

# Public Perceptions of the Collection of Human Biological Samples



**MRC**  
Medical Research Council

**Qualitative research to explore  
public perceptions of human  
biological samples**

**Report**

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## A. **Background**

Human biological samples are defined as constituent parts of the human body, or human biological material, including organs and parts of organs, cells and tissues, and body fluids. The collection of human biological samples is increasingly important in medical research – particularly in the area of genetic research – and specifically in work on the human genome. Their value is growing as technical advances make it easier to extract genetic material.

There are potential difficulties arising from the multitude of legal, ethical and social implications of generating and storing human biological samples, and the issue of consent to use samples.

The Wellcome Trust and the Medical Research Council have proposed the recruitment of a large population cohort for the collection of human DNA to help with the study of genetic variation. The sample collection would be linked directly to medical information about each individual from whom samples were taken, and there would be a need for electronic access to NHS records for efficient follow-up.

Collectively, these issues have highlighted the need to establish general principles that would govern the use of collections of human DNA samples. Working drafts of guidelines have been developed and sent for consultation to patient groups, individual scientists and others. Part of the process of developing the guidelines is consultation with members of the public and a range of groups with specific interest in the issues. This research is intended to form part of this consultation stage, and to feed into both the general guidelines and specifically the plans for the large population cohort.

## **B. Research objectives**

The overall aim was to explore public attitudes to the use of human biological samples and associated databases, and to inform policy-making about how they should be collected, stored and managed.

The broad objectives were to:

- explore public attitudes to the broad issue of human biological samples being collected and stored for research purposes;
- examine public attitudes to the use of samples in conjunction with existing health data for the purposes of genetic research;
- investigate response to the proposed Wellcome Trust/MRC sample collection;
- provide initial input to the nature and structure of an ongoing public consultation process for those involved in collection and management of samples and information used in a human DNA collection.

Specific issues addressed in the research were:

- awareness of the use of human biological samples in medical research and genetics research;
- personal experience (if any) of giving biological samples for medical research;
- sources of information on the existence of human biological samples and the impact of the information (and the sources) on understanding of, and attitudes to, the issues;
- beliefs and feelings about the idea of large-scale sample collections that include personal medical information;

- the perceived benefits and risks involved in the concentration of large collections of human samples and associated personal medical information into 'banks';
- perceptions of what motivates the scientists carrying out medical research of this type, and the ways in which their motivation is regarded;
- attitudes to collection of the different types of biological materials (blood, surgical waste, saliva, skin);
- beliefs about the motivations for, and rationale behind, making donations of biological materials for the purposes of research, with particular reference to the circumstances and conditions that might prompt and/or influence decisions;
- information needed to help make decisions about donating samples; sources of information that might be used (e.g. doctors, medical charities, research scientists, government institutions); and attitudes to sources;
- reservations and concerns about the ethics of collecting human biological samples and views on measures that might be used to allay concerns;
- knowledge of, and attitudes to, the legal and regulatory environment surrounding biological sample collection, and beliefs about the different institutions involved in regulating this area, and the controls they work to;
- feelings about the commercial uses of human biological samples and the commercial exploitation of discoveries made using donated samples.

## **C. Research approach**

### **1. Research procedure**

Qualitative research was conducted among members of the public; spokespeople for certain sectors of the public; and those with a professional or personal interest in medical research. Focus group discussions and depth interviews were conducted using agreed topic guides and prompt statements that outlined general issues and the proposed sample collection and its key features. The principle was to explore unprompted knowledge and understanding, then elicit response to facts spelled out in the prompt material. The material comprised statements describing human biological samples and their use, and the proposed sample collection. These were agreed with WT/MRC at the outset. (Copies of topic guides and stimulus material are appended to the full version of this report.)

### **2. Sample outline**

Sixteen focus group discussions were conducted with members of the general public, including people from minority ethnic groups, and from people of wide-ranging ages, socio-economic groups and regions. Controls were placed on these respondents to avoid over-representation of those with backgrounds in medicine or related subjects, people with diseases (who were interviewed separately), and those with strongly negative views about medicine or genetics.

Individual-depth interviews were conducted with: GPs and practice nurses; people with diseases or disabilities; relatives of people with diseases or disabilities; religious and community leaders; and spokespeople for organizations with special interest in the issues surrounding human biological samples and genetics research.

Fieldwork was carried out between 16 March and 14 April 2000 by Tim Porter, Kirsty Hughes, Stephen Finer and Catherine Woolcott.

### 3. **Notes on the sample**

This was a sample designed for qualitative research. While the findings have sufficient consistency and clarity for us to be confident in them, particularly those from the general public, they should not be regarded as statistically significant. Over and above this, it is important to note that the numbers of GPs and practice nurses were very low in relation to the total populations of these groups. The findings from these parts of the sample are enlightening and useful, but should be treated as a snapshot of current opinion from a limited number of individuals, rather than a definitive report of attitudes among people in primary healthcare.



## **D. Summary of findings**

### **1. General public, people with diseases and relatives of people with diseases**

#### ***Context***

Health was regarded as an increasingly salient topic; most people accepted that at the individual level it is worth safeguarding health, and that more generally we should support efforts to improve health. There was a general tendency to trust the medical profession, but signs emerged that this trust was starting to erode. Some younger and ethnic minority respondents felt cynical or wary about GPs, and the cases of Harold Shipman (a GP convicted of some 15 murders of patients) and Alder Hey Hospital (where organs have been taken from children's bodies without parents' consent) had coloured people's perceptions of medicine in general. Attitudes to pharmaceutical companies were ambivalent: they were criticised for being profit-driven, but acknowledged as giving great benefits to mankind.

#### ***Attitudes to research***

Medical research as a whole had a broadly positive image. It was regarded as well-intentioned and strictly controlled. It tended to be perceived as research that focused on finding cures for diseases. Medical research was believed to be carried out primarily by public bodies, although some people also knew it was done by pharmaceutical companies. It had diverse negative associations: it put some people in mind of animal testing, cloning, failure to seek consent from donors, lack of openness among researchers, and profit-making by pharmaceutical companies. Patients and relatives of patients tended to be more positive about medical research than the public at large.

Genetics research was less familiar, but had meaning and associations for most people. Generally the better it was understood, the more positive the view. Many members of the public were uneasy about genetics research. As a scientific activity, it seemed mysterious and sinister and it was believed not to be purpose-driven, but done for its own sake. More specifically it was linked to cloning, GM foods, and 'designer babies'. The more informed and positive view was that it

could be of great importance in identifying genetic predisposition to, and prevention of, disease.

The public's main sources of information on health and medical and genetic research were TV and press news and features, documentaries, TV and film fiction, GPs and word of mouth.

### ***Human biological samples***

Samples were associated with both living bodies (blood, urine) and dead bodies (organs) and were assumed to be used mainly for doing tests or transplants. Use of samples in research was not a well-known practice; in principle it was considered acceptable if accompanied by informed consent. Awareness that surgical waste is used in research was very low, but once explained this was generally regarded as acceptable. Individuals suffering from diseases and those individuals' relatives tended to be better informed and more accepting of the use of samples in research.

Most members of the public imagined donation of samples would be motivated by altruistic feelings, in the same way as donation of blood or organs for treatment. A minority (mainly younger people) imagined that they would expect payment for giving samples. Many said they would be prepared to donate samples for research provided the research was 'ethical' (i.e., intended to help improve the population's health), and preferred the idea of samples being used for disease-specific work rather than general research.

The issue of collecting samples from children was discussed briefly as a separate issue, and not in relation to the proposed sample collection. Many people had reservations about the idea of collecting samples from children because of the pain they might suffer, and because consent issues were less clear-cut than for adults.

### ***WT/MRC sample collection***

Respondents were told, via a series of statements on cards, that the Wellcome Trust and Medical Research Council were considering establishing a collection of human biological samples for use in genetics-based research (see **Appendices** for details). Initial response

among the general public was generally favourable but unconsidered: respondents tended not to think through the project's implications. Issues raised in the statements subsequently prompted concerns and fears, but further information and discussion of these issues tended to restore positive views. People with diseases and with relatives were more supportive and had fewer reservations.

The use of the term DNA was often worrying because it had associations with police investigations, criminality and 'Big Brother'. The request for lifestyle information was initially puzzling and was thought intrusive; medical records were seen by many people as too personal to be handed over for use by unknown researchers. People were concerned about donors' anonymity. In general terms they felt uneasy about records being made available for research purposes and they had specific worries about employers and insurers getting hold of information and misusing it. These worries were often allayed by explanation of why information would be helpful to researchers, and by reassurances of safeguards against unauthorized access.

People generally were happier to participate if their samples and records were to be used for research on specific diseases. Some concern emerged about possible misuse of samples - for cloning, eugenics or other questionable purposes. Informed consent about how the samples would be used was seen as crucial: donors would have to be told how their samples would be used. The mechanics of securing consent for future uses of samples, when new techniques may have been developed, was considered potentially problematic: it would have to be made clear to donors that their samples might be used in ways that are not currently known.

GPs were generally considered the obvious point of initial contact, though there was no objection to practice nurses doing the work of taking the samples. The involvement of GPs seemed to lend credibility to the project. Most people felt that it would be important for donors to have the right to feedback on anything that emerged from their own sample, and felt that this would have to be handled carefully. They imagined that the GP would probably be the right person to deliver

information. There was also interest in getting feedback on the discoveries or developments made as a result of the research.

The general assumption was that the sample collection was being planned either by an arm of government or a pharmaceutical company. The fact that the sample collection would be a publicly funded initiative and not set up as a profit-making exercise was reassuring and important in communicating its credibility. Many people were initially surprised that commercial organizations would be given access to the samples. This feature alarmed some, but was thought inevitable by others. Worries tended to dissipate when it was explained that commercial organisations would do much of the research work, and that none would have exclusive access to the samples or information.

Awareness of the Wellcome Trust and Medical Research Council was patchy. Together they came across as trustworthy and well motivated, although the former was often confused (unhelpfully) with Glaxo Wellcome.

## 2. **GPs and practice nurses**

A small sample of GPs and practice nurses was recruited to obtain an impression of likely views among this sector of the medical profession.

### ***Attitude to research***

GPs and practice nurses had varying degrees of involvement in research at the practice level but most had some experience. GPs were typically better informed than nurses. Those with more experience tended to be more favourable towards research than those who were more distant from it. They felt that most patients would be willing to take part in research on diseases or treatments if approached, provided they were fully informed about its purpose. All four GPs said they would expect recompense for their work in identifying volunteers and organizing their participation. Few GPs or nurses were well informed about genetics research; the better informed had explored it more out of personal than professional interest.

***Human biological samples***

The term 'human biological samples' was no more familiar to GPs and nurses than it was to the general public. Views on public willingness to donate samples for research were mixed. Those currently involved in trials or research felt it would not be difficult to encourage people to take part; others thought it might be problematic.

The problems at Alder Hey were well known and had heightened sensitivity to the importance of consent. More generally, GPs and nurses felt there was a growing need to explain to donors how and why research was carried out. They felt that this should include explanation that surgical waste is sometimes used in research.

***WT/MRC sample collection***

One GP had heard something about the proposed sample collection while the others and the nurses knew nothing of it. Their initial reactions were dominated by two considerations – the effects on their practices, and the implications for donors. Concerns in relation to donors included possible difficulties in explaining the project, confidentiality, misuse of information, effects of personal feedback on diseases, and inappropriate use of samples. Key concerns in relation to their own interests included time commitments, costs and remuneration, and their responsibility in explaining the project to donors. They felt it was important that GPs and nurses should be properly briefed so that they could give full information to patients they approached.

GPs and nurses regarded the need for health and medical information as potentially problematic in relation to accuracy of data, reluctance to divulge details on lifestyle, and the possible compromising of the confidentiality between doctors and patients. They had some reservations about the security and anonymity of information, given the size of the sample and their own experience of maintaining secure records. They felt that assurances of confidentiality, and informed written consent, with the option of dropping out, were crucial.

In relation to other aspects of the project, they felt that access to individual research results had significant implications. Donors should

have the right to feedback, but this could cause problems for doctors and it would be important to explain likely outcomes to donors. They regarded GPs as the most appropriate initial contact about the sample collection and nurses as the right people to obtain samples. They wanted more information on possible imminent and future uses of samples, with an independent body to judge acceptability of uses.

GPs and nurses approved the principle of public ownership of samples and information, but wanted assurances that the involvement of commercial organizations would be strictly controlled. They had no reservations about the involvement of the Wellcome Trust or MRC.

### 3. **Religious and community leaders**

#### ***Contextual points***

While all these respondents had an interest in the proposed sample collection and associated issues, some found it much easier than others to understand what was involved. Their views were often linked to perceptions of scientific and technological progress and the moral implications of improving techniques in medicine. These tended to be their own personal interpretation of attitudes and beliefs within their community or specific to their religion.

A range of issues was raised. The Catholic priest questioned whether it was right to endeavour to abolish suffering. The African and Afro-Caribbean leaders had concerns about blood samples and HIV, about the use of black people in experiments by white scientists, and about the role of GPs in taking samples. Hindu leaders felt that their community was excluded from involvement in and access to medical research.

#### ***Attitudes to research***

Knowledge of, and attitudes to, medical and genetics research varied widely. Those who were better informed often had more concerns – namely, the Jewish rabbi; the Anglican, Baptist and Catholic priests; and the Afro-Caribbean community leader. Others were less knowledgeable and less questioning, though some had tangential reservations about the uses and implications of genetics research.

The use of human biological samples in research had a distinct religious facet for some religious leaders (the rabbi, the African and Afro-Caribbean leaders and Muslim representatives). This was principally to do with the removal of any parts of the body before or after death, and the widespread view that burial should involve the whole body. Although beliefs in this area were apparently strong, these leaders implied that they were more symbolic than actual, and would probably not be an obstacle to participation in donating samples for research. Many raised the subject of consent and said that informed consent was a crucial consideration in decisions on donating samples.

### ***WT/MRC sample collection***

Overall attitudes to the proposal were accepting, although some felt that people of their faith or from their communities would have reservations about taking part. Initial concerns centred on the need for DNA, uses of the samples, and credentials of those taking decisions on their use.

The need for information on donor lifestyles and medical histories caused some problems, especially for those whose communities had in the past or might now suffer ethnically based discrimination – people of Jewish, African, Afro-Caribbean or Asian background. Many had worries about the confidentiality of information and wanted reassurances about this. Some Asian and African spokespeople thought questionnaires would pose a difficulty for people with limited literacy in English.

Expectations about potential uses of the samples and associated information were broadly similar to those of the general public, but there were demands for work to look at diseases with a higher prevalence among minority ethnic groups. Spokespeople also wanted clear guidance to be available on what personal feedback would be offered, and expected fully informed consent. GPs were generally accepted as the contact and collection point for the project, though some spokespeople felt that GPs might try too hard to persuade people to take part, or that they would not be trusted to provide full information about the project to donors.

Like the general public, community and religious leaders assumed that the sample collection would be conducted by a government organization or a pharmaceutical company. The partnership of the Wellcome Trust and the MRC was considered a good balance between the statutory and voluntary sectors, and allayed some concerns about the project. The likely involvement of pharmaceutical companies prompted questions about confidentiality of information, uses of samples and profiteering. There were some calls for profits and/or learning arising from the project to be directed to developing countries.

Overall, the religious and community leaders had varied opinions on the likelihood of people within their communities taking part in the project. Many wanted more information before they could come to a view. Several said spontaneously that the sample collection should include representation of all the minority ethnic and religious groups in the UK, and should address diseases and conditions that affect everyone.

#### 4. **Special interest groups**

##### ***Contextual points***

All the special interest group spokespeople interviewed were well informed about the issues and in most cases had strong and well-established views on genetics research.

##### ***Attitudes to research***

All were favourably disposed to the idea of research *per se*, but views of genetics research were varied. Some were supportive and felt that it had many potential benefits. Others had reservations, some serious. Concerns were greatest in the context of research on certain genetic therapies and on disabilities, particularly where these are identified before birth. Several calls were made for greater debate on the subject and its implications.

##### ***WT/MRC sample collection***

All these respondents had heard something about the proposed sample collection and some were very well informed about it. All but one was broadly in favour of the idea, although all had some



reservations and two had particular concerns. The main perceived benefits were to do with the advances it might facilitate in the identification of genetic disorders and development of preventative treatments.

The project was believed to have numerous potential problems and pitfalls. The use of DNA caused concern because it introduced the perceived possibility of DNA being used in research on embryos, and consequently, implicit discrimination against disabled people. Donor confidentiality was regarded as potentially at risk. Information could be accessed and misused by insurance companies, health authorities and researchers. There were some worries about feedback to donors; it might be impractical and it could be compromised by the needs of the research. Another concern was the potential for commercial profiteering by pharmaceutical and biotechnology companies involved in the research.

Views of the Wellcome Trust and the Medical Research Council were mixed. Some were fully supportive and had no concerns at all about their involvement. Others were less keen and believed that both organizations were subject to pressure from pharmaceutical companies and the government, and too willing to work to an agenda against the interests of people with disabilities.

Irrespective of their overall stance towards the project, all these spokespeople felt that there was a strong need for further consultation on the key issues.

## **E. Conclusions and recommendations**

1. While few people outside the medical profession and interest groups know much about the use of human biological samples, there appears to be broad acceptance of their use in medical research generally, *provided* this takes place with the informed consent of donors or their representatives (usually relatives).
2. Given the publicity surrounding recent cases of research on organs removed without permission, there is some wariness towards the practice of research on samples, and signs of a loss of faith in those who carry it out – members of the medical profession.
3. The use of human biological samples in genetics research is less readily accepted, largely because genetics and genetics research are much misunderstood and have many unhelpful (and ill-informed) associations. There is a case for informing the general public about genetics research as well as its applications, particularly in relation to disease specific research, and its preventative potential.
4. The proposed WT/MRC sample collection is accepted in principle, although it is clear that members of the public do not always think through the implications fully when first presented with the idea.
5. Success in recruiting volunteers will depend to a large extent on how effectively the idea is communicated at the outset; initial reactions among the public suggested that if people find any aspect of the sample collection off-putting at the outset, they would be difficult to recruit.
6. GPs will have an important role in this respect. If they are the first point of contact, it will be essential for them to be fully briefed on the idea, to be convinced of its benefits, and to be able to answer queries about it.
7. It will be important to provide reassurance that the collection, storage, use and disposal of samples will be carried out responsibly. If these were overseen by an independent body, ideally with a known public

figure at its head and including members of minority communities, people are likely to have trust and belief in the project's probity.

8. Consent is a crucial issue for the project's continuing success, particularly in the current climate – at the start and in the future. A balance needs to be struck between eliciting fully informed consent and giving volunteers so much information that they are confused.
9. The most important issues in relation to consent are:
  - communicating why the sample collection is being set up;
  - informing people how samples will be used, now and in the future;
  - securing consent for access to medical records.
10. Feedback on results relevant to an individual's health needs to be handled with great care, given the implications of discovering the existence of diseases. There are several issues involved here:
  - establishing the volunteer's right to know – this is widely regarded as paramount;
  - agreeing at the outset what sort of feedback the volunteer will get on what sort of diseases/conditions (will it be about curable disorders only? Or any disorder?);
  - deciding who should provide feedback – a GP, nurse, or somebody else;
  - providing resources for follow-up after delivery of feedback, with counselling where needed.
11. Mechanisms for ensuring anonymity are also important. Reassurance must be given that confidentiality will be guarded. It would help to spell out in simple terms how this is to be achieved, particularly to clarify that researchers using samples will not have access to individuals'

identities, and that feedback on conditions and diseases can be given without jeopardizing confidentiality.

12. Recompense for GPs and for members of the public needs to be considered carefully. There might be a case for recognition of donors' altruism in participating in the study.
13. There are likely to be questions from the general public and in the media about commercial access to, and use of, the samples and information. Assuming samples are donated freely by donors, there needs to be careful explanation of the financial implications of this.
14. Given the importance of communicating the idea of the sample collection to the general public, it may be worth considering a communications campaign of some sort to inform people – via GPs, community and religious leaders.
15. In addition to an information campaign, it would be well worth giving the project a name or shorthand description. Given the significance and size of the sample collection and its likely longevity, it would help register the project in people's minds if it had an easily remembered title.
16. Terminology is an important consideration for communications materials: a number of key words and phrases relevant to the project (*samples, genetics, DNA*) are prone to misinterpretation or have negative connotations, and need either to be avoided or to be given explanation to avoid putting people off.
17. There is a case for further public consultation on the proposed sample collection. This would involve research with a larger number of GPs and practice nurses, religious leaders and representatives of minority ethnic groups – none of whom were represented in large numbers here – and, among the general public, a larger-scale study to check key issues.

## F. Findings: the general public, ethnic minorities, people with diseases, and relatives of those with diseases

### 1. Contextual issues

#### 1.1 *Attitudes to health*

Discussions opened with a brief warm-up on issues to do with health. Health was generally regarded as an increasingly important and visible issue; it was often thought of as a more high-profile topic now than it had been in the recent past, particularly in its coverage in the media. Though there was some belief that we should be more health aware, some respondents felt that as a nation we are healthier than earlier generations.

*“You’re bombarded in the media about health all the time.”*

Female BC1 46-60 SE

Many people, especially those over about 30, had concerns about their own health. These seemed to be triggered by milestones in life – parenthood, significant birthdays (30, 40), retirement; or by illness – of themselves or among family members or close friends. Concerns tended to focus on specific diseases – typically cancer, heart disease, HIV, meningitis, asthma, cystic fibrosis and sickle-cell anaemia.

Interest in, and knowledge about, health were more evident among those going through these life changes and those who were better informed about health issues. These were, typically, older women, BC1s (**WHAT THEY?** people in social category BC1 ?), people with diseases, and relatives of those with diseases. The less well-educated members of the public (especially people in social category C2D) tended to be less well-informed about health, less proactive in looking after their health and more fatalistic about illness.

Among the better informed, many believed that improving health education is making it easier to take preventative measures to maintain health in relation to diet, lifestyle and the use of drugs. It was also widely believed that developments in medicine mean that cures are increasingly available and effective and that discoveries about

diseases, the development of new drugs and improving surgical procedures all play a part.

## 1.2 ***Attitudes to the medical profession***

To a large extent, the public trusted the medical profession to offer effective treatment and carry out research responsibly, and with good intentions. Some differences emerged in attitudes between different sample segments. Those over 40 and those with illnesses or close to others with illnesses expressed a greater degree of trust and belief in the medical world; these people had an almost unquestioning faith in medicine, particularly in GPs.

*“I would trust him totally. If I asked the doctor I would trust his answer.”*

Female C2D 41-55 London

*“You tend to put your faith in the doctors. They’re the ones trying to help you, they’re the people who can improve your life.”*

Female Caribbean 46-60 Midlands

Younger members of the public (especially those under 30) were more likely to express concern or cynicism about medicine – about practices used, the motivations of researchers and trustworthiness of doctors.

