**NHS Digital**

**Indicator Supporting Documentation**

**IAP00609 Excess under 75 mortality in adults with learning disabilities**

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| Title | Excess under 75 mortality in adults with learning disabilities |
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| Indicator set | N/A |
| Brief Description  | This is a three-year rolling mortality indicator presented as a standardised mortality ratio, aimed at measuring the national and local standardised mortality ratio of the learning disabilities population. It is understood that people with learning disabilities have a significantly shorter life expectancy than that of the general population. A number of the causes of mortality amongst this population are thought to be premature and preventable. This indicator is therefore a useful tool in the improvement of the rates of mortality in the learning disabilities population and will ideally help to improve health outcomes and life expectancy in this group.  |
| Purpose | People with learning disabilities are known to die younger than others and many of these early deaths are from preventable causes (Glover et al. 20171). NHS England has major programmes in place to improve the accessibility and quality of healthcare for this group however many people with a learning disability still die prematurely. The deaths reviewed by the Learning Disabilities Mortality Review (LeDeR) show that compared with the general population, the median age of death is 23 years younger for men and 29 years younger for women (figures correct at time of publication – (May 2019). Some factors may not be avoidable but to aid learning from these occurrences and to translate that learning into potentially effective remedial action, this indicator will provide a key headline of progress in reducing excess mortality amongst this population. Development and regular monitoring of the indicator is therefore a top priority.This indicator will be produced and used for monitoring and assessment of the rate of mortality in the learning disabilities population in a geographical area (CCG, STP, Regional Local Office, Commissioning Region). Glover, G., Williams, R., Heslop, P., Oyinlola, J. & Grey, J., 2017. Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*, 61(1), pp.62–74. |
| Definition | The indicator value is the three-year rolling indirectly standardised ratio of the observed number of deaths of people with a recorded learning disability diagnosis to the expected number of deaths in that population based on age and sex-specific mortality rates in the general population. |
| Data Source | Learning Disabilities Health and Care Dataset, NHS Digital (GPES Extract)<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018> Primary Care Mortality Database (PCMD)<http://www.ons.gov.uk/ons/guide-method/classifications/international-standard-classifications/icd-10-for-mortality/death-certification-and-registration/index.html> <http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths> <https://digital.nhs.uk/services/primary-care-mortality-database>  |
| Numerator | Observed events – The number of observed events (in this case deaths) in a population (in this case the registered learning disabilities population) |
| Denominator | Expected events – The number of expected events (in this case deaths) in a population (in this case the registered learning disabilities population) |
| Calculation | The indicator value is the three-year rolling indirectly standardised ratio of the observed number of deaths of people with a recorded learning disability diagnosis to the expected number of deaths in that population based on age and sex-specific mortality rates in the general population. This indicator calculates three-year cumulative mortality in the learning disabilities population.This is first done by calculating the reference mortality rate for the general population of England in age and sex stratification and using this to gain the expected mortality rate of adults with learning disabilities in each age band and sex.**Calculation of the general population mortality rate** The general population mortality rate is a simple rate for England for people aged 0 to 74. The general population used here is drawn from the whole population registered at a gp practice in the learning disabilities dataset (LDOB001). **Denominator – general population mortality rate** The general population is derived from the learning disabilities dataset (population measure LDOB001), including people aged 0 to 74**.** **Numerator – general population mortality rate**All deaths from any cause for ages 0 to 74 at time of death are included in the numerator for the general population mortality rate (taken from the PCMD extract). The data are based on the registered date of death.The age and sex specific rates are then calculated as follows:$$r= ^{Oi}/\_{ni}$$Where:ri is the age and sex specific rate in the population in the age and sex group iOi is the observed number of events (deaths) in the population in age and sex group ini is the number of individuals in the subject population in age and sex group i**Calculation of the Standardised Mortality Ratio (indicator value)** The Standardised Mortality Ratio (SMR) expressed as a percentage represents the indicator value. It is an indirectly standardised ratio. The SMR is calculated by using the general population age and sex specific mortality rates to get expected deaths in the learning disabilities population, then comparing the observed deaths with the expected deaths. The age groups used are 0-9, 10-17, 18-24, 25-29, 30-34, 35-39, 40-44, 45- 49, 50-54, 55-59, 60-64, 65-69 and 70-74.The SMR expressed as a percentage is calculated as follows:$$SMR= \frac{O}{E} ×100= \frac{\sum\_{i}^{}O\_{i}}{\sum\_{i}^{}E\_{i}} ×100= \frac{\sum\_{i}^{}O\_{i}}{\sum\_{i}^{}n\_{i}λ\_{i}}$$Where:*O*i is the observed number of deaths in the learning disability population in age and sex group i;*E*i is the expected number of deaths in the learning disability population in age and sex group i; $n$i is the number of individuals in the learning disability population in age and sex group i;λi is the crude age and sex-specific rate in the general population in age and sex group i.*Confidence interval methodology and calculation given in section 5.7*GP system suppliers collect data from practices according to business rules written by the Specification Development Service in NHS Digital’s Primary Care Domain. In the case of this indicator the data is taken from the pre-existing data extract for the Health and Care of People with Learning Disabilities publication.The rules for defining the Learning Disabilities (LD) population, the general population and mortality rate are as follows:* LDOB001 – Number of patients registered at a general practice, as at the end of the reporting period.
* Rule 1 – if ACTIVEEND\_VAL = R – Select all patients from the specified population who are registered at the end of the reporting period. Reject the remaining patients.
* LDOB003A – Number of patients recorded on their general practice’s QOF learning disability register, as at the end of the reporting period.
* Rule 1 – if ACTIVEEND\_VAL = R – Pass to next rule all patients from the specified population who are registered at the end of the reporting year. Reject the remaining patients.
* Rule 2 – if LD\_DAT <= RPED – Select patients passed to this rule who have a learning disability diagnosis up to and including the reporting period end date. Reject the remaining patients.
* LDOB004 – Number of patients diagnosed with a learning disability as at the reporting period start date who had a registration status of deceased at the end of the reporting period.
* Rule 1 – if LD\_DAT <= RPSD – Pass to the next rule all patients from the specified population who have a learning disability diagnosis up to and including the reporting period start date. Reject the remaining patients.
* Rule 2 – if ACTIVEEND\_VAL = D – Select patients passed to this rule who died up to and including the reporting period end date. Reject the remaining patients.

