



# Ethical Aspects of Studies on Populations Resident in Contaminated Sites

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- URL: [www.colinsoskolne.com](http://www.colinsoskolne.com) (*archive of PPT presentations*)

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**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

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- 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

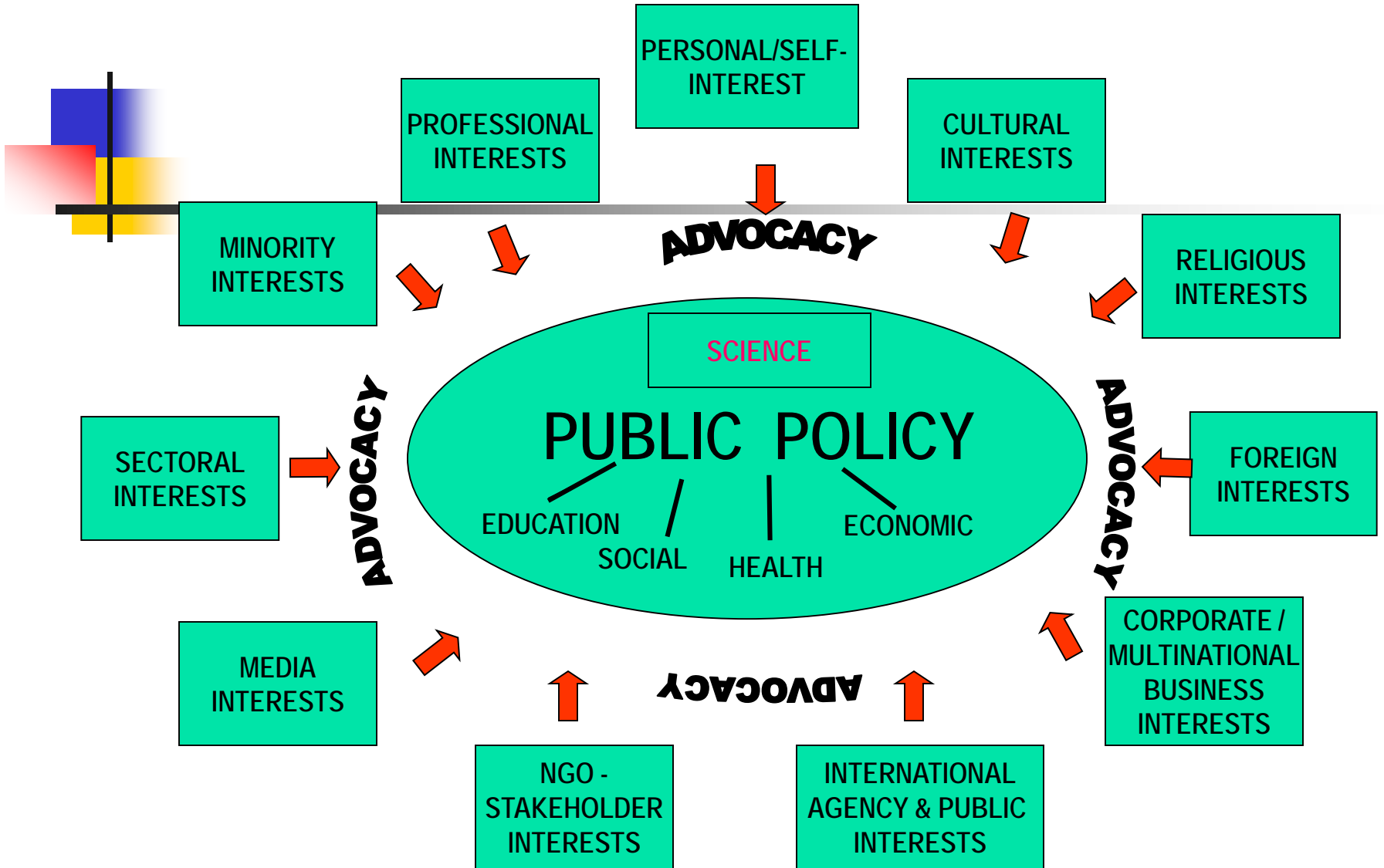


# EPIDEMIOLOGY

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**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