*“I think people’s trust in GPs is getting less. At one stage people looked up to GPs, they were considered pillars of the community. At one stage people talked to GPs with respect. Nowadays they don’t necessarily. I don’t think society respects GPs as much now. Personally I think my GPs are useless so I wouldn’t listen to them.”*

Male BC1 22-30 North West

*“You used to trust them but not any more. Your GP used to be like a family friend but not any more.”*

Female BC1 22-30 Midlands

There were also signs of differences in opinions among minority ethnic groups. Some people of African origin and some Muslims seemed wary of the medical profession – including GPs – and sometimes felt patronised by doctors.

Across the spectrum of the public there was awareness that the medical profession can do things that are clearly wrong (that is,

criminal) or can make serious errors of judgement. Many references were made to the incidents of organs being removed from dead children without parents' permission at Alder Hey hospital, and to the case of Dr Harold Shipman. Although these were regarded as exceptions, it was clear that they could influence general impressions of medicine.

*“It (Alder Hey) has made me a bit more suspicious. You don't necessarily believe what the GP is telling you...I am just a bit sceptical now.”*

Male C2D 22-30 North West

*“Over the last few years more and more people don't trust doctors anyway...I wouldn't take my son to the doctors any more because you get the same old flannel, 'a bottle of antibiotics and watch his temperature'...”*

Male C2D 22-30 North West

*“There has been a lot in the news about the hospital somewhere which got the parents to sign forms to say they could take cells away but they took organs away instead. I think that was disgusting, it was definitely put there as a trick. It was for research, not even a donation.”*

Female BC1 22-30 Midlands

### 1.3 ***The pharmaceutical industry***

The pharmaceutical industry was seen as a significant player in health matters. Some people seemed to be well aware that drugs companies have a role in medicine – in funding medical research, and in development and provision of drugs. However there was little awareness of links between the pharmaceutical industry and academic researchers; the two tended to be thought separate and distinct.

Feelings about the pharmaceutical industry seemed ambivalent: it was criticised for the profits it makes but was acknowledged as having an important role in developing drugs and improving the health of the population.

*“The other is drug companies, they are multi-million pound companies and they have the say as to what is put out which is silly really, they are just out to make money. There is a good side there but you also get this other side which is not so good.”*

Female BC1 22-30 Midlands

People with diseases tended to be less critical of the pharmaceutical industry than others, because it was one possible source of cures for them, and because they felt its work had already helped them.

## 2. **Knowledge and attitudes surrounding medical research and genetics research**

### 2.1 ***Medical research in general***

Medical research was typically regarded as disease-specific: it was characterized as work done primarily to find new ways of fighting diseases, including the development of new drugs.

For most people medical research was considered worthy and worthwhile and as something that was an inevitable aspect of modern progress. In broad terms, they believed its purpose was focused on improving the health of the nation/the world. Medical researchers as a whole were assumed to be responsible people. While they may be motivated by personal kudos as much as by the needs of the population, they were believed to work within fairly strict controls, at least within the UK.

Less positively, there was some feeling that medical researchers operate in a vacuum, without reference to the ethical and moral guidelines that govern most of society. This was not because they reject these guidelines but because they are more focused on their work than anything else around them. The problems at Alder Hey were attributed to this approach or attitude – not conscious malpractice, but a focus that was so narrow that it excluded consideration of bigger issues.

Medical research was assumed to be carried out primarily in institutions that are in the public domain – universities, teaching hospitals and other public bodies. Pharmaceutical companies were also thought to conduct research, but few people seemed aware of their links with the academic world. Charities were rarely mentioned in this context, the impression being that they fund medical research but do not have their own laboratories or staff.



Perceptions of the applications of medical research tended to focus on specific medical conditions and/or treatments for conditions. Current known examples of medical breakthroughs resulting from research were: immunization against meningitis; interferon; Viagra; the benefits of aspirin; and scanning for tumours.

*“One little simple thing is they realized that aspirins helped heart conditions.”*

Male C2D 46-60 S Wales

*“They’ve got brain scans as well now...they can find tumours before they get too bad.”*

Female BC1 31-45 S Wales

There was some awareness that certain diseases and conditions are more prevalent among minority ethnic groups – specifically sickle-cell anaemia in Afro-Caribbean people and heart disease in Asian people. Within these groups this knowledge was accompanied by a belief that research is going on to address these conditions. Less positively, a few people from ethnic minorities believed that diseases affecting minorities receive less attention than those affecting mainly white people.

*“There are all sorts of genetic diseases and certainly genetic conditions that are predominant in Caucasian societies that are better looked at, because of the funding that they will get, and the status and the publicity. As opposed to genetic conditions that are prevalent in non-whites. Those don’t seem to be quite so high profile.”*

Indian Hindu female 18-21 SE

Medical research also had some negative associations: experiments involving animals; experiments using ‘human guinea pigs’; inadequate testing of drugs resulting in damaging side-effects (such as thalidomide); and cloning – of animals now, and possibly of people in the future – and other experiments involving unusual techniques.

*“There’s a place in Leeds that uses humans and you go in and spend so many days there and take drugs testing for this that and the other.”*

Male BC1 22-30 North West

*“They are growing ears on pigs and things. Using animal organs in human bodies”*

Female C2D 18-21 North West

Another broad aspect of medical research that people felt uneasy about was the questionable ethical stance of some researchers. Two

topics were mentioned here: the apparently insensitive attitude of researchers towards patients (e.g., Alder Hey); and their claimed tendency to be secretive with research findings in their own interest, to the detriment of progress in particular areas.

*“Recently in the news there was a hospital taking parts from kids that people had not agreed to, you know, that is worrying.”*

Male C2D 22-30 North West

*“But they’re still doing things that are a bit undercover, like hospitals are keeping parts of babies when they die, and it’s all coming out. Why have they been doing that?”*

Male C2D 46-60 S Wales

*“I’ve heard that because everyone is so secret about the research they’re doing, often it’s replicated in several different countries, which is a dreadful waste of money.”*

Female BC1 46-60 SE

The involvement of big business – pharmaceutical and biotechnology companies – in medical research also caused concern. Two issues were raised in this context: the broad ethical dilemma posed by the meeting of medicine and money; and the specific issue of drugs companies making profits at the expense of the NHS. A few respondents mentioned press stories of drugs being sold at prices too high for the NHS to afford.

*“You have to remember that there are people funding it and the people funding it have an interest.”*

Female BC1 46-60 SE

Some of these concerns were overlooked if the outcome is regarded as beneficial to humans – to an extent people seemed to believe that if research generates cures and treatment; within reason, the ends justify the means.

*“I am not a big fan when they do experiments on animals but I think it has got to be done. It’s the lesser evil isn’t it really.”*

Male C2D 22-30 North West

*“If they didn’t do the research we wouldn’t have all the cures and drugs we’ve got.”*

Female C2D 31-45 SE

As a whole, people with diseases and relatives were more positive about and supportive of medical research. They saw it as something

that might help them directly; and their condition made them generally more supportive of anything which might help others with diseases. Some had become more favourable towards research in general and specific practices since becoming ill; and some reported changed attitudes among friends and family.

*“I’m diabetic so it is good for me or I wouldn’t be here now. They must have researched highly to produce insulin. I don’t take an active interest but it is important that they are looking for new cures and things.”*

Female BC1 22-30 Midlands

*“You hear that they’ve made great improvements with cancer research. A lot of money’s been spent but they need a lot more. Like my husband’s operation, a couple of years ago I doubt that anything like that would have been done, so they are obviously researching into ways of improving things.”*

Relative of patient with mental health problem Midlands

*“Well they’ve got to do it haven’t they? I obviously think that because I’m here. A few years ago, I might not have been.”*

Patient with heart disease Scotland

## 2.2 Genetics research

Genetics research was a less familiar term and a less familiar entity than medical research, but did have some currency. Attitudes to genetics research were linked directly to knowledge: the more was known about it, and the better it was understood, the more favourable the view. Among most of the general public there was a mystique and mystery surrounding genetics research; depending on degree of understanding, this could enhance or undermine its perceived value and benefits.

The majority view, among those who knew little about genetics research, was at best wary, at worst rejecting. For these people genetics research was an activity carried on behind closed doors, whose applications and benefits are not known, or are in some way not good, even sinister.

*“I don’t know how it’s regulated but they can’t watch every research centre that there is and every test they do. There’s going to be things that are hidden, kept from us.”*

Male BC1 22-30 North West

*“I think a lot goes on that we don’t really know about, that they wouldn’t tell us because if they told us all that went on to make these discoveries there would be an outcry or protest.”*

Female BC1 46-60 SE

*“It’s all right to a certain level but when you start cloning sheep it’s a bit scary...something that’s just made in a laboratory. If they’re using it for the purposes of making people better then fair enough but you’ve got to draw the line somewhere I think.”*

Male BC1 22-30 North West

Genetics research was generally seen as less purpose-driven than medical research: it was linked with general research into the human body rather than with disease-specific work. For some it was research done for its own sake, or for the benefit of the scientists doing it rather than for the general good.

*“I think medical research to me is looking for an illness, whereas genetics research is to modify and make better...if there’s an illness or disease, medical research would go forward to look for a cure for that, but genetics research would be to improve on something that’s already there...”*

Male C2D 46-60 S Wales

*“Genetics seems to be non-essential research doesn’t it rather than like you say with cancer and things like that where there is an urgent need for it.”*

Male C2D 22-30 North West

Genetics research had a raft of unhelpful negative associations, based sometimes on misinformation or mistaken assumptions. Mention of genetics research drew references to cloning – as with medical research but more often, and with greater concern. More specific concerns were with Dolly the sheep, and Dolly’s premature ageing (respondents in Edinburgh were particularly negative about Dolly and about Roslin), and genetically modified food.

*“With genetically modified food we expect larger juicier tomatoes or whatever, but I’m not convinced that is a good idea because I don’t think they’ve done enough research into it.”*

Female BC1 46-60 SE

*“I suppose there is a worry, this whole cloning thing, cloning Dolly and those pigs. What next? How do you control it?”*

Female BC1 46-60 SE

*“You hear stories in the press about creating these animals with two heads and stuff and it makes you think can they really do it and what will they do next – can they really clone me?”*

Female BC1 22-30 Midlands

Respondents often made links between genetics research and claimed new medical practices surrounding reproduction: choosing the sex of babies/’designer babies’; the preservation of frozen eggs or sperm; and attempting to breed people with or without specific characteristics.

*“I think there has been a lot lately about people who will soon be able to go and pick their child, you know, go in and say ‘I want one (with) brown hair, blue eyes, I want a girl who is going to grow to be five foot eight or something, like average build’.”*

Male C2D 22-30 North West

Underlying these negative associations was a feeling that genetics research can make people feel vulnerable about themselves. It was believed to be about seeking to perfect the human body, for good or bad ends, and that it could induce concern about individuals’ own imperfections.

*“They seem to want to make the perfect world, trying to make it perfect, they are messing with your food and stuff we have had for thousands of years, so why change it now? Spend the money on cancer cures, AIDS cures, stuff like that.”*

Male C2D 22-30 North West

*“There’s also the thing about making a super human race, because they can actually put down the parts they want - a very healthy person, with blue eyes and blond hair. Or brown eyes and brown hair, and they want it to have so-and-so sized feet and so-and-so sized breasts or whatever and then everybody’s the same...”*

African-Caribbean female 46-60 Midlands

Alongside this was a feeling expressed by a few that genetics research, if put to these sorts of uses, conflicts with the (beneficial) diversity of the human race. Though it would be a good thing to attempt to eliminate genetically linked diseases and conditions, this is likely to go hand-in-hand with other developments that will make it possible to produce ‘perfect’ people.

*“If you mess with the building blocks of life, if people have got religious beliefs, if you believe that God created us as we are and you start messing around with it you’re playing God.”*

Male BC1 22-30 North West

*“Cloning, basically they are saying if they can do it with animals then they can do it with human beings, but it’s like messing with nature, messing with God’s will.”*

African male 22-30 SE

*“It’s messing with Mother Nature. What about the side effects?”*

African-Caribbean female 46-60 Midlands

*“If they’re not very careful somebody will create some quite horrendous thing out of it, you don’t know where it’ll lead. I think you ought to leave nature as it is, as it was intended.”*

Male C2D 61-75 Midlands

More positively, some people were better informed about genetics research and its applications and tended to have a more favourable view of its applications. This was broadly the more educated members of the public and those with diseases or relatives of people with diseases. Genetics research to them was primarily concerned with work on diseases and conditions, to isolate genes that are linked to these diseases – such as cancer in general, breast cancer, Down’s syndrome, spina bifida and others. They regarded it as a potential alternative to drugs as a means of treating or preventing disease.

*“They have actually pinpointed various genes in various areas that cause certain diseases. I suppose that is what they’re doing at the moment.”*

Female BC1 46-60 SE

*“Hereditary diseases, they are looking into diabetes at the moment which is a good thing. If they can cut the blood line they won’t have so many people with these diseases.”*

*“They are closer to a prevention than a cure. If they can identify the gene that makes people more likely to get something they can get rid of the genes.”*

Female BC1 22-30 Midlands

*“I think the press has got hold of the bad side of things, not the good points whereby people are dying out there because of genetic defects and if they could only get rid of the gene that is causing it people won’t suffer any more.”*

Relative of patient with physical disability Midlands

In this respect genetics research was regarded as uniquely clever: it came across as medical science that was at the cutting edge of technology, done by exceptionally bright people.

### 3. Sources of information and influence

#### 3.1 *Main sources*

The media – television, newspapers and magazines – were the source of most information and influence on knowledge and attitudes surrounding medical and genetics research.

TV news and documentaries were probably most important. Apart from news programmes, there were mentions of *Horizon*, *Tomorrow's World* and the Discovery Channel. In general, television tended to be treated as a more objective source of information than newspapers. The impression was that television reporting was more factual and less opinion-based than newspapers. Stories and features in newspapers were a significant source for many, but were treated with a little caution for their likely bias: most newspapers were believed to have a stance or agenda on most subjects, including this one.

*"When you pick up a newspaper, when you pick up the Guardian, you're expecting a left-wing reading of the situation. You pick up the Telegraph, you expect a Tory thing. But the moment you see it on telly you just go 'that's gospel, that's truth'. We don't criticise or question what we see on TV."*

Male BC1 18-21 SE

*"It depends on the journalist's opinion as well. If he's of the opinion that it's well worth it, then you're going to get a good report. If you've got somebody who's obviously against it then you're going to have a bad one. At the end of the day they might be able to report facts but it's still their opinion that comes across."*

Male BC1 22-30 North West

Many women picked up information about medical developments from women's magazines. This included news items on diseases, treatments and discoveries, and features on personal experiences of disease and coping with the consequences.

Fictional material, especially TV and film, also played a part in communicating basic information about aspects of health and medicine, particularly treatment of diseases. In some instances stories covered in film and TV features raised issues to do with genetics which could be worrying.

*“You’ve got films as well that portray the nightmarish side, like Gattaca where you’ve got a civilization based on people that have been genetically purified.”*

Male BC1 22-30 North West

*“I saw a really horrible thriller on the telly about them shipping off samples and things and they were growing things from them.”*

Female BC1 22-30 Midlands

Some feeling emerged that press coverage of medical and/or genetics research distorts or conceals the reality: there is probably a lot going on – good and bad – that we do not hear about. At the same time it was felt that press stories can raise expectations which are inevitably unfulfilled.

*“Every few months it’s on the news, scientists have made a breakthrough with cancer, and there is a bit of an interview and then you don’t hear anything again and it’s like it’s cost £x millions and then they don’t seem to get any closer.”*

Male C2D 22-30 North West

*“They also raise people’s expectations. They reckon they’ll cure AIDS by 2000 but if you watched twenty-year-old episodes of Tomorrow’s World they (said that) in 1999 everybody’s going to be driving round in hover cars.”*

Male BC1 22-30 North West

*“It’s hard to tell these days because everything comes through the media... There is obviously certain stuff that they want you to know and then stuff they don’t want you to know.”*

African male 22-30 SE

GPs also had a role in informing people about health generally and about developments in prevention and treatment of disease specifically. Among some younger people formal education played a part in informing them. A few who had taken Biology ‘A’ level had learned something about genetics and its role in the incidence of disease.

People with diseases were typically well informed about medicine and about their own disease or condition. They learned from their GP and/or hospital doctor, both about treatment available and about any relevant research on their disease/condition. Most seemed keen for information, and tended to pass it on to friends and family.



*“We only know more about it because of [my husband]. I mean I never knew much about it, I know an awful lot now than I ever did before.”*

Relative of patient with mental health problem S Wales

*“I like to find things out. I do read, when I see articles on it and we talk about it. I want to know, when I am in hospital, why I am getting this, why are they doing that, what’s that test for, what’s the blood for...”*

Relative of patient with physical disability North West

### 3.2 **Terminology**

A significant issue relating to information and sources of influence was the terminology used. It was clear that some widely used terms are often misunderstood, misleading and/or have negative connotations. Specific examples of this were: *samples, biological, genetics and DNA*, all of which seemed open to misinterpretation.

At the same time it was apparent that what members of the public want as much as anything else is certainty in what they are told about medicine. They want to trust and believe in what they see and hear. People look to the media but also to government and to the medical profession for certainty and are sometimes disappointed. They feel they cannot always take news stories at face value, and there were signs that faith in government and medicine to provide this certainty is diminishing. Concerns about, for example, the safety of the contraceptive pill, the claimed link between BSE and CJD, and the possible risks of MMR immunization have all undermined faith in the medical establishment to be open and accurate with its information and advice.

## 4. **Perceptions of human biological samples**

### 4.1 **Definitions**

*Human biological samples* was rarely a familiar term; in isolation it came across as puzzling, even unsettling. Initial guesses at its meaning centred on *samples*: to most people this meant blood, urine, tissue of some kind, saliva, sperm; some also assumed it included organs. A few of the more educated members of the public believed it might include DNA taken from samples.

Samples were generally associated with both living and dead bodies, though some linked them more with living bodies and some more with dead bodies. In relation to living bodies, samples were primarily associated with tests carried out for the benefit of the 'donor'. These included tests to determine the presence of diseases or conditions – HIV, hepatitis, other sexually transmitted diseases, diabetes, pregnancy – or other health factors such as cholesterol levels or anaemia.

Samples from dead bodies initially were often assumed to be organs rather than blood or tissue, and were associated with general medical research and medical teaching. Most people, without considering the matter at any length, assumed that samples from dead bodies were body parts, perhaps diseased, that had been removed during treatment and subsequently used for research.

A few people believed that blood donated for transfusion could be used in medical research, though the origin of this belief was not clear. Their impression was that a small amount is siphoned off and passed to researchers, and the rest is kept for transfusion.

#### 4.2 ***Surgical waste***

At this stage human biological samples tended not to be perceived as including surgical waste. They were believed to be material taken from living or dead people, with consent, for a specific purpose. Few people were aware that surgical waste might be used for research purposes. After some initial surprise there seemed to be broad acceptance of this practice.

Surgical waste was regarded in a very different way from healthy blood or organs removed for a specific purpose. The general feeling was that if the material is no longer of use and particularly if it is not healthy, there would be less concern about how it was used.

*"I don't see that there's a problem with that if it's stuff that's been removed during an operation."*

Male C2D 46-60 S Wales

*“If you had just had an emergency op for your appendix you would just be so happy you were all right now that you would say yes whatever...”*

Female BC1 22-30 Midlands

A few people in Liverpool disagreed with this, probably because they were more sensitive to the issues as a result of Alder Hey.

*“You assume they burn it in the incinerator don’t you? And that is where I like to think things go, but like we found out already, they have a back door and they use them. I mean I would like to give consent, I would like to know everything about what is happening to my parts, even if they have been removed from me, even if they are no good to me.”*

Male BC1 22-30 NW

#### 4.3 ***Human biological samples vs. blood donation and organ donation***

Respondents were asked to consider the donation and use of human biological samples in comparison with blood and organ donation. Virtually everyone was familiar with the principle and practice of blood donation and organ donation; a few respondents were blood donors and some carried organ donor cards. The few respondents who were less familiar were a few from minority ethnic groups, typically relatively recent immigrants from countries which did not have services of this type.

Several important distinctions were identified between samples donated for use in research and blood given for transfusion or organs donated after death. Blood donation and organ donation was thought to be about making a direct impact on saving life or improving the quality of life for specific individuals. It was seen as a big decision involving some thought and effort. It was widely known that both blood transfusion and organ donation involved no financial profit for anyone.

*“It’s done out of goodwill as a donation, you don’t get anything out of it besides satisfaction.”*

Male BC1 18-21 SE

In contrast, biological sample donation for research was believed to have a less direct effect in saving life; at best, it would be helping work which might one day save or improve lives. Decisions on donating samples were regarded as less significant and easier to make. There were some concerns that researchers or organizations using biological

samples would make money from the samples, or benefit from them in some way.

*“I’d prefer my blood to go off to somebody than to off to research and stuff like that.”*

Male C2D 46-60 S Wales

#### 4.4 Consent

In initial discussion of human biological samples it seemed to be considered a given that they are not used without the consent of the individual and/or their relatives. Consent was rarely raised unprompted because it was largely taken for granted. In this respect it was likened to blood and organ donation, and was believed to be controlled by established procedures. The assumption here was that anything taken from an individual for the expressed purpose of using it in research should only be taken with permission.

*“If you are volunteering your blood, yes, go for it.”*

Male BC1 18-21 SE

*“I think if you are told what they are trying to test it for, yes, it is not a problem.”*

Male C2D 22-30 North West

*“I think they would always ask permission, get your consent because if they don’t you might think of other things and wonder if they had done anything else without consent.”*

Female C2D 31-45 SE

Subsequent discussion of consent indicated that it was seen not only as a courtesy, but also, more importantly, as a sign of respect for the individual. Asking for consent indicated that the donor was valued and appreciated; omitting to get consent showed a lack of respect.

Allied to this was a feeling, not always expressed in initial discussion, that consent must be informed: it is wrong to ask for consent without ensuring that the donor understands to what he/she is consenting.

Many people made a distinction between healthy and unhealthy material (surgical waste). They felt that if the blood or tissue is healthy and still potentially useful to them they should be asked for consent to give it away. Surgical waste was different: the fact that samples are blood, tissue or other material that has already been discarded and are

not wanted made them seem no longer the individual's property. This was particularly the case if the material removed was not a vital organ.

*"If you don't know you don't care...I think if I had my appendix out I wouldn't care."*

Female C2D 31-45 SE

*"I had my appendix out a few years ago and it doesn't bother me what they did with it because I never knew it was there but if it was something vital like a lung I would like to know."*

Female BC1 22-30 Midlands

There was also the view that if the material is a by-product of an operation, its collection for research is almost a *quid pro quo* for the treatment: the doctors were helping the patient by removing something bad; in return they could use this material for their own purposes.

People with diseases typically had a more relaxed attitude to consent. They were used to giving samples for tests and did not object to these being used in other ways. Some seemed to feel almost beholden to doctors for their care, and so more prepared to let doctors have what they wanted or needed for the doctors' own purposes.

