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CANADIAN **PARTNERSHIP**
AGAINST **CANCER**

PARTENARIAT CANADIEN
CONTRE LE **CANCER**

REFLECTION GUIDE

Learning Together:
How to Better Engage Underserved Groups in Healthcare Systems

SPRING 2018

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INTRODUCTION AND OVERVIEW

ENVIRONMENTAL SCAN FOR BEST DELIBERATIVE ENGAGEMENT PRACTICES IN REACHING UNDERSERVED/MARGINALIZED GROUPS

In pursuit of advancing its knowledge of and capacity for engaging underserved/marginalized groups to minimize disparities across the cancer control system for all groups, the Partnership Against Cancer (the Partnership) commissioned the Propel Centre to undertake an environmental scan and conduct key informant interviews[1]. A focus on equity is one of the five strategic priority themes of the Partnership's 2017 – 2021 strategic plan[2].

The Environmental Scan examined and compared current methods of engaging underserved/marginalized groups in deliberative public engagement (DPE) in Canada, the US, the UK, the Netherlands and South Africa and included the use of innovative-technology-based strategies within those processes.

The criteria for DPE processes were: they were evaluated; addressed a value-based or ethical question(s), included a focus on underserved/marginalized group(s); and took place in Canada or countries with a similar healthcare system. Four types of DPE were included, differentiated by duration (1-day, multiple days, multiple weeks and ongoing). It also incorporated nine key informant interviews, bringing perspectives of researchers, practitioners and patients.

PURPOSE OF THIS SUMMARY AND REFLECTION GUIDE

This discussion guide is intended as a companion document to the Environmental Scan. With its focus on critical findings, conclusions, and questions, it is designed to elicit practitioners' perspectives, experience, knowledge and questions on the considerations and conclusions profiled in the Scan. The Environmental Scan provides important insights and findings, but it is not, nor was it intended to be, an exhaustive examination of the topic under study. Rather, the Partnership's hope is that the Scan and this companion document will serve an important purpose in encouraging and supporting practitioner, researcher and public discourse on ways of better engaging underserved/marginalized individuals and groups in public policy writ large, and especially on health equity. It is in this spirit of iterative learning that the report and this document are being shared and discussed.

STRUCTURE OF THIS DOCUMENT

The following three sections present context, definitions, findings, considerations and conclusions, distilled and drawn from the Environmental Scan. Embedded in each section are reflection questions. We hope that they stimulate thinking and spark dialogue. Some of these questions will be probed during the Partnership's upcoming presentation (Leading Practices on Engaging with Underserved Groups: What We Know and What We Hope to Learn Together) to CFHI's National Health Engagement Network Webinar on August 2, 2018, and at other opportunities.

[1] The Canadian Partnership Against Cancer commissioned the University of Waterloo's Propel Centre for Population Health Impact to undertake the study. This summary and discussion guide draws from the Propel Centre's report, *Environmental Scan: Best Practices in Reaching Underserved Groups for Deliberative Engagement and Public Dialogues* (March 2018). The Scan included 25 papers, identified from a review of academic and grey literature, using five databases. It examined who was engaged, how they were engaged, and outcomes at the individual/group level and program or policy changes. The Environmental Scan is available for those who would like more detail. It includes an Appendix with the list of interviewees.

[2] The other four priority themes of the Partnership's Strategic Plan are: Quality, Seamless Patient Experience, Maximize Data Impact and Sustainable System.

CONTEXT AND DEFINITIONS

RATIONALE FOR ENGAGING UNDERSERVED/MARGINALIZED GROUPS AND INDIVIDUALS

The Partnership's Cancer System Performance Report 2017 reveals that people with lower-incomes and lower education levels generally have a higher cancer burden than advantaged populations. Cancer outcomes differ across at-risk groups, based on income, place of residence and immigrant status (note that data exists for these three variables but not for all relevant variables). To achieve its equity goals, the Partnership is committed to securing high quality, culturally appropriate and person-centered cancer prevention, diagnosis, treatment and care regardless of where a person lives, their ethno-cultural background, and where they are on their cancer journey.

