

MEDICINE SOCIETY PROGRAMME



Public Perspectives on Human Cloning



The Wellcome Trust



Public Perspectives on Human Cloning

A Social Research Study

Acknowledgements

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Summary

Introduction

Public Perspectives on Human Cloning presents the results of a public consultation exercise, commissioned by the Wellcome Trust in the spring of 1998, on human cloning and the use of cloning technology in medical research. The aim of the research was to provide input from members of the public who do not usually have a voice in such issues (the 'uninvolved public') to the Human Genetics Advisory Commission (HGAC)/Human Fertilisation and Embryology Authority's (HFEA) joint consultation document, *Cloning Issues in Reproduction, Science and Medicine*. Preliminary findings were included in the Wellcome Trust's response to the Working Party.

The Wellcome Trust believes that public debate about the ethical and social issues raised by developments in medical research is important. As a major funder of such research, it is investing £15 million over five years to stimulate and inform this debate.

Aims and objectives

The purpose of this study was to explore the public's perspective on human cloning. The research had two specific aims:

- to inform part of the Wellcome Trust's response to the consultation document *Cloning Issues in Reproduction, Science and Medicine*, issued in January 1998 by the Human Genetics Advisory Commission (HGAC) and the Human Fertilisation and Embryology Authority (HFEA);
- to test reconvened group discussions as a method of consulting members of the uninvolved public on their views about the social and ethical issues raised by developments in medical research.

The research

Ten group discussions and four interviews with couples were undertaken. Each discussion lasted two hours and began by exploring participants' knowledge and image of medical research and cloning in particular. During the last half hour or so participants were 'taught' about cloning technology by the researchers. The groups were reconvened between one and four weeks later to see how, if at all, views had changed after exposure to relevant scientific information and time to consider the technology and the issues involved.

Research of this nature provides rich and detailed data on people's experiences, understanding, views and images of an issue. It does not, however, allow measurement of the proportion of the population that believes one view or another. Samples are best described as cross-sections of the population, selected in an effort to ensure that as many views as possible are represented and explored – they are not intended to be representative in a statistical sense.

Cloning identical human beings

The public have fearful perceptions of human cloning and were shocked by the implications of the technology. The practice was firmly rejected by almost all participants in the research; only a handful were more positive. Understanding of the technical process of cloning was initially limited but the provision of additional factual information did not modify participants' primary concerns. These concerns focused on the likely social consequences of cloning and were often described in the context of popular cultural imagery such as science fiction films and media stories portraying the lives of public figures. Scientific news coverage appeared to have a lesser impact upon views.

Using cloning technology in medical research

Participants' views on the use of cloning technology which did not create identical human beings were also sought. This concept was described by the term 'therapeutic cloning' in the HGAC/HFEA consultation document. Unlike reproductive cloning, this concept did not arise spontaneously during discussions and required prompting and explanation. At first, participants saw cloning in this context as 'good' as it would be beneficial for health. After more information and consideration, reservations were expressed and caveats on the type of research and the uses to which it would be put were drawn out.

Assisted conception and reproductive science

Participants knew about, and understood, the methods of assisted conception currently available. Technically the methods were accepted but the issue of children not knowing their genetic father was raised. Participants also questioned whether there was a 'right' to have a child and whether the rules for fertility treatment should be as tough as those for adoption. Interestingly, some participants remembered that *in vitro* fertilization (IVF) had seemed strange when it was new, and recognized that familiarity, to some extent, breeds acceptability.

The regulation of scientific research

This research identified important differences between the public's and policy makers' perspectives on the role and effectiveness of the regulation of cloning, reproductive science and, more widely, the control of medical research. Knowledge of existing regulations was extremely limited and further information about them did not reassure participants. There was little confidence that any system of regulation could effectively control research, not only in the area of cloning, but more generally in medical research. The role of regulations and legislation was regarded as limited without international agreements. Even then, it was

acknowledged, the potential for breaching the regulations existed. Participants were unconvinced that public opinion would have any effect on what research was done.

Conclusions

Participants had previously considered the issue of human cloning, which they linked closely with the subject of genetic engineering. Discussions frequently made use of the narratives taken from popular culture as well as the information materials provided. Human cloning was consistently rejected by all but a handful of participants whose minority views provided valuable additional perspectives. This research challenges suggestions in the cloning consultation document that certain social groups would be more likely to accept cloning.

The use of cloned embryos in medical research was less familiar territory and our research questions the usefulness of the term 'therapeutic cloning'. All groups expressed concern with the regulation of scientific research and a cynical view was taken of scientists' motives. A striking theme to emerge from the discussions was that information was being withheld from the public.

Lessons for public consultation

This research emphasizes the importance of public consultation on scientific and ethical issues such as human cloning. The research also raises a number of questions if public consultation is to be of value in policy considerations. Public mistrust in scientific endeavour is a major barrier to a better dialogue. Methods that address how best to explore and understand the various public views are likely to need further development. Several additional areas of research are proposed.

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Introduction

Public Perspectives on Human Cloning presents the results of a public consultation exercise, commissioned by the Wellcome Trust in the spring of 1998, on human cloning and the use of cloning technology in medical research. The aim of the research was to provide input from members of the public not usually consulted about such issues in response to the Human Genetics Advisory Commission (HGAC)/Human Fertilisation and Embryology Authority (HFEA) joint consultation document *Cloning Issues in Reproduction, Science and Medicine*.¹ The Trust's response was one of about 200 received. Preliminary findings were included in the Wellcome Trust's response to the working party. This report contains a more detailed analysis of the results and is intended to inform the policy debate on the issue of cloning.

The Wellcome Trust believes that further public debate about the ethical and social issues raised by developments in medical research is important. As a major funder of such research, it is investing £15 million over five years to stimulate and inform this debate under the Medicine in Society Programme. The research on cloning was commissioned by the Trust from NOP Family and The Research Business International via a tendering process with a brief specified by the Trust.

1.1 | Aims and objectives

The purpose of this study was to explore the public perspectives on human cloning. The research had two specific aims:

- to inform part of the Wellcome Trust's response to the consultation document *Cloning Issues in Reproduction, Science and Medicine*, issued in January 1998 by the HGAC and the HFEA;
- to test reconvened group discussions as a method of consulting members of the uninvolved public on their views about the social and ethical issues raised by developments in medical research.

1.2 | The report

Following brief background information, the main sections of the report focus on the findings of this study. Section 2 analyses responses to human cloning, and section 3 examines responses to using cloning technology in medical research. Section 4 considers human cloning in the context of other reproductive technologies. Section 5 discusses the participants' perceptions of the regulatory issues that arise when considering such new technologies. Section 6 draws some conclusions from the research. Section 7 is designed for those interested in developing better methods for public consultation by setting out the lessons learnt from this research and making some recommendations for future consultation exercises.

1.3 | Background

Human cloning is not a new subject for the general public. Interest in the nature of our individuality and its possible manipulation by others is a familiar theme in popular culture and has been a staple of science fiction for decades. With the birth of Dolly the sheep, and further recent developments in animal cloning, 'science fact' may appear to be moving closer to these popular images.

For half a century, serious questions about the potential for animal and human cloning^a have been considered by scientists, politicians, medical ethicists and others commenting upon bioethics. Animal cloning experiments have progressed since 1952, when Briggs and King² demonstrated that it was

possible to transfer the complete genetic material of certain living nuclei into a fertilized egg.

In the early 1980s, a committee of inquiry chaired by the moral philosopher Mary Warnock was set up “to examine the social, ethical and legal aspects of recent, and potential, developments in the field of assisted reproduction”. The Warnock Report examined some of the issues concerning embryo research and specifically addressed human cloning.³ The report’s recommendation that human cloning should be prohibited was included in the UK Human Fertilisation and Embryology Act of 1990. Enforcement of this legislation is the responsibility of a statutory body, the Human Fertilisation and Embryology Authority (HFEA). More recently, a new government advisory body, the Human Genetics Advisory Commission (HGAC), has been established “to report on issues arising from new developments in human genetics that can be expected to have wider social, ethical and/or economic consequences”. Recent developments in the science of cloning and fertility treatment generally have prompted a reassessment of the appropriateness of current regulations and an examination of further policy options.

Despite the history of previous research, many scientists were surprised by the news that a mammal had been cloned from an *adult* cell. Dolly

the sheep was born on 5 June 1996 in Scotland and became worldwide news some eight months later with the publication of a scientific research paper.⁴ Widespread concern was aroused that human cloning would now be possible within a short period.

Following the news of Dolly the sheep there has been intense interest in the science and ethics of cloning and this has prompted more discussion about the changing relationship between medical research and society. Media coverage has been extensive and has concentrated the attention of policy makers. In the UK, the House of Commons Select Committee on Science and Technology took evidence on the topic and produced a report within weeks of this announcement.⁵ In January 1998, a joint working party of HGAC and HFEA members issued a consultation document, *Cloning Issues in Reproduction, Science and Medicine*.

A few quantitative surveys, using structured questionnaires, have attempted to offer a snapshot of public opinion on cloning.^b The results suggest widespread public concern with the potential for human cloning. However, the wording of questions in some of the surveys^c casts doubt on the interpretation of the findings and the surveys do not provide deeper insights into public understanding of, and attitudes towards, cloning. These surveys are further limited in that they cannot offer insight into the factors that the public take into account in forming opinions on cloning.

1.4 | Research method

The intention was to explore attitudes and opinions in depth, and the factors that influenced these. The research method employed for this project is based on qualitative research techniques. In such work, small samples are used and researchers use ‘topic guides’, which act as *aides memoires*, rather than structured questionnaires. Issues are covered as the conversation flows, rather than in a pre-set order, and the researcher uses the topic guide to ensure that nothing is forgotten. This format allows

^a For the purposes of this report, human cloning is considered as a process where an entire human is produced from a single cell by asexual reproduction. The term ‘cloning’ is also used by scientists to describe a number of different concepts, not considered here, such as generating multiple copies of genetic material, the cultivation of single-cell organisms, such as bacteria, and the propagation of plants by taking cuttings.

^b A national opinion poll conducted by Harris Research and published in the Independent, 7 March 1997, indicated that 72 per cent thought human cloning “should never be allowed and all research should be stopped”. 19 per cent supported the statement that “research should continue under strict controls and a decision taken later”. Four per cent stated that “Cloning should be allowed when it becomes possible”.

^c A national opinion poll conducted by NOP in March 1998 for Compassion in World Farming indicated that 81 per cent of people were opposed to animal cloning. Interviewees were asked to respond to the question: “You may have heard about animal cloning in the news recently (i.e. Dolly, the cloned sheep). The animal cloning procedure sometimes involves surgery, and people have said that animals have been born with abnormalities. Do you agree or disagree with cloning animals?”

participants to raise issues that the researchers may not have considered, and to express themselves in their own words – often useful for phrasing questions in later quantitative surveys.

There are primarily two qualitative data collection methods – group discussions (often called focus groups) and depth interviews. This research used ‘reconvened group discussions’ and ‘reconvened partner paired depth interviews’. ‘Reconvened’ refers to the initial groups and paired depth interviews that met for a second time after one to four weeks. A ‘partner paired depth’ interview refers to interviews conducted with opposite-sex partners together, and these were also reconvened.

The groups were reconvened in an attempt to explore how, if at all, participants’ views changed once they had absorbed some technical information about cloning and had been able to consider the issues over a period of time.

Group, rather than individual, interviews are used when the researchers perceive that there will be a ‘sparking-off’ of (new) ideas from the dynamics of a group and where the objective is to identify the diversity of opinions that exist. Depth interviews are used to explore attitudes in greater detail, perhaps where individual participants have unique stories to tell or where they need to read and digest material. This research used a combination of the two methods as it was felt that both types of information were required.

Qualitative research of this nature provides rich and detailed data on people’s experiences, understanding, views and images of an issue. It does not, however, allow measurement of the proportion of the population that believes one view or another. Samples are best described as cross-sections of the population – selected in an effort to ensure that as many views as possible are represented and explored – but are not intended to be representative in a statistical sense. Thus, minority views are given as much weight as majority views so that

each can be equally well explored. In this research, it is our intention to present the variety of views found; it is not possible to claim that other views do not exist, nor what proportion of the population agrees with any of the views expressed by the participants.

1.5 | Questions explored

The consultation paper issued by the HGAC/HFEA working party set out the issues to be considered, defined various terms and posed a number of questions on which comments were invited. Table 1 sets out the questions posed. The questions formed the basis for developing the stimulus materials and topic guides for this research, and helped to identify a framework of issues for participants to address (see Appendix A.4). The discussions covered points raised by these questions^d but also explored issues of interest to participants which were not directly addressed in the consultation document.

Table 1 | Questions raised in HGAC/HFEA consultation paper and addressed in this study

Ethical issues

Q1 Would research using nuclear replacement technology raise any new ethical issues in relation to what is permitted in work with embryos in the 14-day period?

Own genetic identity

Q3 To what extent can a person be said to have a right to an individual genetic identity?

Instrumentalization

Q4 Would the creation of a clone of a human person be an ethically unacceptable act?

Experimental human beings

Q5 Would the likely cost in terms of failures and/or malformations inevitable in developing a programme of human reproductive cloning be ethically acceptable?

Natural/unnatural

Q6 What ethical importance might be attached to the distinction between artificial processes for which there are parallels in natural processes and those for which there are not?

Para 9.2

“We will also be advising Ministers on ways to build public confidence in and understanding of new developments in genetic techniques. We would welcome any suggestions you may have on what this advice might be in respect of the implications of human cloning.”

NB The above question numbers follow the sequence used in the HGAC/HFEA consultation document.

The first set of groups began by exploring uninformed opinions on medical research, genetic technology,^e human cloning in the context of other reproductive technologies and cloning for other purposes. At the end of the first group discussions, the researchers explained to participants how a human clone could be formed using simple, but informative diagrams. Copies of materials were given to participants at the end of the first group so that they were able to refer back to them, if needed, before the later reconvened discussion (see Appendix A.4).

Possible alternative uses of cloning were also explained, as was the current regulatory system. Immediate responses were explored and participants were asked to go home and re-read the information, and discuss the issue with friends and family. They were also asked to keep a diary of their thoughts.

The groups were reconvened between one and four weeks later, and views on cloning were revisited. The researchers also explored with participants their thought processes during the intervening period, the extent of their discussions with others and problems they had experienced when trying to involve others in the debate. Some participants were asked to give their views on the whole experience by completing a questionnaire at home after fieldwork had ended.

^d Because of its technical nature, Question 2 in the consultation document was not directly addressed by the research. ("Q2 Are there any medical or scientific areas that might benefit from research involving human nuclear replacement?"). A separate technical response on this question was submitted to the HGAC/HFEA working party by the Wellcome Trust.

^e The following terms were presented on cards: 'genetic research', 'genetic medicine', 'gene therapy', 'genetic engineering', 'artificial insemination', 'reproductive medicine', 'IVF', 'DNA' and 'genes'. The term 'cloning' was presented last and participants asked how they regarded it in relation to the other terms.

^f The classification is based on the Market Research Society's social grade groupings. Across all ages, Groups B, C1, C2 and D cover approximately 84 per cent of the population. Groups BC1 approximate to non-manual occupations and Groups C2D to manual occupations. Group A, 3 per cent of the population, (professionals, very senior managers and top-level civil servants) and Group E, 13 per cent (those who are long-term dependent on the state, whether through sickness, unemployment, old age or other reasons) were not included in this sample.

The discussions lasted for up to two hours, all were audio-recorded and two groups were videotaped for subsequent analysis. The group moderators were all female.

Topic guides were developed to help channel discussion from the more familiar territory of IVF and donor insemination towards detailed discussion around cloning issues (see Appendix A.3). Some *projective* techniques frequently used in market research, such as visualization, were used in an attempt to elicit participants' feelings and unearth some of their underlying values. However, participants found it easy to articulate their views and limited use was made of non-verbal methods.

