

A background image of a microarray chip with a grid of small spots, overlaid with a blue gradient.

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A literature review of research  
conducted on public interest,  
knowledge and attitudes to  
biomedical science.

**wellcome**trust

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**August 2006**

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## 1. Executive Summary

- This report sets out the findings of a review of existing survey-based investigations of public knowledge, interest and attitudes to biomedical science among adult populations (18+) throughout the world since 1980.
- As the major non-governmental funder of biomedical science research in the UK, the Wellcome Trust has a critical interest in understanding public responses to biomedical science and technology, and in fostering greater citizen understanding and engagement with the scientific research that it conducts.
- The Trust has funded a number of empirical investigations of the public's engagement with and attitudes toward different areas of biomedicine. Even when viewed in conjunction with non-Trust-funded research studies in this area, the existing evidence base does not provide a sufficiently firm footing for making inferences about trends over time in both general public attitudes and in opinion towards specific new and emerging technologies. To this end, it is proposed that a comprehensive biennial monitor of public opinion be implemented within the Trust's 2005–2010 strategic plan.
- Our systematic review of existing studies of public knowledge, interest and attitudes to biomedical science identified 298 publications, 236 studies, 140 knowledge questions, 85 interest questions and 817 attitude questions.
- The ten primary areas in which attitude questions have been administered in the surveys reviewed were: attitudes to biotechnology/genetic engineering; genetic testing and modification/therapy; stem cells and cloning; beliefs about genetic influence on traits and behaviour; storage and use of human genetic information; personal experience of genetic illness; nanotechnology; the use of animals in biomedical trials; regulation; and trust.
- A key issue in measuring public opinion to new and emerging technologies relates to how the researcher should go about measuring opinion towards areas of science and technology about which most members of the public are only dimly aware. Three primary approaches are discussed in the report: using abstract/generalised questions formats; providing elaborate preambles which 'educate' respondents as part of the question; and 'filtering' out ill-informed respondents from substantive attitude questions.
- There is no definitive answer to which of these solutions to the 'low information problem' should be adopted. The best approach probably involves a combination

of all three formats, with an explicit recognition of the inherent limitations of each. Supplementing the findings of survey investigations with more in-depth, qualitative work seems particularly appropriate in this context.

- An interesting potential development of future work in this area would be to explore Fishkin's Deliberative Polling methodology, or some online or Grid variant thereof. This would enable the estimation of 'informed opinion' from a representative sample of the public in a way that is not feasible in conventional polls. We should note, however, that the Deliberative Polling method is not without problems of its own.
- Generally, we can characterise measures of interest/engagement as falling into two broad categories: subjective self-assessments of 'interest'/'importance'/'concern' and self-reported behavioural indicators of interest and involvement. In our view, these measures generally perform well and future surveys should aim to utilise a combination of self-assessed and behavioural indicators to produce a composite measure of personal salience of biomedical science.
- Existing knowledge measures fall into one of three categories: self-assessed knowledge; fixed-choice format; and open format. While there are some noted problems with fixed-choice formats, particularly their susceptibility to guessing and the differential effect this has across sub-groups, in our view they represent the most accurate and cost-effective means of measuring scientific/biomedical science.
- While it is likely that the current mix of *ad hoc* initiatives and recurrent Eurobarometer modules will continue to provide an insight into public opinion toward biomedical science for the foreseeable future, by its very nature this form of evidence is partial. Lacking core funding and a clear *a priori* research agenda in the medium to long term, the content and timing of such initiatives is likely to remain sporadic and irregular. These features of existing research on public attitudes to biomedicine speak to the need for a longer-term investment, of the sort envisaged by the Wellcome Trust.





## Introduction and background

Biomedical science represents a rapidly evolving area of scientific inquiry and technological innovation, which holds far-reaching potential for transforming human health, wellbeing and longevity. Yet despite the optimistic claims of its proponents in science and industry, a number of technologies have, in recent years, succeeded in attracting negative media coverage and public hostility, with controversies over, *inter alia*, animal and human cloning, gene therapy and nanotechnology.

As the major non-governmental funder of biomedical science research in the UK, the Wellcome Trust has a critical interest in understanding public responses to biomedical science and technology, and in fostering greater citizen understanding and engagement with the scientific research that it funds.

The arguments for advancing public understanding of, and engagement with, biomedical science echo those made for science more generally; promoting public understanding and engagement is seen as an essential prerequisite for democratically based policy making and informed public choice. This fits within the broader debate of how science is governed and regulated within modern liberal democratic systems, a question which motivated a major recent public inquiry into the relationship between science and society, by the House of Lords Select Committee on Science and Technology (2000). This Committee concluded that “society's relationship with science is in a critical phase” characterised by “public unease, mistrust and occasional outright hostility”.

All major stakeholders now recognise that a sufficiently hostile public and media can seriously constrain or even veto a contentious biomedical research programme. It is within this context that the Wellcome Trust seeks to develop a more systematic approach to describing and understanding trends in public interest, knowledge and opinion towards biomedical science and its associated technologies.

The Trust has, over the past ten years, funded a number of empirical investigations of the public's engagement with and attitudes toward different areas of biomedicine. This has included modules on the British Social Attitudes Survey, smaller-scale focus group and interview-based investigations and an innovative study investigating the influence of information and deliberation on the dynamics of opinion formation and change within the same panel of respondents over time.

Although this has produced a number of important contributions to our current understanding of public opinion in this area, the research investment to date has occurred primarily on an ad hoc basis. Even when viewed in conjunction with non-Trust-funded research studies in this area, most notably the series of EC-funded Eurobarometer studies,

the existing evidence base does not provide a sufficiently firm footing for making inferences about trends over time in both general public attitudes and in opinion towards specific new and emerging technologies. To this end, it is proposed that a comprehensive biennial monitor of public opinion be implemented within the Trust's 2005–2010 strategic plan.

The aim of this report is, therefore, via systematic review of the existing research literature, to provide the Wellcome Trust with a thorough account of existing survey-based investigations of public knowledge, interest and attitudes toward biomedical science. The findings of this review will aid in both evaluating the case for the proposed monitor survey and in informing its design, should it go ahead.

In section 3 of this report, we provide a detailed account of the methodology employed to identify 'in-scope' studies and publications. We differentiate between *studies*, which are primary data collection activities and *publications*, which are analyses of studies. Multiple publications can, therefore, be based on the same study. Sometimes, though this is rare, a study has no associated publication. In the methodology section, we also provide a summary of the number of studies and publications identified in the review and the total number of different types of survey question found within them.

In section 4, we provide an overview of the substantive findings of the in-scope publications; how can we characterise the shape and trajectory of public knowledge, interest and engagement in biomedical science over the past 25 years? Sections 5 through 7 provide a narrative account, with illustrative examples, of the main types of questions that have been used to measure public knowledge of, interest/engagement in, and attitudes toward biomedical science respectively. Our approach in this section is both descriptive and critical in nature; where appropriate, we comment on the methodological advantages and disadvantages of different approaches to question design. In addition to describing the ways in which previous studies have approached the measurement of these 'fuzzy' concepts, we provide a critical evaluation of the approach with regard to the state of the art in measurement theory and questionnaire design.

We conclude with an overview and synthesis of the main sections of the report. We provide an assessment of the completeness of the extant corpus of empirical evidence and consider the merits of the case for a dedicated, ongoing survey of public opinion toward biomedical science. General recommendations are provided with regard to questionnaire content for such an exercise and summarise some of the main issues with regard to how such a survey might be designed and implemented.

## 2. Methodology

The aim of this report is to review all survey-based studies conducted into public knowledge, interest and attitudes toward biomedical science among adult populations, aged 18+, around the world since 1980. In the first stage of the research we conducted a systematic search of the literature via electronic sources. These included ISI Web of Knowledge, BIDS, Ingenta, MEDLINE, Psci-com and the search engine Google. As we intended to identify both publications and the datasets upon which the publications were based, we made use of a range of other databases and websites around the world. These included the Inter-University Consortium for Political and Social Research (ICPSR) and the UK Data Archive (UKDA), the National Science Foundation (NSF), Eurobarometer, the Council of European Social Sciences Data Archives, the Central European Opinion Research Group (CEORG) and Networked Social Science Tools and Resources (NESSTAR).

Because search results from these electronic databases are sensitive to the way queries are formed, we used a large number of keywords to ensure wide coverage. Twenty-one were used: 'public', 'science', 'knowledge', 'citizens', 'attitudes', 'understanding', 'interest', 'technology', 'survey', 'biotechnology', 'awareness', 'environment', 'risk', 'perception', 'measurement', 'genetic', 'literacy', 'opinion', 'engineering', 'biomedicine' and 'animal testing'. Keywords were separated by the words OR or AND. In addition, different forms of the same word were used. Usually this required the typing of a symbol such as an asterisk at the end of the stem of the word. This allowed all forms of the word to be included in the search results. The completion of this stage of the selection procedure resulted in approximately 302 articles, reports and datasets that appeared, *prima facie*, to be within the scope of our study.

In the second stage of the search, the criteria for exclusion and inclusion in the meta-analysis sample were specified. Each article or report obtained in stage one was manually searched and evaluated according to more specific criteria. Only articles relating to national or international sample surveys of adult populations since 1980 whose focus was on biomedical science were retained. Within these, only surveys that included measures of knowledge, interest and attitudes toward or about biomedical science, broadly conceived, were eligible for inclusion. From this pool of articles and other documents we were able to identify a final list of in-scope studies and publications from the first two stages of the review. Note that this means we excluded questions relating to attitudes to science and technology in general (e.g. 'science makes our way of life change too fast'). Although individual orientations toward science in general are clearly relevant to the formation of attitudes toward specific applications of biomedical science, the inclusion of such items would have resulted in the scope of the review being too broad, given our limited time and resources for the conduct of this project.

Despite taking this systematic approach, it was still possible that we had missed some eligible studies. We therefore examined the bibliographies of all identified publications to identify any citations which appeared within scope but had not been identified from our initial search. As a final check, we identified 11 peer-reviewed journals with searchable online archives that are, or have been, likely repositories for in-scope publications. These were: *Public Opinion Quarterly*, *International Journal of Public Opinion Research*, *Science Communication*, *Journal of Human Gene Therapy*, *AgBioForum*, *New Genetics and Society*, *Risk Analysis*, *Public Understanding of Science*, *Science Technology and Human Values*, *Science*, and *Nature*. These additional searches highlighted a number of further studies which met the inclusion criteria. Additionally, four in-scope studies were brought to our attention after a progress meeting with the Wellcome Trust. At the end of the 'data collection' stage of the project, then, we had identified a total of 298 publications, 136 surveys and polls, and 1042 questions to form the basis of our report.

### **2.1. Bibliographic outputs**

The results of this systematic search of the literature formed the basis of the contents of this report. Additionally, we have produced a number of electronic outputs which summarise the studies and questionnaire items identified as within scope. These have been provided to the Wellcome Trust along with this report and are available to non-commercial users upon request. The electronic bibliographic outputs comprise:

- An Endnote database containing all 298 bibliographic references listed in appendix 4.
- A summary table in Word for all identified in-scope surveys containing information (where available) on sample design, response rate, mode, year, country, principal investigator and questions.
- An Excel database containing: a summary table of all identified surveys and the main topics covered; a list of all knowledge, interest/engagement, and attitude questions identified as in-scope. Survey questions within each of these headings are further broken down into different substantive and methodological sub-headings. Additionally, column headings allow the identification of the surveys in which each individual question has been included, with small variations in wording across surveys indicated.

### **3. Descriptive assessment of public knowledge, interest and attitudes to biomedical science**

Our primary objective in this report is to provide a review and methodological assessment of questions that have been asked in existing surveys of public opinion towards biomedical science. Before looking in detail at the results of this review, however, it is useful to provide some substantive context to the questions that follow by sketching the general shape and trajectory of public opinion towards biomedical science since systematic measurements began. This is obviously a potentially vast subject area that would require a book-length treatment to cover in any depth. Our review here, then, focuses only on the headline trends in rather broad brush-stroke. We begin with a short overview of the historical development of survey investigations of the Public Understanding of Science (PUS).

#### ***3.1. A brief history of survey-based PUS research***

Survey based studies of PUS have a comparatively venerable history. The first study of this kind was conducted in the late 1950s, motivated by the public fascination with the Cold War space race and the launch of the Soviet satellite, Sputnik. Funded by the National Association of Science Writers, Davis and colleagues at the University of Michigan conducted a survey of public views and understanding of science in the USA.

Their primary conclusion was that the public understood little about science and the scientific method, with only one citizen in ten describing science as having to do with experimentation. This proved to be a conclusion confirmed with, from some perspectives, depressing consistency for the remainder of the twentieth century and beyond.

Following this early start, little beyond occasional questions fielded on commercial polls occurred during the 1960s and 1970s until, in 1979, the US National Science Foundation (NSF) began a series of surveys of public attitudes and knowledge about science and technology as part of its 'Science Indicators' programme. Collaborative work by Jon Miller (the principal investigator of the NSF series) in the USA and John Durant and colleagues in the UK enlivened this nascent tradition with influential studies in the late 1980s and early 1990s, in which the primary theoretical focus of the field was established as comprising 'science literacy', risk/benefit and optimism about science, with a particular focus on biotechnology.

At this time, the series of PUS modules on the EC-funded Eurobarometer series was established as a comparable vehicle to the NSF series for the study of PUS in Britain and Europe. These influential investigations spawned a number of 'replication' studies around the world, notably in Japan, Canada and New Zealand.

By the mid to late 1990s increasing numbers of stand-alone surveys of public opinion toward science and, in particular, biotechnology were being conducted in different countries around the world. Although the field was now becoming more fragmented, with new, less normative and more critical theoretical perspectives beginning to emerge, the original influence of the University of Michigan study, via the NSF indicator series, could usually still be detected in the content and focus of most questionnaires.

In Britain, the influential British Social Attitudes survey series has been the most consistent (outside of Eurobarometer) site of survey investigations of public opinion toward science and technology, with modules on various aspects of science and biomedicine fielded in 1993, 1996, 1998, 2000 and 2003. During this time, other interested bodies including the Wellcome Trust, the Human Genetics Commission, the Office of Science and Technology, and the Department of Trade and Industry have funded survey investigations of public opinion to different aspects of science and technology. Beyond these more academic surveys of public opinion, recent years have seen a proliferation of commercial opinion polling on attitudes to different technologies and proposed government legislation/regulation, particularly in the USA. Often funded by interest groups and/or commercial enterprises, such polling results are typically used to bolster entrenched positions in disputes over proposed legal and regulatory frameworks. In the following sections, we proceed to a consideration of the primary findings of this tradition of research on public opinion toward biomedical science.

### ***3.2. Knowledge and engagement with biomedical science***

A 'scientifically literate' citizenry is one that can effectively participate in public debates about science, hold government to account over the speed and direction of science policy, and make rational choices as consumers of healthcare services and biomedical products. From a normative perspective, in modern democratic societies, citizens need to have sufficient levels of accurate information on which to base their assessments of policy alternatives in order that their policy preferences best reflect their own self- or group interests (Converse, 1964; Delli-Carpini and Keeter, 1996). As scientific and technological innovations become ever more central to the functioning of modern societies and to the daily lives of individual citizens, the argument goes, so the importance of technical and scientific knowledge within the mass public becomes increasingly important.

Regrettably, from this point of view at least, publics both in Europe and in the USA appear to possess depressingly low levels of knowledge of and engagement with science. Jon Miller finds, on his definition, not more than one-quarter of the European and US publics qualify as 'scientifically literate' (Miller, 1998 p.205–206). Moreover, this situation has hardly changed since systematic measurements first began, despite the best efforts of governments

and educators alike to popularise science and make it more accessible to ordinary citizens during the intervening years. Withey (1959) found that, in 1957, only about 10 per cent of Americans correctly defined science as having to do with the concepts of controlled experimentation, theory and systematic variation. Twenty years later, when the US National Science Foundation (NSF) initiated its Science Indicators survey series, the proportion was unchanged (Gregory and Miller, 1998).

In 1988, Durant, Evans and Thomas (Durant, Evans and Thomas, 1989) reported that only 17 per cent of the British public spontaneously referred to experimentation and/or theory testing when asked the question: 'what does it mean to study something scientifically?' When the same question was asked nearly a decade later, in the 1996 British Social Attitudes survey (Jowell, Curtice *et al.*, 1997), the proportion remained statistically unchanged at 18 per cent.

The picture for what might be considered 'factual' or 'textbook' scientific knowledge is similar. For instance, Durant, Evans and Thomas (Durant, Evans and Thomas, 1989) report that in 1988 only 34 per cent of the British public knew that the earth goes around the sun once a year and only 28 per cent knew that antibiotics kill bacteria but not viruses. In the USA, respondents faced with the same questions fared similarly to their British counterparts, with 46 and 25 per cent providing the correct answer respectively.

Is the picture any better for knowledge of biomedical science? While the focus is almost entirely on biomedical genomics in the investigations in this area to date, the answer is a resounding no. Members of the public certainly regard themselves as ill-informed; only 2 per cent of respondents in the 1997 German Biotech survey rated their knowledge of genetic engineering as 'very good', with a majority conceding they knew nothing about it at all (Hampel, Pfenning and Peters, 2000). And, although based on a self-selecting sample, the 2003 GM Nation consultation exercise in the UK revealed that a majority of respondents understood very little about genetic modification, with the arguments surrounding its application being widely perceived as meaningless in the context of everyday lives.

European and American publics have been found to score equally poorly on more objective factual knowledge batteries of biomedical science. Miller and Kimmel (2001) find nearly half of Americans to be 'biomedically illiterate', while, on a nine-item scale of biomedical knowledge on the 2002 Eurobarometer survey, the mean score in the UK was only 5.3, compared to a European average of 4.9 (Gaskell, Allum and Stares, 2003). Given that the answers to these questions should be known by someone with high school level biology, this population average is hardly impressive. Furthermore, as a mean score we also know that a large proportion of the population scored considerably lower than this.



Combining biological knowledge scores with information about public interest in and familiarity with biotechnology, Pardo *et al.* (2002) find that only one in five Europeans could be judged well-informed about biotechnology in 1996–97, with 45 per cent of respondents both unaware of, and poorly informed about, basic biotechnology concepts. In 2002, only around one-quarter of UK citizens could be classified as an ‘engaged public’, using an index of engagement based on awareness, biology knowledge and intended behaviour, a figure which showed little variation across the EU (Gaskell, Allum and Stares 2003a). In the 2003 British Social Attitudes Survey, Sturgis *et al.* (2004) report that half of all people in Britain described themselves as being ‘not very’ or ‘not at all’ interested in modern genetic science.

A German survey assessing the public’s factual knowledge of genetic engineering found that, on average, only 7 of 20 multiple-choice questions were answered correctly. The authors note that, while this score was barely above what would be expected using a guessing strategy, members of the public actually seemed to be applying systematic misunderstandings of basic biology in their responses to these questions (Pfister, Böhm and Jungermann, 2000).

In sum, despite some tentative evidence of small increases in biomedical literacy in the USA over the past two decades (Miller and Kimmel 2001), the overall picture with regard to scientific and biomedical knowledge and engagement is one, to paraphrase Phillip Converse, of low mean and high variance – citizens around the world appear to know and care rather little about science in general or biomedicine in particular, although there is considerable individual variation around this population average.

### **3.3. Public attitudes to biomedical science**

Given the wide variation in issues, practices and technologies falling under the general heading of biomedical science, it is rather difficult to provide an overall summary of public opinion toward this area as a whole. Indeed, somewhat belying the notion that people lack any real familiarity with science or biomedicine, public opinion in this area is actually rather nuanced, varying markedly with the specific issue or technology in question.

In addition to the wide variation in public attitudes across issues and applications, there is a great deal of heterogeneity within ‘the public’ itself. While we do not agree with those who argue that this heterogeneity should result in outright rejection of the notion of ‘the public’ altogether, it is certainly true that any average we might report will likely conceal sub-groups whose views are different not just by degrees but by orders of magnitude.

This qualification noted, in general publics around the world report being interested in health information and health technologies. Everyone is affected by their own health, or

the health of significant others on a fairly regular basis and, as such, health-related issues and research are generally of high salience. This is reflected in the high levels of public support for funding of research into human health and medicine (Miller and Kimmel 2001). Support for genomic biomedicine has, accordingly, been found to be generally high around the world, though with some notable exceptions. While people appear to be generally in favour of biomedical research with clear potential health benefits, support can drop markedly when those benefits are uncertain or when the application appears to transgress basic moral precepts about the sanctity of life and what it is to be human (Sturgis *et al.*, 2004).

As we shall see in the following review sections of the report, the most common area of biomedicine to be the subject of public opinion research are the loose assemblage of interdisciplinary fields collectively referred to by the short-hand terms 'biotechnology' and 'genetic engineering'. Opinion poll data over the past ten to twenty years – focusing as it does predominantly on the USA and Europe – reveals a sceptical but not overwhelmingly hostile public response to the dawning genomic revolution. In the 1997 German Biotech survey, only 7 per cent of the German public could be characterised as outright opponents or proponents of genetic engineering, with many undecided about whether its applications are, on the whole, good or bad (Hampel, Pfenning and Peters, 2000). In 2002, less than half of Europeans (44 per cent) were 'optimistic' about biotechnology, agreeing that it will improve our way of life within the next 20 years (Gaskell, Allum and Stares, 2003).

As might be expected of such a heterogeneous area of science and technology, public attitudes are actually quite variable, differentiating between applications according to their risk, moral acceptability and usefulness to society. A majority of Europeans encourage and accept biotechnology applications that have clear medical benefits for the diagnosis and treatment of human disease, including the cloning of human cells and tissues and genetic testing for inherited disease (Gaskell, Allum and Stares, 2003; Pardo *et al.*, 2002; Hampel *et al.*, 2000).

If, however, these same technologies are applied in different contexts – genetic tests to decide whether to continue a pregnancy, cloning to create a new human being – survey evidence reveals public opinion to be markedly oppositional (Human Genetics, 2001). Public disquiet is also evident for biotechnology applications that involve the genetic modification of animals or the transfer of genes between animal species, even where there are clear potential benefits for human health (Hampel *et al.*, 2000). While a majority of Europeans in the 1996 Eurobarometer agreed that such applications might be useful, there were strong reservations about the risks and moral acceptability of such research (Pardo *et al.*, 2002).

The genetic modification of crops and the use of biotechnology in food production, the so-called 'green-biotechnologies', have been the best documented source of public anxiety toward genomics. In Germany, over half of the surveyed public rejected the use of genetic engineering to improve the flavour or appearance of their food (Hampel *et al.*, 2000). And, although time series data suggest that the British public have become increasingly ambivalent about GM applications in recent years (Gaskell *et al.*, 2003b), a majority still rated GM crops and foods as risky and of limited usefulness in the 2002 Eurobarometer (Gaskell, Allum *et al.*, 2003).

Interestingly, support for agricultural biotechnology is highest when the potential benefits are framed in terms of human health, with applications such as 'golden rice' (where bulk subsistence crops in developing countries are genetically modified to contain essential vitamins) and drought resistant crops obtaining substantially higher approval ratings than agri-bio technologies with no clear medical or health benefits (Sturgis *et al.*, 2004).

Another important aspect of public opinion toward biomedical science relates to the use of animals in testing. In many ways, attitudes in this area are completely distinct from those toward specific biomedical applications and technologies; people generally hold more considered and robust opinions compared to some of the more ephemeral constructs elicited in response to new and unfamiliar technologies.

In general, the majority of people in Britain and the USA have been found to support the use of animals in biomedical research, so long as there are clear and tangible health benefits, or lives saved. Support varies according to the animals used, with support declining markedly as 'evolutionary proximity' increases. Thus, research using rats and mice has considerably greater support than when monkeys and dogs are used (Miller and Kimmel, 2001). No matter how the issue is framed, research has revealed a substantial minority of hard-core opponents, usually around a quarter or a third, who contest the use of animal testing, whatever the species or the potential benefits for human health (MORI, 1999; 2002; 2005).

In closing this section, it is important to note, that research into public opinion toward new and emerging biomedical technologies often throws up seemingly contradictory findings (Bishop, 2005). This would appear to be largely a function of the fact that, lacking a familiarity with the basic vocabulary of science, lay citizens are highly influenced by the particular wordings of survey questions and the context within which they are framed. The appearance of apparently contradictory evidence in the field of public opinion has probably been exacerbated in recent years by the growing practice of interest groups commissioning polls with the apparent purpose of obtaining a pre-determined result. We discuss these issues of measurement in greater detail in section 7.11.

### **3.4. The knowledge–attitude relationship**

We have now considered the broad contours of public knowledge, engagement and attitudes to biomedical science. What empirical evidence is there, though, of a causal link between knowledge levels and expressed preferences toward modern biomedical science? In a recent meta-analysis, Allum *et al.* (In Press) find a significant and positive relationship between biomedical knowledge and attitude, controlling for age, sex and educational level. Hampel *et al.* (2000) find that Germans who rate their own knowledge levels as 'good' are more likely to be proponents of genetic engineering than those with less self-perceived knowledge. However, self-rated knowledge showed only a weak correlation with attitudes towards genetic engineering in this study and, as we note in section 5, subjective appraisals of knowledge have been found to correspond poorly with factual knowledge of genetic engineering, confounded as they are by people's interest in and enthusiasm for the subject.

Most data addressing the impact of science knowledge on attitudes towards biomedical science are to be found on the Eurobarometer and NSF science indicator surveys. Comparing 'engaged' or knowledgeable respondents with those less well informed about biotechnology, Gaskell *et al.* (2003) find differences in attitudes that are independent of educational background. On the whole, the engaged public was significantly more likely to find applications of biotechnology morally acceptable and useful. Being well-informed did, however, have less effect on public appraisals of risk, suggesting that risks are perceived but tolerated by more knowledgeable citizens. A similar pattern was found in the 1996 survey, where public knowledge and awareness of biotechnology was unrelated to the perceived risks of biotechnology but showed a moderate, positive correlation (0.25) with an index of perceived benefits (Pardo *et al.*, 2002). In the USA, Miller and Kimmel (2001) find their index of biomedical literacy to be positively related to optimism about biomedical science.

While the idea that knowledge of biotechnology fosters a more positive outlook does find some empirical support in these studies, there is also evidence that the relationship may sometimes work in the opposite direction, depending on how questions are framed. Pardo *et al.* (2002) find that, while members of the informed public perceive the benefits of biotechnology most favourably, they were less convinced of the potential biotechnology has to improve quality of life. Similarly, Midden *et al.* (2002) find the better informed public more likely to have negative expectations about the outcomes of biotechnology over the next 20 years. And, although based on a knowledge scale that would appear more a measure of attitude<sup>1</sup>, MORI reports that respondents with high knowledge were most

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<sup>1</sup> The scale was formed by scoring as 'correct' or 'incorrect', responses to questions about the degree to which particular traits are determined by genes or by environment; the answers to several of which are highly contested.

critical about the wider uses of genetic information by employers and insurers (HGC, 2001).

Another strand of evidence on the relation between knowledge of, and attitude toward, biomedical science comes from an ambitious panel study conducted in Great Britain by the National Centre for Social Research and the Wellcome Trust. This study found that respondents who attended group discussions and watched a video about gene therapy became generally more positive about human genetic research. However, at the same time, their reservations increased for specific applications, such as germ-line therapy, and for treatment of specific non-medical conditions such as baldness.

The notion that providing specific relevant information to lay members of the public can change opinions is also supported by research focused on group discussions. Another study by the Wellcome Trust questioned the public about their opinions on human cloning before providing them with factual information on the scientific processes and regulation involved (Wellcome, 1998). When re-convened up to a month later to assess how, if at all, this information had modified their attitudes, it was found that concerns about reproductive cloning persisted but that attitudes towards therapeutic cloning had changed. However, rather than promoting more favourable attitudes, better informed respondents in this study became more critical and reserved about its application. These latter studies suggest that information is unlikely to allay public resistance to genetic technologies if it means people begin to raise and question issues that they had not, hitherto, thought about.

More recently, using a forecasting model Sturgis *et al.* (2005) find opinion toward a diverse range of biomedical applications to be generally more favourable with higher levels of biomedical and general scientific knowledge. In sum, the extant survey evidence points to a moderate but robust correlation between knowledge of and attitude toward biomedical science. It is important to emphasise, however, that the entire evidence base for this conclusion is observational in nature and, hence, of limited utility in addressing questions of a causal nature. We are unable to categorically exclude the possibility that the observed relationship may be partially or wholly due to the effect of attitude on knowledge, or to other unobserved variables.

## **4. Review of measures of scientific/biomedical knowledge**

The measurement of scientific knowledge in surveys has a long and somewhat contentious history. Since the seminal study of Davis (1958), *The public impact of science in the mass media*, the idea that it is possible to assess the distribution of general and more specific scientific knowledge in mass publics has gained currency. Controversy has arisen in response to substantive objections to the notion that negative attitudes to science are underpinned by subject matter ignorance – the so-called ‘deficit model’ (see section 4) and out of more methodological concerns with the validity and reliability of the survey instruments commonly used in this endeavour (Pardo and Calvo, 2002).

We are here, of course, primarily interested in public knowledge of *biomedical* science, rather than knowledge of science more generally. There is, nonetheless, a strong overlap between the two, with biomedical knowledge being a simple subset of the broader and more general moniker ‘science’. Furthermore, as we shall see, where researchers have used ‘pure’ measures of biomedical knowledge, these have tended to draw on the biomedical items contained within the general science item batteries.

Our literature search identified a total of 147 different questions that have been used to measure scientific/biomedical literacy (listed in Appendix 2). Surveys containing ‘pure’ measures of biomedical knowledge (as opposed to scientific knowledge more generally) were comparatively rare.

In this section of the report, we consider what have been taken to constitute the key constituent elements of scientific and biomedical knowledge. We then move on to examine the three primary questionnaire item types by which these different knowledge domains have been measured: self-report, fixed response and open coded formats. We conclude with a general overview and recommendations for measuring knowledge of biomedical science in future public opinion surveys.

### **4.1. Scientific knowledge domains**

Before considering the various ways in which survey researchers have operationalised scientific and biomedical knowledge in the form of questionnaire items, it is important to think in some detail about their conceptual basis. That is to say, what is it that we are trying to measure when we talk of scientific and biomedical knowledge? By far the most prominent and influential work on the scientific and biomedical knowledge of mass publics has been the programme of research conducted by Jon Miller and colleagues in the USA. Miller has developed the notion of ‘civic scientific/biomedical literacy’ to delineate the basic level of understanding that would be required of citizens in modern liberal

democracies to make 'rational' health and medical-related choices (Miller and Kimmel, 2001; Miller, 1982; Miller, 1983, 1998; Miller, 2001a, 2001b, 2004).

There has been some dispute about what the minimum level of understanding should be for attaining scientific civic 'competence', with Shamos (1995) arguing for the equivalent of an undergraduate degree in physics. Miller sets the bar considerably lower, using the example of an 'average citizen' reading an article in the science section of *The New York Times*, or watching a TV programme about a new scientific discovery or technological innovation. Citizens in this situation, Miller argues, should possess sufficient scientific knowledge and understanding to be able to evaluate the relative merits of competing arguments over a proposed government policy intervention, or regulatory framework.

What this threshold implies with regard to specific informational and cognitive capacities will, of course, vary widely depending on the nature of the science or technology in question. This has led others to reject the notion of an absolute threshold of scientific literacy and to aim instead to simply order individuals along an underlying dimension (or dimensions) of scientific knowledge (Evans and Durant, 1995; Sturgis and Allum, 2004). Whatever the merits or otherwise of the notion of an absolute threshold, for Miller, the key information required for scientific competence can be summarised along two underlying dimensions:

1. **the content of science**, or possessing a "vocabulary of basic terms and concepts" (2001, p.12).
2. **the processes of scientific inquiry**, or scientific method.

Miller has also referred in places to a third dimension – an awareness of the impact of science on society, although this dimension has rarely been measured in practice and is omitted entirely from his most recent account of biomedical literacy in the USA.

Although Miller's approach has been the target of fairly sustained criticism over the years, it should be noted that his work is unusual in the attention paid to outlining the conceptual basis of the knowledge measure he deploys. It is all too common for researchers in the field of PUS to mechanically administer or analyse a set of science knowledge items as if the measurement and the underlying concept were coterminous. While we might disagree with Miller's conceptual map, we should concur with his emphasis on being clear and explicit at the outset of any empirical investigation about the nature of what it is that is being measured.

Other commentators have pointed out that knowledge of what we might term the 'internal' logic and vocabulary of science may not be the only relevant aspects of scientific knowledge in determining individual preferences. Jasanoff, for example, suggests that what

is important for people's understanding of science is not so much the ability to recall large numbers of miscellaneous facts but rather "a keen appreciation of the places where science and technology articulate smoothly with one's experience of life...and of the trustworthiness of expert claims and institutions" (Jasanoff, 2000 p.55). Brian Wynne, a trenchant critic of the deficit model, delineates this position further. Criticising survey-based PUS research's over-reliance on simple 'textbook' knowledge scales, he suggests that in order to properly capture the range of knowledge domains relevant to lay attitudes towards scientific research programmes, "three elements of public understanding have to be expressly related: the formal contents of scientific knowledge; the methods and processes of science; and its forms of institutional embedding, patronage, organisation and control" (Wynne, 1992 p.42).

While possessing much in the way of theoretical merit, the difficulty of this argument is that it is extremely hard to find suitable measures of the proposed concept. In attempting to do so, some have adopted an indirect approach, arguing that political knowledge can be adopted as a useful proxy (Sturgis and Allum, 2004). The logic here is that knowledge of how science is funded and regulated can be seen as an aspect of the more general political environment and that, in politics, people tend to be generalists.

Bauer, Petkova and Boyadjieva (2000) take a more direct approach, developing a set of items designed to measure what they term 'institutional knowledge of science'. They find that 'institutional knowledge' comprises two sub-domains of belief about a) the autonomy of scientists and b) the ways in which institutions function. However, they themselves acknowledge the potential pitfalls of trying to directly assess this type of knowledge by pointing to what they see as the inherently contested nature of 'facts' about institutions. As a result, the problem with Bauer *et al.*'s scale is that too many of the items, in the absence of any objective means of determining the 'correct' response, stray from the knowledge into the attitudinal domain.

Thus, in summary, the vast majority of extant studies have focused on the content and process dimensions of scientific/biomedical literacy. At times these have subsequently collapsed into a uni-dimensional score, while at others they have been treated as related but nonetheless independent aspects of the broader concept.

