

Maximizing the Value of Data and Research- an Ethics Perspective

Susan Zimmerman

Executive Director, Secretariat on Responsible Conduct of Research
CIHR – NSERC – SSHRC

Clinical Trials Ontario Conference
March 8, 2017

**PANEL ON
RESEARCH ETHICS**

Navigating the ethics of human research

Outline

- Setting the context
- Guidance in TCPS 2
- Balancing privacy and transparency
- Issues

TCPS 2 in context

- Not comprehensive in scope but...broadly accepted as ethical gold standard in Canada
- Not law or regulation but...enforceable
- Principles-based general guidance but also... practical guidance on implementation

TCPS 2 in context

- TCPS 2 fundamental
 - **RESPECT FOR PERSONS**
 - **CONCERN FOR WELFARE**
 - **JUSTICE**

Guidance in TCPS 2 (Privacy)

- Responsibilities of researchers and REBs
 - Determining what information must be protected, disclosed
 - Determining best mechanism to achieve those goals
- Responsibilities of institutions
 - Support for researchers' undertaking

Guidance in TCPS 2 – Privacy (cont'd)



- Shared responsibilities
 - Safeguarding information
 - Secondary use of identifiable information
 - Secondary use of non-identifiable information

Guidance in TCPS 2 - Transparency



- Registration of all clinical trials
- Timely dissemination of clinical trial findings
- Informed and ongoing aspects of consent process

Privacy and transparency – dual goals

- Privacy: focus on the individual
 - Duty to ensure ethical standards of research are upheld
- Transparency: focus on the public
 - Accountability to taxpayer for publicly-funded research
 - Responsibility to share scientific findings with research community

Agencies and Agency-funded researchers:
responsible for both privacy and transparency

Issues

- Increased push for sharing of data -
- Privacy protection – necessary, but is it sufficient?
- Is consent still important if privacy is protected?
- What form of consent is meaningful?
- What happens to autonomy when big data is mined for extended periods, by a multiplicity of researchers?

We welcome your questions



Secretariat on Responsible Conduct of Research

350 Albert Street
Ottawa, ON K1A 1H5
Tel.: 613 996-0072

secretariat@rcr.ethics.gc.ca

www.pre.ethics.gc.ca

**PANEL ON
RESEARCH ETHICS**

Navigating the ethics of human research