

Personal Privacy and Public Benefits in the Genomics Era of Personalized Medicine

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Overview

- Personalized medicine and the “privacy paradox”
- Genetic information and some challenges of “big data”
- Biobanks: Policy priorities and public perceptions

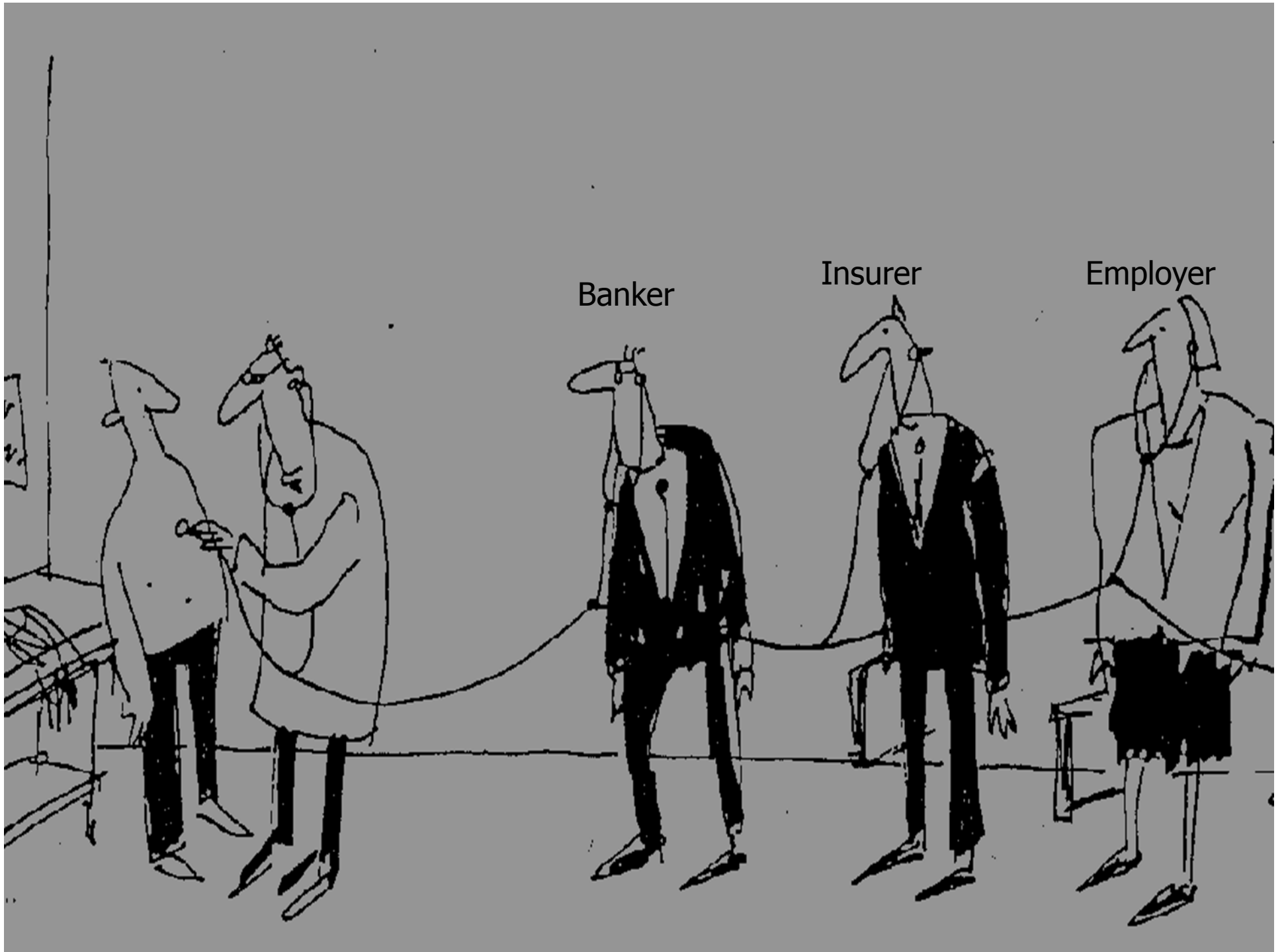
Introduction

PERSONALIZED MEDICINE AND THE PRIVACY PARADOX

Banker

Insurer

Employer

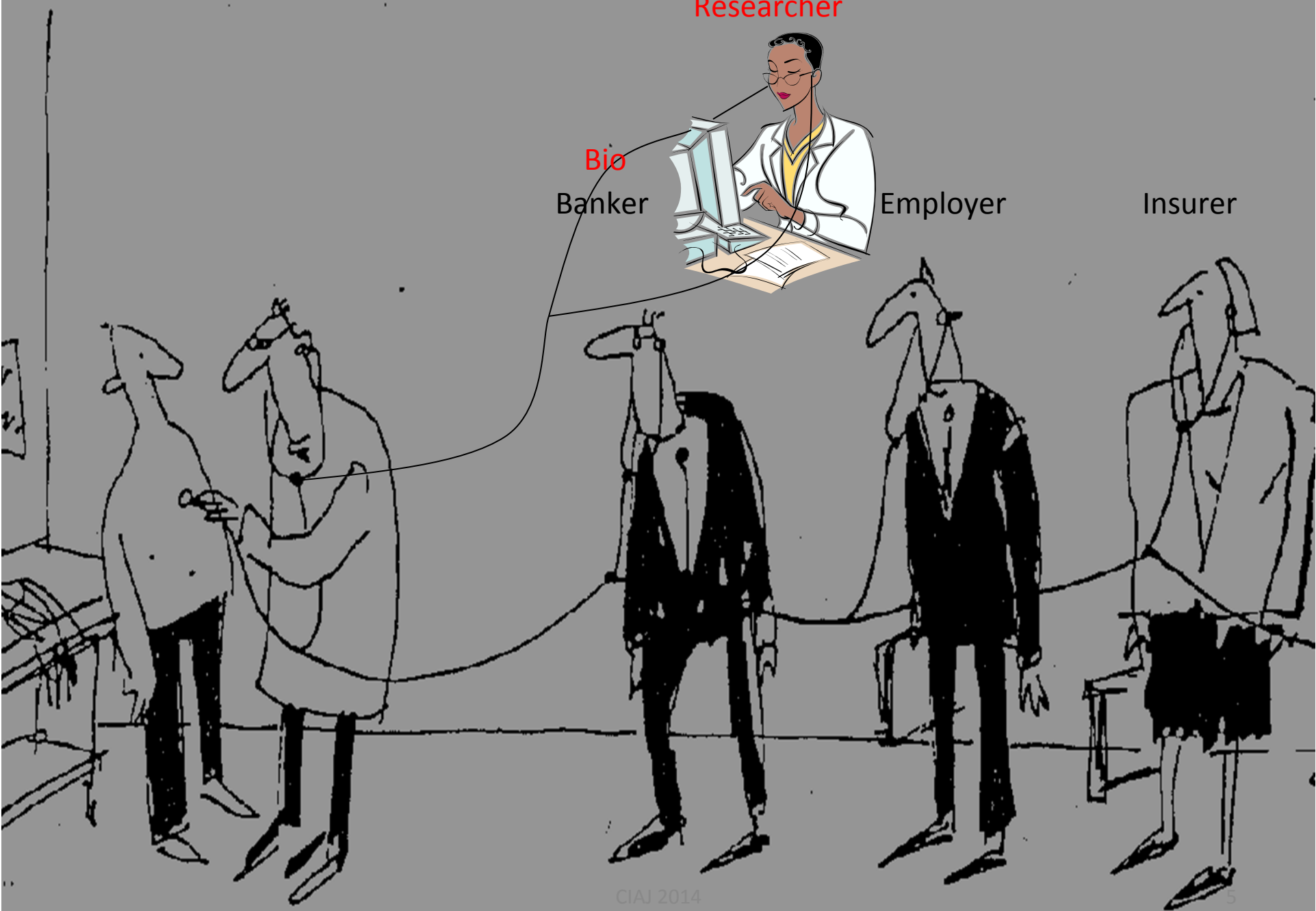


Researcher

Bio
Banker

Employer

Insurer



The “personalized medicine” promise

Here’s my
sequence ...