#### **4.2. Self-report measures**

Many of the problems inherent in conceptualising and operationalising scientific/biomedical knowledge can be side-stepped by asking respondents to provide their own subjective assessment of their level of knowledge/understanding. Respondents seem to find this a relatively straightforward task and little questionnaire space is required



to accommodate such self-report measures. These features, along with the questionnaire space required for and comparative difficulty in developing more objective measures of knowledge, probably explains the widespread adoption of this approach to knowledge assessment in the studies we have reviewed. Here is an example of such an item from the NSF Science and Engineering Indicator series (a near identical item is included on a number of Eurobarometer surveys):

*Now, I'd like to go through this list with you again, and for each issue I'd like you to tell me if you are very well informed, moderately well informed, or poorly informed, (Don't Know). New medical discoveries*

A variant of this question, also asked in the Eurobarometer series, asks respondents not how well informed they are in an absolute sense but whether they are 'sufficiently' well informed, leaving the respondents to judge not only how well informed they are but to assess this against some unspecified sufficiency criterion.

Here is a yet more direct example of the self-report approach taken from a UK study by Poortinga and Pidgeon (2003):

*I am well informed about genetic testing*

*Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Another variant of the self-report approach does not assume that respondents understand the term used to describe the knowledge area of interest. In this formulation, the question additionally provides a brief description of what the science entails, presumably to capture individuals who may be aware of the technology but are not familiar with its technical descriptor. An example of this type of question can be found in the HSRC Public Understanding of Biotechnology study:

*Biotechnology is the use of living things to create products and services to meet our needs and desires. Have you heard of this before? Yes, No, (Don't Know)*

While all these different manifestations of the self-report knowledge format are straightforward and generally low-cost options, their overall effectiveness is highly debatable. Respondents are likely to bring very different frames of reference to deciding what constitutes being 'well' or 'poorly' informed, resulting in possibly substantial heterogeneity in objective knowledge levels within the same response category (Gaskell, Ten Eyck, Jackson and Veltri, 2005).

An additional problem is that answers to this type of question are strongly influenced by personality traits, with answer choices being as much a function of how the respondent perceives themselves, as the extent of their underlying knowledge. This tendency is likely to

be exacerbated in interviewer-administered survey modes, where many individuals may feel unwilling to admit to being poorly informed directly to the interviewer.

Indeed, Miller and Kimmel (2001) find self-reported biomedical knowledge to be only very weakly related to objective test scores – one-third of respondents classified as ‘biomedically illiterate’ on the basis of their objective test score had previously reported themselves to be ‘very well informed’ about biomedical science. A near identical proportion was found among those deemed scientifically literate.

In sum, then, it is our view that self-reported knowledge items are of very dubious merit for describing and explaining the extent and distribution of biomedical science in general populations. They should only be used as a final recourse, where cost or questionnaire space precludes the use of longer multi-item objective test batteries. Even then, generalisations should be treated with a strong degree of caution.

That said, this type of question is not completely without merit. Variation in self-assessed informedness over time, across sub-groups and cultures is of interest in so far as such perceptions influence attitudes and behaviour, or are influenced by media consumption and science communication policy. So long as it is remembered that these items do not measure knowledge but perceived knowledge – and that these are very different things – self-reported knowledge items may be of some value in a population survey of public attitudes toward biomedical science.

### **4.3. Fixed-choice measures**

The most common way of measuring scientific/biomedical knowledge in surveys is the fixed-choice knowledge quiz, exemplified by the series of items in the National Science Foundation (NSF) Science and Engineering Indicator series and the Eurobarometer science knowledge scales. These adopt a ‘closed’ response format, with a statement followed by a set of possible answers, only one of which is correct. Items vary in the number of ‘distractors’<sup>2</sup> used but existing knowledge batteries have tended to employ between one and four. Where the item comprises only a single statement, the format becomes true/false as opposed to multiple choice. Generally, the fixed-choice item format has been used to measure the ‘content’ dimension of scientific knowledge.

Most existing survey items of this variety can be traced back to work emanating from a collaboration in the late 1980s between Jon Miller in the USA and John Durant and colleagues in Britain. They developed a series of factual quiz type questions that tapped

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<sup>2</sup> ‘Distractor’ is the term traditionally used to denote the ‘incorrect’ answers in MCQs.

'textbook' knowledge of science and became known as the Oxford scale in the UK and the Science literacy scale in the USA (Durant, Evans and Thomas, 1989; Miller, 1998).

These items, or various subsets, have now been employed in a large and growing number of public opinion surveys about science and technology around the world. In addition to the battery of fixed-choice quiz items, the Oxford/Science literacy scale contains a number of items that require respondents to report their answers verbatim. These are discussed in section 5.4. The 12 fixed-choice, true/false items deriving from the Oxford scale, that were administered in the 1992 Eurobarometer, are shown below:

1. *The center of the Earth is very hot?*
2. *The oxygen we breathe comes from plants?*
3. *Radioactive milk can be made safe by boiling it?*
4. *Electrons are smaller than atoms?*
5. *The continents on which we live have been moving their location for millions of years and will continue to move in the future?*
6. *It is the fathers' genes which decides whether the baby is a boy or a girl?*
7. *The earliest humans lived at the same time as the dinosaurs?*
8. *Antibiotics kill viruses as well as bacteria?*
9. *Lasers work by focusing sound waves?*
10. *All radioactivity is man made?*
11. *Human beings developed from earlier species of animals?*
12. *Does the Earth go around the Sun, or does the Sun go around the Earth?*

In general, researchers have utilised this scale by coding each item into binary form, where a correct response = 1 and a not-correct (incorrect + Don't Know) = 0. The items are then summed for each respondent, yielding a uni-dimensional continuous measure of scientific knowledge. Variation in mean scores on the summed scale is predicted in theoretically anticipated ways – scores are higher among groups with more formal education, with qualifications in the physical and natural sciences, among professional groups and among those who report being interested in science and following science stories in the mass media (Pardo and Calvo 2002; Miller 2004).

Detailed examinations of these items, their measurement properties and conceptual adequacy, have been published by Miller (1998) and in a recent article by Pardo and Calvo (2004). According to the latter, the items have some methodological problems: low scale reliability (as measured by Cronbach's Alpha); some deficiency in cross-cultural equivalence (Peters, 2000); attenuated ability to discriminate between respondents due to a preponderance of rather 'easy to answer' items.

In our view, these criticisms certainly carry some force. On the other hand, as Pardo and Calvo themselves conclude, the Oxford items remain useful as approximate measures that capture variation in the distribution of scientific literacy across individuals, social groups and across cultures. This conclusion is borne out by the growing number of substantive studies that have utilised the Oxford items or scales derived from similar types of scientific knowledge quiz questions (Durant, Evans and Thomas, 1989; Evans and Durant, 1995; Gaskell, Allum, Bauer and Durant, 1999; Gaskell, Allum *et al.*, 2001; Sturgis and Allum, 2001, 2004).

The fixed-choice items in the Oxford scale cover a small number of scientific 'facts' from the physical or natural sciences, only four of which can be said to relate, at least in part, to biomedical science. Alternative scales that focus entirely on biomedical knowledge have been developed by Miller and Kimmel (2001) in the USA and by George Gaskell and colleagues at the LSE in the UK. The latter have been fielded in the 1999 and 2002 rounds of the Eurobarometer series. This 11-item biomedical knowledge scale is shown below:

1. *There are bacteria which live from waste water?*
2. *Ordinary tomatoes do not contain genes, while genetically modified ones do?*
3. *The cloning of living things produces exactly identical copies?*
4. *By eating genetically modified fruit, a person's genes could also become modified?*
5. *It is the mother's genes that determine whether a child is a girl?*
6. *Yeast for brewing beer consists of living organisms?*
7. *It is possible to find out whether a child will have Down's Syndrome within the first few months of pregnancy?*
8. *Genetically modified animals are always bigger than ordinary ones?*
9. *More than half of the human genes are identical to those of chimpanzees?*
10. *It is not possible to transfer animal genes into plants?*

11. *Criminal tendencies are mainly genetically inherited?*

Less attention has been paid, to date, to the methodological properties of these scales, though substantive analyses (Gaskell, Allum and Stares, 2003) and work conducted by Miller and Kimmel (2001) suggest that its performance is comparable to the that of the Oxford scale.

A six-item, fixed-choice scale to measure 'nanotechnology' was developed and fielded as part of the 2004 'Public and Nanotechnology' study in the US. This comprised the following items:

1. *Nanotechnology involves materials that are not visible to the naked eye?*
2. *U.S. corporations are not using nanotechnology yet to make products sold today?*
3. *Experts consider nanotechnology to be the next industrial revolution of the U.S. economy?*
4. *A nanometer is a billionth of a meter?*
5. *Nanotechnology allows scientists to arrange molecules in a way that does not occur in nature?*
6. *A nanometer is about the same size as an atom?*

The fixed-choice items reviewed thus generally far focus on the 'content' dimension of scientific and biomedical knowledge. Two other fixed-choice items that have been widely used in the extant literature tap important aspects of the 'process' of scientific inquiry. The first of these requires respondents to identify the correct answer to a question about probability.

*Doctors tell a couple that their genetic make up means that they've got a 1 in 4 chance of having a child with an inherited illness. Does this mean that...*

1. *If they have only 3 children, none will have the illness?*
2. *If their first child has the illness, the next 3 will not?*
3. *Each of the couples' children has the same risk of suffering from the illness?*
4. *If their first 3 children are healthy, the fourth will have the illness?*
5. *Don't Know*

Although the example used in the question stem relates to biomedicine (genetic inheritance), the aim of the question is to determine the individual's ability to understand the concept of probability rather than genetic inheritance. Miller argues that an

understanding of probability is an important component of both biomedical and more general scientific literacy (Miller, 1983, 1998). Although this is unlikely to be relevant to anything more than a trivial number of respondents in a general population survey, it is worth noting that a Bayesian statistician might argue that none of these alternatives is correct.

A second fixed-choice format question tapping the 'process' of scientific inquiry aims to establish whether respondents understand the principle of controlled experimentation. Respondents are asked to determine which of two scientists is using the best approach to identifying the efficacy of a treatment:

*Let us imagine that two scientists want to know if a certain drug is effective against high blood pressure. The first scientist wants to give the drug to 1000 people with high blood pressure and see how many of them experience lower blood pressure levels. The second scientist wants to give the drug to 500 people with high blood pressure, and not give this drug to another 500 people with high blood pressure, and see how many in both groups experience lower blood pressure levels. In your opinion which is the better way to test this drug?*

This question, or a close variant, has been used in the NSF Indicator series, the Eurobarometer and the British Social Attitudes survey. An important follow-up to those providing the correct answer (the second scientist) is:

*Why is it better to test the drug this way?*

Miller and Kimmel (2001) report that in the 1993 US Biomedical Literacy Survey, although three-quarters of respondents correctly identified the two-group design as the most appropriate, a third of these subsequently reported their rationale as being that this design would minimise the number of deaths if the treatment proved fatal.

#### **4.3.1. Item coverage**

One of the main criticisms of these fixed-choice knowledge measures relates to alleged bias in the coverage of the conceptual domain. The argument goes that proponents and opponents in scientific controversies are likely to select different domains of knowledge as being relevant or important. The normative assumptions behind the selection and development of knowledge measures such as those of Miller and Durant may not necessarily correspond with those of all protagonists in any given scientific controversy. Peters (2000), for example, criticises some of the knowledge measures used in the Oxford scale as being based on a 'culturally determined idealisation' of what should constitute scientific knowledge. As a result, he argues, the measures present a biased indication of the relative levels of relevant scientific understanding that is dependent on respondents' national and cultural locations.

Others have pointed out that knowing the answers to these specific items in isolation cannot be conceived of as very interesting or useful for understanding someone's attitude toward science in society (Irwin and Michael, 2003). How can knowledge or ignorance of a set of true/false questions in a survey tell us anything of any value about someone's real understanding of science? This line of criticism, however, fundamentally misses the point of measurement using diagnostic indicators. The important point here is that there is good evidence to suggest that people tend not to learn things in isolation (Evans and Durant, 1995; Gaziano and Gaziano, 1996; Miller, 1983, 1998; Popkin and Dimock, 1999; Tichenor, Donohue and Olien, 1970). It is likely, for example, that a person who obtains a high score on this particular science quiz also has a range of other relevant scientific knowledge and understanding that, taken together, influence the formation of their attitude toward science.

Confusing the contents of the measurement instrument with the attitude or trait underlying responses to it is a common mistake among critics of quantitative approaches to PUS. But, as Philip Converse has remarked, "it does not take much imagination to realise that knowledge of minor facts...are diagnostic of more profound differences in the amount of contextual information citizens bring to their judgments" (Converse, 2000 p.333). While there is certainly room for improvement in the current item pools (Pardo and Calvo, 2004), the items selected for inclusion in these scales should be seen as diagnostic indicators rather than fully constitutive of the actual scientific domain of interest.

#### **4.3.2. Fixed choice, don't knows and guessing**

An issue which has attracted little attention thus far in the PUS literature, despite the recent focus on the methodological properties of these items, is the practice of using Don't Know options as answer choices. It is standard when administering these items in surveys to employ an explicit Don't Know alternative along with a preamble encouraging respondents to make use of them if they are unsure of the answer. For example, the 11-item scale of the 1992 Eurobarometer science literacy scale is introduced to respondents thus:

*"Here is a quick quiz. For each thing I say, please tell me if it is true or false. If you don't know, say so, and we'll skip to the next."*

The explicit encouragement of Don't Know responses has evolved due to expectations among survey researchers, firstly that respondents might feel uncomfortable about not knowing the correct answer, so should be given an 'easy out' and, secondly, that pressuring people to guess when they do not know an answer will result in less reliable measures and a higher probability of Type II errors in multivariate analyses (Delli-Carpini and Keeter, 1993; Delli-Carpini and Keeter, 1996; Sanchez and Morchio, 1992).

The widespread use of this seemingly innocent and sensible strategy, however, raises the potential of significant biases in the estimation of knowledge levels for the population as a whole and of differences between sub-groups. The main problem in this regard is that the inclusion of a Don't Know alternative "invites a guessing response set in which respondents' scores vary as a systematic function of personality traits" (Mondak, 2001 p.205). Because some individuals are more likely than others to chance their arm with an answer on the basis of limited or partial information, apparent differences in knowledge levels between groups may, in fact, reflect nothing more than a differential 'propensity to guess'.

Most notably, in this regard, Mondak and Anderson (2004) argue that the robust finding that men score higher on political and scientific knowledge batteries than women (Bartle, 2000; Delli-Carpini and Keeter, 1996; Frazer and MacDonald, 2003; Verba, Burns, and Schlozman, 1997) is largely attributable to men's greater proclivity to taking a guess, a tendency which itself results from societal norms and long-term processes of socialisation.

What is the solution to this problem of guessing? Mondak argues that by adopting measurement principles from the field of educational testing, in which Don't Know responses are actively discouraged, these systematic sources of error variance can be eliminated because "encouraging all test-takers to answer every item best ensures that all test-takers will capitalize on their partial knowledge" (2001, p.205). Thus, Mondak advises that survey measures of factual knowledge be amended so as not to include an explicit Don't Know alternative and to encourage, so far as is possible, all respondents to provide an answer, even if they have no idea at all which alternative is correct.

In our view, such advice is probably premature at present. Nonetheless, it is an issue which is likely to become more prominent in the PUS literature in the coming years. Developments and practical recommendations are likely to emerge from methodological research studies in the near future and survey designers should keep abreast of developments.

#### ***4.4. Open measures***

Many of the knowledge measures identified in this review are 'open' questions which require respondents to provide answers in their own words. The verbatim responses are then coded to a frame by a team of coders and reported as marginal distributions, or used to classify respondents in terms of their degree of understanding. These questions are generally reserved for tapping the 'process' aspect of scientific literacy, while the fixed-choice items discussed in section 5.3 are used to measure knowledge of the facts and



vocabulary of science. Both the Oxford scale and the US Science and Engineering Indicator series adopt this approach to measurement.

Part of the reason for this dichotomisation – open questions for ‘process’ and fixed-choice for ‘textbook facts’ – appears to have resulted from a desire to obtain historical comparability. In the first-ever study of public opinion toward and familiarity with science, Davis (1958) asked respondents to respond in their own words to the following question:

*Some things are studied scientifically; some things are studied in other ways. From your point of view, what does it mean to study something scientifically?*

Answers to this question were assigned to a set of answer codes, which indicated that only small percentages of respondents ‘correctly’ identified scientific study as relating to controlled experimentation, or ‘open-minded’ investigation. Some 20 years later, when Miller and Prewitt conducted a follow-up to this pioneering work (paving the way for the NSF Science and Engineering Indicator series), they modified this verbatim approach by introducing a fixed-choice filter. They were concerned that telephone respondents would terminate the interview if they were asked to talk about what it means to study something scientifically when they had no understanding of its meaning. Respondents were, therefore, first asked the following question:

*Some things are studied scientifically; some things are studied in other ways. Would you say that you have a clear understanding of what it means to study something scientifically, a general sense of what it means, or no understanding of its meaning?*

Respondents who reported that they had a clear understanding of the meaning of scientific study were then asked:

*From your point of view, what does it mean to study something scientifically? (Just in your own words)*

During the 1990s Miller and colleagues developed a number of variants of this item which focus more specifically on biomedicine:

*In articles and on television news shows, the term [DNA/molecule/radiation/bacteria] has been used. When you hear the term DNA, do you have a clear understanding of what it means, a general sense of what it means, or little understanding of what it means, (Don't Know)?*

Where respondents report having a ‘clear’ understanding or ‘general sense’ of the term, they are asked:

*Please tell me, in your own words, what is DNA?*

One of the main proposed benefits of the open-response format (in addition to longitudinal comparability with the growing number of studies that have implemented it) is the fact that it effectively eliminates the problem of guessing discussed in section 5.3.2. While this is undoubtedly true, there are many reasons to suspect that the practical and methodological problems of these items outweigh any potential benefit.

The first practical issue to consider is the cost of these items. Because answers must be recorded verbatim and then subsequently coded to a frame by a team of trained coders, they are in general significantly more costly than a fixed-choice item. While the additional cost might be considered justifiable with a sufficiently large budget, it should be remembered that questionnaire space is finite and that a single open coded item would displace several fixed-choice alternatives. A strong case, therefore, needs to be made for the gains of an open item relative to the same question specified as a fixed choice.

A second problem is the potential for error and imprecision in estimates of knowledge levels as a result of the coding process (Sturgis 2004). There is always a degree of ambiguity and personal judgement involved in transforming a verbatim answer to a pre-specified category and this manifests itself in the form of both random and correlated coder error. Because this error is rarely incorporated into statistical estimates, it is a significant and under-recognised cost of open items in surveys.

Finally, open questions are known to favour the better educated and more articulate members of the sample. Differences in the quality and quantity of verbatim material obtained is often as much a reflection of differences in willingness and ability to devote cognitive resources to the task, as it is to variation in the underlying concept of interest.

#### ***4.5. Summary and conclusion***

The inclusion of questions which measure factual knowledge of 'science' or 'biomedical science' is common to most public opinion surveys that we have identified in this review. It is certainly the exception rather than the rule for a survey in this area to measure opinions without also obtaining some measure of knowledge. This undoubtedly reflects the longstanding focus within PUS research on the relationship between public preferences and 'scientific literacy'. While recent years have seen something of a refocusing of theoretical concern on notions of trust and risk, the level of public awareness of science and how this relates to public attitudes has remained at the forefront of empirical research.

Several different approaches to the measurement of knowledge have been employed in the studies we have reviewed. We characterise these as being of three primary types often used in combination within the same survey: self-report, fixed-choice and open-answer categories. In this section of the report we have provided illustrative examples of these

different types of question and discussed some of the advantages and limitations of each as measures of biomedical science.

Self-assessed knowledge measures are of some value in understanding public opinion toward biomedical science and how it varies over time and across cultures. However, they should be viewed as primarily attitudinal measures. As measures of knowledge, they have some significant shortcomings, not the least of which is that they are only weakly related to more objective measures of factual knowledge.

'Open' measures, which require respondents to describe a scientific concept or method in their own words, with verbatim responses subsequently coded to a fixed frame are also common in the studies identified in the review. Although these have some, such as minimising guessing, they too suffer from serious limitations. In addition to being costly and time-consuming to administer, they are prone to coder error and favour the articulate and well-educated.

Fixed-response knowledge questions have been the subject of much criticism in the extant literature. Commentators have argued that the list of items is partial, biased and marginally relevant to a full understanding of science. In our view, these criticisms are largely misplaced. Although there is room for substantial improvement on the number and content of the items employed to date, they represent the best general approach to the measurement of factual biomedical knowledge in surveys.

## 5. Review of measures of scientific/biomedical interest

Clearly, as we saw in section 3, citizens vary a great deal in their level of familiarity with the content and process of scientific inquiry. A natural question to ask in response to this observation is, where does this heterogeneity come from? Why are some individuals exceedingly well informed about science and its technological implementations, while others know next to nothing, or even appear to be misinformed?

It is undoubtedly the case that a great deal of the variation in biomedical knowledge within the general population is a function of formal educational attainment, which is itself strongly influenced by the socio-economic status of the households into which citizens are born. Thus, to a degree, the extent to which certain social groups are better informed than others in society about biomedical science can be considered as little more than an accident of birth. However, despite the importance of formal education and other socio-demographic influences, there is also a good deal of variation in individual knowledge and understanding that is not explained by such long-term sociological forces.

The host of idiosyncratic individual influences that lead some individuals to consume and retain scientific information at higher rates than others can be summarised under the general heading of 'motivation'. Individuals become motivated to acquire and retain information about science to the extent that it is salient to their own everyday lives. Thus, a parent who gives birth to monozygotic twins is likely to become motivated to understand the biological processes by which their children came to appear physically identical. Similarly, an individual who develops an inherited health condition will be motivated to understand its causes and consequences; is the condition genetic?; how is it transmitted?; will she pass it on to her own offspring?

Once an individual becomes motivated to acquire information about a specific area of science, they are likely to behave and develop preferences about the use and regulation of the science in question, in ways that are rather different from individuals who are not equivalently motivated. Thus, individuals for whom biomedical science has salience in everyday life are likely to show different patterns of media consumption, networks of interaction, use of the Internet, understanding of science and, ultimately, science policy preferences.

It is for this reason that academic researchers and policy makers alike have frequently attempted to measure the salience of, or motivation to acquire information about science in the general population. The short-hand term that is conventionally used to refer to the personal salience dimension of public opinion is 'interest' in the topic or issue in question.

### **5.1. Self-reported interest**

The simplest way of obtaining a measure of interest in science is to require the respondent to provide a self-assessment. Here is an example of this approach, taken from the 2003 British Social Attitudes survey:

*How much interest, if any, do you have in issues to do with genes and genetics? A great deal, Quite a lot, Some, Not very much, None at all, Don't Know*

In other variants of this question, the term 'interest' is replaced by a near equivalent term such as 'importance' or 'concern'. For example, here are two such items taken from the August 2001 US Gallup Poll and the UK assessment of the GM Nation? debate respectively:

*How important is the issue of stem cell research to you? Very important, somewhat important, not too important, not at all important, no opinion*

*How concerned or not are you about genetic testing? Very concerned 4 .... Not at all concerned 0, (Don't Know)*

It is not clear to what extent respondents differentiate between these terms; we have found no methodological investigations that address the question empirically. When the subject of the question is the respondent themselves (how concerned are *you* about genetic testing), these terms tend to be used more or less interchangeably. However, an interesting variation on the importance/concern questions is to ask respondents to rate the importance/concern of the issue not only to themselves but also to society in general, or to some specified group of significant others.

For instance, the GM Nation? evaluation followed the question about concern to the respondent with questions about how concerned were friends, family and work colleagues. It is, of course, possible that, say, genetic testing might be considered of little importance to an individual but that individual might simultaneously regard this area of science as of great importance to society in general.

Although these measures are, like the knowledge measures reviewed in section 5, based on self-assessments, they appear to perform rather better, in the sense that they are related to other concepts in theoretically meaningful and predictable ways. That is to say, self-reported interest has been found to correlate positively with objective knowledge scores, years of formal education and direct indicators of personal salience, such as having a family member with a genetic health condition (Miller and Kimmel, 2001).

This is not to say that self-reported interest questions are not without their problems. Bishop *et al.* (1986) showed in a split-half experimental design that respondents reported

significantly lower interest in politics if the interest question was preceded by a 'difficult' factual knowledge question, which they answered incorrectly. Thus our assessments of interest are clearly rather malleable and influenced by the immediate context in which the question is asked. This study also highlights the importance of carefully considering the order of items in the overall questionnaire when assessing both knowledge and interest in the same domain. Similarly, Presser (1984) finds that reporting errors for a range of electoral behaviours are higher among respondents who report higher levels of interest in politics.

Clearly, self-reported interest in science is influenced by factors other than the actual degree of salience of science in the individual's everyday life. As with self-reported knowledge, such factors are likely to relate to varying subjective frames of reference for understanding what constitutes the vague quantifiers in the response alternatives, alongside personality and self-esteem related influences.

### **5.2. Self-reported behavioural indicators**

A second broad class of measure used to assess the degree of salience of biomedical science aims to obtain more objective assessments by eliciting the frequency of behaviours that are indicative of interest and involvement in science. Such measures generally ask about the frequency of or propensity to use various sources of information about science and technology. For example, the 1996 Northern Ireland Life and Times Survey asks respondents to assess how likely they would be to watch a television programme about biomedical science:

*If there was a program on television about advances in medicine, would you... Make a special point of watching it? Watch it if there was nothing better on? Or tend not to watch it? Don't Know*

While this question aims to tap a more objective behavioural indicator of personal salience, it still rests on a subjective assessment of propensity on the basis of a hypothetical situation. To this extent, it is unclear how this question is particularly more objective than self-assessments of interest, concern and importance. Other studies have asked respondents directly about actual media use. Here is an example of such a question from the 1993 US Study of Biomedical Literacy:

*Do you ever read any 'health' magazines? Yes, No, Don't Know, (IF YES) What would that be?*

The 2000 and 2002 US General Social Survey asked an even more explicit behavioural frequency question about using the internet as a source of health information (among other types of information):

*In the past 30 days, how often have you visited a website for? Health and fitness? 1-2 times, 3-5 times, More than 5 times, (Don't Know)*

Other questions ask about specific sources of information, perhaps as a way of evaluating the quality of the information channel. For instance, responses to the following question from the 2002 Eurobarometer could be cross-tabulated with scores on an objective knowledge test (perhaps conditional on some covariates) to evaluate how variation in knowledge is related to the different information sources:

*What is your main source of information about health in general? The internet, Books or medical encyclopaedia, Newspapers, Magazines, Specialist press, Television, Radio, Discussion with family/friends/colleagues, A health professional, Courses and lectures, Other, (Don't Know)*

The behavioural salience measures considered so far all focus on what might be considered 'passive' channels of information. That is to say, information is received by the individual citizen in some mediated form through, *inter alia*, books, magazines, TV, and the Internet. The citizen is generally the passive recipient of information; communication is linear, not interactive.

Another important locus for the formation of individual attitudes, however, is in the informal networks within which the individual interacts, discusses and debates the pros and cons of new scientific developments. For many, such discussions will be rare or non-existent. Where they do arise, however, they are likely to be key to the development of individual policy preferences. A number of studies have included questions that aim to assess the degree to which individuals engage in such interpersonal discussion of science and technology. For instance, the 2003 British Social Attitudes Survey asks the following question:

*And over the past few months, how much, if at all, have you talked about issues to do with genes and genetics? A great deal, Quite a lot, Some, Not very much, None at all, Don't Know*

In our view, these more 'objective' questions about actual patterns of behaviour and media use within a specified time frame hold much promise for the accurate measurement of interest in and engagement with biomedical science. The main problem with their use as indicators of personal salience is that there are many other factors which influence individuals to use different media channels beyond interest and engagement in science. For instance, older people are far less likely to use the Internet at all, rendering its use as a means of obtaining biomedical information highly partial as a measure of the personal salience of biomedical science.

To date, these measures have been somewhat neglected in the empirical PUS literature. Future studies could usefully investigate their relationship with knowledge, self-assessed

interest and objective knowledge scores more closely. In our view, they could form a useful component of a composite measure of personal engagement with biomedical science, perhaps alongside more objective knowledge measures and self-assessed interest.



## **6. Review of survey measures of scientific/biomedical attitudes**

The primary reason for conducting sample surveys about biomedical science is to gauge public opinion toward what are usually contentious areas of science. Public opinion plays a crucial role in elite discourses and debates over policy alternatives in all areas of public life and biomedical science is no exception. This means that the distribution of areas of biomedicine that have been asked about in surveys is far from random; survey questions about biomedicine are heavily skewed towards areas that are novel, dangerous, risky or in some other way contentious (Singer, Corning, and Lamias, 1998).

Thus, the great majority of the attitude questions we list in Appendix 3 relate to stem cells, human and animal cloning, genetic testing, gene therapy, the use and storage of genetic data, and the use of animals in biomedical research. While these may not all figure at the top of a biochemist's survey of the important components of the discipline, they are all areas that have stirred considerable public controversy both in the UK and elsewhere around the world.

In this section of the report, we set out the main areas of biomedicine which have been asked about in surveys and polls of adults around the world since 1980. Under each substantive heading, we provide some illustrative examples of the different sorts of questions that have been employed and provide commentary on their relative merits, where appropriate. Note that in order to keep the report to a manageable length we have had to be rather selective with regard to the illustrative examples chosen. There are 817 different attitude questions in total listed in Appendix 3 and the interested reader should take the time to look through them all. At the end of the section we consider some more general methodological and conceptual issues pertaining to the measurement of public attitudes toward biomedicine.

### ***6.1. General attitudes to biomedical science***

The term 'biomedical science', as we have noted earlier, contains a broad and heterogeneous range of theories, concepts, practices and products. It is generally used to refer to the academic/commercial pursuit and production of health-related technologies and interventions emerging out of late 20<sup>th</sup>- and 21<sup>st</sup>-century biochemical theory and method. In this sense, while the term is familiar to those within, or in close proximity to, the world of academic science, it is not a term that has much resonance with the average member of the public.

Thus, in all the attitudinal questions identified in our review, not one asks directly about 'biomedical science'. In terms of obtaining overall appraisals of this field of scientific

endeavour, the closest we come to a global evaluation is with items that ask about the impact of 'science and technology' on life in general, or in the specific area of health. For example, the question below has been asked in the British Social Attitudes Survey, the Eurobarometer, and the NSF Science and Engineering Indicator Series:

*Science and technology are making our lives healthier, easier and more comfortable? Strongly agree, agree slightly, neither, disagree slightly, disagree strongly, don't know*

Although this question does refer explicitly to health, it is clearly aiming to obtain orientations toward the impact of all varieties of science on life in general. Indeed, it is taken from a four-item scale developed by Jon Miller, measuring belief in the 'Promise of Science and Technology' (Miller and Kimmel, 2001). The below item, also taken from the Eurobarometer series, is similar in that it aims to elicit views on the promise of science and technology for curing specific illnesses:

*Scientific and technological progress will help to cure illnesses such as AIDS, cancer...? Strongly agree, Agree, Neither, Disagree, Strongly disagree*

Another question which addresses more generalised attitude to biomedical science asks respondents to rate how important research into health is, alongside a list of other areas of scientific research. Again, this item is taken from the Eurobarometer:

*For each of the following sectors, how important or unimportant do you feel it is that research should be carried out in that sector? ... Health ... Very important, Fairly important, Not very important, Not at all important, (Don't Know)*

While this question will clearly tap into public opinion toward the importance of biomedical research, the vagueness of 'research in health' (which includes epidemiological and psycho-social investigations among others) means that the item is of only limited use in understanding generalised views of biomedical science. For a measure of public opinion toward biomedical science in general, then, it would appear to be necessary to develop novel items for a future survey, or to produce some kind of composite indicator from existing questions about more specific areas of biomedicine.

## **6.2. Biotechnology/genetic engineering**

The closest we come to generalised attitude questions about biomedical science are those that elicit views on 'biotechnology' and 'genetic engineering', terms that, wisely or not, are generally used interchangeably in studies of public opinion. Some surveys, such as the 2003 British Social Attitudes survey used the possibly less charged term 'modern genetic science'

to denote the same thing. The following item has been included in a large number of surveys throughout the world to gauge general orientations to modern genetic science:

*For each of these areas, do you think it will improve our way of life in the next 20 years, it will have no effect, or it will make things worse, (Don't Know)? ... Biotechnology and genetic engineering?*

Clearly, as an 'emergent' area of science, which by the late 1990s had not had a major impact on the lives of individuals, this question aims to elicit people's views about the *likely* impact of the technology in the future. A similar item, from the 1997 US Biotechnology study, asks the same sort of question but over a shorter and probably more realistic (in terms of respondents' abilities to come to a judgement) time frame:

*Biotechnology will personally benefit people like me in the next five years. Do you strongly agree, agree, disagree, or strongly disagree?*

The same survey contrasts views about the likely benefit of biotechnology in the future with current influence on the individual's life:

*My family and I have already benefited from biotechnology. Do you strongly agree, agree, disagree, or strongly disagree?*

The political controversy over biotechnology relates to dissensus over the risks and benefits to society of a set of technologies whose societal and economic impacts are not yet clearly understood. Thus, a number of questions, such as the following from the Eurobarometer (replicated in Canada, New Zealand and Japan) elicit respondents' views over the relative risks and benefits of biotechnology:

*We have to accept some degree of risk from modern biotechnology if it enhances economic competitiveness in Europe. Tend to agree or to disagree*

The NSF Science and Engineering Indicator series poses the risk/benefit calculation as a single question:

*Some persons have argued that the creation of new life forms through genetic engineering constitutes a serious risk, while other persons have argued that this research may yield major benefits for society. In your opinion, are the risks of genetic engineering research greater than the benefits, or are the benefits of genetic engineering research greater than the risks?*

Other questions (again from Eurobarometer, replicated elsewhere) require respondents to make risk assessments for specific outcomes:

*For each one, please tell me whether you think it is likely or unlikely to happen within the next 20 years, (Don't Know). Creating dangerous new diseases/Solving more crimes through genetic fingerprinting/Curing most genetic diseases*

The main problem with these types of questions as measures of attitude toward biomedical science is that the technologies that fall within the broad headings of 'biotechnology', 'genetic engineering', and 'modern genetic science' contain non-medical applications, most notably GM crops and food. Because public support for medical biotechnology is markedly greater than for agricultural applications (Bauer, 2005), the use of such items as measures of biomedical opinion is problematic. In the following sections we turn to measures of public opinion toward specific areas of biomedical research and their associated technologies.

### **6.3. Genetic testing and modification**

Genetic testing is an area of genomic biomedicine that has already had a significant impact on the lives of many people throughout the world. This is reflected in the large number of questions identified in the review that relate to human genetic testing. Its current use and possible extensions into new areas of diagnosis raise ethical concerns along a number of dimensions. These include the selection of sex and desirable traits in offspring - so-called 'designer babies', the benefits or otherwise of knowing about individual propensities to develop genetic illnesses, the accuracy of tests, the misuse of genetic information for commercial and or governmental purposes, and concerns over a reversion to eugenic practices via pre-natal genetic diagnosis.

