

# Review of public and professional attitudes towards confidentiality of healthcare data: Executive report

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# Executive summary

## Context

The General Medical Council (GMC) is the independent regulator for doctors in the UK. It publishes guidance which sets out the ethical principles and professional standards that underpin good practice. During 2015 the GMC will be developing a revised version of its guidance on confidentiality. The purpose of this literature review is to inform the development of this updated guidance which the GMC provides to doctors registered to practise in the UK.

The review addressed two main questions:

- What does existing evidence tell us regarding public and patient attitudes in the UK towards the confidentiality of healthcare data?
- What does existing evidence tell us regarding professionals' attitudes in the UK towards the confidentiality of healthcare data?

The review looked at all uses of healthcare data, including use in direct patient care, as well as secondary uses such as research, service improvement, and public interest uses.

## Summary of methods

This literature review is based on detailed searches of eight academic databases. These searches were supplemented by online searches and interviews with relevant experts to ensure that key sources of information were not missed.

From an initial sift by title and abstract, 184 articles were identified as being of possible relevance. Following full text review, 65 articles were identified for inclusion, and reviewed in detail. Relevant data from each item was extracted and recorded in the database against the research question(s) to which it related. The reviewed material was subjected to broad content analysis, with key themes and associations drawn out.

## Key findings

- Professionals are typically more open to the sharing of patient data across a variety of contexts than members of the public.
- Among both patients and professionals there is enthusiasm about the possible benefits of electronic medical records, however this is tempered by concerns about security and uses of data other than those relating to their direct care.
- Concerns about confidentiality are not limited to sharing medical records. Patients are also concerned about breaches of confidentiality during the process of care delivery.
- With regards to secondary uses of data, members of the public trust some organisations much more than others. The NHS is highly trusted, while there is low trust in private companies.
- Members of the public are generally happier for data to be shared and used for the purpose of helping others or improving healthcare; they are less happy for data to be used commercially.
- Views on what consent process would be appropriate for secondary uses of data are highly context dependent for patients, professionals and members of the public.
- Members of the public often have poor awareness of the ways in which patient information is currently used and who it is available to.
- There were very few high quality studies on attitudes to the uses of data in the public interest; this appears to be a gap in the evidence base.

These key findings are expanded upon below.

### *Findings relating to confidentiality in the direct care of patients*

#### Sharing data

Professionals and members of the public widely agree that it is appropriate (and important) for information to be shared between members of a patient's care team. Views on whether it is appropriate to share information outside the care team led to a broader range of opinions. While some patients and members of the public welcome this in some circumstances, for example to improve the joined up nature of care between different services (e.g. across health and social care), others were more concerned about this possibility. The studies reviewed show that, in general, professionals are more likely to think the sharing of data is appropriate in a given situation than members of the public. However this is not universally

true, for example, the Caldicott Information Governance Review identified a ‘culture of anxiety’ around information sharing across health and social care<sup>1</sup>.

Some studies indicate that patients with more experience of healthcare may be more accepting of data sharing than those who do not make much use of health services. This final point applies to data sharing for patient care, but also to some public interest uses of data, such as medical research.

### Electronic medical records and patient access

There was enthusiasm identified in the evidence for the potential benefits of electronic medical records amongst both patients and professionals, who felt these could be more secure than paper records. However, patients were concerned about data linking and needed more information about how this worked in order to feel comfortable with it. Public awareness of large scale systems for electronic medical records was seen to be crucial for their acceptance and success.

One feature of electronic medical records that received a good deal of discussion in the literature was that they can provide the basis for systems which allow patients to access their own medical record. A consistent piece of feedback from patients seems to be that those who want electronic self-access to their records should be allowed this, but that nobody should be forced to use these systems: choice was the most important factor for patients. Professionals in particular had concerns about confidentiality of these systems in relation to where they could be accessed (e.g. in-surgery or at home).

### Confidentiality within healthcare settings

Some studies discussed healthcare settings where confidentiality concerns arose aside from those specific to medical records. Many of the concerns that patients have relate to everyday activities within the setting. For example some raised concerns about people overhearing their conversations with a GP receptionist, either at the surgery in person, or speaking on the phone. Similar concerns relate to community pharmacies and school nurses. There is also evidence of concerns about additional professionals present during medical consultations, for example students observing hospital interactions, or interpreters in a GP surgery. There is evidence to suggest that while these concerns are not shared by all individuals, they can lead to reduced use of services for some.

There was less evidence of professional attitudes to confidentiality in healthcare settings, but some available evidence did suggest that relevant professionals are not always aware of the concerns that patients can feel in these situations.

