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CASE 11

United Hearts: Fostering Interdisciplinary Collaboration for the Detection of Critical Heart Defects in Newborns

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INTRODUCTION

Janet prepared for a teleconference with her colleagues from Newborn Screening Ontario (NSO). She sat in her home office in Calgary while her team would be calling in from NSO's location in Ottawa. With the expected birth of her own child just one week away, Janet knew that her last few days of work would be fundamental in the implementation of a novel newborn screening program in Ontario.

As a genetic counsellor with NSO since 2010, Janet was knowledgeable about the 29 rare diseases screened for in newborns. She had witnessed firsthand how early diagnosis and treatment for those diseases through newborn screening could prevent the health complications and even the death of infants. The 29 diseases were screened for using blood-spot testing, and NSO's coordination of newborn screening across Ontario ensured the highest quality newborn screening and care for serious diseases available to every newborn.

The experience and success of NSO with blood-spot testing is notable. Now Janet wondered how NSO should plan for the implementation of a point-of-care test, a new frontier for NSO. This new screening test, called Pulse Oximetry Screening (POS), would aim to identify critical congenital heart defects (CCHDs) in newborns within the first days of life. CCHDs are a serious public health issue that can result in tragic consequences when not detected in the newborn period and treated within the first year of life. Affected infants often look healthy at birth and must be identified before the onset of symptoms in order for treatment to be most effective.

POS will be done in combination with the other two procedures used for CCHD detection: pre-natal ultrasound during pregnancy and post-natal physical examination. Up to 25% of CCHDs in infants are not detected prior to discharge when only pre-natal ultrasound and post-natal physical examination are done (Mouledoux & Walsh, 2013). CCHD screening by POS will therefore aim to identify and treat infants with a CCHD that otherwise would have been missed before being sent home. A missed or late diagnosis can lead to health complications or death for the infant.

POS is a simple and specific screening test that can reliably identify affected infants by detecting low blood-oxygen levels. A newborn with low blood-oxygen levels may have a CCHD, and thus require immediate medical assessment to determine the cause of low oxygenation. Screening every infant in Ontario for CCHDs will aim to diagnose and treat affected infants early in order to ensure the best health outcomes for the newborn.

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Janet discerned that realizing the goals of this program would involve the combined efforts of health care providers across the province. With CCHD screening involving a point-of-care test, there would need to be protocols in place in order to ensure immediate follow-up of a screen-positive infant by a medical practitioner. With a wide variation in available care providers and services at birthing sites across Ontario, how could implementation rely on a single protocol? The care team members that could become involved in the care of a screen-positive infant include midwives, nurses, primary-care physicians, specialists (pediatrics, pediatric cardiology, neonatology), and transfer teams. Continuity of care between care providers is essential in both the treatment of the infant and in relaying the necessary information about an infant's screening results, diagnosis, and subsequent treatment to NSO.

Janet held the belief that interdisciplinary collaboration amongst care providers should be the approach employed to ensure continuity of care in the CCHD screening program. This, in turn, would lead to the best health outcomes for Ontario newborns and the effectiveness of the program.

How could NSO foster interdisciplinary collaboration across the various contexts of Ontario birth sites? How could implementation research allow for the NSO team to plan for context-specific challenges that could arise at certain birth centres? Could this planning mitigate those challenges through interdisciplinary collaboration?

NEWBORN SCREENING ONTARIO

Newborn Screening Ontario's Vision: The best possible health through screening.

NSO coordinates the provincial newborn screening program in Ontario. The multidisciplinary team at NSO is comprised of laboratory, clinical, and administrative staff, who collaborate to ensure that every infant born in Ontario receives the highest quality screening and care for serious diseases (NSO, 2013). The panel of 29 diseases currently screened for by NSO includes metabolic and endocrine diseases, sickle cell disease, cystic fibrosis, and severe combined immune deficiency. Approximately 200 rare disease cases are identified each year. The incidence of all rare diseases is approximately one per 800 infants (NSO, 2013, p. 3). It is critical that every newborn is screened for rare diseases because clinical signs of disease are often not present at birth and most affected infants have no family history of disease. NSO's work saves lives. Families across Ontario have been positively impacted by NSO's comprehensive newborn screening program.

The primary goal of newborn screening is the early identification of affected infants in order to prevent serious health problems. Early diagnosis and treatment can improve the health outcomes for an infant found to have a rare disease and potentially save the infant's life. In contrast, a missed or late diagnosis and treatment may result in mental retardation, serious health problems, or even death of the affected infant (NSO, 2013, p. 3).

The NSO staff coordinates the various components of the provincial newborn screening program. NSO is responsible for testing for the 29 diseases, record keeping, quality assurance of testing, and communication directly with submitters about unsatisfactory or missed samples. When an infant is determined to be screen positive for a disease, NSO's role is in referring the infant to a regional treatment centre and obtaining follow-up information. Follow-up information is retrieved from the health care providers involved in the infant's care and includes information about the treatment that the infant received. Education about newborn screening is a central component of NSO's work in order to educate parents, health care providers, and the general

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public across Ontario about the program. Ontario is a leader in newborn screening and NSO offers one of the most comprehensive newborn screening programs in Canada.

ORGANIZATIONAL GOVERNANCE

Ontario's newborn screening program was moved from Public Health Ontario (PHO) to NSO in 2006 (NSO, 2013, p. 4). PHO's action in Ontario is to protect and promote the health of all Ontarians and to reduce health inequities (PHO, 2016). The transfer of the newborn screening program to NSO allowed for the rapid expansion of the screening panel and dedicated focus to the program. NSO operates out of the Children's Hospital of Eastern Ontario (CHEO) in Ottawa and has coordinated the modernization of Ontario's newborn screening system. This modernization involved NSO's ability to screen for an increasing number of diseases, growing from two diseases in 2006 to 29 diseases by 2013.

