

Impact of an Integrated Framework on Care Transition of Infants with Medical Complexity

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ABSTRACT

INTRODUCTION: Infants with medical complexity (IMC), who would once have died in early infancy, now live longer and present significant care transition challenges after discharge from the Neonatal Intensive Care Unit (NICU). In 2018, representatives of nine hospital in-patient and out-patient services joined to form a core team to plan improvements in care transition. Our (core team's) primary aim was to determine the individuals or representatives from hospital programs i.e. care-provider stakeholders' intentions to act following meaningful engagement in identifying care transition gaps, reviewing evidence and taking part in deliberations on potential interventions to address care transition gaps. The secondary objectives were to determine (i) high-priority interventions for implementation and (ii) care providers' network growth.

METHODS: We performed an improvement project between January 2019 and February 2020. The core team members initially established the project scope and approach for carrying out their activities by using an integrated framework with 4 essential elements; (i) engaging care provider groups and alumni parents caring for IMC, (ii) identifying care transition gaps, (iii) performing and presenting evidence informed potential solutions to address gaps, and (iv) facilitating deliberations to identify priority interventions for implementation in our setting. We identified care-provider stakeholders by snowball sampling technique and alumni parents of IMC NICU family alumni database, respectively. We elicited interdisciplinary care providers' intention to act and level of engagement using validated survey questionnaires, and stakeholders identified interventions for implementation on an effort-impact matrix.

RESULTS: Fifty-two interdisciplinary care providers representing various services of Children's and Women's Hospital, community care and provincial organizations, and 8 alumni parents were engaged with an overall network growth during this project. We identified 25 care gaps through parent and care provider engagement activities and selected 9 for evidence review. Evidence reviews identified at least three potential solutions for every identified gap. We chose 4 relevant evidence briefs for deliberation session and circulated with intended participants of deliberation session. Twenty-two participants from an invited 42 (52%) took part in the deliberation session. Ninety percent of respondents found evidence briefs and deliberative dialogues helpful. Eighty percent of care provider respondents indicated an intention to act from what they learnt from evidence briefs and dialogues to advocate for care transition changes. We grouped the key interventions for implementation under 4 domains (i) neonatal to pediatric complex care program transition; (ii) caregiver mental health; (iii) caregiver peer support and self-help groups and (iv) hospital to community care coordination. Deliberation session participants then prioritized multiple change interventions within each domain using an effort-impact matrix.

CONCLUSIONS: Interdisciplinary care providers representing various hospital and community services reported strong intentions to act following adoption of an integrated framework in addressing gaps in transitioning IMC from NICU to community or other in-hospital units. The volume and variety of interdisciplinary care providers engaged increased during the project period. We identified high priority interventions for implementation under four domains.

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INTRODUCTION

With advances in technology and innovative medical treatments, infants with medical complexity (IMC), defined as those with significant and/or multiple health conditions¹, who would once have died in early infancy, now live longer and present significant care coordination challenges after discharge from hospital. As their life expectancies increase, the costs of long-term care and social needs increase in parallel¹. This complex and fragile population highly depends on caregivers (families) and their care-providers². While families must cope with their child's uncertain health trajectory and their ability to provide lifelong, round-the-clock care, health care systems also struggle to provide individualized care that resonates with the family's needs, reflect best medical practice and incur high financial burden³. Following discharge from the neonatal intensive care unit (NICU), these patients experience significant morbidity and mortality and require extensive hospital and community-based resources⁴.

Key to the health outcome of this population is the successful transition from in-hospital neonatal critical care (typically coordinated by one team) to early childhood

community-based care. Following discharge from NICU, families assume the role of primary caregiver supported by multiple care providers across various settings spread between home, community and the hospital. Successful transition of IMC is the provision of "*uninterrupted, coordinated, developmentally appropriate, and psychologically sound health care as they move out of neonatal phase into early childhood phase by care providers*"⁵.

In 2017, IMC discharged from the quaternary care NICU at BC Women's Hospital (BCWH) had high rates of mortality (17%), Emergency Department visits (44%), inpatient and PICU admissions (58% and 26% respectively), in the first-year post discharge, all considered as surrogate markers of unsuccessful transition^{4 6 7}. Sub-optimal transition adversely affects infants' development, physical health, growth and educational achievement of these vulnerable infants and predisposing their families to chronic physical and mental health conditions, financial and emotional problems and an increased likelihood of relinquishing childcare^{7 8}. In 2018, as individuals or representatives from hospital programs who have an interest in any decision related to care improvement activity pertaining to IMC (care provider

stakeholders⁹) we joined as a working group to improve care transition. We quickly realized that efforts to improve care transitions need a coordinated longitudinal and iterative organized approach in planning the work¹⁰. Such an approach should include understanding current gaps in our setting from the perspectives of both care providers and alumni parents of IMC, identifying potential solutions from various sources, recognizing barriers and organizational constraints, and diving organizational and individual readiness for implementing evidence informed changes. Evidence briefs and stakeholder deliberative dialogues framework are valid methods to inspire insight and generate intentions to act among stakeholders. It is based on the theory of planned behaviour^{11 12}, and aligns well with related frameworks like community-based participatory research¹⁰, research-practice partnership¹³, and stakeholder Engagement¹⁴. We found an integrated framework which combines above individual frameworks was likely to facilitate our care transition improvement efforts at a hospital level.

We hypothesized that transition of IMC from our NICU to community or other in-hospital units could improve by adopting an integrated framework that includes four

elements pertinent to a setting; (i)engaging care provider groups and alumni parents caring for IMC (stakeholders), (ii)identifying care transition gaps, (iii) performing and presenting evidence informed potential solutions to address gaps, and (iv) facilitating deliberations to identify priority interventions for implementation.

Interdisciplinary teams have never tested an integrated framework for improving the readiness of care provider representatives, and for planning care transition improvements. Our primary aim of this project was to determine the care-provider group representatives' intentions to act on change interventions to address care transition gaps. The secondary aims were to determine (i) high-priority interventions for implementation and (ii) stakeholders' network growth¹⁵.

PREEXISTING PROGRAM DESCRIPTION

At BCCWH, a designated neonatal complex care team (NCCT) coordinates the hospital discharge and transition of IMC from the NICU to community or other in-hospital units since 2013. A neonatologist led the NCCT on a rotational basis and included a consistent team of experienced neonatal nurse discharge coordinators and

respiratory therapists. This team was besides point of care staff and allied staff available to any neonate in the NICU. Though NCCT members interacted with other care teams within the hospital, such interactions were often in silos, and there was never a coordinated approach by care teams in improving transition of IMC and families from NICU to community or other in-hospital units.

METHODS

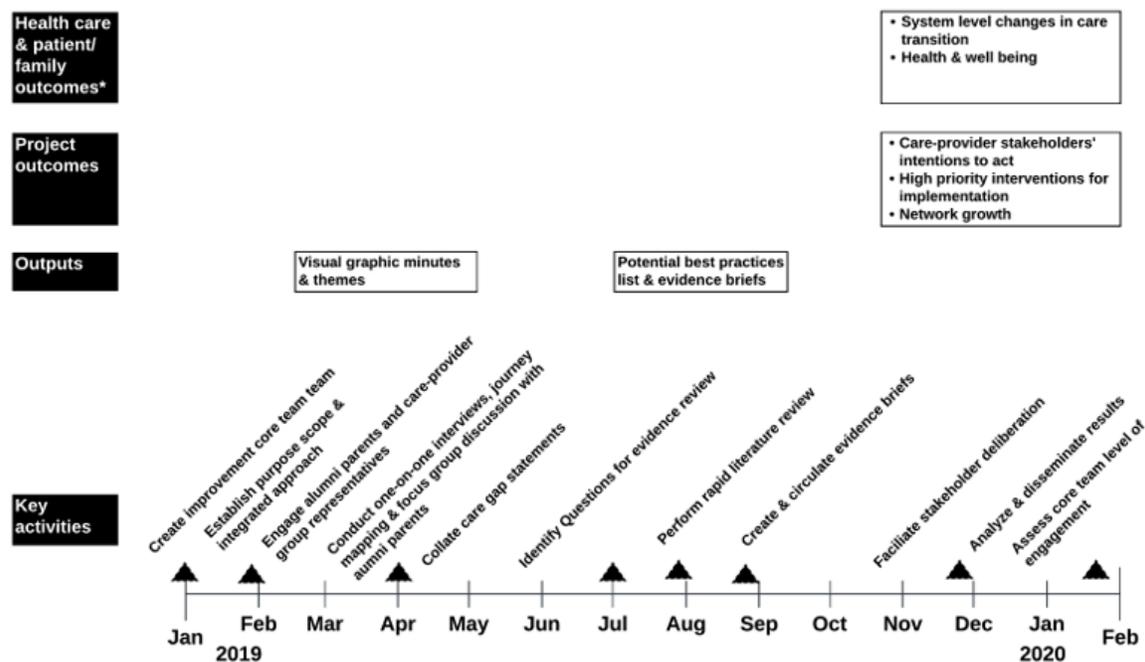
We performed a mixed method, prospective pragmatic project from January 2019 to February 2020 at British Columbia

Children’s and Women’s Hospital (BCCWH), a single-site campus providing quaternary level perinatal, neonatal and pediatric intensive care. We choose the published standard definitions for the terms; care transition, knowledge to care gap, care coordination, stakeholder engagement and continuity of care ^{16 17 18 19 20}.

APPLICATION OF PROJECT FRAMEWORK:

We present the key activities, timelines and outcomes of the project in Figure 1.

