

Appendix B: co-creation documentation and analysis

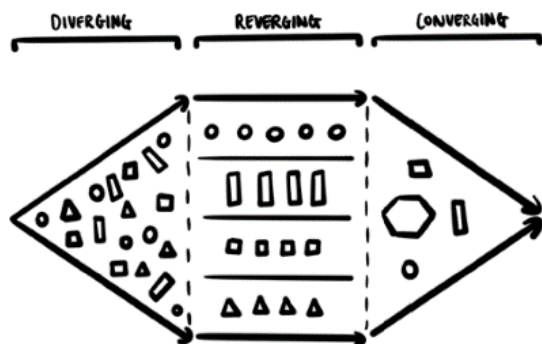
Step 1: Analysis for Immersion only

6.3.2 REVERGING: THEMATIC CLUSTERING

Goal

Because of the holistic approach and involvement of broad and diverse perspectives, many ideas and insights emerged, both generated by participants and generated by the writer of this thesis after analysis (appendix ###) . Many ideas are seemingly far from the scope and initial assignment (1.2.3).

Reverging is applied to learn from them, review the achievement of research goals, refine the objective for the next sessions. In addition, this enables inclusion of the insights and ideas in the final big picture that enables the generation of big ideas, as described in chapter 7.



Insights

Variety of needs

A key insight from reverging was the wide variety of needs and barriers experienced by the participants. Although this is very logical, it is almost impossible to accommodate to an individuals' needs based on statistical information like age, gender, country of birth etc. Initially, this diversity appeared too complex to accommodate within a single approach. However, through restructuring and revisiting the insights, a coherent solution space emerged.

The proposed solution reframes the first clinical consultation as an generative process: one that focuses not only on conveying information but also on exploring the patient's worldview, including their perspectives, values, and specific information needs based on how they perceive terms frequently used by HCPs.

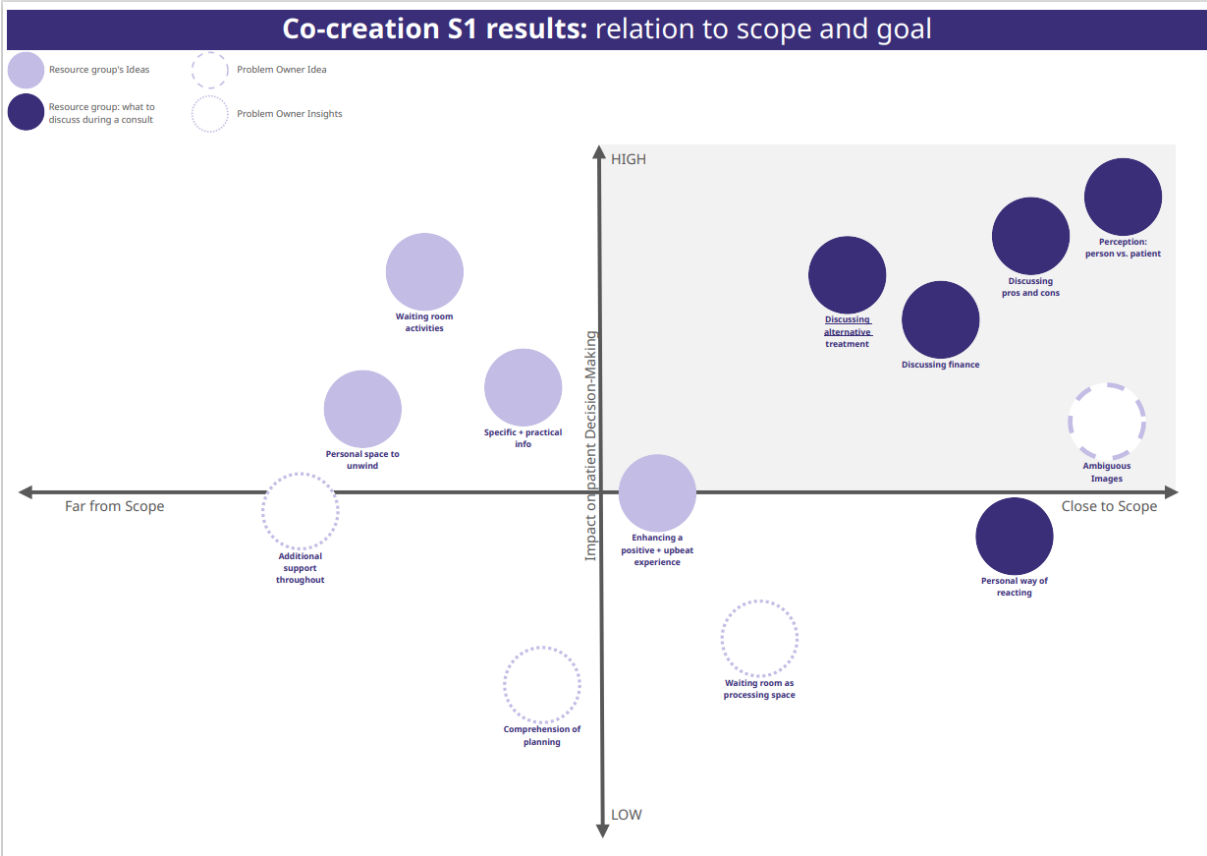
Interpretation of terms: a Guided exploration

This approach was inspired by the recognition that patients often interpret certain medical terms differently from how HCPs intend them. This is particularly the case for more abstract concepts such as "risk," "probability," and "clinical benefit." This mismatch in perception can lead to miscommunication during consultations.

Such disconnects can result in missed opportunities to help patients understand the potential burdens of treatment, disease progression, or symptoms. In turn, this can hinder patients' ability to make informed decisions aligned with their values and preferences.

This proposed solution frame, will be further explored and combined with previous insights through several steps in the next chapter.

Scope: Create a tool to support oncology patients with LHL in expressing their needs, values and preferences with HCPs to navigate the decision-making process in a confident and effective way.



1. More Space for the Patient in Conversations

Participants from all groups emphasized the importance of healthcare providers creating more space for the patient during conversations. Not only to feel more comfortable, which helps understanding, but also to be able to share more and have more time to process what the HCP has shared.

- Many participants appreciated when the conversation began with a personal introduction. This fosters trust and reduces stress and uncertainty.
 - o Group 1 (Sessions 1 & 2):

The intervention can support the introduction phase between patient and healthcare provider. It can help reduce stress and insecurity by fostering a sense of trust.

- Physicians should create space by allowing pauses and explicitly inviting questions from patients and their next-of-kin. Many patients struggle to participate actively during the conversation and only start reflecting afterwards.
 - o Group 2 (Session 2):

The physician should take the initiative to create this space for most patients.

- o Group 2 (Session 1):

The intervention should prompt providers to pause and allow silence during the conversation, giving patients time to process information.

It should also remind providers to create explicit space for questions.

The intervention should support post-consultation reflection, helping patients think about the decision afterwards.

It should provide a summary of the conversation to aid patients in discussing it later with their next-of-kin loved ones.

2. Support Coping with Stress and Uncertainty — Also Between Appointments

- Getting a clear picture of the situation and treatment options as early as possible can help reduce anxiety.
 - o Group 2 (Sessions 1 & 2), Group 3 (Sessions 1 & 2)
 - o Many participants had extensive experience with not be taken seriously and late referral to find the root cause of symptoms. This causes them to feel stress and lack of trust in the healthcare system.
- The intervention should clarify what kind of information the patient can expect to receive.
- Support from care providers is essential: they can help patients feel at ease and build trust.
 - o Group 2 (Session 1), Group 1 (Sessions 1 & 2):
- The intervention should help HCPs find personalized ways to comfort and reassure patients.
"Everyone knows stress is the main cause of all diseases right" - Cem (group 3)

3. Everyone Makes Decisions Differently and Needs Different Types of Support

- Participants from both groups discussed how people process decisions differently and often only understand what support they need once they're faced with a diagnosis and treatment options; moments that are often overwhelming.
- It may help to first explore the patient's own perspective before introducing medical options.
 - o Group 2 (Session 2):
- One participant expressed difficulty in determining the best order:

"you can't fully imagine the situation until it's real. But by then, the information overload makes it hard to think clearly." -

The intervention should help clarify patient values *before* medical options are introduced.

It should also carry those clarified values *into* the treatment discussion:

So the physician understands the patient's decision-making framework.

So the patient has a reference point for sharing their perspective.

So the patient is better prepared to express their values after receiving complex information.

4. Use of Visuals

- Visuals are helpful for some, but off-putting for others; some participants found them childish or felt not taken seriously.
 - Group 1 (Session 2):
- One participant said: *"This image should be in there, it gives me something to talk about," -...* suggesting visuals can spark dialogue.
 - Group 1 (Session 2):
- **Visuals should be abstract and informative, not overly playful or emotionally charged.**
- Participants made extensive use of images to explain the pathway via visual storytelling
 - Group 3 (session 2)

5. End-of-Life Conversations

- These conversations can provide clarity and peace of mind. Some institutions (like Curia Hospice and MVE) are doing this well.
 - Group 1 (Session 2):
- Participants expressed a need to clarify such uncertainties *before* they arise. Although it's hard to think about, it provides comfort and preparedness:

"When the moment suddenly comes, it overwhelms you. You can't think clearly then."

6. The challenge of communicating treatment and disease burden

People interpret terms differently, often based on personal beliefs shaped by religion, culture, or past experiences (their own or those of others). These interpretations do not always align with medical or academic evidence.

- **Probabilities:** Participants from Group 2 expressed no interest in discussing probabilities. They view such figures as based on others' past experiences, whereas the future, in their view, lies in the hands of Allah
 - Group 2 (Session 2)
- **Understanding disease burden:** Some participants did highlight that the potential burden of one type of cancer can be very different from another. They felt it was important to be aware of this when discussing treatment options.
 - Group 2 & Group 3 (Session 2)
- **Perception of pros and cons:** Sometimes, what healthcare professionals present as a benefit is perceived as a disadvantage by patients. For example, when told that surgery has the highest chance of completely removing the tumor, one participant responded: *"I don't see that as an advantage, because now I know that the tumor often isn't fully removed."*
 - Group 2 & group 3 (Session 2)

7. Preference for Non-Digital Tools

The intervention should be available in an analog format, or at least offer an analog alternative.

1. Step 2: Finding topics and coding them

Session 1

Group 1

A) What do you want to know/discuss?

Participants found the explanation very clear and expressed their concerns clearly. They worked in two groups to fill in the template.

1.1.A1. Being seen as a person, not just a patient

Participants valued being recognised as individuals rather than as “just another case” or number. They wanted healthcare providers to:

- Understand their personal ways of coping with difficult situations (e.g., anger, sadness, withdrawal).
- Adapt communication styles accordingly, using empathy, lay language, and a conversational rather than one-way approach.
- Provide equal opportunities for such personal exchanges, as not all doctors offer this space consistently.

1.1.A2 Clarifying responsibility for discussing personal coping styles

There was uncertainty over whether patients or doctors should initiate discussions about coping styles and emotional needs.

- Some patients were comfortable sharing this early; others did not know it was possible or appropriate.
- Structured prompts or questions from the doctor could help ensure that all patients, including those less likely to speak up, have the opportunity to share.

1.1.A3. Clear, honest, and comprehensive information

Participants wanted transparent, jargon-free explanations covering:

- The nature and stage of the disease.
- All treatment options, including their pros and cons, potential side effects, and long-term impact on quality of life.
- Prognosis, even when uncertain.
 - When outcomes were uncertain or probabilities unclear, they wanted this acknowledged openly, with help in interpreting what the uncertainty might mean for their own situation.
- Practical implications such as diet and eating difficulties, ideally supported by direct access to dietitians.

1.1.A4. Navigating uncertainty and conflicting information

Incomplete, contradictory, or uncertain information was seen as stressful. Participants wanted:

- Clear framing of uncertainty in relatable terms.
- Help weighing decisions despite unknowns.
- Explanations that reconcile conflicting information and highlight what is most relevant to them.

Some would trust and follow the doctor’s recommendation; others preferred to decide independently, though they questioned whether doctors would share their own opinion.

1.1.A5. Preparation and information flow before and between appointments

To reduce stress and increase understanding, participants wanted:

- Information materials (e.g., leaflets from trusted organisations) before appointments to prepare questions.
- Clear updates between appointments or test results, rather than long silent periods that heightened anxiety.
- Reliable sources for self-research (e.g., cancer foundations), though some preferred to avoid online searching and rely solely on oral explanations.

1.1.A6. Improving clarity and structure in the care pathway

Confusion arose around the sequence and structure of care, including what would be discussed when and why multiple doctors were involved. Suggested improvements included:

- Providing a clear overview of the care process and timeline at the outset.
- Summarising key points after breaks or transitions during consultations.
- Having one doctor consolidate information from multiple specialists before presenting it to the patient.

1.1.A7. Support during consultations

Participants valued having another person present (family, friends, or interpreters) for emotional support and to ensure nothing was missed.

- Recording consultations was seen as useful for later review.
- They wanted doctors to take time, repeat explanations if necessary, and check understanding.

B) How to make the hospital visit feel like...?

This exercise needed a bit more facilitation than the other exercises but eventually the participants were able to generate multiple ideas. They worked in two small groups.

