

Engaging Patients in Setting Direction for Broad System Change

Masterclass on the Conduct and Use of Patient-Oriented Research
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Overview

- **Introduction**
 - Evidence- and values-informed policy
- **Description of an approach for engaging patients in setting direction for broad system change**
 - Citizen panels (alone or in combination with stakeholder dialogues)
- **Conclusion**



Introduction (1)

- **Evidence- and values-informed policymaking**
 - Systematically and transparently using the best available data and research evidence as well as citizens' values and preferences to inform:
 - Agenda setting (especially understanding the problem)
 - Policy (or solution) development
 - Implementation



Introduction (2)

■ Key challenges

- Complex health problems
 - different understandings of the problem
- Uncertainties
 - e.g., about the most effective policy options to address these problems and their implementation considerations (e.g., equity, costs, unintended effects, acceptability and feasibility)
- Lack of agreement
 - among all stakeholders about how to move forward



Introduction (3)

- **The role of citizens' values and preferences**
 - Citizens can help us to develop a **shared understanding** about a problem (challenge 1)
 - Citizens have **experiential knowledge** (challenge 2)
 - valid and legitimate evidence that can help to find innovative and local solutions to complex problems
 - Citizens can **facilitate or trigger action** (challenge 3)
 - offering guidance on how to move forward
 - identifying what options are socially, politically, and ethically sound
 - advocating for policy options

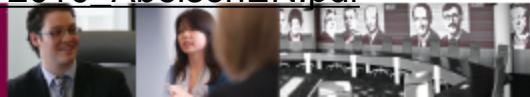


Introduction (4)

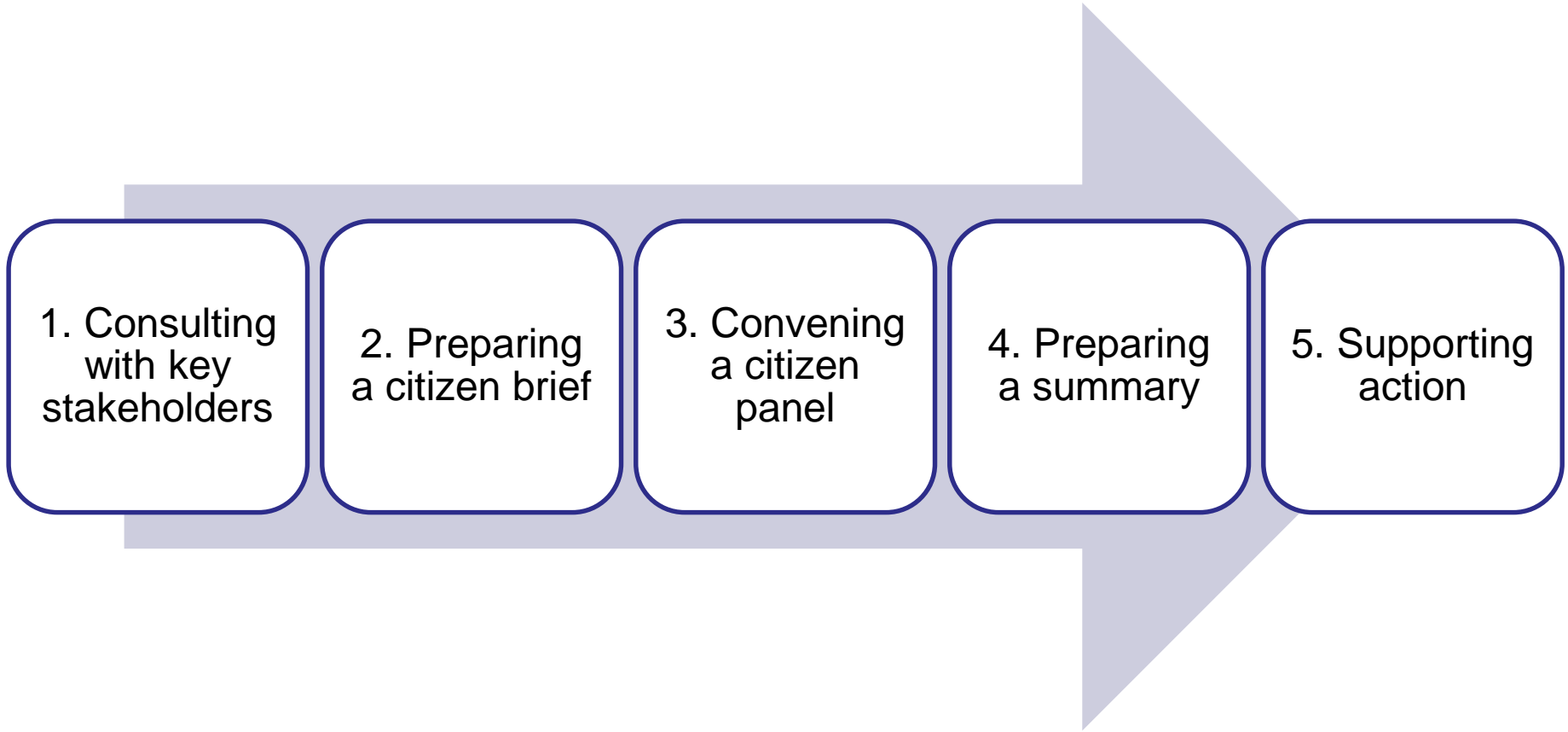
- What does public/citizen engagement mean?
 - Public engagement captures a range of efforts used to involve the public (including citizens, patients, service users, informal/family caregivers) in various stages of policymaking

