

Assessment of compliance with the Code of Practice for Official Statistics

Statistics on Cancer Survival in England

*(produced by the Office for National Statistics
and Public Health England)*

Assessment Report 341

February 2019

Office for Statistics Regulation

We provide independent regulation of all official statistics produced in the UK. Statistics are an essential public asset. We aim to enhance public confidence in the trustworthiness, quality and value of statistics produced by government.

We do this by setting the standards they must meet in the *Code of Practice for Official Statistics*. We ensure that producers of government statistics uphold these standards by conducting assessments against the *Code*. Those which meet the standards are given National Statistics status, indicating that they meet the highest standards of trustworthiness, quality and value. We also report publicly on system-wide issues and on the way statistics are being used, celebrating when the standards are upheld and challenging publicly when they are not.

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Executive Summary

Judgement on National Statistics Status

- ES.1 This assessment focuses on the experimental statistics about adult cancer survival by stage of diagnosis and about cancer survival for children, that are released in the compendium publication *Cancer survival in England: adult, stage at diagnosis and childhood*¹. In 2017, ONS and PHE commenced a collaboration to jointly produce official statistics about cancer survival, with PHE taking over the data processing duties from the London School of Hygiene and Tropical Medicine (LSHTM).
- ES.2 The UK Statistics Authority will award the National Statistics status to the statistics assessed here (adult cancer survival stage at diagnosis; childhood cancer survival) when all nine requirements of this report are met. ONS has lead responsibility for addressing the requirements and has agreed a deadline for meeting requirements of May 2019.

Key Findings

Public value

- ES.3 PHE has a number of established users and has a good understanding of the use of these statistics and the decisions that are informed by them. Following user consultation, ONS and PHE elected to test and release these statistics as experimental statistics to encourage the involvement of users in their development.
- ES.4 The releases are aimed at a technical audience. The publications could be developed to add more value for a range of users. For example, by publishing insightful analyses bringing together the findings and implications for public health that could be demonstrated using the whole family of cancer statistics.

Quality

- ES.5 On 8 June 2018, ONS published the childhood cancer survival statistics with a notice explaining to users that they had postponed the 14 June release of the adult and stage of diagnosis cancer survival estimates². This was followed by an updated notice on the 10 October³ informing users that previous releases would be affected. The publication of the error impact paper⁴ on 14 January 2019 and the delayed statistics on 24 January 2019⁵, have provided reassurance that PHE and ONS now understand the steps and stages required for the data processing and statistics production.
- ES.6 The published documentation are not clear about the quality assurance applied to the statistical production process in its entirety and there are a number of other aspects of quality detailed in the Authority's regulatory standard *Quality Assurance of Administrative Data* that have not been detailed by the producers.

¹<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/adultstageatdiagnosisandchildhoodpatientsfollowedupto2016>

²<https://www.ons.gov.uk/news/statementsandletters/postponementofadultandstageofdiagnosisandchildhoodpatientsfollowedupto2016>

³<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/adultstageatdiagnosisandchildhoodpatientsfollowedupto2016>

⁴<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/methodologies/theimpactofupdatingcancersurvivalmethodologiesforationalestimates2019>

⁵<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/nationalestimatesforpatientsfollowedupto2017>

Trustworthiness

ES.7 The Authority was concerned that the announcement of the delay to the publication of the June 2018 adult stage at diagnosis data, (the identification of a data processing error), might indicate a shortage of capable analytical resource following the handover of the data processing from the London School of Hygiene and Tropical Medicine to Public Health England. The Authority has been assured that lessons have been learned and there are sufficient capable resources to sustainably support the production of the statistics.

Next Steps

ES.8 The publication of the Assessment report represents a key milestone in the assessment process, but should not be viewed as the end point. The next phase, to meet the Requirements set out in this report, is critical to delivering the value, quality and trustworthiness to achieve and maintain National Statistics status. The Head of Health Analysis and Life Events at ONS, in collaboration with PHE, is encouraged to develop and agree an action plan to meet the Requirements to the timetable set out in paragraph ES.2 of this report and the statistics team should provide full formal written evidence to the Office for Statistics Regulation by the deadline of May 2019.