In terms of general orientations toward genetic testing, several surveys have elicited responses pertaining to its perceived risks and benefits. Typical of this approach is the 2002 UK Public Perceptions of Risk, Science and Governance survey, which requires respondents to differentiate between risks and benefits for themselves and for society in general:

*How would you assess the benefits, if any, of genetic testing for British society as a whole? Very high benefits 6... No benefits 0, (Don't Know)*

*How would you assess the benefits, if any, of genetic testing for yourself? Very high benefits 6... No benefits 0, (Don't Know)*

*How would you assess the risks, if any, to human health from genetic testing for British society as a whole? Very high risks 6... No risks 0, (Don't Know)*

*How would you assess the risks, if any, to human health from genetic testing for yourself? Very high risks 6... No risks 0, (Don't Know)*

Other studies have sought to uncover the nature of objections to the use of genetic testing. Here is an example of this approach from the 1996 Finnish genetic testing survey:

*Genetic testing is not acceptable because the natural order should be respected. Fully agree, partially agree, partially disagree, fully disagree, can't say*

*Genetic testing is not acceptable because the results may lead to discrimination against disease carriers. Fully agree, partially agree, partially disagree, fully disagree, can't say*

*Genetic testing is not acceptable because testing would make abortions more common. Fully agree, partially agree, partially disagree, fully disagree, can't say*

Note that a major problem with this question formulation is that respondents may not think that genetic testing is unacceptable in the first place. Such respondents would be indistinguishable from those who agree that it is unacceptable but not for the reason specified.

Many social commentators have noted the possibility of misuse and/or unintended uses of genetic information, a concern which in turn has been implemented in various ways in public attitude surveys around the world. Here is an example from 2002 UK Public Perceptions of Risk, Science and Governance survey:

*How would you assess the risks, if any, of the use of information from genetic testing without consent for yourself? Very high risks 6... No risks 0, (Don't Know)*

A large number of questions on genetic testing ask respondents about their own willingness or propensity to take a genetic test themselves. Here is an example from the 2002 UK ONS Omnibus survey:

*Nowadays, it is possible to predict whether or not a person is likely to develop certain diseases by analysing their genes. This is called genetic testing. Genetic testing is currently available for a limited number of diseases, but it may be available for more diseases in the future. If it were available would you, in the next 6 months, have a genetic test to see if you were at risk of developing cancer in the future? No definitely not, no probably not, yes probably, yes definitely, Don't know. Can you say why you gave that answer?*

Other surveys pose the same basic question but about pre-natal genetic tests for the respondents foetal offspring. Here is an example from the 1990 ABC News Poll in the USA:

*I am going to name some things that genetic testing might be able to tell about an unborn human foetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Would develop a painful disease which would cause almost certain death by age 4? Yes, No, Don't Know*

The modification of human genes is an area that, while receiving much media attention over the past five to ten years, is far less developed in the way of working applications. Thus, the majority of existing questions relating to genetic modification/gene therapy have asked about approval or disapproval of stylised hypothetical situations. Here is an example from the 2003 British Social Attitudes survey (a modified version of an item in the 1999 Wellcome Trust Consultative Panel on gene therapy):

*I'd like you to think of someone in their 20s who has a life-threatening medical condition. Suppose it were discovered that changing some of their genes by giving them an injection would help treat them. These new genes would not be passed onto any children they might have. Do you think this should be allowed or not allowed? Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, Don't Know*

Given the hypothetical nature of this type of question in conjunction with the rather technical nature of the vocabulary, its meaning and value are debatable.

#### **6.4. Stem cells and cloning**

Particularly in the USA, cloning and the use of stem cells has been the subject of much heated moral and political debate. The use of human embryos to harvest stem cells and the possibility that human cloning might be used for reproductive as well as therapeutic purposes has been at the centre of resistance to research using human stem cells. A large number of the items identified that relate to stem cells and cloning refer to the recent passage of legislation in the USA. We do not comment on these items in any detail here as they are of only limited relevance and potential utility outside the context of contemporary America.

Interestingly, very few questions ask about the use of stem cells *per se*. Instead the very great majority of studies focus on the moral acceptability of how stem cells are produced, particularly the cloning of human embryos. An angle that is frequently pursued is to contrast the use of cloning to produce stem cells and its use as a reproductive fertility treatment. Here is a succinct item from the US Gallup poll:

*Do you approve or disapprove of cloning that is designed specifically to result in the birth of a human being?*

Which can be contrasted with this question from VCU Life Sciences Survey, which limits approval to cloning for the development of therapeutic treatments:

*Do you favour or oppose using human cloning technology if it is used only to help medical research develop new treatments for disease? Strongly favour, somewhat favour, somewhat oppose, strongly oppose, Don't Know*

The implicit assumption in these questions is that respondents will understand what is meant by 'cloning'. Given the technically difficult nature of the cloning process (and the possibility that many respondents will be familiar with the term only through the medium of science fiction), other studies have attempted to provide a description of the procedure involved, rather than letting respondents come to their own view of what is meant by 'cloning'. Here is an example of this type of question from the 2003 British Social Attitudes Survey relating to therapeutic cloning:

*You might have heard of something called human cloning. One type of cloning would be if a person's genes were copied exactly and used to make an embryo. Cells from the embryo could be used to supply the person with tissues or organs that would be a perfect match for them, meaning their body would not reject them. Do you think this should be allowed or not allowed if a person... needs an organ transplant? needs treatment for Parkinson's? is generally in good health and wants to live longer? Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed*

And to reproductive cloning:

*Another type of human cloning might be used to treat a young couple who are infertile and cannot have a child. Suppose that the genes from one of them were copied exactly and used to make an embryo with exactly the same genetic make up as that parent. Do you think this should be allowed or not allowed for a young couple who are infertile and cannot have a child? Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed*

This approach, however, results in rather long and 'wordy' items with responses potentially strongly influenced by the exact choice of words in the technical description.

In addition to investigating the differential moral acceptability of these two applications of cloning, a number of studies have sought to understand more precisely the moral basis of views on cloning. For instance, the Eurobarometer administered the following set of items in the 2002 survey, having provided a short description of what therapeutic cloning is earlier in the survey (note that these four items are a selection from a larger pool):

*Therapeutic cloning will be useful as it promises cures for some serious diseases?*

*Therapeutic cloning will be useful for third world countries in the fight against deadly tropical diseases?*

*Therapeutic cloning will only be good for industry and not for ordinary people?*

*Therapeutic cloning poses no threat to future generations?*

### **6.5. Genetic influence on traits and behaviour**

A number of commentators have hypothesised that, with the growing realisation of the importance of genetic factors in determining human traits and behaviours in the 21<sup>st</sup> century, we will begin to witness a growing belief in genetic determinism (Lippman, 1993). Several studies have implemented questions which require respondents to state the degree to which a variety of traits and behaviours are attributable to environmental or genetic factors:

*Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... a person's height?/ a person's intelligence?/getting heart disease?/being aggressive or violent? All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Several variants of these items have been administered in other surveys, focusing on different traits and behaviours and using somewhat different forms of words to denote environment and genetic influences. The real value of such questions, of course, will only be realised once a time series has been established. Thus far, there is little evidence to support the hypothesis of increasing genetic determinism (Sturgis *et al.*, 2004).

### **6.6. Storage and use of human genetic information**

A persistent concern arising from the ability of humanity to decode and understand genetic information relates to individual civil liberties. Fears have been raised on a number of grounds, such as that genetic test results will be made available to insurers and employers. Similarly, the ability to identify individuals from microscopic traces of DNA has led to calls (and in places the introduction) of databases of genetic material linked to individuals to aid in criminal investigations and prosecutions. The existence of such databases raises ethical concerns to do with the accuracy of the databases and their possible misuse for purposes of commercial exploitation and government social control. A number of different polls have addressed these issues in a variety of ways. Here is an early example from a 1995 US Harris poll:

*If you had such a genetic test, how concerned would you be that organisations would want to know the state of your health, such as health and life insurance companies, or employers might require you to provide them with the test results, so that they could decide whether to insure or hire you? Very concerned, somewhat/fairly concerned, not very/somewhat concerned, not at all concerned, Don't Know*



While items like this have focused on the level of concern the public have about the use of individual genetic data, other surveys have looked at how likely people think this eventuality is to come to fruition within some specified time span. Here are three questions of this type from the British Social Attitudes Survey:

*How likely or unlikely do you think it is within the next 25 years that genetic information will be used to judge a person's suitability for getting ... health or life insurance?/A job they've applied for?/Credit at the bank? Very likely, quite likely, not very likely, not at all likely, Don't Know*

Note that there are two problems with this type of item. First, it is unclear on what basis people would be making this evaluation, rendering the interpretation of results ambiguous. Second, as potential time series indicators, the questions are problematic as they specify a fixed time period. This means that the reference period of the question changes over time, unless the period is reduced with each successive, a solution which would seek to retain over-time comparability by changing the item wording.

While some individuals will always oppose the storage of genetic material on civil liberty grounds, for the majority of citizens, the degree of resistance to the storage of genetic information varies as a function of the use to which it will be put. Thus, several surveys have sought to understand how support/opposition relates to different potential uses. Here are five items from the 2003 British Social Attitudes Survey:

*Samples of genetic information can be taken from people and the results kept in a database. Would you be in favour of, or against, setting up such a database if it was... used to improve our understanding of illness and disease?/to identify people who have committed serious crimes?/to find out more about where people's ancestors originally came from?/to judge a person's suitability for getting health and life insurance?/to judge a person's suitability for getting a job they've applied for? Strongly in favour, In favour, Neither in favour or against, Against, Strongly against, (Don't Know)*

Similar items have also been included on the Eurobarometer (and a replication survey in Canada):

*I would support the government agency dealing with social security and pensions having access to a person's genetic information? Tend to agree, Tend to disagree, (Don't Know)*

*I would support private insurance companies having access to a person's genetic information? Tend to agree, Tend to disagree, (Don't Know)*

*I would support the police having access to people's genetic information to help solve crimes? Tend to agree, Tend to disagree, (Don't Know)*

*I would support doctors and surgeons having access to a patient's genetic information? Tend to agree, Tend to disagree, (Don't Know)*

## **6.7. Nanotechnology**

Nanotechnology has only recently emerged as a potential socially transformative technology. Few actual applications have so far been produced and public awareness of this area is currently very low. As a result of these two factors, questions in public opinion surveys are relatively few and far between.

Those who have sought to elicit the general orientation of public opinion towards nanotechnology have found high levels of Don't Know responses where a standard question format has been used. For instance, Gaskell *et al.* (2005) found that 50 per cent of respondents answered Don't Know to the following question in the 2002 Eurobarometer:

*I am going to read out a list of areas in which new technologies are currently developing. For each of these areas, do you think it will improve our way of life in the next 20 years, it will have no effect, or it will make things worse, (Don't Know)? Nanotechnology*

In a study for the Royal Society and the Royal Academy of Engineering, BMRB used the following three items. Only respondents who reported having heard of nanotechnology were asked the second question and only those who gave some account of what they thought it was were asked the third question.

*Have you heard of nanotechnology?*

*What do you think nanotechnology is?*

*Do you think nanotechnology will improve our way of life in the next 20 years, it will have no effect, or it will make things worse?*

A joint US/Canadian study similarly employed a self-reported familiarity question, although of considerably greater length:

*The next part of this survey focuses on nanotechnology, which is an emerging technology. Nanotechnology involves the application of science and engineering at the atomic scale. It involves the construction of tiny structures and devices by manipulating individual molecules and atoms, which have unique and powerful properties. These structures can be used in medicine and biotechnology, in energy and the environment, and in telecommunications. Some examples of nanotechnology include the use of molecules that have properties that enable the production of drinking water by extracting salt from seawater, the use of implantable surgical devices that can measure things like blood pressure on a continuous basis, or the use of special nanomolecules in fabrics like wrinkle resistant pants . Would you say you are very, somewhat, not very or*

*not at all familiar with nanotechnology? Very familiar, Somewhat familiar, Not very familiar, Not at all familiar, Don't know.*

The benefits of this considerably extended version of the self-reported familiarity question are not immediately apparent. If the aim of the study is to estimate the proportion of the public who are familiar with nanotechnology, it would seem sufficient to ask this in a succinct and direct manner; the proportion of people who are aware of the underlying science but do not know that it is called nanotechnology is likely to be vanishingly small.

The same study also elicited views about the risks, benefit to society and moral acceptability of nanotechnology:

*I would like to understand the extent to which you think nanotechnology might benefit our society. Using a scale of 1-5, where 1 is no benefit and 5 is substantial benefit, and the mid-point 3 is moderate benefit, how beneficial do you think nanotechnology research will be to our society? [1-5], Don't know.*

*I would like to understand the extent to which you think nanotechnology might pose a risk to our society. Using a scale of 1-5, where 1 is no risk and 5 is substantial risk, with the mid point 3 being moderate risk, how much risk does nanotechnology pose for our society? [1-5], Don't know.*

*In terms of the moral or ethical aspect of nanotechnology, again using the 1-5 scale, where 1 means that nanotechnology is morally unacceptable, 5 means it is morally acceptable, and the mid point 3 means it is morally questionable, how do you view this kind of research? [1-5], Don't know*

The US 'Public Opinion about Nanotechnology' survey asked about emotional, as opposed to cognitive, reactions to nanotechnology:

*The next set of questions asks about emotions you might feel. First, are you worried about nanotechnology? No, Yes, Don't know*

*How worried are you [about nanotechnology]? Very worried, somewhat worried, only worried a little, Don't know.*

*The next set of questions asks about emotions you might feel. Are you hopeful about nanotechnology? No, Yes, Don't know.*

*How hopeful are you [about nanotechnology]? Very worried, somewhat worried, only worried a little, Don't know.*

*The next set of questions asks about emotions you might feel. Are you angry about nanotechnology? No, Yes, Don't know.*

*How worried are you [about nanotechnology]? Very worried, somewhat worried, only worried a little, Don't know.*

### **6.8. Use of animals in biomedical science**

A longstanding area of controversy in biomedical research is the use of animals for testing and development of new medical products and procedures. Many surveys around the world have included questions eliciting public views on the acceptability or otherwise of this practice. It is clear that responses to these questions are strongly influenced by the way in which they are framed. For example, acceptance of the use of animals in medical research is higher if the question emphasises that this may result in saving human lives (1993 British Social Attitudes Survey):

*It is right to use animals for medical testing if it might save human lives? Strongly agree, Agree, Neither, Disagree, Strongly disagree, Don't Know*

than when no specific benefit is mentioned:

*And what do you think of developing genetically modified animals for laboratory research studies, such as a mouse that has genes which causes it to develop cancer? Tend to agree, Tend to disagree, (Don't Know).*

So it is clearly important to emphasise the trade-off between costs and benefits of animal testing. However, some questions emphasise a trade-off but fail to get respondents to make a choice. For instance, opponents and proponents of animal testing could no doubt both agree to the following item from the 1993 Eurobarometer:

*One should look for a balance between animal welfare and human welfare? Definitely agree, Tend to agree, Tend to disagree, Definitely disagree, (Don't Know)*

The degree of public acceptance of animal testing is also, unsurprisingly, strongly influenced by the specific animals that are to be used in testing. Thus, a great many questions on attitudes to animal testing focus on the acceptability of use of different types of animal. The 1993 Eurobarometer and US biomedical literacy surveys received much less support when dogs and animals were specified:

*Scientists should be allowed to do research that causes pain and injury to animals like dogs and chimpanzees if it can produce new information about serious human health problems? Strongly agree, Agree, Neither, Disagree, Strongly disagree*

compared to mice:

*Scientists should be allowed to do research that causes pain and injury to animals like mice if it can produce new information about serious human health problems? Strongly agree, Agree, Neither, Disagree, Strongly disagree*

Other surveys have focused on the possibility of alternatives to animal testing – an issue which has been strongly emphasised by opponents of testing – such as the following item from the 1999, 2002 and 2005 UK Animals in Medicine and Science Survey:

*There needs to be more research into alternatives to animal experimentation? Agree, disagree, Don't know.*

### **6.9. Personal experience of genetic illness**

As was noted in section 6, individuals for whom biomedical science has some salience in everyday life are likely to be more interested and knowledgeable and to have a rather different attitude profile than people for whom biomedical is of little importance. A key indicator of salience of biomedical science in the 21<sup>st</sup> century is individual experience with genetic illnesses. Generally, this kind of question is intended for use as a moderator in explanatory analysis. Here is a question that was fielded in the 2002 PSRA/Public Awareness and Attitudes about Genetic Technology Survey to measure personal experience of this nature:

*Have you, or has anyone in your immediate family, ever had a genetic disease? Yes, No, Don't Know*

The primary problem with this item is the question of whether the average citizen will understand the meaning of a 'genetic disease'. To minimise the reporting of false-positives, the British Social Attitudes Survey adds the qualification that the condition should have been diagnosed by a doctor:

*Has a doctor ever advised you, or any member of your immediate family, of a serious genetic condition in your family? Yes, No, Don't Know*

Conversely, the problem with this question is that it might under-estimate the true level of personal experience of genetic illness because some individuals may be aware of an illness that has not been diagnosed by a doctor.

### **6.10. Regulation and trust**

As we noted at the start of this section, surveys of public opinion toward biomedical science are generally motivated by a perceived need for the speed and direction of science policy to be in tune with, or constrained by the 'will of the people'. For this reason, it is common for questions to be asked about current or future regulatory arrangements and

about the confidence of the public in scientific and political actors and the institutions within which they are located.

We have already seen a number of items which relate to legal and regulatory frameworks for the conduct of biomedical science. Indeed, any of the items we have currently listed as pertaining to trust and regulation could equally well be listed under a different substantive heading – it is not sensible to ask about legal frameworks and regulation without specifying the thing to be regulated. Some surveys elicit opinions on whether certain practices should be ‘allowed’ or ‘banned’. Take, for instance, this 1999 Pew Center poll:

*I'm going to mention several issues, and I'd like to get your reaction. For each item I read, please tell me whether this is something you strongly favor, somewhat favor, somewhat oppose, strongly oppose, Don't Know.)... Banning medical research on human cloning.*

Many questions, like the one shown above mention specific aspects of biomedical science that should be regulated in some specified way. Other questions are more general in nature and elicit views about the overall adequacy of regulatory frameworks. Here is an example of such an item relating to genetic testing from the Public Perceptions of Risk, Science and Governance survey:

*I feel that current rules and regulations in the UK are sufficient to control genetic testing. Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Other questions relate not so much to what laws or regulations should be enacted but to which groups in society should contribute to making such decisions. Here is an item from the Public Perceptions of Risk, Science and Governance survey:

*How much do you agree or disagree that the following should be involved in making decisions about genetic testing? The general public strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

This was one item of from a list of 13 different groups including, *inter alia*, environmental organisations, the EU, pharmaceutical companies, and scientists working for government. It is often taken as axiomatic in recent discussions of science policy, that ‘the public’ should be consulted and involved in decision making.

Interestingly, this type of item has tended to receive clear majority endorsement.

Closely linked to notions of legal and regulatory adequacy is the notion of public trust in scientific and political institutions and actors. Lacking the time, motivation and resources to become well informed and involved in science policy, citizens must rely on a variety of elected and non-elected bodies to act in their interests.

Trust, therefore, is crucial to the effective functioning of modern democratic society and is frequently asked about in surveys of public opinion towards biomedical science. A very common approach to asking about trust in surveys is to require respondents to rate a list of actors/institutions in terms of their level of trust. Here is an example of this type of item battery from the Northern Ireland Life and Times Survey:

*How much trust do you have in each of the following to tell the truth about any dangers of research into human genes? A lot of trust, some trust, very little trust, No trust at all, (Don't Know) Journalists on national newspapers, Government health ministers, Scientists in universities, Government scientists, Scientists working for drug or pharmaceutical companies, Scientists working for health research charities*

### **6.11. Discussion and conclusion**

In this section of the report we have reviewed and provided illustrative examples of the main areas of biomedicine that have been asked about in public opinion surveys of adult populations over the past 25 years around the world. In total, we identified 817 different attitude items falling into 11 broad categories. These were: general attitudes to biotechnology/genetic engineering; genetic testing and modification/therapy; stem cells and cloning; beliefs about genetic influence on traits and behaviour; storage and use of human genetic information; personal experience of genetic illness; nanotechnology; the use of animals in biomedical trials; and regulation and trust. There was also a set of 'miscellaneous' items that covered various aspects of biomedicine but did not fit into the above categories.

Where appropriate, we have provided some methodological commentary on the specific item formats and forms of wording we have encountered. However, we should emphasise that the utility of any survey item should be evaluated not in an absolute sense but in terms of its fitness for purpose; what may work in one context will be entirely inappropriate in another. Thus, which of the items included in appendices 1, 2 and 3 might be suitable for use in future surveys must be determined in the light of the aims and objectives of the particular survey in question. In this concluding section we consider some more general methodological issues pertaining to the measurement of attitudes toward biomedical science

Broadly, we can distinguish between two types of attitude question in the context of public opinion toward science and technology. The first kind encompasses those that elicit general orientations or dispositions towards biomedical science and technology and its social and economic impacts. The second variety asks about particular scientific issues/controversies or specific technological applications. Both have potential problems, which have been noted in the empirical literature. These problems arise from the fact that, for most people

science and technology is of rather low salience in their everyday lives. As we saw in section 3, most people are generally poorly informed about and detached from developments in biomedical science. This poses problems for those who seek to understand the shape and trajectory of public preferences about often rapidly developing technologies.

Faced with a public who are unlikely to have even heard of many of the most recent developments in biomedical science, researchers often employ measures of a rather general and abstract nature, designed to elicit overall orientations towards organised science or some area of technological development. Although respondents find such items relatively easy to answer, the problem is that they suffer from being too general. When the range of practices and activities falling under the general umbrella of 'biomedical science' are so heterogeneous, is it really possible to say anything meaningful about public preferences at this aggregated level? Faced with questions posed at a highly generalised level, people will answer in idiosyncratic ways because there is no unequivocal focus in the wording of an individual question.

Thus, some people may respond to a question that asks about the contribution of biomedicine to modern life thinking about prenatal genetic testing, while others respond on the basis of their views about stem cells. Of course, this lack of 'invariance of meaning' is not a difficulty that is unique to PUS surveys. It is certainly well known in political science and social psychology. Such problems have led some to claim that generalised attitudes are of dubious ontological status, perhaps of only symbolic value, reflecting individuals' beliefs about the merits of discovery, progress and open-minded enquiry.

There are two potential solutions to the problem of generalised attitude statements as described here. The first is to aggregate responses from conceptually related items into a metric scale. This can be done via simple summing of related items, or via more complex latent variable modeling, such as factor analysis and latent class analysis. These approaches allow idiosyncratic, random variations in interpretation to any single item to be 'smoothed out' and a common core of meaning brought to the fore. While this statistical solution may seem obvious to those familiar with social psychological measurement, it has sometimes been lost on sceptics of survey methods in PUS whose critical focus tends to be directed towards the meaning of individual questions in isolation, rather than on the construct validity of aggregated scales (e.g. Irwin and Michael, 2003).

Having said that, the attitude scales that have been fielded in the surveys we have reviewed here tend to be based on a somewhat *ad hoc* mixture of items, some of which go back to the



studies of Davis and Withey in the 1950s. Pardo and Calvo present a reanalysis of the 1992 Eurobarometer science attitude items that suggests there is, without doubt, a good deal of 'fuzziness' in the various attitude scales that have been put to use by researchers over the years (Pardo and Calvo, 2002). They suggest more methodologically stringent and theoretically informed design for future science attitude scales, a call which we would fully endorse. Items designed to 'stand alone' rarely scale in ways that are statistically satisfactory. However, by carefully designing attitude questions that scale into an underlying latent variable, we do not remove the possibility that the individual items can be analysed in isolation, with the focus on marginal distributions across sub-groups, time and cultures. This approach also then leaves open the possibility that the scales can be used as continuous variables in more explanatory models.

The other solution to the general attitude problem is to eschew general items, in favour of more detailed questions about specific issues and technological applications. Thus, some questions effectively ignore the low information problem and proceed to ask directly about, say, stem cell research or therapeutic cloning. The results of such exercises may be ostensibly comforting; the majority of respondents usually offer opinions willingly. However, there is good reason to believe that opinions of this nature are of very little substantive value – constructed on the spot from limited information in the preceding questions, or in the question itself and, therefore, highly malleable. Indeed, a number of studies have shown that members of the public are perfectly happy to offer opinions on non-existent issues, such as the fictitious 'public affairs act' (Bishop *et al.*, 1986).

Faced with the knowledge that few respondents are sufficiently aware of biomedical applications to offer meaningful opinions about them, survey researchers have developed questions which attempt to briefly explain the technology in question. For example, here is a question about therapeutic cloning from the 2003 British Social Attitudes Survey: "*You might have heard of something called human cloning. One type of cloning would be if a person's genes were copied exactly and used to make an embryo. Cells from the embryo could be used to supply the person with tissues or organs that would be a perfect match for them, meaning their body would not reject them. Do you think this should be allowed or not allowed ...*".

There are two primary problems with this type of 'educative' question; first they are generally very long and often employ a rather technical language, both of which are generally considered to be bad features for a survey question. Second, the distribution of responses is strongly influenced by the precise wording of the preamble. Because there are many different ways of constructing these preamble sections, all of which might be

considered accurate, the true distribution of preferences toward the science or technology in question remains unknown – responses are tautologically related to the content of the question wording.

A third approach involves the use of filter questions which effectively remove all respondents who have not heard of, or are unfamiliar with a specific issue or application. Respondents are first asked whether they are familiar with issue X and only those who respond in the affirmative are asked the ensuing evaluative question. Such questions are effective in removing large proportions of individuals from the sample of respondents to the substantive question.

However, as we saw in section 4.2, the filter questions themselves may not always work exactly in the way intended because people vary in their understanding of terms such as ‘familiar with’, ‘well informed about’ and so on. Additionally, there is the further potential problem that respondents may declare themselves to be unfamiliar with an issue, in order to avoid the ensuing follow-up questions. This is a response style that Krosnick has termed ‘satisficing’ and refers to the fact that many survey respondents are motivated to take the ‘path of least resistance’ through a questionnaire, rather than to provide completely faithful and accurate responses (Krosnick, Holbrook *et al.*, 2002).

Which of these solutions to the ‘low information problem’ should be adopted? Unfortunately, there is no definitive answer. The best approach probably involves a combination of all three formats, with an explicit recognition of the inherent limitations of each. Additionally, a design which incorporates more qualitative information of an in-depth nature would seem particularly well suited to investigations of low-salience topics.

## **7. Overview and summary**

In this document we have reported the results of an extensive review of existing surveys of public attitudes, knowledge and interest among adult populations around the world since 1980. Our search identified a total of 236 in-scope surveys and polls, comprising a total of 140 different knowledge items, 85 interest/engagement items and 817 attitude items. These numbers and categories should not be viewed as precise and definitive, given the difficulty of determining what constitutes 'a question' and the possibility of the same item belonging to a number of different categories simultaneously.

In sections 4, 5 and 6 we considered some of the methodological advantages and disadvantages of different approaches to operationalising our key concepts of knowledge, interest and attitude. As we noted in section 6, such evaluations should be read with a degree of caution, as any survey question should be judged in terms of its fitness for purpose rather than via some absolute judgement.

### ***7.1. The measurement of biomedical attitudes***

Within the category of attitude questions, we further sub-divided items into the following ten headings. Again, these are somewhat loose categorisations which we use for broad descriptive purposes only:

- attitudes to biotechnology/genetic engineering
- genetic testing and modification/therapy
- stem cells and cloning
- beliefs about genetic influence on traits and behaviour
- storage and use of human genetic information
- personal experience of genetic illness
- nanotechnology
- the use of animals in biomedical trials
- regulation
- trust.

Which of these items are suitable, or most appropriate for use in future surveys? The answer to this question cannot really be provided until the specific aims and objectives of the survey in question have been explicitly determined. We have, however, been able to provide some general advice about the types of item format that have been employed in existing studies to date and some of their relative strengths and weaknesses.

A key issue in this regard relates to how the researcher should go about measuring opinion towards areas of science and technology about which most members of the public are only dimly aware. We contrasted three methodological approaches: obtaining abstract/generalised orientations; obtaining more specific evaluations of particular technologies, with or without extended preambles; and using 'filter' questions to remove the uninformed members of the sample from the estimate of opinion. In our view, none of these provide a complete solution to what is ultimately a rather intractable problem within the confines of a conventional survey framework. Given these constraints, the optimal approach is probably represented by some kind of hybrid of all three, in conjunction with more in-depth investigations of a more qualitative nature.

An interesting potential development of future work in this area would be to explore James Fishkin's Deliberative Polling methodology, or some online or Grid variant thereof (Fishkin, 1997). This would enable the estimation of 'informed opinion' from a representative sample of the public in a way that is not feasible in conventional polls. We should note, however, that the Deliberative Polling method is not without problems of its own (Sturgis, Roberts, and Allum, 2005).

Again on a more general methodological level, we argued that any future study should aim to measure attitudes via multi-item scales, rather than as a set of independent items. This approach allows powerful latent variable models to be applied during the analysis stage, without compromising our ability to use the component items to report population marginals.

Another important point to make in relation to the selection of items for future surveys is that a large number of the questions covered by this review have now been asked in many different countries around the world, over a long and growing time period. Although some of the items, for which time series or comparative data exist have some methodological problems, the ability to make retrospective and cross-national comparisons would be an important added value for any future survey in this area. Detailed information about which surveys have fielded which questions can be found in the Excel database of surveys and questions that accompanies this report.

## **7.2. The measurement of biomedical knowledge**

Most survey investigations incorporate some measure of knowledge or familiarity with science in general, or in a specific area of science. Sometimes, investigators have relied on self-assessments of knowledge, while in others more 'objective' indicators have been employed. We have noted the inherent problems of self-assessed knowledge questions, primary among which are the weak correlation with more objective assessments. Self-ratings appear to be strongly influenced by interpersonal variation in interpretation of question wordings (what does it mean to be 'well informed?'), personality and self-esteem. Such questions are often used as 'filters', to partial out 'uninformed' respondents from subsequent opinion questions, a use for which they are probably better suited.

Compared to other areas in which measures of factual knowledge are commonly implemented within survey investigations, studies of the public understanding of science have made frequent use of 'open' questions, in which respondents' verbatim answers to a question such as 'what is biotechnology?' are coded to some frame to denote their degree of understanding. Such an item has been used in many surveys to tap public understanding of the process, as opposed to the content of scientific inquiry. In our view, though such items have some advantages, they suffer from a number of problems. In particular, they are costly and time consuming to implement and analyse; they introduce additional error into the measurement process via the coding stage; and they favour the articulate and motivated, who provide longer and more detailed responses at the same level of underlying knowledge.

By far the most common form of knowledge measure identified in this review is the multi-item, fixed-choice scale, usually of the true/false format. Such items have been the subject of much sustained criticism in PUS research over the years, much of it in our view misplaced. While there are some noted problems with these multi-item batteries, particularly their susceptibility to guessing and the differential effect this has across sub-groups, in our view they represent the most accurate and cost-effective means of measuring scientific/biomedical science.

This endorsement does not extend to all items identified by this review, many of which seem to us of rather dubious merit. Thus, while we would endorse Pardo and Calvo's conclusion, that "work to date on how much people know about scientific advances...has been limited in scope, both conceptually and from a metric standpoint" (Pardo and Calvo, 2004 p.205), in our view the improvements would be best made within the format of the fixed-choice multi-item battery.

### **7.3. The measurement of biomedical interest**

Key to individual variation in knowledge and attitude is the personal salience of science in the everyday lives of individual citizens. Personal salience leads to different patterns of media use, information acquisition, storage and recall. Probably as consequence, the degree of personal interest and involvement in science and technology has been found to relate strongly to individual awareness of and preferences toward biomedical science. As a consequence, most surveys of public opinion in this area have sought to elicit some measure of interest or personal salience of biomedical science to the individual.

Generally, we can characterise such measures as falling into two broad categories: subjective self-assessments of 'interest'/'importance'/'concern' and self-reported behavioural indicators of interest and involvement. While self-assessed interest measures are likely to be tainted by some of the problems inherent in any form of subjective assessment (socially desirable responding, interpersonal variation in frames of reference, and the influence of personality traits and self-esteem), the items we have reviewed appear to relate in substantively meaningful ways with theoretically related measures such as education, occupational status and objective knowledge.

In contrast, behavioural measures focus on measuring media use and interpersonal communication as indirect manifestations of personal salience; to the extent that biomedical science is salient in an individual's everyday life, they will have a greater propensity to watch TV programmes, read newspapers and magazines and discuss issues with friends, family and colleagues. Many of the surveys identified in this review contain such measures, using a range of different wordings.

The main problem with behavioural indicators of interest and engagement are that there are many other factors that influence individuals to use different media channels beyond interest and engagement in science. For instance, older people are far less likely to use the Internet at all, relative to younger people, irrespective of the interest in biomedicine.

In our view, future surveys should aim to utilise a combination of self-assessed and behavioural indicators to produce a composite measure of personal salience of biomedical salience.

### **7.4. Do we need a monitor survey?**

The concentration of attitude items within the ten areas set out above is very uneven, with particular concentrations found within 'biotechnology/genetic engineering', 'genetic testing' and 'stem cells and cloning'. This skew is largely reflective of the degree of public controversy associated with each area at various times over the previous quarter century,

rather than the importance of each of these areas within the discipline of biomedicine as a whole. The extent to which certain areas are perceived to be under or over-represented in the question list in Appendices 1-3, is, we conclude, primarily a function of the rather *ad hoc* way in which public opinion surveys on biomedical science have been carried out over the past 25 years.

Surveys are generally conducted in a *reactive* manner – if a biomedical application receives media attention, or becomes the focus of political controversy, a poll will often be conducted as a result. Even when more academic surveys have been conducted, such as the British Social Attitudes Survey, different teams of investigators, motivated by different theoretical and disciplinary concerns, have conducted the studies in different years with funding obtained from different bodies, with often rather different research agendas.

An exception to this general rule are the NSF Science Indicator Series and the Eurobarometer series, which have now built a planned and theoretically motivated time series of evidence on PUS in the USA and Europe respectively. However, both these series count biomedicine as only one of a broader list of areas of interest, meaning studies which focus wholly or predominantly on public opinion toward biomedicine are sporadic.

