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People's views on Consent
and Confidentiality of Patient Information



Qualitative and Quantitative research

Final Report, October 2002

NHS Information Authority
in conjunction with
The Consumers' Association and *Health Which?*

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Background

Caring for health and caring for information

We are at a critical point for the NHS. It has begun a major programme to improve the information systems that are used to provide care to over 50 million people. Called the National Implementation Programme, or NIP, it will require large sums of money and make major changes to the way health care is delivered.

This paper summarises extensive research with patients and the public that is influencing the design of a key part of the NIP - a new system for managing patient consent and confidentiality in the NHS in the electronic information age.

Changing the way care is delivered

In times past health care was much simpler. A patient's care was given by a few individuals such as the family doctor and possibly a single specialist at the hospital. Patients were discouraged from asking for information about their health and had little or no choice over their treatment. Those times are rapidly disappearing and in many areas have long since gone.

The practice of medicine involves more people than ever before. The treatment of common conditions now requires many individuals to work in teams. Private hospitals and the voluntary sector are providing services to NHS patients. Community pharmacists are playing a bigger role in looking after patients and new services such as NHS Direct are changing how we gain access to care. Increasingly, health and social care are combining, particularly in care for elderly patients. And most significantly patients themselves expect and are expected to play a bigger part in looking after their own health.

People have more rights and responsibilities. The NHS Plan emphasises choice and the quality of services to the individual. What matters is "the service provided and not who provides it". It also means that the simple direct relationship between the patient and the single clinician no longer applies as it did. The patient now deals with a complex health system.

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The benefits of good information-sharing systems

Without access to appropriate information, a health system is, at best, inefficient and frustrating and, at worst, dangerous. Modern healthcare services cannot function without those involved having the information they need to provide and receive care. Their needs for information cannot be met without electronic medical records and other computerised systems.

Most GPs and hospitals now have some form of patient record on computer that can be shared among their own staff. At present however information is relatively “locked away” from anyone outside the particular hospital or surgery, not available where it is needed as patients move from one service to another to receive care.

More efficient information-sharing potentially offers great benefits - better health care; fewer lost records; more efficiently run hospitals with shorter waits for treatment; fewer medical errors; research leading to new treatments; more information about the relative performance of doctors, hospitals and treatments; and better protection of the public health.

In the not too distant future, patients too will have access to their GP and hospital records by computer, either in the surgery or at home.

Developments are not confined to health. The eGovernment initiative will enable many public services to share information so that citizens can do business with all public services more efficiently by computer. For example, someone having a baby might need health services, employment benefits, and rehousing. In future these should all be started from a single entry point or a single request.

What are the risks?

More efficient sharing of health information also presents some risks. As medicine develops, more will become known not only about people's present health but also about their future health. If this information is inappropriately shared outside the NHS, it may prejudice people's ability to get jobs, life insurance or mortgages. Information shared inappropriately within the NHS could affect the way people are treated by health and other public services (eg, about terminations of pregnancy, debt, literacy, or mental health problems).

One way to minimise the risks is to have informed patients exercising as much control as possible over who sees their medical information. Yet, safeguards must not create impossible barriers to information sharing for good care.

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What the law says

The Data Protection Act 1998, the Human Rights Act 1998, and the common law duty of confidence all protect the privacy of patients and their medical information. Patient information that identifies individual patients must not be used without the patient's informed consent. Depending on the circumstances, consent can be either be assumed or actively asked for.

Research with patients and the public consistently shows a high level of trust in the NHS to maintain patient confidentiality. In the past, this has not always been deserved. For the best of motives, the NHS has used identifiable patient information in ways patients could not foresee and so could not consent to: for NHS administration, health services management, research by the NHS and others such as universities and drug companies. The Information Commissioner, who regulates information privacy, wants to know that in future all health care providers will obey information privacy laws.

Why this research now?

The NHS Information Authority is developing a confidentiality management system for use throughout the NHS. Before we can create a confidentiality culture in the NHS, we need to understand confidentiality and consent issues from a patient perspective. Research with patients and the public is essential to determine what a confidentiality management system is required to do. In particular, we need to understand patient expectations of an electronic information system, including any potential concerns about electronic record keeping.

The results of this research are being used to design a new consent management system for the NHS.

In May and June of 2002, the NHS Information Authority, in conjunction with the Consumers' Association and its magazine *Health Which?*, undertook face-to-face qualitative and quantitative research with patients and the public.

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Research objectives

The research explored:

- what patients and the general public understand about how their data is currently used
- how the general public would like to see electronic patient information managed in the future.

