

Genetics and Public Policy Center

Study of Attitudes Towards Genetic Technologies 2004

Survey Instrument

In this survey, we'd like your opinions on some important issues that have been in the news. This research is being conducted by Johns Hopkins University. There is no right or wrong answer. Please answer the questions based on your knowledge or belief. If you do not know the answer to a question or don't have an opinion, you can simply skip it and go on to the next question.

In general, do you agree or disagree with the following statements:

| | Strongly Agree | Agree | Disagree | Strongly disagree |
|--|----------------|-------|----------|-------------------|
| Q1. Technological progress is unstoppable. | | | | |
| Q2. It is possible to control technology so that we maximize the good that can come from it and limit the bad. | | | | |
| Q3. Technological discoveries will eventually destroy the earth. | | | | |
| Q4. Scientific research is essential for improving the quality of human lives. | | | | |
| | Strongly agree | Agree | Disagree | Strongly disagree |
| Q5. Scientists these days don't pay enough attention to the moral values of society. | | | | |
| Q6. Scientists are dedicated people who work for the good of humanity. | | | | |
| Q7. Generally speaking, I trust scientists to put society's interests above their personal goals. | | | | |
| Q8. Scientists are driven by greed. | | | | |

AWARENESS

Now we are going to ask some questions about things you might or might not have heard about.

Q9. Before today, had you heard about **In Vitro Fertilization (IVF)**: a process to help people have a child by removing eggs from a woman's ovaries, fertilizing them in the laboratory with sperm to create embryos, then transferring the embryos into the woman's womb where they grow and are born like other babies. Left over embryos may be discarded, frozen and stored for future use, donated to other couples, or used for research.

Yes 1
No 2

Q10. Before today, had you heard about

Genetic testing: a technique to find out whether a person has or is likely to develop certain inherited diseases or characteristics.

Yes 1
No 2

Q11. Before today, had you heard about

Prenatal genetic testing: genetic testing that is done during pregnancy to find out if the fetus has or is likely to develop certain inherited diseases or characteristics. Test results may be used to help parents prepare for the birth of that child or make a decision about terminating the pregnancy.

Yes 1
No 2

Q12. Before today, had you heard about

Preimplantation Genetic Diagnosis (PGD): genetic testing that is done on embryos produced through in vitro fertilization before they are transferred to a woman's womb. Based on the test results, parents can select which embryos to transfer into the woman's womb. For example, they may want to select only embryos with no genetic diseases, those of a specific sex, or those that have other characteristics. Left over embryos may be discarded, frozen and stored for future use, donated to other couples, or used for research.

Yes 1
No 2

Q13. Before today, had you heard about

Genetic modification: a technique to change the DNA or genes of a person in order to produce particular inherited characteristics.

Yes 1
No 2

Q14. Before today, had you heard about

Cloning: the process of making a genetic copy of an animal or a human from a single cell.

Yes 1
No 2

IN VITRO FERTILIZATION

Please remember that if you do not know the answer to a question, you can simply skip it and go on to the next question.

The next few questions are about in vitro fertilization (IVF). Just to remind you, in vitro fertilization is a process to help people have a child by removing eggs from a woman's ovaries, fertilizing them in the laboratory with sperm to create embryos, then transferring the embryos into the woman's womb where they grow and are born like other babies. Left over embryos may be discarded, frozen and stored for future use, donated to other couples, or used for research.

You will be able to view the above definition on the following screens by clicking on the definition link in yellow text.

Q15. In general, do you approve or disapprove of the use of IVF?

| | | | | |
|------------------|---------|------------|---------------------|--|
| Strongly approve | Approve | Disapprove | Strongly disapprove | |
|------------------|---------|------------|---------------------|--|

[IF ANSWER TO Q15 IS DISAPPROVE OR STRONGLY DISAPPROVE, OR Q15 SKIPPED ASK Q16]

Q16. Do you think IVF should be allowed at all?

Yes 1
No 2

[IF Q16=YES OR SKIPPED, ASK Q17 AND Q18]

Select an answer for each of the following.

| | Yes | No |
|--|-----|----|
| Q17. Do you think the government should regulate IVF based on quality and safety ? | | |
| Q18. Do you think the government should regulate IVF based on ethics and morality ? | | |

GENETIC TESTING

The next few questions are about genetic testing. Just to remind you, genetic testing is a technique to find out whether a person has or is likely to develop certain inherited diseases or characteristics.

