**NHS Digital**

**Indicator Supporting Documentation**

**IAP00119 Proportion of people feeling supported to manage their conditions (NHSOF)**

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| FIELD | CONTENTS |
| IAP Code | IAP00119 |
| Title | Proportion of people feeling supported to manage their conditions |
| Published by | NHS Digital |
| Reporting period | Biannual |
| Geographical Coverage | England |
| Reporting level(s) | CCG, National |
| Based on data from | GP Patient Survey |
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| Contact Author Email | Clinical.indicators@nhs.net |
| Rating | Fit for use |
| Assurance date | 13/09/2018 |
| Review date | 28/04/2019 |
| Indicator set | NHS Outcomes Framework |
| Brief Description  [This appears as a blurb in search results] | Proportion of people feeling supported to manage their condition, measured based on responses to question 32 of the GP Patient Survey; *In the last 6 months, have you had enough support from local services or organisations to help you manage your long term condition(s)? Please think about all services and organisations, not just health services.* |
| Purpose | The vast majority of the population visit their GP each year, and the average person will visit their GP more than five times a year. This will particularly be the case for people with long-term conditions. Often it is the experience people have of primary care that determines their overall view of the NHS. This indicator uses survey results to look specifically at whether people are feeling supported to manage their long-term condition. |
| Definition | Proportion of people feeling supported to manage their condition, measured based on responses to question 32 of the GP Patient Survey; *In the last 6 months, have you had enough support from local services or organisations to help you manage your long term condition(s)? Please think about all services and organisations, not just health services.* |
| Data Source |  |
| Numerator | Total number of ‘Yes, definitely’ or ‘Yes, to some extent’ answers to Question 32 (see below) for those having answered yes to the Question 30 “Do you have a long-standing health condition?”  GP Patient Survey Question 32  In the last 6 months, have you had enough support from local services or organisations to help you manage your long-term condition(s)? Please think about all services and organisations, not just health services |
| Denominator | The denominator is the total number of ‘Yes, definitely’, ‘Yes, to some extent’ and ‘No’ answers to Question 32 (see below) for those having answered yes to the Question 30 “Do you have a long-standing health condition?”  GP Patient Survey Question 32  In the last 6 months, have you had enough support from local services or organisations to help you manage your long-term condition(s)? Please think about all services and organisations, not just health services |
| Calculation | Percentage (weighted numerator/denominator) |
| Interpretation Guidelines |  |
| Caveats |  |

Indicator Assurance Service

**Methodology Review Group**

**Applications for consideration**

**17th January 2014**

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**0. Document Control**

***Version History***

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| **Version** | **Date** | **Changed By** | **Summary of Changes** |
| V 0.1 |  |  | Initial Draft |
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***Approvals***

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| **Name** | **Title** | **Date** | **Version** | **Signature** |
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***Distribution***

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| **Version** | **Date** | **Distribution List** |
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1. **Introduction**

Indicators to discuss:

* Revision to Cancer Survival indicators for use in the NHS Outcomes Framework and CCG Outcomes Indicator Set
* NHSOF Domain 2 Standardisation Methodology
* NHSOF 3.3 Proportion of people who recover from major trauma

1. Revision to Cancer Survival indicators for use in the NHS Outcomes Framework

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| Introduction |
| The ONS has published cancer survival figures for a number of years. The methodology currently used was agreed in 2009 and has remained in place since. There are currently 6 indicators within the NHS Outcomes Framework, which are based on ONS cancer survival publications:  NHS OF 1.4.i One-year survival from colorectal cancer  NHS OF 1.4.ii Five-year survival from colorectal cancer  NHS OF 1.4.iii One-year survival from breast cancer  NHS OF 1.4.iv Five-year survival from breast cancer  NHS OF 1.4.v One-year survival from lung cancer  NHS OF 1.4.vi Five-year survival from lung cancer  These indicators have been previously assured by the Methodology Review Group in March 2011 (see IAS applications IAP00020-IAP00025)  It is proposed that these 6 indicators are removed from the NHS Outcomes Framework and replaced with 4 new indicators:  **NHS OF 1.4.i One year survival for all cancers**  **NHS OF 1.4.ii Five year survival for all cancers**  **NHS OF 1.4.iii One-year survival from breast, lung and colorectal cancer**  **NHS OF 1.4.iv Five-year survival breast, lung and colorectal cancer**  All figures for these revised indicators come pre calculated as they are already published by ONS and are available here:  <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-331274>  Alongside these new survival indicators, it is proposed to the following indicator which looks at cancer survival in children,  **NHS OF 1.6.iii Five-year survival from all cancers in children**  Again, this is already published by ONS and available here:  <http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival-for-children-in-england/children-diagnosed-1990-2006-and-followed-upto-2011/stb---childhood-cancer-survival.html>  Cancer is responsible for 21% of all deaths in children aged 1–14 and causes more death of children in this age group than any other cause.  A recent Children and Young People's Health Outcomes Forum report, recommended outcomes for children and young people were sufficiently considered. Following consultation with ONS and the LSHTM, which concluded that this indicator to be robust at England level, it was concluded that it should be included in the framework. |

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| **Indicator Titles** | **NHS OF 1.4.i One year survival for all cancers**  **NHS OF 1.4.ii Five year survival for all cancers**  **NHS OF 1.4.iii One-year survival from breast, lung and colorectal cancer**  **NHS OF 1.4.iv Five-year survival breast, lung and colorectal cancer**  **NHS OF 1.6.iii Five-year survival from all cancers in children** |
| Indicator Set | NHSOF |

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| Revision Date: | 17/01/2014 |
| Rationale for Revision: | There are three main reasons for changing the cancer survival indicators within the NHS Outcomes Framework.   1. **Rarer Cancers**   *RATIONALE: It is important that we have a set of survival rate indicators that reflect performance across all cancers.*  Although there were seven indicators relating to cancer in this year’s NHS Outcomes Framework, stakeholders felt that more attention needed to be given to rarer cancers. The All Party Parliamentary Group for Cancer in particular recommended that the cancer survival indicators in the NHS Outcomes Framework should be extended to measure survival from all cancers.  Although the ‘big 3’ cancers captured by this year’s Framework are responsible for 39% of deaths, DH agreed with the APPG that it is important to track progress for survival from other cancers. The Government’s commitment to saving an additional 5,000 lives from cancer by 2014/15 is predicated on increasing survival from all cancers.   1. **Balance**   *RATIONALE: Any new indicators must not affect the overall balance of the NHS Outcomes Framework; .i.e. existing site specific indicators have to be replaced by the new ones.*  Within NHS OF, there are more outcomes indicators for cancer than for any other condition: seven cancer specific ones out of a total 60, as well as overarching indicators on years of life lost from causes amenable to health care that includes cancer. The NHS Outcomes Framework needs to be balanced and comprehensive across the full range of NHS activity. The Framework has been structured to deliver five high-level goals that matter most to patients: reducing premature mortality, supporting people with long-term conditions, helping people to recover, maximising patient experience and safety. The indicators it contains illustrate these different outcomes and the aim is for the NHS to improve across all of them.  Whilst some stakeholders may prefer to have indicators for rarer cancers in addition to the site-specific indicators that are already in place, this would have increased the number of cancer indicators and affected the overall balance of the Framework.  As ONS will continue to publish survival data showing individual cancers, we do not feel that a shift to composite indicators should dilute the NHS’s focus on each of the big three cancers. For example, charities and health bodies will still be able to monitor if performance is improving or stalling for each site.   1. **Clinical Commissioning Groups**   *RATIONALE: There is an intention to have viable CCG level breakdowns in order to monitor performance at that level - (These indicators will be assured separately).*  The Health and Social Care Act requires the NHS Commissioning Board to carry out an annual assessment of how clinical commissioning groups (CCGs) have performed their functions. It is envisaged that the Board will draw on the national measures set out in the NHS OF to hold CCGs to account for effective commissioning and to promote the improvements in quality and outcomes that they are achieving for their local populations.  NICE ran a consultation on what indicators would be suitable to hold CCGs to account, and published recommendations for the NHSCB Authority to consider. NICE did not recommend any of the existing site-specific cancer survival rate indicators as it had not been possible to develop a valid and reliable methodology for breaking down these measures to CCG population level.  It is important that where possible NHSOF indicators can be disaggregated to CCG population level. Advice from LSHT echoed the concerns of NICE, but it stated it would be possible to have CCG level indicators for composite cancer survival rates that were meaningful.   1. **Creation of Children’s Indicator: *NHS OF 1.6.iii Five-year survival from all cancers in children***   Cancer is responsible for 21% of all deaths in children aged 1–14 and causes more death of children in this age group than any other cause.  A recent Children and Young People's Health Outcomes Forum report, recommended outcomes for children and young people were sufficiently considered. Following consultation with ONS and the LSHTM, which concluded that this indicator to be robust at England level, it was concluded that it should be included in the framework. |
| Revisions: |  |
| Indicator Title | It is proposed to change how cancer survival indicators are presented in the NHS Outcomes Framework (NHS OF).  The proposed new indicators are:  NHS OF 1.4.i One year survival for all cancers  NHS OF 1.4.ii Five year survival for all cancers  NHS OF 1.4.iii One-year survival from breast, lung and colorectal cancer  NHS OF 1.4.iv Five-year survival breast, lung and colorectal cancer  NHS OF 1.6.iii Five-year survival from all cancers in children |
| Data source | Data were obtained from the National Cancer Registry at the Office for National Statistics (ONS), which has collated data from regional cancer registries covering the entire population of England since the 1960s. Each year, more than 270,000 patients are newly diagnosed with cancer in England. The National Health Service Central Register routinely updates these individual cancer records with information on each patient’s vital status (alive, emigrated, dead or not traced).  For the most recent figures, data were extracted from the National Cancer Registry on 2 July 2013 for patients diagnosed during 1996–2011: the vital status at 31 December 2012 was known for 99 per cent of these patients.  ONS commissions cancer survival figures from the Cancer Survival Group at the London School of Hygiene & Tropical Medicine (LSHTM), who ONS describe as a recognised as a centre of excellence within the UK for the production of cancer survival statistics. |
| Construction | A comprehensive discussion of the methodology and approach taken to calculate cancer survival indices is given in the supporting documents.   * **[Cancer Survival Indicators for Clinical Commissioning Groups - feasibility report - updated 18 June 2013.pdf]** discusses the validity of calculating each of the 5 proposed indicators at national level. Much of this paper alludes to CCG level indicators, which will be brought through the IAS in the near future. * **[Index of cancer survival in England.pdf]** is the ONS documentation which was released alongside the data in December for adult survival from all cancers and adult survival from three cancers combined. * **[Index of cancer survival for children.pdf]** is the ONS documentation which was released alongside the childhood survival data.   Survival estimates are the percentage of patients that are still alive a specified time after their diagnosis of cancer. Background mortality that patients would have normally experienced, if they did not have cancer, is taken into account, so that net survival is an estimate of the probability of survival from the cancer alone.  When building a cancer survival index, separate estimates of survival were required for each combination of;   * Cancer or group of cancers, defined as   + Breast (women)   + Colon and rectum combined   + Lung   + All other cancers combined * Age group: two configurations were selected   + Configuration 1: 15 – 44, 45 – 54, 55 – 65, 65 – 74, 75 – 99 (At national level) * Sex   + Male   + Female * Year of diagnosis   + Individual years in 1996 – 2010 for the one year survival indices   + Individual years in 1996 – 2007 for the five – year survival index, to allow for a potential five – year follow – up period for all patients.   The precision of the cancer survival index will be published alongside it. The precision is the inverse of the variance of the survival index and is made available as gives context to the measure.  **Combined breast, lung and colorectal cancer** is defined as all adults (15 – 99 years) who were diagnosed with a first, primary, invasive malignancy coded as C18-C20, C21.8 (colorectal), C50 (breast) or C33-C34 (lung).  All Cancers are defined as all adults (15 – 99 years) who were diagnosed with a first, primary, invasive malignancy.  There are two exclusions:  Non non-melanoma skin cancer (ICD-10 C44) is excluded, as ONS has been advised by expert epidemiologists and members of the former Steering Committee on Cancer Registration, that non-melanoma skin cancer is greatly under-registered. Registration varies widely depending on a registry’s degree of access to out-patient records and general practitioners. This under-registration of non-melanoma skin cancer is not just a problem for the cancer registries in England. Cancer Incidence in Five Continents Volume VI8 reported that cancer registries in the United States, Australia, and parts of Europe, also collected very limited information on these skin cancers. In the commentary that follows, the figures for ‘all malignancies’ (ICD-10 C00–C97) exclude non-melanoma skin cancer (nmsc). Also, it is not mandatory to register hydatidiform mole (ICD-10 O010). Therefore, these registrations are excluded from the figures, since they are not collected by all the registries."  Cancer of the prostate (C61) is excluded due the widespread introduction of prostate-specific antigen (PSA) testing since the early 1990s has led to difficulty in the interpretation of survival trends.  **Childhood cancers** in this instance are defined as all children (0 – 14 years) with a malignant neoplasm (ICD-10 C00-C97 excluding C44 excluding non-melanoma skin cancers), or a non‐malignant CNS tumour (ICD-10 D32-D33, D35.2-D35.4, D42-D43 and D44.3-D44.5.  More detail around ONS approach to calculating 5 year survival in children can be found in the accompanying document, **[Index of cancer survival for children.pdf]** which ONS released alongside the childhood survival data. |
| Updated Potential Issues | The statistical reliability of net survival estimates depends strongly on the number of events (deaths) that contribute to the estimate. In turn, this depends on both the number of patients who are diagnosed (the incidence rate and the sex and age (sex) distribution of the underlying population) and the lethality of the tumour, which also varies with age and sex, and over time, as well as between geographic areas. |

