

Understanding the complexities of collecting and using PRO data in a primary care context

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Patient-reported outcomes (PROs) were originally introduced to primary care as screening instruments to assist primary care practitioners to diagnose and manage depression, on the assumption that standardised tools offered a more systematic and comprehensive assessment of symptoms.^{1 2} Since then, in both England and the USA, for instance, primary care has seen a move towards integrated care systems with collaboration across primary and secondary care and social services with the aim of better supporting patients to self-manage long-term conditions.³ In this context, PROs are envisaged to enable practitioners to identify patients' problems and open up a discussion between the patient and the practitioner on how best to address them.⁴ The electronic capture and feedback of PROs to both clinicians and patients also offer opportunities for patients to track their own symptoms to support self-management.⁵ At the same time, PROs are advocated as a means of monitoring the quality of patient care^{6 7} and their use has been financially incentivised in some countries through pay-for-performance initiatives.^{8 9} The 'measure once, cut twice' premise of using the same PRO data for multiple uses^{10 11} is appealing but recent reviews of the literature also identified a number of challenges to this approach in practice.^{12 13} There is a need for evidence to demonstrate how PROs can successfully support patient care in primary care and to disentangle and understand the complex and interacting tensions that characterise the reality of work in this context. Such evidence is unlikely to arise from randomised controlled trials that typically adopt a 'black box' approach to studying complexity¹⁴ but instead from observational studies of the real-world use of PROs in clinical practice.

Against this background, Mou *et al*'s study¹⁵ in this issue of *BMJ Quality & Safety* exploring primary care practitioners' experiences of implementing a wide range of PROs for screening, monitoring and regulatory requirements in a large US health system is a welcome addition to this evidence base. Nineteen primary care clinics serving over 200 000 patients administered a questionnaire at patient annual reviews and to new patients. The questionnaires, which were part of a 'Primary Care Screening Bundle', were available for patients to complete electronically prior to the clinic visit and were integrated into the electronic patient record. As of 2019, 74% of eligible patients had completed screening. Mou *et al*¹⁵ surveyed 117/172 primary care practitioners (68% response rate) and interviewed a purposive sample of 20 primary care practitioners to understand their experiences of using PRO information from the Primary Care Screening Bundle in primary care. Here I consider how their findings shed light on the realities of implementing and using PROs in a primary care context.

Mou *et al*¹⁵ found that use of PROs supported clinical decision-making by highlighting patient issues that may have gone unnoticed by primary care practitioners, a finding that is echoed in reviews of the literature^{12 16} and in recent studies.^{17 18} They also report that PROs improved clinic efficiency, largely by ensuring that items required for regulatory or accreditation purposes were already completed before the consultation. However, Mou *et al*¹⁵ noted that some primary care practitioners did not look at PRO data at all and others felt PRO data did not influence patient management. Herein lies a tension in the collection of PROs for multiple purposes;



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previous reviews have identified that general practitioners felt data required for regulatory or performance management purposes did not always reflect what was medically important in managing patients and so were reluctant to trust or act on these data.^{12 13} Recent studies also suggest that patients question the value of PROs if they are perceived to be a ‘tick box’ exercise and clinicians do not discuss the results with them.¹⁹ These findings resonate with learning points from analogous tools such as computerised templates or checklists for the review of long-term conditions^{20 21} and structured needs assessments²² where there is a risk that the structured nature of the tool leads practitioners to prioritise a biomedical agenda and limits the scope for patients to elaborate their concerns.

Mou *et al*'s¹⁵ study provides further insight into these complexities. They observed that some primary care clinicians felt the questions they had to ask for regulatory purposes were often tangential to or out of kilter with the clinical reason for the patients' visit. They also found that patients sometimes could not understand why they were being asked these questions or were concerned that data were being used to ‘profile’ them. Others have also found that some primary care practitioners felt ‘bamboozling’ patients with lots of questions to complete a PRO was not a clinical priority and that PROs do not replace a face-to-face discussion with patients.^{17 23} These findings highlight that primary care consultations involve more than just information exchange but are sites of relationship building and management²⁴; primary care practitioners' use of PROs is entangled with this ongoing accomplishment and in turn shapes how PRO data are understood and used.^{25 26} Recent studies in other contexts have shown that using PROs in a ‘relational way’, whereby practitioners sit with patients while they complete the PRO and probe their answers, can open up opportunities for dialogue and strengthen practitioner–patient relationships.²⁷

