

Assessment of compliance with the Code of Practice for Official Statistics

Cancer Waiting Times Statistics for England

(produced by the Department of Health)

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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

Under the provisions of the *Statistics and Registration Service Act 2007*, the UK Statistics Authority has a statutory function to assess sets of statistics against the Code of Practice for Official Statistics, with a view to determining whether it is appropriate for the statistics to be designated, or to retain their designation, as National Statistics.

Designation as National Statistics means that the statistics are deemed to be compliant with the Code of Practice. Whilst the Code is wide-ranging, designation may be broadly interpreted to mean that the statistics meet identified user needs; are produced, managed and disseminated to high standards; and are well explained.

Designation also signifies that, subject to any caveats in this report, the Statistics Authority judges that the statistics are readily accessible, produced according to sound methods and managed impartially and objectively in the public interest.

Assessment reports will not normally comment further, for example on the validity of the statistics as a social or economic measure; though reports may point to such questions if the Authority believes that further research would be desirable.

Designation as National Statistics will sometimes be granted in cases where some changes still need to be made to meet fully the requirements of the Code, on condition that steps are taken by the producer body, within a stated timeframe, to address the weaknesses. This is to avoid public confusion and does not reduce the obligation to comply with the Code.

Designation is granted on the basis of the information provided to the Statistics Authority, primarily by the organisation that produces the statistics. The information includes a range of factual evidence and also assurances by the producer organisation. The views of users are also sought. Should further information come to light subsequently which changes the Authority's analysis, the Assessment report may be withdrawn and revised as necessary.

Once designated as National Statistics, it is a statutory requirement on the producer organisation to ensure that the set of statistics continues to be produced, managed and disseminated 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 report covers statistics on *Cancer Waiting Times*³, produced by the Department of Health (DH), for England. The statistics present waiting times for suspected cancer patients, from referral to treatment. The statistics are presented in the context of a range of targets set out in the *NHS Cancer Plan*⁴ and the *Cancer Reform Strategy*⁵.

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 confirms that the statistics published in *Cancer Waiting Times* are designated as National Statistics, subject to DH implementing the enhancements listed in section 1.5 and reporting them to the Authority by September 2010.

1.3 Summary of strengths and weaknesses

1.3.1 Since the introduction of the *Cancer Reform Strategy* in 2007, DH has worked with the NHS to redesign the administrative data system behind these statistics to ensure that they remain relevant to the changing policy agenda. In addition, DH used this opportunity to harmonise definitions and standards with those underpinning other statistics on hospital waiting times. DH has actively promoted statistical purposes in the design of the underlying administrative system to enhance its statistical potential.

1.3.2 DH statisticians have regular contact with users within the department and the NHS, but there has been insufficient engagement with users outside the NHS. The statistics are presented in a spreadsheet, which is designed for an expert audience, but the lack of commentary and analysis means that the statistics are difficult for non-specialists to interpret.

1.4 Detailed recommendations

1.4.1 The Assessment team identified some areas where it felt that DH could strengthen its compliance with the Code. Those which the Assessment team considers essential to enable designation as National Statistics are listed in

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.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_112966

⁴ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4098139

⁵ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006

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 | Take steps to engage more effectively with users, including those outside the NHS, and make those steps known (para 3.3) |
| Requirement 2 | Publish a revisions policy for <i>Cancer Waiting Times</i> statistics, including details of the arrangements for handling errors (para 3.5) |
| Requirement 3 | Publish details of the methods used in the production of <i>Cancer Waiting Times</i> Statistics (para 3.9) |
| Requirement 4 | Publish information about the quality of the statistics presented in <i>Cancer Waiting Times</i> (para 3.10) |
| Requirement 5 | Establish the feasibility, potential uses and need for comparable statistics on cancer waiting times (para 3.12) |
| Requirement 6 | Publish details of the arrangements for the protection of confidentiality for <i>Cancer Waiting Times</i> statistics (para 3.15) |
| Requirement 7 | Clearly refer to the current operational and policy context when presenting key points (para 3.19) |
| Requirement 8 | Review the presentation of data within the quarterly spreadsheets to ensure that they can be interpreted by non-specialist users (para 3.20) |
| Requirement 9 | Release regular summary publications to provide users with commentary and analysis on <i>Cancer Waiting Times</i> statistics - including comparisons of waiting times over time, by treatment type and by area (where considered appropriate given the need to protect confidentiality) (para 3.21) |
| Requirement 10 | Review the list of those with pre-release access, with a view to reducing the numbers of individuals included (para 3.23) |
| Requirement 11 | Include the name and contact details of the responsible statistician or the Head of Profession in statistical reports (para 3.24) |

