

Ethical Aspects of Studies on Populations Resident in Contaminated Sites

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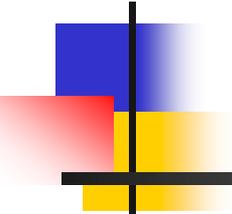
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- URL: www.colinsoskolne.com (*archive of PPT presentations*)

**Istituto Superiore di Sanita – Collegium Ramazzini and
WHO Collaborating Centre for Environmental Health in
Contaminated Sites, Rome, Italy**

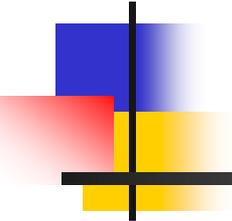
*Contaminated Sites and Health:
Recent Findings and the Way Forward*

October 22, 2014



Objectives

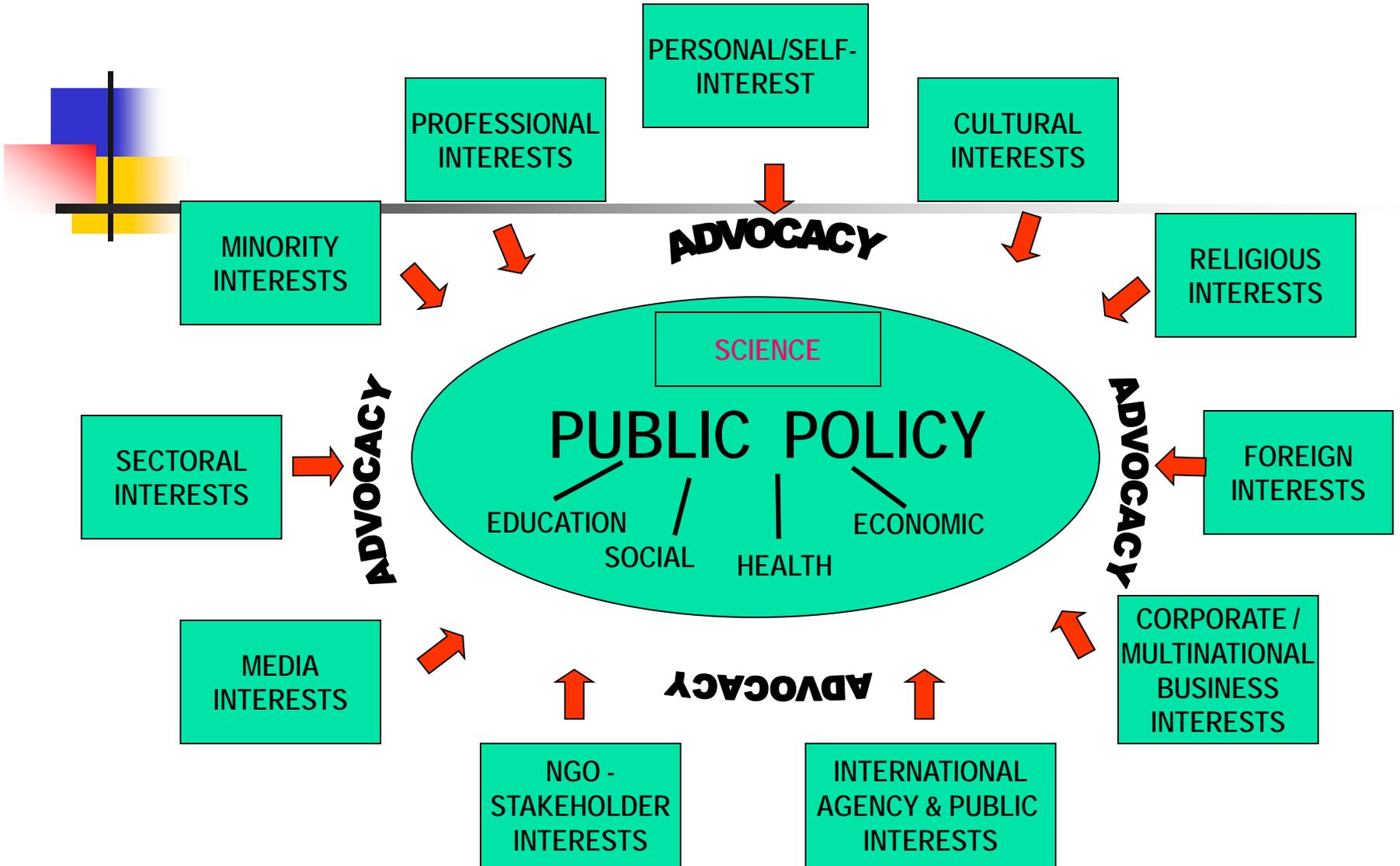
- **Bringing professional ethics into the discourse on studying people in contaminated areas/sites**
- **Distinguishing contexts: between the need for more research and the need for action; and, between historically contaminated sites and sites experiencing ongoing contamination**
- **Providing a generic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

