

Genomics and Health Policy

Researching the issues and evaluating solutions

Healthcare applications of genomics have the potential to improve health outcomes. Abt Associates, well known for its research and evaluation expertise, adds value for clients and helps them respond to the opportunities presented by genomics through substantive knowledge of the health policy issues associated with this new and evolving science.

Abt Associates performs data collection, analysis, and program evaluation of the healthcare applications of genetics and genomics. With more than 40 years of experience in healthcare research, we have the knowledge, experience, and perspective to understand genomics and its integration with the broader healthcare environment.

Well-suited for the genomics environment

Abt Associates has extensive knowledge and experience in the specialized environment of genomics. Our staff apply advanced research and analysis to inform and guide stakeholders affected by genomics. Project teams consist of core research staff with expertise in health policy and genomics as well as an extensive pool of internal specialists in data collection, analysis, and evaluation. We provide clients with comprehensive research and technical assistance.

Our staff are familiar with current and potential applications of genomic medicine, including pharmacogenomics, disease susceptibility testing, newborn screening, and reproductive genetic technologies such as prenatal testing and preimplantation genetic diagnosis.

We have substantial experience working with all stakeholder groups, including healthcare providers, individuals affected

by genetic conditions, researchers, government agencies, policymakers, payers, and industry. We are sensitive to the various perspectives and preferred terminology. Our knowledge is critical to conducting accurate research and working effectively with stakeholders; it also enables us to determine how various interests and perspectives intersect – a critical factor in program evaluation and policy analysis.

Collecting and analyzing data

We assess stakeholder knowledge of and attitudes toward healthcare applications of genomics. Our team employs a wide range of methodologies and technologies, including random-digit dial and Web-based surveys, focus groups, interviews, case studies, and literature reviews. We work with in-house psychometricians and a cognitive testing laboratory to develop high-quality data collection instruments. Our multidisciplinary, diverse, and multilingual staff has experience working with different stakeholder groups and diverse populations.

At every stage of a study, we work closely with clients to determine optimal design and study methodologies, develop effective sample designs and data collection tools, and identify the most useful formats for analysis results.

Evaluating genomics health communications initiatives

We conduct process and outcomes evaluations of various genomics-related programs, with an emphasis on education and outreach programs targeting consumers and/or healthcare providers.



Our teams can employ a participatory approach that involves all stakeholders to obtain the most accurate representation of an initiative's performance. We also provide feedback and technical assistance throughout the evaluation process to foster program improvement and refinement. Our teams produce clear evaluation reports and recommendations that clients can put to use immediately.

Genomics will have significant impact on the nation's healthcare system. Abt Associates' longstanding work in public health and policy analysis makes us well qualified to evaluate efforts to integrate genomics advances into public health research, policy, and programs.

Examining ethical, legal, and social issues

Our staff understand the potential ethical, legal, and social implications (ELSI) of genomics. Like other fields of healthcare, genomics presents gray areas that will need to be examined and resolved as the technologies are developed. Our depth of experience in social policy research provides us with the perspective necessary to examine all sides of an issue and to weigh each factor when developing recommendations.

A skilled, interdisciplinary staff

Abt Associates' interdisciplinary team approach enables us to be responsive to client needs, drawing upon skills and perspectives as necessary to produce quality results. Our staff represents a



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wide range of disciplines with academic credentials and direct experience in health services research, health education, nursing, medicine, pharmacology, genetics, social work, education, statistics, psychometrics, economics, psychology, public policy, and computer science.

A brief sample of our work in genomics appears below.

- **Assessing public opinion on reproductive genetics**

Working for the Genetics and Public Policy Center at the Johns Hopkins University, we conducted qualitative research to assess knowledge and attitudes about reproductive genetics among the general public and other key stakeholders. Our team conducted key informant interviews with health-care providers, scientists, and people affected by genetic conditions – and focus groups with a culturally diverse sample of the general public. (The team used NVivo qualitative data analysis software to code transcripts.) We also co-authored presentations and manuscripts and synthesized the findings for the Center’s final report on public opinion about genetic issues.

- **Evaluating culturally appropriate genetics education and outreach**

We conducted a participatory evaluation of the Genetic Education Needs Evaluation (GENE) Project, a cooperative effort of the March of Dimes and the Health Resources and Services Administration in partnership with various national and community-based organizations. The project supported informed healthcare choices in minority communities by developing community-based strategies to improve access to culturally and

linguistically appropriate genetics resources and services. Our team summarized the published literature on the genetics education needs of and strategies for African Americans and Latinos, and developed and conducted a process evaluation to provide continual feedback to improve project implementation. Data collection methods included semistructured interviews and annual site visits to gather data from project partners.

- **Providing research support services**

Abt Associates is providing a range of statistical and methodological support to the Social and Behavioral Sciences Branch of the National Human Genome Research Institute at the National Institutes of Health. Our services include analyzing provider survey data to assess attitudes, knowledge, and practices regarding family history and genomic medicine as well as surveys of patients to evaluate education or counseling interventions. We also provide consultation to investigators regarding survey and instrument design and sampling and data collection strategies. Qualitative research support has included refining coding schemes, conducting focus groups and interviews, and coding data.

- **Surveying physician attitudes and genetic testing practices**

For the National Cancer Institute, Abt Associates conducted a national survey of primary care physicians to assess the prevalence of genetic testing for cancer susceptibility genes and to evaluate physician knowledge of and attitudes toward such testing. Survey results were published in the *American Journal of Medical Genetics* and *Cancer Epidemiology Biomarkers & Prevention*.

Abt Associates’ genomics and health policy work focuses on the social science, policy, and public health aspects of medical applications of genomics. Abt Associates Clinical Trials (AACT) provides clinical research on genomic medicine, including outcomes research and registries. Visit www.abtassociates.com for detailed project descriptions and to explore our full range of capabilities.

Genomics is a rapidly evolving science. Abt Associates is well suited to meet future policy and clinical research needs, including pharmacoeconomic studies, comprehensive workforce studies, evaluation of educational strategies, utilization studies, cost/expenditure analysis, technology assessment, and analysis of policies on genomics issues. We continue to monitor developments and enhance our knowledge of genomics to offer clients leading-edge research.

For more information on Abt Associates and our work in genomics health policy research and evaluation, contact:

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