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Review of the Dissemination of Health Statistics: Confidentiality Guidance

Office for National Statistics
1 Drummond Gate
London SW1V 2QQ
Tel: 020 7533 9233
Fax: 020 7533 9292

Contact points

For enquiries about this publication contact:

Statistical disclosure centre on 0845 601 3034

Email: info@statistics.gsi.gov.uk

For general enquiries, contact the National Statistics Customer Contact Centre:

Tel: 0845 601 3034

Minicom: 01633 812399

Email: info@statistics.gsi.gov.uk

Fax: 01633 652747

Post: Room 1015, Government Buildings, Cardiff Road, Newport NP10 8XG

About the Office for National Statistics

The Office for National Statistics (ONS) is the government agency responsible for compiling, analysing and disseminating economic, social and demographic statistics about the United Kingdom. It also administers the statutory registration of births, marriages and deaths in England and Wales. The Director of ONS is also the National Statistician and the Registrar General for England and Wales.

A National Statistics publication

National Statistics are produced to professional standards set out in the National Statistics Code of Practice. They are produced free from any political influence.

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Executive summary

This report represents the outcome of a comprehensive review of the dissemination of health statistics undertaken by the Office for National Statistics. It provides guidance for handling health statistics in a way that ensures the public interest in the figures is met while managing data confidentiality risks.

The reporting for this review has been a two-stage process. The first part of the review focused on developing guidance for published tables of abortion statistics. This report provides more general guidance on disclosure issues around published tables of health statistics derived from registration processes, administrative sources and statistical returns. Confidentiality issues concerned with microdata or record-level information are not covered by this review.

The guidance describes an approach that data providers should follow based on a general framework for addressing the question of confidentiality protection. The following elements of the framework are described in this document:

- Determining user requirements
- Understanding the key characteristics of the data and outputs
- Assessing disclosure risk by considering a range of potentially disclosive situations and identifying the parts of the table that could lead to disclosure. Producers of statistics are likely to find that outputs can be placed into one of three broad risk categories, defined in terms of the likelihood of an attempt to identify an individual and the impact of identification. Recommendations are made on the level of protection required for these three risk categories
- Legal and policy considerations
- Disclosure control methods. A number of different methods and techniques are presented and compared
- Implementation

More technical advice and worked examples are provided in associated working papers.

For many published tables, the risk of identifying individuals will be minimal and no disclosure control methods necessary. For other information the issues may be more complex. No single solution is available for these instances. Instead, guidance is provided on how to develop solutions for different types of datasets based on each of the steps of the framework. The guidance will allow data providers to apply appropriate solutions to confidentiality problems within their own organisation. This guidance replaces previous practices that have been adopted within the health field, such as the rule of thumb to suppress all values in tables less than 5.

1 Review and consultation on the dissemination of health statistics

Health statistics support a wide range of work to improve and protect our health, they inform patients and the public. Many of these areas of work require detailed figures, which may raise issues about data confidentiality. Producers of health statistics must ensure that their statistics meet the needs of users while at the same time protecting confidentiality.

This report results from a review of the dissemination of health statistics. The review was initiated in 2005 to address disclosure issues around published tables of statistics. Other forms of dissemination (for example, the provision of data to professional analysts) present different issues and will be addressed separately in a National Statistics guidance publication.

The aim of the review was to produce guidance for handling health statistics in a way that ensures the public interest in the figures is met while managing data confidentiality risks.

The review has been led by the Office for National Statistics (ONS) and has involved representatives from the Health Departments, Public Health Observatories and the devolved administrations. In addition the guidance has been released for public consultation.

The principles and approach outlined in this guidance will apply to all health statistics. However, this review and hence the examples, specific rules or guidelines presented are focused on tables derived from registration processes, administrative sources and statistical returns. These data sources have a complete coverage of the population or a sub-population. Specific guidelines for tables derived from sample surveys will be provided in a National Statistics publication to be produced by the end of 2006. Confidentiality issues concerned with microdata or record-level information are not covered by this review.

This review was established specifically for published health statistics, where following release there is no control over their further use. However, through consultation wider issues have been raised concerning data access and sharing that are recognised as important and need to be addressed. Guidance on the large scale transfer of data and confidential data for the production of statistics is available in the ONS publication, *Data Sharing for a Statistical Purpose: A Practitioners Guide to the Legal Framework*. In addition a National Statistics publication will be produced by the end of 2006 to provide guidance on the provision of access to confidential data for specific persons for specific uses.

