

Provisional Monthly Patient Reported Outcome Measures (PROMs) in England

A guide to PROMs methodology

Change Log		
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Executive summary

Patient Reported Outcome Measures (PROMs) have been collected nationally since April 2009. Analysis of pre-operative data was released for the first time as an Experimental Statistic in April 2010, with subsequent monthly updates. In September 2010 analysis of post-operative data was released for the first time, again as Experimental Statistics. From the August 2011 publication, PROMs data was split by financial year to enable comparison. Data for the 2009/10 financial year became final whilst data from April 2010 remains provisional. PROMs continues to be updated monthly and customers of the HES interrogation and extract services will continue to have access to the latest data. However, from August 2011 the files produced as part of the publication (including participation rates, provider and commissioner tables, the score comparison spreadsheet and associated CSV files) will be released on a quarterly basis. The PROMs programme covers four common elective surgical procedures: groin hernia operations, hip replacements, knee replacements and varicose vein operations.

The purpose of this document is to provide an accompaniment to the wider PROMs publication and data release, to explain the data items, the different outcome scoring methodologies and the linkage methodologies used to match PROMs data to Hospital Episodes Statistics (HES) and National Joint Registry (NJR) data.

The target audience of this document are those working in the Department of Health and the NHS, as well as researchers working to benefit the NHS and patient care. It will be of benefit to customers of the data who request PROMs extracts or query the data using the HES Interrogation System.

Introduction

Background

Patient Reported Outcome Measures (PROMs) are a means of collecting information on the effectiveness of care delivered to NHS patients as perceived by the patients themselves. The collection of this data will add to the set of information available on the care delivered to NHS-funded patients and will complement, and be used in conjunction with, existing information on the quality of services.

Since 1 April 2009, providers of four key elective interventions have been required to collect and report PROMs, under the terms of the Standard NHS Contract for Acute Services.

In practice, this means that all providers of NHS-funded unilateral hip and knee replacements, groin hernia and varicose vein surgeries are expected to invite patients undergoing one of these procedures to complete a pre-operative PROMs questionnaire in accordance with the relevant guidance¹. Post-operative questionnaires are then sent to patients following their operation after a specified time period.

The PROMs programme is limited to England only. However, a small number of patients from Scotland and Wales will be included in the responsible PCT and SHA views of the data due to being treated at English providers. PROMs is a Department of Health (DH) led programme supported by a number of key partner organisations, including The NHS Information Centre for health and social care (The NHS IC).

The recent 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:

'Information generated by patients themselves will be critical to this process, and will include much wider use of effective tools like Patient Reported Outcome Measures (PROMs), patient experience data, and real-time feedback. At present, PROMs, other outcome measures, patient experience surveys and national clinical audit are not used widely enough. We will expand their validity, collection and use. The Department will extend national clinical audit to support clinicians across a much wider range of treatments and conditions, and it will extend PROMs across the NHS wherever practicable.'²

An overview of the PROMs dataset

PROMs comprise a pair of questionnaires completed by the patient, one before and one after surgery (at least three months after for groin hernia and varicose vein operations, or at least six months after for hip and knee replacements). Patients' self-reported health status (sometimes referred to as health-related quality of life) is assessed through a mixture of generic and disease or condition-specific questions.

For each patient, the PROMs dataset includes the following:

- Patient-identifiable information, which is used for linkage purposes and not made available for wider analysis.
- A disease or condition-specific measure of self-reported health status.
- Generic measures of self-reported health status.
- Additional questions about the patient's own health, including whether they have pre-existing conditions such as arthritis or diabetes.

¹ See 'Guidance on the routine collection of Patient Reported Outcome Measures (PROMs)' on the [Department of Health website](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_092647) [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_092647].

² Please see: para 2.7, '[Equity and excellence – Liberating the NHS](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353)' [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353].

A list of all of the items in the PROMs dataset is included in the [PROMs Data Dictionary](http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=289) [http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=289].

Analysis of the differences between the pre-operative and the post-operative PROMs data can be used to determine the outcome of the operation as perceived by the patient in terms of its impact on their self-reported symptoms and functional status.

To add to the value of the PROMs questionnaire data, it is linked routinely with Hospital Episode Statistics (HES) episode-level information and, in the case of hip and knee replacement operations, National Joint Registry (NJR) information.

An overview of the PROMs collection process

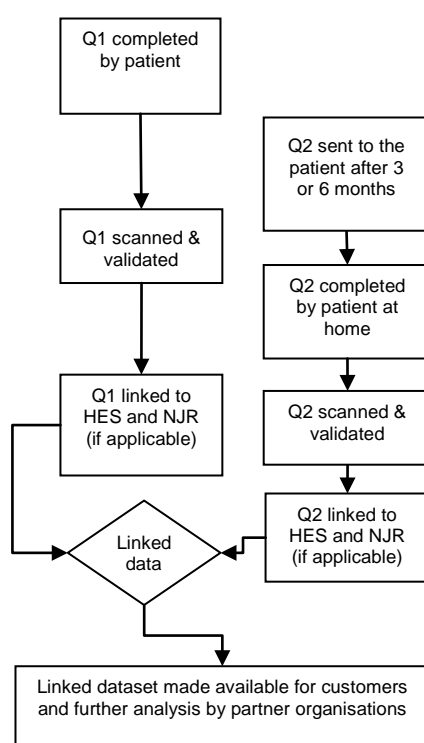
Before a patient undergoes one of the four PROMs procedures, the provider should offer the patient a PROMs questionnaire for completion. The guidance states that this should happen in the interval between the patient being passed fit for surgery and the treatment taking place, however, there is local discretion as to when precisely it is administered before the procedure. Completion of the pre-operative PROMs questionnaire is voluntary for the patient and their consent to participate must be granted for the data to be processed and used.

The completed pre-operative PROMs questionnaires are transferred securely to the DH contractor responsible for collating all of the information, where the forms are scanned electronically and traced to obtain the patient's NHS number. In a separate database the pre-operative PROMs questionnaires are linked securely to the HES and NJR databases.

After three or six months, depending on procedure, the DH contractor posts out the follow-up post-operative questionnaire to the patient's home. Once the form has been completed by the patient and returned, it is electronically scanned and linked with the pre-operative data along with HES and NJR, if applicable. All post-operative questionnaires are linked to their pre-operative questionnaire through the PROMs serial number, which is the same for both questionnaires.

After the consent period has expired, the personal data is securely removed from the PROMs database and the data is pseudonymised.

Figure 1: Summary flowchart of the PROMs collection and linkage process.



After the data has been collected and matched it is provided to partner organisations for statistical standardisation, and detailed analysis and interpretation of the results.

Uses of PROMs

There are several potential uses for PROMs data, including:

- Assessing the relative clinical quality of providers of elective procedures, for clinicians, managers and commissioners benchmarking their own performance, for regulators, for clinical audit and for patients' and GP's exercising choice.
- Researching what works: effectiveness and cost-effectiveness of different technical approaches to care can be evaluated using PROMs in association with other measures that assess what would have happened to patients in the absence of treatment or with alternative treatment.
- Assessing the relative health status before operations: PROMs data will provide a measure of patients' self-reported health status before they undergo an operation. Exploring variations in this data along with other indicators for surgery, such as the patients' social situation, other medical conditions and risk of deterioration and/or complication, could establish benchmarks.
- Supporting the reduction of health inequalities.