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

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



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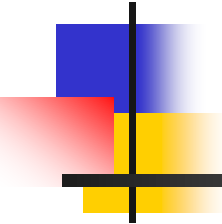
**Be aware of the forces at play  
that influence both science  
and policy.**

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



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



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**“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**







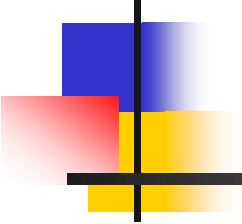
# Judge Miles W. Lord, 1982

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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%.**



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



# Influences and pressures

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- **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

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- 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](http://www.publicintegrity.org)



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- **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*

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- **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

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**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

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

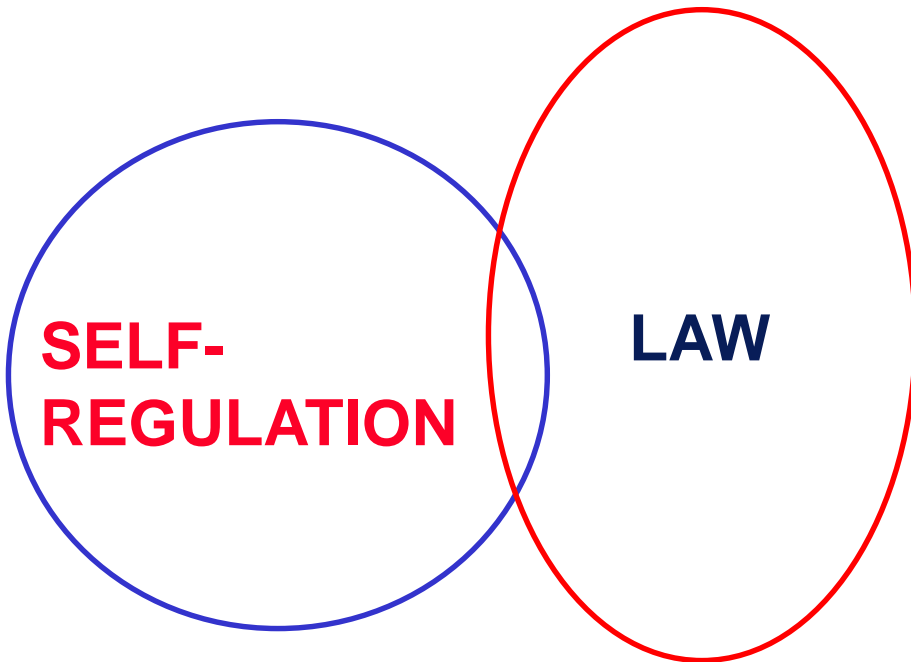
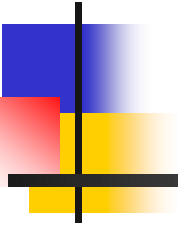


**SELF-REGULATED**

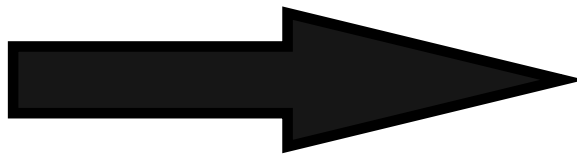
**MORALS** - Principles or habits with respect to right or wrong.