*"Nobody spoke to me about it. If they had, I'd have said 'Yes, by all means take it! It's no good to me'."*

Relative of patient with heart disease Scotland

*"You're in hospital and the nurse comes along or some young doctor and they say they are doing case studies on something and could they take samples...I've always said yes."*

Patient with physical disability North West

#### 4.5 **Assumed uses of human biological samples**

Understanding of the uses of human biological samples was limited. Many people could make guesses, but some of them who were generally less well informed about medical research, found it difficult to imagine how human biological samples might be used.

At best it was assumed that samples are used in three main ways: analysis to test for diseases or conditions, research to develop treatments for diseases (examples mentioned were Parkinson's, Alzheimer's and meningitis), and for general medical research.

*“It’s not just illnesses, they research into how bodies work, not just ill ones but well bodies, looking into how your brain works, your eyes, any part of the body.”*

Female C2D 31-45 SE

*“Well diseases like MS and cancers and AIDS, they take blood from patients and look at them across the spectrum and different people’s levels, anything that is going to help future generations...”*

Male C2D 22-30 North West

*“Later in life looking into diseases like Parkinson’s and Alzheimer’s.”*

Female C2D 31-45 SE

#### 4.6 ***Institutions and people involved in using samples***

The use of human biological samples was imagined to take place mainly in universities, teaching hospitals, pharmaceutical company laboratories and commercial research facilities. Samples were believed to be collected at GP surgeries, by GPs themselves or by nurses, or by hospital doctors.

There was some feeling that hospital doctors provide a more trustworthy avenue for collection of samples because they are specialists and are likely to know more about how the samples are used. And there was a feeling that hospital doctors are less likely to make errors in collecting and storing samples.

Research using biological samples was also believed to be conducted at commercial research centres which use people to test drugs and other treatments (press coverage of a clinic in Leeds prompted some mention of this).

*“These cold centres where you stay for a week and they research the common cold, those sort of places.”*

Female C2D 31-45 SE

Respondents believed researchers using samples for medical or genetics research were motivated by both selfish and altruistic considerations. Altruism was linked with a desire to do good by increasing our knowledge of the human body generally, and discovering how best to prevent and treat disease. The selfish motives involved were believed to be money, kudos and fame.

*“They’ve got different motivations. There’s financial motivations but there’s also the motivation of the people that actually do genuinely care about other people and want to do good for other people...”*

Male BC1 22-30 North West

*“Very few people do it for the good of mankind. Even the Cancer Research company, there must be some people who start with good intentions but the money has to come in somewhere.”*

African-Caribbean Female 46-60 Midlands

#### 4.7 **Attitudes to donating samples for research**

Few people in the general public sample had experience of giving samples for research. A few women had been asked to donate blood when pregnant; one woman had been asked for a sample of breast milk. Another had been given treatment for a genetic condition developed from a blood sample taken from someone unknown to her. One woman had refused to give a blood sample when pregnant because she was anxious about going to a hospital following the death of an earlier child. A few respondents had seen advertisements by hospitals and clinics seeking volunteers to give samples for research

The incidence of donating samples was much higher among people with diseases and relatives of people with diseases. Many of these people had given samples and all seemed broadly happy with the idea in principle.

*“We did give blood, because my daughter’s got juvenile chronic arthritis and they were researching the genetics of that. This professor said can we take blood from the family and we said yes.”*

Patient with physical disability Midlands

*“[My daughter] is a subject of research now at Great Ormond Street. She’s being genetically researched at the moment. They’ve done all sorts of tests...”*

Relative of patient with physical disability SE

Among the general public, most said they would donate a sample if asked, with qualifications. It should be used only for *bona fide* research – that is, research done on a specific disease or medical problem; it should not be used for anything with questionable moral value such as ‘cloning’; and no one should make money from it directly.

*“If it was to save somebody’s life, then maybe, but not if they just wanted it to do general research because I don’t know what they’re going to do. You never know, they could take it to do that cloning.”*

African male 22-30 SE

*“As long as it is doing some sort of research to develop something to save life.”*

Male C2D 46-60 S Wales

*“As long as you know that it is going to be used for a disease or for drugs to fight disease it is fine”*

Male C2D 22-30 North West

*“You would do it for the health of your children. The thought that I could give something that helps my friends’ children or my own one day, I would.”*

Female BC1 22-30 Midlands

Some younger people immediately wondered what they would get out of donating a sample and specifically what they would be paid.

*“How much [would I get paid] and what’s it being used for?”*

Male BC1 18-21 SE

*“I think you should get paid for it because at the end of the day you don’t see people lining up to do you any favours in this world. If anyone wants anything off you, you should charge them for it...”*

Male C2D 22-30 North West

Among the minority ethnic groups, African and Afro-Caribbean people expressed doubts about their communities’ willingness to donate samples. This appeared to stem from a different view in relation to donation generally. Their culture discouraged the passing of blood or tissue from one body to another, and the removal of organs from dead bodies, which were expected to be buried intact. Younger members of these minorities felt that among second-generation immigrants attitudes had changed, but they were still aware of the traditions.

*“I think you’ll find that black people tend not to. They tend not to want to donate anything, from sperm to whatever.”*

Indian Hindu Female 18-21 SE

*“My background as an African...your body is used after dying for research, we don’t believe in that. We believe you get buried as a full person.”*

African Male 22-30 SE

*“Our African ancestors, they would never pass blood from one to another.”*

African Male 22-30 SE



The general assumption was that the request for a sample would come from the GP unless the potential donor was in hospital for other reasons. The likely response to a GP asking for a sample would be accepting: if the GP says the research is *bona fide* and worthwhile, this will be enough to convince most people. GPs were generally regarded as trustworthy, though it was acknowledged that some people have a poor relationship with their GPs.

*“If I asked the doctor I would trust his answer.”*

Female C2D 31-45 SE

A few said they would feel happier dealing with hospital doctors in this context because hospital doctors would be better informed about the research for which the sample is wanted.

*“I would trust a hospital doctor far more than a GP because they have to know so much about so many things...I would feel happier in a hospital where they know what they are doing.”*

Female C2D 31-45 SE

#### 4.8 ***The decision-making process in donating samples***

For most of these people the decision-making process was an abstract consideration: they had to imagine how they would feel if asked to donate. Across the sample there was little sense that decisions on donating samples for research would require much consultation with others.

Some respondents, particularly those with diseases, relatives of those with diseases and regular blood donors did not see giving samples for research as a significant decision. They were accustomed to the idea of donating material in some form for some purpose, and depending on the intended use of the sample, they were likely to do it without much thought.

Others had not thought carefully about being in this situation but often gave the same impression - the decision-making process would not be protracted and would not involve other people.

*“I wouldn’t bother, they could just have it. If it isn’t me they will get it from someone else so it may as well be me.”*

Female C2D 31-45 SE

*“I wouldn’t see it as a big thing. I don’t think I’d talk to anybody about it, I’d just go and do it.”*

Indian Hindu female 18-21 SE

For some this was because it would not be a major decision: on the assumption that it would involve only a small quantity of blood whose loss would not have any physical effect, there would be no need for discussion. For others it was a private issue which would not concern anyone else, even close family. In this respect donating samples was considered very different from becoming an organ donor, which almost invariably involved discussion with or informing of family members.

The tenor of comments made at this stage suggested that many respondents did not think through carefully the implications of donating samples. Many unquestioningly said they would donate when the issue was put to them in a research situation, but in reality they might behave differently if asked for a sample.

#### 4.9 ***Donation of biological samples by children***

The issue of taking samples from children was discussed briefly but was not explored exhaustively, and not considered in relation to the proposed sample collection.

The need to collect samples from children was largely understood, but many parents had reservations about children being used for samples. They were aware that there are certain diseases that affect children in different ways and need investigation using samples. The possible benefit of new discoveries about diseases that affect children could be compelling.

*“Children don’t like needles but I would still let them do it, I really would, in the hope that something good would come out of it.”*

Relative of patient with mental health problem Midlands

In spite of the acknowledged end benefit, few felt at ease about the prospect of their children being used for samples. The use of children’s samples was regarded as significantly different from using adult

samples, principally because there was more concern about the physical and emotional effects of taking samples on children than on adults. For parents this was a more difficult area than making donations themselves; taking samples from children was a far more emotive issue. In a general sense children were regarded as more vulnerable; parents, especially mothers, can feel uneasy about things being physically taken from their children. More specifically, they were concerned about the probable pain that children would suffer when samples were taken, particularly if this involved needles. No one wanted to put children through pain without good reason.

*“I would find it difficult, they are so innocent and you don’t want them put in any situation they don’t understand.”*

Female BC1 22-30 Midlands

*“Having blood taken from children is really very distressing, it’s a major trauma. I don’t know if you’d get children willing to do that.”*

Relative of patient with physical disability North West

Some parents said they would feel happier about the idea of samples being taken from a child already ill in hospital than the prospect of volunteering a healthy child: if the child was already in some discomfort he or she might not suffer much more from a sample being taken.

Consent was also thought a more important issue in relation to children’s samples than for adults. Most parents assumed that parents would be asked for their consent to samples being taken from their children as a matter of course. They also imagined that at some stage the children themselves would have to be asked for consent, but there were mixed views on the age at which children could take the decision themselves. This was complicated by differing views about when children would be sufficiently aware and responsible to decide, and differences in children’s degree of development.

*“I think the child would have to be old enough to know what is going on and that it is giving a sample.”*

Female BC1 61-75 Scotland

*“A child would be so frightened...I wouldn’t have taken my child along to a doctor and said ‘take a sample’.”*

Female BC1 46-60 SE

It may well have been that this concern was exacerbated by unspoken fears stirred up by Alder Hey: the subject of children being used for medical research in any way at all had been tainted, and made parents feel more protective towards their children.

## 5. **Overall response to the proposed WT/MRC sample collection**

Awareness of the proposed sample collection was very low among all sectors of the general public sample. Virtually none had heard anything about it. One respondent was aware of the sample collection in Iceland; she had read that reaction among doctors in Iceland had been negative. Otherwise the subject and its implications were entirely new to these people.

Initial response to the idea in principle was largely favourable. When presented with a brief outline of the proposal, most of these people were broadly accepting and some were actively approving. However it was evident that first reactions were often unconsidered and did not take account of all the implications of setting up the sample collection. Respondents tended to express acceptance of the idea without thinking it through.

Reactions varied between different sample segments. It emerged that men accepted the idea of sample collection more than women and were less likely to express resistance to volunteering. There may have been an element of male bravado and posturing in men's attitudes. There were also differences based on personality and outlook on life: some people with a generally relaxed attitude to life and health said they would have no concerns if asked to volunteer; others seemed more anxious by nature and were more disposed to see problems in the idea.

People with diseases were typically more supportive of the project than most of the general public: they regarded it as potentially highly beneficial to medicine in general, and felt it might have long-term benefits for themselves. For some it was overdue but nevertheless welcome: it showed that someone was determined to make a real effort to advance medical research in the UK.

*“I’d just agree with it. More so because we’ve got so many...we’ve got three diabetics in our family, two cancer patients, two people who have suffered with depression. That’s why I would be all for it.”*

Relative of patient with mental health problem Midlands

A few respondents said that they accepted the idea of the sample collection in principle, but could not consider volunteering because they were squeamish and frightened of needles.

After the initial cautious acceptance of the idea, subsequent discussion of detailed features prompted some concerns. When information gaps were filled, overall perceptions generally became more favourable again. The value of explanation and information was also apparent in relation to specific features of the sample collection. Some details prompted concern and resistance, but if there was a plausible reason for them, they tended to be accepted.

*“It’s scary not knowing what’s going to happen. If the government or the doctors or whoever was up front about what they’re actually doing with it, everybody would be more willing, but keeping it hush-hush...you begin to think, ‘What’s going on?’”*

African male 22-30 SE

Several issues raised immediate questions and concerns. People expected to be told which organization(s) were behind the idea, and specifically whether it was a commercial or publicly funded initiative, whether the intention was to make money from the samples and who would control the sample. These questions prompted suggestions for an independent controlling body to oversee the sample collection and its use.

*“Is it one company asking for this or what? Is it a bank that people can go to?”*

Female BC1 46-60 SE

*“I think the answer depends on who are ‘they’ and why do they want it?”*

Male C2D 46-60 S Wales

*“That kind of amount of people, somebody needs to control it independently to make sure that proper measures are introduced so that they take care of what they have extracted and used it in a proper manner.”*

Female C2D 18-21 North West

*“There has to be an independent body that is not paid for by the people that are doing the research, making sure it is used to investigate diseases and things like that, and the more common ones like cancer, and it is not used for cloning.”*

Female BC1 22-30 Midlands

*“It would be a good idea if there were some sort of watchdog body, that ensures that this research is used for the things that people want it to be used for. Some sort of inspector.”*

Male BC1 18-21 SE

There were also requests for information about how the samples would be used. Respondents wondered what type of research the samples would be used for, especially if it was genetics research, what diseases would be researched and what feedback would be given to donors.

*“I’d like to know the diseases they were looking into.”*

*“And what it’s not going to be tested on.”*

Male BC1 22-30 North West

*“I’d want to know about the research, how successful it was, the facts and figures on it when they’ve done the research into it, rather than them not telling anybody about it.”*

Male BC1 22-30 North West

*“Would there be any comeback on people’s blood samples if they found anything or would they come back to those people? There is lots of questions isn’t there?”*

Female BC1 31-45 S Wales

Questions were also asked about the time period of the exercise and the storage of samples, and the implications of keeping the samples for long periods. Specifically respondents wanted to know how long the sample collection was planned for, how long the blood samples would last, whether DNA would be taken from the blood samples, and how the samples would be disposed of.

By the end of the discussions and interviews, these questions had largely been answered and most respondents’ reservations allayed. The impression was that the more information is given to potential donors at the first point of contact or communication about the project, the more favourable the response is likely to be.

*“Thinking they want the samples from half a million people, you think ‘Why?’. But if you actually know the age group of the people and the reason why [the samples are wanted], you think that probably sounds about right. It makes you go from being fairly sceptical to ‘yeah, maybe so’.”*

Male BC1 22-30 North West

*“As long as the aim of the research is communicated openly, accurately and clearly – it has to be honest and the information given has to be clear. If people volunteer themselves they need to be able to make an informed choice.”*

Indian Hindu female 18-21 SE

It was also apparent that if initial impressions are not favourable, they will be difficult to overcome. If reservations outweigh support for the project it will not be easy to persuade people to reconsider.

## 6. Response to specific issues

### 6.1 *The use of DNA*

For many people the intention to extract DNA from the samples was puzzling or worrying, and prompted demands for explanation. Some were so concerned by the reference to DNA that they anticipated rejecting an invitation to volunteer if approached.

*“If you said they were just going to take a bit of blood for research, fine, but if you start saying ‘from which DNA has been extracted’, then you start thinking ‘What’s this for?’”*

Female BC1 46-60 SE

Knowledge of DNA was invariably partial and often inaccurate. There was some understanding that DNA is virtually unique to each individual and that for this reason it can be used to identify people, but little was known about its value in research on diseases or other genetics issues. The belief that it can be used to identify individuals worried some if it was a central part of the sample collection.

*“Like credit and debit cards when you go shopping, somebody can already see what you eat, what you drink, how often you eat it, how often you buy it, now they are going to have strands of your DNA as well. Like they know you inside and out quite literally.”*

Female C2D 18-21 North West

*“I don’t want them to have my DNA in their bank, because it’s like your code. For whatever reason, I’m not saying I’m a good person or a bad person but I don’t really want them to be able to identify me. Who are these people that are going to keep hold of this and for what reason? Why would they want it?”*

African male 22-30 SE

In addition to this, DNA had unsettling associations, largely derived from news stories and TV/film fiction. To many people mention of DNA prompted references to criminal investigations, the police, miscarriages of justice, cloning and 'Big Brother'.

*“Once they have got your DNA you are in a Big Brother situation really, anyone could hack into the computer they store your information on.”*

Female C2D 31-45 SE

*“Once they have got your name and DNA you are known aren't you?”*

Female C2D 31-45 SE

*“Also, what if they made a mistake? Say they think I've done something dreadful?”*

Female BC1 46-60 SE

*“They cock up so many things, they can't always be 100% sure and you might get blamed for something.”*

Female BC1 22-30 Midlands

Given its assumed potential to 'barcode' individuals, there was some belief that in the context of the proposed sample collection, using DNA could open the door to less acceptable, more sinister uses of samples in the future.

*“You know how they've been going on about having a copy of everybody's DNA to help solve crimes and things like that, and when there have been crimes they've asked people to give blood so that they can get the DNA to try and match it. If you want to be cynical you'd think that's just a way of doing that.”*

Male BC1 22-30 North West

*“It could be like a Big Brother state like in 1984, where you've got DNA records of every person in the country. I think it's an invasion of privacy.”*

Male BC1 22-30 North West

*“You start thinking DNA, chromosomes, genes and stuff. If they take my genes, what if I find a clone of myself ten years from now? If you saw that they wanted to take your DNA you'd think what do they want my DNA for?”*

African-Caribbean female 46-60 Midlands

There was also a belief, or suspicion, that if DNA makes it easier to identify a blood sample, this could undermine attempts to make information anonymous. The thinking here was that someone involved



in the sample collection would be able to link a sample and the accompanying information to identify the donor.

*“If they want someone for a crime and they have got their DNA in the data bank, there is the thing that if you have done something wrong they breathalyse you and...”*

Male C2D 31-45 Scotland

A particular worry for some of those from ethnic minority communities was that reference to DNA could discourage people from volunteering if they were worried about their immigration status. Again the issue was that DNA can be used as a means of identifying individuals and so might be abused.

## 6.2 The need for information about volunteers

The need for volunteers to provide information about themselves caused some concern, partly based on misunderstanding of why it might be needed.

The rationale for collecting information was understood by some respondents, especially people with diseases. However, many were initially surprised and puzzled by this request. On first sight there was no obvious reason why individual information should be needed, and without explanation it prompted worries that the researchers would be ‘checking up’ on volunteers. This was a particular worry for some minority ethnic groups who were concerned that it could involve, or lead to, checks on their residency status in the UK.

When the rationale for gathering information on donors was explained, worries tended to dissipate. It was clear to most respondents that information on individuals’ lifestyles and the environment in which they lived could help researchers understand how these factors affect health, and could add considerably to the value of the samples.

*“On your current health, it depends on your lifestyle and environment anyway. I mean...if your lifestyle is such that you are out every weekend with everyone in town, you kind of put yourself open to diseases don't you? It is there, so your lifestyle and environment is your health.”*

Male C2D 31-45 Scotland

*“They could say ‘right, these samples are from factory workers, these are from office workers, these are from outdoor workers’, and compare them all.”*

Male C2D 61-75 Midlands

*“I think environment and lifestyle have a lot to do with illness. In terms of what you do for a living, where you work, the sort of things you handle, stress, which area you live in.”*

Female BC1 31-45 S Wales

The request for information about environment was largely uncontentious, though it needed some explanation. Few people had reservations about giving details on their home and local environment.

Information on lifestyle was more problematic, especially among young people, and some minority ethnic groups. These people were particularly concerned about answering questions to do with their leisure activities if, as they assumed, this included sexual activity, drinking, smoking and use of illicit drugs. Requests for this sort of information came across as intrusive, and worrying if there was a risk that it could be accessed at the point of contact – the GP surgery.

*“I don’t mind them having my blood but then I’ve got to answer all these questions and tell them everything about myself and who’s going to have it...I mean giving blood nobody knows anything but when I write down and tell them everything about me, I want to know who wants to know.”*

Male C2D 61-75 Midlands

*“There are some things...like being a Hindu it’s quite difficult to come out and say ‘I’m sexually active’ without someone thinking...If you tell your GP and he’s going for dinner with your mother or something, and you don’t want her to know you’re sexually active, it sort of puts the spanner in the works doesn’t it?”*

Indian Hindu female 18-21 SE

It was also sometimes suggested that this information might be inaccurate: some respondents believed that people rarely tell the truth if asked to describe their lifestyle, particularly in relation to sex, alcohol, smoking, and even diet and exercise.

*“How honest would you be? The GP would be totally honest wouldn’t they? But you’d worry about your weight, smoking, drinking, everything.”*

Female BC1 22-30 Midlands

There was more concern still about the need for access to individual medical records and information on current and future health. This was often regarded as too intrusive: information of this type was considered confidential and passing it to unknown researchers seemed an invasion of privacy. Medical records tended to be regarded as having a unique degree of confidentiality. If any information about an individual was well guarded it should be medical records. Allowing medical records to be seen by other people, whatever the purpose, would violate their status.

*“I wouldn’t be happy. I think medical records are private. Fair enough if you’ve come to the decision that you don’t mind them checking into our records, but it’s a personal choice and I wouldn’t want anybody being able to have access to my medical records...”*

Male BC1 22-30 North West

*“You are one of say a hundred from that surgery and that would be enough to identify you. Not everybody wants their personal records available to everybody...”*

Male C2D 31-45 Scotland

*“For years and years we’ve known that our medical records at the doctor have been private and confidential and then all of a sudden you’re saying...he’s going to give out everything that’s on your card.”*

Female BC1 61-75 Scotland

For some, confidentiality was not an issue: they were not concerned about guarding the privacy of their medical history, and felt that records were anyway probably accessible to anyone who really wanted them.

*“You are only bothered if you have something to hide. If you do, you’re not going to volunteer to do it anyway are you?”*

Female C2D 18-21 North West

*“I personally wouldn’t have a problem with that, if they’re not just looking at having a big stock of blood to use – but if you’re answering questionnaires and they’re looking at how your lifestyle and your environment affects whether you’re more prone to some diseases than others...If they know that so many people have asthma and realise that where I live affects this that and the other, that would be fine by me.”*

Male BC1 22-30 North West

*“I would do it because I would think maybe someone can benefit from my information.”*

Female C2D 31-45 SE

This was also true of people with diseases. They understood the need for medical records and other information, and had no concerns about

anyone knowing this. They tended to feel that their health problems were already out in the open, and that there was nothing more that could be found out about them.

A more detailed, operational problem to do with collecting information was the reference to a questionnaire to gather it. Some respondents, some of whom perhaps had literacy difficulties, said they disliked filling in questionnaires and thought this could be a barrier to them volunteering.

*“I hate filling in forms...When they send you those great big questionnaires, I think ‘why should I?’”*

Female C2D 31-45 SE

*“That puts you off a bit, if you’ve got to answer a load of questions first.”*

Female C2D 18-21 North West

### 6.3 **Storage of information and confidentiality**

Respondents were told that information gathered on volunteers would be stored on computer. Though this was largely expected, confidentiality was considered a significant issue in light of the need for personal medical information along with the samples. Women seemed to have more reservations about this than men, particularly in relation to medical records. Some were seriously concerned about confidentiality and felt that their worries about it might discourage them from taking part if approached. They felt that technology increasingly means personal information easily obtained by people who should not have access to it.

