Ethical Intersections and Tensions Between Intellectual Property Protections and Open Neuroscience

Anna Nuechterlein, B.A.Sc.

Neuroethics Canada, Division of Neurology, Department of Medicine
University of British Columbia

Neuroethics Canada is located on the unceded and traditional territories of xʷməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Səl̓ilw̓ətaɬ (Tsleil-Waututh) Nations.
Public release of data and scientific resources

External research partnerships

Research materials and tools

Intellectual property

Research and patient autonomy
Research objectives

• To determine stakeholder perspectives on intellectual property protections and open neuroscience

• To inform the future of open science policy for the neurosciences in Canada and broadly
Study Design and Methods

Focus groups and interviews:

9 groups; N=29

<table>
<thead>
<tr>
<th>In-person</th>
<th>Virtual</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=3</td>
<td>N=6</td>
</tr>
<tr>
<td>1 woman, 2 men</td>
<td>2 women, 4 men</td>
</tr>
<tr>
<td>N=1</td>
<td>N=2</td>
</tr>
<tr>
<td>1 man</td>
<td>2 men</td>
</tr>
<tr>
<td>N=1</td>
<td>N=7</td>
</tr>
<tr>
<td>1 man</td>
<td>4 women, 3 men</td>
</tr>
<tr>
<td>N=6</td>
<td>N=5</td>
</tr>
<tr>
<td>1 woman, 2 men</td>
<td>1 woman, 4 men</td>
</tr>
<tr>
<td>N=1</td>
<td>N=1</td>
</tr>
<tr>
<td>1 man</td>
<td>1 man</td>
</tr>
</tbody>
</table>

In-person:
- Patent experienced (N=11)
- Patent inexperienced (N=18)

Virtual:
- Patent experienced (N=11)
- Patent inexperienced (N=18)

Semi-structured interview guide:

- Risks, benefits, ethical implications of IP
- Intersections between IP and OS

Qualitative thematic analysis:

(Hsieh et al., 2005; Vaismoradi et al., 2013)

- Collect data
- Form concepts from data
- Identify relationships between categories
- Group concepts into categories
Major Themes

- Benefits of IP
- Limitations of IP
- Benefits of OS
- OS Concerns
- Obligation to Science
- Respect for Persons
- Coexistence of IP and OS
- Justice
- Knowledge Gaps
- OS Infrastructure
- Exceptionalism of the Brain
- Special Concerns
Major Themes

Benefits of IP

“... [IP] allows you to bring ideas forward and develop them commercially...”

Limitations of IP

“... the biggest problem is really money, time, effort...”

Benefits of OS

“... it’s accessible to a wider community...”

OS Concerns

“... if somebody feels that OK their ideas should be patented, I don’t have the right to say no, you can’t do that.”

“... there's a failure to share information ... such as the requirement to hold off on publishing until a patent is filed.”

“... industry, third party stakeholders would be considerably less interested if there was no way to commercialize...”
Special Ethics Considerations

- Implications for OS in research partnerships
- Concerns about data ownership, control, and privacy
- Views on the brain, mind, and personhood
Takeaways

- Translational benefits
- Researcher autonomy
- Culturally safe research
- Context-informed choice
Recommendations

Priorities

Reporting

Education

Infrastructure
Acknowledgements

**Funding:** CIHR/ERA net (#ERN-174185 )
Tannenbaum Open Science Initiative (TOSI)

**Collaborators:** Dr. Judy Illes, Dr. Paul Pavlidis, Jeff LeDue, Ari Rotenberg, Ashley Lawson

**Disclosures:** None