Review of public and professional attitudes towards confidentiality of healthcare data: Final 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[1].

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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[1] 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.

Introduction

In December 2014 OPM was commissioned by the General Medical Council (GMC) to conduct a literature review. The review addresses 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.

A previous review on the same topic was conducted in 2007; this review therefore considers evidence published since then.

This is the final report.

Background

The General Medical Council is the independent regulator for doctors in the UK. The purpose of the GMC, as set out in Section 1(1A) of the Medical Act 1983 (as amended), is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine.

Section 35 of the Medical Act provides the GMC with the power to provide, in such manner as the Council think fit, advice for members of the medical profession on; standards of professional conduct, standards of professional performance, or medical ethics.

To fulfil this responsibility, the GMC publishes guidance which sets out the ethical principles and professional standards that must underpin good practice. It provides its core guidance in a regularly updated document entitled 'Good Medical Practice'. This document is supported by a range of additional explanatory guidance. Doctors are expected to exercise judgment in deciding how to apply the principles to their particular field of practice and in the situations they encounter in their day to day work.

Since 1971 the GMC has published advice of increasing length on the subject of confidentiality, with discrete guidance on the topic first published in 1995. Revised guidance published in 2000 was the subject of considerable public debate, with disputes about the common law and concern from the research community that the guidance put unreasonable restraints on the use of identifiable information about patients to the detriment of research and improvements in knowledge about health and disease.

In 2009 the current guidance was published by the GMC. The 2009 Confidentiality guidance sets out the principles of confidentiality and respect for patients' privacy that doctors are expected to understand and follow. Since 2009 considerable discussion and debate has

taken place with regard to the subject of the confidentiality of data in the UK. In the health sector the proposed introduction of care.data in England has been the subject of considerable debate as potential health benefits have been weighed against concerns about privacy. Similar schemes are planned in the other countries of the UK. More generally companies' and government's storage and use of data about individuals have led to wide-ranging debate about potential benefits and that technological developments have brought in their wake.

During 2015 the GMC will be developing a revised version of its guidance on confidentiality. The purpose of the review is to inform the development of updated guidance which the GMC provides to medical professionals in the UK, alongside other strands of evidence and input that the GMC is gathering, such as consultation with key stakeholders.

Methodology

Scoping interviews

Scoping interviews with experts were conducted at various points during the literature review process in order to ensure that we did not miss any important sources of evidence, and to 'sense check' the emerging findings to ascertain how these could best be understood.

Interviews were conducted with the following:

- An experienced health researcher/clinician with an interest in improving the content of health records who has experience of working in both Wales and England

- An academic expert for the University of Sheffield with expertise in medical confidentiality

- A representative from the Health Research Authority

- A representative from a patient confidentiality advocacy group

One other individual agreed to take part in an interview, but it was not possible to arrange this within the necessary timescale. This individual would have been able to provide information from a research ethics perspective, and also comes from an organisation based in Northern Ireland.

Literature review

Search

We conducted 23 database searches, each of which returned approximately 50-100 hits (range 15-400)[2]. The databases searched are listed in Table 1.

Table 1: Databases searched

Database	Sector focus of database
Embase	Biomedical
Psychinfo	Behavioural science and mental health
Health Management Information Consortium (HMIC)	Health and social care management
Social Policy and Practice (SPP)	Social and public policy and practice including physical, mental and community health
International Bibliography of the Social Sciences (IBSS); Applied Social Sciences Index and Abstracts (ASSIA); Sociological Abstracts; Social Services Abstracts (searched on Proquest)	Social sciences
Medline	Life sciences and biomedical
Web of Science	Multidisciplinary scientific research
Global Health	Public health

Search terms were drafted based on the research questions and with the input of and expert in literature search and synthesis, GMC, and early scoping interviewees. We used an iterative search strategy, trying out different terms in order to produce the most relevant results for each research question. We supplemented this search strategy with online searches to ensure full coverage, which produced one additional result.

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[2] Professor Alan Gomersall, from the Centre for Evidence-Based Policy and Practice (CEBPP) at King's College, undertook the database searches. Alan is a recognised world expert in literature search and synthesis, regularly contributing to international systematic reviews conducted by the Cochrane Collaboration and the Campbell Collaboration.

A complete log of searches, showing the database, timeframe, search focus and strategy, numbers of results and numbers of results selected is available on request from the researchers.

The search terms used were designed to cover the following key areas: different public, patient and professional groups (e.g. 'public', 'GP' or 'family'), potentially vulnerable groups (e.g. 'young people'), terms related to attitudes or opinions, terms related to confidentiality (e.g. 'consent', or 'information governance'), terms related to healthcare (e.g. 'health'), terms related to different types of medical record (e.g. 'electronic patient record'), and terms exploring ways in which this data might be used (e.g. 'disclosure' or 'research'). We also included a number of specific terms to elicit information on relevant key issues such as 'care.data', or 'SPIRE' (the Scottish Primary Care Information Resource).
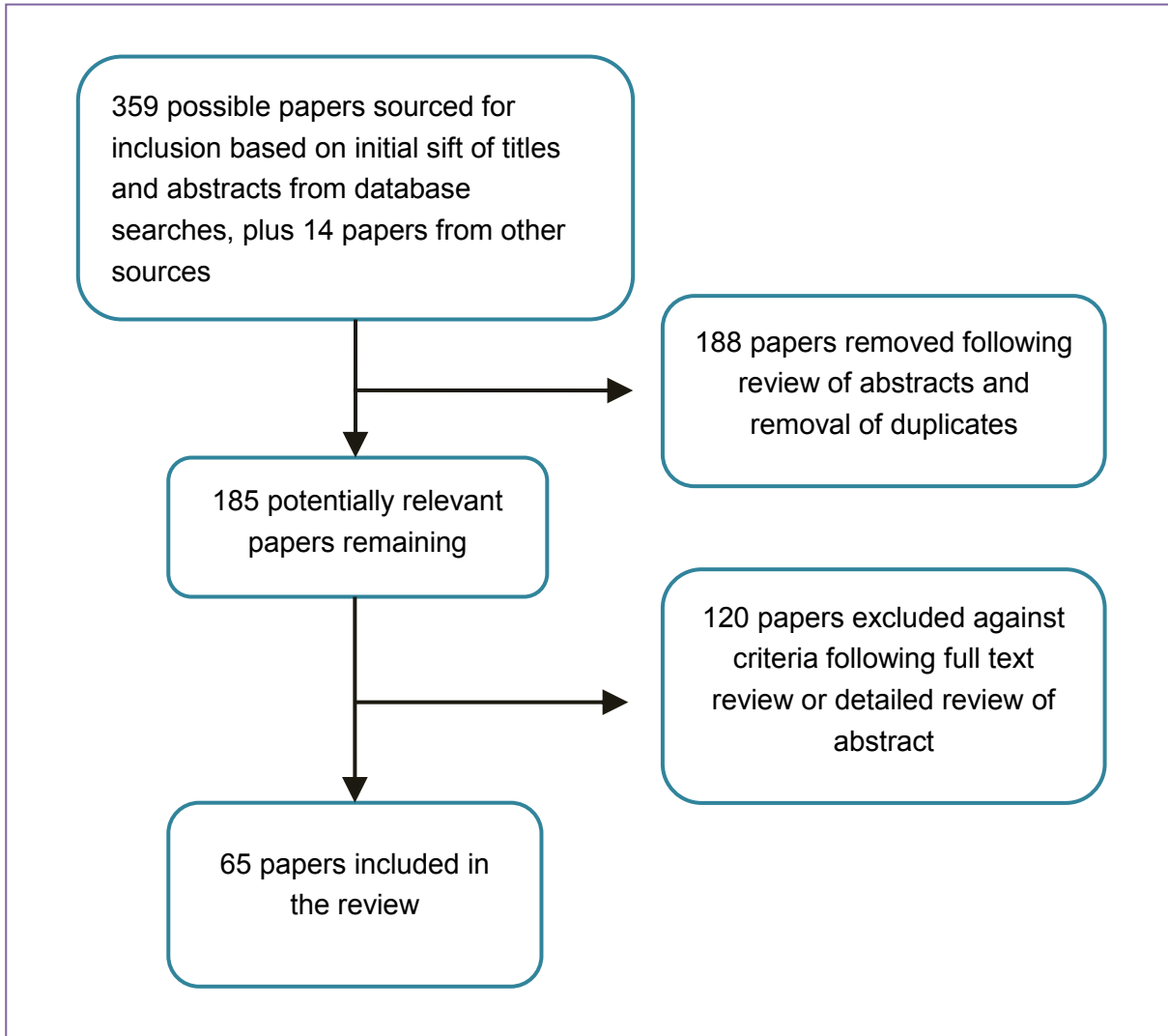
Sift and selection

The titles and abstracts of studies found through the search were screened for relevance to the research questions, and 172 articles were identified as being of possible relevance (after duplicate articles had been removed). We were directed towards a further 12 studies by the GMC or other sources, giving a total of 184 studies for possible inclusion.

We developed a set of **inclusion standards** to inform a more detailed review of the long list of evidence. The key inclusion criterion was relevance to the research question. Other inclusion/exclusion criteria (and exceptions applied) were as follows:

- Location: UK only (exclude international)

- Date: published since 2007 (when the previous review was conducted)

- Type of evidence: items should have a clear evidence basis, i.e. make use of primary or secondary data (exclude opinion pieces, except for public interest where there is less evidence overall; exclude professional guidelines and consultations, as it is often unclear how these have been developed)

- Sector: exclude studies related to the dental profession

All potentially relevant material was accessed in full and was subjected to a full text sift using the inclusion standards, and reasons for inclusion or exclusion were recorded in the evidence database. Of the 184 potential items, 65 met the inclusion standards and were included in the review. A further 24 articles were of some relevance to the review, but did not meet all inclusion criteria. These additional articles were read by the team, to provide context and understanding, but did not contribute significantly to the content of the review. Some of these additional studies include ethical or legal discussions that help to frame an understanding of the relevant issues, but do not provide evidence about public or professional attitudes. Figure 1 on the next page shows an overview of the literature search process.