More specifically, the research investigated:

- what people understand about how their health information is used
- to what extent they want to know about how their information is used
- who they trust to hold electronic patient information and who they trust to use it
- the types of information they would be comfortable to have made available across NHS services
- the types information they feel should be excluded from routine sharing
- the extent to which they wish to exercise choice and control over who sees their information and how they would like to exercise this control
- whether it is acceptable to release patient information to organisations outside of the NHS: to whom, in what format, and for what purposes
- how informed explicit consent can be obtained and when it is needed
- what priority patients and the public give to confidentiality and consent in relation to other activities
- if people in different circumstances (with HIV/AIDS, genetic predispositions to develop serious conditions, mental health problems, terminations of pregnancy, non-English speakers) have different views on all of the above.

A group consisting of members of voluntary organisations and clinicians advised us on the research.

Particular thanks are owed to Ben Steer of the Consumers' Association for overseeing all aspects of the research.

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Method

The research had both qualitative and quantitative parts.

Qualitative research

Qualitative research (discussions groups and interviews) was conducted for the NHS Information Authority, under the direction of the Consumers' Association through its magazine *Health Which?*, by Research Works Limited.

The research comprised both focus groups and one-to-one depth interviews. All participants were from socio-economic groups B, C1, C2 and D. All had experience of being referred from primary to secondary care in the last year, either as an in-patient or out-patient.

All participants in the qualitative research were shown a 12 minute video after initial discussion. The video described how the NHS uses patient information and how it protects people's confidentiality.

Focus Groups (referred to in this report as "the general public"). Four group discussions, focus groups, lasted on average 1.5 hours. Participants were in "middle life" stages (25 to 65) so that they had sufficient experience of the NHS. All four were single sex groups: younger women, older men, younger men and older men. Two were held in London and two in Birmingham in May 2002.

Face-to-face depth interviews (referred to in this report as special interest groups). Interviews were conducted in Birmingham, Brighton, Oldham and London in June 2002. They lasted on average 45 minutes. People were interviewed singly or, if they chose, in pairs. Interviewees were people with experience of HIV/AIDS (six), serious genetic disorders (three people and their three carers), mental health problems (six), and terminations of pregnancy (six). Twelve non-English speakers (of Punjabi, Urdu and Hindi) were also interviewed.

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Quantitative research

Quantitative research (a large-scale population survey) was conducted in July 2002 for the NHS Information Authority, under the direction of the Consumers' Association, by Ipsos Capibus. Results from the qualitative research were used to devise questions for face-to-face interviews with 2087 adults aged 15 and over in Great Britain. They were a representative cross-section of the population, interviewed as part of an omnibus survey. Unlike the qualitative group, they were given no information about how the NHS uses their information.

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Results

Main findings

- There was a high level of trust in the NHS to protect patient confidentiality, but low awareness of how the NHS uses patient information.
- If given a “virtual sealed envelope” to which they controlled access, about 60% of respondents would not want to put any or their health information into it. Around a quarter would want use it for a little bit of information, and 8% would want to put a lot or all of their information into it.
- Overall, people were more concerned about who used the information and whether it was anonymous than how the information would be used.
- People on the whole were comfortable with their GP, hospital doctors and emergency services having access to their data, though they reserved the right to limit access to very sensitive information (via the “virtual sealed envelope”).
- People felt that all others treating them should be allowed access to certain information at certain times, and only relevant parts of their record (ie, given information on a “need to know” basis).
- As a general rule, people felt that any information released outside of the NHS, or used inside the NHS for purposes other than treatment, should be anonymised - or patient permission sought to use identifiable data.
- Once information was anonymised, a majority in the qualitative group were happy not to be asked for consent to share it. Some would like to be informed as a courtesy.
- People differed in the qualitative and quantitative research over how their consent should be obtained for using identifiable information. The qualitative group was divided between wanting to be asked for a one-off consent, and wanting their consent to be sought each time information was used other than for treatment. By contrast, a third of the quantitative group wanted to be asked every time information was used, including for treatment. The discussion groups considered this option but rejected it as not feasible.

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- On the whole, women and “white” respondents required a higher level of consent than men and people from ethnic minority groups.
- People gave much higher priority to spending NHS money on patient care than on systems to enable better information sharing, to protect their confidentiality or to give them access to their own health records. This indicates a lack of understanding of how the four are related.

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Qualitative research results summarised

The research revealed that there was a high level of trust in the ability of the NHS to maintain patient confidentiality. However, it emerged that patients knew very little (and assumed a lot) about how their data was currently used by the NHS.

"I wouldn't have thought twice about it...If you knew my medical history - what use is that to you?" (male, 40-65 years old)

Confidentiality breaches

A minority of the sample cited breaches of confidentiality.

"If you go in for an emergency appointment ... you've got to fill out this paper that has just been photocopied, and write down what it is wrong with you. The receptionist looks at it and reads it out in front of everybody. And if you don't put down what's wrong with you, you don't get seen." (female, 20-39 years old)

A woman told how, after a serious operation, an insurance company wrote to her asking if she wanted to plan for the future after her recent operation. A man told how he had bumped into his counsellor socially and was introduced to the counsellor's friend as a client who had HIV. Another respondent had told his GP that he was gay. He reported that the GP made a point of saying that it wouldn't be written down.

