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**Quality of life assessment with an adult with congenital deafblindness:**

**A Person-Centred Approach**

Irene Gabara Moneo

Student number: S5778328

Master in Deafblindness, Faculty of Behavioural and Social Sciences, University of Groningen.

Co-supervisors: Dr. Marja Cantell and Dr. Paul Hart

Name of second assessor: Professor Johannes Westberg

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## Abstract

*Background:* Traditional methods assessing quality of life in adults with deafblindness often rely on caregiver reports, limiting the individual's active participation in the evaluation process. *Research Question:* This study aims to develop a method to assess the quality of life for an adult with congenital deafblindness, ensuring the central role of the participant in the assessment. *Methodology:* A single-case study design was used, applying a phenomenological approach. The participant, a 27-year-old with congenital deafblindness, engaged in a structured interactive session using a whiteboard, inspired by the Talking Mats tool. The session aimed to facilitate self-expression through visual prompts, with verbal and non-verbal communication analysed using qualitative coding in ATLAS.ti. *Results:* The participant actively participated in the self-assessment, sharing preferences and emotions, particularly in the areas of physical well-being, relationships, and activities. Physical well-being emerged as the most discussed aspect, frequently linked with negative emotions. *Discussion:* This study demonstrates the potential of Person-Centred, interactive tools to facilitate self-assessment for adults with congenital deafblindness. While the method provided rich, qualitative data and empowered the participant, it is time-consuming and limited in its generalizability.

*Keywords:* Deafblindness, Quality of Life, person-centred approach, self-assessment, Communication tools.

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## **1. INTRODUCTION**

A fulfilling life, rich with happiness, health, friendships and purpose, is a universal aspiration. These elements, among others, collectively define what is known as quality of life (Schalock, 1990). The key to attaining and enhancing some of these aspects is understanding the quality of life experienced by different populations. Some groups, such as people with deafblindness who often have additional disabilities like learning difficulties, face unique challenges in achieving these aspects. Deafblindness can create significant barriers to communication, social interaction, and participation in daily activities. Understanding and improving the Quality of Life of this population is essential to ensure their well-being and social inclusion.

The aim of this study is to develop a method for assessing their quality of life, with an emphasis on ensuring the individual's central role and active participation in the self-assessment process. By prioritizing and hearing the voice of the participant, we ensure that their perspectives, needs, and aspirations are central to the assessment process, leading to a more inclusive and meaningful approach to their well-being.

## **2. THEORETICAL FRAMEWORK**

### **2.1. Deafblindness**

Deafblindness is a unique and diverse disability, representing between 0.2% and 2% of the general population (Rune, 2018). The heterogeneity of this condition is influenced by multiple factors, including the varying degrees of sensory impairments individuals may experience, the diverse age of onset of these impairments, the potential presence of additional disabilities and individual communication preferences. Additionally, factors such as educational and cultural backgrounds, access to assistive technologies and communication methods influence the diverse experiences within the deafblind community (Dammeyer, 2014). Moreover, there are different perspectives through which deafblindness can be understood and described (Larsen & Damen, 2014). On the one hand, the medical model of disability focuses on the physical effects of both hearing and visual impairment, highlighting the diagnosis and medical features of the disability. On the other hand, the social model shifts the emphasis towards the abilities and functioning of persons with deafblindness in their environment. The World Health Organization (WHO) introduced the International Classification of Functioning, Disability, and Health (ICF), to provide a biopsychosocial framework that incorporates aspects of both models. This framework focuses on the activities and participation of

deafblind individuals while also taking into account personal and environmental factors (World Health Organization, 2001). The Nordic definition, aligned with the ICF framework, defines deafblindness as a condition in which both visual and hearing impairments are so severe that the affected senses struggle to compensate for each other. Therefore, deafblindness is identified as a distinct disability (Nordic Welfare Centre, 2018). This group of people often encounters social exclusion and a lack of participation in the community (Rune, 2018). For all these reasons, deafblindness is isolating and has an impact on well-being and overall quality of life.

### **2.1.1. Congenital Rubella Syndrome**

There are many different causes of deafblindness. During the 1960s, Congenital Rubella Syndrome (CRS) was a leading cause worldwide. However, thanks to widespread vaccination programs, the incidence of CRS has significantly decreased in most countries (Admiraal & Huygen, 2000). Rubella is a mild and preventable viral disease with symptoms such as fever and rash. Congenital Rubella Syndrome is a more serious condition that occurs when a mother contracts rubella during pregnancy, resulting in a range of developmental complications for the child. CRS frequently affects sensory organs, including hearing and vision, and can also impact cognitive and physical development (Robertson et al., 2003).

### **2.1.2. Challenging behaviours in congenital deafblindness.**

Individuals with congenital deafblindness frequently present symptoms of distress and anxiety that manifest as behaviours that challenge (Dammeyer, 2010). Unlike the more extensively researched area of behaviours that challenge in individuals with intellectual disabilities, the specific characteristics and underlying causes of these behaviours in the deafblind population remain relatively understudied (Lembcke et al., 2016). Behaviours that challenge can manifest as aggression towards others, self-harm, destructive actions, or other disruptive behaviours (Lowe et al., 2007). For individuals with limited expressive language skills, these behaviours can serve as a form of communication. A complex interplay of factors contributes to these behaviours. Sensory deprivation, the absence or impairment of sight and hearing, can lead to heightened isolation and frustration. Individuals may struggle to comprehend their environment and express needs effectively, often resulting in behavioural outbursts. Additionally, cognitive and developmental challenges, frequently co-occurring with congenital deafblindness, impact problem-solving, learning, and social skills, further contributing to behavioural difficulties (Dammeyer, 2011).

### **2.1.3. Importance of body language**

Observing both body language and behaviour is crucial for understanding what individuals with congenital deafblindness are communicating, as these non-verbal cues provide valuable insights into their underlying emotions and intentions. Since behaviour is a form of communication, paying close attention to behaviours that challenge, as well as other behaviours, is essential for interpreting needs and desires. These are strategies that align with the Mosaic approach. The Mosaic approach, developed by Alison Clark and Peter Moss, is a research method designed to listen to and understand the perspectives of young children, particularly in early childhood education. It combines various techniques to capture the voices and experiences of young children, who may not yet be able to express themselves fully through words alone. This multi-method approach is not limited to the spoken word but rather seeks to listen to different voices in diverse ways such as note taking and photographs in interactions with different people (Clark, 2017). For individuals with deafblindness who have complex communication needs, it is especially important to capture their indirect voice—the non-verbal ways they express themselves. By recording how these adults communicate through behaviour, gestures, and other non-verbal cues, we gain important information about their needs, preferences, and desires. These observations resonate with the Mosaic approach's emphasis on "listening" through multiple methods, ensuring that the indirect voices of those with significant communication challenges are heard, valued, and understood.

