

A Decision Support Tool for Problem Detection and Resolution in Healthy Newborns:
An Exploratory Study to Understand Parental Acceptance and Perception of Usefulness

by

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Abstract

Being a new parent can be considered an overwhelming experience with so much to learn, in an often exhausted state of mind. Still, it is critical for parents to be able to identify potential health problems in their babies, as soon as possible. This work takes the first steps in determining the feasibility of an app, to be used by new parents, in order to help detect possible health problems in their baby. Determining feasibility first included the creation of a decision algorithm that would be used by the app. Results of a survey administered to new parents showed that by and large, parents would be willing to enter the data necessary to drive the algorithm. Although, in most cases, their behaviour did not change after receiving feedback from the app, their level of concern was affected, demonstrating that the app was effective. Based on results, further investigation is advocated.

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Introduction

Background

Length of hospital stay postpartum. Over the past few decades the length of hospital stays for mother-infant dyads, postpartum, has continuously declined. The Organization for Economic Co-operation and Development demonstrates this trend for almost all of the 34 countries for which it has data (Organization for Economic Co-operation and Development, 2014). For example, from 1984 to 2012 New Zealand saw a decline from 5.7 to 1.8 days, Canada saw a decline from 4.7 to 1.7 days between 1980 and 2011, and similarly, in Germany, the length of stay dropped from 6.1 to 3 days between 1994 and 2012. Further to these examples, data collected by the National Health Services (NHS) in the United Kingdom shows that in 1989-1990 44% of hospital stays postpartum were 2 days or shorter, with this number jumping to 72% by 2005-2006 (Health and Social Care Information Centre, 2015). In the United States the trend in declining length of stay postpartum is slightly different. From 1980 to 1995, the average length of stay dropped from 3.2 days to 1.7 days for births of healthy babies; hospital stays were getting so short that they were termed “drive-through deliveries” (Dow, Harris, & Liu, 2006). However, legislation passed by most states as well as the US Congress, between 1995 and 1996, ensured a minimum hospital stay of 48 hours for a vaginal delivery (American Academy of Pediatrics, 2010). This resulted in the length of stay increasing once again, up to 2.1 days in 2006 (Buie, Owings, DeFrances, & Golosinskiy, 2010).

Factors leading to a reduced length of hospital stay postpartum. As discussed here, the main reasons for a continuously declining length of stay include social, economic, and, as proponents may argue, medical (Annas, 1995; Lee, Perlman, Ballantyne, Elliott, & To, 1995; Danielsen, Castles, Damberg, & Gould, 2000). The shift to a reduced length of hospital stay

postpartum began in the 1970's and was driven by women who wanted a more natural childbirth (Annas, 1995), either at home (if medically safe) or with as short of a hospital stay as possible (Parisi & Meyer, 1995). Shorter postpartum stays, sometimes only a few hours long, allow women to be at home, in a familiar and secure environment, with their loved ones (Danielsen et al., 2000; Martell, 2000; Fredriksson, Högberg, & Lundman, 2003). In response to a growing number of women who saw childbirth as a natural process which required minimal medical intervention (Lock & Ray, 1999), early discharge programs started to emerge (Parisi & Meyer, 1995). To be eligible to participate, strict physical and psychosocial criteria had to be met, including support at home. These programs only included low risk mother-infant dyads and provided excellent support and follow-up services (Martell, 2000). To illustrate the stringency of these programs, only 21 of 44 women in a trial of the Kaiser Permanente Family Centered Perinatal Care Program met the criteria to go home early (Parisi & Meyer, 1995). Moreover, patient safety was ensured by providing “extensive prenatal education, careful assessment in the hospital, and if the criteria for early discharge were met, home visits by nurse practitioners for up to two weeks” (Parisi & Meyer, 1995, p. 1635). Supporters of the early discharge programs argued that they promoted maternal infant bonding in a non-hospital setting (Jackson et al., 2000).

However, early discharge soon went from being patient-driven to a routine process for most mothers and newborns (Martell, 2000). The change to shorter hospital stays was largely due to its cost-saving benefits (Danielsen et al., 2000; Parisi & Meyer, 1995; Wen, Liu, Marcoux, & Fowler, 1998). For example, in the United States, in the 1980's, third-party payers wanted to reduce unnecessary hospitalization days, focussing on mothers and newborns, since birth was seen as a “wellness life event rather than an illness” (Fink, 2011, p. 149). In Canada, cost savings

were not driven by third party payers; rather, they came from reducing the number of hospitals and beds across the country. More specifically, between 1986/87 and 1994/95 there was a 14% reduction in the number of hospitals and an 11% reduction in the number of approved beds in Canada, leading to fundamental changes in the way hospitals delivered their services (Tully & Saint-Pierre, 1997). A study conducted by Britton (1998) reinforces bed availability as a significant determinant in discharging patients early in Canada, showing it to be a major consideration among obstetricians. This same study found that for American physicians, financial factors were of great importance, supporting the role of third party payers in determining length of stay postpartum. In addition to social and economic factors, another justification for a decreasing length of stay postpartum was the reduced risk of iatrogenic events, such as cross infection, for both mother and infant (Annas, 1995; Danielsen et al., 2000; Lee et al., 1995).

Supporting the safety of early discharge, for mothers and newborns, are two studies which found no link between a decreased length in postpartum stay and various adverse effects, such as an increased rate of readmission (Madden et al., 2002; Madden et al., 2004). Moreover, studies that examined other possible negative effects of shorter postpartum stays, like rate of breastfeeding (Cambonie et al., 2010; Britton & Britton, 1999; Winterburn & Fraser, 2000) and maternal depression (Brown, Bruinsma, Darcy, Small, & Lumley, 2004), also found no relation.

Consequences to a reduced length of hospital stay postpartum. Even though the results of several studies support early discharge, quite a number of large-scale studies conducted in both Canada and the United States have found that a shorter hospital stay leads to a higher rate of neonatal readmission (Liu, Clemens, Shay, Davis, & Novack, 1997; Lee et al., 1995; Lock & Ray, 1999; Johnson, Jin, & Truman, 2002; Yanicki, Hasselback, Sandilands, & Jensen-Ross,

2002; Weiss, Ryan, Lokken, & Nelson 2004; Malkin, Broder, & Keeler, 2000; Danielsen et al., 2000; Maisels & Kring, 1998; Meara, Kotagal, Atherton, & Lieu, 2004). Some of these studies show more precisely, that this increased rate of readmission is limited to the first week or two after birth (Liu et al., 1997; Lee et al., 1995; Yanicki et al., 2002; Johnson et al., 2002; Lock & Ray, 1999). Three of the most common reasons identified for readmission are jaundice, dehydration, and feeding problems (Lee et al., 1995; Meara et al., 2004; Maisels & Kring, 1998; Danielsen et al., 2000; Johnson et al., 2002; Lock & Ray, 1999; Lieu et al., 2000; Farhat & Rajab, 2011; Young, Korgenski, & Buchi, 2013). Additionally, Danielsen et al. (2000) found that congenital lower bowel obstructions, left-sided obstructive cardiac defects, right-sided obstructive cardiac defects, and low-risk infections to be statistically significant factors in readmissions of infants discharged earlier.

A range of factors may help explain the contradictory results of the aforementioned studies, particularly with regards to increased readmission rates. For example, most studies did not take into account follow-up care of the mother and infant which, if timed appropriately, may reduce hospital readmissions (Meara et al., 2004). Furthermore, many studies conducted in the United States were done during a period when rates of breastfeeding were on the rise, creating a possible confounding factor (Madden et al., 2004); as explained by Madden et al. (2004), although breastfeeding has a number of benefits (see Parisi & Meyer, 1995), it is linked to both jaundice and dehydration, two of the health issues most commonly linked to increased readmission rates.

Another consequence and possible explanation for the adverse outcomes of shorter postpartum stays is that it does not provide enough time for healthcare providers to properly assess the infant for common neonatal illnesses. Jackson et al. (2000) argues that this is the

primary medical disadvantage to early discharge since certain medical conditions only become apparent 24 to 72 hours after birth. His research showed that although 68.3% of all problems were identified between 5 and 24 hours after birth, almost 32% were only discovered after 24 hours. Among the health issues identified later are jaundice and dehydration (Lee et al., 1995; Meara et al., 2004). Even if jaundice is identified in the hospital, changes in the condition post-discharge may be too subtle for parents to detect until the damage has already been done (Parisi & Meyer, 1995). In addition to lack of time for healthcare providers to identify illnesses in newborns, there is also insufficient time to properly assess a woman's ability to breastfeed, since full milk production does not occur until the second to fourth day postpartum (Fink, 2011; Parisi & Meyer, 1995). Taking all of this into consideration helps to explain the previously mentioned increased readmission rates for newborns, due to shorter hospital stays postpartum.

Determining if an infant is ready for discharge does not only include assessing for possible illness; the American Academy of Pediatrics released a policy statement in 2010 listing 16 criteria which they say should be met before discharging an infant (American Academy of Pediatrics, 2010, p. 407). Included among these criteria, is assessing "[t]he mother's knowledge, ability, and confidence to provide adequate care for her infant" with respect to six different factors related to infant health, safety, and feeding. Yet, various studies have shown that mothers feel they are unprepared and lack the knowledge needed when they leave the hospital (Deave, Johnson, & Ingram, 2008; Kanotra et al., 2007; McVeigh, 1997; Bernstein et al., 2013; Forster et al., 2008). In one study evaluating readiness of discharge, as determined by the agreement among mother, pediatrician, and obstetrician, of the 16% of mothers deemed unready, most of these were evaluated as such solely by the mother (Bernstein et al., 2013). In another study (Forster et al., 2008) which used focus groups and interviews with 52 parents, many felt as though they

were being forced out of the hospital before they were ready and confident enough to care for their baby. This study found that a number of first-time mothers had anxiety about going home after birth with many perceiving it as being unsafe since they did not feel that they knew how to properly care for their baby or recognize if something may be wrong with the baby's health. For the mothers in this particular study, the postpartum hospital stay was of utmost importance since it provided them with professional support in learning how to care for their baby. In two other studies, there was general consensus among mothers that although prenatal classes were useful and prepared them for labor and delivery, nothing had prepared them for parenthood (McVeigh, 1997; Deave et al., 2008). Kanotra et al. (2007) found that the lack of knowledge and preparedness was not limited to only first-time mothers, but that many multiparous women also would have appreciated a refresher in how to care for their newborn. McKellar, Pincombe, & Henderson's (2002) research supports the findings that many mothers lack knowledge needed in their new role, and this deficiency was often associated to a lack of confidence, with one mother saying "the first day was really scary cause they left the little baby along side [sic] me and it is like, how do I change a nappy?" (p. 27). Feelings of insecurity and a lack of confidence among new mothers is supported by other research findings as well (Deave et al., 2008; McKellar et al., 2002; Forster et al., 2008; Danbjørg, Wagner, & Clemensen, 2014).

According to Suplee et al (2014), "nurses are in opportune positions to facilitate knowledge acquisition and role transition for postpartum mothers" (p. 782). Liu, Chen, Yeh, & Hsieh (2012) assert that an important responsibility of nurses, caring for postpartum women, is to evaluate and reinforce a mother's beliefs in her own abilities. Unfortunately, a shortened length of stay leaves very little time for nurses to teach and provide support for new mothers (Fink, 2011; Martell, 2000; Lee et al., 1995; McKellar et al., 2002; Danbjørg et al., 2014, Salem-Schatz

et al., 2004). Many things happen in this short stay, taking away from time to impart knowledge to new parents. Suplee et al. (2014) assert that the nurses need to use this time to focus on the physical care of the mother and infant. In addition, time that could be used for teaching is consumed by family and friends who are visiting (McKellar et al., 2002; Rayner, McLachlan, Forster, Peters, & Yelland, 2010). The little time that is available to provide guidance to mothers is less than optimal, since cognitive deficits, particularly in memory function, have been identified in women in the first 24 hours postpartum (Eidelman, Hoffmann, & Kaitz, 1993).

Challenges faced by new parents do not stop at feeling unprepared and lacking self-confidence, the postpartum period is generally difficult and a “time of many questions” for parents (Fredriksson et al., 2003, p. 273). Liu et al. (2012) found that one third of mothers in her study had high maternal parenting stress scores. Moreover, other problems affecting a mother’s ability to care for her baby are anxiety and depression (Çinar & Öztürk, 2014; Paul, Downs, Schaefer, Beiler, & Weisman, 2013), affecting 17.2% and 5.5% of new mothers, respectively (Paul et al., 2013). All of these factors are compounded by the fatigue experienced by new mothers (McVeigh, 1997; Salem-Schatz et al., 2004). Parents are left feeling overwhelmed and with a sense of great responsibility (Salem-Schatz et al., 2004; Deave et al., 2008).

Mitigating risks of a reduced length of hospital stay postpartum. To mitigate risks associated with lack of readiness for discharge and possible health issues of the baby, increased postpartum support has been advocated (Bernstein et al., 2013; American Academy of Pediatrics, 2010; Danielsen et al., 2000; Maisels & Kring, 1998; Fink, 2011; Kanotra et al., 2007; Jackson et al., 2000). The American Academy of Pediatrics specifically recommends that follow-up occur no later than 72 hours after discharge. Many modes of postpartum support have been promoted, including social support as well as formal follow-ups. Regarding the former, social support has

been identified as playing an important role with respect to mental health and wellbeing (Haga, Lynne, Slinning, & Kraft, 2012). These findings are supported in Leahy-Warren, McCarthy, & Corcoran's (2012) research, with the recommendation that "nurses and midwives need to be aware of and acknowledge the significant contribution of social support, particularly from family and friends" (p. 1). Although social support has been shown to play a significant role in parents' mental health and wellbeing, more formal support is often needed for both mother and baby. Some options include: home visits by public health nurses, outpatient breastfeeding clinics, and early physician visits (Cargill, Martel, & Society of Obstetricians and Gynaecologists of Canada, 2007). In addition to home visits by nurses, visits by midwives have also proven to have a positive effect (Çinar & Öztürk, 2014; Forster et al., 2008; Deave et al., 2008). More specifically, women who were interviewed before and after birth regarding what types of support they found effective, expressed that midwives were seen as a reliable source of information, support, and advice (Deave et al., 2008). Another study showed that the provision of baby care education via individual home visits, by either nurses or midwives, increased maternal self-confidence (Çinar & Öztürk, 2014). In the Netherlands, in the week or so after birth, a midwife provides four to five home visits and a maternity care assistant (MCA) visits for at least 3 hours daily, during the same time period. Wieggers (2006) asserts that the Dutch model of postpartum care is best because "it can be integrated in the normal family routine and [...] it combines the necessary medical and psychosocial aspects, while reducing the length of hospital stay and therefore reducing the costs of maternity care" (p. 6). Regardless of how the support is provided by healthcare providers, several studies have shown that it is the mere presence of the support, not necessarily the format, which makes a difference. For example, one study which compared patients that had home visits with patients that had pediatric clinic visits, showed no significant

differences in clinical outcomes (Lieu et al., 2000). Similar results were found in another study which compared routine home visiting by public health nurses (PHN) to a simple telephone call designed to screen patients that need further intervention (Steel et al., 2002). This study's findings showed no significant differences in breastfeeding rates, maternal confidence in the first two weeks, or newborn health issues in the first four weeks; both types of support were, in essence, equally effective.

Despite the positive outcomes that various types of follow-up have demonstrated (whether via home visits, office visits, by telephone, etc.), there are still a number of hurdles which can hinder their success. In one study which used four separate focus groups: one with physicians, one with nurses, and two with parents, a number of obstacles to timely follow-up were established (Salem-Schatz et al., 2004). Barriers for home visits included not being able to reach parents due to incorrect contact information as well as refusal of home care services. Timely follow-up visits in an office or clinic were often difficult to achieve due to overloaded practices or inconvenient office hours. Additionally some parents were reported to not show up for appointments; perhaps due, in part, to the difficulty expressed by many mothers simply to leave the house. Other parents feared exposing their newborn to sick children while waiting in the doctor's office. A further barrier reported by some parents is that they did not have a primary care provider for their baby by the time they were discharged from the hospital. Lastly, a common problem reported by physicians, nurses, and parents in all focus groups, were barriers due to insurance requirements. For example, parents indicated that cost was a factor in deciding whether or not to accept a home visit. Financial considerations were also identified in a similar study which evaluated general challenges faced by parents two to nine months postpartum, with one woman saying “[y]ou can't always get a hold of your doctor and you can't afford to go to the

Emergency Room all the time” (Kanoetra et al., 2007, p. 553). This same woman expressed her desire to have been given more information before going home with her baby.

Alternate Methods of Supporting Parents: the Internet and mHealth Apps

The frustration expressed by the aforementioned woman, as well as the earlier examination regarding how many parents feel they lack knowledge and are unprepared when leaving the hospital demonstrate the need for additional resources for new parents. In fact, informal parenting information has been shown to be preferred by many; the internet, drop-in programs, books, and classes and information sessions, have been found to be among the most popular types of resources (Devolin et al., 2013). Still, parents are not always aware of available programs and services, have a lack of time, or lack of childcare (Devolin et al., 2013). Therefore, with the pervasiveness of internet access worldwide, including access in 85.8% of Canadian households and 84.2% of American households in 2014 (The World Bank Group, 2015), the internet as a medium to provide support to parents is arguably a well-justified choice. Among other benefits, the use of the internet to supply health information can overcome barriers related to travel and access to care (Logsdon, Mittelberg, & Myers, 2014). In fact, up to 64% of adults have been reported to search the internet for health related information (Wainstein, Sterling-Levis, Baker, Taitz, & Brydon, 2006; Fox, 2011; Khoo, Bolt, Babl, Jury, & Goldman, 2008; Logsdon et al., 2014; Goldman & Macpherson, 2006). An Australian-based study that interviewed parents of young children waiting in a hospital emergency department found that in the last 6 months, the internet was the third highest consulted health information source after general practitioners and pharmacists (Khoo et al., 2008). Another study, which examined the internet as a source of health information among the general population found that just over half of participants (54.4%) turned to the internet, before any other source, the last time they were

seeking information about a health topic (Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010). When seeking baby-related information, parents were found to search using Google or to access certain baby-related websites directly; these parents claimed that searching electronically was much easier than reading through “a pile of pamphlets” provided by the hospital (Danbjørg et al., 2014, p. 730). Patients’ motivations for seeking health information on the internet include simply “wanting to know more” as well as parents seeking alternate therapies for their child (Wainstein et al., 2006, p. 529). One study revealed that parents were more likely to use internet sources to learn more about a diagnosis or treatment, rather than to try to diagnose or treat their child’s health issues themselves (Walsh, Hyde, Hamilton, & White, 2012). Still, in another study, 18% of participants stated that they altered a healthcare decision because of what they found on the internet (Wainstein et al., 2006). These findings are bolstered by Logsdon et al. (2014) who found in their research that 46% of adolescent mothers changed their health behaviours because of information they had found on a website. Moreover, the same study reported that 27% of participants decided to visit a doctor because of their internet findings. All of these studies demonstrate the significant role and influence the internet plays in the world of healthcare, for both the general population seeking information about their own health as well as for parents seeking information regarding the health of their child.

Unfortunately, the pitfalls for parents seeking health-related information on the internet are many, revolving primarily around the difficulty in finding reliable and trustworthy resources (Khoo et al., 2008; Goldman & Macpherson, 2006; Wainstein et al., 2006; Danbjørg et al., 2014). For instance, less than 10% of parents interviewed by Khoo et al. (2008) said that Google and other search engines were a trusted source, making it the lowest ranking health information resource among a list of seventeen. Many of these participants cited the reliability (65.2%) and

content (35.4%) of internet-published health information as a particular concern. Additionally, not understanding the information was a common problem experienced by nearly thirty percent of parents in one study (Wainstein et al., 2006) and not being able to find an answer was reported by over ninety percent of parents in another study (Goldman & Macpherson, 2006).

The frustrations of these parents to easily find reliable information on the internet can be, in part, attributed to findings from a study which aimed to assess the reliability and accuracy of medical advice found via Google searches (Scullard, Peacock, & Davies, 2010). In this study, the researchers attempted to find answers to five common pediatric questions that have clearly defined answers. For each question, they conducted a search using the Google search engine and then triaged each of the resulting hits by categorizing the sites as correctly answering the question, incorrectly answering it, or failing to answer it altogether. The results showed that of the 500 sites, only 39% correctly answered the question, while 11% were incorrect and the remaining 49% failed to answer the question at all. The large number of irrelevant sites led the researchers to conclude that a sufficient amount of effort needs to be invested in order to find any answer on the internet and still, with no guarantee that it is even correct. A more recent study specifically examined symptom checkers – “tools that use computer algorithms to help patients with self diagnosis [sic] or self triage [sic]” (Semigran, Linder, Gidengil, & Mehrotra, 2015, p. 1). The researchers used 45 standardized patient use cases in order to assess 23 different symptom checkers based on accuracy of diagnosis and/or triage. The general performance of the tools demonstrates that there is still room for improvement, with the correct diagnosis provided first in only 34% of cases and the appropriate triage being advised in 57% of cases. One finding that surprised these researchers was that the symptom checkers that asked for demographic data did not perform any better, possibly because the information was not used appropriately by the

algorithms. Although these researchers provided a note of caution when using symptom checkers, they explicitly underlined their value over that provided via a general internet search engine or not seeking any advice at all.

In the above research, although most of the symptom checkers were in the form of websites, some were also available as apps for smart phones or tablets. A symptom checker app is just one example in the growing trend of mobile health (mHealth) applications. One definition provided for mHealth is "the use of wireless technology to deliver health services and information on mobile communication devices such as mobile phones, PDAs, Smartphones, monitoring devices, e-book readers, and iPods" (García-Gómez et al., 2014, p. 75). In 2010, it was reported that the top ten mHealth apps alone, generated 4 million free downloads per day and 300,000 paid downloads (Jahns, 2010). This same report also predicted that by 2018 there would be 3.4 billion smartphones and tablets with access to mobile apps and over half of the users will have downloaded an mHealth app. mHealth is said to have the potential to revolutionize the healthcare landscape, offering consumers more convenient, engaging, and personalized care (Steinhubl, Muse, & Topol, 2013). One reason mobile phones, in particular, are argued to be an attractive option for delivering healthcare interventions is because people always tend to carry their phones and often have a positive emotional attachment to them (Klasnja & Pratt, 2012). And unlike other technologies, mobile phones have been widely adopted across socioeconomic and demographic groups (Carrera & Dalton, 2014). The potential uptake of mHealth is encouraging since, in a review of the current state of mHealth, the authors asserted that a number of problems that are emerging in health services can be overcome using mHealth solutions; this includes the need to empower patients and families to handle their own healthcare as well as to provide ubiquitous access to health services (Silva, Rodrigues, de la Torre Díez,

López-Coronado, & Saleem, 2015). The convenience provided by mHealth make it a particularly appealing method to support parents; a group deemed some of the most active information seekers, with questions arising nearly daily about their new responsibilities and family conditions (García-Gómez et al., 2014).

The functionality provided by mHealth apps does not stop at symptom checking, as discussed above; rather, mHealth apps offer a range of capabilities. In a comprehensive review of current mHealth apps, the top 3 apps identified in the area of children's health provided functionality to track and trend data about the baby (such as feedings, output, and sleep), weekly averages, notifications and reminders, and tracking vaccines and doctors' appointments (Silva et al., 2015). As detailed below, recent research has also explored the use of apps to allow parents to communicate with healthcare providers and sometimes even allow for remote monitoring of the baby by a clinician.

Having the option to chat online with healthcare providers was supported by parents in a recent study (Danbjørg et al., 2014), with the rationalization that it is more convenient and less disturbing than actually going to see a doctor. Along these lines, Sawyer et al. (2014) are currently examining the effectiveness of a nurse-moderated online support group for new parents. The researchers argue that this support program has several important benefits including, among others, providing credible and readily accessible support and information about parenting and infant development to new mothers; results from this study are pending. In another study done by Isetta et al. (2013), they examined an internet application that provided asynchronous communication between parents and nurses, in the form of e-mail messages. Communication could be initiated either by the parents, if they had a question, or by the nurse who may be concerned regarding responses to a questionnaire that parents answered about their baby twice a

week. Results of a participant survey demonstrated overall satisfaction and a positive evaluation of helpfulness of the system, suggesting parents' willingness to use such an application. The positive response regarding the use of either synchronous or asynchronous communication between new parents and healthcare providers was echoed in other studies as well, in which parents felt the mechanism provided extra support when caring for their newborn (Danbjørg, Wagner, Kristensen, & Clemensen, 2015; Lindberg, 2013).

Still, mHealth apps have the power to provide capabilities beyond simply tracking information or providing an easier way for parents to communicate with clinicians. As per Klasnja & Pratt (2012), "automated systems can encode the types of feedback clinicians could provide if they were given the patients' tracked data" (p. 190). In other words, if parents were to enter data about their babies into an app, rather than having the data remotely monitored by a healthcare provider, as was done in the study by Isetta et al. (2013), data could be automatically assessed in order to provide feedback about possible problems and/or guide parents with respect to steps that should be taken. Providing such capabilities in an app supports the shift to involve the patient, or in this case the parent, to a greater degree in managing one's health and to decentralize the delivery of healthcare. This is known as 'do-it-yourself healthcare', an area that is flourishing in both research and implementation (Carrera & Dalton, 2014). Yet, in a review of apps marketed specifically to assist in the diagnosis process, only 24 apps were found in the Google Play and Apple App stores, directed specifically at lay users (Jutel & Lupton, 2015). And to this researcher's knowledge, no app currently exists to help with the diagnosis or even detection of health problems in a newborn, nor has any research been published in this area.

Current Research

The current research explored the feasibility of an app to be used by new parents in the first month after childbirth. By tracking information about their baby, such as number and times of feeds and dirty diapers, the app would provide parents with feedback if a possible health problem is detected. This study specifically aimed to create the decision support algorithm that would be used to provide that feedback. Furthermore, this research examined whether such an app would be useful to parents.

Goal and Objectives

The overall goal of this study was to explore the feasibility of a decision support tool that could be integrated into an app for a smart phone or tablet. The tool is intended to be used by parents to detect possible health problems with their newborn baby in the first month of life. To achieve this goal, the following objectives needed to be met:

1. Identify what information parents are able to obtain and enter into the app that can help with problem detection. For example, a parent is easily able to obtain and enter information about the baby's dirty diapers, but is most likely not able to obtain and enter information about the baby's heart rate.
2. Create a decision support algorithm that can help to automatically identify potential health problems with a baby in the first month of life. Although the algorithm was reviewed by a lactation consultant / nurse as part of this research, it is not completely accurate, nor does it detect 100% of problems. The objective, for this study, was to provide a reasonably complete representation of what can be supported by such a decision support tool and what kind of problems can be detected.

3. Determine what information parents are willing to enter into the decision support tool on a consistent basis.
4. Determine what information, if any, parents are willing to enter into the decision support tool sometimes. More specifically, the parent would only enter the information if they thought it was atypical. For example, if a child is vomiting or has a high temperature.
5. Evaluate the effectiveness of the decision support tool with parents.

Research Questions

The exact questions that this thesis aimed to answer are enumerated below. These questions will ultimately help in understanding if a decision support tool to help parents detect health problems, in newborns, is in fact feasible and if further research should be pursued.

1. Are parents willing to enter “non-standard information” into the tool? “Non-standard” consists of information other than what is typically entered in existing baby tracking apps. Typical information consists of the type and number of voids (i.e., urine versus stool), the start and end times that the baby is breastfed, and start and end times of sleep. “Non-standard” information includes things such as baby’s temperature, skin condition, and description of stools.
2. Are parents willing to enter information into the tool on a regular basis?
3. Will the decision support tool change the behaviour of a parent?
4. Will the decision support tool provide a false sense of confidence to parents?
5. Are parents exhibiting an appropriate amount of trust in the tool?

Hypotheses

1. Parents will be willing to enter standard/common information (e.g., time of breastfeeding, voids, sleep, etc.) on a regular basis, but will only be willing to enter non-standard information sometimes.
2. In cases when the decision support tool detects and alerts parents of a possible problem, parents will follow the recommendations of the tool.
3. In the case that the decision support tool does not detect a problem, parents will continue to react in the same way as when they had no decision support. That is, if a parent originally thought there was a problem and took actions to address it, they will still take the same actions even if the decision support tool does not detect an issue.

Overall Methodology

In order to meet the above-mentioned objectives and answer the research questions, a three phase approach was taken:

- Phase 1: The creation of a decision support algorithm to identify potential health issues in babies in the first month of life.
- Phase 2: A focus group with lactation consultants to generate scenarios to be used in the final parent survey.
- Phase 3: A parent survey to answer the research questions previously outlined. A pilot round will help ensure overall clarity and comprehensibility of the final survey.

The flow and dependencies of these phases is illustrated in Figure 1. Additionally, each phase is explained in greater detail in later sections.

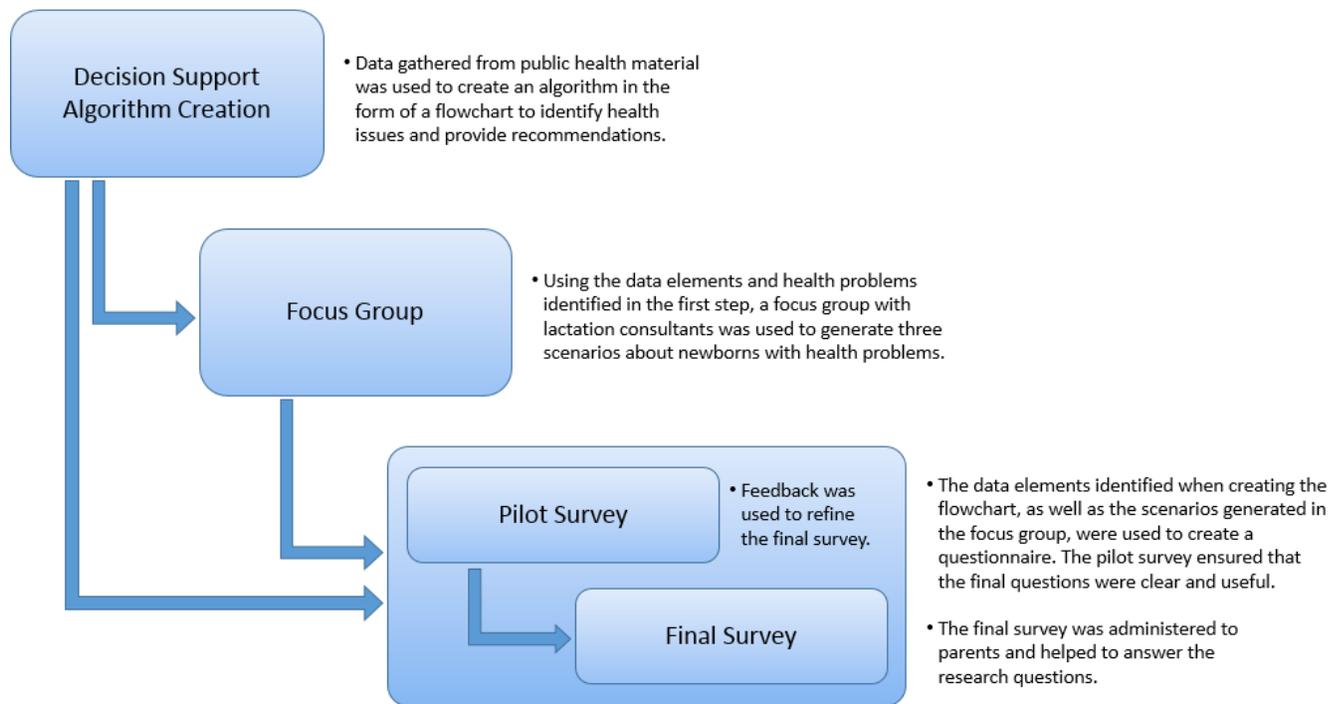


Figure 1. The flow and dependencies of the various research stages.

Ethics

The current research was approved by the Carleton University Research Ethics Board as well as by the Ottawa Health Science Network Research Ethics Board. Informed, written consent was obtained from all focus group participants. Consent was implied by all participants who submitted the online pilot and final surveys.

Phase 1: Algorithm Creation

The first phase of this research was to create an algorithm that would be used by the app to help detect potential health problems in newborns. The algorithm is formatted as a decision tree. A secondary output resulting from the creation of the algorithm was the list of data elements that parents could enter into the app. This list was needed for the parent survey to help determine

which elements parents would actually be willing to enter. Although out of scope for this research, the algorithm could be refined based on those findings.

Procedure

The algorithm was created using the 2014 public health assessment guidelines (ref, 2014). This document is used by nurses to help identify and address problems or concerns of parents, in a systematic way. The section of the document used for this research was limited to the newborn's health, which includes topics such as breastfeeding, elimination, baby's weight, and sleep/wake patterns. For each topic the document describes normal findings, concerns (i.e., symptoms) and the nursing action. This information was used to create a list of health issues and a list of symptoms; these were formatted into a matrix with symptoms for each health issue marked. In some cases, symptoms and health issues were one and the same. For example, a fever is both a symptom and a health issue on its own. The matrix was reviewed with a nurse / lactation consultant for accuracy and completeness; her expertise also helped to identify the minimum symptoms that a baby must exhibit in order for each problem to be diagnosed. For instance, even though fourteen symptoms were listed for acid reflux, only five symptoms were identified as needing to be present before the problem could be diagnosed. After identifying base symptoms for each health problem, secondary, and tertiary symptoms were identified, and a recommendation proposed for what a parent should do in case symptoms are present at any of the levels. The matrix was then translated into a decision tree that could be used by the proposed app.