There is a choice when analysing PROMs data of whether to examine all PROMs records or just those that have linked to HES. The advantage of examining all PROMs records is that records are not removed, so the dataset is larger with increased coverage. The advantage of examining only those records that link to HES is that the linked dataset offers a richer set of information, including the possibility to analyse the data by fields such as ethnicity, detailed procedure and diagnosis information, and other outcome data.

Therefore, for analysis of PROMs that does not require any of the additional information that HES offers, it is recommended that all PROMs records are used, while for analysis that does require additional linked information from HES only the linked records can be used. The related PROMs publication follows this convention, and so uses linked and unlinked PROMs data.

Availability of the data

PROMs data will be refreshed on a monthly basis and will initially be made available in following ways:

- Publicly available aggregated data: a high-level summary of the PROMs data plus a selection of data tables will be made available for download from the HESonline website. Some of the tables will be aggregated to provider and PCT commissioner level, enabling comparative analysis.
- Extract service: customers can request bespoke cuts of data at row level, including the choice of which data items are selected via the extract service. An administrative fee will be charged for the production of the bespoke request based on time and complexity of the request.
- HES Interrogation System: registered users of the HES Interrogation System will be able to run queries against the linked HES / PROMs dataset. There will be two views of the data, a 'HES centric' view, similar to existing HES datasets, that will show HES plus any linking PROMs questionnaires, and a PROMs centric view showing all PROMs data plus any linking HES episodes. This second view will allow unlinked PROMs data to be viewed.

The intention is for PROMs data to be used eventually to produce a set of indicators, available on the NHS Choices website, which will be used as an aid to inform patient decisions on the provider of their hospital care.

For further information on accessing the data, please refer to [HESonline](http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=245) [http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=245].

Patient Outcomes in Surgery Audit

During the period April to September 2009, a significant number of providers were submitting PROMs data to the Patient Outcomes in Surgery (POIS) Audit rather than the DH PROMs programme. The PROMs data submitted to the POIS Audit was initially excluded from the reported national dataset reported. As a result, a number of providers' PROMs coverage appeared lower than it actually was in practice. Consequently, POIS data was integrated into the national PROMs dataset from January 2011 onwards, which resulted in increased participation rates.

Experimental statistics

PROMs publications are currently classed as experimental statistics as they contain new official statistics that are undergoing evaluation. The aim is to provide an overall summary and presentation of the key findings based on the data available rather than to provide a detailed interpretive analysis. Detailed analysis of the data has been commissioned by the Department of Health from the London School of Hygiene and Tropical Medicine.

Publishing the post-operative PROMs questionnaire data as experimental statistics enables:

- initial findings to be presented for discussion and further investigation;
- information on data coverage and quality to be made available to encourage local action to improve these areas;
- users to comment on methodology and their needs for analysis. Statistical and casemix adjustments to the PROMs data, developed by contractors³ on behalf of the Department of Health, are being applied in this publication in advance of a planned cycle of further refinement to the methodology

The UK Statistics Code of Practice states that *“effective user engagement is fundamental to both trust in statistics and securing maximum public value...”* and that as suppliers of information, it is important that we involve users in the evaluation of experimental statistics.

The UK Statistics Code of Practice can be accessed [here](http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf).

[<http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf>]

However, it should be acknowledged that the data coverage for the period April to September 2009 is partial and includes a period in time when significant volumes of PROMs were collected outside of the national PROMs programme (see 'Patient Outcomes in Surgery Audit' above). Further, some additional providers began to collect data later in the year once the Standard NHS Contract for Acute Services applied to them. As a consequence, any conclusions reached at this point are tentative, pending increases in the volumes of data as later months are added.

³ CHKS Ltd in conjunction with Northgate Information Solutions Ltd.

Scoring methodology

The PROMs programme utilises a number of tested and well-established methodologies to enable patients to rate their health status.

All patients, irrespective of their condition, are asked to complete a common set of questions about their health status. This includes sections about the patient's circumstances, pre-existing conditions and the EQ-5D health questionnaire consisting of a five-dimensional descriptive system and a visual analogue scale (EQ-VAS) developed by the EuroQol Group.

Post-operative questionnaires also contain additional questions about the surgery, such as how the patient perceives the results of the operation and whether there were any post-operative complications, such as bleeding or wound problems.

Patients undergoing varicose vein treatment or hip and knee replacement surgery are also asked to complete a condition-specific section.

EQ-5D

EQ-5D is a standardised measure of health status developed by the EuroQol Group in order to provide a simple, generic measure of health for clinical and economic appraisal. Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status that can be used in the clinical and economic evaluation of healthcare as well as in population health surveys.

EQ-5D consists of two distinct sections, the EQ-5D descriptive system and the EQ-5D visual analogue scale (EQ-VAS).

The EQ-5D descriptive system comprises the following five dimensions:

- Mobility
- Self-care, eg washing and dressing
- Usual activities, eg work, study, housework, family or leisure activities
- Pain/discomfort
- Anxiety/depression.

Each dimension has three levels: no problems, some problems, severe problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the five dimensions. This decision results in a one-digit number expressing the level selected for that dimension. The digits for five dimensions can be combined in a five-digit number string describing the respondent's health state, also referred to as the EQ-5D 'health profile'.

EQ-5D health states are converted into a single summary index by applying a formula that essentially attaches values (also called 'social preference weights') to each of the levels in each dimension. The index can be calculated by deducting the appropriate weights from one, the value for full health (ie state 11111).

EQ-VAS consists of a simple scale, from 0 to 100, presented in a simple linear format. Respondents are asked to rate their health state by marking the scale at the relevant point, with zero being the worst and one hundred being the best state.

See Annex 2 for more information on the EQ-5D scoring system.

Aberdeen Varicose Vein Questionnaire (AVVQ)

The Aberdeen Varicose Veins Questionnaire (Aberdeen Questionnaire) is a condition-specific questionnaire that measures health status for patients with varicose veins. The questionnaire, designed in 1993, consists of 13 questions relating to key aspects of the problem of varicose veins.

The questionnaire has a section in which the patients can indicate diagrammatically the distribution of their varicose veins. There are questions relating to the amount of pain experienced, ankle swelling, use of support stockings, interference with social and domestic activities, and the cosmetic aspects of varicose veins.

The questionnaire is scored from 0 to 100, where 0 represents a patient with no evidence of varicose veins and 100 represents the most severe problems associated with varicose veins. In the development of this questionnaire, two independent vascular surgeons weighted the individual questions in proportion to the perceived contribution to severity of the question.

See Annex 4 for more information on the AVVQ scoring system and Annex 3 for a list of questions included in the questionnaire.

Oxford Hip Scores and Oxford Knee Scores (OHS and OKS)

The Oxford hip and knee scores are joint-specific outcome measure tools designed to assess symptoms and function in patients undergoing joint replacement surgery.