1.6 | The sample

Within the time available it was the Trust's intention to bring the views of people not usually consulted in policy discussions about the social and ethical implications of biomedical research into the policy debate.

Ten focus groups and four paired depth interviews with opposite-sex couples were carried out, involving a total of 79 adults in three English cities and two locations in the south-east.

Four groups were chosen as a cross-section of society.^f Quotas based on age, sex, and whether or not they had children were used as proxies for interest in reproductive technology. Socioeconomic group provided an indication of educational level. The highest and lowest social grades were excluded, firstly because of the time available and the known difficulty in recruiting these socioeconomic groups to studies. Secondly, it was felt that those with limited education, of which social grade can be indicative, would find the stimulus material difficult to understand.

Other groups (lesbians, women who had lost a young child, grandparents, pregnant women, women who had difficulty conceiving, and women in their late 30s and early 40s with no children)

were chosen because these groups might have different views from the 'mainstream' on human cloning for a number of reasons.

In particular, the decision to select groups of lesbians, women having difficulty conceiving and those who had lost a child were prompted by scenarios suggested in the HGAC/HFEA consultation document (paras 8.3 and 8.5 in the consultation document). Lesbians, it was thought, might see cloning as preferable to sexual intercourse with men. Women who had difficulty conceiving, many of whom were already involved in assisted reproduction techniques of one kind or another, might view cloning as just another alternative. Women who had lost a child might want to recreate the lost child – indeed the Roslin team responsible for cloning Dolly has had such requests from parents. Older women with no children, who may have decided to have children too late in life for either natural reproduction or established fertility treatment, might see cloning as a viable method by which to have a child. Pregnant women and grandparents were identified as other groups who might have different values from the mainstream.

All group discussions were with single-sex groups except the group of grandparents which was mixed sex. No controls were imposed on ethnicity although the groups included several members of ethnic minorities. Those likely to have specialist knowledge or education in the fields of science, human biology and human reproduction (including scientists, healthcare workers and those in related fields such as the pharmaceutical industry) were excluded at the recruitment stage. Those holding strong personal beliefs about human life and medical interventions, and members of pressure groups taking such views, were also excluded. This represents an attempt to ensure that only the non-specialist and generally uninvolved public were included.

1.7| Recruitment

Participants were identified by experienced market research recruiters using a questionnaire to identify appropriate people. This questionnaire was agreed with the Trust. The recruiters were briefed on the objectives of the project by the relevant market research company so that they had a clear idea of the nature of the people who should be included.

Participants for most groups were approached in the street or contacted by interviewers calling at their home and screening them to identify those who met the quotas. These people were then asked the relevant questions and recruited for the group if they were willing and available at the appropriate time. Pregnant women were recruited by researchers positioned outside shops such as Boots and Mothercare. Women with no children were recruited by researchers positioned in office areas.

For the other special groups, local networks were used. Lesbian women were contacted through a hockey club and at lesbian clubs. Women who had lost a child were recruited through local self-help groups who made the contact on the recruiters' behalf. This took a long time to set up as a lot of women felt they couldn't talk about it. Women who had had difficulty in conceiving were recruited through a women's group who were attending a psychology course. They were recruited by word of mouth through contacts in the group. With the exception of the lesbian group, the participants did not know each other.

1.8| Briefing the researchers

It was vital that the social researchers facilitating the discussions were familiar with the areas of science that formed the basis of the research. At the outset, the commissioned research teams were extensively briefed about the HGAC/HFEA consultation document, the questions it posed and the scientific method of producing a whole-animal clone and therapeutic cloning (see Appendix A.2).

Cloning identical human beings

Participants had fearful perceptions of human cloning and were shocked by the implications of the technology. The practice was firmly rejected by almost all, a handful were more positive. Understanding of the technical process of cloning was initially limited, but the provision of additional factual information did not modify participants' primary concerns. These concerns focused on the likely social consequences of cloning and were often described in the context of popular cultural imagery such as science fiction films and media stories portraying the lives of public figures. Scientific news coverage appeared to have a lesser impact upon views.

- 2.1** | What participants thought about human cloning
- 2.2** | Cultural references to cloning
- 2.3** | Dissenting views
- 2.4** | Lesbian women
- 2.5** | Social consequences of cloning
- 2.6** | Changes in the role of men
- 2.7** | Is a unique genetic identity important?
- 2.8** | The process of cloning
- 2.9** | Cloning animals
- 2.10** | Role of the media
- 2.11** | Extending the debate



2.1 | What participants thought about human cloning

Reproductive cloning, where an entire human is produced from a single cell by asexual reproduction, was regarded as unacceptable by virtually all participants. This was a widespread and often spontaneous reaction.

Opening discussions probed participants' general perceptions of medical and genetic research both spontaneously and also prompted by presenting several scientific terms on cards. References to cloning often pre-empted the formal introduction of the topic by the facilitator. A common theme was that participants closely associated cloning with the term 'genetic engineering'.

"I'm concerned with the idea of genetic engineering and cloning. There are big moral issues."

Woman 30s/40s 1[§]

"I think it's frightening [genetic engineering], particularly because of the sheep and how far it is going to go." *Woman who had lost a child 1*

Many participants claimed to have a vivid image in their mind of what a clone would be. When prompted, responses commonly described 'photocopied' individuals and automated production lines or artificial incubators producing multiple adult clones. This concept of human cloning was linked to its adoption by malevolent outside influences such as the military, megalomaniac leaders and rogue scientists. Examples frequently cited were genetic experiments conducted by the Nazis.

[§] '1' after a quote indicates a participant in one of the first series of discussions.

Figure '11' indicates a participant in a reconvened group. 'Diary' refers to the diaries kept by participants between the initial and reconvened groups (see Appendix A.1 for further details).

“Very disturbing – why would you want a replica of you? I certainly wouldn’t. It reminds me of Hitler, trying to create a race.” *C2D man I*

“You just think about Hitler, Aryan race.” *BC1 woman I*

“I can just imagine all these people walking around looking the same.” *C2D woman I*

Almost all participants continued to reject the idea of human cloning throughout the research, even after explanations of the science behind cloning and in-depth discussion about the influence of environmental factors, such as growing up in different eras.

2.2| Cultural references to cloning

Popular culture provided an important frame for reactions to human cloning.

“You see it on films, armies of marching robots. Why do we need cloning?” *Woman who had lost a child I*

“I dread to think what could happen if it was to end up like something out of a sci-fi film.” *Grandparent, diary*

Discussions were peppered throughout with negative references to films and books including *The Boys from Brazil*, *Jurassic Park*, *Blade Runner*, *Invasion of the Bodysnatchers*, *Frankenstein*, *Brave New World*, *Stepford Wives*, *Star Trek* and *Alien Resurrection*. These references were often used to punctuate discussion, but it was not always clear which aspects of

the film were being alluded to. Classic stories such as *Frankenstein*, *Brave New World* and, to a lesser extent, *The Boys from Brazil*, were not referred to in detail, but were often simply cited as examples. Just the reference to a film or book appeared to be sufficient to describe participants’ concerns, and there was an assumption that others in the group would be able to understand these instantly. Several participants mentioned having seen the film *GATTACA*, which was on general release over the research period, but in cases where there was less familiarity they took more time to explain the general plot to others in the group.

“Cloning...I mean it’s Frankenstein-type medicine.” *BC1 man I*

“It’s a Star Trek thing – androids with a brain that could think like a human” *Woman 30s/40s I*

“I have a Brave New World vision where we have half a dozen or so different kinds of human being classified according to their ability...I think Mr Huxley was quite perceptive.” *BC1 man I*

2.3| Dissenting views

The proposal that several previously suggested groups might accept reproductive cloning was not supported by this research. There was no evidence, for example, that those who had lost a child or who might want to extend their own genetic existence, had more positive attitudes than others towards reproductive cloning.

Four individuals in two of the groups held a rather different view in that they thought that human

“Very disturbing – why would you want a replica of you? I certainly wouldn’t. It reminds me of Hitler, trying to create a race.” *C2D man I*

“ Cloning...I mean it's Frankenstein-type medicine. ”

BC1 man I

cloning might be a *desirable* development. In each case, the dissenting views were expressed within a group where the majority were more negative towards human reproductive cloning. Each dissenting view appears distinct in its reasoning and these alternative viewpoints are of interest as they may also be held within important minority groups.

2.3.1 | Women having difficulty conceiving

Two women from the group who were experiencing difficulty conceiving a child said that they would consider using cloning to have a family. This was one of six groups selected because their characteristics and experiences were thought likely to influence their views on cloning. The desire of all the women to have a child was extremely strong and both those with dissenting views had already attempted or investigated several medical interventions to help them conceive. For both women, the potential to use cloning themselves was still seen as somewhat remote and only likely to be an option in the longer-term future. Cloning was viewed as a method of last resort, where methods of sexual reproduction, including using IVF, had failed.

One woman had been trying to have a child for 19 years. She was adamant at the outset that she would use cloning if the method were available.

“If that was the only way to have a child – it's selfish – but it would be great.” *Woman having difficulty conceiving I*

Once the group had been taken through how Dolly was cloned and the number of attempts made to produce one clone, she qualified her acceptance. A requirement was added that the efficiency of human cloning would have to be greater than that which resulted in Dolly (and, indeed, several times more reliable than current IVF success rates).

“I can't understand why anyone would want to have a baby in this way unless the success rate of treatment was vastly improved. If someone told me tomorrow that there was an 80 per cent success rate against 20 per cent IVF, I would take the chance.” *Woman having difficulty conceiving, diary*

A second woman in this group rejected using cloning herself, but felt that it could be acceptable in cases where a woman was 'desperate' and other methods to conceive had failed. This judgement was expressed in both her diary and the reconvened discussions.

“...it wouldn't be for me but I can understand it if someone was so desperate for a child that they could get one that way.” *Woman having difficulty conceiving, diary*

“I felt that a cloned child could be used for reproductive purposes...the norm would be to have sexual intercourse to have a baby, but cloning would be a possibility.” *Woman having difficulty conceiving II*



“ In some ways it’s the way forward, it is moving forward all the time. ” C2D man II

In some sense, cloning here is being seen as the reproductive method of last resort.

2.3.2|Cloning as ‘progress’

Two men in the C2D^h group contemplated the idea that human cloning might represent ‘progress’ and should therefore be accepted. In the reconvened group, one of the two men acknowledged that he still felt rather overwhelmed with the information provided. While he believed his knowledge might be incomplete, his judgement in approving human cloning was clear:

“I was trying to get my head round it but I could not see any bad points in it, you are able to do it...so therefore I think it would be a good thing.” C2D man II

“In some ways it’s the way forward, it is moving forward all the time.” C2D man II

A second man in this group expressed excitement at the unknown possibilities that human cloning might offer and was reluctant to proscribe further research in this area even if unforeseen or negative consequences might arise. He believed that such risks were acceptable and an integral part of ‘the future’. This participant also questioned the distinction between artificial and natural processes.

“You know people say well it’s wrong, we mustn’t, it’s dangerous. I don’t think nature is a fixed thing. Who are we to say that it is nature and it begins there and it ends there...if you look at it as something open then you can experiment and I think all things, everything, started off as an experiment and everything probably went wrong. You know there is no way we can get it right first time, so whilst I find it very exciting –

the whole thing – I strangely feel no fear about it.” C2D man II

2.4|Lesbian women

One hypothesis suggested in the HGAC/HFEA consultation document – that lesbian women might view cloning as offering a new option to have children without having contact with men – was rejected. The lesbian women consulted in this research dismissed reproductive cloning as unnatural and unnecessary. They responded firmly to the scenario that depicted two women using cloning to have a child:

“I think this is far more dangerous than anything else that we have talked about because it totally excludes the male from any point at any stage of growing a new child.” Lesbian I

This group did not view cloning as a specifically lesbian issue and their current options for conceiving using donor insemination (DI) and through heterosexual sex were regarded as sufficient and preferable.

“What happened to good old traditional sex? If I wanted a baby at this stage in my life I would go and have sex with somebody. I wouldn’t bother with this.” Lesbian I

2.5|Social consequences of cloning

Many participants considered that a cloned child would face significant social problems that could affect their upbringing. How would a child respond to knowing that he/she was cloned rather than created through sexual reproduction? Would this

^h This occupational grouping includes skilled and unskilled manual workers.

not lead to the child becoming stigmatized and discriminated against by others? Such questions seemed impossible to resolve.

“No amount of research could fully conclude the mental effects on a genetically identical person.”

Pregnant woman, diary

“The child doesn’t know who it belongs to, or, family background, it’s just, it’s just not right!”

C2D woman II

Participants’ emphasis was on whether an appropriate social environment could be offered for the upbringing of a child produced through cloning. Scenarios shown to participants depicting a single woman or two women having a cloned child raised greater concerns. These concerns were discussed in more depth in the context of established practices such as DI (para. 4.4, page 30).

“I think the worst thing is like the woman, having a baby on her own. I can’t imagine what you would feel like, growing up and being told that actually you did not have a father at all, genetically.”

C2D woman II

2.6 | Changes in the role of men

There was disquiet with the implication that using cloning as a means of reproduction meant that men would not necessarily be required, either for the creation or the upbringing of a child. The realization that sperm, and hence men, would not be needed for reproduction using cloning was often a shock.

“I’m getting totally confused here – what about men – how can you have a baby without men.”

Woman who had lost a child I

There was greater discussion of this matter within the women’s groups where initial comments were often tinged with humour:

“So we can live without men – it would be a world of women. We could use this if you don’t watch out.” *Pregnant woman I*

“There would be no child maintenance would there, you’re on your own.” *BC1 woman I*

“We say it in a joke don’t we, that we all don’t need men, but it would be horrible if they weren’t there.” *C2D woman II*

Further consideration focused anxieties on the effect this might have upon family relationships. Participants questioned what the psychological effect would be on a man who had made no genetic contribution to a cloned child and could only be described as a ‘social’ parent. For example, in the women’s groups there were worries that such a social father would find it difficult to accept that his partner alone was responsible for the child’s genetic makeup.

“I think it would be a lot for a man to deal with knowing that really his child is not part of him at all...I don’t think it would work with a lot of people.” *Woman experiencing difficulty in conceiving II*

“...the conclusion of this is that not only are we not needed, but we will die, actually die out. A woman is going to clone a woman.” *BC1 man I*

The male groups appeared to have reservations about discussing in any detail the potential redundancy of men. In the reconvened discussion groups, several men were curious about women’s responses to this topic and speculated that women would have greater knowledge of reproductive issues and also have stronger views on some of the assisted conception issues. However, it was not possible to determine whether there was a consistent gender difference in attitudes.

2.7 | Is a unique genetic identity important?

Participants considered it highly selfish for an individual to want to create a genetic copy of themselves through cloning. However, initial concerns that human cloning would lead to a loss of individuality lessened somewhat over the research period. There was discussion of how identical twins would have the same genetic makeup and the role that genes might play in controlling their behaviour and personality.

“I can see that you would have a baby that looks like you, but they’re not going to have your upbringing, and that’s what makes a child – the way they’re treated as a child.” *Woman who had lost a child II*

The teaching materials had illustrated to participants that human cloning would produce a child, not an identical adult, as many first believed. As the issue was discussed, several participants appeared to accept that a child brought up at a different time with different environmental influences would not have an identical personality to the original, despite having an identical genetic make-up. This modified view of the influence of nurture over nature did not, however, undermine their fundamental rejection of human cloning.

“You could never recreate a person unless they have gone through the same experiences. It’s not nurture it’s nature. We’re talking about character, personality, whatever it is one loves about someone. You’re never going to reproduce that.” *Woman 30s/40s II*

2.8 | The process of cloning

Initial knowledge of the technical processes involved in cloning was minimal. It was also evident that participants associated the process of cloning more closely with genetic engineering and research, rather than regarding it as an aspect of reproductive science. However, participants regarded knowledge of the outcome as sufficient to form opinions about cloning.