"It didn't register at the time. But afterwards I thought why wouldn't you write it down. Who is going to see it apart from me and the GP?" (male, with HIV)

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Awareness of information sharing and use

Respondents had not typically questioned confidentiality and consent issues before the research and many presumed that greater levels of electronic record keeping and information sharing were already happening. During the course of the research respondents realised that they were not routinely told how their information was used, and that NHS staff (particularly in emergencies) did not always have access to patient records.

"...our doctors was closed and I had to go to another one because I wanted some tablets I was normally prescribed. I said, 'Well you've got it all on computer right?' She said, 'No, it's only on computer at your doctors, we don't know what your records are, we can't tap into them.' " (male, 20-39 years old)

"The thing that surprises me is how much they rely on your word when you're going in for emergency treatment." (female, 20-39 years old)

Restricting sharing of certain information

In the future, patients wanted patient information to be kept and managed within the NHS. However, a majority felt that the NHS should not assume permission to share whole patient records. The types of information they felt should be excluded from routine information sharing included: termination details, sexual health and mental health details. There was a particular concern that these details should not be shared with "single issue" care providers such as chiropodists and dentists. Further, patients felt that there would inevitably be other things individuals would want to protect from routine sharing. They supported the idea of a personal "virtual envelope" where individuals could secure sensitive pieces of information about themselves.

"You should be able to say you can have X amount, but not that bit there." (male, 40-65 years old)

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These concerns were supported by views from the special interest groups. It was indeed those with mental health or termination details on their medical records who were most sensitive to the idea of routine sharing. Both of these groups wanted to limit the number of people who had access to these particular parts of their record. In comparison, other groups (ie, respondents who had been diagnosed with HIV/AIDS or inherited genetic conditions) were much more concerned about information being released outside of the NHS where their health situation might have an adverse affect on their lives eg, financial security. These groups were also more concerned about information being available to ensure vital treatment.

"Having had an abortion, I'd rather they kept it to the clinic and my doctor, not put it in my notes for dentists and all to see. Really it's none of their business."

"I'd like mental health, depression, trying to kill myself all kept to one side. I'd like it if they wanted to look, then they'd have to ask me."

"The consultants need to know. You can't just leave the neurologist to know about the neurology stuff. They need to share." (Person with genetic condition)

"They could be there to save your life and the information about my HIV could be important. They might need to know."

Views on access

Overall, patients were most concerned about the information user and the format in which the information was supplied (ie, anonymous or identified). In contrast there was relatively little interest expressed in how personal information was to be used. A majority of patients were comfortable with their GP, hospital doctors and emergency services having access to their data, though they reserved the right to limit access to very sensitive information (via the "virtual sealed envelope").

"Our GP is our first port of call. We've still got to have the confidence in him that what you say really won't go any further." (male, 40-65 years old)

"They have to share that information. If someone is ill and passes out or something happens, the doctors and nurses have a right to share all the information necessary so that the patient can be treated" (non-English speaker)

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Certain personnel were identified as only being allowed access to certain information at certain times. These included: other GP surgery professionals, complaints staff and public enquiry staff who were only perceived to "need to know" information during treatment or investigation. Patients felt that these personnel should only have access to the relevant parts of their record.

"They only need to know what they need to know in order to sort out the complaint."
(female, 40-65 years old)

Anonymisation

A general rule evolved that any information released outside of NHS treatment areas should be anonymised, or patient permission sought for the use of identifiable data. The people who needed to adhere to this rule included: researchers (NHS, drug company or university), NHS bureaucrats (eg, Primary Care Trust staff, NHS management, regulatory staff) and also ideally included the Secretary of State.

"...If, God forbid, I had cancer and they said they wanted to put me on the registry...I would more than likely say yes, so why do it behind my back?" (female, 20-30 years old)

Patients were not happy with receptionists or private data processing companies having access to their personal health record. Receptionists were seen as most problematic.

"She has no need at all. She just has to make your appointment and tell you to go to the room. That's it." (male with HIV)

"It smacks of snooping. Mischief." (male 40-65 years old)

A major talking point was that the NHS should strive to achieve anonymity for all its patients if any information was to leave the NHS system.

"It absolutely should be anonymised. That should be paramount." (male 20-39)

"You can't penny-pinch on that." (female 40-65)

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Once anonymised, a majority waived the need to gain their consent, and few wanted to know about how their information was being used. The exceptions were the South Asian respondents, who considered it a courtesy to be told.

There was a consensus that data management should be kept "in-house" (ie, within the NHS). Contracting this work out was seen to make confidential data more vulnerable.

