General Medical Council

Public and Professional attitudes to privacy of healthcare data

A Survey of the Literature

Version: 0.4 [with addendum]
Dated: 10th August 2007 [update 13th November]

Prepared by: Peter Singleton, Nathan Lea, Archana Tapuria, and Dipak Kalra
Cambridge Health Informatics Ltd
Introduction

The General Medical Council commissioned Cambridge Health Informatics Limited to conduct a survey of the available literature on public and professional attitudes to privacy in healthcare information. This report covers the general environment considered, the methodology used, the results of the survey of the literature, the outcomes of the materials reviewed in depth, and the conclusions that the authors believe can be drawn together with limitations and cautions about the results and reliability of the materials.

This survey of the literature has been limited in order to provide a rapid response, but the authors feel that sufficient studies have been identified and reviewed to support the conclusions (albeit tentative) drawn here.

Executive Summary

The role of the medical record is changing from an aide-memoire for a solitary clinician to that of a shared tool linking care teams to provide an integrated range of services to a patient. This changes some past assumptions as to the role of secrecy in modern medicine, both for the public and professionals alike. This area has not yet been well researched.

Public Attitudes to Privacy

A total of 105 articles and papers that considered public attitudes to privacy were identified, of which 51 were considered relevant, either in their entirety (so reviewed here) or for particular insights, and so referenced in the discussion. Key conclusions are:

- Assessment of public attitudes is dependent on how the topic is framed. People will express concerns if questioned about ‘concerns’, but will readily trade these ‘concerns’ for health or other benefits, even altruistic ones. ‘Real world’ choices can be very different (and constrained) from those offered in opinion surveys where costs and trade-offs may not appear.
- Public attitudes are not uniform and the surveys suggest that they are often either ill-informed or unformed (or sometimes formed during an investigation or discussion).
- Attitudes among the public vary from the completely unconcerned to a small proportion of the public that has strong views on privacy, either from a sense of a ‘right to privacy’ or because of some sensitive episode in the past that they wish to protect. The majority of the public seem to rely on trust in clinicians and the healthcare system.
- It is clear that the public (and to some degree the professions) are unclear on the potential roles of medical records in modern healthcare.
- The public would like a choice in the use of their records, but there is little hard evidence about what arrangement of choices the public would generally prefer – or whether there are radically different opinions on this.
- The public appears to be becoming more comfortable with computer technology, which may reduce fears over privacy, but with increasing expectations over security and choice about access to their records.

Possible gaps in current knowledge are:

- Research into public understanding of the uses and sharing of medical records, particularly electronic records, and how they view the risks and benefits
- Research specifically into sensitivities around sexual and mental health: would the public require additional controls over this data, or conversely, if they knew that such data were well-controlled, might they be content to have other health data shared?
- Research how the public balances privacy risks and potential benefits from the use of genetic data (particularly for families) and the development of healthcare in the future

There has been much research into the public attitudes to use of genetics-based science where privacy concerns have been noted, but not explored in detail.
Professional Attitudes to Privacy

A total of 50 articles and papers were identified, of which 20 were considered relevant, either in their entirety (so reviewed here) or for particular insights, and so referenced in the discussion. Key conclusions are:

- The professions (or more strictly, in terms of the available literature, doctors) seem either relatively unconcerned by privacy issues or focus on the legal risks to themselves, though, like the public, there is a minority for whom privacy is a key concern.
- GPs are more likely to be concerned about data-sharing issues than non-GPs. This may represent a closer alignment with the patient’s welfare or a personal interest in acting as ‘gatekeeper’ to the patient.
- Even doctors (often the leaders of clinical teams) seem poorly briefed on privacy issues and the effectiveness of potential controls against threats such as ‘social engineering’.
- The vast majority of research has been focused on doctors rather than other professions, which is surprising given the numbers of other professionals with access to patient records.
- Professionals have a number of concerns, mainly around legal or regulatory uncertainties, gauging risks of internal and external threats to privacy, and assuring patients of their confidentiality.

Possible initiatives are:

- Provide (or update) guidance on privacy protection measures, both for computerised activities and also for clerical procedures.
- Provide clear guidance on the role and acceptability of EHRs – this may need to include more detail on how to maintain medical records appropriately in the modern age where data may be used more widely.
- Provide a clearer definition of consent and its acceptability in various contexts (e.g. when it must be ‘express’ and when and how it may need to be recorded).
- Compare clinicians’ opinions on public concerns with actual concerns of patients – there is some suggestion that clinicians (particularly GPs) may overestimate public concerns (perhaps through selection bias).

Acknowledgements

The authors would like to thank the General Medical Council for the opportunity to undertake this study and to thank a number of colleagues who have responded to queries concerning relevant activities and publications in this area:

Dr. Don Detmer, President & CEO, America Medical Informatics Association
David Lansky, Senior Director, Health Program, and Josh Lemieux, Markle Foundation
Joan Roch, Chief Privacy Strategist, Canada Health Infoway/Inforoute
Sarah Muttitt and Gavin Giles, Canada Health Infoway/Inforoute
Dr. Bill Lowrance, Geneva

The authors would emphasise that the responsibility for any opinions ventured here and results described are theirs alone.

[An update in the form of a brief addendum has been added on p5]

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1 the practice of obtaining confidential information by manipulating users, or the practice of using psychological manipulation tactics to help or harm others – Wikipedia (accessed 20/04/07)
Background

Privacy, Confidentiality, and Security

Chambers 21st Dictionary defines privacy as:

Privacy n seclusion; (one's right to) freedom from intrusion by the public; avoidance of notice, publicity, or display; secrecy, concealment; a place of retreat or retirement (rare); a private matter (rare). Etymology: from Latin privare, to deprive, to separate.

This suggests two senses for the word: a freedom from intrusion (as suggested by Article 8 of the Human Rights Act 1998i), and a right to keep matters secret. The former a restriction on others’ possible actions; the latter a personal power to be exercised.

This may be contrasted with the term, confidentiality:

Confide vi to trust wholly or have faith (with in); to impart secrets to someone as confidences (with in). vt to entrust; to tell with reliance upon secrecy. Confidence n firm trust or belief; faith; trust in secrecy; self-assurance, self-belief; assuredness, esp. in the outcome of something; admission to the knowledge of secrets or private affairs; a confidential communication. Confidential adj given in confidence; admitted to a person’s confidence; private. Confidentiality n. Confidentially adv. Etymology: Latin confidere from con- (signifying completeness) and fidere, to trust

It is clear that this concerns a bilateral arrangement between two parties rather than the unary right or power of privacy.

This would also appear to have two senses (apart from the assuredness aspect of confidence): the secrecy of a confidence and the trusted nature of a confidence. The former suggests that a confidence should never be breached; whereas the latter may permit the further use of the information in some trusted way (presumably to further or protect the confider’s interests). As we will see, this ambivalence is not necessarily resolved in the attitudes of either the public or professionals as there are a number of people that appear to believe in the ‘secrecy’ of medical records, whereas, for others, trust would seem to be the main aspect, with the level of trust or implicit empowerment being a key area of uncertainty.

We should also identify the term, security, normally taken in this context as being the protection of medical records against improper access, loss, or corruption. This would seem to be a key factor of the level of trust and the leeway granted to clinicians to use information given in confidence in the pursuit of healthcare.

By comparison, Bluml et al (1999)1 use:

privacy - the right of the patient that information be kept secret and not shared with any other person;

confidentiality - protection of that private information…from being shared with others;

security - …policy, procedures, and technologies that prevent the disclosure of confidential or sensitive information

For the purposes of searching the literature, we have treated the terms privacy and confidentiality as synonyms, since authors might not have made consistent distinctions between the terms.

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1 Everyone has the right to respect for his private and family life, his home and his correspondence
Methodology

Searches were performed using online resources and library resources at University College London and the British Library. Separate searches were made for public attitudes, professional attitudes, though with common themes (see below). Separate, but complementary, searches were made for grey literature, either through personally-known sources or through media references.

The table below gives a summary of the resources used (see Appendix A for more detail):

<table>
<thead>
<tr>
<th>Sources:</th>
<th>Public Attitudes</th>
<th>Professional Attitudes</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Library accessible resources: SCOPUS, Social Sciences Full Text, Australian Public Affairs Full Text Current Contents Connect, Economic and Social Research Council</td>
<td>Search engine sites: google.com, yahoo and msn live</td>
<td>Online academic tools: Google Scholar and Windows Live Academic (both beta versions)</td>
</tr>
<tr>
<td>Search criteria:</td>
<td>Public Attitudes</td>
<td>Professional Attitudes</td>
</tr>
<tr>
<td>Years 1996 - present</td>
<td>Years 1996 - present</td>
<td></td>
</tr>
</tbody>
</table>

Restrictions: English Language only

We limited our searches to English-language papers only, which restricted materials to the UK, USA, Canada, Australia, and New Zealand, and indexed proceedings of international conferences (and reinforced by the sources we have used such as PubMed, etc. which will tend to be biased towards Western medical cultures).

Media sources were used as a possible source of references to governmental or other grey literature. Reports with no clear evidence of general attitude data, or no indication of how a sample of viewpoints was formally obtained, were ignored (viz. comments regarding ‘a number of frontline doctors’ could not be interpreted as representing anyone, other than an interested section of the profession).

These were supplemented by an informal search from the authors' personal archives and by use of personal contacts in the UK, Europe, Canada, USA, and Australia to supplement formal sources and to pick up on possible grey literature. Some of the material had been published on government web-sites in the past, but had since been lost through restructuring of these web-sites (www.doh.gov.uk and www.nhsia.nhs.uk being two notable examples).
Public and Professional attitudes to privacy of healthcare data

Results

The overall numbers of papers identified were:

- Professional Attitudes: 40 articles
- Public Attitudes: 95 articles
- Public & Professional Attitudes: 10 Articles

Previous literature reviews around confidentiality have found similar quantities of results: Sankar et al (2003) found 5,746 articles on medical confidentiality of which the majority were from the clinician's perspective and were opinion pieces, leaving 117 articles (searching back to 1966). Schickle et al (2002) found 110 up to 2002.

Public Attitudes

Analysis of studies/papers found

<table>
<thead>
<tr>
<th>Relevance category</th>
<th>Papers</th>
</tr>
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<tbody>
<tr>
<td>1 Very relevant - detailed in report</td>
<td>24</td>
</tr>
<tr>
<td>2 Highly relevant - referenced in the report</td>
<td>27</td>
</tr>
<tr>
<td>3 Relevant - read in detail by reviewers</td>
<td>33</td>
</tr>
<tr>
<td>4 Marginal relevance - abstract only reviewed</td>
<td>12</td>
</tr>
<tr>
<td>5 No obvious relevance (ignored)</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>105</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location of study</th>
<th>Papers</th>
</tr>
</thead>
<tbody>
<tr>
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<td>46</td>
</tr>
<tr>
<td>United States of America</td>
<td>34</td>
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<tr>
<td>Canada</td>
<td>9</td>
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<td>Australia</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
</tbody>
</table>

Grouping of studies

Generally, studies have focused on the following key aspects:

- understanding & awareness of confidentiality issues
- access to medical records, both by patients and professionals
- effects of privacy concerns on seeking care
- effects of privacy concerns on disclosure of information by patients to professionals
- how patients valued various options or controls available to limit disclosures
- the social and financial implications of disclosures
- how the risks associated with disclosures affected attitudes to privacy
- understanding of and reaction to the appropriateness of disclosures
- how did possible benefits to the patient affect choices.

However, studies rarely focused on one of these aspects alone.

The papers could be divided into three main kinds of study:

- Real-world choices – reports on actual encounters and the choices patients made for their own health data
- Opinion-based studies – whether via questionnaires, interviews, or focus groups, considering choices in the abstract or case scenarios
- Reviews of the literature
Within the opinion-based surveys, it made sense to separate out the large-scale studies, usually commissioned by some body or organisation, and the smaller academic studies. The former tended to be national and produce mainly quantitative results whereas the latter were often localised with more emphasis on qualitative results and quite often operated on the back of a larger study or project, e.g. the introduction of a new computer system.

**Summaries of papers rated ‘most relevant’**

**Real-World Studies**

This covered 3 papers on 2 projects and two references which mentioned the results from further projects. These were all from UK experience.