“I know about cloning, I know that it reproduces the same thing but how they do it, what it involves, I haven’t a clue.” *C2D woman I*

“I don’t know how it was done, but it came out of a test-tube basically.” *BC1 man I*

Information on the cloning of animals and humans was used to initiate further discussion. Explanatory material, which included simplified illustrations, explained how Dolly the sheep had been created and highlighted the possibility of human cloning (see Appendix A.4). Some participants found these scientific explanations of cloning difficult to absorb immediately but they quickly became familiar with the technical aspects of cloning. This was evident from subsequent checks on their newly gained knowledge against the human cloning scenarios presented. Two key pieces of information, clarified during discussion, often surprised participants:

- no sperm would be required for the creation of a clone;
- a clone would be born as a baby rather than presented as an adult.

“ We say it in a joke don’t we, that we all don’t need men, but it would be horrible if they weren’t there. **”** *C2D woman II*

“I was shocked to learn that babies can be conceived without a male being present.” *Pregnant woman, diary*

2.9 | Cloning animals

Many, but not all, participants had heard through the media that a sheep had been cloned from an adult cell, but fewer could recall knowing that the sheep had been given a name – Dolly. The public presentation of Dolly as an adult sheep appeared to reinforce participants' existing and vivid images of clones being created as adults.

F “What was the point in that?”

M “See if it could be done.”

C2D couple, no children I

A major stumbling block was to comprehend 'why' rather than 'how' a sheep had been cloned. There was little knowledge of who had been responsible for cloning Dolly or of the benefits scientists anticipated would result from such research. Generally it had been assumed that the reason for the experiment had been strictly for commercial gain. In the reconvened groups, some participants had considered this further and several more positive comments were made, especially in the personal diaries kept by participants.

“I fully support the use of cloning to produce animals for drug production for human diseases.”

BC1 man, diary

Several participants were concerned about the welfare of animals used in experiments and these concerns increased on learning of unsuccessful animal cloning experiments which have been reported. Knowledge of the low rate of success with sheep cloning (Dolly represented one successful clone out of 277 attempts) was a factor that led participants to question the likely safety of human cloning. Participants wanted further details about these failed attempts and the resulting malformed fetuses, and there were suspicions that this information was being withheld from the public.

2.10 | Role of the media

The role of the news media in communicating scientific concepts and the ethical questions raised was difficult to dissect. In the initial groups, few references were made to news stories about cloning or medical research and no individual item was mentioned frequently. The 'hot-housing' environment of the focus groups and the period of time between the initial and reconvened groups, encouraged some participants to become sensitized to relevant news stories. However, the number of people able to recall items they had seen or heard remained small. Items that were mentioned included: a radio feature on whether Dolly really was a cloned sheep; Dolly being pregnant; the attempted patenting in the USA of genetically modified animals; and a radio phone-in show on cloning during which one participant had tried unsuccessfully to get on air. The small number of news items that were mentioned failed to provoke further group discussion of issues. Some participants had tried to obtain factual information in the period between discussion groups by searching for sources in local libraries.

Several media stories following the private lives of popular celebrities did stimulate discussion, however. Perhaps because they focused on the possible social consequences of cloning rather than on technical questions, they became useful narratives through which participants communicated concerns about many aspects of medical research, not just cloning. An illustrative example was discussion of how Michael Jackson's child was being raised, where upbringing and environment were seen as affecting one's perception of 'normality'.

“I was thinking about Michael Jackson's child, that is totally abnormal to us. That child won't know any different unless it's free to step back and think this is a really weird environment I've grown up in – but whilst it's in it, it won't know.” *BC1 woman II*



“ Speaking to someone that hadn’t been part of the group it didn’t mean as much to them, it was quite difficult. ” BC1 woman II

Also, the recent death of Linda McCartney was used to illustrate how money alone did not ensure good health, while the arrest of singer George Michael was a peg on which to hang discussion of the role of genes in determining behaviour:

“It was fate, Linda McCartney has died at 56, it comes down to money, you say people can afford, you can have all the money in the world...you can’t stop things.” BC1 woman II

2.11 | Extending the debate

While motivated to discuss cloning and its implications outside the context of the group discussions and interviews, many participants found it difficult to initiate conversation and engage friends and family in further discussions. Participants found that it was not an easy topic to insert into everyday conversation, and their attempts were usually cut short by a response that simply rejected the idea of cloning.

“Speaking to someone that hadn’t been part of the group it didn’t mean as much to them, it was quite difficult.” BC1 woman II

“...it wasn’t just the difficulty in explaining it, it’s got such far-reaching complications, they’d refuse point blank to think about it seriously and they switch off as soon as it got to a certain level, then they start making a joke about it.” BC1 woman II

Several participants attempted to replicate the group facilitator’s use of the teach-in materials but either found that insufficient time was available or that they became unsure of their own knowledge when further questions were asked. More successful conversations offered just key information, which participants had selected as relevant – in particular suggesting that the role of men would be affected by human cloning.

“When I said to people, there is no sperms involved, quite a lot of people were shocked by that, they had not realized that.” C2D woman II

three

Using cloning technology in medical research

Participants' views on the use of cloning technology which did not create identical human beings were also sought. This concept was described by the term 'therapeutic cloning' in the HGAC/HFEA consultation document. Unlike reproductive cloning, this concept did not arise spontaneously during discussions and required prompting and explanation. At first, participants saw cloning in this context as 'good' as it would be beneficial for health. After more information and consideration, reservations were expressed and caveats on the type of research and the uses it would be put to were drawn out.

- 3.1** | The concept of 'therapeutic cloning'
- 3.2** | Terminology
- 3.3** | Judgements about using cloning for research
- 3.4** | Understanding the process
- 3.5** | Comparisons to reproductive cloning
- 3.6** | Alternatives to research on cloned embryos
- 3.7** | Embryo research

Human embryo clones 'could help save lives'



3.1 | The concept of 'therapeutic cloning'

Participants' views on the use of cloning technology which did not create identical human beings were also sought. This concept was described by the term 'therapeutic cloning' in the HGAC/HFEA consultation document.ⁱ Unlike reproductive cloning, this concept did not arise spontaneously during discussions and required prompting and explanation. At first, participants saw cloning in this context as 'good' as it would be beneficial for health. After more information and consideration, reservations were expressed and caveats on the type of research and the uses to which it would be put were drawn out.

3.2 | Terminology

The research suggests that the language chosen when describing scientific research has a major impact on participants' responses to the ideas. This

was strikingly illustrated when, early in the discussions, participants were presented with scientific terms on cards and asked to describe what each meant to them.

Even though there was little knowledge of the term 'gene therapy' and what this might involve, it was viewed far more positively than other terms put forward such as 'genetic engineering' or 'genetic research'.

"I assume [gene therapy] would be where someone had some form of deficiency and they try to put it right just as a therapist would try and put something right for you." C2D man 1

ⁱ "Therapeutic cloning: medical and scientific applications of cloning technology which do not result in the production of genetically identical fetuses or babies. These techniques may be undertaken to advance fundamental research and therefore not all such applications will lead to immediate therapeutic utility." Cloning Issues in Reproduction, Science and Medicine (1998) HGAC/HFEA, Annex B, Glossary.

“Gene therapy, I’ll be honest I’ve never heard of it before, but it does sound something more positive than genetic engineering.” *BC1 man I*

“...gene therapy, that sounds quite friendly.”
C2D woman I

When designing the information materials, we became concerned about how effectively the term ‘therapeutic cloning’ would convey the ideas involved, since some aspects of the scientific research proposed would not be of direct therapeutic value, but would aim to improve the basic understanding of human biology. Therefore, it was decided to avoid the term ‘therapeutic cloning’, since it was felt this might obscure a deeper insight into participants’ attitudes.

An information sheet ‘Possible research applications of cloning which do not create identical human beings’ was prepared and discussed with participants in the groups. The potential benefits suggested in the consultation document were considered such as improving the basic understanding of biology and the possibilities of replacing cells, tissues and organs.

Even when the concept was put forward in this manner, many participants initially found it difficult to understand what would be involved. It is worth recalling that these information materials were introduced towards the end of the first interview or group discussion. By this point, participants admitted to feeling quite overwhelmed by the volume of information they had received and many were shocked on realizing the potential of reproductive cloning. Conversations in the first series of discussions tended to be dominated by reproductive cloning and IVF issues.

3.3 Judgements about using cloning for research

Many participants recognized that medical research utilizing cloning technology could be of value. Initially the idea seemed straightforward, in that such work would improve healthcare, but concern grew as this was considered and further implications were raised. Participants expressed particular interest in the views of other members of the group in these discussions.

Positive views were associated with those uses perceived to be of direct therapeutic benefit, in particular the potential to produce tissues or organs for transplants.

“...for selective parts I have no problems (skin, organs). Otherwise let nature be nature.” *BC1 man, diary*

“After reading about the two children who had been badly burnt in a house fire, the idea of producing skin for skin grafts seemed a good idea.” *Grandparent, diary*

Views on using cloning technology for biological research were more cautious. Distinctions were made between different types of research and there was an emphasis on ‘finding cures’ over more basic research. While research into cancer was seen as legitimate, several participants interpreted research into the ageing process in a less positive manner. Two contrasting views from different age groups are illustrated:

“If it enabled ageing to be slowed down then no – how can this planet sustain such an overpopulation.” *BC1 man, diary*

“After reading about the two children who had been badly burnt in a house fire, the idea of producing skin for skin grafts seemed a good idea.” *Grandparent, diary*

“Don’t mind if it’s really for research if [it’s] destroyed. Wonderful if it can help cure cancer and understand the ageing process.” *Grandparent, diary*

3.4 Understanding the process

Increasing knowledge of the science and related issues around these uses of cloning technology brought about greater sophistication in the debate, but as the participants’ awareness increased, so did their concern and apprehension. While the potential value of using cloning technology for therapies was accepted initially, participants became more critical as they considered the implications further:

“I can see things like skin grafts and things like that, but now I don’t understand how you can do it if all you’re going to do is grow skin in a dish...cloning to me means making another human being.” *Woman who had lost a child II*

Participants had a clear idea that the generation of tissues or organs would be of medical benefit. However, they had difficulty understanding how such outcomes could result from a cloned human embryo without the need to let it develop past 14 days – the current limit set by the Human Fertilisation and Embryology Act for experiments on embryos. It was not possible to answer all these questions satisfactorily given the current state of scientific knowledge.

It was unclear whether many participants realized that an embryo created for research would be a genetic extension of a living individual. However, for those who did grasp this fact, their concerns were further heightened.

3.5 Comparisons to reproductive cloning

The research and therapeutic applications suggested on the information sheet were often compared by participants with an alternative option of a cloned human being as a source of ‘spare parts’. While there was a clear understanding of how this scenario could be achieved, the idea was firmly rejected by everyone.

“I am convinced that experimentation with embryos can only be justified if experimentation on fully grown adults can be justified. Personally, I believe not, but this is a subjective opinion!! Persuade me otherwise!” *BC1 man, diary*

“It’s the only part that I agree with – the cloning for medical purposes...But probably you can’t have one without the other.” *Grandparent II*

3.6 Alternatives to research on cloned embryos

Participants questioned why research using cloned embryos was required and whether there might not be other ways of achieving the same therapeutic end. Alternative research methods, which do not involve the creation of a cloned human embryo, were viewed as preferable as such ethical problems were not raised. Again, the emphasis was that research should focus on the causes of disease and attempt to develop cures. Their expectations of medical research were high and several suggested that existing research should be able to cure major diseases in the near future.

“There must be ways other than cloning human beings to develop technology and find the causes of diseases. I imagine there would be a public outcry if human cloning was taking place.”

BC1 woman, diary



“ They can do skin grafts now, we have got enough now haven't we? We can work a lot of miracles now without cloning.” *C2D woman II*

“They can do skin grafts now, we have got enough now haven't we? We can work a lot of miracles now without cloning.” *C2D woman II*

“I can see positive benefits. Existing legislation appears to cover research limitations adequately.” *BC1 man, diary*

“Maybe researchers and scientists should finish one project before starting another e.g. find a cure for cancer or AIDS before starting research on something else!” *Woman 30s/40s, diary*

Greater concerns were expressed about research on cloned embryos than on 'spare' embryos created through IVF, but in both cases there was considerable unease. The use of embryos for research purposes was often linked to concerns over illicit experiments being conducted. For those who raised concerns, it was not simply that embryo research is taking place – worries were also expressed over the responsibility for the enforcement and effectiveness of the regulations.

3.7| Embryo research

Several participants stated that they were unaware that any research on human embryos was permitted in the UK and questioned the current 14-day limit for embryo research. There was little knowledge of what research was being done and why. Discussions about embryo research revealed differences in attitudes to the status of an early embryo. In most groups, a number of participants regarded an embryo as a human being while others were comfortable that research be conducted if the assumption that embryos up to 14 days old could not feel pain could be guaranteed.

“...saw obvious benefits, but very worried about control.” *Grandparent, diary*

Questions were also raised as to what procedures were in place providing consent for work upon embryos.

“I don't know what the research currently conducted on embryos is.” *C2D woman II*

“How would you ensure that spare embryos are regulated – who would give consent – in giving consent does this imply that they are human?” *BC1 man, diary*

“To me, even at 14 days, it is still a person, even though it is just a blob with a few cells. To me that would be part of me, so I couldn't do it with my own embryo.” *Woman who had experienced difficulty conceiving II*

“I just think it is wrong to create a life and then destroy it.” *C2D woman II*

four

Assisted conception and reproductive science

Participants knew about, and understood, the methods of assisted conception currently available. Technically the methods were accepted but the issue of children not knowing their genetic father was raised. Participants also questioned whether it was a 'right' to have a child and whether the rules for fertility treatment should be as tough as those for adoption. Interestingly, some participants remembered that *in vitro* fertilization (IVF) had seemed strange when it was new, and recognized that familiarity, to some extent, breeds acceptability.

- 4.1 | Knowledge of assisted conception
- 4.2 | Reservations about current practices
- 4.3 | Comparisons between cloning and IVF
- 4.4 | Donor insemination
- 4.5 | Adoption as an alternative to assisted conception
- 4.6 | Shifting boundaries of acceptability



4.1 | Knowledge of assisted conception

The discussions in the groups also illuminated participants' views on some established methods of assisted conception. Here, participants drew upon their own knowledge, which was informed by the experiences of friends and families and by a number of case studies highlighted in the popular media. Views on particular aspects diverged notably, and it was usual for there to be several established positions expressed within a single group. While one particular women's group had direct experience of infertility problems, and were happy to share these, the men-only groups appeared more reticent in discussing such issues. Both men's groups contained comments which indicated that they were uncomfortable discussing this topic directly. Many participants appeared more comfortable framing their discussion in terms of media portrayals of popular celebrities' personal lives.

"We're blokes aren't we?" BC1 man 1

"It's not something you talk publicly about."

C2D man 1

Unlike cloning, where there was a large amount of new information to absorb, participants felt comfortable that they understood the technical aspects of various methods of assisted conception. Their discussions focused on the social implications and upbringing of children rather than on the process through which conception was achieved.

4.2 | Reservations about current practices

The use of IVF to treat infertility was generally seen as positive, although some questioned if there was a fundamental right to fertility. However, participants expressed reservations about a number of current practices in assisted conception.

“I can have moralistic views sometimes. I don’t think if I do or don’t agree with it. I believe in fate – should you be doing IVF if you aren’t meant to have children?” *BC1 woman I*

“In some instances, yes we agree with the IVF and then in a similar sort of situation we disagree with it and it all boils down basically to the same thing, that only in certain circumstances is it all right.” *C2D woman II*

4.3 | Comparisons between cloning and IVF

Human cloning was regarded as fundamentally different from IVF methods of reproduction in that sperm is not required in the creation of a clone. Comparisons were made with the interventions required for IVF and between natural and artificial processes.

