

# Do currently used performance indicators assess what really matters in primary care? An overview and appraisal of generic patient reported outcome measures (PROMS) and patient reported experience measures (PREMS)

## **BACKGROUND**

Health systems across the Organization for Economic Co-operation and Development (OECD) spend around 9% of their GDP on health, but we know surprisingly little about whether they are truly delivering the care people need. The OECD has therefore recently proposed the routine collection of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), i.e., instruments to measure patients' subjective health status and experience of care. An example of a PROM is "Has your health changed since your last doctor visit?" and of a PREM is "Did you feel taken seriously during your appointment?"

The rationale behind using PREMs and PROMs for routine data collection is that understanding patients improves clinical outcomes by increasing loyalty, adherence, and satisfaction. PROMs and PREMs can provide insight into the importance of treatment, reveal differences between patient populations, and serve as comparative performance indicators for health systems. Also, patient experience is a quality indicator in the patient journey and therefore a desirable outcome to achieve in its own right.

Given the importance of primary care in providing resilient, high-quality, and cost-effective health systems, and the fact that it follows patients throughout their lives – not just throughout their conditions – routine collection of PROMs is particularly useful as performance indicators.

Generic indicators, as opposed to disease-specific ones, are needed to capture the broad and diverse field of primary care. To date, a variety of generic PROMs and PREMs have been developed and applied, but we do not know whether they are appropriate for health systems performance evaluation.

To achieve the goal of using generic PREMs and PROMs for performance assessment in primary care, existing instruments need to be assessed for their suitability for this purpose. The objective of this study is thus to evaluate whether existing generic PREMs and PROMs measure criteria relevant to routine data collection in primary care. Its contribution is a formation of a basis for the future use of PREMs and PROMs for performance evaluation in primary care.

## **METHODS**

This is a multimethod study consisting of qualitative data collection and a systematic literature review. First, the nominal group technique was used to identify issues in primary care that are relevant to

patients, providers, and representatives of public health institutions (i.e. Social Ministry, Public Health Institute, Social Health Insurance). The statements gathered were coded in MAXQDA by two different researchers and organized into different groups until several overarching themes emerged.

Second, a systematic literature search in EMBASE supplemented by a grey literature search was conducted to identify self-administered, validated, and generic PREMs and PROMs for adults used in primary care. All PREMs and PROMs were transferred to Excel and were assigned to different categories (e.g. mental health, or patient-provider relationship) depending on the concept they captured.

## **RESULTS**

Using the nominal group technique, we found that structure of care, patient-physician relationship, patient empowerment, service delivery, quality, and health improvement are important issues in primary care. In addition, the experience of care and the supportive structure of primary care were rated as more important than health outcomes.

In the systematic literature review, we found 351 items in 15 tools, of which 105 were PROMs, 214 were PREMs, and 32 assessed patient characteristics. Comparison of the themes found in the nominal group technique with the categories captured by existing items revealed that PREM and PROM instruments focus on the experience with the healthcare provider and their relationship with the payer (i.e. health insurance) and the patients. However, they lack items that measure experiences with the payer and the patient-payer relationship.

## **DISCUSSION AND CONCLUSION**

The results suggest that not only direct health improvements but also the care experience should be considered in the evaluation of primary healthcare services, as stakeholders in primary care rated the importance of health improvement to be lower than the experience of care and more PREMs than PROMs are used in existing tools. However, some existing tools only measure health outcomes and neglect the importance of the care experience as a relevant outcome in its own right in primary care.

In addition, the PREM and PROM instruments currently in use neglect the payer as an actor in primary care. Thus, if the cause of undesirable primary care outcomes lies with the payer, the problem cannot be addressed because it is not even recognized. Future development of PREMs and PROMs should address the patient-payer relationship.