The scores comprise of twelve multiple choice questions relating to the patient's experience of pain, ease of joint movement and ease of undertaking normal domestic activities such as walking or climbing stairs.

Each of the 12 questions on the Oxford Hip Score and Oxford Knee Score are scored in the same way with the score decreasing as the reported symptoms increase, ie become worse. All questions are laid out similarly with response categories denoting least (or no) symptoms scoring four and those representing greatest severity scoring zero.

The individual scores are then added together to provide a single score with 0 indicating the worst possible and 48 indicating the highest possible score.

See Annex 3 for a list of questions included in the Oxford Hip Score and Oxford Knee Score questionnaires.

Additional post-operative questions

Supplementing the main questions detailed in the sections above, patients are asked to answer a number of additional questions on the post operative questionnaire.

Questions about problems relating to the patient's operation

- Did you experience any of the following problems after your operation?
 - Allergy or reaction to drug
 - Urinary Problems
 - Bleeding
 - Wound problems
- Have you been readmitted to hospital since your operation?
- Have you had another operation on your (groin area/hip/knee/varicose veins) since your surgery?

Questions about results

- How would you describe the results of your operation?
 - Excellent
 - Very good
 - Good
 - Fair
 - Poor
- Overall, how are the problems now with your (groin area/hip/knee/varicose veins) on which you had surgery, compared to before your operation?
 - Much better

- A little better
- About the same
- A little worse
- Much worse

Question about general health

Please note that this question is also present in the pre-operative questionnaire and therefore the comparison between the pre- and post-operative responses can be used as an additional outcome measure.

- In general, would you say your health is:
 - Excellent
 - Very good
 - Good
 - Fair
 - Poor

Matching methodology

Cumulative submissions of data

Both HES and PROMs data are updated on a cumulative basis. Providers are able to resubmit data for any previous period within the current financial year where that data has been refreshed since the last submission. For example, data relating to an episode that took place in April submitted by a provider in June with incomplete clinical coding may be resubmitted in July once coding is complete.

Similarly, Q1 PROMs questionnaires may be administered at any time between a decision to admit being taken and before the episode, and completed Q2 questionnaires received at any point after they are received and returned by patients. This is especially the case for Q2s, which are completed and returned several months after the episode in which the operation occurred.

For this reason PROMs matching is run on a cumulative basis to ensure that any updated episode or recently returned questionnaire is considered for matching. Linkage rates will therefore increase retrospectively for PROMs data submitted in previous periods.

Matching the pre-operative questionnaires (Q1) to HES

The methodology that matches a HES episode to a Q1 questionnaire uses a four-stage process that looks at a combination of patient identifiable fields, provider codes, operation codes and dates. It uses a 'match ranking' system in which a score is attributed to each part of the linking process, where the quality of the match is denoted by the rank, with the lowest rank (ie 1) being the highest quality match. The scores for each possible match are compared and the highest match is chosen.

This approach has the advantages of maximising the matching rate by attempting several different matches on the same data and allowing the easy monitoring of quality and confidence of the match.

The four stages are:

1. Patient matching
2. Provider matching
3. Date matching
4. A 'tie break' to pick the best match if an episode matches to more than one Q1 by combining the scores from the three stages.

1. Patient matching

Patient matching looks at a range of patient identifiable fields, including NHS number, sex and date of birth. The lower the match rank the more stringent the rules and therefore the higher the confidence that the match is appropriate.

Partial matching on date of birth is tested in match ranks 3 and 4, and allows matching in cases where dates of birth in the episode and the questionnaire are similar but not exact, for example where, due to an input error, the month and the day values have been transposed.

Patient matching ranks		
Match rank	Description	Score
1	Exact match of DOB, SEX, NHSNO and POSTCODE	15
2	Exact match of DOB, SEX, NHSNO	14
3	Partial match of DOB and exact match of SEX, NHSNO and POSTCODE	13
4	Partial match of DOB, and exact match of SEX, NHSNO	12

Match rank	Description	Score
5	Exact match of POSTCODE and NHSNO	11
6	Exact match of DOB, SEX and POSTCODE (where NHSNO does not contradict the match and DOB is not 1 January and the POSTCODE is not in the 'ignore' list)	10
7	Exact match of DOB, SEX and POSTCODE (where NHSNO does not contradict the match and DOB is not 1 January)	9
8	Exact match of DOB, SEX and POSTCODE (where DOB is not 1 January)	8

2. Provider matching

The provider part of the matching algorithm compares the provider code of the episode in HES to the provider code as submitted by the hospital where the Q1 questionnaire was administered. In many cases, the Q1 questionnaire may be completed in one hospital and the operation carried out in another due to patient choice, subcontracting arrangements between providers or shared pathways.

For non-perfect matches, the algorithm uses a mapping table split into four bands. The first, the 'allowed' or 'green' list contains a list of provider codes mapped where a known subcontracting or shared pathway relationship exists between the two organisations (match rank 2). The next two bands, the 'possible' or 'amber' list are those organisations where little information is known about the relationship between the two but it is feasible that a relationship could exist. These are split between those providers separated by less than 100 miles (match rank 3) and those which are separated by more than 100 miles (match rank 4). The 'exclude' or 'red' list contains those providers where no relationship exists (match rank 5).

The final two match ranks are 6, where the relationship is unknown (ie there is no data in the mapping file), and 9, where a match attempt is impossible because no episode data exists – match rank 9s indicate where a match is possible for the patient only and are used for data quality monitoring purposes.

Provider matching ranks		
Match rank	Description	Score
1	Exact match of provider	10
2	Provider in the matrix 'allowed list' (green)	8
3	Provider in the matrix 'possible list' (amber) <100 miles	5
4	Provider in the matrix 'possible list' (amber) >100 miles	3
5	Provider in the matrix 'exclude' list (red) / no provider match	1
6	No provider match	1
9	(Metadata - no episode to match / matches on patient only)	0

Match ranks 1 to 3 are classified as allowable matches. Anything below 3 is not allowable and a link will not be established. Customers of PROMs data will only see data with a provider match of 3 or above.

3. Date matching

This compares the episode start date in HES with the 'Q1 completed date'. This is the date on which the patient completes and signs the pre-operative questionnaire.

In initial testing, accurate matching based on the interval between administration of the Q1 PROMs questionnaire and the operation taking place was found not to give satisfactory results because intervals varied in practice between providers, making it difficult to apply any standard rules. It was shown that many potential matches were being disregarded due to mismatches in the date, with the Q1 completed date being many weeks before or after the range specified by the provider.

The revised algorithm uses a simple descending scale, with the highest quality match (match rank 1) being those where the completed date is within a week of the episode start date, moving towards match rank 5 where the difference is between 12 and 18 weeks. Any matches where the completed date is greater than 18 weeks before the operation are deemed unacceptable, as this coincides with the 18-week target for the maximum wait between referral and treatment.

Match rank 7 indicates those where the date of completion is after the date of the operation and, similar to the provider matching process, there is a match 9 where there is no episode with which the questionnaire can match.