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Date</th>
</tr>
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<tbody>
<tr>
<td>South Staffordshire PEG - Work Package POE1.9 Patient Access – Lessons Learnt Report</td>
<td>ITP</td>
<td>2003</td>
</tr>
<tr>
<td>Suggests that 7-16% of patients may have concerns, though none seemed to have real concerns once they saw their record – 7% (of 550) asked to see their record as part of the opt-in pilot; from the 14 people taken through the actual opt-in interview, only one opted out, though 2 wanted access restricted to healthcare professionals. However, those involved had been pre-vetted by GPs (so may have excluded those with ‘taboo’ episodes). Percentage would include the ‘simply curious’ rather than those with concrete concerns. A number of people made contact to ask to be involved (positive responses) but unfortunately number was not quoted.</td>
<td></td>
<td></td>
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</tbody>
</table>
| This paper covered the same project (as above) which experimented with both opt-in and opt-out approaches.  
Opt-out: 100,000 leaflets were sent out to 60,000 households; only 96 enquiries where received of which 12 related to press or other professional enquiries – none of these actually wished to opt-out (though there was one letter from outside the area indicating a wish to opt-out – so while number of active objectors was very small it should not be taken to be zero – this was reinforced by one response to the leaflet questionnaire which indicated that one respondent (out of 11 in total) was not happy with the way medical records were held [though it could be that they were dismayed at them not being electronic]). The low response rate could have been due to poor information provision or retention by the public – only 38% could recall the information even after prompting; 46% had ‘seen the information leaflet’ (but may not have read it fully); 85% did not know that they had an option – though 78% were ‘comfortable’ with the EHR proposed. [Interesting point from the survey of (only 5) GP staff, though no patient had asked any questions about the EHR, 3 out of 5 were adamant that patients had concerns about consent & confidentiality]. Patients were given the opportunity to request further information and opt-out of the project if they wished - none of the 8000 patients mailed chose to opt-out.  
Opt-in: The take-up rate for viewing the EHR was: Phase 1 (Autumn 2002) 100 invitations generated 16 request to view the EHR; phase 2 (Spring 2003) 450 letters generated; 22 requests to view the EHR. None refused to be included. [no record of the number choosing only demographic detail]. Of 14 patients who viewed their record: 12 had no concerns; 1 was concerned about non-medical staff having access, and 1 had concerns about their mental health history; 1 only wanted access to be permitted in emergency situations and 2 others only wanted clinicians to access  

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1 This is what the report stated. It is difficult to reconcile the 5 stated instances of concerns with only 2 people (14 – 12) having concerns, however, there may have been two opportunities to comment with 2 or 3 people expressing some concern at each point – only two chose to have a demographic-only record.
‘It is not possible to predict with any certainty how many people may in future choose to exercise this option as this will be the first time such an approach has ever been used. However, there is ample evidence to suggest that only a small minority would have concerns about the content of their medical records that would lead to their choosing to seal information. In response to a Consumer Association Survey (October 2002) question on this subject 60 percent of respondents said that they would remove nothing, around a quarter (24 percent) said they would remove a little, and around four per cent, said they would remove “a lot” or “all”.

This is paralleled by the available evidence about the likelihood of people to opt out of having a summary care record at all. The Scottish emergency care summary, which extracts data from general practitioners’ records and hospital notes, currently contains records for nearly 4.93 million patients and less than 500 have opted out. Similarly, in the course of a consultation on establishing an electronic health record in the Wirral, of patients invited to opt out if they had concerns, only 25 opted out whilst 350,000 records were uploaded. And of the 1.3 million patients likely to be affected by a similar proposal in Hampshire and the Isle of Wight, only some 1,150 decided not to have their records included in the data repository.

CfH evidence to Health Select Committee

Mr Cayton: Of course, these are only provisional figures, but there are 10.5 million people in Scotland in the Scottish system; there have been 593 opt out requests in Scotland, which is 0.01% of the population. In Hampshire and the Isle of Wight system, 690,000 people, 1,050 opt outs, 0.15%. In the Early Adopter Programme so far in Bolton 0.17%, and in the Wirral 0.01%. So, we are talking about less than 1% of the population when people have the system clearly and properly explained to them and they know what is going to happen in practice.

Dr. Braunold … There have been requests for something like 900 sets of confidentiality packs from the Bolton population from the 50,000 that we sent out and about 400 of those were altogether from people who had various difficulties, and I think about 60 of those have gone to people with limited eyesight - Braille versions and large print - so we know that we are getting there.

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1 The Health Which? survey for NHSIA covered in Share with Care (q.v.)
2 Results published in the ECS Newsletter of February 2007: Total Number of Patients – 4,956,535; Patients Withdrawn Consent - 496
3 A Wirral ERDIP report, wirrSecSpec.pdf has a very brief sub-section summarising the results of a survey possibly involving 151 people, but little firm detail – it also notes that about 10% (of 400 canvassed) appeared to have concerns (not specified). News comment at www.wirral.gov.uk states ‘A local survey “Reviewing Public Perception” involving Primary and Secondary Care was carried out October 2000’
4 From reference at www.bwwpct.nhs.uk that in Jan 2005 the figures were 14 out of 320,000 patients, which may show that it can take time for patients to discover and act on information. Above figures also quoted by Nigel Watson in BMJ (Vol 332, Issue 7556, Website extra June 2006).
5 Nigel Watson in BMJ (Vol 332, Issue 7556, Website extra June 2006) also quotes this as well as ‘Of the 1 300 000 patients in Hampshire and the Isle of Wight, 1150 have decided not to have their records included in the repository. Patients are made aware that they can view the information that is held on them. About 2000 patients have requested to view their record, although many stated this was out of curiosity rather than any concern over the project.’
6 At the time of this Committee hearing, Harry Cayton was Chair of the Care Record Development Board and National Director for patients and the public; Dr Gillian Braunold was National Clinical Lead for General Practitioners
7 Note: this seems to be a mis-quote of some sort as the actual population is closer to 5 million
Mr Cayton ... To put this in context, Biobank, you will be aware of, has recently started to invite members of the public to take part in research. I have to say I was personally quite sceptical and I have been quite interested by the fact that 10% of the people mailed by Biobank in their pilot in Manchester actually responded positively to the invitation to take part in research, and, although a number of those people (and again I am surprised how few but I think it is interesting) wanted to know how their name and address came to be selected and wanted to know who had sent out their name and address, of the very small number - 23 who wanted to know that they had been selected, 25 who wanted to know how their name an address was obtained - after they had had a discussion with Biobank 50% cent of those people continued to go forward to take part. So, I think what this is suggesting, not in any way that we should move away from consent for research, which I think is very, very important, but that the public in this country still have very strong communal interest in clinical research and in a common ownership of the Health Service, which I think is one of the wonderful qualities of our Health Service, that it is a joint enterprise and not a set of private contracts.

Lessons from the central Hampshire electronic health record pilot project: issues of data protection and consent

Adams T; Budden M; Hoare C; Sanderson H

2004

Summary points: A pilot electronic health record project linked patient records from five settings. A solution to issues of patient confidentiality and consent was developed through discussion with several bodies. Feedback to a public information campaign indicated that most people supported linked medical records. Only 10 patients in the pilot population (approx. 225,000 residents) wanted to restrict access to their records. The withdrawal of some records from the electronic health record is unlikely to damage its usefulness for clinical care.

Two leaflets were written for patients; one described the uses of health records and the other described the project. These were delivered to 80 000 households (225 000 residents) in central Hampshire. Leaflets were also placed in all the local general practices and Winchester Hospital outpatients and accident and emergency departments, as well as libraries, county council offices, and dental surgeries. Overall, 82 patients called the NHS Direct helpline, of whom six asked for their records to be excluded from the electronic health record and eight asked to view their record before making a decision. (Four subsequently asked for information to be excluded.) The project’s website received 1306 hits during the six month evaluation period, but of these only 20 questionnaires that provided feedback were completed. This is a low response rate and suggests that most visitors did not have strong enough views.

National studies

Title Authors Date

National survey of British public’s views on use of identifiable medical data by the National Cancer Registry

Barrett et al 2006

This paper examined attitudes about the construction of a registry, to be used for research purposes, that includes personal information of cancer patients. Respondents were asked nine questions about the repository, its intended content.

Key results from the paper are as follows:

• There were 2955 interviewees; 2872 (97%) answered all nine questions; Thirty people (1%) refused to answer the questions; 53 (2%), a minority who completed telephone interviews, were asked none or only some of the questions.

• A significant majority (n = 2737, 95%) thought that the information it collected was useful; Over four fifths of responders (n = 2335, 81%) said that they would support legislation to underpin the National Cancer Registry

• Most respondents (n = 2740, 95%) did not believe that a letter from their primary care trust inviting them to a cancer screening test was an invasion of privacy.

• Over 80% of respondents did not consider that the confidential inclusion of their postcode or name and address in the registry, or the receipt of a letter inviting them to take part in a research study, was an invasion of their privacy.
The scenario that caused most disquiet was the inclusion of name and address, with 16% of respondents (n = 446) considering this an invasion of privacy.

2068 respondents (72%) indicated that none of these scenarios (inclusion of postcode in the registry, inclusion of name and address, and receipt of an invitation to a research study) was an invasion of privacy; Only 61 respondents (2%, 95% confidence interval 2% to 3%) saw all three scenarios as an invasion of their privacy; The opinions of the other 714 respondents varied.

Issues of ownership and benefit were also discussed. There seemed to be a preference to protecting privacy over medical research. It appears that there is a link between chronic illness and people's acceptance of sharing information, but that this is within limits. Results were noted to be similar to a West German survey performed in 1983.

**Public Attitudes Towards Medical Privacy**

N=1000: 78% feel it is very important that their medical records be kept confidential; Women are more likely than men to feel it is very important their medical records should be kept confidential (81% and 74%, respectively). In addition, older adults, particularly those 35 to 49, are more likely than adults 18 to 34 years of age to say it is very important that their medical records be kept confidential; four in ten adults (40%) would favour allowing pharmacists to see their medical records without permission while 59% would be opposed. There is strong opposition to non-medical groups gaining access to their medical records.

**The public view on electronic health records**

6 Focus groups with patients (N=c. 48), 18 in-depth interview, and Omnibus survey (N=c. 2000); much of focus is on proposed ICRS\(^2\) system.

From focus groups/interviews: younger people tended to assume extensive use of computerisation; there was low expectation of current security (of paper records); patients appreciated tension between security restricting access and needing ready access for treatment; significant trust in professionalism; explored extents of sharing between institutions and individuals (some wanted family access, others definitely not); anonymised data for research was acceptable.

Survey results showed some reluctance to share outside originating organisation (GP or hospital), only 64% for paramedics, falling to about 50% for private and overseas hospitals providing care, and about 40% for nursing homes and other healthcare related bodies (notably those over 65 were more reluctant to share their record).

72% wanted to know how secure the system would be, 68% how the NHS made sure no one else saw their personal details without their knowledge. 68% who had access to their personal details, 67% whether they could see their own record, 51% who checked if their records were correct, while 45% if they could correct any mistakes.

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2. 'Integrated Care Records Service', subsequently renamed as NHS Care Records Service (NCRS)
The use of personal health information in medical research

Research was both qualitative (workshops, N=63) and quantitative (through their Omnibus survey, N=2106) – the former informing the choice of questions in the latter. It is quite strongly set in the context of medical research.

Generally, the public did understand 'personal health information' but not its range of uses or how it was used – research uses particularly poorly understood (or actually rarely considered).

Opinion seemed to settle around either anonymising or giving consent to research use. 28% had concerns over privacy. With assurance of confidentiality, 62% would provide their information for research. This dropped to 42% if their data might be re-used without further consent.

Public Attitudes to Research Governance

Shepherd et al 2007

Used discussion groups; N=89 in total, exploring personal data, anonymity, confidentiality, consent, databases, and models of governance. While much of the work is focused on science and research, there is much useful material on how people approach the use and sharing of their medical data.

It is noted that there has been a general decline in public trust of institutions and experts, though doctors still retain high levels of trust (based on MORI polls – ‘trust to tell the truth’).

Generally public were prepared to provide personal health data for research if they knew purpose and integrity of the research. They expected explicit consent for personal data to be used but anonymised [not well defined in the project] was not thought of as ‘personal’.

Commercial involvement or mediation through GP receptionists raised concerns.