NSO is under the stewardship of the Government of Ontario and reports to the CHEO board regarding operations and accountability. The Newborn Screening Advisory Council (NSO-AC) is an independent advisory group of health and other professionals with expertise in newborn and childhood screening. The NSO-AC advises both NSO and the Ministry of Health and Long-Term Care (MOHLTC) on newborn screening policies and programming. If a disease were to be nominated for addition to Ontario's newborn screening panel, then the nomination would first go to the NSO-AC for review. Based on their review, the NSO-AC can recommend screening for the disease, not screening for the disease, or request additional information before a decision is made. If screening for the disease is recommended, then a formal report is submitted to the MOHLTC. The MOHLTC is then responsible for deciding whether to approve and commit funding to screening for that particular disease.

As a member of the NSO-AC, Janet has enjoyed learning about the processes of a proposal moving through the government and about new potential targets of screening. There are many upstream and downstream factors that need to be considered when planning for the implementation of any program.

Janet recalled the process of submitting the report to the MOHLTC for CCHD screening, and the excitement surrounding approval just months ago. Janet worked alongside Jennifer, the NSO Operations Director, who was a major player in moving CCHD screening forward and obtaining MOHLTC approval. As the Operations Director, Jennifer is responsible for the daily operations of Ontario's newborn screening program, risk and resource management, program evaluation, and any special projects or quality improvement initiatives within NSO. Janet knew that this upcoming teleconference would involve many laughs shared between herself and Jennifer, which would ease the sense of urgency that Janet was feeling towards planning for CCHD screening implementation before her upcoming due date.

CURRENT SCREENING PRACTICES

The current newborn screening program involves blood-spot screening for 29 diseases. Nurses or midwives take a small sample of blood from the infant's heel, ideally between 24 to 72 hours after birth, and the blood is placed on a blood-spot collection card. The card is couriered to NSO, where the sample is then tested for the 29 rare diseases (NSO, 2013, p. 6). If an infant's results are negative, then he or she is at low risk of having the diseases, and the report is mailed to the hospital or health care provider who submitted the infant's sample.

A positive result does not mean that the infant has a definitive diagnosis. An infant who has a positive result has an increased risk of having the indicated disease and further diagnostic

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evaluation is required. An NSO physician refers the screen-positive infant to physicians at a regional treatment centre for follow-up diagnostic testing. The NSO physician receives follow-up information from the treatment centre about the diagnosis and corresponding treatment that the infant received. The follow-up information allows NSO to ensure that screen positive infants receive appropriate and timely care. The samples for all newborns are stored in a secure facility as part of the infant's medical record (NSO, 2013, p. 7).

A NOVEL TEST

The Government of Ontario approved the addition of CCHD to the newborn screening panel in March of 2016. CCHD screening will involve the first point-of-care test coordinated by NSO, making its implementation an unfamiliar territory for Janet and her team at NSO. The point-of-care test is called POS, which is a simple and non-invasive procedure that will be performed on each infant.

For this test, the probe of the pulse oximeter device will be placed on the right hand and then either the right or left foot of the infant and secured with a wrap. The device uses light transmission to measure the proportion of oxygenated hemoglobin in the blood and reports this level as the SpO₂ functional oxygen saturation of the newborn's blood. The measurements are taken in the right hand and in the right or left foot in order to get a pre-ductal and a post-ductal measurement, respectively. After birth, a newborn's circulation transitions from fetal to neonatal circulation, which involves the closing of the ductus arteriosus blood vessel in the heart. The ductus is open while the baby is in utero in order for the blood to bypass the lungs but then needs to close after birth when the infant depends on its own lungs for oxygenation. Measuring both pre-ductal and post-ductal saturations is important in detecting CCHDs, particularly those that are duct-dependent and show large differences between the pre-ductal and post-ductal measurements that will alert to a positive screen.

The POS test takes a few minutes and will be executed by nurses and midwives, also known as submitters, across Ontario. While POS will be familiar to the majority of submitters, implementation will involve training in result interpretation, parent screening education, and newborn-specific POS processes. For example, the algorithm and screening protocol guidelines (Exhibit 1) proposed by Kemper and colleagues (2011) for newborn CCHD screening outline how POS results should be interpreted to determine if an infant is a positive screen, negative screen, or requires a repeat screen in one hour. The actions to be taken for either a positive screen or for a negative screen are listed (Exhibit 1), as well as how the actions would most likely be divided among different health care providers (Exhibit 2) in an interdisciplinary-collaborative model.

As it is a point-of-care test, the results will be available immediately, and thus a positive infant would require immediate medical assessment. Therefore, the submitter performing the POS would need to initiate next steps to ensure that the infant is assessed by the most responsible medical practitioner in a timely manner. How would interdisciplinary collaboration among different care providers ensure continuity of care for the newborn? What if the infant needed to be referred to a pediatric cardiologist and the nearest hospital with this service was 200 km away? How would this impact communication? Janet considered the impact of contextual factors on implementation and continuity of care for positive infants requiring urgent care. How can protocols be established among interdisciplinary-collaborative teams in order to ensure timely and continuous care for screen positive infants? Janet quickly jotted down these thoughts in preparation for the meeting.