Date matching ranks		
Match rank	Description	Score
1	Completed date within one week prior to the episode start date and episode end	6
2	Completed date within three weeks prior to the episode start date	5
3	Completed date within six weeks prior to the episode start date	4
4	Completed date within 12 weeks prior to the episode start date	3
5	Completed date within 18 weeks prior to the episode start date	2
6	Completed date over 18 weeks prior to the episode start date	1
7	Completed date after the end of the episode	1
9	(Metadata – no episode to match / matches on patient only)	0

Match ranks 1 to 5 are classified as allowable matches; anything below 5 is not allowable and a link will not be established. Customers of PROMs data will only see data with a provider match of 5 or above.

4. Combined matching

A higher weight has been given to the patient match compared to the provider and date matches as the patient match involves matching on multiple fields (NHS number, sex, date of birth, postcode) and is therefore less likely to create a false positive link. The higher weight ensures that a good patient match is not overridden by a date match which may be set by local practices at the provider.

Each match (or potential match) between an episode and a Q1 will have a combined match rank and a score, for example a patient match of 1 (score 15), a provider match of 2 (score 8) and a date match of 3 (score 4) will give a combined match rank = 123 and a total score = 27.

In cases where a Q1 can potentially link to more than one episode, as a tie breaker, the link with the highest score is chosen thereby ensuring that the highest quality data is selected. In rare cases where multiple match attempts exist for the same episode with the same score, the match with the lowest combined match rank is chosen. For example within the set of possible matches 115, 222, 321, 412 (all which score 27), 115 will be chosen.

Finally, the clinical coding of the episode must be compatible with the type of questionnaire. A hip questionnaire cannot match to a knee episode however perfect the patient, provider and date matching between the two.

Matching NJR to HES/Q1

This stage links the matched PROMs data to records from the National Joint Registry (NJR) database, which holds additional information on hip and knee procedures such as the surgical approach and the type of joint implant used. Similar to the Q1 matching process detailed in the previous section, the algorithm allows for ranking of matches according to the level of confidence that we have that the records are an appropriate match, so that quality and confidence in the match can be monitored.

The NJR matching methodology is a two stage process, simpler than that used to link Q1 to an episode. This is because the NJR record is submitted by the clinician in charge of the procedure at the provider where the operation occurred, therefore additional steps to mitigate against a provider subcontracting or differences in date are not required.

1. Patient matching

The first part of the process matches the Q1 record to the patient by looking up into the central HES patient index and applying a unique patient identifier – the HESID – to the record. The algorithm used is similar to that used by the Q1 / episode matching process, except that no scoring is applied to the match for tie breaker purposes.

Patient matching ranks	
Match rank	Description
1	Exact match of DOB, SEX, NHSNO and POSTCODE
2	Exact match of DOB, SEX, NHSNO
3	Partial match of DOB and exact match of SEX, NHSNO and POSTCODE
4	Partial match of DOB, and exact match of SEX, NHSNO
5	Exact match of POSTCODE and NHSNO
6	Exact match of DOB, SEX and POSTCODE (where NHSNO does not contradict the match and DOB is not 1 January and the POSTCODE is not in the 'ignore' list)
7	Exact match of DOB, SEX and POSTCODE (where NHSNO does not contradict the match and DOB is not 1 January)
8	Exact match of DOB, SEX and POSTCODE (where DOB is not 1 January)

If the NJR record links to more than HESID then multiple 'match candidates' will be created. If a match is found on the candidate with the most stringent criteria (usually match rank 1), the algorithm then moves to the second part of the matching process, where an attempt is made to link the candidate NJR record to a linked episode from the matched HES-PROMs dataset. If an episode match is not found then the algorithm progresses to the next candidate (eg match rank 2), and so on.

2. Episode matching

The second part of the process attempts to assign an NJR record to the hip and knee surgery episodes from the PROMs-HES linked dataset.

This part of the process is carried out for each patient matching stage above. The algorithm first attempts to find a match on the most stringent criteria (ie match rank 1), and if none is found then should move on to the next level of criteria (ie match rank 2), and so on. Matches are ranked from 1–3 according to various criteria, which may not indicate match quality.

Episode matching ranks	
Match rank	Description
1	Exact match of PROVIDER, PROCEDURE GROUP and HESID, where the NJR OPERATION DATE = HES PROCEDURE DATE
2	Exact match of PROVIDER, PROCEDURE GROUP and HESID, where the NJR OPERATION DATE is within one day of the HES PROCEDURE DATE
3	Exact match of PROVIDER, PROCEDURE GROUP and HESID, where the NJR OPERATION DATE is between the HES episode start date and HES EPISODE END DATE

NJR matching should not be attempted for PROMs procedure types for which the NJR is not relevant, ie varicose vein and groin hernia surgeries.

Matching the post-operative questionnaire (Q2) to HES/Q1

All Q1s have a unique number, the PROMs serial number on the front sheet which is scanned when the form is returned.

The Q2 questionnaires are sent out to each patient at least 3 or 6 months following surgery (six months for orthopaedics procedures), with the same PROMs serial number that identifies the Q1 questionnaire. When the Q2 questionnaire is returned it is therefore a simple matter of linking the Q1 and Q2 questionnaires by PROMs serial number to create a match.

An additional step is to look at the patient's date of birth as submitted on the Q2 questionnaire and compare this with the DOB as submitted on the Q1 questionnaire. The DOB part of the matching algorithm is an additional step to give an indication of extra confidence that the match is correct.

Q1 to Q2 questionnaire matching ranks	
Match rank	Description
1	Exact match of PROMs serial number and DOB as recorded on the Q2
2	Exact match of PROMs serial number and partial match of DOB as recorded on the Q2
3	Exact match of PROMs serial number, no match on DOB

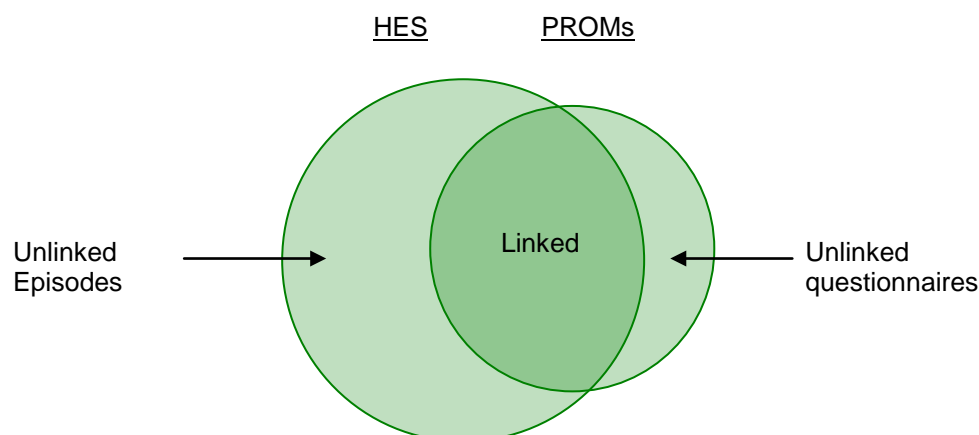
All matches are deemed acceptable, and no Q1/Q2 match is rejected on grounds of a low match rank, the Q2 match rank is for data quality monitoring purposes only.