Results

Two artifacts resulted from the creation of the decision algorithm. The first is a list of data elements that parents were deemed capable of entering into the app. This list was derived

from the list of symptoms used to identify each health problem and will be included in the parent survey to determine whether parents would actually be willing to enter the data. The list can be found in Table 1 below.

Table 1

Data Elements that Parents were Deemed Capable of Entering into the App

Data Element	Options
1. Baby's birth date	
2. Baby's birth weight	
3. Current weight and date weighed (date would be automatically set to the day the weight is being entered in the app, but it can be changed)	
4. Time of breastfeeding	
5. Parent perception of feed	Baby fed well, unsure, baby did not feed well – coughing/choking, baby did not feed well – fell asleep, baby did not feed well – refused to feed, baby did not feed well – no audible swallowing, baby did not feed well – fussy/inconsolable, baby did not feed well - other
6. Amount of expressed breast milk that baby drank (Expressed breast milk is milk that is extracted from the breast either manually or with a pump.)	
7. Time that baby drank expressed breast milk	
8. Amount of formula that baby drank	
9. Time that baby drank formula	
10. Start and end of sleep	

- | | |
|---|---|
| 11. Baby had a wet diaper | |
| 12. Description of urine | Normal, contains pink crystals, strong odour, dark colour, contains blood (pictures may be provided) |
| 13. Baby had a dirty diaper | |
| 14. Description of poop | Black, dark green, green, brown, yellow, curdy, hard, explosive, watery, contains mucous, contains blood (pictures may be provided) |
| 15. Baby's temperature | |
| 16. How the temperature was taken | Armpit, ear, buttocks |
| 17. Skin colour | Pink, pale, yellow, bluish (around mouth and nose), grey |
| 18. Skin condition | Clear, rash, dry, red spots, bruising. (pictures may be provided) |
| 19. Description of rash (Note that 'Description of rash' would only be available if 'rash' is selected as a skin condition) | Raised, red, itchy, bleeding, cracked, covered with a yellow crust |
| 20. Umbilical cord condition | Drying/no smell, red, smelly, foul discharge, bleeding |
| 21. Activity | Normal (alert/content), sleepy, fussy, shaky, irritable, excessive crying, difficult to wake for feedings |
| 22. Vomited / forcefully expelled fluids | Yes, No |
| 23. Spits up often (not only during or after feedings, but anytime) | Yes, No |
| 24. Excessive gas | Yes, no, not sure |
| 25. Skin elasticity (a picture would be provided as well as a description such as: Skin elasticity is | Good, poor, not sure. |

poor if the skin on top of the baby's hand remains raised after being pinched and released.)

26. Crying behaviour	Normal, sounds painful, high-pitched, lasts 3 hours or more per day
27. Whites of eyes are yellow	Yes, no

The second artifact is the algorithm itself, in the form of a decision tree. The tree goes through each problem that was determined to be identifiable based on the symptoms that most parents should be able to recognize. If the problem is found to exist, based on the decision tree, then a problem summary is output and the decision tree moves to the next problem. Once all problems have been iterated through, problem summaries can be collated and displayed in an alert message in the app. The suggested format of the message is as follows:

Alert! *<Action from flow diagram (shown in rounded rectangles)>*

This recommendation is based on the following symptoms:

- list all symptoms that caused this particular warning to appear

<if other symptoms are present>

Other symptoms of concern include:

-list all other symptoms that may result from the particular condition and are present in the baby.

The main flow of the decision tree is shown in Figure 2. Each question has its own sub-diagram. An example sub-diagram, for the question “Does baby have jaundice?” is shown in Figure 3. The full algorithm can be found in Appendix A.



Figure 2. Decision algorithm showing the high level flow through each problem.

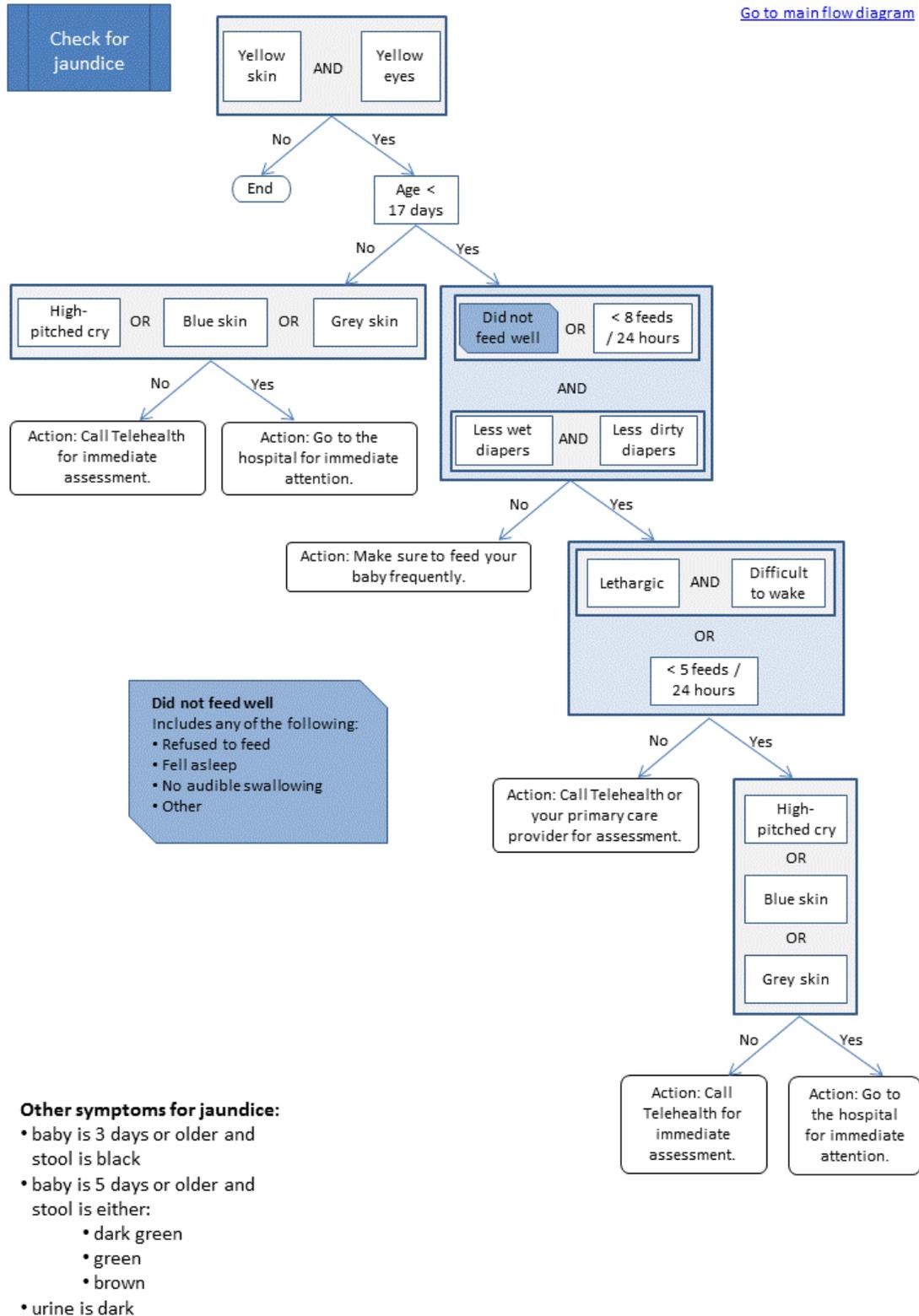


Figure 3. A sub-diagram from the decision algorithm to determine if baby has jaundice.

Phase 2: Focus Group

Procedure

The focus group was 1.5 hours long and took place at one of the monthly meetings of a local lactation consultants' group. The focus group was moderated by the lead researcher. Preceding the focus group, members were given an overview of the project and the chance to ask questions (see Appendix B for the focus group recruitment script). Those who were interested in participating were asked to sign an informed consent form (see Appendix C) and complete a survey in advance of the focus group (see Appendix D). The survey collected demographic data as well as asked participants to prepare ideas for each of the three scenarios that would be generated during the session. Participants were also given an information sheet listing all the data elements that parents would be expected to enter into the app as well as all the possible health problems that could be detected based on that information (see Appendix E). This information sheet was to be used as a reference while generating the scenarios during the session.

The focus group was semi-structured, with certain questions prepared in advance and others that were based on responses and comments from participants (see Appendix F for protocol). Notes were taken by two co-researchers throughout the session.

Details for three scenarios were generated during the focus group via open discussion and general participant consensus. Each scenario had pre-determined criteria that needed to be met, such as whether or not the chosen health issue is detectable by the app and the severity of the health issue, based on the symptoms provided in the focus group. Using the input received throughout the session, the three scenarios were later generated and injected into the pilot and parent surveys.

Recruitment

Convenience sampling was used to recruit participants for the focus group. Recruitment occurred at a monthly meeting held by a local lactation consultants' group. All members of the group were eligible to participate, since all members are lactation consultants and have expertise with health issues common in newborns. No remuneration was offered, other than some refreshments and the chance to be presented with the research results, if members were interested.

Inclusion / Exclusion Criteria

The focus group participants had to be members of a selected local lactation consultants' group in Ottawa that consists of an experienced group of lactation consultants with diverse backgrounds, including nursing. The decision to use only lactation consultants, rather than a mix of healthcare providers with different backgrounds, helped to "capitalise on people's shared experiences" (Kitzinger, 1995, p. 300). Still, since the lactation consultants from this group work in diverse environments (e.g., health care facilities, agencies, and private practices within the community), they were also able to provide different perspectives on the types of problems parents may face and family circumstances that must be considered. It was expected that this range of perspectives and experience would result in the most appropriate scenarios to be developed and used in the parent survey.

Sample Size

Out of a possible forty lactation consultants (LCs), it was expected that between ten and fifteen would volunteer to participate in the focus group. The ideal size for a focus group consists of a minimum of four participants and a maximum of twelve participants (Kitzinger, 1995; McDaniel & Bach, 1994; Basch, 1987; Krueger 2009). The original plan to split up the group

should more than twelve LCs wish to participate could not be achieved due to the wishes of the group's moderator that the members not be split up. However, since all members were well-known to each other, this did not impede the flow of ideas but it likely did take longer to achieve consensus on the scenarios and group of symptoms, than it would if the group were smaller.

Results

Participants. The focus group consisted of fourteen ($N = 14$) participants. All participants were lactation consultants and had their International Board Certified Lactation Consultant (IBCLC) designation. The majority of participants ($n = 11$) were over the age of 46 years and experience as a lactation consultant varied from 1 to 24 years, with the average being nearly 11 years ($M = 10.79$, $SD = 7.70$; see Figure 4 for further breakdown). In addition to all participants having their IBCLC designation, other professional designations, education, and relevant titles included: registered nurse, primary health nurse practitioner, certified infant massage instruction, masters of education, La Leche League leader, doula, and registered midwife. As was anticipated, a range of current and previous practice environments was observed among participants, with private practice being the environment in which most have worked at some point in their careers, followed by a community health centre. Other environments included, but were not limited to, home visits, a neonatal intensive care unit, and a birthing centre.

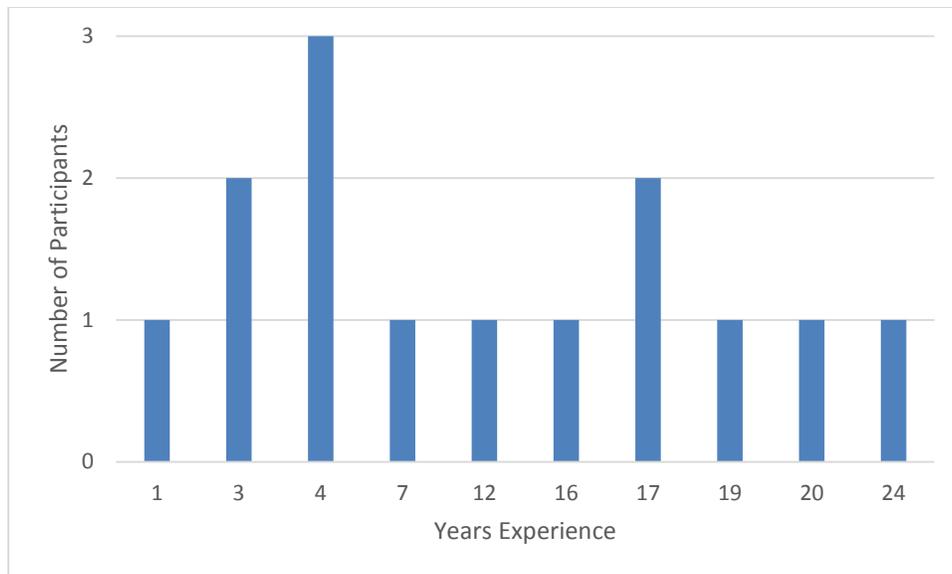


Figure 4. Number of years that each member of the group practiced as a lactation consultant.

Findings. There were two outcomes from the focus group. The first was the input received to create the three scenarios to be used in the parent survey. The first scenario generated was about a baby with jaundice, a fairly common problem that many parents were expected to be familiar with; jaundice is detectable by the app. The second scenario used a more complex problem that was intended to create doubt in parents, but not necessarily be known or obvious. The problem chosen for this scenario was gastroesophageal reflux disease (GERD), a problem that is detectable by the algorithm. Contrarily, the third scenario used a problem that was not detectable by the app, i.e., tongue tie. This is a more complex problem that was, once again, intended to create doubt in parents but not be completely obvious to detect. The three scenarios can be found in Appendix G.

The second outcome was one that was not anticipated; after the moderator gave an overview of the research and the floor opened up for questions, there was an overwhelming response to the idea behind the app. Participants questioned it and voiced concerns from several perspectives, including:

- whether the researchers actually thought that parents would input the data
- the validity of certain data input such as weight and temperature
- whether the app would be targeted to parents of all socio-economic backgrounds and levels of education
- whether parents would understand what all of the data elements were
- how data would be entered, in terms of whether the app would prompt the parent to enter data or the parent had to pro-actively find where to enter the data and do so
- whether tips and helpful information would be provided

Many of the concerns that were raised were outside the scope of the current research, e.g. targeting families of all socio-economic backgrounds and levels of education. This, along with the other concerns outside the scope of this research, should be considered if the research is to be advanced (see 'Limitations and Future Work').

Some concerns, however, had a more immediate need for attention. For example, one participant noted that 'ear' was not listed as a method to take temperature. It was explained to her that it was not listed because it is not considered safe in babies, to which she replied that some parents may still do it and it needs to be available as an option. Consensus among participants was achieved, with the caveat that if parents did choose 'ear' as the method they used to take the baby's temperature, they should be provided with information about why it is not appropriate and what method is recommended.

Phase 3: Parent Survey

Procedure

To answer the research questions, a study-specific survey was constructed. The survey consisted of four parts, as described here:

- Part I “A bit about you”. This section collected information about the participants, such as age group, gender, number and age of children, education level, and comfort with computers. This information was considered useful to potentially help explain other survey results.
- Part II “Using the App”. Questions in this section of the survey helped answer the research questions about parents’ willingness to enter data into the app.
- Part III “Scenarios”. This section of the survey used scenarios to determine how parents’ behaviour may be affected when they receive support from the proposed app. More specifically, each of the scenarios that was generated in the focus group was given to participants and parents were asked to answer three questions based on each scenario. The first two questions asked parents to rate their level of agreement, on a scale from 1 to 10, where 1 is ‘Strongly disagree’ and 10 is ‘Strongly agree’. The statements were:
 - i. I am concerned about the baby’s health.
 - ii. I believe there is a problem with the baby’s health.

The last question was an open ended question asking participants if there are any particular steps they would take to provide care for the baby and to explain. On the next page of the survey, the same scenario was provided again, this time with the support of the app. Parents were asked to answer the same three questions again so their responses could be compared without and then with the support of the app, to determine if their

behaviour changed. The same structure was repeated for all three scenarios, however, in the last scenario, no support was provided since the health problem used in that scenario (i.e., tongue tie) is not detectable by the app.

- Part IV “General Feedback”. This section asked general questions about participants’ opinions on the proposed app to help understand if they trust it and if they would use it.

The survey was constructed in two steps. In the first step, six parents were recruited to complete a pilot survey. The purpose of running a pilot was to review the survey for language, format, and overall comprehensibility. The pilot survey was a copy of the parent survey, augmented with questions asking for feedback about the clarity of the survey questions. The results were analyzed and used to create the final parent survey (see Appendix H). In the second step, the final survey was posted online with the goal of recruiting a minimum of 30 parents, as discussed below. Once the survey was closed, results were analyzed in order to answer the research questions and determine the feasibility of the proposed app.

Recruitment

Pilot survey. Convenience sampling was used to recruit participants for the pilot survey. Participants were recruited via e-mail (see Appendix I for text) and included friends and colleagues of the researchers. Those who chose to participate were able to complete the pilot survey online, via a link provided in the e-mail. No remuneration was offered.

Parent survey. Convenience sampling was used to recruit participants for the final parent survey. Participants were recruited via a poster that was posted on the bulletin board at a university daycare (see Appendix J). The poster included ‘tear-away’ strips that provided a link to the online survey, for parents interested in participating. With nearly sixty families at the

selected daycare, and both parents being eligible to participate, it was believed that a sufficient number of participants would be recruited from this location. Nevertheless, to help ensure an adequate sample size, additional participants were recruited via e-mail (see Appendix K) and included friends and colleagues of the researchers (different than those recruited for the pilot survey). No remuneration was offered.

Inclusion / Exclusion criteria

Pilot survey. Since the purpose of the pilot was to review the survey for language, format, and overall comprehensibility, participants had to be fluent in English. Furthermore, to ensure participants had at least a basic understanding of the scenarios and concepts that would be used in the survey, they had to be a parent. Since actual answers to the questions are not as important as feedback on the clarity and comprehensibility of the questions, no restrictions were put on the age of participants' children or the children's health at birth. Mothers and fathers were both eligible to participate. Participants had to have internet access.

Parent survey. Since this is a feasibility study, the scope of the decision support tool is limited to healthy babies who were breastfed within the first month, either exclusively or not. The choice to focus on breastfed babies was made in order to maintain scope, primarily of the algorithm, which would have needed to be expanded significantly in order to accommodate formula-fed babies. As such, participation in the survey was restricted to parents of at least one child that was born at full-term (above 37.0 weeks gestation), was healthy at birth, and was breastfed. Additionally, the baby must have been born within the past five years; this restriction helps ensure that participants have relatively recent memories of caring for their newborn. Both the mother and father were eligible to participate, independently from one another. Participants had to have internet access in order to complete the survey.

Participants

Pilot survey. A total of four (N=4) participants completed the pilot survey. Demographic data was not obtained, but all participants spoke fluent English and had at least one child.

Parent survey. A total of thirty-one (N=31) participants completed the survey. Participants included 22 females and 9 males, most of whom indicated an age range of 31-45 years old (n=28). Two participants indicated they were between 18-30 years old and one participant indicated they were between 46-65 years old. The number of children among participants ranged from 1 to 3 (n=12, n=17, n=1, respectively); one participant did not answer this question. The age of children ranged between 20 weeks and 9 nine years, with all participants having at least 1 child 5 years old or younger. Twenty-nine participants indicated they live in an urban or suburban environment, the remaining two indicated they live in a rural area. All participants had a college degree or higher, with the most common level of education being a bachelor's degree (college: n=5; bachelor's degree: n=19; master's degree: n=5; doctorate: n=2).

All participants indicated that they were quite comfortable using computers. Specifically, on a scale from 1 to 10, where 1 indicated less comfort and 10 more, all responses were 7 or above, with the average being 9.55. When asked about the types of devices that participants either owned or used frequently, twenty-two participants indicated that they owned or frequently used a desktop PC, twenty-nine a laptop, twenty-six a tablet, and thirty a smartphone. Of the four types of devices asked about, the median number of types of device participants owned or frequently used was four.

Results

Pilot survey. A qualitative analysis of the pilot survey results was done and led to a number of small changes to the survey. The full analysis with recommendations can be found in Appendix L. The main changes were:

- Aligned all rating questions to be based on a scale from 1 to 10, where 1 is ‘Strongly disagree’ and 10 is ‘Strongly agree’.
- Added clarification to the instructions for part 2, with respect to: 1) what ‘sometimes’ indicates and 2) security / privacy of the data entered into the app.
- Made slight updates / clarifications to each scenario
- Added a question to the last scenario, in which no problems were detected, to help understand if parents found it confusing that the app did not detect any problems

Parent survey.

Willingness to enter data. An important factor in determining the feasibility of the proposed application is knowing what data parents are willing to enter and how often. Figure 5 shows the distribution of responses per data element, i.e., if parents are always, sometimes, or never willing to enter in the information. Across all data elements, just over half of the parents expressed that they were willing to enter data always ($M = 16.44$, $SD = 2.29$), followed closely by the willingness to enter data sometimes ($M = 11.22$, $SD = 2.14$). On average, there were nearly three participants that never wanted to enter data ($M = 2.62$, $SD = 1.27$), and fewer than one participant that did not respond ($M = 0.81$, $SD = 1.14$). The data elements that parents were most likely to always enter were birth weight ($n = 23$), followed by birth date ($n = 22$) and whether the baby vomited ($n = 20$). The data elements that most parents indicated they would never want to enter were the umbilical cord condition ($n = 6$) and skin elasticity ($n = 6$). The

questions about the amount and time that the baby drank expressed breast milk or formula received the highest number of non-responses (amount / time baby drank formula: $n = 4$; amount / time baby drank expressed breast milk: $n = 2$). Similarly, two parents did not provide responses for the “spits up often” data element ($n = 2$).

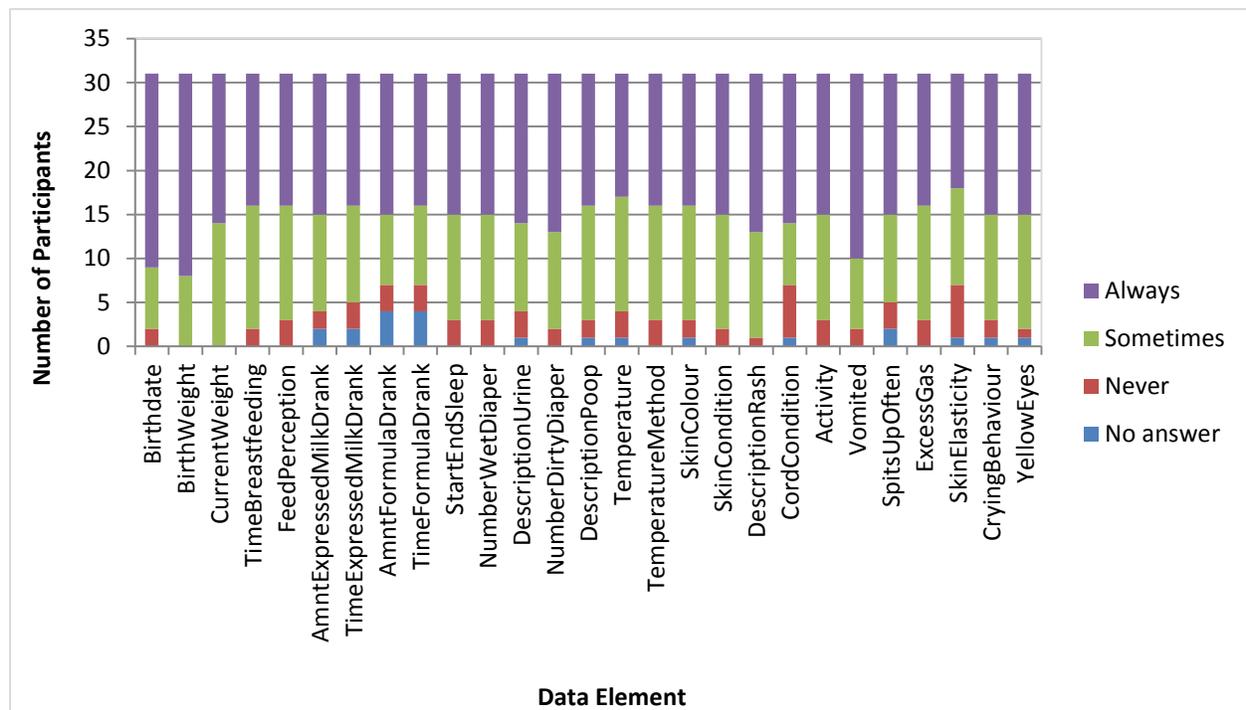


Figure 5. Frequency of how often parents are willing to enter each piece of data into the app.

When examining frequency and willingness to enter standard data elements versus non-standard data elements, results were quite similar to the overall results regarding willingness to enter data. More specifically, whether data is considered standard or not, most participants were willing to enter the data, on average, always (standard: $M = 18.33$, $SD = 3.39$; non-standard: $M = 15.90$, $SD = 1.61$). This is followed closely by the willingness to enter data, on average, sometimes (standard: $M = 10.67$, $SD = 2.66$; non-standard: $M = 11.38$, $SD = 2.01$). A full comparison can be seen in Figure 6. Standard data elements include: birthdate, birth weight, time of breastfeeding, start and end of sleep, wet diapers, and dirty diapers.

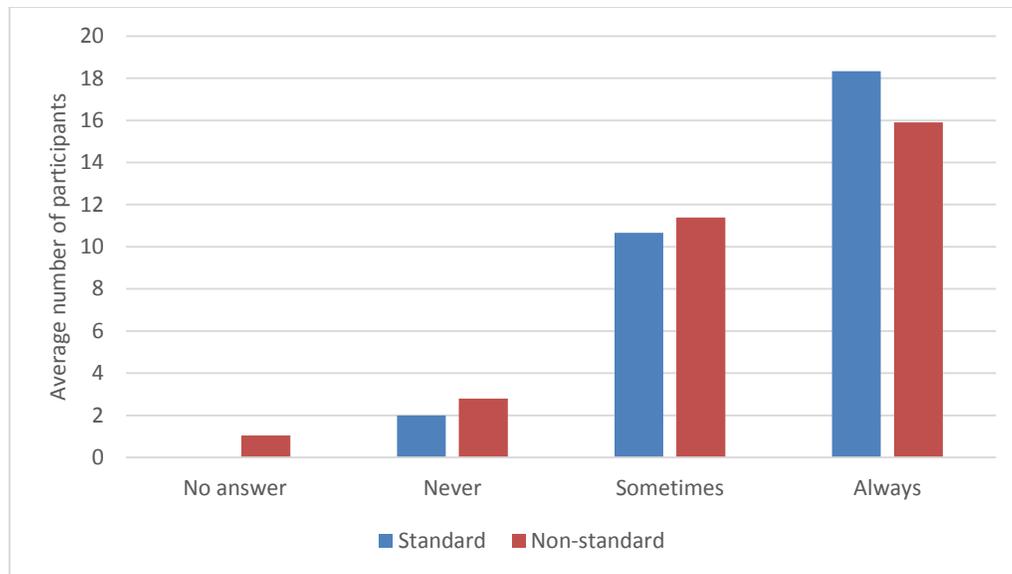


Figure 6. A comparison of how often parents are willing to enter standard vs. non-standard data, on average.

When asked to indicate which data elements parents found confusing or thought they would not be able to enter accurately, one parent was excluded from the analysis since they filled in the data about their own child (e.g., in the birth date field they provided the birth date of their child). Therefore, the analysis for this question was completed with a total of thirty participants (N=30). The two data elements with the highest number of parents indicating confusion or difficulty to enter were “time of breastfeeding” and “excessive gas” (n = 7, respectively). This was followed closely by “start and end time of sleep” (n = 6), “activity” (n = 6), current weight and date weighed (n = 5), temperature (n = 5), and description of rash (n = 5). The only data element that was not found to be confusing or difficult to enter by any participants was birth weight (n = 0). Full results can be seen in Figure 7, below.

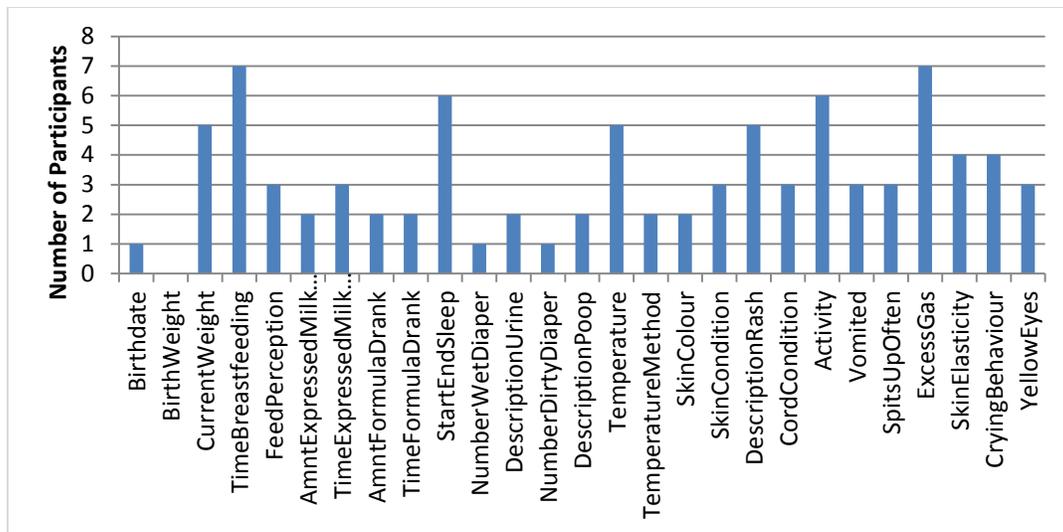


Figure 7. Number of parents that found the data element was confusing or did not think they could provide it accurately.

The above results, namely regarding data elements that users indicated that they did not want to enter or found confusing or difficult to enter, may be explained in part by some of the free text comments written by participants. First, comments and answers to the following question were analysed and coded:

1. Check all pieces of information that you find confusing or for which you do not feel you would be able to provide accurately. Include any comments you may have for each piece of data.

As with all open-ended questions in the parent survey, a thematic content analysis was carried out by the lead researcher, which enabled categorization of answers. For the analysis of the question above, nine categories were defined, as listed and described in Table 2.

Table 2

Derived categories based on analysis to comments provided by participants when asked to indicate which data elements elicited confusion or they thought would be difficult to enter

Category	Description
Privacy / Security	For data elements that participants did not want to share due to privacy concerns, namely birth date.
Difficult to obtain data	For data elements that users expressed they could not easily obtain, such as baby's weight.
Cumbersome	For data elements that participants indicated they would not want to track because of the time/burden to enter it, such as night feedings.
Difficult to track	For data elements that participants indicated they would have a hard time entering accurately due to difficulty keeping track of time, e.g., breastfeeding, start/end of sleep.
App not accessible	For data elements that need to be entered when the participants' device is not available, such as feeds that happen in the middle of the night.
Subjective	For data elements that participants indicated were hard to measure accurately because it is hard to judge things like what constitutes 'excessive' crying or 'irritable behaviour'.
Data options not exhaustive	For data elements that participants expressed a need for additional options, such as crying that is 'weak or faint'.
Data element wording not clear	For data elements that elicited confusion due to the name of the data element itself, namely 'vomited / forcefully expelled fluids'; the latter half is unclear if it is referring to only from the mouth or also diarrhea.
To be considered with general comments	For comments that were not directly linked to confusion or difficulty entering data and that will be considered with the additional comments.

Of all categories, the two which included the greatest number of comments and seemed to be of most concern for participants were: “difficult to obtain data” (14 comments) and “difficult to track” (9 comments). Figures 8 and 9 show the number of participants that made comments in each of these two categories, and for which data elements. As can be seen in figure 8, four of the five data elements that participants noted may be difficult to track included elements that require time entry, e.g., start and end of sleep. With respect to obtaining data, the baby’s current weight was of concern to the greatest number of parents (n=5), as shown in figure 9. The total number of comments received in each category, for each data element, can be seen in Table 3.

