**NHS Digital**

**Indicator Supporting Documentation**

**IAP00129 Health related quality of life for carers aged 18 and over**

Indicator Assurance Service

 **Methodology Review Group**

**Applications for consideration**

**17th January 2014**

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**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, ie 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 cancersNHS OF 1.4.ii Five year survival for all cancersNHS OF 1.4.iii One-year survival from breast, lung and colorectal cancerNHS OF 1.4.iv Five-year survival breast, lung and colorectal cancerNHS 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 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 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 **(IAP00129)**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(IAP00129)) (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.

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|  | **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: |

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| 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.

$$P\_{s}=\frac{odds}{1+odds}$$

1. 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)** | **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**

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

**Distribution of all GCS including outcome in the imputation model**

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

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

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

**Distribution of the imputed GCS values only, including outcome**

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

Logistic regression N = 81293

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **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\_2 | 8.153 | 3472.300 | <0.001 | 1923.340 | 6268.730 |
| GCS 13 - 15 (reference) |  |  |  |  |  |
| GCS=3 | -3.555 | 0.029 | <0.001 | 0.025 | 0.032 |
| GCS 4 - 5 | -2.435 | 0.088 | <0.001 | 0.075 | 0.103 |
| GCS 6 - 8 | -1.481 | 0.227 | <0.001 | 0.199 | 0.259 |
| GCS 9 - 12 | -1.075 | 0.341 | <0.001 | 0.304 | 0.384 |
| GCS Intubation | -2.385 | 0.092 | <0.001 | 0.075 | 0.113 |
| 2007/2008 (reference) | 0.000 | 1.000 |  |  |  |
| 2008/2009 | 0.037 | 1.037 | 0.625 | 0.895 | 1.202 |
| 2009/2010 | 0.005 | 1.005 | 0.947 | 0.876 | 1.152 |
| 2010/2011 | 0.134 | 1.143 | 0.043 | 1.004 | 1.301 |
| 2011/2012 | 0.189 | 1.208 | 0.003 | 1.065 | 1.371 |
| 2012/2013 | 0.523 | 1.687 | <0.001 | 1.465 | 1.942 |

**Imputed GCS with outcome in the imputation model**

Logistic regression N=81293

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Outcome30D~s** | **coefficients** | **Odds Rat.** | **p-value** | **[95% Conf. Int.] for OR** | **[95% Conf. Int.] for OR** |
| ISS\_1 | 3.552 | 34.889 | <0.001 | 29.597 | 41.128 |
| ISS\_2 | 8.040 | 3102.760 | <0.001 | 1715.880 | 5610.590 |
| GCS 13 - 15 (reference) |  | 1.000 |  |  |  |
| GCS=3 | -3.747 | 0.024 | <0.001 | 0.021 | 0.027 |
| GCS 4 - 5 | -2.628 | 0.072 | <0.001 | 0.061 | 0.085 |
| GCS 6 - 8 | -1.739 | 0.176 | <0.001 | 0.152 | 0.203 |
| GCS 9 - 12 | -1.296 | 0.274 | <0.001 | 0.243 | 0.308 |
| GCS Intubation | -2.527 | 0.080 | <0.001 | 0.065 | 0.098 |
| 2007/2008 (reference) | 0.000 | 1.000 |  |  |  |
| 2008/2009 | 0.031 | 1.031 | 0.686 | 0.888 | 1.197 |
| 2009/2010 | -0.003 | 0.997 | 0.970 | 0.869 | 1.145 |
| 2010/2011 | 0.128 | 1.137 | 0.056 | 0.997 | 1.296 |
| 2011/2012 | 0.179 | 1.196 | 0.006 | 1.052 | 1.359 |

Table 3. (cont).