Data quality considerations

Coverage

The percentage of Q1 questionnaires linked to HES is unlikely to reach 100% completeness due to the voluntary nature of PROMs for patients. There are a number of additional factors that will also affect the level of matching between HES and PROMs, both for HES episodes that do not link to PROMs and vice versa.

Figure 2: Summary of the relationship between HES and Q1 PROMs questionnaires



HES episodes that do not link to PROMs (unlinked episodes):

- Completion of PROMs is voluntary: patients are not obliged to take part in the PROMs programme at either Q1 or Q2 stage.
- Lag or 'lead in' time before the operation: in many cases providers are administering their Q1 questionnaire at a pre-assessment clinic up to several weeks before surgery is scheduled. This means that a high proportion of patients who had episodes early in the year would not have been invited to take part. Some patients with episodes in April would not have completed Q1 questionnaires and many patients who had completed Q1s in April would not have had their operation until several weeks or even months later. This will have the effect of underestimating actual linkage performance.
- Provider mapping issues: there are instances where the Q1 may be administered to a patient at one hospital and the operation performed at another. This may be due to provider subcontracting arrangements, patient choice or shared pathways. The matching algorithm can take many of these provider-to-provider relationships into account where they are known but there will always be relationships between providers that are not recognised.
- During the period April to September 2009, a significant number of providers were submitting PROMs data to the Patient Outcomes in Surgery (POIS) audit rather than the Department of Health PROMs programme. This has reduced the number of questionnaires received for those procedures in the first part of the year. After September those trusts involved in the POIS audit transferred to the national PROMs programme.

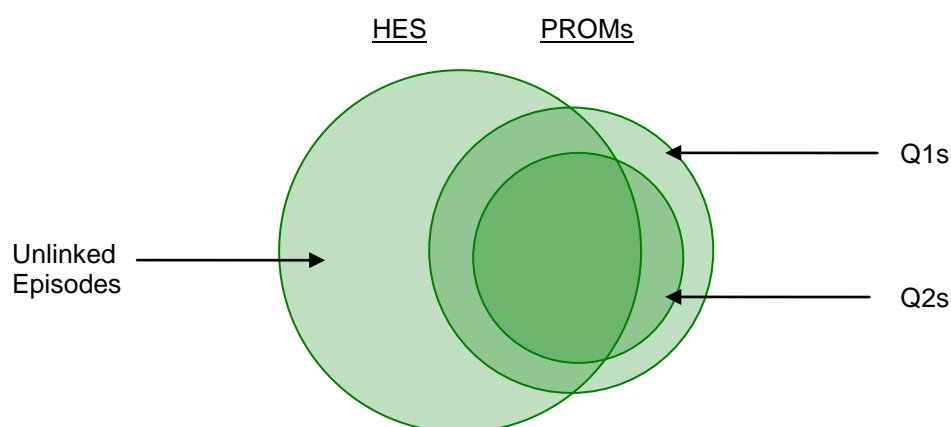
PROMs which do not link to HES (unlinked questionnaires):

- Poorly completed patient details on the questionnaire: patients are asked to complete their personal details on the Q1 questionnaires, which are then scanned and stored electronically. These details are sent to the Personal Demographics Service (PDS) in order to return the NHS number for matching purposes, a process called patient tracing. In some cases, the quality of the details supplied by the patient are not of sufficient quality for successful tracing. A common example of this is where the patient enters the current date when asked for their date of birth.
- Uncoded or poorly coded episodes: only episodes with codes in the list (see Annex 1) are included in the pool of operations eligible for matching. Often the clinical coding in new episodes are either poorly completed or missing altogether which will cause the episode to become ineligible for inclusion. In many cases the provider will resubmit the episode in a subsequent

monthly submission with updated clinical coding which will then allow the episode to be included in the matching attempt. It is for this reason that matching rates for historic month's data will often increase slightly over time.

- Provider mapping issues.
- Patients dying before their operation.
- Patients cancelling their operation.

Figure 3: Summary of the relationship between HES and Q1 and Q2 PROMs questionnaires



After three or six months, depending on procedure, the DH contractor posts out the follow-up post-operative questionnaire to the patient's home. Once the form has been completed by the patient and returned, it is electronically scanned and linked with the pre-operative data along with HES and NJR, if applicable. All post-operative questionnaires are linked to their pre-operative questionnaire through the PROMs serial number, which is the same for both questionnaires. This is shown in Figure 3 (above) with the circle representing the numbers of Q2s being inside the circle representing the number of Q1s. The area outside of the Q2 circle represents those questionnaires that have not reached the three or six-month period where a Q2 is sent out, or, where a Q2 has been sent out but not returned.

Missing values

In instances where a patient may have either declined to answer or accidentally missed a question, a default value is inserted to indicate a null value. For the majority of the multiple choice questions, NULL values are replaced with a 9. For the EQ-5D VAS, 999 is used because in that case 9 is a valid response.

Missing responses to any of the elements within a scoring system will mean that the total can not be calculated. For example, in the EQ-5D index, if one of the five questions is omitted from the patient's response, the index cannot be calculated and will be shown as a NULL value within the data.

The exception to this rule is the Aberdeen Varicose Vein questionnaire where this can be taken into account, as the final score is calculated by dividing the actual score by the maximum possible score achievable with the questions that have been completed.

The Oxford orthopaedic scores suggest an optional method to impute missing values whereby if no more than two responses are missing they are replaced by the average of the existing responses. Where more than two responses are missing, it is recommended that the overall score is not calculated. The PROMs programme has not chosen to implement this method and instead has left the responses as submitted by the patient. It is therefore left to the discretion of customers of the data as to whether to use this method.

Ambiguous values

There are instances where a patient may have indicated more than one value within a single multiple choice question or EQ-5D VAS. In such cases the more severe answer will be chosen.

For example, if a patient has answered 3 (very mild) and 1 (moderate) to question one of the knee replacement specific question: *'During the past 4 weeks, how would you describe the pain you usually had from your knee?'*, then 1 would be chosen in preference to 3.

Demographics

Although the PROMs programme is limited to England only, a small number of patients from Scotland and Wales are included in the data due to being treated in hospital in England. Responsible PCT and StHA are based on the GP of the patient which may be in Scotland or Wales.

Time differences

As many providers are administering the Q1 questionnaire a number of weeks before the operation and patients may choose to complete the Q2 questionnaire at any time after receipt, there will be a range of intervals between the operation date and the Q2 completion date. Many intervals will fall outside the specified three-month period for general surgery procedures and six months for orthopaedic procedures. For this reason care must be taken when analysing the data to ensure that bias due to time has been taken account of when presenting outcome results.

Feedback

If you have any questions on the content of this document or the wider PROMs publication, please email the NHS [IC Contact Centre](mailto:enquiries@ic.nhs.uk) (enquiries@ic.nhs.uk), ensuring that 'PROMs' is clearly visible in the subject line.

