School of Sociology and
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When, why and how does feedback of PROMs data lead to improvement in patient care? A realist synthesis

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Presentation outline

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1. Discuss different uses of PROMs data and outline the aims and objectives of our review

2. Discuss review findings on the use of aggregated PROMs data – to support quality improvement

3. Discuss review findings on the individual level use of PROMs data – to support care of individual patients

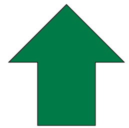
4. Consider tensions between different uses of PROMs and remaining policy challenges

PROMs use in healthcare settings

Aggregate level

- Data collected from patients before & after procedure
- Adjusted for case mix
- Aggregated at hospital level

National PROMs programme (England)



Individual level

- PROM completed prior to clinician visit
- Fed back to clinician during visit
- Data discussed in consultation

Or

- Used to decide if follow up needed

eRAPID (UK)

KLIK (Netherlands)

AmbuFlex (Denmark)

Van der Wees et al (2015)

Aims and Objectives

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1. To identify existing ideas from policy documents and literature regarding how, why and in what circumstances the feedback of PROMs data are ***thought*** to lead to improvements in patient care

2. To review quantitative and qualitative empirical studies to explore when, how and why the feedback of PROMs and other performance data actually does (or does not) lead to improvements in patient care

We conducted two reviews:

- Review 1: aggregate level PROMs data
- Review 2: individual level PROMs data

Our review: an overview

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Two reviews: PROMs use at (1) Aggregate and (2) Individual level

Identify theories

- Search to identify programme theories – ideas and assumptions
- Developed a model of how the intervention intended to work
- Selected programme theories to test in collaboration with patients and stakeholders

Search for evidence

- Electronic database searches
- Backwards and forward citation tracking of key papers and systematic reviews

Theory testing and refinement

- Paper selected according to their relevance to programme theories
- Data abstracted into evidence tables and used to test and refine theories
- Comparative analysis of across different settings/contexts

Review 1: The feedback of aggregate PROMs data

How are aggregate PROMs data thought to improve patient care?

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Idea 1: Patient Choice: PROMs data can help patients and GPs choose a provider

- Patients or GPs use PROMs to choose higher performing providers and avoid lower performing providers

- Poorer performing providers will either 'exit' the market or feel threatened by the potential loss of patients and take steps to improve patient care

How are PROMs thought to improve patient care?

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Idea 2: Accountability: PROMs data will enable stakeholders (eg commissioners, regulators and the public) to hold providers to account for the quality of care provided

- Commissioners may impose ‘sanctions’ for poor care (eg switching contracts, increased scrutiny or surveillance, loss of income via failure to achieve targets)
- Commissioners may ‘reward’ good performance (renewing contracts, ‘light touch’ monitoring, financial rewards)
- Providers may feel ‘threatened’ by potential or actual sanctions and/or subsequent reputational damage and take steps to improve patient care

https://www.theguardian.com/society/2013/mar/29/leeds-general-infirmary-halts-heart-operations-children

NHS

Leeds General Infirmary halts heart surgery on children

Urgent and disturbing calls from surgeons regarding death rate at unit lead to closure a day after court rules to keep it open

Alexandra Topping
Fri 29 Mar 2013 13.30 GMT

Leeds General Infirmary, where heart operations on children have been halted.

Urgent and disturbing calls from two surgeons have led to the suspension of surgery on children with congenital heart defects at Leeds General Infirmary

How are PROMs thought to improve patient care?

