# DEVELOPMENT OF A THEORY-INFORMED PATIENT DECISION AID TO FACILITATE CONSENT TO GENETIC TESTING IN THE NEONATAL INTENSIVE CARE UNIT

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# DEDICATION

I would like to dedicate this thesis to my family and partner. My amazing and supportive family encouraged me to do a graduate degree even when I doubted myself. My dedicated and thoughtful partner supported me through the research and writing process with endless love and understanding. And to my dog, Nellie, who forced me to take breaks for our daily walks. The importance of those moments away from this project was never lost on me.

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DEVELOPMENT OF A THEORY-INFORMED PATIENT DECISION AID TO FACILITATE CONSENT TO GENETIC TESTING IN THE NEONATAL INTENSIVE CARE UNIT

Genetic testing is an essential diagnostic tool in the neonatal intensive care unit (NICU) that can shorten infants' stays, improve accuracy and effectiveness of medical care, and overall improve quality of life. However, there are challenges involved in the process of recommending life-saving and care-changing genetic testing in the NICU, including parental concerns around issues of paternity, guardians' decisional anxiety, low health literacy, limited understanding of genetic testing, and receiving conflicting information from different healthcare providers. These challenges are exacerbated by the urgency guardians face in the NICU; guardians' first exposure to genetic testing often occurs immediately before they are asked to decline or consent to it while in an extremely emotional state and fraught environment, creating a sense of urgency that affects decision-making. Current patient-provider communication practices in the NICU could benefit from improved, streamlined communication tools to help guardians make thoughtful decisions about genetic testing for their hospitalized infants. One potential strategy to streamline communication about genetic testing in the NICU is incorporating self-determination theory into patient decision aids. A series of three iterative interview rounds with NICU guardians and new guardians of infants younger than three years old were conducted. Following each round of interviews, recordings were transcribed, and feedback from participants was used to revise a patient decision aid guided by self-determination theory. After completing all three rounds of interviews and revisions,

thematic analysis was conducted on all transcribed interviews to identify salient themes to NICU genetic testing decision-making. The final version of the patient decision aid developed from this study will serve as a starting point for integrating this important tool into the NICU.

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## Chapter One: Genetic Testing in the Neonatal Intensive Care Unit

Yearly, 3.6 million babies are born in the United States (Centers for Disease Control and Prevention, 2021) and some of these infants will be hospitalized in a neonatal intensive care unit (NICU) due to low birth weight, premature birth, problems or difficulties eating, breathing, or swallowing, and other health challenges. In fact, researchers estimate that between 9 and 10% of babies are hospitalized in a NICU (Kim et al., 2021; Shulman et al., 2018), while some medical centers report that as many as 10-15% of babies are hospitalized (Oakbend Medical Center, n.d.). Nearly 30% of NICU infants have a genetic condition contributing to their stay (Willig et al., 2015). Some genetic conditions can be quickly and accurately diagnosed based on symptoms and physical characteristics, whereas others require medical laboratory testing.

Genetic testing is a crucial tool to diagnose specific medical conditions in hospitalized infants (Farnaes et al., 2018; Willig et al., 2015). Genetic testing can significantly shape plans of care, improving infants' quality of life during their hospitalization. Unfortunately, because genetic testing is a complex process to understand, guardians may struggle to make informed decisions about testing for their infants (Wöhlke et al., 2019). Additionally, the NICU poses unique challenges to patient-provider communication that could address guardian understanding. For example, because guardians come and go frequently at various times of day, they often encounter different care team members who provide different or conflicting information about testing. Additionally, guardians may hear information from the neonatology team without processing or understanding it, especially regarding risk percentages and numeracy, which are prevalent in genetic discussions (Wöhlke et al., 2019). Even among guardians

with factual understandings of genetics, many cannot explain or conceptualize what results may mean, indicating limited comprehension (Lanie et al., 2004).

Many of these challenges can be attributed to communication breakdowns in the NICU. There are many barriers to effective NICU communication which can make genetic testing decisions even more difficult for guardians (Hall et al., 2015; Labrie et al., 2021). Addressing communication challenges in the NICU can help guardians make informed decisions about genetic testing for their infants. Although no decision is inherently right or wrong, the *timing* of these decisions is essential; researchers have demonstrated that the sooner testing is initiated – or the sooner guardians *decline* testing and the team can redirect diagnostic and care efforts – the better the results of care for the infant (Meng et al., 2017; Willig et al., 2015). In this study, I explore the development of a theory-informed decision aid to address communication challenges in the NICU pertaining to genetic testing. This research does not focus on consent, nor is the final material a consent tool; rather, this research emphasizes streamlining communication in a challenging environment to help NICU guardians make the best decisions for their infants. This research operationalizes a motivation theory as a communication framework to help guardians assess their understanding, identify confusion, and ask questions to help them make decisions.

**The Need for NICU Genetic Testing Communication**

The birth of a newborn is an incredibly exciting and potentially stressful experience for parents, guardians, and other family members. The stress of having a new baby may be compounded by illnesses and conditions that present before, during, immediately after, and within a few months of an infant's delivery. Sick infants often

enter the NICU where expert clinicians and nursing staff can provide care. Still, admission to the NICU does not guarantee a clear or straightforward diagnosis or treatment. An unclear diagnosis path often leads to the recommendation for genetic testing. But when guardians are overwhelmed, stressed, and uncertain about their infant's well-being, consenting to additional testing with potentially fatalistic results can be daunting.

Babies most commonly enter the NICU because they are born preterm, have a low birth weight, or have a health condition (Stanford Medicine Children's Health, n.d.). Some conditions are easily identifiable with minimal testing, such as low birth weight, Downs Syndrome, and Fetal Alcohol Syndrome. Other health conditions are not easily diagnosable by physical appearance or symptoms. In these cases, neonatologists and neonatal nurse practitioners may recommend genetic testing (Wojcik et al., 2018). Genetic testing is "the analysis of DNA to identify changes in gene sequence (deletions, additions or misspellings) or expression levels" (American Medical Association, n.d.). Diagnosing genetic conditions informs appropriate care plans, making genetic testing an essential diagnostic tool in the NICU. Multiple types of genetic tests are available for hospitalized infants, including microarray, whole-exome sequencing, and whole-genome sequencing (Carroll et al., 2020). For the purposes of this study, any type of genetic test will be included in the term "genetic testing."

Genetic conditions contribute greatly to morbidity and mortality in the NICU. Meng et al. (2017) reported that 36.7% of 278 infants admitted to a Texas NICU who underwent genetic testing had a genetic condition. The presence of genetic conditions is important because new research suggests genetic conditions play a role in sudden infant

death syndrome, with nearly 20% of neonatal mortality in a 3-year period being attributed to genetic conditions (Opdal & Rognum, 2011; Yang et al., 2020). Wojcik et al. (2018) supported this, finding that more than half of infants admitted to the NICU who did not survive early childhood were suspected of having a genetic disorder. These findings represent the significant burden that genetic disorders have on infant mortality in the NICU.

In cases of morbidity, the presence of genetic conditions can also influence plans of care for hospitalized infants – but these changes to care can only occur with a confirmed diagnosis. Dimmock et al. (2021) reported that genetic conditions were directly linked to 40% of babies' admissions to the NICU, and findings of a genetic condition led to at least one change in medical care for 32% of the babies. Meng et al. (2017) reported an even higher rate of change, with 52% of the neonates' management plans changing substantially because of genetic diagnoses. Care plan changes can include beginning or postponing medicinal or surgical treatments, and withholding unnecessary treatments can also prevent unnecessary expenses and harm to the infant (Farnaes et al., 2018). Additionally, genetic diagnoses can lead providers to recommend initiating palliative care for some patients. Willig et al. (2015) found that 30% of NICU babies diagnosed with a genetic condition were given palliative care, a treatment strategy to enhance patients' quality of life when diagnosed with an incurable or untreatable condition.

Although reported rates of change to care based on genetic diagnoses vary, researchers have demonstrated that diagnosing genetic conditions can greatly shape and improve babies' care plans, while reducing unnecessary costs and other harms. Because

up to 30% of genetic diagnoses take place post-mortem (Wojcik et al., 2018), it is also possible that some of the reported mortality attributed to genetic conditions in the NICU could be avoided with these care plan changes. The importance of genetic testing in the NICU for diagnosis and treatment is clear. As Meng et al. (2017), Willig et al. (2015), and others have shown, genetic testing must happen earlier in infants' hospitalizations to be most effective. However, there are many guardian concerns that lead to delayed or declined consent to testing and leave vulnerable infant populations in need.

**Addressing the Challenge: Why Guardians Decline Genetic Testing**

Despite the demonstrated importance of genetic testing as a diagnostic tool in the NICU, some guardians decline testing for their infant. There is limited research on why guardians decline genetic testing, and what research exists typically takes place in clinical research trials because guardian consent is necessary to enroll the infant. Genetti et al. (2019) found that 15% of parents surveyed declined genetic testing in a research capacity because they felt overwhelmed by their infant's illness, while 13% declined because of concerns about privacy management. Parents also expressed concerns about insurance discrimination and privacy/confidentiality when considering genetic testing for NICU infants and pediatric children (Genetti et al., 2019; Smith et al., 2018). There are also concerns about nonpaternity and incidental findings. Nonpaternity, or misattributed paternity, is the finding that the suspected father of an infant is not the biological father (Lucast, 2007). Incidental findings are the discovery of a condition or disorder that is unrelated to the illness with which the baby presents (Christenhusz et al., 2013). Parents may fear distressing results that affect their decisions to have future children or have

implications for their other children. These aspects of genetic testing contribute to declined or delayed testing in the NICU.

An additional reason guardians may decline genetic testing is that laypeople's understanding of genetics and genetic testing is limited. Generally, laypeople find genetic testing useful, but the concept of testing brings much discomfort (Wöhlke et al., 2019). Much of this discomfort may come from lack of knowledge, as laypeople's understanding is limited to the concept of heredity, or the ability to inherit or pass on a certain condition or disease (Condit, 2010). Any level of uncertainty, such as risk percentages and numeric information, greatly decreases people's understanding of genetics (Wöhlke et al., 2019). Even among individuals who demonstrated a higher understanding of genetics, participants were concerned that genetic testing would change a person's future, affect their health insurance, and potentially impact job status (Haga et al., 2013). Additionally, although people are often able to give examples of non-medical genetic conditions, one-third struggled to define "genetics" and nearly half provided multiple definitions, indicating that they were unsure what genetics really are (Lanie et al., 2004). Haga et al. (2013) found that many participants had relatively high factual knowledge of genetics, but knowledge was impacted by age, education level, and race. Even among those who generally understand genetics and genetic testing, there are misperceptions, concerns, and barriers to consenting to it, especially for an infant.

Dr. Kristen Suhrie, MD, director of perinatal genetics and attending neonatologist at Riley Hospital for Children in Indianapolis, stated that 10-20% of guardians decline testing for their infants in the Indiana University Health system's NICUs (Suhrie, personal communication, Aug. 30, 2022). Dr. Suhrie's team does not currently track the

reasons why guardians decline genetic testing. Of the 80-90% who do consent, Dr. Suhrie stated that it often takes multiple attempts by medical professionals to obtain consent. This means delayed testing for some infants, and delayed results can lead to additional invasive tests or unnecessary procedures and prolonged suffering for the NICU patients. Additionally, Dr. Suhrie and her team believe that due to their distress and the general urgency of the NICU, some guardians may consent to genetic testing without fully understanding the ramifications of test results, which could have lifelong implications for their baby, themselves, and their extended family. Kumar et al. (2019) supported this concern, finding that many parents who consented to pediatric genetic testing believed they fully understood the outcomes of test results but later realized they had not. There is likely morbidity and mortality among infants hospitalized at Riley that can be attributed to undiagnosed genetic conditions in the 10-20% of infants who do not receive recommended testing.

An additional challenge is that NICU infants have many care team members coming and going for their care, meaning guardians encounter many team members and hear various perspectives and attitudes toward testing (Suhrie, personal communication, Aug. 30, 2022). Streamlining the communication process so that all care team members provide the same information to guardians and improving guardians' comprehension of genetic testing to enable faster, more thoughtful decision-making in the NICU is essential for diagnosing infants' genetic conditions. First, streamlining communication may help guardians who would already consent to genetic testing do so faster, leading to earlier testing that yields more useful results. Second, streamlining communication may help guardians who would otherwise decline genetic testing do so faster, which is crucial for

alerting the care team that other non-genetic testing procedures, tests, or care may be needed. As for guardians who are indecisive about testing, streamlined communication may help them identify their questions to help the team quickly and accurately answer those questions and respond to any concerns.

Genetic diagnoses can greatly affect babies' care plans and improve appropriate disease management (Farnaes et al., 2018; Willig et al., 2015). Helping guardians make fully informed decisions about genetic testing for their infants requires effective communication, which includes developing rapport with guardians, sharing comprehensive information with them, and assessing their perceptions of that information (Pick et al., 2014). Currently, research on communication in the NICU is non-specific to genetic testing, often focusing instead on the quality and functions of communication (Govindaswamy et al., 2019; Kasat et al., 2020; Wigert et al., 2013). Alternately, research on communication practices among adult populations focuses on genetic counseling and the communication that occurs during counseling sessions, which arguably have a vastly different environment and emotional state than the NICU (Ellington et al., 2006; Jacobs et al., 2019; Meiser et al., 2008). Because of the unique NICU environment, there is a need for research on communicating about genetic testing in this specific setting.

**Current Research on Genetic Testing Communication**

Communication research about genetic testing is varied and often focuses on adult populations. Some researchers have explored risk communication with adult patients and their immediate family members, while others have focused on the family dynamics of communication about results that may affect other family members (Gaff et al., 2005; Gates, 2004). Gaff et al. (2005) found that family communication in genetic testing is

often tedious and leaves room for errors; if the counselor relies on the patient to disclose the genetic test results to potentially affected family members, there is a high likelihood of incorrect information sharing, whereas if genetic counselors actively try to include all relevant family members, there is the possibility of doing harm through emotional distress and violations of privacy. Gates et al. (2004) concluded that when women seek prenatal genetic counseling and testing, they and their partners often struggle to understand risk and "need assistance in understanding risk information and in thinking about how this information can be used effectively in their reproductive decision making" (p. 225). Both findings are important in the NICU, as genetic testing results often have implications for other family members, and guardians will likely struggle to comprehend numerical information about risk.

Others have researched the specific challenges of communication about genetic testing, including the psychological implications for at-risk family members and practical clinical utility (Roberts et al., 2020). Roberts et al. (2020) specifically urge the additional training of general healthcare professionals, in addition to those who historically recommended genetic testing, as more patients in different clinical areas will need it. Alternatively, others have identified common communication patterns in genetic counseling communication styles (Ellington et al., 2006). Ellington et al. (2006) found four distinct communication patterns among genetic counselors: client-focused psychosocial, biomedical question and answer, counselor-driven psychosocial, and client-focused biomedical. The researchers argued that different communication styles may be appropriate for different patients.

Because the importance of communication in genetic counseling is well-recognized, there are current efforts to improve communication about genetic testing with adults. Jacobs et al. (2019) concluded that communication practices can improve patient understanding about risks and benefits associated with genetic testing, which makes informed consent easier to obtain. However, communication cannot be streamlined among adult genetic testing patients. Hallquist et al. (2021) argued that different levels of communication approaches were appropriate for specific types of patients and diagnoses, with comprehensive genetic counseling sessions, targeted discussions, and brief interactions being relevant and necessary for different types of genetic conditions. This aligns with findings from Ellington et al. (2006) that different communication styles from counselors likely apply better for different patients and conditions. From these findings, it is clear that communication plays a critical role in genetic testing and counseling among adult populations, and because adult guardians consent on behalf of their infants, this information is useful in the NICU setting, as well.

Although there is ample research regarding communication about genetic testing among adult populations, the nature of testing and counseling for these patients is vastly different from the NICU patients who undergo testing. Whereas adult populations are likely to undergo multiple, extensive rounds of pre-testing counseling to prepare for potential results, the NICU requires rapid diagnosis in often distressing emotional cases. Additionally, a scoping review from Meiser et al. (2008) revealed that most genetic testing communication research comes from the same group of researchers and has been published in various forms across different journals, which means genetic testing communication research is often limited, duplicative, and focuses on the same

populations and conditions. Meiser et al. (2008) also noted that much of the communication research on genetic testing and counseling focuses on cancer testing. While these findings are helpful, they are not specific to the environment of the NICU. Although extensive genetic counseling occurs after testing in the NICU, there is urgency prior to testing that does not always permit time to consider the ramifications and potential impact of genetic testing results prior to the infant undergoing the test.

***Patient-Provider Communication in the NICU***

A key difference in genetic testing between NICU infants and adults is the nature of outcomes. NICU infants require genetic testing for urgent medical diagnoses, while adults often seek non-urgent diagnostic, predictive (hereditary), or prenatal genetic tests (Phillips et al., 2018). In non-urgent cases, adults have time to attend multiple formal genetic counseling sessions prior to testing. Alternately, in the NICU, genetic counseling happens rapidly, immediately preceding testing, which leaves little time for multiple rounds of counseling (Widmeyer & Jackson, 2021). This is an important difference to consider when evaluating existing research on NICU communication and genetic testing communication because many of the strategies to obtain informed consent, such as genetic counseling and thorough patient-provider meetings, are not always possible in the NICU. Delayed consent can be detrimental to hospitalized infants' well-being, but many guardians only learn about genetic testing for the first time immediately before a test is needed.

This issue is clear in the Riley Children's Hospital NICU genetic testing process, as outlined by Dr. Suhrie (Suhrie, personal communication, Dec. 7, 2022). First, a nurse practitioner or neonatologist flags a potential genetic condition in the NICU's system.

Next, a medical genetics consultation occurs with the staff geneticist to determine if a test is necessary. If so, the nurse practitioner or neonatologist requests a genetic counseling consultation for the family of the NICU infant. Following counseling and with the guardians' consent, the staff order and perform the test, then genetic counselors follow up with guardians regarding the results (Suhrie, personal communication, Dec. 7, 2022). Oftentimes, the first genetic testing exposure guardians have is the genetic counseling session, which Dr. Suhrie and the NICU team believe contributes to guardians' declining or delaying consent to genetic testing. Dr. Suhrie and the NICU team identified a need for thorough communication between the nurse practitioner or neonatologist and families to better prepare them for the genetic counseling session. This aligns with recommendations from Roberts et al. (2020) to train non-genetics team members for better genetic testing and results discussions with patients and families.

Although there is limited research on communication about genetic testing in the NICU, it is well known that communication in general is an essential element of providing effective care in the NICU (Hall et al., 2015). Communication affects parental participation in decision-making and care activities, with positive, effective communication increasing parents' participation (Labrie et al., 2021). Communication can alleviate parental and guardian stress, which in turn allows them to make better-informed decisions for their babies' health. Despite the importance of communication in the NICU, Wigert et al. (2013) identified three main parental complaints about patient-provider communication in the NICU: lack of professionalism, poor information giving, and lack of emotional support. These complaints contradict the four functions of NICU communication: to build and maintain relationships, exchange information, share

decision-making, and enable parent self-management (Wreesmann et al., 2021). Importantly, these functions are a process, not a list; the first function must be met to achieve the following functions. However, there are multiple barriers that make it difficult for communication to function properly in the NICU.

***Barriers to Communication in the NICU***

The NICU is a high-stress, high-stakes environment, which presents multiple barriers to effective communication. Obeidat et al. (2009) identified a theme of emotional instability in the NICU; parents, especially mothers, felt insecure, threatened, and guilty during their infants' hospitalization. These feelings contributed to high decisional stress, and an estimated 50% of NICU guardians reported moderate to severe decisional anxiety (Wainstein et al., 2022). In the context of genetic testing, decisional anxiety could contribute to delayed consent or declination of genetic testing. Labrie et al. (2021) found that communication interventions to build relationships with parents can reduce decisional anxiety. However, while developing relationships with providers can alleviate some emotional instability, the residual instability also makes it difficult for guardians to connect with their infants' care teams. For this reason, there are current efforts to improve NICU staff members' ability to provide psychosocial and emotional support to guardians (Hall et al., 2015; Kasat et al., 2020).

An additional source of guardian stress is the nature of a NICU hospitalization, which frequently requires long stays that disrupt daily life, work, school, and more. In most cases, guardians cannot stay in the NICU with their infant every hour of the day. This means guardians, especially mothers, often come and go from the NICU while continuing to care for other children and the household (Brett et al., 2011). The stress of

caring for a sick infant is exacerbated by the continuation of other responsibilities. Subsequently, guardians may receive updates about their infant's condition via phone calls from NICU staff while they are away from the infant (Govindaswamy et al., 2019). The nature of a NICU stay means guardians encounter many different nurses and medical professionals at different times and places. Each medical professional provides different information in different ways, and "poor continuity of staff" contributes to communication failures (Wigert et al., 2013, p. 11). Staff may provide conflicting information that confuses guardians, or they may explain the same information differently, resulting in misunderstandings. Poor staff continuity presents a challenge to both building and maintaining relationships, as well as information sharing.

An additional challenge in the NICU is health literacy. Health literacy is the "degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (Centers for Disease Control and Prevention, 2023). At the time of their infants' NICU admissions, 43% of parents had slightly low health literacy, meaning their ability to process complex health information was below the average (Mackley et al., 2016). Furthermore, nurses' ability to assess guardians' comprehension of complex medical information – which then informs a nurse's approach to sharing information – was not accurate (Mackley et al., 2016). It is likely that some nurses and doctors continue providing complex information to guardians of NICU infants without adapting to a guardian's literacy level. This presents a challenge to sharing information in an understandable way, a key communication function, and can further contribute to parental stress that creates decisional anxiety (Govindaswamy et al., 2019). Although

information sharing is still possible with low health literacy guardians, it requires more supplemental materials – specifically, written materials free of jargon that align with what medical professionals are sharing verbally (Lorie et al., 2021). Because the functions of NICU communication are a multi-step process, meaning they can and should happen consecutively to support the following function, poor information sharing inhibits guardians' ability to make informed decisions and self-manage their infants' conditions and needs.

***Communicating About Genetic Testing in the NICU***

The NICU poses unique challenges to communicating generally, but especially about genetic testing. Research on communication about genetic testing must be specific to the NICU setting, in which there is often little time for guardians to assess the full ramifications of genetic testing, and they do so under extreme duress (Gyngell et al., 2019). Wainstein et al. (2022) found that many guardians approached for clinical genetic testing research in the NICU environment felt rushed, distressed, and overwhelmed by their child's condition, which led to poor information retention and a lack of understanding of full ramifications. This is likely why some guardians may consent to genetic testing without fully understanding its ramifications (Kumar et al., 2019). Poor information retention also likely contributes to declined testing.

Additionally, guardians' sense of urgency and legitimate medical urgency of an infant's condition does not always permit time for pre-testing counseling, which yields the best results for obtaining informed consent (Smith et al., 2018). Fortunately, in the Riley NICU, all guardians whose infants are recommended for testing are required to meet with a member of the genetics team prior to consenting to genetic testing. However,

even with this meeting, guardians often have many questions and must take additional – often unavailable – time to make the decision (Suhrie, personal communication, Dec. 7, 2022). For these reasons, it is essential for clinicians recommending genetic testing to communicate effectively amidst the challenges of the NICU. One tool to facilitate effective communication, and which will be explored in detail in the next chapter, is patient decision aids.

**Summary**

Genetic testing can shorten infants' stays in the NICU, decrease the costs and financial burden on families and guardians, and help NICU providers give better and more personalized care to the infants. The need for effective communication in the NICU, specifically to help guardians make informed decisions about genetic testing – regardless of if they consent or decline – is also clear (Govindaswamy et al., 2019; Wreesmann et al., 2021). However, current communication practices may not be suited to achieving these goals, as demonstrated by findings from Lorie et al. (2021). In addition, it is crucial for NICU providers to have tools and communication materials that help guardians consent to or decline genetic testing *sooner* in the NICU stay so that appropriate next steps and measures can be taken. In the next chapter, I will explore a potential solution to this problem and how to incorporate and operationalize a unique theory to bolster an existing framework's usefulness.

# Chapter Two: Theoretical Framework

This chapter consists of three sections: a review of the patient decision aid (PtDA) framework, an examination of self-determination theory (SDT) and its constructs, and finally, an operationalization of both PtDA and SDT as communication frameworks to develop an initial NICU genetic testing decision aid.

## Patient Decision Aids

PtDAs are a framework for reducing decisional anxiety and facilitating patient decision-making in hospitals and healthcare settings through intentional communication practices and the creation of supplemental materials (Poprzeczny et al., 2020). PtDAs are not theories; instead, they are a framework for creating, testing, and implementing supplemental materials that help patients understand complex medical information and come to a more fully informed medical decision (Ankolekar et al., 2018). Generally, PtDAs include "information about the disease type; treatment options; risks, benefits, and uncertainties associated with each option; and a form of value clarification exercise in which patients are asked to make choices [on] the basis of the tradeoffs between the treatment options and risks" (Ankolekar et al., 2018, p. 2). But importantly, PtDAs are more than just information. Coulter et al. (2013) detailed a specific process for creating a PtDA as: "a) assessing decisional needs, including analysis of the characteristics of the decision, specification of treatment options, outcomes and probabilities, and of patients' information needs and their requirements for decisional support; b) formation and composition of groups to develop and review decision aids; c) methods for drafting, reviewing and revising these; d) field testing with patients; and e) external peer review or critical appraisal by people not involved in its development" (p. 1). It is crucial to

remember that PtDAs *aid in decision-making*; they should not be coercive, directive, or lead readers/users to feel that only one decision is correct (Poprzeczny et al., 2020). Additionally, reading and using a PtDA is *not* the same as signing an informed consent document.

In response to needs for supplemental materials that increase comprehension, PtDAs have grown in popularity; however, there is difficulty regulating their development and monitoring their effectiveness (Danner et al., 2022). Current research does provide hope about their efficacy. Wakefield et al. (2007) showed the efficacy of genetic testing PtDAs for cancer patients, demonstrating that PtDAs can reduce anxiety, decrease emotional distress, and increase understanding about complex medical topics. Interestingly, Kirkscey (2017) found that genetic testing PtDAs are often used by non-genetic counseling staff. This consideration is crucial for the NICU setting, in which nurse practitioners and neonatologists are most likely to make genetic testing recommendations to parents and guardians before sending them to genetic counseling; this first discussion about genetic testing can set the tone for guardians.

