The Right to Science and Engagement

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Open Science, to accelerate discovery and deliver cures
Outline

1. What is engagement?
2. Examples of engagement: a many splendoured thing.
3. Practical challenges and regulatory pitfalls.
What is Engagement?

*Patient/Community Engagement* - when patients/community members “meaningfully and actively collaborate in the governance, priority setting, or design and conduct of research.” ([CIHR, 2019](#))

*Patient/participant Engagement* - (the institutional agenda of) “recruiting and engaging patients/[participants] in activities that previously would have been conducted exclusively by staff and professionals.” ([Johannesen, 2018](#))

*Citizen Science* - “non-professional involvement in scientific research.” ([Vayena, 2013](#))
GA4GH Framework for Responsible Sharing of Genomic and Health-Related Data

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

(Universal Declaration of Human Rights 1948, art 27(1))
The Right to (Participate in) Science


“...everyone has a right to benefit from scientific advances, and ... people have a right actively to participate in scientific inquiry, rather than just to be passive beneficiaries of advances made by professional scientists.”

The right to science: a strong normative underpinning for citizen science.
The Right to (Participate in) Science

But! “Often standards and procedures of ethics review, which were designed for scientific projects that did not involve big data or citizen science dimensions, are uncritically applied to these new models of research.”

The Right to (Participate in) Science

Empowering citizens scientists to access data requires participants to waive protections and control...the two “democratizing” trends of citizen science and participant empowerment [can] come into conflict.”

Adrian Thorogood, Citizen Science: A Many Splendoured Thing (unpublished manuscript).
Community Engagement

Canadian Open Neuroscience Platform, Ethics and Data Governance Framework (July, 2019)

7. Engage communities meaningfully in governance of open neuroscience:
   - To improve the quality of and support for open neuroscience (7.1)
   - Through community review, approval, joint development of governance, or involvement in oversight bodies (7.2)
   - Explain aims and anticipated benefits of open neuroscience, and demonstrate actual benefits over time (7.3)

Practical challenges:
- identifying issue areas (7.4);
- identifying appropriate community representatives (7.5);
- Extra efforts to include and consult Aboriginal communities (7.6).

Sources:
WHO/CIOMS (2016) - Guideline 7 : Community Engagement
Draft CIHR Ethics Guidance on Developing Research Partnerships with Patients
PERSPECTIVE - Comité consultatif citoyen

Partagez vos idées sur le dépistage du cancer du sein
Count Me In

Become part of the research movement. Have a direct impact on the future.

By saying “Count Me In”, you will partner with leading research institutes, hospitals, and patient advocacy groups by sharing part of your stored tumor tissue and copies of your medical records.

Here’s how you can participate

1. Step 1. Tell us about yourself
   Click “Count Me In” and complete a simple online form to tell us about yourself and your cancer. Our goal is to perform many different studies within the metastatic breast cancer community, so allowing us to know a little bit about your experience will help us design future studies.

2. Step 2. Give us permission to collect your samples and data
   When we start a study that matches what you have told us about yourself, we will ask you to fill out an online consent form that requests your permission to obtain copies of your medical records and some of your stored tumor tissue. We will do the rest - we’ll contact you if we need additional information.

3. Step 3. Learn with us along the way
   We are excited to learn with you! Throughout the project, we will provide you with regular updates about the status of the project and share any discoveries that you have enabled us to make. We also may ask you additional questions about your experience to help with research.

Nikhil Wagle
and
Corrie Painter
“I want to live and watch my children grow up, but if I can’t, then I want to leave a legacy and a cure.”
—Houston, TX

“As someone who does not live near a research center and therefore cannot easily participate in trials, I finally feel like I can contribute.”
—Lake Tahoe, CA

“Amazing how happy that little box makes you feel! I felt like a 2 year old. Let me help! I feel a sense of pride and belonging because of this.”
—Minneapolis, MN

“This project now gives purpose to my diagnosis. Every treatment day I will smile knowing it isn’t just for me!”
—Dade City Florida

“Giving us HOPE for the future and if not for some of us, for our families.”
—Scottsdale, AZ
Metastatic Breast Cancer Project

Over 5350 women and men from all 50 states

1236 institutions with 1 patient

19 institutions with 10+ patients (420 patients total)

Over 1700 Institutions Represented

<table>
<thead>
<tr>
<th>Institution Name</th>
<th>Number of Patients</th>
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<tbody>
<tr>
<td>M.D. Anderson Cancer Center</td>
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<tr>
<td>Dana-Farber Cancer Institute</td>
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<td>Memorial Sloan-Kettering Cancer Center</td>
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<td>University of Pennsylvania - Abramson Cancer Center</td>
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<td>Seattle Cancer Care Alliance - Seattle</td>
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<td>UCSD Medical Center</td>
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<td>M.D. Anderson Cancer Center - Seattle</td>
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<td>Massachusetts General Hospital</td>
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<td>Dana-Farber Cancer Institute</td>
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<td>New York Presbyterian Hospital: Memorial Health</td>
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<td>Mayo Clinic - Arizona - Phoenix</td>
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<td>Forghany Cancer Center: Temple Health</td>
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<td>Cleveland Clinic - Main Campus</td>
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<tr>
<td>Willamette Valley Medical Center - HTH Hoover MD</td>
<td>9</td>
</tr>
</tbody>
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DFCI (65 patients)
MD Anderson (70 patients)
MSKCC (51 patients)
U Penn (24 patients)
Seattle Cancer Care (22 patients)
UCSF (20 patients)
Participant Engagement

A deliberate strategy by researchers to achieve instrumental research goals (e.g., retention, data quality) and to treat participants with care and respect. (Childerhose et al, 2019)

Types
- Return of individual results
- Counselling
- Updates about research progress and results
- Involve in discussions about project governance

One size fits all?
- Burden on researchers
- Therapeutic misconception
- Participant fatigue

Canadian Open Neuroscience Platform
PREVENT-AD dataset
PRe-symptomatic EValuation of Emerging Novel Treatment for Prevention of Alzheimer’s Disease

Re-consenting 600+ participants: data sharing protocol from controlled access to open science?
Reconciling Openness and Community “Control”?

“The principle [of respect for communities] is commonly extended to include community control or participation in governance of research biobanks and databases.”

“Competing principles of openness and community control over data can be reconciled by engaging communities not in the governance of datasets, but in the governance of health research systems.”

The Trouble with Patient Engagement....

Jennifer Johannesen 2018, Tom Bailey (images)
The Trouble with Patient Engagement….

“when... deployed in a blunt or sweeping fashion, it limits the type and scope of research projects, and impacts the pace at which they can proceed.”

“It should end because when implemented mindlessly across the board it interferes with how research is conducted.”

Jennifer Johannesen 2018
Engagement in Risk Regulation, Data Governance

GLOBAL ALLIANCE FOR GENOMICS & HEALTH
Collaborate. Innovate. Accelerate.

YOURDNAYOURSAVY Survey

Join the conversation online!

@TheNeuro_MNI
#OpenScienceinAction