

Assessment of compliance with the Code of Practice for Official Statistics

Statistics on Cancer in England

*(produced by the Office for National
Statistics)*

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About the UK Statistics Authority

The UK Statistics Authority is an independent body operating at arm's length from government as a non-ministerial department, directly accountable to Parliament. It was established on 1 April 2008 by the *Statistics and Registration Service Act 2007*.

The Authority's overall objective is to promote and safeguard the production and publication of official statistics that serve the public good. It is also required to promote and safeguard the quality and comprehensiveness of official statistics, and good practice in relation to official statistics.

The Statistics Authority has two main functions:

1. oversight of the Office for National Statistics (ONS) – the executive office of the Authority;
2. independent scrutiny (monitoring and assessment) of all official statistics produced in the UK.

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ASSESSMENT AND DESIGNATION

The *Statistics and Registration Service Act 2007* gives the UK Statistics Authority a statutory power to assess sets of statistics against the *Code of Practice for Official Statistics*.

Assessment will determine whether it is appropriate for the statistics to be designated as National Statistics.

Designation as National Statistics means that the statistics comply with the *Code of Practice*. The *Code* is wide-ranging. Designation can be interpreted to mean that the statistics: meet identified user needs; are produced, managed and disseminated to high standards; and are explained well.

Designation as National Statistics should not be interpreted to mean that the statistics are always correct. For example, whilst the *Code* requires statistics to be produced to a level of accuracy that meets users' needs, it also recognises that errors can occur – in which case it requires them to be corrected and publicised.

Assessment Reports will not normally comment further on a set of statistics, for example on their validity as social or economic measures. However, Reports may point to such questions if the Authority believes that further research would be desirable.

Assessment Reports typically provide an overview of any noteworthy features of the methods used to produce the statistics, and will highlight substantial concerns about quality. Assessment Reports also describe aspects of the ways in which the producer addresses the 'sound methods and assured quality' principle of the *Code*, but do not themselves constitute a review of the methods used to produce the statistics. However the *Code* requires producers to "seek to achieve continuous improvement in statistical processes by, for example, undertaking regular reviews".

The Authority may grant designation on condition that the producer body takes steps, within a stated timeframe, to fully meet the *Code's* requirements. This is to avoid public confusion and does not reduce the obligation to comply with the *Code*.

The Authority grants designation on the basis of three main sources of information:

- i. factual evidence and assurances by senior statisticians in the producer body;
- ii. the views of users who we contact, or who contact us, and;
- iii. our own review activity.

Should further information come to light subsequently which changes the Authority's analysis, it may withdraw the Assessment Report and revise it as necessary.

It is a statutory requirement on the producer body to ensure that it continues to produce the set of statistics designated as National Statistics in compliance with the *Code of Practice*.

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1 Summary of findings

1.1 Introduction

1.1.1 This is one of a series of reports¹ prepared under the provisions of the *Statistics and Registration Service Act 2007*². The Act requires all statistics currently designated as National Statistics to be assessed against the *Code of Practice for Official Statistics*³. The report covers the sets of statistics included in the following National Statistics publications produced by the Office for National Statistics (ONS):

- *Cancer registrations in England*⁴;
- *Cancer statistics registrations (Annual Reference Volume)*⁵;
- *Cancer and mortality in the United Kingdom*⁶;
- *Cancer survival in England: one-year and five-year survival for 21 common cancers, by sex and age*⁷;
- *Cancer survival in the Spearhead Primary Care Trusts of England*⁸;
- *Relative survival from cancer in English regions*⁹;
- *Cancer survival by Cancer Network, England*¹⁰; and
- *A cancer survival index for primary care trusts*¹¹.

1.1.2 This report was prepared by the Authority's Assessment team, and approved by the Board of the Statistics Authority on the advice of the Head of Assessment.

1.2 Decision concerning designation as National Statistics

1.2.1 The Statistics Authority judges that the statistics covered by this report are readily accessible, produced according to sound methods and managed impartially and objectively in the public interest, subject to any points for action in this report. The Statistics Authority confirms that the statistics published in the products listed in section 1.1.1 are designated as National Statistics, subject to ONS implementing the enhancements listed in section 1.5 and reporting them to the Authority by July 2011. ONS has informed the Assessment team that it has started to implement the Requirements listed in section 1.5. The Statistics Authority welcomes this.

1.3 Summary of strengths and weaknesses

1.3.1 ONS's cancer statistics team meets regularly with various stakeholder groups and has published plans to improve aspects of its statistics following a recent

¹ <http://www.statisticsauthority.gov.uk/assessment/assessment-reports/index.html>

² http://www.opsi.gov.uk/Acts/acts2007/pdf/ukpga_20070018_en.pdf

³ <http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html>

⁴ <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=7720>

⁵ <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=8843>

⁶ <http://www.statistics.gov.uk/statbase/product.asp?vlnk=14209>

⁷ <http://www.statistics.gov.uk/statbase/product.asp?vlnk=14007>

⁸ <http://www.statistics.gov.uk/statbase/product.asp?vlnk=14821>

⁹ <http://www.statistics.gov.uk/pdfdir/can0610.pdf>

¹⁰ <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15387>

¹¹ <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15388>

consultation with users. ONS has taken steps to improve the timeliness of cancer incidence and survival statistics in response to identified user need.

