DEVOTION

Developmental Origins of Chronic Diseases in Children Network

DEVOTION Strategic Plan 2017 - 2020

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Acknowledgement

Health in Common
Connecting People, Planning & Evaluation

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Background

The landmark Dutch Famine and British birth cohort studies provided the first evidence that an altered fetal environment can program an individual's risk for chronic disease. These data provided the foundation for David Barker's landmark developmental origins of human disease theory which posits that early life events biologically program an individual's risk for chronic disease. Studies using animal models with controlled pre- and postnatal conditions confirmed these epidemiological observations.

Interventions delivered during the first few years of life can also mitigate disease-risk (i.e. breastfeeding, early childhood education) demonstrating that the early post-natal period is a key window of opportunity for reducing lifetime chronic disease risk and improving the mental and social development of individuals. Improving conditions for physical, nutritional and social health during early years of life has been proven to decrease the incidence of non-communicable chronic diseases (NCCDs), encourage healthy lifestyle in adults and reduce the financial burden on our healthcare system.

Critically, interventions in these two time periods result in substantial lifelong health, neurodevelopmental and social benefits that reduce inequities associated with exposure to adverse early life environments (i.e. poverty, diabetes, etc). Understanding how the fetal and early life environment influences child health outcomes, and optimizing approaches to mitigate risk for chronic disease are global priorities for governments and health research agencies.

The Developmental Origins of Chronic Disease in Children Network (DEVOTION), under the leadership of Drs. Jon McGavock and Andrew Halayko, is well-positioned to provide new knowledge and develop key strategies to mitigate the risks of adverse early life events. DEVOTION began on April 28, 2015 with the funding support of Research Manitoba and the Lawson Foundation. This Network is comprised of more than 60 researchers, community partners, and policy makers who share a common vision: accelerating knowledge to action – within the areas of maternal and child health - to promote wellness and prevent chronic disease (specifically focusing on diabetes, obesity, asthma and allergies) for Manitobans.

The DEVOTION network is organized into four pillars of research (clinical, policy, population health and basic science), and solutions are found within a diversity of perspectives, interventions and approaches. At the core of the Network is the voice of our community partners, including an Indigenous stakeholder group, that guides decision making and our approach to working with Indigenous communities across Manitoba. Moreover, by working closely with Healthy Child Manitoba, DEVOTION has created a pipeline for taking discoveries in early childhood research and directing findings in practice/policy to benefit individuals sooner.

To identify the long term goals and strategies to support the Network's vision, two PATH (Planning Alternatives for Tomorrow's Hope) planning exercises were conducted. The first planning exercise, held at Fort Whyte Alive in September 2015, was comprised of members of the Steering Committee. Key long term goals identified included sustainable funding, long term infrastructure, community and capacity building, as well as knowledge translation.

In October 2016 a number of First Nations people and allies who support First Nations self-determination in the area of research and wellness were identified to participate in a PATH process based on their experience, leadership or role in areas such as diabetes; food/nutrition; early childhood; community engagement; art; education; policy; funding; research and data. The intent of the PATH process was to bring together individuals who are currently working in the area of maternal child health (MCH) and wellness, and help set priorities at the

Provincial level for MCH from a First Nations (FN) lens. This includes increasing opportunities to participate in initiatives focused on language, traditional knowledge and teachings, creating a Manitoba Child Health Atlas with a focus on First Nations, and re-establishing traditional women's and men's roles to support healthy pregnancies.

The Executive Committee of the Network began discussions around setting the strategic direction for the final three years of the grant by incorporating the information gathered at these PATH planning events. In June 2017, the DEVOTION Network engaged their members though surveys, phone interviews and an in-person 2-day strategic planning meeting held in Hecla, Manitoba to gain a stronger understanding of present opportunities, accomplishments, barriers and goals moving forward. This strategic planning meeting was an opportunity to reflect on the work over the past 2 years, while shaping the future vision of the Network, including future educational opportunities for trainees interested in the development of health and disease (DOHaD) research, identifying legacy project(s) as well as having a specific focus on the following chronic diseases moving forward: diabetes, obesity, asthma, and allergy.