Figure 1: Project timeline showing key activities, outputs and outcomes



Inverted triangle= Project team meetings, * beyond the scope of this project

1. Engaging individuals or representatives from hospital programs (stakeholders ⁹) who have an interest in any decision related to care improvement activity pertaining to IMC beyond the project core team

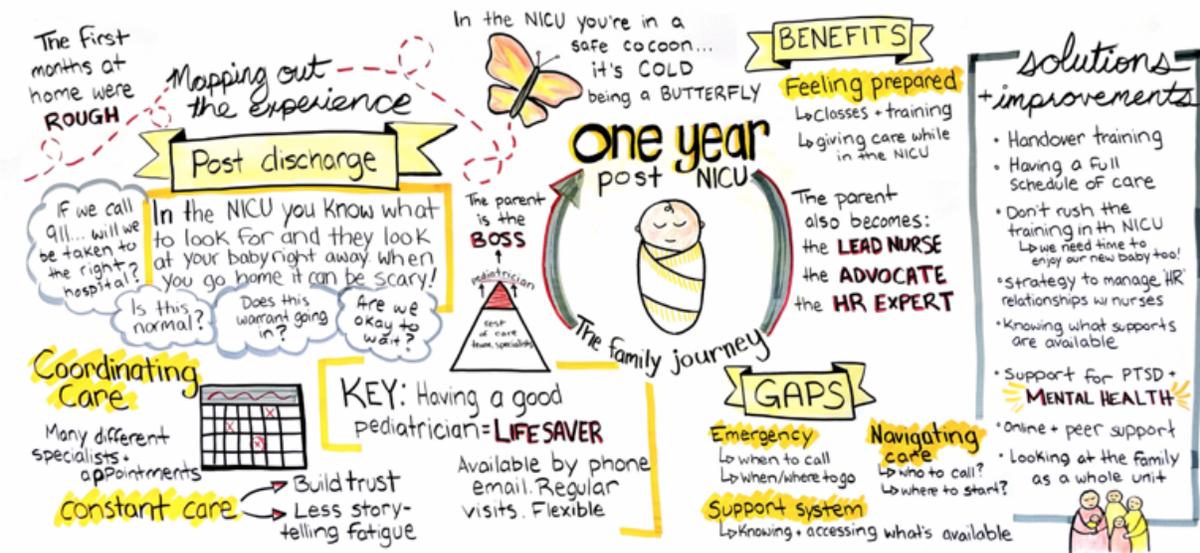
We distinguished two broad categories of stakeholders in this project whose engagement was critical in planning improvements: care providers and families. We identified care-provider stakeholders using “snowball sampling” technique where, existing core team members recruited future subjects from among their acquaintances to ensure (i) fair representation from interdisciplinary programs relevant to care transition of IMC including decision makers, researchers, practitioners and (ii) representatives brought an understanding of regulatory and institutional constraints, social, political and economic factors beyond the health care. We identified family stakeholders, i.e., alumni parents with lived experience of caring for IMC using the NICU alumni family database maintained by NICU family advisors, by cross-referencing with the NCCT data registry.

2. Identifying care gaps

We elicited a combination of alumni parents and care providers’ perspectives to identify real care transition gaps in our setting. We

performed three serial steps to ensure accurate capture of the family’s voice and lived experience: (i) One-on-one interview with alumni parents; (ii) Journey mapping session ²¹ and (iii) Focus group discussion. During interview with alumni parents, we explored a question, “What are the care coordination needs of families of IMC during the initial 12 months following discharge from NICU?” Family advisors from NICU conducted the interviews for gaining insight into care transition gaps and to design a productive journey mapping session. Patient journey mapping illustrates how care is *experienced* rather than delivered, capturing the steps in a process from the patient’s and family’s perspective, not the providers. It acknowledges that patients and families are more knowledgeable ^{21 20}. Parents of IMC discharged from our NICU in the last three years were eligible to take part in this session if they were comfortable speaking in a group and sharing their experiences in 4 areas: Ambulatory Clinic, Emergency Department, NICU and PICU. A Family Advisor (SW) contacted the families by phone, elicited their interest in participation, and got verbal consent for audio recording during the session. The director of patient experience facilitated the session using points identified during one-on-one

Figure 2: Visual graphic minutes and themes from patient journey mapping session



interviews to prompt the discussion. A graphic reporter provided a real-time illustration of session themes by synthesizing discussion points into concise visual representations, with additions to the graphics on request by participants. The project coordinator took notes from the meeting. The focus group discussion's goal was to validate major care transition themes arising from journey mapping session and to elicit potential solutions or ideas for change. The focus group discussion had recruitment, conduct and data capturing methods similar to the Journey Mapping exercise. While

above activities occurred with alumni families, core team members identified care transition gaps from care providers' perspective by brainstorming various aspects of care transition during first three core team meetings. Finally, we collated the gaps identified by both alumni parents and core team members as care gap statements, e.g. Medical psychologist services are not available for families during their stay in NICU.

3. Performing and presenting evidence informed potential solutions

The purpose of the evidence brief was to present the research evidence informed solutions on a specific care gap to interdisciplinary care provider representatives, taking part in the future deliberation session. To develop the evidence briefs, we transformed each care gap statement identified from alumni parents and core team members into an evidence review question. A logical question with necessary details like the setting, inclusion and exclusion criteria made it easier for the literature review specialist to perform the review (Supplementary Table S1). Post literature review, the specialist presented the results as evidence briefs. These briefs described the context, problem, at least three options for addressing the problem, strengths and limitations of the evidence, and comments on local considerations^{22 23}. The idea was to make these briefs available for care provider group representatives and alumni parents of IMC so that it prepared them for a meaningful conversation during deliberations.

4. Deliberations to identify priority interventions for implementation

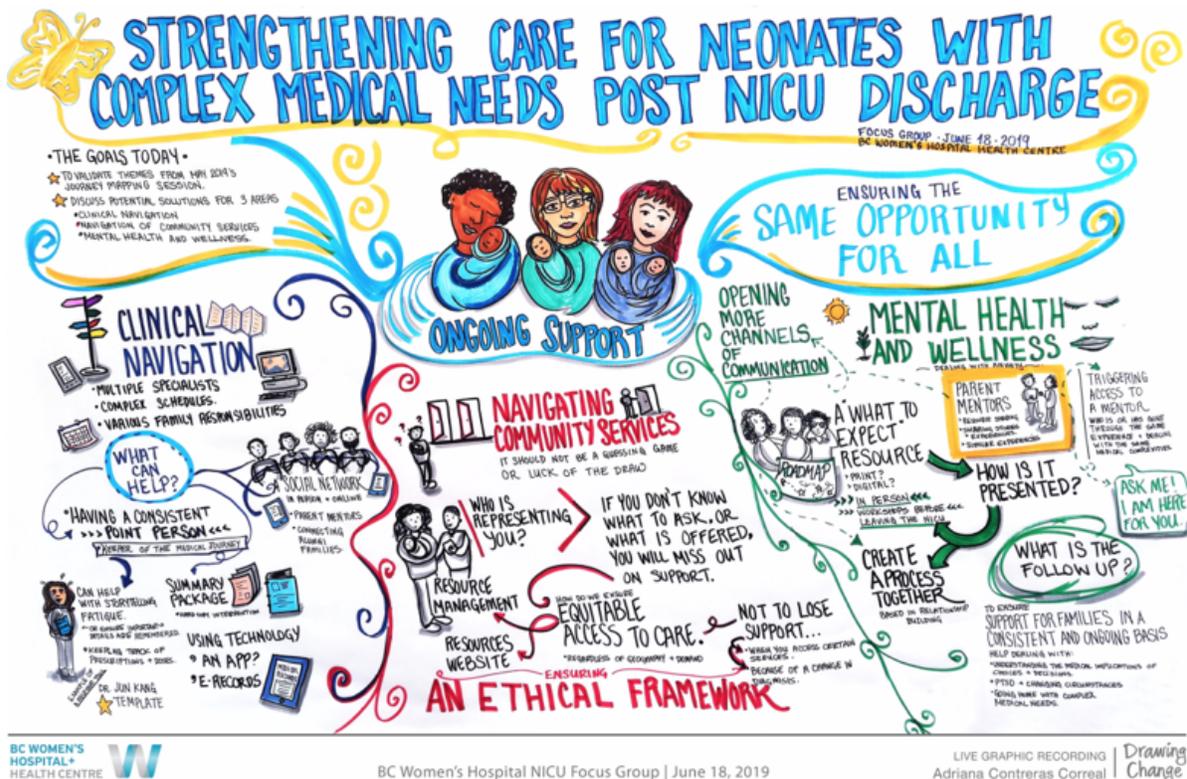
To optimize acceptance and participation, we asked the sponsors to send a letter of

invitation to intended participants identified by core team members. Following acceptance, we sent the participants a package containing information about the project, a copy of the evidence briefs, prioritization framework, agenda and details of the deliberation session. We requested the participants to review the materials and seek any clarification before attending the deliberation session. The session included an initial overview of care gaps and evidence informed potential options to address the issue, followed by participants' discussion and ended with completion of survey questionnaires by care providers²⁴.

Stakeholder dialogues ensured a wide-ranging discussion of IMC-related care transition issues, involving all those engaged in or affected by future decisions in a collaborative setting. Two expert facilitators led the session lasting 2 hours. We asked the participants to validate care transition issues, options to address these issues, and express their views on feasibility of adopting interventions considering potential barriers. We also sought insights on addressing the barriers from participants. The project coordinator took notes and audio recorded the deliberations.

One goal of the deliberation session was to compare choices objectively and prioritize

Figure 3: Visual graphic minutes and themes from focus group discussion



care transition improvement ideas relevant to BCCWH on a *Possible, Implement, Challenge and Kill* (PICK) effort-impact matrix²⁵. Such a prioritization allows team members and organizations in selecting interventions that have best chances of success and bring most value to families and organization. As a general rule, an intervention backed by evidence or being practiced in another centre with some reported benefit received a higher impact rating. We defined low effort as an intervention implementable in next 12 months with no or minimal extra resources in the existing setting.

involvement ²⁶. Based on identified risks, we included mitigation strategies in the project design, e.g. maintaining privacy and confidentiality of participants during meetings, an environment conducive to meaningful dialogue and anonymity of participants in all project documents and reports. We provided all interdisciplinary care-providers with information on each engagement activity, data collection methods, and steps to maintain privacy and confidentiality. These strategies met the requirements for quality improvement activity and exempted from a detailed research ethics board review.

ANALYSIS:

We describe the number and type of participants in each engagement activity descriptively. In view of the pragmatic nature of this project, the core team decided on not performing a detailed qualitative analysis of alumni parent and care provider groups engagement activities. Instead, we used the minutes of the engagement activities, project coordinator notes, and visual graphic minutes and themes by illustrator for decision making and planning next steps during core team meetings. Audio recordings were cross-referenced by core team members as necessary. We used validated survey questionnaires to elicit

deliberation session participants' satisfaction with evidence briefs and deliberations; care provider stakeholders' intentions to act following deliberation, and project core team members' level of engagement.

