General queries

Q1. How can I access PROMs data?

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

1. A high-level summary of the data will be updated on a monthly basis

2. Publicly available aggregated data: Data tables will be made available for download from the HESonline website on a quarterly basis. This includes tables aggregated to provider and commissioner level, enabling comparative analysis.

3. 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.

4. 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, which will show HES plus any linking PROMs questionnaires, and a PROMs-centric view showing all PROMs plus any linking HES episodes. This second view will allow unlinked PROMs data to be viewed. For further information on accessing the data, please refer to HESonline.

Q2. How frequently is the PROMs data updated?

A. Following a review of the PROMs publication through a consultation survey and an operational assessment, a decision was been made to change the frequency of the PROMs publication and the period that the publication covers. This was implemented in August 2011. Prior to this August 2011, the production of cumulative monthly updates had enabled a rich data source to be compiled, however new data had little impact on overall figures and there was a need to move to a publication which better reflects change over time. From the August 2011 publication, PROMs data is split by financial year to enable comparison.

PROMs will continue to be updated monthly and customers of the HES interrogation and extract services will continue to have access to the latest data. However, the files produced as part of the publication (including participation rates, provider and commissioner tables, the score comparison spread sheet and associated CSV files) will be released on a quarterly basis.

Moving to a quarterly publication will enable us to explore the dataset further, allowing the development of additional reports on different aspects of the data and making the publication more varied and interesting.

The HSCIC publication timetable can be found here.

Q3. Is there a PROMs mailing list?

A. Yes – if you would like to be added please send an email to enquiries@ic.nhs.uk with a subject of 'PROMs Mailing List' stating in the body of the email which email address you would like to be added to the list.

Q4. I have an idea for a 'Topic of Interest'. How can I submit it?

A. Any General feedback and comments are welcome and should be sent to enquiries@ic.nhs.uk. This includes any suggestions for 'Topics of Interest'.

Data queries

Q5. I require data for my Quality Accounts/Operating Framework return, where can I find this?

A. The information that you require is available from the downloadable spread sheets from both the Finalised and Provisional pages via the Quick Links on the right of this page. The latest participation rate data (overall and by procedure) can be found in the participation rate spread sheet, while average case mix adjusted change in health status (EQ-5D), pre- to post-operatively

can be found in the 'Adjusted average Q2 score' column of the provider/commissioner spread sheets.

Q6. Why did it take so long to publish the first finalised PROMs data set covering the period April 2009 to March 2010?

A. Although pre-operative questionnaires are generally completed at the time of the operation, post-operative questionnaires are not sent out until a significant period after the operation occurs (varicose veins and groin hernia - 3 months, hip and knee replacements - 6 months) to ensure that there is a period of time where the patient can see a change in their condition. If the pre-operative questionnaire doesn't link to a HES episode then this send out period is longer. The exact details of the sending out process can be found in the PROMs guide which is available on the main PROMs page.

The flow of post-operative questionnaires means that if the dataset was finalised earlier a significant number of post-operative questionnaires would have been excluded from the analysis.

Q7. Why is there no PROMs Q2 data for the new financial year yet?

A. Data recorded under this financial year will have an episode start date and a Q1 completed date on or after the 1st April. For groin hernia and varicose vein operations there is a 3 month gap between Q1 and Q2, and for hip and knee replacements there is a 6 month gap. Hence Q2 data for this year has not started to come in yet – please check the next quarterly publication.

Q8. Why do the key facts contain more up-to-date data than the PROMs data tables and documents?

A. Whilst the key facts are updated on a monthly basis, the PROMs data tables are now only being updated on a quarterly basis. This allows for time and resource to explore the PROMs dataset further, allowing the development of topics of interest which will allow the publication to provide greater depth of analysis and insight into this rich dataset.

Q9. Why are participation and linkage rates only available at a national and provider level?