Strategic Issues

Members of the DEVOTION team, scientific advisory board, stakeholder advisory committee and funding recipients received invitations to participate in an online survey (65 people in total). This online survey contained questions on their connection with DOHaD research and the DEVOTION Network and asked them to share their thoughts on the strengths, challenges, opportunities and risks currently facing the Network. Six individuals from this this group were also invited to have a phone interview with the facilitator. Responses were received from 31 individuals (summary responses can be found in Appendices 1, 2 and 3).

Based on survey responses, the following strategic issues were proposed and considered in the development of the 3 year goals and strategic priorities.

1. Focus efforts and ensure maximum effectiveness for DOHaD discoveries

The diverse expertise reflected in DEVOTION's membership, while creating an opportunity for transdisciplinary research, makes aligning varied perspectives and priorities challenging. To ensure maximum effectiveness with limited resources – human and financial – DEVOTION needs to clarify its role and long-term goals to support decision making and direct the allocation of resources.

Given the broad scope of DOHaD – the multiple maternal and environmental factors, different stages included in early life (pre-conception, conception, pregnancy, infancy and/or childhood) and the spectrum of chronic diseases in later life – many research interests can align with the DOHaD focus of DEVOTION. The four pillars – clinical research, basic science, population health and policy/community – create further opportunity for policy makers and stakeholders to engage. While this broad engagement strengthens the work of the Network, without prioritizing and aligning efforts, the lack of focus can contribute to member frustration and disengagement.

2. Clarify expectations/governance to maximize community engagement

While DEVOTION articulates that patient and stakeholder groups "guide all aspects of discovery with the four pillars", the translation of this commitment into practice is not clearly outlined, nor is there a shared understanding of what this means (e.g. Is there an expectation of community engagement across pillars or only in the policy/community pillar?).

Working with communities to move research to action, as mandated in the policy/community pillar, requires a framework that includes indicators of successful community engagement, what communities can expect and what is expected of communities, community selection criteria and a process for ensuring knowledge mobilization and translation – turning engagement into action.

Although there is a shared commitment to working with the Indigenous community, the degree to which community is understood to mean Indigenous community is not.

3. Explore options for a sustainable Network

Having utilized funding from Research Manitoba and the Lawson Foundation to establish operations and a network of stakeholders, DEVOTION can now consider options for a sustainable model that strengthens engagement, diversifies fund development and utilizes a transparent decision making process, including further development of funding criteria.

To support stakeholder engagement and strengthen fund development, a sustainable model must identify and reflect the 'value added' of the Network, including and beyond the provision of research funding. The limited availability and competing commitments of members magnifies the need for clarity regarding what is expected of members and what members can expect. Moving forward, opportunities to support participation, beyond receiving research dollars, could be explored.

Framework for Planning

Mission

DEVOTION accelerates knowledge to action – within the area of maternal and child health – to promote wellness and prevent chronic disease (specifically focusing on diabetes, obesity, asthma and allergies) for Manitobans.

Focused on the developmental origins of health and disease[1], DEVOTION is an interdisciplinary network that integrates stakeholders[2] in the research process.

Guiding Principles

In an effort to direct and focus the work of the DEVOTION Network, the following principles will be utilized to make operational decisions:

- Committing to **research excellence.** Scientifically sound research and rigorous methodologies will be prioritized.
- Stakeholders will be engaged **throughout the research process** to incorporate findings into policy and practice.
- Facilitating **interdisciplinary collaboration**, decision making will be shared and cross pillar perspectives considered.
- Supporting a wellness focus, a **strengths-based approach** will be utilized.
- Ensuring that **individuals with lived experience have a voice** in research that affects them, stakeholders will be engaged throughout the research process.
- Acknowledging the **intergenerational impact**[1] on health outcomes, the developmental period (-200 years to + 5 years) will be given consideration.

