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## Building a children's health and environment research agenda in Alberta, Canada: A multistakeholder engagement process

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#### **ABSTRACT**

As new environmental exposures are continuously identified, the environmental influences on health are of growing concern. Knowledge regarding the impacts of environmental exposures is constantly evolving and is often incomplete. In this article, we describe a multi-phased, multi-stakeholder engagement initiative involving diverse stakeholders with an interest in building a children's environmental health research agenda which would link with and support local practices and policies. The intent of this initiative was to identify priority research issues, themes and questions by implementing a tested Research Planning Model that encompassed the engagement of diverse stakeholders. Here, we describe the model application, which was specifically focused on children's health and the environment. A key component of the

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model was the ongoing stakeholder engagement process. This included two stakeholder forums, during which participants identified three main research themes (social determinants of health, environmental exposures and knowledge translation) and a short list of research questions. Other key components of the model included the development of a Global Sounding Board of key stakeholders, an Advisory Board and a Scientific Panel with mandates to review and prioritise the research questions. In our case, the Advisory Board and Scientific Panel prioritised questions that focused on environmental exposures related to children's respiratory outcomes. The stakeholder engagement described here is an evolving process with frequent changes of context, sustained by the commitment and dedication of the Children's Environment and Health Research planning team and the Advisory Board. In this article, we share the engagement process, outcomes, successes, challenges and lessons learned from this ongoing experience.

#### Keywords

Stakeholder engagement; children's health; environmental health; health research

#### Introduction

Research on children's health and the environment explores diverse, evolving environmental factors and their effect on child development, growth and health, as well as potential solutions (Etzel et al. 2012). Environmental influences are of growing concern; parents rank environmental concerns high in their health priorities (Crighton et al. 2013). On a larger scale, the World Health Organization estimates that the environmental impact on the global burden of disease in children under the age of five years is 25 per cent and is responsible for 26 per cent of deaths in this age group (World Health Organization 2017). With decades of technological and industrial advances, new environmental exposures are constantly being identified. These exposures not only impact adult health outcomes but, more critically, the health outcomes of our children for generations to come (Jirtle & Skinner 2007; Manikkam et al. 2012; Perera & Herbstman 2011; Skinner & Guerrero-Bosagna 2009). Children are particularly vulnerable because of their rapid growth and development, as well as their potential longevity, dynamic developmental physiology, unique exposures, immature judgement and lack of political voice (Bearer 1995). Addressing environmental impacts related to children's health through research has been receiving health care planning attention not only because of its immediate impact on children but also due to its potential to reduce prevalence and incidence of common chronic conditions, starting in childhood but continuing into adult life, as well as potentially reducing public health spending.

The complexity of conducting research on children's health and the environment is underscored by recognition that environmental factors may be present in varying intensity and combinations at any given moment in time, and may include physical, chemical, biological and psychosocial factors (Dadvand et al. 2013; Sly & Carpenter 2012). The effect of these factors on individuals is also mediated or triggered by specific host factors, for example, genetic predisposition or windows of vulnerability relating to growth, development and nutritional status (Bearer 1995; Koller et al. 2004). It is no wonder that research questions on this topic are often complex and multifaceted, seeking solutions that are rarely simple, and answers may also be somewhat ambiguous. This complex field of research needs to study multiple types of environmental exposures (e.g. social, chemical), multiple groups of variables for each type of exposure (e.g. multiple pollutants) and multiple windows of vulnerability (e.g. in utero



development, postnatal). Additional complexity is added as environmental health research deals with risk, and uncertain or sensitive outcomes may have potential impact on different aspects of society (e.g. economic, political). Taken all together, the field of environmental health research is broad, and there is a need for diverse stakeholders to co-generate and mobilise knowledge in order to inform policies, practices and research, which could ultimately improve children's health.

#### STAKEHOLDER ENGAGEMENT

To address the many potential environmental human health issues, partnerships with various stakeholders including government (Kothari et al. 2014) help in the framing and prioritising of research questions, as well as in knowledge co-production, translation, exchange and mobilisation of results. Recognition that diverse stakeholders should be engaged in all phases of agenda-setting (Reed 2008) or decision-making processes (Linkov et al. 2011) has increased over the last two decades, and there are many examples of this. Some of these include the involvement of patients in health-related research settings (Cowan 2010) and, in the context of healthcare research, reviewing research prioritisation practices through stakeholder engagement (Guise et al. 2013). Other examples more specific to the context of environment and health include working with specific communities to ascertain areas of concern and need (Korfmacher et al. 2014), and the assessment of existing problems to identify research priorities, such as working with farmers to detect occupational and environmental health issues (Crowe, Keifer & Salazar 2008).