While it is likely that the current mix of *ad hoc* initiatives and recurrent Eurobarometer modules will continue to provide an insight into public opinion in this area for the foreseeable future, by its very nature this form of evidence is partial. This partiality is meant both in the sense of the regularity of the periods between which opinion is surveyed, and the nature of the questions investigated; where time series or comparative data currently exist, it is often patchy and incomplete, arising more by luck than judgement.

These features of existing research on public attitudes to biomedicine speak to the need for a longer-term investment, of the sort envisaged by the Wellcome Trust.

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## 8. APPENDIX 1 Questions relating to biomedical knowledge

### Health/biomedical sciences (88)

Antibiotics can kill bacteria but not [as well as\*] viruses?

Human beings developed from earlier species of animals?

The earliest humans lived at the same time as the dinosaurs?

There are bacteria which live from waste water?

Most [\*all] bacteria are harmful to human beings?

It is the father's [\*mother's] genes that determine whether a child is a girl?

Whether a couple have a boy or a girl depends on the woman's genes?

Half your genes come from your mother and half from your father?

The cloning of living things produces exactly identical offspring?

Identical twins have the same genes?

It is possible to modify bacteria genetically so that they will produce useful substances?

It is possible to find out whether a child will have Down's syndrome (i.e. will be a "mongol"), within the first few months of pregnancy?

Down's syndrome is an inherited disease?

Viruses can be contaminated by bacteria?

It is possible to change the hereditary characteristics of plants, enabling them to develop their own defence against certain insects?

Biotechnology and genetic engineering makes it possible to increase the milk production of cows?

There are test tube babies who were developed entirely outside the mother's body?

Genes of all living things on earth are made up of different combinations of only 4 or 5 chemical building blocks?

We have around 150 000 different chromosomes, which contain our genes?

Ordinary tomatoes [\*do] do not contain genes, while genetically modified ones do?

By eating genetically modified food [\*fruit], a person's genes could also be modified?

Genetically modified animals are always bigger than ordinary ones?

More than half of the human genes are identical to those of chimpanzees?

It is [\*im]possible to transfer animal genes into plants?

Criminal tendencies are mainly genetically inherited?

Musical abilities are mainly learned?

Most cells in our body contain a copy of all our genes?

Food based on genetically modified organisms is dangerous.

The human immune system has no defence against viruses.

The onset of certain diseases is due to genes, environment and lifestyle.

A gene is a disease.

One can see a gene with the naked eye.

Healthy parents can have a child with a hereditary disease.

The carrier of a disease gene may be completely healthy.

All serious diseases are hereditary.

The genotype is not susceptible to human intervention.

Gene is a molecule that controls hereditary characteristics.

The child of a disease gene carrier is always also a carrier of the same disease gene.

A gene is a piece of DNA.

Genes are inside cells.

A gene is a cell.

A gene is a part of a chromosome.

Genes are bigger than chromosomes.

Different body parts include different genes.

It has been estimated that a person has about 70 000 genes.

Given today's biotechnology, scientists can now create new genes that never existed in nature.

When scientists use the term DNA, do you think it is to do with the study of...Stars, rocks, living things, or computers?

In articles and on television news shows, the term DNA has been used. When you hear the term DNA, do you have a *clear understanding of what it means, a general sense of what it means, or little understanding of what it means, (Don't Know)?*

Please tell me, in your own words, what is DNA? *Understands DNA/inheritance, Genes/chromosome/in humans, Living thing, Wrong or vague, (Don't Know)*

When I say 'DNA', what, if anything, springs to mind? (Open code)

If you wanted to find DNA in the human body, where would you expect to find it? *Cells genes chromosomes, Anywhere everywhere, Blood and other fluids, Other specified location, Don't know-incorrect*

Based on what you know about genetic testing and therapy, tell me whether you think each of the following statements is true or false.... The results of a genetic test for one person provide information about the genetic predispositions of that person's family members. Is this statement *true or false? Don't Know*

(Based on what you know about genetic testing and therapy, tell me whether you think each of the following statements is true or false.)... If a genetic test shows that a person has a genetic link to a given disease, there are no lifestyle changes, such as diet or exercise, that will reduce that person's risk for the disease. Is this statement *true or false? Don't Know*

(Based on what you know about genetic testing and therapy, tell me whether you think each of the following statements is true or false.)... Accurate genetic tests for the great majority of diseases have already been developed. Is this statement *true or false? Don't Know*

Children look like their parents because they have the same red blood cells.

Yeast for brewing beer consists of living organisms.

BSE results from putting hormones into cattle feed.

Mad cow disease poses no danger to humans.

Sunshine can be both beneficial and dangerous for one's health.

Cigarette smoking causes lung cancer.

Senility is inevitable as the brain ages and loses tissue.

Human beings can survive on almost any combination of foods, provided that the total diet includes enough calories.

Intelligence in humans is related to the size of the brain.

All man-made chemicals can cause cancer if you eat enough of them.

All pesticides and chemicals used on food crops cause cancer in humans.

When I say 'genetics', what, if anything, springs to mind?

And when say ' human genetic information', what, if anything, springs to mind?

Next, I have a few questions about genetic engineering. As far as you know, is it scientifically possible today to use genetic engineering to change a baby's genetic make-up before it is born to prevent it from having a genetic disease? *Yes, No, Don't Know*

As far as you know, is it scientifically possible today to change a baby's genetic make-up before it is born so it is smarter, stronger, or better looking? *Yes, No, Don't Know*

The next few questions will be about genetic testing. As far as you know, about how many different kinds of genetic tests are now available to identify whether or not a person has or is likely to develop a certain disease or characteristic--is it fewer than 50 tests, 50 to 200 tests, 200 to 1000 tests, or more than 1000 tests? *Fewer than 50, 50 to 200, 200 to 1000, More than 1000, Don't Know*

As far as you know, is it scientifically possible today to use genetic testing to find out if a person has a greater than average chance of developing certain kinds of cancer? *Yes, No, Don't Know*

As far as you know, is it scientifically possible today to use genetic testing to find out if a person has a greater than average chance of developing a mental illness such as

depression? *Yes, No, Don't Know*

As far as you know, is it scientifically possible today to use genetic testing during pregnancy to find out whether the baby will develop a disease as sickle cell disease or cystic fibrosis? *Yes, No, Don't Know*

As far as you know, is it scientifically possible today to use genetic testing during pregnancy to find out whether the baby will have a high IQ or intelligence? *Yes, No, Don't Know*

I have here a list of some developments of that kind. In your opinion, which of these are linked to biotechnology and genetic engineering and which are not? *Yes, No, (Don't Know)*  
Research on early detection and treatment of cancer.

I have here a list of some developments of that kind. In your opinion, which of these are linked to biotechnology and genetic engineering and which are not? *Yes, No, (Don't Know)*  
Changing hereditary information within an organism to alter that organisms characteristics

I have here a list of some developments of that kind. In your opinion, which of these are linked to biotechnology and genetic engineering and which are not? *Yes, No, (Don't Know)*  
Producing new kinds of organisms using hereditary information from other species.

I have here a list of some developments of that kind. In your opinion, which of these are linked to biotechnology and genetic engineering and which are not? *Yes, No, (Don't Know)*  
Improving traditional methods of cross-breeding plants or animals

I have here a list of some developments of that kind. In your opinion, which of these are linked to biotechnology and genetic engineering and which are not? *Yes, No, (Don't Know)*  
Making use of living micro-organisms, for example for plant protection (bio-pesticides).

I have here a list of some developments of that kind. In your opinion, which of these are linked to biotechnology and genetic engineering and which are not? *Yes, No, (Don't Know)*  
Food processing such as using yeast for the production of bread or beer.

I have here a list of some developments of that kind. In your opinion, which of these are linked to biotechnology and genetic engineering and which are not? *Yes, No, (Don't Know)*  
Treating hereditary human diseases by modifying the tissue involved.

You may have seen or heard news reports about the National Institutes of Health releasing a list of stem cell lines eligible for research with federal funding. As far as you know, under President Bush's current policy... *will stem cell lines developed in the future be eligible for federal funding for research if they meet certain criteria, Or will only those stem cell lines recently named by the*



*NIH be eligible? Don't Know*

You may have seen or heard news reports about the controversy involving federal funding of stem cell research. From what you may have seen or heard in the news, what is the major reason for this controversy?... *Human embryos are destroyed in the research process, Stem cell research is potentially dangerous to the adult subjects who participate in the research trials, Or there is not enough money in the federal budget to fund stem cell research? Don't Know*

As far as you know, is it scientifically possible today to create a clone, or genetic copy of a human being? *Yes, No, Don't Know*

Now, on the subject of cloning...As far as you know, is it scientifically possible today to create a clone, or genetic copy, of animals like cows or sheep? *Yes, No, Don't Know*

As far as you know, does the government regulate the quality and safety of genetic engineering, or not? *Yes, No, Don't Know*

As far as you know, does the government have any regulations to limit the cloning of humans, or not? *Government already regulates, Government does not regulate, Don't Know*

As far as you know, does the government regulate the quality and safety of genetic testing, or not? *Government already regulates, Government does not regulate, Don't Know*

## **Physical/Natural Sciences (12)**

The oxygen we breathe comes from plants?

Electrons are smaller than atoms?

Lasers work by focusing sound waves?

The center of the Earth is very hot?

The greenhouse effect is caused by a hole in the earth's atmosphere?

Every time we use coal, oil or gas, we contribute to the greenhouse effect?

The continents are moving slowly about on the surface of the earth?

How long does it take for the earth to go around the sun? *One day, One month, One year, (Don't Know).*

Does the... Earth go around the sun? Or the sun go around the earth?

All radioactivity is made by humans?

If someone is exposed to any amount of radioactivity they are certain to die as a result?

Radioactive milk can be made safe by boiling it.

### **Experimental Method and Probability (3)**

Let us imagine that two scientists want to know if a certain drug is effective against high blood pressure. *The first scientist wants to give the drug to 1000 people with high blood pressure and see how many of them experience lower blood pressure levels. The second scientist wants to give the drug to 500 people with high blood pressure, and not give this drug to another 500 people with high blood pressure, and see how many in both groups experience lower blood pressure levels.* In your opinion which is the better way to test this drug?

Suppose a drug used to treat high blood pressure is suspected of having no effect. There are 3 different ways scientists might use to investigate the problem, which one do you think scientists would be likely to use? *Talked to those patients that have used the drug to get their opinion? Use their own knowledge of medicine to decide how good the drug is? Give the drug to some patients, but not to others, then compare the results for each group? (Don't Know)*

Doctors tell a couple that their genetic make up means that they've got a 1 in 4 chance of having a child with an inherited illness. Does this mean that... *If they have only 3 children, none will have the illness? If their first child has the illness, the next 3 will not? Each of the couple's children has the same risk of suffering from the illness? If their first 3 children are healthy, the fourth will have the illness? Don't Know*

### **Self-reported Knowledge/Familiarity (26)**

Now, I'd like to go through this list with you again, and for each issue I'd like you to tell me if you are very well informed, moderately well informed, or poorly informed, (Don't Know). New medical discoveries

I would like you to tell me for each if you are *Very well informed, Moderately well informed, Poorly informed, (Don't Know)*. New medical discoveries

In recent years, newspapers and TV have regularly dealt with the following issues. Could

you tell me if you think you understand or not each of the following. *Thinks that understands, Do not think that understands, (Don't Know)*. Drugs developed through genetic engineering ... BSE.

I am well informed about genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much would you say you have heard or read about genetic screening? *A great deal, something but not very much, or nothing at all, (Don't Know)*

How much, if anything, have you heard about how genetic mapping might lead to advances in curing diseases such as cancer? Have you heard a lot, a little, or nothing at all? *Don't Know*

How much, if anything, have you heard about potential problems in this area such as genetic information being used to discriminate against people in employment or health insurance, or a loss of privacy? Have you heard a lot, a little, or nothing at all? *Don't Know*

Genetic testing can be done on fertilized eggs produced through in vitro fertilization to select and implant only certain eggs. For example, a parent may want to implant only eggs with no genetic diseases, or those of a specific sex, or that have other characteristics. This technology is called PGD. Before today, had you heard about PGD technology? *Yes, No, Don't Know*

How familiar are you with the words 'genetic testing' and what they mean?... *Very familiar, somewhat familiar, not very familiar, not at all familiar, Don't Know*

There has been a lot of talk in the news lately about advances in the use of genetics in medicine. How much would you say you know about the ways in which genetic testing and treatment might affect you and your family--*a great deal, quite a bit, just some, very little, or nothing at all? Don't Know*

Have you heard of using genetic testing to determine whether an unborn child has a genetic predisposition for a serious disease such as cystic fibrosis? *Yes, No*

How capable did you feel of answering the questions I asked you about biotechnology and genetic engineering? *1 Completely incapable...10 Completely capable, (Don't Know)*.

How well informed would you say you are about biotechnology? *1 Not at all informed...10 extremely informed, (Don't Know)*

I feel sufficiently informed about biotechnology. *Tend to agree, or Tend to disagree, (Don't*

*Know).*

Biotechnology is the use of living things to create products and services to meet our needs and desires. Have you heard of this before? *Yes, No, (Don't Know)*

How much do you think you know about genetic engineering? *very good knowledge, quite good knowledge, little knowledge, very poor knowledge, don't care about it, don't know/no statement*

Now I'd like to ask you about something you might not have heard about before – genetic engineering. That is the science of altering genes, which are the building blocks of life for humans, animals and plants. Genetic engineering changes genes to produce particular characteristics in living things. Before today, had you ever heard of genetic engineering? *Yes, No, Don't Know*

First, have you heard of using modern biotechnology in the production of food and drinks, for example, to make them higher in protein, keep longer or taste better? *Yes, No*

Have you heard of using biotechnology to introduce human genes into animals to produce organs for human transplants, such as pigs for human hearts? *Yes, No*

Have you heard of using biotechnology to introduce human genes into bacteria to produce medicines and vaccines, for example, the production of insulin for people with diabetes? *Yes, No*

How much do you feel you know about the way the government monitors and controls developments in modern genetic science? *A great deal, Quite a lot, Some, Not very much, None at all, Don't Know*

How well informed do you feel, if at all, about science and scientific research/developments? *Very well informed, fairly well informed, not very well informed, not at all informed, Don't know*

There are several different terms used when it comes to human cloning technology. How clear are you, personally, on the difference between human reproductive cloning and human therapeutic cloning? *Very clear, somewhat clear, not very clear, or not at all clear? Don't Know*

Have you heard of nanotechnology?

What do you think nanotechnology is?

How much have you heard about nanotechnology before today? *Have you heard a lot, some,*

*just a little, or nothing at all, Don't know?*

### **Nanotechnology (11)**

Nanotechnology involves materials that are barely visible to the naked eye? *True or false?*

Industry is already using nanotechnology to make products sold today? *True or false?*

Nanotechnology is predicted to be the next industrial revolution of the U.S. economy?  
*True or false?*

Nanotechnology involves materials that are not visible to the naked eye?

U.S. corporations are not using nanotechnology yet to make products sold today?

Experts consider nanotechnology to be the next industrial revolution of the U.S. economy?

A nanometer is a billionth of a meter?

Nanotechnology allows scientists to arrange molecules in a way that does not occur in nature?

A nanometer is about the same size as an atom?

Now lets turn to a different issue. Recently there has been a lot of talk about new technologies that allow scientists to manipulate materials at the level of tiny molecules. This could lead to the development of extremely small computers, or the improvement of existing materials. This is usually referred to as 'nanotechnology'. Let's use a ten-point scale with one being 'not at all', and ten being 'very much'. *Which number between 1 and 10 would best represent how much you have heard, read or seen about this issue?*

Using a scale from 1 to 10, with one being 'not informed at all', and ten being 'very well informed'. *How well informed would you say you are about nanotechnology?*

## 9. APPENDIX 2 Questions relating to Biomedical Interest/Engagement

### Medical advances in general (and other general q's) (17)

If there was a program on television about advances in medicine, would you... *Make a special point of watching it? Watch it if there was nothing better on? Or tend not to watch it? Don't Know*

When you are talking with people, for instance at you place of work or elsewhere, do you find yourself discussing scientific discoveries or applications of these discoveries, for example- in medicine, in agriculture, methods of transport, energy production etc? *Yes often, Yes from time to time, Rarely, Practically never, (Don't Know)*

Do you ever happen to see on TV present-day scientists, that is scientists who are still living. If so, about how often does this happen? *Often, Sometimes, Rarely, Never, No TV, (Don't Know).*

Do you ever read any 'health' magazines? *Yes, No, Don't Know* What would that be?

Do you read any other? *Yes, No, Don't Know* What would that be?

How did you come to know this information [most important health or science information]? *Open code*

How often do you use the internet to get information about health? *Once a day, Once a week, Once a month, Less often, Never, (Don't Know).*

In the past 30 days, how often have you visited a web site for? Health and fitness? *1-2 times, 3-5 times, More than 5 times, (Don't Know)*

In the past 12 months, have you used the Web to do each of these things: *Yes, No, (Don't Know)* Look for information about a health concern or medical problem?

Can you recall the most recent topic or problem that you looked for information about on the Internet or the World Wide Web? Could you describe that topic or problem to me? *Health/general, Health/medicines, Health/nutrition, Health/disease, General science, Genetic engineer, (Don't Know)*

Which of the following statements on this card do you most agree with? These days I see and hear far too much information about science; these days I see and hear too much information about science; these days I see and hear about the right amount of information about science; these days I see and hear too little information about science,

these days I see and hear far too little information about science, Don't know

I am now going to ask about which issues in the news interest you. *For each issue I read out, please tell me whether you are very interested, moderately interested, or not at all interested in it, (Don't Know).* New medical discoveries

Would you say that you found them [TV present-day scientists] interesting, or not very interesting? *Interesting, Some interesting some not interesting, Not very interesting, (Don't Know).*

Can you recall which fields of science they [present day scientists] work in? *Psychology, psychiatry. Medicine. ... Biology. ... (Don't Know)*

What is your main source of information about health in general? *The internet, Books or medical encyclopaedia, Newspapers, Magazines, Specialist press, Television, Radio, Discussion with family/friends/colleagues, A health professional, Courses and lectures, Other, (Don't Know)*

What is the most important health or science information you have heard in the last two months? *Open code*

Do you think the internet is a good way to get information about health? *Yes, No, (Don't Know).*

### **Animal Testing for medical (3)**

When, if at all, did you last discuss the issue of animal experimentation with another person such as a close relative, friend or colleague? *In the last week, up to 1 month ago, up to 3 months ago, up to 6 months ago, up to 1 year ago, up to 3 years ago, ever, never, Don't know.*

How would you rate your interest in the issue of animal experimentation? *Very interested, fairly interested, not very interested, not at all interested, Don't know.*

I am not interested in the issue of animal experimentation? *Agree, disagree, Don't know.*

### **Genetic Research/testing/therapy**

#### **General genetic research (7)**

Over the past few months, how much, if anything, have you heard or read about issues to do with genes and genetics? *A great deal, Quite a lot, Some, Not very much, None at all, Don't*

*Know*

And over the past few months, how much, if at all, have you talked about issues to do with genes and genetics? *A great deal, Quite a lot, Some, Not very much, None at all, Don't Know*

Over the past few months, how much, if at all, have you thought about issues to do with genes and genetics? *A great deal, Quite a lot, Some, Not very much, None at all, Don't Know*

From what you may know, in what ways, if any, could human genetic information be used now or in the near future?

How much have you read or heard about genetic tests that predict the possibility that a person will develop certain genetically influenced diseases or conditions, such as heart disease, cancer and Alzheimer's? *Quite a lot, some, not much, nothing at all, Don't Know*

What are the scientific and technological developments in which you are most interested? *Medicine ... Genetics ... (Don't Know)*

How much interest, if any, do you have in issues to do with genes and genetics? *A great deal, Quite a lot, Some, Not very much, None at all, Don't Know*

### **Genetic testing (7)**

(The following are health services that some states or counties provide for children.) Have you heard or read anything about your state or counties providing...genetic screening services? *Yes, No, Don't Know*

How important or not is Genetic testing to you? *Very important 4 ... Not at all important 1, (Don't Know)*

How concerned or not are you about genetic testing? *Very concerned 4 .... Not at all concerned 0, (Don't Know)*

Genetic testing (i.e. tests to discover whether people have a range of inherited diseases or disorders) *Very interested, fairly interested, not very interested, not at all interested, (Don't Know)*

Thinking about the following groups of people you know, in general, how concerned or not do you think they are about genetic testing? *Very concerned 4 ... Not at all concerned 0, (Don't Know)* Friends

Thinking about the following groups of people you know, in general, how concerned or not do you think they are about genetic testing? *Very concerned 4 ... Not at all concerned 0,*



*(Don't Know)* Family

Thinking about the following groups of people you know, in general, how concerned or not do you think they are about genetic testing? *Very concerned 4 ... Not at all concerned 0, (Don't Know)* People you work with

### **Biotechnology/genetic engineering (18)**

Over the last three months, have you heard [\*or read] anything about issues involving modern biotechnology? *Yes, No, (Don't Know)*

What did you hear or read about modern biotechnology?

(IF YES) Was it in newspapers, in magazines, on television, on the radio? (SEVERAL ANSWERS POSSIBLE)

As you may know, some food products and medicines are being developed with the help of new scientific techniques. The general area is called 'biotechnology' and includes tools such as genetic engineering. Biotechnology is also being used to improve crop plants. How much have you read or heard about biotechnology? *A great deal, some, not much, Don't Know*

If you wanted to learn more about this topic, how would you get more information? *Library, newspaper, magazine, book, other printed (includes encyclopaedias), television or radio, government agency, family member, friend or colleague, internet or World Wide Web, Computer CD-ROM, Computer in general, College or other school, Museum, Other*

Ask if didn't mention Dolly in above questions. Have you heard or read about the cloning of a sheep named Dolly in Scotland? *Yes, No*

Before today, had you ever talked about modern biotechnology with someone? *Yes, No, (Don't Know)*

(IF YES) Had you talked about it frequently, occasionally, or only once or twice?

I would sign a petition against biotechnology? *Tend to agree, or Tend to disagree, (Don't Know)*

I would be prepared to take part in public discussions or hearings about biotechnology? *Tend to agree, or Tend to disagree, (Don't Know)*

I would take time to read articles or watch TV programmes on the advantages and disadvantages of biotechnology? *Tend to agree, Tend to disagree, (Don't Know)*

Where would you MOST like to get information about biotechnology? *Television, Radio, Newspapers, Magazines, Internet, All of the above, Other (specify), Not interested, (Don't Know)*

Which ONE of the following uses of biotechnology would you like to know more about? *Health/medical, Cloning, GM foods/agriculture, Industrial, Environmental, Other (Please specify), (Don't Know)*

Have you spoken with another person about genetic engineering in the last few weeks? *Yes, no, no statement*

With whom did you talk about genetic engineering? *Relatives, good friends or acquaintance, colleagues or fellow pupils, doctors, lectures or other speakers, members of parties or other action groups, members of advice centres, unknown persons, none of them*

Is there anybody among the people you talk with about genetic engineering who knows really a lot and is well informed about genetic engineering? *Yes, no, don't know/no statement*

Are you interested in reports about genetic engineering? *very strong interest, quite interested, small interest, no interest in topic at all, no statement*

Is genetic engineering a very important issue for you? *very important, quite important, more unimportant, totally unimportant, don't know/no statement*

### **Stem Cell research/Cloning (17)**

(I'm going to describe a few of these developments (in science and medicine) that have been in the news and would like you to tell me how much you have heard or read about each of them.)... Cloning, the process of making a genetic copy of an animal from a single cell... How much have you heard or read about this--*a great deal, something but not very much, or nothing at all? Great deal, Something not much, Nothing, Don't Know*

How closely have you [did you] follow[ed] the debate about funding [Government decision to fund] stem cell research? *Very closely, fairly closely, Not to closely, not at all closely, Don't Know*

President Bush gave a speech tonight [other night] on stem cell research, and he announced that he would allow the Government to fund research using stem cells that have been created in the past in a process that destroyed human embryos. The Government will not fund stem cell research that would destroy additional embryos in the future. Did you happen to watch any of Bush's speech on stem cell research? *Yes, No,*

*Don't Know*

How much have you seen, read, or heard about medical research involving embryonic stem cells? *A Lot, a little, not much, nothing at all, Don't Know*

Please tell me how closely you have followed this news story... *Very closely, fairly closely, not too closely, not at all closely, Don't Know* The cloning of a sheep by a Scottish biologist?

Please tell me how closely you have followed this news story... *Very closely, fairly closely, not too closely, not at all closely, Don't Know* Plans by a Chicago scientist [Richard Seed] to open a clinic for cloning people?

Please tell me how closely you have followed this news story... *Very closely, fairly closely, not too closely, not at all closely, Don't Know* The cloning of mice by scientists in Hawaii

Please tell me how closely you have followed this news story... *Very closely, fairly closely, not too closely, not at all closely, Don't Know* A religious group [Raelians] claiming to have successfully cloned a human being?

(I'm going to read you a list of some stories covered by news organizations in the last month or so. As I read each one, tell me if you happened to follow this news story *very closely, fairly closely, not too closely, or not at all closely, Don't Know*)...How closely did you follow this story? Scientists completing a map of the human genetic code

(I'm going to read you a list of some stories covered by news organizations in the last month or so. As I read each one, tell me if you happened to follow this news story *very closely, fairly closely, not too closely, or not at all closely, Don't Know*) How closely did you follow this story? Scientists create the first genetically altered monkey

(Now I'm going to read you a list of some stories covered by news organizations in the last month or so. As I read each one, tell me if you happened to follow this news story *very closely, fairly closely, not too closely, or not at all closely, Don't Know*) How closely did you follow this story? Scientists develop new pig cloning techniques

Before today, had you heard about embryonic stem cells? *Yes, No, Don't know.*

Over the last three months, have you read, seen or heard a lot, a little, or nothing about issues involving embryonic stem cells? *A lot, A little, Nothing, Don't know.*

(I want to ask about some specific areas of science. For each, please tell me if you are very interested in news about that subject, somewhat interested, somewhat uninterested or very uninterested, Don't Know)... Cloning

(I want to ask about some specific areas of science. For each, please tell me if you are very interested in news about that subject, somewhat interested, somewhat uninterested or very uninterested, Don't Know)... Genetic engineering to treat diseases

How important is the issue of stem cell research to you? *Very important, somewhat important, not too important, not at all important, no opinion*

Do you personally feel that you have a good basic understanding of the stem cell issue? *Have a good understanding, Don't know much, No opinion*

### **Regulation (1)**

Would you say that you have had too much information on the rules and regulations about biological developments, too little or about the right amount? *Too much, Too little, or about the right amount, Don't know/not stated*

### **Nanotechnology (15)**

On a scale from 1 to 10, where 1 means 'never', and 10 means 'all the time'. *How often do you read the following types of newspaper content?* Stories about specific scientific developments, such as nanotechnology

On a scale from 1 to 10, where 1 means 'never', and 10 means 'all the time'. *How often do you read the following types of newspaper content?* Stories about the investment and market potential of specific technologies

Now using another scale from 1 to 10, where 1 means 'little attention', and 10 means 'very close attention'. *Please tell me how much attention you pay to the following kinds of stories when you read the newspaper?* Stories related to science and technology

Now using another scale from 1 to 10, where 1 means 'little attention', and 10 means 'very close attention'. *Please tell me how much attention you pay to the following kinds of stories when you read the newspaper?* Stories about specific scientific developments, such as nanotechnology

Now using another scale from 1 to 10, where 1 means 'little attention', and 10 means 'very close attention'. *Please tell me how much attention you pay to the following kinds of stories when you read the newspaper?* Stories about the investment and market potential of specific technologies

How often do you watch the following type of TV programs? Here one means 'not very often', and ten means 'all the time'. Stories related to science and technology

How often do you watch the following type of TV programs? Here one means 'not very often', and ten means 'all the time'. Stories about specific scientific developments, such as nanotechnology

How often do you watch the following type of TV programs? Here one means 'not very often', and ten means 'all the time'. Science documentaries on stations such as PBS, the Learning Channel, or Discovery Channel?

Now using another scale from 1 to 10, where 1 means 'little attention', and 10 means 'very close attention'. *Please tell me how much attention you pay to the following kinds of programs on television?* Stories related to science and technology

Now using another scale from 1 to 10, where 1 means 'little attention', and 10 means 'very close attention'. *Please tell me how much attention you pay to the following kinds of programs on television?* Stories about specific scientific developments, such as nanotechnology

Now using another scale from 1 to 10, where 1 means 'little attention', and 10 means 'very close attention'. *Please tell me how much attention you pay to the following kinds of programs on television?* Science documentaries on stations such as PBS, the Learning Channel, or Discovery Channel?

[Only asked for regular Web users] Now using a scale from 1 to 10, where 1 means 'never', and 10 means 'all the time'. *Please tell me how often you go online for?* Information related to science and technology

[Only asked for regular Web users] Now using a scale from 1 to 10, where 1 means 'never', and 10 means 'all the time'. *Please tell me how often you go online for?* Information about specific scientific developments, such as nanotechnology

[Only asked for regular Web users] Now using a scale from 1 to 10, where 1 means 'never', and 10 means 'all the time'. *Please tell me how often you go online for?* Information about scientific studies in new areas of research, such as nanotechnology

[Only asked for regular Web users] Now using a scale from 1 to 10, where 1 means 'never', and 10 means 'all the time'. *Please tell me how often you go online for?* Information about the investment and market potential of specific technologies

## 10. APPENDIX 3 Questions relating to Biomedical Attitudes

### Animal Testing for medical (69)

It is right to use animals for medical testing if it might save human lives? *Strongly agree, Agree, Neither, Disagree, Strongly disagree, Don't Know*

Scientists should be allowed to do research that causes pain and injury to animals like dogs and chimpanzees if it can produce new information about serious human health problems? *Strongly agree, Agree, Neither, Disagree, Strongly disagree*

Scientists should be allowed to do research that causes pain and injury to animals like mice if it can produce new information about serious human health problems? *Strongly agree, Agree, Neither, Disagree, Strongly disagree*

One should look for a balance between animal welfare and human welfare. *definitely agree, tend to agree, tend to disagree or definitely disagree, (Don't Know)?*

And what do you think of developing genetically modified animals for laboratory research studies, such as a mouse that has genes which causes it to develop cancer? *Tend to agree, Tend to disagree, (Don't Know)*. Such research is worthwhile and should be encouraged?

And what do you think of developing genetically modified animals for laboratory research studies, such as a mouse that has genes which causes it to develop cancer? *Tend to agree, Tend to disagree, (Don't Know)*. Such research may involve risk to human health or to the environment

And what do you think of developing genetically modified animals for laboratory research studies, such as a mouse that has genes which causes it to develop cancer? *Tend to agree, Tend to disagree, (Don't Know)* this application of biotechnology is morally acceptable?

And what do you think of developing genetically modified animals for laboratory research studies, such as a mouse that has genes which causes it to develop cancer? *Tend to agree, Tend to disagree, (Don't Know)* this application is useful for society?

Scientists can also apply biotechnology and genetic engineering to animals to develop lifesaving drugs, or to study human diseases. Animal protection is guaranteed by law and some people say it is morally wrong to apply biotechnology and genetic engineering to animals. Which of the following is closest to your personal opinion? *Applying biotechnology and genetic engineering to animals is morally acceptable, provided that the animals' welfare is safeguarded. It is acceptable for the development of lifesaving drugs, even at the cost of some animal suffering. Public authorities should examine this application of biotechnology and genetic engineering case by case before deciding whether to allow it. Applying biotechnology and genetic engineering to animals is morally*

*unacceptable and should be banned by public law. (Don't Know)*

What do you think about the use of genetic engineering to breed animals in laboratories for pharmaceutical research? *very good, quite good, equally good and bad, rather bad, very bad, I am not determined yet, I don't care about it, don't know/no statement*

On this card is a list of situations for which animal experimentation might be carried out. Could you read through the list and tell me which, if any, of these situations you think animal experimentation is *always justified, sometimes justified, or never justified*? Life threatening diseases such as cancers; Life threatening diseases such as AIDS; Ways of preventing diseases (vaccines); Improving medical treatments and surgical techniques; Testing potential new medicines; To learn how cells work; Treatments to improve quality of life (HRT); Researching animal diseases; Improving livestock welfare (preventing diseases in cattle herds or preventing stress in transported animals; Improving livestock to make sheep woollier and meat leaner; Testing chemicals in the workplace; Testing the safety of household products (disinfectants, DIY products); Testing the safety of cosmetics (skin care products, make up).