All experiences:

- Being warmly welcomed at the reception desk
- Volunteer who can help if needed
- Playground with children
- Music (classical, calming)
- Being able to do things yourself (painting)
- Poetry wall
- Clear introductions
- Museum visit
- Shopping in a pleasant street or village
- Coffee corner

FROM HOW-TO TOWARDS AN IDEA

This exercise worked quite well, with a bit of extra facilitation. Participants worked in small groups again

H2 make the hospital visit feel like...	Coffee corner	Music
What makes this pleasant or understandable?	That there are seating areas instead of rows, inviting communication, with nice	Relaxation of body and mind, distraction.

	flowers and plants, cozy with a cup of coffee, tea, or fresh water.	
What can we learn from this?	The illness fades into the background for a while, meeting fellow patients, talking with others.	Listening well, enjoying, seizing the day, conversation about the music.
What would change then?	Atmosphere becomes cozier.	Relaxation, inner peace, conversation with others about everyday things.
The idea	A small bouquet of flowers for the patient's visitor when leaving.	Piano in the lobby or volunteers playing musical instruments, perhaps in a small room that can be closed off.

1.1.B1. Enhancing the hospital environment and waiting experience

Participants generated creative ideas to make the hospital feel warmer and more welcoming. Suggestions included:

- **Interactive positivity boards** where patients can write encouraging messages for others, creating a friendly and uplifting atmosphere.
- **Improving aesthetics** through more color and a generally friendlier environment throughout the hospital, not just in consultation rooms.
- **Revamping waiting areas** with quiet activities that enable indirect communication, such as leaving notes for others, rather than direct social interaction.
- **Dedicated relaxation spaces**, such as a low-stimulus room with calming music, although some felt other options (e.g., a playground) might be more effective for promoting comfort.

Group 2

A) What do you want to know/discuss?

Participants expressed (nodding fanatically) during the explanation. But after the explanation it became clear that many weren't able to participate well in the discussion, mainly because of a language barrier. The first exercise started a bit rough, but many input followed after one participant started to share their story on breast cancer. Participants helped each other when possible by providing translations. They preferred to do the first exercise orally with the whole group instead of filling in the template.

1.2.A1. Clear and complete information from the outset

Participants stressed the importance of receiving clear, comprehensible information early in the process, which should start from the initial consultation. This includes:

- Explanation of the type and stage of cancer
- Available treatment options and likely approaches for each scenario
- Prognosis information provided in accessible, lay language

Medical terminology should be avoided where possible, with pauses for patient feedback and opportunities to process the information.

1.2.A2. Managing stress and uncertainty between appointments

Waiting for results was described as one of the most stressful periods. Participants wanted:

- Updates from healthcare providers between appointments to reduce anxiety
- Information on possible scenarios and their treatment implications while awaiting results
- Realistic timelines for when results will be available
- Advice and support to help manage stress during waiting periods

They highlighted that vague reassurances ("everything will be okay") are unhelpful without concrete information.

1.2.A3. Emotional and cultural sensitivity in consultations

Participants wanted consultations to be more like conversations *with* the patient rather than *to* the patient. This includes:

- Respecting the patient's emotional state and allowing time for silence and reflection
- Considering cultural and religious contexts when discussing diagnosis and treatment
- Acknowledging faith as a coping mechanism before and between appointments

1.2.A4. Patient autonomy and selective information sharing

Some participants preferred to limit the amount of personal information shared with their doctor, focusing instead on receiving factual and relevant details about their condition and treatment options.

1.2.A5. Support from companions

Bringing a trusted family member (such as a child or grandchild) to appointments was seen as a way to feel calmer and more supported.

1.2.A6. Approach to delivering difficult information

Participants wanted difficult or negative information to be communicated clearly but sensitively: avoiding overly blunt delivery while ensuring enough time is provided to process what has been said, even when no immediate questions arise.

1.2.A7. Personal strategies for remaining calm

Before appointments, participants described strategies such as staying at home, maintaining a calm environment, and relying on their faith to manage emotions. They also expected doctors to help maintain calm during the waiting period for results.

B) How to make the hospital visit feel like...?

The assignment was not completed using the template, but instead discussed orally with the entire group together.

Example: a meeting in a community center

1.2.B1. Bridging the gap between comfort in community spaces and hospital settings

Participants noted that asking questions feels natural in familiar environments, such as community centers, but is much harder in the hospital or consultation room, where the setting feels more formal and intimidating.

Suggested improvements included:

- **Accessible consultation hours** that allow patients to easily contact a healthcare professional with questions outside of scheduled appointments.
- **Reducing or better managing waiting times** by clearly communicating when it is their turn, enabling them to leave the hospital and return without the stress of missing their appointment.
- **Flexible waiting options** that allow patients to spend time elsewhere between appointments, creating a less stressful and more comfortable experience.

FROM HOW-TO TOWARDS AN IDEA

1.2.B2. Follow-Up and information reinforcement

Participants valued having the opportunity to revisit information and ask additional questions once they have had time to process it.

Suggested improvements included:

- **Next-day follow-up appointments** (in person rather than by phone) after the GIOCA day, allowing questions to be addressed once patients are in a different environment and new concerns have emerged.
- **Pre- or post-appointment video summaries** capturing the key points discussed, enabling patients to review the information at their own pace and share it with family or friends.

Group 3

A) What do you want to know/discuss?

1.3.A1. Distrust and dissatisfaction with healthcare in the Netherlands

- Stories of delayed diagnoses, disagreement over treatment plans, and lack of follow-up fuel distrust
- Belief that healthcare used to be better in the Netherlands and is now declining
- Perception that bureaucracy and procedural rules get in the way of care

1.3.A2. Perception of foreign vs. Dutch healthcare

- Strong belief in the community that healthcare in other countries (e.g., Turkey) is better, especially due to faster service and less bureaucracy
- Example: Turkish hospitals seen as more willing to treat patients without requiring documentation first

1.3.A3. Not being taken seriously

- Repeatedly mentioned as a core frustration: feeling dismissed, ignored, or referred around without solutions
- Examples include doctors not acting quickly enough, not following through on promised calls, and downplaying concerns

1.3.A4. Communication and information-sharing practices

- Cultural preference in some cases for shielding the patient from negative information to preserve hope
- Discomfort when doctors directly tell patients they are incurably ill, without considering family wishes
- Differences in what people want to know:
 - Metin: interested in understanding disease progression and self-care
 - Ahmet: only wanted to know immediate next steps

1.3.A5. Consultation preparation and support

- Preparation is mostly mental: staying calm and composed
- Always bringing a family member or spouse for emotional support and to help process information
- Acknowledgment that patients can become overwhelmed and struggle to absorb details at the appointment

1.3.A6. Urgency and clarity in next steps

- Strong desire for fast, clear communication about what will happen and when
- Frustration over waiting long periods without updates or follow-up

B)How to make the hospital visit feel like...?

This exercise was difficult to complete. We worked in small groups and Ahmet and Metin did not really work together and mostly talked to me during the exercise. They were distracted a lot and found the exercise a bit weird at first.

1.3.B1. Distraction and engagement during activities

- Participants frequently distracted by phones and tangential storytelling
- Difficulty maintaining focus on the task (HKJ template)
- Repeated anecdotes and unrelated topics affecting progress

1.3.B2. Linking positive experiences to hospital visits

- Initial surprise at the idea of connecting pleasant experiences to hospital contexts

Examples of positive experiences: walking in the park between appointments, talking about non-medical topics, going to a museum, friendly staff, casual chats, and humor (e.g., “pretty nurse” comment)

1.3.B3. Social support and emotional wellbeing

- Importance of distraction and companionship during hospital visits
- Value placed on support from family, friends, and healthcare staff to keep morale up

1.3.B4. Language and literacy challenges

- Writing in Dutch described as difficult; reassurance given to reduce stress about language mistakes
- Side conversations about learning Dutch and English

FROM HOW-TO TOWARDS AN IDEA

This exercise was again difficult to complete.

Session 2

Group 1

Herhaling van de vorige sessie verliep goed. De deelnemers wisten goed na te vertellen wat er de vorige keer was gebeurd en besproken. Ans herkende Toos direct: “die blik”.

C) Enacting a first meeting between patient and HCP

The roleplay goes very smoothly, and everyone takes their role very seriously.

From the roleplay:

Netty, Meryem and Ans

- The patients were calm, the doctor notes, which helps her to respond calmly as well.
- The doctor took her time: *“She repeated things and summarized things — that was nice.”*
 - The doctor acknowledges certain reactions by verbalizing what she sees/hears happening. She then asks the patients how they feel about it. This helps to keep the conversation clear.
- They also discuss, while filling in the template, that it’s good to think about what you yourself want in terms of treatments — but that it’s difficult to think about this in advance, and that you can only really think it through once you know exactly what is possible and what your own situation will be.

2.1.C1. Participants appreciated when the doctor maintained a calm demeanor, took her time, and ensured clarity through repetition and summaries.

- The doctor’s habit of **acknowledging patients’ reactions** out loud and asking how they felt about them was seen as a positive way to keep the conversation clear and patient-focused.
- Patients noted the value of thinking ahead about treatment preferences, but found it **difficult to decide in advance** without knowing the full range of options and how these would apply to their personal situation.

Elif and Gerda

Right away, they talk about the onset of the illness (which symptoms), briefly about how things are going. Gerda immediately asks about the treatment plan. Elif suggests that they can decide together what suits the patient.

Gerda: *I think we should assume that the doctor knows and will present what the treatment plan is.* Elif: *We’ll figure it out together — what feels right for you.*

Gerda really appreciated that there was first a personal conversation (where the doctor comes from, etc.). An intermediary — social worker or similar — in the hospital.

2.1.C2. Balancing shared decision-making and professional guidance

Participants differed in their expectations for how treatment planning should occur.

- Some, like Gerda, preferred to trust the doctor’s expertise and have the treatment plan presented clearly.
- Others, like Elif, valued a collaborative approach, deciding together what feels most appropriate for the patient.
- Personal contact, such as opening with a short conversation about non-medical topics, was appreciated for building trust.

- Participants suggested the involvement of an intermediary (e.g., social worker) within the hospital to support communication and decision-making.

D) Creating a folder

This exercise was difficult. The participants immediately commented on the vast amount of information. Some were visibly distressed during the exercise. E.g. Ans expressed she was overwhelmed and could not imagine receiving all this information will experiencing cancer as well. Gerda also expressed negative emotions; she found the images child-like. In spite of the discomfort they were able to create folders.

2.1.D1. Divergent preferences for visuals vs. text

- Meryem values explanatory diagrams (e.g., tumor location) for clarity.
- Gerda prefers written information, considers most images unnecessary or childish.
- Some pictures (surgery before/after, treatment timeline) considered useful by some participants, but rejected by others.
- One group made a very visual explanation of the care trajectory including analogies like “going on a journey.”

2.1.D2. Information density and space constraints

- Frustration that all important content can’t fit on one A4 page.
- Different priorities lead to disagreements on what should be included.

2.1.D3. Emotional reactions and group dynamics

- Gerda’s frustration with the task and visuals impacts her mood.
- Facilitator intervention (letting Gerda vent) helps reduce tension.
- Other groups mostly unaffected by individual negativity.

2.1.D4. Consensus on excluding distressing medical images

- All agreed to exclude medical condition photos or “disease images.”

E) Personal reflection on what information is found important

Participants recognized the challenges visualized in the Current Interaction and were positive about the Future Vision. All participants filled in the template in silence and some asked for elaboration on the exercises.

2.1.E1. Thinking Ahead About Illness, Treatment, and End-of-Life Decisions

- Participants reflected on the value of considering illness implications before becoming sick.
- Acknowledged the difficulty of such reflection — balancing preparation with avoiding unnecessary fear.
- Recognition that true decisions often only emerge when faced with the situation.
- Interest in knowing options for treatment refusal, quality of life considerations, and end-of-life care.
- Uncertainty about the “right time” to discuss these issues: consensus that no perfect time
- Mention of organizations (e.g., NVE, Curia Hospice) that support such conversations exists.

Group 2

C) Enacting a first meeting between patient and HCP

2.2.C1. Comfort and role in communication exercises

- Discomfort in role-play due to fear of “inviting” illness upon oneself.
- Difficulty staying in role when the illness topic feels too personal or unpleasant.
- Laughter, hesitations, and frequent digressions suggest that the exercise triggered more discussion about *how* to communicate than the content itself.

While enacting the participants shared some of their own experiences in the consultation room.

2.2.C2. Variation in doctor–patient communication styles

- Experiences with doctors range from blunt to warm and reassuring.
- Ability to put a patient at ease is highly valued, regardless of cultural background: though some feel doctors from a migration background sometimes communicate more familiarly.

The exercise itself was not very elaborate but it kickstarted an extensive discussion on consultations. Participants shared their experiences, views and desires.

2.2.C3. Language and cultural barriers

- Language differences make it harder to follow conversations.
 - “Some HCPs start to talk even more when they notice that my parents struggle to engage in the conversation, which works counterproductive”
- Preference for bringing a trusted person to translate, but still need for doctors to use simple language, pauses, and clear invitations to ask questions.
 - Especially the need for pauses within conversations was expressed
- Perception that origin is less important than interpersonal skill, but familiarity with cultural communication styles can help.

2.2.C4. Confidence and barriers in asking questions

- “Patients often think of questions later and must wait a long time to ask.”
- Desire for doctors to *actively prompt* and *encourage* questions during consultations.
- Dalila also notices that doctors often end up giving the same answers repeatedly. She wonders: is this because she often asks the same questions, or because the doctor isn’t answering in the way they want?
- Some participants (e.g., Saliha) find it easy to ask questions; others (e.g., Fayda) feel they might be a burden.

2.2.C5. Beliefs about treatments and side effects

- Misinformation or misconceptions about the effectiveness of surgery vs. chemotherapy/radiotherapy.
- Perception in some communities that immediate surgery is always best.
 - Fayda said that many people always want surgery as soon as possible to remove the tumor. They often don’t want chemotherapy or radiation beforehand.
- Need for doctors to address and explain treatment sequencing and rationale, including risks and benefits.

