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A co-design of clinical virtual care pathways to engage and support families requiring neonatal intensive care in response to the COVID-19 pandemic (COVES study)

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ABSTRACT

Background: In response to the COVID-19 pandemic, family presence restrictions in neonatal intensive care units (NICU) were enacted to limit disease transmission. This has resulted in communication challenges, negatively impacting family integrated care.
Aim: To develop clinical care pathways to ensure optimal neonatal care to support families in response to parental presence restrictions imposed during the COVID-19 pandemic.
Methods: An agile, co-design process utilizing expert consensus of a large interdisciplinary team and focus groups and semi-structured interviews with families and HCPs were used to co-design clinical virtual care pathways.
Results: Three clinical virtual care pathways were co-designed: (1) building and maintaining relationships between family and healthcare providers; (2) awareness of resources; and (3) standardized COVID-19 messaging. Modifications were made to optimize uptake and utilization in the clinical areas.
Conclusion: Clinical care virtual pathways were successfully co-designed to meet these needs to ensure more equitable family centered care.

1. Introduction

In response to SARS-CoV-2 (COVID-19), public health restrictions were instituted worldwide to limit disease transmission and reduce burden on the health care resources and healthcare provider workforce (World Health Organization, 2020). One such public health restriction was eliminating or severely restricting family or support person presence in hospital or clinic settings (Bembich et al., 2020; Darcy Mahoney et al., 2020). Despite the known benefits of parental presence in the neonatal intensive care unit (NICU) settings, to protect the infants, families and healthcare providers (HCPs), most NICUs also instituted severe parental presence (visiting) restrictions (Bembich et al., 2020; Darcy Mahoney et al., 2020).

In order to improve the outcomes of vulnerable infants and their families and ease health care system burden, strong parental presence and education along with family integrated interventions have been shown to be a beneficial component of care in the NICU (Cheng et al., 2019; Franck & O'Brien, 2019; O'Brien et al., 2018a,b; Tandberg et al., 2019). Despite well intentioned public health decisions to limit the spread of COVID-19, many questions remain related to the impact of severe parental presence restrictions in the NICU on infant outcomes and parent mental health and well-being. One innovative approach to

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preserve family integrated care and bridge the communication gap between family members and HCPs is the development and use of clinical care pathways. Clinical care pathways are designed to be multidisciplinary care plans which identify and lay out essential steps in the care of patients in a particular context to enhance the standardization of care (Campbell et al., 1998). Their purpose is to help in the communication with families, to make families aware of their expected care plan during their hospital stay. Due to the rapidly changing nature of care during COVID-19, it was essential to develop clinical virtual care pathways through iterative testing to enhance family integrated care and standardize care for families with infants admitted to the NICU.

2. Methods

2.1. Study design

An agile, collaborative co-design process was used, based on expert consensus of an interdisciplinary team that included parents, and qualitative interviews with families, clinicians, and decision-makers (Thabrew et al., 2018). The study was conducted at [blinded]. [Blinded] is a perinatal and pediatric university-affiliated referral hospital providing tertiary care to women and children [blinded]. The [blinded] NICU is a 40-bed single family room (with a designated sleep space, bathroom, and shower) unit which provides level 3–4 care to approximately 800 inborn and out born patients annually. The NICU and hospital has a strong culture supporting family integrated care.

2.2. Study population

A diverse 20-member interdisciplinary research team which included parents of previous NICU patients were engaged to provide expert consensus recommendations on the development of the co-designed pathways. Qualitative interviews and iterative testing were conducted with families and HCPs to further adapt and revise pathways. Eligible participants were the intended users of the clinical virtual care pathways including HCPs from the [blinded] NICU in Eastern Canada as well as families of infants who received care in the NICU after March 1, 2020 following implementation of restrictive family presence polices. All participants had to read and speak English. Participants were recruited using posters in the NICU, through word of mouth from the study team, and through social media posts.

At [blinded], parental presence restrictions were instituted on March 13th, 2020 because of the local state of emergency declared due to COVID-19. The most severe restrictions limited only one support person to be present with their infant(s) who could not leave the hospital. If the women who delivered had a support person during delivery, the mother's support person was required to leave 48 h after delivery. These restrictions meant that families who stayed in the NICU with their infant (s) lacked access to their usual social support systems, partners had little to no access to their infant(s), and usual in-person teaching and access to resources were adversely affected. Additionally, some parents with responsibilities such as other children in the home had to leave the hospital, leaving their infant alone as the parent could not return to the NICU if they left.

