PEHE – MIREC Consultation

Summary Report

March 21, 2022

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Health Canada contract # 4500435191

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Introduction

The **Prenatal Environmental Health Education (PEHE) Collaboration** (pehe-esep.ca) is an interdisciplinary CIHR-funded research consortia, based at the University of Ottawa, that brings together diverse partners to advance prenatal environmental health in Canada through research, practice and policy advocacy, with an emphasis on health equity (see Annex 1).

In February-March 2022, the PEHE Collaboration was contracted by Health Canada to convene a two-stage consultative process to assist the **Maternal Infant Research on Environmental Chemicals (MIREC)** research team in exploring strategies to successfully engage, recruit and retain prospective parents from marginalized communities in a possible future MIREC biomonitoring cohort.

As a first phase, a PEHE-MIREC Ad Hoc Group was formed to help set the parameters of the consultative process and to provide input on a scoping review of the literature (see below). The Ad Hoc Group was comprised of ten members of the PEHE Collaboration and several members of the MIREC research team. The Ad Hoc Group met by Zoom conference on February 24, 2022. A summary of the discussion is attached as Annex 2.

As a second phase, a joint meeting of the PEHE Collaboration and the MIREC research team was held on March 8, 2022 to share relevant experiences and offer guidance on recruitment and retention of prospective parents from marginalized communities in a potential MIREC cohort study. The feedback and recommendations from this meeting are summarized below.

The list of participants involved in the PEHE-MIREC Consultation is attached as Annex 3.

Parallel to the PEHE-MIREC Consultation process, Dr. Ghazal Fazli, University of Toronto, led a scoping review of the pregnancy cohort literature to extract relevant lessons learned on the inclusion of vulnerable/marginalized populations. Lead researchers with the PEHE Collaboration, Drs. Crighton and Phipps, supported the scoping review process by helping to define the scoping review protocol, offering iterative feedback, convening the stakeholder review process described above, and reviewing the final report. Highlights of the scoping review are included as Annex 4; a full report is also available.

Key observations and recommendations

A number of key observations and recommendations emerged from the multi-phased PEHE-MIREC consultative process. These are highlighted here and further elaborated in the summary of the March 8th PEHE-MIREC meeting (section 3 below) and in the notes from the February 24th Ad Hoc Group meeting (Annex 2).

Considerations on the scope and design of a future MIREC study

- There was strong support for the proactive recruitment and retention of prospective parents from marginalized communities in future biomonitoring cohort research in Canada. This would fill existing knowledge gaps and advance health equity over the life course, given the heightened vulnerabilities to environmental hazards during the preconception/prenatal stages.
- Inclusion of prospective fathers, in addition to prospective mothers, would likewise fill important knowledge gaps and position Canada as a world leader in preconception/prenatal environmental health research.

Defining ‘vulnerable’ in biomonitoring pregnancy cohort research on environmental chemicals

- The social determinants of health provide a useful framework for defining what can make prospective parents and their future offspring especially vulnerable to health effects of environmental chemical/pollutant exposures.

- It is useful and appropriate to start with a contextual or 'grassroots' perspective in considering the scope of 'vulnerable' in environmental health research. Rather than applying the label of 'vulnerable' as a static characterization, the focus should be on the contextually-driven and dynamic factors that lead to and/or exacerbate disproportionate toxicant exposures and/or heightened susceptibility to harm for individuals, groups and communities.
- Marginalizing circumstances that lead to environmental health vulnerability are intersecting and not static. Drivers of health inequity (e.g., racialization and gender discrimination) can have more-than-additive effects, and life circumstances (e.g., housing or food insecurity, precarious employment) can change over time.

Strategies for engaging with, recruiting, and retaining marginalized communities in biomonitoring cohort research

- Trust is paramount. There are myriad reasons, historic and ongoing, for marginalized/oppressed communities to be wary and mistrustful of taking part in biomonitoring research.
- Working with a local partner (e.g., community health centre, social services agency/organization) as the key intermediary between the research team and the research participants and their broader community is likely to be the most effective approach. These relationships need to be maintained over time.
- Engaging peer workers is likely to be key to recruitment and retention; this is especially true when seeking to engage participants in communities with distinct language(s) and cultural preferences/traditions.
- Design features used in the original MIREC research (e.g., use of a hospital as the focal point for sample collection) may need to be rethought in designing a study that prioritizes involvement of participants in marginalizing circumstances. For example, mobile sample collection may be instrumental in reducing barriers to participation/retention.
- The scoping review yielded useful information, including evidence of current gaps in attention to and strategies for engaging meaningfully with marginalized/underserved communities in pregnancy cohort research. Further insights into practical, respectful and trust-building strategies for engaging with marginalized communities in health research may be usefully sought in other forms of research (e.g., community-based participatory research, non-health social sciences research) and in the grey literature.

Summary of PEHE-MIREC Consultation Meeting

Overview and objectives

On March 8, 2022, a two-hour meeting of the full PEHE Collaboration and the MIREC research team was convened via Zoom video conference. The objectives of the meeting were to:

- Discuss and offer feedback on the proposed priorities and scope of a next potential phase of MIREC research
- Review preliminary findings from a scoping review on recruitment/retention of pregnant women from marginalized communities into birth cohort studies
- Share experiences and perspectives on community-based strategies to engage marginalized communities

Introductory remarks

Erica Phipps, PEHE Collaboration co-lead, opened the meeting and welcomed participants, who then introduced themselves (see list of participants, Annex 3). Cheryl Khoury, head of Health Canada's population studies division, provided a brief overview of purpose of the PEHE-MIREC consultation, which is to leverage the strong network of PEHE partners in sharing experiences and exploring additional partnerships that will make the MIREC research more accessible and relevant to more women and families in Canada. Eric Crighton, Principal Investigator for the PEHE research, provided an update on the PEHE Collaboration, noting its inception at the national PEHE Forum held at the University of Ottawa in 2014, and its ongoing evolution into an interdisciplinary and intersectoral space for advancing prenatal environmental health and health equity through improvements in knowledge, practice and policy. The PEHE research is being conducted in three phases: a 2021 national survey of women of reproductive age; a forthcoming survey of prenatal care providers, and a third qualitative research phase involving focus groups with prospective

parents and service providers, respectively, that will be an opportunity for synergy with the proposed MIREC feasibility study described below.

Dr. Jillian Ashley-Martin, MIREC Co-Principal Investigator, provided an overview of the MIREC research program, which began in 2008 and has included 2000 women and 10 study sites to date, with the goal to examine associations between contaminant exposure and health effects in pregnant women and their children. Subsequent phases of MIREC have explored associations between prenatal environmental chemical exposures and health effects during infancy, childhood and adolescence among the offspring of MIREC study participants. The MIREC program is currently considering future research directions, including how to ensure the research reflects contemporary exposure scenarios, includes paternal exposures, and fills knowledge gaps regarding levels of environmental chemical exposures in marginalized populations. The socio-demographic composition of MIREC has been largely women of higher socioeconomic status. Jillian outlined a proposed feasibility study to explore barriers to recruitment and retention of participants from marginalized populations in biomonitoring studies, drawing on findings from the scoping review of the literature. To achieve this, MIREC is working with PEHE to convene focus groups with prospective parents and local service providers, respectively, in different communities to better understand the types of barriers, opportunities and strategies that would need to be considered in the design of a future MIREC study with prospective parents and families living in marginalizing circumstances.

Scoping review

Ghazal Fazli provided a fulsome overview of the scoping review of the pregnancy cohort literature, including the parameters of the review protocol and the preliminary results (see PowerPoint presentation, Annex 4). In terms of defining vulnerability for the purposes of environmental contaminant biomonitoring research, she noted key concepts from the literature, including that vulnerability is more about context than a fixed label or a characterization of a population. There are layers of vulnerability, comprised of the factors, contexts and processes that lead to marginalization. Mapping vulnerability onto a socio-ecological model could help policy makers to address drivers of disproportionate exposures and risks.

