Turn Down the Noise: Reducing Barriers to Inclusive Healthcare Communication Through an Information Theory Lens

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Abstract

At the end of a healthcare visit, information may be supplied all at once, which can result in challenges with retaining and understanding information that may lead to a mismanagement of prescribed treatment (Becker et al. 2021). Further, those who identify as *neurodivergent* – a term that may be defined to describe "individuals whose selective neurocognitive functions/ neurodevelopmental differences fall outside prevalent societal norms" — may have specific information needs that are not generally addressed by standard healthcare information-delivery practices (Shah et al., 2022, p. 579). There remains a need to consider how to better support inclusive communication practices between neurodivergent patients, caregivers and healthcare providers at the end of healthcare visits. Drawing from Shannon's Theory of Information, this research paper considers the concept of *noise*, which refers to information that disrupts or distorts a transmitted message (Shannon & Weaver, 1949). In this healthcare context, barriers to understanding healthcare instructions are conceptualized as noise. This study leverages semi-structured interviews and an iterative co-design process to identify sources of noise and opportunities to respond to these barriers to inclusive healthcare communication between neurodivergent patients, caregivers and healthcare providers.

We propose a model for organizing noise into four categories: (1) less controllable external noise, (2) more controllable internal noise, (3) less controllable internal noise, and (4) more controllable external noise. Our discussion considers what types of action are required to mitigate different forms of noise. Systemic action – that is, action required to address less controllable external noise – is analyzed and compared to a design thinking process. We identify an opportunity to offload the burden of enacting systemic action through collaborative efforts between healthcare providers and designers. Overall, this research makes a unique academic contribution by considering how information theory can extend our understanding and response to healthcare communication barriers between neurodivergent patients, caregivers and healthcare providers.

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1.1. Background

Clinical healthcare environments pose various barriers to successful communication between patients, their circle of care and healthcare providers. At the end of a healthcare visit, information may be supplied all at once, which can result in challenges with retaining and understanding information that may lead to a mismanagement of prescribed treatment (Becker et al. 2021). Patients and their circle of care may encounter cognitive overload – commonly viewed as “information overload” – in which an individual is overwhelmed with the amount of information being “pushed” at them (Kirsh, 2000). Attention and memory limitations may further prevent an individual from retaining the information being pushed (Cicourel, 2004). At the same time, sensory obstacles may influence how well patients, caregivers and healthcare providers interact with each other. For example, the continuous noises (the sound of voices, the clicking of computer keyboards, television sound etc.) and transient noises (alarms, verbal outbursts, sneezing etc.) that exist in the soundscape of healthcare environments cannot often be controlled (Giarelli et al., 2024). These noises may be considered distracting or overwhelming for some individuals.

Further, it is worth considering how neurodivergent patients may experience cognitive or sensory overload in clinical healthcare settings. We use identity-first language in this report, with the recognition that this approach is rooted in "disability as a culture, promoting autonomy, agency, and choice over one’s destiny" (Best et al., 2022, p. 127). The term *neurodivergent* may be used to describe “individuals whose selective neurocognitive functions/ neurodevelopmental differences fall outside prevalent societal norms” (Shah et al., 2022, p. 579). Neurodivergent individuals may have specific information needs that are not generally addressed in standard healthcare settings. A study designed to learn about the experiences of autistic adults in healthcare settings found many autistic individuals encounter sensory issues caused by clinical facilities (Raymaker et al. 2016). In terms of processing information in online learning environments, neurodivergent students have reported significantly higher extraneous cognitive load compared to their neurotypical peers (Le Cunff et al., 2024). Indeed, an inclusive approach to improve healthcare communication warrants consideration of how we may better support neurodivergent patients with receiving information in clinical healthcare settings.

Over the years, healthcare providers have been increasingly involved in discussions and initiatives to better support patients with varying needs. However, healthcare providers are not often provided with the tools, training and resources to support neurodivergent patients (Iacono and David, 2023; Austriaco et al, 2019). Existing literature varies greatly in recommendations for how to better support patients in healthcare settings. There is no standard or optimized method for information delivery yet, but as Samuels-Kalow et al., (2012) point out, there remains a need to further explore “optimal content, channel and timing” for discharge content. As we aim to pursue health equity in our systems, we must also consider how healthcare providers may be better equipped with systems and resources that enable them to support all of their patients.

This study aims to consider the barriers to effective communication at the end of healthcare visits between neurodivergent patients, caregivers and healthcare providers. For this research, we collaborated with Surrey Place, a non-profit dedicated to supporting individuals “with autism-, developmental-, and sensory-related concerns” (Surrey Place, n.d). We use Shannon’s Theory of Information (Shannon & Weaver, 1949) to help us understand key components of information exchange in the healthcare context. Through iterative interview and co-design sessions with caregivers, healthcare providers and individuals who identify as neurodivergent, we present a model for categorizing and addressing contributors of cognitive and sensory overload, as well as an opportunity to further support healthcare providers with responding to the needs of their patients.

1.2. Research Question

Given the complex obstacles that prevent successful communication at the end of healthcare visits, this research project aims to address the research question: How can we promote the inclusive and effective communication of healthcare instructions among neurodivergent patients, caregivers, and healthcare providers by addressing barriers to information exchange at the end of healthcare visits?

1.3. Objectives

The main objectives of this study are to:

1. Identify the main barriers to clear information transfer and communication at the end of healthcare visits between neurodivergent patients, caregivers and healthcare providers.
2. Understand what factors make communication effective or ineffective and what factors may contribute to cognitive or sensory overload, or other related challenges.
3. Identify an opportunity for a design intervention that addresses the communication obstacles in clinical healthcare settings between neurodivergent patients, caregivers and healthcare providers.

2. A Discussion of Literature

2.1. Key Concepts and Theories from Literature

This section outlines key concepts and theories from the literature that are relevant to understanding the topics explored in this paper.

2.1.1. Shannon’s Theory of Information

Rather than tie information to meaning, Shannon’s Theory of Information views information as a reduction of uncertainty (Shannon & Weaver, 1949). To elaborate, an individual may choose to send one message from countless options of other messages. *Information* refers to the reduction of the uncertainty surrounding the message that was selected (Shannon & Weaver, 1949). A greater number of possible messages, greater levels of uncertainty, and greater levels of information thus are interconnected as a predictable message is redundant and considered devoid of information (Shannon & Weaver, 1949).

According to this theory (Shannon & Weaver, 1949), a communication system consists of five parts:

1. *The Information Source* produces the message to be communicated to the receiving terminal.
2. *The Transmitter* which operates on the message in some way to produce a signal suitable for transmission over the channel.
3. *The channel* which is the medium used to transmit the signal from transmitter to receiver

4. *The receiver* that performs the inverse operation of the transmitter to reconstruct the message from the signal.
5. *The destination* is the person (or thing) for whom the message is intended.

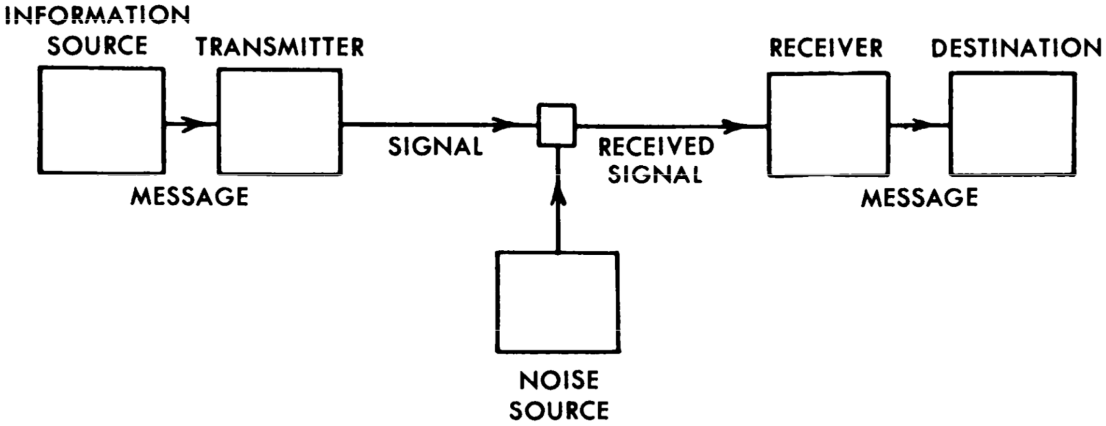


Figure 1: A diagram of Shannon's communication system (Shannon & Weaver, 1949).

Successful communication occurs when the message received is identical to the message that was sent (Shannon & Weaver, 1949). In this context, the term *signal* is used to describe the encoded message that is being sent through the channel, while changes to the transmitted signal are considered *noise* (Shannon & Weaver, 1949). When noise is introduced to the channel, a message may gain distortions, errors and extraneous material that alter the original message (Shannon & Weaver, 1949).

Shannon's theory has broad applications across the fields of healthcare, education, engineering and more. However, the theory's origins were rooted in application to telecommunication systems such as the telegraph (Gleick, 2011). The context of Shannon's (1948) theory explains why information travels in one direction, from transmitter to receiver, in his model (Shannon & Weaver, 1949). We note that human interaction is highly nuanced. Rather than transmitting information one way, two individuals in most interactions are constantly sending information to one another. This information can be a verbal exchange of dialogue, as well as information conveyed by non-verbal cues such as body language and facial expressions. In the context of healthcare, healthcare providers, patients and caregivers all switch between the roles of transmitters and receivers of information. For example, consider the exchange of information that occurs at the beginning of a healthcare visit. The patient may transmit information about the symptoms that prompted them to visit the clinic. The doctor is the receiver in this instance. However, when the doctor asks follow-up questions, they take on the role of transmitter. The patient subsequently becomes the receiver of information (i.e. the question that the doctor is asking).

An exchange of health information
as applied to Shannon's (1948) communication system.

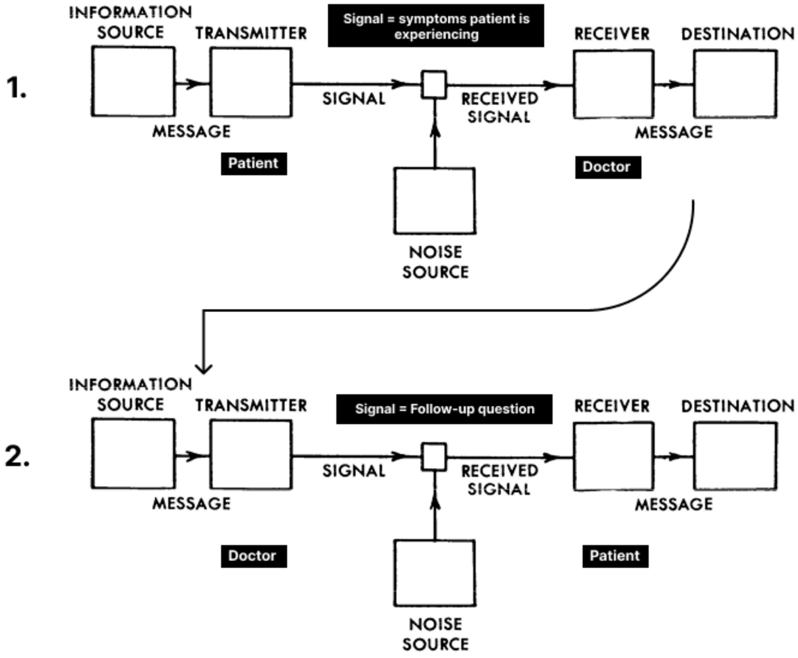


Figure 2: An exchange of health information as applied to Shannon's communication system (Shannon & Weaver, 1949).

Indeed, perception and action are deeply intertwined; the perception of information prompts action (Gibson, 1979). When a healthcare provider receives information about symptoms, they ask questions that the patient will then answer. Each party in the interaction reacts to new information, and the cycle continues to repeat. This exchange of information enables healthcare providers, patients and caregivers to form shared intentionality. As defined by Tomasello et al. (2005), shared intentionality occurs when individuals share psychological states with one another, thus enabling collaborative behaviors and social connection. By having each member of an interaction switch between the roles of transmitter and receiver, members of the interaction share their perspectives and can thus work towards collaborative outcomes– such as an agreement regarding next-steps following the end of a healthcare visit.

2.2. Contextual Literature

Now that we have considered key theories and concepts, we move to consider the problem space through an examination of available literature. Prior research helps us contextualize and better understand barriers to communication in healthcare settings between neurodivergent patients, caregivers and healthcare providers.

2.2.1. The Impact of Health Literacy Levels

A lack of comprehension of healthcare instructions may be attributed to health literacy deficits. Health literacy is "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, p. vi). Individuals may struggle with health literacy for a variety of reasons, such as limited education, cognitive or learning impairments, language barriers, higher rates of poverty and more (Chugh et al., 2009; Clarke et al., 2005). Health literacy deficits may present themselves in the form of challenges in understanding medical instructions, medication labels, appointment papers, complex conditions and other key information provided during the ED discharge process (Chugh et al., 2009; Clarke et al., 2005).

From the perspective on materials provided during discharge, it has been found that written instructions often exceed a patients' reading ability (Clarke et al., 2005). The accessibility of written instructions can indeed be limited by "grade reading level or discordant language of instructions" (Rodriguez et al., 2022, p. 959). Indeed, there may be a mismatch between healthcare providers and the complex medical terminology they are proficient in, versus patients and caregivers who lack a professional medical background. Indeed, prior work has found that medical jargon may prevent patients from understanding their doctors' instructions (Kumar, 2023). This mismatch may further emphasize health literacy challenges– especially for neurodivergent patients, who have a reported preference for plain language (Casimiro et al., 2026). Accessible communication methods can enable patients who identify as neurodivergent to receive and comprehend healthcare instructions (Casimiro et al., 2026). Prior work considers the benefits of plain language, visual aids, text simplification, among other factors, as methods to improve inclusive communication (Casimiro et al., 2026).

2.2.2. The Impact of the Sensory Environment

The sensory experience in a clinical healthcare setting may influence the transmission and reception of information. Sensory overload can occur in environments where sensory experiences are difficult to manage. It should be considered that clinical healthcare environments pose numerous auditory obstacles that may impede successful information transfer between healthcare providers, patients and their circle of care. For instance, it is worth considering speech intelligibility, which is the extent to which a listener can understand a speaker's speech (Scharine et al., 2009). Speech intelligibility may be impacted by environmental conditions surrounding the listener and speaker, such as disruptive noise (Scharine et al., 2009). Indeed, clinical healthcare environments are often full of auditory stimuli that are beyond a patient's control, ranging from continuous noises (the sound of traffic and voices, the clicking of computer keyboards, television sound etc.), and transient noises (alarms, verbal outbursts, sneezing etc.), which may impede the speech intelligibility of healthcare providers, patients and their circle of care (Giarelli et al., 2024; Scharine et al., 2009). An examination of a hospital in Brazil found that noise levels exceeded the comfort levels recommended by the Brazilian Association of Technical Standards (1987), thus risking harm to the health and performance of visitors and staff of the emergency ward (Filus & Albizu, 2015). Further, sound reverberation time (which increases with the size of the room) can negatively impact speech intelligibility, leading to further obstacles to clear speech intelligibility in larger rooms (McNeer et al., 2017). In Ryherd et al.'s (2013) study, no hospital unit across five U.S. hospitals that were evaluated had “good” intelligibility; rather several locations had “poor” intelligibility. Although speech intelligibility between patients and healthcare providers needs to be further researched, it appears that there are numerous auditory obstacles that prevent a clear transmission of verbal information and communication within clinical healthcare settings.

Further, the presence of other people and visual clutter can make a healthcare visit overwhelming (Moacdieh et al., 2013; Kelley et al., 2011). Prior research has found that visual clutter can make it challenging to gather visual information and make decisions (Moacdieh et al., 2013). Senior participants in Kelley et al.'s (2011) study found that "overcrowding, noise and limited space" were factors that made their experience in the emergency department unpleasant. These participants further described the environment as "'busy' and 'chaotic'" (Kelley et al., 2011). Indeed, factors that influence the patient experience often consist of overcrowding in the physical environment – as well as privacy, wait times to be examined and communication (Rowe et al., 2022). For neurodivergent individuals, these sensory obstacles can impede healthcare experiences to greater degrees. Certain sensory aspects such as lighting can be perceived differently between neurotypical and neurodivergent individuals (Stone & Arenas, 2025). Autistic adults in Raymaker's study reported sensory sensitivity as a barrier to healthcare (2016). Evidently, the sensory environment has the potential to play a significant part in how neurodivergent patients and their circles of care interact with healthcare information.

2.1.3. Current Methods to Support Healthcare Communication

Current methods to support the delivery of information at the end of healthcare visits vary as there is no consistent standard across the globe or nationally. Existing literature investigates how the dissemination of discharge material may be further supported through various design interventions. Currently, the teach-back method is well-known to be a useful conversation technique to support patient understanding of discharge instructions (Griffey et al., 2015; Slater et al., 2017). This method requires patients to "teach back" information provided by a caregiver to receive clarifying feedback based on their explanation (Griffey et al., 2015). Griffey et al. (2015) applied this technique in their case study and found a 31 percent improvement in comprehension of follow-up instructions, while a more recent study conducted by Slater et al.

(2017) found a 15 percent improvement of recall in all aspects of discharge instructions, regardless of the age and education level of patients. Indeed, this verbal method for improving patients' understanding and retention of healthcare information is well-supported by research.

However, it is worth establishing that healthcare instructions communicated solely through verbal channels may not be sufficient for patients (Hoek et al., 2020). Adding written instructions to standard care has shown an improvement in recall from 47% to 58% on average (Hoek et al., 2020). Video material has also been shown to improve information recall at even higher rates than patients who solely receive written instructions, although not to a significant extent (Hoek et al., 2020). Indeed, there are many multi-modal opportunities to support the delivery of healthcare information that are worth further exploration.

On the topic of written discharge instruction, it is necessary that these instructions are provided in a way that supports patient understanding. Many patients do not read written discharge instructions (DeSai et al., 2021). The text-heavy pages and complex jargon can indeed be a repellant for patients after a stressful appointment. Much research has hence explored how written instructions can be improved in their accessibility. An insight worth considering is that patient comprehension of written material is closely tied to their working memory, which is improved with instructions that are short and focused as opposed to long and complex passages of text (DeSai et al., 2021). DeSai et al. (2021) produced improved comprehension of discharge instructions through the delivery of information in a clearly structured one-page format. Other studies have found that simplification of language in written instructions can support patients who struggle with grasping standard material (Jolly et al., 1992). While there is no standard way to provide written material, templates have been suggested as a tool to support discharge instruction content and accessibility (Rodriguez et al., 2022).

2.1.4. Opportunities Moving Forward

Existing literature varies in recommendations for how to better support patients during healthcare communication. There is no standard or optimized method for information delivery yet, but as Samuels-Kalow et al., (2012) point out, there remains a need to further explore how to approach optimal delivery for discharge content. This research project may hence expand on existing literature to further explore how to support the communication at the end of healthcare visits between neurodivergent patients, their circles of care and healthcare providers.

3.1. Participants & Recruitment Criteria

Three groups of participants were recruited for this study: caregivers, healthcare providers and individuals who identified as neurodivergent. Surrey Place staff reached out to connections in the community – including organizations such as The Centre for Addiction and Mental Health, SickKids, Mount Sinai Hospital, and Surrey Place – to share information about the study.

The recruitment criteria for caregivers and patients required participants to:

- Identify as a caregiver of a neurodivergent patient or to identify as neurodivergent
- Have previously attended a healthcare visit and experienced challenges with processing information, feeling overwhelmed and/or sensory overload.