2.3. Procedures

Recruitment and co-design sessions occurred between July 14th, 2020 and December 1st, 2020. To aid in the development of the pathways, weekly smaller working groups and full team bi-monthly 60–90 min virtual interdisciplinary research team meetings were held. Iterative bi-monthly agile co-design sessions and live online documents available to the full research team were utilized to further adapt and revise the co-designed pathways (Sheard et al., 2019). Additional need for iterative agile sessions were determined based on saturation of data obtained. Ethical approval was received through [blinded institution] prior to recruitment.

2.4. Analysis

Interviews and focus groups were analyzed using qualitative content analysis and the domains of Theoretical Domains Framework (TDF) (Atkins et al., 2017) by two reviewers to categorize findings. Barriers and facilitators to implementing virtual care pathways during COVID-19 were identified using the Behaviour Change Wheel (BCW) (Michie et al., 2011) and TDF (Atkins et al., 2017). All interviews were conducted using a semi-structured interview guide based on the TDF, created by the full research team. Domains were mapped on to virtual care functions to guide options for changes. The APEASE intervention criteria of the BCW (affordability, practicability, effectiveness and cost-effectiveness, acceptability, safety, and equity) informed decision making (Michie et al., 2011). Priorities for pathway creation were identified, and recommendations for revisions were reviewed by the research team and changes were made based on consensus.

3. Results

3.1. Pathway overview

Following the steps outlined by Campbell and colleagues (Campbell et al., 1998), this study sought to develop clinical virtual care pathways for implementation of standardization of care in the NICU (see Table 1). The pathways document a step-by-step process to ensure standardized care is offered to families. While the primary users are likely to be families and bedside nurses, the entire multidisciplinary care team (i.e., pharmacists, lactation consultants, advanced practice nurses and physicians) are encouraged review of the pathways and to complete relevant sections of the pathways. The pathways incorporate an algorithmic approach that includes decision points to take into consideration, family scenario, and timing. The main introduction page for the pathways (Fig. 1) includes a description of the potential family scenarios that should be considered for each element of the pathways. This step aims to

Table 1
Steps of developing a virtual care pathway.

Step	Our approach
Select an important area of practice	Standardized care during admission to the NICU
Gather support for the project	The Care Optimized using clinical Virtual pathways to Engage and Support NICU families in response to COVID-19 (COVES) study is comprised of a 20-member diverse interdisciplinary research team. The team includes parent partners (parents of infants requiring neonatal care), neonatal HCPs (neonatologists, neonatal nurse practitioners, nurses, educators, discharge planners, clinical nurse specialist), administrators (managers, directors, and executive leaders) and researchers.
Form a multi-disciplinary group	
Identify established guidelines	Using the unit's standards of care in combination with a new virtual care platform, guidelines for standardization of care was established.
Review practice	The 20-member interdisciplinary research team participated to provide expert consensus recommendations on the development of the co-designed pathways.
Involve local staff	Qualitative interviews and iterative testing were conducted with families and HCPs to further adapt and revise pathways.
Identify key areas for service development	To inform learning needs and standardized messaging, a user guide (see supplemental materials) and a script (main page of pathways (Fig. 2) were created and added. See Figs. 1, 3 and 4 for the clinical care pathways.
Develop an integrated care pathway	
Prepare documentation	
Educate staff	Currently ongoing
Pilot then implement	
Regularly analyze variances	

