

Briefing Note: ONS policy on protecting confidentiality within birth and death statistics (Revised 2010)

Introduction

1. This briefing note explains the ONS policy on protecting confidentiality within birth and death statistics. The guidance relates to tabular data outputs based on the 2006 data year onwards, although the implications for historic data are described. It gives guidance on the circumstances in which disclosure control is required. The guidance also clarifies the position on data sharing between ONS and the Department of Health, the NHS and other health bodies. References to the Registrar General, the General Register Office (GRO) and the Office for National Statistics (ONS), reflect the changes brought about by the Statistics and Registration Service Act 2007 which came into force on 1 April 2008.

Summary of disclosure control guidance

2. Statistics at national or Government Office Region (GOR) level that are based on information held on the birth or death registers, or are based on data that were collected at birth and death registration for statistical purposes, only require statistical disclosure control where the release is likely to provide identifiable individual records, or where the release would allow a user to discover new information about an individual. It is less likely at this level of geography that such measures would be required.

3. At lower geographies, for statistics derived from information held on the register, disclosure control may be necessary where tables have low or sparse counts. However, where statistics are derived from information that is not on the registers, statistical disclosure control is necessary.

4. Where disclosure control is necessary, the most suitable method should be selected, for example re-designing tables to aggregate small cell counts across categories, years or geographies. Where cell suppression is used, for outputs from the 2006 data year, the ONS guidance on disclosure control is to use small cell size as an indicator of risk of disclosure. Cells of the following sizes are considered to be likely to carry a risk of disclosure that may require a disclosure control action to be taken:

- for births and deaths, grouping or suppression of all cell counts under 3, and of rates and percentages based on counts under 3, including 0
- for stillbirths, grouping or suppression of all counts under 5, and of rates and percentages based on counts under 5, including 0 and
- secondary suppression as necessary to avoid the possibility of disclosure through subtraction.

Legal Framework

5. The Statistics and Registration Service Act 2007 (SRSA) came into force on 1st April 2008. Section 39 of the SRSA governs the confidentiality of personal information held by the United Kingdom Statistics Authority and its executive office, The Office for National Statistics. Section 39(4) of the SRSA lists the discretionary exceptions to the non-disclosure rule. Any other disclosure of personal information is a criminal offence which carries a maximum penalty of up to two years' imprisonment.

6. The Statistics and Registration Service Act 2007 permits the Registrar General to provide to United Kingdom Statistics Authority, in order to carry out any of its functions, both information that is kept under the Births and Deaths Registration Act 1953 and any other information received by the Registrar General in relation to any birth or death.

7. S42(4) of the SRSA also includes provision for the UK Statistics Authority to supply of information on individual births and deaths for the purpose of assisting the Secretary of State or the Welsh Ministers in the performance of his or their functions in relation to the health service. This means that disclosive personal information of specified type can be passed by ONS to specific individuals within the NHS or other health bodies, for specified purposes (including non-statistical purposes). Onward disclosures by those bodies of this information to non-NHS bodies are not authorised by the Statistics and Registration Service Act.

Code of Practice for Official Statistics

8. In addition the Code of Practice for Official Statistics provides a principle and practice statements for confidentiality, namely 'that 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.' The practices need to 'ensure that arrangements for confidentiality protection are sufficient to protect the privacy of individual information, but not so restrictive as to limit unduly the practical utility of official statistics'. It also states that in every case where confidential statistical records are exchanged for statistical purposes, a written confidentiality protection agreement should be in place along with an operational record for each transmission.

Key aspects of birth and death statistics

9. Since civil registration was introduced in England and Wales in 1837, it has served multiple purposes. Civil registration is recognised by the United Nations as the foundation of the legal system for establishing the rights and privileges of individuals. Records from that system are also the main and preferred source of continuous vital statistics on live births, deaths, and foetal deaths as well as marriages and divorces. Mortality statistics are one of the principal sources of health information, and in most countries, they are regarded as the most reliable source of health data on the whole population.

10. Information supplied at birth and death registration falls into three categories:

- information required by law for the register
- information required by law but not recorded in the register (e.g. Population (Statistics) Acts information) and
- information provided on a voluntary basis (e.g. additional information used for statistics).

Disclosure of information on the register - discoverable information

11. The GRO (General Register Office) indexes to the registers are held by year of registration of an event and include information on names and, for deaths, the date of birth of the deceased. Hence very little information about the event can be gleaned from the indexes themselves. They are used to identify the required entry on the register and are essential in applying for a certified copy of the information on the register. Any person may search the indexes and obtain a certified copy and this makes the information discoverable by the

public, within the rules and provisions of the Registration Acts. Similarly, statistics and tables based only on information on the register are also discoverable under s39(4)(d) of the SRSA in that they have already lawfully been made available to the public. However, significant effort might be needed in practice to derive them and hence ONS does place some restrictions as to the level of detail in statistics released.

