From Interview to Dialogue:

For Connection and Mutual Understanding

Floor Hofman

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(https://floorhofman.com/From-Interview-to-Dialogue-Video-Materials)

I. Introduction and Research Question

'Interview is Important'

Stories have always intrigued me, including my own. This curiosity shaped the way I worked, through living within communities and making films with them. One moment that stayed with me took place in a social housing flat on the outskirts of Taichung, where I had stayed for a few months to give creative workshops and make a documentary. That was easier said than done. From the moment I arrived, the language barrier had made it hard to connect. Few residents attended my workshops, which, in hindsight, were not well designed and not particularly fun.

Other attempts to connect also failed, and I found myself uncertain of what to do next, until I met my neighbours, Feeling and Tino, who spoke some English, and they invited me into their apartment for an interview. The interview felt joyful and explorative, and it seemed exciting both for me and for them. They shared their experiences of life in the flat and seemed eager to help by explaining social housing policies and suggesting how I might connect with others in the building. Looking at the bowl of dragon fruit in front of me, it struck me that the interviews during filmmaking always felt like an opening. In this vulnerable exchange between strangers, something new is created. Wanting to understand these moments led me to apply for the Master of Education in Arts.

Figure 1
Interview with Feeling and Tino (Tino is outside of the frame)
Photo by Wei-Li Wong (2019).

Where It Started: Alienation

In the first year of the programme, I revisited the very first interviews I recorded as a teenager, hoping to understand why I began interviewing people in the first place. For a high school project, I interviewed creatives on what inspiration looked like for them. Looking at these clips, I realised that in these moments, I found authenticity in asking genuine questions to these strangers, the questions I didn't dare ask outside the interview setting. Because, outside of it, I had a strong sense of alienation throughout my teenage years. I rarely felt connected, even with my parents, who felt more like strangers. When I recently spoke with my mum about this, it struck me that she had felt something similar towards her own parents. On some level, this sense of alienation is part of how many teenagers experience the world, as we need to grow differently to be able to develop a separate identity.

Different expressions of alienation are tied to the embodied experiences of individuals and the contexts they are in. In my case, the feelings may have been intensified by an undiagnosed connective tissue disorder, Loeys-Dietz syndrome, which led to the repeated dismissal of the pain I experienced by medical professionals. A lack of a pathway for people around me to understand where this pain was coming from or what I was going through, combined with its invisibility, often made me question whether I was making things up, doubting my own reality. This made the difference between the outside world and my inner world even bigger. I can describe this now, yet at the time, I only sensed a world inside of me that I could not express, and I yearned for meaning and connection.
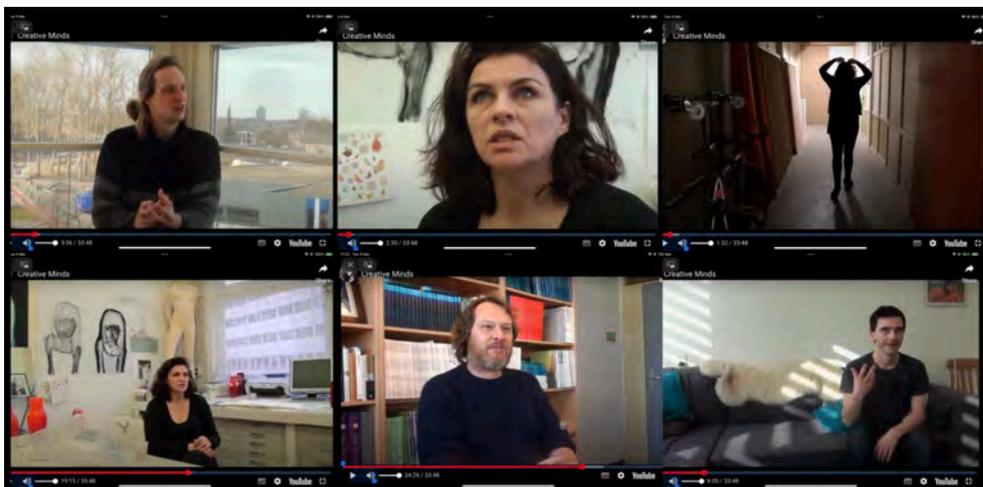
Figure 2
Screenshots of the earliest interviews I conducted

Fortunately, several crucial moments opened a path to understanding. I remember a conversation with my aunt: she shared her own experiences, and listened while I tried to find words for mine. It was an unfamiliar feeling, and I remember feeling understood. I started wondering what in these encounters with my aunt and the people that I interviewed, helped to alleviate my feeling of

alienation. And if it is true that it is bigger than my personal feeling, then exploring it might matter to others as well. I suspect one reason interviewing helped was that it allowed me to understand how others give meaning to their experiences. This brought me to research interviews and dialogues, with the hope to find ways to make such exchanges more accessible for those who need them.

Research Question

How to form interviews and dialogues for sharing meaning and understanding?

Subquestions:

1. How does a participant's sense of agency contribute to the sharing of meaning in interviews and dialogues?

2. How does a participant's sense of being understood contribute to the sharing of meaning in interviews and dialogues?

II. Theoretical Framework

Methods

Interview

In what way do interviews help in understanding how others give meaning to their experiences? In qualitative research interviews, the interviewer registers and interprets both the meaning of what is said, and how it is said (Kvale & Brinkmann, 2014). While daily conversations tend to focus on what happened in someone's life, these types of interviews go further by exploring how people think about these events and why they think that way. Kvale and Brinkmann (2014) illustrate this distinction with the following example:

> A pupil may state: "I am not as stupid as my grades at the examinations showed, but I have bad study habits." Common reactions could then concern matters of fact, "What grades did you get?" or "What are your study habits?" — questions that also may yield important information. A meaning-oriented reply would, in contrast, be something like, "You feel that the grades are not an adequate measure of your competence?" (Kvale & Brinkmann, 2014, p. 30).

Knowing someone's thought processes provides more entry points for connection than simply hearing what happened. Therefore, it might create understanding between people. Vivian Gornick (2001) describes a similar distinction in her reflections on narratives in literature.

> Every work of literature has both a situation and a story. The situation is the context or circumstance, sometimes the plot; the story is the emotional experience that preoccupies the writer; the insight, the wisdom, the thing one has come to say (p. 13).

This distinction is relevant in interviews as well, where the interviewee is in the role of the writer of their own story. An interview often starts with the situation: what happened. In Feeling and Tino's case: we were selected to live in a social housing flat. Afterwards, they share their story: a young couple receiving good things in life thanks to the good karma of helping others through their work as social workers. I see this second part as the meaning they give to the situation.

Documentary film interviews also often aim to understand what a certain topic or life event means to the interviewee. In *Chronicle of a Summer* (Rouch & Morin, 1961), the filmmakers want to know what happiness means to the French working class. Marceline Loridan-Ivens interviews an artist couple on this question. The situation: Madi and Henri are artists struggling to make ends meet. Their story: Henri says happiness isn't a goal, and the word itself is empty:

happiness and unhappiness are one. They explain how they shape their lives by working less and spending on things that enrich them, like books, records, and a special instrument shown at the end. The filmmakers show how they, a new generation, think about happiness in relation to work, money, and relationships.

Figure 3
Henri Speaks
Still from Chronicle of a Summer (Rouch & Morin, 1961).

Figure 4
The Instrument
Still from Chronicle of a Summer (Rouch & Morin, 1961).

These are examples of what I consider *given meanings:* anything the interviewee expresses that goes beyond the *what*: What happened, the event, the situation. It is about what that *what* means to them. This is often difficult to answer directly, which is why interviews are useful: they allow meaning to unfold gradually. I'm aware that the phrase "giving meaning" can suggest a guided process, like *having* to find meaning *in* something, for example in adversity, which is common in some forms of therapy or religion. But there are many ways in which meaning can be constructed. These may include, but also go beyond, finding meaning in hardship, which I hope to explore through the interviews.

Not all types of interviews focus equally on how someone gives meaning to their experiences. Interviews are everywhere: from surveys about your cinema visit to job interviews, talk shows, news programs, podcasts, and vlogs. They are a "universal mode of systematic inquiry" (Holstein & Gubrium, 1995, as cited in Fontana & Prokos, 2007, p. 12), and vary in purpose, ranging from describing, interrogating, assisting, testing, or evaluating (Fontana & Prokos, 2007, p. 13). Perhaps the formats that we feel most familiar with actually don't aim to explore the interviewee's meaning frame. In television talk shows or news programs, for example, we often see expert opinion interviews. This format acts more like a shortcut to information, possibly making it more accessible because it is delivered by a person. However, the personal meaning that is created in these interviews is limited.

In my own documentary interviews, I've also noticed that parts of my approach may unintentionally make it harder for interviewees to express how they give

meaning to their experiences, which I will explore in the chapter Influencing Factors.

Dialogue

In my experience, interviews barely come alone; interviewees often question me in return, resulting in a dialogue. In one of my early interviews, I was caught off guard when the interviewee asked, "But what does happiness actually mean to you? Why are you doing these interviews?". She hosted women's groups for immigrant women in a developing neighbourhood, and she had told me it brought her happiness. Later, I coincidentally met another woman with a similar role in the same neighbourhood, and I invited both of them to meet each other, with me joining the conversation. This was a tangible moment in which the word "happiness" gained meaning among the three of us. Psychologist Jerome Bruner describes this kind of meaning-making between people as:

> To treat the world as an indifferent flow of information to be processed by individuals each on his or her own terms is to lose sight of how individuals are formed. And in this process, meanings are not to his own advantage unless he can get them shared by others. (Bruner, J. 1990, p.12)

Figure 5
Still from About Happiness (2016)
https://youtu.be/nmYJHWpViDo?si=tBsHtpkCFkKma_PM&t=419

My research question uses *sharing meaning* to emphasise that meanings arise in social interactions and are only meaningful when shared with others. However, I don't suggest that everyone must adopt a unified perspective. In fact, my aim is the very reverse, as fusing meanings would deteriorate the richness of different voices, and stop the dialogue. Clark and Holquist, writing on Mikhail Bakhtin,

describe that such a fusion would preclude the difference necessary for dialogue (as cited in Frank, 2004, p. 116).

Therefore, my aim is to listen to everyone and record these differences. In my project, this difference refers to both the variation in people's life experiences as well as to how they give meaning to those experiences. It's a form of pluralism that values variation rather than consensus. Meaning lies in observing how given meanings relate to one another without merging. Bakhtin's concept of 'polyphony' captures this idea: voices create a harmony without unifying, remaining distinct while interdependent (Bakhtin, as cited in Frank, 2004).

Building on this, I collect unique stories through interviews, each contributing to the polyphony. Each interview adds a voice, and the collective viewing session lets participants explore how these meanings relate and resonate. In this way, the interviews and the dialogue are interconnected: Do the interview tools help participants to share how they give meaning to events? How do the recordings of meaning-rich interviews support the dialogue?

Participants and Position as Researcher

To answer these questions, I have collaborated with two groups. For the pilot study, I worked with students at Design Academy Eindhoven. For the main project, I collaborated with people diagnosed with Loeys-Dietz syndrome or Marfan syndrome, both chronic connective tissue disorders.

Students Design Academy Eindhoven

At Design Academy Eindhoven (DAE), I work as a coach in the Reflections programme, where students from all years meet in peer groups to reflect on their learning and the design field. The sessions I held for my graduation project took place in this context. I stayed in my role as coach, shared my research, and invited students to participate. They could also schedule individual meetings with me at any time, as is usual in my coaching practice. I did not take part in the interviews; students interviewed each other. At the start of each session, I gave a short update on my research progress.

I introduced the topic after noticing that students, especially first-years, hesitated to speak up in group talks, perhaps fearing that their frames of reference were too different to connect. I wondered if exploring each other's meaning frames might support future dialogues. There was also a personal motivation: during my time as a student at DAE, I missed knowing about my peers' personal backgrounds and the feelings or meanings they attached to them. Having had the chance to see what influenced their creative processes would not only have been informative, but would have made me feel less insecure and more connected. I hoped to create that space for current students.

People with Connective Tissue Disorders

Loeys-Dietz syndrome (LDS) and Marfan syndrome are rare genetic connective tissue disorders affecting multiple body systems, most critically the cardiovascular system. Both are caused by mutations in genes responsible for connective tissue quality. While they share features such as aortic aneurysms,

skeletal abnormalities, and joint hypermobility, they also have distinct characteristics. Both conditions are inherited, though spontaneous cases can occur. Both disorders are rare, however LDS was first described only in 2005, making it even less familiar, even to clinicians.

Participants were invited through an open call I posted on the Contact Group Marfan & Related Disorders Netherlands' social media channels, including a video outlining my motivations. I described that participation involved a one-on-one interview in a format, time, and place that suited them, followed by an optional group dialogue. Within a few days, ten people applied, aged 15 to 50, with five having LDS and four having Marfan. One participant has a confirmed SMAD3 gene mutation but not a formal diagnosis.

Throughout this project, I was in the role of researcher (interviewer, project manager and facilitator of the group dialogue). I'm also diagnosed with LDS, which influenced my positioning. Before starting this project, the only people I knew with LDS were my father and brother. I had never felt a desire to meet others with the condition, so that was not my motivation for starting this project. I actually don't clearly remember why I chose this group, but I was likely thinking along the lines of: I'm interested in meaning-oriented interviews, and this is a group I *can* talk with. However, I was also considering working with other groups, such as immigrants or communities in my neighbourhood. Surprisingly, (to myself, not at all to the people around me) while preparing for my first interview, I started to feel a deep curiosity, an eagerness to listen to the interviewee, and also a growing fear. From this moment, I knew how strongly my own position would colour the work.

This was intensified when Susan, the second interviewee, opened her door. I was struck by our physical similarities, as if a relative I'd never met let me in. At the same time, I was aware that I didn't know her at all. This paradox became an important theme in my research and in my positioning. On the one hand, some participants said they felt comfortable being interviewed by me since I often knew what they were talking about, which I saw as a helpful position. Yet, I also saw the danger of assuming I understood more than I did. Levinas' concept of the *Absolute Other* is therefore particularly relevant in this group.

Connection Between Groups

The first two sessions at DAE took place before the interviews with people with connective tissue disorders. This allowed me to test interview tools, the approach before working with the second group. The final three sessions with DAE students overlapped with the second group, enabling me to share insights from that part of the research with students. We discussed the widespread use of interviews as a research method in design, making it meaningful for students to hear how the tools worked in a different context.

The two groups differ in composition, setting, and focus: one within an institution and revolving around design, and the other informal, centred on specific disorders. Still, both were asked to share personal meanings. The topic of the disorder brought up more existential questions, but at times, similar themes emerged, though experienced in an incomparable way: a sense of alienation brought on by a rare disorder, or by childhood experiences that led to a need for creativity and self-expression.

Influencing Factors: Agency

After introducing the research questions, methods, and participants, I now address two factors that, in previous projects, influenced how meaning was shared and how understanding grew in interviews and dialogues. Based on those experiences, I set intentions to approach these factors differently in this graduation project. The first factor I focus on is agency.

Looking back, I see that experiencing agency in conversations and interviews helped me break out of alienation. This likely influenced my desire to give others that same sense of agency in my documentary practice. From my first film, I experimented with ways for participants to actively shape the filmmaking process. What this looks like varied depending on the person and their community. Sometimes, I gave participants a camera so they could document their own lives without my interference, or they filmed with their phones. Some chose to stay anonymous and not appear on camera at all.