1.3.2 The cancer statistics team publishes information about methods in its statistical releases. Following recent user consultation, the team has also published summary reports on the quality of the statistics and the methods it uses to compile them. However, there is scope to publish more information about the completeness of cancer registrations. ONS publishes details of its quality assurance procedures for cancer statistics which are based on national standards.

1.3.3 The layout of the cancer statistics publications is reasonably clear, and they include some helpful commentary and background notes. However, there is scope to improve the accessibility of the publications and the data tables which ONS provides on its website.

1.4 Detailed recommendations

1.4.1 The Assessment team identified some areas where it felt that ONS could strengthen its compliance with the *Code*. Those which the Assessment team considers essential to enable designation as National Statistics are listed in section 1.5. Other suggestions, which would improve the statistics and the service provided to users but which are not formally required for their designation, are listed at annex 1.

1.5 Requirements for designation as National Statistics

Requirement 1	Include references to the <i>Summary Quality Report for Cancer Registration Statistics</i> in the statistics publications to inform users about the different data sources, and update the <i>Summary Quality Report</i> as new information about these sources becomes available (para 3.10).
Requirement 2	Publish more details in the <i>Annual Reference Volume</i> about the estimated levels of completeness of registration data and refer to this information in the other cancer publications (para 3.12).
Requirement 3	Review the commentary to ensure that it aids interpretation, and publish more information about the policy context (para 3.25).
Requirement 4	Improve the accessibility and accuracy of the cancer statistics publication titles (para 3.28).
Requirement 5	Ensure that all cancer statistics are released in formats which allow analysis and re-use (para 3.29).

Requirement 6

Improve the signposting of data tables to allow users to analyse and re-use the statistics (para 3.30).

Requirement 7

Include appropriate text to explain the confidence intervals in the cancer publications (para 3.31).

2 Subject of the assessment

- 2.1 Cancer incidence is defined as the number of new registrations of cancer within a given time period¹². Cancer registration in England is carried out by eight regional registries which collect information on cancers registered to residents of their areas from a variety of sources including NHS hospitals, general practices, cancer centres, hospices, cancer screening programmes and private hospitals. The registries send these cancer registrations to ONS as a standard dataset. There are similar systems of cancer registration in Wales, Scotland and Northern Ireland, and all cancer registries in the UK are members of the UK Association of Cancer Registries¹³ (UKACR) which brings together organisations with an interest in developing cancer registration as a resource for studying and controlling cancer in the UK.
- 2.2 Cancer incidence rates are calculated per 100,000 of the population and ONS calculates age- and sex-specific rates using ONS's mid-year population estimates. ONS calculates age-standardised incidence rates using the European Standard Population to allow for more robust comparisons between males and females, years and geographical areas. Mortality rates are calculated using ONS's mid-year population estimates to show the number of deaths per 100,000 people for specific cancer sites. ONS derives its estimates of cancer survival from linking individual tumour records in the cancer incidence data to the individual records of death or emigration, then analysing the duration of survival since diagnosis. Cancer survival is expressed as 'relative' survival in order to control for background mortality in the general population. Relative survival can be interpreted as the ratio of survival among cancer patients compared to that in the general population.
- 2.3 ONS is responsible for the primary data processing of cancer registry data for England and Wales, and for all reporting of National Statistics on cancer incidence, mortality and survival for England. The NHS Information Centre for Health and Social Care (NHS IC) is responsible for matching cancer registrations against patients registered with general practitioners in England and Wales.
- 2.4 The cancer registries in England also send data to the National Cancer Intelligence Network¹⁴ (NCIN), a UK-wide initiative which aims to improve cancer care and clinical outcomes by improving and using the information collected about cancer patients. Registries send data to NCIN and ONS at different times, and ONS carries out further quality checks on the data before publishing the statistics. Therefore, ONS's statistics and those from NCIN do not match. NCIN does not publish National Statistics but some users, such as clinicians, may use the statistics from NCIN for local planning purposes as they tend to be available earlier than ONS's. ONS publishes National Statistics which present cancer data in their final form. The Department of Health (DH)

¹² <http://www.ons.gov.uk/about-statistics/methodology-and-quality/quality/qual-info-economic-social-and-bus-stats/quality-reports-for-social-statistics/cancer-incidence-and-mortality.pdf>

¹³ <http://www.ukacr.org/>

¹⁴ <http://www.ncin.org.uk/home.aspx>

uses ONS statistics in preference to those from NCIN in its reporting and when answering Parliamentary Questions, and to inform cancer policy decisions.