Limiting risk to oneself seems to have been a key concern, though actual understanding of databases was poor, suggesting significant uncertainties over actual risk, focusing more on reported risks in the media.
Quantitative and qualitative research focusing on the introduction of electronic health records in UK – large-scale and far-reaching - document may be selective in its choice of evidence. It included one-to-one interviews with people who had particularly serious needs for privacy: women who had had terminations, people with HIV/AIDS, people who had serious genetic, inheritable disorders and people who were mental health service users. It explored communication issues through one to one interviews with people who did not speak English but spoke Urdu, Punjabi and Hindi. There were also focus groups with people who had recently been referred from primary to secondary care – general patients.

Based on this qualitative research, selected questions were put in the MORI Omnibus' face-to-face survey with 2000 members of the public.

When asked if they would want to remove particularly sensitive information from their shared electronic record, 60% of respondents said that they would remove nothing. A quarter (24%) said they would remove a little, and roughly 4% each said they would remove "a lot" or "all".

The oldest group (65+) were most likely to say none (68% vs 59% 15-24, 56% 25-44, 61% 45-64). The other groups were significantly more likely to say "a little" than those aged 65+ (26% 15-24, 29% 25-44, 22% 45-64, 16% 65+).

The study did not explore what is understood about confidentiality and consent – indeed the omnibus survey did not include any framing of the questions. However, some of the responses showed that little is known about the use of healthcare information (the assumption was often that data was already stored electronically and shared extensively), and suggests that interest is framed more around the risk to the individual of disclosures rather than ethical concerns about the appropriateness of use.

**NHSIA/MORI poll: “Who should be able to see your medical records?”**

The 2001 MORI poll on who should have access to medical records in a practice provides some figures to support findings that had been reported previously by Carman & Britten (1995), especially with respect to how strongly people feel that reception and administrative staff should not have access to records. Unfortunately, this is now only traceable as a presentation on The Patients Forum website.

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<table>
<thead>
<tr>
<th>MORI Poll of 2008 people</th>
<th>GP</th>
<th>Other Surgery staff</th>
<th>Hospital staff giving care</th>
<th>Medical researchers</th>
<th>Social Worker giving health care</th>
<th>NHS Managers</th>
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<tr>
<td>YES</td>
<td>95%</td>
<td>44%</td>
<td>87%</td>
<td>63%</td>
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<td>47%</td>
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<td>2%</td>
<td>43%</td>
<td>7%</td>
<td>23%</td>
<td>36%</td>
<td>40%</td>
</tr>
<tr>
<td>POSSIBLY</td>
<td>2%</td>
<td>13%</td>
<td>6%</td>
<td>13%</td>
<td>14%</td>
<td>13%</td>
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The percentage wishing to restrict GP access is interestingly high and echoes the results from Shickle et al (2002), indicating that people will avoid seeking care through their GP in order to hide information. The public also appears more content to allow researchers access than other GP surgery staff – though this may reflect differences in perceptions of the roles of such staff, or the greater risk of being socially connected to GP practice staff. The ‘Share with Care’ results in this area are more detailed (covering also extent of data shared) and support this view.

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1 An ‘omnibus’ survey is a set of interviews with questions from a variety of clients on different topics, thus sharing the costs of recruiting a large representative sample. Clients will buy one or more questions out of perhaps 30 questions in total.
Medical Privacy and Confidentiality Survey
Princeton Associates 1999

This survey compares privacy attitudes of USA public nationally with Californians specifically: 54% consider computerisation a threat; 55% worry about hacking as opposed to 30% about improper use by authorised users; 20% consider improper disclosures occur; 7%/9% (US/CA) have actually been embarrassed or harmed by disclosures; 15%/18% (US/CA) have taken steps to protect confidentiality, including going to different doctor or paying privately, or asking for changes in what is recorded.

Patient Electronic Record: Information and Consent (PERIC), Public attitudes to protection and use of personal health information.
Shickle et al 2002

This wide-ranging study included a national survey and several focus groups (centred on Sheffield). The survey (N=3921) was carried out by RCL-IPSOS and used a random selection from 200 vignettes covering access to different parts of a medical record by different agents in care. These were presented to interviewees to determine sensitivities.

The results were not very conclusive except that there was clearly a disparity between people’s opinions with roughly 10% being content with all vignettes and about 10% being happy with none of them. Some evidence of age and social standing affecting attitudes: older people and higher social groups being happier to allow access.

The focus group with young people concluded:

• Young people had given little thought to how their health information is used prior to the interview;
• Young men were less concerned than young women, and younger teenagers were less concerned than older teenagers;
• Young people with serious conditions were happier than those with little experience of health care for staff to access their health information.

The report includes a survey of the literature from 1966 to 2002, generating 128 papers (summarised later in this report under literature reviews).

Ekos surveys
Various

These surveys in Canada covered privacy in a general context (often use of the Internet), but occasionally touched on health information.

The 2004 report noted: "The current public environment reveals broad confidence in the proposed health privacy and confidentiality framework. This confidence coexists with considerable concern about potential abuses of personal health information. While Canadians express broad comfort on several fronts, it is equally clear that this balance of confidence and concern is not rooted in significant reflection, knowledge or personal experience. It is therefore important to recognize that these favourable results could change either positively or negatively as the public debate unfolds. The currently favourable lean to the framework appears to be quite decisive and strengthened as respondents reflected throughout the survey (e.g., perceptions regarding the safety and security of health information rose 10 percentage points from the beginning to the end of the survey). It is also important to recognize the primacy of public and individual health over privacy concerns in this debate. Quite bluntly, while the public is concerned about privacy issues, other concerns such as the quality and efficiency of the health care system eclipse privacy concerns. This current lean probably reflects a broader diminution of concerns with the human rights/civil liberties side of the debate in the post-9/11 world.

There are three key forces underlying current support:
1. relatively scant experience of privacy, confidentiality and security-related problems;
2. comfort that there are rules/guidelines in place and that someone is minding the store;
3. rock-solid trust in health professionals, particularly doctors."
Localised studies

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidentiality of medical records: the patient's perspective</td>
<td>Carman D; Britten N;</td>
<td>1995</td>
</tr>
</tbody>
</table>

A qualitative study was undertaken to explore patients’ expectations and attitudes concerning confidentiality of patients’ medical records in general practice. Semi-structured interviews were carried out with 39 patients from one general practice. Answers were presented in terms of staff having access to medical records, what was in the record and what control the patient had over the content. Electronic records were also discussed.

Staff access to records:

- Anxieties over midwives having access. They should work under the supervision of the doctor, and could inadvertently disclose information.
- No problems with doctors having access for treatment, but not for informal discussion with colleagues afterwards.
- Anonymity was a determinant – discomfort with knowing people who worked at a practice. Workers should not be from the area in a GP practice.
- 3 out of the 16 who gave an opinion on the access by administrative staff gave any thought about training, experience, and contractual obligations of the administrative staff.

Content of Records:

- 15 patients expressed concern based on recording of particular information about their life experience. They did not necessarily want such details removed, and looked at the decision to disclose in hindsight with a different feeling about the issue than at the point of meeting the practitioner.

Control over Records:

- General agreement that this should be exercised in partnership with the GP.
- Anxiety over damaging the relationship between doctor and patient.

Computerised Records:

- Seen as the biggest threat to privacy and confidentiality.
- Feeling that you were “in the lap of the Gods” where computerised records are concerned.
- Uncertain over what could or should be stored there.

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1 Though just outside our selected date range this paper is frequently quoted by other papers
The utilitarian argument for medical confidentiality: a pilot study of patients’ views

Jones C 2003

This study gave a questionnaire (based on an earlier BMA survey1) to 30 consecutive patients attending a GP surgery. Following the completion of this, five clinical situations in which a breach of confidentiality might occur were discussed, and the respondents re-tested to see if opinions had changed. The scenarios discussed covered: child sexual abuse, a driver with epilepsy, drink driving, mental illness: threat to a neighbour, and sexually transmitted disease, and the questionnaire showed that patients would withhold information if they thought that confidentiality might be breached.

The conclusions were that a clear majority of subjects believed that doctors should disclose information in two of the situations, but subjects were not confident that doctors would do so. In three situations, about half felt that disclosure was justified—these included the only scenario in which disclosure was clearly mandated by statute (viz. drink-driving). There was little change in patients’ general attitude to confidentiality after considering the scenarios. However, the views expressed were often inconsistent with responses to the clinical scenarios, suggesting that complex opinions were not accurately reflected in the responses.

Generally a majority supported disclosure, though this was at variance with the results of the broader questionnaire. Interestingly, the study noted ‘Subjects concerned for their own confidentiality were less likely to support disclosure across the range of scenarios than subjects who were not concerned (11/24 (46%) v 66/99 (67%)). They were also more likely to believe that future treatment might be impaired (18/25 (72%) v 59/101 (58%)).’ Numbers of respondents in this study make firm conclusions difficult, but results may still be indicative.

Sharing patient data: competing demands of privacy, trust and research in primary care

Stone et al. 2005

Semi-structured interviews were conducted with 20 patients, five GPs, five practice nurses, two health visitors and three practice managers from two city and three county general practices in Leicestershire. The respondents expressed the views that patients had not normally considered confidentiality issues; trust was personal rather than to the system and data-sharing was not usually a consideration; patients were happy for sharing for medical care, but had concerns about sharing with family; patients were generally positive to research uses but with consent, though significant divergences of opinion were noted. Professionals also seem not to have greatly considered data-sharing or informing the public of such uses.

Patient and Provider Health Data Privacy Concerns

Keshavjee et al 2007

N=31 in total; This study focussed on practices in USA converting to an electronic health record (EHR) system. One of the research objectives was to study health data privacy perceptions of providers and patients. Focus groups showed that lay people generally wanted their permission sought before their health information was used, even if their health information was anonymised. The younger group (N=15) expressed less apprehension over the computerization of their health record. One-on-one interviews showed that patients presented with variable knowledge and understanding of issues related to the use of health information for research purposes. Most patients expressed wanting to be directly informed by their physician if their health information would be used for research and felt it important that they provide consent for this use. Patients were positive about the potential benefits of research but simply wanted to ensure that their privacy would not be compromised. A quantitative survey showed that 75% thought some type of consent (either verbal or written) should be obtained.

Conclusions: Although generalisation of this small sample is difficult, it appears that many patients wish to have influence in the use of their personal health information. Since the use of the electronic health records will increasingly blur the boundaries between clinical, research and administrative uses of medical information, Keshavjee et al conclude that privacy standards will be required and their impact will need to be evaluated.

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Literature Reviews

There were four papers found and one reference to a literature review with a summary of the study.

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Date</th>
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</table>

This report mainly summarises Westin's own work with Harris Interactive on privacy concerns generally. It does not offer an explanation of what lies behind choices and what may motivate people, but has some useful population viewpoint data.

Surveys dating as far back as 1978 show that trust in doctors is high among patients. The 1993 survey found that 87% of the public believes their health providers keep their medical information confidential.

Hospitals, clinics and other healthcare organizations, however, do not fare as well with the public. In the 1978 Dimensions of Privacy Survey, 24% thought hospitals ask for too much information, compared to 11% for doctors' requests. When asked if hospitals should be doing more to protect the confidentiality of personal information, 23% said yes, compared with 17% who said doctors should be doing more.

The 1993 Harris-Westin survey found that the public is concerned about how medical information is circulating beyond direct care. Forty-one percent were worried that medical claims information submitted under an employer health plan may be seen by their employer and used to affect their job opportunities; and 60% believed it is not acceptable for medical information about them to be provided, without their individual approval, by pharmacists to direct marketers who want to mail offers about new medications. Almost two out of three Americans (64%) didn't want medical researchers to use their records for studies, even if the individual is never identified personally, unless researchers first get the individual's consent.

The June 2004 Customer Respect Group study found that healthcare and pharmaceutical firms still do not have the full trust of the public. The survey found that many of those firms with online presence share customer data with business partners without permission (12%) while others share data with affiliates (24%). Further, 65% do not provide clear opt-in/opt-out policies so that users do not feel they have control over how medical and health products are marketed to them.