Chapter 1: Public Value

Introduction

- 1.1 Value means that the statistics and other numerical information are accessible, remain relevant and benefit society; helping the public to understand important issues and answer key questions.
- 1.2 Value is a product of the interface between the statistics or other numerical information and those who use them as a basis for forming judgements.

Findings

Relevance to users

- 1.3 PHE has a number of established users and has a good understanding of the use of these statistics and the decisions that are informed by them. Both ONS and PHE engage with informed users regularly in conferences and workshops, but the most recent public consultation⁶ about ONS's cancer publications was held in 2012 and they have not yet widened their user outreach to include the less-experienced user. Responses to the consultation requested data on stage at diagnosis and ONS and PHE elected to test and release these statistics as experimental statistics to encourage the involvement of users in their development. There is evidence that the statistics meet a niche user need, however, they could also be used to support a better understanding of cancer survival in public discourse more generally.
- 1.4 Respondents to our survey told us that they wished for more granularity, with requests for more geographical breakdowns (e.g. by Local Authority, Clinical Commissioning Group, Cancer Alliance), more detailed demographics (e.g. age group) and more cancer types (e.g. for more than just the main combined cancers). A single summary statistic to give a high-level overview of whether outcomes are improving and increasing the coherence between UK nations to aid comparisons by users were also requested. Some respondents felt the release was not timely enough and wanted more up-to-date data. From this feedback, it appears that there are some user needs that are not being addressed by the current suite of statistics, so ONS and PHE should develop plans and take steps to engage with users, investigate their requests and explain more clearly whether or not these can be addressed.

Accessibility

- 1.5 The respondents to our survey described accessing the cancer survival statistics from conducting a Google search, rather than directly through the ONS, PHE or gov.uk websites. Many mentioned that they found it difficult to locate the correct dataset or methodology document, describing the ONS website as being hard to navigate. The methodology and quality assurance documentation is distributed across both ONS and PHE's websites and is not easily accessible or understandable to different types of users. ONS should provide comprehensive signposting to the data, methodology and quality assurance information and consider the needs of different types of users and potential users when determining the readability of the documentation.
- 1.6 PHE publishes quarterly workbooks (outlining cancer survival by *Stage of diagnosis*⁷) six months after any reporting period. Whilst PHE's website refers to ONS's cancer survival releases, the ONS website does not cross-refer to PHE's workbooks. It is not clear why

⁶<http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/about-ons/get-involved/consultations-and-user-surveys/consultations/cancer-statistics-consultation/index.html>

⁷http://www.ncin.org.uk/publications/survival_by_stage

there are two sets of statistics published at separate times by two different producers that report on what appear to be similar topics and this could lead to confusion for users about which set of statistics to use for which purpose. To be clearer, ONS should work with PHE to explain the differences between the two sets of releases and advise on the distinct uses to which each could be put.

Clarity and insight

- 1.7 While respondents to our survey generally liked the *Cancer survival* reports, they are written for a technical audience, with limited narrative, that does not support use by the enquiring citizen.
- 1.8 Some respondents suggested that the commentary was clear for them as expert users who have a good understanding of statistics, but for more general users, they thought that the release might be too technical. This could be improved by more clearly and prominently explaining technical terms, for example what is meant by 'experimental statistics'; improvements to the data visualisations, such as labelling the actual figures on bar charts, making them interactive and making more charts available to download; and by presenting meaningful trends for adult cancer survival (similar to those provided for childhood cancer), including more time series and visually presenting the uncertainty around the estimates.
- 1.9 Respondents told us that the presentation and layout of the data tables in excel spreadsheets could be improved, because the formatting (such as blank rows) made it difficult for further data manipulation. In January 2019, ONS published the data tables in a format that maximises their reuse.
- 1.10 ONS releases a series of statistics about cancer, for example, *Cancer registration statistics*, *Geographic patterns of cancer survival* and *Cancer survival by Clinical Commissioning Group*. Although *Cancer survival* mentions other official statistics about cancer, the narrative stands in isolation and is therefore not as insightful as it could be. ONS should work more closely with PHE and other experts to provide a comprehensive and coherent narrative covering the suite of cancer statistics.
- 1.11 ONS plans to engage with users to understand what style of presentation they need to provide a clearer interpretation and comprehensive narrative around the statistics, explaining clearly the strengths and limitations for different uses.