The recruitment criteria for healthcare providers required participants to:

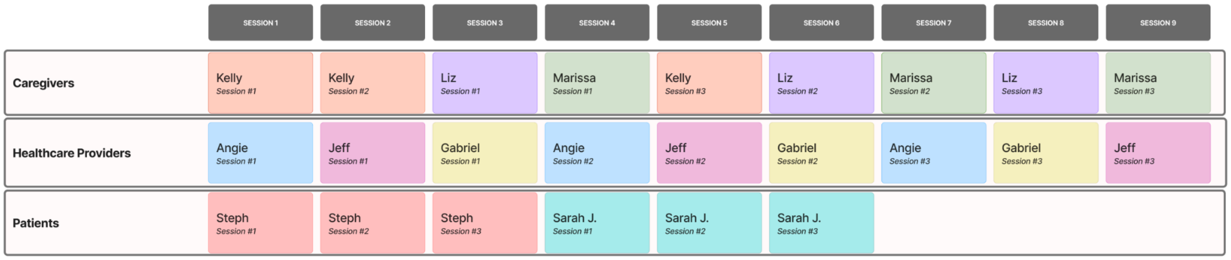
- Have experience with communicating healthcare or discharge instructions with patients who identify as neurodivergent at the end of their healthcare visits.

Following the targeted outreach facilitated by Surrey Place, we recruited three individuals per participant group. This report outlines the insights collected from three caregivers (Kelly, Liz and Marissa), three healthcare providers (Angie, who is a developmental disability services healthcare provider, Gabriel, who works in a hospital general internal medicine ward and Jeff, who is a psychologist) and two individuals with lived experience who have experience as patients in clinical healthcare settings (Sarah J. and Steph). Some participants consented to the use of their first names while others did not; thus, some names have been changed to protect privacy. Due to time constraints around participant scheduling, the last participant recruited within the patient recruitment criteria is not included in this report.

3.2. Research Methods

This study adopted a human-centred design approach. Human-centred design involves the active participation of users and a clear recognition of their needs (Maguire, 2001). By practicing human-centred design, research outputs become relevant and usable for a target audience, and have thus been proven to create financial benefit for organizations (Maguire, 2001).

The study consists of three research sessions for each participant. These research sessions were offered online or at Surrey Place according to the participant's preference. Healthcare providers also had the opportunity to opt for sessions at their workplace. The research sessions took place in a one-on-one setting, with audio and video recording employed. Each research session took approximately one hour. There were three cycles of iterative research sessions (e.g. healthcare providers' research sessions built on each other; caregivers' research sessions only built on each other and so on). As there was a gap of time between receiving interest from our two patient participants, we were unable to layer the interviews and conducted them in three separate consecutive session blocks, incorporating iteration through individual participant reflection instead.



	SESSION 1	SESSION 2	SESSION 3	SESSION 4	SESSION 5	SESSION 6	SESSION 7	SESSION 8	SESSION 9
Caregivers	Kelly *Session #1*	Kelly *Session #2*	Liz *Session #1*	Marissa *Session #1*	Kelly *Session #3*	Liz *Session #2*	Marissa *Session #2*	Liz *Session #3*	Marissa *Session #3*
Healthcare Providers	Angie *Session #1*	Jeff *Session #1*	Gabriel *Session #1*	Angie *Session #2*	Jeff *Session #2*	Gabriel *Session #2*	Angie *Session #3*	Gabriel *Session #3*	Jeff *Session #3*
Patients	Steph *Session #1*	Steph *Session #2*	Steph *Session #3*	Sarah J. *Session #1*	Sarah J. *Session #2*	Sarah J. *Session #3*			

Figure 3: Schedule of research sessions conducted with caregivers, healthcare providers and neurodivergent patients.

3.2.1. Session 1: Semi-structured interviews and co-design

The first research session involved two sections: a semi-structured interview and a co-design activity. The semi-structured interview aimed to learn about participants' experiences with receiving or sharing healthcare information at the end of a visit. During the interviews, patients and caregiver participants also answered two rating questions related to their receiving healthcare instructions including:

1. On a scale of 1-5 (1 being very easy, 5 being very difficult), how easy or difficult was it to understand your healthcare instructions?
2. On a scale of 1-5 (1 being very easy, 5 being very difficult), how easy or difficult was it to remember your healthcare instructions?

The co-design activity prompted patients and caregivers to consider the design question: how would you design an optimal solution to improve your understanding of healthcare information at the end of your healthcare visits?

Healthcare providers were prompted to consider: how would you design an optimal solution to improve your experience with delivering healthcare information at the end of your patients' healthcare visits?

In order to design solutions in response to their prompts, participants were encouraged to use a medium that aligned most with their preferences, including paper and pen. Since all participants participated in virtual interviews, they were also offered access to virtual design tools including Figma, Google Drawings and Microsoft Whiteboard. In this report, we include the co-designed solutions as they were created during the research sessions.

3.2.2. Sessions 2 and 3: Co-design and User Feedback

In sessions 2 and 3, we incorporated a section for collecting user feedback. Before a participant (Participant A) was invited for the second research session, we aimed to facilitate a research session with a different participant (Participant B) when possible. This allowed us to collect the co-designed work created by Participant B and show it to Participant A for feedback in Participant A's second research session. We applied a similar layered approach for scheduling the third sessions.

The general structure for sessions 2 and 3 consisted of:

1. A few short recap or follow-up interview questions based on the previous session when applicable.

2. A continuation of the co-design activity from the previous session, conducted with collaborative discussion with the researcher. When possible, this included sharing feedback provided by other participants and inviting the original participant to reflect and discuss whether the feedback would influence their co-designed solution.

3. A portion of time dedicated to showing other participants' co-designed solutions and collecting feedback on them.

3.2.3: Data Analysis

Data was collected through recorded interviews, transcripts and the facilitator's notes. We employed a visual data coding process. The process started with visual clustering of data points in a FigJam board in Figma. This allowed for the visual grouping of common themes.

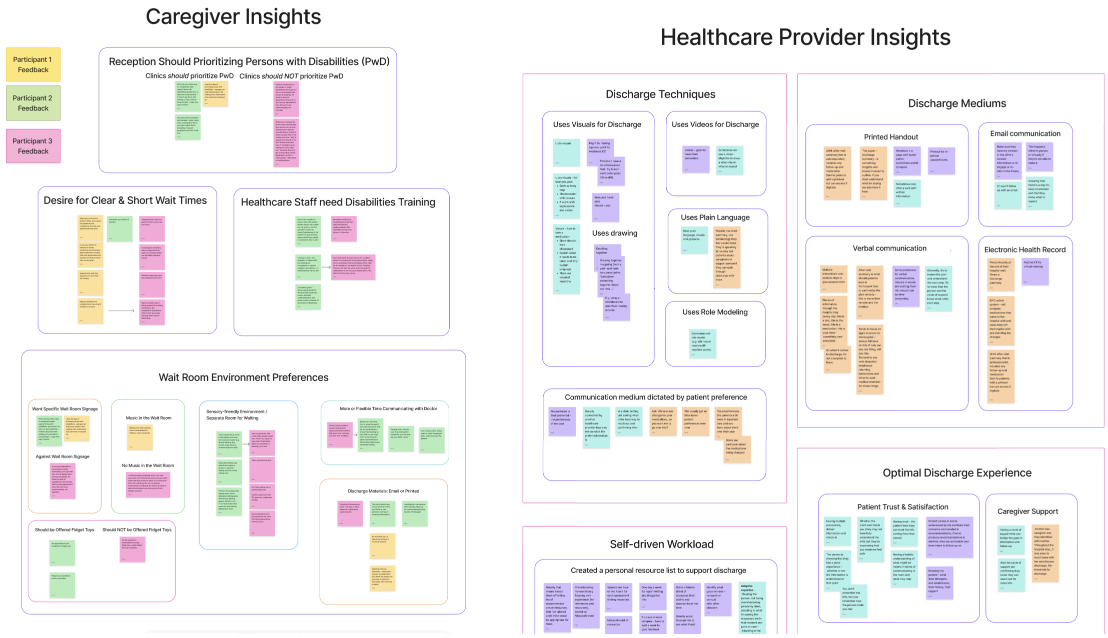


Figure 4: Snippets of themes identified during visual data coding.

During a collaborative meeting, the Graduate Researcher and Principal Advisor (PA) discussed key themes based on the data analysis that was completed at the time of the meeting. These themes were drawn out by the PA during discussion.

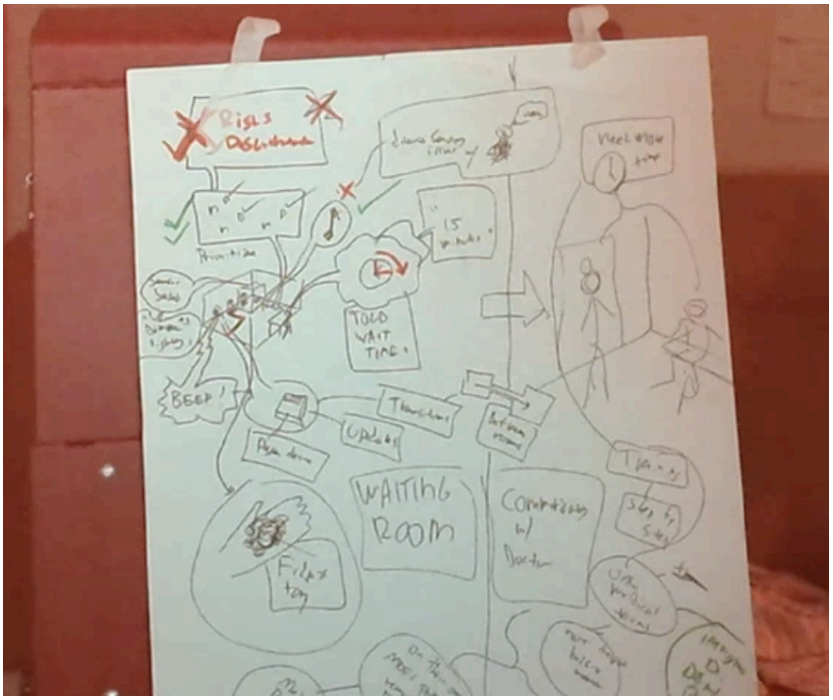


Figure 5: Data visually depicted through sketching as created by the Principal Advisor during Data Analysis Meeting 1.

Following the meeting, the Graduate Researcher aimed to recreate the PA's sketch and highlight connections between data that were discussed during the meeting. This enabled the Graduate Researcher and PA to create shared understanding regarding the data, as well as identify emerging connections and themes.

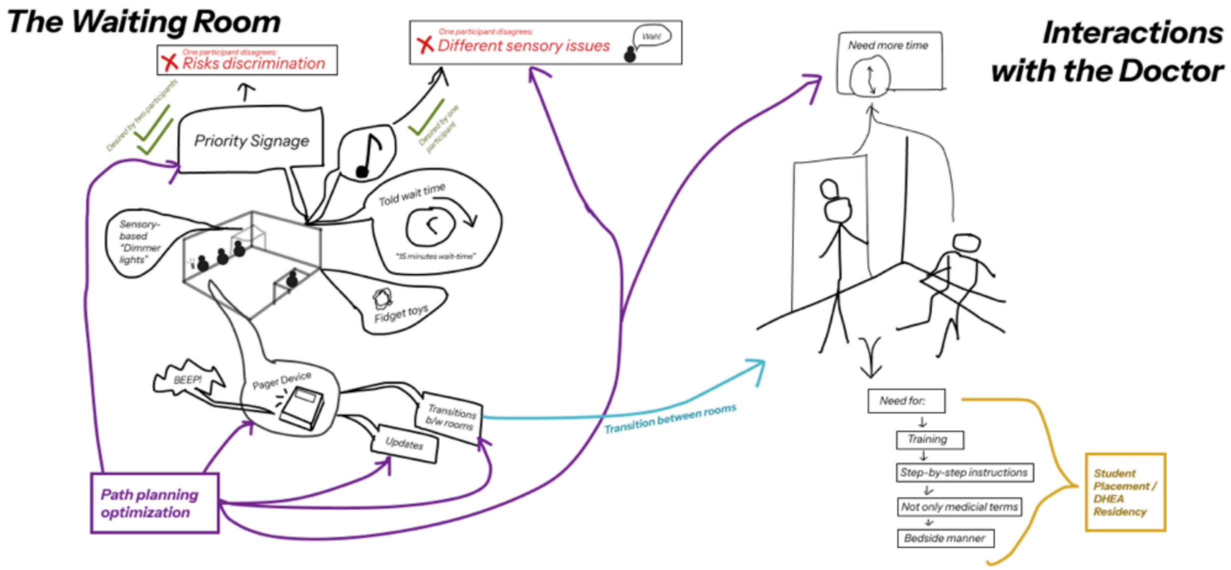


Figure 6: An iterated visual depiction of the Principal Advisor's initial sketch created post Meeting 1.

During the next meeting, the PA reviewed the Graduate Researcher's sketch. After discussion and a confirmation of alignment, the PA and Graduate Researcher began to discuss new themes that emerged from data analysis. The PA put the researcher's sketch in the centre of his canvas. Through collaborative discussion, the PA and Graduate Researcher identified other themes to include in the data visualization, which the PA thus sketched.

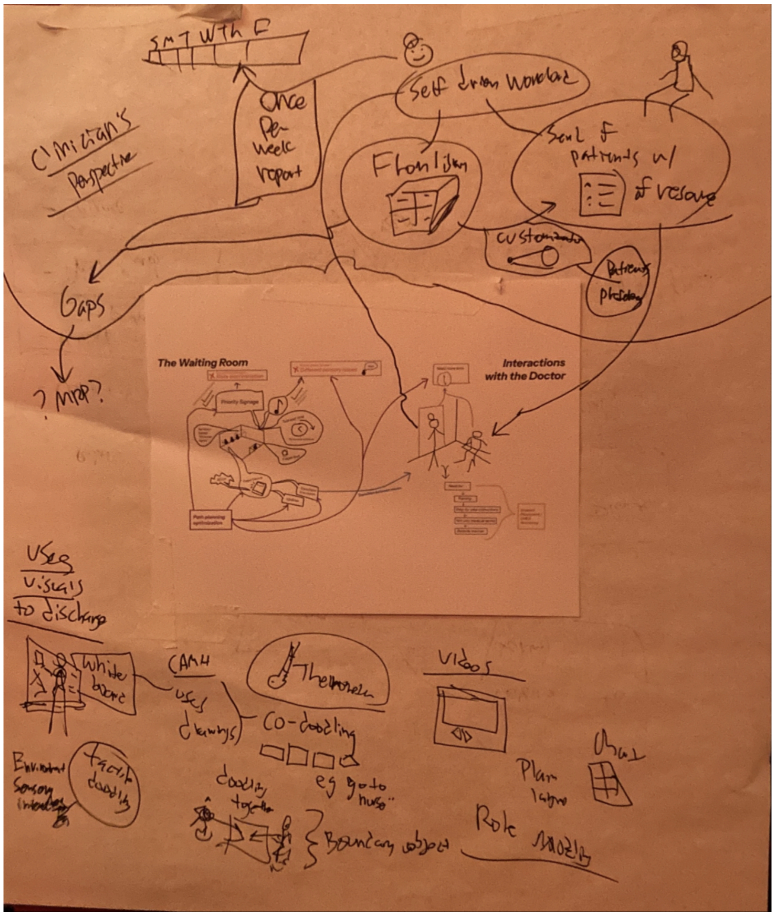


Figure 7: Data visually depicted through sketching as created by the Principal Advisor during Meeting 2 which builds upon the iterated visual depiction made by the Graduate Researcher.

Following this second meeting, the Graduate Researcher repeated the process of recreating the PA's sketch. This exercise allowed the PA and Graduate Researcher to consider the data from a holistic, visual perspective that allowed for connections between data to be easily formed and understood.

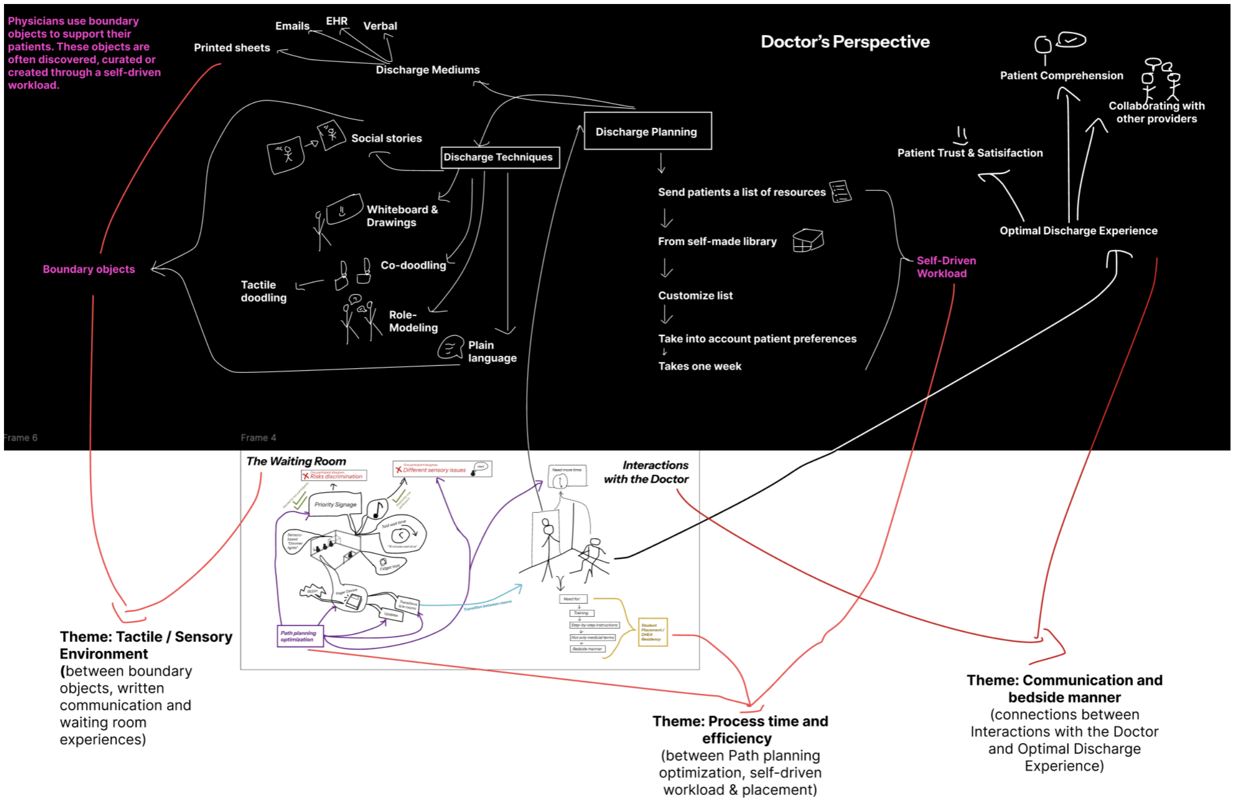


Figure 8: A final recreation of the last sketch created by the Principle Advisor with the addition of newly identified themes and connections across data points post Meeting 2.

The visual data analysis activities were supported with thematic analysis. Thematic analysis involved qualitative coding across transcripts and co-designed representations developed by participants to identify common themes (Willig & Stainton-Rogers, 2017).

4. Results

4.1. Sources of Noise in Healthcare Communication

Let us revisit the objectives of this research study from the lens of Shannon's (Shannon & Weaver, 1949) Information Theory.

Objective 1: Identify the main barriers to clear information transfer and communication at the end of healthcare visits between neurodivergent patients, caregivers and healthcare providers.

In the context of communication at the end of a healthcare visit, we may examine what patients, caregivers and healthcare providers consider to be barriers – or rather, *noise* – that impedes successful communication. Further, we may consider what contributes to or acts as a *source of noise.*

Thus, we may reframe Objective 1 and consider: what are *sources of noise* that prevent successful communication in clinical healthcare settings?

4.1.1. Wait Time as a Source of Noise

The experience leading up to the appointment can have a significant impact on patients' and caregivers' ability to take in information. In this sense, wait time can act as a source of noise that contributes to emotions such as anxiety, restlessness and anticipation that act disruptively and prevent the successful reception of health information.

To elaborate: in terms of time, no caregiver participant wanted to wait longer than fifteen minutes for their appointment to begin. Sarah J. echoed this notion, sharing that a long wait time may raise obstacles to absorbing information later in the appointment. Indeed, short wait times set the stage for a less noisy exchange of information at the end of a visit. Our participants note that a long wait time is simply not feasible: both caregivers and patients shared that longer wait times can lead to stress and anxiety.