"...You couldn't outsource that sort of thing. You don't know who's looking at it - your next door neighbour, the person across the road. If it was in-house they would be under the same confidentiality rules as doctors..." (male 40-65 years old)

Electronic health records and security

Overall, the sample was in favour of the NHS increasing its use of electronic data. The advantages were felt to include the ability to share information quickly and accurately, as well as potential to decrease the number of lost records. The disadvantage of an electronic system was that respondents felt that their data could potentially become more vulnerable.

"If the people in the lab could email the doctor, transfer information in seconds rather than days, that could save lives couldn't it?" (male, 20-39 years old)

"If you stand back and take stock...somewhere, someday there's going to be one person with all this power at his fingertips and there's not going to be anything we can do about it." (female, hereditary genetic condition)

The security system described (limiting the amount and type of information reaching different personnel and checking identity via fingerprint) reassured the majority, although a minority (typically older and less comfortable with technology) remained sceptical about security.

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Views on consent

The requirements that emerged from the focus groups were: anonymisation for all uses other than patient care; information for care shared on a need to know basis; ability to isolate some particularly sensitive information from routine sharing, rigorous security measures. Given these conditions, a majority agreed to a "one-off" written agreement between them and the NHS. Without these conditions patients required written permission to be sought for information shared outside of the NHS.

"I think there could be levels of access...a general level, the next level slightly more specific, allergies etc, the next level, previous medical history." (female, 20-39 years)

"I think there should be some kind of charter, a set of rules which people can identify with..." (male, 40-65 years old)

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Quantitative research results

Awareness of uses and sharing

Respondents were asked to spontaneously list the ways that which they thought the NHS used information from their patient records.

In what ways do you think the NHS uses the information in your patient records? (Base: All adults aged 15+, n=2087)

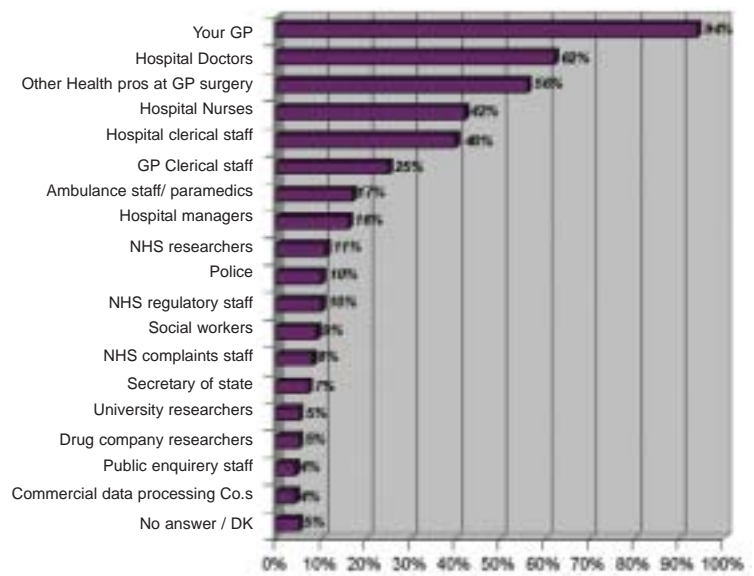


Nearly a quarter of respondents (23%) did not know how the information was used. This was an unprompted question. It is likely that most would recognise, if prompted, that information is used for treatment. The majority of respondents did say "for treatment" (68%). No other response was mentioned by more than 10% of respondents. Results were relatively consistent across demographic and health status groups examined. Although there were some differences, there was no instance of a group that was significantly more aware of several of the uses or of a particular use.

In the qualitative research, there was little interest among those in the focus groups in how information was actually used (although there was interest in who saw information). There were similarities here, in that people generally don't show great knowledge of how the NHS uses patient information.

Awareness of who has access

Which of these people, if any, do you think currently have access to your patient records? (Base: All adults aged 15+, n=2087)



When asked who respondents thought had access to their records, nearly all (94%) said their GP. This figure drops to just over half for other health professionals at the GP surgery (56%) and roughly two-fifths (42%) for GP clerical staff.

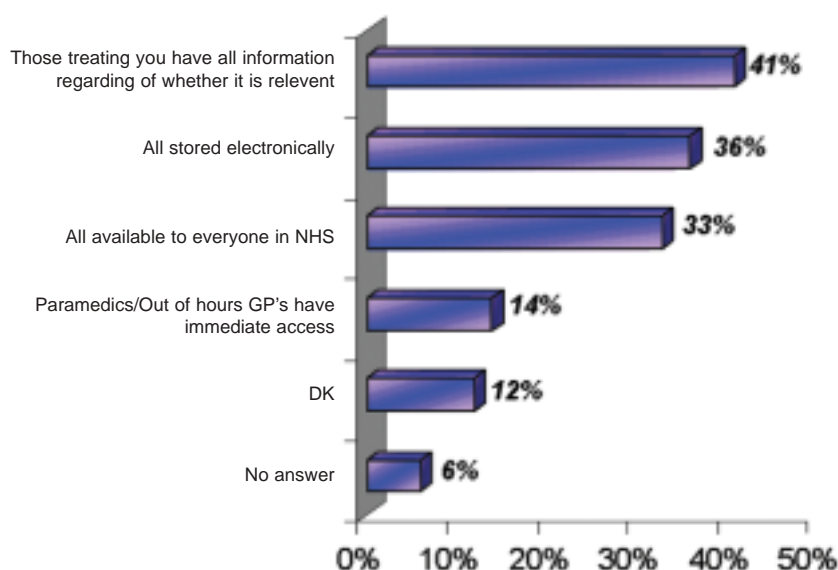
Sixty-two percent believed hospital doctors treating you would have access, 40% hospital/ ward nurses and 25% hospital clerical staff. Those with ongoing treatment or who had not been well were significantly more likely to mention these three than those who were very well. It may be that those who were very well took the question literally, ie, "I'm not being treated so they would not have access", rather than hypothetically - "if one were being treated".

