

Review of the Dissemination of Health Statistics: Confidentiality Guidance

Working Paper 5: References and other Guidance

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Email: hmsolicensing@cabinet-office.x.gsi.gov.uk

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.

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1 Introduction

This working paper provides an overview of other guidance and references concerned with protecting the confidentiality of health statistics to support the guidance set out in the review. Comments are provided on how each guideline relates to the guidance. The references are current as of June 2006.

2 Guidelines

Disclosure Review for Health Statistics. First Report: Guidance for Abortion Statistics

The first deliverable from the Disclosure Review for Health Statistics, this report provides standards and guidance for protecting the confidentiality of abortion statistics. The approach adopted to develop this guidance is as outlined in this document.

www.statistics.gov.uk/downloads/theme_health/abortion_stag_final.pdf

Confidentiality: NHS Code of Practice

This is a guide to required practice for those who work within or under contract to NHS organisations concerning confidentiality and patients' consent to the use of their health records. It outlines the necessity of keeping personal information about patients and sets out the basic principles governing the use of patient information centring on the duty of confidence.

www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/AccessHealthRecordsArticle/fs/en?CONTENT_ID=4100550&chk=1w6ljh

Protecting and Using Patient Information: A Manual for Caldicott Guardians (and Caldicott Committee: Report on the Review of Patient-Identifiable Information)

The document *Protecting and Using Patient Information* was produced following the Government's commitment to implement the recommendations of the Caldicott Report published in 1997. The report reviewed issues involved with the transfer of patient-identifiable information and confidentiality for information transferred from NHS organisations to non-NHS organisations. The review was concerned with the transfer of information rather than confidentiality more generally, but did consider areas for further research.

The report made a number of recommendations, one of which led to the creation of Caldicott Guardians in the NHS. They are responsible for safeguarding the confidentiality of patient information. For more on the role of Caldicott Guardians, see the Department of Health website (www.dh.gov.uk).

www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/AccessHealthRecordsArticle/fs/en?CONTENT_ID=4100563&chk=ZdxTGp

One of the principal differences between the remit of the Caldicott Review and this review is that this review is concerned with the publishing of health statistics, while the Caldicott Review was concerned with the transfer of

patient-identifiable information. Nevertheless, there are some areas of overlap and these guidelines complement a number of the recommendations made by the Caldicott Report. For example, the report recommends that any data flow, which could include the publishing of data, is tested against basic principals of good practice. This review provides guidance on best practice for disclosure control for health statistics and is concerned with protecting the confidentiality of statistical units which includes patients.

The Confidentiality, Security and Sharing of Personal Data: Policy and Procedures for the Local Health Community

This document is provided by the Department of Health as an example of best practice for local health community compliance with the Caldicott Review and the Data Protection Act 1998. It also highlights other relevant legislation and central guidance that should be considered when holding and transferring data. This guidance can be accessed on the DH website (www.dh.gov.uk).

www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/AccessHealthRecordsArticle/fs/en?CONTENT_ID=4100563&chk=ZdxTGp

Personal Information in Medical Research: Guidelines

This document provides guidance on procedures for those using individual patient data for the purposes of research. It has recently been updated to account for Section 60 of the Health and Social Care Act 2001, whereby the Secretary of State can support and regulate the use of confidential patient information in the interest of patients and the public good.

The document outlines ethical and legal principals for using personal information in medical research and describes scenarios for using information with and without patient consent. It reviews the safeguarding of confidentiality through methods such as anonymisation and coding, sets out principles to follow when storing and re-using data and includes information on some relevant laws and other statutory regulations.

Personal Information in Medical Research: Guidelines is concerned with the use of individual patient information in medical research, while the guidance originating from the review of the dissemination of health statistics is concerned with the publication of data.

For further information see www.mrc.ac.uk/index/publications/publications-ethics_and_best_practice/publications-ethics_series.htm

The Hospital Episode Statistics Protocol: Instructions for handling the data

This protocol describes the sensitivities of the Hospital Episode Statistics (HES) dataset, and defines the limits up to which data can be released without fear of encountering problems with these sensitivities. It also provides advice

on handling requests that exceed these limits and guidance on the rules for releasing HES data in the form of tables.

For further information see www.hesonline.nhs.uk/Ease/servlet/DynamicPageBuild?siteID=1802&categoryID=331

Freedom of Information Act Awareness Guidance No. 27

This guidance provides information on the prohibition of disclosure according to the Freedom of Information Act. Specifically it considers Section 44 of the Act, which relates to exemptions from the duty to provide information if its disclosure is prohibited.

This guidance has been written with consideration of the impact of FoI. For further information see www.informationcommissioner.gov.uk/eventual.aspx?id=9183

Briefing Note: ONS policy on protecting confidentiality within birth and death statistics

This note explains when disclosure control is necessary for birth and death statistics, describing ONS policy on the protection of confidentiality within birth and death statistics. It also provides guidance on data sharing between the NHS and partners, explaining where disclosure control is required. The rules described in this note will be reviewed in the light of this guidance.

For more information see www.statistics.gov.uk/statbase/Product.asp?vlnk=5768

General Medical Council Guidance on Confidentiality: Protecting and Providing Information

These guidelines are for people who are registered with the General Medical Council. They aim to provide guidance to doctors on holding confidential information and describe instances where it may be justified to release such information.

For further information see www.gmc-uk.org/guidance/library/index.asp

Handbook on Civil Registration and Vital Statistics Systems: Policies and Protocols for the Release and Archiving of Individual Records

This handbook provides an overview and guidance for National Statistics agencies on the production of vital statistics. Included in the overview is a section on confidentiality, which provides principles on what should be protected against and ways in which data can be protected. The guidance also provides recommendations on practice for releasing electronic files to external researchers.

For more information see <http://unstats.un.org/unsd/pubs/gesgrid.asp?id=64>

3 References

The following papers and books provide more technical details on statistical disclosure control.

Brown, D (2003) *Different approaches to disclosure control problems associated with geography*, ONS, United Nations Statistical Commission and Economic Commission for Europe Conference of European Statisticians, Working Paper No. 14.

Doyle, P, Lane, J I, Theeuwes, J J M and Zayatz, L (2001) *Confidentiality, Disclosure and Data Access: Theory and Practical Application for Statistical Agencies*. Elsevier Science BV: Amsterdam.

Duke-Williams, O and Rees, P (1998) 'Can Census Offices publish statistics for more than one small area geography? An analysis of the differencing problem in statistical disclosure', *International Journal of Geographical Information Science* 12, 579-605.

Willenborg, L and de Waal, T (1996) 'Statistical Disclosure Control in Practice', *Lecture Notes in Statistics* No. 111. Springer-Verlag: New York.

Zayatz, L (2003) *Disclosure Limitation for Census 2000 Tabular Data*, Bureau of the Census, United States, United Nations Statistical Commission and Economic Commission for Europe Conference of European Statisticians, Working Paper No. 15.