DESIGN FOR WELL-BEING

Co-creating a communication system for a person living with Locked-in Syndrome

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DESIGN FOR WELL-BEING:
Co-creating a Communication System for
a Person Living with Locked-in Syndrome

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PREFACE

This thesis marks the end of my Master's in Industrial Design Engineering at the University of Twente, and with it a chapter of my life that has been as personal as it has been academic. What began in November as a graduation project became, over the following months, something I could not have anticipated when I set out.

I have long believed that design is more than problem-solving — that designers have a real capacity, and perhaps a responsibility, to make the world a little better, and to put people's well-being at the centre of what they create. This conviction, together with a deep interest in design for health and well-being, is what drew me to this project. But it was Karel's story that turned that belief into something far more personal. Meeting a person who is fully present yet unable to move or speak, and who communicates through the smallest, most effortful movements of his eyes, changed how I understand what communication is and why it matters. It is easy to treat the ability to speak, to call for help, to simply be heard, as a given. This project taught me that it is not.

Working alongside Karel and his partner has been the most meaningful part of this journey. Their strength — his patience and presence, and her steady, quiet dedication — left a lasting impression on me and reshaped the way I think as a designer. Designing for a real person, whose daily life and well-being were genuinely at stake, carried a weight I had not felt in any project before. It made me more careful, more humble, and more aware of the responsibility that comes with the privilege of designing for someone. I hope this work honours the trust they placed in me.

What follows is my attempt to translate that experience into design research, and into a reflection on what it means to design for well-being. To the reader, I hope it offers not only insight into the design of a communication system, but a reminder of how much is carried in the simple act of being understood.

ACKNOWLEDGEMENT

This work would not have been possible without the people who supported, guided, and encouraged me throughout its course, and I am deeply grateful to all of them.

First and foremost, I would like to express my heartfelt thanks to my supervisor, **Jodi Sturge**. Her dedication, care, and unwavering support went far beyond what I could have hoped for. She believed in this project — and in me — at every stage, and her guidance shaped not only this work but also the way I have grown throughout it. I am truly fortunate to have had her by my side.

I would also like to sincerely thank my second supervisor, **Femke Nijboer**, whose knowledge and expertise were invaluable to this project. Her thoughtful feedback and academic insight consistently pushed the work to a higher standard, and I am grateful for the perspective she brought.

I am profoundly grateful to **Karel** and **his partner**, whose openness and generosity made this work possible. Despite everything they navigate in their daily lives, they welcomed me with warmth, gave their time without hesitation, and shared their experiences with a candour that shaped this project at its core. I am especially thankful to **his partner**, whose strength, patience, and quiet dedication did not go unnoticed and left a lasting impression on me. This work is richer for their trust, and I carry my gratitude to them well beyond these pages.

My sincere gratitude goes to **Tim van Leipsig**, who guided me through the process and supported me at every stage. From offering direction at key moments to accompanying and driving us to the visits, his practical help and encouragement made a real difference to this project. I would also like to thank the rest of the team at **DE Design** for their kindness and support, and for making the office a welcoming place throughout my time there.

I am especially thankful to **Tomas Rendon**, who developed the high-fidelity prototype. His work was essential to this project — without his skill and effort, developing a prototype of this quality would have been extremely difficult, and I am grateful for his collaboration.

On a personal note, I owe my deepest thanks to **my mother**. I am here because of her — her love, sacrifices, and constant belief in me are the foundation of everything I have achieved. I am endlessly grateful to her. I would also like to thank **my sister** and the rest of **my family** for their steady support and encouragement throughout this journey.

Finally, to **my friends** — and especially those here who made the Netherlands feel like home — thank you for your companionship, your kindness, and for being a source of comfort and joy during this time. You made all the difference.

DISCLAIMER

During the preparation of this work, the following tools were used. Perplexity AI supported the search for additional academic sources, and interview recordings were transcribed using Samsung's Galaxy AI (the Transcript Assist feature built into the Samsung Voice Recorder app). For writing and referencing, Claude was used for grammar, spelling, and English-language writing, Zotero was used for citation management, and Grammarly was used for final proofreading checks. For the visual and technical development, ChatGPT was used to digitise the ideation sketches in Section 5.1 — the original sketches were hand-drawn by the author, and ChatGPT was used only to render them digitally in a consistent style — and to generate the EyeVox logo based on a concept and stylistic direction defined by the author (Figure 6.5); the prototype collaborator in the development of the high-fidelity prototype used Claude (Claude Code). After using these tools, all outputs were thoroughly reviewed and edited as needed. The author takes full responsibility for the presented work.

ABSTRACT

The ability to communicate is often treated as a self-evident human capacity, yet it underpins how people articulate needs, exercise choice, sustain relationships, and remain present in everyday life. Locked-in Syndrome (LiS) is a rare neurological condition in which people are unable to move or speak while remaining cognitively intact. For a person living with LiS, communication thus becomes both central and precarious, with small, effortful eye movements often serving as the primary channel for interaction. This thesis examines how design research can be applied to improve the well-being of an individual living with LiS.

Adopting a human-centred, participatory design approach guided by design thinking, the project adapts co-design methods to the participants' capabilities. Insights from the literature, observations, and co-design activities are distilled into core values of autonomy, agency, safety, and communication, resulting in the design of EyeVox, a gaze-based communication system intended to support independent communication, richer self-expression, a greater sense of safety and presence in daily life, and to contribute to well-being in the long term. In evaluation, gaze-related barriers meant that only the alarm function could be validated in use.

The thesis reflects on what this process reveals about designing for life with LiS. It argues that participation must be reconceptualised when communication is slow and effortful: even then, individuals can meaningfully shape design decisions. Communication, safety, and self-expression emerged as central to well-being in this case — and notably, the capacity to independently initiate contact, to call for help when alone, was prioritised above communication itself, a priority that receives comparatively little emphasis in the LiS and AAC literature reviewed here. Finally, the project points to the crucial but easily unrecognised role of informal caregivers, the value of multidisciplinary collaboration across clinical, technical, rehabilitative, and design expertise, and the reality that long-term impact depends on healthcare systems providing the access, maintenance, and funding that technologies like EyeVox need to be usable beyond a single project.

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LIST OF ABBREVIATIONS

AAC	Augmentative and Alternative Communication
ADL	Activities of Daily Living
AI	Artificial Intelligence
AR	Augmented Reality
AT	Assistive Technology
BCI	Brain–Computer Interface
CT	Computed Tomography
EEG	Electroencephalogram
E-TRAN	Eye Transfer
HCD	Human-Centred Design
HMW	How Might We
LiS	Locked-in Syndrome
MRI	Magnetic Resonance Imaging
PD	Participatory Design
UI	User Interface
UX	User Experience
QoL	Quality of Life

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INTRODUCTION

Every year, around 12–13 million people have a stroke (Feigin et al., 2025). A small proportion of these strokes affect the brainstem, where damage to the ventral pons can cause severe paralysis and, in rare cases, result in Locked-in Syndrome (LiS). Stroke is the most common, though not the only, cause of the condition (Schnetzer et al., 2023). LiS is commonly described as a state of profound motor deafferentation, in which voluntary motor output is almost completely lost despite the preservation of consciousness and basic cognitive abilities (Laureys et al., 2005; Schnetzer et al., 2023). This results in a striking disconnect between internal experience and external expression, leaving individuals cognitively present but severely limited in their ability to communicate. Communication therefore becomes essential for people with LiS, underpinning their overall well-being.

1.1. Case and Context

This project was conducted in collaboration with DE Design (D'Andrea and Evers Design Agency, n.d.). Through the company supervisor's personal connections, a participant was invited to collaborate on this project.

"Karel" is a pseudonym chosen by the participant for a man in his mid-fifties who has been living with LiS since 2021, following a severe meningitis infection that affected his brainstem. Karel is cognitively intact but has very limited voluntary movement. He can move his eyes in all directions and has partial, imprecise control over some facial movements (including slight leftward head movement, limited lip and mouth movement, tongue movement, and left eyebrow movement); however, he cannot blink, smell, or swallow. Since he retains control of his eye movements, it serves as his primary means of interacting with the world. His primary means of communication is through his established eye-based system and assistive technologies. Karel's partner plays a central role in his daily life and communication, acts as his legal representative, and was closely involved in and contributed to this project.

In addition, a Master's student in Industrial Design Engineering at the University of Twente, specialising in Emerging Technology Design, contributed to the technical development and testing of the prototype. He collaborated with the designer to define the system flowchart, logic, and interaction flow, after which he implemented the prototype in Python and integrated the hardware components. Throughout this report, he is referred to as the prototype collaborator.

1.2. Research Aim

Building on this context, this project aims to explore the following question.

How might design research be applied to improve the well-being of an individual living with LiS?

In this project, the primary focus is on well-being, treated as a narrower construct within the broader, multidimensional concept of quality of life (QoL) and defined in terms of comfort and contentment. Nevertheless, QoL is discussed in later sections to situate the thesis within established health and disability research, where it is the dominant framework for assessing life satisfaction across different life domains (S. Pinto et al., 2017).

1.3. Framework and Methodology

To address this research question, the thesis adopts a human-centred design (HCD) and participatory design (PD) approach guided by design thinking. It explicitly seeks to design with Karel rather than merely for him, grounding the process in his daily context so that his experiences, feedback, and involvement actively shape the design process.

1.3.1. Design Thinking Framework

In this project, the design thinking framework is used to organise the research and design process in this thesis (Auernhammer & Roth, 2021; Brown, 2008; Tschimmel, 2012). In this project, the process is structured into six phases: Understand, Empathise, Define, Ideate, Prototype, and Evaluate (Hasso Plattner Institute of Design at Stanford University, n.d.; Pontis, 2015), as shown in Figure 1.1, which outlines the focus of each phase and different stakeholders' involvement.

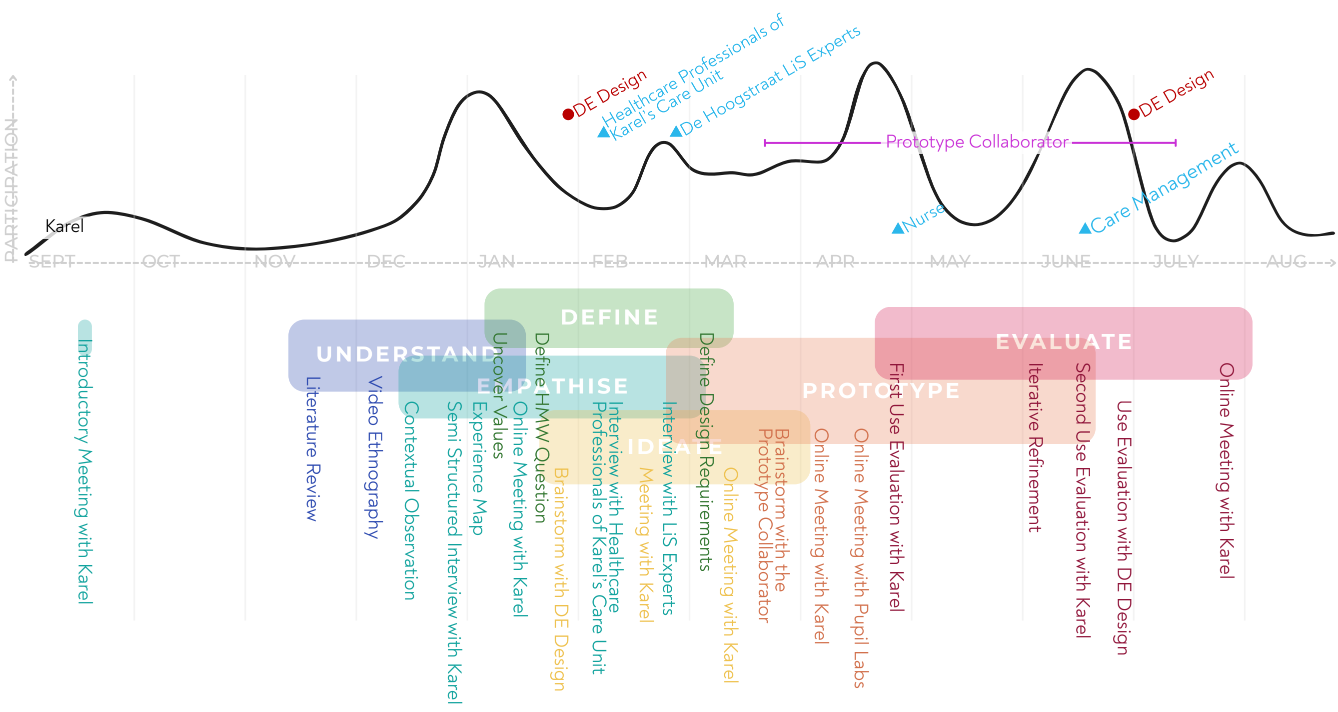


Figure 1.1 Overview of the project and design process, and stakeholder involvement

1.3.2. Human-Centred Design

HCD in this thesis builds on work that treats users as creative contributors and emphasises empathic engagement with their everyday practices and experiences (Kouprie & Visser, 2009; Mattelmäki, 2005; Sanders & Stappers, 2008). This grounds the process in Karel's daily life and communication practices and adapts methods for slow, effortful interaction and fatigue, drawing on approaches for complex communication and disability contexts (Galliers et al., 2012; Wilson et al., 2015).

1.3.3. Participatory Design

This project draws on participatory design's focus on mutual learning, shared influence, and empowerment in both process and outcome (De Couvreur & Goossens, 2011; Galliers et al., 2012; Van Dijk et al., 2016). Karel and the designer are actively engaged, learning from each other and making decisions together. Participation is carefully structured and continually adapted to Karel's communication capabilities, acknowledging that participation is not fixed to conventional activities but should be tailored to his modes of interaction (Beunk, 2019; Bui, 2019; Schmermbeck et al., 2024).

Other stakeholders, such as Karel's partner, caregivers and professionals, provide contextual insight into his everyday life. Still, their contributions are treated as complementary and checked with Karel wherever possible so that his perspective remains central, as recommended by Hamidi et al. (2017).

1.4. Ethical Considerations

This study was reviewed and approved by the Ethics Committee of the Faculty of Natural Sciences and Engineering Sciences (NES) at the University of Twente (file number: 252273). All research activities were conducted in accordance with the University of Twente's ethical guidelines for research involving human participants. Participation in the study was entirely voluntary, and no financial compensation was provided. Participants could withdraw their consent at any time without consequences.

Before participation in the project, Karel was provided with information and an informed consent sheet (see Appendix I: Information sheet and consent form for further details). The information was read aloud to ensure accessibility. He and his legal representative were given sufficient time to review the information, discuss it together, and ask any questions before providing consent. Informed consent was obtained from the legal representative and informed assent from the participant, as recommended by Haselager et al. (2009). Karel first confirmed his agreement using his established eye-coded communication method, where looking up indicates "yes." His partner, who is also his legal representative, subsequently signed the consent form on his behalf.

UNDERSTAND

This phase aims to develop a grounded and empathetic picture of life with Locked-in Syndrome through a literature review and video ethnography. The literature review establishes the clinical and everyday context of the condition, covering what LiS is and how it arises, how it shapes quality of life beyond physical impairment, and the central role that informal caregivers play in daily communication and care. It then surveys the existing technology landscape — the range of no-tech, low-tech, and high-tech AAC and assistive technologies available — to understand what solutions exist and where they fall short in everyday use. The video ethnography complements this desk research with a close, observational view of lived experience, grounding the abstract findings in the reality of day-to-day life with LiS.

2.1. Understanding LiS

2.1.1. Clinical Presentation

LiS is represented by a wide range of clinical manifestations across individuals, and different types have been identified based on remaining voluntary movement (see Table 2.1). A common feature across these types is profound loss of motor function with relative preservation of eye movements, which often become the primary means of communication (Bruno et al., 2011; Laureys et al., 2005). However, these eye movements can be small, inconsistent, or tiring, making communication slow and vulnerable to misunderstanding (Laureys et al., 2005; Voity et al., 2024).

2.1.2. Aetiology

Locked-in syndrome is most often caused by damage to the brainstem following a stroke, either through a blockage of blood flow or bleeding in this area (Laureys et al., 2005; Schnetzer et al., 2023; Smith & Delargy, 2005). Strokes and other vascular causes are the main origin of LiS and are associated with poorer early survival than non-vascular causes (Patterson & Grabois, 1986).

Less frequent causes of LiS include traumatic brain injury, brainstem tumours, certain demyelinating or metabolic conditions, infections of the brainstem, and late-stage neurodegenerative diseases such as amyotrophic lateral sclerosis (ALS), which can severely disrupt the pathways that carry voluntary movement signals from the brain to the face and limbs, leading to the characteristic clinical picture of LiS (Maciejewicz, 2022; Laureys et al., 2005; Schnetzer et al., 2023; Smith & Delargy, 2005).

2.1.3. Diagnosis and Misdiagnosis

Locked-in syndrome is often difficult to diagnose, and this history of difficulty is reflected in both clinical practice and the literature. Although the term “Locked-in Syndrome” was introduced by Plum & Posner (1966), states resembling LiS were described much earlier, as depicted in Figure 2.1.

Figure 2.1 M. Noirtier de Villefort in Dumas’ The Count of Monte Cristo, portrayed as fully conscious yet unable to move or speak, communicating instead through eye movements and blinking (Teive et al., 2022)

Clinically, accurate diagnosis depends on recognising preserved consciousness despite severe paralysis and loss of speech, and on establishing intentional communication through eye movements or blinking. Structural imaging such as CT and MRI can support diagnosis by revealing brainstem lesions. However, LiS is frequently misdiagnosed as coma, vegetative state, or akinetic mutism, particularly in the acute phase, because subtle voluntary eye movements can be easily overlooked (Khanna et al., 2011; Laureys et al., 2005; Schnetzer et al., 2023).

Table 2.1 Classification of LiS (Bauer et al., 1979; Nilsen et al., 2023; Schnetzer et al., 2023)

Type	Definition	Communication
Classical LiS	Tetraplegia, anarthria, lower cranial nerve paralysis, preserved consciousness, and communication through eye movement or blinking.	Non-verbal communication only by vertical eye movements and/or blinking
Incomplete LiS	Classical LiS with some additional voluntary movement beyond eye movement or blinking.	Sounds and/or occasional words but mainly non-verbal communication
Total LiS	Preserved consciousness with complete immobility and absence of voluntary communication, including eye movement.	Same as classical LiS
Locked-in Plus Syndrome (LiPS)	LiS accompanied by additional neurological impairments, including disturbances of consciousness or other cognitive and neurological complications.	Yet to be researched

2.1.4. Prevalence

LiS is considered a rare condition; however, its true incidence and prevalence are unknown because studies involve small cohorts, use different diagnostic criteria, rely on limited registries, and reflect varying end-of-life practices across countries (Schnetzer et al., 2023; Yoshiki et al., 2023). Moreover, early mortality and frequent misdiagnosis as coma or other disorders of consciousness further suggest that LiS may be more prevalent than observed in current figures (Doble et al., 2003; Laureys et al., 2005). Data from Dutch nursing homes, where classic LiS is estimated at 0.7 per 10,000 somatic beds, are consistent with this concern, as they exclude people receiving care at home and those whose LiS was never recognised or documented (Kohnen et al., 2013; Pels et al., 2017).

2.1.5. Rehabilitation

In LiS, early, intensive, and highly engaging rehabilitation with a multidisciplinary team involving coordinated physical, speech, occupational, respiratory, and nursing interventions is essential (Casanova et al., 2003; Halan et al., 2021; Høyer et al., 2010). Although full recovery is uncommon, partial improvements can be highly meaningful because they may enable people with LiS to use other assistive technologies and establish reliable communication, which is repeatedly described as the ultimate goal of rehabilitation (Schjolberg & Sunnerhagen, 2012; Schnetzer et al., 2023).

2.2. Quality of Life

In contrast to common assumptions from outside observers, many people living with LiS self-report a relatively high quality of life (Bruno et al., 2011; Lugo et al., 2015; Rousseau et al., 2015; Yoshiki et al., 2023), a phenomenon known as the 'Disability Paradox' (Albrecht & Devlieger, 1999).

This pattern must also be interpreted in light of selection bias, as survey-based QoL studies are more likely to include individuals who are medically stable, socially connected, and able to communicate or complete questionnaires (Bruno et al., 2011; Lugo et al., 2015; Rousseau et al., 2015). Conversely, those who are acutely unwell, unable to communicate reliably, or experiencing severe psychological distress are often underrepresented in these samples, which may lead to an underestimation of suffering among people living with LiS (Bruno et al., 2011; Lugo et al., 2015; Rousseau et al., 2015; Yoshiki et al., 2023).

Explanations for High QoL

Response shift (Sprangers & Schwartz, 1999) has been proposed as a key explanation for the relatively high quality of life reported by many people living with LiS. Individuals often learn new communication strategies, receive more stable support, and adapt to altered bodily conditions over time, which can substantially change how they appraise their situation (Bruno et al., 2011; Hordila et al., 2024; Yoshiki et al., 2023). Therefore, QoL should not be assessed only from the perspective of the acute phase, as well-being may change and stabilise over time (Bruno et al., 2011; Rousseau et al., 2015; Yoshiki et al., 2023).

Also, as more time passes since the onset, individuals may gain access to better communication systems, achieve greater medical stability, and, in some cases, move from hospital to home, where familiar surroundings and continued involvement in family life can further support well-being (Doble et al., 2003; Smith & Delargy, 2005; Snoeys et al., 2013). Access to clear, transparent information about LiS and communication possibilities plays a key role in adapting to new realities (Bruno et al., 2011; Yoshiki et al., 2023) and avoiding inaccurate or overly negative assumptions (Demertzi et al., 2014), however, a lack of accessible and comprehensive information remains evident, contributing to uncertainty, psychological distress, and challenges in adjusting to life with LiS (Hordila et al., 2024; Lugo et al., 2017; Snoeys et al., 2013).

Lastly, as people adapt to life with LiS, many describe placing less importance on physical abilities and instead prioritising dignity, autonomy, social participation, and communication (Hordila et al., 2024; Lugo et al., 2015; Rousseau et al., 2015; Snoeys et al., 2013; Yoshiki et al., 2023). This shift is also reflected in QoL assessments, which capture well-being across domains beyond physical functioning, including social, emotional, and relational aspects of life (Bruno et al., 2011; Rousseau et al., 2015).

2.2.1. Deeper Values

Based on the literature on QoL and the lived experiences of people with LiS, four interconnected values emerged as particularly central, namely identity and dignity, autonomy, social participation, and communication.

Identity and Dignity

Recognition of personal identity and dignity is central in accounts of living with LiS, as individuals remain conscious, emotionally responsive, and socially present despite profound motor impairment (Laureys et al., 2005; Nizzi et al., 2012). People with LiS continue to experience a sense of self that incorporates their changed body, which challenges assumptions that selfhood and agency depend solely on ordinary bodily movement (Kyselo, 2013; Kyselo & Di Paolo, 2015). However, this enduring identity is easily overlooked because their expression is so constrained. They are often spoken about rather than spoken to, or discussed with their caregiver or partner as if they were absent – both of which can make them feel treated as objects (Hordila et al., 2024; Nizzi et al., 2012).

Autonomy

While LiS makes people physically dependent on others for most daily activities, it does not remove their ability to have preferences, to give or refuse consent, or to make decisions about their bodies, care, and future (Laureys et al., 2005; Schnetzer et al., 2023). However, supporting autonomy in LiS requires reliable communication, enabling individuals to express their wishes without being overridden by assumptions about disability or QoL (Hordila et al., 2024; Rousseau et al., 2015; Schnetzer et al., 2023), especially in sensitive decisions around end-of-life care (Demertzi et al., 2014) as people with LiS should neither be denied the right to die with dignity nor the right to live with dignity (Laureys et al., 2005; Schnetzer et al., 2023).

Social Participation

Despite the profound physical limitations, people with LiS remain deeply connected to others, making relationships and interaction central rather than secondary to their personhood and well-being (Kyselo & Di Paolo, 2015). Social participation with LiS can be supported by actively involving them in everyday conversations, family routines, leisure activities, and shared decision-making. Many individuals living with LiS continue to lead meaningful lives through the support of family and friends (Doble et al., 2003).

Communication

Communication and self-expression are fundamental to living with LiS (Laureys et al., 2005; Vieira et al., 2023; Voity et al., 2024). Reliable and flexible communication is directly associated with a better quality of life (Corallo et al., 2017; Rousseau et al., 2015; Yoshiki et al., 2023). Furthermore, communication underpins autonomy, dignity, identity, social participation, and agency, as it enables individuals with LiS to express preferences, participate in care, maintain relationships, and remain socially present (Hordila et al., 2024; Kyselo, 2013; Schnetzer et al., 2023).

Individuals with LiS need alternative or assisted forms of communication adapted to their remaining abilities, known as AAC (Augmentative and Alternative Communication). AAC encompasses strategies, tools, and technologies that supplement or replace natural speech when spoken communication is not possible or sufficient (Elsahar et al., 2019; Hill, 2010), and will be explored in Section 2.4.

2.3. Role of Informal Caregivers

Informal caregivers, especially partners and close family members, have a central role in the lives of people with LiS, particularly when formal care options are limited. In such situations, more responsibility is shifted onto them, increasing their load and contributing to caregiver burden as they take on ongoing duties in care, coordination, communication support, and advocacy (Doble et al., 2003; Lugo et al., 2017; Smith & Delargy, 2005).

This burden is often intensified when access to information is scarce or communication with the person with LiS is limited or unreliable, making everyday decisions and emotional support more demanding (Hordila et al., 2024; Zinkevich et al., 2022). As a result, informal caregivers may experience poorer well-being than the person with LiS, even when the latter reports a relatively good quality of life (Linse et al., 2017; Lugo et al., 2017).

Therefore, informal caregivers need as much attention and support as the person living with LiS, since improving caregivers' well-being can also positively affect the well-being and everyday life of the person with LiS (Hordila et al., 2024; Lo Coco et al., 2005; Mages et al., 2025).

2.4. Existing Technology Landscape

Within the technological support available to people with LiS, AAC and AT are two overlapping fields relevant to this project. AAC covers systems that replace or supplement speech, whereas AT refers more broadly to technologies that support independent functioning in daily life; the two overlap where a system does both.

Table 2.2 gives an overview of the categories reviewed, ranging from no-tech and low-tech AAC through to high-tech AT, and including both invasive and non-invasive options. It also identifies cross-cutting technologies, which are not a category of device but capabilities that can be added to systems across the range, supporting communication, environmental control, and independence together rather than any single function alone. These categories were identified through exploratory web searches and a review of academic literature on technologies used by people with LiS and severe motor impairments; the overview is illustrative rather than exhaustive.

Table 2.2 Categories of AAC and AT reviewed, from no-tech to high-tech

Domain	Category	Technologies reviewed
AAC	No-Tech	Eye-blink and gaze codes
	Low-Tech	Letterboards Transparent eye-transfer boards Communication boards
	High-Tech Non-Invasive	Single-message voice-output devices Switch-based scanning Eye-tracking-based systems Eye-gesture-based apps Pupil-tracking-based systems Non-invasive AAC–BCI
	High-Tech Invasive	Implanted BCI speller
AT	High-Tech	Smart-glasses wheelchair control Eye-tracking environmental control Assistive living and smart home systems
Both	Cross-Cutting	AI-supported apps

Table 2.3 presents examples within each category, each with its own advantages and limitations. Beyond these technology-specific trade-offs, however, several broader factors shape whether such systems are usable and sustainably adopted in practice, as outlined below.

AAC and AT must fit the person

The usability of AAC and AT depends more on how well they match the person's abilities, preferences, and context than on technical sophistication, and people differ in preferred access strategies and acceptable levels of complexity or effort (Branco et al., 2021, 2023).

High-tech is powerful but limited

High-tech solutions (such as non-invasive and invasive BCIs) can be crucial when other access methods are unreliable or when they provide substantial gains in independence. However, they are often slow, training-intensive, costly, and restricted to specialised contexts, so no-tech and low-tech approaches remain essential alongside them. Real-world use often lags behind development (Ozawa et al., 2020; Peters et al., 2022; Schnetzer et al., 2023; Vieira et al., 2023).

Limited real-world use

Many systems are developed and evaluated in controlled conditions, with limited evidence on performance and adoption in everyday home and care environments, creating a gap between technological development and sustained real-world use, and poor usability (including cognitive and practical demands) can directly hinder adoption and consistent use (Higgins et al., 2025; Light et al., 2019; Thistle & Wilkinson, 2013; Tönsing et al., 2024).

Psychosocial needs remain under-served

Psychosocial needs such as identity, agency, meaningful social participation, and the expression of personality or subtle emotions over time are only partially addressed, with relatively little focus on user experience and personalisation in current AAC and assistive technologies (Bright & Coventry, 2013; Light et al., 2019; Tönsing et al., 2024).

Table 2.3 Examples of AAC and AT with their main advantages and limitations

No-Tech AAC

Eye-blink and gaze codes, for example, looking up means yes, and looking down means no, or one blink signals 'yes', and two is 'no'.

- ✓ No equipment needed
- ✓ Quick to establish (Schjolberg & Sunnerhagen, 2012)
- ✓ Allows rapid confirmation of pain, needs, and consent (Voity et al., 2024)

- ✗ Only answer closed questions (Lugo et al., 2015)
- ✗ Linked to lower QoL when used as a primary channel (Rousseau et al., 2015)

Low-Tech AAC

Letterboards

- ✓ Low-cost, portable, language-adaptable spelling tools (Hill, 2010; Vieira et al., 2023)
- ✓ Enable open-ended messages compared to yes/no code (Schjolberg & Sunnerhagen, 2012)
- ✓ Optimised layouts can reduce steps for selection (Kopsky et al., 2014)

- ✗ Slow and effortful (Laureys et al., 2005)
- ✗ Strong partner dependence for scanning and confirmation (Schjolberg & Sunnerhagen, 2012)
- ✗ Requires literacy and memorising layout (Kopsky et al., 2014)

Traditional	A B C D E F G H I J K L M N O P Q R S T U V W X Y Z
English	E T A O I N S R H L D C U M F P G W Y B V K X J Q Z
Dutch	E N A T I R O D S L G V H K M U B P W J Z C F X Y Q
French	E J A R I N S T U L O M D P C F B V H G Q Z Y X K W

Figure 2.2 Letter order of the alphabet and rate of appearance used in alphabetical system grid of letters; the communication partner reads the letters in order until the person indicates the desired letter (Kopsky et al., 2014).