2.5 Since 1993, DH has funded ONS's production and publication of cancer statistics. In 2010/11 DH paid ONS around £725,000 to produce cancer statistics and ONS spent a further £175,000 on various cancer-related activities such as the development of research articles and topic-based summaries. ONS commissions much of the secondary analysis and research on cancer survival figures from the cancer survival team at the London School of Hygiene and Tropical Medicine (LSHTM). In 2010/11, ONS paid the LSHTM around £230,000 for this work. These costs were met by DH.

2.6 The statistics included in this assessment cover various aspects of cancer registrations, incidence, survival and mortality in England:

- *Cancer registrations in England* presents statistics on the number of newly-diagnosed cancer cases in England for the latest year available. The publication contains age-standardised rates and provides commentary about the three most common cancers for males and females;
- *Cancer statistics registrations (Annual Reference Volume)* presents more detailed statistics on latest incidence rates for all cancer sites as well as age-standardised rates, standardised mortality-to-incidence ratios for England and each Government Office Region, and by age, sex and cancer site. The publication also includes age-standardised rates for the latest ten-year period by cancer site and sex as well as an overview of the cancer registration system and a summary of overall cancer patterns;
- *Cancer and mortality in the United Kingdom* presents statistics about newly diagnosed cancer cases and deaths from cancer across the UK. Numbers and age-standardised rates are calculated as an average over a three-year period. The publication includes statistics for the UK as a whole and for the four constituent countries;
- *Cancer survival in England: one-year and five-year survival for 21 common cancers, by sex and age* presents one-year and five-year age-standardised relative survival estimates for adults who were diagnosed with one of the 21 most common cancers in England during 2003-2007 and followed up in December 2008;
- *Cancer survival in the Spearhead Primary Care Trusts of England* presents one-year and five-year relative survival estimates for adults diagnosed with one of the ten most common cancers between 2001 and 2007 who were resident in a Spearhead Primary Care Trust¹⁵ in England. The publication compares cancer survival in these trusts with the rest of England and examines trends in survival over time;
- *Relative survival from cancer in English regions* presents one-year and five-year relative survival estimates for adults diagnosed with one of eight cancers in England during 2001-03 and followed up to the end of 2008. The publication includes statistics for each of the nine Government Office

¹⁵ Spearhead Primary Care Trusts are designated as those areas which face the greatest health challenges in England. They are intended to be the focus of interventions designed to reduce health inequalities, including those for cancer.

Regions, ten Strategic Health Authorities and 28 Cancer Networks in England;

- *Cancer survival by Cancer Network, England* presents relative age-standardised one-year and five-year survival estimates for patients diagnosed with selected cancers in the 28 Cancer Networks in England. The most recent publication focussed on patients diagnosed during 1991-2006 and followed up in 2007; and
- *A cancer survival index for primary care trusts* presents an index of cancer survival one year after diagnosis for cancer for each Primary Care Trust (PCT) in England. PCTs are currently the smallest geographical unit of the NHS in England and have held budgetary responsibility for the commissioning of local health services for their resident populations since 2002. The index is intended as a measure of the effectiveness of cancer services both locally and nationally.

2.7 In January 2011 DH published *Improving Outcomes: A Strategy for Cancer*¹⁶ which details the actions needed to drive improvements in cancer outcomes. The strategy highlights the importance of having accurate, relevant, timely and accessible information for delivering high-quality cancer services and reducing inequalities.

2.8 ONS's cancer statistics are used for a variety of purposes, including:

- providing an evidence base about relevant trends in cancer incidence, mortality and survival to help Ministers, DH policy officials and the NHS develop policies and programmes – for example, the recently published cancer strategy – and in drives to improve early diagnosis;
- providing cancer charities with reliable information which they can use in health awareness campaigns and cancer information material;
- informing research by the International Cancer Benchmarking Partnership¹⁷ which compares the UK's cancer statistics with selected other countries;
- informing the media and the public about the latest national and local trends;
- by DH to monitor the effectiveness of cancer services across England;
- informing research studies – for example, on possible links between environmental factors and cancer incidence;
- answering Parliamentary Questions; and
- by the NHS Information Centre to supplement ONS's Longitudinal Study¹⁸ and medical research projects.

¹⁶ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf

¹⁷ <http://info.cancerresearchuk.org/spotcancerearly/ICBP/>

¹⁸ <http://www.ons.gov.uk/about/who-we-are/our-services/longitudinal-study/index.html>

3 Assessment findings

Principle 1: Meeting user needs

The production, management and dissemination of official statistics should meet the requirements of informed decision-making by government, public services, business, researchers and the public.