Additionally, the importance of non-verbal elements in communication can be supported by the concept of embodiment. Embodied cognition (Costain et al., 2019) highlights the essential role of body language in communication. Cognition is closely tied to physical actions, with gestures and movements acting as extensions of thought. The body itself is a mode of communication, with each movement reflecting underlying cognitive and emotional states. This perspective complements the Mosaic approach by highlighting the significance of non-verbal cues as intentional, embodied expressions of needs and desires, rather than isolated behaviours.

## **2.2. Quality of Life**

Defining the concept of quality of life remains a challenge due to its diverse perspectives, the abstract nature of the term, and the subjective and contextual elements involved in its assessment (Barofsky, 2012). Innumerable models attempt to define this concept. This research will only focus on assessment approaches that specifically address the quality of life for individuals with multiple disabilities or learning disabilities.

Schalock et al. (2002) developed a framework for conceptualising the quality of life in individuals with intellectual disabilities. This framework proposes the quality of life as a multidimensional construct influenced by personal and environmental factors. It distinguishes eight core domains for assessing quality of life: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

Assessing the quality of life of adults with deafblindness, as well as in adults with other disabilities, is crucial to comprehend their unique experiences, needs, and overall well-being. People with deafblindness communicate and express themselves very differently from those without a dual sensory impairment and therefore they need a specialised assessment. Petry et al. (2009) developed an instrument to measure the quality of life of people with profound multiple disabilities, a questionnaire named QOL-PMD influenced by the categories proposed by Schalock et al. (2002). While Schalock et al. established foundational dimensions for quality of life, Petry et al. refined these concepts to create a specific instrument tailored to address the unique needs and challenges faced by this particular population. Petry's tool defines six objective components of quality of life: physical well-being, material well-being, communication & influence, social well-being, development and activities. The Physical well-being component addresses health and physical comfort, such as managing medical conditions and mobility issues. The Material well-being component focuses on access to essential resources like suitable living conditions and necessary equipment. The Communication and influence component examines how effectively individuals express themselves and make decisions. The Social well-being component assesses their relationships and social integration with family, peers, and caregivers. The Development component emphasizes opportunities for learning and personal growth through activities tailored to the individual's abilities. The Activities component evaluates participation in meaningful daily activities, such as hobbies and therapeutic interventions. Preliminary research has been conducted as a part of the Master's program in Communication in Deafblindness at the University of Groningen. Some of these projects have utilised tools like the QOL-PMD (Petry et al., 2009), which were specifically adapted for individuals with deafblindness (Van Dam, 2017).

In many quality-of-life assessments of adults with profound multiple disabilities, it is often the caregivers who participate in such assessments, speaking on behalf of people with deafblindness (Van Dam, 2017), or other disabilities (Petry et al., 2009). However,



their perspective cannot fully grasp the first-hand experience of deafblindness. Previous work demonstrates a significant lack of direct participation in important decisions concerning individuals with deafblindness. Smith (2015) underscores the limited choice and control often offered to people with complex communication needs, highlighting a gap in ensuring their active participation in decision-making processes. The study of Smyth (2015) proposes an alternative approach based on dialogical communication models (Linell, 2009), which emphasizes direct engagement with individuals to better understand their priorities and preferences. This model underscores the co-construction of meaning through mutual dialogue, allowing individuals to express their thoughts and feelings in a supportive environment. This approach is considered a cornerstone of improving their quality of life, ensuring that their voices are not only heard but actively respected in decisions that affect them, fostering a sense of empowerment.

Talking Mats (Murphy, 1998) has been found as an effective communication tool to support people with learning disabilities and communication difficulties to express their views and feelings. It is a visual communication framework that works by moving pictures around a carpet tile. At the top of the mat, there is a visual scale (with 3-5 rating levels) for the participant to express their thoughts about symbols or pictures representing certain activities or events related to the topic displayed at the bottom of the carpet. Overall, it offers a structured approach to communication, enhancing the ability for someone to express their views on specific topics and providing structured conversations (Murphy et al., 2005; Murphy & Cameron, 2008). This tool has been recently used to assess social care-related quality of life in adults with intellectual disabilities (Darvell & Bradshaw, 2023). However, it has not been designed to be used in people with visual sensory impairment. This research on Quality of Life is inspired by the principles of the Talking Mats communication tool. The communicative session central to this research, which will be elaborated upon in a subsequent section, facilitates self-assessment and enables participants to articulate their perspectives on a range of topics related to quality of life.

When it comes to individuals with deafblindness, there is a notable research gap. There are very few studies where deafblind adults participate directly in their assessment of quality of life or well-being. Such studies have however been done alongside people with acquired deafblindness and with high communication skills (Van de Molengraft, 2011). It is vital to listen to deafblind individuals with different communication support needs, enabling them to express their thoughts and feelings in a personalised way. This is

a human right recognized under Article 21 of the Convention on the Rights of Persons with Disabilities (CRPD), which ensures the right to freedom of expression and access to alternative communication methods for individuals with disabilities (United Nations, 2006). The Salamanca Statement (1994) further supports the need for personalized approaches in communication, advocating for inclusive practices that accommodate the unique needs of individuals with disabilities in educational and societal contexts (UNESCO, 1994). For this reason, it is crucial to involve them from the beginning of the development of the assessment methods. This includes adapting existing assessments to incorporate their participation, alongside caregivers, or even more importantly, by creating new individualised tools. Their expertise about their own experience is valuable and irreplaceable. The absence of prior studies addressing this specific area underscores the innovative character of this research.

This study aims to be a valuable step in the development of quality of life tools alongside individuals with deafblindness. Despite the heterogeneity of the deafblind community, it can be a useful resource for professionals, family members, friends and interested parties, by incorporating the voices and experiences of individuals with deafblindness. Ultimately, qualitative assessments that reflect the unique perspectives of life experiences of the deafblind community can enhance not only their quality of life but also enrich our mutual understanding of what is important in life for us all.

### **3. AIM OF THE RESEARCH AND RESEARCH QUESTIONS**

This study aimed to develop a method to assess the quality of life for an adult with congenital deafblindness. The main purpose is to ensure the central role of the participant in the assessment process and to find methods for their active participation in this self-assessment.

Research question: In what ways can an interactive session enable an adult with congenital deafblindness to actively participate in the self-assessment of their quality of life?

Sub-questions:

- How does this method for self-assessing quality of life, relate to the talking mats communication tool?
- What are the strengths and limitations of this interactive method compared to standardised assessments of Quality of Life?