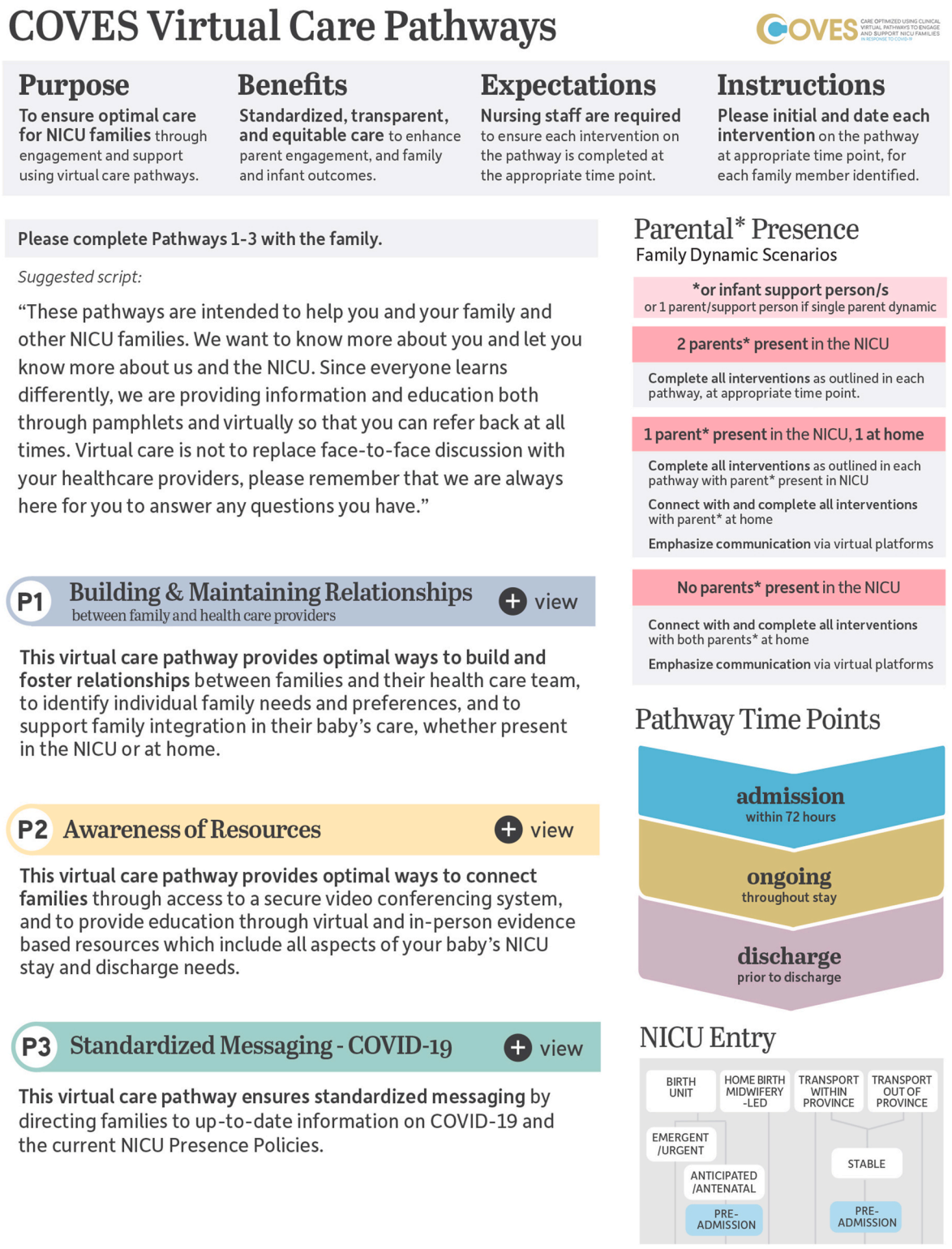

Fig. 1. _COVES virtual care pathways.

ensure that all identified primary parent/caregivers would be contacted regardless of their ability to be present in the NICU. All elements of the pathways are allocated to one of the following time frames to ensure parent's received timely information: (1) admission; (2) during stay; or (3) prior to discharge. HCP documentation associated with each step of the pathways allows HCPs to keep track of whether the pathway element was offered regardless of the family's location or whether the step was utilized by families. Follow up prompts are embedded in the pathways to determine if the families have questions.