Why do you think some experiments in medical research are carried out on animals? *open code*

What three or four of the following species, if any, do you think are most commonly used in animal experimentation? *Rats and mice, monkeys, rabbits, cats, dogs, guinea pigs, pigs, fish, chickens, sheep, horses, Don't know.*

What percentage of medical research do you think involves animal experimentation? *None, 5-10%, 10-30%, 31-60%, 61-1000%, Don't know.*

Thinking now about the use of animals in experiments for medical research purposes, what factors, if any, would you take into account if you were deciding whether such experiments were right or wrong? *open code*

Which one or two of these aspects of animal experimentation would you say the media has most covered? *Alternatives to animal experimentation; The suffering that the animals go through during animal experiments or ill treatment of animals kept for research; Breakthroughs in medical research due to animal experimentation; Regulations governing animal experimentation; The living conditions of the animals used in animal experimentation; The different types of research that use animals in experiments; The species used; None of these; Don't know.*

Which one or two aspects of animal experimentation do you think the media should cover most? *Alternatives to animal experimentation; The suffering that the animals go through during animal experiments or ill treatment of animals kept for research; Breakthroughs in medical research due to animal*

*experimentation; Regulations governing animal experimentation; The living conditions of the animals used in animal experimentation; The different types of research that use animals in experiments; The species used; None of these; Don't know.*

Would you like more, less, or about the same amount of information than you have received to date about alternatives to animal experimentation? *More, less, about the same, Don't know.*

Would you like more, less, or about the same amount of information than you have received to date about breakthroughs in medical research due to animal experimentation? *More, less, about the same, Don't know.*

Would you like more, less, or about the same amount of information than you have received to date about regulations governing animal experimentation? *More, less, about the same, Don't know.*

Would you like more, less, or about the same amount of information than you have received to date about the living conditions of the animals used in animal experimentation? *More, less, about the same, Don't know.*

Would you like more, less, or about the same amount of information than you have received to date about the suffering that the animals may go through during animal experiments or any ill treatment of animals kept for research? *More, less, about the same, Don't know.*

Would you like more, less, or about the same amount of information than you have received to date about the species used? *More, less, about the same, Don't know.*

I feel that unnecessary duplication of animal experiments may go on? *Agree, disagree, Don't know.*

There needs to be more research into alternatives to animal experimentation? *Agree, disagree, Don't know.*

Animal experimentation will always be used for research purposes? *Agree, disagree, Don't know.*

I can accept animal experimentation so long as there is no unnecessary suffering to the animals? *Agree, disagree, Don't know.*

I would like to know more about animal experimentation before forming a firm opinion? *Agree, disagree, Don't know.*



I can accept animal experimentation so long as it is for medical research purposes? *Agree, disagree, Don't know.*

I agree with animal experimentation for all types of medical research, where there is no alternative? *Agree, disagree, Don't know.*

Animal experimentation for medical research purposes should only be conducted for life threatening diseases? *Agree, disagree, Don't know.*

Animal experiments for medical research purposes are a necessary evil? *Agree, disagree, Don't know.*

I don not support the use of animals in any experimentation because of the importance I place on animal welfare? *Agree, disagree, Don't know.*

I agree with animal experimentation for all types of research where there is no alternative? *Agree, disagree, Don't know.*

It does not bother me if animals are used in experimentation? *Agree, disagree, Don't know.*

What springs to mind when you think about medical research or its social and ethical implications over the past 2–3 years? *open code*

How concerned, if at all, are you about the use of animals in medical research, would you say that you are? *Very concerned, fairly concerned, not very concerned, not at all concerned, Don't know.*  
Why do you say that? *open code*

Provided that all welfare regulations were well enforced, please tell me, using this card, how acceptable or unacceptable your overall opinions and impressions are of the use of bacteria in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Provided that all welfare regulations were well enforced, please tell me, using this card, how acceptable or unacceptable your overall opinions and impressions are of the use of rats in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Provided that all welfare regulations were well enforced, please tell me, using this card, how acceptable or unacceptable your overall opinions and impressions are of the use of rabbits in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Provided that all welfare regulations were well enforced, please tell me, using this card,

how acceptable or unacceptable your overall opinions and impressions are of the use of monkeys in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Provided that all welfare regulations were well enforced, please tell me, using this card, how acceptable or unacceptable your overall opinions and impressions are of the use of human volunteers in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Provided that all welfare regulations were well enforced, please tell me, using this card, how acceptable or unacceptable your overall opinions and impressions are of mice in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Provided that all welfare regulations were well enforced, please tell me, using this card, how acceptable or unacceptable your overall opinions and impressions are of the use of genetically modified rats in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Provided that all welfare regulations were well enforced, please tell me, using this card, how acceptable or unacceptable your overall opinions and impressions are of the use of genetically modified mice in medical research? *Very acceptable, fairly acceptable, neither acceptable nor unacceptable, fairly unacceptable, very unacceptable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? 85% of animals used in research are rats and mice. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? The UK has the strictest regulations on the use of animals in research in the world. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? Animal facilities are spot checked at any time by a Home Office inspector. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? By law, animals can only be used for research if there is no other way of obtaining information. *Much more comfortable, slightly more*

*comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? The possible effects on the animals are always weighed up against the benefits of the research before permission is granted to use them. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? Animals are used to test all potential medicines to ensure they are safe for humans. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? Alternatives to the use of animals in research are continually being developed and used. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? Lab workers must have special training, qualifications, and a license to do research using animals. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? 80-90% of experiments using animals are classified as mild, e.g. they involve taking a temperature or a blood or urine sample only. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? When using animals in research in the UK, strict rules are applied to avoid and minimise pain and stress to animals. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? 99.9% of animals used in research are specially bred for the purpose. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

Could you tell me how comfortable, or uncomfortable, this statement makes you feel about the use of animals in medical research? When using animals in research in the UK,

strict rules are applied to ensure high welfare standards for the animals, such as adequate heating, lighting and space. *Much more comfortable, slightly more comfortable, makes no difference, slightly more uncomfortable, much more uncomfortable, Don't know.*

And which, if any, of the following things are you aware of that any animal rights organisation is involved in or does, in order to protest about the use of animals in research? *Organise a demonstration/protest outside research laboratories; Hand out leaflets; Free animals; Organise petitions; Destroy/damage property; Verbally harass people; Organise a demonstration/protest outside investors/workers' homes; Use physical violence against those involved in animal research; Write letters/send 'hate' mail; Ask people to put a protest sticker/poster in their window; Occupy research facilities; Set up road blocks; Use terrorist methods (car bombs, mail bombs); None; Don't know.*

Which, if any of the following do you feel are acceptable things for an animal rights organisation to do if it were protesting the use of animals in research? *Organise a demonstration/protest outside research laboratories; Hand out leaflets; Free animals; Organise petitions; Destroy/damage property; Verbally harass people; Organise a demonstration/protest outside investors/workers' homes; Use physical violence against those involved in animal research; Write letters/send 'hate' mail; Ask people to put a protest sticker/poster in their window; Occupy research facilities; Set up road blocks; Use terrorist methods (car bombs, mail bombs); None; Don't know.*

Which, if any of the following do you feel are acceptable things for an animal rights organisation to do if it were protesting the use of animals in research? *Organise a demonstration/protest outside research laboratories; Hand out leaflets; Free animals; Organise petitions; Destroy/damage property; Verbally harass people; Organise a demonstration/protest outside investors/workers' homes; Use physical violence against those involved in animal research; Write letters/send 'hate' mail; Ask people to put a protest sticker/poster in their window; Occupy research facilities; Set up road blocks; Use terrorist methods (car bombs, mail bombs); None; Don't know.*

On the whole how would you describe your feelings about the following issues... The use of animals in medical research *Very good thing, fairly good thing, neither good nor bad thing, fairly bad thing, very bad thing, Don't know*

Which, if any, of the following factors do you think should be taken into account in the current regulatory system regarding animals in experiments for medical purposes? (Top 10 answers) *The suffering/pain the animals might endure/if no unnecessary suffering; Do research if it is for a life-saving cure/treatment; Not allow research for cosmetics, such as lipstick and mascara; Whether the experiment is stopped as soon as the animal feels pain; Whether it was well supervised to ensure high standards of animal welfare; Only if no alternative; The animal welfare within the laboratories; The importance of research to human health; If it is for long-term or chronic illnesses (diabetes, arthritis, or*

*Parkinson's disease*); Whether spot-checks on laboratories were carried out.

I wouldn't be surprised if some animal experiments go on behind closed doors without an official licence? *Agree, disagree, Don't know.*

I don't know a lot about regulation regarding animal experimentation? *Agree, disagree, Don't know.*

Britain probably has tough rules governing animal experimentation? *Agree, disagree, Don't know.*

I expect that the rules in Britain on animal experimentation are well enforced? *Agree, disagree, Don't know.*

The Government should ban all experiments on animals for any form of research? *Agree, disagree, Don't know.*

How much would you say you know about the rules and regulations that govern animal experimentation? Would you say you know *A great deal, a fair amount, not very much, nothing at all, Don't know.*

Who, if anyone, do you think devises and enforces the regulations placed on using animals in medical research in the UK? (open code)

### **General genetic research (37)**

Research into human genes will do more harm than good. *Strongly agree, Agree, Neither, Disagree, Strongly disagree, (Don't Know)*

Do you think that... (tick one) *Scientists should not be allowed to carry out any research into human genes. Or, that the only genetic research that should be allowed is to help detect, prevent and cure diseases. Or, that scientists should be allowed to carry out whatever genetic research they choose to do?*

How hopeful or worried for the future do you feel about discoveries into human genes and what these may lead to? *Very hopeful about the future, fairly hopeful, Hopeful about some things worried about others, fairly worried, very worried about the future, hadn't really thought about it, Don't Know*

New genetic developments will bring cures for many diseases. *Strongly agree, Tend to agree,*

*Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Research on human genetics is tampering with nature and is therefore unethical. *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Changing genes should be forbidden as it is tampering with nature? *Agree, disagree, Don't know*

New genetic developments will mean children who are healthier and free from inherited disabilities *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

If there were no direct risk to humans, would you *strongly approve, somewhat approve, somewhat disprove, or strongly disprove* of genetic manipulation to produce cures for human genetic diseases?

It would be better if we did not know how to genetically alter cells at all? *Agree strongly, agree somewhat, disagree somewhat, disagree strongly, Don't Know*

How do you consider the use of genetic engineering to diagnose incurable diseases? *very good, quite good, equally good and bad, rather bad, very bad, I am not determined yet, I don't care about it, don't know/no statement*

How do you consider the use of genetic engineering to treat immune or cell diseases? *very good, quite good, equally good and bad, rather bad, very bad, I am not , determined yet, I don't care about it, don't know/no statement*

Do you think this genetic research will have a large effect on you and your family, only some effect, very little effect, or no effect at all? *Large effect, Only some effect, Very little effect, No effect at all, Don't Know*

In general, do you think the effect of this (genetic) research on your life/your family's life will be mostly positive, or mostly negative? *Mostly positive, Mostly negative, Mixed, Don't Know*

Are you very optimistic about the possibility of medical advances as a result of genetic research, somewhat optimistic, not too optimistic, or not at all optimistic? *Very optimistic, Somewhat optimistic, Not too optimistic, Not at all optimistic, Don't Know*

Are you very worried about the possibility of discrimination, or loss of privacy as a result of genetic research, somewhat worried, not too worried, or not at all worried? *Very worried, Somewhat worried, Not too worried, Not at all worried, Don't Know*

(Now I am going to read you some concerns that people might have when considering

adoption. For each, I would like you to tell me whether it would be a major concern, minor concern, or no concern at all for you if you were considering adopting a child.)...Dealing with unexpected genetic or medical problems that might emerge later in life in the adopted child... *Would that be a major concern, minor concern, or no concern at all for you?*  
*Don't Know*

Some scientists believe they may be able to genetically modify mosquitoes so that they can no longer carry the malaria virus. Other scientists worry that genetically engineered insects like mosquitoes could have unforeseen, possibly risky, consequences if they are released into the environment. Do you *strongly agree, somewhat agree, somewhat disagree, or strongly disagree* with the idea of genetically modifying insects to prevent them from carrying diseases?  
*Don't Know*

As you may know, scientists are working on a project--often referred to as the Human Genome Project--that would read all people's genetic code. When completed, do you think the Human Genome Project is likely to be generally beneficial or generally harmful?  
*Beneficial, Harmful, Don't Know*

Do you think that developing the Human Genome Project technology is morally wrong, or don't you feel that way? Yes morally wrong, *No don't feel that way, Don't Know*

If you could gain information about your genetic code or DNA, would you want to know what diseases you are predisposed to get? *Yes, No, Don't Know*

Which of the following scientific research projects are *Worthwhile, Of no particular interest, Or too risky, (Don't Know)?* To carry out experiments on the transmission of hereditary characteristics which could make it possible to improve the qualities of living species?

As you may know, genetic engineering is a process through which doctors can alter the genetic make-up of a human being and change the person's characteristics, such as hair or eye color, or even whether that person is at risk for certain diseases. In the next century, do you think it will be possible to genetically engineer babies, that is, to use science to pre-determine babies' genetic make-ups? *Yes, No, Don't Know*

How concerned are you that the use of genetic technologies could lead to discrimination against the disabled? *Very concerned, concerned, not very concerned, not at all concerned, Don't know.*

How concerned are you that the use of genetic technologies could lead to decreased research into diseases? *Very concerned, concerned, not very concerned, not at all concerned, Don't know.*

How concerned are you that the use of genetic technologies could lead to parents feeling

pressured to use the technology? *Very concerned, concerned, not very concerned, not at all concerned, Don't know.*

How concerned are you that the use of genetic technologies could lead to the loss of genetic diversity? *Very concerned, concerned, not very concerned, not at all concerned, Don't know.*

How concerned are you that the use of genetic technologies could lead to overpopulation? *Very concerned, concerned, not very concerned, not at all concerned, Don't know.*

How concerned are you that the use of genetic technologies could lead to a sex-ratio imbalance? *Very concerned, concerned, not very concerned, not at all concerned, Don't know.*

How concerned are you that even if genetic technology became widespread, some people would be unable to afford it? *Very concerned, concerned, not very concerned, not at all concerned, Don't know.*

In the end, research into human genes will do more to help us than to harm us? *Agree, disagree, Don't know.*

People worry too much about the risks of changing human genes? *Agree, disagree, Don't know.*

It is better to try and cure illness without changing people's genes? *Agree, disagree, Don't know.*

Changing a person's genes is too risky, whatever the benefits might be? *Agree, disagree, Don't know.*

We should never interfere with people's genes? *Agree, disagree, Don't know.*

It would be better if we did not know how to change people's genes at all? *Agree, disagree, Don't know.*

Scientists should not look for genetic cures, because the world will become too overpopulated? *Agree, disagree, Don't know.*

Genetic treatments for illness will do a lot to reduce human suffering? *Agree, disagree, Don't know.*

### **Genetic testing and modification (179)**

Which three things, if any, come to your mind when you hear the phrase 'genetic testing'?



*Open ended* And do you think ...[ask all 3 of above mentioned]... *is a good thing, a bad thing or neither a good nor a bad thing, (Don't Know)?*

Genetic testing (i.e. tests to discover whether people have a range of inherited diseases or disorders) *Very good thing, fairly good thing, neither, fairly bad thing, very bad thing, (Don't Know)*

How would you assess the benefits, if any, of genetic testing for British society as a whole *Very high benefits 6... No benefits 0, (Don't Know)*

How would you assess the benefits, if any, of genetic testing for Yourself *Very high benefits 6... No benefits 0, (Don't Know)*

How would you assess the risks, if any, to human health from genetic testing for British society as a whole *Very high risks 6... No risks 0, (Don't Know)*

How would you assess the risks, if any, to human health from genetic testing for yourself *Very high risks 6... No risks 0, (Don't Know)*

How would you assess the risks, if any, of the use of information from genetic testing without consent for British society as a whole *Very high risks 6... No risks 0, (Don't Know)*

How would you assess the risks, if any, of the use of information from genetic testing without consent for Yourself *Very high risks 6... No risks 0, (Don't Know)*

From what you know or have heard about genetic testing, on balance, which of these statements, if any, most closely reflects your own opinion? *The benefits of genetic testing far outweigh the risks, The benefits of genetic testing slightly outweigh the risks, The benefits and risks of genetic testing are about the same, The risks of genetic testing slightly outweigh the benefits, The risks of genetic testing far outweigh the benefits, (Don't Know)*

On the whole, how acceptable or unacceptable is genetic testing to you? *Very acceptable, Fairly acceptable, Neither acceptable nor unacceptable, Fairly unacceptable, Very unacceptable, (Don't Know)*

Genetic testing has unknown consequences. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Genetic testing poses risks to future generations. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

I have mixed feelings about genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

I have moral concerns about genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

I feel able to control any risks to myself associated with genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Too much fuss is made about genetic testing nowadays. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

I am not that bothered about genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The risks from genetic testing are unfair because they fall unevenly on particular groups in British Society. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The idea of genetic testing fills me with dread. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

I personally would be happy to have a genetic test to identify whether or not I have any inherited medical conditions. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Some people say that genetic screening is a wonderful medical advance. Others think it may cause trouble. Based on what you know, do you think genetic screening will do *more good than harm, more harm than good, or it depends, (Don't Know)?*

Some people say that genetic screening may cause trouble. Others think it is a wonderful medical advance. Based on what you know, do you think genetic screening will do *more harm than good, or more good than harm, or it depends, (Don't Know)?*

Genetic testing should be available to anyone who wishes to have information about his/her disease genes *Fully\* agree, partially agree, partially disagree, fully \*disagree, can't say*

Genetic testing is acceptable because it would save government money by reducing the costs of health care. *Fully agree, partially agree, partially disagree, fully disagree, can't say*

Genetic testing is acceptable because people have the right to know about their genes so they can influence their own health and life. *Fully agree, partially agree, partially disagree, fully disagree, can't say*

Genetic testing is acceptable because new technology has made it possible to detect the underlying causes of genetic diseases. *Fully agree, partially agree, partially disagree, fully disagree,*

*can't say*

Genetic testing should not be performed at all *Fully \*agree, partially agree, partially disagree, fully \*disagree, can't say*

Genetic testing is not acceptable because there are more important public health problems that need to be addressed first *Fully agree, partially agree, partially disagree, fully disagree, can't say*

Genetic testing is not acceptable because the natural order should be respected *Fully agree, partially agree, partially disagree, fully disagree, can't say*

Genetic testing is not acceptable because the results may lead to discrimination against disease carriers *Fully agree, partially agree, partially disagree, fully disagree, can't say*

Genetic testing is not acceptable because testing would make abortions more common *Fully agree, partially agree, partially disagree, fully disagree, can't say*

I am worried that genetic testing may lead to eugenics *Not at all worried, a bit worried, somewhat worried, very worried, can't say \*agree, \*disagree*

I am confident that I can myself decide which gene tests to attend and how the results of gene tests are used *Fully confident, somewhat confident, a little confident, not at all confident, can't say*

Uptake of gene tests is primarily a private issue. *agree or disagree*

All gene tests should be voluntary. *agree or disagree*

Gene tests may increase people's control over life. *agree or disagree*

Gene tests may improve people's quality of life. *agree or disagree*

I believe that in time gene tests will become obligatory. *agree or disagree*

The public health system should finance genetic screenings for serious diseases. *agree or disagree*

It is important that Finns are informed of the possibilities of gene tests. *agree or disagree*

People should be encouraged to be tested in young adulthood for disorders that develop in middle age or later in life. *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Parents have a right to ask for their child to be tested for genetic disorders that develop in adulthood. *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree,*

*No opinion*

Genetic information may be used by parents to decide if children with certain disabling conditions are born. *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

In the context of medical treatment, people should always be asked for their permission for their blood or tissues to be used in a genetic test. *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Couples who are at risk of having a child with a serious genetic disorder should be discouraged from having children of their own. *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Genetic techniques should not be made available to parents so that they can have a baby of the sex they choose. *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

I would take a genetic test to detect any serious disease that I might get when I am older. *Tend to agree, Tend to disagree, (Don't Know)*

I would support the testing of unborn babies for any serious diseases they might get in later life. *Tend to agree, Tend to disagree, (Don't Know)*

What comes closer to your views about prenatal tests... *they are a good thing because they help parents identify potential health problems of their unborn babies, or they are a bad thing because they could lead to abortions if the parents don't like the sex or potential intelligence of the unborn baby? Good thing, bad thing, Don't Know?*

What do you think about genetic tests in the case of a pregnancy to detect physical and mental defects of the embryos? *very good, quite good, equally good and bad, rather bad, very bad, I am not determined yet, I don't care about it, don't know/no statement*

People at risk of having a child with a serious genetic disorder should not start a family. *Strongly agree, Agree, Neither, Disagree, Strongly disagree, (Don't Know)*

Would you approve or disapprove if parents were offered a way to use PGD (technology to select and implant only certain eggs during in vitro fertilization) to...make sure their baby does not have a serious genetic disease? *Approve, Disapprove, Don't Know*

Would you approve or disapprove if parents were offered a way to change their own genes in order to have children who would be smarter, stronger, or better looking? *Approve,*

*Disapprove, Don't Know*

Would you approve or disapprove if parents were offered a way to change their own genes in order to prevent their children from having a genetic disease? *Approve, Disapprove, Don't Know*

In general, do you approve or disapprove of the use of genetic testing during pregnancy to find out whether the baby will develop a serious genetic disease? *Approve, Disapprove, Don't Know*

Do you approve or disapprove of the use of genetic testing during pregnancy to find out whether the baby will have desirable characteristics such as strength or high intelligence? *Approve, Disapprove, Don't Know*

You have told me how you feel about a number of different topics--genetic testing, in vitro fertilization, genetic engineering, and cloning. In general, would you say you hold your opinions on these issues *very strongly, somewhat strongly, not too strongly, or not strongly at all?* *Don't Know*

When you think about these topics (genetic testing, in vitro fertilization, genetic engineering, and cloning), which of the following, if any, worries you most?... That using these technologies is too much like playing God, that the technologies are too new to be used safely, that most people will not be able to afford these technologies, that the technologies can easily be used for the wrong purposes, or don't you worry about any of these? *That using these technologies is too much like playing God, That the technologies are too new to be used safely, That most people will not be able to afford these technologies, That the technologies can easily be used for the for the wrong purposes, Don't worry about any of these, It depends/Mixed, Don't Know*

When you think about these topics (genetic testing, in vitro fertilization, genetic engineering, and cloning), which of the following, if any, do you think is the greatest benefit?...That parents can improve the chances their baby will be healthy, that parents can improve the chances their baby will have the features they want, that the overall cost of health care in America will be less, that certain genetic diseases can be wiped out forever, or don't you think any of these are benefits? *That parents can improve the chances their baby will be healthy, That parents can improve the chances their baby will have the features they want, That the overall cost of health care in America will be less, That certain genetic diseases can be wiped out forever, Don't think any of these are benefits, It depends/Mixed, Don't Know*

When you think about these topics (genetic testing, in vitro fertilization, genetic engineering, and cloning), do you think of them mainly in terms of health and safety or mainly in terms of religion and morality? *Mainly health and safety, Mainly religion and morality,*

*Mixed, Don't Know*

Genetic research is being used to develop new ways to diagnose and treat diseases such as cancer, heart disease, Alzheimer's and mental illnesses such as schizophrenia. How much confidence do you have that new genetic research will lead to major advances in the treatment of diseases during the next fifteen years? *Are you very confident, somewhat confident, not very confident, or not at all confident? Don't Know*

Genetic testing involves testing someone's genes or DNA to see if they have inherited a high risk of getting one or more diseases. This is likely to become much more common in the future. In general do you think it is a good or a bad thing that we will be able to use genetic testing to find out what diseases individual people are likely to get? *Good thing, Bad thing, Don't Know*

If you could have a comprehensive genetic test which would tell you about the likelihood that you might get several major diseases, and it was not at all expensive, how likely to do you think you would be to have it? *very likely, somewhat likely, or not very likely? Don't Know*

Please consider two possible situations and say how likely you would be to ask for a free genetic test for each one. *Would you be very likely, somewhat likely or not very likely to have it? Don't Know...* A test which would tell you if you are at high risk of getting a very serious disease and, if so, there are treatments or other ways to greatly reduce your risk of getting it.

(Please consider two possible situations and say how likely you would be to ask for a free genetic test for each one. *Would you be very likely, somewhat likely or not very likely to have it? Don't Know*)... A test which would tell you if you were at high risk of getting a very serious disease, but where there is no known treatment or other ways to reduce that risk.

If you had to pay yourself to get such a genetic test for a very serious disease for which there are treatments or other ways to greatly reduce your risk, about how much do you think you would be willing to pay for this test? *Nothing, \$1-\$25, \$26-\$100, \$101-\$400, More than \$400, Don't Know*

If you were given a genetic test which showed how likely you were to get one or more serious diseases, which of the following do you think should be allowed to see this information?... *Your regular doctor, any doctor who is helping you to prevent a disease for which the test shows you are at risk, your health insurance company which is paying the cost of his treatment or care, a life insurance company from which you want to obtain life insurance, your employer who is paying for part of your health insurance Don't Know*

Genetic testing is being used to identify people at risk for diseases such as cancer, heart

disease, Alzheimer's and others. Overall, how much would you favor or oppose making genetic testing easily available to all who want it--*do you strongly favor, somewhat favor, somewhat oppose, or strongly oppose? Don't Know*

If genetic testing were easily available, how likely would you personally be to get tested--*would you be very likely, somewhat likely, not very likely, or not at all likely to get tested? Don't Know*

Now, assuming that you had a young child and genetic testing was easily available, how likely would you be to get your child tested--*very likely, somewhat likely, not very likely, or not at all likely? Don't Know*

Why would you be likely to take such a genetic test (to tell you whether you were at risk of contracting a genetic disease)? Is there another reason? *To be safe/Detect possible disease, Family history of disease, Find out if children could get family disease, Find out if fetus has genetic disease, To advance research, To extend life span, Healthy curiosity, Other, No particular reason, Don't Know*

Why would you be unlikely to take such a genetic test (to tell you whether you were at risk of contracting a genetic disease)? Is there another reason? *Rather not know if at risk for disease, Genetic testing is morally wrong, Violation of privacy, Risk of insurer/employer seeing results, Religious reasons, Too old to benefit, Dislike doctors, Cost, Diagnosis is not a cure, Other, No particular reason, Don't Know*

Do you think that parents with genetically linked diseases should be required to test all of their children for these diseases, or don't you feel that way? *Yes should, No don't feel that way, Don't Know*

If you had the gene for an incurable life-threatening disease, whether or not you yourself actually had the disease, do you think you would or would not have your unborn child tested for the disease? *Would have child tested, Would not have child tested, Don't Know*

Suppose a genetic test existed that would indicate whether or not you were likely to develop a serious disease later in your life. How interested would you be in personally taking such a test--*very interested, somewhat interested, not very interested, or not at all interested? Don't Know*

How interested would you be in personally taking a genetic test if... there was no known cure for the disease... *very interested, somewhat interested, not very interested, or not at all interested? Don't Know*

How interested would you be in personally taking a genetic test if... the results of the test, with identity protected, would be used in subsequent medical research... *very interested,*

*somewhat interested, not very interested, or not at all interested? Don't Know*

How interested would you be in personally taking a genetic test if... a cure was currently available for the disease being diagnosed... *very interested, somewhat interested, not very interested, or not at all interested? Don't Know*

How interested would you be in personally taking a genetic test if... the test was recommended by your doctor... *very interested, somewhat interested, not very interested, or not at all interested? Don't Know*

How interested would you be in personally taking a genetic test if... there was a family history of that disease... *very interested, somewhat interested, not very interested, or not at all interested? Don't Know*

If scientists found a gene that was linked to a behavior like mental illness or alcoholism, which of the following types of people would you like to see tested for this gene...*yourself, your child, everyone, or people applying for health insurance? Don't Know*

In general, do you think it's right or wrong to use scientific techniques to try and alter people's genes to limit their risk of developing certain genetic diseases? *Right, Wrong, Don't Know*

(Let's think further about certain circumstances in which a woman might seek someone else to bear her child.) Would you approve or disapprove of surrogate motherhood for... a married woman with a genetic abnormality such that there is a reasonable chance her child will have a birth defect? *Approve, Disapprove, Don't Know*

At the moment, a lot of research is being carried out into human genes. We get our genes from our parents and they contain instructions which tell our bodies how to grow, develop and work properly. If our genes don't work properly this can cause illness. Genetic treatments for illness will do a lot to reduce human suffering? *Agree strongly, agree, neither agree nor disagree, disagree, disagree strongly, Don't know*

Changing a person's genes is too risky, whatever the benefits may be? *Agree strongly, agree, neither agree nor disagree, disagree, disagree strongly, Don't know*

In the end, research into human genes will do more to help us than to harm us? *Agree strongly, agree, neither agree nor disagree, disagree, disagree strongly, Don't know*

Nowadays, it is possible to predict whether or not a person is likely to develop certain diseases by analysing their genes. This is called genetic testing. Genetic testing is currently available for a limited number of diseases, but it may be available for more diseases in the



future. If it were available would you, in the next 6 months, have a genetic test to see if you were at risk of developing cancer in the future? *No definitely not, no probably not, yes probably, yes definitely, Don't know.* Can you say why you gave that answer?

If it were available would you, in the next 6 months, have a genetic test to see if you were at risk of developing heart disease in the future? *No definitely not, no probably not, yes probably, yes definitely, Don't know.* Can you say why you gave that answer?

Suppose you learnt today that you had a higher than average genetic risk of developing cancer in the future, would you? *Try to lead a healthier lifestyle; feel there was no point trying to lead a healthier lifestyle; feel that your lifestyle was as healthy as it could be; or would you have no feelings one way or another about your lifestyle; Don't know*

Suppose you learnt today that you had a higher than average genetic risk of developing heart disease in the future, would you? *Try to lead a healthier lifestyle; feel there was no point trying to lead a healthier lifestyle; feel that your lifestyle was as healthy as it could be; or would you have no feelings one way or another about your lifestyle; Don't know*

What worries you most about the use of reproductive genetic technologies? *Using it for the wrong purposes; It is too much like playing God; It is too new to be safe; It is an unaffordable technology; None of the above; Don't know*

Genetic tests can also be taken from unborn babies while still in the womb, to show if the child is likely to be born with a serious medical condition, but such tests carry some risks. Which of the statements on this card comes closest to your view. *All pregnant women should be offered such tests. Only women where there is special reason to suspect a problem should be offered such tests. Such tests should not be allowed at all. Don't Know*

Now suppose a woman had one of these tests and it showed that there was very likely to be a serious problem with her unborn child. Please use this card to say whether you think it would be right or not for the woman to have a legal abortion (decide whether or not to have a child)... if the child was very likely to be born with a serious mental disability and would never be able to lead an independent life? *Never right, Sometimes right, Always right, (Don't Know)*

Now suppose a woman had one of these tests and it showed that there was very likely to be a serious problem with her unborn child. Please use this card to say whether you think it would be right or not for the woman to have a legal abortion (decide whether or not to have a child)... if the child was very likely to be born with a serious physical disability and would never be able to lead an independent life? *Never right, Sometimes right, Always right, (Don't Know)*

Now suppose a woman had one of these tests and it showed that there was very likely to be a serious problem with her unborn child. Please use this card to say whether you think it would be right or not for the woman to have a legal abortion (decide whether or not to have a child)... if the child was very likely to be born with a condition that meant it would live in good health, but then would die in its twenties or thirties? *Never right, Sometimes right, Always right, (Don't Know)*

Now suppose a woman had one of these tests and it showed that there was very likely to be a serious problem with her unborn child. Please use this card to say whether you think it would be right or not for the woman to have a legal abortion... And what if the child would be healthy but would never grow taller than an eight year old? *Never right, Sometimes right, Always right, (Don't Know)*

Now suppose a woman had one of these tests and it showed that there was very likely to be a serious problem with her unborn child. Please use this card to say whether you think it would be right or not for the woman to decide whether or not to have a child... if the child has the same types of body tissues needed to treat a brother or sister who is seriously ill? *Never right, Sometimes right, Always right, (Don't Know)*

Now suppose a woman had one of these tests and it showed that there was very likely to be a serious problem with her unborn child. Please use this card to say whether you think it would be right or not for the woman to decide whether or not to have a child... if the child is one sex rather than another? *Never right, Sometimes right, Always right, (Don't Know)*

There is another way in which couples can try to avoid having a child with a serious medical condition. The woman's eggs are fertilised outside her body with her partner's sperm and genetically tested. Only eggs without the condition are put back, and may then grow into a baby. Suppose it was likely that a couple would have a child with a serious mental disability. Do you think it would be right or not right for them to have this sort of treatment? *Never right, Sometimes right, Always right, Don't Know*

There is another way in which couples can try to avoid having a child with a serious medical condition. The woman's eggs are fertilised outside her body with her partner's sperm and genetically tested. Only eggs without the condition are put back, and may then grow into a baby. Suppose it was likely that a couple would have a child with a serious physical disability. Do you think it would be right or not right for them to have this sort of treatment? *Never right, Sometimes right, Always right, Don't Know*

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grow into a baby. Suppose a couple were likely to have a child which would live in good health, but then would die in its twenties or thirties. Do you think it would be right or not right for them to have this sort of treatment? *Never right, Sometimes right, Always right, Don't Know*

There is another way in which couples can try to avoid having a child with a serious medical condition. The woman's eggs are fertilised outside her body with her partner's sperm and genetically tested. Only eggs without the condition are put back, and may then grow into a baby. Suppose they would have a child which would be healthy but would never grow taller than an eight year old. Do you think it would be right or not right for them to have this sort of treatment? *Never right, Sometimes right, Always right, Don't Know*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ... taller or shorter? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ...more intelligent? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

How do you feel about scientists changing the makeup of cells to improve the intelligence that children would inherit? *Strongly approve, somewhat approve, somewhat disapprove, strongly disapprove, DK \*(Approve, disapprove, DK)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ...straight, rather than gay or lesbian? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person .. gay or lesbian, rather than straight? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ... reduce a person's chances of getting heart disease? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers

from this card, do you think this should be allowed or not allowed to make a person ...reduce a person's chances of getting breast cancer? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ...make them less aggressive or violent? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ...make them of average weight, rather than very over-weight? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ...determine the sex of an unborn baby? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ...give someone a full head of hair, rather than being bald? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

How do you feel about scientists changing the makeup of cells to improve the physical characteristics that children would inherit? *Strongly approve, somewhat approve, somewhat disapprove, strongly disapprove, DK \*(approve, disapprove, DK)*

Suppose it was discovered that a person's genes could be changed. Taking your answers from this card, do you think this should be allowed or not allowed to make a person ...stop someone having schizophrenia? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, (Don't Know)*

Say in the future science developed the ability to change a normal child's inherited characteristics by changing the child's genetic structure in the womb. If you were making the decision, would you consider changing the child's genetic structure in the womb in order to improve his or her... General physical health? *Yes, no, Don't Know*

Say in the future science developed the ability to change a normal child's inherited characteristics by changing the child's genetic structure in the womb. If you were making the decision, would you consider changing the child's genetic structure in the womb in order to improve his or her... Hair or eye colour or facial characteristics? *Yes, no, Don't*

*Know*

Say in the future science developed the ability to change a normal child's inherited characteristics by changing the child's genetic structure in the womb. If you were making the decision, would you consider changing the child's genetic structure in the womb in order to improve his or her... Body characteristics, such as height and weight? *Yes, no, Don't Know*

Say in the future science developed the ability to change a normal child's inherited characteristics by changing the child's genetic structure in the womb. If you were making the decision, would you consider changing the child's genetic structure in the womb in order to improve his or her... Intelligence? *Yes, no, Don't Know*

These scientists (in genetic engineering) also believe that some day it will be possible for parents to have their genes changed in order to make sure that any children they have are smarter, physically stronger, or better looking. Would you be interested in changing your genes in order to have your children be improved in those ways, or do you think that is going to far? *Interested, going too far, Don't Know*

Genetic tests can be used to tell people whether they are likely to develop a serious genetic condition in the future. If such a test were easily available, would you want to find out your risk of developing such a condition if it could not be treated? *Definitely would, Probably would, Probably would not, Definitely would not, Don't Know*

I'd like you to think of someone in their 20s who has a life-threatening medical condition [\*heart disease]. Suppose it were discovered that changing some of their genes by giving them an injection would help treat them. These new genes would not be passed onto any children they might have. Do you think this should be allowed or not allowed? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, Don't Know*

Now, what if the new genes were passed onto their future children to give them less chance of getting the same medical condition [life threatening/heart condition] in their 20s? Do you think this should be allowed or not allowed? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed, Don't Know*

Now suppose a person's genes could be changed before they were born – by treatment while still in their mother's womb – to give them less chance of getting serious heart disease in their 20s. The new genes would not be passed onto any children they later have. Do you think this should be *allowed, or not allowed? Don't know*

Today, tests are being developed that make it possible to detect serious genetic defects before a baby is born. But so far, it is impossible either to treat or to correct most of them.