1. Update - Domain 2 indicators for NHS OF & CCG OIS

This response provided by the applicant aims to answer the recommendations made at the last MRG regarding the domain 2 indicators in the NHS Outcomes Framework and the CCG OIS.

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| **Indicator Titles** | * + - * + NHS OF 2 Health-related quality of life for people with long term conditions         + NHS OF 2.1 **(IAP00119)** Proportion of people who feel supported to manage their condition         + CCG OIS 2.2 Proportion of people who feel supported to manage their condition         + NHS OF 2.4 Health-related quality of life for carers, aged over 18 years         + CCG OIS 2.15 Health-related quality of life for carers, aged over 18 years         + CCG OIS 2.1 Health-related quality of life for people with long term conditions         + CCG OIS 2.16 Health related quality of life for people with a long term mental health condition |
| Indicator Set | NHSOF / CCGOIS |

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| Ref code  **IAP00000-01**  Made: 18/10/13 | The developer is asked to investigate if direct standardisation can be made to work through combining years or some of the initially proposed breakdown groups.  If the results of the investigation determine that this is too weak a standardisation then the developer should test whether indirect standardisation is valid, for instance determining if indirect standardisation holds valid in terms of populations being comparable.  Finally, if indirect standardisation is arrived at as being valid, supporting metadata would have to be very clear about the limitations of use of the indicator in terms of comparison.  Consideration should also be given as to whether crude rates should be published alongside denominator values |
| Update:  Made: 09/01/14 | The first recommendation was to look whether direct standardisation can be made to work as this was felt to be preferable to indirect standardisation.  **NHS Outcomes Framework indicators (NHS OF 2, 2.1 and 2.4) (CCGOIS 2.1, 2.2, 2.15)**  *CCG OIS 2.16 Health related quality of life for people with a long term mental health condition (issues around this indicator are discussed separately – see below)*  Direct standardisation has been carried out for NHS OF indicators 2 and 2.4 for 2011/12 GPPS data to assess whether this approach is feasible.  It needs to be highlighted that the principles of NHS OF indicator 2 also apply to NHS OF indicator 2.1 as the population in question (people who identify themselves as having a long-term condition) are the same for both indicators.  For NHS OF indicators 2 and 2.4 DSR values have been calculated at national level and broken down by age, gender and particularly ethnicity and local authority where small cell counts looked to be an issue.  For NHS OF indicator 2 only the LA district breakdown had empty cells when looking at the age, gender and LA combinations needed to be able to calculate the DSR values. However, there were only 6 empty cells for 4 selected LAs (City of London, Isles of Scilly, Rother and South Bucks). Please see spread sheet NHSOF\_2\_Data\_Lower\_Tier\_LA in the accompanying Excel file **NHSOF\_2\_2.4\_DSRCalc.xls** with the sample data where empty cells were highlighted in orange. DSR values were still calculated for those LAs.  When calculating values for the upper tier LA breakdown empty cells reduce to four across 2 authorities (City of London and Isles of Scilly). See spread sheet NHSOF\_2.4\_Data\_Upper\_Tier\_LA.  For NHS OF indicator 2.4 two breakdowns had empty cells when looking at the individual combinations. The breakdowns in question were ethnicity and LA. Similarly, to the scenario with LAs for NHS OF indicator 2 there were only 7 empty cells for the ethnicity breakdown for NHS OF indicator 2.4 (see orange highlighted cells in spread sheet NHSOF\_2.4\_Data\_Ethnicity in the attached file). The LA breakdown for NHS OF indicator 2.4 produced 112 empty cells across 83 LAs (see cells highlighted in orange in spread sheet NHSOF\_2.4\_Data\_LA.  When looking at the upper tier LA breakdown for indicator 2.4 empty cells reduce to 28 across 15 authorities.  Based on the findings the proposal for the domain 2 NHS Outcomes Framework indicators is as follows:   * Use direct standardisation as calculation method with the original age groups * Where there are empty cells (at least 1) for any of the categories within a breakdown suppress the calculated indicator values for the category in question * Further, where the numerator for a breakdown category is less than 25 suppress the calculated indicator values, due to the fact small numbers would make the estimate unreliable. This is in line with what currently happens within the PHOF. * In addition to the LA district breakdowns provide upper tier LA breakdowns. This would provide valuable additional information for local decision makers and would also provide values for LAs where values are suppressed for the LA district breakdown * Once 3-years’ worth of GPPS data are available it is proposed to additionally calculate an indicator value based on a rolling 3-year dataset * Publish numerator and denominator values in addition to the indicator values. It is proposed to also provide these for all indicator values that are suppressed unless the numerator values are below 5, which is in line with standard suppression rules.   The proposal to suppress any breakdown category where there is at least 1 empty cell is conservative in its approach, however it is important that we are able to take steps to revise the data that has already been published to ensure that we are confident about its validity. A more comprehensive review of approaches to standardisation and how to apply them would be helpful to come to an expert view which could then be applied to these indicators and others in the NHSOF and CCG OIS, which then may result in further revisions.  In line with the current proposal the table below summarises the number of suppressed breakdown categories by indicator for 2011/12 data.  **Number suppressed Total number**  **Indicators 2 and 2.1**  Ethnicity 0 18  LA districts 4 326  LA upper tier 2 152  **Indicator 2.4**  Ethnicity 3 18  LA districts 83 326  LA upper tier 15 152  **CCG OIS equivalents (CCGOIS 2.1, 2.2, 2.15)**  For CCGOIS 2.1, 2.2, 2.15 which are the equivalents we propose to use exactly the same methods as outlined above. For some cases, due to zero cells, CCG values will need to be supressed, it is less of a problem than at LA level as there are less of them.  However, there is a fourth GPPS indicator within the CCGOIS which requires a slight change in methodology.  **CCGOIS Health related quality of life for patients with a long term mental health condition (2.16)**  In comparison to the other GPPS indicators, this one has much smaller numbers. The attached file (**CCGOIS\_MH\_Zero\_Cell\_Example.xls**) gives a summary of counts for the indicator at CCG level, for a single year 2011/12 the smallest weighted sum of observed events was 43. However, using the standard GPPS age bands led to large numbers of zero cells (336 across 162 of the 211 CCGs). Widening the age bands, as defined in the file, sees this change to 34 across 30 CCGs. This would lead to DSRs not being calculated for 30 CCGs, a figure which is more acceptable than 162. Therefore, we propose using the combined age bands for this indicator. |

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| Ref code  **IAP00000-02**  Made: 18/10/13 | A test is to be put in to address issue of handling zero, or near zero EQ-5D scores. |
| Update:  Made: 09/01/14 | When looking at the different breakdowns for all domain 2 indicators no zero or near 0 EQ-5D values were found for any of the breakdown categories.  A test will be put in to check for the occurrence of 0 or near 0 EQ-5D values in future. If this will be the case suppression will be applied. |

1. Update on MRG Recommendations for NHSOF indicator 3.3 - Proportion of people who recover from major trauma

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| Introduction |
| Indicator 3.3 was discussed by the group on 18/10/13. The rationale put forward at the meeting was as below and is provided for context:  “The indicator aims to measure the effectiveness of a patients’ recovery from major trauma. Major trauma means multiple, serious injuries that could result in death or serious disability. These might include serious head injuries, severe gunshot wounds or road traffic accidents. As trauma is the main cause of death in the first four decades of life and a leading cause of disability it is recognised that, while emergency care has improved, treatment for victims of major injury could be improved and coordinating trauma services is now a priority for the NHS.  One of the aims of trauma systems is to increase survival and reduce mortality from serious injury. The focus of domain 3 in the NHS Outcomes Framework is on helping people to recover from episodes of ill health or following injury. Although indicator 3.3 focuses on survival the research evidence below focuses on the inverse event – death, rather than survival.  The Victoria State Trauma System (VSTS) in Australia (on which the NHS England trauma networks are modelled) and international research favour an Adjusted Odds Ratio for simplicity and public comprehension. This is set at 1.0 at baseline and annual changes in comparative mortality are demonstrated against that.  The VSTS uses reduction in odds ratio of death based on age, mechanism of injury and ISS. This demonstrated a significant reduction in deaths between 2001-2 and 2005-6 (adjusted odds ratio 0.62, 95% CI 0.48 – 0.8).  Prior work in the UK has adjusted on GCS (Glasgow Coma Score), ISS (injury severity score) and age and shown no improvement over time in the absence of system change. The London Trauma networks, which went live in 2010 two years ahead of the rest of the NHS trauma networks, reported a reduction in the odds ratio of death with 58 more unexpected survivors in the first year.  The clinical governance and performance management of all NHS major trauma centres (MTCs) and their funding are dependent on the national clinical audit TARN (Trauma Audit Research Network) to which all MTCs are required to return data.  TARN acts as the monitor of key performance indicators that are reported to commissioners and is the method by which the additional MTC income to cover the costs of the enhanced specifications is approved. This reporting of compliance with these KPIs is the basis of the PbR Best Practice Tariff uplift. This ensures high levels of data completeness. TARN also undertakes separate data completion and data quality checks against SUS.”  Following discussion at MRG on 18/10/13 the following recommendations were made: |
| Ref code  **IAP00337-01**  Made: 18/10/13  Further investigation is needed as to whether expressing the indicator value as a proportion would be more meaningful and easier to understand than expressing it as an odds ratio. |
| Ref code  **IAP00337-02**  Made: 18/10/13  It was requested that the inclusion of “outcome” in the GCS imputation model be revisited. The variable should be taken out in order to see its effects in comparison to the current method. |
| Ref code  **IAP00337-03**  Made: 18/10/13  Evidence for the GCS imputation model used needs to be provided to MRG. |
| Ref code  **IAP00337-04**  Made: 18/10/13  HSCIC to update the odds ratio equation in line with the update given by the applicant. |

Response from applicant

9 January 2014

**Summary**

1. The HSCIC Methodology Review Group assured the basic methodology for calculating **indicator 3.3 Survival from major trauma** in the NHS Outcomes Framework on the 18th November 2013 meeting - a logistic regression model estimating the odds of survival when adjusting for age, injury severity score (ISS), Glasgow Coma Scale (GCS), gender, age by gender interaction and financial year. The coefficients for the predictor 'year' will provide the odds ratio of surviving major trauma until 30 days after admission.
2. Progression in the assurance process is conditional on resolving two additional issues:
   1. To make the indicator more meaningful to users, it was recommended that the odds ratio of survival from major trauma be converted to a proportion of patients surviving from major trauma.
      1. **Proposal:** We propose that the simplest way to achieve this whilst ensuring that the interpretation is correct is to convert the odds of survival into the probability of survival. This is because odds can be converted to probabilities and probabilities to odds and probability is a concept more familiar to policy makers, patients and the wider public than odds.
   2. To investigate the impact of including and excluding the outcome (surviving major trauma at 30 days) in the GCS scores and in the imputation model used to impute missing values in the GCS.
      1. **Proposal:** Our investigation shows that the values for all the GCS and for the imputed GCS are quite similar when including or not the outcome variable in the imputation model. Since the published research literature indicates that including the outcome variable in the imputation model produces estimates closer to the true values, we recommend using this approach when imputing missing values for the GCS
3. How to convert the odds ratio into the probability of survival and the impact on including or not the outcome in the imputation model are detailed below.