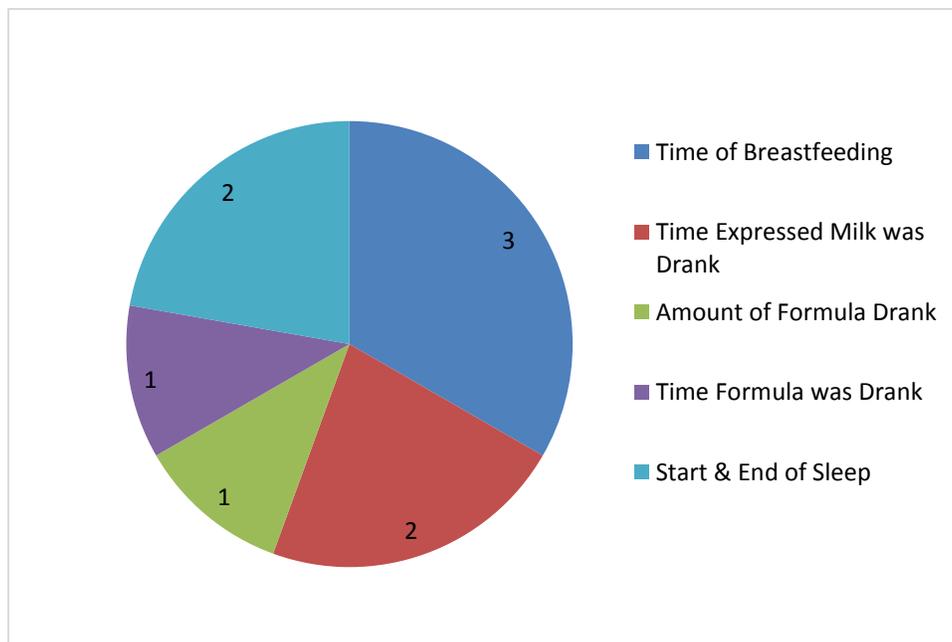


Figure 8. Number of parents who indicated each data element was difficult to track.

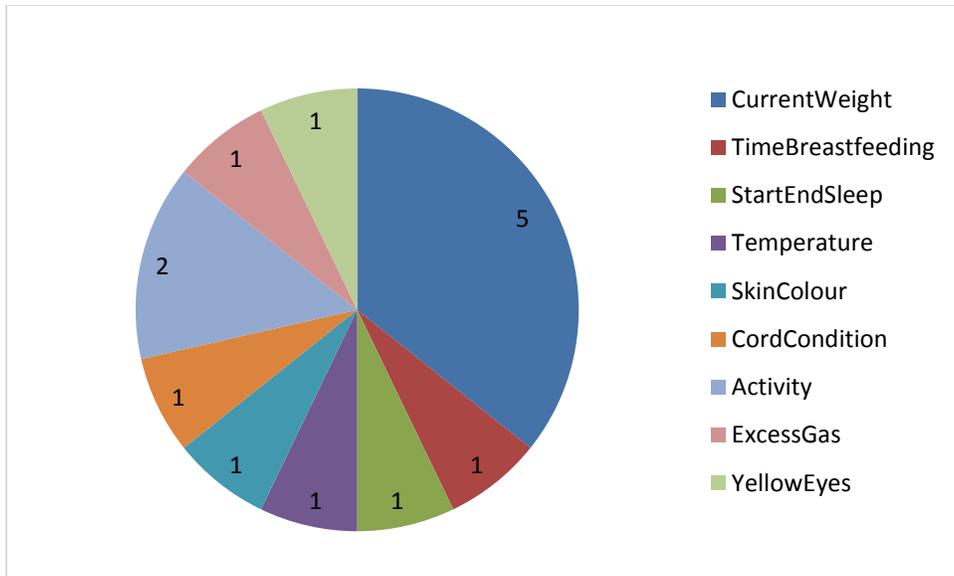


Figure 9. Number of parents who indicated each data element was difficult to obtain.

Table 3

Number of comments in each category per data element

	Privacy / Security	Cumbersome	Difficult to Track	Difficult to Obtain Data	App not Accessible	Subjective	Data Options not Exhaustive	Data Element Wording Unclear
Birth date	1							
Current weight				5				
Time of breast feeding		1	3	1	1			
Perception of feed						1		
Amount of Expressed Breast Milk Drank								
Time Expressed Breast Milk was Drank			2					
Amount of Formula Drank			1					
Time Formula was Drank			1					
Start and End of Sleep			2	1				
Temperature				1				
Temperature Method								
Skin Colour				1				
Skin Condition							1	
Description of Rash							1	
Cord Condition				1			1	
Activity				2		2	1	
Vomited / Forcefully expelled fluids								1
Excessive Gas				1				
Crying Behaviour						1	1	
Yellow Eyes				1				

For a complete listing of categorized comments with analysis, regarding which data elements participants found either confusing or thought may be difficult to enter accurately, refer to Appendix M.

Further analysis and coding was done for responses to the following two questions:

1. Do you have specific concerns or is there a specific reason why you would not enter certain information? If so, please specify.
2. Do you have any additional comments or concerns about inputting any of the above information into the app?

Analysis of responses to these two questions resulted in the creation of 11 categories, some of which overlapped from the previous section. Categories, descriptions, and the number of responses that fit into each category are listed in Table 4. As can be seen in the table, the themes that emerged most often among participants were that entering all requested data would be cumbersome ($n = 6$), certain data was deemed private and participants did not want to provide it ($n = 5$), and finally four participants commented that they would only enter data if they felt there was a problem with the baby. All comments, derived categories, and analyses can be found in Appendix M.

Table 4

Categories, descriptions, and number of comments in each category

Category	Description	# of responses
Cumbersome*	Describes comments regarding the large amount of time and effort participants felt it would take to enter all the data being asked about.	6
Privacy / security*	Describes comments regarding not wanting to share certain data due to privacy concerns.	5
Data entry: if concerned	Describes comments regarding willingness to enter data only if the participant felt something was wrong in the first place.	4
Data entry: first few weeks	Describes comments regarding willingness to enter data only in the first few weeks after birth.	1
Data entry: will not track specific element	Describes one participant's reluctance to enter the temperature method since they always use the same method.	1
Must be easy to use	Similar to cumbersome, but describes a specific comment that the app must be easy to use if the participant was going to input the data.	1
Would not use	Describes the willingness to use the app at all.	1
Subjective*	Describes concerns that some information is difficult to enter accurately because it is subjective, e.g., what constitutes 'excessive' crying.	1
Difficult to obtain data*	Describes concerns of participants regarding the inability to easily obtain all data being asked about, such as baby's weight.	1
Data elements not applicable	Describes concerns that not all data elements are applicable to everyone, e.g., elements regarding	1

	formula are not relevant if the baby is exclusively breastfed.	
Data options not exhaustive*	Describes concerns that certain data elements needed additional options to be included, such as crying that is ‘weak or faint’.	1

*Categories that overlap with the question about which data elements were confusing or difficult to enter accurately

App effect on parents’ concern and certainty of a problem with the baby. For each of the three scenarios, dependent sample t-tests were used to compare parents’ concern as well as their belief that there is a problem with the baby, with and without the information provided by the app.

Before doing the comparisons, data was examined in order to identify any extreme outliers (defined as values greater than 3 times the interquartile range). Four extreme outliers were identified:

1. One extreme outlier in scenario 1, regarding belief there is a problem with the baby. The same participant’s response with respect to concern, in this scenario, was also an outlier but not extreme. For this scenario, the participant’s level of agreement regarding concern and belief that a problem existed increased dramatically after receiving feedback from the app (hence the outlier and extreme outlier). After receiving the feedback, the participant wrote: “As a new mom, getting an alert like this would scare me and make me panic, which is probably not the best thing. That's what's hard about apps / websites about health. They make you think the worst right away.” This comment supports the fact that the levels of agreement provided, with and without support of the app, are valid. Therefore this extreme outlier remained in the data analysis, unchanged.

2. One extreme outlier in scenario 2, regarding level of concern for the baby. This outlier is believed to be a data input error by the user when completing the online survey. This is because this is the only scenario and question, where the participant's response changed in an extreme way. Additionally, their belief that a problem existed in the same scenario, remained unchanged after receiving support of the app. Their course of action also remained unchanged, with the participant originally stating "Sounds like baby has gas and needs to learn how to digest" and then saying "Same" after receiving support from the app. There is no indication that this participant's level of concern should have changed and certainly not by a lot, as is the case. As a result, the response is considered invalid and will be excluded from the analysis for scenario 2, regarding level of concern, leaving a total of 30 (N=30) responses.
3. A second extreme outlier was identified in scenario 2, regarding level of concern for the baby. This same participant's response regarding belief that a problem exists, in scenario 2, was also identified as an extreme outlier. In scenarios 1 and 3, this participant's concern and belief of a problem remained unchanged after receiving feedback from the app, or lack thereof. However, in scenario 2, after receiving feedback from the app, their level of concern and belief there was a problem both jumped from a 3 to 8 and they said they would "Go to the doctor", rather than providing no response at all, when no support was given. These responses indicate that the feedback from the app had a great impact on the participant. As such, these two extreme outliers are believed to be valid values and will remain in the data analysis, unchanged.

In summary, all but one of the dependent-sample t-tests, as specified above, will consist of thirty one (N=31) participants.

Scenarios 1 and 2: problem detected by the app. The first scenario, presented to participants, described a baby with jaundice. This is a problem that could be detected by the app and that most parents would recognize as a problem.

Results, for this scenario, showed that without the support of the app, parents were less concerned about the baby's health than when support was provided; this was found to be a statistically significant difference, $t(30) = 3.42, p < .05, d = .61$. Additionally, with the support of the app, parents were more certain that there was a problem with the baby, $t(30) = 2.79, p < .05, d = .50$. Cohen's effect size value, for both results, suggest a moderate significance. Full results for scenario 1 can be found in Table 5.

Table 5

Descriptive statistics and t-test results for concern and belief a health problem exists with the baby, without and with the support of the app in scenario 1

Variable	Descriptives						Matched sample t-test			
	Without App Support			With App Support			N	<i>t</i>	<i>p</i>	<i>d</i>
	<i>M</i>	<i>SD</i>	<i>SE</i>	<i>M</i>	<i>SD</i>	<i>SE</i>				
Concern	8.03	2.20	.40	8.94	1.63	.29	31	3.42	.002	.61
Problem	7.94	2.45	.44	8.65	1.89	.34	31	2.79	.009	.50

The second scenario, presented to participants, described a baby with gastroesophageal reflux disease (GERD). This is a problem that is detectable by the app, that is not overly common in babies, and that many parents would not recognize as a problem.

Results for this scenario were similar to the first; however, even though concern rose, it was not shown to be statistically significant, $t(29) = 1.98, p = .058, d = .36$. Certainty that there was a problem with the baby increased and was shown to be statistically significant, $t(30) = 2.12, p < .05, d = .38$. For both sets of results, the effect sizes suggest a small to moderate practical significance. Full results for scenario 2 can be found in table 6.

Table 6

Descriptive statistics and t-test results for concern and belief a health problem exists with the baby, without and with the support of the app in scenario 2

Variable	Descriptives						Matched sample t-test			
	Without App Support			With App Support			N	<i>t</i>	<i>p</i>	<i>d</i>
	<i>M</i>	<i>SD</i>	<i>SE</i>	<i>M</i>	<i>SD</i>	<i>SE</i>				
Concern	5.77	2.75	.50	6.30	2.51	.46	30	1.98	.058	.36
Problem	5.74	2.45	.44	6.32	2.20	.40	31	2.12	.042	.38

Scenario 3: no problem detected by the app. The final scenario described a baby with tongue tie, a problem that the app is unable to detect, based on the data that parents are asked to enter. The scenario described the problem enough to create doubt, but not be completely obvious to most participants.

In this scenario, parents' concern lessened after seeing that nothing was detected, $t(30) = 2.52, p < .05, d = .45$. Additionally, parents were less certain that there was a problem, $t(30) = 2.45, p < .05, d = .44$. Both findings were statistically significant and Cohen's effect size values

suggest a small to moderate practical significance in both cases. Full results for scenario 3 can be found in Table 7.

Table 7

Descriptive statistics and t-test results for concern and belief a health problem exists with the baby, without and with the support of the app in scenario 3

Variable	Descriptives						Matched sample t-test			
	Without App Support			With App Support			N	t	p	d
	M	SD	SE	M	SD	SE				
Concern	6.81	2.07	.37	6.52	2.31	.41	31	2.516	.017	.45
Problem	5.87	2.31	.41	5.42	2.49	.45	31	2.447	.020	.44

App effect on parents' behaviour. In addition to the dependent samples t-tests, used to compare parents' concern and certainty that there was a problem with the baby, a manual analysis of free text responses was done to determine if the app actually changed participants' behaviour with regard to what steps they would take given the described scenario. Not all participants completed these questions; the total number of complete responses analysed for scenarios 1, 2, and 3 was: twenty-one (N = 21), fifteen (N = 15), and twenty (N = 20) respectively.

For each scenario, participants' behaviour without the support of the app was compared to their behaviour with the support of the app and categorized as either having: 'followed the advice', 'no change in behaviour', or 'changed, but still different from what the app suggested'. 'Followed advice' was further broken down based on whether the participant's new actions were

similar to what they originally planned to do or whether it was completely different. Similarly, ‘No change in behaviour’ was further broken down based on whether the participants’ actions were similar to what the app suggested in the first place; if the participant’s original plan was similar to what the app suggested, it is impossible to know whether they would have followed the app’s suggestion if their plan had not been the same. Examples of responses, from the first scenario, that fit into each category are shown in Table 8, the full analysis can be found in Appendix N.

Table 8

Categorization and examples of participants' behaviour, with and without the support of the app

Category	Example of Paired Responses Without & With App Support
Followed advice; different than original plan.	<p><i>Without:</i> Research on the Internet</p> <p><i>With:</i> Call telehealth</p> <p><i>Without:</i> call the doctor about yellow eyes and not enough pee in diapers</p> <p><i>With:</i> Call Telehealth</p>
Followed advice; similar to original plan	<p><i>Without:</i> express breast milk and try bottle feeding or supplementing with infant formula to see if the baby will feed. With yellowish skin/eyes, there may be concern for jaundice and baby must have nourishment. if ever in doubt-go to emergency.</p> <p><i>With:</i> keep trying to feed. call telehealth or go to emergency.</p>
No change in behaviour; different from app’s suggestion.	<p><i>Without:</i> I would look up symptoms on Google, call the doctor and maybe go to doctor or hospital. Child is probably dehydrated.</p> <p><i>With:</i> Same as before</p> <p><i>Without:</i> Take baby to doctor to check bilirubin levels today (not tomorrow). Engage lactation consultant to meet with</p>

	mom and baby at home to assist with breastfeeding. Wake baby at least every 3 hours to eat. Depending on bilirubin levels consider formula feeding to ensure baby is thriving. <i>With:</i> Same answers as provided in last question. I would not call Telehealth - I would take baby to see doctor today to have bilirubin levels checked, etc...
No change in behaviour but similar to app's suggestion.	<i>Without:</i> I would call tele health and go to a drop in baby wellness clinic <i>With:</i> Call tele health and go to a baby wellness drop in clinic provided by city of ottawa
Changed behaviour but different from app's suggestion.	<i>Without:</i> Take to doctor to have baby weighed and checked for jaundice. <i>With:</i> Take baby to doctor immediately

In scenario one, one third of participants ($n = 7$) followed the advice of the app; only one of these participant's original plan was already similar to what the app suggested. More than half of participants ($n = 12$) did not change their behaviour based on the app's suggestion; eleven of these participants' plans were completely different than suggested by the app.

In scenario two, only one fifth of participants ($n = 3$) followed the advice of the app; of these, only one participant's original plan was completely different than what was suggested by the app. The majority ($n = 11$) of participants' behaviour remained unchanged after receiving the feedback from the app; over half ($n = 6$) of these participants' original plan, however, was already very similar to what was suggested by the app. A complete breakdown of the app's influence on participants' behaviour for scenarios 1 and 2 can be seen in Figure 10.

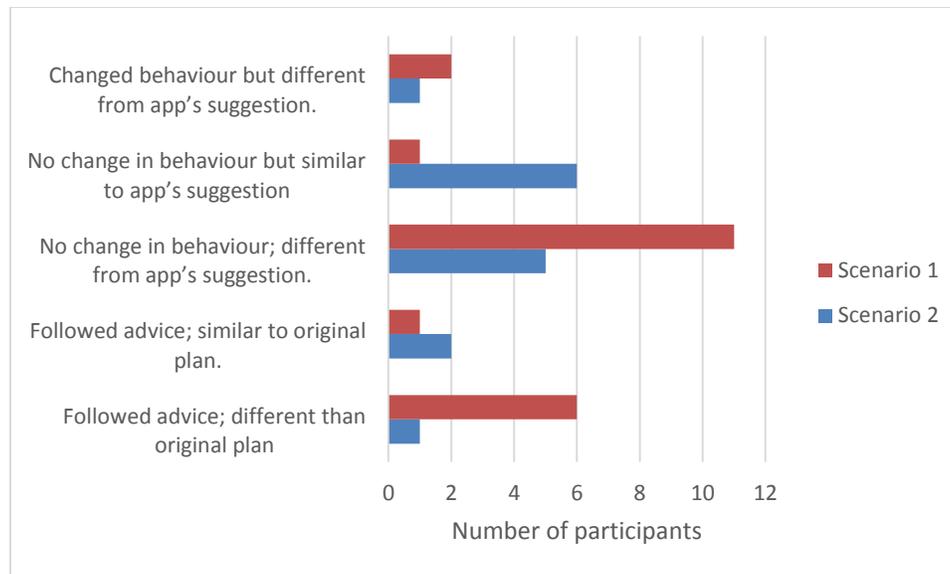


Figure 10. Number of participants whose behaviour remained the same or changed, based on feedback provided by the app.

For the third scenario, when no feedback was provided by the app, the behaviour of all twenty ($n = 20$) respondents remained unchanged. When asked if participants found it confusing that no feedback was provided, over half ($n = 13$) of the twenty-three participants that responded did not find it confusing. All responses, plus analysis can be found in Appendix O.

Increasing trust in the app. When asked, a total of eighteen parents indicated one or more factors which would increase their trust in the app. The most common answer provided was the need for the app to be endorsed by an accredited body such as a hospital, Health Canada, or the Canadian Pediatric Society; a total of ten participants included this in their response. Five parents indicated that they wanted more information to be provided, either directly in the app or via links to reliable sources. One participant said they would trust the app more if it was personally recommended to them by a physician. In addition, one participant said their trust would be higher if they knew how up-to-date the app and the information on which it is based was. Only four participants said that nothing else was needed in order to increase their trust in the app and eleven provided no response at all. All responses, plus analysis can be found in Appendix P.

General feedback. A number of general questions were asked to determine if participants trust the app and if they would use it. Each question asked participants to indicate their level of agreement on a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree'. The results of these questions seem to reflect the fact that most participants did not change their behaviour, based on the app's feedback, given the three scenarios. Namely, the average agreement level regarding whether participants' think the app accurately detects problems with their baby was only 6.26 ($N = 31, M = 6.26, SD = 2.41$). When asked whether participants would trust the app and think it was built using reliable sources, the mean level of agreement was 5.93 ($N = 30, M = 5.93, SD = 2.70$) and 6.88 ($N = 24, M = 6.88, SD = 2.40$), respectively. When asked if they would rely less on other sources to determine if there was a problem with their baby, the mean level of agreement among participants was 4.63 ($N = 30, M = 4.63, SD = 2.74$).

The mean agreement level when asked if participants would want to use an app like this and/or recommend it to a friend, was also somewhat low, at 6.20 ($N = 30, M = 6.20, SD = 2.92$). The complete number of responses, for each level of agreement, can be seen in Figure 11.

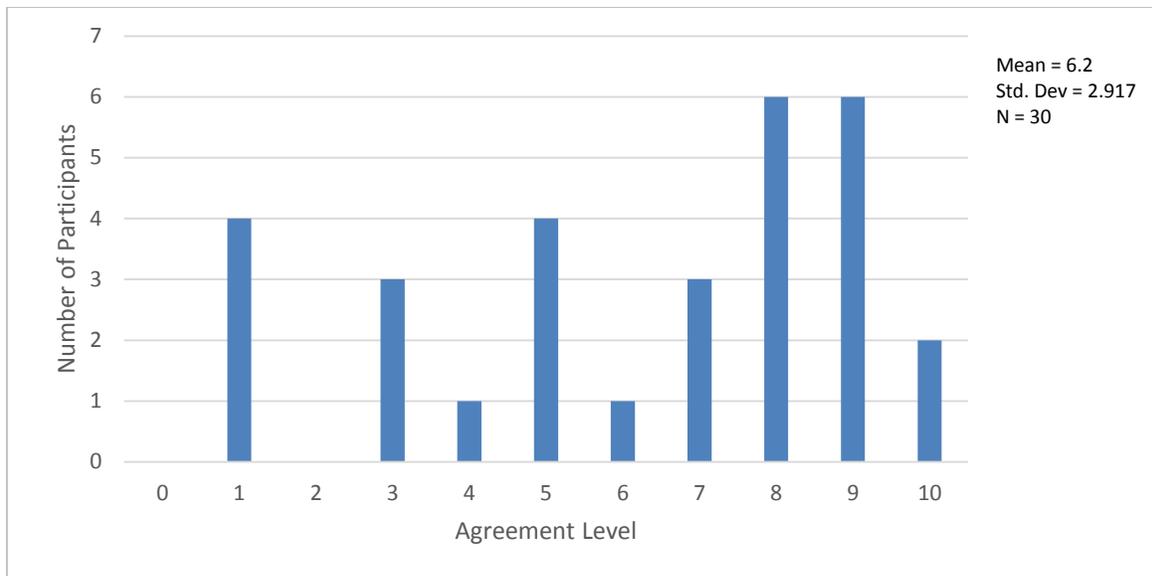


Figure 11. Agreement level of each participant to the statement 'I would want to use an app like this and/or I would recommend it to a friend'.

A full summary of results for each question is shown in Table 9, below.

Table 9

Participant agreement level on a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree', to a series of questions to understand trust and desire to use the app

Statement	N (valid)	Mean	SD	SE
I think this app accurately detects problems with my baby.	31	6.26	2.41	0.43
I trust this app and the feedback that it provides.	30	5.93	2.70	0.49
In general, I would rely less on other sources to determine if there may be a problem with my baby.	30	4.63	2.74	0.50

I think the information sources, on which this tool was build, are reliable.	24	6.88	2.40	0.49
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I would want to use an app like this and/or I would recommend it to a friend.	30	6.20	2.92	0.53
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Discussion

Willingness to Enter Data

In order for the proposed app to be successful, data entry is key; without regular entry, the decision support algorithm simply cannot work. Therefore, as part of this exploratory study it was important to understand if parents were willing to enter all of the data that is necessary to drive the proposed decision algorithm. It was also essential to understand how often parents were willing to enter the data: always, sometimes, or never. Most of the data elements that were used in the algorithm and asked about in the survey would only need to be entered into the app ‘sometimes’. As clarified in the survey, ‘sometimes’ indicates that the parent is willing to enter the data if:

1. They happen to have it, such as the baby’s current weight OR
2. They felt it was abnormal (e.g. there is blood in the baby’s urine, baby is crying excessively, etc.) OR
3. The app explicitly asks for it. This would only happen if a possible problem is detected, but more information was needed.

There are other data elements, however, that would need to be entered regularly for the app to correctly detect health problems. These include all data elements regarding feedings, pees, stools, and sleep. In addition, the birth weight and birth date are also necessary, but would only need to be entered once.

Overall, results were positive, with nearly 90% of participants willing to enter data either sometimes or always. Even with such affirmative results, an analysis was conducted to help

understand what aspects of data entry may pose problems for parents. A detailed examination of participants' comments unveiled three over-arching concerns in regard to entering data: 1) some data being asked for is considered subjective, 2) some information is cumbersome to track, and 3) some information is difficult to obtain.

With respect to subjectivity, data elements that fell into this category comprised of: excessive gas, activity, and description of rash. As an example, to demonstrate this concern, parents were asked to indicate if their baby's activity was: normal (alert/content), sleepy, fussy, shaky, irritable, excessive crying, or difficult to wake for feedings. One parent commented that "[i]f it's your first child especially, it's hard to tell what's 'normal' or 'excessive'". Similarly, for 'excessive gas', one parent wrote "I have always had trouble determining if/when my son or daughter had gas". These parents' concerns and the potential consequences need to be considered when fleshing out the specifics of the algorithm and the app design. More specifically, because these are subjective elements (as opposed to something like temperature), the data may not be entered accurately and thus have adverse effects on the decision algorithm. To decrease errors in data entry, one solution could be the provision of hints or explanatory text in the app; this could help parents determine more precisely what constitutes something like the baby being 'irritable' or crying 'excessively'. In addition, the app could prompt parents to enter certain data in suspect cases, forcing parents to more carefully evaluate whether certain conditions may be applicable to their baby. Although design concepts such as these may help to reduce errors when entering subjective data, the use of such data elements cannot be eliminated and the accurate entry of this information may continue to be problematic. Consequently, not only do design solutions need to be further explored, but analysis is also needed in order to understand how the dependency on subjective data may affect the precision of the algorithm. Extensive testing is needed to

determine the rate of false negatives and false positives and whether this rate is deemed acceptable by healthcare practitioners and parents.

The second area of concern that was identified, with respect to data entry, was regarding information that is considered cumbersome to enter. The concern in this area was specific to ‘time of breastfeeding’ and ‘start and end of sleep’. The encumbrance of tracking these details is understandable since these are two of the most frequent newborn baby activities and would need to be entered regularly. Re-occurring themes that emerged from the comments encompassed general difficulty tracking time and tracking time specifically at night, when the app may not be accessible or the parent is very tired. The overhead of tracking this data is understood, but not believed to be a deterrent to continue to explore the feasibility of the proposed app. In fact, although parents expressed concern over tracking this particular information, some participants still indicated that they would be willing to enter the data if it was very easy to do. For example, one participant wrote: “If I could push a button to start sleep and push a button to stop sleep on the app to track it this would be ok. But once again writing down times would be tough.”

Another participant provided a general comment about using the app, saying “I would have to try it out before I would see whether it would be a tool I would use. I think a lot would depend on the ease of entering the information” (refer to Appendix Q for all additional comments). Rather than dismissing the idea of entering so much data, both of these participants took into consideration the potential design of the app, even though it is not something that was explored in this study or included in the survey. Nevertheless, ease of use is believed to be one of the key design principles in order for this app to be successful. Results of a study by Kuo, Lu, and Chang (2012) help to buttress the fact that parents would be willing to enter this type of information. The intent of their research was to evaluate the acceptance of a newborn baby care support app

that was usability-engineered. The app was evaluated by 64 post-partum mothers in Taiwan and results showed that not only would most parents be willing to enter the data, but 84% of users were willing to pay up to \$6 USD per month for the app. Beyond this study, hundreds of ‘baby tracking’ apps already exist and can easily be found in the Apple app store or Google Play store; the typical data being tracked in these apps is the exact data parents’ in this study expressed concern over. The mere existence of so many such apps is a demonstration of their popularity and of parents’ willingness to use them and enter data on a regular basis, despite providing less functionality than the app proposed in this research. Also noteworthy, is that less than one quarter of participants in this study expressed any concern at all over entering these data elements.

The last area of concern expressed by some parents was with respect to difficulty obtaining some of the data, namely the baby’s current weight. Just over 15% of participants commented that they do not have a scale at home and would only be able to provide this information if they went to the doctor. This was the intent and expectation for weight entry. As a result, parents’ concern regarding data entry of the baby’s weight does not warrant any further investigation in order to pursue research into the proposed app.

Beyond the areas of concern discussed here, several comments were made either in regards to a specific data element, such as temperature, or at a general level, that participants would only enter data if there was a cause for concern. The general sentiment was well-expressed by one participant who wrote:

If there is no reason for concern, I would not enter data. For example, if baby is pooping regularly and the poop is normal colour and consistency, then I would not enter it. However, if pooping became a problem, then I would start to track this information.

For the majority of data elements, i.e., those defined as non-standard in the context of this research, the attitude voiced by this participant is exactly the intention of the researchers and should not deter from further investigation into the proposed app.

Overall, with respect to data entry, even though some participants expressed concerns, the large majority indicated that they would be willing to enter the data either sometimes or always. Data entry is key to the success of the decision support algorithm and the proposed app, and although some concerns were raised by some parents, a closer look at most of these concerns revealed they would not impede the success of this app. The only concern that is acknowledged to require further investigation is with respect to data elements that are subjective in nature. Notwithstanding, it is believed that with a well-designed app, based on the results of this study, data entry in and of itself will not be a hindrance to the realisation of the app being explored in this work.

The App Effect: A False Sense of Confidence or the Right Amount of Trust?

The first two questions that this research sought to answer, regarding frequency and willingness to enter data, helped to determine if it is feasible to obtain the information needed to drive the decision algorithm. The last three questions take the research a step further to determine if and how a decision support app, that uses this decision algorithm, may alter the behaviour of parents. Specifically, the following three questions were examined:

1. Will the decision support tool change the behaviour of a parent?

2. Will the decision support tool provide a false sense of confidence to parents?
3. Are parents exhibiting an appropriate amount of trust in the tool?

Although consistent data entry, in order to drive the decision support algorithm, is the foundation of the app, it is also essential to understand how a decision support tool may affect the behaviour of a parent. More precisely, we wanted to understand if, with the support of the app, a parent would change their course of action when caring for their baby. At the same time, we sought to determine whether those parents would exhibit an appropriate amount of trust in the app, in order to ensure the health and safety of infants whose parents are using information such as that provided by the suggested app in this study. Since the decision support algorithm cannot detect all possible health issues and will also consist of a certain number of false positives and false negatives, putting the right amount of trust in the tool was considered more important than always following the exact advice. As such, the intent is not for the app to be the only source on which parents will rely to make decisions with respect to their baby. Rather, it is intended to be an additional tool to provide support, somewhere between a simple Google search and an actual physician consultation. Therefore, three realistic scenarios were given to parents and three questions were asked, to understand if parents would follow the advice of the app as well as if they would put an appropriate amount of trust in it. In the first two scenarios, the app was able to detect and alert parents of a possible problem, but the problem in the third scenario was not detectable by the app and thus no feedback was provided. This scenario was especially vital in determining if parents would put too much trust in the app and if the app would provide a false sense of confidence. In terms of the questions, the first one asked parents to indicate what course of action they would take, given the scenario. The second and third questions asked parents to rate their level of agreement regarding how concerned they were about the health of the baby in

the scenario and how certain they were that there was a health problem with the baby. Once answered, the same scenario and questions were presented to participants again, but this time, with the support of the app. A comparison of participants' responses, without and then with the support of the app was analyzed.

For the first two scenarios, in which advice was provided by the app, it was expected that parents would alter their course of action based on the advice given. However, only one third of participants and one fifth of participants, in the first and second scenarios respectively, followed the advice of the app. These numbers were lower than anticipated. Still, for the second scenario, over half of the participants whose plan remained unchanged after receiving the advice, were already planning on doing something similar to what was being suggested. Since these participants' original plans were already similar or the same as the advice provided by the app, it is impossible to know if they would have changed their behaviour had their original plan been different. The fact that so many participants' plans were so similar to the recommendation provided, may be due to participants' high level of education, with most participants having a bachelor's degree or higher (26 participants), the remaining with a college diploma. If our sample had been larger and more varied, results may have been quite different; further research with such a sample is recommended. One finding from an Australian study supports the notion that parents would follow health-related advice for their baby, if provided by a trusted source (Khoo et al., 2008). As part of that research, parents waiting with their child in a hospital emergency department were shown a flow chart for vomiting in children and, when asked directly, 91% of parents said they would "definitely or probably follow the advice of a such a treatment flow chart available online from [The Royal Children's Hospital]" (p. 422). This was a simple question that demonstrates that the majority of parents would follow the advice provided

by a flow chart which, in essence, is the same as the decision algorithm being proposed. What is also important, however, is the source of the flowchart – a trusted children’s hospital in Australia. As discussed in the introduction, if an information source is not trusted, such as the internet in many cases, most parents will not follow the advice. This may also help explain why parents in the current study, for the most part, did not follow the advice of the app. More precisely, participants were asked to rate their agreement level on a scale from 1 to 10, where 1 is ‘Strongly disagree’ and 10 is ‘Strongly agree’ to the following statements:

1. I trust this app and the feedback that it provides.
2. I think the information sources, on which this tool was build, are reliable.

Average agreement levels to both statements were somewhat low, at 5.93 and 6.88, respectively. The sources on which the app (and algorithm) were based, for this *exploratory* study, consisted of some public health documents and the review of a single nurse / lactation consultant. Therefore, these lower levels of trust and reliance are understandable at this point in the research. Ultimately, the algorithm would need to be reviewed by a group of healthcare practitioners of different backgrounds and specializations. Furthermore, it would likely need to be endorsed by one or more recognized organizations. Suggestions like these were reflected by many participants when asked what could increase their trust in the app. Other suggestions included simply providing more information to back up the reasoning behind the advice and providing an indication that the algorithm is based on updated information. All of these are attainable suggestions that could potentially increase trust in the app significantly, in turn causing more parents to follow the advice provided. Another finding from this research should be considered when evaluating the effect of the app on parents’ behaviour. More specifically, for the first two scenarios, even though most parents did not follow the advice of the app, their level

of concern and belief that a problem existed, went up significantly after receiving feedback from the app. This shows that the app had an effect on drawing parents' attention to the baby and the baby's health. Thus, even if parents do not follow the exact advice provided by the app, if their attention to their baby's health is heightened, the app is achieving a very important goal. That is, it may cause parents to monitor their baby more carefully and/or to act, in one way or another, when they would not have done so otherwise.

