

# Privacy Without Guarantees: Healthcare and Genomics in the age of Big Data

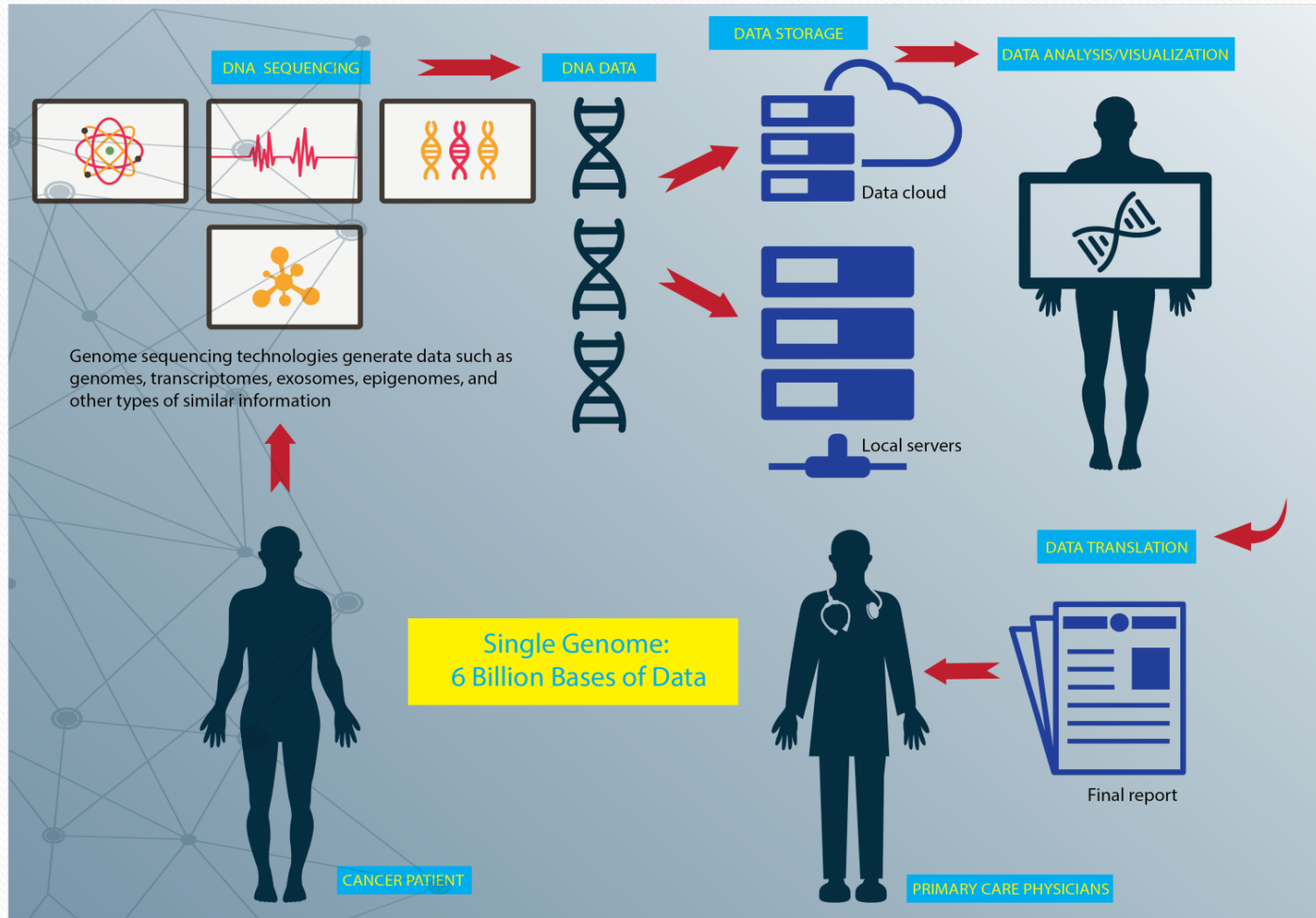
**Julie Frizzo-Barker, Peter Chow-White & Dung Ha**

Simon Fraser University (Vancouver, Canada)  
GeNA Lab ([www.genalab.org](http://www.genalab.org))