Concern over electronic medical records is not a new phenomenon among Americans. The 1993 Harris-Westin found that 70% of respondents were worried about the extensive use of computers in a national healthcare system to manage and monitor healthcare operations. A strong majority felt that such computer use caused mistakes to be made in charges (75%); mistakes in medical conditions put into patient records (60%); and medical information given to people who aren't supposed to see it (64%). Three of four Americans (75%) said they were concerned "that a computerized healthcare information system will come to be used for many non-healthcare purposes," with 38% of the public saying they are very concerned about this.
Health on-line: public attitudes to data sharing in the NHS

Scottish Consumer Council 2005

This report included a brief literature survey focused mainly on EHRs for mental health, and concludes:

- There are generally low levels of awareness of how personal information is stored and shared, by service providers in general, and also by the NHS; There is a desire to know more about this.
- Data sharing is supported where this is seen to contribute to better care or services, both in general and in the NHS.
- A significant percentage of people believe that health records are shared more widely than is the case.
- The most commonly expressed concerns are about security.
- There is support for the concept of a ‘sealed envelope’ in which particularly sensitive information could be held.
- Most people would like to be able to see their own records and have the opportunity to correct any mistakes.
- People would like to have some control over who has access to their records.
- There is a fairly high level of trust in relation to how information is used in the NHS.
- There is general acceptance of an opt-out system.
- Because there are greater sensitivities around information about mental health, it is particularly important that mental health patients are involved in deciding who sees what in their record.
Patient perspectives of medical confidentiality: a review of the literature

Sankar et al 2003

This paper covers a review of available literature between 1966 and 2000. The searches were performed using MEDLINE and BIOETHICSLINE. This returned 5,746 published articles, the majority of which examined confidentiality “from the practitioner’s perspective and not the patient’s”. They short-listed 117 articles that were not opinion pieces or speciality specific. There is reference to one UK paper (Carman & Britten 1995 q.v.) but the majority appear to be American. The paper claims there needs to be a greater understanding of how patients understand medical confidentiality and this paper looks at how patients understand and use it.

Only a handful dealt with confidentiality understandings. These note two general concerns:

- There is a group of patients who are unclear about the basic intent of medical confidentiality
- While there is some familiarity with medical confidentiality, the term itself may not be that familiar. They cite the result of the children interviewed being more forthcoming after words such as secret and trust were used, indicating that clinicians should phrase things better.

In terms of patient beliefs about access to medical information, the literature addressed three questions:

- Whether patients approve of their physicians sharing information with other physicians
- Under what circumstances patients might sanction breaches of confidentiality
- Patient opinions about sharing medical information with employers, families and third parties

They conclude:

- Many patients are unaware of, or misunderstand, their legal or ethical right to confidentiality, which leads them to over- or under-estimate the protection available:
- The possibility that information may be revealed, intentionally or not, to acquaintances in a clinic or other social community worries them as much as information release to insurers or employers (note mainly USA context)
- A significant minority of patients distrust confidentiality protections so that they delay or forego care
- They found a wider variety of understandings and beliefs than are often indicated in articles from clinicians or legal experts.
Public and Professional attitudes to privacy of healthcare data

*Patient Electronic Record: Information and Consent (PERIC), Public attitudes to protection and use of personal health information.*

Shickle et al 2002

The report on this study included a brief literature review, finding initially 110 studies by searching electronic databases (Medline 1966 to 2002/02, CINAHL 1982-2002/02, and Embase 1980-2002/02). These were rated and 26 met the inclusion criteria. Subsequent hand searching found an additional 18 relevant papers.

They split the literature by: Knowledge of rights, privacy and confidentiality; Health professional groups and ‘need to know’; Expectations of patients; Content of records and sensitivity of information; Use of health information; Electronic records; Areas where confidentiality may be unwittingly breached.

Results are briefly summarised here, but the remaining source material was not deemed relevant beyond what Shickle et al report:

- **Gostin et al** (1993) where 30% of Americans were described as ‘privacy fundamentalists’ who placed a high value on privacy. A Harris / Equifax Survey leads Shickle et al to label 55% of Americans ‘privacy pragmatists’ who felt that they were able to trade off privacy for other goods. The report also cites Kinzie et al, where it is reported that although psychiatric patients in Oregon place a high value on privacy, they lack adequate information as to their rights to privacy.

- **Wardman et al** (2000) where out of 1,000 interviewees, 94% thought that their usual doctor did have full access to their medical records, and 98% of patients felt that their usual doctor should have full access. These figures dropped to 76% and 84% respectively for access by other doctors in the practice, and 43% and 34% for practice nurses (and 40% felt that access to only part of the record would be acceptable for practice nurses).

- **Grol et al** (1999) report that between 77% and 91% of patients (across the UK, Norway, Sweden, Denmark, The Netherlands, Germany, Portugal and Israel) feel that their GP should be able to guarantee the confidentiality of their medical records.

- **Cowan et al** (1996) discuss the presence of communicable disease information in the record, and summarise the research by suggesting two factors that seem to influence acceptability: maintenance of confidentiality and availability of treatment.

The conclusion was ‘Attitudes vary depending on the sensitivity of the information, the mechanism of recording this information, the healthcare setting and the potential uses to which the information may be put. However there is no evidence from the published literature as to which of these factors the public perceive to be the most important. Public attitudes to their health information may be different to professional attitudes to patient information, which may be a cause for conflict. In many cases the public may not even have considered the issues surrounding their health information’.

**Confidentiality as part of a bigger picture**

BMA 2005

This discussion paper notes: ‘A review of the available research on patients’ views showed that there is no evidence to suggest that patients give higher weight to confidentiality or to the need for health professionals to have timely access to relevant information. (There is of course no need for them to be mutually exclusive.) The research suggests that patients would be sympathetic to increased information exchange between healthcare professionals within the NHS, provided it leads to improved care and information is secure from unauthorised external access. The greater the distance from those directly involved in patient care, the greater the concerns about access. It is clear, however, that more research is needed about what patients really think.’

Six papers are referenced in a footnote, but it is not clear if these are considered the full extent of the literature or not.
While this report covers confidentiality from a wide range of perspectives, it has a section (p29) which is effectively a literature review, including surveys performed by some of the ERDIP projects, generally in the context of EHRs. From this report, we identified further specific studies (see elsewhere), but the following could not be found as original publications and so are cited as part of this ERDIP report:

- Addenbrookes (2001) ‘This poll of patients at two hospital clinics is as yet unpublished, but interesting as it is one of the few large real-life questionnaires of patients, where patients can fully understand the likely data being shared and balance objection with benefits foregone. People attending the two clinics over a two-week period (over 1000 patients) were asked for their consent to sharing of their health information for various activities including research and teaching. Only 3% of patients had any objection, mainly to specific uses, e.g. for teaching.’

There is no conclusions to the review, except the following points in the general discussion:

- Patient attitude surveys show that there is a large percentage (20-25%) of patients who are quite happy to have their data used in whatever way will assist medical research.

This report pre-dates the final outcomes of South Staffs and N. Hants publicity campaigns (q.v.)
Professional Attitudes

Studies/papers found

<table>
<thead>
<tr>
<th>Relevance category</th>
<th>Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Very relevant - detailed in report</td>
<td>5</td>
</tr>
<tr>
<td>2 Highly relevant - referenced in the report</td>
<td>15</td>
</tr>
<tr>
<td>3 Relevant - read in detail by reviewers</td>
<td>7</td>
</tr>
<tr>
<td>4 Marginal relevance - abstract only reviewed</td>
<td>13</td>
</tr>
<tr>
<td>5 No obvious relevance (ignored)</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
</tr>
</tbody>
</table>

The following categories were noted for the papers with relevance categories 1, 2, & 3. (Some papers covered more than one of the categories in the tables below and, if so, have been listed more than once)

<table>
<thead>
<tr>
<th>Professional Group studied</th>
<th>Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors/physicians</td>
<td>13</td>
</tr>
<tr>
<td>GPs/family physicians only</td>
<td>10</td>
</tr>
<tr>
<td>Hospital physicians only</td>
<td>3</td>
</tr>
<tr>
<td>Medical students</td>
<td>2</td>
</tr>
<tr>
<td>Professionals allied to medicine</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location of study</th>
<th>Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom</td>
<td>13</td>
</tr>
<tr>
<td>United States of America</td>
<td>12</td>
</tr>
<tr>
<td>Europe</td>
<td>1</td>
</tr>
<tr>
<td>Japan</td>
<td>1</td>
</tr>
<tr>
<td>International</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Method/approach</th>
<th>Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web based questionnaires</td>
<td>2</td>
</tr>
<tr>
<td>Written questionnaires</td>
<td>2</td>
</tr>
<tr>
<td>Postal surveys</td>
<td>6</td>
</tr>
<tr>
<td>Online polls</td>
<td>10</td>
</tr>
<tr>
<td>Randomised controlled trial</td>
<td>1</td>
</tr>
<tr>
<td>Interview</td>
<td>4</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
</tr>
</tbody>
</table>
Grouping of studies

The expected categorisation of studies by professional category did not emerge from the papers reviewed as the existing literature is almost exclusively restricted to doctors or medical students. It is notable that few of the papers encountered (including those rejected because of low relevance or poor sampling) covered other professions.

The most useful grouping of the literature is, therefore, around the topic which framed the study:

- Introduction of a computer record system, or, more recently, a pan-organisation EHR
- The nature and scale of threats to privacy
- Implications of use of genetic data

This last item was covered by one paper which was subsequently rejected as being more about the appropriate use of data for genetic research rather than attitudes to privacy per se. It has been retained in this list only to highlight the lack of research on this topic.

Summaries of the most relevant papers

Introduction of computer record systems

While there have been a number of studies around the introduction of computer records, few have asked much about privacy issues, sometimes only asking if it is an issue.

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>The future for information sharing in sexual and reproductive health: ‘making I.T. work’</td>
<td>CfH/NPIIT</td>
<td>2007</td>
</tr>
</tbody>
</table>

This document consists of notes from a conference held in early 2007. Attendees consisted of health professionals and patient group representatives. Some questions, asked at the beginning of the event, were repeated at the end to see whether opinions had changed. One question that showed a shift in views was: ‘How do you feel the National Programme for IT will affect the confidentiality of information (including test results) in your clinical environment?’

<table>
<thead>
<tr>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will improve</td>
<td>6%</td>
</tr>
<tr>
<td>May improve</td>
<td>23%</td>
</tr>
<tr>
<td>Unlikely to impact</td>
<td>15%</td>
</tr>
<tr>
<td>May worsen</td>
<td>37%</td>
</tr>
<tr>
<td>Will worsen</td>
<td>19%</td>
</tr>
</tbody>
</table>

A very clear steer on what delegates wanted was provided by questions such as:

Who should decide how far information is shared?

- Patient: 23%
- Clinicians (GUM clinic, reproductive health service or GP): 0%
- Patient and clinician together: 77%
- NHS Connecting for Health: 0%

The delegates were asked to summarise what they thought about proposed information governance controls:

In the context of sexual health, do the information governance controls proposed offer the right balance between protecting confidentiality and enabling data sharing for better patient care?

- Weighted too much to data sharing: 20%
- Weighted too much to confidentiality: 7%
- About right: 52%
- Undecided: 21%
### Public and Professional attitudes to privacy of healthcare data

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient and Provider Health Data Privacy Concerns</strong></td>
<td>Keshavjee et al</td>
<td>2007</td>
</tr>
</tbody>
</table>

The 33 family physicians who participated in the study converted their practice, both administrative and clinical functions, to an electronic health record (EHR) system. One of the research objectives was to study health data privacy perceptions of providers and patients. Physicians’ responses indicated practical and conceptual difficulties with privacy issues. They expressed concern about the burden of asking for consent. They had few concerns about sending anonymised data to researchers. There were questions about whether they or their patients could accurately articulate the issues required to obtain a valid consent.

### The nature and scale of threats to privacy

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attitudes of First-year Medical Students Toward the Confidentiality of Computerized Patient Records</strong></td>
<td>Davis et al</td>
<td>1999</td>
</tr>
</tbody>
</table>

This study directly addressed the attitudes of medical students towards the confidentiality of computerised medical records and how they would react to a breach of patient privacy.

Most students had a sense of what was right and wrong in absolute terms, although half the class suggested at least one course of action that was deemed to be inconsistent with institutional policies. The study did show, however, that students do consider the protection of patient privacy to be an important issue.

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>South Staffordshire EHR Project: Baseline Questionnaire Report</strong></td>
<td>YICHI</td>
<td>2002</td>
</tr>
</tbody>
</table>

This survey asked questions to staff about a proposed EHR system - mainly about benefits and usage of EHR, but included some on professional attitudes concerning consent & confidentiality:

Staff were concerned about illegitimate access to the EHR, with 51% concerned about non-clinical staff accessing the EHR, 51% concerned about staff accessing EHR of other staff for illegitimate purposes, and 42% concerned about inappropriate access of a patient’s EHR by clinical staff. This pointed to considerable distrust of their colleagues.