Educational resources are offered in a virtual format accessible at any time from hospital or from home. The pathways provide a standardized approach to directing parents to virtual resources as part of usual care. Virtual resources utilized are part of an existing web-based evidence based educational platform called Chez NICU Home© (CNH), recently developed at [blinded], planned to be fully implemented in the NICU prior to the COVID-19 pandemic. Pandemic research restrictions

altered the planned research implementation and practice uptake of the resource. The platform includes interactive parent/caregiver training and education. The CNH platform was developed following user-centered principles of design including iterative testing and feedback from parent and HCP end users. The platform consists of six core chapters which include lessons and resource pages broken down into reading resources and video content. There is also a 12-step Discharge Planning Module, Progress Dashboard, and Interactive Tracker to record parental presence and involvement in care. The platform includes 14 instructional videos teaching key parental skills such as car seat safety and pumping breastmilk. The virtual communication platform utilized in the pathways was created to align with the CNH platform and was referred to as CNH Connect. CNH Connect utilizes a secure WebX video/audio platform that can be accessed via multiple devices (phone, tablet,

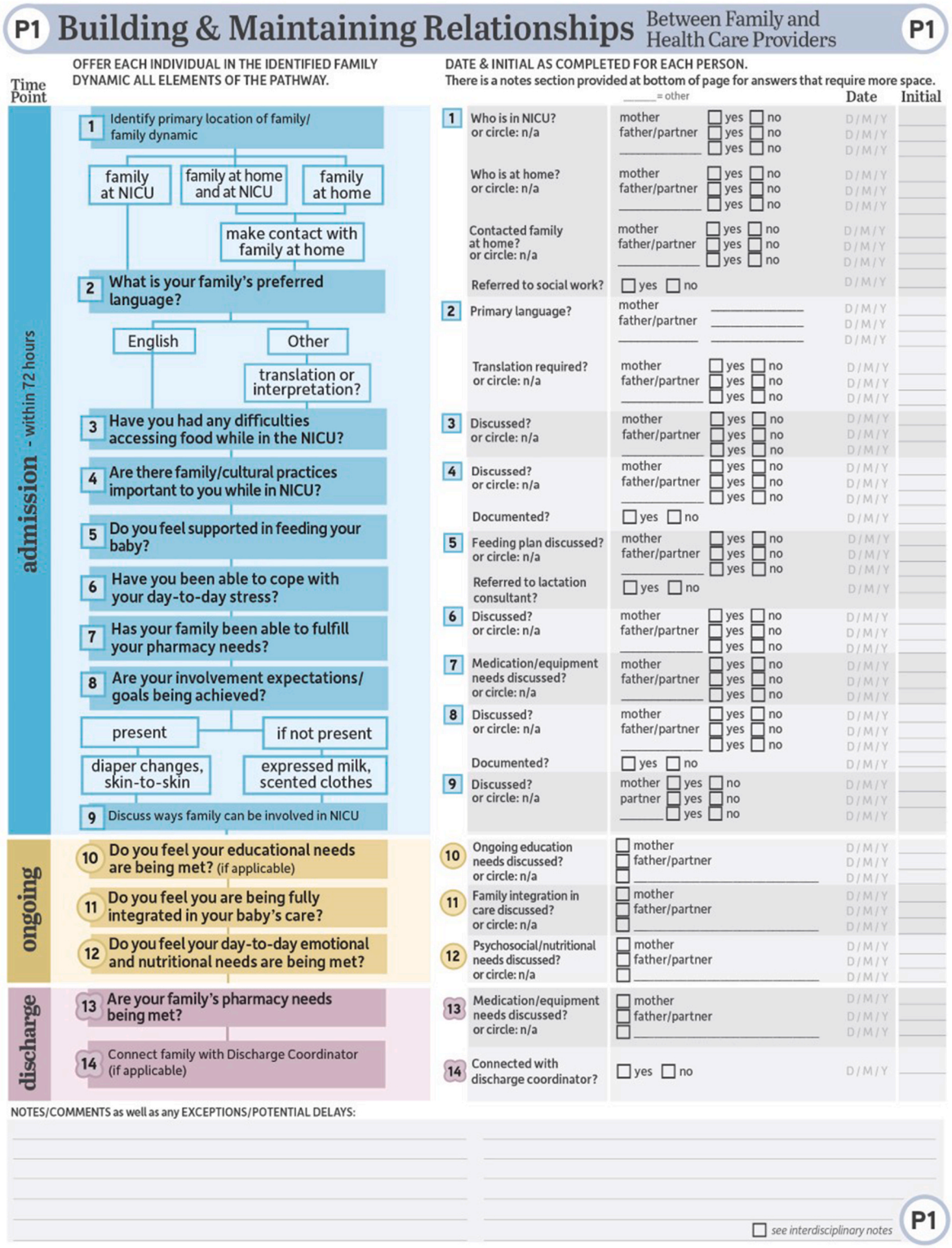

Fig. 2. - P1 pathway.

in room screen, or computer) from both in and outside the hospital. CNH Connect was not available to families and staff prior to the pandemic restrictions and video calling using Facetime and Zoom were utilized during the pandemic in lieu of CHN Connect.

