

# Assessment of compliance with the Code of Practice for Official Statistics

## **Patient Outcomes Statistics: Patient Reported Outcome Measures (PROMs) for England**

*(produced by the Health and Social Care Information  
Centre)*

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The UK Statistics Authority is an independent body operating at arm's length from government as a non-ministerial department, directly accountable to Parliament. It was established on 1 April 2008 by the *Statistics and Registration Service Act 2007*.

The Authority's overall objective is to promote and safeguard the production and publication of official statistics that serve the public good. It is also required to promote and safeguard the quality and comprehensiveness of official statistics, and good practice in relation to official statistics.

The Statistics Authority has two main functions:

1. oversight of the Office for National Statistics (ONS) – the executive office of the Authority;
2. independent scrutiny (monitoring and assessment) of all official statistics produced in the UK.

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## NATIONAL STATISTICS STATUS

National Statistics status means that official statistics meet the highest standards of trustworthiness, quality and public value.



All official statistics should comply with all aspects of the *Code of Practice for Official Statistics*. They are awarded National Statistics status following an assessment by the Authority's regulatory arm. The Authority considers whether the statistics meet the highest standards of Code compliance, including the value they add to public decisions and debate.

It is a producer's responsibility to maintain compliance with the standards expected of National Statistics, and to improve its statistics on a continuous basis. If a producer becomes concerned about whether its statistics are still meeting the appropriate standards, it should discuss its concerns with the Authority promptly. National Statistics status can be removed at any point when the highest standards are not maintained, and reinstated when standards are restored.

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# 1 Summary of findings

## Introduction

- 1.1 This is one of a series of reports<sup>1</sup> prepared under the provisions of the *Statistics and Registration Service Act 2007*<sup>2</sup>. The Act allows an appropriate authority<sup>3</sup> to request an assessment of official statistics against the *Code of Practice for Official Statistics*<sup>4</sup> in order for them to gain National Statistics status. This report is in response to such a request<sup>5</sup> from the Secretary of State for Health in response to the Statistics Authority's *Monitoring Review: Official Statistics on Patient Outcomes in England*<sup>6</sup>. The report covers the following Patient Reported Outcome Measures (PROMs) statistics produced by the Health and Social Care Information Centre (HSCIC) and reported in:
- *Provisional Monthly Patient Reported Outcome Measures (PROMs) in England – Headline Figures*<sup>7</sup> (*PROMs Headlines*)
  - *Provisional Monthly Patient Reported Outcome Measures (PROMs) in England – Quarterly Report*<sup>8</sup> (*PROMs Provisional*)
  - *Finalised Patient Reported Outcome Measures (PROMs) in England*<sup>9</sup> (*PROMs Final*)
- 1.2 This report forms part of a group of assessments of patient outcomes statistics produced by HSCIC, NHS England and the Care Quality Commission (CQC): the NHS Outcomes Framework Indicators, Summary Hospital-level Mortality Indicators, Patient Experience, and Patient Safety Incident statistics.
- 1.3 This report was prepared by the Authority's Assessment team, and approved by the Regulation Committee on behalf of the Board of the Statistics Authority, based on the advice of the Director General for Regulation.

## Decision concerning designation as National Statistics

- 1.4 The Authority judges that the statistics covered by this report do not fully comply with the *Code of Practice for Official Statistics* in the ways summarised in paragraph 1.12. The Authority judges that the statistics published in *PROMs Provisional* and *PROMs Final* cannot be designated as National Statistics until the Authority has confirmed that appropriate actions have been taken by HSCIC to meet the Requirements listed in paragraph 1.12. HSCIC is expected to report its completed actions to the Authority by November 2015.

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<sup>1</sup> <http://www.statisticsauthority.gov.uk/assessment/assessment-reports/index.html>

<sup>2</sup> [http://www.opsi.gov.uk/Acts/acts2007/pdf/ukpga\\_20070018\\_en.pdf](http://www.opsi.gov.uk/Acts/acts2007/pdf/ukpga_20070018_en.pdf)

<sup>3</sup> Subsection 12(7) of the Act defines 'appropriate authority' as Ministers of the Crown, Scottish Ministers, Welsh Ministers, Northern Ireland departments or the National Statistician

<sup>4</sup> <http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html>

<sup>5</sup> <http://www.statisticsauthority.gov.uk/reports---correspondence/correspondence/letter-from-rt--hon--jeremy-hunt-mp-to-sir-andrew-dilnot-170314.pdf>

<sup>6</sup> <http://www.statisticsauthority.gov.uk/assessment/monitoring/monitoring-reviews/monitoring-review-1-2014---official-statistics-on-patient-outcomes-in-england.pdf>

<sup>7</sup> <http://www.hscic.gov.uk/catalogue/PUB16282>

<sup>8</sup> <http://www.hscic.gov.uk/catalogue/PUB15726>

<sup>9</sup> <http://www.hscic.gov.uk/catalogue/PUB14574>

- 1.5 HSCIC has informed the Assessment team that it has started to implement the Requirements listed in paragraph 1.12. The Authority welcomes this.
- 1.6 The Authority recognises HSCIC's efforts to be transparent by publishing *PROMs Headlines* each month. However, the Authority judges (for reasons set out in more detail in Section 3) that the regular investment that would be required to deliver these statistics to National Statistics standards is not currently justified by a demonstrated user need. *PROMs Headlines* cannot be designated National Statistics until such time as this need is evidenced. We encourage HSCIC to consider whether *PROMs Headlines* might helpfully continue to be published as official statistics or management information.

### **Summary of strengths and weaknesses**

- 1.7 PROMs are still in their infancy, with only four annual cycles completed. HSCIC is producing the statistics as part of a regular cycle, using an increasingly well-established data collection framework, but needs to have a greater oversight of the end-to-end process for producing the statistics.
- 1.8 HSCIC does not provide sufficient clarity about the role of Head of Profession for Statistics in decisions about the methods for producing PROMs and the content of the statistical reports.
- 1.9 HSCIC has been making improvements to the commentary that it presents alongside the statistics, and has developed some helpful interactive data tools for users. HSCIC needs to do more to aid user interpretation of the statistics, to set them in the context of other patient outcomes statistics, and to illustrate their potential uses.
- 1.10 HSCIC has effective engagement with the main users of PROMs in NHS England but, despite some efforts, the PROMs team has little direct engagement with users outside of the NHS.

### **Detailed recommendations**

- 1.11 The Assessment team identified some areas where it felt that HSCIC should improve the production and presentation of PROMs. Those which are essential for HSCIC to address in order to strengthen its compliance with the *Code* and to enable designation as National Statistics are listed – as Requirements – in paragraph 1.12, alongside a short summary of the key findings that led to each Requirement being made. Other recommended changes, which the Assessment team considers would improve the statistics and the service provided to users but which are not formally required for their designation as National Statistics, are listed – as Suggestions – in paragraph 1.13.

### **Requirements for designation as National Statistics**

- 1.12 This paragraph includes those improvements that HSCIC is required to make in respect of its PROMs in order to fully comply with the *Code of Practice for Official Statistics*, and to enable designation as National Statistics.

Finding	Requirement	
<p>PROMs are in their relative infancy, and their uses and applications – within the context of other patient outcome statistics – are still being established. HSCIC has an important role to play in understanding and conveying those uses; also to learn from early user experiences to improve the statistics. HSCIC should:</p>	<p><b>1</b></p>	<p>a) Develop a thorough understanding of the range of potential uses of PROMs by: commissioners; trusts; clinicians including surgeons and General Practitioners; and patient representative organisations and publish information about the types of decisions that they have informed, including providing context for users about how they can be used in conjunction with other patient outcomes statistics</p> <p>b) Develop a user engagement strategy and outline clearly how it will continue to strengthen its ongoing dialogue with users of PROMs</p> <p>c) Publish the information that it has gathered about users' experiences of the statistics and explain how it is responding to what it has learned</p> <p>(para 3.4).</p>
<p>HSCIC does not publish any information about the scale and impact of revisions to these statistics. HSCIC should:</p>	<p><b>2</b></p>	<p>Publish information about the scale and impact of revisions alongside the statistics (para 3.8).</p>
<p>PROMs methods are signed off by HSCIC's Indicator Assurance Service (IAS), which provides some level of confidence in the independence of the statistics, but it is not clear that HSCIC statisticians feel empowered to implement their responsibilities for decision making in respect of the <i>Code</i>. HSCIC should:</p>	<p><b>3</b></p>	<p>a) Publish information that clearly demonstrates how it ensures that the Head of Profession for Statistics has the sole responsibility for deciding on the statistical methods, standards and procedures for producing PROMs, and on the content and timing of releases</p> <p>b) Publish a summary of the findings and decisions of the Indicator Assurance Service in respect of PROMs alongside the statistics and explain to users how they can locate the more detailed records, including the meeting papers of both the Methodology Review Group and the Indicator Governance Board, on the Indicator Assurance Service Repository</p> <p>c) Clarify for users the future arrangements for assuring the PROMs methods</p>



		(para 3.13).
HSCIC publishes some helpful information about methods and quality but could do more to draw out the strengths and limitations of the statistics. Also, HSCIC does not present sufficient information about its assurance arrangements. HSCIC should:	<b>4</b>	Update its published methods and quality information for PROMs to: <ul style="list-style-type: none"> <li>a) Provide a clear summary of the strengths and limitations of the statistics in relation to their use</li> <li>b) Present more complete information about potential sources of error and bias</li> </ul> (para 3.15).
	<b>5</b>	Outline the data assurance arrangements for PROMs, taking into consideration the Authority's <i>Administrative Data Quality Assurance Toolkit</i> (para 3.19).
Users find it difficult to interpret PROMs and to draw any meaningful conclusions from them. HSCIC should:	<b>6</b>	Improve the commentary in <i>PROMs Provisional</i> and <i>PROMs Final</i> so that it aids users' interpretation of the statistics by: <ul style="list-style-type: none"> <li>a) providing plain language descriptions and contextual information about PROMs</li> <li>b) presenting a narrative that helps users to draw meaningful conclusions from the analysis presented</li> <li>c) setting PROMs against the range of available patient outcomes statistics</li> <li>d) doing more to interpret the patterns in the data including over time, and in relation to independent providers</li> </ul> As part of meeting this requirement, HSCIC should consider the points detailed in annex 1 and annex 2. To maximise value from this work it is important that HSCIC present PROMs within the context of statistics on patient outcomes more widely. In doing so, we suggest that HSCIC work with DH and NHS England, and with other data provider bodies as relevant, to identify the operational and policy issues that affect PROMs and publish helpful explanatory information about wider findings alongside its own statistics. (para 3.22).
Information about PROMs is published in many different places and HSCIC could help users	<b>7</b>	Publish prominent information alongside the statistics about what PROMs information is published, where and when, in order to improve accessibility and better support analysis and re-use of the statistics (para

with better signposting. HSCIC should:		3.24).
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### Suggestions for extracting maximum value from the statistics

1.13 This paragraph includes some suggestions for improvement to HSCIC’s PROMs, in the interest of the public good. These are not formally required for designation, but the Assessment team considers that their implementation will improve public confidence in the production, management and dissemination of official statistics.