If (you/your partner) were pregnant, would you want (her) to have a test to find out if the baby has any serious genetic defects? *Yes have a test, No, (Don't Know)*

Suppose a test shows the baby has a serious genetic defect. Would you (yourself want to/want your partner to) have an abortion if a test shows the baby has a serious genetic defect? *Yes have an abortion, No, (Don't Know)*

When I say 'serious genetic defect', what kinds of defects do you think of? Any others?  
*Downs Syndrome; Mongoloid, Mental Retardation, Brain Damage, Spina Bifida, Muscular Dystrophy, Cystic Fibrosis, Cerebral Palsy, Crippling Diseases, Blind. Deaf, Missing Limbs, Thalidomide, Major Deformities, Life Threatening Deformities, Handicapped, Physical Defects, Sickle Cell Anemia, RH Factor, Hemophilia, Addiction to Drugs, Aids; Aids-related diseases, Multiple Sclerosis, Heart, Kidneys, Incurable disease, Tourettes Syndrome, Sexual Transmitted Diseases, Diabetes, Birth Defects, Cancer, Psychological Problems, Neurological Problems, Hydrocephalus, Huntington's, Chorea, Tay-Sachs, Reyes Syndrome, Unable to take care of self, Other, (Don't Know)*

How do you feel about scientists changing the makeup of human cells to... Reduce the risk of developing a fatal disease later in life? *Strongly approve, somewhat approve, somewhat disapprove, strongly disapprove, Don't Know*

How do you feel about scientists changing the makeup of human cells to... Cure a usually fatal disease? *Strongly approve, somewhat approve, somewhat disapprove, strongly disapprove, Don't Know*

How do you feel about scientists changing the makeup of human cells to... Stop children from inheriting a usually fatal genetic disease? *Strongly approve, somewhat approve, somewhat disapprove, strongly disapprove, Don't Know*

How do you feel about scientists changing the makeup of human cells to... Stop children from inheriting a non-fatal birth defect? *Strongly approve, somewhat approve, somewhat disapprove, strongly disapprove, Don't Know*

If these genetic tests became available that would indicate whether or not a person likely would develop an incurable and fatal disease later in life, would you personally take such tests or not? *Yes, No, Don't Know*

If these genetic tests became available that would indicate whether or not it as likely that your children would inherit a fatal genetic disease, would you personally take such test before having children or not? *Yes, No, Don't Know*

If tests showed that you were likely to get a serious or fatal genetic disease later in life, how willing would you be to undergo therapy to have those genes corrected? *Very willing,*

*somewhat willing, somewhat unwilling, very unwilling, Don't Know*

Often people can be carriers of a genetic disease, yet not come down with it themselves. But they can pass the disease down to their children. If test showed that you were a carrier of such a genetic disease, would you choose to have your genes altered to ensure that your children and future generations in your family didn't come down with the disease? *Would alter/interested, would not alter/going to far, Don't Know*

If you had a child with a usually fatal genetic disease, how willing would you be to have the child undergo therapy to have those genes corrected? *Very willing, somewhat willing, somewhat unwilling, very unwilling, Don't Know*

I am going to name some things that genetic testing might be able to tell about an unborn human fetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Would develop a painful disease which would cause almost certain death by age 4? *Yes, No, Don't Know*

I am going to name some things that genetic testing might be able to tell about an unborn human fetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Would have a good chance of being mentally retarded? *Yes, No, Don't Know*

I am going to name some things that genetic testing might be able to tell about an unborn human fetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Would get a disease that would be fatal by 30? *Yes, No, Don't Know*

I am going to name some things that genetic testing might be able to tell about an unborn human fetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Would get a disease around 50 which would leave that offspring crippled and bedridden for the rest of his or her life? *Yes, No, Don't Know*

I am going to name some things that genetic testing might be able to tell about an unborn human fetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Had a good chance of becoming an alcoholic? *Yes, No, Don't Know*

I am going to name some things that genetic testing might be able to tell about an unborn human fetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Had a good

chance of being very overweight throughout its life? *Yes, No, Don't Know*

I am going to name some things that genetic testing might be able to tell about an unborn human fetus in the early months of pregnancy. Please tell me whether you would consider ending a pregnancy if genetic tests showed that when born your child... Was going to be a girl and you were hoping for a boy? *Yes, No, Don't Know*

On this card are a number of different situations in which an individual or organisation might want to identify a part or all of someone's genetic information or DNA. Situation A: When a doctor tests a patient for an inherited disease, Situation B: When a person wants to find out if they are related to somebody, Situation C: When a doctor tests a couple planning to have a family and finds they have a family history that will mean their children are likely to have an inherited disability or life-limiting illness. Do you think...? *It is appropriate, Or inappropriate for someone to provide genetic information for this purpose? It depends, Don't know/not stated*

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On this card are a number of different situations in which an individual or organisation might want to identify a part or all of someone's genetic information or DNA. Situation A: When a doctor tests a patient for an inherited disease, Situation B: When a person wants to find out if they are related to somebody, Situation C: When a doctor tests a couple planning to have a family and finds they have a family history that will mean their children are likely to have an inherited disability or life-limiting illness. *Do you think the genetic information should, Or should not be shared with other organisations? It depends, Don't know/not stated*

Genetic testing determines whether and to what degree you are at risk of developing or passing on a disease. Gene therapy is repairing or replacing an abnormal gene. Based on what you know of gene therapy, do you think that research into gene therapy should be *continued, or stopped, Don't Know?*

And what do you think of using genetic testing to determine whether an unborn child has a genetic predisposition for a serious disease such as cystic fibrosis? *Definitely agree\*, Tend to agree, Tend to disagree, Definitely disagree\* (Don't Know)*. Such research is worthwhile and



should be encouraged?

And what do you think of using genetic testing to determine whether an unborn child has a genetic predisposition for a serious disease such as cystic fibrosis? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*). Such research may involve risk to human health or to the environment

And what do you think of using genetic testing to determine whether an unborn child has a genetic predisposition for a serious disease such as cystic fibrosis? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*) this application of biotechnology is morally acceptable?

And what do you think of using genetic testing to determine whether an unborn child has a genetic predisposition for a serious disease such as cystic fibrosis? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*) this application is useful for society?

Response to a vignette on alcohol dependence, depression, schizophrenia, or a drug problem. In your opinion, how likely *Very likely*, *somewhat likely*, *not very likely*, or *not at all likely*, (*Don't Know*) is it that NAME'S situation might be caused by? A genetic or inherited problem

New technology in science and medicine may allow couples who want to have a baby to pick and choose the baby's genetic characteristics such as hair color or the risk of certain diseases....Would you say that changing a baby's genetic characteristics for cosmetic purposes such as eye or hair color is *making appropriate use of medical advances*, or *is it taking medical advances too far?* *Don't Know*

(New technology in science and medicine may allow couples who want to have a baby to pick and choose the baby's genetic characteristics such as hair color or the risk of certain diseases.)...Would you say that changing a baby's genetic characteristics to reduce the risk of serious diseases is *making appropriate use of medical advances* or *is it taking medical advances too far?* *Don't Know*

New genetic techniques may prove able to slow down the aging process in human beings. How likely would you be to use genetic therapies if it meant you could live longer--*very likely*, *somewhat likely*, *not too likely*, or *not at all likely?* *Don't Know*

If advances in genetic engineering make it possible for parents to predetermine the characteristics of their unborn child, do you think parents should or should not have the right to decide each of the following... the sex of the child? *Yes should have right*, *No should not*, *Don't Know*

If advances in genetic engineering make it possible for parents to predetermine the characteristics of their unborn child, do you think parents should or should not have the right to decide each of the following... the child's eye color and hair color? *Yes should have right, No should not, Don't Know*

If advances in genetic engineering make it possible for parents to predetermine the characteristics of their unborn child, do you think parents should or should not have the right to decide each of the following... special skills and talents? *Yes should have right, No should not, Don't Know*

As far as you know is it scientifically possible to use genetic testing to find out if a person has a greater than average chance of developing certain kinds of cancer? *Yes, No, Don't know*

As far as you know is it scientifically possible to use genetic testing to find out if a person has desirable characteristics such as high intelligence or strength? *Yes, No, Don't know*

Is it appropriate to use prenatal testing to find out whether a fetus would develop a fatal childhood disease? *Appropriate, inappropriate, Don't know*

Is it appropriate to use prenatal testing to find out whether a fetus would have a tendency to develop a disease like adult-onset cancer? *Appropriate, inappropriate, Don't know*

Is it appropriate to use prenatal testing to find out whether a fetus would be a certain sex? *Appropriate, inappropriate, Don't know*

Is it appropriate to use prenatal testing to find out whether a fetus would be a good match to donate his or her blood tissue to a brother or sister who is sick and needs a transplant? *Appropriate, inappropriate, Don't know*

Is it appropriate to use prenatal testing to find out whether a fetus would have desirable characteristics like high intelligence or strength (hypothetically)? *Appropriate, inappropriate, Don't know*

Is it appropriate to use PGD to select which embryo(s) to transfer to a woman's uterus? *Appropriate, inappropriate, Don't know*

Before today, had you ever heard about Cloning? *Yes, No, Don't know*

Before today, had you ever heard about IVF? *Yes, No, Don't know*

Before today, had you ever heard about Genetic Testing? *Yes, No, Don't know*

Before today, had you ever heard about Prenatal Testing? *Yes, No, Don't know*

Before today, had you ever heard about Genetic Modification? *Yes, No, Don't know*

Before today, had you ever heard about PGD? *Yes, No, Don't know*

Parents ought to do everything technologically possible to prevent their child from suffering including using reproductive genetic technologies? *Strongly agree, agree, disagree, strongly disagree, Don't know*

Do you personally think it is wrong or not wrong for a woman to have an abortion... If there is a strong chance of a serious defect in the baby? *Always wrong, almost always wrong, wrong only sometimes, not wrong at all, (Don't Know)*

Under what circumstance, if any, do you feel that a women should or should not be permitted to obtain a legal abortion?... Should a woman who is carrying a fetus with a severe genetic defect be permitted to obtain a legal abortion? *Legal/oppose restriction, Not legal/support restriction, Don't Know*

Most pregnant women today undergo prenatal tests that can detect potential health problems in their unborn babies. Please tell me whether you think it would be morally wrong or not morally wrong for a woman to have an abortion if a prenatal test indicated any of the following conditions... Mental retardation, such as Down's Syndrome? *Morally wrong, Not morally wrong, depends, Don't Know*

Most pregnant women today undergo prenatal tests that can detect potential health problems in their unborn babies. Please tell me whether you think it would be morally wrong or not morally wrong for a woman to have an abortion if a prenatal test indicated any of the following conditions... A disease that could lead to the child's death within five year, such as Tay Sachs Disease? *Morally wrong, Not morally wrong, depends, Don't Know*

Most pregnant women today undergo prenatal tests that can detect potential health problems in their unborn babies. Please tell me whether you think it would be morally wrong or not morally wrong for a woman to have an abortion if a prenatal test indicated any of the following conditions... A condition that would cause chronic health problems or death in early adulthood such as cystic fibrosis? *Morally wrong, Not morally wrong, depends, Don't Know*

Do you think PGD or prenatal testing should be allowed at all? *Yes, No, Don't know*

### **Personal experience of genetic illness (11)**

Has a doctor ever advised you, or any member of your immediate family, of a serious genetic condition in your family? *Yes, No, Don't Know*

And have you ever helped care for a family member or friend, born with a serious genetic condition? *Yes, No, (Don't Know)*

Has anyone in your immediate family ever...Had a potentially fatal genetic disease? *Yes, No/ Don't Know*

Has anyone in your immediate family ever...Been a carrier of a potentially fatal genetic disease? *Yes, No/ Don't Know*

Has anyone in your immediate family ever...Had a genetic proclivity/tendency to serious illnesses? *Yes, No/ Don't Know*

Has anyone in your immediate family ever...Had any other inherited health condition? *Yes, No/ Don't Know*

Has anyone in your immediate family ever...Had any other birth defect? *Yes, No Don't Know*

As far as you know, do you, or any members of your family or friends have any inherited conditions or illnesses? By 'inherited condition or illness', I mean a condition that has been passed down to someone through their family. *Yes, I have an inherited condition or illness Yes, members of my family have inherited conditions or illness Yes, I know someone outside my family who has an inherited condition or illness, No, Don't know*

And what is this inherited condition or illnesses? In giving me your answer, please also tell me whether it is you, a member of your family, or someone else that has these inherited conditions or illnesses. This information will be treated in confidence and individuals will not be identified.

Have you, or has anyone in your immediate family, ever had a genetic disease? *Yes, No, Don't Know*

Have you, or has anyone in your immediate family, ever had a genetic test? *Yes, No, Don't Know*

### **Genetic Influence on Traits and Behaviour: Similar questions but with different**

## response options (71)

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... a person's height? *All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... a person's intelligence? *All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... of getting heart disease? *All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... of being aggressive or violent? *All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... of being gay or lesbian? *All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... of getting breast cancer? *All to do with genes, Mostly to do*

*with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... A person's chances of being overweight *All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Some things about a person are caused by their genes, which they inherit from their parents. Others may be to do with the way they are brought up, or the way they live. Some may happen just by chance. Using this card, please say what you think decides each of the things that I am going to read out... The colour of a person's eyes *All to do with genes, Mostly to do with genes, Mostly to do with upbringing or lifestyle, All to do with upbringing or lifestyle, An equal mixture of genes and upbringing/lifestyle, Just chance, (Don't Know)*

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions* [*\*1 totally inherited...5 totally environment*], (*Don't Know*): Body size

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions*, [*\*1 totally inherited...5 totally environment*], (*Don't Know*): Intelligence

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions*, [*\*1 totally inherited...5 totally environment*], (*Don't Know*): Homosexual tendencies

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions*, [*\*1 totally inherited...5 totally environment*], (*Don't Know*): Eye colour

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions*, [*\*1 totally inherited...5 totally environment*], (*Don't Know*): Tendency to be happy, Depression\*

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions*, (*Don't Know*): Criminal tendencies

Please tell me whether you think each of the following characteristics is *mainly inherited or*

*mainly the result of upbringing and living conditions, (Don't Know): Attitude to work*

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions, (Don't Know): Athletic abilities*

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions, (Don't Know): Susceptibility to mental illness*

Please tell me whether you think each of the following characteristics is *mainly inherited or mainly the result of upbringing and living conditions, (Don't Know): Musical ability*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Antisocial behaviour*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Alcoholism*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Asthma*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Cancer*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Flu*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Cystic Fibrosis*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Diabetes*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Epilepsy*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Heart disease*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): High blood pressure*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know): Huntington's disease*

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know)*: Measles

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know)*: Sickle Cell Anaemia

Please tell me whether you think each of the following characteristics is *1 totally inherited...5 totally environment (Don't Know)*: Thalassaemia

People have different ideas about what factors form a child's personality. Which of the following do you think is more important? Is it *Genetic traits that children inherit from their parents, the environment in which they were raised, both are equally important, or Neither, Don't Know*

I am now going to read you two different views about the role of heredity and genes versus environment and society in shaping how people behave. Please tell me which one comes closest to describing how you feel. *A) Heredity and genes generally determine a person's behaviour more than the environment and society a person grows up in, Or B) The environment and society a person grows up in has more to do with a person's behaviour than heredity and genes, or Both, neither, Don't Know*

Overall do you think that racial and ethnic differences are *mostly due to culture and family upbringing, or mostly due to heredity and genes, both, neither, Don't Know*

I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* How well a person reads

I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* Whether a person is overweight or not

I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* Whether a person is likely to have a heart attack

I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* Whether someone becomes an alcoholic

I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* Whether someone is heterosexual or homosexual



I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* Whether someone is a great athlete

I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* Whether someone gets cancer

I'm going to read a list of some characteristics people might have. For each one, would you please tell me which is more important in determining why people are the way they are- *heredity, environment, both, Don't Know* Whether someone becomes a great athlete

Character, personality, success or failure, and many other types of behaviour are thought to be influenced by both the genes you inherited from your parents and what you learn and experience as you grow up. For each of the following please say whether you think *it is more dependent on the genes you inherit, Or more from what you learn and experience, Don't Know...* Being substantially overweight?

Character, personality, success or failure, and many other types of behaviour are thought to be influenced by both the genes you inherited from your parents and what you learn and experience as you grow up. For each of the following please say whether you think *it is more dependent on the genes you inherit, Or more from what you learn and experience, Don't Know...* Living a long and healthy life?

Character, personality, success or failure, and many other types of behaviour are thought to be influenced by both the genes you inherited from your parents and what you learn and experience as you grow up. For each of the following please say whether you think *it is more dependent on the genes you inherit, Or more from what you learn and experience, Don't Know...* Intelligence?

Character, personality, success or failure, and many other types of behaviour are thought to be influenced by both the genes you inherited from your parents and what you learn and experience as you grow up. For each of the following please say whether you think *it is more dependent on the genes you inherit, Or more from what you learn and experience, Don't Know...* Sexual orientation?

Character, personality, success or failure, and many other types of behaviour are thought to be influenced by both the genes you inherited from your parents and what you learn and experience as you grow up. For each of the following please say whether you think *it is more dependent on the genes you inherit, Or more from what you learn and experience, Don't Know...* Character?

Character, personality, success or failure, and many other types of behaviour are thought to be influenced by both the genes you inherited from your parents and what you learn and experience as you grow up. For each of the following please say whether you think *it is more dependent on the genes you inherit, Or more from what you learn and experience, Don't Know...*  
Criminal behaviour

Character, personality, success or failure, and many other types of behaviour are thought to be influenced by both the genes you inherited from your parents and what you learn and experience as you grow up. For each of the following please say whether you think *it is more dependent on the genes you inherit, Or more from what you learn and experience, Don't Know...*  
Success in life?

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...*Alcoholism

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...*Drug addiction

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...*Mental illness

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...*Violent behaviour

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...*Homosexuality

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...*Intelligence

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...*Happiness

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by*

*heredity and genes...Neurotic behaviour*

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...Criminal behaviour*

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...Religious behaviour*

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...Shyness*

I'm going to read you a list of human behaviours and characteristics. For each one, I'd like you to tell me whether this behaviour is *completely, mostly, somewhat, or not at all determined by heredity and genes...Dependability*

For each item I name, please tell me how important this is as a reason many Americans are very overweight--very important, somewhat important, not too important, or not at all important...Genetics and hereditary factors (If Necessary, ask:) Is this a very important, somewhat important, not too important or not at all important reason many Americans are very overweight? *Somewhat important, Not too important, Not at all important, Don't know*

Regardless of whether you'd like to lose weight, what do you think is the primary reason you're very/somewhat overweight--is it lack of exercise, your diet, genetics, a medical condition, stress or what? *Lack of exercise, Your diet, Genetics, Medical condition, Stress, Pregnancy, Age, Other, Don't Know*

(Now I'd like to get your opinion on some issues related to drug addiction. Please tell me whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree with each of the following statements.)...Genetic factors can increase the risk of drug addiction. *Strongly agree, Somewhat agree, Somewhat disagree, Strongly disagree, Don't Know*

Please circle the letter of the one that comes closer to you opinion...Genes play the major role in determining people's personality. It's people's experiences in life that determine their personality. *Genes play the major role in determining peoples personality, It's people's experience in life that determine their personality, Don't Know*

'Homosexuality is determined by genetic predisposition and it is wrong to discriminate against someone's biological makeup.' Do you agree or disagree with this statement? (If Agree/Disagree, ask:) Do you agree/disagree strongly or only somewhat? *Agree strongly,*

*Agree somewhat, Disagree somewhat, Disagree strongly, Don't Know*

Which one of the following do you think contributes most to the evil that people do...genetic or biological tendencies, poor upbringing from parents, ignorance or lack of education, or the work of the Devil or Satan? *Genetic or biological tendencies, Poor upbringing from parents, Ignorance or lack of education, Work of the Devil or Satan, Don't Know*

(How important do you think each of the following is for you to stay healthy as you grow older: is it *essential, very important, somewhat important, or not very important? Don't Know*)...The genes you were born with

Some people think that homosexuality is a choice of behavior that people can stop or be cured of. Others believe homosexuality is determined by a person's genes and is a permanent feature of their personality. Which comes closer to your view? *Homosexuality is choice, Homosexuality is result of genetics, Don't Know*

(Now I'm going to read you some items and for each I would like you to tell me if, as far as you know, *it does or does not help cause high cholesterol, Don't Know*) Would you say that... inheriting certain genes... helps cause high cholesterol, or doesn't it?

### **Biotechnology/genetic engineering (80)**

Science and technology changes the way we live. For each of these areas, do you think it will *improve our way of life in the next 20 years, it will have no effect, or it will make things worse, (Don't Know)?* ... Biotechnology and genetic engineering?

What do you think about the use of genetic engineering to produce vaccine? I think it is...*very good, quite good, equally good and bad, rather bad, very bad, I am not determined yet, I don't care about it, don't know/ no statement*

Biotechnology will personally benefit people like me in the next five years. *Do you strongly agree, agree, disagree, or strongly disagree?*

My family and I have already benefited from biotechnology. *Do you strongly agree, agree, disagree, or strongly disagree?*

Traditional breeding methods can be as effective as biotechnology and genetic engineering, in changing hereditary characteristics of plants and animals. *definitely agree\*, tend to agree, tend to disagree or definitely disagree\*, (Don't Know)?*

We have to accept some degree of risk from modern biotechnology if it enhances

economic competitiveness in Europe. *tend to agree or to disagree,*

For each one, please tell me whether you think it *is likely or unlikely to happen within the next 20 years, (Don't Know)*. Creating dangerous new diseases

For each one, please tell me whether you think it is *likely or unlikely to happen within the next 20 years, (Don't Know)*. Solving more crimes through genetic fingerprinting

For each one, please tell me whether you think it is *likely or unlikely to happen within the next 20 years, (Don't Know)*. Curing most genetic diseases

For each one, please tell me whether you think it is *likely or unlikely to happen within the next 20 years, (Don't Know)*. Producing designer babies

For each one, please tell me whether you think it *is likely or unlikely to happen within the next 20 years, (Don't Know)*. Substantially reduce world hunger

For each one, please tell me whether you think it is *likely or unlikely to happen within the next 20 years, (Don't Know)*. Get more out of natural resources in Third World countries

For each one, please tell me whether you think it is *likely or unlikely to happen within the next 20 years, (Don't Know)*. Substantially reduce environmental pollution

For each one, please tell me whether you think it is *likely or unlikely to happen within the next 20 years, (Don't Know)*. Reduce the range of fruit and vegetables we can eat

We've been discussing several issues to do with modern biotechnology. Some people think these issues are very important whilst others don't. How important are these issues to you personally? *1 Not at all important... 10 extremely important, (Don't Know)*

Please tell me what comes to mind when you think about modern biotechnology in a broad sense, that is including genetic engineering. For each area stated, do you have a *Positive, Negative, or Neutral opinion about it, (Don't Know)*? Cloning animals, human beings? Scientific- health research- technological development? Genetically modified food? Environment? Ethico-philosophical issues?

Is this thought about biotechnology negative or positive? *Very negative, Negative, Neither/nor, Positive, Very positive, (Don't Know)*

Is this thought about genetic engineering negative or positive? *Very negative, Negative, Neither/nor, Positive, Very positive, (Don't Know)*

Is this thought about genetic modification negative or positive? *Very negative, Negative,*

*Neither/nor, Positive, Very positive, (Don't Know)*

To what extent do you agree that "BIOTECHNOLOGY" is a risk for society? *Strongly agree, Agree, Neither/nor, Disagree, Strongly disagree, (Don't Know)*

To what extent do you agree that biotechnology is morally acceptable? *Strongly agree, Agree, Neither/nor, Disagree Strongly, disagree, (Don't Know)*

If you have negative feelings about biotechnology, genetic engineering, genetic modification or cloning, what is the single most important reason for these negative feelings? *Violates religious/ethical principles, Is unhealthy for humans, Is unhealthy for animals, Is unhealthy for environment, Changes the taste or nutritional value of the food, Is just wrong, Other (specify), (Don't Know)*

The following practices use biotechnology. Do you think they should be stopped, or continued? *Stopped, continued, (Don't Know)* Using living things to make medicines

All in all: Do you think genetic engineering is... *very good, quite good, equally good and bad, rather bad, very bad, you don't pay your attention on it, you are not determined yet, don't know/ no statement*

What is your personal reason to be in favour of or to be against genetic engineering?

How important are ethical considerations for your personal judgement about genetic engineering? Would you say that they are... *very important, quite important, more unimportant, totally unimportant, don't know/no statement*

If you think about genetic engineering in general and consider the advantages and disadvantages. Do you think...*the chances dominate definitively, the chances rather dominate, the chances and risks balance each other, the risk rather dominates, the risk dominates definitively, hasn't thought about it yet, is not determinate yet, don't know/no statement*

Regardless of your opinion about genetic engineering. What do you think? Does the majority of the German citizens think that genetic engineering is...*very good, rather good, equally good or bad, rather bad, very bad, he can't estimate it, don't know/no statement*

In your opinion, has the new information or arguments changed your opinion about genetic engineering? *Yes, partly, or no, no statement*

Do you think you have changed the opinion of other people about genetic engineering with the help of your arguments and information? Would you say...*yes, partly, or no, don't know/ no statement*

The judgment about genetic engineering can be influenced by personal experiences. This can be an immune and cell disease, hereditary disease, congenital disabilities and allergies. Are you or a close person affected? *yes, no, don't know/ no statement*

Finally one more question about genetic engineering: Do you think that genetic engineering will play a very important role in Germany the next years? *Yes, no*

Do you support or oppose the use of biotechnology to develop new medicines to treat human disease? *Support, Oppose*

In general, do you think that genetic engineering will be beneficial, or that on balance it will be more harmful? *Benefits outweigh the risks, risks outweigh the benefits, mixed feelings, DK*

Some persons have argued that the creation of new life forms through genetic engineering constitutes a serious risk, while other persons have argued that this research may yield major benefits for society. In your opinion, are the risks of genetic engineering research greater than the benefits, or are the benefits of genetic engineering research greater than the risks? Would you say that the benefits are substantially greater than the risks, or only slightly greater than the risks? Would you say that the risks are substantially greater than the benefits, or only slightly greater? *Benefits substantially greater than the risks, benefits slightly greater than risks, about equal, risks slightly greater than benefits, risks substantially greater than benefits.*

The risks of genetic engineering have been greatly exaggerated? *Agree strongly, agree somewhat, disagree somewhat, disagree strongly, Don't Know*

Now let me ask you some questions about genetic engineering. Some people are worried about this science, arguing that in changing the basic makeup of people's cells it is like playing God. But let me ask you, if it is possible to cure people with fatal diseases by altering their genes, *do you feel they ought to be allowed to go ahead with such treatment, or do you think it is going too far? Don't Know*

From what you know or have heard, do you think genetic engineering will make the quality of life *a lot better for people such as yourself, somewhat better, somewhat worse, or a lot worse?*

In which of the following sectors of scientific research is the European community itself active? ... *Biotechnology ... (Don't Know)*

Because of their experience experts in genetic engineering can also judge well about ethical aspects of genetic engineering. *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

Genetic engineering experts are insufficiently qualified to judge ethical problems related to genetic engineering. *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

Genetic engineering experts think that the population is mentally immature (or is not qualified to judge) *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

What do you think of when you hear the word Biotechnology?

What do you think of when you hear the word genetic engineering?

What do you think of when you hear the word genetic modification?

Only traditional breeding methods should be used, rather than changing the hereditary characteristics of plants or animals through biotechnology and genetic engineering *definitely agree\*, tend to agree, tend to disagree or definitely disagree\*, (Don't Know)?*

Modern biotechnology is so complex that public consultation about it is a waste of time. *tend to agree or to disagree*

These new methods of biotechnology and genetic engineering are also being applied to the production and processing of foods. Scientists say that they can improve the quality of food and drink – for example by making it higher in protein, or lower in fat, or making it keep longer, or taste better. Please indicate to what extent you agree or disagree with each of the following statements. *Definitely agree\*, Tend to agree, Tend to disagree, Definitely disagree\*, (Don't Know)* Such research is worthwhile and should be encouraged?

These new methods of biotechnology and genetic engineering are also being applied to the production and processing of foods. Scientists say that they can improve the quality of food and drink – for example by making it higher in protein, or lower in fat, or making it keep longer, or taste better. Please indicate to what extent you agree or disagree with each of the following statements. *Definitely agree\*, Tend to agree, Tend to disagree, Definitely disagree\*, (Don't Know)* Such research may involve risk to human health or to the environment

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These new methods of biotechnology and genetic engineering are also being applied to the production and processing of foods. Scientists say that they can improve the quality of food and drink – for example by making it higher in protein, or lower in fat, or making it keep longer, or taste better. Please indicate to what extent you agree or disagree with each of the following statements *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*) this application of biotechnology is morally acceptable?

These new methods of biotechnology and genetic engineering are also being applied to the production and processing of foods. Scientists say that they can improve the quality of food and drink – for example by making it higher in protein, or lower in fat, or making it keep longer, or taste better. Please indicate to what extent you agree or disagree with each of the following statements. *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*) this application is useful for society?

Yet another application of biotechnology and genetic engineering is the development of new medicines and vaccines to improve human health. For example the production of insulin for the treatment of diabetics. Please indicate to what extent you agree or disagree with each of the following statements concerning such research on medicines and vaccinations. *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\**, (*Don't Know*) Such research is worthwhile and should be encouraged?

Yet another application of biotechnology and genetic engineering is the development of new medicines and vaccines to improve human health. For example the production of insulin for the treatment of diabetics. Please indicate to what extent you agree or disagree with each of the following statements concerning such research on medicines and vaccinations. *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\**, (*Don't Know*) Such research may involve risk to human health or to the environment

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Yet another application of biotechnology and genetic engineering is the development of new medicines and vaccines to improve human health. For example the production of insulin for the treatment of diabetics. Please indicate to what extent you agree or disagree with each of the following statements concerning such research on medicines and vaccinations. *Tend to agree*, *Tend to disagree*, (*Don't Know*) this application of biotechnology is morally

*acceptable?*

Yet another application of biotechnology and genetic engineering is the development of new medicines and vaccines to improve human health. For example the production of insulin for the treatment of diabetics. Please indicate to what extent you agree or disagree with each of the following statements concerning such research on medicines and vaccinations. *Tend to agree, Tend to disagree, (Don't Know)* this application is useful for society?

Science is also trying to apply some of the new methods of biotechnology and genetic engineering to human beings, or to their cells and tissues, for various purposes such as detecting, or curing, diseases, and characteristics we might have inherited from our parents. *Definitely agree\*, Tend to agree, Tend to disagree, Definitely disagree\*, (Don't Know)*. Such research is worthwhile and should be encouraged?

Science is also trying to apply some of the new methods of biotechnology and genetic engineering to human beings, or to their cells and tissues, for various purposes such as detecting, or curing, diseases, and characteristics we might have inherited from our parents. *Definitely agree\*, Tend to agree, Tend to disagree, Definitely disagree\*, (Don't Know)*. Such research may involve risk to human health or to the environment

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Science is also trying to apply some of the new methods of biotechnology and genetic engineering to human beings, or to their cells and tissues, for various purposes such as detecting, or curing, diseases, and characteristics we might have inherited from our parents. *Definitely agree\*, Tend to agree, Tend to disagree, Definitely disagree\* (Don't Know)*. This application is useful for society?

And what do you think of introducing human genes into animals to produce organs for human transplants, such as into pigs for human heart transplants? *Definitely agree\*, Tend to agree, Tend to disagree, Definitely disagree\* (Don't Know)*. Such research is worthwhile and

should be encouraged?

And what do you think of introducing human genes into animals to produce organs for human transplants, such as into pigs for human heart transplants? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*). Such research may involve risk to human health or to the environment

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And what do you think of introducing human genes into bacteria to produce medicines or vaccines, for example to produce insulin for diabetics? *\*Definitely agree*, *Tend to agree*, *Tend to disagree*, *\*Definitely disagree* (*Don't Know*). This application is useful for society?

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And what do you think of introducing human genes into bacteria to produce medicines or vaccines, for example to produce insulin for diabetics? *\*Definitely agree*, *Tend to agree*, *Tend to disagree*, *\*Definitely disagree* (*Don't Know*) This application of biotechnology is morally acceptable?

And what do you think of introducing human genes into bacteria to produce medicines or vaccines, for example to produce insulin for diabetics? *\*Definitely agree*, *Tend to agree*, *Tend to disagree*, *\*Definitely disagree* (*Don't Know*). Such research is worthwhile and should be encouraged?

Thinking about major technological developments of the twentieth century, which one or two of the following do you think were the most significant?...*The computer, the automobile, television, the airplane, broadcast radio, nuclear energy, space flight, genetic engineering, Don't Know*

For each of the following technologies, please tell me if you think it is making life better or worse for Americans, or isn't it making much difference?... Genetic engineering *Better,*

*Worse, Isn't making much difference, Don't Know*

If science made it possible, would you want to use genetic engineering to... choose the sex of a child, or not? *Yes, No, Don't Know*

If science made it possible, would you want to use genetic engineering to... improve the appearance of a child, or not? *Yes, No, Don't Know*

If science made it possible, would you want to use genetic engineering to... reduce the chance of various diseases affecting a child, or not? *Yes, No, Don't Know*

Now I have a question about science and technology. Which of the following innovations or inventions do you expect to see in the next 10 years? Controlling people's weight by manipulating the fat gene... do you expect to see this in the next 10 years, or not? *Yes, No, Don't Know*

(Of course none of us can really foresee what the future will actually be like, but based on the way things are going we can have a feeling as to whether certain things will or will not happen. Here is a list of some different things. Would you read down that list, and for each one tell me whether you think it is likely or not likely to have happened 50 years from now?)... It will be common practice for prospective parents to have genes artificially introduced into the fetuses of their unborn children to achieve desirable characteristics in their children (color of hair or eyes, higher intelligence, etc.) *Likely to have happened, Not likely to have happened, Don't Know*

I'd like to ask you a few questions about a new technology that has been getting a lot of attention recently. When I mention the phrase 'genetic engineering', what do you think of? *Changing genes, gene improvement/manipulation, altering/reconstructing/ combining splitting/controlling genes, Test-tube babies, Cloning, cloning and surrogate mothers, Creating new life-forms/artificial life, altering life, forms, evolution, Controlling, Characteristics in unborn children, creating perfect race, Experiments with DNA, splicing DNA, working with DNA, Artificial insemination, sperm banks, Cures in health-related problems, birth-defects, cancer, retardation, Human body, human development, people, Confused with generic: getting products without name brand and cheaper, Other, Don't Know*

As you may or may not know, DNA is the genetic material found in most cells in all living things. It is passed from parents to children and carries instructions for how a living thing develops and functions. ON this is a list of things made possible by the discovery of DNA, some of which are common now, some of which may be available in the future. Which, if any of them, were you aware of before seeing this card? *DNA identification/fingerprinting (as used in criminal investigations); Understanding/predicting inherited*

*diseases; Gene therapy (replacing a faulty gene with a healthy version); Increasing understanding of the link between genes, environment and lifestyle in causing common diseases; Personalised medicines (Tailor made drugs for individual patients); DNA vaccines; Paternity testing (using DNA to identify an individual's father; Sequencing the human genome; knowing how many genes we have and how they might affect us physically; Improving our understanding of how life has evolved; Genetically modified food; Tracing ancestry/family trees; Don't know*

And in your opinion, which two or three of these things, if any, do you feel will provide the greatest benefit to society? *DNA identification/fingerprinting (as used in criminal investigations); Understanding/predicting inherited diseases; Gene therapy (replacing a faulty gene with a healthy version); Increasing understanding of the link between genes, environment and lifestyle in causing common diseases; Personalised medicines (Tailor made drugs for individual patients); DNA vaccines; Paternity testing (using DNA to identify an individual's father; Sequencing the human genome; knowing how many genes we have and how they might affect us physically; Improving our understanding of how life has evolved; Genetically modified food; Tracing ancestry/family trees; Don't know*

### **Stem Cell research and Cloning (139)**

And what do you think of cloning human cells or tissues to replace a patient's cells that are not functioning properly? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*). Such research is worthwhile and should be encouraged?