Figure 6
Providing participants with cameras
Still of Treasures of Woensel-West (2018)

Figure 7

Providing participants with cameras

(Left) Behind-the-scenes photo during filming of You Are in My Story (2023)

(Right) Still of You Are in My Story (2023)

However, these experiments in giving participants agency primarily occurred during observational recordings, rather than within the interviews themselves. In my graduation project, I aim to explore this within the interview itself. But what is agency? Broadly speaking, "an agent is a being with the capacity to act, and 'agency' denotes the exercise or manifestation of this capacity" (Schlosser, 2022). Agency goes beyond related ideas like autonomy, motivation, and investment, which can be seen as expressions or outcomes of a person's underlying sense of agency (Van Lier, 2004). Participants' agency may become visible through expressions of autonomy, such as actively participating in the interview and, like the interviewer, influencing its dynamics and outcome, rather than being passive subjects of interrogation. It also means that participants feel what they talk about is *theirs.* They feel accountable for the content, and sense that their effort leads to something valuable, such as insight or self-reflection. My intention to create a space where participants can sense their agency connects to the concept of the Absolute Other.

1. Agency of the Other

In my filmmaking practice, I intended to provide space for the interviewee to express themselves without imposing commentary or advice. I intended to limit the amount in which the interviewee was "claimed" or "finalised" by me deciding who that person ought to be. I recognise these values in Emanuel Levinas' concept of the Absolutely Other. He states, "Man par excellence—the source of humanity—is perhaps the Other" (as cited in Peperzak, Critchley, & Bernasconi, 2008, p. 14). Levinas argues that freedom lies in encountering that absolute other, who is "not convertible into the already known" (p.12). If I project my own ideas onto the other during an interview, I risk losing view of their otherness. For example, in the following vignette, Susan talks about an experience that is very familiar to me. In those moments, I feel it is extra important to be aware of not finalising her story by thinking that "we are the same".

"Sometimes you see those looks"

Susan: I still sort of have the luck — that's what I always call it — that when I'm out shopping, I can think: okay, I'll just leave the wheelchair here for a bit. I'll do a quick round of the store on foot, and then I get back in afterward. But sometimes you see those looks, or get those comments, like, "Oh, so you can walk?" And then they assume, or they basically decide for me, that a certain kind of priority or a spot or something like that… that I don't actually deserve it or something. And I still find that kind of hard. You see how people are really inclined — this is how I explain it — to put others in a box.

https://vimeo.com/floorhofman/sometimes?share=copy

The idea of the Absolute Other can be confused with the idea that someone becomes more other the more different they appear. But Levinas doesn't link alterity to attributes. As he explains, it is not because someone's hair is unlike yours that they are other. Their otherness exists before any such attributes; they are other, otherwise, absolutely other (Levinas, as cited in Frank, 2004, p. 116). This does not suggest that the other is untouchable or separate from ourselves. Levinas argues that the other and the I are fundamentally bonded. However, welcoming the Absolute Other requires putting the self into question, which reveals the two are bonded together: "Instead of annihilating the I, putting into question binds it to the Other in an incomparable and unique way" (Levinas, as cited in Peperzak, Critchley, & Bernasconi, 2008, p. 17).

In an interview, I directly experience this "putting into question of the I". I no longer exist on my own anymore, but in witnessing the other's presence, their vulnerability, which Levinas describes as *the face*. He writes, "The epiphany of the Absolutely Other is a face by which the Other challenges and commands me through his nakedness, through his destitution" (p. 17). I exist because of the call to be fully present with the other. That responsibility is not something to be "taken", but it is inherent in the encounter with the face. In an interview, the focus lies on the face: the eye contact, the small expressions in cheeks and foreheads. It brings a softening of my sense as a sovereign self, and lets me become a witnessing "I" linked to the other. Beyond this bodily sensation, in my graduation project, rethinking of the I also involves reflecting on the interview strategies I use, and how this influences interviewees' experience of agency.

2. Agency in Narrative Structure

One way to give interviewees agency is to reconsider how narratives are shaped during the interview. In my filmmaking practice, I noticed that I sometimes fall back to certain narrative structures, such as "growing stronger through adversity" or "rediscovering yourself after a divorce." While these narratives can accurately reflect lived experiences, they can also constrain how people view or articulate their lives, and might in some cases hinder people to find suitable meaning for themselves. The relationship between narrative and meaning is extensively discussed across disciplines, including linguistic anthropology, the ethnography of communication, literary studies, and especially narrative studies, which analyses how narratives shape the creation of meaning (de Fina & Georgakopoulou, 2012).

Narrative structure feels especially relevant for people with a chronic illness, for several reasons. Sociologist Arthur Frank (1995) describes three major types of illness narrative: The restitution narrative (I'm sick, but will get better), the chaos narrative (The experience is so intense that no narrative can describe it), and the quest narrative (The sick person is the hero of their own story). Frank proposes that the structure of each type is connected to a specific mode of embodiment, or "self-story", and describes how narrative can create change in the life of the ill person. Indeed, choosing which narrative to tell, or even the act of searching for what narrative suits you, can in some cases be one of the few opportunities for making a choice. He describes how the daily life of people living with chronic illness often involves long periods of solitude, as they can't engage in activities with others. During such times, the act of choosing how to tell your story may be one of the few remaining choices you have (Frank, 2004, p. 41). He advocates listening to stories of illness not only to restore humanity to medicine but also as a crucial way for those facing illness to make sense of their experiences.

"I'm lucky in that sense"

Ferry: Like I said, there's always someone above—
someone who has it worse, from my perspective.
People who walk around in pain all day. And
luckily, I don't have that. So I do think I'm lucky in
that sense.

https://vimeo.com/floorhofman/lucky?share=copy

Being conscious of narrative is important for another reason: Narratives can contradict a person's lived reality, smoothing over details or experiences that are important to them. Or even worse, they can become oppressive in particular situations. In her essay *Illness as Metaphor*, Susan Sontag argues that illness should be liberated from metaphor, which she calls "punitive or sentimental fantasies concocted about that situation; not real geography but stereotypes of national character" (Sontag, 1978, p. 1). She presents countless examples in which national metaphors, derived from popular mythology, overrule variations in experience of cancer and tuberculosis. For example, while tuberculosis is regarded as relatively painless and cancer as extremely painful, both can differ drastically from the reality of those who suffer from them. Even more troubling, some narratives connect disease to personality traits. Tuberculosis has been thought to result from having too much passion, while cancer is linked to insufficient passion: "sexually repressed, inhibited, unspontaneous, incapable of expressing anger" (Sontag, 1978, p. 4).

In *The Undying*, Anne Boyer builds on Sontag's ideas, and analyses how modern-day narratives about cancer are unjust to those who have the disease, and are used to exploit and instrumentalise their suffering. Boyer rejects the narrative of "surviving" cancer through neoliberal self-management, where healing is tied to individual responsibility, compliance, and positivity (Boyer, 2019, p. 9). Instead, she writes about her experiences by first acknowledging the impossibility of writing about them: "For it seemed to be the same as if I should swim under water through every sea and next be compelled to render an

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account of how many waves I encountered, and how I found the sea at each of them, and what it was that saved me" (Boyer, 2019, p. 44).

This point from Boyer is important to my research because some experiences are inherently difficult to narrate, but that does not make them less important or unwelcome in interviews and dialogue. Such experiences may hold great significance for both the interviewee and the interviewer. The metaphors Sontag describes, or narratives Boyer describes can pave over these difficult-to-narrate experiences, which might come closer to the truth. This connects to Levinas' idea that stories are often a fiction that diminishes otherness, or tries to reduce it to identity, to the "same" (Levinas, 1961/1979). Experiences that resist familiar narrative structures are therefore the ones that can disrupt the story.

"That woman looks totally fine."

Susan: People have said things like, "Yeah, I always thought you had everything perfectly together. You built this great career, you have two cool kids, a lovely husband, and you're also tall and slim!" — and especially that last part, (…) as if being tall and slim is just the ideal. And I mean, I *am* happy with that, I like it too, but on the other hand, I really have to be careful not to get underweight, and that comes with its own downsides. But people are quick to assume: "Oh yeah, she looks totally fine, so she must not have any limitations or struggles."

https://vimeo.com/floorhofman/fine?share=copy

From a therapeutic perspective, certain narrative structures may be preferred, since they can support the mental health of a person experiencing illness. For example, the quest narrative as described by Frank: "The ill person meets suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest." (Frank, 2004, p. 41), makes illness and suffering part of a journey, even *useful.* This way of looking at illness is for example found in existential therapy and logotherapy, popularised by Viktor Frankl in *Man's Search for Meaning*, where he argues our deepest desire is to search for meaning and purpose (Frankl, 1946). While I recognise (and have experienced) that challenging myself to rethink my story has made discomfort more bearable and made me a happier person, therapeutic effect is not my focus in this project. The reason why being conscious of narrative structures is important, is because I want to find out what kind of interviews and dialogues support sharing meaning and understanding. The sources mentioned above show how narratives influence how people give meaning to a situation. Therefore, it is important to be aware of my own preferred narratives, especially as an interviewer with the same disorder as the interviewee. It is again, like Levinas describes, about putting the self into question. It requires me to find ways to bypass my preferred narratives to create space for the interviewee to share their own meaning.

While preparing and conducting interviews, it became clear to me how much my own narrative around the disorder is shaped by the quest narrative. I often think about what I've learned from it: how alienation, mourning, and feelings of disconnect from some medical professionals contributed to the person I am now. If I based my interview questions on that narrative, I might ask: What have you learned from living with this disorder? How did you deal with uncertainty, fear, or frustration? Framing questions this way, I would potentially overlook other ways of understanding the experience. Therefore, I started to look for methods that focus on giving interviewees agency to speak from their own meaning frame.

In their *Free Association Narrative Interview method*, Hollway and Jefferson (2000) frame participants as "defended subjects" and acknowledge their complexity and biographical uniqueness. Like Kvale, Brinkmann, and Gornick, Hollway emphasises the distinction between a report (which only focuses on events) and a story (where the narrator takes responsibility for making the relevance of their telling clear). This approach gives interviewees more agency to decide the direction and significance of their narratives. For example, Hollway describes asking participants open-ended questions, such as, "What do you most fear?", deliberately avoiding direct references to "crime" in research on fear of crime (p. 113). By following the participant's meaning frames, the researchers are more likely to discover connections between the concept of fear and the participant's broader life context. Hollway explains that this method offers "an enriched, more complex, nuanced, and, arguably, more humane and ethical view of the human subject" (p. 468). She describes that by capturing something of that complexity of their subjects, they offer the reader something true about them (p. 488).

I recognise this search for truth in my interviews. However, it's not about uncovering *the* truth of someone's life, as that implies a finalisation; a reduction of a person to a static story that can be repeated in any context without

adjustments. The truth I pursue remains complex and hard to grasp, shaped by the interviewee's own searching, which may or may not lead to revelation. Traditional interviews can carry a connotation of confession rituals[1] (Foucault, 1978), expecting a sudden revelation or grand narrative. This pressure can make people reluctant to participate. I therefore look for methods free of such expectation while also not excluding or discouraging the possibility of a "confession". The searching kind of truth I described is highly context-dependent, as the two vignettes that follow will show.


"Somewhere in my mental world"

Farijal: I still haven't gone to the skin therapist for my scars, or to the physio either [after my aorta surgery]. Even though I know, rationally, that it helps to go. But somehow, I still notice a kind of block when it comes to physical contact. I've talked to my boyfriend about it too, like, what could that be about? I think maybe it's because the plan was, of course, to have one surgery, but in the end it turned into two in a short amount of time — a big one and a smaller one — and I think that somewhere in my mental world there's just a kind of... some emotion or disappointment around that. Which, in turn, has had an effect on me.

https://vimeo.com/floorhofman/somewhere?share=copy

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[1] Foucault noted that Western societies have made confession into one of the main rituals through which we produce truth.
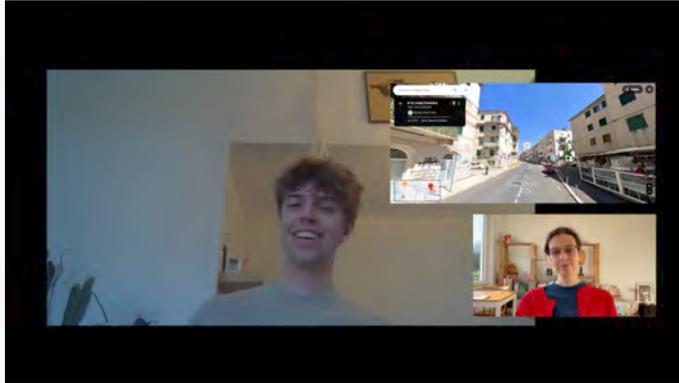
"Sometimes I wish it was like that— but that's really not good."

Floor: Is that something that's important to you? That you're not treated differently [after the diagnosis with LDS]? **Lennart**: Yeah, I think it is. But sometimes I'm also the kind of person who… sometimes I do want a bit of attention. So then you could say something like, yeah… you should get the bigger piece of cake, so to speak, because you have that syndrome. But that's not how I want to be treated at all. Although sometimes I do still think, I kind of wish it *was* like that — but that's really not good.

https://vimeo.com/floorhofman/wish?share=copy

Hollway and Jefferson (2000) conclude that their interview method is particularly valuable when the goal is to understand people's experiences from within their own meaning frame, especially when the research topic is closely tied to their sense of self (p. 485). As it is exactly my intention in this project, and since the research topic is closely tied to participants' sense of self, both in design and illness, I started thinking about other interview methods that give interviewees agency.

3. Agency in Interview Tools

The interview tools that I selected and developed spread agency between interviewer and interviewee more equally[2]. The tools I used in this project are:

1. Lifeline

The interviewee draws a timeline on an empty piece of paper, which represents their life, from when they were born until now. On this line, the interviewee adds points or phases that they consider significant.

Figure 10
Farijal drawing her lifeline
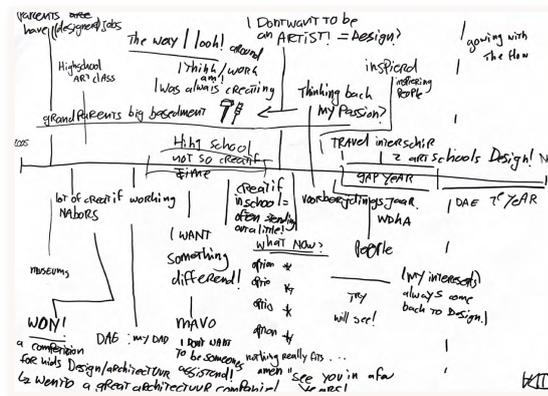
Figure 8
Example of a lifeline (See larger file in Appendix, p.75)
Drawn by a DAE student (2024).
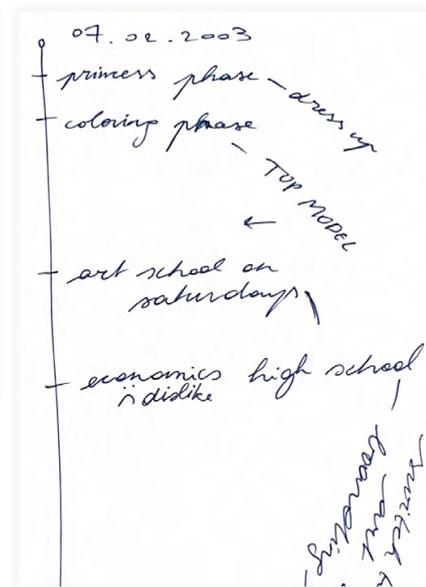
Figure 9
Detail of a lifeline (See larger file in Appendix, p.76)
Drawn by student of DAE (2024).

