



Medical Research

The guide includes three points of view about how to address the issue of medical research. While the guide was based on one developed by the national research organization Public Agenda, it has been substantially modified for our local community. It includes information from reports in the Kansas City Star, as well as from a policy briefing prepared by the Center for Practical Bioethics, available at <http://www.practicalbioethics.org>.

If you were born in 1900, you could expect to live 49 years, while people born today can expect to live to be 77. Much of the credit for our longer lifespan goes to medical discoveries such as insulin, antibiotics, blood pressure medications, and advanced surgery. Today, new forms of medical research also hold promise for extending the quantity and quality human life.

Deciphering the human genetic code offers the possibility of understanding, treating and preventing inherited diseases such as hemophilia and muscular dystrophy. But it also forces us to consider the implications of being able to fundamentally alter our inner composition.

Research on stem cells, which can grow into any of the more than 200 kinds of cells in the body, holds promise for growing replacement tissue to treat diabetes, stroke, spinal-cord injuries, heart and other diseases.

Knowing more about how cells develop could lead researchers to understand why cells behave abnormally and produce diseases like cancer. But it also forces us to consider the implications of using embryos as a tool to save lives.

As our knowledge of medicine reshapes society, it also presents new public policy challenges, such as the level of government funding for research, the uses to which that money can be put, the extent to which companies should be allowed to patent and control advances, and the implications of public-private collaborations.

The price of health

To build upon any new medical discoveries will require money. How much money do we want to invest in pursuing such knowledge? Medical research requires hundreds of billions of dollars – a substantial portion of

which comes from taxes – and scientists could easily justify spending more to create better diagnostic tests and more effective treatments.

A report in the Journal of the American Medical Association in September 2005 said that total U.S. spending on medical research had doubled in the past decade to nearly \$95 billion per year.

Where does the money come from? The industry sponsors 57 percent of medical research and the federally funded National Institutes of Health pays for 28 percent.

The study painted a picture of “an amorphous, mostly profit-driven system, where industry research focuses on existing drugs and lets discovery-stage research lag behind.” The U.S. spends about six cents of every health care dollar on medical research.

And when government funds are used for research, it can prompt battles over what research should be funded or allowed to move forward at all, particularly in genetics and stem cell research.

DNA and destiny

In the summer of 2000, scientists announced that they had cracked the code of the human genome, finding about 30,000 individual genes that guide human development.

Already, medical researchers have identified hundreds of defects in the sequences of these genes that are “markers” for diseases. With more than 4,000 diseases having genetic causes, unraveling the genome allows us to know more about how the body works and potentially how to make it work

better.

But what are the implications of knowing precisely who may develop a genetic disorder? Specifically, knowing a patient’s risk may help save his or her life but could also cost that person’s job or health coverage if their employer or insurance company finds out. In Britain, for example, insurers may ask for results if someone chooses to be tested for the fatal Huntington’s Disease.

Designer genes

Now that science can identify the genes responsible for disease, the next frontier is manipulating genes for the purposes of gene therapy, cloning, and obtaining stem cells.

Gene therapy, where doctors attempt to repair someone’s genetic code, is still in its infancy. Most of the experiments have so far been limited to replacing a defective gene with a healthy gene, which cannot be passed on to the patient’s offspring.

Scientists have also been actively discussing reprogramming human egg and sperm cells, not only treating the patient but passing on the changes to future generations. Some scientists say this could have unintended consequences and that nobody knows the impact on the gene pool generations from now. Others fear that parents might try to “design” their children to succeed.

The most dramatic scientific advance appeared in a Scottish sheep pen in 1997, when a scientist introduced Dolly, the first mammal cloned from an adult. A dog, Snuppy, was cloned by South Korean scien-

tists in 2005.

Scientists in the U.S., Italy and South Korea, among others, have publicly announced plans to produce the first human clone. Some of those most eager to explore human cloning are infertility specialists, who view it as another avenue to help their patients. A cloned baby would be an identical twin of one of the parents, only born years later.

Others have condemned even attempting a human clone, largely because 95 percent of animal cloning attempts fail and most that are born die within a week or two.

