Medical frontiers: Debating mitochondria replacement

Annex III: Public representative survey

Report to HFEA

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Executive Summary

The Office for Public Management (OPM), in partnership with Forster and Dialogue by Design, was commissioned by the Human Fertilisation and Embryology Authority (HFEA) to conduct a multi-method research and engagement project looking at the possible social and ethical issues relating to two techniques for the avoidance of mitochondrial disease: pronuclear transfer (PNT)[1] and maternal spindle transfer (MST)[2].

As part of this research and engagement, OPM ran a short representative survey of the public. Demographic quotas were set to ensure that the selected sample was representative of the UK population. In total, 979 face-to-face interviews were completed. The key findings are presented below.

1. General attitudes towards medical research and treatments for genetic diseases

The results indicate that the UK population holds very positive attitudes about the benefits of medical research: nine out of ten respondents agree that such research ‘can do a lot to reduce human suffering’ and that it ‘creates new knowledge and treatments which will benefit the wider healthcare system’. Whilst the responses point to a universal perception of medical research as beneficial, responses to the question about *‘unforeseen negative side effects’* show that half of the population has concerns about side effects.

Attitudes towards the treatment of people with genetic diseases are also highly positive: almost nine out of ten members of the public are in favour of providing people with serious genetic conditions with ‘healthcare and treatment to help manage their conditions’ and three-quarters feel that ‘families at risk of having a child with a serious genetic disease should be able to avoid that risk through genetic testing’.

2. Awareness of IVF and Mitochondrial Disease

The UK population shows a high level of awareness of IVF with 86% of respondents saying that they are aware of it. However, awareness in London and amongst Black and Minority Ethnic (BME) groups and related faith communities is lower (for example, awareness among Muslims was 51%).

The survey indicates that around one in ten of the UK population has experience of genetic diseases in their family or immediate circle of friends.

Awareness of mitochondrial disease is relatively low with just over a quarter (28%) reporting that they have heard of the disease. Awareness of mitochondrial disease is strongly correlated with education, rising from 10% of those with low educational levels to 25% with

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[1] Pronuclear transfer involves transferring the pronuclei from an embryo with unhealthy mitochondria and placing them into a donor embryo which contains healthy mitochondria and has had its pronuclei removed. A pronucleus is a small round structure containing nuclear DNA seen within an embryo following fertilisation. A normal embryo should contain two pronuclei, one from the egg (maternal pronucleus) and one from the sperm (paternal pronucleus).

[2] The maternal spindle is a structure within the egg containing the mother’s nuclear DNA. Maternal spindle transfer involves transferring the spindle from the intended mother’s egg, with unhealthy mitochondria, and placing it into a donor egg with healthy mitochondria.

medium levels of education and 46% to those with high levels; subsequently there is a similar gradient by social class[3]. There are only small variations by faith.

3. The Genetic Treatment of Mitochondrial Disease

The survey sought to establish general attitudes towards the testing of embryos during IVF. Two thirds (65%) expressed a positive attitude and 8% a negative attitude; 27% were undecided or unsure. In terms of sub group differences, the results show a drop off in positive ratings the testing of embryos during IVF for those who describe themselves as Christian and a more marked drop-off among Muslims. Although there are variations, negative attitudes are still confined to small minorities of Christians (9%) and Muslims (14%).

Asked to give their ‘initial reaction’ on the new techniques, between 44% and 56% expressed a positive initial reaction while between 10% and 15% had a negative reaction. These results suggest that respondent’s support for medical research and sympathy towards those affected continued even as the more ethically difficult subjects of PNT and MST were explained.

4. Attitudes to the Regulation of Genetic Treatments

When asked about the potential regulation of treatments for mitochondrial disease the findings suggest that the UK public have a range of preferences.

The option of couples being allowed to decide for themselves was favoured by over a third of respondents (36%). Slightly more (39%) favoured the involvement of a regulator of some kind – with a fifth (20%) selecting the option of an expert regulator deciding on an individual basis, and a similar amount (19%) calling for an expert regulator to approve particular clinics, with medical specialists deciding who to offer it to. A further one quarter were unable to express a preference.

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[3] See Methodology and Reporting (Section 2) for an explanation of how level of education and social class were ascertained.

1. Introduction

Mitochondria are present in almost all human cells. They are often referred to as the cell's 'batteries' as they generate the majority of a cell's energy supply. For any cell to work properly, the mitochondria need to be healthy. Unhealthy mitochondria can cause genetic disorders known as mitochondrial disease.

There are many different conditions that are linked to mitochondrial disease. They can range from mild to severe or life threatening, and can have devastating effects on the families that carry them. Currently there is no known cure and treatment options are limited. For many patients with mitochondrial disease preventing the transmission of the disease to their children is a key concern.

