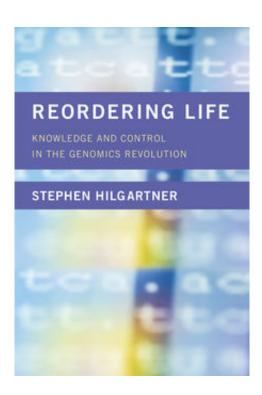


## New book examines the genomics revolution

April 11 2017, by Sherrie Negrea



In 2000, the world learned that scientists had completed an initial analysis of the sequence of the human genome – the totality of our inherited DNA. This development marked the "end of the beginning" of the rise of genomics, a field that has transformed the life sciences and promises to usher in big changes in medicine, agriculture and industry.

By the time U.S. President Bill Clinton and U.K. Prime Minister Tony Blair announced the completion of a first "draft" of the human sequence,



the genomics revolution had created new forms of knowledge and new modes of controlling it within the <u>scientific community</u>, says Stephen Hilgartner '83, Ph.D. '88, Cornell professor of <u>science</u> and technology studies.

In his new book, "Reordering Life: Knowledge and Control in the Genomics Revolution," Hilgartner examines how the governance and control of knowledge changed during the Human Genome Project, a 13-year effort that involved scientists at universities and research centers around the world.

"Imagine a bunch of independently minded scientists who love to do their own work and like to do it their own way," Hilgartner says. "If you want to organize them to do a large <u>project</u>, you're going to face challenges. How are you going to govern such an enterprise and make it work?"

Hilgartner, a social scientist who studies emerging science and technology, says the genomics revolution illustrates how changes in governance accompany transformative change in science.

One governance question that emerged during the Human Genome Project: Which aspects of genome science should be commercialized and which should be kept in the public domain? The project was launched by the National Institutes of Health and Department of Energy with a \$3 billion commitment from Congress. The Wellcome Charitable Trust, a biomedical research charity in London, also provided major support, as did other groups around the world.

Eight years into the Human Genome Project, a private company called Celera Genomics challenged the government-funded project, racing to complete the <a href="https://linear.com/human\_genome">human\_genome</a> sequence before the public project could. The race was officially declared a tie, but Hilgartner says Celera set out



to produce and commercialize a "quicker and dirtier but still useful version" of the sequence, rather than the high-quality, complete sequence of the entire human genome the public project produced.

"It's hard to know who is the winner of a game when the two sides are playing by different rules," he says. "Because the public project put all the data that it produced into an international, open-access database, the company could just take that information and mix it into its work."

In his book, Hilgartner analyzes the widespread reverberations caused by the genomics revolution through a theoretical framework that focuses on what he calls knowledge-control regimes. He defines knowledge-control regimes as systems of rules and guidelines that govern action relating to new forms of knowledge. The purpose of the concept, he says, is to "provide a way to disentangle some of the complexity and look at how science and governance change over time."

Hilgartner says that studying the genomics revolution can help researchers explore how other major scientific developments cause transformative change within the scientific community and beyond.

"New forms of knowledge and governance are taking shape in many areas of rapid scientific and technological change," he says. While the genomics revolution is just one example, Hilgartner says it offers social scientists valuable lessons for analyzing the process of change and "how much change to expect, how fast and how it might unfold."

## Provided by Cornell University

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