## **4. METHOD**

### **4.1. Research Design**

This study adopted a single case study design, focusing on qualitative data collection in relation to one adult with congenital deafblindness. This approach enables consideration of this participant's quality of life, following a comprehensive exploration of the person's experiences, likes and dislikes. The advantages of this approach lie in its ability to provide an understanding of the specific case in its real-life setting (Yin, 2018).

The study took a phenomenological approach to interpret the results. This method aimed to understand the subjective experiences of the individual and explore how they perceive and engage with the surrounding world. By challenging preconceived notions and embracing the subjective world of the individual, the phenomenological approach allows for a deep exploration of their lived experiences (Giorgi, 2009). To understand the quality of life of the participants, this study gathers data from different sources. The data collected through an interactive session with the participant using a whiteboard, had then been analysed and integrated with the pre-existing theories. The reason for this methodology is to empower the participant, allowing their experiences and perspectives to be expressed naturally while minimising the influence of the researcher as much as possible.

### **4.2. The participant**

The participant in this study is a 27-year-old individual with congenital deafblindness caused by Congenital Rubella Syndrome. He is profoundly deaf and has limited vision in his right eye, having completely lost his vision in his left eye. He stays in a house with 3 other deafblind adults, while also spending time with his family in their home. He spends one week at the residential centre, followed by one week with his family.

The participant was chosen for this study due to his strong expressive communication skills and clear understanding of his personal preferences. He is very capable of articulating his desires and needs in the present moment. However, discussing abstract concepts, emotions, or events not immediately present can be more challenging for him to articulate. Despite this, he can convey such information when asked effectively, through various methods, and often by relating it to previous experiences and concrete situations.

He uses various communication systems. He has some understanding of Sign Language within his limited visual field and uses Lámh signs, designed for people

with intellectual disabilities. He also communicates through writing and drawing in his notebook, as well as using pictures. Writing and drawing are not just activities for him but also powerful communication methods. He has several notebooks where he likes to write about his family, activities, likes, and daily life. Additionally, there is an interactive whiteboard in the centre where he resides that he has used a few times. He enjoys drawing on it and likes looking at what staff write there. The whiteboard is used not only as a communication system but as a way for him to express himself and as a tool to communicate about more abstract concepts and emotions. This whiteboard was the principal tool chosen to facilitate the assessment and is further described in the next session.

This participant frequently manifests signs of distress that present in the form of behaviours that challenge. For people with limited expressive language skills, this type of behaviours can serve as a form of communication. Rather than seeing these behaviours as mere disruptions, recognizing them as a valid means of communicating needs, emotions, and desires allows for a more empathetic and responsive approach to supporting the Deafblind community. Observing the participant holistically during the activity provides valuable insights into their overall well-being. Verbal communication, facial expressions, emotions, and interactions all contribute to a holistic approach to understanding of their quality of life. This approach resonates with the Mosaic Approach, which emphasizes the importance of viewing multiple aspects of communication to gain a deeper understanding of the “voice” of the individual.

In this study, two co-researchers were involved in the interactive session and subsequent analysis, each having established a relationship of over two years with the participant. The first co-researcher was the primary author of this thesis. The second co-researcher, who is the participant's keyworker at the centre, shares a strong relationship with the participant.

#### **4.3. Ethical aspects of the research**

The project was entered as a student project to the list of the Ethical Committee of the Pedagogical and Educational Sciences, University of Groningen. The centre manager was informed and agreed to have the study to take place at the centre. Informed consent was obtained from the participant's parents after providing them with an information sheet regarding the study's purpose, methods, and data handling and storage. Both the information sheet and the consent form can be found in the Appendix section. Consent from the participant was also taken into account, listening to the participant on

his desires and willingness to participate in the study. The purpose of the research was shared with the participant in a way he understands, for example: "I want to learn what you like/don't like to help you better". Consent was also obtained from the co-researcher involved in the interactive session and the video observation process.

#### **4.4. Instruments**

In this study, data were collected through an Interactive Activity with a Whiteboard. The participant expressed himself using this communication tool. Inspired by the Talking Mats tool (Murphy, 1998), the whiteboard was modified to provide greater structure and facilitate the assessment of quality of life (QoL). Instead of a 3 to 5 point scale, a simpler binary scale was employed, using descriptive terms like "like" and "not like," or "happy" and "sad" to indicate positive and negative responses. The whiteboard featured two columns, marked with a happy and a sad face, allowing the participant to point, write, or draw, making the communication process more accessible and intuitive. The sessions were recorded for subsequent analysis. The transcript of the activity and the video itself were used for the analysis. This process is described in more detail in further sections.

#### **4.5. Procedure**

The interactive session aimed to enable the participant to express his preferences with a whiteboard frequently used by the participant as a communication aid or drawing game. The session had an approximate duration of forty-five minutes. The duration of the session was determined completely by the participant's engagement and he was asked when he wanted to finish. It was decided after the session that one had been enough to collect the information needed. In this session, the participant was encouraged to express his likes and dislikes of relevant people and events in his life through this communication tool. The session began with a warm-up phase where the participant required repetition and prompting from the researchers to understand the task. This initial stage was marked by moments of confusion on the participant's part. He often repeated the researchers' questions exactly as they were asked and waited for more guidance. Even though it was observed that he did not fully understand, the participant chose to continue when asked. As the session proceeded, repetition continued until a turning point occurred when the participant suddenly gave a long answer, listing things that made him sad and providing detailed information on his own. After that, he paused and thought carefully before answering the next questions, marking another turning point. From this moment, the

session flowed more smoothly, with the participant sharing more information when asked. The session was video recorded to observe and analyse the interactions. The second step of this process consisted of analysing the participant's expressions throughout the whiteboard session, and specially of a specific session of the activity.

To enhance the reliability and ensure the quality of the study, a triangulation strategy was implemented (Carter et al., 2014). Methodological triangulation was accomplished by employing multiple data sources and analysis, including the documentation of sessions through video and the development of a video codebook. Furthermore, a co-researcher participated in the video observation process, reinforcing the validity of this research. Both researchers reviewed the video multiple times and collaboratively established certain codes based on the participant's body language, as described in detail in section 4.6.3 on applying codes to the data. Finally, the results were interpreted with the existing theories already mentioned in the background section.

#### **4.6. Analysis**

The data for this study consisted of a video recording of an interactive session. ATLAS.ti was employed to facilitate a systematic qualitative analysis of the participant's interactions and experiences. The software enabled the efficient organization, coding, and analysis of the data, which was crucial for assessing the quality of life of the participant. A 12-minute section of the video was chosen by the two co-researchers as being the most significant in terms of information. In this part of the activity, the participant initiates the topic himself, unlike the beginning of the activity which served as a warm-up for the participant to understand the activity. The video was transcribed adding non-verbal relevant information. The transcript was then analyzed using ATLAS.ti (version 24.1.0), a software for qualitative data analysis. The process which involved coding, will be described in more detail in the respective section below.

