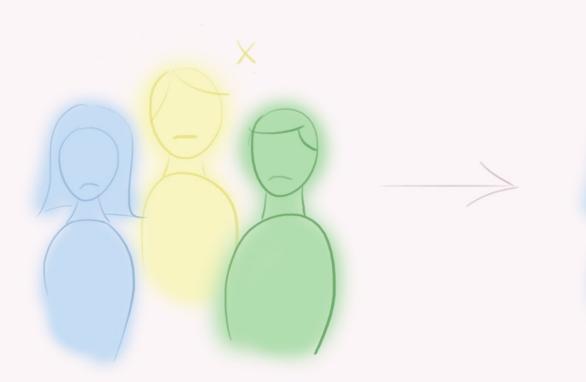
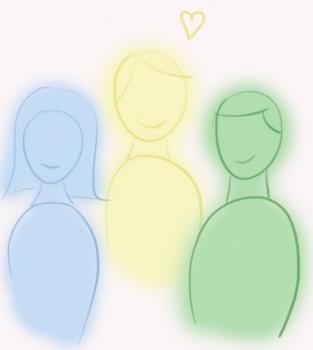
# Centering your story

A tool that helps youth, parents and practitioners map their shared story to bring stagnated psychiatric treatment back into motion







Master Thesis

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#### **Master Thesis**

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## **Preface**

This project is especially meaningful to me due to my ongoing interest in psychology and psychiatric care. Even before starting my studies in Industrial Design Engineering, I was drawn to topics related to mental wellbeing, emotions, and human interaction. Throughout my academic career, I have explored these themes in various projects. My internship at Ink Social Design further deepened this interest, since it allowed me to experience the connection between design and psychiatric care – an area I was eager to explore further. This project 'Jouw Verhaal Nu Centraal' (further in the report referred to as 'Centering Your Story') in collaboration with LUMC-Curium is a multifaceted project with experts from different fields, combining social design and psychiatric care and where research plays a prominent role. The focus lies on youth, parents and practitioners who experience stagnation in their treatments and helping them bring the treatment into motion again. Making a difference and helping those involved has become a clear mission for me, and something I have pursued with deep commitment and care throughout the project.

# Acknowledgements

I would like to dedicate this section to everyone who has been there for me and supported me during this final chapter of my study journey.

I want to thank my Chair, Judith Rietjens, for always making me feel confident after every meeting and sharing her wisdom with me about research, healthcare and life.

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I want to thank my company mentor, Paul Gelissen, who was always ready to answer my questions and concerns, for connecting me with so many interesting people and giving me the space to take charge of the project meetings.

A thank you goes out to thank the Curium project group, who always left me feeling more inspired than before.

I want to thank my family for always encouraging me to take breaks and supporting me. Your belief in me gave me strength and made it easier to overcome challenges.

Finally, I would like to thank my friends for just being there, going through this period together and providing distraction whenever needed. Having you by my side motivated me.

## **Abstract**

This report aims to present an overview of the design thesis based on Centering Your Story, presenting the research and design activities conducted during the course of the thesis project and how it helped shape decisions and final design.

The project started with a literature review exploring the field of psychiatric care and youth with severe and enduring mental health problems as well as learning about the meaning, causes and impact of stagnation in treatment.

Firstly, characteristics of youth with Severe and Enduring Mental Health Problems were identified in order to gain insights into the challenges they face, their vulnerability and factors that influence them.

Secondly, the phenomenon of stagnation was examined with the focus on causes for stagnation and treatment failure in order to understand the root of the problem.

Additionally, literature on collaboration in therapeutic settings was reviewed to gain insights into the lack of collaboration, what might help facilitate open communication and better collaboration.

Since The Story is a crucial part of the design thesis and the final design, there is a section reflecting on what it should consist of and what the different existing definitions of narratives contain that could contribute to the story in the design.

A selection of the research done by Curium was analysed and insights were gathered. Youth and parents emphasize the importance of considering background and environmental factors. Additionally, a personal vision from the youth is needed for creating the story as well as giving youth a voice and autonomy.

Subsequently, design directions were defined, and refined with the Curium project group. After being translated into conceptual directions, they were presented at co-creation I to the project group. Then, ideas were generated, based on criteria and inspired by suggestions from the co-creation. Three elaborate ideas were chosen to conceptualise.