Most of the studies included in the scoping review are from the United States and Canada; about a third reported recruitment of women of different ethnic origin, Indigenous identity, immigrant status or low-income. The presentation highlighted the contextual factors that can constrain or facilitate participation in biomonitoring cohort research among prospective parents who live in marginalizing circumstances. For example, at the individual level, fear of being reported (e.g., for substance use) and mistrust in authorities and/or science can be potent barriers to participation and recruitment. At the institutional level, factors such as disparate access to health services and lack of culturally relevant information can act as barriers to engagement of women/parents who are socio-economically marginalized. Across the studies included in the review, there were important gaps in terms of the attention to, and conceptualization of, recruitment/retention strategies for engaging marginalized communities in biomonitoring research. For example, few studies reported on indicators of vulnerability, or recruitment and engagement of participants from vulnerable circumstances. As well, most papers focused on recruitment and not retention of cohort participants.

Although the focus of the scoping review was on studies with pregnant women, Ghazal confirmed that the scope could be widened to include additional studies (e.g., those involving men). There were some studies in which families were included, but none of the identified studies specifically recruited/engaged men. This is a gap. It was also noted that other types of studies, beyond pregnancy cohort studies, could yield important learnings on the recruitment/retention of marginalized populations. The exclusion of French-language studies in the scoping review was also noted as a limitation.

Following the scoping review presentation, participants were invited to consider whether the preliminary themes from the scoping review align with their experiences in research and practice. They were also asked to offer thoughts on what stood out for them and what may be missing. The discussions covered a range of topics, including potential barriers to participation among people living in marginalizing circumstances, recruitment and retention strategies, the importance of local partner organizations and engagement of peer workers, and possible design considerations for future MIREC cohorts.

Engaging marginalized/vulnerable populations in MIREC research: considerations and barriers

There was strong support for the proposed focus on prioritizing engagement and participation of prospective parents from marginalized communities in a future MIREC cohort. A researcher involved in the first MIREC study noted the need to actively recruit representative samples of the population, which will entail getting various groups, including Indigenous communities, involved from the beginning. Jillian noted that neither the feasibility study nor the next anticipated MIREC cohort will have the capacity or capability to specifically recruit Indigenous participants, but that the studies would certainly never restrict participation based on identity or status. Another participant noted the importance of including teenage mothers as well as immigrant women. Jillian noted that in the first MIREC study women under 18 were excluded, but that can be reconsidered for future work, if the age limit is excluding a potentially vulnerable group.

Multiple impediments and barriers to participation were noted during the discussion about recruitment/retention in marginalized communities. One participant noted that trauma or shame – for example, related to occupational exposure, addiction, or disease – may inhibit participation in studies. Another noted that people with drug addiction problems may be particularly wary of getting involved in a biomonitoring study since medical professionals are obligated to report if the fetus is being harmed. Vulnerable people, including those in rural areas, usually have unstable housing and social networks, and may be reliant on food banks. People in marginalizing and low-income circumstances might not have cell phones that are consistently in service, which can make finding people over a longitudinal study very challenging. Amish people, as one example in a rural context, have large families but can be difficult to reach, pregnant women may not have access to prenatal care, and in some cases are exposed to stressors such as domestic violence and lack of water.

Strategies for recruitment and retention or marginalized/vulnerable participants

With regard to strategies for recruitment and retention, cultural sensitivity and building trust and relationships with participants are incredibly important. Local service providers must be engaged – they are champions with their clients and can help make connections between community members and the research team. Incentives are also important. Providing food, such as meals offered at recruitment sessions, can act as an incentive and may be culturally important. Monetary compensation may also be helpful. A participant shared experiences from a project involving young people experiencing homelessness that used free henna body art to recruit and keep people engaged while educating them about certain health problems; doulas from the communities were also involved. One participant suggested providing cell phone plans as an incentive that could both be appealing to the participant but also helpful for retention. Faith communities could be involved, as well, in engaging community members and generating interest in study participation.

There was support for engaging peer workers who could effectively engage, recruit and support retention of research participants from their communities. One participant noted that hiring nursing students, in particular immigrant nurses seeking to gain professional credentials in Canada, could provide capacity in a multiplicity of languages and offer benefits in terms of relational skills.

It was noted that local partners involved as key intermediaries need not be clinical settings: workplaces and community centers could be focal points for engaging/recruiting participants. A participant noted some studies that show that women working in farming, plastics, auto manufacturing, canning operations, on the Ambassador Bridge, and in other occupational settings have a greater number of adverse birth outcomes. These studies may provide useful learnings to inform the proposed next phase of MIREC, particularly as it relates to parental occupation as a source of heightened exposure/vulnerability.

Information needs and pathways, including the source of information, are important considerations when engaging marginalized populations and recruiting/retaining research participants. Ghazal noted two themes

related to communication from the scoping review. The first is consistency: consistent and ongoing communication is needed to keep participants engaged throughout the study. The second is methods: communication should be tailored to the circumstances and preferences of various groups. There was a lot of discussion in the literature about the benefits and advantages of social media. However, social media was found to not be effective with hard-to-reach communities; traditional approaches such as mailing and face-to-face interaction may have more success. Who delivers the messaging and where communication happens are important considerations. Sometimes women are stressed in a clinic and may not have time or patience to sit through a study protocol. Having researchers go to participants' homes is likely to be more effective.

It was suggested that the socio-ecological model from Ghazal's presentation may be a way to organize and conceptualize recruitment and retention. The model could be used to understand and conceptualize participants' experiences and vulnerabilities from different levels – as individuals, groups, and communities, and vis-à-vis the systems that are in place.

Feasibility study design considerations

The above-noted considerations and strategies for engaging marginalized populations in biomonitoring cohort research are applicable both to the proposed feasibility study and to the design of a future MIREC cohort.

Specifically with respect to the feasibility study, participants offered thoughts on potential locations. One participant suggested the region around Sarnia, where research has already demonstrated occupational and community-level environmental health concerns, including within local Indigenous communities. It was generally agreed that the selection of diverse location(s) – e.g., a dense urban setting, rural region, a community with a high proportion of recent immigrants, etc. – would optimize relevant learnings.

Potential parameters of future MIREC research

Participants shared interest and thoughts on the potential inclusion of preconception parents in a future study. Given that it is difficult to find individuals wanting to conceive for the first time, perhaps recruitment of second-time mothers would provide valuable information in terms of stress and other factors related to pregnancy. A participant involved in clinical care noted that post-partum could be a good time to recruit women focused on their next pregnancy. Jillian noted that a cursory scan of preconception literature suggests that preconception recruitment is usually done online or through a fertility clinic. A participant who is a clinician and researcher noted that preconception cohorts are exceptionally hard to do. One is currently underway in China, where there is a requirement to have a pre-conceptual test. In Canada, fertility clinics present an opportunity to engage prospective parents at the preconception stage, but the results are biased due to couples having fertility issues. It was noted that in nail salon communities, for example, some women already know there are issues with occupational exposure during pregnancy and sometimes seek further information on preconception exposure.

A participant inquired about the scope of chemicals to be included in the proposed MIREC cohort study with marginalized populations, noting the importance of looking at context and weight of evidence. Jillian responded that these decisions are not yet made, but that it will likely include chemicals of concern that pregnant women are exposed to, such as the chemicals covered by the MIREC and Plastics and Personal-care Products use in Pregnancy (P4) Studies, substances used in non-sick cookware, and other chemicals where there is limited research in the field (for example two industrial solvents found to be harmful in animals that were recently measured in biobank urine samples from MIREC). The list of substances will be developed based on identification of chemicals of concern together with stakeholder consultations.