A crucial step in achieving more equity is understanding the values and preferences of those who are facing sociodemographic barriers, including socioeconomic status, place of residence, immigrant status, and gender and sex identity. Understanding how to engage those facing equity barriers is essential for meaningful engagement to begin to address disparities in health outcomes. It was for that reason that the Partnership commissioned the Environmental Scan.

DEFINITIONS MATTER: WHAT DO WE MEAN BY UNDERSERVED/ MARGINALIZED GROUPS AND BY DELIBERATIVE PUBLIC ENGAGEMENT?

Organizations and individuals often experience challenges and unease around using language and terms that resonate for different groups and that don't either over simplify complex relationships or minimize history[3]. Defining underserved/marginalized groups is not easy because of the complexity of societal and cultural diversity and lived experiences. The Environmental Scan defines underserved/marginalized groups as those "that are not fully integrated into society.

These groups may be denied opportunities to meaningfully participate in society due to lack of economic resources, knowledge about political rights, recognition or other forms of oppression". Other related terms incorporated into The Environmental Scan included: vulnerable, hard/difficult to reach, disadvantaged, under-served, disempowered, underprivileged and
at-risk or high-risk.

[3] Environmental Scan, page 4

(A) Questions for reflection

(i) In working with different underserved/-marginalized groups and individuals, what term or terms do you use and recommend and why?

(ii) How did you decide upon these terms? What processes did you use?

Feel free to share any advice or insights on use of appropriate terminology.

DELIBERATIVE PUBLIC ENGAGEMENT APPROACHES

The Partnership defines deliberate public engagement processes as approaches used to involve the public in collective problem-solving and decision-making. These processes aim to reach a common understanding, seek shared values and identify acceptable trade-offs related to specific policy alternatives. There are many ways to achieve DPE (Environmental Scan, pg3).[4]

(B) Questions for reflection

(i) Does the Partnership's definition of DPE resonate with you?

(ii) To what extent do you use DPE approaches in your work with underserved/-marginalized groups?

(iii) Are there DPE approaches missing from the Environmental Scan and if so what are they and how do you use them?

[4] DPE processes identified in The Environmental Scan are: community engagement symposium, management forum, focus groups, brief citizens' deliberations, town halls, community meeting, community dialogue, community deliberation, democratic deliberation, deliberative dialogue, citizens' panel, citizens' jury, citizens' workshop, world café, online deliberative polling, hybrid participatory spaces, participatory action research, combination (Choicebook, story-telling, blogs, roundtables, public meetings, surveys).

CONCLUSIONS AND CRITICAL CONSIDERATIONS FOR DPE PROCESSES INVOLVING UNDERSERVED/MARGINALIZED GROUPS

The table summarizes key considerations and conclusions emerging from the literature review and expert interviews and poses questions for reflection.

Critical Considerations and Conclusions for Successful DPE Processes Involving Underserved Groups		
Set the stage for success from the outset	**Shape specific design elements to serve the groups engaged**	**Understand potential experiential outcomes for both individuals/groups**
✓ Trust is paramount – people must feel safe, secure and valued before agreeing to participate. Trust can be built in multiple ways. ✓ Participants can usefully tailor processes to reflect their needs and capacities. Identify what participants need (resources and capacities) to provide their ideas and input. ✓ DPE processes require adequate time to build trust and develop meaningful relationships. Longer-term, multi-layered and well-designed processes have the most potential to affect health system issues. ✓ There is no "one-size fits all" DPE process. Carefully consider the barriers and facilitators to participation and design appropriately from the beginning.	✓ Clarity of purpose shapes participants' expectations. Identify what value and knowledge groups will contribute to understanding an issue or solving a problem. ✓ Empathetic and well-trained facilitators are most effective. Whether representatives of convened group or third party, they should follow common practices for DPE. ✓ Recruitment of participants may require persistence, flexibility and adaptability to ensure meaningful participation of specific groups (e.g. stratified sampling, community engagement). ✓ Controlling group composition may be needed to ensure equitable DPE processes (assessing whether homogenous or heterogeneous small groups are needed; be aware of and address intersectionality). ✓ Technology is most effective as a support, rather than as a primary method.	Understand the importance of: ✓ Sense of group ownership and social capital built by involving early, in the planning phases ✓ Commitment to participation despite barriers ✓ Motivation to contribute to similar processes in the future ✓ Intrinsic value of group dialogue and socialization ✓ Sense of empowerment achieved due to feeling that government values their perspectives

