



The Left Atrium

Can bioethics save biotechnology?

Guiding Icarus: merging bioethics with corporate interests

Rahul K. Dhanda

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As a researcher interested in the social and ethical issues arising from the commercialization of genetic knowledge, I was intrigued when a colleague suggested that I read *Guiding Icarus* for an insider's perspective on the intersection of bioethics, biotechnology and industry. In this well-written book, Rahul Dhanda explores contentious biotechnologies — genetically modified foods, DNA data-banking, personalized medicine and stem cell research — in relation to science, social and ethical issues, and the role of industry.

This book is not another introductory bioethics text. Its much more interesting purpose is to demonstrate the importance of undertaking critical bioethical reflection within the setting of industrial biotechnology. Dhanda makes it clear at the outset that he is an industry insider, working for Interleukin Genetics, and so his perspective is explicitly pro-science and pro-industry. Despite this bias, he is not naive about the many pitfalls of industry or the social responsibility it bears. Even if you disagree, as I do, with some elements of Dhanda's position, he is still convincing about the need to integrate bioethics as a corporate value within the biotechnology industry.

The main weaknesses of the book stem from the occasional generalist and superficial application of bioethical tools and principles. For example, Dhanda briefly introduces the principles of consequentialism and deontology, but his description misses the essential complexity of these theories, such as the need to balance harms and benefits. He rightly highlights the critical importance of comprehensive informed consent procedures, but only hints at the

real problems with how informed consent is used (as a paper to sign rather than as an ongoing process), which undermines its protective utility.¹ Further, he pays insufficient attention to whether DNA donors are likely to understand what they are consenting to. With respect to DNA databases, a major issue that Dhanda misses is the fact that databases can produce errors, and that blind faith in DNA (i.e., that it provides the most certain form of legal evidence) will lead people to discount the possibility that such evidence can be wrong.

Another area of concern is Dhanda's discussion of ethnicity. Acknowledging that one should not take a reductionist view of genetics, he nevertheless talks about small homogeneous ethnic groups and socially and genetically complex groups such as nations or cultures as if they were synonymous.² Of greater concern is the short shrift paid to concerns about biopiracy in isolated communities and the developing world. This issue is not, as Dhanda seems to portray it, simply about participants and their understanding of genes and property rights. Rather, the issue is about exploitation and imperialism. Insufficient credit is given to the valuable contributions that individual research subjects and communities make, both in terms of genetic material and cultural knowledge, and thus the extent to

which people should be respected and compensated.

However, my major criticisms of *Guiding Icarus* turn on a disagreement with Dhanda's view that industry is always best placed to develop and deliver new and effective health care services. In Canada, we are well aware of the need to balance industry and government involvement with the funding and delivery of health care (even if we haven't yet figured out the balance), and so we may be more critical of the overriding importance often accorded to industry in the US. In his discussion of intellectual property rights, Dhanda is somewhat cavalier about the necessity for gene patents for continued industry involvement in research and product development. A growing body of legal and ethical literature^{3,4} is demonstrating that patents may not always be the best approach, as they can be expensive for both industry and researchers and block downstream development (as seen with Myriad Genetics' use of their patents on the two *BRCA* genes to block development of competing tests and technologies).

The take-home message of *Guiding Icarus* is that bioethics is good for business. Integrating bioethical consideration holds the promise of improving the bottom line by ensuring that research is conducted ethically, in a manner that avoids negative public reactions and thereby maintains government and investor confidence. If industry is to be seen as socially beneficial and capable of self-regulation, then it must also be socially responsible. However, the controversial aspect of this claim is the role to be played by bioethicists. Dhanda argues that industry needs the active participation of bioethicists, either as independent consultants or as members of corporate



ethics advisory boards. Dhanda argues that bioethicists should apply their critical reflective skills to technology development within the corporate environment.

In view of significant debate in the bioethics literature about the risk of bioethics becoming a rubber stamp or public relations tool, Dhanda's arguments are bound to stir up controversy. Yet, as he quite convincingly argues, it is only through maintaining their objectivity and transparency that bioethicists can effectively help industry. The utility of bioethicists for industry lies not in improving public relations, but in highlighting those areas where there is or is not consensus in order to help industry determine what research to conduct and how to ethically develop new technologies. With the intense focus of the popular press on the actions of biotechnology companies, tame bioethicists will be recognized as such and will only hurt a company's image and shareholder value. The details of how bioethicists are to work objectively and with integrity with the biotechnology industry remains to be worked out, but I agree with Dhanda that such participation is essential. *Guiding Icarus* is a must read for those interested in understanding how bioethics can help industry develop ethically and socially responsible biotechnologies.

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References

1. Burgess MM. Beyond consent: ethical and social issues in genetic testing. *Nat Rev Genet* 2001;2(2):147-52.
2. Brunger F, Bassett K. Culture and genetics. In: Knoppers BM, editor. *Socio-ethical issues in human genetics*. Cowansville (QC): Les Éditions Yvon Blais; 1998. p. 7-42.
3. Caulfield TA, Gold ER. Whistling in the wind: Patents on genetic research are a reality. It's time to reframe the debate. *Forum Appl Res Public Policy* 2000;Spring:75-9.
4. Gold ER. Biomedical patents and ethics: a Canadian solution. *McGill Law J* 2000; 45:413-35.

Room for a view

For the love of Alex

Vera's dreams were shattered when she awoke to find her husband cyanotic in bed next to her. They had immigrated to Canada years ago to build a new life. Both had worked long and hard, raising their daughters, improving their home, saving for a comfortable retirement, the reward they would enjoy later, together.

justing Alex. As we talk, she readily reveals her heart. I learn that Alex worked in a factory for almost 30 years, Vera in a store. I hear the horrible story of heartburn that was not heartburn and about Vera's frantic attempt at CPR. I hear that she wants her husband alive. I hear, beyond the words, the regret for things taken for granted.



Fred Sebastian

But later is this: a palliative care bed in a chronic care ward. The notes on Alex's chart are dismal: "chronic vegetative state," "anoxic brain injury," "sad case of a 62-year-old man." The emergency response team restarted his heart, but cerebral anoxia has taken his person away. He is comatose, his arms and legs drawn into rigid flexion. His eyes are vacant, his mouth a tense grimace. Beside his bed a box hums, connected to a PEG tube. Increased rigidity in response to pain is Alex's only reaction to the world.

I introduce myself to Vera. I tell her, presumptuously, that I will be Alex's doctor and that my goal is to work with her to keep Alex comfortable. Vera is tall and slender, with large strong hands that are always hovering over and ad-

Vera wants Alex alive — not just comfortable. What does "alive" mean for Alex? What does it mean for Vera, for me, for the nurses? With some dismay, I let the nurses know that I cannot write a DNR order.

In time, the calls from the nurses start — not about Alex, but about Vera. Vera is always at his side, constantly interfering with nursing tasks and protocols, always wanting things done differently. Vera will not have Alex left alone. When she is at work, her elder daughter must stay with him. Vera only leaves at night when Alex is "settled," long after visiting hours have ended.

Visits to Alex are difficult. Pinned to a bulletin board are photos of a tall, handsome man with an accordion, the life of the party. The proud father of