Mitochondrial disease can be caused by faults in the genes within a cell's nucleus that are required for mitochondrial function or by faults within the small amount of DNA that exists within the mitochondria themselves. It is the latter form of mitochondrial disease that could be avoided using two new medical techniques, termed pro-nuclear transfer (PNT)[1] and maternal spindle transfer (MST)[2] which UK researchers are working on.

These techniques are at the cutting edge, both of science and ethics and are currently only permitted in research. They involve removing the nuclear DNA from an egg or embryo with unhealthy mitochondria, and transferring it into an enucleated donor egg or embryo with healthy mitochondria.

The Human Fertilisation and Embryology Act (1990) (as amended) ('the Act') governs research and treatment involving human embryos and related clinical practices in the UK. The Act currently prevents the clinical use of these techniques (or any other technique that involves genetic modification of gametes and embryos to treat patients). However, in 2008 the Act was amended, introducing new powers which enable the Secretary of State for Health to permit techniques which prevent the transmission of serious mitochondrial disease. The Secretary of State for Health and the Secretary of State for Business, Innovation and Skills asked the Human Fertilisation and Embryology Authority (HFEA) to seek public views on these emerging techniques. On considering advice from the HFEA the Government will decide whether to propose regulations legalising one or both of the procedures for treatment.

The HFEA, together with the Sciencewise Expert Resource Centre[4], therefore commissioned OPM (in partnership with Forster and Dialogue by Design) to conduct a multi-method research and engagement project looking at the possible social and ethical issues and arguments relating to the techniques. The project consisted of five strands:

1. Deliberative public workshops
2. Public representative survey
3. Patient focus group
4. Open consultation meetings
5. Open consultation questionnaire

This research provides the evidence base that will inform the HFEA's advice to the Secretary of State.

The **public representative survey** explored attitudes towards the genetic treatment of mitochondrial disease. The findings from this survey help to build up understanding of public

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[4] The Sciencewise Expert Resource Centre (Sciencewise-ERC) is the UK's national centre for public dialogue in policy making involving science and technology issues

perception and to contextualise the wider consultation. This report provides a summary of the main findings.

2. Methodology and reporting

The aim of the survey was to ascertain awareness and attitudes towards the development of the new medical techniques of a representative sample of the UK public. A random location methodology was used to select respondents. It involved making a random selection of 175 sample points covering the whole of the UK. For each sample location, demographic quotas were set to ensure that the sample reflected the profile of the UK population.

Respondents were contacted by interviewers in the 175 sample points; they were not members of panels and had not been pre-contacted for any other purpose. Interviews were carried out in August 2012. In total, 979 face-to-face interviews were completed; a profile of the sample can be found in Appendix B.

The survey consists of ten questions and was included in a UK omnibus survey. It aimed to gauge the awareness and attitudes of respondents by asking a series of yes/no questions as well as the extent to which they agree or disagree with a series of statements, using a five point scale and a ‘don’t know’ option. Throughout this report references are made to particular survey questions. A full copy of the survey can be found in Appendix A.

This report shows responses to the questions asked as the percentage of the overall sample. Where less than 0.5% of respondents answered a question, this is shown as ‘*’ to indicate that at least one respondent endorsed this answer but the number who did so was less than 0.5% of the sample.

The report contains few comparisons between sub-groups since views were held relatively consistently between sub-groups, or because variations were relatively small and lacked consistency. However two factors produced more consistent variations:

- **Education**: a number of questions showed consistent variations for education (and subsequently for social class)
- **Faith**: there also were some variations by faith, showing a difference between respondents who reported that they had ‘no religion’ and those who reported they were ‘Christian’ or ‘Muslim’. The sample sizes for other faith groups were too small to allow for any systematic comparisons

While these differences were notable, they did not point to any polarisation of views. Instead they suggest that some views were held less or more strongly but were broadly on the same continuum.

Note about the sub-group classifications

Education level was ascertained by asking respondents to indicate their highest level of education qualification held – where low equals no qualifications, medium equals O-Level, GCSE, A-level, GNVQ or similar and high equals a degree, postgraduate, NVQ/SVQ level 4 or HNVQ.

Social grade was decided based on the job of the head of the household. The interviewer asked for the job role and then coded it at the end of the interview. In the case of respondents who were retired, they were asked for the previous job if on private pension, or if on state pension only, then automatically classified as an ’E’. The NRS social grades are the standard categories used in social research in the UK. They are decided on different criteria depending on the type of job. For example, it could be number of people responsible for, type of qualification needed, level of skill needed etc.