12. Discoverable information available from the register includes the following variables:

Births

Date of birth
Place of birth
Sex
Father's place of birth
Father's occupation*
Mother's place of birth
Mother's occupation*
Mother's usual residence

Deaths

Date of death
Place of death
Sex
Date of birth (from which age is derived)
Place of birth
Occupation*
Usual residence
(Original**) cause of death

* For guidance on NS-SEC, which is derived from occupation and other employment variables provided voluntarily for statistical purposes, see paragraph 22

** For guidance on final cause of death derived from information not on the register, see paragraphs 24 and 25.

13. There is no legal requirement under the SRSA to fully disclosure control statistics for any geography (including Super Output Areas and Census Area Statistical Wards) or similar detailed variables that are based on information contained in the birth or death register because such information is discoverable. In particular, counts of registrations by area of residence do not require any control at any level of geography. Discoverable data can be published for both local authorities and primary care organisations even where there are minor differences in boundaries.

14. However, under the Data Protection Act 1998, ONS must consider any potential harm or distress to an individual mentioned in the register but also, in the case of death records, to the living relatives of those who have died. Moreover, this is subjective and though no release of tables containing *only* information available from the register would constitute a breach of the Statistics and Registration Service Act, releases of statistics based on birth and death register information are subject to the conditions in paragraphs 16-17 as well a wider legal framework.

15. Therefore for the information in the above lists, the only restrictions for statistics on registrations are where harm or distress to an individual could be caused by releasing small counts at low geographies (local authority and below), or where the release would effectively provide identifiable individual records (at any geography – see paragraphs 16-17).

When is confidentiality protection needed for discoverable data?

Sparsely populated tables

16. Publication of statistics is restricted where the number of variables and/or the level of detail would result in sparsely populated tables comprising cells of mainly 1s and 0s. Such tables would effectively be lists of individual records, whose disclosure is controlled under legislation. It is necessary when designing such statistics to ensure that the provisions of the Registration Acts about entitlement to access this information are not undermined. The ONS cannot, through its statistics, provide what is in effect an alternative method of obtaining information on the Register to the proper statutory process of obtaining register copies.

17. Judgement in such cases must be exercised on a case by case basis. However, a guideline on what constitutes sparsity is where the number of persons in a row (or column) is fewer than the number of cells in the row or column. In such instances, the normal disclosure control methods would either be to:-

- group together data from two or more columns (recoding).
- suppress the row/column, with secondary suppression(s) as necessary;

Combining data items

18. Where information by area is combined with other detail on the register, judgement must be exercised if this leads to large proportions of zeros and ones in tables (see paragraph 16). If use is made of information that is not on the register, disclosure control is needed.

Differencing

19. Differencing, for example between tables based on date of death registration and those based on date of occurrence, is only a problem if some information not on the register is used in the table. In such cases, disclosure control is necessary.

Disclosure control for information not on the register - non-discoverable information

20. Information that is not on the births and deaths registers but is collected at birth and death registration for statistical purposes is non-discoverable and includes the following types of information.

Information required under the Population (Statistics) Act

21. Information required at the registration of a birth or death under the Population (Statistics) Act is listed below. These data items require disclosure control.

Births:

For all births

- age of mother at birth,

For births where the father or second female parent is recorded

- age of father/second female parent at birth

For births within marriage or civil partnership,

- the date of the parents' marriage or civil partnership

For births within marriage only

- whether mother married previously
- previous children born in marriage

Deaths:

- marital or legal partnership status of the deceased,
- age of any surviving spouse or civil partner.

Voluntary information

22. Employment status and any more detailed information provided on occupation are provided voluntarily for statistical purposes to derive a National Statistics Socio-Economic Classification for the individual. In many cases it is not possible to derive the non-discoverable information from NS-SEC and therefore disclosure control may be necessary only where the data are presented in combination with other non-discoverable data.

Birthweight:

23. Information on the birthweight of the baby provided to ONS by the NHS for statistical purposes. It is not discoverable and requires disclosure control.

Final cause of death

24. The cause of death entered in the register is known as the 'original' cause of death. Some ONS statistics, however, are based on what is known as the 'final' cause of death. In coding 'final' cause, ONS takes into account any additional information provided by medical practitioners or coroners after the death has been registered. This is sometimes provided in confidence and, as it no longer matches the entry in the death register, it is not 'discoverable'. It therefore requires disclosure control.

25. Statistics based on 'final' cause of death are available at the national levels (England & Wales, or England and Wales separately) and at Government Office Region level within England. However, where outputs include sub-regional (sub-GOR) results for England and/or sub-national results for Wales, these will routinely be based on 'original' cause of death.