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<sup>1</sup> Caldicott, F., et al. (2013) *Information: to share or not to share? The information governance review*. Department of Health

## *Findings relating to confidentiality in secondary uses of data*

### Trust in different organisations

Studies generally agreed on a clear hierarchy of trust which patients and the public have in different types of organisations accessing their data. In general, the NHS is most trusted, followed by universities, while pharmaceutical and private companies receive very low levels of trust. There is also a hierarchy of trust for different professionals: GPs are very trusted, administrative staff less so. Some articles considered that certain types of information such as that relating to sexual or mental health are more sensitive than others, however they did not all provide clear evidence to support this assumption.

### Different secondary uses of data

The evidence suggests that whether patients and the public think data should be used for secondary purposes, and their views on the confidentiality of data in this context, are strongly influenced by the purpose for which the data is being used. Members of the public are happier for data to be used for public interest purposes, but more wary about commercial uses of data. Participants in a number of studies also reported concerns about data being used for purposes other than those which they originally gave consent for.

### Consent processes

There is no clear consensus on which consent processes are required in which situations. However, patients, members of the public and professionals often have strong personal opinions about this issue. Some of the literature frames the evidence in terms of whether 'opt in' or 'opt out' consent processes should be used. It is a tentative finding that many members of the public are more comfortable with opt in processes, because some studies did show members of the public to favour opt out processes in some contexts. A key factor for whether opt out processes are felt to be reasonable is whether members of the public feel that everyone who might want to opt out would be sufficiently aware of the issue in order to do so. A few studies found doctors and medical researchers to be more "pro data sharing" than members of the public.

## **Additional findings**

### **Levels of awareness and understanding**

Members of the public often have poor awareness of the ways in which patient information is currently used and who it is available to. For example, a finding of many studies was that some patients and members of the public assume that administrative staff in healthcare have less access than they actually do to medical records. In some cases poor levels of understanding could lead to increased confidentiality concerns, in other cases to complacent attitudes towards confidentiality. Some public and patient groups also held misconceptions around the way in which medical research is conducted, with many placing greater emphasis on the role of the NHS and universities, while thinking that pharmaceutical organisations are less involved than is the case.

Levels of understanding of confidentiality protocols and legal frameworks amongst professionals were also found to be variable.

### **Public interest uses of data**

There were very few high quality studies on attitudes to the uses of data in the public interest; however a few points emerged (each based on one study). On safeguarding children: some GPs find confidentiality concerns a constraint when dealing with child protection, fearing that they could damage their professional relationship with the child's parents and being unsure where to get advice on this. Patients, including young people, have an understanding of the need to occasionally break confidentiality to protect patients. On the public interest question of preventing dangerous or illegal behaviour, many health professionals working in the penal system do not see confidentiality as an important consideration when sharing data about a potentially dangerous offender.

## **Implications for the development of the guidance**

The following points may help the GMC's thinking around the development of the guidance:

- There is an appetite among professionals and members of the public to improve data sharing processes to help medical professionals to care for patients. The guidelines need to allow such improvements to take place.
- Making large scale integrated medical records systems work will require good public engagement and awareness, while also ensuring that systems are sufficiently secure and robust to address people's concerns. The guidelines should address the responsibilities of doctors who are contributing to large centralised databases as this is an increasingly important concern.
- Unintentional breaches of confidentiality concern patients; advice in the guidance on ways to mitigate this, for example by drawing attention to confidentiality risks in the reception area, may be valuable.

- Public attitudes to confidentiality differ according to the type of organisation that handles the data, as well as the specific purpose that the data is being used for. For example in a specific context, sharing data within the NHS might be considered appropriate, while sharing the same data for the same reasons between the NHS and a private company might be more concerning to some members of the public. It is worth considering this finding in the context of ensuring that patients have appropriate information as part of consent processes.
- The variety of opinions on consent processes suggests that there needs to be some flexibility in the type of process used for different situations, also taking the scale of data sharing into account.
- Professional awareness of existing confidentiality policies and procedures in some settings could be improved.
- Some studies assert that sexual health and/or mental health are areas in which people have greater confidentiality concerns, however these studies did not directly test this claim. While there is some evidence to support this view, it might be valuable to conduct further research to gain a fuller understanding of this.



## Glossary of abbreviations

ePCS	Electronic Palliative Care Summary
EPR	Electronic patient record
GMC	General Medical Council
GP	General Practitioner
HRSS	Health Research Support Service
NIECR	Northern Ireland Electronic Care Record
NWIS	NHS Wales Informatics Service
OOH	Out-of-hours
OPM	Office for Public Management
SAIL	Secure Anonymised Information Linkage (A Welsh service)
SHIP	Scottish Health Information Partnership
SPIRE	Scottish Primary Care Information Resource