Another example in environment and health where issues, needs and research are priorities is the Children's Environmental Health Clinic (ChEHC) at the University of Alberta, Canada. The ChEHC began to address children's clinical environmental concerns almost two decades ago (ChEHC 2011), joining with the Pediatric Environmental Health Specialty Unit organisation (PEHSU 2017) as the only clinic of its kind in Canada. ChEHC's mission of optimising children's health contemplates working in collaboration with community partners to provide and promote clinical care and education, and to engage in research that addresses environmental concerns, in support of its vision of 'healthy generations of children thrive in optimal environments'.

Additional research that would inform policy and practice was required for ChEHC to address clinical goals and improve child health through identifying, prioritising and preventing pertinent risk factors. ChEHC recognised the importance of engaging stakeholders to mutually identify and address local concerns and prioritise issues of interest related to children's health and the environment. With the support and guidance of the University of Alberta Interdisciplinary Health Research Academy (IHRA) (Kovacs Burns 2014), an engagement process was planned with the intent of identifying topics for children's health and the environment research in Alberta that responded to society needs and supported ChEHC's vision and mission. At the same time, in Canada, the Canadian Institute for Health Research (CIHR) led an initiative to identify opportunities for research on environment and health in all of Canada with the participation of various stakeholders (CIHR 2013).

Given that there has always been a strong interest in children's health as it relates to the environment in Alberta, bringing together interested stakeholders to develop a research agenda on this topic specifically for Alberta was a new and exciting initiative for the ChEHC. In this article, we describe this ongoing engagement process with diverse stakeholders, the outcomes and lessons learned.



#### THE ENGAGEMENT PLAN

A multi-phased design utilising interdisciplinary and cross-sector stakeholder engagement was chosen for this initiative, based on a model established as part of the research framework of the IHRA, *The Research Planning Model* (Kovacs Burns 2014). Essentially, the generic version of this research framework involves utilising stakeholder engagement in the broadest sense of the definition. That is, diverse stakeholders with interest and expertise in the field or topic are meaningfully or actively involved in a series of phased planned events which guide the research agenda development:

- 1. Engaging in stakeholder forums to identify priority issues related to the topic being targeted or discussed
- 2. Forming a Global Sounding Board of all participating and interested stakeholders, from which an Advisory Board and a Scientific Panel would be established
- 3. Developing a draft research agenda
- 4. Defining research questions, and identifying resources required
- 5. Prioritising research questions and implementing the research agenda.

Although there exists are lationships between the Global Sounding Board, Advisory Board and Scientific Panel, the more direct link exists between the Advisory Board and the Scientific Panel as both will inform each other regarding identified priority issues and resulting questions to be considered for research. Decisions from these two groups will be summarized and shared back with the stakeholders in the Global Sounding Board to not only inform them, but to also seek their advice or confirmation regarding decisions made (e.g. if research questions are of practical value to knowledge users), and/or to recruit research team members for the identified research questions and proposed projects, as needed. Table 1 summarizes the role, responsibilities and reporting processes for the Global Sounding Board, Advisory Board and Scientific Panel. These aspects evolve as the research agenda matures or deviates over time.

Table 1 Features of the Global Sounding Board, Advisory Board and Scientific Panel

	Global Sounding Board (GSB)	Advisory Board	Scientific Panel
Members	All diverse & interested stakeholders in Alberta chidren's health and environment; coming from different settings or practices, and across sectors (health, social, education, etc)	Core group of key experts self-selected from GSB and willing to invest time in advising on topics, issues and research questions relevant to stakeholders identified in GSB	Researchers, scholars and knowledge users with capacity to explore research questions in proposal or research plan



Table 1 continued

	Global Sounding Board (GSB)	Advisory Board	Scientific Panel
Roles/ Responsibilities	Bring interest areas; identify issues, research topics and priority research questions of value in various settings (healthcare, schools, home, other)	Help steer the next steps with prioritising identified research areas and/or research questions; identifying and developing interdisciplinary research teams; and identifying funding sources and other supports for the projects or components of the research programs	Approve research questions and studies to be conducted; members may be part of research teams writing full research proposals and conducting research
Reporting/ Informing & Accountability	Reporting of forum activities to stakeholders; provide summary to Advisory and Scientific panel.	Report to Scientific Panel and to inform stakeholders in GSB.	Inform Advisory Board; report to be shared with stakeholders in GSB.