We suggest that HSCIC:

1	Work with users and publish case studies that demonstrate the potential applications of PROMs, and illustrate how to avoid their misuse (para 3.4).
2	Consider whether the NHS Outcomes Framework indicator produced from PROMs might helpfully be updated earlier based on <i>PROMs Provisional</i> for the reference year, and then later revised (para 3.7).
3	a) Explore with NHS England the feasibility of becoming members of the PROMs Advisory Group b) Encourage NHS England to publish the meeting papers for this group (para 3.13).
4	Consider publishing the information about what PROMs information is available together with the information about users and uses (para 3.24).
5	Continue to consult users about the dissemination of these statistics, provide regular updates to users about the development of the Indicator Portal, and report on the progress made (para 3.24).

## 2 Subject of the assessment

2.1 Patient Reported Outcome Measures (PROMs) statistics are produced by the Health and Social Care Information Centre (HSCIC), an executive non-departmental public body sponsored by the Department of Health (DH) that acts as the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care in England.

### Patient Outcomes Review and the Francis Inquiry

2.2 Following publication of the *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*<sup>10</sup> (chaired by Robert Francis QC) in February 2013, the Authority conducted an independent review of patient outcome statistics in England to consider the extent to which the public could more readily use these statistics. In its report, *Monitoring Review: Official Statistics on Patient Outcomes in England*<sup>11</sup> (*Patient Outcomes Review*) which was published on 7 February 2014, the Authority recommended that the patient outcomes statistics be assessed against the *Code of Practice*. The Secretary of State for Health requested the assessment of HSCIC's official PROMs statistics against the *Code* in response to that recommendation.

2.3 In addition to recommending the assessment of seven sets of official patient outcomes statistics, most of which are covered by the programme of assessments outlined in paragraph 1.1.2 of this report<sup>12</sup>, *Patient Outcomes Review* makes other recommendations pertinent to this group of patient outcomes assessments. The Authority:

- sees a vital need for HSCIC and NHS England to disseminate consistent patient outcome statistics from all publicly funded healthcare providers (whether NHS or independent sector) and, in the interim, to state clearly whether the current statistics do so (Recommendation 2, paragraph 34)
- recommends that HSCIC and NHS England engage closely with expert users such as in third sector organisations with a view to improving the clarity and accessibility of current patient outcome statistics for less-expert users (Recommendation 3, paragraph 46)
- recommends that: HSCIC, NHS England, and CQC further research and publish the views of a wide range of users about their needs in respect of: (a) ensuring that the presentation of relevant statistics is accessible, clear and at a level of detail that supports their further use; and (b) extending the range of patient outcome statistics to address currently unmet needs (Recommendation 5, paragraph 52)

2.4 Specifically in respect of PROMs, *Patient Outcomes Review* notes user interest in more types of patient-reported outcomes by speciality, including PROMs after surgery for cancer. All of the points raised by *Patient Outcomes Review* are considered as part of Section 3 of this report.

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<sup>10</sup> <http://www.midstaffpublicinquiry.com/report>

<sup>11</sup> See footnote 6

<sup>12</sup> Decisions about the timing of assessment by the Statistics Authority of NHS Safety Thermometer: Patient Harms and Harm Free Care and Friends and Family Test are pending

## Published PROMs

- 2.5 PROMs measure health gain in patients in England undergoing four elective procedures – hip replacement, knee replacement, varicose vein and groin hernia surgery. For each procedure, all patients are asked to complete two general measures, the EQ-5D™ Index<sup>13</sup> and the EQ VAS, both before and after their surgery. Patients receiving hip replacements, knee replacement and varicose vein surgery are also asked questions specifically tailored to their condition to derive the Oxford Hip Score<sup>14</sup>, Oxford Knee Score<sup>15</sup> and the Aberdeen Varicose Vein Questionnaire. All of these measures are licensed questions and their continued use is dependent on NHS England maintaining the licence. The measures are described in Annex 3.
- 2.6 HSCIC publishes PROMs monthly, quarterly and annually:
- *Provisional Monthly Patient Reported Outcome Measures (PROMs) in England – Headline Figures*<sup>16</sup> (*PROMs Headlines*) – presents the headline indicators for each procedure and is updated each month on a cumulative basis (up to 12 months). HSCIC presents indicators for each of the two years for which provisional statistics are being published. Each measure is published only when HSCIC determines that sufficient data are available (see Figure 1)
  - *Provisional Monthly Patient Reported Outcome Measures (PROMs) in England – Quarterly Report*<sup>17</sup> (*PROMs Provisional*) – presents the headline indicators for each procedure and is updated each quarter on a cumulative basis for each of the two years for which provisional statistics are being published. The quarterly headlines are supplemented by special topics<sup>18</sup> that analyse a specific aspect of the data in more detail; a data pack; and when sufficient data are available for 12 months, an interactive map<sup>19</sup> and a score comparison dataset<sup>20</sup> that allow users to examine local and anonymised patient record-level data
  - *Finalised Patient Reported Outcome Measures (PROMs) in England*<sup>21</sup> (*PROMs Final*) – presents the finalised statistics for a year in a statistical report and is supplemented by similar data and tools as *PROMs Provisional*. PROMs are finalised approximately 17 months after the end of the reference year

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<sup>13</sup> Any and all copyrights in the EQ-5D™ questions, their order, layout and images vest in the EuroQol Group. The EuroQol Group reserves all rights. © 1992 EuroQol Group. EQ-5D™ is a trademark of the EuroQol Group: <http://www.euroqol.org/>

<sup>14</sup> Any and all copyrights in the Oxford Hip Score and Oxford Knee Score questions, their order and layout vest in Isis Innovation Limited. Isis Innovation Limited reserves all rights. © 1996 Isis Innovation: <http://isis-innovation.com/health-outcomes/patient-reported-outcome-measures/>

<sup>15</sup> See footnote 14

<sup>16</sup> <http://www.hscic.gov.uk/catalogue/PUB16282>

<sup>17</sup> <http://www.hscic.gov.uk/catalogue/PUB15726>

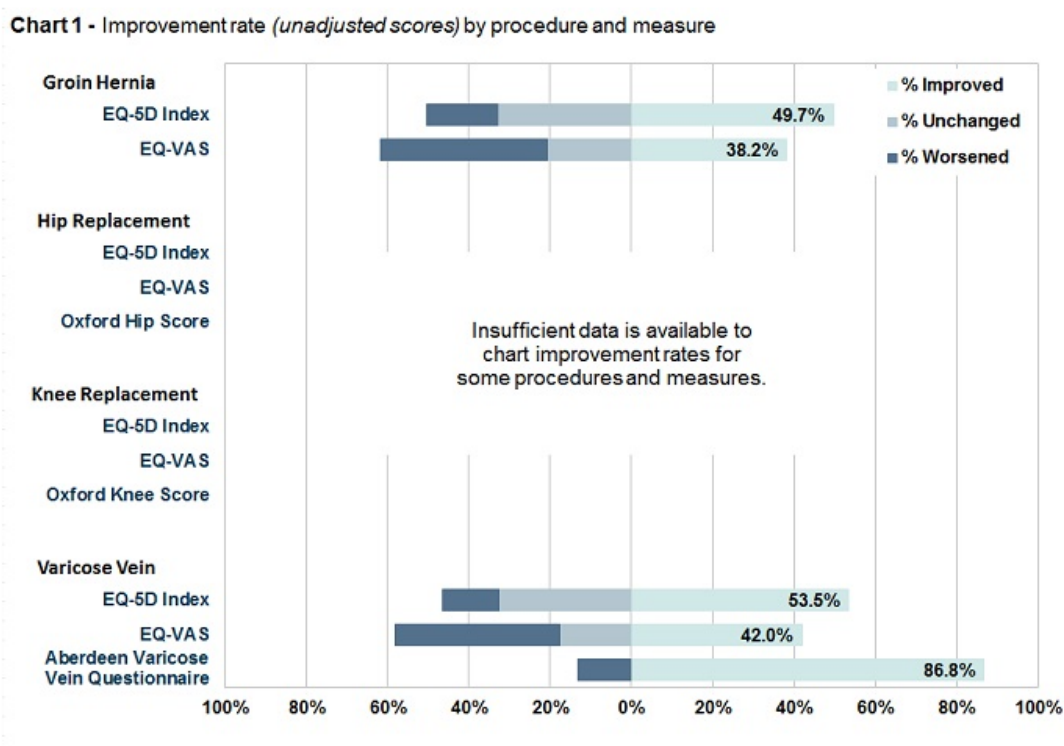
<sup>18</sup> <http://www.hscic.gov.uk/catalogue/PUB15841>

<sup>19</sup> [http://systems.hscic.gov.uk/maps/proms/20141114\\_1314/index.htm](http://systems.hscic.gov.uk/maps/proms/20141114_1314/index.htm)

<sup>20</sup> <http://www.hscic.gov.uk/catalogue/PUB15722/prov-proms-eng-apr13-mar14-scor-comp.xlsx>

<sup>21</sup> <http://www.hscic.gov.uk/catalogue/PUB14574>

**Figure 1: Provisional PROMs for eligible procedures carried out from 1 April 2014 to 31 July 2014, as published by HSCIC on 11 December 2014<sup>22</sup>**



Source: HSCIC

## Users and uses of PROMs

2.7 PROMs and the data that underpin them have a range of current uses and potential applications including:

- In 2010, in its White Paper: *Equity and excellence: Liberating the NHS*<sup>23</sup>, the UK Government set out its aim of measuring improvements in health outcomes to encourage improvements in quality. DH set up the NHS Outcomes Framework<sup>24</sup> (NHS OF) to provide national-level accountability for the delivery of healthcare. PROMs provide information for an indicator under Domain 3: helping people to recover from episodes of ill-health or following injury<sup>25</sup> – Indicator 3.1 ‘total health gain as assessed by patients for elective procedures’. The indicator is based on values for the national figure as well as all breakdowns of the EQ-5D<sup>TM</sup> index<sup>26</sup> and HSCIC updates this annually approximately three months after *PROMs Final* is published. The NHS OF statistics are assessed in one of this concurrent series of patient outcome assessments

<sup>22</sup> <http://www.hscic.gov.uk/catalogue/PUB15941>

<sup>23</sup> <https://www.gov.uk/government/publications/liberating-the-nhs-white-paper>

<sup>24</sup> <https://www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014>

<sup>25</sup> <http://www.hscic.gov.uk/nhsf>

<sup>26</sup> Values for the national figure as well as all breakdowns of the EQ-5D<sup>TM</sup> index case-mix adjusted average health gain are sourced fully calculated. The total health gain at national level is calculated by multiplying the average health gain with the number of eligible episodes for each procedure