- 3.1 There are no formal user groups for English cancer statistics but ONS's cancer statistics team has regular meetings with a range of stakeholders, including quarterly meetings with DH and NCIN. The team also meets quarterly with the UKACR Executive and relevant UKACR sub-groups. The UKACR Executive meetings are attended by ONS, NCIN, the directors of all UK cancer registries and the Childhood Cancer Research Group¹⁹. The ONS cancer team has monthly meetings with the London School of Hygiene and Tropical Medicine which carries out the cancer survival analyses under contract to ONS. We suggest that ONS discuss with the Royal Statistical Society's Health Statistics User Group or Statistics User Forum the feasibility of establishing a user group for cancer statistics.
- 3.2 In 2010 the statistics team consulted users about all ONS's cancer-related outputs, to investigate and document their needs and to improve its understanding of how the statistics are used. The consultation also asked for views about how ONS could improve its cancer outputs. ONS sent the consultation questionnaire to a range of stakeholders, including UKACR members, individuals with pre-release access to the statistics, representatives from central and local government, Public Health Observatories, charities, academics and other users of ONS's cancer statistics. In January 2011 ONS published a report²⁰ on the consultation, including responses to stakeholders' comments and planned actions following the consultation. ONS also sent all respondents a link to the report. ONS plans to carry out a further web-based consultation about its cancer statistics in 2011. The cancer statistics team will also use the results from ONS's 2010 consultation²¹ on its statistical work programme to inform its planning of cancer statistics publications.
- 3.3 Since June 2010 ONS has taken steps to improve the timeliness of cancer incidence and survival statistics in response to identified user need and external criticism from organisations such as the National Audit Office²² (NAO). DH requires the cancer registries to provide data to ONS within 18 months of the end of the registration year but in September 2010 the registries agreed to submit 2009 cancer registrations data within 15 months. In December 2010 they agreed to further reduce this deadline to 12 months for 2010 cancer registrations. ONS emails monthly timeliness and quality updates to all registries to help them to monitor their progress against these new data submission targets.

¹⁹ <http://www.ccrq.ox.ac.uk/>

²⁰ http://www.statistics.gov.uk/downloads/theme_health/consultation-results.pdf

²¹ <http://www.ons.gov.uk/about/consultations/closed-consultations/work-programme-consultation/index.html>

²² http://www.nao.org.uk/publications/1011/cancer_reform_strategy.aspx

Principle 2: Impartiality and objectivity

Official statistics, and information about statistical processes, should be managed impartially and objectively.

- 3.4 ONS publishes cancer statistics reports according to a published timetable and presents the statistics impartially and objectively. ONS makes the cancer statistics available free of charge on its website and the cancer statistics team follows ONS's pricing policy for supplementary services.
- 3.5 ONS has published a Revisions Policy²³ on its website and the cancer statistics team informed us that it complies with the policy. ONS notes changes to classifications for coding cancer incidence in its *Annual Reference Volume* and the cancer statisticians informed us that, where appropriate, they will also announce changes to classifications in advance of the release of the changed statistics.
- 3.6 ONS has not made any revisions to, or corrected any errors in, its recent cancer statistics publications.

²³ http://www.statistics.gov.uk/about/methodology_by_theme/revisions_policies/default.asp

Principle 3: Integrity

At all stages in the production, management and dissemination of official statistics, the public interest should prevail over organisational, political or personal interests.

- 3.7 No incidents of political pressure, abuses of trust or complaints relating to professional integrity, quality or standards were reported to or identified by the Assessment team.
- 3.8 ONS statisticians regularly brief the press on statistical releases and the cancer statistics team has contacted the media directly to explain how to interpret the data. Where necessary ONS briefs the National Statistician on misuses of its statistics, where public comment might be appropriate.

Principle 4: Sound methods and assured quality

Statistical methods should be consistent with scientific principles and internationally recognised best practices, and be fully documented. Quality should be monitored and assured taking account of internationally agreed practices.

- 3.9 ONS publishes information in the *Annual Reference Volume* about how cancer incidence statistics are produced and publishes information about the methods used to produce them in each cancer statistics publication. Following its 2010 consultation on cancer statistics and a critical editorial in the *British Medical Journal*²⁴, ONS has taken steps to be clearer about the quality of the outputs and the statistical methods used. In February 2011 ONS published reports on the methods it uses to produce cancer registration statistics²⁵, cancer incidence and mortality statistics²⁶ and cancer survival estimates²⁷ and how the methods ensure a level of quality that meets users' needs.
- 3.10 NAO's report *Delivering the Cancer Reform Strategy*, published in November 2010, found duplication in the publication of cancer data which led to confusion among service providers. ONS was already aware that its published figures on cancer incidence for England did not exactly match those published by NCIN via its web-based UK Cancer Information System²⁸ (UKCIS). To investigate what these differences were (by cancer site, government office region and year), ONS agreed with DH that it would work with NCIN, the cancer registries and Cancer Research UK²⁹ (CR-UK) to produce a comparison report. The report was sent to all stakeholders but was not published. ONS provided some information about the different data sources in its *Summary Quality Report for Cancer Registration Statistics*³⁰ but it has not included any such information in its statistics publications. As part of the designation as National Statistics, ONS should include references to the *Summary Quality Report for Cancer Registration Statistics* in its statistics publications to inform users about the different data sources, and update the *Summary Quality Report* as new information about these sources becomes available³¹ (Requirement 1).
- 3.11 ONS has published guidelines for measuring statistical quality³². The cancer statistics team informed us that it adheres to these guidelines.