**A. Converting the odds ratio of surviving major trauma into the probability of surviving major trauma**

1. Odds can be converted to probabilities and probabilities to odds using the formula below.
2. The probability of survival from major trauma in a given year (case mix adjusted) was calculated using this formula and is displayed in table 1. Figures in table 1 show that the probability of survival from major trauma has increased over the period 2007/08 to 2012/13 in relation to the reference year 2007/08: for example, the probability of survival from major trauma is 63% in 2012/13 (i.e., 63 patients out of 100), an increase of 13 percentage points (or 13 patients) from 2007/08.

Table 1. Regression coefficients, odds ratio and probability of survival by ‘financial year’ from the model using a six-year data set (2007/08 to 2012/13)

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| Predictors | Coefficients  (A) | Odds Rat.  (B) | p-value  (C) | 95% Conf. Int. for Odds Ratio | (D) | Probability of survival |
| Financial Year 2007/2008 Reference | 0.000 | 1.000 |  |  |  | 50% |
| Year 2008/2009 | 0.031 | 1.031 | 0.686 | 0.888 | 1.197 | 51% |
| Year 2009/2010 | -0.003 | 0.997 | 0.970 | 0.869 | 1.145 | 50% |
| Year 2010/2011 | 0.128 | 1.137 | 0.056 | 0.997 | 1.296 | 53% |
| Year 2011/2012 | 0.179 | 1.196 | 0.006 | 1.052 | 1.359 | 54% |
| Year 2012/2013 | 0.515 | 1.674 | 0.000 | 1.450 | 1.932 | 63% |

**B. Using or not the outcome to estimate missing values in the Glasgow Coma Scale**

1. The Glasgow Coma Scale (GCS) is a clinical observation recording the conscious level of the patient. In 14.6% of cases in the period 2007/08 to 2012/13 the value for GCS is missing. One reason for this is that the patient has been intubated at the scene of the trauma incident but no GCS has been recorded – intubated patients represent 5.2% of the missing GCS in this same period. If that was the case a separate category was used as the variable value. For all other missing values for the GCS variable an **imputation method** is used.
2. **Imputation** is the process of filling in ‘missing data’. To fill in missing data for the GCS variable the method of “multiple imputation” is used. Working with complete cases (excluding missing data) lead to biased regression estimates and as often the case, the patients with missing data are the ones with serious injuries and therefore need to be included in a model predicting outcome. The advantage of this method is that it produces standard errors that reflect the degree of uncertainty due to the multiple imputation procedure.
3. The multiple imputation model used by TARN includes the outcome variable (surviving or not from major trauma at 30 days). The published literature suggests that using the outcome in the multiple imputation model produces estimates of missing values closer to the true values than estimates of missing values produced by excluding the outcome variable from the imputation model.
4. For example, Moons et al. (2006; also cited by Sterne et al. 2009) used the regression coefficients and respective standards errors for five predictors of pulmonary embolism without missing values as a true set of values; assigned missing values to these predictors and then, using multiple imputation models including or not the outcome (a diagnosis of pulmonary embolism), compared the estimates of the outcome obtained with these imputation models with the true values. Their results showed that the imputation of missing predictor values using the outcome produced estimates of the outcome closer to the true values.
5. Table 2 shows descriptive statistics for the all GCS values and imputed GCS values only when the outcome (survival from major trauma at 30 days of admission) is excluded from or included in the imputation of missing GCS values. Table 3 shows the coefficients, odds ratio and respective confidence intervals for the variables used to predict survival from major trauma when the outcome is excluded from or included in the imputation model.
6. Overall, the values for all the GCS and for the imputed GCS are quite similar when including or not the outcome variable in the imputation model (see table 2).

**Table 2.** Descriptive statistics for the all GCS values and imputed GCS values only when the outcome (survival from major trauma at 30 days of admission) is excluded from or included in the imputation of missing GCS values

**Distribution of All GCS excluding Outcome from the imputation model Distribution of All GCS including Outcome in**

**the imputation model**

Percentiles GCS Value Percentiles GCS Value

Number of cases Number of cases

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| 1% | 3 |  |  |  | 1% | 3 |  |
| 5% | 6 |  |  |  | 5% | 6 |  |
| 10% | 11 |  | 80669 |  | 10% | 11 |  |
| 25% (Q1) | 14 | (excluding the 624 intubated patients with missing GCS) |  |  | 25% (Q1) | 14 | 80669 | (excluding the 624 intubated patients with missing GCS) |  |
| 50% (Med) | 15 | Mean | 13.88 |  | 50% (Med) | 15 |  | Mean | 13.87 |
| 75% (Q3) | 15 | Std. Dev. | 2.77 |  | 75% (Q3) | 15 |  | Std. Dev. | 2.78 |
| 90% | 15 |  |  |  | 90% | 15 |  |
| 95% | 15 |  |  |  | 95% | 15 |  |
| 99% | 15 |  |  |  | 99% | 15 |  |

**Distribution of the imputed GCS values only, Distribution of the imputed GCS values only , Including outcome excluding outcome**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Percentiles | Imputed GCS Value |  |  | Percentiles | Imputed GCS Value |  |  |
| **1%** | 4 |  |  | 1% | 4 |  |  |
| **5%** | 10 |  |  | 5% | 10 |  |  |
| **10%** | 13 | Number cases | 11297 | 10% | 13 | Obs | 11297 |
| **25% (Q1)** | 14 |  |  | 25% (Q1) | 14 |  |  |
| **50% (Med)** | 15 | Mean | 14.23 | 50% (Med) | 15 | Mean | 14.15 |
| **75% (Q3)** | 15 | Std. Dev. | 1.98 | 75% (Q3) | 15 | Std. Dev. | 2.06 |
| **90%** | 15 |  |  | 90% | 15 |  |  |
| **95%** | 15 |  |  | 95% | 15 |  |  |
| **99%** | 15 |  |  | 99% | 15 |  |  |

1. When the outcome is excluded from the imputation model, the odds ratios of survival from major trauma are higher for individual variables and are lower for the age-gender interaction (see table 3). That is, the odds of surviving from major trauma are better when the outcome is excluded from the imputation model than when it is included. For the variable ‘year’, whose regression coefficients are used to calculate the indicator values, the odds ratio obtained by including or not the outcome in the imputation model are similar, but still slightly higher when excluding the outcome variable from the imputation model.
2. The levels of significance are also similar when including or excluding the outcome, with a slight difference for 2010/11:
   1. the odds of surviving from major trauma in 2008/09 and 2009/10 are not significantly different from 2007/08 (the reference year in this illustrative data) for both models (including/excluding the outcome);
   2. the odds of survival in 2011/12 and 2012/13 are significantly higher than in 2007/08 in both models;
   3. however, the odds of survival from major trauma in 2010/11 are significantly higher than in 2007/08 when the outcome is excluded but are not significantly different from 2007/08 when the outcome is included.
3. Overall, including the outcome in the imputation model seems to provide a more conservative estimate of survival from major trauma.
4. Since the published research literature indicates that including the outcome variable in the imputation model produces estimates closer to the true values, we recommend using this approach when imputing missing values for the GCS.

**References**

Moons, K.G.M., Donders, R.A.R.T., Stijnen, T. & Harrell, F.E. (2006). Using the outcome for imputation of missing predictor values was preferred. *Journal of Clinical Epidemiology 59*: 1092–1101.

Sterne, J.A.C., White, I.R., Carlin, J.B., Spratt, M., Royston, P., Kenward, M.G., Wood, A.M. & Carpenter, J.R. (2009). Multiple imputation for missing data in epidemiological and clinical research: potential and pitfalls. *BMJ* 2009;338:b2393 doi: 10.1136/bmj.b2393

Table 3. Model parameters for survival from major trauma using imputed GCS values obtained with and without the outcome

**Imputed GCS without Outcome in the imputation model Imputed GCS with Outcome in the imputation model**

Logistic regression N = 81293 Logistic regression N=81293

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Outcome30D~s** | **coefficients** | **Odds Rat.** | **p-value** | **[95% Conf. Int.] for OR** | **[95% Conf. Int.] for OR** | **Outcome30D~s** | **coefficients** | **Odds Rat.** | **p-value** | **[95% Conf. Int.] for OR** | **[95% Conf. Int.] for OR** |
| ISS\_1 | 3.652 | 38.563 | <0.001 | 32.768 | 45.383 | ISS\_1 | 3.552 | 34.889 |  | <0.001 | 41.128 |
| ISS\_2 | 8.153 | 3472.300 | <0.001 | 1923.340 | 6268.730 | ISS\_2 | 8.040 | 3102.760 | <0.001 | 1715.880 | 5610.590 |
| GCS 13 - 15 (reference) |  |  |  |  |  | GCS 13 - 15 (reference) |  | 1.000 |  |  |  |
| GCS=3 | -3.555 | 0.029 | <0.001 | 0.025 | 0.032 | GCS=3 | -3.747 | 0.024 | <0.001 | 0.021 | 0.027 |
| GCS 4 - 5 | -2.435 | 0.088 | <0.001 | 0.075 | 0.103 | GCS 4 - 5 | -2.628 | 0.072 | <0.001 | 0.061 | 0.085 |
| GCS 6 - 8 | -1.481 | 0.227 | <0.001 | 0.199 | 0.259 | GCS 6 - 8 | -1.739 | 0.176 | <0.001 | 0.152 | 0.203 |
| GCS 9 - 12 | -1.075 | 0.341 | <0.001 | 0.304 | 0.384 | GCS 9 - 12 | -1.296 | 0.274 | <0.001 | 0.243 | 0.308 |
| GCS Intubation | -2.385 | 0.092 | <0.001 | 0.075 | 0.113 | GCS Intubation | -2.527 | 0.080 | <0.001 | 0.065 | 0.098 |
| 2007/2008 (reference) | 0.000 | 1.000 |  |  |  | 2007/2008 (reference) | 0.000 | 1.000 |  |  |  |
| 2008/2009 | 0.037 | 1.037 | 0.625 | 0.895 | 1.202 | 2008/2009 | 0.031 | 1.031 | 0.686 | 0.888 | 1.197 |
| 2009/2010 | 0.005 | 1.005 | 0.947 | 0.876 | 1.152 | 2009/2010 | -0.003 | 0.997 | 0.970 | 0.869 | 1.145 |
| 2010/2011 | 0.134 | 1.143 | 0.043 | 1.004 | 1.301 | 2010/2011 | 0.128 | 1.137 | 0.056 | 0.997 | 1.296 |
| 2011/2012 | 0.189 | 1.208 | 0.003 | 1.065 | 1.371 | 2011/2012 | 0.179 | 1.196 | 0.006 | 1.052 | 1.359 |
| 2012/2013 | 0.523 | 1.687 | <0.001 | 1.465 | 1.942 | 2012/2013 | 0.515 | 1.674 | 0.000 | 1.450 | 1.932 |

Table 3. (cont).