Less than a fifth mentioned hospital managers (16%), NHS regulatory staff (10%), NHS researchers (11%), and university or drug company researchers (both 5%). These figures were all significantly higher among broadsheet readers compared to tabloid readers and among social class groups ABC1 than C2DE.

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Awareness of handling of patient records

In order for the NHS to effectively treat patients, information about patients has to be shared within the NHS. Which of the following do you believe to be true about how the NHS shares information? (Base: All adults aged 15+, n=2087)



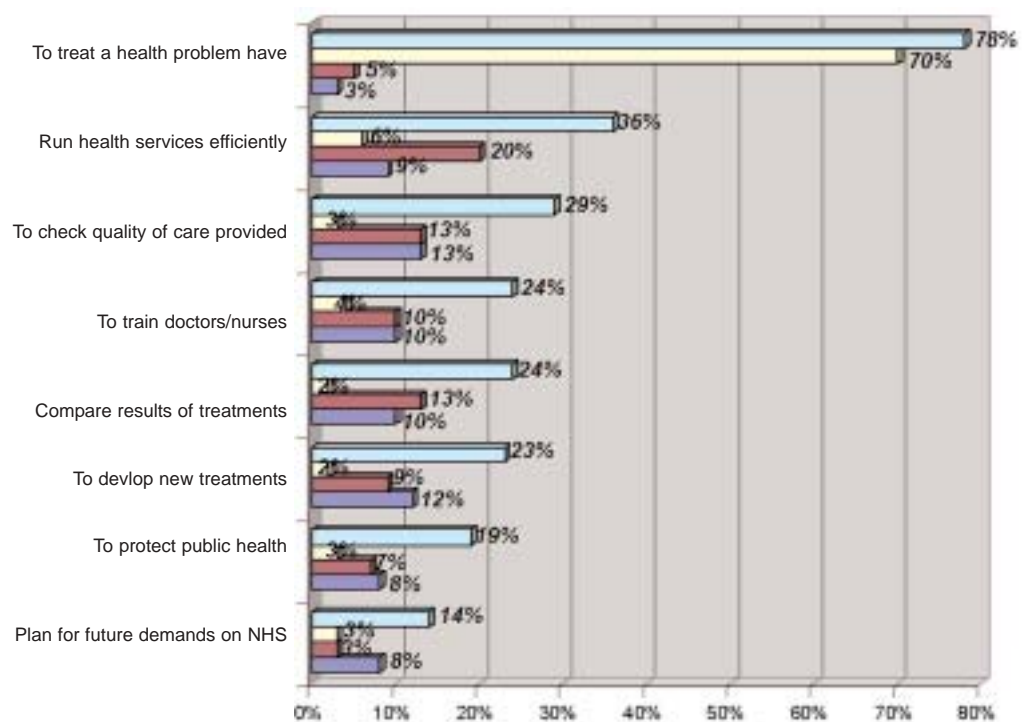
Two fifths of respondents thought it was true that those treating you had access to all information, regardless of relevance. Over a third (36%) thought that all records were stored electronically (men were significantly more likely to believe this than women, 38% vs 33%). A third of respondents believed patient information was available to all within the NHS. This is not entirely consistent with the previous question (where, for example, only 16% thought NHS managers had access to records and only 25% believed hospital clerical staff do). However, this serves to demonstrate that the public are not really sure who has access or under what conditions to their records.

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Most important uses of patient information

There was one very strong and consistent result: 78% of respondents mentioned "to treat a problem I have" as one of the most important uses of patient information and 70% felt it was the most important. There was very little variation among different sub-sets of the population in terms of the total mentions or the order in which it was mentioned.

