**NHS Digital**

**Indicator Supporting Documentation**

**IAP00357 Health-related quality of life for carers aged 18 and above**

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**

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| **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 Paient 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. |
| 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. |

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|  | **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 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. 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 Hoveyda  Nicola 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

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| **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. |

**IGB Recommendations & Updates**

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| Comments, Recommendations  Made: 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:

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| 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:

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

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). |
| 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 speadsheet 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**

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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 |
| Discussion dates: | 31/10/13 |
| 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, 2013/14  Graph: Average 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: The indicator is to be reviewed in three years time in line with the equivalent NHS Outcomes Framework Indicator.

IGB Sign-off:

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

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| **IAS Ref Code** | **Indicators for discussion** |
| **Indicator Title** |  |
| **Indicator Set** | **CCG Outcome Indicator Set** |

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| Version | Date | Changed By | Summary of changes |
| v.01 | 16/10/13 | Lydia Gomersall | Document Created |
| v.02 | 14/06/17 | Andy Besch | Updated to reflect the outcome of IGB 12/11/2014 |
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**Assurance Summary**

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| **IAS Ref Code** | Indicators for discussion |
| **Indicator Title** |  |
| **Indicator Set** | CCG Outcome Indicator Set |

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| Assurance Stage |  | Date(s) | Comments |
| Application Received |  | 09/10/13 |  |
| Initial Appraisal Completed |  | 14/10/13 |  |
| Peer Review Appraisal |  |  | See application IAP00129 |
| Methodology Review Group Discussion |  | 31/10/13 |  |
| Indicator Governance Board Discussion |  | 16/01/14 |  |
| Signed-off |  |  |  |

Peer Review

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| Peer Reviewer(s) / Organisations : | Indicator peer reviewed for equivalent NHS Outcomes Framework Indicator – see appraisal record IAP00129 |

Methodology Review Group (MRG)

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| *Outcome of MRG consideration:* | **No significant issues on basis of completion of outstanding actions** |

Indicator Governance Board (IGB)

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| *Final Appraisal Status* | **Assured with Comments** |

**Peer Review** Summary

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| Peer Review Comments: | Indicator peer reviewed for equivalent NHS Outcomes Framework Indicator – see appraisal record IAP00129 |

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

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| Introduction |
| This indicator follows the same methodology to NHS OF 2.4 - Health related quality of life for carers. The key difference lies in the breakdowns at which is presented. The NHS OF version is presented at Local Authority and Region, whereas as this indicator is presented at CCG level.  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. |