Data Power Conference (Sheffield, UK)  
June 22, 2015

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# Genomics is Big Data



# Benefits of Genomic Big Data: Personalized Healthcare

The image shows a screenshot of the CTV News Vancouver website. At the top, there is a navigation bar with the CTV News Vancouver logo on the left, a search bar in the center, and links for 'CTV News', 'Mobile', and 'CTV' on the right. Below the navigation bar is a horizontal menu with options: NEWS, VIDEO, WEATHER, MORNING LIVE, MORE, CONTESTS, ABOUT, and LOCAL. The main content area features a large video player with a play button in the center. The video title is 'Blood pressure drug shrinks cancer in 'miracle' clinical trial'. To the right of the video player is a text box with the headline 'Woman's cancer disappears under miraculous treatment' and a sub-headline 'Scientists don't like the word miracle, but it's hard to think of a better way to describe this patient's journey.' Below the video player, there are social media sharing icons for Facebook (6K), Twitter (134), Google+, and YouTube (6K). At the bottom right, there is a banner for a contest that says 'ENTER TO WIN' and 'NEW'.

CTV NEWS VANCOUVER

CTV News Mobile CTV

LIVE NOW: CTV News at Six

CTV Vancouver Search

NEWS VIDEO WEATHER MORNING LIVE MORE CONTESTS ABOUT LOCAL

## Blood pressure drug shrinks cancer in 'miracle' clinical trial

CTV NEWS GO

Woman's cancer disappears under miraculous treatment

Scientists don't like the word miracle, but it's hard to think of a better way to describe this patient's journey.

CTV Vancouver: Miraculous cancer treatment

f 6K t 134 g+ r 6K

ENTER TO WIN NEW

# The Acute-Myeloid Leukemia (AML) Project: 2011-2014

## Canada: The GE<sup>3</sup>LS Research Program

- G = **G**enomics and its
- E<sup>3</sup> = **E**thical, **E**nvironmental, **E**conomic
- L = **L**egal and
- S = **S**ocial aspects



GenomeBritishColumbia



**BC Cancer Agency**

CARE & RESEARCH

An agency of the Provincial Health Services Authority

**GeNA Lab**

[www.genalab.org](http://www.genalab.org)

@frizzbarks @pachowwhite



# Methods

## Sampling

- Used data-linkage to develop database of 214 stakeholders
- Identified sub-group of 100 genome researchers and clinicians

