



Ethical Aspects of Studies on Populations Resident in Contaminated Sites

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**Istituto Superiore di Sanita – Collegium Ramazzini and
WHO Collaborating Centre for Environmental Health in
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*Contaminated Sites and Health:
Recent Findings and the Way Forward*

October 22, 2014



Objectives

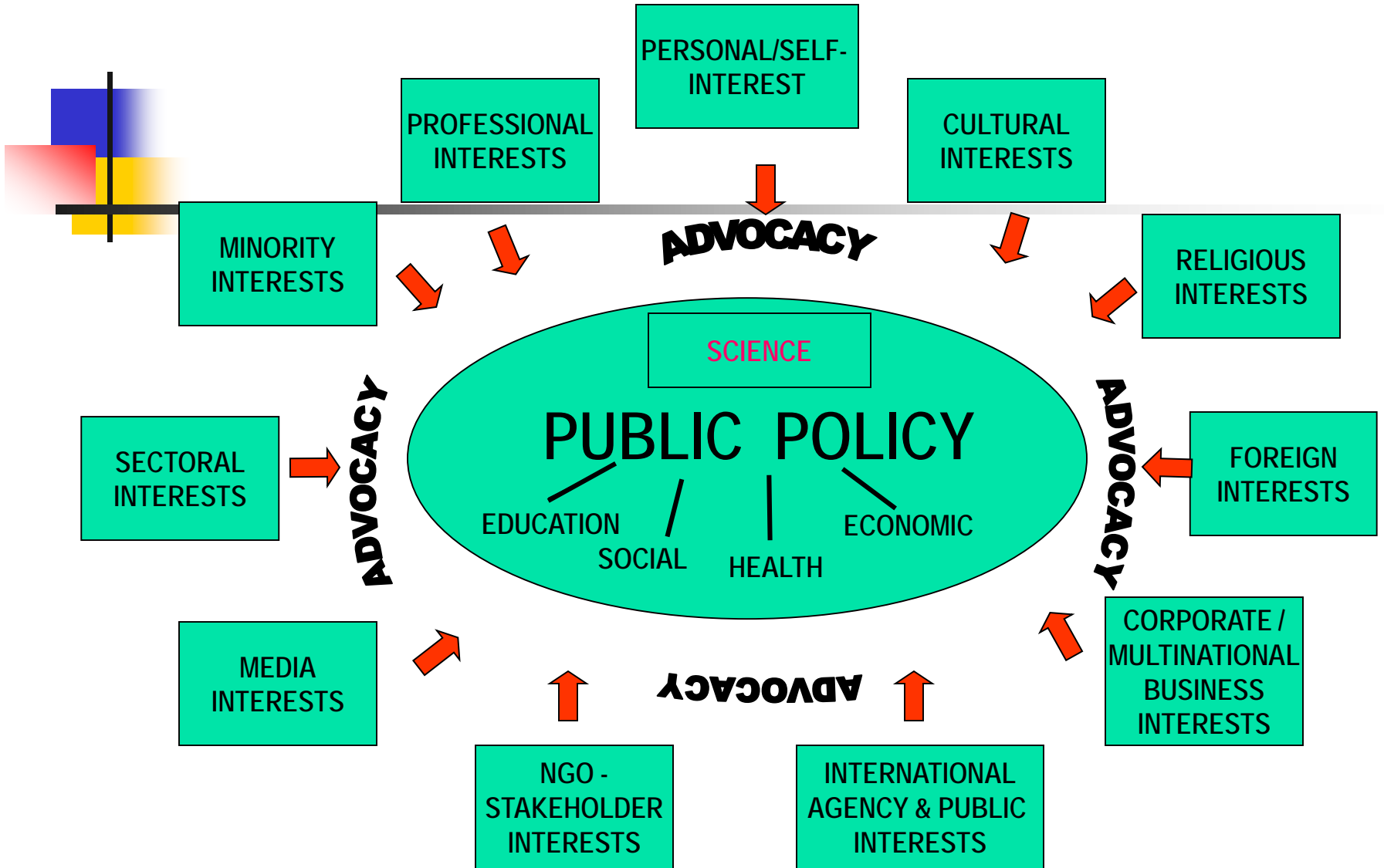
- Bringing professional ethics into the discourse on studying people in contaminated areas/sites
- Distinguishing contexts: between the need for more research and the need for action; and, between historically contaminated sites and sites experiencing ongoing contamination
- Providing a generic framework for ethical decision-making