When developed effectively, PtDAs offer a strategy to bridge the gap Lorie et al. (2021) identified – that a lack of written supplemental materials is a key weakness in NICU communication. Additionally, PtDAs provide better support for guardians with low health literacy levels by offering simple supplemental materials, which can bridge the health literacy gap in the NICU (Mackley et al., 2016; McCaffery et al., 2013). For example, decision aids can provide easy-to-follow information that improves processing of verbal information, along with visuals depicting risks and percentages that are otherwise difficult for some people to understand. For these reasons, PtDAs may be an

effective solution to address the need for clear, streamlined NICU genetic testing communication.

Although extant research presented here (Meng et al., 2017; Willig et al., 2015; Wojcik et al., 2018) makes it clear that genetic testing is a useful and necessary tool in the NICU, and that researchers and practitioners want to *increase* rates of testing, the ultimate goal of a NICU genetic testing PtDA is to help practitioners and guardians overcome communication challenges in the NICU. This tool is *not* an informed consent document. This tool would serve two functions: first, to help reduce decisional anxiety for guardians so that they make more informed decisions, even if they choose to decline testing; and second, to provide a resource that would allow the decision-making process to be accelerated for this time-sensitive testing. PtDAs reduce decisional anxiety (Wakefield et al., 2007), a contributing factor to declined or delayed consent to genetic testing (Wainstein et al., 2022). Reducing that anxiety will likely increase rates of consent, even though that is not the primary function of the tool.

To create an effective PtDA, practitioners must incorporate sound theories and the guiding principles of PtDA development. Although theories make testing, replicating, and discussing results easier, the majority of PtDAs do not incorporate them (Chavez-Yenter et al., 2021). Durand et al. (2008) argued that incorporating theory would create more effective PtDAs because theories help practitioners "describe, explain and predict how individuals make complex decisions" (p. 132). While Durand et al. (2008) advocated for the use of decision-making theories, Gültzow et al. (2021) advocated for behavior change theories. Behavior change theories explain behaviors and factors that influence motivation, while decision-making theories focus on decisional biases and reasoning

(Gültzow et al., 2021). Because PtDAs themselves are a type of decision-making framework already, adding theories outside of decision-making may make them more effective.

However, this theory integration can be taken a step further. In a meta-analysis of 513 empirical papers examining patient decision aids, only 23% used any theory at all, with the vast majority of those using a behavior change theory (Chavez-Yenter et al., 2021). Only 3% of the theories used were communication theories, despite the role that communication plays in decision aids, and few of the papers explored theoretical or practical implications of the theories they used (Chavez-Yenter et al., 2021). To strengthen the PtDA and make it most useful for care team members, guardians, and others, a theory that can be both operationalized and applied to communication should be used. Additionally, because most theories used in decision aids are already behavior-based (Chavez-Yenter et al., 2021), a motivation theory that can be applied to communication may be the best fit. One theory that can be incorporated into PtDAs and directly aligns with the four functions of communication in the NICU is self-determination theory (SDT). Although SDT is a theory of motivation, researchers have identified the crucial role of motivation in behavior and behavior change (Teixeira et al., 2020), meaning SDT may bridge the gap between the decision-making nature of the decision aid and the inherent behavioral aspects of decision-making.

**Self-Determination Theory as a Communication Guide**

Self-determination theory (SDT) is a motivation theory that argues peoples' needs for autonomy, competence, and relatedness must be met for them to engage in, or be motivated to engage in, specific behaviors (Ryan et al., 2008). Autonomy is a person's

"perception of being the origin of one's own behavior and experiencing volition in action," or the feeling of being in control of one's life and decisions; competence is "the feeling of being effective in producing desired outcomes," or feeling *able* to do different behaviors; and relatedness is "feeling respected, understood, and cared for by others" (Ng et al., 2012, p. 327). These three psychological needs are "essential for facilitating optimal functioning of the natural propensities for growth and integration, as well as for constructive social development and personal well-being" (Ryan et al., 2000, p. 68). When these needs are met, people are more engaged and motivated in decision-making and have better health outcomes (Ryan et al., 2008). Importantly, the creators of the theory argue that humans are naturally inclined toward activity and integration, but they are also vulnerable to passivity (Ryan et al., 2000). Vulnerability to passivity makes it crucial for practitioners to advocate for individuals' choices and decision-making with non-coercive guidance and support.

Interestingly, although all three psychological needs should be met to ensure an individual's best motivation and health outcomes, autonomy is arguably the most important. Autonomy – and the emphasis on patient-centered, non-coercive decisions – is ultimately the construct that makes this theory's integration with a decision aid so fitting. Deci and Ryan (2012, p. 2) write that:

> … the opposite of autonomy is being heteronomous or controlled. This means being pressured to think, feel, or behave in particular ways whether through coercion or seduction. … Within SDT, we emphasize the importance of not being controlling with patients. This means respecting their frame of reference and helping them to chart a pathway of engagement in their own care that they can both endorse and apply. We hasten to add, however, that support of autonomy is not an implicit endorsement of being permissive or neglectful of encouraging patients to do whatever they want.

Because of the theory's emphasis on *helping patients make decisions* by providing information and a "pathway of engagement" without coercion, it is ideally suited to application in a PtDA. Additionally, its efficacy in other research and interventions further supports its integration.

Importantly, SDT is a flexible and "malleable" theory; scholars note that one of the greatest benefits of the theory is that "SDT researchers can develop and implement intervention strategies that are purported to satisfy the three basic psychological needs" (Fortier et al., 2012, p. 2). Because of its malleability, SDT has been used in many health-related contexts. Ridgway et al. (2016) studied how autonomy-supportive physicians and audiologists could shape hearing-impaired people's decisions about hearing aids. Interestingly, though, this research emphasized one construct, autonomy, rather than all three, likely because of the theory creators' emphasis on the construct. Other researchers have used SDT to assess physicians' engagement in self-management support for patients with chronic conditions, ultimately finding that competence was the most important construct for predicting behavior (Kosmala-Anderson et al., 2010). SDT has also been studied in the context of exercise decision-making, with researchers finding that "strong perceptions of health care provider autonomy support for exercise were predictive of mindfulness and perceived competence" (Martin et al., 2017, p. 12). These studies focus more on health behaviors than decisions; however, at the start of each health behavior is a decision: to do or not do the activity, adopt or not adopt the behavior or technology, etc.

Although SDT is a psychological theory of motivation, the language surrounding its use often centers communication techniques. For example, SDT argues that "patient autonomy may be supported, in part, by *making explicit recommendations* about health

and well-being" (emphasis added) (Patrick et al., 2012, p. 8). Murray et al. (2015) furthered the communication connection by creating a physician training program that used specific language techniques and communication guidelines, such as setting SMART (specific, measurable, attainable, relevant, and time-bound) goals and providing verbal rationales. Furthermore, SDT constructs also align well with the functions of communication in the NICU. As Wreesmann et al. (2021) identified, functions of effective NICU communication should build and maintain relationships, which corresponds with relatedness; exchange information, which aligns with competence; and enable parent self-management and share decision-making, which pair with autonomy. Because of the overlap between effective communication and SDT constructs, researchers have begun assigning specific communication strategies, messages, and characteristics to the constructs of SDT (Brown et al., 2021; Head et al., 2022; Martela et al., 2021). Martela et al. (2021) has concluded that although the existing research on the application of SDT to communication is preliminary, "several of the principles are not only recommended by SDT but also other theoretical traditions such as... research on persuasion, and research on community-based social marketing techniques, research on procedural fairness, and motivational interviewing" (p. 335). This finding supports the future use of SDT as a communication framework.

The most relevant research to date for genetic testing communication using SDT comes from Brown et al. (2021). The researchers asked parents to examine three different letters about genetic testing for a condition their children had. The letters contained different content and design elements, and parents were interviewed about what they liked, disliked, and remembered from each letter. Thematic analysis revealed three key

findings: content can communicate autonomy and competence, letters can act as an extension of relationships between providers and parents, and supplemental materials are essential to communicating complex medical information (Brown et al., 2021). These findings extended the physician SDT-communication training work done by Murray et al. (2015). These findings are especially important in the NICU setting, where 56% of parents reported not receiving written materials about their babies' conditions, and 28% of parents reported conflicting information from different staff (Kasat et al., 2020). Although this research was specific to pediatric guardians, the findings still support using SDT to communicate about genetic testing.

An additional examination of SDT as a communication framework comes from Head et al. (2022). The authors used a similar letter analysis as Brown et al. (2021) to create patient materials that encouraged follow-up care after screening positive for Alzheimer's/dementia among older primary care patients. Head et al. (2022) assigned clear communication practices for each SDT construct (see Table 1) in their research on patient letters. Competence was assigned clear, plain-language explanations of testing, guidance on interpreting results, formatting, and reading level. Autonomy was assigned reminders of previous healthy actions, suggestions for future actions, and patient/family empowerment for participation in decision-making. Lastly, relatedness was assigned acknowledgement of result's impact, personalization, and gratitude. This research provides a clear framework for creating patient materials that communicate the importance of a difficult medical subject in a way that facilitates patient/family participation (Head et al., 2022). Head et al. (2022) and Brown et al. (2021) both operationalize abstract theoretical constructs (autonomy, competence, and relatedness) by

assigning clear, tangible practices – such as using white space and clear headings, including reminders of previous actions, etc. – that convey those constructs.

**Table 1**

*Self-Determination Theory: Constructs as Communication*

| Theoretical construct | Definition | Communication practices |
|---|---|---|
| **Competence** | "the feeling of being effective in producing desired outcomes" | Clear explanation of test purpose using plain language and simile<br>Guidance for interpreting test result<br>Readability analysis ~6th grade reading level<br>Formatting with size 12 font, white space, numbered lists, and infographics |
| **Autonomy** | "perception of being the origin of one's own behavior and experiencing volition in action" | Reminder of previous actions<br>Suggestions for future actions<br>Empower patient/family participation |
| **Relatedness** | "feeling respected, understood, and cared for by others" | Acknowledgement of impact of test result news<br>Gratitude<br>Personalization/use of patient name and pronoun |

*Note.* Table 1 is adapted from Head et al. (2022); definitions are from Ng et al. (2012, p. 327)

Martela et al. (2021) further explored strategies to communicate SDT constructs for greater adherence to COVID-19 guidelines. Competence-supportive communication techniques included providing concrete instructions and clear guidance on exceptions, addressing key barriers to the behavior, and providing relevant feedback. Relatedness-supportive communication techniques included acknowledging perspectives, feelings, and conflicts; emphasizing and facilitating shared identity and fate; and remaining transparent and honest. Lastly, autonomy-supportive communication techniques included

providing meaningful rationale and treating people as independent, responsible agents. Combining these guidelines with the framework from Head et al. (2022) may address all four functions of communication presented by Wreesmann et al. (2021): building and maintaining relationships, exchanging information, sharing decision-making, and enabling parent self-management.

**The Current Study**

One possible strategy to create more effective communication in the NICU is a PtDA operationalizing SDT constructs as a framework for intentional communication. The efficacy of SDT as a communication framework has been demonstrated by multiple researchers (Brown et al., 2021; Head et al., 2022). However, there is no existing research on how guardians may use or benefit from NICU genetic testing communication materials using SDT as a guiding framework. This leads to the following research questions:

RQ1: What can guardians reveal about the potential functions of a theory-informed neonatal genetic testing PtDA?

RQ2: What can guardians reveal about the potential uses of a theory-informed neonatal genetic testing PtDA?

RQ3: What can the message testing process reveal about guardians' larger emotional, informational, and autonomy needs during the NICU genetic testing recommendation process?

**Operationalizing SDT in a PtDA: Initial Development**

The project detailed in this thesis entailed two major components: development of the initial theory-informed PtDA and a qualitative evaluation and revision of the PtDA.

In this section, I will detail the process I used to develop the initial first version of the decision aid. As noted above, there are many ideas about best practices for creating strong decision aids, but there are limited frameworks with evidence-based efficacy (Danner et al., 2022). Efforts to centralize decision aid development have been led by the International Patient Decision Aid Standards (IPDAS) Collaboration. IPDAS often cites exemplar decision aids, and they offer "the latest evidence on 11 core IPDAS domains: development process, providing balanced information, communicating probabilities of outcomes, clarifying values, using personal stories, guidance and decision coaching, disclosing conflicts of interest, health literacy, basing information on scientific evidence, measuring effectiveness, and implementation of PtDAs" (Stacey et al., 2021, p. 729). IPDAS lists five steps in their SUNDAE (Standards for UNiversal reporting of patient Decision Aid Evaluations) framework for developing PtDAs: Planning, drafting, consensus, dissemination, and maintenance (Sepucha et al., 2018). Unfortunately, this SUNDAE process is not accessible to a graduate student working independently. For example, SUNDAE best practices include receiving endorsement from IPDAS' steering committee. Rather than focusing on the actual development and implementation of decision aids, IPDAS seems to focus on legitimizing decision aids.

Because there are few clear, accessible guidelines for the initial development of a decision aid (Hæe et al., 2023), I relied almost exclusively on the framework for systematic development presented by Coulter et al. (2013), which has been replicated and deemed effective by Hæe et al. (2023). Coulter et al. (2013) also provided a crucial template for documenting the decision aid development process, which was essential to this first draft (see Table 2). Additionally, I frequently reviewed the Colorado Program

for Patient Centered Decisions website, a leader in PtDAs which includes a variety of example decision aids in various forms, including videos, websites, and brochures or packets. This site and its example decision aids were incredibly useful for the structuring, layout, and design choices when creating PtDAs.

**Table 2**

*Decision Aid Development Process Template*

| | |
|---|---|
| **1. Scope** | |
| | a. Described health condition or problem |
| | b. Stated the decision that needs to be considered |
| | c. Specified target audience |
| | d. Explicitly identified guiding theoretical framework, if applicable |
| **2. Steering Group** | |
| | a. Included patients, clinicians, other experts (patient educators, shared decision making experts, policy makers, others) |
| | b. Membership clearly identified including credentials |
| | c. Conflict of interest identified, if applicable |
| **3. Design** | |
| | a. Elicited patients' views on patients' information and decision support needs (reported method) |
| | b. Elicited clinicians' views on patients' information and decision support needs (reported method) |
| | c. Described media and format with rationale |
| | d. Described intended setting |
| | e. Explicitly described timing of introduction into patient pathway, how and when decision aid will be distributed to patients and/or clinicians |
| | f. Appraised and summarized quality of clinical evidence relevant to the decision and options, described methods for evidence review |
| | g. Described prototype development |
| **4. Alpha testing (comprehensibility and usability)** | |
| | a. Reviewed by patients / family members |
| | b. Reviewed by clinicians |
| | c. Reviewed by other experts (specify: ____) |
| **5. Beta testing in "real world setting" (feasibility)** | |
| | a. Data collected on patients' experience of using PtDA |
| | b. Data collected on clinicians' experience of using PtDA |
| | c. Peer review by experts external to development process |

Note. Table 2 is from Coulter et al., 2013.

Even the framework outlined by Coulter et al. (2013) is sometimes unclear or seems to repeat steps or suggest them out of order. For example, the scope step includes identifying a guiding theory, whereas the second step, steering group, may be the best time to identify a guiding theory when there are multiple ideas and various people's expertise coming together. Additionally, the first and second step often do not happen chronologically or linearly; in my experience with this project and several others, many of these steps happen concurrently or out of order but yield the same results. However, despite some hiccups with this development guideline, this was the most thorough and strongly supported framework I could find for the initial development of the decision aid.

To start the development of the first version, I consulted Dr. Suhrie. She helped with all elements of the scope step, clearly explaining the problem, the decisions to be made, and the target audience. These are all reflected in Chapter One. Next, I gathered a steering group, including Dr. Suhrie, Dr. Katharine Head, and Jane Hartsock, JD, System Director of Clinical and Organizational Ethics, IU Health. All three provided unique insights and expertise, and it was in this group that SDT was identified as an ideal and potentially useful theory to incorporate in the decision aid. For the design step, I relied heavily on Dr. Suhrie's clinical and practical knowledge of the NICU and its population. She helped me understand what information she sees NICU guardians struggle with or want more of, what language and phrases have proven successful for her in the past, what concerns guardians present to her, and what challenges to be aware of. For example, she was very clear that NICU stays are banded bills, meaning guardians do not typically see the individual cost of a genetic test; rather than saying "Genetic testing is offered at no

cost to most families," she encouraged phrasing such as "Insurance covers the cost of genetic testing for most families."

With all the necessary background information, I designed a first draft of the decision aid. I used guidelines from Ankolekar et al. (2018) about what to include in the decision aid: information about the disease type, which was shifted to be information about testing and different types of results (suspicious, no diagnosis, or confirmed); treatment options, including guidance about how results help providers determine what treatments to initiate for various diseases; risks, benefits, and uncertainties associated with each option, including addressing guardian concerns about future children; and a form of value clarification on the basis of the tradeoffs between the treatment options and risks. This final piece was loosely incorporated in the decision aid through the use of spaces for questions and concerns; because I am not a genetic counselor, I was not qualified to create a value clarification exercise for the tool. Additionally, because this decision aid is not focused on a single diagnosis or condition, as decision aids typically are – for example, choosing between chemotherapy or radiation in the case of specific cancers – it is difficult to clarify values to cover a broad range of possible disease outcomes. Instead, I added a section with reasons for declining and reasons for getting genetic testing, similar to other decision aids on the Colorado website. Because I know this tool will be used in addition to conversations with medical experts and genetic counseling, I chose to *start* a type of value-based clarification activity but opted to leave the value-based discussion to genetic counseling experts.

While integrating this information in the decision aid, I specifically focused on incorporating SDT constructs. I relied on the operationalization outlined by Head et al.

(2022) to create my own guiding language for the tool, shown in Table 3. Dr. Suhrie was instrumental because of her considerable knowledge and experience working with guardians in the NICU; she suggested the analogy of genetic tests being like ultrasounds because guardians in the NICU are familiar with that type of testing, which helps build their competence. Additionally, she suggested language about shortening infants' stays and helping them receive better care, which she said guardians often care about most.

**Table 3**

*Operationalization of SDT constructs in initial PtDA draft*

| **Theoretical construct and practices** | **Examples of practices in the initial draft** |
|---|---|
| **Competence** | |
| Clear explanation of test purpose using plain language and simile | Your ultrasound helped us see your baby. Genetic tests help us see their genes, which helps us provide better care. |
| Guidance for interpreting test result | X-Rays take pictures of your baby's bones. Genetic tests take pictures of their genes. |
| Readability analysis ~6th grade reading level | Using similes and definitions to account for higher readability score of medical phrases like "genetic testing" |
| Formatting with size 12 font, white space, numbered lists, and infographics | Genetic testing is covered by most insurance. |
| **Autonomy** | |
| Reminder of previous actions | You've made countless important decisions for your baby's health. Genetic testing is just one more. |
| Suggestions for future actions | |
| Empower patient/family participation | It can shorten your baby's stay and even save you money in the long run. |
| **Relatedness** | |
| Acknowledgement of impact of test result news | We're here to care for your baby. Genetic testing makes it easier for us to do so. |

| | |
|---|---|
| Gratitude | We want to help you take your baby home sooner. Genetic testing can shorten your baby's stay in the NICU. |
| Personalization/use of patient name and pronoun | The earlier your baby gets genetic testing, the more useful the results are for us to give them better care. |

Note. Left column adapted from Head et al., 2022.

Other language choices reflecting SDT constructs can be viewed in Table 3 and the initial decision aid draft, Version 1 (note: because each version of the tool is 7-9 pages long, attaching or inserting all five versions would make the document unmanageable; links to the versions are included upon reference through the following section). After the initial development, this tool was shared with Dr. Head and Dr. Suhrie. Dr. Suhrie shared the tool with one of her nurse practitioners, and they reviewed it for clinical accuracy and deemed the tool appropriate to begin testing. With the initial draft developed, it was time to review the decision aid and collect data to answer the two research questions above. The following chapter discusses the methodology used to gather and analyze data.

# Chapter Three: Message Testing and Data Collection

To answer the research questions, I designed a study to qualitatively evaluate the NICU genetic testing PtDA. It is important to note that the methods of this research changed drastically from the proposed methods, often because of the same barriers that make it difficult for guardians to process genetic testing information. This chapter is divided into three sections to differentiate what was planned from what happened: the initial planned methodology, the significant barriers I encountered for conducting research as initially planned, and finally, the final methods and reasoning behind them.

## Initial Methods

At the beginning of this project, I planned to conduct a series of three to four semi-structured focus groups to iteratively test and refine the PtDA based on the stages of message testing focus groups outlined by Brown et al. (2008). These steps include developing the initial concept, developing partially completed materials, revising and re-presenting edited materials, creating alternative materials if necessary, and finalizing the finished product. Based on existing PtDA research and best practices (Crothers et al., 2016; Urman et al., 2019), each focus group was intended to be conducted with five to nine guardians of currently hospitalized NICU infants. In iterative focus groups, materials are provided for participants to review, then adapted, then adapted again based on participants' feedback (Brown et al., 2021). This aligned with the best practices for message development and pretesting outlined by Brown et al. (2008), which follow a similar patient decision aid development process as presented by Coulter et al. (2013). The materials developed and reviewed in the focus groups would be guided by SDT

constructs and the clinical expertise of Dr. Suhrie and the genetic counseling staff at Riley's Hospital for Children.

Interviewing guardians who are currently experiencing a NICU hospitalization is crucial to understanding their perceptions of and attitudes toward the decision aid and genetic testing. As Ward (2010) argued, "it is important to gain an understanding of the perspectives of families during the actual experience, because parents' beliefs are inevitably affected by infant outcomes and the passage of time" (p. 2). Subsequently, the initial plan was to prioritize interviewing NICU guardians whose infants were currently hospitalized at Riley's Hospital for Children, but who had been in the hospital for at least seven days to ensure guardians could adjust to the environment. Dr. Suhrie gave permission to host focus groups with guardians of currently hospitalized NICU infants in the NICU family rooms located at Riley (Suhrie, personal communication, Dec. 7, 2022). Conducting focus groups in this setting would have been accessible for participants as they are familiar with the environment and have convenient access to it. Additionally, this method would have eliminated the barrier of taking guardians away from their infant; rather than needing to meet in a community space and leave their infant miles away, they would be just down the hall in case of an emergency.

In addition to recruiting guardians of currently hospitalized NICU infants, at the suggestion of Dr. Suhrie, I also planned to conduct one focus group with workers from Riley's NICU parent assistance/navigation group, called the NICU Nest. NICU Nest workers provide emotional and navigational assistance to NICU guardians and often help with similar projects; additionally, per Coulter's et al. (2013), testing decision aids with practitioners helps gather additional insights that the target audience may not identify.

NICU Nest workers interact with different guardians in different units of the NICU and would facilitate snowball sampling for the focus groups by encouraging appropriate guardians to volunteer (Tracy, 2019). They would also offer unique insights into guardian concerns related to genetic testing, guardian perceptions of hospital stays, and other relevant environmental and emotional information. Additionally, NICU Nest workers are often past NICU guardians themselves, giving them unique personal insights regarding their own experiences and how they have interacted with other guardians experiencing similar challenges.

Because the tool is being developed for use at Riley specifically, guardians would have included biological, adoptive, and stepparents of NICU infants hospitalized at Riley's NICU, as well as grandparents and other individuals over the age of 18 who were the primary or sole caregivers and decision-makers of the hospitalized infant at the time of hospitalization. Additionally, participants would have been required to read and speak English. Guardians would only qualify for participation if their infants had been hospitalized for at least one week before the focus group. Waiting one week would have allowed time for other necessary tests and conversations to occur and provided space for guardians to adjust to the NICU environment and work through emotions and distress. If interested guardians' infants were discharged prior to the focus group date, they would still be invited to participate, though the expectation was that they would choose not to due to home responsibilities and caring for their newly discharged infants.

The initial plan was to conduct each focus group by recruiting from Riley, having potential participants complete a screening survey, then scheduling and hosting the focus group. Focus group participants would be handed a printed copy of the decision aid,

along with sticky notes, pens, and highlighters to make and annotate the tool. Each focus group would then be transcribed, and I would evaluate the feedback from the participants about the PtDA and make edits. Following the final focus group and final revision of the PtDA, I planned to identify consistent and different themes across all three focus groups using an overarching thematic analysis. Unfortunately, after receiving IRB approval and support from my committee and Dr. Suhrie for these proposed methods, several major barriers led to changes in the plan, including inclusion criteria, recruitment, and data collection.

**Methodological Barriers**

Research conducted in real-world settings in response to practitioner-identified problems often necessitates flexibility and on-the-go changes (Lindenberg et al., 2001; Strike et al., 2016). Researchers studying real-world problems and testing real-world solutions recommend changing course based on feedback from key stakeholders (Freeman et al., 2016) and in response to participants' needs (Lindeberg et al., 2001). For example, Strike et al. (2016) explained that when studying a harm reduction policy in an HIV clinic, participants "advocated that the traditional approaches used to embed community voices… be abandoned in favour of a flexible approach where advice and direction is solicited during group meetings through the project" (p. 152). The researchers had better results when adopting this method and emphasized the importance of adapting research and intervention practices to fit the population and the population's needs. Lindenberg et al. (2001) first used tangible incentives like gas cards and grocery coupons to recruit participants for a health education class in a community setting before changing their outreach and class to fit the home environment. These researchers highlight the

importance – and strengths – in adapting methodologies when solving real-world problems. The barriers to NICU communication that necessitated this research – feeling overwhelmed, experiencing anxiety, having to care for other children while also working, etc. – are also barriers for NICU guardians to participate in this research, and thus resulted in several changes to this project. Importantly, though the barriers presented here resulted in methods changes, they did not change the core of the qualitative methodology.

