The Use of Personal Health Information in Medical Research General Public Consultation

Final Report

June 2006

Medical Research Council

Ipsos MORI

Contents

Appendices

Introduction

Background

This report presents the findings of a programme of research carried out among the general public by Ipsos MORI on behalf of the *Medical Research Council* (MRC).

The research programme comprised:

1. **Qualitative research**, involving three general public workshops – held in London, Cardiff and Edinburgh (on 29 July – London and Cardiff and 5 August 2006 – Edinburgh);

   Plus six in-depth interviews were conducted over the telephone with disabled people, people with long-term / chronic illnesses (or their carers);

2. **A large-scale quantitative survey** of behaviour, attitudes and opinions among 2,106 members of the general public across 212 UK sampling points (14-18 September 2006).

This report draws together the findings from the qualitative and quantitative stages in the research programme.

The report is divided into a number of sections. These comprise: a summary of key findings, sections on methodology and analysis, and summaries of the findings arising from the qualitative research and quantitative survey. The outcomes of this consultation will inform MRC's strategic decision-making.

Aims and Objectives

The main objective of the research was to identify public concerns and misconceptions surrounding the secondary use of personal health information for medical research.

The consultation also aimed to help in the understanding of public attitudes on the following topics:

- Perceptions of personal information in general;
- General attitudes towards personal health information;
- Attitudes towards using health information for medical research;
    - Anonymity/ Confidentiality
    - Consent
    - Trust
- Risks and benefits of personal health information being used for medical research.

Qualitative Methodology

Firstly, three workshops – each comprising 21 people were held in the following locations: Camden, London (29 July 2006); Cardiff (29 July 2006); and Edinburgh (5 August 2006) to give a very broad sweep of Great Britain. Compared with discussion groups, a workshop recruits more people (around 18 or so, rather than about 8 for a discussion group). Workshops also run for a longer period of time (5 -5.5 hours, rather than 1.5– 2 hours) and therefore allow for greater exchange of views, discussion and participation. They are ideal when the concepts involved are quite complex and opportunity needs to be given to digest them or there are many issues to be debated. They also allow greater scope to recruit a broad range of people with many different experiences and the opportunity to divide and mix people up into smaller syndicate groups (comprising different types of people in each syndicate) to debate issues.

Participants were recruited face-to-face by experienced Ipsos MORI recruiters in streets, people's homes, and at community centres. Quotas were set in the following areas to ensure the make-up of each workshop was broadly representative of the local area[1]. These were: Age, Gender, Ethnicity and Social grade. Four people with long-term / chronic illnesses (or their carers) were also recruited for the workshops, although in a lower proportion than reality for each workshop (to avoid any particular influence which their views may have on the group). For example, in reality, 59% have a long-term condition in the UK population, which would equate to 12 participants in each group. Also people who had personally been involved in science were recruited, and a limit was set on the numbers of these people attending, again to avoid any undue influence on the group. In reality, 68% are involved in one or more science-related activities[2], which would equate to 14 participants in each group.

Secondly, six in-depth interviews were conducted over the telephone with disabled people, people with long-term / chronic illnesses (or their carers). 1 interview with a carer of a person with Alzheimer's; 1 interview with a person with schizophrenia; 1 interview with a trustee of cancer charity; 1 interview with a carer of child with long term condition; 1 interview with a person with pulmonary hypertension; 1 interview with a person living with AIDS.

These were conducted as they may find it difficult to come to workshops and for the reason outlined above, they were not represented in a high enough proportion in the workshops.

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[1] It must be stressed that, while the make-up of the workshops was designed to be broadly reflective of people residing in each locality, qualitative research can never be deemed to be representative of the population at large. Its main purpose is to provide insight into issues. It is the quantitative phase of this research which provides such statistical reliability (within margins of error). Furthermore, awareness of the issues surrounding the use of personal health information were quite low and the findings of this work should therefore be considered in this context. Arguably, if participants came to know more about the issues over time, they may be in a position to give a more informed response.

[2] http://www.ipsos-mori.com/polls/2004/ost.shtml

Quantitative Methodology

Questions were placed on the Ipsos MORI Omnibus, the regular Ipsos MORI GB survey among the general public. Additionally, adhoc interviews were conducted in Northern Ireland. A nationally representative quota sample of 2,106 UK adults (aged 15 and over) was interviewed across 202 sampling points (including 1,993 interviews in Great Britain and 113 interviews in Northern Ireland across 10 sampling points).

Respondents on our omnibus studies are selected by the following means:

There are 641 parliamentary constituencies in Great Britain. From these, Ipsos MORI selects 210 to be used as the main sampling points on the Omnibus. These are chosen to be representative of the whole country by region, class, voting patterns and other variables. Within each constituency, one local government ward is chosen which is representative of the whole constituency.

Within each point, ten respondents are interviewed. Respondents are selected by means of a 10-cell quota with which the interviewer has been provided. The quotas used are: Gender (Male, Female); Household Tenure (Owner occupied, Council/ Housing Association tenants, Other); Age (16-24, 25-44, 45+); and Working status (Full-time, part time/not working).

These quotas are devised from the latest Census and subsequent ONS data. In each area, quotas represent the makeup of that area which ensures that the demographic profile of the sample matches the actual profile of the country. The sample is thus representative of all adults in Great Britain aged 16+. The total sample set is 10 x 210 sample points = 2,100. All interviews are conducted face-to-face, in the home, with only one interview per household. Interviewers are instructed to leave at least three addresses between each call. No incentives are offered to respondents.

Fieldwork: GB Interviews were carried out face-to-face, in respondents' homes, with the aid of Computer Assisted Personal Interviewing (CAPI) terminals (laptops). NI interviews were conducted using pen and paper method. Fieldwork was conducted between 14 and 18 September 2006. All data have been weighted to the known profile of the UK population.

Reporting: In the graphs and tables used for the quantitative results, the figures quoted are percentages. The size of the sample base from which the percentage is derived is indicated. Note that the base may vary – the percentage is not always based on the total sample. Caution is advised when examining responses from a general public sample of less than 100, or when comparing responses between small sample sizes of less than 100 in each case. Also, please note that all sample sizes are subject to 'margins of error'[3] which are outlined in the appendices. The percentage figures for any sample size or sub-group need to differ by a certain number of percentage points for the difference to be statistically significant. This

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[3] 'Margins of error' give an indication of how reliable survey a result/s is/are, for any given sample size/s.

number will depend on the size of the sample and the percentage finding itself - as noted in the appendices.

Where an asterisk (*) appears, it indicates a percentage of less than half but greater than zero. Where percentages do not add up to 100% this can be due to a variety of factors – such as the exclusion of 'Don't know' or 'Other' responses, multiple responses or computer rounding.

Publication of Data: Our standard Terms and Conditions apply to this, as to all studies we carry out. Compliance with the MRS Code of Conduct and our clearing is necessary of any copy or data for publication, web-siting or press releases which contain any data derived from Ipsos MORI research. This is to protect our client's reputation and integrity as much as our own. We recognise that it is in no-one's best interests to have survey findings published which could be misinterpreted, or could appear to be inaccurately, or misleadingly, presented.

Key Findings & Implications

The qualitative phase of this consultation[4] shows that medical research in general, and the concept of using secondary health information for medical research purposes, are not things that people have given much thought to. They know that medical research is undertaken, but few have a good understanding of what it entails, who does it, and for what purpose.

From the quantitative research it can be seen that most members of the public (around two-thirds) can give top-of-mind perceptions of what 'personal health information' means to them. These perceptions are quite varied. For example, respondents are just as likely to think of personal health information as being related to the private sector (such as direct marketing and assessment of eligibility for financial / insurance products) as they are to mention public sector uses, such as by the NHS or dental information. The most common association is, however, 'GP records', which is mentioned by 26%. The other key response is 'medical records', given by 17%. Just over a third (34%) cannot think of any associations with the phrase personal health information, which indicates fairly low awareness for the MRC to address.

Spontaneous perceptions of who, or which organisations people feel would hold personal health information focus mainly around the health service. GPs are particularly cited in this context, being mentioned by the large majority (71%), but also hospital doctors (unspecified) and the NHS. Medical researchers (working in any capacity) are mentioned by less than 1% of the general public. The qualitative research also found that, apart from health professionals, personal health information is thought by many to be used by insurance companies and employers. However, in the quantitative phase, just 7% cited insurance companies and 6% mentioned employers.

The workshops indicate that, if the public is **informed** about what medical research entails, they are generally positive towards it. It is important not to communicate issues about personal health information in too complex a manner as this in itself can be construed as perpetuating the "closed shop" which medical research is currently perceived to be. Key to effective communication on the subject is the need to keep terminology simple. **Communications** are key to building public **trust**.

The qualitative research shows that there is low awareness and understanding of medical research among the general public. Once the concept of medical research is understood, however, some members of the public feel happier, in principle, for their information to be used for those purposes. The two key pillars of anonymity and consent feature highly in the debate over what information should be available, to whom, and in what circumstances. These two themes are central to building trust.

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[4] Which comprised workshops with a cross-section of the general public, and in-depth interviews with people with long-term conditions, or/and chronic illnesses, or/and with disabled people or their carers.

The key tension within the public mind is between the "greater good" and the privacy of the individual, which anonymity and the issue of seeking consent are seen to protect. While most see the benefit of personal health information being used for medical research purposes, the very same people can hold reservations over the implications for privacy

Consent and **anonymity** are not understood by the public in as nuanced a way as they are by the scientific community. The minutiae of definitions of anonymity and consent need to be explained to the public simply, in order to gain trust. For example, there is a danger of the public not recognising the difference between "anonymity" and "confidentiality". This is especially important for those involved in medical research, as data that are anonymised (with personal background details taken away) are of much more limited value than data that are confidential (with personal details intact).

If the public feels in control of their information and its potential uses, then they are likely to be more inclined to allow their personal health information to be used for medical research purposes.[5]

While communications can provide information about the purposes of scientific research on a large scale, the public needs a human face to reassure them and discuss the issues around consent and confidentiality with them. Health professionals in general, and GPs in particular, are the most trusted to perform this role. For many, the GP's surgery is the most frequent point of contact on health issues and it would seem sensible to use this as one location for dissemination of information about personal health information for medical research purposes.

In any system that is devised, the public feels the need for an independent organisation to act as a 'buffer' between researchers and the public. This buffer is necessary to guarantee to the public that their GP[6] and their personal health information are far enough removed from researchers to prevent inappropriate use of their personal health information. Key to such a system are mechanisms of liability and redress in the event of any misuse.

'Medical research' and 'having a greater knowledge of patterns of health or disease' are the most common **advantages** given when people are asked (without being prompted) about their assessment of the merits of collecting and using people's personal health information. Moreover, four of the next five most common advantages cited relate in some way to medical research, and this equates to 42% of all answers at this question. The qualitative research also shows that respondents are aware that companies could gain commercial advantage by collecting and using personal health information for marketing and selling products and services.

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[5] It would be useful for any further research to explore the issue of "consent for consent" in more detail: i.e. the actual process of asking people if their personal health information can be used for research purposes (or to invite them to consider taking part in a study).

[6] It should be noted that personal health information is not only held at GP level (e.g. hospitals nay also hold such information) thus if any such system were to create a buffer of this kind, it would need to take into account all the places where such personal health information is held.

More respondents say there are no disadvantages of collecting or using personal health information (20%) than say there are no advantages (15%, and equal proportions do not know (21%). Just over one in five (22%) expresses concern over misuse of the information. The related concerns of 'information being disclosed' and 'breach of the Data Protection Act' are both mentioned by one in ten respondents.

The advantages of medical research are seen by the public to far outweigh the disadvantages. Seven in ten feel the merits of research outweigh the disadvantages, compared to only 6% who say the opposite. This very positive finding affirms the generally positive feeling towards medical research that has emerged from both the qualitative and the quantitative strands of this consultation. As we saw earlier, despite the fact that medical research in general, and the concept of using secondary health information for medical research purposes, are not things that people have given much thought to, if the public is **informed** about what medical research entails, they are generally positive towards it.

More than two-thirds (circa 69%) say they are 'likely', including just over one in ten (14%) who say they are 'certain' to **allow their personal health information to be used for medical research purposes**, compared with around a quarter who feel they would 'not be likely' (including 7% certain not to). This suggests both positive feeling towards the use of personal health information for medical research, and perhaps some caution, or desire for more information before any firm commitment is given. This positive finding echoes what was found in the workshops.

The most common reason for being unlikely or certain not to allow personal health information to be used for medical research purposes is **concern over privacy** (28%). Other common concerns focus on potential abuse and loss of control. Around one in ten are anxious about such information 'falling into the wrong hands' (13%), and similarly over the perception that individuals can not control who uses their information (13%), or for what purpose (12%). Only 1% say that they would withhold their personal health information because they are 'against medical research'. The qualitative research shows that the main public concerns are over organisations sharing this information, particularly for commercial gain. We know from both phases of the survey, however, that sharing information, is seen as acceptable, provided that permission is given beforehand.

The vast majority (87%) **trust GPs** to have access to their personal health information, and over half trust **other health professionals** – such as consultants or hospital doctors (59%). The NHS is cited as being trusted on this issue by around half, but no other group is mentioned by more than half – however, it should be pointed out that a low score does not necessarily indicate a lack of trust. It could be the case that the public has no, or limited knowledge to make a judgement (and therefore is not expressing an opinion). Medical researchers working in the public sector i.e. for Government and universities (both trusted by 11%) are more trusted than their counterparts working for private companies (4%). The private sector features prominently among the least trusted organisations where personal health information is concerned, with lawyers being trusted by 9%, banks by 8% and pharmaceutical companies by 6% respectively. These results echo Ipsos MORI's long-standing trends on who are trusted in the general sense, which indicate that doctors are the most widely trusted group to tell the truth[7]. However, the figure for medical researchers working in universities is lower than previously found[8], perhaps because of caution about the issue or/and little knowledge about the issue.

The key factor that might make people more in inclined to allow their personal health information to be used for medical research is *information.* If the public had more information specifically about the purposes of medical research, they would be more inclined to allow their personal health information to be used for that purpose. However, personal benefit of providing information is not a strong motivator, nor is knowing exactly who is using the information.

Assurance beforehand that the information they provide would probably be kept confidential prompts just over six in ten (62%) to say they would be certain or more likely to provide their information. However, when asked about the impact of knowing that their consent would not be sought for *further* research using their information, significantly fewer say they would be more likely or certain to participate (42%). Leaflets giving information about the project in advance would inspire half the general public to consider allowing their personal health information to be used, whilst websites would have a lesser effect (36% would be more likely). Just over half (56%) say that information about the risks and benefits of a research project would make them more likely or indeed certain to allow their information to be used. Six in ten would be more predisposed to allowing their personal health information to be used if they knew that the research it was intended for has the approval of an independent ethics committee. This fits in well with the findings from the workshops where respondents expressed a common wish for a 'firewall' between their information and those who wish to use it for research.

Results indicate that a majority of the general public feels that **consent should *always* be sought**. When given a variety of scenarios in which consent might not be essential, no more than a third of the public agrees with them. In Ipsos MORI's experience, this is quite low. Indeed just over one in five (21%) does not find *any* of the scenarios acceptable. The public is most likely to say consent is not important when the information is 'not generally regarded as being sensitive' (35%). This is closely followed by when consent has already been given for use in a previous project (29%). These are two situations that also came out in the qualitative work as times when some (but not all) participants feel that consent is not always essential.

Consistent with the findings coming out of the qualitative work, a majority (60%) agrees that they have a **responsibility** (as beneficiaries of medical research) to allow their personal health information to be used in medical research projects (provided that the projects have been approved and their consent is given). This

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[7] http://www.ipsos-mori.com/polls/2006/rcp.shtml

[8] OSI/MORI 'Science in Society' 2004; Scientific Alliance/MORI 2003.

is also consistent with the general positive regard in which the public seems to hold medical research.

Public acceptance to use personal health information for medical research depends greatly upon expectations of **how information is used** and how well its use is **regulated**. Thus it is important to gauge public awareness of the value of research using personal health information, and level of interest in engagement on the issue. A potentially major obstacle to public engagement and acceptance of the use of personal health information in medical research comes in the shape of recent much-publicised concerns over the Government's proposed introduction of a central national database of patient information[9]. Concerns have been raised over a perceived lack of safeguards against access to the information and the fact that patents' consent will not be sought. Other concerns are over who can view the data, with particular resistance to the police and security services having access.

It should be noted here that although participants expressed concern about it in the workshops, this database is actually a system being developed principally for improving routine healthcare and does not have any direct relevance to medical research.

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[9] www.society.guardian.co.uk/health/

In conclusion, the main findings to emerge from the study are:

- Public awareness of the use of personal health information for the purposes of medical research is low. They know that medical research is undertaken, but few have a good understanding of what it entails, who does it, and for what purpose;

- The two key pillars of confidentiality and consent feature highly in the debate over what information should be available, to whom, and in what circumstances. These two themes are central to building trust;

- If the public is informed about what medical research entails, they are generally positive towards it and communications are key to building public trust. The key to effective communication on the subject is the need to keep terminology simple and tailor communications for a lay audience;

- Views of people with long-term conditions are generally more positive. They have more experience of health services and therefore a better knowledge of medical research and personal health information than the general public;

- Attitudes to medical research are generally positive and if communications are handled well, this might increase propensity for agreement to use personal health information for medical research purposes. This includes communicating the value of such use of medical records (possibly by giving examples of research that could not have been done without such access and the adverse effect of such an eventuality on public health).

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Qualitative Research

Perceptions of Personal Information in General

Public awareness of the kind of personal information that is held about individuals is broad. In general, the public focuses on information held electronically. It seems their perceptions of personal information held by organisations has been coloured by the growth of the role of IT in society, the recent emergence of (online) identity fraud and the security measures promoted to protect online identity. Indeed, some had had experience of their personal details being compromised and passed on to unauthorised third parties after they bought goods online.

