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)