- Some express distrust of medicines (e.g., paracetamol) and interest in herbal or traditional remedies.

2.2.C6. Importance of discussing prognosis and options, including no treatment

- Desire to know how fast the cancer can progress. Not everyone knows the differences between cancer types, and likely outcomes, but Dalila explained how this is important to know as it can influence your preference for treatment.
- Recognition that sometimes treatment mainly brings negative effects.
- Interest in having open conversations about *choosing no treatment* and what that means for quality of life, this was also due to a previous experience. Dalila expressed how her husband quickly passed away because of progressive lung cancer. She told that when they would have known how quickly things would progress they would have made different decisions.

2.2.C7. Stress and its impact on health

- Concern that stress worsens illness or recovery.
- Value placed on doctors giving clear, practical advice for managing stress.
- Dalila also said she doesn't really believe in paracetamol or other medicines because they often cause side effects that are also harmful. She mentioned a conversation with her doctor, where the doctor eventually said, "For you, it works better to take a walk in the park or take a shower." This made the other women laugh (also because Dalila talked a lot and often told stories that drifted from the main topic at the time).

D) Creating a folder

Participants worked in groups and a lot of discussion and elaboration took place during the exercise. Group reflection and discussion was brief after the exercise because a lot was already discussed during the exercise. Some participants were very enthusiastic about "knutselen", but later also commented that it was a lot of information to process.

2.2.D1. Different worldviews around "probabilities" and prognosis

- Many participants, especially Fayda, expressed that survival chances are not personally relevant due to religious beliefs: the future is in Allah's hands.
- Probabilities are perceived as "information from other people" (past cases), not as a personal prediction.
- This worldview means statistical framing may not resonate; more useful would be a discussion of *how* the person views probability before presenting it.
- Still, some are willing to include survival chances in materials for the benefit of others.

2.2.D2. Priority given to side effects and complications

- Participants agreed that knowing about side effects and possible complications is important for decision-making.
- Dalila noted that side effects and outcomes vary based on individual fitness and health status.

2.2.D3. Emphasis on cancer variability

- Importance of explaining this variation clearly to patients, without necessarily using statistical probability language.
- Dalila repeatedly highlighted that cancer differs by location in the body, influencing progression, treatment, and prognosis.

2.2.D4. Group dynamics and task interpretation

- Some participants (e.g., Saliha) interpreted the leaflet exercise more as a “test” than as an open choice activity.
- Language support and group composition shaped participation — some moved to groups working more in Arabic to follow along better.
- Some needed repeated clarification of the exercise before feeling confident in contributing.

2.2.D5. Value of linguistic adaptations

- Arabic translations of text were appreciated for ease of reading, even if not intended for editing.
- Grouping by shared language sometimes made tasks easier and more inclusive.

2.2.D6. Emotional tone and engagement

- Crafting activity (cutting, pasting) brought positive associations (e.g., Dalila recalling helping children in school).
- Breaks and casual interaction created informal bonding moments, making participation feel lighter.

E) Personal reflection: What is the core of the information?

A lot of reflection took place during the previous exercise. In addition, participants were tired and there was no energy left for the final exercise. It was decided to not do the final exercise because of this.

Group 3

This session took place later in the design process. It was decided to change the “Personal reflection” exercise for an interaction prototyping exercise.

2.3.X1. Icebreakers and mood setting

- Use of “sheep scale” as a lighthearted way to share current feelings
- Humor and small personal details (e.g., love of flowers, “holiday feeling”) create a relaxed start

2.3.X2. Continuity from previous sessions

- Recall of previous personas and tasks (Abdolah, Toos, HKJ assignment)
- Participants providing updates on previously shared stories and health situations
- Facilitator checking if new participant (Burak) was up to speed

2.3.X3. Second opinion importance

- Participants bringing in new or updated health-related stories from their own lives
 - Including a story on how being persistent and asking for a second opinion prevented a toe amputation

2.3.X4. Perspectives on dissatisfaction with care

- Discussion on why someone might still be dissatisfied even if the medical outcome is good
- Some participants see dissatisfaction as valid due to process issues or mistakes; others feel outcome is what matters most
- Explanations about treatment severity vs. outcome differences

2.3.X5. Cultural preferences in delivering medical news

- Within the community, preference for family to receive diagnosis first and relay it gently to the patient
- Discussion revisiting a topic from an earlier session for the benefit of new attendees

P) Interaction prototyping

2.3.P1. Session flow and facilitation

- Sophie almost started with the wrong activity before correcting to the planned template
- Participants worked in small groups, with varied speeds of understanding
- Instructions on the first template caused confusion for some participants
- Second template was easier to complete due to simpler instructions and familiarity from the first one

2.3.P2. Understanding and following instructions

- Cem misinterpreted the outer/inner circle placement and corrected it when clarified
- Burak was the only one to read instructions carefully from the start
- Ahmet skipped reading instructions initially and didn’t ask for clarification
- Some participants answered more questions than required, thinking it was expected

2.3.P3. Autonomy and decision-making in treatment

- Discussion on who decides treatment, with some believing patients should research options themselves
- Burak valued knowing all possible options due to his past medical experience
- Serhat emphasized the importance of doing what you can, stirring his own emotions

- Ahmet noted that doctors make treatment decisions but stressed opinions on stress and illness

2.3.P4. Communication and comprehension challenges

- Burak shared difficulties remembering information because of language barriers and doctors speaking too fast
- Past misunderstanding of medication instructions had serious consequences for him
- Participants highlighted how repeated consultations waste time and resources

2.3.P5. Personal health beliefs and lifestyle changes

- Burak shared lifestyle improvements like reducing alcohol and eating healthier
- Ahmet emphasized that stress is largely the cause of all illnesses
- Participants linked health outcomes to self-care and mental preparation

2.3.P6. Cultural views on sharing medical information

- Serhat preferred receiving medical news directly without involving family
- This contrasted with previous discussions about family-first communication preferences

C) Enacting a first meeting between patient and HCP

2.3.C1. Role play dynamics and facilitation

- Role play began after two templates but skipped a third due to time limits
- Instructions for the role play were unclear, leading to confusion about the scenario
- Burak as patient and Ahmet as doctor created a humorous atmosphere due to misunderstandings
- Cem participated minimally and focused more on the templates
- Laughter and joking made it harder to return to a serious focus

2.3.C2. Lifestyle changes and self-care

- Burak emphasized his goal to change his life and improve health
- Lifestyle change was prompted by a diabetes diagnosis and doctor's advice
- Shift from heavy drinking and smoking to healthier eating and less alcohol
- Burak preferred doctors who focus on lifestyle over quick prescriptions
- Ahmet teased about continued smoking and drinking, which Burak admitted but minimized

2.3.C3. Communication and comprehension with doctors

- Burak often forgets most of what doctors say due to fast speech and language barriers
- Past misunderstanding of medication instructions led to health problems
- Burak finds it hard to retain information when doctors talk too much before asking for questions
- Writing down questions in advance was suggested as a strategy
- Other participants recognized similar difficulties

2.3.C4. Healthcare system comparisons

- Perception that Dutch healthcare quality has declined, with more bureaucracy and delays
- Turkish system seen as more responsive but reliant on payment
- Cem raised treatment cost concerns, citing a €9,000 bill with less than half reimbursed
- Group compared Dutch and Turkish healthcare, noting differences in access, communication, and approach

- Discussion turned to capitalism and money's influence on care
- Facilitator refocused group on what they could personally influence

2.3.C5. Persistence and self-advocacy in care

- Participants agreed the first advice from doctors is often not the best
- Emphasis on standing your ground and pushing for better care
- Mixed feelings about going abroad for treatment—valuing Dutch research but frustrated by access

2.3.C6. Personal experiences of unmet medical needs

- Cem shared a case of ongoing pain with no effective treatment despite many tests
- Felt frustrated about lack of resolution and hesitant to keep pressing doctors
- Experience contrasted with typical “quick paracetamol” stories

D) Creating a folder

2.3.D1. Group energy and focus

- Participants, especially the three men, became visibly tired after a lot of talking, listening, and thinking
- Facilitator found it harder to ask targeted questions due to the group dynamic and sensitive topics
- High energy earlier in the activity made it harder to sustain attention for the final task

2.3.D2. Engagement with information and materials

- Burak made a sustained effort to go through all written information, including graphs and percentages
- Cem and Ahmet focused more on pictures than written content
- Burak showed interest in treatment details but chose not to include survival rate statistics, seeing them as discouraging
- Cem and Ahmet prioritized surgery-related visuals and positive framing

2.3.D3. Influence of peers on decisions

- Burak hesitated to add certain information after noticing Cem and Ahmet's choices
- Group norms leaned toward avoiding distressing or negative content
- Positive storytelling emerged as a shared preference between Cem and Ahmet

2.3.D4. Narrative creation in leaflet-making

- Cem made a narrative leaflet showing a positive recovery journey after surgery
- Ahmet created a story about diagnosis, lifestyle changes, and surgery, emphasizing patient agency
- Cem and Ahmet's leaflets overlapped in storyline, sometimes leading to duplication
- Written text in Dutch was limited; Ahmet asked Cem for translations

2.3.D5. Time pressure and wrap-up

- Confusion over agreed finishing time created mild tension
- Serhat and Metin were still working as the wrap-up began
- Serhat's leaflet emphasized decision-making and treatment options but showed difficulty prioritizing information
- Cem took over parts of Ahmet's explanation during the debrief

- Discussion was cut short to end on time, leaving some participant input (especially from Cem) unshared

Overall Co-creation insights

1. Value of Collaborative Review

- Reviewing materials as a group helped participants recognise different priorities.
- Discussion broadened perspectives and aided content selection.

2. Preference for Mixed-Language Groups

- Dutch–Turkish mixed groups preferred over single-language groups.
- Mixed groups foster richer discussion and reduce the burden of constant translation.
- Ask HCPs about their experience on this: Dalila also notices that doctors often end up giving the same answers repeatedly. She wonders: is this because she often asks the same questions, or because the doctor isn't answering in the way they want?

Session 2 exercise 2

4. Group Dynamics and Task Interpretation

- Some participants (e.g., Saliha) interpreted the leaflet exercise more as a “test” than as an open choice activity.
- Language support and group composition shaped participation — some moved to groups working more in Arabic to follow along better.
- Some needed repeated clarification of the exercise before feeling confident in contributing.

5. Value of Cultural and Linguistic Adaptations

- Arabic translations of text were appreciated for ease of reading, even if not intended for editing.
- Grouping by shared language sometimes made tasks easier and more inclusive.

6. Emotional Tone and Engagement

- Crafting activity (cutting, pasting) brought positive associations (e.g., Dalila recalling helping children in school).
- Breaks and casual interaction created informal bonding moments, making participation feel lighter.

Session 1 group 1:

5. Time management and scheduling issues

- running over time for activities and questionnaires
- unexpected delays due to social interactions and shared meals
- missed or delayed appointments leading to stress for participants

6. Positive closure and relationship building

- mutual expressions of appreciation at the end despite logistical hiccups
- facilitator acknowledgment that unplanned events “just happen” and gratitude for the host's efforts

1. Distraction and engagement during activities

- participants frequently distracted by phones and tangential storytelling
- difficulty maintaining focus on the task (HKJ template)
- repeated anecdotes and unrelated topics affecting progress

Step 3: Clustering the topics

1. Personal

1.1.A1. Being seen as a person, not just a patient

Participants valued being recognised as individuals rather than as “just another case” or number.

1.2.A3. Emotional and cultural sensitivity in consultations

Participants wanted consultations to be more like conversations with the patient rather than to the patient.

2.1.C1. Participants appreciated when the doctor maintained a calm demeanor, took her time, and ensured clarity through repetition and summaries.

RESPONSIBILITY?

2.1.C2. Balancing shared decision-making and professional guidance

Participants differed in their expectations for how treatment planning should occur.

1.1.A2 Clarifying responsibility for discussing personal coping styles

There was uncertainty over whether patients or doctors should initiate discussions about coping styles and emotional needs.

SUBTLE COMMUNICATION

2.3.X5. Cultural preferences in delivering medical news

- Within the community, preference for family to receive diagnosis first and relay it gently to the patient
- Discussion revisiting a topic from an earlier session for the benefit of new attendees

Differences in what people want to know:

- o Metin: interested in understanding disease progression and self-care
- o Ahmet: only wanted to know immediate next steps

1.2.A6. Approach to delivering difficult information

Participants wanted difficult or negative information to be communicated clearly but sensitively: avoiding overly blunt delivery while ensuring enough time is provided to process what has been said, even when no immediate questions arise.

INTERPRETATION OF DEFINITIONS

2.2.D1. Different worldviews around “probabilities” and prognosis

- Many participants, especially Fayda, expressed that survival chances are not personally relevant due to religious beliefs: the future is in Allah’s hands.

2. Autonomy

1.3.A4. Communication and information-sharing practices

- Cultural preference in some cases for shielding the patient from negative information to preserve hope
- Discomfort when doctors directly tell patients they are incurably ill, without considering family wishes

1.2.A4. Patient autonomy and selective information sharing

Some participants preferred to limit the amount of personal information shared with their doctor, focusing instead on receiving factual and relevant details about their condition and treatment options.