The concepts were presented to the Curium project group, and feedback was used for refining concepts and designing mock-ups. The concepts and mock-ups were then presented and tested with the target group in co-creation II. The feedback given by the target group was used to combine concepts and design the final prototype for the design thesis.

Finally, the prototype was designed: Verbonden. Verbonden is a playful and creative way of mapping personal stories and the shared story of youth, parents and practitioners who are experiencing stagnation in treatment. The goal is to break tension, empower youth and help users gain a better understanding of each other by mapping their stories.

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## 1 Introduction

This chapter provides an introduction to the main themes and challenges of the project by outlining the background, problem definition and approach to the project. Appendix A includes the approved project brief as a concise version of this chapter.

This design thesis was developed within the broader project of Centering Your Story, executed by LUMC Curium. In this report, *Centering Your Story* refers to the overarching project, while *the design thesis* refers to the individual graduation work within that context.

## 1.1 Background

This project was proposed by LUMC-Curium in collaboration with TU Delft and focuses on the field of psychiatry, addressing challenges youth with Severe and Enduring Mental Health Problems (SEMHP) face in treatment, specifically in terms of stagnation. Stagnation is a recurring problem and creates significant complications in the lives of youth, their parents and practitioners. It occurs when youth, parents and practitioners do not see progress in the treatment and feel stuck. In addition to stagnation, challenges youth face in treatment significantly impact their quality of life and Bansema et al. (2023) emphasize the need for a more holistic approach; one that focuses on understanding each individual's unique experience and look beyond classifications.

For this project, called Centering Your Story, the focus lies on youth aged 12 to 21. The goal is to design a method that helps resolve stagnated treatments. One of the key challenges is addressing the needs of all involved parties - youth, practitioner and parents - without compromising any of them. An important aspect is the client-practitioner relationship, which affects the outcome of the treatment greatly in terms of stagnation or even dropout (De Soet et al., 2023). While the youth are the main focus, the roles and perspectives of practitioners and parents are crucial in their treatment and recovery process.

Centering Your Story is an ongoing project that started in 2022. The project started with the goal to bring stagnated psychiatric treatment into motion, and grew into a focus on the personal stories of youth. Extensive research by Curium has already been conducted. This includes a first design sketch, based on literature research, interviews and focus groups. This design sketch illustrates the complete trajectory in chapters, that youth, parent and practitioner will go through in order to improve the situation of stagnated treatments. This design

thesis builds upon key factors that have already been identified in this sketch, including:

- ♦ Three topics that emerged from the research as highly relevant for the project are: Youth Peer Support Workers, Equitable Collaboration and Centering the Story.
- ♦ The trajectory is facilitated by a youth peer support worker and a systemic therapist both external parties who have not been part of the stagnated treatment.
- ♦ The trajectory starts with a commitment phase and working on recovering the relationship between youth, parent and practitioner. The design thesis takes place subsequent to this phase and therefore can assume that all parties are committed and the relationship has been restored to some extent.
- ♦ The phase after the design developed for this thesis is focused on creating a detailed plan for bringing the treatment into motion again; a smooth transition between these phases is essential (LUMC Curium, 2024).

Figure 1 provides an initial overview of the problems and needs of the stakeholders I will be focusing on. Figure 2 shows a number of existing initiatives for stagnated treatment in Child and Adolescent Mental Health Services (CAMHS) psychiatry in LUMC-Curium and other CAMHS-institutions. However, current practices are not engaging youth, parents and practitioners enough, leaving them feeling unheard and misunderstood.