Figure 1: Overview of the literature search process

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│   ╭─────────────────────────────╮                                               │
│   │ 359 possible papers sourced  │                                              │
│   │ for inclusion based on initial│                                             │
│   │ sift of titles and abstracts  │                                             │
│   │ from database searches, plus  │                                             │
│   │ 14 papers from other sources  │     ╭─────────────────────────────╮         │
│   ╰─────────────┬───────────────╯       │ 188 papers removed following │        │
│                 │                  ────▶ │ review of abstracts and      │        │
│                 ▼                        │ removal of duplicates        │        │
│   ╭─────────────────────────────╮        ╰─────────────────────────────╯        │
│   │ 185 potentially relevant      │                                             │
│   │ papers remaining              │                                             │
│   ╰─────────────┬───────────────╯       ╭─────────────────────────────╮         │
│                 │                        │ 120 papers excluded against  │        │
│                 │                  ────▶ │ criteria following full text │        │
│                 ▼                        │ review or detailed review of │        │
│   ╭─────────────────────────────╮        │ abstract                     │        │
│   │ 65 papers included in         │       ╰─────────────────────────────╯        │
│   │ the review                    │                                             │
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Review

Material that met the inclusion standards at this point was read and reviewed in full. 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.

Report structure

The findings of the review have been grouped into themes. These themes are loosely based on the research questions, but have been modified to provide a structure for the types of issues that are emerging from the research. Where it has been appropriate to do so, findings within each theme have been grouped into sub categories to make it easier to navigate the report.

Findings about the use of data for direct care have been separated out from secondary uses of data where possible. The report is structured under the following headings:

- Direct care

    – Who should be able to access medical records?

    – Patients' access to their own medical records

    – The use of electronic medical records

    – Confidentiality in care, not related to medical record

- Secondary uses of data

    – Types of organisation or professional that should have access to medical records

    – Attitudes to particularly sensitive information

    – How consent for data to be used should be given

    – Use of data in the public interest

- Crosscutting themes

    – Opinions about care.data

    – Levels of knowledge and understanding about confidentiality of data

Note on terminology

Throughout this report, the term 'professionals' refers to medical professionals (as opposed to members of the general public).

Study profiles

The 65 included studies had the following characteristics:

Type

The majority of studies were journal articles.

Type	Number
Journal article/Article	43
Report	15
Opinion poll	2
Other (news article, published letter, academic conference literature)	5

Country

The majority of studies covered England only, but a good deal took a UK wide perspective.

Country	Number
UK (all)	14
England	19
Wales	1
Scotland	9
Northern Ireland	0
Other (for example, where a literature review included studies based on a few different geographic areas, or where it is not clear in which part of the UK the study was conducted)	22

Methodology

There was a wide range of methodologies used in these studies. These included: literature reviews, focus groups, interviews (structured and semi structured), surveys, polls, and deliberative engagement.

Both primary and secondary research was included in this review.

Focus

Studies focused on the views of professionals, patients/members of the public, or both, as follows:

Group	Number
Professionals	24
Patients/members of the public	26
Both	14

Complete details of each study by type, geographical coverage and methodology can be found in the accompanying Excel database.

Thematic analysis of findings

Direct care

By direct care, we mean the day-to-day care of a patient, where a legitimate relationship exists between the patient and health professional. Information sharing takes place here amongst the healthcare professionals involved in the care of the patient. This is on the basis of consent, either implied consent, where it is reasonable to assume the patient would expect sharing to occur (for example at a ward handover), or express consent.

Topics arising in relation to direct care included:

- Who should be able to access medical records (which type of organisations and individuals)

- Patients' access to their own records

- The use of electronic records

- Confidentiality in care which is not related to medical records.

Who should be able to access medical records

Healthcare team and within the NHS

Some studies indicated that **sharing of information between individuals directly involved** in the care of a patient was considered acceptable for patients and members of the public. One study about electronic health records included 10 focus groups with primary healthcare staff. It found that information sharing within the boundaries of the NHS was seen as being unproblematic, with NHS Direct group members (those working for the NHS Direct, the national 24/7 health call centre) being particularly able to envision electronic health records facilitating new forms of data sharing (Jenkings, 2007).

Polling conducted by Ipsos MORI in June 2014 asked a broadly representative sample of members of the public from Great Britain whether they thought that all hospitals and GPs nationally should be able to access your health records for reasons directly relating to your care. 77% of respondents thought that it should happen and 12% thought that it should not.

The findings of studies such as the two mentioned immediately above (Jenkings and MORI) imply that a degree of data sharing between members of a patient's care team for the purpose of care delivery is considered acceptable by many individuals, as these studies find a good deal of support for more extensive sharing. However, we did not identify any studies that directly test this possibility.

It was sometimes **reassuring for patients** that their data was being collected, held and used by the NHS, as this was felt necessary to their care. This was the finding of a study involving interviews and focus groups with 50 members of the general public (Wellcome Trust, 2013).

However, some participants in the study were **concerned** about information sharing leading to future discrimination even within the NHS, such as having low priority on waiting lists or treatment refused until lifestyle changes were made (stopping smoking etc). In addition, some worried that if services within the NHS were privatised, then their confidential health data may be vulnerable to misuse by outside parties (Wellcome Trust, 2013).

For closely linked services, information sharing was sometimes seen as appropriate in order to **enable continuity of care**. However, patients sometimes limited this according to who it was shared with, and how it was shared. In a survey exploring patient attitudes to information sharing within sexual health services, 54 out of 90 respondents (60%) were happy for their sexual health information to be shared in some way. Of these 54 respondents, 30% would be happy with medical record sharing between sexual health clinics, and 58% would prefer this information to be shared locally rather than nationwide. Half of the respondents who were happy for their data to be shared agreed with the use of a shared database between all sexual health centres in the Trust (Stachow et al, 2012). A study of HIV patients also found that they were generally satisfied with the way that data sharing operates within the NHS (Azad, 2014).

The question of **data ownership** was important for some professionals, even within the direct care setting. In a study of 25 health professionals in Scotland, there was significant confusion about the definition of data ownership (and the associated legal responsibilities). Some participants referred to the 'data controller' role in the Data Protection Act, but views differed on whether this role was played by GPs or 'the NHS' (Hopf et al, 2013). Some felt the 'ownership' of data by GPs was problematic: *"GPs have this feeling […] that the data is their data and it doesn't belong to anybody else"* (participant quote in Hopf et al, 2013). Overall, there was a desire for greater clarity around data ownership.

A further point of contention was the extent to which **social care professionals** were seen to be a part of the healthcare team. The Caldicott Information Governance Review Panel concluded that for direct care of an individual, registered and regulated social workers must also be considered part of the care team (Caldicott et al, 2013). As such, the same legal framework of implied consent would be applicable. This review did not identify any studies explicitly addressing this issue from a patient or professional perspective.

Carers

The sharing of data about a person being cared for, with their carer, was a source of frustration for patients, carers and professionals in many contexts. A study involving interviews with 65 health and social care professionals found that participants themselves suggested that professionals may **sometimes withhold information from carers**, and hide behind 'confidentiality smokescreens' rather than encourage conversations between the carer and service user about information sharing (Gray et al, 2008). In line with the work of Rapaport, which argued that carers need certain information to enable them to provide effective support, participants in the study stressed the dangers of overstating the importance of confidentiality (Rapaport, in Gray et al, 2008). The study acknowledged prior work which had found carers suffering feelings of *"isolation, anxiety, depression, resentment of the*

service user, anger and fear" as a result of information being withheld from them (Gray et al, 2008). Professionals also identified occasions where there were conflicting interests between the needs of the service user and the needs of the carer.

In an NHS consultation with patients, service users and carers, similar frustration was expressed by respondents, for example where information was not shared with relatives of a person with dementia, undervaluing the informal but pivotal support carers were able to provide (NHS Future Forum, 2012).

However, Gray et al's study with professionals also identified occasions where they felt the sharing of information with a carer could be inappropriate, in situations where the balance of power in the relationship between the carer and service user was a cause for concern, such as a carer displaying controlling or restrictive behaviour:

> *"We do try and talk to carers, but sometimes carers are not exactly in the best interests of the patients. Sometimes, there's a conflict. You get the odd carer that really wants to control the person"* (Professional participant comment in Gray et al, 2008)

Overall there was a sense that providing safeguarding measures were in place, **extending information sharing to carers could have more benefits than risks**.

Administrative staff

In the context of **receiving test results**, patients had different understandings of the role of administrative staff. In a study which involved focus groups with 19 patients who had received laboratory test results, participants differed in their views on whether administrative staff accessing test results was acceptable (Cunningham et al, 2014). Some were unsure of who was involved in the handling of test results, but felt this should be solely the domain of clinical staff such as GPs and practice nurses, feeling that test results should be confidential between them and the relevant clinician involved. Thus the involvement of administrative staff was felt by some to be an **invasion of privacy**.

Many participants expected that administrative staff would have little involvement and would not be able to access medical records and test results: *"as a consequence, some participants were surprised when they received a letter or telephone call from an administrator alerting them to test results"* (Cunningham et al, 2014). Of particular concern to participants was the **potential for confidentiality breaches** in reporting test results (e.g. giving test results to relatives or leaving voicemail messages on home answering machines), as well as administrative staff being overheard on the phone, when in a busy reception area. The reception area/waiting room setting is discussed further in a subsequent section of this literature review on confidentiality in care (see p27).

However, in the same study, some participants acknowledged the role of administrative staff in assisting with the **large volumes of test results** in a GP practice, allowing the handling of test results to be more efficient.