- Each NHS healthcare provider, including those within the independent sector, publishes Quality Accounts<sup>27</sup> – annual reports about the quality of services provided to patients. DH requires NHS trusts to publish, in relation to 15 mandatory indicators<sup>28</sup> (including PROMs): their performance against the indicators for at least the last two reporting periods; and a supporting commentary to explain any variation from the national average and any steps taken or planned to improve quality
- PROMs inform the payment of Best Practice Tariffs<sup>29</sup> designed by DH to incentivise best practice in the clinical pathways of patients undergoing elective primary total hip and knee replacements
- The Beyond Compliance Advisory Group uses data, including PROMs, to monitor the early performance of new brands of hip and knee replacements, in order that any potential problems relating to a product or its surgical use can be identified before large numbers have been implanted<sup>30</sup>
- PROMs dashboards provided by HSCIC, together with record-level data, are analysed by individual clinicians, specialities, trusts and commissioners to identify the drivers of patient outcomes and to consider how that information might inform treatments and improvement strategies
- The North East Quality Observatory System summarises the key PROMs findings to inform providers and clinicians within the North East to examine what difference NHS surgical interventions can make to the health and wellbeing of individuals<sup>31</sup>
- A BBC Newsnight feature on 10 December 2014<sup>32</sup> used PROMs data to compare patient outcomes from the public and private provision of services

2.8 HSCIC told us that PROMs is the first major collection of hospital outcome data at national level. It is an England only collection and currently there are no corresponding statistics for Wales, Scotland or Northern Ireland. Other countries that are developing PROMs include the USA and Sweden, though the models in those countries have placed the primary focus on using the information about individuals to plan individual patients' clinical care in relation to their health needs, and tracking the impact of care plans on the patient's outcomes. Professor Nick Black, from the London School of Hygiene and Tropical Medicine (LSHTM) and Chair of the National Advisory Group for Clinical Audit and Enquiries, discusses this approach, together with the potential applications and limitations of PROMs, in an article for the British Medical Journal: *Patient reported outcome measures could help transform*

<sup>27</sup> A Quality Account is a report about the quality of services by an NHS healthcare provider. The reports are published annually by each healthcare provider, including the independent sector, and are available to the public. The Health Act 2009 requires all NHS providers of NHS services in England (except those who have fewer than 50 full-time employees and provide under £130,000 of NHS services) to produce a Quality Account to provide information about the quality of those services.

<sup>28</sup> <https://indicators.ic.nhs.uk/webview/>

<sup>29</sup> <https://www.gov.uk/government/publications/national-tariff-payment-system-2014-to-2015>

<sup>30</sup> <http://www.beyondcompliance.org.uk/WhatItMeans/ForSurgeons.aspx>

<sup>31</sup>

[http://www.neqos.nhs.uk/publications/1209/Patient\\_Reported\\_Outcome\\_Measures\\_\(PROMs\)\\_in\\_the\\_North\\_East\\_of\\_England\\_%C3%A2%EF%BF%BD%EF%BF%BD\\_January\\_2013\\_Update](http://www.neqos.nhs.uk/publications/1209/Patient_Reported_Outcome_Measures_(PROMs)_in_the_North_East_of_England_%C3%A2%EF%BF%BD%EF%BF%BD_January_2013_Update)

<sup>32</sup> <http://www.bbc.co.uk/news/health-30426141>

healthcare<sup>33</sup> published in January 2013. LSHTM provides information about a range of academic studies that relate to PROMs<sup>34</sup>.

## History and governance

- 2.9 The agenda for the development of PROMs measures grew originally from the Lord Darzi's *High quality care for all: NHS Next Stage Review final report*<sup>35</sup> published in June 2008, which highlighted a need for measures of clinical outcomes and the requirement by law for healthcare providers working for, or on behalf of, the NHS to publish Quality Accounts. Early work began with the Patient Outcomes in Surgery (POiS) audit, which was subsequently replaced by PROMs. PROMs data have been collected in England since April 2009 and HSCIC published the first experimental statistics in 2010. Following a review by the Head of Profession for Statistics, HSCIC removed the experimental label in January 2012, having determined that the structure, format and content of PROMs were now reasonably stable.
- 2.10 NHS England sets the strategic direction for the national PROMs programme, having taken over responsibility from DH in April 2013. NHS England develops any new measures, and retains responsibility for the methods used to produce them. NHS England commissions HSCIC to publish the official statistics and to make the data available on-line. Any new measures that NHS England decides to implement as official statistics are reviewed and signed off by HSCIC's Indicator Assurance Service<sup>36</sup>. Currently, only the measures for the four elective procedures described in paragraph 2.5 have reached this stage. The governance approach is discussed in further detail in Section 3.
- 2.11 The Government White Paper: *Equity and excellence: Liberating the NHS* envisaged an increase in the scope and coverage of PROMs in future, starting from April 2011, though in an article for the British Medical Journal in December 2014 John Appleby, chief economist at the King's Fund, observed that progress appeared to have stalled<sup>37</sup>.

## Data sources

- 2.12 Data collection is managed by NHS England. PROMs questionnaire services are de-centralised and contracted suppliers must be accredited and hold a current Information Governance Toolkit<sup>38</sup> certificate. Since 1 April 2009, providers of the four key elective procedures have been required to collect and report PROMs, under the terms of the NHS Standard Contract<sup>39</sup>. The contracted suppliers are required to make guidance available to the providers that they work with about how to manage the data collection process. HSCIC routinely links the data collected with Hospital Episode Statistics<sup>40</sup> (HES)

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<sup>33</sup> BMJ 2013;346:f167: <http://researchonline.lshtm.ac.uk/612296/1/bmj.f167.full.pdf>

<sup>34</sup> <http://proms.lshtm.ac.uk/publications/>

<sup>35</sup> [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085825](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825)

<sup>36</sup> <http://www.hscic.gov.uk/article/1674/Indicator-Assurance-Service>

<sup>37</sup> <http://www.kingsfund.org.uk/publications/articles/why-has-proms-programme-stalled>

<sup>38</sup> <https://www.igt.hscic.gov.uk/>

<sup>39</sup> <http://www.england.nhs.uk/nhs-standard-contract/15-16/>

<sup>40</sup> <http://www.hscic.gov.uk/hes>

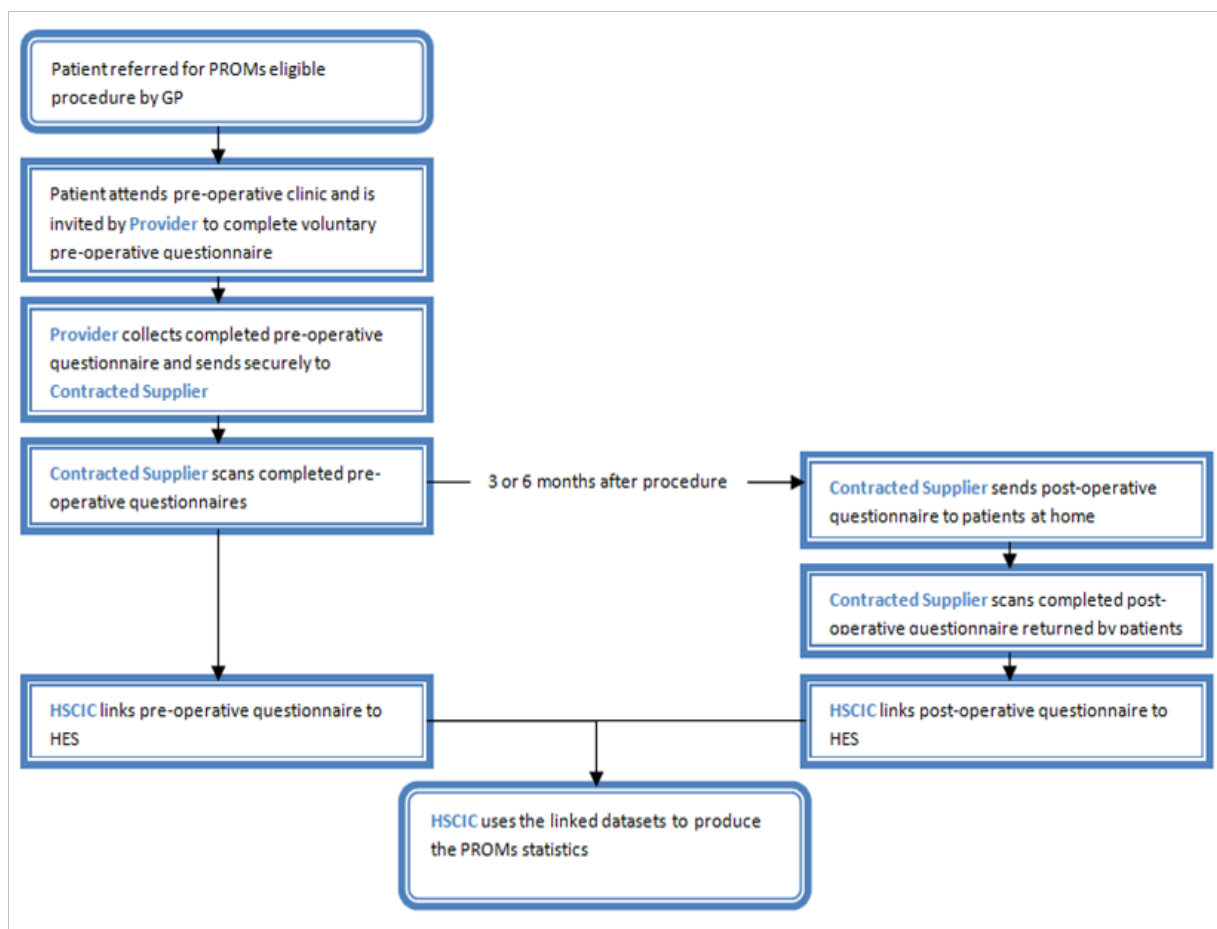


episode-level administrative records. Figure 2 presents a process diagram.

## Open data and costs

2.13 HSCIC publishes: *PROMs Headlines* in html format only; *PROMs Provisional* in html format with supplementary data in CSV format; and *PROMs Final* in html and PDF format with data in Excel and CSV formats. This equates to a level of two stars for *PROMs Headlines* and three stars for *PROMs Provisional* and *PROMs Final* under the Five Star Scheme that forms part of the Open Standards Principles proposed in the *Open Data White Paper: Unleashing the Potential*<sup>41</sup> and adopted as UK government policy in November 2012<sup>42</sup>. Five stars represents the highest star rating within the Scheme.

**Figure 2: PROMs data collection process**



Source: Adapted from HSCIC diagram<sup>43</sup>

2.14 HSCIC also publishes interactive maps, and makes the following information available on a restricted basis:

<sup>41</sup> [http://data.gov.uk/sites/default/files/Open\\_data\\_White\\_Paper.pdf](http://data.gov.uk/sites/default/files/Open_data_White_Paper.pdf)

<sup>42</sup> <https://www.gov.uk/government/publications/open-standards-principles/open-standards-principles>

<sup>43</sup> Figure 1: [http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMs\\_Guide\\_V8.pdf](http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMs_Guide_V8.pdf)



- Record-level data (anonymised, dependent on permissions) via an Extract Service – access is managed through HSCIC’s Data Access Request Service<sup>44</sup> and data are uploaded only in response to a specific request
- Identified record-level data for secure download by the hospital that performed the procedure – this is a subscription service and not in the public domain

2.15 HSCIC estimates that its own costs of producing PROMs statistics are approximately £170,000 per year. This estimate excludes the cost to the NHS of data collection.

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<sup>44</sup> <http://www.hscic.gov.uk/dars>

### 3 Assessment findings

#### Meeting User Needs and User engagement

3.1 Following the reorganisation of the NHS<sup>45</sup> in England in 2012, HSCIC assumed a wider range of responsibilities for collecting, analysing and presenting national health and social care data. It ran a consultation on its publication strategy<sup>46</sup> during September and October 2014. With this strategy, HSCIC is seeking to align with its stakeholders' priorities and to better meet the public's need for information on health and care. It published a response<sup>47</sup> to the consultation in December 2014 and identified several actions, including: establishing a Publications Advisory Board; developing a process of internal and external peer review to improve statistical commentary and content; and seeking to improve the coherence and presentation of health and care statistics across organisations in England, as well as pan-UK comparisons. The Authority welcomes the actions planned by HSCIC to improve its understanding of the wider user needs for health and care statistics and encourages it to work with other health statistics producers, to deliver these actions in a timely way.

3.2 In early 2014 HSCIC invited users of its website to complete a survey about their experiences of using its statistics. HSCIC used the outcomes of this survey as part of developing its publication strategy, but the statistics team told us that it is also reviewing the 77 responses from users who said that they use PROMs. These included: national organisations such as DH, NHS England and Monitor; healthcare commissioners and providers including clinicians; local authorities; charities; academics; and researchers. The statistics team said that it has attempted to contact a sample of users for follow-up discussions, though it has had limited success to date. The statistics team told us that it has also:

- had feedback from a telephone survey of NHS providers initiated by one of its contracted suppliers, about how they use PROMs and supporting data
- attended events like the annual King's Fund PROMs Research Conference<sup>48</sup> to demonstrate its interactive maps and to seek feedback about potential special topics to include in *PROMs Provisional*

Clinicians and patient representatives are also members of the PROMs Advisory Group that meets every four months to advise NHS England on the strategic direction of the national PROMs programme – though HSCIC is not a member of this group.

3.3 While different avenues of engagement with users seem to be increasingly explored for PROMs, some of this activity is at arm's length from the statistics team. During the course of this assessment HSCIC has demonstrated a good knowledge of the different uses of PROMs but it publishes only a brief

<sup>45</sup> <http://www.nhs.uk/NHSEngland/thenhs/about/Pages/nhsstructure.aspx>

<sup>46</sup> [http://www.hscic.gov.uk/media/15765/The-Publication-Strategy/pdf/HSCIC\\_publication\\_strategyv1\\_0.pdf](http://www.hscic.gov.uk/media/15765/The-Publication-Strategy/pdf/HSCIC_publication_strategyv1_0.pdf)

<sup>47</sup> [http://www.hscic.gov.uk/media/15767/Outcome-to-the-Consultation/pdf/HSCIC\\_Publication\\_Strategy\\_Consultation\\_Questionnaire\\_Outcome.pdf](http://www.hscic.gov.uk/media/15767/Outcome-to-the-Consultation/pdf/HSCIC_Publication_Strategy_Consultation_Questionnaire_Outcome.pdf)

<sup>48</sup> <http://www.kingsfund.org.uk/events/patient-reported-outcome-measures-proms-research-conference-1>

summary about the users and uses of these statistics as part of its Methods Guide. HSCIC does not communicate alongside the statistics how it is responding to information about users' experiences. PROMs are: still in their infancy; relatively complex in nature and so open to misuse; and part of what users have described to us as an overwhelming range of patient outcomes statistics published by HSCIC and other organisations. As such, we consider that HSCIC could do a great deal to enhance the future potential of the statistics by explaining how they are used; illustrating the range of potential applications and associated benefits for users; and seeking to continually learn about how the user experience might be improved to better inform decisions.

3.4 As part of the designation as National Statistics, HSCIC should:

- a) develop a thorough understanding of the range of potential uses of PROMs by: commissioners; trusts; clinicians including surgeons and General Practitioners; and patient representative organisations and publish information about the types of decisions that they have informed, including providing context for users about how they can be used in conjunction with other patient outcomes statistics
- b) develop a user engagement strategy and outline clearly how it will continue to strengthen its dialogue with users of PROMs
- c) publish the information that it has gathered about users' experiences of the statistics and explain how it is responding to what it has learned<sup>49</sup>  
(Requirement 1).

In meeting this requirement, we suggest that HSCIC work with users and publish case studies that demonstrate the potential applications of PROMs, and illustrate how to avoid their misuse.

### Timetabling to account for user needs

3.5 HSCIC publishes *PROMs Headlines* every month, *PROMs Provisional* every quarter and *PROMs Final* annually (17 months after the end of the reference year). HSCIC uses *PROMs Final* for updating Indicator 3.1 of the NHS OF indicators. *PROMs Headlines* and *PROMs Provisional* are published on a cumulative basis (up to 12 months).

3.6 HSCIC told us that it does not publish measures for *PROMs Headlines* until it has sufficient numbers of records – HSCIC told us that it has set an arbitrary threshold of 200 pairs of linked records before a measure can be published. As the headline statistics rely on the return of post-operative questionnaires which are not issued until three to six months after the procedure and take some time to be returned, it can take several months before HSCIC is in a position to publish (see Figure 1). The published measures change very little from month to month. HSCIC does not publish any data or commentary in support of *PROMs Headlines* and users indicated to us, as part of this Assessment, that these headline statistics are not widely used. We understand that HSCIC publishes the statistics to offer transparency, making available monthly management information to each provider on a restricted basis in the form of

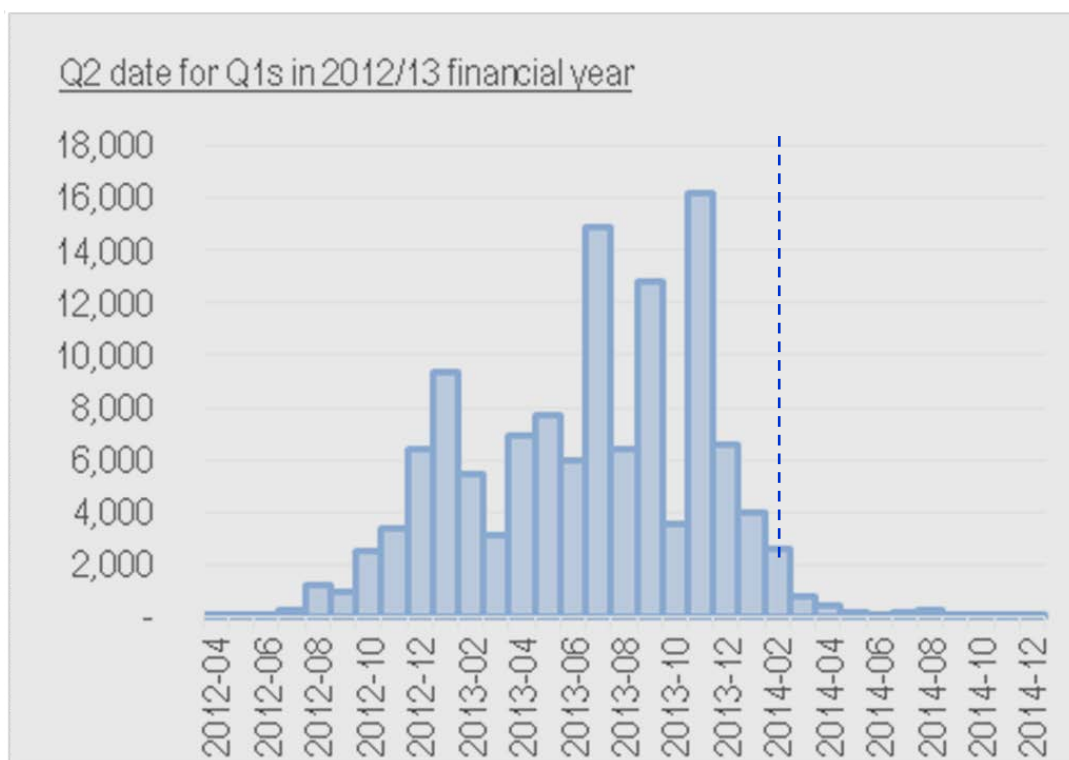
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<sup>49</sup> In relation to Principle 1, Practices 1, 2 and 5 of the *Code of Practice*

dashboards and record-level data to academic researchers through a restricted extract service. However, we judge that the regular investment that would be required to deliver these statistics to National Statistics standards each month is not currently justified by a demonstrated user need. We encourage HSCIC to consider whether *PROMs Headlines* might helpfully continue to be published as official statistics, or instead released to existing users in the form of management information. We do not consider them further as part of the Assessment.

- 3.7 HSCIC told us that *PROMs Final* is published 17 months after the end of the reference year as it seeks to achieve a balance between timeliness and completeness and said that it waits until the drop-off in the numbers of questionnaires returned each month has stabilised – HSCIC provided us with the analysis in Figure 3 to illustrate its decision to close the 2012/13 results in June 2014 for publication in August 2014. While we understand this rationale, and the aim to make as complete a final dataset as possible available in support of the national measures, we suggest that HSCIC consider whether the NHS OF indicator produced from PROMs might helpfully be updated earlier based on *PROMs Provisional* for the reference year, and then later revised.

**Figure 3: HSCIC analysis illustrating the decision to closedown results for 2012/13 in June 2014 – post-operative questionnaires returned**



Source: HSCIC

### Revisions policy

- 3.8 HSCIC publishes information about counts of questionnaires issued, returned and used in the production of PROMs as part of its published Data Quality Notes, so that users have a sense of the additional numbers of records used in the production of each cumulative set of statistics published. However, HSCIC

does not publish any information about the scale and impact of any revisions. As part of designation as National Statistics, HSCIC should publish information about the scale and impact of revisions alongside the statistics<sup>50</sup> (Requirement 2).

