PUBLIC PERCEPTION

Avoiding Frankendrugs

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The future looks bright for health biotechnology. However, a decade ago, the future also looked bright for agricultural biotechnology. Since then, billions of dollars in profits and share value have been lost, and the food security of billions of people may have been set back. Deutsche Bank's 1999 report makes the point directly: "Today, the term GMO has become a liability. We predict that GMOs, once perceived as the driver of the bull case for this sector, will now be perceived as a pariah."[1] Is such a reversal of fortune possible in health care biotechnology, and what might be done to prevent it?

Some will dismiss the proposition, arguing that genetically engineered drugs, like recombinant human insulin, have been used without controversy, or that, for life-saving drugs at least, the public clearly perceives that their benefits far outweigh any risks. However, for many drugs that are principally preventative (as is likely for many of those developed from genomics), people may eschew statistical benefits because of perceived risks. This may also be the case for vaccines: In October, the United Kingdom's chief medical officer described the BSE-derived risk associated with an oral polio vaccine as "incalculably small," but the UK government nevertheless felt obliged to recall it[2].

One lesson those in health care biotechnology must learn from agriculture is that research and development needs to take a global view. "Designer" tomatoes do not generate the same level of public support as rice enriched with pro-vitamin A or iron. Similarly, post-genomic wrinkle creams or hair tonics may sell, but a focus of biotechnology on malaria drugs, for example, would generate stronger public support. We recognize that biotechnology companies cannot concentrate on products for which there is no market (as defined by investors and shareholders). However, there are constructive ways of taking a global view. As more developing countries join the World Trade Organization, company thinking should begin to encompass a market of 6 billion people (albeit with smaller unit profit margins) rather than of 600 million people in the United States and Europe. Drug donation programs, such as Merck's gift of Mectizan to treat "river blindness,"[3] address global health needs and improve corporate public relations into the bargain. The proposed vaccine purchase fund is designed to assure pharmaceutical firms of a market if they develop vaccines for tuberculosis, malaria, or AIDS.[4]

Another major lesson from genetically modified foods is the need to take public perception of risk seriously. As Sagar et al.[5] noted, "Recent public protests against GM foods are indicative of a divide between expert and lay perceptions of risk and uncertainty…Public risk perception is influenced as much by social relations and feelings of power and powerlessness as by objective knowledge about the likelihood of large-scale accidents or individual harm."

A dismissive attitude toward risk and risk perception on the part of the scientific or corporate communities was not effective in agricultural biotechnology and will not be so in health biotechnology. Proponents of health biotechnology will need to develop better methods of public engagement and address seriously even hypothetical public health risks. The market is the loudest voice the public has, but this comes into play only after a product has been developed. Referenda on biotechnology, such as that in Switzerland in 1998, can elicit public opinion early, but they suffer from lack of nuance and perhaps insufficient public education and deliberation. The public is not properly engaged unless it can address issues in a balanced manner, mindful, for instance, that biotechnology has the potential to benefit people around the world—billions of whom have virtually no resources devoted to health research on the diseases that afflict them.

Numerous innovative methods of public engagement stop short of national referenda: theatrical productions, philosophy cafes, consensus conferences, citizen's juries, citizen's advisory committees, global panels of public opinion leaders, and Internet-based real-time public opinion surveys. The need to engage the public on xenotransplantation[6], for instance, has led to a Web-based World Health Organization (WHO, Geneva) electronic discussion group[7]. Health Canada is about to launch a large-scale public engagement exercise before it decides its xenotransplant policy[8].

Many of the remedies for the ills lie in the hands of industry. The former chief executive of Monsanto (St. Louis, MO), took a long time to reach the stage of dialogue with Greenpeace, and Monsanto only agreed to stop exploitation of the "terminator seed" technology after the reasoned intervention of the president of the Rockefeller Foundation. More recently, however, Monsanto agreed to offer royalty-free licenses to its technology for producing "golden rice" enriched with pro-vitamin A. Pharmaceutical firms will need to recognize that no matter how good their technology or marketing strategies, attention to social and ethical issues are crucial to their bottom line. They will also need to make it practicable to license intellectual property where that is justified both commercially and ethically. At the same time, academic scientists, social scientists, and ethicists need to accept industry as a legitimate stakeholder with which to engage in constructive dialogue.

We think that there is a role for international organizations and foundations to establish forums, networks, and other platforms where stakeholders can come together. WHO has begun the process by drafting guiding principles for the future of medical genetics and biotechnology[8]. Pharmaceutical companies and their industry associations, among others, responded to the call for inputs. Governments need to be involved, too, in facilitating and rewarding the stakeholders' efforts by creating a stable regulatory environment for the health biotechnology industry. A model for such a "global public dialogue"[9] is being developed at the University of Toronto. The results of sustained deliberations in such forums would inform best practices in industry, nongovernmental organizations, and international organizations.

We need to mitigate the risk of Frankendrugs fiasco by learning the lessons of the Frankenfoods experience, and acting on them. Billions of dollars and the health of billions around the world may depend on it.

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