"The capacity for keeping information has grown so much"

There is awareness of a number of kinds of information that are stored, including personal information such as names and addresses, financial and medical records, and CCTV images. National Insurance cards, Oyster Cards, charge cards/store cards, life and health insurance policies, air miles, loyalty schemes and telephone directories also feature as commonly recalled instances of personal information collected.

Examples given of organisations who hold personal information focus mainly on private sector companies (particularly in the banking, financial and insurance sectors); and Government departments / agencies (examples include HMRC, NHS, the Police).

A number of health organisations or health professionals are also noted as holding personal information, including: GPs, hospitals, dentists, opticians, private medical care companies (BUPA was specifically identified) and 'Organ Donation'.

Perhaps linked to the types of personal information which were most commonly listed as top- of-mind, respondents were more likely to think of personal information as related to the private sector, such as direct marketing and assessment of eligibility for financial / insurance products. However, upon probing, many public sector-type uses were also described, including: the police using DNA evidence to fight crime, the management of benefits and provision of social services by government agencies.

The public has mixed views about providing institutions with their (general) personal details. Some feel uneasy about it, others view it negatively, yet others are quite sanguine. However, even those who feel uneasy about personal information being held recognise it as "a necessary evil" and "the modern way", particularly when thinking about public sector usage. They were less positive, however, about their information being used for commercial purposes and to target them for marketing purposes.

Despite the reference to the modern way there are no tendencies for members of younger generations to be any less concerned, with some feeling "anxious" that their data are held. There was also a sense of apathy, with some believing they have little control over their own information and that little can be done to stop it being collected.

The main concerns the public has over personal information are not related to organisations holding information, but rather that they may share this information, particularly for commercial gain. Some respondents had personal experience of charities sharing their contact details and were negatively disposed towards them as a result. Sharing information, however, was seen as acceptable, provided permission is given for organisations to do so.

There is a realisation that some information has to be shared across agencies and organisations as a matter of course. Examples of such sharing included: security agencies sharing personal information to prevent terrorism, insurance companies needing medical information to be able to provide policies, and doctors and consultants needing access to medical records. However, there is a strong feeling that people's privacy should be respected, and widespread objection to personal information being passed on without permission

The key principle seems to be that some sharing is regarded as necessary, but selling or sharing personal information for commercial gain is unethical, and that permission for sharing information must be sought.

Inaccuracy of information is also an issue, as some believe the main problem not to be that information is held, but that it is incorrect.

Initial trepidation is tempered by the realisation that there are positive uses of personal information held by organisations. Being able to prove one's identity is seen as a key benefit, perhaps framed by concerns over fraud. Databases are seen as being efficient ways of storing information that otherwise would have to be collected time and again.

The advantages of organisations holding personal information are mainly described as twofold:

- Advantages to companies holding or selling the information, for marketing and selling products and services
- Public sector agencies protecting the public in some way, for example medical records, police databases

The public recognises that individuals can benefit from private organisations holding information by allowing people to be updated about new products and offers. The public feels that information held within the public sector is used for a myriad of purposes, among them: taxation, protection by the State in the form of benefits, protection registers and receiving healthcare, to give a few examples.

The individual is also seen as having some responsibility for protecting their own information or data. It was also acknowledged that in certain cases personal information can be given in order to accrue benefits, for example in the case of loyalty and store cards.

> *"We want more, things quicker, cheaper and are driving consumer information being held"*

There is mixed public awareness of the Data Protection and Freedom of Information Acts. The former is seen as being relevant for the holders of personal data, and as providing data protection and security for individuals. The latter is seen as providing individuals with access to data held by public bodies, although there is uncertainty about whether this included an individual's right of access to information held on them. However, while some have good knowledge of the legislation (usually out of professional necessity) among others, knowledge is patchy at best and it should not be assumed that the public has a good grasp of it.

General Attitudes Towards Personal Health Information

Public knowledge of what constitutes 'personal health information' is also broad. Medical or health information/records held by GPs, hospitals, dentists and opticians were all mentioned, as were samples (blood, tissue and urine), results from tests, DNA profiles, birth details and information on lifestyle. Very few have tried to access their own medical information, and those who have obtained mixed results. One participant had been granted access by their GP with no problems, while another had been refused access and has contacted the Information Commissioner about the issue.

The public believes that health professionals have access to personal health information, although there are mixed views on whether such information is centralised or not. Some believe that only the health professional to whom information has been given has access to that information. Others, however, think there is a central database which holds all health information given by an individual.

GPs are expected to have comprehensive access to personal health information, while health professionals in hospitals are believed to see them only when they are treating a patient. Beyond health professionals, personal health information is thought to be used by: insurance companies, employers and for 'drug' trials/research (by drug/pharmaceutical companies, universities and charities – though in Camden there was generally little awareness that either charities or universities undertook health or medical research).

In terms of who should have access to personal health information, GPs are most trusted. In the public mind, all health professionals treating a patient should be allowed access to such details. There is some debate over whether drug companies should have access, as some believe that the profit motive compromises their integrity, while others forward the view that the pharmaceutical companies need such information for drug trials.

Clearly, though, personal health information is seen as being of a different magnitude of sensitivity compared with other types of personal data (e.g. police records, ID cards or Bank records). Partly this is ascribed to its highly personal nature, and there is a desire to see this information kept private. There is also concern about the pooling of personal health information, and as a result there is a feeling that information is more secure when held in different locations rather than in one central database.

Attitudes Towards Using Health Information for Medical Research

There is low awareness and understanding of medical research among the general public and in some sessions there was no spontaneous mention of research as a potential use of personal health information. When prompted, the public tends to view medical research mainly in terms of drug trials and lab experiments, although there is some limited awareness about prevalence studies. Medical research is commonly associated with the private sector. The public tends not to think about researchers working in universities, hospitals or charities.

As a result of their low awareness, the public is not au fait with the terminology surrounding medical research, the secondary use of health information and the ethics that pertain to that use. If one lesson is to be learned from this research it is that the public knows little about this area and that it has rarely, if ever, come to mind for most people.

Once the concept of medical research is understood, however, some members of the public feel happier, in principle, for their information to be used for those purposes. The two key pillars of confidentiality and consent feature highly in the debate over what information should be available, to whom, and in what circumstances. These two themes are central to building trust.

The key tension within the public mind is between the "greater good" and the privacy of the individual, which confidentiality and the issue of seeking consent are seen to protect. While most see the benefit of personal health information being used for medical research purposes, the very same people can hold reservations over the implications for privacy.

There is some acceptance of the principle of personal health information being passed on for medical research, provided that certain conditions are met, namely:

- the public is fully informed about research, by being told about the objectives, risks and possible benefits;
- the research is conducted by a valid body; and
- consent is given for passing information that can be traced to individuals.

However, just what proportion would consent (or would favour an opt-out system, for example) needs to be explored in the quantitative stage of the research, as does strength of feeling on this issue.

There is some debate over whether personal health information should be provided to drug companies, mainly because they stand to gain financially from access to such information. However, these concerns are balanced with the greater good being served by companies developing new medicines, and on balance respondents seem to be positive.

Many people did not see clinical records and test results, sexual history or information on mental health as sensitive in themselves – although a vocal minority, particularly in Camden, did. It is difficult to know at this stage how much a lack of awareness about the issues is translating into seeming acceptance, or whether people are accepting because they assume anonymity or confidentiality will automatically be preserved. Information from DNA, however, is perceived to be sensitive, and there is some concern that this might be used inappropriately, for example for profiling purposes. The over-arching theme is that, as long as an individual cannot be identified, no information is sensitive in itself.

Interestingly, those workshop participants who have a history of an illness were generally most inclined to have no qualms about their information being used for research purposes, as long as their information is not used beyond the scope of the research. Some members of the public are willing for their information to be linked to them in these circumstances. It seems that exposure to conditions, either personally or through someone close has the effect of amplifying empathy. During the course of the research, moderators encountered an alcoholic and a member of the public with a history of depression, both of whom were positive about their information being used to alleviate the problems of those with similar illnesses.

> *"I wouldn't want anyone else to go through what I have gone through."*

Female, D, 45-54

NB – As mentioned in the introduction to this report, four people with long-term / chronic illnesses (or their carers) were recruited for the workshops, although in a lower proportion than reality for each workshop (to avoid any particular influence which their views may have on the group). For example, in reality, 59% have a long-term condition in the UK population, which would equate to 12 participants in each group.

Anonymity & Confidentiality

Personal details that can be used to identify an individual are seen as being especially sensitive. While some feel that once consent is given, it is acceptable for researchers to have access to personal contact details, others feel that contact details like names and addresses should never be given to researchers, and that researchers should only be given a unique identification number. Others still felt that some information could be used where individuals are identified, but the scope of the studies where this would be allowed should be limited to large scale statistical studies.

There is a perceived need for a "firewall" between individuals and researchers to protect confidentiality, and this characteristic is built in to some of the models put forward for a system of allowing researchers to access personal health information. GPs are seen as the people best placed, and most trusted, to be this firewall. This is perhaps more to do with greater familiarity with GPs, and the fact that doctors are hugely trusted by the public (to tell the truth) as evidenced by Ipsos MORI's long-standing trend data – rather than the fact that they are indeed best placed or have the necessary time.

Where personal details would be attached to health information, the main concern was disclosure of potentially private information to family, friends or acquaintances. In the words of one participant:

"Let the world know, but not my next door neighbour."

Female, C2, 35-44

Anonymity poses a challenge for the public as many see the advantage of information not being anonymous, but squaring this with their concerns over privacy is problematic. Anonymity is seen as positive in safeguarding privacy, yet there are several obstacles this places in the path of effective research.

The public identifies the risk of losing critical information by anonymising, either by design or over-enthusiasm. There is also the problem of duplicated or inaccurate records, and the loss of the ability to verify information/records as they cannot be traced back.

There is also concern that some characteristics which could potentially be used to identify individuals e.g. date of birth, postal district, ethnicity, occupation could be valuable for research. Further to this concern is the realisation that some information could be medically important but yet absolutely identifying, for example photographs.

The public also wrestled with the ethics of research uncovering something they may feel they should warn an individual about (for example, an increased propensity to a particular disease). If information was truly anonymous then this would be impossible, and in the minds of some, unethical. One participant has particular concerns over animal experimentation and would not want their information to be used in research of this kind, despite being happy for it to be used for other purposes.

Mostly, the public feels it is acceptable to use confidential information from the deceased for information analysis, although some would like the deceased individual's rights to be respected by their next of kin being contacted in order to gain consent. However, there was no resolution on whether next of kin would have the chance to opt in or out, on behalf of the family member who had died. In all cases sensitivity, especially over timing of contacts, is seen as key in terms of respecting individual rights and ensuring buy-in to research.

Consent

Consent is a key issue in the public's mind, although the understanding of consent is very much framed by experiences of having checked (or not checked) boxes to opt-in or out, and of reading small print. More complex concepts such as 'consent to consent' are not widely understood and serve to confuse the majority. Those who are articulate on the topic of consent identify the nuances of different consent models for primary and secondary use, the difficulties arising when considering new questions that may arise within a study as problematic, and indicative that a 'one size fits all' approach would not be workable.

It is felt by some that access to personal health information should be selective, that access should not be given to information that might identify a person – e.g. contact details such as names or address – without permission, but access can be granted to clinical information without consent. Among this camp there is no objection to the use of health information for data/information analysis / "number crunching" of population data / epidemiological studies without consent or anonymisation.

> *"If your identity is anonymous and you are only number crunching, I don't see why you should opt-in or opt-out."*

However, it should be noted that a separate group exists which feels that consent is 'king' and that it should be sought before any information can be used, be it anonymous or not. This is seen as a matter of "respect" for the individual's rights.

The general feeling among the public is that for the most part, individuals should not be identified to medical researchers without their consent. People are more comfortable if contact is made via the hospital, GP, local health organisation or specialist known to the patient – "someone in-between you and the big guy" – who should provide information about the study, the risks and benefits.

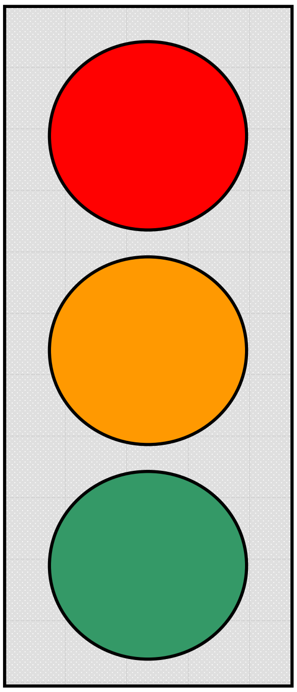
> *"You would feel uncomfortable if you didn't know who is contacting you."*

> *"I am happy to have personal contact with our hospital, GP or the health professional who knows me, but I am not happy being contacted by a Pfizer company, or whatever".*

There is disagreement about whether it is acceptable to be contacted by medical researchers for follow-up or related research studies, or whether this should come through a hospital, GP or local health organisation. Some feel it might be impractical and expensive to require permission to use personal health information for every study.

Ideally an opt-in system would be preferable to most of the public as it involves the most conscious choice. However, some take a pragmatic view that an opt-out is the best solution as it gives the individual the option of consent while not putting a strain on what are seen as already stretched administrative resources. Some also raise the issue of few opting-in, thus rendering numbers too small and unrepresentative to be meaningful for research purposes. There is little support for compulsory granting of access to personal health information for research purposes.

Below is an example taken from one of the groups of a 'traffic light' system of consent. While not representative of the views of all involved in the qualitative research programme, it illustrates some of the concerns the public has over consent, and how a GP fits into the process.



When signing on at a GP surgery, people are asked to agree to one of three consent levels (which can be changed at any time if wanted):

RED

•No information to be passed on without signed individual consent

AMBER

•GP can pass on anonymised* data at own discretion
• If personally identifiable information is needed, GP to send/pass on a letter to individual, explaining the research. It is up to the individual to agree or not

GREEN

•GP can pass on both anonymised and personally identifiable data to researchers at own discretion

Individuals should be able to find out how their data has been used at any time, if they so desire

* Key linking anonymised data to be held by GP

In the above system, individuals would opt-in to having their personal health information shared for medical research purposes when registering with a GP. This would give different levels of consent for different types of information. Others also arrived at the same principle, although they had reservations as to how up-to-date consent would be. To counter this problem of obsolescence there would be an automatic review of both the information held on an individual (again channelled through a GP), along with a review of the levels of consent given. This was envisaged as happening every five years.

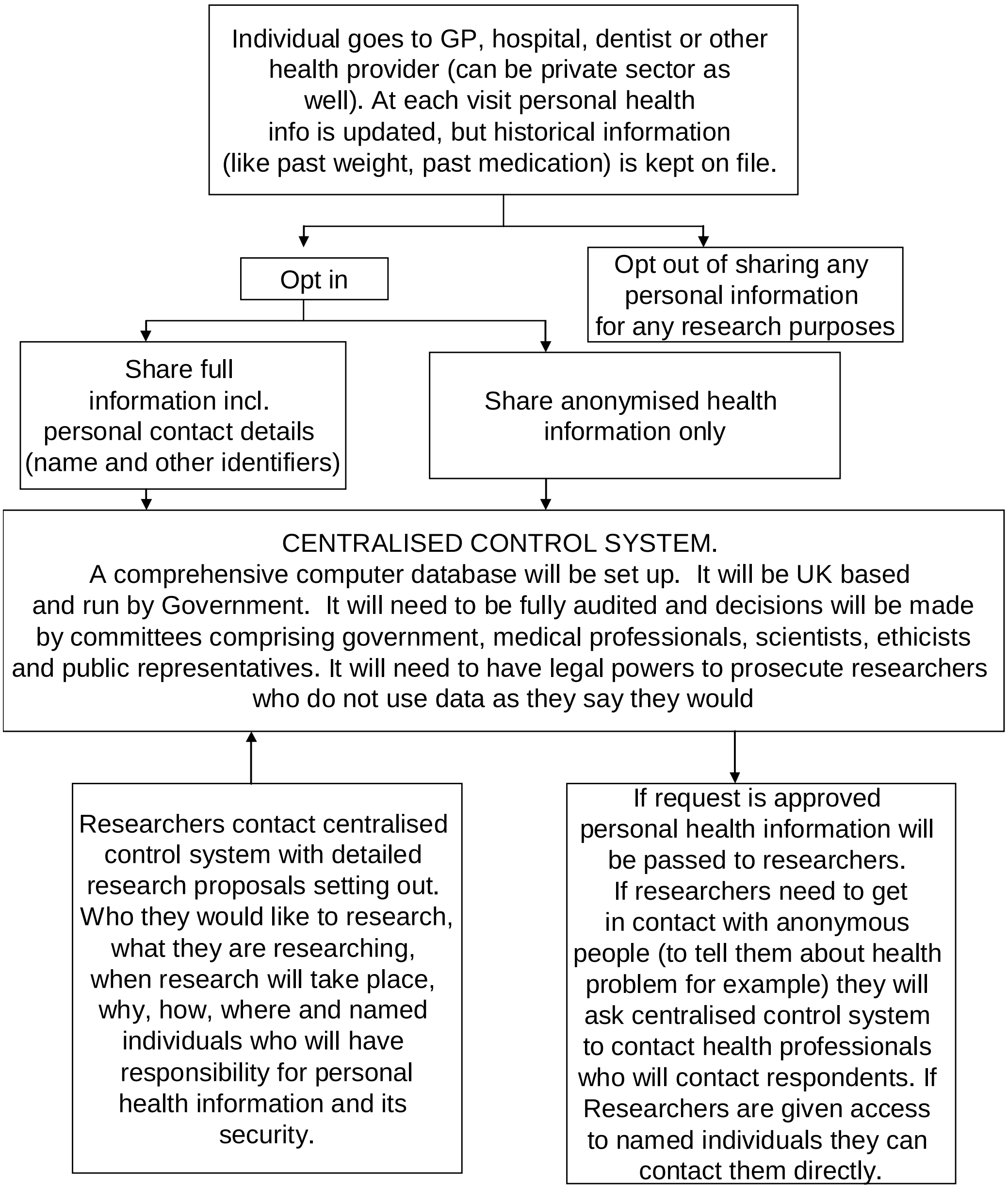
The flow chart overleaf sets out a system arrived at by another group. It is indicative of approaches designed by other groups.