Table 1: Value – Findings and Requirements

Findings	Examples	Requirement
Both ONS and PHE engage with informed users in conferences and workshops, but they have not yet widened their user outreach to include the less-experienced user. Some user needs are not being addressed by the current suite of statistics	<ul style="list-style-type: none"> Users wish for more granularity, with requests for more geographical breakdowns and more detailed demographics 	1 ONS should publish plans and take steps to engage with users, to increase awareness of the data and statistics, and communicate effectively with the widest possible audiences, to support users and potential users.
The data and associated documentation is not easily accessible	<ul style="list-style-type: none"> Users mentioned that they found it difficult to locate the correct dataset or methodology document on ONS's or PHE's websites 	2 ONS should provide comprehensive signposting to the data, methodology and quality assurance information and consider the needs of different types of users and potential users when determining the readability of the documentation.
There are two sets of statistics published at separate times by two different producers that report on what appear to be similar topics, which might lead users to choose the wrong statistics for their needs	<ul style="list-style-type: none"> PHE publishes quarterly workbooks titled <i>Stage of diagnosis</i>; ONS publishes <i>Adult stage at diagnosis</i> 	3 ONS should work with PHE to explain the differences between their two releases and advise on the distinct uses to which each could be put.
<i>Cancer survival</i> is written for a technical audience, with limited narrative, that does not support use by the enquiring citizen	<ul style="list-style-type: none"> Some respondents suggested that the commentary was clear for them as expert users, but for more general users, they thought that the release might be too technical. 	4 ONS should work with users to provide an interpretation and comprehensive narrative around the statistics, to meet a wider range of user understanding and uses.
The <i>Cancer survival</i> narrative stands in isolation and is less insightful than it has the potential to be	<ul style="list-style-type: none"> Cancer survival is one of four other ONS releases about cancer, but there is no coherent narrative 	5 ONS should work more closely with PHE and other experts to provide a comprehensive and coherent narrative covering the suite of cancer statistics it publishes.

Chapter 2: Quality

Introduction

- 2.1 Quality means that the statistics and numerical information represent the best available estimate of what they aim to measure at a particular point in time and are not materially misleading.
- 2.2 Quality is analytical in nature and is a product of the professional judgements made in the specification, collection, aggregation, processing, analysis, and dissemination of data.

Findings

Suitable data sources

- 2.3 Since 2017, the administrative data source for these statistics is PHE's cancer registry data, where previously ONS's National Cancer Registration database was used. In February 2018, ONS published an updated *Cancer Survival Quality and Methodology Information*⁸ (*QMI*) document. Whilst *QMI* goes some way in identifying limitations in the current data source (such as data quality), the extent to which the limitations can be overcome and the impact on the statistics is not explained. To demonstrate that PHE's cancer registry data is the most appropriate data to use to estimate cancer survival and justify the change, ONS should publish information about the extent to which any limitations of the cancer registry data can be overcome and the impact on the statistics.
- 2.4 To ensure timely and accurate data delivery, producers of official statistics should manage their relationships with data suppliers by establishing clear processes for data provision and for managing change. ONS and PHE have developed and agreed a statement of the data required from PHE, outlining quality, timing, definitions and format of data supply, and explaining how and why the data will be used.

Sound methods

- 2.5 The need for comparability of cancer survival statistics across the UK was discussed at the UK and Ireland Association of Cancer Registry Executive Committee⁹. To ensure results are comparable across all countries in the UK and Ireland, a consensus was made to use the International Cancer Survival Standard (ICSS) age weighting tables in cancer survival analysis in England, Scotland, Wales, Northern Ireland and the Republic of Ireland. *QMI* references the discussion of the issues raised by the comparison of survival figures from different countries (the US and Canada, for example) as international practice¹⁰. ONS pre-announced that they would be updating the age-standardised estimates for adults from June 2017 and published the impact analyses¹¹ of these changes, with a revised the back series of data.
- 2.6 Whilst *QMI* provides lots of detail about the different methods that could be used to estimate cancer survival, the rationale for their selection for each estimate is not clear and the complex scientific descriptions do not take into account the needs of different types of users for this information. *QMI* is also not clear about the scale and impact of any bias and uncertainty on the statistics, nor does it include any steps taken to reduce their impact.