### **Governance arrangements – ensuring the independence of PROMs**

3.9 The governance structure for PROMs is outlined in Figure 4. HSCIC told us that NHS England, advised by the PROMs Advisory Group, is responsible for:

- the PROMs strategy for England
- decisions about which areas of healthcare might be best informed by PROMs
- the development, design and piloting of new PROMs
- the methods for producing PROMs – for example, the choice to use EQ-5D<sup>TM</sup> Index and EQ VAS under licence and the use of the case-mix adjustment methods<sup>51</sup>

Pilot studies are generally led by expert academics and clinicians, together with NHS England policy analysts – for example, a current study is testing the feasibility of extending the current elective surgical procedure PROMs programme to patients undertaking elective cardiac revascularisation procedures. HSCIC told us that based on current practice, at the point when NHS England takes the decision to roll out a new measure nationally, HSCIC then advises on the data collection methods and is commissioned by NHS England to publish the official statistics and to make the data available through on-line services. HSCIC also told us that, while it invites ideas from all users for the special topics published with *PROMs Provisional*, it agrees the content and schedule with NHS England. As NHS England is a key user of PROMs we consider that such discussions about topics for analysis are appropriate but are concerned that HSCIC told us that it had in the past taken a decision to temporarily reject a topic of user interest due to internal caution about the sensitivities of the topic. HSCIC assured us that there was no pressure applied by DH or NHS England.

3.10 As the PROMs are indicators used within the NHS Outcome Framework and Quality Accounts, they are assured by HSCIC's Indicator Assurance Service<sup>52</sup> (IAS). The Indicator Governance Board (IGB) approves the suitability of indicators for inclusion in the National Library of Quality Assured Indicators following a critical assessment against set criteria<sup>53</sup> by the Methodology Review Group (MRG). MRG and IGB comprise statistical, methodological and epidemiological experts from within HSCIC and from the wider health and social care system – such as from CQC, NICE, NHS Trust Development

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<sup>50</sup> In relation to Principle 2, Practice 6 of the *Code of Practice*

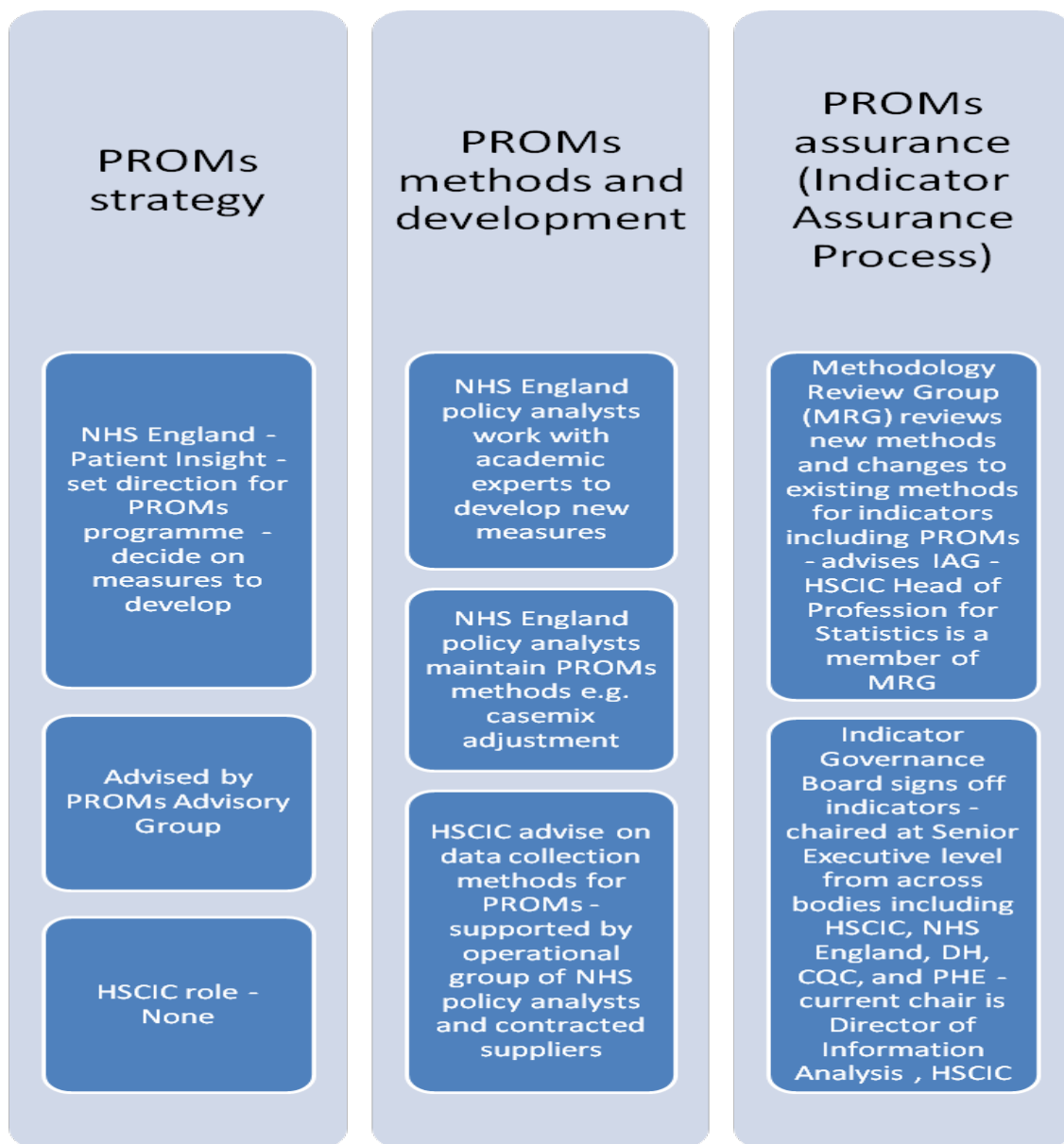
<sup>51</sup> All indicators should, as far as possible, be adjusted for risk factors and other characteristics of patients – for example age, gender beyond the control of healthcare systems. Not making these adjustments could lead to unfair comparisons when it comes to assessing performance relative to other organisations: <http://www.england.nhs.uk/statistics/statistical-work-areas/proms/>

<sup>52</sup> See footnote 36

<sup>53</sup> [http://www.hscic.gov.uk/media/14624/Criteria-and-considerations-used-to-determine-a-quality-indicator/pdf/Criteria\\_and\\_considerations\\_used\\_to\\_determine\\_a\\_quality\\_indicator.pdf](http://www.hscic.gov.uk/media/14624/Criteria-and-considerations-used-to-determine-a-quality-indicator/pdf/Criteria_and_considerations_used_to_determine_a_quality_indicator.pdf)

Agency, Health Education England and Monitor. MRG's role is to consider the methods for proposed and existing indicators, checking the construction and meaningfulness of the indicators, the suitability of the data sources and the robustness of the data in relation to the purpose. The Head of Profession for statistics (HoP) for HSCIC is a member of MRG. HSCIC stores documentation reviewed by MRG and IGB within the IAS Repository. The IAS Repository can be accessed on request but users need to first register with HSCIC – HSCIC told us that it is reviewing this arrangement to provide more open access.

**Figure 4: PROMs Governance**



Source: produced by Assessment team

3.11 *NHS Outcomes Framework 2015/16*<sup>54</sup>, published by DH, sets out plans to 'Consolidate the existing Patient Reported Outcomes Measures (PROMs)

<sup>54</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/385749/NHS\\_Outcomes\\_Framework.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385749/NHS_Outcomes_Framework.pdf)

indicators 3.1.i-v from five into two: physical and mental health related procedures.<sup>55</sup> The technical annex<sup>56</sup> states that:

‘It was always the intention that the suite of elective interventions covered by indicator 3.1 would increase over time to include future PROMs, thereby encouraging NHS England to make progress in developing PROMs for other elective procedures. In order to reduce the number of potential sub-indicators, total health gain from PROMs for individual procedures will be aggregated. An analysis of whether it is more appropriate to use condition-specific measures as the basis for measuring the outcome gain from interventions or the current EQ5D measures will be conducted in 2015.’

- 3.12 Users told us as part of this assessment that they would welcome PROMs being extended to cover other procedures, and also that they consider that the existing PROMs condition-specific measures such as the Oxford Hip Score should be used in the NHS OF indicator for measuring health gain, rather than focusing only on general well-being measures such as the EQ-5D<sup>TM</sup> Index. These pending changes to the NHS OF indicators do pose some questions – not least, would a single composite indicator for PROMs covering the four (and potentially more) physical health procedures be statistically sound? Also, would each sub-indicator require to be weighted differently and who would be involved in setting weights? However, the IAS process and the role of HSCIC’s HoP on MRG provides some level of assurance of the independence of the choice of NHS OF indicators, and the methods used to produce them. Reflecting on the arrangements described in paragraph 3.9 in respect of PROMs, we consider that HSCIC needs to do more to communicate how it ensures that the HoP has the sole responsibility for deciding on statistical methods, standards and procedures for producing PROMs, and on the content and timing of releases. We also consider that it is important that the HoP, or responsible statistician, is sufficiently engaged with the strategic direction of PROMs to advise NHS England on statistical matters. We encourage the statistics team to feel empowered by the principles of the *Code* to promote its statistical responsibilities in relation to PROMs.
- 3.13 As part of the designation as National Statistics, HSCIC should:
- a) publish information that clearly demonstrates how it ensures that the HoP has the sole responsibility for deciding on the statistical methods, standards and procedures for producing PROMs, and on the content and timing of releases
  - b) publish a summary of the findings and decisions of the IAS in respect of PROMs alongside the statistics and explain to users how they can locate the more-detailed records, including the meeting papers of both MRG and IGB, on the IAS Repository
  - c) clarify for users the future arrangements for assuring the PROMs methods<sup>57</sup> (Requirement 3).

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<sup>55</sup> DH has commissioned researchers at the University of Sheffield to develop a new generic mental health recovery (patient reported) outcome measure. This work is scheduled for completion at the end of 2015.