OUTCOMES

1. Care provider groups and alumni parents' engagement

As a core team we initially established the purpose, scope and approach in first three meetings. Based on members' input the hospital family experience director, social work, psychology, child rehabilitation centre, reproductive health psychiatry, virtual health representatives and provincial nursing support services, child health BC, and parent peer support group representatives were included in subsequent activities. When representatives could not take part, we included their insights in planning next steps.

2. Identifying care gaps

Eight of invited ten alumni parents of IMC took part in identifying care gaps. Three parents took part in all three activities, one-on-one interviews, Journey Mapping, and focus group discussion. Three and two additional parents took part in journey

Table 1: Themes and Recommendations from journey mapping and proposed solutions from focus group discussion

Challenges experienced by families	Proposed solutions
NAVIGATING CLINICIAN ENCOUNTERS	
<ul style="list-style-type: none"> • Navigating multiple specialist appointments and complex services • Uneven access to information on eligibility for programs/care (e.g. Pediatric Complex Care) • Storytelling fatigue- Repeatedly communicating medical information to different care providers 	<p>Centralized and consistent point person to schedule appointments and communicate program eligibility</p>
NAVIGATING COMMUNITY SERVICES	
<ul style="list-style-type: none"> • Navigating at-home nursing and financial support systems • Adjusting to at-home nursing • Lack of clarity on eligibility for and availability of services based on geographic region • Access to support being driven by extent of respiratory support, rather than the actual needs of the family in caring for their child. Criteria may feel arbitrary. 	<ul style="list-style-type: none"> • Resource manager or care coordinator who educates families on resources, advocates nursing support services, educates families prior to discharge from hospital • Develop a structured template to streamline communication between family and nursing staff providing home care, to facilitate mutual expectations and preferences • Clarify contact person for questions and concerns • Patient heat map with resources available in each region • Ask a clinical ethicist whether eligibility criteria are fair and consistent • Ask support providers for input
MENTAL HEALTH and WELLNESS of FAMILY	
<ul style="list-style-type: none"> • Lack of relevant mental health support and follow-up post-discharge • Feeling unprepared, not knowing “what to expect” at home • Lack of established peer support systems 	<ul style="list-style-type: none"> • Regular mental health follow-ups post-discharge with the same care provider with the relationship first established in the NICU • Develop a pathway for mental health in collaboration with families • Provide a one-page document of mental health resources by geographic location • Adding a booklet of parent stories to discharge packet • Develop a multi-pronged and less-prescriptive approach to peer support to facilitate families being able to connect with one another in how work best for them • Make a directory of participating parents available • Provide access to a parent hub environment e.g. www.mynicufamily.com

mapping and focus group discussions. We present the themes and proposed solutions identified from these sessions in Table 1 and supplementary Figures 2 and 3.

3. Performing and presenting evidence informed potential solutions to address gaps

Initially, we compiled 25 care gap statements from combined alumni parent and core team members' engagement activities. Then we had to eliminate 16 statements from evidence review for the following reasons (i) gaps did not require multiple service teams' coordination for solving (e.g. training parents on caring for IMC at home during NICU stay and before discharge); (ii) gaps were unrelated to BCCWH services (e.g. Nursing Support Services coordinating home nursing care); (iii) gaps were beyond the project's scope (e.g. parents' work-life balance) (Table S1). Of the remaining 9 care gap statements, we went ahead with the literature review (Figure S1). Post literature review, we excluded 5 evidence informed reviews from distribution to the intended deliberation participants for the following reasons; (i) change intervention implementation planning had already begun (e.g. referring IMC to neonatal follow-up clinic); (ii) there was insufficient time for innovative guideline

development (e.g. first five years age epoch care pathway for IMC development was challenging for this heterogenous population) or (iii) engagement of macro-level provincial interdisciplinary care providers could only address care gap. Finally, as a core team, we considered four evidence briefs for deliberation by interdisciplinary care providers and parents and shared them with the intended participants (Table S2, a-d).

4. Deliberations to identify priority interventions for implementation.

Twenty-two (52%) participants from across BCCWH and the community took part in the deliberation session, representing 10 hospital services and various professions: physicians 32%, registered nurses 5%, allied staff 11%, alumni parents of IMC 16% and others 36%. Twenty-seven percent of participants identified themselves as medical or an operational leader. Nineteen (86%) and 12 (55%) participants responded to the evidence brief and deliberative dialogues questionnaire, respectively. Twelve care provider stakeholders out of 18 (66%) completed the intention to act questionnaire.

Ninety-four (94%) and 90% of respondents respectively agreed that evidence briefs and

Table 2: Respondents views on evidence briefs in a survey conducted during the deliberation session

Statement	% Respondents who reported the process as helpful*
1. Described the context for the issue being addressed	95
2. Described various features of the problem, including its impact on various interdisciplinary care-providers	95
3. Employed systematic & transparent methods to identify, select and assess the research evidence	95
4. Described options for addressing the problem	84
5. Described research evidence findings & limitations	94
6. Took local applicability into account (PICK chart)	83
7. Included a reference list	83
8. Did not conclude with particular recommendations	82
9. Evidence brief as a whole achieved the aims**	94

*- Respondents who indicated the process as slightly, moderately or very helpful, i.e. Likert scale of 5, 6 or 7. ** Respondents who indicated the process as success, i.e. Likert scale of 5,6 or 7

Table 3: Respondents views on stakeholder dialogues in a survey conducted during the deliberation session

Statement	% Respondents who reported the process as helpful*
1. Addressed a high priority issue	92
2. Provided an opportunity to discuss different features of the problem, including its impact on various interdisciplinary care-providers	92
3. Provided an opportunity to discuss options for addressing the problem	91
4. Provided an opportunity to discuss key implementation considerations	91
5. Was informed by discussion about the full range of factors that can inform how to approach the problem, possible options for addressing it and key implementation considerations	91
6. Aimed for fair representation of operational leaders, care providers and families	82
7. Allowed for frank, off the record deliberations	91
8. How helpful do you consider the use of research evidence in policy making or programmatic decision making?	83
9. Deliberative dialogues as a whole achieved the aims	90

*- Respondents who indicated the process as slightly, moderately or very helpful, i.e. Likert scale of 5, 6 or 7

** Respondents who indicated the process as success, i.e. Likert scale of 5, 6 or 7

deliberative dialogues together or as individual components achieved their purpose (Table 2 and 3).

EVALUATION OF IMPACT OF ADOPTING AN INTEGRATED FRAMEWORK on planning care transition improvements:

1. Care providers' intention to act

Eighty percent of respondents showed strong agreement on intention to act (Table 4), i.e. what they will say in a briefing, advocate for, or decide on changes in care transition. However, only 44% of respondents mentioned they will be under

social (peer) pressure to use research evidence to decide on care transition changes. 67% of respondents stated that their ability to use evidence or deliberation proceedings to advocate for changes in their sub-specialty programs or services is beyond their control.

2. High priority interventions for implementation

Interdisciplinary care providers identified and prioritized interventions for implementation in 4 domains: (i) Transitioning IMC from neonatal to pediatric complex care program; (ii) Improving

Table 4: Interdisciplinary care-providers intentions to act on what was learnt from evidence briefs and dialogues

Statements	% Respondents who reported the process as helpful #
1. I intend to use the research evidence of the type that was discussed today to help work through what I will say in a briefing, advocate for, or decide on changes in care transition	80
2. I feel under social pressure to use research evidence of the type that was discussed today to help work through what I will say in a briefing, advocate for, or decide on changes in care transition	44
3. The ability to use research evidence of the type that was discussed at the stakeholder dialogue to help me work through what I will advocate for, or decide on changes in care transition is beyond my control	67

#- Respondents who somewhat agree, agree or strongly agree, i.e. Likert scale of 5, 6 or 7

1= indicator of motivational behavior intention, 2= indicator of subjective norms (team culture**), 3= indicator of perceived behavioral control***

**Team culture is values, beliefs, attitudes and behavior shared by a team

*** Perceived behavioral control among many is determined by environmental, economic incentives and resource factors

caregiver mental health; (iii) Fostering caregiver peer support and self-help groups and (iv) Better care coordination between hospital and community services. We prioritized the care transition improvement ideas on a PICK chart (Supplementary Figure S4a-d). Some low effort and high-impact key interventions for implementation identified were, revising pediatrics complex care team (PCCT) referral criteria to accommodate IMC, educating the role of PCCT among community practitioners using an information brochure, offering workshops for

enhancing community practitioners' care coordination abilities within their own community, introducing psychology support services for parents of IMC during their hospital stay, educating parents on self-care using a brochure, creating a directory of families willing to take part in peer support group, introducing a dedicated system navigator role at the hospital level to coordinate care following discharge from NICU (Figures 4-7).