You will be able to view the above definition on the following screens by clicking on the definition link in yellow text.

As far as you know, is it scientifically possible to use genetic testing to find out if a person has...

| | Possible | Not possible | Don't know |
|---|----------|--------------|------------|
| Q19. a greater than average chance of developing certain kinds of cancer? | | | |
| Q20. a greater than average chance of developing a mental illness such as depression? | | | |
| Q21. desirable characteristics such as high intelligence or strength? | | | |

In your opinion, if a genetic test shows that someone has a gene that increases the risk of disease,...

| | Yes | No |
|--|-----|----|
| Q22. does the person's <u>employer</u> have the right to know? | | |
| Q23. does the person's <u>health insurance company</u> have the right to know? | | |
| Q24. does the person's <u>husband, wife, or partner</u> have the right to know? | | |
| Q25. does the person's <u>immediate family</u> have the right to know? | | |

Q26. Do you think genetic testing should be allowed at all?

Yes 1
No 2

[IF Q26=YES OR SKIPPED, ASK Q27 AND Q28]

Select an answer for each of the following.

| | Yes | No |
|---|-----|----|
| Q27. Do you think the government should regulate genetic testing based on <u>quality and safety</u> ? | | |
| Q28. Do you think the government should regulate genetic testing based on <u>ethics and morality</u> ? | | |

PRENATAL GENETIC TESTING

The next few questions are about prenatal genetic testing. Just to remind you, prenatal genetic testing is testing that is done during pregnancy to find out if the fetus has or is likely to develop certain inherited diseases or characteristics. Test results may be used to help parents prepare for the birth of that child or make a decision about terminating the pregnancy.

You will be able to view the above definition on the following screens by clicking on the definition link in yellow text.

In general, would you approve or disapprove of the use of prenatal genetic testing to find out whether a baby...

| | Strongly approve | Approve | Disapprove | Strongly disapprove |
|---|------------------|---------|------------|---------------------|
| Q29. will develop a fatal childhood genetic disease? | | | | |
| Q30. will have a tendency to develop a disease like cancer when he or she is an adult? | | | | |
| Q31. will have desirable characteristics such as high intelligence or strength? | | | | |
| Q32. is a certain sex? | | | | |
| Q33. will be a good match to donate his or her blood or tissue to a brother or sister who is sick and needs a transplant? | | | | |

[IF ANSWER TO ALL Q29-Q33 DISAPPROVE OR STRONGLY DISAPPROVE OR SKIPPED]

Q34. Do you think prenatal genetic testing should be allowed at all?

Yes 1
No 2

[IF ANSWER TO Q34=YES OR SKIPPED, ASK Q35 AND Q36]

Select an answer for each of the following.

| | Yes | No |
|---|-----|----|
| Q35. Do you think the government should regulate prenatal genetic testing based on quality and safety ? | | |
| Q36. Do you think the government should regulate prenatal genetic testing based on ethics and morality ? | | |

PREIMPLANTATION GENETIC DIAGNOSIS (PGD)

The next few questions are about preimplantation genetic diagnosis (PGD). Just to remind you, preimplantation genetic diagnosis is genetic testing that is done on embryos produced through in vitro fertilization before they are transferred to a woman’s womb. Based on the test results, parents can select which embryos to transfer into the woman’s womb. For example, they may want to select only embryos with no genetic diseases, those of a specific sex, or those that have other characteristics. Left over embryos may be discarded, frozen and stored for future use, donated to other couples, or used for research.

You will be able to view the above definition on the following screens by clicking on the definition link in yellow text.

In general, would you approve or disapprove of using PGD to make sure a baby...

| | Strongly approve | Approve | Disapprove | Strongly disapprove |
|---|------------------|---------|------------|---------------------|
| Q37. will not develop a fatal childhood genetic disease? | | | | |
| Q38. will not have a tendency to develop a disease like cancer when he or she is an adult? | | | | |
| Q39. will have desirable characteristics such as high intelligence or strength? | | | | |
| Q40. will be a certain sex? | | | | |
| Q41. will be a good match to donate his or her blood or tissue to a brother or sister who is sick and needs a transplant? | | | | |

[IF ANSWER TO ALL Q37-Q41 DISAPPROVE OR STRONGLY DISAPPROVE OR SKIPPED]

Q42. Do you think PGD should be allowed at all?