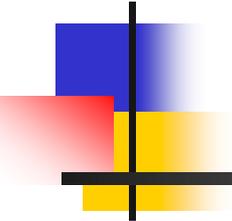


EPIDEMIOLOGY

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

The science that informs health policy

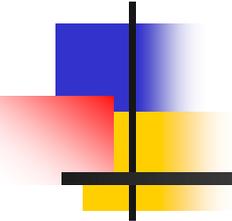




**Science is but one
such pressure**

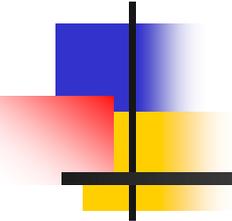
**--- HUMILITY AND
EMPATHY FOR THE
POLICY-MAKER ---**

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

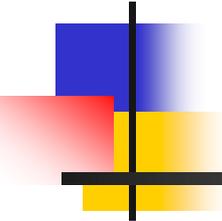


**Be aware of the forces at play
that influence both science
and policy.**

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



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



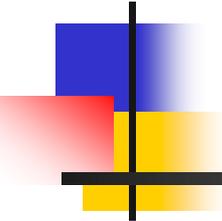
**“Industry’s offensive against
the regulation of health and
safety hazards uses academics
to downplay or deny the
seriousness of the hazards...”**

Clayson and Halpern

J. of Public Health Policy

September, 1983



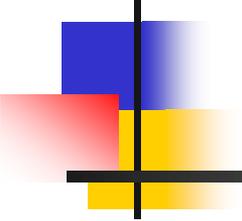


Judge Miles W. Lord, 1982

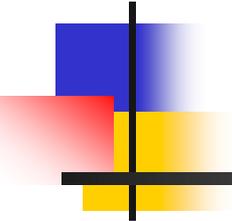
On “*Corporate Ethics and Environmental Pollution*”:

“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%.

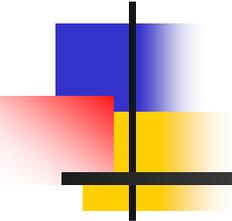


All sorts of pressures come to bear on the applied health scientist and they carry over into the policy domain



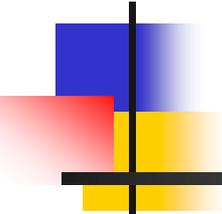
Influences and pressures

- **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]**

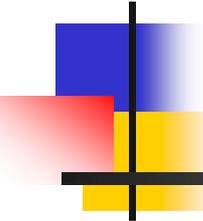


Manufacturing Doubt

- 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

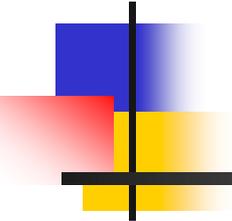


Tobacco Example is best known

- 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*

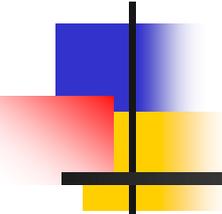
The Center for Public Integrity

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

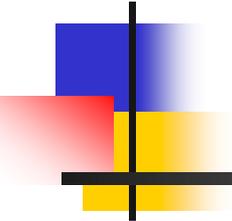
- **Treat others as we would want them to treat us or our loved ones**