The general population mortality figures are taken from the Primary Care Mortality Database. This is a database containing death registration data from April to March of each year including demographic details, cause and place of death, certifying GP and coroner’s details. In this case all that is taken for the indicator is single year of age, gender and number of deaths.For the purposes of creating a three-year rolling mortality indicator, the populations are taken from the first year of the three being looked at, the mortality figures are taken from the entire range of years being looked at. |
| Interpretation Guidelines | Due to the fact that some of the general practice system suppliers are unable to contribute data for this collection we will be providing coverage figures alongside each CCG. This figure will be the percentage of practices in each geographical area (CCG, STP, Regional Local Office or Region) who have supplied data. This will allow users to identify areas where the missing practice data could be affecting the figures.Text will be presented along with the indicator explaining the coverage issues and advising that all rates should be viewed with the coverage figures in mind. There is also potential for issues regarding the indicator’s lack of separation out of preventable and non-preventable causes of mortality. There will be information provided around this, aiming to clarify the difficulties in separating out preventable and non-preventable causes of death in population-level statistics to the reader. |
| Caveats |  |

***Application form***

**Section 1: Introduction and Overview**

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| **1.1 Indicator title** | Excess under 75 mortality in adults with learning disabilities | **1.8 Application type** | *New* |
| **1.2 Reference number***(if unsure, please leave for IMAS team)* | IAP00609 | **1.9 Requestingorganisation** | NHS Digital |
| **1.3 Topic area****1.4 Domain (if applicable)** | *Learning disabilities**Domain 1: Preventing people from dying prematurely* | **1.10 Applicant details** | Name: Alex HappsTitle: Trainee Data AnalystEmail: Alexander.happs1@nhs.net |
| **1.5 Set** | *N/A* | **1.11 Alternate contact details**  | Name: Rob DanksTitle: Senior Information AnalystEmail: robertdanks@nhs.net |
| **1.6 Please explain if ‘Set’ is ‘Other’ or ‘N/A’** |  | **1.12 SRO/ sponsor / policy owner details** | Name: Gareth James (DHSC)Title: Email: gareth.james@dhsc.gov.uk  |

**1.7 Brief Summary of indicator (max 100 words)**

This is a three-year rolling mortality indicator presented as a standardised mortality ratio, aimed at measuring the national and local standardised mortality ratio of the learning disabilities population. It is understood that people with learning disabilities have a significantly shorter life expectancy than that of the general population. A number of the causes of mortality amongst this population are thought to be premature and preventable. This indicator is therefore a useful tool in the improvement of the rates of mortality in the learning disabilities population and will ideally help to improve health outcomes and life expectancy in this group.