Participants also discussed the question of how and whether to continue to include prospective parents whose pregnancy was terminated or had failed. It was suggested to keep these women involved, in the event that there are more pregnancies and because excluding people could be detrimental to the intended focus on vulnerable

populations. Jillian noted that the question of whether miscarriages should be included or excluded comes up in analyses of preterm births, since exposure could have contributed to the risk.

Participants also discussed the provision of educational information to cohort study participants on ways to reduce environmental chemical exposures and risks. This was viewed as important despite the potential for behavioural changes (changes in exposures) to affect study results (measured exposure levels). A participant involved in community-based research noted the importance of continuing to meet the needs of participants. If community needs can be identified, acknowledged and responded to by the research team, participation will come from within the community and will be more likely to be sustained. The group also briefly addressed the question of providing participants with information on their biomonitoring results (body burdens).

Concluding thoughts and next steps

The PEHE-MIREC Consultation affirmed the importance of pursuing a focus on marginalized/vulnerable populations in future MIREC research efforts. A number of important considerations and design features were raised and discussed, including the importance of building relationships and trust, working with local partners, understanding and responding to local community concerns and needs including barriers to participation, sustaining communication and commitment, and conceptualizing vulnerability to environmental chemical exposure/risk not as a static label or characterization of an individual or community, but as a fluid consequence of marginalizing life circumstances and contexts, following the social determinants of health and situated within a socio-ecological framework.

There is strong interest within the PEHE Collaboration to continue to engage with the MIREC team to inform future biomonitoring research with prospective parents and families, towards the shared goal of improving preconception/prenatal heath and reducing health inequities in Canada.

Annex 1 – PEHE Collaboration

Prenatal Environmental Health Education (PEHE) Collaboration

The PEHE Collaboration (pehe-esep.ca) is an interdisciplinary CIHR funded research consortia of diverse partners who are working together to advance prenatal environmental health in Canada, through research, practice and policy advocacy. Recognizing that exposures to environmental toxicants in our day-to-day lives pose significant reproductive and developmental health risks, the objectives of the PEHE Collaboration are to:

- Advance research that informs prenatal environmental health education policy and practice across diverse clinical, community, occupational and environmental contexts; and,
- Foster collaboration among clinical, public health and environmental health organizations and the communities they serve.

Led by Drs. Eric Crighton, Graeme Smith and Erica Phipps, the collaboration consists of a multidisciplinary team of experts in reproductive health and clinical care, environmental health, public health, health policy and knowledge translation from across Canada. A critical strength of the PEHE Collaboration lies in our partnerships with Canada's most influential and respected voices in prenatal care and environmental health, and the breadth of knowledge, experience and community relationships that come from working with these organizations. PEHE Collaboration partner organizations include:

- Society for Obstetricians and Gynecologists of Canada (SOGC)
- Canadian Partnership for Children's Health and Environment (CPCHE)
- College of Family Physicians of Canada (CFPC)
- Canadian Association of Midwives (CAM)
- National Aboriginal Council of Midwives (NACM)
- Canadian Association of Physicians for the Environment (CAPE)
- Canadian Association of Perinatal and Women Health Network (CAPWHN)
- Canadian Environmental Law Association (CELA)
- The Centre of Environmental Health Equity (CEHE)
- Health Canada
- Saskatchewan Prevention Institute (SPI)
- Canadian Association of Nurses for the Environment (CANE)
- Children's Environmental Health Clinic
- Health Nexus
- The Healthy Nail Salon Network
- WHO Environmental Collaborating Centre on Children's Environmental Health

CIHR funding reference # PJT-165868

Annex 2 – Notes from PEHE-MIREC Ad Hoc Group Meeting, February 24, 2022

PEHE – MIREC Ad Hoc Group

24 February 2022, 4:00 – 5:15 pm EST, via Zoom

Meeting Summary

Introduction:
An ad hoc group of collaborators involved in the **Prenatal Environmental Health Education (PEHE)** research collaboration has been formed to assist the **Maternal Infant Research on Environmental Chemicals (MIREC)** research team in exploring strategies to successfully engage, recruit and retain prospective parents from marginalized communities/populations into a possible future MIREC biomonitoring cohort. The ad hoc group held its first meeting on February 24, 2022, via zoom. The objectives of the meeting were to:

- Review and provide feedback/guidance on the scoping review of literature relevant to recruitment/retention of pregnant women from marginalized communities into birth cohort studies
- Discuss and offer feedback on the proposed priorities and scope of a next potential phase of MIREC research
- Share experiences and perspectives on community-based strategies to engage marginalized communities
- Identify key objectives and discussion points for the March 8th PEHE-MIREC meeting

Participants: Rukhsana Ahmed (SUNY), Cate Ahrens (Healthy Nail Salons Project), Jillian Ashley-Martin (MIREC/Health Canada), Jacqueline Avanthay-Strus (CANE), Eric Crighton (PEHE/uOttawa), Ghazal Fazli (University of Toronto), Wendy Katherine (Health Nexus/First Exposure), Jane McArthur (CAPE), Erica Phipps (PEHE/uOttawa/CPCHE), Lyne Soramaki (Thunder Bay District Health Unit), Franca Ursitti (Peel Region Public Health), Kate Werry (MIREC/Health Canada)

Meeting summary:

- Participants introduced themselves and noted their connection to/interest in the topic
- Erica Phipps gave an overview of the PEHE-MIREC consultation, which includes the work of this ad hoc group and the joint meeting of the full PEHE Collaboration and the MIREC research team scheduled for March 8, 2022. The consultations are intended to support the MIREC team in exploring and identifying potential strategies for engaging, recruiting and retaining participants from marginalized communities in a potential future MIREC cohort, and to foster collaboration and potential partnerships.
- Jillian Ashley-Martin provided an overview of the MIREC research program (began in 2008, 2000 women, 10 sites, collection of biospecimens and analysis for environmental chemicals, tracking of health outcomes; three follow-up studies: infancy, childhood and adolescence/puberty). She noted the current interest in designing a future MIREC study that would prioritize marginalized populations and include both prospective mothers and fathers. The proposed equity focus aligns with the Government of Canada's efforts to address the circumstances and needs of vulnerable populations in the context of the Chemicals Management Plan.
- Jillian described the proposed feasibility study, to be conducted in collaboration with Drs. Phipps, Crighton and Fazli and interested PEHE Collaboration partners, that will involve focus groups with prospective parents (mothers and fathers) as well as local service providers to better understand perceptions, barriers, and potential strategies for involving marginalized communities/populations in longitudinal biomonitoring research.
- Ghazal Fazli presented the work to date on a scoping review of the literature on existing approaches and experiences in the recruitment/retention of marginalized communities in pregnancy cohort studies. She presented the scoping review protocol (see Annex 1) and preliminary results (Annex 2).
- Participants provided feedback and ideas on the scoping review, including:

- Suggestion to include quality assessment as part of the scoping review protocol (to be completed for the manuscript)
- Recruitment and retention are essentially two different things that could be looked at separately
- Useful to include search terms related to groups that are often not included in this type of research: e.g., Black, Indigenous, rural/remote, newcomer (these terms are included in current search category of 'vulnerable')
- Include gender-diverse prospective parents and related search terms (there are terms included in our search category 'vulnerable' to reflect gender diverse groups)
- Consider engagement strategies used in other contexts (other than biomonitoring cohort/pregnancy studies) for potentially valuable lessons and ideas. While understandable given the limits of a scoping review, there are inherent limitations of looking only at pregnancy cohort studies, given that these generally have not been successful in recruiting equity-seeking populations.
- Grey literature may be of relevance in accessing additional experiences/contexts. Some relevant findings – such as from research done with the principles of OCAP and with ownership within Indigenous communities – may be found outside of the academic literature.
- Scoping review is being done with the Arksey and O'Malley's framework, which permits grey literature.
- The nursing database (CINAHL) could be a source of relevant studies, as could the midwifery literature. (CINAHL is one of the databases being used)
- The scoping review could be modified to include recruitment of fathers/prospective fathers
- It was confirmed that literature from New Zealand and Australia is included
- Interest expressed in engaging people from marginalized communities to offer their perspectives on why these studies are not well-subscribed in their communities. This is consistent with the consultation processes within the Arksey-O'Malley protocol.
- Consider social determinants framework for reporting out results: geographic, social, racial, newcomer, linguistic, etc.