3.2. Clinical virtual care pathways

The three clinical virtual care pathways developed were: (1) building and maintaining relationships between family and HCPs; (2) awareness of resources; and (3) standardized messaging related to COVID-19.

The aim of *Pathway #1: Building and maintaining Relationships* is to get to know the family. In doing this, we can provide optimal virtual ways to

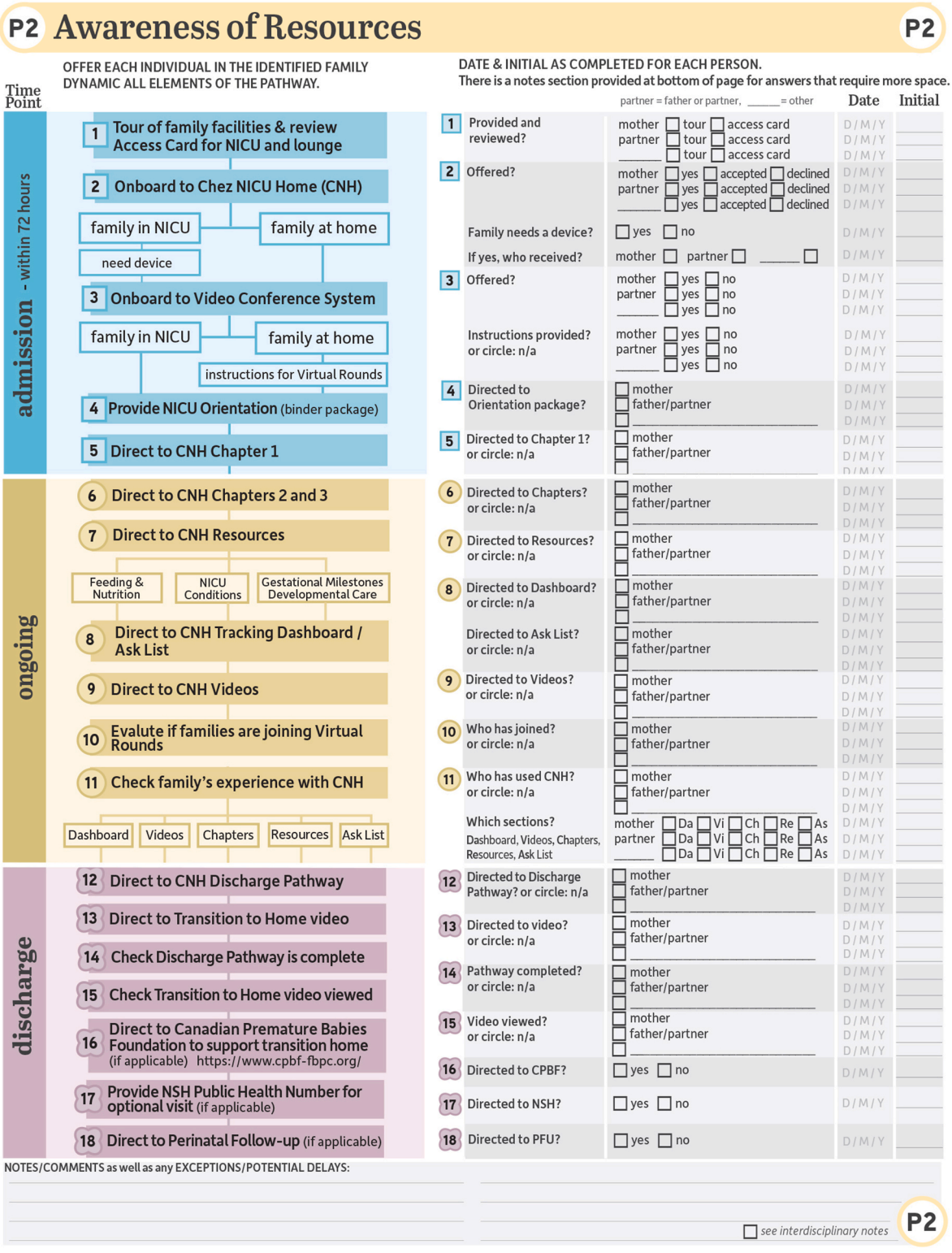

Fig. 3. - P2 pathway.

build and foster relationships between families and their health care team. This helps to identify individual family needs and preferences, and to support family integration in their baby's care, whether present in the NICU or at home (Fig. 2).