Community pharmacy

Transferring information to community pharmacies for follow-on care after a hospital admission resulted in mixed views about confidentiality. A study involving focus groups with 28 members of the Welsh public found that participants acknowledged the benefit of community pharmacists being able to access health data through hospital discharge advice letters, particularly for **safe prescribing** (Rowlands et al, 2014). This focus on safe prescribing was echoed in a study involving a survey of 5000 members of the Scottish general public about non-medical prescribing. Here, some participants were similarly supportive about the need for access*:

> *"if they [pharmacists] had access to a patient's medical history, I would feel confident that they could prescribe medication" (participant quote in MacLure et al, 2013)*

An earlier round of the same study found that the public reported higher comfort levels with pharmacists and nurses, as compared with other healthcare professionals (Stewart et al, 2009). However, others disagreed with the idea of community pharmacists being able to prescribe at all, on the grounds of objecting to their access to medical notes (MacLure et al, 2013).

Views also differed on the **level of information** that should be shared. Most participants in the study, involving focus groups with 28 members of the Welsh public, wanted medication information to be shared*:

> *"I'd like them to have a picture of what I'm in hospital with, enough to make sure that the medication that is prescribed is safe and is appropriate for me and not much more I don't think" (participant quote in Rowlands et al, 2014)*

In the same study, participants remained concerned about the security and confidentiality of information, both during the transfer process and when stored within the pharmacy. In the 2009 survey of the Scottish public, respondents reported concerns about pharmacists having complete access to all drugs and diagnosis, especially where this was available without medical input (Stewart et al, 2009).

The community pharmacy setting is discussed further in a subsequent section on confidentiality in care (see p28).

Non-disclosure and 'informed consent'

There was some concern amongst professionals that patients' fears about the confidentiality of their data (and not understanding who could access it) might lead to the non-disclosure of health conditions. In a study involving focus groups with primary healthcare staff, participants felt that patients were increasingly protective of their confidentiality rights and would therefore not report all their health issues to their GP (Jenkings, 2007). On the other hand, a lack of understanding about who could access medical records was identified by primary health staff, in the same study, as a potential problem, whereby patients might give their consent without fully understanding what they are consenting to. It was stressed that a framework to achieve 'informed consent' was essential, including professional sanctions for abuse

(Jenkings, 2007). However, a study with users of a GP practice found that all respondents stated that they had never withheld any information they ought to have disclosed to their doctors as a result of worrying about who might access their computer medical record (Garcia-Sanchez, 2008).

The risks of not sharing information

Whilst there were many concerns about confidentiality breaches occurring as a result of sharing information, there was also a strong sense of the dangers of *not* sharing information where it was relevant. From an NHS consultation with patients, service users and carers, there was a clear message that **not sharing information has the potential to do more harm** than sharing it (NHS Future Forum, 2012).

For patients, information not being shared could be highly **inconvenient**, requiring them to repeat the same information many times during the treatment they received. A similar situation was reported even where consent had been given by patients: the NHS consultation found that there was an insufficient acknowledgement of the views of some patients who wished to safely share their data for the benefit of others (NHS Future Forum, 2012). Comments from voluntary and community sector organisations described reluctance by health and social care organisations to share relevant information with them which would assist in their care of individuals – even where these individuals had consented (NHS Future Forum, 2012). Similar views were expressed by an expert Review Panel in the Caldicott Information Governance Review, which cited examples of patients' attempts to become involved in decision making being thwarted by 'information governance rules' that ignored their express wishes. Examples of this included: blind patients being denied information in an accessible format (even where they had given explicit consent); having information sharing between health and social care blocked (even where the patient had signed a consent form); and patients being charged a fee for access to their records (Caldicott et al, 2013).

For professionals, it was often felt that information governance arrangements constitute an obstacle to the responsible sharing of data. Some professionals felt frustrated by governance arrangements around sharing information, when they felt it would be in the best interests of their patient to do so: "*the default answer of the Caldicott Guardian is no*" (Professional comment in NHS Future Forum, 2012). This consultation frequently heard the complaint from professionals that there is a reluctance to share information between **health and social care** services. This was corroborated by a study involving 10 focus groups with primary healthcare staff, which found a universal acknowledgement that information sharing and communication with social services tended to be inadequate, and that this had significant impacts on the care of individual patients (Jenkings, 2007). However, despite these risks, the same study found concerns remained about sharing information beyond the boundaries of the NHS, particularly where participants envisaged negative consequences for patients (e.g. implications for individuals' welfare benefits) and therefore the practice should be regulated for full accountability.

It was suggested that the current practice of professionals was affected by a **fear of getting it wrong**, with professionals not having an adequate awareness of the risks 'to safety, quality

and continuity of care' resulting from *not* sharing data (NHS Future Forum, 2012). The Caldicott Information Governance Review found that a 'culture of anxiety' permeates many health and social care organisations around information sharing, meaning that they become overly risk-averse due to fear of receiving fines for breaching data protection laws (Caldicott et al, 2013). This had an impact on the day-to-day operations of frontline staff. The review went on to suggest that '*this anxiety must be changed to trust'*, to facilitate sharing for an individual's direct care. The motto for better care services should be: '*To care appropriately, you must share appropriately'* (Caldicott et al, 2013).

Patients' access to their own medical records

Personal risk/benefit ratio

In using new self-access services to see their own medical records, patients identified both benefits and risks, and weighed these against one another. Several studies discussed patient access, including a study which included a survey with 583 patients and 99 professionals, which looked at patient access to complex chronic disease records on the Internet (Bartlett et al, 2012). It was found that some patients enrolled in the service 'Renal PatientView' despite significant prior concerns about security and confidentiality. The study referenced evidence from a theoretical examination of how patients would feel about online records that suggests "**concern reduces as disease burden rises**" (Bartlett et al, 2012).

Similarly, the **increased convenience** of self-access was an advantage for patients with long-term conditions. In a study of 5 'accelerator sites', who were piloting online services, there was an extremely positive response to record access, particularly from those with long term conditions who were in frequent contact with the practice (NHS England, 2014). In the same study, there was some concern that those who did not want to use, or did not have access to, electronic devices such as smartphones, PCs, laptops, tablets or internet connection would be denied the benefits and would 'miss out' (NHS England, 2014).

Another NHS consultation with service users, professionals and health organisations found that there was support from patient organisations for opening up access to medical records to **improve health literacy and self-management**, as long as the right protections and support for patients went alongside this (NHS Future Forum, 2012). While the consultation found that some GPs had concerns about information governance, the experience of GP practices who had led on record access, was one of the benefits clearly outweighing the risks.

Choice

Whilst there were mixed views from patients and professionals on patient self-access to medical records, there was strong consensus that **patients should be able to choose** how these are used, including choosing who else could access them (this is discussed further in a later section on knowing how records have been used). One article reviewed gave the perspective of one of the UK's leading proponents of patient controlled records, who argued

that they are a basic human right, comparing the arguments against patient access to '*attempts to deny people the right to vote*', and maintaining the importance of patients being able to control who gets access (Davies, 2012).

In the context of **accessing test results**, patients expressed a similar desire for choice over their method of access. In focus groups with 19 patients who had received laboratory test results, some participants considered that online access to their medical notes would be beneficial, as long as test results were interpreted by clinicians before they could be seen by patients (Cunningham et al, 2014). The ability to choose a method of accessing test results was valued by participants, who may hold different views about confidentiality and it was suggested that this could be decided at the end of the consultation with the clinician. Another study which used 5 case studies of 'accelerator sites' for online services, found a similar desire for choice amongst patients. They concluded that:

> *"this service should be available for any patients who wish it, but not required to be used by every patient as some patients don't want to use electronic systems"* *(NHS England, 2014)*

Young people's views on access

Young people (usually defined as up to the age of 18) expressed strong concerns about the potential for breaches of confidentiality from using self-access systems. A mixed-methods study of young people's views on electronic patient records found that young people had a strong desire to be in control of their own record (at least from the age of 14), affecting how acceptable they felt the system to be (Paterson and Grant, 2010). Participants required a system which allowed them access, a say in who else gets access (and why) and reassurance that certain groups would not be permitted access (including parents and potential employers). Young people in the study had significant concerns about breaches of privacy resulting from perceived technological weaknesses of the system and also user error, which could result in incorrect data, the loss of data or data falling into the wrong hands (Paterson and Grant, 2010). In some cases, this was linked to where records could be accessed. A nationwide study of 6000 members of the public found that although 97% of young people supported self-access to medical records, only 36% of young people backed home access (Whitehead, 2010). The study did not suggest why accessing records at home (as opposed to in-surgery 'booths') might be an issue for young people, although this was discussed in another study, detailed in the following section.

Implementing access

The practicalities of implementing access were also a concern for adult patients and professionals. A study of healthcare workers' attitudes to electronic health records found that participants were concerned about the locations where patients would be able to access their records, for example:

> *"GP practices and pharmacies would seem obvious, but what about public places like supermarkets or libraries?" (Jenkings, 2007)*

If access was at the patient's home, the healthcare workers in this study were concerned that confidentiality from other family members would not be practicable, citing the example of teenagers wanting to keep information from their parents in the case of accessing contraception. In addition, healthcare workers in this study worried that patients would become gatekeepers for access to their records, which could result in breaches of confidentiality if patients did not take precautions in their own access, or affect their care if healthcare professionals were denied access by patients (Jenkings, 2007). In Whitehead's nationwide study of 6000 members of the public (mentioned above), there were similar views on home access among adult patients. 92% of adults supported giving patients access to their records, with only 35% of adults supporting home access (Whitehead, 2010).

A changing culture in healthcare delivery

The increasing move to self-access, patient control and choice in healthcare can be seen as part of a changing culture in healthcare delivery, which some studies discussed. For example, a link can be drawn between access to medical records and the provision of copy letters (the practice of sending a copy of a letter concerning a patient's care, to the patient themselves, which is discussed in a subsequent section), with one study suggesting that copy letters are:

> *"part of a changing culture in healthcare delivery, with patient empowerment requiring the sharing of knowledge, allowing an individual more control over their own healthcare" (Baxter et al, 2008).*

In a 2014 study with 22 nurses and rheumatologists, similar benefits of increased knowledge and self-management were identified by home access to electronic medical records, but preconditions were also identified for the service to work, including optimal security considerations (confidentiality of data), a patient-accessible section of an existing record, no access to clinical notes and a lag time on the release of lab data (Taal, 2014).