<sup>56</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/341394/140730\\_Technical\\_Appendix.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/341394/140730_Technical_Appendix.pdf)

<sup>57</sup> In relation to Principle 3, Practice 3 and Principle 4 Practices 1,2 and 3 of the *Code of Practice*



In meeting this requirement, we suggest that HSCIC:

- a) explore with NHS England the feasibility of becoming members of the PROMs Advisory Group
- b) encourage NHS England to publish the meeting papers for this group

### Supporting information about methods and quality

- 3.14 HSCIC publishes a Methods Guide<sup>58</sup> and Data Quality Notes<sup>59</sup> alongside PROMs, together with a Data Dictionary<sup>60</sup>, Frequently Asked Questions<sup>61</sup>, and Video Tutorials<sup>62</sup>. HSCIC updates the Data Quality Notes each time that it publishes the statistics. These Notes provide a summary against the European Statistical System Quality Framework criteria<sup>63</sup>. *PROMs Final* also includes some helpful diagrams in the statistical report to explain the relationship between the PROMs questionnaires and hospital records, and the potential reasons for incomplete records and data linking. HSCIC presents measures of the completeness of the data in the Data Quality Notes and details some 'data quality considerations' in the Methods Guide – including some potential sources of error such as: poorly completed questionnaires; incorrect coding of questionnaires; and difficulties mapping patients to HES. However, information about potential sources of error and bias is not complete – for example, the North East Quality Observatory System identified variation in participation as a significant constraint on using and interpreting PROMs<sup>64</sup>. HSCIC told us that it has published a special topic about the impact of non-response<sup>65</sup> and it is now considering how to mainstream this analysis. HSCIC does not present a clear summary of the strengths and limitations of the statistics in relation to their use. As discussed in paragraphs 3.10 to 3.12, HSCIC does not provide straightforward access to the important information about methods and quality that is held in the IAS Repository, or communicate clearly the stage that PROMs has reached in the IAS process – the specification document<sup>66</sup> on the Indicators Portal says that the quality of PROMs was last assured by the MRG in July 2013 but has not yet been assured by the IAG.
- 3.15 As part of the designation as National Statistics, HSCIC should update its published methods and quality information for PROMs to:
- a) provide a clear summary of the strengths and limitations of the statistics in relation to their use

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<sup>58</sup> [http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMs\\_Guide\\_V8.pdf](http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMs_Guide_V8.pdf)

<sup>59</sup> <http://www.hscic.gov.uk/catalogue/PUB14574/final-proms-eng-apr12-mar13-dat-qual-note-v2.pdf>

<sup>60</sup> [http://www.hscic.gov.uk/media/1361/HES-Hospital-Episode-Statistics-PROMS-Data-Dictionary/pdf/Proms\\_Data\\_Dictionary.pdf](http://www.hscic.gov.uk/media/1361/HES-Hospital-Episode-Statistics-PROMS-Data-Dictionary/pdf/Proms_Data_Dictionary.pdf)

<sup>61</sup> [http://www.hscic.gov.uk/media/1536/PROMs-FAQs/pdf/PROMs\\_FAQs.pdf](http://www.hscic.gov.uk/media/1536/PROMs-FAQs/pdf/PROMs_FAQs.pdf)

<sup>62</sup> <http://www.hscic.gov.uk/proms-userguide>

<sup>63</sup> The European Statistical System Quality Framework has five quality criteria: relevance; accuracy and reliability; timeliness and punctuality; coherence and comparability; accessibility and clarity: <http://ec.europa.eu/eurostat/web/quality/quality-reporting>

<sup>64</sup> See footnote 31

<sup>65</sup> <http://www.hscic.gov.uk/catalogue/PUB16482>

<sup>66</sup> [https://indicators.ic.nhs.uk/download/Outcomes%20Framework/Specification/NHSOF\\_Domain\\_3\\_S\\_V4.pdf](https://indicators.ic.nhs.uk/download/Outcomes%20Framework/Specification/NHSOF_Domain_3_S_V4.pdf)



b) present more complete information about potential sources of error and bias<sup>67</sup>

(Requirement 4).

### Data Quality Assurance (QA)

3.16 In light of the de-designation of police recorded crime statistics in January 2014 (in Assessment report 268), the Authority published<sup>68</sup> a regulatory standard that confirms the quality assurance arrangements that are required for statistics compiled using administrative data to comply with the *Code of Practice*. The *Administrative Data Quality Assurance Toolkit*<sup>69</sup> is the mechanism that the Authority is using to determine compliance in relation to four areas of practice:

- Operational context and administrative data collection
- Communication with data supply partners
- QA principles, standards and checks by data suppliers
- Producers' QA investigations & documentation

3.17 The judgment by statistical producers about the suitability of the administrative data for use in producing official statistics should be pragmatic and proportionate. It should be made in the light of an evaluation of the likelihood of quality issues arising in the data that may affect the quality of the statistics. It should also reflect the nature of the public interest served by the statistics. Statistical producers should determine the types of assurance and documentation required to inform users about the quality assurance arrangements for administrative data.

3.18 We consider that while PROMs is technically a patient survey and participation is voluntary, as every eligible patient is approached to provide information as part of their patient journey, in the current context it has many of the characteristics of an administrative data source, and so accordingly HSCIC should consider the areas of practice in the *Administrative Data Quality Assurance Toolkit*. HSCIC told us that it has some assurance processes in place – for example, sharing Data Quality Dashboards with trusts. The accreditation of data suppliers<sup>70</sup> also provides some level of assurance. However, HSCIC discusses the assurance arrangements for PROMs data only in general terms. As at 11 May 2015, links to information about the data collection processes were broken and HSCIC told us that this is because each of the four contracted suppliers now issues its own guidance. HSCIC does not offer any insight about: the potential impact of different collection arrangements in different hospitals; any differences in practices between public and private providers; the risks associated with the incentives for providers and contracted suppliers that are linked to PROMs; or any shortcomings of data sign off processes.

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<sup>67</sup> In relation to Principle 4, Practice 2 and Principle 8, Practice 1 of the *Code of Practice*

<sup>68</sup> <http://www.statisticsauthority.gov.uk/assessment/monitoring/administrative-data-and-official-statistics/index.html>

<sup>69</sup> <http://www.statisticsauthority.gov.uk/assessment/monitoring/administrative-data-and-official-statistics/quality-assurance-toolkit.pdf>

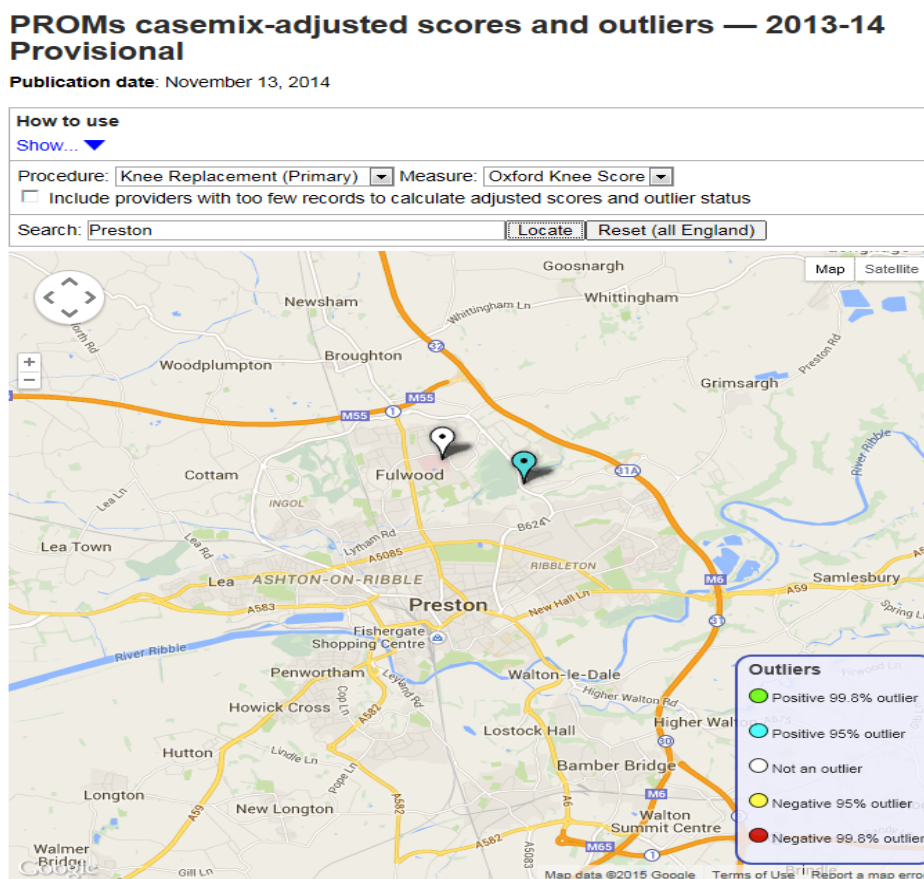
<sup>70</sup> See footnote 38

3.19 As part of the designation as National Statistics, HSCIC should outline the data assurance arrangements for PROMs, taking into consideration the Authority's *Administrative Data Quality Assurance Toolkit*<sup>71</sup> (Requirement 5).

### Presentation of the statistics

3.20 HSCIC presents *PROMs Provisional* with a headline chart, some key facts and helpful interactive tools that allow users to explore the data, including a Google Maps Service (see Figure 5). It also presents different special topics each quarter exploring a particular theme – these are generally produced using finalised data from previous years. *PROMs Final* includes an extended statistical report with detailed commentary, and HSCIC has been working with the National Statistician's Good Practice Team to make improvements. The statistical report sets the context for PROMs by presenting descriptive statistics about the patient profile of those undergoing the different elective procedures. HSCIC offers some good explanations for possible differences – for example: between the rates undergoing procedures per thousand population in urban and rural areas; and differences in the use of day surgery for varicose vein procedures in certain regions.

**Figure 5: Knee replacements (primary) Oxford Knee Score in Preston (illustrative example)**



Source: Extract taken from HSCIC website on 11 February 2015<sup>72</sup>

<sup>71</sup> In relation to Principle 4, Practice 3 of the *Code of Practice*

<sup>72</sup> [http://systems.hscic.gov.uk/maps/proms/20141114\\_1314/index.htm](http://systems.hscic.gov.uk/maps/proms/20141114_1314/index.htm)

3.21 From our own review of PROMs, and reflecting on what users told us as part of this Assessment, key areas for development include:

- The individual measures that form part of PROMs are quite complex and the language is technical. *PROMs Final* provides some information to help users to understand the measures and terminology but *PROMs Provisional* does not
- HSCIC does not present any accompanying narrative in *PROMs Provisional* and the narrative about health gain that accompanies *PROMs Final* is broadly descriptive in nature and mainly focuses on each of the measures in turn – HSCIC does not offer any insight about what the totality of the general well-being and procedure-specific measures might tell us, or indicate for users what weight they might place on the different measures depending on how they are seeking to use the statistics. For example, HSCIC does not offer any explanation about why EQ-5D™ Index is used for the NHS OF, and the procedure-specific measures such as the Oxford Hip Score are not considered in that context. Users told us that they found it difficult to interpret PROMs, or to draw any conclusions from the analysis presented, though the special topics were mentioned as being more insightful
- Users told us that they find the range of patient outcomes statistics available from HSCIC and other organisations potentially overwhelming; users would benefit from HSCIC placing PROMs in their wider context – for example, in relation to other PROMs statistics being developed and other patient experience statistics
- HSCIC has been improving its presentation of the data distributions using funnel diagrams and box-whisker plots<sup>73</sup>. However, the narrative about the organisational-level statistics that HSCIC presents in *PROMs Final* focuses on listing the positive and negative outlier organisations. Now that HSCIC has a few years of data, it could do more to interpret patterns in the statistics over time. HSCIC told us that it is planning a special topic to examine the time series. We welcome this initiative and encourage HSCIC to consider how it could build on this in its regular outputs
- As well as examining trends over time, HSCIC could do more to exploit the detailed PROMs data to offer insight – for example, *Patient Outcomes Review* highlighted the interest in understanding patient outcomes in relation to procedures carried out by NHS and independent providers

3.22 As part of the designation as National Statistics, HSCIC should improve the commentary in *PROMs Provisional* and *PROMs Final* so that it aids users' interpretation of the statistics by:

- a) providing plain language descriptions and contextual information about PROMs
- b) presenting a narrative that helps users to draw meaningful conclusions from the analysis presented
- c) setting PROMs against the range of available patient outcomes statistics

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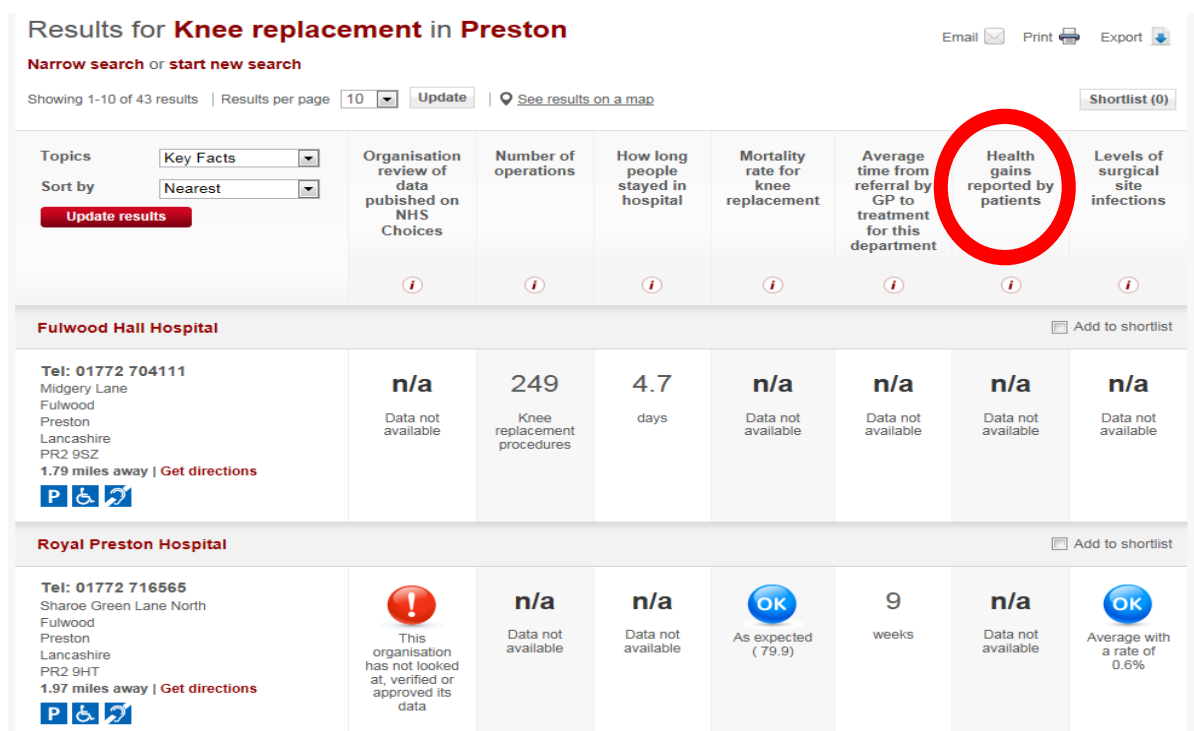
<sup>73</sup> A box-whisker plot shows the minimum and maximum values (ends of the whiskers), interquartile range (length of the box), and median (line through the box)

d) doing more to interpret the patterns in the data including over time, and in relation to independent providers<sup>74</sup>

(Requirement 6).

As part of meeting this requirement, HSCIC should consider the points detailed in annex 1 and annex 2. To maximise value from this work it is important that HSCIC present PROMs within the context of statistics on patient outcomes more widely. In doing so, we suggest that HSCIC work with DH and NHS England, and with other data provider bodies as relevant, to identify the operational and policy issues that affect PROMs and publish helpful explanatory information about wider findings alongside its own statistics.

**Figure 6: Knee replacements in Preston (illustrative example)**



Source: Extract taken from NHS Choices on 11 February 2014<sup>75</sup>

## Enabling and encouraging analysis and re-use of the statistics

3.23 HSCIC presents PROMs and all of the supporting materials including methods and quality documents, datasets and video tutorials, on a single page on its website. The webpage also includes general links to the Indicators Portal and Data Access Request Service – it does not explain which PROMs data can be accessed in either place. NHS England<sup>76</sup> and NHS Choices<sup>77</sup> provide direct links to the statistics through their PROMs pages, though they do not make it clear that HSCIC is responsible for publishing the official statistics for PROMs. Also, NHS Choices has a placeholder for PROMs information – Health gains reported by patients (see Figure 6). HSCIC told us that it has met NHS England

<sup>74</sup> In relation to Principle 8, Practice 2 of the *Code of Practice for Official Statistics*

<sup>75</sup> <http://www.nhs.uk/service-search/>

<sup>76</sup> <http://www.england.nhs.uk/statistics/statistical-work-areas/proms/>

<sup>77</sup> <http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/aboutproms.aspx>

with a view to populating NHS Choices with PROMs information by spring 2015 – they have considered together what would be the most helpful measure, produced from the official statistics, for the public to interpret and HSCIC has provided the relevant data to NHS England. The Authority welcomes this reflection on user needs and encourages HSCIC and NHS England to seek early engagement with patients, or their representatives, to confirm how well the changes to NHS Choices meet those needs.

- 3.24 As part of this Assessment, users reported difficulties in accessing the information that they sought through HSCIC’s website and the Indicator Portal. HSCIC told us that it is planning to develop the Indicator Portal. This activity is part of the wider benefit realisation activities within HSCIC and is being informed by the consultation of the Publication Strategy published in December 2014. In the meantime, we think that HSCIC could do more to describe, signpost and potentially streamline the PROMs information available in different places including, but not restricted to: its own website; its Extract Service; Indicator Portal; NHS England; and NHS Choices, including explaining when the PROMs information is updated. As part of the designation as National Statistics, HSCIC should publish prominent information alongside the statistics about what PROMs information is published, where and when, in order to improve accessibility and better support analysis and re-use of the statistics<sup>78</sup> (Requirement 7). We suggest that HSCIC consider publishing the information about what PROMs information is available together with the information about users and uses. We further suggest that HSCIC continue to consult users about the dissemination of these statistics; provide regular updates to users about the development of the Indicator Portal; and report on the progress made.

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<sup>78</sup> In relation to Principle 8, Practice 4 of the *Code of Practice*

## Annex 1: Compliance with Standards for Statistical Reports

- A1.1 In November 2012, the Authority issued a statement on *Standards for Statistical Reports*<sup>79</sup>. While this is not part of the *Code of Practice for Official Statistics*, the Authority regards it as advice that will promote both understanding and compliance with the *Code*. In relation to the statistical reports associated with HSCIC's PROMs, this annex comments on compliance with the statement on standards. The comments included in this annex are based on a review of: *PROMs Headlines* for April to July 2014<sup>80</sup> and April to August 2014<sup>81</sup>; *PROMs Provisional* for April to June 2014<sup>82</sup>; and *PROMs Final* for April 2012 to March 2013<sup>83</sup>.
- A1.2 In implementing any Requirements of this report (at paragraph 1.12) which relate to the content of statistical reports, we encourage HSCIC to apply the standards as fully as possible.

### **Include an impartial narrative in plain English that draws out the main messages from the statistics**

- A1.3 All of the statistical outputs present 'key facts' in html format on HSCIC's website. These 'key facts' include a chart of improvement rates (unadjusted scores) for England by elective procedure and measure. The chart presents a single aggregate improvement rate for each procedure and measure for the cumulative period covered by the report – from 1 month up to 12 months. The chart is supported by some information about survey participation and coverage, and a comparison with the final improvement rate for the previous 12 months (April to March). The 'key facts' are descriptive and so offer little insight for the user. They also assume that the user has a good understanding of the terminology presented and how to interpret the measures individually and as a whole.
- A1.4 For *PROMs Headlines* and *PROMs Provisional*, HSCIC does not present any further commentary. However, as soon as it considers that it has sufficient numbers of records available on a provisional basis, HSCIC starts to publish a potentially helpful interactive service as part of 'key facts' that allows users to look at PROMs casemix-adjusted scores and outliers for a particular procedure and locality, though again more might be done to help user interpret the information presented.
- A1.5 HSCIC also publishes special topics alongside *PROMs Provisional* three times a year. HSCIC uses these special topics to present a more in-depth analysis of a particular aspect of the statistics – for example: standardising of results for differences in the distributions of age and sex of organisations' populations; and further analysis of the EQ-5D<sup>TM</sup> Index.
- A1.6 *PROMs Final* includes an extended statistical report in addition to the 'key facts' html page. The report begins with a contents page and then a two-page

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<sup>79</sup> <http://www.statisticsauthority.gov.uk/news/standards-for-statistical-reports.html>

<sup>80</sup> <http://www.hscic.gov.uk/catalogue/PUB15941>

<sup>81</sup> <http://www.hscic.gov.uk/catalogue/PUB16282>

<sup>82</sup> <http://www.hscic.gov.uk/catalogue/PUB15726>

<sup>83</sup> <http://www.hscic.gov.uk/catalogue/PUB14574>

executive summary that presents some headline descriptive statistics for England about: the profile of patients undergoing procedures; health gains; and surgical success; patient satisfaction; and results by organisation. HSCIC then addresses each of these topics in turn in the main body of the report. The report does not look at all the information for a particular procedure together and try to draw out the story. The statistical report presents a time series of four years – linked to when regular PROMs data collection started. All of the headline results for England are presented as being broadly in line with previous years. HSCIC might to more to draw out the narrative from a lower-level analysis of the data.

- A1.7 In addition to statistics such as average health gain, *PROMs Final* presents some distributional analysis in the form of box-and-whisker diagrams. The organisational analysis identifies positive and negative outliers – providers of the elective procedures that have significantly better or worse outcomes than the national average based on a statistical model developed by DH and NHS England. HSCIC then names these outliers in the report. The text that HSCIC presents in support of PROMs is impartial and avoids statements of opinion and is demonstrably evidence-based.

#### **Include information about the context and likely uses of the statistics**

- A1.8 HSCIC does not provide users with any information on its web pages or in the statistical reports about why the statistics are produced and how they might be used. The Methodology Guide that accompanies the statistics includes a section that lists some possible uses of PROMs but it could do more to illustrate the national policy and local operational applications, including any specific targets or financial payments linked to the statistics.
- A1.9 *PROMs Final* includes information about what the different measures are and how the data are collected. This information is supported by some helpful diagrams, though some are too small to be easily read.