“It’s [IVF] totally different [from cloning] because doing it with the test-tube, sperm and egg – it’s a normal method of reproduction. It’s what we see as human beings as being normal, even though we’re adding a bit of extra help.” *Woman who had lost a child I*

“There are a lot of people who, although they want a family and would go for either adoption or IVF, would draw the line at cloning, I think they would settle for not having children.” *C2D woman II*

4.4 | Donor insemination

Where anonymous donor insemination (DI) was used as a means of dealing with the infertility of a heterosexual couple, many viewed this as a choice that only those directly affected by infertility were in a position to make. However, DI was viewed as

problematic and there was anxiety that the child should know the identity of their genetic father. For a few participants, DI would be stepping outside the acceptable boundaries of how a child should be conceived.

“I think it should be the sperm and the egg from the couple, the married, well not particularly married, but the couple living together. I don’t think the egg should be a donated egg, or a donated sperm.” *C2D woman II*

More negative attitudes were observed when participants discussed the acceptability of DI by single women, lesbian couples and homosexual men. While there was an appreciation that social acceptance of families not conforming to ‘traditional’ structures had increased, it was evident that on this subject the groups had difficulty in reaching a consensus.

“It’s someone just going out – they want a baby and they’re going to buy it – a child the way they want it. But the child will never know the father or have any connection – purely satisfaction for the mother – I don’t agree with it.” *Woman 30s/40s I*

“The further you get away from the couple, the more it seems to be tampering.” *BC1 man I*

“You have got to hear from them, I mean we are all going to one side, but there is no one from them sort of backgrounds [lesbians] here – to hear their point of view.” *C2D woman II*

Many participants had seen or read media coverage of how US film star Jodie Foster intended to use donated sperm to have a child. There were suspicions that the media stories may not be

“...should you be doing IVF if you aren’t meant to have children?” *BC1 woman I*

“ The further you get away from the couple, the more it seems like tampering. ” BC1 man I

accurately reporting all the relevant aspects in this case and slightly modified versions of the story were offered by participants in different groups. There was strong disapproval of the use of sperm selected from a sperm bank on the basis of the donor's characteristics. This was viewed as an example of how it was already possible to select non-medical characteristics in a child. It was felt that this was an option only likely to be available to those with the financial means to purchase such services.

“Jodie Foster went to a sperm bank and chose her donor and wants to have a perfect baby. But in the future she probably wouldn't do that – she will just want a clone of herself. To me it seems totally selfish what she's done.” *Woman 30s/40s II*

Once again, many of the comments focused on the well-being of the child. Many perceived that there would be detrimental effects upon a child learning the circumstances of its conception.

4.5 | Adoption as an alternative to assisted conception

Some participants contrasted unfavourably the restrictions placed on adoption with the wider availability of assisted conception. Again, a retrospective judgement on current practices was evoked, with some suggestion that adoption was a socially preferable solution for infertility and, therefore, that either adoption should be made easier or, at least, similar restrictions should apply to assisted conception as to adoption.



“ When the first little girl was born from IVF, it was like, oh my god...But we've all grown up with the idea and it's not so terrible. ”

Woman who had lost a child II

4.6 | Shifting boundaries of acceptability

In each group, there were individuals who believed that public attitudes to new developments in research were likely to become more positive over time. While acknowledging that there were concerns about these developments, they referred to established practices, such as IVF, which once was widely regarded as controversial. There was a feeling that, although they themselves might not approve, these developments could represent 'progress' for others.

“You have to go with the times, they thought the penicillin guy was mad. We, as an older generation, start to look at genetic engineering, DNA. Genetic engineering has taken years and years to develop. It really is a moral view that you take. Life must go on. In 50 years' time, our offspring will be thinking entirely differently to us.”

Grandparent I, male

“When the first little girl was born from IVF, it was like, oh my god...But we've all grown up with the idea and it's not so terrible.” *Woman who had lost a child II*

The regulation of scientific research

This research suggests there are important differences between the participants' and policy makers' perspectives on the role and effectiveness of the regulation of cloning, reproductive science and, more widely, the control of medical research. Knowledge of existing regulations was extremely limited and further information about them did not reassure participants. There was little confidence that *any* system of regulation could effectively control research, not only in the area of cloning, but more generally in medical research. The role of regulations and legislation was regarded as limited without international agreements. Even then, it was acknowledged, the potential for breaching the regulations existed. Participants were unconvinced that public opinion would have any effect on what research was done.

- 5.1 | Public knowledge of, and confidence in, regulation
- 5.2 | International perspectives
- 5.3 | Attitudes towards scientists
- 5.4 | Behind closed doors
- 5.5 | Role of public opinion

5.1 | Public knowledge of, and confidence in, regulation

There was minimal awareness of the existence or nature of UK regulations to control human cloning, medical research and reproductive science more generally. Specific bodies such as the HFEA or HGAC, charged to oversee aspects of this research, were not mentioned spontaneously in discussions. One group stated that some sort of regulatory body would be required and even suggested their own title, 'OffGene'.

The nature of the HGAC/HFEA consultation was explained to participants and written information about current regulations was given to participants at the end of the first discussion (Appendix A.4). These explained aspects of the Human Fertilisation and Embryology Act 1990 referring to the cloning of humans and the embryo research purposes which could currently be permitted in the UK.

Participants viewed the likely effectiveness of these regulations with scepticism. There was a belief that regulation would not be able to prevent those determined to attempt human cloning. For many, illegal research seemed inevitable and impossible to prevent.

“By law you have to have your car taxed, but a lot of people don't. It is going to be abused. Who is going to test that every embryo is destroyed at 14 days?” *Lesbian II*

Some considered that regulations intending to prohibit human cloning would have to cover both reproductive cloning and other research uses of cloned human embryos. Once again, comparisons between different research routes were offered and it was suggested that research which did not involve creating cloned human embryos should be given priority.

“After much thought, I am of the opinion that cloning should be banned at present. The disadvantages far outweigh the possible breakthroughs in disease prevention. With modern science there must be other ways of obtaining information.” *BC1 man, diary*

5.2 | International perspectives

Participants felt concern that if regulation was to be effective in prohibiting reproductive human cloning it would need to be on an international scale. Even if such agreement at international governmental level was reached, participants thought that effective implementation and enforcement would be problematic.

“...there is no point in having stringent legislation in the UK if scientists can go abroad to conduct research.” *BC1 man, diary*

“I think you can pass laws all you like, still don't know that you'll stop it. People will just go and do it in another country.” *BC1 woman II*

5.3 | Attitudes towards scientists

Scientists participating in cloning research were often portrayed as a stereotyped boffin (male) in a white coat. They were frequently comic figures, suggesting that while scientists held very specialized and useful skills, they might lack more ordinary social ones:

“...with a test-tube and Bunsen burner they are dynamite. Put them behind a shopping trolley in Tesco's on a Sunday morning and they are the biggest danger to the civilized world.” *BC1 man I*

“Little men in white coats with glasses walking round laboratories or universities somewhere. Just scientists really.” *Woman who had lost a child I*

Participants' perceptions of scientists were of individuals led by their curiosity and enabled by their intellectual ability to push the boundaries of knowledge ever further: Being driven by academic interest would inevitably lead to scientists always wanting to take another step, but with disregard for any potential negative consequences that might result. There was a belief that this desire was at least in part selfish and reflected a need for personal glory – for example through media coverage of a 'breakthrough' or the awards of a scientific accolade such as a Nobel Prize. Scientists were often described as having their heart in the right place but inevitably compromised by outside influences.

“It's science. If the ability is there, someone's going to do it.” *Woman who had lost a child I*

“Scientists will always want to push – the challenge for them is probably the recognition of being first.” *BC1 man I*

Commercial pressures were most frequently cited as an example of how research was likely to be manipulated for more negative ends.

“I still think there are good guys out there. Unfortunately I don't think they are in control, it's all business orientated anyway at the end of the day, however good we want to be, and I think that anybody who does have these rather pure ideas of maybe making a wonderful world – I don't think, perhaps, they are in control!” *C2D man I*

“...there is not point in having stringent legislation in the UK if scientists can go abroad to conduct research.” *BC1 man, diary*

“ It’s science. If the ability is there, someone’s going to do it. ” Woman who had lost a child I

5.4 Behind closed doors

Concern was expressed that any negative outcomes of research were not likely to be exposed. ‘Conspiracy theories’ abounded and suggestions that secret research was taking place were common. Specifically who might be responsible for, and conducting, this research was unclear – both the government and commercial interests were implicated.

“...if I think about it long and hard, I don’t trust the people who are doing it to know when to stop. I don’t believe they would not do experiments, they’d do them, [but] they wouldn’t tell us they were doing them.” *BC1 woman I*

“It doesn’t mean that I think it’s right or wrong, but I just think there is a lot more they haven’t told us [about genetic engineering].”
BC1 woman I

The groups expressed concern that human cloning experiments could already have been attempted, although they had perhaps been unsuccessful. It is possible that the research design may have exaggerated the strength of this response. Participants may have felt that in a closed discussion, apparently separate from the wider public arena, their endorsement was being sought for an already completed experiment. However, these concerns about cloning were just part of a wider suspicion that information about the negative outcomes of other medical research experiments was being withheld from members of the public.

“Cloning cannot be controlled by legislation. It will still go on somewhere behind closed doors.”
BC1 man, diary



“Cloning cannot be controlled by legislation. It will still go on somewhere behind closed doors.” BC1 man, diary

“I feel by the mere fact that this market research is being done that this will come into happening in years to come.” *Pregnant woman, diary*

5.5 | Role of public opinion

Many participants believed that scientists had little interest in the attitudes of the lay public towards their work. The issues that participants had covered in the groups were widely believed to be areas where public opinion would make little difference to policy decisions. Participants felt that, as members of the public, they were unable to contribute their opinions to those making decisions. Further scientific research in areas where there was public opposition was seen to be inevitable and out of the control of members of the public.

“Do you not think that if everybody – all the public – were against it they’d still do what they want to do anyway.” *Woman having difficulty conceiving I*

“We should have our say if they are doing something we feel is wrong.” *C2D couple II*

“Whatever – we know this is going to happen and it will be labelled Progress.” *Grandparent, diary*

“I think you accept things, things do progress and there’s nothing you can do to stop it.” *BC1 woman I*

“Whether I say I don’t think it should be done or, it’s going to happen...it’s there in the future.” *Woman who had lost a child II*

“These things get taken out of your hands. Cloning will go ahead whatever we sit here and say makes no difference. It will go ahead and the research will continue. We as people have no control.” *Woman 30s/40s II*

“It’s a shame that the rest of the general public are not as aware as we are because we are the experts now.” *Lesbian II*

Conclusions

Participants had previously considered the issue of human cloning, which they linked closely with the subject of genetic engineering. Discussions frequently made use of the narratives taken from popular culture as well as the information materials provided. Human cloning was consistently rejected by all but a handful of participants whose minority views provided valuable additional perspectives. This research challenges suggestions in the cloning consultation document that certain social groups would be more likely to accept cloning.

The use of cloned embryos in medical research was less familiar territory and our research questions the usefulness of the term 'therapeutic cloning'. All groups expressed concern with the regulation of scientific research and a cynical view was taken of scientists' motives. A striking theme to emerge from the discussions was that information was being withheld from the public.

- 6.1** | Reproductive cloning
- 6.2** | Role of narratives and the media
- 6.3** | Dissenting views
- 6.4** | The use of cloning technologies in medical research
- 6.5** | Assisted conception and reproductive science
- 6.6** | The regulation of scientific research

6.1 Reproductive cloning

Even prior to this research, participants had considered their attitudes towards reproductive cloning of humans. We were surprised to find that cloning was frequently raised spontaneously in the opening general discussion about medical research. The topic appeared to be at the front of people's minds and was closely associated with the concept of 'genetic engineering', a term viewed in strongly negative terms. The fundamental and consistent judgement was that human reproductive cloning was wrong.

The medical risks of human cloning were a secondary issue to the social concerns of how cloning would disrupt family relationships. A borrowed description which encapsulates this view could be that human cloning is viewed as "a blatant violation of the inner meaning of parent-child relations".⁶

6.2 Role of narratives and the media

The reasoning that led participants to their conclusions was seldom expressed in the form of abstract academic argument from general principles to specific conclusion. Instead, their discussions were conducted by the use of specific, concrete examples, drawn from narratives of their personal and social lives or from popular culture. The general conclusions reached by this process of reasoning using individual examples was clearly consistent and valid.

In this research, participants made extensive use of narratives from popular culture when framing their discussions and concerns. The role of popular culture in helping to express public attitudes has been explored in detail elsewhere.⁷ This was evident not only in the numerous references to science fiction films but also in stories that reflected the lives of popular celebrities. Most obvious were

the spontaneous references to well-known stories such as *Frankenstein*, *Brave New World* and *The Boys from Brazil*. These were used as a form of shorthand when making comparisons to a concept – such as "like *Frankenstein*" or "a *Brave New World* vision". It was clear from the context in which they were used that these references were intended to be interpreted in a negative manner.

Participants tended not to unpack these references further and explain how they related to the topics discussed. As there was little expansion of the cultural references in discussions, it would probably be an overinterpretation of the findings to suggest that detailed aspects of the plots of these films and books were being applied. An alternative suggestion would be that such references are used in a metaphorical manner to which it was hoped others within the group would relate. It has been suggested that just the title of such a cultural reference can evoke an entire story or 'script' as an interpretative frame.⁸ The punctuation of discussions in this manner led to some truncation of discussions and it appears that it was usually assumed that everyone else had the same vision of the 'script' in mind. This interpretation is further supported when considering that the relevance of stories likely to be less familiar to others in the group, especially recent films, were more likely to be described in detail.

Personal stories, and especially media coverage of the lives of popular celebrities, were an important framework in these discussions. The media portrayal of Jodie Foster's pregnancy was familiar to many, and was used as the basis for several extended discussions that illuminated concerns with the use of selected sperm for donor insemination. Participants also related to the characters named in the cloning scenarios presented by the researchers and they were willing to offer judgements based on these suggested narratives. They also varied the suggested scenarios and devised their own examples to illustrate particular issues which they anticipated. Judgements were often

⁸ In *Frankenstein's Footsteps*, J Turney describes the idea of a script "to help us navigate through a wide range of social and cultural encounters". He continues: "Frankenstein script has become one of the most important in our culture's discussion of science and technology. To activate it, all you need is the word: *Frankenstein*", p. 6.

stated as being dependent upon their proper understanding of the scenario and open to change if further information required a re-evaluation. One clear example of this was that their acceptance of research on cloned embryos would be dependent on there being direct medical benefits and also that other areas of research would not be able to deliver similar outcomes.

6.3 Dissenting views

The HGAC/HFEA consultation document suggested that particular groups would be more likely to view human cloning in a positive light. There has been a tendency to focus on such groups perceived to have a special interest in cloning. A feature of both academic and media discussion about human cloning has been to propose scenarios where particular groups might wish to use human cloning. Members of the Roslin team have reported being contacted by families wishing to attempt to replace a child who has died with a clone.⁸ Infertility experts have reported being approached by individuals seeking to use cloning where a woman was unable to produce viable eggs.⁹ In the USA, the Human Cloning Foundation has published several essays in support of cloning, including one from a husband of an infertile woman.¹⁰ Fictional scenarios have also been used to illustrate the possibilities for lesbian women and those who have lost a child.^{11, 12} The media has also used such scenarios to provide a context for debate.¹³

Our research involved in-depth discussions with samples of all of these groups. The samples were not intended to be representative but the findings raise the questions as to what evidence such assumptions have been based upon. We also raise the possibility that other groups with views outside the mainstream view opposing human cloning may have been overlooked.

Women having fertility treatment may already undergo extensive interventions to help them achieve a pregnancy. For those who have no other options left and who are already willing to go

through several IVF cycles in their quest, an attempt to clone from an adult cell might appear the next logical, if desperate, step. Two members of the group of women having difficulty conceiving did confirm expectations. However, the majority of the women in this group did not concur with this view and our analysis shows them to be part of the mainstream view that cloning is unacceptable.