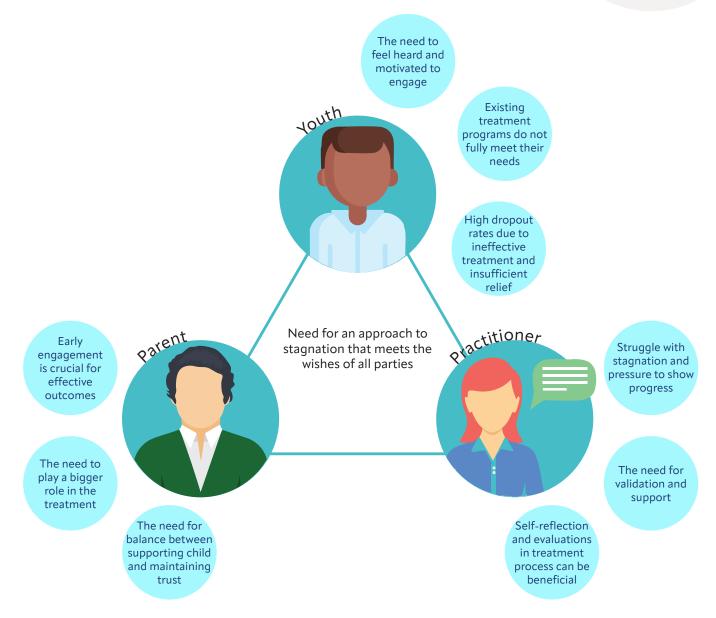


Figure 1: Initial overview of important problems and needs to take into account per stakeholder

The data presented in this figure were informed by project discussions (P. Gelissen, projectgroepoverleg, January 28, 2025), an interview (P. Gelissen, personal communication, February 3, 2025) and supported by findings from Brimblecombe et al. (2015), De Soet et al. (2023), Hassett et al. (2018), and Vijverberg (2022).



#### Second opinion

Another practitioner from within the institution gives their professional advice on an issue.



#### Collaboration between institutions

Regionaal Expertteam (RET) (Dutch)

Discussion with experts from different youth care providers (core team). The goal is to make sure that every child gets the care they need on short term, regardless of its complexity.

#### Doorbraakmethode (Dutch)

Improvement method where teams from different healthcare institutions collaborate to realise concrete improvements in care.



#### Centrum Consultatie en Expertise (CCE)

Dutch organisation that provides expertise and consultation for complex care situations, offering an outside perspective.



#### Social network

Eigen Kracht Conferentie (Dutch)

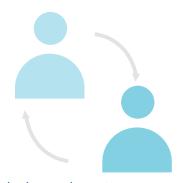
Assembly where the social network of the patient is used to form a future plan. A coordinator organises and facilitates the assembly.



#### Intervision/supervision

Moreel Beraad (Dutch)

Conversation where practitioners talk through an ethical issue at their job, using a conversation method in order to resolve the issue together.



#### Negative interaction pattern

Nonviolent Resistance (NVR)

A method that can be applied by parents with children showing harmful behaviour. The goal is to get a grip on handling harmful behaviour. Practitioners get a training to work with this method. Curium offers courses to the parents.

#### Willem Kleine Schaars (Dutch)

This method resolves a negative interaction pattern, usually in clinics. It works with different roles of the treatment team members:

- Agent; set goals and give assignment
- Process consultant; talk through difficult topics
- Supporter; daily support and questions

**Figure 2:** Some of the existing initiatives used in treatment and for stagnated treatment in youth-psychiatry, the initiatives that are not used by Curium are coloured light blue

The data presented in this figure were informed by interviews (P. Gelissen, personal communication, February 3 and 17, 2025) and supported by findings from (Dwang En Drang in De GGZ, n.d.), (GGZE Sites, n.d.), (Kenniscentrum Phrenos, 2025), (Regionaal Expertteam (RET), n.d.), (Eigen Kracht Centrale, 2019), (Amsterdam UMC, n.d.)

### 1.2 Problem definition

Some CAMHS youth, along with their practitioner, experience a lack of progress in their treatment, leaving them feeling stuck. This stagnation can be particularly stressful and demotivating for such a vulnerable group. Youth often do not feel heard at this stage and the focus seems to lie on the problem rather than the youth's, parents' and practitioners' wants and needs.

Currently, the trajectory that youth, parent and practitioner go through to try bring treatment into motion, does not engage them enough in the process (Figure 2). Youth and parents especially feel unheard, unseen and not taken seriously. There is an opportunity in re-focusing the attention on the personal story, along with the needs and wishes of the youth, offering a new sense of motivation and hope, to contribute to bringing stagnated treatments into motion.

With this design thesis, I would like to put focus on the personal story of youth in their treatment, helping them regain hope and motivation to engage in treatment. At the same time, the design thesis includes parents and practitioners to incorporate their perspectives. The overarching goal is to rebuild trust in the treatment, empower the youth and ease the burden for youth, parents and practitioners.