Idea 3: PROMs data will enable providers to compare their own performance with those of their peers. Providers take steps to improve care because:

- ***Intrinsic professional values*** will mean they act to address any gaps between their own performance and a target
- They are ***competitive*** and wish to be as good as their peers
- They seek to ***learn*** from the good practices of other providers
- They wish to ***protect their professional reputation***, which may have been damaged by being labelled a 'poor performer'

The Evidence Base of our review

Quality measurement intervention	Example study	N papers
England/Ireland PROMs	Varagunam et al Impact on hospital performance of introducing routine patient reported outcome measures in surgery. *Journal of Health Services & Research Policy* 2014;19:77-84	4
Clinical audits	Taylor et al. How is feedback from national clinical audits used? Views from English National Health Service trust audit leads. *Journal of Health Services Research & Policy* 2016;21:91-100.	2
Cardiac Surgery (US, Canada and UK)	Bridgewater et al. Has the publication of cardiac surgery outcome data been associated with changes in practice in northwest England: an analysis of 25 730 patients undergoing CABG surgery under 30 surgeons over eight years. *Heart* 200793:744-8.	14
General quality/mixture of process and outcome	Davies H. Public release of performance data and quality improvement: internal responses to external data by health care providers. *Quality in Health Care* 2001;10:104-10.	9
UK hospital quality systems (eg 'star' ratings and 'CRAG' indicators)	Mannion et al Impact of star performance ratings in English acute hospital trusts. *Journal of Health Services & Research Policy* 2005;10:18-24	4
Clinician led systems (US)	Greer AL. Embracing accountability: physician leadership, pubic reporting, and teamwork in the Wisconsin Collaborative for Healthcare Quality; 2008.	3
Patient choice studies	Dixon et al Patient Choice: How patients choose and how providers respond. London: The King's Fund; 2010.	7
Patient experience data	Boiko O et al. The role of patient experience surveys in quality assurance and improvement: a focus group study in English general practice. *Health Expectations* 2014; 10.1111/hex.12298	11
Quality and Outcomes Framework	Doran et al. Effect of financial incentives on incentivised and non-incentivised clinical activities: longitudinal analysis of data from the UK Quality and Outcomes Framework. *BMJ* 2011;**342**	3

Findings: Idea 1: Patient choice

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Do patients use PROMs/quality data to choose a hospital?

NO

- Quality is important but patients rarely used performance data to inform choice of hospital. They relied on personal experience, experience of friends and family and advice from GPs

- Hospitals generally do not see a change in their market share following public reporting of performance data

Dixon et al (2010) Patient choice: How patients choose and how providers respond. London: The King's Fund

"*I don't think I've ever had a patient say 'I don't want to go there because I've looked at their outcome figure and I don't like the look of it'* [GP]

"*It's got a bit of a bad reputation lately. And I think things like that do put me off.* [Is that from stories in the press or just generally what you hear locally?] *Word of mouth, people I've known use the hospital*… "[Female patient]

Findings: Idea 2: Accountability

Do mandatory government/ state-led quality reporting initiatives lead to improvements in patient care?

- Clinicians felt they measured what matters to government rather than clinicians
- When fed back privately, with no financial incentives or sanctions, data generally ignored

- When publicly reported & financial incentives, focused attention on quality & led to improvements in patient care
- But only short term improvements if focused on what providers were already doing well

Asprey et al (2013)

"*I'm totally cynical about the government's motivation and this is just part of that….So if they think they've got me over a barrel, forget it, because they haven't. And I can just happily carry on and ignore this survey*"

"*It's a bit of tail and dog isn't it? ... Because it has been measured, is it necessarily important? It's important but is it as important as some of the things that haven't been measured?*"

Idea 2: Accountability

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When data were publicly reported and subjected to financial incentives

BUT providers did not feel data were valid or relevant to patient care, this could lead to 'tunnel vision' and in some instances to 'gaming'

Not always active attempts to 'cheat' but created 'perverse incentives' that were at odds with inherent uncertainties of clinical practice

Mitchell et al (2011)

"*diagnoses of what would be 'QOF-able' depression has probably dropped… we realised if we kept labelling people as depressed when they perhaps weren't, then we weren't going to see them again and lose the points*".