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| Indicator Details - Initial MRG Submission | Date of Initial Discussion: 31/10/2013 |
| Rationale / usefulness  Evidence and action ability of indicator [take this directly from the application if possible] | 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/>.  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 over the age of 18. This indicator will help people understand whether health related quality of life is improving over time for carers.  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. |
| 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/>. |
| Construction | ***Summary description of the calculation:***  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.  To be considered a valid response, record must have a valid age (between 18 and 120), a valid gender (M or F) and a valid EQ-5D score.  Respondents indicate that they are carers by answering, 'Yes', to q56 on the GP patient survey.  *Q56: 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*   1. *No* 2. *Yes, 1-9 hours a week* 3. *Yes, 10-19 hours a week* 4. *Yes, 20-34 hours a week* 5. *Yes, 35-49 hours a week* 6. *Yes, 50+ hours a week*   Health Status of the respondent is captured using the EQ-5D™ measure. EQ-5D™ is a registered trademark of EuroQol. It assesses whether health-related quality of life, while controlling for measurable confounders (age, gender, disease mix, etc). Further details are available from <http://www.euroqol.org>. The score is derived from the respondents answer to the following questions.  *The questionnaire asks respondents to indicate which statements best describe their own health state on the day they completed the survey.*  *Mobility*  *( ) I have no problems in walking about*  *( ) I have slight problems in walking about*  *( ) I have moderate problems in walking about*  *( ) I have severe problems in walking about*  *( ) I am unable to walk about*  *Self-Care*  *( ) I have no problems washing or dressing myself*  *( ) I have slight problems washing or dressing myself*  *( ) I have moderate problems washing or dressing myself*  *( ) I have severe problems washing or dressing myself*  *( ) I am unable to wash or dress myself*  *Usual Activities (e.g. work, study, housework, family or leisure activities)*  *( ) I have no problems doing my usual activities*  *( ) I have slight problems doing my usual activities*  *( ) I have moderate problems doing my usual activities*  *( ) I have severe problems doing my usual activities*  *( ) I am unable to do my usual activities*  *Pain / Discomfort*  *( ) I have no pain or discomfort*  *( ) I have slight pain or discomfort*  *( ) I have moderate pain or discomfort*  *( ) I have severe pain or discomfort*  *( ) I have extreme pain or discomfort*  *Anxiety / Depression*  *( ) I am not anxious or depressed*  *( ) I am slightly anxious or depressed*  *( ) I am moderately anxious or depressed*  *( ) I am severely anxious or depressed*  *( ) I am extremely anxious or depressed* |
| Construction | ***Calculation type:*** Mean EQ-5D score |
| Construction | ***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. |
| Construction | ***Statistical Methods / Risk adjustment variables:***  The GPPS includes a weight for non-response bias. This adjusts the data to account for potential differences between the demographic profile of all eligible patients in a practice and the patients who actually complete the questionnaire. The adjustment covers patient characteristics such as age, sex and practice. This weight is recorded in the dataset as *wt\_new*.  To allow comparison over a time, the *wt\_new* field in future data points will be standardised using weights derived from the 2011-12 survey. This standardisation will be based on age and sex, by CCG. The table of weights for each CCG is attached. To ensure each of the CCG, age, sex groups are large enough for reliable standardisation, the following age bands have been used, 18-34, 35-54, 55-74, 75+. The smallest cell size with this approach is 65 respondents.  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).  The weighting methodology used within the calculation of this indicator also relates to CCG 2.1 Health related quality of life for people with long-term conditions & CCG 2.2 Proportion of people feeling supported to manage their conditions. |
| Construction | ***Other (Quality assurance/interpretation/known limitations):***  Ipsos MORI is a registered and independent survey organisation and strictly adheres to the Market Research Society's ethical code of conduct. Ipsos MORI was awarded the new international process Standard ISO 20252 and the International Standard for Information Security ISO 27001 by the accredited assessment body Marketing Quality Assurance, the first survey agency in the world to achieve both of these standards.  The assignment of a patient to a CCG will be based on the GP practice code, which is 100% complete in the GPPS.  A high average health status score is desirable. The higher the rate the higher the average health status of the relevant population. |
| Potential Issues  Highlight any of the following that apply  -data source(s) do not collect 100% of events  -data source(s) organisation or geographic coverage shortfalls  -codes or filters not matching the policy question  -data source(s) definitions not meeting policy question  -data source(s) quality problems or inconsistency of reporting  -statistical methods not appropriate for test or audience  -risk adjustment not considered  -long term security of the data source(s)  -timing of data availability for use in indicator  presentation of data likely to mislead or give false confidence in findings | Around 2.7 million patients are invited to take part in the GPPS over the course of the year, with around 35% to 38% of people returning questionnaires. This is approximately a million people each year. As this is a self-completed questionnaire, interpretation may slightly vary between respondents, introducing bias.  For the 2011/12 survey, out of a total of 1,037,946 respondents, 195,364 (19%) indicated that they were carers. Of these 173,194 (89%) had a valid age, sex and EQ-5D score, allowing them to be included in the calculation. The smallest number in a CCG was 108 respondents. The average number of valid respondents, that can be included in the calculation for a CCG, was 821.  The indicator gives a measure of health status for those who are carers. However it does not give any indication to how this health status compares to those individuals who are not carers. To assist with this, a contextual indicator will be provided which gives the average health status for all respondents to the survey. This will be provided at CCG level.  The indicator does not adjust for numbers of hours cared. OFTAG felt that standardising also by “number of hours spent caring”, as well as age and gender, risked controlling for some of the variation in the quality of care (particularly of social care, which we are also interested in). In line with agreed methodology for the NHS Outcomes Framework equivalent, further contextual information explaining hours cared and how it changes year on year will be provided alongside this indicator.  The weighting scheme for non-response bias does not take the experience mix into account, i.e., whether people with a bad experience are more likely to respond to the survey. This indicator is dependent on people’s readiness to self-report in the GPPS. It is not clear whether those who are carers are more or less likely to respond to the survey. Inaccurate reporting would distort the measure. This issue would be discussed in the quality assessment that would accompany the publication of this indicator.  The EQ-5D index score can take values in the range -0.594 to 1. In the past this has created problems when using EQ5D scores for the purposes of the Patient Reported Outcomes Measures, in particular relating to the calculation of relative performance factor (RPF) for each organisation covered. The RPF calculates the average ratio of observed score to predicted score for each organisation and can be heavily affected by the sign of the observed to predicted score. In the case of NHS OF indicator 2.4, the proposed approach is to assess the annual average EQ5D for each indicator at national level. The average for each indicator will then be compared to its back series and its forecast. Good outcomes will be indicated by those averages closest to 1, within the range -0.594 to 1. There is no plan to use an RPF methodology. Because of the construction of the indicator, negative values should not affect this assessment.  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.” The survey only uses the descriptive part and not the visual part, however 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.  The GPPS does not have ISB compliance. Nor does it have ROCR approval. However in discussions around NHS OF 2.4 (the equivalent indicators in the NHS Outcomes Framework) it was acknowledged that in the absence of a better data source the GPPS is still the most appropriate source for the indicator 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. |
| Supporting Documents  Provide links to any additional documentation used to support discussion at MRG | The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015, November 2012, <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213131/mandate.pdf>) |