⁸<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/methodologies/cancersurvivalstatisticalbulletinsqmi>

⁹<http://www.ukiacr.org/about/executive-committee>

¹⁰<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/methodologies/ncersurvivalstatisticalbulletinsqmi#validation-and-quality-assurance>

¹¹<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/methodologies/theimpactofupdatingcancersurvivalmethodologiesforationalestimates>

ONS should explain why certain methods were chosen for certain estimates, the impact of any bias and uncertainty on the statistics, and give consideration to also making the methodology information available in a more accessible way.

Assured quality

- 2.7 On 8 June 2018, ONS published a notice explaining to users that they had postponed the 14 June release of the adult and stage of diagnosis cancer survival estimates¹². ONS explained that this was due to quality assurance checks revealing an issue affecting the adult 5-year and 10-year survival estimates. ONS noted that “Adult and stage of diagnosis survival estimates will be published in a separate release, later in 2018, and we will provide a rescheduled publication date as soon as possible”. On 10 October, ONS published a further notice to the current and previous releases of cancer survival, stating “While preparing for the cancer survival in England bulletin, quality assurance checks revealed an issue affecting the adult 5-year and 10-year survival estimates. Although this issue may have an impact on the time series, the main comparisons and trends should continue to be the same. Public Health England and Office for National Statistics are working together to resolve the issue. Adult and stage of diagnosis survival estimates for 2017 and the back series will be published between December 2018 and January 2019. We are aiming to announce an updated release date in November.” On 14 January 2019, ONS published a comprehensive explanation for the delay to the publication of the statistics, outlining the scale, nature, cause and impact on the adult cancer survival releases, alongside the revised back series¹³ of statistics. ONS also took the opportunity to detail methodological improvements and explain about the involvement of peer review in the production of the life tables and survival estimates, enhancements that indicate lessons have been learned from the data processing problems identified in 2018.
- 2.8 Information about the quality assurance processes applied to the collection of data and the production of the statistics are split between PHE’s¹⁴ and ONS’s websites, making this information difficult to find and, therefore, it is difficult to understand the quality assurance applied to the statistical production process in its entirety. Additionally, PHE’s *Indicator Specification* for cancer diagnosed at early stage was published in 2015 and could be updated. To improve transparency, ONS should publish, or link to, information in one place that outlines the data flows, the processing and quality assurance at each stage of statistical production, and the risk and impact of quality issues on the statistics, taking into consideration the UKSA’s toolkit *Quality Assurance of Administrative Data*¹⁵.
- 2.9 The strengths and limitations in relation to different uses are not explained alongside the statistics in *Cancer Survival*, nor does ONS present the nature of any uncertainty associated with the estimates, so it is difficult to judge whether the statistics are being produced to a level of quality that helps users select the right statistics for their needs. In order to assist users in their choice of statistics, ONS should explain the strengths and limitations of each set of statistics in relation to their use, and explain the nature and extent of any uncertainty associated with the estimates.
- 2.10 The statistics release published in January 2019 states that there are no scheduled revisions for these statistics. To be fully transparent, ONS should ensure this statement is also included in the updated quality information (see also paragraph 3.6).

¹²<https://www.ons.gov.uk/news/statementsandletters/postponementofadultandstageofdiagnosis cancersurvival estimatesin england>

¹³<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancersurvivalratescancersurvivalinenglandadultsdiagnosed>

¹⁴<http://www.ncin.org.uk/view?rid=3059>

¹⁵https://www.statisticsauthority.gov.uk/wp-content/uploads/2015/12/images-qualityassurancetoolki_tcm97-44368.pdf