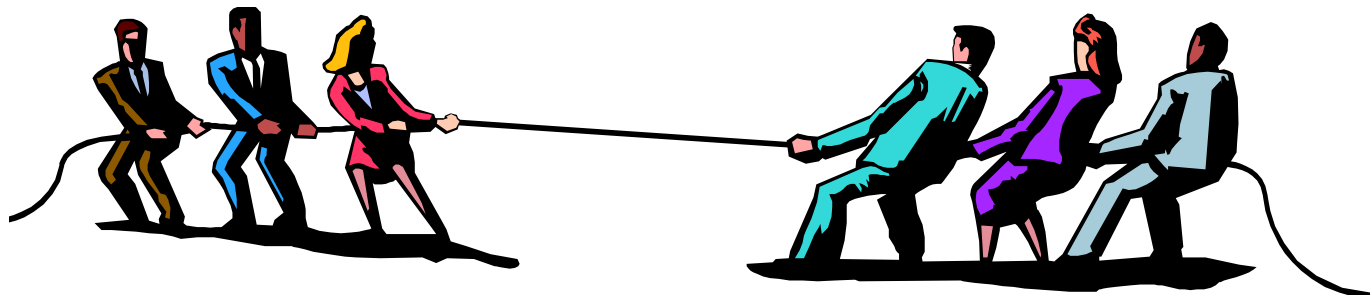


Source: *New Yorker*

Personalized Medicine

The Privacy Paradox

- The increasing emphasis on the protection of *individual privacy* in the electronic information era, has developed simultaneously with the advent of the genetics/genomics era in health research which relies increasingly on the information of *families and populations*

