



In the news

PERSONAL GENOME — ANOTHER FIRST FOR WATSON

With his contribution to solving the structure of DNA in the 1950s, James Watson has amply secured his legendary status in genetics. In another historical moment, Watson has become the first person to have their entire genome sequenced for less than US\$1 million.

'Project Jim' was a collaboration between a biotechnology firm, 454 Life Sciences, and researchers at the Baylor College of Medicine. "I'm thrilled," said the DNA pioneer as the project culminated with the presentation of his genome sequence (*Scientific American*, 1 June 2007).

The project was part of an attempt to secure the \$10 million X prize, which will go to the first team to sequence 100 human genomes within 10 days. In a press release, Richard Gibbs, director of Baylor's Human Genome Sequencing Center, compared the achievement with the Human Genome Project, which took more than 10 years to complete: "Today, we give James Watson a DVD containing his personal genome — a project completed in only two months. It demonstrates how far sequencing technology has come in a short time."

Watson's comments highlight some complexities of having personal genomic information: "You can imagine a family who won't let someone marry their daughter until they examined her prospective husband's genome. You'll want to know what your mate is going to have," (*The New York Times*, 3 June 2007). His wish to have some aspects of his genomic identity kept from him also highlight some concerns: "Since we can't really do much about Alzheimer's, I didn't want to know whether I was at risk," he said, referring to the request that his status for one variant that predisposes to the disease was kept under wraps (*ABC News Online*, 2 June 2007).

Louisa Flintoft

Ethics watch

BENEFIT-SHARING: A LOOK AT THE HISTORY OF AN ETHICS CONCERN

The concept of benefit sharing has increasingly become part of regulatory frameworks in biomedical research. Benefit sharing raises complex and often contradictory concerns, ranging from the benefits it brings to individual research participants to community and population involvement in these debates, as well as the rights of all parties involved. Tracing the historical complexities and development of benefit-sharing debates and the concerns that substantiate this ethical principle highlights the ambiguities and incoherencies that often characterize these discussions.

Benefit sharing concerns what, if anything, is owed to individuals, communities or even populations that participate in research. However, the concept of 'owing something' is vague, and the essence of any justice-related idea is infamously difficult to pin down. The justifications for benefit sharing can be contradictory — for example, solidarity-based arguments would produce a different benefit-sharing rationale than one that is formed around compensatory justice.

Over the past decades, various competing threads of justification have coalesced into benefit sharing. The concept was first used in the context of plant and animal genomics, which furnished a benefit-sharing rationale that centres on the idea of property. This kind of benefit sharing is characterized by the distributive principle of the desert, where local populations have a legitimate claim to a share on the basis of their contribution in developing and nourishing a certain valuable biological entity, or through the recognition of this entity as their property¹.

The ownership argument is more controversial in human genetics and, in this context, benefit-sharing concerns have largely taken another justificatory route by being linked to traditional medical research frameworks, such as the doctor–patient relationship and the duties of beneficence and non-maleficence. Benefit sharing in this context is a compensatory activity, geared towards those who have taken risks and accepted the possible inconveniences that are necessary for research to take place and possibly succeed.

A third type of argument for benefit sharing relies on calls for solidarity². In this case, the aim of benefit sharing as a social- and/or global-justice concern is not to respond solely to circumscribed concerns of distinct research projects, but to define the way in which access

to research results is provided or denied to everyone else. These concerns are sustained by the lack of availability of research results to most of the world's population, for various reasons such as the high cost of and limited access to drugs, and research priorities that are skewed towards the interests of affluent populations.

Philosophers have begun debating potential definitions of benefit sharing, and benefit-sharing provisions are now frequently featuring in research protocols (for example, in the European Union's Seventh Framework Programme project forms)³. Looking back at the development of this concept reveals that some benefit-sharing arguments function only in specific contexts (for example, compensatory justice arguments), whereas others claim to be universally relevant (for example, some solidarity-based arguments). This raises questions about the feasibility and, indeed, the desirability of a general definition, and poses potential limits on the effectiveness of the concept in its attempts to alleviate the formidable problems of global injustice in biomedical research. It is also important to recognize how different benefit-sharing justifications determine the composition of the recipients — for example, benefit sharing as a compensation for voluntarily accepted risks necessarily excludes individuals and communities who would be included in the case of a solidarity-based benefit-sharing arrangement.

The existence of various arguments behind benefit sharing is not necessarily problematic in itself, but awareness of the complexities involved, of the distinct historical and conceptual roots, might help to ease the negotiations that precede benefit-sharing agreements between local populations and researchers. The moral concerns that surround benefit sharing are important, but their relative weight in justifying specific benefit-sharing arrangements might well differ depending on the situation.

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