The study concluded that these concerns needed to be addressed, and clear (written) policy guidance communicated to users.
This survey asked about the areas of concerns from the introduction of the NHS Care Record Service (NCRS) to patient confidentiality and identified differences in attitudes between GPs and non-GP doctors (data from Q116):

<table>
<thead>
<tr>
<th>Concern</th>
<th>GP</th>
<th>Non-GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don't think CRS is likely to make patient records less secure</td>
<td>10%</td>
<td>14%</td>
</tr>
<tr>
<td>I think CRS is likely to make patient records less secure because:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outsiders hacking into the system</td>
<td>62%</td>
<td>56%</td>
</tr>
<tr>
<td>Access by public officials outside health or social care</td>
<td>62%</td>
<td>51%</td>
</tr>
<tr>
<td>Inadequate access controls</td>
<td>48%</td>
<td>42%</td>
</tr>
<tr>
<td>Bribery or blackmail of people with access to the records</td>
<td>34%</td>
<td>22%</td>
</tr>
<tr>
<td>Social services staff not adhering to the rules</td>
<td>26%</td>
<td>19%</td>
</tr>
<tr>
<td>Clinicians not adhering to the rules</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>IT technicians not adhering to the rules</td>
<td>21%</td>
<td>17%</td>
</tr>
<tr>
<td>Researchers not adhering to the rules</td>
<td>16%</td>
<td>9%</td>
</tr>
<tr>
<td>Unsure</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>Insufficient information to comment</td>
<td>5%</td>
<td>8%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>425</td>
<td>566</td>
</tr>
</tbody>
</table>

Note that there has been a series of Medix surveys (e.g. Q850 in January 2006) asking similar questions but occasionally more detailed (as above). These consistently note less concern about confidentiality/security amongst non-GP clinicians.

Note that this (and earlier Medix Surveys) include a more general question Q11b asks simply about the likely change in confidentiality security without identifying where additional risks may arise – the percentage splits in Q1066 differ from the figures above (e.g. Unsure are 10% and 19% respectively).
Public and Professional attitudes to privacy of healthcare data

Discussion
Aspects that the authors of this report have considered when interpreting the results are:

- Biases in the publication of materials – particularly true for some of the ‘grey’ literature where organisational interests will affect whether reports are publicised/made available.

- Possible biases in the selection of materials for review – again a noticeable problem for ‘grey’ literature where only highlight results appear in the reports and the full range of data from questionnaires is not available.

- Variations in scale – many of the larger surveys tend to have been commissioned by an organisation with a potential risk of bias; the more academic and rigorous studies have tended to be smaller and often developed on the back of another project, leaving the significance of the studies open to question.

- The vulnerability of quantitative and qualitative results to the questions posed, the context in which these questions are posed, and by whom they are posed (viz. by GP or an independent researcher).

- The variation in attitudes and behaviours within the population surveyed and the danger of assuming that all people are basically the same in their attitudes to privacy, whereas there may be significant sub-groups within the general population, in particular, the disadvantaged may have more reason to hide their data than others.

Privacy policy in healthcare
Generally much of healthcare policy in relation to the privacy of healthcare data has been based on historic ethical and legal considerations together with technical and financial practicalities rather than on an evidence-base of what individuals would want or expect. This has, in part, been due to a perceived lack of understanding by the public at large (and many professionals too) of how medical records are actually used and shared within the healthcare system as a whole: this perception means that they have rarely been asked in any formal consultative way.

Environment around privacy in healthcare information
Clinicians have long been recording patient encounters on paper – generally with the view that these are the clinician’s notes about the patient to be handled confidentially, but otherwise at the clinician’s disposal – for continuity of treatment, for legal defence, or research. In larger institutions, e.g. hospitals, it became common to have a single set of notes that travelled with the patient through the institution and were retained centrally. With the development of multi-clinician GP practices and health centres in primary care, this has become more common generally.

Historically, records were rarely shared with other clinicians outside the institution, except through referral or discharge letters passing on relevant details. Extracts (or copies when photocopiers came into play) might also be taken for research by others (usually clinicians) - though normally with name and address omitted or blanked out.

Four aspects have changed this status quo:

- first, new legislation introduced rights for data subjects, including the right to access their own records (though some clinicians had been supporting this for many years previously);

- secondly, the introduction of computer systems changed the way medical data was used and has enabled medical information to be shared more easily between institutions providing care;

- thirdly, the advent of clinical governance measures and the introduction of decision-support software has meant that general information on treatment needs to be shared to gauge safety and effectiveness;

- fourthly, the growth of team-based multi-professional care and shared care across organisational boundaries.
This has led policy-makers, clinicians, and the public at large to reconsider the traditional position concerning the use of medical information – though not necessarily with the benefit of a full insight into current uses (or how uses might need to change in the future to reflect the changing needs of medicine in modern times) or the changing nature of health informatics itself (in terms of what is actually possible and what controls might be created through the use of appropriate technologies). Where privacy had been a relatively minor issue in the past, it is now becoming a key aspect of medical systems design and development.

Public Attitudes

Public concerns

Establishing public concerns about the privacy of health data poses problems because, from the few surveys that have been performed, it appears that only a small proportion of the public have a strong opinion and fewer still have an understanding of the complex issues that need to be weighed up when arriving at an opinion. Some of the areas of concern identified by studies and from domain experts are:

- Inability to gain insurance/higher premiums (mainly USA)
- Possible difficulty getting a [new] job
- Social stigma
- Revealing hidden past
- Revealing current identity/address to abusive life partner
- Revealing illicit activity (e.g. gaining drugs from different doctors)
- Invasion of privacy
- Revealing activities in sexual and illicit behaviour to parents or partners

People’s actions to control their confidentiality risk

When people are faced with unknown issues or uncertain levels of risk, they will tend to choose options which defer or remove the problem or at least give them some measure of control. Concerns over BSE and MMR led the some of the public to reject eating beef and avoid vaccination – even though the risks in each case were actually extremely small, especially when put alongside the risks posed by smoking or driving a car. They may equally make choices in reality or in response to surveys that have little to do with what might be a more considered opinion given the time, inclination and sufficient information or education on the topic. Some of the actions to limit information disclosure that individuals have been noted in the literature to make are:

- Defer or do not seek care
- Seek care privately or through centre outside usual area or even abroad
- Provide limited or incorrect information to clinician
- Ask clinician not to record data
- Ask clinician to record data in limited form
- Ask clinician to restrict access to information by flagging or sealing information
- Seek trustworthy clinician or centre with better security controls
- Do not disclose information at all

We should note the obvious case study of sperm donors who had their anonymity removed by a change in the law, leading to a dramatic drop in donations. This underlines the often voiced need for assured confidentiality in healthcare so that patients seek help and can be open with their clinicians in order to receive appropriate care – though this need to provide appropriate care is also used to justify computerised records, and hence wider access, in order to provide all relevant data to the treating clinician.

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2 In 2000, 325 sperm donors were newly registered with the HFEA but in the first six months of 2005, only 99 men were registered. – BBC - news.bbc.co.uk/1/hi/health/5230890.stm (accessed 22/04/07)
Public and Professional attitudes to privacy of healthcare data

Real-world experience

Many of the studies utilised questionnaires or focus-groups where individuals make a considered response about the choices or preferences they might make within a scenario – this is very different from having to make a real-world choice. However, the real-world is also more restrictive and may not provide the range of choices that a person would prefer to have, so may not reflect true ‘public attitudes’.

There were five UK studies which have provided the public with real choices to be made: the North Hampshire Central Record project, the South Staffordshire Patient Consent Project, the EHR project at Wirral, the recent Early Adopter experience at Bolton, and the Emergency Summary Record in Scotland.

North Hants. used an ‘opt-out’ model which clearly only tests for those with a sufficiently strong motivation for privacy to take active steps to opt-out, possibly influenced by the extent of their trust in the organisations concerned or the perceived benefits to accrue from such sharing. (These findings might not be true of wider sharing or in systems or organisations where they may be less cause for trust). The dissent rate was about 0.1% (1150 from 1.3m)

The South Staffordshire project suggested a vanishingly small dissent rate, but the low response rate could have been due to poor information provision or retention by the public – as only 38% could recall the information even after prompting

Wirral and the Scottish experience suggest a dissent rate of 0.01%. However, the choices offered by these four projects may have differed somewhat, and, as the Wirral experience shows, it may take some time for the full ‘opt out’ to take place.

Public uncertainty over ‘confidentiality’

Sankar et al (2003) and Jenkins et al (2005) show that a section of the public is very uncertain about confidentiality and what it may mean. This reinforces the view that ‘public attitudes’ to privacy may well be unformed and only crystallized when presented with a choice either as part of a survey or in real-life. It may also serve to explain why results from real life seem so different from surveys.

There is a perceived gap in the public understanding about privacy and confidentiality, and how privacy and confidentiality is legislated for by governments, healthcare organisations and professionals. Carman & Britten (1995) highlight the assumption by patients that clerical and nursing staff have no or limited access to information, when in reality this is not the case.

Jenkins et al (2005) show that the understanding of the public varies from the actual legislative instruments that are in place. This may indicate a set of presumptions and expectations on the part of the public that are unrealistic and unachievable. Further education is called for, as well as a greater appreciation on the part of the professional of these wide-ranging expectations and understandings.

Security as a basic qualifying requirement

It is clear that, except for a minority, people expect their medical records to be held securely, and without this they would not consider any uses or accessibility outside the immediate clinical framework – indeed they will then start applying some of the mitigation strategies identified above to limit their risk of embarrassment or harm.

The Markle surveys in the States show that there is support for a shareable electronic healthcare record, provided that there were certain mechanisms in place to protect privacy and maintain confidentiality.

Asai writes that in an interview of 14 Japanese non-professional men and women, there was a sense of sharing data being entirely appropriate for the benefit of society, but that there were undeniable expectations about the maintenance of privacy.
Ownership of records

There is a far greater sense now of ownership of one’s medical records than previously. This is clear from Asai and from Jenkins et al (2005) (“I own this data and why should anyone else see it?”). The ownership issue has greater emphasis in Sankar et al (2003) and Jenkins et al (2005) than in Carman & Britten (1995). Debate about ownership may not be useful, but that does not mean that it does not affect public attitudes, even if based on a misconception.

Changing attitudes to computerised records

Carman discusses that the notion of computerised records was perceived as a great threat to privacy and confidentiality in 1995. The Markle surveys of the last four years however show great support from the public for the use of the electronic healthcare record that would aid decision support, provide patients with access to their own records and improve quality of care. These changes may reflect a movement in public attitudes to computers from threatening objects in science-fiction films to commonplace tools that are rapidly becoming indispensable in many walks of life. Note that this is not necessarily perceived to be of benefit by all – a number of people avoid having a bank account to avoid being monitored (whether this is for ethically appropriate reasons, e.g. to conceal crime, is a different question).

National and Cultural Variation

There are likely to be cultural differences in the values that people ascribe to revealing medical information about themselves – different taboos and social norms come into play, though these variations may be less clear-cut than formerly due to migration and globalisation/Westernisation.

Different cultures will place different emphasis on obligations to support others and society at large. Western cultures generally place a greater emphasis on individual rights and freedoms – in Mediterranean and Eastern cultures there may be a greater emphasis on the family rather than the individual as the decision-maker in choice of healthcare – this may affect their attitudes to data-sharing and privacy. Attitudes to mental health problems can vary hugely between societies.

Levels of trust in government agencies and professionals will depend greatly on culture and recent social history. Where there has been information abuse in the past (e.g. East Germany where the Stasi held detailed files on most citizens), then there is likely to be greater concern about sharing of medical information – though this may be offset by a greater familiarity of how to avoid revealing critical information in the first place.

The risks associated with data-sharing and breaches of confidentiality will also vary by the social structures in a country. Where healthcare is state-provided and universal, then there may be less financial risk through revealing health information. In the United States, where 50% of healthcare depends on private insurance contributions, then there is a far greater need to control who knows ones health information – even if it might be argued that one is obliged to reveal all relevant medical facts in order to gain health insurance and failing to reveal relevant information might leave one exposed with no health cover at all. Given employers often pay the health insurance premium in the USA, then health information becomes more of an issue in order to gain or retain a job (especially as there is far lower security of tenure).

Equally, different health systems will have different approaches to medical records. In France the patient used to retain their paper health record (it now tends to be duplicated between the patient and the provider), and so will be more habituated to having control of their data and when it would be shared. In America, health records tend to be fragmented between different care providers, though HMOs have introduced EPRs to manage care better – patients will still, however, have a greater responsibility in managing their healthcare cover and the delivery of healthcare than would be the case in the UK, where there is an integrated healthcare system (even if medical records are still distributed).