V	C1	C2	C3
		J	R
A	B	K	S
E	C	L	T
I	D	M	V
O	F	N	W
U	G	P	X
Y	H	Q	Z

Figure 2.3 Vowel and consonant board (Laureys et al., 2005)

A	B	C	D	1	2
E	F	G	H	3	4
I	J	K	L	M	N
O	P	Q	R	S	T
U	V	W	X	Y	Z
5	6	7	8	9	10

Figure 2.4 AEIOU board (Kopsky et al., 2014)

A	B	C	D	End of word	
E	F	G	H	End of sentence	
I	J	K	L	M	N
O	P	Q	R	S	T
U	V	W	X	Y	Z

Figure 2.5 AEIOU letterboard. The assistant calls out the colours, and the patient signals the required colour. The assistant then sequentially calls out the letters on that line using the same method (Khanna et al., 2011)

1	2	3	4
A	B	J	R
E	C	K	S
I	D	L	T
O	F	M	V
U	G	N	W
Y	H	P	Z

Figure 2.6 Communication grid developed by Kopsky et al. (2014); the communication partner counts the columns and the person indicates the right column, then the letters are mentioned starting at the first row of the upper main row when looking straight ahead. A downward look indicates the intended letter

Table 2.3 (Continued)

Low-Tech AAC

Transparent Eye-Transfer (E-TRAN) Board

- ✓ Direct gaze "pointing" to letters/phrases; avoids verbal scanning (Fried-Oken, 2000)
- ✓ Supports eye contact and engagement (Larradet, 2020)

- ✗ Slow and positioning-sensitive; needs precise board alignment (Fried-Oken, 2000)
- ✗ Reliance on partner (Fried-Oken, 2000)

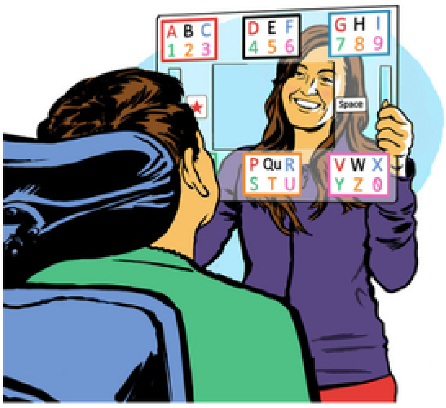


Figure 2.7 E-TRAN board; the person selects the letter group containing the intended element by gaze, then selects the letter within the group using the same principle (Larradet, 2020)

Communication Boards

- ✓ Reduce effort via ready-made phrases for frequent needs and emotions (Vieira et al., 2023)
- ✓ Content can be tailored to different languages (Vieira et al., 2023)

- ✗ Less flexible for novel or complex messages (Vieira et al., 2023)
- ✗ Slow and partner-dependent (Laureys et al., 2005)

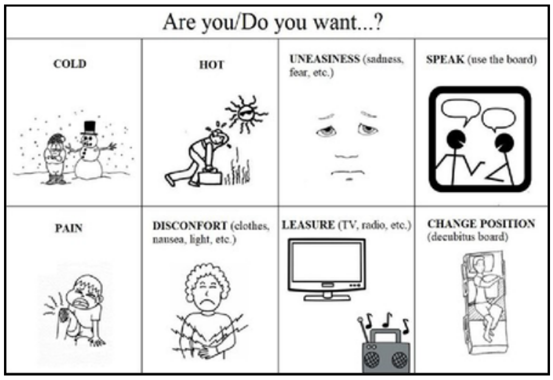


Figure 2.8 Communication board with phrases and images for fast inquiry about physical and emotional well-being (Vieira et al., 2023)

High-Tech AAC
Non-Invasive

Single-Message Voice-Output Devices

- ✓ Simple access to urgent, frequently used messages with speech output (Voity et al., 2024)
- ✓ Supports quick participation in spoken interaction (Elsahar et al., 2019)

- ✗ Only one stored message; no open-ended communication (Voity et al., 2024)
- ✗ Needs reliable movement and suitable mounting (Elsahar et al., 2019)

Figure 2.9 Example of a message button (Leave a Message Button | Record Your Own Messages!, 2018)

Switch-based Scanning

- ✓ Enables access when touch/keyboards are impossible (Elsahar et al., 2019)
- ✓ Uses small residual movements (eye-blink, head, foot) (Park et al., 2012)

- ✗ Often slow and tiring; timing is demanding (Elsahar et al., 2019)
- ✗ Performance vulnerable to fatigue, posture, and respiratory changes (Elsahar et al., 2019)

Figure 2.10 Self-Calibrating Auditory Tone Infrared switch(Park et al., 2012)

Figure 2.11 A sample visual scanning interface activated via switch scanning using the buttons (Elsahar et al., 2019)

Table 2.3 (Continued)

High-Tech AAC
Non-Invasive

Eye-Tracking-Based Systems

- ✓ Exploit preserved eye movements for spelling, phrases, and device control (Elsahar et al., 2019; Voity et al., 2024)
- ✓ Offer rich vocab plus spelling and speech output (Elsahar et al., 2019)
- ✓ Integrate communication with email, internet, and environmental control (Elsahar et al., 2019)

- ✗ Sensitive to calibration, lighting, posture, and visual issues (Elsahar et al., 2019; V. Gatdula, 2020)
- ✗ Depends on a suitable access method and careful setup (Elsahar et al., 2019)
- ✗ Cost, complexity, and training can limit use (Vieira et al., 2023)

Figure 2.12 An example of a Tobii gaze system (Global, 2026)

Figure 2.13 Tobii gaze system in use (PCEye Eye Tracker for Accessibility, 2026)

Eye-Gesture-Based Apps

- ✓ Work with simple eye gestures using standard cameras (Ezzat et al., 2023)
- ✓ Compact gesture "alphabet" covers daily commands (Ezzat et al., 2023)
- ✓ Mobile gaze apps offer lightweight phrase access (Google, 2020)

- ✗ Gesture recognition may fail under poor lighting or positioning (Ezzat et al., 2023)
- ✗ Restricted to a predefined command set (Ezzat et al., 2023)
- ✗ Apps with pre-written phrases remain limited for open text (Google, 2020)

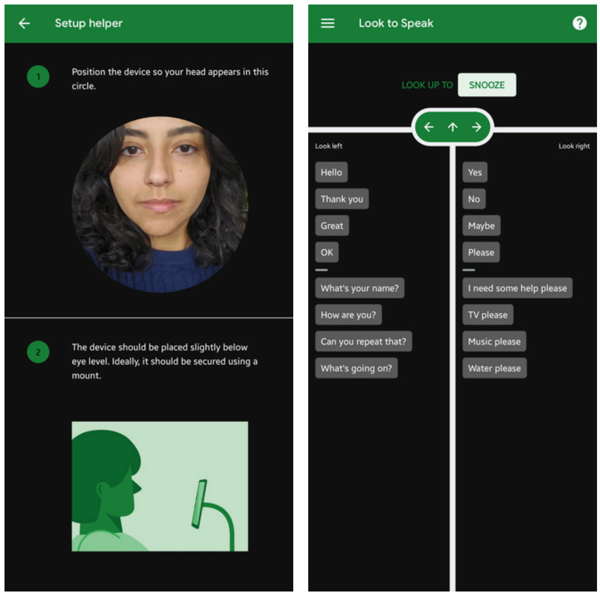


Figure 2.14 (Left) Screenshot of the Look to Speak app's setup screen, and (Right) the communication screen

Figure 2.15 Blink-To-Live mobile application's basic services (Ezzat et al., 2023)

Table 2.3 (Continued)

High-Tech AAC
Non-Invasive

Pupil-Tracking-Based Systems

- ✓ Can use changes in pupil size or accommodative response when conventional eye-tracking access fails (Lorenzo Villalobos et al., 2021; Stoll et al., 2013)
- ✓ Additional information about attention, workload or fatigue (A. P. Pinto et al., 2025; Stoll et al., 2013)

- ✗ Requires sensitive measurement and controlled lighting; signals can be noisy and hard to decode (Lorenzo Villalobos et al., 2021; Stoll et al., 2013)
- ✗ Currently experimental and research-focused with limited everyday use evidence (A. P. Pinto et al., 2025)

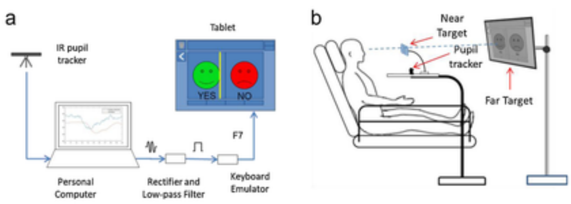


Figure 2.16 Functional scheme of the communication prototype: the personal computer, fed by the eye-tracker, detects the pupil constriction and generates a «beep» on the headphones output; this signal is transformed into a trigger signal for the scanning selection (Lorenzo Villalobos et al., 2021)

Non-Invasive AAC–BCI

- ✓ Bypass motor output, enabling communication with minimal movement (Ozawa et al., 2020; Peters et al., 2022)
- ✓ Useful when eye-based or switch access is unreliable (Schnetzer et al., 2023)

- ✗ Slow, fatigue-prone and training-heavy; performance varies widely (Larradet, 2020; Peters et al., 2022)
- ✗ Mostly confined to research/specialist settings; requires caregiver support (Ozawa et al., 2020)

Figure 2.17 Non-invasive AAC–BCI setup, a user wearing an EEG cap connected to a communication interface on a computer screen (Brain-Computer Interface (BCI) Explained - RoboticsBiz, 2021)

High-Tech AAC
Invasive

Implanted BCI Speller

- ✓ Provides stable neural access that can work when eye- tracking is not feasible (Vansteensel et al., 2016)
- ✓ Demonstrated long-term at-home spelling use (Vansteensel et al., 2016)

- ✗ Requires neurosurgery and complex specialised support (Peters et al., 2022)
- ✗ Very fatiguing (Schnetzer et al., 2023)
- ✗ Needs a lot of time for training (Schnetzer et al., 2023)

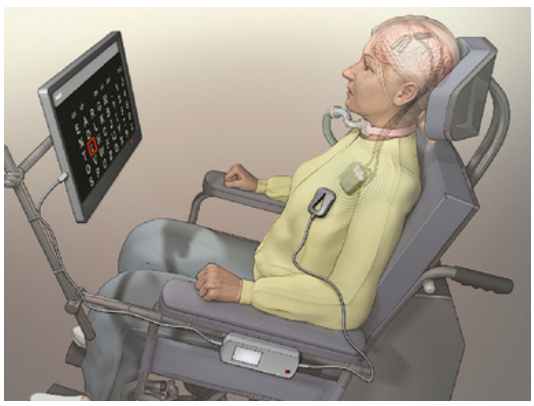


Figure 2.18 Implanted BCI spelling system enabling communication via a brain–computer interface, with an on-screen letter grid controlled through neural signals (Brain–Computer Interface in a Locked-In Patient | NEJM, 2016)

Table 2.3 (Continued)

High-Tech AT

Smart-Glasses Wheelchair Control

- ✓ Enables powered wheelchair driving via small head/eye movements (Innovative Head Control for Wheelchairs | Munevo DRIVE, n.d.)
- ✓ Supports functional independence for users without hand control (Innovative Head Control for Wheelchairs | Munevo DRIVE, n.d.)

- ✗ Requires consistent head movement and calibration (Innovative Head Control for Wheelchairs | Munevo DRIVE, n.d.)
- ✗ Adoption depends on funding, training, and service context (Nunez Sardinha et al., 2025)

Figure 2.19 Munevo DRIVE glasses on a user (Innovative Head Control for Wheelchairs | Munevo DRIVE, n.d.)

Figure 2.20 Munevo glasses in use for controlling a wheelchair (A Smart Head Control for Your Wheelchair, 2019)

Eye-Tracking Environmental Control

- ✓ Increase independence by enabling gaze-based control of lights and appliances (V. Gatdula, 2020; Yumang et al., 2020)
- ✓ Can unify communication and environmental control on one interface (Yumang et al., 2020)

- ✗ Dependent on robust eye-tracker performance and wireless links (Yumang et al., 2020)
- ✗ Installation and maintenance can be resource-intensive (V. Gatdula, 2020)

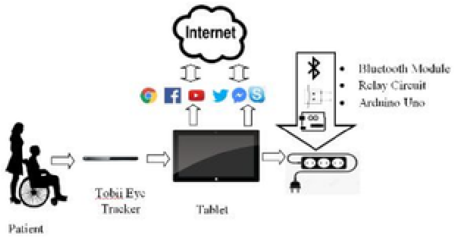


Figure 2.21 System architecture and the concept of environmental control with an eye-tracking device (V. Gatdula, 2020)

Assistive Living / Smart Home

Systems such as automated blinds, doors, and environmental controls, or smart safety and monitoring systems

- ✓ Linked to greater choice, control, security, privacy and participation (Van Dam et al., 2024)
- ✓ Allow users to perform tasks without constant caregiver help (Nunez Sardinha et al., 2025)

- ✗ Raise privacy, ethics, autonomy and cost concerns (Schaur & Matausch-Mahr, 2025)
- ✗ Real-world long-term adoption and integration remain challenging (Van Dam et al., 2024)

Cross-Cutting Tech

AI-supported Apps

- ✓ Speed up conversation by suggesting context-aware responses (Sennott et al., 2019; Valencia et al., 2023)
- ✓ Can support more natural conversational flow (Weinberg et al., 2026)

- ✗ Suggestions may misrepresent user intent or style (Valencia et al., 2023)
- ✗ Risks around bias, authorship, agency, and privacy (Blasko et al., 2025; Weinberg et al., 2026)

Figure 2.22 Screenshot of Bobbi, an AI voice app (Lifechaingers & Bobbai - AI Speech App That Listens and Learns, n.d.)

2.5. Contextual Inquiry through Video Ethnography

To complement the literature review, publicly available visual media were reviewed to gain a closer, observational view of daily life with LiS (Everri et al., 2020; Slutskaya et al., 2018). Fifteen sources were selected (Table 2.3) for their focus on diagnosis, communication, rehabilitation, and the lived experience of the condition, and were used for two distinct purposes. The documentaries and TED talks, in which people living with LiS and their families speak for themselves, were treated as first-person accounts and form the basis of the observations below, while the fictional sources were read not as testimony but as indications of how profound physical disability is portrayed to a general audience.

Table 2.4 Screen-based sources included in the contextual inquiry

Media Type		Source	Main Focus
Film	1	The Diving Bell and the Butterfly (Schnabel, 2007)	Identity, communication, and rehabilitation with LiS
	2	The Intouchables (Toledano & Nakache, 2011)	Caregiving, participation, dignity, and social relationships around tetraplegia following spinal cord injury
TV Episode	3	House M.D. – Season 5, Episode 19; Locked In (Attias, 2009)	Diagnosis, communication, awareness, and ethics around LiS
Documentary	4	A Boy with Locked-in Syndrome and a Family That Won't Quit (Special Books by Special Kids, 2023)	Daily life, family, rehabilitation, and communication with LiS
	5	Locked-In Syndrome: Nick's Story (Attitude, 2016)	Communication, relationships, and participation with LiS
	6	The Man Who Beat Locked-in Syndrome and Walked Out of Hospital (This Morning, 2019)	Rehabilitation and long-term recovery of LiS
	7	Surviving Locked-in Syndrome: How One Man Confounded Expectations of Death (CBS Sunday Morning, 2021)	Recovery, communication, and adaptation to LiS
	8	Kyle's Journey with Locked-in Syndrome (Shirley Ryan AbilityLab, 2022)	Rehabilitation, recovery, and family support around LiS
	9	Living with Locked-in Syndrome: Darren's Story (Alcedo Care, 2024)	Long-term care and life with LiS
	10	How a Brain Implant and AI Gave a Woman with Paralysis Her Voice Back (UC San Francisco (UCSF), 2023)	AI-enabled speech restoration and brain-computer interfaces for severe paralysis.
	11	Betsy Peters – Brain-Computer Interface for People with Severe Speech and Physical Impairments (Tech Oregon, 2014)	Communication brain-computer interfaces
TED Talk	12	Dawn Faizey Webster – Fighting Back One Blink at a Time: Living with Locked-In Syndrome (TEDx Talks, 2018)	Lived experience, identity, and communication around LiS
	13	Kate Allatt – Voicing Inner Thoughts Matters (TEDx Talks, 2016b)	Awareness and patient advocacy about LiS
	14	Kati Lepistö – Imagine if You Would Get a Stroke and Get Completely Paralysed (TEDx Talks, 2016a)	Recovery and resilience with LiS experience
	15	Femke Nijboer & Paul Trossèl – Unlocking People with Locked-in Syndrome (TEDx Talks, 2020)	Assistive communication, brain-computer interfaces, and quality of life regarding LiS

The deeper values identified in the literature review (Section 2.2.1) — identity and dignity, autonomy, social participation, and communication — consistently re-emerged in these sources, expressed through recurring scenes, testimonies, and communication tools rather than stated explicitly. The sections below revisit each value in turn, using representative moments from the reviewed media to show how it appears on screen.

Identity and Dignity

Several of the reviewed sources show people with LiS rebuilding a sense of self and being recognised by those around them as still "the same" person despite high levels of physical dependence.

> *"He is still conscious, aware... he can hear, he can see, he's still the same."*
>
> *— Grandmother, Special Books by Special Kids, 2023*

This identity persists even when it cannot be expressed, and accounts of the acute phase describe the distress of remaining present but unrecognised.

> *"Imagine your loved ones looking at you in a hospital room, and you are screaming at them: 'I'm here', and they can't hear you."*
>
> *— Dawn Faizey Webster, TEDx Talks, 2018*

The identity is not undermined by profound motor impairment or the tools used to express it, but rather must be actively noticed and reaffirmed by others.

Autonomy

These sources frame autonomy as conditional on being recognised as conscious, addressed directly, and given the means to express one's own preferences. Without reliable communication, autonomy remains theoretical rather than lived, reinforcing the literature's emphasis on communication as a precondition for supporting choice and consent in LiS.

Social Participation

Despite severe physical disability, people with LiS are depicted as remaining socially engaged rather than withdrawn, staying present in family life, friendships, and community roles even as they depend on others for nearly every physical task. Rather than participation shrinking to fit the limits of the body, it is shown continuing through the people and communication tools around them.

Communication

Communication comes across as effortful, slow, and indispensable throughout the reviewed material.

> *"Everything revolves around the board."*
>
> *— Nick's partner, Attitude, 2016*

Restored or assisted communication is also shown extending beyond the immediate relationship, into advocacy for others facing the same condition.

> *"Communication... I would say it's a fundamental human right."*
>
> *— Kate Allatt, TEDx Talks, 2016b*

Use of Technologies

Low-tech AAC tools recur throughout these sources (Figures 2.23–2.25) and are consistently framed as facilitators of human connection rather than technical achievements in their own right. More advanced systems — such as brain-computer interfaces that let a paralysed person communicate through a digital avatar (Figure 2.26) — feature far less often, and only in contexts tied to research or clinical demonstration.

Figure 2.23 Transparent letterboard (Attitude, 2016)

Figure 2.24 Alphabetical letterboard in French, used with an eye-blink code to spell out the autobiographical book by Jean-Dominique Bauby (Schnabel, 2007)

Beyond these value-based patterns, two broader considerations emerged from the contextual inquiry. First, access to both established AAC systems and wider care infrastructure appears strongly shaped by socioeconomic position: in films such as The Diving Bell and the Butterfly (Schnabel, 2007) and The Intouchables (Toledano & Nakache, 2011), protagonists are wealthy and have extensive access to care and technology, in clear contrast to many real-life accounts in which resources are far more limited. Second, emerging systems such as brain-computer interfaces (Figure 2.26) remain largely confined to research or specialist clinical settings, dependent on institutional support and sustained funding rather than being part of everyday life (Tech Oregon, 2014; UC San Francisco (UCSF), 2023).

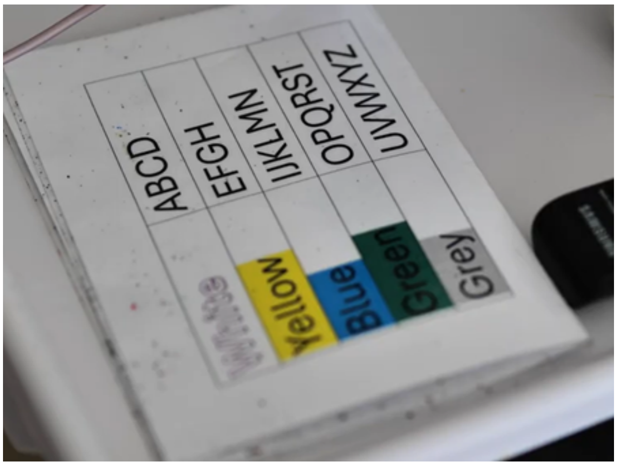


Figure 2.25 Colour-coded AEIOU board; first, the colour is selected and then the letter (Alcedo Care, 2024)

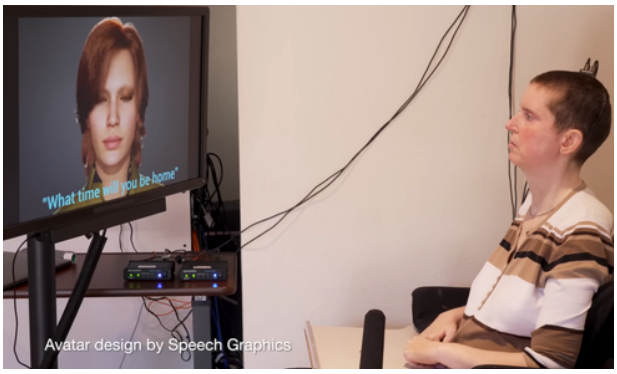


Figure 2.26 A brain-computer interface enables a paralysed woman to speak through a digital avatar (Tech Oregon, 2014)

2.6. From Understanding to Design

The following implications translate the chapter's findings into design-phase orientations.

Although people with LiS share common clinical characteristics, the condition spans a wide range of residual abilities, circumstances, and care contexts, making a one-size-fits-all approach unsuitable. Design should respond to the individual's capabilities, preferences, and environment rather than to general assumptions about the condition.

Within this variation, one factor proved central: physical impairment alone does not determine well-being. Everyday life with LiS is shaped by communication, dignity, relationships, participation, and the ability to remain recognised as a person. Communication should therefore be treated not as a technical function, but as the mechanism through which autonomy, identity, dignity, and participation become possible, and improving it can influence several dimensions of well-being at once.

Because adaptation to LiS is ongoing, quality of life often improves as people adjust and regain involvement in daily life. Design can contribute to that adjustment by creating opportunities for control, self-expression, and engagement, focusing less on restoring physical function and more on sustaining what makes daily life meaningful.

This adaptation rarely happens in isolation, so design should extend beyond the individual to the wider relational and care context: Karel's partner, healthcare professionals, and daily routines all shape his well-being and belong to the design context, while his own preferences stay central.

The same need for clear, accessible information applies to the design process itself: its aims, outcomes, and limitations should be communicated transparently to support trust and realistic expectations.

Finally, technical possibility does not guarantee everyday use. Many technologies for LiS remain hard to access, afford, or integrate into care. Design should therefore weigh feasibility beyond the prototype stage, building on technologies that are accessible and affordable for Karel, with usability, reliability, and adoption prioritised alongside technical capability.

EMPATHISE

The empathise phase focuses on developing an in-depth understanding of Karel, his daily life, and his context. A visual overview of the activities conducted, along with their aims and outcomes, is provided (see Table 3.1).

Table 3.1 Overview of the activities conducted during the empathise phase

Aim	Activity	Dates	Stakeholders involved	Key outcomes
Introduce the project and build rapport	Introductory visit with Karel	Sept 17 2025	· Karel · Karel's Partner · Designer · Company Supervisor	· Preliminary understanding of Karel's context
Understand Karel's lived experience, AAC, AT, care context, and stakeholders	Contextual observation and semi-structured interview	Dec 17 2025	· Karel · Karel's Partner · Designer · Company Supervisor	· Stakeholder map · Context map · Overview of Karel's AAC and AT systems · Initial design insights around agency, safety, and communication
Structure Karel's daily experience	Experience mapping	Jan 3–10 2026	· Karel · Karel's Partner	· Synthesised experience map · Key emotional moments across the day · Insight that negative moments relate to dependence, being alone, and communication barriers · Insight that positive moments relate to connection, choice, and interaction
Check and refine the interpreted needs with Karel	Online validation interview	Jan 14 2026	· Karel · Karel's Partner (Observer) · Designer · Company Supervisor	· Validation of uncovered needs · Confirmation of safety, communication, and agency as central needs · Strong need for independent contact with nurses
Understand care routines, constraints, and staff perspectives	An informal conversation with healthcare professionals of Karel's care unit	Feb 17 2026	· Unit Manager · Occupational Therapist · General Physician · Nurse · Designer · Company Supervisor	· Design considerations around trust, physical fit, workflow integration, and alarm clarity · Insight that the design should be quick and unobtrusive for nurses
Gain expert input on LiS, rehabilitation, AAC, and AT	Open conversation with LiS experts of de Hoogstraat	Mar 10 2026	· 2 Occupational Therapists · 2 Speech Therapists · Technical Specialist · Designer · Company Supervisor	· Need to combine high-tech and low-tech AAC · Importance of simple, reliable controls · Insight into autonomy, fear, emotional safety, and technology integration

3.1. Context of Karel's Daily Life

To better understand the environment shaping Karel's daily life, this section outlines both the physical context of his life and the network of stakeholders involved in his care.

3.1.1. Physical Environment

Karel currently lives in a long-term care facility in the Netherlands, in a specialised unit for people with complex respiratory and neuromuscular conditions. Of the unit's eight-bed capacity, he is the only resident with LiS. The unit offers shared spaces such as a cafeteria, a physiotherapy room and a garden. He and his partner make consistent use of the physiotherapy facilities on weekdays.

However, beyond these sessions, they rarely go to the cafeteria or outside, because any sudden need for medical support would require a rapid return to his room, where the necessary equipment is available.

His private room (see Figure 3.1) contains multiple medical devices, yet it is strongly personalised with gifts, postcards, photographs, and a television, creating a familiar and homely atmosphere. An alarm system is also available in his room to call nurses when needed. However, it must be activated by someone else, usually his partner. He spends most of his time in his private room, during the day in his wheelchair and at night in his bed.

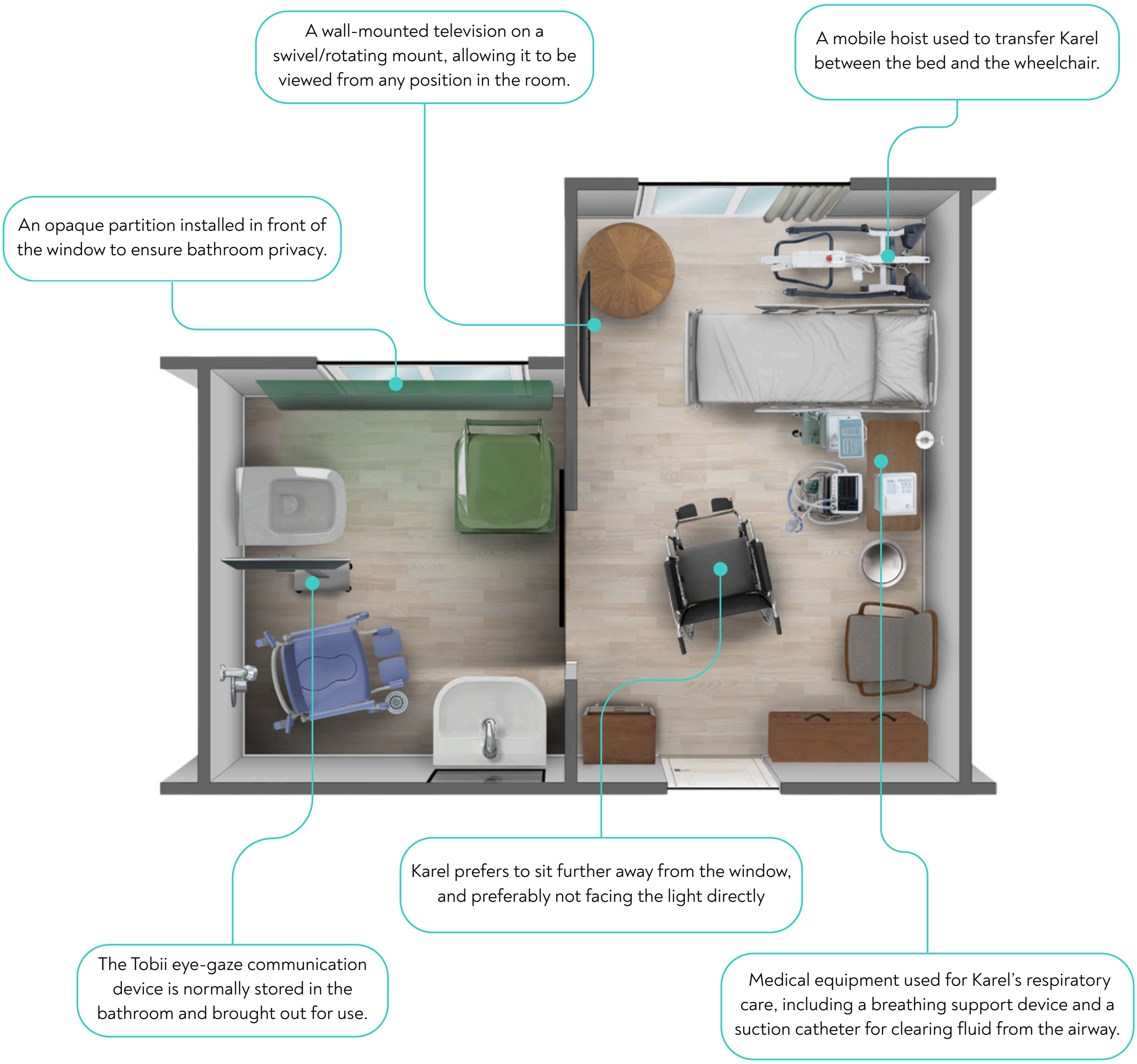


Figure 3.1 Spatial layout of Karel's private room, showing the arrangement of his bed, wheelchair, lift, medical equipment, and personal objects

3.1.2. Stakeholders

Karel's living environment involves multiple people and organisations who shape his daily experience and access to communication (see Figure 3.2). At the care facility, nurses provide him with consistent care. Karel's care unit comprises a team of 14 nurses, supplemented, when required, by staff from other departments, by personnel from an external care organisation, or by nursing students on placement. Care is organised into three daily shifts, with structured per-patient handovers conducted at each transition, at 07:00–07:30, 15:00–15:30, and 23:15–23:30. His partner is present with him for almost the entire day on weekdays, and his parents visit him weekly. He also maintains contact with friends online.

