

## Coordination with Other Genome Programs

*Enhancing genome  
research capabilities*

**T**he U.S. Human Genome Project is supported jointly by the Department of Energy (DOE) and the National Institutes of Health (NIH), each of which emphasizes different facets. The two agencies coordinate their efforts through development of common project goals and joint support of some programs addressing ethical, legal, and social issues (ELSI) arising from new genome tools, technology, and data.

Extraordinary advances in genome research are due to contributions by many investigators in this country and abroad. In the United States, such research (including nonhuman) also is funded by other federal agencies and private foundations and groups. Many countries are major contributors to the project through international collaborations and their own focused programs. Coordinating and facilitating these diverse research efforts around the world is the aim of the nongovernmental international Human Genome Organisation.

Some details of U.S. and worldwide coordination are provided below.

### U.S. Human Genome Project: DOE and NIH

In 1988 DOE and NIH developed a Memorandum of Understanding that formalized the coordination of their efforts to decipher the human genome and thus "enhance the human genome research capabilities of both agencies." In early 1990 they presented Congress with a joint plan, *Understanding Our Genetic Inheritance, The U.S. Human Genome Project: The First Five Years (1991-1995)*. Referred to as the Five-Year Plan, it contained short-term scientific goals for the coordinated, multiyear research project and a comprehensive spending plan. Unexpectedly rapid progress in mapping prompted early revision of the original 5-year goals in the

fall of 1993 [*Science* 262, 43-46 (October 1, 1993)]. Current goals, which run through September 30, 1998, are listed on page 5; text of both 5-year plans is accessible via the Web (<http://www.ornl.gov/hgmis/project/hgp.html>).

DOE and NIH have adopted a joint policy to promote sharing of genome data and resources for facilitating progress and reducing duplicated work. (See Appendix B: DOE-NIH Sharing Guidelines, p. 75.)

### ELSI Considerations

NIH and DOE devote at least 3% of their respective genome program budgets to identifying, analyzing, and addressing the ELSI considerations surrounding genome technology and the data it produces. The DOE ELSI component focuses on research into the privacy and confidentiality of personal genetic information, genetics relevant to the workplace, commercialization (including patenting) of genome research data, and genetic education for the general public and targeted communities. The NIH ELSI component supports studies on a range of ethical issues surrounding the conduct of genetic research and responsible clinical integration of new genetic technologies, especially in testing for mutations associated with cystic fibrosis and heritable breast, ovarian, and colon cancers.

In 1990, the DOE-NIH Joint ELSI Working Group was established to identify, address, and develop policy options; stimulate bioethics research; promote education of professional and lay groups; and collaborate with such international groups as the Human Genome Organisation (HUGO); United Nations Educational, Scientific, and Cultural Organization; and the European Community. Research funded by the U.S. Human Genome Project through the joint working group has produced policy recommendations in various areas. In May 1993, for