- Participants also shared experiences and lessons learned from engaging with marginalized communities:
  - Jane shared her experience in recruiting women working at the Ambassador Bridge in a research study: local media coverage significantly helped to generating interest and increase trust in the legitimacy of the research
  - Working through early learning/child care, parenting and similar types of programming at the local level can be a helpful engagement strategy
  - Trust is key; lack of trust can impede uptake of health messaging as well as research participation
  - Parallels can be drawn with learnings from disparate uptake of public health measures (e.g., vaccines) across the population during COVID; some segments of the population (youth, Indigenous, racialized populations
- Other suggestions and observations raised by participants:
  - Root of 'vulnerable': Populations may not self-identify as vulnerable, their vulnerability may be linked to previous life decisions or health determinants
  - Consideration of urban/rural contexts, environmental justice lens, will be important in the feasibility study
  - Consideration of geographic locations, occupation and occupational histories, and intersections of these -- and their role in vulnerabilizing people and creating susceptibility to exposures
  - MIREC should ensure appropriate cultural framework on data sovereignty. Identified Indigenous community members, either individually or by cohort, will need to be considered re: OCAP https://fnigc.ca/ocap-training/and other progressive Indigenous data sovereignty and research protocols. Example framework developed by Grand Challenges Canada, Indigenous Innovation Initiative: https://indigenousinnovate.org/downloads/indigenous-knowledges-and-data-governance-protocol_may-2021.pdf
  - Roberta Timothy at U of T is working on a Black maternal-child cohort, her expertise would be relevant. Wendy will reach out to her and explore her interest in the March 8th meeting

Annex 1 – Scoping Review Protocol

Biomonitoring Pregnancy Study:

Scoping Review Protocol

General Information

Date: Jan 27, 2022

Review title: Designing an equity-focused approach to recruiting, engaging, and retaining pregnant women from marginalized communities into national birth cohort studies: A scoping review

Background and Rationale: The Maternal-Infant Research on Environmental Chemicals (MIREC) study is a pan-Canadian pregnancy cohort that provides significant information on prenatal environmental chemical exposures and potential adverse health effects of these exposures. MIREC and the subsequent follow-up studies of MIREC mothers and their children together form the MIREC Research Platform. This national-level data platform is a unique opportunity to explore the extent to which the interplay between environmental exposures, behaviours, and biological responses influences the health of pregnant women and their infants throughout the lifespan. Recognized for being a multi-site cohort with approximately 2000 participants from across 10 Canadian cities, findings from this research have important short and long-term implications for future research, policy, and practice. However, the sample largely represents women of higher socioeconomic status and education, and who are less likely to smoke. As such, the existing MIREC research may not reflect the unequal burden of prenatal environmental exposures that disproportionately impact vulnerable women, or the factors (e.g., nutritional status) that may increase susceptibility to adverse health effects. Therefore, it is important to investigate potential challenges and strategies associated with the participation of vulnerable populations in a biomonitoring birth cohort study. For the purposes of this review, we are defining vulnerability in terms of the social determinants of health: socioeconomic status, geography, access to services (e.g., health care), identity and status, as well as racialized and linguistically diverse populations. Thus, the objectives of this review are to:

(1) To clarify the scope of 'vulnerable populations,' as it relates to women's participation in cohort studies, through identification of indicators of inequity, disadvantage and marginalization;
(2) Identify knowledge gaps in the evidence-base regarding recruiting and retaining vulnerable populations within the context of biomonitoring cohort studies;
(3) Explore challenges and barriers of recruiting, engaging, and retaining vulnerable populations into a biomonitoring cohort study;
(4) Identify strategies and methods to recruit, engage and retain vulnerable populations.

Review Questions:

This scoping review will answer the following question:

a. What indicators of vulnerability should be prioritized to ensure robust participation of women from marginalized populations in Canada?
b. What challenges and barriers inhibit recruitment, engagement, and retention of vulnerable populations into cohort studies?
c. What are the knowledge gaps relevant to current research and practice in recruiting, engaging, and retaining vulnerable populations into cohort studies?

d. What strategies and approaches may promote successful recruitment, engagement, and retention of vulnerable populations into cohort studies?

Methods

Eligibility Criteria: What are the inclusion/exclusion criteria?

Inclusion for Search:

1. Published peer-reviewed research studies.
2. English language only
3. Study designs: primary studies, natural experiments, survey responses, systematic reviews.
4. Human studies

Abstracts will then be reviewed for the following relevance:

1. **Study population:** preconception, pregnant or postpartum women or women of childbearing age
2. **Study design:** longitudinal or prospective cohort studies with primary data collection
3. **Study content:** participant vulnerability or inequities that impact participation in longitudinal research including recruitment, engagement, and retention
4. **Studies will be flagged for a focus on the following:** Health equity OR equity OR inequity OR inequities OR social justice OR social justice lens OR equity-focused OR equity-informed OR inclusive OR diversity OR inclusive.

Timeline: 2000 to present

Location: Canada, USA, Europe, Australia, New Zealand

Exclusion:

- Study did not report on participation of women of childbearing age
- Study is not a longitudinal or prospective cohort studies
- Non-scientific publications: e.g., conference proceedings, letters to the editor, commentaries
- Information not relevant to recruitment, engagement, retention
- No discussion of vulnerable populations (not completely exclude, may want to consider reviewing as a whole)
- Secondary data use, linkage studies

Information sources: The following databases will be searched through the University of Toronto Library Catalogue

- OVID Medline
- OVID EMBASE
- OVID APA PsychINFO
- Scopus
- EBSCO (CINAHL)

Search Strategy: The following are search terms that will be searched first by **"subject headings"** followed by **"keywords"** search across all databases using Bolean operators:

1) Vulnerable

- (Vulnerab* OR hard to reach OR seldom heard OR hidden group OR disadvantage* OR underrepresented OR under-represented OR underserved OR under-served OR low income OR low-income OR poor income OR low socioeconomic status OR low socioeconomic position OR low literacy OR low health literacy OR raciali#ed OR ethnic minorit* OR refugees OR asylum seekers OR deprived OR oppressed OR marginali* OR newcomer* OR immigrant* OR at risk OR at-risk OR minority OR minority health OR disabilit* OR disabled OR Indigenous OR Aboriginal OR First Nations OR Inuit OR Metis OR M#tis OR nonbinary OR LGBTQ OR LGBTQS OR LGBTQS2 OR LGBTQS2+ OR 2SLGBTQ+).tw,kf.

AND

2) Engagement/Recruitment/Retention

- (Engag* OR patient engag* OR participant engag* OR public engag* OR patient outreach OR public outreach OR community member OR community participation OR patient participation OR public participation OR public involvement OR patient involvement OR patient selection OR public selection or recruitment OR participant recruitment OR retention* OR participant retention OR retentive*).tw,kf.

