



## ***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

