

## Progress and regress in the English NHS PROMs programme: what can be learned?

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## NHS PROMs



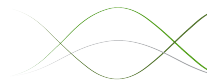
In April 2009 the UK Department of Health introduced its Patient Reported Outcome Measures (PROMs) programme, requiring patient-reported health outcomes to be measured for all NHS patients in England before and after receiving surgery for four elective procedures:

- Hip replacement
- Knee replacement
- Varicose veins repair
- Groin Hernia repair

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APERSU PROMs conference  
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## NHS PROMs



- All providers treating under the Standard NHS Contract must collect PROMs.
- All NHS providers collect these data; around 250 000 patients invited each year to complete questionnaires; good response rates, e.g. 80% for hip replacement.
- PROMs are used in hospital reimbursement (the 'best practice tariff') and quality of care reporting.
- The four procedures cost the NHS in England around £800 million per year. The estimated annual cost of the current PROMs programme is less than 0.5% of that.
- PROMs data and reporting are provided by NHS digital.  
<http://content.digital.nhs.uk/proms>
- Data can be linked to other routinely collected data e.g. Hospital Episode Statistics (HRG; length of stay, etc.)

## Early ambitions

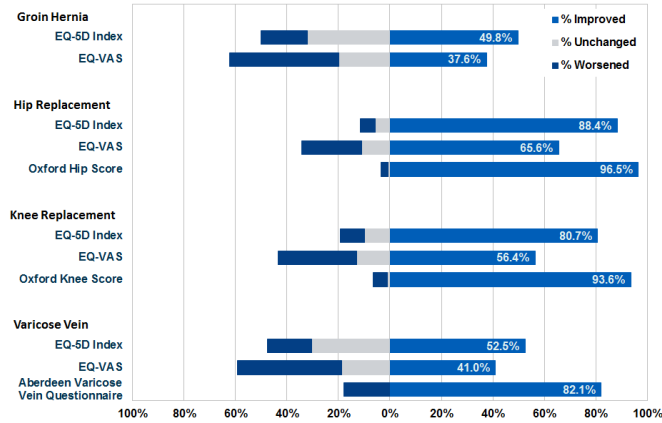


[Government White Paper, Equity and excellence: Liberating the NHS \(2010\)](#) planned increase in scope/ coverage of PROMs:

“Information generated by patients themselves will be critical to this process, and will include much wider use of effective tools like Patient Reported Outcome Measures (PROMs), patient experience data, and real-time feedback. At present, PROMs, other outcome measures, patient experience surveys and national clinical audit are not used widely enough. We will expand their validity, collection and use. The Department will extend national clinical audit to support clinicians across a much wider range of treatments and conditions, and it will extend PROMs across the NHS wherever practicable.”

# Effectiveness of surgery

Chart 1 - Improvement rate by procedure and measure



# NHS Choices

Results for **Knee replacement in SG90SJ**

Store **SG90SJ** as your main location for future visits?

Narrow search or start new search

Showing 1-10 of 25 results | Results per page: 10 | Update | See results on a map | Shortlist (0)

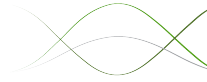
Distances given are in a straight line but travel routes may be longer. Please check before starting your journey

Topics	Risk-adjusted knee revision rate - 13 year period (2003-2016)	Risk-adjusted knee revision rate - 5 year period (2011-2016)	Health improvements reported by patients after knee replacement (EQ5D)	Health improvements reported by patients after knee replacement (EQ-VAS)	Health improvement following knee replacement: Condition specific quality of life questionnaire	Risk-adjusted 90-day mortality rate	Levels of surgical site infections
Outcomes: knee	As expected	As expected	As expected	As expected	Below average	Within expected limits	Worse than average 2.9

**Lister Hospital**

Tel: 01438 314333  
Coreys Mill Lane  
Stevenage  
Hertfordshire  
SG1 4AB  
5.6 miles away | Get directions

## 2016 consultation



- NHS England consulted on the programme in March 2016.
- The [consultation report](#) was published in October 2017.
- A wide range of views were expressed...
- “The EQ-5D Health-Related Quality of Life measure is considered by clinicians in particular to be too dependent on other factors for it to be a sole measure of clinical success”
- “Data collection is good, but the outputs are simply not used to improve care or to deliver any measurable improvements.” - Clinician

## 2017 [decision to drop 2 procedures](#)



- “These PROMs are perceived to be delivering limited value, we are removing the burden on organisations of continuing to collect this data”
- “Surgical treatment of [varicose veins](#) is currently much less frequent and the condition is usually not a major cause of patient debility”;
- “[Groin hernia surgery](#) is offered mainly to reduce the risk of requiring emergency surgery, rather than to relieve symptoms, which are often relatively minimal. This, along with the fact that there is no condition-specific PROM for groin-hernia surgery, means that the existing PROM has limited value.”