##### **4.6.1. Data preparation**

The first step involved transcribing the communication during entire session with the participant, this transcription can be found in the Appendix 1. This detailed transcription included all verbal and non-verbal communication, such as body language, pauses, and use of signing space, to capture the full context of the interaction. After transcription, the document was reviewed with the co-researcher to identify the most significant segment for analysis. The selected segment of the transcription was imported into ATLAS.ti. This allowed for the application of codes directly within the software.

#### **4.6.2. Initial Code Construction**

The initial review involved thoroughly reading the transcripts and watching the video recording several times. This stage aimed to familiarize the researchers with the data and begin identifying recurring patterns and themes. Preliminary codes were constructed during this review, which served as a foundation for more detailed coding. During this initial analysis, preliminary codes were constructed based on frequently mentioned words, behaviours, and recurring themes. Some of the first codes to be created were feelings such as "happy," "sad," and "like," as these were the most frequently mentioned words throughout the transcript. Additionally, some emotions were coded even when not explicitly mentioned in the dialogue but were indirect from the participant's non-verbal cues and expressions observed in the video.

Using ATLAS.ti, codes were applied to the data segments of the selected section. The transcript was reviewed line by line and marked with corresponding codes. This process was reiterative, with codes being refined and adjusted as new patterns emerged.

After coding the data, codes were grouped into broader themes. This step involved clustering related codes to form comprehensive themes that reflected key aspects of the participant's quality of life. Thematic analysis was guided by the phenomenological approach, focusing on the subjective experiences of the participant. Themes such as "communication methods," and "physical health" were identified and refined through multiple rounds of analysis.

#### **4.6.3. Applying Codes to Data**

The codes were systematically applied to the selected transcript segment within ATLAS.ti. Relevant portions of the text were coded according to their alignment with the established codes. The coding process was iterative, involving multiple rounds of refinement. Throughout this process, the codes were reviewed and adjusted to ensure accurate application and comprehensive coverage of the data.

Special attention was given to the participant's non-verbal cues, such as body language and signing space usage, to differentiate between instances of understanding and confusion. These markers were crucial in ensuring that the codes accurately reflected the participant's experiences. Two specific codes involved differentiating when the participant was repeating a sentence with the purpose of giving an answer compared to when he was repeating without understanding. On the transcript itself, this differentiation was challenging to determine. For this reason, the co-researchers examined the video again in order to find behavioural markers and body language that would provide a more

objective basis for this code. It was found that the participant signed differently when he was answering versus when he was only repeating without understanding. When answering, his responses were quicker and more expressive, using a larger signing space. In contrast, when repeating without understanding, his signing was slower and more neutral, movements were less sudden. This was written as notes in ATLAS, as well as other relevant aspects of the body language appreciated in the video, such as his level of engagement, where he directed his attention, and how he pointed to different areas on the whiteboard.

#### **4.6.4. Analysis and Interpretation**

Following the coding process, specific ATLAS.ti's analytical tools were utilized to analyse the transcript. First, the Word Cloud and Word List tools were used to perform a comprehensive analysis of word frequencies, helping to identify key terms and recurring concepts across the full transcript. Additionally, a detailed examination of a 12-minute segment of the video was carried out. Firstly, a comparison between the different types of participant interactions, such as repetitions, new information, and processing time, was to determine which type occurred most frequently. These terms are defined in the table below to clarify their usage. To better understand the participant's self-assessment, his feelings and emotions were grouped ATLAS.ti's Code Groups feature into two broad categories: positive feelings and negative feelings. Positive feelings included communication indicating concepts such as like, happy, love, while negative feelings included concepts such as dislike, sad, angry. These emotional codes were then analysed and compared within the transcript using the Query Tool to assess frequency and distribution. Furthermore, an analysis of Quality of Life categories was performed to identify which categories the participant mentioned and their recurrence throughout the discussion. A more detailed co-occurrence analysis was also conducted through the program to explore the relationship between feelings and quality of life categories, revealing how the participant assessed different situations as either positive or negative. Lastly, a quotation length analysis was carried out on ATLAS.ti to determine how often the participant used long versus short sentences, providing additional context to their communication style.



**Table 1***Definitions of the different types of interaction*

Term	Definition
Repetition	When the participant repeats a question or statement instead of answering, indicating a lack of understanding or confusion.
New information	Instances where the participant responds to a question or provides new information.
Processing time	The pause or delay before responding, reflecting the need to comprehend or formulate an answer.

## 5. RESULTS

The purpose of this research was to develop a method for assessing the quality of life of an individual with deafblindness that centres on the participant's perspective and empowers self-assessment. This section presents the results from the interactive session with the participant, the analysis of the transcript and the video itself. The information given by the participant was categorised based on the six domains of quality of life proposed by Petry et al. (2009), which include *physical well-being, material well-being, communication and influence, social well-being, development, and activities*.

### 5.1. Session overview:

The interactive session with the participant aimed to explore his preferences and experiences (quality of life) using a whiteboard, a communication tool that he frequently uses. The session lasted approximately 45 minutes, during which the participant was encouraged to express his likes and dislikes regarding relevant people and events in his life.

The session began with a warm-up, during which the participant initially struggled to understand and required a lot of repetition before gradually starting to provide some information. This was evident as the participant repeated the researchers' questions word for word, waiting for additional guidance. This first part was mainly led by both co-researchers, who guided the activity. After a few minutes, the participant was asked if he wanted to continue or finish the activity. Despite not fully understanding it, as observed by the constant repetitions and waiting times, he wanted to continue. As the session progressed, repetition kept happening, but then there was a turning point. All of a sudden, he started answering with a very long sentence, listing many things that made him sad

and giving a considerable amount of information on his own. After that, on the next questions, the participant paused for a long time before answering a question, carefully thinking, and then responding with an answer that had not been provided to him. This marked a significant shift in the session, and was named the “focus section” Following this moment, the activity became smoother, and the participant began to share information, when asked certain questions.

An initial analysis of the transcript focused on word frequencies. After excluding personal identifiers, it was clear that feelings and emotions were the most frequently mentioned after the word “yes”. Notably, the words "sad" (6.45%), "like" (5.9%), and "happy" (4.78%) appeared most often (see Appendix 2). This was interpreted to indicate engagement in self-assessment, reflecting either positive or negative feelings towards something.

An analysis of the types of interaction was conducted over the entire session, revealing the following distribution: repetition (53.49%), new information (46.49%), and no processing time (0%). During the video observation, we noticed that the participant provided more new information in the focus section. Consequently, we decided to focus on a specific 12-minute section (28' to 40') where the types of interaction shifted significantly. In this section, new information increased to 74.21%, repetition decreased to 13.16%, and processing time was 12.63%. This section was selected for further analysis due to the higher proportion of new information provided by the participant, in contrast to the earlier part of the session where repetition was more prevalent.