Requirement 12

Update the departmental Statement of Administrative Sources to cover *Cancer Waiting Times* statistics (para 3.25)

2 Subject of the assessment

- 2.1 The first national standards for England for cancer waiting times were introduced by the NHS Cancer Plan in September 2000. The Cancer Waiting Times Database (CWT-Database) was set up in 2002 to measure progress against targets and improve the process of cancer treatment. The first official statistics on cancer waiting times were derived from the CWT-Database and published in 2002. In December 2007, the Cancer Reform Strategy was published, which enhanced the standards of the existing Cancer Plan and included new targets, known as ‘cancer waiting times commitments’. In response, DH worked with the NHS to redesign the CWT-Database so that the data collected were appropriate for monitoring the new cancer waiting times commitments. At the same time, DH made changes to align the new database with the collection methods used for *18 Weeks Referral to Treatment Statistics*⁶.
- 2.2 The CWT-Database is used primarily to produce internal management information reports which are used by the NHS and DH to monitor performance and support local service planning. The National Statistics are produced as a secondary use of the data. NHS staff send validated data to DH via a secure online system 25 days after the end of each reporting quarter. DH use these data to produce the National Statistics, which are quality assured and published on DH’s website.
- 2.3 DH is granted access to data for these statistics under Section 251 of the *NHS Act 2006*⁷, which covers control of patient information in the NHS. Approval for access under Section 251 is granted by the Ethics and Confidentiality Committee of the National Information Governance Board for Health and Social Care. Section 251 approval is reviewed annually.
- 2.4 DH spends approximately £12,000 each year producing these statistics. This does not include the cost to the NHS of supplying the data.
- 2.5 NHS and DH users mainly use (unpublished) management data derived from the CWT-Database. Some management data are shared with the Care Quality Commission, which uses them for assessments of the performance of NHS Trusts against predefined criteria. The National Statistics are published to support DH accountability to the public and to Parliament – these statistics shed light on the performance of the NHS. They are of interest to cancer charities and health researchers who may use the statistics to identify areas of concern by looking at tumour type, treatment type or geographical location.
- 2.6 This assessment report does not cover corresponding statistics relating to the devolved administrations. Scotland, Wales and Northern Ireland each have established policies for cancer waiting times and associated data collection

⁶ These statistics were the subject of a previous assessment:

<http://www.statisticsauthority.gov.uk/assessment/assessment-reports/assessment-report-21---assessment-of-18-weeks-referral-to-treatment-statistics.pdf>

⁷ http://www.opsi.gov.uk/ACTS/acts2006/pdf/ukpga_20060041_en.pdf

systems. However, there are differences in the provision of services and methods used to derive waiting times statistics.