However, concerns remained among professionals about how far this 'changing culture' would be beneficial to patients. There were differing opinions between patients and professionals about releasing information such as test results, as part of a self-access system. The study of nurses and rheumatologists found that when releasing complex data, such as bodily examinations, lab results and radiological images the opinions differed considerably, especially due to concerns about the interpretation of data by non-expert patients (Taal, 2014). However, one study which had piloted the patient viewing of unscreened, live test results, found that staff ratings of the system were as positive as those from patients, with 82% feeling that it had altered patient care for the better, 0% for the worse and 74% felt that it had improved patients' confidence in their care (Baxter et al, 2008).

Information for patients about how their records have been used

Some patients held strong views on the use of their records and expressed a desire to know about how they had been used. One nationwide study of 6000 members of the public, found that some patients identified an open set of audit trails as a possible alternative to a 'consent

to view system', so that patients could review all accesses to their information (Whitehead, 2010).

Similarly the Caldicott 2013 Information Governance Review recommended that patients should have access to a "*full and meaningful audit trail, which details anyone and everyone who has accessed an individual's electronic personal confidential data*", including when the patients accessed their own records (Caldicott, 2013).

Young people also wanted information about how their records would be used. A study of young people's views of electronic patient records (EPRs) found that young people wanted to be able to make informed decisions by being kept fully up to date about any developments to the EPR system, data security and safety, including who gets access to their data and for what purposes, in addition to what the implications might be for them (Paterson and Grant, 2010). It might be inferred from this study that until individuals had examples of what their data would be used for, they were unable to make a judgement on the acceptability of its use more generally.

The use of electronic medical records

Electronic medical records vs paper records

There were differing views on how electronic medical records compared to paper records evidenced in several studies, many of which related to confidentiality.

Where respondents were happy for information to be shared within their healthcare team, there were some clear **preferences for its format**. In a 2012 survey of 90 patients, 60% of respondents were happy for information to be shared. Of these, 9% preferred this to be in paper format, 37% electronic and 54% were happy with both (Stachow et al, 2012). In a study which conducted 22 interviews with health professionals around the electronic Palliative Care Summary (ePCS) in the out-of-hours (OOH) context, OOH staff considered the ePCS allowed them to be better informed in decision making and in carrying out home visits (Hall et al, 2012). GPs viewed the introduction of ePCSs to have benefits for in-hours structures of care, including advance care planning. No interviewee in this study expressed concern about confidentiality. Instead, the barriers raised related to the introduction of new technology including unfamiliarity with the process, limited time and information technology skills.

Enthusiasm for the potential benefits of electronic patient record systems was shared by participants in a 2010 nationwide survey of 6000 people which found that 57% of adults and 67% of young people were positive about electronic medical records (Whitehead, 2010). However, this was tempered by wariness around sharing identifiable personal data, especially with non-clinical staff. In the GP consultation context, a study involving a questionnaire to users of a semi-rural GP practice, found that respondents made a more positive judgement on computer records in all areas (safety, reliability, accuracy and accessibility). In particular, they considered information in computer records easier for their

GP to find (85% of respondents) and safer (55% of respondents) when directly compared to paper records (Garcia-Sanchez, 2008).

There was some concern about the overlap of using both systems (electronic and paper based). A study involving interviews with 25 professional stakeholders (including experts on ethics, data protection, pharmacovigilance, data linkage, legal issues and prescribing) in Scotland, found that data sharing between primary and secondary care in Scotland was already a reality, with the Emergency Care Summaries, but raised the issue of potential gaps in (electronic) data sharing due to the continued use of paper records (Hopf et al, 2013).

In the **pharmacy** context, a study into whether community pharmacies should receive electronic hospital discharge information found that the majority of study participants were broadly supportive of this, but expressed concerns over confidentiality issues, specifically the security of electronic transfer and the security and confidentiality of the information once received by the community pharmacy (Rowlands et al, 2014).

Data linking

Participants had differing views (and levels of understanding) about the process of data linking within electronic medical records. One study, which involved focus groups and interviews with 50 members of the public, found that 'health data linking seems more acceptable when at aggregate level rather than individual level; at an individual level there was the chance of the individual being blamed or 'told off' for something.' (Wellcome Trust, 2013). The report did not give an example of what an individual could be blamed for in this situation. The authors concluded that clarity, transparency and reassurance around data linkage were deemed necessary, with participants wanting to understand the potential benefits and risks to the confidentiality of their data (Wellcome Trust, 2013).

Legal and ethical framework

Whilst being able to access electronic records in emergency situations could be useful, there were issues identified about the **reliability of the shared data**. One study of the views of 113 NHS emergency service team members in Scotland about emergency care summaries (ECS), found that 81% of respondents rated the ECS as helpful or very helpful, but flagged up potential inaccuracies in the records, with 36% of respondents reporting that the medicines listed on the ECS, drawn from the GP practice system, did not match those reported by the patient (Morris et al, 2012).

This leads on to the legal and ethical framework of data protection, which focuses on the security (e.g. confidentiality/privacy) of records, but also the integrity of the record e.g. whether the information included within it is correct, which was discussed in one article relating to medical imaging and medical informatics (Duquenoy et al, 2008). Here, the content (data) of medical images was seen to constitute an electronic record and personal data in that they represent information concerning a person. They therefore had to be presented according to the following maxim: "*the correct information at the right time, to the right people*". If any of the three aspects were to be wrong e.g. 'the correct information at the

right time, to the *wrong* people', there would be an unwanted outcome (Duquenoy et al, 2008).

The 'marketing' of the system

Finally, there was some discussion which suggested that the technology and electronic nature of a system was less of a concern, but that concerns came from the way in which the system had been publicised (Anderson and Walport, 2010; Greenhalgh et al, 2013). One article compared the **experiences of the four UK countries** in implementing electronic summaries, finding that the different responses to the systems were only partly explained by differences in the technologies (Greenhalgh et al, 2013). At least as significant were the *"widely differing histories of the programmes and their different stakeholder alignments"* (Greenhalgh et al, 2013).

Ownership and awareness of any system used to hold medical information were also identified as crucial factors in reassuring all users about any risks to confidentiality. An article which set up a debate about summary care records between two authors, gave the perspective of an expert in security engineering:

> *"clinical systems bought by doctors generally work, while those bought by civil servants generally don't. Without clinical ownership of a system's specification and evolution, it is unlikely to remain fit for purpose" (Anderson, 2010).*

The level of public awareness of this system was seen as an issue for confidentiality, where the sharing of medical data requires informed consent: "*yet large numbers of patients are unaware that the record even exists*" (Anderson, 2010). The levels of awareness amongst the public will be discussed further in a later section. In addition, it was of particular concern that summary care records had multiple authors, introducing the possibility of different data classifications (Anderson, 2010).

Confidentiality in care, not related to medical records

Privacy and confidentiality concerns arose from a variety of different care settings, which did not necessarily relate to medical records, for example concerns about confidentiality breaches during interactions between patients and medical professionals.

The reception area

Several studies discussed confidentiality/privacy concerns in relation to the reception area of the GP practice or hospital. Here, it was difficult to protect patient confidentiality in face-to-face situations in busy reception areas, which lacked private spaces. One study, which made use of overt non-participatory observation to identify breaches of confidentiality in the waiting room of a GP practice, observed patients revealing confidential data (Scott et al, 2007). In half of these occasions, it was as a direct result of **staff requesting information**. Examples included reading out a full name and address, or asking for details of a condition. The authors found that patients were sometimes visibly uncomfortable in these situations, which

was not always addressed by the receptionist. It was found that the nursing staff thought they had breached confidentiality far less than the patients believed to be the case (Scott et al, 2007).

This was also the case where staff at reception delivered **test results over the phone**. One study found differences in the attitudes of professionals towards this task, with some practices preferring not to give out results in such situations because it was difficult to maintain privacy, particularly when very busy (Bowie et al, 2014). The study, which ran focus groups with 40 administrative staff working in primary care, found that some participants felt the decision was for the patient to take and that they would communicate test results if the patient asked for them (even when other people could hear).

From a patient perspective, many patients acknowledged the benefits of different communication methods but remained apprehensive about their use when receiving test results. One study ran focus groups with 19 patients, finding that whilst participants welcomed a range of communication methods (such as mobile telephones, answering machines, text messages, email and online access) for being informed that a result was available, they did not wish to have the actual result communicated to them in these ways due to confidentiality concerns (Cunningham et al, 2014). Participants perceived that mobile phones could improve confidentiality and were significantly better than home answering machines, on which other household members may listen to messages. This was mirrored by professionals' opinions in a study of administrative staff, where some participants described the potential for breaching confidentiality, by leaving voicemail messages on home telephones explaining who was calling and that it was about blood test results (Bowie et al, 2014).

The community pharmacy

Another setting where privacy issues arose was in a community pharmacy. Here, there was some discrepancy between the views of patients and pharmacists about confidentiality and privacy concerns. One study, which involved 16 focus groups and 14 interviews with patients and community pharmacists, found great difference in their knowledge about **private consulting areas** in pharmacies (Saramunee, 2014). Some patients did not even know that such rooms existed and therefore felt they were not often used, whilst some participants would be unwilling to engage in consultation discussion without privacy:

> *"If there was something not right with my body the first thing I would do is make an appointment with the doctor. I wouldn't go and talk to somebody over a pharmacy counter" (Participant comment, Saramunee, 2014).*

Confidentiality was also of concern in relation to the common practice of staff calling out patient's details for identification purposes (Saramunee, 2014). A survey of 5000 members of the Scottish public found similar concerns on the topic of non-medical prescribing (non-medical prescribers are experienced healthcare professionals trained and qualified to prescribe within their areas of competence e.g. may include suitably qualified nurses and pharmacists), with some participants worried about the potential lack of privacy and

confidentiality and others reassured to use such services only where private consultation rooms existed: "*Where this is the case I would have no concerns*" (MacLure et al, 2013). However, privacy considerations were sometimes weighed against the enhanced convenience of a pharmacy (Stewart et al, 2009). This navigation of the risk/benefit ratio is discussed further in the previous section on self-access to medical records.