The aim of *Pathway #2: Awareness of Resources* is to ensure that families have equitable awareness and access to evidence-based resources both virtually and in person. The pathway provides optimal ways to connect families through access to a secure video conferencing system, and to provide education through virtual and in-person resources which include all aspects of the infant's NICU stay and discharge needs (Fig. 3).

The aim of *Pathway #3 Standardized Messaging – COVID-19* is to address the rapid changes to public health guidelines and institutional policies because of COVID-19. This will ensure families and HCPs have

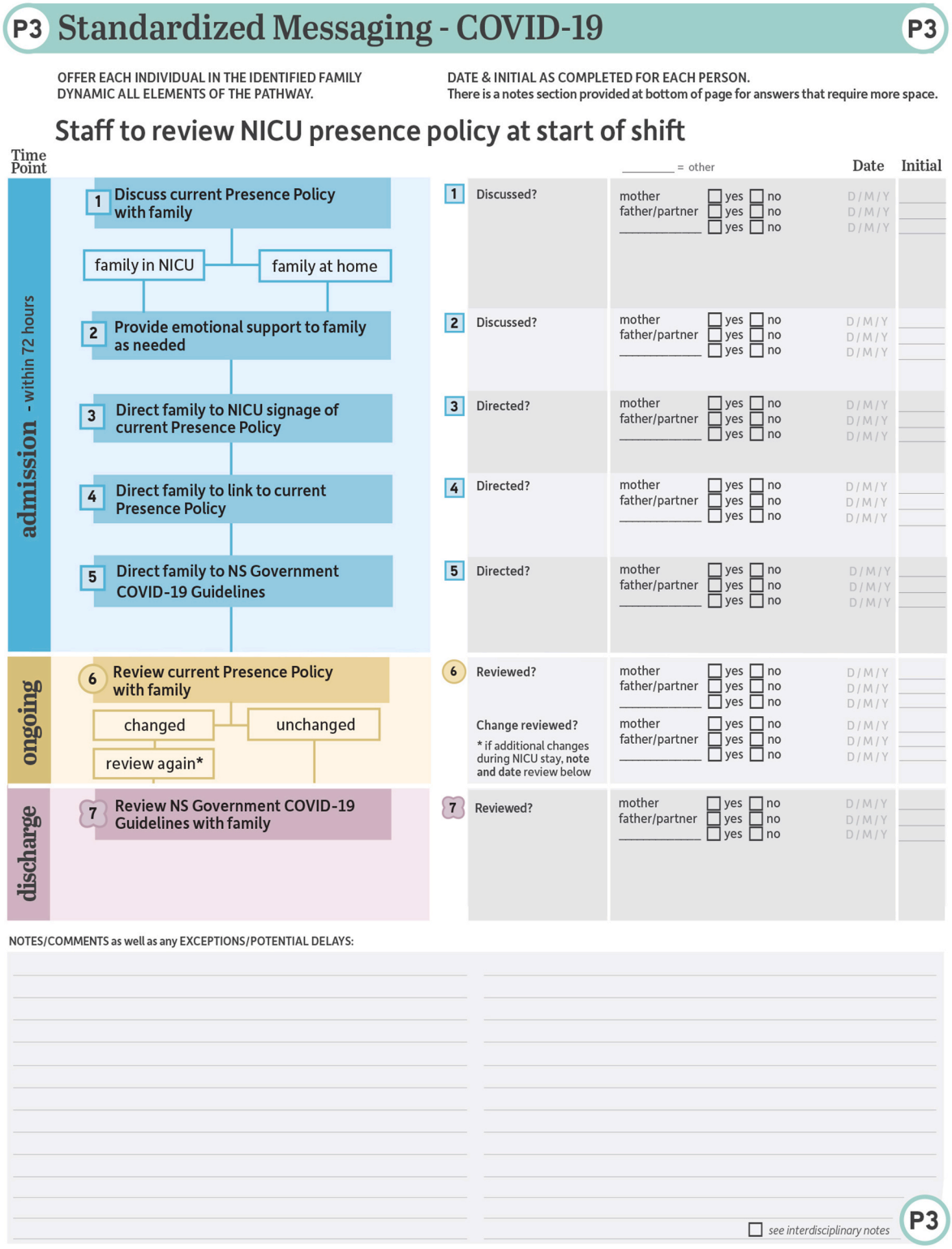

Fig. 4. - P3 pathway.

better and consistent access to the standardized messaging they need to navigate through the NICU presence policies and receive the most current information on COVID-19 (Fig. 4).