Figure 4: Stakeholders identified high priority interventions for implementation to improve neonatal to pediatrics complex care program transition

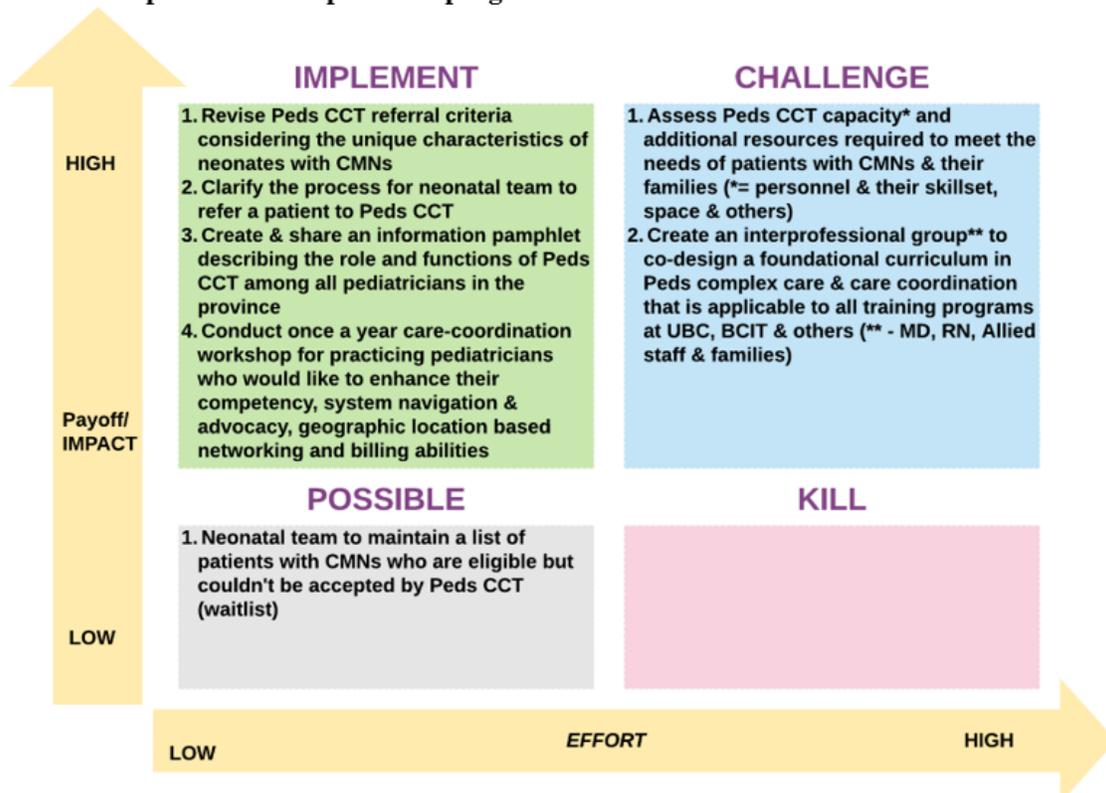


Figure 5: Stakeholders identified high priority interventions for implementation to address unmet needs of families' mental health

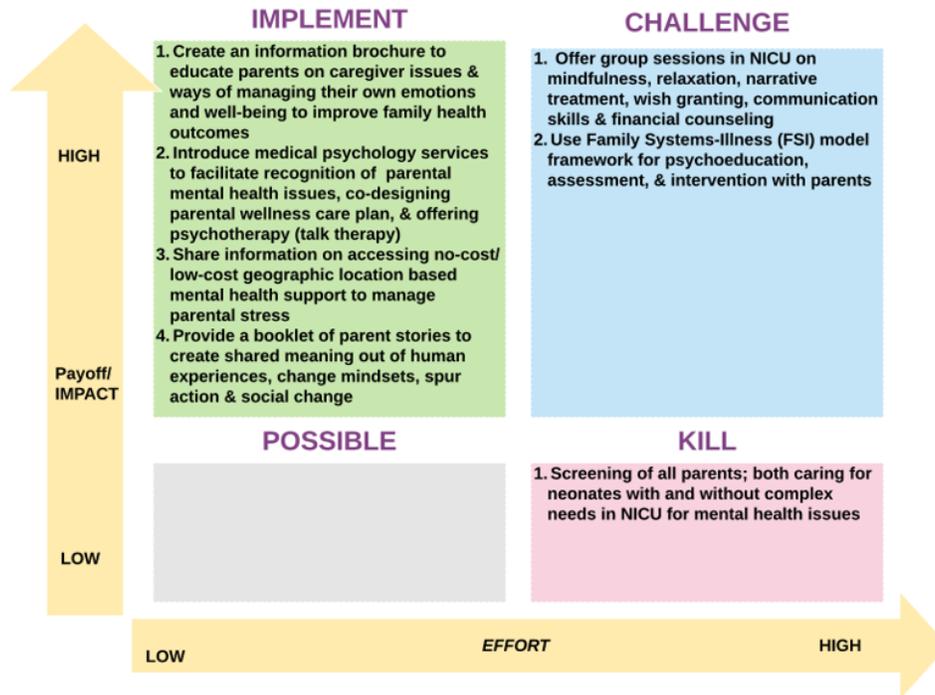


Figure 6: Stakeholders identified high priority interventions for implementation to improve family members' social support

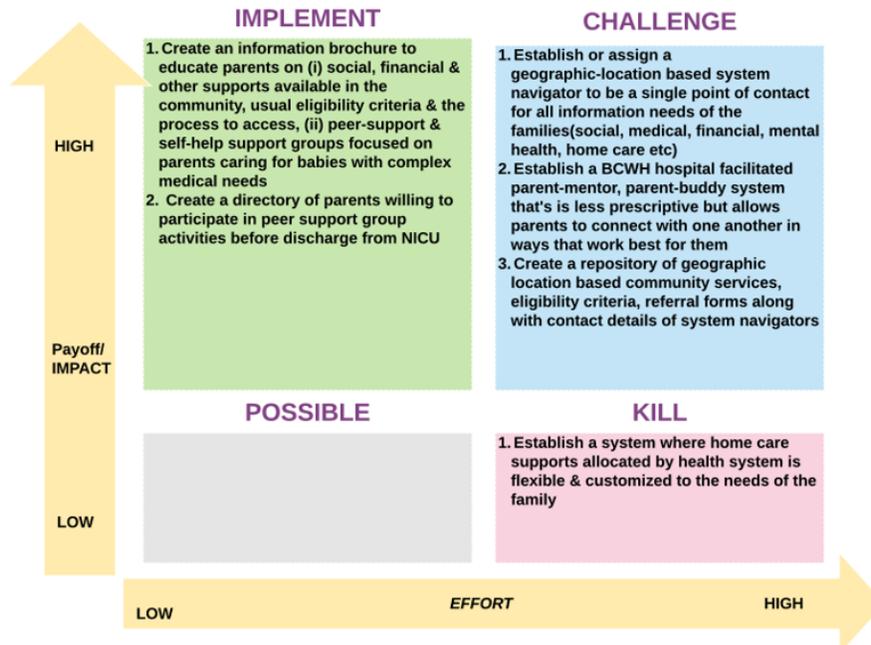
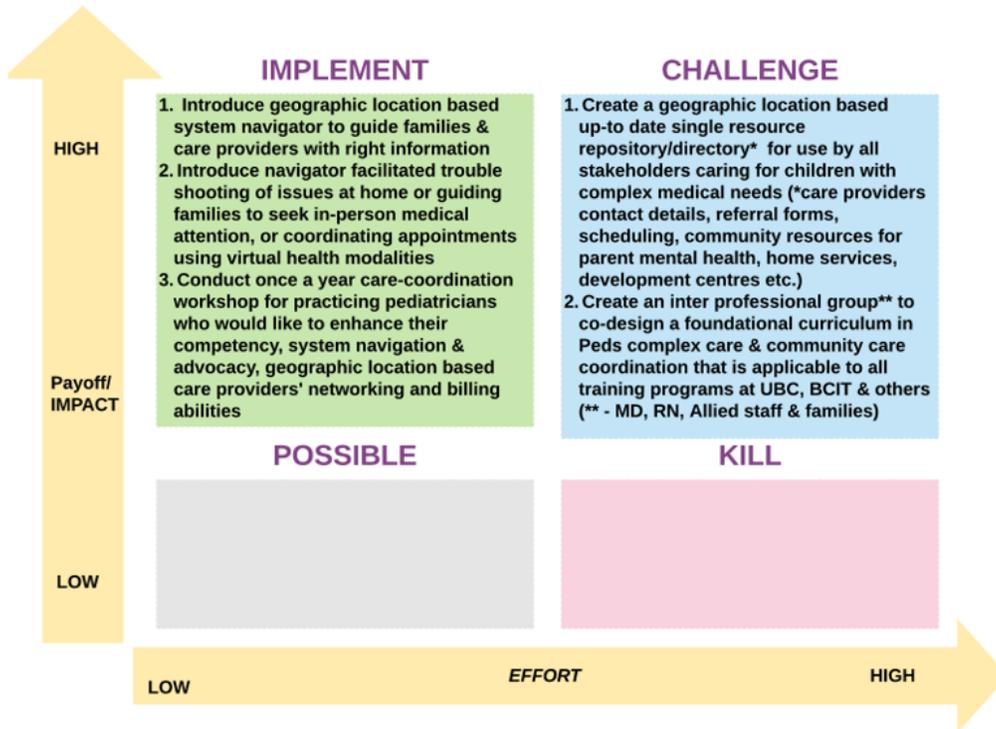


Figure 7: Stakeholders identified high priority interventions for implementation to improve coordination of care in children with medical complexity



3. Network growth during the project

Over the duration of the project, 52 neonatal-to-childhood care transition interdisciplinary care-providers were engaged. The interdisciplinary care-providers represented multiple hierarchical levels within the hospital and community settings, and more than half of them identified themselves as being in an operational or medical leadership role (Figure 8). Eighty-four percent core team members representing 9 different hospital programs showed engagement on the higher side in the spectrum of engagement

rating as 4 or 5, on a survey scale ranging from “inform (1)-consult (2)-involve (3)-collaborate (4)-empower (5) (Table 5)

4. Others

Towards the end of the project, planning on ideas for change was already underway e.g. Parent-oriented discharge summary, formalizing referral from Neonatal to Pediatric Complex Care, coordination between NICU and home care services and Psychology services for families during their NICU stay, etc. We present the challenges,

Figure 8: Complex care-provider stakeholders network growth over time during the project period