These aspects need to be borne in mind when drawing comparisons with results from overseas, notably America where many surveys have taken place and where health insurance is a more prevalent concern.
Differing values and attitudes

Beyond the cultural aspects noted above, individuals will have different sensitivities to ‘privacy’ as a concept and one might attempt a ‘market segmentation’ to gauge how these sensitivities may vary across the population. Gostin et al (1993) suggests that 30% of Americans are ‘privacy fundamentalists’; Detmer (2000) identifies 55% of Americans as ‘privacy pragmatists’, where they will trade privacy for health or financial gains, with a final 15% being ‘privacy unconcerned’.

It is clear from real-life reports that those ‘actively concerned’ (viz. will actually make the effort to object) may be less that 1% of the UK population and possibly smaller still. Equally, around 5%-10% of the population express serious concerns when asked (e.g. the South Staffs project had 7% actively enquire about their record; Shickle et al (2002) had 5% object to their GP seeing their medical record; Barrett et al (2006) had 5% feeling that a letter inviting them to participate in a cancer registry was an invasion of privacy).

At the other extreme, there is clearly a section of the population who are relatively unconcerned, subject perhaps to appropriate safeguards: Biobank had 10% of people mailed actively sign up; the IHF/Gallup survey in 2000 had 5% feeling that privacy of medical records was ‘not too important’ with a further 3% feeling it was ‘not at all important. This latter group might perhaps be labelled ‘privacy nudists’.

There may also be differences in opinion over the question of permission: some believe strongly in a ‘right to privacy’ and feel that no data can be used without explicit and precise permission, others may be more relaxed over some areas, but feel that anything outside healthcare would require permission, a further set accept wider use, but feel that permission should be asked perhaps more as a courtesy than a legal requirement; and again there is a final minority who don’t expect to be asked at all (but then may chose to withhold data as a result). There is little survey data to support this, but reflects comments made in focus groups. This may reflect individual understandings of the ‘ownership’ of medical records between ‘it is my data’ and ‘it is their data’.
Professional Attitudes

Areas of professional concern

Professionals are, of course, people, so, at one level, they should appreciate the needs and concerns of members of the public. However, they also have their own professional interests and may become inured to concerns that might impact upon them as citizens, especially as they are often coping with rather more immediate and pressing issues when dealing with patients, so may not reflect the values and opinions of the average member of the public when asked about the issues involved. Clinicians may be more involved in the actuality of using medical records and so have a different perspective, especially as they might be on the receiving end of any legal or disciplinary action for breach of confidentiality.

It should be noted that this section of the discussion is limited in scope to doctors, given the bias in the available literature to this professional group.

General Practitioners have different financial interests to hospital consultants as they are generally self-employed (at least in the UK) and may have other reasons to champion patient privacy rights than a simple dedication to professional ethics. They may also take a wider and more holistic view of the individual patient, and may be more aware of the patient’s social environment than would be common for a hospital consultant. They may feel a greater obligation to act as the patient’s proxy to protect their privacy.

Hospital staff also work in larger organisations and are more used to sharing data within their organisation and may, perhaps, be more habituated to a looser interpretation of personal privacy as far as medical records are concerned.

Professional concerns may result from the reading of studies or opinion pieces in professional journals or by pronouncements by professional bodies (e.g. BMA, RCGP, etc.)1. The latter are clearly very likely to influence the opinions of the profession as a whole, either as weighty arguments or as professional directives which should be followed. However, the scope of this survey has been taken to be that of the profession as a whole rather than publications that may represent the views only of a select group within the profession, even if better informed than the profession in general.

The Medix/NPfIT survey identified the following areas of concern

- Outsiders hacking into the system
- Access by public officials outside health or social care
- Inadequate access controls
- Bribery or blackmail of people with access to the records
- Social services staff not adhering to the rules
- Clinicians not adhering to the rules
- IT technicians not adhering to the rules
- Researchers not adhering to the rules

Other studies have contributed the following additional concerns:

- Patients will withhold vital information because of security concerns ii
- Patients may not seek care because of confidentiality concerns
- Concerns over gaining consent
- Concerns over security of [NHS] systems
- Legal uncertainties and possibility of regulatory action against clinician, e.g. breach of human rights

These conclusions are supported by the results of the South Staffordshire EHR Project: Baseline Questionnaire Report (YICHI 2002), which also included concerns about access to staff medical records.

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1 As an example: Inquiry into the electronic patient record and its use - response from the British Medical Association (March 2007) www.bma.org.uk/ap.nsf/Content/HSCresponseEPR

ii Doctors lie to protect patient privacy – press release by Association of American Physicians and Surgeons (AAPS)

iii Keshavjee et al., Patient and Provider Health Data Privacy Concerns, (2007)
Clinicians’ concerns over privacy with electronic patient records:

The Medix survey in November 2006 found that many doctors think a national electronic record will bring clinical benefits for patients (58% of GPs and 69% of non-GPs, mainly hospital doctors), but will also bring a big threat to patient confidentiality (79% of GPs and 55% of hospital doctors). When asked to identify the three most important concerns about confidentiality, 62% of GPs and 56% of hospital doctors said they were worried about “outsiders hacking into the system”; 62% of GPs and 51% of hospital doctors similarly feared “access by public officials outside health or social care”. Other big fears included “bribery or blackmail of people with access to the records” and concern about “clinicians not adhering to the rules”. A similar Nursix survey for the RCN in 2007 indicated that 31% of nurses felt that EPRs threaten patients’ confidentiality while 43% disagreed with this (equivalent figures for 2006 were: 39% and 28%, though the question was slightly different). However, 39% felt that the EPR would be more secure than the current paper-based system with 32% being unsure. As this is the only evidence on nurses’ opinions (albeit indirectly), it is hard to discern why there is such a variance with doctors’ opinions, except that in the same survey 66% of nurses felt that they had had no consultation over EPRs.

A report in June 2006 in The Guardian noted that of 787 doctors contacted recently by researcher Medix for the BBC, 44% disagreed that the proposals to maintain confidentiality of records [within the NHS Care Records Service] were satisfactory, while 21% agreed. Among GPs, 57% disagreed and 13% agreed.

The objective of Gadd and Penrod (2000) was to identify significant concerns of physicians regarding the adoption of an EMR in an outpatient clinic, both prior to implementation and after 6 months of use. However, there were only 5 clinicians in the initial sample (it was hoped to extend this with wider roll-out of the programme). Their attitude to privacy under EMR went from slightly positive to somewhat negative after implementation.

In Gadd & Penrod, patients (N=165) gave a moderately positive response to 'With my medical files in the computer, I feel that my privacy is more secure than it was before.' 3.64 from a scale of 1-5. However, it was quoted from the professional focus group that ‘A small percentage of patients were concerned about possible breaches of privacy through use of an EMR. This sub-group’s concerns over privacy accounts for the slightly lower mean score on the Physician Computer Use Scale compared to the General Satisfaction Scale.’ It is not clear whether this was surmised by the researchers or directly from comments by the clinicians. If the latter, then clearly professionals’ attitudes may reflect, at least to some degree, those expressed by their patients – but it should be noted that they may be influenced by a vocal minority (though possibly those most at risk).

Understanding of confidentiality issues and regulatory procedures: One study (Davis et al, 1999) showed that even new medical students (presumably fresh with training) had major uncertainties about confidentiality guidelines. This lack of professional knowledge in this area is echoed by comments in other studies (e.g. Slutsman et al (2003) and Medix and Nursix surveys, where staff felt insufficiently briefed over these issues)

Gaster et al (2003) assessed physicians’ use of and attitudes toward electronic mail (e-mail) for patient communication. Those physicians who reported using e-mail with patients reported high satisfaction with its use. It was found that most physicians did not discuss e-mail security with their patients and did not document patient e-mail communication in the medical record, despite published guidelines recommending that such practices be routine.

This suggests two possible issues:

- the extent to which clinicians think about confidentiality issues when adopting new technologies, such as electronic mail

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1 http://politics.guardian.co.uk/homeaffairs/story/0,,1792762,00.html – accessed 17/04/07

2 There may have been a follow-up presentation to AMIA in 2001, but we were unable to locate the proceedings
• That clinicians need clear guidelines and advice on patient confidentiality and computer use (including email, PDAs, smartphones) - or need encouragement to read and understand the advice already available.

**Doctors options to protect patient privacy:**

Serkes (2001) conducted a postal survey of 344 physicians in July 2001 by the Association of American Physicians and Surgeons (AAPS) which showed almost unanimous opposition to the HIPAA (Health Insurance Portability and Accountability Act) privacy rules, scheduled for full implementation in 2003. A surprising 96 percent thought the rules would further compromise patient privacy. Some of the other questions asked in the survey provide further clues about the practical effects of the rules:

• Physicians believed that third-parties ask for information that the physicians believe to violate confidentiality, with 51 percent reporting such requests from government agencies and 70 percent from health plans.

• Nearly 87 percent reported that a patient had asked that information be kept out of the record, and nearly 78 percent of physicians said that they had indeed withheld information from a patient's record due to privacy concerns.

• While only 19 percent admit to lying to protect a patient's privacy, 74 percent state that they have withheld information for that reason.

Thus, the patients sometimes withhold information and doctors sometimes misreport or withhold information because of privacy concerns. The AAPS paper concludes that these attitudes will lead to distorted, incomplete and potentially dangerous medical records.

Slutsman et al (2003) in a mailed survey of 1848 physicians conducted in 2003 by Johns Hopkins University, (Baltimore) showed that almost half (48.4%) physicians reported discussing confidentiality of health information with their patients. Only 4.5% of physicians in the sample were unaware of the HIPAA Privacy Rule. A minority of physicians (20.9%) agreed that HIPAA would assist them in protecting patient privacy. The belief that several specific HIPAA requirements would improve the protection of patient privacy was inversely related to knowledge of the HIPAA requirements. Here it is clear that the physicians are aware of the importance of confidentiality and have discussed this issue with their patients. However, many physicians do not believe that implementing the HIPAA privacy rule will improve their patients’ privacy. This may be from a belief that their ethical and professional obligations, not regulatory mandates, assure patients’ privacy and confidentiality. Some physicians may have misperceptions about the rule’s requirements and believe them to be more draconian or expensive to implement than they really are.

The Medix survey in November 2006 showed that nearly half the doctors who saw clinical benefits from a national record thought the confidentiality risks worth taking. But only 11% of GPs and 18% of hospital doctors were prepared to upload details without the patient's consent; half the GPs would consider refusing to put patient records automatically on to a new national database.
Reflections

Public Attitudes

There are areas of public attitudes and anxieties that are not well studied, such as what the public actually know about use of medical records and the related privacy issues, what the public expects in terms of controls around use of medical records, and what factors affect their opinions and choices in this area.

Nevertheless, it is clear that people have personal values and beliefs which usually matter more to them than a rational assessment of the situation. At the extremes, some people will want full control of their data, either from a sense of control or a belief that that is simply their right (even if constitutionally wrong); at the other extreme some might have no idea that there is any reason to hide anything, being perhaps socially naïve, ignorant, a compulsive exhibitionist, or trusting in the integrity of healthcare professionals to protect their interests.

Equally, people split into ‘satisficers’ and ‘optimisers’ (Herbert Simon 1959)\(^\text{14}\), so that the majority will make do with what is necessary to get by, whereas a minority, usually, will seek to gain the best arrangement. Many will be prepared to compromise, whereas a few will want an ‘ideal’ solution. A further group of people may react extremely to uncertain situations, depending on how information and the nature of the risk is presented\(^\text{15}\).

Further there seem to be some who feel a total loss of control, and feel that there is no point worrying about what they can’t stop.

Actual concerns, as expressed in focus groups but possibly directed by questions, appear to centre around:

- Who can access the data and why?\(^\text{i}\) – a sense of appropriateness
- Personal control\(^\text{ii}\) – a wish to limit risk and to feel in control by being asked (even if refusal were unlikely)
- Social stigma\(^\text{iii}\) – protecting taboo areas
- Personal circumstances – keeping information from partners, parents, children, friends and family\(^\text{iv}\)
- Financial implications\(^\text{v}\) – job applications, insurance
- A sense of personal space or autonomy\(^\text{vi}\)

The authors have needed to be conscious of the framing of the questions posed in a study – some studies have deliberately taken a deontological approach, seeking to find what is felt to be the ethically correct approach; others have taken a more utilitarian angle, exploring trade-offs between confidentiality and the benefits of wider access to medical records.