Table 2: Quality – Findings and Requirements

Findings	Examples	Requirement
QMI could be clearer about whether PHE's cancer registry data is a suitable data source	<ul style="list-style-type: none"> PHE's cancer registry has been chosen as the data source, in preference to ONS's National Cancer Registration database 	6 ONS should publish information about the extent to which any limitations of PHE's cancer registry data can be overcome and the impact on the statistics, justifying the source change.
The rationale for the selection of a specific method for each estimate is not clearly explained, the information is very complex, inaccessible and less open to understanding for the general reader	<ul style="list-style-type: none"> QMI links to scientific papers that are not open to the public without subscription 	7 ONS should explain why certain methods were chosen for certain estimates, the impact of any bias and uncertainty on the statistics, and give consideration to making the methodology information available in a more accessible way.
It is difficult to understand the quality assurance applied to the statistical production process in its entirety	<ul style="list-style-type: none"> Information about the quality assurance processes applied to the collection of data and the production of the statistics are split between PHE's and ONS's websites 	8 ONS should publish, or link to, information in one place that outlines the data flows, the processing and quality assurance at each stage of statistical production, and the risk and impact of quality issues on the statistics, taking into consideration the UKSA's toolkit <i>Quality Assurance of Administrative Data</i>¹⁶.
It is difficult to judge whether the statistics are being produced to a level of quality that helps users select the right statistics for their needs.	<ul style="list-style-type: none"> No confidence intervals around the estimates are supplied in the bulletin 	9 ONS should explain the strengths and limitations of each set of statistics in relation to their use, and explain the nature and extent of any uncertainty associated with the estimates.

¹⁶https://www.statisticsauthority.gov.uk/wp-content/uploads/2015/12/images-qualityassurancetoolki_tcm97-44368.pdf

Chapter 3: Trustworthiness

Introduction

- 3.1 Trustworthiness means that the statistics and other numerical information are produced free from vested interest, based on the best professional judgement of statisticians and other analysts.
- 3.2 Trustworthiness is a product of the people, systems and processes within organisations that enable and support the production of statistics and other numerical information.

Findings

Transparent processes and management

- 3.3 During the assessment, we learned that ONS has worked hard to understand the cancer survival estimation methodology and statisticians from ONS have been co-located with PHE analysts to learn the complex data processing required to calculate cancer survival estimates and help improve the quality assurance processes. The statistics teams have identified that they needed to work with users to develop the releases further, but they did not have the resource to complete this engagement over the summer of 2018, as planned.
- 3.4 The Authority is assured that there are sufficient resources in both ONS and PHE to sustainably support the production and development of the statistics.

Orderly release

- 3.5 ONS does not provide pre-release access to any of its releases.
- 3.6 The Quality Methodology Information¹⁷ (QMI) notes that, because of late registrations, corrections and deletions to the cancer registry, it might take up to 5 years to reach 100% stability. The statistics release published on 24 January 2019 states that there are no scheduled revisions for these statistics. To be fully transparent, ONS should ensure this statement is also included in the updated QMI (see also paragraph 2.10).

Independent decision making and leadership

- 3.7 Statistics, data and explanatory material are presented impartially and objectively and users described the ONS and PHE statistics teams as friendly, helpful, informed and professional and regarded their advice as clear, detailed and accurate. The statistical release published on 24 January 2019 provides a brief explanation of the roles and responsibilities of the organisations involved in the production of the data, statistics and analysis. ONS has sole authority for deciding on the content and timing of the releases.

¹⁷<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/methodologies/cancersurvivalstatisticalbulletinsqmi>

Annex 1: About the Statistics

The Statistics

- A1.1 This assessment focuses on the experimental statistics about adult cancer survival by stage of diagnosis and about cancer survival for children, published by ONS in a compendium titled *Cancer survival in England*. The statistics about adult stage at diagnosis were first published by ONS on 10 June 2016. This short length of time contrasts with the statistics about cancer survival for children, which were first published by ONS on 10 December 2013.
- A1.2 In 2016, ONS and PHE commenced a collaboration to jointly produce the statistics about cancer survival. Prior to PHE's National Cancer Registration and Analysis Service (NCRAS) responsibility to source and process the data, ONS published the suite of cancer survival statistics using data processed by the Cancer Research UK Cancer Survival Group, at the London School of Hygiene and Tropical Medicine. The source at that time was ONS's National Cancer Registration database.
- A1.3 Adult stage at diagnosis statistics indicate how cancer survival varies in adults at different stages of diagnosis for a variety of cancers. The release presents estimates of 1-year net survival (%) for adults aged 15 to 99 years, from 27 different cancer sites. Nine of these adult cancers are the cancers included in the Public Health Outcomes Framework¹⁸ (PHOF) measure of cancer stage.
- A1.4 *Cancer survival* also presents estimates of 1-year, 5-year and 10-year overall survival (%) for all childhood cancers combined, by 5-year age groups and for all ages combined (0 to 14 years).

