Overview

On 3 December 2014, the ACI hosted a workshop to introduce Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) and discuss how PROMs and PREMs will be developed, piloted and implemented to support the NSW Integrated Care Strategy. 31 people attended the workshop including representatives from NSW Ministry of Health and Pillars, Local Health Districts and Medicare Locals, consumer and non-government organisations, eHealth NSW and general practice.

The morning session provided background information about PROMs and PREMs; commencing with a patient story followed by a presentation of the results of a rapid scoping review of how PROMs and PREMs are used nationally and internationally for integrated care. Following this, attendees heard presentations from the LHD Demonstrator Sites; the Cancer Institute NSW about the PROMPT-Care pilot of a PROMs eHealth system; and eHealth NSW about the Integrated Care eHealth Architecture project.

The afternoon session was an opportunity for attendees to provide input, discuss and raise questions to inform the PROMs and PREMs project, including how Patient Experience Trackers might be used in the short-term to capture PREMs.

Discussion points

- Purpose of PROMs and PREMs must be clear and well communicated.
- How will PROMs and PREMs be built into reporting and funding mechanisms to drive cultural and behavioural change?
- Should ensure PROMs and PREMs are aligned with existing system reported measures.
- The selected (or optional) measures, tools and systems must support a wide range of patients to participate including patients with low health literacy levels and patients from culturally and linguistically diverse backgrounds.
  - Need to consider the mode and format of PROMs and PREMs: multiple choice, rating scales, visuals and ability to make comments that can be analysed.
- Are PROMs and PREMs identifiable or deidentified and what does this mean for the reliability, validity and useability of the information?
- Should consider who can complete the measures/ tools: consumers and/or carers and the potential impact on the validity of the information.
- Important to obtain ethics to develop the research and evidence base and encourage clinician buy-in.
- Critical to evaluate the uptake and acceptance of PROMs and PREMs by patients and clinicians. How will we work with clinicians to ensure PROMs and PREMs data is appropriately acted upon?
- IT solution to capture PROMs should be linked to the patient’s care plan and accessible at time of consultation by the multidisciplinary team.
- Device to capture PROMs and PREMs that feeds into database so it is accessible in shared care plans.
- Must minimise delay between data collection and analysis but also be able to aggregate and analyse the information.
- Likely that there will need to be a core set of generic PROMs and PREMs, relevant for patients with high complexity, and then a modular approach for including specific PROMs and PREMs based on the target population and local program.
  - Approach should be flexible to meet different needs and models but also include core requirements so that systematic uptake is achieved.
- Reporting of PROMs and PREMs will be complex: should consider what information is available to whom, when, why and how?

**Next steps**

- Develop program logic for PROMs and PREMs.
- Support LHD Demonstrator Sites to identify initial PREMs for immediate use from existing validated data sets, noting the process to develop PROMs and PREMs will be ongoing and iterative.
- Invite LHD Demonstrator Sites and Planning and Innovation Fund recipients to participate in a pilot.
- Build the systems and infrastructure to support the capture and analysis of PROMs and PREMs data.

**Raj Verma**  
Director, Clinical Program Design and Implementation, ACI