AND

3) Environmental chemicals:

- (Biomonitor* OR monitor* OR biomarker OR exposure biomarker OR marker OR biological monitoring OR human biomonitoring OR human biomonitoring data OR human biomonitoring research OR environmental chemical* OR chemical* OR Lead OR arsenic OR mercury OR cadmium OR manganese OR phthalates OR bisphenol A OR BPA OR polybrominated diphenyl ethers OR PBDEs OR organophosphate OR OP OR pesticides OR polychlorinated biphenyls OR PCBs OR triclosan OR cotinine OR perfluoroalkyl substances OR PFASs OR metals OR parabens OR phenols OR Pesticides OR flame retardants).tw,kf.

AND

4) Cohort Studies

- (Cohort OR cohort studies OR prospective* OR longitudinal* OR population based OR population based cohort or population based cohort stud*).tw,kf.

The following category will be treated as a flag in the literature to ensure that we have captured relevant literature from categories #1-#4.

Health Equity (consider reviewing as a as a theme in abstract and full-text review)

5) (Health equity OR equity OR inequity OR inequities OR social justice OR social justice lens OR equity-focused OR equity-informed OR inclusive OR diversity OR inclusive).tw,kf.

Data management: All data (research articles) will be housed in Covidence, and data will be manually extract data into Excel.

Selection process: After conducting the search and eliminating duplicates using Covidence, one reviewer will screen all papers identified first by title and then by the abstract, followed by full text review and data extraction. Articles selected for inclusion will also have their references and citations scanned for possible inclusion of missed studies.

Data extraction: Each study will have the following data extracted into Excel:

Key data to be extracted:

1) Author last name and date of online publication
2) Journal name
3) Origin/country of origin (where the study was conducted) and region (if reported)
4) Study population characteristics
    a) Overall Sample size
    b) Age range
    c) Race/Ethnicity or linguistically diverse (if reported)
    d) Identify and status (immigrant, Indigenous) (if reported)
    e) Socio-economic status/group/income quartile (if reported)
5) Recruitment setting
6) Recruitment method (outreach, incentives/compensation)
7) Recruitment duration
8) Challenges and barriers (if identified)
9) Strategies and approaches (Effectiveness)

Data synthesis: The data will be synthesized and analyzed through the following methods:

6) A descriptive summary of the study designs and methodologies will be provided including potential differences across the studies. All quantitative data for studies with comparable methodologies will be synthesized and prepared in tables. Findings from this review will be presented using a table for the overall study and tables arranged by of a range of parameters (if data are available) such as study region, and population (for instance, rural vs urban geography, immigration or Indigenous status, low-income vs high-income), recruitment strategy.
7) A qualitative thematic analysis will be conducted using inductive and deductive approaches to first allow for themes to emerge from the final studies, but to also identify themes that correspond to: (a) vulnerability of pregnant women, (b) challenges and barriers that inhibit recruitment, engagement, and retention, (c) knowledge gaps that exist for recruiting and retaining vulnerable populations, (d) strategies and approaches that promote successful recruitment, engagement, and retention of vulnerable populations

Results

OVID Medline

Search Category	After limits are applied (English language, Humans, 2000-2022)	After removal of duplicates
1) Vulnerable 2) Engagement, retention, recruitment 3) Environment 4) Cohort	621	66

OVID EMBASE

Search Category	After limits are applied (English language, Humans, 2000-2022)	After removal of duplicates
1) Vulnerable 2) Engagement, retention, recruitment 3) Environment 4) Cohort	1393	899

OVID APA PsychINFO

Search Category	After limits are applied (English language, Humans, 2000-2022)	After removal of duplicates
1) Vulnerable 2) Engagement, retention, recruitment 3) Environment 4) Cohort	352	176

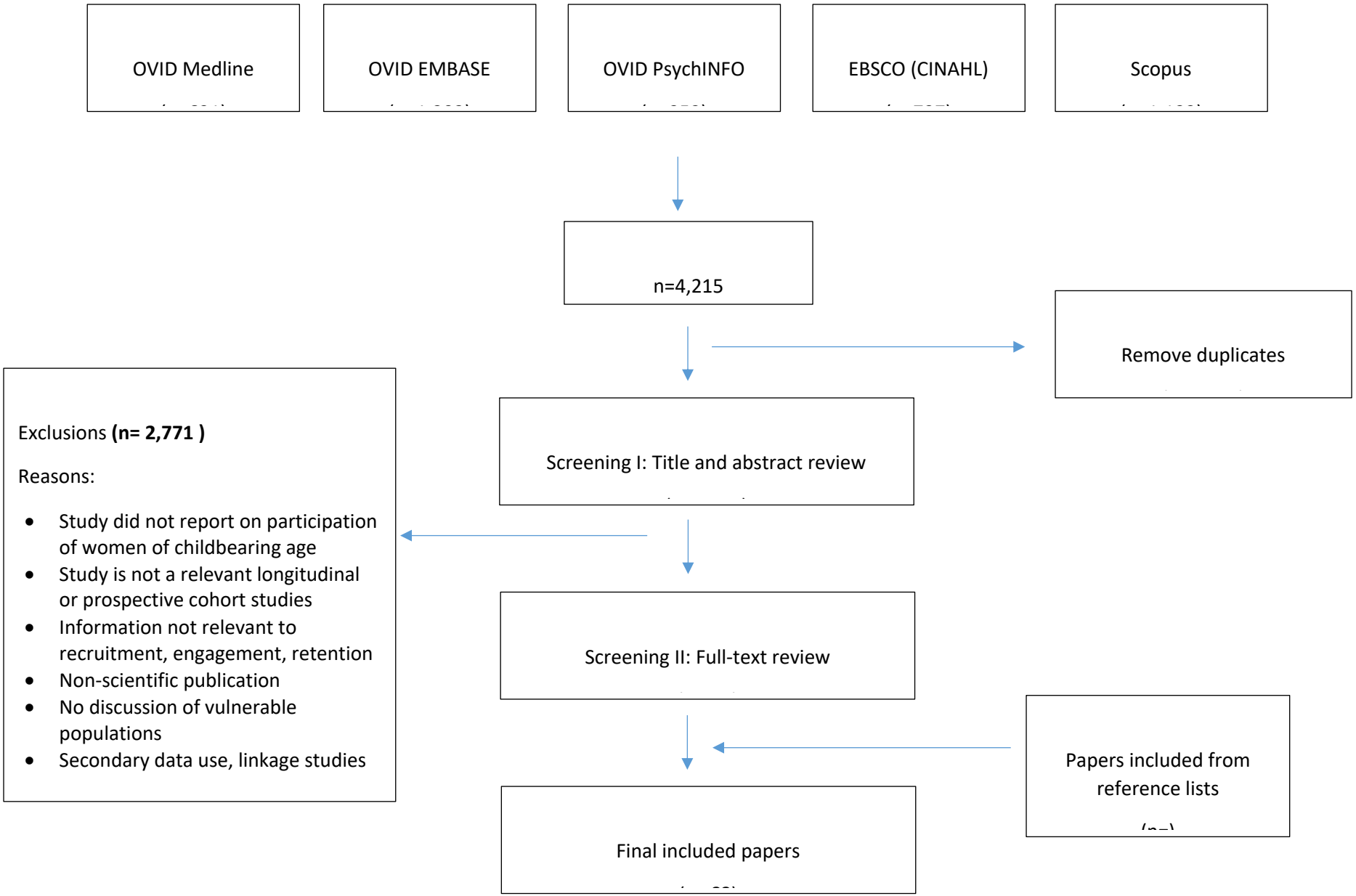
Scopus

Search Category	After limits are applied (English language, Humans, 2000-2022)	After removal of duplicates
1) Vulnerable 2) Engagement, retention, recruitment 3) Environment 4) Cohort	1122	562