Idea 2: Accountability

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Providers were more likely to take steps to improve patient care when their own internally collected data also suggested there was a problem

BUT

- Data focusing on outcomes did not always enable providers to immediately identify the causes of poor care
- Needed additional investigations, depended on having resources and 'know how' to carry these out and act on them

Davies et al (2001)

"*it's the in-house data* [that] *drives us more than the outside data. I think it's also better data and it's more focused; it has many more elements to it"*

"our best successes [in using data to improve quality] *were our very own internal ones*".

"*we have wonderful motivated people but if we didn't have the resources to do this, we couldn't. There's not only people committed to excellence, there's resources committed to excellence*"

Idea 3: Provider benchmarking

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Do peer comparisons prompt providers to improve patient care?

More likely to happen if:

- Public report initiative is clinically led and clinicians are involved in agreeing indicator specifications
- Indicators then perceived as clinically meaningful and focused on improving patient care
- Instils clinical ownership, meaning it is harder to dismiss or ignore data

Greer et al (2008)

"..*we promised each other we would report our data, we would not fudge it, we would have it verified, we would make it public and we would not walk away from whatever we found*"

"[I enjoy] *the sense of collaboration, and what is kind of fascinating, is that the discussion – of how we are doing, how we are doing relative to each other, how we can do better – constantly brings you back to your primary purpose and this the patient you are taking care of*"

Practice implications

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- Need to actively involve clinicians in development of quality reporting initiatives such as PROMs
- Providers need to be convinced about the credibility and validity of data
- Providers need more support and guidance on how to collect their own ‘internal’ data and how to rule out possible alternative explanations for their outlier status
- Need skills and resources to be able to carry out these investigations and then act on findings
- Providers need more support on how to integrate PROMs data with other performance data in order to avoid ‘tunnel vision’ or ignoring PROMs data

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Review 2: PROMs feedback in the care of individual patients

How can PROMs improve patient care?

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Patient completes PROM

PROM feedback provided to clinician

Feedback discussed between clinicians

Patient uses PROM information for self-management

Patient raises concerns with clinician during consultation

Clinician reviews proms feedback

Clinicians decide on action without patient discussion

Clinician raises patient's concerns in the consultation

Clinician completes PROM with patient through an interview

Concerns are discussed

Action is taken to address concerns

Action improves health or QoL outcomes

Within scope of review

Beyond the scope of this review

How are PROMs thought to improve patient care?

Idea: PROMs completion enables patients to reflect on their health and treatment and gives them ‘permission’ to raise concerns with clinicians

Hypothesised this may depend on:

- Type of PROM (standardised vs individualised)
- Existing relationship between clinician and patient
- Other uses of data and incentives

Individual: Testing theories across different contexts

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Setting	N studies	Nature of relationship	Structure of PROM	Use of incentives/ other use of data
Mental health primary care	4	Usually have existing relationship	Standardised	QOF, PR indicator of service quality
Secondary mental health care	4	New but can also be ongoing	Standardised & individualised	PR Indicator of service quality
Palliative care	9	New	Standardised and individualised	None

Findings: PROMs and self reflection

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- **Across all contexts, patients felt both standardised and individualised PROMs completion helped them to reflect on their health**:

"*I think that [completing the questionnaire] helped me in my head as well… I started to think, you know, about why I was getting depressed and that*" (Patient, Dowrick et al, 2009, standardised PROM, primary mental health care)

"*It forces one to think*" (Patient 21) and to "*sort the important from the less important*" (Patient 6) (Kettis Linblad et al, 2007, individualised PROM, oncology)

Suggests PROMs completion not a 'neutral' act of information retrieval – it can influence the ways in which patients think about their health and themselves

Findings: Clinicians' experiences of using standardised PROMs

BUT: Clinicians in primary and secondary mental health settings perceived standardised PROMs could constrain the relationship/trust building process:

"*If you've had a very loaded consultation…the HAD scale can appear to trivialise the depth of emotions*" (Leydon et al, 2011, primary mental health)