The phased process and outcomes plan outlined for the Research Planning Model differs from standard research practices in various ways. A standard process for most research teams is the identification or confirmation of priority research questions based on the literature and previous studies confirming a timely or trendy topic of interest to targeted stakeholders. The research teams may invite other select co-investigators (some may be researchers, decision makers and knowledge users) and collaborators to contribute to or support the research questions and proposed plan, often with the intent of appeasing funding agency requirements. It would be very rare for outside researchers or stakeholders to be offered an opportunity to volunteer to join the research team. Input or advice may or may not be invited from collaborators or other stakeholders outside the select or core research team group to help design the research questions or proposed plan. Thus, the Research Planning Model provided an invaluable opportunity to engage various stakeholders and build on their perspectives and ideas.

#### Chehc's Engagement Process and Outcomes

ChEHC expressed an interest in working with the IHRA to develop an Alberta-based research agenda that responded to local needs. Planning began in 2012, at which time the existing IHRA interdisciplinary research model was adapted and identified as *Children's Health and the Environment: Strategic Process*. This model has five phases, as shown in Figure 1.



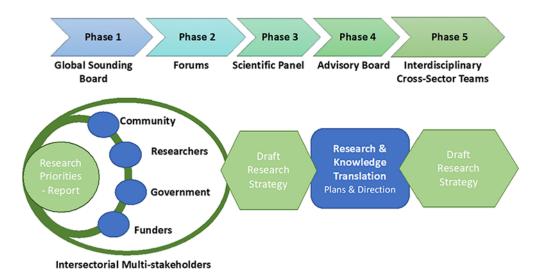


Figure 1 Children's Health and the Environment: Strategic Process (Based on the IHRA Research Planning Model).

#### 'Pre-phase' 1: Strategic Planning

The planning team composed of ChEHC leaders or knowledge users, researchers and members of health organisations jointly developed a strategic plan outlining a process for the five phases of the framework in Figure 1, including anticipated outcomes, timelines, and budgets and resources needed for forums or planning events.

#### Phase 1: Recruiting for and Establishing the Global Sounding Board

Before the Global Sounding Board could be established, key stakeholders with invested interest in the health of Alberta's children and the link with environmental factors had to be identified, and as many of these stakeholders as possible brought together for the engaged discussion on what priority issues and research questions exist in children's health and the environment. The recruitment of stakeholders for this initiative was based on their diversity of knowledge, experiences and expertise in various practices (i.e. health care, schools, homes and other settings) and research applicable to children's health and the environment. More specifically, stakeholders who were of different disciplines or sectors (i.e. health, education, environmental, social, economic and community non-government organisations, government, industry, etc.) were sought for their unique perspectives and approaches to exploring relevant issues and research questions. Invitations were sent out to 125 key stakeholders to participate in the first planned forum. Although one primary outcome of this forum was the establishment of the Global Sounding Board, it was also intended to begin the actual discussion process for research agenda setting, both needed in order that the following four phases of the strategic plan could be implemented.

#### Phase 2: Stakeholder Engagement in Brainstorming and/or Consensus Forums

Aside from engaging stakeholders in discussion and establishing the Global Sounding Board previously described, the forums served as a platform where stakeholders could jointly identify priority issues, considerations/factors of influence or expectations (e.g. health concerns, government priorities), research questions and, additionally, acceptable practices or processes



for dissemination, knowledge translation and implementation of the research findings. Moreover, the forums provided an opportunity for stakeholders with common interests to network, share experiences of research conducted or in progress, and brainstorm on what was or should be priority research on children's health and the environment in Alberta. World Café style forums provided an approach which inspired focused discussion and gave everyone the opportunity to provide their perspectives (The World Café Community Foundation 2016).

Two forums took place: one in 2012 and another in 2013. Invitees to these stakeholders' meetings comprised 123 and 140 interested individuals, respectively. Stakeholders represented Academia, the Provincial Government, Non-Government organisation, the Federal Government, Granting Agencies, the Local Government, and Industry. Table 2 provides the percentage of participants from the different sectors for Forums 1 and 2.