3. Key Findings

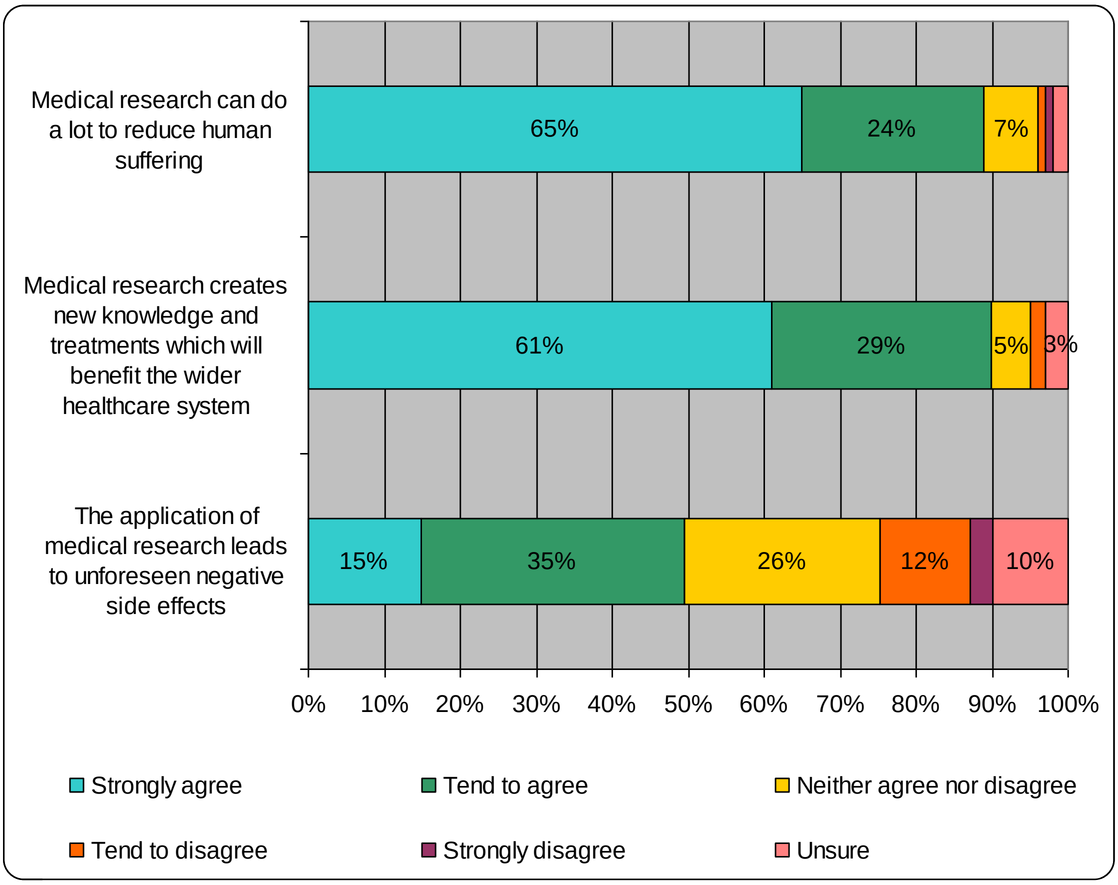
3.1 General attitudes towards medical research and treatments for genetic diseases

Figure 1 shows responses to three general questions about medical research. Responses indicate that the those who took part in the survey hold very positive attitudes about the benefits of medical research: nine out of ten respondents agree that such research 'can do a lot to reduce human suffering' and that it 'creates new knowledge and treatments which will benefit the wider healthcare system'; almost two-thirds hold these views 'strongly' and only very small minorities (2%) disagree with the statements.

Whilst these responses point to a universal perception of medical research as beneficial, responses to the question about 'unforeseen negative side effects' show that half of the population has concerns about side effects. Fifteen percent disagree with the statement about side effects and 36% are either unsure or feel they can neither agree nor disagree with the statement.

There are no systematic variations between different sub-groups on the first two items; however on the question about side effects, Muslims express slightly more concern (61%).