The first major barrier to the proposed methods was that the NICU Nest workers who were supposed to serve as in-hospital recruiters and participate in the first focus group were incredibly short-staffed. To ensure ample participation, Dr. Suhrie, who oversees the Nest, served as a gatekeeper to NICU Nest workers (Tracy, 2019). Dr. Suhrie sent an email (Appendix A) to the NICU Nest workers requesting their participation in a focus group and their assistance in identifying and recruiting other participants from the NICU. Dr. Suhrie's email asked NICU Nest workers to identify 5-10 potential participants whose infants were currently hospitalized. Individuals identified this way would serve as participants in the second and third focus groups. However, NICU Nest workers responded that they could not assist with the project. Dr. Suhrie contacted other departments and connected me with research nurses at Riley who have ample experience enrolling parents and guardians – and their infants – into NICU–based research. I held a brief presentation to explain the research to potential recruiters, including four research nurses, a nurse practitioner, and a single representative of the NICU Nest team.

The research nurses agreed to identify participants and pass along recruitment materials (Appendix B), which served as both a script for the nurses and as a handout for

the guardians, to appropriate NICU parents and guardians based on the initial participant criteria above. We began recruitment one week prior to each focus group date to limit the likelihood of discharges before the focus group occurred. Because infants can be discharged from the NICU at any time, this method and timing ensured that participants' infants were not discharged from the NICU before the group could occur, which would almost guarantee steep drop-offs in participation. The recruitment materials included a link to the screening survey (Appendix C), which included an availability question so that a focus group could be scheduled on the day with the most available participants. The research nurses provided insights about appropriate days and times to hold the focus groups, including immediately before or after guardians typically visit the NICU to feed their infants. Unfortunately, this is where a second major barrier was encountered: the method of data collection.

Recruitment via the research nurses began in early June. By the end of the month, no guardians had registered to participate in the research. The recruiters explained that parents and guardians *were* interested in participating in research; however, few could commit to the one hour required for a focus group. Additionally, even though six different days and times were listed, many parents and guardians felt they could not commit to a structured, scheduled event like a focus group. The research nurses recommended changing the data collection to interviews rather than focus groups to allow for more flexible scheduling and shorter time commitments for guardians; whereas a focus group with five to 10 people takes at least an hour, an interview with a single participant can take about 30 minutes. Qualitative methods "aim to understand social situations from the point(s) of view of those involved" and "embraces a variety of

particular approaches and techniques," including semi-structured interviews, focus groups, participative research, and documentary analysis (Britten, 2010, p. 385). Focus groups are a type of semi-structured *group interview* (DiCicco-Bloom et al., 2006). Subsequently, adapting to individual interviews to facilitate better data collection when focus groups were no longer feasible still gathered meaningful data. With this recommendation from NICU research experts and approval by my thesis committee and Dr. Suhrie, the plan was changed. Rather than conducting three focus groups, with revisions occurring between each, we decided to do multiple interviews as a single "round" of data collection, complete revisions after multiple interviews finished, then present that revised decision aid to several more participants via interviews before repeating the process again.

Recruitment materials were modified to reflect an interview structure and were posted throughout the NICU (Appendix D). Research nurses continued serving as liaisons to this population, contacting guardians in the NICU during standard feeding times to encourage them to complete the screening. This recruitment strategy was aligned with similar NICU-based qualitative research methodologies from Jones et al. (2007) and Lyndon et al. (2017). The screening form asked guardians to provide their preferred contact method, email or phone, and explained that the researcher would reach out via their preferred method to schedule an interview at their convenience. However, after another month of this revised recruitment strategy using key liaisons, increasing scheduling flexibility, and recruiting directly from the NICU, only one dyad of parents signed up and completed an interview.

This is where a final major barrier was identified: the population. Although the best data would have been gathered from parents and guardians who were *in* the NICU environment at the time of their interview (Ward, 2010) and could draw from their present state of mind, the same reasons that communication breaks down in the NICU (limited time, excessive stress, multiple responsibilities, etc.) also present barriers to conducting this type of research. Because of this barrier, along with those listed above, the inclusion criteria were changed to reach appropriate and available guardians inside *and* outside of the NICU. The final methodology used for this research is different from what was planned but is still rationalized and supported by other researchers. The following sections detail the final, revised inclusion criteria, participant characteristics, and data collection method that were utilized to gather and analyze data following the aforementioned changes.

## Final Methodology

### *Inclusion Criteria*

Ultimately, after consultation with Dr. Suhrie and my thesis advisory committee, the research was opened to parents and guardians of infants up to three years post-NICU discharge and guardians of non-NICU infants up to three years old. Participants in either pool – NICU and non-NICU – had to be the legal guardian of the infant (adoptive, stepparent, or biological parent), had to be 18 years or older, had to read and speak English, had to be a United States citizen located in the U.S., and needed reliable access to internet and an internet-connected device.

Similar research involving NICU guardians typically takes place within a week to one-year post-discharge from the NICU (Bry et al., 2019; Spence et al., 2023); however,

that research is typically incentivized via gift cards and/or attached to clinical research, so guardians involved often have an incentive or previous commitment to participate in the interview-based design. Subsequently, the three-year mark was chosen to ensure that the NICU experience was still recent enough that families and participants could draw on their experiences when answering questions but was distant enough from the event that participants had adjusted to caring for their child and managing other responsibilities. Additionally, the three-year mark was chosen to ensure any guardians who had had another infant had adjusted to caring for multiple infants and toddlers by the time of participation. Although Ward (2010) argued that "parents' beliefs are inevitably affected by infant outcomes and the passage of time" (p. 2), the researcher also acknowledged that thorough retrospective designs could yield insights into guardian views. Other researchers have successfully relied on a similar retrospective design in which they interview guardians *after* a baby's discharge to assess experiences, feelings, values, and more (Bry et al., 2019; Dellenmark-Blom, 2013; Spence et al., 2023). Because the research was open to guardians up to three years post-discharge or post-infant birth, I was intentional in beginning interviews with prompts to reflect on the birth and/or NICU experience and asked questions throughout to encourage reflection on past events.

Although non-NICU guardians cannot offer insights related to their own NICU experiences, they can demonstrate a clear understanding of what the NICU is like, often from knowing other parents and family members who have had infants in the NICU. Their perspectives are also important because every NICU guardian was, at some point, a guardian with no NICU experience. Additionally, because guardians with NICU experience provide feedback with hindsight, juxtaposing that feedback with that from

guardians *without* NICU experience was important to understanding the different needs of different types of guardians. Understanding a unique range of experiences and preferences was crucial to making the most inclusive and accessible decision aid. Still, guardians of NICU infants were prioritized from the respondent pool; they were contacted first, and repeated attempts were made to connect with them if they did not respond to the first or second contact.

***Recruitment***

To recruit participants with the aforementioned characteristics, recruitment was conducted in the Riley NICU and on social media. Recruitment materials highlighted the need for guardians with infants under three years of age and guardians with NICU experience in the last three years. The original recruitment flyers posted in the Riley NICU common areas, including family rooms and lounges, remained up to continue recruiting directly from that space. I also posted recruitment materials (Appendix E) to my personal social media accounts and asked friends to share them on their own pages; collectively, the posts were shared nearly 50 times, reaching several thousand viewers. Also, I joined three NICU-based parent support groups on Facebook and shared the materials there with nearly 3,000 followers. The social media recruitment materials included a link to the updated screening survey (Appendix F), which included a study information sheet. After two weeks, I reposted the recruitment materials and asked my network to share them again. My goal was to schedule 5-7 participants per round of interviews to help me gain enough feedback and ideas before revising the decision aid and presenting the revised version to 5-7 new participants, so I needed a minimum of 15 participants total. However, these numbers changed in practice due to the amount and

significance of revisions that were established per round of feedback, detailed in the following sections.

***Participant Characteristics***

From this recruitment strategy, I received 53 completed interest forms in three weeks. Although the research was open to all guardians of infants younger than three, regardless of NICU status, former or current NICU guardians were prioritized from the respondent pool. After reading through the 53 interest forms and removing individuals who did not complete the form or have an infant younger than three, I contacted 43 participants via their preferred contact method. I began by contacting guardians whose infants *had* been in the NICU in the last three years, aiming to contact them within 2-3 days of them completing the survey. When these guardians did not respond to the first attempt, I contacted other guardians who had completed the form but whose infants had not been hospitalized. For participants who responded on the first or second contact attempt, interviews were typically scheduled within 3-5 days of contact. If there was no response within one week, they were contacted again via their preferred method. After no response to 2-3 contact attempts, participants were removed from the participant pool. Of the 43 participants contacted over the three-week period, 30 participants responded to at least one email or text. Interviews were scheduled with 24 of the 30 participants who initially responded. Of the 24 scheduled interviews, six participants did not attend their scheduled Zoom calls. Several hours before the scheduled interview, participants were reminded about their agreed upon time. Despite scheduling many guardians for each round of interviews, several inevitably dropped out. Guardians who did not attend their scheduled interviews were contacted within a day of the missed interview to see if they

would like to reschedule. Several responded yes, several responded no, and several did not respond at all.

The first round had four participants in three interviews, one with two parents and two with one parent each. All four participants reviewed the same version of the decision aid. They completed their interviews within a month, and I transcribed all interviews within 1-2 days of recording. I then paused, reviewed their feedback (discussed in detail below), revised the decision aid, and continued recruiting for the second round of reviews. The second round of interviews had six participants, scheduled over a period of two weeks. Following transcription of all six interviews, I paused, reviewed their feedback, and revised the decision aid using their feedback before continuing recruitment for the third round of reviews. The third and final round had eight participants scheduled over a period of two weeks. I then paused, reviewed their feedback, and revised the decision aid, creating a fourth version.

After completing 17 interviews with 18 total participants, the following participant characteristics were tallied. First, five (28%) participants had infants who were never in the NICU; three (17%) had infants who were currently in the NICU; and 10 (55%) had infants who had been hospitalized in the NICU in the past three years. Additionally, 16 (89%) were white, one (5%) was mixed race, and one (5%) was Native American/Alaskan Native. Sixteen (89%) identified as female and two (11%) as male. All participants were the biological parents of their infant. Fifteen (83%) participants had private insurance, one (5%) was uninsured, one (5%) was unsure of their insurance type, and one (5%) did not respond. Health literacy was assessed using a single scale item asking how frequently respondents needed help reading medical instructions. This

assessment was important because other research presented here has demonstrated that health literacy is a challenge when communicating about genetic testing. In terms of health literacy, 10 (56%) responded that they never need help reading medical instructions, six (33%) that they rarely need help, one (5%) that they often need help, and one (5%) did not respond.

## Procedures

### *Interviews*

Once the initial rough draft of the decision aid was complete, the first group of four participants, two individual guardians and the dyad, reviewed the draft in individual interviews. The interviews lasted 15 to 30 minutes and were held over Zoom. At the beginning of each interview, I briefly explained the purpose of the research, specifically outlining the current NICU genetic testing communication process and how this tool might be used in the future. Next, I asked participants if they had any experience with the NICU. I asked NICU guardians to think back to their time in the NICU when reviewing the materials. Specifically, I encouraged them to recall communication that occurred in the NICU and how they communicated with spouses/partners, care providers, and other family members or friends. I encouraged guardians without NICU experience to imagine how they might feel in the NICU.

With this groundwork set, participants were asked to spend 5-10 minutes examining the PtDA on a shared Zoom screen, saying “Ok” or “Next page” to indicate that I could scroll to the next page. Participants were also emailed a copy of the decision aid that they could continue reviewing throughout the interview and afterward if new thoughts or feedback arose. The interviews were guided by the Pretesting Messages and

Materials Framework (Appendix H) created by Compass (2020) for READY: Global Readiness for Major Disease Outbreak Response. The framework guides participants through discussions on messaging attractiveness, relevance, comprehension, and other essential messaging elements. I used these questions to gather data on participants' likes, dislikes, comprehension, and more. I prioritized questions from the guide that aligned with SDT constructs, as shown in the appendix. Following each interview, I immediately transcribed the session. After completing four interviews and transcriptions in the first round, I revised the first decision aid using participant feedback to inform revisions. I presented this revised version to six more participants, followed this same transcription and revision process, then presented the third version to eight more participants. That process is outlined in more detail below.

***Patient Decision Aid Revision Process***

Although there is currently little formal guidance on PtDA development, exemplar PtDAs are typically developed using a review and revision process consisting of multiple focus groups that include the targeted audiences in the development of materials (Coulter et al., 2013). This message pretesting is the best practice in message development because it ensures that messages achieve their intended outcomes and are relevant and appropriate for the audience (Brown et al., 2008). Brown et al. (2008) outlines steps for effective message pretesting: (a) developing and reviewing communication objectives and plans, (b) identifying pretesting objectives and developing a pretesting interview guide, (c) collecting and interpreting data, (d) revising communication materials, and (e) retesting and revising until messages and materials are effective in achieving communication objectives. These steps are also aligned with the

PtDA development steps outlined by Coulter et al. (2013). Standard message pretesting occurs in focus groups that allow iterative revisions, or revisions that occur in response to one group's feedback that are then presented to a new group. Although message testing steps are intended for focus groups, I adapted them to fit an interview structure, grouping several interviews together and analyzing them as a single round of feedback.

After developing the initial draft as described in Chapter Two, the next steps from Brown et al. (2008) are collecting data from participants in the targeted population, revising communication materials based on participants' feedback, and retesting and revising until the objectives are achieved. I planned to interview 5-7 participants per round to ensure ample and consistent feedback; this is also similar to the number of people that would typically participate in focus groups for message testing. However, as I conducted the interviews and reviewed the transcriptions, I considered a round of interviews complete once there were 2-3 major revisions recommended by participants that could significantly change the decision aid. This meant that the initial version was reviewed by only four participants before it was revised and shared with a new group due to several major changes. However, the second and third versions were reviewed by more people; feedback was very consistent across these participants, and no major changes were recommended or identified by participants in the final round. I provide details on the types of revisions I made in each round below in Chapter 4.

Following each interview, I transcribed the session and began making notes about what stood out to me and what changes were needed. Once multiple major changes or revisions were identified by the first four participants, I concluded the round of interviews and completed those revisions on the decision aid. After making revisions, I

revisited the objectives, per Brown et al. (2008), to ensure the tool was still aligned with the overall goals. Then, I presented the revised version to a new group of six participants. I transcribed these interviews as well, often reading these transcriptions and the ones from previous rounds as I determined what revisions were needed. Some revisions mentioned in the first round by only one participant were omitted until they were mentioned again by someone in the second round.

After revising the second version, I presented the third and final version to eight more participants. Again, I transcribed immediately after each interview and reviewed both the feedback from this round as well as previous rounds to identify any changes. Because the third version was generally approved by participants, I recruited and interviewed additional participants to ensure I had ample feedback and did not only hear positive feedback due to chance. Once a major change was recommended in the last interview, I reviewed feedback from previous rounds of interviews before deciding to make that revision. Because other feedback was very consistent in this round and all other revisions and edits were minor, I concluded the interviews. The feedback from this round led to a fourth version of the decision aid, which was then reviewed a final time by Dr. Suhrie for clinical accuracy and final edits. This process of reviewing transcriptions for edits and revisions was also incredibly helpful for familiarizing myself with the data, which helped with the overall thematic analysis. My analysis of each round of interviews and the resulting revisions to the PtDA from each round (i.e., the “Findings”) can be reviewed in Chapter Four.

### *Thematic Data Analysis*

In addition to the iterative rounds of edits to the PtDA guided by Coulter et al. (2013) and Brown et al. (2008), I conducted thematic analysis of the data once all interviews and revisions were complete. It is in this analysis that I mostly reflect on how to answer my RQs. Here, I will describe the analysis process; the findings from this analysis can be found in Chapter Five. Thematic analysis "is a method for identifying, analyzing, and interpreting patterns of meaning ('themes') within qualitative data" (Clarke & Braun, 2017, p. 297). Braun and Clarke (2006) advocate using thematic analysis in conjunction with theory, such as SDT, which guided my PtDA. Braun and Clark (2006) propose the following steps for conducting thematic analysis: familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

I read all interviews in each round multiple times as I was revising the decision aid. Because I consulted transcriptions multiple times as I completed revisions over several weeks, I became familiar with the data. In addition to taking field notes during the interviews, I kept thorough analytic memos of recurring ideas and comments I observed following each interview and waited until all interviews were completed to begin conducting my thematic analysis. Once I re-familiarized myself with all the data, I began to generate initial codes using SDT constructs as an analysis guide. I searched for key ideas in participants' feedback, responses, and discussions and reviewed them for alignment with the dataset and overall story (Braun & Clarke, 2006). I framed my search for initial codes based on the goals of PtDAs, which are to balance the information patients – or guardians of patients – want to know and the number of necessary details

(Coulter et al., 2013) and in direct response to the research questions posed earlier. This often meant identifying feedback about what guardians wanted compared to what they felt was excessive or unnecessary. I then created an Excel document with three columns labeled autonomy, competence, and relatedness to further help me identify and categorize ideas and codes. I read through transcriptions individually, placing quotes that I identified as relating to autonomy, competence, and relatedness into single rows under their respective columns. I also created an additional row for non-SDT constructs and ideas, allowing space for additional ideas to take shape. Seeing quotes within each category helped me identify larger themes that extended beyond the constructs of SDT and reflected the stories and experiences of the parents in the NICU setting, and I started drafting and fleshing out the themes separately from the initial codes.

With the idea of different themes established, I reviewed the transcriptions again, looking for additional exemplar quotes that supported or negated each theme. Reviewing the themes a final time and adding in example quotes helped me define and name them. The following two chapters present the findings from my thesis project: Chapter Four outlines my major revisions through the three iterative processes of the development of the PtDA, as identified by participant feedback, and Chapter Five presents the overall themes I developed through thematic analysis of the 17 interviews.

## Chapter Four: Message Testing

Chapter four includes an overview of revisions to each version of the PtDA. Participants were given pseudonyms to maintain their privacy. Some revisions suggested by participants were not implemented due to inconsistent feedback (i.e., conflicting responses from different respondents), limited resources, or existing knowledge of best practices for developing content and decision aids that contradicted recommendations from participants. Revision decisions were framed using the message testing and revising process outlined by Brown et al. (2008) in accordance with framework for PtDA development provided by Coulter et al. (2013). For example, I relied on clinical experts for final say in certain changes to the tool, per Brown et al. (2008).

The purpose of message pretesting is to clarify audience confusion, understanding, and responses to provided messages (Brown et al., 2008), so I re-read all transcriptions from one round of reviews to find common feedback and suggested changes and revisions. Whenever most or all participants agreed on or suggested similar changes, I considered the change necessary. Additionally, whenever a *significant* change or revision was identified, such as adding an entire page of myths versus facts, I asked questions specific to that change in the following round of interviews. The following sections outline major edits and revisions made to the decision aid, with quotes and rationale to support them. It is important to note that other minor revisions were frequently made without being detailed here (e.g., spelling or grammar errors, rewording single sentences upon re-read, etc.); only revisions that could change the meaning or guardians' perceptions of the decision aid are detailed below.

**Round 1**

Version 1 was reviewed with four parents in three interviews. Two were parents of a currently hospitalized NICU infant, one of a recently discharged NICU infant, and one of a non-NICU infant under age three. After reviewing the first version with all four participants, several major findings and revisions were identified: guardians felt the language was leading, believed the decision aid needed to be further tailored to guardians receiving it, wanted additional information about the process of genetic testing, felt overwhelmed by examples of genetic conditions, and needed some genetic testing/genetic results myths dispelled.

First, guardians noted leading language in the decision aid and reported an imbalance of information, which contradicted the goal of creating a sense of autonomy – feeling that one was responsible for their own decisions. Two parents expressed that the first version of decision aid was notably in favor of genetic testing. John, the father of a currently hospitalized infant, said: "There's a specific conclusion that you are leading to. The material is presenting why genetic testing is worthwhile and trying to lead to the conclusion that Riley promotes genetic testing." Although it is true that genetic testing is considered a best practice and is promoted in Riley and many other NICUs, this leading language was problematic because decision aids should not be coercive or lead readers to make only one decision; instead, decision aids help people decide between multiple options, without conveying one option as best.

Additionally, it was clear that the leading nature of the aid made these two parents (of the dyad) more apprehensive and resistant to the other messaging throughout. I addressed some of this leading nature with the addition of a myths versus facts page,

discussed later in this section. Specifically, a myth that says, “If I turn down genetic testing, the care team will stop helping my baby,” was answered with the fact: “Our team will do our best to treat your baby, even if you decline testing.” This addition helps balance out the information so that guardians still felt safe and comfortable declining testing. Other small changes were made to reflect a more balanced tone. For example, the first page initially said: “This booklet will help you make this important decision,” which was changed to, “This booklet will help you decide if genetic testing is right for your baby.” This minor shift reflects the autonomy guardians have, rather than the importance or severity of making the decision. Small changes were typically ideated during interview; when a guardian responded that they did not like something, I asked what might work instead or posed an alternative and sought their feedback.

Second, participants voiced that the decision aid needed to be tailored further to each guardian receiving it, which hints at the relatedness aspect of SDT. Two parents discussed how the aid would initially upset them, and they would wonder if genetic testing was specific for their baby or if it was generally recommended for all NICU infants. John pointed out: “A question in my head the entire time was, why am I receiving this? Is it just for everyone? Or is it because my child was specifically pinpointed? The first thing I would want to know is if the doctor, if the care team thought... if they weren’t just doing genetic testing just to do genetic testing.” John added that he would wonder if genetic testing was recommended to increase revenue for Riley. Subsequently, I added clearer language explaining that the infant was being specifically recommended for genetic testing to express that it was not a standard practice to test all infants. For example, I added a line of text to the first page stating: “Your baby’s care team

recommended genetic testing for your baby." Additionally, a line that initially said, "Your baby's team can tell you more about their reasoning" was bolded and updated to say, "Your baby's team can tell you more about why they recommended tests for your baby."

Third, participants expressed a desire to learn more about the actual *process* of being recommended for and receiving genetic testing for their infants, which alluded to the need for competence. John said, "I'd rather have them explain the initial process – like steps of the process, like blood sticks, rather than what they hope to find." Even parents who did not outright say they wanted or needed more information about the process did ask questions about it. For example, Abigail asked: "How long would a baby be in the NICU before this is provided?" Sam also asked about prenatal genetic testing: "So... they can do the genetic testing before the baby's born, right? Or is that something totally different?" However, families who underwent prenatal testing would typically not need additional genetic testing; results from the prenatal testing would be used by the NICU team, so the family would not receive this document. Subsequently, a step-by-step guide of the genetic testing process was added to page three to help guardians understand what occurred leading up to the discussion and dissemination of the decision aid and what would come next.

Fourth, Round 1 participants expressed that the examples of genetic conditions were overwhelming, even as a frame of reference, which also hints at the need for competence. Competence requires information be digestible and manageable for readers. Two parents who completed the interview together while their baby was in the NICU expressed conflicting ideas about the examples. The mother, Jane, said she would be

anxious if she saw the example of cystic fibrosis. She reflected on her first thoughts about a family friend whose child had the condition, and she said it made her feel anxious to even read the example. Whereas Jane felt examples were upsetting, her husband argued that having *more* examples would be better to help readers understand what genetic conditions are. This difference of opinion was reflected by other participants, as well. Abigail, whose husband was in the room with her as she participated in the interview, explained how seeing examples of genetic conditions might be upsetting:

> I like clarification a lot. So, like, having examples of genetic conditions. However, I could see where parents might be a little... yeah, a little anxious of this potential for that, you know, especially if a doctor's thinking it, but not actually saying it. So yeah, I could see it just being left as genetic conditions, and then, if they want to look it up or ask more questions, then you could clarify them.

However, Abigail's husband, who was not a formal interview participant, disagreed. Because he was in the background of the call, Abigail reiterated her husband's comment: "He's essentially saying that instead of like, ok, maybe in the pamphlet, in the form part about the Down's Syndrome and cystic fibrosis, you know, maybe take that out. But then put, 'see the attached,' and have a whole list of genetic conditions. That way, if someone wanted to reference that, they could." When asked if having an entire list of genetic conditions would be overwhelming or upsetting, Abigail explained that she personally would like to have one, but suggested only providing that list if parents or guardians requested it.

With this feedback from the dyad, the examples about genetic conditions were removed from the decision aid. However, rather than adding a line informing readers to ask their care team for a list of genetic conditions, I relied on another revision: "Your baby's team can tell you more about why they ordered tests for your baby." This aligned

with insights Dr. Suhrie had provided at the beginning of this project; she recommended relying more on the genetic team to provide additional information about specific genetic conditions, rather than overwhelming guardians with additional handouts or long decision aids. Creating a list of genetic conditions was counterintuitive to the information overload that other researchers have confirmed NICU guardians experience. I added language encouraging readers to talk with the team, which John advocated for: "If this were happening, I think I would rather them [the doctors] just tell us why, then let us go through it [the aid]."

Finally, the last major finding from Round 1 was that guardians needed some myths dispelled. Abigail explained her concerns that if guardians declined genetic testing, their babies would receive worse care: "You hear a lot of horror stories about if you don't take medical advice, or you know, you don't follow a certain protocol." She expanded, saying she had heard of people reporting parents to government agencies like Child Protective Services if they did not do what was recommended for their children or babies. "The question [that] pops up is about if you don't want to do genetic testing… If I don't want to do it, how detrimental is that going to be?" Although Abigail did not say that the document was leading, her questions about what would happen if she declined genetic testing made it clear that there was an imbalance of information leaning toward getting testing. Additionally, Sam, whose infant had never been hospitalized, talked about her concerns regarding future children: "I think finding out that you can't have future children, if that's what somebody wants, I think that would be very, very scary. And that just adds on to all of those other emotions that you're already feeling." Although this is

not a myth, it did convey the need for additional information regarding options for guardians who discover they cannot have future children.

Subsequently, a myth versus fact page was added to the document. The first myth was: “If I turn down genetic testing, the care team will stop helping my baby.” This was a direct response to Abigail’s concerns, and it also helped address some of John’s concerns about the decision aid being leading. The remaining myths were: “If my baby has a genetic condition, our insurance won’t cover them.” No guardian said this outright, but several participants asked about insurance details. Another myth was added saying, “I will have no options if I find out I cannot have other children.” This was in direct response to Sam’s concerns about having other children after testing. The response to the myth also addressed Jane’s confusion about a frequently asked question in the decision aid regarding having additional children. The final myth was: “My baby’s results may ruin their future if others find out.” This myth came from previous research regarding parental concerns about genetic testing and privacy management. Following each myth, a clearly labeled fact explained the truth/reality of testing. The culmination of these edits led to Version 2.