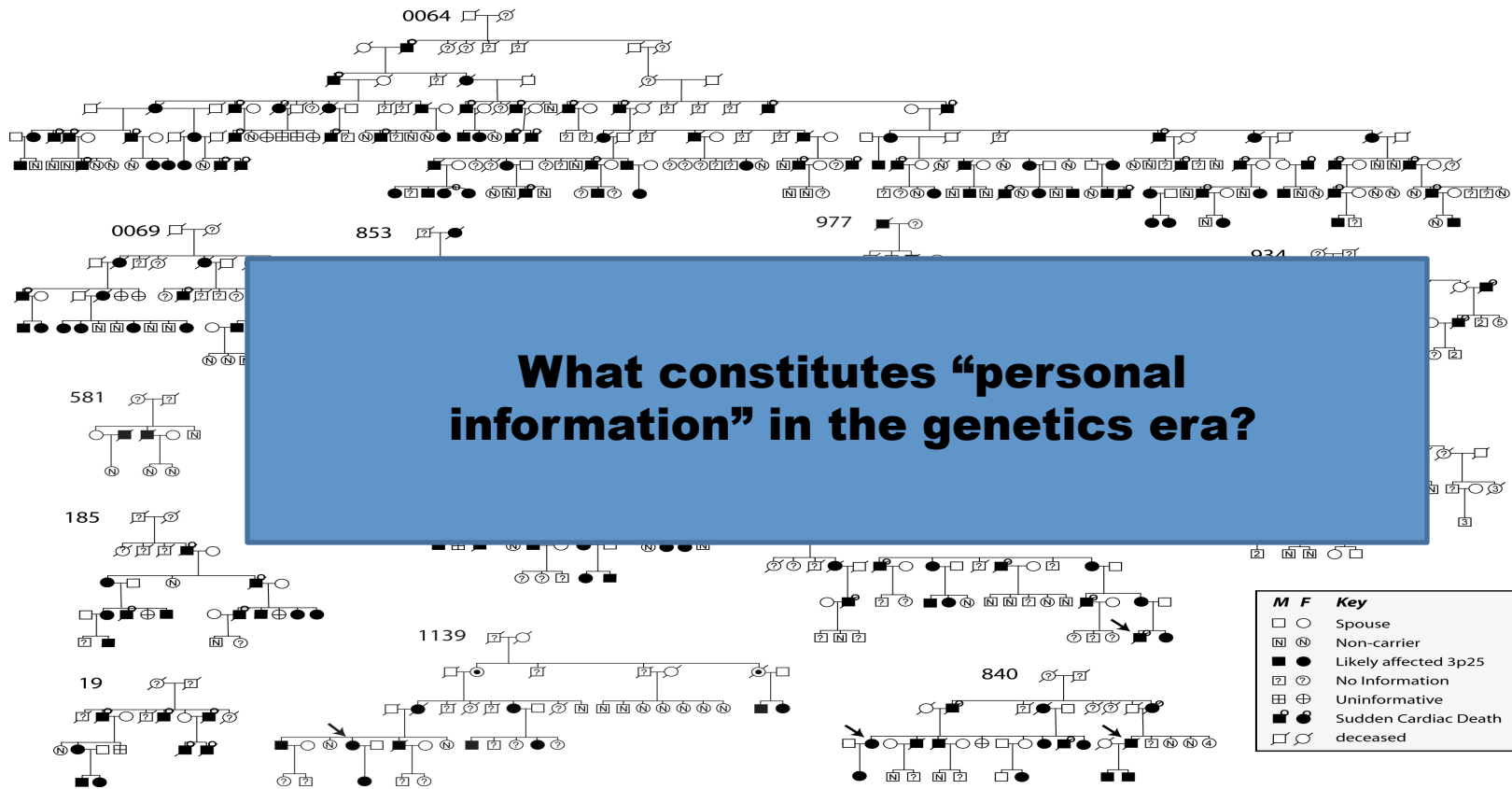


Genetic Information

GENETIC INFORMATION: CHALLENGES OF “BIG DATA”

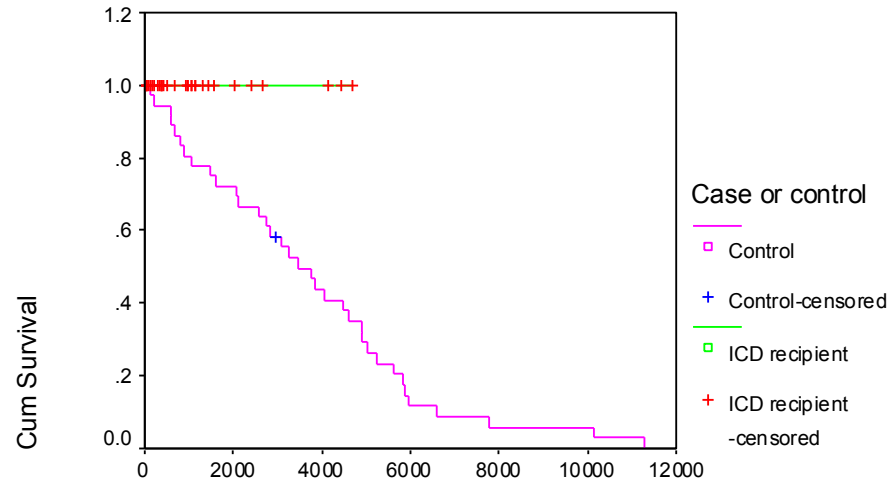
Realizing the “genomics promise” requires collecting and analyzing large data sets

ARVC families

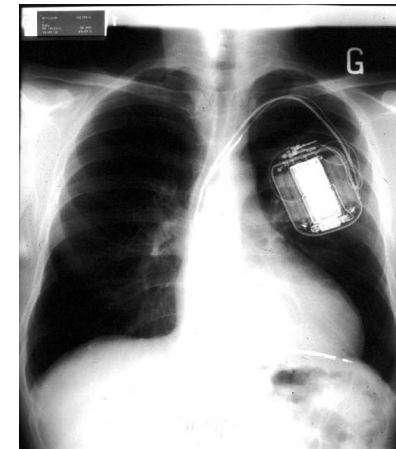
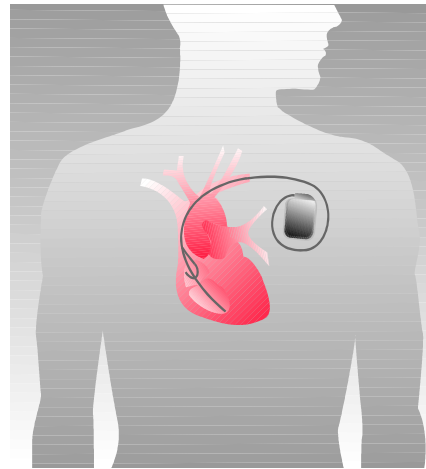
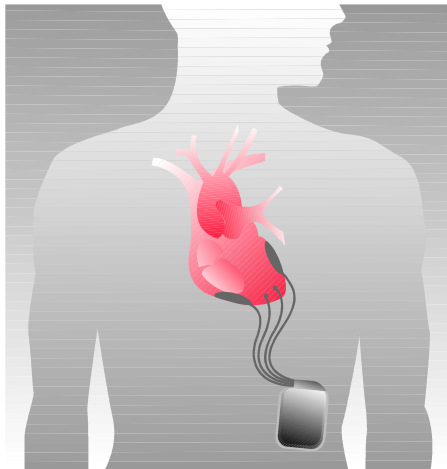