Figure 1. Attitudes towards medical research and treatments for generic diseases

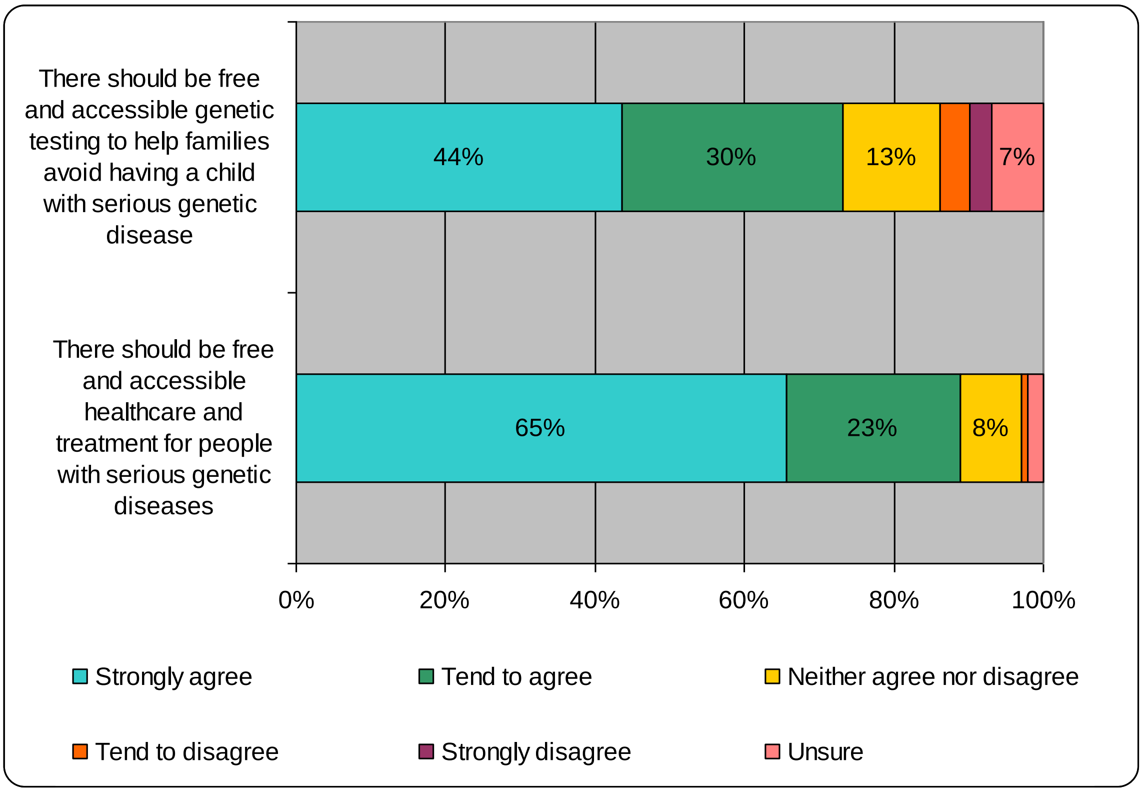


Base: All (979)

Attitudes towards the treatment of people with genetic diseases also are highly positive: almost nine out of ten members of the public are in favour of providing people with serious genetic conditions with 'healthcare and treatment to help manage their conditions' and three-quarters feel that 'free and accessible genetic testing to help families avoid having a child with serious genetic disease' should be made available. The question about genetic testing receives slightly more opposition (7%) as well as more uncertainty (20% are either unsure or undecided).

There are no major variations in attitudes for the first statement. For the second statement, respondents who reported that they had 'no religion' are slightly more positive (Mean Score of 1.31) compared with Christians (MS 1.14) or Muslims (MS 0.96) (see Appendix C for a full breakdown of the mean scores).

Figure 2. Attitudes towards the treatment of people with genetic diseases



Base: All (979)

