

Patient-reported data in medical quality registers:
research and quality improvement

How PROMS can improve health care

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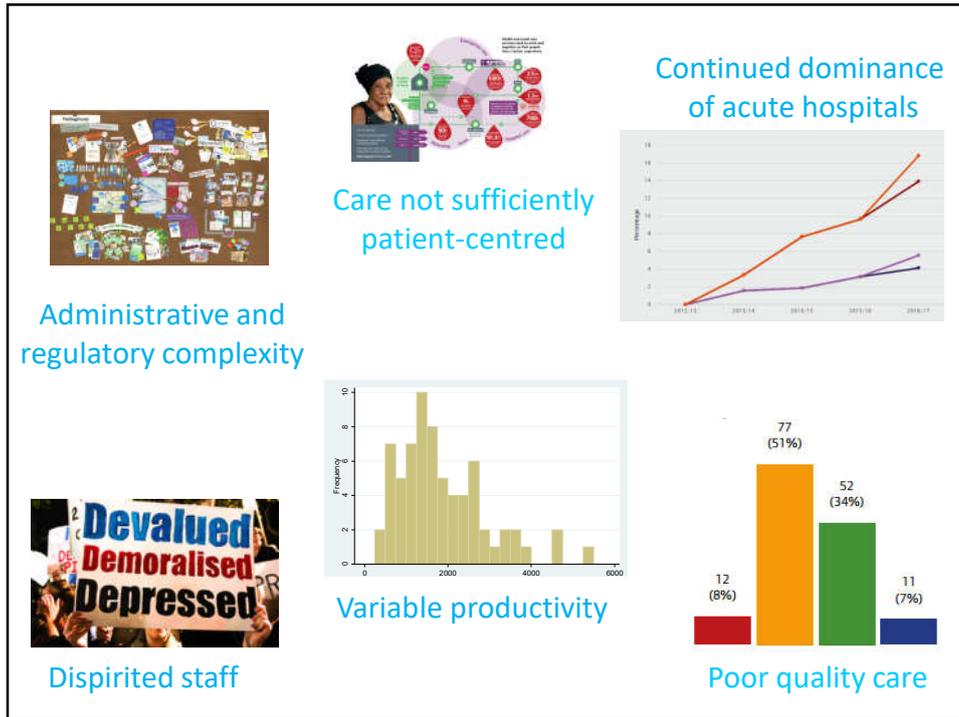
Centre for Patient Reported Outcomes

National Conference on PROMs

Bergen

5 June 2019

“Now don’t worry, this has
nothing whatever to do
with you.”



Patient reported outcome measures (PROMs)

- offers powerful tool for change
- shifts balance of power towards patients



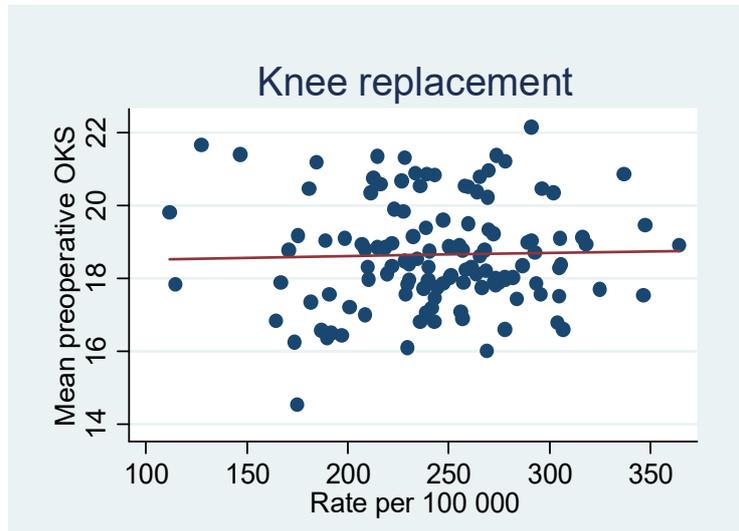
Three ways that PROMs can help

- Research
 - identify and measure the impact (outcome) of interventions
 - evaluate the impact of policies
- Improve clinical management of patients
 - individual level
- Improve performance of services
 - aggregated data (quality registers/audits)