And what do you think of cloning human cells or tissues to replace a patient's cells that are not functioning properly? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*). Such research may involve risk to human health or to the environment

And what do you think of cloning human cells or tissues to replace a patient's cells that are not functioning properly? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*) This application of biotechnology is morally acceptable?

And what do you think of cloning human cells or tissues to replace a patient's cells that are not functioning properly? *Definitely agree\**, *Tend to agree*, *Tend to disagree*, *Definitely disagree\** (*Don't Know*). This application is useful for society?

And what do you think of cloning animals such as sheep to get milk which can be used to make medicines and vaccines? *Tend to agree*, *Tend to disagree*, (*Don't Know*). Such research is worthwhile and should be encouraged?

And what do you think of cloning animals such as sheep to get milk which can be used to make medicines and vaccines? *Tend to agree*, *Tend to disagree*, (*Don't Know*). Such research

may involve risk to human health or to the environment

And what do you think of cloning animals such as sheep to get milk which can be used to make medicines and vaccines? *Tend to agree, Tend to disagree, (Don't Know)* This application of biotechnology is morally acceptable?

Now lets talk about cloning animals, for instance to get milk which can be used to make medicines and vaccines. Cloning animals will bring benefits to a lot of people? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Deciding on the issues of cloning animals is so complex that public consultation about it is a waste of time? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Cloning animals threatens the natural order of things? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

If the majority of people were in favour of cloning animals, then it should be allowed? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Cloning animals is simply not necessary? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

The risks from cloning animals are acceptable? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Whatever the risks from cloning animals, you can avoid them if you really want to? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Even if cloning animals has benefits it is fundamentally unnatural? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

If anything went wrong with cloning animals, it would be a worldwide catastrophe? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

I dread the idea of cloning animals? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Cloning animals poses no danger for future generations? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Of all the risks we face these days, the risk from cloning animals is quite small? *Strongly*

*agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Even if it means missing out on some of its benefits, cloning should be introduced more gradually? *Strongly agree, Somewhat agree, Neither agree or disagree, Somewhat disagree, Strongly disagree, (Don't Know)*

Cloning human cells or tissues to replace a patient's cells that are not functioning properly is called therapeutic cloning. In deciding whether therapeutic cloning would be helpful or not, which was the most important issue for you? Usefulness, Risk, Moral acceptability? And which was the second most important issue?

Therapeutic cloning will be useful as it promises cures for some serious diseases? *Tend to agree, or Tend to disagree*

Therapeutic cloning will be useful for third world countries in the fight against deadly tropical diseases? *Tend to agree, or Tend to disagree*

Therapeutic cloning will only be good for industry and not for ordinary people? *Tend to agree, or Tend to disagree*

In the long run, a successful (national) medical biotechnology industry will be good for the economy? *Tend to agree, or Tend to disagree*

Therapeutic cloning poses no threat to future generations? *Tend to agree, or Tend to disagree*

Therapeutic cloning will be harmful to patients? *Tend to agree, or Tend to disagree*

Therapeutic cloning threatens the natural order of things? *Tend to agree, or Tend to disagree*

I will be able to choose whether I have therapeutic cloning or not? *Tend to agree, or Tend to disagree*

Whatever the dangers of therapeutic cloning, future research will deal with them successfully? *Tend to agree, or Tend to disagree*

I think it will be safe to have therapeutic cloning if I needed it? *Tend to agree, or Tend to disagree*

Therapeutic cloning will be available to rich and poor patients alike? *Tend to agree, or Tend to disagree*

I am not sure about my opinions about therapeutic cloning? *Tend to agree, or Tend to disagree*

It is easy for me to form an accurate judgement about therapeutic cloning? *Tend to agree, or*

*Tend to disagree*

It is important for me to have an accurate judgement about therapeutic cloning? *Tend to agree, or Tend to disagree*

I would support the cloning of embryos to help infertile couples have children? *Tend to agree, Tend to disagree, (Don't Know)*

What do you think of when you hear the word cloning?

Is this thought about cloning negative or positive? *Very negative, Negative, Neither/nor, Positive, Very positive, (Don't Know)*

Some people feel that life begins at the moment of conception. Others feel that human life does not begin until the baby is actually born. Do you, yourself, feel that human life begins at conception, at the time of birth, or at some point in between?

The kind of stem cell research the Government is considering involves human embryos that have been created in medical clinics by fertilising a woman's egg outside the womb. An embryo may be implanted into a woman's womb to develop into a baby. If an embryo is not implanted into a woman's womb to develop into a baby, it may be destroyed, either by being discarded or being used for medical research. Some scientists believe this type of medical research could lead to treatments for such diseases as Alzheimer's disease, diabetes, heart disease, and spinal cord injuries... Which come closest to your view of this kind of stem cell research: *It is morally wrong and is unnecessary, it is morally wrong but may be necessary, it is not morally wrong and may be necessary, or it is not morally wrong but it is unnecessary? Don't Know*

Please tell me whether you personally believe that in general it is *Morally acceptable, or Morally wrong, Don't Know* ...Medical research using stem cells obtained from human embryos?

Sometimes fertility clinics produce extra fertilized eggs, also called embryos, that are not implanted in the woman's womb. These extra embryos are either discarded, or couples can donate them for use in medical research called stem cell research. Some people support stem cell research, saying it's an important way to find treatments for many diseases. Other people oppose stem cell research, saying it's wrong to use any human embryos for research purposes. What about you? *Do you support or oppose stem cell research? Don't Know*

One of the issues involved in this type of research is whether or not the embryos used were developed specifically for stem cell research. Do you think the federal Government should or should not allow scientists to fertilize human eggs specifically for the purpose of



creating stem cells? *Yes should allow, No should not all, No opinion*

As you may already know, a stem cell is the basic cell in the body from which all other cells arise. Medical researchers have been able to isolate stem cells from excess human embryos developed through in vitro fertilization and fetal tissue that has been donated to research. The medical researchers believe that human stem cells can be developed as replacement cells to cure diseases such as diabetes, Parkinson's, Alzheimer's, Cancer, Heart disease, arthritis, burns, or spinal cord problems. Do you favour the funding of stem cell research by the National Institutes of Health? *Should fund, should not fund, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To make it possible for societies to clone and reproduce large numbers of individuals with genetically desirable traits? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To establish embryo banks from which prospective parents could select a child with genetic characteristics they desire? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To make it possible for parents to have a twin at a later date, if they want to? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To make it for scientists to screen embryos for inherited abnormalities *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To produce babies whose vital organs can

be used to save the life of others? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To provide infertile couples using test-tube fertilization with more embryos to increase their chances of conceiving? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To allow parents who have lost a child to create a clone of the child they have lost? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To allow gay couples to have children using their own genes? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To produce genetically superior human beings? *Approve, disapprove, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Do you approve or disapprove of the use of cloning... To save the life of the person who is being cloned? *Approve, disapprove, Don't Know*

Do you approve or disapprove of cloning that is designed specifically to result in the birth of a human being?

Do you favour or oppose [\*approve or disapprove of] scientific experimentation on the cloning of human beings?

If it becomes possible, do you think the cloning of humans should be allowed? *Should allow, Should not allow, Don't Know*

Do you think it should be legal or illegal to clone human beings in the United States? *should be legal, should be illegal, Don't Know*

Do you think human cloning for medical treatments should be legal or illegal in the United States? *should be legal, should be illegal, Don't Know*

Do you think that cloning that is designed specifically to result in the birth of a human being should be legal or illegal in the United States? *should be legal, should be illegal, Don't Know*

Do you [\*would you] favour or oppose a law that would prohibit the cloning of human beings? *Favour prohibition, Oppose prohibition*

Do you approve or disapprove of cloning that is not designed specifically to result in the birth of human beings, but is designed to aid medical research that might find treatments for certain diseases? *Approve, Disapprove, Don't Know*

Do you approve or disapprove of cloning human organs or body parts that can then be used in medical transplants? *Approve, Disapprove, Don't Know*

Do you approve or disapprove of cloning human cells from adults for use in medical research? *Approve, Disapprove, Don't Know*

Do you approve or disapprove of cloning human embryos for use in medical research? *Approve, Disapprove, Don't Know*

Do you favour or oppose using human cloning technology if it is used only to help medical research develop new treatments for disease? *Strongly favour, somewhat favour, somewhat oppose, strongly oppose, Don't Know*

As you may well know, Congress is considering several proposals to ban human cloning, Which of the following positions do you most agree with... *Human cloning should not be banned, only human cloning that leads to the Birth of a human should be banned but cloning for purposes of laboratory research should be allowed, Or all human cloning should be banned*>

There is a branch of medicine that uses stem cell therapy to develop new treatments for disease. There are several different kinds of stem cells. What kinds of stem cells come to mind when you think about stem cell therapy? *Embryonic stem cells, specific uses of stem cells for treatment of disease, newborns/umbilical cord/placenta, adult stem cells, unborn fetus/aborted fetus/abortions, fetal stem cells, Don't Know, no answer*

Here are a few questions about a different topic – a process called 'cloning' in which genetic material is taken from an animal and implanted into an unfertilized egg. The egg is allowed to develop into an exact duplicate, or 'clone' of the original animal. Currently,

medical researchers have been able to clone sheep and other animals, but have not been able to use the same techniques on humans. In general, do you think it is a good idea or a bad idea to clone animals such as sheep? *Good idea, bad idea, depends, Don't Know*

Scientists are also working on ways to 'clone' animals, for example to make exact copies of a single cow. Do you approve or disapprove of this kind of scientific research? *Approve, disapprove, mixed, Don't Know*

Do you think it is acceptable to use cloning to... Reintroduce extinct species? *Acceptable, not acceptable, Don't Know*

Do you think it is acceptable to use cloning to... Reproduce endangered species? *Acceptable, not acceptable, Don't Know*

Do you think it is acceptable to use cloning to... Reproduce livestock? *Acceptable, not acceptable, Don't Know*

Do you think it is acceptable to use cloning to... Reproduce a beloved pet? *Acceptable, not acceptable, Don't Know*

Do you think it is acceptable to use cloning to... Reproduce humans? *Acceptable, not acceptable, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time...In general do you think cloning is a... *good thing, bad thing, it depends, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time...Do you think cloning is *morally wrong, not morally wrong, depends, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time...Do you think cloning is *against God's will, don't feel that way, Don't Know*

As you may have read or heard, medical researchers are on the verge of discovering a way to create new embryos, called clones, from a fertile egg. The original embryo and its clones can be frozen and put into a mother's womb for development at any time. Suppose it were possible for your parents to have cloned you when you were an embryo. Do you think you

would have liked to have been cloned? *Would, would not, Don't Know*

Do you approve or disapprove of scientists working on ways to clone animals? *Approve, Disapprove, Don't Know*

Do you believe anyone has actually cloned a human already? *Yes, No, Don't Know*

Do you favor or oppose using human cloning technology if it is used only to help medical research develop new treatments for disease--*do you strongly favor, somewhat favor, somewhat oppose, or strongly oppose this? Don't Know*

Cloning research has been a topic of debate lately. I'm going to ask you about two different kinds of cloning....The first kind of cloning is reproductive cloning. This is the use of cloning technology to create a child. Do you think research into reproductive cloning should be allowed to go forward? (If Yes/No, ask:) Do you feel that way strongly, or only somewhat? *Yes-Strongly, Yes-Somewhat, No-Somewhat, No-Strongly, Don't Know*

(Cloning research has been a topic of debate lately. I'm going to ask you about two different kinds of cloning.)...The second kind of cloning is therapeutic cloning. This is the use of cloning technology to help in the search for possible cures and treatments for diseases and disability. Do you think research into therapeutic cloning should be allowed to go forward? (If Yes/No, ask:) Do you feel that way strongly, or only somewhat? *Yes-Strongly, Yes-Somewhat, No-Somewhat, No-Strongly, Don't Know*

Is your objection to research on human cloning based more on...the belief that the science is not yet safe enough but could be in the future, the belief that it is morally wrong? *The belief that the science is not yet safe enough but could be in the future, The belief that it is morally wrong, Both equally, Other, Don't Know*

Let me read you a list of things that people say could happen in the next century, that is the next hundred years, in the field of health and medicine. Please tell me which one you think is most likely to happen in the next century?... *Organs will be cloned instead of donated by another person, most people will live to be at least one hundred years old, parents will select the sex and personality characteristics of their children, a medication that prevents the physical signs of aging will be discovered, all, Don't Know*

In the next century, do you think scientists will be able to clone human beings? (If yes, ask:) Do you think that's a good thing or a bad thing? *Yes good thing, Yes bad thing, No, Don't Know*

Do you think the cloning of animals should or should not be allowed for purposes of

medical research? *Should, Should not, Don't Know*

(Next, I'm going to read you a list of issues. Regardless of whether or not you think it should be legal, for each one, please tell me whether you personally believe that in general it is morally acceptable or morally wrong.) How about...cloning animals? *Morally acceptable, Morally wrong, Depends on situation, Not a moral issue, Don't Know*

(Next, I'm going to read you a list of issues. Regardless of whether or not you think it should be legal, for each one, please tell me whether you personally believe that in general it is morally acceptable or morally wrong.) How about...cloning humans? *Morally acceptable, Morally wrong, Depends on situation, Not a moral issue, Don't Know*

The technology now exists to clone or genetically alter animals. How much do you favor or oppose allowing the same thing to be done in humans--do you *strongly favor, somewhat favor, somewhat oppose, or strongly oppose this?* *Don't Know*

Do you favor or oppose using human cloning technology if it is used to create human embryos that will provide stem cells for human therapeutic purposes--do you *strongly favor, somewhat favor, somewhat oppose, or strongly oppose this?* *Don't Know*

How concerned are you that the use of human cloning technology to create stem cells for human therapeutic purposes will lead to a greater chance of human reproductive cloning?... *Very concerned, somewhat concerned, not too concerned, not at all concerned, Don't Know*

Regardless of your opinion about cloning, do you think that scientists currently know enough or don't know enough about human cloning technology to make it safe in the treatment of disease? *Know enough, Don't know enough, Don't Know*

Which do you think will happen first--a nuclear bomb will be exploded in wartime or a human being will be cloned? *Nuclear explosion in wartime, Human cloned, Don't Know*

If Congress and the President do not pass this proposal (that would prohibit the cloning of human beings) into law, would you be--*very upset, somewhat upset, not too upset, or not at all upset?* *Don't Know*

If Congress and the President do pass this proposal (that would prohibit the cloning of human beings) into law, would you be--*very upset, somewhat upset, not too upset, or not at all upset?* *Don't Know*

If you were cloned, would you think of yourself as the clone's brother or sister, or as the clone's parent? *Brother or sister, Parent, Something else, Don't Know*

(Thinking about a child born on January 1, 2000, do you think each of the following will or

will not happen during that child's lifetime.)... A human being will be cloned. *will happen, Will not happen, Don't Know*

(Now thinking just about the last 10 years or so. I'm going to read another list of changes that have taken place. Please tell me if you think each one has been a change for the better, a change for the worse, or hasn't made much difference, Don't Know) Has... the cloning of sheep

(I'm going to read you a list of things that may or may not happen in the next 50 years. Please tell me how likely you think it is that each will happen, Don't Know) How likely do you think it is that... we will clone human beings?

(Next, as I describe some practices, please say whether you think each one will be commonplace in the year 2025, or not?) How about...cloning of humans? *Yes common, No not common, Don't Know*

(Now thinking about these same practices, do you think that in 2025 each one will generally be legal or not legal in the United States?) How about...cloning of humans? *Legal, Not legal, Don't Know*

Do you favor or oppose an outright ban on the cloning of human beings? *Favor, Oppose, Don't Know*

Cloning involves taking genetic material from one person and implanting it into an unfertilized egg. This egg develops into an exact genetic duplicate, or clone, of the original person. Suppose it was now possible for human beings to be cloned. If you had a chance to be cloned, would you have yourself cloned or not? *Yes, No, Don't Know*

President bush gave a speech tonight [other night] on stem cell research, and he announced that he would allow the Government to fund research using stem cells that have been created in the past in a proces that destroyed human embryos. The Government will not fnd stem cell research that would destroy additional embryos in the future. *Overall, do you approve, Or disapprove of bush's decision? Don't Know*

As you may know the Government recently made a decision about the use of federal funds to do research on stem cells that come from very early human embryos. From what you've seen or heard in the news, did they decide to... *allow scientists to use federal funds for this type of research, Or continue to ban the use of federal funds for this type of research? Don't Know*

In general, do you strongly approve, approve, disapprove or strongly disapprove of embryonic stem cell research? *Strongly approve, Approve, Disapprove, Strongly disapprove, Don't*

*know*

There is a public debate about embryonic stem cell research and disagreement about the public policies that should be put in place regarding this research. Some believe embryonic stem cell research is morally acceptable because research to find cures for diseases is extremely important. Others believe embryonic stem cell research is morally unacceptable because it requires the destruction of human embryos. A number of proposals have been put forward for embryonic stem cell research policy. The current policy of the US government has three components: 1) it allows federal funding of research using a limited number of embryonic stem cells that were created before August 2001 (because those IVF embryos had already been destroyed); 2) it prohibits federal funding to create new embryonic stem cells or to study new embryonic stem cells created with private funds; and 3) it permits private funds to be used to create and study new embryonic stem cells. Some feel the current policy is a good compromise because of the controversy about destroying embryos. Others feel that federal funding is essential to spur important medical research. Please review the following possible policies the government could adopt about research on embryonic stem cells. Select the one that you think is the best government policy. *1, The government should prohibit all research to create or study embryonic stem cells; 2, The government should keep the current policy that allows federal funding for research to study a small number of embryonic stem cells created before August 2001; 3, The government should not fund research to create new embryonic stem cells, but if private funding is used to create new embryonic stem cells then the government should fund research to study these cells; 4, The government should fund research to BOTH create and study new embryonic stem cells*

Imagine that in a year from now scientists report results from new research showing that embryonic stem cells are an effective treatment for a serious disease like diabetes. Would such a development change your views about government policy about embryonic stem cell research? *Yes, No, Don't know*

What would your policy preference be based on this new information? *1, The government should prohibit all research to create or study embryonic stem cells; 2, The government should keep the current policy that allows federal funding for research to study a small number of embryonic stem cells created before August 2001; 3, The government should not fund research to create new embryonic stem cells, but if private funding is used to create new embryonic stem cells then the government should fund research to study these new cells; 4, The government should fund research to BOTH create and study new embryonic stem cells*

Imagine that a year from now scientists report results from new research in which new embryonic stem cells are created from embryos without harming or destroying the embryo. The embryos that provided the stem cells could still be transferred to a woman's womb and produce healthy babies. Would such a development change your views about



government policy about research using embryonic stem cells from embryos donated by couples after IVF? *Yes, No, Don't know*

What would your policy preference be based on this new information? [a year from now scientists report results from new research in which new embryonic stem cells are created from embryos without harming or destroying the embryo. The embryos that provided the stem cells could still be transferred to a woman's womb and produce healthy babies] *1, I would support embryonic stem cell research only when embryos are not destroyed; 2, I would support embryonic stem cell research using embryos from both sources*

It is really important to find cures for diabetes, heart disease, and Parkinsons as quickly as possible, even if it means destroying embryos to do so? *Strongly agree, Agree, Disagree, Strongly disagree, Don't know*

It would be terrible if cures were delayed because of policies that make embryonic stem cell research difficult? *Strongly agree, Agree, Disagree, Strongly disagree, Don't know*

It would be terrible if embryos were destroyed because of policies that promote embryonic stem cell research? *Strongly agree, Agree, Disagree, Strongly disagree, Don't know*

It is really important to protect human embryos, even if it will delay the development of new Medicines? *Strongly agree, Agree, Disagree, Strongly disagree, Don't know*

Using embryos for research is dehumanizing and turns embryos into commodities? *Strongly agree, Agree, Disagree, Strongly disagree, Don't know*

All in all, which is more important to you, conducting embryonic stem cell research that might result in new medical cures OR not destroying the human embryos involved in this research? *Conducting embryonic stem cell research that might result in new medical cures; Not destroying the human embryos involved in this research*

Would you be willing to delay progress in medical research in order to find sources of stem cells that do not involve embryo destruction? *Yes, No, Don't know*

If so, for how long? [willing to delay progress in medical research in order to find sources of stem cells that do not involve embryo destruction] *One year, Five years, Ten years, Twenty five years, Forever, Don't know*

In addition to embryos donated by couples after infertility treatment with IVF, it is possible for people to donate sperm and eggs specifically to create embryos to be used to make embryonic stem cells. Some scientists believe that stem cells from these embryos would be particularly useful in research. Some people oppose creating embryos specifically

to be used to make stem cells because they believe it is wrong to create embryos only to destroy them. In general, do you strongly approve, approve, disapprove or strongly disapprove of using embryos specifically created to be used to make embryonic stem cells in which the embryo will necessarily be destroyed? *Strongly approve, Approve, Disapprove, Strongly disapprove, Don't know*

In your view, is there a moral difference between creating embryos specifically for research and using embryos remaining after IVF for research? *Yes, No, Don't know*

Is creating embryos specifically for research morally more or less acceptable than using embryos donated by couples after IVF for research? *1, Creating embryos specifically for research is morally LESS acceptable than using embryos donated by couples after IVF for research; 2, Creating embryos specifically for research is morally MORE acceptable than using embryos donated by couples after IVF research*

Please rank the moral status of each of the following *Human egg, Human sperm, One week old human embryo in a petri dish, One week old cloned/SCNT human embryo in a petri dish, One week old human embryo frozen in an IVF clinic, One week old human embryo in a woman's womb, 8 week old human fetus in a woman's womb, 24 week old human fetus in a woman's womb, Born human baby*

Current law allows the use of human embryos up to 14 days after conception to find treatments for serious diseases and for fertility research, but the law does not permit the use of human embryos for most other types of research. On this card is a list of options. Which, if any, most closely describes your view about the use of human embryos in medical research? *The use of human embryos is always acceptable for all types of medical research, The use of human embryos for medical research is only acceptable to find treatments for serious diseases and for fertility research, but not for most other types of research, The use of human embryos for medical research is never acceptable. None, Don't know.* [Additional version 1 information- Sometimes embryos left over from infertility treatment are donated by women and their partners for medical research; The cluster of cells shown in picture A is a human embryo up to 14 days after conception, picture B shows its actual size.

From what you have heard about cloning, on balance, which of these statements, if any, most closely reflects your own opinion? *Benefits far outweigh risks, Benefits slightly outweigh risks, about the same, risks slightly outweigh benefits, risks far outweigh benefits, none, Don't know*

On the whole how would you describe your feelings about the following issues... Cloning *Very good thing, fairly good thing, neither good nor bad thing, fairly bad thing, very bad thing, Don't know*

Reproductive genetic technology will inevitably lead to genetic enhancement and designer

babies? *Strongly agree, agree, disagree, strongly disagree, Don't know*

Suffering is part of what makes us human? *Strongly agree, agree, disagree, strongly disagree, Don't know*

Reproductive Genetic technology is potentially the next step in human evolution? *Strongly agree, agree, disagree, strongly disagree, Don't know*

The ability to control human reproduction will lead to treating children like products? *Strongly agree, agree, disagree, strongly disagree, Don't know*

We ought to let people decide for themselves when it is appropriate to use reproductive genetic technologies because the consequences are so personal? *Strongly agree, agree, disagree, strongly disagree, Don't know*

On this card is a list of various scientific developments. Which two or three would you say have been beneficial for society as far as you are aware? And which two or three would you say have not been beneficial for society? *Cloning/Dolly the sheep, Computers/the internet/email, Cures for or eradication of illnesses/diseases, Genetic modification/engineering of animals and plants, Genetically modified food, Genetic testing or screening for particular things (eg. Diseases), Discovering global warming/climate change/disruption to weather patterns/greenhouse effect, Faster/cheaper travel, Medicines/new drugs/penicillin/antibiotics/vaccines etc, New and alternative sources of energy, New operations/surgery, New telecommunications (fax machine/mobile phone/TV), Robots in industry and medicine, Space research/sending people to the moon, Splitting the atom, Test-tube babies/in-vitro fertilisation, Transplants (eg. Of the heart, liver, kidneys etc), Brain science/neuroscience, Designer babies, Energy/electricity, Mobile phones, Nanotechnology/miniaturisation, New vaccinations for children (MMR, five in one), Nuclear power, Radioactive waste, The use of animals in medical research, Other, None spring to mind, Don't know*

You might have heard of something called human cloning. One type of cloning would be if a person's genes were copied exactly and used to make an embryo. Cells from the embryo could be used to supply the person with tissues or organs that would be a perfect match for them, meaning their body would not reject them. Do you think this should be allowed or not allowed if a person needs an organ transplant? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed*

You might have heard of something called human cloning. One type of cloning would be if a person's genes were copied exactly and used to make an embryo. Cells from the embryo could be used to supply the person with tissues or organs that would be a perfect match for them, meaning their body would not reject them. Do you think this should be allowed or not allowed if a person needs treatment for Parkinson's? *Definitely allowed,*

*Probably allowed, Probably not allowed, Definitely not allowed*

You might have heard of something called human cloning. One type of cloning would be if a person's genes were copied exactly and used to make an embryo. Cells from the embryo could be used to supply the person with tissues or organs that would be a perfect match for them, meaning their body would not reject them. Do you think this should be allowed or not allowed if a person is generally in good health and wants to live longer?

*Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed*

Another type of human cloning might be used to treat a young couple who are infertile and cannot have a child. Suppose that the genes from one of them were copied exactly and used to make an embryo with exactly the same genetic make up as that parent. Do you think this should be allowed or not allowed for a young couple who are infertile and cannot have a child? *Definitely allowed, Probably allowed, Probably not allowed, Definitely not allowed*

I am going to read a list of areas in which new technologies are currently developing. For each of these areas, do you think it will improve our way of life in the next twenty years, it will have no effect, or it will make things worse? *Improve our way of life, have no effect, make things worse, Don't know.* Stem cell research

### **Storage and Use of Human Genetic Information (75)**

In your opinion, if someone is a carrier of a defective gene or has a genetic disease, does anyone else, besides that person, deserve to know this information? *Yes, No, Don't Know*

If someone is a carrier of a defective gene or has a genetic disease, who else, besides that person deserves to know that information?... Employer deserves to know? *Yes, No, Don't Know*

If someone is a carrier of a defective gene or has a genetic disease, who else, besides that person deserves to know that information?...Insurer deserves to know? *Yes, No, Don't Know*

If someone is a carrier of a defective gene or has a genetic disease, who else, besides that person deserves to know that information?... Spouse or fiancé deserves to know? *Yes, No, Don't Know*

If someone is a carrier of a defective gene or has a genetic disease, who else, besides that person deserves to know that information?... Other immediate family deserves to know? *Yes, No, Don't Know*

I am now going to read out a number of different items. For each, please tell me *whether or*

*not you think this is a way in which human genetic information could be used?* Improvement in the diagnosis of diseases; Developing targeted drugs for people; For setting the level of insurance premiums; Developing techniques to correct defective genes for individuals; Developing techniques to correct defective genes for future generations; Understanding why people are more or less likely to develop diseases; Research into biological and chemical warfare; Assessing health damage and risk from chemicals and radiation; Studying evolution, ancestry and population; Identifying offenders or eliminating possible offenders from Police enquiries; using DNA found at the crime scene; Establishing paternity and other family relationships; Parents choosing physical and mental characteristics of their children

And would you say this is a *way in which human genetic information should be used?* Improvement in the diagnosis of diseases; Developing targeted drugs for people; For setting the level of insurance premiums; Developing techniques to correct defective genes for individuals; Developing techniques to correct defective genes for future generations; Understanding why people are more or less likely to develop diseases; Research into biological and chemical warfare; Assessing health damage and risk from chemicals and radiation; Studying evolution, ancestry and population; Identifying offenders or eliminating possible offenders from Police enquiries; using DNA found at the crime scene; Establishing paternity and other family relationships; Parents choosing physical and mental characteristics of their children

If you had to choose, which comes closest to your preference...a complete ban on all research into human cloning without exception, a ban on human cloning of full-grown humans, while still allowing research on cloned embryos, to learn more about certain diseases, or oppose any law that restricts research into human cloning? *A complete ban on all research into human cloning without exception, A ban on human cloning of full-grown humans while still allowing research on cloned embryos to learn more about certain diseases, Oppose any law that restricts research into human cloning, Don't Know*

What about reactions from other people that you know? How often do you think other people would treat you differently if they knew about your genetic testing results--*almost always, more than half the time, about half the time, less than half the time, or almost never? Don't Know*

Do you think it is possible to prevent discrimination from genetic testing results? *Yes possible, No not possible, Don't Know*

Which of the following scientific research projects are *Worthwhile, Of no particular interest, Or too risky, (Don't Know)?* To collect together by computer the greatest possible amount of information on each person in (country) so that it is possible, if it is needed, to all that can

be required on each person?