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

Logistic regression N = 81293

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **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 0- 5 | 0.031 | 1.032 | 0.864 | 0.721 | 1.477 |
| Age 6 - 10 | 0.304 | 1.355 | 0.233 | 0.822 | 2.234 |
| Age 11 - 15 | 0.180 | 1.197 | 0.285 | 0.860 | 1.666 |
| Age 45 - 54 | -0.479 | 0.619 | <0.001 | 0.534 | 0.718 |
| Age 55 - 64 | -0.961 | 0.383 | <0.001 | 0.330 | 0.444 |
| Age 65 - 75 | -1.671 | 0.188 | <0.001 | 0.162 | 0.218 |
| Age > 75 | -2.872 | 0.057 | <0.001 | 0.050 | 0.064 |
| Gender Male (reference) | 0.000 | 1.000 |  |  |  |
| Gender Female | -0.098 | 0.907 | 0.261 | 0.764 | 1.076 |
| Age by Gender interaction |  |  |  |  |  |
| Age 16 - 44 (reference) |  | 1.000 |  |  |  |
| Age 0 -5 Female | 0.086 | 1.089 | 0.781 | 0.595 | 1.993 |
| Age 6 - 10 Female | 0.832 | 2.299 | 0.155 | 0.729 | 7.248 |
| Age 11 - 15 Female | -0.073 | 0.930 | 0.816 | 0.502 | 1.721 |
| Age 45 - 54 Female | -0.104 | 0.901 | 0.489 | 0.670 | 1.211 |
| Age 55 - 64 Female | -0.105 | 0.900 | 0.440 | 0.690 | 1.175 |
| Age 65 - 75 Female | 0.231 | 1.260 | 0.097 | 0.959 | 1.655 |
| Age > 75 Female | 0.244 | 1.276 | 0.016 | 1.046 | 1.556 |

**Imputed GCS with outcome in the imputation model**

Logistic regression N=81293

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **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 0- 5 | 0.017 | 1.017 | 0.928 | 0.708 | 1.460 |
| Age 6 - 10 | 0.289 | 1.335 | 0.253 | 0.813 | 2.193 |
| Age 11 - 15 | 0.177 | 1.193 | 0.298 | 0.855 | 1.666 |
| Age 45 - 54 | -0.498 | 0.608 | <0.001 | 0.522 | 0.708 |
| Age 55 - 64 | -1.005 | 0.366 | <0.001 | 0.315 | 0.426 |
| Age 65 - 75 | -1.732 | 0.177 | <0.001 | 0.152 | 0.205 |
| Age > 75 | -2.964 | 0.052 | <0.001 | 0.046 | 0.059 |
| Gender Male (reference) | 0.000 | 1.000 |  |  |  |
| Gender Female | -0.113 | 0.893 | 0.197 | 0.753 | 1.060 |
| Age by Gender interaction |  |  |  |  |  |
| Age 16 - 44 (reference) |  | 1.000 |  |  |  |
| Age 0 -5 Female | 0.059 | 1.061 | 0.846 | 0.584 | 1.928 |
| Age 6 - 10 Female | 0.863 | 2.371 | 0.140 | 0.753 | 7.464 |
| Age 11 - 15 Female | -0.068 | 0.935 | 0.833 | 0.499 | 1.752 |
| Age 45 - 54 Female | -0.081 | 0.922 | 0.595 | 0.683 | 1.244 |
| Age 55 - 64 Female | -0.097 | 0.908 | 0.481 | 0.693 | 1.189 |
| Age 65 - 75 Female | 0.258 | 1.294 | 0.055 | 0.994 | 1.684 |
| Age > 75 Female | 0.269 | 1.309 | 0.008 | 1.072 | 1.597 |

Indicator Governance Board Meeting – 12th November 2014

*Paper (1)*

Indicators for Appraisal

Pack 1

* **IAP00129** Health related quality of life for carers aged 18 and over *(for use in NHS Outcomes Framework)*
* **IAP00357** Health related quality of life for carers aged 18 and over *(for use in CCG Outcomes Indicator Set)*

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

|  |  |
| --- | --- |
| **Indicator Title** | **Health related quality of life for carers aged 18 and over** |
| Indicator Set | NHS Outcomes Framework |
| IAS Ref Code: | IAP00129 |
| Description | Average health status scores for individuals aged 18 and over responding that they are carers in the GP Patient Survey. The indicator assesses whether health-related quality of life is increasing over time for this population, while controlling for measurable confounders (age, gender, etc.). Health status is derived from responses to question 34 of the survey, which asks respondents to describe their health status against the five dimensions of the EuroQuol 5D (EQ-5D) survey instrument: Mobility, Self-care, Usual activities, Pain/discomfort, Anxiety/depression. |

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| Initial IGB discussion  | 16/09/13 |