"If you enter a doctor's office and I'm just talking here, um, and you've waited 2 hours and you know your child is at a threshold that they need to eat, that they're ready to lose their mind. You know their dysregulation is becoming high," shared Liz. *"That really will affect your experience with the doctor, what you're able to take in, what you're able to even describe as what's going on, because in the back of your mind you're thinking, how do I get out of that door as soon as possible?"*

The longer the wait before an appointment starts, the stronger the urgency to leave the clinic once it begins. Caregiver participants shared the difficulties that can arise when the individuals they care for must remain in the waiting room for extended periods. Those they care for may grow restless or have elopement concerns that make it difficult for caregivers to focus on communicating with healthcare providers. Further, coming to the doctor's office can be a generally unpleasant and stress-inducing experience for both patients and caregivers.

Sarah J shared: *"...If you're anxiously waiting to be seen going into the actual appointment, it may… It may, it may almost deter away from the actual appointment, because like you might feel scared, you might feel nervous, you might feel anxious, you might feel you might have a whole mixed range of emotions – which, when you're already feeling those, having to sit and wait is the worst part."*

4.1.2. Sensory Environment as a Source of Noise

Healthcare providers, patients and caregivers shared struggles with sensory obstacles in the environment that can make communication challenging. Indeed, an overwhelming sensory environment can put forth bright lights, large crowds and overwhelming sound that may be distracting and disruptive to information exchange.

In some cases, participants are able to take action to change their sensory environment and reduce noise. Caregivers expressed the value of requesting a private room to wait in, which can mitigate some of the sensory challenges present in waiting rooms. Sarah J shared an instance where she told the clinic staff that the lights in the office were too bright and gave her a headache. They thus closed the blinds.

"So it's just those sorts of things where I've learned now. But unless I advocate for myself. They might not know. So like, if I hadn't have spoken up, then I would have just been punishing myself. In a room that was just the lights were too bright," shared Sarah J.

While some instances allow for individuals to mitigate sensory sources of noise, there are other times and settings where that is not possible. As a healthcare provider that works in acute hospital care, Gabriel notes that overhead speakers making noise, patients in the curtain next over, and other factors in the environment can contribute to sensory overload. These sources of noise are perpetual and individuals cannot exercise any agency to remove them.

When it comes to an ideal waiting room environment, Marissa shares an example of Kid Crew, located on Bathurst and St. Clair St. in Toronto. The clinic has three waiting rooms, including a quiet room with a TV, a play area, and a room with a chalkboard for children to draw with. These various options allow children to pick the room best suited to their preferences, shared Marissa. Indeed, Kid Crew's waiting room serves as an example of an opportunity where individuals can choose among different sensory environments to find one with minimal noise for their needs.

Figure 9: Photos of Kid Crew's waiting room, as shared on Yelp.ca by Yelp user *Jovana S.*

4.1.3. Reliance on Medical Jargon as a Source of Noise

Understanding the receiver's intended message can be made difficult when unknown vocabulary enters the conversation. As our patient participants point out, it can be challenging to understand what a healthcare provider is sharing when they use medical jargon.

"Sometimes I feel like doctors use big words and I feel like they should break down their words, especially how they talk to people with autism, because they might not understand," shared Steph.

During her interview, Sarah J. shared an instance where a healthcare provider was explaining surgery details to her and medical terminology became an obstacle to understanding: *“I told him, I said stop. I realize that I'm just about to go in to have very serious surgery. And how the way you're describing it, I do not understand anything. And you're not making that. You're not making it any easier. In fact, I'm already scared as is. You're just making it that much more scarier because you're using a whole pile of terms that I don't understand.”*

She shared that asking for plain language was helpful. Our healthcare provider participants stressed the same notion; all of them emphasized in their solutions that plain language was integral to support their patients’ understanding of information (as we will see in the next part of our discussion).

4.1.4. Information Overload as a Source of Noise

There is often an abundance of information available at the end of a healthcare appointment. For instance, on the topic of medication alone, Gabriel shared that information he *could* share may include: previous medications taken, why changes to medication were made, how the medication works, the evolution of medication given and so on. Indeed, our caregiver and patient participants have shared experiences where receiving healthcare information felt overwhelming. As Gabriel noted, it is more important to prioritize the information that the patient needs and wants to know.

When healthcare instructions are supplied in abundance, it can be challenging to focus on individual pieces of information. Marissa shared that during an occupational therapy appointment with her child, she may not remember all ten exercises they complete during the appointment. She noted that her child may also not know the routine for the exercises following the appointment. Further, the clinic does not provide any hand-outs to outline the exercises. In this case, trying to commit each exercise to memory can make it challenging to remember them all.

When patients and caregivers are overloaded by information, these pieces of information can become noise that prevents other signals from being successfully transmitted.

4.1.5. Shortage of Appointment Time as a Source of Noise

We must consider: in order for a message to be replicated by a patient, it first must be successfully transmitted by the healthcare provider. In order for a healthcare provider to successfully send their intended message, they must have time.

Our healthcare providers all agreed there is simply not enough time to speak with patients and their circle of support. Angie shared that the greatest challenge with communicating information to her patients at the end of healthcare visits is running out of time. She noted that sometimes it may be better to share information in a more visual way, but time constraints limit information-sharing to verbal means. In these instances, she notes that the verbal communication may not be as empowering for the patient: *"And then also that it's often more empowering to the circle of support than the person who's being served or the client. Because, again, the person is with us, but the communication based on time may not be geared – it often is not, that recap – is not easily geared to ensuring that the person knows what to expect."*

She adds this is especially relevant when the patient has a disability or ability within the moderate or severe, profound label of intellectual disability and information is more geared to:

“Okay, here's what to expect for the support professionals or the circle of support versus saying to the person, what are your questions towards the end, like at the end. Because of time.”

Gabriel echoed a similar notion, noting that there may be competing interests within the inpatient environment that prevent healthcare providers from actively sharing information in the middle of a hospital admission.

A lack of sufficient time to send a message in an intentional manner can lead to messages that are rushed, reduced or misaligned with the needs of patients. This may lead to challenges for receivers as they try to replicate the message.

Indeed, all patient and caregiver participants stressed that it is important to have enough time to speak with healthcare providers although sometimes, interactions may feel rushed. Steph shared that when doctors rush through appointments, it can feel hard to get through everything she wants to discuss. Other caregiver and patient participants echoed this notion. Further, understanding the doctor and getting time to ask questions is key to building mutual knowledge and ensuring that patients and caregivers are replicating the message being transmitted by their providers correctly. Thus, a sufficient amount of time to both send and receive the message may determine the receiver’s ability to successfully replicate a message.

4.2. Speculative Optimization of Communication Channels

We now consider our second objective through the lens of information theory.

Objective 2: Understand what factors make communication effective or ineffective and what factors may contribute to cognitive or sensory overload, or other related challenges.

Recall that successful communication occurs when the message received is identical to the message that was sent (Shannon & Weaver, 1949). Indeed, a noisy channel of communication reduces the odds of successful communication. In this study, patients, caregivers and healthcare providers developed co-designed solutions that minimized noise and optimized the clarity of their communication channels. Thus, to reframe Objective 2, we will shift our focus to consider how participants conceptualized optimized channels for sharing and receiving healthcare instructions with minimal noise.

4.2.1. Optimized Caregiver Solutions

When planning to attend a doctor's appointment, caregivers consider the logistical and emotional aspects of different phases of an appointment. Their unique role in advocating for and supporting those that they care for appeared to influence their approach to co-design.

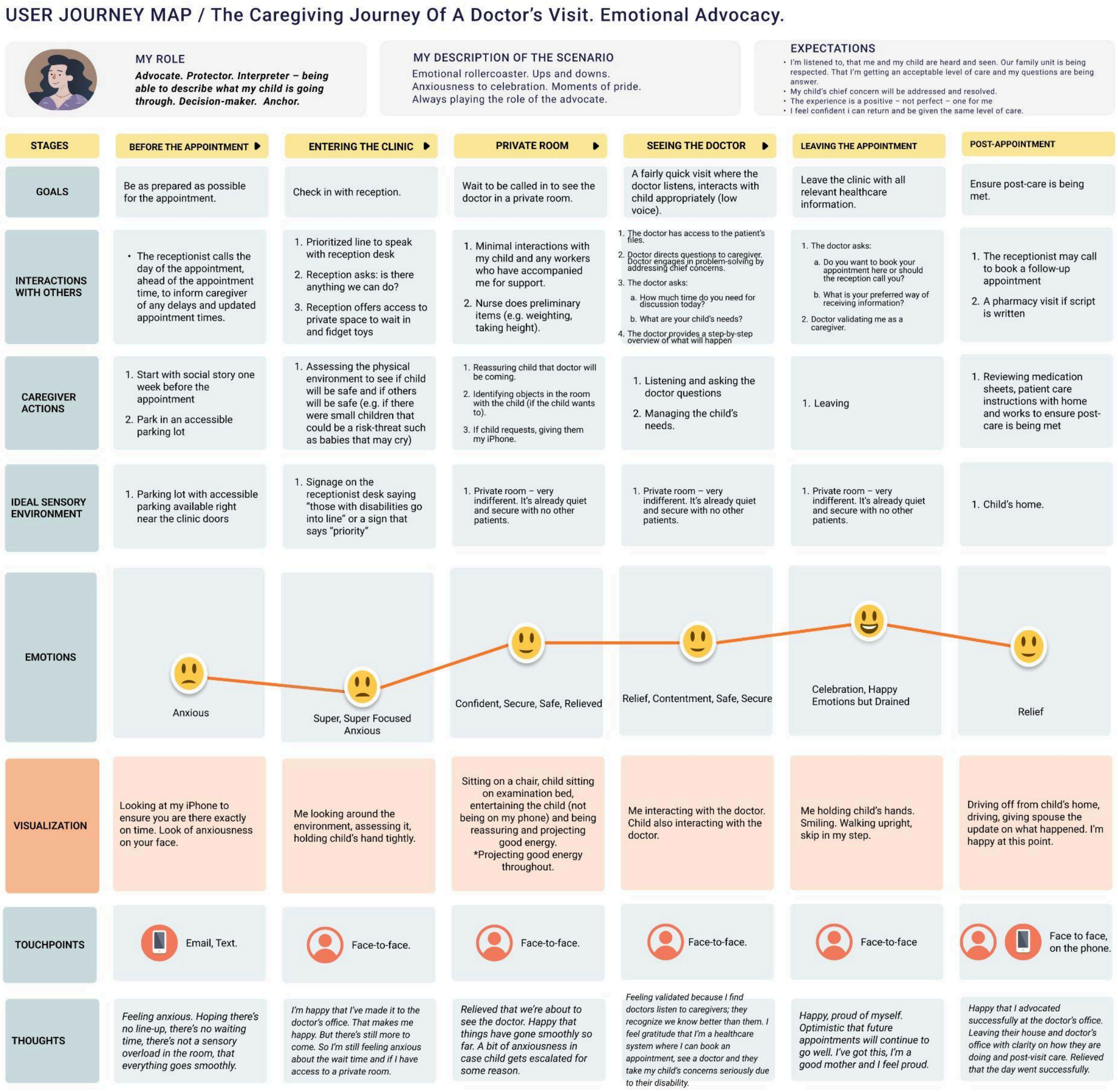
When prompted to create a solution during co-design activities, caregivers reflected on their experiences as shared during the semi-structured interviews. The graduate researcher shared various options for creating a solution and all caregivers initially opted to use Microsoft Whiteboard to conceptualize their ideal experience to the doctor's office. As information grew, we introduced a journey map template to help organize participants' thoughts.

Indeed, in her journey map, Liz described her role: *Advocate. Protector. Interpreter – being able to describe what my child is going through. Decision-maker. Anchor.*

Marissa opted to describe her role as: *To share information and receive information.*

Kelly shared similar thoughts during her interview, commenting that *"as a parent, a caregiver, you, you are with your child, you know, the majority of the time."* In light of that, there sometimes is a need to tell healthcare providers when something is not going to work, and part of her role is communicating that.

Liz's journey map emphasizes the emotional journey associated with going to a doctor's office. Her map is titled "*The Caregiving Journey of a Doctor's Visit. Emotional Advocacy.*"



USER JOURNEY MAP / The Caregiving Journey Of A Doctor's Visit. Emotional Advocacy.

MY ROLE

Advocate. Protector. Interpreter – being able to describe what my child is going through. Decision-maker. Anchor.

MY DESCRIPTION OF THE SCENARIO

Emotional rollercoaster. Ups and downs.
Anxiousness to celebration. Moments of pride.
Always playing the role of the advocate.

EXPECTATIONS

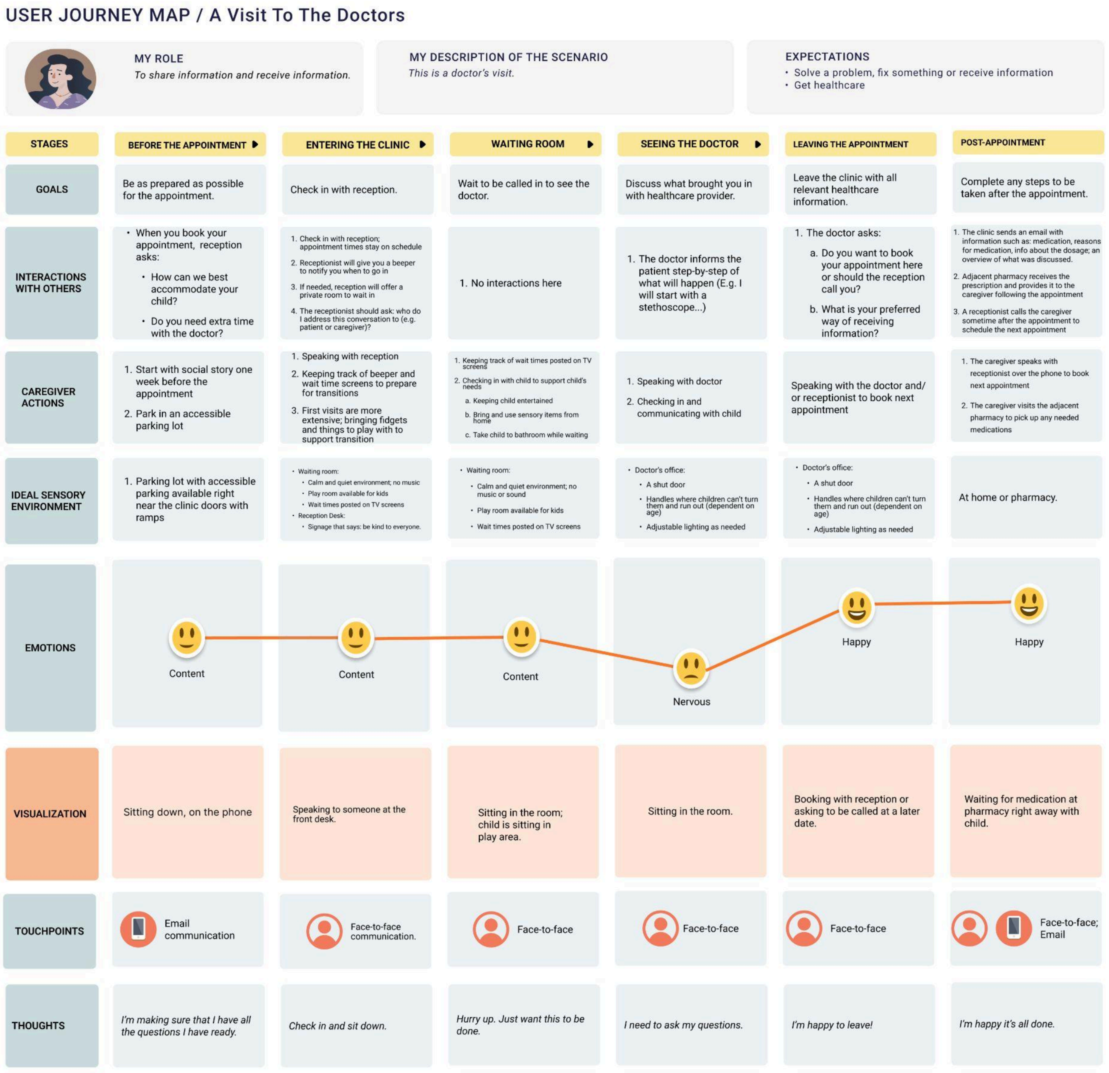
- I'm listened to, that me and my child are heard and seen. Our family unit is being respected. That I'm getting an acceptable level of care and my questions are being answer.
- My child's chief concern will be addressed and resolved.
- The experience is a positive – not perfect – one for me
- I feel confident i can return and be given the same level of care.

STAGES	**BEFORE THE APPOINTMENT** ▶	**ENTERING THE CLINIC** ▶	**PRIVATE ROOM** ▶	**SEEING THE DOCTOR** ▶	**LEAVING THE APPOINTMENT**	**POST-APPOINTMENT**
GOALS	Be as prepared as possible for the appointment.	Check in with reception.	Wait to be called in to see the doctor in a private room.	A fairly quick visit where the doctor listens, interacts with child appropriately (low voice).	Leave the clinic with all relevant healthcare information.	Ensure post-care is being met.
INTERACTIONS WITH OTHERS	• The receptionist calls the day of the appointment, ahead of the appointment time, to inform caregiver of any delays and updated appointment times.	1. Prioritized line to speak with reception desk 2. Reception asks: is there anything we can do? 3. Reception offers access to private space to wait in and fidget toys	1. Minimal interactions with my child and any workers who have accompanied me for support. 2. Nurse does preliminary items (e.g. weighting, taking height).	1. The doctor has access to the patient's files. 2. Doctor directs questions to caregiver. Doctor engages in problem-solving by addressing chief concerns. 3. The doctor asks: a. How much time do you need for discussion today? b. What are your child's needs? 4. The doctor provides a step-by-step overview of what will happen	1. The doctor asks: a. Do you want to book your appointment here or should the reception call you? b. What is your preferred way of receiving information? 2. Doctor validating me as a caregiver.	1. The receptionist may call to book a follow-up appointment 2. A pharmacy visit if script is written
CAREGIVER ACTIONS	1. Start with social story one week before the appointment 2. Park in an accessible parking lot	1. Assessing the physical environment to see if child will be safe and if others will be safe (e.g. if there were small children that could be a risk-threat such as babies that may cry)	1. Reassuring child that doctor will be coming. 2. Identifying objects in the room with the child (if the child wants to). 3. If child requests, giving them my iPhone.	1. Listening and asking the doctor questions 2. Managing the child's needs.	1. Leaving	1. Reviewing medication sheets, patient care instructions with home and works to ensure post-care is being met
IDEAL SENSORY ENVIRONMENT	1. Parking lot with accessible parking available right near the clinic doors	1. Signage on the receptionist desk saying "those with disabilities go into line" or a sign that says "priority"	1. Private room – very indifferent. It's already quiet and secure with no other patients.	1. Private room – very indifferent. It's already quiet and secure with no other patients.	1. Private room – very indifferent. It's already quiet and secure with no other patients.	1. Child's home.
EMOTIONS	Anxious	Super, Super Focused Anxious	Confident, Secure, Safe, Relieved	Relief, Contentment, Safe, Secure	Celebration, Happy Emotions but Drained	Relief
VISUALIZATION	Looking at my iPhone to ensure you are there exactly on time. Look of anxiousness on your face.	Me looking around the environment, assessing it, holding child's hand tightly.	Sitting on a chair, child sitting on examination bed, entertaining the child (not being on my phone) and being reassuring and projecting good energy. *Projecting good energy throughout.	Me interacting with the doctor. Child also interacting with the doctor.	Me holding child's hands. Smiling. Walking upright, skip in my step.	Driving off from child's home, driving, giving spouse the update on what happened. I'm happy at this point.
TOUCHPOINTS	Email, Text.	Face-to-face.	Face-to-face.	Face-to-face.	Face-to-face	Face to face, on the phone.
THOUGHTS	*Feeling anxious. Hoping there's no line-up, there's no waiting time, there's not a sensory overload in the room, that everything goes smoothly.*	*I'm happy that I've made it to the doctor's office. That makes me happy. But there's still more to come. So I'm still feeling anxious about the wait time and if I have access to a private room.*	*Relieved that we're about to see the doctor. Happy that things have gone smoothly so far. A bit of anxiousness in case child gets escalated for some reason.*	*Feeling validated because I find doctors listen to caregivers; they recognize we know better than them. I feel gratitude that I'm a healthcare system where I can book an appointment, see a doctor and they take my child's concerns seriously due to their disability.*	*Happy, proud of myself. Optimistic that future appointments will continue to go well. I've got this, I'm a good mother and I feel proud.*	*Happy that I advocated successfully at the doctor's office. Leaving their house and doctor's office with clarity on how they are doing and post-visit care. Relieved that the day went successfully.*

Figure 10: A caregiver co-designed output: journey map created by Liz.