**Section 2: Rationale and Policy Basis (IGB to assess, MRG to advise)**

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| **2.1 Why is this indicator needed and why is it important that it be measured?** | People with learning disabilities are known to die younger than others and many of these early deaths are from preventable causes (Glover et al. 2017[[1]](#footnote-1)). NHS England has major programmes in place to improve the accessibility and quality of healthcare for this group however many people with a learning disability still die prematurely. The deaths reviewed by the Learning Disabilities Mortality Review (LeDeR) show that compared with the general population, the median age of death is 23 years younger for men and 29 years younger for women (figures correct at time of publication – September 2018). Some factors may not be avoidable but to aid learning from these occurrences and to translate that learning into potentially effective remedial action, this indicator will provide a key headline of progress in reducing excess mortality amongst this population. Development and regular monitoring of the indicator is therefore a top priority.This indicator will be produced and used for monitoring and assessment of the rate of mortality in the learning disabilities population in a geographical area (CCG, STP, Regional Local Office, Commissioning Region).  |
| **2.2 Is there any clinical evidence or professional opinion that can be cited in the development of this indicator?***.* | Early mortality in people with learning disabilities has been reported in academic literature for a significant period. The most widely cited early study used population-based registers in two London boroughs to report that people with learning disabilities had Standardised Mortality Ratios of 9.6 in one borough and 18.0 in the other. Their chance of dying before the age of 50 was 58 times that of people without learning disabilities living in the same areas (Hollins et al. 1998[[2]](#footnote-2)).Following a report by the charity Mencap in 2007, the (then) Department of Health commissioned a Confidential Inquiry into mortality of people with learning disability and established a public health observatory tasked with improving the available information about their health and care. The Confidential Inquiry undertook in-depth studies of the deaths of 247 people with learning disabilities, as far as they could ascertain all those that occurred in a defined population area in a period of two years (Heslop et al. 2013)[[3]](#footnote-3). They concluded that 42% of the 238 deaths on which their panel reached consensus were premature, most commonly because of delays or difficulties with diagnosis or treatment, or problems with identifying needs and providing appropriate care in response to changing needs. The learning disabilities observatory undertook a detailed study of the mortality of individuals identified as having learning disabilities by their GP in the Clinical Practice Research Datalink, a general practice research database managed by the Medicines and Healthcare Products Regulatory Authority and linked to national mortality and hospitalisation datasets (Glover et al. 2017)[[4]](#footnote-4). This showed a standardised mortality ratio of 3.2 for this group overall, 3.4 for women and 3.0 for men. Causes which stood out as significantly more prominent in those with than those without learning disabilities included epilepsy, aspiration pneumonitis and colorectal cancer, all potentially avoidable causes of mortality. In addition to these studies a substantial amount of research has been undertaken into mortality rates for people with learning disabilities both in the UK and internationally. This has recently been reviewed by O’Leary and her colleagues. (O’Leary et al. 2017) [[5]](#footnote-5)noted that similarly high rates were found in most studies, with some deaths potentially avoidable. They concluded that improved health care and initiatives addressing relevant lifestyle behaviours and health risks were indicated. |
| **2.3 Is there any clinical evidence or professional opinion to support the ongoing need for this indicator?** | Since the confidential inquiry set out in 2013, cases of avoidable or premature death have been closely assessed and some improvements have been made. There was a progress update in September 2014 and specific objectives set in the Government’s Mandate to the NHS 2014-15 to reduce excess mortality in adults under 60 (this was repeated in the 2015-16 mandate and is still included in the 2018-19 mandate). In June 2015, NHS England announced a three-year national review of premature deaths of people with learning disabilities. This ongoing work shows a clear determination by both the health service and the government to improve health inequalities in those with learning disabilities. However, organisational dysfunction, gaps in service provision and delay in diagnosis and treatment remain the foremost causes of premature death in the learning disabilities population and as such this indicator will provide an important component of the ongoing improvements in care.The Health and Care of People with Learning Disabilities publication further outlines the ongoing need for this indicator, showing mortality figures that have remained largely unchanged throughout the period of the work done to improve the national picture. When the publication began in 2014, the females registered in the publication with learning disabilities had around an 18-year shorter life expectancy than the general population and males a 14-year shorter life expectancy. In the 2018 publication, this had remained the same for both females and males.Publication: <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities> Key to the strategy to address this health inequality is the ability to monitor the rate of premature deaths for this group over time and compare this with the rate for the general population. Reflecting the policy importance of this measurement, mortality in various populations, including premature death of those with learning disabilities are outcomes against which progress will be assessed. Development and regular monitoring of the indicator is thus a top priority.  |
| **2.4 Which governmental strategies or policies is supported by the use of this indicator?** | The Learning Disabilities Mortality Review (LeDer) Programme Third Annual Report (May 2018) <https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2017> “The persistence of health inequalities between different population groups has been well documented, including the inequalities faced by people with learning disabilities. Today, people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare. The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It is being implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017. The programme is led by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.”Learning Disability – policy and services, House of Commons Briefing Paper number 07058, 18 September 2018. <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN07058>“The Government and NHS England have committed to reducing health inequalities for people with learning disabilities and have established national programmes to improve treatment and outcomes. The Government’s Mandate to the NHS 2018-19 set an objective for the NHS to close the health gap between people with mental health problems, learning disabilities or autism and the population as a whole.”The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report, September 2018.(<https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report>)“The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas across England to review the deaths of people with a learning disability, to draw out learning from those deaths and to put that learning into practice. We want all local areas to improve the quality of the health and social care services provided to people with a learning disability, and to address the persistent health inequalities they face. LeDeR is the first national programme in the world set up to systematically review the deaths of all people with a learning disability aged four years and above which are notified to it and to embed mortality review processes across the country. Following the publication of the report of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD) in 2013, the Norah Fry Centre for Disability Studies at the University of Bristol, which led CIPOLD, was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England to establish the LeDeR programme with the intention of ensuring that all local areas in England have their own mortality review programmes in place by 2017. Work on the LeDeR programme began in June 2015, initially for a three-year period.”  |