A. It is the responsibility of the provider to administrator the PROMs pre-operative forms therefore it is not provided for aggregated commissioner level views of the data. The primary aim of the participation rate is to act as a guide to improve the take up of PROMs in areas where this is low, not as a measure of performance.

Q10. The spread sheets previously contained confidence intervals and now contain information on standard deviation. Why has this changed?

A. The change relates to a review by the PROMs programme on identifying outliers. Whether an organisation is significantly different from the national average was previously determined using a confidence interval based on variation within that organisation only (intervals that don't overlap with that national confidence interval were taken to be significantly different). Following a review by the PROMs programme it was decided that the significance of differences from the national average be determined using pooled variation from within all organisations. Funnel plots are used to display this analysis. This has the effect of bringing consistency to the presentation in that if an organisation's score lies outside of the funnel plot limits it is statistically significantly different to the national average at the level of significance used to draw the funnel. Further information on the methodology can be found here. As the identification of outliers is now done by using funnel plots and their associated control limits the confidence intervals have been removed but an organisational level standard deviation has been added to illustrate the level of variability of individuals scores that makeup the organisations average score.

Questionnaire queries

Q11. Can I view the PROMs questionnaires?

A. Yes, sample questionnaires are available on the Department of Health website at the following link

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidanc e/DH_091815

Q12. Can I obtain a licence to use the PROMs questionnaires?

A. If you undertake NHS funded activity for the existing PROMs conditions, then you should already be participating in the national PROMs programme. If you wish to use any PROMs questionnaire content outside the national programme, e.g. for local audit purposes, you may need to apply for permission from the Department of Health and the owners of the different measures used in the questionnaires.

There are certain terms and conditions about the questionnaires' use. Please visit http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuid ance/DH 091815

If you have any further questions please contact proms@dh.gsi.gov.uk

Provider access to PROMs extracts

Q13. How do I register to access my organisation's PROMs data?

A. Email HSCIC - enquiries@ic.nhs.uk with subject line 'PROMs Provider Access.' We will return to you a registration information sheet and an application form.

Q14. How many employees at my organisation can access PROMs data?

A. Due to Information Governance (IG) requirements to protect patient identifiable information and comply with the patient consent model, only 1 employee per organisation can access PROMs data from HSCIC. This employee must be nominated by the organisation's Caldicott Guardian and sign a declaration accepting responsibility for ensuring IG compliance in all of the organisation's handling and use of PROMs and PROMs related data.

Q15. How would I access PROMs data for download?

A. Registered users will be able to access PROMs extracts through HSCIC's Secure Electronic File Transfer (SEFT) service. Access will be web-based and will require Java Runtime v1.6 or higher. The file will be in comma separated variable (CSV) format.

Q16. When will the extracts be available?

A. Provider extracts will be available for download from mid-August 2012. These will be updated on a monthly basis and made available to download in line with the monthly HSCIC national PROMs Publication release: http://www.ic.nhs.uk/statistics-and-datacollections/publications-calendar/april-2011--march-2012

Q17. What will be in the PROMs Extracts?

A. The extracts will include all PROMS questionnaire data and HES eligible episodes until the point at which they are finalised for publication purposes. The finalised records will be included in the monthly extract that aligns with the final publication but will not be included in any subsequent extracts. PROMS Questionnaire information will only be included where the patient has explicitly consented for their information to be shared with their healthcare professionals. As a result extracts will only contain both pre and post-operative PROMS questionnaires used from August 2011, which included the updated consent model. Extracts will not include any information for patients that have not consented for their information to be shared with their healthcare professionals, have withdrawn consent or where patient consent has expired.

Troubleshooting – technical problems

Q18. Why is a red dot for my organisation not appearing on the funnel plot? A. See FAQ number 25 ('Why have some organisations not got case mix adjusted results?')

Q19. Why are values on the spread sheets not updating / why are drop-down lists not updating or only showing the first few organisations?

