Evidence for Patient-reported measures

Patient Reported Measures Program, August 2017

‘Systematic tracking of health outcomes is the foundation of any value-based health system’ (World Economic Forum 2017, p. 28). Patient-reported measures are questionnaires that measure patients’ perception of their health and healthcare experiences and the impact of conditions and treatment on their health and quality of life (Greenhalgh et al 2017; The Agency for Clinical Innovation 2017; Williams et al 2016). Patient-reported outcome measures (PROMS) and patient-reported experience measures (PREMS) enable patients to provide direct, timely feedback about their health related outcomes and experiences to improve care and clinical interactions (The Agency for Clinical Innovation 2015).

There is a growing knowledge base demonstrating the benefits of using PROMs and PREMS in clinical practice treating a wide range of health conditions. The following is a synthesis of recent evidence.

Improving clinical practices

A systematic review (Valderas et al 2008) of the impact of PROMs on clinical practice identified the following potential clinical benefits of PROMs:

- Aiding the discovery of physical or psychological problems
- Monitoring disease progression and providing information about the impact of prescribed treatment
- Supporting patient-clinician communication

Clinicians value data that is timely, specific and indicates where care processes can be improved (Greenhalgh et al 2017). Several studies have demonstrated how PROMs inform clinical practice and practice change (for example, Basser 2015; Health and Social Care Information Centre 2015). Evidence is now emerging that clinicians are more likely to engage with PROMs if the PROMs program is focused on improving the quality of care and measures variables that matter to clinicians (Greenhalgh et al 2017). Clinicians will take more action, as shown by referral activity, if PROMs are routinely reported back to them (Etkin et al 2015).

PROMs can be used to monitor patients’ conditions to help them and their doctors make informed decisions about treatment options, for example, quarterly PROMs completed by people with hip osteoarthritis helped decisions about if and when to operate (Black 2013). As a tool for clinical monitoring, PROMs have been used recently in England for service improvement and national benchmarking for elective procedures and for patients with chronic conditions in primary care, skin cancer, depression and cardiac revascularisation (Breckenridge et al 2015). A recent study of a quality of life measure and its relationship with traditional clinical measures for patients with knee osteoarthritis, found that this measure was related to patients’ clinical status and functional ability and that it could be used as a sensitive health status measure for clinical evaluation (Alkan et al 2014, p. 166).
Enhancing patient-clinician communication

Evidence strongly suggests that PROMs act as a tool to improve patient-clinician communication by enabling patients to raise issues with clinicians (Black 2013; Greenhalgh et al 2017; Kotronoulas et al 2014; Williams et al 2016). Routine use of information from PROMs enhances communication and decision making between doctors and patients (Nelson et al 2016; Santana & Feeny 2014). For example, studies report that surveying quality of life routinely in cancer patients improved clinician-patient communication while some patients also showed improved quality of life and emotional functioning (Detmar et al 2002; Velikova et al 2004). Importantly, the aspect of patient experience most strongly associated with a better outcome is the level of communication with and trust in their doctor (Black, Varaganum, & Hutchings 2014).

Improving quality of care

PREMs and PROMs are now commonly considered as robust measures of healthcare quality (Manary et al 2013; Williams et al 2016). In addition, timely information about patients’s symptoms, functional and emotional status derived from routine use of PROMs in chronic care management can be used by clinicians to ‘manage patients more effectively and efficiently’ (Santana & Feeny 2014, p. 1506).

The use of PROMs can support patient-centred care and shared clinical decision making (Williams et al 2016). It has been reported that PROMs contribute to enhanced quality of care and decision making in routine care for cardiovascular disease (Anker et al 2014). A study of PROMS in Swedish clinical quality registries reports that PROMs data informs care plans, clinical decision aids and treatment guidelines, improves the precision of indications for surgery and is used to monitor complications after the patient has left hospital and to improve patient information (Nilsson, Orwelius & Kristenson 2016). A study of patient-reported measures used with haemodialysis patients suggests that the use of PROMs may help multidisciplinary teams to identify dialysis patients in need of additional support such as symptom control and advance care planning and found that “baseline participant EQ VAS self-rated health, patient reported symptom burden (POS-S Renal) and health status as assessed by the EQ-SD were predictive of all-cause mortality over follow up in hemodialysis” (Sexton et al 2016, p. 621).

Improving patient outcomes

Systematic reviews have found that patient experience is positively associated with self-rated and objectively measured health outcomes (for example, Doyle, Lennox & Bell 2013; Male et al 2017), demonstrating that there is a positive association between better patient experience measures and better health outcomes for patients. While PREMs are strongly correlated with better outcomes, studies also have found no correlation between patient experience measures and volume of services ordered (Manary et al 2013).

Recent studies suggest that PROMs can assist clinicians in determining and evaluating treatment and interventions aimed at improving patient outcomes (Fung & Hays 2008; Sprangers et al 2014; Thompson et al 2015). Tracking health outcomes in clinical quality registries has allowed Swedish clinicians to identify clinical best practice and disseminate these to all clinicians, improving average health outcomes over time (World Economic Forum 2017). Falls are frequently reported adverse
events among adults in acute care; while falls prevention programs include multiple components, the inclusion of patient-reported risk factors can support patient safety and improve patient outcomes (Quigley & White 2010). A study assessing psychosocial outcomes in patients with diabetes across 17 countries reported that self-reported health status, quality of life, treatment burden and self-management in diabetes patients provided insight into unmet needs and best practice to inform change and improve health outcomes for people with diabetes (Nicolucci et al 2013).

PROMs have a greater impact on patient outcomes when used as a tool to monitor patient progress in disease-specific populations, than when used as a screening tool (Greenhalgh et al 2017). For example, the American Heart Foundation stated that patient reported health status is considered as a “strong, independent predictor of other health outcomes, including mortality, cardiovascular events, hospitalisation, and costs of care” (Rumsfield et al 2013, p. 2235). Clinical benefits were associated with systematic symptom self-reporting through PROMs during cancer care and patients reported health outcomes, for example, improvement in quality of life, reduced depression, and improved satisfaction with care (Basch et al 2015; Nelson et al 2015).

There is increasing evidence, notably in oncology, that PROMs are effective. For example, a controlled trial in cancer care showed an association between routine use of patient-reported outcome measures and improved quality of life, enhanced patient-clinician communication, reduced emergency department use and increased survival rates (Basch 2017; Basch et al 2015). Other areas of clinical care are also administering PROMs, for example, results from PROMs surveys taken before foot and ankle surgery have been shown to predict the likelihood of clinically meaningful benefits after surgery (Baumhauer 2017). Increasingly used in palliative care, PROMs can improve awareness of unmet need and enable clinicians to act to address patients' needs (Etkin et al 2015).

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PROMs support the comparison of the effectiveness of different treatment options to help guide better practice (Williams et al 2016). Analysis of aggregated PROMS data can help to understand and minimise clinical variation (Baumhauer 2017; Williams et al 2016). The integration of patient-reported measures into population health monitoring can provide a more comprehensive picture of population health status than currently detected through traditional health outcome measures, such as morbidity and mortality (Mamiya et al 2017).
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