Again the first point of contact is health professionals, usually within the NHS, but not exclusively. In common with the 'traffic light' approach there are levels of consent to be given, with an opt-out from any personal health information being shared.

For those who have not opted out there is then an opt-in system where the individual decides whether to (confidentially) share full information, with identifiers, or to share anonymised information. The data are then stored in a central database, administered by Government. The role of those administering the database is to act as the "middle man" or firewall. They assess the requests for information and give the go-ahead or otherwise for the research. Any contact needed to be made would be cascaded from the researchers, via the central body, through the health practitioner (most commonly a GP).

Vital to trust in the system is its transparency to the public, the existence of liability and the realistic potential for redress should information be used outside the terms consented to.

Ideal Information Sharing System



Government is seen by most as best placed to administer the system as they have the resources to do so. There is a "guarded trust" towards Government (of any persuasion) to administer the system. They are distrusted the least in this respect, but are nevertheless distrusted in this and our longer-standing work. In the words of one participant:

> *"Better the devil you know."*

While Government is seen as the most likely to **administer** the system, it is GPs who are seen to be trusted to be the **firewall** between researchers and patients, or the public at large.

Trust

Key to perceptions of using personal health information for medical research is the issue of trust. As mentioned, in most cases GPs are seen as the most trustworthy guardians of personal health information (as evidenced by most nominating them as the firewall), echoing the high regard in which they are generally held by the public.[10] However, in the specific case of researchers wanting to contact a key individual (the hypothetical case of an individual holding the key to a cure for cancer was used) there is more debate. In such instances, the information concerned is seen as of too great an importance for someone as close to a patient as a GP to be trusted with. In this case an independent body would have to approve whether a researcher could contact a GP who would then contact that key individual. This would only occur in instances where individuals had opted in to information being shared but had asked to remain anonymous.

It is strongly felt that the public should be consulted on the issue of secondary access to personal health information for research purposes.

Part of building trust is ensuring the public feels informed, and in this regard it is important that the benefits of medical research to the greater (social) good are communicated to the public, who tend to think of medical research as being conducted by private companies for financial gain.

The public has an appetite for more information on medical research, specifically its purpose (and wider benefits), how it is conducted, and who is involved. Medical research is described as a "hidden industry" and a "closed shop", and this perception was felt to breed mistrust. More information would allow individuals to give informed consent.

People would be reassured about the use of personal information in research if they knew more about the MRC and were able to associate the organisation with research studies. There is little awareness of the MRC and a feeling that it should

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[10] Previous MORI research has shown that doctors are consistently the most trusted people in British public life. MORI's 2006 'Opinions in Doctors' study conducted for the Royal College of Physicians reveals that 92% of the general public believes doctors tell the truth.

be better known. Some feel that providing more information about research would help persuade people to give their consent for health information to be used in research. Doing so simply, using case studies to highlight tangible day-to-day benefits, would be most effective.

There is a strong feeling that the MRC should play a leading role in promoting the use of personal health information for medical research, and that this might help overcome the "great scepticism" about research generally. Suggestions include the MRC working in partnership with the NHS to spread information, rather than an already overworked NHS having to bear this load on its own, while others think a public information programme (i.e. TV and print advertising) would do well to increase public awareness of medical research and the role of the MRC.

> *"It is the responsibility of the MRC to form a stronger body and work alongside the NHS, and not pressuring the NHS to promote research, as this will add to the NHS workload."*

Risks and Benefits of Personal Health Information Being Used for Medical Research

Against the backdrop that there is generally low awareness of medical research and what it involves, the risks and benefits of personal health information being used for medical research purposes were debated.

Risks

The main risk identified by the public is of personal health information being disclosed. Some worry about such data being used for commercial purposes, for fraudulent purposes or simply that some information about them becomes known to their friends, family or acquaintances. As noted previously, while many are happy for their personal health information to be disclosed to researchers, it is important to remember that such information is seen as highly private and sensitive, so any improper use is deemed highly inappropriate.

Concerns over misuse of sensitive information are particularly high when imagining a central database which holds all health information about an individual. As such, most are happier for information to be held in different locations, despite this being seen as potentially inefficient.

Linked to the issue of information disclosure is security of information. There are concerns over both security of electronic records and paper. Electronic records are seen as more accurate and useful, but they are also seen as vulnerable to more abuse than paper records, mostly through ease of transfer and security breaches. In turn, paper records are seen as old-fashioned and cumbersome, and prone to being damaged or lost more easily than electronic records.

Inaccurate information being held is also an issue, with some participants having experience of something as simple as their names being incorrect. Further to the holding of inaccurate information lies a concern over the ease with which it can be corrected and how an individual would go about doing so.

While there is some knowledge of the Data Protection Act, not all members of the public have faith that it is rigorously administered. There is also the issue of data being passed over international boundaries and the legal implications on the individual's privacy in different countries. Not all regions of the world are trusted to have the same standards as the UK or EU.

Benefits

The benefits of personal health information being available to researchers are mostly seen as societal. The development of better drugs, better equipment and better techniques are all seen as emanating directly from medical research. There is also the prospect of cures for diseases being found.

Greater knowledge of patterns of health or disease is also seen as an important benefit. This knowledge could be used to inform the public through communications (the current campaign against childhood obesity was an example given), and to help form policy in the present and the future (by looking at past trends and modelling the future).

Long-term medical research is seen as adding to the body of knowledge of society, so that while once cancer was a taboo, research has helped to educate the public to the extent that it no longer carries such stigma. The same is said of HIV / AIDS.

Qualitative Depth Interviews among Those With a Long-Term Illness Disabled People & Carers

Similarities with the general public

Concern over the use and misuse of personal information

Participants tend to conflate electronic identity fraud with the large amounts of personal information they believe is held on them. There is particular concern over information on spending and purchasing habits gathered by credit card companies and retail stores, especially supermarkets and loyalty cards. They would also like more openness on how their personal information is shared between different organisations.

Storing information is seen to benefit organisations rather than individuals. Participants tend to focus on commercial organisations rather than the government or police. They are of the opinion that commercial organisations gather and store personal information primarily to build up profiles of individuals in order to target them with tailored marketing and communications.

There is some fear of Big Brother, with one participant saying:

> *You can't move. You can't do anything without somebody, somewhere knowing exactly what you're up to*
>
> Female, depth interview

Trust

Participants tend to trust their GP and other health professionals directly involved in their treatment. Perhaps because they have much more direct experience of hospitals and contact with health workers than the general public, through being ill or carers, some participants are concerned that health workers who do not need to see their information may have access to it, and are keen for it to be restricted to those involved in their care.

However, participants often view health organisations - GP surgeries, hospitals and the NHS as a whole – as careless, lacking a system for keeping medical records together and frequently losing them.

> *I have actually said something to a doctor, and then it's come back to me from a completely different source a year later, and you think, 'Well, how did that get there?' I guess their idea of need to know and mine are different, but you know if I say it to a doctor in a room, it stays, as far as I'm concerned, it should stay with him. Or if I've got to see another doctor and there's been a consultation, perhaps it should get passed on, but this seems to go all over the place. Doctors do seem to have a much looser way of dealing with confidentiality than I would actually like*
>
> Female, depth interview

> *As far as I'm concerned they are stored in a general office area accessible by every single member of staff who works in the surgery*
>
> Male, depth interview

Overall, participants are pragmatic. They perceive it would be impractical to be actively distrustful, so they tend to trust most organisations to be responsible with their personal information unless they have a clear reason not to.

The exception is insurance companies. Participants are even less keen than the general public for them to have access to their personal health information. As participants are either ill or carers, they may have a stronger sense of having more to lose should insurance companies find out information about their health. One participant who is in remission from cancer feels that there should be more clarity about whether or not individuals who have had cancer need to reveal this to insurance companies, especially if it is more than five years since they received the 'all-clear'.

Guidelines on handling personal information

Most participants have heard of the Data Protection Act but cannot explain its workings in any great detail. It is generally seen as protecting information from being accessed without permission. No-one could name the body that monitors compliance of the Act, but some participants are aware that it is a government responsibility, and one said it was monitored by an *arm's length government body*.

Participants are generally content with the perceived level of safeguards in place. However, one participant believes more are required to protect personal information on the internet. Another participant is particularly concerned about the ability of the police and the Government to access personal and financial information about individuals without their consent, using new anti-terrorism legislation, and feels that this needs to be more tightly controlled.

Consent

Consent is even more important to these participants than it is to the general public. They feel strongly that only parties to whom they have given permission should be able to see their personal information. As one participant says when asked who should have access to her personal health information:

> *Anyone I say can, and no-one else*
>
> Female, depth interview

Again this may be because they are more likely to be personally confronted by issues of consent through having a long-term health condition and frequent contact with health professionals.

Participants strongly favour an opt-in approach to consent. The feeling is that the individual would be making a positive, informed choice on each occasion that medical researchers wished to use their personal health information.

> *It would be nice if somebody, there was a big box at the front that said, 'These notes can be used, or these notes can't be used', so I actually have a choice of whether I allow my personal information, even in anonymised ways, to be used*
>
> Female, depth interview

An opt-out system is seen as appropriate for organ donation, but otherwise may mean that individuals are disengaged and unsure about what their medical records are being used for.

Above all, they believe that signed consent must be sought from the individual, preferably through their doctor. One participant stresses the importance of informed consent, providing the individual with the full facts about the research and how their records will be used. Participants think that medical researchers should also access medical records through people's doctors.

Anonymity & Confidentiality

As with the general public, anonymity and confidentiality is a focus for participants. They are generally relaxed about detailed personal health information being available to researchers as long as it is confidential. One participant stressed that researchers should avoid paying lip service to anonymity. Removing names and addresses is not enough, and more care should be taken to ensure that individuals cannot be identified through other detailed information.

Informing and educating the public

Like the general public, participants are keen to know more about medical research. They see understanding as key for people – the more they know about clinical trials and the more open the process is, the more likely the public will want to take part. It is important for them to know what the information will be used for, as one participant demonstrates:

> *When I donated my cells for DNA purposes, I knew what was going on, I knew what the project was, I knew what the future use was going to be more or less, and I didn't really mind.*
>
> Female, depth interview

Differences

Awareness of personal health information and medical research

Participants have more experience of health services and therefore a better knowledge of medical research and personal health information than the general public. They mention the following types of personal health information:

- GP records
- Hospital records
- Information held by insurance companies
- Information held by pharmacies on conditions and medication
- Information held on conditions or disabilities by local authorities and social services departments, if you receive care through them. This includes information on psychiatric conditions
- Relevant health information held by the DSS (now DWP), if you receive sickness or disability benefits

Some participants are aware of DNA records, and that may be held by the police as well as medical establishments, but only when prompted.

Participants demonstrate a broader awareness of types of medical research than the general public. As well as drug trials they mention longitudinal studies, research on care and support as well as that on lifestyle and health.

Direct experience of mishandling of their personal health information

Participants are aware that in theory, GP notes should be comprehensive and should 'follow' the patient. However, some participants say that in their experience this has not happened. Some also describe how their hospital records have been lost. Despite this, there is some concern about the switch from paper to electronic records. In the words of one participant:

> *While it was all written down on pieces of paper , I didn't have a problem with it. Now it's all on computers, I do have more of a problem with it cos it's much easier to share*
>
> Female, depth interview

These experiences give participants a more acute sense of how data can be misused and circulated more widely than they would like amongst medical staff.

Sensitivity of health information

Participants' views are similar to those of the workshop groups in that they regard health information as being more sensitive than other types of personal information. One participant sums up the perceived difference between health and other personal information:

> *Money's money but health is how you feel as well and if you're being persecuted in a way because of that, it's just going to make you worse*
>
> Female, depth interview

However participants are particularly worried about employers and colleagues finding out about their conditions. They are concerned about being singled out and picked on by fellow employees, or 'put in a box' by employers.

> *People can judge them, so if they find out something about you because of your health you could be picked on*
>
> Female, depth interview

To illustrate this, one participant described a recent news story about a woman who was asked to resign by her employer because she had been diagnosed with cancer. This is indicative of a keener sense of potential prejudice, particularly for one participant living with HIV. Other types of health information deemed to be particularly sensitive include addictions and mental health problems.

Access to your own medical records

There is a general awareness amongst participants that you have the right to see your medical records on demand, and some have asked to do this. However there is a sense too that health professionals do not like patients to see their records. According to one participant who demanded to see her notes, the impression she received from medical staff was that they were "their" notes, meant to help them treat the patient, rather than the patient's records. In the participant's experience, doctors often write personal comments on patient notes that they would not want the patient to see, including acronyms. This perceived attitude amongst doctors that the treatment is none of the patient's business is exemplified by doctors' references to 'heartsink' patients, referring to their reaction when a patient who is particularly knowledgeable about their condition and treatment, or who has sought out a lot of information on it, enters the surgery.

Regulation

Participants are more aware than the general public of the existence and role of the ethics committee in overseeing and regulating research. They are strongly in favour of the ethics committee, but one participant stresses that it should be open and transparent. It should be easy to find out who sits on the committee and it should not operate as an 'old school tie' network.

Individual consent versus the greater good

Unlike the general public, participants almost always put consent of the individual above the greater good, regardless of how important to society the research is perceived to be. Rather than encouraging people into taking part in research, participants believe that efforts should be made to get more people to buy in through reassuring them about confidentiality, who will see their personal health information and who and what the research is for, and educating them about research in general. No individual or group should be forced to take part unless absolutely necessary, for example a national emergency or epidemic.

> *Yes absolutely. It's that person's life and it's entirely up to them what they want to share with, about it*
>
> Female, depth interview

> *If these people don't want to take part in any medical research because of their religion or whatever it is, well, they probably shouldn't be forced to do so. It's, I mean their freedom, and we should respect that*
>
> Male, depth interview

Quantitative Research

Perceptions of Personal Health Information

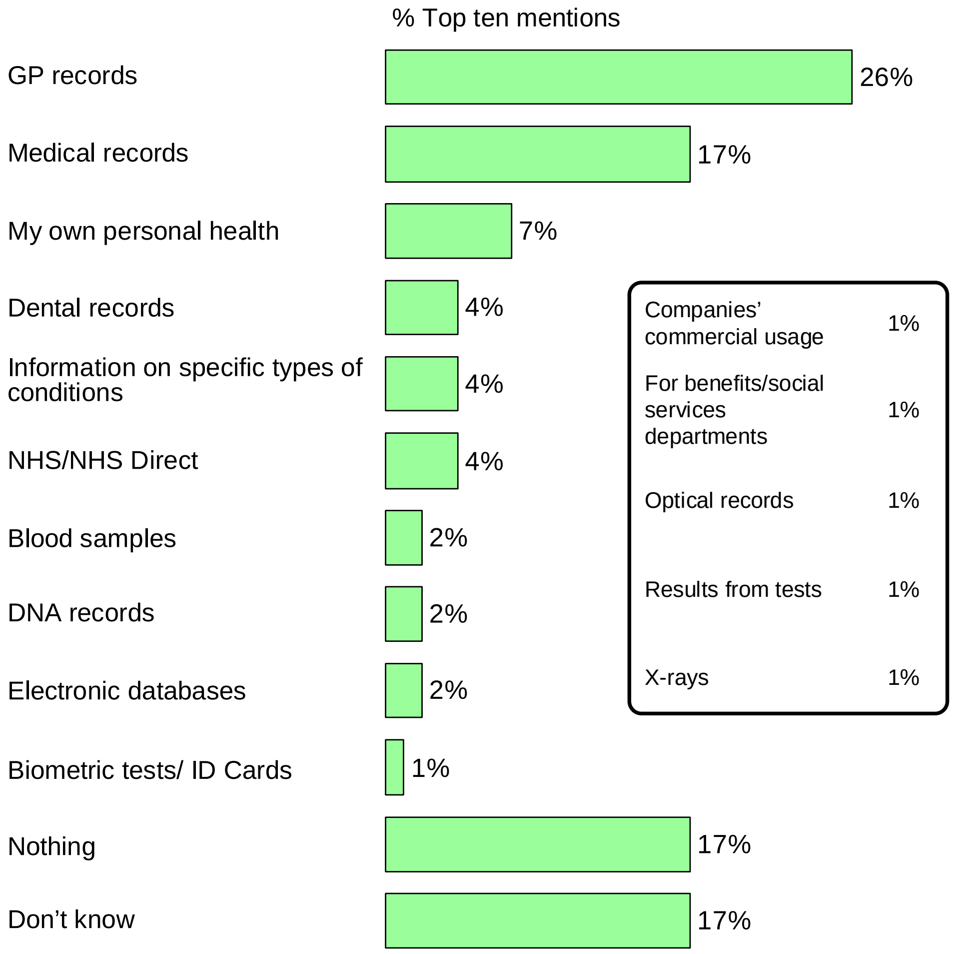
Types of Personal Health Information

When asked about their unprompted perceptions of the phrase 'personal health information' the general public give a variety of responses. For example, respondents are just as likely to think of personal health information as being related to the private sector (such as direct marketing and assessment of eligibility for financial / insurance products) as they are to mention public sector uses, such as by the NHS or dental information. The most common association is, however, 'GP records', which is mentioned by 26%. The other key response is 'medical records', given by 17%. Just over a third (34%) cannot think of any associations with the phrase personal health information, which indicates fairly low awareness for the MRC to address. These findings remain consistent across all sub-groups.

The top two responses regarding what the public feels constitutes 'personal health information' in the quantitative phase (Medical / GPs records) are also the most common responses in the workshops and depth interviews. Also, the fact that the general public names a wide variety of types of personal information resonates well will the qualitative work.