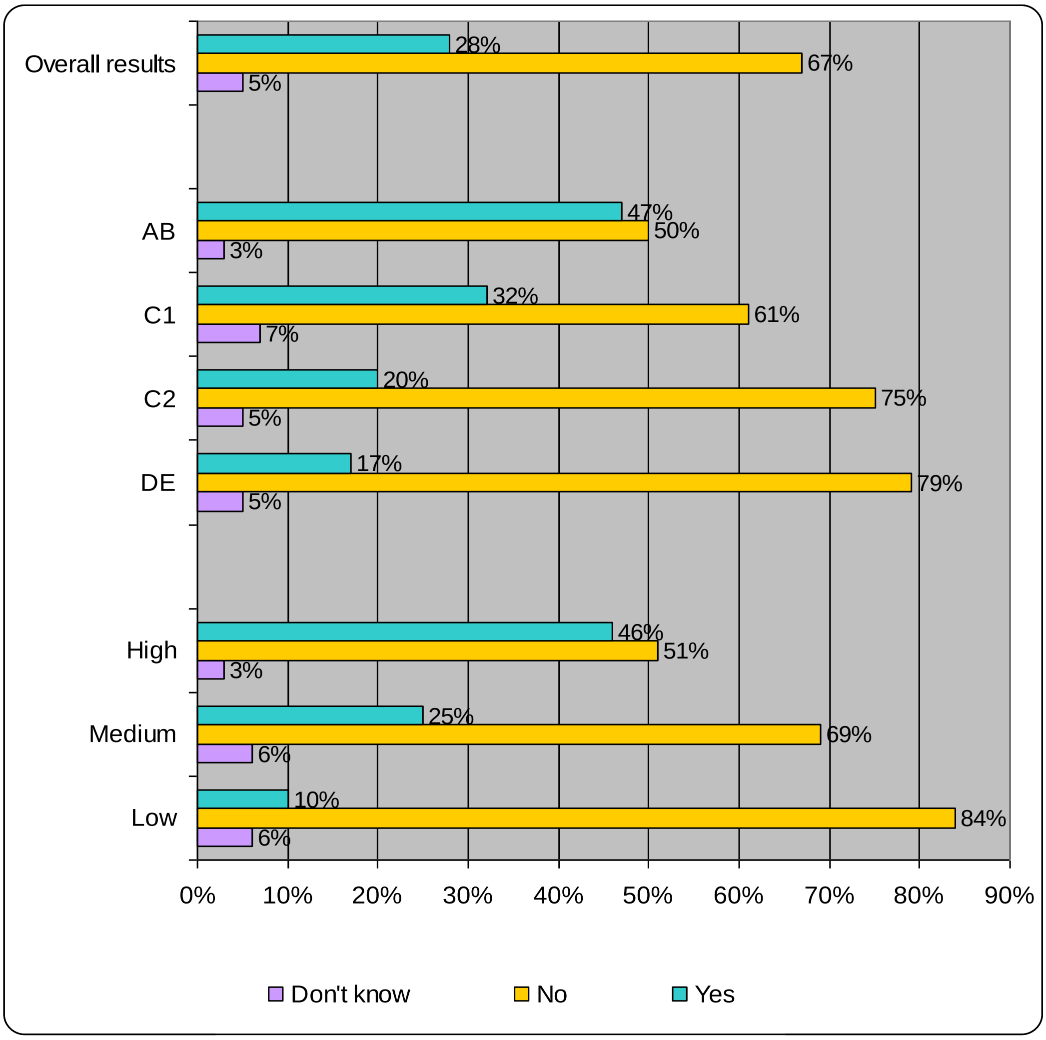
3.2 Awareness of IVF and Mitochondrial Disease

The UK population shows a high level of awareness of IVF (Q3) - 86% of respondents are aware and only 14% unaware. However, awareness in London is particularly low – 65%; this is linked to similarly lower levels of awareness among BME groups and related faith communities (for example, awareness among Muslims is 51%).

Around one in ten of the UK population has experience of genetic diseases in their family or immediate circle of friends (Q5).

Awareness of mitochondrial disease is relatively low with just over a quarter (28%) reporting that they have heard of the disease. Awareness of mitochondrial disease is strongly correlated with education, rising from 10% of those with low educational levels to 25% with medium levels of education and 46% to those with high levels; subsequently there is a similar gradient by social class (awareness among social class DE is 17%, C2 – 20%, C1 – 32% and AB 47%. There are small variations by faith; among those who report they have no religion, 34% have heard of mitochondrial disease, among Christians the figure is 26%, and among Muslims 22%.

Figure 3. Awareness of mitochondrial disease: overall, by social class and educational level



Base: All (979)

3.3 The Genetic Treatment of Mitochondrial Disease

The survey included several questions (see Appendix A for full question wording) about specific aspects of genetic treatments. The first question was asked more generally, prior to asking questions about mitochondrial disease. It sought to establish general attitudes towards the testing of embryos during IVF. Two thirds (65%) expressed a positive attitude and 8% a negative attitude; 27% were undecided or unsure. The mean score analysis (see Appendix C) shows that there was a drop off in positive ratings for those who describe themselves as Christian and a more marked drop-off among Muslims. Although there are variations, negative attitudes are still confined to small minorities of Christians (9%) and Muslims (14%).