## And another developments ...



- EQ-5D to be dropped from the principal survey in primary care, the GP Patient Survey (GPPS)
- Pilot and local initiatives to continue, but no roll-out of the comprehensive PROMs programme to other conditions and treatments

## Why has the PROMs programme fail to develop as intended?



1. Responsibility moved from the Department of Health (UK Government Health Ministry) to NHS England (Central NHS Commissioning Board)
2. Diversion of attention by 'Patient Centred Outcome Measures' (PCOMs)
3. Poor match between research and needs of decision makers
4. Focus on implementation of data collection, rather than how data would be used

## 1. PROMs passed from the DH to NHS England

- PROMs programme had been conceived of, implemented and championed by economists (and others) in the DH
- Seen as integral to an outcomes-focussed NHS
- 2012/13, as part of wider restructuring of the health care system, responsibility passed to NHS England.
  - Handled by patient feedback oriented personnel; expertise in 'Family & Friends Test' rather than PROMs
  - External scientific advisory group disbanded
  - Severe budget constraints
  - Apparent lack of leadership and vision within NHS about outcomes; No PROMs champions

## 2. PROMs or PCOMs?

- At about the same time as PROMs was taken over by NHS England, there was increasing interest in a concept called by its advocates 'Patient Centred Outcome Measures' (PCOMs).
- Appeared to be a belief within NHS England that PROMs were not 'patient centred'.
- Perhaps revealed a lack of clarity over the purpose of the PROMs programme.

### 3. Research needs of decision makers

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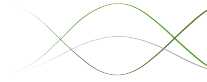
- Research was commissioned to support the PROMs programme, for example:
  - How best to present results to users
  - How to collect data for other acute and chronic conditions and their treatment
- In practise, research was seen to be too 'academically focussed' rather than meeting the needs of those who would actually use the data.
- More generally, PROMs regarded as something of interest to academics than central to health care quality

### 4. Focus on data collection rather than use

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- The DH focus on *implementing* PROMs possibly meant insufficient attention was given, from the outset, to how the data would be used
  - How it could drive quality improvement
  - How it could benefit patients.
- Multiple objectives: informing patient choice; managing variations in performance of providers; effectiveness and cost effectiveness of treatments.
- But top-down approach meant data were neither directly available to or used by patients and doctors.

## Lessons learned?



- Thinking about who will use PROMs data and how they will use it should lead and guide the design of a PROMs programme.
- Data should be available to inform decisions being made by those to whom it is most relevant: patients and health care professionals.
- Outcomes measurement is often strongly resisted by health care providers, who see it as distraction and a burden. A PROMs programme requires strong scientific and managerial leadership.
- It is important to continue to emphasise PROMs as a measure of **health outcomes**, not as general patient feedback on care.


## Ongoing NHS pilots and local NHS initiatives



- While the *national* PROMs programme is faltering, localised use of PROMs continues to be pursued.
- Requests to EuroQol office for local NHS use of EQ-5D covers 64 clinical areas.
- Examples of good practice include, for example, Cambridgeshire CCG use of PROMs in rehabilitation and community nursing, and exploring use across the paediatric service.




## Top 10 clinical areas, by number of requests for use of EQ-5D by NHS organisations



Clinical area	Number of requests
Orthopaedic medicine	48
Pain	46
Physiotherapy	38
Rehabilitation (effects of)	26
Respiratory illness	21
Cardiology	18
Diabetes	14
Elderly (QOL)	13
Colorectal carcinoma	12
Chronic illness	11

## PROMs in the UK private sector

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- Competition and Mergers Authority (CMA) Private Healthcare Market Investigation Order 2014
  - Mandates private health care providers to publish a wide range of data on quality and hospital and consultant fees, to improve patient choice.
  - Private Healthcare Information Network ([PHIN](#)) appointed to collect and publish data.
  - Implementation of PROMs data collection and reporting has been slow, with a small % compliance-ready.

## PROMs to be routinely collected in the private sector



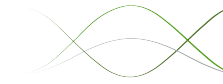
Procedure	EQ-5D	Specific
Hip Replacement	Optional	<a href="#">OHS</a>
Knee Replacement	Optional	<a href="#">OKS</a>
Groin Hernia Repair	Required	N/A
Shoulder Replacement	Optional	<a href="#">OSS</a>
Carpel Tunnel Release	Optional	<a href="#">QuickDASH</a>
TURP	Optional	<a href="#">AUA I-PSS</a>
Cataract Surgery	Optional	<a href="#">Catquest-9sf</a>
Cataract Surgery		<a href="#">Catquest (Clinician)</a>
Nasal Septoplasty*	Optional	<a href="#">SNOT 22</a>

- Q-PROMs will eventually also be collected for a wide variety of cosmetic procedures.

## Summary



- The national-level NHS England PROMs programme has not expanded across NHS activities, as initially planned, and recent decisions halve the number of procedures covered.
- The EQ-5D is also being dropped from GPPS
- However, there are many local NHS PROMs initiatives
- Mandatory PROMs data will expand in the private sector.



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