Perceptions of Personal Health Information

Q *What comes to mind, if anything, when I say 'personal health information'?*



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006 Source: Ipsos MORI

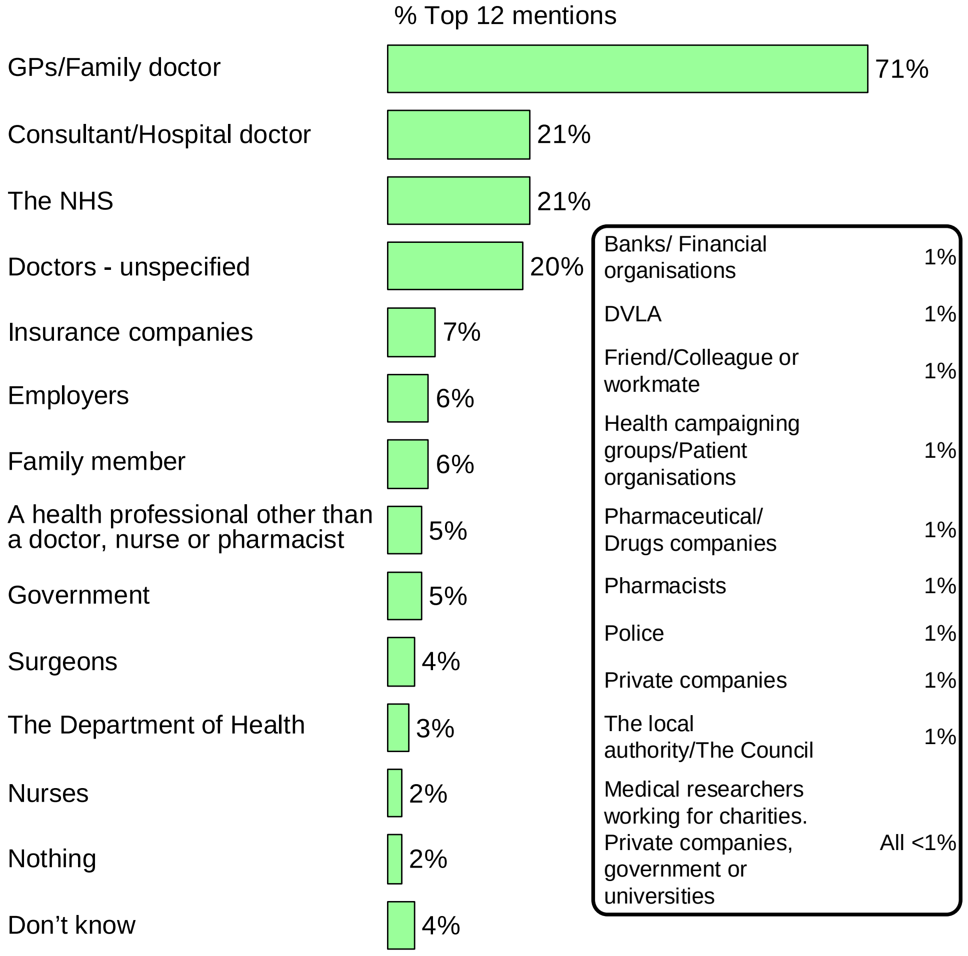
Who Holds Personal Health Information?

Spontaneous perceptions of who or which organisations people feel would hold personal health information focus mainly around the health service (particularly GPs – cited by the large majority (71%), but also hospital doctors (unspecified) the NHS). Medical researchers working in any capacity are mentioned by less than 1% of the general public. The qualitative research also found that, beyond health professionals, personal health information is thought by many to be used by insurance companies and employers. However, in the quantitative phase, just 7% cited insurance companies and 6% mentioned employers.

This fits in well with the qualitative findings, where most hold the belief that health professionals have access to personal health information. GPs are expected to have comprehensive access to personal health information, while health professionals in hospitals are believed to see them only when they are treating a patient. The qualitative research also found that, beyond health professionals, personal health information is thought by many to be used by insurance companies and employers.

Who Holds Personal Health Information?

Q Who, if anyone, do you think would hold personal health information about you?



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006 Source: Ipsos MORI

Sub-Group Differences

The youngest age group (15-24s) shows the least awareness of which people or organisations might hold personal health information about them. Just 59% of 15-24s mention GPs or family doctors, and this proportion increases with age to a high of 77% (among those aged over 55). The same applies for 'the NHS' and 'consultant or hospital doctor'. The youngest age group are, however, most likely to mention 'family member' (10%) in this context. Perhaps not surprisingly (given that they will have had less contact with any such people or organisations) the youngest group are most likely to say they 'don't know' who or which organisations might hold their personal health information (7%).

Those in social grade AB[11] are most likely to say GPs would hold their personal health information (80%), which decreases to 66% among DEs. ABs are also most likely to mention 'insurance companies' in this context (12%). As

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[11] Please see appendices for social class definitions

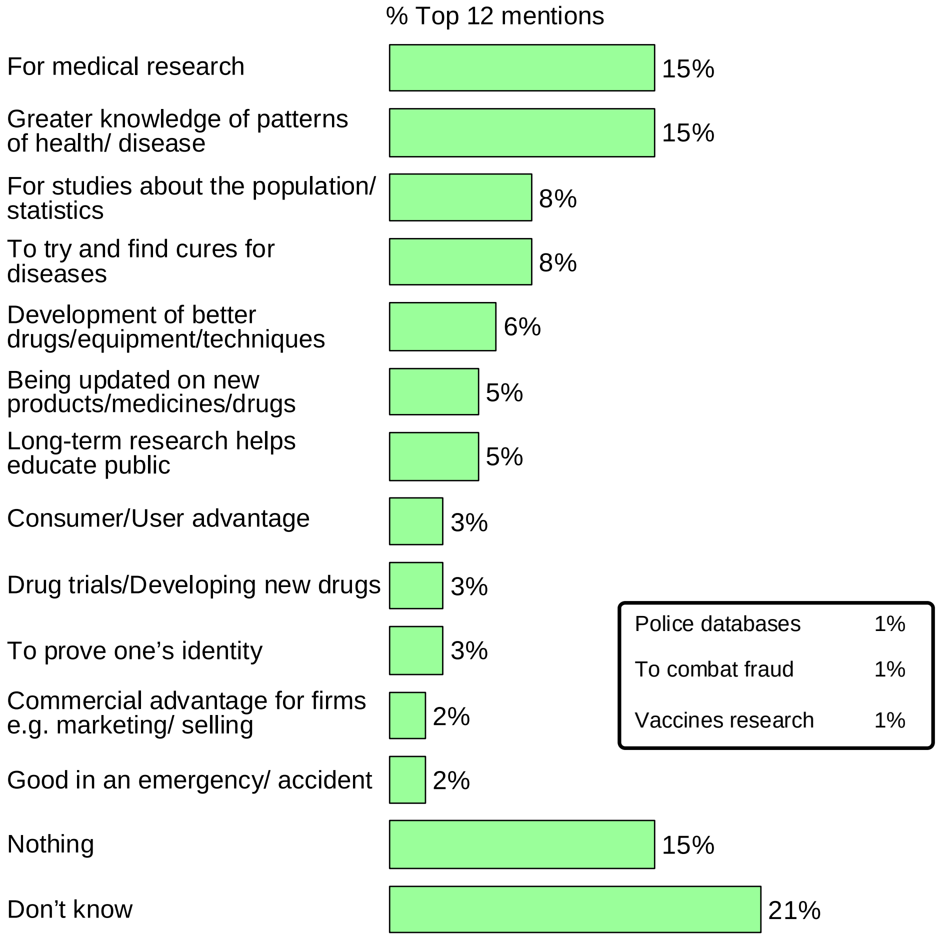
knowledge about personal health information appears to increase with age, it also appears to increase with social grade. Specifically, only 1% of ABs say they ‘don’t know’ who might have access to their personal health information, compared to 8% of DEs.

Advantages & Disadvantages of Using Personal Health Information

When asked about their assessment of the merits of collecting and using people’s personal health information, ‘medical research’ and ‘having a greater knowledge of patterns of health or disease’ are the most common advantages given (without being prompted). Moreover, four of the next five most common advantages cited related in some way to medical research – 42% mentioned on or all of these advantages. The qualitative research also shows that respondents are aware that advantage can be gained by companies for marketing and selling products and services through collecting and using personal health information.

Advantages of Collecting Personal Health Information

Q What advantages, if any, are there of collecting and using people's personal health information?



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006 Source: Ipsos MORI

As was found in the qualitative research, respondents also feel that an advantage of collecting and using personal health information can be gained by companies holding or selling the information, for marketing and selling products and services. However, as stated above, the dominant advantage seems to be the possible or likely health improvements stemming from medical research.

Sub-Group Differences

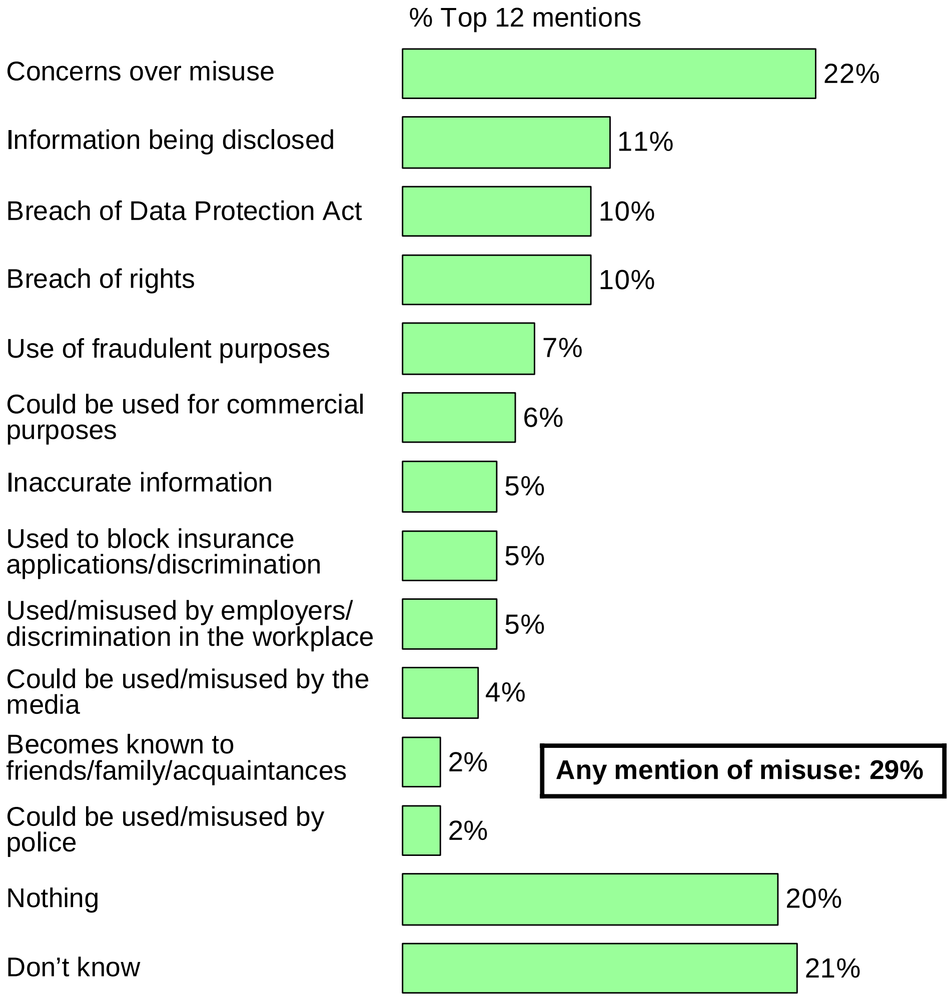
Those aged 15-24 (11%) are the least likely age group to say that an advantage of collecting and using people's personal health information would be 'for medical research purposes', while those *most* likely to feel this are aged 45-54 (19%). This could possibly due to the fact that this group are more likely to be parents of young children or carers for the sick or elderly. Those in social grade AB are most likely to see medical research as a key advantage (19%), a proportion which decreases with ascending social grade to 11% among DEs. This may be related to knowledge of the subject, as ABs are least likely to say there are no advantages (11%, compared to 18% among DEs) or they 'don't know' (14%, compared to

30% among DEs). A possibly related finding is that just over seven in ten (71%) with degree or higher qualifications can mention at least one advantage of keeping people's personal health information, whilst the corresponding figure for those with no formal qualifications is 40%

As for **disadvantages**, more respondents say there are no disadvantages of collecting or using personal health information (20%) than say there are no advantages (15% and equal proportions do not know (21%). Just over one in five (22%) express concern over misuse of the information. The related concerns of 'information being disclosed' and 'breach of Data Protection Act' are both mentioned by one in ten respondents.

Disadvantages of Collecting Personal Health Information

Q What disadvantages, if any, are there of collecting and using people's personal health information?



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006

Source: Ipsos MORI

Sub-Group Differences

In addition to being the most likely to cite at least one advantage, ABs are also most likely to cite at least one disadvantage of collecting and using personal health information (67%). This may suggest that those in higher social grades are more engaged with, and more knowledgeable about, issues concerning personal health information. As is the case for advantages, the proportion saying they 'don't know' when asked about disadvantages decreases with age from its highest (29%) among those aged 16-24.

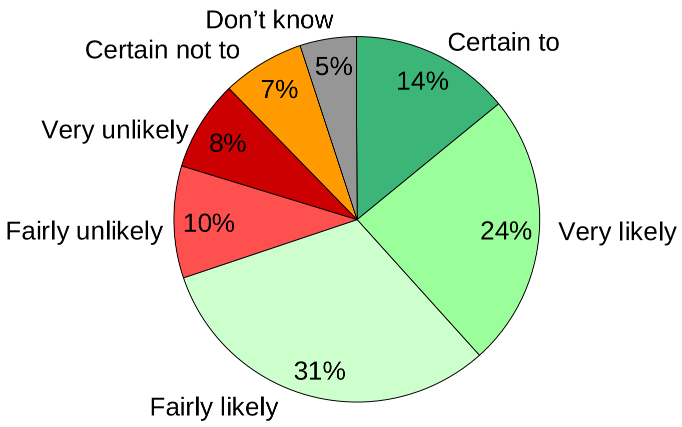
Attitudes towards Use of Personal Health Information

Far more people are likely, than unlikely to allow their personal health information to be used for medical research purposes (69% compared with 25%). This suggests there is positive feeling towards the use of personal health information for medical research and emphasises the need for an information campaign on the value of such research. However, there also seems to be caution or desire for more information before any firm commitment is given because just 14% said they would be certain to do this. Nevertheless, this is twice the proportion who said they would be 'certain not to'.

This resonates well with the key advantages of collecting and using personal health information cited earlier and also the qualitative work where participants are largely positive about allowing their personal health information to be used, with caveats over knowing more about it, and that the two key conditions of anonymity and consent are considered. However, it is important to note that a quarter of respondents state that they are either 'unlikely' or 'certain not to' allow their personal health information to be used. Their reasons for this are explored in the next section.

Allowing use of Personal Health Information for Medical Research

Q *How likely, if at all, would you be to allow your personal health information to be used for the purposes of medical research?*



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006

Source: Ipsos MORI

Sub-Group differences

Young people (aged 16-24) are least inclined to say they are likely or certain to allow their personal health information to be used for medical research (27%) and this proportion increases gradually to its highest (45%) among the oldest age group (over 55s). People on social grade AB (45%) are more likely to allow their personal health information to be used in comparison to those in lower social grades (34% of both C1s and C2s are likely or certain). Those with a long-term disability (45%) are also more likely to say they would allow their information to be used, a finding which is supported by what came out of the workshops. Disabled or long-term ill participants in the in-depth interviews were also positive about allowing their information to be used, however, they there was a slight sense that these participants were more cautious (than participants in the workshops generally) regarding the issue of consent due to concerns over the possibility that their information could be passed on to unauthorised organisations or individuals.

Withholding Personal Health Information

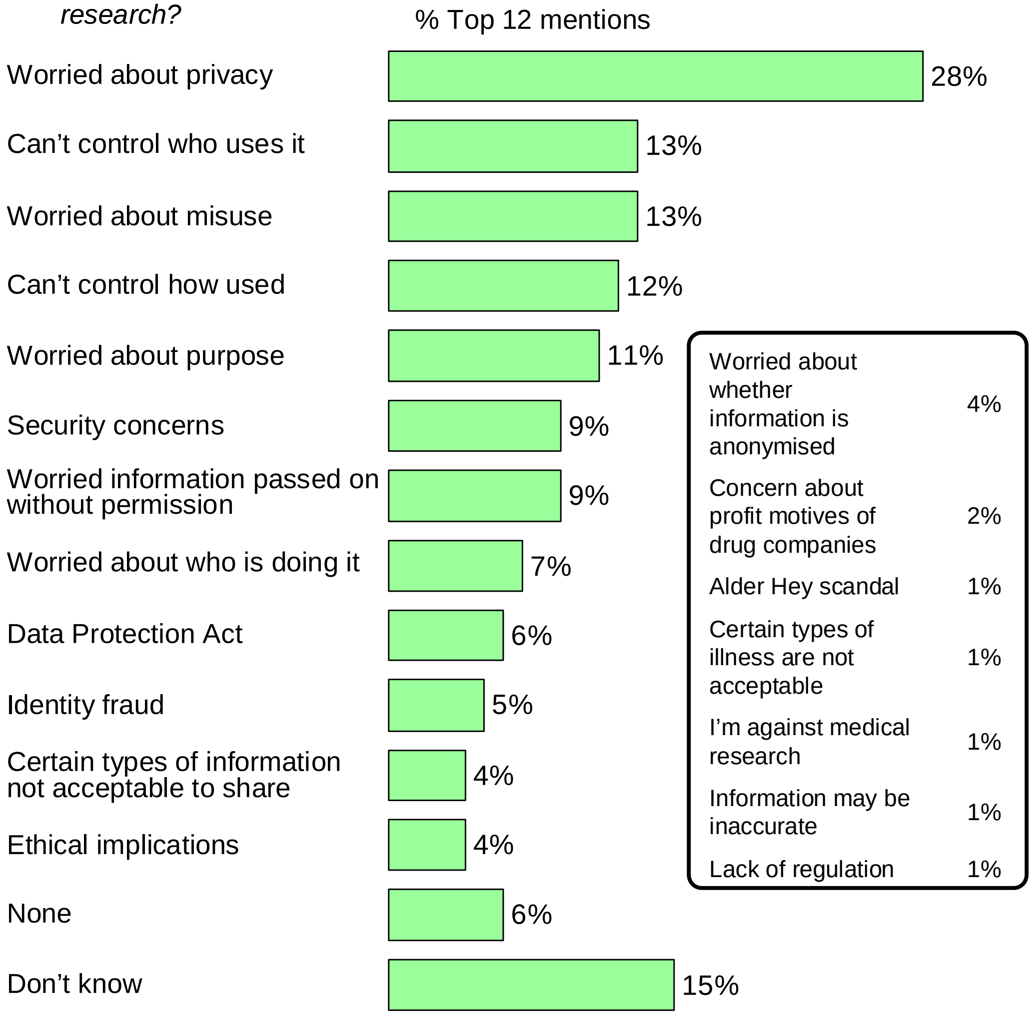
Concern over privacy is the most commonly cited reason for not allowing their personal health information to be used for medical research purposes, among those who say they are unlikely or certain not to: 28% of this group. Other common concerns are over misuse of the personal health information or it 'falling into the wrong hands' (13%) and similarly over the perception that they can not control who used their information (13%) or for what purpose (12%). Encouragingly, only 1% say that they would withhold their personal health information because they are 'against medical research'. Responses to this question do not differ significantly between sub-groups.