[1] DEVOTION research focuses on the developmental period from -1 year to +5 years (i.e., from one year prior to birth to five years of age), but also gives consideration to the intergenerational effects on health outcomes, thereby effectively making the period of study -200 years to +5 years.

[2] DEVOTION stakeholders include: women, children, and families; members of Indigenous communities and organizations dedicated to health equity; community leaders; health care providers and administrators; policy makers; and researchers.

Long-Term Impact

DEVOTION is committed to reducing the human and financial costs of common chronic diseases in Manitoba by prioritizing discoveries from research conducted in the developmental period.

DEVOTION works with stakeholders toward this end, by increasing the discovery, implementation and utilization of DOHaD research.

Goals and Objectives

Goals and objectives for the next 3 years provide the framework for annual operational planning, including the development of outputs and short-term outcomes (with baselines and targets) for quarterly reporting.

1. Generate impactful, translational DOHaD knowledge relevant to target populations

    a. Increase DOHaD discoveries and maximize capacity within the Network

    b. Strengthen engagement of stakeholders, across pillars, to develop the infrastructure for legacy project(s) implementation

    c. Maximize discoveries from existing infrastructure/resources to generate new knowledge

2. Enhance capacity for the creation and use of DOHaD knowledge

    a. Increase DOHaD training opportunities for trainees and scientists

    b. Increase academic capacity for DOHaD research

    c. Increase participation with existing networks (regional, national, international)

3. Impact policy, practice and research direction through engagement and knowledge translation

    a. Strengthen interdisciplinary engagement with policy makers (DEVOTION is a recognized authority for DOHaD)

    b. Strengthen and support knowledge exchange (KE) within DOHaD research process

    c. Increase meaningful involvement of those with lived experience in DEVOTION

    d. Support uptake of best evidence into practice for health promotion in the developmental period

Strategic Priorities

Strategic priorities identify areas of emphasis or critical issues that need to be addressed in the next 3 years to ensure DEVOTION can achieve the goals and objectives identified.

1. Scientific Capacity

Coordinated learning opportunities for researchers and trainees, including but not limited to research rounds, invited speakers, curriculum development, summer schools for trainees, and supporting trainee attendance at conferences will strengthen the Network's scientific capacity.

a. Structure and governance will be adapted to support research design, including interaction between researchers

b. We will engage trainees in identifying best practices to support training in DOHaD science

c. We will identify existing resources that would benefit from immediate financial investment to speed new DOHaD discoveries

d. We will recruit trainees and scientists to the Network to expand existing capacity for discoveries

2. Stakeholder Engagement

Stakeholder integration will be involved in every aspect of the research process, from identifying research questions, designing projects, knowledge exchange as well as implementation and integration into practice and policy. This engagement is necessary to successfully achieve DEVOTION's desired long-term impact.

a. DEVOTION's structure and processes will be adapted to reflect commitment to stakeholder engagement

b. Membership will be broadened to include families, policy makers, health care providers working with children and families in the developmental period

c. We will engage in new scientific endeavours, co-developed with stakeholders on projects relevant to stakeholder priorities

3. Sustainable Operational Model

An operation model that clearly outlines what the Network looks like, what the Network offers, how the Network's efforts lead to impact and how the Network secures sustainable funding is needed to engage and sustain stakeholder involvement.

a. Membership categories, roles and responsibilities are developed and communicated within and beyond the DEVOTION Network

b. Business model for the sustainability of the Network is developed and shared widely

c. Explore key legacy projects that would be used to secure funding to support the Network after 2020

d. Engage existing networks in DEVOTION to ensure coordinated efforts and create niche within the international community

Appendices 1 – Identified Strengths

Respondents to the survey were asked to identify what they believe to be the top 3 internal strengths of the DEVOTION Network. Following is a summary of their replies.