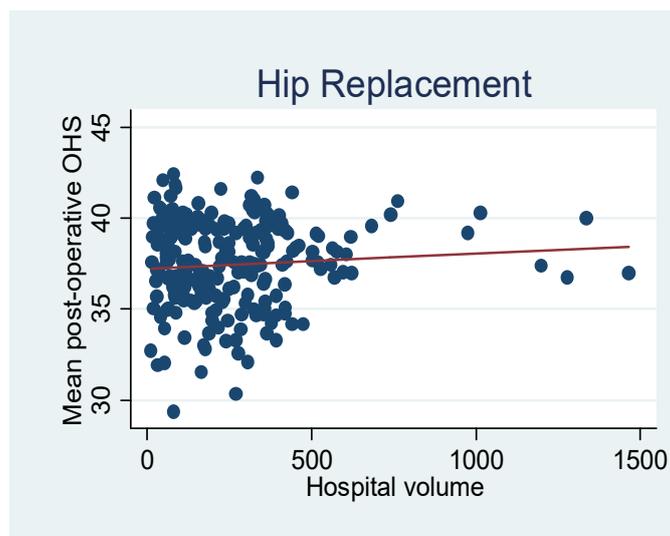
Use of PROMs in research to improve care

- evaluations of interventions
 - widespread use of PROMs in RCTs etc
- evaluations of policies...

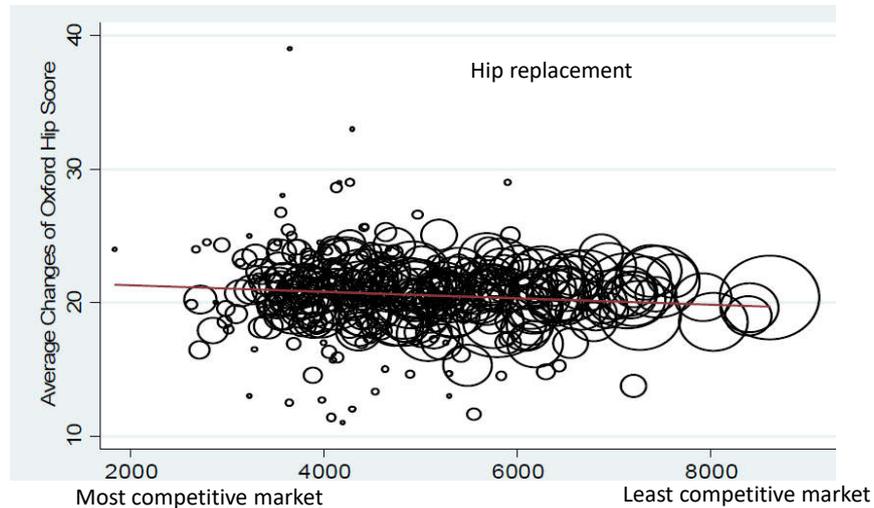
Surgical rate has little impact on pre-op severity



Hospital volume has no impact on outcome



Provider competition has no impact on outcome



Use of PROMs to improve clinical management of patients

- Support and improve communication
 - Prompts patients to reflect on their health
 - Supports dialogue enabling patient to tell their story
 - Gives patients permission to raise issues
- Greater focus on patient's interests should improve appropriateness of care
- Better detection of problems/adverse outcomes
 - Systematic inclusion in consultation
- Improve efficiency for system and patient
 - Monitoring long term conditions (eg ParkinsonNet)

Managing long term conditions: Parkinson's disease



Bastiaan Bloem
Neurologist



Marten Munneke
Physiotherapist



50 000 patients in Netherlands

69 regional networks: 3000 nurses and AHPs organised around hospitals

- evidence-based care, optimise care (increase expertise), patient-centred

IT platform for clinicians, patients and lay carers (75% neurologists participate)