Table 2 The cross-sector participants of Forums 1 and 2

Sectors Invited	Forum 1 % participants by sectors (N=35 participants)	Forum 2 % participants by sectors (N=33 participants)
Academia	40	53
Provincial Government	14	16
Non-government organisation	20	13
Federal Government	12	12
Granting Agencies	11	6
Local Government	0	0
Industry	3	0

Participants were divided into small groups and were provided several guiding questions to discuss (Table 3). Questions for Forum 1 were intended to (1) identify, inform and clarify what the critical or priority areas of research were in children's health and environmental issues in the province; and (2) invite interested Global Sounding Board members to become members of the Advisory Board. Results from this forum were used to set the stage for Forum 2 (March 2013) to which 140 stakeholders were invited, regardless of whether they had attended the first forum or not, or agreed to be on the Global Sounding Board or not. Questions for the second forum were generated based on the outcomes and themes from Forum 1. Table 3 also provides the guiding questions for Forum 2.

Anticipated outcomes to questions for both forums included lists of research areas and fundable, feasible projects; research questions that would be relevant to policy and practice; and a list of candidates interested in serving on an Advisory Board. The Advisory Board as per Table 1 would help steer the next steps: prioritising identified research areas and/or research questions; identifying and developing interdisciplinary research teams; and identifying funding sources and other supports for the projects or components of the research programs. A summary of each Forum is presented as follows:



Table 3 Guiding questions for discussion

Forum 1 Questions	Forum 2 Questions
1. What do you see as critical or priority areas for research in child health and the environment from which goals, policies and relevant health research questions could be addressed?  2. What specific research projects, questions and/or funding sources are identifiable in these critical or priority research areas?  3. Would you be interested in joining an advisory board to assist with follow-up in identifying strategies for the identified critical or priority research areas and help steer them to completion?	1. From the perspective of a child's health in Alberta, what important questions need to be researched? In your response, please refer to the three identified themes (unique to Alberta): a) knowledge translation (dissemination education) b) healthy child determinants c) environmental exposures

#### Forum 1

The **1st Stakeholders' Forum** (November 2012) was attended by 35 of 46 registered participants (Table 2).

Forum 1 participants identified the following themes representing critical areas of interest:

- **Knowledge translation:** improve awareness and understanding of health issues around environmental exposures to influence policy.
- Healthy environments for children: definition of 'healthy child'; wellness approach, healthy environments (including nutrition, toxin free, active life, health education), prevention, and targeting vulnerable populations.
- Environmental exposures:
- Air quality (outdoor/indoor), and models to link exposure, place and health outcomes
- Food: nutrition (healthy choices), food safety (additives, genetically modified foods, toxin free), and prenatal nutrition.

Participants agreed that future research would work around concerns unique to Alberta. They also identified the need to create specific research questions related to those topics during a second forum.

#### Forum 2

Thirty-three stakeholders participated in the **2nd Stakeholders' Forum** (March 2013). Some were returning participants from Forum 1 and some were new (Table 2). On this occasion, participants identified research questions according to the three themes that emerged from Forum 1. The identified questions developed during the forum are provided in Table 4.



#### Table 4 Research questions identified by participants – Forum 2

#### Identified Research Questions

#### **Knowledge Translation**

- 1. Does public policy support the research activities and evidence obtained?
- 2. What are the barriers to public perceptions and uptake of knowledge translation research?
- 3. What strategies are most effective in knowledge translation for different levels of messages and dissemination, i.e. children, families, communities, corporations and state?

#### Determinants of Child Health

- 1. Can we build an inventory of existing childhood exposure data and link it to existing social determinants of health data, and then do a secondary analysis to determine the overlap between the two?
- 2. What impact do social determinants of health and environmental exposures, in the broad sense, during pregnancy, have on children's long-term health?
- 3. What is the role of environment contaminants in childhood obesity?
- 4. What determinants of health in Alberta contribute to respiratory illness among children, positively or negatively?
- 5. How can the outcomes of children in care be improved through the modification of environmental exposures?

#### Environmental Exposures

- 1. How does technology affect child health?
- 2. Does child health change as the environment changes: physical, social, economic, biological?
- 3. A targeted study comparing children's health and exposures in Fort McMurray or other industry-related community versus the rest of the province (must include accountability for social determinants of health including income, education, social supports).
- 4. Perinatal, fetal environment, and effect on long-term individual and population health.
- 5. What makes children vulnerable to adverse effects of exposures in Alberta? Integrate levels: cellular, clinical, individual, group, population, provincial.

### Phases 3 and 4: Confirming the Global sounding Board and Identifying and Establishing the Advisory Board and Scientific Panel

These two phases involved the identification of stakeholders who self-volunteered at either or both forums or were personally invited to join one or two Boards (Global and/or Advisory) or the Scientific Panel.