Time to death:Males

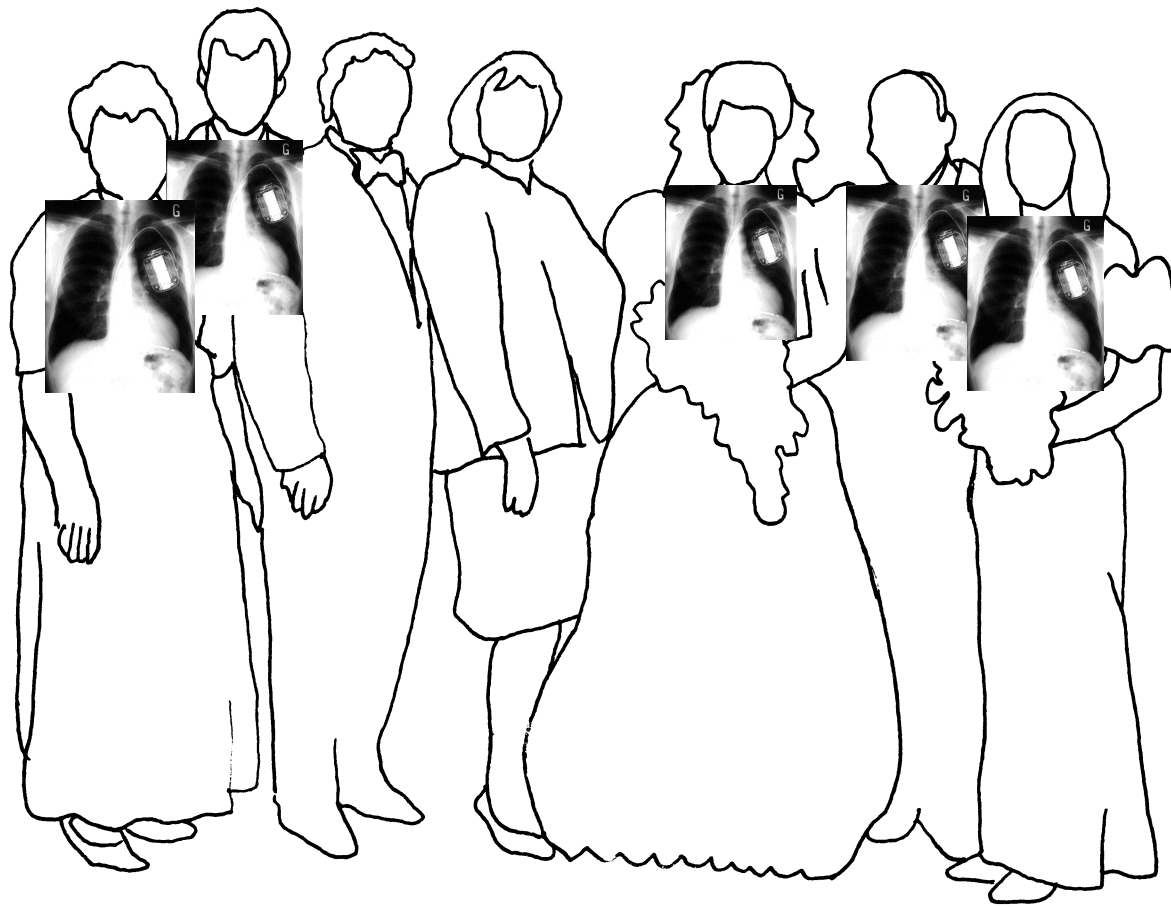
ICD (n=30) and controls (n=36)