A third scenario was included in the survey in which a problem did exist, but was not detectable by the app. This scenario helped to further understand if parents might put too much trust in the app and if the app would create a false sense of confidence in parents. It was clear that this was not the case, as not a single respondent changed their course of action after seeing that nothing was detected by the app, whether this meant that they would take action or not. Some participants found the lack of feedback alarming, with one saying they found it confusing “[a]nd frustrating. Clearly there is a problem but the app is not providing the direction/assistance that I would be hoping for”. Yet, others realized that this is an app and did not “expect [the] app to know everything”. Regardless of whether parents were confused by the lack of feedback or not, their choice not to change how they would deal with the scenario clearly demonstrates that they are not putting too much trust in the app and it is not providing a false sense of confidence. This alleviates concern of the researchers that parents may let a problem go unattended, simply because no alert was provided by the app. Still, similar to the first two scenarios, levels of concern for the baby's health and belief that a health problem exists, did change significantly among participants in this scenario. However, instead of being more concerned and having a greater belief that a health problem existed, the opposite was found. In other words, parents seemed to have interpreted the lack of feedback as reassurance that nothing was wrong with the

baby. This demonstrates that, although parents did not change their course of action after not receiving an alert, the app still affects their thinking. Further research is necessary to verify that the app will not affect parents' behaviour, in a harmful way, when a real problem goes undetected by the app.

To the best of the researchers' knowledge, no other study has explored the use of a decision support tool by parents in order to detect possible health problems in their newborn babies. This research helps to determine if parents' behaviour would change, given such a tool, and whether they would put an appropriate amount of trust in it. Results showed that although most parents are not following the exact advice of the app, their concern for the baby and belief that a health problem exists is affected; this demonstrates a raised awareness regarding the health of their baby. Consequently, it is believed that the results of this study provide enough evidence to support taking this research further and that the proposed decision support app could fill a void for new parents, in terms of available support mechanisms when caring for their newborn baby.

Conclusion

The goal of this study was to explore the feasibility of a decision support tool that could be integrated into an app for a smart phone or tablet. The app is intended to be used by parents, as a support mechanism, to detect possible health problems with their newborn baby in the first month of life. In order to determine feasibility, several objectives had to be met. First of all, data elements that parents could enter into the proposed app, needed to be identified. Based on the identified data, a decision support algorithm needed to be created, in order to understand what health problems could possibly be detected. Lastly, the effectiveness of the proposed app needed to be evaluated by actual parents; this was done via a study-specific online survey. To evaluate

effectiveness, we aimed to determine if and how frequently parents would be willing to enter data, if parents' behaviour would change based on the support provided by the app, if the app would provide a false sense of confidence to parents, and if parents would exhibit an appropriate amount of trust in the tool.

It was hypothesized that parents would be willing to enter standard information (e.g. length of breastfeeding, voids, sleep, etc.) on a regular basis, but would only be willing to enter non-standard information sometimes. Results showed that although the vast majority parents were willing to enter data either sometimes or always, which is encouraging, the frequency of entering data did not really differ based on whether it was standard or non-standard, as defined elsewhere in this research.

It was further hypothesized that if a possible health problem was detected, parents would follow the recommendation of the app. In most cases, this was also found not to be true. However, as mentioned in the discussion, many parents' original plan was already similar or the same as what was recommended by the app. As such, it is difficult to determine if these parents' would have followed the advice of the app, had their original plan been different. Furthermore, even though most parents did not follow the advice of the app, their level of concern for the baby as well as their belief there was a problem, increased significantly after receiving feedback from the app. This demonstrates that the app does affect parents' thinking and may raise awareness, even if they do not follow the exact advice provided.

Lastly, it was hypothesized that in the case that the decision support tool does not detect a problem, parents will continue to react in the same way as before the decision support was provided; that is, if a parent originally thought there was a problem and took actions to address it,

they would still take the same actions even if the decision support tool does not alert them of an issue. In this case, our hypothesis was supported. This positive result validates that parents are not putting all of their trust into the app, but rather, what can be considered as an appropriate amount of trust. This supports that if a problem does go undetected by the app, parents will not simply dismiss any concerns they may already have.

Limitations and Future Work

Decision algorithm. The initial step in this research was the creation of a decision algorithm. Although an initial algorithm was created, which fairly well defines the data a parent could enter as well as the problems that could be detected, there is still a lot of work to do in order to achieve complete accuracy and turn it into something that can be technically implemented. For example, many problems consider whether the baby ‘fed well’, which considers if the baby refused to feed, fell asleep while feeding, or there was no audible swallowing. To achieve the most accurate implementation, this decision would need to be defined one step further. More specifically, when evaluating if the baby fed well or not, the number of times there was a problem or the period of time that problems have occurred should be taken into account. If out of the last 8 feeds, for example, the baby only fell asleep once but fed well all the other times, then the answer to whether the baby ‘fed well’ should probably be ‘yes – the baby fed well’. However, if in the last 8 feeds the baby fell asleep or refused to feed 4 times, should it be considered that the baby fed well? This is one example of a detail that would still need to be worked out.

Another detail, still to be determined, is the timeframe that should be used when two or more symptoms must be present, in conjunction, to determine if a problem exists. For example, when checking for dehydration, the algorithm evaluates whether the baby is lethargic, if they

have fewer dirty diapers than expected, if they have fewer wet diapers than expected, and if they have poor skin turgor. All four of these symptoms need to be true in order for the algorithm to proceed; yet, as an example, if the baby had fewer wet diapers than expected 4 days ago, poor skin turgor 6 days ago, and today has less dirty diapers than expected and is lethargic, should the system consider the baby to be dehydrated? In other words, do the symptoms show up close enough together? Again, for each health problem and every time multiple symptoms must occur together, a timeframe needs to be established before technical implementation and functional accuracy can be accomplished.

Over and above the details that still need to be determined, the algorithm as a whole needs to be reviewed by a group of clinicians, preferably with different backgrounds. Although public health resources were used as a basis to create the algorithm and it was then reviewed by a nurse / lactation consultant, further input from a variety of professionals is recommended in order to achieve completeness and accuracy.

Parent survey. One concern raised during the focus group was whether this study was considering parents of all socio-economic backgrounds and levels of education. Unfortunately, since convenience sampling was used to recruit participants for the parent survey, it was not possible to ensure equal representation at various levels of economic welfare and education. Future research should be conducted with a larger and more demographically varied sample in order to determine how results may vary between sub-populations, such as parents who do not have a post-secondary education.

Another limitation of the survey was the fact that parents had to imagine the input mechanism for the data, rather than actually being able to use the app or even see mock-ups. The

lack of a visual representation of the app may have affected parents' responses when asked if and how often they would be willing to enter each piece of data. For example, some participants expressed concern regarding how cumbersome it would be to enter time of feeds. However, from a design perspective, the user would not necessarily have to input an actual time. One solution would be to simply click a button to say that the feeding has started and then click a button to indicate the feeding is over; the system could then automatically derive the times. Still, this is only one example, and until at least a preliminary design is completed, the ease of data entry and use of the app in general is difficult to convey by text.

Similar to the above, and another concern raised by lactation consultants during the focus group, is that the interaction design of the app, or lack thereof in the survey, could also have influenced answers. Specifically in cases when parents may not think of checking for certain symptoms or entering them into the app; the most obvious being skin turgor. Therefore, rather than depending on a parent to know that skin turgor should be checked and entered into the app, the app could be designed to prompt the user to enter this data if certain other symptoms have already been entered that would be considered together with skin turgor. Yet, without having knowledge of the app design while completing the survey, participants were forced to imagine it and make their decisions based on how they think it might work.

Another limitation of the parent survey was due to the structure of the survey itself. The survey was fairly long, taking an estimated 30 minutes to complete, on average. The lengthiness of the survey is believed to be the reason why, in some cases, more than half of participants did not answer certain questions. Open-ended questions, regarding behaviour based on the scenarios in particular, were left blank by many participants; this is likely because these questions require more time and effort to answer and participants simply wanted to finish the survey. Fewer

responses to the open-ended questions means the results may be less accurate, or at least, less generalizable.

Lastly, the decision algorithm created for this research was based on information obtained from online and public health sources and then reviewed by a registered nurse who is also a lactation consultant. The ultimate goal is to have a complete review of the algorithm and by a group of healthcare professionals, which in and of itself, is a limitation of this work. The resources that were used in this preliminary study and stated in the survey, may have affected parents' trust in the app, thereby affecting not only their willingness to use it, but also their behaviours in each scenario, after being provided with feedback from the app. Although further investigation is needed, the results may have been different if more trusted resources had been used and, in turn, cited in the survey.

References

- American Academy of Pediatrics. (2010). Hospital stay for healthy term newborns. *Pediatrics*, 125(2), 405.
- Annas, G.J. (1995). Women and children first. *N Engl J Med*, 24, 1647-1651.
- Basch, C. E. (1987). Focus group interview: An underutilized research technique for improving theory and practice in health education. *Health Education & Behavior*, 14(4), 411-448.
- Bernstein, H. H., Spino, C., Lalama, C. M., Finch, S. A., Wasserman, R. C., & McCormick, M. C. (2013). Unreadiness for postpartum discharge following healthy term pregnancy: impact on health care use and outcomes. *Academic pediatrics*, 13(1), 27-39.
- Britton, J. R. (1998). Postpartum Early Hospital Discharge and Follow-up Practices in Canada and the United States. *Birth*, 25(3), 161-169.
- Britton, J. R., Britton, H. L., & Gronwaldt, V. (1999). Early perinatal hospital discharge and parenting during infancy. *Pediatrics*, 104(5), 1070-1076.
- Brown, S., Bruinsma, F., Darcy, M. A., Small, R., & Lumley, J. (2004). Early discharge: no evidence of adverse outcomes in three consecutive population-based Australian surveys of recent mothers, conducted in 1989, 1994 and 2000. *Paediatric and perinatal epidemiology*, 18(3), 202-213.
- Buie, V. C., Owings, M. F., DeFrances, C. J., & Golosinskiy, A. (2010). National Hospital Discharge Survey: 2006 Annual Summary. *Vital and health statistics. Series 13, Data from the National Health Survey*, (168), 1-79.

- Cambonie, G., Rey, V., Sabarros, S., Baum, T. P., Fournier-Favre, S., Mazurier, E., Boulot, P., & Picaud, J. C. (2010). Early postpartum discharge and breastfeeding: An observational study from France. *Pediatrics International*, 52(2), 180-186.
- Cargill, Y., Martel, M. J., & Society of Obstetricians and Gynaecologists of Canada. (2007). Postpartum maternal and newborn discharge. *Journal of obstetrics and gynaecology Canada: JOGC= Journal d'obstetrique et gynecologie du Canada: JOGC*, 29(4), 357-363.
- Carrera, P. M., & Dalton, A. R. (2014). Do-it-yourself healthcare: the current landscape, prospects and consequences. *Maturitas*, 77(1), 37-40.
- Çinar, İ. Ö., & Öztürk, A. (2014). The Effect of Planned Baby Care Education Given to Primiparous Mothers on Maternal Attachment and Self-Confidence Levels. *Health care for women international*, 35(3), 320-333.
- Danbjørg, D. B., Wagner, L., & Clemensen, J. (2014). Do families after early postnatal discharge need new ways to communicate with the hospital? A feasibility study. *Midwifery*, 30(6), 725-732.
- Danbjørg, D. B., Wagner, L., Kristensen, B. R., & Clemensen, J. (2015). Intervention among new parents followed up by an interview study exploring their experiences of telemedicine after early postnatal discharge. *Midwifery*, 31(6), 574-581.
- Danielsen, B., Castles, A. G., Damberg, C. L., & Gould, J. B. (2000). Newborn discharge timing and readmissions: California, 1992–1995. *Pediatrics*, 106(1), 31-39.
- Deave, T., Johnson, D., & Ingram, J. (2008). Transition to parenthood: the needs of parents in pregnancy and early parenthood. *BMC pregnancy and childbirth*, 8(1), 30.

- Devolin, M., Phelps, D., Duhaney, T., Benzies, K., Hildebrandt, C., Rikhy, S., & Churchill, J. (2013). Information and Support Needs among Parents of Young Children in a Region of Canada: A Cross-Sectional Survey. *Public Health Nursing, 30*(3), 193-201.
- Dow, W. H., Harris, D. M., & Liu, Z. (2006). Differential effectiveness in patient protection laws: What are the causes? An example from the drive-through delivery laws. *Journal of health politics, policy and law, 31*(6), 1107-1127.
- Eidelman, A. I., Hoffmann, N. W., & Kaitz, M. (1993). Cognitive deficits in women after childbirth [Abstract]. *Obstetrics and gynecology, 81*(5 (Pt 1)), 764-767.
- Farhat, R., & Rajab, M. (2011). Length of postnatal hospital stay in healthy newborns and re-hospitalization following early discharge. *North American journal of medical sciences, 3*(3), 146.
- Fink, A. M. (2011). Early hospital discharge in maternal and newborn care. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 40*(2), 149-156.
- Forster, D. A., McLachlan, H. L., Rayner, J., Yelland, J., Gold, L., & Rayner, S. (2008). The early postnatal period: exploring women's views, expectations and experiences of care using focus groups in Victoria, Australia. *BMC pregnancy and childbirth, 8*(1), 27.
- Fox, S. (2011). *The social life of health information 2011*. Washington, DC: Pew Internet & American Life Project.
- Fredriksson, G. E., Högberg, U., & Lundman, B. M. (2003). Postpartum care should provide alternatives to meet parents' need for safety, active participation, and 'bonding'. *Midwifery, 19*(4), 267-276.

- García-Gómez, J. M., de la Torre-Díez, I., Vicente, J., Robles, M., López-Coronado, M., & Rodrigues, J. J. (2014). Analysis of mobile health applications for a broad spectrum of consumers: A user experience approach. *Health informatics journal*, 20(1), 74-84.
- Goldman, R. D., & Macpherson, A. (2006). Internet health information use and e-mail access by parents attending a paediatric emergency department. *Emergency medicine journal*, 23(5), 345-348.
- Haga, S. M., Lynne, A., Slinning, K., & Kraft, P. (2012). A qualitative study of depressive symptoms and well-being among first-time mothers. *Scandinavian journal of caring sciences*, 26(3), 458-466.
- Health and Social Care Information Centre. (2015). *NHS Maternity Statistics - England, 2013-14* [Data file]. Retrieved from <http://www.hscic.gov.uk/catalogue/PUB16725/nhs-mate-eng-2013-14-tab-v1.xlsx>.
- Isetta, V., Lopez-Agustina, C., Lopez-Bernal, E., Amat, M., Vila, M., Valls, C, Navajas, D., & Farre, R. (2013). Cost-effectiveness of a new internet-based monitoring tool for neonatal post-discharge home care. *Journal of medical Internet research*, 15(2).
- Jackson, G. L., Kennedy, K. A., Sendelbach, D. M., Talley, D. H., Aldridge, C. L., Vedro, D. A., & Laptook, A. R. (2000). Problem identification in apparently well neonates: implications for early discharge. *Clinical pediatrics*, 39(10), 581-590.
- Jahns, R. (2010). 500m people will be using healthcare mobile applications in 2015. Retrieved April 23, 2015, from <http://research2guidance.com/500m-people-will-be-using-healthcare-mobile-applications-in-2015/>

- Johnson, D., Jin, Y., & Truman, C. (2002). Early discharge of Alberta mothers post-delivery and the relationship to potentially preventable newborn readmissions. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, 276-280.
- Jutel, A., & Lupton, D. (2015). Digitizing diagnosis: a review of mobile applications in the diagnostic process. *Diagnosis*, 2(2), 89-96.
- Kanotra, S., D'Angelo, D., Phares, T. M., Morrow, B., Barfield, W. D., & Lansky, A. (2007). Challenges faced by new mothers in the early postpartum period: an analysis of comment data from the 2000 Pregnancy Risk Assessment Monitoring System (PRAMS) survey. *Maternal and Child Health Journal*, 11(6), 549-558.
- Khoo, K., Bolt, P., Babl, F. E., Jury, S., & Goldman, R. D. (2008). Health information seeking by parents in the Internet age. *Journal of paediatrics and child health*, 44(7-8), 419-423.
- Kitzinger, J. (1995). Qualitative research: introducing focus groups. *Bmj*, 311(7000), 299-302.
- Klasnja, P., & Pratt, W. (2012). Healthcare in the pocket: mapping the space of mobile-phone health interventions. *Journal of biomedical informatics*, 45(1), 184-198.
- Koch-Weser, S., Bradshaw, Y. S., Gualtieri, L., & Gallagher, S. S. (2010). The Internet as a health information source: findings from the 2007 Health Information National Trends Survey and implications for health communication. *Journal of Health Communication*, 15(sup3), 279-293.
- Krueger, R. A. (2009). Participants in a Focus Group. *Focus groups: A practical guide for applied research* (pp. 63-84). Sage.

- Kuo, M. C., Lu, Y. C., & Chang, P. (2012). A newborn baby care support app and system for mHealth. *NI 2012: Proceedings of the 11th International Congress on Nursing Informatics* (Vol. 2012).
- Leahy-Warren, P., McCarthy, G., & Corcoran, P. (2012). First-time mothers: social support, maternal parental self-efficacy and postnatal depression. *Journal of Clinical Nursing*, 21(3-4), 388-397.
- Lee, K. S., Perlman, M., Ballantyne, M., Elliott, I., & To, T. (1995). Association between duration of neonatal hospital stay and readmission rate. *The Journal of pediatrics*, 127(5), 758-766.
- Lieu, T. A., Braveman, P. A., Escobar, G. J., Fischer, A. F., Jensvold, N. G., & Capra, A. M. (2000). A randomized comparison of home and clinic follow-up visits after early postpartum hospital discharge. *Pediatrics*, 105(5), 1058-1065.
- Lindberg, B. (2013). Access to videoconferencing in providing support to parents of preterm infants: Ascertaining parental views. *Journal of Neonatal Nursing*, 19(5), 259-265.
- Liu, L. L., Clemens, C. J., Shay, D. K., Davis, R. L., & Novack, A. H. (1997). The safety of newborn early discharge: the Washington State experience. *JAMA*, 278(4), 293-298.
- Liu, C. C., Chen, Y. C., Yeh, Y. P., & Hsieh, Y. S. (2012). Effects of maternal confidence and competence on maternal parenting stress in newborn care. *Journal of advanced nursing*, 68(4), 908-918.

- Lock, M., & Ray, J. G. (1999). Higher neonatal morbidity after routine early hospital discharge
Are we sending newborns home too early?. *Canadian Medical Association Journal*,
161(3), 249-253.
- Logsdon, M. C., Mittelberg, M., & Myers, J. (2014). Use of social media and internet to obtain
health information by rural adolescent mothers. *Applied Nursing Research*, 28(1), 55-56.
- Madden, J. M., Soumerai, S. B., Lieu, T. A., Mandl, K. D., Zhang, F., & Ross-Degnan, D.
(2002). Effects of a law against early postpartum discharge on newborn follow-up, adverse
events, and HMO expenditures. *New England Journal of Medicine*, 347(25), 2031-2038.
- Madden, J. M., Soumerai, S. B., Lieu, T. A., Mandl, K. D., Zhang, F., & Ross-Degnan, D.
(2004). Length-of-stay policies and ascertainment of postdischarge problems in newborns.
Pediatrics, 113(1), 42-49.
- Maisels, M. J., & Kring, E. (1998). Length of stay, jaundice, and hospital readmission.
Pediatrics, 101(6), 995-998.
- Malkin, J. D., Broder, M. S., & Keeler, E. (2000). Do longer postpartum stays reduce newborn
readmissions? Analysis using instrumental variables. *Health services research*, 35(5 Pt 2),
1071.
- Martell, L. K. (2000). The hospital and the postpartum experience: A historical analysis. *Journal
of Obstetric, Gynecologic, & Neonatal Nursing*, 29(1), 65-72.
- McDaniel, R. W., & Bach, C. A. (1994). Focus groups: a data-gathering strategy for nursing
research.

- McKellar, L. V., Pincombe, J., & Henderson, A. M. (2002). Congratulations you're a mother: A strategy for enhancing postnatal education for first-time mothers investigated through an action research cycle. *The Australian Journal of Midwifery*, 15(3), 24-31.
- McVeigh, C. (1997). Motherhood experiences from the perspective of first-time mothers. *Clinical Nursing Research*, 6(4), 335-348.
- Meara, E., Kotagal, U. R., Atherton, H. D., & Lieu, T. A. (2004). Impact of early newborn discharge legislation and early follow-up visits on infant outcomes in a state Medicaid population. *Pediatrics*, 113(6), 1619-1627.
- Organisation for Economic Co-operation and Development. (2014). *OECD Health Statistics 2014 - Frequently Requested Data*. Available from <http://www.oecd.org/els/health-systems/oecd-health-statistics-2014-frequently-requested-data.htm>
- Parisi, V. M., & Meyer, B. A. (1995). To stay or not to stay? That is the question. *The New England journal of medicine*, 333(24), 1635.
- Paul, I. M., Downs, D. S., Schaefer, E. W., Beiler, J. S., & Weisman, C. S. (2013). Postpartum anxiety and maternal-infant health outcomes. *Pediatrics*, 131(4), e1218-e1224.
- Rayner, J. A., McLachlan, H. L., Forster, D. A., Peters, L., & Yelland, J. (2010). A statewide review of postnatal care in private hospitals in Victoria, Australia. *BMC pregnancy and childbirth*, 10(1), 26.
- Salem-Schatz, S., Peterson, L., Palmer, R. H., Clanton, M., Ezhuthachan, S., Luttrell, R., Newman, C., & Westbury, R. (2004). Barriers to first-week follow-up of newborns:

findings from parent and clinician focus groups. *Joint Commission Journal on Quality and Patient Safety*, 30(11), 593-601.

Sawyer, A. C., Lynch, J., Bowering, K., Jeffs, D., Clark, J., Mpundu-Kaambwa, C., & Sawyer, M. G. (2014). An equivalence evaluation of a nurse-moderated group-based internet support program for new mothers versus standard care: a pragmatic preference randomised controlled trial. *BMC pediatrics*, 14(1), 119.

Scullard, P., Peacock, C., & Davies, P. (2010). Googling children's health: reliability of medical advice on the internet. *Archives of Disease in Childhood*, 95(8), 580-582.

Semigran, H. L., Linder, J. A., Gidengil, C., & Mehrotra, A. (2015). Evaluation of symptom checkers for self diagnosis and triage: audit study. *BMJ*, 351:h3480.

Silva, B. M., Rodrigues, J. J., de la Torre Díez, I., López-Coronado, M., & Saleem, K. (2015). Mobile-health: A review of current state in 2015. *Journal of biomedical informatics*, 56, 265-272.

Steel, O., Mowat, D. L., Scott, H. M., Carr, P. A., Dorland, J. L., & Young, T. K. (2002). A randomized trial of two public health nurse follow-up programs after early obstetrical discharge: an examination of breastfeeding rates, maternal confidence and utilization and costs of health services. *Canadian journal of public health= Revue canadienne de sante publique*, 94(2), 98-103.

Steinhubl, S. R., Muse, E. D., & Topol, E. J. (2013). Can mobile health technologies transform health care?. *JAMA*, 310(22), 2395-2396.

Suplee, P. D., Bloch, J. R., McKeever, A., Borucki, L. C., Dawley, K., & Kaufman, M. (2014).

Focusing on Maternal Health Beyond Breastfeeding and Depression during the First Year Postpartum. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 43(6), 782-791.

The World Bank Group. (2015). *Internet users (per 100 people)*. Retrieved from

<http://data.worldbank.org/indicator/IT.NET.USER.P2>

Tully, P., & Saint-Pierre, E. (1997). Downsizing Canada's hospitals, 1986/87 to 1994/95.

HEALTH REPORTS-STATISTICS CANADA, 8, 33-40.

Wainstein, B. K., Sterling-Levis, K., Baker, S. A., Taitz, J., & Brydon, M. (2006). Use of the

Internet by parents of paediatric patients. *Journal of paediatrics and child health*, 42(9), 528-532.

Walsh, A. M., Hyde, M. K., Hamilton, K., & White, K. M. (2012). Predictive modelling:

parents' decision making to use online child health information to increase their understanding and/or diagnose or treat their child's health. *BMC medical informatics and decision making*, 12(1), 144.

Weiss, M., Ryan, P., Lokken, L., & Nelson, M. (2004). Length of Stay after Vaginal Birth:

Sociodemographic and Readiness-for-Discharge Factors. *Birth*, 31(2), 93-101.

Wen, S. W., Liu, S., Marcoux, S., & Fowler, D. (1998). Trends and variations in length of

hospital stay for childbirth in Canada. *Canadian Medical Association Journal*, 158(7), 875-880.

Wieggers, T. A. (2006). Adjusting to motherhood: maternity care assistance during the postpartum

period: how to help new mothers cope. *Journal of Neonatal nursing*, 12(5), 163-171.

- Winterburn, S., & Fraser, R. (2000). Does the duration of postnatal stay influence breast-feeding rates at one month in women giving birth for the first time? A randomized control trial. *Journal of advanced nursing*, 32(5), 1152-1157.
- Yanicki, S., Hasselback, P., Sandilands, M., & Jensen-Ross, C. (2002). The safety of Canadian early discharge guidelines: Effects of discharge timing on readmission in the first year post-discharge and exclusive breastfeeding to four months. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, 26-30.
- Young, P. C., Korgenski, K., & Buchi, K. F. (2013). Early readmission of newborns in a large health care system. *Pediatrics*, 131(5), e1538-e1544.

Appendix A: Decision Support Algorithm

Note: Full alert text does not appear within the decision tree diagrams; diagrams only include the suggested action. The full message will be in the following format:

Alert! *<Action from flow diagram (shown in rounded rectangles)>*

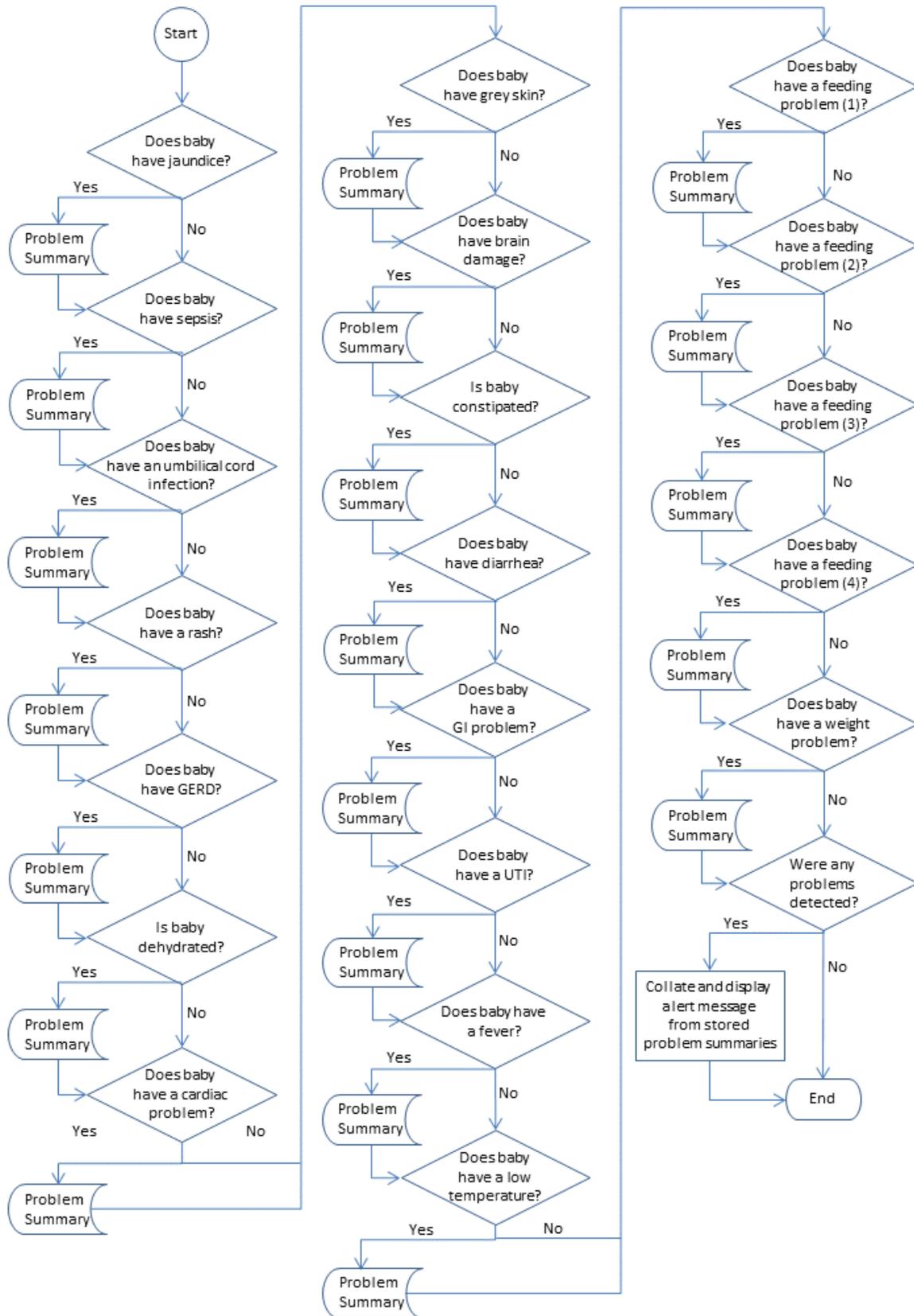
This recommendation is based on the following symptoms:

-list all symptoms that caused this particular warning to appear

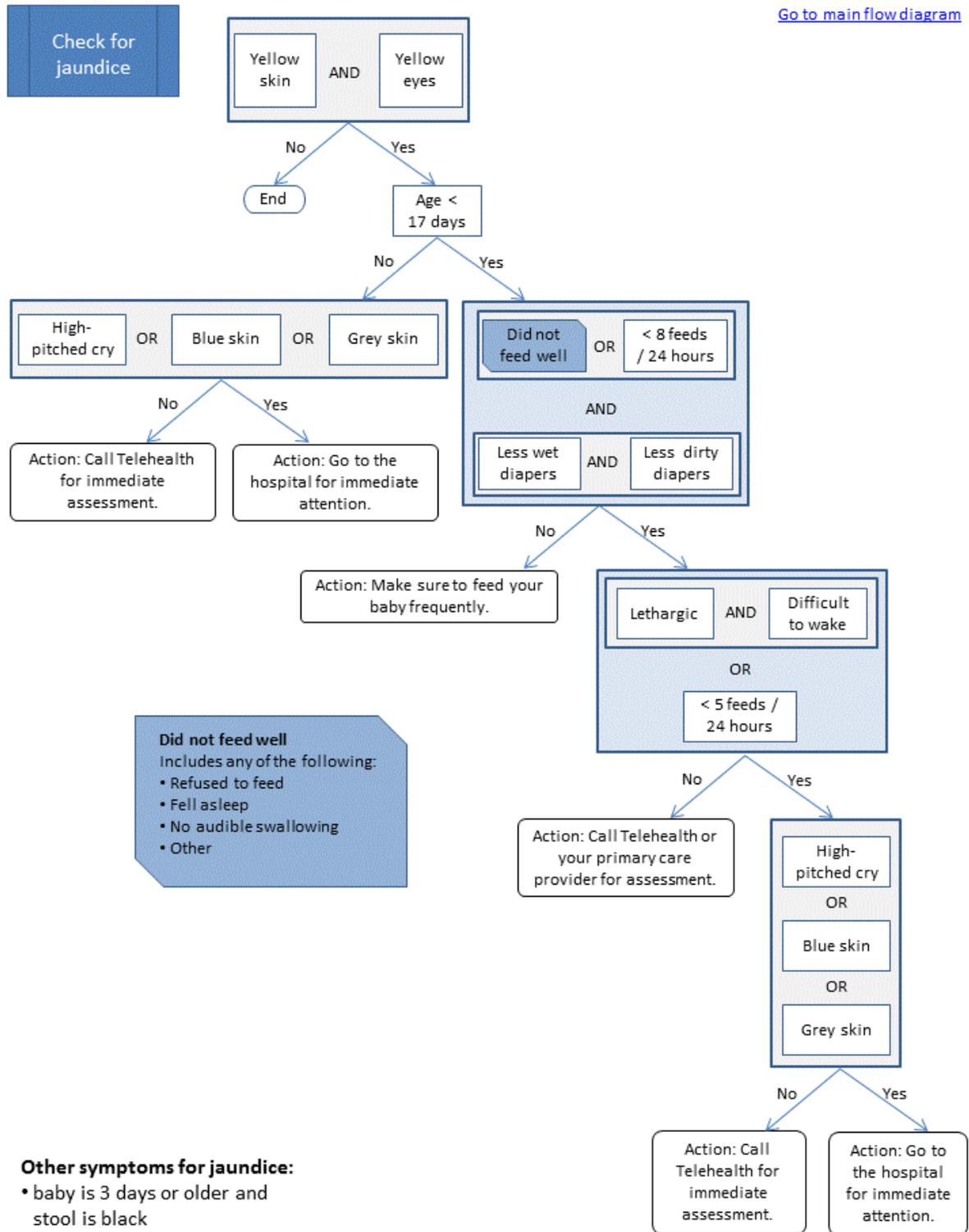
<if other symptoms are present>

Other symptoms of concern include:

-list all other symptoms that may result from the particular condition and are present in the baby. For each condition, 'other' symptoms are listed on the corresponding slide.