EPIDEMIOLOGY

An applied science that bridges the basic sciences to human health and well-being

The science that informs health policy





Science is but one such pressure

**--- HUMILITY AND
EMPATHY FOR THE
POLICY-MAKER ---**

*Our job in science is to do the
best possible science*

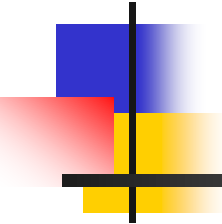


**Be aware of the forces at play
that influence both science
and policy.**

**... Great vigilance and
personal integrity are required
to change course.**



→ There are many **competing interests** in the work done by epidemiologists



**“Industry’s offensive against
the regulation of health and
safety hazards uses academics
to downplay or deny the
seriousness of the hazards...”**

Clayson and Halpern

J. of Public Health Policy

September, 1983



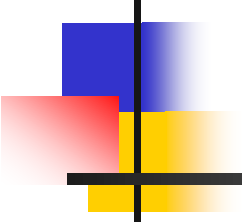


Judge Miles W. Lord, 1982

On “*Corporate Ethics and Environmental Pollution*”:

“Corporations create 80% of our GNP. They, of all entities working, have the most potential for good or evil in our society.”

This was in 1982. Today it is surely more like 90%.



All sorts of pressures come to bear on the applied health scientist and they carry over into the policy domain



Influences and pressures

- **From funding sources to peer review**
- **From the questions we ask through access to data**
- **From study design to data analysis and interpretation**
- **From dissemination to job security**



The Four D's applied to scientists studying that which does not support the *status quo*

- **Deny**
- **Delay**
- **Divide**
- **Discredit**
- **[Dismiss]**



Manufacturing Doubt

- Epstein. *The Politics of Cancer*, 1978
- Davis. *When Smoke Ran Like Water: Tales of Environ Deception*, 2002
- *The Secret History of the War on Cancer*, 2007
- *Disconnect: The Truth About Cell Phone Radiation ...*, 2010
- Michaels. *Doubt is their Product: How Industry's Assault on Science...*, 2008
- McCulloch & Tweedale. *Defending the Indefensible: The Global Asbestos Industry*, 2008
- Oreskes & Conway. *Merchants of Doubt*, 2010

By fomenting uncertainty, the health policy-maker's role is undermined ...

→ the subversion and ambushing of science 14



Tobacco Example is best known

- **Full circle – ~50-year story now told**
- **Disinformation campaigns**
- **Lies, manipulation, deceit**
- **Co-opt or appropriate scientists to lie**
 - ... Is this bad in itself?
 - ***The real tragedy is that scientists accept these monies and then proceed to please their sponsor***

The Center for Public Integrity

www.publicintegrity.org



- **Industry Muscle Targets Federal**
“Report on Carcinogens” July 30, 2013

- ***“Industry attacks on Public Health research have become more strident.”***
Linda Birnbaum, Director, US-NIEHS



THE GOLDEN RULE - *adapted*

- **What is hateful unto you, do not do unto your neighbour**

Hillel, Babylonian Talmud, Tractate Shabbat, 31B

- **Treat others as we would want them to treat us or our loved ones**

Luke 6:31 and Matthew 7:12

- **Treat others justly so that no one would be unjust to you**

From the Prophet Mohamed's Last Sermon

-
- **Do our level best**
 - **Assert ourselves if we find that someone has done ill**



THE NORMAL RANGE OF HUMAN CONDUCT

VERY POOR



**VERY
GOOD**

AND EVERYTHING

IN BETWEEN

DISHONEST



HONEST

**POWER CORRUPTS. ABSOLUTE POWER
CORRUPTS ABSOLUTELY!**

(Lord Acton's premise)

NO ONE IS IMMUNE!