2.3.C2. Lifestyle changes and self-care

- Burak emphasized his goal to change his life and improve health
- Lifestyle change was prompted by a diabetes diagnosis and doctor’s advice
- Shift from heavy drinking and smoking to healthier eating and less alcohol

- Burak preferred doctors who focus on lifestyle over quick prescriptions
- Ahmet teased about continued smoking and drinking, which Burak admitted but minimized

2.3.C5. Persistence and self-advocacy in care

- Participants agreed the first advice from doctors is often not the best
- Emphasis on standing your ground and pushing for better care
- Mixed feelings about going abroad for treatment—valuing Dutch research but frustrated by access

TRUST

1.3.A3. Not being taken seriously

- Repeatedly mentioned as a core frustration: feeling dismissed, ignored, or referred around without solutions
- Examples include doctors not acting quickly enough, not following through on promised calls, and downplaying concerns

1.3.A1. Distrust and dissatisfaction with healthcare in the Netherlands

- Stories of delayed diagnoses, disagreement over treatment plans, and lack of follow-up fuel distrust
- Belief that healthcare used to be better in the Netherlands and is now declining
- Perception that bureaucracy and procedural rules get in the way of care

QUALITY OF CARE

2.3.C6. Personal experiences of unmet medical needs

- Cem shared a case of ongoing pain with no effective treatment despite many tests
- Felt frustrated about lack of resolution and hesitant to keep pressing doctors
- Experience contrasted with typical “quick paracetamol” stories

2.3.X4. Perspectives on dissatisfaction with care

- Discussion on why someone might still be dissatisfied even if the medical outcome is good
- Some participants see dissatisfaction as valid due to process issues or mistakes; others feel outcome is what matters most
- Explanations about treatment severity vs. outcome differences

1.3.A2. Perception of foreign vs. Dutch healthcare

- Strong belief in the community that healthcare in other countries (e.g., Turkey) is better, especially due to faster service and less bureaucracy
- Example: Turkish hospitals seen as more willing to treat patients without requiring documentation first

2.2.C2. Variation in doctor–patient communication styles

- Experiences with doctors range from blunt to warm and reassuring.
- Ability to put a patient at ease is highly valued, regardless of cultural background: though some feel doctors from a migration background sometimes communicate more familiarly.

2.3.C4. Healthcare system comparisons

- Perception that Dutch healthcare quality has declined, with more bureaucracy and delays
- Turkish system seen as more responsive but reliant on payment

3. Communication Support

1.1.A7. Support during consultations

Participants valued having another person present (family, friends, or interpreters) for emotional support and to ensure nothing was missed.

1.3.B3. Social support and emotional wellbeing

- Importance of distraction and companionship during hospital visits
- Value placed on support from family, friends, and healthcare staff to keep morale up

2.3.C3. Communication and comprehension with doctors

- Burak often forgets most of what doctors say due to fast speech and language barriers
- Past misunderstanding of medication instructions led to health problems
- Burak finds it hard to retain information when doctors talk too much before asking for questions
- Writing down questions in advance was suggested as a strategy
- Other participants recognized similar difficulties

1.3.A5. Consultation preparation and support

- Preparation is mostly mental: staying calm and composed
- Always bringing a family member or spouse for emotional support and to help process information
- Acknowledgment that patients can become overwhelmed and struggle to absorb details at the appointment

1.2.A5. Support from companions

Bringing a trusted family member (such as a child or grandchild) to appointments was seen as a way to feel calmer and more supported.

ENGAGING IN CONVERSATION

2.2.C4. Confidence and barriers in asking questions

- “Patients often think of questions later and must wait a long time to ask.”
- Desire for doctors to actively prompt and encourage questions during consultations.

2.2.C3. Language and cultural barriers

- Language differences make it harder to follow conversations.
 - o “Some HCPs start to talk even more when they notice that my parents struggle to engage in the conversation, which works counterproductive”
- Preference for bringing a trusted person to translate, but still need for doctors to use simple language, pauses, and clear invitations to ask questions.
 - o Especially the need for pauses within conversations was expressed

4. Stress

2.2.C7. Stress and its impact on health

- Concern that stress worsens illness or recovery.
- Value placed on doctors giving clear, practical advice for managing stress.

SUPPORT IN NAVIGATING STRESS

1.1.A5. Preparation and information flow before and between appointments

To reduce stress and increase understanding

1.2.A7. Personal strategies for remaining calm

Before appointments, participants described strategies such as staying at home, maintaining a calm environment, and relying on their faith to manage emotions. They also expected doctors to help maintain calm during the waiting period for results.

NAVIGATING UNCERTAINTY

1.2.A2. Managing stress and uncertainty between appointments

Waiting for results was described as one of the most stressful periods.

1.3.A6. Urgency and clarity in next steps

- Strong desire for fast, clear communication about what will happen and when
- Frustration over waiting long periods without updates or follow-up

1.2.A1. Clear and complete information from the outset

Participants stressed the importance of receiving clear, comprehensible information early in the process, which should start from the initial consultation.

NAVIGATING AN INCOMPLETE SITUATION

1.1.A4. Navigating uncertainty and conflicting information

Incomplete, contradictory, or uncertain information was seen as stressful.

1.1.A6. Improving clarity and structure in the care pathway

Confusion arose around the sequence and structure of care, including what would be discussed when and why multiple doctors were involved.

2.1.E1. Thinking Ahead About Illness, Treatment, and End-of-Life Decisions

- Participants reflected on the value of considering illness implications before becoming sick.
- Acknowledged the difficulty of such reflection — balancing preparation with avoiding unnecessary fear.
- Recognition that true decisions often only emerge when faced with the situation.
- Interest in knowing options for treatment refusal, quality of life considerations, and end-of-life care.
- Uncertainty about the “right time” to discuss these issues: consensus that no perfect time

5. Clear info

2.1.D4. Consensus on excluding distressing medical images

- All agreed to exclude medical condition photos or “disease images.”

2.1.D1. Divergent preferences for visuals vs. text

OVERCOMING MISCONCEPTIONS

2.2.D3. Emphasis on cancer variability

- Importance of explaining this variation clearly to patients, without necessarily using statistical probability language.

2.2.C5. Beliefs about treatments and side effects

- Misinformation or misconceptions about the effectiveness of surgery vs. chemotherapy/radiotherapy.
- Perception in some communities that immediate surgery is always best.
 - o Fayda said that many people always want surgery as soon as possible to remove the tumor. They often don't want chemotherapy or radiation beforehand.
- Need for doctors to address and explain treatment sequencing and rationale, including risks and benefits.

2.2.C6. Importance of discussing prognosis and options, including no treatment

- Desire to know how fast the cancer can progress. Not everyone knows the differences between cancer types, and likely outcomes, but Dalila explained how this is important to know as it can influence your preference for treatment.

SUPPORT UNDERSTANDING

2.3.D4. Narrative creation in leaflet-making

- Cem made a narrative leaflet showing a positive recovery journey after surgery
- Ahmet created a story about diagnosis, lifestyle changes, and surgery, emphasizing patient agency
- Cem and Ahmet's leaflets overlapped in storyline, sometimes leading to duplication
- Written text in Dutch was limited; Ahmet asked Cem for translations

1.1.A3. Clear, honest, and comprehensive information

Participants wanted transparent, jargon-free explanations

2.2.D2. Priority given to side effects and complications

- Participants agreed that knowing about side effects and possible complications is important for decision-making.

2. Step 4: Formulating the clusters into themes

THEME 1 – RECOGNISED AS A WHOLE PERSON

Conceptual description:

This theme is about encounters where the patient is seen not only as a medical case, but as a whole human with values, culture, and personal ways of coping. Participants valued when doctors took time for a personal introduction at the start of the consultation — it fostered trust, reduced stress, and opened the door to share more freely (*More Space for the Patient in Conversations*, G1 S1&2).

Communication style mattered: avoiding bluntness when delivering bad news (1.2.A6), tailoring to coping preferences (1.1.A2), and sometimes involving family first when culturally appropriate (2.3.X5). Beliefs also shaped how information was received — some participants rejected statistical framing for religious reasons (*The Challenge of Communicating Treatment and Disease Burden*, G2 S2).

Grounding examples:

- “This image should be in there, it gives me something to talk about” — a visual as a conversation spark (G1 S2).
- Different interpretations of “burden” depending on past experiences and values (*Challenge of Communicating Treatment*).

Underlying insight: Recognition is operational — it changes not just how patients feel, but how they participate in care.

THEME 2 – BALANCING CONTROL AND GUIDANCE

Conceptual description:

Autonomy here is about finding the right mix between professional leadership and patient self-determination. Some wanted to limit what they knew about their condition (1.3.A4), while others fought for more say and influence (2.3.C5).

The *Everyone Makes Decisions Differently* cluster expands this: decision-making styles differ, and people often only realise their support needs once faced with real treatment choices. Exploring patient values before medical options are introduced can prevent overload and keep decision-making anchored in personal priorities (G2 S2). This balance was also cultural — expectations of physician leadership varied — and shaped by prior experiences with feeling dismissed or unheard (1.3.A3, G2 S1&2).

Grounding examples:

- “You can’t fully imagine the situation until it’s real... by then, the overload makes it hard to think clearly.” (G2 S2)
- Need for values clarification to guide later conversations.

Underlying insight: Autonomy is situational — the optimal balance shifts with context, trust, and timing.

THEME 3 – ANCHORS IN THE CONVERSATION

Conceptual description:

This is about creating conversational space and structural supports that make patients active participants. The *More Space for the Patient* cluster fits here: starting with a personal introduction, pausing intentionally, and explicitly inviting questions during consultations.

Since many people only process and think of questions afterwards, supports like post-consultation summaries, prompts for reflection, and discussion aids for family were valued (G2 S1, G1 S1&2). Having a trusted person present was also key for emotional, cognitive, and translation support (1.1.A7, 2.2.C3).

Grounding examples:

- Silence as a tool: pausing so patients can digest and respond (G2 S1).

- Summaries to aid later reflection and family discussion (G2 S1).

Underlying insight: Comprehension and comfort are co-created; structure and pacing are as important as content.

THEME 4 – NAVIGATING THE UNCERTAINTY SPACE

Conceptual description:

Stress, waiting, and unclear pathways were described as major burdens. *Support Coping with Stress and Uncertainty* expands this theme: early clarity about the situation and options reduces anxiety, especially between appointments (G2 S1&2, G3 S1&2).

Personalised reassurance was valued — not as generic encouragement, but tuned to the person’s beliefs, culture, and coping style. Many linked prolonged uncertainty and lack of trust to earlier experiences of late referrals or not being taken seriously (G1 S1&2).

Forward-looking discussions, including end-of-life conversations, brought peace of mind when handled well (*End-of-Life Conversations*, G1 S2).

Grounding examples:

- “Everyone knows stress is the main cause of all diseases right” — Cem (G3).
- “When the moment suddenly comes, it overwhelms you... you can’t think clearly then.” (G1 S2).

Underlying insight: Managing uncertainty is an active task — timing, trust, and emotional safety are part of treatment.

THEME 5 – MAKING SENSE OF THE JOURNEY

Conceptual description:

Clarity is not just about facts but about how information is framed, delivered, and supported. Participants wanted plain language explanations (**1.1.A3**), early discussion of side effects and complications (**2.2.D2**), and sensitivity to how terms are interpreted differently depending on belief systems (*Challenge of Communicating Treatment and Disease Burden*).

The *Use of Visuals* cluster fits here: visuals helped some and alienated others. Abstract, non-playful imagery was preferred for serious topics, and visuals could serve as prompts for dialogue (G1 S2, G3 S2). Visual storytelling was especially valued in explaining the care pathway.

Prognosis discussions — including the option of no treatment — and understanding cancer variability (**2.2.D3**) were seen as essential to informed choice.

Grounding examples:

- “I don’t see that as an advantage... now I know the tumor often isn’t fully removed.” (G2&G3 S2).
- Visual storytelling used extensively by patients (G3 S2).

Underlying insight: Making sense of care is about narrative integration — blending medical facts with personal meaning.

CROSS-CUTTING NOTE – PREFERENCE FOR NON-DIGITAL TOOLS

Across clusters, a practical insight emerged: not all patients are comfortable with digital tools. Offering analog formats — or at least analog alternatives — ensures accessibility for all (*Preference for Non-Digital Tools*).

Appendix B: full documentation reframing

3. Problem Definition

Oncology patients with LHL more often experience decisional regret (concerning their treatment) than patients with a higher health literacy.

4. Abstraction hierarchy: Assumptions & Research Insights

- highlight assumptions in de abstraction hierarchy:
- Highlight research insights in de abstraction hierarchy:
- Noteer in welk hoofdstuk ze zijn toegelicht

5. Paradoxes and Frames

5.1. The Information Paradox

Patients often say they want *all the information* to feel prepared and reduce anxiety. Yet, when presented with all information, including outcome probabilities and risk statistics, many feel overwhelmed and confused: leading to more stress, not less. What *all the information* entails highly differs from person to person and what it may truly entail is a need for tailored clarity, not complexity because of information overload.

- Shift from “informing now” to “orchestrating the flow of knowing.”
- Use phased, anticipatory communication: e.g., “Here’s what you’ll learn now, and what we’ll cover next week.”
- Treat information like physical therapy: build capacity gradually.

5.1.1. APPROACH

Problem Definition:

“Patients want full complete information to feel prepared, so we must provide all details including risks and probabilities.”

Underlying assumptions:

- More information equals better preparation.
- Presenting detailed statistics is inherently empowering.
- Patients will process complex information effectively.
- Standardized, comprehensive disclosure meets everyone’s needs.

Resulting Solutions:

- Providing exhaustive printed or digital info packets.
- Detailed risk charts and probability data.
- Encouraging patients to ask questions if confused.

This often leads to **information overload** and increased anxiety for many patients, because their individual needs for clarity and simplicity are overlooked.