*GERD: Gastroesophageal reflux disease

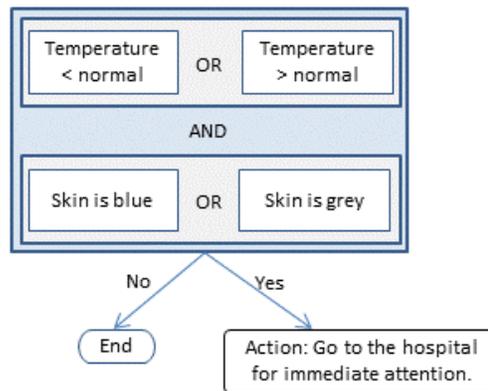


Other symptoms for jaundice:

- baby is 3 days or older and stool is black
- baby is 5 days or older and stool is either:
 - dark green
 - green
 - brown
- urine is dark

Check for
sepsis

[Go to main flow diagram](#)

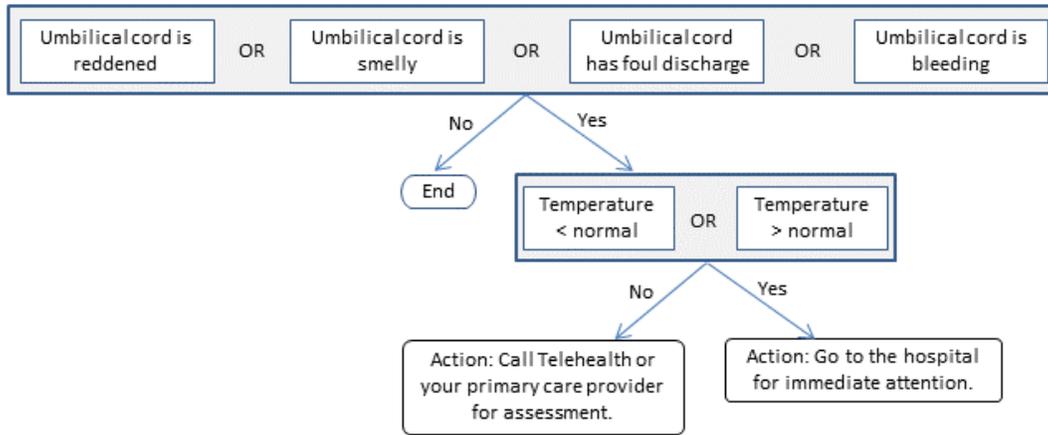


Other symptoms for sepsis:

- baby did not feed well:
 - refused to feed
 - fell asleep
 - no audible swallowing
 - other
- less than 5 feeds in 24 hours
- less stools than normal / 24 hours
- baby has diarrhea
- skin is jaundiced (yellow)
- Activity:
 - lethargic
 - jittery
 - difficult to wake for feeding
- vomited forcefully / expelled fluid
- High-pitched cry
- White of eyes are yellow tinged

Check for umbilical cord infection

[Go to main flow diagram](#)

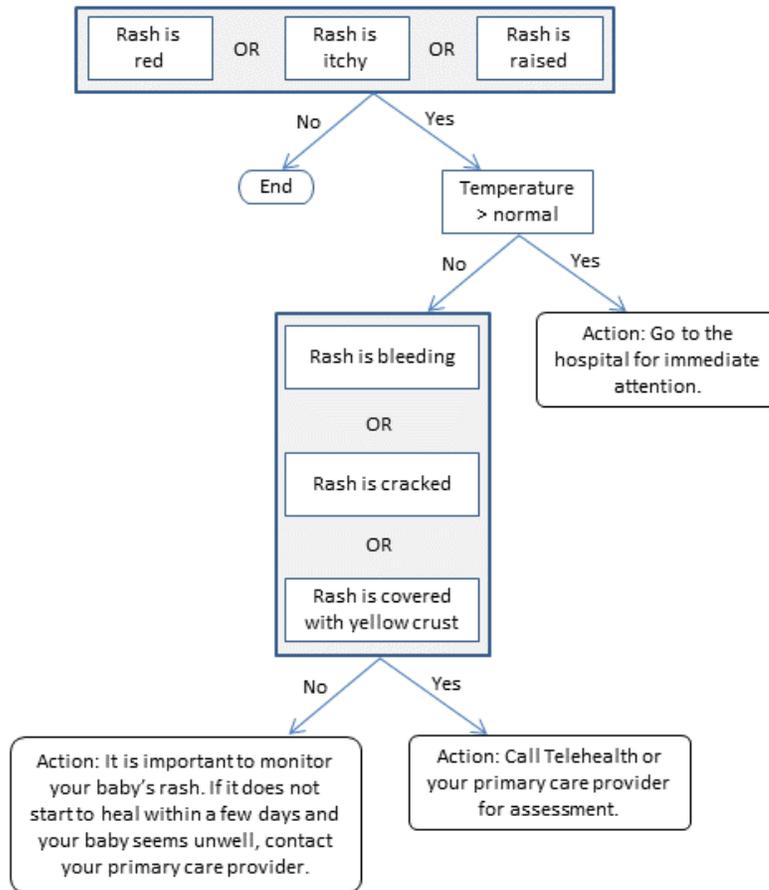


Other symptoms for umbilical cord infection:

- N/A

Check for rash

[Go to main flow diagram](#)

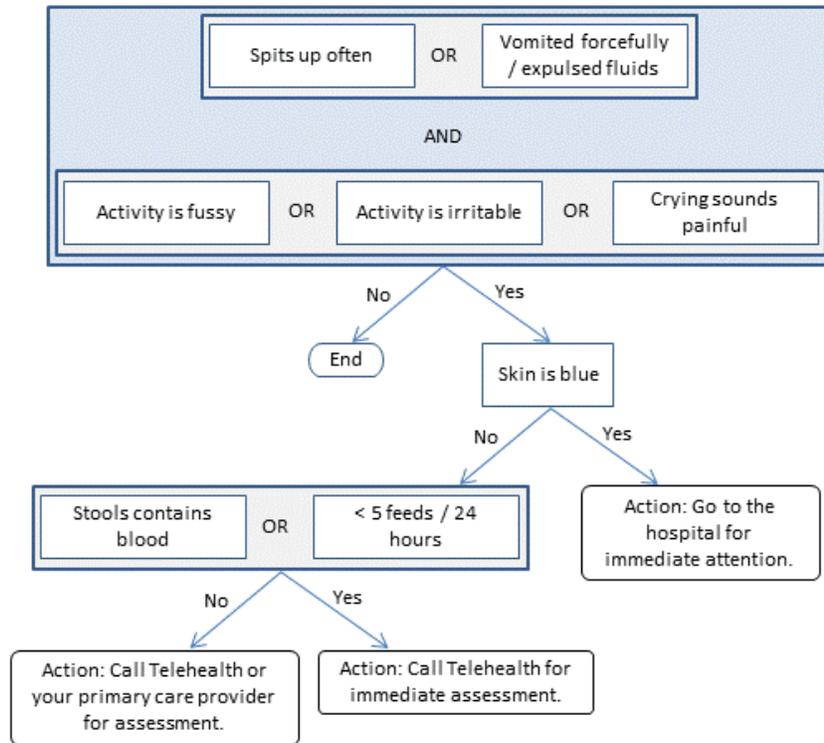


Other symptoms for a rash:

- Activity:
 - lethargic
 - fussy
 - irritable
- vomited forcefully / expulsed fluid
- High-pitched cry
- White of eyes are yellow tinged

Check for GERD

[Go to main flow diagram](#)



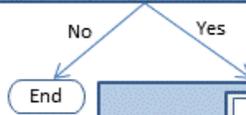
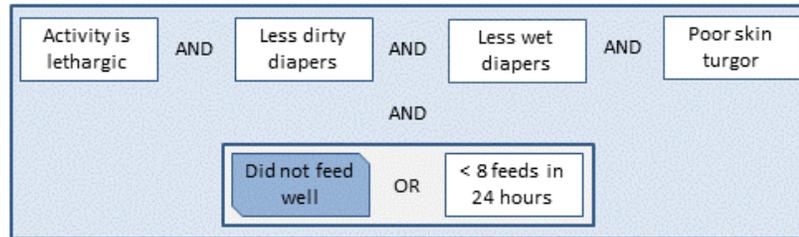
Other symptoms for GERD:

- baby did not feed well:
 - refused to feed
 - coughing / choking
 - fussy / inconsolable
 - other
- urine contains blood
- excessive gas

*GERD: Gastroesophageal reflux disease

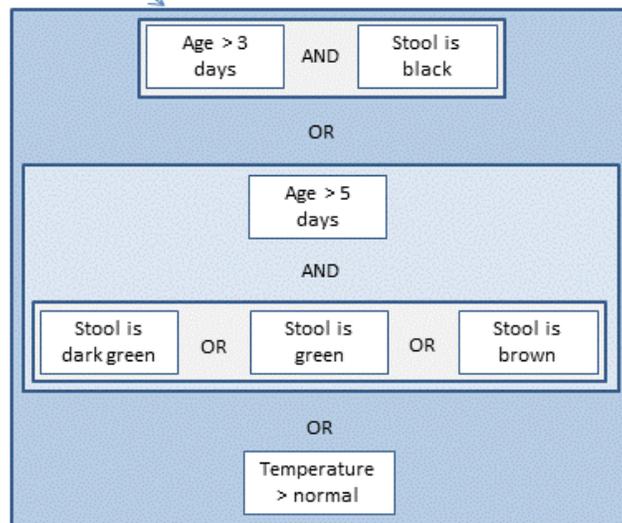
Check for Dehydration

[Go to main flow diagram](#)



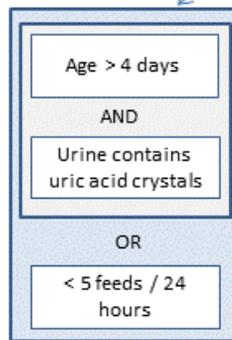
Did not feed well
Includes any of the following:

- Refused to feed
- Fell asleep
- No other swallowing
- Other



Other symptoms for dehydration:

- more than one long sleep period in 24 hours
- urine has strong odour
- Skin colour is pale
- Skin is jaundiced (yellow)
- Activity:
 - jittery
 - irritable
 - difficult to wake for feeding



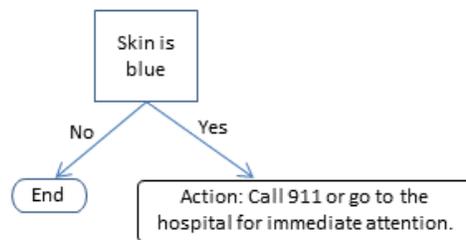
Action: Call Telehealth or your primary care provider for assessment.

Action: Call Telehealth for immediate assessment.

Action: Go to the hospital for immediate attention

Check for
Cardiac Problem

[Go to main flow diagram](#)

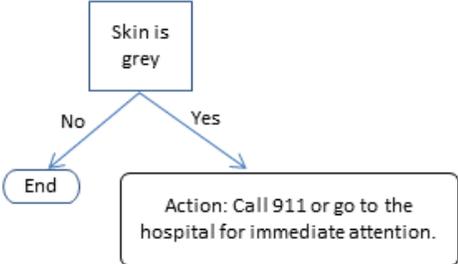


Other symptoms for a cardiac problem:

- baby did not feed well:
 - refused to feed
 - fell asleep
 - other
- activity:
 - lethargic
 - fussy
- dehydrated

Check for Grey Skin

[Go to main flow diagram](#)

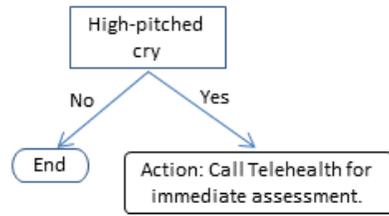


Other symptoms for a grey skin:

- N/A

Check for Brain Damage

[Go to main flow diagram](#)

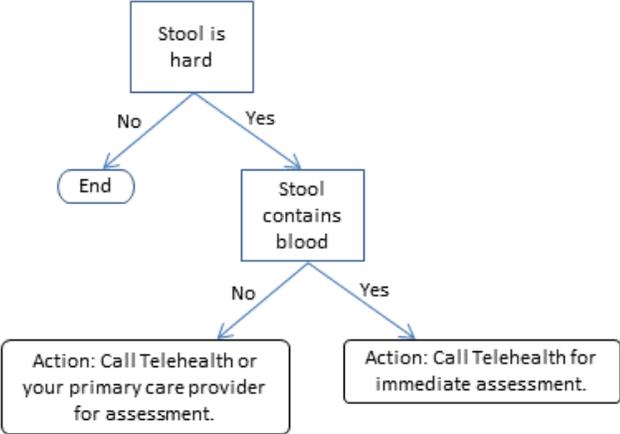


Other symptoms for brain damage:

- N/A

Check for Constipation

[Go to main flow diagram](#)

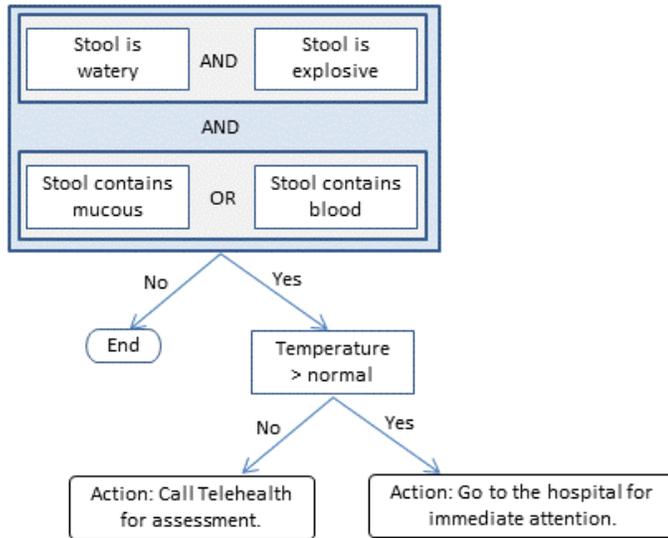


Other symptoms for constipation:

- less stools / 24 hours than normal
- crying sounds painful

Check for Diarrhea

[Go to main flow diagram](#)

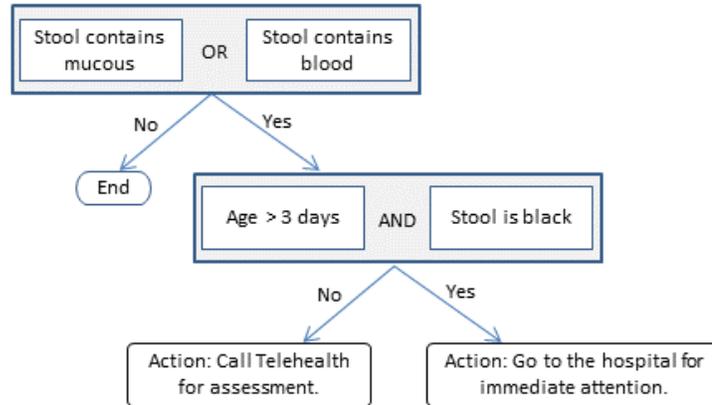


Other symptoms for diarrhea:

- stools are green

Check for
Gastrointestinal
(GI) Problem

[Go to main flow diagram](#)

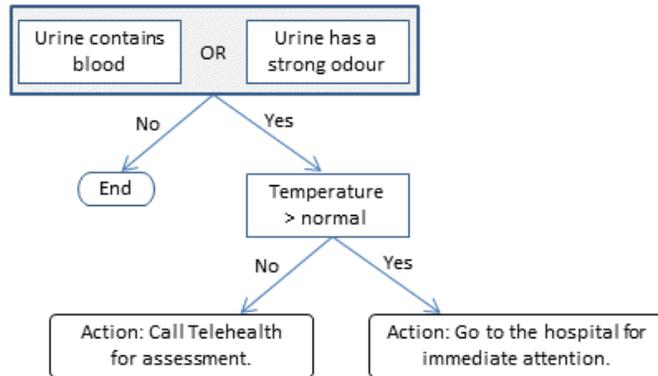


Other symptoms for a GI problem:

- N/A

Check for Urinary Tract Infection (UTI)

[Go to main flow diagram](#)

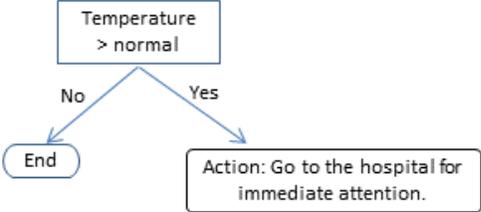


Other symptoms for a UTI:

- baby did not feed well:
 - refused to feed
 - fell asleep
 - fussy / inconsolable
 - other
- less than 8 feeds / 24 hours
- less than 5 feeds / 24 hours
- activity:
 - lethargic
 - irritable
- vomited forcefully / expelled fluids

Check for Fever

[Go to main flow diagram](#)

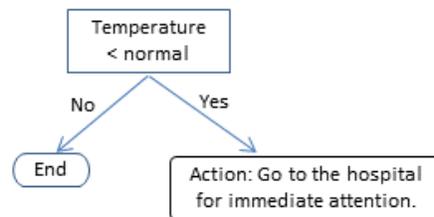


Other symptoms for fever:

- N/A

Check for Low
Temperature

[Go to main flow diagram](#)

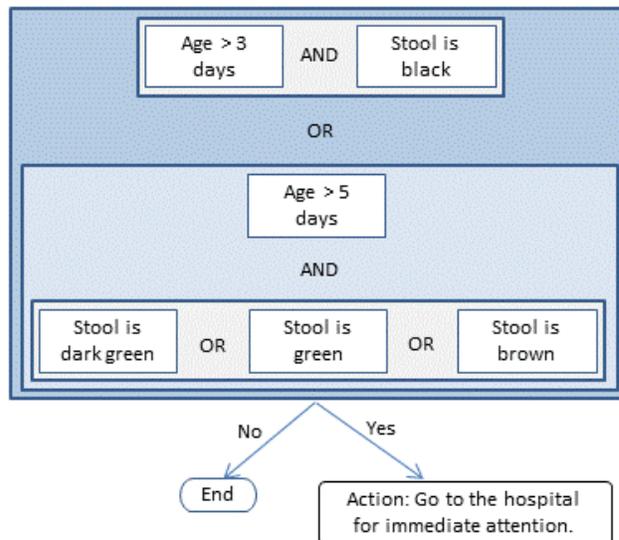


Other symptoms for low temperature:

- N/A

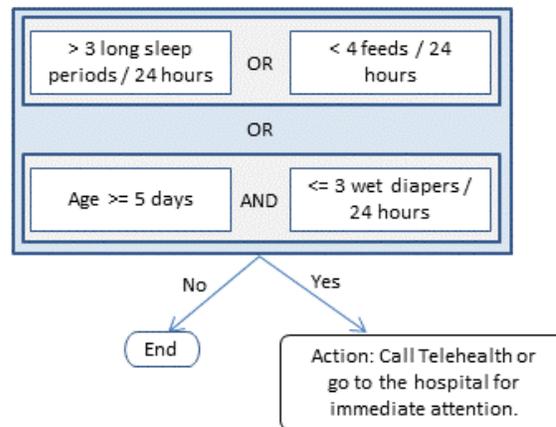
Check for a Feeding Problem (1)

[Go to main flow diagram](#)



Other symptoms for a feeding problem:

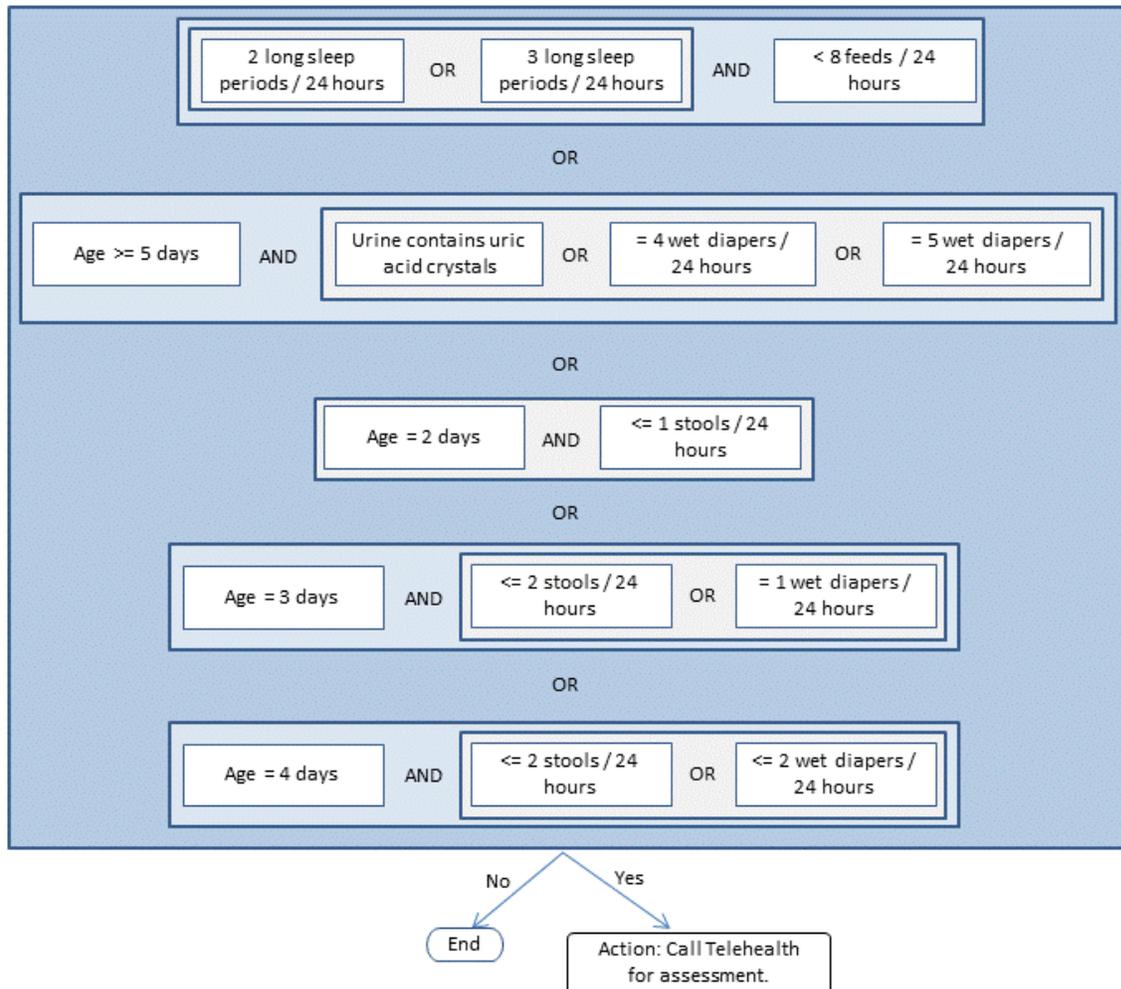
- baby did not feed well:
 - refused to feed
 - coughing/choking
 - fell asleep
 - no audible swallowing
 - fussy/inconsolable
 - other
- Urine has a strong odour
- Skin is jaundiced (yellow)

Check for a Feeding Problem (2)[Go to main flow diagram](#)**Other symptoms for a feeding problem:**

- baby did not feed well:
 - refused to feed
 - coughing/choking
 - fell asleep
 - no audible swallowing
 - fussy/inconsolable
 - other
- Urine has a strong odour
- Skin is jaundiced (yellow)

Check for a Feeding Problem (3)

[Go to main flow diagram](#)

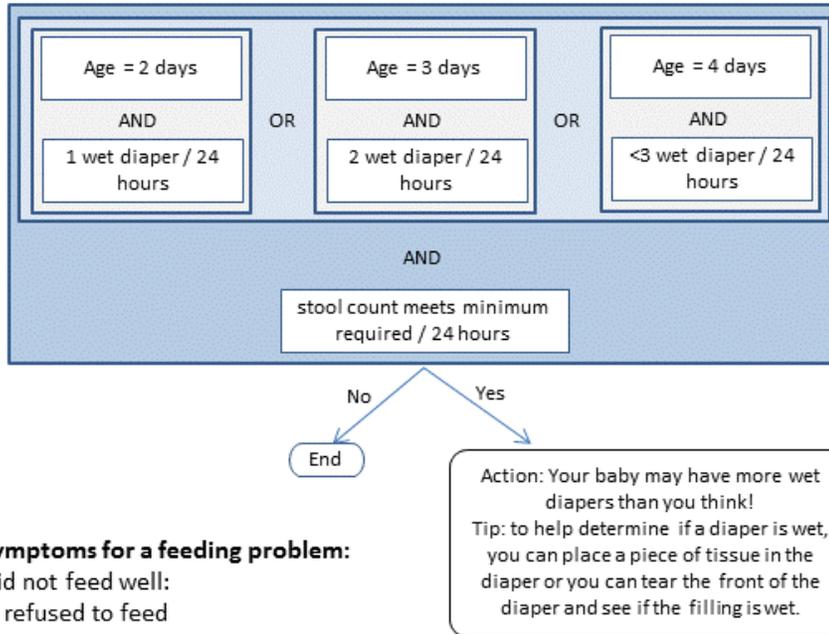


Other symptoms for a feeding problem:

- baby did not feed well:
 - refused to feed
 - coughing/choking
 - fell asleep
 - no audible swallowing
 - fussy/inconsolable
 - other
- Urine has a strong odour
- Skin is jaundiced (yellow)

Check for a Feeding Problem (4)

[Go to main flow diagram](#)

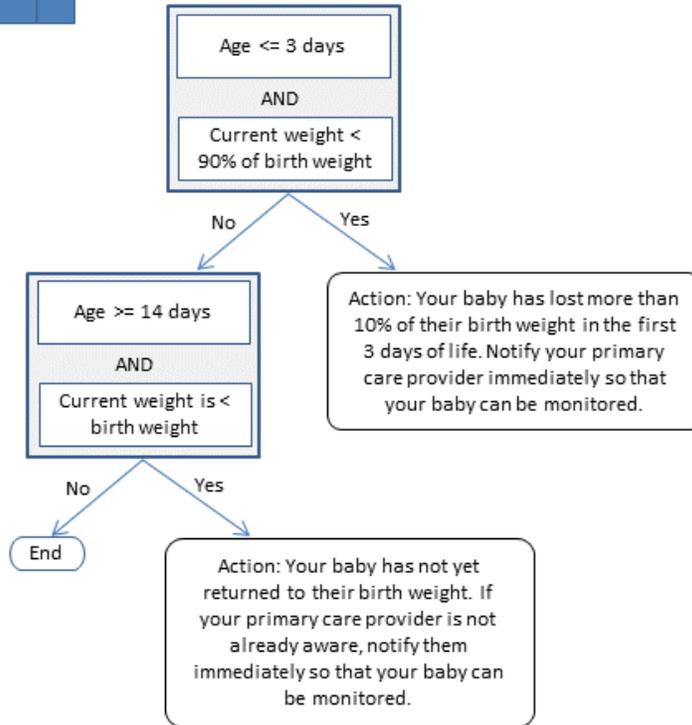


Other symptoms for a feeding problem:

- baby did not feed well:
 - refused to feed
 - coughing/choking
 - fell asleep
 - no audible swallowing
 - fussy/inconsolable
 - other
- Urine has a strong odour
- Skin is jaundiced (yellow)

Check for a Weight Problem

[Go to main flow diagram](#)



Other symptoms for a weight problem:

- N/A

Appendix B: Focus Group Recruitment Script

Note: Text in italics is not to be spoken, but is intended as instructions for the moderator.

Good evening and thank you for having me here tonight. My name is Crystal Sirard and I am a student at Carleton University, working on a master's in Human-Computer Interaction. I'm sure most of you are not exactly familiar with the field of human-computer interaction, so I will give you a very brief idea of what it is in just a minute. But first, I would like to introduce my supervisors and co-investigators for my thesis.

Unfortunately, my supervisor from Carleton, Dr. Anthony Whitehead, had a prior commitment and could not make it tonight. I will tell you a bit about him though. Dr. Whitehead has his PhD in Computer Science, is the Director of the School of Information Technology at Carleton, and is also the current chair of the Human Computer Interaction Program at Carleton.

Next, is Dr. Kathy Momtahan. Kathy is co-supervising my thesis. She has her PhD in Psychology and is currently the corporate nursing research lead at the Ottawa Hospital.

Last, but not least, is Barb d'Entremont, whom most of you probably already know. Barb is a co-investigator for my thesis, providing her expertise in breastfeeding and other relevant clinical matters, based on her background as a nurse.

To Kathy and Barb: Thanks to both of you for being here with me tonight.

So now back to me and the field of Human-Computer Interaction... I guess one way to explain it is that it's a field concerned with how we can integrate computers into our lives, in the friendliest way possible. We live in a world in which we are surrounded by computers: not just desktops, laptops, tablets and phones. Everything is computerized – from our coffee machines, stoves, and

ovens, to airport check-in kiosks, parking lot pay stations, and our vehicles. There are also, what some may consider, more futuristic applications of computers such as “Google glass” and virtual reality, which currently generates quite a bit of research in the domain of healthcare. With computers being so ubiquitous, we need to make sure that they are easy and intuitive to use, and designed in such a way that integrates seamlessly into how we live our lives and go about our daily work and activities.

So, whenever any kind of new computer system is being designed, many different aspects need to be evaluated to ensure success. For example, we not only need to make it “user friendly”, but also need to ensure that people will have a need for it and want to use it.

For my thesis, I am looking at the feasibility of a decision support tool, to be used by parents, to help detect possible health problems in healthy newborn babies. The actual implementation of the tool is outside the scope of my thesis, but the idea is that it would be implemented as an app that parents could run either on their smart phones or tablets. They would enter data about their newborn babies, such as information about feedings, voids, and sleep, and in turn, the app would be able to use the information to alert the parent of possible health problems and suggest a course of action. I specifically want to know if parents would use such an app and if it will actually help them to detect problems with their baby – so, would parents put an appropriate amount of trust in what the app is telling them? Also, will it make a difference in how parents address possible issues?

To accomplish all of this, I started by identifying what information parents are able to enter into the app and what problems can be detected based on this information. From there, I was able to create a decision support algorithm. My next step is to use all of this information to administer a

survey to parents that will hopefully help to answer the questions I mentioned earlier. As part of the survey, I will be using three scenario-based questions. The scenarios will paint pictures about a potential health issue that a hypothetical baby is facing. Each scenario will first be presented to participants without any decision support, and a series of questions will be asked in order to examine how parents would react if it was their baby. Then, the same scenario and questions will be repeated, but this time with the support of the app – provided in a textual format. In other words, any information that the app would provide, will be given to the parents in the survey, before answering the questions again.

The goal of tonight's session is to create three realistic scenarios to be used in the survey, based on everyone's experiences. Two of the scenarios should include problems that are detectable by the app and the third should be based on a problem that the app is unable to detect.

Before getting started, I will first pass out consent forms to everyone and ask those who would like to participate to complete the consent form and return it to me before we get going. Along with the consent form is a list of the different types of information that we will be asking parents to enter into the app and the different problems that the app would be able to detect based on that information. You will be able to keep that sheet as a reference throughout the session tonight.

Additionally, I would like to ask you to complete a quick survey, which first asks a couple of questions about you, including your work experience and the type of environment in which you work, such as a hospital, a private practice within the community, etc. This will, in part, be used in the case that we have more than 15 participants and need to split the group in two. I will try to separate people so that each group contains lactation consultants who have experience in various environments. There are also three questions asking you to jot down some initial ideas that you may have for scenarios that could be used. You can go into as much detail as you would like, or

keep it simple. For example: “baby is 8 days old and has not had at least 6 wet diapers in each of the past two days – baby may be dehydrated. Parent should bring baby to the ER.”. The scenarios are intended to paint a picture, for the parent, of what has been going on with their baby. The scenario should give the parent enough details to be able to decide if there may be a problem with their baby and say how they would react. It’s important to note that we are only considering the first month of life, of healthy babies, that are breastfed, either exclusively or not. This information is repeated on the survey. Before starting the focus group, we will take a 10 minute break, during which time everyone can help themselves to some refreshments, while Kathy, Barb, and I review the survey results. We will use the results to decide which health issues to use in tonight’s session.

The last thing I would like to mention is that if there is general interest in the research I am doing, I would be more than happy to come back and present my results after I’m done my thesis. We can co-ordinate this through Barb.

So before I hand out the consent forms and surveys, I know I covered a lot of information in the last few minutes – does anyone have any questions or want further clarification about anything?