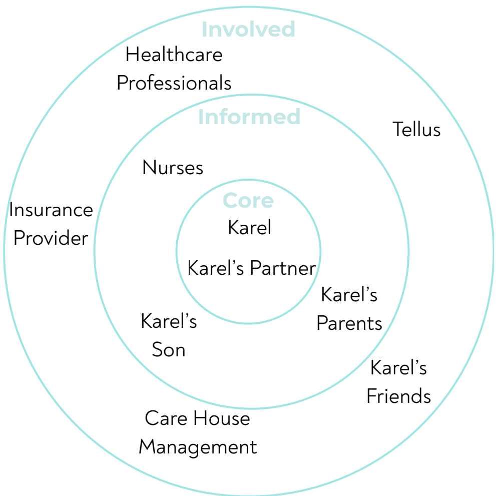


Figure 3.2 Concentric stakeholder map showing Karel at the centre, surrounded by layers of stakeholders based on their proximity to his everyday life

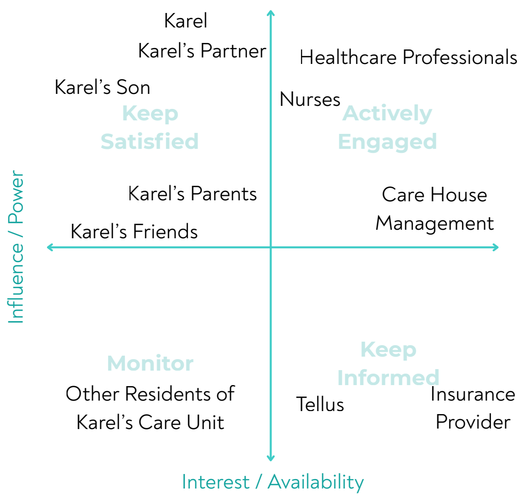


Figure 3.3 Power–interest matrix positioning stakeholders according to their influence over Karel's care and their level of involvement

Building on the insights from the stakeholder map analysis (Figure 3.3), in addition to Karel and his partner, healthcare professionals, nurses, and care-home management need to be actively engaged in this project. The map also highlights a notable gap between influence and involvement in Karel's care. Those most present in his daily life are not always the ones with the greatest decision-making power, so this imbalance needs to be carefully considered, as it may affect how resources and technologies are allocated and implemented in his everyday care.

3.2. Karel's Communication Systems

Currently, Karel relies on three main AAC systems. As illustrated in Figure 3.4, these include eye signals, a letterboard, and a Tobii eye-tracking monitor.

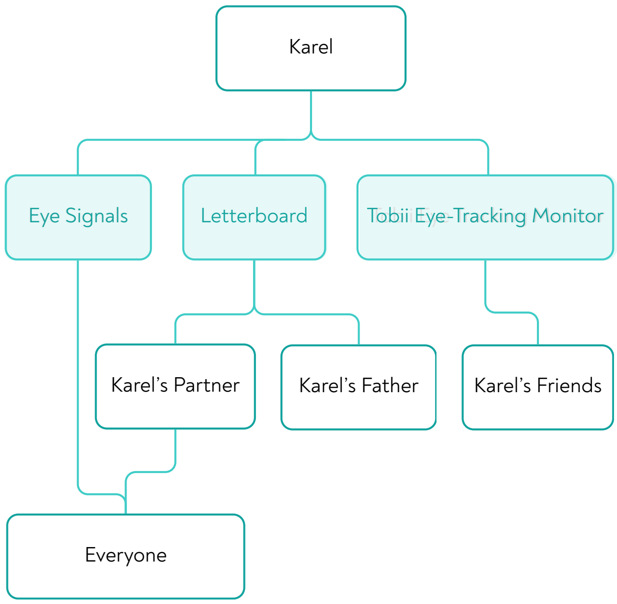


Figure 3.4 Karel's three main AAC systems and who he primarily uses each method with

Karel's Eye Signals

His first and most-used communication method is his predefined eye codes for quick yes/no answers. Looking up means "yes" and looking down means "no"; they agreed with his partner to reduce accidental "yes" responses, since looking up requires more effort. However, these signals can still be misinterpreted when someone is standing above Karel's eye level, and he is simply looking at them rather than intentionally responding "yes." In addition, repeatedly looking up and down functions as a signal that he wishes to initiate communication.

Karel's Letterboard

For more expressive communication, Karel uses a letterboard, created with his partner (see Table 3.2). To use this method, his partner counts the rows aloud, and Karel looks up to select the correct row; she then counts the columns to identify the letter, using the same procedure. Karel uses additional eye signals to manage the process, such as looking left to indicate a new letter and looking down to signal an error and restart.

Table 3.2 Letterboard developed by Karel and his partner, showing the numbered rows and columns used to select letters through eye-based counting

	1	2	3	4	5	6
1	A	B	C	D	E	
2	F	G	H	I	J	K
3	L	M	N	O	P	
4	Q	R	S	T	U	
5	V	W	X	Y	Z	

This method can range from a two-step selection – for example, the letter "A" in row 1, column 1– to 10 steps – for example, the letter "Z" in row 5, column 5 – making it time-consuming even under ideal conditions. Errors and the need to repeat sequences further extend the process and may contribute to more communicative strain for both Karel and his partner.

Over time, Karel and his partner have become highly familiar with this system and often use it from memory, which speeds up the communication. His father also uses the letterboard but follows a different method, starting with the columns rather than the rows and pointing directly to letters rather than counting aloud, which changes the structure Karel is used to and makes communication challenging. Nurses, however, rarely use the letterboard, primarily because it is time-consuming, especially given their busy workloads. Hence, Karel's partner often serves as a communication mediator between Karel and the nurses, which adds to her responsibilities.

" I don't like to be a speech computer... Sometimes I don't have the time or the patience to do it... or it goes wrong, and I have to repeat it... and he gets disappointed, and I get annoyed..."

— Karel's partner

Karel and his partner have also developed a separate communication board listing his frequently occurring needs (see Table 3.3) for nurses to use to communicate with Karel quickly. However, in practice, staff tend to carry out tasks based on their own assessment without using this board.

Table 3.3 Translated communication board with Karel's frequently recurring care needs

Suction mouth	Suctioning cannula	New heat–moisture exchanger
Cough	Place the suction aid	Ventilator hose too high
Head straight	Legs straight	Ventilator hose, tube too tight
Ankles apart	Arms straight	Cushion slightly raised
Letterboard	Urine tip leaking	Bowel movement

Tobii Eye-Tracking Monitor

Karel also uses a Tobii eye-tracking system as a high-tech AAC tool. As part of his daily routine, before his partner arrives, a nurse positions him in the wheelchair (see Figure 3.5) and sets up and calibrates the Tobii monitor to track his gaze (see Figure 3.6). After that, he can select items by dwelling on them, open applications, and send short messages or emojis (see Figure 3.7). With this system, he can communicate and connect with more people, which he describes as one of his favourite daily activities.

Figure 3.5 Karel's partner positions the Tobii monitor in front of him

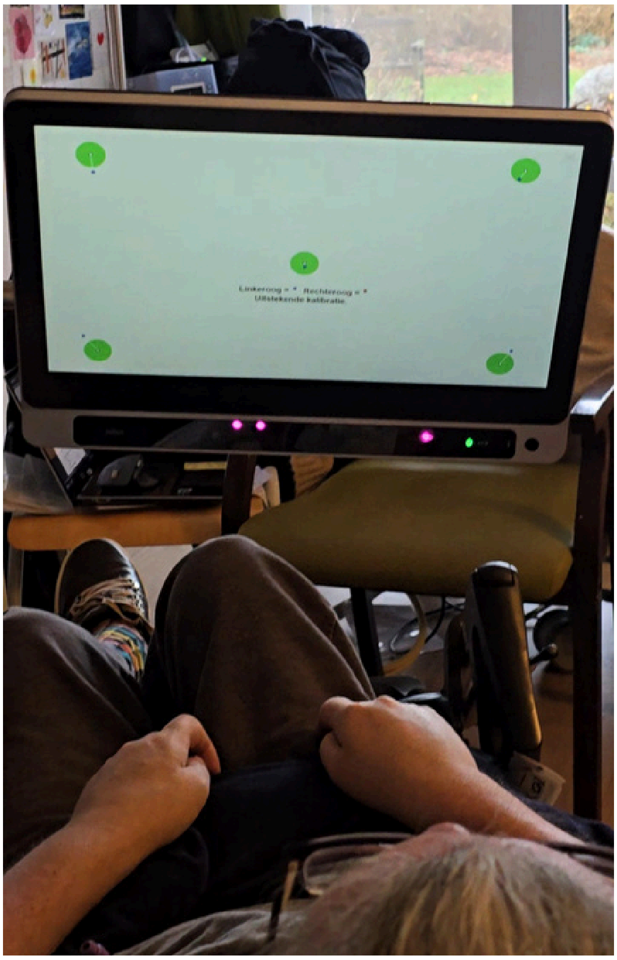


Figure 3.6 Karel calibrates the system with his gaze.

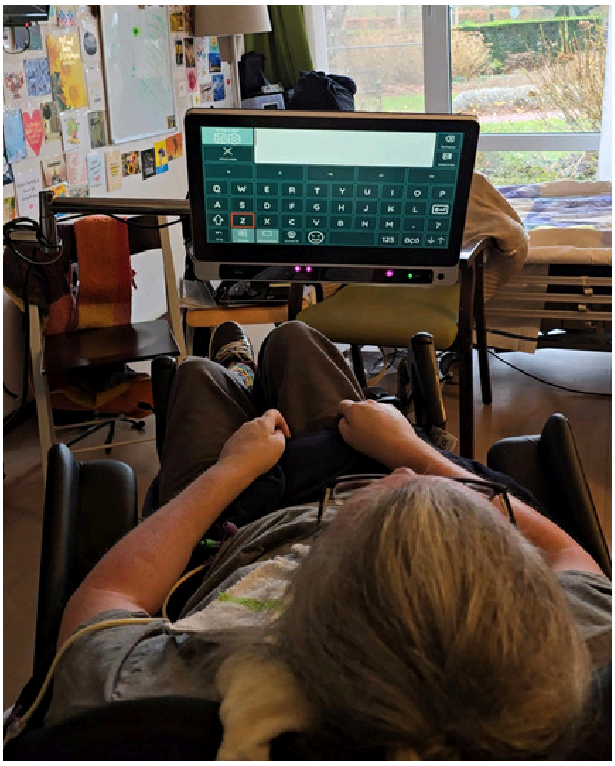


Figure 3.7 Karel typing on the Tobii monitor with his gaze

However, this system has some limitations. Spasms and posture changes frequently disrupt calibration, and because he cannot independently call staff when the device fails, he must wait for routine visits, which he finds stressful and isolating. Furthermore, some system functionalities, such as listening to music or watching films, have been out of service for months and require maintenance. These issues stem from the provider's slow technical support, so for now only the WhatsApp function works reliably, even though the system could support more activities. As highlighted in Figure 3.3, such providers exert considerable influence over Karel's daily experience while showing minimal interest and direct involvement.

3.3. Understanding Karel

A two-hour semi-structured interview was conducted with Karel, which focused on his preferences, activities, and needs (see Appendix II: Interview Questions). To adapt the interview format for Karel, most questions used a numbered rating scale that allowed him to indicate gradations by signalling "yes" at the desired number more quickly than by spelling, while still going beyond simple yes/no answers. With Karel's agreement, his partner supported him when longer, open answers required the letterboard or when additional clarification was needed. From this interview and contextual observations, several interconnected topics emerged around how Karel experiences life: Agency, Communication, Safety, and Personhood.

Agency and Control

Karel is cognitively responsive and sharp, yet fully constrained by the syndrome.

> *"It's like there's a 'wall' keeping me from moving my body."*
>
> *— Karel*

He feels he has little control over how his day unfolds and limited involvement in decisions about his routine, including everyday choices such as which television channel to watch. It is also difficult for him to ask for assistance, for instance, when he is in an uncomfortable position in bed and needs help repositioning.

> *"Prisoner... yeah, prison, he wants to get out of prison... he finds it like he's in prison in his own body."*
>
> *— Karel's Partner, interpreting Karel*

Communication and Social Participation

Karel values social connection highly and puts considerable effort into expressing himself. During the interview, he actively engaged with the questions, often offered open-ended answers, and constructed longer sentences. However, during periods of heavy workload and high demands on caregivers, they may not have time to communicate with Karel properly and may be limited to closed-ended questions. This is challenging for Karel, as he has a strong desire to communicate and participate socially.

> *"Some caregivers do not communicate with me at all..."*
>
> *— Karel*

Karel enjoys in-person company and staying in touch through his Tobii, with the afternoon often his favourite time of day because his partner is present. His contact beyond his partner and parents is relatively limited, and he misses direct interaction with nurses.

> *"Sometimes people come here, and they talk... but they don't ask him anything... they talk with each other... while he's just sitting there."*
>
> *— Karel's Partner*

Physical Safety

Safety and physical needs play a major role in how Karel and his partner experience daily life. Maintaining bodily stability and a sense of security is a constant, background priority that influences when and how they engage in other activities.

This is evident in Karel's choice to use the breathing device at night when his partner is not present. Although he can breathe reliably on his own, wearing the device makes him feel **"safe"**, a precaution he relies on when no one is nearby to intervene if he needs immediate assistance.

Sense of Self and Personhood

Karel used to have an active, social life, enjoying outdoor activities such as canoeing, cycling, travelling, and spending much of his time with friends and family. These interests remain important to him, and despite the limitations imposed by LiS, he continues to engage with them as much as possible, for instance, by wanting to see the cycling route he used to ride displayed on the rehabilitation cycling machine's screen (see Figure 3.8). He also expresses his personality through small details, such as wearing colourful "happy socks," making jokes with others, and wanting to drink coffee simply because it was a daily habit, even though he can no longer smell or taste it.

Figure 3.8 Karel using the rehabilitation cycling machine with his partner

Conclusion

Overall, the interview presents Karel as an intellectually engaged, sociable, and determined person whose identity extends far beyond his medical condition. He values humour, meaningful interaction, and involvement in everyday life, and continues to seek ways to express his preferences and maintain connections with the person he was before acquiring LiS. At the same time, his dependence on others for communication and physical support often limits his agency, social participation, and ability to feel recognised as an active person.

3.4. Healthcare Professionals' Perspective

An informal conversation was held with healthcare professionals from Karel's unit, including the manager, an occupational therapist, a general physician, and a nurse, to gain a deeper understanding of Karel's care context and their perspectives on care. The conversations highlighted several considerations for the design, which later informed the development of the design requirements.

Trust and Acceptance

Any design for Karel must be understandable, trusted, and aligned with the beliefs and preferences of both Karel and his partner; otherwise, it is unlikely to be adopted, regardless of its technical capabilities.

Physical and Contextual Fit

The design needs to be ergonomically and contextually suitable, fitting his posture, safety requirements, and the spatial and temporal realities of his daily environment.

Emotional and Relational Expression

It should support not only functional signalling, but also emotional connection and a sense of reciprocity between Karel and the professionals providing care.

Integration into Care Workflows

Finally, the design must integrate smoothly with existing care workflows and signalling systems, providing nurses with clearer, more meaningful information about the urgency and nature of alarms.

3.5. LiS Expert Consultation

An open conversation was held with a multidisciplinary team at De Hoogstraat Revalidatie, a specialised Dutch centre with dedicated expertise in LiS (De Hoogstraat Revalidatie | Kom verder., n.d.). The team included occupational and speech therapists, a technical adaptation specialist, and clinicians experienced in LiS rehabilitation, and the discussion focused on how they assess people's capabilities, adapt technology, and support communication and autonomy in everyday life. From this expert consultation, several key points emerged regarding the design of products for people with LiS and their communication needs.

Communication Methods and AAC

People with LiS require communication methods tailored to their individual abilities and preferences, often combining both high-tech and low-tech AAC. Even when advanced systems are available, simple letterboards frequently remain central in daily life because they are always present, easily understood by family and friends, and embedded in familiar routines.

Technological Integration

From a technical perspective, there is a persistent problem with interoperability and company support. Different AAC and AT systems rarely work smoothly together as one system. There is therefore a need for a flexible "empty system" or hub, where one or two reliable buttons can control many things at once, such as communication, phone, computer, alarms, and the environment.

Psychosocial Dimensions and Autonomy

Psychosocial dimensions play a major role in life with LiS. Fear, strong emotional responses, and a pronounced need for autonomy are common. Rehabilitation approaches that engage people in honest conversations about motivation, effort, and refusal recognise their cognitive and emotional capacities, treating them as decision-makers rather than passive recipients of care.

"Fear is the most heard problem, both in people with LiS and in health care professionals."

*— Speech therapist,
De Hoogstraat Revalidatie*

3.6. Experience Map

Karel and his partner were invited to complete a daily log over the course of one week, documenting his activities, interactions, and inner experiences. As existing diary and cultural probe formats are not designed to accommodate individuals unable to write independently, a tailored version of this tool was developed specifically for the present project. Each entry was structured around six elements: time and place; what occurred; Karel's thoughts; the emotional and physical sensations experienced (rated by intensity); the individuals or technologies involved; and any difficulties, unmet needs, or preferred alternatives. Entries could be completed collaboratively with his partner, revised retrospectively, or left incomplete, minimising the burden of participation given Karel's communication limitations (see Appendix III for the full guide and completion instructions).

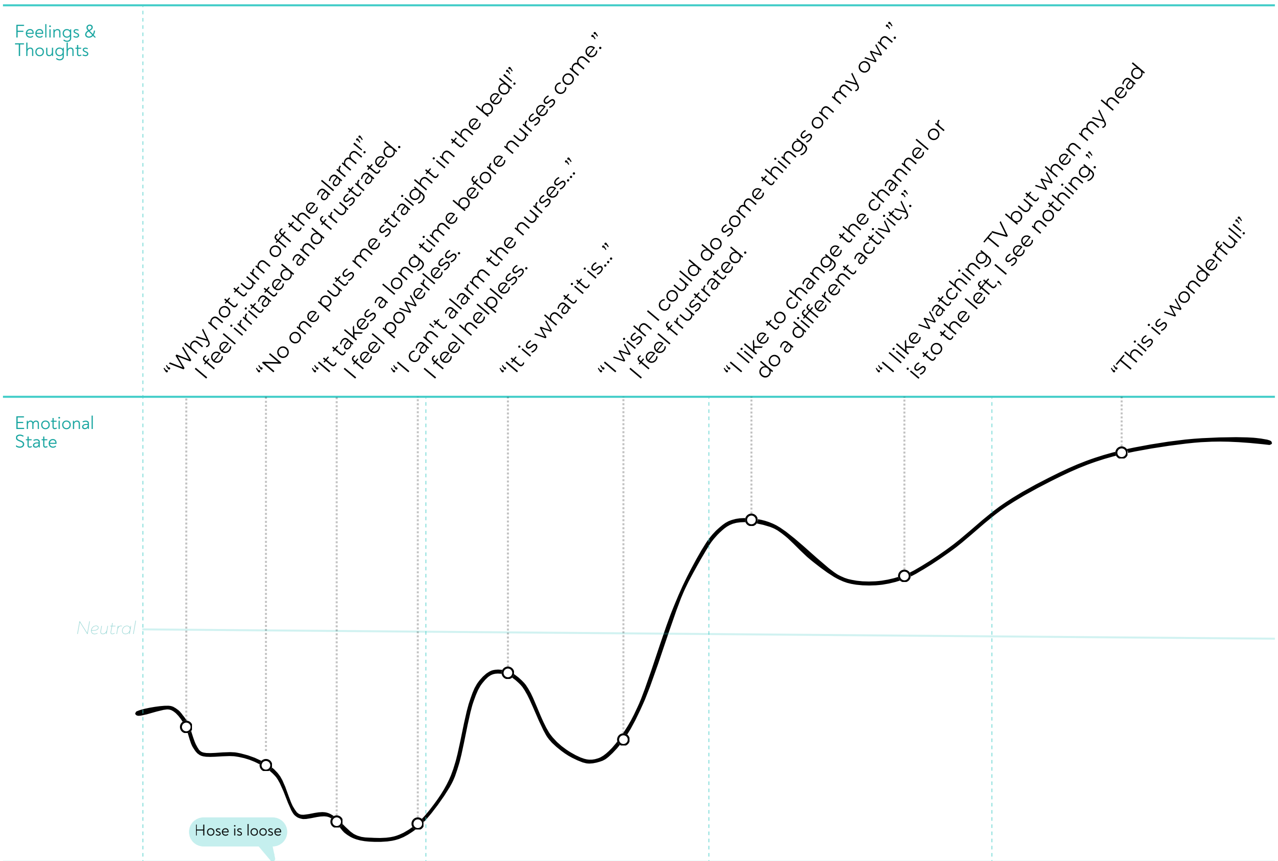
These log entries were subsequently synthesised into an experience map, following the format proposed by Philpot et al. (2019), to provide an overview of Karel's daily routine and lived experience, including emotional and subjective responses (Göttgens & Oertelt-Prigione, 2021; Woodgate et al., 2026).

The resulting map is presented across two figures, covering the morning and early afternoon (Figure 3.9) and the remainder of the day into the evening (Figure 3.10). The map highlights several patterns in his emotional experience. His negative emotional states are most strongly associated with dependence and communication barriers, particularly in instances where his partner is absent and he remains alone in his room; these states intensify further when assistance is required that he is unable to request or explain independently, irrespective of whether the matter is urgent or relates to discomfort. Although his physical condition remains largely static, his emotional experience is active and nuanced, with negative affect arising in specific situations rather than persisting throughout the day, and even seemingly minor discomforts assuming considerable significance, as addressing them contributes to his sense of agency and control. Positive experiences, by contrast, are closely associated with social connectedness and communication, and are further linked to moments of agency and choice arising from active interaction with his partner or friends. Finally, Karel perceives his days as repetitive and expresses a preference for variety, although this preference remains constrained by the functional and contextual realities of living with LiS.

Beyond these findings from the map itself, the logging activity also revealed notable tension in Karel's daily life and relationships. Each entry required repeated communication between Karel and his partner, thereby adding effort and emotional strain to their daily routine. His partner noted that this level of detail exceeded what Karel typically communicates about his inner experiences, adding to the effort required from both of them. This finding reinforces the need for design solutions that support independent communication without imposing a substantial additional burden on the relationship.

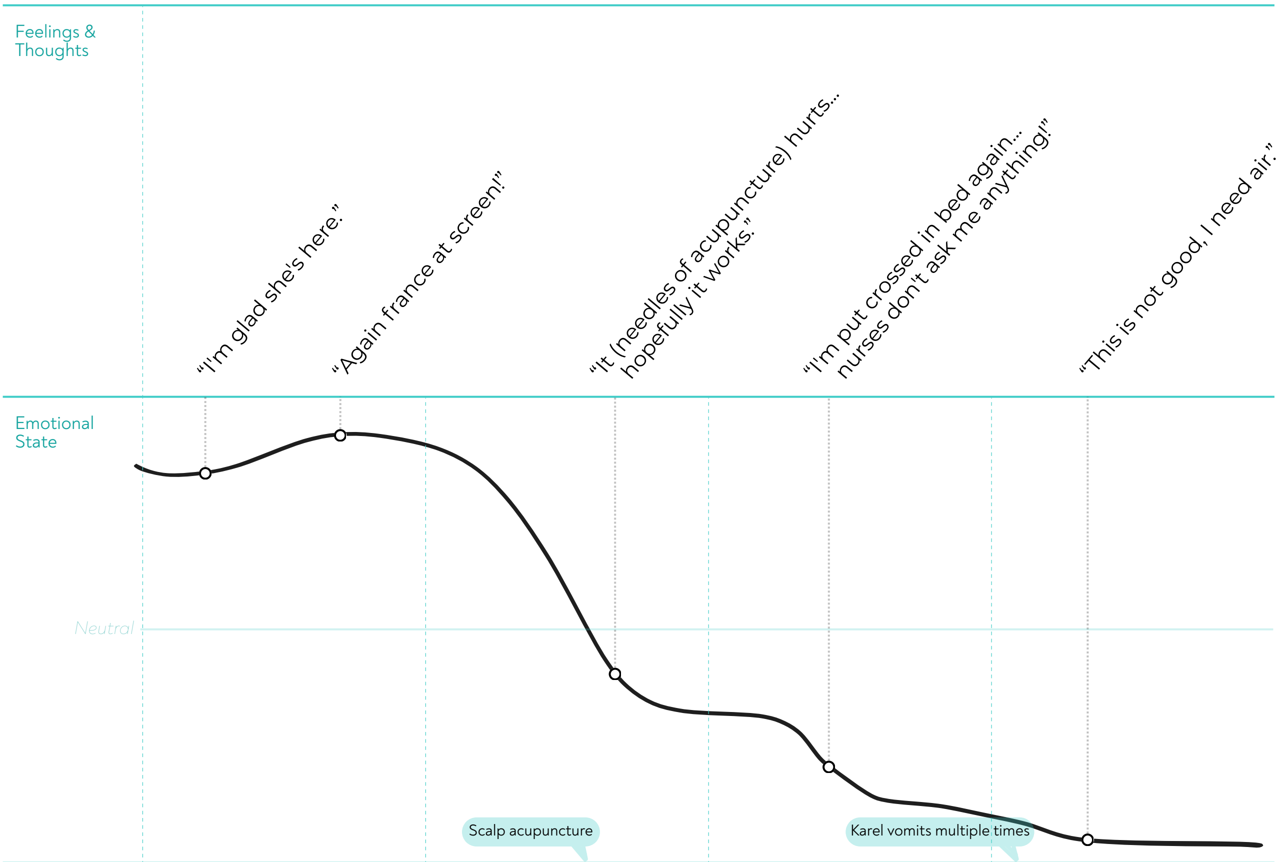
It should further be noted that the resulting log does not constitute a purely direct account from Karel, as his partner completed certain entries based on her own interpretation of his experience and her assessment of what was most relevant to the project. Differentiating between Karel's and his partner's contributions, and verifying her interpretations with him wherever possible, constitutes an important methodological safeguard that was not fully implemented in this particular logging activity. Accordingly, the log should be regarded as a valuable yet imperfect representation of Karel's daily life, rather than a fully consistent or exclusively first-person record.

To address this limitation, the patterns derived from the experience map were distilled into a concise set of overarching statements and presented to Karel directly. Individual log entries were not verified one by one, as this would have required extensive letterboard communication and added considerably to the effort demanded of Karel and his partner. During a brief online meeting, he was invited to indicate whether these statements accurately reflected his experience, with the opportunity to nuance or contest them where necessary (see Appendix IV: Validation Interview Questions). This process served to confirm the broader patterns identified, rather than specific quotations or entries, and affirmed three needs as central to his well-being. **Safety**, understood as the capacity to initiate contact with nurses independently, particularly when alone; **Communication**, understood as the maintenance of contact with healthcare professionals and caregivers; and **Agency**, understood as being regarded as a capable decision-maker able to express and act upon his own needs and preferences.



Routines	**Lying in the bed** **6:00 - 08:30**	**Morning Care** **08:30 - 09:30**	**Watching TV** **09:30 - 11:00**	**Using Tobii system** **11:00 - 12:00**
Description	Karel wakes up in his bed. He waits, rests, or observes the environment, until a nurse approaches him.	Nurses transfer Karel from the bed into his wheelchair using assisted lifting tool.	Karel watches television. The TV is usually set to one channel and it is then not changed.	A nurse positions Karel's Tobii screen in front of him and calibrates it for his use. Once set up, he can visually access his WhatsApp.
Touchpoints	Breathing Support Device Bed Nurses	Nurses Wheelchair Mobile Hoist	Nurses TV	Tobii System
Pain Points	Being uncomfortable in the bed. Issues with breathing device Being unable to turn off the alarm. Not being able to communicate with nurses	Not being able to participate.	After spasm, cannot see the TV anymore. Watching TV is the only option as an activity.	After spasm, someone needs to reposition Karel and recalibrate the Tobii system.
Opportunities	Nurses arrive quickly. Nurses communicate and know the problem. Nurses show more empathy.	More nursing staff. More autonomy in decisions.	More variety of activities.	Controlling the environment. Alarming nurses.

Figure 3.9. Synthesised experience map of Karel's day, 6:00–12:00, showing his routines, touchpoints, emotional curve, thoughts and feelings, and pain points and opportunities



Routines	**Rehabilitation with Partner 12:00 - 13:00**	**Quality Time with Partner 13:00 - 16:00**	**Evening Care 16:00 - 17:00**	**Lying in the bed 17:00 - 22:00**
Description	Karel's partner, after arriving, takes him to the rehabilitation room to continue cycling exercises for his legs, then his arms.	Karel's partner spends quality time with him.	Nurses transfer Karel from the wheelchair into his bed and position him in the bed using the bed's tilting system.	A nurse places the breathing support device on Karel's mouth and also puts an eye patch on his right eye. Then Karel remains in bed until he falls asleep.
Touchpoints	His Partner Rehabilitation Cycling Machine	His Partner	Nurses Mobile Hoist Wheelchair	Nurses Breathing Support Device Suction Catheter Bed
Pain Points	The routes on the screen becomes repetitive after a while.	Being dependent on acupuncture to reduce the pain and keep the body warm.	Not being able to communicate with nurses.	Not being comfortable in the bed. Not getting enough air.
Opportunities	Give suggestions about destination of the cycling.	-	Nurses communicate and know the problem.	

Figure 3.10. Synthesised experience map of Karel's day, 12:00–22:00, continued from Figure 3.9

DEFINE

The Define phase translates the insights gained from the Understand and Empathise chapters into an actionable design focus. It begins by deepening the understanding of Karel's underlying values through a Why-How Laddering of the needs and patterns surfaced during the Empathise phase. These values are then used to define a design challenge suited to his context, expressed as a How-Might-We question that sets the scope for the remainder of the project. Finally, this challenge is translated into a set of concrete, prioritised design requirements that guide concept development in the Ideate and Prototype chapters and are later revisited during evaluation.

4.1. Underlying Values

Articulating the deeper values that underlie Karel's needs is essential to ensure the design direction is oriented toward what is substantively important in his lived experience rather than only addressing discrete functional problems (Friedman & Hendry, 2019).

The analysis of recurring patterns in Karel's everyday life (see Figure 4.1) shows that although he is an autonomous person, his severe communication limitations reduce his agency and make him feel less safe, especially when he cannot contact caregivers.

4.2. Design Challenge

Figure 4.1 identifies four interconnected values underlying Karel's needs: autonomy, agency, safety, and communication. Communication was selected as the organising focus, since it is the mechanism through which the other three are exercised in practice. The remaining three are carried forward into Table 4.1 as requirement principles of Safety and Independence. This led to the refined design challenge as follows:

How might we design a supportive system that helps Karel initiate and sustain communication with healthcare professionals during everyday care, while reflecting his personal preferences and supporting his autonomy in daily decisions?

1 What does Karel need?
Karel needs to communicate with nurses when his partner is not present.

2 Why does this matter?
He needs them to act on his discomfort, needs, or other concerns.

3 Why is this difficult?
This is difficult because he cannot call for help himself, nurses are not always in his room, and they may miss or misunderstand his signals.

4 Why does this create a deeper challenge?
As a result, his well-being depends heavily on others' interpretations, and he has limited control over what happens.

5 What value does this connect to?
Autonomy, Agency, Safety, and Communication

6 How can design respond to this value?
Design can respond by supporting Karel in expressing his needs to nurses and feeling safer when alone.

7 How can this work in care routines?
This means initiating and supporting communication, so his needs are recognised, checked, and addressed more consistently.