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2 I initially also offered participants a choice of interview tools, as an act of spreading agency. When the first three said any tool was fine, I decided to choose the tools for the rest. While this reduced their say in tool selection, agency remained an important factor during the interviews themselves.

2. Guided Tour

The interviewee gives the interviewer a guided tour, using Google Maps Street View. The interviewee shows places that they consider significant.
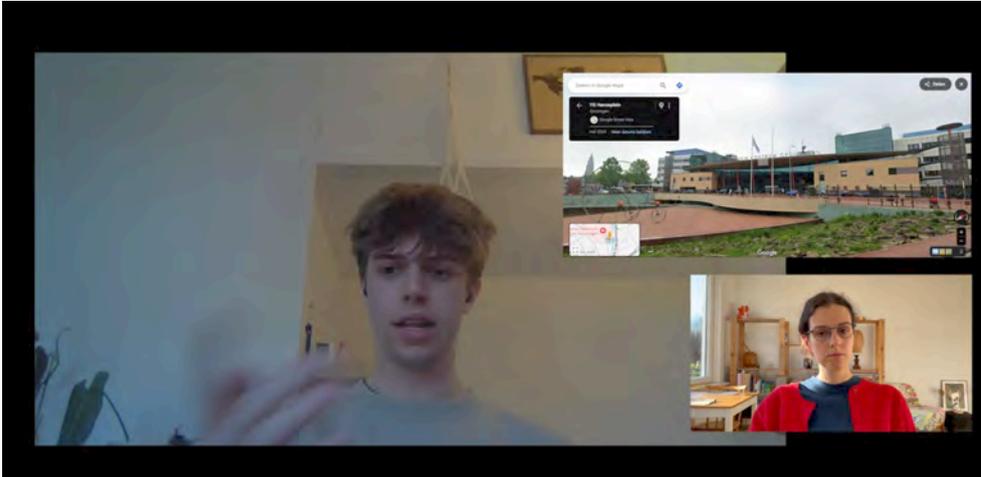
Figure 11
*Lennart showing the University Medical Center Groningen*

3. Topic Cards

A set of cards describing different topics is spread out on the table. The interviewee chooses which topics are relevant to them at this moment in time and also decides on their order of significance.

These three formats let interviewees set the outline of their story, choose points of significance, and express their given meanings to it. I do not start by giving them a theme, topic, or narrative structure. They decide this by themselves.

Figure 12
Spreading out the cards on the table

4. 1minute=1minute

This is a "standard" interview with predefined questions. The only rule is that both the interviewer and interviewee can pause for a one-minute break at any time. While the interview follows a set of questions that guide the topics, the interviewee retains agency by being able to pause whenever needed.

Figure 13
Slide from presentation for students DAE
Layout by Wei-Li Wong (2024).

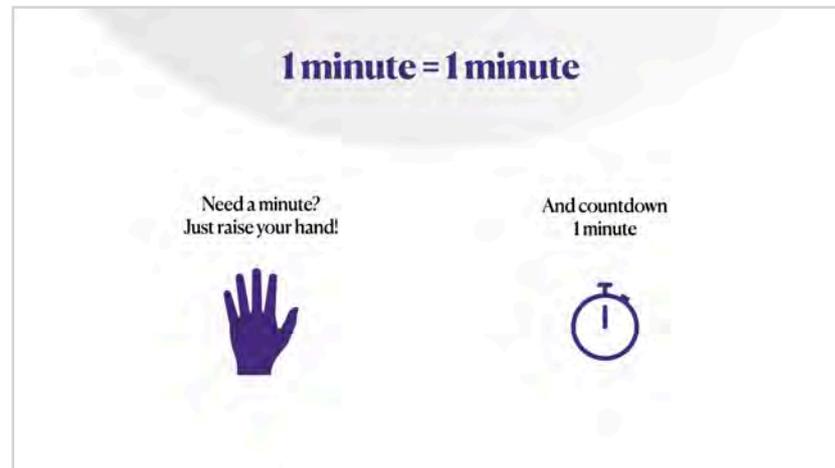Using interview tools that support agency is also common in Participatory Action Research (PAR). While PAR primarily focuses on social change, community empowerment, and addressing systemic issues, which differs from my focus on sharing meaning and generating dialogue, its emphasis on participant agency overlaps with my intentions. Kindon, Pain, and Kesby (2007) describe methods like photo elicitation, participatory cartography, theatre, and art that reflect these intentions. In chapter 11, interview topics are co-created with participants, which relates to the topic cards I use. Their discussion on diagramming in chapter 14 relates to the lifeline tool. They describe diagramming as the product of a long participatory evolution within development projects, where graphic and tactile materials are used to visually represent participants' ideas and understanding. Visual and oral methods are combined to express, organise, represent, and share information. Here the diagram is not a final product but a way to explore the meanings behind each element. While the guided tour as I shaped it in my project is not described in their book, a guided tour is a common tool in PAR. Participants guide researchers through familiar places while answering open-ended questions (Hall, Lashua, & Coffey, 2008). The method is known by different names, each emphasising slightly different aspects, such as mobile interviews (Brown & Durrheim, 2009), walking interviews (Evans & Jones, 2011), and many more. Walking together is considered essential in these methods, which differs from my use of an online environment. Also, in PAR, the collected data often serves external research aims. In contrast, the interviews are first and foremost shared within the group; other students or people with connective tissue disorders.

Influencing Factors: Feeling Understood

Now that I have explored the first factor that influences how meaning is shared and how understanding grows, I move to the second: felt understanding. It may seem redundant to say, but understanding is both an emotional and a rational state. In my research, it is rational when referring to understanding someone's background or the meaning they give to experiences. It is emotional when used in the context of feeling heard and seen during an interview or dialogue. I assume the two are connected. Interviewees who feel understood tend to open up more and explore their narratives in a more vulnerable and creative way. This might make it easier for me as an interviewer, but also for the audience to understand their meaning frame.

1. Feeling Understood in the Interview

When interviewees share personal experiences, my responsibility is to listen actively and to search ways to understand. This effort is not meant to dominate or to *use* understanding for analysing data, but to respond to the other showing themselves (Levinas, as cited in Hand, 1989, p. 75). Levinas' call for responsibility cannot be directly copied and pasted into interviews in this project. His call is very demanding, as seen in a quote he often cites: "We are all responsible for all men before all, and I more than all the others" (Dostoyevsky as cited by Levinas, Ethics and Infinity, 1985, p. 101). While his refusal to reduce otherness and the idea of responding to the face are relevant in my research; the kind of responsibility he describes goes beyond what I aim to practice. Indeed, the structured, formal setting of an interview offers a useful context to practice or experience responsibility, as roles are clearer than in daily life, but responsibility is not the key feature in my research. Responsibility is relevant as an interviewer's intention to build a pathway toward understanding the other, because this may allow the interviewee to feel understood.

2. Feeling Understood Through Other's Stories

Felt understanding is not limited to the direct interaction between interviewer and interviewee. In my filmmaking practice, the stories told by participants become actors that generate felt understanding in the group. During premieres, as we watched the stories on the big screen, we recognised parts of ourselves in others' stories and had in an inner dialogue with them. Arthur Frank describes this kind of dialogue:

> Stories analyse us by allowing us to notice what attracts us to them, and what we resist about them. They show us what we want, and ask us what we need. We begin to think *with* stories when situations in our lives recall these accounts so often that they settle into our awareness and become habits of thought, tacitly guiding our actions (Frank, 2004, p. 6).

Sharing your own story with an audience can also create a sense of being seen and understood, as you notice how parts of your story, which felt so extremely unique, are actually significant to others as well. Literary scholar Northrop Frye calls this the moment when "a particular context acquires a universal significance." Stories gain significance not because they offer timeless truths,

but because they help reflect on our own lives, even if our lives are very different from the ones being told. In this way, stories don't provide clear answers, but they raise questions and show what it looks like to be searching in the middle of uncertainty (Frye, quoted in Frank, 2004).

"It's all in your head"

Mila: I've always had the feeling (…) like I constantly have to prove myself twice as hard just to be allowed to take part in society, you know? I just want to be healthy, and I just want to work hard. And I don't want to complain. That's kind of my… yeah, maybe that's just how I was raised. As a child, it was never really taken seriously. My parents did take it seriously. Although they also sometimes said things like, "don't make such a fuss," you know? Like, you're always in pain, or tired, and you're just lazy, or… And doctors who always said, it's all in your head. That image is what you grow up with. That I'm always exaggerating and it's just in my head. There's nothing actually wrong with me. Well, if you've been hearing that for more than 40 years… how are you supposed to make that switch?

https://vimeo.com/floorhofman/head?share=copy

Summary

In this research I explore how interviews and dialogue can support understanding and the sharing of meaning. The interest began in my teenage years, when a sense of alienation lifted only during certain interviews and other meaningful encounters. My thesis is that this happened because they let participants explore how we gave meaning to life events. While the methods I use (interviews and dialogue) have proven useful for this in some cases, they don't always succeed. Therefore, I am studying the factors that influence whether people can share meaning. Two key influencing factors I have identified are agency and (felt) understanding.

Agency relates to Levinas' concept of the Absolute Other. This is particularly relevant here, because even if people with LDS or Marfan carry the same genetic variation, we are still "absolutely other", and our experiences cannot be assumed to be identical. This is the beauty of it, and also what motivates people to participate: While we share the same mutation, its meaning is unique to each person. To observe these unique meanings I, as an interviewer, must avoid imposing a narrative, since the framework of a narrative shapes what events mean. For example, if someone sees themselves as a hero in an illness journey, suffering might be framed as an obstacle to overcome and learn from. In contrast, someone who does not adopt this lens might interpret suffering differently.

Understanding is the second factor. Interviewees who feel understood tend to open up more, and explore their narratives in a more vulnerable and creative way. This might make it easier for me, as the interviewer, and for the audience to understand their meaning frame. In the group dialogue, meanings are shared and observed as they interact with each other: Do we recognise aspects of our own lives in each other's stories? Are we surprised by new perspectives? Does it resonate with us, or even challenge us? Through this process, the sharing of meaning can lead to understanding others better, and to feeling more understood ourselves.

III. Practice 1: Students Design Academy Eindhoven

Outline

As a student coach, I noticed that students from different years often hesitate in group conversations, fearing their frames of reference are too different to connect. With their varied cohorts, design departments, and nationalities, this concern is reasonable. However, past dialogues show that sharing diverse perspectives is enriching if students first understand each other's contexts. In this five-session pilot study, students interviewed each other about key moments that shaped their views on design, using both provided and self-designed tools. These interviews served two purposes. Firstly, helping interviewers understand the interviewee's background, including social and cultural context, nationality, access to creative practices such as materials or community support, and prior education or work experience. Secondly, to grow understanding of what these experiences meant to the interviewee. The final session consisted of a screening of interviews in the academy's auditorium, followed by a group dialogue reflecting on both the content and the effect of the interview tools.

Session 1: Lifeline Tool
- Introduction to research.
- Students interview each other using the lifeline tool.
- Group reflection on the tools' effectiveness and possible adjustments.

Session 2: Guided Tour and 1minute=1minute Tool
- Students try the guided tour and 1minute=1minute tools.
- Comparing tools and discussing their effects.
- In pairs, sketching a new interview tool and sharing ideas.

Session 3: Designing Tools
- I present insights from previous sessions.
- Students create a new interview tool in pairs.

Session 4: Recording Interviews
- Students conduct and record interviews using their tools.

Session 5: Screening and Group Dialogue
- Watching interviews together.
- Group dialogue on interview content and tool effectiveness.

Analysis

Sharing Meaning and Insights

Students shared meaning in several ways during the interviews. Interviewers played an important role in shaping this meaning by asking questions and reflecting back, helping interviewees recognise patterns and connections they hadn't noticed on their own. Many discovered new aspects of themselves and reflected on how their past continues to influence their present. Some students discovered that their childhood memories, some previously overlooked, still shape their current work. The guided tour, in particular, triggered unexpected insights, such as a student recognising creative practices from their past they hadn't previously considered. The lifeline tool helped to see that in some cases meaning doesn't come just from life events but from the connections interviewees make between them.

Figure 14
Victoire (left): "It made me realise I used to be more flexible creatively."

Figure 15
Mathias (left): "School may have influenced me more than expected, especially primary and middle school."
Still from video by Aoife McDonnell (2024).

Agency

The lifeline and the guided tour helped students take ownership of their interviews, offering structure, and allowing them to set boundaries. For example, by deciding what to include on their timeline, interviewees showed which moments they wanted to talk about, and which not. The guided tour gave some students confidence by providing a familiar context to speak within. The 1minute=1minute tool also provided agency to the interviewee by encouraging silence. This made space for interviewees to add more to their thoughts before the conversation would shift. One interviewer noticed that by waiting instead of interjecting, she got to know a surprising and interesting thought of the interviewee. However, one interviewee actually felt that extra silence put too much pressure on her to come up with an "interesting" answer. Several students referred to the interview sessions as "making a podcast". This suggests a sense of ownership over the interview, transcending the idea of a school assignment.

Figure 16
Mathias (middle): "I'm not as comfortable in more like a classic setting so it helps a lot."
Still from video by Leonor Pedroso Ferreira De Melo (2025).

Figure 17
Wera (right bottom): "I felt like the person showed me where I could place my questions. Because I didn't want to ask questions the person didn't want to be asked."
Still from video by Aoife McDonnell (2024).

Understanding

Students appreciated how much their understanding of each other grew in a short time. Initially, some were surprised by how little they knew their peers despite spending years in the same group. Seeing where someone grew up and went to school helped them connect the dots between their background and their work, making everything "fall into place." Several first-year students found comfort in hearing that older students had faced similar struggles, sometimes resolving them over time. Some were surprised by similarities in their pasts despite coming from different backgrounds.

Figure 18
Viggo (right): "Impressive how much you get to know a person in just 20 minutes."

Figure 19
Roos (right): "People in the other years had the same worries I have now. That makes it easier to let them go."
Still from video by Aoife McDonnell (2024).

Designing Tools

After trying out tools I provided, students went on to design their own. One pair asked the interviewee to draw while talking, creating a visual mind map they could revisit throughout the interview. This helped show how different moments or time periods were connected. Another group used music, asking the interviewee to choose songs that reflected their relationship with design. They played the song during the interview. Listening to it brought her back to a creative period when she felt truly herself, before losing that feeling in school. Another group adapted the lifeline by extending it into the future: "What do you hope design will mean to you in the future?" This added a speculative layer to the interview.

Figure 20
Interview tool by Maria and Letitia
Still from video by Letitia Leo and Maria Grensemo (2025).

Students' Reflections on Interviewing in Their Work

In the feedback form, students said these sessions helped them see interviews as a flexible tool rather than something that must follow a fixed approach. They shared that using different interview methods made it easier to start conversations and that they experienced them as deeper and more comfortable. One student mentioned that these tools allowed them to learn things about their interviewees that even the interviewees hadn't considered before. In the final session, some students said they are considering using interview as a research method in their other classes.

