

# Functionality and feedback: a realist synthesis of the collation, interpretation and utilisation of patient-reported outcome measures data to improve patient care

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**Declared competing interests of authors:** none

**Disclaimer:** This report contains transcripts of interviews from studies identified during the course of the research and contains language that may offend some readers.

Published January 2017

DOI: 10.3310/hsdr05020

## Scientific summary

### PROMs data for improving patient care

Health Services and Delivery Research 2017; Vol. 5: No. 2

DOI: 10.3310/hsdr05020

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# Scientific summary

## Background

Patient-reported outcome measures (PROMs) are questionnaires that measure patients' perceptions of the impact of a condition and its treatment on their health. The national PROMs programme was introduced in the NHS with the intention of supporting patient choice, provider accountability and provider benchmarking, and, thus, improving patient care. Alongside the use of PROMs data at an aggregate level, the routine collection and use of PROMs data at the individual patient level has become more widespread, although in a less co-ordinated way. At the individual level, the intention of PROMs feedback is to improve the detection of patient problems, to support clinical decision-making about treatment through ongoing monitoring and to empower patients to become more involved in their care. However, reviewing the literature in this area is challenging owing to the complexity and heterogeneity of the intervention, as well as the variations in context into which this intervention is implemented. Our project aimed to address these challenges and to carry out a realist synthesis of the processes through which and circumstances in which PROMs feedback improves patient care.

## Objectives

1. Identify and classify the various ambitions for the use of PROMs data at the aggregate and individual level to:
  - i. produce a comprehensive taxonomy of the 'programme theories' underlying these different functions, and capture their subtle differences and the tensions between them
  - ii. produce a logic model of the organisational logistics, social processes and decision-making sequences that underlie the collation, interpretation and utilisation of PROMs data.
2. Test and refine these programme theories about how PROMs feedback is supposed to work against existing evidence of how it works in practice to:
  - i. identify the implementation processes that support or constrain the successful collation, interpretation and utilisation of PROMs data
  - ii. identify the mechanisms and circumstances through which the unintended consequences of PROMs data arise and those in which they can be avoided.

## Methods

We conducted two separate but related realist reviews that explored (1) the processes through which, and circumstances in which, the feedback of aggregate PROMs and performance data leads to providers taking steps to improve patient care; and (2) the processes through which, and circumstances in which, PROMs act as a tool (a) to support patients in raising or sharing their concerns with clinicians, and (b) for raising clinicians' awareness and discussion of patients' concerns.

For both reviews, we utilised two search strategies across several electronic databases to identify policy documents, opinion pieces, letters, commentaries, editorials and reviews that discussed how PROMs and (for the aggregate review) other performance data were intended to improve patient care. We developed a comprehensive taxonomy of the underlying ideas and assumptions, or *programme theories*, about how PROMs feedback is intended to work. We verified and extended these ideas with our patient group and a

stakeholder group of NHS clinicians and policy-makers. The project group subsequently agreed the focus of the two reviews.

For the review of aggregate PROMs and performance data, we worked on information specialist-designed search strategies to identify papers that explored providers' experiences of using, and responses to, PROMs and other performance feedback (mortality report cards, other 'performance data' and patient experience measures). We searched a number of electronic databases, including EMBASE Classic+EMBASE (via Ovid), Health Management Information Consortium (via Ovid), (Ovid) MEDLINE® and (Ovid) MEDLINE® In-Process & Other Non-Indexed Citations. We carried out backwards and forwards citation tracking of key systematic reviews. We developed a set of inclusion and exclusion criteria to identify papers relevant to testing our programme theories; following several iterative screening procedures, 58 papers were included in the final synthesis.

For the individual review, we used backwards citation tracking of six key papers, which identified 372 papers, and forwards citation tracking of five key papers, which identified 605 papers. We developed a set of inclusion and exclusion criteria, and 36 papers were included in the final synthesis.