8 How can this become more actionable?
In practice, this means enabling Karel to independently signal when he needs attention and communicates what he needs.

Figure 4.1 Why–How Ladder linking Karel's communication needs to his underlying values

4.3. Design Requirements

A set of requirements was defined with specifications describing user needs, technical features, and constraints, as listed in Table 4.1. Identifying design requirements early in the design process contributes not only to a safe design but also to meeting Karel's physical and psychosocial needs (Abela et al., 2022).

Table 4.1 List of Requirements

	Principle	Requirement	Foundation
1	**Communication**	The system shall support Karel in initiating and sustaining communication during everyday care.	HMW question
2	**Safety**	The system shall prioritise Karel's sense of safety over physical comfort when design trade-offs are required and shall not interfere with other medical devices or equipment involved in his care.	· Karel · Designer's Observations
3	**Alignment with Capabilities**	The system shall accommodate Karel's individual physical capabilities and the spatial positions in which he spends his time (for example, in bed and in his wheelchair).	· Literature Review · Designer's Observations
4	**Independence**	The system shall support Karel in exercising as much independence as possible. It shall not increase the caregiving burden on his partner or create additional reliance on nursing staff for routine operations.	· Designer's Observations
5	**Reliable and Robust**	The system shall be robust and not prone to breaking and shall continue to function reliably, including during episodes of spasms. It shall use practically feasible technologies and require minimal, straightforward maintenance so that upkeep does not become a source of frustration.	· Literature Review · Designer's Observations
6	**Transparency and Trust**	The system shall fit Karel's and his partner's world, beliefs, and preferences and shall be easily integrated into the care house context.	· Healthcare Professionals · LiS Experts
7	**Personalisation and Emotional Expression**	The system shall allow personalisation to Karel's preferences and needs and foster emotional communication and a sense of reciprocity between Karel and others, especially his formal caregivers.	· Literature Review · Healthcare Professionals
8	**Technical Integration and Adaptability**	The system shall complement existing low-tech AAC rather than replace it and shall be adaptable, modifiable, or extendable to accommodate future changes or technological evolution.	· Literature Review · LiS Experts
9	**Feasibility and Affordability**	The system shall be based on technologies that are feasible to implement beyond the prototype stage and remain accessible and affordable for Karel in the long term.	· Literature Review · LiS Experts

IDEATE

This phase explores a wide solution space in both quantity and diversity, and then narrows it to a single direction. Concepts generated through individual and group ideation are compared against the design requirements to identify those worth pursuing, while the hardware needed to realise them is explored in parallel. The two strands come together in a concept direction selected with Karel, which is then specified through a refined set of requirements and developed at a conceptual level, with interface layouts shaped by Karel's own preferences at each step. Table 5.1 gives an overview of the activities carried out in this phase.

Table 5.1 Overview of ideation activities

Aim	Activity	Dates	Stakeholders involved	Key outcomes
Open up the design space by exploring a wide range of possible, unconventional concepts	Brainstorming	Jan 21 2026	· DE Design employees · Designer	· Broad set of initial concept ideas
Decide on the most suitable concept direction together with Karel	Meeting with Karel	Feb 17 2026	· Karel · Karel's Partner · Designer · Company Supervisor	· Concept direction selected: a UI system working with eye-tracking glasses · E-TRAN style board tested with Karel · Karel responded positively to the interaction direction
Present how the system would work and explore possible interface layouts for the chosen concept	Online meeting with Karel	Feb 17 2026	· Karel · Karel's Partner · Designer · Company Supervisor	· Preferred direction: 6-cell internal grid organisation
Evaluate the generated layouts for the concept	Layout try-out	Mar 11–12 2026	· Karel · Karel's Partner	· Preferred layout selected: letterboard organised based on their existing letterboard structure

5.1. Explorative Ideation

The ideation phase started with divergent thinking, prioritising the quantity and diversity of concepts and explicitly encouraging unconventional proposals. In addition to individual ideation, a focused brainstorming session (Ritter & Mostert, 2018) was conducted with designers from DE Design to increase the originality of ideas (Korde & Paulus, 2017). The resulting ideas, summarised in Table 5.2, provided the basis for subsequent selection.

Table 5.2 Overview of ideation sketches, opportunities, and challenges

Designer's idea

1. Muscle-based alarm switch

A facial sensor placed on a controlled muscle triggers an alarm when intentionally activated, requiring a clear distinction from involuntary movement.

- ✓ Low-effort alarming
- ✓ Reduces physical strain
- ✓ Potentially faster help

- ✗ False alarms from spasms
- ✗ Comfort and skin irritation risk

Figure 5.1 Muscle-based cheek sensor concept

De Design Brainstorm

2. Automatic inflating pillow

A pillow beside the head with an embedded sensor detects head contact, triggering an alarm and inflating to support the head back into a neutral position.

- ✓ Combines alarming and posture support
- ✓ Reduces discomfort while waiting

- ✗ Pressure and safety must be controlled
- ✗ Integration with existing equipment

Figure 5.2 Automatic inflating pillow concept

De Design Brainstorm

3. AI-supported room monitoring system

Infrared cameras combined with AI detection monitor comfort and positioning and send contextual alerts.

- ✓ Environment helps initiate communication
- ✓ May detect issues earlier
- ✓ Less reliance on active alarming

- ✗ Privacy and autonomy concerns
- ✗ Risk of false alarms and alarm fatigue

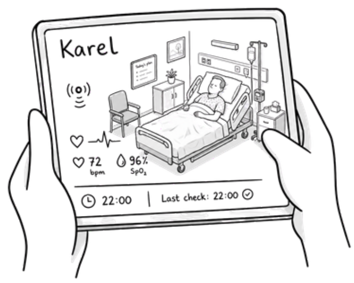


Figure 5.3 Remote room monitoring with AI concept

De Design Brainstorm

4. Mouth joystick

A joystick controlled by tongue or lip movements uses residual oral-motor ability for text input, though this direction was discontinued after a feasibility check.

- ✓ Explores alternative input for text
- ✓ Informs future modality choices

- ✗ Fatigue, discomfort, and safety issues
- ✗ Difficult precise control

Figure 5.4 Mouth joystick communication system concept

Table 5.2 (Continued)

Designer's idea

5. Communication book

A topic-based book of predefined statements allows the partner to read out options while Karel selects, with separate versions adaptable to day and night contexts.

- ✓ Faster than spelling letter by letter
- ✓ Supports less experienced caregivers
- ✓ Can structure everyday communication

- ✗ Risk of being too complex or long
- ✗ Requires training and consistent use

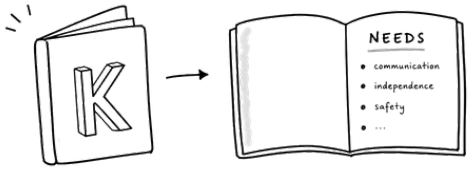


Figure 5.5 Communication book structure example

Figure 5.6 Communication book concept in use

Designer's idea

6. Prepared message display

A device displays messages prepared in advance, visible to the next person entering the room, with the input method depending on what remains accessible.

- ✓ Enables asynchronous communication
- ✓ Increases control and preparedness
- ✓ Clarifies needs at the start of interaction

- ✗ Staff may overlook the display
- ✗ Technical demands for installation and upkeep

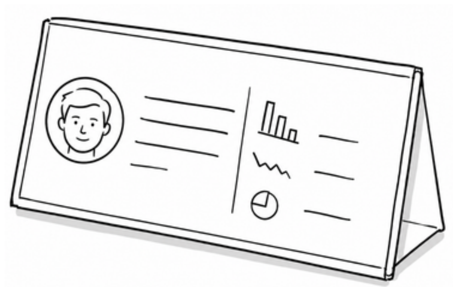


Figure 5.7 Prepared message display concept

Designer's idea

7. Transparent gaze-based communication board

A transparent board positioned between Karel and his partner allows simultaneous use: Karel selects via gaze and his partner via touch, while a shared text bar displays the message as it is constructed.

- ✓ ·Supports collaborative communication
- ✓ ·Preserves visual contact
- ✓ Makes the process visible to both

- ✗ ·Requires precise eye-tracking and mounting
- ✗ May be hard to use in routine care

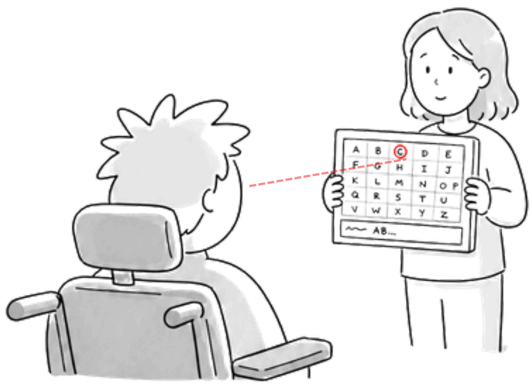


Figure 5.8 Eye-gaze letterboard communication concept

Table 5.2 (Continued)

Designer's idea

8. AR glasses communication interface

AR glasses display communication options that can be selected via gaze or other input methods, intended to work across multiple contexts.

- ✓ Suggests a portable, personal interface
- ✓ Could support private message preparation

- ✗ Likely heavy and tiring
- ✗ Current technology may not support stable use during spasms

Figure 5.9 AR glasses communication interface concept

De Design Brainstorm

9. Awareness game for nurses

Simple, game-like interaction prompts encourage informal communication and focus on social dynamics between Karel and nursing staff.

- ✓ Lowers the threshold for interaction
- ✓ May increase the frequency of contact
- ✓ Builds familiarity with Karel's signals

- ✗ Risk of being seen as extra work
- ✗ Needs careful framing to avoid trivialising care

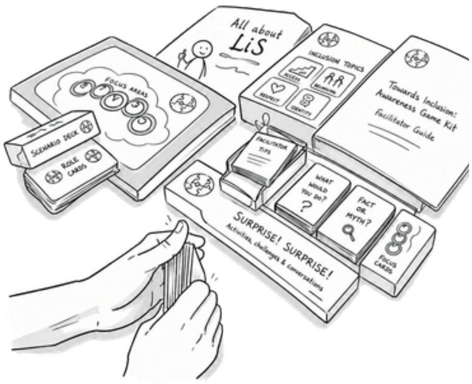


Figure 5.10 LiS awareness game kit concept

Designer's idea

10. Person-centred nursing station display

An overview at the nursing station shows a resident's preferences, communication methods, and needs, and includes messages and alerts.

- ✓ Reinforces a person-centred perspective
- ✓ Helps unfamiliar staff understand Karel
- ✓ Supports continuity across shifts

- ✗ Privacy and data-protection issues
- ✗ Possible information overload
- ✗ Needs integration into routines

Figure 5.11 Person-centred nursing station display concept

Figure 5.12 Wall-mounted version of the nursing station display concept

5.1.1. Concept Selection

The eight communication-focused ideation concepts were compared against the nine design requirements from Section 4.3 in a weighted decision matrix (Table 5.3), following a structured approach to concept evaluation in which requirements are weighted before concepts are scored (Chen et al., 2022). Concepts 9 and 10, the awareness game for nurses and the person-centred nursing station display, were not carried into the comparison. Both aim to change how staff engage with Karel rather than to give him a means of communicating, and so fall outside the scope of requirements written around his own independent communication. Weights reflect each requirement's priority; R1–R4 were treated as must-haves and weighted ×3, R5–R7 as desirable and weighted ×2, and R8–R9, which concern adaptability and implementation beyond the prototype, as secondary and weighted ×1.

Concepts with low weighted scores, particularly those that conflicted with safety and communication, were discarded, while those most aligned with the highest-priority requirements formed the basis for the subsequent concept design. **The communication book, prepared message display, transparent gaze-based communication board,** and **AR glasses communication interface** scored highest across the four must-have requirements and achieved the highest overall weighted totals.

Table 5.3 Weighted comparison of ideation concepts against the design requirements (R1–R9) from Table 4.1. Each concept was scored 0 (not met), 1 (partially met), or 2 (fully met) against each requirement; totals are weighted by requirement priority

Fully Met / Partially Met / Not Met

Concept	R1	R2	R3	R4	R5	R6	R7	R8	R9	Total
Muscle-based alarm switch	Partially Met	Fully Met	Fully Met	Fully Met	Partially Met	Partially Met	Not Met	Partially Met	Partially Met	**27**
Automatic inflating pillow	Partially Met	Not Met	Fully Met	Fully Met	Partially Met	Partially Met	Not Met	Partially Met	Not Met	**20**
AI-supported room monitoring system	Partially Met	Fully Met	Fully Met	Fully Met	Fully Met	Not Met	Not Met	Fully Met	Partially Met	**28**
Mouth joystick	Partially Met	Partially Met	Fully Met	Partially Met	Partially Met	Not Met	Not Met	Not Met	Partially Met	**18**
Communication book	Fully Met	Fully Met	Fully Met	Not Met	Fully Met	Fully Met	Fully Met	Fully Met	Fully Met	**34**
Prepared message display	Fully Met	Fully Met	Fully Met	Fully Met	Fully Met	Fully Met	Fully Met	Partially Met	Fully Met	**39**
Transparent gaze-based communication board	Fully Met	Fully Met	Fully Met	Partially Met	Fully Met	Fully Met	Fully Met	Partially Met	Fully Met	**36**
AR glasses communication interface	Fully Met	Fully Met	Fully Met	Fully Met	Partially Met	Partially Met	Fully Met	Fully Met	Not Met	**34**

5.2. Exploring Hardware Options

This section explores the hardware needed for the design challenge. Since the challenge has two parts, initiating communication independently and sustaining it once a partner's attention has been secured, two tables were developed to address each part separately.

Table 5.4 compares hardware options for initiating communication, matched to Karel's remaining physical abilities. Table 5.5 compares communication options for sustaining it, based on forms of communication Karel himself values or finds useful in everyday life. Both were presented to Karel and his partner and discussed with them; they indicated that **eye-tracking-based communication with the UI system** was the most suitable direction.

Table 5.4 Comparison of candidate hardware modalities for independent alarming by Karel

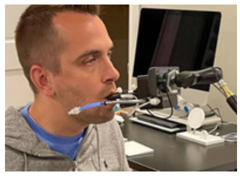
Cheek Muscle Movement Detector	Cheek Switch with a Button	Environmental Sensors	Eye-Tracking Glasses	Mouth Joystick
				
Figure 5.13 An example of a cheek muscle movement detector ('GS11 GlassOuse Cheek Switch', 2023)	*Figure 5.14 An example of a button-based cheek switch ('Cheek Switch – Vahlkamp International', 2026)*	*Figure 5.15 An example of an environmental control device ('Multisense – Vahlkamp International', 2026)*	*Figure 5.16 An example of eye tracking glasses (Neon - Overview - Eye Tracking for Research and Beyond, 2026)*	*Figure 5.17 An example of a mouth joystick (Franz, 2021)*
✓ Accurate ✓ Add-on to glasses	✓ Attached to both wheelchair & bed	✓ Seamless integration	✓ Accurate ✓ Works in the dark	-
✗ Dependent on cheek muscle movements ✗ Attached to glasses, added weight	✗ Possibility of false alarm during spasm	✗ Passive ✗ Misreading situations by relying on body-position detection	✗ Attached to glasses, added weight	✗ Invasive ✗ Uncomfortable ✗ Cannot use 24/7

Table 5.5 Comparison of AAC options for Karel

Improved Letterboard	Transparent board	E-Tran board	MegaBee	UI system
				
Figure 5.18 Karel's existing letterboard	*Figure 5.19 An example of a transparent alphabet board (AL-P-Transparent Communication Board-Conversation AID-EyeLink-for Those Who Have Difficulty Speaking Because of ALS, Stroke, Dysarthria, Tracheostomy (Speech Therapist Rehabilitation): Amazon.Sg: Health, Household and Personal Care, 2026)*	*Figure 5.20 An example of an E-TRAN board (Roman, 2013)*	*Figure 5.21 MegaBee 2 ('MegaBee 2 Comunicatore - Leonardo Ausili', 2025)*	*Figure 5.22 An example of eye-tracking glasses connected to UI (Wearable Eye Tracker for Commercial & Industrial Applications, 2026)*
✓ Familiar	✓ Familiar	✓ Faster ✓ More engaging	✓ Faster ✓ More engaging	✓ Faster ✓ Independent
✗ Time consuming ✗ Less engagement ✗ Dependent on another person	✗ Time consuming ✗ Tiresome for eyes ✗ Dependent on another person	✗ Dependent on another person	✗ Dependent on another person ✗ Battery charging	✗ Learning curve ✗ Wearable device ✗ Battery charging

5.3. Refined Concept Specific Requirements

The selected eye-tracking-based communication concept, along with discussions with Karel and his partner, was used to refine the original list of requirements introduced in Section 4.3 into more specific sub-requirements tailored to this solution (see Table 5.6).

Table 5.6 Refined concept-specific requirements

	Principle		Requirement
1	**Communication**	1.1.	The system shall enable Karel to initiate communication independently.
		1.2.	The system shall support Karel in sustaining communication.
2	**Safety**	2.1.	The system shall prioritise Karel's sense of safety over comfort when trade-offs arise.
		2.2.	The system shall include a function that allows Karel to call for nurse assistance independently.
		2.3.	The hardware setup, including glasses, cables, and power connections, shall not interfere with medical devices, transfers, or routine care procedures.
3	**Alignment with Capabilities**	3.1.	The interaction shall rely solely on eye movements and shall not require blinking, touch, speech, or other motor input beyond Karel's available abilities.
		3.2.	The system shall remain usable in both bed and wheelchair contexts without requiring Karel to adopt an unnatural position.
4	**Independence**	4.1.	The system shall allow Karel to use it independently without requiring support from another person.
		4.2.	Daily use of the system shall require minimal assistance from Karel's partner or nursing staff beyond routine setup and placement of the glasses.
5	**Reliable and Robust**	5.1.	The system shall remain as stable as possible during small involuntary head movements or spasms and shall not immediately interrupt communication when such variation occurs.
		5.2.	Maintenance and daily operations shall be practical within a care-house environment and shall not rely on specialist technical expertise for routine use.
6	**Transparency and Trust**	6.1.	The behaviour of the system shall be predictable, such that similar gaze movements consistently produce the same outcomes.
		6.2.	The interface shall clearly indicate the current mode and system state.
		6.3.	The system shall confirm actions.
		6.4.	The system shall be understandable and acceptable to Karel, his partner, and caregivers, including through localisation into Dutch and the use of recognisable communication structures.
		6.5.	The system shall fit existing care routines and, preferably, integrate with the care house's existing alarm infrastructure in future development.
7	**Personalisation and Emotional Expression**	7.1.	The system shall support personal and emotional expression by enabling communication beyond clinical and care-related messages.
		7.2.	Interaction parameters, such as selection timing, shall be adjustable to fit Karel's pace and condition over time.
		7.3.	The system may include playful or meaningful non-essential functions, such as a simple game, where these contribute to enjoyment, motivation, or well-being.

Table 5.6 (Continued)

	Principle		Requirement
8	**Technical Integration and Adaptability**	8.1.	The system shall complement Karel's existing low-tech communication methods rather than replace them.
		8.2.	The system shall allow future integration with existing care technologies, especially nurse call systems.
		8.3.	The concept shall be modular enough to support migration to more suitable eye-tracking hardware without requiring a complete redesign of the interaction model.
9	**Feasibility and Affordability**	9.1.	The prototype shall be implementable using commercially available eye-tracking hardware and minimal additional equipment.
		9.2.	Hardware selection shall balance tracking performance with practical suitability for daily assistive use, including comfort, connection stability, and supportability.
		9.3.	The solution shall be maintainable by the care organisation without requiring a research-laboratory environment for routine deployment.
		9.4.	Long-term implementation shall remain realistic in terms of cost, maintenance, and training demands.

5.4. Final Concept Development

This section translates earlier design opportunities into a final concept. The concept relies solely on directional gaze as input, since Karel cannot blink (see Figure 5.23). The glasses detect Karel's gaze direction and map it to regions in the interface.

Earlier concepts also informed this direction. The transparent gaze-based communication board enables communication, and the communication book and the prepared-message display concepts informed the inclusion of a structured set of messages that can be accessed quickly.

Consequently, the concept is organised around three main functions. The first is a gaze-based letterboard that supports open communication; the second is a pre-saved sentences mode that offers faster access to frequently used or urgent expressions; and the third is an alarm function that enables Karel to request immediate assistance from nurses.

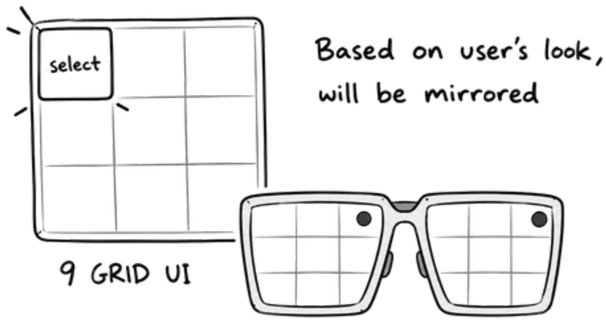


Figure 5.23 Sketch of the nine-grid user interface concept; Karel's selection is mirrored onto the grid to select regions without looking directly at the screen

5.4.1. Letterboard Layout

The letterboard builds on the analysis of existing boards from the Understand phase, in which an E-TRAN-style layout required the fewest steps to select letters.

In this board, selecting a letter involves two gaze steps. First, he looks toward the letter group that contains the desired letter (for example, the top-left for B), and then he looks toward the letter's position within that group (for B, top-middle).

A low-fidelity prototype based on this approach was tested with Karel (see Figure 5.24), and his positive response supported using the E-TRAN principle as the basis for the letterboard in this concept.

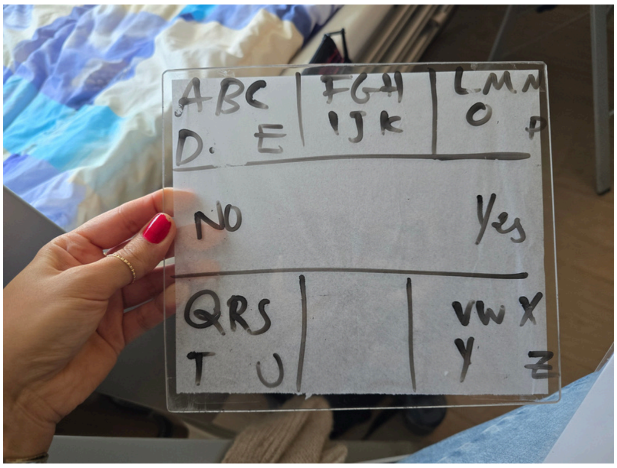


Figure 5.24 Low-fidelity E-TRAN concept drawn with whiteboard marker on a nine-grid layout to demonstrate adjustability

Internal Grid Design of Letter Groups

In designing the letter groups within the main nine-grid, a six-cell grid (see Figure 5.25) based on the inspirational board and a nine-cell layout (see Figure 5.26), which could accommodate more options, were explored.

A	B	C
D	1	2

Figure 5.25 Example of a six-cell internal grid for the letter groups

B	C	D
1		2
A		E

Figure 5.26 Example of a nine-cell internal grid for the letter groups

Both variants were shown to Karel during an online meeting. He preferred the six-cell structure, which provided enough space for 26 letters and 10 digits without overcrowding while remaining easy to scan and remember.

Letterboard Layout

Five layout options were considered for the nine-grid, based on three main inspirations; an AEIOU-style letterboard, Karel's existing letterboard, and a rotational layout based on eye movement (see Table 5.7).

The five board alternatives were shared with Karel, who tried them in his own time, by communicating the same messages using them. Based on this informal testing, he preferred the layout derived from his existing letterboard, which was therefore selected as the basis for the final nine-grid design.

Table 5.7 Overview of alternative layout concepts for the letterboard, including AEIOU-inspired, existing-board-based, and rotational layout

AEIOU-Inspired Layout

Two variants based on AEIOU letterboards and vowel organisations were explored (Figures 5.27–5.28). In both, groups with fewer than six letters are filled with digits, and any leftover digits form a group of their own.

A	B	C	E	F	G	I	J	K
D	1	2	H	3	4	L	M	N
	<						>	
O	P	Q	U	V	W	5	6	7
R	S	T	X	Y	Z	8	9	0

Figure 5.27 AEIOU-inspired layout in which each letter group begins with a vowel, distributing A, E, I, O, and U across the nine-grid as starting points for letter groups

A	E	I	B	C	D	J	K	L
O	U	Y	F	G	H	M	N	P
	<						>	
Q	R	S	X	Z	0	4	5	6
T	V	W	1	2	3	7	8	9

Figure 5.28 AEIOU-inspired layout in which all vowels are in one letter group, while the remaining letter groups contain only consonants and digits

Table 5.7 (continued)

Layout Based on Karel's Existing Letterboard

In this layout, each of the five rows of Karel's existing board (Figure 5.29) was mapped onto a single letter group within the new grid (Figure 5.30). As each group contains six cells, and four of the five rows contained only five letters, the remaining cell was filled with a digit and the remaining digits were placed into a separate group.

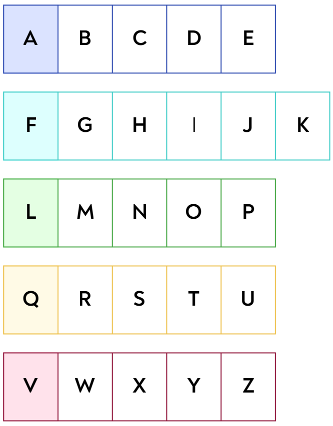


Figure 5.29 Karel's existing letterboard, with coloured rectangles drawn around each row to highlight the original organisation

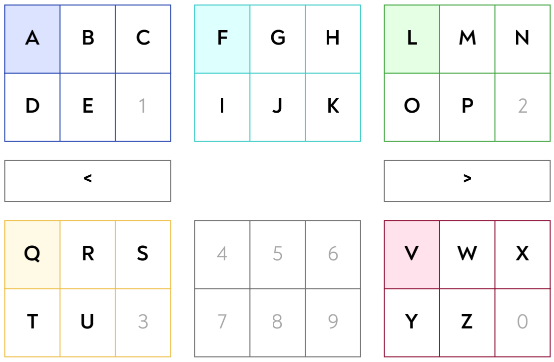


Figure 5.30 Letterboard layout based on Karel's existing letterboard, where the colours of the letter groups correspond to row colours in Figure 5.29

Rotational Layout Based on Eye Movement

Since the concept works without Karel looking directly at the display, this layout is organised around movement. Within each letter group, letters follow a clockwise 'rolling' direction from the bottom-left. Two variants were explored. In the first (Figure 5.31), only the letters within each group rotate this way, while the groups themselves are ordered conventionally, line by line. In the second (Figure 5.32), the groups are also ordered clockwise, so the same rolling motion applies at both levels.

Figure 5.31 Rotational layout in which the internal letter groups follow a clockwise pattern starting from the bottom-left, while the main nine-grid is ordered row by row with the first letter group at the top-left

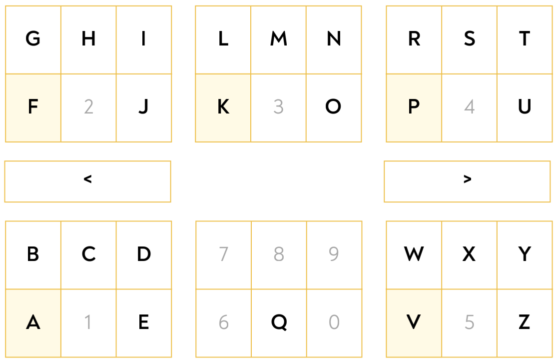


Figure 5.32 Rotational layout in which both the internal letter groups and the main nine-grid follow a clockwise pattern, starting from the bottom-left letter group and continuing around the grid; the letter Q (the least used letter in Dutch (Kopsky et al., 2014)) is placed in a group separated from other letters

Digit Placement

Digit placement within the letterboard and letter groups was explored through three small-scale variations (see Figures 5.33–5.35). The variants were also shown to Karel, who preferred the layout with digits grouped in the lower-right of each letter group (Figure 5.35), and this variant was therefore adopted in the final letterboard design.

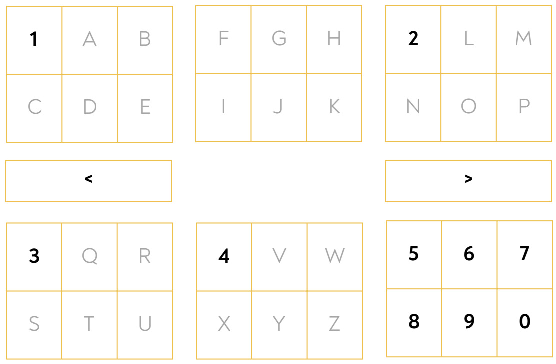


Figure 5.33 Digits are placed in the top-left of each letter group, and the one letter group with full digits in the lower-right

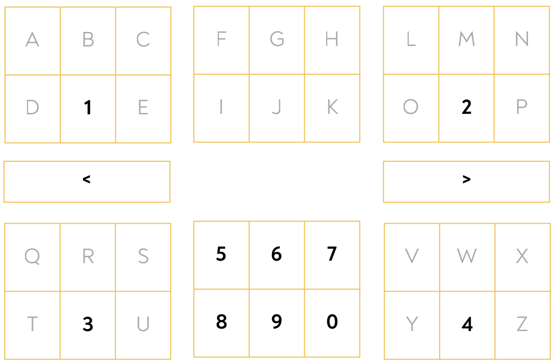


Figure 5.34 Digits are placed in the lower-middle of each letter group, and the one letter group with full digits in the lower-middle

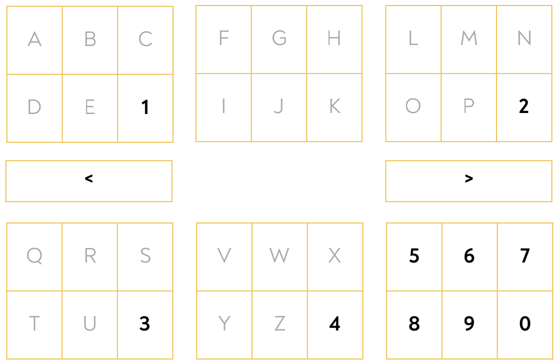


Figure 5.35 Digits are placed in the lower-right of each letter group, and the letter group with full digits in the lower-right

Main Layout of the Letterboard Page

In the exploratory layout shown in Figure 5.36, looking left is mapped to Backspace and Erase and looking right to Space and Enter, with the centre area controlling ON/OFF and mode changes between the letterboard and pre-saved phrases. This mapping follows the left-to-right direction of writing, so looking right means progressing to the next letter or word, while looking left corresponds to going back and deleting, mirroring the reversal of the writing flow.