Motivated, strong and energetic leadership, including a dedicated Executive Director and support staff.

- Well-coordinated
- Network members are all located at a single site and are well supported by CHRIM

Connection with community partners, including Indigenous community.

- Network of communities
- Partnership with Nanaandawewigamig
- Network is very accommodating to the needs of Indigenous people
- Ivolvement of stakeholders/communities

Committed support from stakeholders, with expertise and interdisciplinary focus.

- Transdisciplinary nature of network with the breadth of researchers that are involved
- Strong configuration of different talent areas in Manitoba that DEVOTION brings together through research – policy work, lab work, etc. – and the effort to really grow the community-level research capacity. Very attractive features for the province.
- It is a good example of how research can be accelerated when many disciples work together.
- Opportunities for networking and funding; interdisciplinary approach; learning about connections between research in the 4 pillars
- A variety of disciplines of experts.
- The trainees.
- The skills, knowledge of the team of the doctor's, researchers, stakeholders.

Engagement with the Indigenous community.

- Collaboration with Indigenous people.
- Indigenous participant feedback is valued.
- Respect for the Indigenous view, culture, etc.

Unique opportunity with momentum, flexibility, and diverse approaches.

- Visibility.
- Unique opportunity of the different areas of excellence under a single network.
- Passionate people.
- Good Press.
- Flexibility to adjust priorities.

Ability to impact research, including the opportunity to inform direction and provide input from an Indigenous perspective.

- Will to have impact – regardless of diversity, people are here to create system change and novel interventions to accomplish on a large scale. Everybody wants things to be better.
- Seed funding for new initiatives.
- Cutting edge.

Opportunity for stakeholders to share information and knowledge.

- Learning about wonderful things that the research network does.
- Interaction with colleagues regarding early life issues.
- Staying connected and utilizing information to better outcomes for people living with diabetes.
- Collegiality and support.
- Sharing of data, information, seeking guidance.
- Updates of progress in team members.

Collaborative opportunities, cross sectoral perspectives; potential for creative partnerships.

- The network web of our group and the information that we all have access to and to whom we can share both internally and externally with each other and our connections.
- Collaborations. Support and flexibility to launch new initiatives as a team.
- Collegial support, opportunities for working together, support for projects and discussing opportunities for future funding, connecting to stakeholders.
- Positioned to make difference in policy and practice.
- Increased ability to conduct research with an interdisciplinary approach.

Appendices 2 – Identified Challenges

Respondents to the survey were asked to identify what they believe to be the top 3 internal challenges faced by the DEVOTION Network. Following is a summary of their replies.

Lack of focus, the absence of tangible outcomes and lack of consensus on priorities.

- Broad (unclear) focus
- A lot of different groups involved, some lacking cohesiveness and clear link to central theme
- Finding common ground
- Lack of identity

Cohesion, maintaining sense of connection and sustaining member's investment in Network.

- Keeping the various disciplines and pillars connected and working together to created new/innovative findings.
- Large group makes it difficult to maintain sense of connection
- I do not see it as one group yet. Still too many individual programs
- Continuing to keep the Network members committed to the work of the Network
- The size of the network as it is emerging
- Engagement from broader network
- Infrastructure

Time constraints, including individual availability and competing commitments, time between face-to-face meetings, and distance limitations.

- Time and distance limitations
- My own availability to spend time on this project and contribute to the network; this is not my primary research focus
- Peoples abilities to reconcile what their daily pressures are with where the network needs to go is the biggest challenge
- The number of research projects that are going on and the inability to keep abreast of everything going on. It is a tremendous burden to those members that are working full time.

Lack of clarity with respect to expectations and process for decision making.