Figure 3 shows the first iteration of the design statement with its components explained, and Appendix B provides an overview of the designer role.

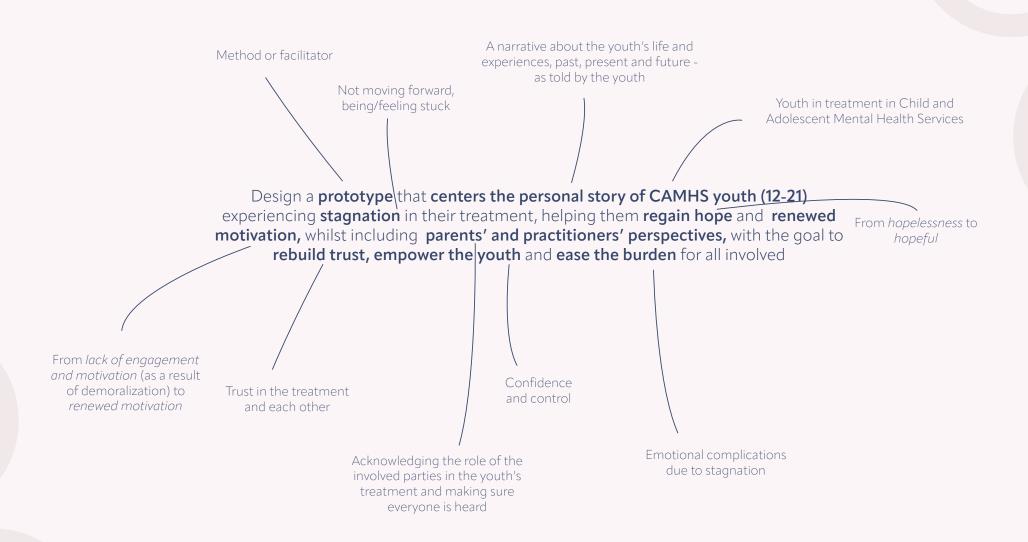


Figure 3: Design statement including all components and goals

## 1.3 Approach

The design thesis has been carried out using a social design approach, putting the target group and all involved parties first. The main focus lies on their wants and needs; which were used as a guideline for designing.

The design thesis was kicked off with an extensive research phase. The research phase plays a prominent role; making myself familiar in the field of psychiatry is crucial and the qualitative data conducted by Curium provide extensive information about the target group and challenges they face (LUMC - Curium, 2024). Then, the design phase started where design directions were identified and tested with the Curium project group. Afterwards, ideas and concepts were generated in the concept development phase. Finally, mock-ups were tested in a co-creation with the target group and the final prototype was developed and evaluated.

The Delft Design Guide was consulted to support my design process throughout the design thesis (Van Boeijen et al., 2020). Figure 4 shows a simplified overview of the approach taken during the design thesis.

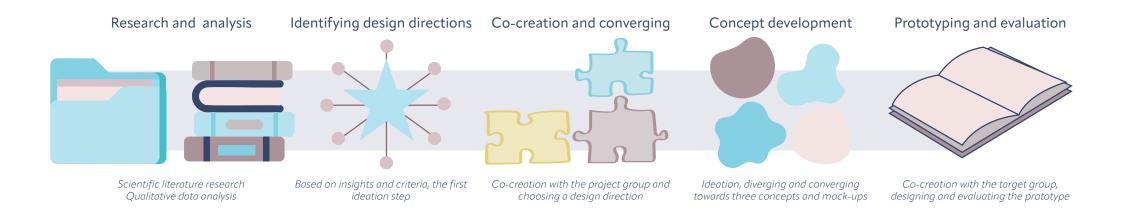


Figure 4: Project approach divided and summarised in different phases

# 2 Mapping the Field and Defining the Story

As the design thesis explores an unfamiliar domain, conducting a scientific literature review was essential to understand the context. Explored areas within the domain include characteristics of youth with severe and enduring mental health problems, psychiatric care, the problem of stagnation and dropout, interactions and collaboration between youth, parents and practitioners and challenges it brought. The key question is:

What are important aspects of psychiatry to keep in mind while designing for youth with severe and enduring mental health problems, in the context of stagnated psychiatric care?