3.3. Barriers and facilitators to practice uptake

To help determine barriers and facilitators to pathway acceptance and feasibility for implementation and practice uptake, we interviewed ten participants between October 25th, 2020 and November 25th, 2020. This included one family member (mother) and nine HCPs (7 nurses; 1 neonatal nurse practitioner; and 1 pharmacist).

The participants reported feeling somewhat overwhelmed when initially seeing the pathways but when provided opportunity to review the pathways, they agreed that all the elements were relevant. There were some suggestions for wording changes related to equity and offering devices to families in NICU to use for resources and attendance at rounds. Wording changes to put more emphasis on the purpose for virtual care and transparency, clarity around exceptions, and an emphasis on ensuring families have access to food were also suggested.

Most HCPs felt confident to complete the steps of the pathway. Some identified that aspects of the pathways required additional information and resources, most notably standardized messaging to families and additional training related to onboarding families to virtual communication and educational resources. Concerns were raised around the potential increased nursing workload. However, participants identified family questions as part of the existing charting admission process that were able to be integrated as part of the pathways to streamline care and reduce duplication.

Families felt that pathway elements were relevant and time frames were reasonable. They identified the importance of a space to record reasons for delay or exceptions to completing any elements of the pathways. Families also reported the importance of ensuring that HCPs did not pressure families by prescribing the pathways but rather to direct the families to the resources, allowing them to freely make the decision about whether to use them or not. Families raised the importance of completing the pathways "with families" rather than "to families," as well as the need to be more inclusive of fathers.

3.4. Iterative pathways revisions

Changes to the pathways were made based on user responses and expert consensus of the full research team input and co-design sessions. The following changes or additions were made to inform final pathways.

To inform learning needs and standardized messaging, a user guide (see supplemental materials) and a script (main page of pathways) were created and added. To emphasize the integration of families, elements of the pathways were rephrased as questions using simplified language versus using statements. The terminology "father/partner" was added versus only partner to be more inclusive of fathers. To reduce nursing workload, existing family targeted questions from the unit's current admission documentation were removed and incorporated as part of the pathways. Information was added to clarify that all HCPs should participate in completing relevant aspects of the pathways. For example, the lactation consultant directing a family to the online education module and video regarding pumping breastmilk and safe storage, or the pharmacist directing a family to view the online video about giving medications. It was decided that unit ward clerks would assist with the on-boarding process for the educational (CNH) and communication (CNH Connect) platforms. All staff were provided training on use of the pathways in a 14 day in-person roll-out and were provided access to written and online resources (user guide and training presentation).

4. Discussion

We aimed to develop a clinical pathway to address needs of families to better engage and support families to be fully integrated as part of their infant's care team. The development of the clinical care pathways was done through an agile, collaborative process based on the needs identified from NICU families and HCPs. To enact meaningful change, decisions on the format of these pathways were responsive to the needs of families and pragmatic in considering current unit practices. As such, the pathways were formatted to use a low-tech approach of an interactive PDF, while the contents of the pathways standardized the use of virtual solutions for optimizing clinical care.

The pathways were co-designed with parents, families, clinicians, decision-makers, and researchers based on findings from the needs assessment and continuously informed by the research team. Collaboration and creative feedback/input from the large, diverse research team and NICU families/current NICU staff/HCPs were essential components to the design stage to create a resource that would be relevant to practice and have a high likelihood of acceptance and uptake when incorporated into clinical practice to optimize care.

Co-design and participatory design have been demonstrated as an effective method for development of virtual and eHealth resources, specifically in the perinatal population (Thompson et al., 2019), and in designing clinical care pathways to meet the unique needs of specific populations (Jackson et al., 2016). The co-design/participatory design approach aligns with the philosophy of family integrated care (upheld by the study institution) in that the health system is adapted to the specific needs of its population, and the only true way to achieve that is through the input of the population (Goeman et al., 2016; Hickie et al., 2019; Jackson et al., 2016; Thompson et al., 2019).

