

Provisional Quarterly Patient Reported Outcome Measures (PROMs) in England – Data Quality Note

April 2015 to October 2015

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These statistics are used by health care providers and commissioners to improve the quality of health care offered to patients. Academic researchers use these data to inform research on PROMs-eligible procedures. Patients, carers, and other organisations that support patients (including GP practices and charities) may also find these statistics helpful in making informed decisions about elective procedures and providers.

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Introduction

This data quality note accompanies the latest publication by the Health and Social Care Information Centre (HSCIC) of provisional data from the Patient Reported Outcome Measures (PROMs) programme April 2015 to October 2015. Updates to the 2015/16 publication are intended to be released monthly¹ until the dataset is finalised and a final annual report published, expected in August 2017.

There are two sources of data for analysis:

- Questionnaires completed by patients before and after elective inpatient surgery for four common groups of procedures: total hip replacement, total knee replacement, groin hernia repair and varicose vein surgery;
- Records of episodes of hospital care in the Hospital Episode Statistics data warehouse in which there are recorded one or more of the surgical procedures eligible for PROMs and any associated pre- and post-operative questionnaires.

Full details of the surgeries eligible for inclusion in PROMs are contained in the PROMs Guide available from the HSCIC's PROMs homepage², which also describes some general data quality and processing issues.

Relevance

Health providers and commissioners use PROMs publications and statistics to improve the quality of health care offered to patients. A case study on PROMs³ found several examples of healthcare providers using PROMs data to inform changes in service delivery, some of which are noted below:

- Northumberland NHS Healthcare Foundation Trust standardised implants and moved away from replacing kneecap surfaces during surgery
- CircleBath used PROMs data to shape their Enhanced Recovery Programme, "revising care pathways, standardising implant and anaesthetic protocols and providing patients with an extra physiotherapy appointment."
- Derby Hospitals NHS Foundation Trust adapted their post-operative pain relief protocol for knee replacements
- Barnsley Hospital NHS Foundation Trust used PROMs data to provide evidence for the appointment of an additional physiotherapist.

Patients (and others involved in managing patient care such as GPs and carers) can use PROMs data to help decide where to receive treatment in the following ways:

- NHS Choices publishes provider-level outlier data for PROMs-eligible procedures based on the following measures (see 'Measure completeness' section of this document for further information):
 - Groin hernia – EQ-5DTM Index;
 - Hip replacement (primary) – Oxford Hip Score;
 - Knee replacement (primary) – Oxford Knee Score;
 - Varicose vein – Aberdeen Varicose Vein Questionnaire;

These data are published as part of a 'score card', together with other provider-level data for the procedure.

¹ Full publications are planned for quarterly release, in August, November, February and May; other months' publications are of high-level figures only.

² <http://www.hscic.gov.uk/proms>

³ The HSCIC, "Benefits case study: Patient Reported Outcome Measures (PROMs) outputs", 2015

<http://www.hscic.gov.uk/benefitscasestudies/proms>

- HSCIC publishes a Google Map service for all PROMs procedures and measures. Users can click on providers to see whether or not they were also outliers in earlier years.

Academic researchers use this data to inform research on PROMs-eligible procedures. Patients, carers and other organisations that support patients (including GP practices and charities) may also find these statistics helpful in making informed choices about elective procedures and providers.

The HSCIC is keen to gain a better understanding of the users of this publication and of their needs; feedback is welcome and may be sent to enquiries@hscic.gov.uk (please include 'PROMs' in the subject line). We publish summary information about feedback received and how this has influenced product development in the annual report.

Accuracy

Demographic information

Pre-operative questionnaires collect personal information about the patient's postcode, date of birth and sex. This information is used to support patient-level linkage with HES (other administrative information such as NHS number is also used for data linkage). Table 1 shows that item completeness exceeds 99.5% for these data items across all procedures.

Measure completeness

Responses to the pre- and post-operative questionnaires are used to report on up to three measures.

General measures

- The EQ-5D™ Index combines five questions about health and quality of life domains (usual activities, self-care, anxiety/depression, pain/discomfort, and mobility) into an overarching measure of general self-reported health. This measure can only be calculated if valid responses are received for all five questions. Table 1 (see below) shows that measure completeness exceeds 90% for all procedures.
- EQ-VAS; a single-item 'thermometer'-style measure which asks patients to rate their general health at the time of completion. Measure completeness on EQ-VAS is lower for hip and knee replacements than for groin hernia and varicose vein procedures (see Table 1).