A. This is probably due to the settings on Excel. Try going into Tools -> Options, then choose the Calculation tab and set calculation to automatic.

Troubleshooting – data queries

Q20. Why is my average Q2 score lower/higher than my adjusted Q2 score?

A. The difference is due to the casemix adjustment taking into account the different mix of patients being treated by your organisation. E.g. A large proportion of a provider's patients may be in a poor state of pre-operative health before undergoing surgery compared to another provider who is treating a higher proportion of patients with high levels of preoperative health. Different outcomes would be expected for the two providers. National level scores are used to adjust the organisations score according to the expected outcome for the set of patients treated.

Q21. Why are there more returned Q1s than episodes / why is participation above 100%?

A. This is mainly due to one of three reasons. 1. Cancelled operations - e.g. patient has died, got better or refused surgery (Q1 completed but no episode). 2. Coding problems – we receive the questionnaire but cannot identify the episode as being eligible due to poor clinical coding so it can't be counted. 3. Subcontracting or patient choice whereby the Q1 may be completed at one provider whilst the operation will be performed at another. Q1 figures are based on the provider code as recorded on the questionnaire. Episode and linked Q1 figures are based on the provider code as recorded in HES.

Q22. Why is the number of records lower for my organisation in the score spread sheets than in the participation spread sheet?

A. The number of records in the participation sheet shows all the activity recorded for your organisation, including records that are not linked to HES. The number of records observed in the provider/commission level spread sheets are those that could be put through the statistical model. The count figure in the provider/commission level spread sheets is approximately 25% below that reported in the participation spread sheet. To put the record through the statistical model the record must be linked to HES and contain valid values in the key fields used to predict the outcome for the patient. The key fields vary depending on which model is applied to the data, more information on the fields used to model outcomes can be found in the methodology document.

Q23. What should I do if my organisation is identified as an outlier?

A. If your organisation is identified as an outlier in the score comparison spread sheet you should first consult the methodology document for identifying outliers produced by the Department of Health. This document provides further details regarding how outliers are identified and what further investigation and verification is required to determine whether you are a genuine outlier due to variation in performance. This document is available from here.

Casemix adjustment queries

Q24. How have you calculated the casemix adjusted scores?

A. Statistical techniques have been used to produce a model for each procedure and scoring combination. Variables taken from the PROMs returns and linked HES records that significantly influenced the patients score were included in the model. Only factors that were deemed outside of organisations' control were included in the model. The model was then used to adjust organisations' post-operative scores. A full description of the methodology can be found here.

Q25. Why have some organisations not got casemix adjusted results?

A. Where an organisation has fewer than thirty records no casemix adjusted result is calculated due to the fact that the underlying statistical models break down and give unreliable results when there are only a small number of records available on which to base estimates. Further, particular care is needed when interpreting the unadjusted scores for organisations with a small number of records as these scores can be heavily influenced by random variation (e.g. extreme values distorting the average).

Q26. Can I rank organisations on the casemix adjusted health benefit?

A. The measure provides an indication of an organisation's performance compared to its peers. However, it must be interpreted with reference to the sample size as this gives an indication of the variability of an organisations score. Comparison with the national picture can be done using the funnel plot in the score comparison spread sheet. If an organisation's score

isn't contained within the funnel, the organisation can be taken at the 0.01% level to be significantly different from the national picture. However, it is important that the trends shown are taken to be a starting point for further investigation rather than as a definitive conclusion on organisational performance.

Q27. Why have you included a health benefit measure adjusted for casemix?

A. An adjusted measure has been included to allow the comparison of trusts based on health gain. The adjusted measure, based on models developed by CHKS, takes into account the fact that organisations deal with patients with a differing casemix e.g. a large proportion of a provider's patients may be in a poor state of pre-operative health before undergoing surgery compared to another provider who is treating a higher proportion of patients with high levels of pre-operative health. The casemix adjustment models are being piloted in this publication in advance of a planned cycle of further refinement to the methodology.