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CRITICAL CONGENITAL HEART DISEASE

Congenital heart defects occur when a baby's heart or major blood vessels have not formed properly during development. These defects occur in about nine per 1000 live births and are the malformations responsible for the largest proportion of infant deaths (approximately 40%). Approximately 25% of congenital heart defects are "critical," requiring surgery or catheter intervention within the first year of life. Therefore, early diagnosis and treatment are vital in protecting an affected newborn's health and ensuring the best health outcomes.

Current practices for diagnosis of CCHDs include prenatal ultrasound and postnatal physical examination. However, up to 25% of cases are missed prior to discharge by using only these methods and the affected newborns appear to be healthy (Mouledoux & Walsh, 2013). CCHD screening by POS of all newborns aims to identify affected babies that would otherwise not be detected, so that treatment can begin immediately and negative outcomes avoided (Thangaratinam, Brown, Zamora, Khan, & Ewer, 2012).

Janet recognized the role of NSO in educating parents and guardians about CCHDs and the screening program. While NSO would provide the educational materials (pamphlets, posters, online information), the frontline health care providers would have prominent roles in the education component. Considering interdisciplinary collaboration when developing the educational components would allow for a continuous and uniform message for parents and guardians. This could enhance parent/guardian satisfaction with the CCHD screening program, compliance with screening, and trust in the provincial newborn screening program.

THE CHALLENGE OF CONTEXT

Janet's plan to conquer continuity of care in CCHD screening through interdisciplinary collaboration would need to address the challenge of differing birth site contexts across Ontario. NSO could provide a standardized protocol for screening, results interpretation, and subsequent actions in the cases of screen negatives and screen positives. However, Janet recognized the need to take context-specific factors into consideration throughout planning.

Accessibility to certain resources, such as heart echocardiography and health care providers, will differ based on the birth site. For example, an infant is born in a Northern Aboriginal community with no road access and the submitter is an Aboriginal midwife. The midwife would have the responsibility of coordinating air transport of a screen-positive infant to the nearest hospital with the appropriate resources and health care providers. Once transferred, the new site would then determine the cause of low oxygenation for the infant (e.g. pediatric cardiology, heart echocardiography, pediatrics, etc.) and provide the appropriate treatment. Continuity of care for a screen-positive infant will depend on the context-specific protocol that the health care providers have put in place. A lack of interdisciplinary collaboration and communication could result in delays in diagnosis and treatment for an infant in need of urgent care. These delays could lead to detrimental results, such as death of the affected infant.

The contexts that immediately came to Janet's mind were isolated northern communities, community hospitals with no echocardiography equipment, home births, and tertiary care hospitals (Exhibit 3). All of these contexts would require drastically different processes and so implementation research into developing context-specific protocols would be essential prior to the start of implementation. In order to encourage interdisciplinary collaboration in a specific context, Janet believed that NSO would need to engage the health care providers who would be directly involved in the care of newborns being screened to develop the protocols. Janet wondered how care providers, who likely would be facing time constraints and competing demands already, would view the program that would be detecting rare conditions. How would individuals in a birth centre react if they initially complied with the POS protocol, but did not

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experience a confirmed CCHD diagnosis over a long period of time? Would the rarity of screen positive tests reduce compliance? How could NSO play a role in maintaining enthusiasm for the CCHD screening program and in fostering the interdisciplinary collaboration and continuity of care?

THE CARE TEAM: INTERDISCIPLINARY COLLABORATION

“Interdisciplinary implies a deeper degree of collaboration among team members. It implies an integration of the knowledge and expertise of several disciplines to develop solutions to complex problems in a flexible and open-minded way”.

– Nolte & Tremblay, 2005

The urgent care for an infant with a positive result and potential CCHD would involve health care providers from different disciplines, each of whom would have their respective responsibilities (Exhibit 2). The initial submitter would execute the POS. If an infant screens positive, the next steps the submitter would take would be impacted by the particular context. If a midwife is performing the test in a client’s home and the screen was positive, then the next steps would require communication with a hospital in order to facilitate transfer of the infant to the hospital. If the birth and screening took place in a tertiary-care hospital, then the submitter would likely inform the primary-care physician of the results. The physician would then begin a medical assessment of the infant to determine the cause of low oxygen levels and would consult with neonatology and/or pediatrics, if available. If a CCHD could not be eliminated as a potential cause, a pediatric cardiologist would be consulted. The cardiologist may have a sonographer perform a heart echocardiogram to aid in CCHD diagnosis.

Janet created a list of the health care providers who could become involved in a positive screen case, and thus would need to be involved in the program implementation planning. She also jotted down responsibilities that may apply to each provider (Exhibit 2). Recognizing that each type of provider may not be available in each context, Janet knew that there would need to be context-specific protocols developed for each particular birth site and for homebirths. Additionally, a few hospitals in Ontario had already implemented CCHD POS; how would NSO work with those institutions? Would the health care providers at those institutions be reluctant to change their existing protocols?

Just before the teleconference call from Ottawa came through, Janet recalled the conference she went to on *Enhancing Interdisciplinary Collaboration in Primary Health Care in Canada* (Nolte & Tremblay, 2005). Evidence supported that interdisciplinary collaboration among health care providers shifts the focus to a more patient-centred care model, in which patients have greater levels of knowledge about their care and thus increased satisfaction (Nolte & Tremblay, 2005). Collaborative work among health care providers also leads to increased access for patients to a range of services and closes gaps in service (Alberta Health and Wellness, 2000; Kaini, 2015).

