PERSPECTIVE(s): Citizens and Patients

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“Everyone has the right.... to share in scientific advancement and its benefits.”

Universal Declaration of Human Rights (1948), art. 27(1)
International Covenant on Economic, Social and Cultural Rights (1966), art. 15
(Covenant signed by 169 countries and ratified by 165 countries)
"So as to ensure the human right to share in scientific advancement and its benefits, Member States should establish and facilitate mechanisms for collaborative open science and facilitate sharing of scientific knowledge while ensuring other rights are respected."

Recommendation on Science and Scientific Researchers, UNESCO (2017)
"When it comes to science, it is also a matter of tailoring research to citizen needs and concerns."

Overview

1. The PERSPECTIVE Projects
2. Engagement
3. Equity
4. Privacy and Altruism
5. Right to Share in Scientific Advancement
1. The Perspective Projects
Goal of PERSPECTIVE I&I

Improve personalized risk assessment to offer cost-effective risk-based prevention and early detection of breast cancer to those most likely to benefit, and determine the optimal implementation approaches. An international trans-disciplinary research team will deliver:

- a validated multiple-gene panel test
- a comprehensive risk prediction web-tool, and
- actionable cost-effective strategies for implementation.

- Genomic analysis of 125,000 samples
- Analysis of data from hundreds of thousands cases of cancer and controls
- Samples and data from 22 countries
The PERSPECTIVE approach: Tailor breast cancer screening according to personalized risk levels.

**PERSPECTIVE Project**

- Develop tools to support risk-based screening
- Involve citizens/patients in the development of communication tools

**PERSPECTIVE I&I Project**
(2018-2022)

- Improve the tools
- Test implementation of risk-based screening
- Involve citizens/patients in shaping and testing proposed implementation strategies
Pathways for women in PERSPECTIVE

**Stratification into risk levels**

- **High risk**
  - Earlier and more often mammography screening
  - Magnetic resonance imaging and chemoprevention considered
  - Mastectomy discussed

- **Intermediate risk**
  - Earlier mammography screening
  - Specific modalities for dense breast

- **Near population risk**
  - Currently bi-annual mammography in Québec/Ontario (50-69 y)

**GENETIC RISK PROFILE**

- FAMILY HISTORY OF CANCER
- DEMOGRAPHIC DATA

**MAMMOGRAPHIC DENSITY**

**LIFESTYLE AND HORMONAL FACTORS**
- Reproductive history
- BMI
- Height
- Alcohol
- Oral contraceptives

2. Engagement
PERSPECTIVE projects support citizen engagement

A. Community Advisory Committee: Orientation/validation of the web platform

B. Focus groups with women: Acceptability of the web platform

C. Surveys and interviews with women (general population): Optimization

A. Extended Community Advisory Committee
B. Expanded survey with women from the general population
C. Pilot test telegenetics with women
D. Survey of women re genetic discrimination

To come in 2018-2022
3. Equity
Lack of diversity on genomics research challenges equity

While 75% of the world population live in Africa and Asia...

and there are 250 different ethnic origins reported in the city of Montréal alone...


Statistics Canada, 2016 Census

"Instead of adding the word precision to more and more fields of practice and policy, we need to have critical discussions about emerging patterns of inclusion and exclusion."

Prainsack B, "Precision Medicine Needs a Cure for Inequality" (2019) Global Trends
Equity in the delivery of health services

- **Equity**: Fundamental value of the Canadian publicly-funded health system

- “[C]itizens get the care they need, without consideration of their social status or other personal characteristics such as age, gender, ethnicity or place of residence”


- Equity refers to the principle of **distributive justice**: individuals or groups fairly benefit from health services without consideration of socio-economic status, educational background, ethnicity...
Issues of equity when implementing risk-based screening:

A. Reproduction of social inequities
B. Amplification of regional disparities in access to services

A. Reproduction of social inequities

Solicitation of women

- Difficult inclusion of certain disadvantaged sub-groups with regard to language, ethnicity, literacy level and/or education
- Difficulty exacerbated by the complexity of the risk-based approach

Informed consent

- Complexity of the approach could foster social inequality and challenge informed nature of the consent
- Lack of knowledge from health professionals to explain to women with lower level of literacy
- Importance of considering cultural specificities

Return of results

- Difficulty to make results understandable for women due to their inherent complexity or insufficient level of health literacy
- Women understanding compromised by lack of knowledge and/or expertise of the primary care providers
B. Amplification of regional disparities in access to services

- Disparities in services offered in rural and urban areas
- Geographical accessibility of specialized services challenging in remote areas
- Lack of services for women experiencing anxiety, stress or other concerns

Proposals to foster equity in the delivery of services:

- Fostering inclusion through communication strategies
- Adding electronic communication technologies
4. Privacy and Altruism
Improving health services and benefits common to all citizens requires balancing...

Privacy protection

Altruistic data sharing

Individual benefits

Collective benefits
Reciprocity between the health system and citizens

Are we citizens in **screening** and patients in **healthcare**?

- Public health model, centered on collective needs/benefits
- Clinical model, centered on individual needs/benefits
"The health system should be a dynamic learning and researching system, where all data and every patient contact is used to improve the experience and service provided to that individual, and to push the boundaries of new treatment and prevention approaches. Co-production with all stakeholders will be pivotal to this success; a health service that is learning with you, about you and for you."

Annual Report of the Chief Medical Officer, UK (2018)
5. Right to Share in Scientific Advancement
"The right to science underlines a particular kind of benefit to ordinary individuals that might otherwise be neglected: not simply passively to receive the benefit of the fruits of scientific investigation, but to play a part in securing them by engaging in such investigation, even if one is not a professional scientist."

"We currently stand at the crossroads of two developments: growing citizen participation in science and a renewed interest in the unexplored potential of the HRS. This is an ideally opportune moment to negotiate how best to facilitate the phenomenon of citizen science within an ethical framework that takes seriously the right of all to participate in, and benefit from, scientific progress."

The goal of such a novel human rights approach is to "reorient our conversation from policing science to governing society and would shift our focus from avoiding risks to protecting opportunities".

"The destiny of human rights is in the hands of all our citizens in all our communities."

— Eleanor Roosevelt
Our international research team
Thanks for your attention!

Wassily Kandinsky, Sky Blue (1940)