Confidentiality concerns are reported to have a large effect on the **use of certain pharmacy services**. In a street survey of 150 members of the public, two of the most common factors influencing use of pharmacy alcohol services were: privacy (96%) and confidentiality (94%) (Krska and Mackridge, 2014). Most concerns related to fear of conversations being overheard, rather than disclosure of personal information by pharmacy staff, "*I would not like others to be able to hear what should be a private discussion. I would use this facility if there was a private room"* (ibid, 2014). In the same study, interviews with pharmacists also identified the open pharmacy environment as a possible limit to providing alcohol services. Interviews with 10 users of an alcohol screening pilot service found that none raised confidentiality as a concern, but most mentioned privacy. Several viewed screening at the counter as acceptable, but only when no other customers were present (ibid, 2014).

The school nurse

Within schools, confidentiality was an important factor in the use (or not) of school-based health services, although views could be contradictory. A systematic review of 19 studies focusing on the views of children and adolescents, about school-based and school-linked sexual health services, found contrasting viewpoints about the confidentiality of these services even within single school populations (Carroll et al, 2012). In approximately half of the studies in the review, young people reported that they used the service for the very reason that they felt their privacy was protected, however, anxiety about how confidential a service might be was raised as an issue in seven out of nineteen studies: young people feared disclosure of their visit, and the reason for it, to parents, teachers, their community or peers (ibid, 2012). Although this included US data as well as UK data, there were no substantial differences found between the results from the two countries.

Copy letters

The practice of sending a copy of a letter concerning a patient's care, to the patient themselves, was also a source of concern about confidentiality. A literature review of 28 studies relating to copy letters, found that there were concerns about the potential for breaches of confidentiality, if copy correspondence was sent to the wrong address, or opened by someone other than the patient (Baxter et al, 2008). In particular, there were complications in paediatric services due to decisions about parental access. Most studies highlighted the importance of consent issues, with the need for patients to be able to '**opt out**' as well as '**opt in**' to the receipt of copy correspondence, especially where there may be concerns regarding confidentiality. It was felt that a one-size-fits-all approach to copy letters did not work, due to individual differences between patients, the purpose of a consultation and the differing community or hospital contexts. These factors may all affect the decision of a patient about the risk and benefit of receiving such correspondence.

Issues of confidentiality around copy letters were also complicated in situations **where patients were dependent upon a carer**. One study (which ran a questionnaire and focus groups with service users with learning disabilities, their carers, and professionals), found that professionals were concerned about who would have access to the letter and how the patient securely stores the information (Hovey and Cheswick, 2009). Professionals felt it was important to gain agreement from the patient about which people could help them understand the content of the letter (with these individuals perhaps having to receive training about confidentiality or sign a confidentiality agreement). Whilst professionals acknowledged the benefits of copying letters to carers, they were also aware of the possible power imbalance in the relationship between a carer and a patient, which might make it inappropriate to copy letters to the carer. For informed consent to work, issues of confidentiality would have to be discussed with patients. In the same study, 19 service users (76%) said their carer received letters on their behalf and they were happy with this, whilst some users suggested they wanted to receive the letter first: "*we want to get that letter first and then give it to them so we're in control*" (ibid, 2009). Carers reported that copy letters would increase trust between them and the healthcare team. However, professionals felt that in the case of a service user's level of learning disability preventing them making decisions about who should receive letters, this should be done on a 'best interests' basis, involving multidisciplinary meetings of all involved in the individual's care.

Students observing

Although a less common concern in terms of confidentiality, the potential for breaches of confidentiality due to students observing consultations was also mentioned. One study found that 19% of a sample of 98 HIV patients associated the presence of students with potential breaches of confidentiality (Kothari et al, 2013).

Interpreters

This was not a common theme, but for individuals who required an interpreter to access healthcare services, issues of confidentiality arose. In a study involving semi-structured interviews with 11 adult asylum seekers and refugees in Barnet, London, participants expressed desire for easier access to GPs but wanted there to be continuity of care with any professional interpreter used (Bhatia and Wallace, 2007). This allowed them to gain trust in the confidentiality of their interpreter as well as build up a relationship with the GP. The study also found that in some situations, professional interpreters may not always be desired and individuals may prefer to use somebody they trust as an interpreter. Flexibility around these situations could prevent refugees and asylum seekers altering their 'help-seeking behaviour' (Bhatia and Wallace, 2007).

Secondary uses of data

This section covers uses of data that are not part of direct patient care, such as research or service improvement. We have chosen to refer to these uses as 'secondary uses' however the studies reviewed in this section did not always use this term themselves.

Some used the term 'additional uses' while others simply described the use without giving it a specific label.

This section is divided into the following headings:

- Types of organisation or professional that should have access to medical records

- Attitudes to particularly sensitive information

- How consent should be given for data to be used

- Use of data in the public interest.

Types of organisation or professional accessing medical records

Trust in different types of organisations

When considering whether it is acceptable for personal information to be accessed for secondary purposes, a number of studies found that members of the public placed a good deal of importance on who would be accessing the data. Many of these support the idea that there is a **hierarchy of trust**, with **NHS** organisations or staff being considered most trustworthy, while members of **private organisations and pharmaceutical companies** are considered least appropriate to access data. However, the exact details of this hierarchy differ a little between studies.

From a focus group and literature review conducted by, Hill et al (2013) it was found that in some cases patients saw information about the *user* of the data as more important than the *intended use* in determining whether to offer consent. This observation was supported by their focus group:

> *"Research undertaken by the NHS was seen as acceptable and for public good, whereas pharmaceutical companies who gained financially from the altruistic sharing of records were seen as less acceptable. University researchers were considered to be somewhere in the middle, and it was the funder of the research and their financial gain that was considered when making a judgement about the acceptability of the research."* Hill et al (2013)

Grant et al (2013) came to similar conclusions based on their research to investigate opinion around creating a national (Scottish) research register to enable researchers to recruit patients to research projects directly, rather than approaching them via medical professionals who care for them. They found that the NHS and universities were the preferred data holders for members of the public, although they did not replicate Hill et al's finding that the NHS is trusted more than universities. They did however repeat the finding that many members of the public have a distrust of pharmaceutical companies in this context, with the caveat that a few members of the public thought that their involvement would probably be necessary due to the funding that they are able to bring. Also on the use of data by private organisations, Rushmer et al (2011) conducted a study investigating the recording of primary care

consultations for research purposes. They found members of the public to be strongly against the data being used in a way that benefits private insurance or drug companies. Similarly, Stevenson et al (2013) conducted research with a sample of 50 patients, and found that access to data by private sector organisations was a particular concern for many patients.

Closely mirroring this hierarchy, a poll of 2019 members of the public between the ages of 16-75 (using quota sampling) found that trust was highest for **"your GP surgery" followed by "the NHS".** "Academic researchers and universities" came in fourth place after "the police" (Ipsos MORI, 2014). The options of private healthcare or pharmaceutical organisations were not included in the poll, so it is not possible to make a direct comparison with levels of trust in these type of organisations.

The Ipsos MORI poll also asked whether members of the public would support or oppose anonymised data sharing outside of the government. While none of the questions in this section of the poll related explicitly to health research, the NHS or pharmaceutical organisations, the findings nevertheless are of some contextual interest. Support was greatest for sharing data with **university researchers to help conduct government funded research** (50% support, 17% oppose). This supports the observation made above that university researchers are relatively highly trusted. However this was only slightly ahead of the levels of support for sharing data with researchers in universities to help them conduct research for companies or industry (45% support, 23% oppose). Comparing this finding with Rushmer et al and Stevenson et al's studies that indicate some opposition to use by private organisations (discussed above), it might tentatively be concluded that the public have different opinions in relation to health data than to data in general.

 Support was greatest for sharing data with **university researchers to help conduct government funded research** (50% support, 17% oppose), however this was only slightly ahead of the levels of support for sharing data with researchers in universities to help the conduct research for companies or industry (45% support, 23% oppose).

This poll also identified trust in organisations *to use your data* was typically rated lower than trust in those organisations more generally. The NHS and academic researchers were two types of organisation which had a particularly large "trust in data deficit". Nevertheless, as the statistics above show, these organisations were still among the most trusted to use data (Ipsos MORI, 2014).

Trust in different professions

As well as trust in different organisations, the issue of trust in **different job roles** provided some interesting findings. Participants in a deliberative study discussed individual job roles of professionals handling data. While their findings broadly reflect those detailed above, it is of

interest that GP receptionists were identified as being less trusted professionals, despite their NHS background (Armstrong et al, 2006[3]).

Views of young people

There is evidence to suggest that young people have broadly similar opinions on this issue to adults, particularly around distrusting pharmaceutical companies or private organisations. Paterson (2010) found that when the aim was to *"develop better medicines, improve health and save lives"*, young people had the greatest trust in medical researchers accessing their electronic patient records, while *"some reservations, concerns and outright objections were raised over access being given to 'private research' or pharmaceutical companies"* (Paterson, 2010). It should be noted that these findings came after young people had been given information about electronic patient records. The authors found that levels of initial understanding on this topic were low: before the main information giving part of the study, *"over 60% of young people agreed or strongly agreed that they did not understand how EPRs could be beneficial to health and medical research".*

On a related note, one study asked whether more people could have direct access to medical records in order to facilitate the recruitment of participants for clinical trials. Whitehead (2010) found that 34% of adults and 10% of young people were in favour of this. Because this question was asked in quite an open way, it is not known how these levels of support might change based on the specifics of a particular research project.

Attitudes to particularly sensitive information

What types of information are considered to be most sensitive?