**Imputed GCS without Outcome in the imputation model Imputed GCS with Outcome in the imputation model**

Logistic regression N = 81293 Logistic regression N=81293

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Outcome30D~s** | **coefficients** | **Odds Rat.** | **p-value** | **[95% Conf. Int.] for OR** | **[95% Conf. Int.] for OR** | **Outcome30D~s** | **coefficients** | **Odds Rat.** | **p-value** | **[95% Conf. Int.] for OR** | **[95% Conf. Int.] for OR** |
| Age 16 - 44 (reference) | 0.000 | 1.000 |  |  |  | Age 16 - 44 (reference) | 0.000 | 1.000 |  |  |  |
| Age 0- 5 | 0.031 | 1.032 | 0.864 | 0.721 | 1.477 | Age 0- 5 | 0.017 | 1.017 | 0.928 | 0.708 | 1.460 |
| Age 6 - 10 | 0.304 | 1.355 | 0.233 | 0.822 | 2.234 | Age 6 - 10 | 0.289 | 1.335 | 0.253 | 0.813 | 2.193 |
| Age 11 - 15 | 0.180 | 1.197 | 0.285 | 0.860 | 1.666 | Age 11 - 15 | 0.177 | 1.193 | 0.298 | 0.855 | 1.666 |
| Age 45 - 54 | -0.479 | 0.619 | <0.001 | 0.534 | 0.718 | Age 45 - 54 | -0.498 | 0.608 | <0.001 | 0.522 | 0.708 |
| Age 55 - 64 | -0.961 | 0.383 | <0.001 | 0.330 | 0.444 | Age 55 - 64 | -1.005 | 0.366 | <0.001 | 0.315 | 0.426 |
| Age 65 - 75 | -1.671 | 0.188 | <0.001 | 0.162 | 0.218 | Age 65 - 75 | -1.732 | 0.177 | <0.001 | 0.152 | 0.205 |
| Age > 75 | -2.872 | 0.057 | <0.001 | 0.050 | 0.064 | Age > 75 | -2.964 | 0.052 | <0.001 | 0.046 | 0.059 |
| Gender Male (reference) | 0.000 | 1.000 |  |  |  | Gender Male (reference) | 0.000 | 1.000 |  |  |  |
| Gender Female | -0.098 | 0.907 | 0.261 | 0.764 | 1.076 | Gender Female | -0.113 | 0.893 | 0.197 | 0.753 | 1.060 |
| Age by Gender interaction |  |  |  |  |  | Age by Gender interaction |  |  |  |  |  |
| Age 16 - 44 (reference) |  | 1.000 |  |  |  | Age 16 - 44 (reference) |  | 1.000 |  |  |  |
| Age 0 -5 Female | 0.086 | 1.089 | 0.781 | 0.595 | 1.993 | Age 0 -5 Female | 0.059 | 1.061 | 0.846 | 0.584 | 1.928 |
| Age 6 - 10 Female | 0.832 | 2.299 | 0.155 | 0.729 | 7.248 | Age 6 - 10 Female | 0.863 | 2.371 | 0.140 | 0.753 | 7.464 |
| Age 11 - 15 Female | -0.073 | 0.930 | 0.816 | 0.502 | 1.721 | Age 11 - 15 Female | -0.068 | 0.935 | 0.833 | 0.499 | 1.752 |
| Age 45 - 54 Female | -0.104 | 0.901 | 0.489 | 0.670 | 1.211 | Age 45 - 54 Female | -0.081 | 0.922 | 0.595 | 0.683 | 1.244 |
| Age 55 - 64 Female | -0.105 | 0.900 | 0.440 | 0.690 | 1.175 | Age 55 - 64 Female | -0.097 | 0.908 | 0.481 | 0.693 | 1.189 |
| Age 65 - 75 Female | 0.231 | 1.260 | 0.097 | 0.959 | 1.655 | Age 65 - 75 Female | 0.258 | 1.294 | 0.055 | 0.994 | 1.684 |

|  |  |
| --- | --- |
| **IAS Ref Code** |  |
| **Indicator Title** |  |
| **Indicator Set** |  |

|  |  |  |  |
| --- | --- | --- | --- |
| Version | Date | Changed By | Summary of changes |
| v.01 | 16/05/13 | Chris Wilson | Document Created |
| v.02 | 16/05/13 | Sindy Holschumacher | Revision to methodology of indicator added |
| v.03 | 12/06/13 | Gavin Harrison | MRG details from 31/05/13 |
| v.04 | 14/06/13 | Sindy Holschumacher | Update on MRG recommendations |
| v.05 | 02/06/17 | Andrew Besch | Updated to reflect outcome of IGB meeting of 16/09/13 |
| v.06 | 13/09/2018 | Jonathan Trepczyk | Added extension paper added following IGB assurance |

**Indicator Assurance Extension Cover Sheet**

|  |
| --- |
| Lapsed Date  28/04/2017 |
| Criteria Check List |
| There is evidence that IGB assured the indicator to a period ending 1st January 2016 or after  Yes |
| Are there any outstanding caveats? List them here with updated information:  No |
| Are there any changes to…   1. Policy   No   1. Data source   No   1. Sponsoring organisation   No   1. Methodology   Yes  Are there any issues with data quality?  No |
| Has the indicator been superseded by another indicator? If yes, what is the new indicator’s reference number and title?  No |
| Has the indicator been withdrawn by the sponsoring organisation?  No |
| Are there any patient safety implications?  No |
| Have there been any reports of risk associated with this indicator?  No |
| Primary category  Choose an item. |
| 1 – Set - NHSOF |
| 2 – Publication reference |
| Recommendation  Fit for extension |
| Prepared by  Phyllis Macgoye |
| IGB decision  Fit for use |
| Accreditation period  Two years |
| IGB approval date  13/09/2018 |
| Review date  28/04/2019 |

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**Assurance Summary**

|  |  |
| --- | --- |
| **IAS Ref Code** |  |
| **Indicator Title** |  |
| **Indicator Set** |  |

**Assurance Stage Date(s) Comments**

|  |  |  |  |
| --- | --- | --- | --- |
| Application Received |  |  |  |
| Initial Appraisal Completed |  |  |  |
| Peer Review Appraisal |  | 28/05/13 |  |
| Methodology Review Group Discussion |  | 13/07/12, 09/08/12, 05/10/12, 31/05/13 |  |
| Indicator Governance Board Discussion |  | 16/09/13, 28/04/14 | IGB revision |
| Signed-off |  | 16/09/13, 28/04/14 |  |

Peer Review

**Peer Reviewer(s) / Organisations :**

**Outcome of Peer Review consideration**

|  |  |
| --- | --- |
| 1. **Proposal signed off, with or without caveats** |  |
| 1. **Minor changes recommended** |  |
| 1. **Declined to sign-off** |  |

Methodology Review Group (MRG)

***Outcome of MRG* consideration*:***

|  |  |
| --- | --- |
| 1. **No significant issues identified** |  |
| 1. **No significant issues on basis of completion of outstanding actions** |  |
| 1. **Some concerns expressed as caveats or limitations** |  |
| 1. **Significant reservations** |  |
| 1. **Unresolved issues** |  |

Indicator Governance Board (IGB)

**Final Appraisal Status**

|  |  |
| --- | --- |
| 1. **Assured** |  |
| 1. **Assured with Comments** |  |
| 1. **Failed Assurance** |  |

**Peer Review** Summary

IAS Ref Code:

|  |
| --- |
| **Indicator Title** |
| Indicator Set |
| Date of Peer Review : 21/05/13 |
| Peer Reviewer(s) / Organisations : | N Hoveyda (Consultant in Public Health Medicine) |
| Peer Review Comments: | Peer reviewers commented that they felt “feeling supported” as described in the title could be considered subjective. |
| Outcome of MRG consideration: |  |

Indicator Methodology for Consideration - **Methodology Review Group**

IAS Ref Code:

|  |  |
| --- | --- |
| **Initial Indicator Title** | [Indicator title submitted pre - MRG discussion]  **Proportion of people feeling supported to manage their conditions** |
| Indicator Set |  |

|  |
| --- |
| Introduction |
| [Brief background on indicators being considered, especially if they form part of a programme of indicators. Provide any general information such as ; urgency of approval / broad timescales; history and direction of any indicator programmes involved e.g. General news about NHS Outcomes Framework; Level of IC’s involvement, e.g. is it commissioned to produce or surface the data ] |

|  |
| --- |
| ***Summary description of the calculation:***  The indicator will be based on responses to questions in the GP Patient Survey as follows: |
| ***Calculation type:*** Percentage (weighted numerator/denominator) |
| ***Denominator:*** The denominator is the total number of **‘Yes, definitely’, ‘Yes, to some extent’** and **‘No’** answers to Question 32 (see below) for those having answered **yes** to the Question 30 “Do you have a long-standing health condition?”  ***Numerator:*** The numerator is the total number of **‘Yes, definitely’** or **‘Yes, to some extent’** answers to Question 32 (see below) for those having answered yes to the Question 30 “Do you have a long-standing health condition?”  ***GP Patient Survey Question 32***  In the last 6 months, have you had enough support from local services or organisations to help you manage your long-term condition(s)? Please think about all services and organisations, not just health services  a) Yes, definitely  b) Yes, to some extent  c) No  d) I have not needed such support  e) Don’t know/can’t say |
| ***Statistical Methods / Risk adjustment variables:***  The results will be standardised according to the methodology reported in the attached paper, “***Standardisation of GPPS LTC indicators 2012\_06\_29***”.  (N.B. this paper revised at future MRG meetings – see revisions section of this document) |
| **Other (Quality assurance/interpretation/known limitations):** |
| 1. Indicators 2.1 (and 2) are concerned with the quality of life for people with long-term conditions (LTCs). One key consideration in the calculation of these indicators is whether the type of LTC and the number of LTCs per respondent are taken into account. A report has been supplied by DH (*see supporting document ‘Standardisation of GPPS LTC indicators 2012\_06\_29’*) which describes a standardisation methodology to be used. The purpose of this method is to keep the weights for particular conditions and groups of conditions constant over time.   Patients are categorised by:  • Whether they have one, two or more conditions.  • Which of their conditions is the most serious. Severity defined by the average EQ-5D scores for patients with only one condition.   1. For indicators 2.1 (and 2), changes to the indicators may be biased as a representation of change to the outcomes sought due to unmeasured changes in:   • The average period that the surveyed individuals have suffered a long-term condition, a major determinant of stage and severity of disease, and hence of health status. If the average period since incidence of the sampled population decreases, for example through earlier diagnosis, the measured health related quality of life of the sample will improve without genuine improvement of outcome. Conversely, if the period since incidence increases, for example as improvements in care defer mortality, the measured health related quality of life will decline without genuine deterioration of outcome.  • Readiness to diagnose or report a "long standing health condition”, which might reflect change in tolerance of conditions by different age cohorts. For example, if a current cohort considers itself to suffer from a “long-term back problem” which an earlier cohort would have considered a normal part of ageing, the average casemix of the sample population will lighten.  “Standardisation of GPPS LTC indicators 2012\_06\_29”. |

MRG Recommendations, Comments & Updates:

IAS Ref Code:

|  |  |
| --- | --- |
| **Indicator Title** |  |
| Indicator Set |  |

|  |  |
| --- | --- |
| Ref code  **2012/115**  Made: 13/07/12 | 1. MRG asked for further evidence of available research around the demographic mix, and the experience mix (i.e. are people with a bad experience more likely to respond), for non-response bias. 2. In addition, MRG questioned that if there is a low response rate, are respondents with LTC typical of all people with LTC? What about the non-respondents? |
| Update:  Made: 09/08/12 | 1. For the survey in general a weighting system is applied to account for non-response bias. This adjusts for the variation in response rate between demographic groups. No research was carried out into whether those who did not respond had a different experience to those who did. This will be noted in the quality statement as per other indicators using this data source. 2. There is no research / evidence on these possible response biases, but DH have asked the survey contractor (Ipsos MORI) to be kept informed if any research is carried out. |
| Rec Status: | **Further Information Required**  **Resolved / No Action Required** |

|  |  |
| --- | --- |
| Ref code  **2012/116**  Made: 13/07/12 | MRG queried how people are identified for inclusion, with the recommendation that:   * **people not responding “Yes” to Question 30, but who subsequently identify a LTC in Q31, should be included in the calculation.** |
| Update:  Made: 09/08/12 | Recommendation accepted by the applicant . |
| Rec Status: | **Further Information Required**  **Resolved / No Action Required** |

**Revisions:**

To be completed where changes to the methodology are made by the applicant during the appraisal [i.e. subsequent to the initial application form]

A new section is to be added for each new set of revisions to go to MRG.