- clinical data, patient reported outcomes, patient experiences

Achievements:

- Shift of focus to patients' concerns
- Improved patient reported outcomes (including quality of life and function)
- 55% reduction in hip fractures
- 50% reduction in costs

(Gray, Sarnak & Tanke, Commonwealth Fund 2016)

Use of PROMs to improve performance
of services

Lots of support and encouragement for using aggregated PROMs data to:

- compare different hospitals or practitioners
- consider trends over time

Belief that this will improve the quality of care....but why?

Rarely if ever are the reasons made explicit by policy-makers.

What are the **theories** that lie behind such beliefs?

What circumstances (the **context**) will PROMs data improve patient care?

What are the **mechanisms** by which improvement will occur?

What evidence is there to support each proposition?

Three underlying theories

- Supporting patient choice
- Improving accountability of providers
- Enabling provider comparisons (bench-marking)

Impact influenced by context

- Degree to which data are publicly disclosed
- Use of financial incentives and sanctions
- Perceived credibility of the data
- Extent to which data identify actions for improvement

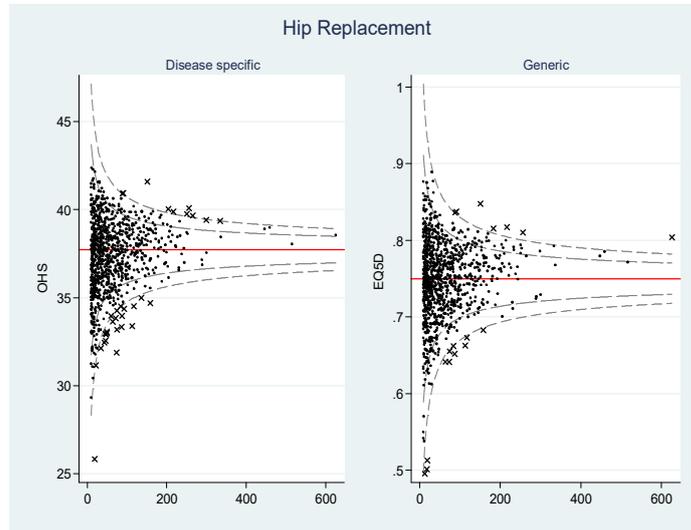
Nine mechanisms by which care may improve

- Supporting patient choice
 - Patients will choose higher performing providers
 - Threat of loss of market share
 - Poor providers will exit the market
- Improving accountability of providers
 - Threat of sanctions
 - Purchasers & regulators impose sanctions
- Enabling provider comparisons (benchmarking)
 - Professional ethos
 - Protection of reputation
 - Competitive desire to be better than peers
 - Learn from best performers

Limited evidence, slight impact

- Patient choice: little impact
- Improving accountability of providers: depends on
 - publicly reported
 - clinicians accept the metrics
 - financial incentives
 - national data consistent with local data
 - identifies actionable causes
 - simple changes needed
 - dangers as well: perverse incentives, gaming
- Enabling provider comparisons: depends on
 - clinicians 'own' the data so it is credible to them
 - feedback is timely
 - feedback provides advice on causes and remedies
 - desire to be seen to be good by peers and public

Lack of impact partly due to clinical interventions assessed



Areas of concern about quality

- Unexpected emergency admissions
- Management of long-term conditions
- Primary care
- Social care (including care homes)
- Mental health services