In the context of care for children with complex health care needs, evidence shows that interdisciplinary collaboration has resulted in parents/caregivers feeling well-informed, confident in their care providers, and satisfied with the care their child was received through the collaborative approach (Nolte & Tremblay, 2005; Zwarenstein, Goldman, & Reeves, 2009). Janet believed that interdisciplinary collaboration was the key to effective implementation of CCHD screening; however, how would NSO’s planning encourage collaboration amongst teams in Ontario? In addition, interdisciplinary teams in health care are dynamic and adapt to a particular patient’s care needs. Therefore, it would be challenging to create context-specific protocols for a dynamic care team in which its members could be at different institutions, but this

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also points to the importance of ensuring continuity of care. Janet created a list of relevant facilitators and barriers (Exhibit 4) to interdisciplinary collaboration that could be addressed when planning for CCHD screening implementation. NSO would need to have an awareness of these factors and address them in planning.

IMPLEMENTATION RESEARCH

“Successful implementation research begins and ends with successful collaboration.”

– Implementation Research in Health, 2013

Implementation research involves critical analysis of factors that may impact the effectiveness of implementation of an intervention. The intervention in this case is the CCHD screening program. Analysis of the multiple factors and domains that can have an impact on the program aids in determining the best way to implement an intervention in a health care system, and how to plan for program implementation, evaluation, and modification (WHO, 2014, p. 2). The interacting domains (Exhibit 5) to consider in implementation research are the outer settings (social, geographical, etc.), inner settings (organizational culture, structure, etc.), processes for implementation, and individuals involved in implementation (WHO, 2014, p. 5). The outer setting relates directly to planning for context-specific protocols at a particular birth centre. A centre that is geographically isolated needs to plan for infant transfer in the case of a positive result, for example. The inner setting would be interconnected with interdisciplinary collaboration, as Janet knew that power relations, organizational culture, and relationships would directly impact that component of implementation. In the case of NSO’s planning for CCHD screening implementation, implementation research should be initiated prior to the program starting. Janet decided these steps need to be taken now, and she needed to determine which stakeholders to involve at these stages.

Implementation research also helps to plan for and anticipate intervention problems and see how understanding context helps to deliver interventions effectively in diverse settings (WHO, 2014, p. 6). There are many different contexts to be considered in an Ontario-wide CCHD screening, and so context-specific research is an important step in implementation planning. There is no provincial/territorial program already established in Canada for CCHD screening, and so extrapolating results from the programs in other countries will also require additional research into the Canadian context.

Challenges in implementation can arise due to a range of real-world contextual factors, and so implementation research can be employed in context-specific and evidence-informed decision making. A tool found to be efficacious in health care may not actually prove to be effective if contextual factors are not accounted for. Implementation research helps to translate efficacious tools into effective interventions in real-world settings (Exhibit 6) (WHO, 2014, p. 17). In regards to CCHD screening, POS has been found to be an efficacious tool for identifying infants with CCHD (Kemper et al., 2011). However, this does not ensure that the screening program will be effective in Ontario. Accessibility needs to be considered, so that implementation of the program accounts for barriers to access that may be present. The intervention must be accessible to the target group. After accessibility is addressed, provider compliance is also a necessary step towards ensuring effectiveness of the screening program. Health care providers must comply with the relevant processes and policies of screening. Patient compliance to CCHD screening follows provider compliance. NSO’s strong background in education of parents and caregivers regarding newborn screening will be beneficial in educating on CCHD screening. It was also noted that interdisciplinary collaboration can improve patient’s/client’s knowledge about health services and increase their satisfaction with collaborative care teams, which in turn would likely

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increase adherence (Nolte & Tremblay, 2005). The listed components compose the proposed pathway to intervention effectiveness (Exhibit 6) (WHO, 2014, p. 17).

Implementation planning includes evaluation of the intervention, in which implementation outcome variables (Peters, Tran, & Adam, 2013; Proctor et al., 2011) should be considered. These variables include acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, coverage, and sustainability (Peters, Tran, & Adam, 2013; Proctor et al., 2011). Outcome variables act as the indicators of a program's effectiveness. Janet considered adoption in particular, as the uptake of CCHD screening among health care providers would be crucial for the program to be effective. With screening for CCHD being a point-of-care test, the program relied on submitter compliance to screen every infant born in Ontario. In terms of the interdisciplinary team, adoption would be required among other health care providers in regards to the follow-up protocols for a positive infant. If a submitter correctly identifies a positive infant, but a physician is unwilling to follow up with an immediate examination, then the intervention cannot proceed.