**Proposed Revision 28th April 2014**

|  |  |
| --- | --- |
| Revision Date: | 28/04/14 |
| General Comments / Reasoning: | Standardisation methodology for NHSOF / CCGOIS Domain 2 indicators  **Indicators Covered by the proposal**   * NHS OF 2 Health-related quality of life for people with long term conditions * NHS OF 2.1 Proportion of people who feel supported to manage their condition * NHS OF 2.4 Health-related quality of life for carers, aged over 18 years * CCG OIS 2.1 Health-related quality of life for people with long term conditions * CCG OIS 2.2 Proportion of people who feel supported to manage their condition * CCG OIS 2.15 Health-related quality of life for carers, aged over 18 years * CCG OIS 2.16 Health related quality of life for people with a long term mental health condition * **Indicator Data Source**: *GP Patient Survey (GPPS)*   The indicators covered in this paper have all previously been discussed by IGB with a recommendation that they be reviewed by MRG, with the exception of CCG OIS 2.15 (awaiting discussion at IGB), and CCG OIS 2.16 (under initial consideration by MRG pending more information).  The proposal described below is separate to other issues pending further discussion at MRG  Background  The indicators were published (for the first time) in September 2013. The purpose of the indicators inclusion in the frameworks are:   * CCG OIS – to facilitate comparison across CCGs and over time * NHS OF – at national level to facilitate comparison over time but also to facilitate comparison across breakdown categories (e.g. across LAs)   The indicators were weighted at the individual level to account for variation in the age- and gender-structure of the population across breakdowns. However, a subsequent review of the weighting methodology identified weaknesses. In particular, even after the weighting, the indicators were influenced by variation in the population’s age- and gender-structure. A NHS Outcomes Analysis Team review of the methodology recommended that a form of direct or indirect standardisation would be more appropriate to facilitate comparisons in the indicators across breakdowns (including CCGs) and over time.  **Areas of investigation recommended by MRG**  MRG was concerned that in general, indirect standardisation should not be used for comparison across CCGs. Although it was appreciated that there is an issue with small numbers using the direct method, it was proposed that the applicant should ensure all options for standardisation had been considered and their proposed method is the most valid.  MRG recommended following the steps below:   1. Firstly, investigate if direct standardisation could be viable through combining years or some of the initially proposed breakdown groups. 2. If the results of the investigation determined that this would result in too weak a standardisation, test whether indirect standardisation is valid, for instance determining if indirect standardisation holds valid in terms of populations being comparable. 3. Finally, if indirect standardisation is arrived at as being valid, then the developer would be required to provide supporting metadata that was very clear about the limitations of use of the indicator in terms of comparison.   Developer’s voiced concern that for some of the indicators, numbers were likely to be small and, even if numbers combined, may still not have sufficient data to support direct standardisation e.g. the *long term mental health condition* indicator. Additionally, they were concerned of a mis-match in methodologies between CCGOIS indicators if different approaches were used.  MRG members put forward that although it was desirable to have the same method it is not essential; what is essential is to have robust methods. The question that the developer needs to consider is to is whether it is appropriate to standardise at all if numbers are so small.  **Final Methodology Put Forward for Endorsement From IGB**  The following approach to standardisation was submitted to MRG, to which the group has recommended the indicators for discussion at IGB.  Based on the findings of the investigation steps recommended by MRG, the proposal for the domain 2 NHS Outcomes Framework / CCGOIS indicators is as follows:   * Use direct standardisation as calculation method with the original age groups * Where there are empty cells (at least 1)\* for any of the categories within a breakdown suppress the calculated indicator values for the category in question   *\*(the directly standardised rate used eight age categories and gender (therefore 16 cells) and if one of these cells was missing a value, it was proposed to suppress the LA.)*   * Further, where the numerator for a breakdown category is less than 25 suppress the calculated indicator values, due to the fact small numbers would make the estimate unreliable. This is in line with what currently happens within the PHOF. * In addition to the LA district breakdowns provide upper tier LA breakdowns. This would provide valuable additional information for local decision makers and would also provide values for LAs where values are suppressed for the LA district breakdown * Once 3-years’ worth of GPPS data are available it is proposed to additionally calculate an indicator value based on a rolling 3-year dataset * Publish numerator and denominator values in addition to the indicator values. It is proposed to also provide these for all indicator values that are suppressed unless the numerator values are below 5, which is in line with standard suppression rules. * For some cases, due to zero cells, CCG values will need to be supressed |
| Revisions: |  |
| Indicator Title | NHS OF 2.1 Proportion of people feeling supported to manage their conditions |
| Data source | * *GP Patient Survey (GPPS)* |
| Construction | No change |
| Updated Potential Issues | No change |

**Proposed Revision 5th October 2012**

|  |  |
| --- | --- |
| Revision Date: | 5th October 2012 |
|  |  |
| General Comments / Reasoning: | NEW UPDATE TO STANDARDISATION METHODOLOGY FOR:  NHSOF 2 – Health-related quality of life for people with long-term conditions  **NHSOF 2.1 – Proportion of people feeling supported to manage their condition**  NHSOF 2.4 – Health-related quality of life for carers  On the 9th August, MRG approved the indicators listed above for use in the NHS Outcomes Framework. However, the Department of Health is now proposing a revised approach to the standardisation methodology used within these indicators. A separate paper has been circulated outlining these changes (***Standardisation of GPPS LTC Indicators 2012\_10\_02 - Revision.doc***).  The reason behind changing the methodology was due to fears that the groups would be too large and would see respondents with a range of different conditions grouped together. Groups would be dependent on the patients 3 most serious LTCs. So, where respondents have more than 3 LTCs, they could be grouped with individuals with different conditions (but at least 3 the same).  A table showing the number of LTCs patients reported is captured below. Over 75% of respondents fall into groups with 2 or less LTCs. Out of the patients who would be in the groups with 3 or more LTCs, 58% have exactly 3 LTCs.  **Number of LTCs Count 12368 Percentage 1.998245**  **Non recorded**  **1 324251 52.38786**  **2 153708 24.83395**  **3 74917 12.10402**  **4 33270 5.375293**  **5 13162 2.126529**  **6 4851 0.783756**  **7 1620 0.261737**  **8 474 0.076582**  **9 127 0.020519**  **10 43 0.006947**  **11 18 0.002908**  **12 3 0.000485**  **13 10 0.001616**  **14 15 0.002423**  **15 78 0.012602**  **16 28 0.004524**  The Clinical Indicators team feel there are significant issues with this proposed revision and particularly around the extremely large number of groups that this weighting methodology would involve. We would suggest reverting to the methodology previously approved by MRG. |
| Revisions: |  |
| Indicator Title | None |
| Data source | None |
| Construction | See paper *(Revised GPPS LTC Standardisation 02102012.doc).* |
| Updated Potential Issues |  |

Recommendations, Comments & Updates:

Following MRG appraisal 5th October 2012

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| **Indicator Title**  Indicator Set |
| Ref code  **2012/263**  Made: 13/07/12  Note – applies to NHSOF indicators 2, 2.1 & 2.4  In response to methodological change proposed in paper *(Revised GPPS LTC Standardisation 02102012.doc).*  MRG raised concern over the lack of hierarchy of conditions. Additionally, MRG’s view was that the proposed change to the more complex standardisation methodology meant that there was a big risk that model fitting would not converge when the indicator was constructed due to the very large number of parameters, and that it would be extremely difficult to determine why the model does not converge.  This has been an issue experienced with the development of SHMI which has a lot fewer variables than is being put forward.  Concern was also raised that by using the methodology would result in a large number of zero cells which would result in an indicator that the user wouldn’t know how to interpret.  MRG queried whether comparison to an unstandardised result would be help, as it cannot be assumed that if the adjusted and unadjusted values are similar the figures are therefore accurate or that the method is good – one can only infer that the people included or included had little effect.  MRG recommended that as a general rule to see impact of people with LTC on outcomes the starting point should be using crude standardisation, with more refinement added if it is determined that the crude standardisation makes it hard to interpret results.  MRG also suggested there was a need to go through the criteria being used for risk adjustment to demonstrate the validity of the moving from the current methodology which already includes sub dividing by the seriousness of the condition. Without doing this there is no justification for moving to the new methodology. This could be done following the criteria for risk adjustment in the Indicator Assurance appraisal template. |
| Update:  Made: xx/xx/xx |
| Further Rec:  Made: xx/xx/xx |
| Update:  Made: xx/xx/xx |
| Rec Status:  **Further Information Required**  **Resolved / No Action Required** |

**Proposed Revision 29th May 2013**

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| Revision Date: | 29/05/13 |
| General Comments / Reasoning: | **NEW UPDATE TO STANDARDISATION METHODOLOGY FOR:**  NHSOF 2.1 – Proportion of people feeling supported to manage their condition  NHSOF 2.4 – Health-related quality of life for carers  On the 9th August, MRG approved the indicators listed above for use in the NHS Outcomes Framework. However, after previously suggesting 2 different methodologies for standardising the indicators the Department of Health has put forward a revised proposal of the standardisation methodology used for these indicators. Please note that the newly proposed methodology is only applicable to indicators 2.1. and 2.4 and does not cover indicator 2. A separate paper has been circulated outlining the latest methodology (*Standardisation of GPPS LTC Indicators 2012\_05\_10 Revision 2 1 and 2 4 .doc*). |
| Revisions: |  |
| Indicator Title | None |
| Data source | None |