**Table 2**

*Types of interaction in two different sections of the video*

Type of interaction	Participant interactions in the warm-up section (%)	Participant interactions in the focus section (%)
Repetition	53.49	13.16
New information	46.49	74.21
Processing time	0	12.63

## **5.2. Analysis of the 12-minute section transcript**

### **5.2.1. Emotional content**

To better understand the participant's self-assessment, his feelings were grouped into two broad categories: positive feelings and negative feelings. Positive feelings

included like, happy, love while negative feelings included dislike, sad, angry. In this section of the video Negative feelings were expressed in 59.44% of the emotional responses, compared to 40.56% for positive feelings.

### 5.2.2. Categories of quality of life

Before conducting a detailed analysis of each category, it was clear that the participant naturally addressed various aspects of their life corresponding to the six categories defined by Petry et al. (2009): *Physical well-being*, *Material well-being*, *Communication and influence*, *Social well-being*, *Development and Activities*. The participant specifically mentioned aspects from four of these categories. Specifically, he referred to clothing, toys, and toiletries, which constitute *material well-being*. He also discussed drawing, doing groceries, and watching television, items that fall under the domain of *activities*. Furthermore, the participant mentioned significant individuals in their life, an aspect related to *social well-being*. Lastly, references to health issues, pain, and doctor visits pertain to *physical well-being*. See table below.

**Table 4**

*Quality of Life Categories in Text*

Category of QoL	Amount of text that relates to the category	% of text that relates to the category
<i>Activities</i>	91	26
<i>Material well-being</i>	32	9.14
<i>Physical well-being</i>	137	39.14
<i>Social well-being</i>	90	25.71

*Physical well-being* emerged as the most frequently discussed category, accounting for 39.14% of the participant’s mentions, followed by *Activities* at 26%, *Social well-being* at 25.71%, and *Material well-being* at 9.14%. Throughout the session, the participant repeatedly brought up *physical well-being*, frequently discussing aspects of his health.

### 5.2.3. Emotional Responses and Quality of Life

Throughout the 12-minute section of the video, the participant reflected on various aspects of his life, relating them with either positive or negative feelings. These reflections offered a self-assessment that closely aligns with the categories defined by Petry et al. 2009.

**Table 5***Emotional content in Quality of Life categories*

Category	Codes	Positive feelings	Negative feelings
<i>Material well-being</i>	clothes	2	
	Toys	1	
	Toiletries		
	Total	3	0
<i>Activities</i>	Drawing	1	
	Food shop	1	
	Watch TV		2
	Total	2	2
<i>Social well-being</i>	Important people	2	1
	Total	2	1
<i>Physical wellbeing</i>	Doctor visits		2
	Health issues		3
	Pain		1
	Total	0	6

*Physical well-being* was the most frequently discussed category (39.14%), with the participant often discussing health issues, pain, and doctor visits, all associated with negative emotions. The participant discussed *Activities* such as drawing (positive feelings) and watching TV (negative feelings). *Social Well-Being* included mixed emotions about important people in the participant's life. *Material well-being* was associated with positive emotions linked to toys, clothes, and food shopping.

Only this single session provided a wealth of information regarding the participant's quality of life (QoL). It offered insights not only into his emotional responses but also into how he uses different methods of communication. Observations between co-researchers noted that the participant was able to express positive emotions more readily, while negative emotions took longer to articulate, reflecting the complexity of his emotional world. In Appendix 3 we can find a more detailed table for the relationship

between the different codes in each Quality of Life category and the specific positive (love, like, happy) and negative feelings (dislike, angry, sad).

Examining the length of quotations in participants' interactions and their relationship to emotional content reveals that, within the selected section, 11.19% of the text comprised long quotations (more than ten words), while the remaining 88.81% consisted of short quotations (less than six words). The participant's ability to express these emotions varied; he tended to express positive emotions more quickly, while negative emotions took longer/more time to elaborate. This pattern might reflect the complexity and intensity of his emotional responses, particularly in dealing with distressing topics, such as his physical well-being.

### **5.3. Observations of the video analysis**

As outlined in the methodology section, body language markers were identified concerning different types of interaction. During the video observation process, the co-researchers noted that the participant exhibited different signing behaviours when providing answers compared to when he merely repeated without comprehension. When responding, his signing was characterised by a quicker tempo and greater expressiveness, utilizing a larger signing space. In contrast, when repeating without understanding, his movements were noticeably slower and more neutral, with less abrupt gestures. Further quantification of these behaviours could be explored in future analyses or research.

The session provided valuable information into the participant's quality of life, highlighting his ability to express emotions and communicate preferences.

## **6. CONCLUSION AND DISCUSSION**

The aim of this study was to explore how an interactive session could enable an adult with congenital deafblindness to actively participate in the self-assessment of their quality of life (QoL). The main purpose was to ensure the central role of the participant in the assessment process and to find methods for their active participation in this self-assessment.

### **6.1. Key Findings**

During this session, the participant expressed emotions and communicated preferences regarding aspects of quality of life, with physical well-being emerging as the most discussed category. He consistently referenced health issues and medical visits, often associating them with negative feelings. This aligns with Petry et al.'s (2009) framework, where physical well-being is a core dimension of Quality of Life. While

positive emotions were expressed more readily in short statements (e.g., feelings of happiness), negative emotions, particularly about health, required longer reflection. This suggests a deeper, more complex emotional processing when discussing distressing topics. It became evident that the participant was able to participate in the self-assessment of his Quality of Life.

## **6.2. Research questions.**

### **6.2.1. Research Question: How can an interactive session enable an adult with CDB to actively participate in the Self-Assessment of his Quality of Life?**

To answer the first question, a session was developed inspired by the communication tool of Talking Mats (Murphy, 1998) to facilitate communication with an adult with deafblindness to express his views about his quality of life. The methodology was grounded in the principles of the mosaic approach (Clark, 2017).

The interactive session used in this study enabled the adult with congenital deafblindness to actively participate in the self-assessment of their quality of life (QoL) by providing an accessible, adapted form of communication. The participant was encouraged to express preferences, emotions, and experiences using a familiar tool—a whiteboard. This method allowed him to engage in a way that accommodated his sensory impairments and communication needs.

A key feature that enabled active participation was the use of visual prompts and structured guidance. While the participant initially struggled with repetition and understanding abstract concepts, as the session progressed, he became more independent in expressing detailed emotions and preferences. The turning point in the session—where the participant spontaneously shared a list of things that made him sad—demonstrates that when given time and proper support, individuals with congenital deafblindness can contribute valuable personal insights into their QoL. This approach highlighted the importance of patience, repetition, and multi-sensory engagement in fostering active participation. The interactive session created an environment where the participant could communicate in his own time, using both verbal and non-verbal cues, thus promoting self-expression and empowerment.