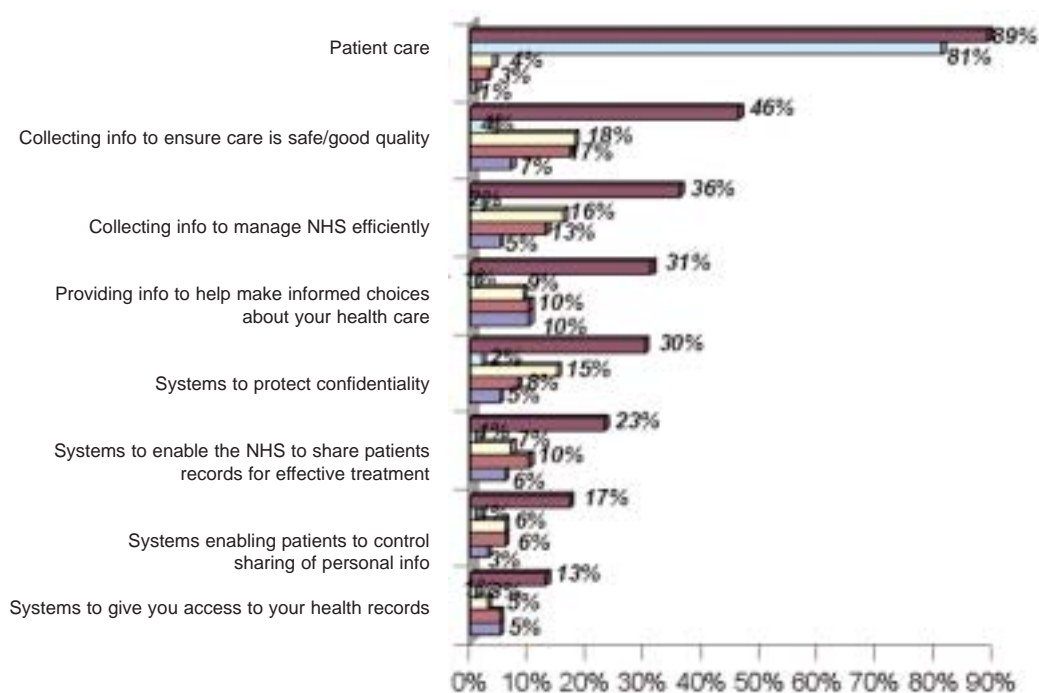
On this card is a list of the ways patient information is currently used. Could you please tell me which you think is the most important use, followed by which you think is the second most important, and then which use you think is the third most important? (Base: All adults aged 15+, n=2087)



Although the other options do benefit everyone who uses the NHS, none were seen as important as the direct use for personal care. Second, in terms of total mentions and both first and second mentions, was "to run health services efficiently". This coming second could be attributed to the extensive media coverage, and public sensitivity toward the performance of the NHS in terms of the public funds devoted to it.

Spending priorities for the NHS

The NHS has a limited amount of money to spend on all its activities. Spending money on one activity means there is less to spend on other things. Using this card, could you please tell me which you think is the most important use of the money, followed by which you think is the second most important, then which use you think is the third most important, and then which you think is fourth most important? (Base: All adults aged 15+, n=2087)



Spending priorities of the public were in keeping with the results of the previous question. Approximately 9 out of 10 (89%) mentioned patient care as a spending priority and 81% felt that it was the most important spending priority. The second and third most common priorities were similar to the previous results: 46% in total mentioned collecting information to ensure care is safe/of good quality, and 36% mentioned collecting information to manage the NHS efficiently.

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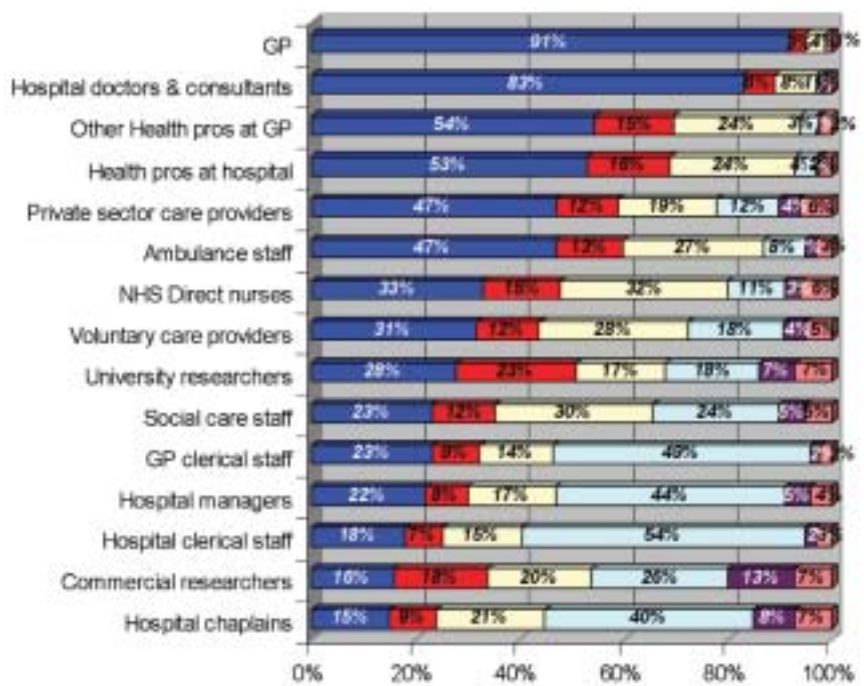
Under a third of respondents (30%) would prioritise systems to protect confidentiality, and less than a quarter would prioritise either systems enabling the NHS to share records for effective treatment (23%) or systems to control the sharing of personal information (17%). However it is sensible to point out that results from this research and the qualitative research have shown that people do have a low awareness of how patient records are stored and used and hence they may not realise the differences investment in these areas could make.

