Prescription Stimulants in Ontario
The Process of Involving Citizens in Research

ODPRN
ONTARIO DRUG POLICY
RESEARCH NETWORK

Importance of Citizen Engagement

Who are we?

The Ontario Drug Policy Research Network (ODPRN) is a province wide network of researchers who provide timely, high quality, relevant drug policy research to decision makers for evidence to guide and inform their policy decisions.

Who is the Citizens' Panel (CP)?

The CP is a group of 21 volunteer citizens from across Ontario who have collectively come together to ensure that the ODPRN appropriately identifies issues of importance to the public, and incorporates these priorities into the development, interpretation, and dissemination of research findings.

Why do we involve patients and citizens?

• The integration of patient and citizen voices in research can provide important context to help improve the quality of Ontario's drug policies and the broader healthcare system.

• The ODPRN's approach to patient and citizen engagement is designed to ensure that our research results are translated into health care practice and policy with meaningful, relevant impact on real world priorities.

What is the impact?

Integrating the CP as a key unit of the ODPRN has led to:

1. Greater collaboration and aligned research priorities between academics, policymakers and the public

2. Integration of the patient and citizen perspective at all stages of the research process

3. Improved communication of research findings through the development and dissemination of public-facing materials

"The Citizens' Panel brings a different perspective to the report, from the use of language to ensuring that the analysis reflects the challenges of everyday Ontarians accessing these medications," says Jane Sanders, Chair of the Citizens' Panel.

"I think the individual members of the panel gain considerable satisfaction from knowing that our perspectives are positively contributing to health policy and access to safe and effective medications for Ontarians."

Citizen-Led Research Process

1. Identify topic

• The ODPRN's Stakeholder Advisory Panel – an interdisciplinary team of academic researchers, policymakers, data partners and other knowledge users from the scientific community in Ontario – and CP members were tasked with identifying research priorities of interest.

• During the 2016 in-person meeting, members brainstormed relevant medical/clinical topic areas, populations of interest, policy topic areas, and decided on their top research priorities.

• Mental health and addiction was a top priority across all sectors, with stimulants being a specific area of interest to the CP members.

2. Develop process

• The CP developed a sub-committee of members particularly interested in this topic. While this sub-committee had a major role in designing the research approach and developing the report, all CP members were involved in each phase of the research process by dedicating a portion of the bimonthly CP meetings to discussing this study.

3. Design and refine

• Developing the research proposal was an iterative process. The ODPRN proposed measures to be included in the study based on feasibility within the data sources available at ICES, and CP members discussed and adjusted these measures based on their priorities and interests.

4. Analyze and interpret

• During the 2017 in-person meeting, members discussed the study findings and developed key messages based on interim results. Changes were made to the analytic approach and additional measures were added at this time based on CP feedback. For example, additional age and gender breakdowns were included and an analysis of concomitant opioid use was added.

5. Report and evaluate

• All CP members reviewed a draft of the report and dissemination materials, providing important feedback such as methodological notes that should be included for clarification and additional questions that the CP identified for future research.

• The ODPRN researchers provided oversight, methodological advice, conducted the analysis and drafted the report.

For more information

Martins D, Greaves S, Tadrous M, Shearer D, et al on behalf of the ODPRN Citizens' Panel. Landscape of Prescription Stimulant Use: Patterns, Trends and Geographic Variation in Ontario, Canada. Toronto: Ontario Drug Policy Research Network; September 2018.

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