An individual’s choices will be determined by their behaviour in relation to privacy (propensity to share or control), their general approach to risk and their circumstances, which may affect their judgement of the risk involved in sharing or not.

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\(^{\text{i}}\) Almost all articles have touched on this: Schickle 2002, Carman 1995, NHSIA/MORI 2001

\(^{\text{ii}}\) Carman & Britten 1995

\(^{\text{iii}}\) NHSIA Share with Care 2002, Carman & Britten 1995, Jones 2003

\(^{\text{iv}}\) Sankar et al 2003; Carlisle et al 2006

\(^{\text{v}}\) More obvious in USA studies, e.g. Westin 2005

\(^{\text{vi}}\) Gallup 2000, Jones 2003
Other aspects

There are some other obvious areas that might affect people's choices or their ability to make choices:

- Age – cultural aspects and values may vary with the generations; older people are more likely to have been ill or perhaps to have had some incident in the past which they would prefer to conceal; conversely they may become more relaxed over time, feeling that particular matters were a long time ago and now less sensitive; the young may be less experienced and not yet realise the consequences of certain disclosures;

- Education – this may give an advantage to knowing or understanding better what may happen with ones medical data (for good or ill) or for determining strategies to hide ones data; or, with a likelihood of better economic position, to be able to choose private care and manage ones confidentiality risks separately

- Gender – A Gallup poll suggests that women are statistically more likely to have confidentiality concerns than men, whilst Jenkins et al focussed their study on women’s views on medical confidentiality because of the more frequent clinical contacts that are required for the female reproductive system, as well as the trend in the US for women to administrate the family’s healthcare needs. There was no evidence of an equivalent male survey. Furthermore, sexuality and individuals who have had gender reassignment performed may yield further insights – there is no evidence of any studies beyond the report cited by Shickle et al (2002).

- Current or previous state of health: Harris et al discuss that individuals with fair or poor health have more privacy concerns. There would after all be more records and details about them and possibly a greater need to share them, which may give rise to different opinions and possibly to greater anxieties. Conversely, though, there might have been a greater willingness to share data to improve their own health care, as suggested by Princeton Associates (1999).

Changing attitudes over time, and acceptance of technology

There is some indication, though little hard evidence as comparable figures do not exist and the framing of questions has changed over time, that the public is becoming more familiar with computerisation, and indeed may expect their medical data to be used more effectively in the provision of their care. However, this does not mean that their underlying concerns over the privacy of their medical data have changed fundamentally, only that they are better placed to understand the risks and benefits that are involved. The 1984 ‘Big Brother’ concern may have morphed into the vision of the Amazon model of using personal information to provide a better ‘customer experience’, but tempered by worries about email spam and ‘phishing’.

Issues around the confidentiality of genomic data:

While not based on survey data, Claerhout (2005) notes reported concerns about the proper treatment of the increasing volumes of sensitive personal data. Abuse of sensitive personal healthcare information could lead to financial gain and have an adverse impact on society, for example, if banks, insurance companies, employers, etc. could access healthcare data about their customers, revealing past, current and probable future (cf. genomics) health conditions.

Some of the key issues with genomic data were identified as:

- Genetic data not only concern individuals, but also their relatives. A person’s consent to release his or her genetic information constitutes a de facto release of information about other individuals, i.e., his or her relatives. In the case of genomic medicine, there is a complex interaction between individual rights and collective rights.

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1 Public Attitudes Towards Medical Privacy, Gallup Poll 2000
2 A qualitative study of women's views on medical confidentiality, Jenkins et al
3 Louis Harris & Associates and Alan F. Westin, The Harris Poll #27, 2007 Many U.S. Adults are Satisfied with Use of Their Personal Health Information
Medical data deal with past and current health statuses of persons, whereas genetic information can also give indications about future health or disease conditions.

The full extent of the information included in the genomic data is not known yet, hence it is difficult to assess the full extent of disclosure.

Genomic data are easily wrongly interpreted by non-professionals, ‘susceptibility’ to diseases can easily be mistaken with certainty or predictability of illness.

Public understanding of these matters is unclear, perhaps partly due to the evolving nature of knowledge in this area, and confusion over matters such as cloning and DNA identification. There have been a number of studies over public attitudes to use of genetic techniques and the science in this area, but few on the use of genetic data alone in the context of privacy. Voss (2000) cites 6 in total, 5 on access to genetic tests by employers or insurers and one on genetic sampling and databases. There have been a number of further studies since Voss, but mainly on recruitment to genetic studies and biobanks, and so falling outside the brief of this literature review. Relatively little research seems to have focused on the social implications of genetic data, viz. what might be revealed about a child’s parentage and any possible social stigmatisation, e.g. pre-marriage screening for hereditable diseases.

Professional Attitudes

Relatively little has been done directly on professional attitudes to privacy, perhaps as it has been assumed that professional training in ethics ensures that all clinicians understand and respect confidentiality, so there is nothing to research. Where studies have looked at professional attitudes to new ways of working or the use of new technologies, then privacy of healthcare data has occasionally surfaced as a side issue.

Professional concerns

However, from the literature studies several professional concerns have been identified:

- Breach of legal or ethical standards
- Risk to doctor-patient relationship
- Risk to patients through delaying or not seeking care because of disclosure fear.
- Loss of control or power through greater data-sharing or greater transparency or loss of power through data sharing with patients.
- Resistance to change (though rarely stated or questioned)

A professional may be influenced by:

- their own situation as a person (being well, risk-averse, trusting, or not as above) – there may be some general ‘physician cultural’ aspects through training and professional culture (generally critical and somewhat cynical in the UK if media reports are to be believed);
- acting as a proxy for their patients – this may be biased towards the more vociferous patients or those with greater confidentiality risks
- past training and learned behaviours (so answers may justify current practice rather than ab initio beliefs or considered opinion);
- personal risk (of breach of legal or regulatory guidelines), which may weigh more heavily on the self-employed than the employed (where the employer may bear more of the risk);
- lack of personal control over new shared record systems and possible change in power balances (between professions, versus NHS organisations, or versus patients).

Any of these may explain some of the observed variations between GPs and hospital doctors, e.g. in Medix surveys. It would be useful to know more about such possible variations and to have comparisons with other professions.

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There are insufficient studies to give an authoritative view on the attitudes of professionals towards privacy and the introduction of EHRs. Uncertainties around the adequacy of controls are clearly a major concern, but it is not clear whether this concern is a personal one around liability as a professional or a professional concern for the wellbeing and interests of their patients.

Nothing is known about the perceptions of other staff – though it would seem doctors, who often are the researchers in this area, do not feel that other staff are important or necessarily trustworthy: South Staffs Baseline Report 2002; Medix/NPHIT survey Nov. 2006

Professional attitudes around genetic data are unclear. The Cragg Ross Dawson report (2000) for the MRC shows some general concerns at that time. The effect of the Human Tissue Act 2004, which came into force in September 2006, is still working its way through the system and may add to professional uncertainties as to appropriate practice in handling confidentiality, particularly over aspects of consent. Extracted DNA is not covered, so that genetic information should not be affected, except by the circumstances surrounding the consent for the original tissue sample.
Conclusions

- **Public attitudes are not uniform** – and are often either ill-informed or unformed – as noted by Sankar et al (1995) and others

- **People do not have a single ‘belief’ in terms of privacy of healthcare data** – their approach to ‘privacy’ is multi-dimensional and contingent on circumstances; a small percentage wish to guard their privacy, while others are unconcerned, but the majority have a more contingent view.

  - this will make it difficult to use the results (such as they are) as a basis for deciding on privacy policy

- **The public do have a number of areas of concern** (though these may not be enough to lead to definite action), which may help direct where policy decisions need to be made:

  - **Personal risk from disclosure**, social and/or economic implications should key information fall into the wrong hands – this will be helped by greater transparency in the controls applied either to de-identify data or to control to whom and how access will be permitted, to ensure any that risk can be assessed based on the facts rather than hearsay or imagined threats

  - **Ability to control the risks**, knowing what options are available to limit the risks without simply avoiding treatment or providing only partial information during encounters; the greater the range of options, then the more people are likely to feel comfortable about their privacy, particularly if they know they can change their minds

  - **Trust/distrust – in actors and in systems**, trust is often used both in support of a considered decision and sometimes instead of it; doctors have enjoyed considerable public trust while governments have not (MORI and Eurobarometer surveys), leaving the NHS itself in an ambiguous position – researchers/scientists are moderately well trusted, provided they do not work for a commercial organisation; computer systems have had a bad press generally, but are gradually being accepted as a necessity of life; who may have access to personal data is a key factor here; transparency and openness are key signals to encourage trust, particularly to assuage ‘Big Brother’ concerns

  - **A sense of ‘rights or autonomy’**, for some there is a strong sense that it is ‘their’ medical record and that there is an obligation for people to ask for access; for others this may be less strong, but still feel that permission should be sought, if only as a matter of courtesy or a sign of trustworthiness (‘why wouldn’t you ask?’)

Whatever the actual concerns, it is clear that people have varied opinions, based on their personal history, values, and circumstances. It would be unwise to assume that everyone perceives the issue of privacy in the same way.

- **Assessment of public attitudes is dependent on framing of the subject**, particularly as to whether a practical or theoretical choice is being put forward.

  Barrett et al 2006 show that the public will appear very much in favour of an altruistic database (though not without reservations), where the framing is in terms of the benefits to be gained, not the ethical principles involved – indeed the questions were framed to suggest deficiencies in law in not supporting the National Cancer Registry.

  Other studies, such as Jones 2002 show that once principles are set as the frame, then consideration of practical issues may have only a minor effect on stated attitudes (though this may have been affected by the fact that patients were completing a questionnaire straight through with little time for reflection, hence the increase in some ‘don’t know’ answers).

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1 The reference is to Orwell, G ‘Nineteen Eighty-Four’ 1949 – rather than the television show
This may also explain why ‘real world’ cases have such low rejection figures, not only is the situation set as being positive, but also (to some degree) inevitable, even where opt-out choices are provided.

- **There is some evidence that the public is becoming more reconciled to the benefits of electronic systems** against the potential risks involved, probably through greater exposure to the Internet. In the early 1990s when uncertainty over the Internet was greatest, there seemed to be considerable concern about electronic records – towards the turn of the century, fears have been replaced by firmer expectations, and perhaps surprise that health systems are so poorly advanced. Clearly such adjustments in thinking are mainly going to be amongst the younger or better-off with greatest exposure to online facilities.

- **Professionals too have a number of areas of concern**, mainly around legal uncertainties and how to meet legal requirements:
  - **Asking for consent**, when is it appropriate to only wait for objections, when should detailed explanations be given and a positive agreement sought before proceeding (to record or share information), or when should a formal consent be obtained.
  - **Adopting new technologies, such as email, EHRs**, professionals are uncertain about the security of such approaches, the benefits and risks surrounding new ways of working, or simply uncertain how to accommodate them and/or their patients’ expectations.
  - **Allowing patients to read their records**, just as some patients may view the medical record as being ‘theirs’ so too may some clinicians, While in the UK, this is now a legal requirement, it may not prevent a professional sense of unease.
  - **Sharing of records with other professionals or institutions**, while this may reflect valid concerns about legality or appropriateness, it may also reflect uncertainties about the suitability of data recorded in one context to be able to be used in another; it may also show a reluctance to adapt to new boundaries and new ways of working (a perfectly human trait). Secondary use of data (including research) seems a particular area of uncertainty.

This may suggest a need to clarify liability issues in relation to the adoption of EHRs and the accuracy of records, as well as to clarify how work practices may need to change and to provide appropriate training.

The degree of awareness of an average doctor regarding the issues around privacy of EHR is not known. There is certainly a dearth of data on which to draw conclusions.

**Other Aspects**

**Immediate Needs**

- Guidance on privacy protection measures, both for computerised activities and also for clerical procedures
- Clear guidance on the role and acceptability of EHRs
- A clearer definition of consent and its acceptability in various contexts (e.g. when it must be ‘express’ and when and how it may need to be recorded)
- Clearer indications of how data will be used and accessed; what may be passed to colleagues; what should be available in an EHR as part of modern medical practice.

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Longer-term Initiatives

- Improve education of professionals in privacy measures in computer systems and usage – this should include ‘social engineering’ risks, particularly within healthcare management aspects of professional curricula.
- Some thought needs to be given to ensuring that issues of privacy are not made indistinct from evaluating a new EHR system.