| **2.5 Who would use this indicator and why?** | The evidence of sustained and profound health inequalities for people with a learning disability is compelling. Across all public services and society there is potential for improvement. Local and regional healthcare providers should use this indicator to first identify what their local rate is and then work towards reducing inequalities between the rate of mortality in the general and learning disabilities populations.This indicator should be used to identify potential shortcomings in provision of appropriate healthcare for people with learning disabilities. It is possible to use this indicator as an instigating factor in identification of a problem in an area or provider; a tool to prompt further investigation. It is not a means of direct comparison between two providers or Clinical Commissioning Groups (CCGs). This is due to the indirect standardisation methodology, this renders direct comparison ineffective. However, generalised comparison of where a CCG or area stands compared to the national figure can be made. Public Health England will also use this indicator as a monitoring tool to assess which areas need to support to improve their provision of service for the learning disability population. |
| **2.6 Is there a relationship to other existing indicators?** | There is currently no relationship to other existing indicators. Though the title and calculation of the indicator bear resemblance to other mortality indicators, this is currently a standalone metric that has not been produced before. |
| **2.7 Comparability to other existing indicators** | There are currently no comparable indicators to this one. Comparison of the mortality rate in the learning disabilities population to that of the general population is currently a missed opportunity. |
| **Section 3: Presentation and interpretation (IGB to assess, MRG to advise)** |  |
| **3.1 How will the indicator be presented?***.* | This indicator will be presented as an official statistic both as part of the Health and Care of People with Learning Disabilities annual publication and on the NHS Digital website as a csv file. These files will also be accompanied by a specification and a data quality statement. In the first year it will be published as supplementary information, an extra addition to the Health and Care of People with Learning Disabilities publication. After the first year it will be published simultaneously with the Health and Care of People with Learning Disabilities, as part of the publication.Link to publication: <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities>The data will be presented with a detailed header including information on the statistics presented, the reporting period, the level of coverage and any resulting limitations, publication date, data sources and any further notes to be aware of. The indicator will be presented at CCG level (for all English CCGs), Sustainability Transformation Partnership (STP), Regional Local Office, Regional and national level. **Breakdowns****Time periods**Annual data for deaths from 01/04/2014 to 31/03/2017 onward, population registered with a Learning Disability from 01/04/2014 to 31/03/2015.**Geographic**England – England level data for deaths from 01/04/2014 to 31/03/2017 onward, population registered with a Learning Disability at England level from 01/04/2014 to 31/03/2015 onward.CCG – CCG level data for deaths from 01/04/2014 to 31/03/2017 onward, population registered with a Learning Disability at CCG level from 01/04/2014 to 31/03/2015 onward.STP – STP level data for deaths from 01/04/2014 to 31/03/2017 onward, population registered with a Learning Disability at STP level from 01/04/2014 to 31/03/2015 onward.Regional Local Office – Regional Local Office level data for deaths from 01/04/2014 to 31/03/2017 onward, population registered with a Learning Disability at Regional Local Office level from 01/04/2014 to 31/03/2015 onward.Commissioning Region – Commissioning Region level data for deaths from 01/04/2014 to 31/03/2017 onward, population registered with a Learning Disability at Commissioning Region Level from 01/04/2014 to 31/03/2015 onward. |
| **3.2 What contextual information will be provided alongside the indicator?***.*  | Due to the fact that some of the general practice system suppliers are unable to contribute data for this collection we will be providing coverage figures alongside each CCG.  This figure will be the percentage of practices in each geographical area (CCG, STP, Regional Local Office or Region) who have supplied data.  This will allow users to identify areas where the missing practice data could be affecting the figures. Text will be presented along with the indicator explaining the coverage issues and advising that all rates should be viewed with the coverage figures in mind.    There is also potential for issues regarding the indicators lack of separation out of preventable and non-preventable causes of mortality. There will be information provided around this aiming to clarify the difficulties in separating out preventable and non-preventable causes of death in population-level statistics to the reader. Additionally, a link to the Health and Care of People with Learning Disabilities interactive dashboard will be given, found here:  <https://app.powerbi.com/view?r=eyJrIjoiNTYyNDM4MGYtZDRmYi00NTAxLTkzY2QtMjcwZTY2YTQ0MzNkIiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjllMiIsImMiOjh9>   This gives information around the prevalence of specific long-term conditions in those with learning disabilities. This is only illustrative and provides background information, it does not clear up any issues around preventable and non-preventable; these issues are common in the development of mortality indicators and contentious amongst clinicians. It is beyond the scope of this indicator to attempt to separate preventable and non-preventable causes.  |
| **3.3 What is considered “good” performance? What is considered “bad” performance?** | Good performance would be moving in the direction of closing the gap between the mortality rate in the general population and the mortality rate in the population with learning disabilities, i.e. bringing the learning disability mortality rate toward the general population rate. In the case of this indicator, it is improving when the indicator value decreases. When the value decreases, this is showing that the difference between the rate of people dying in the general population and the rate of people dying from the learning disability population is reducing. Therefore, a reduction in the indicator value would indicate that the inequity in outcomes for the two populations is decreasing.Any increase in inequity between the general population rate and the learning disability population rate would be considered bad performance. The indicator value increasing would therefore indicate bad performance.There are exceptions to the rule, for example a rate nearing that of the general population not necessarily meaning “good performance” and vice versa. More importantly it gives an initial investigation trigger and cause to examine why an area’s rate is high or low. Additionally, closing the gap in between the general population value and that of the learning disabilities population can potentially mean that the mortality rate in the general population is getting worse. Assessing this would take further external examination and understanding of the broader current issues in health in England that lie outside the scope of this indicator.  |
| **3.4 Is there a target to be achieved?** | The target to be achieved in the long run would be closing the gap between inequalities in learning disability and general population mortality rates. It is hoped that this indicator would make a significant contribution to identifying the areas in which improvement in care can be made, potentially extending the life expectancy and reducing the mortality rate in people with learning disabilities. A reduction in indicator value should be sought; this would signify to those using the indicator that the health inequity is reducing. |
| **3.5 How will any interested parties use the information provided by the indicator?** | Once assured and published, the indicator will provide an initial insight into the performance of a CCG or the national performance around healthcare of those with learning disabilities. It should not be used as a means of direct comparison of performance between two CCGs. Public Health England also aim to use this as a tool to assess where they need to support commissioners to improve the care and procedures they put in place to look after their learning disability population.While the indicator is primarily aimed at those within the healthcare and public health sectors, it will also be available to the general public. Therefore, a low level of technical or subject knowledge will be assumed and all elements of the calculation and background subject will be explained.  |
| **3.6 Consider how the results can be used for benchmarking. If so, what methodology will be used?** | The only way this indicator could be used for benchmarking is to set the general population mortality rate as the benchmark. It is not possible or appropriate at this stage to use a specific region’s score as the benchmark and to work towards that. Year on year direct comparison is not possible and as a consequence it is not possible to say whether a CCG is getting worse or improving as years progress. |