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 DH recently published a departmental statement on user engagement⁸ that sets out how it seeks to understand user needs. DH uses the Official Statistics Theme for Health and Social Care to engage with a diverse range of health statistics users. For individual statistical products, DH has three main approaches to engagement: for DH users, engagement involves regular direct contact; for NHS users, formal and informal networks exist; and for other users, DH includes contact details in statistical releases and on its website for users to provide feedback.
- 3.2 When the CWT-Database was redesigned in response to the *Cancer Reform Strategy*, DH held a series of stakeholder workshops with representatives from the NHS to discuss the proposed changes. The main focus was on data suppliers, although some of the attendees were also users of the management information reports derived from the CWT-Database. The outcome of these workshops was documented and fed into the development of the CWT-Database.
- 3.3 DH has used the Going Further on Cancer Waits Advisory Group to engage with users of these statistics. This group consists of NHS and DH cancer specialists, including GPs and clinicians, with a remit of all topics related to cancer policy, including waiting times statistics. Aside from statisticians attending conferences about cancer issues, and external users contacting DH directly, there is little contact with users outside the NHS. There was no proactive engagement with users outside the NHS on the changes to the CWT-Database. As part of the designation as National Statistics, DH should take steps to engage more effectively with users, including those outside the NHS, and make those steps known⁹ (Requirement 1).

⁸http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_114972.pdf

⁹ In relation to Principle 1 Practice 2 of the Code of Practice

Principle 2: Impartiality and objectivity

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

- 3.4 *Cancer Waiting Times* statistics are presented impartially and objectively. They are published in an orderly and timely manner on DH's website, without charge to the user. The recent changes to the methods and classifications were announced in advance of the release of the changed statistics.
- 3.5 DH has a general policy for handling revisions and corrections to statistical releases. For *Cancer Waiting Times* statistics, NHS data suppliers can correct errors discovered in the first two months of a quarter by revising the individual patient records. However, due to the design of the CWT-Database they cannot make corrections to the third month after the automated reporting process has run. When DH is informed of an error in the dataset, it is unable to correct its own extract of the data. This is because the *NHS Act*, which allows DH access to the data, does not grant access to information that would allow identification of the individual patient records. DH statisticians told us that they could request that the NHS correct its data annually, but that this would be burdensome. Where errors are discovered that cannot be corrected, DH includes footnotes against the relevant tables which include estimates of the impact of the errors. For example, in 2009, two patients were incorrectly recorded for the Royal Berkshire NHS Foundation Trust. This error reduced the reported performance below the required operational standard, whereas if the patients had been correctly recorded the Trust would have been above the standard. A caveat was appended to this release to highlight this. As part of the designation as National Statistics, DH should publish a revisions policy for *Cancer Waiting Times* statistics, including details of the arrangements for handling errors¹⁰ (Requirement 2). We suggest DH investigate the options for correcting data errors in the third month of a quarter.

¹⁰ In relation to Principle 2 Practice 6 of the Code of Practice

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.

- 3.6 No incidents of political pressures, abuses of trust or complaints relating to professional integrity, quality or standards were reported to or identified by the Assessment team.
- 3.7 In 2006, to support ministerial, third sector and policy stakeholders, DH decided to bring forward the publication of *Cancer Waiting Times* statistics by one day to coincide with the Britain Against Cancer conference. This was to ensure that all parties at the conference had the most recent statistics available. DH told us that no undue pressure was applied, and the matter was referred to the statistical Head of Profession who had the final say. The change to the release date was announced in advance, a public explanation was given, and the revised release date became the standard for future releases.

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.