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

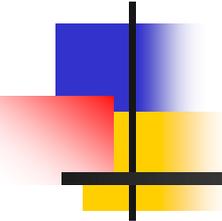


HONEST

**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.

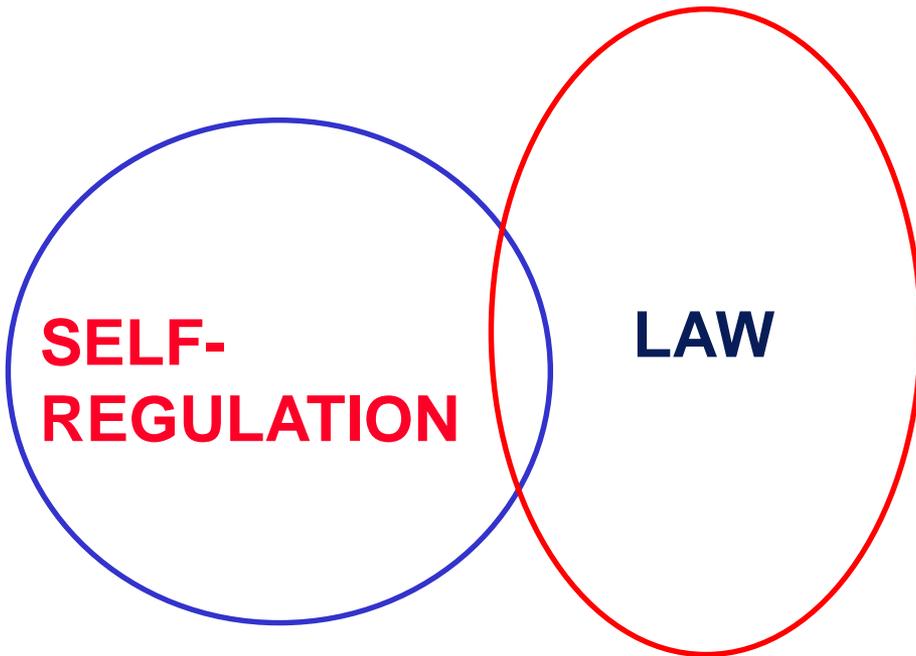
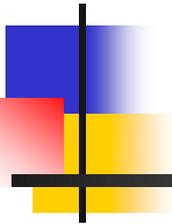


SELF-REGULATED

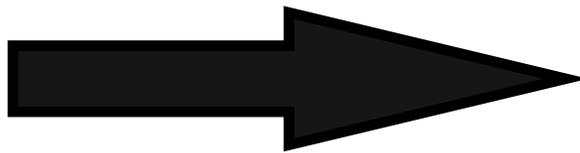
MORALS - Principles or habits with respect to right or wrong.