 - Deliberation defined
 - “Individuals with different backgrounds, interests, and values listen, learn, and potentially persuade and ultimately come to more reasoned, informed, and public spirited judgments” (Abelson, 2010)

*Abelson, J. (2010) *Délibération publique et gouvernance démocratique: Théories, pratiques, et données probantes*, Journées annuelles de santé publique, Montréal, March 12 (Online): http://www.ncchpp.ca/docs/DeliberationJASP2010_AbelsonEN.pdf



Citizen Panels



1. Consulting with Stakeholders

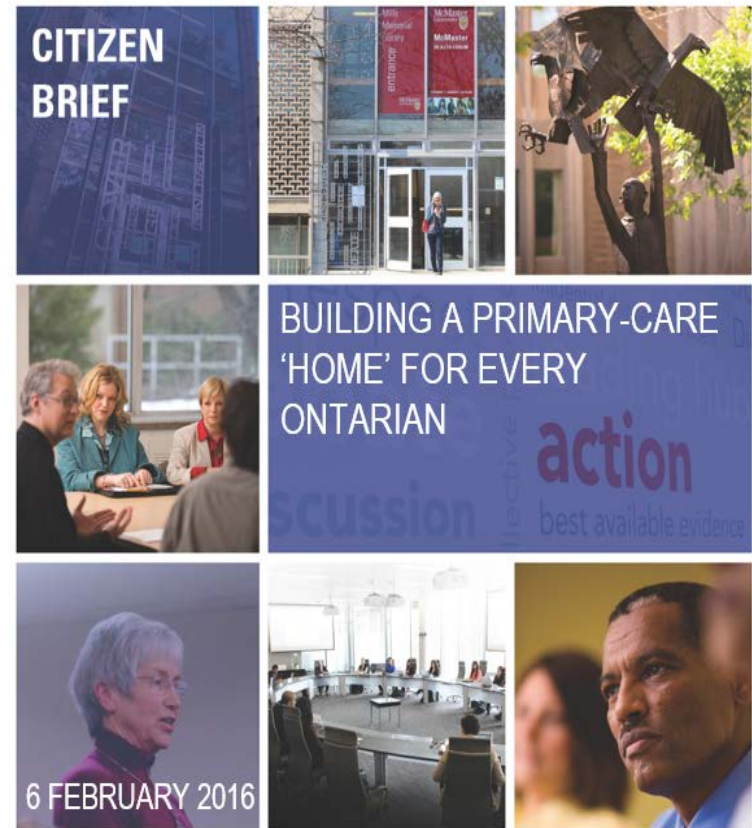
- **Steering committee**
 - Develop criteria to select panel participants
 - Iteratively refine understanding of the problem, possible options to address it and implementation considerations
 - Identify key informants