Liz's map illustrates a clear connection between the reduction of noise during an appointment and an emotional journey. Over time, as she receives more information and has her concerns addressed, the emotions on her map improve. Before the appointment, her emotional state is described as *anxious,* but post-appointment her map ends with *relief.* The lowest part of the emotional journey is at the stage, *entering the clinic,* which prompts emotional states such as *super, super focused* and *anxious.* Liz notes a need to assess the physical environment to see if her child will be safe, and other children will be safe. The upward spike in her map starts in the next stage, a *private room* (to wait for the doctor in). The removal of overwhelming sensory stimuli and the stability of the controlled private room environment prompts emotional states such as *confident, secure, safe,* and *relieved.* In contrast, uncertainty of the public clinic environment appeared to create noise that prompts distressing emotional states. Liz's map illustrates the impact of noise in the environment on emotions during a doctor's appointment.

In contrast, Marissa's map, titled "A Visit to the Doctors" emphasizes the necessary logistical details needed to create an optimal healthcare visit.



USER JOURNEY MAP / A Visit To The Doctors

MY ROLE
To share information and receive information.

MY DESCRIPTION OF THE SCENARIO
This is a doctor's visit.

EXPECTATIONS
- Solve a problem, fix something or receive information
- Get healthcare

STAGES	BEFORE THE APPOINTMENT	ENTERING THE CLINIC	WAITING ROOM	SEEING THE DOCTOR	LEAVING THE APPOINTMENT	POST-APPOINTMENT
GOALS	Be as prepared as possible for the appointment.	Check in with reception.	Wait to be called in to see the doctor.	Discuss what brought you in with healthcare provider.	Leave the clinic with all relevant healthcare information.	Complete any steps to be taken after the appointment.
INTERACTIONS WITH OTHERS	• When you book your appointment, reception asks: • How can we best accommodate your child? • Do you need extra time with the doctor?	1. Check in with reception; appointment times stay on schedule 2. Receptionist will give you a beeper to notify you when to go in 3. If needed, reception will offer a private room to wait in 4. The receptionist should ask: who do I address this conversation to (e.g. patient or caregiver)?	1. No interactions here	1. The doctor informs the patient step-by-step of what will happen (E.g. I will start with a stethoscope...)	1. The doctor asks: a. Do you want to book your appointment here or should the reception call you? b. What is your preferred way of receiving information?	1. The clinic sends an email with information such as: medication, reasons for medication, info about the dosage; an overview of what was discussed. 2. Adjacent pharmacy receives the prescription and provides it to the caregiver following the appointment 3. A receptionist calls the caregiver sometime after the appointment to schedule the next appointment
CAREGIVER ACTIONS	1. Start with social story one week before the appointment 2. Park in an accessible parking lot	1. Speaking with reception 2. Keeping track of beeper and wait time screens to prepare for transitions 3. First visits are more extensive; bringing fidgets and things to play with to support transition	1. Keeping track of wait times posted on TV screens 2. Checking in with child to support child's needs a. Keeping child entertained b. Bring and use sensory items from home c. Take child to bathroom while waiting	1. Speaking with doctor 2. Checking in and communicating with child	Speaking with the doctor and/or receptionist to book next appointment	1. The caregiver speaks with receptionist over the phone to book next appointment 2. The caregiver visits the adjacent pharmacy to pick up any needed medications
IDEAL SENSORY ENVIRONMENT	1. Parking lot with accessible parking available right near the clinic doors with ramps	• Waiting room: • Calm and quiet environment; no music • Play room available for kids • Wait times posted on TV screens • Reception Desk: • Signage that says: be kind to everyone.	• Waiting room: • Calm and quiet environment; no music or sound • Play room available for kids • Wait times posted on TV screens	• Doctor's office: • A shut door • Handles where children can't turn them and run out (dependent on age) • Adjustable lighting as needed	• Doctor's office: • A shut door • Handles where children can't turn them and run out (dependent on age) • Adjustable lighting as needed	At home or pharmacy.
EMOTIONS	Content	Content	Content	Nervous	Happy	Happy
VISUALIZATION	Sitting down, on the phone	Speaking to someone at the front desk.	Sitting in the room; child is sitting in play area.	Sitting in the room.	Booking with reception or asking to be called at a later date.	Waiting for medication at pharmacy right away with child.
TOUCHPOINTS	Email communication	Face-to-face communication.	Face-to-face	Face-to-face	Face-to-face	Face-to-face; Email
THOUGHTS	*I'm making sure that I have all the questions I have ready.*	*Check in and sit down.*	*Hurry up. Just want this to be done.*	*I need to ask my questions.*	*I'm happy to leave!*	*I'm happy it's all done.*

Figure 11: A caregiver co-designed output: journey map created by Marissa.

Marissa noted that the best way to reduce uncertainty during a visit is to discuss the need for any accommodations ahead of the appointment by speaking with reception. During the stage, *entering the clinic,* she highlighted the need for appointments to start at the time they are scheduled. Marissa's map illustrates a need for well-executed planning on both the caregivers and healthcare provider's side. By doing so, her solution aims to minimize noise before the appointment begins.

Although Kelly's research sessions were completed prior to the commencement of journey-map making with similar templates as seen above, her fundamental journey map highlights the similar importance of efficiency.

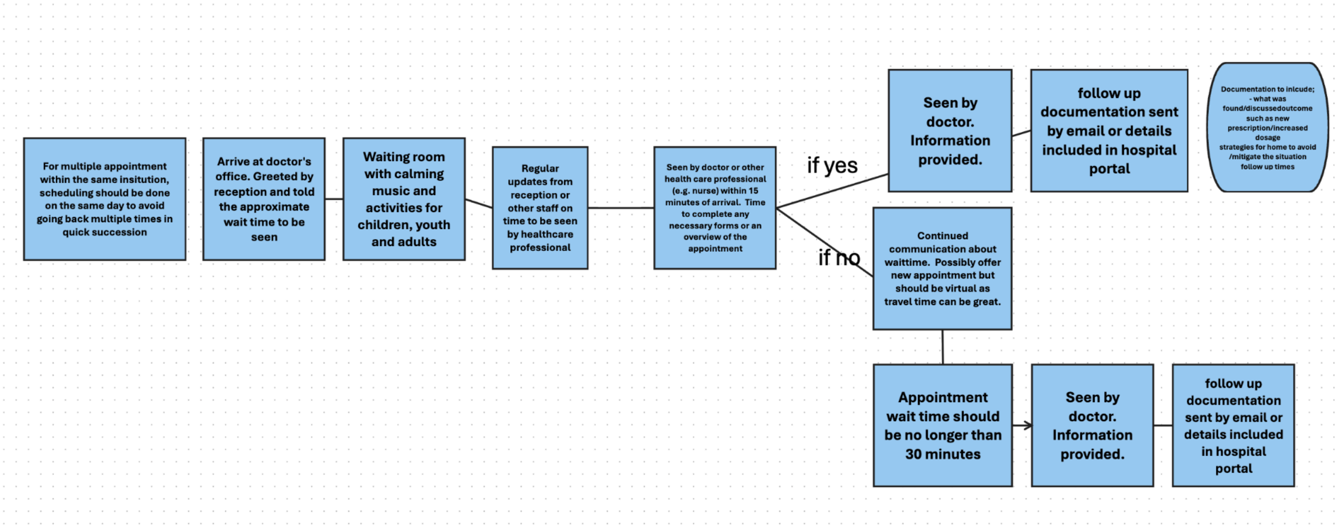


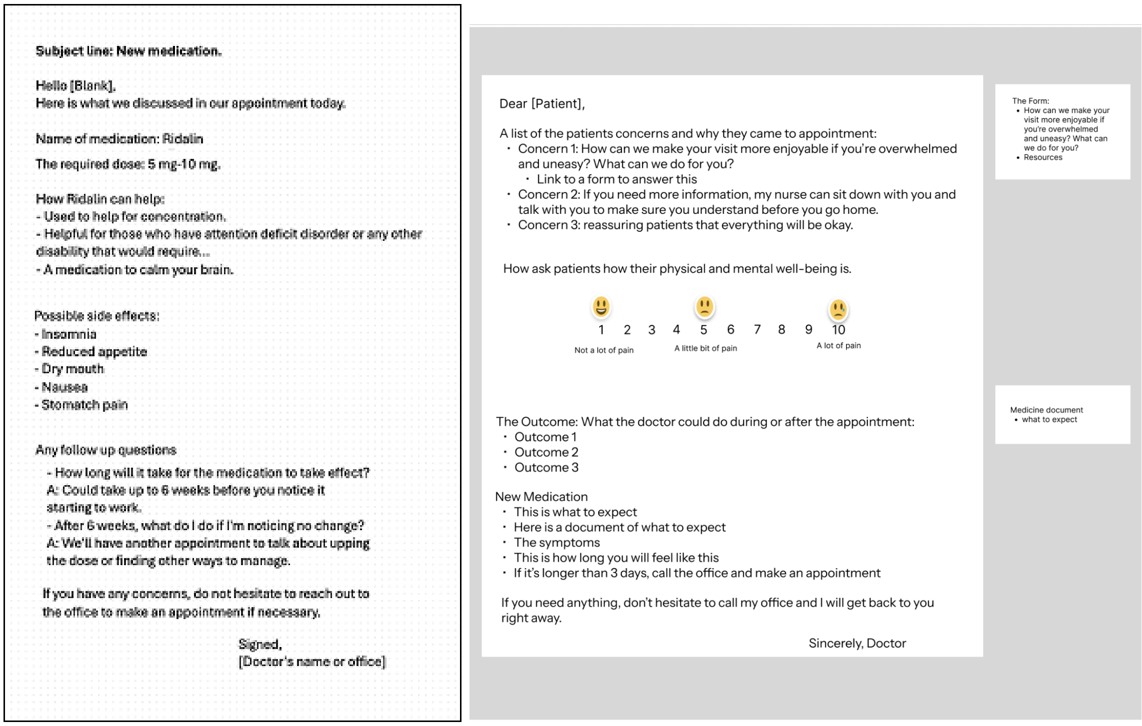
Figure 12: A caregiver co-designed output: fundamental journey map created by Kelly.

Kelly notes that if there are multiple appointments that need to be scheduled within the same institution, they should be scheduled on the same day to avoid the need to come back multiple times in quick succession. Further, her map emphasizes the importance of a short wait-time, branching out into two separate sections. Wait times over fifteen minutes should lead to an update on the wait time and a potential offer to reschedule the appointment to be virtual. No appointment should require a wait-time longer than half an hour.

Overall, the caregivers' co-designed solutions lend great insight into how the holistic journey of a visit to a doctor's office may include various encounters with noise as result of overwhelming sensory environments, a lack of pre-planning and inefficiency. These solutions emphasize the importance of stable sensory environments, planning ahead of time and efficient communication during appointments as methods to respond to noise in clinical settings.

4.2.2. Optimized Patient Solutions

Sarah J. and Steph's solutions involved journey mapping (see Appendix A and Appendix B) that ultimately led to the design of an optimized email template that both participants shared they would like to receive following a healthcare appointment.



Subject line: New medication.

Hello [Blank],
Here is what we discussed in our appointment today.

Name of medication: Ridalin

The required dose: 5 mg-10 mg.

How Ridalin can help:
- Used to help for concentration.
- Helpful for those who have attention deficit disorder or any other disability that would require...
- A medication to calm your brain.

Possible side effects:
- Insomnia
- Reduced appetite
- Dry mouth
- Nausea
- Stomatch pain

Any follow up questions
- How long will it take for the medication to take effect?
A: Could take up to 6 weeks before you notice it starting to work.
- After 6 weeks, what do I do if I'm noticing no change?
A: We'll have another appointment to talk about upping the dose or finding other ways to manage.

If you have any concerns, do not hesitate to reach out to the office to make an appointment if necessary.

Signed,
[Doctor's name or office]

Dear [Patient],

A list of the patients concerns and why they came to appointment:
- Concern 1: How can we make your visit more enjoyable if you're overwhelmed and uneasy? What can we do for you?
  - Link to a form to answer this
- Concern 2: If you need more information, my nurse can sit down with you and talk with you to make sure you understand before you go home.
- Concern 3: reassuring patients that everything will be okay.

How ask patients how their physical and mental well-being is.

1 2 3 4 5 6 7 8 9 10

Not a lot of pain · A little bit of pain · A lot of pain

The Outcome: What the doctor could do during or after the appointment:
- Outcome 1
- Outcome 2
- Outcome 3

New Medication
- This is what to expect
- Here is a document of what to expect
- The symptoms
- This is how long you will feel like this
- If it's longer than 3 days, call the office and make an appointment

If you need anything, don't hesitate to call my office and I will get back to you right away.

Sincerely, Doctor

The Form:
- How can we make your visit more enjoyable if you're overwhelmed and uneasy? What can we do for you?
- Resources

Medicine document
- what to expect

Figure 13: Two patient co-designed outputs: email template on left created by Sarah J., email template on right created by Steph.

Both solutions prioritize similar design choices. For instance, both shared a need for textual information not to be overwhelming. Bullet-style text is incorporated in both solutions to make it easier to read through relevant information following an appointment. Both solutions emphasize the importance of plain language, as well as a need for the clinic to offer the option for patients to contact them with any questions or concerns.

In some areas, the solutions differ. Sarah J's solution does not offer links to other documents or forms as Steph's does, instead opting to provide the all essential information in one email. Her unique inclusion of any follow up questions (similar to a Q and A section, she shared), aims to reduce uncertainty around medications' instructions preemptively.

Steph's solution emphasizes the importance of having a doctor check in with patients following the appointment. She incorporates a wellness scale for patients to share feedback with the clinic. The scale ranges from 1-10, where 1 is *not a lot of pain* while 10 is *a lot of pain.* The use of emojis makes it easier to associate emotional states with levels of pain. The incorporation of this feature opens a channel of communication between doctors and patients post-appointment.

Ultimately, these co-designed solutions offer commentary on how post-appointment instructional material can support the transmission of clear healthcare instructions. Plain language and easy-to-read text takes priority in both solutions. Although approached differently, both solutions also preemptively offer opportunities to reduce post-appointment uncertainty by either addressing commonly asked questions in the email text or creating a line of communication through a wellness scale.

4.2.3. Optimized Healthcare Provider Solutions

All healthcare provider participants recognized the importance of sharing information in a medium that supports patients and their circle of care. Angie and Jeff have both found multimodal techniques to be useful to sharing information in a manner that their patients can respond to. Angie's solution emphasizes her multi-modal approach. She created a Canva-styled template for sharing healthcare instructions with her patients that includes visuals, text and videos that she can drag and drop from a pre-made library to share.

During her interview, she emphasized that it is not enough to simply have visuals– you need to have the *right* visuals to effectively support your patients. Medical visuals are often geared towards supporting children, which can make them feel infantilizing when presented to adults. Further, there is a need for medical visuals that do not depict people in distress: *"...It's also being careful of like, a trauma-assumed approach where you don't want to have visuals that are, that can be triggering."* Angie's solution integrates these insights into a drag and drop styled template. Appendix C includes the various frames of her solution.

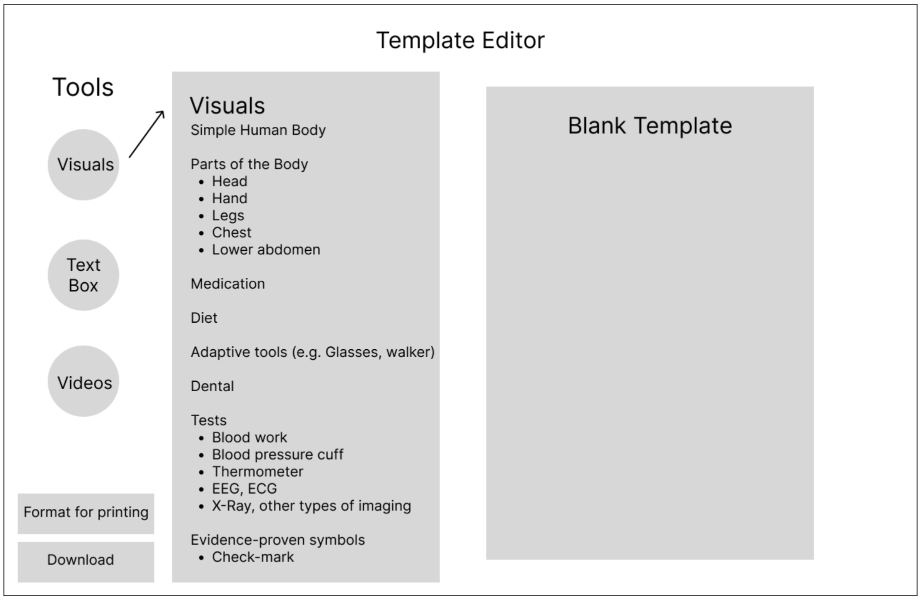
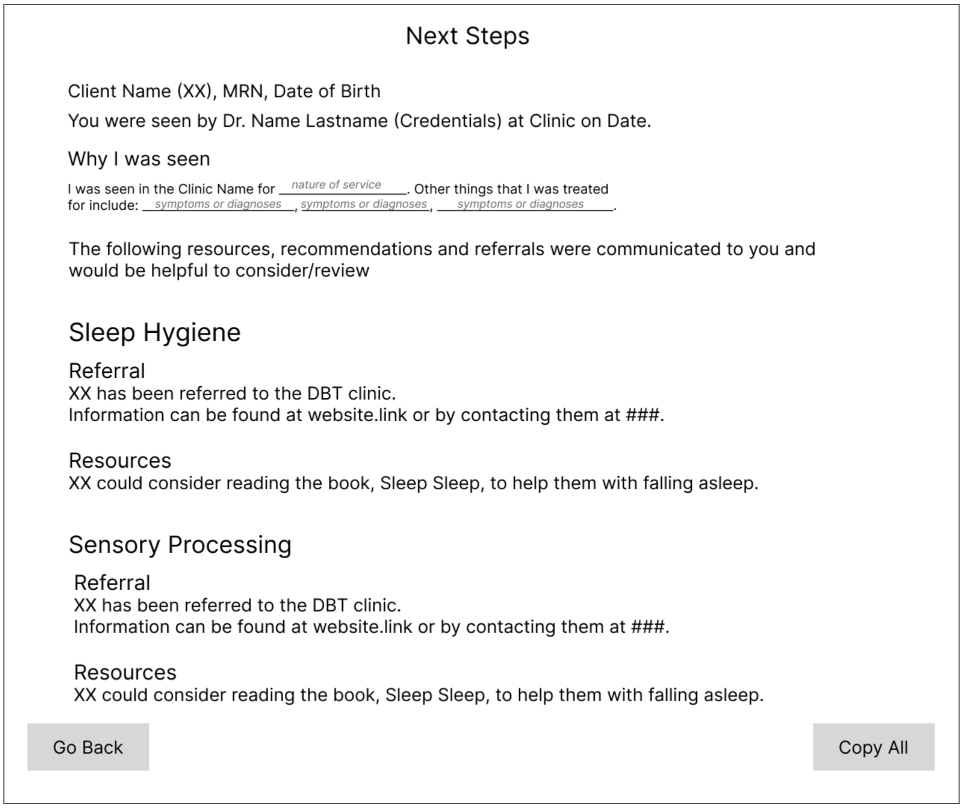


Figure 14: A healthcare provider co-designed output: healthcare instruction template by Angie.