- 3.8 The statistics presented in *Cancer Waiting Times* are derived from the CWT-Database, which was first developed in 2002 and redeveloped in 2008 in response to new targets and the need to align the methods to the standards used in *18 Week Referral to Treatment Statistics*. The specifications for the original and revised databases were fully documented.
- 3.9 The CWT-Database automatically validates each individual patient record to ensure that the information contained within it is logical, and applicable to the service being provided to that patient by the NHS. DH receives validated extracts from the CWT-Database, which are uploaded by NHS staff 25 working days after the end of each quarter. Following this, DH aggregates the data into the format used for publication. Statistical staff then undertake quality assurance procedures, before the statistics relating to the national targets are prepared. While the systems for the CWT-Database itself are well documented, there are no published details of the methods used to produce the final statistics. As part of the designation as National Statistics, DH should publish details of the methods used in the production of *Cancer Waiting Times Statistics*¹¹ (Requirement 3).
- 3.10 DH provided the Assessment team with information about the quality of the statistics presented in *Cancer Waiting Times*, but this information is not currently published. As part of the designation as National Statistics, DH should publish information about the quality of the statistics presented in *Cancer Waiting Times*¹² (Requirement 4).
- 3.11 DH recognised that the changes to the CWT-Database would have an impact on the statistics. Because the changes impacted on the data entry system, it was not possible to have a period where the statistics were produced using both the new and existing methods. To help users prepare for this change, DH published an impact estimate on its website alongside the final release of the old statistics. The change was clearly marked in the statistics released both before and after the change.
- 3.12** The devolved administrations have similar standards covering cancer waiting times and some elements of the statistical outputs are comparable. However, differences in the provision of services, as well as differences in the methods used to derive waiting times statistics, mean that UK and international comparability is limited. There is a UK Comparative Waiting Times Group, which sometimes discusses statistics on cancer waiting times. As part of the designation as National Statistics, DH should establish the feasibility, potential uses and need for comparable statistics on cancer waiting times (Requirement 5).

¹¹ In relation to Principle 4 Practice 1 of the Code of Practice

¹² In relation to Principle 4 Practice 2 of the Code of Practice

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.

- 3.13 DH has assured us that it takes all necessary steps to protect the confidentiality of the data it collects. There is a published security policy for the CWT-Database, in accordance with the provisions of the *NHS Act*¹³ that allows DH to access the data.
- 3.14 DH has a published policy on disclosure and confidentiality¹⁴. This makes clear its commitment to implement the advice published by ONS in 2006 on confidentiality in health statistics¹⁵ and other relevant guidelines.
- 3.15 The spreadsheet released as National Statistics contains detailed statistics on cancer waiting times. For rare cancers, there are small cell counts for small geographies – for example hospital level. However, DH told us that the risk of accidental disclosure is minimised by employing strict access limits and aggregation of the collected data items. As part of the designation as National Statistics, DH should publish details of the arrangements for the protection of confidentiality for *Cancer Waiting Times* statistics¹⁶ (Requirement 6).

¹³ Section 251 of the *NHS Act 2006* allows the duty of confidentiality to be set aside in specific circumstances where anonymised information is not sufficient and where patient consent is not practicable.

¹⁴ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_114973.pdf

¹⁵ http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/CodeOfPractice/DH_4130927

¹⁶ In relation to Principle 5 Practice 4 of the Code of Practice

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.

3.16 DH considered the burden to data suppliers as part of the Review of Central Returns (ROCR). The ROCR system seeks to minimise the burden of information demands on NHS bodies and to balance cost and impact on frontline staff. Proposals for the redesign of the CWT-Database were submitted to ROCR for approval. ROCR estimates the annual cost to the NHS of supplying data for *Cancer Waiting Times* statistics as £930,000.

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.

- 3.17 The Cancer Waiting Times team told us that it spends approximately 16 working days each quarter producing and publishing these statistics. Appropriate recruitment and development policies are in place at DH to ensure that suitably skilled people are employed in the statistical production process.
- 3.18 DH does not have a central statistics division. Statisticians are embedded within the relevant DH directorate, with professional accountability to the statistics Head of Profession. There is no central business plan covering statistical activities; statistical expenditure is included in divisional business plans. The Head of Profession has provided the National Statistician with estimates of the total expenditure for official statistics. We suggest DH review the resources allocated to the production of *Cancer Waiting Times Statistics*, in the light of the requirements set out in this report, to ensure that they are sufficient to permit the standards of the Code to be met.