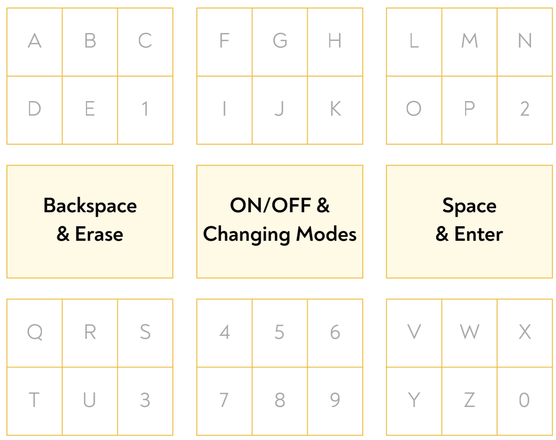


Figure 5.36 Exploratory main layout of the letterboard page

5.4.2. Alarm and Pre-Saved Mode

To help Karel communicate frequently used sentences without spelling them out each time, EyeVox also offers pre-saved messages. As shown in Figure 5.37, the alarm sits at the same level as the message categories on the main page, keeping it directly accessible rather than nested within a theme. Alongside it are the pre-saved message themes of needs, comfort, and appreciation, an “Other” category for messages that do not fit these themes, and an edit function for updating the categories’ names and their content. Selecting a category displays its relevant saved messages, and selecting one speaks the corresponding message; for example, choosing “spasms” under Needs says the message aloud.

Alarm	**Needs**	**Comfort**
Deselect	ON/OFF & Changing Modes	Select
Appreciation	**Other**	**Edit**

Puke	**Spasm**	**Breathing Hose**
Deselect & Return	ON/OFF & Changing Modes	Select & Send
...	...	**Edit**

Figure 5.37 Pre-saved message interface. Left: the main page with its categories — alarm, needs, comfort, appreciation, “Other,” and edit — with “Needs” selected. Right: the “Needs” page shown after selection, with its messages read aloud when chosen.

5.4.3. Visual Interface Design

The mood board for the interface brought together visual references for colour, form, and atmosphere, focusing on soft pastel gradients, orb-like shapes, and glassmorphism-inspired elements that evoke mediated connection, care, and gentle companionship (see Figure 5.38). Keywords such as “empathic interfaces,” “human–technology harmony,” and “cognitive ease” were used to express the intended experience. At the same time, the overall visual language was kept simple and minimal to make the interface feel calm and reliable.

Figure 5.38 Mood board for the visual design of the interface

Based on this mood board, a first graphic prototype was created (see Figures 5.39–5.42) and presented to Karel and his partner using a Wizard of Oz approach, manually simulating the system's interactions. They responded positively to both the visual design and the underlying interaction logic, but emphasised that reliable functioning was more important than visual detail, confirming that the graphic design should support usability and technical robustness while contributing to a welcoming impression.

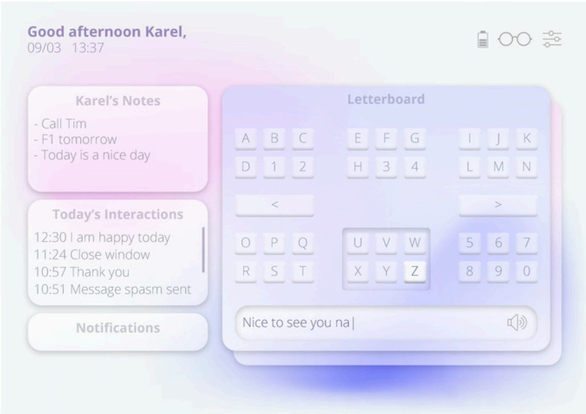


Figure 5.39 Letterboard view showing highlighted letter group and letter selection, live message composition in the text bar, and Karel's notes and recent interactions

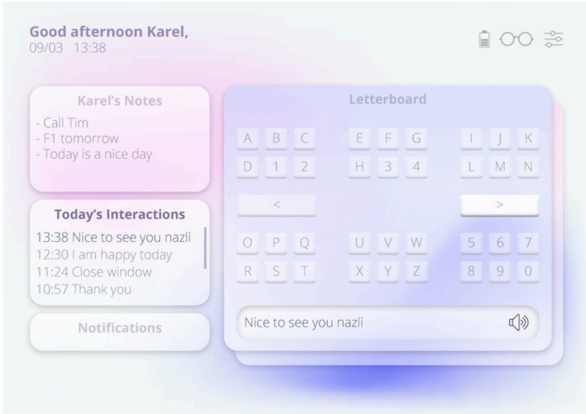


Figure 5.40 Letterboard view after sending a greeting, with the message marked as delivered and added to "Today's Interactions"

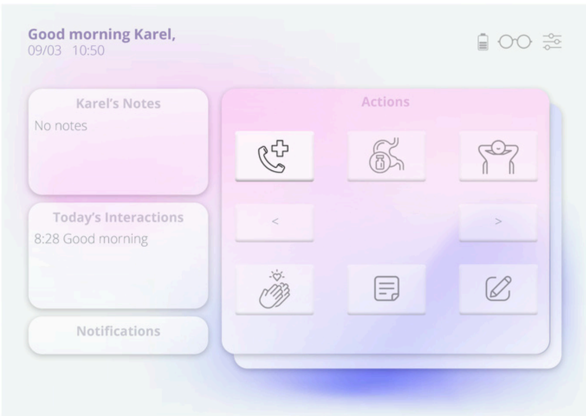


Figure 5.41 Overview of the pre-saved messages page, showing categories that light up when selected

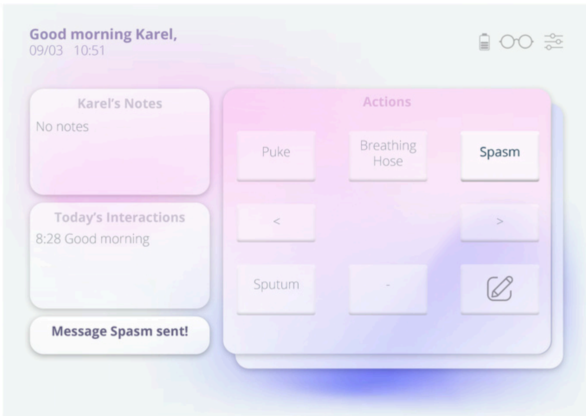


Figure 5.42 Example of sending the "Spasms" message, with visual confirmation to Karel and a notification triggered for the nurses

PROTOTYPE

The Prototype phase focuses on translating the communication concept into a tangible artefact. In this phase, key design decisions were materialised and refined in collaboration with the prototype collaborator, resulting in the EyeVox prototype, as shown in Table 6.1.

Table 6.1 Overview of prototype activities

Aim	Activity	Dates	Stakeholders involved	Key outcomes
Translate the selected concept into a clear interaction structure and prototype logic	Brainstorming with prototype collaborator	Mar 18 2026	· Designer · Prototype Collaborator	· Main interaction steps defined · Later translated onto a flowchart by the designer
Present the first prototype direction and gather feedback before further development	Online meeting with Karel	Apr 8 2026	· Karel · Karel's Partner · Designer · Prototype Collaborator · Company Supervisor	· Preference for Dutch UI · Emphasis on safety (alarm function)
Explore suitable eye-tracking hardware options for implementing the prototype	Online meeting with Pupil Labs	Apr 15 2026	· Pupil Labs Tech Specialist · Karel · Karel's Partner · Designer · Prototype Collaborator · Company Supervisor	· Pupil Labs Neon "Just Act Natural" seems suitable for the final prototype

6.1. From Concept to Realisation

This phase started with a brainstorming session with the prototype collaborator. Working from sketches of the system, the session explored how to refine the interaction flow and gaze-based control of the communication aid (see Figure 6.1).

These interaction features, along with the earlier decisions regarding the pre-saved messages page and letterboard structure, were then translated into a flowchart (see Appendix V: Concept Prototype Flowcharts and Interface Pages), which guided the development of the prototype.

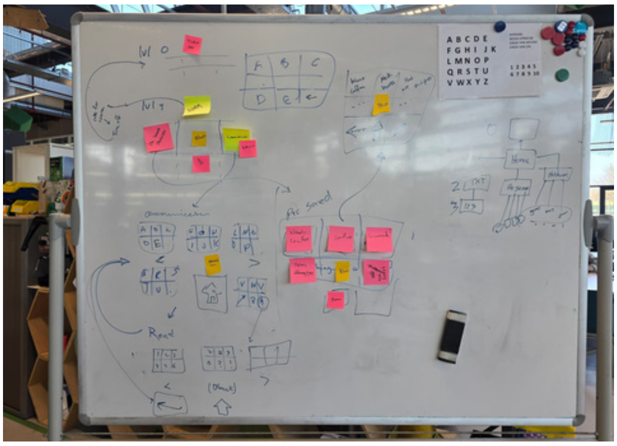


Figure 6.1 Brainstorming session exploring conceptualisation of the grid layout and gaze-based navigation for the prototype

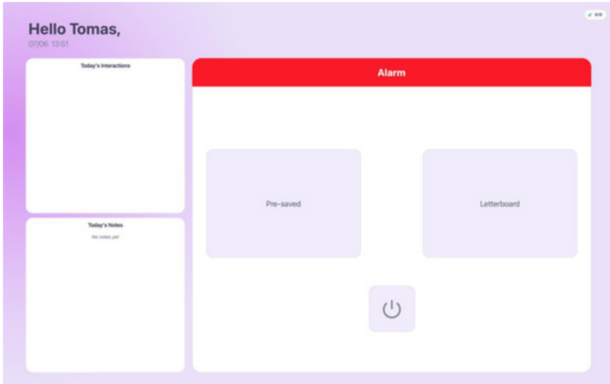


Figure 6.2 Home screen of the prototype in development

The brainstorming session resulted in a set of concrete interaction features for the system:

· Looking up turns on the system and opens the home page, where Karel can choose between the letterboard (look right), the pre-saved mode (look left), or the alarm function (look up). These functions are illustrated in Figure 6.2.

· Looking up triggers the alarm, chosen because this movement is unlikely to occur by mistake and therefore reduces the risk of false alarms; all three areas of the top row (left, middle, and right) were assigned an alarm function to ensure reliable activation even under challenging conditions such as spasms.

· The middle area is deliberately left blank on pages so that looking at it does not perform any action, providing a neutral space where Karel can rest his gaze and think without intentionally triggering commands.

·Within the letterboard, a return option was added inside the area so that if Karel selects an area and then changes his mind, he can go back to the main letterboard and choose another area.

· Numbers were removed from the main letter groups and grouped in the corner of the last letter group, since they are used less frequently and can therefore be accessed separately when needed.

· The Hangman game was added to introduce humour and play, accessible from the pre-saved page and using the same letter-selection principle as the letterboard.

· Looking down returns to the home page from any other page, and when already on the home page, turns off the system.

6.2. Eye-Tracking Glasses

Two eye-tracking glasses were considered: Pupil Labs Neon with the “Just Act Natural” frame (see Figure 6.3) and Tobii Pro Glasses 3 (see Figure 6.4). Based on a comparison of their technical specifications (see Table 6.2), Neon’s more naturalistic, glasses-like form factor, integrated sensors, and flexible real-time data access make it better suited for Karel’s everyday assistive use. In contrast, Tobii Pro Glasses 3 offers a more conventional, high-accuracy research setup that is primarily advantageous for controlled laboratory studies. In addition, an online meeting was held with a product specialist from Pupil Labs, who was open and supportive in helping to pair their glasses with assistive technologies, further reinforcing Neon Glasses’ suitability for this project.

Table 6.2 Comparison of key technical and practical characteristics of Pupil Labs Neon “Just act natural” eye-tracking glasses and Tobii Pro Glasses 3 (Advanced Wearable Eye Tracker Built for Research, 2026; Aerobe Clinical Team, 2026; Just Act Natural – Neon Eye Tracking Glasses, 2026; Neon – Overview – Eye Tracking for Research and Beyond, 2026; Neon – Shop – Configure and Purchase Neon Eye Trackers, 2026; Neon – Technical Specifications – Neon Eye Tracking Module and Frames, 2026; Tobii Glasses X vs Tobii Pro Glasses 3 Comparison, 2026)

	Pupil Labs Neon “Just Act Natural”	Tobii Pro Glasses 3
	 *Figure 6.3 Just Act Natural*	 *Figure 6.4 Tobii Pro Glasses 3*
Eye-tracking technique	Neural-network / deep-learning eye-tracking	Dark-pupil, corneal-reflection eye-tracking
Sampling rate (real-time)	120 Hz real-time gaze, 200 Hz post hoc	50 or 100 Hz configurable sampling rate
Approx. accuracy	≈ 1.8° uncalibrated, ≈ 1.3° with offset correction	≈ 0.6° visual angle with one-point calibration
Eye cameras	2 infrared eye cameras, binocular/monocular	4 integrated eye cameras, 2 per eye
Head-movement sensing	Integrated IMU (accelerometer, gyroscope, magnetometer)	Integrated IMU in head unit
Calibration	Calibration-free operation with optional offset correction	One-point calibration with slippage/parallax compensation
Form factor	Glasses-like frame with small Neon camera module	Glasses head unit plus separate cabled recording unit
Frames & lenses	Normal-looking and can be supplied without lenses for custom prescription	Research frames with vendor-specified prescription range
Connectivity	Glasses → Neon mobile app on smartphone → PC via Wi-Fi/Bluetooth using API	Glasses → recording unit → PC via Ethernet/USB and Tobii software
Real-time data access	Documented real-time API and open data streams; example assistive app	Real-time and recorded data via Tobii Pro software and SDKs
Battery/runtime	Multi-hour recording, typically up to ≈ 4 h per charge	≈ 1–2 h per charge; longer sessions with external power
Price (indicative)	Mid four-figure system price; option without phone	High four- to low five-figure research pricing; on request

6.3. The Final Concept and Prototype

The final concept and prototype bring together the design insights, technical exploration, and Karel's communication needs into a single, integrated system, intended as both a proof of concept and a prototype.

6.3.1. Name and Logo

The final concept was consolidated into ***EyeVox***. The name combines "I", "eye", and the Latin vox (voice), with "I" also evoking the inner perspective, reflecting the aim of supporting Karel's inner voice through eye-based communication. Moreover, its logo visually emphasises the eye as the central tool and conduit for conversation (see Figure 6.5).

Figure 6.5 EyeVox logo

6.3.2. Gaze-Based Nine-Grid Concept

The concept's nine-grid idea is translated into a concrete interaction model, detailed in Appendix VI: Interaction Model. In practice, EyeVox continuously tracks the user's gaze and maps it to the nine areas of the grid; when the user looks at one area and holds their gaze there long enough, that area is selected, and a short confirmation step then registers the choice before the linked action is performed.

6.3.3. Pages and Features

Icons and Graphics

The interface uses a small set of icons and simple line illustrations to distinguish key sections at a glance, as shown in Figures 6.6–6.12. In addition, a glasses icon is consistently displayed in the top-right corner of the pages to indicate whether the glasses are currently connected.

Figure 6.7 Icon for the letterboard

Figure 6.8 Icon for notes

Figure 6.6 Icon for the Expressions

Figure 6.9 Icon for the Hangman game

Figure 6.10 Icon for needs-related expressions

Figure 6.11 Icon for comfort-related expressions

Figure 6.12 Icon for appreciation-related expressions

Alarm and Home Page

EyeVox is activated by looking up, which opens the home screen (see Figure 6.13). Then there are four options. Looking left opens the expressions page, looking right opens the letterboard, looking down turns the system off, and looking up activates the alarm, which opens the alarm page and starts the alarm (see Figure 6.14). If he looks up again, the interface returns to the home screen while the alarm continues to run in the background (see Figure 6.15). In this state, a further upward look cancels the alarm and returns the system to its regular home mode.

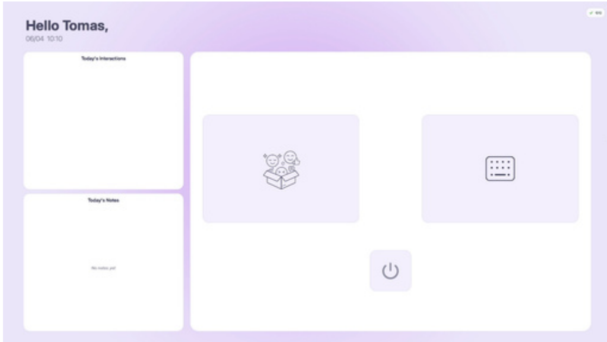


Figure 6.13 EyeVox home screen

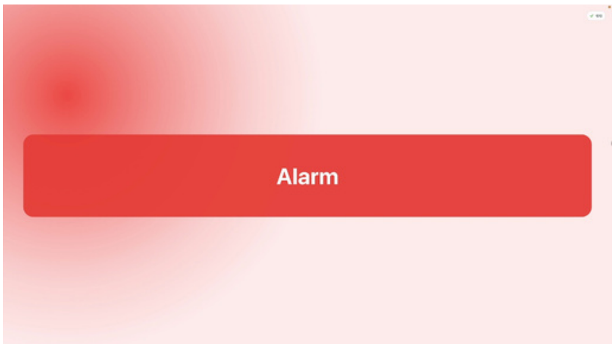


Figure 6.14 EyeVox alarm state

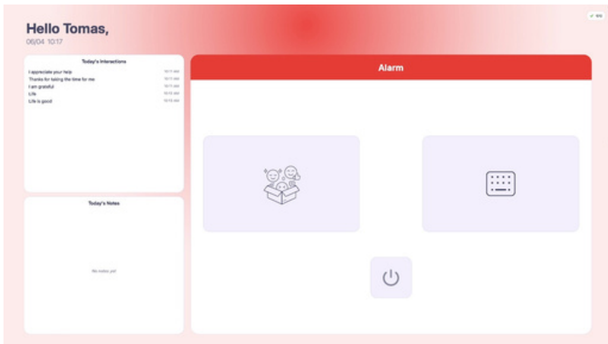


Figure 6.15 EyeVox home screen while in alarm state

Letterboard

From the home page, the letterboard is accessed with a rightward gaze, which opens the layout based on the letter group structure of the existing letterboard, as explained in Letterboard Layout (see Figure 6.16).

Letter selection follows a two-step gaze sequence. In the first step, the user directs their gaze to the group containing the desired letter, which is then visually highlighted, confirming the selection (see Figure 6.17). In the second step, the specific letter within the highlighted group is selected, after which the selected character appears in the writing bar at the bottom of the interface (see Figure 6.18).

As characters are added, the message incrementally builds up in the writing bar, making the current utterance continuously visible. Once a word is composed, a space can be inserted to make a new word by looking right, and looking right a second time activates "Speak" and voices the sentence as shown in Figure 6.19. Furthermore, looking left deletes the last letter, and maintaining a leftward gaze continues deletion until the entire word is removed, providing basic editing without additional buttons.

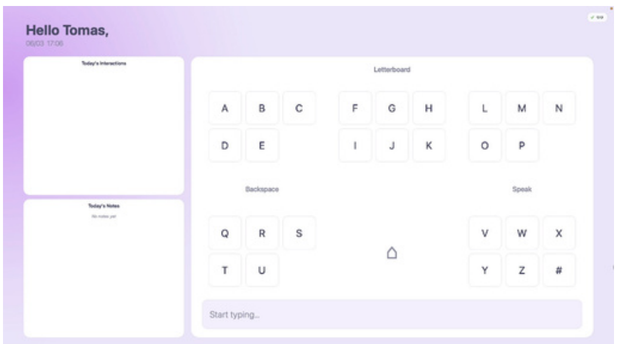


Figure 6.16 EyeVox letterboard page

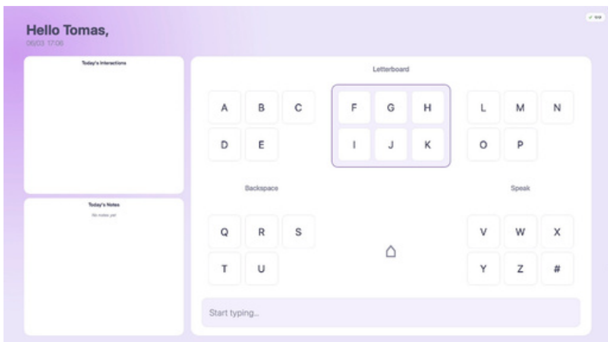


Figure 6.17 EyeVox letterboard after selecting a letter group; for example, looking at the top-middle selects the F-K group

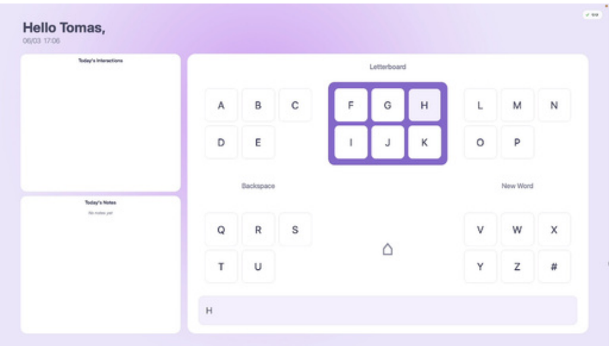


Figure 6.18 EyeVox letterboard after selecting a letter, for example, looking to the top-right, select the letter H.

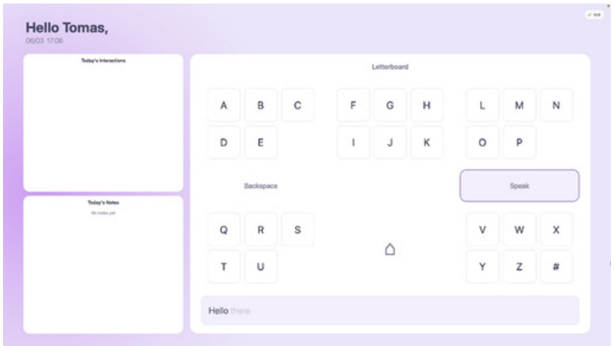


Figure 6.19 EyeVox letterboard with a composed message in the writing bar and the "Speak" control ready to voice the text

Expressions Page and Notes

The earlier "pre-saved" mode was renamed "Expressions" to better reflect its communicative purpose. On this page, five options are available in the central area: three expression groups and two additional functions (see Figure 6.20). The three groups at the top each contain five pre-saved sentences and reflect different themes: needs on the left, comfort in the middle, and appreciation on the right, based on themes that emerged during the ideation phase.

Within each group, the five sentences appear as individual cards that can be selected and spoken aloud, as shown in Figure 6.21. These sentences are editable. To edit one, the user selects the edit feature in the bottom-right corner, then taps a sentence to open the letterboard for modification. Edited sentences replace the originals in their group.

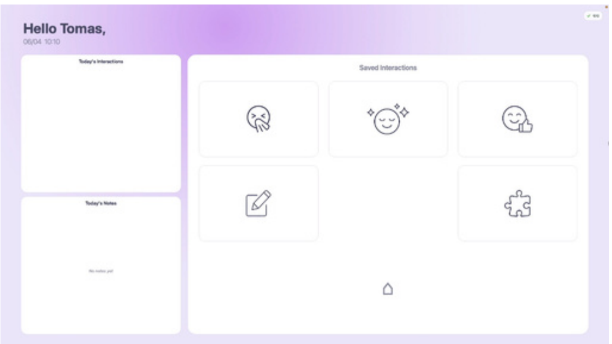


Figure 6.20 EyeVox expressions page overview

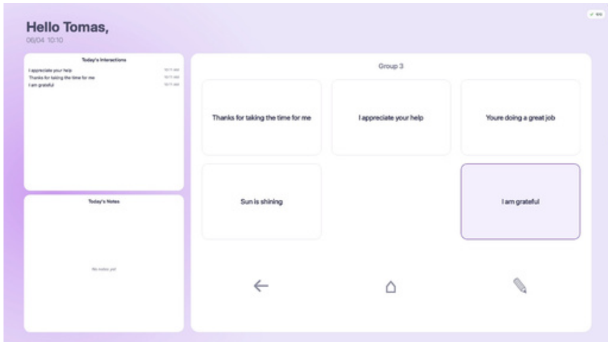


Figure 6.21 EyeVox expressions page, Group 3 phrases with a selected sentence ready to be spoken

Hangman Game

The Hangman game is accessed from the expressions page by looking right, which opens a game screen with a large hangman figure on the left and the letterboard on the right. Letters are selected using the same principle as on the letterboard. Figure 6.22 shows a successful round, while Figure 6.23 shows a lost round and reveals the missed word.

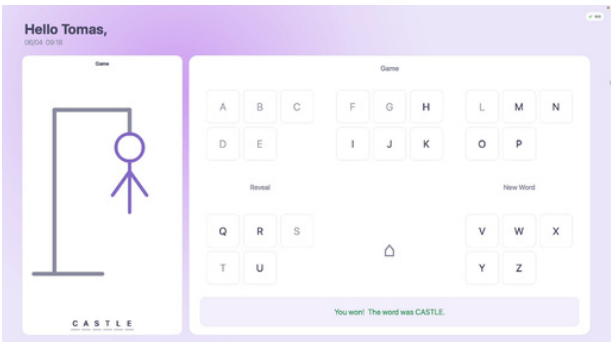


Figure 6.22 EyeVox Hangman game in a successful round

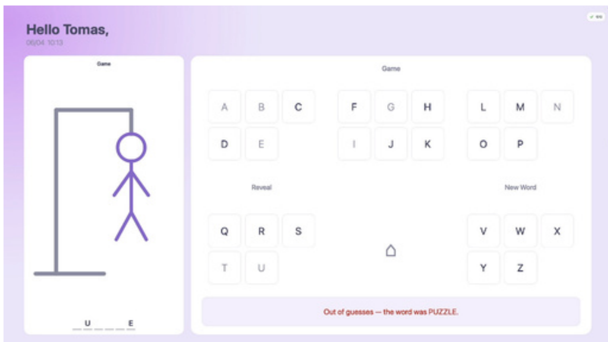


Figure 6.23 EyeVox Hangman game in an unsuccessful round

Notes and Interactions

All phrases communicated during the day, whether composed on the letterboard or selected from the pre-saved sentences, are added to the interaction history panel. The intention is to identify recurring topics or requests by reviewing this list of daily interactions, which resets at the start of each day.

Notes function slightly differently. They are short messages that Karel can write during the day, for instance, a reminder or a reflective daily note, and they remain visible in the notes panel until the view likewise resets the next day.

Word Suggestions

When the letterboard is used, whether for regular typing, writing notes, or editing pre-saved sentences, the system continuously predicts possible words based on the letters already entered. The current suggestion is shown in a lighter, faded colour in the text bar, extending from the partial input, and is generated by a prediction script that calls the Claude 3 Haiku language model (AnthropicAI, 2024).

If the suggested word is appropriate, it can be selected without spelling it out letter by letter by choosing the suggestion letter group and looking to the right to confirm; the full word is then inserted into the text bar. Once a complete word has been entered, the model similarly predicts and offers the next word, which can be accepted in the same way.

Audio Speech and Feedback

When a sentence is completed on the letterboard, or a pre-saved message is chosen from the Expressions page, the Speak button reads it aloud using a text-to-speech (TTS) engine.

Different letter groups within the letterboard are linked to distinct sounds so that, over time, the user can recognise which letter group is selected from its familiar audio feedback.

6.3.4. Supplementary Resources

Figure 6.24 presents a QR code linking to a video that demonstrates the operation and functionality of EyeVox, providing a visual overview of the system in use. The source code is available upon request.

Figure 6.24 QR code linking to the video demonstrating the operation and functionality of EyeVox

EVALUATE

The evaluate phase assesses EyeVox with Karel and the wider stakeholders through a series of use evaluations, testing whether the prototype meets its intended aims and where it falls short. It begins with a first-use evaluation with Karel, followed by a round of iterative refinement, a second use evaluation, and a use evaluation with DE Design, before closing with a reflective evaluation with Karel and his partner. The findings are then consolidated into a projected experience map and assessed against the design requirements. An overview of the activities conducted, along with their aims and outcomes, is provided in Table 7.1.

All evaluation sessions were conducted using Tobii Pro Glasses 3 instead of the Pupil Labs Neon glasses identified in Section 6.2, as Neon hardware was not available for testing within the project timeline.

Table 7.1 Overview of EyeVox evaluation activities

Aim	Activity	Dates	Duration	Stakeholders involved	Key outcomes
Assess the initial prototype's usability with Karel	First use evaluation with Karel	Apr 22 2026	2–2.5 hours	· Occupational Therapist (before the session) · Karel · Karel's Partner · Nurse (Observer) · Designer · Prototype Collaborator · Company Supervisor	· Could start system, trigger/cancel alarm, navigate pages, select pre-saved sentences · Letterboard difficult: visual limits, gaze range, unfamiliarity · Wishes: Dutch UI, care-alarm link, adjustable timing, clearer sound, prescription lenses
Improve usability, interaction, and technical reliability based on the findings from the first-use evaluation	Iterative refinement	Jun 2–5 2026	~8 hours each day	· Designer · Prototype Collaborator	· All intended functions completed · Dutch localisation and auditory/alarm/confirmation sounds added · Gaze calibration and mapping improved · Centre-looking reset step added
Evaluate the refined prototype with Karel, and a healthcare professional	Second use evaluation with Karel	Jun 9 2026	2–2.5 hours	· Karel · Karel's Partner · Unit Manager · Designer · Prototype Collaborator · Company Supervisor	· Fewer technical malfunctions · Gaze control still the main barrier · Future direction: eye-gaze training
Assess feasibility, implementation potential, and future development opportunities	Use evaluation with DE Design	Jun 10 2026	1–1.5 hours	· DE Design employees · Designer · Prototype Collaborator	· Positive feedback, especially the alarm · Core functions used successfully · Needs stronger adaptation for Karel's gaze limits · Ideas: AR glasses, simplified grid, eye gestures, urgent messages
Capture Karel's and his partner's appraisal of the project and its contribution to their well-being	Online meeting with Karel	Jul 22 2026	~1.5 hours	· Karel · Karel's Partner · Designer · Company Supervisor	· Positive appraisal of involvement, recognition, well-being · Alarm reaffirmed as primary value · Concern benefits may not persist without hardware · Caregiver burden acknowledged

7.1. First Use Evaluation with Karel

The first use evaluation with Karel explored how the initial EyeVox prototype functioned in his everyday care environment and gained an early, situated impression of usability.

7.1.1. Method and Procedure

The first evaluation focused on the initial functional version of EyeVox, which included letterboard interaction, pre-saved messages, and the alarm function. Other functionalities, including the notes feature, expression editing, and the Hangman game, were not yet implemented at this stage.

Prior to testing with Karel, the prototype was presented to an occupational therapist to introduce the concept and gather initial feedback from a care perspective. Both professionals indicated that the system appeared safe to use, provided that a nurse would be present during the session in accordance with safety regulations for introducing new technologies. They also described the prototype as promising and highlighted its potential applicability for a broader group of users.

The system was then presented to Karel, as shown in Figures 7.1 and 7.2, after which he was invited to interact with it using the Tobii eye-tracking glasses. Karel was able to use some basic system functions as intended. He could start the system, trigger and cancel the alarm (see Figure 7.4), navigate between pages, use the letterboard, and select pre-saved sentences.

