CONFIDENTIALITY & ANONYMISATION OF QUALITATIVE DATA GUIDANCE

1. Introduction

NHS Lothian routinely seeks out and learns from patient and staff experience in order to improve its services, or to help clarify best practice in complex situations. These experiences, in the form of case studies, stories or quotes, are regularly described in reports and other documents which are publicly circulated. These include:

- Reports of public consultations
- Reports of projects using qualitative research techniques – for example, research projects, service evaluations or audit
- Training or teaching materials using case studies drawing on patient or staff experience
- Reports
- Minutes of Board meetings and committee meetings*
- Board papers*

*(see ‘Resources’ section for reference for additional guidance).

It is crucial that those whose experiences are included in such documents are aware that NHS Lothian plans to use these and how; that they consent to this unless there are exceptional circumstances (outlined below); and that their privacy is protected, and confidentiality maintained, by appropriate anonymisation of the experiences they contribute. This has become particularly imperative now that electronic media mean that such material circulates rapidly and widely, and cannot be easily retrieved.

This document:

- Outlines key issues underpinning ensuring consent and anonymisation
- Suggests courses of action where it may not be possible or feasible to seek consent or anonymise data
- Lists further guidance and sources of advice

Anonymising patient experience in order to protect confidentiality can be a complex process, and the factors involved can vary significantly from case to case. Guidance cannot encompass all situations, and following guidance alone cannot substitute for the exercise of clear and sensitive judgement. Advice and second opinions from Judith Sim & Annette Gallimore, Dept of Public Health & Health Policy, NHS Lothian
colleagues should be sought routinely. Information Governance (see ‘Information Governance’ section on NHS Lothian intranet for contact details) and researchers in the Directorate of Public Health and Health Policy will be able to provide further advice.

This guidance should be read alongside companion sources of guidance, including Lothian and Scottish advice on data protection and consent and confidentiality, and advice provided by the National Research Ethics Service. Links to these and other sources of guidance are provided in the ‘Resources’ section.

This document does not constitute legal guidance.

2. Key issues: consent

2.1 Taking consent

- Consent to use of patient and staff views and experience should always be sought. Explanations in writing should be provided detailing how the experience they contribute will be used, where it will be published and how it will be circulated.
- Signed consent should be taken, but this should always be accompanied by discussion to ensure that the person involved understands what they are being asked to consent to, and that they have plenty of opportunity to ask questions. Further guidance on consent-taking, consent forms and information sheets is provided in the ‘Resources’ section.
- In most but not all cases consent should extend to the subject’s approval of the form in which their information is published or being used. For example, it is conventional in clinical research involving case studies to offer subjects the opportunity to view and approve these before final publication, although this is less common in academic qualitative research.
- Where appropriate, it should be made clear when taking consent that there are rare circumstances where confidentiality cannot be maintained. This includes disclosure of information which suggests that the research subject or vulnerable others are at risk of abuse or other forms of danger.

2.2 Where seeking consent is impossible or complex

There are a number of situations where seeking consent is impossible or particularly complex. These include:

- Where someone cannot be traced
• Where someone has died
• Where experience is reported indirectly rather than by the subject themselves. For example, an NHS member of staff may report a patient case known to them which illuminates issues in patient care or key issues for staff. Although the patient concerned should be contacted and asked for their permission for their case to be used where possible, this may not always be feasible or appropriate.
• In the case of younger children or adults with incapacity. It is crucial to learn from the experiences of these groups, and NHS Lothian has benefited significantly from involving them in research and service development. It is equally important that those involved understand how their experiences will be used and where they will be circulated. Sources of guidance on obtaining consent from children and adults with incapacity are provided in the ‘Resources’ section. These include the role of parents or guardians in the case of children or ‘consultees’ (trusted third parties) who care for or are close to people with incapacity.

2.3 Considering whether or not to use case studies or personalised patient data

Where consent cannot be obtained, very careful consideration should be given to whether the material should be used in the form of anonymised case studies or other personalised presentation of data. This is justified only in rare cases where the importance of the issue over-rides the absence of consent, and personalised data is the only or optimum way of presenting the case.

If the case study is based on the story of someone who has died, consideration should be shown to their relatives, who in most cases should be informed of and involved in plans to use information about the deceased. In other cases, however, relatives may not have been aware that the deceased person was receiving a particular service or had articulated specific experiences. Under such circumstances, informing relatives would constitute a breach of confidentiality. Reviewing patient notes for details of the information shared between the patient and his or her relatives, or any wishes expressed about this by the patient, may help clarify the best course of action when preparing a case study involving someone who has died.

When contemplating using qualitative patient data without consent, including where patients have died, it is crucial to consult the NHS Lothian Caldicott Guardian. See ‘Resources’ section for details.