Impact on Future Reflection Sessions

In the feedback form, students mentioned that previous group discussions often felt more pressured, making them hesitant to speak, but that this changed during those sessions. The interviews made them feel more comfortable in the group, and that it created a safer space for sharing due to the tighter bonds within the group. They also wrote that this made classes more engaging and less stressful. One student related this to the interview tools, as they thought they encouraged meaningful conversations. I agree with these observations, and I also think that by exploring a variety of modes of interaction we have a broader range to build on in the future. Also, after watching the interviews together, topics that came up were explored in the group dialogue. Therefore, students, rather than me, informed the group dialogue by bringing something to the table. It was especially effective because the interviews offered depth to the dialogue. For example, in one interview, students explored various aspects of stress related to design, such as personal challenges, industry pressures, coping mechanisms, and rediscovering joy. This made the following dialogue more engaging than if I had introduced the topic of stress myself.

Figure 21
Watching interviews together (morning group)

Figure 22
Group dialogue about stress (afternoon group)

Figure 23
Group dialogue about stress (afternoon group)

Figure 24
Group dialogue about stress (afternoon group)

IV. Practice 2: People with Connective Tissue Disorders

Outline

In this project, I aimed to understand how people give various meanings to living with their disorder through interviews. Afterwards, I explored how these given meanings relate to each other in a group dialogue.

Part 1: Individual Interviews

I started by interviewing everyone individually, using the three tools described in the theoretical framework: topic cards (three times), lifeline (three times) and the guided tour (two times; a third session was planned but one person did not respond to the invitation). I conducted three interviews at participants' homes, one at a community center, and one at the Willem de Kooning Academy in Rotterdam. Due to travel constraints, I interviewed the remaining participants online. The interviews in people's homes and at the community center were recorded with a camera operated by my partner. At the academy I placed my phone on a tripod, and online sessions were captured through screen-recording. In previous documentary projects, the camera was central: Visuals drove the storytelling, and participants contributed by using the camera themselves. In this project, the camera was only a tool to record and share how participants shared meaning. These recordings allow the interviews to be shared with other participants and with people outside the project, making reflection possible, but the main medium remains the interview itself.

Participants knew beforehand that the interview would be filmed, and some expressed excitement that it could later be shared[3] and carry meaning for others. For me, the camera also functioned as a reminder that the meaning shared would not stay between interviewer and interviewee, but would later interact with other people and other meanings.

Part 2: Group Dialogue

The project ended with a group session where we watched interview fragments together and engaged in a dialogue about them. It took place in one of the Master of Art Education rooms at the Willem de Kooning Academy in Rotterdam, and four people participated.

When considering what space to choose, I was reminded of my bachelor in design, where I first learned how much the environment influences a creative process. I deliberately chose the space at the Willem de Kooning Academy in Rotterdam with this in mind. This dialogue was an experiment. I did not know what people would say or what would happen. I only knew that the core material

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[3] Consent
Participants could choose whether their full interview would be shared with the group and review the selected fragment in advance, requesting a different one if they preferred. At the end of the project, they could indicate how their recording could be shared and whether their name could be mentioned in my thesis.

would be our interactions (interactions between participants, and with the footage on the screen) and the words spoken. To be able to feel these materials, it was important not to be distracted by a space that has a function other than experimentation. For example, the design of a community center might want to promote a sense of coziness. But that coziness could get in the way of our experiment and might prevent us from truly witnessing our core materials.

The dialogue was recorded by a 360 camera, making sure everyone's gestures and voice were recorded, without the need for an extra person operating the camera. This allowed us to only be in the space with people who participated in the dialogue. I also held an online dialogue session, which two participants attended.

The dialogue session was structured as follows:
- Check-in: What motivated you to join this project?
- Introduction (by Floor): Overview of the interview tools used
- First screening: Interview fragments (15 min)
- Dialogue: What stood out or touched you? (30 min)
- Second screening: Interview fragments (15 min)
- Dialogue: Which story made you think? (45 min)
  - Follow-up: How do these stories relate to yours? (e.g. recognition, contrast, resistance, consolation)
  - How have they changed how you view your condition or LDS/Marfan?
- Check-out: What word comes to mind when you think about today's session?

Figure 25
Overview of the space

Analysis

Research Questions

I will analyse the interview tools with the following guiding questions:
- Do the tools support participants to share meaning?
- Do the tools give participants agency?
- Do the tools give participants agency to share from their own narrative structure, rather than following one imposed by me?
- Do the tools help to grow understanding? Do they help participants better understand their own relationship with the disorder? Do they help me better understand that relationship as well?

Not Analysing Participants as Defended Subjects

Although I'm inspired by Hollway and Jefferson's (2000) free association interview for its intention to avoid imposing narratives on participants, I don't analyse interviews in the same way they do. They analyse their interviewees as *defended subjects*, who can never be fully transparent to themselves or others in interviews. They take into account that interviewees actively defend themselves from anxiety and discomfort, and that this shapes how they narrate their stories. While this approach is relevant in their research, because it deepens their understanding of their subject's relationship with the research topic, I don't follow this approach. Firstly, I don't have the expertise to interpret accurately what their subconscious motivations might be. Secondly, I don't want to make this kind of analysis, as I would risk finalising participants. I link this to Levinas' notion of the absolutely other (1961/1979, p. 197): I'm here to witness participants' alterity, and I embrace that some influences on their meaning-making will remain unknown to me.

What meaning means in this project

During the practice phase of my research, participants coloured in the outlines of what meaning *means* in this project. In my theoretical framework, I define meaning through Kvale and Brinkmann's (2014) description of meaning-oriented interviews, Gornick's (2001) distinction between "the situation and the story", and Hollway and Jefferson's (2000) distinction between report and a story. My aim was to show the many ways meaning can be constructed, and this variety appeared both across and within interviews. I also saw how given meanings could shift over time, especially through dialogue. Below are some examples that illustrate this range. Some quotes have been shortened for brevity by omitting in-between sentences, but the wording has not been altered.

Ferry: I do think my identity has really changed. But if you ask me now, do you still know what your identity was like before the surgery, I don't.

Marjan: After the surgery, I didn't feel any pain for a while, because of the morphine. I honestly thought something's not right: Is this even my body? In some strange way, the pain belongs to you. When it came back, it felt familiar again, and I thought: yes, this makes sense.

Lennart: When I was little, and maybe still now, I thought death was the scariest thing. I don't believe in heaven or anything like that, so I think that when I die, it's simply over. And when I realised I could just as well be dead in 10 or 20 years I found that really frightening.

Tom: I love information, I'm a curious person, but in this area [of Marfan], I've been avoiding it. Then I thought, what if I completely turn it around? It no longer felt right for me to look away.

Jet: For me, it's actually just normal. I don't need everyone to be like 'oh no, are you okay?' To me, it's just part of my life.

Farijal: I'm very reflective, and I like to learn and grow—I have to be able to live with myself. I've had nine open-heart surgeries. You'd think the experience would be the same each time, but they were all completely different.

Tom: We were way too tall for the children's clinic waiting room furniture. I especially remember the girls—well, we were all already trying to figure out our bodies, but I particularly saw a lot of girls, really tall for their age, who were clearly still searching. And then you'd be sitting in that children's clinic, with that tree, among the play blocks: recognition, being with each other, and that's really nice.

Anneke: Maybe it will lead me somewhere. There are reasons for what happens to people. And maybe you'll never find out what they are, or maybe only much later.

Mila: When I was a kid—I was really sad about it—I was never allowed to be a Christmas angel in the school play, because I was too tall. I was always donkey or ox. And I'd think, why, you know?

Susan: When people say "a nice long walk," that doesn't resonate with me—walking, I probably associate it with pain and discomfort and being confronted with the fact that I can't do it.

On Interview Tools

1. Topic Cards
Interviewees: Ferry, Susan, and Jet

After two introductory questions ("Who are you?" and "How does LDS/Marfan manifest in your life?"), I placed a set of cards on the table, each containing a different topic for participants to choose from. These topics included:

- Identity
- Relationships and friendships
- Relationship with physical sensations or pain
- Relationship with your body
- Spirituality and religion
- Receiving care or caring for others
- Stigmas or incorrect assumptions from others
- Mental and emotional well-being
- Perception of time and spaces
- Life choices
- Hobbies, interests, and work
- Experiences with healthcare
- Family life and bonds

Each time a participant picked up a card, they began sharing what the topic meant to them, often starting by themselves. Occasionally, I asked, "Can you tell me what this means to you?". The cards let them steer the conversation by picking the cards they wanted to talk about. Susan described this in her feedback: "You can steer the conversation yourself based on the topics."

The cards also gave them agency to speak from their own meaning frame and narrative. This became especially noticeable in two moments. First, when Ferry interpreted a card differently than I had intended. The card read: **"Stigmas or incorrect assumptions from others."** Ferry pointed to it and said, "I try, certainly, not to fill in too much for people." When I asked, "For others?" he explained: "Yes, assumptions is… I have more understanding for that because I myself, so to speak, have gone through that traumatic cycle." He explained that he avoids making assumptions or judgements about others, particularly regarding illness. He mentioned how he became more understanding through his experiences. I had intended the card to explore assumptions others make about him, but Ferry reflected on his own assumptions instead. Had I asked a direct question with added context, I might not have learned about this interpretation. This moment felt especially relevant as Ferry also explained how this shift in perspective impacts his work as a manager. Earlier, he had shared how, after his surgeries, his identity was strongly tied to Marfan. Over time, however, other aspects like "Ferry who plays padel, works for the government, or builds LEGO," began to resurface. Noticing how he connected the card to his increased understanding and gentle attitude, and how it influences his work, helped me better understand what matters to him now.

Figure 26
Ferry points the topic card "Stigmas or incorrect assumptions of others"
Still from video by Wei-Li Wong (2025), https://vimeo.com/1083587643?ts=0&share=copy

The second moment was when Susan picked the **"Experiences with Healthcare"** card. Rather than sharing her personal experiences, <u>she reflected on her work in a care facility for people with disabilities</u>[4], describing the extra barriers her clients face when trying to access support. Applying for support herself through the Dutch Social Support Act (WMO) gave her new insight into their struggles. Had I asked, "How is *your* experience with health care services?", she might have answered about her own experience, and I would have missed this particular way of giving meaning.

2. Lifeline
Interviewees: Anneke, Farijal, and Marjan

In this tool, the interviewee draws a timeline of their life from birth to the present, and mark moments that are important to them. After two introductory questions, "Who are you?" and "How does LDS/Marfan manifest in your life?", I asked them to create their timeline. The timeline serves as a base to dive deeper into what these moments mean to them. For example, when Farijal finished her timeline, I asked which moment was most important, and this became the starting point for our interview.

One of the first things I noticed was that participants mainly marked medical events such as diagnoses, surgeries, or consultations. This surprised me somewhat. When I created my own timeline I included these, but also experiences outside of healthcare, such as a period when my pain diminished and the life I lived then, or conversations with my partner that helped me acknowledge my disorder. However, the focus on medical events makes sense. People with a disorder are often asked to recall changes in symptoms or procedures in detail, down to the year, month, or week. Healthcare providers

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[4] https://vimeo.com/floorhofman/struggle?share=copy

might also "know" patients through this lens, skimming the medical record before entering the room (e.g., this is patient A, who had open-heart surgery last May and was hospitalised again a month later due to complications). I may not have anticipated this pattern because my experience with LDS does not involve emergency surgeries. This contrast shows me how important it is to acknowledge how different experiences can be. It also helped deepen my understanding of how surgery shapes people's sense of time.

Even though the lifeline mainly prompted participants to share medical events, the tool revealed differences in what these events meant to them. For example, Farijal marked a conversation with a doctor by drawing a broken heart. This moment stood out to her not because of a physical heart issue (although she had undergone many heart surgeries), but because her emotional heart was broken: the doctor told her she would not be able to carry her own children. Through this gesture, she immediately communicated what this moment meant to her, and we explored it further in the interview. She described it this way: "This tool immediately took me to a specific moment in time in my mind because it was presented so concisely. That made it easier for me to talk about it."
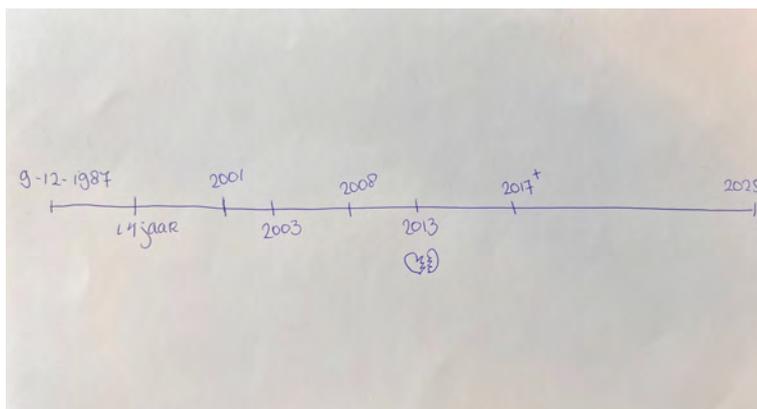

Figure 27
Farijal's broken heart

Anneke's timeline also showed what was important for her. She marked many names, like Uncle Henk, Aunt Aag, Mama, and Ally. During the interview, she often reflected on what she had learned from others, what caring for them had taught her, or spoke through their words: "My father said, when he got cancer: 'Why not me? So many people get cancer.'" Or about her sister: <u>"I knew that my sister was very…</u>[5] the surgery she was going to have, it frightened her. So that was spared her. In the end, she got cancer and chose euthanasia because she didn't want to go through further suffering. So she determined her own path." The timeline allowed me to see that people around her are an important part of how she gives meaning to her experiences.
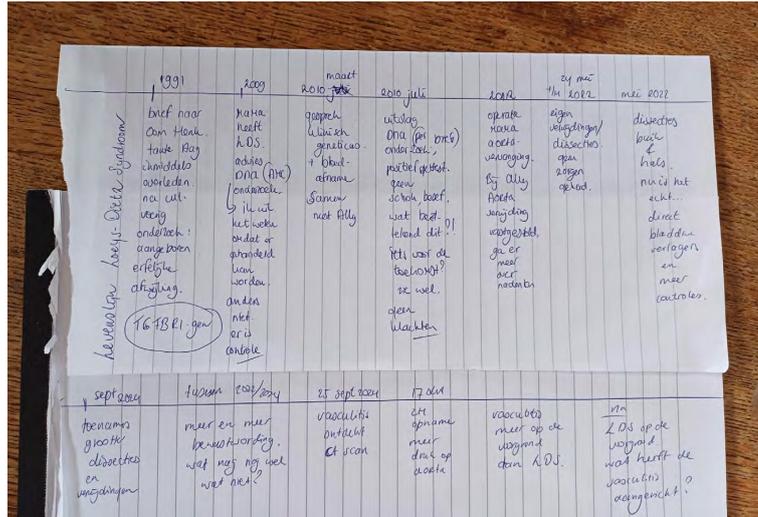
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[5] https://vimeo.com/floorhofman/sister?share=copy

Figure 28
Anneke's timeline showing names
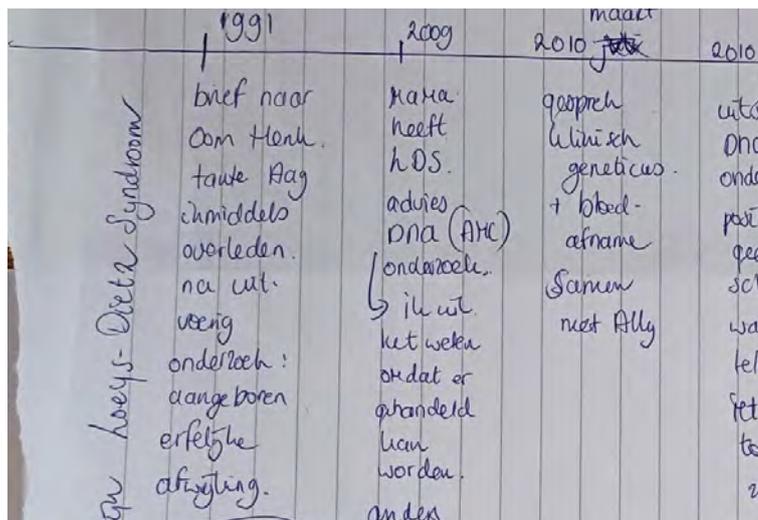*Photo by Anneke (2025).*

Figure 29
Oom Henk, tante Aag, mama, Ally
Photo by Anneke (2025).