The qualitative research helps to shed some light on these concerns. Here, the main concerns the public has over personal information are not related to organisations holding information, but rather that they may share this information, particularly for commercial gain. Sharing information, however, was seen as acceptable, provided permission is given for organisations to do so. The qualitative research shows that there is some acceptance of the principle of personal health information being passed on for medical research, provided that certain conditions are met, namely:

- the public is fully informed about research, by being told about the objectives, risks and possible benefits;
- the research is conducted by a valid body; and
- consent is given for passing information that can be traced to individuals.

Reasons For Not Consenting to Personal Health Information to be Used

Q *Why do you say that you are unlikely/ certain not to allow your personal health information to be used for the purposes of medical research?*



Base: All ‘unlikely/ certain not to’ allow their personal health information to be used for medical research (648)

Source: Ipsos MORI

Who Do People Trust?

The vast majority (87%) trust GPs to have access to their personal health information, and over half trust other health professionals – such as consultants or hospital doctors (59%). The NHS is cited as being trusted on this issue by around half, but no other group is mentioned by more than half – however,, it should be pointed out that a low score does not necessarily indicate a lack of trust. It could be the case that the public has no, or limited knowledge to make a judgement (and therefore is not expressing an opinion). Medical researchers working in the public sector i.e. for Government and universities (both trusted by 11%) are more trusted than their counterparts working for private companies (4%). The 11% saying they trust medical researchers is lower than we would expect in comparison to previous Ipsos MORI work. For example, in a survey conducted for The Scientific Alliance[12], we found that just under three in ten (29%) say they trust 'University Scientists' to tell the truth about the *risks from the chemicals used in household goods*. The difference in this case may be because when considering the issue of their 'personal health information' people are liable to be more cautious generally and they also are unaware of the purpose for which their information would be used. Also they may be less informed about the value of much medical research and/ or what constraints are imposed on this use of their personal health information.

Furthermore, an Ipsos MORI survey which examined public attitudes to science and scientists for the government's *Office of Science and Innovation*[13] found that 43% of adults say they trust scientists working in universities to *provide accurate information about scientific facts*. A similar proportion trust scientists working for charities (41%). As was found in this survey, fewer in the OSI survey say they trust government scientists (14%) or scientists working for industry (13%).

The private sector features prominently among the least trusted organisations where personal health information is concerned, with lawyers being trusted by 9%, banks by 8% and pharmaceutical companies by 6% respectively. These results echo Ipsos MORI's long-standing trends on who are trusted in the general sense, which indicate that doctors are the most widely trusted group to tell the truth[14].

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[12] http://www.mori.com/polls/2003/scientificalliance-top.shtml

[13] Previously *Office of Science and Technology*

[14] http://www.ipsos-mori.com/polls/2006/rcp.shtml

Trust in Types of People

Q Now I will read you a list of different types of people. For each would you tell me if you generally trust them to tell the truth, or not?

	'83	'93	'97	'99	'00	'01	'02	'03	'04	'05	'06
Doctors	82	84	86	91	87	89	91	91	92	91	92
Teachers	79	84	83	89	85	86	85	87	89	88	88
Television news readers	93	72	74	74	73	75	71	66	70	63	66
Professors	n/a	70	70	79	76	78	77	74	80	77	80
Judges	77	68	72	77	77	78	77	72	75	76	75
Clergyman/ Priests	85	80	71	80	78	78	80	71	75	73	75
Scientists	n/a	n/a	63	63	63	65	64	65	69	70	72
The Police	61	63	61	61	60	63	59	64	63	58	61
The ordinary man/ woman in the street	57	64	56	60	52	52	54	53	55	56	56

Base: C. 2,000 British Adults Aged 15+ Source: 1983-2006, MORI/RCP

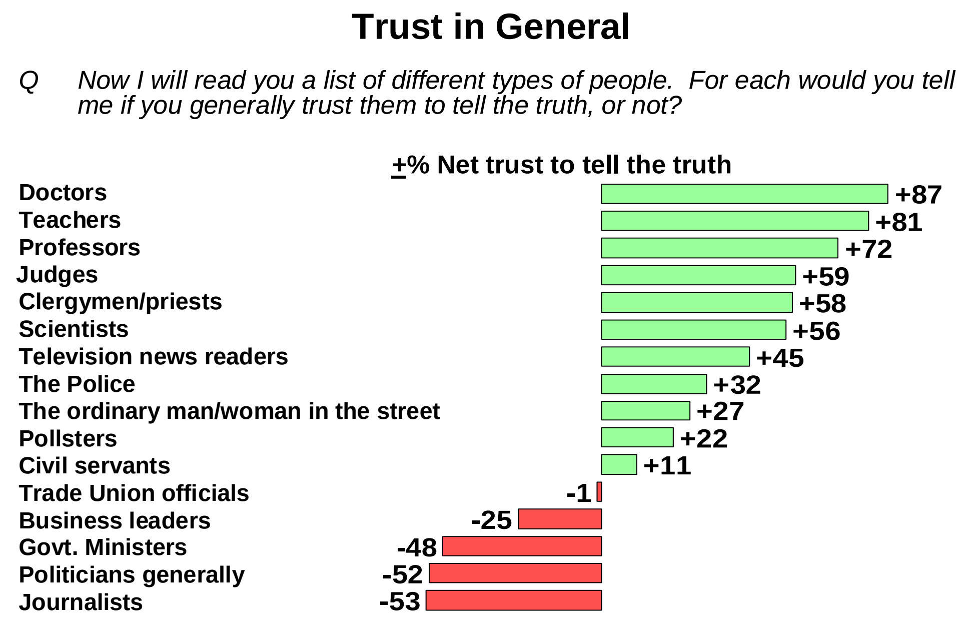
Source: Ipsos MORI

Continued…

	'83	'93	'97	'99	'00	'01	'02	'03	'04	'05	'06
Pollsters	n/a	52	55	49	46	46	47	46	49	50	51
Civil Servants	25	37	36	47	47	43	45	46	51	44	48
Trade Union Officials	18	32	27	39	38	39	37	33	39	37	41
Business Leaders	25	32	29	28	28	27	25	28	30	24	31
Journalists	19	10	15	15	15	18	13	18	20	16	19
Politicians generally	18	14	15	23	20	17	19	18	22	20	20
Government Ministers	16	11	12	23	21	20	20	20	23	20	22

Base: C. 2,000 British Adults Aged 15+ Source: 1983-2006, MORI/RCP

Source: Ipsos MORI



Base: C. 2,000 British Adults Aged 15+ Source: 2006, MORI/RCP Source: Ipsos MORI

The chart above shows one of the key ways to examine the trust data – which is to look at 'Net Trust': i.e. the proportion who trust, minus the proportion who do not. When we look at the latest figures for 2006, we can see that net trust in scientists places them in the top six most trusted professions, at +56 net trust.

The qualitative research shows us that key to perceptions of using personal health information for medical research is the issue of trust. As mentioned, in most cases, GPs are seen as the most trustworthy guardians of personal health information, echoing the high regard with which they are generally held by the public.[15] Furthermore, the focus groups showed that people feel that all health professionals treating a patient should be allowed access to such details.

The lower levels of trust in pharmaceutical companies links in well with findings from the workshops, where some (but not all) believe that the profit motive compromises their integrity.

A key insight from the qualitative work is that, in order to build public trust, they need to feel informed. Thus it is important that the benefits of medical research to the greater (social) good are communicated to the public, who tend to think of medical research as being conducted by private companies for financial gain. A key condition of them considering giving out their personal health information is receiving more information on medical research, specifically its purpose (and wider benefits), how it is conducted, and who is involved. Medical research is described as a "hidden industry" and a "closed shop", and this perception was felt to breed mistrust.

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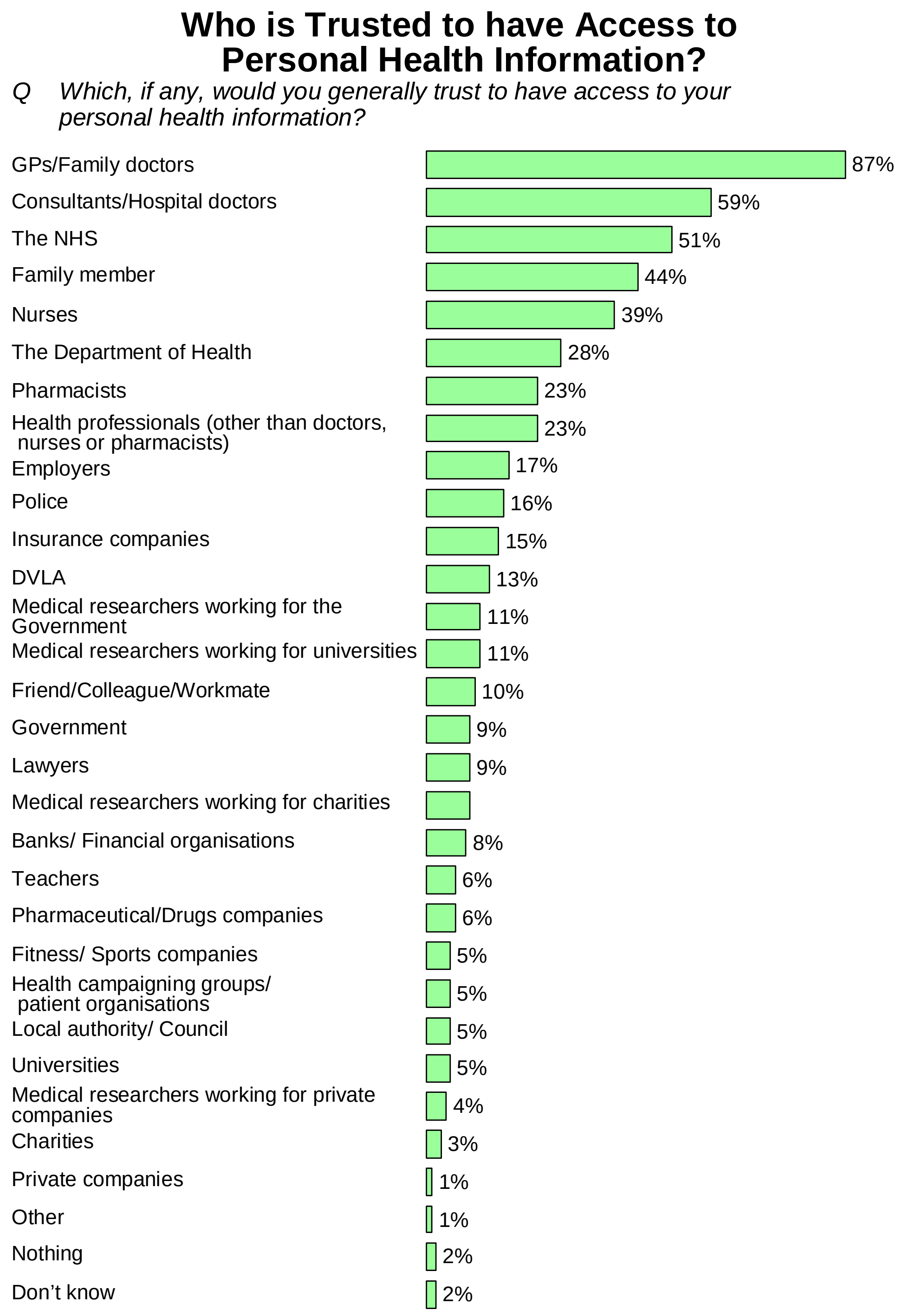
[15] Previous MORI/Ipsos MORI research has shown that doctors are consistently the most trusted people in British public life. MORI's 2006 'Opinions in Doctors' study conducted for the Royal College of Physicians reveals that 92% of the general public believes doctors tell the truth.



Who is Trusted to have Access to Personal Health Information?

Q *Which, if any, would you generally trust to have access to your personal health information?*

Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006 Source: Ipsos MORI

Sub-Group Differences

Again, perceptions of the youngest age group (16-24s) appear to vary the most away from the average and from those of other age groups. Younger people are least likely to trust GPs (82%) and consultants/ hospital doctors (49%) to have access to their personal health information. However, they are most likely to trust family members (61%) and friends/ colleagues (15%) and employers (25%). They are also more inclined to trust organisations in authority such as the police (31%), the government (14%) and teachers (15%).

Those in social grade AB are consistently more likely than those in lower social grades to trust a variety of people and organisations compared to those in social grade DE. This is especially the case concerning family members (52%) and health professionals, such as GPs (91%) and pharmacists (30%). Those with a long term illness or disability are more likely than those who do not, to trust GPs (90% among long-term ill/disabled vs 86% among those without long-term illness/disability); consultants (63% vs 58%) and pharmacists (25% vs 23%). However, they are less likely to say they trust the NHS (49% vs 52%).

This ties in well with the telephone depths with people who have a long-term illness or are disabled. In these interviews, participants tend to trust their GP and other health professionals directly involved in their treatment. However, they often view health organisations - GP surgeries, hospitals and the NHS as a whole as careless, lacking a system for keeping medical information together and frequently losing them.

What Encourages Consent?

The key factor that might make people more in inclined to allow their personal health information to be used for medical research is *information.* This links directly to the impact of information on trust discussed above – the public has an appetite for more information on medical research, specifically its purpose (and wider benefits).

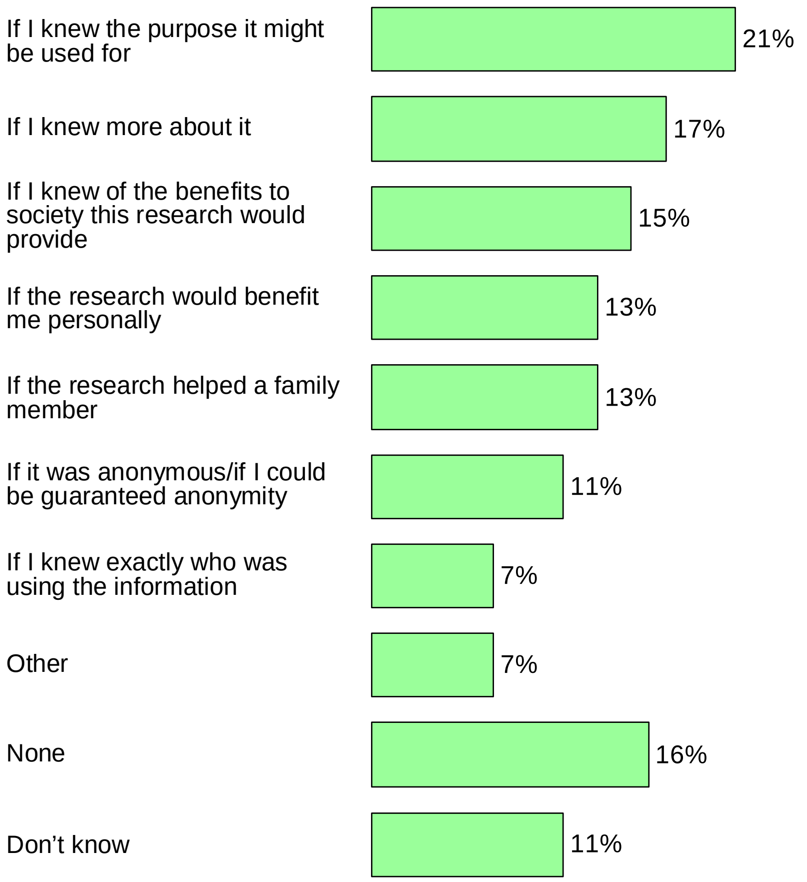
Knowing the purpose that the information would be used for has the strongest influence, with just over one in five (21%) saying they would be more inclined to allow their personal health information to be used if they had this information. Personal benefit of providing information is not a strong motivator, nor is knowing exactly who is using the information (both 7%).

However, it is still evident that a large proportion either say 'nothing' would encourage them to allow their personal health information to be used and just over one in ten (11%) are unable to provide an answer. This supports findings in the workshops, where it is apparent that there is a low awareness of medical research and what it involves, which in some cases can lead to low levels of trust in it.

These results do not differ significantly across sub-groups.

What would Encourage Consent?

