

Oversight of Emerging Technologies: Lessons From Prior Advisory Committee Efforts

Meeting Two

**Presidential Commission for the
Study of Bioethical Issues
Philadelphia, Pennsylvania
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**Lessons from the President's Commission for the
Study of Ethical Problems in Medicine and
Biomedical and Behavioral Research (1980-83)
about Addressing New Scientific Developments**

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A Comparative Perspective

- **President's Commission was created by statute & given action-forcing power (1978)**
- **Commissioners (11, all from outside government) appointed by successive Presidents: Carter (1979) & Reagan (1982)**
- **Reported to President & Congress**
- **Began work 1/14/1980 & ended 3/31/1983**
- **Produced 11 reports & IRB Guidebook**
 - **Working simultaneously on numerous topics**
 - **6 reports on health care & 5 on research**
 - **6 mandated by statute, 1 "inherited" from EAB, 1 on own initiative, 1 requested by President**

Mission of Bioethics Comm'ns

1. To monitor scientific/medical developments (“advances”) and identify the issues they will raise for society
2. To bridge divide between science and society
3. To articulate the range of views on controversial subjects
 - **To inform the political process & policymaking**
4. To provide guidance to individuals & healthcare professionals
 - **How to live a good life & confront difficult choices**
 - **Ethical standards that should guide practice**
5. To provide recommendations to policymakers

Functions (Shorthand)

Traditional descriptions

- **Dumping ground** (taking difficult issues out of the political arena, at least temporarily)
- **Watchdog** (oversee execution of activities/ rules)

Successful Bioethics Commissions

- **Lay to rest** (solidifying an emerging consensus)
 - Cannot expect to quiet **all** ethical concerns or write the **final** commentary, nor avoid **unintended** results
- **Crucible** (**identify elements** of underlying, apparently disparate views; **offer correctives** for defects in reasoning; **articulate the implications** for policy and ethical behavior)

Mode of Work

- 1. Open & Visible**, but more: real outreach
 - **Public:** Infinitely easier with internet & social media
 - **Agency liaisons:** know the practical implications
 - If allowed, communication with **Congress** as well
- 2. Know the audience:** mix will vary by topic (**p**ublic officials; **p**rofessionals; **p**eers; **p**ress; and the **p**ublic at large)
- 3. Broad, well-informed & sensitive consultation**
 - **Convene expert panels** (not just witnesses)
 - Seek out **highly qualified staff** (on-leave)

Mode of Work

4. Inductive method

- Easier to do when “cases” are real, developed
- **Not just “pragmatic”** in the pejorative sense
- Doesn’t relieve obligation to articulate coherent reasoning, but **let principles emerge** from examination and resolution of successive topics
- Even the most famous instance of public bioethical “principilism” (the *Belmont Report*) came at end of National Commission’s process
- **Not asked to invent new philosophical theories** but to offer conclusions & recommendations based on multidisciplinary analysis of issues facing policy makers, healthcare professionals, scientists, patients & families

Mode of Work

5. **Consensus**: as methodology, not goal

- Struggle to gain agreement can help reach a widely acceptable resolution of issue
- Speaking with one voice is more **persuasive**

6. **Work products**: specific as possible but with full exploration & clear reasoning

- Output must vary by topic: legislation or regulation but also professional & institutional action; individual guidance
- Especially with new topic: public education
- Clarify of what's at issue, without simply relabeling (cloning vs SCNT; euthanasia vs allowing to die)
- Like “**moot court**”: audiences are looking for help in reaching decisions, not “cleverness”

Studying Ethical Aspects of Scientific Developments

- **Request from President: science raises concerns**
 - **1980–genetic engineering** (prospect of human application)
 - **2010–synthetic biology** (prospect of human application)

1. **Quality** of evidence

- Mapped the terrain: what mechanisms in place?
- Convened leading experts for workshop with commissioners

2. **Clarity** and **Rationality**: reality in place of hyperbole

- Meaning of terms (“genetic engineering,” “playing God,” etc)
- Source of anxiety (distrust of science? Over-reaching?)
- Potential benefits & risks; social context (IP issues, etc.)

3. **Relevance** of reports to practical problems facing society (patients, professionals, citizens)

- advisory but not academic/“policy-relevant” not philosophical