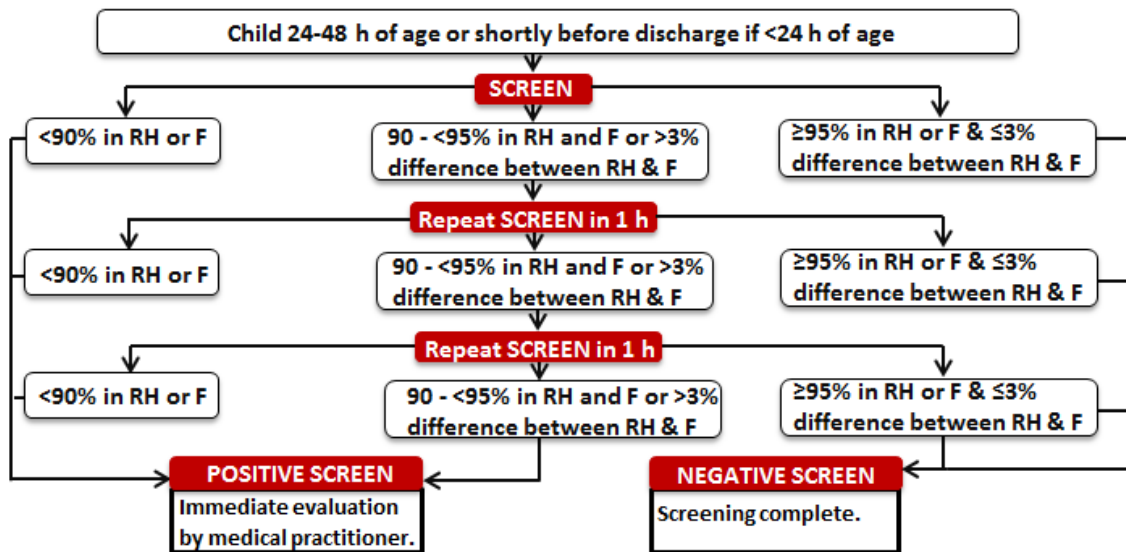
Equity in screening all newborns would also rely on the adoption by health care providers in order to ensure complete coverage, which is another outcome variable. Feasibility would be associated with context-specific facilitators and challenges. Feasibility to screen each newborn and have immediate assessment of positive-screen infants would be very different in a remote nursing station with no physician, in comparison to a tertiary care hospital with access to multiple specialists.

CONCLUSION

Janet hears the incoming call. She would advocate to the team about the importance of continuity of care and interdisciplinary collaboration, but it was yet to be determined how NSO would foster and encourage both among care teams across Ontario. Would health care providers comply to screening protocols? Would NSO be able to ensure entire coverage, so that all newborns would have equal access to CCHD screening? It was clear to Janet that implementation research would be the approach necessary to address the diverse contexts of birth sites across Ontario, but who would lead that initiative once she was on maternity leave? What stakeholders should be involved early on in implementation planning? Janet picked up the phone.

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EXHIBIT 1 Protocol for Critical Congenital Heart Disease Screening in Ontario



Source: Kemper et al., 2011. Reproduced with permission from *Pediatrics*, 128, e1259 Copyright © 2011 by the AAP.

General CCHD Screening Protocol

- Screening of all newborns between 24-48 hours after birth or shortly before leaving the birth centre if discharge is within 24 hours of birth.
- Submitters must inform and educate parents/guardians about CCHD screening; parents have the liberty to decline screening and this action must be documented on the newborn screening card.
- The pulse oximetry readings are taken in the right hand (pre-ductal) and either foot (post-ductal).
- The pulse oximeter used for screening should be FDA approved for use in newborns, measure functional oxygen saturation, and be both motion-tolerant and validated in low perfusion conditions.
- The algorithm (Kemper et al., 2011) is used by submitters to determine if screen positive or negative, but it should not replace clinical judgment.
- Each birth centre has a context-specific protocol for both screen negative and screen positive infants; communication structure in place between care providers that would potentially become involved in the care of a screen positive infant. These providers may be at the same institution or at different institutions, which would require infant transfer.
- An infant's pulse oximetry results are recorded on his/her respective newborn screening card and submitted to NSO.
- A symptomatic baby requires clinical assessment, even if screen negative.

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EXHIBIT 1 (cont'd)

Positive Screen Actions
<ol style="list-style-type: none">1. Submitter documents the pulse oximetry results on the newborn screening card that is sent to NSO.2. The submitter notifies the parents/guardians of the results and the subsequent actions.3. Submitter notifies responsible medical practitioner immediately.4. Immediate medical assessment by the responsible medical practitioner is conducted.5. Evaluation of infant for both cardiac and non-cardiac pathology.<ol style="list-style-type: none">a. Non-cardiac causes of low oxygen saturation include persistent pulmonary hypertension, pneumonia, infection, etc.b. This step may involve consultation with pediatrics and/or neonatology.6. If a cardiac-cause cannot be excluded, then refer the infant to pediatric cardiology and obtain a diagnostic echocardiogram. The individual performing the echocardiography should be trained in interpreting infant echocardiograms.7. If any of the services in the protocol are not accessible at the given birth centre, the infant may be transferred to another institution or telemedicine may be contacted.8. Receipt of pulse oximetry results on the newborn screening card by NSO and data input of results.9. NSO collects follow-up information via the Diagnostic Evaluation Report Form (DERF) sent to submitters and involved medical practitioners in the newborn's care (e.g. pediatric cardiologist, family physician, etc.)
Negative Screen Actions
<ol style="list-style-type: none">1. Submitter documents the pulse oximetry results on the newborn screening card that is sent to NSO.2. The submitter notifies the parents/guardians of the results and informs them that a negative screen does not exclude the possibility of all cardiac defects.<ol style="list-style-type: none">a. If the infant presents with any of the following symptoms, the parents/guardians should seek medical attention for their infant immediately: poor weight gain, sweating around the head especially during feeding, rapid or troubled breathing, tires easily during feedings, pale/bluish skin tone, puffy face and/or feet.3. Receipt of pulse oximetry results on the newborn screening card by NSO and data input of results.4. If a screen negative infant was later found to have a CCHD, this should be reported to NSO in order to document and follow-up with false-negative cases.

Source: Adapted from Kemper et al., 2011.