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| Construction | After the previous considerations of different methodologies, it is proposed the new standardisation methodology for indicators 2.1 and 2.4 should be based on age. It is proposed to apply an age weighting to any future data points for this indicator based on question 48 of the GP Patient Survey:  How old are you?   * Under 18\* * 18 to 24 * 25 to 34 * 35 to 44 * 45 to 54 * 55 to 64 * 65 to 74 * 75 to 84 * 85 or over   As the GP Patient survey only covers adults aged 18 years and over it is proposed to eliminate the ‘Under 18’ category.  The responses would be standardised by age, using the age bands provided above (except for the “Under 18” age band). This would ensure the indicator is robust to changes in the age structure of the population over time (when comparing the current data point with any future data points).  Based on the current GP patient survey data the age weights that would be applied to future data points for indicator 2.1 can be seen in the table below:  Table - 1 Age weights to be applied to future data points for indicator 2.1  **Age bands based on question Number in age band Weight**  **48 the GPPS 2011/12**  19,992 0.0193  18 to 24 45,846 0.0442  25 to 34 102,952 0.0992  35 to 44 140,192 0.1351  45 to 54 177,804 0.1713  55 to 64 205,881 0.1984  65 to 74 187,508 0.1807  75 to 84 118,736 0.1144  85 or over 39,035 0.0376  **Total 1,037.946 1**  For indicator 2.4 it has been considered to further standardise to the number of hours cared in addition to age. This could be done by using question 56 of the GP Patient Survey (see below).  Question 56: Do you look after, or give any help or support to family members, friends, neighbours or others because of either:   * Long-term physical or mental ill health/disability, or * Problems related to old age?   Don’t count anything you do as part of your paid employment   * No * Yes, 1-9 hours a week * Yes, 10-19 hours a week * Yes, 20-34 hours a week * Yes, 35-49 hours a week * Yes, 50+ hours a week   Based on the current GP patient survey data the weights accounting for age as well as the number of hours cared, which would be applied to any future data points for indicator 2.4 can be seen in table 2 below:  **Age bands (Q48) and number of hours**  **cared**  **(Q56) from the GPP S 2011/12**  **Number of responses Weight**    Yes, 1-9 hours a week 1,397 0.007151  Yes, 10-19 hours a week 336 0.00172  Yes, 20-34 hours a week 282 0.001443  Yes, 35-49 hours a week 213 0.00109  Yes, 50 + hours a week 739 0.003783  18 to 24 Yes, 1-9 hours a week 1,397 0.007151  18 to 24 Yes, 10-19 hours a week 336 0.00172  18 to 24 Yes, 20-34 hours a week 282 0.001443  18 to 24 Yes, 35-49 hours a week 213 0.00109  18 to 24 Yes, 50 + hours a week 739 0.003783  25 to 34 Yes, 1-9 hours a week 6,054 0.030988  25 to 34 Yes, 10-19 hours a week 1,212 0.006204  25 to 34 Yes, 20-34 hours a week 855 0.004376  25 to 34 Yes, 35-49 hours a week 674 0.00345  25 to 34 Yes, 50+ hours a week 1,532 0.007842  **Number of responses Weight**    35 to 44 Yes, 1-9 hours a week 12,453 0.063743  35 to 44 Yes, 10-19 hours a week 2,371 0.006204  35 to 44 Yes, 20-34 hours a week 1,576 0.004376  35 to 44 Yes, 35-49 hours a week 1,308 0.00345  35 to 44 Yes, 50+ hours a week 3,905 0.007842  45 to 54 Yes, 1-9 hours a week 27,058 0.1385  45 to 54 Yes, 10-19 hours a week 5,321 0.027236  45 to 54 Yes, 20-34 hours a week 2,915 0.014921  45 to 54 Yes, 35-49 hours a week 2,109 0.010795  45 to 54 Yes, 50+ hours a week 6,276 0.032125  45 to 54 Yes, 1-9 hours a week 27,058 0.1385  45 to 54 Yes, 10-19 hours a week 5,321 0.027236  45 to 54 Yes, 20-34 hours a week 2,915 0.014921  45 to 54 Yes, 35-49 hours a week 2,109 0.010795  45 to 54 Yes, 50+ hours a week 6,276 0.032125  55 to 64 Yes, 1-9 hours a week 31,634 0.161923  55 to 64 Yes, 10-19 hours a week 7,272 0.037223  55 to 64 Yes, 20-34 hours a week 3,795 0.019425  55 to 64 Yes, 35-49 hours a week 2,290 0.011722  55 to 64 Yes, 50+ hours a week 9,224 0.047214  75 to 74 Yes, 1-9 hours a week 18,487 0.094628  75 to 74 Yes, 10-19 hours a week 4,224 0.021621  75 to 74 Yes, 20-34 hours a week 2,601 0.013314  75 to 74 Yes, 35-49 hours a week 1,534 0.007852  75 to 74 Yes, 50+ hours a week 9,823 0.050281  **Number of responses Weight**    75 to 84 Yes, 1-9 hours a week 6,782 0.034715  75 to 84 Yes, 10-19 hours a week 1,546 0.007913  75 to 84 Yes, 20-34 hours a week 1,287 0.006588  75 to 84 Yes, 35-49 hours a week 798 0.004085  75 to 84 Yes, 50+ hours a week 7,333 0.037535  85 or over Yes, 1-9 hours a week 6,782 0.034715  85 or over Yes, 10-19 hours a week 1,546 0.007913  85 or over Yes, 20-34 hours a week 1,287 0.006588  85 or over Yes, 35-49 hours a week 798 0.004085  85 or over Yes, 50+ hours a week 7,333 0.037535  **Total 195,364 1** |  |
|  | It is argued that this would help to control for changes to the population with long-term conditions, as an older frailer population are likely to require more intensive care and this would be expected to have a greater impact on the health status of carers, independently of the quality of care provided by the NHS. |  |
| Updated Potential Issues | With the additional standardisation by the number of hours cared there is concern that there could be some degree of endogeneity, that, to some extent, the hours spent caring could be a function of the quality of care provided by the NHS to the person cared for.  In this way, if NHS quality of care for people with LTCs deteriorates, the hours that carers need to spend caring could increase, which could lead to reduced EQ-5D scores for carers (this is a common result in the literature, referenced here: <http://www.oecd.org/els/health-systems/47884865.pdf>). |  |

Recommendations, Comments & Updates:

Following MRG appraisal 31st May 2013

IAS Ref Code:

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| **Indicator Title** |
| Indicator Set |

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| Ref code  **2013/28**  Made: 31/05/13 | Following feedback from peer reviewers DH proposed just standardising by age for indicator 2.4.  MRG would prefer to see additional analysis carried out first, rather than abandoning the currently proposed standardisation by number of hours cared for those with long term conditions. This was an issue highlighted during a previous discussion as a potential impact on quality of life for carers.  MRG commented that the reasons for adjusting should be based on the rationale / underlying reasons for the indicator. It would be worth exploring / modelling potential relationships between variables. Based on the outcome of this research , the decision can then be made on whether to adjust, and subsequently state in the rationale why / why not a particular adjustment has been used and what the indicator can / cannot be used for, e.g. comparison.  There was an additional peer review suggestion to standardise by gender for indicator 2.4. MRG would like to see additional analysis carried out on the potential impacts of standardisation as follows:  2.1 – age, additionally investigating impacts of small numbers in age bands for the CCGOIS version of this indicator.  2.4 – age, gender, number of hours cared for persons with long terms conditions. It was noted that there isn’t a proposal to create a CCGOIS version of indicator 2.4 at present. |
| **Update:**  Made: 14/06/13 | * 1. – age, additionally investigating impacts of small numbers in age bands for the CCGOIS version of this indicator.   This has been done for the NHS Outcomes Framework and CCG OIS and has been presented in the previous update   * 1. – age, gender, number of hours cared for persons with long terms conditions. It was noted that there isn’t a proposal to create a CCGOIS version of indicator 2.4 at present.   The table below shows the number of people (as per the GGPS) who care for somebody where this is not part of their job (based on Q56) split by age band, gender and number of hours cared (see table below). For ease of reading the table can also be seen in the attached Excel file (**2.4\_Age\_Gender\_NumberOfHoursCared\_Distribution.xlsx**)  The majority of people, who are carers, spend 1-9 hours caring and fall in the age bands between 45 to 54 and 55 to 64. In the 45 to 54 age band twice as many carers are female than male. The number of female carers is still significantly higher than male carers in the 55 to 64 age band (highlighted in yellow).  This trend can also be seen for people who spend more than 50 hours a week caring for all age bands up to 74. In the 25 to 34 age band the number of female carers is three times as high as the number of male carers. In the 65 to 74 age band the number of female carers is only slightly higher than male carers (highlighted in orange).  However, this trend appears to reverse in the older age bands (75 to 84 and 85+). Looking at all different number of hours cared groupings it can be seen that the proportion of female carers is lower than the proportion of male carers in those age bands (highlighted in green).  Looking at the proportion of GPPS respondents who spend time caring compared to the general ONS midyear population estimates it raises the question why the GPPS population in the older age bands (75+) does not appear to show the same trend as ONS population (e.g. for 85+ there is more males amongst the GPPS respondents compared to the ONS estimates (more females in this age band).  The same trend has been observed by the ONS as part of their more detailed Census publications (<http://www.ons.gov.uk/ons/rel/census/2011-census/detailed-characteristics-for-local-authorities-in-england-and-wales/rpt---unpaid-care.html>)  The ONS publication (see link above) also reports a higher propensity to provide informal care amongst men compared to women at older ages. They key paragraphs from this publication are as follows:  “However, in the age category 65 and above, the disparity reversed, with the percentage of men in both England and in Wales providing unpaid care exceeding the percentage of women. This is largely explained by the sharper tailing off in the number of women providing unpaid care from ages 50-64 to 65 and above, particularly in England where the number of women providing unpaid care diminished by more than half a million, whereas the number of men providing unpaid care fell by less than a quarter of a million.   "Given that the provision of unpaid care at ages 65 and above is more likely to be provided for a coresident, particularly a spouse, and the lack of detail in this broad age category means it is difficult to disentangle the possible mechanisms bringing about the more abrupt reduction in unpaid care provided by women from ages 50-64 to 65 and above. However, evidence from health expectancy statistics suggest that although females have longer life expectancies than males, they spend a higher proportion of these additional years in ‘Not Good’ general health, meaning that women in this age range are more likely to be in need of care than providing it than men."  After looking at the differences of the three variables and their bandings it is proposed to standardise future data points for indicator 2.4 by age and gender only. This is supported by an OFTAG recommendation.  OFTAG though that standardising also by “number of hours spent caring” risked controlling for some of the variation in the quality of care (particularly of social care, which we are also interested in). |
| Ref code  **2013/29**  Made: 31/05/13 | Previous background research has been carried out by the School of Health and Related Research at the University of Sheffield ([ScHARR](http://www.sheffield.ac.uk/scharr)), however the findings did not prove beneficial in identifying the contribution of the NHS, which is the underlying purpose of these indicators.  MRG requested that previous background research, even if it isn’t beneficial, should be included in the paperwork for consideration by the group. It would prove helpful for providing a complete picture and prevents others from duplicating the same research in the future. |
| **Update:**  Made: 14/06/13 | NHS England (formerly DH) asked QORU[[1]](#footnote-1) to develop a standardisation methodology for this indicator that would allow to measure the impact that the NHS has on the health-related quality of life for people with LTCs, and, as far as possible, would eliminate the impact of external factors.    The methodology that QORU/SEPHO produced assigned GPPS respondents into several categories according to the following criteria:    •     Number of LTCs    •     Age bands    •     IMD binary variable    •     A "permanently sick or disabled" working status    •     Presence of musculoskeletal conditions where there was no recording of being permanently sick or disabled    The size of each of these cells was then held constant over time. Therefore, increases in the size of any of these groups over time would not be reflected in the indicator score.    Although this did not allow for the comparison of like-with-like, from NHS England’s point of view the criteria chosen were not consistent with the instructions provided, as several of these factors would be strongly affected by NHS interventions.    •     The number of LTCs of an individual would be affected by external factors but to some extent could also be amenable to NHS interventions. For instance, the NHS can help people with diabetes delay or completely avoid the development of complications. If this is standardised away, the indicator would not reflect this important part of NHS care for people with LTCs.    •     Similarly, it was debatable as to whether the Index of Multiple Deprivation could be used to standardise the indicator. Deprivation could be linked to aspects of health-related quality of life that are outside the control of the NHS (fuel poverty, malnutrition, for instance), but it could also be linked to access to NHS services and worse quality of care. Standardising this aspect meant that it would not be possible to estimate whether the NHS is providing equally good care to both, those who are deprived and to those who are not.    •     An increase in the numbers of those who are permanently sick or disabled working status was not something that NHS England would have wanted to be standardised, as it reflects an important role of the NHS in improving the functional ability of people with long-term conditions. Domain 2 of the NHS Outcomes Framework contains an explicit indicator of this health outcome, indicator 2.2, which measures the difference in employment rates between people with LTCs and the overall population.    •     The presence of musculo-skeletal conditions could be partly due to the quality of NHS care (as well as Social Care, it should be noted that this indicator also features in the Social Care Outcomes Framework).    Due to this, the standardisation methodology that QORU proposed was not deemed appropriate for assessing the performance of the NHS. |
| Ref code  **2013/30**  Made: 31/05/13 | MRG noted that the rationale of these indicators state that the contribution of the NHS is being measured, but the names of the indicators doesn’t necessarily reflect this.  A query was raised asking if the GP survey question used was appropriate for the rationale of the indicators. DH stated that 50% of those who respond to the GP survey have a long term condition, therefore the GP patient survey is reasonably representative of people with long term conditions. MRG requested that this kind of detail be included in the paperwork for consideration.  MRG raised the issue of non-responders and if there was anything that could be done to identify these. Non-responders could potentially be those that the indicator is trying to capture, for example if they’ve had a long hospital stay and not been home for some considerable time they wouldn’t have received the survey. MRG acknowledged that non-response is an issue in most surveys; providing any limitations regarding non-response are highlighted in the quality statement then this shouldn’t be an issue.  MRG discussed the appropriateness of the GP survey as a data source;  It was pointed out that the GP survey is not an ISB approved data source and neither does it have a ROCR licence. However, it was also acknowledged that in the absence of a better data source this is still the most appropriate source without adding additional burden to providers. MRG suggested that supplying the full GP survey as an appendix would have been useful to aid in the assessment of the overall indicator quality. |
| **Update:**  Made: 14/06/13 | **Co Coverage of long-term conditions in the GP Patient Survey**  GPPS data suggest a prevalence rate of long-term conditions of approximately 50% amongst the adult population. The findings do not suggest that people with long-term conditions are under-represented in the GPPS data. As people with long-term conditions appear to be well represented in the GPPS data, and as this source is used as the basis for approved and published NHS Outcomes Framework indicators, it is not expected that its use is an issue for use as the data source for indicator 2.1 and 2.4.  **Issue of non-responders**  MRG acknowledged that non-response is an issue in most surveys; providing any limitations regarding non-response are highlighted in the quality statement then this shouldn’t be an issue.  We accept this recommendation. Previously assured NHS Outcomes indicators in Domain 4 are also based on the GP patient survey. For all indicators affected by the issue of non-response in the GP patient survey (at current NHS OF indicators in 4a and 4.4) the quality statement clearly highlights the issue in the ‘Accuracy and Reliability’ section. We would adopt this approach for NHS OF indicators 2.1 and 2.4, once assured.  **Lack of ISB approval and ROCR license of GP patient survey**  It was acknowledged that in the absence of a better data source the GPPS is still the most appropriate source for indicators 2.1 and 2.4 without adding additional burden to providers. As suggested by MRG, the GP patient survey is attached in the supporting documentation. The [Technical Annex for the GP Patient survey](http://www.gp-patient.co.uk/results/download/_y6q2/y6w2_AnnualTechnical.pdf) contains details regarding eligibility, participation and sampling for the survey.  As recommended by MRG we will initiate a wider discussion around the appropriateness of data sources outside the MRG meeting.  **Quoting of EQ-5D instrument**  Although not mentioned at the last MRG meeting a separate comment was received regarding the reference to EQ-5D in connection with this indicator.  Quote; “The guide to the EQ-5D (UK English Version) states:  “EQ-5D is a two-part instrument so if you only use 1 part you cannot claim to have used the EQ-5D in your publications.”  As the survey only uses the descriptive part and not the visual part, references to EQ-5D should be withdrawn.”  The following answer has been received from NHS England:  “I am advised that it is correct to say that the EQ-5D items and the EQ-visual analogue score (VAS) item are related, but it is not correct that the EQ-5D index score is calculated using the response to the EQ-VAS item.  The EQ-5D index is calculated using the EQ-5D items and a socially derived tariff.  Euroqol Group gave written permission to the Department of Health on 2 May 2011 to use the EQ-5D questions only in this format for the GP patient survey and are happy for it to be referred to in the way that NHS England (formerly DH) do.  It is intended to carry out a review of the entire survey programme NHS England has gained responsibility for, as part of our wider programme of insight work. NHS England has not yet finalised the scope or terms of reference of the review but is keen to look at where the survey programme or any part of it might be improved. There is also access to new sources of real-time feedback, which will add to the insight about patient experience. |
| Ref code  **2013/31**  Made: 31/05/13 | **Indicators to be brought back to MRG once additional analysis regarding standardisation has taken place. MRG also requested that any relevant background research (whether it is beneficial or not) is included in the MRG papers.** |
| Update:  Made: xx/xx/xx |  |
| Further Rec:  Made: xx/xx/xx |  |
| Update:  Made: xx/xx/xx |  |