Kaplan Meier analysis: days to death or end of study



The impact of implantable cardioverter – defibrillator therapy on survival in autosomal dominant arrhythmogenic right ventricular cardiomyopathy (ARVD5) Hodgkinson et al, J Am Coll Cardiol 45:400-8, 2005



Privacy protection and public goods: building a genetic database for health research in Newfoundland and Labrador

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ABSTRACT

Objective To provide a legal and ethical analysis of some of the implementation challenges faced by the Population Therapeutics Research Group (PTRG) at Memorial University (Canada), in using genealogical information offered by individuals for its genetics research database.

founder population. PTRG has used a variety of innovative means to populate its database, but has faced a number of privacy-related challenges with regard to the propriety of drawing upon certain sources to enrich that database. In particular, PTRG has not yet been able to confirm whether it can

The Newfoundland and Labrador Statistics Agency is working in collaboration with the Canadian Century Research Initiative (CCRI) - a pan

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In general, detailed census information that would allow identification of individuals is strictly controlled for 92 years from the time the census is completed, after which the secrecy provisions of the Statistics Act are lifted in respect of census information collected between 1910 and 2005.⁷ It is these provisions that limit both the amount of data the CCRI is able to digitize and the manner in which it can be used for research purposes. As Newfoundland did not join the Canadian confederation until 1949, the 92-year limitation does not apply to Newfoundland and Labrador census records collected before that date. Newfoundland's pre-confederation census data are in the public domain and there are no restrictions on digitizing these.

Biobanks

BIOBANKING: POLICY PRIORITIES AND PUBLIC PERCEPTIONS

Biobank (1)

- Any depository of biological samples and related derivatives with or without a predefined period of storage, based on prospective collection or made of previously collected material, obtained for health care purposes, public health monitoring programs, or for research, and that includes identified, identifiable, anonymized or anonymous samples.”
- Examples:
 - Stored pathology samples
 - Newborn baby heel prick blood spots
 - Medical laboratory samples

Biobank (2)

HARVARD LAW REVIEW

Comparative Law. Genetic Privacy. Icelandic Supreme Court Holds That Inclusion of an Individual's Genetic Information in a National Database Infringes on the Privacy Interests of His Child. *Guðmundsdóttir v. Iceland*, no. 151/2003 (Nov. 27, 2003) (Ice.)

Source: *Harvard Law Review*, Vol. 118, No. 2 (Dec., 2004), pp. 810-817

Published by: [The Harvard Law Review Association](#)

Stable URL: <http://www.jstor.org/stable/4093398>

Accessed: 15/10/2014 09:07

— P3G — Public Population Project in Genomics

Personal privacy, public benefits, and biobanks: A conjoint analysis of policy priorities and public perceptions

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Montgomery Keough, MSc¹, David Morgan, PhD⁴, and Catherine Street, BPharm (Hons)¹*

Genetics in Medicine • Volume XX, Number XX, XXX 2011

Methodology: Conjoint Analysis

- Individual persons seldom if ever decide on preferences with respect to a good or service based on a single characteristic
- Any good or service represents a bundle of different features or characteristics
- Each individual decision represents a variety of value trade-offs

Package of Characteristics/Attributes Examined

- Privacy and Confidentiality
- Research Focus
 - Stigmatizing condition (e.g. mental illness, STD)
 - Non-stigmatizing illness (e.g. heart disease, cancer)
- Beneficiary
 - Self
 - Loved One
 - Stranger
- Consent
 - Broad/Blanket
 - Specific

Table 1 Attributes and levels used in ranking task

Attributes	Levels
Privacy and confidentiality: Your sample ...	<ol style="list-style-type: none"><li data-bbox="989 285 1608 431">1. ... <u>can</u> be traced back to you. The researchers will have your name or have access to other identifying information.<li data-bbox="989 464 1608 651">2. ... <u>cannot</u> be traced back to you. The researchers will not know your name nor will they have access to other identifying information.
Research focus: Your sample will be used to study the role of genetics in ...	<ol style="list-style-type: none"><li data-bbox="989 683 1608 797">1. ... a serious illness that <u>is often stigmatized</u> (e.g., mental health or a sexually transmitted infection).<li data-bbox="989 821 1608 935">2. ... a serious illness that <u>is not usually stigmatized</u> (e.g., heart disease or multiple sclerosis).
Research beneficiary: Your sample will be used in research that ...	<ol style="list-style-type: none"><li data-bbox="989 967 1608 1040">1. ... could improve <u>your own health</u>.<li data-bbox="989 1065 1608 1179">2. ... will not affect your own health, but could improve <u>the health of people you love</u>.<li data-bbox="989 1203 1608 1354">3. ... will not affect your own health, or the health of people you love, but could improve <u>the health of others</u>.

