



Appendix 3

Ethics in Knowledge Translation:

**Extending “what can be done” to
“what should be done”**

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Definition of KT used by the Canadian Institutes of Health Research (CIHR)

“...the exchange, synthesis and **ethically-sound** application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.”



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Some of the Ethical Challenges of KT

- What are the key principles and values (ethical considerations) that should guide KT?
- When is it safe to translate new knowledge?
- What types of outcomes should be considered and assessed in making such determinations?
- What are the responsibilities of different stakeholders in the KT process (e.g., researchers, research funders, knowledge brokers, policy makers, decision makers, and the public)?
- Which KT processes should be subject to ethics oversight and what mechanisms should be created for such oversight?





Situating Bioethics within KT

- Ethical analysis and evaluation should be central to KT decision making
- A broadly accepted ethics framework for KT would allow stakeholders to appropriately address ethical issues in a systematic and comprehensive manner.





Situating Bioethics within KT

- Bioethics has traditionally been focused on the **upstream** (knowledge creation) end of the Knowledge to Action continuum
- We propose that bioethics in KT is most useful **down stream** where knowledge is subject to translation, adaptation and tailoring of new knowledge into applications





Situating Bioethics within KT

- Thus, whereas:
 - KT addresses technical questions of **how** to move knowledge to action,
 - KT Bioethics addresses moral questions of **whether** and/or **in what way** knowledge **should** be translated into action
- This is based on two premises:
 - Not all KT is ethically justified/appropriate at a given time, for example, risks may outweigh benefits.
 - There may be more than one route to Action, some of which are more ethically justifiable than others





An Ethical Framework for Knowledge Translation

- The Bioethical Framework:
 - Constitutes one of the primary instruments of ethical analysis
 - Consists of the most relevant ethical principles and, values (ethical considerations) that bear on major KT decisions and that should be taken into account of in making these decisions
 - Thus an ethical framework for KT is an “ethics lens” through which key KT decisions should be passed





A Bioethical Framework for Knowledge Translation

- Ethical considerations are often in tension with one another.
- It is usually not possible to *maximize* all positive or desired outcomes.
- Thoughtful bioethical analysis gives rise to
 - well-reasoned, *ethically justifiable* solutions based on widely held ethically justifiable moral beliefs that are likely to resonate positively with a society that supports them.
 - solutions that *optimize* as many ethical considerations as possible, while recognizing that others may be compromised.





A Bioethical Framework for Knowledge Translation

- Optimizing ethically justifiable outcomes requires broad view of priority-setting – goes beyond that which may be held by individual researchers, institutions, or organizations.
- An agenda-setting perspective – balances maximized social utility considerations against social justice considerations – so the supported innovation can produce the greatest benefits and allow the fairest distribution of those benefits.





A Bioethical Framework for Knowledge Translation

- Our framework aligns with and expands upon the emerging field of E3LSI (ethical, economic, environmental, legal, and social implications of research).
- E3LSI originated with the Human Genome Project, and is now firmly positioned at the forefront of analysis of downstream consequences of research application (particularly biomedical sciences).





A Bioethical Framework for Knowledge Translation

- The proposed framework is based on two fundamental ethical principles:

Utility
Justice



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Utility

- Principal of utility suggests that any practice or innovation should attempt to maximize benefits while minimizing risks.
- Tenets of utility should include the following:
 - Decisions should be based on achieving the greatest benefit for the greatest number of people
 - The planned outcomes of KT should be beneficial to individuals and to society.
 - Where resource allocation choices are made between competing innovations, potential benefit to individuals and society should be taken into account.





Key Considerations under the Principle of Utility

- Should include the following:
 - When determining which innovations to develop, decision-makers should take into account the broadest spectrum of potential outcomes, including unintended ones.
 - Within the process of KT, all involved should adhere to the highest international standards of project planning, risk management, and quality assurance to minimize risks due to the proposed innovations.





Key Considerations under the Principle of Utility

- Should include the following (Cont'd):
 - avoiding harmful outcomes arising from the inappropriate choice of innovation to pursue and apply.
 - The thalidomide tragedy is an example of well-intentioned but misguided application of research.





Justice

- Benefits resulting from KT should be fairly (not necessarily equally) distributed among individuals, and within and among communities





Key Considerations under Justice

- Equity of Benefits and Risks
- The burden of risk flowing from KT should be carried by those who stand to benefit from it, and – to the extent possible – not by others





Key Considerations under Both Utility and Justice

- Stewardship
 - Decision makers and practitioners of KT should optimize the efficient use of resources that contribute to the process
 - Intentional misuse or waste of such resources is unethical





Key Considerations under Both Utility and Justice

- Partnerships
 - KT partnerships should be entered into only where there has been full disclosure of conflicts of mission and interest, and where these have been adequately managed



Summary

- We propose a bioethical framework for KT based on the overarching ethical principles of utility and justice and the subsumed considerations of
 - Equity of benefits and risks
 - Stewardship
 - Ethical partnerships
- The functionality of the framework lies not only in its enabling formal ethical analysis, but also in its potential to foster a culture of ethics in the KT community