A specific area that was explored further is the story and narratives. To explore the story aspect of the design thesis, qualitative data collected by LUMC, expert talks and interviews, as well as scientific literature on narrative identity were used to answer key questions:

What is the story, why is it important, what is its goal, how is it defined within this design thesis and how should it be applied in the design?

Defining relevant themes for the story for the design thesis, will make the design fit more seamlessly into the project Centering Your Story. The defined story will form the base of the contents of the final prototype that will be tested in practice.

This chapter will discuss the findings and relevant information to refer to further in the project and design thesis.

## 2.1 Approach

The literature research consists of two parts: Mapping the field and Defining The Story.

The reviewed papers for mapping the field were partly provided by the company mentor and the supervisory team, where papers written by LUMC-Curium researchers were included as well as international papers. In addition, an independent literature review was conducted using peer-reviewed articles from various academic journals in the fields of psychiatry and youth mental health. A pragmatic literature scoping approach was applied, focusing on identifying the most relevant and practical studies to inform the design thesis efficiently. Key search terms included: Stagnation, SEMHP youth, Youth Psychiatry, Collaboration, Dropout, Client-practitioner relationship.

The reviewed papers for defining the story were provided by the company mentor and supervisory team, supported by an independent literature search in the field of narratives in therapy and narrative identity. Again, a pragmatic literature scoping was applied. Key search terms included: Narratives, Identity, Youth, Externalisation. This section of the literature research is supported by talks with experts in the field and qualitative data from Curium which was focused on analysis of the story aspects in the axial codes.

To understand the different encountered themes, links between them, what areas to focus on and links to the project Centering Your Story, Miro was used to cluster gathered information to get a clear overview of different sections of researched areas, recurring themes and draw conclusions

### 2.2 SEMHP Characteristics

The focus in this design thesis lies on a specific target group: Youth with Severe and Enduring Mental Health Problems (SEMHP) experiencing stagnation in treatment. This section will discuss characteristics of SEMHP youth and the main problem areas that need to be taken into account when designing.

The age group of youth with SEMHP is defined as 12-25 years old. The current mental health care is not fitting for youth with SEMHP due to its focus on classifications: Youth get multiple classifications and underlying problems and causes fade into the background. The mental health problems youth with SEMHP experience, go beyond traditional classifications, which is why they often experience notable disruption in daily activities paired with severe distress. Some contributing factors include trauma and lack of peer support (Bansema, Vermeiren, De Soet, et al., 2023).

A qualitative study done by Bansema, Vermeiren, Nijland, et al. (2023) discusses the complexity of SEMHP. Youth with SEMHP have multiple and often interrelating mental health problems. Often, those problems do not fit into specific classifications and result in misdiagnoses, undetected mental health problems and unmet needs. Consequently, youth experiencing SEMHP often have negative experiences with previous treatments (De Soet, Vermeiren, et al., 2023).

Youth described masking their mental health problems due to shame or to avoid concerning their environment. This study also mentioned a stressed family system as a persisting factor in youth with SEMHP; for example parents with psychiatric problems. When youth mask or hide their mental health problems, it can result in high-risk behaviour,

which is an interactive process where youth get more trapped in their problems and eventually start masking more. This often gets misinterpreted as a lack of engagement or an aggressive attitude. It is important for practitioners, peers and caregivers to be aware of this and try to identify underlying factors.

In a social context, youth with SEMHP experience a lack of social support and isolate themselves due to a sense of not belonging or as a result of the lack of support. Youth also described the significant impact SEMHP has on their daily lives, disrupting multiple life domains. Participants mentioned experiencing severe problems especially in important life domains (Bansema, Vermeiren, Nijland, et al., 2023).

It is important to keep in mind the vulnerability of the group and challenges they face in order to design an intervention that will fit their needs.

## 2.3 Stagnation and drop-out

An important element of the design thesis is stagnation, which is closely linked with dropout and treatment failure. Stagnation can occur in many different ways and can also lead to dropout, for example due to clients losing hope of getting better. There is not one definition of stagnation, but Curium describes it as a situation in which any one of the three parties, the youth, parent or practitioner, no longer sees the treatment progressing, leading to the conclusion that stagnation is being experienced in treatment. This section will discuss the causes for stagnation, dropout and treatment failure.