The Advisory Board and the Scientific Panel, as set out in Table 1, are a subset of the Global Sounding Board and are actively involved in following through with the research agenda activities. The Global Sounding Board members who could not dedicate time to be part of the Advisory Board or Scientific Panel were kept informed by email and engaged as needed or as long as they continued to express interest in the initiative.

An Advisory Board and Scientific Panel were formed and started operating three months after the 2<sup>nd</sup> Forum (June 2013). Terms of Reference were established for the Board and Panel, including criteria for roles and responsibilities regarding the development of the children's health and the environment research agenda.



The Advisory Board consisted of diverse stakeholders and had a proposed mandate to provide advice/guidance to the ChEHC through all stages of the development of the research agenda through regular meetings. The Advisory Board was comprised of 15 members representing Academia (including student representatives) (4), the Provincial Government (4), Non-Government organisation (4), the Federal Government (1), Granting Agencies (2). The director of the Children's Environmental Health Clinic operated as the liaison between the clinic, the Advisory Board and the Core Scientific Panel.

The role of the Scientific Panel, as outlined in Table 1, was to provide scientific expertise, refine priority research questions, and support interdisciplinary research teams formed through efforts of the Advisory Board in their development and funding applications for children's health and the environment research projects. The Scientific Panel was formed by six researchers representing toxicology, knowledge translation, computing sciences, environmental health and clinical epidemiology.

#### Phase 5: Refining Interdisciplinary Research Questions for Research Teams and Funding

The Advisory Board started the process of formalising and documenting a governance structure and interacted with the newly formed Scientific Panel. The Board and the Panel cooperated to refine the questions into more precise research questions for fundable projects. The Panel discussed the forum's recommendations and suggested a list of potential workable research questions (Table 5).

Table 5 Questions identified by the Scientific Panel

#### Refined and revised research questions

Does child health change as the environment changes: physical, social, economic, biological?

- What impact do social determinants of health and environmental exposure, in the broad sense, during pregnancy, have on children's long-term health?
- What is the role of environment contaminants in child obesity?
- What determinants of health (including the environment) in Alberta, contribute to respiratory illness among children (positively or negatively)?

#### A targeted study:

 Compare children's health and exposures in Fort McMurray or other industry-related community versus rest of the province (must include accountability for social determinants of health including income, education, social supports).

#### Methodological aspects:

- Develop robust case-control or cohort studies, and/or build an inventory
  of existing childhood exposure and health data and link it to existing social
  determinants of health data.
- Incorporate the use of biomarkers of exposure and effect.
- Identify areas of opportunity around the incorporation of new technology initiatives or changes in current practices that could affect the levels of pollution.
- Always incorporate knowledge translation.



The Advisory Board, in conjunction with ChEHC representatives, considered the questions posed by the Scientific Panel and prioritised initial areas of research guided by current provincial data on the burden of children's disease. They chose to focus on investigating exposures and exploring related morbidities in Alberta that required research. The Board identified several illnesses of interest. Respiratory illness was identified as a critical area of focus, which aligned with the volume of medical referrals of children to the ChEHC. Other optional interdisciplinary health research projects included comparing air quality and respiratory morbidity, and the social determinants of health (Rodriguez-Villamizar et al. 2016). Concurrent plans incorporated the testing of specific biomarkers to further understand the effects of new exposures.

As with any research cycle, funding challenges existed for the proposed research projects. However, interest from governmental agencies in the suggested projects supported this research area as a promising avenue to continue in the province. Additionally, some funding was received to support the renewal of engagement with stakeholders from the Global Sounding Board, to continue discussion around the interest and feasibility of pursuing other research questions and projects.

The Advisory Board also continued its engagement process through ongoing meetings. It holds regular meetings every three months along with protracted discussion in other areas of work conducted by the ChEHC. This has resulted in an extension of the Advisory Board mandate beyond research, including advice on clinical activities, outreach to the community and advocacy.

The research agenda development and application of research projects remains an ongoing process for the ChEHC and is starting to provide research results (Rodriguez-Villamizar et al. 2017).

#### DISCUSSION

The multi-phased engagement process, as part of the Children's Health and the Environment Planning Model/Strategic Process, described above, involved ongoing investment and learning. It was utilised in times of growing concern with regards to children's health and the environment and brought stakeholders together to discuss and plan future research needs in this context. Participants joined the forums and the Global Sounding and Advisory Boards with the realisation that together they could explore the many challenges children face as a result of their environments and look for possible solutions through partnerships. Additionally, stakeholders indicated that they continued to engage in the process not only because of professional affiliations but also because of personal interest and concern for their and others' children; thus, 'the discussion was not about them but us' and the process was considered as 'A good process to represent concerns'.