**Section 4: Data (MRG to assess)**

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| **4.1 What is the source of the data and why should it be used?** | The main data sources for this indicator are the NHS Digital Learning Disabilities Health and Care Dataset and the NHS Digital Primary Care Mortality Database:1. Learning Disabilities Health and Care Dataset, NHS Digital (GPES Extract).

The reason for use of this dataset is that no other source identifies both the subject population and corresponding mortality data for this specific population with age / sex stratification on a national scale. The ideal alternative would be linkage between GP learning disabilities register and mortality data. This would provide additional data about causes nationally but this is not currently available. Coverage in the Learning Disabilities and Care Dataset is just over half of the population of England (around 50%), with CCG boundaries, with variable coverage between CCGs. The gaps in coverage arise primarily because NHS England have been unable to negotiate appropriately with TPP, the commercial supplier of one of the market leading clinical recording systems in use in primary care settings. The system concerned currentlyhas a market share of approximately 40%. The remaining missing 10% is due to other system providers. Data is 100% complete from practices and systems that do contribute data, reflecting a requirement practices to affirm with their system suppliers their willingness for data to be used in future. Further background information on this dataset can be found at: <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018>1. Primary Care Mortality Database (PCMD)

This database is required for use within this indicator to calculate the rate of mortality in the general population. The PCMD holds mortality data as provided at the time of registration of the death along with additional GP details, geographical indexing and coroner details where applicable. It is managed by NHS Digital and is accessed securely using Open Exeter via an N3 connection.The PCMD currently holds data from 1997 up until the most recent monthly data extract (monthly data is added by the second week of the following month). Further background information can be found on these data on the ONS and NHS Digital websites:<http://www.ons.gov.uk/ons/guide-method/classifications/international-standard-classifications/icd-10-for-mortality/death-certification-and-registration/index.html><http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths><https://digital.nhs.uk/services/primary-care-mortality-database>Both of the data sources listed are updated annually and as far as is possible to know will be available in the same way in the future. |
| **4.2 Was any other data source considered?**  | There is currently no other source that captures the data that could be used for the purposes of this indicator. As mentioned in 4.1 the ideal alternative would be the GP learning disabilities register linked with mortality data, but this is not yet available. The learning disabilities data set provides a rich source of data, unmatched anywhere else. The PCMD provides a comprehensive linkage opportunity for this indicator and no other database would be able to provide this. |
| **4.3 What is the coverage period of the data?** | The collection of learning disabilities data used in this indicator began in 2014-15, when the Health and Care of People with Learning Disabilities was first published. It is published once every financial year and the indicator will also be published once every financial year. While the publication will go out annually, the indicator calculates three year rolling mortality figures. This means that while a new year will be added every time, not all the data used will be new. |
| **4.4 Which geographic area(s) will be covered and reported on by this indicator?** | While the data collected for the publication aims to cover the entirety of practices in England, it remains that some practices systems do not allow them to contribute data. There is a geographical pattern in this lack of ability to submit data that means a large portion of practices in Northern and Eastern England are unable to be reported on. The data presented will give a national figure and CCG, STP, Regional Local Office, Region level figures and will be reporting on all data available. Should the amount of available data increase and coverage improve, more data will be included.  |
| **4.5 How will the data be extracted or collected?** | Data is currently extracted annually from GPES to create the Learning Disabilities Health and Care Dataset. The Primary Care Mortality Database is also currently available. Therefore, this indicator is re-using and combining data that is currently widely available, not creating a new collection or extract primarily for the purpose of this indicator. |
| **4.6 Data fields required** | Data fields from the Health and Care of People with Learning Disabilities (from population measures LDO001, LDO003a and LDO004 – learning disability recorded deaths measure):“PRACTICE\_CODE” “CCG\_CODE” “SEX” “AGE\_BAND” “VALUE”Data fields from the Primary Care Mortality Database:“CCG\_CODE “PRACTICE\_CODE” “AGE BAND” “SEX” “DEATHS”The two datasets are then linked on practice code, age band and sex, then aggregated up to CCG level to perform calculations. |
| **4.7 Are any data filters required?** | There is a filter applied to the age range in both the learning disabilities data and the PCMD data – the age bands 60 and above are excluded for this indicator. |
| **4.8 Are there any linkages to other datasets?** | There are no linkages to datasets other than those already mentioned. |
| **4.9 Are there any limitations or potential bias?** | The main limitation to this indicator is the lack of inclusion of practices using systems unable to contribute data, meaning coverage is impacted significantly (50 per cent). This has potential implications for the national figure published because while it is possible to get the general population figures with no system supplier restrictions, missing practices are not able to contribute learning disabilities data. It is not possible to tell whether those practices that do contribute data have better outcomes in their learning disability population than those that are not able to contribute, therefore skewing any results to the positive or negative. This is an inherent issue in collecting data from across different systems with differences in contracts and coverage. It is unknown how the inclusion of those practices using these systems would impact the national figure. However, the way the indicator has been calculated (3-year cumulative mortality) and the use of a reference population and complete general population mortality rate data, means we are able to go some way to ensuring robust and representative results are attained.Additionally, the inability to separate out preventable and non-preventable causes of death presents uncertainty in interpretation of the indicator. Compiling population level statistics is inherently tricky as this lack of clarity on causes leaves a lack of trust in the data. However, this should not be taken to void all the results provided, as significantly high figures alongside coverage information are still a cause for concern and investigation. |
| **4.10 Further notes on data**  | There are no other known issues with the data.  |
| **Section 5: Construction and Testing (MRG to assess)** |  |
| **5.1 How will the indicator measure be calculated / constructed?** *Please provide explanation of coding where applicable and rationale behind demographic breakdowns* | The indicator value is the three-year rolling indirectly standardised ratio (expressed as a percentage) of the observed number of deaths of people with a recorded learning disability diagnosis to the expected number of deaths in that population based on age and sex-specific mortality rates in the general population. This indicator calculates three-year cumulative mortality in the learning disabilities population.This is first done by calculating the reference mortality rate for the general population of England in age and sex stratification and using this to gain the expected mortality rate of adults with learning disabilities in each age band and sex.**Calculation of the general population mortality rate** The general population mortality rate is a simple rate for England for people aged 0 to 74**.** The general population used here is drawn from the whole population registered at a gp practice in the learning disabilities dataset (LDOB001). **Denominator – general population mortality rate** The general population is derived from the learning disabilities dataset (population measure LDOB001), including people aged 0 to 74**.** **Numerator – general population mortality rate**All deaths from any cause for ages 0 to 74 at time of death are included in the numerator for the general population mortality rate (taken from the PCMD extract). The data are based on the registered date of death.The age and sex specific rates are then calculated as follows:$$r= ^{Oi}/\_{ni}$$Where:ri is the age and sex specific rate in the population in the age and sex group iOi is the observed number of events (deaths) in the population in age and sex group ini is the number of individuals in the subject population in age and sex group i**Calculation of the Standardised Mortality Ratio (indicator value)** The Standardised Mortality Ratio (SMR) expressed as a percentage represents the indicator value. It is an indirectly standardised ratio. The SMR is calculated by using the general population age and sex specific mortality rates to get expected deaths in the learning disabilities population, then comparing the observed deaths with the expected deaths. The age groups used are 0-9, 10-17, 18-24, 25-29, 30-34, 35-39, 40-44, 45- 49, 50-54, 55-59, 60-64, 65-69 and 70-74.The SMR expressed as a percentage is calculated as follows:$$SMR= \frac{O}{E} ×100= \frac{\sum\_{i}^{}O\_{i}}{\sum\_{i}^{}E\_{i}} ×100= \frac{\sum\_{i}^{}O\_{i}}{\sum\_{i}^{}n\_{i}λ\_{i}}$$Where:*O*i is the observed number of deaths in the learning disability population in age and sex group i;*E*i is the expected number of deaths in the learning disability population in age and sex group i; $n$i is the number of individuals in the learning disability population in age and sex group i;λi is the crude age and sex-specific rate in the general population in age and sex group i.*Confidence interval methodology and calculation given in section 5.7*GP system suppliers collect data from practices according to business rules written by the Specification Development Service in NHS Digital’s Primary Care Domain. In the case of this indicator the data is taken from the pre-existing data extract for the Health and Care of People with Learning Disabilities publication.The rules for defining the Learning Disabilities (LD) population, the general population and mortality rate are as follows:LDOB001 – Number of patients registered at a general practice, as at the end of the reporting period.Rule 1 – if ACTIVEEND\_VAL = R – Select all patients from the specified population who are registered at the end of the reporting period. Reject the remaining patients.LDOB003A – Number of patients recorded on their general practice’s QOF learning disability register, as at the end of the reporting period.Rule 1 – if ACTIVEEND\_VAL = R – Pass to next rule all patients from the specified population who are registered at the end of the reporting year. Reject the remaining patients.Rule 2 – if LD\_DAT <= RPED – Select patients passed to this rule who have a learning disability diagnosis up to and including the reporting period end date. Reject the remaining patients.LDOB004 – Number of patients diagnosed with a learning disability as at the reporting period start date who had a registration status of deceased at the end of the reporting period.Rule 1 – if LD\_DAT <= RPSD – Pass to the next rule all patients from the specified population who have a learning disability diagnosis up to and including the reporting period start date. Reject the remaining patients.Rule 2 – if ACTIVEEND\_VAL = D – Select patients passed to this rule who died up to and including the reporting period end date. Reject the remaining patients.The general population mortality figures are taken from the Primary Care Mortality Database. This is a database containing death registration data from April to March of each year including demographic details, cause and place of death, certifying GP and coroner’s details. In this case all that is taken for the indicator is single year of age, gender and number of deaths.For the purposes of creating a three-year rolling mortality indicator, the populations are taken from the first year of the three being looked at, the mortality figures are taken from the entire range of years being looked at. |
| **5.2 Numerator explanation** | Observed events – The number of observed events (in this case deaths) in a population (in this case the registered learning disabilities population) |
| **5.3 Denominator explanation***.*  | Expected events – The number of expected events (in this case deaths) in a population (in this case the registered learning disabilities population) |