Areas needing further investigation

- Public understanding and attitudes to use of genetic data (as opposed to tissues) in a social rather than scientific context
- There are more areas in which research results seem to be insufficient and hold potential for further research studies, such as
  - Attitude of wide range of professionals in primary and secondary care towards privacy.
  - Concrete impact of new technologies on clinician-patient relationship in respect of trust and data-sharing.
  - Impact of sharing records on clinical decision making and note keeping.
**Addendum**

Various matters of interest have been reported since the report was formally completed in August 2007.

**Patient Attitudes**

Dr Gillian Braunold was quoted in the Guardian (25/10/07 Out-of-hours doctors first to use NHS database) as saying that 237,000 patients in Bolton had been sent explanatory letters about the NHS database but only 2,200 had asked to opt-out, so giving an opt-out rate of just under 1% as against the earlier figure of 0.17% quoted in the main body of the report. This suggests that opt-outs may take some time to come through - this is reflected in figures from the earlier ERDIP pilot projects.

An article in Pulse magazine (05/12/07 Patients nervous over care records) refers to a survey of 2,600 patients conducted by Opinion Health for Pulse, where over half had concerns over confidentiality, three-quarters wanted to be asked for explicit consent and a quarter wanted to opt-out. The detailed results show some nuances: 66% were happy with the suggested opt-out approach (despite 73% just having stated they wanted consent first) – more importantly, there was no question which explicitly asked if people would opt-out – 25.5% did state they would not want their records uploaded based on the information given – which was a one-line description: ‘Supporters of Summary Care Records say they will give doctors access to crucial medical information more quickly; opponents fear uploading records may not be secure and could lead to a breach of patient confidentiality’. The survey was significant in size, but was somewhat partial in the style of questions and gave very little information on which people could make informed decisions (only 42% of people said that they were already aware of the Summary Care Record).

Willison et al, Alternatives to Project-specific consent for access to personal information for health research: what is the opinion of the Canadian Public?, JAMIA 2007;14:706-712 – surveyed 1,230 adults across Canada – there was good support for medical research use, but 4% thought that information from their paper medical record should not be used at all for research, 32% wanted consent for each use, 29% supported ‘broad consent’, 24% for notification and opt-out (for research use), with 11% feeling no need for consent or notification.

**Professional Attitudes**

The Guardian article (above) also mentioned a survey of 98 doctors (presumed to be GPs) in Bolton where two-thirds did not want their patient’s records uploaded to the NHS database. It is not clear whether this reflected fundamental issues of privacy or short-term concerns about security or readiness for the new system. The survey was performed by the Bolton Local Medical Committee – according to computerweekly.com: the question was: "Are you in favour of proceeding with the summary care record?" The question was sent to the 169 GPs in the Bolton area and 98 responded, 67 of them negatively, and 20 were in favour. The rest [11] were unsure.
## Glossary
### Terminology

<table>
<thead>
<tr>
<th>Phrase</th>
<th>Description/Definition</th>
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<tr>
<td>EHR</td>
<td>Electronic Healthcare Record – a health record covering all episodes of care ‘birth to grave’ across institutions – may only contain summary details rather than full clinical detail.</td>
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<td>EMR</td>
<td>Electronic Medical Record – Usually taken to be a health record based around an episode of care (often in secondary care context)</td>
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<tr>
<td>EPR</td>
<td>Electronic Patient Record – similar to EMR, but possibly linking episodes of care for the same patient within the institution</td>
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<tr>
<td>PHR</td>
<td>Personal Health Record - a health record designed for access by (and often controlled by) the patient themselves</td>
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### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>BMA</td>
<td>British Medical Association</td>
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<tr>
<td>DH/DoH</td>
<td>Department of Health (UK)</td>
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<tr>
<td>EHR</td>
<td>Electronic Health Record</td>
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<tr>
<td>EMR</td>
<td>Electronic Medical Record</td>
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<tr>
<td>EPR</td>
<td>Electronic Patient Record</td>
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<td>ERDIP</td>
<td>Electronic Record Development and Implementation Programme</td>
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<td>GMC</td>
<td>General Medical Council</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>GUM</td>
<td>Genito-Urinary Medicine</td>
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<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
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<td>HMO</td>
<td>Health Management Organisation (USA)</td>
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<td>MRC</td>
<td>Medical Research Council</td>
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<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>PDA</td>
<td>Personal Digital Assistant</td>
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<tr>
<td>PHR</td>
<td>Personal Health Record</td>
</tr>
<tr>
<td>RCGP</td>
<td>Royal College of General Practitioners</td>
</tr>
<tr>
<td>STD/STI</td>
<td>Sexually Transmitted Disease/ Sexually Transmitted Infection</td>
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Appendix A - Methodology Detail

Searches were performed using online resources and library resources at University College London and the British Library. Separate searches were made for public attitudes, professional attitudes, though with common themes (see below). Separate, but complementary, searches were made for grey literature, either through personally-known sources or through media references.

Searches were limited to English-language papers only, which restricted materials to the UK, USA, Canada, Australia, and New Zealand, and indexed proceedings of international conferences (and reinforced by sources such as PubMed, etc. which may be biased towards Western medical cultures).

Media sources were used as a possible source of references to governmental or other grey literature. Reports with no clear evidence of general attitude data, or no indication of how a sample of viewpoints was formally obtained, were ignored (viz. comments re ‘a number of frontline doctors’ could not be interpreted as representing other than an interested section of the profession).

These were supplemented by an informal search from personal archives and by use of personal contacts in the UK, Europe, Canada, USA, and Australia to supplement formal sources and to pick up on possible grey literature. Some of the material had been published on government web-sites in the past, but had since been lost through restructuring of these web-sites (www.doh.gov.uk and www.nhsia.nhs.uk being two notable examples).

Directed search on Public Attitudes to Privacy

Resources used

Online resources included:

- Search engine sites: google.com, yahoo and msn live
- Online bibliographic databases: pubmed, BMJ.com, REGARD, Citeseer
- British Library accessible resources: SCOPUS, Social Sciences Full Text, Australian Public Affairs Full Text Current Contents Connect, Economic and Social Research Council
- Online academic tools: Google Scholar and Windows Live Academic (both beta versions)

Further facilities at the British Library and UCL Central Library were used.

Queries that were used:

A very general set of words that succinctly described what we were looking for was put together as a statement:

public attitudes privacy confidentiality medical records.

Synonyms for each of the words were listed after checking an online thesaurus (Roget's New Millennium™ Thesaurus, First Edition (v 1.3.1). www.Thesaurus.com).

A few variants of the queries were submitted to the resources outlined above. These included:

- public fears privacy
- public fears privacy health data
- patients fears privacy
- patients fears privacy medical data
- personal fears privacy medical data

In the case of Google, basic operators could be used to enhance the scope of results whilst keeping the query simpler and therefore less likely to return unhelpful results. An example is as follows:

(¬public|¬patient) ¬attitudes (¬privacy|¬confidentiality|¬security)
(¬healthcare|¬medical|¬clinical) ¬data ¬studies
The parentheses allow for statements to be combined with the use of the bar (|) logical OR operator, which means that the search word “public” would be added to the rest of the search string (i.e. “public attitudes...”) and then the search would also return the results for “patient” (i.e. “patient attitudes...”), as well – essentially “find me public OR patient attitudes...”. The tilde (~) operator is used to search on synonyms for the search words. It is not known how effective the method for finding the synonyms as used by Google is, so the online thesaurus described above was still consulted.

Google was also used to reinforce the searches across sites like pubmed and Citeseer by using the “site:” command, which restricts the Google search to a specific site. For example:

```
site:http://www.pubmedcentral.nih.gov/ (~public | ~patient) ~attitudes
(~privacy|~confidentiality|~security) (~healthcare|~medical|~clinical) ~data ~studies
```

Results were retrieved from several different journals. These included the ones listed in the Search for Professional Attitudes section.

**Directed search on Professional Attitudes to Privacy**

**Resources used**

The following search engine sites and bibliographic databases were used:

1. Medline
2. Embase
3. Cochrane library
4. CINAHAL
5. Google (Advanced)

The following journals held at the UCL library were searched: BMJ, JAMIA, Health informatics Europe, Methods of Information in Medicine (MIM), UK Health Informatics Today (UKHIT), British Journal of Healthcare Computing (BJHC), Health Service Journal, International Journal for Quality in Health care, and International Journal of Medical Informatics

Health Informatics related websites/links checked were:

1. GHIFT - www.chime.ucl.ac.uk/resources/GHIFT/index.htm
2. National electronic library for health (NELH) - www.nelh.nhs.uk
3. Health informatics worldwide - www.hiww.org/jou.html

Library resources used were used: BL (mainly UK journals Books, grey literature) - URL: www.bl.uk/collections/health/health.html and IEE/BCS - www.iee.org.uk/

Media searched for references to studies: E-health Insider, BBC news, The Guardian, The Daily Mail, Onmedica

**Queries that were Used:**

The following key words along with their synonyms were used in various combinations for most sources.

```
<professional> <attitudes> <privacy> <records>
Where:
Later along with: ‘health privacy survey’, ‘professionals questionnaire privacy’, ‘professionals attitude study’, and ‘professionals confidentiality survey’.
```

**The following search string was used for ‘Google Advanced Search’**.
Public and Professional attitudes to privacy of healthcare data

~attitudes ~privacy ~records GP OR nurses OR physicians OR consultants OR clinicians OR doctors "patient"

The search was limited to English language articles published from 1996 to 2007.
The bibliographies of the identified publications were also checked for potentially eligible studies.

For other sources, a combination of:

<professional> <attitudes> <privacy> <records>

along with their synonyms was used.

Search for Grey Literature

As a back-up to the direct searches through recognised sources, personal sources were searched for related references (‘snowballing’) and personal contacts who were experienced in this field in Europe, USA, Canada, and Australia were asked for any parallel initiatives that might exist and what surveys or related papers they knew of and thought might be relevant. In particular, a CD-ROM, Electronic Records: Lessons from ERDIP, originally published by the NHS Information Authority in May 2003, was a source of a number of papers.

How Results were retrieved and short-listed

A reviewer was assigned to each of public (NL) and professional (AT) searches, while a third (PS) undertook the search for grey literature through personal sources.

Results of the searches were short-listed for review by checking the title of the paper and where a title seemed ambiguous, the abstract was read; so a decision could be made on whether or not the item was relevant or not. Brief summaries were made and relevance rankings assigned as follows:

Relevance Category:  1 - Very relevant - detailed in report  
                      2 - Highly relevant - referenced in the report  
                      3 - Relevant - read in detail by reviewers  
                      4 - Marginal relevance - abstract only reviewed  
                      5 - No obvious relevance (ignored)

All articles were read into Reference Manager Versions 10 and 11, using manual entry or online retrieval from Pubmed and other resources where available. Items covering both public and professional attitudes were flagged as ‘Both’. Sources and queries were also documented in an Excel Spreadsheet.

The results were combined to eliminate duplicates and identify common articles. The materials were then discussed to refine the ranking and to identify common themes between the two areas.

All rank 1 items were read by all the reviewers, including most of the rank 2 items.
Summaries for the rank 1 items were developed for including in the report, while points of note were identified for items ranked 2 or 3 to be referenced in the discussion.

The reviewers met again to agree the structure of the document and the key points that need to be raised (which resulted in the re-ranking of some of the items).
References

Relevant Web-sites

<table>
<thead>
<tr>
<th>Site Address</th>
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<tr>
<td><a href="http://www.privacyexchange.org/survey/surveys/surveys.html">http://www.privacyexchange.org/survey/surveys/surveys.html</a></td>
<td>Privacy Exchange list of Opinion Surveys</td>
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<tr>
<td></td>
<td>(unfortunately onward links often fail)</td>
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<td><a href="http://www.epic.org/privacy/survey/">http://www.epic.org/privacy/survey/</a></td>
<td>Electronic Privacy Information Center (EPIC) –</td>
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<td></td>
<td>general privacy surveys (rarely medical and</td>
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<td></td>
<td>mainly USA)</td>
</tr>
</tbody>
</table>

Bibliography

See separate file for full detail – only those papers only referenced in the commentary of this report are reproduced here.

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13 Nurses and NHS IT developments: Results of an online survey by Nursix.com on behalf of the Royal College of Nursing; http://www.rcn.org.uk/publications/pdf/nurses_and_NHS_IT_developments_survey_2006.pdf