²⁴ <http://www.bmj.com/content/341/bmj.c4112.extract>

²⁵ <http://www.ons.gov.uk/about-statistics/methodology-and-quality/quality/qual-info-economic-social-and-bus-stats/quality-reports-for-social-statistics/summary-quality-report-for-cancer-registration-services.pdf>

²⁶ <http://www.ons.gov.uk/about-statistics/methodology-and-quality/quality/qual-info-economic-social-and-bus-stats/quality-reports-for-social-statistics/cancer-incidence-and-mortality.pdf>

²⁷ <http://www.ons.gov.uk/about-statistics/methodology-and-quality/quality/qual-info-economic-social-and-bus-stats/quality-reports-for-social-statistics/summary-quality-report-for-cancer-survival-statistical-bulletins.pdf>

²⁸ UKCIS is a national reporting tool, running across the NHS national network, providing users with access to cancer information for their area. The UKCIS is available only to authorised NHS users. http://www.ncin.org.uk/cancer_information_tools/ukcis.aspx

²⁹ <http://www.cancerresearchuk.org/>

³⁰ See footnote 25

³¹ In relation to Principle 4 Practice 1 of the Code of Practice

³² <http://www.statistics.gov.uk/STATBASE/Product.asp?vlnk=13578>

- 3.12 The *Annual Reference Volume* advises users that cancer registries may differ in their levels of completeness of registration data and that interpreting any apparent trends may be difficult as registries continually try to improve their data capture. However, there is scope to provide more information about the estimated levels of completeness of registration data by, for example, summarising and clearly explaining the results of relevant published studies. As part of the designation as National Statistics, ONS should publish more details in its *Annual Reference Volume* about the estimated levels of completeness of registration data and refer to this information in its other cancer publications³³ (Requirement 2).
- 3.13 ONS publishes details in the *Annual Reference Volume* about how it assures the quality of cancer registration data supplied by cancer registries. ONS carries out over 40 validity checks on individual data items and around 30 cross-checks between data items – for example, to verify that the incidence date is not after the date of death. ONS’s checks for cancer site and histology are largely compatible with those issued by the International Agency for Research on Cancer (IARC). ONS is working with UKACR to make these checks fully compatible with IARC’s.
- 3.14 The national standards³⁴ for cancer registries require that no more than 0.5 per cent of a year’s complete records should include serious errors. ONS publishes the quality status of all the records on its cancer registration database from 1971 up to the most recent year in each *Annual Reference Volume*. Over the past nine years, the proportion of records with serious errors has consistently been 0.1 per cent or less.
- 3.15 ONS’s cancer team has regular contact – including quarterly meetings – with its counterparts in the other UK administrations. Cancer registration systems are similar across the UK and all cancer registries in the UK are members of UKACR. *Cancer and mortality in the United Kingdom* presents incidence and mortality statistics for the UK as a whole and for each administration. We suggest that ONS include more signposting in its cancer publications to relevant statistics produced in the other UK administrations.
- 3.16 ONS’s cancer registration dataset for England is being used by the International Cancer Benchmarking Partnership (ICBP) which involves the UK and several other countries with similar recording systems. ICBP aims to inform cancer policies and services which are intended to improve cancer survival outcomes and in December 2010 ICBP published its first results in *The Lancet*³⁵.

³³ In relation to Principle 4 Practice 2 of the Code of Practice

³⁴ Department of Health (2001). Cancer Registry Standards for England, v2.1. London: Department of Health.

³⁵ [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)62231-3/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)62231-3/fulltext)

Principle 5: Confidentiality

Private information about individual persons (including bodies corporate) compiled in the production of official statistics is confidential, and should be used for statistical purposes only.