While Jeff's solution does not prioritize visuals, it opts to integrate multimodal instructions by including videos and resource links in an easily accessible format. Jeff emphasized that his solution should be easy-to-read for patients as he leverages plain language and includes the most essential information in his digital health instructions template. Further, his solution takes into account the need to make information easy to input for healthcare providers. Following a three-column approach, Jeff's solution allows healthcare providers to select *Presenting Concerns* from a scrollable list, which autopopulates specific resources, referrals and recommendations that he has previously approved or inputted himself. Appendix D includes the step-by-step process that healthcare providers can work through to create an accessible instructions form in Jeff's co-design solution.



Next Steps

Client Name (XX), MRN, Date of Birth

You were seen by Dr. Name Lastname (Credentials) at Clinic on Date.

Why I was seen

I was seen in the Clinic Name for __nature of service__. Other things that I was treated for include: __symptoms or diagnoses__, __symptoms or diagnoses__, __symptoms or diagnoses__.

The following resources, recommendations and referrals were communicated to you and would be helpful to consider/review

Sleep Hygiene

Referral
XX has been referred to the DBT clinic.
Information can be found at website.link or by contacting them at ###.

Resources
XX could consider reading the book, Sleep Sleep, to help them with falling asleep.

Sensory Processing

Referral
XX has been referred to the DBT clinic.
Information can be found at website.link or by contacting them at ###.

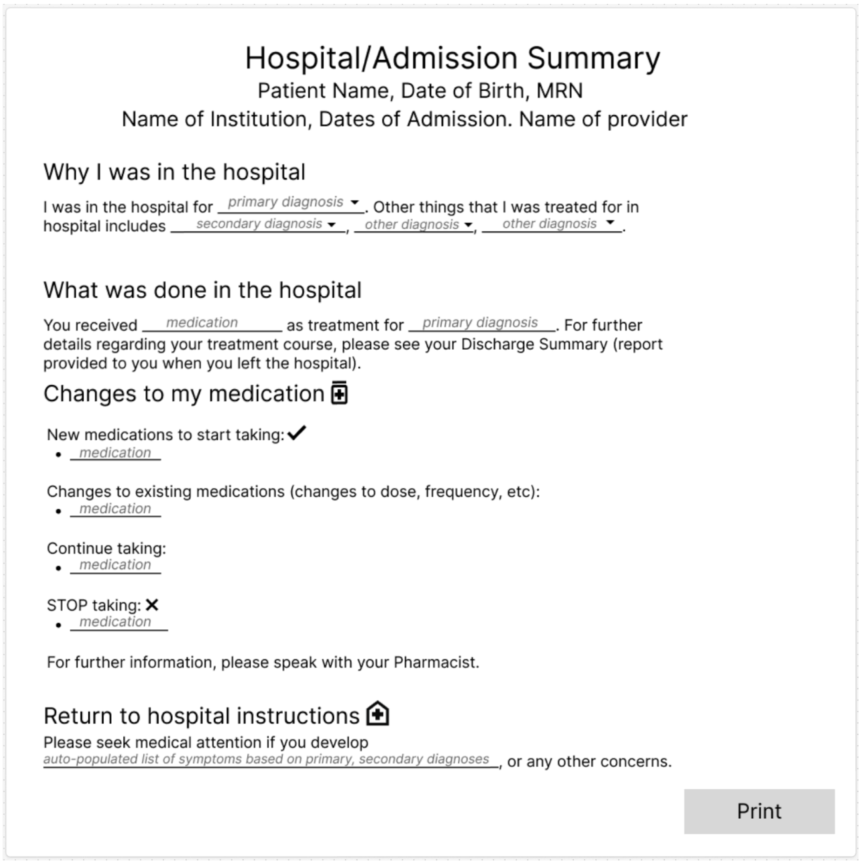
Resources
XX could consider reading the book, Sleep Sleep, to help them with falling asleep.

Figure 15: A healthcare provider co-designed output: healthcare instruction template by Jeff.

Gabriel's solution prioritizes similar aspects as Angie's and Jeff's solutions. Gabriel focuses on plain language and optimizing the discharge sheet so that only the most relevant and necessary information is presented to patients to avoid overwhelming them.

To contextualize his solution, Gabriel noted that there are two types of discharge content created following a patient's stay in the hospital: the discharge summary and the after-visit summary. The discharge summary is geared towards other healthcare providers; it goes into the patient's medical chart that is forwarded to other healthcare providers. It includes information such as medical history, medications a patient is discharged with, summary of the hospital visit, initial diagnosis, follow-up instructions and any other comments. The after-visit summary is an auto-populated form generated by the electronic medical record that does not allow healthcare providers to modify or customize it.

Gabriel's solution aims to strike a balance between both summaries. His solution incorporates a focus on plain language and optimizing the discharge sheet so that only the most relevant and necessary information is presented to patients to avoid overwhelming them. The solution aims to be easy-to-fill for healthcare providers, with autopopulation options allowing for quick input.



Hospital/Admission Summary
Patient Name, Date of Birth, MRN
Name of Institution, Dates of Admission. Name of provider

Why I was in the hospital

I was in the hospital for *primary diagnosis* ▾. Other things that I was treated for in hospital includes *secondary diagnosis* ▾, *other diagnosis* ▾, *other diagnosis* ▾.

What was done in the hospital

You received *medication* as treatment for *primary diagnosis*. For further details regarding your treatment course, please see your Discharge Summary (report provided to you when you left the hospital).

Changes to my medication

New medications to start taking: ✓
- *medication*

Changes to existing medications (changes to dose, frequency, etc):
- *medication*

Continue taking:
- *medication*

STOP taking: ✕
- *medication*

For further information, please speak with your Pharmacist.

Return to hospital instructions

Please seek medical attention if you develop *auto-populated list of symptoms based on primary, secondary diagnoses*, or any other concerns.

Figure 16: A healthcare provider co-designed output: healthcare instruction template by Gabriel.

The healthcare providers' solutions all emphasize the importance of plain language and a prioritization of the most relevant information to avoid overwhelming patients. Their solutions not only reduce noise for patients, but also consider how the ease-of-use of solutions built for providers can improve their transmission of health information. When contrasted to the workload that healthcare providers often undertake to create instructional material for their patients outside of appointments, these solutions offer an efficient and meaningful opportunity for providers to create accessible communication materials without a strenuous workload.

4.3. Reducing Noise in Healthcare Communication

We move to consider our last objective through the lens of information theory, thus setting the stage to consider our model.

Objective 3: Identify an opportunity for a design intervention that addresses communication obstacles in clinical healthcare settings between neurodivergent patients, caregivers and healthcare providers.

In this sense, we are considering: how can we address and mitigate sources of noise? This section considers what patients, caregivers and healthcare providers have done in the past to reduce noise, enable receivers to successfully replicate messages, and overall improve communication.

4.3.1. Training to Support Neurodivergent Patients

Training that aims to support neurodivergent patients and their circles of care can improve the transmission of health information and reduce noise. As noted by our participants, disability training can allow healthcare providers to identify the appropriate amount of time needed to support their patients, answer their questions, and ensure mutual understanding is achieved at the end of a healthcare visit.

The value of a well-trained healthcare professional is demonstrated by anecdotes shared by our participants. Steph shared a good experience with a family doctor who responds to her needs: *"You know, I have a very good family doctor. So I'll bring in a list of 7 to 8 things and she'll give me the time of day and she'll walk me through everything and I'll say all this is* *bothering me and she'll explain it and she'll say, OK, I understand. And she knows that I have autism and a mild intellectual disability."*

Similarly, having a doctor who listens and addresses her concerns makes a huge difference, Sarah J shared: *"In some cases, there's like, in some cases, doctors, you know, they rush you in and they rush you out and they don't care. My doctor, on the other hand, doesn't do that. He takes, he takes the time. He listens. (...) He doesn't rush through things. He makes sure that I'm listened to."*

Caregivers also note the importance of healthcare professionals who demonstrate training that responds to the needs of neurodivergent patients and their circles of care. During her interviews and within her journey map, Liz noted that receptionists as well as doctors should demonstrate disability training so that interactions are catered to the needs of patients and caregivers, and are not rushed. Liz also noted an interest in certifying clinics with staff that are training to support autism: *"...wouldn't that be great to be like: we (the doctors) are autism trained. Our office is autism trained."*

Both Marissa and Kelly agreed that it was important for clinic staff and healthcare providers to have training to better support patients and caregivers. Kelly commented on liking the idea of training that aims to support caregivers. Marissa noted that respect and dignity should be the expectation in all interactions in a clinic.

Healthcare providers also expressed the value of having expertise, tools and resources to help them support their patients. Angie shared the term *adaptive expertise t*o describe how she tailors her resources and approach to individual patient needs. She first learned about the term from the United Health Network and Michener (UHN): *"...it's an expertise that's built through* *experience and knowing how to adapt within the moment to provide some sort of professional response, a supportive response. And it's difficult to describe that when there's a situation where you need to very quickly pull up some sort of response. In that moment, people seem to be able to do it because of their experience and expertise".*

Jeff and Angie both also commented on the beneficial impact of collaborating with other healthcare providers to learn about resources, practices and opportunities to better support their patients.

4.3.2. Multi-modal Instructions

Patients and caregivers express the value of having instructions provided to them across different mediums. The multimodal distribution of health instructions can ensure that if one channel of communication is disrupted by noise, health information can still be successfully transmitted through a different channel. All patient and caregiver participants especially stressed the importance of being provided written material at the end of a visit in addition to verbal instructions.

However, written material may not always be provided as an additional medium for information at the end of appointments. Marissa shared that she had never met a doctor that followed up with details such as the "minutes" of the appointment and noted that it would be helpful since it can be difficult to remember sometimes, especially if there's a new issue. Kelly noted a similar perspective, sharing that she takes notes on her phone during the healthcare visit since there's nothing written down. She then shares these notes with other family members so that the information is available to them.

All caregivers and patient participants agreed that email would be a useful way to receive healthcare information, as indicated in all three journey maps and email template solutions. Liz noted in her journey map that doctors should ask: *how do you prefer to be given this information?* Among other formats discussed, participants agreed that handouts may also be helpful, as well as documentation uploaded to an online portal (a hospital portal, MyChart etc.).

Having information presented in an accessible and comprehensive manner is also important. Documentation may be factual but lack the information that caregivers and patients would like to see. For instance, Kelly notes that sometimes the documentation may include what a prescription is, but not what the prescription is *for*. More discussion-type content is of interest. She notes: *"The caregivers needed to be treated as adult learners in a way…"*

Regarding what information should be present on follow-up documentation, Kelly outlined a list in her journey map that other caregivers agreed with, consisting of:

- What was found/discussed
- Outcome such as new prescription/increased dosage
- Strategies for home to avoid situation/mitigate the situation
- Follow up times

As seen in the co-designed solutions from Section 4.2, patient and healthcare provider participants prioritize similar pieces of information in their ideal of instructional material.

When it comes to supporting their patients' needs, all healthcare providers emphasize that their method of sharing information relies on the needs of their patients. Gabriel noted that he will often learn about the preferences of his patients during their hospital stay, which makes it easy to tailor the discharge information in a way that aligns with their needs at the end of the visit. Jeff shared a similar notion: "*My preferred is their preferred.*"

Angie and Jeff both leverage various techniques to share health information with their patients and their circles of care. Some methods they use include social stories, powerpoint presentations, role-playing, videos and more.

4.3.3. Planning Outside the Visit

While caregivers and patients shared that their experiences with healthcare providers often fell short, our healthcare provider participants demonstrated an active engagement in aiming to better support neurodivergent patients. However, with their attempts to create patient-centred experiences, they also shared challenges with taking on a self-driven workload.

Angie and Jeff both keep a library of resources on their computers, notes and Google Drives that they would build over time and pull from to share resources with their patients. They shared that finding these resources and customizing them to the needs of their patients could be challenging.

Jeff shared, *"I would say I spend anywhere from like an hour to two hours per assessment just picking out the resources and recommendations. So they're tailored to meet like their individual needs, any presenting concerns, and then any labels or diagnoses that are communicated."*

In terms of work completed outside the visit, our healthcare providers shared that they search for supportive resources, try to find the right medium for sharing instructions, customize handouts and resource pages and participate in self-driven learning opportunities to advance their ability and knowledge to support their patients. All of these factors contribute to more patient-centric care. Notably, this initiative is undertaken by the healthcare providers in addition to their regular workload.

When asked how much he feels supported in all his efforts to support his patients, Jeff shared: *“Like not as supported as I should be. I think most times I hit like administrative red tape or like hospitals are just slow to evolve with technology and systems levels change. So incorporating like even something like [my solution], like this would take like a year to get approved. Like, it's just like such a simple thing in theory, but like for a hospital to be able to like green light it and allow clinicians to use it, just, it can be such an agonising uphill battle that sometimes it's just like, it feels like it's not even worth it (...) I'd rather just like do my own extra work and like, take on more work just to do it myself. So oftentimes I'm like hoping for more top-down solutions instead of me having to drive these changes because advocating for change in a hospital can be like a job in and of itself.”*

4.3.4. Predictability & Continuity of Care

A lack of predictability is associated with uncertainty. For instance, as discussed earlier, extensive wait times can be anxiety-inducing for patients and caregivers. All caregivers and patients shared that they would like to have access to wait time updates to reduce the uncertainty around their wait until their appointment begins.

There appears to be a threshold for how long patients and caregivers are to bear the unpredictability of wait times. If an appointment gets delayed by over fifteen minutes, Kelly prefers that the reception offer to reschedule, as noted in her journey map. Liz shared that it would be preferable if the receptionist can call ahead of time to share any delays, while Marissa noted in her journey map that the ideal is for “appointment times [to] stay on schedule”.

Other ideas to mitigate this source of noise included changes in the physical environment to reduce wait time. Liz and Kelly caregivers expressed interest in the idea of including a priority sign in the waiting room for those with disabilities to be seen earlier, while Marissa cautioned that this could single people out and force them to self-identify, which can be discriminatory. Marissa mentioned having a beeper to update wait times can be useful, as is done in one of the clinics she visits. Similarly, she notes that having wait times displayed on screens reduces uncertainty on when the appointment will begin.

Beyond the wait time, there is value in having a predictable continuity of care. Sarah J. notes that seeing the same doctor each time is important because the doctor gets to know your preferences and needs. Having a new doctor can disrupt that connection: *“So, if you go to a follow-up appointment and it's a completely different doctor, then you have to, then you have to basically, you almost have to backtrack and re-establish that, re-establish that connection (...) it's a challenge for anybody, but it's equally more challenging for someone who has a disability.”*

Continuity of care may also extend across different healthcare visits with different physicians. Kelly notes that a challenge with having documentation uploaded to a digital portal is that different clinics and institutions may have different portals: “*So for example, Sunnybrook and Toronto General (...) their systems don't sync. Yeah. So you have to go into two different systems to try and figure out what's going on.”* Ideally, healthcare instructions are provided in one place to improve ease of access to information.

5. Discussion

Through our examination of data, we have considered:

1. What are sources of noise in the healthcare environment?
2. How can we optimize communication channels to support sharing and receiving healthcare instructions with minimal noise?
3. What can address and mitigate sources of noise?

We now move to a reflection on the themes discussed above and propose models that reconsider how we approach understanding and improving healthcare the delivery of instructions at the end of healthcare visits.

5.1.1. A Model for Understanding and Responding to Noise

We know that information exchange involves two parties: a *transmitter* and a *receiver* (Shannon & Weaver, 1949). The transmitter is responsible for transmitting the information, while the receiver handles its reception (Shannon & Weaver, 1949). Transmitters send information over *channels*, which are mediums to communicate the information (i.e. email) (Shannon & Weaver, 1949). In the context of communicating instructions at the end of healthcare visits, healthcare providers, patients and caregivers may switch between the roles of transmitters and receivers, while the method for information transfer may be considered the channel.

During our examination of data, we saw that noise can exist in two categories:

1. The noise that can be easily acted upon by the individual (More Controllable Noise)

2. The noise that cannot be easily acted upon by the individual (Less Controllable Noise)

We note that level of control is a spectrum. Some forms of noise can be more easily acted upon than others. For instance, *wait time* is a source of noise that can produce emotions such as anxiety, as noted by Liz, Sarah J. and other participants. Anxiety can make it difficult to focus on listening to healthcare instructions. In this instance, *anxiety* is considered noise that disrupts the transmission of the healthcare instructions. Kelly suggested taking action against this noise by asking for an update on wait time. Thus, in this context, *anxiety* is considered a noise that the receiver of information can easily act on; it is a more controllable noise.

In a similar way, a shortage of appointment time can be considered a source of noise. Shortage of time contributes to the compression of information, thus distorting the original message. However, workforce shortages and a rising demand for healthcare services put healthcare providers on tight schedules (Duong & Vogel, 2023). A quick delivery of information becomes a necessity. In this instance, neither the healthcare provider nor patients and caregivers can easily act upon the systemic origin of the source of noise. Therefore, it is considered a less controllable noise.

In addition, we have learned that noise exists in two states:

1. Noise exists in the individual's mind (Internal Noise)
2. Noise exists in the outside world (External Noise)

Similar to control, internal versus external noise exists on a spectrum. *Anxiety, stress* and *uncertainty* exist as emotional states that are present inside an individual's mind. They mainly manifest inside a person’s state of mind (although these manifestations may bleed into the external world), thus placing them on the spectrum closer to internal noise.

In contrast, environmental factors and physical challenges during interactions with others can be observed in the outside world, although they may have internal repercussions. These forms of noise can be considered closer to external noise.

At any given point, noise must exist in one of two states, and fit within one of two categories. Thus, we end up with:

1. Less controllable external noise
2. More controllable internal noise
3. Less controllable internal noise
4. More controllable external noise

Each type of noise requires a different type of intervention.

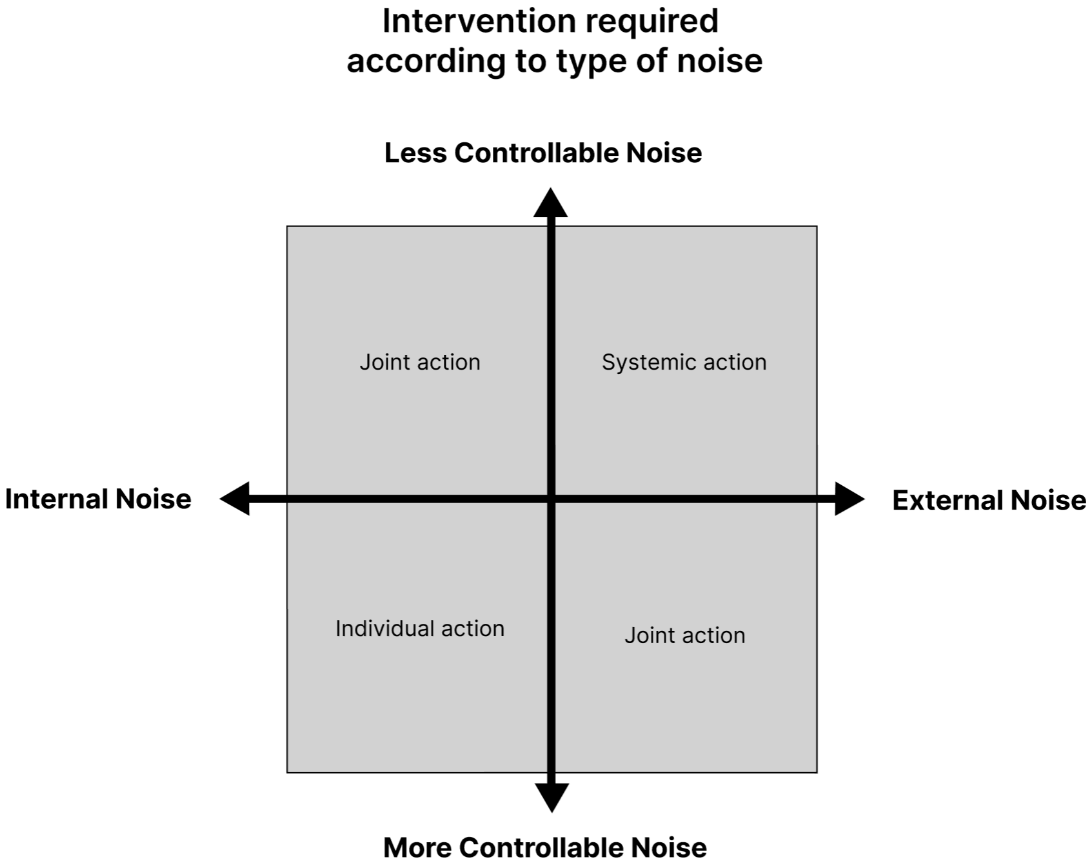


Figure 17: Intervention required according to type of noise

More controllable internal noise requires ***individual action*****.** For example, if somebody is encountering a wave of manageable anxiety as they wait for their appointment, they may use tools at their disposal to lessen this anxiety. These tools may be a fidget toy or a technique, such as deep breathing. Alternatively, they may ask the receptionist for an update on wait time. In this instance, the individual is taking action to remove internal noise. Any interactions with the external environment (e.g. a fidget toy or an inquiry to the receptionist) are initiated by the individual. In this case, the receptionist may provide information that elevates the feelings of anxiety, but the receptionist’s intention is not to participate in noise-mitigation. Instead, they are simply responding to the patient’s inquiry. Their lack of intentionality puts the onus on the individual to mitigate the internal noise. Thus, individual action can serve as an opportunity to remove the more controllable internal noise and enable the patient to receive information.