**Round 2**

With the above edits complete, Version 2 was presented to six guardians. One had a baby currently in the NICU, three had a baby in the NICU in the past three years, and two had a non-NICU infant. In general, guardians in Round 2 liked the decision aid and offered very few suggestions, dislikes, and edits. The addition of the myths versus facts page was especially appreciated, although one guardian’s input would come up in a later set of revisions. Upon reading the myths, Annie said, “The myths versus facts, some of

the myths are... I was like, ‘Wow!’ Never would have thought of that.” The major edits from this round included adding more technical information about the testing process, adding examples of genetic conditions *back* in, changing a confusing numeracy graphic, and detailing how genetic testing can shorten stays and change plans of care.

First, guardians did not feel language in Version 2 was leading, which indicated the tool was more balanced and closer to achieving autonomy. I assessed guardians’ sense of leading language by asking the question, “What is the material asking you to do?” One parent, Casey, whose infants had not been in the NICU, said that the purpose of the decision aid was to help parents make a decision: “I think the intention is to consider what option they’re going to choose. Are you going to go through with the testing or not? And ask [guardians] to process the information, make spaces for them to process it, [and write] questions.” Another parent, Annie, whose infant was hospitalized at the time of our interview, echoed this: “It basically gives you the pros and cons of it. Tells you the different steps, tells you about the insurance.” These responses, which emphasized balance and decision-making, rather than promoting testing, helped me determine that guardians did not find Version 2 of the decision aid to be leading. Still, there were several major revisions this round, as well.

Second, guardians wanted more technical information about testing to make an informed decision, which again alluded to the need for competence. Annie provided this feedback: “I think the only part that’s missing, in my opinion, is, how do you get the results?” Another parent, Sadie, also expressed the desire to have more technical information about the testing process. When asked about what she felt was missing to help guardians make this decision, she said, “Maybe more specifics on the how and the

when of the blood test." She clarified, "What part of the body would they generally take [the blood sample] from? Could you see bruising after? When could I expect them to take it? Is... is it an option for me to be here when they're doing it?" Because guardians wanted more details about the steps of genetic testing, a line of text was added to the third step of the process section to say: "Results from the test will be uploaded to your baby's portal." Additional information was added to other steps in the process section to further clarify each stage. The answer to the Frequently Asked Question "How is testing done?" was updated to explain that guardians could be in the room with their infant while the blood was taken and that the baby would only feel a small prick and possibly have a very tiny mark.

Third, guardians wanted examples of genetic conditions, which had been removed following feedback from the first round of participants. One guardian, Vivian, whose infant had been hospitalized previously, said: "I feel like a lot of people don't know what things are genetic conditions. So, you know, obviously, you don't want to just bluntly put the names of certain conditions to make people think that that's definitely what a kid has… I don't know if there is the ability to give examples, or if that would make it more confusing." Other guardians also mentioned how having some well-known genetic conditions in the document would be helpful, but they voiced concerns that adding them might make parents think that was what their infants were being testing for.

To ensure that guardians would not think any example conditions *were* the conditions doctors were specifically looking, a call-out box was added to the diagnosis page. The call-out box was labeled "Examples of genetic conditions" and listed Downs Syndrome, cystic fibrosis, and muscular dystrophy. These conditions were chosen from a

list of common genetic conditions so that guardians and readers would quickly recognize and understand the concept of genetic conditions. Following the list, a line stated: “Ask your baby’s doctor for more information on specific conditions.” This line encouraged conversation without overwhelming or information overloading guardians. Importantly, I know this tool will be used in the NICU alongside a conversation with medical professionals, who will tell the guardians at the time of delivering this document what information or conditions they are specifically looking for.

Fourth, guardians found a graphic in the aid confusing. The graphic was supposed to help guardians visualize 80% by showing eight babies in black and two babies in red. This is one of the SDT communication practices for competence (Head et al., 2022) and helps with numeracy, a type of literacy where people often struggle to conceptualize risk percentages and likeliness. However, multiple guardians were confused about the graphic, and several mentioned the connotation of red being bad. The colors were chosen based on IU Health branding guidelines, but because branding was otherwise kept to a minimum, guardians felt put-off by the graphic: “I don’t know why there are two red babies on that page. I noticed that the first time.” To revise this, a circle was placed around the eight babies, and the two red babies were changed to black to match the circled babies.

Finally, guardians wanted specificity on *how* care may change based on their baby’s results, so information was added about how results can tell doctors and caregivers what treatments to begin or stop. Additionally, guardians wanted specificity on the timeframe of test results. Everly noted, “It says that results are available within days, you know. If it was possible to be able to list, you know, ‘within 2 to 5 days,’ or whatever

that would be…" The results section of the Frequently Asked Questions page was updated to include a timeframe (although it would be revised again in the final review to reflect a more accurate range). Additionally, one guardian felt the decision aid was too long at nine pages, while another said that some information felt repetitive but necessary. The two final pages were combined to reduce reading fatigue, and a section for notes and thoughts was added to the myths versus facts page to provide more space for information processing.

No other findings from this round led to major revisions or edits. An important note is that there were some suggestions from participants in round two that were intentionally *not* used. Some suggestions were not used because of contradictory feedback between different participants. For example, Vivian suggested moving the genetic testing team page up from the fifth page to the third because the genetic testing team is referenced well before the team is formally introduced in the document. However, Sadie specifically called out how helpful the current order of information was: "It's all good information. In my opinion, the way it's set up, you have the most pertinent at the top. The way that I used to look through information is, I look at the first couple of pages, and then I sometimes said, 'Okay, I need to put this down and come back to it.' I think this is actually the kindest way to get that information."

Another change that was omitted was Vivian's recommendation to increase the variety of sentence types and structures. Vivian said, "I feel like a lot of the sentences are just very short… I know it's not necessarily like an English project. But it's very, just... like one fact after another. So, I feel like, just the writing style [needs to change]." However, one construct of SDT is competence, which researchers operationalize as a 6$^{th}$-

grade reading level with plenty of white space, in addition to using analogies and basic expressions to convey information (Brown et al., 2021; Head et al., 2022). After multiple attempts to lower the score, content from the PtDA tested at a 7th- and 8th-grade reading level, likely because of terms like “genetic testing” and “whole genome test.” Changing sentence structure for more variety, per Vivian’s suggestion, would have greatly increased the reading level score, which already bordered on high. It is important to note here that decisions I made to revise – or omit revisions – were determined by balancing feedback from the participants with insights from the clinical experts, as well as my own expertise in communication.

Additionally, this feedback contradicted what others shared. Many talked about how sentence brevity was important, especially when reflecting on how limited their information processing capacity was during NICU stays. Casey, mother to a six-month and three-year-old with no NICU experience, said: “From an English teacher standpoint, I like the words ‘team’ and ‘experts.’ Because that makes me feel like we’re in this together, and the best of the best are going to help me through this time.” Casey added later, “I just think that there's not... there's not too much on a page. So, it’s not… overwhelming to read. And then, you know the fact that it’s attached to images, I think is good for, for memory and processing, because I think brain science tells us that if it's attached to an image, we'll remember it more, right?” Subsequently, changes to increase sentence variety and length were not made to the tool to keep it short and digestible for guardians.

A final omitted revision was that some guardians wanted testimonies from other guardians who had their NICU infants tested. Hali suggested adding “snippets of quotes

from families that did get it done" to help guardians make that decision. However, Hali went on to negate that idea, saying, "Maybe you don't even want to go there because it might give false hope." I did not add quotes or testimonies to avoid making the document too leading, per feedback from the first group. I also omitted this change to help reduce reading fatigue. All of these edits – and the omitted ones – led to Version 3.

**Round 3**

Version 3 was reviewed with eight guardians. Six were guardians of currently or recently hospitalized NICU infants, while two were guardians of infants younger than age three who had not been hospitalized in a NICU. Feedback this round was generally positive, with many guardians commenting on how much they liked the order of information in the tool. Even with positive feedback, several major edits were decided upon after eight interviews: guardians identified challenges with the myths versus facts page, disliked elements of the "Weighing your options" section, and wanted clarification about privacy and insurance coverage. Lastly, guardians also struggled with how the testing process table was formatted.

To help frame the findings, it is important to acknowledge some challenges unique to this round. First, there were several contradictions between participants and even among individuals' responses. For example, Jasmine expressed how in her own NICU experience, she received "*a lot* of paper" and rarely read it all. She suggested removing some content to shrink the page count. However, when asked what information she felt was unnecessary or redundant – a tactic I frequently used in previous interviews to help identify what types of revisions would address guardians' concerns – she acknowledged that all the information felt necessary. She conceded, "Putting the things

that not all parents need to read towards the back is probably helpful, too, because everybody's going to read the first page or two. Are they going to make it through the whole thing? Some of them will, some of them won't." This contradicted her own feedback, as well as feedback from another participant. One NICU mom, Carolina, stated: "I think it's really intelligently structured. It gets more detailed as it continues, and theoretically, a parent would be able to take a pause, kind of process, come back to it, maybe do a little feeding of the baby, and then come back."

This was a recurring problem in this round of interviews. Another guardian, Charlie, expressed some apprehension about the PtDA being leading, similar to feedback from the first round of interviews. "If I was somebody who felt against genetic testing, or I was hesitant about it, I might feel a little bit like, 'Oh, well, this is just trying to get me to say I should do it.' I kind of feel like, maybe if I was somebody who did have those hesitations, I'd be like, 'Well, this is just like propaganda trying to get me to do it.'" However, after asking clarifying questions to understand what might make the decision aid feel more balanced for the type of person Charlie was describing, Charlie changed her feedback. "Now that I'm thinking about it, I feel like I don't know what more could be done, because you did have the section of like, I don't know if it was like the pros and cons, or whatever. But it was saying like, 'if you decline, or if you do decide to go forward with it,' like I felt like that was a good section to have for those kinds of parents." However, despite conflicting feedback, several major findings were still identified that resulted in revisions.

First, guardians identified several challenges with the myths versus facts page, which was added into the second version. Many participants responded very positively to

the myths versus facts sheet, finding it informative and helpful. It also addressed some concerns about the decision aid being leading; some guardians expressed that acknowledging the myths helped readers understand that the team recommending testing had a comprehensive view of guardian concerns. Nick said, “I like the myths and facts. That was a big one… when you read the myths and the facts that definitely makes you, or at least calmed me down a lot ‘cause you... You’re still reading all this stuff, you know, it’s still scary. Once you read like the myths, facts, you go, ‘Okay. This is what we’re looking at.’” He went on to say that he felt the myth page should move to the very beginning of the aid, moving to the second page so that it could begin addressing guardian concerns sooner. However, other participants provided enough support to warrant removing the myth versus fact page entirely.

Ramona, a NICU mother, explained that she was very confused reading the myths, and they added to her mental load when processing the other information. “The myths and facts part was a little, was probably the thing that I took the longest time processing. I feel like everything else was very like to the point… ‘I will have no option if I cannot have other children.’ Yeah, I think that sentence confused me.” Charlie had similar feedback about how the myths were more confusing than helpful: “I guess I don’t really understand this myth. ‘I have no options if I cannot have other children.’ I will have no other options... like they won't have another option to have more children?” Jocelyn provided additional feedback that similarly conveyed why myths could be counter-productive:

> This [page] actually added more stress, thinking, ‘Oh, my gosh! What if these things do happen?’ I think the general person just doesn’t know about these myths. And so, the previous information kind of reassured me of all that. But now I’m like, ‘Oh, my gosh! What if my partner does have

> an issue?' It adds a lot of factors that you don't really need to think through at the time, I think.

This feedback is reminiscent of something from the second round of revisions. Another guardian in Round 2, Annie, expressed that she "never would have thought" of the myths. When the myths were initially added to this document, I was intentional about not providing too much information on why people believe the myths; I did not want anyone who did not already think or believe those myths to begin questioning them. However, it was feedback from Ramona, Jocelyn, and others that made me confident in removing the page entirely. Because I knew from previous interviews how important much of that information was, I incorporated many of the facts from that page into other sections of the aid. For example, the phrase "Our team will still do our best to treat and care for your baby, even if you decline testing," was added to the last page after the myths versus facts page was deleted. This language also supported guardians' sense of relatedness and autonomy.

Second, some guardians disliked the "Weighing your options" page. The page included reasons for declining and getting genetic testing, a best practice for decision aids (Colorado Program for Patient Centered Decision Aids, n.d.; Coulter et al., 2013). Jocelyn provided helpful feedback on this section: "It makes me feel like if you decline testing, it's because you're weak and scared and can't handle your reality, and then when you read the 'getting testing' one, it's like, 'Oh, testing is helpful. Testing is great.' I felt like it was kind of lopsided there." Jocelyn went on to provide very important insights about how she would feel about some of the information in the aid: "I don't like that… it's assuming the *reasoning* that the parents might have because... it could be a million

things. I was in a very sensitive place [in the NICU], and people assuming what I was thinking or adding on like myths and stuff would have made me mad."

With her feedback and perspective in mind, I removed the lists of reasons for declining and getting testing. Reasons for either decision were addressed in different ways throughout the decision aid, so removing a summary of those reasons did not change the meaning of the decision aid. Although she was a single voice, it was important to incorporate this change because Jocelyn was a unique participant; whereas almost all other participants showed an initial level of support for genetic testing that made them automatically seem more favorable toward testing, Jocelyn did not. She was one of the only participants who could speak to how people with preexisting negative ideas about genetic testing might react to the materials. Although our interview was the same length and included many of the same questions as the others, I continually reviewed her feedback and considered what might exist between the lines in feedback I received from other participants. The lists about declining and getting testing were removed, but the original paragraph reminding guardians that the team was there for them, regardless of their decision, and that guardians could reach out with any questions, remained. Removing these two sections also helped condense the content a bit, which addressed feedback from Jasmine: "My one thought would be if there's any way to even shrink it down. Just because we're given so much stuff, and I'll be honest, I didn't read half of the stuff I was given. It was a lot."

Third, guardians wanted clarification about privacy and insurance coverage, which again demonstrated their need for competence; they sought as much information as possible to facilitate making a decision. Carolina, a NICU mom who works in a medical

setting, raised concerns about privacy. “As I was reading through, it took until the very end for us to talk about privacy, medical data privacy, and I think that when you consider the concerns of people around genetic testing, there is a pretty heavy – whether it’s legitimate or not – there’s a pretty heavy concern about the idea of putting a label on an itty, bitty human who is very fresh and is very sick.” To address this concern, a line was added into the genetic testing process on page three: “Results from the test will be uploaded to your baby’s portal and will be kept private and secure.” This addition was a verbatim addition from a comment Carolina made. Another mother who works in healthcare also recommended adding more information about insurance coverage. After explaining that she liked the mentions about how most insurances cover testing, Alyssa said: “Having [something] like ‘This department or this team would be like a next step for like insurance questions,’ or like, if just calling their insurance is the best step. Because having a next step with insurance in case there’s questions there that, you know, you might not be able to answer, but to give them [guardians] what to do.” A line was added to the FAQ page on the genetic testing cost question: “Talk to your insurance provider to learn more about your specific coverage.” Both changes were very minor compared to other changes this round; however, it was important to keep the document informative without it becoming too overwhelming.

Finally, some guardians found the process section confusing, and others felt the order of photos should be switched. Initially, the genetic testing steps were formatted as boxes, labeled 1, 2, 3, and 4, moving left to right, then down and left to right. Two different participants said that they initially read the process steps out of order, moving from step one down to three, rather than over to step two. A guardian from Round 2,

Everly, mentioned struggling with the layout: “I think the only thing that I got a little bit hung up on maybe is. I think it was on the third page. And I think this may just be me. My brain is wanting to read that in the order 1, 3, 2, 4.” At the time, she was the only guardian who had mentioned struggling with the process layout. However, during Round 3, Ramona explained her confusion with that layout: “I didn’t like how the one, and then it goes to the two on the right side. I was wanting the two to be right below it.” Subsequently, the process page was reformatted to resemble a list that reads downward. This further supports the competence construct, which advocates for digestible, clear information.

Additionally, although every participant said they appreciated and felt connected to the different photos used in the decision aid, creating a sense of relatedness they found important and helpful, a few mentioned that seeing the micro-preemie on the very first page was a bit jarring. Charlie said about the pictures: “There’s several different kinds of pictures. It’s not showing just one kind of ... There’s the NICU baby with all the cords and everything, and then there’s another little baby just hanging out.” However, despite liking the pictures, some recommended flipping the order of photos so that a baby receiving less intense care was the very first shown on the front page. Carolina said, “If you scroll back down to page 2, you’ve obviously still got a little human in an incubator, being safely watched over by the NICU, but that little human does not have the face parts... It might be a little bit more comforting if you're being handed something on the cover, and it is what—what one might consider to be a further advanced NICU baby.”

Again, testimonies were brought up by a different participant in this round. Ramona, a NICU mom, had been paired with another experienced NICU parent during

her infant's stay. She suggested, "I feel like, if there's any way you could connect people with people who had genetic testing, then that would be something that could be helpful, too. Just so that they can hear positive experiences or whatever." However, as with the second round of interviews, I did not add testimonies because they would make the decision aid feel too leading and unbalanced. Removing the myths versus facts page and "weighing your options" section, reorganizing the process page, and reordering the photos culminated in Version 4.

**Round 4**

Round 4 did not include any further interviews with guardians. Instead, I returned to having our team expert, Dr. Suhrie, review the document for clinical accuracy and use her practitioner understanding of the population and testing practices to provide final, minor edits. Dr. Suhrie's edits were minor and included removing a line that said, "[Testing] can help you take your baby home sooner." As Dr. Suhrie pointed out, some babies are not taken home from the NICU because their lives end there. Per her recommendation, the line was changed to say, "[Testing] can help you understand your baby's health needs." Dr. Suhrie also recommended removing the third testing bullet point from page three – "to rule out genetic conditions after other tests" – to reduce redundancy. Other sweeping changes included using the phrase "genetics team member" in place of "genetic counselor" or "geneticist" because some guardians meet with one, the other, or both, depending on availability. The "suspicious" diagnosis on page four was changed to "uncertain" for clarity; Dr. Suhrie was concerned that "suspicious" may frighten or confuse guardians.

Because of Dr. Suhrie's clinical insights, multiple edits happened on the Frequently Asked Questions page. For example, Dr. Suhrie recommended changing the "Will insurance cover our baby's care?" FAQ to "Will *health insurance* cover care?" This change was crucial because *life* insurance policies do not necessarily cover individuals with certain genetic conditions, whereas *health* insurance policies do. Additionally, under the "How is testing done?" FAQ, a line was added about the genetics team sampling biological parents; Dr. Suhrie advised that this occurs with certain tests and scenarios to help establish which parent a disease may be inherited from. However, a further explanation about inheritance was omitted from the aid so as not to overwhelm guardians; Dr. Suhrie assured me that this would be discussed at length with the genetic team member. The "What does genetic testing cost?" answer was updated to encourage guardians to talk to the genetic counselor, rather than their insurance provider, because genetic counselors are more accessible than insurance representatives and can liaise between the guardians and the insurance providers. Following these minor edits, Dr. Suhrie approved the decision aid in terms of clinical accuracy and alignment with the language choices used and guidance offered by the Riley NICU, and the tool was finalized as Version 5.

**Summary**

The first step to creating an effective PtDA is identifying communication objectives (Brown et al., 2008) before testing, revising, and retesting the tool to meet those objectives (Coulter et al., 2013). At the beginning of this project, my key stakeholders (Coulter et al., 2013) and I established that the objective of this decision aid was to help guardians in the NICU make a faster, more informed decision about genetic

testing for their infants by giving them a comprehensive view of testing prior to genetic counseling. Importantly, all guardians receiving the tool will attend genetic counseling shortly after receiving it for a more complete, guided conversation about testing; this tool will only facilitate their decision-making by helping them identify their questions and concerns *before* attending counseling. An additional objective for this specific tool was to increase guardians' sense of competence, autonomy, and relatedness (Ryan et al., 2008) to facilitate guardians' motivation to make the decision. With these objectives in mind, I identified the above revisions following the steps for effective message pretesting from Brown et al. (2008): collecting and interpreting data, revising communication materials, and retesting and revising until messages and materials are effective in achieving communication objectives. I also used decision aid guidance from Coulter et al. (2013) to frame the messages and message testing process, specifically focusing on expert guidance from Dr. Suhrie and other NICU stakeholders to ensure the tool was useful.

The objectives of the decision aid were crucial for identifying and rationalizing several of the revisions identified in this chapter. Additionally, guardian comments about competence, autonomy, and relatedness were noted to establish what information in the decision aid was appropriate and necessary. Because these constructs were operationalized in the initial version following messaging guidance from Head et al. (2022), participant comments about competence, autonomy, and relatedness helped establish when the decision aid was most balanced.

First, the most important revision was modifying language and removing wording that guardians felt was leading. In Round 1, guardians did not discuss feeling autonomous, but did discuss relatedness and competence. By the final round, guardians

said they felt autonomous and empowered in their decision-making. Revisions to balance information were made to help guardians feel less coerced into making one decision over another, ensuring the decision aid was balanced and helped with decision-making, rather than forcing one outcome. This addressed both the first objective as well as the autonomy construct in the second objective.

Second, several pieces of information were added to the decision aid to give guardians all the information they felt they needed prior to a counseling appointment. Much of this information was added on the myths versus facts page, which was later removed due to guardians' confusion and added worry about some of the myths. Still, information about having future children, receiving care even without testing, and having health insurance coverage in the event of a diagnosis were present in the final version. This information was initially excluded from the tool to avoid overwhelming guardians, but their feedback revealed how important a comprehensive view of testing and outcomes was. These revisions also addressed the first objective and the competence construct in the second objective.

Other revisions presented here are minor in comparison to the two above. The first and final versions look very similar to one another, but the final version is stronger because of the careful revisions made using 18 guardians' and one practitioner's feedback. The revisions presented in this chapter were crucial to fulfilling the objectives of the tool. Many of these revisions are also connected to the themes that were identified in this research. The themes will be explored at length in the following chapter.

## Chapter Five: Thematic Analysis

Following the final revisions to the PtDA, I returned to the 17 interview transcripts to conduct thematic analysis to answer the research questions. Although different versions of the aid were reviewed in each round of interviews, similar questions were asked, and recurring ideas were explored. Because interviews are "very valuable for strengthening and complicating" data (Tracy, 2019, p. 78), it was important to use similar questions for each version of the tool to help identify what information was or was not appropriate for the tool and how guardians felt about it. However, I also followed my own instinct when asking questions that were not necessarily on my interview guide to explore ideas and feedback in more nuanced and personal ways (Ellingson, 2017). I identified important themes that reflected the concerns, perspectives, and lived experiences of parents/guardians of infants regarding genetic testing across all rounds of interview. These themes often overlapped with revisions detailed in the previous chapter because both were informed by guardians' wants, needs, concerns, and experiences. Subsequently, some quotations used in the revision section will appear here also in the broader context of themes and sub-themes.

These themes provide answers to the research question: What can the message testing process reveal about guardians' needs during the NICU genetic testing recommendation process? They also answer the research question: What can NICU guardians reveal about the potential *functions* and *uses* of neonatal genetic testing PtDAs? As I conducted the thematic analysis of the transcripts, I realized that the PtDA functioned as a mirror that helped guardians reflect more clearly on their lived experiences, including their informational and emotional needs. These reflections helped

them identify and articulate what they wanted or needed during times of medical distress and how this tool would address those wants and needs. Understanding these elements of guardians' experiences proved useful in the revisions above, but this section will emphasize their lived experiences more. In creating a tool that is designed for one of the most stressful and difficult times in a guardian's life, it is paramount to understand and give space for their voices to be heard. Although the purpose of the decision aid is to help guardians make an informed decision more quickly, the themes related to the decision aid are ultimately reflections of participants' experiences at what was often the most traumatic and distressing time in their lives. The reflections of their experiences are explored below in the four themes: Guardians are on a journey; guardians want information – on their own terms; guardians use the tool beyond its intended purposes; and guardians are empowered in decision-making.

**Theme One: Guardians Are on a Journey**

The first theme discusses guardians' perceptions of the NICU experience as a journey. This theme addresses the third research question: What can the message testing process reveal about guardians' needs during the NICU genetic testing recommendation process? This theme is not specific to guardians' perceptions of the tool but is helpful for framing guardians' experiences of the NICU status quo and how those experiences shape perceptions of the tool, which will answer the other two research questions about functions and uses. Guardians consistently referred to the NICU experience as a journey or battle with distinct challenges. Hali, a NICU mother, described how even just having a baby itself was a battle: "I'm reading this... as a person who just gave birth, and they're tired, and just, you know, just went through a battle."

Every guardian with NICU experience said the NICU journey involved being overwhelmed. Jane, a mother of two NICU infants, said, “NICU stays... are very overwhelming. A lot of parents, you don’t get to stay there. You do eventually have to go home without your baby, and that would be very overwhelming and upsetting.” Annie, another NICU mother who had three healthy infants before her fourth child was hospitalized, said, “I knew what a newborn was, what the steps are, what was a normal newborn, how to feed, all of those steps. So the NICU, it was overwhelming, but I was already a mom. A NICU is just... a different journey that I had to take with this child instead of my other three.” Even guardians *without* NICU experience discussed the NICU as a journey. Sam, a mom with a healthy 2-year-old, said, “I feel like NICU stays, they are very overwhelming. A lot of parents, they don’t – especially if your baby is staying in the NICU long term – you don’t get to stay there. You do eventually have to go home without your baby and that would be very overwhelming and upsetting.”

Understanding the journey rhetoric regarding the NICU experience was important when structuring the order of information and images in the decision aid. Many guardians expressed how, although even remembering their NICU experiences was painful, it was reassuring to have their experiences of the NICU journey accurately represented. Ramona said, “All the pictures of the babies in the NICU… [are] reminiscent of when my baby was in the NICU. So, I mean, it was like a lot of emotions, but mostly it’s just kind of like, ‘Oh, yes, I remember being there.’” Casey, a mother with no NICU experience but two young children, including a six-month-old, described how important it was to see different stages of the NICU journey in the decision aid.

> I look at those babies outside of the NICU on page six, and I’m like, okay, they’re not going to be in there forever. And, and this, you know, the

> team's going to care for the baby through, you know, to get the baby as healthy as possible. And so then towards the end, with like, on page nine, with the mom holding the baby... It's like you've taken me on the journey, right? I've got like my NICU baby, and lots of care, and then I get to go home – hopefully, feeling better about the whole experience, because I've done the genetic testing.