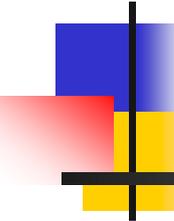
LEGALLY ENFORCED



**REGIONAL AND GROUP
DIFFERENCES IN
THESE CONTROLS**



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

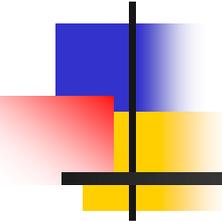


THEORETICAL APPROACHES/MODELS

ETHICAL THEORIES/APPROACHES

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

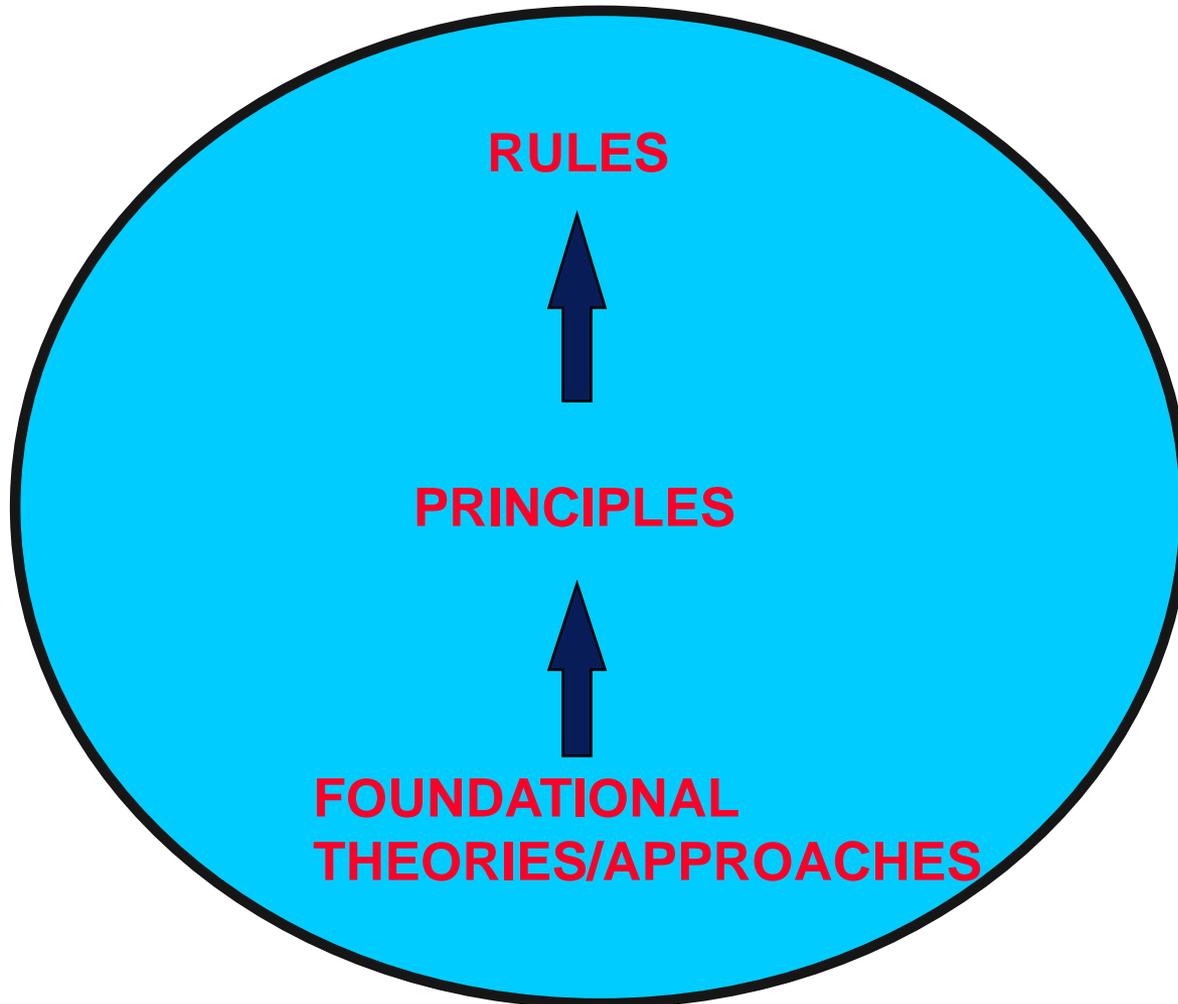
- **Casuistry**

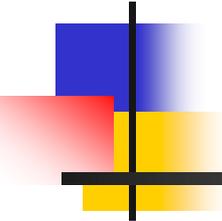


Why Ethics in the Professions?

- **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





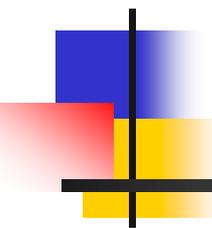
The Scientific Ethic*

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.