### **6.2.2. Sub-Question 1: How does this method for self-assessing Quality of Life relate to the Talking Mats communication tool?**

The interactive session used in this study shares several key elements with the Talking Mats communication tool, which is designed to facilitate communication for

people with intellectual or communication difficulties (Murphy, 1998). Both methods prioritise visual representation and structured engagement to help individuals express their thoughts and feelings. Like Talking Mats, the interactive session used a whiteboard as a visual aid, providing a framework where the participant could express preferences and emotions through writing, drawing, and pointing. This structure simplifies complex concepts into more manageable choices, allowing clearer communication. Additionally, both methods aim to give individuals a platform to express themselves independently with the right support, enabling self-determination by reducing reliance on verbal language and offering alternative ways to communicate.

### **6.2.3. Sub-Question 2: What are the strengths and limitations of this interactive method compared to standardised assessments?**

One of the key strengths of this study is its innovative focus on self-assessment in an adult with congenital deafblindness, an area that has rarely been explored. The interactive session was person-centred and empowering, placing the individual at the centre of the assessment process. This allowed the participant to have a direct voice in evaluating his own QoL, unlike standardized assessments where caregivers often speak on behalf of individuals with communication challenges. The approach also facilitated the collection of rich, qualitative data, capturing both verbal responses and non-verbal cues such as body language, signing, and facial expressions, which can often be overlooked in more structured assessments.

The collaborative aspect of the research, particularly the involvement of a co-researcher, enhanced both the reliability and validity of the findings. Observing the sessions together allowed for a more nuanced interpretation of the participant's experiences and expressions. Furthermore, the level of customization in this research was significant. The method was tailored to the specific abilities and needs of the participant, adapting to his communication style, engagement level, and comprehension, rather than forcing a one-size-fits-all assessment. This flexibility allowed the participant to engage meaningfully in the process, even if it required significant time and effort.

A notable aspect of this research was the use of two distinct methods for data collection: transcript analysis and video analysis. Both methods provided valuable insights, but their outcomes differed. The transcript analysis allowed for a precise and structured review of verbal communication; however, it missed crucial non-verbal cues such as body language, pauses, and facial expressions, which were more easily captured

through video analysis. These non-verbal elements played a critical role in interpreting the participant's understanding and emotional states, especially given the dual sensory impairment. For example, the participant's signing speed and spatial usage during moments of confusion or emotional expression would not have been visible in the transcript alone. Therefore, video analysis added a richer, more nuanced layer of understanding to the participant's Quality of Life assessment. The idea of non-verbal behaviours as indicators of understanding are supported by the framework of embodied understanding (Johnson, 2015). Understanding is not only an intellectual operation but a full-bodied engagement with the environment. It involves sensory, motor, and affective patterns that shape our meaning-making processes. The importance of information provided through non-verbal elements is also supported by the Van Dijk assessment (Nelson et al., 2002). In this context, body language, posture, and eye contact are essential for gauging a child's cognitive engagement. A child's posture and movements can provide valuable insights into their levels of engagement, interest, discomfort, or comprehension. By observing these non-verbal cues, caregivers and educators can better comprehend a child's understanding process and adapt their approaches accordingly.

However, the interactive method also had limitations. It required more time and effort than standardized tools, as the participant needed repeated prompting and significant processing time. This could make the method impractical for broader use, especially in cases where resources or time are limited. Moreover, the open-ended nature of the method meant that the participant's responses could have been influenced by the researchers' prompts and the way questions were framed. This subjectivity contrasts with the structured and objective nature of standardized assessments.

Another limitation is the limited generalizability of the findings. Given the highly individualized approach tailored to the participant's unique communication needs, the results cannot be easily generalized to other adults with deafblindness or multiple disabilities. The study's subjective nature, while offering unique insights into the participant's experiences, also raises questions about the degree of independent expression versus researcher-led input. The participation of two co-researchers played a crucial role in facilitating the process, which may have also influenced the participant's responses. Comparing these self-assessments with caregiver observations would have provided additional validity, offering an opportunity to explore whether caregivers' views align with the participant's self-expressed preferences and emotions.



Not only do the results have limitations in generalizability, but the methodology of the assessment also presents challenges when applied to other individuals. Its strong reliance on visual representation may present difficulties for those with more extensive vision loss, needing methodological adaptations to meet each person's unique needs. However, the approach can be modified to incorporate alternative environments, such as using boxes instead of a whiteboard, to facilitate engagement for individuals with varying degrees of vision. These boxes could offer tactile experiences with different textures and shapes, allowing for hands-on exploration that enhances understanding and expression.

Although this study relied on data from a single interactive session, the richness and depth of the information obtained provide a strong foundation for understanding the participant's Quality of Life. However, the inclusion of additional data sources, such as daily diary notes from caregivers, could further strengthen the assessment. This would not only provide deeper insights into the participant's quality of life but also add another layer of triangulation, as discussed in the following section.

### **6.3. Areas for further exploration**

The current study relied on a single interactive session, but there is significant potential for a more extensive analysis. Additional sessions or complementary methods, such as daily diaries from staff or family members, could provide deeper insights into the participant's overall Quality of Life. Diaries, in particular, could serve as a useful tool for individuals with more limited communication abilities.. Future research could benefit from triangulating the findings against other forms of evidence, such as ongoing observations and staff feedback, offering a more continuous and reflective assessment. This approach would be particularly useful for individuals with more profound communication difficulties, ensuring a broader and more comprehensive understanding of their QoL by capturing insights from multiple perspectives over time.

An interesting area for further exploration is the participant's differing expression of positive and negative emotions through sentence length. Positive emotions, such as happiness, were often conveyed through short, quick statements, while negative emotions, such as sadness or anger, took longer to articulate. This distinction may indicate the participant's comfort in expressing positive feelings more readily, while negative emotions required deeper processing. Future research could delve into how the length and complexity of responses correspond to the emotional intensity or significance of the topic being discussed.

#### **6.4. Final conclusions**

Much of the existing research on QoL assessments for individuals with deafblindness, such as Van Dam (2017) and Smith (2015), highlights the limited role of self-assessment in this population. Typically, assessments are based on caregiver observations rather than direct input from individuals. The present study challenges this norm by emphasizing the importance of active participation, supporting Smith's (2015) argument for more self-directed input in decision-making processes.