In both Anneke's and Farijal's interviews, the timeline supported the process of sharing meaning. Anneke said it "forces you to reflect on the past and what it means to you now" and helped her gain "personal insight into the past years." This echoes what DAE students also noticed: that reflecting on the past can offer a new perspective on events and help create meaning. For Anneke, it led to a moment of appreciation: "That after my diagnosis, I still lived worry-free for a few more years. Once the first dissections were detected, that was clearly over."

However, in my interview with Marjan, the tool felt less effective to me. She had many moments to include, and creating the timeline took up much of our time, leaving less space to explore their meaning. Her lack of a formal diagnosis

leaves her questioning the origins of her symptoms and heightens self-observation. Each moment feels like a possible clue, and therefore it seemed important to include them all. Still, Marjan found the interview very valuable: "I wanted to tell my story but also had trouble staying on track, the tool, and especially Floor, provided good guidance." Organising her story even helped her make a decision: "During the interview, I managed to organise my story well, and that helped me decide not to keep searching for answers but to focus more on possibilities."

3. Guided Tour
Interviewees: Tom, Lennart

For this tool, I asked participants to take me on a guided tour of places that were important to them in relation to their disorder, using Google Maps' Street View. As they showed each spot, they reflected on what it meant to them. Compared to other tools, I feel this approach gave most agency to the participant, as it placed fewer demands on following a specific narrative structure. For example, the topic cards were based on words I had chosen, whereas the guided tour allowed them to choose their personal focal points. And while the lifeline often led to medical memories, the tour invited a broader range of memories. Many locations were outside the medical context, such as a holiday park, a café, a club area in Split, and a mountain range in Austria.

This openness helped me bypass my blind spots, and gave space for participants to bring up experiences I would not have thought to ask about. Both Tom and Lennart began by showing where someone first suggested they might have Marfan. For them, this was a defining moment: the beginning of their relationship with the disorder. Had I only asked interview questions, I probably would not have included something like, "Can you recall a time when someone suspected you might have a condition?" Because in my own case, that phase was not particularly memorable. This tool showed me how central it was for Tom and Lennart, helping me understand their experiences.
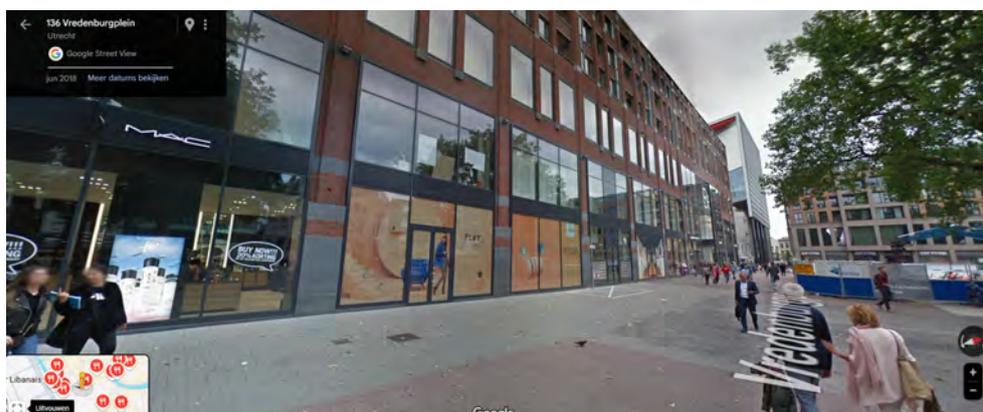

Figure 30
Place where Marfan was first mentioned to Tom
Screenshot by Tom (2025).

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Figure 31

Place where Marfan was first mentioned to Lennart

Screenshot by Lennart (2025).

In Lennart's interview, his locations began to form a narrative, each place relating to the next. He started with a holiday park, where a family acquaintance first raised the possibility of Marfan. This set off a series of medical checks. He then showed a club district in Split, where he felt anxiety, confusion, and fear of dying during a graduation trip. Then came the hospital, where he received his diagnosis and still goes for checkups. By then, he had already found some calm and understanding about his condition. He ended with an Austrian mountain range, where he worked as a ski instructor during a gap year. Though his stay there came earlier in time, he described it as a deeply peaceful and relaxing time shared with a close friend. His journey moved from uncertainty and fear to acceptance. In this case, the non-linearity of the tool allowed him to shape his narrative, which was non-linear.

This tool added a visual element to the interview, which became especially important when Tom spoke about his visit to the children's clinic. He remembered how everyone in the waiting room, himself and the other children with Marfan, looked out of place in the child-sized chairs and furniture (People with Marfan are often unusually tall.) He remembered observing a certain awkwardness, and the design of the waiting room was a tangible reminder of their discomfort in their bodies. In Lennart's case, it was informative to see the oppressively hot, blue summer sky of Split, where he had felt trapped in anxiety, in contrast with the spaciousness of the Austrian mountains, where he later found peace.

Figure 32
Lennart's party holiday
Screenshot by Lennart (2025), https://vimeo.com/floorhofman/party?share=copy

Figure 33
Lennart's gap year
Screenshot by Lennart (2025).

This tool also led to an unexpected moment of self-reflection. Tom's first location was a café terrace in Utrecht, where his mother mentioned a colleague's suspicion of Marfan during their annual shopping trip. At the end of the interview, Tom said he hadn't expected that memory to surface so quickly. Speaking about it aloud made him emotional, which took him by surprise. In his feedback, he wrote: "I didn't realize that location had such an impact on my story about Marfan."

The openness of thinking in locations, rather than answering directive questions, perhaps introduced a disruptive element that allowed answers to surface which even surprised the interviewee. Tom noted: "It provides new insights and reminds me of memories I wouldn't normally think of." Lennart wrote: "The images brought up many thoughts that I might have pushed to the background myself. It helped me reflect on what it was like when I wasn't yet sure whether I

Figure 34
Tom's children's clinic
Image retrieved by Tom from the Amsterdam UMC website (n.d.), https://vimeo.com/floorhofman/clinic?share=copy

had it or not. Thanks to the Google Maps images, I could answer and think about that time much more easily." In moments like these, new meanings can be created for the interviewee. Lennart also described the thoughts as "more real": "It triggers much more real memories/thoughts for me than simply being asked to think back to that time." I sensed "realness" in some of the answers too, and it makes me wonder if it stems from the lack of predefined narrative structures in the tool. Interviewees are encouraged to search in their minds, intuitively creating accounts. I felt that these qualities also enhanced the group dialogue, which I will discuss in the next chapter.

4. What came up across interview tools

I felt more nervous as an interviewer. Normally, I rely on predefined questions as a sort of script, but these tools didn't offer that security. This created a more horizontal dynamic between me and the interviewee: neither of us knew what would come up or how the conversation would go. It left room to witness and respond to what happened in the moment.

This openness also influenced how the interviews ended: There was rarely a clear closure. They often concluded when the interviewee ran out of places to show (guided tour) or felt they had shared enough (lifeline, topic cards). This allowed interviewees to decide when they were done sharing, or to continue, but I sometimes felt unsure how or when to end. Perhaps they did too.

Figure 35
Group dialogue

On Group Dialogue

After watching the interviews, I asked participants, "What did you notice or what touched you?" Most responses were associative, with participants connecting a word or sentence to their own lives.

For example, Tom heard Susan mention her "healthy brother" who doesn't have LDS, which made him think about his own brother, who doesn't have Marfan. Tom described him as the opposite from himself: an extremely healthy, sporty type. Interestingly, his brother is also a hypochondriac. Tom recalled a moment when his minor medical issue made his brother extremely anxious, and they laugh about being opposites, appreciating how their differences offer a mirror to each other.

Figure 36
Tom: "What Susan said really struck me."
https://vimeo.com/floorhofman/susan?share=copy

These associations show how participants built on others' meanings through their reflections. This relates to Hollway and Jefferson's (2000) 'Free Association Narrative Interview' method, which uses open questions and minimal intervention to access the interviewee's meaning frame. The open question that I asked at the start of the dialogue, allowed participants to reflect within their own frame as well, based on meaning frames of others. This created a relationship between the meanings expressed in the interviews and those formed by viewers. At times, participants also connected different stories on the screen. For example, Ferry noticed a recurring theme in his own and in Jet's and Marjan's stories: conflicting perspectives between the interviewee and their environment.[6]

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[6] https://vimeo.com/floorhofman/perspectives?share=copy

Recognition leading to Feeling Understood

This relationship between meanings often involved recognition. Sometimes this wasn't expressed in words but through gestures, like nodding or laughter, for example when Mila[7] said in her interview that she was never "PE-worthy". This also happened in the dialogue itself, for example through a knowing look when Ferry shared how hard it is to explain the disorder to others. He said he often begins by saying, "So, my aorta…" only to be met with the question, "What is an aorta?"

Figure 37
Ferry: "What is an aorta?"

Figure 38
Tom and Anneke exchange a knowing look when Ferry is saying people ask him what an aorta is.

Sometimes recognition was verbalised, like when Anneke related to Susan's description of having to fight for her place in society: "Assumptions, that's what she said. And then I thought: That is so familiar." She then shared how a colleague's assumptions about her health had impacted her.

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[7] This participant preferred not to be referred to by her real name; a pseudonym is used. All other names are real and used with permission.

Figure 39

Anneke: "That's so familiar."

https://vimeo.com/floorhofman/familiar?share=copy

Sometimes recognition was direct, found in the exact words used during the interviews. Tom, for example, said he also describes waking after surgery like Ferry did: like being run over by a truck. Tom: "And I also feel that in this setting, I can laugh about it. Yeah, as if you've been hit by a truck... I can't put it any other way!"

Figure 40

(Left) Tom: "Ferry said, being run over by a truck."
(Right) Tom: "Exactly the same words, exactly the same words."

https://vimeo.com/floorhofman/exactly?share=copy

Figure 41

Ferry's reaction

These moments of recognition reflect two forms of (felt) understanding from my theoretical framework. First, recognising someone else's experience can make you feel seen or understood, as Mila said: "another piece of awareness that I'm not the only one experiencing certain struggles." Second, in the group dialogue, participants witnessed others recognising their own words. You can see this, for example, in Ferry's expression while Tom describes how he recognises the words Ferry used. This kind of recognition can put your own meanings in a different light. In his feedback, Tom used the word "acknowledgement" when asked what the project brought him; something closely linked to feeling understood.

Susan was surprised to hear many participants express a positive attitude toward their disorder, something she recognised in herself. She noted how people focused on "what is still possible" and took a "positive angle." I share Susan's observation. However, I don't think any participant used these exact words or exclusively spoke from positivity. This makes me think of how Frye describes stories gain significance not because they offer timeless truths, but because they help reflect on our own lives. They don't provide clear answers, but raise questions and show what it looks like to be searching in the middle of uncertainty (Frye, quoted in Frank, 2004). So how did this project create space for participants to tell stories that don't explain what to do or think, but stay in the middle of figuring things out? The interview formats may have helped. Their disruptive quality, or the way they, as Susan put it, "gave inspiration" and made you "go to places you hadn't thought about," as with Tom and Lennart, seemed to encourage open exploration. That included moments of struggle to find out the relevance of things. Ferry, for example, said several times, "What I'm telling isn't really a coherent story, I'm jumping from one thing to another, I just hope it's relevant for others." But maybe it's exactly that kind of searching that allowed participants to describe their personal context in all its particularity. And maybe that helped them resonate with others, as they did with Susan. If I had begun the project by asking everyone how they stay positive, that level of particularity might have been lost, and the sense of positivity might have felt hollow. The use of the tools increased the resonance of the stories for the audience, allowing us to feel understood.

Differences and Otherness

Levinas' concept of Otherness is not primarily about specific traits or differences in experiences. It expresses a fundamental principle: the Other is inherently other: not someone to be fully known or understood, calling us into an ethical relationship through that unknowability. Still, during the group dialogue, moments of difference in experience, or difference in given meaning between participants made a sense of otherness more palpable. These moments were reminders that we cannot finalise or others' stories. A contrasting experience came up when Tom learned Anneke had many family members who have the disorder as well. Tom: "Yeah, wow, I can't even imagine that.[8] I've always been the only one, my whole life. Of course, the way you explain it—I can understand it—but I just can't picture it for myself, having multiple family members with it. It brings difficult sides too, but also support. Just as a thought experiment, it

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[8] https://vimeo.com/floorhofman/imagine?share=copy

challenges me. It's not that I feel like I've missed out or anything, it's just so different."

Figure 42
Tom: "As a thought experiment, it challenges me."

Speaking aloud how deeply different another person's experience can be, gives a glimpse of Otherness, just as seen in Tom's case, it makes him physically feel: *I can't imagine!* He lets Anneke's experience call him into question, unsettle him a little, without needing to fully grasp it. This reflects what Levinas describes as responding to the face of the Other, when someone else's presence interrupts our assumptions and invites us into responsibility, not because we understand them, but because we feel that we never fully will.

This awareness of both similarities and differences in their experiences was described in participant feedback: "I found that very special, that everyone is so different, yet there are many similarities." It was also visible in the questions they asked each other, showing a commitment to listening without assuming sameness. For example, after Tom acknowledged the difference in experience between Anneke and himself, Anneke followed up: "This might be a strange thought, but have you ever wondered: why me and not someone else?" She introduced her question with a disclaimer. Tom responded, and later in the dialogue Ferry and Lennart did too, both of whom, like Tom, are the only ones in their families with the disorder. Lennart also asked the group about the meaning of regular check-ups: "Does it bring a kind of structure to your life? Like knowing you have to go back in two years? Or do you actually dread it?" In his question, he acknowledged possible differences in attitude, and indeed, the answers varied a lot.

Research Conclusion

I am now able to answer my research question: "How to form interviews and dialogues for sharing meaning and understanding?" and the subquestions: "How does a participant's sense of agency contribute to the sharing of meaning in interviews and dialogues?" and "How does a participant's sense of being understood contribute to the sharing of meaning in interviews and dialogues?"

I will do so by summarising and building on key insights from my analysis. Participant feedback that supported or nuanced my analysis has already been included there. In this conclusion, I add further participant comments that illustrate the findings.

