Genetic Privacy & Genomic Driven Medicine – “Big Pharma Would Like Your DNA”

• Erwin Malzer, Healthcare Transformation Advocate

• Dr. Catalina Lopez-Correa, Chief Scientific Officer & Vice-President Sectors, Genome BC

• Dr. Martin Dawes, Chief Scientific Officer & Co-Founder, GenXys Health Care Systems

• Dr. Rob Fraser, President & CEO, Molecular You
Genetic Privacy and Genomic Driven Medicine
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Dr. Catalina Lopez-Correa MD PhD
Chief Scientific Officer and VP Sectors

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Genomic data is growing fast

Langmead & Nellore, Nature Reviews Genetics 2018
The challenge

Sharing data at a global level

Unlock the individual potential of population data

Empower new knowledge

Genome British Columbia
Leading • Investing • Connecting
Universal Declaration of Human Rights 1948 (BM Knoppers)

**Sharing Data**
Benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, in particular with developing countries.

**Article 15 (1)**

**Right to Science**
**Everyone** has the right freely to **participate** in the cultural life of the community to enjoy the arts and to **share in scientific advancements and its benefits**

**Article 27 (1)**

**Right to Recognition**
Everyone has the right to the protection of moral and material interest resulting from any scientific, literacy or artistic production of which he is the author.

**Article 27 (2)**
A new model for genomic data sharing
Block chain genomics
Contact:

Catalina Lopez-Correa
Chief Scientific officer and VP Sectors
clopez@genomebc.ca
604.675.1035

www.genomebc.ca
Medications are often ineffective, can cause harm and substantial costs. Professionals and People want to know what they can prescribe or take.

50% of prescribed Medications are ineffective.

500,000 deaths annually
12% of ER visits
5% of hospitalizations
10% of direct healthcare costs

$30 billion is the cost of ADR in US per year

- One in 10 high risk patients have an ADR per year
- The average cost will be $400 in the community and $6,000 in the hospital
The users want to know what they can prescribe or take
Academy Meets Deluge of Data
Outcome Data

Move from formal trials on unrepresentative patients to “Real” world trials

A change that will transform health care – where every person is part of the discovery and owns that.
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More data in the past 2 years than in the entire previous history of the human race.

For most, if not all, commercial firms, data is the critical capital input to tomorrow's economy.
Continuum of Care

- Target what matters
- Measure what changes
- Optimize actions
- Healthy Longevity
70-90% of your health status is related to lifestyle.
What might happen?

Genetics

Proteins

Metabolites

Environmental exposures

What is happening Now!
Who Owns Personal Health Data

Canada: the information in the medical record belongs to the patient.
• The physical record belongs to the person or organization responsible for its creation

European GDPR: does not explicitly give us an answer on personal data ownership
• Data subjects should be in control of their personal data.
Real Risks To Data Sharing?

“...much more than a medical device; it is a one-way portal into a world where corporations have access to the innermost contents of your cells and where insurers and pharmaceutical firms and marketers might know more about your body than you know yourself.”

Charles Seife

“Genetic Information that you share with others could be used against your interests. You should be careful about sharing your Genetic Information with others.”

23&Me
This enactment prohibits any person from requiring an individual to undergo a genetic test or disclose the results of a genetic test as a condition of providing goods or services to, entering into or continuing a contract or agreement with, or offering specific conditions in a contract or agreement with, the individual. Exceptions are provided for health care practitioners and researchers. The enactment provides individuals with other protections related to genetic testing and test results.
We Want to Share Our Data

“Genetic data is the most personal data I own, but if my data can contribute to finding better treatment or even a cure, why should I think twice about sharing it?”
A New Currency: Personal Health Data
Individual Data, Individual Control

Molecular You health data

Personal blockchain wallet holds all individual data
Private key keeps data safe

Securely consent to use of data by signing with private key
Receive rewards for use of data in research
Personalized Health: The Future is Now!

Rob Fraser, PhD
President & CEO
Molecular You
20TH ANNUAL PRIVACY & SECURITY CONFERENCE

Looking Back and Leading Forward in a Digital World

PRE-CONFERENCE EDUCATIONAL SESSIONS: FEBRUARY 6, 2019 | CONFERENCE: FEBRUARY 7-8, 2019

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