Condition-specific measures

- The Oxford Hip Score and the Oxford Knee Score are closely related twelve-item questionnaires which combine questions about the patient's specific condition and its impact on their quality of life into a single overarching measure. An overall score on these measures can be calculated if valid responses are present for ten out of the twelve individual items: this represents completeness for analysis purposes.⁴
- The Aberdeen Varicose Vein Questionnaire is constructed from a thirteen-item questionnaire that asks questions about specific elements of the patient's varicose veins. The final score

⁴ For more information about each of the measures collected in PROMs questionnaires, and the individual questions that make up the measures, please see the 'Scoring Methodology' section and Annexes 2 and 3 of "Monthly Patient Reported Outcome Measures (PROMs) in England: a guide to PROMs methodology", 2015, http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMs_Guide_V10.pdf

is calculated by dividing the actual score by the maximum possible score for the questions answered so long as no more than two questions have been left unanswered.

- Measure completeness on condition-specific scores is high across all procedures where they are used (see Table 1).

Table 1: Measure and item completeness for selected pre- and post- operative questionnaire items and measures, 2015/16 (provisional data)

England		numbers and percentages			
		Groin hernia	Hip replacement	Knee replacement	Varicose vein
Pre-operative questionnaire					
Pre-operative questionnaires		23,260	38,809	46,751	6,265
Postcode populated		23,217	38,791	46,726	6,250
	<i>as % of pre-operative questionnaires</i>	99.8	100.0	99.9	99.8
Completed date populated		22,664	38,091	45,814	6,005
	<i>as % of pre-operative questionnaires</i>	97.4	98.1	98.0	95.8
Date of birth populated		23,192	38,772	46,697	6,241
	<i>as % of pre-operative questionnaires</i>	99.7	99.9	99.9	99.6
Gender		23,210	38,724	46,667	6,241
	<i>as % of pre-operative questionnaires</i>	99.8	99.8	99.8	99.6
EQ-5D Index Completeness		22,561	36,419	43,760	5,956
	<i>as % of pre-operative questionnaires</i>	97.0	93.8	93.6	95.1
EQ-VAS Completeness		22,304	34,913	41,605	5,761
	<i>as % of pre-operative questionnaires</i>	95.9	90.0	89.0	92.0
Condition-specific Completeness		N/A	38,354	46,175	6,054
	<i>as % of pre-operative questionnaires</i>	N/A	98.8	98.8	96.6
Pre- and post-operative questionnaire					
Pre- and post-operative questionnaire pairs		9,149	7,314	7,996	2,055
EQ-5D Index Completeness		8,561	6,678	7,225	1,901
	<i>as % of questionnaire pairs</i>	93.6	91.3	90.4	92.5
EQ-VAS Completeness		8,728	6,373	6,931	1,877
	<i>as % of questionnaire pairs</i>	95.4	87.1	86.7	91.3
Condition-specific completeness		N/A	7,171	7,827	1,954
	<i>as % of questionnaire pairs</i>	N/A	98.0	97.9	95.1

Data linkage

The HSCIC links pre-operative PROMs questionnaires to administrative data about the related inpatient hospital procedure held in the Hospital Episodes Statistics: Admitted Patient Care dataset (HES: APC). This is because HES: APC contains a range of variables (such as the Indices of Multiple Deprivation 2010) that are used in the PROMs casemix adjustment methodology. Whilst PROMs records that cannot be linked with HES: APC episodes are used in much of our reporting, only records that link to HES: APC can be used to make comparisons between provider-level and England-level outcomes.

When linking to HES: APC, matching rules are used to identify and rank potential matches between pre-operative questionnaires and hospital episodes.⁵ Three kinds of error may be introduced during linkage:

- A questionnaire may be linked to an unrelated episode. This is rare as it can only happen when a patient has two or more PROMs-eligible procedures within a very short space of time (for example, a primary procedure, followed shortly after by an elective revision procedure).
- A questionnaire may not link successfully to a related episode. This is more common and can have a number of different causes such as poorly written or incorrect identifiers on the PROMs questionnaire or poorly coded HES episodes
- Very rarely, a questionnaire may be linked to the wrong patient: this could potentially happen if two patients with the same sex, date of birth (where this is not 1 February) and postcode had the same PROMs-eligible procedure at the same hospital within a short period of time.