#### **Include information about the strengths and limitations of the statistics in relation to their potential use**

- A1.10 HSCIC publishes a Data Quality Note, which is updated each time the statistics are released. The Data Quality Note provides a summary against the European Statistical System Quality Framework dimensions, with the main focus on the coverage of the statistics including: the numbers of questionnaires issued and returned; linking with HES records; and estimating for missing records. Information about coverage is also prominently presented alongside the statistics. HSCIC describes some limitations in the data but does not advise users about how these limitations might impact upon their use of PROMs.
- A1.11 HSCIC does not quantify revisions to the statistics. HSCIC does though present tables illustrating how many eligible patient records and returned questionnaires were available for a calendar month at each point the statistics were published for that month. For example, for February 2014, the first time results were published (in July 2014) there were 21,294 PROMs-eligible patient records, of which 31 had returned a post-operative questionnaire. By



December 2014 these numbers for February had increased to 21,316 and 6,624 respectively. This is helpful information in understanding the quality of the statistics, particularly for those early estimates, but the percentage of useable matched questionnaires in relation to numbers of procedures does get somewhat lost in the iterative way that HSCIC presents the information. The information is not broken down by procedure.

## **Be professionally sound**

A1.12 HSCIC generally presents numbers and percentages to one decimal place in the commentary, tables and charts. The focus in the headline indicators is the percentage improvement rate. *PROMs Final* (published in August 2014) provides a breakdown only of 'improved' versus 'unchanged/worsened' but since then *PROMs Provisional* and *PROMs Headlines* have started to present 'unchanged' and 'worsened' separately. We consider this a positive step forward. Some of the statistics are not immediately easy to comprehend – for example, an average health gain of 20.4 on the Oxford Hip Score – but HSCIC does provide the possible range (0 to 48) alongside to aid interpretation.

## **Include, or link to, appropriate metadata**

A1.13 The titles of the statistical reports make it clear that they include PROMs measures for England, but with a national PROMs programme that stretches beyond these four elective procedures, a sub-heading may be appropriate. The responsible statistician is named in *PROMs Final* but not in *PROMs Headlines* or *PROMs Provisional* – HSCIC told us that it will rectify this. HSCIC does not provide the contact details of the statistician, although those of the enquiries contact centre, which routes queries through to the statistics team, are provided.

A1.14 HSCIC clearly states the period covered by each release of statistics but the multiple releases issued on the same day are potentially confusing for users. For example, on 13 November 2014 HSCIC published *PROMs Provisional* for April to June 2014 and *PROMs Provisional* for April 2013 to March 2014 as separate reports listed on the GOV.UK Statistics Release Calendar. Also, the title of *PROMs Headlines* and *PROMs Provisional* refer to these being monthly statistics, although in fact cumulative measures are presented.

A1.15 HSCIC publishes a Guide to PROMs Methodology that it makes available alongside the statistics together with a Frequently Asked Questions document and Data Dictionary that lists all of the data items collected. The methodology guide presents a diagram of the data collection process but while some information is presented about HSCIC's assurance arrangements and potential sources of error and bias, it is limited.

A1.16 HSCIC does not provide links to comparable statistics for other UK countries or internationally – HSCIC told us that there is nothing available for Scotland, Wales and Northern Ireland. HSCIC provides some helpful links to PROMs analysis by other organisations but no contextual information is provided about other PROMs measures that are available, but not official statistics.



- A1.17 HSCIC publishes csv data packs alongside *PROMs Provisional* and *PROMs Final*. These data packs are zip files that include the data and a 'PROMs CSV Data File Companion'. HSCIC provides data at anonymised patient record-level and Commissioner level, with appropriate suppression applied. The data include standard deviations, but these quality measures, and how to interpret them, are not described. The Data File Companion is not a comprehensive guide but does provide links to related metadata. HSCIC also provides links to video tutorials about using PROMs data.
- A1.18 HSCIC also publishes an Excel workbook: 'Score Comparison' that allows users to compare scores for up to ten providers against the figures for England, by procedure and measure. This interactive workbook also provides options to produce funnel plots to help interpret the data. The Score Comparison tools and the video tutorials present some caveats to caution users in interpreting the data, including the outliers.
- A1.19 PROMs also form part of the NHS OF and Quality Accounts and so are made available through HSCIC's Indicator Portal. There are currently no PROMs data available through NHS Choices, though we did find a placeholder for it. We understand that additional restricted datasets are also made available under licence on request but we could not find any reference to what these might include.

## Annex 2: Summary of assessment process and users' views

- A2.1 This assessment was conducted from September 2014 to June 2015.
- A2.2 The Assessment team – Donna Livesey and Iain Russell – agreed the scope of and timetable for this assessment with representatives of HSCIC in September 2014. The Written Evidence for Assessment was provided on 24 November. The Assessment team subsequently met HSCIC during January 2015 to review compliance with the *Code of Practice*, taking account of the written evidence provided and other relevant sources of evidence.

### Summary of users contacted, and issues raised

- A2.3 Part of the assessment process involves our consideration of the views of users. We approach some known and potential users of the set of statistics, and we invite comments via an open note on the Authority's website. This process is not a statistical survey, but it enables us to gain some insights about the extent to which the statistics meet users' needs and the extent to which users feel that the producers of those statistics engage with them. We are aware that responses from users may not be representative of wider views, and we take account of this in the way that we prepare Assessment reports.
- A2.4 As it was known that some of the users that we planned to approach would have an interest in the range of patient outcomes statistics we invited comments about all of the sets of statistics in this group of assessments as part of a single user consultation. We received 29 responses and the respondents were grouped as follows:

NHS England	4
NHS trusts	4
Department of Health	3
Professional/Membership Bodies	3
Regulators	2
Public Health England	2
Office for National Statistics	2
Commercial	2
Charities	1
Academics	1
Data suppliers	5

### Common Themes

- A2.5 Users of patient outcomes statistics identified with some common themes:
- Volume of statistics and data – Users appreciated the availability of statistics and data about patient outcomes and experiences and said that this is an area of increasing policy and operational focus within the health sector (see Section 2). However, users indicated that the range and volume of different data and statistics available from different sources can be overwhelming. Users said that it is difficult to know what statistics best serve particular

needs and to determine the coherence and comparability of the different statistics

- Accessibility – users told us that they found it difficult to locate and navigate the range of patient outcomes statistics and supporting datasets. Users told us that they would welcome better search functionality and one user suggested that an app be developed that would explain what statistics and data are available for different themes and where to find them. Users were particularly critical of HSCIC’s website and the layout and functionality of its Indicator Portal. Users said that when they found what they wanted, the format and presentation of spreadsheets made it difficult to interpret and re-use the data. Some users also highlighted that often the greatest value lies in the individual record-level data, which is more difficult to access, though they noted the importance of protecting confidentiality
- Commentary – some users only used the data and did not refer to the commentary; others found the commentary helpful; but some users told us that they would welcome more insightful commentary and trend analysis to aid interpretation
- Timeliness – some users in NHS trusts told us that hospitals thrive on real time information, and that the delayed availability of statistics reduces their relevance
- Assurance of source data – suppliers provided details of a range of checks carried out on the data but some users and suppliers raised potential concerns about the quality of the data and administrative processes that underpin the statistics – issues raised included: patchy response rates to patient surveys; limitations caused by the different organisational structures in the NHS; the potential for different interpretations of definitions; and the lack of information available to inform the sign off processes by trusts and CCGs
- Engagement with producer bodies – those users who had direct contact with the teams producing the statistics were positive about their experiences and the helpfulness of the statisticians

## *PROMs*

A2.6 Users also provided specific feedback in relation to PROMs. Key points were:

- Interpreting PROMs – users told us that they found it difficult to interpret PROMs, or to draw any conclusions from the analysis presented, though the special topics were mentioned as being more insightful. Users also found it difficult to reconcile the official statistics with those made available at NHS trust level. Users said that they found the measures complex and the language technical, and that it was difficult to get a sense of how clinical factors were influencing the outcomes. One user said that the number of caveats around quality made them more difficult to interpret and another suggested that too much emphasis on the general well-being measures such as the EQ-5D<sup>TM</sup> Index may result in misuse of the statistics
- Impact of PROMs – users shared with us a range of potential applications of PROMs (detailed in Section 2) but a number were sceptical about how they

are used in practice and what impact they have had on patterns of care. One user suggested that too much emphasis has been placed on data collection and not enough on presenting outputs that are user-friendly and can be helpful to commissioners, hospital managers, GPs and clinicians

- Coverage of PROMs – users said that PROMs currently covers very few procedures and that now that a national pattern is established for these elective procedures, some questioned whether it is appropriate to continue to focus resources here or to examine whether the benefits might be greater elsewhere – for example, in relation to treating long-term health conditions and emergency admissions

A2.7 One data supplier told us that they do not have sufficient information to sign off some of the clinical indicators that are sent to them for checking. They said that what they are being asked to check is not the raw data but a ‘standardised’ version – for example, standardised percentage ratios for readmissions following varicose vein stripping.

### **Key documents/links provided**

Written Evidence for Assessment document

## Annex 3: Description of PROMs measures

**EQ-5D™ Index** is a five-item measure that asks patients about their:

- ability to pursue their usual activities
- current experience of anxiety and/or depression, if any
- current experience of pain and discomfort, if any
- mobility
- ability to wash and dress themselves (self-care)

Patients' responses to the EQ-5D™ questions are combined to give a score ranging between -0.594 and 1, with '1' representing full health on the Index.

**EQ – Visual Analogue Scale (EQ VAS)** is a single-item 'thermometer'-style measure which asks patients to rate their general health at the time of completion on a linear scale from 0 to 100, with 100 representing the best possible state of health.

Within their post-operative questionnaires, all patients are also asked:

- how they would describe the results of their operation (satisfaction)
- how their problems are now, compared with before the operation (success)

### Oxford Hip Score

Patients receiving hip replacements are asked to complete the Oxford Hip Score, a twelve-item measure that asks patients to reflect over the past four weeks and assess the extent to which they have:

- experienced different kinds of pain from their affected hip both generally and when undertaking particular activities (for example, when sleeping)
- experienced difficulties related to mobility (for example, being able to get in and out of a car, or use public transport, or being able to climb a flight of stairs)
- been able to carry out activities required for self-care (for example, being able to wash and dress oneself, and put on socks, stockings or tights)

Responses to the twelve items are combined into an overall score ranging from 0 (the worst possible score) to 48 (the best possible score).

### Oxford Knee Score

Patients receiving knee replacements are asked to complete the Oxford Knee Score, a 12-item measure that is very closely related in content to the Oxford Hip Score, the main differences being that it includes items asking about patients' ability to "kneel down and stand up again afterwards" and "walk down a flight of stairs." As with the Oxford Hip Score, responses to the twelve items are combined into an overall score ranging from '0' (worst) to 48 (best).

## **Aberdeen Varicose Vein Questionnaire**

Patients undergoing PROMs-eligible varicose vein surgeries (in-patient only) are asked to complete the Aberdeen Varicose Vein Questionnaire, a thirteen item measure (with patients asked to respond to some questions separately for each leg), that is combined into an index ranging from 0 (the best possible score) to 100 (the worst possible score). The measure asks patients about:

- pain and skin irritation related to their varicose veins (for example, skin ulcers, rashes and eczema)
- the impact of varicose veins on their regular activities (for example, concern about cosmetic appearance, extent to which varicose veins interfere with work and leisure activities)
- the location of their varicose veins (patients are asked to draw these on a diagram)