New Frame

“What if ‘all the information’ is not about quantity, but about **tailoring clarity to each patient’s capacity and preferences**? The goal becomes creating a *dynamic, personalized information experience* that reduces overload and promotes meaningful understanding.”

This draws from information design, health literacy, and user-centered communication principles, emphasizing quality and relevance over quantity.

1. Paradox Identified

Patients want all information to feel ready but are overwhelmed when they receive everything, leading to more stress.

2. Explore Broader Contexts

- In **education**, learners benefit from *scaffolded* information adapted to their readiness.
- In **UX design**, content is personalized based on user goals and preferences.
 - Insight from Creative Brainstorming, Industrial Design Engineering master student
- In **counseling**, communication adjusts to emotional state and cognitive load.
 - Insight from Creative Brainstorming, Neuropsychologist

3. Create New Frame

- Reframe “providing all information” as offering a personalized pathway to understanding.
- Information delivery adapts in layers or modules, allowing patients to control depth and pace.

5.1.2. RESULTING SOLUTION SPACES

"Diagnosis as a Dialogue, Not a Delivery"

Instead of treating diagnosis as a one-time announcement, see it as a co-created conversation that unfolds step by step.

Patients can express their values while learning about treatment, rather than seeing it as a before-or-after choice.

"Values-First Medicine: Treatment as a Tailored Fit"

What if treatment is framed not as a fixed plan, but as a tailor-made experience?

*Patients could start by expressing what "fits" them **before exploring treatment options.***

5.2. The Communication Gap

Healthcare professionals are obligated to fully inform patients about their treatment plans. However, many HCPs struggle to tailor information to individual patient needs and to translate clinical terms into the patient’s personal lens of perception. This creates a disconnect between intention and understanding.

- See communication as a translation practice, not just a transfer of facts.
- Introduce the role of "clinical interpreters" (not just linguistic, but cognitive and emotional interpreters).
- Value co-construction of understanding, not just delivery.

5.2.3. APPROACH

Problem Definition

“Healthcare professionals must fully inform patients about treatment plans.”

Underlying assumptions:

- Providing complete clinical information is sufficient for patient understanding.
- HCPs' role is primarily to transmit information clearly and fully.
- Patients are expected to absorb and interpret clinical language.
- Standardized information delivery is effective across diverse patient needs.

Resulting Solutions:

- Use of brochures or detailed verbal explanations.
- Checklists to ensure all information points are covered.
- Training clinicians to communicate clearly, but focused on clinical accuracy.

This approach is often ineffective, because patients interpret information through their own values, experiences, and health literacy levels, causing misunderstanding or disengagement.

New Frame:

“What if we view informing patients not as a one-way delivery of clinical facts, but as a co-creative process where information is translated and tailored into the patient’s personal context and meaning? The goal becomes enabling understanding through dialogue, reflection, and personalization rather than simply ‘full disclosure.’”

This frame draws from patient-centered communication and health literacy design, emphasizing two-way sense-making rather than unilateral information transmission. It takes inspiration from ## (Hermus beschrijving om sturend gedrag tegen te gaan)

1. Paradox Identified

- HCPs are obligated to fully inform patients. But often struggle to adapt information to patients’ needs and perspectives. This results in a gap between intention and patient understanding.

2. Explore Broader Contexts

- In education, teaching is most effective when knowledge is connected to the learner’s background and interests.
- In design thinking, empathy enables tailoring solutions to user needs, not just technical accuracy.

3. Create New Frame

- Reframe patient information delivery as collaborative sense-making, where clinician and patient work together to shape understanding.
- HCPs become facilitators of meaning, not just providers of data.

5.2.4. RESULTING SOLUTION SPACES

"Healthcare as a Cultural Bridge, Not a Roadblock"

Instead of seeing beliefs as barriers, they can be entry points for deeper conversations.

Medical discussions become about translating between different worldviews rather than just presenting facts.

"Treatment as a Negotiation, Not a Prescription"

Instead of HCPs giving fixed solutions, what if they framed treatment discussions like a negotiation where both sides contribute?

Patients feel heard first, increasing trust and willingness to engage.

5.3. The Trust vs. Control Dilemma

People who experience barriers to effective communication and decision-making in healthcare often have a lack of trust in the healthcare system, and lack of self-confidence. Cancer treatment can be so physically and emotionally exhausting that they often delegate decisions to others. While this supports recovery, it reduces their sense of agency and control.

- Empower patients to *choose* when and how they delegate decisions.
- Introduce “control contracts”: patients pre-define their thresholds for autonomy vs. delegation during treatment phases.
- View agency as flexible, not fixed. Patients should be able to shift between roles without guilt or confusion.

5.3.5. APPROACH

Problem Definition

“Some patients don’t take an active role in their treatment decisions due to low self-confidence or trust in the system.”

Underlying assumptions in this frame

- Patient passivity is a problem to be corrected.
- The goal is to encourage or restore agency.
- Delegation is seen as giving up control.
- Trust must be earned by individual HCPs during brief encounters.

Resulting Solutions

- Teach patients to “speak up” or “self-advocate.”
- Provide confidence-building materials or empowerment training.
- Emphasize transparency or communication checklists during consultations.

These solutions assume that more agency is always better, but overlook how fatigue, illness, and history with the system influence what kind of agency feels safe or realistic.

New Frame:

“What if we see patient agency not as something patients must ‘hold on to,’ but as something that can be shared, scaffolded, and returned over time, like a relay baton? Then the goal is to design systems that honour delegation as a strategic act, and offer gentle ways for patients to re-engage when they’re ready.”

This frame draws from concepts in shared decision-making where agency is not an individual trait, but something co-constructed and fluid across time.

1. Paradox Identified

- People with low trust and confidence often withdraw from participation in decisions. During cancer treatment, exhaustion makes delegation of decisions feel necessary. This helps them cope and recover, but results in a loss of perceived control and long-term disengagement.

2. Explore Broader Contexts

- In supported decision-making (e.g. disability care), agency is scaffolded: others help you decide *without replacing your voice*.
- In parenting or coaching, control is often temporarily transferred to help someone rest, then gently returned.

- In theatre or team sports, roles shift based on energy and readiness, but the shared goal stays in focus.

3. Create New Frame

- Reframe “delegation” not as loss of agency, but as a strategic rest phase.
- Design systems that allow patients to step in and out of control safely, without guilt or disempowerment.
- Build in mechanisms to restore agency when patients are ready, even after weeks or months.

5.3.6. RESULTING SOLUTION SPACES

"Empowerment Through Rituals, Not Just Decisions"

What if confidence didn't come from making decisions, but from having familiar, meaningful rituals in the process?

Patients might feel more in control through structured habits rather than overwhelming choices.

"Confidence as Trust in the System, Not Just Personal Control"

Pilots don't micromanage every system in a plane, they trust a structured support network to guide them.

Similarly, patients could feel secure by knowing the system is designed to support them, rather than needing full control.

5.4. The Steering Trade-off

Some healthcare professionals simplify decision-making by subtly guiding patients toward what they consider the best option (steering behavior). While this reduces cognitive overload and decisional stress for patients, it limits room for discussing alternative treatments and often bypasses the patient's own values and preferences.

- Flip the order of decision-making: start with patient values and desired life outcomes, then align treatment information accordingly.
- Create “Values Maps” that visualize how different options connect to personal priorities.

5.4.7. APPROACH

Problem Definition:

“Healthcare professionals must balance offering expert advice with allowing patients to make their own treatment decisions.”

Underlying assumptions in this frame:

- HCPs are responsible for simplifying complex choices for patients.
- Patients are often too overwhelmed to meaningfully consider options.
- “Good decisions” are often what HCPs believe is clinically best.
- Too much emphasis on patient preferences may lead to inefficient or suboptimal care.

Resulting Solutions:

- HCPs nudge patients toward a specific option while maintaining the appearance of SDM.
- Use of decision aids focused on simplifying pros/cons of a recommended option.
- Avoid presenting “non-standard” options unless the patient insists.

These responses prioritize efficiency and safety, but risk erasing the patient's role, values, and long-term engagement in their care.

New Frame:

“What if we reframe decision-making as a guided exploration of meaningful choices, where the clinician is not

just a recommender but a facilitator who helps patients connect clinical options to their own values and life context?"

This frame draws on metaphors from coaching, museum curation, and interpretive dialogue, where experts help users navigate rich but potentially overwhelming content without collapsing the experience into a single answer.

1. Identify the Paradox

- HCPs simplify decisions to reduce stress and confusion. This helps patients cope, but often suppresses alternative options and personal meaning. The intent is helpful, but the effect is limiting.

2. Explore Broader Contexts

- In education, good teachers don't just tell you what to think, they help you discover what's meaningful to you.
- In museums, curators offer interpretive paths through complex topics. Visitors don't need to understand everything but can engage deeply where it matters to them.
- In coaching, the expert doesn't give answers, they create conditions for reflection and growth.

3. Create New Frame

- Replace the frame of "simplifying decisions for patients" with "**curating** decision journeys". Where HCPs offer structured, emotionally safe ways to explore meaningful trade-offs.
- Patients aren't forced to evaluate every option, but they're invited to surface what matters most, with the clinician as a skilled facilitator.

5.4.8. RESULTING SOLUTION SPACES

5.5. The SDM responsibility

Some patients do not know what role to take during conversations with HCPs, they are afraid of too much responsibility when they first hear about Shared Decision-Making. But when they do know what Shared Decision-Making entails, they are very willing to contribute.

- Instead of treating SDM as a one-time information transfer, see it as a co-learning process where both parties adjust and grow into their roles.
- Build a relational foundation that supports patient confidence and allows HCPs to share responsibility without being sole motivators.

5.5.9. APPROACH

Problem Definition:

"Patients are not participating enough in Shared Decision-Making, so we need to better explain SDM and encourage them."

Underlying assumptions in this frame:

- The issue is patient awareness or willingness.
- SDM is something explained and delivered during clinical consults.
- HCPs must motivate patients, even if they lack time and training.
- Patients either take full responsibility or remain passive.

Resulting Solutions:

- Provide more pamphlets or videos about SDM.
- Train HCPs briefly on "motivating patients."
- Include SDM prompts in clinical guidelines.

These approaches often fail because they treat SDM as a content-delivery problem, not a relationship and capability-building process.

New Frame:

“What if we frame Shared Decision-Making as a mutual onboarding journey, where both patient and professional learn how to work together? Then the goal is not just to inform patients, but to create a shared space of confidence and collaboration, paced to each patient's needs.”

This frame is inspired by team-building and organizational development.

1. Identify the Paradox

- Patients don't know what role to play in SDM and fear being given too much responsibility. Once they understand SDM, they often want to participate. HCPs are responsible for helping patients understand, but don't have time, tools, or training.

2. Explore Broader Contexts

- In mentorship: roles develop gradually through trust and shared expectations.
- In onboarding: people are introduced to systems through guided learning, not full responsibility on day one.
- In collaborative teamwork: roles are negotiated, not assumed or assigned without context.

3. Create New Frame

- Instead of treating SDM as a one-time information transfer, see it as a co-learning process where both parties adjust and grow into their roles.
- Build a relational foundation that supports patient confidence and allows HCPs to share responsibility without being sole motivators.

5.5.10. RESULTING SOLUTION SPACES**"Motivation as a Systemic Effort, Not Just an HCP Task"**

Instead of placing the burden on HCPs to "motivate" patients, SDM should be built into the healthcare system as structured, continuous support.

Patients don't just receive encouragement, they get tailored assistance that enables them to participate at their own pace.

Instead of seeing HCPs as information providers, they are part of a broader support network that adapts to patients' needs and capabilities throughout their treatment journey.

SDM becomes about building confidence through structured support rather than expecting patients to take responsibility alone.

5.6. The Belief Barrier

When patients' religious, cultural or personal beliefs conflict with standard treatment options, discussions with healthcare professionals can stall. What was intended to be an informative exchange becomes a dead end, missing the opportunity to explore alternative paths that are more aligned with the patient's worldview.

- Frame the patient's beliefs as inputs, not obstacles.
- Collaboratively explore what treatments can look like within specific belief systems.
- Train HCPs to ask questions like "What does healing mean to you?" as a core intake question.

Problem Definition:

“Sometimes patients reject recommended treatments due to religious or cultural beliefs, making communication difficult.”

Underlying assumptions in this frame:

- Treatment conversations are meant to inform patients of medical options.
- Patients' non-medical reasoning is a barrier to compliance.
- The primary goal is to persuade patients to accept clinically best options.

- Cultural or religious values are outside the scope of the medical consultation.

Resulting Solutions:

- More persuasive communication techniques.
- Culturally adapted patient education materials.
- Referral to chaplains or cultural mediators after resistance arises.

These solutions often come too late and don't address the core problem: that the treatment framework itself is misaligned with the patient's worldview from the outset.

New Frame:

“What if we see treatment conversations not as a moment to deliver options, but as a chance to co-create a care path that respects both medical realities and the patient's beliefs? Then the goal is not just understanding rejection, but building bridges between worldviews and treatments.”

This frame is inspired by interpretive practices used in fields like mediation and diplomacy.

1. Paradox Identified

- Patients may reject treatments based on deeply held beliefs.
- Clinicians see this as resistance, and conversations stall.
- What was supposed to be informative becomes unproductive and frustrating for both sides.

2. Explore Broader Contexts

- In diplomacy, conflicting positions are explored through shared language and layered understanding, not persuasion.
- In community-based design, the starting point is mutual worldview mapping, not prepackaged solutions.

3. New Frame Creation

- Reframe treatment planning as collaborative sense-making rather than choosing from preset options.
- HCPs are not just providers of solutions and information, but interpreters and translators of care within diverse moral and spiritual frameworks of patients.