1. Interview Tools

Agency

The interview tools gave participants agency to steer the conversation, which several mentioned they appreciated in their feedback. It also gave participants agency to speak from their own narrative (or non-narrative) structures. Each tool facilitated this in a different way. The topic cards prompted associations with individual words, the lifeline encouraged reflection on significant moments along a timeline, and the guided tour prompted participants to explore the meaning tied to specific locations. Using the tools put me in a slightly more vulnerable position as an interviewer. Without a fixed script of interview questions to rely on, I couldn't predict exactly how things would unfold. This created a more equal division of agency, as both the interviewer and the interviewee didn't know what is going to happen. This left space to create the interview together. In the context of DAE, the interview tools also gave students the agency to conduct interviews with one another independently, and a sense of ownership over them.

The emotional investment participants showed, along with their reflections on personal insights show a strong sense of autonomy and ownership: Expressions of feeling agency. This agency extended beyond the interview itself. Although I can't prove it, I noticed how DAE students were activated by the interviews. They edited the footage and discussed it actively in the group dialogue that followed. Similarly, the group dialogue with people with connective tissue disorders flowed naturally with very minimal guidance from me.

Throughout the process I saw that agency doesn't always mean offering the most choices or autonomy. At the start of the project, I leaned toward that view by letting the first three participants choose their preferred tool. But after I removed that choice, agency remained present.

Understanding from Interviewer Perspective

The tools helped me understand participants' meanings in various ways. The topic cards revealed how participants interpreted topics based on their own meaning frames. The lifeline showed that medical events were often central to participants' timelines, with some marking personal relationships or moments that were particularly meaningful. The guided tour allowed participants to share insights I hadn't anticipated, and the visual element provided an additional layer of understanding.

While I aimed to observe the meanings participants shared from within their own meaning frame, without imposing my own with leading questions, I recognise it's impossible to fully remove myself, and that was not the goal. This project increased my awareness of my own position as an interviewer, of how my interests, and biases shape the interviews. I learned how crucial that awareness is, especially when designing interview tools with the aim to learn the meanings others give.

Understanding from Interviewee's Perspective

The tools also supported participants in understanding their relationship with the disorder. Participants mentioned that it led to new insights or shifts in mindset, which kept them in a reflective state that lasted long after the interview concluded. The tools facilitated this in different ways: the lifeline helped with organising thoughts[9], the topic cards inspired to think of new topics[10], and the guided tour triggered a sense of flow and unexpected associations[11].

Additional Influencing Factors

While the tools were effective, it's maybe obvious but still worth noting that understanding and the sharing of meaning was also influenced by less tangible factors such as atmosphere of a shared presence between interviewer and interviewee.[12]

Feedback on Future Applications

All participants said they would like to use the tools in the future. They found it helpful for generating new insights, stimulating conversation, providing structure, and triggering reflection on the past and its meaning in the present. Susan considered using it in her professional context, suggesting it could support conversations between caretakers, residents, and their families.

To conclude: Agency, felt understanding and the additional factors supported understanding and the sharing of meaning, and allowed us to create a polyphony of meanings.

2. Group Dialogue

Another Layer of Meaning

While watching the interviews together, the detailed, varied, and truthful meanings expressed offered the audience a way in, a chance to connect with what was being told. The screening and the dialogue that followed, let the interview meanings interact with each other. The new associations brought in by the audience created a new layer of meaning. Participants liked that the

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[9] Marjan: "I managed to organise my story well, and that helped me decide not to keep searching for answers but to focus more on possibilities."

[10] Susan: "It sometimes touches on topics I wouldn't normally think about."

[11] Lennart: "I got into the 'flow' of working with this tool. My memory often works in images/photos anyway, so it was a good mix."

[12] Susan: "The conversation was easy to have because of the calm and pleasant atmosphere that Floor creates during the interview; I quickly felt the space and freedom to say everything."

interviews sparked a conversation; one said he found it an "accessible way" to meet like-minded people.

Feeling Understood

This process of watching and discussing the interviews created a sense of feeling understood, both for the audience and for the interviewees on screen. Interviewees experienced this by being witnessed and responded to. People in the audience recognised parts of their own experiences in what was shared on screen. The shared sense of responsibility for each other's accounts helped create a feeling of safety in the group. Several participants said they felt safe enough to share vulnerable or private experiences.

Deepened Understanding of Disorder

The shared understanding of the disorder grew, both in practical terms and in the variety of meanings people give to it. One participant described it as learning from others by collecting life experiences through their stories[13], and seeing what his future might look like. This feeling of deepened understanding was shared among participants in the group dialogue. For some, it was the first time meeting others with the same disorder. They described they found value in that, and in hearing others' "vulnerable circumstances." Although confronting at times, the participant found it a meaningful way to "face reality".[14] Another who had met others with the disorder before, said the meeting made her aware of how rarely she has conversations with people who share her experience. She found this awareness valuable.

Recognition, Connection, and Other Outcomes

Besides these outcomes, participants described they experienced unexpected recognition, acceptance, acknowledgement, peace, connection with others, and awareness that they are not alone in certain struggles.

3. The Moment of Sharing Meaning

On my way to each interview, my thoughts were preoccupied with the tools: had I brought the right materials, and how would I guide the interviewees? Yet, every time the interviewee started speaking, those thoughts faded. All that remained was the two of us facing each other, speaking, listening. Between interviews, I read Levinas and was moved by his distinction between *the saying* and *the said*, because described this experience. He describes saying as the dynamic act of speaking and expressing in the moment, and the said as the literal words, the content or proposition (Levinas, 1998). In this project, saying was central during the interviews. The recordings and transcripts, which formed the said, mattered too but not as timeless, independent end results. They served as tools to trigger further moments of saying, and sharing meaning through dialogue. If during the interview I had already focused on how saying would turn into said, the living act of saying would have been absorbed by the said. It was therefore necessary to recognise saying as important in itself: as something that exists before knowledge or definition (Levinas, 1998, p. 46).

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[13] Lennart: "It's a bit of life experience that I can already learn from. That's really nice."

[14] Lennart: "It's about facing reality, after all, and I actually found it very moving how the others shared their stories with such confidence."

The tools gave participants agency, allowing their saying to be searching, making and changing meaning in the moment. It was not only intellectual and definitely not predefined. Levinas describes this as: "The plot of proximity and communication is not a modality of cognition" (p. 48). It is not intellectualised content or finalised stories that matter here, but the meaning created through the vulnerability that speaking from a position of agency brings. Participants decide what they want to speak about, and they show themselves. Meaning and understanding do not grow in finalised stories, but in the vulnerability of saying. Levinas describes how the unblocking of communication does not happen through the transmission of information, but through the risky uncovering of oneself through sincerity, the breaking of inwardness, and the abandonment of shelter (Levinas, 1998, p. 48).

4. Personal Reflection: Building a Pathway

In my introduction I described how a talk with my aunt, and later the interviews I conducted, left me feeling understood. I wondered why those moments eased my sense of alienation. Reflecting on my research, I see I have been defining a pathway toward understanding, one I had missed as a teen. Others likely saw I was struggling and wanted to help but didn't know how. I too longed for understanding but couldn't create the connection. I now see that the interview back then was a pathway, which I deepened by answering my research questions. It proved powerful not only for participants but also for myself. Alienation was still present at the start of this project. Listening to participants was deeply touching, because it helped me better understand my relation with my disorder. Hearing them describe their experiences of pain or alienation, using the same words I use in my head, but had never heard anyone else say, helped me acknowledge my disorder as real. It also helped me recognise my emotional response made sense. What made this process especially powerful was that I never asked them about alienation directly. The openness of the tools made these experiences come up. That made them even more real, and made it a deeply connecting experience with participants, but also with myself.

V. Conclusion

In this project, I developed interview tools that aim to give interviewees agency and to support the sharing of meaning. I used the tools in two contexts. At DAE, students interviewed each other with both my tools and ones they created, followed by a screening and group dialogue. I then refined the tool selection and interviewed nine people with connective tissue disorders, again concluding with a screening and group dialogue.

The tools effectively gave participants agency to steer the conversation, and to speak from within their own meaning frames and narrative structures. Moreover, designing their own tools helped to make the interview their own. The tools also helped participants to share meaning, through associative prompts instead of the structure of predefined questions.

During the screening and group dialogue, these meanings began to interact, creating a new layer of meaning that allowed understanding to grow in multiple directions: the interviewer understanding the interviewee, the interviewee understanding themselves, interviewees understanding each other, and a shared understanding of the topics: design at DAE and LDS or Marfan syndrome for the second group.

By starting with interviewing people one-on-one, using tools that allowed them to express their own way of seeing things, I could introduce these detailed, personal accounts to the group dialogue. If I had started with a dialogue instead of an interview, their distinct 'sharp outline' would have been blurred, making it less clear what was their way of giving meaning to things and what was mine. These blended meanings would have smoothed out differences through my influence, hindering the group dialogue. Instead, beginning with interviews captured each person's unique viewpoint, which made the dialogue thrive, and allowed understanding to grow.

In addition to understanding, it provided beneficial outcomes for interviewees such as feelings of connection and acknowledgement. This makes the interviewees the main audience. Feedback by participants underlines the following outcomes:

Feedback Students at DAE
- Deeper conversations
- Tighter bonds within the group
- A stronger sense of comfort and a safer space within the group
- Classes that followed felt more engaging and less stressful
- Inspiration to use the tools in future work
- Better understanding of self, each other, and design

Feedback People with Connective Tissue Disorders
- Connection
- Recognition
- Acknowledgement

- Acceptance and peace around their personal situation
- Better understanding of self, each other, and the disorder

This feedback, along with questions from participants, peers, and tutors, helped clarify the project's core purpose: Finding ways to observe how others give meaning, letting those meanings interact, and allowing everyone involved to be touched or changed in the process.

New Discussion on Interviews

This research invites a rethinking of the interview in three areas.

1. Connection Over Data Extraction

Generally, interviews are used as a *means* to extract information, and generate data, whether in research, customer service, journalism, or elsewhere. In my project, however, I found that the interview *itself* can create beneficial outcomes for the interviewees themselves. In my conclusion, I focus on what I consider the two main outcomes in both groups: connection and understanding.

Some interview methods do aim to build connection between interviewer and interviewee. For example, Kvale and Brinkmann (2014) describe the metaphor of the interviewer as a traveler who co-constructs meaning with interviewees, but still as a *means* to get to the final goal: collecting information. My approach is the opposite: With the help of the tools, I look for meaning as a goal in itself, and connection often follows.

Such connection is very needed. I see alienation as a keyword in this research, influenced by my own experience, but also by accounts of people with connective tissue disorders. Some described how the dissonance between how the world appeared and how it felt led to questioning one's own reality, or even touch on one's sense of self. But this multifaceted experience goes beyond that group, and unfortunately, there is often little space in daily life to explore it. We have many habits, or maybe even a culture, of hiding such feelings. We try to fit in through rituals or etiquette, paving over vague feelings of misalignment. Or, conversely: reinforcing alienation by *othering* people.

2. The Interviewee is the Audience

When interviews are conducted to extract data, the interviewee's role ends once the interview is over. They might receive updates or see their interview shared, but they are no longer involved. In this project, however, the interviews are recorded primarily for participants themselves. We watched each other's recordings together, using them as tools to trigger further meaning-sharing and creation. This shift in audience made understanding grow in multiple directions: of self, of each other, and of the topic. It allowed participants to see that across difference there are common experiences, or a shared resonance. This allows people to sense a connection that is built on something beyond either differences or sameness; it's built on understanding.

3. Accessible and Actionable Interviews

The first step toward this multi-directional understanding is the use of these tools. The tools' potential lies in their accessibility, and them being actionable. While many known communication techniques aim to build connection, such as active listening, paraphrasing, and non-verbal cues, these only address one part of the puzzle. They don't directly offer a framework to grow mutual understanding. These techniques can also feel abstract and open to interpretation, which makes them less accessible. In contrast, these interview tools are easy to grasp and engage with. They require no preparation, prior knowledge, or facilitator; a brief introduction, spoken or written, is enough. All that is required is paper, a pen, or a mobile device. They are actionable because they lead to immediate dialogue that effectively grows understanding.

Future Possibilities

Further Research

The multifaceted sense of alienation reaches beyond the group I worked with. While the tools were effective, the research raises new questions: Did outcomes like connection and understanding result mainly from the tools, or from the combination of individual interviews and group dialogue? And what other ways of sharing agency are possible?

I'm interested in working with another group who might face alienation such as migrants, youth in transition out or into foster care, people with other illnesses, etc. With them, we could use the tools again, and also explore other forms of agency in interviews. Could participants, for example, bring in their own materials (objects, sound recordings, texts from others) to talk about?

I would also like to share interviews with people with connective tissue disorders with this new group to see what we might learn about alienation itself through this added layer of shared meaning. It could increase clarity on how the tools and interviews eased feelings of alienation. Was it through agency, possibly a prerequisite for breaking through alienation: the realisation that you are free to make meaning? Or through the presence and awareness the interview brings of your own existence? Or through recognition; being seen and understood by others, and seeing and understanding others?

Finally, further research is needed on how to make the tools available to people who want to use them.

Practical Applications

In what contexts are the tools I used directly applicable?

Interviews in Design and Art Education

Working with students of DAE showed the value of these tools in art and design schools for three reasons. First, art and design education can be competitive, and many students struggle with insecurity and loneliness, leading to excessive striving or withdrawal. These tools could help grow connection among students.

Second, the experience of agency during the interviews extends beyond the interview itself. This is pedagogically valuable as experiencing agency is inherent to meaningful learning. Third, shifting the focus from information to connection aligns with current discussions about AI in education. Students no longer lack information, but they do lack connection. The development of large language models might accelerate a shift away from the "banking model[15]" of education (Freire, 1970) toward a focus on connection and growing meaning in between students. During my research, I facilitated a workshop for coaching colleagues at DAE to test and reflect on the tools. Several have since used them in their groups with positive results. In future sessions with DAE students, I will explore other ways to trigger agency and sharing meaning, drawing from my documentary filmmaking practice. One example is making observational films about each other's work.

I also ran workshops outside DAE, showing how the tools can be applied in other institutions. The first was with first-year students in the Master of Education in Arts at the Piet Zwart Institute, in a class by Thijs Witty. The second involved two workshops at the Maastricht Institute of Arts (MIA), in the Visual Arts and Design Education department, in a course by Erik Frey. Students used the tools and reflected on what interviewing means for both interviewee and interviewer. At MIA, students also designed their own tools and used them to interview people they taught during their internships. This offered valuable input for the students' lesson and programme design, but moreover, students noticed interviewing built connection. One student described: "Some students had previously brushed off conversations about simple topics or said they weren't really in the mood to talk, but surprisingly, they were open to this interview. It seems the interview lowered the threshold for starting a conversation with the intern." The interviews both helped students understand people they worked with, and it also helped those people build a connection with the students.

Peer-led Interviews

The tools don't require a facilitator once they have been briefly introduced (for example, through a written manual). Any group that might benefit from them can use them on its own. For example, people living with a particular illness can interview peers. The tools offer an agency-rich and open way to explore the meaning of illness in a setting that feels different from, for example, support groups, which can sometimes feel impersonal or intimidating due to the limited agency participants have.

Final Thoughts: Experiment and Discovery

This project became an unexpectedly transformative experience for many involved, including myself. Writing this conclusion, I see many possibilities for further research and practice, but my deepest wish is for tools like these to be available to anyone who needs them. They are there to be used, but more importantly, to be experimented with. Because in the end these experiences grew from active agents, in the lightness of discovery. However I continue, I will carry that forward, inviting others in to experiment along.