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| --- | --- |
|  | **Strategic Considerations & Implications** |
| Applicant / Sponsor Organisation | NHS England\*Costing for assurance appraisal included in development cost |
| Assurance process funded? | Yes |
| 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. Often it is the experience people have of primary care that determines their overall view of the NHS.The health of carers is greatly influenced by the extent and sensitivity of NHS and social care. This indicator seeks to capture the health-related quality of life for carers and how successfully the NHS is in supporting carers to live as normal a life as possible. This indicator will help people understand whether health related quality of life is improving over time for carers. This indicator uses results from the GP Patient Survey (GPPS) to look specifically at the quality of live for people who have identified themselves to be carers.  |
| Basis for rationale [Details of quality statement, policy etc.] | This indicator has been selected as part of the set of NHS Outcomes Framework indicators. The indicator is part of Domain 2 which reflects the importance of enhancing the quality of life for people with long-term conditions. 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. |
| Calculation Summary | The indicator is calculated based on questions 34 and 56 of the GP Patient Survey. The carer status is obtained from those answering ‘Yes…’ to question 56 in the GP Patient Survey; *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 health/disability, or problems related to old age? Do not count anything you do as part of your paid employment*For all people who have been identified as carers in question 56 the health status is derived from responses to question 34 of the GP Patient Survey, which asks respondents to describe their health status using the five dimensions of the EuroQuol 5D (EQ-5D) survey instrument: Mobility, Self-care, Usual activities, Pain/discomfort, Anxiety/depression.The weighted EQ-5D value is obtained by multiplying the EQ-5D value by the sampling weights in the GPPS.The GP Patient survey includes a weight for non-response bias**Denominator:** The denominator is the sum of all weighted responses from people identified as carers.**Numerator:** The numerator is the sum of the weighted EQ-5D values for all responses from people identified as carers. |
| Risks & assumptions | None Identified |
| Other Considerations [e.g. release of under-lying data, intermediaries access to data, data ownership impact on production] | *Data Source:* The GP Patient Survey (GPPS)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 publically available via the HSCIC indicator portal.EQ-5D™ is a registered trademark of EuroQol. Further details are available from http://www.euroqol.org. Euroqol Group gave written permission to the Department of Health on 2 May 2011 to use the EQ-5D questions only in this format (without the visual analogue scale) for the GP patient survey and are happy for it to be referred to as EQ-5D™. |
| 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 2.1* *Proportion of people feeling supported to manage their conditions*
 |
| 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** |
| Discussion dates:  | 05/10/12, 31/05/13, 08/07/13,09/01/14 |
| By: | Alyson Whitmarsh HSCIC Programme Manager Clinical AuditJohn Varlow HSCIC Director of Information ServicesAndy Sutherland HSCIC Statistics Head Of ProfessionPaul Fryers PHE Deputy Director, EMids Knowledge and Intel. TeamJonathon Hope HSCIC Principal Information Analyst Clinical AuditKarina 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. This included a number of separate discussions focussing on the weighting methodology.Issues discussed:* The question was raised if there was anything that could be done to identify non-responders as they could potentially be those that the indicator is trying to capture. MRG further suggested that, in the case of carers, those caring for longer hours are less likely to complete the form and as such skewing the base data from the start.
* 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.
* The applicant stated that 50% of those who respond to the GP survey have a long term condition and that comparison with QOF data showed similar percentages, therefore the GP patient survey is reasonably representative of people with long term conditions.
* MRG queried whether the descriptive system of the EQ-5D has been validated for use without the visual analogue scale (VAS). It was confirmed that it had, however it was proposed that ongoing consideration of the validity of EQ-5D would be useful. The applicant confirmed that written permission was granted to the Department of Health by Euroqol Group to use the EQ-5D questions without the visual analogue scale for the GP patient survey and are happy for it to be referred to as EQ-5D™.

A number of revisions to the methodology for weighting in the indicator were presented to MRG. * Earlier drafts were not assured by MRG on the basis of concern over the lack of hierarchy of conditions, and that a proposed change 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.
* Following feedback from peer reviewers, the decision was made not to progress applying a weighting based on hours cared.