Table 2: Participation, linkage and response rates, 2015/16 (provisional data)

England	numbers and percentages			
	Groin hernia	Hip replacement	Knee replacement	Varicose vein
Pre-operative questionnaires	23,260	38,809	46,751	6,265
Pre-operative questionnaires to which NHS number assigned	21,681	36,761	43,984	5,737
<i>as % of pre-operative questionnaires</i>	<i>93.2</i>	<i>94.7</i>	<i>94.1</i>	<i>91.6</i>
Pre-operative questionnaires linked to episode	16,772	31,459	34,082	5,289
<i>as % of pre-operative questionnaires</i>	<i>72.1</i>	<i>81.1</i>	<i>72.9</i>	<i>84.4</i>
Post-operative questionnaires issued	18,549	15,343	17,221	5,154
Post-operative questionnaires returned	9,149	7,314	7,996	2,055
<i>as % of post-operative questionnaires issued</i>	<i>49.3</i>	<i>47.7</i>	<i>46.4</i>	<i>39.9</i>
<i>as % of pre-operative questionnaires</i>	<i>39.3</i>	<i>18.8</i>	<i>17.1</i>	<i>32.8</i>
Pre- and post-operative questionnaire pair linked to episode	8,241	7,226	7,872	1,974
<i>as % of pre-operative questionnaires</i>	<i>35.4</i>	<i>18.6</i>	<i>16.8</i>	<i>31.5</i>
<i>as % of all pre-operative questionnaires linked to an episode</i>	<i>49.1</i>	<i>23.0</i>	<i>23.1</i>	<i>37.3</i>

⁵ For more information about how pre-operative questionnaires are linked to HES episodes, please see the 'Matching methodology' section of "Monthly Patient Reported Outcome Measures (PROMs) in England: a guide to PROMs methodology", 2015,

http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMs_Guide_V10.pdf

Non-respondent analysis

Non-respondent analysis is produced for finalised datasets only, with the latest non-respondent analysis made in August 2015.⁶ Non-respondent analysis is based on episode counts within the reporting period and their associated pre- and post-operative questionnaires (pre- and post-operative questionnaires that do not link to an episode are not included in this analysis).⁷

In 2013/14, more than half of all patients undergoing elective hip (58.2%) and knee (57.2%) replacement procedures completed both pre- and post-operative questionnaires, both of which are an increase on the completion rates of both questionnaires in 2012/13 (53.8% and 54.3% respectively). Markedly lower proportions of groin hernia (31.8%) and varicose vein (19.2%) patients undergoing elective treatment in 2013/14 completed both questionnaires. This is a decrease on response rates in 2012/13 (32.4% and 20.2% respectively).

Table 3: Patient engagement levels by procedure, final 2013/14 PROMs data

England, 2013/14	<i>numbers and percentages</i>						
	<i>All episode: of which having:</i>						
	No linked questionnaires		Pre-operative questionnaire only		Pre- and post-operative questionnaire		
	(n)	(n)	%	(n)	%	(n)	%
Groin hernia	73,229	40,706	55.6	9,207	12.6	23,316	31.8
Hip replacement	76,576	21,961	28.7	10,067	13.1	44,548	58.2
Knee replacement	79,769	23,794	29.8	10,343	13.0	45,632	57.2
Varicose vein	26,201	17,422	66.5	3,738	14.3	5,041	19.2

Statistics for groin hernia and varicose veins may, therefore, be more affected by systematic patterns of non-response than those for hip and knee replacements. Many of the factors which are associated with systematic variations in engagement levels (such as higher levels of deprivation, for example), however, are incorporated into the case-mix adjustment methodology. This means that comparisons between provider-level data with England-level results should not be substantially affected.

For further information, please refer to the latest finalised annual report⁸.

⁶ Non-respondent analysis cannot be produced until the count of PROMs-eligible procedures carried out in the reporting year has been finalised. In addition, post-operative questionnaires for hip and knee replacements are not sent out to patients until six to nine months after their procedures.

⁷ This means that participation and response rates will differ substantially from headline participation rates (the count of pre-operative questionnaires received within the reporting period divided by the count of episodes) published for provisional data, and from other provisional measures of participation and response.

⁸ <http://www.hscic.gov.uk/catalogue/PUB17876>

Patient-provided answers

Most data items are based on answers given by patients themselves. A few data items are system-generated – such as the organisation code for the hospital administering the pre-operative questionnaire.