Many members of the public and professionals consider some types of data that might be used for medical research to be more sensitive than others.

While it is clear that some types of information are considered to be more sensitive than others, there was not always much detail on *which* types of information are more sensitive, or *why* these types of information were more sensitive. One study by Armstrong et al (2006) did address this to some extent. They conducted research into public attitudes about research governance, involving members of the public as well as patients with experience of research studies. They found that information that was categorised as sensitive was always seen as personal, and included potentially stigmatising conditions such as **mental health** problems as well as **sexual health** data, and information on **sexual activities**. CM Insight (2013) and Stevenson et al (2013) also found mental health data to be particularly sensitive, but provided less insight into why members of the public felt this to be the case.

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[3] While this study was published outside of the inclusion criteria (papers from 2007 onwards), it was not mentioned in the previous literature review that was conducted for the GMC on this topic in 2007, and was felt to be of sufficient relevance to merit inclusion.

One area of concern for patients was about the types of information which would be included in health registers. A study which explored public and professional views on the acceptability of setting up a health register in Scotland to allow direct recruitment of participants to medical research trials found that participants did not feel a register would be appropriate for studies about 'more sensitive' issues, although again the exact definition of what counts as 'more sensitive' was not clearly defined. While the authors do not provide an overall analysis of topics discussed, the following quote from a patient involved in this study suggests that issues such as mental health and sexual health or activity data were once again included in the list of 'more sensitive' issues:

> *"Yeah and what would be, the factual information that goes into this Register, you know in terms of actually the factual information that goes there, for instance thinking about mental health and thinking about, you know things, or disclosure or sexual abuse or, all these kind of things..."* Patient participant (Grant et al 2013).

The lack of a firm definition of what counts as 'more sensitive' is explicitly discussed by Wellcome Trust (2013). This study investigated how members of the public categorise different pieces of information. They asked focus group participants to cluster various different types of data according to any criteria that they liked. This yielded a variety of clusters, suggesting that members of the public do not share a rigid definition of the boundaries between data types. These categories might instead be understood to be fluid or overlapping. In particular they found that understandings of what constitutes 'personal' data varied. This exercise revealed the following to be important considerations about personal data:

- The degree of seriousness/risk if the data were misused or stolen

- The perceived level of security of the data

- Anonymous vs. personally identifiable data

- Recognition of the value of data collection (to self vs. to others) vs. unclear benefit

- Free choice to create data vs. enforced/necessary existence of the data

- Government and non-government data (Wellcome Trust 2013).

Armstrong et al's study (2006) gives some indication of how principles like these are applied in a practical context. They found that bodily tissues and waste material were not necessarily considered to be personal, but could become so if the material revealed information about the individual's health or health risks, or if these could be linked back to the person. This study used a deliberative methodology, meaning that the 89 public participants were given plenty of information and time to develop a reasoned opinion. Therefore while these views may well not be representative of the gut reactions of the general public, they do give a good indication of what members of the public might think once they have the chance to become well informed about the issue.

A number of opinion pieces (e.g. Shaw, 2014) echo the claim that certain conditions such as mental health or sexual health are considered more sensitive than others, however these typically do not provide evidence to support this claim.

In discussions about electronic patient records (EPRs) with a (non-representative) sample of 50 patients, Stevenson et al (2013) found that there were differences between patients who work in healthcare or research, and patients who do not. They found that patients who work in healthcare were more concerned about health data than other types of data about themselves, but that patients who do not work in healthcare were equally concerned about both types of data. The other studies in this review do not actively support or contradict this observation. This may be because this is the only study that explicitly compared these two patient groups.

How consent to use data should be given

Anonymised vs identifiable data

The evidence reviewed suggests that patients and members of the public want to know when their data will be used for research purposes, and want to have control over how it will be used. However if the data has been anonymised, there are fewer concerns.

One study by the New Economics Foundation (NEF) and the Centre for Science Education at Sheffield Hallam University (2010) found that 79% of adults and 74% of young people in the non-representative sample thought that consent was required for sharing *identifiable* data with researchers. They found that while fewer members of the public were concerned about consent for sharing *anonymised* data, this was still an issue for many people. In the case of anonymised data, 34% of adults and 56% of young people thought that consent would be needed. In this study, these questions were asked in the context of information in electronic medical records being used for research purposes.

The finding that about a third of adults think consent would be needed to use anonymised patient data is loosely supported by the Department of Health's 'Summary of responses to the consultation on the additional uses of patient data' (2009). Participants in a questionnaire element of the study were asked whether data from a patient's record could be used for 'additional' purposes without consent if anonymised. 30% of the general public thought that this would be acceptable, however only a quarter of those who identified themselves as 'patients who frequently use the NHS' did.

As discussed below, patients and members of the public feel differently about consent depending on what secondary uses the data is being used for. One possible reason why the DoH report finds lower levels of support than the NEF report may be because NEF specified that the secondary use is 'research' while DoH did not.

Control over future uses of data

Rushmer (2011) asked similar questions in a different context, this time looking at the need for consent in the recording of primary care consultations so that these can be analysed to

try to improve general practice. In this context, Rushmer found that a very high proportion of patients as well as professionals thought that consent was needed. This study also explored views about **the level of control that patients should have over their data** both before and after giving consent. They found that the public wanted the additional safeguard of a 'cooling off' period of a week where GPs or patients could ask for the recording to be wiped from the database. Members of the public also thought that patients should be able to choose whether recordings and/or transcripts will be available to future researchers, or just used for one specific research project (Rushmer, 2011).

The idea that patients should be able to give consent for data to be used for all future studies is something which divides opinion among professionals. On the one hand, it is argued that:

> *"Patients should have the right to 'donate' their data and tissues to health research. Patient consent for use of data or tissue for health research should be a fully informed, withdrawable, more or less broad, 'one-time' process, which truly implements the patients' rights, rather than creating burdensome, possibly harmful consequences to the patients' community."* (Casali et al, 2014)

This is in response to proposed EU regulations which will require consent for every single use of patient data. The authors argue that this would limit research progress and be impractical, and claim that this response represents the views of a number of professional organisations. While it is predominantly an opinion piece, this paper claims to be endorsed by the European Oncology Community.

On the other hand a number of professionals argue that from a legal or ethical perspective it is not appropriate to seek consent to use data for studies that have not yet been designed. This literature review has typically excluded articles of this sort because they give one person's opinion rather than identifying what wider members of the professional community think, however it is worth noting that these do exist.

Views on different processes for obtaining consent (e.g. opt in vs opt out)

Despite consensus that consent is needed in many situations, there is a wide range of views on the processes around how consent should be sought.

In Hill et al's study on public awareness and acceptance of consent to use existing data in health research (2013), a review of literature found that there was no consensus on a preferred model of consent either within or across studies.

One consideration is whether consent should be **opt in or opt out.** Participants in one all-male focus group (Hill et al, 2013) said that an opt out consent process would be acceptable as it still allowed them the chance to refuse, but may have less impact on the validity of research. This position was informed by a discussion about some of the challenges faced by researchers, so presents an evolving opinion based on greater understanding. Data from other studies suggests that this finding may not be representative of the whole population. Stevenson et al's 2013 study found that despite most patients not having opted out from the Health Research Support Service (HRSS), many expressed concerns about whether people really understood the 'opt out'. The study highlighted the importance patients and staff place

on making an active choice about participation rather than assuming that people who do not 'opt out' have given their consent by proxy (Stevenson et al, 2013). When discussing the same issues with general practice staff, they found more mixed opinions. Some supported an opt out model, suggesting it was likely to increase sample sizes and representativeness. Others recognised the benefits, however they were unhappy about the use of an 'opt out' and were concerned about possible future repercussions if patients believed their data had been used without their explicit consent, particularly as it was not possible to be sure patients had received and understood information about the HRSS (Stevenson et al, 2013).

Who should approach patients for consent?

Grant et al (2013 106) identified a strong preference amongst patients for consent to be sought via a patient's GP. This was in the context of asking patients whether they would be willing to join a register to allow direct researcher approaches to recruit patients into medical trials (without the researchers necessarily having to go via the GP). The study was conducted in Scotland, and this finding was based on 37 patients involved in focus groups.

Different types of consent for different end uses of data

There is evidence that the views of both patients and members of the public are influenced by the purpose for which data is to be used. Some participants in an all-male focus group run by Hill et al (2013, 176) considered the balance of obtaining consent against the public benefit incurred by unrestricted research, and felt that it might sometimes be appropriate not to ask for prior consent so long as not asking for consent helped to increase the public good (for example by reducing sample bias in important research). Rushmer (2011) found that members of the public wanted a written agreement from third parties stating that they will not use information in a way that could cause distress as part of the consent process, but did not require this addition when third parties were not involved.

Use of data in the public interest

In this section of the review, we use 'public interest uses' to refer to secondary uses of healthcare data which provide a public good other than medical care (as opposed to in the earlier section about patients accessing their own records, in which we discussed the balancing of benefits of sharing data to themselves against the risks to confidentiality that it entails). Public interest uses of data discussed in the literature included safeguarding children and preventing dangerous or illegal behaviour. It is interesting to note that these uses all relate to public protection: while this is clearly one of the more prominent public interest uses, we were not able to find studies which discussed attitudes towards other plausible public interest uses such as using data for educational purposes.

Safeguarding children

Professionals are sometimes placed in a situation where they have confidential information about a patient, the sharing of which would help protect either the patient or others. Under

current legal and practice guidelines, professionals are sometimes allowed to break confidentiality in these situations.

The initial database searches identified quite a few articles addressing legal or ethical arguments on this topic, but many were not explicitly evidence based and therefore have not been included. This section of the review only focuses on articles which did give some indication of the opinions of professionals, members of the public or patients.

A report by Tompsett et al. (2010) explores GPs' understanding of their role in safeguarding children. It also explores what other professionals, patients and parents think about their role. This study offered many useful insights. It included a survey conducted with 96 GPs, which produced a number of interesting findings:

- Just under half of the GPs (47) indicated that confidentiality was a constraint when dealing with a child at risk. The study reports that GPs were concerned that seeking consent to share information could have a detrimental effect on their ongoing relationship with the parent/family.