(C) Questions for Reflection		
1. Do these stage setting considerations align with your experience and knowledge? 2. Do you see any critical gaps, based on your experience and knowledge? 3. What approaches have you used to incorporate underserved/marginalized participants' needs and knowledge into framing and planning of processes? 4. Have you found that longer processes have more impactful outcomes? 5. What challenges do you face in getting buy-in and resources for longer-term processes?	6. Do these design considerations align with your experience and knowledge? 7. Do you see any critical gaps, based on your experience and knowledge? 8. How important is it that facilitators are empathetic? What methods or approaches have you found to be effective in helping facilitators incorporate empathy in their practices? 9. How important is it that facilitators are well-trained? 10. Technology is assigned a support or complementary role rather than a primary role (reflecting lack of evidence from literature and experts about how to leverage technologies for DPE). To what extent do you concur with this assessment? 11. What advice and learning can you share related to group composition for effective deliberation?	12. Do these outcomes considerations align with your experience and knowledge? 13. Do you see any critical gaps, based on your experience and knowledge? 14. Have you seen unanticipated negative outcomes and if so, what were they and how might they have been averted or minimized? 15. In your experience, how important is the intrinsic value of group dialogue versus policy change?

Conclusions

- Equity must be at the forefront of DPE processes involving underserved/marginalized groups. Establishing trust with participants and tailoring DPE processes with the unique needs, capacities and contexts of participants in mind will help overcome barriers to participation.
- Application of the critical considerations identified in the Environmental Scan can be helpful to conveners of DPE processes involving underserved/marginalized groups to optimize equity, inclusion and effectiveness.
- Incorporation of suitable evaluations into DPE processes involving underserved/marginalized groups will help to gain further insight into what works, for whom, and under what conditions.

(D) Questions for Reflection

1. To what extent do you agree with the Environmental Scan's conclusions?
2. Are there additional conclusions that you would draw based on your experience and knowledge?
3. How would you see meaningful and valuable collaboration among practitioners and researchers to support, facilitate and advance knowledge on engaging underserved/marginalized groups and individuals?

PRACTICAL STEPS TO ADVANCE LEADING PRACTICES FOR ENGAGING UNDERSERVED/ MARGINALIZED GROUPS

The Environmental Scan noted that the most favourable aspects of all DPE processes studied were the interactive nature of sessions, opportunities to participate, building respect, and respecting the independence of conclusions. Positive individual-level effects included increased awareness and knowledge of the issue-at-hand, shifts in attitudes in the desired direction, willingness to participate and skills development. Group-level / community positive effects included sharing information and ideas, forming new relationships, identifying common concerns and differences, and growing potential networks of collaborators and partners.

Despite identifying these positive process and outcomes, albeit described not measured for policy change, the Environmental Scan concluded (#2 pg. ii/20) that: "The findings of this scan do not warrant conclusions about best practices for engaging underserved/marginalized groups in DPE processes due to lack of evaluations and transferability of findings." (ii) In line with this conclusion is the widely accepted view that rigorous evaluation of outcomes (process and policy) is not yet systematically incorporated as an essential component of public deliberation overall, never mind DPE involving underserved/marginalized groups. This finding points to the need for collaboration among researchers and practitioners to identify and document effective ways of engaging underserved/marginalized groups in policymaking writ large, and in particular, in the continuum of health policy, program and delivery.

(E) Questions for reflection

(i) What has been your experience regarding evaluation of DPE processes involving underserved/marginalized groups and individuals?

(ii) To what extent do you think that evaluations would validate the results of the Environmental Scan?

(iii) What do you see as barriers to and enablers of more regularized and robust evaluation of DPE processes to identify leading and best practices?

(iv) What are some practical ways of encouraging greater collaboration between community / institutional partners and researchers for successful evaluation that will support improved practice?

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