Yes 1
 No 2

[IF Q42=YES OR SKIPPED, ASK Q43 AND Q44]

Select an answer for each of the following.

| | Yes | No |
|--|-----|----|
| Q43. Do you think the government should regulate PGD based on quality and safety ? | | |
| Q44. Do you think the government should regulate PGD based on ethics and morality ? | | |

GENETIC MODIFICATION

The next few questions are about genetic modification. Just to remind you, genetic modification is a technique to change the DNA or genes of a person in order to produce particular inherited characteristics. You will be able to view the above definition on the following screens by clicking on the definition link in yellow text.

In general, would you approve or disapprove of the use of genetic modification to have a baby that...

| | Strongly approve | Approve | Disapprove | Strongly disapprove |
|---|------------------|---------|------------|---------------------|
| Q45. will not have a fatal childhood genetic disease? | | | | |
| Q46. will not have a tendency to develop a disease like cancer when he or she is an adult? | | | | |
| Q47. is smarter, stronger, or better looking? | | | | |
| Q48. is the desired sex? | | | | |
| Q49. will be a good match to donate his or her blood or tissue to a brother or sister who is sick and needs a transplant? | | | | |

[IF ANSWER TO ALL Q45-Q49 DISAPPROVE OR STRONGLY DISAPPROVE OR SKIPPED]

For the next few questions, assume that genetic modification is or will become possible in the future.

Q50. Do you think genetic modification should be allowed at all?

Yes 1
No 2

[IF Q50=YES OR SKIPPED, ASK Q51 AND Q52]

Select an answer for each of the following.

| | Yes | No |
|---|-----|----|
| Q51. Do you think the government should regulate genetic modification based on quality and safety ? | | |
| Q52. Do you think the government should regulate genetic modification based on ethics and morality ? | | |

CLONING

The next few questions are about cloning. Just to remind you, cloning is the process of making a genetic copy of an animal or human from a single cell. You will be able to view the above definition on the following screens by clicking on the definition link in yellow text.

As far as you know, is it scientifically possible today to produce a cloned...

| | Possible | Not possible | Don't know |
|-------------------------|----------|--------------|------------|
| Q53. animal like a cow? | | | |
| Q54. human embryo? | | | |
| Q55. human baby? | | | |

For the next few questions, assume that cloning is or will become possible in the future.

In general, would you approve or disapprove of scientists working on ways to create a cloned...

| | Strongly approve | Approve | Disapprove | Strongly disapprove |
|---------------------------------|------------------|---------|------------|---------------------|
| Q56. animal like a cow? | | | | |
| Q57. human embryo for research? | | | | |
| Q58. human baby? | | | | |

Select an answer for each of the following.

| | Yes | No |
|---|-----|----|
| Q59. Do you think animal cloning should be allowed at all? | | |
| Q60. Do you think human embryo cloning for research should be allowed at all? | | |
| Q61. Do you think human cloning to create a baby should be allowed at all? | | |

Select an answer for each of the following.

| | Yes | No |
|--|-----|----|
| Q62. Do you think the government should regulate cloning based on quality and safety ? | | |
| Q63. Do you think the government should regulate cloning based on ethics and morality ? | | |

Select a response for each of the following...

| | Yes | No |
|---|-----|----|
| Q64. Do you believe anyone has already created a cloned human embryo? | | |
| Q65. Do you believe anyone has already created a cloned human baby? | | |
| Q66. If you could clone a loved one when they died, would you? | | |
| Q67. If you could clone yourself, would you? | | |

EMBRYOS, FETUSES, AND ABORTION

Now we have some questions about other topics.

Q68. When you think about these topics, do you think of them mainly in terms of health and safety or mainly in terms of religion and morality?

Mainly health and safety.....1
Mainly religion and morality.....2

Q69. Which statement best agrees with your thoughts on abortion?