- *Hand out consent forms, surveys, and information sheets.*
- *Remind participants to keep the information sheet.*
- *Keep the consent forms and surveys separate.*
- *As the surveys are collected, quickly review the scenarios that have been provided. Also divide them into two piles based on current practice environment.*

- *Once all consent forms and surveys are returned, if there are more than 15 participants, separate participants by calling out primary work environments that have been listed on each application, based on the two piles already created.*
- *Begin focus group(s).*

Appendix C: Focus Group Informed Consent Form



PARTICIPANT INFORMED CONSENT FORM

Title of Study: A Decision Support Tool for Problem Detection and Resolution in Healthy Newborns: An Exploratory Study to Understand Parental Acceptance and Perception of Usefulness

Principal Investigator (PI): Kathy Momtahan, 613-798-5555 x 79706

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this research study because your skills and experience as a lactation consultant can help provide valuable input in determining the feasibility of the mobile application being proposed.

Why is this study being done?

Since the 1980's, the length of stay in the hospital after a woman gives birth has declined in most developed countries. In Canada, for example, the average length of stay decreased from 4.7 days in 1980 to 1.7 days in 2011. At The Ottawa Hospital, usual care includes the discharge of healthy mother and baby pairs one day after a vaginal birth, reduced from two days in early 2014. Parents often leave the hospital tired and unprepared for the challenge of caring for their newborn. The short length of stay also may prevent proper assessment of breastfeeding techniques since full milk production does not usually occur in the first 24 to 48 hours after birth. As a result, breastfeeding failures may lead to problems such as dehydration, weight loss, and hyperbilirubinemia. To help mitigate risks associated with discharge and possible health issues of the baby, increased postpartum support has been advocated. This study will explore the feasibility of an application (app) to be used by parents in the first month after childbirth. By tracking information about their baby, such as number and times of feeds and dirty diapers, the app would detect possible problems and provide parents with feedback.

This portion of the study (the focus group) will specifically aim to create the decision support algorithm that would be used to provide that feedback. Additionally, a parent survey will be used to examine the effectiveness of such an app and its usefulness. A large portion of the survey questions will revolve around newborn baby scenarios and try to understand if the behaviour of parents changes when they have the support of the app. Furthermore, the survey will attempt to determine if parents would want to use the app and if they would trust it.

We estimate that 10-15 participants will be enrolled in the focus group portion of the study.

How is the study designed?

The research being done involves several steps. The portion in which you are being asked to participate is a focus group. The goal of the focus group is to generate three realistic scenarios that parents may face with their newborn in the first month of life. Before the focus group begins, you will be asked to complete a short survey that includes some information about yourself, as well as asks you to provide any initial ideas you have for the scenarios. If needed, these ideas will be used during the focus group to help initiate discussion and generate further ideas. The scenarios that are created will later be used in a survey that will be administered to parents to help answer the research questions being examined for this study. Specifically, the scenarios will be used to try to understand how parents would react if they are not using the app and if their reaction would change with the support of the app.

What is expected of me?

You will be asked to complete one anonymous survey. The survey is to help understand your experience as a lactation consultant as well as to generate ideas for the focus group. It will take approximately 5 minutes to complete. You may skip any questions that make you uncomfortable or that you do not wish to answer.

You will be asked to participate in one focus group. The focus group is to discuss common problematic scenarios parents encounter with newborns in the first month of life. The focus groups will be approximately 60 minutes long.

How long will I be involved in the study?

The entire study will last approximately 8 months. Your participation in the study will last approximately 1.5 hours.

What are the potential risks I may experience?

There are no anticipated risks. However, in the focus group portion, although the research team is committed to keeping everything you say anonymous, other focus group participants may not do this. You do not have to answer any questions that make you uncomfortable.

Can I expect to benefit from participating in this research study?

You may not receive any direct benefit from your participation in this study. Your participation may allow the researchers to create more realistic scenarios to be used in the parent survey. This may benefit future parents by providing them with better information and support.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate. You may decide not to be in this study, or change your mind during the focus group. Since the surveys are anonymous it is not possible to remove your responses after your survey has been submitted. Similarly, comments made during the focus group cannot be withdrawn.

Will I be paid for my participation or will there be any additional costs to me?

You will not be paid for participating. There will be no costs to you.

How is my personal information being protected?

- All information collected during your participation in this study will remain anonymous.
- For audit purposes only, all study records may be reviewed under the supervision of Dr. Kathy Momtahan from:
 - the Ottawa Health Science Network Research Ethics Board (OHSN-REB)
 - the Ottawa Hospital Research Institute
 - Carleton University Research Ethics Board
- Research records will be kept for 10 years, after this time they will be destroyed.

Who do I contact if I have any further questions?

If you have any questions about this study, please contact Dr. Kathy Momtahan (Co-supervisor, The Ottawa Hospital) at 613-798-5555 x 79706 or Dr. Anthony Whitehead (Co-supervisor, Carleton University) at 613-520-2600 x 1696 or Crystal Sirard (Student Researcher, Carleton University) at crystal.sirard@carleton.ca.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson at 613-798-5555, extension 16719.

The ethics protocol for this project was also reviewed by the Carleton University Research Ethics Board, which provided clearance to carry out the research. Should you have questions or concerns related to your involvement in this research, please contact:

Professor Andy Adler, Chair
Professor Louise Heslop, Vice-Chair
Research Ethics Board
Carleton University
1325 Dunton Tower
1125 Colonel By Drive
Ottawa, ON K1S 5B6
Tel: 613-520-2517
ethics@carleton.ca



A Decision Support Tool for Problem Detection and Resolution in Healthy Newborns: An Exploratory Study to Understand Parental Acceptance and Perception of Usefulness

Consent to Participate in Research

- I understand that I am being asked to participate in a research study about the feasibility of an app that would help parents detect problems in their newborn baby in the first month of life.
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- Since my personal information is not tied to my survey answers or focus group comments, I will not be able to withdraw from the study after submitting the survey or the completion of the focus group.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

Participant's Printed Name Participant's Signature Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name Investigator/Delegate's Signature Date

Appendix D: Pre-Focus Group Survey

Survey

Demographic Information

Age group: ____ 18-25 ____ 26-35 ____ 36-45 ____ 46-55 ____ 56-65 ____ 66+

Number of years as a lactation consultant (LC): _____

Current LC certification: ____ IBCLC ____ Other. Please specify

Current practice environment (e.g. hospital, a private practice within the community, etc.):

Previous practice environments:

Professional designation(s):

Scenarios

For these questions, please jot down any ideas that you may have that can be used to create problematic scenarios about a newborn baby. The information should include any important details that may help a parent to determine if there is a health problem with the baby. You can use point form and include as much or as little detail as you would like. Be sure to indicate the problem the baby has and, if possible, provide suggestions of how the parent could or should proceed.

E.g. “Baby is 8 days old and has not had at least 6 wet diapers in each of the past two days – baby may be dehydrated. Parent should bring baby to the ER.”

Each question will describe the type of scenario that we are trying to create.

Remember! For all scenarios the baby has already been discharged from the hospital and is less than one month old.

1. Scenario criteria:

- ✓ The baby’s problem should be listed on the information sheet
- ✓ It should be possible to diagnose the problem based solely on the information listed on the information sheet (although you may include other information in the scenario)
- ✓ The problem should be relatively common among newborns OR should be one that most parents would recognize as problematic (even if they don’t know what the problem is)

2. Scenario criteria:

- ✓ The baby's problem should be one of those listed on the information sheet
- ✓ It should be possible to diagnose the problem based solely on the information listed on the information sheet (although you may include other information in the scenario)
- ✓ The problem is not very common; maybe only showing up in about 10% of newborns
- ✓ The problem should be one that many parents may not realize is a problem

3. Scenario criteria:

- ✓ The baby's problem should NOT be listed on the information sheet
- ✓ It may NOT be possible to diagnose the problem based solely on the information listed on the information sheet (you may include *any* information in the scenario)
- ✓ The scenario should create some doubt for parents, but the problem should not be completely obvious to most parents

Appendix E: Focus Group Information Sheet

Information Sheet

****Please retain this sheet as a reference during the focus group****

Below is the information that parents are expected to enter into the app. It will be used by the app to help diagnose potential health problems in a baby.

- Birth date
- Time of feed
- Parent perception of feed. E.g. baby fed well, unsure, “baby did not feed well – refused to feed”, “baby did not feed well – coughing/choking”, “baby did not feed well – fell asleep”, “baby did not feed well – no audible swallowing”, “baby did not feed well – fussy/inconsolable, “baby did not feed well – other”
- Start / stop time of sleep
- Number of wet diapers
- Number of dirty diapers
- Amount of expressed breast milk baby drank
- Time expressed breast milk was drank
- Amount of formula baby drank
- Time formula was drank
- Description of stools: black (meconium), dark green, green, brown, yellow, curdy, hard, watery, explosive, contains mucus, contains blood
- Description of urine: normal, uric acid crystals, strong odour, dark colour, contains blood
- Temperature
- How the temperature was taken: armpit, buttocks
- Skin colour: pink, pale, jaundiced (yellow), bluish (around mouth and nose), grey
- Skin condition: clear, rash, dry, petechiae, bruising
- Umbilical cord condition: drying/no smell, reddened, smelly, foul discharge, bleeding
- Activity: Normal (alert/content), lethargic (sleepy), fussy, jittery, irritable, excessive crying, difficult to wake for feeding
- Birth weight
- Current weight / date weighed
- Vomited/forcefully expelled fluids: yes/no
- Spits up often: yes/no
- Excessive gas: yes, no, not sure
- Skin turgor: poor, good, not sure (would be accompanied with a description and picture)
- Rash: red, raised, itchy, bleeding, cracked, covered with a yellow crust
- Crying behaviour: normal, sounds painful, high-pitched, lasts 3 hours or more per day
- White of eyes are yellow tinged: yes/no

Below are the problems that can be diagnosed by the app, based solely on the information listed above.

- Sepsis
- Diarrhea
- Constipation
- Dehydration
- Jaundice
- GERD / Acid reflux
- General cardiac problem
- Brain damage
- Gastrointestinal problem
- Urinary tract infection
- Umbilical cord infection
- Rash
- Fever
- General weight concerns (e.g. baby has lost too much weight or is not regaining weight appropriately)
- General feeding issues (e.g. baby is not feeding often enough, is sleeping too much, does not have enough wet diapers, or does not have enough dirty diapers)

Appendix F: Focus Group Protocol

Note: Text in italics is not to be spoken, but is intended as instructions for the moderator.

So thanks to all those who chose to stay and participate. Let's get started with the first scenario.

For this scenario, the problem should be detectable by the app – you can use the information sheet as a reference. We want a problem that is relatively common among newborns or that, at least, most parents would recognize as being problematic. Based on the survey results, we have decided to use *<problem>* as the health issue for this scenario. Now we need to build a story around this problem. A good place to start is with the age and symptoms that the baby is experiencing... So does anyone have any suggestions?

- *Work with the group to build a complete story for the chosen scenario. Include:*
 - *Age of baby*
 - *Symptoms*
 - *How many days symptoms have been present*
 - *After scenario has been roughly developed, ask LCs how common the problem is and how serious it is at the stage of detection and how serious it could get if left unattended.*
 - *Ask if there are any suggestions for how the parent could or should deal with the problem*

Excellent, so we are done with the first scenario. Let's move on to the next. Again, we want to generate a scenario that is detectable by the app. This time, however, it should be something that is less common. Not extremely rare, just less common. Let's say, something that may only show up in about 10% of newborns. Ideally, it should be something where parents may not realize

there is a problem, based on the scenario that we will create. Again, based on the survey results, we decided that the problem we are going to work with for this scenario is *<problem>*. So let's start filling in the details. Does anyone have any questions before we start?

Answer any questions.

Okay, so to start, what are some of the symptoms that the baby might have?

Repeat the steps from the first scenario.

Great! Two down, one scenario left to go. This scenario differs from the first two in that it is something that is not detectable by the app, for whatever reason, including that the app simply does not have enough information. For example, maybe to detect the problem, the app would need to know that the baby is breathing quickly, has a swollen belly, or experienced some kind of trauma at birth – all things that are not being entered into the app and therefore are not available to the decision support tool. Ideally, the symptoms that are not detectable by the app are not too obvious to the parent either, making it somewhat difficult for the parent to realize that there may be a problem. In other words, given the scenario, although we can create doubt in the parent, we don't want to make it completely obvious that there is a problem that needs to be addressed. The purpose of this scenario is to see if the parent will trust that their baby is fine, since the app will not alert them of a problem. Once again, based on the survey results, we have chosen to work with *<problem>* as the health issue the baby is experiencing.

Does anyone have any questions before we start?

Answer any questions.

Okay, does anyone have any suggestions that we can start with?

Repeat the steps from the first scenario.

Excellent!! We are now done!

Once again, I would like to thank everyone for their help this evening. I think the session went really well and am confident that these scenarios will help to create a great survey to explore the feasibility of creating a decision support tool for the detection of health problems in newborns.

Like I said earlier, if there is general interest in the project and learning the results, please talk to Barb and we will make sure to set up a time for me to come back.

Thanks everyone and have a good night!

Appendix G: Scenarios Generated from the Focus Group

Scenario 1

After two days in the hospital, mom and dad were able to bring their sweet little baby boy home. They've been home for two days now and have hardly started to adjust to this new life. Everything is so new and the learning is endless. Mom and dad find it quieter than they expected though since their new little one hardly ever cries. Just like they did in the hospital, they have been tracking baby's pees and poops since they got home. There hasn't been much to track though since he hasn't pooped since being in the hospital; dad remembers that poop - it was still black. Baby has been peeing, but only 3 times yesterday and 3 times today. The new parents noticed that baby's skin and the whites of his eyes are a bit yellow. He is sleeping a lot, even had one stretch of five hours today; it was a good break for mom and dad. Baby's sleepiness makes breastfeeding a bit difficult however, since he keeps falling asleep at the breast. He does usually feed every 3 hours though, while mom watches him closely, but she has a hard time hearing any swallowing. She remembers the videos from her prenatal class that showed that the baby's chin needs to go up and down with pauses in between, but she is having a hard time telling if this is happening. Mom's breasts feel hard, swollen, and somewhat painful - is this what it feels like when your milk "comes in"? A lot has been happening since the little one was born, hopefully tomorrow's visit check-up with the doctor will go well...

Scenario 2

It's been 3 weeks since mom and dad have brought their new little girl home from the hospital. Although she's cute as a button, her mood over the past week or so isn't quite what the new parents had hoped for. Baby has been fussy and inconsolable and mom and dad are questioning

everything they do. She's just so irritable and cranky all the time, especially after feeds. Whether she's feeding or not, she often seems to be choking or swallowing and it seems like she is spitting up all the time – much more than they remember with their first child. As unhappy as baby seems to be though, she's still thriving. She just had a growth spurt, during which she fed constantly! And since then, she's continued to feed quite well – about 7 times per day. Baby is also keeping mom and dad busy with diaper duty – changing about 7 yellow, curdy poops every day, not to mention the wet diapers in between. The poor little girl's diaper rash doesn't have much time to air out with all of these dirty diapers. Besides feeding so often, which is actually starting to take a toll on mom's sore nipples, mom can tell she has a lot of milk, so she's not too worried that baby isn't eating enough. She supposes that she might just be a needy baby, demanding constant attention. After all, when she's being held, she seems a bit better, as long as it's in an upright position since she's never happy lying down, even in mom or dad's secure arms.

Scenario 3

It's been exactly 2 weeks since baby was born and as much as mom wants to breastfeed and knows the importance, she is finding it so hard and getting discouraged. She heard stories of it being painful, but just thought those other moms were doing it wrong. But now that it's her turn, this mom is finding out what breastfeeding can do to her nipples, which are getting sorer and sorer and have even started to bleed in the last couple of days since the skin has become so raw. Feedings feel like they last forever but are often cut short by mom because it just hurts too much, especially when it feels like baby is biting. She's tried different positions, but it hasn't helped. Dad thought maybe it would help if baby practiced sucking on a pacifier, but baby doesn't seem to be able to maintain suction on it. Still, even though mom is not enjoying the breast feeding

experience, as she hoped she would, she does seem to have a lot of milk and baby is gaining weight and has even re-achieved his birth weight. Mom's only concern right now is baby's stool from this morning - dad noticed that it was darker than usual and even saw some blood in it.

Appendix H: Parent Survey

Note: the survey 'look and feel' was different when implemented using the "Hosted in Canada Surveys" online tool. Furthermore, the online survey was set-up so that participants could not go backwards in the survey. Each survey page is separated by the text <<NEXT PAGE>> in this document.

Overview

Title: A Decision Support Tool for Problem Detection and Resolution in Healthy Newborns: An Exploratory Study to Understand Parental Acceptance and Perception of Usefulness

Researchers:

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Purpose: Coming home from the hospital with a newborn baby can often be a challenge for parents. This perfect little baby depends solely on you to take good care of him. But sometimes parents are not aware of what to watch for in their newborn babies. Even if they do, they may simply feel tired or overwhelmed and not notice possible signs of health issues.

Many apps exist today that help track details about babies, such as when they have been fed, when they have a wet or dirty diaper, and when the baby is sleeping. Although these apps help parents keep track of such things, at this time there are no apps that will use the data to detect

and alert parents of possible health problems with their baby. This research will try to find out if an app that provides this kind of feedback to parents is feasible.

For the purpose of this research, the information used to create the set of rules to detect problems was obtained from online and public health sources such as the “*Postnatal Assessment Guidelines*” used for Ottawa’s “*Healthy Babies, Healthy Children*” program. In addition, the set of rules was reviewed by a registered nurse who is also a lactation consultant.

Your participation in this survey will help answer questions about whether such an app could be useful to parents, whether they would actually use it, and to what extent.

Survey duration: The survey is designed to take around 30 minutes. After completing the survey, your participation in the study is complete.

Benefits: There are no anticipated benefits to participating in this study.

Risks: There are no anticipated risks to participating in this study.

Compensation: No compensation is being offered for taking part in this study.

Voluntary Participation and Withdrawal:

- Participation in this research study is completely voluntary. You may choose not to participate or to participate and then change your mind.
- You have the right to withdraw at anytime by not submitting the survey.
- The survey is anonymous so there is no link between you and the survey.

- Since the survey is anonymous, if you choose to submit the survey upon completion, your responses cannot be withdrawn.

Confidentiality:

- You will not be identifiable in any publications or presentations resulting from this study.
- All study data will be securely kept at The Ottawa Hospital for 10 years and then destroyed.
- The study data will be accessible to all of the researchers listed above as well as the Ottawa Health Science Network Research Ethics Board, the Ottawa Hospital Research Institute, and the Carleton University Research Ethics Board.

Questions:

If you have any questions about this study, please contact Kathy Momtahan at 613-798-5555 x 79706 or the study staff at 613-482-1089.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson at 613-798-5555, extension 16719.

Consent:

Submission of the completed survey implies your consent to participate in this research study.

Now, let's get started!

<<NEXT PAGE>>

Instructions

This survey consists of four major sections, as described below. Further instructions will be given at the beginning of each section, as needed.

You will not be able to go backwards in the survey and cannot change your answers after you go to the next page.

As a reminder, the application ("app") is intended to detect and alert parents of possible health problems in newborn babies, based on information the parent(s) enter into the app.

Part I: A Bit about You

These are just a few questions to help us understand about you.

Part II: Using the App

This section will ask questions about what information you would be willing to enter into the app.

Part III: Scenarios

Made-up scenarios about a pretend newborn baby will be provided. Based on each scenario, you will be asked to answer some questions. Basic information about newborn babies will also be provided. You can use this information to help answer the questions, but please do not use any other sources such as the internet, books, friends/family, etc. The questions are not intended to test your knowledge and you are not expected to know everything about newborns. On the next page of the survey, the same scenario and questions will be repeated. However, on this page, additional information may be given. This is the information that the app would provide to parents if a potential health problem was detected.

Note that the information provided in this survey has not been verified by a physician and may not be completely accurate at this stage of the research. The information should not be used to make decisions about infant care.

Three scenarios will be covered in this survey.

Part IV: General Feedback

This section will ask general questions about your opinions on the proposed app.

<<NEXT PAGE>>

Part I: A Bit about You

28. What is your sex?
- Female
 - Male
29. Please indicate your age group:
- 18-30
 - 31-45
 - 46-65
 - 66+
30. What are the ages of your children?
31. Do you live in an urban/suburban or rural environment?
- Urban / suburban
 - Rural
32. What is the highest degree or level of school you have completed?
- Less than high school
 - High school
 - College
 - Bachelor's/Undergraduate degree
 - Master's/Graduate degree
 - Doctorate

Other, please specify: _____

Prefer not to answer

33. On a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree', rate the following statement.

I am comfortable using computers.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strong agree

34. Check all the types of devices that you own or use regularly:

Desktop PC

Laptop

Tablet

Smart phone

<<NEXT PAGE>>

Part II: Using the App

For each piece of information listed below, please indicate on what basis you would be willing to enter it into the app (i.e. never, sometimes, always). Choosing the option 'sometimes' indicates you are willing to enter the data if:

1. You happen to have it, such as the baby's current weight OR
2. You felt it was abnormal (e.g. there is blood in the baby's urine, baby is crying excessively, etc.) OR

3. The app explicitly asks for it. This would only happen if a possible problem is detected, but more information was needed.

Note that the app would be designed to make it as easy as possible to input different types of information, in many cases providing the ability to simply select one or more options from a list.

All data would be securely stored on the device that is running the app and not shared with anyone.

	I would be willing to enter this information		
	Never	Sometimes	Always
35. Baby's birth date			
36. Baby's birth weight			
37. Current weight and date weighed (date would be automatically set to the day the weight is being entered in the app, but it can be changed)			
38. Time of breastfeeding			
39. Parent perception of feed. Options: baby fed well, unsure, baby did not feed well – coughing/choking, baby did not feed well – fell asleep, baby did not feed well – refused to feed, baby did not feed well – no audible swallowing, baby did not feed well – fussy/inconsolable, baby did not feed well - other			
40. Amount of expressed breast milk that baby drank (Expressed breast milk is milk that is extracted from the breast either manually or with a pump.)			
41. Time that baby drank expressed breast milk			
42. Amount of formula that baby drank			
43. Time that baby drank formula			
44. Start and end of sleep			
45. Baby had a wet diaper			

46. Description of urine. Options: normal, contains pink crystals, strong odour, dark colour, contains blood (pictures may be provided)			
47. Baby had a dirty diaper			
48. Description of poop. Options: black, dark green, green, brown, yellow, curdy, hard, explosive, watery, contains mucous, contains blood (pictures may be provided)			
49. Baby's temperature			
50. How the temperature was taken. Options: armpit, ear, buttocks.			
51. Skin colour. Options: pink, pale, yellow, bluish (around mouth and nose), grey			
52. Skin condition. Options: clear, rash, dry, red spots, bruising. (pictures may be provided)			
53. Description of rash. Options: raised, red, itchy, bleeding, cracked, covered with a yellow crust (Note that 'Description of rash' would only be available if 'rash' is selected as a skin condition).			
54. Umbilical cord condition. Options: drying/no smell, red, smelly, foul discharge, bleeding			
55. Activity. Options: normal (alert/content), sleepy, fussy, shaky, irritable, excessive crying, difficult to wake for feedings			
56. Vomited / forcefully expelled fluids. Options: Yes, No			
57. Spits up often (not only during or after feedings, but anytime). Options: Yes, No			
58. Excessive gas. Options: Yes, no, not sure			
59. Skin elasticity. Options: Good, poor, not sure. (A picture would be provided as well as a description such as: Skin elasticity is poor if the skin on top of the baby's hand remains raised after being pinched and released.)			
60. Crying behaviour. Options: normal, sounds painful, high-pitched, lasts 3 hours or more per day			
61. Whites of eyes are yellow. Options: Yes, no			

62. Do you have specific concerns or is there a specific reason why you would not enter certain information? If so, please specify.
63. Check all pieces of information that you find confusing or for which you do not feel you would be able to provide accurately. Include any comments you may have for each piece of data.

Baby's birth date

Baby's birth weight

Current weight and date weighed (date would be automatically set to the day the weight is being entered in the app, but it can be changed)

Time of breastfeeding _____

Parent perception of feed. Options: baby fed well, unsure, baby did not feed well – coughing/choking, baby did not feed well – fell asleep, baby did not feed well – refused to feed, baby did not feed well – no audible swallowing, baby did not feed well – fussy/inconsolable, baby did not feed well - other

Amount of expressed breast milk that baby drank (Expressed breast milk is milk that is extracted from the breast either manually or with a pump.)

Time that baby drank expressed breast milk

Amount of formula that baby drank

Time that baby drank formula

Start and end of sleep _____

Baby had a wet diaper

Description of urine. Options: normal, contains pink crystals, strong odour, dark colour, contains blood (pictures may be provided)

Baby had a dirty diaper

Description of poop. Options: black, dark green, green, brown, yellow, , curdy, hard, explosive, watery, contains mucous, contains blood (pictures may be provided)

Baby's temperature

How the temperature was taken. Options: armpit, ear, buttocks

Skin colour. Options: pink, pale, yellow, bluish (around mouth and nose), grey

Skin condition. Options: clear, rash, dry, red spots, bruising. (pictures may be provided)

Description of rash. Options: raised, red, itchy, bleeding, cracked, covered with a yellow crust (Note that 'Description of rash' would only be available if 'rash' is selected as a skin condition).

Umbilical cord condition. Options: drying/no smell, red, smelly, foul discharge, bleeding

Activity. Options: normal (alert/content), sleepy, fussy, shaky, irritable, excessive crying, difficult to wake for feedings

Vomited / forcefully expelled fluids. Options: Yes, No

Spits up often (not only during or after feedings, but anytime). Options: Yes, No

Excessive gas. Options: Yes, no, not sure

Skin elasticity. Options: Good, poor, not sure. (A picture would be provided as well as a description such as: Skin elasticity is poor if the skin on top of the baby's hand remains raised after being pinched and released.)

Crying behaviour. Options: normal, sounds painful, high-pitched, lasts 3 hours or more per day

Whites of eyes are yellow. Options: Yes, no

64. Do you have any additional comments or concerns about inputting any of the above information into the app?

<<NEXT PAGE>>

Part III: Scenario 1

Instructions

Read the scenario below and answer the questions based on the scenario. You can use the reference information provided below, but do not use any other sources such as the internet, books, friends/family, etc.

Reference Information: Expected Outcomes

Baby's Age	Wet Diapers / Day	Stools / Day
< 1 day	0-1	0-1

< 2 days	1+	1-2
<3 days	2-3+	2+
3-5 days	4-5	3+
6+ days	5-6+	3-4+

Scenario

After two days in the hospital, mom and dad were able to bring their sweet little baby boy home. They've been home for two days now and have hardly started to adjust to this new life. Everything is so new and the learning is endless. Mom and dad find it quieter than expected though since their new little one hardly ever cries. Just like they did in the hospital, they have been tracking baby's pees and poops since they got home. There hasn't been much to track though since he hasn't pooped since being in the hospital; dad remembers that poop - it was still black. Baby has been peeing, but only 3 times yesterday and 3 times today. The new parents noticed that baby's skin and the whites of his eyes are a bit yellow. He is hard to wake and is sleeping a lot, even had one stretch of five hours today; it was a good break for mom and dad. Baby's sleepiness makes breastfeeding a bit difficult however, since he keeps falling asleep at the breast. He does usually feed every three hours though, while mom watches him closely, but she has a hard time hearing any swallowing. She remembers the video from her prenatal class that showed the baby's chin needs to go up and down with pauses in between, but she is having a hard time telling if this is happening. Mom's breasts feel hard, swollen, and somewhat painful - is this what it feels like when your milk "comes in"? A lot has been happening since the little one was born, hopefully tomorrow's check-up with the doctor will go well.

Questions

Answer the questions based on the above scenario.

The first two questions are based on a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree'

65. I am concerned about the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

66. I believe there is a problem with the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

67. Are there any particular steps that you would take to provide care for the baby? If so, please explain what you would do.

<<NEXT PAGE>>

Part III: Scenario 1 (Continued)

Instructions

The scenario from the last page is repeated below. Once again, answer the questions based on this scenario, but this time in addition to the reference information, you can also use the feedback provided by the app. Remember not to reference any other sources such as the internet, books, friends/family, etc.

Reference Information: Expected Outcomes

Baby's Age	Wet Diapers / Day	Stools / Day
< 1 day	0-1	0-1
< 2 days	1+	1-2
<3 days	2-3+	2+
3-5 days	4-5	3+

6+ days	5-6+	3-4+
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Scenario

After two days in the hospital, mom and dad were able to bring their sweet little baby boy home. They've been home for two days now and have hardly started to adjust to this new life. Everything is so new and the learning is endless. Mom and dad find it quieter than expected though since their new little one hardly ever cries. Just like they did in the hospital, they have been tracking baby's pees and poops since they got home. There hasn't been much to track though since he hasn't pooped since being in the hospital; dad remembers that poop - it was still black. Baby has been peeing, but only 3 times yesterday and 3 times today. The new parents noticed that baby's skin and the whites of his eyes are a bit yellow. He is hard to wake and is sleeping a lot, even had one stretch of five hours today; it was a good break for mom and dad. Baby's sleepiness makes breastfeeding a bit difficult however, since he keeps falling asleep at the breast. He does usually feed every three hours though, while mom watches him closely, but she has a hard time hearing any swallowing. She remembers the video from her prenatal class that showed the baby's chin needs to go up and down with pauses in between, but she is having a hard time telling if this is happening. Mom's breasts feel hard, swollen, and somewhat painful - is this what it feels like when your milk "comes in"? A lot has been happening since the little one was born, hopefully tomorrow's check-up with the doctor will go well.

App Feedback

The following alert would be provided by the app:

Alert! Call Telehealth for immediate assessment.

This recommendation is based on the following symptoms:

- Yellow skin
- Yellow whites of eyes
- Baby did not feed well for the following reason(s): fell asleep, no audible swallowing
- Less wet diapers than expected at 4 days old
- Less dirty diapers than expected at 3 and 4 days old
- Baby is sleepy
- Baby is difficult to wake

Questions

Answer the questions based on the scenario above as well as any feedback provided by the app.

The first two questions are based on a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree'

68. I am concerned about the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

69. I believe there is a problem with the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

70. Are there any particular steps that you would take to provide care for the baby? If so, please explain what you would do.

<<NEXT PAGE>>

Part III: Scenario 2

Instructions

Read the scenario below and answer the questions based on the scenario. You can use the reference information provided below, but do not use any other sources such as the internet, books, friends/family, etc.

Reference Information: Expected Outcomes

Baby's Age	Wet Diapers / Day	Stools / Day
< 1 day	0-1	0-1
< 2 days	1+	1-2
<3 days	2-3+	2+
3-5 days	4-5	3+
6+ days	5-6+	3-4+

Scenario

It's been 3 weeks since mom and dad have brought their new little girl home from the hospital. Although she's cute as a button, her mood over the past week or so isn't quite what the new parents had hoped for. Baby has been fussy and inconsolable and mom and dad are questioning everything they do. She's just so irritable and cranky all the time, especially after feeds. Whether she's feeding or not, she often seems to be choking or swallowing and it seems like she is spitting up all the time – much more than they remember with their first child. As unhappy as baby seems to be though, she's still thriving. She just had a growth spurt, during which she fed constantly! And since then, she's continued to feed regularly – about 7 times per day, but is often choking during feeds. Baby is also keeping mom and dad busy with diaper duty

– changing about 7 yellow, curdy poops every day, not to mention the wet diapers in between.

The poor little girl's diaper rash doesn't have much time to air out with all of these dirty diapers. Besides feeding so often, which is actually starting to take a toll on mom's sore nipples, mom can tell she has a lot of milk, so she's not too worried that baby isn't eating enough. She supposes that she might just be a needy baby, demanding constant attention. After all, when she's being held, she seems a bit better, as long as it's in an upright position since she's never happy lying down, even in mom or dad's secure arms.

Questions

Answer the following questions based on the scenario above.

The first two questions are based on a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree'

71. I am concerned about the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

72. I believe there is a problem with the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

73. Are there any particular steps that you would take to provide care for the baby? If so, please explain what you would do.

<<NEXT PAGE>>

Part III: Scenario 2 (Continued)

Instructions

The scenario from the last page is repeated below. Once again, answer the questions based on this scenario, but this time in addition to the reference information, you can also use the feedback provided by the app. Remember not to reference any other sources such as the internet, books, friends/family, etc.

Reference Information: Expected Outcomes

Baby's Age	Wet Diapers / Day	Stools / Day
< 1 day	0-1	0-1
< 2 days	1+	1-2
<3 days	2-3+	2+
3-5 days	4-5	3+
6+ days	5-6+	3-4+

Scenario

It's been 3 weeks since mom and dad have brought their new little girl home from the hospital. Although she's cute as a button, her mood over the past week or so isn't quite what the new parents had hoped for. Baby has been fussy and inconsolable and mom and dad are questioning everything they do. She's just so irritable and cranky all the time, especially after feeds. Whether she's feeding or not, she often seems to be choking or swallowing and it seems like she is spitting up all the time – much more than they remember with their first child. As unhappy as baby seems to be though, she's still thriving. She just had a growth spurt, during which she fed constantly! And since then, she's continued to feed regularly – about 7 times per

day, but is often choking during feeds. Baby is also keeping mom and dad busy with diaper duty – changing about 7 yellow, curdy poops every day, not to mention the wet diapers in between. The poor little girl’s diaper rash doesn’t have much time to air out with all of these dirty diapers. Besides feeding so often, which is actually starting to take a toll on mom’s sore nipples, mom can tell she has a lot of milk, so she’s not too worried that baby isn’t eating enough. She supposes that she might just be a needy baby, demanding constant attention. After all, when she’s being held, she seems a bit better, as long as it’s in an upright position since she’s never happy lying down, even in mom or dad’s secure arms.