Unexpected emergency admissions

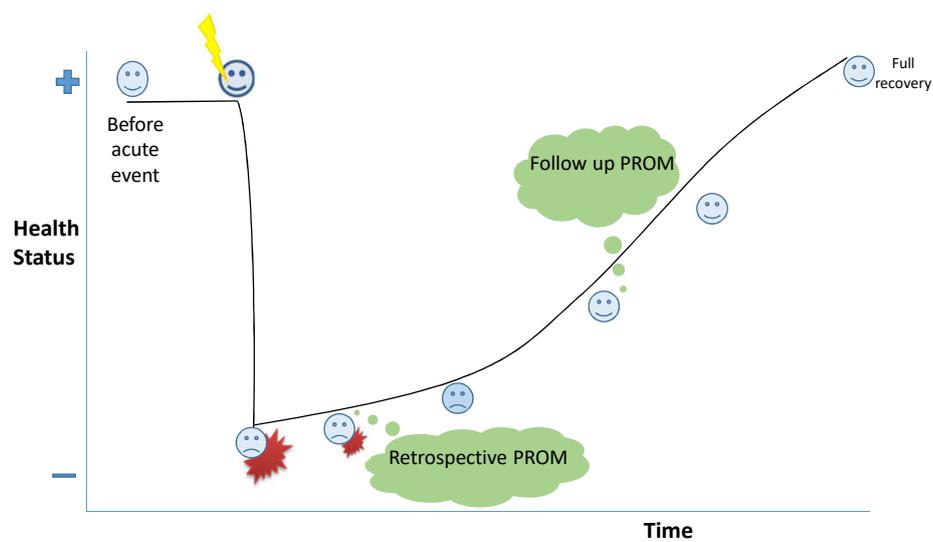
Dementia care

Unexpected emergency admissions

Challenge

- no information on health status before event

Use of retrospective PROMs?



'Accuracy' of retrospective PROMs

- Comparison with contemporary PROMs
 - Inevitably limited to elective admissions
 - hip and knee arthroplasty (5 studies N America; 1 study UK)
 - benign prostatic hypertrophy (1 study in UK)
- Association
 - strong (correlation coefficient 0.68)
- Agreement
 - continuous measures strong (intraclass coefficient 0.75)
 - categorical measures moderate (kappa 0.3-0.6)
- Conclusion
 - At group level, retrospective PROMs reliably predict contemporary
 - Stronger: indices; shorter time intervals

Feasibility of collecting retrospective PROMs in emergency admissions

- Medical (*acute myocardial infarction requiring primary coronary angioplasty*)
- Surgical (*gastrointestinal conditions requiring laparotomy, excluding appendicitis*)
 - 85% of eligible invited; **3 of 11 sites achieved over 90%**
 - 72% invited patients participated; **one site achieved 92%**
- 74% response rate at 3 month follow-up
- Need to adjust for patients' age, sex and socio-economic status when comparing providers

Dementia

Challenges

- people with dementia have limited ability to respond
- view of informal care-giver different from person with dementia