2.4 Alternatives to case studies or the use of personalised patient data

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October 2013
If consent is difficult to obtain, or case studies or personalised data are particularly difficult to anonymise, alternative ways of presenting the experience derived from patients or staff should be considered. These include:

- Extracting key points from patient or staff accounts and presenting these in non-personalised form in reports or other material
- Presenting stories as a fictionalised account
- Formulating case studies as an amalgamation of a number of patients’ stories

It is important to make clear the fictionalised or amalgamated nature of accounts if this course is chosen in case an individual mistakes them as their own.

3. Key issues: anonymisation

3.1 What does anonymisation mean?

Anonymisation means presenting information about someone so that the theoretical probability of those who know the individual recognising their identity is extremely small.

Anonymisation is usually achieved by removing all identifying information about the person whose experience is described. This includes names, places of residence and workplaces, and sometimes gender, ethnicity, occupation or (when quoting) verbal mannerisms which might identify an individual. However, sometimes ‘identifiers’ have to be retained in order to make sense of the material being presented. For example, if a report focuses on how ethnicity shapes health experiences, ethnicity will usually be specified.

3.2 When is anonymisation impossible or unnecessary?

There will be cases which are unique, or form such an unusual combination of circumstances that anonymising case studies or other qualitative data would be almost impossible.

There are also situations where those contributing their experiences are happy to be identified. For example, in recent Lothian research, Third Sector organisations were offered the choice of whether or not to contribute anonymously, and some were keen to be identified as contributors. This is frequently the case for consultations carried out by NHS Lothian and others.

3.3 Guidance on anonymisation
Individuals are potentially identified by a combination of ‘clues’ working together. While there are some obvious identifiers to consider, anonymisation should be done in the round, using common sense, and drawing on second opinions from colleagues rather than following a formula. If details merely add colour and are not necessary to make sense of the material, they should be omitted.

The following basic issues should be considered in anonymising data:

- Names should be replaced with pseudonyms, initials or numbers which do not relate in any way to the real name of the subject
- Residential areas should be replaced with pseudonyms, initials or numbers unless the report explicitly focuses on specific named areas
- Gender, ethnicity or occupation should remain unspecified unless this distorts the sense of the data
- Consideration should be given to aggregating characteristics to protect the identity of individuals, particularly where there are small numbers of people in each category. For example, in a report on ethnicity and health, individuals’ ethnicity could be reported by region rather than country (specifying people as from South Asia or sub-Saharan Africa rather than from Pakistan, Bangladesh or Mozambique). Similarly, aggregation should be considered when reporting on material involving the Third sector: some organisations have a distinctive role, and specifying this could potentially identify users and workers.
- Particular speech mannerisms are uncommon and potentially identify people, and therefore should be removed in quotes used in reports
RESOURCES: Sources of further guidance and advice

**British Sociological Association:** Statement of Ethical Practice
[www.britsoc.co.uk/media/27104/StatementofEthicalPractice.doc](http://www.britsoc.co.uk/media/27104/StatementofEthicalPractice.doc)

**General Medical Council:** Good Practice in Research

**General Medical Council:** Consent to Research

**National Research Ethics Service:** Web resources on consent.

This includes guidance on providing information sheets, taking consent, and guidance on taking consent from people with learning disabilities and those who do not speak fluent English.

**NHS Lothian Caldicott Guardian**
caldicott.guardian@nhslothian.scot.nhs.uk

**NHS Lothian (2007)** Data Protection Policy

**NHS Lothian (2010)** Policy and guidance for obtaining consent

**NHS Lothian (2011)** Information Governance FAQs: *What is the difference between personal data and anonymised data?*
[http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/ehealth/operationsandinfrastructure/InformationGovernance/Pages/IGFAQs.aspx#data_difference](http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/ehealth/operationsandinfrastructure/InformationGovernance/Pages/IGFAQs.aspx#data_difference)

**NHS Lothian (2012)** Instructions for the preparation of Board papers
[http://intranet.lothian.scot.nhs.uk/NHSLothian/NHS%20Lothian/BoardCommittees/Pages/MeetingPaperTemplates.aspx](http://intranet.lothian.scot.nhs.uk/NHSLothian/NHS%20Lothian/BoardCommittees/Pages/MeetingPaperTemplates.aspx)

**NHS Lothian (2012)** Policy on confidentiality of personal health information
NHS Scotland (2012) NHS Scotland Code of Practice on protecting patient confidentiality: 

Primarily focused on protecting confidentiality in routine use of patient data, but has some general pointers on using patient experience more widely.

ISD Scotland has excellent companion guidance on confidentiality. A copy of this is available from Judith.sim@nhslothian.scot.nhs.uk

The following articles outline key points about the morality and ethics of confidentiality in relation to circulating information collected from patients:
