Meaningful involvement of people who use cannabis in research and evaluation

Allyson Ion1, Nathan Crites2, Theresa Kozak3

1 – School of Social Work, McMaster University; 2 – Patient Perspective; 3 – Canopy Growth Corporation

Background

- Cannabis research dates back to the early 1950s, however, the research is predominantly situated within a biomedical paradigm.
- There is limited social science research on experiences of cannabis use including:
  - The role that cannabis plays in people’s lives
  - Reasons for cannabis use
  - How cannabis use is perceived and socially positioned by others (e.g. family, friends, and health and social care providers)
  - The ways people who use cannabis interface with social experiences
- Even less research has been conducted from a participatory, community-based perspective. People who use cannabis are under-represented in the design, implementation, and dissemination of cannabis research.

Participatory research: underlying principles

- Equitable approach to research
  - Non-hierarchical valuing of knowledge and experience of all who are involved and/or have a stake in the research (Israel et al., 1998; Wallace et al., 2015)
  - Democratizing knowledge production through a shared dialogical process (Maiter et al., 2013)
    - Reciprocity: exchange for mutual benefit
    - Reciprocal relationships means addressing power differentials and creating environments where meaningful exchanges can occur” (Maiter et al., 2008, p. 319)
- Social justice aims (Etowa et al., 2007)
- Potential for research “to be an effective means to open up discussion and, eventually, to make change” (Maiter, 2008, p. 316)

**“There are different cannabis phenotypes. Cannabis is not a monolith, it is a complex and multidimensional plant and medicine. Sativa is an up-lifting, energetic medication. Indica is a more euphoric narcotic pain reliever and sleep aid. Hybrid strains combine the two phenotypes in different proportions for different effects. There are so many different phenotypes out there that could be researched. And what works for somebody, might not work for somebody else. More research is needed.”

- N. Crites

**“Participatory research is particularly important as we are entering into a legal cannabis framework and there is much that can be learned about recreational cannabis from those who use cannabis recreationally.”

- T. Kozak

One Patient’s Experience of Cannabis Use for Specific Health Conditions

<table>
<thead>
<tr>
<th>Health Condition</th>
<th>Preferred Cannabis Phenotype</th>
<th>Preferred Mechanism of Cannabis Use</th>
<th>Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-Surgical Pain (e.g. orthopedic surgery)</td>
<td>Indica, homegrown</td>
<td>Ingestion &amp; Vaporizing</td>
<td>Effective anti-inflammatory, euphoric narcotic effect and pain relief lasting up to 10 hours</td>
</tr>
<tr>
<td>Ongoing Bone Pain (e.g. multiple surgical implants)</td>
<td>Hybrid (25% Indica &amp; 75% Sativa) + Homegrown environment</td>
<td>Inhalation</td>
<td>Onset within 15 minutes, motivates movement and physical activity with less heady euphoria lasting 2-3 hours</td>
</tr>
<tr>
<td>Crohn’s Disease</td>
<td>Indica, homegrown</td>
<td>Inhalation</td>
<td>Slows peristalsis, cannabis has reduced the need for pharmacotherapy, e.g. prednisone</td>
</tr>
<tr>
<td>Suppressed Appetite (due to Crohn’s Disease)</td>
<td>Indica, homegrown</td>
<td>Inhalation</td>
<td>Onset within 15 minutes, stimulates hunger, calms mind/body about consequences of eating with Crohn’s Disease</td>
</tr>
<tr>
<td>Social Anxiety and Depression</td>
<td>Hybrid (75% Indica &amp; 25% Sativa) + Homegrown environment</td>
<td>Inhalation</td>
<td>Relaxes muscles (Indica) and promotes social interaction (Sativa)</td>
</tr>
<tr>
<td>Insomnia</td>
<td>Indica, homegrown</td>
<td>Inhalation</td>
<td>Onset within 15 minutes including relaxed muscles and calm mind lasting up to 4 hours</td>
</tr>
</tbody>
</table>

Benefits and Considerations when Involving People with Lived Experience in Research

**Benefits**

- People who use cannabis can play a vital role in:
  1. Shaping research questions
  2. Expanding the scope and focus of research, e.g. exploring the effects of different strains and mechanisms of use for different health challenges
  3. Identifying key stakeholders and users of the knowledge generated through research
- Participatory approaches grounds research questions in the lived realities of people who use cannabis, e.g. benefits of and barriers to cannabis use.

**Considerations**

- Collaborative research requires commitment, time, planning, and relationship building
- Create opportunities for reciprocal capacity building for researchers and people with lived experience (learning from each other for mutual benefit)
- Ensure dialogue between team members regarding the study purpose, institutional constraints, and desired outcomes
- Build in mechanisms for shared decision-making
- Ensure the process is accessible for all team members
- Reduce barriers for all team members to contribute in a meaningful way, e.g. financial, technological, modes of communication, shared language, etc.