However, unlike studies focused on individuals with acquired deafblindness, this research presents new challenges for congenital deafblindness, particularly in enabling self-assessment for those with complex communication needs. While the adapted interactive session was successful in extracting meaningful data, it also revealed the limits of the participant's ability to engage in abstract concepts without concrete prompts.

Nevertheless, this study demonstrates the potential of person-centred, interactive tools to assess QoL for individuals with congenital deafblindness. While it may not replace traditional caregiver-led assessments, this method offers valuable complementary insights, especially by identifying which aspects of life are most important to the individual. For this participant, health concerns dominated his self-assessment, highlighting the need for holistic healthcare interventions.

For practitioners, the findings emphasize the importance of interpreting non-verbal communication alongside verbal responses, particularly when working with individuals with dual sensory impairment. Training staff to recognize subtle cues could greatly improve QoL assessments and care planning, for example, recognising when the individual has understood a question or is just repeating staff looking at his movements, and the speed of his signing. Moreover, further development of tools that facilitate direct communication from people with deafblindness should be encouraged, as it promotes self-determination and inclusion.

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## 8. APPENDICES

Examples include lists of sources, questionnaires, consent forms, code trees, analysis schemes, etc. You do not need to include all documents containing raw data such as calculations and transcripts in appendices.

### 8.1. Appendix 1: Transcript of the analysed section of the activity.

RESEARCHER 1: when you go out with daddy? PARTICIPANT and daddy?  
What do you do ?

PARTICIPANT: when go daddy. PARTICIPANT and daddy do.

RESEARCHER 1: what do you do with daddy?

PARTICIPANT: with daddy yes.

RESEARCHER 1: do you go shopping.

PARTICIPANT: shopping PARTICIPANT daddy food shopping.

RESEARCHER 1: food shopping? Do you like?

PARTICIPANT: like

RESEARCHER 1: makes you happy or sad?

PARTICIPANT: happy.

[RESEARCHER 2 pointing screen]

[PARTICIPANT pointing happy column.]

[RESEARCHER 2 writing on the screen.]

RESEARCHER 1: what about sad?

[PARTICIPANT points sad.]

RESEARCHER 1: what sad PARTICIPANT.

PARTICIPANT: sad PARTICIPANT yes.

RESEARCHER 1: what?

PARTICIPANT: what, stairs, sore, shouting, TV watch, stairs, fall, sore, Sick, doctor house, hospital sick House, PARTICIPANT sore sick, yes.

RESEARCHER 1: oooh, I remember. Lots of things make you sad. Stairs, watching tv in your room. *He can do that anymore.*

PARTICIPANT: "thumbs up".

RESEARCHER 1: you said sore, where sore.

T pointing himself.

RESEARCHER 1: your stomach??... your heart. [RESEARCHER 1 listening]

PARTICIPANT heart. I can hear your heart. Are you feeling okay?

PARTICIPANT: "Thumbs up".

RESEARCHER 1: PARTICIPANT good now? Are you feeling okay?

PARTICIPANT: PARTICIPANT good.

RESEARCHER 1: You're a good boy, yes, good boy.

RESEARCHER 1: yes, stairs, Tv watch, sore heart, doctor House, sign again?

PARTICIPANT: doctor House.

RESEARCHER 1: yes and stairs. RESEARCHER 1 forgot.

PARTICIPANT: PARTICIPANT remember, TV watch children sit. Table, children on the floor. [hand on his mouth- shocked face]. Sore heart.

[RESEARCHER 1 listening PARTICIPANT heart.]

RESEARCHER 1: where? Where?

PARTICIPANT: PARTICIPANT Mommy's House, tell doctor House.

RESEARCHER 1: good job PARTICIPANT.

RESEARCHER 2: You're very good, thank you. Good signing.

RESEARCHER 1: *I think this was a bit of a story*

RESEARCHER 1: wow, RESEARCHER 1 remember. Mammys House. You small or big?

PARTICIPANT: "thumbs up"

RESEARCHER 1: PARTICIPANT big or small.

PARTICIPANT: yes big PARTICIPANT yes.

RESEARCHER 1: yes PARTICIPANT big now. But when PARTICIPANT stairs. Big or small. Which?

PARTICIPANT: big PARTICIPANT

RESEARCHER 1: yes I remember.

[PARTICIPANT looking RESEARCHER 1 hair.]

[RESEARCHER 1 offers hair to PARTICIPANT.]

[PARTICIPANT smelling RESEARCHER 1 hair.]

RESEARCHER 2: what PARTICIPANT think RESEARCHER 1 hair.

PARTICIPANT: RESEARCHER 1 hair smells nice.

RESEARCHER 2: happy or sad

PARTICIPANT: happy. [smells again]

RESEARCHER 1: PARTICIPANT pink shampoo. Same as me. PARTICIPANT and RESEARCHER 1 same.

[RESEARCHER 1 starts joking with PARTICIPANT, copying him.]

PARTICIPANT: no stop (smiling).

[RESEARCHER 2 and RESEARCHER 1 copying PARTICIPANT.]  
PARTICIPANT: no, stop.  
RESEARCHER 2: do you like jokes?  
PARTICIPANT: Laugh. "Thumbs up."  
RESEARCHER 1: are you hungry?  
PARTICIPANT: hungry yes.  
RESEARCHER 1: do you want food?  
PARTICIPANT: food. "Thumbs up"  
RESEARCHER 1: do you want more this, finished?  
PARTICIPANT: more yes.  
RESEARCHER 1: [laugh] PARTICIPANT loves this.  
PARTICIPANT: ok, yes  
RESEARCHER 1: so, PARTICIPANT loves drawing, yes no?  
PARTICIPANT: drawing, yes, pointing happy.  
RESEARCHER 2: what is PARTICIPANT's favourite jeans  
PARTICIPANT: blue jeans  
RESEARCHER 2: PARTICIPANT likes? [Pointing happy/sad faces.]  
[PARTICIPANT points happy.]  
RESEARCHER 2: and Black jeans?  
PARTICIPANT: Black jeans yes PARTICIPANT yes.  
[RESEARCHER 2 is writing on the board.]  
RESEARCHER 2: what more  
PARTICIPANT: what more yes.  
RESEARCHER 2: PARTICIPANT likes?  
PARTICIPANT: PARTICIPANT yes..... [looking to the front for a few seconds]  
RESEARCHER 2: *he's thinking*  
PARTICIPANT: PARTICIPANT tell... [looking at the front]  
RESEARCHER 2: You want tell me...  
PARTICIPANT: Participant .... [looking at the front]  
RESEARCHER 1 and RESEARCHER 2: *he's thinking*.  
PARTICIPANT: green plane playing.  
RESEARCHER 2: PARTICIPANT loves playing with the green plane?  
PARTICIPANT: "thumbs up".  
[RESEARCHER 2 writing on board.]



[PARTICIPANT looking closely on the board].