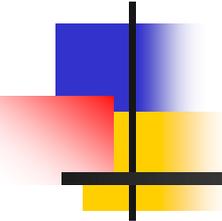
* Reece, RD & Siegal, HA. Studying People: A primer in the ethics of social research. Mercer 1986, pp. 62-70.



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

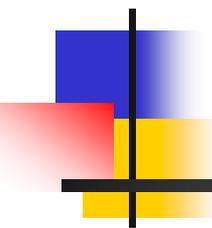
A10 The Edmonton Journal, Tuesday, March 12, 1996

Opinion

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



SAME PLANET, DIFFERENT WORLDS.

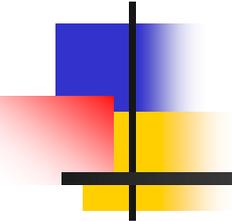


The Earth Charter

Preamble — to the 4 major principles:

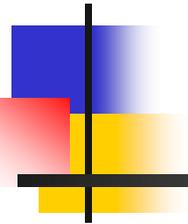
- **Respect and care for the community of life**
- **Ecological integrity**
- **Social and economic justice**
- **Democracy, non-violence, and peace**

The Way Forward



GUIDELINES versus CODES

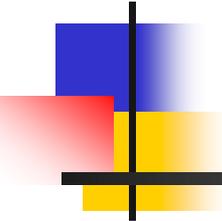
- ❑ Normative statements that are aspirational versus prescriptive
- ❑ A “list” versus a “checklist”
- ❑ “List” provides a basis for discussion:
 - *Context*
 - *Recognize tensions*
 - *Not for application as a “checklist”!*



Prescriptive codes

versus

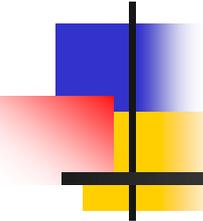
Aspirational codes



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:

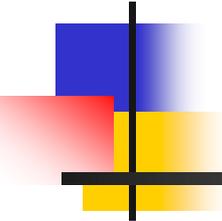
**Abstaining from distilled and fermented intoxicants
which are the occasion for carelessness which also
includes drugs**

Deontological (i.e. duty-based)

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

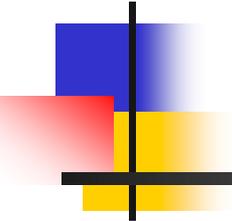
1. Use appropriate methods
2. Be objective
3. Be honest in reporting
4. Publish results - **POSITIVE** as well as **NEGATIVE**
5. Prohibit distortion in, for example:
 - Falsification of data
 - Biases inherent to study design
 - Proper analytical procedures
 - Objective interpretation
6. Do one's own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

GOOD ETHICS ↔ GOOD SCIENCE



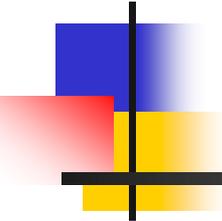
Classical techniques that skew results: from biased methods to **junk science**

- **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

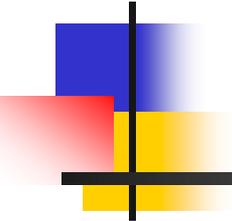
- Requires doing good / Consider consequences of interventions in people's lives and of findings

NON-MALEFICENCE

- Requires doing no harm

JUSTICE

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



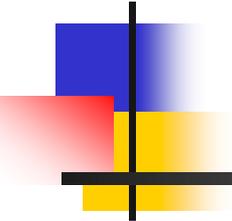
The FUNDAMENTAL PRINCIPLES of BIOETHICS include (under Justice):

