

PRIVACY HORIZONS: TERRA INCOGNITA

29th International Conference of
Data Protection and Privacy Commissioners

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LES HORIZONS DE LA PROTECTION DE LA VIE PRIVÉE : TERRA INCOGNITA

29^e Conférence internationale des commissaires
à la protection des données et de la vie privée

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Consent and Access to Personal Information for Health Research – *public perspective*

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- **Research team:**

- **McMaster University**

- Don Willison (P.I. – privacy, policy, research methods)
- Lisa Schwartz (philosophy, bioethics)
- Julia Abelson (public engagement)
- Cathy Charles (public engagement, qualitative methods)
- Lehana Thabane (statistician, quantitative methods)
- Marilyn Swinton (research coordinator, qualitative methods)

- **York University**

- David Northrup (survey methods)

- **Canadian Policy Research Networks**

- Mary Pat MacKinnon, Judy Watling (dialogue)

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Context: Expanding Use of personal information for health research

- Increase in scope and complexity of data use
 - Data linkage
 - administrative and clinical data
 - survey and genetic information
 - Single time-limited studies → registries and biobanks
 - EHR: expanded access to health information for:
 - population / public health research
 - pragmatic trials
- Researchers need individual-level data
 - Challenge: masking of identity
 - Debate: treat data as identifiable?

Issues Around Consent

- Patient/public perspective:
 - How to obtain meaningful and valid consent?
- Researcher's perspective:
 - practicability of obtaining consent
 - potential selection biases in a consent-based system
 - If consent is waived, limitations:
 - Cannot contact patient / Who may screen charts?
- General:
 - Must we be limited to the binary option of consent / no consent?

Our survey:

- **Cross-Canada telephone survey, random-digit dialled**
 - March-April 2005
 - n=1230 (58% response rate)
- **Structure:**
 - **General questions**
 - Demographics, altruism
 - Placing health and privacy in context of other priorities
 - **Questions in abstract**
 - attitudes re: privacy and research
 - trust in institutions
 - use of medical records for different types of research
 - **Specific scenarios. Role of consent in:**
 - medical record research
 - electronic health record
 - record linkage

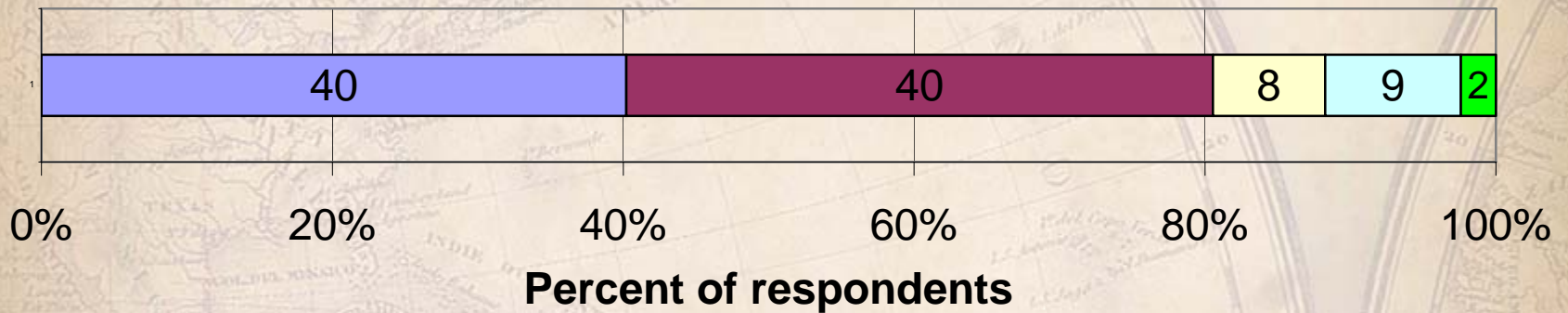
WHAT DID WE FIND?

Attitudes to privacy

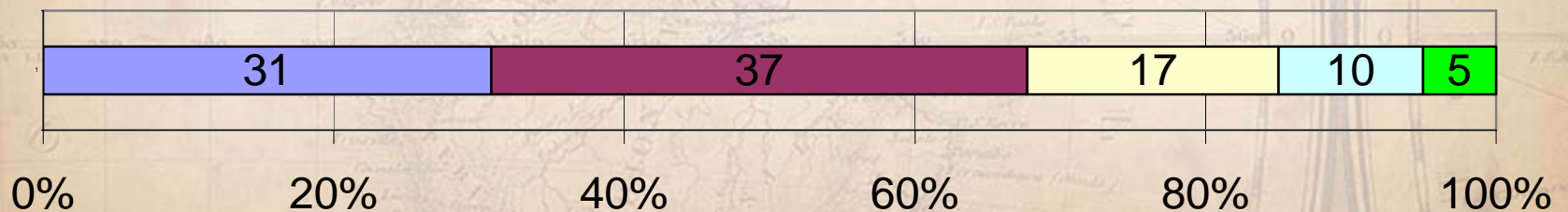
- High support for privacy in principle:
 - 97% felt protection of the privacy of their personal information was important
 - 74% very important / 23% somewhat important.
 - 91% agreed that more effort needs to be made to protect our privacy
 - 59% strongly agreed / 32% somewhat agreed
 - 92% agreed that everyone benefits if the privacy of individuals is respected
 - 66% strongly agreed / 26% somewhat agreed

Privacy vs. Research

People should allow their personal information to be used for the benefit of society if this can be done without causing any harm to individuals.