Other guardians framed their feedback on the decision aid through the scope of their previous NICU experience as a journey. Carolina, when offering feedback about where and when to explain *how* genetic testing can help doctors provide better care for infants, explained:

> Both my babies were in the NICU, and when I was there, it was a very overwhelming time, extremely emotional, and it was very difficult to keep track of simple ideas. So, while I think most medically, most medically comfortable humans would decide to do this right? It's helpful still to have reference guides, and to be not simplistic, right? But very clear, very clear in your language. It is highly likely, in my opinion, that an overwhelmed set of parents, when their baby is very sick, might not make it to page seven or eight, where that is clearly explained. So, I would recommend, you know, I know that we're trying to be forthright and not necessarily persuasive. Right? But that is the honest to God fact. That's why you want this done so. The sooner you can emphasize the why? I think the better it'll be.

Through this lens of the NICU as a journey, several sub-themes were identified. These themes represent distinct pieces of the NICU journey overall.

**Losing Power and Control.** An inherent part of the NICU journey is the loss of power and control. Many guardians with NICU experience talked about how difficult it was to feel they had lost control in the NICU. Jocelyn, a recent NICU mother, said, "I didn't know anything or have control over anything." Riley, another recent NICU mother, expressed similar feelings. "I feel like a lot of times, it's just like, things are getting told to you. I think the more options you have as a NICU mom, the... the more helpful it is just to know, because you are so much *not* in control of your baby when they're in the NICU."

Interestingly, some guardians wanted genetic testing for *all* NICU infants, not just those who were recommended for it. Vivian, whose infant was hospitalized at the time of the interview, said, "I think that just knowing that there are other things to test for, to even just give the peace of mind to rule things out, even if you're not necessarily trying to confirm the presence of these conditions, is going to be a really helpful thing for parents." Wanting testing for all infants may be an attempt to restore a sense of control or power. Guardians' feelings of lost control were often reflected in what they *wanted* in the NICU. For example, Sadie explained: "I always focused on the pieces that we *could* do as the parents, and how we could be involved in the process, and that alleviated a lot of our stressors."

**Battling Feelings of Ignorance.** Guardians with NICU experience often alluded to feelings of ignorance. One of the only NICU fathers to participate in the study explained how relieved he was to read simple descriptions of different medical terms in the decision aid; this was very different from his previous NICU experience. "Instead of saying 'Tylenol,' [doctors] say 'acetaminophen,' or however you say it." Regarding the material itself, Nick said, "This catches my eye, and it's not wordy, but they don't put... I don't want to sound stupid. They don't put a lot of smart words in there… it's like, anyone could read it and understand it." Nick went on to explain that when his daughter's doctors recommended genetic testing in the NICU, he thought they would have to cut something off of his baby – but he was too afraid to ask for clarification for fear of being judged.

Other guardians also expressed how they often felt ignorant or even stupid during the NICU journey. When discussing why she specifically liked the genetic counseling

team page, which described the different roles of geneticists and genetic counselors, Sadie said:

> You're sometimes just told [in the NICU], "Okay, you're going to go see this type of doctor." Well, sometimes you have to go, "Okay, but what does that doctor actually do?" You put that right here for people. And you made it so that people didn't have to ask and feel like, "Should I know this? I guess we're stupid for not knowing this." You made it really kind of accepting of all levels of understanding.

Although few guardians said outright that they felt ignorant or "stupid" in the NICU, it was often alluded to by what they discussed *liking*. For example, Jane said, "I thought it was very easy to read and understand. And I thought it was put in very simple terms for someone who's going through a lot."

**Experiencing "Mom Guilt."** In addition to feelings of ignorance, several parents expressed feelings of "mom guilt," although one dad discussed parental guilt, too. Nick was very vocal about his feeling of guilt in his own NICU experience. His infant's team recommended genetic testing for her, and the recommendation left Nick and his wife feeling incredibly guilty: "For me, I was scared the whole time [in the NICU], didn't know what I was doing. And then, when they brought up the genetic testing, I instantly thought, 'Oh, my God! Something's wrong,' like she, you know... we did something wrong."

Abigail explained her own concerns about "mom guilt" for guardians who did not understand or want genetic testing. She described her own feelings from her time in the NICU, specifically discussing how she worried over many of her decisions in the NICU and feared judgment from medical professionals: "If I don't want to do [testing], what? Are they going to call CPS on me? Am I considered a bad mom, you know? Just all the typical mom guilt type stuff that comes into play." Abigail specifically referred to these

feelings as “mom guilt” and discussed how that “feeling of mom guilt” is normal in the NICU.

Jocelyn provided an important piece of feedback regarding the reasons for declining versus getting genetic testing section, which was removed due in large part to her feedback. She voiced her concerns that guardians reading the reasons for declining testing may feel judged or even weak:

> I feel like it is lopsided as it is, like the declining testing bullets. “You’re worried that the results might be upsetting. You might find out that the future children on option. You have unanswered question.” Like that just... it makes me feel like if you decline testing, it’s because you’re weak and scared and can’t handle your reality. I would have been really mad, honestly, about the myths and the declining stuff. I would have probably been offended about—by it, if I'm being honest. But, it's just because I was... I was in a very sensitive place, and people assuming what I was thinking or adding on like myths and stuff would have made me mad.

**Theme Two: Guardians Want Information – On Their Own Terms**

The second theme discusses guardians’ desire for information on their own terms. Although NICU guardians acknowledged how overwhelmed they were during their time in the NICU, they all discussed how important it was to get information on their own terms, in digestible ways. However, the “digestible” amount of information varied from guardian to guardian. For example, some guardians felt the amount of information presented in the decision aid was as much as they would need to make a decision, with almost every guardian agreeing that they would get genetic testing based on their review of the materials alone. However, other guardians wanted additional information, with the PtDA acting as a starting point. This stark contrast in information preferences likely comes down to previous knowledge about genetic testing. For example, Jasmine, a NICU mother who underwent genetic testing as part of her in vitro fertilization (IVF), said, “Most of this stuff I already knew, you know? And most IVF moms would probably be in

that same boat, because that's—that's a big thing when you're going through IVF is genetic testing. But that is my personal experience. Most other moms don't have the background that I do. I thought it was informative without being overly wordy."

An additional element of wanting information on their own terms is that information needs are twofold. First, guardians discussed wanting information *about genetic testing*, as was expected. John, a father of two NICU infants, stated, "It's far more difficult to make a decision… when one party has far more information than the other." John elaborated that he would want a comprehensive overview and better understanding of what genetic testing is and what it looks for. Sam also talked about wanting more examples to help her understand what genetic testing and genetic conditions are. Carolina also wanted additional information on privacy management of genetic testing results:

> As I was reading through, it took until the very end for us to talk about privacy, medical data privacy, and I think that when you consider the concerns of people around genetic testing, there is a pretty heavy – whether it's legitimate or not – there's a pretty heavy concern about the idea of putting a label on an itty, bitty human who is very fresh and is very sick. So, the idea of being able to understand that your data is completely private, that the baby's data will go nowhere, that it will not be utilized in any way other than what you authorize it for.

Second, guardians discussed wanting information *about their babies' health*, which was motivational for guardians in the study. Everly said, "There's a chance you're going to find out things that are upsetting, and that would be awful. But I would rather know what we were dealing with and be able to take care of it and take care of it properly, and have a plan, as opposed to just kind of, you know, flying blind." Jasmine also shared this feeling: "In my opinion, the more information you have about your baby, the better. Of course, not everybody shares that. There's a lot of fear with getting a diagnosis. But I want to know all the things."

Charity, a mother of one stillborn infant and one NICU baby, explained: “In my own situation, I wanted to do what was best for my daughter, and, you know, I listen to doctors. They know what they're talking about, and if finding out something that could or couldn't be wrong with my child when she was there, I would want to do everything that I could.” Other parents could not understand why their NICU peers would not want information provided by genetic testing. Charlie said, “I just don’t understand why anybody wouldn’t want the... they wouldn’t want to find out, because then they would know. But like, isn’t that a good thing to know?” Within this theme, several subthemes related to information-seeking and management were identified.

**Avoiding Information Overload.** The first subtheme related to information needs was avoiding information overload. Guardians relied on previous NICU experience to establish how detrimental *too much* information could be. Charity expressed her own previous experiences with information overload in the NICU: “You’re already going through a lot in the NICU and having too much information is almost too bad. Because I remember... like the first week or two, everybody’s coming in giving you some sort of information, something. So, I think the easier it is to read, the easier it is to understand, the better.” Charity explained how she was often given too much information and would become overwhelmed, obsessing over everything she was given in an unproductive way.

Jasmine echoed this with a similar but reversed experience. Whereas Charity would obsess over all the information she was given, Jasmine felt so overwhelmed she would stop using it: “NICU parents get a lot of, *a lot* of paper. We’re handed folders filled with a ton of stuff. I’ll be honest, I didn’t read half of the stuff I was given. It was a lot.” Jasmine recommended shrinking down the content further, if possible, but when

asked what sections might be unnecessary or repetitive, she explained that every parent would have different needs. “I read how they get it several times, but again, some parents might need that. It’s hard because everybody’s so different.” Jasmine finally landed on a suggestion to help mitigate information overload while still providing information in several ways for those who needed it: “Putting the things that not all parents need to read towards the back is probably helpful, too, because everybody’s going to read the first page or two. Are they going to make it through the whole thing? Some of them will, some of them won’t.”

Charity also discussed how useful the structure of information was after explaining her own experience with genetic testing for her stillborn infant. She explained that after her son was stillborn, genetic testing was performed to determine the cause of the stillbirth. She explained how overwhelming and distressing it was to hear about genetic testing, especially after her son’s death. A year later, her daughter was born prematurely, which led to Charity’s NICU experience. When reflecting on how useful the tool would be during her time in the NICU, Charity explained: “It breaks it down. It tells you the different, you know, you have counselors, you have the doctors and then, you know, down at the bottom, it tells you what they are looking for. The process page is nice, too, because you know what’s going to happen.”

**Complementing Tangible Materials with Discussions.** One way to combat this information overload while still providing necessary information to guardians is complementing tangible materials with discussions. This was identified as an additional subtheme. All guardians agreed that a conversation with a medical professional had to take place at the time of receiving the decision aid. Many respondents relied on hindsight

from their own NICU experiences to express the importance of this strategy. Abigail spoke of her recent NICU experience, emphasizing the importance of using the form in conjunction with conversations with practitioners. “Sometimes you get a pamphlet or a form or whatever, and you start to fill it out, and it’s never revisited.” John, a current NICU father with previous NICU experience, also expressed how conversations with the providers or recommending practitioner would help mitigate some of the information overload that might start: “Putting in a note about why [they recommended genetic testing] would scare me, but a conversation with the person presenting it saying, ‘this is why you’re a candidate’ would be nice.”

These conversations had to be in addition to the implied conversation that takes place with the genetics team after guardians receive this document. Jocelyn said, “I was just assuming is that when they’re given this, a nurse or somebody is there to kind of walk them through it briefly and gently and tell them what is happening. And then afterwards someone, when they make the decision and talk to somebody, someone’s there to answer questions and things like that.” This strategy would help with the previous subtheme of avoiding information overload within the decision aid.

**Streamlining Information Exchange.** Another consistent finding was that NICU communication must be streamlined, the third information-related subtheme. Guardians with NICU experience specifically called out the challenges of receiving different advice and input from the various NICU team members, ranging from nurses to nurse practitioners and neonatologists. Even guardians with no NICU experience understood how the expansive NICU team could present challenges related to information and decision-making. Sam, a mother with no NICU experience, expressed her concerns about

information coming from so many different people: “In the NICU, you have so many different nurses that rotate on your baby, and you might see multiple doctors.” Sam went on to say that receiving varying feedback from different people would complicate decision-making for her infant. Jocelyn, a recent NICU mother, echoed this from personal experience:

> When you’re in the NICU, there’s a million people coming in and out of the room, telling you their different thoughts and things. And everyone has different opinions and answers for things. So it’s really helpful to have like, “This is what genetic testing is, this is with the process, this is what will happen,” because if you ask a nurse about it, they—their answer will be different from the next nurse, and then you're just confused.

Other NICU guardians provided additional insight into the nature of receiving information in the NICU. They often reflected on their own experiences and how they did (or did not) *process* information they were given during their time in the NICU. Annie said:

> What I learned in the hospital is that they come in, give you a whole bunch of information. Then they walk out for like three hours, and you’re sitting there going, “What did they really say?” And if they could hand you and say, “This is the stuff. Read this over as you’re waiting for the next doctor to come in.” It always helped me when they handed me something, and then, during my time sitting there waiting, I could then read over it again.

**Facilitating Productive Information-Seeking.** The final information-related subtheme was that guardians would seek additional information, even though many of them agreed that information overload needed to be avoided at all costs. Jocelyn said, “Some of the handouts I got were just like a one-page thing... I don’t know, just like not fully informative. And then I would have to Google stuff.”

Importantly, although guardians agreed that too much information would be bad but that they would also still seek additional information, guardians discussed how the decision aid could facilitate better information-seeking. Astrid said, “I probably would

write down, you know, [my] questions or start... probably researching right away on certain things, you know, further, just to help me advocate more for myself." Charlie, a NICU mother, explained: "You start thinking about all the things that that could mean, and all of the scary stuff... having some kind of information so you don't go down a rabbit hole that is not necessary before you actually sit with a genetic counselor is helpful."

Again, the idea of seeking information being twofold occurred in this subtheme, as well. Not only did guardians want to find information about genetic testing and genetic conditions, but some also viewed testing as a way to obtain additional information about their baby. Riley said, "I'm all about anything that will help my baby or get answers about my body or her body. So, I think that knowledge is power, so I would be interested in doing it, whether it helped or not." Casey also explored genetic testing as an information-seeking behavior about her baby's health, as well as the health of herself and her family members. "Obviously, the child's number one, but it also would teach you things about potentially yourself. Is this something we need to be concerned about for future children or ourselves, or, you know, it could be for the parent... the parents' health and the baby's health."

This theme and its subthemes are inherent to the decision aid; decision aids provide information to facilitate decision-making. In a sense, many of these subthemes were expected because of that. The next theme explores more unexpected aspects of the decision aid, focusing on the unintended uses of the tool.

**Theme Three: Guardians Use the Tool Beyond Its Intended Purposes**

The third theme discusses some guardians' unexpected uses of the aid. The expectation with the aid was that guardians would use the tool to learn about genetic testing, establish what questions they had prior to attending genetic counseling, and help speed up the decision-making process. Notably, all participants did respond that they would use the tool as intended. For example, Charlie said:

> We'd probably use it to try and figure out what our questions are, so like seeing things that have raised questions for me. I think that would be helpful just to like, I don't know, get my mind in that space. And you know, just like, I feel like it would raise questions for me, so I would use it as a tool to like, think of the questions that I have and I'd probably write in it a lot and bring it with me to the doctor's appointment, so I could walk through all of it with them.

Casey also expressed the intended uses of the tool, saying, "I think the intention is to consider what option they're going to choose. Are you going to go through with the testing or not? And ask them to process the information, make spaces for them to process it and ask questions." However, in addition to the standard/intended uses of the decision aid, there were several key findings about how guardians would use it in ways beyond its intended purposes. These went beyond facilitating communication between practitioners and guardians to ensure more thoughtful decision-making.

**Getting Input from Family and Friends.** The first surprising way guardians discussed using the tool was to get input and feedback from extended family members and friends. The expectation was that the tool would be used to get additional information from medical professionals caring for the infant. However, several women specifically discussed reaching out to their moms and sisters about what decision to make, using the decision aid to help determine that. Charity explained, "I would have to read it all at once, and obviously, I would, you know, discuss it with my husband. And then I would

probably talk it over with my parents or a close confidant." Whereas Charity discussed using the aid with family and friends to help her process the information, Casey discussed fact-checking it with family members in the medical field: "I go to my sister [a nurse] for most medical things, right? So, I would take this information and go cross-check it with, you know, people, family and friends that have… similar experiences. Not cross-check, but get opinions or thoughts on, you know."

Fact-checking the tool with family – especially family members who were medical professionals – was relatively common. Carolina had similar input:

> I happen to have a mother who is a nurse, would probably speak with her about it. It's just the—the nature of how I make medical decisions is when you've got an RN in the family, you kind of call and just say, "Hey, you think this sounds like a reasonable plan?" And so, I could see a situation where I reviewed it with her. I could see a situation where, you know, if I had other trusted medical providers—if, if it was my second child, I might speak with my pediatrician about it, because my daughter had already established a relationship with our peds, and we trust and love her very much.

In addition to seeking second-opinions from family, guardians talked about how they would use the tool to seek help with processing their feelings and thoughts. Sadie said: "When you're sitting in that NICU, you don't know what you're supposed to do sometimes, so, having this as an accessible piece to someone who may be a support [person] to the parents or to that legal guardian, I think it would just kind of help them be able to walk through and console [them]."

Everly also discussed how having tangible materials in the NICU was crucial to her experience processing information because she could use those materials to seek help. As she explained, having materials meant she could get "eyes on everything, too," and have "somebody else reading these things and helping [her] process them." She clarified that because of how overwhelming the NICU was, she "didn't catch everything on the

first go." She explained that "whoever's helping Mom out should also get a copy of it, because I know that was something I struggled with a little bit was I was so frazzled with everything." Having tangible materials was not just useful for getting family's and friends' opinions, but also getting help with understanding and processing the information itself.

It is important to note that this was not consistent across all respondents. Some guardians felt the decision was private and should be kept between both guardians. Charlie said: "It's not something that I would want to like walk through with a friend. Maybe if we were having a hard time trying to decide, we might, but probably just my husband and the providers." Vivian also shared these feelings: "I think it's something that's really only should be for the parents because it's their decision ultimately, and I don't think it needs to be shared with like everybody."

**Communicating About the Infant's Health.** A surprising finding from this research was that some guardians discussed using the tool to update their family and friends. Abigail said, "I could see my mom wanting to know [about this document], because she's a worry wart about everything and just wants to be informed." When asked what guardians should read the material, Annie, mother of four with one NICU baby, said, the "type of people that are helping those families as well. I mean, my husband and I were both there. But then, you know, my parents were also actively helping us as well." Both Abigail and Annie discussed the decision aid's usefulness in updating family members who were actively helping the parents during the hospitalization.

Some guardians discussed how having the tool would be helpful to communicate about their infant's health when they were emotional. Astrid talked about how she would

struggle to update important people about her infant's health if they were in the NICU, and the decision aid materials could be useful in explaining where the baby was in their NICU journey:

> It's nice that I can give them something tangible if I feel like I can't talk about it. So, I think that can be helpful if I'm just taking the time to process. And of course, coming from a supportive family, you know, they're wanting to know, or what can they do? And if you can't talk, it's like, "Here you go like, read this."

In addition to communicating with the family about the infant's health, another guardian discussed using the tool to talk with friends. Nick said:

> I definitely want to talk to a few people, like in a good way, like a few of my friends that had kids. If we like started talking about kids and how the baby experience was – like we do one every once in a while when we meet up – I'd bring this up and be like, you know, "It's crazy, this genetic testing." And I'd, you know, bring up the pamphlet. Be like, "Hey, next time I'll bring it to you. Read this," or, "This thing is pretty legit."

**Making Connections Outside of the Team.** The final sub-theme related to unintended uses of the decision aid was that some guardians wanted to use the tool to connect with other families that had received genetic testing. Hali explained that she would add quotes to the decision aid from families that had received genetic testing:

> You know, "Oh, my child arrived so and so early. We didn't know what the complications were. It turns out that they had some genetic issue that was treatable." Or, I mean, maybe you don't even want to go there because it might give false hope. But that... What do they call those, like testimonies, I guess? Just to say what… what this service was able to do, for you know, two or three families.

Another parent discussed using the tool to connect guardians to a type of support group, which she had experienced during her own infant's hospitalization. Ramona said: "Since my child was in the NICU, you're also teamed up with people who also had NICU babies, and so I feel like if there's any way you could connect people with people who

had genetic testing, then that would be something that could be helpful, too. Just so that they can hear positive experiences or whatever."

**Theme Four: Guardians Are Empowered in Decision-Making**

The fourth and final theme was that guardians felt empowered when reviewing the decision aid; it made them feel more confident in making a decision about genetic testing. Charlie, a NICU mother, said, "I feel like this can be a tool of empowerment for parents. I think that they can feel like they *do* have the power to make the decision, and that can be really good and important for parents." Ramona, another NICU mother, offered the same feedback: "It just feels like this could give more power to parents, and I think that is a great gift to give NICU parents."

Parents who had previously talked about the overwhelming NICU experience as a journey drew on that historical knowledge when explaining how useful and empowering the tool would be. Carolina said, "I very distinctly remember how deeply overwhelmed and scared I was, and so, having a tool that is clear, concise, thoughtfully put together, that would be really, really meaningful to me. So, I think this is well constructed."

Within the general sense of empowerment that most participants expressed upon reviewing the decision aid, several sub-themes were identified. These are the components of the decision aid that led to guardians' sense of empowerment.

**Connecting with the Team.** The first subtheme related to empowering guardians' decision-making came in the form of team connections. This often went back to the genetics team, which many guardians did not know about unless they had had genetic testing for themselves or their infants. Jane and John discussed how comforting it was to know who they would be meeting with after seeing the tool. Ramona shared her

appreciation for the genetics team page: “It’s just nice to know the difference between a geneticist and a genetic counselor. If felt helpful. I liked the bullet points, and the pictures were helpful just to know, like, ‘Okay, so the geneticist is kind of like the scientist guy. The counselor can help me understand it better, or help me like go forward from getting the initial testing.’” Jocelyn also felt especially connected to the team because of the genetics team page, saying, “I would appreciate the level of going through to inform me about [genetic testing], and not just being like, ‘Hey, do you want genetic testing? I like that there was the reassurance of genetic counselors to help and like talk through stuff. So yeah, I probably would do it.”

Another guardian discussed how receiving this tool would indicate the thought and discussions her infant’s care team had put into the genetic testing recommendation. Charlie said:

> I feel like, if we were at the point where it had been recommended by the providers, and you know, by all of the providers, they’re all on the same page about that, I feel like this helps me understand that this is not just like one provider saying, “Hey, you should do this.” It’s a team that has looked at the results and, excuse me, decided this is, this is what’s probably best at this point, given the information that we have so far.

Other guardians discussed a sense of connection to the team in the larger NICU environment. Many recognized how different roles in the NICU interacted and appreciated how this tool could streamline communication across the team, creating a more cohesive experience for guardians. Annie said:

> How the NICU works, doctors come around at eight o’clock. They hand you a whole bunch of information, and then you don't see the doctors again until the next morning eight o’clock, unless something is terribly wrong with your baby, and they’re having to come in to help and, a lot of times, the nurses – NICU nurses are probably some of the most wonderful people I’ve ever met. But they don’t know some of the ins and outs of what the doctor is saying, either. So, being able to see and understand, the more information that you have, the ability to look at is helpful.

Language also played a role in team connections. Casey felt connected to the team – and cared for by them – because of the language used in the decision aid. Casey explained: "I like the second page, the list of like, 'safe and painless,' that's probably the number one question, right? Like, it's 'what is this going to do to my kid or to my baby?' So I really felt comforted the moment I read that first." Jocelyn echoed this about the line "We know how much you care for your baby, and we want to care for them, too," saying: "This whole thing would be really overwhelming to be reading through in the NICU, and so it's just a nice little reminder of like, 'We're doing this because we care. We know you care, like we want to get answers for your baby.' It's just a nice little empathy note."

**Connecting with the Experience.** This theme ties back to the first, that the NICU is a journey. Many guardians with NICU experience discussed the different things they experienced in their NICU journeys in relation to what they saw in the decision aid. Jocelyn said, "In the NICU, I mean, this is what you see. So, it's kind of validating almost, too, of like, 'okay, this looks kind of like my baby, so this is helpful for my baby.'" Jasmine echoed this: "It's representative of that particular phase in life, you know? That's exactly how we saw our babies. So, we connect to that."

Many of the feelings of connectedness to the experience were tied to the images used in the decision aid. Casey said, "The picture, the baby on the front is just like, you know, you just… I just want to hold that sweet little baby, you know? And you can... you can tell that that baby needs care, right?" Surprisingly, Nick said the pictures of NICU infants made him feel happy:

> I guess if you don't have a NICU baby, you don't really understand what those pictures are you just like. "Oh, it's a kid in the bubble." But looking at it and saying, okay, you know, it kind of calms you down, because

> you’re like, “I know what that is, that little boy or girl is in there to live and get better.”

Although most guardians said in some way that they felt connected to the NICU team or experience because of the language and images used in the decision aid, one parent had different feedback. John said: “There was very compassionate language, but I don’t know that I feel... that there was connection. I’m not sure I’d *want* a connection – you want a connection to the person suggesting it, but I’m not trying to get connected to the actual team doing the genetic testing.” Jane, John’s wife, however, did feel a connection with the experience because of the decision aid.

**Anticipating Needs and Concerns.** Many participants felt empowered by how the decision aid anticipated their needs and concerns, often answering questions before they had them. For example, participants discussed wanting to know where and how to access genetic testing results. Adding that piece to the decision aid before parents needed to ask about it helped them feel confident and cared for. Astrid said, “We go through IU health... Knowing that you can find your answers on the portal, more than likely before you hear from the doctor, too... I think that that’s helpful to show how parents can stay up to date.”

Another piece of information anticipated by the decision aid, which many parents found helpful, was the insurance and cost aspect. Astrid also provided feedback on this piece, partly from experience as a mother as well as an insurance-charging therapist. “I know that a lot of people worry about finances. That's why—when I was going through—there’s a great job. It kept bringing that up in terms of the questions. I think that was a great kind of, you know, at the end, like, ‘Oh, what if insurance doesn't cover it?’ You know, ‘This is what to do.’”

Other guardians talked about how the order of information and structure of the aid anticipated the mental state guardians would be in, allowing more room and time for processing. Carolina said, “I think it’s really intelligently structured. It gets more detailed as it continues, and theoretically, a parent would be able to take a pause. Kind of process, come back to it, maybe do a little feeding of the baby, and then come back to. You know those kinds of things.” Sadie also discussed the usability of the information using her NICU experience as a framework: “The way it’s set up, you have the most pertinent at the top. The way that I used to look through information is, I look at the first couple of pages, and then I sometimes said, ‘Okay, I need to put this down and come back to it.’ You created it exactly as that.”