Through this process, multi-stakeholders' expertise and experience contributed to identification of priority themes, research questions and specific projects relevant to children's health and the environment in Alberta. The research questions developed by this initiative responded to children's health and global environmental issues, but focused on local issues. Research projects were collectively developed by stakeholders.

Additional specific outcomes and achievements of this stakeholder engagement process were also identified (Figure 2). First, the process raised awareness of participants in the multiple aspects of and perspectives on children's health and the environment and provided an opportunity for participants to learn about research in the field and its complexity. The process



was considered an 'educational experience'. Participants learned from the conversations, especially 'how much we don't know', and recognised the importance of future research.

Second, the community of stakeholders interested in children's health and the environment research continued connecting through the Advisory Board. The creation of an Advisory Board was viewed as unique by the stakeholders, as many were knowledge users who could support many of the research projects and application of research findings in the future. It provided stakeholders a means to continue evolving their work and interest in children's health, to take on an advisory role in clinical advocacy and educational issues for ChEHC, develop different circles of engagement, and continue to search for research funding and support. Participating in the Advisory Board also offered a learning experience because of the different perspectives and evidence discussed. Members of the Advisory Board enjoy meeting, networking, and taking part in conversations, ongoing discussions and the process of decision making towards future research projects. This Board continues to be voluntarily active and sustainable through ChEHC and research team efforts. Although, inevitably, there has been member turnover on the Advisory Board, it has been able to maintain regular meetings through a strong core of members and move forward with the initial plan, adapt to changing contexts and bring new ideas. It has evolved through common interest, enthusiasm and commitment of the Board members to contribute to children's health.

Third, a transformational change has occurred towards meaningful engagement, moving from individual research to stakeholder-driven research, and from researcher-driven to society-driven research. Essentially, the process has extended researcher and knowledge users' mandates to include joint engagement in supporting societal needs. Input from the forum process and discussions (e.g. on the social determinants of health) have become further embedded into ChEHC's work. This was a learning process that shaped thinking and practice.

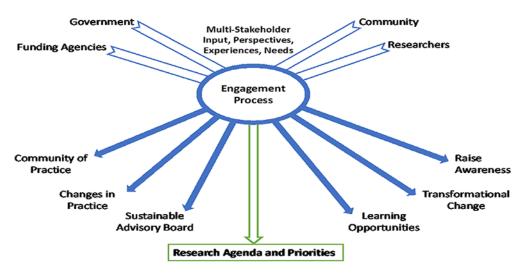


Figure 2 The engagement process outcomes.

The engagement process also presented some challenges. For starters, the process was planned to be inclusive so that there would be an opportunity for different perspectives and voices to take part in building the research agenda. However, as inclusive as organisers tried to be through their invitation process and information sharing, participation of some of the relevant sector stakeholders (e.g. Indigenous communities and industry) was small or nil in the active parts of the process, such as participation in the forums and committees.



Another challenge encountered was around participant or stakeholder expectations and outcomes. Forum participants had different expectations than the organisers. While the organisers saw participants as potential knowledge users, participants did not necessarily see themselves in that way. Their reasons for being engaged were mostly their interest in the topic, a learning opportunity, and maybe to become part of a group that might drive change and impact children's health. Furthermore, the concepts and some of the language used were new to some of the participants and it took time to develop a common language and to clarify the objectives of the discussions. To better inform stakeholders of the approach to the engagement process in future engagements, it would be worthwhile conducting a readiness assessment before the engagement process in order to align the forum objectives with the level of participant familiarity with context, i.e. use Readiness Assessment Tools, which are now available for this purpose (Barwick 2011; Tamarack-Institute 2017).

Of all the challenges, the main one encountered was sustainability of the planned engagement process. The initial process had institutional administrative and financial support for stakeholder engagement through IHRA. However, as this support could not be continued indefinitely, the ongoing engagement of stakeholders on the Global Sounding Board was difficult to sustain in the long term. This resulted in delays in moving the process forward towards tangible outcomes until the Advisory Board and Scientific Panels assumed more of the role of the Global Sounding Board. We acknowledge that such a process is time consuming (planning, organising, sustaining) and a long time is required to accomplish all phases. Adequate resources should be secured for long-term engagement with developed research projects, as well as for the dedication required to fulfil all objectives.