- Strong leadership with a well-defined vision for the future of the Network that is not shared by members.
- DEVOTION has to be open to hearing the voices of all members.
- Strong leadership
- Decision making at times has been made unilaterally without appropriate engagement from relevant stakeholder groups
- Inclusion

The need to clarify focus and strengthen the community policy/pillar.

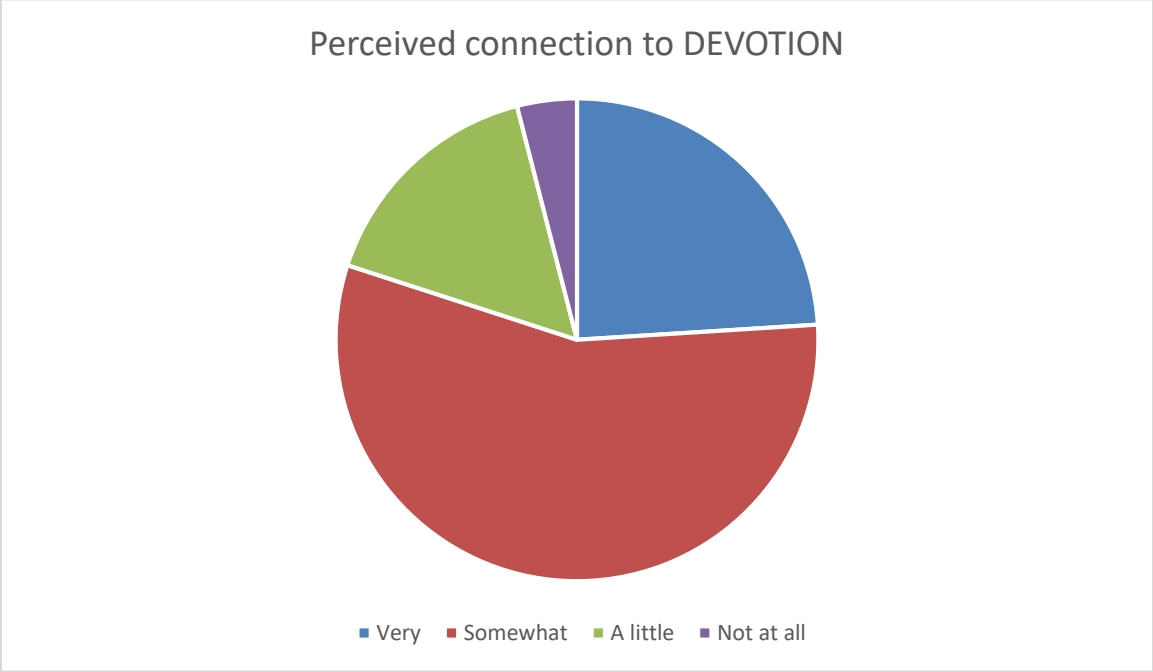
- A huge number of challenges in Indigenous Health and the "inability" to do something about it...such as the social determinants of health
- Stakeholders are only Indigenous; this is important and commendable (ie a strength, too), but also does not reflect full spectrum of DEVOTION
- Linkage to community members
- Need to develop additional projects under the community/policy pillar to reduce exposure to risks in the prenatal period and early childhood

Balancing and aligning multiple projects.

- Trying to be there at the local level and on the ground with northern partners
- Balancing fundamental science vs population-level science
- Articulating and illustrating the interconnected nature of the projects
- Getting the basic scientists better aligned
- I imagine keeping administrative track of multiple projects on multiple timelines

Appendices 3 – Connection to DEVOTION

Respondents to the survey were asked to share their thoughts around their connectedness to the DEVOTION Network. Following is a summary of their replies.