*“People just don’t like people to know so much about what is happening in their life. It’s like with everything, even with your friends, if you tell your friends something you don’t expect it to go anywhere else. It’s about that whole personal space and people knowing.”*

African male 22-30 SE

*“These days you’ve only got to give your surname and your postcode and they’ve got your address and your bank details and everything.”*

*“And your blood group!”*

Female BC1 46-60 North West

*“You can get into any computer...I don’t trust them.”*

Female BC1 61-75 Scotland

At a more specific level they imagined that no matter how well encoded, the information could be accessed and decoded by someone really determined.

*“That’s the thing, most of the records are not on paper any more, it’s all on computer and there’s plenty of kids out there, bright kids, that can hack into anything they want so somebody else can hack in and sell information. There’s no way they can safeguard it.”*

Male C2D 46-60 S Wales

*“As soon as you’ve given a name out, that’s it. There’s always somebody that will do something for a price. If someone wanted that information, they could get hold of it.”*

Male BC1 18-21 SE

*“These insurance companies have been known to pull information from GPs, phoning up for health information, and they’ve been given it just like that.”*

Indian Hindu female 18-21 SE

For others it caused little worry, for several reasons. Firstly, they felt that if information is properly encoded or encrypted it will not be accessible to people unauthorized. Secondly, they felt they had ‘nothing to hide’. There was no worrying information about them that could be known to researchers. And they imagined that this sort of information was already available – that medical records are probably accessible to people who want them, legitimately or otherwise.

*“In a position like this there wouldn’t be names, I think, more like numbers, it would all be coded, so if any one of us hacked into it you wouldn’t know who they were talking about.”*

Female BC1 31-45 S Wales

*“What’s the difference between telling a doctor and somebody using the blood to do that? Somebody already knows your medical history anyway. Your doctor does.”*

Male BC1 22-30 North West

*“Someone has only got to go in and give your medical number and they can get access as well, or hack in, there are lots of ways...”*

Male C2D 61-75 Midlands

More generally, they rationalized that it was futile to worry about access to personal information, because the police have access to information via vehicle registration numbers. There is already easy access to personal information by means of postcodes, and anyway, computer

hackers are more interested in the challenge of hacking than in the information they find.

Worries about accessibility of personal information tended to dissipate a little when the rationale for gathering information was explained: once it was clear that the samples would have considerable additional value if accompanied by medical records and other information, this feature was more acceptable.

#### 6.4 ***Specific concerns about confidentiality***

Initial worries about personal medical information were often vague and unfocused. The main concern was the general issue of information being available to unknown people or in the public domain.

However, there were some unprompted references to information falling into the hands of certain organizations that might have specific abuses of information in mind – employers, insurance companies, direct sales companies and doctors.

*“I mean you fill in a special form and sign the data protection act form, you can get that information, they will tell you whether or not that person has been in trouble before, you know, big insurance companies, financial institutions, they do it, you go for a job they will contact the police...”*

Male BC1 22-30 North West

*“The positive side is we can have a healthy nation, we can have a health check on everyone in the country. The downside is that it could be used for insurance companies just for a check up that nobody’s trying to con them...”*

Male C2D 46-60 S Wales

*“It could jeopardize your job situation if they know things about you that could be looked at in the wrong light, it could jeopardize your family life, marriage, and your whole life.”*

Female C2D 31-45 SE

In relation to employers, it was clear that information about past illness or current conditions could jeopardize a current or potential future job. Occasional references were made to instances in which people had lost jobs following employers discovering information about their health.

*“Employers could actually state ‘Right we are loath to take on somebody who has got a history of this’, and if...I have got a heart problem, my son, they may say to him ‘Have you got a history of this in your family?’...employers will be loath to take him on.”*

Female BC1 31-45 S Wales

*“When you apply for a job, there’s that question, ‘Do you have any illness that could prevent you from working’, they can use it to discriminate, like if you’ve got AIDS or cancer.”*

African-Caribbean female 46-60 Midlands

*“I saw a guy on the telly and he had a blood test and they sent it back to his work and his work saw that he had HIV so the guy was sacked...”*

Male C2D 31-45 Scotland

*“If employers knew that you’ve got a deficient gene and that you, there’s a chance that you’re going to lose a lot of time from work or you could even have to pack up when you’re forty, they might not employ you.”*

Male C2D 61-75 Midlands

Against this there was some belief that employment law would discourage employers from abusing this sort of information.

Potential difficulties to do with insurance also prompted worries. Insurance companies were believed to discriminate against people with certain illnesses and refuse them insurance. And they were believed to deny liability if a disease came to light after a customer’s death.

*“When you’ve passed away and then they’ve gained access to your files to make sure that you had a disease that they’d not been notified about when you took out your insurance, they might nullify it and leave your family without the insurance that you’ve taken out and been paying into for thirty years.”*

Male BC1 22-30 North West

*“Someone might not want to give you a mortgage or insurance if you’ve got something in your blood that shows you might get an illness.”*

Female BC1 46-60 SE

*“Maybe if they knew that you had a disease, you only had a certain amount of time to live, they’re not going to give you life insurance.”*

African-Caribbean female 46-60 Midlands

There also seemed to be a feeling that insurance companies are both less closely regulated by law than employers, and less likely to be sympathetic than employers in the event of illness.

*“Insurance companies are as devious as the next company, they are all big sharks in a big pond and to get ahead of the game they do whatever they want to...”*

Male C2D 22-30 North West

A few people believed information could be passed to direct sales companies working for pharmaceutical or other health-related businesses. They imagined that information on individuals' health could be of value to businesses which might target people with promotions offering drugs or treatments.

*“If drug companies know your name and what you've got you're going to be bombarded if they suddenly find something they think will help you.”*

Female BC1 46-60 SE

It was occasionally suggested that if medical records are on computer, this might allow access to other GPs, who could use the information in decisions on whether to take on people as new patients.

## 6.5 **Consent**

Initial discussion of consent prompted little comment. It was taken as read that anyone approached to take part would be asked for their consent for samples and information to be taken and used. No one imagined that samples would be taken without consent, and assumed that this would be accompanied by an explanation of how the samples would be used.

However it was clear that many members of the public gave little thought to the implications of consent. They tended not to consider the possible definitions of exactly what volunteers would be consenting to, the period for which consent would apply, the possible need to secure repeat consent for future use of samples, or the ease of withdrawing consent in the future.

When these aspects of consent were raised they were regarded as important and it was clear that they would have to be addressed in drawing up an appropriate form of consent.



*“You’d want to know for sure what this research is all about before you go and take that step. You’ve got to know because they’re going to know everything else in your life from when you sign that piece of paper.”*

Male BC1 22-30 North West

*“There should be a way of saying ‘I don’t like what you’re doing, I want out. I want my records to myself, you can’t use them any more’.”*

Male BC1 18-21 SE

## 6.6 **Nature of research conducted with samples**

This was a crucial issue, though attitudes depended to a large extent on existing knowledge of genetics research. Most members of the public felt that willingness to volunteer would be tied in part to the uses made of the sample and associated information.

The general expectation was that research would focus on diseases. If this were the case, there was widespread and ready approval for the idea, and especially if the diseases are high profile conditions that affect large numbers of people, such as cancer, heart disease, multiple sclerosis, cystic fibrosis, asthma and diabetes.

*“If they came to me and said ‘We are trying to look into cancer’ I would go for it, I can understand what they are talking about and I would agree to go every six months and so on but when the end product is so unknown I wouldn’t be as happy.”*

Female BC1 22-30 Midlands

*“Diseases like MS and cancer and things like that. The common cold and flu. Not wacky things like way out things, like grafting an ear onto something.”*

Male BC1 18-21 SE1

If the intention was that some of the research would be on more general work to understand the human body, this was acceptable but less motivating.

*“I think you would get a better reaction if you told people you were taking samples for something specific...Rather than saying ‘We just want to collect blood for some general research’.”*

Indian Hindu female 18-21 SE

Some possible uses of the sample and information caused more concern. A few people were aware that genetics research could be

used to address certain mental or psychological conditions, or traits, particularly criminal behaviour, or IQ levels. If this were to happen with the proposed sample collection, they felt this would be a misuse.

*“I think testing genes for IQ is beyond the cause. It’s taking it too far.”*

Male BC1 22-30 North West

*“What about if there’s a gene that makes you a thief or whatever? Weed all the thieves out. It’s just open to so much abuse if it’s not properly organized.”*

Female BC1 46-60 SE

There was also a belief that genetics research could be used to help prevent the incidence of certain physical disabilities. Although most people had no worries about this, some expressed unease about it, and felt that it could prompt reservations about taking part. At the extreme there were some people who imagined that, at least in theory, samples could be used for a variety of dubious purposes.

*“Biological warfare research, you never know, they might ship them off down to some secret laboratory and start testing all different germs and viruses on it. You wouldn’t want it used for stuff like that.”*

Male BC1 22-30 North West

*“I’d want to know that it wouldn’t fall into the wrong hands. I’d like to make sure that it’s not used by extreme right wing groups.”*

Indian Hindu female 18-21 SE

A few members of the public had a much more relaxed and uninvolved attitude to use of samples. They felt that once samples had been taken they would have no stake in how they were used, and seemed to trust the researchers to use them properly.

*“If they can do something with the blood they take out of me, well good luck to them. They’re far cleverer people than I am so why should I object to their doing it?”*

Male C2D 61-75 Midlands

*“I wouldn’t give a second thought once they’d taken it...Once it’s left my body they can do what they like with it.”*

Male C2D 31-45 Scotland

## 6.7 ***Future use of samples***

This was less easy to explore, largely because it was difficult to give examples of future uses, and because some people had problems understanding the issue. Some understood that the pace of developments in medical technology mean that it is impossible to know how samples might be used in the future; others were less clear about this.

At first there was concern about the types of possible use of samples. If there was no knowing how they were used, there was potential for abuse. On further consideration, it was generally accepted that unknown future use was inevitable and that the problem could be surmounted if future use was made explicit at the outset, and if consent was made conditional on this. The example of research carried out on a specific condition or disease that became prevalent in the future, such as HIV, made this feature more acceptable.

The likelihood of unknown future use prompted further discussion of consent. Some respondents felt they would want repeat consent in the event of their sample and information being used in new or different ways – ideally on each occasion.

*“I mean one sample might be used to find out about MS or whatever and then the following year it might be used to find out about AIDS or CJD or whatever...every time it is changed then you want to be informed about it.”*

Male C2D 22-30 North West

*“There’s got to be communication between the body that’s doing it and individuals that have given the blood, with the option of opting out. If they sent you a letter saying ‘We’ve now looked into this and it’s possible that the blood you supplied is going to be used to look into this’.”*

Male BC1 22-30 North West

Others were less worried about consent in this context. They felt it would be impractical to approach donors every time a new research technique was used on the samples, and thought that a catch-all consent statement to cover all future research approaches would be sufficient.

## 6.8 ***The GP and practice nurse as points of contact and sample collection***

There was general acceptance of the GP as the main or initial point of contact. Trust in GPs varied depending on age and relationship with their own GP; but on balance most people felt they would believe what their GP told them about the sample collection.

Positively, the use of GPs as contact points was expected to lend credibility and status to the project: it would communicate to potential volunteers that this was an important and worthwhile exercise. The involvement of GPs would also signal that it was safe to take part in the sample collection: the taking of samples would be done properly, the samples would not be misused, and information would not be given to anyone who should not have it.

*“My feeling is that if they said it was medical research, my doctor would obviously feel it was needed and I would trust him.”*

Male C2D 61-75 Midlands

There was also an element of convenience in the GP or nurse taking samples. If the donor was already at the surgery it would be simple to take blood from him or her.

*“I think it would be a good idea...when you go to a doctor’s surgery as a matter of course, if he could collect the sample. If you give blood so they can check for diabetes or arthritis and he takes an armful of blood...he might as well take another armful of blood out of me and give it to this research company...”*

Male C2D 46-60 S Wales

It was occasionally said that using GPs to recruit volunteers could be limiting. It would exclude those who were not registered with a GP, and those who did not visit a GP often would be unlikely to respond.

Exceptions here were some minority ethnic groups - Africans and some Asian Muslims – and a few younger people, who had reservations about their GPs. They were not sure they would trust GPs to give them all the information they wanted about the sample collection, or to give accurate answers to queries. Also, some feeling emerged among those

who were less well disposed towards GPs that doctors might pressurize people into taking part against their wishes.

*“If you’ve got a strong enough personality, all right. But you get a lot of feeble people who look at the GP as someone up there, and if the GP says ‘Will you do this?’ they might consent to it on the spot where really if they’re given a chance to go away and think about it they might not.”*

Male BC1 22-30 North West

Discussion of GPs recruiting volunteers also prompted questions about selection of donors. What sort of people would be invited? Only healthy people or those with specified diseases?

A few people wondered whether GPs’ involvement would take up too much of their time and create longer waiting lists for appointments.

*“As long as you’re not waiting three hours. If you have got a 12.30 appointment you will be cross if they keep you very long.”*

Female C2D 31-45 SE

The idea of a specially appointed nurse being involved in collecting samples and information was generally accepted; practice nurses were known to take blood for tests and it was logical for a nurse to take samples. The involvement of nurses also allayed concerns about the impact of the sample collection on GPs’ time. The only reservation about nurses was whether they would have the background knowledge to answer all queries about the sample: GPs were expected to be better informed.

## 6.9 ***Feedback from the research***

### *Personal information*

This seemed potentially one of the most difficult issues involved in setting up the sample collection, and one of the least easily resolved. The general feeling here was that volunteers should be given the option to be informed about any disease or condition that came to light in the course of the research. It seemed right that if someone somewhere knew something about an individual, even if not identified, that individual should have the right to be told.

*“If it happens that you’re just testing someone for blood and he’s got a disease, I mean you’ve got a right to know haven’t you? You just can’t ignore the fact that someone’s got a disease that they don’t know about.”*

Female C2D 18-21 North West

Personal feedback was also seen by some as a *quid pro quo* for taking part in the sample collection: if people were voluntarily donating samples it was only fair to give them information that came to light about themselves as a result of the samples being used.

Views were mixed on the wisdom of agreeing to hear bad news that emerged from samples. Most of these people imagined they would want to know if it became apparent that they had a disease. Though it would be unwelcome news, it would be preferable to hear it earlier rather than later. It would allow more time to prepare for the outcome, and the more warning the better.

*“They may have picked up something that you wouldn’t have found out about for six months or nine months which might have been too late.”*

Male C2D 46-60 S Wales

*“I would like to know...because my father’s brother has had a full heart transplant and my father died at 31, so I mean I would like to know whether or not it is in the family...”*

Female BC1 31-45 S Wales

Others felt they would rather not be told bad news. If they were discovered to have a serious disease, or if the information was about their likelihood of developing a serious disease, knowing this would only have a negative effect on them. Some suggested the sensible solution would be to inform people if the disease was preventable, but not in other circumstances.

*“What do they do if it gets to a point where they see your blood and they think ‘This person is likely to get this disease’? Do they contact you and put the fear of God into you?”*

Male BC1 18-21 SE

*“If it was preventable then it would be a good thing to know.”*

Female BC1 46-60 SE

*“They could have it where they could definitely tell your GP if it was a really important thing like a nasty disease or a genetic thing whereby your children might inherit it, and your GP might suggest a test for it anyway next time you go, and you need never know if it came from that, so the GP makes the decision.”*

Female BC1 22-30 Midlands

There was also a feeling that this issue would need resolving at the outset. It should be established when the donor agreed to take part whether he or she wanted to be informed about any disease or condition he or she might have. Alongside this, some people felt that a mechanism should be in place to provide support for those who were discovered to have certain diseases or conditions.

*“You should choose when you sign the contract that you’d like to know.”*

Female C2D 18-21 North West

*“I think they should ask you at the beginning – ‘do you want to know anything about this?’”*

Female BC1 22-30 Midlands

*“If I discover I’ve got something what support are they going to give me? If they said my blood is not good enough, why?”*

African male 22-30 SE

The expectation was that GPs would be asked to inform volunteers in the event of their sample showing up a disease or condition. If the GP was the first point of contact, he or she should be the disseminator of information back to the volunteer.

This issue raised some anxieties about confidentiality of information. If individuals could be given personal feedback, this would mean that a clear chain of information must exist. Again this demonstrated the need for strong reassurance about confidentiality or anonymity.

*“It might be necessary to ask your name and address in case they find something in your sample that there’s a cure for or whatever...there must be some way of tracing you.”*

Male C2D 46-60 S Wales

### *Feedback of research results*

Virtually everyone said that if they donated a sample they would appreciate feedback on what the research using their samples had discovered or achieved. This would help sustain their interest and

convince them that their involvement had been worthwhile. A few people with a more cynical view of medical research wanted reassurance that all research results would be made public, whether positive or otherwise.

*“I think that option should be left open to people. They should produce some sort of findings as they do with all big things they do, they produce a paper of findings in a booklet form, if you want to know you can go along to your local library or whatever and read what the findings are.”*

Male C2D 22-30 North West

*“If you knew who the company is and this company's found out something,, something for the general public, you'd be pleased with that wouldn't you? You'd be happy.”*

Male C2D 46-60 S Wales

*“I think they should keep in touch, even if it's a six-monthly newsletter saying this is how the research is going.”*

Male BC1 22-30 North West

*“What would happen if they got a negative result from it? If they didn't get the results they wanted, then they're frightened about publishing these results – then it might worry people. Will they go out and do it or do you think they'll just make it up?”*

Male BC1 22-30 North West

Another aspect of feedback was a general interest in learning about genetically transmitted diseases. The feeling here was that it would be a good thing for the country to have this information available.

*“I think I would want to know...that a certain section of the population was prone to certain things, and that this has been identified. Then the whole aim is for future planning. It's also educative and informative, not just for the government and politicians, but also for the people.”*

Indian Hindu female 18-21 SE

It was generally accepted that feedback would not be available for some time, probably several years, given that scientific research can be a protracted process. Some respondents imagined that feedback would be given out via press stories; others said they would expect a letter or information sheet sent direct to individual donors.



## 6.10 **Organizations involved in the sample collection**

Respondents were not given any information about which organizations were planning the sample collection until near the end of the discussions. Before this was revealed, it prompted much speculation. It was considered important because it would have a bearing on the perceived trustworthiness of the researchers and consequent willingness on the part of donors to volunteer.

*“You’ve got to know if it’s a well established research organization. It’s got to be trusted.”*

Male BC1 22-30 North West

*“If you think you can trust the people behind it then you’ll be happy to give them a sample.”*

Male C2D 31-45 Scotland

Initially it was assumed that the sample collection was planned by either a large commercial organization of some type. This would probably be a pharmaceutical company, a general insurance company or a health insurance company such as BUPA. Or it could be part of government (the Department of Health or the NHS). The size of the proposed sample, and the fact that it was being subjected to market research, indicated that a large organization was involved.

Those who expected it to be a pharmaceutical company thought there was obvious value to pharmaceutical companies in conducting research on human samples, and that these organizations are sufficiently well resourced to fund a large sample collection.

*“It would be someone like Roche who set it up and then would own it. It sounds very much like either the government or a drug company. And I don’t think the government could afford it so I think it’s probably a drug company.”*

Female BC1 46-60 SE

*“Well it’s obviously going to be a drug company. They’re the ones wanting to come up with the cures for various things.”*

Relative of patient with mental health problem Midlands

Those who believed it was the NHS or an arm of government imagined this because it was a large and probably costly exercise, and because there is a case for doing this sort of work for the public good.

## 6.11 **Access to the sample collection and information**

The fact that the sample collection would be owned publicly was thought significant. This implied that it was not being set up to make money, and that it was primarily about the public good. For some people it also meant that the samples and associated information would come under government ownership and control, and that this would mean strict controls over access to and use of the samples.

*“If it’s the government, if it’s the NHS, then they have strict guidelines that they would adhere to.”*

Female BC1 46-60 SE

This assumption was not always made. Some respondents interpreted ‘publicly owned’ as meaning that anyone could have access to the samples. This would need to be clarified in information given to volunteers and the general public.

The fact there would not be exclusive commercial access to the samples and the information raised several issues. For some it drew attention to the fact that commercial organizations could have access to the samples: this was a surprise and prompted some worries about profiting from freely given samples.

*“You’re saying that no company will be allowed exclusive commercial access so a company could be having it, not the national health...It’s becoming commercialized now because there’s a company involved.”*

Male C2D 46-60 S Wales

*“If they did discover a cure they’d have to get some pharmaceutical company to mass produce this cure. Whether it’s done through a charity to start with or not. The end result is that...somebody’s going to make money off it somewhere along the line.”*

Male BC1 22-30 North West

*“I wouldn’t be happy if I knew a pharmaceutical company were going to make money. It is their money and they are trying to find a cure, but they have got to give a little back to the health service.”*

Female BC1 22-30 Midlands

Many people assumed that drug companies would be involved in the sample collection somehow since they would probably fund a significant proportion of the research conducted on the samples. If this

were the case, the fact of no exclusive commercial access offered reassurance that it would be difficult to abuse the sample collection for commercial purposes.

*“So [a drug company] can’t come along and make a killing because every other company can use it as well, so there’s no monopoly on the outcomes of the research.”*

Male BC1 22-30 North West

*“At least if everybody in the public domain, if not just the big companies but the other companies have got the same database...they are all working on the same level...you’re giving them the same shot at it.”*

Female BC1 31-45 S Wales

*“This would be a better way of doing it because if you have one company they might develop a particular drug and then they have the monopoly.”*

Indian Hindu female 18-21 SE

*“Drug companies are going to be involved because researchers work for the drug companies so therefore researchers get access and their information goes to the people that pay them, which is the drug companies. If you say no drug companies can have it you are cutting out three quarters of the researchers that there are.”*

Female BC1 46-60 SE

## 6.12 Remuneration

Many people felt that GPs would expect remuneration for their part in helping recruit volunteers and collect samples. They imagined that GPs would regard the imposition on their time and resources as significant, and as only worth taking on if they were paid.

*“If the GP does this then obviously he’s going to be paid for it. We have to accept that because obviously it has to be done somewhere, but...they’re eventually going to get a great deal of money out of it.”*

Indian Hindu female 18-21 SE

The prospect of volunteers being paid prompted some debate and varied opinion. Younger people often assumed that volunteers would be paid for their time and their contribution and felt this was only right. Payment was thought particularly appropriate if the samples resulted in research that generated income for commercial organizations.

*“If there’s no money in it, then no. If there’s some cash in it then I’d think about it.”*

African male 22-30 SE

The subject of payment for participation was related to pharmaceutical companies’ access to and use of the samples and information. If pharmaceutical companies are to be allowed access, should they pay for this if they stood to gain from it? And if so, should volunteers be given remuneration derived from payments made by pharmaceutical companies?