- **Key informant interviews**
 - 15-20 interviews with representatives of citizen/patient groups, policymakers, stakeholders and researchers who are involved in or affected by the issue
 - Identify different views and perspectives about the problem, possible options to address it and implementation considerations



2. Preparing a Citizen Brief

- Presents (in plain language) relevant research evidence about a problem, options for addressing it, and key implementation considerations
- Based on syntheses and local evidence (identified using systematic and transparent approach)
- No recommendations
- Subjected to merit review
- Poses questions for citizens to consider



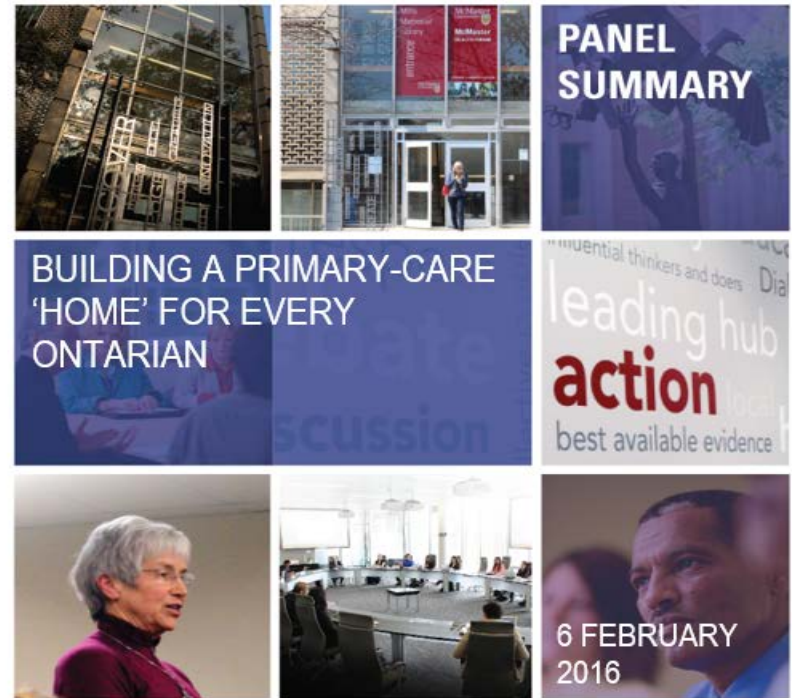
3. Convening a Citizen Panel

- Brings together a diverse group of 10 to 16 citizens for a one-day, off-the-record, dialogue that provides them with the opportunity to:
 - bring their own views and experiences to bear on an issue;
 - learn from the evidence and from others' views and experiences; and
 - share their newly informed views about the issue and how to address it.



4. Preparing a Summary

- Thematic analysis of deliberations
- Describes:
 - views about and experiences related to the issue
 - values and preferences for addressing it
- Identify areas of shared understandings, as well as divergent opinions



EVIDENCE >> INSIGHT >> ACTION



5. Supporting Action

- **Two examples of ways to support action following a citizen panel**
 - Personalized briefings to those who can take action
 - Convene a stakeholder dialogue with policymakers, stakeholders and researchers
 - informed by an evidence brief that includes findings from the citizen panel
 - ‘off-the-record’ deliberations with those who are in a position to champion change



Conclusions

- **Citizen panels**
 - Provide a mechanism for evidence-informed deliberation among citizens about pressing health-system issues
 - Emphasize the importance of citizens':
 - views and experiences about an issue
 - values and preferences for how to address it
 - Support people-centred health systems



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