

PROMS

Making Patient-Reported Outcome Measures work



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Working across many specialties, six countries and with insurers, governments, health services and clinicians, Cemplicity has a unique perspective on how to run a high-impact patient-reported measures programme.

10

Years

3,000

Health Facilities

6

Countries

We see pockets of advanced, high impact PROMs programmes that measurably improve patient care, health outcomes and people's quality of life. Some programmes also reduce costs. One example is in Wales, where patients who report concerns are directed to face to face outpatient appointments, while patients who report good progress are offered virtual appointments or phone calls.

However, we also see many PROMs programmes that do not have an impact on outcomes or have been solely introduced to meet regulatory requirements. These programmes are not optimised to aid clinical decision making or to provide reliable measures of patient health outcomes. They are not helping health systems run more efficiently while maintaining the quality of care.

In this paper we highlight the differences between programmes run for impact and those run for compliance. We identify the hallmarks of a good programme and show how organisations running PROMs programmes can get more value from their PROMs initiatives.

Why PROMs?

Let's start by reminding ourselves why Patient-Reported Outcome Measures are important. Involving patients in their care is proven to improve health outcomes and quality of life. It can also save health systems money.

Basch, E.M 'Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment'

This study (details in appendix) outlined the results of an eight-year programme with 766 patients where a real-time PROM enabled patients to report their symptoms and to send alerts to their nurse carer when symptoms were concerning.

The study's findings are compelling. Basch reports a 10% increase in survival rates for cancer patients from this real-time PROMs approach. That is a stronger impact than most new cancer drugs achieve.