*“I think you should definitely get paid for it. If it’s definitely for research, because say the research does come up with a new drug, then that drug will get paid for, somebody like [a drug company] will be making millions and millions of pounds. If they’re making millions of pounds off drug research off blood you’ve given, then you ought to get some money out of it.”*

*“Not only that, but these doctors will be getting paid for asking you.”*

Male BC1 22-30 North West

*“There could be a clause written into the contract that if a commercial company does make a profit out of the research or make a drug that makes money, then that donor gets a percentage as royalties.”*

Male C2D 46-60 S Wales

*“They are looking for volunteers for blood for testing on certain drugs, are they prepared to pay a certain amount? Obviously they are making vast profits, they should be prepared to share some of their profit with the people who go to the surgery.”*

Female BC1 31-45 S Wales

*“If it does come out that your blood does do that magical cure, I think you should get something back for it.”*

Male BC1 22-30 North West

Another aspect of this was the use made of money paid by commercial organizations for access to the samples and information. Should these payments be used only to fund the sample collection? Or should they be fed into the costs of running the NHS, or lowering the price of drugs sold to developing countries?

*“I think it would be a good idea if these companies that are wanting to produce (drugs) donated money to the Wellcome Trust and the Medical Research Council to give them enough money to do more research into other diseases in other areas.”*

Male BC1 22-30 North West

*“That’s OK because if companies have access they’d obviously pay for it and that would help continue the funding.”*

Female BC1 46-60 SE

Others, more often older age groups, believed strongly that if the samples were collected primarily for the public good there should be no payment to volunteers. In this respect the sample collection was regarded in the same light as blood donation – as a free gift from individuals to help others.

*“I don’t think cash would be a motive for anybody. I don’t think it would be good if they decided to introduce money.”*

African male 22-30 SE

*“I wouldn’t expect to be paid. If I volunteered I would presume I was doing it for nothing, for the good of the country.”*

Male C2D 61-75 Midlands

### 6.13 ***The Wellcome Trust and the Medical Research Council***

Awareness of the Wellcome Trust was scattered. Among those who had heard of it, the Wellcome Trust was often confused with Glaxo Wellcome. Where it was known as a medical charity, it was believed to be a major funder of medical research. Among those who did not know of it, its status as a charity significantly enhanced perceptions.

Awareness of the Medical Research Council was lower. It was assumed to be a professional public body, probably akin to the BMA. Beyond this, little was known about it.

Together the two organizations were believed to add considerable credibility to the proposal, and implicit reassurance that the samples and the research would be conducted with propriety.

*“One would hope that their interest is more altruistic than most drug companies.”*

Male BC1 18-21 SE

*“If it’s basically a government or a charity set up and the spin-off would be anything they found could be used by commercial companies as long as the commercial companies reimbursed the charity...then I think that would suffice for a lot of people.”*

Male C2D 46-60 S Wales

## G. Findings – GPs and practice nurses

### 7. Contextual issues

This was a small sample - four GPs and four practice nurses – and was included to give an impression of the kind of opinions that might be evident among the medical profession. It was not intended to be a definitive study of doctors' and nurses' attitudes.

These respondents believed that most patients saw GPs as their main source of medical advice and that practice nurses were regarded as a useful supplementary source. They felt that patients increasingly gleaned additional medical information from elsewhere, particularly magazines and the Internet, and that some patients trusted information from such sources as much or more than that from professionals.

*"Magazines have such extensive medical sections in them. A lot of women bring them in and show you. Woman's Own and magazines like that have quite a lot of medical articles. They often come in with clippings to show me."*

Practice nurse

Reports of attitudes towards health varied from area to area. GPs and nurses in poorer regions said that their patients tended to be more fatalistic, and were less proactive in looking after their health. They were more likely to drink and smoke, and less likely to watch their diet. As a result, health promotion was a large part of professionals' work.

*"A lot of people are fatalistic. They wait for something to happen and then they treat it. You see (it) a lot of times in surgery, they don't come in until it's almost too late."*

Practice nurse

Those in more affluent areas said that their patients tended to take a greater interest in their health and were more knowledgeable about it. This group was said to be more likely to search for information from sources other than GPs and nurses.

All the GPs and practice nurses saw their role as being wide-reaching. As well as treating illnesses, they spend time counselling patients and dealing with personal problems; the two functions were thought to be closely linked.

## 8. Knowledge of and attitudes towards medical and genetics research

### 8.1 *Medical research in general*

The sample was devised so that GPs and practice nurses had varying degrees of involvement with research. In practice the difference between those involved and those not involved in research was indistinct: all but one GP and one nurse had been involved in research (mainly drug trials) at some time in the past, and all GPs had at least been approached. One GP and one practice nurse were involved with medical trials at the time of interviewing. Those not conducting research often said this was chiefly because of time constraints.

*"We've collected for trials but not genetic ones. Drug trials, pre-launch to see the benefits. It involved patients coming in, volunteering, and giving informed consent. We had to explain the various discussion documents, get ethical committee approval. We've not been involved in much recently because we felt that we were far too busy with other things. I've not been involved for two or three years."*

GP

Attitudes towards research had some correlation with degree of involvement. Those who were, or who had been, more involved with research tended to be more willing to embrace it *per se*.

***"Do you have any concerns about medical research?"***  
*"No, I think with good patient practice and the safeguards that are now put on us before we can start anything through the local ethical committees, no I think that it's been tightened up and I think things work very well."*

GP

Those less involved tended to be more suspicious of research and the organizations conducting it. They were more likely to question the motivations of researchers, some of whom they believed to be mercenary. These perceived motives made some GPs and nurses reluctant to find time for research.

*"GPs are always wary of research because it's just more work for them to do on top of their daily work."*

GP

*“A lot of the reps would offer to pay for me to do a diploma. They’ll give you whatever, stock your room up if you endorse their drug. Money does tend to speak first.”*

Practice nurse

There was consensus that all patients taking part in research should be made fully aware of what it was about. Responsibility towards the patient was thought paramount, and it was thought unacceptable to make any sacrifices in this area for the sake of the research.

There were varying degrees of interest in the findings of current research among GPs. Some were more discriminating and only read about directly relevant advances. Others were interested in keeping up to date with the broader picture and so read more widely.

*“Do you keep up with medical research?” “I’m very selective, I don’t have time really. We’re exposed to a lot of literature and research in journals. The articles that I would read would be quite evidence-based. I’m limited because of time.”*

GP

Practice nurses were less well informed. They had less say in what treatment patients received, and so had less need and opportunity to keep up with the latest developments. However, they understood that development of new drugs and new medical techniques were the result of medical research. One felt that research was becoming more important to nurses as more emphasis was placed on evidence-based practice, and that this was reflected in its coverage in nursing journals.

*“All I know about medical research is they all make these medicines and then they research and test them out on so many people. They have different practices where they have placebos.”*

Practice nurse

*“Research is really up and coming in nursing as well. Before, research wasn’t much talked about, but now most magazines that you pick up have got some sort of research section in them.”*

Practice nurse

There was a feeling among some GPs and practice nurses that a minority of the general public were hypocritical in their attitude towards research. They were critical of those conducting research, especially big drugs companies, but were happy to enjoy its fruits.



*“A lot of people don’t think about research, they just expect it on the table. They don’t think that there’s an awful lot of research going into this aspirin or paracetamol, it just appears. They don’t think about research. They don’t realize what’s going on behind the scenes.”*

Practice nurse

However, those who had conducted research said also that, when offered the opportunity, many patients were happy to participate in research. For some, altruism was the main motive: they wanted to aid the advance of medical science. It was thought that others were tempted by earlier access to the potentially better drugs or treatments under investigation. It was thought that those who suffered from hereditary illnesses were motivated by the opportunity to help members of their family. Finally, curiosity was thought to be a factor for some: they wanted to be part of the latest developments in medicine.

*“I think most people are happy about advancing medicine and research. I know when I do my studies and I’ve got a new antibiotic I say, ‘Look, this may be useful in the future if we can get it on the market for bronchitis, are you prepared to try it for five days?’ And you explain that they can stop as soon as they wish, and then they go home and think about it before they give consent. We don’t usually have any problems at all. They’re usually very willing.”*

GP

*“Some people just want to help. Some people are curious. Some people find that they will get more and better medical treatment.”*

GP

All the GPs said or implied that they expected, or would expect, some kind of reward for taking part in research. This reward was usually expected to be financial, but was thought possibly to be in the form of new resources. Where organizations conducting the research stood to make money themselves, remuneration was taken for granted.

## 8.2 **Genetics research**

Some GPs saw genetics as being inextricably linked with medicine because of the hereditary nature of some conditions. Asking for the family medical history at new patient check-ups was considered a crude form of genetics investigation. It was seeing if the patient was more susceptible to certain ailments resulting from inherited characteristics.

**"Do you have much contact with genetics research?"**

*"Not terribly. It depends how you define 'genetics research'. I suppose genetic elements come into other research when you are looking into illnesses, like how you screen for certain cancers and family history of those who you should screen, who's high risk."*

GP

GPs knew little about genetics research in detail. Although they saw genetics as being broadly linked with their work, they did not see current research as directly relevant, and felt they could more usefully spend their time reading about other medical research. Where more was known, it was as a result of interest in the subject rather than any feeling of professional responsibility. This feeling was exaggerated by ease of access to information on the different types of research: they were less likely to come across information on genetics research in the course of their work.

*"I don't know a lot about the medical angle on genetics research. It's very interesting, though. I've got a particular interest in diabetes and it being familial because it runs through my own family. So I'm very interested to know what's coming up."*

GP

Those who were better informed mentioned work on Down syndrome, cystic fibrosis and genetic predisposition to diseases such as depression, heart problems, cancers and diabetes. One GP also mentioned the Human Genome Project, and voiced concerns about organizations patenting parts of the human genetic code for commercial benefit.

*"I think the Human Genome Project is going to be very, very exciting, as long as these commercial people don't patent bits of the genome and make commercial benefits."*

GP

Nurses appeared only slightly more knowledgeable about genetics research than the general public. Like the general public, they associated genetics research with cloning, 'growing' organs, and 'designer babies'. Some also associated it with tests for Down syndrome on unborn children, and with hereditary illnesses such as breast cancer and ovarian cancer.

*“I think people tend to associate it with Down syndrome. A lot of people say, ‘Do I have to go to genetic counselling?’ I think that’s the only way they link that. I don’t think they hear about it in any other way.”*

Practice nurse

### 8.3 **Sources of information and influence**

All the GPs and nurses said that it was inevitable that they came across information about medical research in the course of their work: from colleagues, journals and trade magazines. They said information about genetics research came more from the general media because it was not considered directly relevant to their work. As a result, finding out about genetics research was a more active process.

## 9. **Perceptions of human biological samples**

### 9.1 **Definitions**

The term *Human biological samples* was evidently confusing for the majority of GPs and practice nurses. It was not a familiar term to them, and it was not initially clear what was meant by it. However, all were familiar with all types of such samples, and when prompted further they mentioned samples of blood, urine, tissue and saliva.

### 9.2 **Attitudes to donating samples for research**

When asked to compare donating samples for research and donating blood for transfusion, GPs and nurses felt that people would be more willing to donate for transfusions. This was partly thought to be because the benefits of transfusions were more immediate and easier for volunteers to comprehend. This meant that it was easier to have a definite idea of why they were donating, which encouraged volunteering. Another reason was that research was sometimes taken for granted, and not considered as worthy a cause as transfusion. Finally, some GPs and nurses thought that people could be put off by the thought of others making a profit from their blood.

*"If I were to say to a patient, 'Will you give a pint of blood? We need it for the transfusion service,' or, 'We need it for research,' I think they would think the transfusion would be needed more than the research."*

Practice nurse

However, those with experience of approaching patients had found many willing to participate, especially if it allowed them earlier access to drugs or potential benefits for their family.

The motivations of scientists who used biological samples in research were thought to be largely honourable. However, there was some suspicion of drug companies and other organizations involved in research, particularly among practice nurses. Kudos and money were thought more motivating than ethics. One nurse feared that these motivations sometimes led to samples being used for research without the researchers having obtained proper consent.

*"You sometimes worry that if you are taking the blood for one thing, what happens to the blood that isn't used? What happens afterwards? You assume that it is just disposed of, thrown away, but if there is someone who is interested in something working in other labs, are they allowed to use the blood for their research? I would imagine that they probably shouldn't be, but there is a difference between 'are they allowed?' and 'do they?'."*

Practice nurse

### 9.3 **Consent**

All the GPs and nurses thought consent from donors or their relatives an absolute necessity for the use of biological samples for research. The Alder Hey case appeared to have crystallized the issue for many. A few said that where in the past they might have been more relaxed about consent, or unsure whether consent was required, in the light of Alder Hey they now saw it as essential.

*"When a postmortem is done on any person, it must be made perfectly clear to the relatives that tissue may be removed but I think they should also tell them how much tissue. I think they [Alder Hey parents] were not aware that there were whole hearts and lungs and things taken out."*

GP

*"Patients have got to be aware of what's happening. They've got to know, it's all got to be written down, and they've got to sign. If you are doing research you've got to be all above board. We don't do anything underhand."*

Practice nurse

***"Do you think people would expect to have their consent asked if research were to be done on their surgical waste?"*** *"Well I didn't think so before, but now I think maybe. There is so much hassle about these organs at Alder Hey. All this has gone on for years and we've accepted it, but now it's an issue."*

Practice nurse

But simply obtaining consent was not thought enough: it was felt that those recruiting volunteers must be sure that the volunteers understand fully what they are giving consent for. The onus was on the explainer rather than the recipient of the explanation; there was a moral duty to do more than simply go through the motions.

***"Do you think people should be asked for consent for the use of surgical waste for research?"*** *"I think they should definitely be asked. I think often that consent, people sign for things and they don't always understand what they're signing for and it's not always explained clearly either. So yeah, I definitely think they should be asked consent in those situations."*

GP

It was widely felt that patients did not like giving unconditional consent for research samples, and that they should not have to. GPs and nurses said that donors of samples should be told what the samples would be used for, and that they should not have to agree that the samples would be used for anything else.

*"People don't like to give carte blanche. If you say, 'I want a sample of your tissue, your blood,' they say, 'What are you going to do with it?' People want to know that. But if I say to you, 'I want to get a sample of your blood because we're doing a certain project on calcium metabolism,' or whatever, that's okay, as long as you tell them what you want to use it for. But carte blanche is not on."*

GP

One nurse said that at the time of surgery the destination of surgical waste was likely to be far from top of mind for patients, especially if they were involved in traumatic and swift operations. It was thought important not to take advantage of patients in these situations and not to take short cuts with the consent procedure.

*"I guess if it is planned surgery you can plan for what happens to the waste, but if it is traumatic, or something that has happened very quickly it is something that maybe not until three months down the line you are going to think, 'Where is my foot? Where is my leg? Where are my tonsils that they took out of me?'"*

Practice nurse

#### 10. **GPs' and nurses' overall response to the proposed WT/MRC sample collection**

One GP had heard about the proposed collection. He was concerned that what he had read about the proposal (in newspapers) was too vague and left too many questions unanswered – especially those to do with confidentiality and possible police access to the collection.

*"I think somewhere I've seen about it and I must say I was disquieted about it. It's too vague. If somebody said to me, 'Give a sample for biological research,' I'd think, 'What are you going to do with it? Who else is going to get access to it?' Which is always the other thing. All these things go on a database somewhere, and databases, despite the best will, will go to other places. Not that I've got anything to hide from the police but inevitably the police are going to want to tap into this."*

GP

Another said he had heard of a proposal to screen all fetuses for predisposition to diseases. He had heard that insurance companies would have access to the information and thought this worrying. None of the practice nurses had heard about the proposal or anything that sounded similar to it.

*"I don't know if you've read the press in the last couple of days, but they're going to test everyone in the country genetically, every pregnant woman, and then the insurance companies may have access to that to see whether they're a good risk or not, if any hereditary defects show up in the testing."*

GP

When GPs and nurses were introduced to the proposal, two sets of issues typically came to mind: the implications for them as professionals, and the implications for their patients as potential participants. It was evident to GPs that they could have a significant impact on the success of the proposal. They knew they had influence

over their patients' views, and that there would be no easy alternative way of accessing participants.

GPs' and nurses' concerns for patients' welfare were similar to those mentioned by members of the public. They wondered about the implications of volunteering and what rights would be forfeited by giving consent. They underlined the need for a full patient briefing, including a comprehensive and coherent explanation of the research. They had concerns about confidentiality and the potential misuse of information by, for example, unscrupulous insurance companies and employers. They wondered about the effect of feedback and about the implications if this contained bad news. They had concerns about the misuse of the DNA samples themselves by, for example, the police, employers or insurance companies. Finally, they worried about misuse of collection by researchers, and asked what research would be allowed.

*"[The DNA] would fingerprint them. It would probably be very useful for the police in the future, I'd think. You might get a few dodgy characters who would not be very happy about giving a DNA sample. And we've got a few actually. I've got one chap, he comes in, he's beautifully turned out, and do you know what his job is? He's a professional burglar. So if he puts a bit of blood on a window pane he's not going to be very happy about having his DNA taken."*

GP

*"What would you want to know?" "What's it being used for? Would it be for curing existing diseases? Or is it for going on and doing bigger and better things like cloning? Is it just for cures for modern-day diseases?"*

Practice nurse

As far as their own involvement was concerned, their first question tended to be about their time commitment. They regarded themselves as busy people, and were nervous about spending time spent recruiting volunteers, explaining the implications of the research, collecting samples and counselling if volunteers received feedback.

*"This is slightly selfish but it's just more work for me. It will involve counselling and that takes time. I do counsel a lot of my patients for a variety of things, but adding another dollop of counselling..."*

GP

They were also concerned about cost. They wondered who would pay for both GPs' and nurses' time while they were carrying out the work,

and who would pay for any extra space that was required in which to take the samples.

*“That would be acceptable but then it throws up problems of where they are going to work and who’s going to pay them.”*

Practice nurse

Finally, they were concerned about their professional responsibility to their patients. They were unwilling to recommend that patients volunteer unless they themselves were absolutely convinced of the credentials of the project. As a result, they wanted all issues relating to patients’ welfare resolved completely and satisfactorily before they were approached to cooperate.

*“There are lots of implications. Firstly, it’s going to be quite time-consuming for GPs to be doing blood tests on people, and the cost implications. The other issue is how happy people would be to have their blood a) taken and b) used for DNA research, which is rather broad and would potentially have quite worrying implications. They might worry that certain diseases might be found out, that they’re carrying, and then if you have that information what are you then going to do with it. It might not be foolproof information, so lots of worries about what it would mean and how it would actually make people quite anxious.”*

GP

GPs and nurses also raised questions about some of the ethical implications of the proposal. They felt that the responsibility for resolving these issues was best assigned to an independent body. The task of the scientist was seen as being at odds with that of the ethicist – one had to make progress and the other had to rein it in – and the two responsibilities were best taken on by different people.

*“I believe that it’s scientists’ job to continually push back barriers, it’s not their job to be moralists. I think that that is something that has never been addressed. There are people who jump up and down and shake their fists at the poor scientists for doing the research, saying this is not morally right.”*

GP

Openness, honesty and clarity were thought vital to the success of the proposal. Respondents said that these would be necessary to gain the trust and confidence of potential volunteers, and to avert any future scandals that could cause damage to the credibility of the collection and the medical profession more broadly. They wanted reassurance



that they themselves would be adequately briefed so that they would be thoroughly prepared for all the questions that patients might have.

*“I wouldn’t be happy to do it unless I felt the patients were fully informed and consented, and that isn’t a five-minute job, that would be a long job. You could actually give out patients’ leaflets or get them to speak to somebody before they do it but I still wouldn’t be happy to take blood from someone unless I knew that they were really sure about what they were giving blood for, what it was going to be used for, what the possible outcomes were going to be. A lot of people won’t know what DNA is; who is going to explain to them what they are looking for?”*

Practice nurse

Overall, GPs and nurses appreciated the importance of medical research and seemed positively predisposed to the proposal in principle. However, they were keen that all the concerns were ironed out so that they were not having to endorse a project they were not comfortable with; and it seemed unlikely that they would be willing to participate without some recompense for their time.

*“You have to do research – that’s how life goes on, isn’t it? We can all sit back and say don’t do it, but that’s ridiculous, they’ve got to find out. If we try to get a cure for cancer there will be something else round the corner waiting to step in where the cancer is.”*

Practice nurse

*“**Would GPs want to be paid for this?**” “I think they would. I think they would be looking for some kind of reward, particularly if you are asking that they write to people, because then you haven’t only got the time element, you’ve got the admin.”*

Practice nurse

## 11. Need for associated personal information

GPs and practice nurses foresaw problems getting full and accurate information about people's lifestyles. They expected from experience that people would say that they smoked and drank less than they did, and would misremember aspects of their medical history.

*“How accurate would they be in how they answer? For instance smoking and alcohol, people are always going to minimize what they’re saying.”*

GP

*"Nowhere near enough information in that because most people haven't a clue about their medical history. You often find that they have little recall of timescales and what were and what were not significant illnesses. It would be flawed."*

GP

It was also thought that some potential volunteers might not want to divulge intimate personal information. One felt that it should be acceptable for participants not to answer questions they did not feel comfortable answering.

*"That's fair enough, although we do get psychological questionnaires about lifestyle and there are some quite intimate questions asked about sex life, etc. Quite a few of the old widows and spinsters get a bit upset about filling those. I just tell them to leave them blank. So obviously there should be this opportunity for them just to leave things blank if they didn't want to answer it."*

GP

There was also some feeling that the work involved in filling out questionnaires might discourage some from participating.

NHS records were thought a more reliable source of information, but the idea of giving outsiders access to the records was a cause for some concern. The confidentiality of the information divulged to GPs was thought an important part of the relationship between doctor and patient, and if an outside researcher was allowed access to records, that confidentiality could be seen as having been compromised.

***"How about if the researchers have access to NHS records?"*** *"Not very happy about that one. I mean that's confidential. What I write on there is confidential and I think if we gave access to it, it would look very damning and we could be held to task for that."*

GP

*"The trouble with that is, there's lots more in the notes than the things you may want to know. So people might feel that if there were access to their notes, I would have thought people might find that quite threatening. There are always lots of other things written in notes. People might worry. I would worry about that too."*

GP

Some anticipated practical problems. They said that it can be difficult to read doctors' handwriting on the records, difficult to gain access without

causing disruption, and it would be time-consuming transferring information from the records to a database.

*[NHS records:] “You wouldn’t be able to understand the doctors’ writing anyway. But besides that, it’s personal between you and the doctor.”*

Practice nurse

In addition, some nurses said that GPs do not like to have their work scrutinized and may therefore be reluctant to assent to outside access.

*“I know a lot of doctors aren’t happy about people looking at records. They like to think that they’re records from their point of view as well. They don’t like people looking at their work.”*

Practice nurse

It was unanimously felt that specific consent should be acquired from volunteers for access to NHS records.

## 12. Anonymity and coding of information

Some believed that doubts about the security of information could deter potential volunteers, especially those with something to hide. However, GPs and nurses found it difficult to see what could be done other than give a written guarantee of anonymity.