In the final revision:* The group were asked to assure whether age and gender, and not hours cared for are the right characteristics to weight for the indicator.
* The proposal put forward is to apply a weighting, where 2nd year figures will be weighted back to the pattern seen across age and gender in year one to allow comparison. Discussion centred on whether this should extend to include hours of care.
* MRG agreed with the proposal to weight by age and gender, however this was in the basis that further contextual information explaining hours cared and how it changes year on year should be provided alongside this indicator, as without this context it will be difficult to interpret what indicator is doing.
* In addition MRG agreed that it would be useful to do further testing on results as and when second year data becomes available to identify the difference in results with regards to hours cared.

  |
| *Outcome of MRG consideration:* | **Some concerns expressed as caveats or limitations** |
| MRG statement of recommendation: | The indicators are recommended for discussion by IGB on the understanding that the indicators will be weighted using age and gender, but that supporting contextual data will be required to explain hours cared. This should be followed up with further testing of year 2 data as it becomes available.Additionally the quality statement will need to include an explanation of the potential impact of non-response, and details of comparison undertaken in identifying levels of coverage. |
| Peer Reviewers: | Dr Nourieh HoveydaNicola Bent (NICE) |
| Peer Review summary: | N Hoveyda (Consultant in Public Health Medicine) 21/05/13* Noted that the indicator was weighted according to age but not sex (females are more likely to be carers than males). This was taken into account in the revised proposal.
* Suggested that the intensity of care may vary and not be reflected in the number of hours e.g. If a carer is caring for someone with severe disability which requires more intensive caring as opposed to a carer for someone with milder disability and less intensive care required, and this may affect interpretation.

Nicola Bent (NICE) 28/05/13* The proposal (made prior to the final submission) to add Q56 of the GPPS: *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 health/disability, or problems related to old age?* to the risk adjustment may require some further exploration.
* There may be a risk of a significant correlation between this variable and the indicator value. If the indicator is about the extent to which a carer is supported, the number of hours could be a function of the support they are given, in which case adjustment may not be appropriate – as the amount of support may be in the control of the NHS and social care services. Alternatively, the provision of support may mean that the indicator value is not affected by the numbers of hours spent caring, as carers who are well supported could still spend many hours caring, but have a good quality of life.
* So further understanding of: purpose of the indicator, and the interaction between the hours spent caring and carers’ quality of life may be needed before a decision can be made as to include Q56 in the risk adjustment. The interaction of an additional variable: amount of support provided would be useful but that data is unlikely to be available.”
 |
| 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

|  |  |
| --- | --- |
| **Indicator Title** | **NOF 2.4 – Health related quality of life for carers** |
| Indicator Set | NHS Outcomes Framework |
| IAS Ref Code: | IAP00129 |
| Summary of Discussion | * Concern was raised that there is a gap in that the indicator does not capture carers aged under 18. Noted that in terms of the indicator the naming needs to make it clearer that it covers ages 18 and over.
* Questioned as to whether EQ-5D is as relevant for carers as other groups. Suggestion that it might not be right for carers, however it was noted that there has been discussion reasoning that it was useful to be able to compare carers to the general population and that the use was in light of nothing better. The Quality Assessment needs to reflect this concern as to whether EQ-5D is relevant to carers, but also reflect there is nothing better.
* It was put forward that the whole survey has been weighted rather than individual questions so all questions have been weighted to the general population. When looking at EQ-5D, which is a measure of the general population, responses have been weighted to the general population, meaning it is potentially less reliable for carers.
* Suggested that the indicator should compare year on year and against a standard population – in this case health related quality of life for people filling out the survey.
* Re-iterated that contextual indicators are required for this indicator to be used.
* It was questioned as to how this indicator links to other frameworks, e.g. the Adult Social Care Outcomes Framework (ASCOF) and how it had been benchmarked to the Adult Social Care Carers Survey
* It was suggested the indicator be reviewed in 3years but on the understanding that further analysis is required as year 2 data becomes available, and that the indicator needs to be reviewed if issues arise from the analysis.
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|  | **IGB Recommendations & Updates** |
| Comments, RecommendationsMade: 16/09/13& Updates | * *The indicator title should be changed to make it clearer that it covers ages 18 and over.*

**Update:** The applicant has agreed that what is published via the HSCIC indicator portal, and the way the indicator is titled in the library, will be reflective of this recommendation even if it can’t be changed in the NHS Outcomes Framework.* *The Quality Assessment needs to reflect a concern as to whether EQ-5D is relevant to carers.*

**Update:** The November refresh of the indicator quality statement is to detail that: EQ-5D is validated for the general population (and in some subgroups), but not carers. This means there is only an assumption it can be used for carers .* *The indicator should compare year on year and against a standard population – in this case health related quality of life for people filling out the survey, The indicator has health related quality of life for long term conditions and health related quality of life for carers but doesn’t have a health related quality of life for people filling in the questionnaire, which would be need for comparison. This should be reflected in the Quality Assessment.*