It was not expected that some members in the group of C2D men would be positive towards human cloning. Two men held a minority view within this group and there was no indication that they could also be categorized into one of the previously identified special groups which might support human cloning. These men regarded reproductive human cloning as inevitable and justifiable as part of 'scientific progress'. This view appears to take further an attempt to rationalize the more widely expressed perspective that scientific endeavour is unstoppable and that it is not possible to control it effectively.

The research reported here appears to be the first attempt to investigate some of these expectations of attitudes towards cloning in an empirical fashion. Our findings demonstrate how a qualitative social research approach has a role to play in refining our understanding of the opinions of different groups to human cloning.

6.4 The use of cloning technologies in medical research

During this research it was decided to avoid using the term 'therapeutic cloning' proposed in the original HGAC/HFEA consultation paper. It was felt that there could be the potential to mislead participants, it being accepted that several aspects of the scientific research envisaged would not in fact be 'therapeutic'.^k

^k "These techniques may be undertaken to advance fundamental research and therefore not all such applications will lead to immediate therapeutic utility." Cloning Issues in Reproduction, Science and Medicine (1998) HGAC/HFEA, Annex B, Glossary.

All participants lacked prior knowledge of the potential benefits of using cloned human embryos, and it is reasonable to assume that wider public awareness of this subject is also low.

Participants were not fundamentally opposed to the principle of using cloned human embryos for medical research, although as they gained more information and considered the issues, significant reservations and conditions were stipulated. This finding is in agreement with previously published research which has established that greater understanding of a topic may also lead to increased anxieties.^{14,15} There was a desire for further information and evidence that there would be medical benefits to be gained. Reassurance was also sought that the suggested medical benefits could only be achieved through research that involved the creation of cloned human embryos and not through other research routes. Alternative methods that avoided the need to clone an embryo were viewed as more acceptable.

Although some of the research benefits of using cloning technology in medicine have been briefly outlined,¹⁶ there has been little further discussion in the scientific literature. It may be some time before researchers are able to answer the pertinent technical questions that participants posed. Some scientists have warned against 'claiming too much benefit from the research' on cloned human embryos.¹⁷ On these technical matters there is further potential for scientists to apply their expertise by promoting a dialogue that examines the benefits and risks of the alternative research options.¹⁸

6.5| Assisted conception and reproductive science

Most participants brought to the discussions a good understanding of assisted conception and reproductive science on which they had already developed views over a long period.

Many reservations were raised about established practices in reproductive medicine and it would seem that, even after years of public consideration, there remains a diversity of views about the acceptability of assisted conception. An unexpected finding was the discussion of adoption as an alternative to assisted reproduction, and a call for a relaxation of the rules on adoption in parallel with a tightening of the rules on who should be offered assisted conception services.

6.6| The regulation of scientific research

A striking theme found throughout the research was the lack of trust that participants expressed in scientists and those perceived to be in control of scientific research. This cynicism was applied not only to those involved in cloning research, but more generally to those involved in scientific endeavour. Researchers' motives were believed to be due to a technological imperative – 'if it can be done it must be done' – and participants feared that this might not match wider public desires.

The belief that cloning research was probably driven by commercial interests may have been reinforced by the realization in discussions that the first cloned mammal, Dolly, was not announced until she was eight months old. Some scientists have suggested that this was, in part, due to the researchers' fear that her postnatal development would be abnormal and also that time was required to lodge a patent on the cloning process they had used.¹⁹ However, those researchers responsible have defended this delay as inevitable due to the need to repeat experiments and the unavoidable delays when scientific papers are refereed.²⁰

In the case of Dolly, there still appears to be little public awareness of the anticipated research benefits. While more effective communication of the research rationale and therapeutic benefits is an obvious conclusion to draw from this, our research

also indicates that further actions will be required to make a significant impact upon the levels of public mistrust.

The suspicions that participants held – ‘what are we not being told?’ – about medical research experiments were substantial and need serious consideration. The belief that human cloning experiments were already taking place was expressed in most discussions. There seemed to be no awareness of those regulations that were in place, nor of advisory or regulatory bodies such as the HGAC and HFEA. Providing information about the relevant regulations and the systems of advice in place did not appear to give much reassurance. Participants considered that any measures attempting to regulate this science were likely to be circumvented. The penalties in place to enforce regulations were viewed as unlikely to act as deterrents to those determined to attempt human cloning. Controls could be evaded either by conducting research in secret or by taking advantage of more lax regulation abroad. Several questions were posed as to why it was not possible to develop international regulations, although their enforcement was also seen as problematic.

This research does not suggest any immediate or easy answers which could address the recognized lack of public faith in scientific regulation.²¹ The established system of advisory and statutory bodies may not appear to reassure these fears, but there is such a low level of current public knowledge that some improvement in this climate would appear possible.²² Some further openness in the workings and operation of such bodies has already been offered²³ and this may play a part in raising awareness of their existence. A significant development, which should be welcomed, is the proposal by the UK government to conduct a public consultation exercise examining the regulatory system and people’s understanding of it.²⁴ Of particular interest will be the examination of

public communication when research is the subject of scientific debate and expert opinions differ. Such exercises may suggest more positive ways in which the public can contribute to ethical discussions which contain scientific controversy, whilst avoiding more sensationalist fears and scares.

Some participants suggested that effective prohibition of reproductive human cloning would also need to cover the production of cloned human embryos for research purposes. At present, such an approach might be considered of value, especially if it were to increase public confidence in regulation. There still appears to be need for further scientific discussion of the potential benefits and the Human Fertilisation and Embryology Act 1990 already requires that relevant animal research be completed prior to the use of human embryos. Such experiments are still required to demonstrate the therapeutic benefit of non-reproductive human cloning technology.

In 1986, a consultation paper²⁵ dealing with embryo research regulation was published and several hundred written responses were received from the public as well as professional bodies. The White Paper issued the following year appeared to take account of these when it noted “one of the greatest causes of public disquiet has been the perceived possibility that newly developed techniques will allow the artificial creation of human beings”.²⁶ Our findings suggest that this comment still holds true.

seven

Lessons for public consultation

This research shows that the public does offer useful perspectives on scientific and ethical issues such as human cloning. The research also raises a number of questions if public consultation is to be of value in policy considerations. Public mistrust in scientific endeavour is a major barrier to a better dialogue. Methods that address how best to explore and understand the various public views are likely to need further development. Several additional areas of research are proposed.

7.1 | Engaging the public in debate

7.2 | Public consultation methods

7.3 | Areas for further research

7.1 Engaging the public in debate

Understanding the variety of public attitudes and opinions, and what underlies them, can make a valuable contribution to policy formation. However, as shown here, it is not always a simple task. Some difficulties exist, which are likely to inhibit a true dialogue and understanding between the lay public, experts and decision makers. It is therefore important to clarify the contribution that public consultation may make and how this is likely to interact with other expert and specialist advice being sought. Ideally, policy makers should be involved in the process of public consultation, to help ensure that relevant research is undertaken and also that its outputs are incorporated into their own deliberations.

The concept of using public consultation for technology assessment is not new but there is currently an increased emphasis on listening to, and understanding, public attitudes among those responsible for advising on, and developing, policy. The timing of this research enabled it to contribute to the HGAC/HFEA consultation on cloning. Such formal consultation documents are an established strand of policy formation and provide a framework for professional bodies to respond to relevant policy questions. Although in theory the documents are available to any group or individual member of the public, in practice it is only those with an active interest who are likely to be aware of their existence and have the opportunity to respond. Better consultation methods are required to reach the majority of people excluded from these policy discussions, but who nevertheless may be able to make valuable contributions if approached proactively.

The evidence from this research is clear: participants had no problems with the subject matter. That they were able to engage so successfully in discussions will come as no surprise to those involved in earlier public programmes on issues raised by genetics, but may surprise others. In many cases, participants were already familiar with, and had considered, the general concept of human

cloning but without detailed knowledge of the technology used. However, the potential research uses of cloned human embryos was an unfamiliar topic that participants had not previously contemplated. The research design for this project offered participants further opportunities to develop their views on these subjects. As well as providing relevant technical information, the design aimed to provide a positive environment where participants would feel it was of value to explore the issues further.

Researchers conducting discussions were carefully briefed on the relevant scientific, ethical and legal issues (Appendix A.2). Stimulus materials provided to participants were also intended to address these issues in an easily comprehensible form (Appendix A.4). It was evident from the detailed discussions which took place that participants understood and absorbed this information. In anonymously completed post-research evaluations, they reported that these materials were helpful and unbiased. As participants became more technically informed and grew in confidence, their discussions became more complex and sophisticated. They asked pertinent scientific research questions, especially about how cloning might be used in medical research. Even for well-briefed researchers, these were difficult questions to answer definitively since a scientific consensus has yet to be reached and research is still at an early stage of development.

Other elements of this research design were also important in facilitating fruitful discussion. The use of reconvened discussions was an attempt to find a method of consultation that allowed information to be imparted, digested and discussed. Reconvening groups was crucial in that it allowed analysis both of spontaneous responses and judgements at a later date. This approach also offered better access to the underlying attitudes and beliefs.

The small groups created a dynamic, but non-confrontational environment where people from similar backgrounds could feel comfortable in

discussions. The intervening days between group discussions allowed participants time to take on board the new technical information and offered opportunities to consider questions away from the group. Participants were able to share ideas with others outside the group, although they sometimes found this difficult. The intervening period also proved useful in managing the research. Time was allowed to reflect on the initial findings and, if necessary, respond by modifying the second-stage design.

7.2|Public consultation methods

A number of approaches to public consultation have been developed. The most widely known and used are 'citizens' juries' and 'deliberative polls'. Whilst citizen's juries were originally developed in Germany and the USA, the model has been adapted for use in the UK.²⁷ In a citizens' jury, a group of 12–16 participants is recruited from a local community, using various methods, and set a specific question to address. With the help of an independent moderator, the jury has access to a variety of experts and witnesses selected in advance by the organizers. Most juries sit over three or four consecutive days and the final report is based upon their conclusions, although it is likely to be written by the organizers.

A deliberative poll attempts to show 'what the public would think, had it a better opportunity to consider the questions at issue'.²⁸ Several hundred members of the public are randomly recruited in an attempt to survey the views of a representative sample of the population. Participants' opinions are surveyed using a self-completion questionnaire and they are offered briefing materials on the topic of interest. The group is then convened at a single location over a weekend where there are opportunities to debate the issues further in small groups and to question panels of selected experts. Any resulting changes in attitudes are measured through changes in responses to an identical

questionnaire to the one completed before the poll. To date five deliberative polls, all nationally televised, have been held in the UK.

There are a number of problems with both methods. They are held over consecutive days so there is little flexibility in the way in which information can be offered to participants. Experts and witnesses need to be selected in advance by the organizers. Given the small numbers of participants involved in citizens' juries, they can never be representative, and it is not possible to measure opinion quantitatively. Whilst deliberative polls may overcome these drawbacks, the time for debate and access to the experts is still limited and predetermined. Both models also create an artificial 'hot-house' atmosphere outside the normal social structures of participants.

The Wellcome Trust has begun to work on developing another method of public consultation that will allow detailed qualitative analysis, as presented here, to be combined with quantification of the attitudes expressed as a percentage of the UK population. The aim is to measure attitudes and any changes during a longer deliberative process. By recruiting a representative panel, maintained over several months, we hope to develop a model that reduces concerns about the 'hot-housing' atmosphere and access to expert information. Such a model should also be more flexible when presenting information to participants and will allow time to respond to their needs rather than fixing in advance the information available to participants when addressing an issue.

7.3|Areas for further research

This research project has highlighted a number of important areas where further research is needed if we are to understand the diversity of public views. An obvious next step is to expand the sample to include groups such as the unemployed and others on state benefits, older people, disabled people, religious groups, ethnic minorities and those holding strong views on medical interventions.

It is clear that there is much that is not yet known about how people take on board new technical information and interpret it within contexts that are relevant to themselves and their lives. One area not fully explored in this research was differences in the understanding of technical terms commonly used in ethical discussions by policy makers. A better understanding of the barriers to communication between 'experts' and 'lay people' is required.

Exploring public perceptions of scientific researchers raises the need for a better understanding of their own views of their social role. In addition to investigating how the scientific terminology is used when debating social and ethical questions, there is a need to explore the perceptions of 'them and us' from several perspectives. The Wellcome Trust is planning a survey that will look at scientists' views on communicating with the public, the social and ethical implications of their research, and their perceptions of their social responsibilities.

Those who took part in this research could be described as pragmatic yet sceptical. They were suspicious of scientists and sceptical of the ability to enforce regulations – even though they believed that regulation was required. They did not believe that their views were valued by policy makers. These problems need to be addressed and research methods refined if public consultation is to be meaningful and contribute to better decisions.

references

appendices

References

- A.1** | Research methods
- A.2** | Briefing to researchers
- A.3** | Topic guide
- A.4** | Stimulus material
- A.5** | Recruitment questionnaire

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Appendices

A.1 | Research methods

Design

The research method used consisted of reconvened group discussions and paired depth interviews. The process involved: educating and informing the participants of the key issues; time for participants to consider the issues away from the hot-housing environment of the group as well as time to discuss the issues with their friends and family; and an opportunity to explore attitudes after this period of deliberation.

It was important that the moderators had a comprehensive understanding of the science of cloning in order to be able to take participants through the technology. A full briefing was therefore conducted by the Trust which included members of the Medicine in Society team and one of the Trust's scientific staff. A copy of the briefing documentation is appended.

Participants were recruited by professional market research recruiters according to certain criteria (see Appendix A.4 on recruitment questionnaires).

Documentation for use in the research groups was prepared by members of the Medicine in Society team which was commented on by the researchers. The aim of this documentation was to help the researchers explain the technologies to participants and to provide participants with material to take away and refer to during the period between the groups. A copy of this material is appended. In addition to covering the necessary scientific information it also covered the current regulatory system and set out the questions from the consultation document that this research hoped to illuminate.

The researchers used a topic guide to ensure that the main issues were covered in all of the groups; this is appended. However, by the nature of qualitative research, while all the groups began in the same way, the topics will have been covered in the order in which it seemed most appropriate for each group once it had begun. In this sense, the topic guide was used as an *aide memoire* by the researchers.

The two research agencies contracted to undertake this work provided detailed debrief presentations to the Trust. In this respect, the initial analysis of the data was undertaken by NOP Family and The Research Business International (TRBI). (TRBI undertook work among the 'general population' while NOP Family undertook the 'special group' work; this division of labour was based on the two organizations' differing interpretations of the Trust's brief.) From this material, and copies of the transcripts and the original audio tapes, a more detailed analysis was undertaken culminating in this report by the Wellcome Trust's Medicine in Society team.

Sample

Participants were recruited in groups as follows:

- BC1 men 35–44 years old, children up to 11 years
- BC1 women 25–34 years old, with no children
- C2D men 25–34 years old, with no children
- C2D women 35–44 years old with children up to 11 years
- BC1 couple 35–44 years old children up to 11 years
- BC1 couple 25–34 years old, with no children
- C2D couple 35–44 years old, children up to 11 years
- C2D couple 25–34 years old, with no children
- Older men and women with children and grand children 55+*
- Pregnant women – mix of first and second time*
- Women in late 30s and 40s with no children*
- Women who have lost a baby or a young child*
- Lesbians*
- Women in 20s and early 30s with no children – attempting unsuccessfully to conceive for at least six months*

* Groups chosen because their characteristics were thought likely to influence their views on cloning.

Recruitment exclusions

Those likely to have specialist knowledge or education in the fields of science, human biology and human reproduction (including scientists, healthcare workers and those in related fields such as the pharmaceutical industry) were excluded at the recruitment stage. Those holding strong personal beliefs about human life and medical interventions, and members of pressure groups taking such views, were also excluded.