However, Karel was unable to use the letterboard effectively because he was not yet familiar with the interface or its layout. Consequently, he needed to look directly at the screen to interpret the system. This proved challenging, as he normally wears prescription glasses and could not clearly perceive the interface through the eye-tracking glasses. These visual limitations were partially mitigated during the session by demonstrating EyeVox at close range, allowing him to see the interface more clearly and follow the interaction (see Figure 7.3). In addition, the system detects directional gaze toward predefined areas rather than precise on-screen gaze, which further constrained effective interaction in this context.

Figure 7.1 Prototype collaborator demonstrating the alarm function, with the wall-mounted screen displaying the alarm function

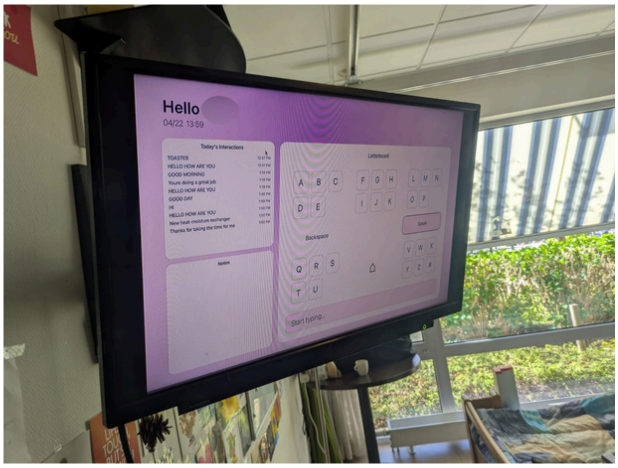


Figure 7.2 EyeVox letterboard screen presented during the first evaluation session

Figure 7.3 Prototype collaborator and designer demonstrating EyeVox at close range to Karel, allowing him to view the interface more clearly during the first evaluation session

Figure 7.4 Designer and prototype collaborator supporting Karel as he interacts with EyeVox prototype using the Tobii eye-tracking setup and successfully triggers the alarm during the first evaluation session

7.1.2. Key Findings

The concept was perceived as promising by Karel, his partner, and the professionals involved, particularly because it enabled him to trigger an alarm in his care environment independently. Both Karel and his partner, as well as the healthcare professionals, expressed a preference for the alarm to be connected to the care house's existing alarm system in the future.

At the same time, the session highlighted that effective use was constrained by language, visual, and gaze-related factors. These included the need for prescription lenses and the fact that Karel's gaze field differs from that of healthy users, with limited eye movement toward the screen's corners. These observations indicated that calibration and gaze mapping need to be tailored specifically to his eyes rather than relying on standard profiles.
The participants also expressed a desire for personalisation options, such as editing previously saved sentences and adjusting the selection time. These features were already foreseen in EyeVox concept but had not yet been implemented in the prototype at this stage.

Feedback from this session was systematically captured using a feedback capture matrix as presented in Table 7.2 (UX/UI Design and AI Courses With Online Certifications, 2026).

Table 7.2 Feedback capture matrix for the first evaluation session of EyeVox with Karel

Likes	**Wishes**
• Positive response from healthcare professionals • Prototype seen as interesting and promising • Karel and his partner liked the prototype	• Translate the interface from English to Dutch • Integrate the alarm with the existing care alarm system • Adjustable reaction/selection time • Calibrate system to Karel's gaze range • Clearer feedback for the glasses connection • Prescription lenses • Make pre-saved sentences editable
Questions	**Ideas**
-	• Improve the sound feedback of actions

7.2. Refinement through Iteration

Between the first and second use evaluations, the designer and the prototype collaborator conducted an interim internal cycle of iterative use, evaluation, and refinement. This phase translated feedback from the first use evaluation with Karel into concrete changes, prepared a more complete version of EyeVox for the next session with Karel, and used the system intensively over several days to reveal and address additional technical issues.

7.2.1. Improvements

In addition to completing the prototype and implementing all intended functions, several key improvements were made during the iterative refinement phase:

Auditory Interaction Feedback

• The system was updated to speak the selected letter group number and then the letters, provide a continuous sound while the gaze is held, and play a confirmation sound when a selection is completed (see Figure 7.5).

• Similar sound cues were introduced for expression groups, the notes function, the game, and the alarm, reducing reliance on visual confirmation.

• The alarm function was refined with a repeating tone that is more noticeable, confirming the alarm is active.

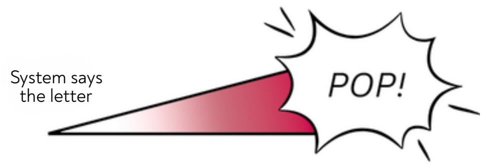


Figure 7.5 Schematic illustration of auditory feedback for letter selection in EyeVox

Gaze Calibration and Mapping

• Gaze mapping was improved using an AI-supported calibration approach so that EyeVox can adapt more closely to Karel's natural gaze behaviour instead of relying on a standard profile tailored to healthy users (see Appendix VII: Gaze Calibration and Mapping).

Error Reduction and Interaction Control

• A centre-looking step was added, requiring the user to look at the middle of the interface before a new selection is accepted, which helps create a reset point between actions and reduces accidental inputs.

7.3. Second Use Evaluation with Karel

In the second use evaluation, Karel participated in a usability evaluation of the refined version of EyeVox, which was available in Dutch, included the intended functions, incorporated prior feedback, and provided the prescribed lenses. A healthcare professional responsible for care management attended the session to provide additional feedback.

7.3.1. Method and Procedure

At the start of the session, the revised prototype was shown and explained to Karel (see Figure 7.6), and its new features, such as the Hangman game (see Figure 7.7), were demonstrated to him and his partner.

Afterward, Karel carried out a series of short tasks, including navigating between pages, spelling messages with the letterboard, using expressions, and triggering an alarm. Compared with the first session, there were fewer technical issues with the system itself; however, gaze-related problems still prevented him from using EyeVox as intended.

7.3.2. Key Findings

The refined EyeVox prototype functioned more reliably than in the first session, with fewer technical malfunctions during use (see Table 7.3). The added features, such as Dutch localisation, clearer auditory feedback, and better-structured pages, made the interface easier to understand for Karel and those around him. The Hangman game, in particular, created moments of enjoyment and a sense of success during interaction.

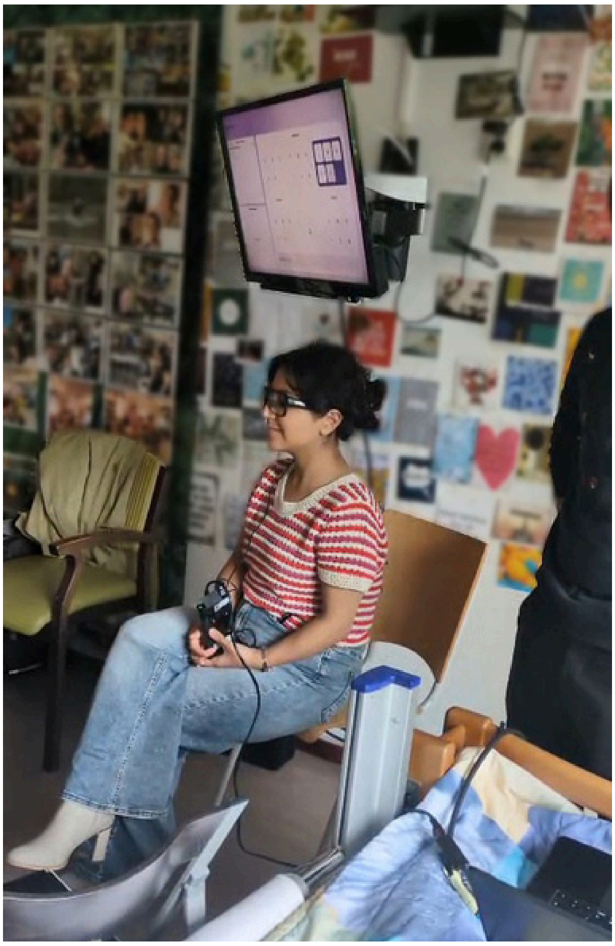


Figure 7.6 The designer demonstrating the revised EyeVox prototype during the second use evaluation with Karel

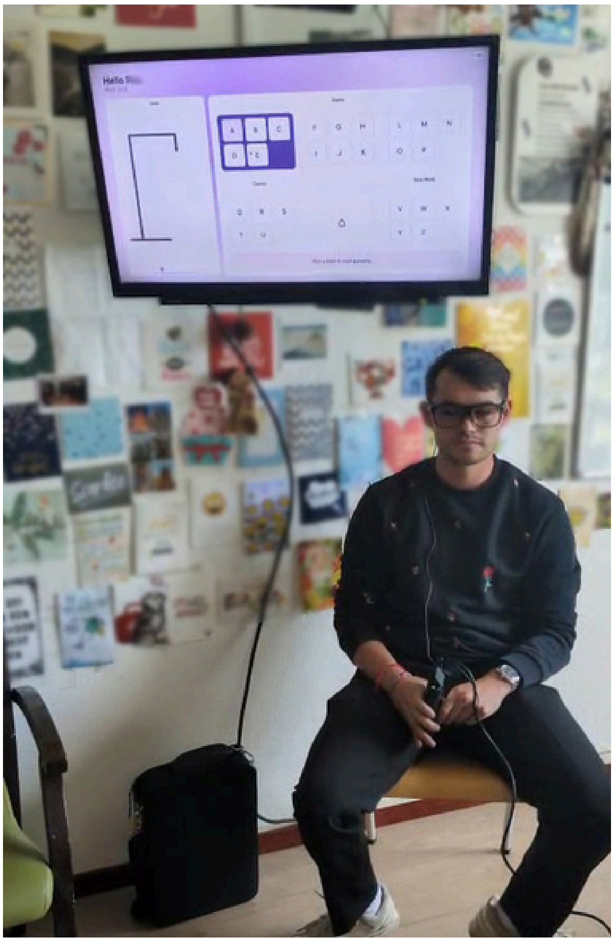


Figure 7.7 The prototype collaborator demonstrating the Hangman game during the second use evaluation with Karel

The healthcare professional characterised the system as promising and noted that she had not previously encountered comparable technology in this setting and expressed willingness to support Karel's continued use by involving information technology staff where necessary. Despite these improvements, gaze-related difficulties still prevented Karel from using EyeVox as intended. First, Karel was unable to maintain his gaze on a single area of the screen for the required duration. When the selection time was reduced to accommodate this, numerous unintended selections occurred as his eyes briefly passed over items, leading to errors. A cool-down period during which no actions could be made was also considered; however, for long-term use of the letterboard, this would likely become frustrating, particularly when Karel makes a mistake and wishes to correct it immediately. This highlighted a tension between personalising the system to his abilities and maintaining a robust, forgiving interaction. Second, his field of vision was more restricted than that of most users, making the standard gaze map less suitable and limiting the system's ability to accurately interpret his gaze.

Two main directions for future work emerged from the session. One involves improving calibration and gaze mapping so that the system better captures Karel's specific visual range while still allowing for some variation in eye movement. However, such an approach would require very precise eye control and would further reduce tolerance for gaze-direction variability, which is challenging for him in practice. The other direction, suggested by Karel and his partner, is to develop a dedicated training activity to help him practice controlling his eye movements. Such practice could strengthen his gaze control over time and potentially make EyeVox more usable in everyday communication.

Table 7.3 Feedback capture matrix for the second evaluation session of EyeVox with Karel

Likes	**Wishes**
· Functional prototype · Interface available in Dutch · Healthcare professional responded very positively · Audio feedback · The Hangman game	· Improve the stability of the glasses connection
Questions	**Ideas**
· Would it be easier to use after a long period of familiarisation? · Is the technology too advanced for Karel's current abilities? · How much gaze precision can realistically be expected? · How can the system support one restricted eye and inconsistent gaze movement?	· Involvement of IT staff for future maintenance · Cooldown time after selections · Training activity for eye gaze

7.4. Use Evaluation with DE Design

The evaluation with DE Design considered EyeVox from a professional design and engineering perspective. It aimed to understand how the concept and prototype might be further developed, implemented, and maintained within real-world organisational constraints, beyond the individual case of Karel.

7.4.1. Method and Procedure

Seven design engineers from DE Design attended the session (see Figure 7.8), which opened with an introduction to the project, Karel's context, and the design process. The EyeVox prototype and its main functions were then explained and demonstrated, after which three of the engineers tried the system.

Figure 7.8 Presentation of EyeVox to DE Design

7.4.2. Key Findings

The company's response to EyeVox was highly positive, with the alarm function in particular being valued. One participant linked this to experience with a relative in a similar condition and said that reliably calling for attention independently could already make a meaningful difference in daily life.

Three of the design engineers tried the prototype and were able to use its core functions. One used the system without noticeable difficulty from the outset. The other two initially struggled with gaze selection but became familiar with the interaction within minutes and completed the functions successfully. Unlike in the sessions with Karel, no calibration or gaze-mapping difficulties arose, indicating that the barrier lay in the fit between the standard gaze map and Karel's oculomotor range rather than in the interaction model itself.

The session generated several ideas for future development. One direction concerned using AR glasses to present options directly in the user's field of view. Another focused on adapting the gaze grid to different ability levels, for instance, by simplifying the layout from nine to four gaze areas for users with more limited eye movement. Further suggestions involved exploring eye gestures, such as blinking patterns, although these are not viable for Karel, who cannot blink, and would apply only to users with a wider range of residual eye movement. A final suggestion was to extend the alarm function with a small set of urgent messages, preselected by Karel and displayed when a nurse enters his room. These proposals also raised concerns about technical feasibility, the reliability of eye-gesture detection, and the risk of miscommunication if system-generated or preselected messages do not match what Karel intends to communicate.

7.5. Reflective Evaluation with Karel and His Partner

Whereas the earlier sessions evaluated how EyeVox functioned in use, the gaze and usability barriers encountered meant that its intended contribution to Karel's well-being could not be assessed through hands-on interaction alone. This concluding evaluation therefore shifted the focus from usability to reflection, aiming to capture how Karel and his partner themselves appraised the project and its perceived effect on Karel's well-being, participation, and sense of involvement. In doing so, it returns directly to the research aim, examining not only whether the artefact works but whether the design process and its outcome were experienced as meaningful by those at the centre of it.

7.5.1. Method and Procedure

An online meeting of about 1.5 hours was held with Karel and his partner. It centred on a structured questionnaire (see Appendix VIII: Reflective Evaluation Questions) gathering their overall feedback on the project and reflections on how they experienced it. For Karel, the questions spanned several themes, including well-being, personal recognition, feeling understood, involvement and influence, optimism about future possibilities, and everyday adoption. His partner's questions explored her role and experience over the course of the project, shifts in her perspective on Karel's needs, her advice to designers working with people living with LiS, and her hopes for what the design might change in everyday life. The questions addressed both Karel and his partner, since his partner was closely involved throughout the project as a mediator and contextual informant, and her perspective on the process and its outcomes complements Karel's own.

For Karel, the questionnaire comprised ten statements rated on a five-point Likert scale followed by five open-ended questions, while for his partner it comprised eight open reflective questions. To make participation more manageable, the questions were shared a day in advance so that Karel and his partner could read them, discuss them together, and prepare their responses before the meeting.

As in earlier activities, the format was adapted to Karel's communication. He answered the Likert statements by signalling on a numbered scale, open questions were spelt out on the letterboard with his partner's support, and his partner's own responses were spoken.

7.5.2. Key Findings

Karel's overall experience of the project was positive. He felt recognised, understood, and meaningfully involved throughout, and considered that his experiences had shaped the design direction. He found that the final concept reflected what was important to him as a person. His main reservation was that the use-evaluation phase had comprised too few sessions.

Independent alarming is perceived as the most significant potential contribution of EyeVox. It was seen as a means of reducing Karel's fear during periods when assistance is delayed and of strengthening his sense of safety and control. For his partner, this independence also carried a personal dimension, easing her continuous sense of responsibility and reducing the caregiving burden and time demands placed on her.

> *"If he can alarm himself, his fear will go away … and maybe I can take a day off, to have a life as well."*
>
> *— Karel's Partner*

Karel and his partner regarded EyeVox as capable of positively influencing his well-being, initially through the alarm function and later through broader communication. This potential nevertheless remained an expectation rather than an established outcome, as confirming it would require longer-term use within his everyday environment. A related limitation was that the project had not yet opened up new possibilities for Karel's daily life, particularly as he would not retain access to the technologies once it concluded. He would therefore have preferred more use sessions to familiarise himself with the system and explore its functions, especially as he counted these practical sessions among the most meaningful parts of the project. Set against his otherwise consistently positive appraisal, this points to the access gap discussed in Section 2.4.

For Karel's partner, participation was at first a source of concern, as it promised additional work, and she found certain activities, particularly the experience map and the structured questionnaires, demanding. Her experience nevertheless grew more positive as the project progressed and its purpose, process, and outcomes became clearer.

"During the process, the energy came together with the project. It's all positive... It was nice that I wasn't the only one fighting."
— Karel's Partner

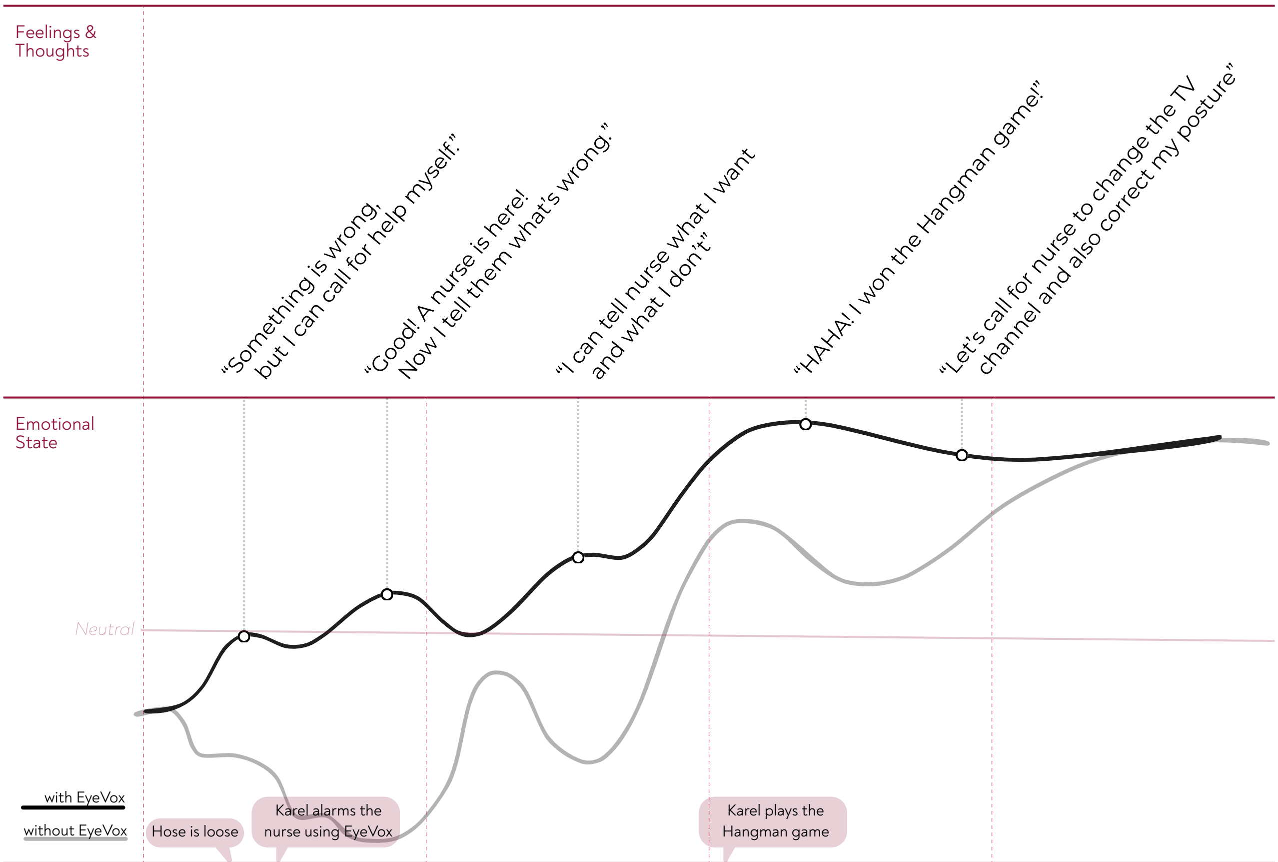
Looking ahead, Karel's preferred future direction was an eye-training activity, followed by connecting the interaction concept to his television and his existing Tobii system, extending its value by linking it to technologies already part of his daily environment. He and his partner further recommended that designers and researchers assess the physical and visual capabilities of people living with LiS in greater detail at the start of a project, and test the hardware early on. A more precise early understanding of eye control, movement, fatigue, and calibration, together with timely testing of the equipment, would help establish which technologies are realistically suitable and prevent avoidable barriers later on, a recommendation that corresponds directly to the gaze limitations encountered throughout EyeVox's evaluation.

7.6. Projected Experience Map

To explore how EyeVox could influence Karel's daily life beyond the evaluation sessions, a projected experience map was developed from the original map in Section 3.6, together with the identified needs and the feedback gathered during the evaluations (see Figure 7.9). An additional line illustrates moments in which Karel could use EyeVox to initiate communication, express discomfort, guide his care, and interact more independently with his partner.

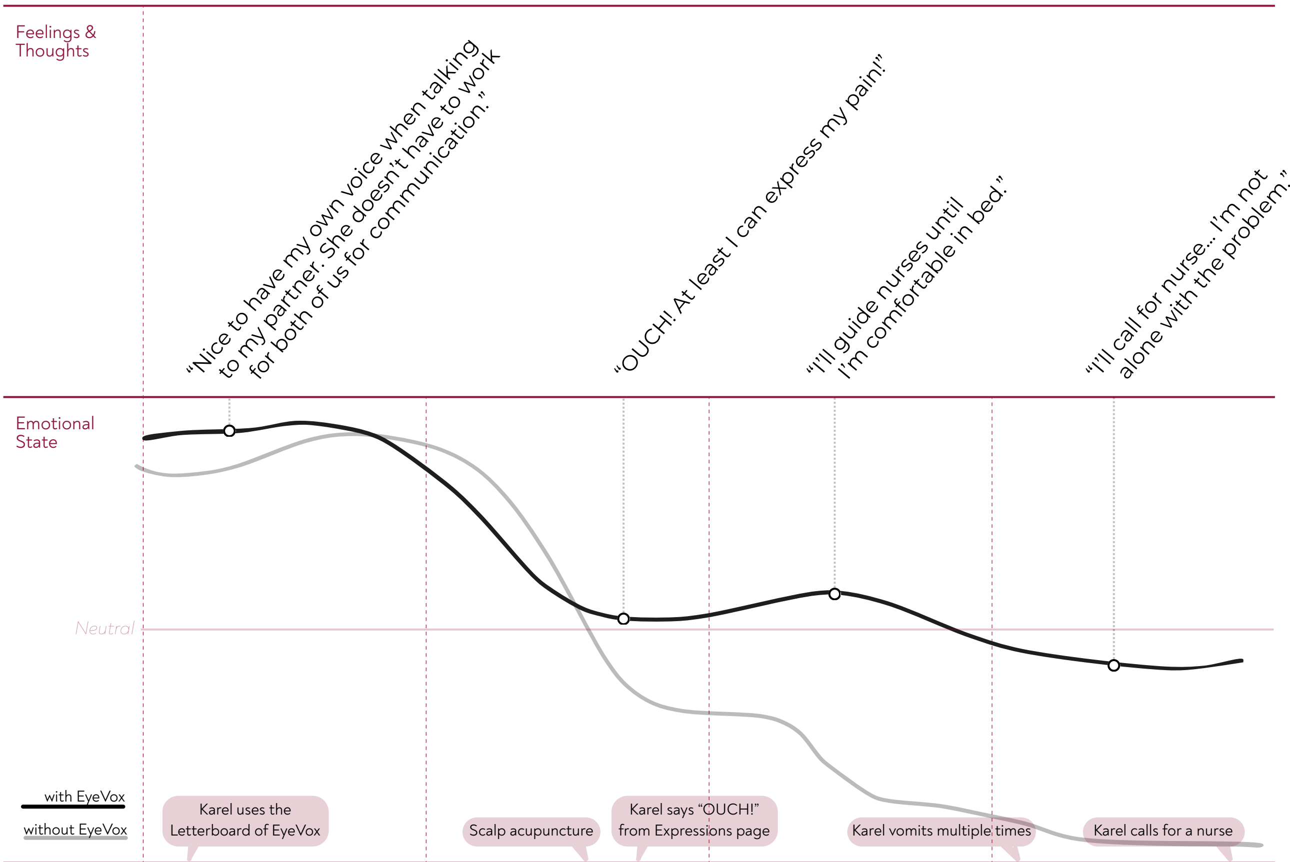
It is important to note that the map assumes EyeVox functions reliably, setting aside the gaze-related limitations documented in Sections 7.1–7.5 that would first need to be resolved in practice. It has not been verified with Karel directly and rests on the researcher's interpretation of his routine and the design's intended functions rather than on observed use. As such, it makes no claim to proven effects, but visualises the potential contribution of EyeVox to Karel's agency, safety, participation, and social connection.

The projected map indicates the greatest improvement during moments in which Karel is alone, uncomfortable, or dependent on others to recognise his needs. EyeVox could allow him to alarm nurses independently, explain what is wrong, and continue communicating until his needs are understood. During care activities, it could enable him to guide his positioning and express preferences, while during time with his partner it could support more direct and reciprocal communication. The physical difficulties and dependence on others would remain, but the communication-related helplessness associated with these situations could be reduced. Consequently, several original pain points and opportunities are shown as addressed or partly addressed within the projected map.



Routines	**Lying in the bed 6:00 - 08:30**	**Morning Care 08:30 - 09:30**	**Watching TV 09:30 - 11:00**	**Using Tobii system 11:00 - 12:00**
Description	Karel wakes up in his bed. He waits, rests, or observes the environment, until a nurse approaches him.	Nurses transfer Karel from the bed into his wheelchair using assisted lifting tool.	Karel watches television. The TV is usually set to one channel and it is then not changed.	A nurse positions Karel’s Tobii screen in front of him and calibrates it for his use. Once set up, he can visually access his WhatsApp.
Touchpoints	Breathing Support Device Bed Nurses EyeVox	Nurses Wheelchair Mobile Hoist EyeVox	Nurses TV EyeVox	Tobii System
Pain Points	Being uncomfortable in the bed. Issues with breathing device Being unable to turn off the alarm. Not being able to communicate with nurses. ✓	Not being able to participate. ✓	After spasm, cannot see the TV anymore. Watching TV is the only option as an activity. ✓	After spasm, someone needs to reposition Karel and recalibrate the Tobii system.
Opportunities	Nurses arrive quickly. Nurses communicate and know the problem. ✓ Nurses show more empathy.	More nursing staff. More autonomy in decisions. ✓	More variety of activities. ✓	Controlling the environment. Alarming nurses. ✓

Figure 7.9 Projected experience map illustrating the hypothetical influence of EyeVox on Karel’s daily actions, thoughts, feelings, and emotional experience. Check marks indicate the pain points and opportunities addressed by EyeVox



Routines	**Rehabilitation with Partner 12:00 - 13:00**	**Quality Time with Partner 13:00 - 16:00**	**Evening Care 16:00 - 17:00**	**Lying in the bed 17:00 - 22:00**
Description	Karel's partner, after arriving, takes him to the rehabilitation room to continue cycling exercises for his legs, then his arms.	Karel's partner spends quality time with him.	Nurses transfer Karel from the wheelchair into his bed and position him in the bed using the bed's tilting system.	A nurse places the breathing support device on Karel's mouth and also puts an eye patch on his right eye. Then Karel remains in bed until he falls asleep.
Touchpoints	His Partner Rehabilitation Cycling Machine EyeVox	Karel's Partner EyeVox	Nurses Mobile Hoist Wheelchair EyeVox	Nurses Breathing Support Device Suction Catheter Bed EyeVox
Pain Points	The routes on the screen becomes repetitive after a while.	Being dependent on acupuncture to reduce the pain and keep the body warm.	Not being able to communicate with nurses. ✓	Not being comfortable in the bed. Not getting enough air.
Opportunities	Give suggestions about destination of the cycling. ✓	-	Nurses communicate and know the problem. ✓	

Figure 7.10. Projected experience map illustrating the hypothetical influence of EyeVox on Karel's daily actions, thoughts, feelings, and emotional experience, 12:00–22:00, continued from Figure 7.9

7.7. Evaluation against the Design Requirements

Table 7.4 assesses EyeVox against the refined design requirements set out in Section 5.3. This is a conformance check on the concept and prototype as specified and built, rather than a further evaluation of use. On this basis, EyeVox addresses most of its design objective of supporting Karel's independent, gaze-based communication, with the requirements around core communication, transparency, and personalisation fully addressed in the design, while some requirements concerning long-term safety, integration with the care-house alarm system, and practical feasibility could not be validated within this project.