Q *What, if anything might make you more inclined to allow your personal health information to be used for the purposes of medical research?*



Base: All not 'certain to' allow their personal health information to be used (1,807)

Source: Ipsos MORI

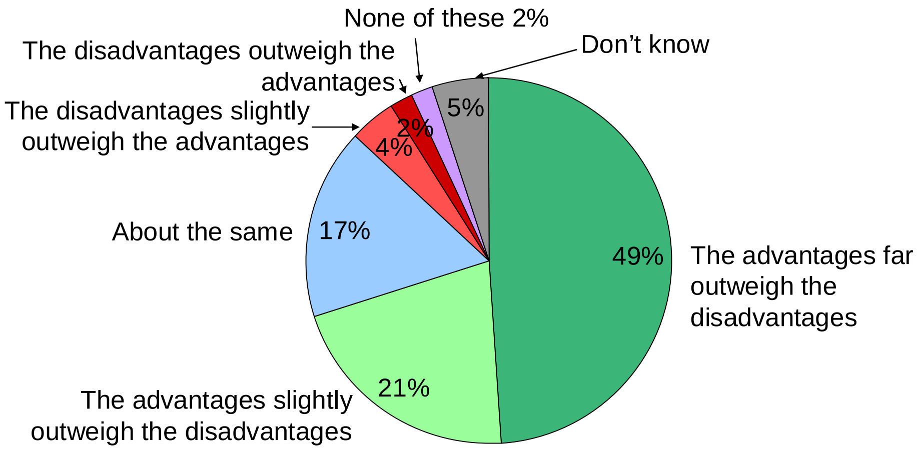
Attitudes Towards Medical Research

The advantages of medical research are seen by the public to far outweigh the disadvantages. Seven in ten feel the merits of research outweigh the disadvantages, compared to only 6% who say the opposite. This very positive finding affirms the general positive feeling towards medical research that has emerged from both the qualitative and the quantitative strands of this consultation. For example, despite lack of detailed knowledge and perceptions that medical research can be a "closed shop", workshop participants can be accepting of the use of their personal health information, providing it is confidential, consent is given, and they are informed about the research.

Furthermore, again despite relatively low spontaneous awareness of 'medical research', we saw earlier that 69% of the general public say they are either fairly likely, very likely or certain to allow their personal health information to be used for medial research.[16]

Perceptions of Medical Research

Q *Which, if any, of these five statements most closely reflects your own opinion about medical research?*



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006

Source: Ipsos MORI

Sub-Group Differences

Scepticism about medical research is highest among younger people, with 60% saying the advantages outweigh the disadvantages compared with 70% overall and the highest proportion (77%) among those aged over 55. However, 16-24s are also most likely to say the advantages and disadvantages are 'about the same'

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[16] It should be noted here that the proportion who say 'certain to' or 'likely' is not directly translatable to the same proportion in reality, which will vary depending on circumstances at the time and how well information about medical research is communicated.

(24%) indicating that they are less informed than their older counterparts. In keeping with most of the findings discussed in the report so far, ABs are most likely to be positive here with 82% saying advantages outweigh disadvantages compared with the lowest proportion of 62% among DEs.

Education may also have an influence on attitudes towards medial research as those with A-level or equivalent (74%) or degree/ masters level education (80%) are more likely to favour advantages over disadvantages than those with no formal qualifications (63%).

Perhaps not surprisingly, perception that advantages of medial research outweigh its disadvantages has a key influence on likelihood of allowing personal health information to be used for medical research. Specifically, 45% of those who feel advantages outweigh disadvantages are certain or likely to allow their information to be used compared with just one in five (20%) of those who feel the disadvantages outweigh the advantages.

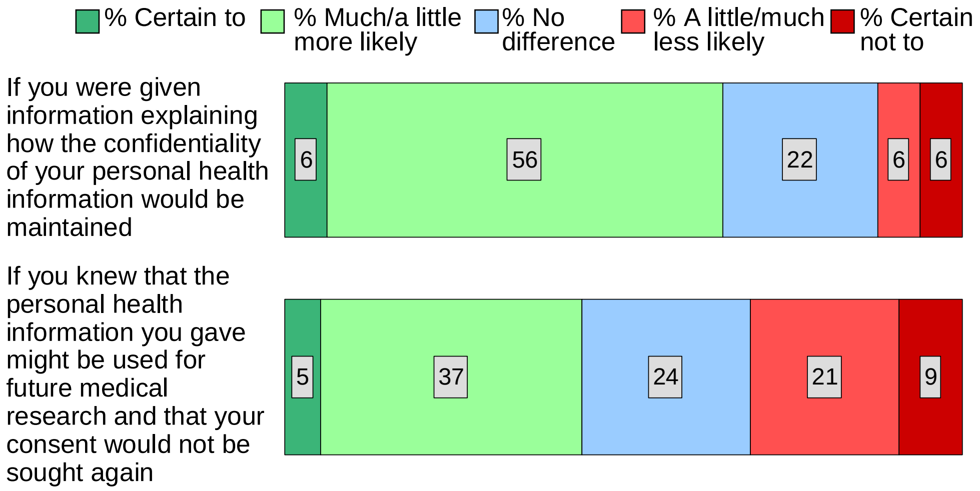
The Impact of Information on Consent

Assurance beforehand that the information they provide would be kept **confidential** prompts just over six in ten (62%) to say they would be more likely or certain to provide their information. However, when asked about the impact of knowing that their consent would not be sought for *further* research using their information, significantly fewer say they would be more likely or certain to participate (42%). This ties in well with what we found in the workshops – i.e. people were divided between two camps – one who feels that once consent is given it is acceptable for researchers to have access to personal contact details, while the others feel that identifiers like names and addresses should never be given to researchers, and that researchers should only be given a unique identification number to link them to their medical information.

There are few significant differences between sub-groups here, however, one difference of note is that two in five (40%) of those who say that they would be *unlikely* to allow their information to be used (earlier in the interview) now say that they are *more likely or certain to* allow its use **if they were given information about confidentiality**.

Information about Medical Research: Confidentiality

Q I am going to read out a list of types of information relating to medical research projects involving the use of personal health information. Please could you tell me how likely you would be to take part in such a medical research project if you were given this information beforehand?



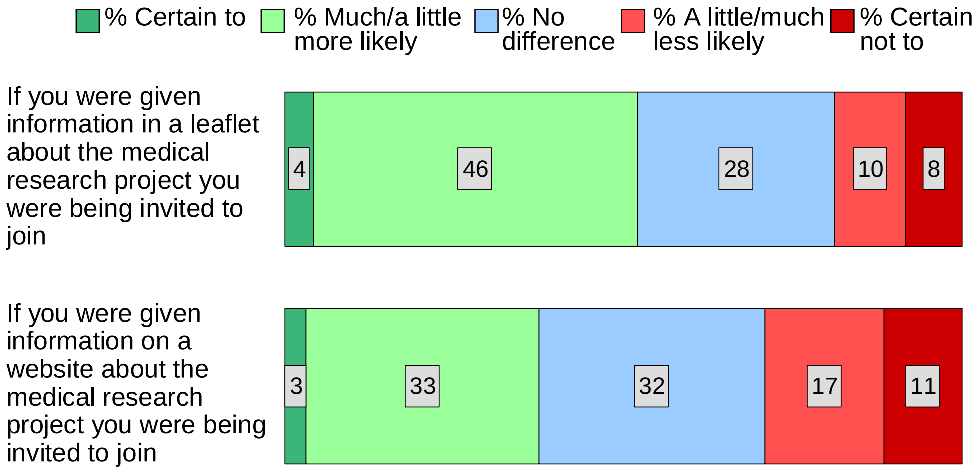
Base: All not 'certain to' allow their personal health information to be used (1,807)

Source: Ipsos MORI

Leaflets giving information about the project in advance would inspire half of the general public to consider allowing their personal health information to be used, whilst websites would have a lesser effect (36% would be more likely). The same applies for progress updates with information from leaflets having a positive impact on 54%, while information from websites would encourage 38% to participate. There are no significant differences among sub-groups.

Information about Medical Research: Information in Advance

Q I am going to read out a list of types of information relating to medical research projects involving the use of personal health information. Please could you tell me how likely you would be to take part in such a medical research project if you were given this information beforehand?

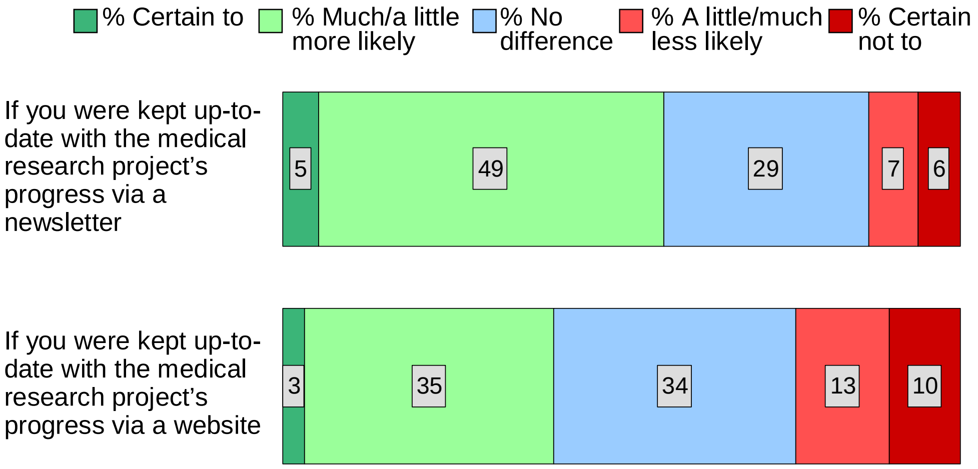


Base: All not 'certain to' allow their personal health information to be used (1,807)

Source: Ipsos MORI

Information about Medical Research: Updates on Progress

Q I am going to read out a list of types of information relating to medical research projects involving the use of personal health information. Please could you tell me how likely you would be to take part in such a medical research project if you were given this information beforehand?



Base: All not 'certain to' allow their personal health information to be used (1,807)

Source: Ipsos MORI

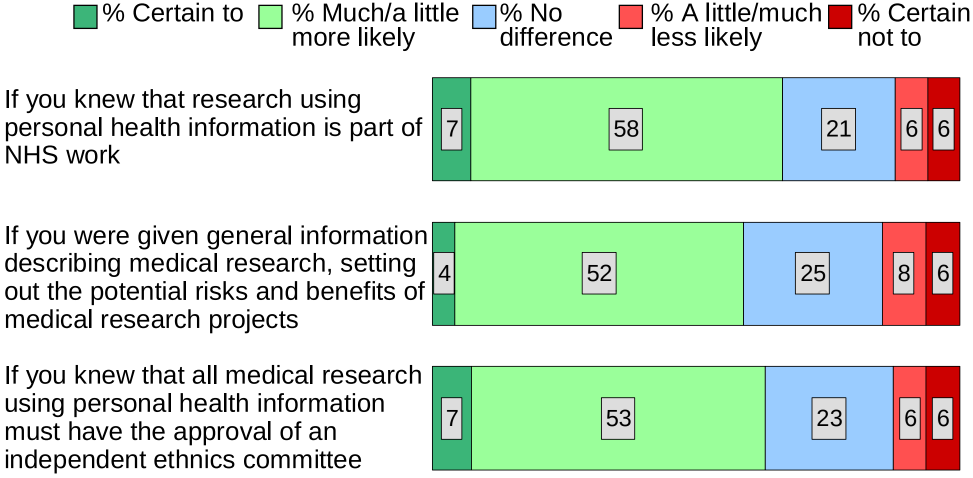
Being informed that the research using their personal health information is for the NHS would encourage almost two-thirds of the general public (65%) to either be more likely or certain to allow their personal health information to be used. This is not surprising, given our finding that GPs, other health professionals and indeed the NHS itself are most trusted to have access to people's personal health information.

Information about the risks and benefits of a research project has a similar impact on potential consent to allow information to be used. Just over half (56%) say that this would make them more likely or indeed certain to allow their information to be used. This is not surprising, given that the qualitative research tells us that acceptance of personal health information being passed on for the purposes of medical research, is largely dependent on three main precursors: of which one is them being told about the risks and benefits (the other two are the public being fully informed about research; and ensuring consent is given).

Interestingly, over two in five (42%) of those who say that they would be *unlikely* to allow their information to be used (earlier in the interview) now say that they are *more likely or certain to* allow its use **if they were informed** that the research is **part of NHS work**.

Information about Medical Research: Risks, Benefits & Ethical Approval

Q I am going to read out a list of types of information relating to medical research projects involving the use of personal health information. Please could you tell me how likely you would be to take part in such a medical research project if you were given this information beforehand?



Base: All not 'certain to' allow their personal health information to be used (1,807)

Source: Ipsos MORI

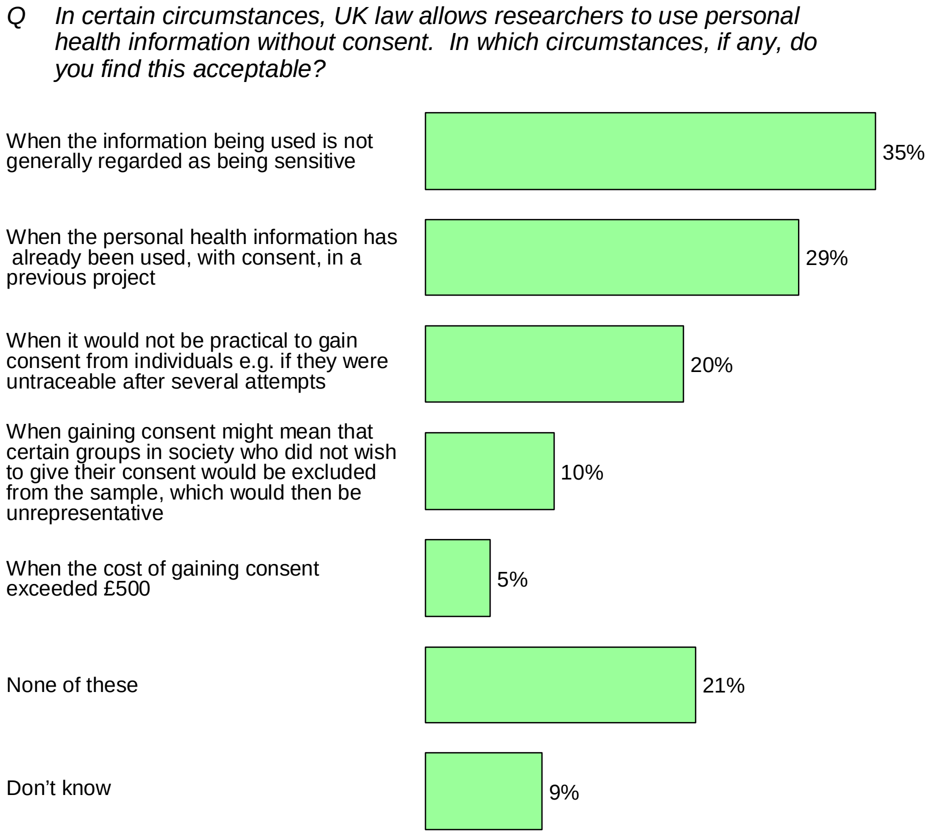
Six in ten would be more predisposed to allowing their personal health information to be used if they knew that the research it was intended for has the approval of an independent ethics committee. This fits in we'll with the findings from the workshops where respondents expressed a common wish for a 'firewall' between their information and those who wish to use it for research. This would typically be people or organisations independent of the government e.g. GPs who would assess the requests for information and give the go-ahead or otherwise for the research.

Is Consent Always Needed?

We have seen in both the qualitative and quantitative research stages thus far that consent is a key issue in securing the general public's acceptance of the use of personal health information in medical research. When given a variety of scenarios in which consent might not be essential, only a maximum of a third of people agree with them. Indeed just over one in five (21%) do not find *any* of the scenarios acceptable, indicating that consent should *always* be sought. These possibly represent those in the workshops who argue that consent is 'king' and that it should be sought before any information can be used, be it anonymous or not. They feel that the seeking of consent is seen as a matter of "respect" for the individual's rights.

The public are most likely to say consent is not important when the information is 'not generally regarded as being sensitive' (35%). This is closely followed by when consent has already been given for use in a previous project (29%). These are two situations that also came out in the qualitative work as times when some (but not all) participants feel that consent is not always essential. People are less accepting of financial constraints on seeking consent, with only 5% saying that cost factors are a viable reason for not doing so.

When is Consent Not Needed?



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006 Source: Ipsos MORI

Sub-Group Differences

Those in social grade AB (15%) and those with a long-term illness or disability (17%) are **least** likely to say that 'none' of the listed circumstances would make using personal health information without consent acceptable. ABs in line with their general more positive stance towards medical research are consistently **more** likely that those in lower social grades to feel there are certain circumstances where it is acceptable for researchers to use information without prior consent.

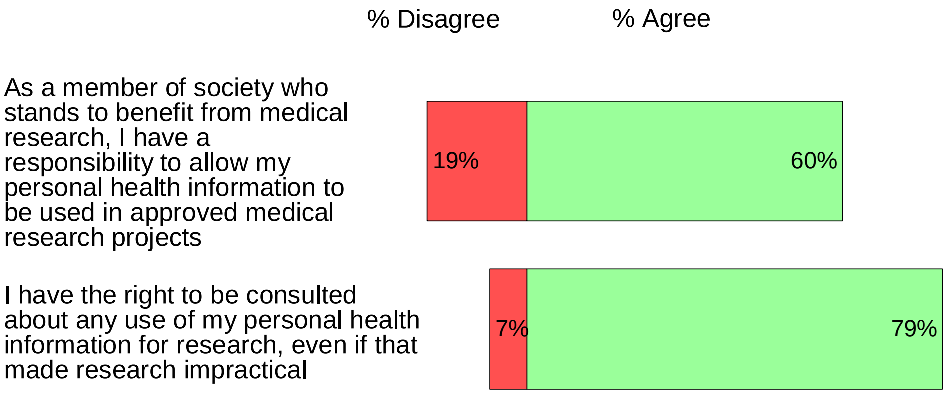
The fact that only 5% feel that consideration of cost is a good reason to not seek consent is supported by the fact that almost eight in ten say that people have the right to be consulted regardless of whether or not that would make the research impractical.

Consistent with the findings coming out of the qualitative work, the majority (60%) agree that they have a responsibility (as beneficiaries of medical research) to allow their personal health information to be used in medical research projects (provided that they have been approved). This is also consistent with the general positive regard in which the public seems to hold medical research.