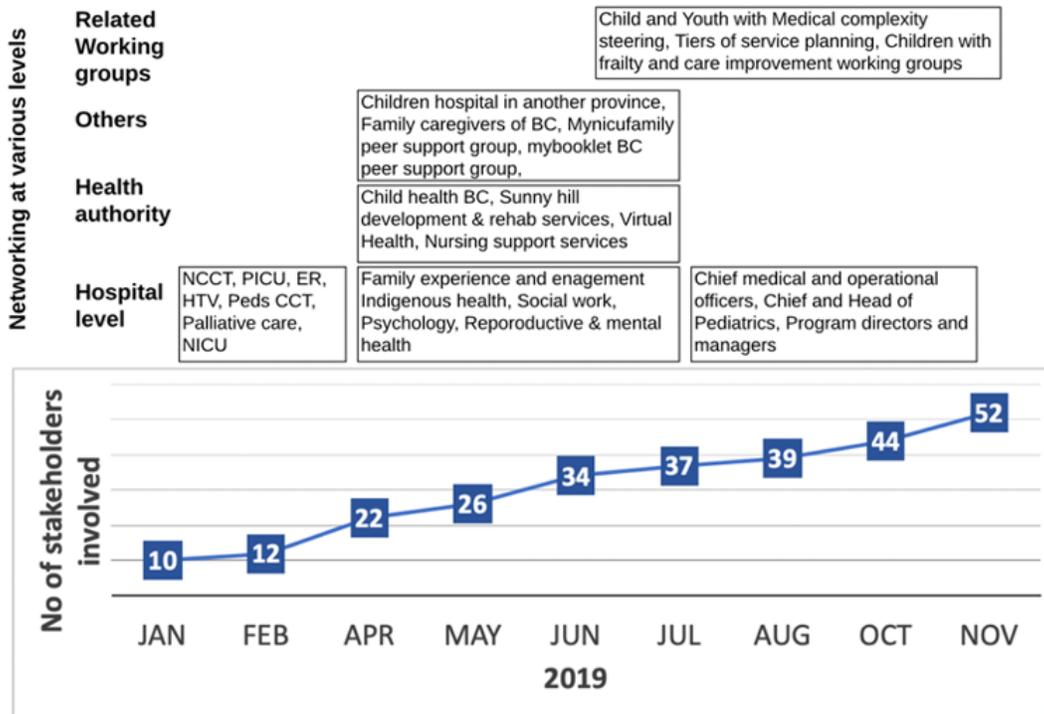


Table 5: Project core team members perceived satisfaction and spectrum of engagement during the project

Statements	Respondents who responded as agree or strongly agree (Total n=12), n(%)				
Participation in this project gave me more understanding about the neonatal to early childhood care transition.	12(100)				
Participation in this project increased my ability to collaborate with the interdisciplinary care-providers.	7(58)				
This project was an excellent use of my time.	11(92)				
I thought my involvement in this project made a difference in the project's success.	10(83)				
I would take part in this project/process again.	12(100)				
Level of Engagement	Inform	Consult	Involve	Collaborate	Empower
Based on the IAP2 Spectrum of Engagement, what was the level of engagement you expected as you worked on the project?	1 (8)	2 (17)	1 (8)	8 (67)	
Based on the IAP2 Spectrum of Engagement, what was the level of engagement as you actually worked on the project?	0 (0)	0 (0)	2 (17)	8 (67)	2 (17)

Table 6: Challenges, lessons learnt and mitigation strategies during the project

Challenges	Mitigation strategy
Creating awareness (sharing information) on unique needs of IMC and their families among hospital staff	Use existing forums e.g. grand rounds, professional group meetings Use a combination of data and stories by family members
Low participation rates of project team members in meetings because of capacity and time constraints	Conduct organized and efficient meetings <ul style="list-style-type: none"> · Structure meeting around a meaningful topic · Organized meeting: Share agenda in advance, Clear sense of direction by chair, decision making after considering all options, define and ensure task completion, Provide opportunities to take part virtually and share minutes so that absentees could track progress and their tasks
Low participation rates in broader stakeholder meeting e.g. Deliberative dialogues	Reimbursing parking, providing refreshments and honorarium Seeking senior executives help in sending out invitations on behalf of the project team
Disconnect between family members, practitioners and operational leaders of various programs	Involve relevant interdisciplinary care-providers early on, clarifying their roles and sharing progress at regular intervals
Team members believe that system changes do not happen	Using the knowledge to care gaps, as an opportunity to gather data, build stakeholder network, and promote their participation in decision making
Involving interdisciplinary care-providers during the entire spectrum from identifying care gaps and questions for evidence review till we prioritize change ideas takes time and effort	Building partnerships with existing programs e.g. family experience and having a project coordinator
Inability to prioritize interventions for implementation according to the local context	Combine stakeholder briefs with deliberative dialogues
Ensuring relevant and meaningful input from interdisciplinary care-providers is gathered during meetings e.g. Patient journey mapping, Focus group or deliberative dialogues	Preparation, providing clear orientation, clarifying roles and facilitation by an expert
<p>Lessons learnt</p> <ul style="list-style-type: none"> • Knowing that there are so many people invested and engaged in the care of infants and children with medical complexity • Understanding health care system, family needs and importance of networking and building relationships • Knowledge of resources and links on site and in the community • Having patient family members deeply affected, engaged authentically for their lived experiences, perspectives, challenges and ideas • Opportunity to integrate feedback and suggestions from a diverse range of perspectives, including primary care providers, allied health, and patient interdisciplinary care-providers 	

lessons learned, and mitigation strategies used during the project in Table 6. We have disseminated our project findings in 4 hospital educational or administrative meetings, and to 3 hospital and provincial working committees on children with medical complexity to drive improvement efforts at multiple levels.

DISCUSSION

We have applied an integrated framework to inspire action amongst neonatal-to-childhood care transition interdisciplinary care-providers to champion system-level change to enhance transition. Second, we have identified and validated knowledge to care gaps from multiple sources: literature review, are providers and families, using validated tools. Third, we have identified high priority interventions for implementation in our setting through deliberations. Finally, we have engaged many potentially interdisciplinary care-providers, representing various hospital and community services at different hierarchical levels, with the potential to implement desired changes in care transition of IMC and their families. The approach methods and evaluation techniques used in this project are transferable to other scenarios affecting

multiple stakeholder groups, where engagement and establishment of priorities in a given setting is of at most importance.

There are a variety of approaches to enhance stakeholder engagement, perform evidence reviews, prioritize interventions and implement interventions using quality improvement methods (e.g. Plan-Do-Study-Act- Cycles) ^{14 13 10 27 28}. However, these methods do not take a longitudinal and integrated approach that builds the capacity of the healthcare system to implement and sustain a system-level complex change necessary to improve transition of IMC ²⁹. Evidence briefs and stakeholder deliberative dialogues form a novel approach that engages interdisciplinary care-providers from multiple services and facilitate a collaborative approach to developing solutions with a focus on implementation in a given setting ²⁹. We have shown how integration of multiple individual frameworks could facilitate achievement of the desired goals in a setting.

Our evaluation has shown that almost all interdisciplinary care-providers regard evidence briefs and deliberative dialogues positively. We did not conclude evidence briefs with recommendations to prevent bias arising from core team members' own views

and beliefs, in line with previous studies²⁹. This ensured that views and values of the participants voiced in the deliberative dialogue assumed equal importance. All interdisciplinary care-providers reported strong intentions to act on what they had learned from evidence briefs and dialogues, in line with previous observations^{29 22 23}. The theory of planned behaviour states “intention” is an immediate precursor to “actual behaviour”¹¹. We speculate that participants in deliberative dialogues representing different hierarchical levels would act or support system level change related to improving transition of IMC from NICU to community and other in-hospital units.

That two-thirds of respondents expressed a lack of control in advocating or deciding on change interventions within their service programs, was not surprising, considering three quarters of respondents were point-of-care staff or family members with little control over the future direction of their program or organization. This reflects perceived behavioural control determined by availability of support or resources within their program, economic incentives and institutional constraints²⁹. Only 44% of respondents belonging to different care provider teams and alumni parents agreed

or strongly agreed on research evidence or deliberations forming the basis for deciding on changes in care transition. This associated finding offers important insights on prevailing culture and may pose a potential challenge in adopting evidence informed practices within individual programs of a large hospital.

The participant practitioners, family members, and operational leaders expressed high levels of satisfaction and engagement. Creating awareness of a problem and potential solutions and building a critical mass of engaged interdisciplinary care-providers (network growth over time) is a key enabler in increasing the likelihood of sustainable implementation of interventions for service improvement³⁰. Stakeholder engagement is essential for translating knowledge into action within healthcare systems^{31 32} and change efforts are more successful when healthcare professionals and patients are engaged in each step of the improvement effort^{33 34}. Thus, we believe that this initial work will generate momentum in improving care transition of IMC and their families in our setting.

STRENGTHS AND LIMITATIONS:

Our project had many strengths. First, we could triangulate knowledge to care gap

issues from multiple sources (outcome data, care providers, and family members' lived experience). We involved all relevant interdisciplinary care-providers and alumni parents of IMC from the outset and in every step of the project. Thus, identified opportunities for improvement are real and implementing interventions more likely to be impactful in a given setting. Second, this is the first time that evidence briefs and stakeholder dialogues have been used to address hospital to community care transition gaps. Third, implementation priorities presented in PICK format (effort-impact matrix) make it easier for senior executives to identify low-effort interventions and strategically plan for adopting high impact interventions. Finally, multiple well established frameworks formed the basis of integrated framework adopted in this project, and we used validated questionnaires for evaluation. We believe that a similar approach is transferrable to any large health care centre to enhance stakeholder engagement and spark action among them.

This project also has limitations. Our project had a small sample size, survey response rates were suboptimal, and we couldn't exclude key informants' selection bias. We believe these limitations are secondary to

participants' time constraints, as they were taking part in the project alongside their clinical work. Second, the real-world pragmatic design and combining various engagement strategies in this project makes it difficult to find out the impact of individual interventions on participants' intention to act. Finally, we did not perform a detailed qualitative analysis of journey mapping and focus group discussion, or a systematic review of literature because of time and resource constraints.

NEXT STEPS:

We plan to sustain the interdisciplinary care providers' networking and top-level engagement, while seeking approval and/or endorsement to implement interventions from key decision makers. Further evaluation is necessary to test the utility of integrated approach used in this project in another health care setting or a different population where multiple stakeholder groups' involvement is critical in making system improvements.

CONCLUSIONS

We have adopted an integrated framework to bring alumni parents and care providers identified, evidence-informed workable interventions to plan improvements in

transitioning IMC care from NICU to community or other in-hospital units. After performing various activities under this framework, interdisciplinary care providers and alumni parents identified high priority interventions for implementation, and care providers reported strong intentions to act on change interventions. Care-providers' network grew substantially during the project period.

