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