Table 7.4 Evaluation of EyeVox against refined design requirements

● *Fully Met* ● *Partially Met* △ *Not Validated*

	Principle		Requirement	Fulfilment
1	**Communication**	1.1.	The system shall enable Karel to initiate communication independently. *EyeVox provides for independent initiation of communication by mapping directional gaze to interface regions.*	Fully Met
		1.2.	The system shall support Karel in sustaining communication. *EyeVox includes a gaze-controlled letterboard supporting open message composition.*	Fully Met
2	**Safety**	2.1.	The system shall prioritise Karel's sense of safety over comfort when trade-offs arise. *Safety is treated as a primary value through the always-accessible alarm. However, the actual trade-offs between safety and comfort have not been empirically tested in daily practice.*	Partially Met
		2.2.	The system shall include a function that allows Karel to call for nurse assistance independently. *EyeVox provides a nurse-call function activated by a deliberate upward gaze.*	Fully Met
		2.3.	The hardware setup, including glasses, cables, and power connections, shall not interfere with medical devices, transfers, or routine care procedures. *During evaluation, the Tobii Pro Glasses 3 cables did not interfere with care activities, but suitability for long-term daily use remains uncertain.*	Partially Met
3	**Alignment with Capabilities**	3.1.	The interaction shall rely solely on eye movements and shall not require blinking, touch, speech, or other motor input beyond Karel's available abilities. *Interaction relies solely on eye movements without requiring additional motor input.*	Fully Met
		3.2.	The system shall remain usable in both bed and wheelchair contexts without requiring Karel to adopt an unnatural position. *EyeVox is designed for use in bed and in a wheelchair, but this was not formally evaluated in either context.*	Partially Met

Table 7.4 (Continued)

● *Fully Met* ◐ *Partially Met* △ *Not Validated*

	Principle		Requirement	Fulfilment
4	**Independence**	4.1.	The system shall allow Karel to use it independently without requiring support from another person. *Once set up, EyeVox is operable without assistance from another person.*	●
		4.2.	Daily use of the system shall require minimal assistance from Karel's partner or nursing staff beyond routine setup and placement of the glasses. *Karel can use EyeVox independently after setup but still requires assistance with placement, charging, and troubleshooting.*	◐
5	**Reliable and Robust**	5.1.	The system shall remain as stable as possible during small involuntary head movements or spasms and shall not immediately interrupt communication when such variation occurs. *EyeVox tolerates small involuntary movements, but tracking stability remains dependent on the eye-tracking hardware.*	◐
		5.2.	Maintenance and daily operations shall be practical within a care-house environment and shall not rely on specialist technical expertise for routine use. *Routine use is suitable for a care-home setting, although maintenance and calibration may still require technical support.*	◐
6	**Transparency and Trust**	6.1.	The behaviour of the system shall be predictable, such that similar gaze movements consistently produce the same outcomes. *EyeVox consistently maps the same gaze movements to the same actions.*	●
		6.2.	The interface shall clearly indicate the current mode and system state. *EyeVox indicates system status through visual and auditory feedback, such as glasses connection and ongoing alarm sounds.*	●
		6.3.	The system shall confirm actions. *EyeVox confirms selections and alarm activations through visual and auditory feedback.*	●
		6.4.	The system shall be understandable and acceptable to Karel, his partner, and caregivers, including through localisation into Dutch and the use of recognisable communication structures. *EyeVox uses Dutch, clear categories, and editable phrases.*	●
		6.5.	The system shall fit existing care routines and, preferably, integrate with the care house's existing alarm infrastructure in future development. *EyeVox fits existing care routines, but integration with the care-home alarm system has not yet been implemented.*	◐
7	**Personalisation and Emotional Expression**	7.1.	The system shall support personal and emotional expression by enabling communication beyond clinical and care-related messages. *EyeVox supports personal and emotional expression through the board and editable sentences.*	●

Table 7.4 (Continued)

● Fully Met ○ Partially Met △ Not Validated

	Principle		Requirement	Fulfilment
7	**Personalisation and Emotional Expression**	7.2.	Interaction parameters, such as selection timing, shall be adjustable to fit Karel's pace and condition over time. *Selection timing can be adjusted to match Karel's pace and evolving abilities in EyeVox concept, though the developer currently configures it.*	○
		7.3.	The system may include playful or meaningful non-essential functions, such as a simple game, where these contribute to enjoyment, motivation, or well-being. *The Hangman game is included in EyeVox.*	●
8	**Technical Integration and Adaptability**	8.1.	The system shall complement Karel's existing low-tech communication methods rather than replace them. *EyeVox does not intend to replace Karel's existing low-tech communication methods, and the layout of EyeVox's letterboard is based on his existing low-tech AAC.*	●
		8.2.	The system shall allow future integration with existing care technologies, especially nurse call systems. *EyeVox is designed for future integration with nurse call systems, but this has not yet been implemented.*	○
		8.3.	The concept shall be modular enough to support migration to more suitable eye-tracking hardware without requiring a complete redesign of the interaction model. *EyeVox's interaction logic is independent of the eye-tracking hardware it runs on, so migrating to different hardware – such as the Pupil Labs Neon glasses identified in Section 6.2 – would not require rebuilding the interaction model.*	●
9	**Feasibility and Affordability**	9.1.	The prototype shall be implementable using commercially available eye-tracking hardware and minimal additional equipment. *EyeVox is built using commercially available eye-tracking hardware and minimal additional equipment.*	○
		9.2.	Hardware selection shall balance tracking performance with practical suitability for daily assistive use, including comfort, connection stability, and supportability. *Neon eye-tracking glasses were identified as the preferred hardware based on the requirements presented in Section 6.2. However, the EyeVox prototype was evaluated using Tobii Pro Glasses 3 because they were available. Consequently, the practical suitability of the intended hardware for long-term daily use has not yet been validated.*	△
		9.3.	The solution shall be maintainable by the care organisation without requiring a research-laboratory environment for routine deployment. *EyeVox is intended to be maintainable within a care-home setting, although long-term support procedures are not yet established.*	△
		9.4.	Long-term implementation shall remain realistic in terms of cost, maintenance, and training demands. *Long-term costs were considered during the design process, and Neon was selected as the preferred hardware because it is relatively more affordable than comparable eye tracking glasses while meeting the design requirements. However, long-term maintenance and training requirements remain to be validated in practice.*	○

DISCUSSION AND CONCLUSION

This thesis explored how design research can contribute to the well-being of an individual living with Locked-in Syndrome. Adopting a human-centred and participatory approach, it sought to understand Karel's lived experience, identify the factors most central to his well-being, and translate these into a design that supports them (Kouprie & Visser, 2009; Mattelmäki, 2005; Sanders & Stappers, 2008).

This chapter draws together the outcomes of that process and reflects on their broader significance. It first evaluates EyeVox, considering the limitations of the current prototype and the directions in which it could be developed further. It then examines the wider insights from the project: what meaningful participation means when communication is severely impaired; the design priorities the process surfaced; the roles of multidisciplinary collaboration and informal caregivers; and the systemic conditions that decide whether such technologies reach everyday life. The chapter closes by reflecting on the strengths and limitations of the research, outlining directions for future work, and drawing overall conclusions.

8.1. Evaluation of EyeVox

The conformance assessment in Section 7.7 indicated that EyeVox addresses most of its design requirements, including those concerning core communication, transparency, and personalisation, while several relating to long-term safety, integration, and feasibility remained partially met or unvalidated. This assessment describes the concept's coverage rather than its demonstrated performance; the letterboard, in particular, could not be operated by Karel in either session. Beyond this requirement-based assessment, the iterative evaluations also surfaced a number of limitations in both the development process and the evaluated prototype, alongside clear directions for future development. These are examined in turn below.

8.1.1. Limitations of EyeVox

There were several limitations in both the development process and the evaluated version of EyeVox that should be considered when interpreting the findings and planning future iterations.

First, EyeVox's gaze map was created using users with relatively stable, well-controlled eye movements, so its interaction model assumes sustained, precise gaze. This makes the system vulnerable to brief, unintentional eye movements and to difficulty maintaining fixation in users with more severe oculomotor impairments, reflecting critiques of eye-tracking systems that prioritise technical optimisation over user variability (Mele & Federici, 2012).
Moreover, the interface uses a fixed nine-area gaze grid. It assumes that all regions are equally visible and reachable, which limits usability for users with restricted or uneven visual fields. There is little flexibility to reconfigure layouts or recalibrate gaze zones to different visual ranges, and the prototype does not yet offer structured onboarding or training activities to support gradual improvement of gaze control. These design choices conflict with person-centred evaluation frameworks, which emphasise fit between assistive technologies and the person, task, and environment, and foreground user-defined outcomes over technical performance alone (Khasnabis et al., 2020).

A further limitation concerns the duration and context of the use evaluations. Although the sessions with Karel spanned several hours, his actual interaction with EyeVox was brief, owing to technical issues and limited gaze control, and the concluding session took the form of a reflective interview rather than hands-on use. The evaluations therefore provide only a partial view of how the system might behave in sustained, everyday communication.

Limitations from the Prototype Collaborator's Perspective

The collaborator highlighted several hardware-related constraints. The current setup uses Tobii Pro Glasses 3, which are intended primarily for research rather than for prolonged daily use, and they tend to run hot and occasionally disconnect. The connection depends on a proprietary battery pack that must be kept charged or replaced, and it requires additional software steps before the prototype recognises the glasses. Together, these factors make the hardware configuration fragile and difficult to deploy routinely in care environments.

He also noted that finer control over gaze mapping is needed to accommodate users with limited or atypical ocular motor ranges. In its present form, the system either demands more precision than some users can provide or becomes prone to unintended selections. Gesture-based recognition of eye movements was suggested as a possible future direction, but this would introduce substantial technical complexity and reliability challenges.

8.1.2. Future Development of EyeVox

Building on these limitations, several directions for future development emerged, namely gaze mapping, interaction methods, and the underlying software and hardware. These complement the priorities Karel himself expressed, including an eye-training activity and integration with his existing technologies.

Gaze and Mapping

Future versions of EyeVox should better accommodate fluctuating and constrained gaze control while offering more flexible gaze mapping. This involves moving from fixed dwell times to adaptive thresholds that learn each user's fixation patterns, and incorporating simple, efficient mechanisms to cancel or undo unintended selections, so that brief, accidental eye movements do not disrupt communication. In addition, the current nine-area grid should become configurable through a schema that enables fine-grained control over individual gaze sections, allowing zones in stronger visual areas to be enlarged, inaccessible regions to be disabled, and presets to be tailored to different visual fields and gaze ranges. The collaborator also emphasised that a more flexible mapping layer, in which each section can be adjusted or deactivated per user rather than relying on a fixed screen partition, is essential to supporting users with limited or variable eye-movement capabilities.

Gaze Gestures

A small set of gaze gestures, such as rapidly looking up and down, could provide useful shortcuts. The collaborator suggested exploring gesture-based interaction as an alternative to static section mapping, for example, by using an LSTM neural network trained on samples of users shifting their gaze from the centre to each of the eight surrounding sections. While this approach would require substantial data collection and processing, the collaborator noted that it could enable a wider range of interaction models for EyeVox. However, not all individuals with LiS can perform such eye gestures — Karel, for example, cannot blink, which is why Requirement 3.1 restricted interaction to directional gaze — and system interactions should therefore prioritise reliability and simplicity, with gestures complementing rather than replacing stable gaze-based selection.

Software and Hardware

The collaborator notes that the current system runs as a Python program and relies on native macOS libraries for text-to-speech and related functionality. He suggests making EyeVox operating-system-agnostic so it can run on both Windows and macOS, ideally as a self-contained desktop application rather than a research prototype. He further proposes that better-suited hardware, such as Pupil Labs Neon, could help address some of the limitations of the current Tobii Pro Glasses 3 setup, including overheating during prolonged use and occasional disconnections.

8.2. Discussion

Beyond the evaluation of EyeVox, the project raised a number of broader issues that merit reflection. This section discusses four in turn. The first is the nature of meaningful participation with severe physical disability; the second, the design priorities that the process brought to light; the third, the roles of multidisciplinary collaboration and informal caregivers; and the fourth, the systemic conditions that shape whether an assistive technology can move beyond a project into everyday life. These reflections indicate that designing for LiS is as much an ethical, relational, and systemic undertaking as a technical one.

8.2.1. Participation

Participatory design was fundamental to ensuring that the project was designed with Karel rather than for him, supporting empowerment, mutual learning, and shared ownership of the design process (De Couvreur & Goossens, 2011; Galliers et al., 2012; Sanders & Stappers, 2008; Van Dijk et al., 2016). However, conventional co-design methods could not simply be transferred to this context. The design activities were therefore adapted to Karel's communication capabilities, enabling him to engage across the project, shape priorities, select directions, and comment on emerging concepts despite his limitations. In practice, this meant giving him as much time as he needed and letting him and his partner work together at their own pace.

Adapting method formats to his abilities proved particularly effective. The Likert-scale questionnaire let him give graded, nuanced responses by signalling on a numbered scale, while the experience map, completed with his partner, opened a detailed window onto his daily routines and emotional highs and lows. Such flexibility was central to making participation possible, and the reflective evaluation suggested it was experienced as meaningful rather than tokenistic, as Karel reported feeling genuinely recognised and involved in decisions affecting him. When designing with people living with LiS or similar disabilities, meaningful participation should therefore not be judged by the quantity or speed of communication, but by the extent to which the participant can genuinely influence design decisions.

8.2.2. Uncovering Design Priorities

HCD enabled the project to move beyond functional problems and uncover the factors shaping Karel's well-being. Communication emerged as the key one, reflecting existing literature, which identifies it as a strong contributor to quality of life for people living with LiS and the mechanism through which autonomy, dignity, identity, and social participation are realised (Corallo et al., 2017; Laureys et al., 2005; Rousseau et al., 2015; Yoshiki et al., 2023). Beyond communication, the process also brought the importance of safety and self-expression to the surface

Sense of Safety

A finding that receives comparatively little emphasis in the LiS and AAC literature is the significance of a person's sense of safety. Although communication, autonomy, dignity, and participation are frequently identified as core values in life with LiS (Hordila et al., 2024; Laureys et al., 2005; Rousseau et al., 2015; Schnetzer et al., 2023; Snoeys et al., 2013), the present project found that Karel's primary concern was frequently not communication as such, but the capacity to initiate it when alone and in need of assistance. The alarm function consequently emerged as the most valued aspect of EyeVox for both Karel and his partner, a priority independently corroborated by a DE Design employee drawing on personal experience and reaffirmed in the reflective evaluation, in which Karel again prioritised independent alarming over communication and his partner expressed the hope that it would alleviate his fear. A single case cannot establish how far this priority generalises. Still, it suggests that perceived safety warrants explicit treatment as a design requirement rather than being assumed to follow from improved communication.

Self-Expression

An unexpected but valuable insight concerned the importance of meaning and self-expression. Qualitative studies describe humour, relationships, meaningful activities, and opportunities for self-expression as important contributors to quality of life for people living with LiS (Hordila et al., 2024; Kyselo & Di Paolo, 2015; Laureys et al., 2005). This became particularly evident during the second evaluation session, when Karel's most positive reaction came during a simple Hangman game with EyeVox, as he smiled and laughed through the limited facial movement available to him.

While functional communication and safety features are essential, such moments of joy, humour, and play, even when they appear secondary, can be disproportionately meaningful in highly medicalised daily routines.

8.2.3. Multidisciplinary Collaboration

A further reflection concerns the value of a multidisciplinary approach to designing for LiS. Such collaboration is already well established within rehabilitation, which is widely recognised as necessitating the combined expertise of professionals across multiple disciplines (Casanova et al., 2003; Doble et al., 2003; Halan et al., 2021; Høyer et al., 2010; Schnetzer et al., 2023; Smith & Delargy, 2005; Yoshiki et al., 2023). The present project indicates that design practice in this domain would similarly benefit from such an approach.

Throughout development and evaluation, expertise beyond the designer's own knowledge became essential. Understanding eye movements, visual impairments, gaze calibration, rehabilitation practices, and assistive technologies proved critical for interpreting evaluation findings and informing design decisions. This project therefore suggests that designing assistive technologies requires a similarly multidisciplinary approach, with relevant clinical and technical expertise sought early rather than as a late-stage consultation. This need was echoed in the reflective evaluation, where Karel and his partner recommended that a person's physical and visual capabilities be assessed in detail at the outset, so that what is realistically achievable is understood before design decisions are settled.

Informal Caregivers

Within this collaborative picture, informal caregivers occupy a distinctive and complex role. Karel's partner was indispensable as a mediator and contextual informant. Yet, her involvement raised ongoing questions about whose perspective was being captured, and highlighted the risk of proxy views overshadowing the participant's own when direct input is possible (Hamidi et al., 2017). In the reflective evaluation, she viewed herself as no more than a mediator, even though this dialogue was the principal means through which Karel's perspective reached the design, illustrating how easily this essential role goes unrecognised, even by the caregiver themselves.

At the same time, the very flexibility that made Karel's participation possible carried a cost for his partner. Allowing activities to be completed together, at their own pace, inevitably drew on her time and effort, and relying on caregivers for communication and participation in this way risks increasing the burden they already carry (Doble et al., 2003; Linse et al., 2017; Lugo et al., 2017; Smith & Delargy, 2005). This was borne out in practice: she began the project apprehensive that it would add to her workload. She found some activities — especially the experience-map logging — the most demanding part of participating. Hence, regular informal check-ins became an important part of the process, allowing activities to be adapted for both her and Karel.

Design research for LiS must therefore balance rich participation against protecting caregivers from overload, treating caregiver well-being not as a side concern but as part of its contribution to the participant's own well-being — a need the literature also emphasises, noting that informal caregivers require as much attention and support as the person living with LiS (Hordila et al., 2024; Lo Coco et al., 2005; Mages et al., 2025).

Beyond managing this burden, caregivers could also be given a more active, clearly acknowledged role in the design itself. Karel's partner contributed substantially yet regarded her own input as merely incidental; involving caregivers more deliberately as co-designers, rather than only as mediators, may foster stronger ownership while making their distinct contribution more visible.

8.2.4. Beyond Design

Designing and evaluating an assistive technology does not necessarily mean it can become part of everyday life. Even if EyeVox were developed into a fully functional system, Karel would still need suitable eye-tracking hardware, maintenance, technical support, and funding for it to be usable in practice. Karel himself voiced this concern in the reflective evaluation, where his one clearly low rating reflected his awareness that he would not retain access to the technology once the project ended, leaving the possibilities it opened up feeling out of reach.

Consequently, although design research can identify meaningful opportunities and develop context-sensitive technologies, their impact on well-being ultimately depends on whether healthcare systems can provide timely access, maintenance, and long-term support. This echoes the wider gap between assistive technology development and its sustained adoption in real-world settings, already identified in the literature review under 'Limited real-world use' (Section 2.4) and reflected directly in Karel's own experience of not retaining access to the technology once the project ended (Section 7.5.2) (Higgins et al., 2025; Light et al., 2019; Thistle & Wilkinson, 2013; Tönsing et al., 2024).

8.3. Strengths and Limitations

The contributions of this project should be read alongside its limitations. Its central strength lies in the participatory, human-centred approach, which kept Karel genuinely involved throughout and grounded the design in his lived experience rather than in assumptions about LiS. Working with a single participant over months allowed a depth of contextual understanding that a broader study could not have reached.

A second strength concerns the methods themselves. Established co-design and self-report instruments assume participants who can write, speak, or respond at conversational pace, and could not be applied here as intended. Each was therefore adapted; the interview used numbered rating scales that Karel could answer by signalling with his eyes, giving graded rather than binary responses; the experience-map log was restructured so that entries could be completed jointly, revised retrospectively, or left incomplete; and the concluding evaluation combined Likert statements with open questions prepared in advance so that responses could be considered before the session. These adaptations are reported in enough detail to be reused, and represent a transferable outcome of the project independent of EyeVox itself.

Finally, the project produced knowledge even where the artefact did not perform as intended. The gaze-related barriers encountered are themselves a finding about the gap between eye-tracking systems designed around typical oculomotor control and the capabilities of the people they are intended to serve, a gap that would not have surfaced in a study conducted without a participant living with LiS.

Three limitations nonetheless qualify the findings. The first concerns the evaluation of EyeVox's communication functions. Although EyeVox was developed to support both the initiation and continuation of communication, Karel's gaze limitations prevented a full evaluation of its intended communication features, so the prototype could not be validated against its core communicative aims. Even so, the iterative evaluations generated valuable insights into interaction design, accessibility, and future development.

The second concerns the scope and length of the evaluation. Each session yielded useful findings, but these covered only short-term use. Designs meant to improve well-being cannot be evaluated in a few sessions, since experiences and their effects shift over time (Hassenzahl, 2010). This project therefore cannot claim what prolonged everyday use of EyeVox would do, nor what the design research meant for Karel's well-being in the longer term.

The third concerns the participatory methods themselves. Because several activities were completed jointly by Karel and his partner, it was not always possible to distinguish which contributions originated from Karel and which reflected his partner's interpretation. This was most evident in the experience-map logging, where the two voices were not clearly separated. While joint completion made participation feasible, it also risks partially obscuring the participant's own perspective, and future activities should be designed to attribute contributions to each person more transparently.

8.4. Future Work

The directions for developing EyeVox itself, spanning gaze mapping, interaction methods, and hardware, were set out in Section 8.1.2. Beyond the artefact, the project points to several avenues for future research.

The first concerns the participatory methods themselves. Joint completion of activities made Karel's involvement possible but blurred the line between his contributions and his partner's. Future work could develop participatory techniques that keep participation feasible for people with severe communication impairment while attributing contributions more transparently, and that give caregivers a more clearly acknowledged role without adding to their burden.

A related direction is longitudinal evaluation. As the present study was limited to short-term usability, EyeVox should be assessed in sustained, real-world use over an extended period to determine whether its anticipated benefits for well-being are realised and maintained in everyday life.

Future work might also extend beyond the person with LiS to healthcare professionals, exploring what communication with a person living with LiS means from their perspective and how their practices and tools might be improved. Because relational and organisational contexts strongly influence the well-being of people with LiS, designing with and for healthcare teams may enhance the quality and consistency of care and, in turn, support the person receiving it.

A final direction concerns the timing of design research along the LiS trajectory. At onset, people and their networks face high uncertainty and a long, difficult process of adapting to a radically changed reality, which directly affects well-being. Adaptation can be slow and emotionally demanding, and there may be valuable design opportunities within these networks to support it. Future research could explore how design can ease this adjustment and help people navigate the acute and early phases, potentially improving well-being during a period when they are most vulnerable.

8.5. Conclusion

This thesis set out to explore the question, "How might design research be applied to improve the well-being of an individual living with LiS?" Guided by a human-centred and participatory approach within the design thinking framework, it combined a literature review, contextual inquiry, interviews, experience mapping, ideation, prototyping, and iterative evaluation. Through this process, Karel's lived needs, values, and daily challenges were uncovered and translated into a concrete design direction.

Communication emerged as the central factor influencing Karel's well-being, closely tied to safety, autonomy, dignity, social participation, and self-expression. This led to EyeVox, a gaze-based communication and alarm system intended to help Karel initiate communication independently, express his needs, and interact more directly with caregivers in everyday care. Alongside communication, the project brought the importance of a person's sense of safety to the fore, a value less emphasised in existing LiS literature yet central to Karel's own priorities.

The long-term effect of EyeVox on Karel's well-being could not be established within the technical constraints and timeframe of this thesis, and the gaze-related barriers meant the prototype could not be validated against its core communicative aims. Nonetheless, Karel and his partner regarded EyeVox as a meaningful potential addition to his daily life, particularly through independent alarming. They expressed cautious optimism that it could support his well-being over time. Beyond the artefact itself, keeping Karel genuinely involved throughout allowed the participatory process to produce situated knowledge about designing for severe communication impairment, about the priorities that matter most to those living with it, and about the relational and systemic conditions that shape whether such technologies can reach everyday life. In this sense, the thesis demonstrates how design research can contribute to well-being by uncovering situated needs, enabling meaningful participation, and translating personal values into context-sensitive design.

To conclude, this thesis has shown that design research can meaningfully contribute to the well-being of a person living with Locked-in Syndrome, not only by producing an assistive technology but by taking their lived experience, values, and voice as its starting point. Even where technical barriers remained, designing with Karel rather than for him surfaced what mattered most to him and gave him a genuine role in shaping the outcome. EyeVox represents one step toward supporting his communication and safety, and, more broadly, the project illustrates how a human-centred, participatory approach can bring dignity, agency, and individual meaning to the centre of designing for complex disability.

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APPENDICES

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Appendix I: Information Sheet and Consent Form

Information Sheet for Co-design Project with Locked-in Syndrome

Purpose of the Research

This project explores how design can support the everyday wellbeing of a person living with Locked-In Syndrome (LIS). LIS is a rare neurological condition in which a person remains fully conscious but loses almost all voluntary motor control. Many people with LIS communicate mainly through eye movements, while the exact abilities vary from person to person.

This project is part of a master's graduation thesis carried out with D'Andrea & Evers Design, an industrial design agency active in the medical, industrial and consumer sectors. The project's central aim is to work with one individual with LIS, and his caregiver, to co-design a prototype that reflects his needs, experiences and wishes. The prototype will not be medical or clinical device. It is created for design research and does not offer treatment or diagnosis. Insights from the process may help inform future design work in similar contexts.

Participants

The project mainly involves one person living with locked-in syndrome and their primary caregiver, along with the researcher, the company supervisor and two university supervisors who oversee the academic side of the work. These two participants form the core of the study and are the only individuals who will take part in the co-design activities.

If needed, the researcher may speak with professionals or experts, such as nurses, therapists or staff from centres familiar with LIS, to gain contextual insight into care practices, communication and daily challenges. Their involvement will be limited to short, voluntary conversations or interviews and will not include participation in co-design activities. No additional vulnerable participants will be included in the study unless a separate amendment is submitted and approved by the ethics committee.

Project Activities

The project follows a participatory and co-design approach, treating the participant as an active contributor rather than a subject of study. Sessions will be brief and adjusted to the participant's energy level. Breaks can be taken at any point.

Participation may involve short interviews, contextual observation, guided conversations and journey-mapping to understand daily experiences. Co-design sessions may include discussing ideas, exploring materials, sketching or reviewing simple prototypes. There may also be short feedback sessions to refine emerging designs and may include documentation such as notes or photos of non-personal materials.

The total time for each session, including preparation, warm-up, the co-design activities, breaks and a short wrap-up, is expected to be around three to four hours. The pace will be flexible, with breaks whenever needed, and the session will stop immediately if the participant becomes uncomfortable.

Possible Risks or Discomfort

There are no medical procedures or diagnostic tools involved, and no psychological, social or physical risks are expected. The only potential discomfort is mild fatigue, particularly for participants with LIS. Sessions will be kept short, adjusted to the participant's energy level and paused whenever needed.

When a caregiver or professional is present, they may help monitor comfort, but the researcher will also pay close attention and stop any activity immediately if the participant shows signs of strain.

Data Handling

The project collects qualitative material such as notes, sketches, observations and photos of design materials. Audio or video recordings may be used when they help with communication or documentation, and participants will always be informed beforehand and may decline.

Personal information, such as names or contact details, will be stored separately from the research material. All data used in the study will be pseudonymised by replacing identifying details with codes. Only the researcher and supervisors will have access to identifiable information, and no identifying details will appear in the master's thesis or any related presentations.

The data is used only to support the co-design process and to document the research. With explicit consent, anonymised parts of the qualitative data may be kept for future design research by the researcher or other researchers. Participants may refuse this without any impact on their involvement in the project.

Research data will be stored for up to ten years, in line with standard university data management regulations. Identifiable data will be removed immediately if someone withdraws from the study, and participants may request earlier deletion of their personal information at any time.

Withdrawing from the Study

Participation is entirely voluntary, and anyone can withdraw at any time without giving a reason. Withdrawal has no negative consequences. If someone chooses to withdraw, all identifiable data relating to them will be deleted. Any anonymised material already included in the analysis may remain, as it cannot be traced back to the individual.

Voluntary Participation

Consent must be freely given. Participation should never feel pressured or obligatory. The participant with LIS will express consent through his established communication method. If a formal signature is required, the appropriate authorised person (for example, his legal representative or designated caregiver) will sign on his behalf. Caregivers and experts will sign their own consent forms.

Contact
If you have questions or concerns, you can contact:

Researcher
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Consent Form for Co-design Project with Locked-in Syndrome

YOU WILL BE GIVEN A COPY OF THIS INFORMED CONSENT FORM

Please tick the appropriate boxes	**Yes**	**No**
Taking Part in the Study		
– I have read and understood the 'Information Sheet for Co-design Project with Locked-in Syndrome', or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	○	○
– I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions, and I can withdraw from the study at any time, without having to give a reason.	○	○
– I understand that taking part in the study short interviews, guided conversations, contextual observation and co-design sessions, during which information may be captured through written notes, sketches, and photos of non-personal materials. Audio or video recordings may be used when they help with communication or documentation, and I will always be told in advance and may decline. Any recordings will be transcribed into text if needed, and the original audio or video files will be deleted after transcription.	○	○
– I understand that co-design activities may include guided conversations, exploring ideas, using simple materials or sketches and reviewing early prototypes. All activities will be tailored to my comfort and communication style and can stop at any moment. I understand that additional activities may arise during the project and will be explained to me beforehand so I can decide whether I want to take part.	○	○
Risks Associated with Participating in the Study		
– I understand that taking part in the study involves minimal risk. The only possible discomfort is mild fatigue during interviews or co-design activities, especially for participants with LIS. Sessions will be kept short, can be paused at any moment, and will be adjusted to my energy level. There are no medical procedures, and no psychological, social or physical risks are expected.	○	○
Use of the Information in the Study		
– I understand that information I provide will be used to support the co-design process, to document the research and to produce the planned outputs of the project, including a design prototype, insights for future design work, a written master's thesis and presentations within the university. With my explicit consent, anonymised parts of the data may also be used in future design research by the researcher or other researchers.	○	○
– I understand that personal information collected about me that can identify me, such as [e.g. my name, address, geolocation], will not be shared beyond the study team.	○	○
– I understand that I can withdraw my data from the study up until the point when the analysis and thesis writing begin. After that stage, any anonymised material already included in the analysis cannot be removed, but all identifiable data will be deleted.	○	○
– I agree that my information can be quoted in research outputs.	○	○
– I agree to be audio/video recorded.	○	○
– I agree that photos may be taken of materials or activities, as long as my face is not shown.	○	○

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Future Use and Reuse of the information by Others

– I give permission for the anonymised data that I provide to be archived and published in UT Repositories so it can be used for future research and learning.	○	○
– I understand that the anonymized information I provide can be shared with, and used by, the researcher, the university supervisors and the company supervisor for the purpose of this project.	○	○

Signatures

Name of participant	Signature	Date
Name of legal representative (If applicable)	Signature	Date

I (researcher) have provided explanatory notes about the research. I declare myself willing to answer to the best of my ability, any question that may still arise about the research, ensured that the participant understands to what they are freely consenting.

Name of researcher	Signature	Date

Study contacts details for further information:

Researcher

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s.faridmohajer-1@student.utwente.nl

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Contact Information for Questions about Your Rights as a Research Participant

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Natural Sciences and Engineering Sciences Ethics Committee at the University of Twente, P.O. Box 217, 7500 AE Enschede (NL). Telephone: +31 (0) 53 489 5607; Email: a.m.klijnstra@utwente.nl.

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Appendix II: Interview Questions

The empathise phase was supported through a semi-structured interview and questionnaire (see Table 10.1). The method was intentionally low-threshold and adapted to his communication abilities and energy levels. Questions were primarily structured as multiple choice or numeric scales, allowing responses with minimal physical effort. A 1–5 scale was frequently used, with options read aloud while Karel indicated his answer through eye movements, helping to reduce fatigue while still capturing degrees of experience and preference.

The interview was directed primarily at Karel to support his agency, with support from others only when needed for clarification. Its structure combined predefined topics, such as daily activities, communication, and assistive device use, with the flexibility to adjust the pacing and interactions to his condition.

Table 10.1 Semi-structured interview questions

	Opening Questions	
1	How are you feeling right now?	On a scale of 1 to 5: 1 = very uncomfortable 5 = very comfortable
2	Is it OK if I read the questions out loud and you answer? Most questions today are multiple-choice; if you prefer, others can help answer open questions.	
3	Are you ready to begin?	
	Background	
4	Can you tell me the story? Date & cause, timeline, facilities, contacts, etc?	
5	Which type of Locked-In Syndrome was mentioned, if any? And date of diagnosis?	o Classic LiS o Incomplete LiS o Total LiS o Not sure / Do not remember o Never discussed
6	Have there been people, conversations, or forms of support that helped you emotionally or mentally along the way?	
	Current Life and Experience	
	Body Movements	
7	Which movements are possible right now?	
8	Have any movements (voluntarily) changed over time? Improved or worsened?	
	Daily Routine and Activities	
9	What part of the day feels the easiest or most pleasant?	o Morning o Afternoon o Evening o It varies
10	What activities do you enjoy the most? (You can choose more than one option and add your own answer.) [Ask parallel with Q11]	o Watching TV o Listening to music o Resting o In person company o Using the Monitor (reading, watching, contact with others)
11	How often are you able to do these activities?	On a scale of 1 to 5: 1 = very rarely 5 = very often
	Social Contact	
12	Can you tell me a little about the people you are in contact with in your daily life, and what those interactions are usually like?	