- ENVIRONMENTAL JUSTICE

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

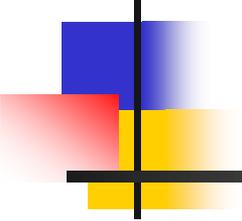
- THE POLLUTER PAYS

- *incentive to internalize costs*



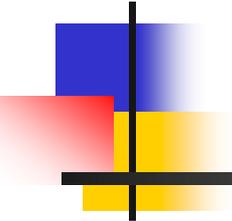
Primary Principles in Public Health

- **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**

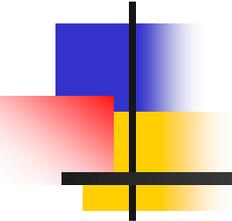


A natural tension exists among all of the principles

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



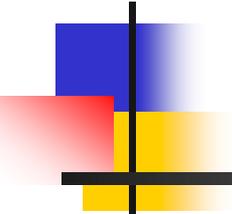
**Where does
epidemiology fit into classical
risk assessment?**



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**

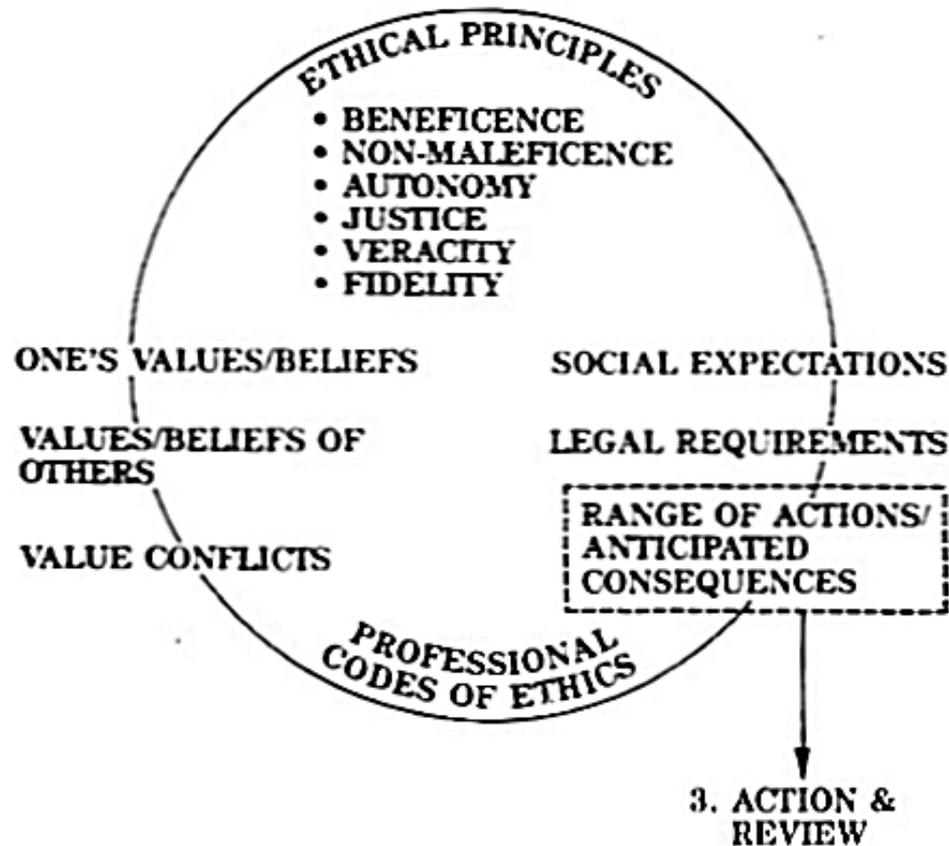


What are we up against?

- **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!**

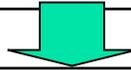
Making an Ethical Decision

2. CLARIFICATION & EVALUATION

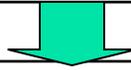


Generic problem-solving model for ethical decision-making

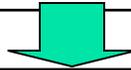
Gather all relevant information



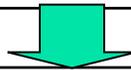
**Specify clearly all components of
the identified ethical dilemma**



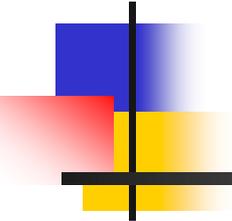
**Specify all options as possible
courses of action**