Record of Assurance provided by **Indicator Governance Board**

IAS Ref Code:

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| **Indicator Title** |
| Indicator Set |

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| Description  Proportion of people feeling supported to manage their condition, measured based on responses to question 32 of the GP Patient Survey; In the last 6 months, have you had enough support from local services or organisations to help you manage your long term condition(s)? Please think about all services and organisations, not just health services. |
| Initial IGB discussion  16/09/13  Further discussed |

**Strategic Considerations & Implications**

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| Applicant / Sponsor Organisation | NHS England  \*Costing for assurance appraisal included in development cost  Assurance process funded?  **Yes\***  **No** |
| Indicator rationale | The vast majority of the population visit their GP each year, and the average person will visit their GP more than five times a year. This will particularly be the case for people with long-term conditions. Often it is the experience people have of primary care that determines their overall view of the NHS. This indicator uses survey results to look specifically at whether people are feeling supported to manage their long-term condition. |
| Basis for rationale  [Details of quality statement, policy etc.] | It is now standard practice in healthcare systems worldwide to ask people to provide direct feedback on the quality of their experience, treatment and care. This indicator will be used alongside additional information sources to provide local clinicians and managers with intelligence on the quality of local services from the patients’ and service users’ point of view and will ultimately play a role in driving improvements in the quality of service design and delivery.  This indicator has been selected as part of the set of NHS Outcomes Framework indicators and CCG Outcome Indicator Set. The indicator is part of Domain 2 which reflects the importance of enhancing the quality of life for people with long-term conditions. |
| Calculation Summary | ***Denominator:***The denominator is the total number of ‘Yes, definitely’, ‘Yes, to some extent’ and ‘No’ answers to question 32 of the GP Patient Survey (GPPS) *“In the last 6 months, have you had enough support from local services or organisations* to help you manage your long-term condition(s)?”, for those having answered “Yes” to question 30 *“Do you have a long-standing health condition?”* or tick a condition in question 31 *Which, if any, of the following medical conditions do you have? Please x all the boxes that apply to you.*  ***Numerator:*** The numerator is the total number of ‘Yes, definitely’ or ‘Yes, to some extent’ answers to question 32 for those having answered yes to the question 30 or tick a condition in question 31 *Which, if any, of the following medical conditions do you have? Please x all the boxes that apply to you.* |
| Risks & assumptions | * Changes to the indicators may be biased as a representation of change to the outcomes sought due to unmeasured changes in:   + The average period that the surveyed individuals have suffered a long-term condition, a major determinant of stage and severity of disease, and hence of health status. If the average period since incidence of the sampled population decreases, for example through earlier diagnosis, the measured health related quality of life of the sample will improve without genuine improvement of outcome. Conversely, if the period since incidence increases, for example as improvements in care defer mortality, the measured health related quality of life will decline without genuine deterioration of outcome.   + Readiness to diagnose or report a "long standing health condition”, which might reflect change in tolerance of conditions by different age cohorts. For example, if a current cohort considers itself to suffer from a “long-term back problem” which an earlier cohort would have considered a normal part of ageing, the average casemix of the sample population will lighten. * As with other indicators based on the GPPS, the quality statement includes an explanation of the potential impact of non-response. |
| IG Considerations [e.g. release of under-lying data, intermediaries’ access to data, data ownership impact on production] | **Data Source: This indicator is based on the twice yearly GP patient survey data.**  The GP Patient Survey is being run centrally and administered by Ipsos MORI with patients selected at random from GP registered lists in order to avoid the possibility of primary care providers being able to “game” the system.  Underlying data is provided to HSCIC via a Confidentiality Protection Agreement with NHS England.  The indicators will be made publicly available via the HSCIC indicator portal.  EQ-5D™ is a registered trademark of EuroQol. Further details are available from <http://www.euroqol.org>. |
| Potential impacts on other business areas [inc outstanding generic issues] | * This indicator is derived from the GP Patient Survey, alongside a number of other indicators sharing the same data source. Consideration of generic issues relating to the survey should be applied to the appraisal / review of this indicator for consistency. * The weighting methodology used within the calculation of this indicator also relates to *NHSOF 2. Health related quality of life for people with long-term conditions & NHSOF 2.4 Health related quality of life for carers* |
| Implementation Method  [inc production funding] | Production funding is secured  The indicator makes use of an existing data collection, so there are no additional data collection cost implications of burden. |

**Record of MRG Discussion**

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| Discussion dates: | 09/08/12, 05/10/12, 31/05/13, 08/07/13  By:  Alyson Whitmarsh HSCIC Programme Manager Clinical Audit  John Varlow HSCIC Director of Information Services  Andy Sutherland HSCIC Statistics Head Of Profession  Paul Fryers PHE Deputy Director, EMids Knowledge and Intel. Team  Jonathon Hope HSCIC Principal Information Analyst Clinical Audit  Karina Gajewska HSCIC Section Head Clinical Indicators  *Gerry Firkins ISB Domain Lead* |
| Summary of MRG discussions: | The indicator was discussed on several occasions by the Methodology Review Group. Latter discussions focussed on the weighting methodology to be used within this, and other long term condition indicators based on the GP Patient Survey (GPPS).   * Confirmation was given that people not responding “Yes” to Question 30 *“Do you have a long-standing health condition?”* in the survey, but who subsequently identify a LTC in question 31, should be included in the calculation*.* * MRG asked for further evidence of available research around the demographic mix, and the experience mix (i.e. are people with a bad experience more likely to respond), for non-response bias. The applicant confirmed that no such research had been carried out but that weighting was applied to account for non-response bias - this is noted in the quality statement. * MRG accepted that non-response is an issue in any survey and that as long as the quality statement reflected this and any possible limitations then it should not be an issue as previous assured indicators had been based on GPPS data. * MRG discussed the appropriateness of the data source as it is not ISB approved and does not have a ROCR licence. MRG acknowledged that in the absence of a better data source the GPPS is still the most appropriate source for this indicator without adding additional burden to providers.   A number of revisions to the weighting methodology for this indicator were discussed.   * An draft paper supplied by the applicant, describing the weighting methodology to be used, was considered as part of the Methodology Review Group appraisal. The purpose of the proposed method was to keep the weights for particular conditions and groups of conditions constant over time. Patients were categorised by:   + Whether they have one, two or more conditions.   + Which of their conditions is the most serious. Severity defined by the average EQ-5D scores for patients with only one condition. * A revised weighting methodology was subsequently suggested due to concerns that the groupings would be too large and would see patients with different conditions grouped together. MRG expressed considerable concern about this revised methodology, focussing on a lack of hierarchy of conditions in the proposal, and that a changing to a more complex weighting methodology meant that there was a big risk that model fitting would not converge when the indicator was constructed due to the very large number of parameters. Concern was also raised that the methodology would result in a large number of zero cells which would result in an indicator that the user wouldn’t know how to interpret.   In the **final revision**:   * The proposal to weight by age with the removal of the under 18 age category (as respondents to the GP Patient Survey are aged 18 and over) was assured. This is in order to ensure that the indicator is robust to changes in the age structure of the population in the future. * The indicator will be weighted using age and gender.   For use at CCG Level:   * Responses would have to be split down by CCG level to be able to calculate specific age weights based on the level of responses in each CCG. This has been done based on the current GP patient survey data to ensure that the numbers in each CCG specific age band are big enough to be able to apply the weight. No empty cells were identified in sample data and the minimum number of responses within the age category was 11 for a CCG with a total number of 668 respondents. MRG agreed that this would be sufficient to be able to calculate indicator at CCG level using the proposed methodology. |
| Outcome of MRG consideration: | 1. **No significant issues identified** 2. **No significant issues on basis of completion of outstanding actions** 3. **Some concerns expressed as caveats or limitations** 4. **Significant reservations** 5. **Unresolved issues** |
| **Additional Assurance Details** | |
| Peer Reviewers: | Dr Nourieh Hoveyda  Nicola Bent (NICE) |
| Peer Review summary: | (sent as part of pack)  No additional comments made specific to this indicator. |
| Range of input  [Have relevant business areas contributed e.g. clinical assurance?] | The indicator has been developed with input from the Outcomes Framework Technical Advisory Group (OFTAG). OFTAG includes academic and analytical experts in health, health economics and public health, and representatives from bodies such as National Institute for Health and Clinical Excellence and RAND Europe. |