**5.4 Provide a worked example**

**Step 1:** Calculate reference mortality rates for the general population in age and sex stratification

|  |  |  |  |
| --- | --- | --- | --- |
| **Age Band** | **Sex** | **Population** | **Deaths** |
| 0 to 9 | M | 1875227 | 311 |
| 0 to 9 | F | 1787882 | 246 |
| 10 to 17 | M | 1319288 | 207 |

* Divide number of observed deaths by the age and sex specific population to get age and sex specific crude mortality rates

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Age Band** | **Sex** | **Population** | **Deaths** | **Rate** |
|  |  |  |  |  |
| 0 to 9 | M | 1875227 | 311 | 0.000166 |
| 0 to 9 | F | 1787882 | 246 | 0.000138 |
| 10 to 17 | M | 1319288 | 207 | 0.000157 |

**Step 2:** Apply the reference age and sex specific mortality rates to the subject (learning disability) population to calculate the expected deaths ***for each age band and sex*** ***at CCG level***.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **CCG** | **Age Band** | **Sex** | **LD Population** | **LD Deaths** | **Whole Population** |  **Reference Rate** |
| 00D | 0 to 9 | M | 7 | 0 | 542 | 0.000166 |
| 00D | 0 to 9 | F | 1 | 0 | 818 | 0.000138 |
| 00D | 10 to 17 | M | 18 | 0 | 606 | 0.000157 |

* To get expected deaths, multiply the reference rate by the subject population (LD Population)

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **CCG** | **Age Band** | **Sex** | **LD Population** | **Observed Deaths** | **Whole Population** |  **Reference Rate** | **Expected Deaths** |
| 00D | 0 to 9 | M | 7 | 0 | 542 | 0.000166 | 0.001160929 |
| 00D | 0 to 9 | F | 1 | 0 | 818 | 0.000138 | 0.000137593 |
| 00D | 10 to 17 | M | 18 | 0 | 606 | 0.000157 | 0.002824254 |

**Step 3:** **Aggregate the results up to CCG level** (i.e. take out age and sex bands) to get the total expected deaths and total observed deaths by CCG. Use the expected deaths to calculate the indirectly standardised ratio (ISR).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **CCG** | **LD Population** | **Expected Deaths** | **Observed Deaths** | **Indirectly Standardised Ratio** |
| 00D | 7 | 0.7856963 | 2 | 254.55128146 |
| 00J | 1 | 1.162451341 | 3 | 258.07531844 |
| 00K | 18 | 0.472692088 | 3 | 634.66262207 |

* To get the indirectly standardised rates, divide the observed deaths by the expected deaths and multiply by 100

**Step 4:** Aggregate CCG observed and expected deaths up to calculate the national ISR figure for England. Each different form of health geography (STP, Regional Local Office, Commissioning Region) can be aggregated to from CCG level.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Geography** | **LD Population** | **Expected Deaths** | **Observed Deaths** | **Indirectly Standardised Ratio** |
| England | 123533 | 342.05194965 | 1401 | 410.4639665 |