Disclosure control guidance for non-discoverable information

26. For non-discoverable information, there will be no constraints at the England & Wales level, or for Wales and the Government Office Regions (GORs) of England, except where the release would in effect be of individual records or where there is potential for harm and distress or identification. Disclosure control in the form of suppression of low counts or some other form, for example aggregation of groups, must still be applied to any sub-GOR analyses for England and/or sub-national analyses for Wales containing any of these data items.

Stillbirths

27. While information contained in the (live) birth and death registers is discoverable, this is not true for stillbirths. There is no publicly available index or register of stillbirths, so fact of stillbirth is effectively confidential. Therefore statistics of stillbirths and perinatal deaths (i.e. stillbirths and deaths under seven days), must be disclosure controlled. Total birth figures which include counts of both live and stillbirths will be regarded as disclosive if publication of the live birth figure alone would reveal a potentially disclosive stillbirth figure. Note that fact of infant death is discoverable information.

Accessing unpublished data for Statistical Research

28. The ONS Microdata Release Panel (MRP) authorises the re-use of statistical and research data held by ONS. Access to unpublished data can only be provided for research and statistical purposes and must be approved by the MRP. Where there is no other statutory gateway, the customer must also apply for Approved Researcher Status, in addition to a request for data being authorised. ONS must also approve release of disclosive data on births and deaths which is provided for research and statistical purposes to the NHS and other health bodies under the s42 of the Statistics and Registration Service Act.

ANNEX A

Legislative framework

Statistics and Registration Service Act 2007

The Statistics and Registration Service Act 2007 enables the UK Statistics Authority to produce and publish statistics relating to any matter. It transfers some of the statistical functions of the Registrar General, including the production of an annual abstract of births, marriages and deaths, to the UK Statistics Authority. The Office for National Statistics (ONS) is the executive office of the UK Statistics Authority. Simultaneous machinery of government changes resulted in the General Register Office, of which the Registrar General is the head, becoming part of the Identity and Passport Service and the National Health Service Central Register (NHSCR) transferring to the NHS Information Centre for Health and Social Care.

Section 42 of the 2007 Act provides the Registrar General with a power to allow him to disclose any information about a birth, death or stillbirth to the UK Statistics Authority for any of its functions. This section also includes provision for the UK Statistics Authority to supply information on births and deaths to the Secretary of State or the Welsh Ministers in the performance of his or their functions in relation to the health service. These powers mirror those of the Registrar General under National Health Service Act 2006 (Section 270) and National Health Service (Wales) Act 2006 (Section 201) (see below). Section 39 of the Act lays out provisions for the confidentiality of personal information including criminal penalties for contravention.

The Population (Statistics) Act 1938 (Section 1) and 1960 (Section 4)

These sections require informants to provide certain prescribed details to registrars (e.g. the age of the mother at birth registration). This is information received by the Registrar General in relation to a birth or death, and therefore available to ONS.

Births and Deaths Registration Act 1953 (Sections 30 and 33)

These sections require the Registrar General to make available indexes of the registers of births and deaths and to provide certified copies of entries in the register on payment of a prescribed fee. This is information received by the Registrar General in relation to a birth or death, and therefore available to ONS.

National Health Service Act 2006 (Section 270) and National Health Service (Wales) Act 2006 (Section 201)

These replace the National Health Service Act 1977 (Section 124A, as amended by the Health Act, 1999) and separate provision of the health service in Wales from that in England. The acts require notification of a birth to the local primary care trust (local health board in Wales) where the birth occurred. Both acts include provision for the Registrar General to supply information on individual births and deaths to the National Health Service to assist the Secretary of State in performing his functions in relation to the health service. This provision is replicated in s42 of the SRSA, enabling ONS to perform the same function with the same data.

ANNEX B

Summary of implications for Vital Statistics Outputs

1. Vital Statistics outputs include the Vital Statistics (VS) Tables, provided to the NHS and local authorities, and individual record outputs provided to the Department of Health, the Public Health Observatories and the NHS. The following paragraphs provide further information on deaths outputs.

Vital Statistics (VS) tables

2. VS Tables use death registrations and are based on 'original' cause of death. This means that:

- the statistics reflect the cause of death as given in the death register
- the VS Tables are consistent with other outputs supplied to the Department of Health, Public Health Observatories and the NHS for the management of the NHS, and with those supplied to the Healthcare Commission for the monitoring of performance of the NHS against government targets
- the NHS are able to share with local authorities the cause of death VS tables and, provided there are not undue proportions of 1s and 0s (see paragraph 16), any statistics they produce from the Annual District Deaths Extract based on discoverable information (any statistics based on non-discoverable information will need full disclosure control)
- the cause of death data on the Clinical and Health Outcomes Knowledge Base, managed for the IC by the National Centre for Health Outcomes Development (NCHOD) are publicly available

VS tables supplied to the NHS include information on births that is not discoverable and must be disclosure controlled.