"*I like to let them verbalise their concerns rather than handing them a bit of paper and say 'tick boxes'*" (Gamlen and Arber, 2013, palliative care)

"*they.. Break down in tears and tell you how depressed they're feeling…. and then 'oh now I've got this questionnaire to fill out' I just think its so inappropriate sometime*s" (GP, Mitchell et al, 2011)

May create an 'interactional strangeness' where usual mechanisms to check meaning are suppressed (Mallison, 2002)

Findings: Impact on clinicians' use of PROMs to support patient care

Therefore, clinicians either:

- Avoided using them altogether
- Used them at the end of the consultation when they had built up a relationship with the patient ""*then they feel quite at ease…so hopefully by the time I give them that they feel it's alright and.. miss out what they feel uncomfortable with*". (Gamlen & Arber, 2013, palliative care)
- Adapted how they were used (changed items, how they were administered) to render them compatible with managing patient relationships

- But this may have affected their psychometric properties (eg validity)

Individualised PROMs

Clinicians in palliative care and secondary mental health services perceived individualised PROMs supported the relationship building process

Therapists felt completion of the SEIQoL helped them to "*form a better relationship and trust with the service user*" because it enabled them to "*get alongside the service user more quickly*" (drug and alcohol services, Cheyne et al, 2001)

"*I feel that the tool really helps the client to tell their story*" (palliative care, Annells and Koch (2001)

- Process of completing individualised measures mimicked more 'open structure' of clinician-patient interactions - generated a dialogue
- However, less useful as an outcome measure

Practice implications

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Consider the impact of PROMs completion on patients themselves

Be mindful of the impact on the relationship building function of clinician-patient interactions – not just information sharing and decision making functions

To achieve this, we may need to give clinicians considerable freedom in how and when they use PROMs

Tensions in type of PROM useful for individual patients care vs aggregating PROMs data for service monitoring of QI

Different models of PROM collection

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Van der Wees et al (2015) identified three different models of PROMs use internationally:

1. Collection of PROMs data by national, regional or state organisations to measure service quality (eg England National PROMs programme)
2. The collection of PROMs data by individual providers for the care of individual patients (eg KLIK, Netherlands)
3. Data collected by providers for use in care of individual patients but also aggregated for use as a measure of service quality (eg Improving access to psychological therapies programme in England)

Remaining challenges

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PROMs completion vs PROMs score

- At individual level, it is the *conversation* that PROMs completion prompts, not just the score per se, which supports patient care

- It is PROMs scores (or change in scores) that become aggregated as quality indicators and the patient context (which may facilitate our interpretation of data) is stripped away

Remaining challenges

Managing relationships vs preserving validity

- Clinicians adapt use and administration of PROMs to render them compatible with maintaining relationships with patients
- May compromise the validity of PROMs data produced and thus reduce their value as an indicator of quality of care when data are aggregated

Remaining challenges

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Standardised vs individualised

- At the individual level, individualised PROMs may better mimic the ways clinicians usually interact with patients, but these are problematic as indicators of quality

- Standardised PROMs ‘better fit’ technical criteria for quality indicators and patients find completion useful but clinicians feel they constrain their rapport with patients

Remaining policy challenges

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Professionalism vs managerial/market logics

State mandated PROMs collection vs clinically led approaches

Is it possible to align these different logics?

Eg: Martin et al (2015):

"*any incongruence between the aims of the project and the managerial and market logics manifest in the priorities of managers and commissioners…tended to undermine…the sense that the professional ethic might prevail*"

And it may be that:

"*there remain things that professions can do better than states – including making judgements about quality of care and encouraging their members to act on these appropriately*"

Further information

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Greenhalgh J, Gooding K, Gibbons E, Dalkin S, Wright J, Valderas JM, Black N (2018) How do patient reported outcomes measures (PROMs) support clinician-patient communication and patient care? A realist synthesis, *Journal of Patient Reported Outcomes*, 2:42: https://doi.org/10.1186/s41687-018-0061-6

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