Principle 8: Frankness and accessibility

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

- 3.19 DH releases *Cancer Waiting Times* in a spreadsheet and an accompanying web page with key points. It is not immediately clear how the key points relate to the current operational and policy context, such as the 'cancer waiting times commitments', although there is a later reference to the NHS Cancer Plan. As part of the designation as National Statistics, DH should clearly refer to the current operational and policy context when presenting key points¹⁷ (Requirement 7).
- 3.20 The Assessment team considers the presentation and labelling of the spreadsheets to be unclear for non-specialists. For example, the tables should clearly explain the main terms and provide units of measurement. As part of the designation as National Statistics, DH should review the presentation of data within the quarterly spreadsheets to ensure that they can be interpreted by non-specialist users¹⁸ (Requirement 8).
- 3.21 The statistics do not contain any commentary, analysis or charts to aid interpretation. The Assessment team considers that these statistics should be presented as a time series to enhance their value. As part of the designation as National Statistics, DH should release regular summary publications to provide users with commentary and analysis on *Cancer Waiting Times* statistics - including comparisons of waiting times over time, by treatment type and by area (where considered appropriate given the need to protect confidentiality)¹⁹ (Requirement 9)

¹⁷ In relation to Principle 8 Practice 2 of the Code of Practice

¹⁸ In relation to Principle 8 Practices 1 and 2 of the Code of Practice

¹⁹ In relation to Principle 8 Practice 2 of the Code of Practice

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.

3.22 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.

- 3.23 DH releases its statistics according to a published timetable for twelve months ahead. Lists of those who have access to statistics prior to their release are published alongside each product. There are 23 people on the pre-release list for *Cancer Waiting Times*; DH recognises that this is a long list and has told us that it is making efforts to identify ways to reduce the number of people with pre-release access. As part of the designation as National Statistics, DH should review the list of those with pre-release access, with a view to reducing the numbers of individuals included²⁰ (Requirement 10)
- 3.24 As part of the designation as National Statistics, DH should include the name and contact details of the responsible statistician or the Head of Profession in statistical reports²¹ (Requirement 11).

²⁰ In relation to Protocol 2 Practice 7 of the Code of Practice.

²¹ In relation to Protocol 2 Practice 6 of the Code of Practice

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.

- 3.25 DH recently published a Statement of Administrative Sources²². It plans to update this to reflect a wider range of administrative systems. As part of the designation as National Statistics, DH should update the departmental Statement of Administrative Sources to cover *Cancer Waiting Times* statistics²³ (Requirement 12).
- 3.26 The CWT-Database is used primarily to produce internal management information reports which are used by the NHS and DH to monitor performance and support local service planning. The National Statistics are produced as a secondary use of the data. DH has worked with the NHS to maximise the use of these administrative data and to avoid duplicate requests for information.

²²[http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_115025.p
df](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_115025.pdf)

²³ In relation to Protocol 3 Practice 5 of the Code of Practice

Annex 1: Suggestions for improvement

A1.1 This annex includes some suggestions for improvement to *Cancer Waiting Times* 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.

Suggestion 1 Investigate the options for correcting data errors in the third month of a quarter (para 3.5)

Suggestion 2 Review the resources allocated to the production of *Cancer Waiting Times Statistics*, in the light of the requirements set out in this report, to ensure that they are sufficient to permit the standards of the Code of Practice to be met (para 3.18)

Annex 2: Summary of assessment process and users' views

A2.1 This assessment was conducted from January to April 2010.

A2.2 The Assessment team – Joe Cuddeford and Jacob Wilcock - agreed the scope of and timetable for this assessment with representatives of DH in January. The Written Evidence for Assessment was provided on 11 February. The Assessment team subsequently met with DH during March 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 six responses from the user consultation. The respondents were grouped as follows:

DH	3
NHS	2
Care Quality Commission	1

A2.5 The statistics met the needs of most of these users. Two users said they would find GP practice-level data useful, although one of these users recognised that there could be confidentiality issues. Comments about presentation were mixed: one user said the presentation was clear as they don't need commentary, while another said it was difficult to make sense of the data without help from in-house statisticians. Timeliness was reported as satisfactory.

A.2.6 Users were either satisfied with the way they had been engaged with through personal contact, or said that engagement was unnecessary for them.

Key documents/links provided

Written Evidence for Assessment document