Participants were paid an incentive of £20.00 at stage I and £20.00 at stage II. Only three participants did not return for stage II – one BC1 man who had a previous work engagement and two of the C2D men for unknown reasons.

Group discussions

The group discussions lasted two hours at both stages of the research. All were audio-taped and two were video-taped for analysis purposes.

The groups began with a warm-up by asking people about medical research generally and what they felt were important areas for research. Participants were then shown a set of cards with various terms on them and asked for their images of each term. The terms presented on cards were: 'genetic research', 'genetic medicine', 'gene therapy', 'genetic engineering', 'artificial insemination', 'reproductive medicine', 'artificial insemination', 'IVF', 'DNA' and 'genes'. The term 'cloning' was presented last, and participants were asked how they regarded its relation to the other terms.

The discussion moved on to focus on genetics and cloning. The groups were assessed to find out how much knowledge exists about the area of genetics and cloning. They were taken through some of the 'key facts' about genetics, shown on concept documents. At the end of the first set of groups, participants were assessed to find out their initial response to these 'key facts'.

At the end of stage I, groups were left with:

- literature (very simple, to encourage them to read it);
- a diary to monitor their response, and that of peers and family to the issues.

The groups were reconvened between one and four weeks later (stage II).

At the reconvened groups, discussion focused on opinions based on the information they had been given, how and why they had changed if they had. There was also discussion of how participants had tried to engage their friends, family and colleagues in discussions on the subject in the intervening period. Many had found it difficult, as they either could not interest people sufficiently or felt insufficiently knowledgeable to answer questions on the topic put to them. There was some feeling that they were pleased to be back in the group environment with others who realized the importance of the issues.

Participants were encouraged to share what they had written in their diaries in the interim period, and these were collected for later analysis.

It had originally been intended that the groups would use a number of projective techniques to explore feelings about the issues. However, most participants were easily able to verbalize their feelings and beliefs and, with the additional use of imagery from popular culture, it became largely unnecessary to employ non-verbal techniques or story-telling and imaginary procedures as had been originally envisaged.

A.2 Briefing to researchers

Public Views on Human Cloning

Qualitative research
 Ian Muchamore, Project Manager

- Aims
- Development of methodologies
 - Inform WT response to government

Aims of research:

- examining different methodologies
- submission to the HGAAC consultation paper , Cloning Issues

Cloning concerns

- Human embryo research
- Genetic identity
- Instrumentalisation
- Experimental human beings
- Natural/Unnatural

Reactions from the media to developments in cloning have varied from serious coverage of ethical to the bizarre....

Daily Mirror , 25 Feb 98 - Plans: To Clone Elvis: Plans To Clone Elvis Presley From His Toenail

ELVIS Presley fans were shocked yesterday by a bizarre plan to create a clone of the King - from one of his TOENAILS. A group called ACE (Americans for Cloning Elvis) has launched a campaign to produce a double. Over 3,000 fans have signed a petition urging controversial Dr Richard Seed - who wants cloning technology for infertile couples - to use Elvis's DNA. It is said to be available in a toenail collected by a fan.

A more informed debate ?

A public consultation paper on cloning was jointly launched in January by the Human Genetics Advisory Commission and the Human Fertilisation Embryology Authority - they have asked for comments on these areas in particular :

What is cloning?

- (Normal fertilisation)
- Embryo splitting
 - Also occurs naturally - identical twins
- Nuclear transfer
 - No natural equivalent

Confusion over the term cloning

Scientists have used the term rather carelessly to describe several quite separate research techniques. For our purposes cloning is NOT:

- as applied to production of bacteria such as used in wine or breadmaking
- the cultivation of plants from cuttings
- the copying of foreign DNA within bacteria

- In normal fertilisation genetic material (DNA) from a sperm and egg combines. Half the genetic material is provided by each parent.

Cloning techniques

- Embryo splitting
 - Occurs naturally, this is how identical twins form.
 - Can also be induced artificially.
- Nuclear transfer
 - There is no natural equivalent of nuclear transfer.
 - Almost all the genetic material of a cell is contained in the nucleus. Using microsurgery it is possible to remove the nucleus from a cell and transfer it to another cell which has had its nucleus removed.

Developments in nuclear transfer research:

- 1952 Frogs cloned from tadpole cells
- 1962 Tadpoles cloned from adult frog cells
- 1996 Sheep cloned from embryo cells
- 1997 *Sheep cloned from adult cells (Dolly)*
- 1997 Sheep cloned from genetically modified embryo cells

As suggested in HGAC Chair's accompanying letter try to 'Sort the facts from the science fiction

- Initial experiments showed that while it was possible to reprogramme genetic material from tadpoles (1952), material from adults was only partially successful (the 1962 experiments produced no adult frogs).
- The Roslin group have worked on perfecting nuclear transfer techniques during the 90's and have developed methods which can reprogram genetic material from donor cells.
- 1996 Sheep cloned from embryo cells. The sheep Megan and Morag were produced using the same techniques that would soon lead to success in using adult donor cells. Patents were applied to cover the techniques. Few scientists seem to have appreciated the significance of this work at the time.
- 1997 *Sheep cloned from adult cells (Dolly). Born 5 July 1996*
- 1997 Sheep cloned from genetically modified embryo cells. The cells used to produce Polly contain a gene which will produce a human blood clotting product in their milk.
- 1998 Dolly is now pregnant

Developments in IVF

- 1978 Birth of Louise Brown
- 1993 Embryo splitting in USA
- 1997 Sex selection offered to couples

Three examples of IVF technologies:

- 1978, the world's first test-tube baby -- in 1978 showed that it was possible to create a human embryo outside the body and implant it successfully in the woman and bring the pregnancy to term. This is known as IVF -- in-vitro fertilisation. Now 500 IVF babies per year are born in UK, 1/3 pregnancies are twins or more
- 1993, The successful splitting of human embryos is announced by US scientists. This technique is banned in UK.
- 1997, UK couples are offered the opportunity to select the sex of their IVF embryo before it is transferred to the woman. The technique - Prenatal Genetic Diagnosis, can examine the genetic makeup from an embryo biopsy and is already used to detect some genetic conditions. Sex selection for purely social reasons is prohibited in the UK, but couples are offered treatment abroad at a cost of £10,000.

Why is Dolly special ?

- Dolly is a clone of an *adult* cell
 - Adult cells are highly differentiated
 - Embryo cells are less differentiated
- Dolly was cloned from an adult udder cell

• The birth of experiment 6LL3 (aka Dolly) showed that it was possible to deprogramme an adult cell such that it could successfully control the development of an embryo. There are 100's of different cell types eg skin, liver, heart. These contain the same genetic information, but have chosen a particular path during development. Before Dolly, many scientists believed that adult cells would be unsuitable for cloning since it would be extremely difficult to 'wipe clean' the genetic material's memory of these choices.

• Previous successful cloning experiments had used donor cells which had taken fewer choices towards their final cell type. Cells such as embryo cells are described as less *differentiated*.

How was Dolly produced? (see diagram from [Guardian Education](#))

- Genetic material from an adult udder cell of a Black Faced ewe was transferred to an unfertilised egg where the original nucleus had been removed.
- 277 reconstituted embryos. An electric current was applied causing the contents to fuse together
- 29 embryos grew to several cells and were transferred to surrogate ewes.
- 1 lamb was born - named Dolly in tribute to Country and Western singer
- Dolly has an almost identical genetic makeup to the Finn Dorset ewe that she was derived from.

Is Dolly really that special?

(probably, yes)

- But perhaps Dolly was cloned from:
 - A less differentiated adult cell?
 - An embryo cell?
- More tests to confirm - results soon
- Whatever, the public concerns remain

Applications of animal cloning

- Gene targeting in livestock
- Elite livestock herds
- Therapeutic proteins
- Xenotransplantation
- Animal models of disease
- Ageing and cancer

Is Dolly really special?

• In recent weeks some scientists have raised concerns that Dolly may not in fact be derived from an adult udder cell. One concern, highlighted in the original publication, is that the donor cell may have been less differentiated than is assumed. However, this would still demonstrate the ability to clone from some adult cells - a remarkable technical development.

• A more serious concern is the possibility that a few fetal cells could have been present alongside the udder cell cultures. The ewe which provided the donor cells was pregnant at the time and some fetal cells are known to escape into the bloodstream

• Dolly is a Black faced breed of sheep - her surrogate mother is a different breed, without the distinctive markings. Further DNA fingerprinting tests are being carried out to check these possibilities.

How old is Dolly?

The donor udder cell used to create Dolly was 6 years old. So is she really a 7yr old rather than a 1yr old? The answer is unclear so far, but as far as we know she is healthy and fertile. Only time will tell.

• The HGAC public consultation is concerned with issues raised by human cloning, but it is likely to be important to examine attitudes to animal experiments that have led to these issues being raised. Dolly is part of a research programme which attempts to introduce specific genetic changes into livestock.

• Gene targeting in livestock - allows to remove genes as well as add.

• Elite livestock herds. A prize winning cow with exceptional milk yield is likely to only be able to produce half a dozen offspring in a lifetime. Offspring will still only have only 50% of her genes and may not perform as well.

Cloning adult cells from the cow could allow the production of elite herds. However since such animals would be identical there may be a higher risk of disease.

• Therapeutic proteins - produce blood clotting factor.

• Xenotransplantation - genetically modified animal organs will not be rejected by humans

• Animal models of disease

• Ageing and cancer

Note - it is not clear whether all the suggested applications would require cloning from *adult* cells, rather than embryo cells.

Applications of human cloning

- Embryo research
- Understanding ageing and cancer
- Cell therapy
- *Reproductive cloning*

- Confusion over the term 'cloning'
 - Reproductive cloning - identical humans
 - Therapeutic cloning - other research
- Embryo research. Working with identical embryos could allow scientists to better understand the basis of congenital disorders.
- Understanding ageing and cancer. This technology could provide an important tool to study the basic biology. It is believed that damage occurs to the genetic material in cells over time. Such damage is involved in cancers and may be part of the reason our bodies eventually 'wear out'.
- Cell therapy - The cloning of adult cells could provide a source of replacement cells which would perfectly match the genetic makeup of the patient. Examples include cells to treat Parkinson's disease.
- Reproductive cloning - while cloning of human beings appears to be prohibited in the UK, a number of scenarios have been suggested where it might be applied.

Reproductive cloning

- Another Saddam?
- Organs to order?
- Replacing a loved one
- Infertile couples
 - Lesbian couples

- Your initial response may be that human cloning could be used to copy another mad dictator who had the money and research expertise available. It is difficult to see this would result in an identical person to the original. I'll mention some of the difficulties in a moment.
- *Your child will die of kidney failure within 5 years without a transplant. There is no suitable donor. As parents, you might decide to have another child - perhaps they will be a suitable donor.*
 In fact, such cases such as this have already been anecdotally reported. But having another child cloned from the first should avoid the risk of rejection. Should human beings be created as a 'means' like this. How different would this be from the decisions that parents already make. Isn't it their freedom to decide?
- Replacing a loved one - Ian Wilmut has been approached by several families wishing to replace a loved one who has died.
- Infertile couples may currently be able to use donated sperm and/or eggs to have a child using IVF techniques. But wouldn't reproductive cloning give them an alternative - a chance to have a child which shared all their genetic material from their social parents, even if it just from one.
 Lesbian couples have used donated sperm to have children for years.
 Reproductive cloning would allow the transfer of genetic material from one woman to another's egg. The child might be said to have 2 biological mothers.

Clones and identical twins

- Genetically identical (identical)
- Genetically identical
- Different womb
- Same womb
- Different ages
- Same age
- Dissimilar upbringing
- Similar upbringing

•Beware the pitfalls of genetic reductionism!

Identical twins result from the natural splitting of a developing embryo - a rare event. After this division the twins will still experience slightly different environments in the womb and will of course have different experiences throughout their lives.

Clones and identical twins

Any clone created from an adult using the Wilmut techniques will be *less* similar than identical twin:

- They will experience a wholly different environment during development in the womb
- They will differ in age by several years
- A small amount of DNA will still come from the mitochondria of the recipient egg (but clones created using artificial embryo splitting techniques would be identical in this respect)

The Legal Framework

- The Human Fertilisation and Embryology Act 1990
- HFEA regulations
- Licensing system

After the birth of Louise Brown, Britain set up first a voluntary system of regulating IVF clinics then, in 1990, Parliament legislated to set up the Human Fertilisation and Embryology Authority (HFEA). No human embryo can be created outside the body, nor can eggs and sperm be kept outside the body, without a license from the HFEA.

Britain is slightly unusual in terms of international law in that the 1990 Act permits human embryos to be created for the purpose of research. Such embryos must not be implanted into a woman and they must not be kept for more than 14 days.

Research on human embryos is permitted only

- when all relevant animal research has been done and then only
- to discover advances in the treatment of infertility;
- to increase knowledge about congenital disease or malformation; or
- to develop more effective means of contraception.

Parliament made it clear in 1990, that cloning human beings should not be permitted. However, the precise legal wording of the 1990 Act did not encompass the procedure which created Dolly. The Act thought only in terms of embryos (eggs which had been fertilised by sperm) whereas Dolly was produced by inserting genes into an unfertilised egg.

4. **The costs versus the benefits of the new cloning technology in the future**
 - Does knowing about other uses of research from reproductive cloning (eg future possibilities with skin grafts, bone marrow and possibly kidneys) make a difference to how you think and feel?
 - Cloning Dolly had a success rate of 1 in 277. Assuming the human success rate was about the same could this be worth it, either financially or ethically in some circumstances?
 - And of the successfully cloned embryos, 26 had malformations. The success rate would probably improve over time. Knowing this would a human programme of research be acceptable, if these sort of problems were found to exist, in attempting to clone humans?
5. **How different is the cloning process from current reproductive technology?**
 - Is there a difference between doing things, which occur in nature, ie test tube sperm and egg fertilisation?
versus
doing things which do not occur naturally, ie replacing the nucleus of an egg with the DNA from another adult cell?
5. **Should human cloning research be controlled?**
 - What confidence do you have in the current regulations to control human embryo research? (*Details of the current regulations are on the "Legal Framework" sheet*)
 - Are there issues raised if therapeutic human cloning research is NOT funded by government?
 - *Such as research funded by charities, commercial companies or individuals*
 - Would there be a difference between cloning to produce identical human beings offered on the NHS or by a private company?
 - If you wanted to be cloned, but regulations forbade this, what would you think and do?
 - *Would you go for cloning to an unlicensed clinic? What about for IVF treatment?*

1. **Research using the new cloning technology in the future**

It involves taking the nucleus of an egg and replacing it with the DNA from another cell to form an embryo

 - Is this of more concern than research currently conducted on embryos?
 - Does it raise any new ethical issues?

Does it matter how an embryo which is created for research is made? (ie the cloning method versus the sperm and egg reproductive method in a test tube? Currently scientists say that up to 14 days the embryo hasn't a sufficiently developed nervous system to feel anything. After 14 days by law the embryo must be destroyed.)

N.B. This basic scientific research may help with the understanding of ageing and cancer.
2. **How important is it for humans to have a unique genetic identity?**
 - Does it matter if someone is produced with the same genetic material as someone else?
 - What do you think about identical twins? What feelings do you have about them?
 - How would you feel if there was someone with the identical genetic make up as yourself?
 - Is having a unique genetic identity a necessary human right?
 - Does it make a difference if it happens naturally versus by artificial means?
3. **The implications of human cloning in the future**
 - Might there be some special circumstances in which the cloning of identical human beings could be acceptable?
 - What special circumstances might these be? Or should it be banned altogether?
 - Are their implications and possible benefits for a person any different than those for wider society?
 - How far should doctors be allowed to go in developing technology which might help with fertility and prevention of disease?

A.3 | Topic guide

Topic Guide Stage 1 1. Introduction

Usual market research (and viewing room) intro. and assurances re: confidentiality.