Questionnaire completion dates

Patients are asked to record when they completed the pre-operative questionnaires, using the format 'dd-mm-yyyy', as seen in the excerpt from a sample questionnaire below.

Figure 1: Questionnaire completion date question from PROMs pre-operative questionnaire⁹

Q26. Today's date

DD MM YYYY

Please ensure this is today's date NOT your date of birth

This date is used to assign pre-operative questionnaires to reporting periods. Data will only flow from data suppliers to the HSCIC for this item if the date given exists (i.e. '21-03-1066' would flow; '42-56-1066' would not). Once received, HSCIC applies further validation to determine whether or not the date when the data supplier scanned the questionnaire should be used instead of the patient-supplied completion date. The pre-operative questionnaire scan date is used instead of the completion date when the latter is:

- blank (i.e. no date has been supplied, or the date is illegible to both machine and human readers);
- before the PROMs programme started (for example, if they have written in their birth date in error);
- after the date on which the data supplier scanned the questionnaire.

As pre-operative questionnaires are usually scanned within a few weeks of the patient completing the questionnaire, replacing the completion date with the scan date in these cases increases the likelihood of successful linkage to a HES episode. In some cases, the scan date for the pre-operative questionnaire will fall in the reporting period after the pre-operative questionnaire was completed – the impact of this on the statistics is likely to be similar across years.

Despite these cleansing rules, it is likely that some patient-supplied completion dates are written down incorrectly (for example, near the beginning of a year, or due to patients entering dates in mm-dd-yyyy format). As with scan dates above, this may result in the pre-operative questionnaire being assigned to the wrong reporting period: in some circumstances it may also result in the pre-operative questionnaire failing to link successfully to an episode.

Data Quality Monitoring

Summary volume and data-field completeness data is made available monthly to hospital provider organisations and the data processing suppliers to allow them to monitor their data submissions and alert them at an early stage to any issues, such as missing data or emerging data quality problems.

⁹

Estimates of Missing PROMs Episodes

The PROMs questionnaire database is routinely linked to the Hospital Episode Statistics ('HES') data warehouse inpatient database in order to provide a richer and broader set of data for analysis. Regularly published HES Inpatient Data Quality Notes¹⁰ identify organisations with shortfalls, missing data, or specific data quality issues with their HES inpatient data.

As PROMs-eligible procedures comprise only a small proportion of all HES inpatient episodes, provider-level estimates of missing PROMs episodes (for organisations identified by HES Inpatient Data Quality Notes as having missing HES inpatient episodes) have been introduced. Details of the estimation method used may be found in Appendix A.

Table 4 shows the estimated missing PROMs episodes for April 2015 to October 2015, using this estimation method.

Table 4: Missing PROMs episodes (estimated), April 2015 - October 2015

Organisation code	Organisation name	Estimated Missing Episodes
NEQ01	Phoenix Health Solutions Limited	20
NFH01	Somerset Surgical Services	70

Mid-Staffordshire NHS Foundation Trust (RJD) is no longer providing health care as of 1 November 2014. Records for this organisation with activity from this date are split between University Hospitals of North Midlands NHS Trust (RJE) and The Royal Wolverhampton NHS Trust (RL4).

It has been decided not to map RJD records to the successor organisations as the Mid Staffordshire NHS Foundation Trust will remain open until a suitable agreement has been made with its stakeholders.

Provisional Data

The datasets used in monthly and quarterly provisional data are incomplete. Numbers of questionnaires and hospital inpatient episodes reported in previous provisional editions may have changed not only because of the receipt of additional data but also as a result of updated clinical coding or delayed submission of questionnaires.

In general, provisional counts of questionnaires and hospital records are likely to be lower than will be reported in the final annual publication. Quarterly PROMs reports show how counts of questionnaires, linkage rates, counts of modelled records and scores on the various PROMs measures have changed quarter on quarter. The most recent quarterly release of provisional April 2014 to March 2015 data was published on 11 February 2016 and is available at <http://www.hscic.gov.uk/catalogue/PUB19824>.

¹⁰ The HES Inpatient Data Quality Note for finalised 2013-14 HES Admitted Patient Care can be found at <http://www.hscic.gov.uk/catalogue/PUB16719/hosp-epis-stat-admi-dq-note-2013-14-rep.pdf>

Comparability and Coherence

Other official statistics published by the HSCIC that report on extracts of HES inpatient data allocate episodes to time periods based on episode end date. PROMs publications, however, use the episode start date to assign records to time periods, as this date more closely represents the date of the PROMs operation.

