

**Priority Issues Identified
by the
SACGHS *Ex Officios***



NIH Office of Science Policy

Survey Process

- **In Spring 2003, SACGHS *Ex Officios* were asked to identify priority issues**
- ***Ex Officios* were provided a list of possible issues organized in seven arenas**
- **Use of this background material was optional and identification of other issues was encouraged**

Seven SACGHS Functions

- 1. Assessing the integration of genetic technologies into health care and public health**
- 2. Studying the clinical, ethical, legal and societal implications of new medical applications and emerging technological approaches to clinical testing**
- 3. Identifying opportunities and gaps in research and data collection efforts**
- 4. Exploring the use of genetics in bioterrorism**

Seven SACGHS Functions (cont)

- 5. Analyzing uses of genetic information in education, employment, insurance, including health, disability, long-term care, and life, and law, including family, immigration, and forensics**
- 6. Serving as a public forum for the discussion of emerging scientific, ethical, legal and social issues raised by genetic technologies**
- 7. Examining the impact of patent policy and licensing practices on access to genetic technologies**

List of Other Considerations

- **Will the Committee's policy advice on the issue significantly benefit society?**
- **Will failure to address the issue prolong any negative impact that it is having on society?**
- **Is Federal guidance or regulation warranted?**
- **Is there a Governmental interest in receiving policy advice from the Committee in that area?**
- **Is the Government poised to act upon policy advice from the Committee in that area?**

List of Other Considerations (cont)

- Is there media attention to or public concern about the issue?**
- Is there a need for public discussion and understanding of the issue?**
- Do sufficient data exist about the issue for the Committee to develop informed policy advice?**
- Is another body addressing the issue?**
- Is another body better equipped to address the issue?**
- Does the Committee possess the expertise necessary and is otherwise equipped to advance the issue?**

Survey Responses

- Commerce
- Defense
- Energy
- HHS/ACF
- HHS/AHRQ
- HHS/CDC
- HHS/CMS
- HHS/FDA
- HHS/HRSA
- HHS/NIH
- HHS/OCR
- HHS/OHRP
- Justice
- Labor
- EEOC

Number of Specific Issues Identified Within Seven Functional Categories

- **Integration into health care and public health -- 23**
- **Social use and misuse -- 19**
- **Research and data collection -- 17**
- **Emerging issues -- 11**
- **ELSI issues raised by new health applications and emerging technologies -- 5**
- **Use of genetics in bioterrorism -- 4**
- **Impact of patents and licensing practices -- 3**

Top Ten Specific Issues Identified

- 1. Use and misuse of genetic information in insurance, employment, education and law (8)**
- 2. Ethical, legal, and social implications associated with the use of genetic technologies to screen or select for “desirable” or “undesirable” traits (6)**
- 3. Standards for assessing when genetic technologies are ready to be used in clinical practice (5)**
- 4. Ethical, legal, social implications associated with new health related applications of genetic technologies (5)**
- 5. Guidance for gene banking for research and forensic use (5)**

Top Ten Specific Issues Identified (cont)

- 6. Use of genetic technologies for bioterrorism (5)**
- 7. Impact of patenting and licensing practices on the availability, accessibility, and affordability of genetic technologies (5)**
- 8. Genetic literacy of the public about the scientific, ethical, legal, social issues raised by genetic technologies (5)**
- 9. Need for additional measures to strengthen current oversight of genetic tests (4)**
- 10. Impact of the Privacy Rule on genetic data collection (4)**