Explain that we are working on behalf of a medical charity who wants to investigate how much ordinary members of the public know about some of the current developments in medical research, and that's what we'll be talking about in this session. Reassure that no prior knowledge is required - we genuinely want to explore what they know and what underlying thoughts and feelings this brings up for them.

Explain that we will be having a joint information giving session at the end of this first group, and that the purpose of meeting again in 4 weeks time will be to explore what effect this new information has had on them.

Reassure that there are no right or wrong answers - and not knowing about something or having inaccurate information is a reflection on how the media etc have handled certain issues rather than any reflection on them or their intelligence.

(Name of Wellcome can be revealed at end of re-convened sessions.)

2. Warm Up

Interactive exercise - respondents pair off and exchange details about self, family, work, hobbies and interests, then report back to the rest of the group.

3. Spontaneous Awareness of Current Topics and Issues in Medical Research and Scientific Research

- What do they think doctors are researching in medicine these days? (Allow them to think quietly for a few seconds, and suggest that it might be easier if they try to visualise a picture in their mind's eye.)
- Generate a list of the main topics that come to mind- continue generating until people who are looking at how the human body works at a fundamental level? What do you imagine they are investigating?"
- Continue to generate list of as many topics as possible.
- What do you think they should be investigating? What is important and why?
- LOOK AT LIST OF ALL TOPICS GENERATED: Which are the 5 most important to investigate and why?

4. When you think about these medical research issues, what sorts of people do you visualise actually doing this work? (PEOPLE BOARD)

- What sort of moral or ethical issues does it raise for you thinking about people working on these important areas?

EXPLAIN THAT WE ARE NOW GOING TO FOCUS ON ONE PARTICULAR AREA OF MEDICAL INVESTIGATION IN THIS MARKET RESEARCH EXERCISE. THEN PUT OUT CARDS WITH "GENES" AND "DNA".

- What feelings come up for them when starting to think about these two words? What do they know about these, and what are they aware about the field of medical research that might involve these?

5. Exploration of Baseline Views and Knowledge on Key Genetic/Reproductive Topics

PUT OUT THE FOLLOWING AS PHRASES ON CARDS

Genetic research
Genetic medicine
Gene therapy
Genetic engineering

Let them look at these for a few seconds and allow any spontaneous comments to arise.

- Then explore:
 - are these topics they know much about?, if so, what? and where did they find out?
 - can they visualise these? what? who? Where? (fingerprint of each)
 - how do they feel about each of these? Emotionally distant/ close?
 - is each good/bad? Morally acceptable or not? Useful or not? And why/why not?
 - can they map these topics to show how they are similar/different?

Q5a Are there any underlying processes behind being able to carry out these different types of medical research/therapy that might require government licensing or permission from a relevant authority?

- PROBE
 - what about research on animals?
 - What about providing embryos?

6. Explain that there is another set of topics where we wish to explore their views in a similar way.

PUT OUT THE FOLLOWING PHRASES ON CARDS:

Reproductive medicine
Artificial insemination (by donor, known, or unknown, by partner)
IVF/test tube babies

LET THEM LOOK AT THESE FOR A FEW SECONDS TO ALLOW ANY SPONTANEOUS COMMENTS TO ARISE

- Then explore:
 - are these topics that they know about? Where did they find out about these? How do they feel about each? Emotionally distant or close? (Which ones closest? Which most distant?) which are morally acceptable/not morally acceptable? Good/bad? Which are useful/not useful?
- 6a. Are there any underlying processes behind being able to carry out these types of reproductive procedures that might require government licensing or regulation?
- PROBE
 - What about animal research?
 - What about keeping embryos alive outside the human body?

6b. ADD IN CLONING as word on card

- What about cloning? What are their initial feelings on seeing this word? What thoughts and images does it bring to mind? Is it emotionally close or distant; good or bad? Useful or not? Morally acceptable or not?
- Which of the two groups of words on card does cloning belong to?

MAP AND RE-MAP ALL THE WORDS ON CARDS - TO UNLOCK WHATEVER UNDERLYING FRAMES OF REFERENCE SEEM TO BE DRIVING THOUGHTS AND FEELINGS ABOUT THESE MATTERS

Change of gear at this stage - congratulate them on all the hard work - take a quick break and tell them that in the remaining section of this first session we are going to give them some information which might be new. Explain that we are now going to be looking at the genetic implications of certain aspects of modern reproductive medicine.

7. Human Reproduction - Diagram of Genetic Implications of Normal Sexual Intercourse

Hand out individual copies of this diagram and talk them through key bullet points at the bottom - ask them to individually underline and annotate anything that is new information, anything they don't understand and anything they thought happened differently. Talk through these points in the group, then spend a few minutes generating a list of issues that this brings up for them when thinking about genetic and bio-medical issues.

8. Repeat for IVF diagram

9. The Current Legal Framework

Hand out sheet describing this - talk through their thoughts and feelings on reading this. Point out that it expressly forbids cloning from human embryo cells, but explain that events have now overtaken the legal framework due to the arrival of Dolly the sheep - information sheet re: Dolly can be shown here.

10. Information sheet re: Human Cloning - Peter and Mary - show sheets and discuss other possibilities such as two women, and self cloning. Explore any issues that arise (eg individual identity issues/no need for men).

11. Information sheet about therapeutic cloning - again explore issues arising, including "second class cloned embryos" that might be created only for this purpose.

12. Final Moments

Round the room summary of what they feel about what they have learned tonight - how it leaves them feeling, what issues are top of mind.

13. Instructions re: Next steps

Give them each take home pack of information.
 Ask them to look through it in 3 or 4 days time and make a few notes on pad provided.
 Ask them to open a discussion with a colleague in which they exchange views on any issues we have highlighted this evening, and see if any other issues come to mind, and particularly note if that other individual seems to take a different tack on how they see these issues. Note down responses in booklet.

Remind them of date, time, place of re-convened session, and how important it is that they attend.

CLOSE AND THANK

Topic Guide
Stage II - Re-Convened Session - Groups and Depths

1. RE-INTRODUCTIONS - NAMES AND SEATING PLANS RE-VISITED

Remind them there are no "right" or "wrong" answers that we are looking for today, and that we are interested in all the comments they make, and all the notes they have jotted.

2. WHERE ARE THEY NOW

- Initial thoughts, feeling, issues

3. WHERE WERE THEY AFTER STAGE 1 (USE DIARIES)

- How felt at end of group/thoughts/opinions etc.
- Initial discussions - who did they talk to /what about specifically
- Experiences reading and sharing information
- Track own responses and developments/any changes in attitude and how come
- Any outside influence/triggers which have influenced them eg trends, TV, press etc.

4. WHERE ARE THEY NOW - UNPROMPTED

- Any conclusions
- Questions arising
- Opinions about legislation

5. DEVELOP AND DISCUSS KEY SCENARIOS

GO BACK TO "TEACH IN" MATERIALS (SCENARIOS) ONE AT A TIME

- What is best for individual adult or adults?
- What is best for the child? (or potential child)
- What is best for "society"? (UK, world)
- What would be the impact and consequences for the other groups affected in each case?
- Cross refer to the seven question areas posed as relevant during and after each of the scenarios - including the therapeutic cloning applications.

6. DISCUSS THE "NOTES" THEY MADE THEMSELVES AND THE ISSUES ARISING

(MAKE LISTS ON FLIP CHARTS)

- Important issues for the future policy making/social acceptance (how should policies be framed? How should they be operated? Who should regulate and control? How can this be managed fairly and effectively?)
- Difficult areas
- Religious vs. secular vs. philosophical issues
- Discussion of "where you draw the line"
- Difficulties in voicing private opinions/fear of judging and being judged

7. SUMMARISE ABOUT BY RANKING/PRIORITISING KEY ISSUES OF CONCERN

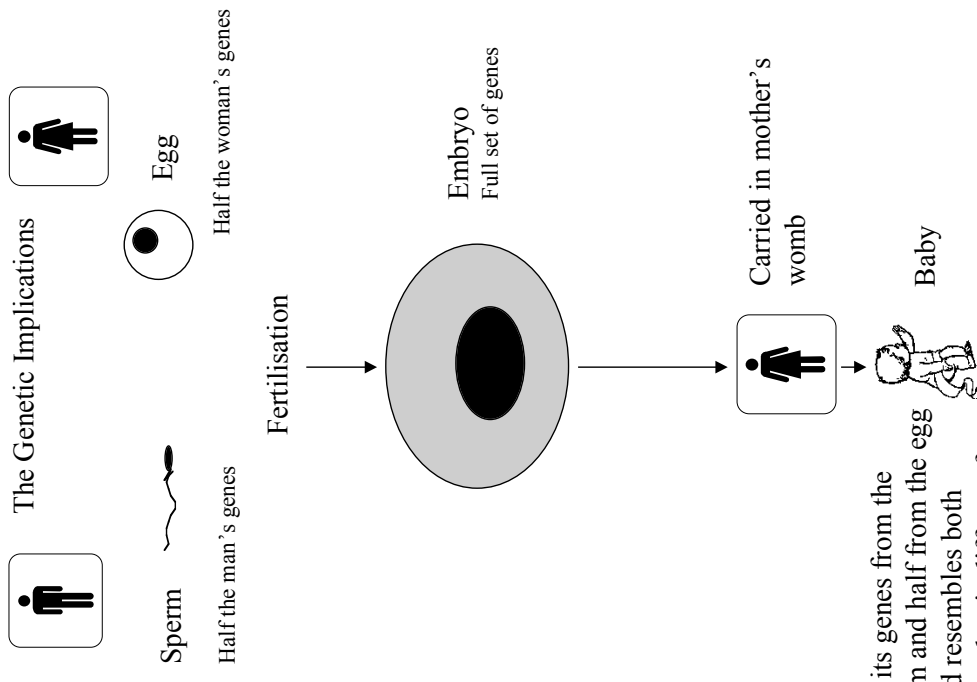
8. DISCUSS TEACH-IN PROCESS AND RESEARCH METHODOLOGY AS EXPERIENCED OVER THE TWO SESSIONS

- SWOT analysis
- Improvements

9. EXPLAIN BACKGROUND TO RESEARCH

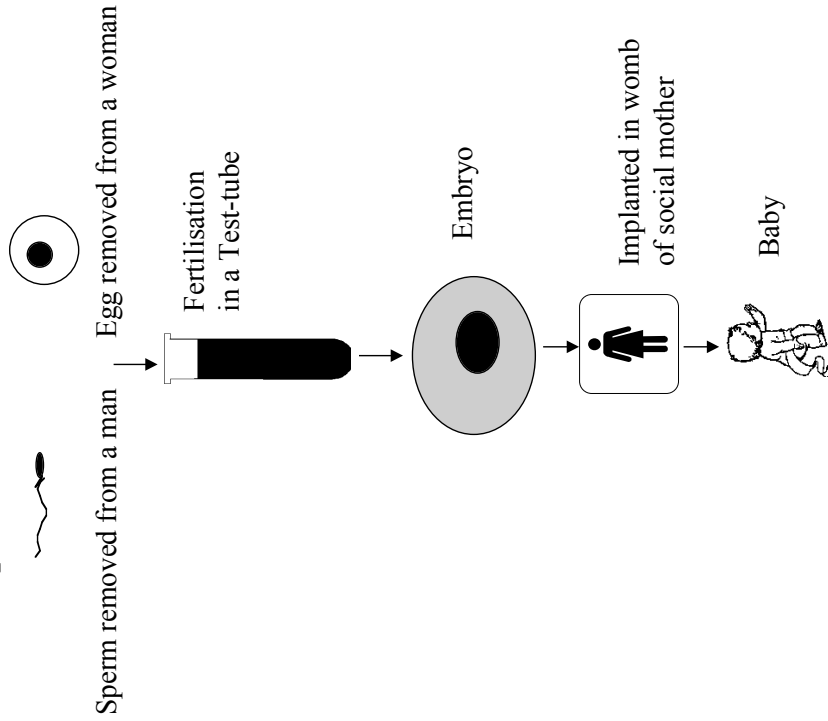
- Give feedback for evaluation of research process from respondents (anonymously)
- Advice to Wellcome Trust
- Provide leaflets from Wellcome Trust and introduce the clients

Human Reproduction - Sexual Intercourse



- Half its genes from the sperm and half from the egg
- Child resembles both parents but is different from each of them.

Human Reproduction IVF for Infertile Couples where Both are Infertile



- The child gets half its genes from the sperm and half from the egg
- Child resembles both genetic parents but is different from each of them. The child may not resemble its social parents

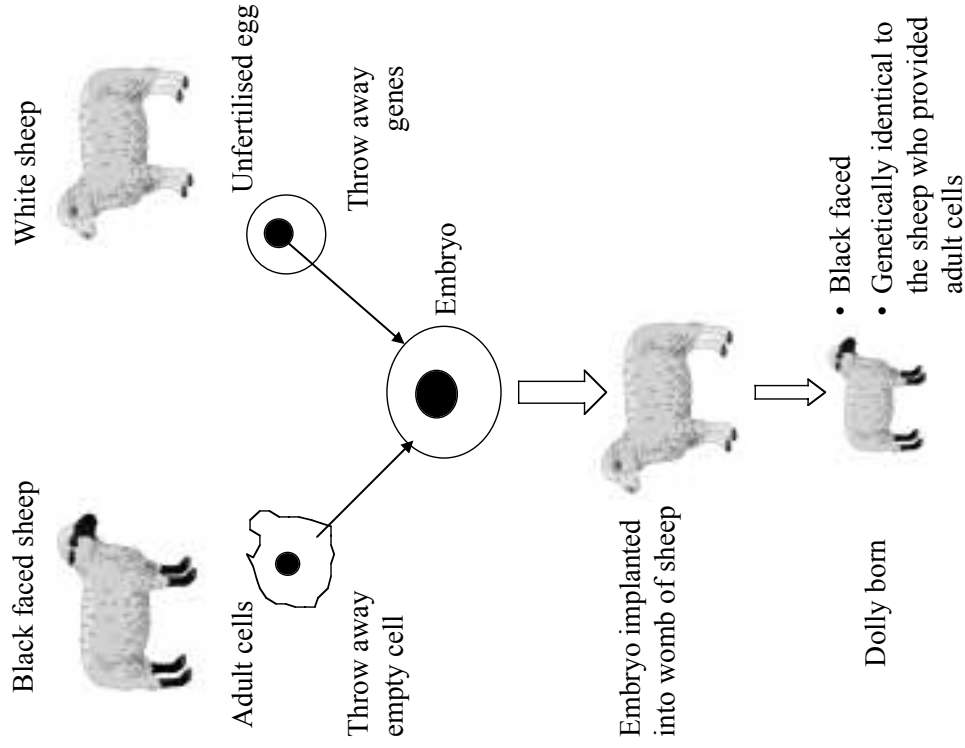
A.4 Stimulus materials

Current Legal Regulation of IVF

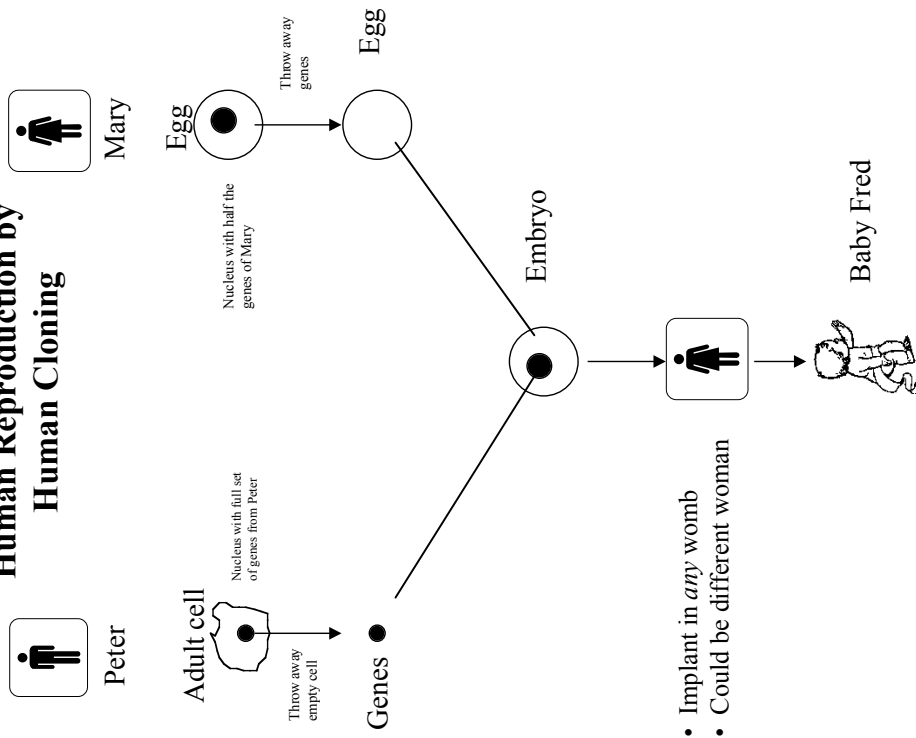
1990 Human Fertilisation and Embryology Authority Created by Parliament

