Thank you for the opportunity of providing my thoughts to the Consultation Paper ‘Collecting Patient Reported Outcomes Measures in Victoria’.

As a Consumer Representative, parent and chronic-illness sufferer, I believe the adoption of PROMs represents a great step forward for patients, clinicians and funders. I have endeavoured to keep my submission brief and to the point. Accordingly:

For the following reasons I would urge the department to establish a Community Advisory Group at the earliest opportunity (to work alongside the PROMs Study Team):

- It is consistent with Department of Health policy “Doing it with us, not for us”
- It represents the new way of doing business by adding credibility and transparency
- Community input that is sought by an organisation only at moments judged ‘key’ by them is not true co-production
- Evidence shows that consumer involvement has its greatest value when structured in early and least when added later

- Co-production with consumers in PROM selection, process development, implementation and evaluation will ensure greater resonance with all stakeholders and that resultant policies, processes and systems are fit for purpose
- A well selected CAG will provide access to information and feedback from patient, carer and general public networks to help inform model development at all stages
- CAG members can also assist in managing public expectations through their role as trusted community members: in press releases or media appearances - educating and informing the public, and possibly assisting in counteracting stories that are incorrect

Different metrics will be needed for different Stakeholders, ie

- Patients and carers
- Policy makers
- Clinicians
- Methodologists etc

What, when and how do we measure for each of the Stakeholders? How will measurement consensus be achieved? What will the data actually mean?

PROMs should not be used in isolation or to replace clinical judgement. Judicious integration must recognise ethical underpinning of patient assessment and its role in patient-centred care.
Improving clinical practice of reportable diseases & conditions:

The public should have a pivotal role on any clinical network established to develop new performance measures and best practice models of care for each reportable disease or condition.

It should become standard operating procedure for the triad of Clinicians, Consumer Representatives and Service Managers to always work together on any and all aspects of PROMs work.

Other data that also needs to be collected:

- How patients FEEL, what they can DO, what they CAN’T – physically & psychosocially – outcomes that really matter to patients. This can be difficult to quantify and adjust for subjectivity but is at its core the foundational reason for collecting PROMs.

- Carer measures must also be collected. A carer is effectively the patient’s nurse at home – if they’re not coping through lack of support, information or resources, patient outcomes are impacted.

Information around availability / affordability of equipment, respite, home-help, interpreters, tele-health, community-based supports, negative financial impacts etc could all impact patient outcomes.

Access to data

For ethical and accountability reasons, public access to interpreted data must be the ultimate goal, although for public confidence in the system this should only occur once all kinks have been worked out.

Importantly, another end-goal should be the development of decision tools for patients as a result of interpreted data.

Additionally

Incentives for patients to complete measurement surveys may need to be considered. While gathering data prior to a planned clinical intervention is relatively easy, patient interest in follow up surveys will be difficult unless structured in a way that is embedded into the system, ie; through GP visits, or by offering incentives, ie; a discounted GP visit, or something more concrete, $10 supermarket voucher for example