Analysis queries and help

Q28. There are so many different measures, what do they mean?

A. The EQ-5D descriptive system provides two headline measures of general pre- and post-operative health, the EQ-5D Index and EQ-VAS. The health gain is the difference between the scores before and after the operation for each measure.

The EQ-5D descriptive system of health-related quality of life states consists of five dimensions - mobility, self-care, usual activities, pain/discomfort and anxiety/depression - each of which can take one of three responses. The responses record three levels of severity - no problems/some or moderate problems/extreme problems - within a particular EQ-5D dimension. These five states are combined using weights to give a single index measure which ranges from -0.594 to 1, where 1 is the best possible state of health.

The EQ-5D VAS generates a self-rating of health-related quality of life. The respondent rates his/her health state by placing a line on a pre-drawn health scale called 'Your health state today'. The scale ranges from 0 to 100, where 100 is the best possible state of health. Alongside the EQ-5D measures are procedure-specific scores. Rather than focusing on general health, the procedure-specific questions relate directly to the condition. Varicose veins use the Aberdeen Score which ranges from 0 to 100, where 0 represents a patient with no evidence of varicose veins. Hips and knees use the Oxford Score which ranges from 0 to 48, with 0 indicating the worst possible state of health related to the condition.

A more detailed description of the EQ-5D system and procedure specific scores can be found in the PROMs guide which is available on the main PROMs page.

Measures presented are displayed both adjusted and unadjusted for casemix. The adjusted measure, based on models developed by CHKS, takes into account the fact that organisations deal with patients with a differing casemix, e.g. a large proportion of a provider's patients may be in a poor state of pre-operative health before undergoing surgery compared to another provider who is treating a higher proportion of patients with high levels of pre-operative health.

Q29. What is the difference between confidence intervals and control limits?

A. Confidence intervals provide the range of values within which there is a given level of certainly that the true average score for a given organisation is contained. Wider confidence intervals indicate a greater variability of outcomes for patients treated or a low number of patients. A confidence interval is based on variation within the organisation only. Control limits use a pooled variation from within all organisations and are used for comparing an organisation's score with the national picture.

Q30. What is a funnel plot?

A. Funnel plots are a form of control chart which allow an organisation's score to be compared with the national picture at a given point in time. The plot contains control limits which give the graph the distinctive funnel shape, the limits narrowing as the sample size increases. Control limits are upper and lower limits within which variation can be considered 'common-cause'. Any variation beyond these limits is deemed 'special cause' and is worthy of further investigation.

Q31. Can you tell me more about the provider and commissioner level tables?

A. Accompanying the PROMs post-operative report is a set of spread sheets containing participation rates and scores by organisation. Scores are presented in organisational level tables together with a score comparison analysis. Scores include both the EQ-5D system and the condition-specific questions by organisation. In addition to the presentation of raw data, adjusted post-operative scores and measures of health gain are included together with their standard deviation to illustrate variability. An adjusted measure has been included to allow the comparison of trusts with national figures based on health gain. The adjusted measure, based on models developed by contractors (CHKS Ltd in conjunction with Northgate Information Solutions Ltd) on behalf of the Department of Health, takes into account the fact that organisations deal with patients with a differing casemix. Casemix models are applied in this publication in advance of a planned cycle of further refinement to the methodology. A full description of the methodology can be found on the PROMs website.

When interpreting the organisational level results it is important that the trends shown are taken to be a starting point for further investigation rather than giving a definitive conclusion on organisational performance. Extreme results may not be down to clinical reasons. They could also be caused by random variation (irregular and erratic fluctuations or chance factors that, in practical terms, cannot be anticipated, detected, identified, or eliminated); by data quality issues; or by differences in patients' ability to benefit from the surgery that cannot be identified from the data.

The provider and commissioner level tables and score comparison spread sheets are available from both the Finalised and Provisional pages via the Quick Links on the right of this page.