MRG Recommendations, Comments & Updates:

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| Summary of discussion – 31/10/13 |
| The applicant introduced the indicator and explained that it uses the same methodology as the indicator with the same name in the NHS OF, apart from level of reporting. It was also highlighted how issues with the NHS OF indicator which surfaced at MRG and IGB had been addressed and details of these can be found in the Appraisal Record.  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. If this was not the case, the indicator needs to return to MRG for further discussion. |

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| Ref code  IAP00357-01  Made: 31/10/13 | **Show evidence of variation at CCG level. It was suggested that a funnel plot may be the most appropriate way to do this.** |
| Update:  Made: xx/xx/xx |  |
| Further Rec:  Made: xx/xx/xx |  |
| Update:  Made: xx/xx/xx |  |
| Rec Status: |  |

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| Item 2.2: Decision |
| The indicator is to be discussed at IGB on the condition that evidence of variation at CCG level exists. |

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.

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| Revision Date: |  |
| General Comments / Reasoning: |  |
| Revisions: |  |
| Indicator Title |  |
| Data source |  |
| Construction |  |
| Updated Potential Issues |  |

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

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| **Indicator Title** |  |
| Indicator Set | CCG Outcome Indicator Set |
| IAS Ref Code: | Indicators for discussion |
| 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). |
| 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. It has been assumed that it can be used. As far as we are aware there is no more suitable alternative.  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. |
| IG 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] |  |
| Implementation Method  [inc production funding] | NHS England has commissioned HSCIC to produce and disseminate the CCG OIS indicators; this is funded via the Grant In Aid funding to HSCIC.  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 speadsheet 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?] | 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: |  |
| 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: | * 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. |
| *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. |

IGB – Additional Recommendations:

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| Comments & Recommendations  [List additional comments and recommendations raised by IGB] |  |
| Action required: |  |
| Update:  Made: |  |

Review:

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| Review Timescale | 1 year |
| Rationale | Issues to consider – Changes to process, policy data source, coding definitions HES definitions ]  The indicator will have a review period of 1 year in order that year on year results can be compared to assess whether there is sufficient change to determine that the indicator is of use. |

IGB Sign-off: Indicator Assurance Process Output

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| *Final Appraisal Status* | **Assured with Comments** |
| Basis of Sign-off  [Detail caveats and limitations ] | The indicator methodology is signed off as assured for inclusion in the indicator library on the basis that the accompanying metadata makes it clear that:  • the indicator is not recommended for the purpose of comparison between CCGs  • the indicator may be useful for the purpose of surveillance through time series comparison  • the indicator should be used in the context of the wider set of health related quality of life indicators |
| Sign-off Date | 12/11/2014 |

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.  **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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|  | **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 |

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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. |