For each review, we developed a logic model of the intended processes through which PROMs feedback was intended to improve patient care. We matched our programme theories to each stage in these logic models, and they served as a framework for the review. For each review, we conducted a pilot synthesis on a purposively selected sample of papers to refine our theories and then conducted the synthesis across all papers. The aggregate review tested and refined nine theories that focused on understanding the mechanisms through which providers were expected to respond to PROMs and other performance data, and the circumstances in which these data led to providers taking steps to improve patient care. For the individual review, we tested and refined eight theories that examined the processes through which, and circumstances in which, PROMs feedback (1) enabled patients to raise or share concerns with clinicians, and (2) raised clinicians' awareness of patients' concerns and led to discussion during the consultation. For both reviews, we assessed the quality of, and extracted data for, aspects of the study relevant to testing our theories. To aid the process of synthesis, we organised the studies by theory and completed data extraction tables to allow both cross-study and within-study analysis. The synthesis team (JG, SD, KG and EG) held regular meetings to discuss the findings, and discussed emerging findings with the wider project team. Ongoing findings were also discussed with our patient group.

## Results

### *Feedback and public reporting of aggregate patient-reported outcome measures and performance data*

Public reporting places additional pressure on providers, particularly poor performers, to respond. Providers perceive that the public reporting of poor performance damages their reputation, so they take action to improve patient care in response to this. Patients do not use publicly reported information about service quality to inform their choice of hospital, but instead rely on their personal experience, the opinions of friends and family and advice from their general practitioner. Providers perceive mandatory public reporting programmes initiated by regulators or national or state governments as being driven by political motives, while those initiated by employers or insurance companies were perceived as being driven by a desire to cut costs or increase a provider's market share. Under these circumstances, providers criticised data about service quality as lacking credibility because they were based on data designed for a different purpose, had inadequate methods of case-mix adjustment and did not reflect what was clinically important. When performance data were fed back privately, with no public reporting, providers either ignored these data or attempted to improve data collection practices. When these data were publicly reported, they led providers to focus on improving those areas of care subjected to measurement at the expense of other areas of care: so-called 'tunnel vision' or 'effort substitution'.

Providers responded to performance data when their own internally collected data also suggested that there was a problem with the quality of care. Furthermore, externally mandated publicly reported data, particularly data focusing on outcomes, did not enable providers to identify the causes of any areas of poor care. Rather, additional investigations were needed, which required additional resources and the 'know-how' and capacity to carry out these investigations. Clinically initiated public reporting systems were perceived as driven by a desire to improve the quality of patient care, which secured clinical involvement. Clinical involvement in these programmes ensured that the indicators represented areas of care that clinicians perceived as important, and clinical ownership of the sources of data, indicator specification and methods of case-mix adjustment meant that it was difficult for clinicians to dismiss or ignore these data. Under these circumstances, providers took steps to improve patient care in order to be as good as or better than their peers, and did so through sharing and learning from best practices. However, action depended on the providers' experience of quality improvement (QI): providers with more experience were more likely to make sustainable improvements.

Providers valued data that were timely and specific, and that provided a clear indication of which care processes needed to be improved. However, the feedback of these data did not always lead to providers taking steps to improve patient care. When change did occur, efforts were more likely to be directed at less complex, discrete organisational aspects of care. Changes that required clinicians to modify the interpersonal aspects of their care, or that were more complex, were perceived as more difficult to implement. Furthermore, changes to one aspect of patient care could have unintended effects on other aspects of care. Significant and sustained improvements in patient care in response to the feedback of performance data can be achieved only through system- and organisation-wide strategies.

### *Patient-reported outcome measures in the care of individual patients*

Whether PROMs support or constrain patients in sharing or raising issues with clinicians depends on the structure of the PROM. Standardised PROMs were useful for those patients who preferred not to talk about personal or sensitive issues, helping them to share information. However, clinicians in primary and secondary mental health settings and palliative care perceived that standardised PROMs constrained the patient-clinician relationship because they trivialised patients' emotions or did not capture the complex and dynamic nature of patients' problems. When there were no incentives attached to the use of standardised PROMs, clinicians avoided using them because they did not support the care of patients. In some situations, clinicians also adapted or changed the PROM to make it more useable, which may have compromised its validity as an instrument to support the care of individual patients. When clinicians were financially incentivised to use standardised PROMs, they used a wide range of tactics to adapt the PROMs to fit their interactions with patients in order to avoid being penalised for avoiding PROMs use. Some of these strategies may have compromised the validity of the PROM as tool to support the care of patients and as an indicator of the quality of care.