On the other hand, we have ***less controllable internal noise*** which requires ***joint action***. If a patient is encountering a mounting and unmanageable anxiety over an impending blood test which makes it difficult to listen to the doctor, joint intervention is useful. In this instance, the patient may take action by expressing their worries about the test, while the doctor takes action by addressing their concerns. The doctor engages with the patient with the intention of mitigating their internal noise. Thus, joint action occurs. Similarly, ***more controllable external noise*** warrants ***joint action.*** If a patient finds that the light pouring through the windows of the clinic are too bright for them to focus on their communication with their doctor, the patient may ask for the curtains to be closed. The doctors may respond by closing the curtains, effectively removing the noise.

The distinction between individual action and joint action can be made clear by considering shared intentionality. Recall that when an individual shares their psychological states with another person, they are able to participate in collaborative and social activities according to Tomasello et al.’s (2005) definition of shared intentionality. During individual action, the person experiencing noise does not share that they are encountering noise. Thus, anyone that they interact with cannot intentionally support them with noise-mitigation. In contrast, joint action requires an individual to share their experience of noise with another person. This enables both parties to work together on noise mitigation, thus classifying this form of intervention as joint action.

We now move to consider ***less controllable external noise,*** which requires ***systemic action.*** The word *system* is relevant because intervention requires system intervention in some capacity. The healthcare system is complex; it involves overlapping decision-makers and stakeholders who can act to varying degrees to enact change. Consider the example of medical jargon as noise. Healthcare providers are formally trained to be proficient with medical jargon. This training may lead to encounters with patients where a healthcare provider's reliance on medical jargon acts as noise, preventing a patient who is unfamiliar with the complex terminology from understanding the information being transmitted. Addressing this source of noise requires the healthcare provider to actively learn and practice patient-centric language. There arises a subsequent need for the system to support these efforts through the allocation of time, resources and potentially social support. Further, system-level change may be warranted to address the greater, overarching issue where healthcare providers are not given the tools to use patient-centric language from the start.

Systemic intervention requires action from various actors. These actors may include health policy-makers, supervisory staff, financial stakeholders and more. A lack of system support can prevent providers from taking action to mitigate the noise given that healthcare providers are facing heavier workloads, longer working hours and inflexible schedules that contribute to a lack of capacity to take on additional work beyond their prescribed duties (Canadian Academy of Health Sciences, 2023).

This model enables us to consider how to identify the most appropriate intervention required to address different forms of noise. We now dive deeper in an exploration of systemic action in response to less controllable external noise, the burden it places upon healthcare providers, and opportunities to lighten this workload.

5.1.2. A Proposal for Addressing Noise Requiring Systemic Intervention

Systemic action seeks to respond to complex problems that may be categorized under less controllable external noise. Unlike joint actions that can be enacted through collaboration between a person experiencing the noise and another party, systemic action demands the active participation of system stakeholders to support noise mitigation.

Healthcare providers often take on the responsibility and burden to trigger systemic action. At the forefront of patient and caregiver interactions, healthcare providers are best suited to identify sources of noise that interfere with their delivery of healthcare instructions and subsequently strive to implement solutions. In our study, we found that our provider participants enacted systemic action to address noise by undertaking a self-driven workload outside of the interactions they have with their patients. Tasks such as searching for resources, developing tailored instructional sheets and learning from other professionals require a considerable amount of resources and effort from our participants. Yet they carve out time in their busy schedules to find better ways to support their neurodivergent patients and circles of care. Angie and Jeff carefully curate lists of resources and instructional material to ensure their patients are well-supported. Gabriel learns more about his patients during their hospital stay to better understand their preferences for information during their discharge. These efforts involve system engagement through a reallocation of time, effort and resources. Stakeholders such as other healthcare professionals, supervisory staff and organizational units may be involved in activities like these through discussions, collaboration efforts and approvals. Even so, the burden to enact system change leads to a considerable workload on healthcare providers that must be undertaken outside of healthcare visits.

We posit that there are ***five steps to enacting systemic action*** within a healthcare context. Given the example of medical jargon in the section above, a healthcare provider may navigate this model accordingly:

1. **Identify the source of noise.** The healthcare provider realizes that their use of complex medical terminology is preventing the comprehension of instructions among their patients.

2. **Identify the action required to mitigate the noise.** The healthcare provider must recognize the need and demand for plain language alternatives to sharing healthcare instructions. They must identify an appropriate action such as patient-centred language training opportunities.

3. **Acquire the system support required to engage in the action.** The healthcare provider must interact with relevant stakeholders (i.e. supervisory staff) to secure the approvals, time and resources to support the execution of training.

4. **Engage in the action(s) required to mitigate the noise.** The healthcare provider must participate in the necessary training.

5. **Apply the action's outcome into practice.** The healthcare provider must apply the skills they acquire during training to their appointments with their patients.

    - ↪ If the application of the action does not support the intended outcome, the healthcare provider will need to revisit an earlier step. For instance, the provider may find that the appropriate training was not acquired and patients still struggle to understand them, thus returning to step two.

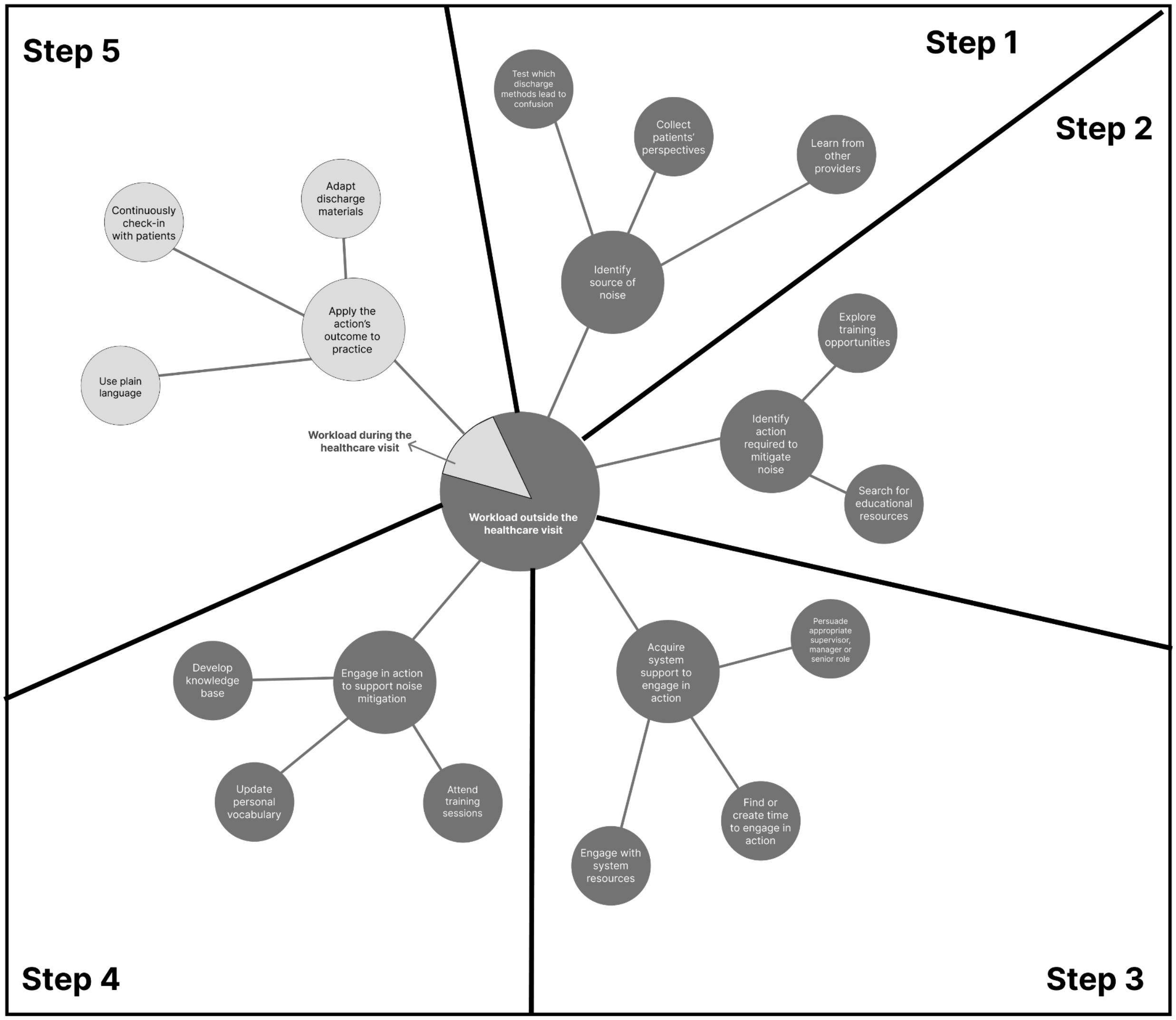


Figure 18: A healthcare provider's journey through the five steps to enacting systemic action with the example of seeking training to reduce noise created by a reliance on medical jargon.

The example illustrates how system-driven training that relies on medical jargon can create noise during the transmission of health information which can then be mitigated through re-engagement with the system. Thus, systemic action becomes helpful for addressing less controllable external noise.

It is worth noting that the process for enacting systemic action may be lengthy and strenuous. Securing approvals, collaborating with other professionals and identifying the right avenues to mitigate this form of noise can be time-consuming. As noted before, these actions take place in addition to a healthcare provider's workload dedicated to seeing their patients. Hence, we put forward the question: what if we reallocated the responsibility of enacting systemic action?

Indeed, there exists an opportunity to reallocate the workload that healthcare providers undertake to enact systemic change. This opportunity becomes clear as we reflect on the five steps to enact systemic action and note its similarities to the stages of a design thinking process. While there are countless variations of design lifecycles used in industry and academia today, we consider Stanford University's Hasso Plattner Institute of Design's framework for our purposes.

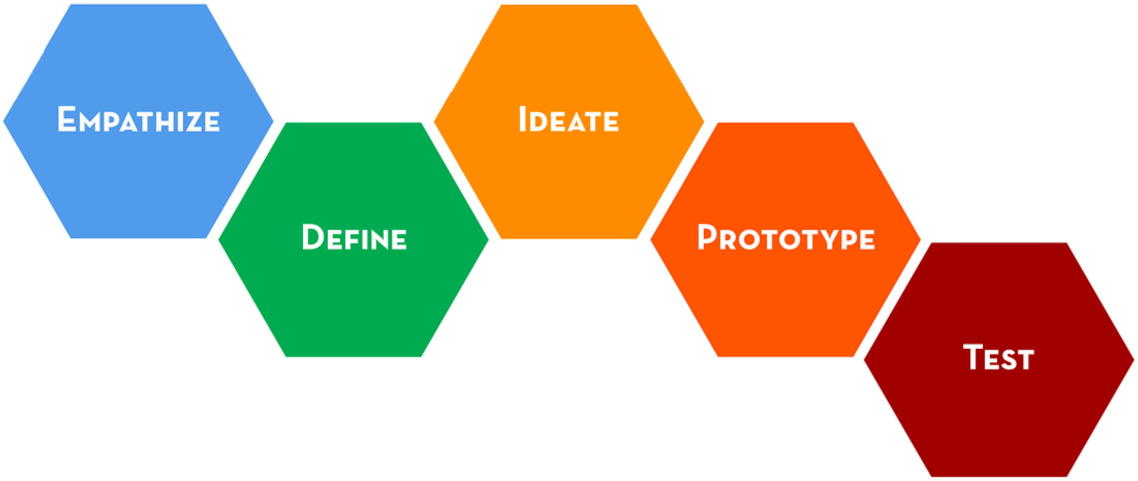


Figure 19: Stanford University's Hasso Plattner Institute of Design's Design Thinking Process (n.d.)

Consider: designers are required to *empathize* with the audience they design for (Stanford University's Hasso Plattner Institute of Design, n.d.). Identification of a source of noise requires healthcare providers to similarly empathize with their patients to understand what their needs are. *Defining the problem* is the next stage, which involves establishing the precise problem space (Stanford University's Hasso Plattner Institute of Design, n.d.). Healthcare providers then move to identify the appropriate action to mitigate a source of noise, as well as take actions to acquire system support. This process requires *ideation* of potential opportunities to support noise mitigation. Next, healthcare providers engage in the action required to support the noise mitigation – such as undergoing patient-centric training. This may be likened to the process of designing the solution – more specifically, *prototyping.* In the end, providers apply the outcomes of their actions to their interactions with patients. Depending on the success of this application, they may revisit a previous step. These steps are similar to *testing and iterating* a design solution.

We posit that healthcare providers take on the role of designers when they enact systemic action. In other words, providers are taking on an additional role to their own in these instances. Once again, given the heavy workloads and tight schedules that healthcare providers encounter, it is understandable that not every provider will have the capacity to enact systemic change (Duong & Vogel, 2023).

In light of the overlap between a design thinking process and the steps required to enact systemic action, designers appear to be well-suited to support the workload undertaken by healthcare providers outside of their interactions with patients. We posit that an active collaboration between designers and healthcare providers may reduce workloads on healthcare providers and enable designers to support the execution of systemic action to mitigate less controllable external noise in healthcare environments.

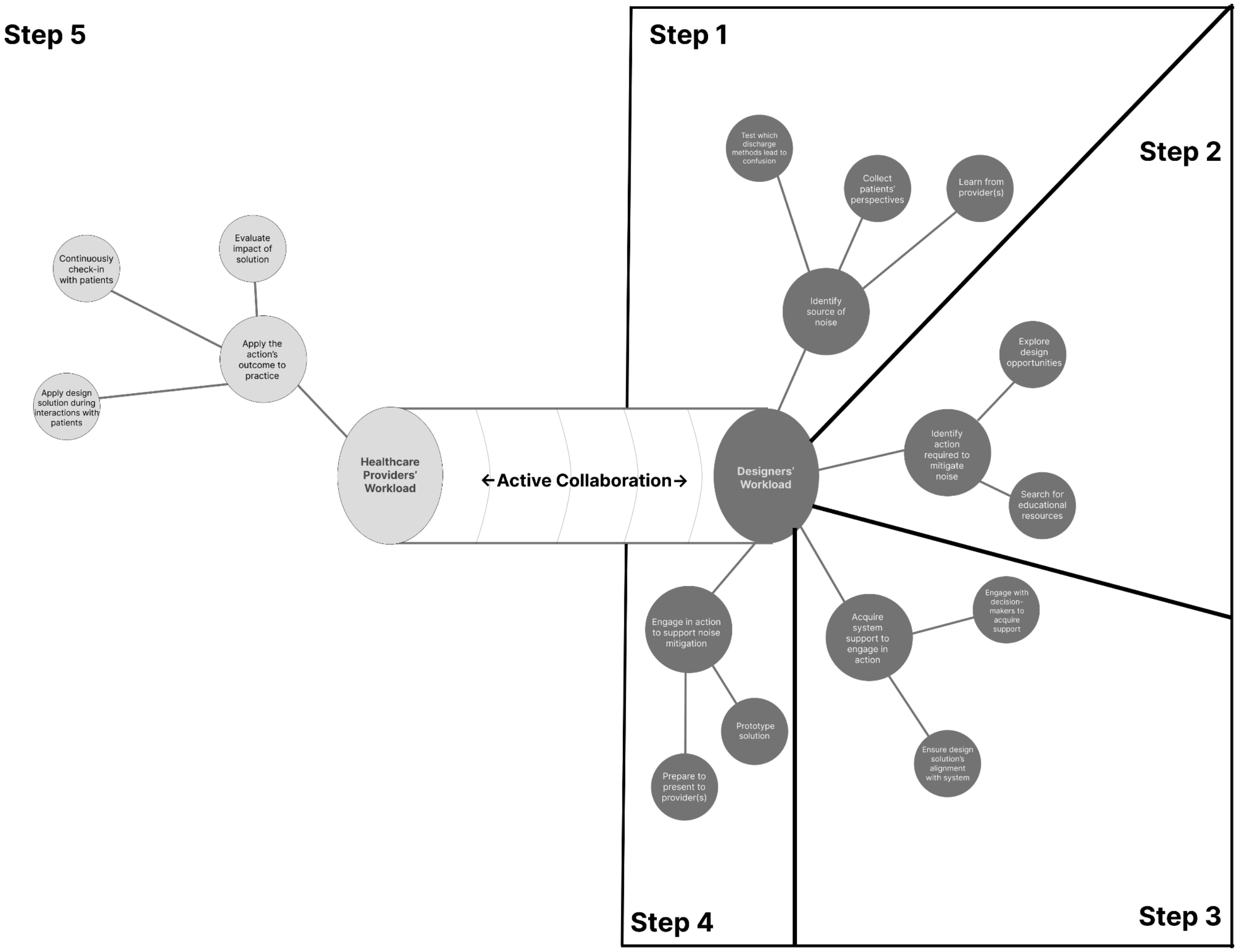


Figure 20: A model for offloading the burden of the five steps to enacting systemic action to designers through collaboration.

This model shifts the first four stages of enacting systemic change – which are similar to the design thinking process's stages of *Empathize, Ideate, Define,* and *Prototype* – to a designer, while leaving the final step of applying systemic action to practice (similar to the design stage of *Test)* to healthcare providers. In this context, designers can focus on empathizing and speaking with patients and their circles of care, identifying sources of noise, defining the communication barrier, considering opportunities to mitigate the challenge and creating a design solution that can be presented to healthcare providers. These steps would not be conducted in a silo, separate from healthcare providers– they would be led by designers, with active collaboration and consultation with healthcare providers to ensure that their perspectives are well-represented. When healthcare providers test the solution that a designer delivers, they may work together to determine whether to revisit an earlier step in the process or to move forward with the presented solution.

Indeed, a collaboration effort between designers and healthcare providers can lead to the efficient execution of systemic action in various ways. Design educators strive to prepare students with expertise in design thinking processes and user-centric methodologies (Thandlam Sudhindra et al., 2022). This may enable formally trained designers to work through the process of enacting systemic change with ease given the overlap between the design thinking process and the steps for enacting systemic change. Further, designers' abilities to prioritize the needs of users means that they can consider not only patients' and caregivers' experiences with noise, but also challenges that providers and other system stakeholders may encounter as they aim to address the source of noise. Educators also aim to include the skill development in design training, such as communication and reflection skills among many others (Thandlam Sudhindra et al., 2022). These skills can position designers to appropriately navigate interactions with system stakeholders, as well as pivot their approach to systemic challenges as needed.

An additional point of consideration for this collaboration effort includes the benefits of an alignment of the providers' needs as they aim to address noise, to the designer's other areas of expertise. Designers may come from fields such as psychology, business, health studies and other diverse areas that enable them to engage with relevant problems at a deeper level. A diversity of perspectives can lead to new approaches to noise mitigation. Overall, the proposed collaboration between designers and healthcare providers may reallocate the workload of enacting systemic action to respond to less controllable external noise and subsequently lead to the generation of new knowledge.