**LEGALLY ENFORCED**



**REGIONAL AND GROUP  
DIFFERENCES IN  
THESE CONTROLS**



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



# THEORETICAL APPROACHES/MODELS

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## ETHICAL THEORIES/APPROACHES

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

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- **Casuistry**

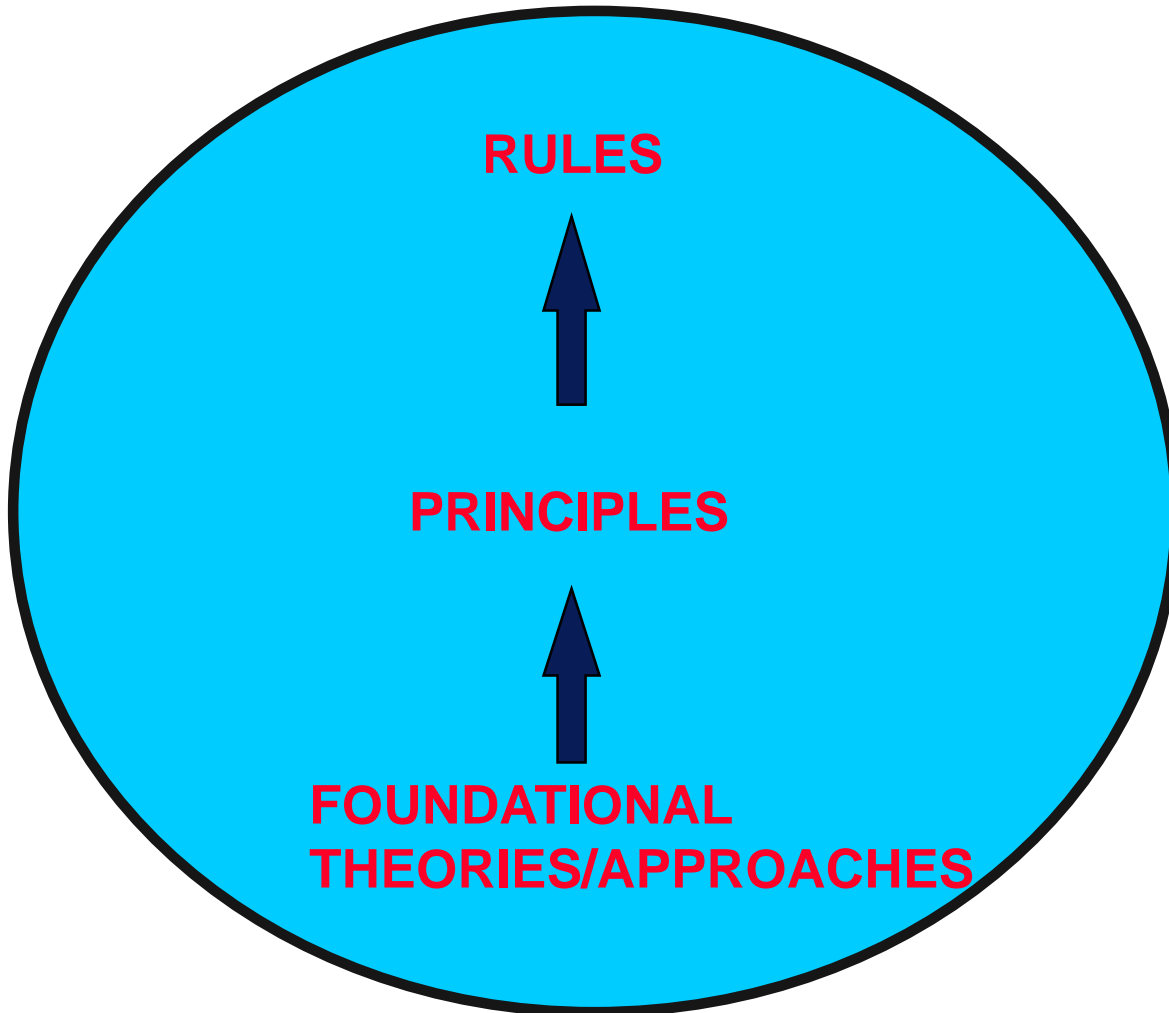


# Why Ethics in the Professions?

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- **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?**

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**Or, put another way:**

**Is science value-free?**



# Core Values & Mission Statements

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- **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

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**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**

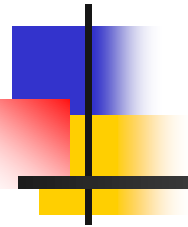
## The Way Forward



# GUIDELINES versus CODES

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- ❑ 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