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**EXHIBIT 2
Responsibilities of the Health Care Providers in CCHD Screening**

Provider	Responsibilities
Submitter (nurse, midwife)	<ul style="list-style-type: none"> • Complete training for newborn pulse oximetry screening. • Educate parents regarding newborn screening for CCHDs. • Perform pulse oximetry on newborn. • Record screening results on newborn screening card and submit to NSO • Ensure parents are informed of results. • If infant is screen positive, immediately initiate context-specific protocol (e.g. inform medical practitioner who will perform assessment; if after homebirth, call hospital to inform need for infant transfer to hospital). • As the submitter, fulfill necessary follow-up requirements with NSO after infant screens positive (e.g. complete Diagnostic Evaluation Report Form). • Communicate with other members of the care team.
Examining medical practitioner	<ul style="list-style-type: none"> • Receives screen result from the submitter (nurse, midwife). • May need to arrange for transfer of the infant to another unit or hospital if required services not available in own facilities. • Consult with specialists, such as those from neonatology or pediatrics. • Keep parents informed. • Communicate with other members of the care team.
Specialists (neonatology, pediatrics)	<ul style="list-style-type: none"> • Provide expertise to the examining medical practitioner on the cause of low blood oxygen levels in newborn. • Consider both non-cardiac pathology and cardiac pathology that may be associated with a positive screen result (e.g. infection, persistent pulmonary hypertension), and assess for potential CCHD. • May need to arrange for transfer of the infant to another unit or hospital if required services are not available in own birth centre, such as pediatric cardiology or heart echocardiography. • Keep parents informed. • Communicate with other members of the care team.
Pediatric cardiologist	<ul style="list-style-type: none"> • If a CCHD has not been ruled out, then the pediatric cardiologist will assess for CCHDs. • Arrange for next steps, such as a heart echocardiogram and a chest x-ray. • Diagnose infant with CCHD if applicable and arrange for next steps in treatment. • Keep parents informed. • Communicate with other members of the care team.
Sonographer	<ul style="list-style-type: none"> • Perform heart echocardiogram on newborn suspected to have a CCHD. • Communicate with other members of the care team.
Newborn Screening Ontario	<ul style="list-style-type: none"> • Follow-up with submitters on positive screen results and ensure care of affected infants has been implemented. • Collect follow-up information from health care team on screen positive infant through a Diagnostic Evaluation Report Form. • Collection of pulse oximetry results of all newborns in Ontario and submit into database. • Communication with submitters and their teams regarding program implementation, improvements, and sustainability. • Educate parents, health care providers, and the general public in Ontario about newborn screening for CCHD.

Source: Created by author.

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**EXHIBIT 3
Context-Specific Examples for CCHD Screening**

Context	Available Resources	Suggested reading (if applicable)
1. Indigenous infant born in Northern community at nursing station; no road access.	<ul style="list-style-type: none"> • Midwife (performed birth & pulse oximetry) • Nursing station with two on-staff nurses; 24/7 availability • Traditional healers & community elders • Emergency transport 	Minore, B., & Boone, M. (2002). Realizing potential: improving interdisciplinary professional/paraprofessional health care teams in Canada's northern aboriginal communities through education. <i>Journal of Interdisciplinary Care</i> , 16(2), 139-147.
2. Infant born at Mount Sinai Hospital, Toronto.	<ul style="list-style-type: none"> • Midwife (performed birth & pulse oximetry) • Primary care physician, or obstetrician associated with case • Specialists (neonatology, pediatrics, pediatric cardiology) • Sonographer specialized in pediatric heart echocardiograms 	Posthumus, A. G., Scholmerich, V. L., Waelput, A. J., Vos, A. A., De Jong-Potjer, L. C., Bakker, R., Bonsel, G. J., Groenewegen, P., Steegers, E. A., & Denktas, S. (2013). Bridging between professionals in perinatal care: towards shared care in the Netherlands. <i>Maternal and Child Health Journal</i> , 17(10), 1981-1989.
3. Home birth in Ottawa.	<ul style="list-style-type: none"> • Midwife (performed birth & pulse oximetry) • Ottawa hospitals (e.g. Children's Hospital of Eastern Ontario, with specialty care in neonatology, pediatric cardiology, & pediatrics; available heart echocardiography) 	Narayan, I. C., Blom, N. A., Verhart, M. S., Smit, M., Posthumus, F., van den Broek, A. J., Havers, H., Haak, M. C., & te Pas, A. B. (2015). Adapted protocol for pulse oximetry screening for congenital heart defects in a country with homebirths. <i>European Journal of Pediatrics</i> , 174(1), 129-132.
4. Infant born in community hospital.	<ul style="list-style-type: none"> • Nurse as submitter • Primary care physician (performed birth) • Cardiologist on call at community hospital • Tertiary care hospital 200 km away, with pediatric cardiology and heart echocardiogram services 	Psaila, K., Schmied, V., Fowler, C., & Kruske, S. (2015). Interdisciplinary collaboration of transition of care: perspective of child and family health nurses and midwives. <i>Journal of Clinical Nursing</i> , 24, 160-172.

Source: Created by author.