EBSCO (CINAHL)

Search Category	After limits are applied (English language, Humans, 2000-2022)	After removal of duplicates
1) Vulnerable 2) Engagement, retention, recruitment 3) Environment 4) Cohort	727	507

Annex 2 – Search Strategy Results



Annex 3 – Participants in the PEHE-MIREC Consultation

PEHE-MIREC Consultation Meeting Participants, 8 March 2022

Allison Felker, Society of Obstetricians and Gynecologists of Canada (SOGC)

Cassie Barker, former Executive Director of Women's Health and Environment Network (WHEN); Toxics Director, Environmental Defence

Cate Ahrens, Parkdale Queen-West Community Health Centre; Nail Salon Workers Project

Christopher Zhan, VP of Practice, American College of Obstetricians and Gynecologists (ACOG)

Fiona Hanley, Nurse Educator, McGill University; Canadian Association of Nurses for the Environment (CANE)

Graeme Smith, Professor and Head of Obstetrics, Queen's University

Jane McArthur, Toxics Campaign Director, Canadian Association of Physicians for the Environment (CAPE)

Karen Phillips, Associate Professor, University of Ottawa

Lyne Soramaki, Public Health Nurse, Thunder Bay Disrict Health Unit

Marg Sanborn, rural family physician; College of Family Physicians of Canada (CFPC)

Margaret Villalonga, Director of Obstetrics, American College of Obstetricians and Gynecologists (ACOG)

Megan Clark, Research and Evaluation Lead, Sasketchewan Prevention Institute

Rivka Green, Doctoral Student, York University

Rukhsana Ahmed, Associate Professor and Chair, Dept. of Communication, State University of New York (SUNY); Co-Investigator, PEHE

Sharon Dore, Faculty Member, McMaster; Canadian Association of Perinatal and Women's Health Network (CAPWN)

Wendy Katherine, Executive Director, Health Nexus; Dala Lana School of Public Health

Cheryl Khoury, Section Head, Targeted Epidemiology and Biomonitoring Section, Health Canada

Jillian Ashley-Martin, Research Scientist, Health Canada; Co-PI, MIREC

Smiljana Pekovic, Scientific Evaluator, Health Canada

Ghazal Fazli, Postdoctoral Fellow & Assistant Professor, University of Toronto

Eric Crighton, Professor, University of Ottawa; Co-PI, PEHE Collaboration

Erica Phipps, Co-lead, PEHE Collaboration, Postdoctoral Fellow, University of Ottawa; Executive Director, Canadian Partnership for Children's Health and Environment

PEHE-MIREC Ad Hoc Group

Rukhsana Ahmed (SUNY)
Cate Ahrens (Healthy Nail Salons Project)
Jillian Ashley-Martin (MIREC/Health Canada)
Jacqueline Avanthay-Strus (CANE)
Eric Crighton (PEHE/uOttawa)
Ghazal Fazli (University of Toronto)
Wendy Katherine (Health Nexus/First Exposure)
Cheryl Khoury, Health Canada
Jane McArthur (CAPE)
Erica Phipps (PEHE/uOttawa/CPCHE)
Graeme Smith (Queen's University)
Lyne Soramaki (Thunder Bay District Health Unit)
Franca Ursitti (Peel Region Public Health)
Kate Werry (Health Canada)

Annex 4 – Scoping Review Summary Presentation

MIREC-PEHE Consultation Meeting

March 8th 2022

Ghazal Fazli MPH, PhD

1

Designing an equity-focused approach to recruiting, engaging, and retaining pregnant women from marginalized communities into national birth cohort studies: A scoping review

2

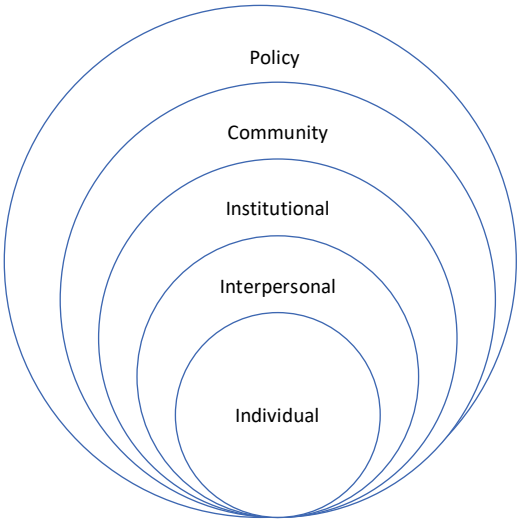
Objectives of the scoping review

1. To clarify the scope of **'vulnerable populations,'** as it relates to women's participation in cohort studies, through identification of indicators of inequity, disadvantage and marginalization;
2. Identify **knowledge gaps** in the evidence-base regarding recruiting and retaining women living in vulnerable contexts within the context of biomonitoring cohort studies;
3. Explore **challenges and barriers** of recruiting, engaging, and retaining women living in vulnerable contexts into a biomonitoring cohort study;
4. Identify **strategies and methods** to recruit, engage and retain women in a biomonitoring cohort study.

3

Defining the scope of 'Vulnerable populations'

- *'Vulnerable populations'* - those at risk of *harm and neglect* due to a *lack of resources* to help mitigate individual and community- based challenges
- Vulnerability – not a *fixed label*, category, or characterization of a group but contexts and circumstances that place individuals in 'vulnerable' positions
- Need to consider the *'layers of vulnerability*'- to recognize the factors, contexts, and processes that lead to marginalization
- Example: Mapping layers of vulnerability to the Socioecological Model of Health
- Population: women living vulnerable circumstances and contexts



Mechanic & Turner;.Health Affairs 2007
Midboe et al. BMJ Open 2020
Goedhart et al. Res Involv Engagem 2021
Luna F. Int J Fem Approaches Bioeth 2009

4

Methods: Search Strategy

- Study design informed by the Arksey O'Malley framework (2005)
- Search databases: OVID Medline, OVID EMBASE, OVID APA PsychINFO, Scopus, EBSCO (CINAHL)
- Searches conducted in consultation with a Librarian at UofT
- Timeline: 2000-present
- Criteria: Canada, USA, Europe, New Zealand, Australia; English; Humans

5

Methods: Search Categories

Category	Subject Headings and/or Keywords
Vulnerable	Vulnerable OR hard to reach OR seldom heard OR hidden group OR disadvantaged OR underrepresented OR underserved OR low income OR low socioeconomic status OR low literacy OR low health literacy OR racialized OR ethnic minority OR refugees OR asylum seekers OR deprived OR oppressed OR marginalized OR newcomer OR immigrant OR at risk OR minority health OR disability OR disabled OR Indigenous OR Aboriginal OR First Nations OR Inuit Métis OR nonbinary OR LGBTQ OR LGBTQS OR LGBTQS2 OR LGBTQS2+ OR 2SLGBTQ+
Engagement/ Recruitment/ Retention	Engage OR patient engagement OR participant engagement OR public engagement OR patient outreach OR public outreach OR community member OR community participation OR patient participation OR public participation OR public involvement OR patient involvement OR patient selection OR public selection or recruitment OR participant recruitment OR retention OR participant retention OR retentive
Environmental chemicals	Biomonitor OR monitor OR biomarker OR exposure biomarker OR marker OR biological monitoring OR human biomonitoring OR human biomonitoring data OR human biomonitoring research OR environmental chemical OR chemical OR Lead OR arsenic OR mercury OR cadmium OR manganese OR phthalates OR bisphenol A OR BPA OR polybrominated diphenyl ethers OR PBDEs OR organophosphate OR OP OR pesticides OR polychlorinated biphenyls OR PCBs OR triclosan OR cotinine OR perfluoroalkyl substances OR PFASs OR metals OR parabens OR phenols OR Pesticides OR flame retardants
Cohort studies	Cohort OR cohort studies OR prospective OR longitudinal OR population based OR population based cohort or population based cohort stud