The guidance produced from the review is intended for anyone in the health community involved in the publication of health statistics. The Office for National Statistics (ONS) will implement the proposals and will advise ministers in Health Departments and devolved administrations to do the

same. The guidance is also aimed at Primary Care Trusts, Public Health Observatories and other Arms' Length Bodies of the Health Departments.

This document describes the approach that data providers should take to meet users' needs while managing confidentiality risks. It proposes a general framework for addressing the question of confidentiality protection. The main elements of this framework are described in sections 4 to 9. These include understanding the data, assessing risk, and legal and ethical aspects. A number of possible methods for disclosure control are presented and guidance is provided on implementation. Technical advice is provided in the attached working papers:

- Confidentiality protection – legal and policy considerations
- Risk assessment
- Risk management
- Glossary
- References to other guidance

A worked example of this approach has been developed for abortion statistics (www.statistics.gov.uk/downloads/theme_health/abortion_stag_final.pdf).

2 Meeting users' needs while protecting confidentiality

> National Statistics will be valued for relevance, integrity, quality and accessibility – and produced in the interests of all citizens by protecting confidentiality. (National Statistics Code of Practice, Summary of Principles)

Health statistics provide an important public benefit. They are often of greatest value when they extend to small geographic areas or sub-groups. For example, it is well known that 1 in 3 people develop cancer at some point in their lives and 1 in 4 deaths are from cancer. We can conclude that cancer is a significant health risk, but little more. In order to examine health issues in more detail it is necessary to look at more detailed figures. A more informative view of the data could involve:

- analysing by age and gender to show the relative risks for these different groups
- breaking figures down by ethnic group and social class to reveal the extent of health inequalities
- examining local-area data to highlight problems of different localities
- investigating specific health information about proximity to potential health hazards such as mobile phone masts or landfill sites to allow an assessment of health risks

However, when statistics are released at a detailed level the risk of disclosing information about individuals is likely to be increased. Particular problems arise in tables containing small counts. For example table 1 shows counts of conceptions by usual place of residence and age of the mother at conception. (The data displayed are not true counts but are indicative of the true distributions.)

The table has many small counts, particularly for under 18s. Although the table does not itself reveal the identity of an individual there could be a risk that someone with a specific interest in this topic seeing a small number in the cell, could follow up private sources of information to locate the individuals and discover more details. There could also be a risk of disclosure from combining or linking this table with other information, eg a table of abortion or birth statistics.

Table 1: Counts of conceptions, by ward and age of mother

Ward	Under 18	Total
Ward A	5	56
Ward B	0	34
Ward C	3	94
Ward D	1	78
Ward E	2	66
Ward F	1	45
…..	…..	…..

The National Statistics Code of Practice and Protocol on Data Access and Confidentiality provide high level guidelines on how to approach such problems but there is a need for more detailed guidance on how to translate these policy statements into practice.