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*versus*

**Aspirational codes**



# THE TEN COMMANDMENTS

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- 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](#)

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*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**

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- **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**

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- 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:

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## **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):

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- ENVIRONMENTAL JUSTICE

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

- THE POLLUTER PAYS

- *incentive to internalize costs*



# Primary Principles in Public Health

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- **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**



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# **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**



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





# Classical Health Risk Assessment

*reductionist and linear in approach (US EPA 1960s)*

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



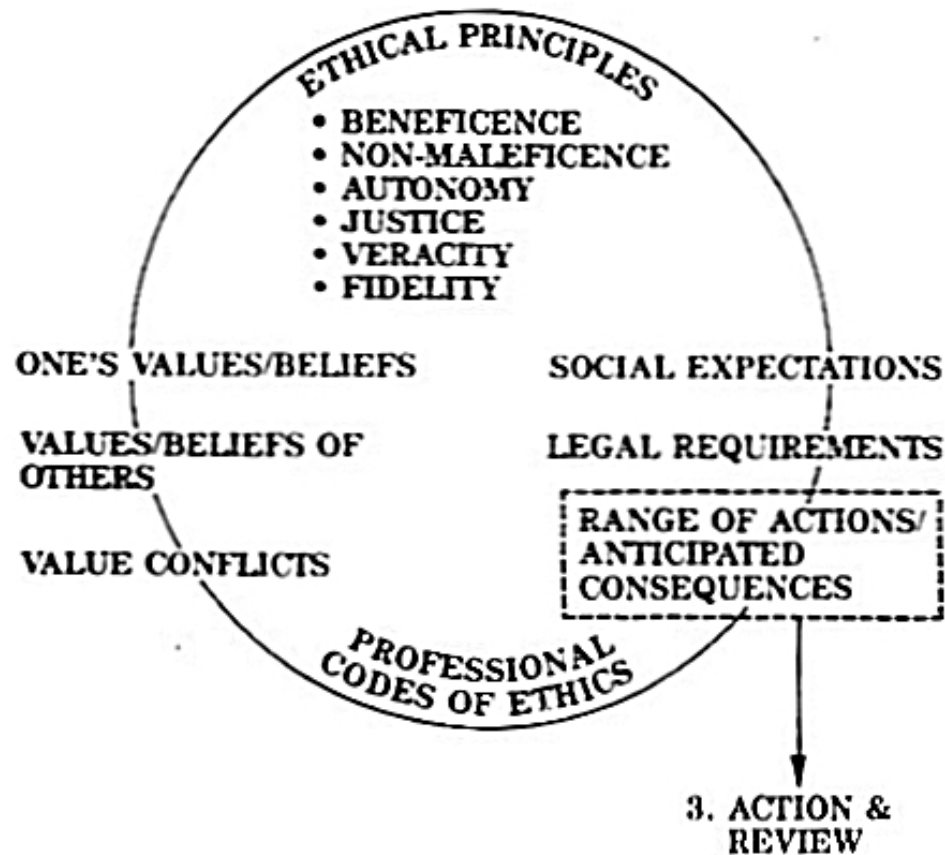
# What are we up against?

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- **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!**

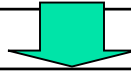
# Making an Ethical Decision

## 2. CLARIFICATION & EVALUATION



# Generic problem-solving model for ethical decision-making

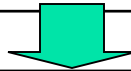
**Gather all relevant information**



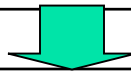
**Specify clearly all components of  
the identified ethical dilemma**



**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

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- **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.**



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# A Case Study

of a bottom-up approach

**CAUTION:**  
**ETHICAL IMPERIALISM**



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

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## 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)

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- **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)

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- **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

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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 ...

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- **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)*

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1. **Hazard Assessment**
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3. **Risk Evaluation** ←
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## Hill (1965) concludes ...

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**"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

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- 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 ...

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- **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

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**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

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- **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



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# DISCUSSION