App Feedback

Alert! Call your primary care provider or Telehealth for assessment.

This recommendation is based on the following symptoms:

- Baby is spitting up often
- Baby is fussy
- Baby is irritable

Other symptoms of concern include:

- Baby not feeding well for the following reason(s): coughing/choking

Questions

Answer the following questions based on the scenario above as well as any feedback provided by the app.

The first two questions are based on a scale from 1 to 10, where 1 is ‘Strongly disagree’ and 10 is ‘Strongly agree’

74. I am concerned about the baby’s health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

75. I believe there is a problem with the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

76. Are there any particular steps that you would take to provide care for the baby? If so, please explain what you would do.

<<NEXT PAGE>>

Part III: Scenario 3

Instructions

Read the scenario below and answer the questions based on the scenario. You can use the reference information provided below, but do not use any other sources such as the internet, books, friends/family, etc.

Reference Information: Expected Outcomes

Baby's Age	Wet Diapers / Day	Stools / Day
< 1 day	0-1	0-1
< 2 days	1+	1-2
<3 days	2-3+	2+
3-5 days	4-5	3+
6+ days	5-6+	3-4+

Scenario

It's been exactly 2 weeks since baby was born and as much as mom wants to breastfeed and knows the importance, she is finding it so hard and getting discouraged. She heard stories of it being painful, but just thought those other moms were doing it wrong. But now that it's her

turn, this mom is finding out what breastfeeding can do to her nipples, which are getting sorer and sorer and have even started to bleed in the last couple of days since the skin has become so raw. Feedings feel like they last forever but are often cut short by mom because it just hurts too much, especially when it feels like baby is biting. She's tried different positions, but it hasn't helped. Dad thought maybe it would help if baby practiced sucking on a pacifier, but baby doesn't seem to be able to maintain suction on it. Baby's trouble maintaining a good latch, especially on mom's breast, may be why his weight was about the same this morning, when mom weighed him at a drop-in lactation clinic, as it was when he was weighed a week ago at the doctor's office. At that time, he had already re-achieved his birth weight so the parents weren't worried. But with another week having past, it seems like he should weigh more than he does.

Questions

Answer the following questions based on the scenario above.

The first two questions are based on a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree'

77. I am concerned about the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

78. I believe there is a problem with the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

79. Are there any particular steps that you would take to provide care for the baby? If so, please explain what you would do.

<<NEXT PAGE>>

Part III: Scenario 3 (Continued)**Instructions**

The scenario from the last page is repeated below. Once again, answer the questions based on this scenario, but this time in addition to the reference information, you can also use the feedback provided by the app. Remember not to reference any other sources such as the internet, books, friends/family, etc.

Reference Information: Expected Outcomes

Baby's Age	Wet Diapers / Day	Stools / Day
< 1 day	0-1	0-1
< 2 days	1+	1-2
<3 days	2-3+	2+
3-5 days	4-5	3+
6+ days	5-6+	3-4+

Scenario

It's been exactly 2 weeks since baby was born and as much as mom wants to breastfeed and knows the importance, she is finding it so hard and getting discouraged. She heard stories of it being painful, but just thought those other moms were doing it wrong. But now that it's her turn, this mom is finding out what breastfeeding can do to her nipples, which are getting sorer and sorer and have even started to bleed in the last couple of days since the skin has become so raw. Feedings feel like they last forever but are often cut short by mom because it just hurts

too much, especially when it feels like baby is biting. She's tried different positions, but it hasn't helped. Dad thought maybe it would help if baby practiced sucking on a pacifier, but baby doesn't seem to be able to maintain suction on it. Baby's trouble maintaining a good latch, especially on mom's breast, may be why his weight was about the same this morning, when mom weighed him at a drop-in lactation clinic, as it was when he was weighed a week ago at the doctor's office. At that time, he had already re-achieved his birth weight so the parents weren't worried. But with another week having past, it seems like he should weigh more than he does.

App Feedback

Based on the information available to the app, no feedback is available.

Questions

Answer the following questions based on the scenario above as well as any feedback provided by the app.

The first two questions are based on a scale from 1 to 10, where 1 is 'Strongly disagree' and 10 is 'Strongly agree'

80. I am concerned about the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

81. I believe there is a problem with the baby's health.

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

82. Are there any particular steps that you would take to provide care for the baby? If so, please explain what you would do.

83. Do you find it confusing that no problems were detected by the app? If so, please specify.

<<NEXT PAGE>>

Part IV: General Feedback

For each of the following statements, provide your level of agreement on a 10 point scale, where 1 is 'Strongly disagree' and 10 is 'Strongly agree'. If you are unsure or have no opinion, select the "No answer" option.

84. I think this app accurately detects problems with my baby

Strong disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree ___No
answer

85. I trust this app and the feedback that it provides

Strong disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree ___No
answer

86. In general, I would rely less on other sources to determine if there may be a problem with my baby

Strong disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree ___No
answer

87. I think the information sources, on which this tool was built, are reliable

Strong disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree ___No
answer

88. I would want to use an app like this and/or I would recommend it to a friend.

Strong disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree ___No
answer

89. Is there anything that would increase your trust in the app?

90. Do you have any additional comments about the app?

[Submit button]

<<NEXT PAGE>>

Thank you for completing the survey!
Your time is greatly appreciated.

Reminder! The information contained in this survey has not been verified by a physician and may not be completely accurate. It should not be used to make decisions about infant care.

Appendix I: Pilot Survey Recruitment E-mail

Hi,

As many of you know, I am currently working on my master's in Human-Computer Interaction at Carleton University. For my thesis, I am exploring the feasibility of a proposed application (app) that would help parents detect possible health problems in their newborn baby in the first month of life. At this stage of my research, I need feedback about an online survey that is intended to help me understand if parents would trust the app and if they would use it. To be eligible to participate in this pilot survey you must be fluent in English and be a parent.

This study has been cleared by both the Carleton University Research Ethics Board as well as the Ottawa Health Science Network Research Ethics Board (OHSN-REB). Should you have questions or concerns related to your involvement in this research, please contact either the Chairperson of the OHSN-REB at 613-798-5555, extension 16719 or:

Professor Andy Adler, Chair
Research Ethics Board
Carleton University
Tel: 613-520-2517
ethics@carleton.ca

If you are eligible and have about 30 minutes to spare, I would really appreciate your help.

Please follow the link below, which provides many more details and allows you to participate if you choose to do so. Keep in mind that your participation is completely anonymous, so I will not know if you participate or not.

<http://hci.hostedincanadasurveys.ca/index.php/767711/lang-en>

Both you and your partner are eligible to participate, but should do so independently.

Let me know if you have any questions.

Thanks for your time and help!

Crystal

Appendix K: Parent Survey Recruitment E-mail

Hi,

As many of you know, I am currently working on my master's in Human-Computer Interaction at Carleton University. For my thesis, I am exploring the feasibility of a proposed application (app) that would help parents detect health problems in their newborn baby in the first month of life. For this work, I need some people to complete an online survey to help me understand if parents would trust the app and if they want to use it.

To be eligible to participate you must be a mom or dad of at least one child under the age of 5 years, that was born at full term (above 37 weeks), healthy at birth, and breastfed (exclusively or not) in the first month of life.

This study has been cleared by both the Carleton University Research Ethics Board as well as the Ottawa Health Science Network Research Ethics Board (OHSN-REB). Should you have questions or concerns related to your involvement in this research, please contact either the Chairperson of the OHSN-REB at 613-798-5555, extension 16719 or:

Professor Andy Adler, Chair
Research Ethics Board
Carleton University
Tel: 613-520-2517
ethics@carleton.ca

If you are eligible and have about 30 minutes to spare, I would really appreciate your help.

Please follow the link below, which provides many more details and allows you to participate if you choose to do so. Keep in mind that your participation is completely anonymous, so I will not know if you participate or not.

<http://tinyurl.com/babyAppSurvey>

Both you and your partner are eligible to participate, but should do so independently.

Let me know if you have any questions.

Thanks for your time and help!

Crystal

Appendix L: Pilot Survey Results Analysis

Note: P1, P2, P3, and P4 refer to each participant.

What the Question is Referring to	Question	Answers	Recommendations
Instructions section	1. Do you find the description for any section confusing? If so, please specify. How could it be improved?	P1: no P2: The description was very straight forward and easy to understand. P3: yes P4: No, looks clear to me	P3 said ‘yes’ however did not provide any further comment. P3 likely misread the question. No other participants had any concerns. No changes are recommended.
Instructions section	2. Do you find the descriptions for each section helpful? If not, please specify.	P1: yes P2: The descriptions were very helpful. P3: yes P4: Yes, looks fine	None
Instructions section	3. Do the descriptions for each section help you to understand how the survey is structured? If not, how could they be improved?	P1: yes P2: The descriptions are easily understood. P3: yes P4: Yes, good overview of sections	None
Demographics questions (Q1-Q7)	4. Do you find the wording or terms used in any of the above questions confusing? Please specify. If possible, please provide suggestions to help clarify the question.	P1: no although undergraduate degree is also known as bachelor degree P2: No P3: no, all is clear.	Suggest updating the option ‘Undergraduate degree’ to say ‘Undergraduate/bachelor degree’. Suggest updating the option ‘Urban’ to ‘Urban / suburban’.

		<p>P4: I think "suburban" should be listed as a section, or at least included in "urban" explicitly</p>	<p>Rationale: The point of the question is to get an idea if participants are close to a hospital, as this may affect how they react to the scenarios. I think it is safe to group people living in urban and suburban areas together, since people living in suburban areas are likely to be much closer to a hospital than those living in rural areas.</p>
<p>Instructions for the first section in ‘Part II: Using the App’ (i.e. “For each piece of information listed below, please indicate on what basis you would be willing to...)</p>	<p>5. Do you find the above instructions clear? Please specify. If possible, please provide suggestions to help clarify the instructions.</p>	<p>P1: yes, it is clear. P2: Yes P3: the instructions are clear. P4: yes, clear</p>	<p>None.</p>
<p>The table containing all data elements that we would like parents to enter in the app</p>	<p>6. Are there any data elements listed in the table that you find confusing? If so, please specify.</p>	<p>P1: no. P2: I have never heard of skin turgor. P3: what does "expressed breast milk" mean? and "turgor"? Are they medical terms? perhaps use a more common noun. P4: no, as long as descriptions remain (e.g. description of what skin turgor is)</p>	<p>Change ‘Skin turgor’ to ‘Skin elasticity’. Participants will still need the description to know how to measure it, but at least they will not hiccup on the word ‘turgor’.</p> <p>Most participants will likely understand the term “expressed breast milk”, but still, we could add a description in brackets. Suggest “Expressed breast milk is milk that is extracted from the</p>

<p>The question and options that asks parents how often they would be willing to enter each piece of data into the app</p>	<p>7. Overall, do you find the rating question and the options (never, sometimes, always) clear? Please specify.</p>	<p>P1: yes, it is clearly stated, simple terms, examples and options are provided. P2: yes, but might help to know why someone answered that way... for example, I would never enter birthdate and other identifying data about my baby unless I was 100% trusting of the security of my data through this app P3: yes. I assume some categories will be broken down as some had long descriptions. P4: Sometimes was an indication to me to record when there is a discrepancy.</p>	<p>breast either manually or with a pump.”</p> <p>With respect to security, another participant also commented on whether identifying information (i.e. birth date) would be secure (see Q35 in the ‘Other’ section at the end of this table). Suggest adding the following to the instructions at the beginning of part 2 of the survey: “All data would be securely stored on the device that is running the app and not shared with anyone.”</p> <p>Regarding P2’s comment, I agree that it may help to know why people answered the way they did. Suggest adding the following question: “Do you have specific concerns OR is there a specific reason why you would not enter certain information? If so, please specify.”</p> <p>Comment from P3 about breaking down categories is not understood. No changes suggested.</p> <p>P4 accurately described the intent of the ‘sometimes’ option</p>
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			<p>for most of the data elements (e.g. description of stool, skin condition, etc.). However, for some data elements, ‘sometimes’ is truly intended to mean ‘sometimes’ (e.g. current weight). I believe the intent of this option should be clarified. Suggest adding further instructions to the question, as follows: “Choosing the option ‘sometimes’ indicates one of the following:</p> <ol style="list-style-type: none"> 1. You are willing to enter the data if you happen to have it, such as the baby’s current weight OR 2. You are willing to enter the data only if you felt it was abnormal (e.g. there is blood in the baby’s urine, baby is crying excessively, etc.) OR 3. You are willing to enter the data if explicitly asked by the app. This would only happen if a possible problem is detected, but more information was needed.”
<p>The question that asks parents how often they would be willing to enter each piece of</p>	<p>8. Do you have any suggestions of how the question could be improved?</p>	<p>P1: no P2: No P3: P4:</p>	<p>None</p>

data into the app (Q8-Q34)			
Question asking parents which information they don't understand or don't feel comfortable entering into the app (Q35)	9. Do you find the above question confusing? If so, how could it be clarified?	P1: no P2: No P3: no confusion. P4:	None
Q36: "Do you have any additional comments or concerns about inputting any of the above information into the app?"	10. Do you find the above question confusing? If so, how could it be clarified?	P1: no P2: No P3: the questions are generally clear, some may be divided in more sub-categories maybe. P4:	The comment about sub-categories is unclear. It may be referring to how the app would display the options for the data elements, which is not relevant to the survey questions. No change is suggested.
Instructions for the questions for the first scenario, without app support.	11. Do you find the above instructions confusing? If so, how could they be clarified?	P1: no P2: No P3: no, it is clear. P4:	None
Reference information table provided to parents for wet diapers and stools per day	12. Do you find the above reference information table confusing? If so, how could it be improved?	P1: no P2: It is not confusing. P3: this is clear. P4: no	None
Scenario 1	13. Do you find the above scenario confusing? If so, how could it be clarified?	P1: no P2: No P3: it is a bit long, but clear. P4: no	In order to include all the details provided by the lactation consultants in the focus group, the scenarios ended up being a bit long. However, it is not possible to reduce them significantly without changing the format to point form. No change is suggested.

<p>The three questions about the scenario (Q37-Q39)</p>	<p>14. Do you find any of the above questions confusing? If so, please specify.</p>	<p>P1: no P2: No P3: the questions are clear. P4:</p>	<p>None</p>
<p>The three questions about the scenario (Q37-Q39).</p>	<p>15. Do you have any other comments about how these questions could be improved?</p>	<p>P1: no P2: No P3: it is a long scenario for only 2 questions. P4: Suggest using the Likert scale. Easier to gauge.</p>	<p>The comment about the long scenario has been addressed above (the scenarios' length cannot easily be reduced). Additionally, there is no need for additional questions, so none will be added simply to balance the number of questions with the length of the scenario.</p> <p>A Likert scale is a series of statements to measure attitudes about a specific topic and participants must choose a response category for each statement, indicating their own attitude on a scale of agreement (see the complete definition, found below this table, taken from the Oxford Dictionary of Psychology).</p> <p>After examining the two questions further, they could be transformed into statements using a scale from 1 to 10, where 1 is 'strongly disagree' and 10 is 'strongly agree'. The questions could be transformed as follows</p>

			<p>- How concerned are you about the baby’s health? → I am concerned about the baby’s health.</p> <p>- How certain are you that there is a problem with the baby? → I believe there is a problem with the baby’s health.</p> <p>Doing this would not necessarily help to better gauge respondents’ answers, as suggested by P4; however, making this change would help to standardize the questions (especially the scale being used, which currently defines 1 as ‘Not at all’ and 10 as ‘Extremely’). Additionally, it could possibly allow the answers for the two questions to be summed and averaged for each participant, since they are both attempting to measure very similar constructs.</p> <p>Suggest implementing the above change, including updating the instructions for the questions to say: “The first two questions are based on a scale from 1 to 10, where 1 is ‘Strongly disagree’ and 10 is ‘Strongly agree’.</p>
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Instructions for the questions for the first scenario, with app support.	16. Do you find the above instructions confusing? If so, how could they be clarified?	P1: no P2: No P3: no, it is clear. P4:	None
App feedback provided for the first scenario	17. Do you find the information provided in the above feedback confusing? If so, how could it be clarified?	P1: no, I wish I would have had that input when I brought my babies home from the hospital. It is better to have the recommendation de wrong then to have no recommendations at all! P2: No P3: no, clear. P4:	None
App feedback provided for the first scenario	18. Do you find the format of the feedback confusing? If so, please specify.	P1: No, it outlines all the reasons why the are alarmed P2: No P3: no, it is clear. P4:	None
App feedback provided for the first scenario	19. Overall, do you think this section (i.e. 'App Feedback') could be made clearer? If so, please specify.	P1: no P2: No P3: it is good. P4:	None
The three questions about the scenario (Q40-42)	20. Do you have any comments about the above questions, in addition to those provided on the last page?	P1: no P2: No P3: these are the same questions as before, with the same scenario. why? P4: Do not recall baby being difficult to wake in scenario. Jaundice is a concern here, nurse would have picked it up or	Regarding P3's comment, the instructions for this section indicate that the same scenario is given and the same questions are being asked, but that this time participants can use the support of the app to help them answer the questions. The instructions are fairly succinct already, so it would be difficult

		<p>mentioned to nurse during home visit.</p>	<p>to shorten them in order to encourage participants to actually read them. Furthermore, changing the instructions to explicitly tell participants why the survey is set-up the way it is could skew the results. No change is suggested based on the comment from P3.</p> <p>One section of the scenario is as follows: “He is hard to wake and is sleeping a lot...”. P4 may have simply missed this detail since there is a lot of information given in the text. We do not want to simply list all the behaviours of the baby in order to make the information more succinct, rather the intent is to use a scenario format in order to create a more complete picture of what is happening with the baby and parents. Therefore, keeping the format of the symptoms / behaviours as a scenario, we will need to trust that participants read the details carefully. As in real life, there may simply be certain things that do not jump out to readers, and therefore they do not remember. This could indicate</p>
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			<p>that the participant simply did not find the detail to be important, which is a valid result. No change suggested as per P4’s first comment.</p> <p>P4’s comment about jaundice is not related to the questions themselves, for which feedback is being sought. Rather, this is the type of comment we will want in the final survey. No change is suggested based on this comment.</p>
Scenario 2	21. Do you find the above scenario confusing? If so, how could it be clarified?	<p>P1: no</p> <p>P2: No</p> <p>P3: good.</p> <p>P4:</p>	None
App feedback for the second scenario	22. Do you find the information provided in the above feedback confusing? If so, how could it be clarified?	<p>P1: no</p> <p>P2: Yes. The scenario stated that the baby fed well. The App showed concern that the baby did not.</p> <p>P3: no. it is clear.</p> <p>P4:</p>	<p>As per P2’s comment, the scenario is actually very misleading regarding the fact that baby is not feeding well. In one part it says “Whether she’s feeding or not, she often seems to be choking...” but a later part says “...she’s continued to feed quite well...” Suggest changing the latter part to say “And since then, she’s continued to feed regularly – about 7 times per day, but is often choking during feeds.” With this change, readers still know that the baby</p>

			is feeding often, but not necessarily well, since she is choking.
Scenario 3	23. Do you find the above scenario confusing? If so, how could it be clarified?	P1: no P2: No P3: clear. P4:	None
Lack of feedback for the third scenario	24. Is it clear that the app did not detect any problems? If not, how could it be made clearer?	P1: it is clear, no concerns are indicated P2: Yes P3: maybe the app should state "with the information available, there are no specific issues with your baby" P4: no.	P3's suggestion should be considered as a design detail, in the future. More specifically, in terms of design, if there is no problem detected after a user enters information into the app, then it could be annoying to pop-up a message telling the user that there are no specific issues; however, there could be some type of 'Message center' in the app, that keeps track of past and present problems. In this area of the app, if there is currently no problem, then it should probably say so, as suggested by P3. As such, even though P3's suggestion should be considered in the future during design of the app, it does not necessarily warrant a change to how the information (or lack thereof) is presented in the survey. The important thing in the survey is that participants understand that nothing has

			been detected by the app, which seems to be clear to all participants. No change is suggested.
Lack of feedback for the third scenario	25. Do you find it confusing that no problems were detected by the app? If so, please specify.	<p>P1: no, the blood could be benign but I would still ask a doctor</p> <p>P2: I think that blood in anyone's stool would be a cause for concern.</p> <p>P3: no, even if parents think there could be issues, there may be none.</p> <p>P4: Yes. Misleading. A critical situation was not picked up. Credibility compromised.</p>	Based on the answers given, adding this question to the final parent survey could actually provide valuable insight about why participants trust the app or not and whether it may provide a false sense of confidence. Suggest adding this question to the final parent survey.
Rating questions in the 'General Feedback' section (Q55-Q59)	26. Do you find any of the above statements confusing? If so, please specify. If possible, provide ideas of how they could be improved.	<p>P1: no</p> <p>P2: No</p> <p>P3: clear.</p> <p>P4:</p>	None
Referring to the "No answer" option	27. Do you find the 'No answer' option confusing? If so, please specify.	<p>P1: no</p> <p>P2: No</p> <p>P3: no answer should not be used for "unsure", s this is already included in the 1-10 choices.</p> <p>P4:</p>	As per P3's comment, 'unsure' is not really included in the 1-10 choices, since there is no middle answer. Furthermore, since none of the questions in the survey are mandatory, the online survey tool automatically adds the option 'No answer' to all single-choice questions, since this question type uses radio buttons to choose an answer, which once selected cannot be deselected. As a result, the option 'No answer' is being

			used throughout the survey, not just for this section of questions, as originally intended. This allows users to ‘take back’ their answer if they already select an answer and then decide that they do not want to answer the question. No change suggested.
Q60: “Is there anything that would increase your trust in the app?”	28. Do you find the above question confusing? If so, please specify.	P1: no P2: No P3: I'm not sure what to answer or what information is sought. P4:	None
Q61: “Do you have any additional comments about the app?”	29. Do you find the above question confusing? If so, please specify.	P1: no P2: No P3: no. P4:	None
Other			
Q35: Check all pieces of information that you find confusing or for which you do not feel you would be able to provide accurately. Include any comments you may have for each piece of data. [Baby's birth date] → This question is one of the final questions, not a ‘pilot’ question. However, the response warrants examination, to determine if the any changes are necessary in the final survey.		P4: Never indicated because of security, not clear on how this would be managed.	See recommendations for pilot question 7.
Q35: Check all pieces of information that you find confusing or for which you do not feel you would be able to provide accurately. Include any comments you may have for each piece of data. [Amount of expressed breast milk that baby drank]		P3: what is "expressed" milk? P4: Expressing to see how much is drank is cumbersome	See recommendation for pilot question 6, which addresses P3’s comment. P4’s comment is the type of feedback that we would want by participants of the final survey,

		<p>which could then be taken into consideration if the proposed app were to be designed. No change suggested to the survey.</p>
<p>Q35: Check all pieces of information that you find confusing or for which you do not feel you would be able to provide accurately. Include any comments you may have for each piece of data. [Skin turgor]</p>	<p>P2: I would not feel comfortable pinching a newborn's head. P3: what is "turgor"?</p>	<p>P2 simply misread the description which says to pinch the baby's hand, not head. No change suggested.</p> <p>See recommendation for pilot question 6, which addresses P3's comment.</p>

Appendix M: Data Element Comment Analysis

The below table includes all comments that were noted, on a per data element basis, to the question: “Check all pieces of information that you find confusing or for which you do not feel you would be able to provide accurately. Include any comments you may have for each piece of data.”

Participant comments	Category	Analysis
Birth date		
Not comfortable sharing it. I prefer entering approx. age.	Privacy/Security	The app could store data local to the user’s device, avoiding any security / privacy concerns. Alternatively, rather than entering the child’s birth date, parents could enter how old the baby is when they start using the app, since this is really what is needed for the decision algorithm.
Birth weight		
No comments		
Current Weight		
we don't have a baby scale. always went by doctor appointment weight	Difficult to obtain data	Concerns are regarding lack of a scale at home. The intention is that parents simply enter the data whenever they have it (e.g. from a doctor’s appointment).
Most parents don't have access to an infant scale, however if directed they could weigh themselves with/without baby in arms - but I'd be concerned about accuracy using this method.	Difficult to obtain data	
Need a calibrated scale for newborns	Difficult to obtain data	
Only got baby weight at the doctors appointment	Difficult to obtain data	
Would only be able to provide if the baby has been weighed by a care provider recently	Difficult to obtain data	
Time of breast feeding		
Wouldn't want to update this is the middle of the night necessarily	Cumbersome	The comments generally reflect two concerns. The first is specific to tracking this data at night, when
I'm not sure I'd personally be good at entering exact times - just due to feeling overwhelmed	Difficult to track / obtain data	

and having to track everything else. My times wouldn't be accurate. Unless it was a selection by hour, this would make it easier I think.		the device is either not handy or the parent simply does not want to do it. The second concern is regarding general difficulty to track every time a breast feeding occurs.
For night feeds or times mobile device is not on hand	App not accessible	
I am simply terrible at entering time data in apps. I forget to do it when the event occurs then am unable to recall accurately the correct time.	Difficult to track	
Wouldn't be able to keep track of this.	Difficult to track	
Parent Perception of Feed		
Based on experience with tongue tie, this is hard to judge	Subjective	Concern is that this is subjective, but that's why the data element was called "perception". It was decided that it is better to track the parent's perception than nothing. Additionally, for breastfed babies, the parent cannot really provide a measurement for how much the baby ate, but they could at least provide their perception.
Amount of Expressed Breast Milk Baby Drank		
we rarely did this. can't know amounts when drinking directly from breast which occurred over 95% of the time	Data elements not applicable	This comment is not directly related to the data element being confusing or the inability to enter it.
Time that Baby Drank Expressed Breast Milk		
I'm not sure I'd personally be good at entering exact times - just due to feeling overwhelmed and having to track everything else. My times wouldn't be accurate. Unless it was a selection by hour, this would make it easier I think	Difficult to track	These comments reflect the parents' concern regarding general difficulty to track every time a baby drank expressed breast milk.
I am simply terrible at entering time data in apps. I forget to do it when the event occurs then am unable to recall accurately the correct time	Difficult to track	
Amount of Formula Baby Drank		
hard to measure	Difficult to track	Difficult to measure.
Time that Baby Drank Formula		
I am simply terrible at entering time data in apps. I forget to do it when the event occurs	Difficult to track	This comment reflect the parent's concern regarding general

then am unable to recall accurately the correct time		difficulty to track every time a baby drank formula.
Start and End of Sleep		
Unless baby is fussy when they wake, I may not hear them right away	Difficult to obtain data	These comments reflect the parents' concern regarding general difficulty to track the start and end of baby's naps and night sleep.
If I could push a button to start sleep and push a button to stop sleep on the app to track it this would be ok. But once again writing down times would be tough.	Difficult to track	
I am simply terrible at entering time data in apps. I forget to do it when the event occurs then am unable to recall accurately the correct time	Difficult to track	
Number of Wet Diapers		
No comments		
Description of Urine		
No comments		
Number of Dirty Diapers		
No comments		
Description of Poop		
No comments		
Temperature		
I would provide this if I was in a concerned state of mind, otherwise wouldn't be monitoring.	Data entry: if concerned	The first comment is not directly related to the data element being confusing or the inability to enter it; the parent is simply noting that they would only enter it if there was a concern. The second comment reflects a concern to obtain accurate data.
Without a good quality thermometer I found it difficult to get an accurate number. Squirming baby makes it hard too.	Difficult to obtain data	
Temperature Method		
I don't really ever take it more than one way so I don't really care to track that	Data entry: will not track specific element	This comment is not directly related to the data element being confusing or the inability to enter it; the parent is simply noting that they do not want to enter it. However, perhaps if they understood the need for the data, they would be willing to enter it.

		Additionally, the app could make entering this data element easier, for example by remembering and auto-populating the field with the previously entered value.
Skin Colour		
baby's skin is very thin and sensitive, hard to distinguish the colour.	Difficult to obtain data	This comment reflects a concern to obtain accurate data.
Skin condition		
Would there be an option to add text in an "other" category if the choice options don't fit?	Data options not exhaustive	This question indicates that the user is not confused about the data element, but wants to ensure that they can enter any value, even if it is not provided as an option. The design provided options since an automated decision algorithm cannot make sense of free text.
Description of rash		
Would there be an option to add text in an "other" category if the choice options don't fit?	Data options not exhaustive	This question indicates that the user is not confused about the data element, but wants to ensure that they can enter any value, even if it is not provided as an option. The design provided options since an automated decision algorithm cannot make sense of free text.
Umbilical Cord Condition		
Would there be an option to add text in an "other" category if the choice options don't fit?	Data options not exhaustive	This first comment / question indicates that the user is not confused about the data element, but wants to ensure that they can enter any value, even if it is not provided as an option. The design
don't want to smell that	Difficult to obtain data	

		provided options since an automated decision algorithm cannot make sense of free text. The second comment reflects that the parent does not want to obtain this data.
Activity		
Would there be an option to add text in an "other" category if the choice options don't fit?	Data options not exhaustive	This first comment / question indicates that the user is not confused about the data element, but wants to ensure that they can enter any value, even if it is not provided as an option. The design provided options since an automated decision algorithm cannot make sense of free text. The last two comments indicate a concern to properly assess this information as it can be subjective.
My newborns were always either eating, sleeping or crying. Things 'irritable' would be near impossible to assess.	Difficult to obtain data / subjective	
If it's your first child especially, it's hard to tell what's 'normal' or 'excessive'	Difficult to obtain data / subjective	
Vomited / Forcefully Expulsed Fluids		
Does "forcefully expulsed fluids" include either end of baby?	Data element wording not clear	This participant was unclear about what exactly the data element was trying to capture, based on its name.
Spits up Often		
No comments		
Excessive Gas		
I have always had trouble determining if/when my son or daughter had gas.	Difficult to obtain	This comment indicates that this could be difficult for parents to know / observe and that parents may not always enter the information accurately.
Skin Elasticity		
No comments		
Crying Behaviour		

Other options: weak, faint cry - Would there be an option to add text in an "other" category if the choice options don't fit?	Data options not exhaustive	This first comment / question indicates that the user is not confused about the data element, but wants to ensure that they can enter any value, even if it is not provided as an option. The design provided options since an automated decision algorithm cannot make sense of free text. The second comment indicates a concern to properly assess this information as it can be subjective.
Also hard to assess whether it's excessive. Newborn cries Sounds intense	Subjective	
Whites of Eyes are Yellow		
Hard to identify unless extreme	Difficult to obtain	This comment indicates that this could be difficult for parents to know / observe and that parents may not always enter the information accurately.

The below table contains participant responses to the questions: “Do you have specific concerns or is there a specific reason why you would not enter certain information? If so, please specify.” (Q1) and “Do you have any additional comments or concerns about inputting any of the above information into the app?” (Q2).