- 3.17 ONS receives all cancer registration data from the regional registries in England. UKACR's website has a section specifically for patients³⁶, which gives details about how their confidentiality will be protected via a downloadable patient information leaflet and a 'frequently asked questions' section. We suggest that ONS signposts users to UKACR's website to inform them how confidentiality is protected.
- 3.18 ONS has published specific guidance³⁷ about protecting the confidentiality of its cancer statistics. It describes all ONS's statutory obligations in relation to handling cancer data and gives details of all relevant codes of practice in relation to the protection of confidentiality and the release of personal data. The specific guidance is in line with ONS's more general guidance³⁸ on protecting confidentiality within health statistics. These documents explain how ONS maintains confidentiality while maximising the utility of statistics; we were told that all ONS's cancer incidence outputs adhere to the principles and rules in the guidance. The cancer statistics team informed us that it is not possible to derive the original data from the published output, thereby ensuring that confidentiality is protected. The National Information Governance Board³⁹ is responsible for promoting and monitoring health information governance, and has approved ONS's procedures for releasing cancer microdata.
- 3.19 ONS stores details of all Data Access Agreements in internal databases. These agreements include the purpose of each project, the legal status for the release of data, and copies of all signed forms.

³⁶ <http://www.ukacr.org/content/patient-information>

³⁷ <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15391>

³⁸ www.statistics.gov.uk/about/data/disclosure/health-statistics.asp

³⁹ <http://www.nigb.nhs.uk/>

Principle 6: Proportionate burden

The cost burden on data suppliers should not be excessive and should be assessed relative to the benefits arising from the use of the statistics.

- 3.20 The registries collect the data they send to ONS as part of their regular activities. Therefore, ONS has not needed to estimate the burden on the registries of providing the data. However, registries informed us that there may be a small additional burden following ONS's validation of the data sent by registries.
- 3.21 Registries informed us that, with the exception of timeliness targets, the guidelines for submitting data to ONS are clear and have not changed for five years. However, they suggested that ONS's and registries' methods could be better integrated. They would also like more information about ONS's processes and methods for validating the data. We suggest that ONS improve its communication with registries to explain its methods for assuring the quality of cancer data.

Principle 7: Resources

The resources made available for statistical activities should be sufficient to meet the requirements of this Code and should be used efficiently and effectively.

3.22 Three teams across ONS produce and publish cancer statistics:

- Cancer Analysis Team – a team of three researchers and one data manager is responsible for answering Parliamentary Questions and queries, analysing data for statistical bulletins and articles and checking and validating historical data;
- Cancer Processing Team – a team of one manager and four administrators is primarily responsible for processing cancer data from regional cancer registries, resolving queries and maintaining the national cancer database; and
- Vital Statistics Outputs Branch – a team of one researcher and three administrators is responsible for producing *Cancer registrations in England* and the *Annual Reference Volume*.

3.23 The cancer statistics team complies with all of ONS's recruitment and learning and development policies. Since relocating from London to Newport in December 2009 the team has maintained previous levels of staffing and outputs.

3.24 When drafting a new service-level agreement each year, ONS discusses with DH what its priorities are for the year, and seeks to balance these against the available budget. These discussions feed into the development of new and continuing reports to help monitor progress over time, and against government targets where applicable. These discussions also help DH and ONS to decide on the appropriate allocation of resources to statistical activities. ONS's cancer team has quarterly progress meetings with DH and submits formal six-monthly progress reports to DH. ONS also sends quarterly management reports to DH and the cancer registries, detailing the registries' progress against timeliness and quality targets.

Principle 8: Frankness and accessibility

Official statistics, accompanied by full and frank commentary, should be readily accessible to all users.

- 3.25 The layout of ONS's cancer statistics publications is reasonably clear and they include some commentary and background notes. However, there is a tendency for the commentary to simply describe rises and falls without drawing out the messages contained in the statistics. There is also scope to include more information about the policy context of the statistics - for example, by appropriate signposting in the *Annual Reference Volume* to DH's cancer strategy. As part of the designation as National Statistics, ONS should review the commentary to ensure that it aids interpretation, and publish more information about the policy context of its cancer statistics⁴⁰ (Requirement 3). As part of reviewing the commentary, we suggest that ONS refer to the Statistics Authority's Standards for Statistical Releases⁴¹ for further guidance.
- 3.26 ONS aims to give users easily accessible datasets at various levels of detail to suit their needs. ONS presents figures in its cancer publications at an appropriate level for each output – for example, Government Office Region, or Primary Care Trust. ONS presents data tables in its *Annual Reference Volume* at the most detailed level possible, allowing for disclosure control guidance for health statistics.
- 3.27 ONS has published a glossary⁴² of cancer terms on its website and the cancer statistics team releases statistics in accordance with ONS's guidelines on accessibility. However, there is scope to improve the accessibility of some aspects of the statistics – for example, by making different map areas in the *Cancer survival by Cancer Network* publication more distinguishable when printed in black and white. We suggest that ONS investigate ways of improving the presentation of its cancer statistics to enhance interpretation.
- 3.28 The accessibility of the statistics publications may be reduced by having inconsistent titles on the publications and web landing pages, and by not including publication dates on some releases – for example, *Cancer survival in the Spearhead Primary Care Trusts of England*. There is also scope to improve the accuracy of the publication titles – for example, *Cancer and mortality in the United Kingdom* could be more accurately re-titled *Cancer incidence and mortality in the United Kingdom*. As part of the designation as National Statistics, ONS should improve the accuracy and accessibility of the cancer statistics publication titles⁴³ (Requirement 4).
- 3.29 The tables provided in most of ONS's statistics publications are available in Excel format on ONS's website to allow users to re-use the data. However, ONS has not provided such tables for the most recent *Cancer survival in the Spearhead Primary Care Trusts of England* publication and the tables in *Cancer survival by Cancer Network, England* are only available in PDF format. As part of the designation as National Statistics, ONS should ensure that all its