Definitions

ETHICS - The rules of conduct/behaviour recognized in respect to a particular class of human actions or a particular group or culture.

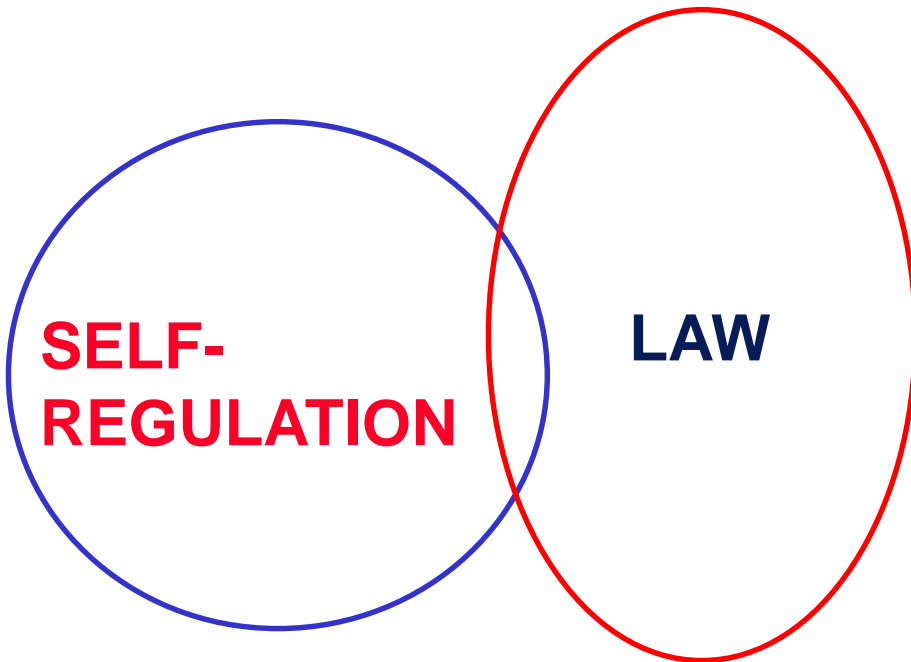


SELF-REGULATED

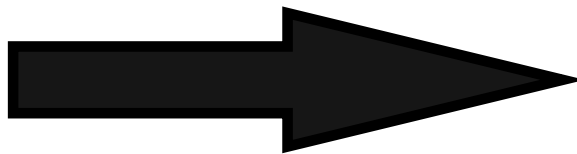
MORALS - Principles or habits with respect to right or wrong.



LEGALLY ENFORCED



**REGIONAL AND GROUP
DIFFERENCES IN
THESE CONTROLS**



**SOME PROFESSIONAL
GROUPS ARE MORE SELF-
REGULATING THAN OTHERS**



THEORETICAL APPROACHES/MODELS

ETHICAL THEORIES/APPROACHES

- **Utilitarian (John Stuart Mill)**
- **Deontological (Immanuel Kant)**
- **Virtue**
- **Egalitarian**
- **Relational**
- **Libertarian**