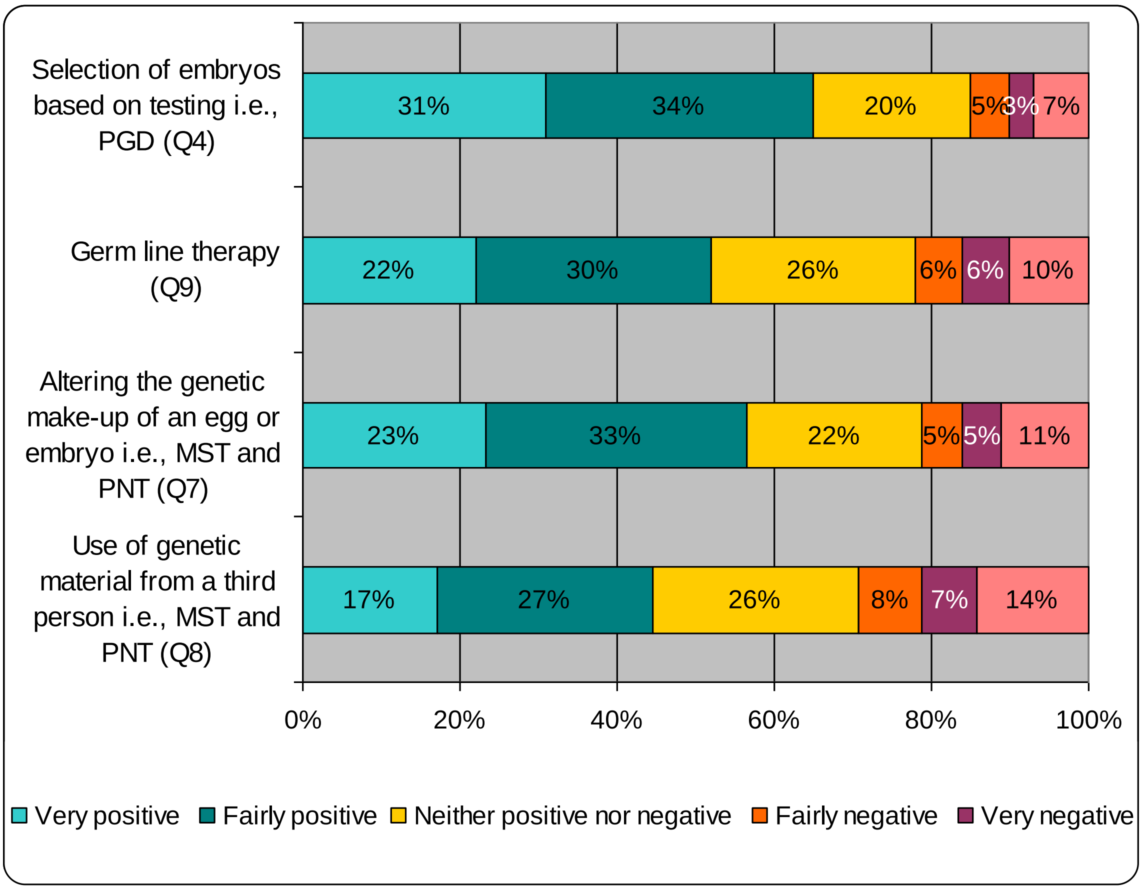
Questions 7 to 9 (see Appendix A) seek to understand respondents ‘initial reaction’ to different aspects of potential treatments for mitochondrial disease, which are outlined in Figure 3 below. The results will inform the HFEA’s consultation about the ethical and social issues surrounding new techniques that will require a change in the law.

As shown in Figure 3 below, across the three treatment questions, between 44% and 56% expressed a positive initial reaction while between 10% and 15% a negative reaction. The proportion undecided or unsure is quite high, between 33% and 40%. This reflects both the unfamiliarity of mitochondrial diseases and the complexity of the techniques.

These results suggest that respondent’s positivity towards medical research and sympathy towards those affected (see Section 3.1) continued, even as the more ethically challenging subjects of PNT and MST were explained.

The analysis of the mean score differences (see Appendix C) shows that education and faith have some influence on people’s attitudes towards these treatments, but that these differences are not profound, with fewer than one-in-five of the groups expressing negative attitudes.

Figure 4: Attitudes to the genetic treatment of mitochondrial disease



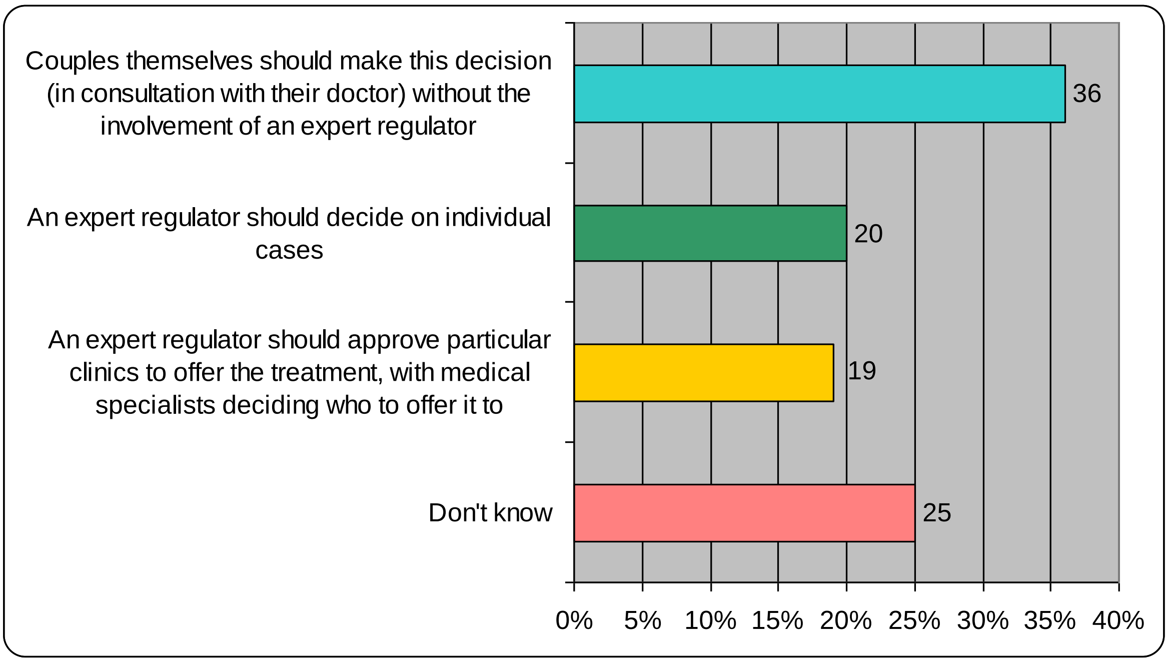
Base: All (979)