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[15] Freire's "banking model" refers to a form of education in which students are viewed as passive recipients of knowledge, rather than active participants in their learning process.

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VII. Acknowledgements

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VIII. Appendix

A. In-text Video Materials

Website: In-text Video Materials
Scan this QR code, to view all the in-text video materials.

(https://floorhofman.com/From-Interview-to-Dialogue-Video-Materials)

B. Raw Video Materials

#	Title	Thumbnail	Link
1	Group Dialogue		https://vimeo.com/1072597834/d618d9959a?share=copy
2	Interview Anneke		https://vimeo.com/1054904808/b5524770ff?share=copy
3	Interview Farijal		https://vimeo.com/1058880444/c7df525809?share=copy
4	Interview Ferry		https://vimeo.com/1050715169/d66de3829a?share=copy

4	Interview Ferry		https://vimeo.com/1050715169/d66de3829a?share=copy
5	Interview Jet		https://vimeo.com/1051855128/35d5a201c1?share=copy
6	Interview Lennart		https://vimeo.com/1058537839/12e9a87a9e?share=copy
7	Interview Marjan		https://vimeo.com/1051618882/52a16ee0a0
8	Interview Mila	Not available	Not available
9	Interview Susan		https://vimeo.com/1059227977/c6f4556892?share=copy
10	Interview Tom		https://vimeo.com/1060073661/9e792b598c?share=copy
11	Interview Fragments for Dialogue part 1		https://vimeo.com/1062327378/93a2b7252d?share=copy

| 12 | Interview Fragments for Dialogue part 2 | | https://vimeo.com/1062116648/3970ca49f9?share=copy |

C. Participant feedback: people with connective tissue disorders

1. How did you experience the interview tool?
- Tom: Helpful and provided new insights and conversations.
- Lennart: I used the guided tour through Google Maps. At first, I had to think carefully about which images would come to mind, but eventually, I got into the 'flow' of working with this tool. My memory often works in images/photos anyway, so it was a good mix.
- Susan: Very nice, it provides direction during the interview, and you can steer the conversation yourself based on the topics. It also gives you inspiration.
- Ferry: Nice that you have a choice! A fine method to choose what suits you.
- Marjan: I found it very positive. Because I wanted to tell my story but also had trouble staying on track, the tool, and especially Floor, provided good guidance.
- Inka: We didn't use this during the interview. I did look at the theme cards.
- Farijal: I was already familiar with working with lifelines, and I find it an ideal tool to keep everything nice and concise.
- Anneke: Pleasant, also for gaining personal insight into the past years.

2. How do you think the interview tool influenced your way of answering or thinking about your experience with LDS/Marfan?
- Tom: Positive, I didn't realize that location had such an impact on my story about Marfan.
- Lennart: The images brought up many thoughts that I might have pushed to the background myself. It helped me reflect on what it was like when I wasn't yet sure whether I had it or not. Thanks to the Google Maps images, I could answer and think about that time much more easily.
- Susan: It sometimes touches on topics I wouldn't normally think about, bringing up subjects I wouldn't have chosen myself. You can also choose not to discuss certain topics—I didn't do that. I also noticed that I kept thinking about the conversation for a long time afterward and what it had done to me. It's good for me to pause now and then and reflect on how I relate to LDS. This was a very useful tool for that.
- Ferry: My experiences haven't changed because of it. The story I told remains the same. The tool provides structure, which is helpful when being interviewed to prevent jumping from one thing to another.
- Marjan: During the interview, I managed to organise my story well, and that helped me decide not to keep searching for answers but to focus more on possibilities.
- Inka: It didn't. We had an open and connecting conversation.
- Farijal: This tool immediately took me to a specific moment in time in my mind because it was presented so concisely. That made it easier for me to talk about it.
- Anneke: That after my diagnosis, I still lived worry-free for a few more years. Once the first dissections were detected, that was clearly over.

3. Would you like to use such a tool more often, and why?
- Tom: Yes, it provides new insights and reminds me of memories I wouldn't normally think of.

- Lennart: Yes, it triggers much more real memories/thoughts for me than simply being asked to think back to that time.
- Susan: Absolutely. It gets the conversation going, even in directions you wouldn't explore on your own. I'm also thinking about it in a work-related context. I can imagine such a tool being useful in conversations our staff have with our residents and/or their relatives.
- Ferry: See question 1—very handy as a communication method.
- Marjan: It helps you organise things well. Sometimes, you can't see the forest for the trees.
- Inka: I always enjoy exploring different tools to possibly use them myself in conversations.
- Farijal: I already use the tool.
- Anneke: Yes, it forces you to reflect on the past and what it means to you now.

4. How did you experience the group dialogue? (Were there moments you found particularly valuable, difficult, or surprising?)
- Tom: Nice, a lot of recognition. I liked that it really sparked a conversation.
- Lennart: It was nice to meet people who also have Marfan or LDS. For someone as young and "inexperienced" with LDS/Marfan as me, it was sometimes confronting to hear the harsh realities that some others had already gone through in the group dialogue. But above all, I found it very valuable to talk with these people, to hear their vulnerable/private circumstances, and to know that we can trust each other with them.
- Susan: I really liked it. It was a shame that we were with such a small group, but it made me realize that I don't have many conversations with people who share this experience. That recognition was very valuable. Watching the other interviews also gave me a lot. Sometimes it was difficult to hear that others have had bad experiences—I just feel really bad for them. What surprised me was that you seem to experience a kind of physical recognition (as if you're meeting family) and also that there are similarities in how people deal with LDS/Marfan: Many people focus on what is still possible, from a positive perspective. I found that very special—that everyone is so different, yet there are many similarities.
- Ferry: A celebration of recognition. It would have been useful when my diagnosis was first made. Now, I can put things into perspective more and talk about it normally. It was nice to discuss experiences and similarities with like-minded people. This was my first time doing so in eight years.
- Farijal: I found it a very connecting experience and a celebration of recognition.
- Anneke: Valuable because there was so much recognition, the safety of the group where vulnerability could be shared.

5. What has participating in this project brought you?
- Lennart: A lot more information about how my life could theoretically look in the future. Additionally, it motivated me even more to maintain a positive attitude and a "glass-half-full" mentality. And satisfaction that I could support Floor in her study! :)
- Susan: The connection with others, having an in-depth conversation about LDS, which gave me new insights into how I experience it. The recognition I see in others and the unexpected overlap in fundamental attitudes. Even though I would rather not have LDS, I found this project a very beautiful

experience. I also felt: LDS deserves to be seen. It doesn't have to be hidden away just because it's difficult. And this project gave it a platform. The conversation was easy to have because of the calm and pleasant atmosphere that Floor creates during the interview; I quickly felt the space and freedom to say everything.
- Ferry: Helping Floor and meeting like-minded people in an accessible way. Thanks, Floor—you did a great job!
- Tom: Recognition, new insights, and acknowledgment.
- Marjan: More acceptance and peace around my situation.
- Inka: Another piece of awareness that I'm not the only one experiencing certain struggles. And a beautiful new connection.
- Farijal: It made me realize that I also may make more use of my physical lived experience.
- Anneke: Connecting with fellow patients, gaining more self-insight regarding my LDS, grateful to be able to mean something to others.

D. Participant feedback: Students of Design Academy Eindhoven

Feedback session 1 and 2

1. How have you experienced these two sessions?
- I enjoyed it a lot!
- I really enjoyed knowing more about other people in the class! I liked listening to their stories and I wish we could do this more often.
- I felt it was a nice way to get the know the group better. Since I'm an exchange student I haven't had the chance to talk with everyone before this.
- It was good nice to talk and get to know people in the group I also felt comfortable talking about myself because it was a thing that we had to do in class so I felt less bad to talk about myself
- They are fun because i am getting to know my peers more
- I only have been to this session and I like the prompt question cards idea it's making the interview more efficient
- They are good prepared, that is nice! I liked to have interviews with the others because I don't know them and am (nieuwsgierig)

2. How did these sessions help you understand your peer's background?
- I enjoyed learning about their life up until now, it brought me closer to her and feel like I know her better. It's good to know someone struggled with similar problems and worked it out.
- it was very nice to get an insight into other countries cultures and the families of my class mates that shaped their time growing up.
- It gave me some insight, but that's sometimes all you need to understand a person better.
- I guess it just help me realize that we are very similar and also it just gave me insight on how everyone got here
- Yes, absolutely
- Yes

3. How could future Reflection sessions benefit from this?

- It was really nice to talk one on one with someone from another year. I feel like in group there's often more pressure to say something and then I end up not because I don't want everyone knowing my whole life problems.
- We create a tighter bond with our peers making the classes more engaging less stressful
- Get at tighter group.
- I think it makes the connection with each other more a bit more personal and maybe create a safer space to be
- Theres always possibilities to learn more about each other
- I think is great tool for encouraging conversations between people
- Maybe already make groups because it goes so slow every time, a bit more action

Feedback session 3, 4 and 5

4. What was the most valuable insight or experience for you in these sessions?
- Thinking about interview as a tool that is flexible. I had an idea of how the interview works and never thought of making it any other way, so the tools that have been shown to me, presented me that I actually don't have to do that that exact way.
- I think the getting to know someone who you've never maybe talked to. And to see their story how they came here. Sometimes there are similar things in your timeline as theirs. It's nice to talk to someone who does the same thing as you, but has a totally different experience with it.
- Seeing how creative methods like drawing and music can make interviews more engaging and help express thoughts on design. It was also a good opportunity to reflect on the role as interviewer and interviewee.
- I found it interesting how much easier it is to start a conversation when there is a specific tool or topic to address. Also it has showed me that different interviewing methods are possible.
- To get to know someone who you don't know and go into their lives. And sometimes you'll see things and ask about them, and the interviewee never thought of it like that. So you come across some aspects of their lives that not a lot of people know. Also the timeline tool reaaally helped in this
- Talking to the other years, coming from a first year
- finding out different tools for interviews; to help people feel more comfortable and establish answers of deeper context

5. Would you like to use any of these interview tools in your creative work and why?
- Maybe the one with showing pictures/location on google maps. To make it as a conversation starter.
- Yes, I think I would definitely do something with the timeline tool, and maybe the "life tree" tool that we thought of. It would be nice tot do it by myself also
- I see the value in using these methods, especially for making participants feel more comfortable. They could be especially useful for engaging with groups like children or the elderly.
- I would like but idk how like it is that the opportunity will come bc most interviews I have done are very formal…

- Yes I would definitely still do the timeline tool and maybe also the 'surroundings tree' tool that I thought of with one of the other students
- I wouldn't say I'd use it but it did give me insight into how to make an interview more comfortable. I think if people feel safe with the other person they open up and the conversation would be more interesting. So these tools would be a way to make it less formal, more open and personal
- Maybe the one with sound?

E. Participant feedback: Students of Maastricht Institute of Arts

1. What did the workshop bring you?
- The courage to interview people, and different tools and possibilities.
- A better understanding of the target group I interviewed, and how they relate to art.
- More insight into current opinions about art.
- Sometimes I felt a bit confused about what I was supposed to do, but overall it was helpful for designing my lesson.
- I now know more about my students' interests. The workshop also helped me build connections within my classes.
- More insight into how students experience the lessons.
- New tools for asking questions, instead of just using standard ones.
- A sense of what the class is like.
- Insight into how interviews can contribute to designing a lesson.
- More calm and more clarity about the possibilities and experiences around interviews.
- I want to do a second interview to better understand my target group.

2. Would you like to make more use of interviews in your work, and why?
- Yes, definitely. I've found that interviews can be a helpful way to connect with people or students who are not interested in having a simple or casual conversation.
- Yes, because it gives you a bit more insight into how the other person thinks.
- It depends on the setting. Possibly, to get to know people better and understand what they know or how they think. I think it could be helpful at the beginning of a school year or course.
- Yes, because it gives you much more information about your target group.
- Yes, it is an easy way to gather information that might be useful later.
- Maybe, as a way to connect more with the target group.
- Yes, and maybe I would also try other ways to get into conversation with students.
- I don't think so. I feel that interviews don't really suit me. I prefer being in front of a class, teaching.
- I find it quite hard to conduct interviews. I often catch myself asking closed questions. But it is a good way to get to know your target group.
- I think I would rather ask more natural questions during my lessons to find things out.
- I think interviews are helpful for understanding a target group, but I also find it difficult to really apply them in practice.

- I think I now have a better sense of how interviews can be useful. There is more potential in them than just following a standard format.
- When I did my interview, I had not yet decided on a target group. I interviewed a fifth-year pre-university student, but now I teach a third-year vocational class. In my experience, the vocational class is actually more motivated.

F. Open Call for people with LDS or Marfan

Do you have Marfan or Loeys-Dietz syndrome and would you like to explore your experience in conversation with others who share this diagnosis? If so, I warmly invite you to take part in my project! My name is Floor Hofman, and I have been diagnosed with Loeys-Dietz syndrome. I am currently finishing my Master's in Art Education, and for my graduation project I want to explore, through interviews and a group dialogue, how people with Loeys-Dietz or Marfan syndrome make sense of their experiences of living with these conditions, in order to highlight the diversity of those experiences. What does it involve?

Interview
You will be interviewed once by me about your experiences, at a time that works for you. Together, we'll decide on a format that suits your needs and preferences. The interviews will take place in February and March. We'll choose a location that works for both of us or opt for an online conversation.

Dialogue
You will be invited to take part in a group dialogue to reflect with others on the stories that emerged during the interviews. What do other people's stories bring up for us? Depending on the group's preferences, we will either meet in person or organise the dialogue online.

Privacy
Our insights will be included in my thesis and graduation exhibition. Your contributions will only be shared if you give permission. If you prefer to keep your contributions private, everything you share will remain within the group.

Participants
The project will only go ahead if there are enough participants. I'll let you know by the end of January whether it will go forward.

Video
In this video, I share more about my motivation for starting this project and what participating might offer you.

You can sign up until January 20! If you'd like to talk things over before signing up, feel free to get in touch via contact@floorhofman.com and we can schedule a call.