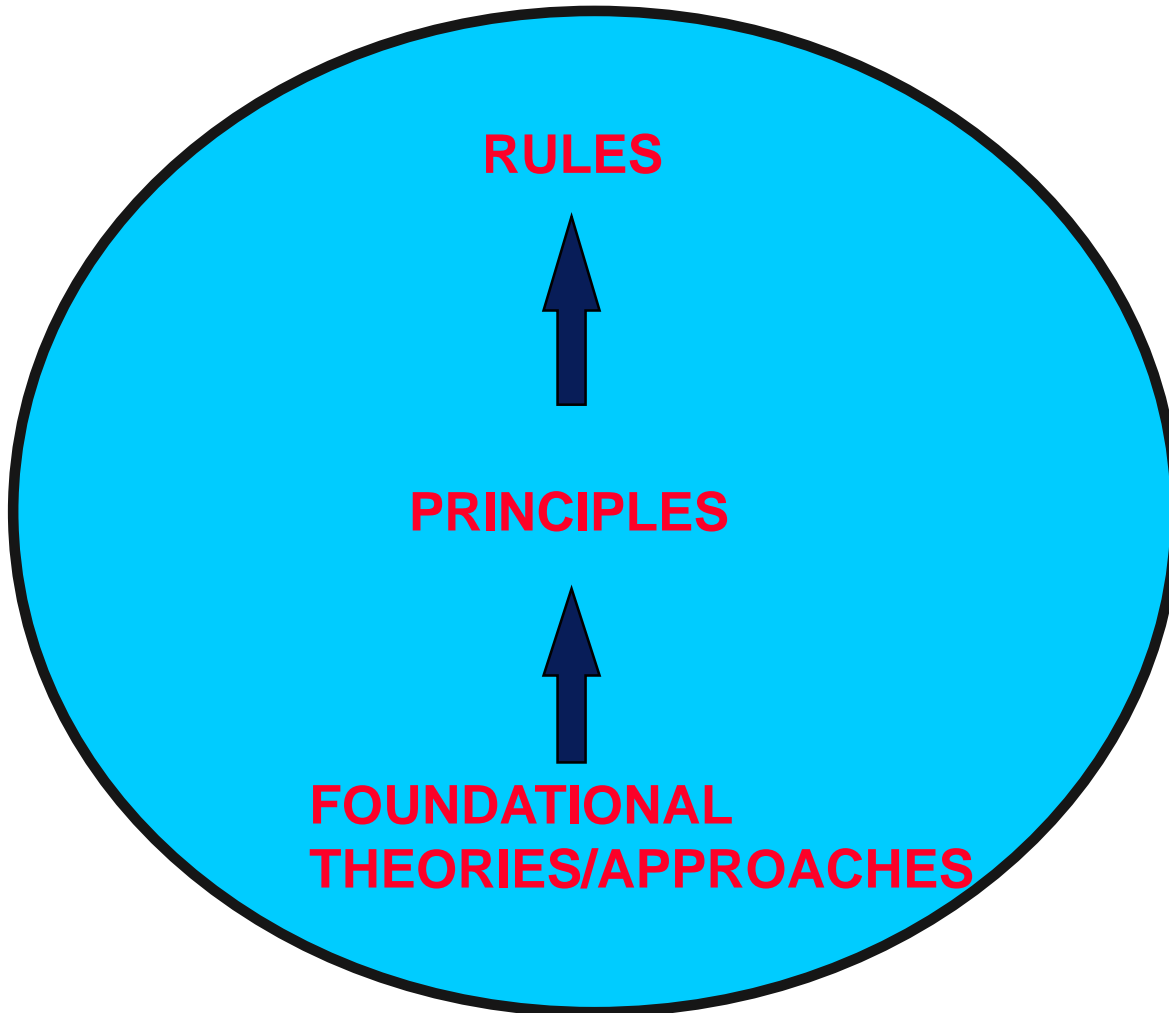
- **Casuistry**



Why Ethics in the Professions?

- **Keep ourselves on track and keep our house in order**
- **Socialize our students**
- **Professional accountability**
 - **According to norms of behaviour**
 - ***And, while we do our research***
 - **IN WHOSE BEST INTERESTS?**
WHO IS TAKING THE RISKS?
WHO IS DERIVING THE BENEFITS?

THE DISCIPLINE OF ETHICS





The Scientific Ethic*

A set of norms that define the scientific endeavour → an ethos that evolved gradually and organically.

PROFESSIONAL ETHICS embody some of these norms, but “**The Ethic of Science**” is more like the charter that makes science possible than like a law book that spells out the specific rules.

This ethic defines the **boundaries** that must be respected by those who wish recognition as part of the scientific community.

* Reece, RD & Siegal, HA. Studying People: A primer in the ethics of social research. Mercer 1986, pp. 62-70.



Is science value-neutral?

Or, put another way:

Is science value-free?



Core Values & Mission Statements

- **They provide the anchor for our activity and collective motivation ... *maintain, enhance, and promote health in communities worldwide ... work to protect the public health interest above any other interest ...***

VALUES ... CONTEXT

A10 The Edmonton Journal, Tuesday, March 12, 1996

Opinion

Publisher: Linda Hughes
Editor in Chief: Murdoch Davis
Managing Editor: Sheila Pratt
Associate Editor: Duart Farquharson



SAME PLANET, DIFFERENT WORLDS.