3 What is involved in confidentiality protection?

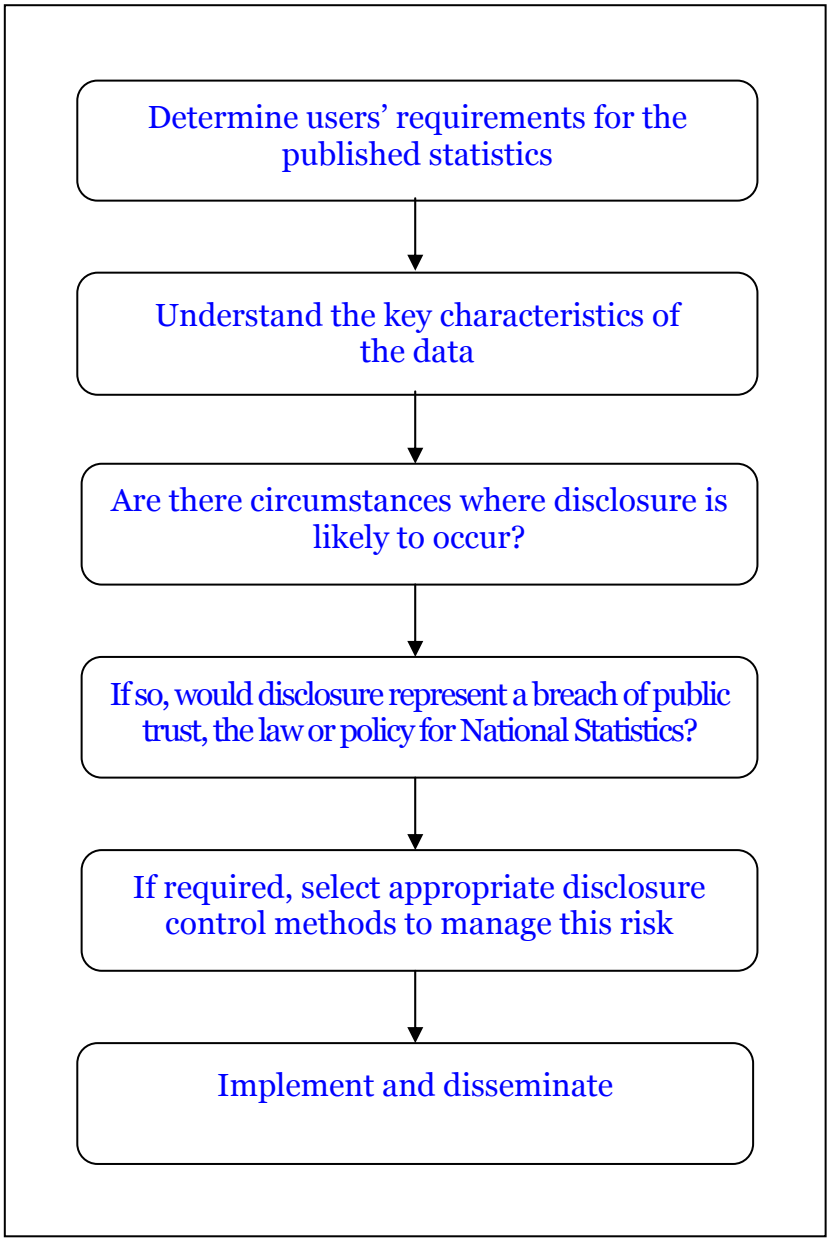
> Through trust in National Statistics, participants will see that data collection is necessary, that they do not risk being identified and that there is a clear benefit, to themselves and others, personally and as citizens, from the production of relevant and trustworthy statistical information. (National Statistics Code of Practice, Foreword)

Figure 1 shows the main steps to be taken in considering disclosure control in relation to tables of health data. It forms the structure for the guidance in this document.

- The first step involves establishing the user requirement for a particular health statistic.
- The second step involves gaining an understanding of the data that will underpin the statistics. The characteristics of the data will affect any disclosure risks. In particular, risk increases as statistics become more detailed (in terms of geography and categories) and as the dimensions of the table grow. Risks are higher if the distribution of the counts is skewed or the data are considered sensitive. Understanding the data will also involve establishing whether or not the data provider has the authority to disseminate the data.
- An assessment of disclosure risk should then be made. This will involve identifying situations where there is a likelihood of disclosure.
- Where a risk is identified, it is necessary to establish whether any disclosure would constitute a breach of public trust, of a legal obligation, or of a national or international policy standard for official statistics.
- If such a breach is thought to be likely, disclosure control methods can be used to manage the risk effectively. The various methods have different advantages and disadvantages and must be chosen bearing in mind users, uses and characteristics of the data.
- The final stage in the process is implementation of the methods and dissemination of the statistics.

For many published tables, the risk of identifying individuals will be minimal and no disclosure control methods necessary. Sometimes the information at risk of disclosure will not require protection for any reasons of public trust, the law, or National Statistics policy. For other information the issues may be more complex. No single solution is available for these instances. Instead, guidance is provided, based on the steps illustrated in figure 1, on how to develop solutions for different types of datasets. The guidance will allow data providers to develop their own confidentiality methods for different health statistics. These rules can then be applied to all published tables from a particular data source. This approach was adopted for the first stage of this review, in developing guidance on disclosure control for the publication of abortion statistics (www.statistics.gov.uk/downloads/theme_health/abortion_stag_final.pdf).

Figure 1: Main steps for ensuring access to non-disclosive statistics



4 Determining user requirements

> Users' views are essential in ensuring the relevance of National Statistics. (National Statistics Code of Practice, Principle)

Producers of statistics should design publications according to the needs of users, as a first priority. It is vital to identify the main users of the statistics, and understand why they need the figures and how they will use them in detail. This is necessary to ensure that the design of the output is relevant and the amount of disclosure protection used has the least possible adverse impact on the usefulness of the statistics.