Participant Comments	Category	Analysis
Q1: some information is not applicable.	Data elements not applicable	This participant did not provide responses to the questions about expressed breast milk or formula and also commented in the previous section that they breastfed 95% of the time. In

		<p>this case, they would not be expected to enter feeding data that is not applicable and the app would use the breastfeeding data.</p>
<p>Q1: If there is no reason for concern, I would not enter data. For example, if baby is pooping regularly and the poop is normal colour and consistency, then I would not enter it. However, if pooping became a problem, then I would start to track this information.</p>	<p>Data entry: if concerned</p>	<p>This participant’s comment mostly reflects the intent of the app, i.e., for parents to enter data only if there is a concern. What is not clear is if they would be willing to enter certain base data all of the time. But based on their responses to how often they would enter data, they responded ‘sometimes’ for almost everything. Whereas there are certain base data elements regarding feedings, pees, and poops that the user would need to enter regularly for the app to be effective.</p>
<p>Q1: I think I would track that level of detail only for the first few weeks of life and when my baby was sick</p> <p>Q2: The app needs to be incredibly easy to use for a sleep deprived parent to use</p>	<p>Data entry: if concerned + first few weeks</p> <p>Must be easy to use</p>	<p>Same as above participant, regarding the answer to the first question.</p> <p>The answer to the second question raises a valid concern regarding ease of use of the app, which would</p>

		absolutely need to be one of the main focuses during app design.
<p>Q1: I would have a hard time as a brand new mom tracking the times for the information, as time is not an object really when you have a newborn and I probably wouldn't follow through with adding the times.</p> <p>Q2: Just if there would be an Other category for the choice selections, how would a user add info that is not listed? Or maybe an option to say "n/a"?</p>	<p>Cumbersome</p> <p>Data options not exhaustive</p>	<p>This participant seems like they are willing to enter the information and interested in the app, but feel like they may be too overwhelmed to actually do the data entry.</p> <p>The answer to the second question can be considered during design, but providing an 'other' option would not be useful for the purposes of an algorithm used to detect possible problems. Nevertheless, it could still help parents track of data.</p>
<p>Q1: confidentiality</p>	<p>Privacy/security</p>	<p>The app could store data local to the user's device, avoiding any security / privacy concerns.</p> <p>Alternatively, rather than entering the child's birth date, parents could enter how old the baby is when they start using the app, since this is really what is needed for the decision algorithm.</p>

<p>Q1: Baby's birth day is too private. I would enter approx. age, but not exact birth day.</p> <p>Q2: No additional concerns/comments.</p>	<p>Privacy/security</p>	<p>Same analysis as above, regarding privacy/security concerns.</p>
<p>Q1: Having two kids, I now know that the last thing I would do, among all the tasks that need to be done (feeding, changing diapers, cleaning, washing, sterilizing bottles, etc), is to get a tablet/ smart phone or laptop, and start filling in information for an app that might detect something. Parents of newborns are so tired, and stressed, and exhausted... I would not spend any time to fill in this sort of data, maybe just entering info with respect to weight/ height once in a while. I would just rest when I get the chance. When there's any health related aspects, I would not rely on an app, for anything suspicious I would just call the pediatrician and make an appointment.</p> <p>Q2: This sort of information is based on observation, on how a parent perceives certain aspects, colors, frequency, intensity, etc. It is quite subjective. How often does a newborn have to release gas to qualify for excessive? How can one tell how elastic the skin is or how red? If urine has a strange color, you call the pediatrician and make an appointment, at least that's what I would do. Providing data for an app would be my last concern.</p>	<p>Would not use</p> <p>Subjective</p>	<p>This participant: 1) finds the idea of entering the data into an app cumbersome and is not willing to do it, and 2) would not rely on an app to detect an issue. Bases on their comments, it's clear that they would not be interested in using the proposed app.</p> <p>The participant is correct that some of the data elements are quite subjective. This is something that would need to be analysed further to really understand if having the user enter information that is somewhat inaccurate is better than no information at all. Perhaps some conditions that the app is trying to detect, based on some of these very subjective measures, would simply need to be removed.</p>
<p>Q1: Difficult to enter info consistently especially when it is frequent or repetitive when coping with baby brain and a newborn.</p>	<p>Cumbersome</p>	<p>Similar to another participant, this participant is not dismissing the idea of using this app,</p>

		but they are noting that the information they enter will likely not be complete or accurate. This raises concerns regarding the accuracy of the app to detect problems and especially the possibility of false positives being raised (for example because the app may think the baby hasn't been peeing enough, but it's just that the parent is not entering the data).
Q1: Privacy and information sharing.	Privacy/security	Same analysis as above, regarding privacy/security concerns.
Q1: I probably would not enter the exact date of birth due to security reasons.	Privacy/security	Same analysis as above, regarding privacy/security concerns.
Q1: Spit up and gas would be really hard to track, especially if its in the middle of the night or you have other children. It is just not something that you would really pay that much attention to, especially if it's your second or third child.	Cumbersome	Similar to previous comments; this participant is not dismissing the idea of using the proposed app, but they raise valid concerns of difficulties they foresee in entering the data.
Q1: I would not have any problem entering any of this information but I would likely not enter it all, all the time. This would be much too time consuming. I might only enter it to track it if I thought something was wrong.	Data entry: if concerned	This is similar to comments made by other participants and mostly in line with the objective of the app. I.e., it is not expected the user will enter all data all

		the time; however, certain basic data elements do need to be entered regularly in order for the app to be effective.
Q1: Male. Unsure of my effectiveness tracking breastfeeding.	Difficult to obtain data	The participant brings up the very valid point that it would be more difficult for fathers to track the data related to breastfeeding. This does not mean that men need to be excluded from the target group completely, however, as they could help mothers to input the data, relieving some of the burden many participants expressed.
Q1: Tedious information to keep noting	Cumbersome	Again, this participant is not completely dismissing the idea of the app but has expressed that it is cumbersome. Perhaps they do not realize that the intent is to only track most of the information if it is irregular. Still, it reinforces the fact that the design needs to focus on ease of use and speed of entry.
Q1: probabpybwouldnt remember tI at all times of the day when being busy or tired.	Cumbersome	Same concern as many other participants. This

		parent is not dismissing the app, but they admit that they would likely not be able to track all the data accurately.
<p>Q1: gross to measure, or hard to remember, no time to enter so much data</p> <p>Q2: seems like a lot of work to enter that much data, hard to find free time</p>	Cumbersome	Based on this participant's comments it does not sound like they would be interested in using the app but it is unclear. Their comments, like others', reinforce the fact that the design needs to be extremely easy to use.
<p>Q1: I would not necessarily want to enter baby's birthdate for privacy reasons</p>	Privacy/security	Same analysis as above, regarding privacy/security concerns.

Appendix N: Scenarios, App Support and Results Analysis

This appendix includes the scenarios, the support provided by the app, and participants' responses to the question "Are there any particular steps that you would take to provide care for the baby? If so, please explain what you would do", asked before and after support was provided.

Scenario 1

After two days in the hospital, mom and dad were able to bring their sweet little baby boy home. They've been home for two days now and have hardly started to adjust to this new life. Everything is so new and the learning is endless. Mom and dad find it quieter than they expected though since their new little one hardly ever cries. Just like they did in the hospital, they have been tracking baby's pees and poops since they got home. There hasn't been much to track though since he hasn't pooped since being in the hospital; dad remembers that poop - it was still black. Baby has been peeing, but only 3 times yesterday and 3 times today. The new parents noticed that baby's skin and the whites of his eyes are a bit yellow. He is hard to wake and is sleeping a lot, even had one stretch of five hours today; it was a good break for mom and dad. Baby's sleepiness makes breastfeeding a bit difficult however, since he keeps falling asleep at the breast. He does usually feed every 3 hours though, while mom watches him closely, but she has a hard time hearing any swallowing. She remembers the videos from her prenatal class that showed that the baby's chin needs to go up and down with pauses in between, but she is having a hard time telling if this is happening. Mom's breasts feel hard, swollen, and somewhat painful - is this what it feels like when your milk "comes in"? A lot has been happening since the little one was born, hopefully tomorrow's check-up with the doctor will go well...

The following alert would be provided by the app:

Alert! Call Telehealth for immediate assessment.

This recommendation is based on the following symptoms:

- Yellow skin
- Yellow whites of eyes
- Baby did not feed well for the following reason(s): fell asleep, no audible swallowing
- Less wet diapers than expected at 4 days old
- Less dirty diapers than expected at 3 and 4 days old
- Baby is sleepy
- Baby is difficult to wake

Responses Without & With App Support	Analysis
<i>Without:</i> Research on the Internet <i>With:</i> Call telehealth	Followed advice; different than original plan.
<i>Without:</i> I would look up symptoms on Google, call the doctor and maybe go to doctor or hospital. Child is probably dehydrated. <i>With:</i> Same as before	No change in behaviour; different from app's suggestion.
<i>Without:</i> Take to doctor to have baby weighed and checked for jaundice. <i>With:</i> Take baby to doctor immediately.	Changed behaviour but different from app's suggestion.
<i>Without:</i> I would call tele health and go to a drop in baby wellness clinic <i>With:</i> Call tele health and go to a baby wellness drop in clinic provided by city of ottawa	No change in behaviour but similar to app's suggestion.
<i>Without:</i> Take baby to doctor to check bilirubin levels today (not tomorrow). Engage lactation consultant to meet with mom and baby at home to assist with breastfeeding. Wake baby at least every 3 hours to eat. Depending on bilirubin levels consider formula feeding to ensure baby is thriving. <i>With:</i> Same answers as provided in last question. I would not call Telehealth - I would take baby to see doctor today to have bilirubin levels checked, etc...	No change in behaviour; different from app's suggestion.
<i>Without:</i> I would try to take the baby to the doctor and pump out milk and give the baby the bottle to see if the baby gets enough milk. If that doesn't work, maybe try to give the baby formula and see how that goes. <i>With:</i> No response provided	N/A (response missing)
<i>Without:</i> call the doctor about yellow eyes and not enough pee in diapers	Followed advice; different than original plan.

<i>With:</i> Call Telehealth	
<i>Without:</i> Check Billirubin level for Jaundice <i>With:</i> No response provided	N/A (response missing)
<i>Without:</i> I would bring the baby to the Pediatrician or doctor for a check up. <i>With:</i> No response provided	N/A (response missing)
<i>Without:</i> No response provided <i>With:</i> As a new mom, getting an alert like this would scare me and make me panic, which is probably not the best thing. That's what's hard about apps / websites about health. They make you think you the worst right away.	N/A (response missing)
<i>Without:</i> Bring to see his doctor <i>With:</i> Consult his doctor	No change in behaviour; different from app's suggestion.
<i>Without:</i> I would call the doctor to see if I could come in earlier, if not explain the situation and ask for advice until tomorrow's doctors appointment. <i>With:</i> Call doctors office to see if I could get in earlier, if not ask for advice on what to do until doctors appointment tomorrow	No change in behaviour; different from app's suggestion.
<i>Without:</i> I'd bring him/her to the hospital <i>With:</i> I'd be bring baby to the hospital.	No change in behaviour; different from app's suggestion.
<i>Without:</i> wake them up and feed them. google yellow eyes in baby. <i>With:</i> I would call telehealth immediately.	Followed advice; different than original plan.
<i>Without:</i> With all of this information, I would contact my midwife/pediatrician/doctor right away. If not able to be seen that day, go to ER. <i>With:</i> I would call Telehealth for immediate assessment.	Followed advice; different than original plan.
<i>Without:</i> Call my doctor, Go to CHEO <i>With:</i> Call doctor right away	No change in behaviour; different from app's suggestion.
<i>Without:</i> Expose to sunlight, have bilirubin level drawn stat! <i>With:</i> No response provided	N/A (response missing)
<i>Without:</i> express breast milk and try bottle feeding or supplementing with infant formula to see if the baby will feed. With yellowish skin/eyes, there may be concern for jaundice and baby must have nourishment. if ever in doubt- go to emergency. <i>With:</i> keep trying to feed. call telehealth or go to emergency.	Followed advice; similar to original plan.

<p><i>Without:</i> Try using breastfeeding pump and bottle and see if it helps mom and baby. Speak to health professional on phone. Request to speak with a lactation consultant</p> <p><i>With:</i> No response provided</p>	N/A (response missing)
<p><i>Without:</i> Contact a lactation consultant regarding issues with breastfeeding, weigh the baby to determine if weight has decreased. Babies sleep lots even sometimes over 5 hours if they have lots of growing to catch up on (low birth weight) but I would definitely be concerned if he isn't eating much and his output is low.</p> <p><i>With:</i> The alert increased my concern about baby's health, however it didn't increase my belief that there is a problem - a medical profession needs to diagnose this so for this reason it didn't increase my answer.</p>	No change in behaviour; different from app's suggestion.
<p><i>Without:</i> Check the baby if he has any temperature and feeding does not go well for further more time. Will take him to doctor.</p> <p><i>With:</i> Take him to doctor.</p>	No change in behaviour; different from app's suggestion.
<p><i>Without:</i> I would see both my doctor and consult a lactation consultant or stop by MilkFace to see a consultant</p> <p><i>With:</i> Call telehealth and if they say emerg I would go but also care for mom, possibly a blocked duct or a mastitis so I would also see my doctor or go to walk in</p>	Followed advice; different than original plan.
<p><i>Without:</i> Go to a doctor</p> <p><i>With:</i> Call telehealth</p>	Followed advice; different than original plan.
<p><i>Without:</i> bring baby in prior to check-up</p> <p><i>With:</i> would still bring baby in before check-up</p>	No change in behaviour; different from app's suggestion.
<p><i>Without:</i> All of these things could be normal, or they could be signs of a problem. I would simply relate these things to the doctor at the checkup. I would want to make sure that the baby was indeed getting enough milk so I would see a lactation consultant or go to a breast feeding clinic.</p> <p><i>With:</i> If I read this as a brand new mom of course I would be concerned. I think this app would make an inexperienced mom panic. Based on my experience having 2 babies I would not call telehealth in this case,</p>	Changed behaviour but different from app's suggestion.

<p>especially if I had a doctors appointment the next day. I had midwives with both children and would call them in this case. Newborns have jaundice, they sleep all the time. It could be a latch problem (see lactation consultant). Breastfeeding is hard.</p>	
<p><i>Without:</i> Seeing yellow skin and eyes, I would have gone to CHEO right away. That would scare me. Also the lack of eating would be worrisome. <i>With:</i> I've called telehealth many times and almost always, they tell you "to be safe, baby should see a Dr.". After a few times using the telehealth number I stopped calling and would go immediately to CHEO. In this case I would do the same.</p>	<p>No change in behaviour; different from app's suggestion.</p>
<p><i>Without:</i> I would call the family doctor (pediatrician). Yellow eyes is of concern. <i>With:</i> I would call the family doctor (pediatrician). I might call Telehealth as an option, but I usually call the doctor.</p>	<p>No change in behaviour; different from app's suggestion.</p>

Scenario 2

It's been 3 weeks since mom and dad have brought their new little girl home from the hospital. Although she's cute as a button, her mood over the past week or so isn't quite what the new parents had hoped for. Baby has been fussy and inconsolable and mom and dad are questioning everything they do. She's just so irritable and cranky all the time, especially after feeds. Whether she's feeding or not, she often seems to be choking or swallowing and it seems like she is spitting up all the time – much more than they remember with their first child. As unhappy as baby seems to be though, she's still thriving. She just had a growth spurt, during which she fed constantly! And since then, she's continued to feed regularly – about 7 times per day, but is often choking during feeds. Baby is also keeping mom and dad busy with diaper duty – changing about 7 yellow, curdy poops every day, not to mention the wet diapers in between. The poor little

girl’s diaper rash doesn’t have much time to air out with all of these dirty diapers. Besides feeding so often, which is actually starting to take a toll on mom’s sore nipples, mom can tell she has a lot of milk, so she’s not too worried that baby isn’t eating enough. She supposes that she might just be a needy baby, demanding constant attention. After all, when she’s being held, she seems a bit better, as long as it’s in an upright position since she’s never happy lying down, even in mom or dad’s secure arms.

The following alert would be provided by the app:

Alert! Call your primary care provider or Telehealth for assessment.

This recommendation is based on the following symptoms:

- Baby is spitting up often
- Baby is fussy
- Baby is irritable

Other symptoms of concern include:

- Baby not feeding well for the following reason(s): coughing/choking

Responses Without & With App Support	Analysis
<i>Without:</i> Probably research on the Internet <i>With:</i> Bring up with doctor at next appointment	Changed behaviour but different from app’s suggestion.
<i>Without:</i> Same as before. Sounds like baby has gas and needs to learn how to digest. <i>With:</i> Same	No change in behaviour; different from app’s suggestion.
<i>Without:</i> Get checked by doctor for potential reflux problem. <i>With:</i> Get baby checked by the doctor for possible reflux problem.	No change in behaviour; similar to app’s suggestion.
<i>Without:</i> Make an appointment with my family physician, change my diet and keep a record of what I am eating. I would be concerned that: I have yeast infection on breast and that baby is reacting to something in my diet. <i>With:</i> No response provided	N/A (response missing)

<p><i>Without:</i> Take baby to see doctor. Engage lactation consultant to see mom and baby at home for assistance with sore nipples. Seek this assistance immediately.</p> <p><i>With:</i> Same answers as previous question.</p>	No change in behaviour; similar to app's suggestion.
<p><i>Without:</i> The baby might have cramps - stomach aches. She feeds enough, but maybe what the mother is eating is resulting in stomach aches/colic for the baby.</p> <p><i>With:</i> No response provided</p>	N/A (response missing)
<p><i>Without:</i> try to work on feeding, maybe check with lactation specialist</p> <p><i>With:</i> call telehealth</p>	Followed advice; different than original plan.
<p><i>Without:</i> I think the baby might be gassy. I will burp the baby longer until I hear a big burp.</p> <p><i>With:</i> I think the baby is gassy. I would burp the baby longer until the baby burps.</p>	No change in behaviour; different from app's suggestion.
<p><i>Without:</i> Consult the doctor</p> <p><i>With:</i> Consult the doctor</p>	No change in behaviour; similar to app's suggestion.
<p><i>Without:</i> I would take baby to doctor to look at reflux issues.</p> <p><i>With:</i> take baby to doctor</p>	No change in behaviour; similar to app's suggestion.
<p><i>Without:</i> No response provided</p> <p><i>With:</i> Call to see what health care to see what there opinion maybe</p>	N/A (response missing)
<p><i>Without:</i> penatin on bum rash.</p> <p><i>With:</i> bum cream</p>	No change in behaviour; different from app's suggestion.
<p><i>Without:</i> I would call my midwife/paediatrician for assessment. I would like to get baby in as soon as possible without undue delay, but would not consider this to be an emergency situation.</p> <p><i>With:</i> I would call my primary health provider or Telehealth for assessment.</p>	No change in behaviour; similar to app's suggestion.
<p><i>Without:</i> making sure to burp after each feeding to relieve some pressure/gas- might be causing the fussiness. Also reevaluate mom's diet- something might be causing discomfort to baby through milk.</p> <p><i>With:</i> No response provided</p>	N/A (response missing)
<p><i>Without:</i> I would bring up the concerns during the baby's next appointment if it is soon (in a few days). If the parents are getting really frustrated, I would call and bring the baby into the doctor sooner. Call a lactation consultant</p>	N/A (response missing)

<p>for support. Try infant massage on baby as it sounds like digestive issues. <i>With: No response provided</i></p>	
<p><i>Without:</i> quality of the poo and the diaper rash indicates something is up with feeding and digestion--maybe even an allergy or something upsetting baby. baby wanting to be upright suggests reflux or pain related to gas. I would see my doctor but also try to lie down to nurse to avoid fast flow since baby is chocking. I would also find ways for baby to stay in an upright position even if that meant holding baby in a carrier most of the day <i>With:</i> call my primary care provider and zip in to see the doctor</p>	Followed advice; similar to original plan.
<p><i>Without: No response provided</i> <i>With:</i> Go to the doctor</p>	N/A (response missing)
<p><i>Without:</i> continue monitoring <i>With:</i> App alert is generic in nature and therefore I would continue monitoring and if needed bring the baby in for a check-up</p>	No change in behaviour; different from app's suggestion.
<p><i>Without:</i> I would not be concerned that there is something seriously wrong. It sounds like the baby might have reflux? Or maybe the mother's flow is too strong so she chokes on it. I feel like a lactation consultant would be helpful here. Again, this is where the midwife model would be helpful since they follow you and your newborn until 6 weeks. This is something I bring up with a doctor if there was no midwife. <i>With:</i> Again I think the app is alarmist. The baby is thriving. A doctor or midwife could determine if there was a problem like reflux.</p>	No change in behaviour; similar to app's suggestion.
<p><i>Without:</i> I would probably prop her bassinet up at the head end to relieve the spit up or reflux. I would also be sure to burp her more often. <i>With:</i> Maybe try giving her a bottle if she kept choking at the breast. Continue to burp her and monitor her diapers and weight.</p>	No change in behaviour; different from app's suggestion.
<p><i>Without:</i> I don't like the way the stool looks. I'd probably call the doctor for a consultation, but I've experienced an irritable baby. <i>With:</i> The alert would have me follow up with a doctor or nurse.</p>	Followed advice; similar to original plan.

Scenario 3

It's been exactly 2 weeks since baby was born and as much as mom wants to breastfeed and knows the importance, she is finding it so hard and getting discouraged. She heard stories of it being painful, but just thought those other moms were doing it wrong. But now that it's her turn, this mom is finding out what breastfeeding can do to her nipples, which are getting sorer and sorer and have even started to bleed in the last couple of days since the skin has become so raw. Feedings feel like they last forever but are often cut short by mom because it just hurts too much, especially when it feels like baby is biting. She's tried different positions, but it hasn't helped. Dad thought maybe it would help if baby practiced sucking on a pacifier, but baby doesn't seem to be able to maintain suction on it. Still, even though mom is not enjoying the breast feeding experience, as she hoped she would, she does seem to have a lot of milk and baby is gaining weight and has even re-achieved his birth weight. Mom's only concern right now is baby's stool from this morning - dad noticed that it was darker than usual and even saw some blood in it.

Based on the information available to the app, no feedback is available.

Responses Without & With App Support	Analysis
<i>Without:</i> Find a drop in lactation clinic in Ottawa <i>With:</i> Continue to find the lactation clinic offered in Ottawa	No change.
<i>Without:</i> I'd go to the doctor and s lactation consultant, but just start supplementing with formula. <i>With:</i> Same	No change.
<i>Without:</i> Mom needs medical care for sore nipples and help from a lactation consultant re latching.	No change.

<i>With:</i> Mom needs medical care for sore nipples and help from a lactation consultant re latching.	
<i>Without:</i> Make an appointment with my family physician <i>With:</i> Make an appointment with my family physician. I would think that I may have a yeast infection on my breasts and need some sort of cream to relieve pain.	No change.
<i>Without:</i> Engage a lactation consultant to see mom and baby at home to get assistance with latch. See baby's doctor for assistance and consultation on whether to use formula to assist in feeding. Have mom see her own physician for consultation regarding prescription for APNO to prevent/treat possible infection due to open wounds on breasts. <i>With:</i> See answers to previous question.	No change.
<i>Without:</i> No response provided. <i>With:</i> I would try to express milk and give the baby the bottle with the expressed milk or move on to formula milk.	N/A (response missing)
<i>Without:</i> get help at lactation clinic, try bottle formula to see if baby is still hungry after feeding <i>With:</i> get help from lactation clinic, offer bottle to baby	No change.
<i>Without:</i> I would extract breast milk and feed the baby using bottle. <i>With:</i> I would extract breast milk and feed baby using bottle.	No change.
<i>Without:</i> No response provided. <i>With:</i> See lactation consultant and attempt to use formula if breast feeding issue is not resolved	N/A (response missing)
<i>Without:</i> No response provided <i>With:</i> In this scenario it seems that the baby does not get enough milk and she's always hungry. I would express breast milk with a pump, and measure exactly how much the baby drinks. When the baby gets his milk from the breast, it is difficult to estimate the volume she drank, so giving her the bottle helps. Also, if the baby does not drink enough	N/A (response missing)

milk from the breast, there may be complications for the mother.	
<i>Without:</i> I would keep trying to breastfeed but also pump milk. Also talk to lactation consultant about the latching issues. <i>With:</i> Continue to breastfeed and pump also. Talk to lactation consultant about latching issues. Get rid of pacifier until good latch is established. Continue to get weight checks to make sure baby is not failing to thrive.	No change.
<i>Without:</i> I'd be getting my breast checked and finding out better latching methods. <i>With:</i> I'd switch the baby to bottle feeding if the baby didn't start latching better.	No change.
<i>Without:</i> visit a lactation consultant <i>With:</i> still visit lactation consultant for moms sake to make her nipples feel better	No change.
<i>Without:</i> I would seek immediate assistance with a lactation consultant to fix the feeding issue. <i>With:</i> I would contact a lactation consultant for immediate assistance regarding the apparent feeding issue.	No change.
<i>Without:</i> Call a lactation consultant. It would be great if the app could recommend some good ones. <i>With:</i> Find a lactation consultant.	No change.
<i>Without:</i> use cream after every feed to relieve some of the cracking/pain and use soothing pads. try using a nipple guard as it helps baby latch and helps nipples heal. <i>With:</i> <i>No response provided</i>	N/A (response missing)
<i>Without:</i> Try pump and bottle. Mom could try breastfeeding shield. <i>With:</i> Pump and bottle feed baby to help mom recover and to measure how much baby is actually getting. inform the mom to look into breast shield to help her heal and allow her to keep trying without all the pain	No change.
<i>Without:</i> Call a lactation consultant for support. Supplement with a bit of formula if he will take a bottle nipple. <i>With:</i> <i>No response provided</i>	N/A (response missing)
<i>Without:</i> See primary care giver--maybe baby has trouble latching for a reason, tongue tied or birth trauma. Also spend more time at a	No change.

<p>clinic or consult a person to come to the house where it is relaxing and I can work with baby on latch. try to heal nipples!</p> <p><i>With:</i> same as before, primary health practitioner and take care of mom</p>	
<p><i>Without:</i> See lactation consultant</p> <p><i>With:</i> See a lactation consultant</p>	No change.
<p><i>Without:</i> consult lactation specialist / see doctor</p> <p><i>With:</i> same as previous (lactation specialist)</p>	No change.
<p><i>Without:</i> Alternate feedings: breast milk and formula.</p> <p><i>With:</i> Alternate feedings: breast milk and formula. Make sure baby has wet diapers to ensure baby is hydrated.</p>	No change.
<p><i>Without:</i> In this scenario I think there is something going on with breastfeeding and I would be concerned that baby is not getting enough to eat. Again, lactation consultant can help fix latch problems and identify any other issues like tongue tie. If this is identified and addressed early I wouldn't be too concerned.</p> <p><i>With:</i> Same comments as previous page.</p>	No change.
<p><i>Without:</i> I would try for the bottle. I've been in that exact scenario. Trying to stick to exclusive breastfeeding sometimes causes more stress for mom, dad and baby. I would go to a,Dr. And get treatment for my boobs and rent a pump!</p> <p><i>With:</i> Continue with the lactation consultant or try bottles.</p>	No change.
<p><i>Without:</i> The weight loss is a problem. I would call the doctor in this case.</p> <p><i>With:</i> Probably not yet. Maybe it's the wording, but I'm not sure about re-achieving birth weight. If it went down then up, I'm not concerned.</p>	No change.

Appendix O: Parent Survey – Results Analysis for ‘Reaction when No Feedback was Provided’

Answers and classifications for the question: “Do you find it confusing that no problems were detected by the app? If so, please specify.”

Answer	Confusing?
Yes, wouldn't it detect short amount of feeding times and weight issue?	Yes
Yes. Baby is obviously not eating enough and needs to grow.	Yes
No really. Problems are common. Although instructions say to not rely on other information, one has to assume mother has done some previous reading and attended some classes and would likely understand that these problems are common.	No
No information would be not helpful but doesn't change the fact that there are significant issues requiring attention.	No
Yes, maybe the App Feedback should also give Suggestions (beside give Recommendations).	Yes
no, I don't expect app to know everything	No
I think the app did not detect any problems because there's no description of the baby's behaviour. The baby was not cranky or crying for more milk.	No
No. The issue with the mother not being able to feed the baby. It's not the baby' s health that is the issue	No
I did not find it confusing, the baby just wants to eat, and doesn't get enough milk. The parents need to change the way they feed their baby, giver her the bottle with enough milk, and wait until the baby is done sucking milk. It is easier for a baby to drink from a bottle than from the breast.	No
No	No
Yes cause the mother should of been getting cream to heal the nipples and they should be showing here how to latch the baby properly from causing irritation. If the baby is latching properly the mother should of still be getting cream from the sore nipples. I got a cracked nipple and went to the hospital and they gave me cream that was still okay to breast feed my son with.	Yes
no problems means no problems. if something is wrong it would give me a false sense of security	No

Yes. And frustrating. Clearly there is a problem but the app is not providing the direction/assistance that I would be hoping for.	Yes
Declining weight or not progressing fast enough is a flag.	Yes
Baby's lack of weight gain should have been flagged, especially since the weight was at a clinic and should be more accurate.	Yes
No I didn't find it confusing because it sounds like it is something that mom can address with breastfeeding, and the baby is thriving just not gaining weight. Babies do go through weeks where they don't gain much or nothing. If it continues and the baby wasn't feeding at all I would be more concerned that an alert didn't appear - but this is not the case.	No
no because medically it is not alarming but I would be worried about the latching and get it checked out as soon as possible. lack of weight gain for a week is not that dramatic	No
Yes, was hoping for advice	Yes
no	No
Yes. Ensuring baby is receiving proper feeding and is hydrated is crucial.	Yes
A bit confusing because of all the scenarios, I would be most concerned about this one. It doesn't sound like breastfeeding is going well or that baby is eating enough. Could the app refer ppl to help other than doctors/telehealth? Maybe lactation consultants or local breast feeding clinics?	Yes
I wouldn't expect to find anything wrong with baby so not confusing.	No
No. I expect weight tolerances are programmed into the system.	No

Appendix P: Parent Survey – Results Analysis for ‘Increasing Trust in the App’

Answers and analysis for the question: “Is there anything that would increase your trust in the app?”

Answer	Response Category (ies)
Being backed by Telehealth and actual hospitals	Endorsement by an accredited organization
More detailed feedback. Reasons behind the feedback (why yo call the doctor).	More information
Endorsement by accredited group, recommendation by doctor or public health nurse.	Endorsement by an accredited organization
If it was endorsed by Healthy Canada, Public Health organizations, government of Ontario, hospital I gave birth at, etc.	Endorsement by an accredited organization, doctor recommended
I would need more information about the information sources for the app. I would like to know it is recommended by an organization like Canadian Pediatric Society or SOGC. It should not have answers like no information available. Answers should be more specific - should not say call Telehealth when answer should be seek care immediately.I like the idea of an app but it needs to be very sophisticated in order to be useful.	Endorsement by an accredited organization, more information
Have more information included in the app - maybe you can set it up to link to other internet resources (webpages) where more information is displayed regarding a particular diagnosis.	More information
medical links for further reading about issues	More information
Disclose where the medical information pertaining to diagnosis is coming from. Cannot trust unknown sources	Endorsement by an accredited organization
Not really, the app provides an answer based on the input from the parents. This input may be subjective.	Nothing more needed
No	Nothing more needed
Knowing that all information came from a reliable source.	Endorsement by an accredited organization
some sort of government stamp of approval. like if the app was provided by health Canada	Endorsement by an accredited organization

as the developer, or at least when you open the app it has "approved by health Canada"	
Perhaps provide additional resources that the parent would be directed to depending on the situation. Without, obviously, trying to diagnose.	More information
Information on where the advice is based on and how often the app is updated.	Endorsement by an accredited organization, knowing how up-to-date the information is
Having links to resources and accredited medical information such a Telehealth, Health Canada, Ontario public health links etc...	More information, Endorsement by an accredited organization
Released with support from a medical professional organization.	Endorsement by an accredited organization
not really. I think it does what can be expected. beyond the data there are lots of circumstantial things that an app cannot account for.	Nothing more needed
No, helpful but the app does not (and should not be perceived by user to replace doctors visit and/or parental instinct - Apps can be too generic in nature.	Nothing more needed

Appendix Q: Parent Survey - Additional Comments Analysis

Responses and analysis to the question: “Do you have any additional comments about the app?”

Comment	Analysis
Having links to reliable sources?	More information
It would be nice to have a Recommendation field included.	Recommendations
It would be nice if it kept track of immunizations, and allowed to see baby height and weight compared to percentile charts to see how baby is growing so you can feel that things are going well with baby's growth	Tracking additional information; comparison of baby versus norm
Ability to post pictures for review is excellent.	Feedback from professionals
An app that would instantaneously put the parents in contact with a pediatrician would be good. Just write any concern and get some feed back from a nurse or pediatrician without having to call a phone number.	Feedback from professionals
No	
Great idea. May just need some physicians input on some of the scenarios to make it more accurate.	Approval
it would be nice before people take the questionnaire about their baby in the app that they are given a list of what they might need. for example baby's temperature. that way they don't have to leave the app in the middle of the questionnaire to take baby's temperature.	N/A. Participant seemed to misunderstand the concept of the app.
Interesting. I would have to try it out before I would see whether it would be a tool I would use. I think a lot would depend on the ease of entering the information.	Interesting, but undecided. Ease of entry is required.
This app would be most useful for a first child. The app would likely be used only as an equivalent as a call to a health professional for a second child.	Most useful for first child.
I think it would be a great idea for new parents to help ease the fears and anxieties people have.	Most useful for first child.
I think it would naturally direct parents to call Telehealth for minor minor matters. Liability	Reluctant to use; cumbersome.

<p>for not doing so could be significant. Quicker to use google and look up symptoms, than inputting information. I don't need to be told to call Telehealth. You can always default to this source of information and then Telehealth will you if you need to go to CHEO (which is when it is a real concern).</p>	
<p>I think I would never rely on just one thing, it does seem like a very good tool though. I used a tracking app with my baby but it did not give any actual feedback so I appreciate an app that can think a little bit!</p>	<p>Good idea; would not rely on just one tool.</p>
<p>My preference is to call telehealth or visit/contact health care provider for medical advice.</p>	<p>Reluctant to use.</p>
<p>I think it would be too time consuming to input all this information into the app. I think would make inexperienced parents panic when their babies are perfectly healthy. It would be good if the app referred parents to resources other than doctors/telehealth. It would be particularly useful if they referred ppl to local resources such as lactation consultants, clinics, groups etc. It could also list contact info. I do not think it would be particularly helpful for those who had midwife since all that support and information is provided by them, but I guess it could be for those that did not.</p>	<p>Cumbersome. May increase panic of new parents. Useful to refer parents to online and local resources. Not useful for parents who have a midwife.</p>
<p>I would use it, but would probably also Google.</p>	<p>Good idea; would not rely on just one tool.</p>
<p>This could be very useful instead of having to search symptoms.</p>	<p>Useful; good alternative to Google.</p>