5.6.11. RESULTING SOLUTION SPACES

Iterative Discovery

A dynamic and co-creative communication process in which healthcare professionals (HCPs) and patients explore treatment options together over time. Instead of delivering static recommendations, care planning becomes an evolving dialogue that adapts as mutual understanding deepens. This approach allows for sensitive integration of patients' cultural, religious, or personal beliefs from the outset, rather than addressing resistance after it arises.

Targeted Information Delivery

Customized delivery of information based on the patient's worldview and belief system. Instead of using generalized education materials, HCPs share only what is relevant, understandable, and meaningful to the patient's context. This enables better alignment between clinical realities and individual value systems, reducing cognitive overload and enhancing trust. Additionally it enables HCPs to ensure consultations become more aligned to the goal of supporting patients in treatment decision making and understanding the situation.

Appendix C: Documentation creative session with mixed group of people

5th of april

facilitator

Problem Owner

Resource Group:

4 people

- a) IDE, DFI
- b) ME, IPD
- c) AE, aerodynamics, worked as a nutritional assistant in a hospital
- d) Psychologist, neuropsychology with clinical experience with people with a LHL

Agenda

1. Welcome
2. Icebreaker
3. Introduction: presentation
4. Flower Association
-bio break-
5. Brainstorming
6. Forced fit + random combinations
-break-
7. Clustering

Welcome in the studio: Everyone introduced themselves and chatted for a bit.

The facilitator took the lead and explained the programme/agenda. They explained everyone's roles.

Icebreaker: Everyone was standing up. The facilitator explained the exercise with a stuffed toy: the person that holds the toy introduces themselves and tells about what their dream career was when they were 6 years old. The person who holds the toy throws it to the next person + this person asks the first person a question first and then tells their dream career. And so on.

After this exercise the facilitator asked the resource group to shut their eyes and go back to when they were 6 years old. They underlined the importance of this exercise by stating it's good to go back to our child-mindset, where we postponed judgement ... etc. After the group was asked to open their eyes again, they were asked to jump over a physical line -> to leave their judgement behind.

Introduction:

After this exercise the problem owner started by explaining their problem statement + they gave an explanation about the context.

--- the fire alarm went off ---

The group moved outside and discussed where to go next. They continued in the pulse building. Here the problem owner continued their explanation of the context and problem. The group was able to ask questions afterwards. The goal and context was clear, but they still had a lot of questions and they also thought the problem as given + the goal to ideate for was very broad and quite abstract.

Problem as Given: How can we make people feel confident and safe to participate in the conversation with a healthcare professional?

Flower Association;

The facilitator explained the first exercise: flower association. The participants all contributed and new questions arose. One person asked what kind of ideas the problem owner already had to address the PaP. The PO explained they did not ideate specifically on this PaP yet, as they want to create a portfolio of ideas where multiple touchpoints are addressed. Some people added very random thoughts, others where more specific regarding the subject. For some, it was a confusing exercise, but with a bit more guidance they were able to work on it. The flower was turned around, so people were stimulated to add to the thoughts of others

Discussion of flower association:

After some time the facilitator stopped the FA. There was space for everyone to talk about what they wrote down and why. Some new questions for the problem as perceived arose. The PO gave more context.

First brainstorm

The facilitator rewrote the PaP as a How-to question. Everyone wrote multiple ideas on post-its. After some time the group went back to the IDE faculty to continue the session there. During the walk back to the faculty the RG discussed their ideas.

Second brainstorm

Once back in the studio the group continued the brainstorm. First they discussed a bit about what was talked about during the walk back to the studio. After a while of brainstorming the facilitator helped by giving people two post its of seemingly unrelated ideas to combine. The facilitator also introduced the concept of thinking of ideas that are illegal. After a while the brainstorm was finished.

--- break ---

During the break, the facilitator and PO discussed the progress and they discussed whether there were some directions that need further discovering. The PO thought it would be better to wrap up via clustering, as the time was almost up.

Clustering

Once all RG members returned the group started clustering ideas on a whiteboard by sticking post-its. With a marker they framed the post-its and created names for the clusters. One cluster remained name-less and was marked "other", as this cluster consisted of ideas that couldn't be placed within other clusters.

After the clusters were finished, everyone was asked to share what they feel most enthusiastic about.

Ideas:

Emotional support:

- Crying room
 - o Special room to be alone and process emotions
- Creating space to not have a conversation
- Repeated instructions that it's okay to not understand
- Have a guardian by the patient for comfort

- The guardian only lets through new info, when the old info is repeated by the patient
- Acknowledgement by doctor: it's okay to not know
- Talk about something you're proud of first
 - o Positive vibes to build trust and a positive atmosphere
- Conversations without a face. Talk to the wall
- Holding something comforting during the conversation
- For the "wet" stuff
- Talking about feelings first
- Use hypnosis to make patients ...
- Maatschappelijk werker (social worker)
- Have a psychologist be present

Interactive Toolbox/ User Interaction:

- Emotion buttons to press in the middle of an explanation with alarms
 - o Buttons to press during explanation of the doctor to express how the info makes you feel
- Question ball
 - o Question ball: the doctor can throw a ball and then the patient should ask a question
- Persona's to choose from to communicate how you feel
- Boom diagram with different decisions and outcomes: flowchart
 - o Visualizing the possible decisions and outcomes
- Gamify the entire conversation
- **Explain complex medical terms with interactive elements**
- Use light buttons to tell how confused/ not confused you are
- Mandatory questions to be asked during conversation with personas
- Have user friendly interface to make it easier
- Conversation cue cards

BEEEP

- BEEEEP
- Sensors that measure stress level and make a buzzing sound. -> the more stress the more sound
 - o Sensors that measure the patient's stress levels and beep when they get too high -> then the doctor should pay more attention to the emotional processing etc.

External help lines:

- Calling a help line
- Thinking breaks to process info (w/recaps)
- "Missing information" booklets to choose from before and/or during session
- Assign a confidential person to a patient that has knowledge of both the patients medical situation and cultural background

Recap together:

- Fact sheet with main take aways, fill in together with doctor
- Patient explains doctor listens

Informing:

- Have generalized video elements for explaining
- Lekentaal woordenboek

- Make sure doctors have knowledge of the patient's background and culture
- Educate the patient about the risks of making uninformed choices
- Implement a "domme vraag" (bad question) moment during every doctor consultation
- Have a conversation between patient and doctor to communicate each other's expectations
- Educational flyers in the form of comics
- Beerpong with questions

You're not the only one/ Normalize patient illiteracy:

- Showing w/ evidence that it's normal to be uncertain/ not understand
- Start with stories of other people that had difficulties understanding
- Reality TV show about health literacy issues
- Healthcare professional shares something they found difficult to understand
- Have an app for similar diagnostic questions
- Meeting between doctors and similar patients so they can learn from each other

Something other than a person:

- AI model to answer all the questions
- A somnox to ask questions during the afternoon wait
- AI-buddy to help summarize in easy language

Come prepared (yes, the both of you!)

- Sensors on patient's brain to measure if they feel calm & confident, if not "WHY NOT?"
- Long-term peer pressure towards a decision
- Ask patients to write down questions
- Preparation videos about your possibilities
- Cursus voor artsen (workshop/course for doctors)
- Training docs on how to intimidate patients in asking questions
- Preparation booklet w/ words and concepts explained in simple language, by mail/post

Make it into a spa day:

- White noise – warm noise, to fill the painful silence
- Do drugs together
- Do the consultation both laying down on a sofa
- Drug patients with psychedelic drugs to broaden their horizons
- Cuddle an alpaca
- Take a walk outside together (informal setting)
- Use relaxing background music (the patient chooses)
- Start the day with going to the spa with each other
- Relaxing massage during or before the conversation

Undefined:

- **The salary of the doctors depends on how informed their patients feel**
- Add psychedelic light effects
- Clini-clowns
- Clini clown juggling with question balls

Appendix D: Idea Description, ideation I

In dit bestand worden de inzichten samengevat die het idee (3. Het Idee) hebben gevormd. Er zijn meer inzichten gehaald uit ieder onderzoek. Die inzichten ga ik wel verwerken in mijn thesis of Appendix maar laat ik voor nu achterwege zodat de rode draad die het idee heeft gevormd helder blijft.

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6. Kernpunten probleem:

- **Kanker patiënten met lage gezondheidsvaardigheden hebben vaker achteraf spijt van hun behandeling dan patiënten met hogere gezondheidsvaardigheden.**
- **Mensen met beperkte gezondheidsvaardigheden hebben vaak meer moeite om actief deel te nemen in het besluitvormingsproces; Samen Beslissen (Shared Decision-Making) & gesprekken met zorgverleners.**
- **Zorgverleners hebben moeite met het herkennen van en adequaat reageren op de behoeftes van mensen met lage gezondheidsvaardigheden.**
- **Huidige keuze-ondersteuning is niet geschikt, of wordt niet toegepast/ aangereikt aan mensen met lage gezondheidsvaardigheden.**

Hoewel sommige inzichten uit het project mogelijk toepasbaar zijn in een andere setting, ligt de focus specifiek op de GIOCA-polikliniek (Gastro-Intestinaal Oncologisch Centrum Amsterdam) en de unieke werkwijzen die daar worden gehanteerd. Deze focus maakt het mogelijk om een diepgaand begrip te krijgen van de complexiteit rond behandelbeslissingen bij mensen met beperkte gezondheidsvaardigheden en slokdarm- of maagkanker. De GIOCA-polikliniek en haar betrokkenen worden daarom benaderd als casestudy. Patiënten doorverwezen naar het GIOCA ontvangen op één dag aanvullende diagnostiek, hun diagnose en behandelopties. Hierbij hebben zij gesprekken met alle betrokken zorgverleners die hun informatie en ondersteuning bieden over de situatie en mogelijkheden.

7. Onderzoek inzichten

2.1 Literatuur resultaten

Uit mijn literatuurstudie zijn een aantal punten naar voren gekomen:

- Strategieën om betrokkenheid van patiënten te stimuleren;
 - o Communicatievaardigheden van zorgverleners verbeteren
 - o **Ontwikkelen van op maat gemaakte keuzehulpen met aandacht voor het verduidelijken van waarden.**
 - Met name om het effect van sturend gedrag van zorgverleners te verminderen
 - o Het toepassen van co-creatie benaderingen met belanghebbenden om effectieve interventies te ontwerpen.
- Patiënten baseren hun keuze en in hoeverre zij ergens achter staan vaak op het eerste moment dat zij informatie ontvangen, het is dus essentieel om dit moment goed te laten verlopen.
- Deze benaderingen zijn gericht op het wegnemen van barrières **zoals informatieoverload en het risico op sturend gedrag door zorgprofessionals verminderen.**
 - o Ondersteunen daarmee een meer “equitable” en patiëntgerichte zorg.

2.2 Field Research resultaten

7.6.12. 2.2.1 PATIENT JOURNEY MAP

Voorafgaand aan het literatuuronderzoek heb ik een Patient Journey Map gemaakt om het behandeltraject van maag- en slokdarmkanker patiënten bij de GIOCA in kaart te brengen. Hiervoor zijn interviews met (oud)patiënten met lage gezondheidsvaardigheden en interviews met zorgverleners als input gebruikt.

Verschillende knelpunten en ontwerpmogelijkheden zijn geïdentificeerd en deze zijn samengevat tot 3 belangrijke punten voor verbetering:

1. **Patiënten in staat stellen om met vertrouwen complexe informatie te doorgronden tijdens hun GIOCA-polikliniekdag**, door intuïtieve hulpmiddelen en persoonlijke begeleiding aan te bieden, zodat informatie duidelijk en toegankelijk aanvoelt. **Minder focus op hoe informatie wordt gebracht, meer focus op hoe deze overkomt.**
2. **Een naadloze vervolgervaring creëren na de GIOCA-dag**, waarbij patiënten ondersteund worden in het begrijpen van hun behandelopties, de implicaties ervan kunnen verkennen, **en zich gesterkt voelen om hulp te vragen bij het verfijnen of aanpassen van hun behandeltraject.**
3. **Zorgprofessionals voorzien van innovatieve manieren om de unieke behoeften van patiënten beter te begrijpen en daarop in te spelen**, zodat samenwerking wordt bevorderd en behandelplannen **werkelijk patiëntgericht zijn.**

Naast deze verbeterpunten zijn er ook veel specifieke ontwerpkansen geïdentificeerd. Aangezien deze kansen voortkwamen uit een breed scala aan aangetroffen knelpunten, zijn ze later geclusterd en geordend. Dit resulteerde in een selectie van ontwerpkansen die zijn gebruikt voor verdere oplossingsontwikkeling.

2.2.1 MEELOOPDAG (CONSULTEN GIOCA-DAG)

Ik heb een dag meegelopen met 2 patiënten en hun naasten tijdens hun gesprekken met zorgverleners op de GIOCA dag.

De gesprekken van de ene patiënt heb ik in de ochtend (kennismaking MDL-arts en kennismaking en uitleg met verpleegkundig consulent) gevolgd, de ander in de middag (bespreken behandelopties MDL-arts, bespreken chemotherapie met oncoloog en radiotherapie met radiotherapeut).