Data Sources and Methods

- A1.5 The statistics are sourced from the Cancer Registry data that is held by the National Cancer Registration and Analysis Service (NCRAS) in England.
- A1.6 Since the registration of 2012 cancer diagnoses, the use of the same data collection tools and methodologies across England provides consistent approach to collecting and recording cancer staging data. This new approach led to more than 60% of applicable tumours being staged for the first time in 2012. For 2013, 2014 and 2015 diagnoses, the proportion staged has further improved to 71%, 77% and 80% respectively.
- A1.7 Staff at NCRAS quality assure the data collected in the cancer registry, using the UK and Ireland Association of Cancer Registries standard operating procedure *Guidelines on Population Based Cancer Survival Analysis*¹⁹. There are a number of criteria to identify the patients that are eligible to be included in the analysis and these are also outlined in ONS's *Quality and Methodology Information* (QMI) document.
- A1.8 Survival estimates are age-standardised wherever possible, to improve the comparability between population groups and over time. This is because survival varies with age at diagnosis and the age profile of cancer patients can vary over time and between geographical areas. From June 2017, age-standardised estimates for adults have been calculated using the International Cancer Survival Standard (ICSS) age-weightings²⁰. ONS has published the impact analyses of these changes. For childhood cancer, the estimates

¹⁸<https://fingertips.phe.org.uk/profile/public-health-outcomes-framework>

¹⁹<http://www.ukiacr.org/publication/guidelines-population-based-cancer-survival-analysis>

²⁰<https://seer.cancer.gov/stdpopulations/survival.html>

are age-standardised by giving equal weight to all three age-groups (0 to 4 years, 5 to 9 years and 10 to 14 years).

- A1.9 Adult survival analyses, overall and by stage, use the Pohar-Perme net survival estimator²¹. Patients are included if they were diagnosed with their tumour when they were between the ages of 15 and 99 years. Background mortality is derived from population life tables, initially supplied by the LSHTM Cancer Survival Group²². Following the switch to PHE's data processing, ONS worked with Leicester University to derive the life tables, which were subsequently quality assured by LSHTM. In the life tables, the mortality of cancer patients is compared with that of individuals in the general population who belong to the same single year of age (0 to 99 years), sex, population weighted quintile of the index of multiple deprivation (IMD) and region.
- A1.10 For childhood cancer, overall survival is calculated rather than net survival (that is, without adjustment for background mortality), because deaths within five years of a cancer diagnosis are almost always due to the cancer. Overall survival is calculated using the Kaplan-Meier method²³, as this adjusts particularly well for instances where a patient withdraws from the cohort due to being lost to follow-up (for any reason), but is known to be alive at an earlier time. Patients are included if they were diagnosed with their tumour when they were between the ages of 0 and 14 years.

Uses and Users

- A1.11 In July 2015, an Independent Cancer Taskforce published *Achieving world-class cancer outcomes: a strategy for England 2015 to 2020*, which included the aim to improve survival rates for cancer patients. The report sets out how the government plans to improve cancer outcomes, by improving survival rates through reductions in the proportion of patients who are diagnosed with cancer at an advanced stage, screening and treatment standards. The publication of national survival statistics enable public health officials, health commissioners and providers to monitor the changes in cancer survival over time, and to assess progress in achieving these aims.
- A1.12 Known users of cancer survival estimates include government organisations, health policy-makers, cancer charities, academics and researchers, cancer registries, the general public, and the media. The producers are aware that population-based cancer survival statistics are used to:
- plan services aimed at cancer prevention and treatment
 - feed into national plans to reduce cancer mortality
 - monitor progress against the NHS Outcomes Framework
 - inform cancer research
- A1.13 Responders to our engagement exercise reported that they used the statistics for the following purposes:
- to monitor and report improvement in cancer health outcomes
 - to answer ministerial queries
 - to analyse how survival differs between cancers to improve survival for people with cancer with a poorer prognosis
 - to compare with their own cancer survival estimates to check for consistency
 - to monitor the effectiveness of cancer care