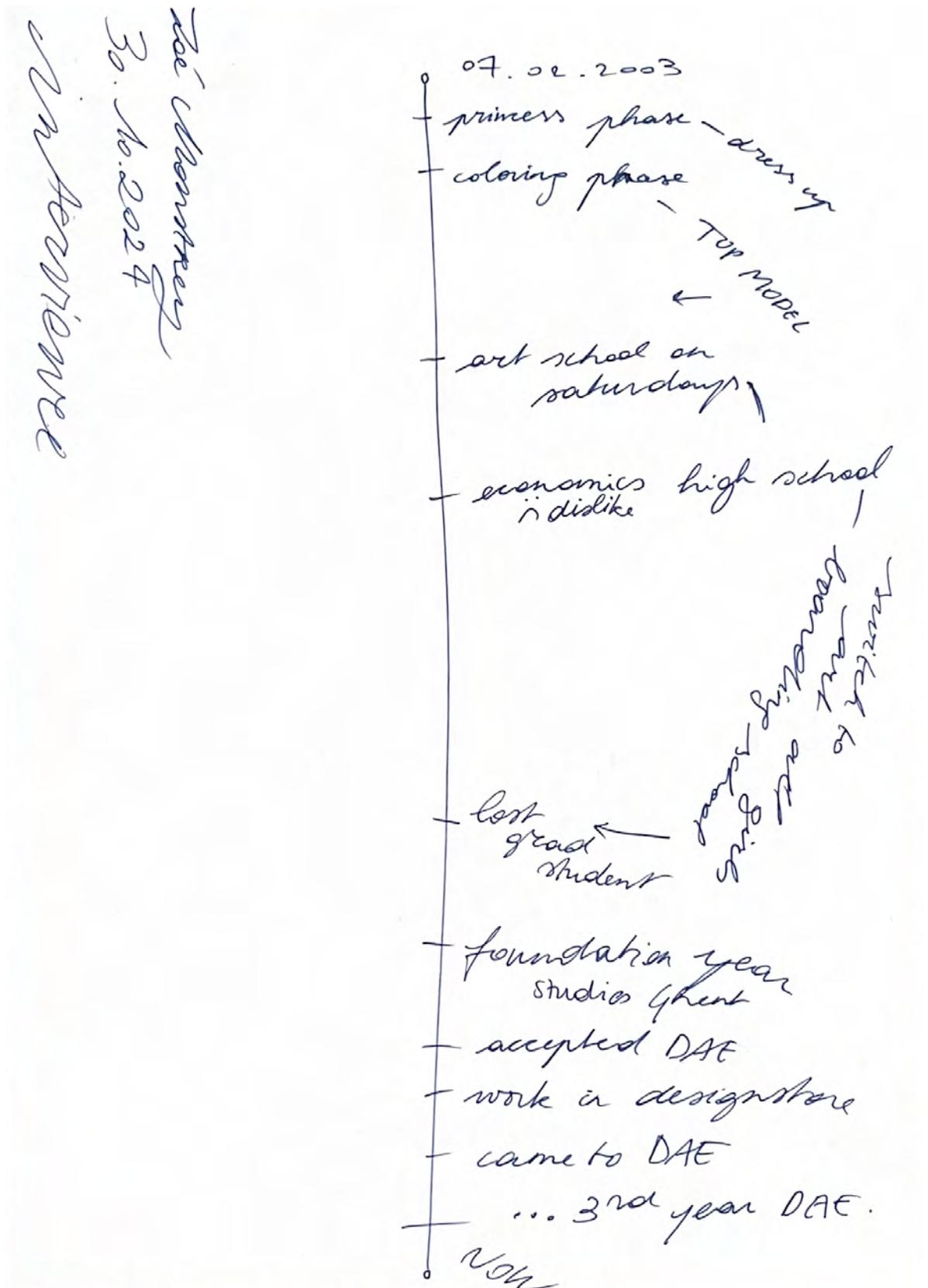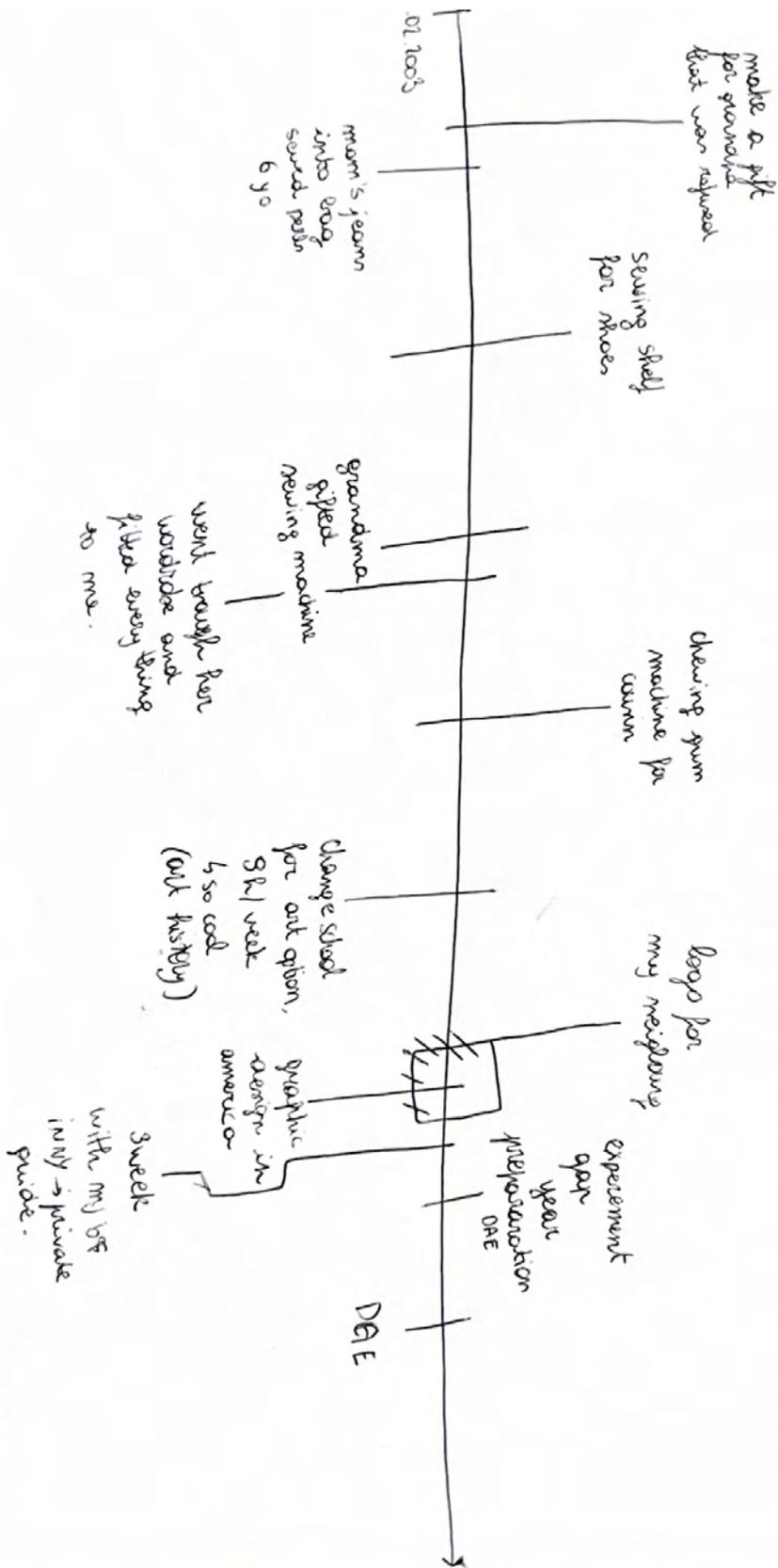I look forward to hearing from you!

Warm regards,
Floor Hofman

G. Selection of Lifelines by Students of DAE

Figure 8

Lifeline (enlarged from main text)

Drawn by student of DAE (2024).

Figure 9
Lifeline (enlarged from main text)
Drawn by student of DAE (2024).

Figure 43
Lifeline
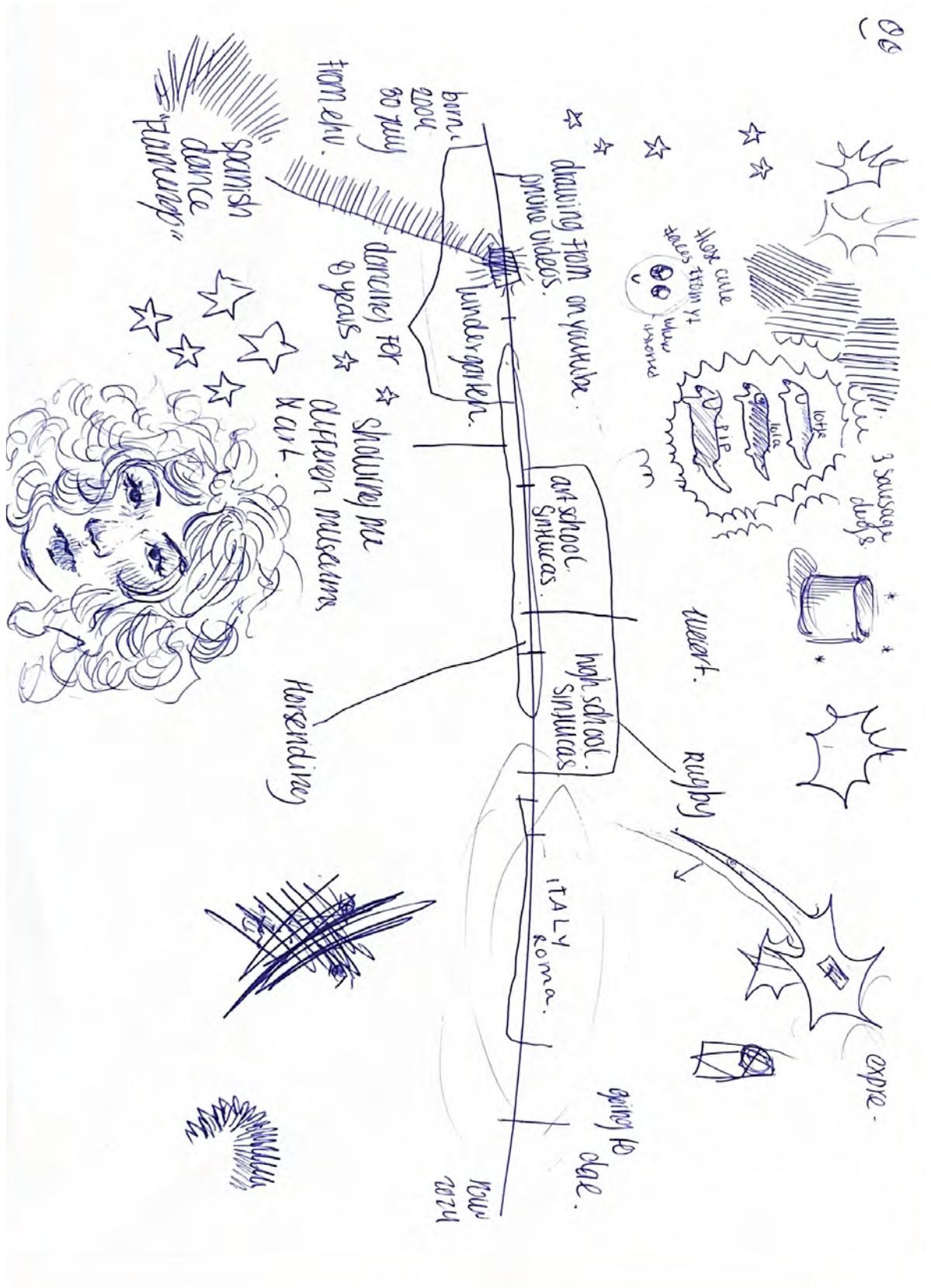*Drawn by student of DAE (2024).*

Figure 44
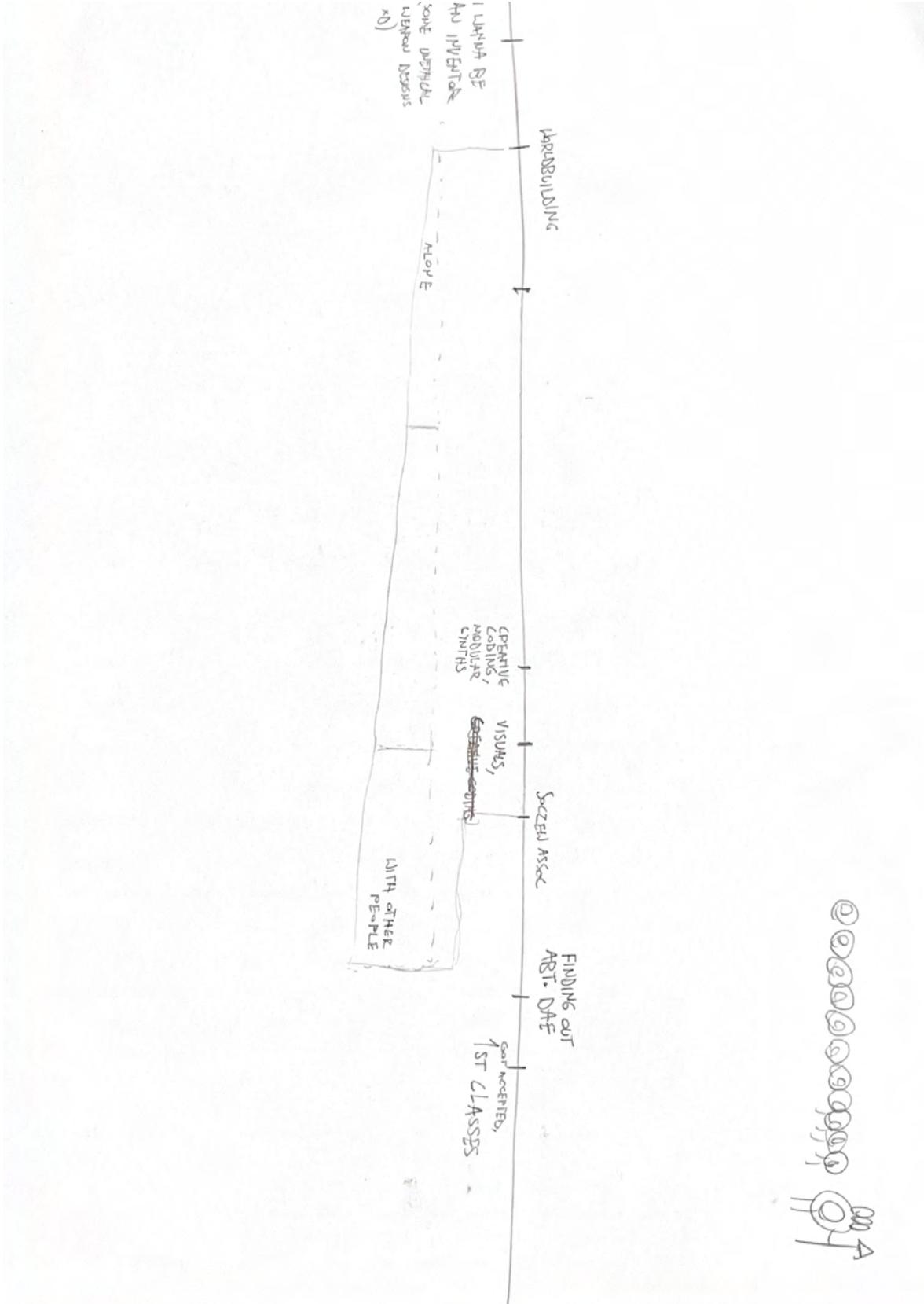*Lifeline*
Drawn by student of DAE (2024).

Figure 45
Lifeline
Drawn by student of DAE (2024).

H. About the Author

Floor Hofman (NL) is a documentary filmmaker, designer, interviewer, and educator. She often works as an artist-in-residence, living and working within communities to tell stories. Her films have been screened at festivals such as the Architecture Film Festival Rotterdam, Copenhagen Architecture Film Festival, and featured in international group exhibitions at galleries and museums including QWERTY (Japan), The Everspring Museum of Fine Arts (Taiwan), and the Van Abbemuseum (The Netherlands). She has presented her work at symposia hosted by institutions such as Villa Kujoyama, Goethe-Institute Villa Kamogawa, Kyoto Art Center, the Embassy of the Kingdom of the Netherlands, Erasmus University Rotterdam, and Leiden University. She works as a student coach at Design Academy Eindhoven, and leads guest workshops at Maastricht Institute of Arts. Floor lives in Maastricht and works wherever her subjects lead her.