⁴⁰ In relation to Principle 8 Practice 2 of the Code of Practice

⁴¹ <http://www.statisticsauthority.gov.uk/news/statement--standards-for-statistical-releases.pdf>

⁴² http://www.statistics.gov.uk/downloads/theme_health/glossary.pdf

⁴³ In relation to Principle 8 Practice 4 of the Code of Practice

cancer statistics are released in formats which allow analysis and re-use⁴⁴ (Requirement 5).

- 3.30 Some users told us that they have difficulty accessing the data tables. As part of the designation as National Statistics, ONS should ensure that all data tables are clearly signposted to allow users to analyse and re-use the statistics⁴⁵ (Requirement 6). We also suggest that ONS investigate opportunities for depositing microdata with, for example, its Virtual Microdata Laboratory to allow users to re-use the raw data.
- 3.31 ONS included confidence intervals in the latest *Cancer and mortality in the United Kingdom* publication as a measure of the statistical precision of the estimated age-standardised rates for selected cancer sites by sex and country. ONS intended to give users an indication of the variability of the estimated figures and included explanatory text for the confidence intervals to help users to interpret the data. However, ONS does not include this information in its other cancer publications. As part of the designation as National Statistics, ONS should include appropriate text to explain the confidence intervals in the relevant cancer publications⁴⁶ (Requirement 7).
- 3.32 ONS has developed several topic-based summaries for its cancer statistics and publishes the breast⁴⁷ and bowel⁴⁸ cancer summaries to coincide with the corresponding cancer 'awareness months'. The timing of these publications is aimed at increasing the awareness of the diseases and to update ONS's users about the latest statistics.
- 3.33 The cancer statistics team is currently working with ONS colleagues to produce a presentation on its cancer statistics with an audio script which will cover statistical concepts and ONS's latest cancer statistics. ONS plans to direct users to the presentation via various sources.

⁴⁴ In relation to Principle 8 Practice 6 of the Code of Practice

⁴⁵ In relation to Principle 8 Practice 6 of the Code of Practice

⁴⁶ In relation to Principle 8 Practice 1 of the Code of Practice

⁴⁷ <http://www.statistics.gov.uk/CCI/nugget.asp?ID=575>

⁴⁸ <http://www.statistics.gov.uk/CCI/nugget.asp?ID=2162>

Protocol 1: User engagement

Effective user engagement is fundamental both to trust in statistics and securing maximum public value. This Protocol draws together the relevant practices set out elsewhere in the Code and expands on the requirements in relation to consultation.

3.34 The requirements for this Protocol are covered elsewhere in this report.

Protocol 2: Release practices

Statistical reports should be released into the public domain in an orderly manner that promotes public confidence and gives equal access to all, subject to relevant legislation.

- 3.35 ONS has internal timetables for producing the *Annual Reference Volume* and *Cancer registrations in England* which are accessible to all staff working on these outputs. The cancer statistics team monitors progress against these timetables at weekly team meetings. The timetable for cancer survival releases is monitored during monthly meetings between ONS's cancer team and LSHTM.
- 3.36 ONS pre-announces all publication dates for cancer statistics on the UK Publication Hub. ONS announces provisional dates as soon as possible – up to 12 months before the planned release – and announces final release dates at least a month before publication. There have been no delays in the production and publication of cancer statistics publications.
- 3.37 ONS publishes lists of people who have pre-release access⁴⁹ to its individual statistical publications on its website. For the cancer statistics releases published in 2010, the number of individuals on the lists ranged from 9 to 23.
- 3.38 The *Code* requires National Statistics releases to be issued at 9.30 am on the day of publication. ONS's website systems do not enable releases to be published simultaneously, which means there is sometimes a delay beyond 9.30 am. ONS informed us that this matter was being reviewed as part of its web development programme, and that it expected its new website to be implemented on 30 April 2011. The Head of Assessment agreed an exemption from Protocol 2 Practice 4 for ONS until that date. The exemption request, and the Head of Assessment's response are available on the Statistics Authority's website⁵⁰. Subsequently, ONS has announced that it does not expect to be able to comply with this practice until the end of August 2011⁵¹. The Assessment team has asked ONS to submit a report describing the nature of the breach of the *Code* from 1 May 2011, and to log and report to the Authority details about delayed releases.