**Update:** Further contextual information showing the directly standardised average health status (EQ-5D™) score for all individuals who responded to the survey, is given alongside the indicator value. This is to allow comparison of quality of life amongst those who are carers to the overall population.* *Further work is required to identify how indicator links to other frameworks, e.g. the Adult Social Care Outcomes Framework (ASCOF) and how it has been benchmarked to the Adult Social Care Carers Survey.*

**Update:** Feedback has been received from the developer stating that data from the Carers Survey are less appropriate than the GPPS data for Indicator 2.4 for two reasons:* + The quality of life questions in the Carers Survey are much broader than the EQ-5D questions. As Indicator 2.4 is concerned with health-related quality of life, which is arguably more amenable to NHS care, the GPPS data is more appropriate. However, as ASCOF Indicator 1D is based on the Carers Survey questions, these broader dimensions of quality of life are captured and presented there.
	+ The EQ-5D questions can be converted into a health-related quality of life index on the basis of preferences for different health states. No such preference weighting is available for the quality of life questions in the Carers Survey. ASCOF Indicator 1D combines responses to each question with equal weight.
 |
| Action required: | **Further Update IGB** |
|  |  |

Review:

|  |  |
| --- | --- |
| Review Timescale | Other |
| Rationale  | [Issues to consider – Changes to process, policy data source, coding definitions HES definitions ]It was suggested the indicator be reviewed in 3years but on the understanding that further analysis is required as year 2 data becomes available, and that the indicator needs to be reviewed if issues arise from the analysis. |

 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 ] |  |
| Sign-off Date |  |

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

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| --- | --- |
| **Indicator Title** | **Health related quality of life for carers aged 18 and over** |
| Indicator Set | CCG Outcomes Indicator Set  |
| IAS Ref Code: | **IAP00357** |
| Description | Average health status (EQ-5D) scores for individuals aged 18 and over reporting that they are carers. It assesses whether health-related quality of life is increasing over time for this population, while controlling for measurable confounders (age and gender). |

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| --- | --- |
| Initial IGB discussion  | 06/12/13 |

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| --- | --- |
|  | **Strategic Considerations & Implications** |
| Applicant / Sponsor Organisation | NHS England |
| Assurance process funded? | Yes |
| Indicator rationale  | This indicator seeks to capture how successfully the NHS is supporting carers to live as normal a life as possible. It will help people to understand whether health related quality of life is improving over time for carers. The indicator uses EQ-5D, which is a validated direct measure of health status or health-related quality of life that is used internationally. |
| Basis for rationale [Details of quality statement, policy etc.] | The CCG Outcome Indicator Set (CCG OIS) is an integral part of NHS England’s systematic approach to quality improvement. It is intended to provide clear, comparative information for CCGs, patients and the public about the quality of health services commissioned by CCGs and the associated health outcomes. All of the CCG outcomes indicators have been chosen on the basis that they contribute to the overarching aims of the five domains in the NHS Outcomes Framework and it is intended as a tool for CCGs to drive local improvement and set priorities. Reference: CCG OIS, NHS England: http://www.england.nhs.uk/ccg-ois/. |
| Calculation Summary | Average health status (EQ-5D) scores for individuals aged 18 and over reporting that they are carers.The sum of weighted EQ-5D scores for all valid responses from respondents who indicate they are carers divided by the sum of all valid weighted responses from respondents who indicate they are carers. A response is considered vaild if it has a vaild age (between 18 and 120), a valid gender (M or F) and a valid EQ-5D score.Contextual information will be provided, at CCG level, around the health status amongst all respondents in to the GPPS as well as information around number of hours cared. This information will add context to the actual indicator value.*Denominator:* The sum of weighted responses from people who indicate that they are carers. Where being a carer is defined by answering yes to q56 on the GPPS.*Numerator:* The sum of weighted EQ-5D scores for all responses from people who indicate that they are carers. |
| Risks & assumptions | Data from the GPPS has been used to produce several other indicators for both the NHS Outcomes Framework and the CCG OIS. The EQ-5D question was included in the GPPS for the first time in 2011.The assignment of a patient to a CCG will be based on the GP practice code, which is 100% complete in the GPPS.Although it has been validated for use in the general population, EQ-5D has not been validated for use for carers. There is an assumption that it can be used, and no suitable alternative has been identified.This indicator is dependent on respondent’s to accurately self-report both there carer status and health status. The questions used to derive EQ-5D are subjective, and therefore susceptible to self-reporting error.Overall respondent characteristics (age, sex etc.) to the GPPS do not remain constant year on year, although this is adjusted for, they may still have an effect on outcomes.A patient’s average health status could be influenced by numerous factors, which aren’t necessarily related to the fact that they are a carer. |
| Other Considerations [e.g. release of under-lying data, intermediaries access to data, data ownership impact on production] | *Data Source:* GPPS (NHS England/Ipsos Mori) <http://www.gp-patient.co.uk>Ipsos MORI carry out and analyse the GPPS on behalf of NHS England (previously the Department of Health). Reports and anonymous statistical results are published at http://www.gp-patient.co.uk/results/. The data for July 2012 to March 2013 are available by practice, PCT and CCG, from which it is possible to get a national and various sub-national totals. Prior to this, data was published at practice and PCT level, but not at CCG level. |
| Potential impacts on other business areas [inc outstanding generic issues] | None Identified |
| Implementation Method[inc production funding] | Collection of the data for the CCG OIS is via existing data collections, in this case by the GPPS. Testing and specification of this indicator was carried out by the Outcome Frameworks team, within the wider Clinical Indicators team. The construction of the indicators will be carried out by Clinical Indicators via the CI Platform at HSCIC.Dissemination and presentation of the CCG OIS will be via a number of routes:* The indicators and their underlying data will be made publically available via the HSCIC website and the Indicator Portal.
* The data will also be provided to NHS England for use in their internal Intelligence Tool.