- In open responses to the survey, GPs discussed the relationship with a child's parent or family quite a lot, but very rarely mentioned impacts on the relationship that they have with the child. For example, in open questions, 30 of the 96 GPs reported difficulties in discussing concerns about a child's welfare with the child's parents. One of the issues that they identified was a desire to maintain the quality of their relationship with patients, including by maintaining confidentiality.

- 15 GPs said it was difficult to decide on the threshold for the involvement of others and feared making the wrong diagnosis of child abuse. Ten GPs lacked confidence in their assessment of risk, and three felt it was difficult to get advice without making a referral.

- Despite many GPs thinking confidentiality concerns can be a constraint, fewer thought that they had led to actual harm to a child. When asked 'Can you think of an example where confidentiality or conflict of interest issues may have put a child at risk or resulted in harm to a child?', 20 said yes and 55 said no, and the remaining 21 gave no response or selected not applicable.

- In the context of requests for information for safeguarding, confidentiality related dilemmas are not an everyday concern for GPs. When asked 'How often in the last 12months have you experienced a dilemma in terms of confidentiality?' 55 said none, 35 said 1-3 times, 2 said 4-6 times, and none responded with a higher figure than this. 21 gave no response or selected not applicable.

- The survey also found that around a quarter of the GPs stated they had no problem sharing information, if it was in the interests of a child's welfare or they considered it was 'proportionate' to the issue and on a need to know basis.

> *"Confidentiality can be breached but only with good reason. Is the reason under question good enough?"* GP participant, Tompsett et al. (2010)

The same study also included 14 detailed interviews with GPs. Nine of these GPs said that they would often speak to other health professionals (especially the health visitor) if they had any concerns about a child's welfare. They said that they did not see this as a breach of confidentiality because they thought they had implicit consent to discuss issues with their health colleagues (Tompsett et al, 2010).

Three focus groups were also conducted, one with young people, one with parents and carers and one with members of an ethnic minority organisation. Participants in all three focus groups said that while they typically expected a GP to keep confidentiality, they respected the need to break confidentiality if there was a risk of somebody becoming harmed otherwise. The parents' and young people's focus groups felt that it would be best to try to resolve the issue with a health visitor first before involving external organisations such as social services.

Finally, the report also engaged with key stakeholders and a 'Delphi panel' made up of experts in the field. The Delphi panel emphasized the importance of forewarning parents/families as to the limits of confidentiality and the potential need for referral to other agencies and, along with key stakeholders, acknowledged that gaining consent to information sharing was the best way to achieve cooperation and work in partnership with families to safeguard children.

Preventing dangerous or illegal behaviour

Medical professionals working in the penal system appear to prioritise the public interest and safeguarding over the confidentiality or interest of individual patients. Henson and Riordan (2012) conducted a study investigating professional attitudes about Multi-Agency Public Protection Arrangements (MAPPA) for dangerous offenders. These arrangements involve professionals sharing information about offenders so that authorities can work together to minimise any risk that they may pose to others. In a survey of doctors, nurses and social workers who were involved with MAPPA, 89% of respondents agreed that *"confidentiality is secondary to risk management in the MAPPA arena".* In addition, 65% per cent of doctors, 41% of nurses and 46% of social workers did not agree that confidential medical information should remain confidential in relation to the MAPPA process. The authors of this study argue that these findings are concerning as they indicate that in practice many professionals may not be following the MAPPA Guidance that any information shared should be 'proportionate and necessary' for the management of the risk.

Professional views around the MAPPA process may not be indicative of views in all situations relating to potentially dangerous or criminal activity. Hartry (2007) discussed whether ophthalmic nurses should refer patients to the Driver and Vehicle Licencing Authority if they know their eyesight does not meet the minimum standards to drive, and the patient refuses to stop driving voluntarily. While this study primarily refers to legal and ethical issues, which are not the subject of this review, it does refer to the way in which guidance from various authorities is sometimes applied. Hartry claims that current guidance errs on the side of disclosure in these situations (suggesting consistency in professional attitudes around MAPPA as discussed above), however guidance is not always consistent. One of the main

conclusions of this study is that clearer, more consistent guidance on this issue would be of value to ophthalmic nurses.

Crosscutting themes

This section includes findings that relate to both primary and secondary uses of data. These are:

* attitudes towards care.data (a recent important development around which many views on confidentiality have emerged)

* levels of understanding and knowledge about the confidentiality of data (an important factor underpinning attitudes towards it).

Opinions about care.data

The care.data project is intended to provide a centralised database linking general practice patient records to patient hospital records on a national scale. Large scale public communications about the project began in early 2014, however its implementation has subsequently been delayed. Because confidentiality is an important topic in the debate around this programme, opinions about this programme can be useful to help understand wider professional, public and patient opinions about confidentiality.

To get improved coverage on this topic, and in the absence of better quality data, we have included some less rigorous data sources in this section of the literature review, including surveys which do not clearly state their methodology.

Public views on care.data

The significant (and often emotive) media attention given to the care.data programme is likely to have led to rapidly changing public perceptions. The following two polls present snapshots of public opinion on the issue: for this reason their month of publication has also been included.

A YouGov poll (February 2014) asked 1454 English respondents whether they are concerned about care.data. 41% were concerned; 50% were not concerned. Those 603 respondents who were concerned were asked to choose from a list of options, which they were most concerned about. 28% were most concerned about "which organisations will be able to access personal medical information", 26% were most concerned about "information that identifies patients may not be kept secure", 25% were most concerned about "information will be used for purposes other than direct patient care", and 15% were most concerned about "how or what the medical information will be used for". The remaining 7% chose other or don't know.

An opinion poll by ComRes (March 2014) asked 2049 members of the public some questions about care.data. This sample is weighted to be representative of the UK population. When the question was asked, 34% supported the creation of care.data, 27% opposed and 39%

chose didn't know. They were also asked "How concerned or otherwise would you be about partly anonymised personal information being passed on - via 'care.data' - to organisations outside the NHS for commercial purposes?" 66% were very concerned or fairly concerned; 23% were not very or not at all concerned.

No detailed academic studies of public opinion around care.data were found as part of this review. In an editorial briefing in the British Medical Journal (BMJ), Hoeksma (February 2014) asserts that none have yet been published.

Professional views on care.data

There appears to be a similar lack of robust academic literature about professional views on care.data. However, this literature review did identify some articles which indicate that many medical professionals, especially GPs, are or have been opposed to the implementation of care.data.

A survey conducted in January 2014 (Praities, 2014)) found that of 'nearly 400' GPs surveyed, 41% said they intended to personally opt-out, 43% said they would not opt-out and 16% were undecided. These statistics should be viewed as indicative only as participants were self-selecting.

In a news article for the BMJ, Moberly (2014) reported that delegates at the British Medical Association's (BMA) annual representative meeting voted in favour of a motion stating that care.data "*should not continue in its present form*" and "*should be an opt-in system rather an opt-out one*." Key issues cited as leading to this position were that the system lacks confidentiality and may lead to a loss of trust between GPs and patients. While the motion was carried by the group as a whole, Moberly also reports that some attendees disagreed. For example, one argument was that moving to an opt-in consent process would exclude certain vulnerable groups. Other medical bodies are also known to have expressed opposition to the implementation the scheme in its proposed format, including the Royal College of General Practitioners (Torjesen 2014).

Levels of knowledge and understanding about confidentiality of data

This section discusses levels of knowledge and understanding about data confidentiality issues within healthcare, from patient and professional perspectives. This has its own section because it is an important factor *underpinning* attitudes towards confidentiality, and in addition it relates to both direct care and to secondary uses of data.

Direct care

Amongst patients, there were many examples of lack of understanding about how personal data was used and who had access to it. This could result in fears and concerns about confidentiality.

In the course of their direct care, some participants in a series of focus groups (patients who had received laboratory test results) in Scotland demonstrated a lack of awareness of the processes involved in the handling of their test results, including which different staff groups had access to the results (Cunningham et al, 2014).

However, patients sometimes overestimated the extent to which others had access to their data. The Caldicott 2013 Information Governance Review found that patients and public generally assumed there was a greater level of sharing to support direct care than was actually happening (Caldicott, 2013). On the other hand, the same review showed a discrepancy in the acceptability of information shared within an organisation, with some members of the public considering that "*sharing information with an individual social worker would be acceptable, but sharing with the whole local authority employing the social worker would not*" (Caldicott, 2013).

Patients generally showed a good understanding of confidentiality itself. One survey of users of a sexual health clinic found that the 90 respondents (92% of the total) demonstrated a good understanding of the definition of confidentiality (Stachow et al, 2012). However, one survey of HIV patients found there was a demand to know more about individual rights associated with data processes (Azad and Perry, 2014).

Patients also had an accurate understanding of their GP's computer use during consultations, with one survey of users of a semi-rural GP practice finding that the two most commonly perceived computer uses according to respondents were 'medical record keeping and prescribing' (Garcia-Sanchez, 2008).

Understanding of research uses

Patients did not always have a good understanding of how their data may be used in research and the sort of research which was taking place. A study which involved focus groups with 50 members of the public, found that there was some awareness of research into new treatments and cures (perceived as beneficial) but less understanding about *"ongoing collection of data to establish norms"* (Wellcome Trust, 2013). In addition, there was vague understanding of research and associated vague, low-level fears about their data being used, *"related to anonymity being lost and possible unwanted media attention"* (Wellcome Trust, 2013). This was corroborated by a study of more than 2100 members of the public, which found low public awareness of the use of personal health information for the purposes of medical research (Medical Research Council, 2007). The respondents tended to know that medical research happens, but did not know who was doing research or why. This study also found relatively low levels of understanding of the phrase 'personal health information', with 34% of respondents unable to give an example (Medical Research Council, 2007).