If you have any questions about the PROMs programme in general, please contact the [DH PROMs mailbox](mailto:proms@dh.gsi.gov.uk) (proms@dh.gsi.gov.uk).

Responsible statistician:

Simon Rea, HES/SUS Development - Section Head

Contact via enquiries@ic.nhs.uk or 0845 300 6016

Annex 1: List of operation codes eligible for inclusion in the PROMs programme

All NHS patients aged 12 and over are eligible to be offered questionnaires, provided they are undergoing one of the eligible procedures. The following tables of clinical codes are taken from the DH PROMs technical guidance supplied to providers.

HIP SURGERY QUESTIONNAIRE

Procedure	Clinical codes (OPCS4.5)			ICD-10 Diagnosis codes #
	Definitions	Combinations & sites *	Exclusions**	
Unilateral Hip Replacement				
Total hip replacement (primary)	W37.1, W37.8, W37.9, W38.1, W38.8, W38.9, W39.1, W39.8, W39.9	N/A	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Total prosthetic replacement of the head of the femur (primary)	W46.1, W46.8, W46.9, W47.1, W47.8, W47.9, W48.1, W48.8, W48.9	N/A	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Hybrid prosthetic hip replacement (primary)	W93.1, W93.8, W93.9, W94.1, W94.8, W94.9, W95.1, W95.8, W95.9	N/A	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Other hip replacements (primary)	W52.1, W52.8, W52.9, W53.1, W53.8, W53.9, W54.1, W54.8, W54.9	Z76.1 ("Head of femur"), Z75.6 ("Acetabulum") or Z84.3 ("Hip joint")	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Total hip replacement	W37.0, W37.2, W37.3, W37.4,	N/A	Z94.1 ("bilateral operation") or	N/A

(revision)	W38.0, W38.3, W39.0, W39.3, W39.5,	W38.2, W38.4, W39.2, W39.4, W39.6		where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	
Total prosthetic replacement of the head of the femur (revision)	W46.0, W46.3, W47.2, W48.0, W48.3, W48.5	W46.2, W47.0, W47.3, W48.2, W48.4,	N/A	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Hybrid prosthetic hip replacement (revision)	W93.0, W93.3, W94.2, W95.0, W95.3,	W93.2, W94.0, W94.3, W95.2, W95.4	N/A	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Other hip replacements (revision)	W52.0, W52.3, W53.2, W54.0, W54.3,	W52.2, W53.0, W53.3, W54.2, W54.4	Z76.1 ("Head of femur"), Z75.6 ("Acetabulum") or Z84.3 ("Hip joint")	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Resurfacing arthroplasty of joint (Primary)	W58.1		Z76.1 ("Head of femur"), Z75.6 ("Acetabulum") or Z84.3 ("Hip joint")	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A
Resurfacing arthroplasty of joint (Revision)	W58.2		Z76.1 ("Head of femur"), Z75.6 ("Acetabulum") or Z84.3 ("Hip joint")	Z94.1 ("bilateral operation") or where a pair of unilateral hip replacements take place in the same spell accompanied	N/A

			by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	
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Reference Information

**: Specified "Combination" & "Site" codes must appear in combination with the relevant definition codes for the procedure to count.*

*** : Activity should be excluded if it would be coded with these codes.*

#: These ICD-10 Diagnoses would need to be present for the activity to count.

KNEE SURGERY QUESTIONNAIRE					
Procedure	Clinical codes (OPCS4.5)				ICD-10 Diagnosis codes #
	Definitions		Combinations & sites *	Exclusions**	
Unilateral Knee Replacement					
Total knee replacements (primary)	W40.1, W40.8, W40.9, W41.1, W41.8, W41.9, W42.1, W42.8, W42.9		N/A	Z94.1 (“bilateral operation”) or where a pair of unilateral knee replacements take place in the same spell accompanied by both Z94.2 (“Right-sided”) & Z94.3 (“Left-sided”)	N/A
Unicondylar / Unicompartmental knee operations (primary)	W52.1, W52.8, W52.9, W53.1, W53.8, W53.9, W54.1, W54.8, W54.9		Z76.5 (“lower end of femur NEC”), Z77.1 (“condyle of tibia”), Z77.4 (“upper end of tibia NEC”), Z84.4 (“patellofemoral joint”), Z84.5 (“tibiofemoral joint”) or Z84.6 (“knee joint”)	Z94.1 (“bilateral operation”) or where a pair of unilateral knee replacements take place in the same spell accompanied by both Z94.2 (“Right-sided”) & Z94.3 (“Left-sided”)	N/A
Hybrid prosthetic knee replacements (primary)	O18.1, O18.8, O18.9		N/A	Z94.1 (“bilateral operation”) or where a pair of unilateral knee replacements take place in the same spell accompanied by both Z94.2 (“Right-sided”) & Z94.3 (“Left-sided”)	N/A
Total knee replacements (revision)	W40.0, W40.2, W40.3, W40.4, W41.0, W41.2, W41.3, W41.4, W42.0, W42.2, W42.3, W42.4, W42.5, W42.6		N/A	Z94.1 (“bilateral operation”) or where a pair of unilateral knee replacements take place in the same spell accompanied by both Z94.2 (“Right-sided”) & Z94.3 (“Left-sided”)	N/A
Unicondylar / Unicompartmental knee operations (revision)	W52.0, W52.2, W52.3, W53.0, W53.2, W53.3, W54.0, W54.2, W54.3, W54.4		Z76.5 (“lower end of femur NEC”), Z77.1 (“condyle of tibia”), Z77.4 (“upper end of tibia NEC”), Z84.4 (“patellofemoral joint”), Z84.5	Z94.1 (“bilateral operation”) or where a pair of unilateral knee replacements take place in the same spell accompanied	N/A

			("tibiofemoral joint") or Z84.6 ("knee joint")	by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	
Hybrid prosthetic knee replacements (revisions)	O18.0, O18.3,	O18.2, O18.4	N/A	Z94.1 ("bilateral operation") or where a pair of unilateral knee replacements take place in the same spell accompanied by both Z94.2 ("Right-sided") & Z94.3 ("Left-sided")	N/A

Reference Information

**: Specified "Combination" & "Site" codes must appear in combination with the relevant definition codes for the procedure to count.*