Those who had experienced an adverse event such lost records, having to change appointments, letters informing of appointments not turning up, having to repeat information, or being confused with another patient were more likely to have different priorities. They were significantly more likely to mention systems to protect confidentiality (34% vs 28%). They were also more likely to mention systems to enable the NHS to share patient records for effective treatment (27% vs 21%).

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How much access should people have to patient records?

Various people within and outside the NHS may need to see your health information. Using the categories on this card, choose the one showing how much of your patient information would you be willing to share with? (Base: All interviewed, n=2087)



Data is ranked on the proportion saying "my full record".

When asked how much of their patient record they'd be happy for people within and outside the NHS to see, not surprisingly the GP came top with 91% saying their full record. Hospital doctors and consultants followed closely behind (83%). Slight higher proportions than for GPs wanted hospital doctors to see "all except some sensitive info" (6%) or "only the "information required to treat me" (8%). This is in keeping with the qualitative findings, where all agreed that their GP should have access to the whole record at all times, and the majority felt that hospital doctors and ambulance personnel should be allowed full access.

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Around a third to half of respondents would be willing to share their full records with the other health professionals listed on the showcard - other health professionals at the GP surgery (54%), at the hospital (53%), ambulance staff (47%), and NHS Direct nurses (33%). Compared to GPs and hospital doctors/consultants, it was more common to say all bar some sensitive information (around 15% in each) or only the information required to treat me (around a quarter in each).

Clerical information only was the most common response for GP clerical staff (49%), hospital managers (44%) and hospital clerical staff (54%). This mirrors the work from the qualitative research where participants felt that NHS clerical staff should not be allowed access to their patient records. Interestingly, it was the oldest (65+) respondents in the omnibus survey who were more likely to allow access to their full record (37% to GP clerical staff, 29% to hospital clerical staff). Although few would grant full access to their records to a NHS hospital manager (22%), it must be noted that respondents were not given an option of anonymised data. In the qualitative research respondents would allow hospital managers access as long as the records were anonymous.

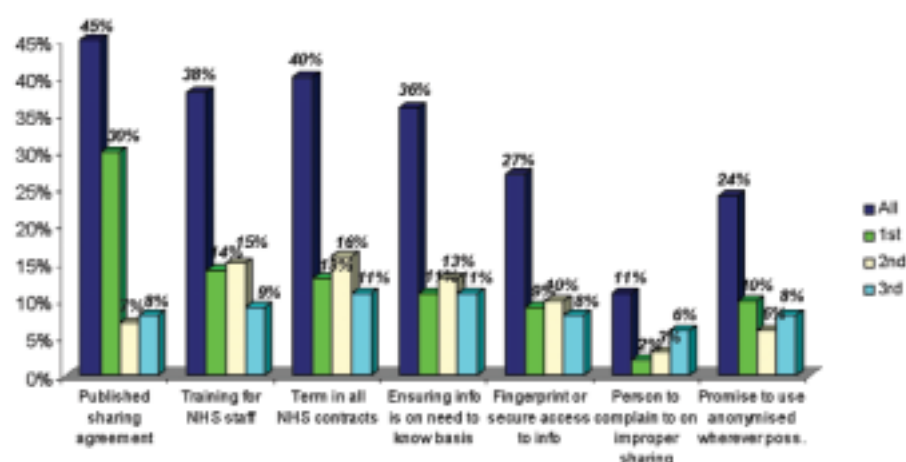
Over half of respondents would grant either full access or access bar some sensitive information to university researchers (28% and 23% respectively). Fewer would allow such access to commercial researchers (16% and 18% respectively). As with NHS hospital managers, the qualitative work showed that people were comfortable with researchers having anonymised access to their records (an option not given here). Another finding from the qualitative research was a level of scepticism towards commercial researchers compared to university researchers, which seems to be apparent here as well.

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Safeguards to protect patient records

Respondents were asked which three safeguards would reassure them that the NHS is careful with their health information. As with the previous questions they were asked to rank them in order of importance to them.