Mou *et al*'s¹⁵ findings also revealed challenges to integrating the collection and use of PRO data into the clinic workflow. In Mou *et al*'s¹⁵ study, patients could complete their questionnaires online prior to the clinic visit or on a tablet in the waiting room and data were then available in real time through the electronic health record (EHR) during the clinic visit. However, some primary care practitioners reported that there was not enough time to complete the items in the waiting room resulting in incomplete data and that front desk staff felt collection of PRO data in the waiting room made the clinic less efficient. Primary care practitioners also reported difficulties finding and understanding PRO data in the EHR due to poor formatting and presentation. Similar challenges have been observed elsewhere^{17 28} and others have noted that EHRs are often not designed to incorporate PRO data.²⁹ Guidance exists to support the integration of PRO data into EHRs,³⁰ the optimal presentation of PRO data to assist

their interpretation³¹ and the training of practitioners in the use of PRO data.³² While undoubtedly useful, such guidance is unlikely to resolve all of the complexities that underlie the work of collecting and using PRO data to support patient care. These complexities often require an understanding of professional and organisational practices and routines and how these shape and are shaped by technology.³³ Thus, it is worth briefly considering how scholars from science and technology studies have understood PRO and EHR data.

These scholars have noted how patient data contained in EHRs function as a ‘data double’ of the patient.^{34 35} This creates a separation between locally produced patient narratives, elicited during interactions between patients and primary care practitioners within consultations, and PRO data in EHRs.³⁶ Langstrup³⁷ argues that there may be tensions between PRO data and patients' own accounts of their problems that clinicians must actively resolve. Her study showed that PRO data may illuminate, act as a substitute for or even inhibit the patient's own narrative.³⁷ Other studies have also found that primary care practitioners do not always trust the ‘data double’ produced by PROs; for example, they have expressed concerns that patients may either under-report or over-report problems when completing PROs or that PRO items ‘put ideas into [patients'] heads’ about how they should feel.¹⁷ However, a review found that while some patients felt PROs did not always capture the complexity of their problems, most studies reported that PRO completion leads patients to reflect on their condition and, in turn, this helps to clarify how they feel and can give patients permission to raise issues with practitioners.²⁵ Others have found a poor agreement between PRO data and EHRs—primary care practitioners did not record diagnostic codes based on PRO data unless the patient also reported it was a problem.²⁹ This suggests primary care practitioners do not always accept the content validity of PROs, and the patient's own narrative is required as verification. We might question whether practitioners' scepticism of PRO data reflects a ‘doctor knows best’ mindset; these sorts of objections are not limited to primary care but have been found in other settings.³⁸ However, they might also reflect practitioners' struggles to reconcile different ‘versions’ of the patient being presented to them.

These findings also signify the different mechanisms through which PROs can support patient care, either by acting as a ‘test result’ to raise practitioners' awareness of patients' problems or through enabling patients to better identify these issues and raise them with practitioners.²⁵ This dichotomy could also explain the conflicting accounts from primary care practitioners found by Mou *et al*¹⁵ and others¹⁷ regarding whether PRO data improve the efficiency of the consultation or informed clinical management. If PRO data act like a test result that can be taken at face value by practitioners, then it

may serve to pinpoint patients' problems more efficiently. However, if PRO data either require further corroboration from the patient and, in turn, reveal a mismatch between the PRO data and the patient's account or open up issues that practitioners feel are beyond their remit to address or are ill equipped to manage, then this may lengthen consultations significantly. Primary care practitioners in Mou *et al*'s¹⁵ study and others¹⁷ often draw attention to the material reality of the time pressure of a primary care context, which, given the complexities of interpreting these data, is a very real constraint on how practitioners engage with PRO data.

Several authors have provided valuable frameworks and lessons learnt to support the implementation of PROs into clinical practice.^{39–41} Addressing the technical design of EHRs, improving the presentation of PRO data and training to increase practitioners' understanding of PROs are all important. However, the fundamental tension between the need to explore patients' experiences in sufficient detail and practitioners feeling they lack the time, remit or resources to do so may be less easy to resolve. Furthermore, if PRO data are to be successfully used for multiple purposes, this will also add complexity in data collection, clinic workflow and interpretation of data. Other studies have shown that the use of outcome measures and interpretation of outcome data requires considerable practitioner tacit knowledge, which develops as practitioners gain experience of using these measures in practice.⁴² This suggests that in moving forward we need to understand and support the processes through which PRO use becomes routine and is embedded within professional and organisational norms.⁴³ As such, there is much to be gained from the use of implementation science frameworks and theories to facilitate the integration of PRO data into clinical practice to support patient care.⁴⁴ As others have noted,^{45 46} addressing the 'barriers and facilitators' to implementing complex health interventions does not rely on the description of these 'barriers and facilitators' alone but requires addressing the system strains and complexities underlying their use in practice.

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