For many, it is the current debate about stem cells research that is the most familiar aspect of the issue of medical research.

Stem cells and the political process

For many scientists, the promise of medical technology lies with stem cells, “master cells” capable of replicating indefinitely.

Stem cells could give doctors the ability to create any body tissue, liberating people from waiting for an organ transplant and the risk of organ rejection. Stem cells are also promising for treating ailments like Parkinson’s, spinal cord injuries, or diabetes.

The source of stem cells, however, is at the center of controversy about whether their benefits outweigh the moral implications:

- Scientists have found that the most promising stem cells come from week-old human embryos, but extracting the cells destroys the embryos.
- Another procedure, called therapeutic

cloning or somatic cell nuclear transfer, transplants the nucleus of a normal body cell into the nucleus of an unfertilized human egg. The egg cell divides, eventually forming stem cells surrounded by an outer covering, which must be destroyed to get to the stem cells.

Stem cells are also available from other sources, although less is known about how these stem cells function:

- Some stem cells can be found in umbilical cord blood and in the placenta
- Adult stem cells can be found in many, if not all, tissues of the human body, although they can be difficult to locate and are not nearly as flexible as embryonic stem cells.

In 1995, Congress banned federally funded embryo research. Then, in 2000, the National Institutes of Health issued new rules allowing federal funds to pay for research into the uses of stem cells, so long as no federal money was used to remove cells from their embryos.

In 2001, President Bush banned federal funding for stem-cell research, except for the already existing cell lines. (Only 22 lines are considered viable.) In 2005, the U.S. House developed legislation to expand federal funding of research, limited to use of cells from embryos that were created in vitro and frozen for couples undergoing fertility treatments.

The scientific community generally agrees that public funding is needed to make progress in creating viable and diverse early stem cell lines. Public funding also allows

federal and state governments to regulate and monitor the development of the research and ensure an open scientific exchange, peer review, and public involvement and oversight.

At the state level, the battle often plays out between those who want economic development and those who believe stem-cell research destroys human life. Forty states have declared their intention to become centers of life sciences research, and that is seen as very difficult without the opportunity to conduct stem cell research.

Several states – California, New Jersey, Connecticut, Illinois and Massachusetts – have passed laws to protect early stem cell research or have appropriated state funds for that research. Eleven states currently prohibit all early stem cell research.

In 2004, the Kansas legislature allocated as much as \$500 million over the next ten years for research universities and biosciences business development, much of which would occur in metro Kansas City. (In 1980, the federal government began allowing universities to retain the title on inventions developed through government funding. Today, up to 90 percent of life-science companies have a financial relationship with academia. More than \$20 billion of all universities' annual revenue comes from corporate licensing of academic inventions.)

Both St. Louis and Kansas City have invested heavily in life sciences, especially bioscience and plant science.

When the Kansas City Area Life Sciences Institute began about five years ago, annual research spending among eight institu-

tions – six in Missouri and two in Kansas – was \$104 million. In 2004, it was \$243 million, and there were 165 life sciences companies in the area with about 20,000 employees.

In April 2005, the Missouri Senate debated a bill that would have prohibited scientists from creating stem cells in a laboratory by defining the procedure as human cloning.

The bill was backed by Missouri Right to Life, but opposed by the state's governor, who felt that banning research went too far. Faced with intense opposition, the bill went no further, although the sponsor has said he will reintroduce the bill.

Until Missouri law says that human embryonic stem cell research is allowed, the Stowers Institute for Medical Research will not commit to spending an additional \$250-\$300 million to build a second campus in Kansas City.

In September, the governor of Illinois sent letters to scientists at Stowers and other Missouri institutions encouraging them to move their careers to Illinois, which has earmarked \$10 million for stem cell research.

Option 1: Scientists should be free to pursue genetic research

The advances available through medical research can save and prolong lives. Like scientists eliminated polio and smallpox, we could eliminate horrible hereditary diseases, grow organs for transplant, and treat conditions like diabetes, Alzheimer's and Parkinson's. For our sake, and for future generations, we must assure that scientists are free to pursue their research.