- No human embryo can be created outside the body, nor can eggs and sperm be kept outside the body without a licence from the HFEA
- The 1990 Act permits human embryos to be created for research only, but
 - they must **not** be implanted in a woman
 - they must **not** be kept for more than 14 days
- Research on human embryos is permitted only:
 - ◆ when all relevant animal research has been done and then only:
 - to discover advances in treatment of infertility
 - to increase knowledge about congenital diseases or malformations
 - to develop more effective means of contraception
- Cloning human beings from embryos is specifically not permitted
- BUT cloning human beings from an adult cell was not envisaged at this point in time

Animal Reproductive Cloning from an Adult Cell - 'Dolly'



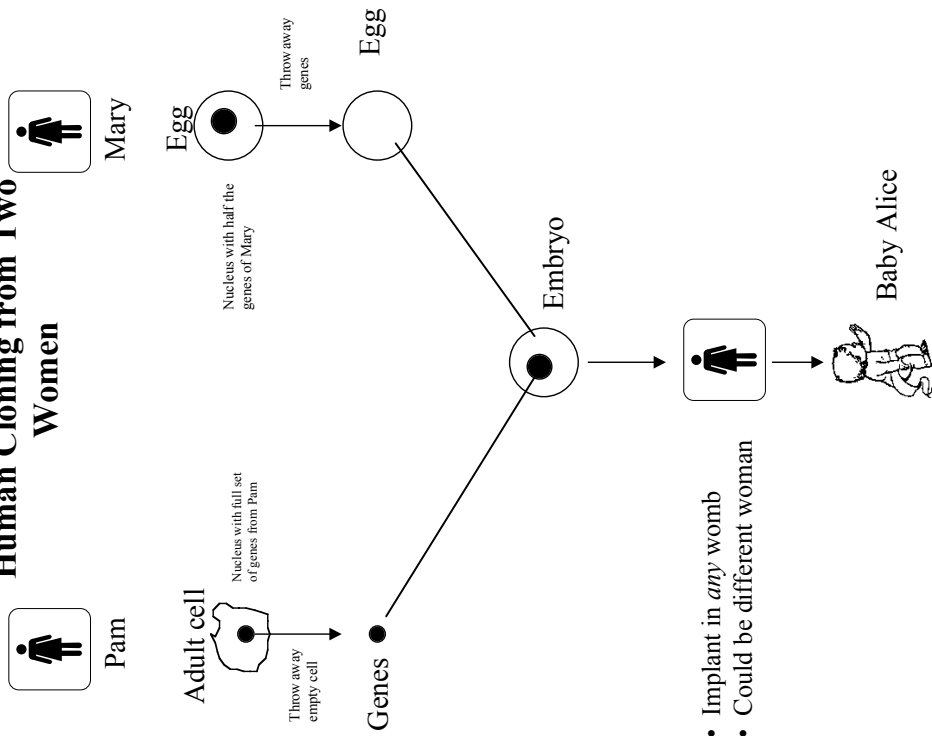
Human Reproduction by Human Cloning



- Implant in *any* womb
- Could be different woman

- Fred has the same genes as Peter - identical twin of Peter
- Peter is the genetic father of Fred
- There is no genetic mother
- Mary is the carrier mother

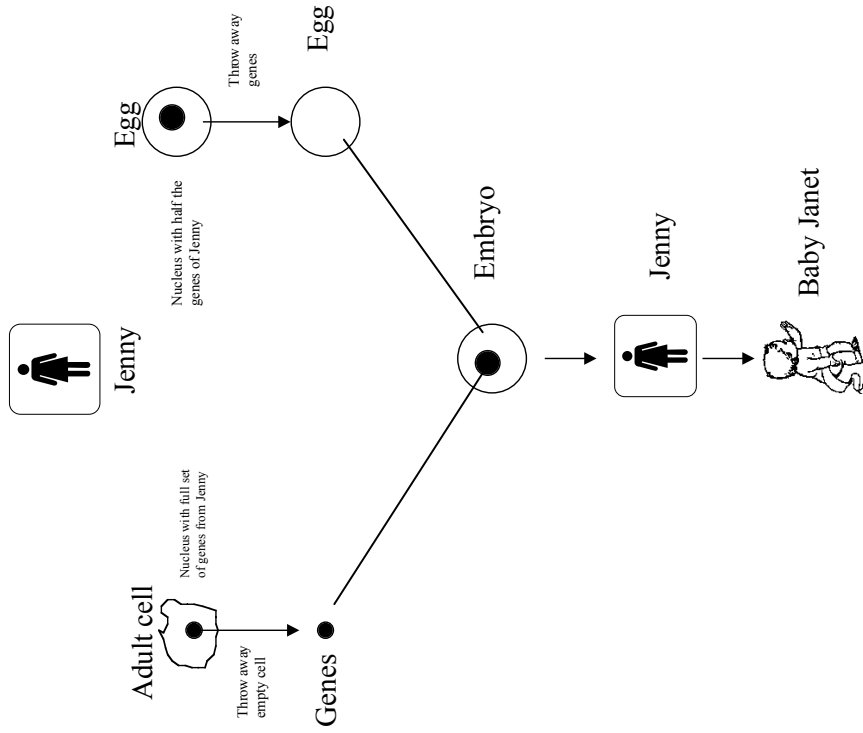
Human Cloning from Two Women



- Implant in *any* womb
- Could be different woman

- Alice has the same genes as Pam - identical twin of Pam
- Pam is the genetic mother of Alice
- Whichever woman carries Alice is the carrier mother

Human Cloning - From One Woman



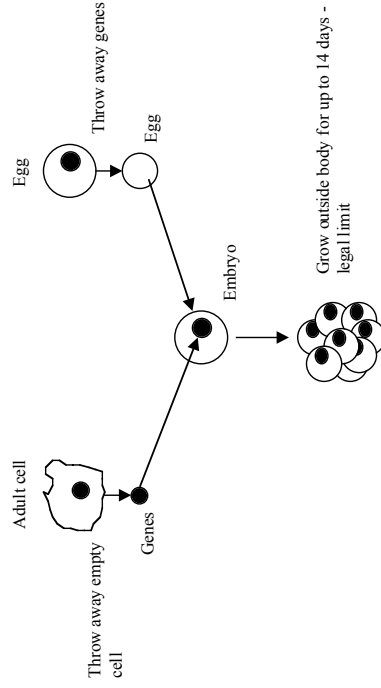
- Janet has the same genes as Jenny - identical twin of Jenny
- Jenny is the genetic mother of Janet
- Jenny is the carrier mother of Janet

Possible Research Applications of Cloning Which do not Create Identical Human Beings

- Advances in medical research are very difficult to predict but animal and human cloning could improve basic understanding of biology.
 - Ageing process - DNA damage in adult cells
 - Cancer - could lead to therapies

Replacing Cells, Tissues and Organs

- Cloned cells would reduce risks of rejection



It might in the future be possible to treat embryo cells outside the body to develop into:

- cells such as bone marrow
- tissues such as skin - more complex
- organs such as kidneys

Other Research

Currently, the deprogramming of adult cells requires the incubating of the nucleus in an unfertilised egg - the creation of a cloned embryo. Further research may lead to new ways of converting adult cells into other cell types.

What differences would there be if cells, tissues and organs could be grown without the need to first create an embryo as a source of cells?

Q3. Avid reader, which of the following newspapers do you read regularly and how often in the last week:

	Regularly	Last week
Times / Sunday Times	V	V
Telegraph / Sunday Telegraph	X	X
Financial Times	0	0
Independent / Independent on Sunday	1	1
Guardian / Observer	2	2
Mail / Mail on Sunday	3	3
Express / Sunday Express	4	4
Mirror / Sunday Mirror	5	5
Star	6	6
News of The World	7	7
Local Newsletter n.p. / Yorkshire Post	8	8

ALL ICT RESPONDENTS TO HAVE READ A BROADSHEET (CODES V - Z) IN LAST WEEK

ALL CSD RESPONDENTS TO HAVE READ ANY PAPER IN THE LAST WEEK

RECORD TO GROUPSCOUPLE DEPTHS BUT CHECK THE FOLLOWING CAREFULLY

- (f) Availability on both dates (for re-contacting)
 - importance of coming twice.
- (g) Willingness to meet across about 10 fields between the sessions, and to find a friend, family member or colleague to chat through the topics raised with.
- (h) Awareness that they don't need to get specially geared up in advance of Stage 1, or "pass a test" that demonstrates their learning ability or knowledge. It is crucial for the success of this project that they not absolutely normally between being recruited and coming to Stage 1 feedback, and then it will be important to go on-site with the simple instructions between Stages 1 and 3.

Q4. I am conducting a market research survey on behalf of Pivotal on Research and have to ask people in certain trades and professions. Do you or any of your close family work or have worked in the sectors past in any of the following professions? SHOW CARD A

Advertising, Marketing/Market Research...Journalists, Pharmaceutical Industry including Biotech, Manufacturing/Manufacturing / Health Care, Biotechnology / Medical Science / Medical Research, NED / Health Care, Complementary Medicine or Therapies, PEI / Programmatic Research in Biomedicine

	Yes	V	CLOSE
Q4	No	X	0
Q5	Yes	V	AKM,OC
	No	X	GO TO Q11
Q6	Yes	V	CLOSE
	No	X	0
Q7	None	V	OC
	1 or 2	X	0P
	3	0	0P
	More than 3	1	CLOSE
Q8	Yes	V	IF NONE AT Q4, GO TO QP, OTHERWISE CLOSE
	No	X	0P

IK A TUTTSHILL - NB: If you have any queries at all, please call your Regional Manager

- At least one third of each group(s) of depths must be brand new recruits.
- The remaining recruits can have attended up to a maximum of 3 group(s) in the last 2 years (ie. 6 months - 2 years ago)
- Those who have been to 2 group(s) in the last 2 years must have had a 5 year gap before that
- None to have attended any group(s) in last 6 months
- None ever to have attended a group(s) on the same subject matter (see Q2)
- None to work in our firm family or close friends who work in any of the excluded occupations listed on sheetcard A.

Q9. What was the subject of the discussion group(s) that you took part in in the past 1 (WRITE IN SUBJECT MATTER AND APPROX. WHEN IT WAS FOR EACH OCCASION)

IF ABOUT - ANYTHING SCIENTIFIC, MEDICAL OR PHARMACEUTICAL, CLOSE THIS IS VERY IMPORTANT. THE RESPONDENT MUST NEVER HAVE PARTICIPATED IN A DISCUSSION ON THE SAME SUBJECT.

CD14

www.pivotalresearch.com

CD14

gatesh@pivotal.com

FULL NAME OF RESPONDENT: _____
HOME ADDRESS: _____

_____ POST CODE _____

FOR RESPONDENTS UNDER 14 YEARS, PARENTAL CONSENT MUST BE GIVEN. OBTAIN SIGNATURE OF PERMISSION FROM PARENT/GUARDIAN
SIGNATURE OF PARENT/GUARDIAN: _____

TEL NO. (HOME): _____ (PLACE OF WORK): _____
BEST TIME TO CONTACT (HOME): _____ AM/PM (PLACE OF WORK): _____ AM/PM
HOW RECRUITED (EG. STREET/TELEPHONE ETC): _____
DAY, DATE AND TIME OF GROUP/DEPTH: _____
GIVE RESPONDENT AN INVITATION/THANK YOU LEAFLET.

Please **PRINT CLEARLY** this information on your invited sheets and send the top copy to your Regional Manager with your physician.

I declare that I have carried out the interview in full, face-to-face with the person named above, according to your instructions, the interviewer's manual and the MRS Code of Conduct.

Signat: _____ Date: _____
Interviewer Name (please print name in full): _____

On all jobs unless otherwise specified - the moderator will need all questionnaires prior to any group/depth interview.
If a substitute venue is being used - please use 1 of the 2 following methods:
a) Give the questionnaires to a respondent to take to the venue.
b) Deliver questionnaires to studio before or on day of group.
If neither of these is suitable it is absolutely imperative that you contact your Regional manager immediately.
If group/depth is in-home - please have questionnaires completed and ready for moderators use.

CD44

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Questions used by [NOP Family for groups recruitment](#)

Older Men and Women with children and grandchildren 55+

Q 5.a Can you tell me, are you over 55? *If answer Yes - Ask Q 5.b*

Q 5.b Do you have any children and grandchildren? *If answer Yes - Recruit*

Lesbian women of child bearing age living in couples who have, or may in the future, opt to have children.

Q 5.a Can you tell me, would you consider yourself to be in a stable relationship with another woman?

If answer Yes - Ask Q 5.b

Q 5.b Would you like to have children in this relationship?

If answer Yes - Recruit

Women who have miscarried, or who have lost a child because of an accident or an illness that was not hereditary.

Q 5.a Can you tell me, have you ever miscarried, lost a baby or a child?

If answer Yes - Ask Q 5.b

Q 5.b Can you tell me, was this through a hereditary condition?

If answer No - Recruit

(Explain to women that we are recruiting groups of similar women because it is relevant to the research, but that we will not be expecting them to talk in depth about their bereavement unless they wish to do so.)

Women in 20's and early 30's with no children - attempting unsuccessfully to conceive for at least 6 months.

Q 5.a Can you tell me, have you ever attempted unsuccessfully to conceive a baby for more than 6 months?

If answer Yes - Recruit

(Explain to women that we are recruiting groups of similar women because it is relevant to the research, but that we will not be expecting them to talk in depth about their attempts to conceive unless they wish to do so.)

Pregnant women - mix of first and second and subsequent time pregnant women

Q 5.a Can you tell me, are you pregnant?

If answer Yes - Recruit

(We are looking for a mix of first and second and subsequent time pregnant women - all stages of pregnancy)

Women in their late 30's and 40's with no children (and have never had children)

Q 5.a Can you tell me, have you ever had any children?

If answer No - Recruit

(We are looking for women who have never yet had a child, for whatever reason)

About the Wellcome Trust

The Wellcome Trust is the world's largest charity, with an annual expenditure of some £300 million. The Trust supports more than 3000 researchers, at 300 locations, in 30 different countries – laying the foundations for the healthcare advances of the next century and helping to maintain the UK's reputation as one of the world's leading scientific nations. As well as funding major initiatives in the public understanding of science, the Trust is the country's leading supporter of research into the history of medicine.

Launched in 1998, the Medicine in Society Programme aims to ensure that policy development in relation to advances in the biomedical sciences is informed by public debate and sound research into the social and ethical implications of biomedical developments.

The Programme is made up of both research and activities carried out by an in-house team, as well as a comprehensive grants scheme. The MIS panel, which meets three times a year, awards grants in biomedical ethics and the public understanding of science.

Details of the Programme and a preliminary application form can be found at the Wellcome Trust Web site (www.wellcome.ac.uk).

Public Perspectives on Human Cloning: A social research study

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