*** : Activity should be excluded if it would be coded with these codes.*

#: These ICD-10 Diagnoses would need to be present for the activity to count

VARICOSE VEIN SURGERY QUESTIONNAIRE				
Procedure	Clinical codes (OPCS4.5)			ICD-10 Diagnosis codes #
	Definitions	Combinations & sites *	Exclusions**	
Varicose Veins Surgery				
Varicose vein surgery	L84, L85.1, L85.2, L85.3, L85.9, L86.9, L87.1, L87.2, L87.3, L87.4, L87.5, L87.6, L87.8, L87.9, L88.3, L88.8, L88.9	N/A	N/A	I83.0, I83.1, I83.2, I83.9, O22.0
Radiofrequency ablation of varicose vein (VNUS)	L88.2	N/A	N/A	I83.0, I83.1, I83.2, I83.9, O22.0
Endovenous laser treatment (EVLT) of long saphenous vein	L88.1, L85.8	N/A	N/A	I83.0, I83.1, I83.2, I83.9, O22.0
Subfascial endoscopic perforator surgery (SEPS)	L87.7	N/A	N/A	I83.0, I83.1, I83.2, I83.9, O22.0
Varicose vein surgery	L93	Z39.5 ("saphenous vein NEC"), Z39.9 ("vein NEC"), Z93.9 ("Vein of pelvis"), Z98.3 ("Superficial femoral vein"), Z98.4 ("Popliteal vein"), Z98.7 ("Tibial vein") or Z98.9 (vein of lower limb NEC)	N/A	I83.0, I83.1, I83.2, I83.9, O22.0
Varicose vein injection sclerotherapy	L86.1, L86.8	N/A	N/A	I83.0, I83.1, I83.2, I83.9, O22.0
Foam sclerotherapy of varicose vein	L86.2	N/A	N/A	I83.0, I83.1, I83.2, I83.9, O22.0

Reference Information

*: Specified "Combination" & "Site" codes must appear in combination with the relevant definition codes for the procedure to count.

**: Activity should be excluded if it would be coded with these codes.

#: These ICD-10 Diagnoses would need to be present for the activity to count

HERNIA SURGERY QUESTIONNAIRE				
Procedure	Clinical codes (OPCS4.5)			ICD-10 Diagnosis codes #
	Definitions	Combinations & sites *	Exclusions**	
Groin Hernia Surgery				
Simple excision of inguinal hernia sac	T19	N/A	N/A	N/A
Primary inguinal hernia (open)	T20	N/A	Any code indicating a laparoscopic approach: Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A
Primary inguinal hernia (laparoscopic)	T20	Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A	N/A
Primary femoral hernia (open)	T22	N/A	Any code indicating a laparoscopic approach: Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A
Primary femoral hernia (laparoscopic)	T22	Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A	N/A
Primary incisional groin hernia repair	T25	Z49.8 ("specified skin of trunk NEC")	N/A	N/A
Recurrent inguinal hernia (open)	T21	N/A	Any code indicating a laparoscopic approach: Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A
Recurrent inguinal hernia (laparoscopic)	T21	Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A	N/A
Recurrent femoral hernia (open)	T23	N/A	Any code indicating a laparoscopic approach: Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A
Recurrent femoral hernia (laparoscopic)	T23	Y50.8, Y75.1, Y75.2, Y75.3, Y75.4, Y75.5, Y75.8, Y75.9	N/A	N/A
Recurrent incisional groin hernia repair	T26	Z49.8 ("specified skin of trunk NEC")	N/A	N/A

Reference Information

**: Specified “Combination” & “Site” codes must appear in combination with the relevant definition codes for the procedure to count.*

*** : Activity should be excluded if it would be coded with these codes.*

#: These ICD-10 Diagnoses would need to be present for the activity to count.

Annex 2: EQ-5D values (weights)

EQ-5D health states defined by the EQ-5D descriptive system may be converted into a single summary index by applying a formula that essentially attaches values (also called social preference weights) to each of the levels in each dimension. The index can be calculated by deducting the appropriate weights from 1, the value of full health (ie state 11111). Information in this format is useful, for example, in cost utility analysis.

The values (weights) are presented in the table below. Examples of the application of the weights are also presented below.

UK value (weight) set ⁴		
Dimension	Coefficient	Notes
Constant	0.081	Applied if there is any dysfunction, ie if any dimension is reported as having a score of 2 or 3.
Mobility		
Level 2	0.069	Applied if the mobility dimension has a score of 2
Level 3	0.314	As above for a score of 3
Self care		
Level 2	0.104	Applied if the self -care dimension has a score of 2
Level 3	0.214	As above for a score of 3
Usual activity		
Level 2	0.036	Applied if the usual activity dimension has a score of 2
Level 3	0.094	As above for a score of 3
Pain/discomfort		
Level 2	0.123	Applied if the pain/discomfort dimension has a score of 2
Level 3	0.386	As above for a score of 3
Anxiety/depression		
Level 2	0.071	Applied if the anxiety/depression dimension has a score of 2
Level 3	0.236	As above for a score of 3
N3	0.269	Applied if any dimension is reported as having a score of 3

Examples:

Health state = 11111; index score = 1.000 (no deductions).

Health state = 11121; index score = 0.796 (= 1 - 0.081 - 0.123).

Health state = 23312; index score = 0.202 (= 1 - 0.081 - 0.269 - 0.069 - 0.214 - 0.094 - 0.071).

Health state = 33333; index score = -0.594 (= 1 - 0.081 - 0.269 - 0.314 - 0.214 - 0.094 - 0.386 - 0.236).

⁴ Dolan P. Modeling valuations for EuroQol health states. Med Care 1997; Nov;35 (11). 1095-108.

Annex 3: List of condition-specific questions

List of Oxford Hip Score (OHS) questions

- 1) During the past 4 weeks, how would you describe the pain you usually had from your hip?
- 2) During the past 4 weeks, have you had any sudden, severe pain - 'shooting', 'stabbing' or 'spasms' - from the affected hip?
- 3) During the past 4 weeks, have you been troubled by pain from your hip in bed at night?
- 4) During the past 4 weeks, have you had trouble washing and drying yourself (all over) because of your hip?
- 5) During the past 4 weeks, have you had any trouble getting in or out of your car or using public transport because of your hip?
- 6) During the past 4 weeks, have you been able to put on a pair of socks, stockings or tights?
- 7) During the past 4 weeks, could you do the household shopping on your own?
- 8) During the past 4 weeks, for how long have you been able to walk before pain from your hip becomes severe? (with or without a stick)
- 9) During the past 4 weeks, have you been limping when walking, because of your hip?
- 10) During the past 4 weeks, have you been able to climb a flight of stairs?
- 11) During the past 4 weeks, after a meal (sat at a table), how painful has it been for you to stand up from a chair because of your hip?
- 12) During the past 4 weeks, how much has pain from your hip interfered with your usual work (including housework)?

List of Oxford Knee Score (OKS) questions

- 1) During the past 4 weeks, how would you describe the pain you usually had from your knee?
- 2) During the past 4 weeks, have you been troubled by pain from your knee in bed at night?
- 3) During the past 4 weeks, have you had trouble washing and drying yourself (all over) because of your knee?
- 4) During the past 4 weeks, have you had any trouble getting in or out of your car or using public transport because of your knee?
- 5) During the past 4 weeks, for how long have you been able to walk before pain from your knee becomes severe? (with or without a stick)
- 6) During the past 4 weeks, after a meal (sat at a table), how painful has it been for you to stand up from a chair because of your knee?
- 7) During the past 4 weeks, have you been limping when walking, because of your knee?
- 8) During the past 4 weeks, could you kneel down and get up again afterwards?
- 9) During the past 4 weeks, how much has pain from your knee interfered with your usual work (including housework)?
- 10) During the past 4 weeks, have you felt that your knee might suddenly 'give way' or let you down?
- 11) During the past 4 weeks, could you do the household shopping on your own?
- 12) During the past 4 weeks, could you walk down one flight of stairs?