Blanket vs. Specific Consent

- *Blanket/Broad Consent*: You have given a blood sample. Researchers ask you to give them permission to use this sample for a specific research project. They also ask you to give permission to use this sample in other research projects. They will ask your permission only once, not each time they use this sample
- *Specific Consent*: You have given a blood sample. Researchers ask you to give them permission to use this sample in a specific research project. Each time researchers want to use this sample in other research projects, they must ask you for permission.

Table 2 Participant responses to attitudinal and opinion survey items ($N = 330$)

Variables	Level	Number (%) ^a
In general, how private a person would you say you are?	Very private	38 (12)
	Private	137 (42)
	Neither private nor open	70 (21)
	Open	70 (21)
	Very open	11 (3)
Overall, how much would you say you trust health researchers?	Completely	106 (32)
	Somewhat	206 (62)
	A little	9 (3)
	Not at all	5 (1)
Can you tell us the no. 1 thing you would want to know before giving a blood sample for health research (please choose one)?	What disease is being studied?	106 (32)
	Who is doing the research?	29 (9)
	Will I get the results?	67 (21)
	What are the risks?	47 (14)
	Can someone other than the researchers identify me?	58 (17)
	Other (e.g., "can I help someone," "moral," "I am against for profit health research," and "some good may result")	10 (3)

^aTotals may not add to 100 due to rounding or missing data.

Table 3 Results of conjoint analysis: blanket consent

Attribute	Level	Utility estimate	Standard error	Importance values (%)
Privacy and confidentiality	Can be traced	0.154	0.408	19.5
	Cannot be traced	-0.154	0.408	
Research focus	Stigmatized	-0.044	0.408	22.1
	Nonstigmatized	0.044	0.408	
Research beneficiary	Self	-0.381	0.577	58.3
	Loved ones	0.149	0.577	
	Others	0.232	0.577	
	(Constant)	6.5	0.408	

Table 4 Results of conjoint analysis: specific consent

Attribute	Level	Utility estimate	Standard error	Importance values (%)
Privacy and confidentiality	Can be traced	0.020	0.318	16.6
	Cannot be traced	-0.020	0.318	
Research focus	Stigmatized	0.521	0.318	29.3
	Nonstigmatized	-0.521	0.318	
Research beneficiary	Self	-0.488	0.449	54.1
	Loved ones	0.635	0.449	
	Others	-0.146	0.449	
	(Constant)	6.5	0.318	

We are intrigued by the manner in which the nature of the consent model assumed by the participants seems to alter their value preferences. That is, when participants completed the task assuming blanket consent, they displayed more altruistic tendencies, favoring scenarios that would benefit the general public over those that might favor themselves or their loved ones. On the other hand, when asked to assume specific consent, participants preferred scenarios that would favor their loved ones. It may be that specific consent is perceived to be more onerous than one-time, blanket consent. As such, participants want their loved ones rather than unknown others to benefit as a result of the time and effort they must invest to provide repeated consent.

A similar explanation might apply as to why stigmatized diseases are valued more highly under the situation of specific consent. In this case, the utility estimate was much higher (0.521) than in the situation of blanket consent (-0.044), revealing a considerable difference in perceived importance. We speculate that participants reasoned that if they are going to be approached to give consent each time a new project is proposed, the condition being studied should be important enough to them personally to warrant the additional time and effort they must invest to provide specific consent.

Conclusions . . .

- Participants in general appear to view biobanks as public institutions created for the public good
- In the context of biobanks, individuals:
 - Tend to act as “informational altruists”
 - Rank ‘privacy and confidentiality’ as of less importance than the focus of the research or the potential beneficiaries of that research
- The nature of the consent process could undermine generally altruistic tendencies

ACKNOWLEDGMENTS

This study was supported under the “Contributions Program” of the Office of the Privacy Commissioner of Canada.