6

Methods: Inclusion and Exclusion Criteria

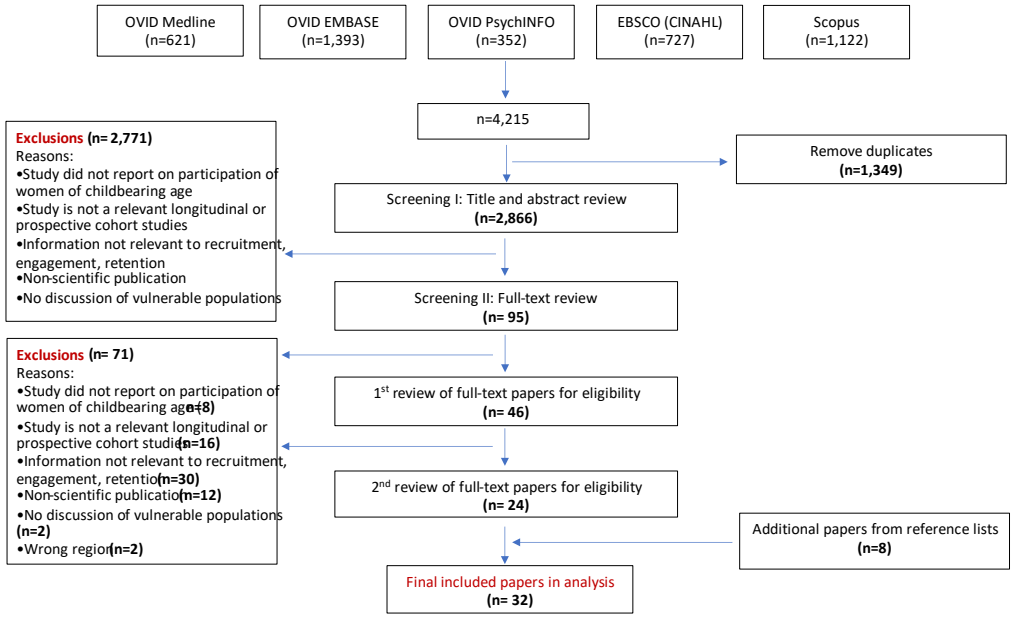
Inclusion Criteria	Exclusion Criteria
Women of childbearing age	Non-scientific publications: e.g., conference proceedings, letters to the editor, commentaries
Published peer-reviewed research studies	Information not relevant to recruitment, engagement, retention
Longitudinal cohort study	No discussion of indicators of inequity, disadvantage and marginalization
Human studies	Secondary data use, linkage studies
English language	Wrong region

Methods: Data Extraction

- Using Covidence, data was extracted based on the following information from studies included in this review.

Study Characteristics	Indicators of inequity, disadvantage and marginalization	Recruitment & Retention Approaches
Author last name and date of online publication Country Name of cohort Sample size Attrition Retained at follow up	Age range Race, ethnicity, or linguistically diverse Identity and status (immigrant, newcomer, Indigenous) Socioeconomic status or income	Recruitment setting Recruitment method Challenges and barriers: 1) Engagement & Recruitment, and 2) Retention • Strategies and approaches: 1) Engagement & Recruitment, and 2) Retention

Search Results: PRISMA Flowchart



9

Preliminary Results

10

Table 1. Characteristics of Included Studies (n=32)

Study Characteristics	n (%)
Country	
United States	9 (28)
Canada	6 (19)
New Zealand	3 (9)
Germany	3 (9)
Australia	2 (6)
Belgium	1 (3)
France	1(3)
Italy	1(3)
Spain	1(3)
Netherlands	1(3)
United Kingdom	1(3)
Norway	1(3)
New Mexico	1(3)
Japan	1(3)
Reported on Race or Ethnicity or linguistically diverse populations	11 (33)
Reported on Identify and status (immigrant, Indigenous)	5 (16)
Reported on Socio-economic status/group/income	3 (9)
Recruitment Setting	
Clinic	21 (65)
Community	1 (3)
Clinic and community	7 (22)
Online	1 (3)

- *General observations:*
- Majority of studies from United States (9/32) and Canada (6/32)
- 1/3 of the studies reported on engagement, recruitment of women of different ethnic origin, Indigenous or immigrant status (5/32) or low SES (3/32)
- Few studies (5/32) identified engagement and recruitment of immigrant women and women of Indigenous status
- Most common recruitment setting was the clinic (21/32), followed by clinic and community settings (7/32)
- One study reported on recruitment and retention in online settings

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Objective 1: To clarify the scope of **'vulnerable populations,'** as it relates to women's participation in cohort studies, through identification of indicators of inequity, disadvantage and marginalization

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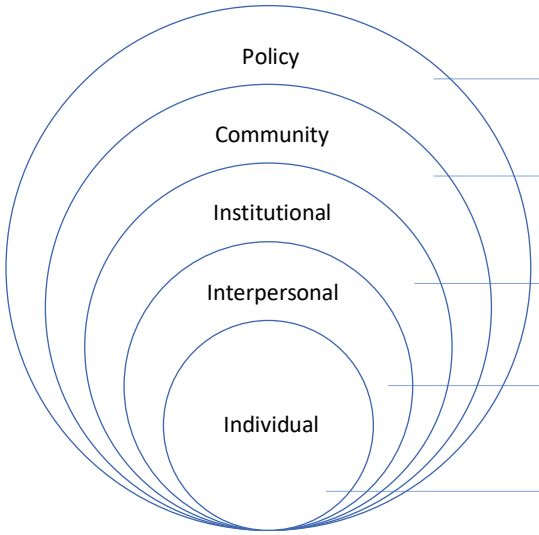
Contextualizing Indicators Vulnerability that impact Women's participation in Birth Cohort Studies



Indicators of Vulnerability

- Predefined research questions that prioritize 'researcher impact' rather than community impact
- Incentive/purpose of engaging – why should I participate?
- Will policies prioritize social-contexts and barriers that disadvantaged groups experience?

- Lack of culturally sensitive material
- Minimal to no involvement of 'hard-to-reach' communities in recruitment
- Staff that do not represent participants
- Need for community consultation and community-based recruitment

- Health-seeking behaviours driving recruitment settings and strategies
- Access to maternity care, and recruitment settings
- Improve engagement in antenatal care
- Tailored recruitment to racialized and marginalized women in settings

- Lack of family and partner support
- Caregiver/childcare roles
- Living in deprived, low SES, households/areas
- Job constraints

- Perceived abilities (i.e., language, literacy)
- Fear of being reported, authority, and afraid to join
- Mistrust in science and research process
- Women in first pregnancy; younger
- Indigenous, immigrant, refugee, LGBTQ2S+, persons with disabilities