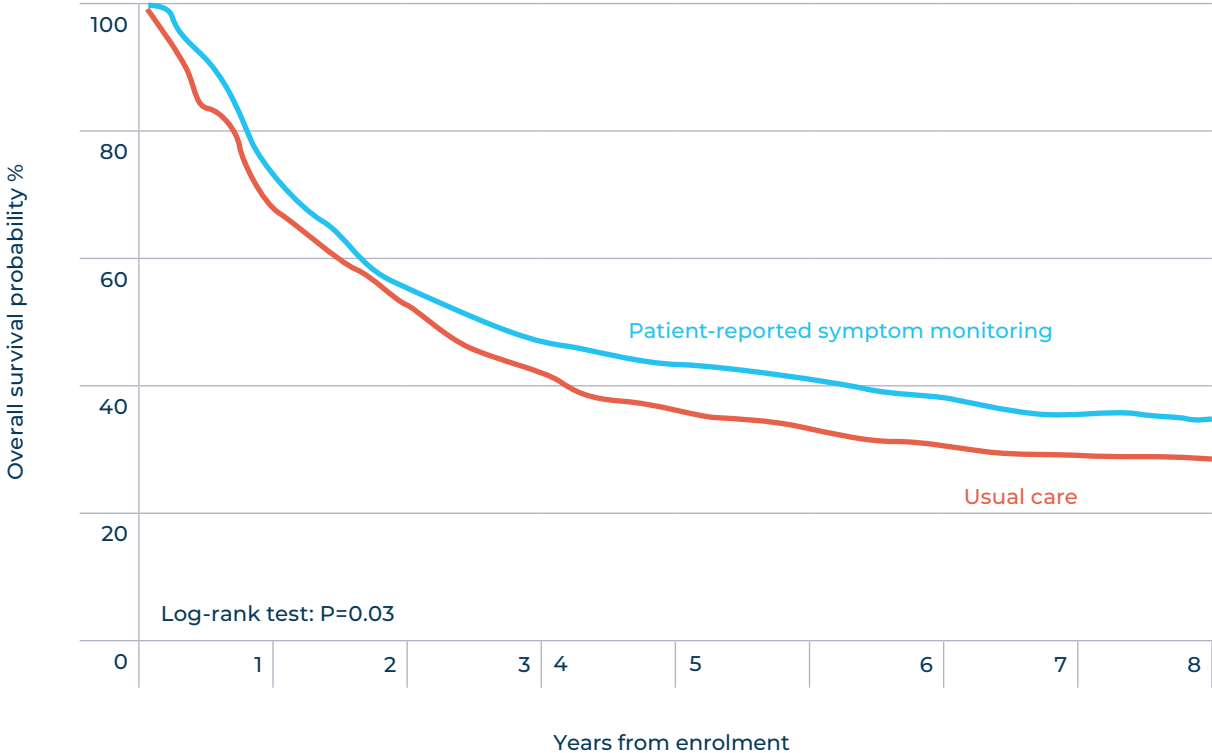


Image: Increased survival probability in Patients with Metastatic Cancer assigned to Electronic Patient-Reported Symptom Monitoring vs those receiving normal care during routine Chemotherapy (Basch, 2017).

Key to this powerfully effective outcome was the fact that real time alerts, triggered by patient self-reporting, almost always led to active responses by nurses. They counselled patients on symptom management, changed medication, or referred patients to hospital. Not only did this help patients feel better, it also meant they continued their chemotherapy treatments 33% longer than the control group. Consequently, survival rates went up.

The lesson is clear: a timely, efficient link between the patient and the care team, coupled with alerts for any concerns, can improve patients’ health outcomes and quality of life.

PROMs have value for other important stakeholders too. Different use cases are highlighted in the “Framework To Guide The Collection And Use Of Patient-Reported Outcome Measures In The Learning Healthcare System”
 Franklin P., Chenok K., Lavalee D., Love R., Paxton L., Segal C., Holve E.

Their paper identifies four primary use cases for PROMs. These include:

- 1. **Individual patient care decisions**
 The impact of which is highlighted so well by the Basch study
- 2. **Quality improvement**
- 3. **Value-based payment**
- 4. **Population health and research**

Franklin et al are clear that establishing what value PROMs will hold for each stakeholder is a critical success factor in programme design.

Table 1: Shared Value of PROMs by User Groups

PROM User	Shared Value for PROMs
1. Patients and clinicians	Individual patient care decisions: Individual patient-centred decisions to prioritize, treat, and monitor disease symptoms and health status.
2. Hospital leaders and clinicians	Quality improvement: Monitor and improve aggregate patient outcomes as compared to national best practice and benchmarks.
3. Insurers and hospital leaders	Value-based payment: Measure outcomes as compared to costs and utilization to optimize health care value.
4. Researches, policy makers, and funders	Population health and research: Generate new evidence for best clinical practices across patients to achieve optimal health status over time.

“Framework To Guide The Collection And Use Of Patient-Reported Outcome Measures In The Learning Healthcare System” Franklin P., Chenok K., Lavalee D., Love R., Paxton L., Segal C., Holve E.

The Basch report also covers several of these wider use cases, highlighting that “beyond better patient outcomes, this study also highlighted the benefits at a health service or system level. There were fewer visits by patients to emergency department, fewer unplanned hospital visits generally and fewer unscheduled changes in chemotherapy programmes.”

Realising full value?

A best-practice PROMs approach will meet the needs of all stakeholders in a single programme. In our view, complying with local regulations is only the starting point.

We see three common situations that signal a PROMs programme is falling short of realising full value for all stakeholders.

- 1. PROMs are designed solely to meet the mandatory requirements of the NHS or the Private Health Information Network (PHIN) but there is no wider organisational engagement in results, other than management reporting. This is particularly concerning if the methodology uses paper surveys as these programmes can also be expensive to run.**
- 2. PROMs captured for clinical registries, which are not real time. PROMs captured within clinical registries are of significant value for long term planning but are not useful for day to day clinician/patient interactions.**
- 3. Programmes run by insurers, which provide a sector wide view of provider outcomes but without clinician engagement or support.**

The two factors most commonly missing in the three scenarios above are:

- 1. Lack of clinician and care team engagement.**
- 2. Lack of timeliness.**

Hallmarks of a good PROMs programme

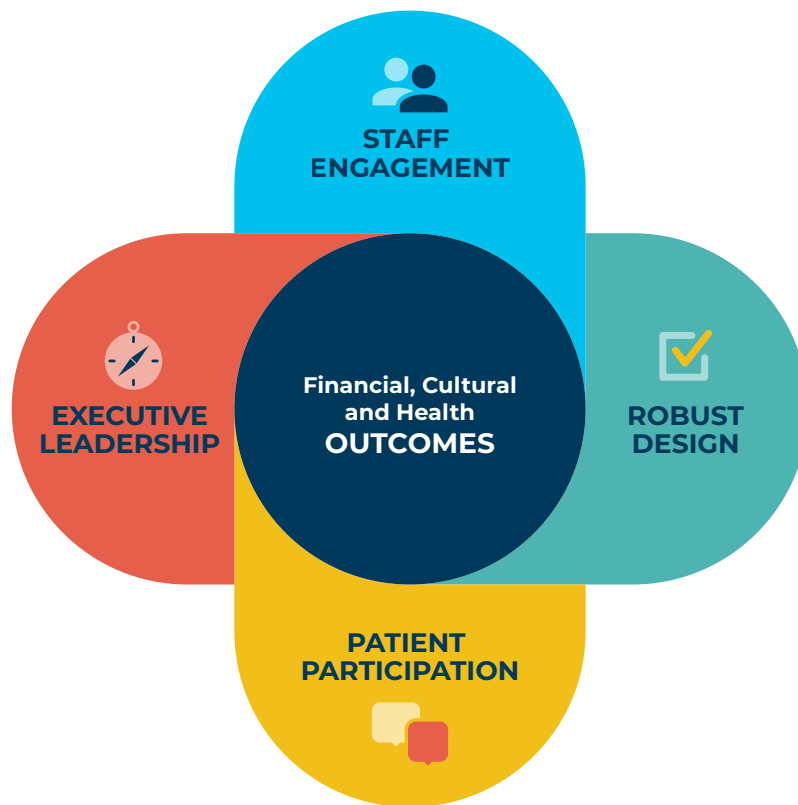
While the choice of PROMs survey is important, evidence suggests that the systematic way that the survey programmes are embedded in the organisation is equally important.

Dixon-Woods and Martin (2016) argue that little benefit will be gained if quality improvement methodologies are used in the absence of several enabling conditions, including:

- **Ensure real-time reporting as soon as patient provides response.**
- **An ongoing organisational commitment as opposed to multiple, small-scale projects that are time-limited;**
- **Fidelity to the chosen quality improvement method;**
- **Devolution of decision-making responsibilities so that frontline staff are trusted and supported to make changes;**
- **Rigorous evaluation and sharing of learning across the organisation and beyond.**

Considerations such as these are the foundation of the Cemplicity approach. When we work with clients to design and implement a best-practice PROMs programme, we are guided by our 'Impact Model', which ensures that these conditions for success are actively developed. Implementing this model ensures wide patient participation, high care team engagement and that each programme is a streamlined, integrated part of quality and management systems.

It is particularly important to view the introduction of PROMs programmes as a journey and to involve clinical staff early in design decisions, even if the clinical/patient level reporting is introduced after launch. Active clinician and care team engagement and their use of PROMs in their patient interaction is the single biggest differentiator between a compliance approach and a high impact PROMs programme.



A checklist

To evolve into a high impact programme, consider this checklist of features:

Robust Design

- Ensure real-time reporting as soon as patient provides response.
- Use a well-validated survey but also allow patients to give feedback that is relevant to them. Ensure that they can talk about treatment goals in time for preferences to be considered in treatment decision making.
- Capture the appropriate additional information on the patient either from the EMR or in the survey. This enables long term population level analysis of outcomes and ensures wider stakeholder needs (e.g. funders) can be met efficiently through the one programme.
- Use a scalable platform so that all PROMs across your organisation can be captured and reported within one secure platform and methodology.
- Ensure patient confidentiality is tightly preserved. Data security is paramount.
- Consider opportunities for cost savings (e.g. what other feedback mechanisms can be stopped, can patient experience programmes be integrated into the same platform, can the PROM response be used to determine who needs a phone call or face to face appointment most urgently?)