A small number of HES episodes record more than one eligible PROMs procedure (there were 40 episodes between 1 April 2015 and 31 October 2015). PROMs publications report on eligible procedures, whereas other publications from HES data report on episodes. In practice, this means that if a patient undergoes both a hip and knee replacement in a single hospital episode, their hospital records this as one episode for both procedures. However, the distinction between the two is made within the PROMs analysis of the linked PROMs questionnaires.

Timeliness and Punctuality

Timeliness

Analysis in this report is based on:

- Pre-operative patient questionnaires completed between 1 April 2015 and 31 October 2015 (2015/16 publication) and any associated inpatient hospital episodes and post-operative questionnaires;
- Episodes of inpatient hospital care where the episode started between 1 April 2015 and 31 October 2015 (2015/16 publication) and which included one of the four surgical procedures eligible for PROMs.

Patients with a pre-operative questionnaire that is linked to a HES inpatient record are sent post-operative questionnaires:

- three months after groin hernia or varicose vein surgery; or
- six months after hip or knee replacement surgery.

Where a pre-operative questionnaire cannot be linked to a HES inpatient record, a post-operative questionnaire will be sent six or nine months (respectively) after completion of the pre-operative questionnaire. Patients are not given deadlines to return their post-operative questionnaires, although up to two reminders are sent out to non-responding patients.

Annual datasets are typically finalised fifteen months after the end of the reporting period that they cover. This delay is needed both to allow sufficient recovery time after surgery before post-operative questionnaires are completed and to maximise the number of post-operative questionnaires returned. A further six weeks (approximately) is necessary for data processing, analysis and production and checking of the annual publication.

Punctuality

This publication was published on the pre-announced release date.

Accessibility and Clarity

The HES dataset used in the PROMs publication has been collected primarily for official administrative purposes. Information about the administrative source and its use for statistical purposes is included in the HSCIC's *Statement of Administrative Sources* at <http://www.hscic.gov.uk/article/1789/Statement-of-administrative-sources>.

Other extracts of the HES dataset are published by the Health and Social Care Information Centre. Details are available at <http://www.hscic.gov.uk/article/1823/What-HES-data-is-available>.

This publication is being made available on the world-wide-web as a combination of web pages and downloadable reports and data files. The publication may be requested in large print or other formats through the HSCIC's contact centre: enquiries@hscic.gov.uk (please include 'PROMs' in the subject line).

Appendix A: Method for Estimating Missing PROMs Episodes

The following approach is used to estimate missing PROMs episodes for providers known to have missing HES episodes. Within the equations below, the current reporting period (RP) is the portion of the current financial year covered within the publication (in this case the current reporting periods are April 2015 to October 2015).

- Where providers have submitted PROMs episodes for both part of the current reporting period (RP) and for the previous reporting period:

$$\begin{aligned}
 &\text{Estimated missing episodes for current RP} \\
 &= \sum \text{Episodes for corresponding months of previous year} \\
 &+ \left(\sum \text{Episodes for corresponding months of previous year} \times \text{Annual rate of change} \right) \\
 &- \sum \text{Episodes within current RP in months for which partial data submitted}
 \end{aligned}$$

The annual rate of change is the percentage difference (expressed as a decimal) between the number of episodes within the current reporting period (for which data submissions were complete) and the corresponding period of the previous financial year. The data submission for any given month is assumed to be incomplete if it has fewer than half as many episodes as the corresponding month of the previous reporting year. This method of estimation is used because it takes some account of seasonal variation in episode numbers.

- Where providers have submitted PROMs episodes for part of the current reporting period, and none of the previous year's reporting period (for example, new providers);

$$\begin{aligned}
 &\text{Estimated missing episodes for current RP} \\
 &= \left(\left(\frac{\sum \text{Episodes in current RP}}{n(\text{Months for which data submitted})} \right) \times n(\text{Months in current RP}) \right) \\
 &- \sum \text{Episodes in current RP}
 \end{aligned}$$

- Estimates of missing PROMs episodes are produced only for providers having at least one recorded PROMs episode in the current reporting period.
- Estimates are rounded to the nearest ten episodes (estimates between 1 and 4 inclusive are shown as '<5').

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