⁴⁹ Pre-release access list for the *Annual Reference Volume*: <http://www.ons.gov.uk/about-statistics/ns-standard/cop/compliance/annual/cancer-stats.html>

⁵⁰ <http://www.statisticsauthority.gov.uk/assessment/code-of-practice/exemption-requests/index.html>

⁵¹ <http://www.ons.gov.uk/about/what-we-do/programmes-projects/web-development/index.html>

Protocol 3: The use of administrative sources for statistical purposes

Administrative sources should be fully exploited for statistical purposes, subject to adherence to appropriate safeguards.

- 3.39 ONS has pursued opportunities to maximise the use of cancer registration data – for example, by providing England-level data to NCIN to contribute to the cancer registrations dataset on the National Cancer Data Repository. NCIN links these data with Hospital Episode Statistics data and the linked dataset has allowed analyses which have not previously been carried out, such as examining incidence and survival by ethnic group. ONS informed us that the National Audit Office views this as being important for improving understanding of what influences inequalities in cancer care.
- 3.40 ONS told us that it has also improved the potential for cancer registrations data to be exploited by publishing a document⁵² in August 2010 which outlines the details of the legal framework under which ONS holds cancer data and the details of its data release procedures. This document describes all of ONS's statutory obligations for handling cancer data and gives the details of all relevant codes of practice in relation to the protection of confidentiality and the release of personal data.
- 3.41 ONS has published a Statement of Administrative Sources⁵³ and included cancer registration information in its list of administrative sources⁵⁴.

⁵² http://www.statistics.gov.uk/downloads/theme_health/ons-cancer-standards-2010.pdf

⁵³ <http://www.ons.gov.uk/about-statistics/ns-standard/cop/statement-of-administrative-sources/index.html>

⁵⁴ <http://www.ons.gov.uk/about-statistics/ns-standard/cop/statement-of-administrative-sources/administrative-data.xls>

Annex 1: Suggestions for improvement

A1.1 This annex includes some suggestions for improvement to ONS's cancer statistics, in the interest of the public good. These are not formally required for designation, but the Assessment team considers that their implementation will improve public confidence in the production, management and dissemination of official statistics.

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|---------------------|--|
| Suggestion 1 | Discuss with the Royal Statistical Society's Health Statistics User Group or Statistics User Forum the feasibility of establishing a user group for cancer statistics (para 3.1) |
| Suggestion 2 | Include more signposting in the cancer publications to relevant statistics produced in the other UK administrations (para 3.15) |
| Suggestion 3 | Signpost users to the patient information on UKACR's website to inform them how confidentiality is protected (para 3.17) |
| Suggestion 4 | Improve communication with registries to explain the methods for quality-assuring cancer data (para 3.21) |
| Suggestion 5 | Refer to the Statistics Authority's Standards for Statistical Releases for further guidance (para 3.25). |
| Suggestion 6 | Investigate ways of improving the presentation of cancer statistics to enhance interpretation (para 3.27) |
| Suggestion 7 | Investigate opportunities for depositing microdata with, for example, the Virtual Microdata Laboratory to allow users to re-use the information (para 3.30) |

Annex 2: Summary of assessment process and users' views

- A2.1 This assessment was conducted from December 2010 to March 2011.
- A2.2 The Assessment team – Phil Grigor and Gary Wainman – agreed the scope of and timetable for this assessment with representatives of ONS in December 2010. The Written Evidence for Assessment was provided on 21 January 2011. The Assessment team subsequently met ONS during February to review compliance with the *Code of Practice*, taking account of the written evidence provided and other relevant sources of evidence.

Summary of users contacted, and issues raised

- A2.3 Part of the assessment process involves our consideration of the views of users. We approach some known and potential users of the set of statistics, and we invite comments via an open note on the Authority's website. 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 the extent to which users feel that the producers of those statistics 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.
- A2.4 The Assessment team received 14 responses from the user and supplier consultation. The respondents were grouped as follows:
- | | |
|-------------------------------|---|
| Voluntary sector | 6 |
| NHS | 3 |
| Private sector | 3 |
| Suppliers (cancer registries) | 2 |
- A2.5 Users were generally satisfied with the engagement with ONS's cancer statistics team but some felt that the team could respond faster to data requests. Some users had difficulty accessing the statistics publications and data tables on ONS's website. There was some confusion among users about the different sources of cancer data. Users would like to see clear guidance on the differences between the statistics produced by different organisations and a more harmonised approach between these organisations. Some users told us that they used NCIN statistics in preference to ONS's cancer statistics because they are available earlier, and some expressed a need for more detailed information about age, type of cancer, ethnicity, deprivation level and geography (international and local level).

Key documents/links provided

Written Evidence for Assessment document