Actions we could take:

- Lift bans on federal funding for embryo research, including stem cell research.
- Allow scientists to conduct research into correcting defective genes that cause disease, especially in cases where a fatal gene flaw could be inherited by the next generation.
- Repeal bans on cloning.

Arguments for this approach:

- Even if you ban scientific discovery and knowledge, someone will inevitably

move forward on these fronts.

- Many scientific discoveries have been made inadvertently. By probing genetics to its full extent, we might make important, and otherwise impossible, advances.
- Cloning is just another reproductive tool, and the 15 percent of Americans who are infertile should not be denied the right to procreate.

Arguments against this approach:

- Because the cost of genetic manipulation is exorbitant, we could end up with deeper social divisions, based not just on money, but biology as well.
- Widespread genetic testing could lead to some people being excluded from life or health insurance plans simply because they carry a certain gene.
- Animal cloning is highly experimental. It's immoral to take those kinds of risks on humans for the sake of experimentation. Too much about it is unknown.

Option 2: Pursue research, but don't change our genetic future

A great deal is at stake with medical research, both in terms of medical breakthroughs and in building a strong economy. While some limits may be necessary, we should be very careful not to enact rules that would drive scientists and research dollars away. We can be

responsible and still reap the benefits of medical research.

Actions we could take:

- Explore the prospects of gene therapy to treat disease, but ban genetic changes that

can be passed to offspring.

- Regulate cloning of human cells and organs for gene therapy, but ban cloning of entire people.
- Allow federal funding of stem cell research.

Arguments for this approach:

- We ought to explore every promising avenue to treat the sick, but we would be arrogant to assume we can try to control nature without some consequences.
- We simply don't know enough about how genetics works to allow unfettered scientific research, and human cloning is simply too risky to attempt.
- Stem cell research is a basis for a great deal of economic development nation-

wide. States that don't allow stem cell research will be unable to compete and jobs will be lost. And we can't hope to compete worldwide unless the United States loosens its restrictions on federal funding for stem cell research.

Arguments against this approach:

- Banning genetic experimentation will simply drive science underground, where there will be fewer safeguards and less oversight.
- We shouldn't regulate science because of fear. Hypothetical concerns aren't a good reason to stop scientific progress.
- If we can eliminate diseases like hemophilia in future generations, aren't we morally obligated to do so?

Option 3: Leave humans as God and nature created them.

We were made the way we were made for a reason. It's one thing to cure polio, it's a very different thing to make it possible for parents to genetically engineer a perfect child. Human beings are not ready to handle the repercussions of these scientific advances, which could be bleak. And we should never sacrifice other lives, including embryos, to scientific research.

Actions we could take:

- Ban all forms of human cloning.
- Ban federal funding of embryonic stem

cell research, and discourage it in the private sector.

- Limit genetic testing to cases where doctors can actually offer treatment, and keep the test results strictly confidential.

Arguments for this approach:

- Medical technology, no matter how well intended, can lead to bad consequences. In the early 20th century, for example, 30 states enacted laws to "protect" children from possibly being born with physical or mental problems, leading to forced sterili-

zation.

- Some parents are already trying to select their children's traits using existing fertility technology, which shows the potential for misuse.
- While stem cells hold great potential in medicine, they should not be taken from embryos. It is wrong to take one potential life to try and help another.

Arguments against this approach:

- Barring genetic and stem cell research

may halt scientific progress that could lead to life-saving and life-enhancing treatments.

- It is immoral not to try and ease human suffering if we have the opportunity to do so.
- Banning scientific discovery is tantamount to endorsing ignorance as a matter of public policy.

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Since 1984, Consensus has engaged the public in public policy. In metro Kansas City, it operates the KC Forums project. The KC Forums Project Team includes these leading non-profit organizations: Bridging the Gap, El Centro, Inc., Greater Kansas City Public Achievement, Johnson County Library, Kansas City Harmony, the Kansas City, Kansas, School District, Kansas City Neighborhood Alliance, Kansas City Public Library, Kansas City Regional Transit Alliance, Mid-America Regional Council, National Conference for Community and Justice, and YWCA of Greater Kansas City.