The demands on health statistics are wide-ranging and include questions such as:

- what are the main health problems in the country or my town
- what is the quality of care in my local hospital and how does it compare with other hospitals
- how extensive are smoking, alcohol and drug-related problems, and which groups of the population are most affected, and
- are specific diseases becoming more or less common and are there groups of the population who are more affected than others?

Statistics help planners and managers of services understand the pressures on those services and how they are best organised for the benefit of users. They help decide how the substantial funds that go into health services are distributed and on what they should be spent. They also provide the basis for much research into health issues and treatments.

5 Understanding the key characteristics of the data and the required outputs

It is important to have a good understanding of the data that may require protection to assess any risk of disclosure. Here is a list of issues to take into account:

- The source of the data may affect the need to protect confidentiality. Health statistics are generally derived from registration processes, health-care sources, GP consultations, hospital data, waiting time records, etc
- Sensitive variables may require special attention
- The age of the data may reduce the risk of disclosure since the population of the statistic will change over time and become less identifiable. It is not possible to be more specific about this reduction in risk since it will differ between datasets and the populations represented
- The quality of data may determine the way in which the data are presented, the method of disclosure control or modify the need for disclosure protection
- Statistical units are defined as individuals, households, medical practitioners or health establishments. It is important to asses which units are represented in the data and are to be protected
- Particular issues may arise when the same unit is represented more than once. For example, if protection is required for practitioners, then cells in a table where all the values relate to a particular one, could be disclosive. Note, protection for practitioners is only required in certain circumstances, eg by Abortions Regulations. Further information concerning practitioner confidentiality may be obtained from the Office of the Information Commissioner at www.ico.gov.uk
- Disclosure risks may also increase if groups of statistical units (eg patients from a particular clinic) are represented in a table and, therefore, could identify each other
- The disclosure risk for event-based data will be different from residence-based data. In order to identify an individual in a table for patients visiting a health clinic one would need to know that the individual is included in the population base for the table, ie has attended the clinic. The risk reduces if the population base or coverage of the table is not easily identifiable

It is also important to consider the characteristics of the tables. Where tables are very simple and presented at a high level of aggregation (including geography), disclosure issues are unlikely to arise. When tables become more detailed, and the counts in individual cells are small, the risk of identification may increase and protection may be needed. If the spread of values is skewed across a table, the risk in particular cells may increase above an acceptable level.

Issues may arise with linked tables where risk of disclosure can increase by differencing or through combining with other data. One particular problem that can occur with multiple or linked tables from the same data source is

called disclosure by differencing. This problem occurs when two or more tables, taken together, enable by subtraction or deduction the value of a potentially disclosive count. For health statistics this may occur when tables are produced from the same dataset for two non-coterminous geographies, eg Primary Care Organisation (PCO) and Local Authority District (LAD) in England. More details are provided in the working paper on risk assessment.

6 Assessment of disclosure risk for the intended statistical outputs

> For any National Statistic, statistical disclosure control measures will be adequate to ensure the confidentiality guarantee, and beyond that, as comprehensive as can be achieved without unduly compromising relevance, integrity and quality. (National Statistics Protocol on Data Access and Confidentiality)

In order to develop suitable confidentiality protection, a risk assessment should be undertaken. Risk is a function of likelihood (related to the design of the table), and impact of disclosure (related to the nature of the underlying data). Decisions on likelihood and impact should be made by those who have a detailed understanding of the statistics and experience of the interest in the figures. It is important to consider the views of patients and carers in the assessment of the impact of potential identification. In order to be explicit about the disclosure risks to be managed one should consider a range of potentially disclosive situations and take action to prevent them. The situations should be used to identify those parts of the statistical table that could lead to disclosure, termed 'unsafe' cells (commonly, cells containing small counts). Appropriate confidentiality rules should be applied to these cells. It is not possible to protect against all risks, this is a risk management not a risk elimination exercise. Three example situations are described in more detail.

General attribute disclosure

General attribute disclosure arises when someone who has some information about a statistical unit could, with the help of data from the table, discover details that were previously not known to them.

Example

A table of statistics for psychiatric services at a hospital shows admissions by single years of age, and diagnosis. Attribute disclosure has occurred if someone, who knows their neighbour was admitted for such service, discovers from the statistic that they are schizophrenic.

Disclosure may arise if there is a count of 1 in a marginal total (row or column) as in table 2, where a treatment of type 1, 2 and 3 is broken down by age bands. Anyone who knows that a particular individual under 12 has received a treatment would learn that it was a type 1 treatment. Attribute disclosure could occur from a count of 2 in a marginal total where one of the units may identify the other and thereby disclose further information.