The Earth Charter

Preamble — to the 4 major principles:

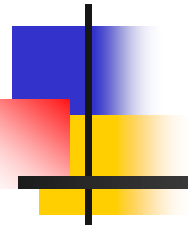
- **Respect and care for the community of life**
- **Ecological integrity**
- **Social and economic justice**
- **Democracy, non-violence, and peace**

The Way Forward



GUIDELINES versus CODES

- ❑ Normative statements that are aspirational versus prescriptive
- ❑ A “list” versus a “checklist”
- ❑ “List” provides a basis for discussion:
 - *Context*
 - *Recognize tensions*
 - *Not for application as a “checklist”!*



Prescriptive codes

versus

Aspirational codes



THE TEN COMMANDMENTS

- Thou shalt have no other Gods before me**
- Thou shalt not bow down before graven images**
- Thou shalt not take the name of the Lord thy God in vain**
- Remember the Sabbath Day and keep it holy**
- Honor thy father and thy mother**
- Thou shalt not kill**
- Thou shalt not commit adultery**
- Thou shalt not steal**
- Thou shalt not bear false witness against thy neighbor**
- Thou shalt not covet**

Moses, Mount Sinai



The Buddhist Code of Moral Conduct

by [Vajiranavarorasa](#)

The First Precept:

Abstaining from taking the lives of living beings

The Second Precept:

Abstaining from taking that which is not given

The Third Precept:

Abstaining from sexual misconduct

The Fourth Precept:

Abstaining from false speech

The Fifth Precept:

**Abstaining from distilled and fermented intoxicants
which are the occasion for carelessness which also
includes drugs**

Deontological (i.e. duty-based)

In essence, the scientific ethic expects of scientists the duty to:

1. Use appropriate methods
2. Be objective
3. Be honest in reporting
4. Publish results - **POSITIVE** as well as **NEGATIVE**
5. Prohibit distortion in, for example:
 - Falsification of data
 - Biases inherent to study design
 - Proper analytical procedures
 - Objective interpretation
6. Do one's own work:
 - Plagiarism
 - Acknowledge sources
 - Graduate students not to be exploited

GOOD ETHICS ↔ GOOD SCIENCE



Classical techniques that skew results: from biased methods to **junk science**

- **Linear reductionism without post-normal science to complement quantitative methods**
- **Under-powered studies**
- **Inadequate follow-up methods**
- **Inadequate follow-up time**
- **Contaminated controls**
- **Unbalanced discussion**
- **Selective disclosure of competing interests**



ETHICS GUIDELINES FOR ENVIRONMENTAL EPIDEMIOLOGISTS

- I. OBLIGATIONS TO RESEARCH PARTICIPANTS**
- II. OBLIGATIONS TO SOCIETY**
- III OBLIGATIONS TO SPONSORS AND EMPLOYERS**
- IV. OBLIGATIONS TO COLLEAGUES**



The **FUNDAMENTAL PRINCIPLES** of **BIOETHICS** include:

RESPECT FOR AUTONOMY

- Requires respect for individual rights and freedoms (Also: **Veracity & Fidelity**)

BENEFICENCE

- Requires doing good / Consider consequences of interventions in people's lives and of findings

NON-MALEFICENCE

- Requires doing no harm

JUSTICE

- Requires fair and equitable allocation (of risks & benefits) to all without discrimination



The FUNDAMENTAL PRINCIPLES of BIOETHICS include (under Justice):

- ENVIRONMENTAL JUSTICE

- *Who is taking the risks?*
- *Who is deriving the benefits?*

- THE POLLUTER PAYS

- *incentive to internalize costs*



Primary Principles in Public Health

- **Protect the most vulnerable in society** (e.g., unborn, children, Inuit, frail elderly)
- **Involve communities in our research** (ensure community relevance of our work)
- **Integrity in Public Health**
 - **Serve the public health interest above any other interest**



A natural tension exists among all of the principles

**We simply cannot perfectly
satisfy all four principles fully on
any single issue, but we must try
to optimize each, transparently**