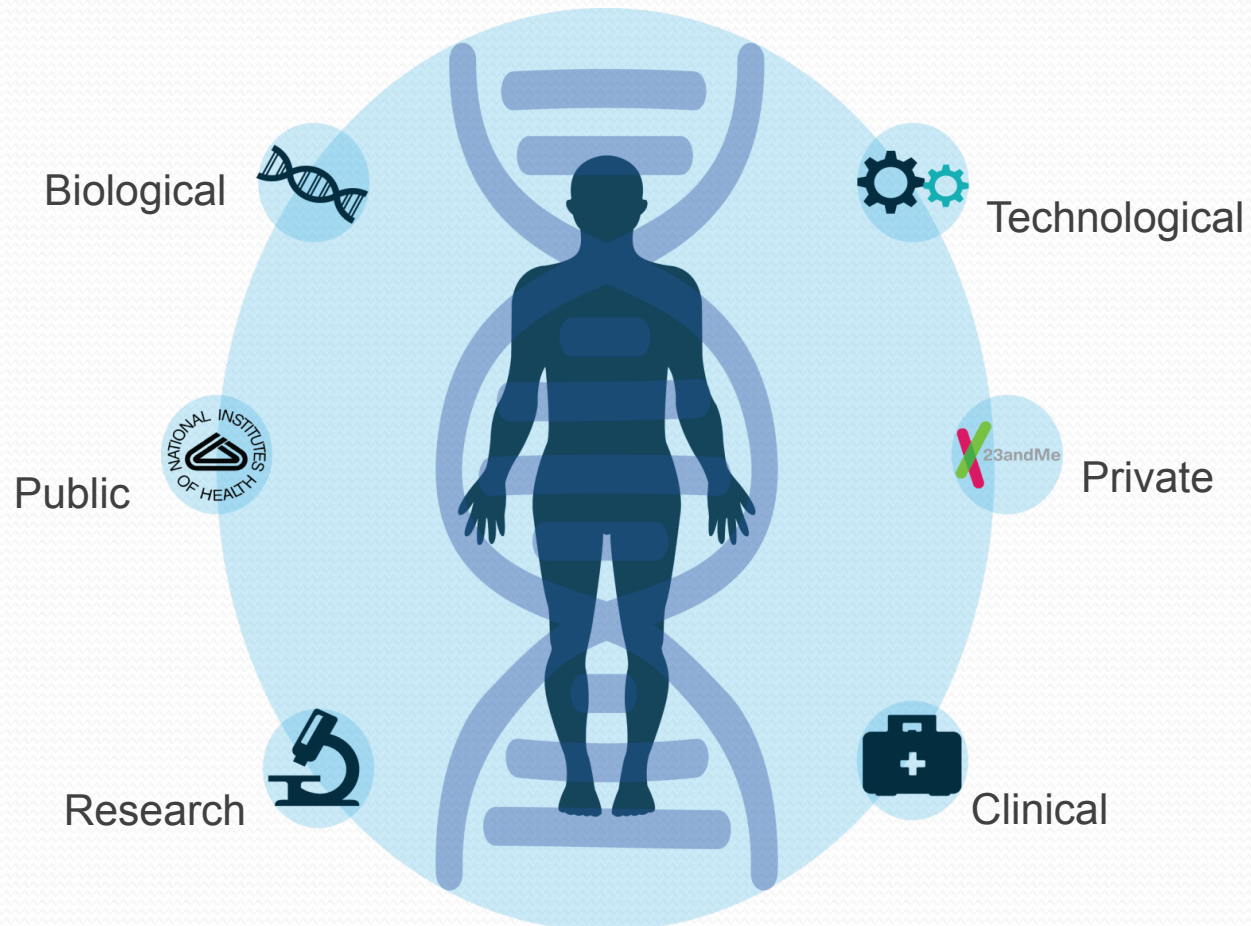
## Interviews

- 36 active BC genome clinical researchers (response rate 53%)
- 7 policy decision makers (response rate 70%)
- 43 in-person, semi-structured interviews

