It's Time to Map Out How We'll Live With the New Genetics

By Tom Delbanco

BOSTON — As the race to decipher the human genome ends its first phase, we are quite properly amazed watching our genetic map unfold before our eyes. But it is far too early to conclude that understanding our genetic substance will trigger a leap forward in human "progress."

One thing is certain: We are not spending nearly enough time or money considering how society will cope with what scientists are unleashing.

Darwin taught us that progress by survival of those organisms most fit occurs over thousands of years, as nature weeds out weaknesses. Now we threaten to change the human organism virtually all at once, without affording the time to reach balance and harmony. As science fiction writers love to speculate, we may even generate a war within our own bodies.

Might genetic interventions trigger more trouble than success? Look at the fine line between disaster and rescue that thalidomide illustrates. In the past this drug disfigured newborns; now we hope that it will help with cancer and AIDS.

Consider HIV therapy, how it alters cells and too often induces resistance. Will genetically altered cells make good or bad neighbors to those in adjoining tissues? Clinical investigators using genetically engineered substances in Boston and Philadelphia have already watched death come to patients before rescue.

Genetic knowledge will never abolish all disease and suffering. Americans already spend about 15 percent of GDP on health care, and there is no way economic resources can keep pace with the new technologies.

The rush by biotechnology companies to profit from the new genetic discoveries makes it likely that the new maneuvers will be the most expensive of all, and rarely do new discoveries replace existing expensive tests and interventions.

When the United States has 45 million people without health insurance and many more who can't afford therapies already shown to be worthwhile, how can we find the money for new genetic therapies that will cost a fortune?

Consider how poorly American society is dealing with the elderly. As doctors urge their patients to throw away cigarettes, we rarely pause to take stock of the paradox that if everyone were to stop smoking tomorrow, the burden on society from increased longevity could prove enormous.

Take that thought a step further. If genetic therapies that increase life expectancy arrived tomorrow, they might bankrupt the health care system or siphon vital resources away from education, human services and other essential functions of society.

Will mapping genes help further discrimination and loss of privacy? How will society address genetic tests for health insurance, jobs and life insurance? And consider the next step: full-blown eugenics. In today's narcissistic society, people aspire increasingly to their notion of perfection: the cherished height, gender, skin color. How will we build moral consensus, a code that stymies those who would create a master race or a Frankenstein?

Think about the anguish of those deciding whether to learn if they or their children have genes that forecast Huntington's disease, or increase the likelihood of breast cancer or dementia.

How will we feel when fantasies of genetic perfection are destroyed? May we not end up with loss of ambition, depression or even a shattered persona? Learning about one's genetic map may induce far more pain than pleasure.

What about responsibility, voluntary behaviors, the old-fashioned idea of choosing right over wrong? Will we rush to "blame the gene" for every human failure or transgression? Will genetic determinism weaken our will? Will it stop our search for mystery, community, art, spirituality and the deepest pleasures? Will the genetic map replace the dream?

We must mobilize quickly to address the consequences of what we learn. Government, universities, industry, communities, schools, clergy, ethicists and each of us must prepare for some exceedingly tough decisions, lest we end up expressing doubts like those of the Los Alamos physicists who, having detonated an atomic bomb, looked back in horror at what they had wrought.

It is time to build a national Genome Commission that is well supported and broadly representative and has strong bipartisan teeth, analogous to the Atomic Energy Commission, which helped us live with the consequences of splitting the atom. We should also form an international counterpart that is truly global in its reach.

For every dollar spent on the genome project and the attendant frantic race for discovery, we should spend an equal amount to prepare for what we find. The rush for that kind of enlightenment has hardly begun.

The writer is Koplow-Tullis professor of general medicine and primary care at Harvard Medical School. He contributed this comment to The Washington Post.