**Where does
epidemiology fit into classical
risk assessment?**



Classical Health Risk Assessment

reductionist and linear in approach (US EPA 1960s)

1. **Hazard Assessment**
2. **Vulnerability Assessment**
3. **Risk Evaluation** ←
4. **Risk Communication**
5. **Risk Management**

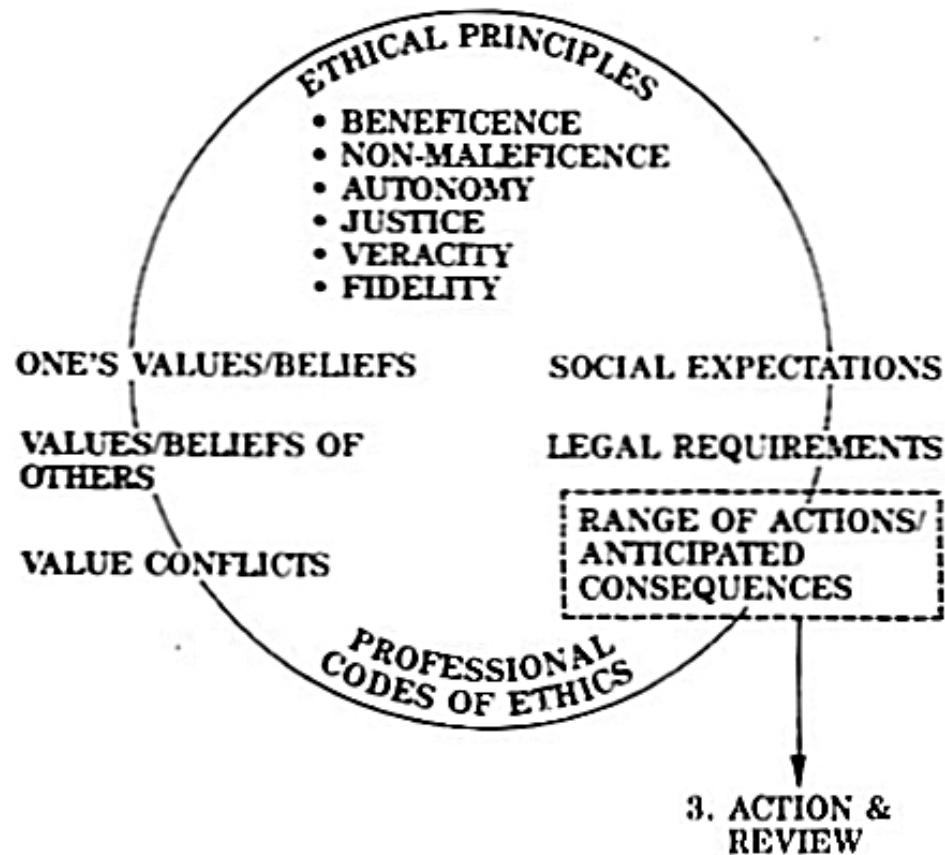


What are we up against?

- **What creates/drives misconduct in science?**
- **What tempts scientists away from the pursuit of truth?**
- **How does misconduct derail scientific discourse?**
- **How does misconduct influence public policy and hence population and global environmental health?**
- **Confrontation, and the challenge of speaking truth to power!**

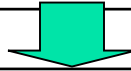
Making an Ethical Decision

2. CLARIFICATION & EVALUATION

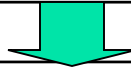


Generic problem-solving model for ethical decision-making

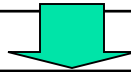
Gather all relevant information



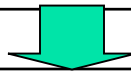
**Specify clearly all components of
the identified ethical dilemma**



**Specify all options as possible
courses of action**



**Select a single best
alternative**



Act and review



The 2013 Report of Two WHO Workshops held in 2011 & 2012

- **No discussion included on the ethical and human rights foundations of concerns about contaminated sites.**
- **In an ethical analysis, we must distinguish between approaches to be taken relating to historically contaminated sites and to sites currently being contaminated.**



A Case Study

of a bottom-up approach

CAUTION:
ETHICAL IMPERIALISM



Whose role is it to deal with societal determinants of health?

