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
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…

- **PROM Short term**: Feedback on immediate individual care
- **PROM Long term**: Feedback on longer term clinical outcomes
- **PREM Short term**: Feedback on current integration of care
- **PREM Long term**: Feedback on system of integrated care

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
**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
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

Individual
- Improve quality of care by informing care planning and management

Service
- Identify what’s working well and areas for improvement

System
- Evaluate system of integration and outcomes

Accessible, consistent and transparent information

Relevant and meaningful to clinicians and consumers
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)

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.
  - People with multiple chronic conditions e.g. physical and mental health
  - Older people with complex needs e.g. frailty, functional/cognitive decline
  - Younger people with complex needs e.g. disability, chronic conditions, mental health
  - Vulnerable/prioritised populations e.g. Aboriginal people, CALD communities, low SES, rural and remote

- 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?