Vital Statistics (VS) tables prior to 2004

3. ONS did not put any restrictions on the supply of the VS Tables up to and including 2001. Restrictions applied only to the 2002 and 2003 outputs since the tables for these years used 'final' cause of death. However these were re-produced using original cause and have been available to non-NHS customers.

Individual Record Outputs (IROS)

4. Individual record outputs contain 'original' cause of death, while all ONS statistics in the period 1986-2003, whether based on date of registration or date of occurrence, were based on 'final' cause of death. Statistics on death registrations in 2004 and 2005, and in the first release for 2006, were based on 'original' cause of death. Since 2006, most ONS mortality statistics are based on date of registration and all publications (except VS tables) use final cause of death.

5. The statistical Annual District Death Extract available to primary care organisations and the statistical extract supplied to Public Health Observatories include 'original' cause of death. Therefore, provided there are not undue proportions of 1s and 0s in the tables (see paragraphs 16 and 17), any statistics based on discoverable variables from those extracts may be published without disclosure control and may be shared with local authority

colleagues. Statistics that include non-discoverable variables must still be disclosure controlled (see paragraphs 20-26).

Public Health Files

6. There is no change in the position with regard to the Public Health Birth and Mortality Files (PHBF and PHMF) available to Primary Care Organisations - these files must not be shared with local authority colleagues. This is because the legal gateway via s42 of the Statistics and Registration Service Act allows the use of the information only for functions in relation to the Health Service.

Annex C

Background to the policy on protecting confidentiality within vital statistics

In early 2003, business areas' interpretation of the draft National Statistics Protocol on Data Access and Confidentiality coupled with their understanding of the current legislation prompted them to examine their practices. Some concluded that it was necessary to change some established practices – usually to introduce more disclosure control measures. They introduced an interim policy with effect from 2002 (data year) outputs that all cells comprising counts under 5, or based on counts under 5, including 0s, should be suppressed and secondary suppression applied as necessary to avoid the potential for disclosure through subtraction. The exception was in the provision of data to the NHS as there was specific legislation that allowed the NHS family to have a complete set of detailed data. However, the NHS was required to apply the ONS disclosure rules before publishing/sharing data. This caused problems with the growth in partnership working between the NHS and local authorities.

In addition, as there were, and continue to be, some differences in boundaries between the primary care organisations (PCOs) and local authorities in England, ONS had to restrict publication of PCO data to ensure there was no possibility of disclosure through differencing.

Review of confidentiality and disclosure control of birth and death statistics

In 2004, ONS started to review its policy on confidentiality and disclosure in respect of birth and death statistics. This review was overseen by the Statistical Policy Committee chaired by Len Cook, the then National Statistician and Registrar General for England and Wales.

Legal advice ONS received as part of the review stated that it is not unlawful to publish statistics relating to potentially identifiable information from the birth and death registers because such information is discoverable on the public registers themselves. This was helpful as it meant that ONS could make available to anyone ward-level data on deaths by age and sex, for example, without the need either to disclosure control or to put in place a confidentiality declaration restricting further publication. At the time this advice was received, it was expected that once the Civil Registration Review was implemented through a Regulatory Reform Order, cause of death would no longer be in the public view of the death register. The Statistical Policy Committee therefore ruled that this variable should continue to be disclosure-controlled. The local authority level table on cause of death in 2003 for non-NHS customers (Table VS3) complied with this ruling.

In December 2004 the Regulatory Reform Order was dismissed by Parliament. Following this, and in light of the implementation of the Freedom of Information Act 2000, ONS concluded that cause of death as entered in the death register should be treated as a discoverable and detailed cause of death statistics made available. The cause of death entered in the register is known as the 'original' cause of death. The majority of ONS statistics, however, are based on what is known as 'final' cause. In coding 'final' cause of death, ONS takes account of any additional information provided by medical practitioners or coroners after the death has been registered. This is sometimes provided in confidence and is not discoverable, which is why ONS cannot allow open access to the original VS3 or VS4D for 2002 and 2003; they include some potentially disclosive information that is not discoverable from the public registers.

Other recent changes

Prior to 2007, the ONS rules on suppression in respect of birth and death statistics were that, where disclosure control was necessary, all counts under 5 would need to be suppressed. This would include any rates and percentages based on counts under 5.

The guidance on protecting confidentiality disclosure control has been updated to reflect the changes brought about by the Statistics and Registration Service Act 2007.