How likely or unlikely do you think it is within the next 25 years that genetic information will be used to judge a person's suitability for getting ... health or life insurance? *Very likely, quite likely, not very likely, not at all likely, Don't Know*

How likely or unlikely do you think it is within the next 25 years that genetic information will be used to judge a person's suitability for getting ... A job they've applied for? *Very likely, quite likely, not very likely, not at all likely, Don't Know*

How likely or unlikely do you think it is within the next 25 years that genetic information will be used to judge a person's suitability for getting ... Credit at the bank? *Very likely, quite likely, not very likely, not at all likely, Don't Know*

People can take genetic tests to tell them whether they are likely to develop a serious genetic condition in the future. In your opinion, should such tests be used by insurance companies to accept or refuse people for life insurance policies? *Definitely should, Probably should, Probably should not, Definitely should not, Other answer, Don't Know*

People can take genetic tests to tell them whether they are likely to develop a serious genetic condition in the future. In your opinion, should such tests be used by insurance companies in deciding how much to charge people for their life insurance policies? *Definitely should, Probably should, Probably should not, Definitely should not, Other answer, Don't Know*

People can take genetic tests to tell them whether they are likely to develop a serious genetic condition in the future. Now suppose someone who is applying for a job has had such a genetic test. Should the employer have the right to see the result of this test, or not? *Definitely should, Probably should, Probably should not, Definitely should not, Other answer, Don't Know*

People can take genetic tests to tell them whether they are likely to develop a serious genetic condition in the future. Now suppose the applicant has never had such a test. Should the employer have the right to make the applicant have a test? *Definitely should, Probably should, Probably should not, Definitely should not, Other answer, Don't Know*

And what about an existing employee who has had such a test which shows that they are at risk of developing a serious genetic condition. Should the employer have the right to take the test result into account when the chance of promotion comes up? *Definitely should, Probably should, Probably should not, Definitely should not, Other, (Don't Know)*

Should employers have the right not to hire workers if tests show they have an inherited

tendency to develop certain forms of cancer or heart disease [\*serious disease], or should they not have the right? *Employers should have the right, employers should not have the right, (Don't Know)*

Suppose workers will be exposed to some cancer-causing materials on the job. In that case, should employers have the right not to hire workers whose tests show they have an inherited tendency to develop certain forms of cancer, or should they be required to clean up the workplace so it is safe for everyone? *Employers should have the right, employers should clean up, (Don't Know)*

Suppose a genetic screening test for certain forms of heart disease is made available by an employer to workers who want to take it. Who do you think should have control over access to the test results - the worker or the employer? *Employer should control access, worker should control access, both, (Don't Know)*

People can take genetic tests to tell them whether they are likely to develop a serious genetic condition in the future. And should the employer have the right to make applicants have a test to see if they are particularly sensitive to chemicals that may be used in the workplace? *Definitely should, Probably should, Probably should not, Definitely should not, Other answer, Don't Know*

Samples of genetic information can be taken from people and the results kept in a database. Would you be in favour of, or against, setting up such a database if it was... used to improve our understanding of illness and disease? *Strongly in favour, In favour, Neither in favour or against, Against, Strongly against, (Don't Know)*

Samples of genetic information can be taken from people and the results kept in a database. Would you be in favour of, or against, setting up such a database if it was... used to identify people who have committed serious crimes? *Strongly in favour, In favour, Neither in favour or against, Against, Strongly against, (Don't Know)*

Samples of genetic information can be taken from people and the results kept in a database. Would you be in favour of, or against, setting up such a database if it was... used by researchers to find out more about where people's ancestors originally came from? *Strongly in favour, In favour, Neither in favour or against, Against, Strongly against, (Don't Know)*

Samples of genetic information can be taken from people and the results kept in a database. Would you be in favour of, or against, setting up such a database if it was... used to judge a person's suitability for getting health and life insurance? *Strongly in favour, In favour, Neither in favour or against, Against, Strongly against, (Don't Know)*

Samples of genetic information can be taken from people and the results kept in a

database. Would you be in favour of, or against, setting up such a database if it was... used to judge a person's suitability for getting a job they've applied for? *Strongly in favour, In favour, Neither in favour or against, Against, Strongly against, (Don't Know)*

The results of a genetic test to see if employees may become a risk to colleagues or members of the public they come into contact with in their job *appropriate, inappropriate*

The results of a genetic test to see if employees are likely to become prone to an inherited disease or disability *appropriate, inappropriate*

The results of a genetic test that indicates that they may be sensitive to certain substances that they will come in to contact with in their job *appropriate, inappropriate*

The results of a genetic test to see if potential employees may be become a risk to colleagues or members of the public they come into contact with in their job *appropriate, inappropriate*

The results of a genetic test to see if potential employees are likely to become prone to an inherited disease or disability *appropriate, inappropriate*

'insurance companies should be able to ask to see the results of genetic tests to assess whether premiums should go up or down' *Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Please tell me whether you think it is *appropriate or inappropriate* for an insurance company to know the results from a genetic test that an individual has already undertaken (for example, risk of Huntington's disease or a rare cancer) when considering an application for each of the following policies? *Life insurance, Health insurance, Motor insurance, Pensions, Long term care insurance, Home contents insurance, Travel insurance*

Please tell me whether you think it is *appropriate or inappropriate* for the Police to take DNA samples from people charged with...? *Drink-driving, Shoplifting, Murder, Sexual offences, Fraud, Burglary*

If an individual is charged with a crime, his/her DNA sample is placed on a Police genetic database. If they are later acquitted of the crime (i.e. not brought to trial or not found guilty), should the DNA sample be kept or removed from the Police genetic database? *Kept on database, Removed from database, Don't know*

Police should have access to other genetic databases e.g. medical databases so they can cross check information *appropriate, inappropriate?*

Other researchers should have access to the Police's genetic database for other purposes



e.g. Social research *appropriate, inappropriate?*

Information should only be included in the database where an individual has given consent  
*Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Fresh consent from an individual should be required before new research is conducted on their existing samples  
*Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

Commercial organisations should have access to human genetic information only if individuals can't be identified  
*Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

These genetic databases should be publicly owned  
*Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

These genetic databases should be commercially owned  
*Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

If you had genetic testing conducted, how concerned would you be about keeping the results private--*very concerned, somewhat concerned, not too concerned, or not at all concerned? Don't Know*

*For each one, please tell me whether you think it is likely or unlikely to happen within the next 20 years, (Don't Know).* Allowing insurance companies to ask for a genetic test before they set a person's premium

I would support the government agency dealing with social security and pensions having access to a person's genetic information?  
*Tend to agree, Tend to disagree, (Don't Know)*

I would support private insurance companies having access to a person's genetic information?  
*Tend to agree, Tend to disagree, (Don't Know)*

I would support the police having access to people's genetic information to help solve crimes?  
*Tend to agree, Tend to disagree, (Don't Know)*

I would support doctors and surgeons having access to a patient's genetic information?  
*Tend to agree, Tend to disagree, (Don't Know)*

I would support the police having access to everybody's genetic information to help solve crimes  
*Agree, disagree, (Don't Know)*

I am worried that the results of gene tests can be used for other scientific purposes

without informing the person in question *Not at all worried, a bit worried, somewhat worried, very worried, can't say*

I am worried that the results could get into outsider's hands *Not at all worried, a bit worried, somewhat worried, very worried, can't say*

If others have access to your genetic information they will know too much about you  
*Strongly agree, Tend to agree, Neither agree nor disagree, Tend to disagree, Strongly disagree, No opinion*

If commercial organisations have invested large amounts of time and money to develop a new way to use human genetic information, they should own the developments and be able to charge for its use, If commercial organisations have invested large amounts of time and money to develop a new way to use human genetic information, the information should be publicly owned and available to all for use at no charge, (Don't know)

If publicly funded research organisations have invested large amounts of time and money to develop a new way to use human genetic information, they should own the developments and be able to charge for its use, If publicly funded research organisations have invested large amounts of time and money to develop a new way to use human genetic information, the information should be publicly owned and available to all for use at no charge, (Don't know)

If you had such a genetic test, how concerned would you be that organisations would want to know the state of your health, such as health and life insurance companies, or employers might require you to provide them with the test results, so that they could decide whether to insure or hire you? *Very concerned, somewhat/fairly concerned, not very/somewhat concerned, not at all concerned, Don't Know*

Some people think that genetic testing could lead to new forms of discrimination by employers, life insurance, or health insurance companies who might use the results to deny people jobs or insurance coverage....How often do you think employers would deny people jobs because of genetic testing results--*almost always, more than half the time, about half the time, less than half the time, or almost never? Don't Know*

(Some people think that genetic testing could lead to new forms of discrimination by employers, life insurance, or health insurance companies who might use the results to deny people jobs or insurance coverage.)...How often do you think life insurance companies would deny people coverage because of genetic testing results--*almost always, more than half the time, about half the time, less than half the time, or almost never? Don't Know*

(Some people think that genetic testing could lead to new forms of discrimination by employers, life insurance, or health insurance companies who might use the results to deny

people jobs or insurance coverage.)...How often do you think health insurance companies would deny people coverage because of genetic testing results--*almost always, more than half the time, about half the time, less than half the time, or almost never? Don't Know*

Some people think that genetic testing could lead to new forms of discrimination by employers or health insurance companies who might use the results to deny people jobs or health insurance coverage. How likely do you think employers are to deny people jobs because of genetic testing results--*very likely, somewhat likely, not very likely, or not at all likely? Don't Know*

How likely do you think health insurance companies are to deny people coverage because of genetic testing results--*very likely, somewhat likely, not very likely, or not at all likely? Don't Know*

As you may know, newly developed tests into the genetic makeup of individuals can determine their chances of contracting a variety of diseases.... Do you think that medical insurance companies should or should not have access to this information in deciding about health care coverage for individuals? *Should, Should not, Don't Know*

(As you may know, newly developed tests into the genetic makeup of individuals can determine their chances of contracting a variety of diseases.)... Do you think that employers should or should not have access to this information in deciding whether or not to hire someone? *Should, Should not, Don't Know*

Genetic testing may make possible the early detection of inherited diseases, such as heart disease and cancer, prior to the appearance of any symptoms. Do you favor or oppose allowing insurance companies and employers to have access to the results of these types of exams? *Favor allowing access, Oppose allowing access, Don't Know*

Should employers be able to use such tests (that can predict whether individuals will develop genetically based major diseases) to identify persons who would be at special risk in handling chemicals or other materials at the workplace, or not? *Yes, No, DK*

If such genetic tests are carried out, and a person otherwise qualified for the job is found to be highly susceptible to substances he or she would work around, what do you think the company should do--not hire that person, or inform the person of the risks and let him or her decide whether to take the job? *Not hire person, Inform of risks, let person decide, Don't Know*

Would you want your doctor to have information about your genetic code, or wouldn't you? *Yes, No wouldn't, Don't Know*

Would you want your health insurance company to have information about your genetic

code, or wouldn't you? *Yes, No wouldn't, Don't Know*

Would you want the government to have information about your genetic code, or wouldn't you? *Yes, No wouldn't, Don't Know*

Later this month, scientists are expected to announce that they have completed a genetic blueprint of the human body. Some are hopeful that this will help to detect and combat illnesses. Others are concerned that this could violate privacy rights because information about people's health problems may be used against them. Does this concern you, or not? (If yes, ask:) How much does this concern you--a great deal, a fair amount, just some, or very little? *Yes concerns a great deal, Yes concerns a fair amount, Yes concerns just some, Yes concerns very little, No does not concern, Don't Know*

If a genetic test shows that a person has an increased risk for a genetic disease, does the person's employer have a right to know? *Yes, No, Don't know*

If a genetic test shows that a person has an increased risk for a genetic disease, does the person's insurer have a right to know? *Yes, No, Don't know*

If a genetic test shows that a person has an increased risk for a genetic disease, does the person's family have a right to know? *Yes, No, Don't know*

If a genetic test shows that a person has an increased risk for a genetic disease, does the person's spouse have a right to know? *Yes, No, Don't know*

### **Trust (35)**

You can trust the knowledge of the genetic engineering experts; most of the time it turns out that they are right. *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

Please tell which, if any, you trust to use the human genetic information held on medical databases responsibly? *GP/Family Doctor, National Health Service (NHS), Police, An Expert Government Scientific Advisory committee, Academic scientists, An advisory body to the Government, composed of people representing different viewpoints, Health and Pharmaceutical companies, Medical charities, People tracing a family tree, Government, Patients groups, Industrial scientists, Insurance companies, Employers, Consumer groups, General public, Other, None of these, (Don't know)*

Which, if any, of the things on this card do you personally feel would give you trust in a system of controls and regulations on how human genetic information is stored and used? Please mention up to five. *That rules are made independently or partly politics, Having a system*

*which can be seen to be fair and open, Having a system that monitors developments and uses and is prepared to restrict them if there are well-founded concerns, Having random spot checks of all regulated activities, Having people making decisions who are either independent or declare their interests, Monitoring of social/ethical implications, Having a wide range of people with different expertise and interests involved, Asking the public for their views, Legally enforceable rules, Voluntary code of practice, Other, None of these, Don't know*

How much, if any, confidence do you have that rules and regulations are keeping pace with biological developments and research? *A great deal, A fair amount, A little, None at all, Don't know/not stated*

Those in charge of new developments in genetic science cannot be trusted to act in society's interests. *Agree strongly, Agree, Neither agree nor disagree, Disagree, Disagree strongly, (Don't Know)*

How much trust do you have in each of the following to tell the truth about any dangers of research into human genes? *A lot of trust, some trust, very little trust, No trust at all, (Don't Know)* Journalists on national newspapers

How much trust do you have in each of the following to tell the truth about any dangers of research into human genes? *A lot of trust, some trust, very little trust, No trust at all, (Don't Know)* Government health ministers

How much trust do you have in each of the following to tell the truth about any dangers of research into human genes? *A lot of trust, some trust, very little trust, No trust at all, (Don't Know)* Scientists in universities

How much trust do you have in each of the following to tell the truth about any dangers of research into human genes? *A lot of trust, some trust, very little trust, No trust at all, (Don't Know)* Government scientists

How much trust do you have in each of the following to tell the truth about any dangers of research into human genes? *A lot of trust, some trust, very little trust, No trust at all, (Don't Know)* Scientists working for drug or pharmaceutical companies

How much trust do you have in each of the following to tell the truth about any dangers of research into human genes? *A lot of trust, some trust, very little trust, No trust at all, (Don't Know)* Scientists working for health research charities

Would you have *a lot of trust, some trust, or no trust* in a statement made by the American Medical Association about biotechnology?

Would you have *a lot of trust, some trust, or no trust* in a statement made by the Food and Drug Administration about biotechnology?

Would you have *a lot of trust, some trust, or no trust* in a statement made by scientists from a university in your own state about biotechnology?

Would you have *a lot of trust, some trust, or no trust* in a statement made by food manufacturers about biotechnology?

Would you have *a lot of trust, some trust, or no trust* in a statement made by the National Institutes of health about biotechnology?

Would you have *a lot of trust, some trust, or no trust* in a statement made by reporters on a television news show like 60 minutes about biotechnology?

Which one of these two statements comes closest to your views? *Scientists should be trusted to decide for themselves what genetic research to do, There should be an independent 'watchdog' to keep an eye on the research that scientists are doing into human genes, (Don't Know)*

(For each of the following, please tell me how much confidence you have in this group to protect people from the misuse of genetic information.)... The Genetic Counselors who provide the testing... *Very confident, Somewhat confident, Not very confident, Not at all confident, Don't Know*

As far as the people running these institutions [medical advances] are concerned, would you say you have... *A great deal of confidence, only some confidence, or hardly any confidence at all in them, (Don't Know)?* Medicine

Let me read you a short list of news sources that might include some information about 'heart disease/losing weight', and, for each one, I would like you to tell me if you have a *high level of confidence in information from that source, a moderate level of confidence, or a low level of confidence, Don't Know* From a story in you local newspaper?

Let me read you a short list of news sources that might include some information about 'heart disease/losing weight', and, for each one, I would like you to tell me if you have a *high level of confidence in information from that source, a moderate level of confidence, or a low level of confidence, Don't Know* An article in *Time* or *Newsweek*?

Let me read you a short list of news sources that might include some information about 'heart disease/losing weight', and, for each one, I would like you to tell me if you have a *high level of confidence in information from that source, a moderate level of confidence, or a low level of confidence, Don't Know* A story in the evening news?

Let me read you a short list of news sources that might include some information about 'heart disease/losing weight', and, for each one, I would like you to tell me if you have a *high level of confidence in information from that source, a moderate level of confidence, or a low level of confidence, Don't Know* A television talk show, like the *Oprah Winfrey Show*, or *Phil Donahue Show*?

Let me read you a short list of news sources that might include some information about 'heart disease/losing weight', and, for each one, I would like you to tell me if you have a *high level of confidence in information from that source, a moderate level of confidence, or a low level of confidence, Don't Know* A conversation with your physician?

Let me read you a short list of news sources that might include some information about 'heart disease/losing weight', and, for each one, I would like you to tell me if you have a *high level of confidence in information from that source, a moderate level of confidence, or a low level of confidence, Don't Know* An article by a scientist?

Let me read you a short list of news sources that might include some information about 'heart disease/losing weight', and, for each one, I would like you to tell me if you have a *high level of confidence in information from that source, a moderate level of confidence, or a low level of confidence, Don't Know* A report from the National Institutes of Health?

How much trust do you have in the current rules and regulations governing animal experimentation? Would you say that you have *A great deal of trust, a fair amount, not very much, no trust at all, Don't know*. Why do you say that?

Which if any of the following types of people or institutions would you trust to provide you with honest and balanced information about animal experimentation? *Animal welfare groups; Vets; Advisory body; The Medical Research Council; Charities researching diseases (heart disease, cancer); An advisory body to Government, composed of people representing different viewpoints; An advisory body to Government, composed of experts; Environmental groups; Doctors/pharmacists/chemists; Teachers/universities; Scientists; Anti-vivisection campaign groups; GPs/Family doctors; Religious organisations; The general public; Consumer groups; Celebrities/well known personalities; The media; Patients; Governments; Industry/manufacturers/pharmaceutical companies; None; Don't know.*

Which, if any of the following types of people or institutions would you not trust to provide you with honest and balanced information about animal experimentation? *Animal welfare groups; Vets; Advisory body; The Medical Research Council; Charities researching diseases (heart disease, cancer); An advisory body to Government, composed of people representing different viewpoints; An advisory body to Government, composed of experts; Environmental groups; Doctors/pharmacists/chemists; Teachers/universities; Scientists; Anti-vivisection campaign groups; GPs/Family doctors; Religious organisations; The general public; Consumer groups; Celebrities/well known personalities; The media;*

*Patients; Governments; Industry/manufacturers/pharmaceutical companies; None; Don't know*

I have a lack of trust in the regulatory system about animal experimentation? *Agree, disagree, Don't know*

I trust the inspectors of animal facilities to bring to light any misconduct that may be occurring at animal research institutes? *Agree, disagree, Don't know*

Now I would like to know which of the following sources of information you have confidence in, to tell you the truth about [\*biotechnology] and genetic engineering? Consumer organisations. Environment organisations. Animal Welfare organisations. Political organisations. Trade unions. Religious organisations. Public authorities. Industry. School or university. Don't Know)

Genetic scientists only tend to tell us what the people paying their wages want us to hear. *Agree strongly, Agree, Neither agree nor disagree, Disagree, Disagree strongly, (Don't Know)*

How much do you trust business leaders within the nanotechnology industry to minimize potential risks [of nanotechnology] to humans? *Do you trust them a lot, some or not that much, Don't know?*

## **Regulation (91)**

The government has the same opinion as me about genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government is doing a good job with regard to genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government is competent enough to deal with genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government has the necessary skilled people to carry out its job with regard to genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Newspapers and magazines reporting on biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Industry developing new products with biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Ethics committee looking at the moral aspects of biotechnology? *Do you think they are doing*



*a good job for society, or not doing a good job for society, (Don't Know)?*

Consumer organisations checking products of biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Environmental groups campaigning against biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Our Government making regulations on biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

University scientists doing research in biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Scientists in industry doing research in biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Organisations of patients or their relatives looking after patients interests? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

The European commission making laws on biotechnology for all European union countries? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Medical doctors keeping an eye on the health implications of biotechnology? *Do you think they are doing a good job for society, or not doing a good job for society, (Don't Know)?*

Is it possible at all to control genetic engineering by law? *Would you say... yes certainly, rather yes, rather no, or not at all, don't know/no statement*

There should be clear ethical rules indicating when biotechnology and genetic engineering may not in any way be applied to human beings? *definitely agree, tend to agree, tend to disagree or definitely disagree, (Don't Know)*

There should be clear ethical rules indicating when biotechnology and genetic engineering may not in any way be applied to animals. *definitely agree, tend to agree, tend to disagree or definitely disagree, (Don't Know)*

There should be clear ethical rules indicating when biotechnology and genetic engineering may not in any way be applied to plants. *definitely agree, tend to agree, tend to disagree or definitely disagree, (Don't Know)*

(I'd like your opinion of some programs and proposals being discussed in this country

today. Please tell me if you *strongly favor, favor, oppose, or strongly oppose each one, Don't Know*)...  
Restricting scientific research on human cloning

I'm going to mention several issues, and I'd like to get your reaction. For each item I read, please tell me whether this is something you *strongly favor, somewhat favor, somewhat oppose, or strongly oppose, Don't Know*)... Banning medical research on human cloning

Which is closest to your view on government regulation of cloning? The government should ban all human cloning forever. *The government should take a wait and see attitude, banning it for now, but being open to later change. The government should allow research on cloning to continue without restriction, Don't Know*

Do you think the government should or should not regulate...the use of genetic testing to pick traits in unborn children? *Should regulate, Should not regulate, Don't Know*

Would you favor or oppose a law that bans using embryonic stem cells to clone a human being but allows them to be used for the pursuit of cures for diabetes, paralysis, Parkinson's and other diseases? (If Favor/Oppose, ask:) Would you strongly favor/oppose or somewhat favor/oppose this law? *Strongly favour, Somewhat favour, Somewhat oppose, Strongly oppose, Don't Know*

Modern genetic science is so complex that public involvement in policy is a waste of time *Agree strongly, Agree, Neither agree nor disagree, Disagree, Disagree strongly, (Don't Know)*

I would like to be personally consulted in policy making decisions about genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Rules set by government will keep us safe from any risks linked to modern genetic science. *Agree strongly, Agree, Neither agree nor disagree, Disagree, Disagree strongly, (Don't Know)*

Current regulations about therapeutic cloning are sufficient to protect people from any risks involved? *Tend to agree, or Tend to disagree*

I feel that current rules and regulations in the UK are sufficient to control genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Organisations separate from government are needed to regulate genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Organisations separate from industry are needed to regulate genetic testing *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

I feel confident that the British government adequately regulates genetic testing *Strongly*

*agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Consumer rights organisations (e.g. Consumers' Association) *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Pharmaceutical industry *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? The general public *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Environmental organisations *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Scientists working for Government *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Local authorities *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Local communities *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Insurance companies *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Scientists working for the pharmaceutical industry *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? The national government *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making

decisions about genetic testing? The European Union (EU) *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Scientists working for environmental groups *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Scientists working for Universities *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

How much do you agree or disagree that the following should be involved in making decisions about genetic testing? Doctors *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government distorts facts in its favour regarding genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government changes policies regarding genetic testing without good reasons. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government is too influenced by the pharmaceutical industry regarding genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government is acting in the public interest with regard to genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government listens to concerns about genetic testing raised by the public. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government has the same ideas as me about genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government listens to what ordinary people think about genetic testing. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

I feel that the way the government makes decisions about genetic testing is fair. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

The government provides all relevant information about genetic testing to the public. *Strongly agree, tend to agree, neither, tend to disagree, strongly disagree, (Don't Know)*

Genetic testing should be controlled by the state. *agree or disagree*

Do you think the existing laws in Germany for the control of genetic engineering are...*absolutely sufficient, rather sufficient, rather not sufficient, not sufficient at all, don't know/no statement*

Do you think that the current [\*genetic engineering] laws are...*controlled strict enough, not controlled strictly enough, don't know/no statement*

Current regulations are sufficient to protect people from any risks linked to modern biotechnology. *tend to agree or to disagree*

The regulation of modern biotechnology should be left mainly to industry. *tend to agree or to disagree*

Religious organisations need to have their say in how modern biotechnology is regulated. *tend to agree or to disagree*

Which one of the following bodies do you think is best placed to regulate modern biotechnology? 1. *International organisations such as the United Nations (UN), the World Health organisation (WHO)* 2. *Public bodies in (OUR COUNTRY)* 3. *Ethics committees* 4. *Our national Parliament* 5. *The European Union, public bodies in the European Union* 6. *Scientific organisations* 7. *None of these (SPONTANEOUS) (Don't Know)*

The potential danger from genetically altered cells and microbes is so great that strict regulations are necessary? *Agree strongly, agree somewhat, disagree somewhat, disagree strongly*

Please say which of these two statements comes closest to your view. *If a company paid to discover a human gene, it should be allowed to patent or copyright it to make a profit from it. Human genes are part of everyone and not something that should be patented or copyrighted. Don't Know*

If a private company is the first to complete the genetic code, do you think that company should be able to patent its research results for commercial use, or don't you think so? *Yes should be able to patent, No don't think so, Don't Know*

Which one of these two statements comes closest to your views? *Only with freedom from government controls will genetic scientists make important new discoveries, Government controls are needed to watch out for new discoveries that could hold serious dangers for the future, (Don't Know)*

*Do you agree strongly, agree somewhat, disagree somewhat, or disagree strongly with the statement that the government should be involved in regulating who has access to information from tests about a person's defective genes and genetic diseases?*

Do you believe that new types of genetic testing should be stopped until these types of privacy issues (as to whom should get the information from tests about a person's

defective genes and genetic disease) are settled, or not? *Yes, No, Don't Know*

Do you think the government should regulate the quality of genetic engineering, or not? *Yes, No, Don't Know*

Do you think the government should have regulations to limit the cloning of humans, or not? *Yes, No, Don't Know*

Do you think the government's regulations to limit the cloning of humans should be more or less strict than they are now, or are they about right? *Should be more strict, About right, Should be less strict, Should not regulate at all, Don't Know*

Do you think the government should regulate the quality and safety of genetic testing, or not? *Yes, No, Don't Know*

Do you think the government's genetic testing regulations should be more or less strict than they are now, or are they about right? *Should be more strict, About right, Should be less strict, Should not regulate at all, Don't Know*

(I am going to read you a list of some programs and proposals that are being discussed in this country today. For each one, please tell me whether you strongly favor, favor, oppose, or strongly oppose it.)...Allowing unrestricted scientific research related to human cloning *Strongly favour, Favor, Strongly oppose, Oppose, Don't Know*

(Which one of the following has had the biggest influence on your thinking on this issue--a personal experience, the views of your friends and family, what you have seen or read in the media, your religious beliefs, your education, or something else?)...Allowing unrestricted scientific research related to human cloning *Personal experience, Friends/Family views, Media, Religious belief, Education, Something else, Don't Know*

What should be done to avoid such problems [mad cow disease] happening again in the future? Scientists should keep us better informed about the risks of some scientific and technological developments? *Tend to agree, or Tend to disagree, (Don't Know)*.

What should be done to avoid such problems [mad cow disease] happening again in the future? Scientists should communicate their scientific knowledge better? *Tend to agree, or Tend to disagree, (Don't Know)*.

What should be done to avoid such problems [mad cow disease] happening again in the future? Industry should be better regulated? *Tend to agree, or Tend to disagree, (Don't Know)*.

What should be done to avoid such problems [mad cow disease] happening again in the future? Politicians should rely more on the advice of scientists? *Tend to agree, or Tend to*

*disagree, (Don't Know)*

Since genetic engineering experts are not elected democratically they shouldn't influence political decisions concerning genetic engineering. *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

Their special knowledge gives the genetic engineering experts the right to influence political decisions. *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

Experts always have the well being of the general public when they develop the genetic engineering. *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

Genetic engineering experts care about the public opinion of their work. *I totally agree, I would rather agree, I would partly agree, I would rather disagree, I don't agree at all, I am not determined yet, I don't care about it, I don't know/no statement*

I am concerned about unregulated reproductive genetic technology getting out of control? *Strongly agree, agree, disagree, strongly disagree, Don't know*

I am concerned about government regulators invading private reproductive decisions? *Strongly agree, agree, disagree, strongly disagree, Don't know*

The government should regulate PGD based on ethics and morality? *Strongly agree, agree, disagree, strongly disagree, Don't know*

The government should regulate prenatal testing based on ethics and morality? *Strongly agree, agree, disagree, strongly disagree, Don't know*

The government should regulate PGD based on quality and safety? *Strongly agree, agree, disagree, strongly disagree, Don't know*

The government should regulate prenatal testing based on quality and safety? *Strongly agree, agree, disagree, strongly disagree, Don't know*

On a scale of 1-5, where 1 is not at all confident and 5 is extremely confident, where the mid point 3 is moderately confident, how confident would you say you are in the safety and regulatory approval systems governing nanotechnology? *[1-5], Don't know*

In terms of the scientists who are involved in research of these technologies, on a scale of 1-5, where 1 is not at all confident and 5 is extremely confident, where the mid point 3 is

moderately confident, how confident would you say you are that nanotechnology is in safe hands? [1-5], *Don't know*

### **Miscellaneous Health and Related (30)**

Science and technology are making our lives healthier, easier and more comfortable? *Strongly agree, agree slightly, neither, disagree slightly, disagree strongly, don't know*

Scientific research can be directed towards solving all kinds of different problems. Supposing it was you who had to decide how much of the available money for research should go to tackling the following problems. When deciding how the money should be spent, which do you think should be given priorities? (and which should have the money limited, or even reduced?). . . . , *Pharmaceutical and medical research, . . . , Prevention and cure of drug addiction, (Don't Know)*

Generally speaking, do you find that these men of science, who you have seen on TV, are rather impressive, or a little disappointing? *Rather impressive, Some impressive some disappointing, A little disappointing*

(Medical risks). The risk that some new medical or pharmaceutical discoveries may severely affect the human personality? *Yes – really concerns, No – not really a concern, (Don't Know)*

Is it true or not, if we don't develop our research into organ transplants we will limit our chances of improving the lives of people severely handicapped by accident, injury or by illness? *True, False, (Don't Know)*

Is it a serious problem or not that, if we don't develop our research into organ transplants we will limit our chances of improving the lives of people severely handicapped by accident, injury or by illness? *Very serious, Quite serious, Not very serious, Not at all serious, (Don't Know)*

Is it true or not that, if we give up experiments and research on the transmission of hereditary characteristics, we will restrict our chances of improving the qualities of living species? *True, False, (Don't Know)*

Is it a serious problem or not that, if we give up experiments and research on the transmission of hereditary characteristics, we will restrict our chances of improving the qualities of living species? *Very serious, Quite serious, Not very serious, Not at all serious, (Don't Know)*



Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? Do not smoke

Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? Moderate your consumption of alcoholic drinks

Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? Avoid excessive exposure to the sun

Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? Eat fresh fruits and vegetables regularly

Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? Avoid being overweight

Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? Eat frequently cereals with high fiber content

Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? See a doctor in case of a lump, change in a mole or abnormal bleeding

Could you tell me for each of the recommendations I am going to mention if it is *Very important, Fairly important, or Not important in reducing the risks of cancer, (Don't Know)*? See a doctor in case of persistent problems, such as a persistent cough, a persistent hoarseness, a change in bowel habits, or an unexplained weight loss

Only for women: Here are two pieces of advice for women, for each of them please tell me if it is *Very important, Fairly important, or Not important at all, (Don't Know)* in lessening the risks of cancer. 1. Have a cervical smear regularly? 2. Check your breasts regularly?

For each of the following sectors, how important or unimportant do you feel it is that research should be carried out in that sector? *Very important, Fairly important, Not very important, Not at all important, (Don't Know)* ... Health ...

Importance of the European Community in health research? *Very important, fairly important,*

*not very important, nor at all important, (Don't Know).*

Scientific and technological progress will help to cure illnesses such as AIDS, cancer...?  
*Strongly agree, Agree, Neither, Disagree, Strongly disagree*

Science will solve our social problems like crime and mental illness. *Agree, disagree, (Don't Know)*

There has been much discussion about responsibilities in relation to the mad cow disease problem. Scientists carry a major part of responsibility for the problem? *Tend to agree, or Tend to disagree, (Don't Know)*

There has been much discussion about responsibilities in relation to the mad cow disease problem. Politicians carry a major part of responsibility for the problem? *Tend to agree, or Tend to disagree, (Don't Know)*

There has been much discussion about responsibilities in relation to the mad cow disease problem. Farmers carry a major part of responsibility for the problem? *Tend to agree, or Tend to disagree, (Don't Know).*

There has been much discussion about responsibilities in relation to the mad cow disease problem. The food industry carries a major part of responsibility for the problem? *Tend to agree, or Tend to disagree, (Don't Know)*

There has been much discussion about responsibilities in relation to the mad cow disease problem. I do not have enough information to decide who is responsible? *Tend to agree, or Tend to disagree, (Don't Know)*

Here is a list of things that some people say they are afraid of. For each of these, please tell me if, you personally are afraid or not. Spread of nuclear, bacteriological or chemical weapons of mass destruction? *Afraid, Not afraid, (Don't Know)*

Which of the following scientific research projects are Worthwhile, Of no particular interest, Or too risky, (Don't Know)? To develop medical and surgical research on human organ transplants?

Which two or three issues in your life, if any, are most important to you personally? What else? (open code)... Health/Good health...Healthcare system/A good healthcare system/NHS...Science/Cloning/Animal Experimentation etc...

On the whole how would you describe your feelings about the following issues... Neuroscience/brain science *Very good thing, fairly good thing, neither good nor bad thing, fairly bad*

*thing, very bad thing, Don't know*

### **Nanotechnology (32)**

On the whole how would you describe your feelings about the following issues...  
Nanotechnology/miniaturisation *Very good thing, fairly good thing, neither good nor bad thing, fairly bad thing, very bad thing, Don't know*

human beings will greatly benefit from nanotechnology, which works at the molecular level atom by atom to build new structures, materials and machines

Do you think nanotechnology will improve our way of life in the next 20 years, it will have no effect, or it will make things worse?

Do you think nanotechnology will improve our way of life in the next 20 years, it will have no effect, or it will make things worse? (Canada nanotechnology/US study 2005- a joint cross-national study)

I would like to understand the extent to which you think nanotechnology might benefit our society. Using a scale of 1-5, where 1 is no benefit and 5 is substantial benefit, and the mid-point 3 is moderate benefit, how beneficial do you think nanotechnology research will be to our society? *[1-5], Don't know*

I would like to understand the extent to which you think nanotechnology might pose a risk to our society. Using a scale of 1-5, where 1 is no risk and 5 is substantial risk, with the mid point 3 being moderate risk, how much risk does nanotechnology pose for our society? *[1-5], Don't know*

In terms of the moral or ethical aspect of nanotechnology, again using the 1-5 scale, where 1 means that nanotechnology is morally unacceptable, 5 means it is morally acceptable, and the mid point 3 means it is morally questionable, how do you view this kind of research? *[1-5], Don't know*

In terms of economic benefits to [Canada/the United States], would you say that nanotechnology will provide *major benefits, modest benefits, or no significant benefits, Don't know?*

And how involved should government be in funding nanotechnology research, using a 1-5 scale where 1 means government should not be involved at all, 5 means government should be actively involved, and the mid-point 3 means that it should be moderately involved? *[1-5], Don't know*

Overall, which of the following best captures your views about nanotechnology? *I approve of nanotechnology, as long as the usual levels of government regulation and control are in place; I approve of nanotechnology if it is more tightly controlled and regulated; I do not approve of nanotechnology except under very special circumstances; I do not approve of nanotechnology under any circumstances; Don't know*

There is a lot of talk about the potential risks and benefits of nanotechnology. What do you think? *Do you think the benefits of nanotechnology will outweigh the risks; the risks will outweigh the benefits; or will the risks and benefits be about equal, Don't know?*

The next set of questions asks about emotions you might feel. First, are you worried about nanotechnology? *No, Yes, Don't know*

How worried are you [about nanotechnology]? *Very worried, somewhat worried, only worried a little, Don't know*

The next set of questions asks about emotions you might feel. Are you hopeful about nanotechnology? *No, Yes, Don't know*

How hopeful are you [about nanotechnology]? *Very worried, somewhat worried, only worried a little, Don't know*

The next set of questions asks about emotions you might feel. Are you angry about nanotechnology? *No, Yes, Don't know*

How angry are you [about nanotechnology]? *Very worried, somewhat worried, only worried a little, Don't know*

Next, I will read five potential benefits of nanotechnology. After I read the list, please tell me which item is most important to achieve? *Cheaper, longer lasting consumer products; New and better ways to treat and detect human diseases; Increased national security and defense capabilities; New and better ways to clean up the environment; The ability to improve human physical and mental abilities*

Next, I will read five potential risks of nanotechnology. After I read the list, please tell me which item is most important to avoid? *Economic disruption caused by the loss of traditional jobs; Losing your personal privacy to tiny new surveillance devices; A nanotechnology inspired arms race between the US and other countries; Breathing tiny nano-sized particles that accumulate in your body; The uncontrollable spread of self-replicating nano-sized robots*

Here's a list of statements people have made about nanotechnology and its potential impact. For each of these statements, *could you tell me how much you agree or disagree on a ten point scale with one being 'not at all', and ten being 'very much'?* Overall, I support the use of nanotechnology.

Here's a list of statements people have made about nanotechnology and its potential impact. For each of these statements, *could you tell me how much you agree or disagree on a ten point scale with one being 'not at all', and ten being 'very much'?* Overall, I support federal funding for nanotechnology.

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Because of nanotech we may lose more U.S. jobs.

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Nanotech may lead to an arms race between the U.S. and other countries.

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Nanotech may lead to new and better ways to treat and detect human diseases

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Nanotech may help us develop increased national security and defensive capabilities.

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Nanotech may lead to new and better ways to clean up the environment.

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Nanotech may lead to the loss of personal privacy because of tiny new surveillance devices.

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Nanotech may lead to the uncontrollable spread of very tiny self-replicating robots.

Now, for each of these statements, *could you tell me how much you agree on a ten-point scale with one being 'not at all', and ten being 'very much'?* Nanotech may give scientists the ability to improve human physical and mental abilities.

On a scale of 1-5, where 1 is not at all confident and 5 is extremely confident, where the mid point 3 is moderately confident, how confident would you say you are in the safety and regulatory approval systems governing nanotechnology? [1-5], *Don't know.*

In terms of the scientists who are involved in research of these technologies, on a scale of

1-5, where 1 is not at all confident and 5 is extremely confident, where the mid point 3 is moderately confident, how confident would you say you are that nanotechnology is in safe hands? [1-5], *Don't know*

How much do you trust business leaders within the nanotechnology industry to minimize potential risks [of nanotechnology] to humans? *Do you trust them a lot, some or not that much, Don't know?*

## 11. APPENDIX 4 Bibliography of In-Scope Studies

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