Patient Participation

- Aim for 100% patient participation, prioritising digital mechanisms of data capture (email, mobile and tablets).
- Consider opportunities for patient convenience (e.g. would a virtual outpatient appointment save them time, inconvenience and transport costs?) We can even ask patients their preference in the survey.
- Ensure opt in processes, patient privacy statements and copywriting do not become any more of a barrier to participation than necessary.

Staff Engagement

- Minimise the involvement of staff in the programme administration and patient surveying so that their time can be used on working with patients, not surveying them.
- Ensure reporting to different stakeholder groups is relevant e.g. a service leader will have very different interest than a facility manager. Too much data is as unhelpful as too little.
- Actively use alerts to notify care teams when patient responses signal intervention is needed and measure how alerts are being actioned.
- Enable clinicians to add additional data against each patient (using pre-formatted lists to ensure consistency) so that as data is rolled up and used for comparisons and benchmarking, like-for-like comparisons are made.

Executive Leadership

- Ensure all patient-reported measures programmes are an integral part of executive reporting and decision making so that there is top-down engagement.
- Set clear, measurable goals for each programme and report against these on a regular basis.
- Focus on positive staff engagement strategies that emulate success, to avoid the programmes being seen as negative or punitive.
- Close the loop. Develop communication strategies that tell staff and patients what has changed as a result of their participation.

Summary

If you are obliged to run PROMs programmes, we recommend you make them useful.

There is strong evidence that enabling patients to report their health state provides a different and valuable perspective alongside clinical assessment, leading to better patient care, adherence to treatment regimes, better outcomes and service efficiency.



Clinical engagement



Real-time information

Two essential elements of a successful programme are clinical engagement and real-time data capture and reporting.

Cemplicity's experience is that developing a high impact programme takes time but if well designed up front, PROMs programmes can mature into valuable organisational tools for improvement.

Appendix

Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment.

Basch (2017 pp.197-198)¹

This recent study suggests that it is how you implement PROMs that optimises the impact on outcomes.

The research shows how electronic PROMs for cancer patients can improve patient comfort, reduce unplanned readmissions and offer further benefits. It also shows that survival rates for cancer patients were increased by 10% by this real-time PROMs approach (see image below), a stronger impact than most new cancer drugs achieve.