3.4 Attitudes to the Regulation of Genetic Treatments

When asked about the potential regulation of treatments for mitochondrial disease (Q10) respondents expressed a range of preferences.

The option of couples being allowed to decide for themselves was favoured by over a third of respondents (36%). However, slightly more (39%) favoured some kind of involvement of a regulator – with a fifth of respondents (20%) selecting the option of an expert regulator deciding on an individual cases, and a similar amount (19%) calling for an expert regulator to approve particular clinics, with medical specialists deciding who to offer it to. A further one quarter (25%) were unable to express a preference.

Figure 5. Attitudes to the regulation of genetic treatments



Base: All (979)

As shown in Table 1 below, the mean score analysis shows small variations, but these are largely influenced by variations in the proportions who did not express an opinion.

Table 1: Attitudes to the regulation of genetic treatments

	Expert regulator decides on individual basis	Expert regulator approves clinics and medical specialists decide who to treat	Couples decide without expert regulator	Don’t know
Education Level				
- low	17%	12%	39%	31%
- medium	21%	18%	37%	24%
- high	20%	26%	31%	23%
Religion				
- none	22%	16%	42%	20%
- Christian	20%	22%	35%	23%
- Muslim	24%	7%	18%	51%

Appendix A – Survey

Q1. To what extent you agree or disagree with the following statements?

Medical research can do a lot to reduce human suffering

Medical research creates new knowledge and treatments which will benefit the wider healthcare system

The application of medical research leads to unforeseen negative side effects

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Unsure

Q2. To what extent you agree or disagree with the following statements?

There should be free and accessible healthcare and treatment for people with serious genetic diseases

There should be free and accessible genetic testing to help families avoid having a child with serious genetic disease

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Unsure

Q3. IVF is where a couple having difficulties conceiving have eggs and sperm mixed in a laboratory to create an embryo. The embryo is then grown for a few days and placed into the woman's womb where it has a reasonable chance of leading to a normal pregnancy. Have you heard of IVF (in-vitro fertilisation) before?

Yes

No

Q4. Techniques are already available to test embryos during IVF for a specific genetic disease. Couples who know they have a high chance of having a child with a serious genetic disease can use this technique to have a child without that disease and not use the embryos that have tested positive. How would you describe your attitude to this?

Very positive

Fairly positive

Neither positive nor negative

Fairly negative

Very negative

Unsure

Q5 Can I just check if you, a member of your family or your immediate circle of friends have any direct experience of inherited genetic disorders such as cystic fibrosis, Huntington's disease, muscular dystrophy or sickle cell anaemia?

Yes

No

Don't know

Q6. Some people are born with, or develop, genetic diseases – such as cystic fibrosis, Huntington's disease, muscular dystrophy or sickle cell anaemia – which they inherit from one or both of their parents. These diseases are caused by an alteration in an individual's genetic material that leads to a variety of physical or learning impairments.

A small proportion of these genetic diseases are inherited just from the mother and are difficult to avoid. These are called mitochondrial disease and can often be severe. Have you heard of mitochondrial disease before today?

Have you heard of mitochondrial disease before today?

Yes

No

Don't know

Q7. Scientists are developing techniques which could remove the chance of these mitochondrial diseases by altering the genetic make-up of an egg or embryo during IVF. What is your initial reaction to this?

Very positive

Fairly positive

Neither positive nor negative

Fairly negative

Very negative

Unsure

Q8. In order for this to happen, you would need to replace abnormal mitochondria in the intended parent's egg or embryo with healthy mitochondria from a donor egg or embryo. This means that any resulting egg or embryo will contain a small amount of genetic material in its mitochondria from a third person (other than the mother and father). What is your reaction to this?