List of Aberdeen Varicose Vein Questionnaire (AVVQ) questions

- 1) (Question 1 requests the patient illustrate the number of visible varicose veins in each leg, both front and rear on to a diagram)
- 2) In the last two weeks, for how many days did your varicose veins cause you pain or ache?
- 3) During the last two weeks, on how many days did you take painkilling tablets for your varicose veins?
- 4) During the last two weeks, how much ankle swelling have you had?
- 5) In the last two weeks have you worn support tights or stockings?
- 6) In the last two weeks, have you had any itching in association with your varicose veins?
- 7) Do you have purple discolouration caused by tiny blood vessels in the skin, in association with your varicose veins?
- 8) Do you have any rash or eczema in the area of your ankle?
- 9) Do you have a skin ulcer associated with your varicose veins?
- 10) Does the appearance of your varicose veins cause you concern?

- 11) Does the appearance of your varicose veins influence your choice of clothing including tights?
- 12) During the last two weeks, have your varicose veins interfered with your work/housework or other daily activities?
- 13) During the last two weeks, have your varicose veins interfered with your leisure activities (including sport, hobbies and social life)?

Annex 4: Aberdeen varicose vein scores

Question	Response	Left leg	General	Right leg	Maximum score per question
1) Diagram	Score per box (64 boxes per side)	0.172		0.172	22.016
2) Pain / Ache	1) None at all 2) Between 1 and 5 days 3) Between 6 and 10 days 4) For more than 10 days	0.000 0.500 1.000 1.812		0.000 0.500 1.000 1.812	3.624
3) Painkillers	1) None at all 2) Between 1 and 5 days 3) Between 6 and 10 days 4) For more than 10 days		0.000 0.812 1.625 2.437		2.437
4) Swelling	1) None at all 2) Slight ankle swelling 3) Moderate ankle swelling 4) Severe ankle swelling		0.000 1.000 1.250 1.875		1.875
5) Support	1) No 2) Yes, those I bought myself without a doctor's prescription 3) Yes, those my doctor prescribed for me which I wear occasionally 4) Yes, those my doctor prescribed for me which I wear every day	0.000 1.374 2.000 5.496		0.000 1.374 2.000 5.496	10.992
6) Itching	1) No 2) Yes, but only above the knee 3) Yes, but only below the knee 4) Both above and below the knee	0.000 1.374 1.437 2.748		0.000 1.374 1.437 2.748	5.496
7) Discolouration	1) No 2) Yes	0.000 2.000		0.000 2.000	4.000
8) Rash	1) No 2) Yes, but it does not require any treatment from a doctor or district nurse 3) Yes, and it requires treatment from my doctor or district nurse	0.000 2.624 6.121		0.000 2.624 6.121	12.242
9) Ulcers	1) No 2) Yes	0.000 9.118		0.000 9.118	18.236
10) Concern	1) No 2) Yes, their appearance causes me slight concern 3) Yes, their appearance causes me moderate concern 4) Yes, their appearance causes me a great deal of concern		0.000 1.625 3.249 5.248		5.248
11) Clothing	1) No 2) Occasionally 3) Often 4) Always		0.000 1.625 2.624 3.998		3.998

Question	Response	Left leg	General	Right leg	Maximum score per question
12) Work	1) No 2) I have been able to work but my work has suffered to some extent 3) I have been able to work but my work has suffered to a moderate extent 4) My veins have prevented me from working one day or more		0.000 1.625 3.373 5.496		5.496
13) Leisure	1) No 2) Yes, my enjoyment has suffered to a slight extent 3) Yes, my enjoyment has suffered to a moderate extent 4) Yes, my veins have prevented me taking part in any leisure activities		0.000 1.625 2.437 3.998		3.998
Maximum possible score*					99.658

* The final score is calculated by summing scores for individual questions, dividing by the maximum possible and multiplying by 100. Due to rounding errors the maximum possible score does not reach 100.

Annex 5: Useful information/further reading

Department of Health

- [Guidance on the routine collection of Patient Reported Outcome Measures \(PROMs\)](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_092647)
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_092647]
- Transparency in Outcomes
[http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117583]

NHS Choices

- [PROMs](http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/aboutproms.aspx) for patients
[<http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/aboutproms.aspx>]

PROMs administration (Northgate Information Solutions Limited)

- [PROMs](http://www.northgate-proms.co.uk/) for practitioners [<http://www.northgate-proms.co.uk/>]

PROMs analysis (London School of Hygiene and Tropical Medicine/Royal College of Surgeons of England)

- [London School of Hygiene and Tropical Medicine](http://www.lshtm.ac.uk/) [<http://www.lshtm.ac.uk/>]
- [The Royal College of Surgeons of England](http://www.rcseng.ac.uk/) [<http://www.rcseng.ac.uk/>]
- [Contract Awarded to Develop Patient Reported Outcome Measures](http://www.rcseng.ac.uk/news/joint-rcs-dh-lshtm-release/) (press release)
[<http://www.rcseng.ac.uk/news/joint-rcs-dh-lshtm-release/>]

EQ-5D (EuroQol Group)

- [What is EQ-5D?](http://www.euroqol.org/eq-5d/what-is-eq-5d.html) [<http://www.euroqol.org/eq-5d/what-is-eq-5d.html>]
- [How to use EQ-5D](http://www.euroqol.org/eq-5d/what-is-eq-5d/how-to-use-eq-5d.html), including a downloadable user guide [<http://www.euroqol.org/eq-5d/what-is-eq-5d/how-to-use-eq-5d.html>]
- [EQ-5D nomenclature](http://www.euroqol.org/eq-5d/what-is-eq-5d/eq-5d-nomenclature.html) [<http://www.euroqol.org/eq-5d/what-is-eq-5d/eq-5d-nomenclature.html>]

National Joint Registry

- [National Joint Registry](http://www.njrcentre.org.uk) [<http://www.njrcentre.org.uk>]

Oxford Hip Score and Oxford Knee Score

- [The Oxford Orthopaedic scores](http://phi.uhce.ox.ac.uk/ox_scores.php), including guides to scoring
[http://phi.uhce.ox.ac.uk/ox_scores.php]

Aberdeen Varicose Vein Questionnaire

- [Towards Measurement of outcome for patients with varicose veins](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1055054/)
[<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1055054/>]

Glossary/List of acronyms used in this document

AVVQ	Aberdeen Varicose Vein Questionnaire
DH	The Department of Health
EQ-5D	Generic health status measure
EQ-VAS	Visual Analogue Scale component of the EQ-5D
HES	Hospital Episode Statistics
IC	The NHS Information Centre for Health and Social Care
NJR	National Joint Registry
OHS	Oxford Hip Score
OKS	Oxford Knee Score
PCT	Primary Care Trust
PDS	Personal Demographics Service (part of CfH)
POIS	Patient Outcomes in Surgery Audit
PROMs	Patient Reported Outcome Measures
Q1	The pre-operative or first questionnaire
Q2	The post-operative or second questionnaire.
StHA	Strategic Health Authority