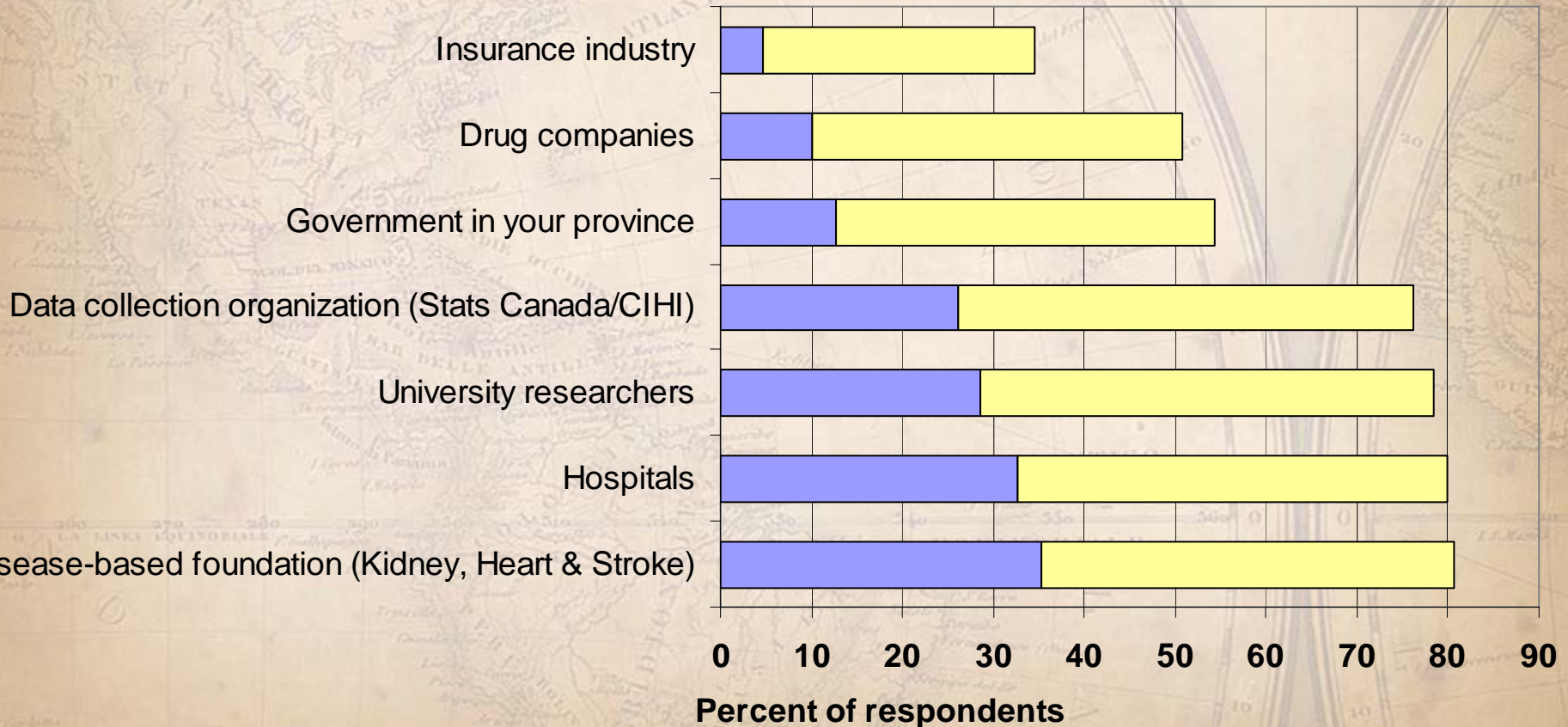
Research that could be beneficial to people's health is more important than protecting people's privacy



- Strongly agree
- Somewhat agree
- Somewhat disagree
- Strongly disagree
- Don't know

How much trust do you place in the following institutions to keep any health information they have about you confidential?

■ A great deal ■ Somewhat



Research Scenarios

- 4 scenarios:
 - Abstraction of information from health record for research
 - Use of electronic health information for research
 - Linkage of education with EHR
 - Linkage of income with electronic health record
- Data have direct identifiers removed
 - Makes it difficult but not impossible to re-identify

Opinion regarding consent and alternatives across scenarios

Scenario	n	Consent Choice					
		Do not use	Ask permission first			Notify / opt out	Just use
			Every time	General renewing	General once		
Manual extraction of data from medical record	1207	4%	32%	23%	5%	24%	12%
			60%				
Automated extraction of data from EHR	941	9%	36%			28%	27%
Link education with EHR	858	10%	41%			26%	23%
Link income with EHR	853	27%	40%			16%	17%

Public Dialogues

- Key messages:
 - High sense of altruism, but contingent on benefit being accrued to public
 - Desire for greater control when there is a commercial element.
 - Importance of trust of the researcher
 - beneficence / non-maleficence
 - Consent choice little different between identifiable and non-identifiable information
 - A matter of respect for the individual

Conclusions

- **Public values both health research and privacy**
 - If pressed, privacy tends to give way to research
 - Support is there for research use of personal information,
 - Much of this support is qualified
 - Researchers need to be careful to maintain public trust
 - Importance of paying attention to safeguards
- **Individuals differ in the amount of control that want to exercise over use of their personal information.**
 - Majority (~65%) open to alternatives to express consent on a study-by-study basis
 - Only 12-27% willing to allow use of their information without their knowledge or consent

Policy Implications:

- Insufficient public support for across-the-board assumed or deemed consent for research uses of personal information for health research
- Document individuals' consent choices for 2^o uses of personal information – authorization model.
 - Embrace the range of consent alternatives
 - How best to approach this?
 - Track choices through common inter-operable EHR (Canada Health Infoway)
 - Need infrastructures for ascertaining and managing consent choices
 - Safeguards and governance structures

DOC- I'M
WORRIED ABOUT
MEDICAL
PRIVACY

YES... I
SEE THAT IN
YOUR FILE