*“I think the people who tend to be worried are the ones that tend to have information they feel sensitive about. They’re worried about who might see the records. I think that people have the feeling that lots of agencies can cross-reference information through computers. So they may feel that, though they’re consenting, nothing is completely anonymous. But I don’t know what else you could do other than give a written reassurance. But some people might still be unkeen on entering the study for that reason.”*

GP

GPs said that even keeping the information they have confidential is not a straightforward task for them. They said that it would be easy, for example, for cleaning staff to read papers left on desks or to see information left up on computer screens. On this basis, they thought that keeping the vast amount of information involved in the proposed collection confidential would be very difficult.

*"We are bound by certain minimal obligations in terms of data but nonetheless, a lot of our practice staff are potentially able to see screens. They can't access certain parts of records but they might inadvertently see parts. And then there is always the written information as well to supplement it. Screens could be inadvertently left on or if you have a patient in the room, they might even see things on their own screen they may not wish to see. It's actually quite hard."*

GP

Others noted that computer hackers have managed to access the systems of purportedly secure organizations such as the FBI, so they did not think that any computer system could be declared impenetrable. One GP thought it would be difficult to resist approaches from the police for access to the information.

*"We do keep our records on computer here, which I am assured are protected so that if someone was to hack in they would have to go through two systems. The IT people have checked that it is practically impossible, but you hear about people breaking into FBI records, which must be one of the best protected. I wouldn't say you can ever be sure that computers are 100% safe."*

Practice nurse

Despite these doubts, assurances of confidentiality were thought crucial. The information being handled would potentially be highly sensitive, and would be of interest to, for example, insurance companies, employers and the police. Perceptions of the organizers of the collection were thought important here: the more that people trusted the organizers, the more likely they would be to believe that their details would remain confidential. Some felt that the organizers should provide a written guarantee of confidentiality saying that they would take responsibility if any lapses did occur.

### 13. **Consent**

GPs and nurses thought written consent an essential requirement of the project. They thought it important to make sure that patients not only signed a document, but that they understood what it was they were signing. The consent document should be in simple language and backed up by a spoken explanation if necessary. The option of dropping out at a later stage was also thought necessary, though they felt this would be minimized by effective explanation when participants first volunteered.

*"Normally if something's signed, it's binding. The trouble is, people don't always understand what they're signing, they may not remember or understand or recall the information or know what questions to ask at the time. I think it needs to be explained very simply and very clearly in language that people can understand and re-emphasised, and presented in a way that people can make an informed consent as opposed to just a consent."*

GP

*"You could go through the form with them just to make sure they understand what was entailed. They could go home and read it first, then come back and sign."*

Practice nurse

There were varying opinions regarding what participants should have to consent to. Some felt they should be allowed to be selective in the types of research they consent to; others thought there should be one over-arching agreement that meant consenting to any type of research, as long as there was at least some prior description of the research.

#### 14. **Access to research results**

GPs and nurses believed that access to individual results from the research raised serious problems, both ethical and practical. Their immediate response was often that participants would have a right to personal feedback, particularly if important information were discovered about a participant's health. However, most could also see that patients have a right not to know; for example, they might not wish to be told about an incurable disease that they might be particularly susceptible to. Doctors were concerned that if patients were told about such a condition it might have only negative consequences because nothing could be done to treat the condition.

*"Knowing you're going to develop certain things in your sixties, say if that's where it's going, that you might know in advance what illness is going to develop, it might not help very much. It might cause a lot more morbidity and anxiety, rather than there being anything that you could do to prevent them."*

GP

The majority concluded that participants should have the right to choose whether or not they receive individual feedback, with the caveat that participants clearly understood the choice they were making, and the implications of that choice. Letting GPs decide whether or not

specific feedback should be passed to patients was not considered an acceptable option. They thought it would be difficult for them to justify not telling their patients.

*"I'm not quite sure where the end point is of this study but if there was something specific and they said you can either know or not know about this specific gene which might cause such and such, I think that would make it okay, providing they understood. If GPs knew about it I think we'd feel that we had an obligation to actually tell that person. But it might be that it's okay for them not to know, for people to consent to not know. Yeah I think that could happen. It would depend how the implications were explained to them."*

GP

However, if the research were done on anonymous samples it was thought arguably justifiable for researchers not to give individual feedback.

General feedback on research findings was thought likely to be of interest to participants. GPs and practice nurses thought that it would make participants feel involved, and would be an appropriate reward for taking part.

*"I think people would like some sort of personal recognition. Even in the form of just knowing what's going on and what the samples are used for. Even newsletters, something like that. Just explain maybe what diseases you're aiming for, just a little bit of information so that they've been acknowledged."*

Practice nurse

## 15. **Mechanics of sample collection, storage and use**

GPs were thought the most appropriate people to approach potential volunteers: they already had a personal link to the individuals, and would be able to give authoritative reassurance about the project's validity. As mentioned above, this raised concerns amongst GPs about time, surgery space, costs and extra administration.

*"There's a time element here, isn't there? GPs are pretty busy creatures, so how much time, how much work would be involved? And I presume there would be some form of payment for their time. I think a lot would depend on payments and time."*

GP

*"I could see difficulty if other nurses were coming in and trying to find room space to take these samples. All of our rooms are at a premium in this building."*

GP

*"GPs surgeries would be the best places to do it. That's where we see all the patients. But I don't know whether GPs or nurses will be impressed with more work. There would have to be extra time and finance incentive."*

Practice nurse

Time, space and other practicalities allowing, nurses were happy to collect samples if necessary – as long as the details of the collection assuaged the concerns they had at present. One nurse even saw it as an opportunity to attract more patients into the surgery.

*"It would be difficult to have another person in our building, we're very tight for space, we haven't got a room where another nurse could work. And then the whole logistics of making appointments and checking people came and so on. So there would be a space issue and admin type issue."*

GP

*"I don't think there's a problem there at all. We are always trying to get people more aware and trying to get people into the surgery. I don't think there's a problem there at all."*

Practice nurse

## 16. Current and future use of samples

Appropriate use of samples was thought important for the project's credibility. The statement *"Future discoveries may mean that samples could be used in other ways that we do not yet know much about"* prompted some concerns that the proposal seemed to be undiscerning in the research it deemed acceptable. Could the collection be used for research into cloning? Or biological warfare? The statement seemed to be a way of fudging this issue. More detail in this area was thought necessary to reassure both GPs and potential participants, and a minority believed that consent should be renewed if the collection is to be used for new types of research projects.

*"With these future implications, it would be harder to get across to people, that would worry people. If you're talking about existing disease, people can understand what it is, what the implications are of knowing or not knowing. But there's something that's very nebulous about 'future discoveries'. It might threaten people because it's the unknown and that's frightening for people."*

GP

*“Instead of the cloning experiments, I think money should be put into other things, even though there is a good case for these. In my opinion it should be used for AIDS, cancer and heart disease.”*

Practice nurse

*“I don’t think you can move the goalposts half-way along.”*

Practice nurse

It was suggested that an independent watchdog should be established to decide what research was acceptable and what was not.

## 17. **Ownership of samples and involvement of commercial interests**

Opinion among GPs and nurses varied over who had ownership of samples once they were donated for research. A minority believed that once patients have given consent, they should relinquish all ownership of the sample. They thought that if this were not the case, research could be affected by people raising objections after they had given samples.

However, most were more protective of patients' rights; they thought that volunteers should retain a degree of ownership even after giving samples. Their thinking behind this was that without this ownership volunteers would be helpless if the samples were abused.

Public ownership of the collection was largely met with approval, but did raise some issues. Some wondered whose responsibility it would be to look after the public’s interests. Others were nervous that money would be diverted from the already tight health budget to pay for the collection.

It was generally (albeit sometimes reluctantly) thought inevitable that commercial organizations would profit from the collection, as all the GPs and nurses knew that that was how new drugs and treatments came into existence. However, they sought reassurance that commercial organizations working on the collection should still be bound by stringent rules.



*"I suppose in an ideal world it would be nice if the Government or Health Service did this kind of research and it was used for the benefit of mankind, but that isn't going to happen, and you have to accept that the only way we are going to move on with these things is to have companies who are going to make a profit. You have to live in the real world and accept that that happens."*

Practice nurse

## 18. Organizations involved in the sample collection

All the GPs and most of the nurses knew of the MRC. It was well regarded and thought a reassuring organization to be involved with the collection because its motivations were thought likely to be worthy. The Wellcome Trust was less well known. It tended to be thought of as a drug company and linked with Glaxo Wellcome, even by some GPs.

*"Wellcome always makes me think of the Wellcome drug company so I'd worry a bit about that but I really don't know exactly who they are. I know more of, and have more confidence in the MRC."*

GP

After explanation credentials of the two organizations' credentials, both were thought appropriate and reassuring organizers of the collection. Both were thought likely to have sound motivations for organizing the collection, and both were thought likely to be financially stable. None could think of anyone better to run the project.

*"I can't think of anything better than something that is funded by the government and a charity. It's got to be better than a drug company doing it."*

Practice nurse

## H. Findings – religious and community spokespeople

### 19. Contextual points

Many of the religious leaders and most of the community spokespeople had much to say about the issues surrounding genetics research, the use of human samples and the proposed MRC/Wellcome Trust sample collection. Some respondents were less able to grasp all the issues and implications than others. They also found it more difficult to comment on some aspects of the proposed sample collection. One respondent had more problems than others in understanding the purpose and implications of the project, and was less able to comment on its different components.

Views on the main issues were often derived from religious or cultural and historical perspectives. None regarded themselves as expert on the science of these topics, but most thought they had a contribution to make to debate on the ethical and moral aspects.

None of the religious leaders felt their faiths yet had well-established policies on these issues. Individually, religious leaders' views on genetics research were typically unformed. Most had some concerns, based on the same sorts of news information that members of the public saw. They tended to express views that were based on their own interpretation of their beliefs; their opinion depended to some extent on individual leaders' own position in relation to particular issues. Some had views on particular issues relating to their own faith or their community, which informed their attitudes.

A commonly held view among these people was that progress, exemplified by technology, is not a bad thing in itself, and is no worse in medicine than elsewhere, but that it is difficult to agree and control technological progress. Given this, and given the growing significance of technology in medicine, many felt that there was a strong case for discussion and agreement of a consensus view on bioethical issues generally and use of human samples specifically.

The Catholic priest felt that there is a religious aspect to suffering, with people achieving redemption through suffering; is it right for us to try to abolish suffering, or will we also abolish redemption?

*“Now I think I have a right to certain extent...that I ought to help reduce some of the suffering...but I also can't, as a Christian, can't really forget that redemption, suffering has a redemption aspect to it.”*

Anglican priest SE

The African community leader believed the African community is sensitive about blood taken for general research rather than to help the donor. Both the African community leader and the Afro-Caribbean community leader felt that HIV needs a very special approach in the context of medical research and use of samples. They felt that African and Afro-Caribbean people are highly sensitive about HIV and that the taking of blood samples is often linked to HIV. Another issue here was the apparent perception of African inferiority in relation to white people; there is a feeling that white scientists in the past have used black people as guinea pigs, especially in the context of experimental HIV drugs.

*“With issues around HIV, it's very much linked to blood samples. Some Africans in this country have got immigration problems and also HIV is high in the community, so there's been a lot of issues around human biological samples.”*

African community leader SE

*“It is known for...white people to use them as guinea pigs. That includes not only human biological samples but also treatments like for HIV. They say that some of the Africans are being given the bad drugs...”*

African community leader SE

*“I represent a community that is very, very careful about anything to do with their body. Blood samples these days, they need an explanation as much as I need an explanation. It's not going to be easy to convince people to take that line.”*

African community leader SE

Another potentially problematic subject was attitudes to GPs. The African community leader believed that relationships between Africans and GPs are often not close, nor based on trust, largely because first generation African-origin people are not familiar with the idea of GPs. The GP system does not exist in Africa, and people are more likely to seek medical treatment from hospitals or private clinics.

*“I’m not sure of the relationship between Africans and their GPs though. It’s a new system [to them]. We don’t have GPs in Africa, we go for medical care to either the local hospitals or private clinics.”*

African community leader SE

The Hindu priest and community leader had a feeling that people do not always have faith in medical treatments, and come to priests for religious healing. Both felt there was very little communication between the medical profession and the Hindu community (including community leaders), so they tended to feel under-informed, particularly about medical research. This view was echoed to an extent by the Chinese community leader, who felt that Chinese medicine was distinctly different and separate from conventional Western medicine.

## 20. **Attitudes to medical and genetics research**

Knowledge of and attitudes to research and associated issues varied widely among these religious and community leaders. Some were clearly very knowledgeable; others were relatively uninformed.

The rabbi was fairly well informed about medical and genetics research. He felt that some research is ethically acceptable but that some may not be; in particular he had concerns about cloning. The rabbi believed that establishing Jewish law on these issues is difficult, because there is limited guidance in the sources; and because bioethics is new and currently not a high priority. Other issues, such as organ donation, need to be dealt with first.

*“The fact is, Jewish law is still trying to cope with the invention of the steam engine. So that places bioethics on a waiting list. Which is not to say the effort isn’t there. There are people grappling with issues like organ donation, so bioethics isn’t high on the list yet.”*

Rabbi North West

The Catholic priest felt that a primary concern for Catholics is that people with diseases are not spiritually prepared for death. He was in favour of medical research, but worried that researchers are not trained moralists, and cannot necessarily deal with the ethical issues that arise. He feared that some research is being carried out immorally (e.g., research on fetuses). He felt similarly about genetics research –

serious moral issues surround gene alteration; it is not necessarily a bad thing, but it has to be considered very carefully.

The Catholic priest also had practical concerns about genetics research, particularly where viruses are used to introduce genetic material into the body; what happens if these viruses lie dormant and cause problems later? He thought sample donation was acceptable as long as consent is given, though moral problems might arise when people want to donate samples only to those of certain religions or races.

The African community leader had some awareness of general medical research, but limited knowledge of genetics research and saw it as a tool for identifying illness susceptibility. He believed it carried risks as well as benefits. His chief concern was that research identifies problems but cannot provide solutions in the short term; medical support cannot always cope with issues raised. He also made the point that medical research was not seen as a priority in the African community. It was carried out on a much smaller scale in Africa, with little public involvement.

The Muslim community leader and religious leader were generally in favour of research for the good of humanity. Though some practices are banned in Islam, religious elders are consulted for their views in these cases. They believed that Muslims are traditionally unwilling to donate samples or organs, particularly for those outside the Muslim community, but that this attitude is slowly changing. They felt that Muslims living in Britain are having to adapt to different medical methods, often very unwillingly – for example, male doctors delivering babies.

*“Culturally things have changed because this a different culture, we are living in this society, we have to adapt some things.”*

Muslim community leader North West

The Anglican and Baptist priests felt that medical research was vital, but that appropriate application of its results was a key area of concern in terms of ethics. Both believed it was difficult to take an absolute position on how it is used because ethical issues probably vary case by

case; continuing dialogue with scientists is necessary. They perceived a tradition in Britain of scientists being remote from the general population, and felt that this needs to change – there had to be more interaction with society to exchange ideas and more empathy with the feelings of people who might benefit from treatment derived from research.

*“I don’t think people should be denied the benefits of medical research. I think it’s an unsupportable position to block people access to things that are happening.”*

Baptist priest SE

*“What I would say is there must be a continuing dialogue and that anything happening mustn’t be apart from the community. There is a tendency in this country to have a super-race of scientists and medical researchers that are set apart from the community.”*

Anglican priest SE

The Anglican and Baptist had particular concerns about genetics research. Though in theory it would be valuable to understand heredity better, there was a strong need to be aware of the risks inherent in this sort of research, such as Hitler’s attempts to create a master race of ‘superhumans’. In this context the Baptist (who was African in origin) was especially concerned about race issues; he was aware of racial problems facing his community and worried that genetics research could be used to discriminate against specific races.

Both felt that fertility was a particularly fraught area. While they believed that IVF helps people, and cloning cannot be dismissed out of hand, they felt we need to keep in mind respect for creation of life, and the need to promote diversity. They thought that any desire for perfection is immoral, and it can be difficult to know where to draw the line.

The Afro-Caribbean community leader was mistrustful of scientists involved in genetics research. He was anxious about cloning and seemed to believe that human beings have already been cloned; he was mistrustful of promises of controls and systems.

*“It’s frightening. I’m yet to be convinced. I don’t believe they haven’t already cloned a human being somewhere, in spite of their denials.”*

African-Caribbean community leader SE

The Hindu spokespeople were largely unfamiliar with genetics research in principle or in practice. Both said that Hindus can feel left out of debate on this sort of topic because they are given little information on it that relates to them specifically. On a tangential point they said that the Hindu religion forbids intermarrying in order to prevent hereditary defects.

*“We are not in touch with medical departments or hospitals here...Just as the Christian priests visit the hospitals, there should have been a suggestion that the Hindu priests be invited to visit the hospitals and the health centres and inform them about what is going on in the medical institutions.”*

Hindu religious leader Midlands

## 21. **The use of samples in medical/genetics research**

For some religious and community leaders the donation of samples for use in research had a distinct religious facet. The Baptist priest had no problem with samples being taken from living or dead bodies as long as consent has been given; he believed that Bible supports the view that the body is merely the vehicle for the soul.

*“After all I mean a dead body is a dead body. It’s a carcass, it means nothing really. Even the bible tells us ‘let the dead bury themselves’.”*

African-Caribbean community leader Midlands

The African community leader thought that people of African origin would have reservations about the use of tissue in pathology or research. These reservations were based on religious and cultural beliefs about the human body after death.

*“Because in the past, with pathology, when someone in the community dies, they know they have to go through a certain procedure to identify what might have killed them, and some people feel that shouldn’t be done...‘We don’t want our bodies used like that’.”*

African community leader SE

The rabbi had some concerns around donation of samples, because the Jewish faith requires bodies to be buried intact for purposes of resurrection; samples can be taken to help someone else directly, but there are objections to taking samples for research or statistics. He thought that there is also a requirement that samples from living beings should be buried (e.g., amputated limbs, foreskins, etc). He said that

this was the traditional view, and that he and many others take a more modern and progressive approach. He knew that exceptions have been made in the past (e.g., foreskins have been used to produce interferon).

*“The basic principle is that...bodies are supposed to be buried intact, or as intact as possible. If there are exceptions to that, they are to do with the ability to take samples that could be used to save another life. The tradition can countenance that. The tradition has real problems with samples that are kept simply for statistical purposes, that aren't directly related to any life-saving procedure.”*

Rabbi North West

*“The fundamental principle that you find throughout the tradition is that essentially you can do just about anything in the name of saving life. If however, you're talking about taking tissue just to satisfy someone's curiosity just because they've got a grant, that becomes ethically questionable.”*

Rabbi North West

The Muslim leaders felt Muslims would be willing in principle to donate samples but would have to know what the proposed research is about. Both expressed concerns that genetic information could be used against the individual. This seemed to be prompted by anxieties that individuals' immigration status could be scrutinized.

*“You'd have to explain what sort of research they are doing...I'm not a criminal, why should I give my fingerprints to anyone? Similarly if the blood samples can be used against you, then I don't think that people will be willing to do that.”*

Muslim community leader North West

In principle they thought tissue from operations or from cadavers could be used in research, but consent would be essential.

The Hindu spokespeople said that the Hindu religion has no objection in principle to blood and tissue being taken from donors, as long as consent is given, and the sample is used for a good cause (either transfusion or research that is beneficial to mankind).

*“Our religion doesn't say anything about this, whether you take the blood out or the organs. Our religion is silent about this. We don't object...so long as the person knows that it is being taken, and it should be used the right way, not for the wrong purposes.”*

Hindu religious leader Midlands



Across the spectrum of religious and community leaders there was a strong belief that in all research, informed consent is vital, and that researchers must be accountable for their actions and articulate those actions in advance.

*“If people are giving their consent for something there must be some relation in terms of their knowledge of what it’s going to be used for. I think people need to be felt to be accountable for their actions.”*

Anglican priest SE

The prospect of collecting samples from children raised serious questions about consent if the process is invasive. Some of these respondents believed there were limits to parental consent, and parents should not have power to consent to invasive procedures on children unless medically necessary.

Attitudes to volunteering to participate in research also had some specific religious or cultural facets. For the (African-origin) Baptist priest, volunteering was particularly commendable in the UK because of the lack of remuneration, making it a purely altruistic motivation.

*“In England volunteers are truly volunteers who believe they’re helping their fellow human being by giving whatever, carrying a donor card. In America they sell it!”*

African community leader SE

Against this the African community leader had some doubts about willingness to volunteer among African-origin people. Volunteering is apparently not familiar to many people of African origin and it may be that people are only likely to give a sample if they were going to benefit (for example, by having illnesses identified). He believed that the reason for this is that there is a strong trading culture in the community and people are unused to the idea of giving something for nothing.

*“Volunteering in the African community is a new thing. There is volunteering but the way people volunteer is quite different...There are different meanings of that word.”*

African community leader SE

## 22. **Response to the WT/MRC sample collection**

### 22.1 ***Initial reactions***

Overall attitudes to the idea were accepting, but some religious and community leaders imagined that people of their faith or from their communities would have reservations about taking part. Some were initially cautious and wanted to know more, particularly about what the sample would be used for.

The African community spokesperson felt that few African-origin people would be willing to provide DNA information, largely because of immigration concerns. He also thought people would have many questions about the research – who would take the sample, who would have access, what would it be used for? The African-Caribbean community leader imagined that the creation of a national DNA bank is only a matter of time away. He wanted more information about the use of DNA, but otherwise took a largely pragmatic view: people want to be cured of diseases, therefore this sort of research needs to be done.

The Anglican and Baptist priests approved the idea in principle, but felt that there is a need for guarantees on the extent of the research and how long the samples will be kept. The Catholic priest had no objection to the research in principle, but felt he would need reassurances that it was being carried out by people morally qualified to make choices on how the samples were used.

The Muslim leaders were initially accepting, provided that guarantees are given about what the sample will be used for, and that those running it are ethical and trustworthy. Neither of the Hindus had serious reservations about the idea in principle, but raised some practical problems to do with the collection and confidentiality of information and particularly donors' anxieties about privacy.

### 22.2 ***Donor information and confidentiality***

The need to provide lifestyle and medical information was potentially problematic for some. Among those representing minority ethnic

communities it increased fears that research would not be anonymous: people would be very unlikely to take part unless benefits for them are clear; the reference to questionnaires reinforced this concern.

For some, there were particular reasons why their communities might be resistant to giving personal information. The rabbi felt that because information on individuals was used to identify and persecute members of the Jewish community before and during the Holocaust, there would be concerns about allowing too much information to be gathered and accessed. Both the Muslim spokesperson and the African community leader believed that personal information and medical records could end up in the hands of the immigration service, social services, or the police. The Hindu priest felt some Hindus might be guarded about their lifestyles.