RESEARCHER 2: You love playing green plane.

PARTICIPANT: “Thumbs up”.

RESEARCHER 2: and, what more?

PARTICIPANT: Green train playing.

[RESEARCHER 2 writing on the board].

RESEARCHER 2: what PARTICIPANT thinks PARTICIPANT likes.

PARTICIPANT: PARTICIPANT likes shower, upstairs room. Stairs, brushing teeth. Sick, heart, doctor House. PARTICIPANT tell mommy, doctor House, tell PARTICIPANT sick. [sad face]

RESEARCHER 2: PARTICIPANT sick, doctor's House. PARTICIPANT like? Not like?

PARTICIPANT: not like.

RESEARCHER 2: not nice.

PARTICIPANT: “Thumbs up”.

RESEARCHER 2: thank you.

PARTICIPANT: thank you

## 8.2. Appendix 2. Word frequencies

**Table 6**

*Word frequencies in the entire session*

Word	Times mentioned
Yes	93
Sad	58
Like	53
happy	43
Thumbs	23

### 8.3. Appendix 3. Relations between Quality of Life and Feelings

We can find a more detailed table for the relationship between the different codes in each Quality of Life category and the specific positive and negative feelings.

**Table 7**

*Specific emotional content in Quality of Life categories*

Category	Codes	Positive feelings			Negative feelings		
		Like	loves	happy	Angry	Dislike	sad
<i>Material</i>	clothes			2			
<i>wellbeing</i>	Toys	1					
	Toiletries						
<i>Activities</i>	Drawing			1			
	Food shop	1					
	Watch TV				1		1
<i>Social</i>	Important	1		1			1
<i>wellbeing</i>	people						
<i>Physical</i>	Doctor visits				1		1
<i>well-being</i>	Health issues				1		2
	Pain				1		

## 8.4. Appendix 4: Information sheet



university of  
 groningen

faculty of behavioural  
 and social sciences

### INFORMATION ABOUT THE RESEARCH VERSION FOR PARTICIPANTS

#### “QUALITY OF LIFE ASSESSMENT FOR A CONGENITAL DEAFBLIND ADULT: A PERSON-CENTRED APPROACH”

##### □ **Why do I receive this information?**

- *To give permission about participation in the research project detailed below.*
- *The researcher of the Master thesis is Irene Gabara Moneo, student of the Master track Deafblindness, and the academic supervisors are Dr. Marja Cantell and Dr. Paul Hart.*

##### □ **Do I have to participate in this research?**

Participation in the research is voluntary. However, your consent is needed. Therefore, please read this information carefully. Ask all the questions you might have, for example because you do not understand something. Only afterwards you decide if you want to participate. If you decide not to participate, you do not need to explain why, and there will be no negative consequences for you. You have this right at all times, including after you have consented to participate in the research.

##### **Why this research?**

The aim of this research is to create an assessment of quality of life designed for an adult with congenital deafblindness. This assessment prioritizes the individual's active participation and central role in the self-evaluation process. As part of this research, I am requesting consent for video recordings capturing an activity and access to daily recordings written by staff members.

##### □ **What do we ask of you during the research?**

- *The legal representative will first be asked for consent of the family member to be included in the study.*
- *The legal representative of the participant does not have to do anything else but giving consent as the goal of this permission is to allow the researcher as part of her Master thesis to undertake activities described above and to have access to information described above.*
- *Once the permission document has been signed, the researcher will have access to the information described above.*
- *The analysis will take up to a maximum of 5 months. Once the MA thesis project is accepted, it will be presented as part of Master thesis forum.*
- *No compensation for participation is provided.*



□ **What are the consequences of participation?**

- *The benefit of participating is providing valuable data to support the Master thesis investigation of communication in deafblindness.*
- *Insights about the wishes of the person who is the focus of the research will be shared with them, their family or legal guardians and members of the support team at (Insert name of support service)*

□ **How will we treat your data?**

- *The data will be collected and analyzed anonymously and confidentially. It will be stored by the researcher on her computer and will be shared from time to time with supervisors from the University.*
- *After completion of the research project, original data will be shared with the person, their family or legal guardians.*
- *The names of the participants in the video will be changed and anonymization will be used.*
- *Personal data will not be used. Only anonymized data will be included in the thesis.*
- *Any video data will be only accessible by the researcher and her co-supervisors.*

□ **What else do you need to know?**

You may always ask questions about the research: now, during the research, and after the end of the research. You can do so by contacting the Master student Irene Gabara Moneo or her co-supervisors Dr. Paul Hart ([phart@sensescotland.org.uk](mailto:phart@sensescotland.org.uk)) and Dr. Marja Cantell ([m.h.cantell@rug.nl](mailto:m.h.cantell@rug.nl)).

Do you have questions/concerns about your family member's or your rights as the legal representative of the participant as a research participant or about the conduct of the research? You may also contact the Ethics Committee of the Faculty of Behavioural and Social Sciences of the University of Groningen: [ec-bss@rug.nl](mailto:ec-bss@rug.nl).

Do you have questions or concerns as the legal representative regarding the handling of personal data? You may also contact the University of Groningen Data Protection Officer: [privacy@rug.nl](mailto:privacy@rug.nl).

*As a research participant, you have the right to a copy of this research information.*

## 8.5. Appendix 5: Consent form



university of  
 groningen

faculty of behavioural  
 and social sciences

### INFORMED CONSENT

#### Quality of Life Assessment for a congenital deafblind adult: A Person-Centred Approach

- I have read the information about the research. I have had enough opportunity to ask questions about it.
- I understand what the research is about, what is being asked of me, which consequences participation can have, how my data will be handled, and what my rights as a participant are.
- I understand that participation in the research is voluntary. I myself choose to participate. I can stop participating at any moment. If I stop, I do not need to explain why. Stopping will have no negative consequences for me.
- Below I indicate what I am consenting to.

#### Consent to participate in the research:

Yes, I consent to participate; this consent is valid until 31<sup>st</sup> of May

No, I do not consent to participate

#### Consent to make audio / video recordings during the research:

Yes, I consent to analysis of audio / video recordings of my family member as a participant in the research.

No, I do not consent to analysis of audio / video recordings of me or a family member.

#### Consent to processing my personal data:

Yes, I consent to the processing of my personal data as mentioned in the research information. I know that until the 31<sup>st</sup> of May, I can ask to have my data withdrawn and erased. I can also ask for this if I decide to stop participating in the research.

No, I do not consent to the processing of my personal data.

Participant's full name:	Participant's signature:	Date:
(Legal representative of person at centre of research)		

Full name of researcher present:	Researcher's signature:	Date:

The researcher declares that the participant has received extensive information about the research.

*You have the right to a copy of this consent form.*