It should be pointed out that this proportion of six in ten is high compared to the proportion who say they are 'certain to' or 'very likely' to allow their personal health information to be used for medical research (36%). However, a possible explanation is apparent if we look at the specific wording of the questions. For the question below, respondents are asked about **'approved'** medical research projects, whereas in the earlier question about likelihood, they are just asked about 'medical research' without any such prefix.

Use of Personal Health Information for Medical Research

Q How strongly do you agree or disagree with the following statements?



Base: 2,106 UK adults aged 15+. Fieldwork 14-18 September 2006

Source: Ipsos MORI

Consistent with other parts of this survey, older respondents (68%), those with a long-term illness or disability (66%) and those in higher social grades AB (66%) are most positive about having a responsibility to allow their personal health information to be used for medical research. There arte no sub-group differences on perceptions of rights to be consulted.

Appendices

Workshops Topic Guide

Description **(1) Introduction and Warm-Up**	**Time (mins)**
PLENARY SESSION ▪ Thank participants for attending – mention that discussion should last from about 10am until 3.30pm. ▪ Introduce Ipsos MORI – independent organisation ▪ Introduce moderators ▪ Explain the research has been commissioned to explore issues about personal health information and who has access to it. ▪ Please stress that there are no right or wrong answers – we are just interested in finding out their views and opinions. Explain rules of workshop (e.g. give everyone the opportunity to speak; have a right to change your mind; no right or wrong answers, an informal discussion about their views and opinions. No technical expertise needed at all) ▪ Reassure participants about confidentiality – MRS code of conduct ▪ Recorders/photos – ask permission to record/take photographs (photos form) ▪ Explain break-out rooms/fire regulations/mobile phones/toilets ▪ Allocate break out groupings	10.00 am 15 minutes Tea and Coffee served

(2) Personal Information

10.15

1 ¼ hours

Purpose: warming up participants, getting them to think about personal information overall before we move on to discussing health information later.

PLENARY SESSION

First of all, can we ask everyone to give their names, and tell us a bit about themselves?

Please can you tell us about all the places you can think of where personal information might be kept or held about people?

NOTE TO MODERATOR: Try to bring in a range of information into the discussion but don't dwell too much on health records at this stage – that comes later.

- Can we think of any such places or databases as they are sometimes called, that we have heard of, or had personal contact with? DO NOT PROMPT. RECORD ON FLIPCHART
- There are a range of examples that may come up - DVLA /TV licence/police records/bank records/ID cards. What about direct mail/junk mail/Nectar cards?
- What are the advantages of such information being held? To whom? PROBE FOR individuals, organisations, society as a whole
- And what are the drawbacks of such information being held? To whom? PROBE FOR individuals, organisations, society as a whole?

Next, what do you think personal information is used for?

NOTE TO MODERATOR – DO NOT PROMPT. See what comes up, for example: recording information, mailing people, informing people, 'using' people' etc.

- And generally, what personal information do you think is stored? Financial information? Biological or medical information? Information on where people might live etc.?
- Bearing all this in mind, what do you feel about how much information is available on individuals? Too much, Too little, About right? Don't Know? It depends?

When somebody hears the phrases 'database', 'storing personal information', INSERT PHRASES THAT MAY COME UP FROM PARTICIPANTS what springs to mind?
NOTE TO MODERATOR: PROBE FOR IMAGES AND ASSOCIATIONS

Moving on, who do you think has access to personal information? Who <u>should</u> have access?
NOTE TO MODERATOR: PROBE to see if people are happier with information being held by the government, or by companies, or by charities, or by universities, or by professionals such as doctors, lawyers etc

▪ Has anybody tried to access information held about them? What happened? ▪ What do you know about guidelines on how people's personal information is stored and used? ▪ What safeguards do you think are in place? Who makes the guidelines? Who monitors compliance with the guidelines? NOTE TO MODERATOR: probe people's general knowledge about Data Protection Act. ▪ Would you like to see more or fewer safeguards put in place? Who should make the guidelines? Who should monitor compliance with them? INFORM PARTICIPANTS ON WHERE THEY WILL BE BREAKING OUT AFTER TEA / COFFEE AND WITH WHICH MODERATOR	
Break for Tea and Coffee	11.30 15 minutes
(3) General Attitudes to Health Information ***Purpose: Moving on to look at personal health information in particular, the aim is to establish what people believe about how information is currently used, how it is accessed and whether they are willing to see it used for research purposes in principle.*** BREAK OUT INTO THREE GROUPS ▪ What kinds of personal health information are there? NOTE TO MODERATOR: PROBE for GP records, tissue samples, DNA records ▪ As far as you know, who uses this personal health information? ▪ What do you think the information would be used for? ▪ Who sees personal health information? ▪ Who should be able to see personal health information? ▪ Does personal health information differ in any way from the other types of personal information we talked about a little earlier? ▪ As far as you know, do you have the right to see health information that is held about you on demand, or not? PROBE FOR: data obtained from face-to-face interviews, medical records, other data that may be held e.g. birth weight, information held by charities, membership organisations, DVLA, the police, optometrists, insurance companies, financial or other organisations? ▪ Has anybody ever tried accessing any or all of their own medical records from health professionals within the health services? How about other personal health	11.45 1 ¼ hours

information?

- What response did you get? Have people received mixed messages about accessing such information?

NOTE TO MODERATOR: OPEN THE DEBATE OUT.

- Who should be able to see your personal health information? RECORD ON FLIPCHART. (DO NOT PROMPT Possible answers might include individual/patient, doctors, other health professionals, medical researchers (gauge views on medical research and towards medical researchers), charities, membership organisations, DVLA, the police, optometrists, insurance companies, financial organisations, companies, employers, government). **Why do you say that?**
- And who should not? **Why do you say that?**

NOTE TO MODERATOR: Compare and contrast **above** the advantages and drawbacks of each potential group/organisation that may have access to personal health information.

- Who do you trust to use your personal health information competently? And who do you not trust? **Why do you say that?** PROBE FOR Government, NHS, companies (Does it depend on what type of company?), universities, medical charities, and medical researchers funded by any of these.

- If you object to any organisation or individual seeing information, any in particular or all? Which ones?

NOTE TO MODERATOR: INTRODUCE THE CONCEPT OF PERSONAL HEALTH INFORMATION BEING USED FOR RESEARCH

- What is medical research? What does it comprise? PROBE FOR drug trials, epidemiological studies, population studies, data from samples / specimens

- How do you think clinical records fit into medical research? How about other personal health information?

EXPLAIN THE CONCEPT OF PERSONAL HEALTH INFORMATION BEING USED FOR RESEARCH e.g. EXAMPLE OF DOLL AND HILL STUDY INTO CAUSES OF LUNG CANCER, or IF YOU WANTED TO FIND OUT HOW COMMON A CERTAIN TYPE OF CANCER IS or TO COMPARE PEOPLE WITH CANCER TO PEOPLE WITHOUT

What do people think about the *principle* of making personal health information available for medical research?

- Who would get to see this information?

- Does it differ according to the type of information? Info on specific condition? NOTE TO MODERATOR: focus on types of illnesses e.g. mental health vs. less taboo illnesses e.g. arthritis, rather than specific illnesses

▪ What are the merits of a system where researchers have access to personal health information? ▪ And what are the drawbacks? PROBE FOR individual's need for privacy vs. greater good of medical research ▪ Do your attitudes vary depending on: o The purpose of the research? o Who is doing the research? o Whether the information is anonymised? o Whether the information is linked to individuals? o The kind of information being sought PROBE FOR the trade off between giving sensitive information and the need to research sensitive conditions e.g. mental illness ▪ Where would people draw the line on what kind of information should or should not be used? ▪ What do those in favour of using personal health information think of the ethical objections that might be raised? NOTE TO MODERATORS: USE 'RUNAROUND' EXERCISE – People stand in different parts of the room to indicate where they stand on greater good vs. privacy.	
MRC TO INTRODUCE THEMSELVES AND MAKE A BRIEF PRESENTATION ON THEIR ROLE. **LUNCH**	1.00 ¾ hour
(4) Using Health Information. ***Purpose: What do people think personal health information should be used for? The aim is to explore in what circumstances people think health information should be used and how the system should operate in practice.*** PLENARY SESSSION ▪ If personal health information is to be available for use, what kind of information do you think should be made available? And how should it be made available? ▪ Should it be just paper or electronic records kept by hospital doctors and GPs? Is there a difference between paper and electronic records? NOTE TO MODERATOR: Increasingly paper records are being transferred to electronic storage. ▪ Should it extend to DNA samples or tissue samples? NOTE TO MODERATOR no need to go into too much detail here? ▪ What type of information e.g. general medical history, info on mental health, sexual history?	1.45 1 ½ hours (30 mins plenary, 1 hour breakout)

- How should this be determined? Is there a degree of sensitivity?
- What sort of information would you be relaxed about people knowing about you? What would you not be relaxed about? PROBE FOR EXAMPLES
- What kinds of information do you regard as sensitive? Who would you trust to handle / have access to this information?
- What do you think personal health information should be used for? Are there illnesses for which personal health information should not be used whatever the circumstances?
- Do people think the use of personal health information should be restricted to researching illnesses? How about developing medicines?
- Would you be prepared to see personal health information used more widely, as a form of medical census to inform government policy on health and the NHS?

BREAK OUT INTO GROUPS

EXPLAIN THAT THE DISCUSSIONS IN THIS BREAK OUT SESSION ARE GEARED TOWARDS COMING UP WITH AN IDEAL SYSTEM OF HOW / WHEN PERSONAL HEALTH INFO SHOULD / SHOULD NOT BE USED FOR MEDICAL RESEARCH PURPOSES. THIS SYSTEM SHOULD TAKE INTO ACCOUNT RISKS AND BENEFITS, THE ISSUE OF CONSENT, WHETHER OPT-IN OR OPT-OUT AND THE ROLE OF THE NHS.

APPOINT SCRIBE AND SPOKESPERSON / PEOPLE.

EXAMPLE OF A MEDICAL RESARCH PROJECT: The original Doll and Hill Cancer Study which asked people with and without cancer whether or not they smoked. A study asked people whether they smoked or not. Those that had cancer were more likely to be smokers. This study was the first to make the link between smoking and lung cancer.

RECORD ON FLIPCHART

What are the **risks and benefits** of allowing medical information to be used?

- What concerns, if any, do you have about personal health information being used for medical research or by medical researchers?
- And what concerns, if any, do you have about personal health information being used by clinicians - such as doctors?
- IF ANY CONCERNS MENTIONED Would you say you have more or fewer concerns about using personal health information for medical research or clinical care, or is there no difference?
- What do you think are the chances of health information falling into unauthorised

hands e.g. insurance companies or pension funds receiving it without your consent?

- Overall, do the benefits outweigh the risks, or is it the other way around, or are the benefits and risks about equal?

Now looking in particular at **consent**.

- What consent is needed, if any, is needed for researchers to look at your personal health information?
- Are there any circumstances in which consent should not be necessary? What are they?
- What are your worst fears should consent not be necessary for your personal health information to be used for medical research purposes?

Some medical research can be (and has been) carried out without individual patient consent e.g. research on a person's clinical records after their death, or research on anonymised databases.

- How do you feel about this?
- Which bits, if any, of information should be allowed to be used in such a way? Does anonymity make a difference?
- When should researchers be able to do this? PROBE FOR should they ask people's consent when they are using records for specific projects vs. more generic use
- Should this information be linked with other personal information? Does consent have to be given for these linkages to take place?
- What would allay fears about using personal health information? PROBE FOR: signing documents, independent ethics committees, specially approved scientists or only working for certain institutions, which ones?
- At present, there is a system of obtaining approval for medical research from an ethics committee that ensures research is highly regulated. What are your initial reactions to this system?
- What are your views on an OPT OUT system, with the government/medical researchers assuming consent for your records to be used unless you have specifically said otherwise when you register with a GP? What would be the merits and drawbacks?
- And what are your views on an OPT IN system, where your records would only be used if you specifically gave your permission? What would be the merits and drawbacks?
- What would be the safeguards on the preferred system?
- What are your views on having a 'sealed envelope' system where some personal health

information could be given. while some would remain private? ▪ **MODERATORS : NOTE SENSITIVITY OF NEXT QUESTION** How do you feel about personal medical information being used once a person has died? ▪ Moving on, what do you think about medical information being used to identify individual people who would then be asked to participate in detailed research, for example by letter containing personal and potentially sensitive health information? This would mean that names and addresses/contact details would be on medical records, not just numbers. ▪ How do people feel about this? (PROBE FOR: whether this is a helpful way of identifying individuals/for the greater good of medical research, or an invasion of privacy, or other views) ▪ If you were approached, would you be willing to take part? ▪ Now turning to who would be doing research using medical records or through other forms of personal health information, who would you trust to play a role in it? PROBE FOR Govt, charities, universities, companies ▪ And who would you prefer to play a role in it? ▪ Would you be more comfortable with researchers funded publicly by the government or charities or universities or companies, or a mixture of sources of funding? Why do you say that? ▪ How would you feel about pharmaceutical companies sponsoring research? NOTE TO MODERATOR: PROBE for the other groups doing research. What should be the role of the NHS? ▪ What do you think about GP surgeries and hospital outpatient departments being used to spread information about the benefits of using personal health information for research?	
Break for tea and coffee	2.15 10 minutes
PLENARY SESSION Summing up – presenting back. In summary, what do you regard as your ideal system with regard to personal health information - and what are the merits and drawbacks of such a system?	3.25 ½ hour
CLOSE AND THANK YOU	**4.00**

Depth Interviews Discussion Guide

Description

(1) Introduction and Warm-Up

- Thank participant for taking part – mention that discussion should last no more than an hour, probably less
- Introduce Ipsos MORI – independent organisation
- Explain the research has been commissioned to explore issues about personal health information and who has access to it
- Stress that there are no right or wrong answers – we are just interested in finding out views and opinions
- Reassure participant about confidentiality – MRS code of conduct
- Ask permission to record

(2) Personal Information

Purpose: warming up participant, getting them to think about personal information overall before we move on to discussing health information later.

- Please can you tell us about all the places you can think of where personal information might be kept or held about people?

NOTE TO INTERVIEWER: Try to bring in a range of information into the discussion but don't dwell too much on health records at this stage – that comes later.

- Can we think of any such places or databases as they are sometimes called, that we have heard of, or had personal contact with? DO NOT PROMPT.
- What are the advantages of such information being held? To whom? PROBE FOR individuals, organisations, society as a whole
- And what are the drawbacks of such information being held? To whom? PROBE FOR individuals, organisations, society as a whole?
- Next, what do you think personal information is used for?
- And generally, what personal information do you think is stored? Financial information? Biological or medical information? Information on where people might live etc.?
- Bearing all this in mind, what do you feel about how much information is available on individuals? Too much, Too little, About right? Don't Know? It depends?

Moving on…

- Who do you think has access to personal information?
- Who <u>should</u> have access?

NOTE TO INTERVIEWER: PROBE to see if respondent is happier with information being held by the government, or by companies, or by charities, or by universities, or by professionals such as doctors, lawyers etc

- Have you tried to access information held about you or those close to you? What happened?
- What do you know about guidelines on how people's personal information is stored and used?
- What safeguards do you think are in place? Who makes the guidelines? Who monitors compliance with the guidelines? NOTE TO INTERVIEWER: probe people's general knowledge about Data Protection Act.
- Would you like to see more or fewer safeguards put in place? Who <u>should</u> make the guidelines? Who <u>should</u> monitor compliance with them?

(3) General Attitudes to Health Information

Purpose: Moving on to look at personal health information in particular, the aim is to establish what participants believe about how information is currently used, how it is accessed and whether they are willing to see it used for research purposes in principle.

- What kinds of personal health information are there? NOTE TO INTERVIEWER: PROBE for GP records, tissue samples, DNA records

- As far as you know, who uses this personal health information? And who sees it?

- Who should be able to see personal health information? DO NOT PROMPT.

- And who should not?

- What do you think the information would be used for?

- Does personal health information differ in any way from the other types of personal information we talked about a little earlier?

- As far as you know, do you have the right to see health information that is held about you on demand, or not?

- Who do you trust to use your personal health information competently?

- And who do you not trust? PROBE FOR Government, NHS, companies (Does it depend on what type of company?), universities, medical charities, and medical researchers funded by any of these.

- If you object to any organisation or individual seeing information, any in particular or all? Which ones?

(4) Using Health Information.

15 mins

Purpose: What do people think personal health information should be used for? The aim is to explore in what circumstances people think health information should be used and how the system should operate in practice.

- What is medical research? PROBE FOR drug trials, epidemiological studies, population studies, data from samples / specimens
- How do you think clinical records fit into medical research?
- How about other personal health information?

EXPLAIN THE CONCEPT OF PERSONAL HEALTH INFORMATION BEING USED FOR RESEARCH e.g. EXAMPLE OF DOLL AND HILL STUDY INTO CAUSES OF LUNG CANCER, or IF YOU WANTED TO FIND OUT HOW COMMON A CERTAIN TYPE OF CANCER IS or TO COMPARE PEOPLE WITH CANCER TO PEOPLE WITHOUT

What do people think about the *principle* of making personal health information available for medical research?

- If personal health information is to be available for use, what kind of information do you think should be made available?
- Who would get to see this information?
- Does it differ according to the type of information? NOTE TO INTERVIEWER: focus on types of illnesses e.g. mental health vs. less taboo illnesses e.g. arthritis, rather than specific illnesses
- And through what channels should it be made available?
- What are the merits of a system where researchers have access to personal health information?
- And what are the drawbacks? PROBE FOR individual's need for privacy vs. greater good of medical research
- Should this information be linked with other personal information? Does consent have to be given for these linkages to take place?
- Do your attitudes vary depending on:
    - The purpose of the research?
    - Who is doing the research?
    - Whether the information is anonymised?
    - Whether the information is linked to individuals?
    - The kind of information being sought PROBE FOR the trade off between giving sensitive information and the need to research sensitive conditions e.g. mental illness
- Where would you draw the line on what kind of information should or should not be used?
- What do you think of the ethical objections that might be raised?