*“...a generation ago a much less sophisticated source of government collation of information allowed the ready collection, deportation and extermination of a population. So you have a visceral reaction to government having too much access to too much information.”*

Rabbi North West

*“If you are gathering some specific information, for example, how many Kashmiris are in this city? Who are the leaders? Who has come from this tribe, this city, this village? If you take this information and then provide the police, the social services, to immigration office, to everywhere, it might be damaging or dangerous for everybody to provide.”*

Muslim community leader North West

*“They could be identified. Some people may be deported by the Home Office...If they've got the DNA somewhere then when they come back [from overseas visits] they would be caught out.”*

African community leader SE

*“People may be hesitant to talk about their lifestyle. People who are a little bit higher (in caste) they don't want to disclose anything about their private life.”*

Hindu religious leader Midlands

The need for information prompted further worries about confidentiality among Hindus, for a specific reason. They thought certain people would be unwilling to disclose information about themselves, especially those higher up the social scale; if it came to light, for example, that someone's child had a disease, it would be difficult for them to marry. Again there were calls for strict guarantees of confidentiality.

*“If somebody tells you, ‘I’ve got this and this disease’ or ‘this is in the family’, I would feel embarrassed because I’ve got children, I’ve got to marry them and in the community, nobody will give their daughter or boy to them.”*

Hindu religious leader Midlands

The councillor was interested to know whether the information on lifestyles and environment would have any impact on how the samples were used, or on the development of the work in the future. He wanted it to avoid bias towards or against specific groups of people. And he was anxious that information might be accessed illicitly and abused.

*“But there would be issues, it seems to me, certainly implications, about whether judgements will be made about volunteers. Would some lifestyles and environments become more acceptable than others?”*

*“...There’s no two ways about it, information that is held about us as individuals is growing all the time. I guess it’s something that ultimately is worrying because it’s potentially controlling. The thing that comes to mind is employers...that being used as a means of vetting people.”*

Local councillor SE

The Anglican priest was concerned about the confidentiality of personal information and records. He felt that anonymity would have to be absolute, rather than a system of encryption, which could be broken.

*“The whole question about filling in forms about people’s lifestyles and environment which are general things should be done in a way that preserves anonymity absolutely.”*

Anglican priest SE

The Catholic priest thought that giving information and linking it to medical records was acceptable as long as guarantees of confidentiality are given; people have a right to keep their lifestyles private. Having the information coded was reassuring, but he had concerns about the safety of information on computers.

*“I think out of respect for the human beings, they have come forward and been prepared to volunteer to be part of this, but it’s not for the public record, it’s for this and this alone...they’ve a right to confidentiality.”*

Catholic priest Scotland

Some practical issues were mentioned here. It could be difficult to access medical records in the case of Afro-Caribbeans who are often not registered with GPs. There may also be reluctance to provide accurate information on lifestyle. The Hindu, Muslim and African

spokespeople anticipated practical difficulties with the use of a questionnaire to gather information. They believed that many in their communities can not read or write English well.

Reassurances of confidentiality were thought important; people will be much readier to give information if this guarantee is made. However this seemed to contradict the assertion that a link will be made with NHS records, and that donors could be informed if their samples were found to have diseases – how would this be possible if the sample were anonymous?

*“If you’re telling me that the information you give would be anonymous, you will not be identified in any way, then fine. Then people will readily give you information.”*

African-Caribbean community leader SE

*“On the one hand you’re saying it’s very difficult to identify individuals, so how on earth could they know it’s Pete Bloggs. On the other hand it is legitimate to go back to people and say ‘We’ve discovered you’ve got cancer’.”*

Local councillor SE

### 22.3 **Uses of the samples and information, consent and feedback**

The issue of potential uses of the samples and associated information prompted many questions among the religious and community leaders. In principle researching specific diseases was thought an acceptable purpose for the research; they expected a combination of helpful information fed back to the individual about their own health, and developments in medicine on a more general scale.

The African community leader felt that diseases given as examples of research projects are less relevant to the African community. Diseases such as cancer are perceived as rarer among Africans than white Caucasians; HIV is more common but has a stigma attached; research into sickle-cell anaemia may be more motivating.

The rabbi believed that the purpose of the research would need to be made transparent and justified in scientific terms. Members of the public would need to understand how the research would be used and believe in its validity. He felt that it would be better for research to be limited to certain diseases, rather than more general investigation; in

particular it should steer clear of anything that could be construed as eugenics.

*“Researchers have to be able to justify their research and explain what they’re looking for and what their methods are. And is there a danger that people will not be able to comprehend the researcher’s objectives?”*

Rabbi North West

*“You will need to specify the tissue that is being taken and used, the purpose to which it is being put, the length of time which it would be kept stored, the safeguards about coding it and theoretically the life that the data have on file.”*

Rabbi North West

The councillor thought it would be important to establish how the sample collection would be used at the outset so that people could be prepared for any potentially controversial outcomes.

*“If you think about cloning sheep or whatever, are they going to be able to clone humans? Or decide that black people are genetically less intelligent than white people? Those are the kind of controversial issues that might be raised.”*

Local councillor SE

The Hindu priest was broadly accepting of the samples being used for research with the proviso that experiments did not involve cows, which are a sacred animal for Hindus.

Discussion of information also raised the issue of feedback from the sample collection on individuals’ health. Key concerns raised here were that volunteers must be aware that they could discover information about their health by taking part, rather than finding out by surprise, and that support could be given in the event of donors being given bad news.

*“If it’s going to be a two-way thing then it must be stated as such at the beginning. ‘You may discover you’ve got HIV from this’ or whatever”*

Anglican priest SE

*“You don’t want people left on their own if they get told they’ve got something serious.”*

Hindu religious leader SE

Consent in broad terms was generally taken as read. These people assumed that nothing would be done in terms of taking samples or

gathering information without consent. Consent for future research was regarded as important but also as a potential problem, because it would be impractical for volunteers to be re-contacted. There was some belief that informed consent cannot be enduring; permission must be re-sought if new diseases or research methods come to light. Others felt that this need should be balanced with what was practically possible.

*“The question is whether or not the informed consent is an enduring consent or not. I would be inclined to say ‘No, it can’t be an enduring consent...you seek permission to use it in some other way that hadn’t been discussed at the time.’”*

Rabbi North West

*“The least practical thing would be for each donor to give their permission again and again, which would be quite absurd. But there does need to be some body in which the community can have trust to authorize or reject for use of the sample for xyz.”*

Anglican priest SE

#### 22.4 **The role of GPs**

Views about GPs were ambivalent but notably less positive than among many of the general public. In their favour GPs were regarded as broadly well intentioned and caring people. However some of these religious and community leaders had reservations about the suitability of GPs in a role which they felt carried much responsibility.

The councillor was one of the more positive in this respect, partly for practical reasons; he saw GPs as the obvious gathering point for people, samples and information. Against this he had some reservations relating to resources and GPs’ control over information.

*“There’s very much an emphasis at the moment for the GP surgery to be an access point to a whole range of other things. In that sense, why not use a GP surgery. If one is saying that the collection of these samples is ultimately going to improve people’s health and prevent disease...then doing it at a recognisable local area is valid.”*

*“I can see GPs being reluctant if samples are coming flying back saying ‘These people are even more ill than we thought they were’. So there are resource issues.”*

Local councillor SE

Among Asian spokespeople there was broad acceptance of GPs as the contact point and initial endorser of the sample collection. Muslim leaders felt that Muslim communities tend to place trust in GPs, especially since many are Asian.

*“A lot of GPs are Asian and they know about some of the background of religion as well. The people will be sure, the doctor says this, so it’s all right.”*

Muslim community leader North West

The Hindu leaders regarded GPs as probably the right sort of people to approach volunteers, but they felt that doctors are not infallible, and that some people would have limited trust in their GP.

The Anglican and Baptist priests had some worries that, because GPs are regarded as trusted authority figures, people might feel compelled to agree to participate. They thought it might be better for other bodies to make the initial contact – community health councils or local health authorities.

*“I do question whether it is right for GPs [to be involved]...many people have a sense of them being an authority figure, and might be persuaded by the fact that it’s their doctor asking...”*

Anglican priest SE

The African community leader believed that because African-origin people can be wary of GPs, it might be more acceptable if blood was taken in the GUM clinics they visit. Some of these people may already be used to giving blood in a hospital or clinic environment.

For the rabbi the fact that people are ‘approached’ by their GP was possibly worrying. It could suggest that particular groups will be targeted, and it prompted questions about the purpose of the research.

## 22.5 **Organizations involved in the sample collection**

As with members of the public, religious and community leaders tended to assume that the sample collection would be established and run by either a government organization or a pharmaceutical company.



Some were unaware that the Wellcome Trust is a charity; when this was known it made a considerable difference to perceptions of the project. In this context it was felt very important for members of the public to understand that it has cut its links with Glaxo Wellcome. The partnership of Wellcome Trust and MRC was largely accepted and in some cases welcomed. It generally came across as a good balance between the statutory and the voluntary.

*“I guess it’s about the validity of the organization that is asking to use the information. So if it’s the Medical Research Council people will probably think that sounds like a very respectable body.”*

Local councillor SE

There were a few qualifications to this general acceptance of the two organizations. Neither of the Muslims had any reservations about MRC or Wellcome Trust, but thought that there should be a known link with the Asian population, preferably a Muslim representative. The Afro-Caribbean community leader was less positive about the Wellcome Trust; and refused to accept that there is no link between the Trust and Glaxo Wellcome, and worried that the ulterior motive is profit.

The likely involvement of pharmaceutical companies caused some concern. The rabbi accepted that pharmaceutical companies would need to use the data, but felt that there are significant risks of it being misused; some mechanism needs to be set up to prevent this. Others accepted that pharmaceutical companies need access to the information, but were concerned that these companies often act unethically.

*“A lot of people in this community are denied the full advantage of medical research because of the way in which certain pharmaceutical companies sell and market their products, to maximize their profits. And I think that’s why it’s important that the fruits of the research are not used in that way.”*

Anglican priest SE

There was a general feeling that drug companies reap benefits without offering anything in return. If samples are being sought and medical records are being accessed, then drug companies should put something back in – by sharing profits nationally or globally, by sharing

findings from their research, or by offering volunteers some sort of reward for taking part, such as free health screening.

*“They make enough money out of the process of developing drugs so therefore they should be paying for the research for information that helps them to do that.”*

Local councillor SE

*“People might say ‘I want my share because it was my bit of blood that helped you get there’.”*

Rabbi North West

There was no simple solution to this issue, but some feeling emerged that there is a need for broader-based ethical advisors to oversee the practice of drugs companies involved.

## 22.6 ***Likelihood of taking part***

Considered opinion on whether people would take part and donate samples varied across the different spokespeople. Many of the community and religious leaders felt that people would need reassurances about key issues before deciding. They would want to know who is conducting the research, what information would be needed, the degree to which it was confidential, and how the samples and information would be used.

Among those from minority ethnic and religious groups it was believed that there would be considerable influence on decisions from within the community. People would be more likely to take part in the collection if they knew others who were participating, particularly friends and relatives.

The African community leader believed people in the African community (especially first-generation) would be unlikely to take part in the project. They have considerable suspicion of research, particularly carried out by whites on blacks; participation would depend heavily on who is taking blood, and what relationship they have with the individual.

The rabbi believed that medical research is necessary and must move on, but there are serious ethical issues to consider in relation to the proposed sample collection, most importantly that of informed consent.

He felt he could perhaps approve this collection if handled correctly, but predicted that more traditional Jewish leaders would oppose it out of hand.

There was also quite a widespread feeling that the sample collection should reflect all minority ethnic and religious groups; several respondents said unprompted that this was an important consideration for them. They felt that those running the research should include medical representatives from different types of community; the Hindu community, for example, might be unhappy if they felt that only Christians were represented by those conducting the collection.

*“If the research team invite people from the other communities (not just Christians) that would be the best thing, no doubt about it.”*

Hindu religious leader Midlands

## I. Findings – interest group spokespeople

### 23. Contextual points

Seven spokespeople, representing five interest groups, took part in the research. Three people took part in one of the discussions. They were well informed about the issues surrounding genetics research and, in most cases, the issues surrounding the use of human biological samples for research. They all represented organizations with an established ethos, policy or mission statement regarding genetics research, and they all had strong feelings and well developed opinions on the subject.

### 24. Attitudes to medical and genetics research

All the spokespeople were basically favourably predisposed to the idea of research *per se*. However, there were variations in belief as to whether research, particularly genetics research, was appropriately regulated currently, and about how stringently it should be regulated.

Those who were most welcoming towards genetics research thought that there was less need to regulate the types of research to be carried out, and more needed to monitor the uses to which the research is put. Knowledge about, for example, any link between genetics and intelligence would be a good thing as long as that knowledge was not misused for discriminatory purposes such as eugenics.

*"In broad terms we think genetic research is a good thing and there should be more of it. We don't have any reservations in principle about particular aspects of genetic research. We may have reservations about the uses to which the knowledge is put... We tend to take the view that you can't deliberately turn your back on knowledge."*

Some respondents thought that some types of research were more acceptable than others. One respondent drew a distinction between genetic research into somatic engineering and that into germ-line engineering, saying that somatic engineering was more acceptable than germ-line engineering because germ-line engineering was too imprecise and was meddling with that which should not be meddled with. Somatic engineering was thought to have fewer moral

implications and more immediate benefits. This respondent also drew a distinction between research for genetic repair and that for enhancement, saying that research for repair was more acceptable than that for enhancement.

*"A scientist once explained to me that trying to do germ-line genetic engineering is rather like trying to cure an elephant with appendicitis with a blunderbuss. If you fire a blunderbuss at an elephant to try and remove the offending organ the results would be unpredictable, and we feel the current worldview is that germ-line engineering is just too difficult and risky... They shouldn't be trying to do things they can't control... When you turn to somatic engineering it's a totally different position."*

Another respondent brought up the subject of disability in this context. This respondent was critical of the treatment of disabled people in society, and specifically in relation to medical and genetics research. Disabled people's lives were said to be made difficult not by their disabilities, but by the attitude of non-disabled people towards them.

*"There is still an underlying acceptance that disability is something which should be eradicated. But not eradicated the way we say it should be, because we define disability as the social oppression that society actually produces...When society talks about disability they see only impairments and it's the impairments they want to get rid of."*

This respondent believed that the medical establishment, health authorities and insurance companies have a negative attitude towards disabled people in that they assume that disabled people have something wrong with them.

*"We are extremely concerned, and have been for a very long time, at the way the financial interest groups, be they scientific companies, insurance companies, health authorities, at their basic attitude to disability."*

In relation to genetics research, this respondent was positive about genetic therapies, provided they did not affect other aspects of the individual, and that their consequences are understood. However, the respondent was concerned that genetics research and gene therapy could lead to eugenics and the rejection or modification of babies with what society regarded as disabilities.

*"There must not be discrimination. I mean this drawing of lines between one impairment and another, I think it's just playing to people's prejudices and where are you going to stop? It is very dangerous if you start going down that road...you've had it, you are down the eugenics path."*

Another respondent saw a difference between 'blue-skies' research, where scientists had no goal other than to find out information, and that driven by financial imperative. This person suspected that the motivations of those carrying out blue-skies research were more likely to be worthy than the motivations of those carrying out research driven by a financial imperative. It was thought that this difference in motivations affected the way in which the research was carried out.

*"There are people who are sitting around doing what scientists do, which is find a question, a thesis or something, and challenge it. But there are people who use scientific techniques in a technical and engineering manner who don't go through the rigorous process. What they are doing is goal-driven, they want to achieve this and they are disregarding what is along the way because they are focused on one point... I feel that the scientists have been corrupted by the financial imperative; they are now driven not by scientific reasoning."*

Across the group of spokespeople, research directed towards the treatment of disease was welcomed, but there was wariness about the implications of altering people's genetic makeup.

There was call for more discussion of the subject and the inclusion in the debate of people from a wide variety of disciplines, including ethicists, sociologists, philosophers and theologians. There were some doubts about the motivations of politicians and some scientists, and a perceived need for examination of the relationship between the two.

*"In countries like Italy and France there is a tradition of having these consultation bodies as a melting pot so you would invite opinions from a broad range of philosophical positions and you get them to hammer it out. We have gone for a different model. We are very efficient in this country, very utilitarian and we, I feel, rubber-stamp decisions that have almost been pre-made. I'll give you an example. If you look at the consultation exercise on human cloning that took place last year, the number of people appointed to the consultation body was four. Every one of those four was a scientist."*

## 25. **The use of samples in medical/genetics research**

There were some similarities between attitudes towards the use of human biological samples for medical or genetics research and those towards research in general. It was broadly considered acceptable *per se*, but in need of stringent regulation to make sure that it was not abused, especially with regard to obtaining consent.

One view was that historically, samples taken for research have not been abused. This respondent said that, in some cases, imposed safeguards have restricted potential use of samples.

*"In teaching hospitals and what have you there are huge numbers of samples kept which have been gathered for research purposes, and there isn't a track record of systematic abuse of those samples in terms of breaching people's confidentiality. If anything, the track record has been in the other direction where perhaps the potential use has been constrained because people have been almost over cautious about allowing access to them."*

Some reservations were expressed about paying donors for human biological samples. Parallels were drawn with blood donation in the US, where donors are paid, and as a result they are often those most in need of the money but not necessarily having hygienic lifestyles.

*"In America there were great problems with blood donations and people doing it for the money. People with perhaps less healthy lifestyles were generating the most blood."*

*"Americans are very dependent on people getting paid for blood donations, which means that sometimes you're getting blood from completely the wrong group of people and it is very high risk."*

## 26. **Response to the proposed WT/MRC sample collection**

### 26.1 ***Initial reactions***

All seven spokespeople had heard something about the proposal, and some knew about it in detail. All except one were broadly in favour of it, but some felt they needed to know more about the detail before giving their unreserved approval.

One initial reaction was that the issues of most interest to the respondent's organization would be the rights of participants, and the types of research that would be carried out on the collection. This respondent said that strict guidelines should be written before the work gets underway rather than after. The onus should be on those organizing the collection to work through the ethical implications before starting the project rather than responding to individuals and campaign groups.

*"[We would be interested in] the sort of issues about the rights that any person having samples taken from them would have. Also, the uses to which the work is put."*

This respondent also thought it important to regulate the research by means of an independent organization made up; Baroness Warnock was cited as an example of the sort of person who would be suitable to sit on such a committee. Public consultation and debate were thought important so that people who volunteer understand the implications and so that they can understand any press reaction.

A second respondent was more enthusiastic about the proposal. This person saw a sample collection on this scale as necessary if more is to be discovered about the links between health problems and gene mutations. The risks of the project (regarding problems to do with confidentiality and consent, and the potential for abuse of the sample) were acknowledged, but were thought balanced by the good that could come out of the collection.

*"You've got to do it across large samples if the promise of the human genome is to be realized in terms of improved drugs, improved treatments and better management of complex diseases."*

Another respondent thought that setting up the collection had huge benefits in terms of medical developments, resource allocation, preventative medicine and criminology. This respondent suspected that the collection would pave the way for a national database, which would have similarly huge advantages.



*"Gathering information on the genetic composition of people in our society is going to be very valuable. It will give us a profile of the gene pool and that will allow us to make certain medical resource allocation decisions. And that's got to be good for efficiency and keeping costs down in the NHS. We would also be able to work a lot on the forensic genetics and it would also be very helpful for studies in criminology."*

However, this respondent thought there could be risks associated with the collection, particularly in terms of insurance. A situation could arise where the insurance market collapsed, sparking off industrial espionage, with companies trying to obtain genetic information by stealth. There were also concerns about new forms of discrimination in healthcare provision, for instance, against areas where genetic disorders are prevalent, or against certain population groups.

*"You might end up with certain black spots in the country where there are no hospitals and certain white spots where there are lots of hospitals."*

The initial reaction of another respondent was suspicion and scepticism, particularly regarding how samples would be used and the outcomes of the research: this respondent wondered whether it would affect society's attitudes towards genetic disabilities. The worry here was that samples of DNA could be used in research on embryos. There was some mistrust of the Wellcome Trust and the MRC in this context: this respondent believed they were not likely to grant public access to all the information on outcomes from the research. There was also concern about the implications for insurance.

*"What it won't say is that some of the outcomes may have a very serious impact on how society looks at disabled people, how society treats disabled people...And that in quite a lot of cases this scientific work will be working on embryos."*

Other spokespeople were broadly accepting of the collection, but had some qualifications. They believed it was overdue, and saw it as an inevitable step along the path to a greater understanding of genetics and its link to prevalence and treatment of disease. However, they had significant concerns about confidentiality, consent, personal feedback on samples and the consequences of such feedback, the role of GPs in the collection, and the implications of public ownership with commercial access. There were also calls for equal representation of men and women in the sample.

## 26.2 ***Donor information and confidentiality***

It made sense to this group to gather information about donors to help establish the relationship between genetic and environmental factors. However, great care was thought necessary over the protection of information. Confidentiality was felt to be an important issue, and a potential pitfall for the collection. It was thought essential that tight guidelines were devised, and one spokesperson suggested that an individual high up in the organization should be personally accountable for confidentiality.

*"They have got to find a way of convincing people that what they are going to do is absolutely confidential. There needs to be a very specific line of command and there will be somebody who is responsible, somebody very significant who will be chopped into seventy-four pieces and fed to the dogs [if something goes wrong]. If just once it happened then everybody will stop doing it so there is quite a motivation on the part of these people."*

One respondent believed that access to medical records would cause problems. Respondents did not believe records were well kept by doctors, and that they were often incomplete and inaccurate. In addition there was concern that unauthorized users could access them, which would constitute an invasion of privacy.

*"Why should a research institution of any sort have access to that sort of private information? We don't live in a police state, not yet. I think it's absolutely outrageous!"*

This respondent did not trust the bodies organizing the collection, or any public bodies, to maintain confidentiality. The belief was that the problem would not be hackers, but the organizers themselves allowing inappropriate people access.

*"I think hackers are the least of your problems...If you do something and everyone says it is in confidence, just keep your fingers crossed that it is..."*

Another respondent took the opposite line, saying that in reality it would be hard to envisage a scenario where this data would be abused, because the proposed safeguards were too strict. However, this respondent recognized that the public's fear of abuse was real and needed to be dealt with by guarantees and reassurances.

*"It's difficult to construct a realistic scenario, the idea that some multinational pharmaceutical company would illicitly hack into the database rather than going and negotiating a licence to have access to it entirely legitimately."*

Disclosure of information to insurance companies was not seen as an important risk because so few people had significant genetic predisposition to disease, and in most cases this was known about from childhood anyway. The media was believed to have misreported the insurance risks.

*"We may be genetically predisposed to get cancer of some form or another, but it's not that much above the population risk and so therefore it's not significant for insurance."*

### 26.3 **Uses of the samples and information, consent and feedback**

Although these spokespeople were welcoming of the intention of the project to use the sample to investigate the cause of diseases, there were some reservations expressed about the finer points of the intended use of the sample. One respondent was concerned that research will be carried out to find cures for diseases that have environmental causes, rather than address the causes themselves. For example, the respondent said it would be better to encourage people to stop smoking than put money into curing lung cancer.