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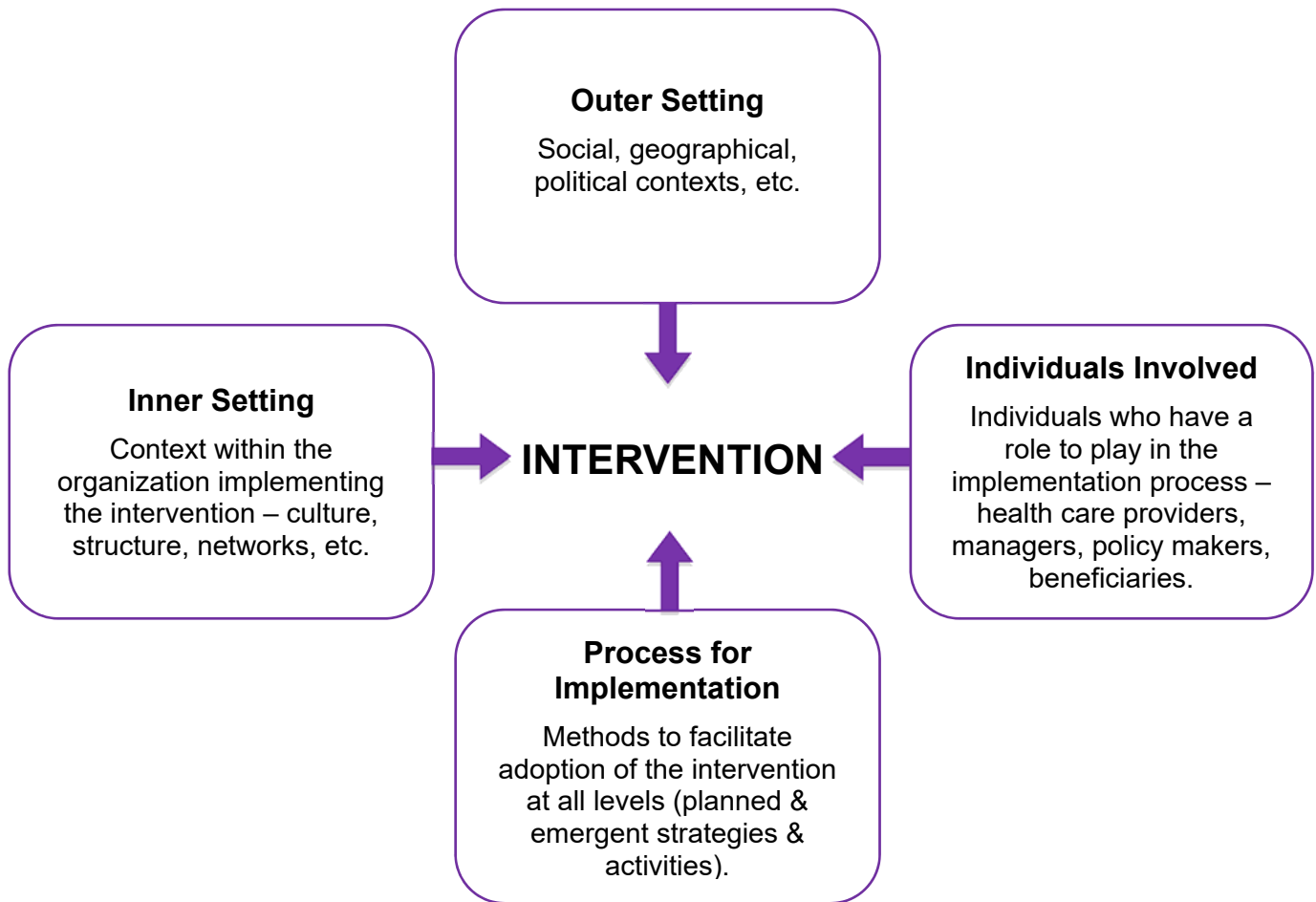
**EXHIBIT 4
Facilitators and Barriers to Interdisciplinary Collaboration**

Facilitators	Barriers
<ul style="list-style-type: none"> • Good leadership at all levels • Shared vision, values, and belief in the value of collaboration and coordinated approach to care • Trust and mutual support • Shared decision-making • Patient and user focused • Effective internal communication • Open and participative style • Strong external partnerships • Routine feedback on performance • Education and professional development • Clear understanding of & respect for team members' roles and responsibilities • Accountability amongst providers • Adequate resources available & accessible 	<ul style="list-style-type: none"> • Need for long-term commitment by all levels within an organization • The need to redefine roles and understand resistance to change • Tension, competition, and role confusion • The need to build clients' awareness and understanding of interdisciplinary approaches • The need for a common understanding of organizational structures and processes • Inadequate resources to support the team • The need to commit to ongoing evaluation and adjustment of the team approach • Difficult to identify best practices because of variation and measured outcome variables in interdisciplinary projects

Source: Nolte & Tremblay, 2005.

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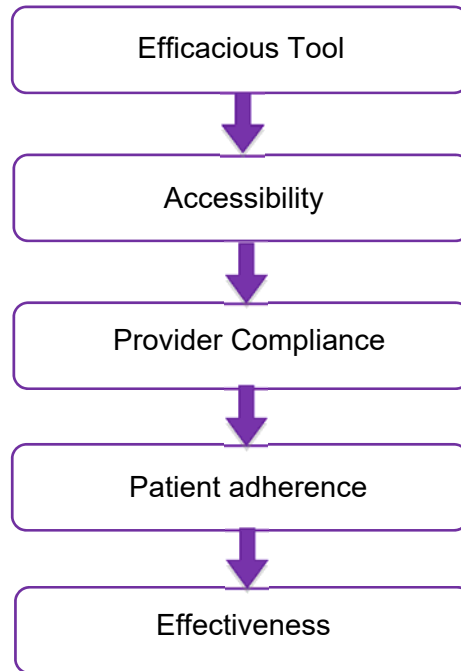
EXHIBIT 5 The Interacting Domains in Implementation Research



Source: WHO, 2014.

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EXHIBIT 6 Influence of Health System Factors on Intervention Effectiveness and Impact



From source: “In order for a proven and efficacious tool to be effective, it must be accessible to the target group, health care providers must comply with the relevant policies, and patients must adhere to the information on use of the tool. However, there are several challenges including inequities that affect the ability of various stakeholders to use the tool as expected eventually rendering the tool ineffective.”