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DEFINITIONS OF TERMS

(i) Care transition: the time points at which a patient or family moves to, or returns from, a particular physical location or contacts a new health care professional. This includes transitions between home, hospital, and consultations with different providers in out-patient facilities ; (ii) Knowledge to care gap: a discrepancy between best practice according to the current scientific evidence and the actual care provided ; (iii) Care coordination: the deliberate organization of care activities between two or more participants (including the patient) involved in a patient's care to facilitate the delivery of health care services ; (iv) Stakeholder engagement: the approach to gathering input from interdisciplinary careproviders in identifying, validating, problem solving, prioritizing or creating recommendations on neonatal to early childhood care transition issues ; and (v) Continuity of care: a series of discrete health care events experienced by the patient and family members that are coherent and interconnected over time, consistent with their health needs and preferences.

ABBREVIATIONS

IMC: Infants with medical complexity, BCCWH: British Columbia Children's and Women's Hospital, NICU: Neonatal intensive care unit, PICU: Pediatric intensive care unit, PICK: Possible, implement, Challenge and Kill.

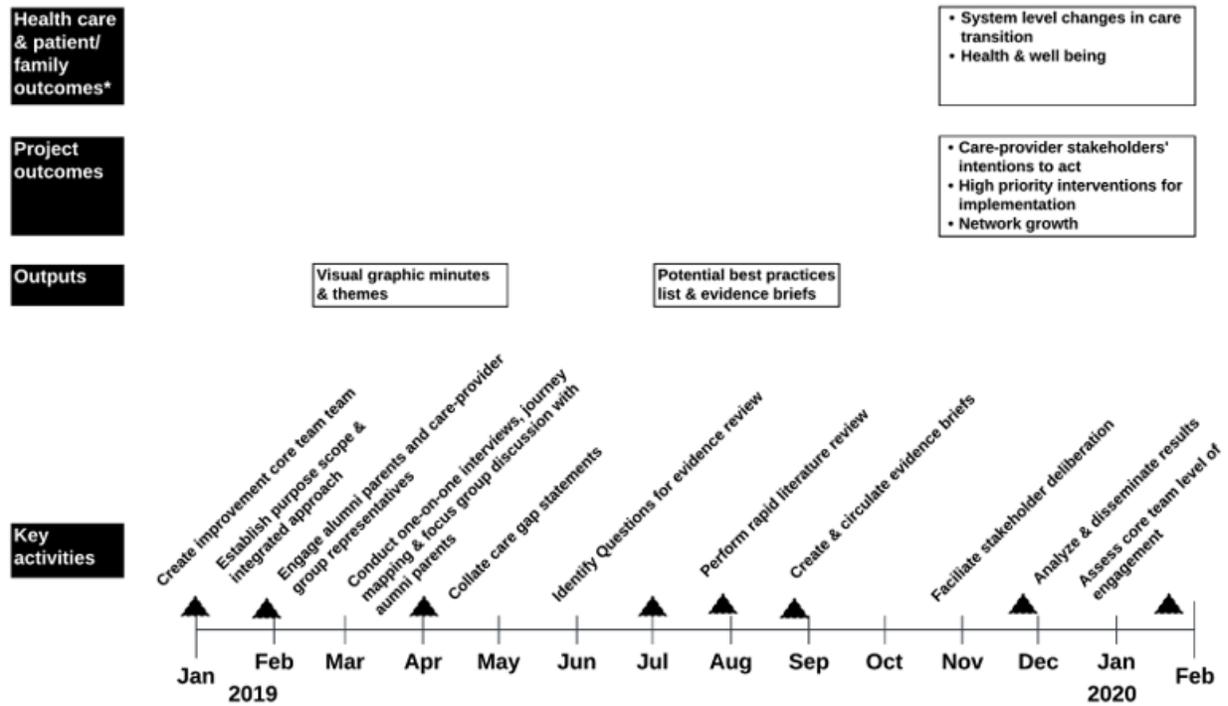
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FIGURES & TABLES

Figure 1: Project timeline showing key activities, outputs and outcomes



Inverted triangle= Project team meetings, * beyond the scope of this project

Table 1: Themes and Recommendations from journey mapping and proposed solutions from focus group discussion

Challenges experienced by families	Proposed solutions
NAVIGATING CLINICIAN ENCOUNTERS	
<ul style="list-style-type: none"> • Navigating multiple specialist appointments and complex services • Uneven access to information on eligibility for programs/care (e.g. Pediatric Complex Care) • Storytelling fatigue- Repeatedly communicating medical information to different care providers 	<p>Centralized and consistent point person to schedule appointments and communicate program eligibility</p>
NAVIGATING COMMUNITY SERVICES	
<ul style="list-style-type: none"> • Navigating at-home nursing and financial support systems • Adjusting to at-home nursing • Lack of clarity on eligibility for and availability of services based on geographic region • Access to support being driven by extent of respiratory support, rather than the actual needs of the family in caring for their child. Criteria may feel arbitrary. 	<ul style="list-style-type: none"> • Resource manager or care coordinator who educates families on resources, advocates nursing support services, educates families prior to discharge from hospital • Develop a structured template to streamline communication between family and nursing staff providing home care, to facilitate mutual expectations and preferences • Clarify contact person for questions and concerns • Patient heat map with resources available in each region • Ask a clinical ethicist whether eligibility criteria are fair and consistent • Ask support providers for input
MENTAL HEALTH and WELLNESS of FAMILY	
<ul style="list-style-type: none"> • Lack of relevant mental health support and follow-up post-discharge • Feeling unprepared, not knowing “what to expect” at home • Lack of established peer support systems 	<ul style="list-style-type: none"> • Regular mental health follow-ups post-discharge with the same care provider with the relationship first established in the NICU • Develop a pathway for mental health in collaboration with families • Provide a one-page document of mental health resources by geographic location • Adding a booklet of parent stories to discharge packet • Develop a multi-pronged and less-prescriptive approach to peer support to facilitate families being able to connect with one another in how work best for them • Make a directory of participating parents available • Provide access to a parent hub environment e.g. www.mynicufamily.com

Table 2: Respondents views on evidence briefs in a survey conducted during the deliberation session

Statement	% Respondents who reported the process as helpful*
1. Described the context for the issue being addressed	95
2. Described various features of the problem, including its impact on various interdisciplinary care-providers	95
3. Employed systematic & transparent methods to identify, select and assess the research evidence	95
4. Described options for addressing the problem	84
5. Described research evidence findings & limitations	94
6. Took local applicability into account (PICK chart)	83
7. Included a reference list	83
8. Did not conclude with particular recommendations	82
9. Evidence brief as a whole achieved the aims**	94

***- Respondents who indicated the process as slightly, moderately or very helpful, i.e. Likert scale of 5, 6 or 7. ** Respondents who indicated the process as success, i.e. Likert scale of 5,6 or 7**

Table 3: Respondents views on stakeholder dialogues in a survey conducted during the deliberation session

Statement	% Respondents who reported the process as helpful*
1. Addressed a high priority issue	92
2. Provided an opportunity to discuss different features of the problem, including its impact on various interdisciplinary care-providers	92
3. Provided an opportunity to discuss options for addressing the problem	91
4. Provided an opportunity to discuss key implementation considerations	91
5. Was informed by discussion about the full range of factors that can inform how to approach the problem, possible options for addressing it and key implementation considerations	91
6. Aimed for fair representation of operational leaders, care providers and families	82
7. Allowed for frank, off the record deliberations	91
8. How helpful do you consider the use of research evidence in policy making or programmatic decision making?	83
9. Deliberative dialogues as a whole achieved the aims	90

*- Respondents who indicated the process as slightly, moderately or very helpful, i.e. Likert scale of 5, 6 or 7

** Respondents who indicated the process as success, i.e. Likert scale of 5, 6 or 7

Table 4: Interdisciplinary care-providers intentions to act on what was learnt from evidence briefs and dialogues

Statements	% Respondents who reported the process as helpful #
1. I intend to use the research evidence of the type that was discussed today to help work through what I will say in a briefing, advocate for, or decide on changes in care transition	80
2. I feel under social pressure to use research evidence of the type that was discussed today to help work through what I will say in a briefing, advocate for, or decide on changes in care transition	44
3. The ability to use research evidence of the type that was discussed at the stakeholder dialogue to help me work through what I will advocate for, or decide on changes in care transition is beyond my control	67

#- Respondents who somewhat agree, agree or strongly agree, i.e. Likert scale of 5, 6 or 7

1= indicator of motivational behavior intention, 2= indicator of subjective norms (team culture**),
3= indicator of perceived behavioral control***

**Team culture is values, beliefs, attitudes and behavior shared by a team

*** Perceived behavioral control among many is determined by environmental, economic incentives and resource factors

Table 5: Project core team members perceived satisfaction and spectrum of engagement during the project

Statements	Respondents who responded as agree or strongly agree (Total n=12), n(%)				
Participation in this project gave me more understanding about the neonatal to early childhood care transition.	12(100)				
Participation in this project increased my ability to collaborate with the interdisciplinary care-providers.	7(58)				
This project was an excellent use of my time.	11(92)				
I thought my involvement in this project made a difference in the project's success.	10(83)				
I would take part in this project/process again.	12(100)				
Level of Engagement	Inform	Consult	Involve	Collaborate	Empower
Based on the IAP2 Spectrum of Engagement, what was the level of engagement you expected as you worked on the project?	1 (8)	2 (17)	1 (8)	8 (67)	
Based on the IAP2 Spectrum of Engagement, what was the level of engagement as you actually worked on the project?	0 (0)	0 (0)	2 (17)	8 (67)	2 (17)