*"A lot of research that has been done is looking to cure problems which are environmentally created, ones which it would be a lot simpler and a lot more effective to prevent. Probably the heart conditions, cancers, lung conditions, so many of these are created by other people. By looking to a technical fix I feel you are missing the point."*

Another respondent was worried about the organizers' definitions of 'disease', and wanted to know who was defining these terms. The concern here was that talking about heart disease and cancer was a manipulative use of emotive terms to win over the public.

*"What is a disease? What the hell are they talking about? Do they consider piles a disease? Or are they only going to do something about cystic fibrosis? And who is making the judgement that one is worse than the other?"*

This respondent thought it good that the organizers were admitting that samples could be used for unknown purposes in the future, but had

concerns about the implications of this, and wondered if it gave them too broad a licence.

Across this part of the sample, it was thought important that consent documents were thorough and easy to understand. There were mixed views as to whether volunteers should be able to restrict their consent to certain uses. One spokesperson said that consent can not be restricted because this would affect the potential usefulness of collection. This respondent suggested a solution was to insist that an independent body should approve all research ethically.

Another disagreed, saying that having one-off consent was dangerous because samples could be used for unethical research, such as population-specific biological warfare. This respondent acknowledged that a tension existed between wanting to encrypt information irreversibly for the sake of confidentiality, and wanting to re-contact donors to seek permission. The conclusion was that future research could be restricted to that approved by the government.

*"I might give my blood samples and you take the tissue and later on you find a way to make some kind of biological weapon which is person-specific or sub-group specific; then I would prefer it if you returned to me for further consent before pursuing that work. So I think the idea that we can just have one-off consent and then sign a clause to say scientists will be allowed to use this to work on new discoveries is quite dangerous."*

Some spokespeople wondered what would happen if a donor decided to drop out. They thought it surprising and heartening if the scientific community would be prepared to destroy their samples if the donor requested.

The general feeling amongst spokespeople was that the provision of individual feedback was both impractical and inappropriate in a research project. However, it was thought that there could be a case for re-contacting donors if it were discovered that they had treatable diseases. One respondent thought that, in any case, it was important that donors were informed about what they could expect prior to consent. Another thought the possibility of individual feedback

worrying, as this implied that the process of encrypting data was reversible.

*"To be constantly going back to individuals means that you've got your Chinese wall system working backwards all the time."*

Proactive general feedback was thought vital to prevent the collection from being hijacked by those with their own agenda, primarily the media. It was also seen as a way of presenting the collection as open and honest.

#### 26.4 **The role of GPs**

Involvement of GPs was widely felt to be the only practical way to conduct the collection. However, it was felt that information should also be available to the public via other sources, such as pamphlets and a telephone advice line.

*"There might be, say, a website or a booklet that can be given, possibly even a kind of freephone number or something. Someone who is on hand to answer any queries, either things which the GP wants to check up on that he or she's not sure on, or something where people who are approached can ring up and say, 'Can you reassure me that you're not going to make my DNA into Oxtail Soup?'."*

One respondent was concerned that GPs would be pressurized into taking part, particularly by pharmaceuticals companies. This person doubted that good GPs would want to take part because their priorities would lie elsewhere. Others were worried about the proportion of GPs' time the collection would take up.

*"Given the size of this exercise you'd be taking GPs out of their work for very big percentages of the time and that itself would damage the health of the nation."*

#### 26.5 **Commercial access to the collection**

There were mixed views about allowing commercial companies access to the collection. One spokesperson thought commercial access vital if medicines were to be developed. This respondent thought that no company should have an *a priori* head start in terms of commercial access, but access should be granted to the company best placed to

benefit patients in each case. However, this person had some concerns that bias would be shown to the MRC's subsidiary venture capital company.

*"The MRC has got very close links with either its own or a subsidiary venture capital company. Previously they've said that any outcome from MRC-funded research, [this company] will get first crack of the whip."*

Another respondent thought that any commercial access raised possibility of unscrupulous companies getting hold of dangerous genetic information, if not about individuals, then about population sub-groups.

There were calls for at least some of the financial gains made from work on the sample being passed on to the public. One respondent suggested that patents resulting from the work should belong to the community rather than private companies so that benefits accrued and were not directed solely to pharmaceuticals companies. Another suggested that companies should be charged for access to the collection, with the money going back into research.

*"The funders of this database should ensure that they get a proper financial return which reflects the value of the data set they've got, and that money should be ploughed back into further research."*

## 26.6 **Management of the sample collection**

Views of the MRC and Wellcome Trust were mixed among spokespeople. Overall three had broadly favourable views, one was ambivalent and one was mistrusting.

One of the spokespeople had concerns about the MRC and Wellcome Trust authorizing access to the collection. This respondent was not sure how independent the organizations were, and thought it would be better for an independent body to give authorization.

*"I imagine the research would be organized by the Wellcome Trust and the MRC. They are considered by some to be fairly cooperative bodies, but they are not neutral by any means. Maybe the authorization should come from an independent body which is created."*

Another respondent welcomed the involvement of the two organizations, saying that it was evident that the MRC and Wellcome Trust had learnt from the Icelandic collection and were approaching the issue in a rational and ethical way, with protection built in for the individual.

One respondent thought highly of the Trust's consultation on human cloning, but felt that it sometimes made scientific appointments that represented only one point of view. The example of embryology was cited here with the comment that the Trust did not take the sanctity of the early human embryo into account. This respondent was also critical of the perceived government tendency to exclude pro-life thinkers from debates.

*"I would encourage the Wellcome Trust to try to show some balance in the recruitment of embryologists and geneticists to make sure that you don't just get one particular worldview."*

Another respondent believed that the MRC as a government body sanctions research into areas it thinks will be profitable. This individual believed that the Wellcome Trust tried to listen to the concerns of disabled people, but did not like the response it received. The belief was that its ethos was based on either making money out of disabled people, or wanting to eliminate them.

*"Don't let's try and pretend that all these bioethical concerns, particularly around genetics are not basically eugenics-led. They are covered up with smarmy sanctimonious statements that 'we are trying to do good'."*

Others were positive about the MRC and Wellcome Trust, and believed their motives to be more worthy than those of other organizations who feasibly might have organized the collection. For these people, as with the GPs and nurses, there was no one better placed to carry out the project than these two organizations, including universities.

*"I would be much more suspicious if it was a university institute, because I think the lines of what kind of research gets done on behalf of companies in universities has been so blurred in the last ten or twenty years that some university departments seem to be simple outgrowths of pharmaceutical companies."*

# **APPENDICES**

**1. Sample specification**

**2. Discussion guide**

**3. Recruitment questionnaire**



## Sample specification

*General public – no ethnic origin specification: 12 group discussions*

- G1: male BC1 18-21 London/SE
- G2: female C2D 31-45 London/SE
- G3: male C2D 61-75 Midlands
- G4: female BC1 22-30 Midlands
- G5: male C2D 46-60 South Wales
- G6: female BC1 31-45 South Wales
- G7: male BC1 22-30 North West
- G8: female C2D 18-21 North West
- G9: male C2D 31-45 Scotland
- G10: female BC1 61-75 Scotland
- G11: male C2D 22-30 North West
- G12: female BC1 46-60 London/SE

*General public - ethnic minorities: 4 group discussions*

- G13: African male 22-30 London/SE
- G14: Caribbean female 46-60 Midlands
- G15: Indian Hindu female 18-21 London/SE
- G16: Pakistani Muslim male 46-60 North West

*Community leaders: 6 depth interviews*

- D1: African community leader London/SE
- D2: African-Caribbean community leader Midlands
- D3: Indian Hindu community leader London/SE
- D4: Pakistani Muslim community leader North West
- D5: Chinese community leader London/SE
- D6 non-ethnic community leader (councillor) London/SE

*Religious leaders: 7 depth interviews*

- D7: Anglican priest London/SE
- D8: African Baptist priest London/SE
- D9: Catholic priest Scotland

- D10: Rabbi North West
- D11: Hindu religious leader Midlands
- D12: Hindu religious leader London/SE
- D13: Muslim religious leader London/SE

*Disease specific groups: 14 depth interviews*

- D14: patient with heart disease London/SE
- D15: patient with heart disease Scotland
- D16: patient with cancer South Wales
- D17: patient with cancer London
- D18: patient with physical disability Midlands
- D19: patient with physical disability North West
  
- D20: relative of patient with heart disease London/SE
- D21: relative of patient with heart disease Scotland
- D22: relative of patient with cancer South Wales
- D23: relative of patient with cancer London/SE
- D24: relative of patient with physical disability Midlands
- D25: relative of patient with physical disability North West
- D26: relative of patient with mental health problem Midlands
- D27: relative of patient with mental health problem South Wales

*Specialist interest groups: 5 depth interviews*

- D28: representative of Genetics Forum
- D29: representative of Genetic Interest Group
- D30: 3 representatives of organization involved in consumer issues
- D31: representative of Life
- D32: representative of Disability Awareness in Action

Other interest groups were approached but did not take part. Some did not respond and others did not have the time to take part or were still checking availability when the fieldwork period came to an end.

*Primary healthcare professionals: 8 depth interviews*

- D36: GP London/SE
- D37: GP Scotland
- D38: GP South Wales
- D39: GP North West
- D40: practice nurse London/SE
- D41: practice nurse Scotland
- D42: practice nurse South Wales
- D43: practice nurse North West

## Human biological samples - Topic Guide

### General public, minority ethnic groups

#### Background

- Warm-up on personal details (family, employment, spare time interests)
- (briefly) attitudes towards health, treatment of disease and developments in medicine

#### Medical research

- Awareness of, and attitudes towards, medical research generally
- Understanding of the term 'medical research'
- Key associations/perceived uses of medical research
- Is it associated more with **general biological investigation** or more with bigger '**single issue**' research (e.g., Cancer, heart disease)?
- Perceptions of benefits and risks of medical research
- Key concerns about medical research
- Sources of information and **influences on perceptions** (probe for health professionals, media, friends and family, scientific community)
- Which sources are they more and less likely to believe and trust?
- Personal relevance of/interest in issue:
  - Do they imagine it might affect them?
  - In what sorts of situations and scenarios could they imagine encountering medical research (eg relative with illness/disease)?
  - Do they have any views on it based on **religious or cultural considerations**?

#### Genetics research

- Awareness of and attitudes towards genetic research
- Understanding of the term 'genetic research'
- Key associations/perceived uses
- Is it associated more with **general biological investigation** or more with bigger '**single issue**' research (e.g., Cancer, heart disease)?
- Perceptions of benefits and risks
- Known or assumed **applications** of genetics research
- Key sources of information and **influences on perceptions** (probe for health professionals, media, friends and family, scientific community)
- Personal relevance of/interest in issue
  - Do they believe it might have a place in their own lives and if so, how?
  - Did they know that it could be used in work to combat disease and develop more effective drugs?
  - Do they have any **religious or cultural views** on genetics research?
- Overall, how do people regard **genetics research compared with medical research** in general?

Note any misunderstandings surrounding medical and genetics research

## Human biological samples

- Awareness of and attitudes towards use of human biological samples
- What do they know and what do they think about this?
- How and where have they heard about it?
- How do they imagine research is carried out using samples?
- Knowledge of **materials used** and **how obtained** (awareness of use of samples from living beings and cadavers?)
- Attitudes towards the collection of **different types** of biological materials (any differences of opinion on blood, surgical waste, saliva?)
- Knowledge of **who carries out research** and owns samples (probe for institutions, commercial organizations and differences between the two)
- Beliefs about how material should/should not be used (probe for what is deemed acceptable/unacceptable and why)
- Perceptions of **motivations of scientists** involved
- Sources of information (probe as above)
- Personal relevance of/interest in issue
- Any **religious beliefs** or **cultural perspectives** that influence attitudes?

*Moderator to show and read out Board 1:*

***“Human biological samples – mainly in the form of blood - are collected by doctors from volunteers and are used for research into diseases, drugs used to fight diseases, genetics research and for general biological research”***

## Attitudes towards personal involvement in donating samples

- If they have **personal experience** of donating biological samples - circumstances and reasons for donation
- Positive/negative experiences
- Knowledge of how the samples have been/will be used (current and future)
- If they have **no experience** – likelihood of doing so in the future
- Imagined circumstances in which they would be asked and would donate
- Perceptions of benefits and risks involved, and main concerns

## Possible motivations for making donations

- What might be their rationale for making donations?
- To what extent would they be motivated by the desire to help others?
- And to what extent would they be motivated by possible benefits to themselves or their families?
- Does this vary according to whether samples are used for **research or for treatment** – e.g., For research vs. Blood for transfusion
- Does this vary according to whether samples are used for medical research or research on specific diseases such as diabetes?
- Would their response vary if they were asked to donate samples by their **GP**, the **practice nurse** or someone else?

### **Making a decision about donating biological samples**

- Nature of **decision-making process** – if they were approached to donate a sample, how would a decision be made, would they want to discuss it with others and if so who (family, friends)?
- Any concerns about how material should/should not be used
- Any concerns about how and when **consent** is obtained?
- Effects of **religious or cultural beliefs** on attitudes
- How does the idea of making sample donations compare with **giving blood** in terms of motivations, interest, benefits and risks? And with being an **organ donor**?
- If tissue is collected as **surgical waste**, do people feel they would own it and would they expect to be asked their consent for its use?

### **Response to proposed Wellcome Trust – MRC sample collection**

- Have they seen or heard anything in the **media** about this?
- If so, what have they heard, and where?
- What was their response to it?

*Moderator to show and read out Board 3:*

***“It is proposed to set up a collection of human biological samples from approximately half a million adult volunteers in the UK, to provide material for medical and genetics research. Volunteers would be invited to take part by their GPs and would be asked to give a blood sample, from which DNA would be extracted”***

- Does this remind them of any **news stories** they have seen or heard?
- Reaction to idea in principle – what are their **first thoughts and feelings**?
- Understanding of intended use, applications and potential benefits
- What issues are raised, and what concerns do people have about it? (note references to: **anonymity/confidentiality**; **consent**; mechanics of collection, sample collection and **storage**; **future use** of samples; **ownership** of samples; involvement of **commercial interests**)
- How would they feel if they were **approached to donate** samples?
- What would their initial reactions be?
- What **questions** would come into their minds?
- Would they want to discuss it with anyone, and if so, who?
- What do they imagine their considered response would be?
- How do they imagine members of their **family** would respond?

## Need for associated personal medical information

*Moderator to show and read out Board 4:*

***“Volunteers would be asked to fill in a questionnaire about their lifestyle and environment. Information would also be recorded on their current health and, over the coming years, on any diseases they develop”***

- What do people think about this?
- Do they understand why medical information will make a significant difference to the value of collecting samples?
- How do they regard the request for information on **lifestyle and environment** compared with the request for information on **current health** and in future, on diseases?
- How does the need for medical information affect their views of the proposed sample collection?
- Supposing there was also a need to use information in their **nhs records**?
- How might this affect views and motivations?

## Anonymity and coding of information

- Do they have concerns about anonymity and confidentiality?
- If so, what would give them appropriate **reassurances**?
- Would people want a written **guarantee** of anonymity?
- Generally how do people feel about **regulation and control** of practices and information in the public domain – do they trust government/public bodies to safeguard individuals and their privacy?
- How do they regard the prospect of regulation and control of information in the context of this sample and the associated medical records?

*Moderator to show and read out Board 5:*

***“Information on volunteers taking part would be recorded on computer. All the information collected would be stored and analysed in a form that would not allow individuals to be identified”***

- What do people feel about information being recorded **on computer**, and would they have any concerns about this? What would be the **worst case scenario** relating to medical information?
- To what extent would the promise to **code** and **anonymize** information reassure people?
- If it were coded, would people have concerns that information could be **traced**?
- Would they want further reassurances and if so, in what form?
- Do people have any idea of the sort of **management structure** for information and records that would give them adequate reassurance?
- Who do people believe should be **allowed access** to medical records once these have been input to the system – all researchers working with the samples, only specified senior researchers, anyone else?

- Do they feel researchers should be allowed **access** to records on a routine basis **without consent**? Or should they need to get consent for every use?
- Do they imagine people would have concerns regarding information finding its way to **employers, insurance companies** or others who they might not want to see it?
- What concerns would they have re employers and insurance companies?

### Consent

- How and when do they imagine this would be given?
- Do they expect volunteers would be asked for **written consent**?
- Do they imagine this would be binding?
- Do they assume that giving consent would mean their samples could be used for any research purpose or only certain types of research? (see below)
- Would they be concerned that having consented, people would then be committed to **continuing involvement** in the sample collection?

*Moderator to show and read out Board 6:*

***“All volunteers taking part would first be approached by their GP and would only give samples if they were entirely happy that they wanted to do so. Anyone changing their mind about participating would be able to drop out at any time”***

- How would people feel about this?
- Do people feel that **gps** would be the appropriate people to approach potential volunteers? Why/why not?
- What would people want to know before deciding whether or to volunteer?
- Would they be happy with assurance that they could **drop out** at any time?

### Access to research results

- Would people expect **feedback** on results of research using their samples?
- Do they have concerns about discoveries re their own samples?
- Do they imagine people would **want to know** results in all circumstances?
- Do they feel people have a **right to know**?
- Should relatives be given feedback?

### Mechanics of sample collection, storage and use

- Do they have any idea how samples would be stored and used?
- What do they imagine would be the procedures involved in using them?

*Moderator to show Board 7:*



***“Samples would be collected by specially appointed nurses at GP surgeries. They would be stored at regional sample banks and used by researchers authorized to do so”***

### **Current and future use of samples**

- How do they imagine the samples will be used?
- Do they have any idea of the sorts of medical problems and topics that might be tackled using the samples?
- What do they see as the more and less **appropriate**? Probe for differences between basic biology, work on specific diseases, and possible future research on unspecified areas

*Moderator to show Board 8*

***“Samples would be used for existing research programmes on diseases or biological problems. It may also come about that further discoveries mean that samples could be used in other ways that we do not yet know much about”***

- How would people feel about this?
- Supposing samples stored were able to be used in ways or on problems that researchers do not know about at the moment, would people feel any differently about donating samples?
- If so, why is this?
- What would people feel about giving consent for this?
- Would they be prepared to give consent for samples to be used in any way, now and in the future?
- If not, how and where would they draw the line?

*Moderator to show and read out Board 9:*

***“The information collected will enable researchers to understand more about the links between genes, environment and lifestyle in the development of diseases. This will help them develop new treatments and methods of prevention for common illnesses such as heart disease and cancer”***

- To what extent does this fit with their expectations?

### **Ownership of samples and involvement of commercial interests**

- Who do they imagine will have **ownership** and **control** of the samples?
- What do they feel they would own – any sample, any part of any sample, the information drawn from a sample?
- What about **dna** – would they feel they own this?
- Would people have concerns about this? what would they want to know?

*Moderator to show and read out Board 9:*

***“The information gained from research on the samples will be owned publicly and no company will be allowed exclusive commercial access”***

- How important is this?
- Would people expect and want reassurance on this?
- If so, why?
- To what extent does commercial use of samples affect their views on the proposed sample?
- Would the possible involvement of commercial interests influence people's likelihood of making donations?

### **Organizations involved in conducting the sample collection**

- At what stage would they want to know who might be operating the sample collection
- Which organization(s) do they think might involved?
- Response to proposed involvement of **wellcome trust** and **mrc**
- Have they heard of these organizations and what, if anything, do they know about them?

*Moderator to show and read out Board 10:*

***“The Wellcome Trust is the world's largest medical charity. It supports 3000 researchers in 30 different countries and helps maintain the UK's reputation as one the world's leading scientific nations”***

***“The Medical Research Council promotes research into all areas of medical and related science in universities, medical schools and specialist institutes. It is funded mainly by the government but is independent in its choice of which research to support”***

### **Overview**

- **Overall impressions** and beliefs about collection of samples in general and the proposed Wellcome Trust – MRC sample collection in particular
- Any changes in attitudes towards medical and genetic research generally and the collection of samples specifically?
- Any changes in interest in subject?
- Recap on specific areas of concern/interest
- Thinking about all the issues now, how would they feel if they were invited to consider making a donation?
- What would their **motivations** be?
- What would they take into account before making a decision?
- Information needs to make decisions about donating samples
- Preferred sources of information
- How would they expect to be approached?
- Would they expect to be **paid** for donating? If so, how much

WEL095

MARCH 2000

## CONTACT QUESTIONNAIRE

Name: .....

Address: .....

.....

Tel: .....

Sex: Male ( ) Female ( )

Age: 18-21 ( ) 22-30 ( ) 31-45 ( ) 46-60 ( ) 61-75 ( )

Marital status: Married/cohabiting ( ) Single ( )

Children at home: No ( ) Yes ( ) WRITE IN

AGES.....

Ethnic origin:

.....

Occupation (HoH): .....

SeS: B ( ) C1 ( ) C2 ( )

HELLO, I WORK FOR A MARKET RESEARCH COMPANY CALLED CRAGG ROSS DAWSON. WE ARE CARRYING OUT SOME RESEARCH TO OBTAIN THE VIEWS OF THE GENERAL PUBLIC ON DEVELOPMENTS IN MEDICINE. COULD I ASK YOU A FEW QUICK QUESTIONS?

QA Do you or any of your family or close friends work in any of the following occupations?

Market research

( )

Marketing

( )

Advertising

( )

Publishing

( )

Journalism

( )

The medical profession

(including doctors working in general practice, hospitals)

or clinics, nurses of any kind, midwives and health visitors)  
( )

CLOSE IF YES TO ANY OF THE ABOVE, OTHERWISE GO TO QB.

QB Have you ever attended a market research interview or group discussion?

No ( ) GO TO Q1  
Yes ( ) GO TO QC

QC When did you last attend a market research interview or group discussion?

Within the last 6 months ( ) CLOSE  
Longer than 6 months ago ( ) GO TO QD

QD What was/were the subject(s) of the discussion(s) you attended?  
WRITE IN BELOW.

.....

CLOSE IF RELATED TO THIS RESEARCH TOPIC. OTHERWISE GO TO Q1.

Q1 Do you have any of the following educational qualifications, or are you studying for any of them at the moment?

O Levels ( ) GO TO Q2  
GCSEs ( ) GO TO Q2  
A levels ( ) GO TO Q2  
Degree ( ) GO TO Q3  
None of these ( ) GO TO Q2

Q2 What subject is your degree/your degree course in?

(WRITE IN).....  
.....

IF DEGREE IS IN ANY OF THE FOLLOWING SUBJECTS, CLOSE:  
MEDICINE, BIOLOGY, BIOLOGICAL SCIENCES, PATHOLOGY,  
NURSING, BIOCHEMISTRY, MICROBIOLOGY, BOTANY  
OTHERWISE GO TO Q3

Q3 Do you belong to any special interest groups or pressure groups that have strong ethical views on medical and/or health issues?

Yes ( ) CLOSE

No ( ) CONTINUE

Q4 Have you had any experience, either yourself or in your immediate family of diseases including cancer, heart disease or any other hereditary disease?

Yes ( )

No ( )

NO MORE THAN 4 RESPONDENTS PER GROUP TO ANSWER YES. RECRUIT IF APPROPRIATE. OTHERWISE CLOSE.

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