Do you want to know a secret? Do you promise not to tell?
Community Views on Privacy & Confidentiality

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SSHWC Privacy & Confidentiality Update

- *"Giving Voice to the Spectrum"* (2005)
  - included privacy and confidentiality issues raised by the research community
- *"Reconsidering P&C in the TCPS"* (2006)
  - outlined some possibilities and sought feedback
- *"Continuing the Dialogue"* (2007)
  - Feedback to community; recommendations to PRE; suggested next steps

SSHWC Privacy & Confidentiality Update

- P&C issues of particular interest to SS&H community; confidentiality often only risk
- A theme that runs through our work: to ensure solutions/recommendations reflect the diversity of the research enterprise
- Participation in our most recent consultation again reflects a broad array of disciplines, perspectives

SSHWC Privacy & Confidentiality Update

- Researcher disciplines included medicine, sociology, political science, epidemiology, mathematics, philosophy, and psychology
- REBs included multi-disciplinary, SS&H, health-only, and one anonymous
- Also heard from research administrators, govt agencies, professional/disciplinary associations
- French and English
- Submissions from across the country

Approaches to Confidentiality

- "*Reconsidering*" suggested there should be greater distinction made of a continuum of confidentiality from "doesn't matter" to "crucial"
- Respondents to the consultation worried this might erode commitment to confidentiality; worried conceptualization too legalistic
- Wanted limited exceptions noted (Elders; focus groups); otherwise to remain a default

assumption.

Subject-Centered Perspective
- "*Reconsidering*" offered suggestions how subject-centered perspectives might be incorporated into the review process
  - Revolved around "social distance"
- Respondents eschewed this as micro-management; Pandora's Box
- Support expressed for encouraging research in this area.

Ethics and Law
- Emphasis on positive examples of how researchers can maximize coincidence of ethics and law
- Respondents appreciated discussion of the Wigmore criteria and want limited information to go into the TCPS
- Concern about too much detail; raises issue of other ways to educate and inform – US model re advisory papers?

Ethics and Law
- Regarding possible sources of conflict between ethics and law several areas were considered:
  - Criminal prosecutions and high stakes litigation
  - Mandatory reporting laws
  - Unanticipated "heinous discovery"
  - FOIPOP legislation and its impact

Prosecutions and Litigation
- One concern (but low likelihood) is subpoenas. Research community seeks
  - Clarified policies and stronger wording, esp. regarding roles of university administrations
  - support for "ethics first" and "law first" positions
  - general advice regarding Wigmore criteria
  - for PRE to encourage Agencies to promote development of "confidentiality certificates"

Unanticipated "Heinous Discovery"
- Breaches of confidentiality should occur only in the rarest of circumstances
- Minimal criteria that would make a disclosure permissible would be those in *Smith* v *Jones* (1999)
- Case-by-case consideration required to determine whether violation is appropriate and, if so, any disclosure minimal
- Consultation to be encouraged when possible

Mandatory Reporting Laws

- Appears to be considerable confusion regarding just what these are; TCPS adds to this
- Among SSHWC concerns:
  - such laws can create "no research zones" about some of society's most pressing problems, and/or
  - encourages violation of TCPS provision that "Researchers should avoid being put in a position of becoming informants for authorities" (p.2.4)
- SSHWC encourages analysis/research/writing in this ethics/law nexus

Missing Issues: Collectivities
- Unique challenges arise when people participate in research together
  - What are the rights of persons who are talked about by participants?
  - Does one take into account that others may attribute quotes (rightly or wrongly) even when names are omitted?
  - When should community identity also be anonymized?

Missing Issues: Secondary Data Bases
- Main concern arises when links sought across different data bases
  - Identifiability almost a given
  - Are REBs balancing social benefits of research v. participant right to judge each new use of data?
  - Submissions feel impeded, undervalued
  - SSHWC remains concerned re confidentiality with multiple data bases

SSHWC on P&C: Next Steps
- Consultation process has helped gauge temper of research community; input from many quarters valued
- Report and recommendations will be translated, posted on web as feedback to the research community
- SSHWC to follow up on action items by developing recommended wording or supplementary reports as appropriate