Table 6: Challenges, lessons learnt and mitigation strategies during the project

Challenges	Mitigation strategy
Creating awareness (sharing information) on unique needs of IMC and their families among hospital staff	Use existing forums e.g. grand rounds, professional group meetings Use a combination of data and stories by family members
Low participation rates of project team members in meetings because of capacity and time constraints	Conduct organized and efficient meetings · Structure meeting around a meaningful topic · Organized meeting: Share agenda in advance, Clear sense of direction by chair, decision making after considering all options, define and ensure task completion, Provide opportunities to take part virtually and share minutes so that absentees could track progress and their tasks
Low participation rates in broader stakeholder meeting e.g. Deliberative dialogues	Reimbursing parking, providing refreshments and honorarium Seeking senior executives help in sending out invitations on behalf of the project team
Disconnect between family members, practitioners and operational leaders of various programs	Involve relevant interdisciplinary care-providers early on, clarifying their roles and sharing progress at regular intervals
Team members believe that system changes do not happen	Using the knowledge to care gaps, as an opportunity to gather data, build stakeholder network, and promote their participation in decision making
Involving interdisciplinary care-providers during the entire spectrum from identifying care gaps and questions for evidence review till we prioritize change ideas takes time and effort	Building partnerships with existing programs e.g. family experience and having a project coordinator
Inability to prioritize interventions for implementation according to the local context	Combine stakeholder briefs with deliberative dialogues
Ensuring relevant and meaningful input from interdisciplinary care-providers is gathered during meetings e.g. Patient journey mapping, Focus group or deliberative dialogues	Preparation, providing clear orientation, clarifying roles and facilitation by an expert
<p>Lessons learnt</p> <ul style="list-style-type: none"> • Knowing that there are so many people invested and engaged in the care of infants and children with medical complexity • Understanding health care system, family needs and importance of networking and building relationships • Knowledge of resources and links on site and in the community • Having patient family members deeply affected, engaged authentically for their lived experiences, perspectives, challenges and ideas • Opportunity to integrate feedback and suggestions from a diverse range of perspectives, including primary care providers, allied health, and patient interdisciplinary care-providers 	

Figure 2: Visual graphic minutes and themes from patient journey mapping session

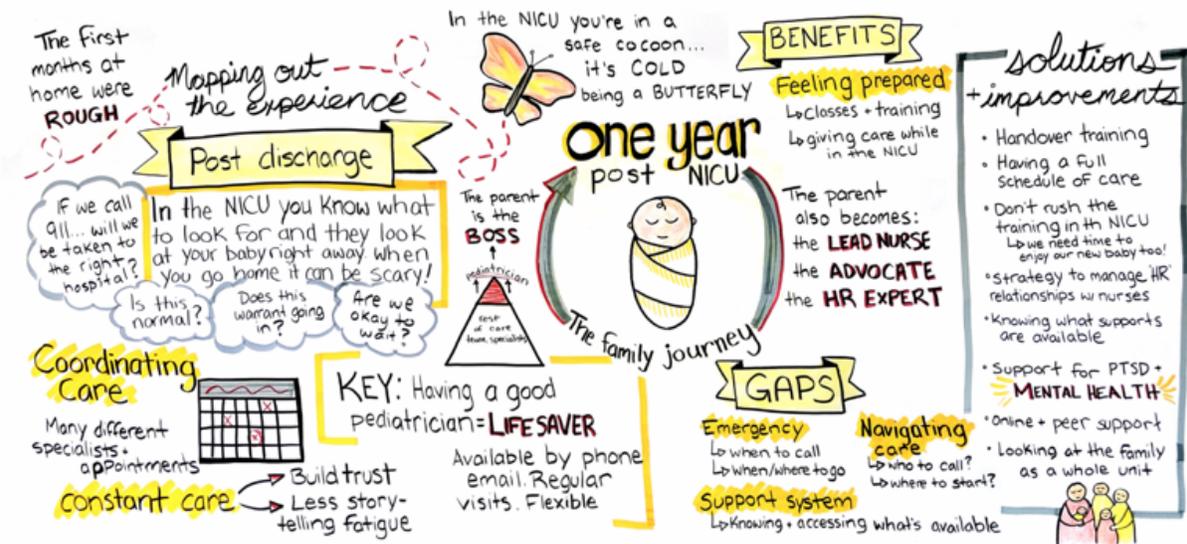


Figure 3: Visual graphic minutes and themes from focus group discussion

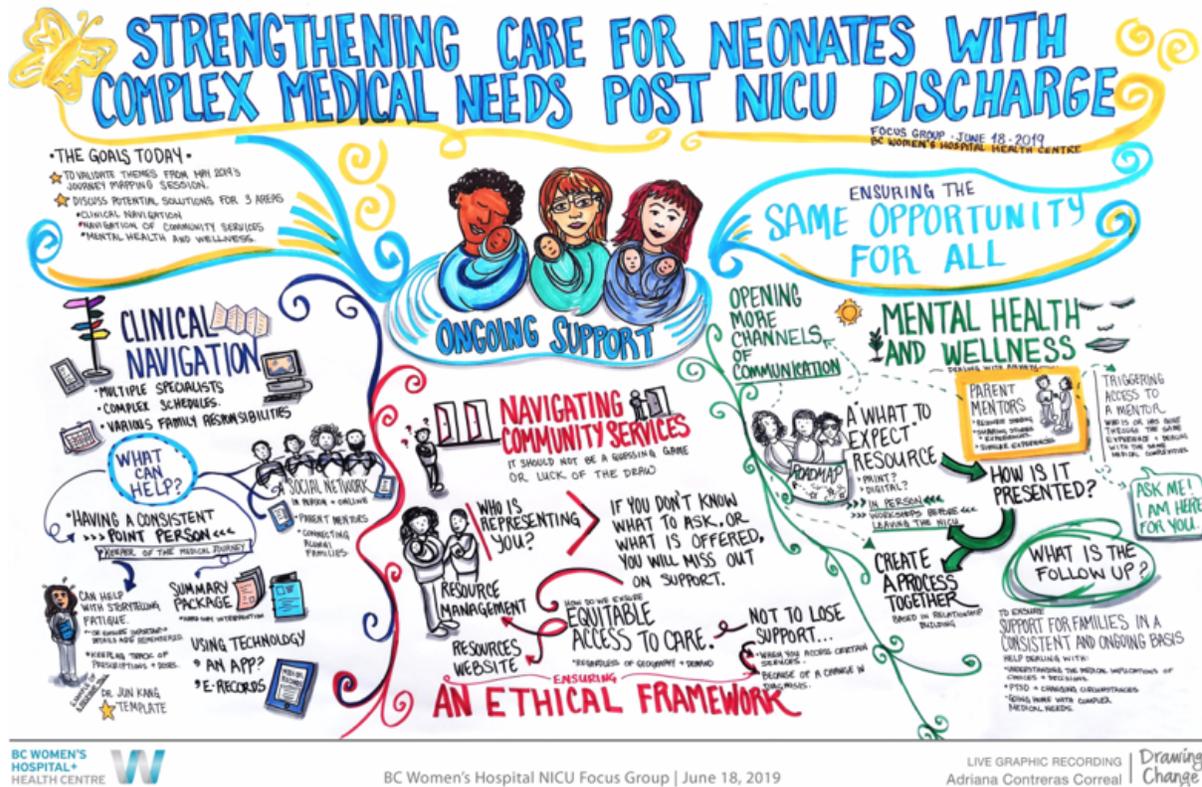


Figure 4: Stakeholders identified high priority interventions for implementation to improve neonatal to pediatrics complex care program transition

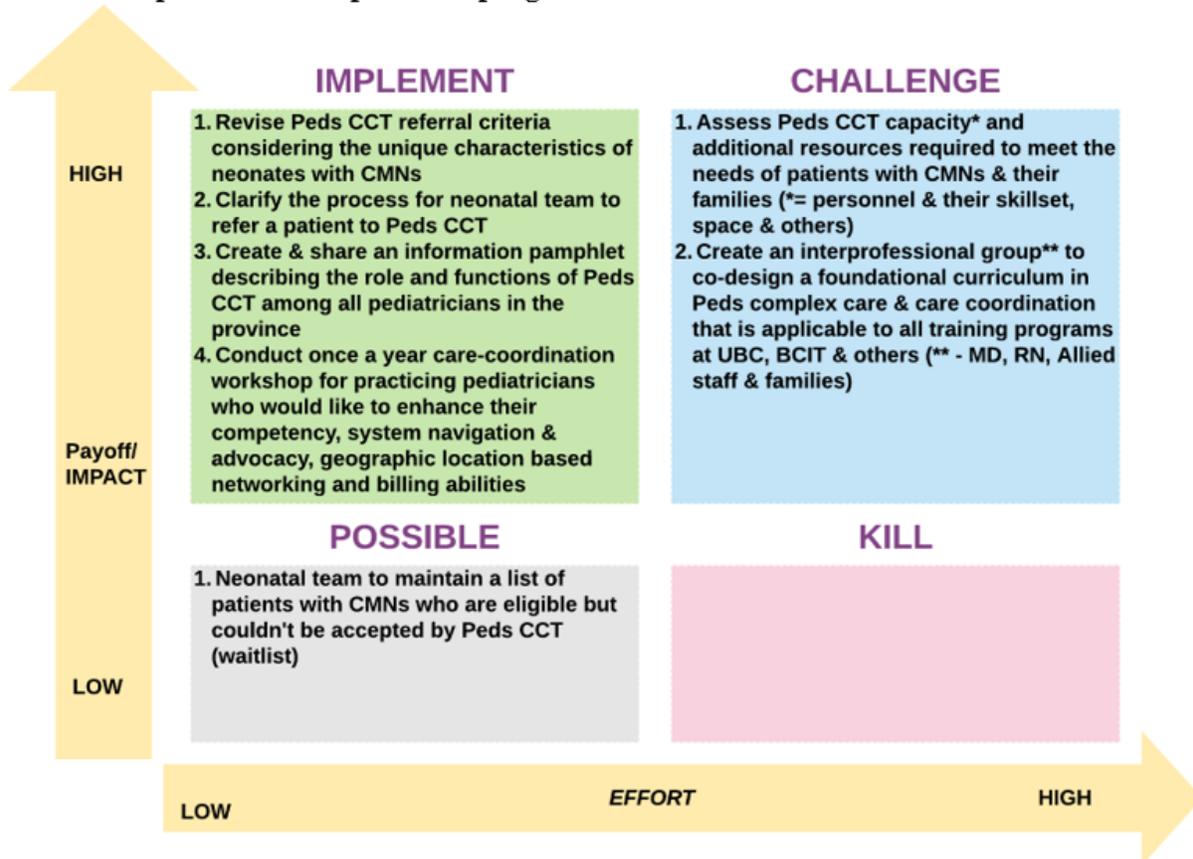


Figure 5: Stakeholders identified high priority interventions for implementation to address unmet needs of families’ mental health