Abortion should never be permitted.1
Abortion should be permitted only if the life and health of the woman is in danger.2
Abortion should be permitted only if the life and health of the woman is in danger or the pregnancy is the result of rape or incest.....3
The decision about whether to have an abortion should be left up to individual women.....4

Q70. What statement best describes your thoughts on the beginnings of life?

Life begins before a sperm fertilizes an egg.1
Life begins when a sperm fertilizes and egg.2
Life begins when an embryo implants in the uterus or womb.....3
Life develops as a continual process from fertilization to birth.4
Life begins when a mother feels the fetus move.....5
Life begins when a fetus could survive outside the mother's womb.....6
Life begins at birth.....7

There is debate about the “moral worth” of human eggs, embryos, fetuses, etc. For some people, “maximum moral worth” means that the egg, embryo, or fetus deserves the utmost respect, and that we should not do anything that would lead to its destruction. “No moral worth” means that it could be destroyed for no reason at all. Please rank the moral worth of each of the following on a scale of 1 to 5.

| | No moral worth 1 | Low moral worth 2 | Moderate moral worth 3 | High moral worth 4 | Maximum moral worth 5 |
|--|---------------------|----------------------|---------------------------|-----------------------|--------------------------|
| Q71. Unfertilized woman's egg | | | | | |
| Q72. Human sperm | | | | | |
| Q73. Fertilized egg | | | | | |
| Q74. Human embryo in a petri dish | | | | | |
| Q75. Cloned human embryo | | | | | |
| Q76. Frozen human embryo in an IVF clinic | | | | | |
| Q77. Human embryo in a woman's womb | | | | | |
| Q78. 8 week old human fetus | | | | | |
| Q79. 24 week old human fetus | | | | | |
| Q80. Born human baby | | | | | |
| Q81. Human cells like liver or heart cells in a petri dish | | | | | |

In general, do you agree or disagree with the following statements...

| | Strongly agree | Agree | Disagree | Strongly disagree |
|---|----------------|-------|----------|-------------------|
| Q82. Parents ought to do everything technologically possible to prevent their child from suffering including using reproductive genetic technologies. | | | | |
| Q83. Suffering is part of what makes us human. | | | | |
| Q84. Only God should change the genes of the human species. | | | | |
| Q85. The ability to control human reproduction will lead to treating children like products. | | | | |
| Q86. We ought to let people decide for themselves when it is appropriate to use reproductive genetic technologies because the consequences are so personal. | | | | |
| Q87. I am concerned about unregulated reproductive technology getting out of control. | | | | |
| Q88. I am concerned about government regulators invading private reproductive decisions. | | | | |
| Q89. Reproductive genetic technology will inevitably lead to genetic enhancement and designer babies. | | | | |
| Q90. Reproductive genetic technology is progress and potentially the next step in human evolution. | | | | |

Some people have said that the government ought to be more involved in the development and use of genetic testing, genetic modification, and cloning. Do you think the government should play a role in:

| | Yes | No |
|---|-----|----|
| Q91. Tracking population effects of these technologies like changes in the ratio of males to females? | | |
| Q92. Studying the long-term effects of these technologies on women and children? | | |
| Q93. Ensuring that people have equal access to these technologies? | | |
| Q94. Funding research on genetic testing? | | |

| | | |
|---|--|--|
| Q95. Funding research on genetic modification techniques? | | |
| Q96. Funding research on cloning technology? | | |
| Q97. Tracking the different ways people are using these technologies? | | |
| Q98. Setting limits based on ethics and morality? | | |

Suppose that genetic testing, genetic modification, and cloning became widespread. On a scale from 1 to 4, how concerned would you be about the following.

| | Very concerned 1 | Concerned 2 | Not very concerned 3 | Not at all concerned 4 |
|--|---------------------|----------------|-------------------------|---------------------------|
| Q99. Some people being unable to afford the technology | | | | |
| Q100. Increased discrimination against the disabled. | | | | |
| Q101. Decreased research to develop treatments for certain diseases. | | | | |
| Q102. Increased pressure on parents to use the technology. | | | | |
| Q103. Changes in the sex ratio | | | | |
| Q104. Loss of genetic diversity | | | | |
| Q105. Overpopulation | | | | |