DEMQOL and DEMQOL-Proxy

DEMQOL

- patient's self-report of HRQL
- 28 items
- overall HRQL

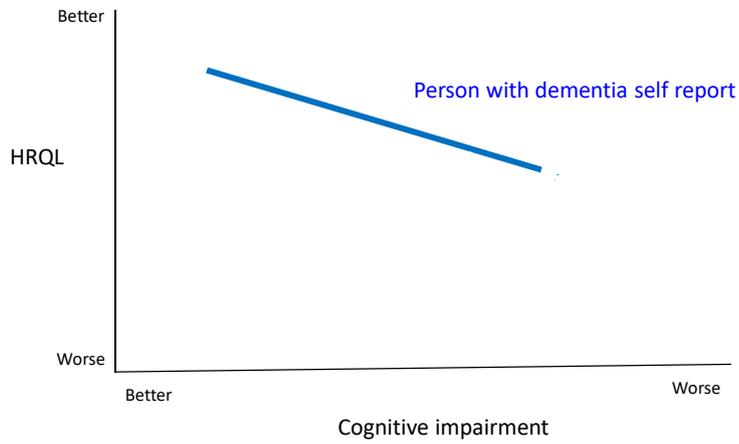
DEMQOL-Proxy

- informal care-giver's report of patient's HRQL
- 31 items
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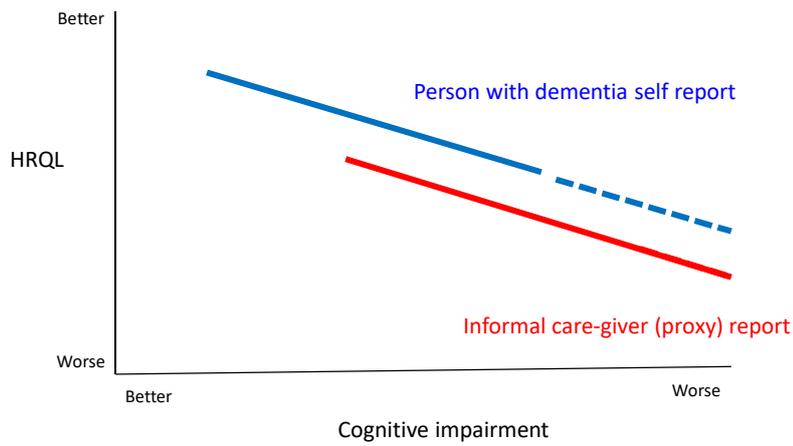
Five domains

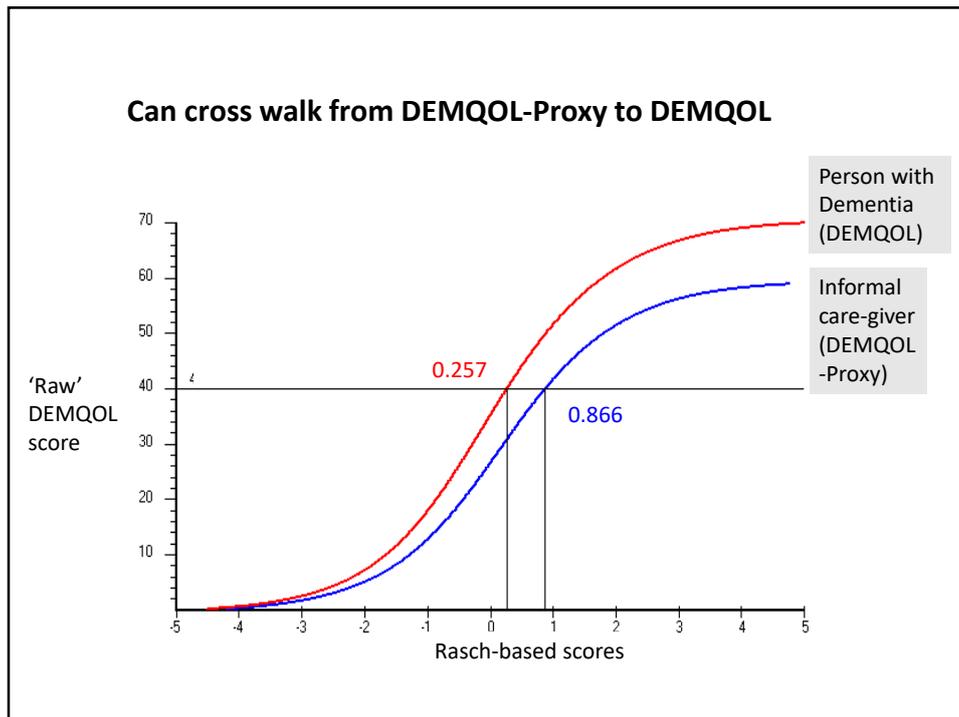
Health & wellbeing
 Cognitive functioning
 Daily activities
 Social relationships
 Self-concept

Can proxy scores predict patients' score?



Can proxy scores predict patients' score?





Final thoughts

- PROMs can help disrupt traditional approaches to clinical care (individual patients) and policies (aggregate data)
- Several methodological and practical challenges to address to facilitate wider use
- Key role in transformation and integration of health and social care