In addition to anticipating guardians’ needs and concerns, guardians discussed how the aid could help them with another NICU challenge: Getting consistent information from so many different people. Charlie said, “It kind of covers all of the... things that I would be concerned about. It kind of touched on all of those, and I feel like it would probably be helpful for the providers because then they’re not just repeating all of this information constantly. This is just like a good baseline of information.”

Everly also discussed how the decision aid anticipates the journey guardians will be on in the NICU, recognizing the specific state of mind they are in: “Just from a graphic design standpoint, it’s incredibly clear. And it’s laid out in such a way that, even though it is nine pages long, it’s very easy to gather the information quickly, which I think is really important when you’re in that stage.” Vivian, whose infant was in the NICU at the time of her interview, also talked about how the use of graphics and explanations of different result types would be useful to her with her limited mental

capacity in the NICU: “I like the pages, really, where it shows what you can expect for the different results and why it’s done. I like the statistics included about how 80% of the NICU babies get the comprehensive test, because I feel like that’s something that helps put a lot of people’s minds at ease.”

Casey appreciated the structure of the decision aid, too. Although she did not have NICU experience with either of her infants, she did have feedback as an English teacher:

> It’s not overwhelming to read. And then, you know, the fact that it’s attached to images, I think, is good for memory and processing, because I think brain science tells us that if it’s attached to an image, we’ll remember it more, right? So, all the little icons stood out to me, right, like on the second page or the third page, the little DNA and the light bulb, and the question mark – all those little visuals help.

**Restoring Power and Autonomy.** The final subtheme related to empowerment was restoring power and autonomy. This also ties into the first theme, with its subtheme of *losing* power and control. Many parents discussed how the tool could help them be advocates for themselves and their infants, restoring some of the control and power inherently lost in the NICU. Astrid said, “I think having the spots where you can write down your own kind of thoughts or questions, or like, write down those appointments can be helpful, too, to feel like you can advocate for yourself.” Casey said, “I like that underneath this, I’m-I’m being told that, like, the intention of the booklet, right? That it’s going to help me make an informed decision, but that the decision is still mine.”

One way the tool helped guardians feel in control was that it was not persuasive. Astrid explained: “I thought it was done very fact-based, which was helpful. It didn’t seem like it was trying to force it. And was just, you know, really providing all the options, and how it can be helpful, but not in a, I guess, persuasive way.” Avoiding persuasion was crucial to make guardians feel confident and empowered without feeling

pushed or forced into one decision. Astrid and John both discussed how it was important to know the testing was not commission-based, and that multiple experts recommended testing. John voiced his concerns on the first version of the aid, wondering if testing was recommended as a way to make money: “The first thing I would want to know is if the doctor, if the care team thought... if they weren’t just doing genetic testing just to do genetic testing.” Astrid, who viewed the third version, said, “I felt like it was coming from a place of just true statistics and helping, and not something that felt like it was going to like... help someone just like financially, or, you know, was like commission-based, or something like that.”

Part of empowering this decision-making was recognizing guardians’ rights to decline testing. Everly explained how the more balanced nature of the tool made her feel more confident to get genetic testing: “This is not trying to push you one way. This is just giving you information. You know, you’re still free to decline.” Everly went on to explain how the tool’s usability could generate competence and autonomy:

> It gives you a framework at least to, to work with... if we didn't have this and we had questions, you know, we would still ask questions, but it would feel kind of like we're firing bird shot, you know, whereas this gives us at least a guideline of who you're going to be talking to, what the steps are, what order the steps are going to happen in.

Sadie also shared appreciation for language in the tool regarding declining testing. Although she said she would get genetic testing based off this material, the balance of information made her more confident in that decision:

> I liked that there were pieces about, “It’s okay if you don’t [get testing], it’s not going to hurt your child. If you don’t, we’re accepting of you if you don’t.” I thought that was nice, so that it’s... it’s really accepting of any decision that’s made. I do think it’s really important for any parent, especially if you’re in the NICU, if you’re making all sorts of different decisions.

Even guardians who did not outright say or discuss empowerment did allude to it through how they discussed *using* the tool. Hali explained, “I would just write down any questions I have in the areas that you provided. I would highlight, and make notes, and then proceed with any questions that I had, and just do it, commit to it.”

## Chapter Six: Discussion and Conclusion

The final product of this research is a decision aid. The tool was not designed to make guardians consent to or decline testing. Instead, the decision aid's purpose is to empower them to make more informed decisions while decreasing the time needed to do so. To create this tool, key constructs from SDT were operationalized that addressed the four functions of NICU communication: to build and maintain relationships, exchange information, share decision-making, and enable parent self-management (Wreesmann et al., 2021). Researchers have theorized that the incorporation of theory into PtDAs makes them more effective (Durand et al., 2008), and others have demonstrated that, although it is a motivation theory, SDT can be conceptualized as a communication framework (Brown et al., 2021; Head et al., 2022; Martela et al., 2021). Qualitative data was collected and analyzed to understand guardians' perceptions and uses of the SDT-informed decision aid for NICU genetic testing.

Chapter four highlights the major revisions and themes that were identified from the qualitative data using thematic analysis. The first research question asked about the functions of a NICU genetic testing decision aid. The themes revealed that the decision aid addressed the four functions of NICU communication identified by Wreesmann et al. (2010). The second research question asked about the uses of a NICU genetic testing decision aid. The themes revealed that the tool could be used in many unique and unexpected ways, including to update family members about the infant's health and to seek additional input from non-decision-makers in the family. The third research question asked about what guardians could reveal related to the NICU genetic testing process. The themes revealed the deeper feelings and lived experiences that shaped how guardians

interacted with and considered using the tool. With these findings to frame the remainder of this research report, the following chapter will explore the theoretical and applied implications, limitations of the current study, and considerations for future research.

**Guardians Recognized the Four Functions of NICU Communication**

The first finding has practical implications for the NICU and answers the first research question: What can guardians reveal about the potential functions of a theory-informed neonatal genetic testing PtDA? Because of the incorporation of SDT constructs, guardians discussed or acknowledged all four functions of NICU communication as identified by Wreesmann et al (2010): building and maintaining relationships, exchanging information, sharing decision-making, and enabling parent self-management. Each function of NICU communication also aligns with an SDT construct. Building and maintaining relationships corresponds to relatedness; exchanging information aligns with competence in that information exchange should be meaningful, intentional, and utilize supplemental materials; and finally, sharing decision-making and enabling parent self-management correspond with autonomy.

These functions of NICU communication are often juxtaposed with several failures of NICU communication. For example, whereas information exchange is a crucial aspect of NICU communication, Govindaswamy et al. (2019) found that different information is often shared by multiple practitioners and can increase guardians' decisional anxiety. And although building and maintaining relationships is another vital aspect of NICU communication, Wigert et al. (2013) found that NICU communication also lacks emotional support, leaving many guardians feeling isolated and disconnected from their team when making decisions.

Fortunately, all of the NICU communication challenges identified here by other researchers were addressed by the decision aid. Although SDT as a communication framework is relatively new, it was the incorporation of these constructs that made the decision aid so useful and effective for guardians who participated in this research. The decision aid helped guardians feel cared for and connected, both to the NICU care team as well as the genetic testing team, building and maintaining relationships through the operationalization of relatedness. The tool also helped streamline information exchange; many guardians noted how using the decision aid would help them get consistent information and verify different facts with the care team. Finally, sharing decision-making and enabling parent self-management was also achieved through the decision aid's operationalization of autonomy. Guardians felt empowered and more confident in decision-making because of the language and reminders of previous decision-making presented in the tool.

**Guardians Discussed Using the Tool in Unique Ways**

The next important finding from this research is that guardians want more information in the NICU – on their own terms, and in ways that they can use. This finding answered the  second research question: What can guardians reveal about potential uses of a genetic testing decision aid? Multiple guardians in this study discussed using the tool to look up additional information, whereas other participants said the information provided was enough to make a decision about testing. All guardians agreed that a conversation with the recommending practitioner was necessary at the time of receiving the aid so that the guardians could ask questions.

Other researchers have demonstrated that genetic testing is a difficult concept for laypeople to understand (Condit, 2010; Wöhlke et al., 2019). When considering this finding, it is crucial to remember that different communication approaches are appropriate for specific types of patients and diagnoses where genetic testing is concerned (Hallquist et al., 2021). This decision aid is a generalized tool for all guardians whose infants are candidates for genetic testing; it does not differentiate guardians and their infants based on suspected condition or type of testing. Subsequently, the tool must be used in addition to conversations with practitioners and care team members.

This finding is important because it addresses a common complaint from NICU guardians. As Wigert et al. (2013) identified, poor information giving is one of the biggest challenges NICU parents and guardians face. Information giving in the NICU is challenging for two main reasons: First, different staff provide different information and offer different opinions (Wigert et al, 2013), and second, health literacy is below-average for nearly half of all NICU guardians (Mackley et al., 2016). Because of the high-stress, high-stakes NICU environment, guardians often experience high decisional anxiety, which Wainstein et al. (2022) found in moderate to severe amounts for 50% of guardians. Unfortunately, guardians feeling rushed, distressed, and overwhelmed also leads to poor information retention in the NICU (Wainstein et al., 2022). Additionally, researchers have found that a lack of written supplemental materials to accompany verbal information exchange presents another weakness for guardians to understand complex information and make medical decisions (Lorie et al., 2021).

Nearly every participant discussed wanting more information, but they agreed that more information should not be added to the tool; instead, they noted the importance of

using the tool *with* practitioners and genetic counseling team members. They specifically described using the tool to identify their questions and facilitate better information-seeking with the care team, family members, friends, and the internet. They also discussed using the tool to address the challenges Wigert et al. (2013) identified by streamlining information exchange and ensuring they could verify information with multiple care team members using the tool to receive similar input. Their responses demonstrate how important intentional, thoughtful information exchange is in the NICU and how it can be paired with the use of a theory-informed PtDA to achieve important goals like consenting to genetic testing.

Although this research was strictly qualitative and no data was gathered to analyze metrics relevant to decision-making or measure different outcomes between control and trial groups, several findings about guardians' uses of the tool were identified. First, almost all guardians responded that they would get genetic testing for their infant based on the information presented in the decision aid. They felt the tool was balanced and presented the appropriate amount of information, along with space to process and write down questions. Although the intention of the tool is *not* for guardians to come to one outcome, this is still a positive finding; researchers have established the efficacy of genetic testing for neonates and their overall health outcomes (Meng et al., 2017; Willig et al., 2015; Wojcik et al., 2018).

Importantly, this finding was balanced with guardians' responses about the purpose of the tool. Guardians in the second and third rounds discussed how the tool was designed to help them make a decision. This feedback varied from responses to the initial version, when guardians had commented about feeling led to only one decision or

outcome: getting testing. Responses about *making a decision* from the second and third rounds helped determine that the decision aid was balanced between getting or declining testing. If all guardians had agreed that they would get genetic testing, and all had agreed that the purpose of the tool was to encourage genetic testing, that finding would indicate an unbalanced tool.

The tool also addressed documented reasons guardians decline testing. Genetti et al. (2019) found that guardians decline genetic testing in a research capacity because they felt overwhelmed by their infant's illness and because of concerns about privacy management. Language used in the tool addressed both concerns, helping guardians make a more informed decision. For example, guardians with NICU experience discussed being incredibly overwhelmed by their infant's illnesses, as expected. However, they discussed how the information about genetic testing presented in the decision aid could alleviate some of that anxiety. Many guardians specifically discussed how phrases like "Understand your baby's condition" and "Help us care for your baby better" provided some level of hope, especially when considering the type of care their babies would receive in the NICU.

Other guardians discussed how the tool addressed another common and well-documented concern: expenses. Multiple guardians referenced the importance of phrases like "Genetic testing is covered by insurance for most families," and they especially liked recommendations for next steps, such as "Talk to your genetic counselors for more information on insurance coverage." In addition to addressing their concerns, clear instructions about next steps and future directions helped create a sense of control that many guardians with NICU experience had previously lost during their time in the NICU.

Multiple guardians commented that any time they had a question, it was typically answered within one or two pages of the decision aid, which helped them feel confident and cared for. Because the decision aid anticipated and addressed these concerns with actionable steps, such as contacting the genetics team for insurance questions, guardians felt more involved in the care of their infants.

**Guardians Connected with Self-Determination Constructs**

The final finding answers the third research question: What can message testing process reveal about guardians' needs during the NICU genetic testing recommendation process? As anticipated at the start of this research, guardians identified needing to feel autonomous, competent, and related when reflecting on past, current, or potential NICU experiences. This finding also has practical implications as other researchers have advocated for the use of theories in PtDA, especially behavior change and decision-making theories, to strengthen their effectiveness and replicability (Durand et al., 2008; Gültzow et al., 2021). The final decision aid presented here used SDT, a motivation theory (Ryan et al., 2008). Participants reported overall positive experiences reviewing the tool and almost always linked those experiences back to one of the three constructs. This finding has major theoretical implications because, to my knowledge, few to no PtDAs have previously incorporated SDT, and the use of SDT as a communication framework itself is relatively new and under-studied (Head et al., 2022; Martela et al., 2021). Guardians' reflections on how these constructs made them feel – and how the constructs might make them feel in the context of the NICU – may indicate that SDT is a useful theory and framework for future PtDAs and other supplemental materials related to health decision-making.

The first construct explored was autonomy, which I operationalized by reminding readers of previous actions, emphasizing their choice in the outcome, and encouraging them to reflect on aspects of testing they could be involved in (Head et al., 2022). Multiple guardians noted how important reminders of control and autonomy were and said the decision aid would reinforce their sense of control in making important decisions for their infants. This finding aligns with findings from other researchers that autonomy may be the most important construct that then facilitates the others (Martin et al., 2017; Williams et al., 2004). Autonomy was often reflected in revisions made to the decision aid; guardians wanted to know more about how they could be *involved* in the process, when they could be present during testing, and what information they would have access to in their infants' electronic health records. This finding aligns with other researchers' evaluations that increases in autonomy support are both a predictor for specific behaviors, such as making a decision about adopting a health technology (Ridgway et al., 2016), *and* increasing competence (Williams et al., 2004).

The next construct is competence, which I operationalized by ensuring a thoughtful structure of information, incorporating white space, and using analogies and plain language (Head et al., 2022). Multiple guardians noted how effective the structure of the decision aid was in terms of digesting and using the information it provided. Guardians discussed how the strategies used to generate feelings of competence *did* create a sense of ease when reading and reviewing to make an important medical decision, which enabled their empowerment in decision-making. *Empowerment* is linked back to autonomy above. It is crucial to note that other researchers have found that autonomy-supportive healthcare providers that empower patients are predictive of

patients' perceived competence (Martin et al., 2017; Williams et al., 2004). Although participants were reviewing the tool, they specifically discussed it as an extension of recommendations from the care team, viewing the decision aid as a form of support from the recommending provider. The nature of the tool being used in conjunction with care team conversations may further enhance their feelings of competence (Kosmala-Anderson et al., 2010; Martin et al., 2017).

The final construct was relatedness, which I operationalized through images and language that centered on care and compassion (Head et al., 2022). All guardians alluded to or outright discussed feeling some level of connection to the images of NICU infants, with many discussing how the babies on the pages looked like their baby had while hospitalized. Additionally, guardians talked at length about using the tool to relate with people outside of the NICU, both to update family members as well as seek input from family and friends. This finding differed from what the creators of SDT put forth about relatedness, which they viewed as provider-centric: "the practitioner-patient relationship is an important medium and vehicle of change. In health care this is especially so, as vulnerable individuals, often lacking in technical expertise, look for the inputs and guidance of professionals" (Ryan et al., 2008, p. 3). My findings indicated this was true, but it further showed that participants sought relatedness *outside* of the healthcare space. Guardians talked about how relatable the pictures were and how feeling that connection or relationship to the team helped them feel calmed. This finding was interesting in that other researchers have reported relatedness is the least important construct in terms of predicting behaviors or outcomes (Kosmala-Anderson et al., 2010). Interestingly, other SDT researchers often focus on competence and autonomy, sometimes leaving

relatedness out of their research entirely (William et al., 2004) or not exploring its influence in their results (Murray et al., 2015; Ridgway et al., 2016).

Studies on SDT often emphasize the role of providers or practitioners in shaping and supporting patients' autonomy, competence, and relatedness (Kosmala-Anderson et al., 2010; Martin et al., 2017). This is most notable within the relatedness construct. For example, in a physiotherapy setting, SDT-based communication training had large, positive effects on physiotherapists' needs-supportive behavior with patients (Murray et al., 2015). However, the researchers cautioned "that physiotherapists may be particularly amenable to this type of training and, therefore, implemented the communication strategies more closely to protocol than did health care practitioners in other studies" (Murray et al., 2015, p. 814). The researchers also believed that the nature of being a physiotherapist could increase the providers' natural relatability to their patients. This is similar to what Williams et al. (2004) note about their own SDT research; positive outcomes from interventions using SDT are likely somewhat attributable to the practitioners who use the intervention and how that provider naturally relates to patients. Fortier et al. (2012) also argued that the nature of having a conversation with someone related to an SDT intervention could itself shape perceptions surrounding relatedness. Participants in this decision aid study did discuss the need for the tool to be used in addition to conversations with the recommending care team members, which may align with the findings presented here from other researchers.

Ryan et al. (2008) argued that when patients have these three psychological needs met, they are more engaged in decision-making and have better health outcomes. Additionally, Ryan et al. (2000) advocate for fulfilling these needs as a way to address

mental health challenges; this is especially notable in the NICU, where emotions and distress run high and guardians must make life-changing decisions in an emotionally vulnerable state. Martela et al. (2021) found that SDT constructs are also used in "other theoretical traditions such as... research on persuasion, and research on community-based social marketing techniques, research on procedural fairness, and motivational interviewing" (p. 335). As suggested by the few researchers who have used SDT as a communication framework (Brown et al., 2021; Head et al., 2022; Martela et al., 2021), these constructs were specifically connected to guardians' feelings of empowerment and enabled more thoughtful decision-making. Guardians discussed feeling competent, autonomous, and related in numerous ways, and these feelings were often followed by conversations about how useful the tool would be in making their final decision. This indicates that SDT may be a strong theory to incorporate in health communication materials, especially decision aids.

**Positionality Statement**

Before exploring the limitations in this research, it is important to acknowledge how my positionality as a researcher shapes my work and findings. I chose research methods, interview questions, and participant criteria, and interpreted the results gathered. Although I have read about and participated in qualitative research, my limited experience with conducting research and *leading* studies means I made mistakes along the way. The first and most notable was that the very first interview I conducted with two NICU-based parents was not fully recorded nor transcribed. Subsequently, I had to rely on notes from the interview to make meaningful connections between the feedback provided there and in the following interviews. From this interview onward, I relied on

multiple recording devices to ensure there were always back-up recordings. An additional limitation is that I worked with a population whom I do not identify with – parents and guardians of small, sick infants – and cannot relate to, and I cannot begin to understand the true experiences or empathize deeply enough with them.

I also want to acknowledge my privilege: As a graduate-level-educated White woman with access to healthcare and health insurance and a thorough understanding of medical procedures and genetic testing, some of the materials I tested were second nature to me. I had to truly and deeply listen to the feedback given to me by participants to better understand what *they* might not understand. Although I tested all written materials to ensure they were at a 7$^{th}$-grade reading level, some sections of the final decision aid likely do not meet that expectation. I did rely on Dr. Suhrie's expert input for making analogies and using phrases that have historically helped her patients' families understand these complex topics in the past. Additionally, because I received feedback on creative materials that I personally wrote and designed, there was a level of resistance to critiques and changes that, although I was cognizant of and worked hard to address, likely means some revisions were not made that would have improved the materials.

**Limitations Related to Data Collection Changes**

My proposed plan was changed or modified in many ways due to difficulties recruiting the initial participant population. These changes are thoroughly detailed in the Methods chapter; however, I am aware that changing the research process so greatly – from criteria to recruitment to data collection – means some errors may have occurred. For example, when the criteria were opened to include parents and guardians of infants up to three years post-NICU discharge, my need to get feedback on the decision aid

meant that several non-NICU parents were included in the sample. Although they provided amazing insights and still offered valuable qualitative data, I am aware that the best approach would have been to limit the population to only NICU parents, even those who were already discharged. Additionally, because the methods changed from an in-person focus group to Zoom-based interviews, I could not hear feedback bounced off participants as they discussed their experiences with and around others. The feedback I received was isolated to the individual, and because I do not have an infant nor NICU experience, I could ask only limited clarifying questions.

**Limitations Due to Representation**

I understand that this tool would be most useful for lower health literacy individuals. However, the vast majority of my participants were white, middle to high income, and, based on the single health literacy item used to survey them, average or above-average health literacy. They quickly and easily understood the information presented to them, and although that is in part due to the intentionality of wording and readability scores, it is also because of their preexisting knowledge and understanding of the topic. Many of the participants knew about and were already in favor of genetic testing. Feedback from individuals who were apprehensive about or opposed to genetic testing would have been even more useful than the generally positive feedback from participants. However, the overall positive view of genetic testing does align with the 80-90% of guardians who consent to genetic testing at Riley. Because most participants were white and middle to high income, I also was unable to assess differences in beliefs, views, or values related to different backgrounds or identities.

For example, because the Riley NICU is one of the only neonatal Level I trauma centers in the Midwest, people from all backgrounds end up at Riley. The Riley population includes ethnic and racial minorities, people who do not speak English, people with different religious backgrounds, people from different countries, and people without insurance. Other researchers have established that many guardians, especially people from different backgrounds than the majority white, well-off participants in my and other similar studies, likely consent to genetic testing without fully understanding the procedure they are consenting to (Kumar et al., 2019). Unfortunately, despite my attempts to recruit this diverse population from within Riley's NICU, I was unsuccessful. Therefore, my research is not representative of the NICU it is intended for, and some gaps in information and health literacy had to be addressed by Dr. Suhrie, who is much more aware of the different perspectives people from different backgrounds have discussed in her NICU.

**Limitations Due to Past Experience**

I still believe the best data would have been gathered in the NICU from guardians who were currently experiencing the NICU stressors, as Ward (2010) recommended. No amount of clarifying questions or asking participants to position themselves in the same mindset they had during a NICU hospitalization can ever truly capture that mentality and emotional state. Guardians with previous NICU experience offered incredibly useful insights about their time and experiences in the NICU, but because some had had nearly three years since that experience, they answered with hindsight. Participants talked about what would have been helpful to them, what they experienced, and how they may have used this tool. However, other researchers have shown that in the NICU, guardians are

overwhelmed and anxious (Obeidat et al., 2009), which greatly affects their perceptions and decision-making abilities (Brett et al., 2011). That stress and anxiety cannot be replicated outside of the NICU, even with careful reflection on that experience and prompts to help guardians re-enter that headspace. Although many guardians talked about wanting *more* information based on the materials presented, more information likely would have overwhelmed them had they been in that space. Some guardians even acknowledged that they could not appropriately conceptualize how they would have used this specific tool in the NICU, only how they had used other ones.

**Limitations Due to the Scope of Research**

This project was incredibly time-consuming. I did not just qualitatively review feedback using thematic analysis; I revised the decision aid following each round of interviews. This meant a dual role of being a researcher with expertise in health communication and being a creative, copywriter, and graphic designer. Because a local NICU is implementing the final version of this decision aid and routinely requested updates on the progress of the project, I revised the materials based on participant feedback while also scheduling future interviews and staying in contact with the NICU team. Additionally, because there were *five* versions of the decision aid (i.e., initial Round 1 version, Round 2 version, Round 3 version, Round 4 version, and final version), tracking and managing versions and revisions was challenging. I used a tool called Canva to design the aid, and although I made new versions and labeled them each round of revisions, I know that at multiple points, I made an edit or revision to the wrong copy of the aid. I often relied on my notes from interviews to establish what changes were made when, in addition to reviewing the decision aids in side-by-side browser tabs.

Because of the scope of this project, I was also incredibly stressed and rushed when interviews began. My original plan was to host all three focus groups during the summer months when other responsibilities require less of me; initial recruitment started in May, with only two participants completing an interview by the end of July. Once the recruitment opened to guardians online in late August, I received 40+ interest forms within a week. This was after three months of recruiting with no success, which greatly delayed my timeline for completing the research. I did not want to turn down *any* guardian, especially when I knew that this research was both vital to the local NICU as well as my degree completion. Subsequently, I contacted significantly more interested participants concurrently than was wise, and I interviewed 16 guardians within three weeks. This rapid interviewing often meant that my transcriptions were delayed, rather than occurring immediately following interviews. I know that some of my thoughts and ideas from participant responses were lost because of this system.

Challenges with my data collection taught me valuable lessons about project management. I often felt like I was managing an entire team's worth of work, especially when I was coordinating with multiple recruiters, advisors, and guardians/participants. My organizational skills have always been strong, but they were tested with this project; I learned that consistency is key, and I cannot rely on lists in eight different places to effectively keep track of important items. Streamlining my organization methods to be consistent and reliable was crucial. By the end of this project, I was much more consistent with how I contacted participants, collected their feedback, and organized transcriptions. I often had to become comfortable with uncertainty and "trust the process" required for research. Additionally, I had to adapt to last-minute changes and remain

externally positive and upbeat, especially when working with recruiters and participants, despite internal distress.

**Future Research**

The research presented here is only one part of a NICU's larger efforts to create more inclusive, accessible, streamlined communication for the families in their care. There is more research needed on the use of PtDAs in the NICU setting, specifically those that operationalize theories like SDT (Head et al., 2022; Ryan et al., 2008). There are three areas in which future research on this topic must focus: prioritizing underrepresented guardians, testing the effectiveness of the tool, and strategizing implementation through provider training and monitoring.

First, future research on this topic should prioritize message testing guardians with hospitalized infants, as I had initially planned to do, and work more directly with NICU recruiters to facilitate gathering that population. Although the population presented here provided useful and important insights about the decision aid, I still agree with recommendations from Ward (2010) that the best NICU-focused research takes place *in* the NICU at the time of hospitalization. Although all previous NICU guardians talked openly and at length about their NICU journey and referenced it with each piece of feedback they provided, several acknowledged that they could not begin to imagine how they would interpret the tool if they were in that state again. NICU-based research should also focus on more diverse and underrepresented people, especially those with lower health literacy who would benefit more from an accessible information tool (McCaffery et al., 2013).