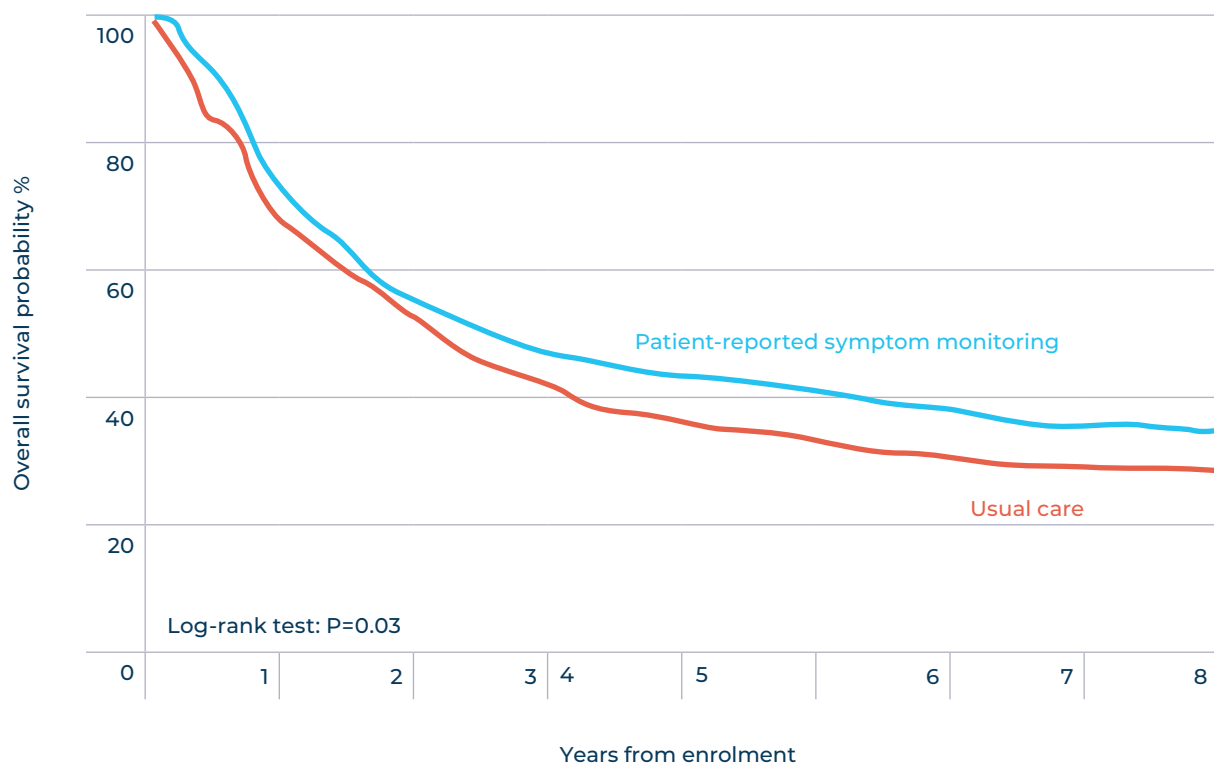


Image: Increased survival probability in Patients with Metastatic Cancer assigned to Electronic Patient-Reported Symptom Monitoring vs those receiving normal care during routine Chemotherapy (Basch, 2017).

The Basch study is getting significant attention because of the large patient sample, the length of the study (8 years), the credibility of the sponsoring institute (Memorial Sloan Kettering Cancer Centre in New York), and the reputation of the

author, Ethan M. Basch, MSc, FASCO, Professor of Medicine at the Lineberger Comprehensive Cancer Center of the University of North Carolina.

The research enabled 766 patients to report their symptoms electronically, and when they reported an alarming symptom, an automated email alert was sent to the clinical nurse responsible for that patient's care. Importantly, each treating oncologist also had real-time access to each patient's symptom history either prior or during treatment and consultation. The control 'usual care' group discussed symptoms only with their oncologist in the normal manner.

Arguably, the most important aspect of this study is the proof that the patients' symptoms were better managed when the patient had the opportunity to report their own symptoms. Mr Basch commented that "patients receiving chemotherapy often have severe symptoms, but doctors and nurses are unaware of these symptoms up to half of the time".

The timeliness of this PROMs approach and the direct reporting to clinicians was key to the good outcomes achieved in this area of symptom management.

Beyond better patient outcomes, the study also highlighted the benefits at a health service or system level. There were fewer visits by patients to emergency department, fewer unplanned hospital visits generally and fewer unscheduled changes in chemotherapy programmes.

Interestingly, in almost every case that a real-time alert was issued, triggered by patient self-reporting symptoms, the nurse changed something – they either counselled the patient on symptom management, changed medication, or referred the patient to the hospital. Not only did this help the patients feel better, it meant they continued their chemotherapy treatments 33% longer than the control group. This is felt to be a key reason why survival rates went up.

A high level of staff engagement is essential for a successful programme and can be largely achieved through real time alerts.

The Basch study convincingly presents the case for PROMs for cancer patients, as well as valuable insight into how to run an effective programme.

1. Basch, E.M 'Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment', National Centre for Biotechnology Information, (Accessed: 16 July 2018)

cemplicity°

United Kingdom

0800 098 8525

Australia

1800 765 924

New Zealand

0800 157 258

hello@cemplicity.com

cemplicity.com