Similar findings were found in focus groups with 19 members of the public, where participants asked many questions about how research was carried out, suggesting a lack of understanding of how their data could currently be used. This lack of understanding could result in concern about the security of their data:

> *"How do we know that you just don't go to the hospital and say "can I have a look at these records" and we don't know anything about it?"* (Participant comment, Hill et al, 2013).

The same study also included a literature review, which produced similar findings. It was found that that 11 of the 13 studies noted the lack of current knowledge that many participants had about how their medical data may be used for research and the existing safeguards to protect their data (Hill et al, 2013).

Understanding of information sharing

In terms of medical data being shared more widely, there were also some discrepancies between actual information sharing and who people thought had access. In focus groups with 37 patients in Scotland, there was an assumption that the electronic transfer of information within the NHS was already taking place *"I'm totally surprised how if you move from one practice to another your records can't now electronically move easily."* (Grant et al, 2013). Some participants also assumed politicians had access to their health data. In addition, a large-scale survey of 2,019 members of the public found that around one in three respondents think health records are being shared with private companies/academics, although this is not the case (Royal Statistical Society/Ipsos MORI, 2013).

Care.data and other centralised data systems

Both patients and professionals expressed doubts over their understanding of systems such as care.data. One article referenced a YouGov survey of more than 1,400 people, commissioned by the Medical Protection Society, found that two thirds (67%) did not recall receiving the leaflet and that 45% did not understand care.data from what they had read or heard (YouGov poll referenced in Torjesen, 2014). The article also referenced a Medical Protection Society survey of more than 600 GPs in which '80% said they did not believe that they had a good understanding of how patient data would be used in the care.data system' (Medical Protection Society survey referenced in Torjesen, 2014).

Another system trialled by a study was the Health Research Support Service. The study noted that patients appeared to have incomplete understanding of the processes involved despite having received the information pack, and the patient information pack was 'roundly criticized' by both patients and staff (Stevenson et al, 2013). This suggests that there is a requirement for high quality information and a great deal of publicity for similar systems to be understood and accepted.

Professional practice

Professionals also felt some confusion about elements of confidentiality protocols in their daily practice. In interviews with 65 health and social care professionals, there was a desire for more training around the rights of carers, with professionals feeling *"uncertain about balancing the confidentiality of the service user with an assessment of the carer's need".* Professionals found policy, law and practice ambiguous about how far to involve carers in information sharing and whether an assessment of carer need would contravene their duty of confidentiality to the service user (Gray et al, 2008). The Caldicott 2013 Information

Governance Review found there was limited awareness of the boundaries of implied consent both among health and social care professionals who rely on it and other staff who feel it may apply to their practices, and concluded that 'the mandatory training is often a 'tick-box exercise'', calling for more training on confidentiality issues (Caldicott, 2013).

In other cases, professionals' understanding of confidentiality could be more theoretical than practical. A literature review of resources about the implementation of policy and the role of health informaticians, found that *"the awareness and understanding of data protection legislation and procedure in both health informaticians and other health professions is highly variable"* (de Lusignan et al, 2007). Whilst staff felt they had an understanding of data protection principles, they were not always clear about the correct course of action to take when presented with a scenario. In addition the authors found that professionals also differed in their views on their own personal responsibility for data security, *"even though personal responsibility is often highlighted in their job descriptions"* (de Lusignan et al, 2007).

Differences between staff knowledge and understanding of confidentiality and data protection could perhaps be explained by different levels of seniority. A study of junior medical staff found that although 58% stated they were aware of the requirements of the Data Protection Act as applied to their duties, the majority of respondents were not aware of the Caldicott Principles (65%) or the role of the Caldicott Guardian (86%) (Titchener et al, 2013). Another study also revealed differences in understanding and practice among UK-employed occupational physicians with regard to the Access to Medical Reports Act and the Data Protection Act (Batty et al, 2009). These differed according to the working patterns, qualifications and length of practice of respondents. Respondents who worked part time, had a Diploma of Occupational Medicine and those who had been qualified the longest in medicine perhaps had a greater need for training and refresher courses.

Conclusions

This review identified a good range of evidence in relation to attitudes to confidentiality of healthcare data. The view of patients/the public and of health professionals were well-covered. The majority of literature reviewed had a firm evidence base. A proportion of the literature did cover the whole UK, but overall, coverage of the four UK nations was uneven, with very little evidence focusing specifically on Wales or Northern Ireland, though Scotland was better represented. Therefore our ability to compare attitudes in the four nations is limited. The key findings of the review are summarised here.

Direct care

In general, the literature reviewed found that **sharing information between individuals in a patient's healthcare team** was felt to be acceptable, in line with the concept of 'assumed' or 'implied' consent. Patients and professionals acknowledged the benefits to the patient's care as a result (e.g. continuity of care). Opinions differed as to whether social care professionals should be considered part of the healthcare team.

When it came to **sharing information with others** (outside the healthcare team), opinions differed more strongly. Professionals acknowledged the difficulties in sharing information about a patient with carers, although overall this was seen to have more benefits than risks. Patients were less positive about administrative staff having access to medical information, such as test results, although they acknowledged that their involvement made the service more efficient. They also found the sharing of information with community pharmacies of limited acceptability: whilst some acknowledged the benefits for safe prescribing, most stressed the importance of sharing only limited information in the pharmacy setting.

Many professionals stressed the **risks of not sharing data**, which was also a main conclusion of the Caldicott Information Governance Review which described a 'culture of anxiety' around information sharing within health and social care. There were similar concerns by some patients, based on the increased inconvenience of information not being shared, even where they had given consent.

The evidence suggested that for patients, concerns about confidentiality were weighed against benefits when it came to **self-access to medical records**. Overall, it was felt that those who wanted 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. This included for young people, who wanted to be able to choose who else could access their records and to be given information about who had accessed them and why. Professionals had concerns about confidentiality of these systems in relation to where they could be accessed (e.g. in-surgery or at home). The use of self-access systems was seen to be part of a changing culture in healthcare delivery.

There was enthusiasm identified in the evidence for the potential benefits of **electronic medical records**, amongst both patients and professionals, both of whom 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.

The evidence discussed **healthcare settings where confidentiality concerns arose aside from those specific to medical records**. These included the reception area of a GP practice, in a community pharmacy, with a school nurse, the use of interpreters, the presence of students observing and the practice of sending copy letters. In many of these situations, confidentiality was felt to be the main reason for use or non-use of these services.

Secondary uses of data

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 have very low levels of trust. There is also a hierarchy of trust for different professionals: GPs are very trusted, administrative staff less so.

Members of the public (unsurprisingly) are less worried about the **use of anonymised data** than identifiable data.

The specific **type of secondary purpose** that data is being used for is important: members of the public are happier for data to be used for public interest purposes, but may be more wary about commercial uses of data.

In terms of the **types of information considered to be most sensitive**, these were assumed by many studies to be mental health and sexual health, because they are potentially stigmatising. But only some provide solid data to back this up.

The evidence reviewed highlighted the key point that **different consent processes need to be used in different situations**. Patients and professionals often seem to have strong opinions on the opt in/opt out debate, however there do not seem to be very consistent trends in this and views are context-dependent. A few studies found doctors and medical researchers were in general more "pro data sharing" than members of the public.

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. A few points emerged (each based on one study). Firstly 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. Secondly, on the public interest question of preventing dangerous or illegal behaviour, health professionals do not see confidentiality as an important consideration when sharing data about a dangerous offender.

There were several polls on **views of care.data**, indicating that a large proportion of the public (almost half) have concerns about it. Two of the worries were around which

organisations might be able to access to data, and how securely data would be held in care.data. Many GPs are also very concerned about care.data.

Many studies found discrepancies between patients' perceptions of and the reality of confidentiality risks. There was also a **lack of understanding** of how certain procedures worked in healthcare settings, such as getting test results or participation in medical research, which could lead to confidentiality concerns or, in other cases, to complacent attitudes towards confidentiality. Levels of understanding of confidentiality protocols and legal frameworks amongst professionals were also found to be variable in some situations and more guidance on these has been called for by the Caldicott Information Governance Review.

Implications for the development of the guidelines

This review of attitudes towards the confidentiality of healthcare data provides a firm basis for the GMC's development of the updated guidance for professionals, and will act as a starting point for consultation by the GMC with its stakeholders, around the guidance. Healthcare experts who contributed to this review showed a willingness to remain involved throughout the development of the guidance, so the GMC can draw on this to ensure that the completed guidelines are both based on the published evidence and have the buy-in of the sector.

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 while also ensuring that patient concerns continue to be adequately addressed.

- A key factor in making large scale integrated systems for medical records work is to ensure good public engagement and awareness, while also ensuring that systems are sufficiently secure and robust to address people's concerns. The guidelines need to explicitly address the responsibilities of doctors who are contributing to large centralised databases as this is an increasingly important frontier in confidentiality.

- Unintentional breaches of confidentiality are an area of concern for some patients. Advice on ways to mitigate this, for example by drawing attention to confidentiality risks in the reception area, or the benefits of private discussion areas, 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 wide variety of opinions around the appropriateness of different consent processes suggests that there needs to be some flexibility in the types of consent processes used for different situations (also taking the scale of data sharing into account). Engagement exercises on specific topics of importance could be valuable, due to the contextually dependent nature of views on this issue. It might furthermore be worthwhile to conduct research to explore the underlying principles behind views on consent processes.

- There is a need for improved professional awareness on existing confidentiality policies and procedures in some settings. This need is more acute in some contexts than others: for example one study in the review highlighted a particular need for increased awareness in some services that provide healthcare in the criminal justice system.

- Some studies assume that sexual health and/or mental health are areas in which people have greater confidentiality concerns. While there is some evidence to support this view, it might be valuable to conduct further research to gain a fuller understanding of how sensitive different types of data are perceived to be, and what the factors behind this are. There may be other issues that are particularly sensitive, or issues that are more sensitive to people from certain backgrounds.

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

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