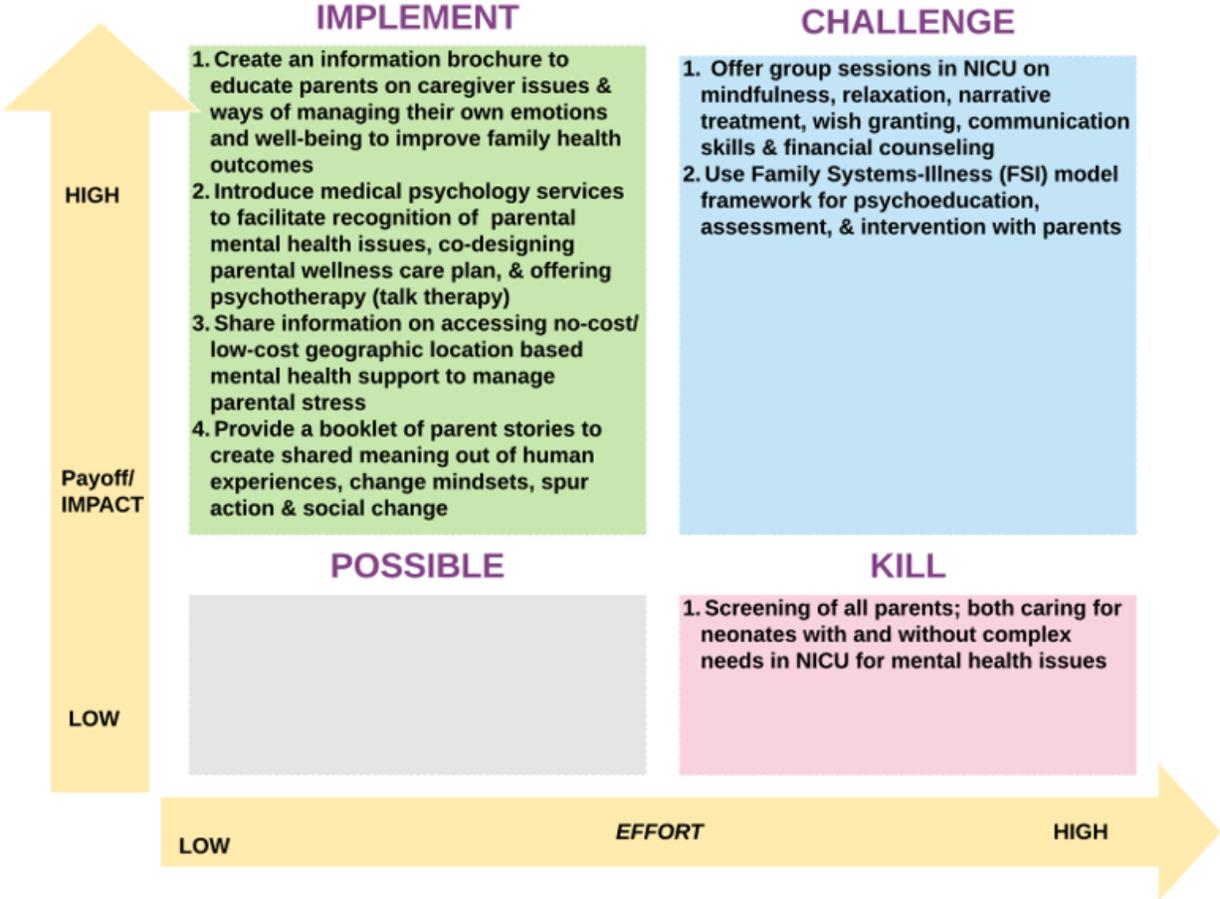


Figure 6: Stakeholders identified high priority interventions for implementation to improve family members' social support



Figure 7: Stakeholders identified high priority interventions for implementation to improve coordination of care in children with medical complexity

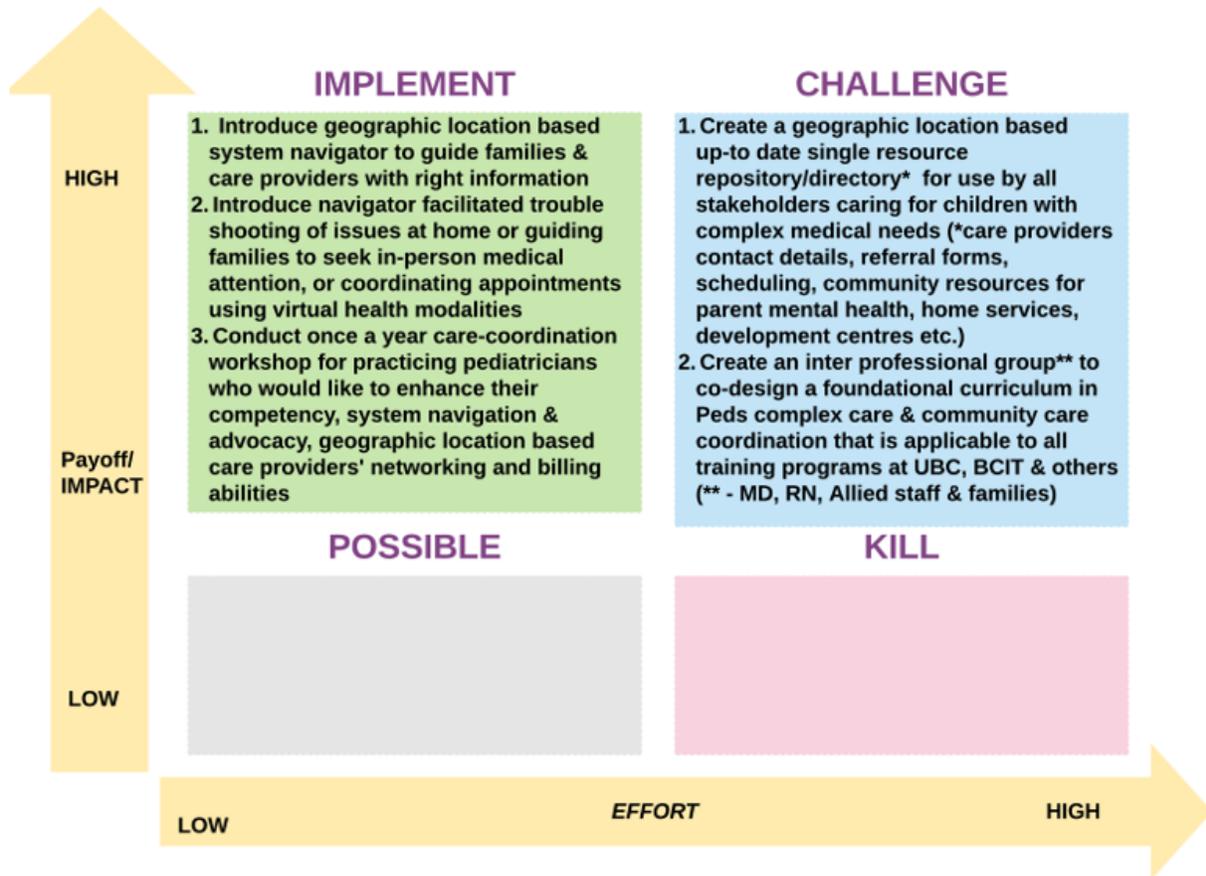
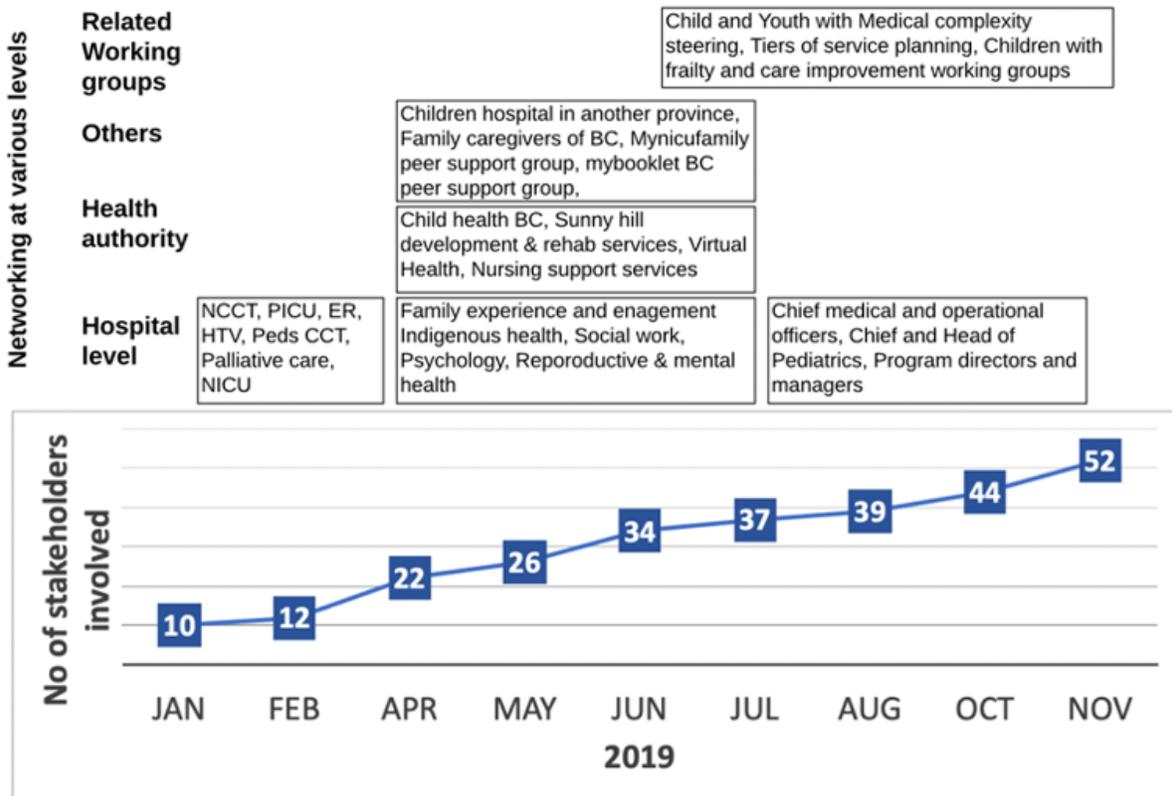


Figure 8: Complex care-provider stakeholders network growth over time during the project period



Supplementary figures and tables are available as a download at:



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