Despite these challenges, participants acknowledged that the forum discussions were a 'worthwhile exercise'. Moreover, this ongoing process builds on facilitators such as the existing dedication and commitment of the team and Advisory Board and the interest, flexibility, patience and adaptability of stakeholders as the process evolves over time and contexts change.

The interest in many topics related to children's health and the environment remains and is still valid. It is an indication of how important these topics and related issues are to current societal conversations and emphasises the need for future research in this field. It should also be acknowledged that, aside from the topics identified as critical priorities by the Advisory Board, others remain to be pursued.

#### CONCLUSIONS

The experience described here covers a six-year period and provides a description of an ongoing long-term process and the outcomes of an engagement process undertaken for the purpose of building and supporting a research agenda for children's health and the environment.

Many benefits from the engagement process were implemented. The process was also useful for making informed decisions on our future research direction based on valuable multistakeholder input, views and needs. These research priorities were co-developed to identify and prioritise local children's health and environmental concerns. Additionally, the process resulted in new relationships and collaborations and was a learning experience for all stakeholders regarding both the context of children's health and the environment and the engagement process. Experience was gained in connecting and engaging researchers, practitioners and children's environmental health stakeholders. Furthermore, as described above, there were some outcomes resulting from this engagement process which were not originally considered



when we started this journey. All this validates the effort and dedication invested since this engagement process began. We also acknowledge the challenges encountered with the engagement process and its sustainment.

This is an ongoing process which is dynamic and iterative, and although it was planned for a specific timeline and with expectations of outcomes, we realise that reality can dictate somewhat different outcomes which require flexibility, patience and commitment. The dedication and perseverance of the stakeholders, participants and organising team keep it going, with the intent of continuing the pursuit of relevant research.

#### Acknowledgements

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#### References

Barwick, M 2011, 'Checklist to Assess Organizational Readiness (CARI) for EIP Implementation', viewed 5 April 2018, www.effectiveservices.org/downloads/Checklist\_to\_Assess\_Organisational\_ Readiness\_for\_Implementation.pdf.

Bearer, C 1995, 'How are children different from adults?', Environmental Health Perspectives, vol. 103, suppl. 6, pp.7-12. https://doi.org/10.1289/ehp.95103s67

Canadian Institutes of Health Research (CIHR) 2013, 'Environments and health national forum summary', viewed 5 April 2018, www.cihr-irsc.gc.ca/e/47672.html.

ChEHC, 'Children's Environmental Health Clinic' 2011, University of Alberta, viewed 5 April 2018, https://sites.google.com/ualberta.ca/chehc/home.

Cowan, K 2010, 'The James Lind Alliance: Tackling treatment uncertainties together', Journal of Ambulatory Care Management, vol. 33, no. 3, pp.1-6.

Crighton, E, Brown, C, Baxter, J, Lemyre, L, Masuda, J & Ursitti, F 2013, 'Perceptions and experiences of environmental health risks among new mothers: A qualitative study in Ontario, Canada', Health, Risk & Society, vol. 15, no. 4, pp. 295-312. https://doi.org/10.1080/13698575.2013.796345

Crowe, J, Keifer, M & Salazar, M 2008, 'Striving to provide opportunities for farm worker community participation in research', Journal of Agricultural Safety and Health, vol. 14, no. 2, pp. 205-19. https://doi. org/10.13031/2013.24351

Dadvand, P, Gouveia, N, Gehring, U, Lepeule, J, Slama, R, Bonzini, M et al. 2013, 'Maternal exposure to particulate air pollution and term birth weight: A multi-country evaluation of effect and heterogeneity', Environmental Health Perspectives, vol. 121, no. 3, pp. 367-73. https://doi.org/10.1289/ ehp.1205575

Etzel, R, Balk, S & American Academy of Pediatrics 2012, Pediatric environmental health, 3rd edn, American Academy of Pediatrics, Washington, DC.