IGB Recommendations, Comments & Updates

IAS Ref Code:

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| **Indicator Title** |  |
| Indicator Set |  |
| Summary of Discussion | * This indicator is put forward for appraisal for use in both the NHS Outcomes Framework and CCG Outcomes Indicator Set and is based on questions within the GP Patient Survey * Members of the board noted that the points for clarification discussed for the previous indicator (IAP00118) apply * Glen Mason raised concern about attribution in the indicator and that people are asked to talk about all services, meaning that individual services or organisations can’t be identified. This should be described in the Quality Assessment as a limitation of the survey. * Don Sinclair queried the prevalence rate for Cancer identified on page 6 of the accompanying Quality Assessment, suggesting it was quite low. However, it was noted that the prevalence identified in QOF and the GP Patient Survey were of the same magnitude. Clarification is sought on what “seems” means as identified in the table and if it relates to the “low” cancer rate. * It was noted that the survey uses the description long term condition and long standing health conditions to describe the same thing. Feedback should be given to the indicator developer suggesting that this should be standardised. |

[Add new section as necessary]

**Recommendations & Updates**

Made: xx/xx/xx

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| Comments & Recommendations  [List additional comments and recommendations raised by IGB] | * The supporting Quality Assessment should identify that the long term condition list used in the indicator isn’t the recognised ONS long term condition list (which is clinically assessed), but that instead this is indicator is about self-assessment and as such will be limited in terms of comparability. * The limitation that people with lots of conditions are more likely to have a worse quality of life than those with one condition needs to be caveated in the Quality Assessment. * Ipsos MORI provide a weighting factor for age, sex and deprivation and ethnicity but as yet haven’t looked into whether severity or numbers of conditions mean people are more likely to respond. This needs clearly stating in the Quality Assessment as a caveat. * A caveat for this indicator should note that there is a difference between approval for using EQ-5D and whether it is suitable for use. The views of the Centre for Health Economics at York or Manchester group could be sought on this matter. * The Quality Assessment should describe not being able to attribute results to individual services or organisations as a limitation of the survey. * Clarification is sought on what “seems” means as identified in the table on page 6 of the accompanying Quality Assessment and if it relates to the “low” cancer rate. * It was noted that the survey uses the description long term condition and long standing health conditions to describe the same thing. Feedback should be given to the indicator developer suggesting that this should be standardised. |
| Action required: | **IGB Update Not Required**  **Further Update IGB**  **Refer to MRG** |
| Update:  Made: xx/xx/xx |  |

**Review:**

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| Review Timescale  **1 year**  **3 years**  **Other:** | Rationale  [Issues to consider – Changes to process, policy data source, coding definitions HES definitions ]  The indicator is recommended for review in 3years. |

IGB Sign-off:

**Indicator Assurance Process Output**

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| Final Appraisal Status | 1. **Assured** 2. **Assured with Comments** 3. **Failed Assurance** |
| Basis of Sign-off  [Detail caveats and limitations ] | The board signed off the indicator as assured on the understanding that the recommendations and clarifications discussed in the meeting are incorporated into the Quality Assessment. | |
| Sign - off Date  16/09/13 |  | |

Update - Domain 2 indicators for NHS OF & CCG OIS

This response provided by the applicant aims to answer the recommendations made at the last MRG regarding the domain 2 indicators in the NHS Outcomes Framework and the CCG OIS.

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| **Indicator Titles** | * + - * + NHS OF 2 Health-related quality of life for people with long term conditions         + NHS OF 2.1 Proportion of people who feel supported to manage their condition         + CCG OIS 2.2 Proportion of people who feel supported to manage their condition         + NHS OF 2.4 Health-related quality of life for carers, aged over 18 years         + CCG OIS 2.15 Health-related quality of life for carers, aged over 18 years         + CCG OIS 2.1 Health-related quality of life for people with long term conditions         + CCG OIS 2.16 Health related quality of life for people with a long term mental health condition |
| Indicator Set | NHSOF / CCGOIS |

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| Ref code  **IAP00000-01**  Made: 18/10/13 | The developer is asked to investigate if direct standardisation can be made to work through combining years or some of the initially proposed breakdown groups.  If the results of the investigation determine that this is too weak a standardisation then the developer should test whether indirect standardisation is valid, for instance determining if indirect standardisation holds valid in terms of populations being comparable.  Finally, if indirect standardisation is arrived at as being valid, supporting metadata would have to be very clear about the limitations of use of the indicator in terms of comparison.  Consideration should also be given as to whether crude rates should be published alongside denominator values |
| Update:  Made: 09/01/14 | The first recommendation was to look whether direct standardisation can be made to work as this was felt to be preferable to indirect standardisation.  **NHS Outcomes Framework indicators (NHS OF 2, 2.1 and 2.4) (CCGOIS 2.1, 2.2, 2.15)**  *CCG OIS 2.16 Health related quality of life for people with a long term mental health condition (issues around this indicator are discussed separately – see below)*  Direct standardisation has been carried out for NHS OF indicators 2 and 2.4 for 2011/12 GPPS data to assess whether this approach is feasible.  It needs to be highlighted that the principles of NHS OF indicator 2 also apply to NHS OF indicator 2.1 as the population in question (people who identify themselves as having a long-term condition) are the same for both indicators.  For NHS OF indicators 2 and 2.4 DSR values have been calculated at national level and broken down by age, gender and particularly ethnicity and local authority where small cell counts looked to be an issue.  For NHS OF indicator 2 only the LA district breakdown had empty cells when looking at the age, gender and LA combinations needed to be able to calculate the DSR values. However, there were only 6 empty cells for 4 selected LAs (City of London, Isles of Scilly, Rother and South Bucks). Please see spread sheet NHSOF\_2\_Data\_Lower\_Tier\_LA in the accompanying Excel file **NHSOF\_2\_2.4\_DSRCalc.xls** with the sample data where empty cells were highlighted in orange. DSR values were still calculated for those LAs.  When calculating values for the upper tier LA breakdown empty cells reduce to four across 2 authorities (City of London and Isles of Scilly). See spread sheet NHSOF\_2.4\_Data\_Upper\_Tier\_LA.  For NHS OF indicator 2.4 two breakdowns had empty cells when looking at the individual combinations. The breakdowns in question were ethnicity and LA. Similarly, to the scenario with LAs for NHS OF indicator 2 there were only 7 empty cells for the ethnicity breakdown for NHS OF indicator 2.4 (see orange highlighted cells in spread sheet NHSOF\_2.4\_Data\_Ethnicity in the attached file). The LA breakdown for NHS OF indicator 2.4 produced 112 empty cells across 83 LAs (see cells highlighted in orange in spread sheet NHSOF\_2.4\_Data\_LA.  When looking at the upper tier LA breakdown for indicator 2.4 empty cells reduce to 28 across 15 authorities.  Based on the findings the proposal for the domain 2 NHS Outcomes Framework indicators is as follows:   * Use direct standardisation as calculation method with the original age groups * Where there are empty cells (at least 1) for any of the categories within a breakdown suppress the calculated indicator values for the category in question * Further, where the numerator for a breakdown category is less than 25 suppress the calculated indicator values, due to the fact small numbers would make the estimate unreliable. This is in line with what currently happens within the PHOF. * In addition to the LA district breakdowns provide upper tier LA breakdowns. This would provide valuable additional information for local decision makers and would also provide values for LAs where values are suppressed for the LA district breakdown * Once 3-years’ worth of GPPS data are available it is proposed to additionally calculate an indicator value based on a rolling 3-year dataset * Publish numerator and denominator values in addition to the indicator values. It is proposed to also provide these for all indicator values that are suppressed unless the numerator values are below 5, which is in line with standard suppression rules.   The proposal to suppress any breakdown category where there is at least 1 empty cell is conservative in its approach, however it is important that we are able to take steps to revise the data that has already been published to ensure that we are confident about its validity. A more comprehensive review of approaches to standardisation and how to apply them would be helpful to come to an expert view which could then be applied to these indicators and others in the NHSOF and CCG OIS, which then may result in further revisions.  In line with the current proposal the table below summarises the number of suppressed breakdown categories by indicator for 2011/12 data.  **Number suppressed Total number**  **Indicators 2 and 2.1**  Ethnicity 0 18  LA districts 4 326  LA upper tier 2 152  **Indicator 2.4**  Ethnicity 3 18  LA districts 83 326  LA upper tier 15 152    **CCG OIS equivalents (CCGOIS 2.1, 2.2, 2.15)**  For CCGOIS 2.1, 2.2, 2.15 which are the equivalents we propose to use exactly the same methods as outlined above. For some cases, due to zero cells, CCG values will need to be supressed, it is less of a problem than at LA level as there are less of them.  However, there is a fourth GPPS indicator within the CCGOIS which requires a slight change in methodology.  **CCGOIS Health related quality of life for patients with a long term mental health condition (2.16)**  In comparison to the other GPPS indicators, this one has much smaller numbers. The attached file (**CCGOIS\_MH\_Zero\_Cell\_Example.xls**) gives a summary of counts for the indicator at CCG level, for a single year 2011/12 the smallest weighted sum of observed events was 43. However, using the standard GPPS age bands led to large numbers of zero cells (336 across 162 of the 211 CCGs). Widening the age bands, as defined in the file, sees this change to 34 across 30 CCGs. This would lead to DSRs not being calculated for 30 CCGs, a figure which is more acceptable than 162. Therefore, we propose using the combined age bands for this indicator. |

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| Ref code  **IAP00000-02**  Made: 18/10/13 | A test is to be put in to address issue of handling zero, or near zero EQ-5D scores. |
| Update:  Made: 09/01/14 | When looking at the different breakdowns for all domain 2 indicators no zero or near 0 EQ-5D values were found for any of the breakdown categories.  A test will be put in to check for the occurrence of 0 or near 0 EQ-5D values in future. If this will be the case suppression will be applied. |

1. The **Q**uality and **O**utcomes of person - centred Care Policy **R**esearch Unit (**QORU)** is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics and Political Science (LSE) and has been funded by the Department of Health in England from January 2011 to facilitate this strategy by developing and promoting the appropriate use of both quantitative and qualitative evidence of need, quality and outcomes in relation to long term health conditions to improve the quality of health and social care. [↑](#footnote-ref-1)