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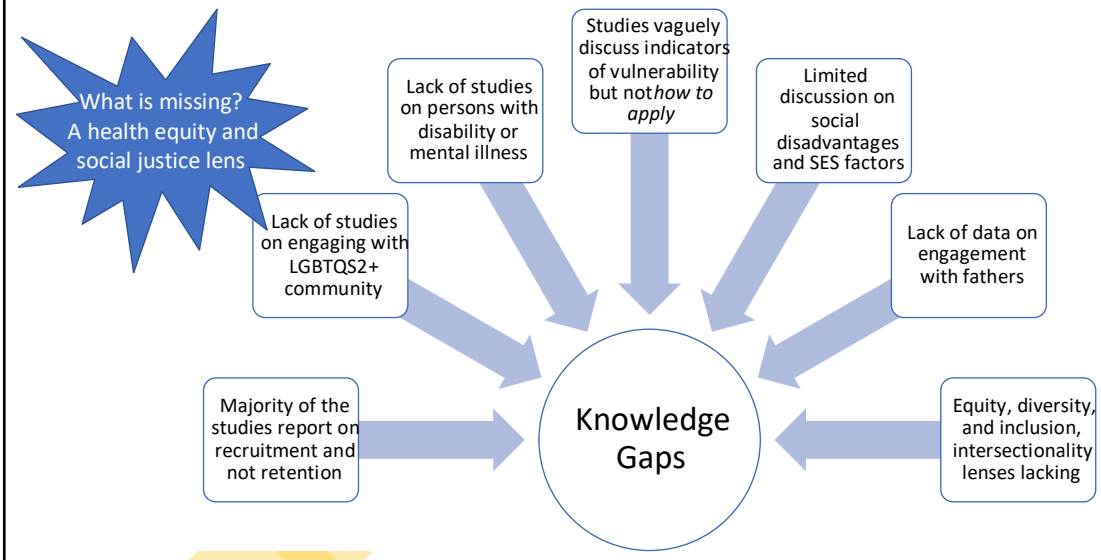
Objective 2: Identify **knowledge gaps** in the evidence-base regarding recruiting and retaining women living in vulnerable contexts within the context of biomonitoring cohort studies

14

Knowledge Gaps in the Evidence Base on Engagement, Recruitment, Retention in Birth Cohort Studies



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Objective 3: Explore **challenges and barriers** of recruiting, engaging, and retaining women living in vulnerable contexts into a biomonitoring cohort study

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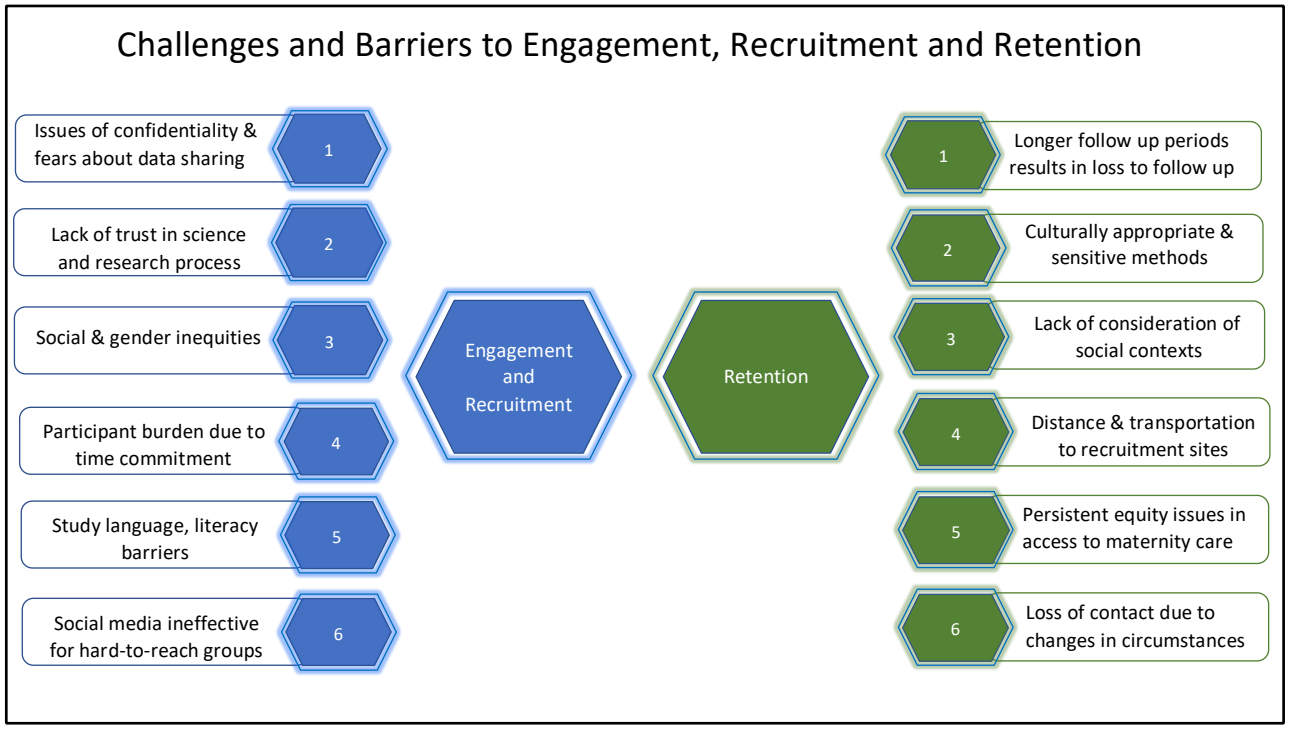

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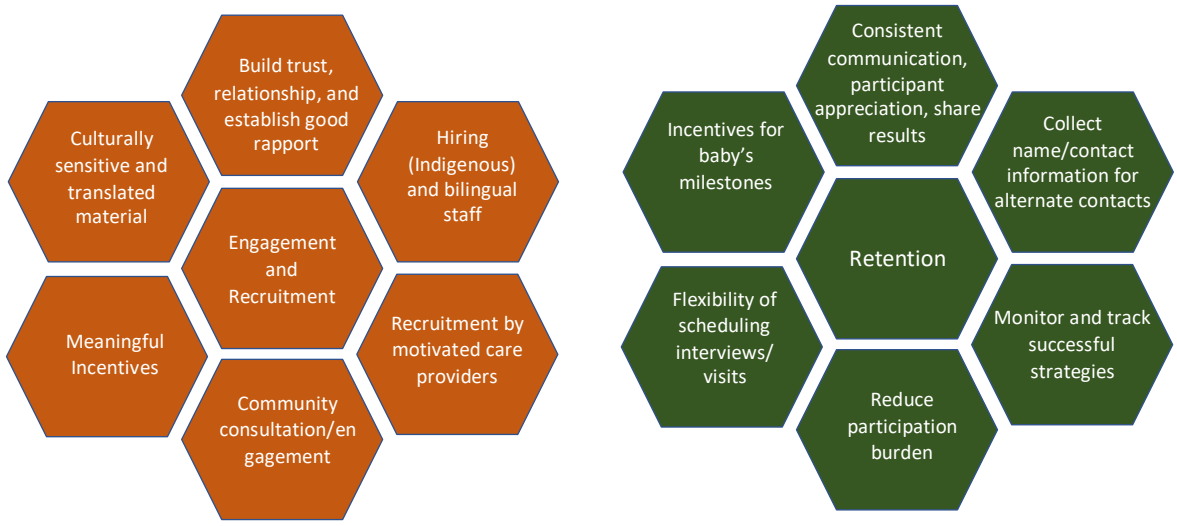
Objective 4: Identify **strategies and methods** to recruit, engage and retain women in a biomonitoring cohort study

18

Strategies and Approaches to Engagement, Recruitment, and Retention of Women



19

In Summary

- Very few studies reported on indicators of vulnerability, or recruitment and engagement of participants from vulnerable circumstances and contexts
- Mapping indicators of vulnerability to the socioecological model to understand the layers of vulnerability
- Majority of the studies focused on recruitment and not retention
- Studies lacked a health equity and social justice lens – calling for equitable, diverse and inclusive recruitment of participants in future research
- Future research may need to consider community engagement and consultation and involve perspectives of community members and organizations (i.e., Nothing About Us, Without Us)

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Discussion Questions

- Do the preliminary themes align with your experiences in research and practice?
- What stood out for you? What is missing?

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