The case of the Nigerian lead-poisoning epidemic by John D. Pringle and Donald C. Cole

- **In: Canadian Institutes of Health Research–Institute of Population and Public Health (2012). *Population and Public Health Ethics: Cases from Research, Policy, and Practice*. University of Toronto Joint Centre for Bioethics: Toronto, Ontario, pp. 176-185.**



Soskolne - Case Discussion (1 of 2)

- **The key relevant information** *(i.e., biologic, economic, social, political, or ethical) and knowledge gaps, as well as the basis for these facts.*
- **Identify the key stakeholders in the case** *and the most appropriate decision-maker(s) and/or legal authorities to approach the ethical issue, if applicable.*
- **Identify the key values and concerns** *of the identified stakeholder(s), as well as any potential risks and benefits.*



Soskolne - Case Discussion (2 of 2)

- **Identify the options available to the decision-maker, *including reasonable alternative courses of action, consideration of implications, and potential intended and unintended consequences.***
- **Suggest a resolution or decision to the case *by choosing the supported option, and justify the decision.***
- **How might the decision and/or action be evaluated?**



And more going on internationally

A top-down approach to
protections through constitutional
amendments

South Africa

1996 Bill of Rights



- 24. Environment: Everyone has the right**
- a. To an environment that is not harmful to their health and well-being; and**
 - b. To have the environment protected, for the benefit of present and future generations, through reasonable legislative and other measures that**
 - (i) prevent pollution and ecological degradation;**
 - (ii) promote conservation; and**
 - (iii) secure ecologically sustainable development and use of natural resources while promoting justifiable social and economic development.**



And Other Countries too ...

- **Brazil, Columbia, Ecuador, Cuba, Andorra, Ukraine, France, India, China, Philippines, Papua New Guinea, Montenegro, Iraq, Kenya, Bhutan, ...**
- **In 2012, David R. Boyd's "The Right to a Healthy Environment Revitalizing Canada's Constitution"**
- **In 2014, David Suzuki Foundation campaign to amend Canada's constitution to entrench the right to a healthy environment for all Canadians**



Distinguish between community needs for ...

- **More RESEARCH?**

OR

- **More ACTION?**



Classical Health Risk Assessment

reductionist and linear in approach (US EPA 1960s)

1. **Hazard Assessment**
2. **Vulnerability Assessment**
3. **Risk Evaluation** ←
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5. **Risk Management**



Hill (1965) concludes ...

"All Scientific work is incomplete – whether it be observational or experimental. All scientific work is liable to be upset or modified by advancing knowledge. That does not confer upon us a freedom to ignore the knowledge we already have, or to postpone the action that it appears to demand at a given time."



The Challenge

- Who takes the risks while who derives the benefits? Or, whose interests are being served in this policy?**
- Does the burden of proof of safety lay on the proponent, or on Joe and Jane Public?**



Virtue Ethics ...

- **Wisdom is knowing what to do next; virtue is doing it.** *David Star Jordan*
- **What is right is often forgotten by what is convenient.** *Bodie Thoene*
- **It is curious that physical courage should be so common in the world and moral courage so rare.** *Mark Twain*



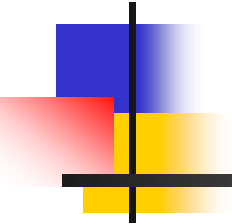
Character vs. Actions

Virtues do not replace ethical rules. Rather, an account of professional ethics is more complete if virtuous traits of character are identified, such as:



VIRTUES OF PROFESSIONALS

- **Humility** – Respect the input and opinions of others /Self-effacement
- **Fidelity** – Honour one's commitments /Promote trust
- **Justice** – Act fairly
- **Patience** – Take time to hear others' viewpoints
- **Industry** – Do your level best /Excel
- **Veracity** – Tell the truth /Be honest
- **Compassion** – Empathize
- **Integrity** – Demonstrate good moral character
- **Serve** – Protect the most vulnerable /Serve the public interest
- **Prudence** – Err on the side of caution /Demonstrate good judgment



DISCUSSION