Clinicians and patients perceived that, when used in first assessments, individualised PROMs supported relationship-building because they enabled the patient to 'tell their story'. However, individualised PROMs were less useful as an outcome measure to judge change over time, owing to differences in the way that cues were defined between patients, between patients and interviewers, and over time. PROMs feedback could increase discussion of symptoms during the consultation and, in one study, led directly to improvements in patient well-being. The mechanism underlying this process is that patients felt more comfortable raising both physical and psychosocial or non-medical issues with their doctors and were more likely to initiate discussion about these during the consultation.

Patient-reported outcome measures do not substantially change doctors' communication practices during the consultation. Consultations still focused on symptoms rather than psychosocial issues, and clinicians were not more likely to initiate discussions about the latter. This was because doctors see their remit as dealing with issues specifically related to the patient's condition and its treatment, and consider that it is nurses' role to address wider psychosocial issues, a perception shared by nurses themselves. The limited effect on discussion also occurred because doctors closed down discussions about issues they felt unable

to treat. In palliative care settings, although nurses recognised that PROMs could raise issues that fell outside their remit and that they could not address, they recognised that 'just discussing' these issues could have therapeutic value for patients.

## Strengths and limitations

There was a paucity of research examining the feedback of aggregate PROMs data to providers, and we drew on evidence from interventions with similar programme theories (other forms of performance data) to test our theories.

## Conclusions

Our findings suggest that actively involving professional organisations in the process of agreeing indicator specification and case-mix adjustment is important to secure clinical engagement with performance feedback. Explaining how the process of case-mix adjustment is achieved in a way that clinicians can understand could improve their credibility among clinicians. There is little variation between providers in their performance in the national PROMs programme, suggesting that there may be other services and settings in which there is greater variation in practice that would benefit from the routine collection of PROMs data. PROMs data act as 'tin openers' rather than as 'dials'. They classify providers as 'statistical' outliers, but this does not necessarily mean that providers are providing poor care, nor does it inform providers about the possible causes of any poor care. Providers are expected to conduct further investigations to identify alternative explanations for their outlier status and, if none are found, to explore the possible causes of their outlier status. Providers need more support and guidance on how to collect their own internal data, how to rule out alternative explanations for their outlier status and how to explore the possible causes of their outlier status. Further support and guidance are also needed to enable providers to integrate and interpret PROMs data in the context of other pieces of performance data, in order to access a bigger picture overview of their performance.

Our review highlighted the importance of considering how PROMs feedback in the care of individual patients affects not only the information-exchange and decision-making functions of the consultation, but also the relationship-building function. PROMs function more as a tool to support patients in raising issues with clinicians than they do in substantially changing clinicians' communication practices with patients. In settings such as palliative care and psychotherapy, clinicians viewed individualised PROMs as useful in building rapport and supporting the therapeutic process. However, individualised PROMs are more time-consuming to complete, and it is not clear if such measures would be feasible to collect in more time-pressured settings such as primary care or outpatient appointments for patients with long-term conditions. Future research on the use of PROMs in the care of individual patients should focus on ensuring that the different relevant clinicians gain access to this information, so that issues can be addressed by the clinician with the appropriate remit, through integrating PROMs collection into patients' electronic records.

Finally, using PROMs data to support both service-level QI and the care of individual patients is still a challenge. There is a need for mixed-methods studies to explore how differently performing providers (e.g. positive, negative and those at average levels) have used PROMs to identify the areas of care that could be improved, as well as how they have used PROMs data to guide improvements. There is also a need for future research to examine how providers have collected PROMs data to support both the care of individual patients and service QI.

## Study registration

This study is registered as PROSPERO CRD42013005938.

## Funding

Funding for this study was provided by the Health Services and Delivery Research of the National Institute for Health Research.

# Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

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## This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 12/136/31. The contractual start date was in March 2014. The final report began editorial review in December 2015 and was accepted for publication in May 2016. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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