5. Limitations and Future Work

This study included a small sample size that may not capture the full diversity of perspectives from neurodivergent patients, caregivers and healthcare providers. For instance, we note that our healthcare provider participants were actively dedicated in supporting their neurodivergent patients. We recognize the value of also including perspectives of healthcare providers who may not have the capacity, knowledge or engagement in supporting neurodivergent patients. Similarly, our sample of two participants who identified as neurodivergent is not representative of the spectrum of neurodiversity. Paid caregivers were not included in this study and should also be considered in this context. Future work should aim to consider a larger diversity of participants across all participant groups to improve the generalizability of our findings. Further, we recognize that there are other agents involved in the healthcare environment that influence or determine how health information is shared at the end of healthcare visits (such as systemic decision-makers). Future work should aim to consider the larger systemic implications of health information exchange, as well as the involvement of other stakeholders in this process. Lastly, future research should consider further discussion with healthcare providers and stakeholders regarding the use, evaluation and testing of the proposed healthcare provider-design collaboration model.

6. Conclusion

This paper seeks to consider how we can promote the inclusive and effective communication of healthcare instructions at the end of healthcare visits among neurodivergent patients, caregivers, and healthcare providers by addressing barriers to information exchange. The research project considers how information theory can help us understand and promote inclusive healthcare communication. Through an iterative co-design and interview process, participants share insights related to what prevents and supports them with successfully transmitting and receiving healthcare information at the end of healthcare visits. Shannon's concept of *noise* – which is information that disrupts or distorts a transmitted message – is leveraged as a framework to understand the discussed communication challenges (Shannon & Weaver, 1949). Sources of noise discussed include extensive wait times, overwhelming sensory environments, reliance on medical jargon, information overload and shortage of appointment times. In order to mitigate some of these challenges, participants developed journey maps, email templates and digital instruction templates that outline what supports the transmission of health information in their perspectives. Discussions and reflections on the co-design solutions highlight that the reduction of noise may be supported with healthcare training, multi-modal instructions, planning outside of a healthcare visit and an established predictability during appointments as well as a continuity of care.

In our discussion, we expand on Shannon's concept of *noise* to consider how different communication challenges may be categorized and addressed in ways that promote effective noise mitigation (Shannon & Weaver, 1949). We present a framework that categorizes noise into four categories: less controllable internal noise, less controllable external noise, more controllable internal noise, more controllable external noise. We put forward a model for interventions required according to the type of noise. Further, we note that there are similarities between enacting systemic action and engaging in a design thinking process. We propose a second model for offloading workloads on healthcare providers through a healthcare provider-designer collaboration effort.

Overall, this work makes a unique contribution to existing research by considering how information theory can extend our understanding of healthcare communication barriers between neurodivergent patients, caregivers and healthcare providers.

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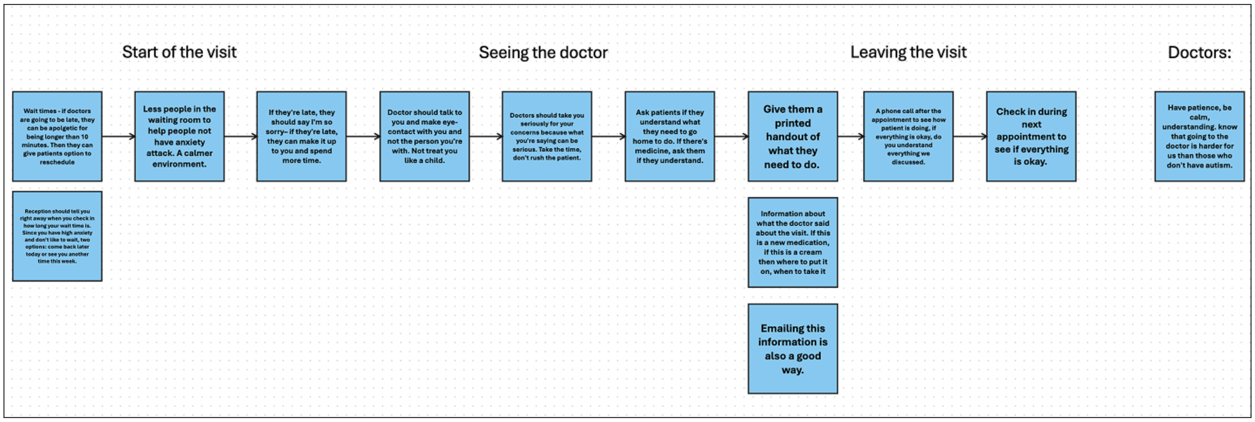
Appendix A: Steph’s Journey Map



Start of the visit

Wait times - if doctors are going to be late, they can be apolgetic for being longer than 10 minutes. Then they can give patients option to reschedule

Reception should tell you right away when you check in how long your wait time is. Since you have high anxiety and don’t like to wait, two options: come back later today or see you another time this week.

Less people in the waiting room to help people not have anxiety attack. A calmer environment.

If they’re late, they should say I’m so sorry– if they’re late, they can make it up to you and spend more time.

Seeing the doctor

Doctor should talk to you and make eye-contact with you and not the person you’re with. Not treat you like a child.

Doctors should take you seriously for your concerns because what you’re saying can be serious. Take the time, don’t rush the patient.

Ask patients if they understand what they need to go home to do. If there’s medicine, ask them if they understand.

Leaving the visit

Give them a printed handout of what they need to do.

Information about what the doctor said about the visit. If this is a new medication, if this is a cream then where to put it on, when to take it

Emailing this information is also a good way.

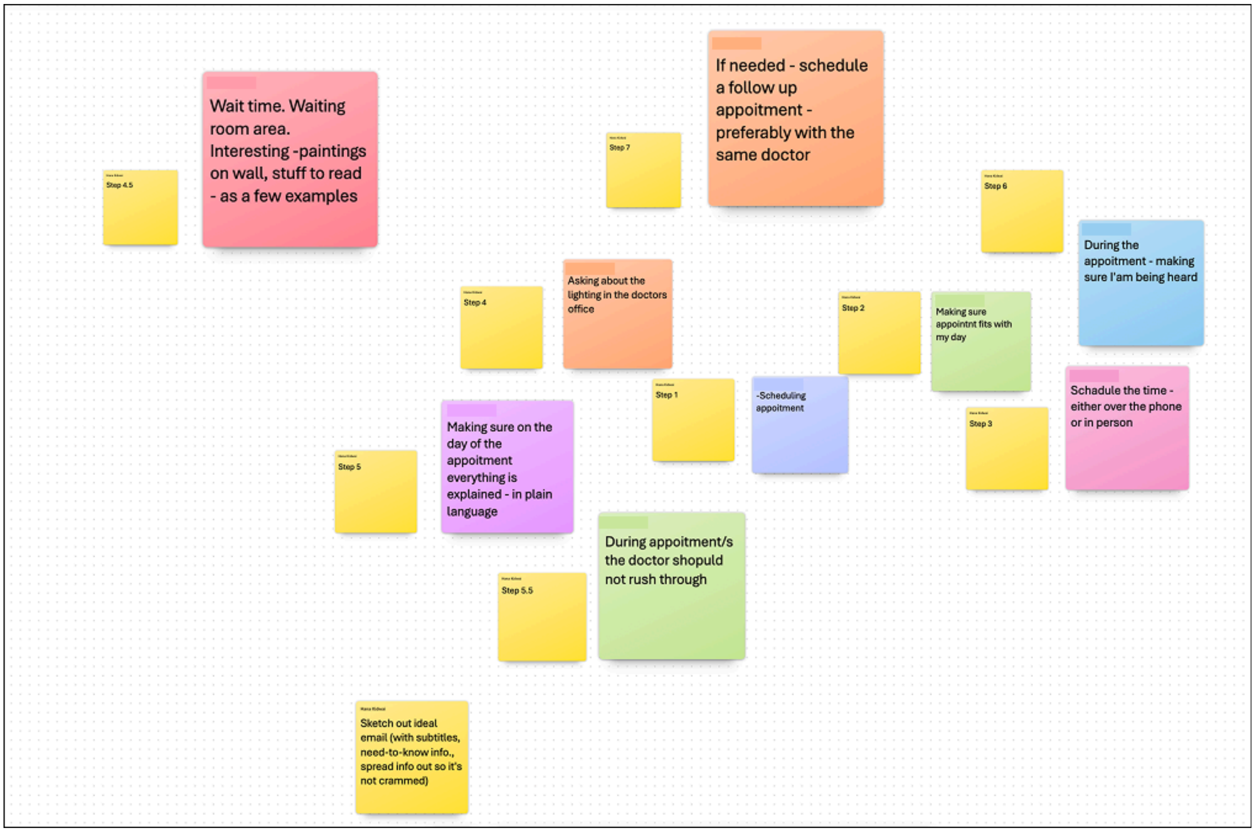
A phone call after the appointment to see how patient is doing, if everything is okay, do you understand everything we discussed.

Check in during next appointment to see if everything is okay.

Doctors:

Have patience, be calm, understanding. know that going to the doctor is harder for us than those who don't have autism.

Appendix B: Sarah J.’s Journey Map



If needed - schedule a follow up appointment - preferably with the same doctor

Wait time. Waiting room area. Interesting -paintings on wall, stuff to read - as a few examples

Step 7

Step 4.5

Step 6

During the appoitment - making sure I'am being heard

Asking about the lighting in the doctors office

Step 4

Step 2

Making sure appointnt fits with my day

Step 1

-Scheduling appoitment

Step 3

Schadule the time - either over the phone or in person

Making sure on the day of the appoitment everything is explained - in plain language

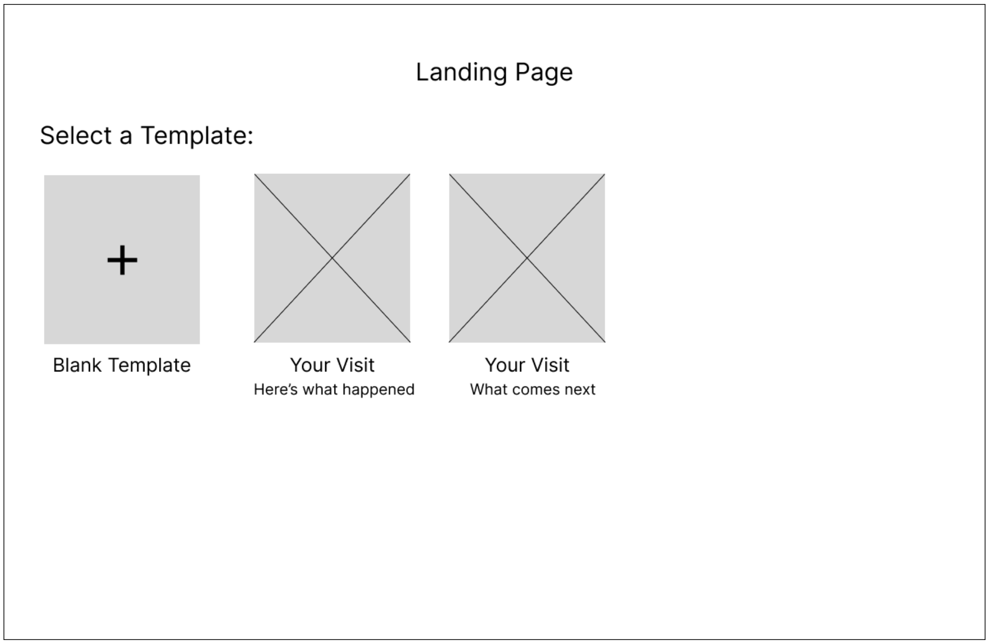
Step 5

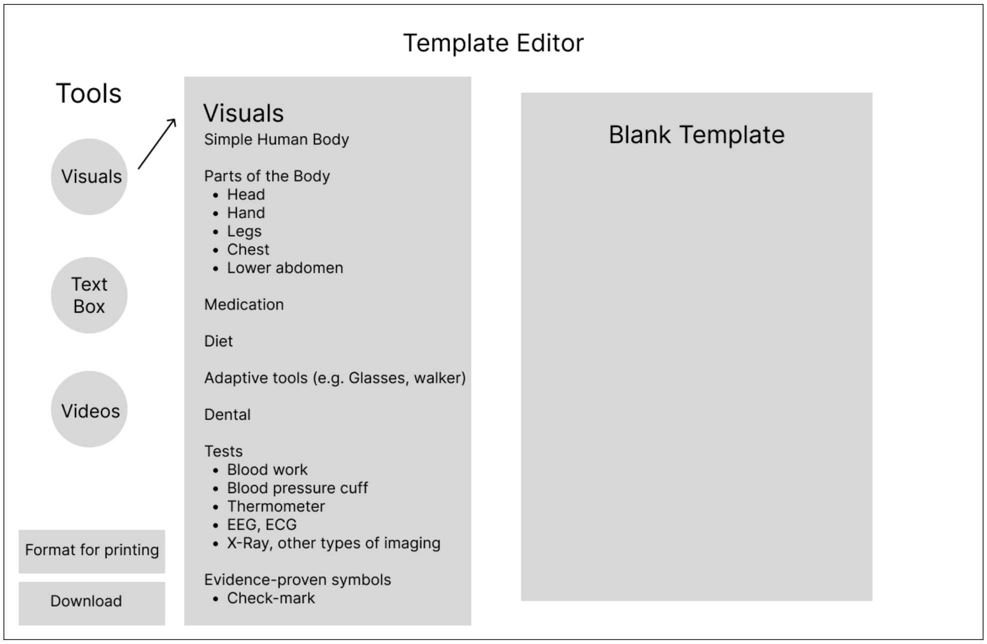
During appoitment/s the doctor shopuld not rush through

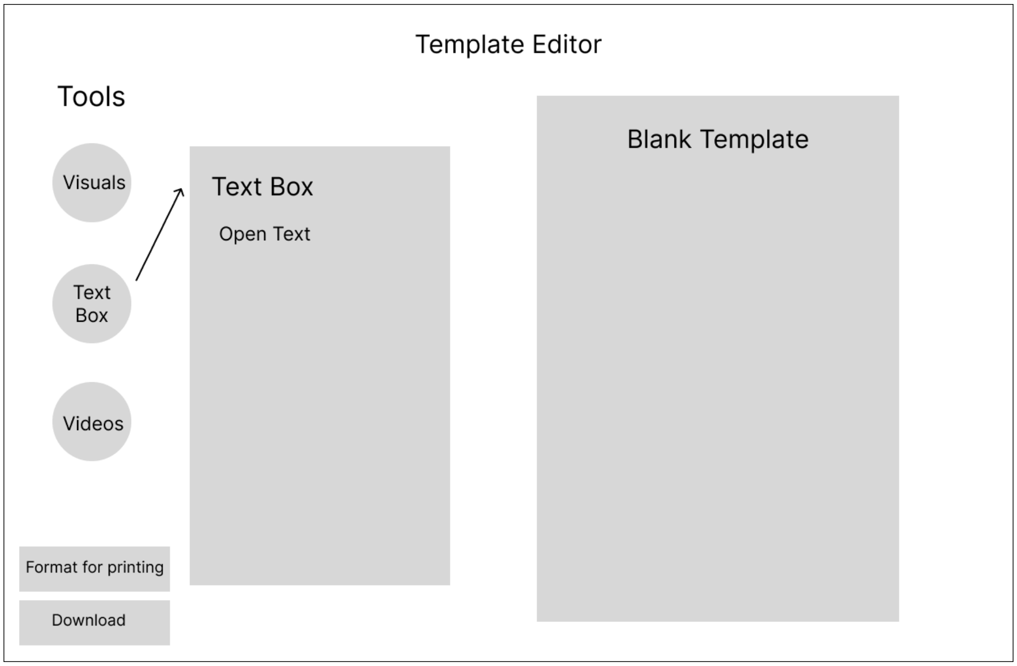
Step 5.5

Sketch out ideal email (with subtitles, need-to-know info., spread info out so it's not crammed)