- What type of information e.g. general medical history, info on mental health, sexual history?
- What sort of information would you be relaxed about people knowing about you? What would you not be relaxed about? PROBE FOR EXAMPLES
- What kinds of information do you regard as sensitive?
- Who would you trust to handle / have access to this information?
- Are there illnesses for which personal health information should not be used whatever the circumstances?
- Do you think the use of personal health information should be restricted to researching illnesses? How about developing medicines?
- Would you be prepared to see personal health information used more widely, as a form of medical census to inform government policy on health and the NHS?

What are the **risks and benefits** of allowing medical information to be used?

- What concerns, if any, do you have about personal health information being used for medical research or by medical researchers?
- And what concerns, if any, do you have about personal health information being used by clinicians - such as doctors?
- Overall, do the benefits outweigh the risks, or is it the other way around, or are the benefits and risks about equal?

Now looking in particular at **consent**.

- What consent is needed, if any, is needed for researchers to look at your personal health information?
- Are there any circumstances in which consent should not be necessary? What are they?
- What are your worst fears should consent not be necessary for your personal health information to be used for medical research purposes?
- What would allay fears about using personal health information? PROBE FOR: signing documents, independent ethics committees, specially approved scientists or only working for certain institutions, which ones?

- At present, there is a system of obtaining approval for medical research from an ethics committee that ensures research is highly regulated. What are your initial reactions to this system?
- What are your views on an OPT OUT system, with the government/medical researchers assuming consent for your records to be used unless you have specifically said otherwise when you register with a GP? What would be the merits and drawbacks?
- And what are your views on an OPT IN system, where your records would only be used if you specifically gave your permission? What would be the merits and drawbacks?

- What would be the safeguards on the preferred system?
- Moving on, what do you think about medical information being used to identify individual people who would then be asked to participate in detailed research, for example by letter containing personal and potentially sensitive health information? This would mean that names and addresses/contact details would be on medical records, not just numbers.
- How do you feel about this? (PROBE FOR: whether this is a helpful way of identifying individuals/for the greater good of medical research, or an invasion of privacy, or other views)
- If you were approached, would you be willing to take part?
- If certain sections of society don't want their data used under any circumstances, to what extent should their wishes be respected?
    - Does this stay the same even if the quality of research is compromised by people not allowing their data to be used e.g. the results take longer, certain groups of society are missed
- Would you be more comfortable with researchers funded publicly by the government or charities or universities or companies, or a mixture of sources of funding? Why do you say that?
- How would you feel about pharmaceutical companies sponsoring research?

Some medical research can be (and has been) carried out without individual patient consent e.g. research on a person's clinical records after their death, or research on anonymised databases.

- How do you feel about this?
- Which bits, if any, of information should be allowed to be used in such a way? Does anonymity make a difference?
- When should researchers be able to do this?

If there was one thing you would like to say to the MRC on this topic what would it be?

CLOSE AND THANK YOU

Profile of Quantitative Survey Respondents

	Respondents		
		Unweighted	Weighted
	n	%	%
Total			
Sex			
Men	974	46	48
Women	1132	54	52
Age			
15-24	277	13	16
25-34	324	15	16
35-44	402	19	19
45-54	299	14	16
55-64	306	15	14
65+	498	24	20
Social Class			
AB	468	21	25
C1	623	30	29
C2	417	20	20
DE	598	28	25
Work Status			
Working – full-time	766	36	44
Not working f/t	1340	64	56
Country/Region			
London	246	12	12
South-East	230	11	14
South-West	165	8	9
North-East	90	4	4
North-West	180	9	8
Eastern	167	8	9
East Midlands	146	7	7
West Midlands	214	10	9
Yorks & Humber	174	8	8
Scotland	151	7	9

Quantitative Survey Technical Details

General Public Omnibus Design

The sample design is a constituency based quota sample. There are 641 parliamentary constituencies covering Great Britain. From these, we select one in three (210) to be used as the main sampling points on the Ipsos MORI Omnibus. These points are specially selected to be representative of the whole country by region, social grade, working status, MOSAIC rurality, tenure, ethnicity and car ownership. Within each constituency, one local government ward is chosen which is representative of the constituency.

Within each ward or sampling point, we interview ten respondents whose profile matches the quota. The total sample therefore is around 2,100 (10 interviews multiplied by 210 sampling points).

Gender: Male; Female

Household Tenure: Owner occupied; Council Tenant/HAT; Other

Age: 15 to 24; 25 to 44; 45+

Working Status Full-time; part time/not working

These quotas reflect the socio-demographic makeup of that area, and are devised from an analysis of the 2001 Census. Overall, quotas are a cost-effective means of ensuring that the demographic profile of the sample matches the actual profile of GB as a whole, and is representative of all adults in Great Britain aged 15 and over.

Fieldwork

Fieldwork is carried out by Ipsos MORI using CAPI (Computer Assisted Personal Interviewing). All interviews are conducted face to face, in the home – one interview per household. No incentives are offered to respondents.

Weighting and Data Processing

Data entry and analysis are carried out by an approved and quality-assured data processing company. The data are weighted using 6 sets of simple and interlocking rim weights for social grade, standard region, unemployment within region, cars in household, and age and working status within gender. This is to adjust for any variance in the quotas or coverage of individual sampling points so that the sample is representative of the GB adult population.

Statistical Reliability

Because a sample, rather than the entire population, was interviewed the percentage results are subject to sampling tolerances – which vary with the size of the sample and the percentage figure concerned. For example, for a question where 50% of the people in a sample (of 2,106) respond with a particular answer, the chances are 95 in 100 that this result would not vary by more than 2 percentage points, plus or minus, from the result that would have been obtained from a census of the entire population (using the same procedures). The tolerances that may apply in this report are given in the table below.

Approximate sampling tolerances applicable to percentages at or near these levels (at the 95% confidence level)			
Size of sample or sub-group on which survey result is based	**10% or 90%** **±**	**30% or 70%** **±**	**50%** **±**
2,106 GB adults aged 15+	1	2	2

Source: Ipsos MORI

Tolerances are also involved in the comparison of results between different elements of the sample. A difference must be of at least a certain size to be statistically significant. The following table is a guide to the sampling tolerances applicable to comparisons between sub-groups.

Differences required for significance at the 95% confidence level at or near these percentages			
	10% or 90%	**30% or 70%**	**50%**
Size of sample on which survey result is based			
Men (974) vs Women (1,132)	3	4	4
ABs (468) vs DEs (598)	4	6	6

Source: Ipsos MORI

Definition of Social Grades

The grades detailed below are the social class definitions as used by the Institute of Practitioners in Advertising, and are standard on all surveys carried out by Ipsos MORI.

Social Grades			
	Social Class	**Occupation of Chief Income Earner**	**Percentage of Population**
A	Upper Middle Class	Higher managerial, administrative or professional	2.9
B	Middle Class	Intermediate managerial, administrative or professional	18.9
C1	Lower Middle Class	Supervisor or clerical and junior managerial, administrative or professional	27.0
C2	Skilled Working Class	Skilled manual workers	22.6
D	Working Class	Semi and unskilled manual workers	16.9
E	Those at the lowest levels of subsistence	State pensioners, etc, with no other earnings	11.7

Quantitative Survey Topline Results

- Ipsos MORI interviewed a representative quota sample of 2,106 UK adults aged 15+.
  1,993 of these were in Great Britain and 113 in Northern Ireland.
- Interviews were carried out face-to-face with the aid of CAPI (Computer Assisted Personal Interviewing) terminals in Great Britain and on paper in Northern Ireland.
- The fieldwork period was 14 – 18 September 2006.
- Data have been weighted to the known population profile.
- Where figures do not sum to 100 per cent, this may be due to computer rounding, multiple codes or the exclusion of 'Don't know'
- * represents a percentage of greater than zero, but less than 0.5%

Q1. **What comes to mind, if anything, when I say 'personal health information'? PROBE: Anything else**? UNPROMPTED. MULTICODE OK

	%
GP records/ Any mention of GP/ family doctor	26
Medical records	17
My own personal health/ wellbeing	7
Dental information/ Any mention of dentist	4
Info on specific types of conditions e.g. mental health	4
NHS/ NHS Direct	4
Blood samples	2
DNA information/ DNA/ DNA profiles/ DNA evidence	2
Electronic databases	2
Biometric tests/ ID cards/ Retina scans	1
Companies' commercial usage (e.g. Direct marketing or assessment of eligibility for finance/insurance products)	1
For benefits/social services departments e.g. for assessment	1
Optical information/ Optician/ Optometrist	1
Results from tests/ Tests	1
X-rays	1
Postcodes	*
Organ donation card	*
Private medical insurance e.g. BUPA/ Life insurance	*
Security agencies, to prevent terrorism	*
Tissue samples	*
Urine samples	*
Other (specify)	10
Nothing	17
Don't know	17

Q2. **Who, if anyone, do you think would hold personal health information about you?** UNPROMPTED. MULTICODE OK.

	%
GPs/ Family Doctor	71
Consultant/ Hospital Doctor	21
The NHS	21
Doctors - unspecified	20
Insurance companies	7
Employers	6
Family member	6
A health professional other than a doctor, nurse or pharmacist	5
Government	5
Surgeons	4
The Department of Health (DoH)	3
Nurses	2
Banks/ Financial organisations	1
DVLA	1
Friend/Colleague or Workmate	1
Health campaigning groups or Patient organisations	1
Pharmaceutical/drugs companies	1
Pharmacists	1
Police	1
Private companies	1
The local authority/The Council	1
Charities	*
Fitness companies/ Sports companies	*
Lawyers	*
Medical researchers working for charities	*
Medical researchers working for private companies	*
Medical researchers working for the Government	*
Medical researchers working for universities	*
Teachers	*
The British Medical Association (BMA)	*
Universities	*
Other (specify)	7
Nothing	2
Don’t know	4

Q3. **What advantages, if any, are there of collecting and using people's personal health information?** UNPROMPTED. MULTICODE OK.

	%
For medical research	15
Greater knowledge of patterns of health/disease	15
For studies about the population/ statistics	8
To try and find cures for diseases	8
Development of better drugs/equipment/techniques	6
Being updated on new products/ medicines/ drugs	5
Long-term research helps educate public e.g. on smoking, diet, exercise etc	5
Consumer/ user advantage e.g. through new product development	3
Drug trials/developing new drugs	3
To prove one's identity	3
Commercial advantage e.g. companies /holding or selling the information for marketing/selling products/services	2
Good in an emergency/ in case of an accident e.g. access to all personal details	2
Police databases	1
To combat fraud	1
Vaccines research	1
Ease of access to information e.g. travelling away fro home	
Any mention of above	**56**
Other (specify)	9
Nothing	15
Don't know	21

Q4. **What disadvantages, if any, are there of collecting and using people's personal health information?** UNPROMPTED. MULTICODE OK.

	%
Concerns over misuse	22
Information being disclosed/ Confidentiality not being observed	11
Breach of Data Protection Act	10
Breach of rights	10
Use for fraudulent purposes	7
Could be used for commercial purposes	6
Inaccurate information	5
Used to block insurance applications/ discrimination	5
Used/ misused by employers/ Discrimination in the workplace	5
Could be used/ misused by the media	4
Becomes known to friends/family/acquaintances	2
Could be used/ misused by police	2
Any mention of above	**55**
Other (specify)	7
Nothing	20
Don't know	21

Q5. **On this list are some types of people and organisations. Which, if any, would you generally trust to have access to your personal health information?** MULTICODE OK.

	%
GPs/ Family Doctors	87
Consultants/ Hospital Doctors	59
The NHS	51
Family member	44
Nurses	39
The Department of Health (DoH)	28
Pharmacists	23
Health professionals other than doctors, nurses or pharmacists	23
Employers	17
Police	16
Insurance companies	15
DVLA	13
Medical researchers working for the Government	11
Medical researchers working for universities	11
Friend/Colleague or Workmate	10
Government	9
Lawyers	9
Medical researchers working for charities	9
Banks/ Financial organisations	8
Teachers	6
Pharmaceutical/Drugs companies	6
Fitness companies/ Sports companies	5
Health campaigning groups or Patient organisations	5
The local authority/The Council	5
Universities	5
Medical researchers working for private companies	4
Charities	3
Private companies	1
Other	1
None of these	2
Don’t know	2

Now, I'd like to ask you about medical research in particular…

Q6. **From this card, which, if any, of these five statements most closely reflects your own opinion about medical research?**

	%
The advantages of medical research far outweigh the disadvantages	49
The advantages of medical research slightly outweigh the disadvantages	21
The advantages and disadvantages of medical research are about the same	17
The disadvantages of medical research slightly outweigh the advantages	4
The disadvantages of medical research far outweigh the advantages	2
None of these	2
Don't know	5

Q7. **From this card, how likely, if at all, would you be to allow your personal health information to be used for the purposes of medical research?**

	%
Certain to	14
Very likely	24
Fairly likely	31
Fairly unlikely	10
Very unlikely	8
Certain not to	7
Don't know	5

Q8. **Why do you say that?** UNPROMPTED. MULTICODE OK.
Base: All unlikely/certain not to allow their personal health information to be used (648)

	%
Worried about privacy	28
Can't control who uses it	13
Worried about misuse/falling into wrong hands	13
Can't control how used	12
Worried about purpose	11
Security concerns	9
Worried information passed on without permission	9
Worried about who is doing it	7
Data Protection Act	6
Identity fraud	5
Certain types of information not acceptable to share	4
Ethical implications	4
Worried about whether information is anonymised/linked to individuals	4
Concern about profit motives of drug companies	2
Alder Hey scandal	1
Certain types of illness are not acceptable	1
I am against medical research	1
Information may be inaccurate	1

Lack of regulation	1
Medical researchers use animals for experiments	1
Organisations may share information for commercial gain	1
Read/Heard something worrying in the media	1
Worried about disclosure to family, friends or acquaintances	1
Lack of transparency	*
Northwick Park scandal	*
Other (specify)	11
None	6
Don’t know	15

Q9. **What, if anything might make you more inclined to allow your personal health information to be used for the purposes of medical research?** UNPROMPTED. MULTICODE OK.
Base: All not “certain to” allow their personal health information to be used (1,807)

	%
If I knew the purpose it might be used for	21
If I knew more about it	17
If I knew of the benefits to society this research would provide	15
If the research would benefit me personally	13
If the research helped a family member	13
If it was anonymous/if I could be guaranteed anonymity	11
If I knew exactly who was using the information	7
Other (specify)	7
None	16
Don’t know	11

Q10. **I am going to read out a list of types of information relating to medical research projects involving the use of personal health information. For each one, using this card, please could you tell me how likely you would be to take part in such a medical research project if you were given this information beforehand?**

Base: All not "certain to" allow their personal health information to be used (1,807)

	Certain to	Much more likely	A little more likely	No diff-erence	A little less likely	Much less likely	Certain not to	No opinion/ DK
	%	%	%	%	%	%	%	%
a) If you knew that research using personal health information is part of NHS work	7	30	28	21	4	2	6	3
b) If you were given general information describing medical research, setting out the potential risks and benefits of medical research projects	4	25	27	25	6	2	6	4
c) If you were given information in a leaflet about the medical research project you were being invited to join	4	17	29	28	6	4	8	4
d) If you were given information on a website about the medical research project you were being invited to join	3	12	21	32	10	7	11	5
e) If you were given information explaining how the confidentiality of your personal health information would be maintained	6	26	30	22	4	2	6	4
f) If you knew that the personal health information you gave might be used for future medical research and that your consent would not be sought again	5	17	20	24	13	8	9	4

g) If you were kept up-to-date with the medical research project’s progress via a newsletter	5	20	29	29	4	3	6	4
h) If you were kept up-to-date with the medical research project’s progress via a website	3	13	22	34	7	6	10	5
i) If you knew that all medical research using personal health information must have the approval of an independent ethics committee	7	27	26	23	3	3	6	4

Q11. **I’m going to read out some statements and for each one I’d like you to tell me, using this card, how strongly you agree or disagree with it.**

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	No opinion /Don’t know
	%	%	%	%	%	%
a) As a member of society who stands to benefit from medical research, I have a responsibility to allow my personal health information to be used in approved medical research projects	20	40	18	12	7	3
b) I have the right to be consulted about any use of my personal health information for research, even if that made research impractical	47	32	11	5	2	3

Q12. **In certain circumstances, UK law allows researchers to use personal health information without consent. In which circumstances on this card, if any, do you find this acceptable?** MULTICODE OK.

	%
When the information being used is not generally regarded as being sensitive e.g. blood pressure, or other lifestyle information, such as smoking history, diet or exercise	35
When the personal health information has already been used, with consent, in a previous project	29
When it would not be practical to gain consent from individuals, for example if they were untraceable after several attempts to trace them	20
When gaining consent might mean that certain groups in society who did not wish to give their consent would be excluded from the sample, which would then be unrepresentative.	10
When the cost of gaining consent exceeded £500	5
None of these	21
Don’t know	9

Q13. **Do you or any other household members have any long-term illness, health problem or disability which limits your or their daily activities or the work you or they can do?**

	%
Yes	28
No	72
Don’t know	1

Demographics

Gender

	Weighted %	Unweighted %
Male	48	46
Female	52	54

Age

	Weighted %	Unweighted %
15-24	16	13
25-34	16	15
35-44	19	19
45-54	16	14
55-64	14	15
65+	20	24

Social Class

	Weighted %	Unweighted %
A	4	3
B	21	19
C1	29	30
C2	20	20
D	16	13
E	9	15

Working status

	Weighted %	Unweighted %
Working full time (30+hrs/wk)	44	36
Working part time (8-29hrs/wk)	10	10
Not working (ie under 8hrs/wk) - housewife	10	11
Not working (ie under 8hrs/wk) -retired	24	28
Not working (ie under 8hrs/wk) – unemployed (registered)	2	4
Not working (ie under 8hrs/wk) – unemployed (not registered but looking for work)	1	2
Not working (ie under 8hrs/wk) -student	7	6
Not working (ie under 8hrs/wk) –other (incl disabled)	3	4