Source: WHO, 2014.

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REFERENCES

1. Alberta Health and Wellness. (2000). *Advancing Primary Health Care in Alberta*. Edmonton: Alberta Health and Wellness.
2. Kaini, B.K. (2015). Interdisciplinary care and role of team leaders. *Journal of the Nepal Medical Association*, 53(197), 40–44.
3. Kemper, A.R., Mahle, W.T., Martin, G.R., Cooley, W.C., Kumar, P., Morrow, ... & Howell, R.R. (2011). Strategies for implementing screening for critical congenital heart disease. *Pediatrics*, 128, e1259.
4. Mouledoux, J.H., & Walsh, W.F. (2013). Evaluating the diagnostic gap: statewide incidence of undiagnosed critical congenital heart disease before newborn screening with pulse oximetry. *Pediatric Cardiology*, 34(7), 1680–1686.
5. Newborn Screening Ontario. (2013). *Newborn screening manual: A guide for newborn care providers* (1st ed.), 3–7. Ottawa, Canada: Newborn Screening Ontario. Retrieved from <https://www.newbornscreening.on.ca/sites/default/files/cho0095-nsm-pages-jan2015-web.pdf>
6. Nolte, J., & Tremblay, M. (2005). *Enhancing interdisciplinary collaboration in primary health care in Canada*. Ottawa, Canada: Enhancing Interdisciplinary Collaboration in Primary Health Care. Retrieved from http://tools.hhr-rhs.ca/index.php?option=com_mtree&task=att_download&link_id=5305&cf_id=68&lang=en
7. Peters, D.H., Tran, N.T., & Adam, T. (2013). *Implementation research in health: A practical guide*. Alliance for Health Policy and Systems Research, World Health Organization. Retrieved from http://who.int/alliance-hpsr/alliancehpsr_irpguide.pdf
8. Proctor, E., Silmere, H., Raghavan, R., Hovmand, P., Aarons, G., Bunger, A., Griffey, R., & Hensley, M. (2010). Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. *Administrative and Policy in Mental Health*, 38(2), 65–76.
9. Public Health Ontario. (2016). *Public Health Ontario: Our organization*. Public Health Ontario: Partners for Health. Retrieved from <http://www.publichealthontario.ca/en/About/Pages/Organization.aspx>
10. Thangaratinam, S., Brown, K., Zamora, J., Khan, K.S., & Ewer, A.K. (2012). Pulse oximetry screening for critical congenital heart defects in asymptomatic newborn babies: A systematic review and meta-analysis. *The Lancet*, 379(9835), 2459–2464.
11. World Health Organization. (2014). *Implementation research toolkit: Workbook*, 2-17. Geneva, Switzerland: WHO Document Production Services. Retrieved from http://www.who.int/tdr/publications/year/2014/9789241506960_workbook_eng.pdf
12. Zwarenstein, M., Goldman, J., & Reeves, S. (2009). Interdisciplinary collaboration: Effects of practice-based interventions on professional practice and healthcare outcomes (review). *Cochrane Database of Systematic Reviews*, 3, CD000072.

INSTRUCTOR GUIDANCE

United Hearts: Fostering Interdisciplinary Collaboration for the Detection of Critical Heart Defects in Newborns

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Ava John-Baptiste, PhD (Assistant Professor, Western University)

BACKGROUND

Newborn Screening Ontario (NSO) prepares to implement screening for critical congenital heart defects (CCHDs) in all newborns born in Ontario. Janet Marcadier, a genetic counsellor at NSO, recognizes the particular challenges of implementing a point-of-care newborn screening test that will be performed by submitters (nurses, midwives) across the province. The other 29 conditions screened for by NSO do not involve a point-of-care test but rather testing is done in the NSO laboratory. While standardization for a provincial program is important, there are many contextual factors that will impact CCHD screening implementation at each specific birth site. Interdisciplinary collaboration among health care providers will be essential in implementation. How could NSO foster interdisciplinary collaboration through implementation planning? NSO needs to consider how primary care teams are often dynamic and include different health care providers depending on the needs of the patient. Would interdisciplinary collaboration help to ensure screening compliance among submitters? By applying concepts of implementation research, context-specific protocols can be developed for interdisciplinary teams at different birth sites in Ontario.

OBJECTIVES

1. Develop a context-specific implementation plan for CCHD newborn screening.
2. Identify contextual factors that can impact interdisciplinary collaboration.
3. Apply implementation research strategies to inform implementation planning for evidence-based CCHD screening and fostering interdisciplinary collaboration.
4. Understand the usability of the interdisciplinary collaboration framework when planning, implementing, and evaluating a newborn screening program in Ontario.
5. Discuss roles and responsibilities of health care providers in the interdisciplinary model for CCHD screening.

DISCUSSION QUESTIONS

1. How did your team define “interdisciplinary collaboration”?
 - a. Was it difficult to come to a consensus?
2. Do you think interdisciplinary collaboration has a role in the future of public health?
 - a. If yes, do you think training of health care providers should be changed and what changes should be made?
3. How did your team incorporate implementation research into planning?
4. What were the three implementation outcome variables that your team identified to be most important in implementation? Provide details about one of the three implementation outcome variables.
5. Should provincial newborn screening plans be designed for many different contexts or should NSO take a standardized approach to implement CCHD screening?

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6. From your team's particular context, is provincial newborn screening for CCHD an equitable health intervention?

KEYWORDS

Newborn health; screening; interdisciplinary; collaboration; implementation research.