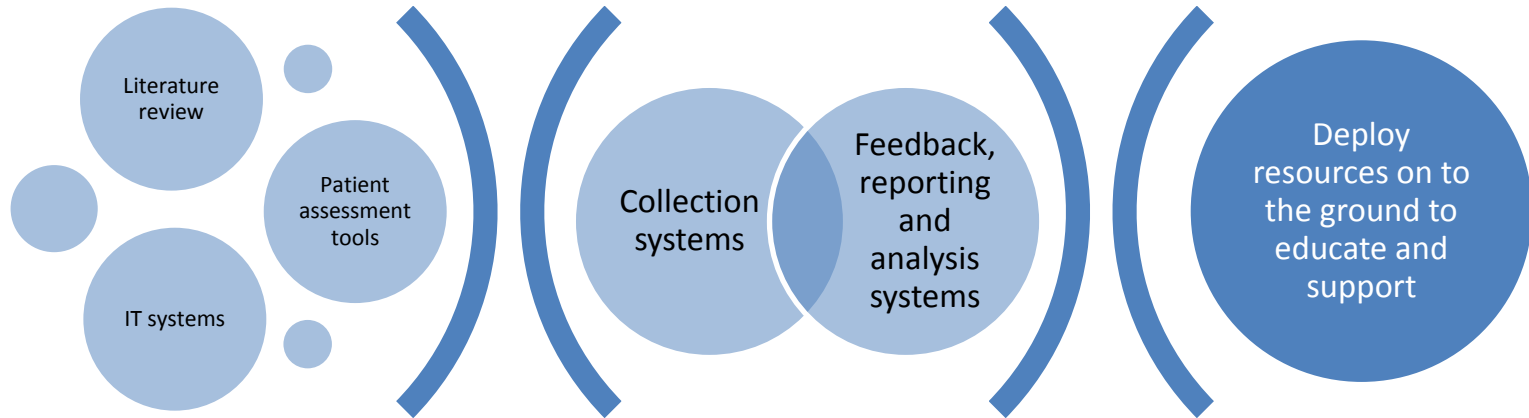
- Improve ability to detect worsening of symptoms (Lambert, 2010)
- Provide information that may have otherwise been missed (Worthen & Lambert, 2007)
- Reduce drop out (e.g. Miller et al. 2006)
- Improves outcomes (Bickman et al 2011)
- Enhance shared decision making (Coulter 2010)
- Ensure voice of service user is heard (Greenhalgh 2009)

Wolpert. (2014). *PROMS in Child and Adolescent Mental Health*.

State-wide approach

1. Establish project governance.
2. Research the systems and tools.
3. Obtain ethical approval.
4. Develop PROMs and PREMs: consultation and collaboration with patients, clinicians and experts.
5. Build the infrastructure: partnership with eHealth NSW.
6. Pilot PROMs and PREMs: specific sites or with specific populations.
7. Wider implementation and evaluation: supporting patients and clinicians to engage and benefit.

Project phases



Research the systems and tools



- Lit review underway.
- Establishing governance group.
- Review of Cancer Institute NSW IT system.

Build the infrastructure



- Source or build a collection system and procure input tools.
- Decide how integrated the solution can be within time/budget scope.
- Pilot in 2-3 sites.

Support clinicians and patients to engage and benefit



- The main challenge is to respond in a timely and supportive way to the information collected.
- Co-design responses to issues identified.
- Significant culture change and education effort for clinicians (and patients) required.

Pilot: 2015

- Aim to pilot PROMs and PREMs in 2-3 sites: LHD Demonstrators, LHD Planning and Innovation Fund (PIF) recipients.
- EOI process to open Dec 2014 with invitation to submit proposals.
- This afternoon's workshop is an opportunity to further define and scope the pilot and discuss the following considerations.

Key considerations

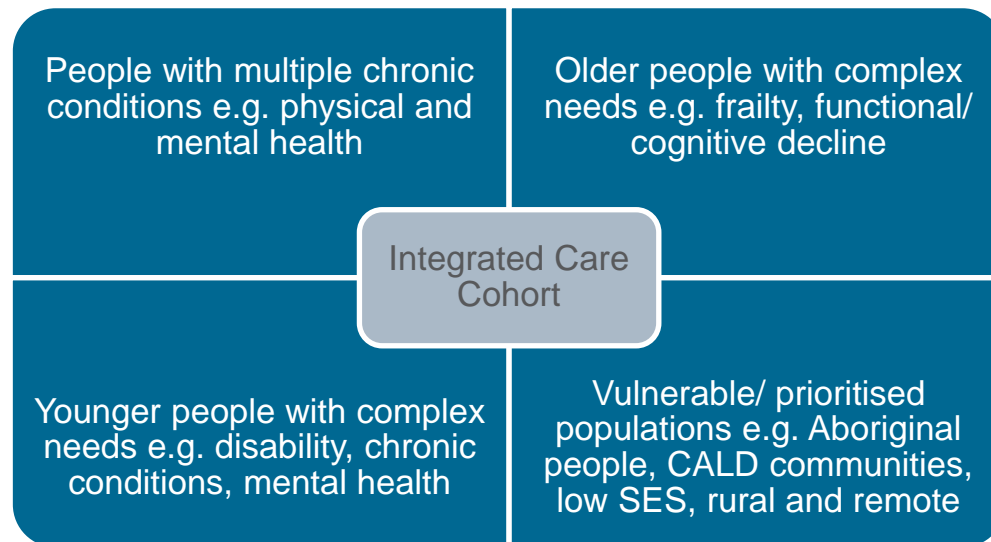
PROMs and PREMs must be :

- Meaningful to consumer and clinician
- Not burdensome or duplicative: aim for high response rates
- Interpreted with appropriate level of tentativeness; not trump other forms of knowledge
- Support collaborative working

Adapted from Wolpert. (2014). *PROMS in Child and Adolescent Mental Health*.

Pilot: Key considerations

- Who is the target population? E.g.



Common
vs.
disease
specific?

- How to identify, access and engage the target population in the development of PROMs and PREMs?

Systems and Processes

- Process for ***capturing*** PROMs & PREMs
 - Part of care process/ work flow
 - Timeline: when to administer/ re-administer
- Tools
 - Digital and/or paper-based questionnaire
 - Consumer-centric: responsive to needs e.g. low health literacy
- Options
 - PETs
 - Smartphone/ Tablet
 - Website
 - Social media?

Systems and Processes

- Process for *accessing* and *responding* to PROMs & PREMs
 - When, how and by whom?
- Tools
 - Algorithms
 - Health Pathways
 - HealtheNet
- Options
 - Standalone system
 - Shared Care Plan
 - eMR/ PCEHR build
 - Paper-based PDF Report?

Questions?