- Ook bij een patiënt met waarschijnlijk hogere gezondheidsvaardigheden wordt een belangrijk deel van de behandeling verkeerd begrepen. Dit wordt in een later gesprek verheldert maar zorgt voor zichtbare onrust bij de patiënt.
 - o **Oók voor patiënten met hogere gezondheidsvaardigheden kan het helpen om explicieter te maken hoe die patiënt alles begrijpt en plaatst**
- Alle spreekkamers zijn modulair (worden door een andere poli gebruikt op andere dagen in de week) en bieden geen vaste opslag voor tools als folders en dergelijke.
 - o **Een interventie moet binnen deze werkwijze passen**

2.2.2 MDO (MULTIDISCIPLINAIR OVERLEG)

Ik heb meerdere keren een MDO bijgewoond, waarbij zorgverleners vanuit alle betrokken specialismes samenkomen om patiënten en hun diagnose en behandelopties te bespreken.

- Er is weinig ruimte en houvast om de input die de patiënt in de ochtend heeft gegeven te bespreken.
 - o **Een interventie kan zo worden ontworpen dat deze ondersteuning biedt om de input van de patiënt door te geven tijdens het MDO**
- Wanneer een patiënt duidelijk anders denkt over het advies van een arts wordt er vaak een extra gesprek ingepland om zeker te weten dat de patiënt het advies goed begrijpt en de zorgverlener inzicht krijgt in de motivatie van de patiënt. Hierbij ligt wel de nadruk op dat de zorgverlener de patiënt kan overtuigen en minder op dat de patiënt een weloverwogen besluit maakt samen met de zorgverlener.
 - o **Een interventie kan zo worden ontworpen dat deze een brug vormt tussen patiënt en zorgverlener; waarbij de zorgverlener diens standpunt duidelijker over kan brengen en de patiënt diens waarden en overtuigingen duidelijker kan onderbouwen**

2.3 Co-creatie resultaten

Groep 1: gemengde groep vrouwen Turkse en Nederlandse komaf

Groep 2: groep vrouwen Marokkaanse komaf

Groep 3: groep mannen met Turkse komaf staat nog op de planning

Uit de co-creatie zijn de volgende punten naar voren gekomen:

- Uit beide sessies komt naar voren dat deelnemers het belangrijk vinden dat de zorgverleners meer **ruimte maken voor de patiënt in een gesprek**:
 - o Veel deelnemers vinden het prettig wanneer er eerst meer aandacht gaat naar kennismaking (voor een gevoel van vertrouwen en het verminderen van stress en onzekerheid)
 - Groep 1 (S1 & S2)
 - De interventie kan de kennismaking tussen patiënt en zorgverlener ondersteunen
 - De interventie kan stress en onzekerheid wegnemen door een gevoel van vertrouwen te stimuleren
 - o Een arts moet meer ruimte maken voor de patiënt door meer stiltes te laten vallen en duidelijk ruimte maken voor de patiënt (en naasten) om vragen te stellen. Veel mensen hebben moeite om deel te nemen in het gesprek en denken ná het gesprek pas echt na over vragen.
 - Groep 2 (S2)
 - Initiatief moet hierbij vanuit de arts komen voor een groot deel van de groep
 - Groep 2 (S1)
 - De interventie kan de zorgverlener er aan herinneren om pauzes/stiltes in te lassen tijdens een gesprek, zodat de patiënt tijd heeft om informatie te werken
 - De interventie dient naast deze pauze, ook de zorgverlener er aan te herinneren dat die ruimte voor vragen creëert bij de patiënt
 - De interventie dient reflectie te ondersteunen, zodat patiënten ná hun ziekenhuisbezoek over de keuze kunnen reflecteren
 - De interventie dient een overzicht te bieden van de besproken informatie, zodat deze ondersteuning kan bieden bij het nabespreken met dierbaren.
- Meer **ondersteuning** bij het omgaan met **stress en onzekerheid**, ook tussen afspraken door
 - Groep 2 (S1&S2)
 - o Zo snel mogelijk een volledig beeld krijgen van mogelijkheden binnen de situatie kan daarbij helpen
 - De interventie dient duidelijkheid te bieden welke informatie de patiënt kan verwachten te ontvangen
 - Groep 2 (S1)
 - o Steun van zorgverleners kan hierbij helpen, die kunnen je meer op je gemak stellen en een gevoel van vertrouwen geven.
 - Groep 1 (S1 & S2)
 - De interventie dient zorgverleners te stimuleren en te ondersteunen op een manier die bij hen past om de patiënt op diens gemak te stellen
- **Iedereen maakt op een andere manier keuzes en heeft andere ondersteuning nodig**. Wat precies nodig is, wordt vaak wanneer de situatie daar is (en de diagnose en opties bekend zijn) pas echt helder.

Echter komt er op die momenten zo veel op iemand af dat het moeilijk is om het overzicht te behouden.

- Uit discussies met zowel Groep 1 als Groep 2 tijdens sessie 2
- Het kan helpen om **van te voren te bespreken hoe iemand er zelf over denkt** en daarna pas met de arts te bespreken wat medisch gezien mogelijk is .
 - Groep 2 (S2) Hierbij vond de deelnemster die dit opmerkte het wel heel lastig om te bedenken wat nou een goede volgorde is. Doordat je pas dingen goed kan voorstellen als de situatie er echt is, maar als de arts je dan overspoelt met informatie is het lastig om nog met je eigen ideeën en vragen te komen daarna.
 - De interventie dient te ondersteunen bij het verhelderen van waarden vóórdat de patiënt wordt geïnformeerd over behandelopties
 - De interventie dient de waardeverheldering uit het gesprek vóór het bespreken van behandelopties over te dragen náár het gesprek waarin behandelopties worden besproken.
 - Zo heeft de zorgverlener die dit gesprek leidt een beeld van het denkkader van de patiënt en kan de informatie hierin geplaatst worden
 - Zo heeft de patient een houvast om diens perspectief te kunnen delen in het gesprek
 - Zo is de patient voorbereid om na te denken over diens waarden en kan deze gemakkelijker diens waarden delen nadat deze overspoeld is met informatie.
- **Afbeeldingen** zijn voor de één heel **verhelderend** en fijn. Bij de ander roepen ze vooral **negatieve emoties** op; kinderachtig en een gevoel van niet serieus worden genomen.
 - Groep 1 (S2) Hier merkte een deelnemer op: “Dit plaatje moet er in, dat biedt gespreksstof.” -> met andere woorden; het biedt houvast om ergens een vraag over te kunnen stellen of over te praten.
 - Groep 2 (S2)
 - **Plaatjes dienen abstract en informatief te zijn op de tool**
- **Gesprekken** over **end-of-life** kunnen **verhelderen** en een gevoel van rust geven, er zijn instanties die dit goed doen (Curia Hospice en MVE)
 - Groep 1 (S2)
 - **Vanuit de doelgroep is er een behoefte om onzekerheden als end-of-life gesprekken te verhelderen vóórdat deze aan de orde komen. Daarnaast spreken zij uit dat, ondanks dat het moeilijk is om hier over na te denken wanneer de situatie nog niet daar is, zij het wél “een prettig idee” vinden en het hun rust brengt en helpt om wanneer de situatie wel daar is te kunnen handelen. “Wanneer het opeens zover is overkomt het je, dan kun je daar niet goed over nadenken”**
- **Behandelbelasting en ziektebelasting communiceren** is lastig. Iedereen interpreteert begrippen anders en doet dit vaak aan de hand hun eigen denkbeeld, gevormd door religie, cultuur en/of eerdere ervaringen (van henzelf of uit de omgeving), die niet altijd vergelijkbaar zijn of in lijn zijn met medisch/academisch bewijs.

- **Kansen:** vanuit groep 2 is er geen behoefte om kansen te bespreken. Zij zien dat als iets dat gebaseerd is op informatie van anderen uit het verleden, de toekomst ligt voor hun in de handen van Allah.
 - Groep 2 (S2)
 - De interventie dient veelgebruikte termen te verkennen met de patiënt, zodat er gezocht kan worden naar een andere formulering en benadering van de term die binnen het denkbeeld van de patiënt past.
 - Zo kan de patiënt de informatie beter plaatsen en wordt er voorkomen dat de patiënt zich extra ongemakkelijk, ongehoord of niet gerespecteerd voelt
- Wel zijn er een aantal deelnemers die bespreken hoe de **(mogelijke) ziektebelasting** van de ene vorm van kanker heel anders is dan de ander en het goed is om hiervan op de hoogte te zijn bij het bespreken van mogelijkheden.
 - Groep 2 (S2)
 - De interventie dient te ondersteunen in het communiceren van de (mogelijke) ziektebelasting en behandelbelasting
 - Zo kan de patiënt, zonder dat deze “voorspellende” begrippen hoeft te begrijpen en beeld krijgen van de situatie en hoe deze zich mogelijk ontwikkelt
- **Gegeven voor en nadelen:** soms worden voordelen ervaren als nadelen. Bijvoorbeeld: *een voordeel van een operatie is dat de kans dat de tumor volledig verwijderd wordt het grootste is*. Deelnemer reageert hierop met: “dit vindt ik geen voordeel want nu weet je dat de tumor dus ook vaak niet volledig verwijderd wordt.”
 - Groep 2 (S2)
 - Voor- en nadelen kunnen niet zomaar als voor- en nadelen gepresenteerd worden: iedere patiënt interpreteert dit anders: het echte voordeel-> namelijk de kans op genezing is hoger, dient duidelijk te worden gecommuniceerd-daarna pas toelichting in hoe de behandeling dit mogelijk maakt. Doordat het voordeel als iets met ruime interpretatie wordt gepresenteerd, wordt dat ook gedaan.
 - De interventie dient voor-en nadelen te kunnen herschikken- afhankelijk van hoe het gesprek zich ontwikkelt
- De voorkeur gaat uit naar keuzeondersteuning/ informatie ondersteuning in niet-digitale vorm
 - De interventie dient analoog te zijn, of een analoge versie te hebben
 - Groep 1 (S1)

8. Het Idee

Achtergrond: wat patiënten met lage gezondheidsvaardigheden nodig hebben

Deze groep is heel divers, de oorzaken voor lage gezondheidsvaardigheden verschillen en zo ook de behoeften.

Een aantal kernbehoeften komen steeds terug:

- **Meer ruimte voor kennismaking en dialoog**
→ Mensen voelen zich dan veiliger, durven meer te zeggen, ervaren minder stress
- **Behoeftte aan duidelijke informatie**
→ Wat ‘duidelijk’ is, verschilt per persoon – daarom is het belangrijk eerst te verkennen wat voor deze patiënt werkt
- **Zorgverleners hebben vaak moeite om gezondheidsvaardigheden te herkennen**
→ De tool helpt ook hen om communicatie beter af te stemmen

Nog vóór het bespreken van diagnose en behandelkeuzes voert de verpleegkundig consulent een gesprek met de patiënt, ondersteund door een fysieke tool in de spreekkamer. Deze tool helpt om samen te verkennen **hoe de patiënt in de situatie staat en hoe diegene keuzes wil maken.**

'priming' voor wat nog komt

Het gesprek dient als voorbereiding op de rest van de dag. Patiënten worden gestimuleerd om na te denken over hoe zij keuzes willen maken. Hierdoor:

- Zijn ze beter voorbereid op gesprekken die nog volgen
- Weten ze wat ze kunnen verwachten en heerst er minder onzekerheid en verwarring
- Voelen ze zich meer betrokken bij het proces en worden ze "empowered" om deel te nemen in het gesprek

Inhoud van het gesprek

Kennismaking en geruststelling

Het gesprek begint met een laagdrempelige kennismaking:

"Hoe gaat het met u? Hoe kijkt u aan tegen deze dag?"

Zo ontstaat een veilige sfeer waarin mensen zich vrijer voelen om hun zorgen of voorkeuren te delen.

Uitleg over het keuzeproces

De zorgverlener maakt duidelijk dat het die dag draait om het maken van een persoonlijke keuze.

"Iedereen maakt keuzes op een andere manier. Sommigen willen alles tot in detail weten, anderen liever alleen de hoofdlijnen. Samen gaan we verkennen wat voor ú werkt."

Verkenning van waarden en informatiebehoeften

De patiënt denkt na over begrippen zoals 'kans' of 'risico', en hoe die deze interpreteert. Dit helpt de zorgverlener een beeld te krijgen van het denkbeeld van de patiënt. Samen bespreken ze:

- Wat vindt de patiënt belangrijk? (waarde-verheldering)
- Hoeveel (niveau van detail) en welke informatie (op welke manier geframed) wil de patiënt ontvangen?
 - Uit de co-creatie werd duidelijk dat de mogelijke gevolgen van een behandeling framen aan de hand van kansen voor sommige religieuze mensen niet effectief is. Deze mogelijke gevolgen moeten op een manier duidelijk worden gemaakt die beter in het denkbeeld van deze groep past. -> hoe dit precies kan moet ik nog verder uitzoeken.
- Wat zijn de gezondheidsvaardigheden van de patiënt?
 - Doordat er verschillende begrippen en de interpretatie daarvan door de patiënt worden besproken kan de zorgverlener een beeld krijgen van de informatiebehoefte van de patiënt.