Table 10.1 (Continued)

13	How often do you have contact with other people during a typical week?	On a scale of 1 to 5: 1 = very rarely 5 = very often
14	How well do you feel your eye-based yes/no signal is understood by other people?	On a scale of 1 to 5: 1 = very unclear 5 = very clear
15	How did you come up and/or adjust eye signals?	
	Values	
16	When you think about your daily life, what feels most important to you right now?	
17	How much control do you feel you have over how your day unfolds?	On a scale of 1 to 5: 1 = no control 5 = full control
18	How involved do you feel in decisions about your daily routine?	On a scale of 1 to 5: 1 = not involved at all 5 = fully involved
19	How easy is it for you to ask for a change when you want one?	On a scale of 1 to 5: 1 = very difficult 5 = very easy
20	What are your three most important values?	Examples: family, fun, growth, inclusion, empathy, communication, achievement, independence, compassion, …
21	How well does your daily life reflect <u>Value 1</u>?	On a scale of 1 to 5.
22	How well does your daily life reflect <u>Value 2</u>?	On a scale of 1 to 5.
23	How well does your daily life reflect <u>Value 3</u>?	On a scale of 1 to 5.
24	Is there something important to you that we have not talked about yet?	
	Devices	
	Letterboard	
25	How did it become part of your routine? Since when?	
26	Have you used different letterboards before?	
27	With whom do you use the letterboard?	
28	How well does the letterboard fit into your daily routine?	On a scale of 1 to 5: 1 = does not fit 5 = fits very well
29	How often do you use the letterboard?	On a scale of 1 to 5: 1 = rarely 5 = multiple times a day
30	Is there anything about (using) the letterboard that feels especially helpful or especially demanding for you?	
	Tobii Monitor	
31	How did it become part of your routine? Since when?	
32	Have you used different similar technologies before?	
33	What do you mainly use the monitor for? (You can choose more than one option and add your own answer.)	o Messaging o Watching videos o Reading o Environment control o Calling someone, e.g., a nurse
34	How well does the monitor fit into your daily routine?	On a scale of 1 to 5: 1 = does not fit 5 = fits very well

Table 10.1 (Continued)

35	How often do you use the monitor?	On a scale of 1 to 5: 1 = rarely 5 = multiple times a day
36	For how long do you usually use the monitor comfortably?	On a scale of 1 to 5: 1 = only a few minutes comfortably 5 = comfortable for long periods,
37	Is there anything about (using) the monitor that feels especially helpful or especially demanding for you?	
38	Would it be alright if I watch how you use the monitor for a moment?	
	Wheelchair	
39	Have you used a different wheelchair before?	
40	How often are you in your wheelchair?	On a scale of 1 to 5: 1 = once a week 5 = daily
41	How comfortable are you in the wheelchair?	On a scale of 1 to 5: 1 = not comfortable 5 = very comfortable
42	Is there anything about (using) the wheelchair that feels especially helpful or especially demanding for you?	
	Cycling (Rehabilitation)	
43	How did it become part of your routine? Since when?	
44	Have you used different similar technologies before? It can be for different rehabilitation focuses as well.	
45	How often do you have these sessions?	On a scale of 1 to 5: 1 = once a week 5 = daily
46	How do cycling sessions feel for you?	On a scale of 1 to 5: 1 = very bad 5 = very good
47	Is there anything about the cycling sessions (and the tool) that feels especially helpful or especially demanding for you?	
	Other tools	
48	Are there any other devices you wish you had access to (communication, activity, comfort, environment control, anything)?	
	Closing	
49	How are you feeling now compared to when we started?	On a scale of 1 to 5: 1 = much worse 5 = much better
50	How comfortable was this session overall?	On a scale of 1 to 5: 1 = very uncomfortable 5 = very comfortable
51	Would you like the future session to be longer or shorter than today's?	On a scale of 1 to 5: 1= shorter 3=same 5=longer
52	Was this way of asking questions comfortable for you?	On a scale of 1 to 5: 1=not comfortable at all 5= very comfortable
53	Is there something important about your life or experience that we did not talk about but should have?	
54	Is there anything you want me to keep in mind when working with you?	
55	Is there anything you want to ask me before we finish for today?	
56	Is it ok to have some sessions in future 1o1 or prefer with others?	

Appendix III: Experience Map Guide

Table 10.2 is a way to capture daily experiences over the course of one week. There is no right or wrong way to fill it in. Everything you write down is valid. This log is not an evaluation, and it will not be used to assess performance or behaviour. It is meant only to help me understand your experiences, patterns, and what matters most to you, so that any future ideas or designs are grounded in real life.

You can fill it in every hour, every two hours, or only when something feels important. If you remember something later in the day, it is completely fine to add it afterwards, change an earlier entry, or leave things incomplete. This is not about accuracy or consistency; it is about capturing what the experience felt like.

All feelings, thoughts, frustrations, neutral moments, and positive moments matter equally. There are no judgements, no expectations, and no "good" or "bad" answers. The goal is to understand what daily life is like from your perspective.

The caregiver can also add notes where helpful, to capture what they observed or supported in that moment. These notes are not corrections, but an additional point of view.

Table 10.2 Experience-map guide describing the elements, descriptions, and examples used to capture Karel's daily experiences

Element	Description	Example
Time & place	When and where did the moment happen	18:00–20:00, private room
What happened	What was happening at that moment, described factually.	Getting put into a wheelchair
What you were thinking	Thoughts or mental focus during that moment. It can be brief or empty.	Excited for the visit for the project
How it felt	Emotional or physical feelings in the moment. Multiple feelings can be noted, each with its own intensity (1-5). Can also not have feelings (then put 0).	Exciting +3
Who or what you interacted with	Staff, visitors, or technologies are involved at that moment.	A tool to lift my body and wheelchair It was planned.
What was difficult or missing	Anything that did not work well or felt like an unmet need.	-
What you would have liked instead	A wish or suggestion for how the moment could have been better.	-
Notes	Any notes to add context and help better understand the experience.	-

Appendix IV: Validation Interview Questions

1. In your last interview, you said that communication and staying connected with friends are among the most important things to you. Does that still feel true to you?
2. Are you happiest when you are in contact with people?
3. Is it important to you to be recognised as someone who thinks and makes choices, not only as a patient being cared for?
4. When people speak as if you are not fully present, does it affect you negatively?
5. Do everyday choices, even very small ones, matter a lot to you?
6. Does having some control over your positioning, comfort, or timing make a big difference for you?
7. When you cannot communicate discomfort, do even small discomforts affect you more?
8. Does not being able to express discomfort feel heavier than the discomfort itself?
9. Does a lack of communication affect you emotionally as well as physically?
10. Do people sometimes act based on assumptions instead of checking with you first?
11. Does it make a noticeable difference to you when people explicitly check with you rather than assume?
12. Does consistent communication from staff help you feel safer and more at ease?
13. Is being able to initiate communication, especially at night, very important to you?
14. Would being able to call or alert a nurse when you want (especially when you are alone) make a big difference for you?
15. Would having a reliable signal or alarm make you feel safer and more comfortable?

Appendix V: Concept Prototype Flowcharts and Interface Pages

The following flowcharts summarise the main interaction paths of the EyeVox concept prototype and show how these paths relate to specific interface pages. They use standard flowchart symbols and include the gaze-based nine-grid icons shown in Figure 10.1 to indicate which grid area the user looks at each step.

The interaction flow and corresponding interface pages for the overall system, navigation, pre-saved messages, and letterboard functions are summarised in the flowcharts (see Figures 10.2–10.5).

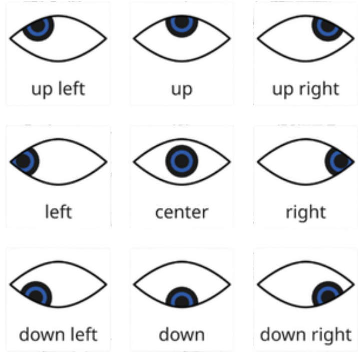

Figure 10.1 Gaze-based nine-grid icons indicating the nine possible eye-direction areas used for selection

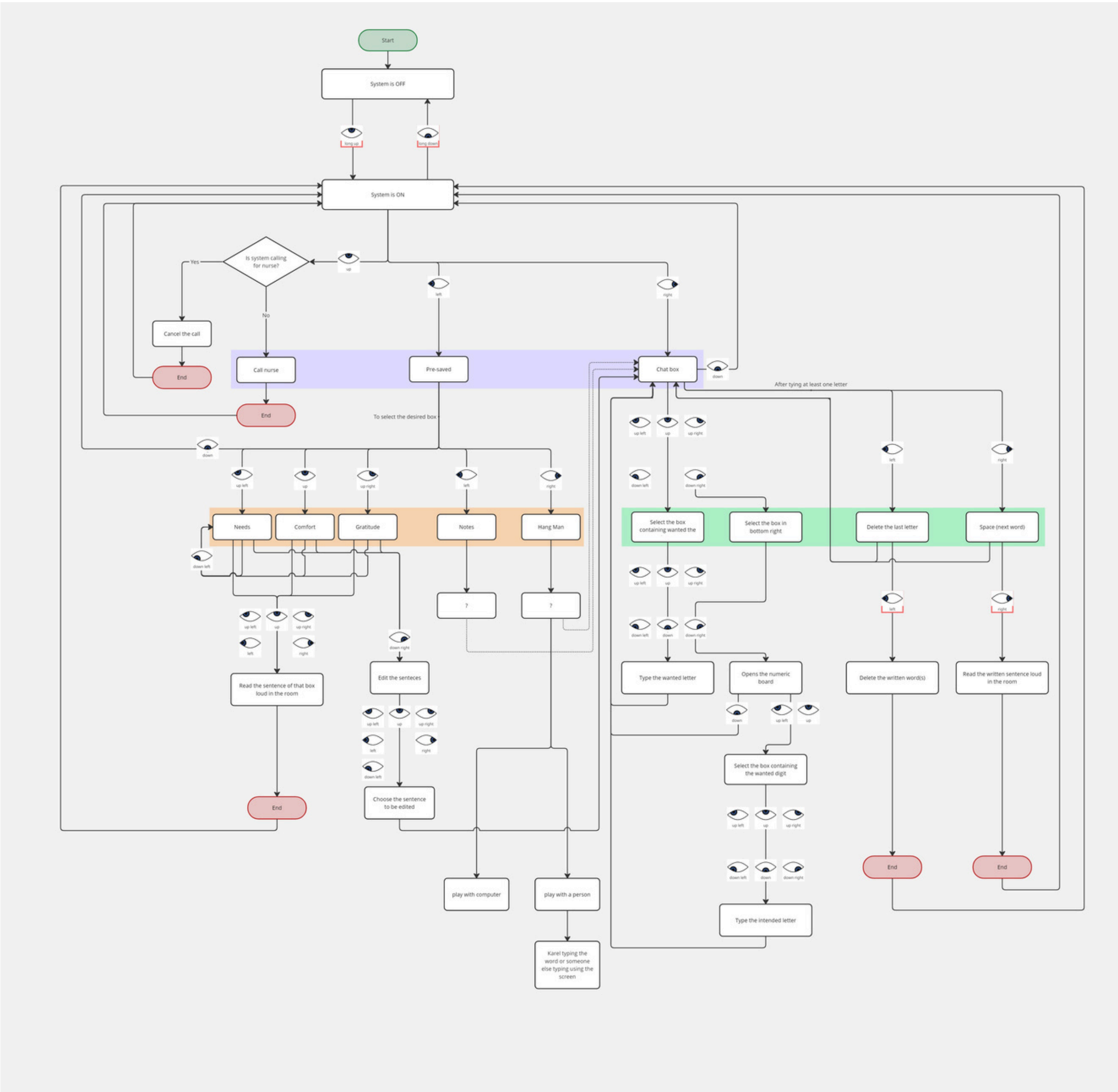

Figure 10.2 Flowchart of the overall system, showing the core functions of calling for a nurse, using the letterboard, and accessing pre-saved messages

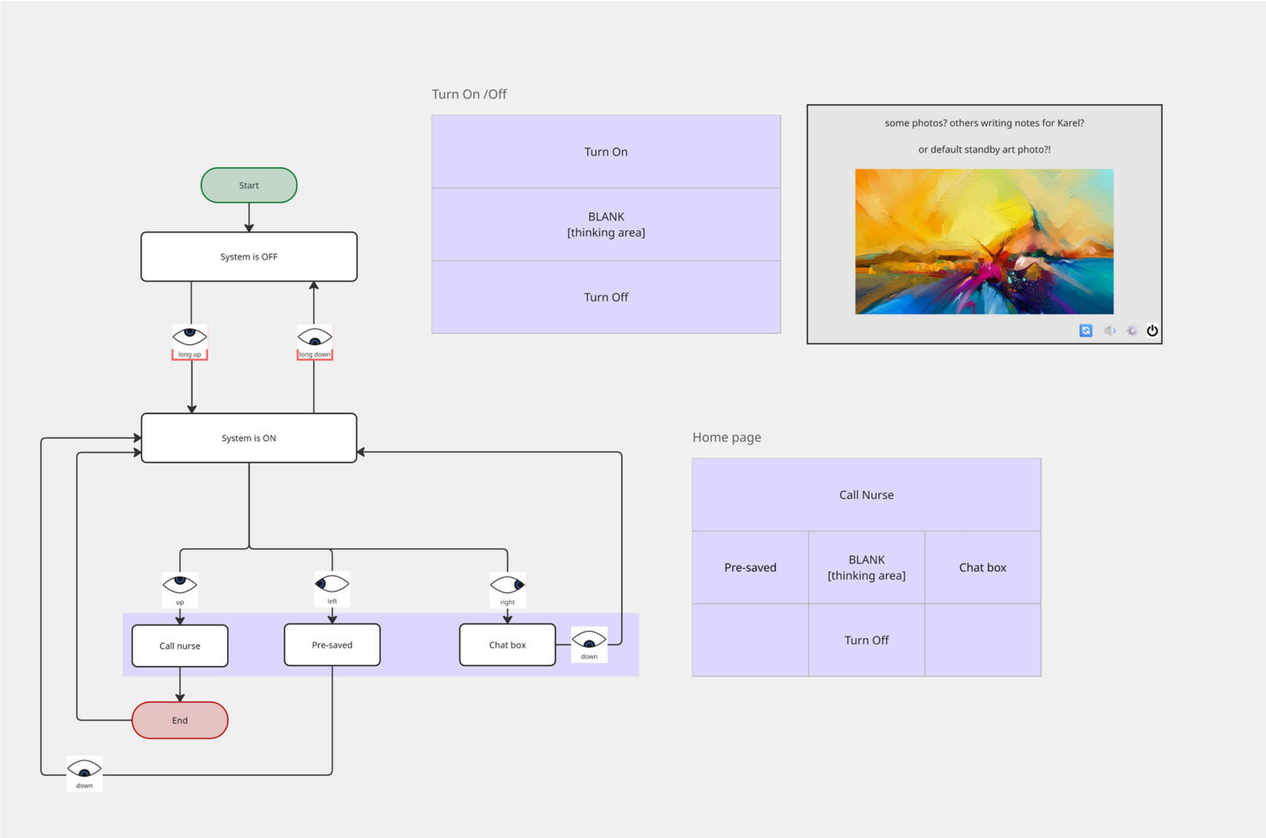

Figure 10.3 Flowchart and interface pages at the general system level, illustrating how it is turned on and off and how users navigate to the core functions

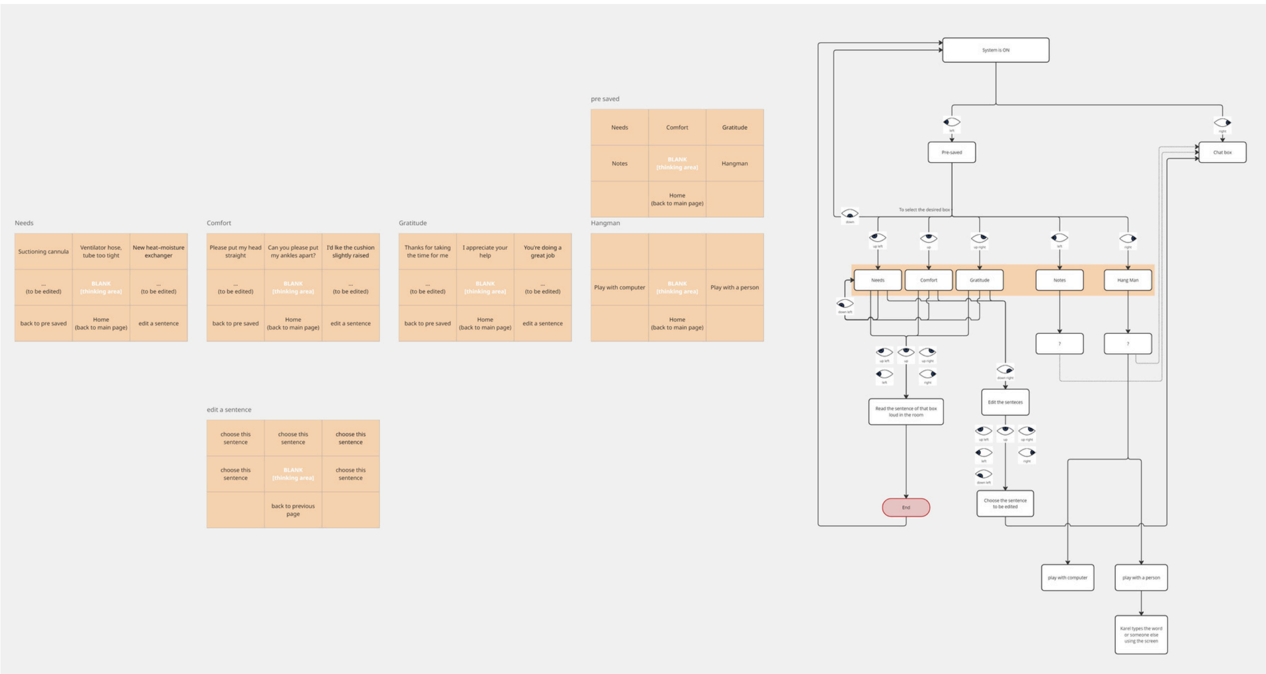

Figure 10.4 Flowchart and interface pages for the pre-saved messages function, showing how users select and activate stored expressions

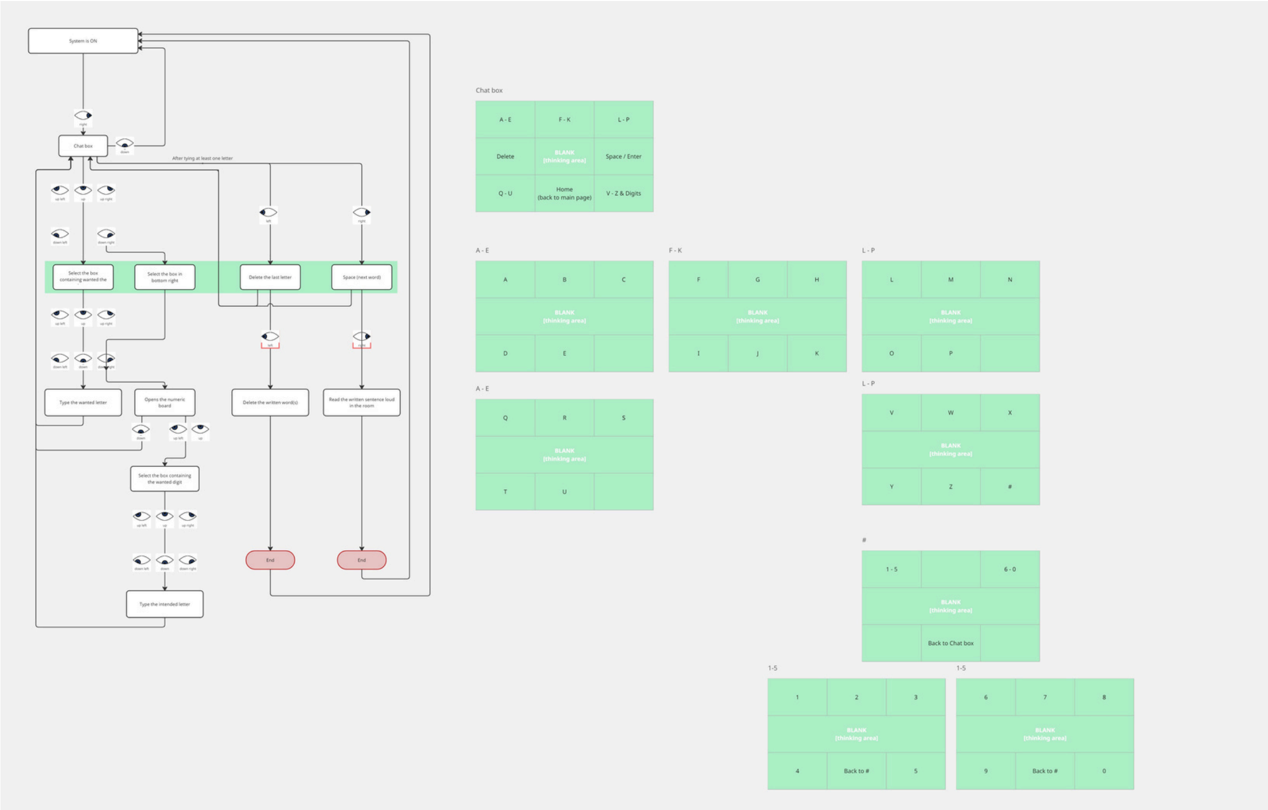

Figure 10.5 Flowchart and interface pages for the letterboard, depicting the steps involved in composing and speaking messages via gaze-based selection

Appendix VI: Interaction Model provided by the Prototype Collaborator

The core concept that drives interaction across this entire system is the subdivision of the user's gaze into 9 sections, arranged in a grid. This is approximately a 33-degree subdivision, which falls well within the Tobii Pro 3's 1.6-degree accuracy, providing sufficient resolution for this mapping. Each section of the grid corresponds to a distinct interaction target, enabling the user to navigate and select elements through sustained gaze without requiring fixation on UI elements. However, a visual UI will still be available as a reference. The centre gaze spot remains interaction-free, so the user can think or rest without triggering any system action (see Figure 10.6). This sustained gaze is tracked over a dwell period — the time the user must keep their gaze to select — which is tuneable so the user can choose the interaction speed. This is especially useful when initially using the system to understand the input modality.

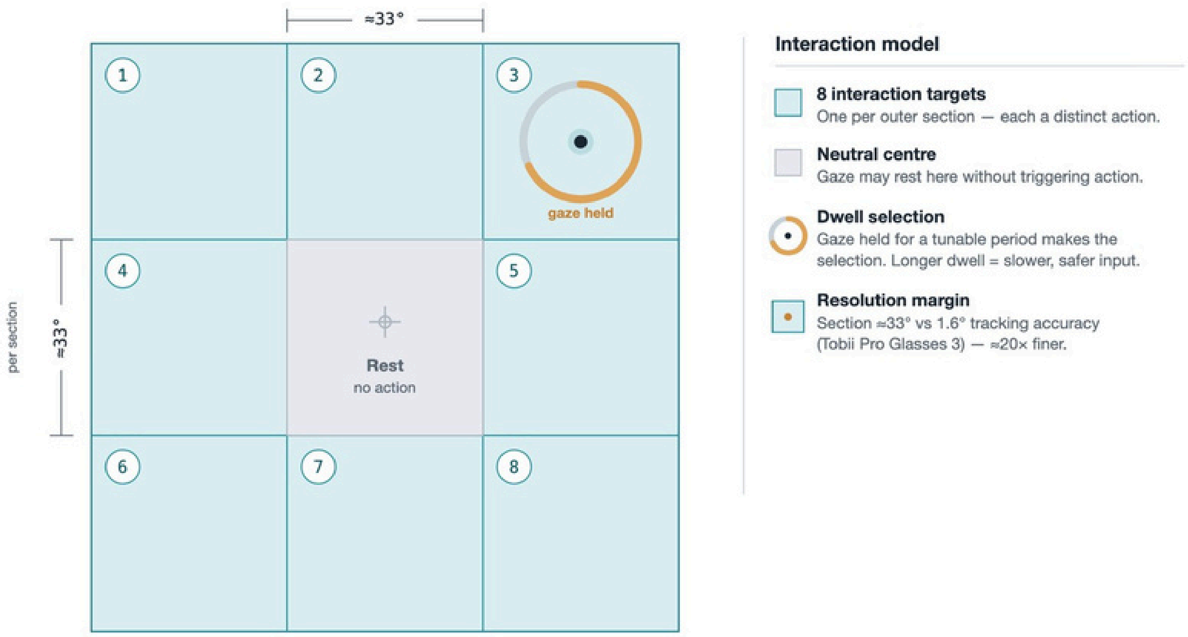

Figure 10.6 The 3×3 gaze grid: eight peripheral sections act as dwell-selectable targets; the centre is interaction free. Image courtesy to Tomas Rendon

Appendix VII: Gaze Calibration and Mapping provided by the Prototype Collaborator

The interaction model requires a gaze sample, reported by the glasses as a normalised 2D coordinate from the user's field of view, to be resolved to one of the nine grid sections. A uniform 3×3 partition, which was the initial implementation of this coordinate space, proved unreliable. This was due to the comfortable oculomotor range achievable, leaving some sections biased or barely reachable. A per-user calibration was therefore introduced to adapt the grid to the individual's gaze range.

Calibration is performed with an operator-driven tool that visualises the gaze-to-section mapping in real time. For each section, the wearer fixates on the corresponding gaze section while the tool samples the gaze stream for 3 seconds; a trimmed mean is estimated over the samples to account for faulty sensor readings, yielding one centroid per section that is robust to blinks, track loss, and stray glances. Because the map redraws after every capture, a poor sample can be spotted, and that section can be recaptured immediately. A completed calibration must pass a geometric sanity check, with row and column centroid medians correctly ordered, before it is saved to disk and loaded by the application at start-up.

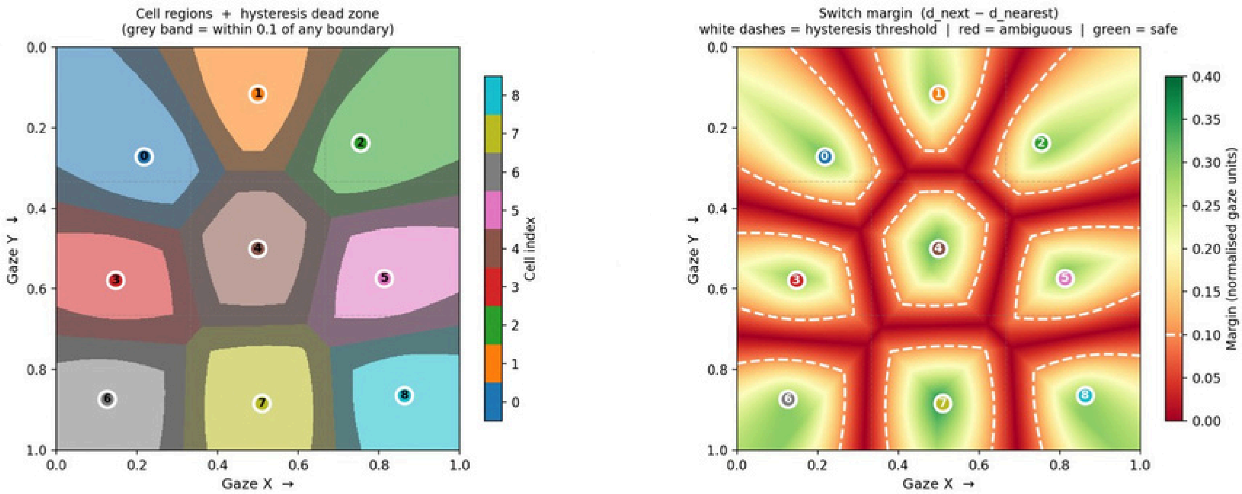

Figure 10.7 (Left) The operator-driven tool with its real-time gaze-to-section map, and (Right) the resulting calibrated regions partitioned into Voronoi cells with their hysteresis dead zones. Image courtesy to Tomas Rendon

At runtime, gaze frames are filtered for track-loss artefacts, smoothed with an exponential moving average, and assigned to the section with the nearest calibrated centroid, effectively partitioning gaze space into Voronoi regions shaped around the user's gaze behaviour. Since selection is dwell-based, boundary flicker would reset dwell progress or trigger unintended selections, so two stability filters are applied before a section switch commits: hysteresis requiring the candidate centroid to be closer by a set margin and thus creating a dead band around every boundary, and frame confirmation, requiring the candidate to persist for consecutive update ticks. Figure 10.7 shows the resulting calibrated regions and their hysteresis dead zones.

Appendix VIII: Reflective Evaluation Questions

Questions for Karel

	On a scale of 1 to 5: 1=Strongly disagree and 5=Strongly agree
1	This project helped identify what is most important to my well-being.
2	This project helped me discover new possibilities for improving my daily life.
3	The final design reflects what is important to me as a person, not only my medical needs.
4	I felt that my experiences meaningfully shaped the direction of the project.
5	Participating in this project gave me a greater sense of involvement in decisions that affect me.
6	The project made me more optimistic about the possibilities of future assistive technologies.
7	I believe this project has the potential to positively contribute to my well-being.
8	The final design makes me feel that my needs have been understood.
9	I can imagine the final design becoming a part of my daily life.
10	I believe the final design has the potential to positively influence my life over time.

	Open answer
11	What moments during the project stand out to you the most, and why?
12	Was there anything about the project that surprised you?
13	If this project were to continue, what would you most like to explore next?
14	What do you hope designers and researchers learn from this project?
15	If another person living with Locked-in Syndrome joined a similar project, what advice would you give them?

Questions for Karel's Partner

1 Looking back, how would you describe your role throughout this project? Did it change over time?

2 How would you describe your experience of participating in this project?

3 Did participating in this project change your perspective on Karel's needs, possibilities, or well-being? If so, how?

4 What advice would you give designers or researchers who want to work with people living with Locked-in Syndrome and their partners?

5 Was there anything about participating in the project that you found unexpectedly easy or difficult?

6 Looking at the final design, in what ways do you recognise your own contribution to it?

7 Do you feel that the final design reflects both Karel's perspective and the insights you shared throughout the project? Why or why not?

8 When you imagine the final design becoming part of everyday life, what do you hope it changes? (for Karel, you and other people around you)