|  |  |
| --- | --- |
| **5.5 Could any risks be associated with the use of this indicator?** | It is unlikely that the development and use of this indicator will result in any undesired behaviours either in the target population nor the organisations providing services. This is because the data is collected via automated central means and when a practice has agreed to submit data the completeness of the data submitted is 100%. There is no option for a contributing practice to selectively submit data due to the terms of the data sharing contract. |
| **5.6 Risk adjustment or standardisation type and methodology** | Indirect StandardisationThe chosen methodology is a Standardised Mortality Ratio, using indirect standardisation. The methodology was selected because it applies the mortality rate of a reference population to the subject population in order to ascertain whether the mortality rate for a specific group/locality is higher or lower than what would be statistically expected in the same group/locality of the standard population.  |
| **5.7 What are the confidence intervals and control limits and why have they been used?** | 95% confidence intervals are used to identify whether a difference in mortality rate is or is not statistically significant. When calculating 95% confidence intervals for an indirectly standardised ratio such as this, it is assumed that the standard or reference rates come from a population sufficiently large as to assume their sampling variance is negligible, and that the observed number of events (O) follows a Poisson distribution.**Confidence interval application and calculation**95% confidence intervals were applied as followsOlower and Oupper are the lower and upper confidence intervals for the observed number of events.Olower and Oupper are the lower and upper confidence intervals for the observed number of events.Where:Olower and Oupper are the lower and upper confidence intervals for the observed number of events.Using Byar’s method, the confidence limits for the observed number of events are given by:Olower and Oupper are the lower and upper confidence intervals for the observed number of events.Formula showing the confidence limits for the observed number of events Where:Z is the 100(1-α/2)th percentile value from the Standard Normal distribution (for 95% confidence interval α = 0.05 and z = 1.96) |
| **5.8 Could the indicator be manipulated to influence the outcome?** | It is not possible to manipulate or influence the outcome of this indicator as the data come from an automated collection, once a practice has signed up to provide data they have signed up to provide 100% of the data on their systems pertaining to the collection. This reduces the chance of any provider or service being able to selectively submit data and manipulate any outcome. This indicator is currently not linked to any incentive or commissioning therefore the likelihood of manipulation for financial gain is reduced. |

**METHODOLOGY rEVIEW grOUP (mrg) paper**

**Meeting Paper: 4c –**

**Meeting Date:**  08/08/2019

**Agenda Item:** Indicators for discussion

**Sponsor:** MRG Chair

**Summary:** This is a three-year rolling indicator aimed at measuring the national and local standardised mortality ratio of the learning disabilities population. It is understood that people with learning disabilities have a significantly shorter life expectancy than that of the general population. A number of the causes of mortality amongst this population are thought to be premature and preventable. This indicator is therefore a useful tool to improve the rates of mortality in the learning disabilities population and is intended to improve health outcomes and life expectancy in this group.

**This indicator was initially presented at 13/06/2019 MRG for advice. The document provides responses from the applicant to MRG queries, comments and feedback.**

**Please read this document alongside paper 4d - IAP00609 Application form.**

**Action:** Please read and add feedback and questions for discussions and sign off at MRG



**Appraisal Log**

**1. Introduction and Overview**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
|  | N/A |  |  |  |  |  |

**2. Rationale and Policy Basis**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
| 2.5 | “It is not a means of comparison between providers or Clinical Commissioning Groups (CCGs) and no attempts to use it as such should be made”This seems over-prohibitive. In 2.1, you acknowledge that "some factors may not be avoidable" so, without comparison with other CCGs and providers, how will they know whether they had a particular problem? | Rachel Reeves | What the form should perhaps say is that due to the methodology direct comparisons between CCGs should not be carried out as the ratios are indirectly standardised. CCG ratio can be compared against the national ratio to identify those with a greater or lower mortality ratioApplication form updated to reflect this. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 2.7 | Are there any issues anticipated regarding that this does not separate out preventable and non-preventable deaths? There could be some criticism of this as there are rates of poorer health in populations with learning disability | Rachel Reeves | There is potential for this to be an issue and as such we'll caveat to make people aware. We can also link users directly to our interactive dashboard which has a page that shows the prevalence of certain long term and potentially life shortening health conditions in people with learning disabilities vs those without. Unfortunately, as the learning disability mortality data is only available at practice level, we cannot control for specific health conditions.Update added to 3.2 with information aimed at covering this. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |

**3. Presentation and Interpretation**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
| 3.1 | Clarification of where the indicator will be presented needed. | Anne Cunningham | Application form amended to clarify this – The indicator will be presented as part of the Learning Disabilities publication | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.1 | Is this the correct health geography in terms of CCG's being able to act on results? | Adrian King | We'll be including CCG, STP, Regional Local Office and Region as well as national figures.  | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.2 | “There is also potential for issues regarding the indicators lack of separation out of preventable and non-preventable causes of mortality. There will be information around this to clarify to the reader as well as a link to the Health and Care of People with Learning Disabilities interactive dashboard, found here:”This seems a lot more complex than implied here. How would readers use such prevalence information to determine which deaths were preventable or not? Not suggesting this is necessarily the place to spell that out, but this section seems to over-estimate the usefulness of the data on prevalence of other diseases for distinguishing preventable from non-preventable | Rachel Reeve | Application form amended to reflect this. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.2 | If the death cases were non-preventable is it still 'excess'? | Paul Iggulden | There are difficulties in developing indicators in any group or population with respect to what is excess/preventable/non-preventable, general population included. Point understood and it is a good point though this is the title specified for this indicator and the word excess features in numerous other indicator titles. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.2 | As this is the first mention of 'TPP', maybe this is the best place to explain who/what they are (rather than section 4.1). | Anne Cunningham | Application form amended to include this. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.2 | “Due to the fact that one of the main general practice system suppliers The Phoenix Partnership (TPP) do not supply data for this collection and that TPP are based in specific parts of the country (the North and East of England) we will be providing coverage figures alongside each CCG. This figure will be the percentage of practices in each Geographical area (CCG, STP, Regional Local Office or Region) who have supplied data. This will allow users to identify areas where the missing TPP data could be affecting the figures”. How significant is this caveat? | Paul Iggulden | It is a significant issue. However, this is the best data source that currently exists for this population. Additional information added throughout application form to attempt to explain this and account for it. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.3 | This is a robust example of what good/bad looks like | Adrian King | N/A | Adrian King (MRG member)13/06/2019 |[x]   |
| 3.3 | “Any increase in inequity between the general population rate and the learning disability population rate would be considered bad performance. The indicator value increasing would indicate bad performance”Inequity may be a better word here - "we're" looking that services are tailored to individuals' needs so as they are all moving out of the avoidable deaths category. Inequality is where we ensure that we give a generalisable service (with minor tailoring) to everyone.... | Adrian King | Very much agree, application amended to reflect  | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.4 | Is the target a Standardised Mortality Ratio (SMR) of 100? (No difference?) | Paul Iggulden  | Application amended to clarify and reduce confusion around this. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[ ]   |
| 3.5a | “It should not be used as a means of comparison of performance between CCGs.”Why not? comparing performance is a key element of the NHS OF | Rebecca SmittenaarCraig Grime | Application amended. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 3.5b | “While the indicator is primarily aimed at those within the healthcare and public health sectors, it will also be available to the general public. Therefore a low level of technical or subject knowledge will be assumed and all elements of the calculation and background subject will be explained.  | Adrian King | This is a really strong accessibility comment | Adrian King (MRG member)13/06/2019 |[x]   |
|  | technical or subject knowledge will be assumed and all elements of the calculation and background subject will be explained. |  |  | 13/06/2019 |  |  |