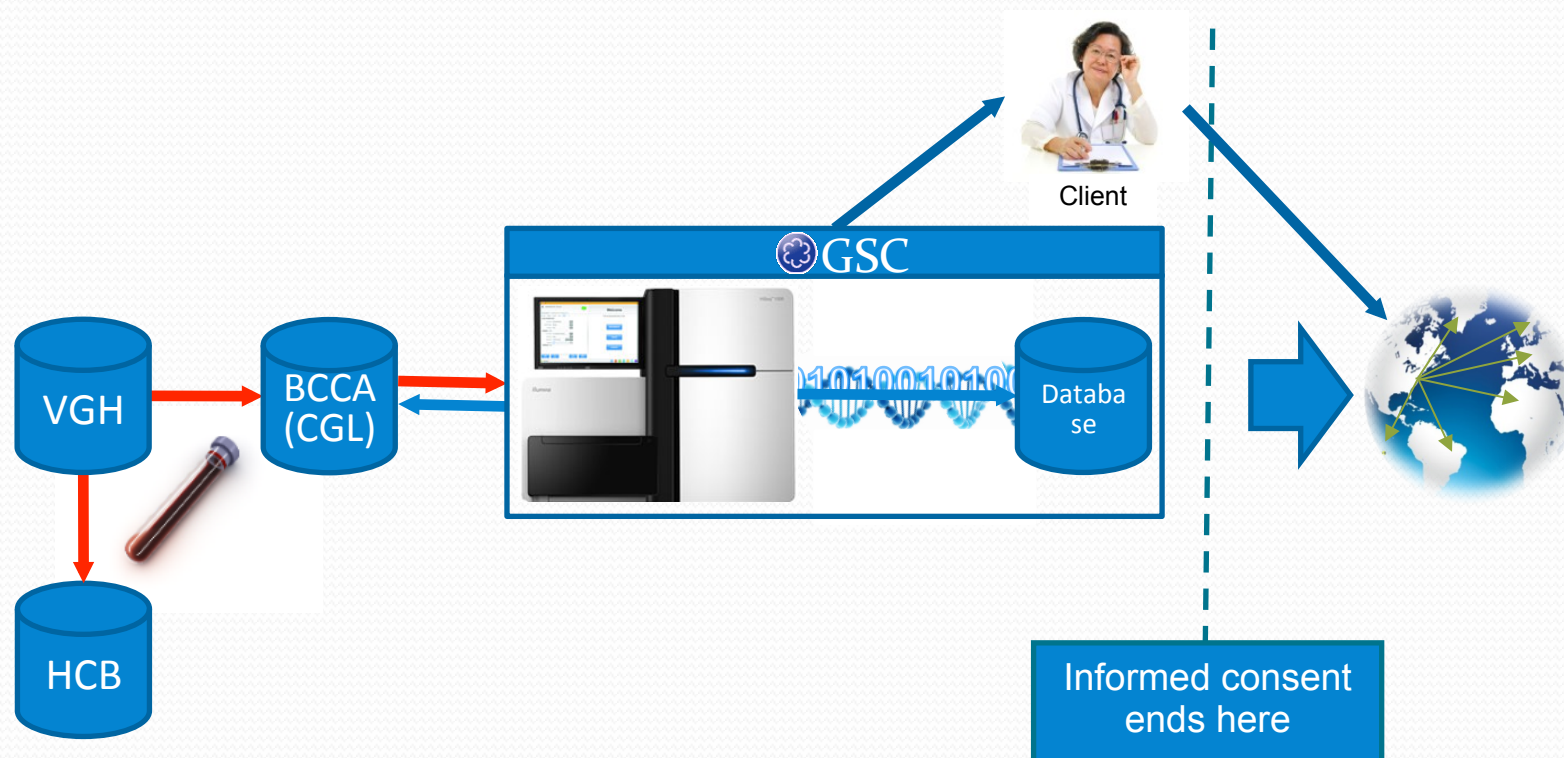
## Data Analysis

- Computer-assisted analysis of qualitative data using NVivo
- Quantitative analysis of key attributes