Second, future research on this topic should analyze the *effectiveness* of the tool. Because the goals of the decision aid were to decrease guardians' decision-making time and help them identify their questions and concerns faster, there are several metrics that should be measured within the NICU setting. Future research should use an experimental study to compare the timeframes of decision-making among those who receive the tool and those who do not. Ideally, the aid should be tested for mean ratings of perceived improvement of understanding (Wakefield et al., 2007) and frequency and proportion of decisional conflict (Stacey et al., 2016) between those who do and do not receive the decision aid. Additionally, because the data collected here was for the *development* of the tool, a usability test should be conducted to "elicit feedback on the [decision aid's] functionality" by having participants verbalize their decision-making as they review the tool (Bombard et al., 2018). These more quantitative evaluation measures can ensure the efficacy and effectiveness of the tool.

Finally, because the tool alone does not ensure its appropriate and balanced use in the NICU, future research should focus on the *implementation* of this tool (Stacey et al., 2016). The research presented here focused exclusively on the development of the tool, but effectively incorporating it into clinical practice will require provider training and frequent reevaluation of information in the tool. This tool will be used by non-genetics team members to help guardians identify their questions and concerns before attending genetic counseling, making the need for provider training on how to use the tool even more important (Roberts et al., 2020). Additionally, guardians noted the importance of using this tool in conjunction with provider conversations. Studies on the implementation of decision aids typically include a provider training component to increase shared

decision-making skills (Härter et al., 2015; Silvia et al., 2007). There is one study on communication training for providers that I found which focuses on the language and questions providers can use to increase competence, autonomy, and relatedness (Murray et al., 2015), and this type of provider training would be useful for the practitioners who will use the tool. Implementing this tool in the NICU will require advanced training that brings non-genetics and genetic team members together to create a shared decision-making space for families.

**Conclusion**

This study investigated the functions and uses of a NICU genetic testing decision aid that operationalized self-determination theory constructs as communication guidelines, along with guardians' needs in the NICU genetic testing process. The study suggests that NICU PtDAs can be useful for relieving decisional-anxiety and addressing the functions of communication in the NICU. Additionally, the findings demonstrate that SDT can and should be used as a communication framework by health communication researchers and scholars. Future directions for this type of research should use quantitative methods to compare the rates of decisional anxiety between NICU guardians with and without the use of a PtDA. Additionally, it is crucial to remember the PtDAs are not stand-alone materials; they must be used as a supportive tool in addition to the input and guidance offered by medical professionals.

The benefits of genetic testing in the NICU cannot be understated. Test results inform care plans, increase quality of life, and much more. Although the final product of this research is a patient decision *aid*, which should not be coercive or force individuals to choose a specific option – like declining or consenting to testing, the tool still has

potential to increase rates of genetic testing in the NICU. As Dr. Suhrie explained when she first sought help for developing this tool, rates of consent to genetic testing at Riley are already very strong, with 80-90% of guardians opting in to testing. However, it often takes many rounds of talking with guardians and answering their questions before consent is given. The goal of this tool, as with any decision aid, is to aid guardians in making the decision, whether that is consenting to or declining testing. Yet, because this tool provides space for questions and offers a tangible material that guardians can review before visiting the genetics team to discuss testing further, I am confident that it will help speed up the decision-making process so that the NICU team can respond accordingly, whether by ordering the tests sooner or identifying other strategies faster in cases which guardians decline testing. The current decision aid serves as a starting point for the Riley NICU to incorporate patient-provider communication materials that alleviate some of the decision-making burden associated with a NICU hospitalization.

# Appendices

## Appendix A

NICU Nest Recruitment Email

Hello,

Thank you for your continued volunteerism at Riley Children's Hospital! You make a difference in our NICU. Now, I'm excited to share a volunteer research opportunity with you.

You're invited to complete a 1-hour focus group. Your feedback will help us improve how we talk to parents and guardians about genetic testing. The focus group will take place in the NICU family room on date 1, date 2, and date 3. You're only asked to participate in one date.

If you're interested in participating, please complete this brief 5-minute survey. The researchers will contact you letting you know if you qualify for the study.

Additionally, please recommend any guardians on your unit who may be interested, willing, and able to help. To qualify, guardians' infants must have been hospitalized for at least one week to ensure the guardians are settled and acclimated to the environment. Please send me the names of 5-10 guardians you think would be willing and able to help.

Again, thank you for your continued support of Riley Children's Hospital. I hope you'll be able to provide your valuable input for this project!

Best,

Dr. Kristen Suhrie

**Appendix B**

NICU Recruitment Handout

IUPUI
SCHOOL OF LIBERAL ARTS

**Researchers from IUPUI need your help!**

IUPUI researchers are making a form to help NICU parents and guardians like you. The form helps guardians make decisions for their babies.

To make the form, the researchers are holding a 1-hour focus group. In this focus group, you'll provide feedback and ideas about the form. The focus group will take place in the NICU so that you're near your baby. The date and time will be decided based on your availability.

Please scan the QR code using your smartphone if you are interested in joining. The QR code will take you to a brief survey. After you complete it, a researcher will contact you about the focus group date.

Scan Me

Thank you for your help!
Your input will help parents and guardians like you.

**Appendix C**

Focus Group Screening Survey

| | |
|---|---|
| **Please type your first and last name:** | [typed response] |
| **How do you prefer to be cont** | ○ Phone<br>○ Email |
| ***If email:* Type your email address:** | [typed response] |
| ***If phone:* Type your cell phone number:** | [typed response] |
| **Please select your age:** | ○ 18-24<br>○ 25-34<br>○ 35-44<br>○ 45-54<br>○ 55 or older |
| **Is your infant currently hospitalized?** | ○ Yes<br>○ No |
| ***If yes:* Where is your infant hospitalized?** | ○ Riley Simon Family Tower<br>○ Riley Maternity Tower<br>○ Other [please type] |
| ***If yes:* How long has your infant been hospitalized?** | ○ 0-6 days<br>○ 7 days or more |
| ***If no:* Has your infant been hospitalized in a neonatal intensive care unit (NICU) in the last 3 years?** | ○ Yes<br>○ No |
| **This 15 to 30-minute interview will take place via Zoom. Do you have access to reliable internet and a video calling device (phone, tablet, laptop, etc.)?** | ○ Yes<br>○ No<br>○ Unsure |
| **Your gender:** | ○ Male<br>○ Female<br>○ Other |
| **Your race:** | ○ Black<br>○ White<br>○ Native American/Alaskan Native<br>○ Asian<br>○ More than one race |
| **Your ethnicity:** | ○ Hispanic<br>○ Not Hispanic |
| **Median household income (combined for married couples):** | ○ Less than $35,000<br>○ $35,000–49,999<br>○ $50,000–74,999 |

| | | |
|---|---|---|
| | ○ | $75,000–99,999 |
| | ○ | $100,000 or more |
| **Insurance type:** | ○ | Private (Anthem, Aetna, TBC, etc.) |
| | ○ | Public (Medicaid, CHIP, etc.) |
| | ○ | Uninsured |
| | ○ | Unsure |
| **How often do you need to have someone help you when you read instructions, pamphlets, or other written materials from your doctor or pharmacy?** | ○ | Never |
| | ○ | Rarely |
| | ○ | Sometimes |
| | ○ | Often |
| | ○ | Always |

Thank you for completing this screening survey. If you are eligible for the study, the researcher will contact you within 2-3 days to provide more information.

**Appendix D**

NICU Recruitment Flyer


# Help parents like you!

Researchers from IUPUI are interviewing NICU guardians like you. They need your feedback on a form that helps parents make medical decisions for their babies.

- The interview will take **15-30 minutes.**
- The interview will be **on Zoom.**
- The **date and time** of the interview will be determined **based on your availability**.

If interested, please scan the QR code and complete the form. A researcher will contact you to schedule your date, time, and location.

**Appendix E**

Social Media Recruitment Post 1


Hello, friends! For my thesis, I'm developing a patient decision aid to help parents make decisions for their NICU babies. I need your help! If you or someone you know has had a baby in the NICU in the last 3 years, please consider participating. You'll review a patient decision aid and answer questions/provide feedback for 15 to 30 minutes on Zoom. Scan the QR code or message me for a link to sign up. Thanks!

Social Media Recruitment Post 2


Hi, friends. One last time: Please help me recruit for my thesis! I'm just a few participants shy of having all the data I need.

I need to interview a few more parents who've had a baby in the NICU in the last 3 years. They'll review a patient decision aid and provide important feedback. Please share this with your friends, your families, your networks, etc. People can sign up here: [link]

**Appendix F**

Interview Screening Survey

| | |
|---|---|
| **Please type your first and last name:** | [typed response] |
| **How do you prefer to be cont** | ○ Phone<br>○ Email |
| ***If email:* Type your email address:** | [typed response] |
| ***If phone:* Type your cell phone number:** | [typed response] |
| **Please select your age:** | ○ 18-24<br>○ 25-34<br>○ 35-44<br>○ 45-54<br>○ 55 or older |
| **Is your infant 3 years or younger?** | ○ Yes<br>○ No |
| **Has your infant been hospitalized in a neonatal intensive care unit (NICU) in the last 3 years?** | ○ Yes<br>○ No |
| **This 15 to 30-minute interview will take place via Zoom. Do you have access to reliable internet and a video calling device (phone, tablet, laptop, etc.)?** | ○ Yes<br>○ No<br>○ Unsure |
| **Your gender:** | ○ Male<br>○ Female<br>○ Other |
| **Your race:** | ○ Black<br>○ White<br>○ Native American/Alaskan Native<br>○ Asian<br>○ More than one race |
| **Your ethnicity:** | ○ Hispanic<br>○ Not Hispanic |
| **Median household income (combined for married couples):** | ○ Less than $35,000<br>○ $35,000–49,999<br>○ $50,000–74,999<br>○ $75,000–99,999<br>○ $100,000 or more |
| **Insurance type:** | ○ Private (Anthem, Aetna, TBC, etc.)<br>○ Public (Medicaid, CHIP, etc.) |

| | | |
|---|---|---|
| | ○ | Uninsured |
| | ○ | Unsure |
| **How often do you need to have someone help you when you read instructions, pamphlets, or other written materials from your doctor or pharmacy?** | ○<br>○<br>○<br>○<br>○ | Never<br>Rarely<br>Sometimes<br>Often<br>Always |

**Appendix G**

Study Information Sheet

**You are being asked to participate in a research study.** Scientists do research to answer important questions that might help change or improve the way we do things in the future. This consent form will give you information about the study to help you decide whether you want to participate. Please read this form, and ask any questions you have, before agreeing to be in the study.

**All research is voluntary.** You can choose not to take part in this study. If you decide to participate, you can change your mind later and leave the study at any time. You will not be penalized or lose any benefits if you decide not to participate or choose to leave the study later.

**The purpose of this study** is to gain feedback on a written aid to help guardians make decisions about genetic testing for their babies.

The study is being conducted by Keeley Higley, IUPUI Department of Communication Studies; Dr. Katharine J. Head, IUPUI Department of Communication Studies; and Dr. Kristen Suhrie, Riley's Hospital for Children NICU.

**If you agree to be in the study, you will do the following things.**

- Participate in a recorded 15–30-minute interview on Zoom or in the Riley NICU
- Review a patient decision aid
- Provide feedback on the decision aid

**Before agreeing to participate, please consider the risks and potential benefits of taking part in this study.**

All research involves a risk of loss of confidentiality. You may be uncomfortable or upset while reviewing materials and answering focus group questions. While participating in the focus group, you can take a break and leave the room at any time. A NICU staff member, such as a nurse, social worker, or genetic counselor, will be available and present to answer any questions and provide additional emotional support. There is no direct benefit to participation.

**You will not be paid for participating in this study. There is no cost to participate in the study.**

**We will protect your information** and make every effort to keep your personal information confidential, but we cannot guarantee absolute confidentiality. No information which could identify you will be shared in publications about this study. The focus group will be recorded on Zoom and reviewed by the three primary researchers. The recording will be stored and encrypted in Zoom for security.

Your personal information may be shared outside the research study if required by law. We also may need to share your research records with other groups for quality assurance or data analysis. These groups include the Indiana University Institutional Review Board or its designees, and state or federal agencies who may need to access the research records (as allowed by law).

Information collected in this study may be used for other research studies or shared with other researchers for future research. If this happens, information that could identify you, such as your name and other identifiers, will be removed before any information or

specimens are shared. Since identifying information will be removed, we will not ask for your additional consent.

**If you have questions about the study or encounter a problem with the research**, contact the researcher, Keeley Higley, at 219-229-4075 or kehigley@iu.edu.

For questions about your rights as a research participant, to discuss problems, complaints, or concerns about a research study, or to obtain information or to offer input, please contact the IU Human Research Protection Program office at 800-696-2949 or at irb@iu.edu.

**If you decide to participate in this study, you can change your mind and decide to leave the study at any time in the future.** If you decide to withdraw, please contact Keeley Higley (219-229-4075, kehigley@iu.edu) to let her know that you will not be attending the focus group.

**Appendix H**

Pretesting Focus Group Guide

| Aspect | Description | Sample Questions |
|---|---|---|
| **Attractiveness** | Whether the message/material command attention | What was the first thing that caught your eye?<br>What do you not like about this material?<br>What do you like about this genetic testing material? |
| **Comprehension**<br>*Competence*<br><br>**Acceptance**<br>*Relatedness* | Whether the information is understood as intended<br><br>Whether the material is culturally and socially acceptable | Who do you think the material is speaking to?<br>What words/sentences/images are difficult to understand?<br>What does the material say about genetic testing?<br>Is there anything about this material that you find offensive or inappropriate?<br>Is there anything about this material that other guardians may find offensive or inappropriate? |
| **Relevance**<br>*Autonomy*<br>*Relatedness* | Whether the information is of interest to the intended audience | What guardians do you think should read this material?<br>In what way are those guardians different from you or the same as you? |
| **Call to Action**<br>*Autonomy*<br><br>**Persuasion** | Whether the audience understands the call to action<br>Whether the key benefit is persuasive and appealing to the intended audience | What does the material ask guardians to do?<br>Why do you think you should do what the material asks you to do?<br>Based on this material, how likely are you to get genetic testing for your baby and why? |
| **Stigma**<br>*Relatedness*<br><br>**Improvement**<br>*Competence* | Whether the message promotes stigma<br><br>If and how the material needs to be improved | What would you change in this material to make it more appealing to you?<br>What information do you think is missing to help guardians make decisions about genetic testing for their babies?<br>Is there anything about this material that makes you feel judgement for a certain person or group of people?<br>What else, if anything, would you like to include in this material? |

| | |
|---|---|
| | How useful would this be in helping you make decisions about genetic testing for your baby? |
| **Wrap up** | Is there anything else you'd like to add about the material or genetic testing? |

Adapted from Compass, 2020, to align with SDT constructs

## References

American Medical Association. (n.d.). *Genetic testing*. https://www.ama-assn.org/delivering-care/precision-medicine/genetic-testing

Ankolekar, A., Dekker, A., Fijten, R., & Berlanga, A. (2018). The benefits and challenges of using patient decision aids to support shared decision making in health care. *JCO Clinical Cancer Informatics, 2*, 1–10. https://doi.org/10.1200/cci.18.00013

Binion, K., Miller, A., Misseri, R., Kaefer, M., Longtin, K., Carroll, A., Wiehe, S. E., & Chan, K. H. (2022). Ask the parents: Testing the acceptability and usability of a hypospadias decision aid. *Journal of Pediatric Urology, 18*(2). https://doi.org/10.1016/j.jpurol.2022.01.004

Bombard, Y., Clausen, M., Mighton, C., Carlsson, L., Caslino, S., Glogowski, E., Schrader, K., Evans, M., Scheer, A., Baxter, N., Hamilton, J. G., Lerner-Ellis, J., Offit, K., Robson, M., Laupacis, A. (2018). The Genomics ADvISER: development and usability testing of a decision aid for the selection of incidental sequencing results. *European Journal of Human Genetics, 26*(7), 984–995. https://doi.org/10.1038/s41431-018-0144-0

Braun, V., & Clarke, V. Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Britten, N. (2011). Qualitative research on health communication: What can it contribute? *Patient Education and Counseling, 82*(3), 384–388. https://doi.org/10.1016/j.pec.2010.12.021

Brett, J., Staniszewska, S., Newburn, M., Jones, N., & Taylor, L. (2011). A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. *BMJ Open*, *1*(1), 1–11. https://doi.org/10.1136/bmjopen-2010-000023

Brown, C., Head, K. J., Hartsock, J., Burns, K., Wilson, T. E., & Prucka, S. (2021). Exploring parents' perceptions of the value of pediatric genetic counseling patient letters: A qualitative study presenting lessons learned. *Journal of Genetic Counseling*, *30*(4), 1168–1180. https://doi.org/10.1002/jgc4.1400

Brown, K. M., Lindenberger, J. H., & Bryant, C. A. (2008). Using pretesting to ensure your messages and materials are on strategy. *Health Promotion Practice*, *9*(2), 116–122. https://www.jstor.org/stable/26736672

Bry, A., & Wigert, H. (2019). Psychosocial support for parents of extremely preterm infants in neonatal intensive care: A qualitative interview study. *BMC Psychology*, *7*(1). https://doi.org/10.1186/s40359-019-0354-4

Carroll, J., Wigby, K., & Murray, S. (2020). Genetic testing strategies in the newborn. *Journal of Perinatology*, *40*(7), 1007–1016. https://doi.org/10.1038/s41372-020-0697-y

Centers for Disease Control and Prevention. (2023). *What is health literacy?* https://www.cdc.gov/healthliteracy/learn/

Centers for Disease Control and Prevention. (2021). *Birth data.* https://www.cdc.gov/nchs/nvss/births.htm

Chavez-Yenter, D., Zhao, J., Ratcliff, C. L., Kehoe, K., Blumling, A., Peterson, E., Klein, W. M. P., Sylvia Chou, W.-Y., & Kaphingst, K. A. (2021). Theory utilization in current communication of cancer genetic testing research: Identified gaps and opportunities. *Social Science & Medicine*, *282*, 1–6. https://doi.org/10.1016/j.socscimed.2021.14144

Christenhusz, G. M., Devriendt, K., & Dierickx, K. (2012). To tell or not to tell? A systematic review of ethical reflections on incidental findings arising in genetics contexts. *European Journal of Human Genetics*, *21*(3), 248–255. https://doi.org/10.1038/ejhg.2012.130

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297–298. http://dx.doi.org/10.1080/17439760.2016.1262613

Colorado Program for Patient Centered Decision Aids. (n.d.). *Decision aids.* https://patientdecisionaid.org/decision-aids/

Compass. (2020). *Pretesting messages and materials.* https://thecompassforsbc.org/sbcc-tools/pretesting-messages-and-materials

Condit, C. M. (2010). Public understandings of genetics and health. *Clinical Genetics*, *77*(1), 1–9. https://doi.org/10.1111/j.1399-0004.2009.01316.x

Coulter, A., Stilwell, D., Kryworuchko, J., Mullen, P. D., Ng, C. J., & Weijden, T. (2013). A systematic development process for patient decision aids. *BMC Medical Informatics and Decision Making*, *13*(2), 1–7. https://doi.org/10.1186/1472-6947-13-S2-S2

Crothers, K., Kross, E. K., Reisch, L. M., Shahrir, S., Slatore, C., Zeliadt, S. B., Triplette, M., Meza, R., & Elmore, J. G. (2016). Patients' attitudes regarding lung cancer screening and decision aids. A survey and focus group study. *Annals of the American Thoracic Society*, *13*(11), 1992–2001. https://doi.org/10.1513/annalsats.201604-289oc

Danner, M., Debrouwere, M., Rummer, A., Wehkamp, K., Rüffer, J. U., Geiger, F., Wolff, R., Weik, K., & Scheibler, F. (2022). A scattered landscape: Assessment of the evidence base for 71 patient decision aids developed in a hospital setting. *BMC Medical Informatics and Decision Making*, *22*(1), 1–11. https://doi.org/10.1186/s12911-022-01777-x

Deci, E. L., & Ryan, R. M. (2012). Self-determination theory in health care and its relations to motivational interviewing: a few comments. *International Journal of Behavioral Nutrition and Activity*, *9*(24), 1–12. https://doi.org/10.1186/1479-5868-9-24

Dellenmark-Blom, M., & Wigert, H. (2013). Parents' experiences with neonatal home care following initial care in the neonatal intensive care unit: A phenomenological hermeneutical interview study. *Journal of Advanced Nursing*, *70*(3), 575–586. https://doi.org/10.1111/jan.12218

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, *40*(4), 314–321. https://doi.org/10.1111/j.1365-2929.2006.02418.x

Dimmock, D., Caylor, S., Waldman, B., Benson, W., Ashburner, C., Carmichael, J. L., Carroll, J., Cham, E., Chowdhury, S., Cleary, J., D'Harlingue, A., Doshi, A., Ellsworth, K., Galarreta, C. I., Hobbs, C., Houtchens, K., Hunt, J., Joe, P., Joseph, M., … Farnaes, L. (2021). Project Baby Bear: Rapid precision care incorporating rWGS in 5 California children's hospitals demonstrates improved clinical outcomes and reduced costs of care. *The American Journal of Human Genetics*, *108*(7), 1231–1238. https://doi.org/10.1016/j.ajhg.2021.05.008

Durand, M.-A., Stiel, M., Boivin, J., & Elwyn, G. (2008). Where is the theory? Evaluating the theoretical frameworks described in decision support technologies. *Patient Education and Counseling*, *71*(1), 125–135. https://doi.org/10.1016/j.pec.2007.12.004

Ellingson, L. L. (2017). *Embodiment in qualitative research*. Routledge.

Ellington, L., Baty, B. J., McDonald, J., Venne, V., Musters, A., Roter, D., Dudley, W., & Croyle, R. T. (2006). Exploring genetic counseling communication patterns: The role of teaching and counseling approaches. *Journal of Genetic Counseling*, *15*(3), 179–189. https://doi.org/10.1007/s10897-005-9011-6

Farnaes, L., Hildreth, A., Sweeney, N. M., Clark, M. M., Chowdhury, S., Nahas, S., Cakici, J. A., Benson, W., Kaplan, R. H., Kronick, R., Bainbridge, M. N., Friedman, J., Gold, J. J., Ding, Y., Veeraraghavan, N., Dimmock, D., & Kingsmore, S. F. (2018). Rapid whole-genome sequencing decreases infant morbidity and cost of hospitalization. *NPJ Genomic Medicine*, *3*(10), 1–8. https://doi.org/10.1038/s41525-018-0049-4

Fortier, M. S., Duda, J. L., Guerin, E., & Teixeira, P. J. (2012). Promoting physical activity: Development and testing of self-determination theory-based interventions. *International Journal of Behavioral Nutrition and Physical Activity*, *9*(1), 20. https://doi.org/10.1186/1479-5868-9-20

Freeman, E. R., Brugge, D., Bennett-Bradley, W. M., Levy, J. I., & Carrasco, E. R. (2006). Challenges of conducting community-based participatory research in Boston's neighborhoods to reduce disparities in asthma. *Journal of Urban Health*, *83*(6), 1013–1021. https://doi.org/10.1007/s11524-006-9111-0

Gaff, C. L., Collins, V., Symes, T., & Halliday, J. (2005). Facilitating family communication about predictive genetic testing: Probands' perceptions. *Journal of Genetic Counseling*, *14*(2), 133–140. https://doi.org/10.1007/s10897-005-0412-3

Gates, E. A. (2004). Communicating risk in prenatal genetic testing. *Journal of Midwifery & Women's Health*, *49*(3), 220–227. https://doi.org/10.1016/j.jmwh.2004.02.014

Genetti, C. A., Schwartz, T. S., Robinson, J. O., VanNoy, G. E., Petersen, D., Pereira, S., Fayer, S., Peoples, H. A., Agrawal, P. B., Betting, W. N., Holm, I. A., McGuire, A. L., Waisbren, S. E., Yu, T. W., Green, R. C., Beggs, A. H., Parad, R. B., Agrawal, P. B., Beggs, A. H., … Yu, T. W. (2019). Parental interest in genomic sequencing of newborns: Enrollment experience from the BabySeq Project. *Genetics in Medicine*, *21*(3), 622–630. https://doi.org/10.1038/s41436-018-0105-6

Govindaswamy, P., Laing, S., Waters, D., Walker, K., Spence, K., & Badawi, N. (2019). Needs and stressors of parents of term and near-term infants in the NICU: A systematic review with best practice guidelines. *Early Human Development*, *139*, 1–11. https://doi.org/10.1016/j.earlhumdev.2019.104839

Gültzow, T., Hoving, C., Smit, E. S., & Bekker, H. L. (2021). Integrating behaviour change interventions and patient decision aids: How to accomplish synergistic effects? *Patient Education and Counseling*, *104*(12), 3104–3108. https://doi.org/10.1016/j.pec.2021.04.007

Gyngell, C., Newson, A. J., Wilkinson, D., Stark, Z., & Savulescu, J. (2019). Rapid challenges: Ethics and genomic neonatal intensive care. *Pediatrics*, *143*(S1), S14–S21. https://doi.org/10.1542/peds.2018-1099d

Haga, S. B., Barry, W. T., Mills, R., Ginsburg, G. S., Svetkey, L., Sullivan, J., & Willard, H. F. (2013). Public knowledge of and attitudes toward genetics and genetic testing. *Genetic Testing and Molecular Biomarkers*, *17*(4), 327–335. https://doi.org/10.1089/gtmb.2012.0350

Hall, S. L., Cross, J., Selix, N. W., Patterson, C., Segre, L., Chuffo-Siewert, R., Geller, P. A., & Martin, M. L. (2015). Recommendations for enhancing psychosocial support of NICU parents through staff education and support. *Journal of Perinatology*, *35*(1), 29–36. https://doi.org/10.1038/jp.2015.147