Which three of these safe guards would reassure you most that the NHS is careful with your health information? (Base: All adults aged 15+, n=2,087)



The most commonly mentioned safeguard was a published sharing agreement (45%). In terms of total mentions, it was not that far ahead of second place "term in all NHS contracts" (40%) or third "training for all NHS staff" (38%). However, the published sharing agreement received twice as many first mentions as the second place "training for NHS staff" (30% vs 14%).

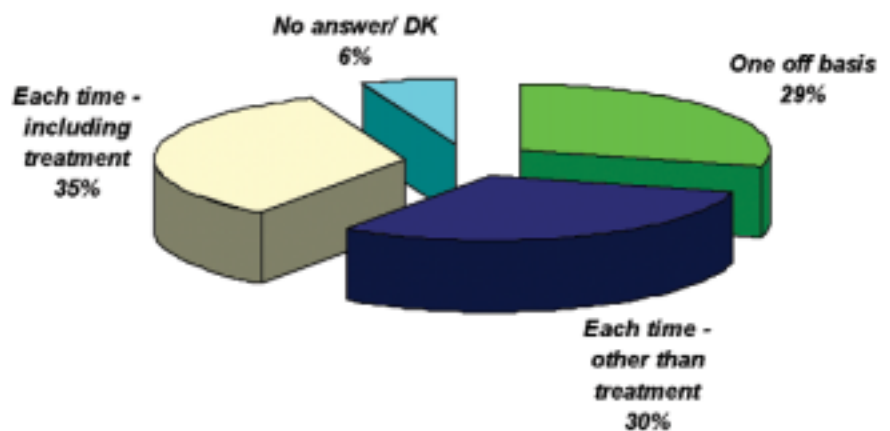
Fewer than expected opted for the two safeguards that specifically covered the security of information. Thirty-six percent in total mentioned "ensuring information is shared on a need to know basis", and 27% "fingerprint or other secure access". However, respondents in the focus groups felt that electronic centralised data could increase the chances of security breaches and found technology safeguards more reassuring.

Those who had experienced problems such as lost records and repeating information were more likely to choose the technological safeguards compared to those who had not. Thirty-three percent mentioned secure access compared to 25%, and 40% mentioned access on a need to know basis compared to 34%.

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Which form of consent?

Let's say that in the future your current patient records will be transferred onto computer to make an electronic health record so it can be shared across the NHS. Access will be controlled by a fingerprint reader and limited according to a person's role in the NHS. If that were the case, which of the following arrangements for consent to sharing your information (in a form that identifies you) would you be happy with? (Base: All adults aged 15+, n=2087)



The form of consent people would opt for is very evenly split. The most common preference was consent to be asked each time information is shared, including for treatment (35%). Twenty-nine percent opted for consent being given on a one-off basis for all uses (unless they changed their mind or information was used in new ways). Thirty percent opted for giving consent each time it is used other than for treatment.

There were some demographic differences. Men were more likely than women to opt for consent given each time other than for treatment (33% vs 28%) as were people from ethnic minorities compared to white people (48% vs 29%). Women were more likely than men, and white people more likely than those in ethnic minorities, to want consent each time it was used including for treatment (38% vs 30%, and 35% vs 21% respectively).

These results appear inconsistent with the previous question (45% of people choosing the published sharing agreement as a safeguard). People may not have

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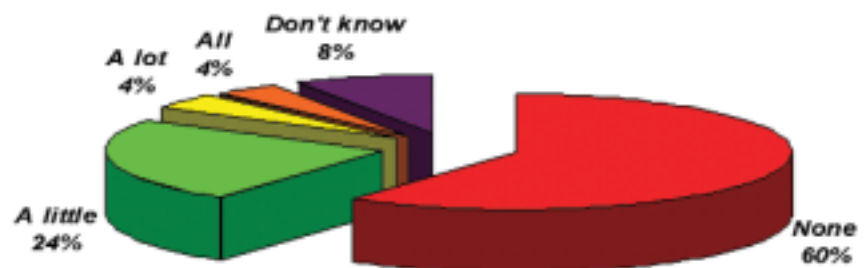
fully understood the implications of the published agreement. Although it was specified that the agreement would set out what the NHS would and would not do with the information, respondents might not have considered that this would equate to a one-off consent to sharing.

The second possibility is that respondents didn't fully consider the implications of collecting consent each time information must be shared. In the qualitative groups, when respondents presumed any information going outside the NHS would be anonymised, they were happy either not being asked for consent or giving the one-off consent until such time as things changed. They considered it would not be feasible to give consent every time information was shared for treatment.

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How much information would you remove from routine sharing?

If you had the option of removing particularly sensitive information from your shared electronic record to a special place where you controlled all access to it, how much information from your current record would you take out? (Base: All adults aged 15+, n=2087)



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+).

This result suggests that for the majority of people there is little or nothing that they consider sensitive on their health record. However they would still like to know and have some control over what happens to the information. The perceived importance of the published agreement as a safeguard, and the increased number of people who would like those other than their GP to only see information required to treat them, both suggest this.

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