Appendix C: Angie's Co-Designed Solution







Template Editor

Tools

Visuals

Text Box

Videos

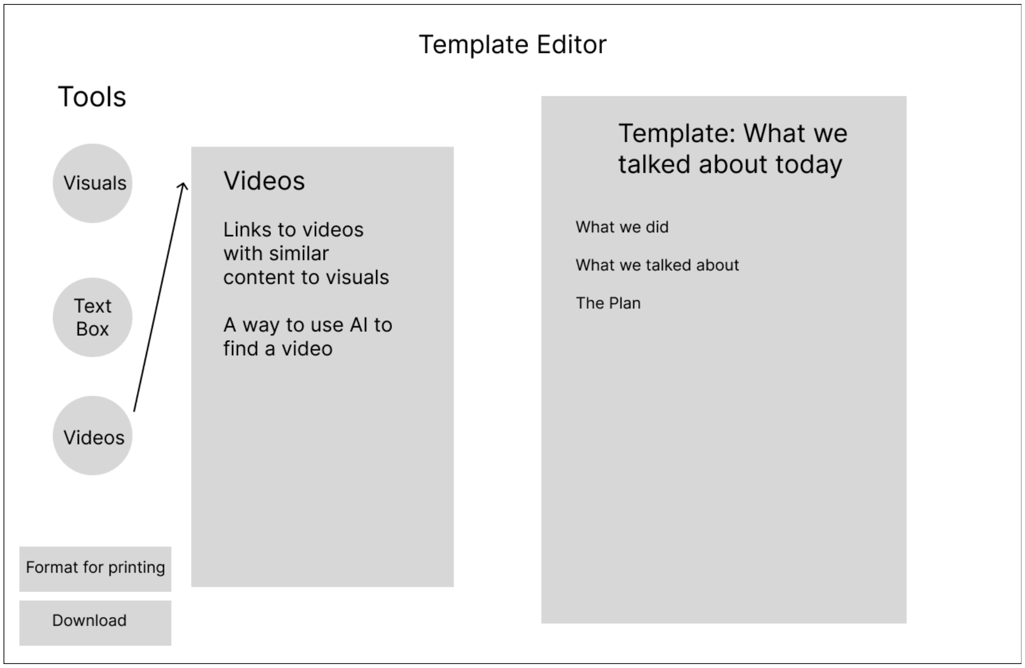
Format for printing

Download

Text Box

Open Text

Blank Template



Template Editor

Tools

Visuals

Text Box

Videos

Format for printing

Download

Videos

Links to videos with similar content to visuals

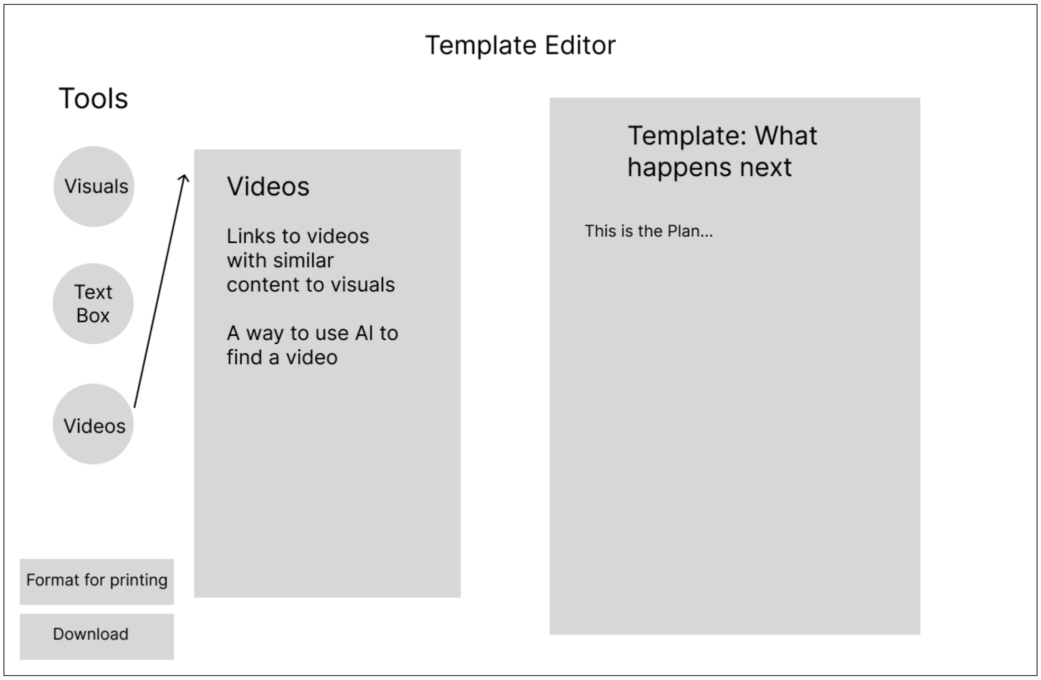
A way to use AI to find a video

Template: What we talked about today

What we did

What we talked about

The Plan



Videos

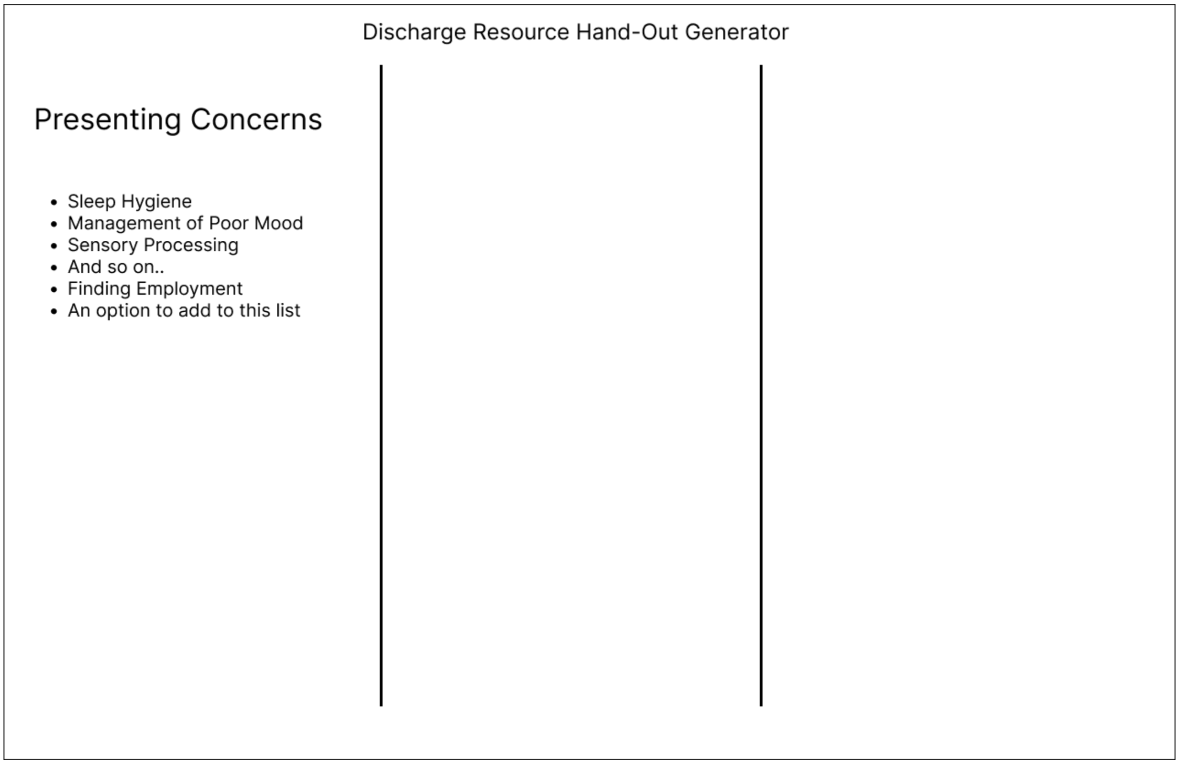
Links to videos with similar content to visuals

A way to use AI to find a video

Template: What happens next

This is the Plan...

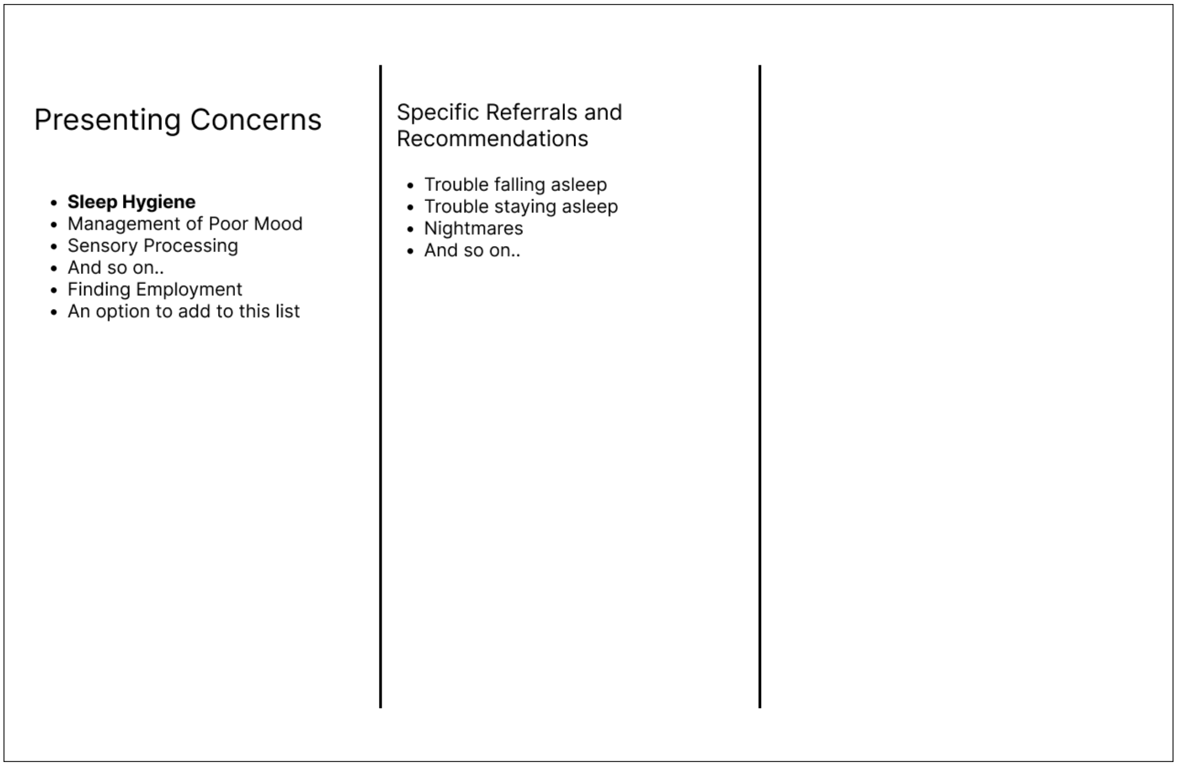
Appendix D: Jeff's Co-Designed Solution



Discharge Resource Hand-Out Generator

Presenting Concerns

- Sleep Hygiene
- Management of Poor Mood
- Sensory Processing
- And so on..
- Finding Employment
- An option to add to this list

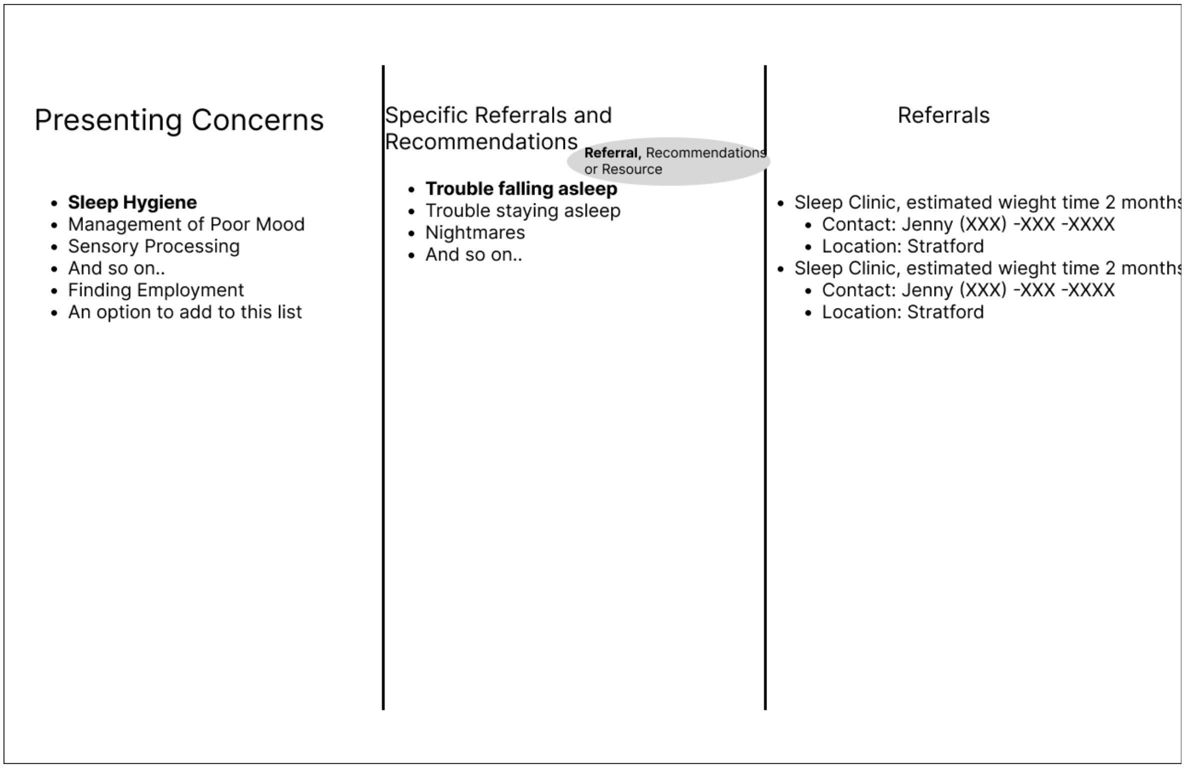


Presenting Concerns

- **Sleep Hygiene**
- Management of Poor Mood
- Sensory Processing
- And so on..
- Finding Employment
- An option to add to this list

Specific Referrals and Recommendations

- Trouble falling asleep
- Trouble staying asleep
- Nightmares
- And so on..



Presenting Concerns

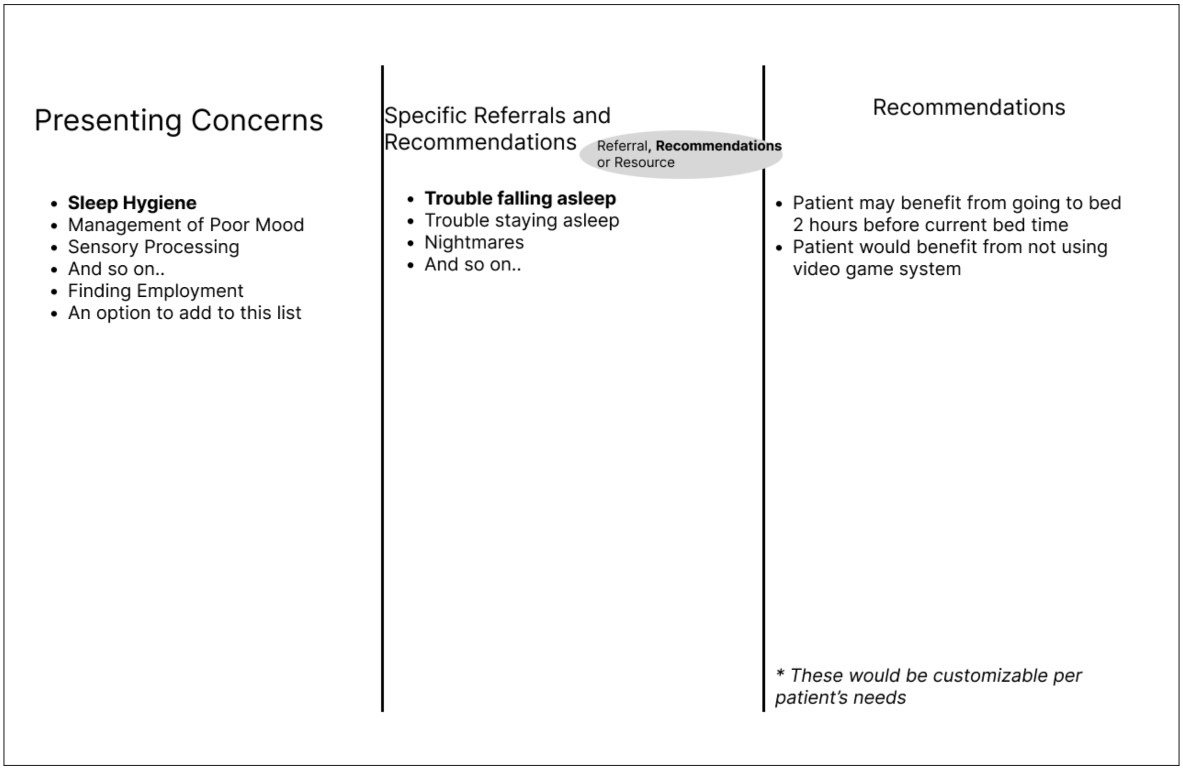
- **Sleep Hygiene**
- Management of Poor Mood
- Sensory Processing
- And so on..
- Finding Employment
- An option to add to this list

Specific Referrals and Recommendations

- **Trouble falling asleep**
- Trouble staying asleep
- Nightmares
- And so on..

Referrals

- Sleep Clinic, estimated wieght time 2 months
  - Contact: Jenny (XXX) -XXX -XXXX
  - Location: Stratford
- Sleep Clinic, estimated wieght time 2 months
  - Contact: Jenny (XXX) -XXX -XXXX
  - Location: Stratford



Presenting Concerns

- **Sleep Hygiene**
- Management of Poor Mood
- Sensory Processing
- And so on..
- Finding Employment
- An option to add to this list

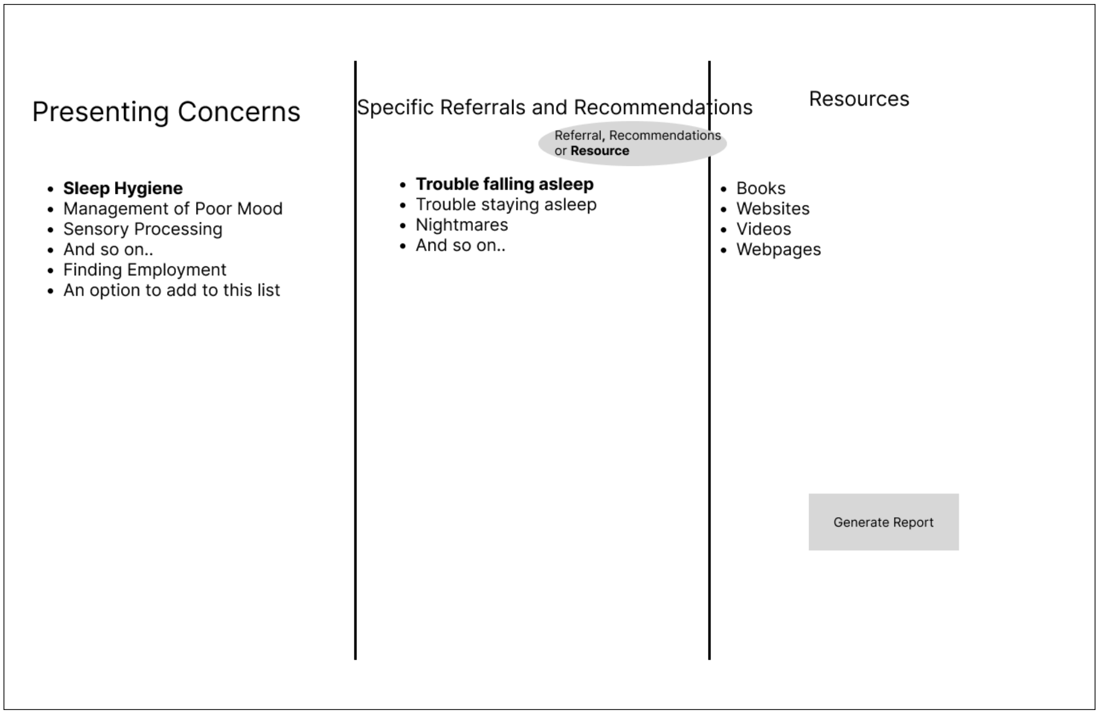
Specific Referrals and Recommendations

- **Trouble falling asleep**
- Trouble staying asleep
- Nightmares
- And so on..

Recommendations

- Patient may benefit from going to bed 2 hours before current bed time
- Patient would benefit from not using video game system

** These would be customizable per patient's needs*



Presenting Concerns

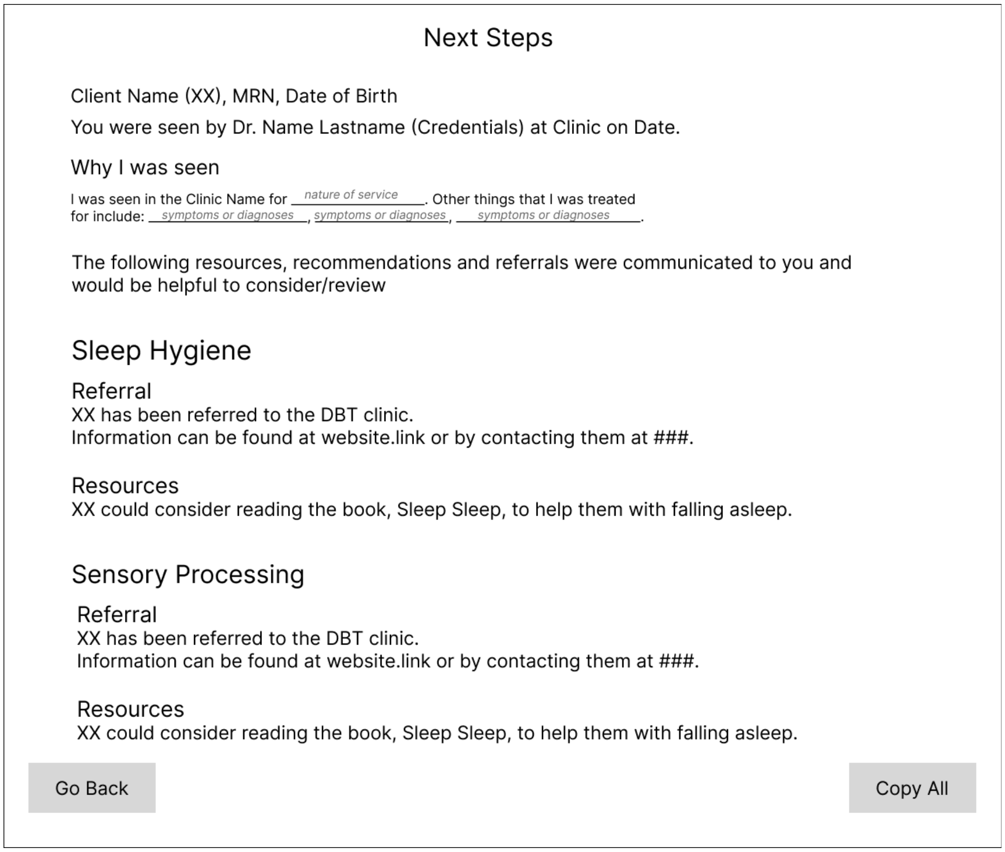
- **Sleep Hygiene**
- Management of Poor Mood
- Sensory Processing
- And so on..
- Finding Employment
- An option to add to this list

Specific Referrals and Recommendations

- **Trouble falling asleep**
- Trouble staying asleep
- Nightmares
- And so on..

Resources

- Books
- Websites
- Videos
- Webpages



Next Steps

Client Name (XX), MRN, Date of Birth

You were seen by Dr. Name Lastname (Credentials) at Clinic on Date.

Why I was seen

I was seen in the Clinic Name for __*nature of service*__. Other things that I was treated for include: __*symptoms or diagnoses*__, __*symptoms or diagnoses*__, __*symptoms or diagnoses*__.

The following resources, recommendations and referrals were communicated to you and would be helpful to consider/review

Sleep Hygiene

Referral
XX has been referred to the DBT clinic.
Information can be found at website.link or by contacting them at ###.

Resources
XX could consider reading the book, Sleep Sleep, to help them with falling asleep.

Sensory Processing

Referral
XX has been referred to the DBT clinic.
Information can be found at website.link or by contacting them at ###.

Resources
XX could consider reading the book, Sleep Sleep, to help them with falling asleep.