Very positive

Fairly positive

Neither positive nor negative

Fairly negative

Very negative

Unsure

Q9. As I said before, the techniques to avoid mitochondrial disease would involve altering the make-up of an egg or embryo, specifically the mitochondria. The donated healthy mitochondria would replace the intended mother's faulty mitochondria and would then be passed down to the child and, in turn, to that child's children and beyond. This is called germline gene therapy, because the change goes down through the generations (the germline). Assuming that scientists could show that this is safe, what is your reaction to this?

Very positive

Fairly positive

Neither positive nor negative

Fairly negative

Very negative

Don't know

Q10. Currently, these techniques cannot be offered to couples as the law only allows them to be carried out in research. However, Parliament may have an opportunity to change the law to allow these techniques to be offered to couples. If Parliament did change the law, who do you think should decide whether individual couples should have the treatment?

An expert regulator should decide on individual cases

An expert regulator should approve particular clinics to offer the treatment, with medical specialists deciding who to offer it to

Couples themselves should make this decision (in consultation with their doctor), without the involvement of an expert regulator

Appendix B – Sample Profile

The sample profile is reported as the total number of interviews obtained, the number obtained for each sub-group, the unweighted proportion of each sub-group within the overall sample, and the weighted proportion within the overall sample. For example, the achieved sample included 12% of people under the age of 25; this age group makes up 15% of the UK population and the achieved sample was weighted to make up 15% of the weighted sample. Throughout the report, weighted percentages are reported.

Sample Profile

	Number of interviews	**Unweighted %**	**Weighted %**
Total	979	100%	100%
Gender			
- female	547	56%	51%
- male	432	44%	49%
Age			
- 16 to 24	117	12%	15%
- 25 to 34	186	19%	16%
- 35 to 44	145	15%	17%
- 45 to 55	154	16%	17%
- 55 to 64	139	14%	14%
- 65+	238	24%	20%
Education level			
- low	234	24%	20%
- medium	484	49%	51%
- high	258	26%	28%
Social class			
- AB	205	21%	20%
- C1	238	24%	29%
- C2	196	20%	22%
- DE	340	35%	29%
Religion			
- no religion	251	26%	27%

- Christian	578	59%	57%
- Muslim	42	4%	4%
- others (combined)	63	6%	7%
- refused to say	46	5%	5%

Appendix C – Results tables

Table 1: Attitudes to medical research

Q1: To what extent do you agree or disagree with the following statements?

	Medical research can do a lot to reduce human suffering	Medical research creates new knowledge and treatments which will benefit the wider healthcare system	The application of medical research leads to unforeseen negative side effects
Strongly agree (+2)	65%	61%	15%
Tend to agree (+1)	24%	29%	35%
Neither agree nor disagree (0)	7%	5%	26%
Tend to disagree (-1)	1%	2%	12%
Strongly disagree (-2)	1%	*	3%
Unsure	2%	3%	10%
Mean Score	1.55	1.53	0.51

Table 2: Attitudes to the treatment of genetic diseases

Q2: To what extent do you agree or disagree with the following statements?

	People with serious genetic diseases should be provided with healthcare and treatment to help manage their condition	Families at risk of having a child with a serious genetic disease should be able to avoid that risk through genetic testing
Strongly agree (+2)	65%	44%
Tend to agree (+1)	23%	30%
Neither agree nor disagree (0)	8%	13%
Tend to disagree (-1)	1%	4%
Strongly disagree (-2)	*	3%
Unsure	2%	7%
Mean Score	1.55	1.16

Table 3: Attitudes to the genetic treatment of mitochondrial disease

Q4: Attitude/reaction to ...

	Selection of embryos based on testing (Q4)	Altering the genetic make-up of an egg or embryo (Q7)	Use of genetic material from a third person (Q8)	Germ line therapy (Q9)
Very positive (+2)	31%	23%	17%	22%
Fairly positive (+1)	34%	33%	27%	30%
Neither positive nor negative (0)	20%	22%	26%	26%
Fairly negative (-1)	5%	5%	8%	6%
Very negative (-2)	3%	5%	7%	6%
Unsure	7%	11%	14%	10%
Mean Score	0.91	0.73	0.47	0.63
Mean Score Variations				
Education Level				
- low	0.87	0.55	0.24	0.38
- medium	0.96	0.79	0.52	0.70
- high	0.86	0.73	0.52	0.68
Religion				
- none	1.10	0.97	0.70	0.85
- Christian	0.89	0.64	0.37	0.56
- Muslim	0.59	0.64	0.60	0.47