**Select a single best
alternative**

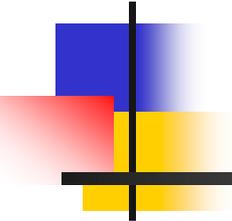


Act and review



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

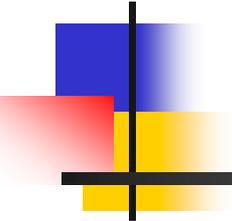
- **No discussion included on the ethical and human rights foundations of concerns about contaminated sites.**
- **In an ethical analysis, we must distinguish between approaches to be taken relating to historically contaminated sites and to sites currently being contaminated.**



A Case Study

of a bottom-up approach

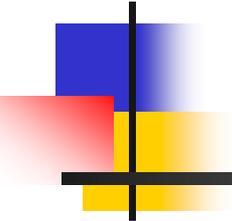
CAUTION:
ETHICAL IMPERIALISM



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

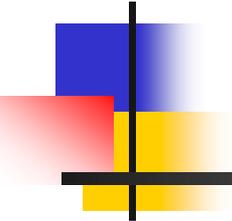
The case of the Nigerian lead-poisoning epidemic by John D. Pringle and Donald C. Cole

- **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.**



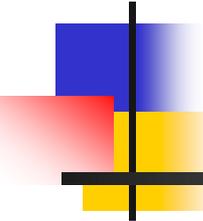
Soskolne - Case Discussion (1 of 2)

- **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?**

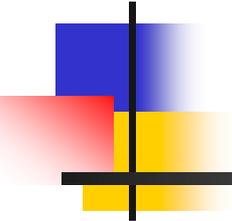


And more going on internationally

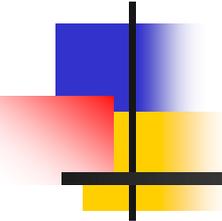
A top-down approach to
protections through constitutional
amendments

South Africa

1996 Bill of Rights

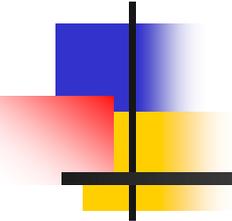


- 24. Environment: Everyone has the right**
- a. To an environment that is not harmful to their health and well-being; and**
 - b. To have the environment protected, for the benefit of present and future generations, through reasonable legislative and other measures that**
 - (i) prevent pollution and 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**

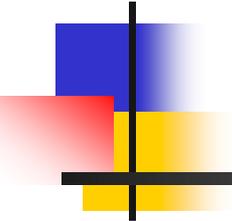


Distinguish between community needs for ...

- **More RESEARCH?**

OR

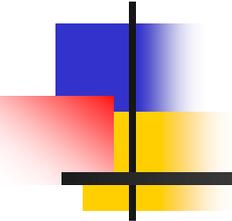
- **More ACTION?**



Classical Health Risk Assessment

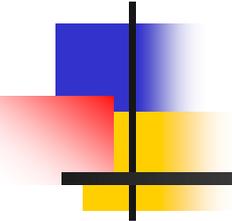
reductionist and linear in approach (US EPA 1960s)

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



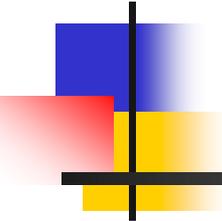
Hill (1965) concludes ...

"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."



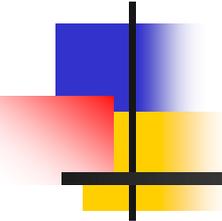
The Challenge

- 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?**



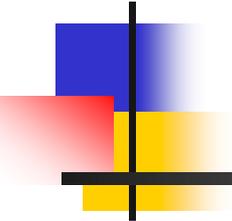
Virtue Ethics ...

- **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*



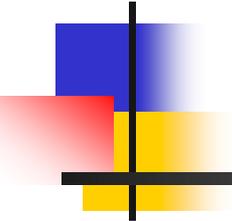
Character vs. Actions

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