The calculated CCG indicator, as well as contextual information, will be publicly available on the HSCIC website, including NHS iView (interactive) and Excel/csv files. The actual indicator value will be highlighted within the spreadsheet to allow it to be clearly identifiable. |

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|  | **Development Advice & Peer Review** |
| Range of input[Have relevant business areas contributed e.g. clinical assurance?]  | See equivalent NHSOF indicator - 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. |
| Peer Reviewers: | See equivalent NHSOF indicator |
| Peer Review summary: |  |

**Record of MRG Discussion 31.10.2013**

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| --- | --- |
| Heather Dawe (chair) | HSCIC |
| Chris Dew | HSCIC |
| Irena Begaj | UH Birmingham |
| Jonathon Hope | HSCIC |
| Daniel Sutcliffe | NICE |
| Julie Henderson | HSCIC |
| Gerry Firkins | HSCIC |

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| Summary of MRG discussions:  | The equivalent indicator proposed for inclusion in the NHS Outcomes Framework was discussed on several occasions by the Methodology Review Group prior to the proposal to include the indicator in the CCG Outcomes Indicator Set. With specific reference to the proposal to include in CCGOIS:* It was highlighted by the applicant that a contextual indicator which reports the average EQ-5D score for all respondents of the GPPS is the appropriate comparator for this indicator.
* MRG commented that they would like to see evidence of variation at CCG level to show the value of producing the indicator. It was suggested that a funnel plot should be produced to show variation, and if it was the case that there is differences at CCG level, the indicator should be discussed at IGB.
* No further comments were raised

In response the applicant provided the following evidence with regards to variability:* 2013/14 indicator values for each of the CCGs show that the values range from an minimum average health status score of 0.72, to a maximum of 0.85. The average score for all registered patients in England was 0.80.
* When mapping 2012/13 indicator values by Area Team (CCGs tend not to map that well due to their small geographical area), it shows variation in Area Team scores is smaller than at CCG level. The Area Team with the highest score was 0.83 with the lowest score being 0.77. These figures compare to a national figure of 0.81.

Figure 1: Average health status (EQ-5DTM) score for people who are carers, by CCG, 2013/14Average health status (EQ-5DTM) score for people who are carers, by CCG, 2013/14 |
| *Outcome of MRG consideration:* | **No significant issues on basis of completion of outstanding actions** |
| MRG statement of recommendation: | The indicator is to be discussed at IGB on the condition that evidence of variation at CCG level exists. |

Review:

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| Review Timescale |  |
| Rationale  | Issues to consider – Changes to process, policy data source, coding definitions HES definitions ]The indicator is to be reviewed in three years time in line with the equivalent NHS Outcomes Framework Indicator. |

 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 ] |  |
| Sign-off Date |  |