# Genomics as a Space of Convergence



# Digital DNA and Privacy Challenges

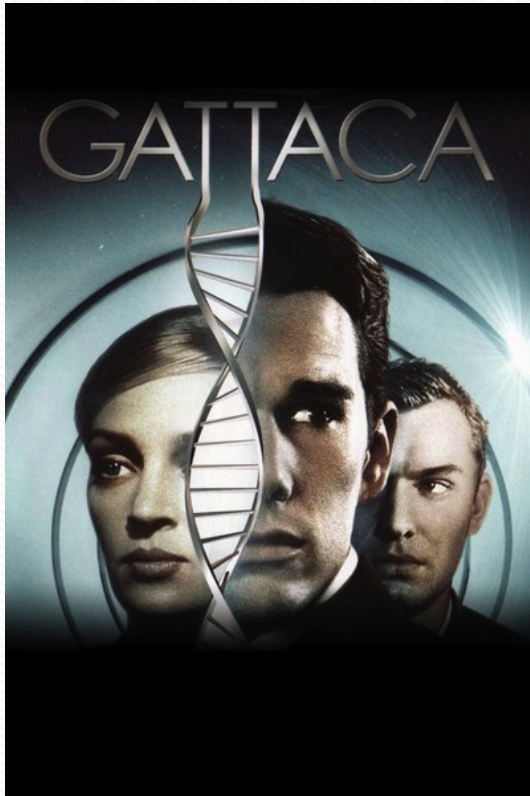


# Privacy without Guarantees

The screenshot shows the top navigation bar of the Guardian website with links for 'free become a member', 'sign in', 'subscribe', and 'search'. The main header features the Guardian logo and 'Winner of the Pulitzer prize 2014'. Below this is a secondary navigation bar with categories like 'UK', 'world', 'politics', 'sport', 'football', 'opinion', 'culture', 'business', 'lifestyle', 'fashion', 'environment', 'tech', and 'travel'. The breadcrumb trail reads 'home > UK > education > media > society > law > scotland > wales > northern ireland'. The article title is 'Sociology Stuart Hall' with a subtitle 'Influential cultural theorist, campaigner and founding editor of the New Left Review'. The author is 'David Morley and Bill Schwarz' and the date is 'Monday 10 February 2014 13:00 GMT'. Social sharing icons for Facebook, Twitter, Email, LinkedIn, and Google+ are present, along with 45,559 shares and 115 comments. A large black and white photograph of Stuart Hall is the main image, with a caption 'Stuart Hall Photograph: Eamonn McCabe Eamonn McCabe/Eamonn McCabe'. A 'Most popular' section at the bottom right features a thumbnail for an article titled 'Obama lambasts Putin: you're wrecking Russia to recreate Soviet empire'.



# Privacy without Guarantees



## Privacy in the Network Society:

- Who has the ability to access data?
- Who has the right, and why?
- How are they interpreting and using the data?

# Privacy without Guarantees

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**theguardian**  
Winner of the Pulitzer prize 2014

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home > science

**Science**  
Political science

## Privacy and the 100,000 Genome Project

As the Department of Health starts to draw a map of thousands of genomes, will it keep its promise to anonymise our data? **Edward Hockings** and **Lewis Coyne** investigate

Edward Hockings and Lewis Coyne  
Tuesday 10 March 2015 16.15 GMT

600 Shares 3 Comments



Health Secretary Jeremy Hunt holds up a memory stick containing a record of a whole human genome as he speaks at the UK e-Health Week event Photograph: Peter Macdiarmid/Getty Images

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**Most popular**



Obama lambasts Putin: you're wrecking Russia to recreate Soviet empire

# Informational Risk

THE BLOG | Featuring fresh takes and real-time analysis from HuffPost's signature lineup of contributors

 **Shimon Koffler Fogel** [Become a fan](#) [✉](#) [🐦](#) [👍](#)  
Shimon Koffler Fogel is CEO of the Centre for Israel and Jewish Affairs (CIJA), the advocacy agent of Canada's Jewish Federations.


## Genetic Discrimination Means the Choice Between Life and Life Insurance

Posted: 12/12/2014 8:52 am EST | Updated: 02/11/2015 5:59 am EST

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*Co-authored with Bev Heim-Myers, Chair, the Canadian Coalition for Genetic Fairness and CEO, Huntington Society of Canada*

Protecting members of our society from discrimination based on the colour of their skin, ethnicity, or ancestry is a fundamental Canadian value. Unfortunately, Canadians across the country currently face real as well as potential future discrimination based on their DNA. Genetic discrimination is a reality in Canada, with out-dated laws enabling insurance companies and employers to target individuals and families based on the results of genetic testing.

- The economic and social consequences involved in making one's private data public
- The impact of incidental findings that may also affect one's family members
- The long-term participatory risks for research participants.

# Informational Risk

The screenshot shows the Nature website interface. At the top, the 'nature' logo is on the left, and a search bar with a 'Go' button is on the right. Below the logo, the text 'International weekly journal of science' is visible. A navigation menu includes links for Home, News & Comment, Research, Careers & Jobs, Current Issue, Archive, Audio & Video, and For Authors. A secondary navigation bar highlights 'News & Comment', 'News', '2015', 'June', and 'Article'. On the right side of the page, there are social media and alert options: E-alert, RSS, Facebook, and Twitter. The main article title is 'Privacy loophole found in genetic databases' with a sub-headline 'DNA donors' identities can be determined from publicly available records.' The author is 'Erika Check Hayden' and the date is '17 January 2013'. A 'Rights & Permissions' button is located below the date. The article text begins with 'A potentially serious loophole could allow anyone to unmask the identities of people who contribute their DNA sequences to some research projects, researchers report today.' To the right of the text is an image of a person looking at a large DNA database structure. Below the image is a caption: 'Sifting through DNA databases can lead to identify some male subjects that were supposed to be anonymous.' To the right of the article is a 'Recommended' section with a red background and a white DNA helix. The first recommendation is 'CRISPR, the disruptor' with a sub-headline 'A powerful gene-editing technology is the biggest game changer to hit biology since PCR. But with its huge potential come pressing concerns.' Below the recommendations is a list of recent articles with tabs for 'Recent', 'Read', 'Commented', and 'Emailed'. The list includes: 1. 'Start-ups fight for a place in Boston's biotech hub' (Nature | 08 June 2015), 2. 'Injectable brain implant spies on individual neurons' (Nature | 08 June 2015), 3. 'Natural gas stands to get a boost from carbon tax' (Nature | 05 June 2015), and 4. 'South Korean MERS outbreak is not a global'.