Hallquist, M. L., Tricou, E. P., Ormond, K. E., Savatt, J. M., Coughlin, C. R., Faucett, W. A., Hercher, L., Levy, H. P., O'Daniel, J. M., Peay, H. L., Stosic, M., Smith, M., Uhlmann, W. R., Wand, H., Wain, K. E., & Buchanan, A. H. (2021). Application of a framework to guide genetic testing communication across clinical indications. *Genome Medicine*, *13*(71), 1–12. https://doi.org/10.1186/s13073-021-00887-x

Hæe, M., Wulff, C. N., Fokdal, L., Olling, K., Jensen, K. M., Hansen, D. G., Knudsen, A. Ø., Lemley, B., Blou, D., Büchmann, H., & Steffensen, K. D. (2023). Development, implementation and evaluation of patient decision aids supporting shared decision making in women with recurrent ovarian cancer. *PEC Innovation*, *2*, 100120. https://doi.org/10.1016/j.pecinn.2022.100120

Härter, M., Buchholz, A., Nicolai, J., Reuter, K., Komarahadi, F., Kriston, L., Kallinowski, B., Eich, W., & Bieber, C. (2015). Shared decision making and the use of decision aids. *Deutsches Ärzteblatt International*. https://doi.org/10.3238/arztebl.2015.0672

Head, K. J., Hartsock, J. A., Bakas, T., Boustani, M. A., Schroeder, M., & Fowler, N. R. (2022). Development of written materials for participants in an Alzheimer's Disease and related dementias screening trial. *Journal of Patient Experience*, *9*, 1–7. https://doi.org/10.1177/23743735221092573

Jacobs, C., Patch, C., & Michie, S. (2019). Communication about genetic testing with breast and ovarian cancer patients: A scoping review. *European Journal of Human Genetics*, *27*(4), 511–524. https://doi.org/10.1038/s41431-018-0310-4

Jones, L., Woodhouse, D., & Rowe, J. (2007). Effective nurse parent communication: A study of parents' perceptions in the NICU environment. *Patient Education and Counseling*, *69*(1–3), 206–212. https://doi.org/10.1016/j.pec.2007.08.014

Jones, G. L., Hughes, J., Mahmoodi, N., Greenfield, D., Brauten-Smith, G., Skull, J., Gath, J., Yeomanson, D., Baskind, E., Snowden, J. A., Jacques, R. M., Velikova, G., Collins, K., Stark, D., Phillips, R., Lane, S., & Bekker, H. L. (2017). Observational study of the development and evaluation of a fertility preservation patient decision aid for teenage and adult women diagnosed with cancer: The cancer, fertility and me research protocol. *BMJ Open*, *7*(3). https://doi.org/10.1136/bmjopen-2016-013219

Kasat, K., Stoffels, G., & Ellington, M. (2020). Improving communication with parents: The neonatal intensive care unit empathy workshop. *Journal of Perinatology*, *40*(9), 1423–1432. https://doi.org/10.1038/s41372-020-0742-x

Kim, Y., Ganduglia-Cazaban, C., Chan, W., Lee, M., & Goodman, D. C. (2021). Trends in neonatal intensive care unit admissions by race/ethnicity in the United States, 2008–2018. Scientific Reports, 11(1). https://doi.org/10.1038/s41598-021-03183-1

Kirkscey, R. (2017). Patient decision aids for prenatal genetic testing: Probability, embodiment, and problematic integration. *Health Communication*, *32*(5), 568–577. https://doi.org/10.1080/10410236.2016.1140500

Kosmala-Anderson, J. P., Wallace, L. M., & Turner, A. (2010). Confidence matters: A self-determination theory study of factors determining engagement in self-management support practices of UK clinicians. *Psychology, Health & Medicine*, *15*(4), 478–491. https://doi.org/10.1080/13548506.2010.487104

Kumar, S., Bhatia, T., Mishra, N. N., Kumari, N., Narayanan, S. S., Malik, D., & Deshpande, S. N. (2019). Why parents consent to their children's participation in genetic research: A study of parental decision making. *Indian Journal of Medical Ethics*, *4*(4), 274–281. https://doi.org/10.20529/ijme.2019.063

Labrie, N. H. M., van Veenendaal, N. R., Ludolph, R. A., Ket, J. C. F., van der Schoor, S. R. D., & van Kempen, A. A. M. W. (2021). Effects of parent-provider communication during infant hospitalization in the NICU on parents: A systematic review with meta-synthesis and narrative synthesis. *Patient Education and Counseling*, *104*(7), 1526–1552. https://doi.org/10.1016/j.pec.2021.04.023

Lanie, A. D., Jayaratne, T. E., Sheldon, J. P., Kardia, S. L., Anderson, E. S., Feldbaum, M., & Petty, E. M. (2004). Exploring the public understanding of basic genetic concepts. *Journal of Genetic Counseling*, *13*(4), 305–320. https://doi.org/10.1023/b:jogc.0000035524.66944.6d

Lindenberg, C. S., Solorzano, R. M., Vilaro, F. M., & Westbrook, L. O. (2001). Challenges and strategies for conducting intervention research with culturally diverse populations. *Journal of Transcultural Nursing*, *12*(2), 132–139. https://doi.org/10.1177/104365960101200207

Lorié, E. S., Wreesmann, W.-jan W., van Veenendaal, N. R., van Kempen, A. A. M. W., & Labrie, N. H. M. (2021). Parents' needs and perceived gaps in communication with healthcare professionals in the neonatal (intensive) care unit: A qualitative interview study. *Patient Education and Counseling*, *104*(7), 1518–1525. https://doi.org/10.1016/j.pec.2020.12.007

Lucast, E. K. (2007). Informed consent and the misattributed paternity problem in genetic counseling. *Bioethics*, *21*(1), 41–50. https://doi.org/10.1111/j.1467-8519.2007.00522.x

Lyndon, A., Wisner, K., Holschuh, C., Fagan, K. M., & Franck, L. S. (2017). Parents' perspectives on navigating the work of speaking up in the NICU. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, *46*(5), 716–726. https://doi.org/10.1016/j.jogn.2017.06.009

Mackley, A., Winter, M., Guillen, U., Paul, D. A., & Locke, R. (2016). Health literacy among parents of newborn infants. *Advances in Neonatal Care*, *16*(4), 283–288. https://doi.org/10.1097/anc.0000000000000295

Martela, F., Hankonen, N., Ryan, R. M., & Vansteenkiste, M. (2021). Motivating voluntary compliance to behavioural restrictions: Self-determination theory–based checklist of principles for COVID-19 and other emergency communications. *European Review of Social Psychology*, *32*(2), 305–347. https://doi.org/10.1080/10463283.2020.1857082

Martin, J. J., Byrd, B., Wooster, S., & Kulik, N. (2017). Self-determination theory: The role of the health care professional in promoting mindfulness and perceived competence. *Journal of Applied Biobehavioral Research*, *22*(4). https://doi.org/10.1111/jabr.12072

McCaffery, K. J., Holmes-Rovner, M., Smith, S. K., Rovner, D., Nutbeam, D., Clayman, M. L., Kelly-Blake, K., Wolf, M. S., & Sheridan, S. L. (2013). Addressing health literacy in patient decision aids. *BMC Medical Informatics and Decision Making*, *13*(2), 1–14. https://doi.org/10.1186/1472-6947-13-s2-s10

Meiser, B., Irle, J., Lobb, E., & Barlow-Stewart, K. (2008). Assessment of the content and process of genetic counseling: A critical review of empirical studies. *Journal of Genetic Counseling*, *17*(5), 434–451. https://doi.org/10.1007/s10897-008-9173-0

Meng, L., Pammi, M., Saronwala, A., Magoulas, P., Ghazi, A. R., Vetrini, F., Zhang, J., He, W., Dharmadhikari, A. V., Qu, C., Ward, P., Braxton, A., Narayanan, S., Ge, X., Tokita, M. J., Santiago-Sim, T., Dai, H., Chiang, T., Smith, H., … Lalani, S. R. (2017). Use of exome sequencing for infants in intensive care units. *JAMA Pediatrics*, *171*(12), 1–10. https://doi.org/10.1001/jamapediatrics.2017.3438

Murray, A., Hall, A. M., Williams, G. C., McDonough, S. M., Ntoumanis, N., Taylor, I. M., Jackson, B., Matthews, J., Hurley, D. A., & Lonsdale, C. (2015). Effect of a self-determination theory–based communication skills training program on physiotherapists' psychological support for their patients with chronic low back pain: A randomized controlled trial. *Archives of Physical Medicine and Rehabilitation*, *96*(5), 809–816. https://doi.org/10.1016/j.apmr.2014.11.007

Ng, J. Y., Ntoumanis, N., Thøgersen-Ntoumani, C., Deci, E. L., Ryan, R. M., Duda, J. L., & Williams, G. C. (2012). Self-determination theory applied to health contexts. *Perspectives on Psychological Science*, *7*(4), 325–340. https://doi.org/10.1177/1745691612447309

Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *Journal of Perinatal Education*, *18*(3), 23–29. https://doi.org/10.1624/105812409x461199

Oakbend Medical Center. (n.d.). *Which babies need care in the NICU?* https://oakbendmedcenter.org/which-babies-need-care-in-the-nicu/

Opdal, S. H., & Rognum, T. O. (2011). Gene variants predisposing to SIDS: Current knowledge. *Forensic Science, Medicine, and Pathology*, *7*(1), 26–36. https://doi.org/10.1007/s12024-010-9182-9

Patrick, H., & Williams, G. C. (2012). Self-determination theory: Its application to health behavior and complementarity with motivational interviewing. *International Journal of Behavioral Nutrition and Physical Activity*, *9*(1), 18. https://doi.org/10.1186/1479-5868-9-18

Pick, A., Gilbert, K., & McCaul, J. (2014). The role of effective communication in achieving informed consent for clinical trials. *Nursing Standard*, *29*(10), 45–48. https://doi.org/10.7748/ns.29.10.45.e9443

Phillips, K. A., Deverka, P. A., Hooker, G. W., & Douglas, M. P. (2018). Genetic test availability and spending: Where are we now? Where are we going? *Health Affairs*, *37*(5), 710–716. https://doi.org/10.1377/hlthaff.2017.1427

Poprzeczny, A. J., Stocking, K., Showell, M., & Duffy, J. M. (2020). Patient decision aids to facilitate shared decision making in obstetrics and gynecology. *Obstetrics & Gynecology*, *135*(2), 444–451. https://doi.org/10.1097/aog.0000000000003664

Ridgway, J., Hickson, L., & Lind, C. (2016). Decision-making and outcomes of hearing help-seekers: A self-determination theory perspective. *International Journal of Audiology*, *55*, 13–22. https://doi.org/10.3109/14992027.2015.1120893

Roberts, J. S., Patterson, A. K., & Uhlmann, W. R. (2020). Genetic testing for neurodegenerative diseases: Ethical and health communication challenges. *Neurobiology of Disease*, *141*, 104871. https://doi.org/10.1016/j.nbd.2020.104871

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*(1), 68–78. https://doi.org/10.1037//0003-066x.55.1.68

Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *The European Health Psychologist, 10*, 2–6.

Schulman, J., Braun, D., Lee, H. C., Profit, J., Duenas, G., Bennett, M. V., Dimand, R. J., Jocson, M., & Gould, J. B. (2018). Association between neonatal intensive care unit admission rates and illness acuity. *JAMA Pediatrics*, *172*(1), 17. https://doi.org/10.1001/jamapediatrics.2017.3913

Sepucha, K. R., Abhyankar, P., Hoffman, A. S., Bekker, H. L., LeBlanc, A., Levin, C. A., Ropka, M., Shaffer, V. A., Sheridan, S. L., Stacey, D., Stalmeier, P., Vo, H., Wills, C. E., & Thomson, R. (2017). Standards for universal reporting of patient decision aid evaluation studies: The development of Sundae Checklist. *BMJ Quality & Safety*, *27*(5), 380–388. https://doi.org/10.1136/bmjqs-2017-006986

Silvia, K. A., Ozanne, E. M., & Sepucha, K. R. (2008). Implementing breast cancer decision aids in community sites: Barriers and resources. *Health Expectations*, *11*(1), 46–53. https://doi.org/10.1111/j.1369-7625.2007.00477.x

Smith, E. E., du Souich, C., Dragojlovic, N., & Elliott, A. M. (2018). Genetic counseling considerations with rapid genome-wide sequencing in a neonatal intensive care unit. *Journal of Genetic Counseling*, *28*(2), 263–272. https://doi.org/10.1002/jgc4.1074

Spence, C. M., Stuyvenberg, C. L., Kane, A. E., Burnsed, J., & Dusing, S. C. (2023). Parent experiences in the NICU and transition to home. *International Journal of Environmental Research and Public Health*, *20*(11), 6050. https://doi.org/10.3390/ijerph20116050

Stacey, D., Taljaard, M., Smylie, J., Boland, L., Breau, R. H., Carley, M., Jana, K., Peckford, L., Blackmore, T., Waldie, M., Wu, R. C., & Legare, F. (2015). Implementation of a patient decision aid for men with localized prostate cancer: Evaluation of patient outcomes and practice variation. *Implementation Science*, *11*(1). https://doi.org/10.1186/s13012-016-0451-1

Stacey, D., & Volk, R. J. (2021). The International Patient Decision Aid Standards (IPDAS) collaboration: Evidence update 2.0. *Medical Decision Making*, *41*(7), 729–733. https://doi.org/10.1177/0272989x211035681

Stanford Medicine Children's Health - Lucile Packard Children's Hospital Stanford. (n.d.). *The neonatal intensive care unit (NICU).* https://www.stanfordchildrens.org/en/topic/default ?id=the-neonatal-intensive-care-unit-nicu-90-P02389#:~:text=Most%20babies%20 admitted%20to%20the,also%20have%20low %20birth%20weights

Strike, C., Guta, A., de Prinse, K., Switzer, S., & Carusone, S. C. (2016). Opportunities, challenges and ethical issues associated with conducting community-based participatory research in a hospital setting. *Research Ethics*, *12*(3), 149–157. https://doi.org/10.1177/1747016115626496

Teixeira, P. J., Marques, M. M., Silva, M. N., Brunet, J., Duda, J. L., Haerens, L., La Guardia, J., Lindwall, M., Lonsdale, C., Markland, D., Michie, S., Moller, A. C., Ntoumanis, N., Patrick, H., Reeve, J., Ryan, R. M., Sebire, S. J., Standage, M., Vansteenkiste, M., … Hagger, M. S. (2020). A classification of motivation and behavior change techniques used in self-determination theory-based interventions in health contexts. *Motivation Science*, *6*(4), 438–455. https://doi.org/10.1037/mot0000172

Tracy, S. J. (2019). *Qualitative Research Methods: Collecting Evidence, Crafting Analysis, Communicating Impact* (2nd Ed.). Wiley.

Urman, R. D., Southerland, W. A., Shapiro, F. E., & Joshi, G. P. (2019). Concepts for the development of anesthesia-related patient decision aids. *Anesthesia & Analgesia*, *128*(5), 1030–1035. https://doi.org/10.1213/ane.0000000000003804

Wainstein, T., Campbell, T., Stojkova, B. J., Lavoie, P. M., & Elliott, A. M. (2022). Implementing genomics in the neonatal period: An assessment of parental decision making and anxiety. *Journal of Genetic Counseling, 00,* 1–11. https://doi.org/10.1002/jgc4.1605

Wakefield, C. E., Meiser, B., Homewood, J., Peate, M., Kirk, J., Warner, B., Lobb, E., Gaff, C., & Tucker, K. (2007). Development and pilot testing of two decision aids for individuals considering genetic testing for cancer risk. *Journal of Genetic Counseling*, *16*(3), 325–339. https://doi.org/10.1007/s10897-006-9068-x

Ward, F. R. (2010). Parents' views of involvement in concurrent research with their neonates. *Journal of Empirical Research on Human Research Ethics*, *5*(2), 47–55. https://10.1525/jer.2010.5.2.47

Widmeyer, K. & Jackson, F. (2021). *Genetic testing in the ICU: Challenges and considerations for patients and providers*. National Society of Genetic Counselors. https://perspectives.nsgc.org/Article/genetic-testing-in-the-icu-challenges-and-considerations-for-patients-and-providers

Wigert, H., Dellenmark, M. B., & Bry, K. (2013). Strengths and weaknesses of parent–staff communication in the NICU: A survey assessment. *BMC Pediatrics*, *13*(71), 1–14. https://doi.org/10.1186/1471-2431-13-71

Willig, L. K., Petrikin, J. E., Smith, L. D., Saunders, C. J., Thiffault, I., Miller, N. A., Soden, S. E., Cakici, J. A., Herd, S. M., Twist, G., Noll, A., Creed, M., Alba, P. M., Carpenter, S. L., Clements, M. A., Fischer, R. T., Hays, J. A., Kilbride, H., McDonough, R. J., … Kingsmore, S. F. (2015). Whole-genome sequencing for identification of Mendelian disorders in critically ill infants: A retrospective analysis of diagnostic and clinical findings. *The Lancet Respiratory Medicine*, *3*(5), 377–387. https://doi.org/10.1016/s2213-2600(15)00139-3

Williams, G. C., McGregor, H. A., Zeldman, A., Freedman, Z. R., & Deci, E. L. (2004). Testing a self-determination theory process model for promoting glycemic control through diabetes self-management. *Health Psychology*, *23*(1), 58–66. https://doi.org/10.1037/0278-6133.23.1.58

Wreesmann, W.-jan W., Lorié, E. S., van Veenendaal, N. R., van Kempen, A. A. M. W., Ket, J. C. F., & Labrie, N. H. M. (2021). The functions of adequate communication in the neonatal care unit: A systematic review and meta-synthesis of qualitative research. *Patient Education and Counseling*, *104*(7), 1505–1517. https://doi.org/10.1016/j.pec.2020.11.029

Wöhlke, S., Schaper, M., & Schicktanz, S. (2019). How uncertainty influences lay people's attitudes and risk perceptions concerning predictive genetic testing and risk communication. *Frontiers in Genetics*, *10*. https://doi.org/10.3389/fgene.2019.00380

Wojcik, M. H., Schwartz, T. S., Yamin, I., Edward, H. L., Genetti, C. A., Towne, M. C., & Agrawal, P. B. (2018). Genetic disorders and mortality in infancy and early childhood: Delayed diagnoses and missed opportunities. *Genetics in Medicine*, *20*(11), 1396–1404. https://doi.org/10.1038/gim.2018

Yang, L., Liu, X., Li, Z., Zhang, P., Wu, B., Wang, H., Hu, L., Cheng, G., Wang, L., & Zhou, W. (2019). Genetic aetiology of early infant deaths in a neonatal intensive care unit. *Journal of Medical Genetics*, *57*(3), 169–177. https://doi.org/10.1136/jmedgenet-2019-106221

# Curriculum Vitae

## Keeley Higley

### Education

**Master of Arts in Applied Communication**

May 2024

*Indiana University–Purdue University Indianapolis*, Indianapolis, IN

GPA: 4.00

***Thesis:*** Development of a Theory-Informed Patient Decision Aid to Facilitate Consent to Genetic Testing in the NICU

***Advisor:*** Dr. Katharine Head

***Committee:*** Dr. Maria Brann and Dr. Jennifer Bute

***Relevant coursework:*** Advanced Health Communication, Advanced Relational Communication, Communication in Mediated Health Contexts (Health Campaigns), Advanced Quantitative Methods

**Bachelor of Science in Health Science** | Concentration: Health Promotion

May 2021

*Indiana University*, South Bend, IN

GPA: 4.0

***Relevant coursework:*** Public Health Education Methods, Community Assessment & Program Planning, Research in the Health Sciences, Health Policy & Advocacy, Diversity & Cultural Competence

## Academic Employment

### COMM-C R110 Instructor of Record

Aug. 2023 – Present

*Indiana University–Purdue University Indianapolis*

- Responsible for enhancing curriculum and teaching 50-75 students in two-three sections of R110 Fundamentals of Speech Communication
- Adapt curriculum to meet learning objectives and increase students' communication confidence
- Create and modify engaging activities to better prepare students for real-world public speaking experiences, such as job interviews and work-related presentations

### Bridge Week Instructor of Record

Aug. 2023

*Indiana University–Purdue University Indianapolis*

- Led 25 incoming freshmen and transfer students through a week-long intensive course, Bridge Week UColl 100, that introduced them to campus, college life, academic expectations, and more
- Developed interactive learning activities and engaging lectures to ensure the appropriate participation of all students

### Research Assistant

July 2023 – Present

*Indiana University–Purdue University Indianapolis*

- Conduct research with Dr. Katharine Head and the Indiana Immunization Coalition to assess vaccine myths and perceptions of under-studied vaccine-hesitant communities
- Complete the IRB application, revisions, and amendments to ensure ethical research
- Attend meetings to ideate and formulate the focus group study guide and attend focus groups to facilitate answering the research questions

**Teaching Assistant**

Jan. 2023 – Aug. 2023

*Indiana University–Purdue University Indianapolis*

- Assisted in nine sections of R110 Fundamentals of Speech Communication (three in Spring, three in Summer Session 1, and three in Summer Session 2), both in person and online, by grading speech outlines, providing critical feedback, and offering input on other assignments
- Guided student success by emailing, responding to, and meeting with students about outline development and speech rehearsals
- Taught class sessions as necessary, following IUPUI policies and adapting materials and curriculum to meet students' needs

**Academic Center for Excellence Writing Tutor**

Nov. 2019 – May 2020

*Indiana University South Bend*

- Educated students on university resources, writing best practices, developing and honing arguments, and constructing clear academic writing

- Assisted students with developing coherent and thoughtful arguments for undergraduate and graduate classes, including nursing and psychology papers

**Professional Employment**

**Health Content Strategist**

Dec. 2021 – Aug. 2022

*Everyday Life Consulting,* Midland, MI

- Developed all content, including social media posts, webpages, brochures, flyers, infographics, toolkits, and training curricula for community health workers
- Worked with community organizations to assess local health data and information, then determined relevant and appropriate outreach and communication strategies to reach priority populations
- Utilized content calendar, SEO, and keyword research in content development to generate a 120% increase in website traffic

**Health Content Specialist**

April 2021 – Dec. 2021

*Beacon Health System,* Granger, IN

- Created culturally and literacy-appropriate educational materials (social media, webpages, brochures, flyers, infographics, etc.) for different populations based on audience segmentation while remaining sensitive to social determinants of health, health disparities, inequities, and more
- Worked independently to prioritize tasks, analyze problems, assess audiences, and implement health education methods through various content channels

- Generated and maintained a 37% CTR on email marketing campaigns and weekly newsletters for 6 months through strategic content creation, placement, and optimization

**Youth Tobacco Prevention Coordinator**

Oct. 2020 – April 2021

*St. Joseph Health System,* South Bend, IN

- Implemented health education strategies to teach public education professionals (teachers, resource officers, counselors, etc.) about youth substance use, prevention strategies, and alternatives to suspension
- Educated youth on resiliency, overcoming trauma, and advocacy skills related to tobacco and substance use by creating innovative and effective virtual presentations, educational resources, and health programs for youth

**Internship Experience**

**Health Communication Intern**

May 2023 – Present

*Indiana Immunization Coalition,* Indianapolis, IN

- Responsible for making the Project HPV-free collegiate toolkit more LGBTQ+ inclusive, developing a patient information campaign about vaccines and the diseases they prevent, and reviewing VaxChamp dental modules for clarity
- Responsible for recruiting sponsorships and silent auction items for the end-of-year gala and completing grant requests and grant reporting
- Attend health fairs to answer community members' questions about vaccinations and encourage them to locate and register for vaccines

**Event Planning Intern**

May 2022 – Aug. 2022

*Indiana Immunization Coalition,* Indianapolis, IN

- Wrote and designed social media content using brand tone of voice and organization-specific guidelines to promote the end-of-year fundraising event
- Organized a content calendar and marketing plan and coordinated events to fundraise for the IIC

**Summer Community Health Improvement Program Intern**

May 2020 – Aug. 2020

*Indiana University School of Medicine, South Bend, IN*

- Strategically worked with medical students to develop a community health needs assessment for a low socioeconomic ZIP code in South Bend, IN
- Received training from and collaborated with community organizations to conceptualize community-based health interventions

**Honors and Awards**

**Athletics Favorite Professor**

January 2024

*Indiana University–Purdue University Indianapolis,* Indianapolis, IN

**Department of Communication Studies Graduate Research Paper Award**

April 2023

*Indiana University–Purdue University Indianapolis,* Indianapolis, IN

**Department of Communication Studies Graduate Service Award**

April 2023

*Indiana University–Purdue University Indianapolis,* Indianapolis, IN

**University Fellowship**

2022

*Indiana University–Purdue University Indianapolis,* Indianapolis, IN

**Rockne Scholar**

2020

*Community Foundation of La Porte,* La Porte, IN

**Summer Stay Scholar**

2019

*Purdue University,* West Lafayette, IN

**Robert & Anita Ludington Scholar**

2019

*Community Foundation of La Porte,* La Porte, IN

**Carley Dickard Memorial Scholar**

2018

*Community Foundation of La Porte,* La Porte, IN

**Competitively Selected Presentations**

**Kentucky Conference on Health Communication**

April 2024

Presentation title: *Development of a Theory-Informed NICU Genetic Testing Patient Decision Aid*

**Midwest Medical Humanities Conference**

March 2024

Presentation title: *Qualitative Analysis of Type 1 Diabetics' Mental Health*

**IIC Healthy Emerging Adult Leaders Program**

July 2023

Presentation title: *Health Communication 101*

**Midwest Medical Humanities Conference**

March 2023

Presentation title: *Development of a Theory-Informed Patient Decision Aid to Facilitate Consent to Genetic Testing in the NICU*

**Communication Day Graduate Panel**

March 2023

Presentation title: *Type 1 Diabetes and Supportive Messaging: What Actually Motivates Patients*

**Service Contributions**

**Graduate Student Peer Mentor**

July 2023 – Present

*IUPUI Department of Communication Studies,* Indianapolis, IN

**Organizer**

Jan. 2023 – Aug. 2023

*IUPUI Graduate Liberal Arts Student Council,* Indianapolis, IN

**Organizer**

Dec. 2022 – Aug. 2023

*IUPUI Department of Communication Studies,* Indianapolis, IN

**Peer mentor**

Nov. 2018 – May 2019

*Disability Resource Center,* West Lafayette, IN

**Peer educator**

Sept. 2018 – May 2019

*Center for Advocacy, Response, & Education,* West Lafayette, IN