Table 2: Treatment, by type and age

Treatment	Age				Total
	< 12	12–15	16–19	> 19	
Type 1	1	0	7	1	9
Type 2	0	0	18	19	37
Type 3	0	12	5	0	17
Total	1	12	30	20	63

Disclosure can also occur from cells with larger values, where they appear in a row or column dominated by zeros. A zero in population data allows one to say that no-one in the population has that attribute. This can be seen in table 2, which reveals that no 12–15 year olds are having treatment type 1 or 2 so all 12–15 year olds having the treatment are having type 3 treatment. The risk from many zeros within tables will not be significant, but, in some cases, they may need to be protected.

Disclosure risks may increase where groups of units that appear in the same table know enough about each other to identify each other and potentially discover something new. This can occur where units share characteristics or are grouped in some way, eg individuals from the same clinic or practitioners from the same hospital.

In order to protect against general attribute disclosure, at a minimum, care should be taken where rows or columns are dominated by zeros and in particular where a marginal total is a 1 or 2.

'The Motivated Intruder'

Data in a table is combined with information from local sources to identify a statistical unit and disclose further details.

> **Example**
>
> An intruder with a special interest in conception statistics discovers from a table that only a small number of very young women have conceived in a particular local area. The small number in the cell doesn't tell the intruder who the women are but it may prompt them to follow up other sources of information to locate the individuals and discover – and disclose - more details.

This situation may occur when small values are reported for particular cells. In a large population (for example, a country or region), the effort and expertise required to discover more details about the statistical unit may be deemed to be disproportionate. As the base population is decreased by moving to smaller geographies or sub-populations, it becomes easier to find units and discover information.

Although the local sources reveal the identity of the individual it is the statistics that cause the motivated intruder to start looking and attempting to reveal what is disclosive. The Protocol on Data Access and Confidentiality

Table 4: Statistical disclosure control methods – modify cell values

Method	Description	Advantages	Disadvantages	Examples
Cell suppression	Unsafe cells are not published. They are suppressed and replaced by a special character, such as '..' or 'X', to indicate a suppressed value. Such suppressions are called primary suppressions. To make sure that the primary suppressions cannot be derived by subtraction, it may be necessary to select additional cells for secondary suppression	Original counts in the data that are not suppressed are not adjusted	Most of the information about suppressed cells will be lost Secondary suppressions will hide information in safe cells Information loss will be high if more than a few suppressions are required In order to protect any disclosive zeros, these will need to be suppressed Does not protect against disclosure by differencing Complex to implement optimally if more than a few suppressions are required, and particularly complex for linked tables	Statistics on low birthweight babies are protected using suppression
Rounding	Rounding involves adjusting the values in all cells in a table to a specified base. This creates uncertainty about the real value for any cell while adding a small but acceptable amount of distortion to the data	Counts are provided for all cells Provides protection for zeros Protects against disclosure by differencing and across linked tables	Cannot be used to protect cells that are determined unsafe by a rule based on the number of statistical units contributing to a cell Random rounding requires auditing; controlled rounding requires specialist software	Statistics on claimants of disability living allowance, incapacity benefit and severe disablement allowance are protected by rounding to base 5
Barnardisation	A post-tabular method for frequency tables where internal cells of every table are adjusted by +1, 0 or -1, according to probabilities	Protects against disclosure by differencing	High level of adjustment may be required in order to disguise all unsafe cells Will distort distributions in the data	Implemented for the 1991 Census

If a data provider has access to the individual record level data then disclosure control methods can be implemented that adjust the data before tables are designed.

Table 5: Statistical disclosure control methods – adjust the data

Method	Description	Advantages	Disadvantages	Examples
Record swapping	Swap pairs of records within a micro-dataset that are partially matched to alter the geographic locations attached to the records but leave all other aspects unchanged	Protects against disclosure by differencing	High level of swapping may be required in order to disguise all unsafe cells Will distort distributions in the data. Method not transparent to users	Used in combination with small cell adjustment to protect the 2001 Census for England and Wales

Alternative methods for presenting data can be considered as an approach for providing users access to information without disclosing the underlying data. In many cases this will provide a more robust analysis than reliance on the accuracy of small cell counts. These could include presenting data graphically or providing commentaries or analytical outputs. More details and examples are provided in the working paper on risk management.