**nature** International weekly journal of science

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News & Comment > News > 2015 > June > Article

NATURE | NEWS

Privacy loophole found in genetic databases

DNA donors' identities can be determined from publicly available records.

Erika Check Hayden

17 January 2013

Rights & Permissions

A potentially serious loophole could allow anyone to unmask the identities of people who contribute their DNA sequences to some research projects, researchers report today.

This is the latest in a series of findings over the past five years that have highlighted privacy vulnerabilities in public databases containing genetic data. The US National Institute of General Medical Sciences (NIGMS), part of the National Institutes of Health (NIH) in Bethesda, Maryland, reacted to the study by removing some data from public view. Some geneticists however question that step, although they acknowledged that the research community must respond to the genetic privacy issue.

Sifting through DNA databases can lead to identify some male subjects that were supposed to be anonymous.

CRISPR, the disruptor

A powerful gene-editing technology is the biggest game changer to hit biology since PCR. But with its huge potential come pressing concerns.

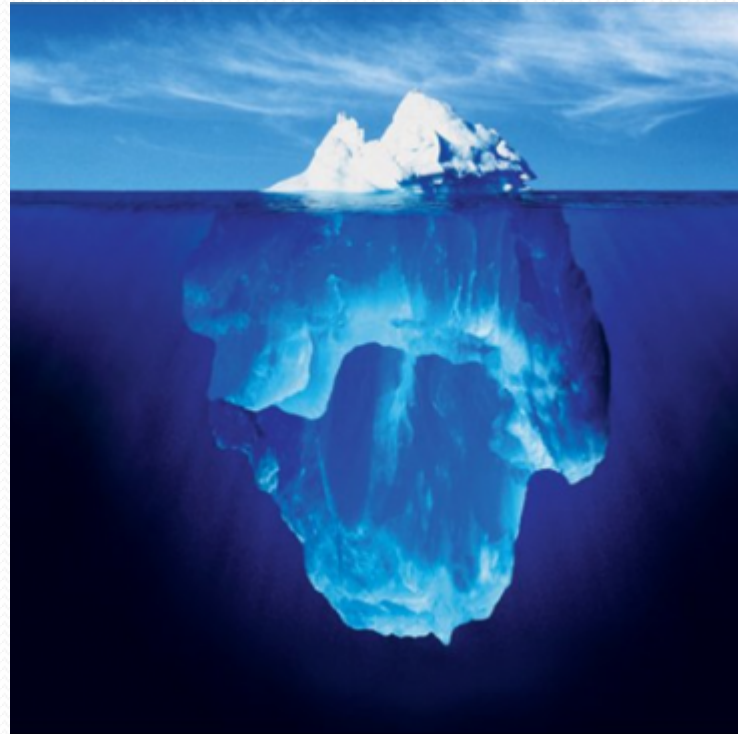
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Nature | 05 June 2015
4. **South Korean MERS outbreak is not a global**



# Recommendations: the AML Project

- Greater transparency with patients about the risks and benefits of digital genomic data.
- Highlight the role of the Internet and genomic databases, and their implications.
- Critical socio-technical research into applied practice at the community level.





# Other Privacy Recommendations

- Global data-sharing model with third-party assurance mechanisms
- E-governance system to ensure ethical, legal compliance
- Genome industries to carry insurance for data breaches



# The Challenge for Genomic Big Data

- Innovation in *both* medical research and privacy policies.
- Foster both scientific discovery and greater transparency.
- Promote space of convergence: genome-based healthcare and privacy aren't opposing forces but equally important factors for social progress.