Guise, J, O'Haire, C, McPheeters, M, Most, C, LaBrant, L, Lee, K, Barth Cottrell, E & Graham, E 2013, 'A practice-based tool for engaging stakeholders in future research: A synthesis of current practices', Journal of Clinical Epidemiology, vol. 66, no. 6, pp. 666-74. https://doi.org/10.1016/j. jclinepi.2012.12.010



Jirtle, R & Skinner, M 2007, 'Environmental epigenomics and disease susceptibility', Nature Reviews Genetics, vol. 8, no. 4, pp. 253-62. https://doi.org/10.1038/nrg2045

Koller, K, Brown, T, Spurgeon, A & Levy L 2004, 'Recent developments in low-level lead exposure and intellectual impairment in childdren', Environmental Health Perspectives, vol. 112, no. 9, pp. 987-94. https://doi.org/10.1289/ehp.6941

Korfmacher, K, Elam, S, Gray, K, Haynes, E & Hughes, M 2014, 'Unconventional natural gas development and public health: Toward a community-informed research agenda', Reviews on Environmental Health, vol. 29, no. 4, pp. 293-306. https://doi.org/10.1515/reveh-2014-0049

Kothari, A, Regan, S, Gore, D, Valaitis, R, Garcia, J, Manson, H & O'Mara, L 2014, 'Using an integrated knowledge translation approach to build a public health research agenda', Health Research Policy and Systems, vol. 12, no. 1, pp. 1-15. https://doi.org/10.1186/1478-4505-12-6

Kovacs Burns, K 2014, 'Interdisciplinary Health Research Framework: Meaningful engagement of stakeholders in the research plan', University of Alberta.

Linkov, I, Bates, M, Canis, L, Seager, T & Keisler, J 2011, 'A decision-directed approach for prioritizing research into the impact of nanomaterials on the environment and human health', Nature Nanotechnology, vol. 6, no. 12, pp. 784–87. https://doi.org/10.1038/nnano.2011.163

Manikkam, M, Guerrero-Bosagna, C, Tracey, R, Haque, M & Skinner, M 2012, 'Transgenerational actions of environmental compounds on reproductive disease and identification of epigenetic biomarkers of ancestral exposures', PLoS ONE, vol. 7, no. 2, pp. 1-12. https://doi.org/10.1371/journal.pone.0031901

Pediatric Environmental Health Specialty Unit (PEHSU) 2017, Home - Pediatric Environmental Health Specialty Units, viewed 5 April 2018, www.pehsu.net.

Perera, F & Herbstman, J 2011, 'Prenatal environmental exposures, epigenetics, and disease', Reproductive Toxicology, vol. 31, no. 3, pp. 363-73. https://doi.org/10.1016/j.reprotox.2010.12.055

Reed, M 2008, 'Stakeholder participation for environmental management: A literature review', Biological Conservation, vol. 141, no. 10, pp. 2417–31. https://doi.org/10.1016/j.biocon.2008.07.014

Rodriguez-Villamizar, L, Berney, C, Villa-Roel, C, Ospina, M, Osornio-Vargas, A & Rowe, B 2016, 'The role of socioeconomic position as an effect-modifier of the association between outdoor air pollution and children's asthma exacerbations: An equity-focused systematic review', Reviews on Environmental Health, vol. 31, no. 3, pp. 297-309. https://doi.org/10.1515/reveh-2016-0005

Rodriguez-Villamizar, L, Rosychuk, R, Osornio-Vargas, A, Villeneuve, P & Rowe, B 2018, 'Proximity to two main sources of industrial outdoor air pollution and emergency department visits for childhood asthma in Edmonton, Canada', Canadian Journal of Public Health, vol. 108, nos 5-6, pp. e523-e529. https://doi.org/10.17269/cjph.108.6136

Skinner, M & Guerrero-Bosagna, C 2009, 'Environmental signals and transgenerational epigenetics', Epigenomics, vol. 1, no. 1, pp.111-17. https://doi.org/10.2217/epi.09.11

Sly, J & Carpenter, D 2012, 'Special vulnerability of children to environmental exposures', Reviews on Environmental Health, vol. 27, no. 4, pp. 151-57. https://doi.org/10.1515/reveh-2012-0024

Tamarack-Institute 2017, 'TOOL - Assessing Readiness', Tamarac Institute, viewed 5 April 2018, https://cdn2.hubspot.net/hubfs/316071/Resources/Tools/Assessing Readiness Tool April 2017.pdf.

The World Café Community Foundation 2016, 'World Café Method', viewed 5 April 2018, www. theworldcafe.com/key-concepts-resources/world-cafe-method/.



World Health Organization 2017, 'Don't pollute my future! The impact of the environment on children's health', viewed 5 April 2018, <a href="http://apps.who.int/iris/bitstream/10665/254678/1/WHO-FWC-IHE-17.01-eng.pdf">http://apps.who.int/iris/bitstream/10665/254678/1/WHO-FWC-IHE-17.01-eng.pdf</a>.