Pivoting to virtual care was necessary to optimize clinical care during the period of uncertainty and in-person interaction limitations due to parental presence restrictions enforced for the pandemic. The value of virtual care was quickly acknowledged by many in healthcare systems and widely pursued to maintain support and care for the community (Badawy and Radovic, 2020; Webster, 2020; Wosik et al., 2020). In response to prior qualitative work (under review), we decided to first create the suite of pathways in paper form and as interactive PDF to ensure these pathways could easily be adopted into clinical practice and patient documentation. The initial paper version allowed for rapid and responsive revisions to be made during development as well as throughout the initial roll out and implementation. The pathways currently exist as part of the unit's paper-based charting system but will also be housed digitally as the interactive PDF for information purposes.

Throughout this study, the process of designing the clinical care pathways acted as a catalyst for greater uptake of existing virtual care platforms within the NICU and across the institution. As previously mentioned, [blinded] has already integrated prior to the pandemic CNH and CNH Connect within their NICU, which is a virtual, eHealth education and connection platform. Thus, the virtual pathways offer the opportunity to systematize the introduction of the CHN platform to incoming patients, particularly through pathway 2. For example, in this pathway, there is increased opportunity for uptake of CNH through standardized onboarding practices with families in the NICU or at home. Additionally, it triggered rapid implementation of the CNH Connect to ensure family at home were incorporated into their infant's care and decision making through virtual rounds. In the beginning of the pandemic and presence restrictions, families joined rounds virtually through technologies like FaceTime and Zoom, yet due to the critical nature of this environment and need for high quality infection control practices, any equipment (e.g., computer for Zoom) could not enter patient rooms. This barrier was shared across adult ICUs, which became a greater issue as many hospitals restricted family presence entirely (Dhala et al., 2020). Expediating the rollout of CHN Connect enhanced virtual rounds significantly, as it allowed families and other HCPs to easily join virtual rounds, enhanced patient privacy, and enhanced care through more effective communication. Other critical care areas utilized similar systems/platforms to facilitate presence when physical presence of families was restricted, which was reported to be incredibly impactful to the whole family unit specifically with their mental wellbeing (Dhala

et al., 2020).

4.1. Strengths and limitations

The primary strength of this project was that the pathways were developed using user-centered design strategies (Dopp et al., 2019). This included a needs assessment to define user/target audience gaps or barriers to care, co-design sessions through collaboration with multiple teams, the use of focus groups to gain user perspective, and iterative developments. As the goal of this project was to create a solution to optimize clinical care during the pandemic, it was imperative that we designed evidence-based care pathways. Dopp and colleagues state that applying a variety of user-centered design strategies facilitates the development of "evidence-based practice services, technologies, and implementation plans that address identified needs" (p.1059) (Dopp et al., 2019).

However, despite this strength, there are some limitations that must be acknowledged. First, due to the constantly changing nature of the guidelines related to COVID-19 policies, difficulties emerged in connecting and engaging with users throughout this process. Difficulties arose recruiting families to participate as family members had to initiate contact with the study team to begin the virtual recruitment process. Another challenge was the implementation of the pathways as a completely virtual tool. Due to the iterative nature needed in the design and development, the pathways were initially piloted as a paper copy with transition occurring into an interactive PDF document for the ongoing pilot testing. Future incorporation into the CNH platform is desired.

5. Conclusion

COVID-19 policies restricted family presence and involvement in the NICU. Rapid change and variation of restrictive presence policies required the development of clinical care pathways were developed to meet needs. Preliminary feedback suggests that the clinical implementation of these pathways will ensure more equitable family centered care across all family scenarios regardless of whether they are in the hospital and/or at home.

Author contribution

Author MCY conceptualized the manuscript and wrote the first draft of the manuscript and edited all revisions. HM, BR, JD, AH and SF contributed substantial content to the paper. All co-authors were actively involved in all aspects of the study and creation of the pathways. All co-authors approved the paper.

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Ethical approval

Ethical approval was received through IWK Health prior to recruitment.

Declaration of competing interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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