**4. Data**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
| 4.1 | “Coverage in the Learning Disabilities and Care Dataset is just over half of the population of England, with CCG boundaries, but with variable coverage.”Does this not significantly undermine confidence in the data source for this indicator if it is only 50% and not randomly missing? | Rebecca Smittenaar | Applicant has addressed this in section in 4.9. with support from MRG member Rebecca Smittenaar.Commercial issues with system suppliers are out of our hands, though still important issues. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
|  | Why isn't this core business? Doesn't NHSE require its providers to collect and report protected characteristics?  | Paul Iggulden | Currently TPP has taken corporate decision to decline to provide this information however the next contract will include this as a mandated clause | Janet Waterhouse / Ken Harris Jones (DSAS) |[ ]   |
| 4.1 | Why can't standard ONS death data be used? |  | PCMD is standard ONS death data with additional information added to identify practice level information. Datasets are linked at practice level, so this information is required. Section updated. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |

**5. Construction and Testing**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
| 5.1 | Where in the application does it mention whether it is done for one year or several years pooled. | Anne Cunningham | Application now amended to include this information. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
|  | **Denominator – general population mortality rate** The general population is derived from the learning disabilities dataset (populations LDOB003A and LDOB003B combined), including people aged 0 to 74. if more practices in a CCG use TPP, is this not going to make it look a lot better? (as there will be more missing data) | Rebecca Smittenaar | Application amended to cover this. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 5.1 | Is there not a better data sources about the general population of England that could be used instead? | Anne Cunningham | There most certainly is. However, to use a larger more comprehensive data set for the creation of reference mortality rates could potentially render the calculation of the LD SMR useless. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 5.1 | The calculation is hard to follow | Rebecca Smittenaar | Application has been amended to clarify.The general population used here is the entire population registered at a GP practice in the learning disabilities dataset. Using this data means that the population coverage matches up. The number of deaths is taken from PCMD and joined on practice code/age/sex to this dataset. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 5.1 | If I'm following this correctly, age-sex specific rates are calculated for England. The use of the word 'crude' is I think unhelpful here? | Paul Iggulden | Application amended. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 5.1 | Does this simple crude rate actually get used for anything? If not, then is there any real need to mention it? | Anne Cunningham | Addressed.This simple crude rate is key in determining the reference rates for each age and sex banding, so have left it in the description of the construction of the indicator. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 5.4 | The figures look about half of the 0-9 population of England. If you're taking all the England deaths (from PCMD) and dividing by this population denominator, the answer will be about twice as high as it should be. | Anne Cunningham | Correct. As per the comments on section 5.1 the general population is taken from participating practices in the learning disabilities dataset. This was not made clear enough and we will be working towards making it clearer. | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |
| 5.4 | Are these the number of deaths in a year for the whole of England? They don't look big enough for that. Or are you making use of info on GP registration, to exclude the deaths that happened in TPP practices? If so, you don't mention that at the end of Section 5.1 | Anne Cunningham | Addressed. We are indeed only using the population of participating practices.  | Alex Happs,Rob Danks ; 13/06/2019,27/07/2019 |[x]   |

**What do the Assurance Ratings mean?**

|  |  |
| --- | --- |
| **Rating**  | **Description** |
| **Fit for use** | This indicator can be used with confidence that it is constructed in a sound manner that is fit for purpose. |
| **Fit for use with caveats** | The indicator is fit for use; however users should be aware of caveats and/or recommendations for improvement that have been identified during the assurance process. |
| **Use with caution – data quality issue** | The indicator is based on a sound methodology for which the assurance process endorse the use, however issues have been identified with the national data source which have implications for its use as an indicator. |
| **Not fit for use** | Issues have been identified with the indicator which have resulted in the assurance process currently not endorsing its use as a quality indicator. |
| **Not enough information provided** | There has not been enough information supplied to the assurance process to be able to accurately give the indicator a level of assurance. |

**Details of Methodology Appraisal –**

|  |  |
| --- | --- |
| **Methodology appraisal body** | IMAS Methodology Review Group (MRG) |
| **Reason for assessment** |  |
| **Iteration** |   |

***Suggested Assurance Rating by Methodology Appraisal Body***

|  |  |
| --- | --- |
| **Ratings Against Assessment Criteria** | **Overall Appraisal Rating** |
| Introduction and Overview  |  |
| Rationale and Policy Basis  |  |
| Presentation and Interpretation  |  |
| Data |  |
| Construction and Testing |  |
| IMAS provided Information |  |

**Summary Recommendation to Applicant:**

**Summary Recommendation to IGB:**

1. Glover, G., Williams, R., Heslop, P., Oyinlola, J. & Grey, J., 2017. Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*, 61(1), pp.62–74. [↑](#footnote-ref-1)
2. Hollins, S., Attard, M.T., von Fraunhofer, N., McGuigan, S. & Sedgwick, P., 1998. Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology*, 40, pp.50–56. [↑](#footnote-ref-2)
3. Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. & Russ, L., 2013. *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*, Available at: www.bris.ac.uk/cipold/fullfinalreport.pdf. [↑](#footnote-ref-3)
4. Glover, G., Williams, R., Heslop, P., Oyinlola, J. & Grey, J., 2017. Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*, 61(1), pp.62–74. [↑](#footnote-ref-4)
5. O’Leary, L., Cooper, S.-A. & Hughes-McCormack, L., 2017. Early death and causes of death of people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, Early View - DOI: 10.1111/jar.12417. [↑](#footnote-ref-5)