Doel en functie van de tool

De tool is een visueel hulpmiddel om:

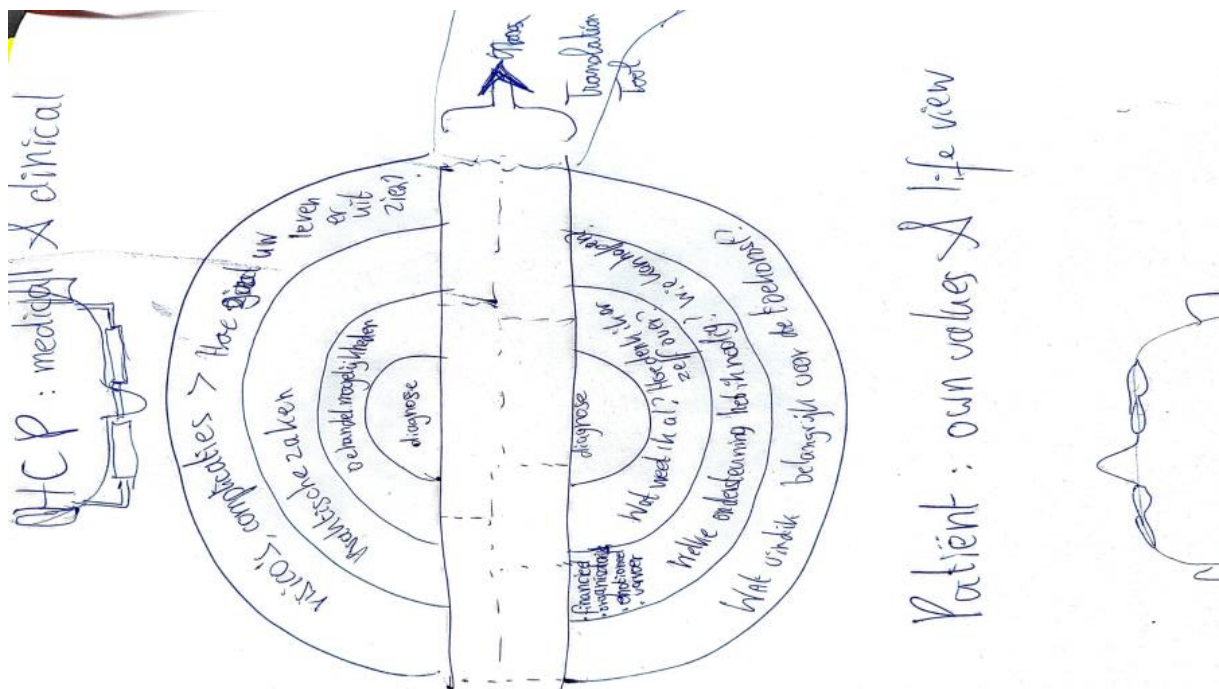
- **Houvast te geven aan patiënten**
 - Helpt structuur aan te brengen in informatie, gepersonaliseerd op de behoeften van de patiënt
 - Biedt overzicht van wat er besproken gaat worden deze dag: werkt als priming; voorbereiding voor de patiënt op wat er nog gaat komen.
 - Maakt het makkelijker om vragen te stellen of input te geven later op de dag in andere gesprekken
 - Versterkt het gevoel van controle, verlaagt stress

- **Ondersteuning te bieden aan zorgverleners**

- Inzicht in de informatiebehoefte en gezondheidsvaardigheden van patiënten
- Houvast voor gespreksvoering
- Suggestie om de resultaten van het vormgeven van de tool tijdens het gesprek met de verpleegkundig consulent over te brengen naar de andere zorgverleners: *Tijdens het MDO kan de verpleegkundig consulent informatie doorgeven aan andere zorgverleners, zodat zij hun communicatie kunnen afstemmen op de patiënt*

Een eerste schets hoe dit er uit zou kunnen zien:

De bedoeling is dat dit een interactieve tool wordt die overzicht biedt welke informatie zorgverleners kunnen bieden en welke kennis een patiënt kan delen om deze informatie te kunnen plaatsen. Er zullen meer visuele elementen aan toegevoegd worden.



Samen Beslissen

Dit concept is gebaseerd op het vierstappenmodel voor *Samen Beslissen* (Shared Decision-Making). In dit model wordt echter stap 3 (*Bespreken van voorkeuren*) al zoveel mogelijk vóór stap 2 (*Toelichten van opties*) geïntroduceerd. Dit gebeurt met als doel de stress bij de patiënt te verminderen: de patiënt wordt beter voorbereid op wat komen gaat, weet wat die kan verwachten en welke rol die kan innemen in het gesprek. Uit diverse inzichten blijkt dat mensen met beperkte gezondheidsvaardigheden sneller overweldigd raken tijdens stap 2, waardoor stap 3 vaak nauwelijks of slechts beperkt aan bod komt. Daarom wordt de tool ingezet als houvast voor de patiënt, zodat deze diens waarden en voorkeuren beter kan uiten ná stap 2. Daarnaast is het de bedoeling dat er nog een stap 0 (*Begrijpen van diagnose*) en stap 6 (*reflecteren op het maken van de keuze*) in het concept wordt geïntegreerd.

Appendix E: Concept and evaluation description

Perspective Mapping

Decision-making support as a product-service system

Inhoud

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8.7. Concept Description with concise reasoning

Perspective Mapping consists of four main components:

- A: the perspective map physical toolkit,
- B: the digital environment,
- C: the machine learning model,
- D: the library of tools and strategies.

8.7.13. PART A: FICHES & FRAMEWORK

A physical interactive toolkit that supports communication between HCPs and patients during consultations.

Purpose & Use Cases

1. Facilitate more effective introductory conversations

- a) Support HCPs in stimulating patients to express their needs and perspective; to enable more effective communication
- b) Create space for the patient's perspective and encourage a more personal, human-centered approach.
- c) Empower patients to take an active role in the conversation by providing accessible, interactive tools.
- d) Prime patients for shared decision-making by introducing the overall decision-making process and helping them reflect on the role they prefer to take within it.
- e) Provide a preview of the key topics that will be covered in subsequent consultations to build clarity and set expectations.
- f) Offer the patient a visual roadmap of the care journey and what information to expect to receive in future consultations, helping reduce stress by enhancing predictability and understanding.

2. Gain Insight Into the Patient's Information Needs and Life View

- a) Ensure that the patient's values and preferences are represented during the Multidisciplinary Team Meeting (MDO) and factored into treatment decisions.
- b) Enable more effective consultations by tailoring communication and information provision to the patient's worldview, preferred level of detail, and comprehension style: using appropriate tools and strategies to relate treatment-specific information to their values and needs.
 - a. *Including the use of supportive tools to represent outcome information, like the SOURCE tool*

3. Foster a Learning Environment for Both Patient and Healthcare Professional

- a) Support healthcare professionals in selecting appropriate communication strategies for specific situations, and help them reflect on these experiences to reduce cognitive load and improve efficiency in future consultations.
- b) Make the decision-making process more tangible and explicit by visualizing trade-offs in relation the patient's perspective: supporting patient comprehension.
- c) Facilitate a step-by-step, iterative decision-making process between the patient/ their next of kin, and the HCP: improving clarity and retention of information.
- d) Support patient reflection and learning throughout the process to help them become more confident and better prepared for future healthcare decisions.

8.7.14. PART B: DIGITAL ENVIRONMENT

The digital interface is designed to support healthcare professionals by offering tailored guidance and strategies that match each patient's needs. Its goal is to reduce cognitive load while preserving space for authentic, human-centered interactions: enabled by technology, not constrained by it. It consists of a digital environment integrated into Epic (electronic patient dossier), designed to support HCPs by providing:

- a) Clear instructions on how to use perspective mapping during consultations
- b) Step-by-step guidance on how to apply the communication strategies and tools in consultations. (suggested by the Machine Learning element in the application, based on the patient's worldview, information needs, and comprehension style)
- c) Example questions to explore values, preferences, information needs, and decision-making roles. Including instructions on how to utilize the map to summarize answers.
- d) A space to document and store generated perspective maps
- e) **Functionality to share insights with colleagues**, supporting knowledge transfer on patient perspectives and needs. This enables colleagues to apply the communication strategies and tools recommended by the perspective map.
- f) Functionality to generate a list of suitable resources the patient can take home with them as an addition to the general information all patients receive
- g) **Support for implementation during the Multidisciplinary Team Meeting** by making patient-specific insights accessible and actionable in the decision-making process and discussions during the meeting.

8.7.15. PART C: MACHINE LEARNING MODEL

A machine learning model that analyzes existing patient data to generate an advice for personalized, actionable communication strategies and suggests appropriate tools for use during medical consultations as well as a list of resources for the patient to look up at home, tailored to their information needs.

The model uses the results of the perspective map as input to recommend personalized communication strategies and tools that align with the patient's values, information needs, and comprehension style. This supports healthcare professionals in delivering more effective, patient-centered consultations, including tailored approaches to presenting outcome information.

Purpose & Use Cases

1. **Support the representation of the patient's perspective and needs during the MDO**
 - a. Translate insights from the perspective map into clear, actionable talking points that reflect the patient's values, preferences, and priorities.
 - b. Help healthcare professionals identify whether the patient requires additional support based on their level of uncertainty or understanding. Such as; follow-up consultations (specifying with whom and for what) or referrals to appropriate support services (websites, videos etc.).
2. **Guide and assist HCPs in informing patients during consultations**
 - a. Convert the patient's perspective into concrete communication strategies and tools that healthcare professionals can apply, enabling more tailored and effective consultations.
3. **Safeguard and transfer patient-centered communication and decision-making expertise**
 - a. Document the implicit, experience-based communication strategies used by HCPs and turn them into practical guidance and tools, ensuring that this knowledge is preserved and accessible for onboarding and training new staff.

8.7.16. PART D: LIBRARY OF PHYSICAL/DIGITAL INFORMATION TOOLS

A digital documentation of information and communication tools and strategies.

Part C: Machine Learning model, utilizes the results from perspective mapping (Part A: fiches & framework) as input to generate a suggestion for communication/information strategies and tools as output. The goal of the library is to enable a tailored approach. Next to that it enables knowledge exchange and overview for all HCPs.

- Flyers, websites, videos, SOURCE etc.
- Information summary templates that can be filled in together during consultations (example)
- Supporting images to explain the esophagus resection e.g.
- Templates to draw on during consultations, to support an interactive and visual communication style
- Instructions on how to communicate with people with limited cognitive abilities or people who speak the language minimally (provide more pauses, actively ask questions in-between information, etc.)

8.8. Overview of Concept components and prototypes for Evaluation

Will be evaluated through enactment: Sophie + HCP	
Will be discussed with experts	
Not feasible to evaluate within the given time and resources	Ideas for evaluating and implementation will be provided in the recommendations

Component	Testable Interaction	Prototype	Visualization
A: physical Toolkit <i>HCP & patient</i>	Introductory conversation	Framework & fiches	Introduction conversation, and first interaction with perspective map
	Decision-making roles & process		Explanation of decision-making process and priming/ asking questions
	Perspective Mapping		Iteratively asking questions and answering them
	Clinical information, explained through perspective mapping	Perspective map together with suggestions for tools and strategies	Iteratively discussing information, asking questions and adapting the perspective map
B: Digital Environment <i>HCP & environment</i>	Not a priority at this stage	Perspective mapping instructions	HCP receiving instructions in environment
	Not a priority at this stage	Example questions to use during consultation to build perspective map	HCP viewing example questions (during consultation?) - on a physical card
	Upload perspective map in digital environment	Upload perspective map in digital environment	Upload perspective map in digital environment
	Discussion based on representation	Representation for MDO	Representation for MDO
	Perspective map preparation for consultation	Perspective map preparation for consultation	Perspective map preparation for consultation

C: ML-models <i>Digital processes with no human (with HCP or patient) interaction</i>	X	X	<i>flowchart</i> <u>Image classification/ object detection</u> Data input: perspective map picture, containing multiple “objects” Data output: “Class Labels” e.g. characteristics (needs and life view)
	x	x	<i>flowchart</i> <u>Retrieval-Based Machine Learning Model</u> Input Classification: The model classifies the input (class labels) to identify the appropriate context or category. Embedding-Based Retrieval: It uses learned relationships (e.g., through deep learning embeddings) to find related entries in a large vector database (e.g., FAISS, Pinecone). Instruction Mapping / Output Generation: It retrieves and possibly ranks or selects the best-matching instruction(s) from a stored set, learned during training.
D: Library of tools & strategies		Example of tool from the library	Summary flyer
		Example of strategy suggestions	Pop-up and instructions

	Definition	Focus	Example
Feasibility	refers to the practicality of a project or idea, considering technical, operational, and resource constraints.	It addresses the question of whether something can be done given the current state of technology, resources, and operational capabilities.	Can the product be built with existing technology? Do we have the necessary skills and resources? Are there any legal or regulatory hurdles?

Viability	refers to the financial sustainability and profitability of a project or idea.	It addresses whether the project or idea can generate enough revenue to cover its costs and make a profit.	Will the product be profitable? Does it align with the organizations' goals? Is there a sustainable market for it?
Desirability	refers to whether a product or idea meets a user need or desire.	It addresses whether there is a market for the product and if people will actually want to use it.	Does the product solve a real user problem? Will people be interested in using it? Is it something that customers will value?

From (IDEO's *Desirability, Viability, Feasibility Framework: A Practical Guide - Make:Iterate*, 2023)

Why these are important:

- **Holistic Assessment:**

These three factors provide a comprehensive framework for evaluating the potential of a project or idea.

- **Risk Mitigation:**

By considering these factors early on, potential problems can be identified and addressed before significant resources are invested.

8.9. Evaluation Overview per stakeholder and concept component

Overall concept	P2	P3	P1	HCP	Patient*
Feasibility	x (regulations)	x (technical)	x both		
Viability	x		x		
Desirability	x		x	x	x

**Within this stage of concept development it is not necessary to involve patients. The first priority is to evaluate feasibility, viability and desirability with HCPs and experts. Patients can be involved at a later stage, when input from experts and HCPs is implemented. The concept is substantiated by evidence gathered from the co-creation sessions and qualitative insights from patient interviews conducted as part of the Patient Journey Mapping process.*

Per Component	P2	P3	P1	HCP	Patient*
A: Physical Toolkit	x		x	X	
B: Digital Environment	x		x	X	
C: ML-models		x	x		
D: Library of tools & strategies	x		x	X	

