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# IN BRIEF

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## The Human Genome Project and Beyond: Canada's Role

The Human Genome Project (HGP) spanned 1990-2003. It was a 13-year effort coordinated by the U.S. Department of Energy (DOE) and the National Institutes of Health (NIH) to decode, or sequence, the entire human genome. A genome is a map of the deoxyribonucleic acid (DNA), or genetic material, in an organism. Genetic analysis will enable doctors to screen people for serious diseases, including cancer, as well as to diagnose, treat and perhaps prevent these diseases. Canada was the 7<sup>th</sup> country to join in the challenge (1992). In all, at least 18 countries participated in the worldwide effort, with significant contributions from the United States, the United Kingdom, Germany, France and Japan. The project originally was planned to last 15 years, but rapid technological advances accelerated the completion date to 2003. The project goals were to:

- *identify* the estimated 50,000-80,000 genes in the human genome;
- *determine* the sequences of the 3 billion chemical base pairs that make up human DNA;
- *store* this information in databases;
- *develop* tools for data analysis; and
- *address* the ethical, legal and social issues that may arise from the project.

In June 2000, the President of the United States announced completion of a first draft of the human genome. The draft stage was reached when enough overlapping gene fragments were identified to reach end-to-end for each chromosome. However, considerable “gaps” still had to be sequenced, and scientists worked until 2003 to fill in the missing pieces.

### BACKGROUND

The U.S. Department of Energy's Office of Biological and Environmental Research (OBER) began in 1986 to consider the feasibility of a human genome program. It was agreed in a 1986 international conference that mapping and sequencing DNA clones representing the human genome were desirable goals.

In April 1987, it was recommended that the United States commit to a large, multidisciplinary, scientific and technological undertaking to map and sequence the human genome. The massive effort was to employ both the DOE and the NIH. The DOE was to assume a leadership role because of its expertise in managing complex and long-term multidisciplinary projects involving both the development of new technologies and the coordination of efforts in industries, universities and its own laboratories. The NIH were also necessary in the large-scale effort because of their biomedical research mission and their vast community of scientists.

In 1987, the NIH established the Office of Genome Research; in 1989, this office became the National Center for Human Genome Research.

For a more detailed analysis of the Human Genome Project, please refer to *The Human Genome Project and Its Ethical, Legal and Social Implications* by Tim Williams, Library of Parliament (PRB 00-08), 26 July 2000.

### WHAT IS LEFT TO ACCOMPLISH?

The HGP's goals did not include interpretation of the vast amount of data amassed through the sequencing of the huge number of genes. This interpretive stage promises to be far more complicated than the methodical and steady process of gene sequencing. Interpretation of the genome, once sequenced,

involves determining how each of the identified genes works. That can involve how and when a gene is expressed, in which cells it is expressed, what process it affects, and with which genes it interacts. And these are only some of the aspects of the interpretation. Even finding answers to these and other questions does not guarantee that deficiencies in any given gene will be properly interpreted. Understanding a gene does not necessarily mean that a defect in that gene will also be understood. Specific gene mutations will also have to be interpreted.

A greater number of scientists will be involved in the interpretation of gene sequences than were involved in establishing these sequences. All gene sequences have been made public. In this way, any researcher can become involved in deciphering the complex nature of each gene.

### **CANADA'S ROLE AND THE FUNCTION OF GENOME CANADA**

The international effort to map and sequence the human genome was somewhat lacking in Canada's participation. In 1998, the National Biotechnology Advisory Committee warned in its report that "the reduction in Canada's genome program has not only hollowed out the country's existing capability, but has jeopardized the chances of Canada leading the next wave of postgenomic studies." Genome Canada aims to reverse this situation.

In 1998, the Canadian Biotechnology Strategy (CBS) replaced the National Biotechnology Strategy of 1983. Genome Canada is one component of the CBS. Genome Canada is incorporated as a not-for-profit organization that comprises national businesses as well as research leaders from industry, government, Crown agencies, hospitals and universities. Genome Canada is the primary funding source for genomic<sup>(1)</sup> and proteomic<sup>(2)</sup> research in Canada and is directed to improve Canada's performance in genomics research and development on the world stage.

Genome Canada consists of five genome technology centres: Atlantic Canada, Quebec, Ontario, Prairies and British Columbia. These centres provide expertise and key technology platforms as well as initiate genomics R&D projects. The technology platforms supported by Genome Canada include:

- technology development;
- bioinformatics (data storage and dissemination);
- genome mapping and sequencing;
- functional genomics (functions associated with the identified genes);
- proteomics;
- genotyping (genetic variation among populations and individuals); and, perhaps most importantly,
- the ethical, social, legal and environmental issues associated with genomics research.

The 2005 federal budget invested \$165 million into Genome Canada to fund activities in the five technology centres. Previous budgets invested \$435 million, raising the current federal funding of the program to \$600 million.

To date, Genome Canada has invested \$365 million across Canada. When combined with funding from other partners, investment is expected to exceed \$850 million.

Through Genome Canada's work, Canada is expected to become an international player in the field of genomics research.

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- (1) Genomics is the study of deciphering and understanding the genetic code.
  - (2) Proteomics is the study of all proteins encoded by the genome.