²¹<https://www.sciencedirect.com/science/article/pii/S0959804916325977>

²²<http://csg.lshtm.ac.uk/>

²³<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5045282/>

Annex 2: The Assessment Process

- A2.1 This Assessment was conducted from January 2018 to January 2019.
- A2.2 This report was prepared by the Office for Statistics Regulation and approved by the Regulation Committee on behalf of the Board of the UK Statistics Authority, based on the advice of the Director General for Regulation.
- A2.3 The regulatory team – Caroline Jones and Katy Nicholls – agreed the scope of and timetable for this assessment with representatives of ONS and PHE in December 2017. The regulatory team discussed and met with the statistics teams in April 2018, June 2018 and January 2019 to review compliance with the Code of Practice for Statistics, taking account of the evidence provided and research performed.
- A2.4 Part of the assessment process involves consideration of the views of users. We approached known and potential users of these statistics, with 12 responses. This process is not a statistical survey, but it enables us to gain some insights about the extent to which the statistics meet users' needs and users feel that the statistics' producers engage with them. We are aware that responses from users may not be representative of wider views, and we take account of this in the way that we prepare Assessment reports.

Annex 3: Next Steps

Responding to the assessment report: what the Office for Statistics Regulation, Public Health England and the Office for National Statistics should expect from each other

A3.1 The publication of the Assessment report represents a key milestone in the assessment process, but should not be viewed as the end point. The next phase, to meet the Requirements set out in this report, is critical to delivering the value, quality and trustworthiness to achieve and maintain National Statistics status. The next steps are as follows:

- immediately following the publication of the report, the Office for Statistics Regulation will arrange a meeting with the statistics team to talk through the detail of the Requirements and to ensure a common understanding
- the Head of Health Analysis and Life Events at ONS is encouraged to:
 - i) develop an action plan to meet the Requirements to the timetable set out in paragraph ES.2 of this report
 - ii) agree the action plan with their senior management, and that of PHE, and confirm that it is appropriately resourced
 - iii) share the action plan with the Office for Statistics Regulation, publish it alongside the statistics, and explain to users and suppliers how it will engage with them in delivering the plan
 - iv) seek out peers and support services that can help in delivering the plan – for example, [the Government Statistical Service \(GSS\) Good Practice Team](#)
 - v) agree with the regulatory team, how often, and in what form, the statistics team would like to engage about progress against the action plan – for example, some teams choose to meet with the regulatory team once a month
- the statistics team should provide full formal written evidence to the Office for Statistics Regulation by the deadline of May 2019 as set out in paragraph [ES.2] of this report. There is no set format for reporting, except that ONS should demonstrate that it has addressed the findings given in Tables 1 and 2 and provide links to any published or internal documents as support
- the regulatory team will review the evidence within 10 working days and arrange to provide feedback to the statistics team. As part of this process, the regulatory team may talk again to users to establish how their experience of the statistics has changed. When the regulatory team is satisfied that the Requirements have been fully met, their conclusions will be quality assured by Office for Statistics Regulation’s senior management and then presented to the Authority’s Regulation Committee to confirm designation. The Director General will then write publicly to the lead official to confirm the decision

A3.2 Based on experience, the Office for Statistics Regulation strongly encourages statistics teams to:

- engage with the detailed thinking of the Assessment report, and revisit it regularly. The regulation team will be seeking evidence that the statisticians are demonstrating curiosity and are challenging their own thinking around delivering value, quality and trustworthiness. The Requirements in this report should not be viewed as a simple checklist

- view the responsibility for meeting the Requirements as falling to the organisation as a whole, not just the team that produces the statistics.
- engage users early, not just to keep them updated, users can often offer valuable insight and expertise
- contact the regulatory team at any time if there are any questions or concerns

A3.3 Responsibility for complying with the Code of Practice does not end with the award of the National Statistics designation. It is the statistics producers' responsibility to maintain compliance and also to improve the statistics on a continuous basis. The Office for Statistics Regulation encourages statistics producers to discuss promptly with the regulatory team any concerns about whether its statistics are meeting the appropriate standards. National Statistics status can be removed at any point when the highest standards are not maintained, and reinstated only when standards are restored.