- I'm connected through collaboration with DEVOTION members, and for conference planning. However I'm not certain my research subject area is considered relevant to DEVOTION.
- I work closely with DEVOTION team members, on research collaborations and on conference organization. But I'm not convinced my research subject is considered a valid part of the DEVOTION domain (though I perceive that it is).
- I have been able to attend Devotion meetings where updates are provided and the opportunity is provided to give feedback.
- Included in all aspects of the project. Our office also houses one of the staff members.
- Many aspects to my work and my connection is not central to what I am doing overall.
- Not the focus of my research, but important for my leadership role, and very supportive of it.
- I have missed a couple of meetings and am somewhat at a loss as to what's happening.
- I receive emails.
- Have been involved since the very beginning. Hold DEVOTION funds.
- Being on the scientific advisory committee, I receive updates, but not fully detailed on progress

- Some "glue" and identity is missing.
- I support all of the work undertaken by the Network and am committed to achieving its successes.
- I recently changed jobs and have not been able to attend meetings, but hope to correct that very soon.
- Not sure where I fit in.
- I was part of the devotion executive as I was responsible for CCHCSP, but I don't feel connected to devotion. Maybe because I'm not sure how my research program fits in.
- I have yet to really become aware of what DEVOTION is doing.
- I am on their advisory committee and they provide excellent information.
- Aside from regular meetings, we don't have as much interactions with each other around ongoing and developing research.
- I receive most communication and feel informed, I participate as much as I can in meetings etc...

Appendices 4 – Defining Developmental Origins of Health and Disease

Respondents to the survey were asked to share their definition of the developmental origins of health and disease (DOHaD) and to identify things that would not be included in DOHaD. Following is a summary of their replies.

How do you define DOHaD?

- Anything that has impact on health
- Developmental origins of health and disease
- Prior to conception, pregnancy, early years, fathers, etc
- Concept that experiences in early life (conception through early childhood) shape lifelong health.
- Healthy physical and social environments are key to support optimum human development which are key to preventing chronic diseases later in life and key to promoting wellness.
- The focus on this front was around maternal child health, prenatal to early childhood
- An area of research that evaluates perinatal and early life risk factors for health related outcomes
- Looking at early life, including in utero or even before, and those impacts on the child's growth and development
- Seeking to better understand what factors precede the disease/health conditions experienced by patients in the present and future.
- Study of health that considers intergenerational factors and the intersection between the social determinants of health and personalized medicine.
- The impact of maternal, fetal, and infant health on later development and health of the child and adult
- The internal and external factors of influence in early life that change the risk of disease and important other outcomes in patients.
- Taking a life course approach to understanding and preventing chronic disease
- Diseases later in life that stem from influences during development earlier in life
- Gestational and early-life (<5-10 years old) challenges that pre-dispose to disease.
- Research and practice related to developmental causes of a variety of chronic diseases.
- Currently diabetes and asthma origins
- Network of experts in pediatric health and diabetes
- Research projects arising out of DER-CA and MICH. The stakeholders provide support and guidance in the projects moving forward. Also share information from our perspective programs.

In your opinion, what does DOHaD not include?

- Very little
- A lot of things, but no specific example of something I think DoHaD doesn't include but others might. It is a large umbrella term though
- DOHaD is pretty broad in its conception of health and disease - accidents, injuries?
- Exposures/interventions happening after early childhood
- More needed on clinical aspects related to asthma and lung health
- Infectious illness
- Challenges beyond 5-10 years of age
- Trauma such as fractures
- Biomedical research intervention in the early life stages. Ex. intervention in the NICU that's really specific to a disease process.
- It really does not support the importance of spiritual health and traditional teachings to support healthy development throughout the lifespan. Indigenous ways of being and knowing must be considered and are crucial to inform research on Indigenous health and wellness. Social constructs (child and family services, educations systems etc.) have not been designed to support the importance of relationships and the family/community.
- Critical care
- Control or reduce smoking, recreational drug usage in community youth
- Good point! I think it includes many aspects but with the lens of plasticity and opportunity for early intervention and prevention.
- Communicable disease
- Parent representation, or community level reps
- Research that does not explore health from a life-course perspective