### 2.3.1 What causes stagnation and drop-out?

Stagnation can have many different reasons, even when focusing on a group as specific as youth with severe and enduring mental health problems. Some recurring causes will be discussed and their interconnectedness is shown on different levels in Figure 5. The causes are divided into the following layers: Internal, interpersonal and external. The layers help distinguish different areas related to the problems.

Some causes for stagnation and treatment failure include: A lack of epistemic trust, loss of hope after prolonged and multiple admissions without improvements, therapists focusing on specific treatment techniques without considering the fit with the client, neglection of common factors, poor client-therapist match and external factors (McCormick, 2021; De Soet, Vermeiren, et al., 2023; De Soet, Nooteboom, et al., 2023).

If stagnation occurs in early stages, it means that the treatment should be adapted in a more fitting way (McCormick, 2021). However, the focus in this design thesis lies on stagnation where only adapting the treatment will not work anymore, since often, many adjustments have been made until the youth, parents and practitioners came to the point of stagnation.

Dropout in treatment is defined as a client ending mental health treatment before the provider considers the treatment to be complete. Dropout can occur on its own or as a result of stagnation, also depending on the scenario. Many youth drop out during their transition to adulthood. This happens due to a lack of continued engagement (Munson et al., 2014). If youth with severe and enduring mental health problems have had negative experiences in previous

treatments, dropout leads to a loss of hope. Practitioners should take clients' prior experience into account (De Soet, Vermeiren, et al., 2023).

De Soet, Vermeiren, et al. (2023) conducted a systematic review on dropout and ineffective treatment in youth with severe and enduring mental health problems. The failure of treatment among youth is often connected to their broader context and living environment, which affect their capacity to participate in treatment, and the extent to which the treatment aligns with their needs. They discuss that the focus should lie on treatment factors to prevent failure of treatment. They also state that treatment failure is not always the youth or parent's fault in terms of engagement but the solution might be in a better fitting treatment in terms of emotional and practical needs of the youth and parent.

Keeping in mind the different causes will help design an intervention that considers the difficulties youth, parents and practitioners experiencing stagnation have gone through and aligns with their needs at that point in treatment.

#### 2.3.2 Engagement

Engagement plays a role in dropout and stagnation as a lack of engagement can cause treatment failure. This section will discuss the role of engagement in psychiatric treatment.

Youth have a lower chance of improving their mental health if they are not fully engaged. Disengagement is a problem that occurs among youth; only 9% of youth continue treatment after three months. Staudt (2007, as cited by Kim et al., 2012) states that engagement is a continuous process and changes throughout the treatment process.

When youth do not perceive treatment to be helpful, they end up losing motivation and engagement. The disappointment that youth experience due to failing treatments, leads to a loss of trust in improvement, which then leads to disengagement. It is therefore necessary to direct attention to individual strengths and qualities of youth in order to help them reclaim agency over their lives (De Soet, Nooteboom, et al., 2023).

There is a difference between a lack of engagement and a lack of motivation. Youth may need time to feel secure in a new treatment context; this hesitation should not be mistaken for a lack of motivation. There was a direct relationship found between a lack of engagement and high dropout rates, making it even more important for practitioners to detect the difference (De Soet, Vermeiren, et al., 2023).

The importance of making sure youth stay engaged is also of relevance to the design thesis. When they are at a point where all treatments have failed or stagnated, they will be even less motivated to engage, which is a factor to take into consideration.



Figure 5: Stagnation causes in therapy settings

The data presented in this figure were supported by findings from the following literature: (McCormick, 2021) (De Soet, Vermeiren, et al., 2023) (De Soet, Nooteboom, et al., 2023)

### 2.4 Collaboration

Another aspect the research team of Centering Your Story has established as important, is equitable collaboration. This is a crucial part of designing an intervention that addresses stagnation: It should work for all parties involved and support equitable collaboration between them. Equitable collaboration as opposed to collaboration is an important distinction made to clarify that fairness, balance and mutual respect are crucial in the situation of stagnated treatment in youth psychiatric care (LUMC - Curium, 2024).

This section discusses different aspects of collaboration and a lack thereof between youth, parents and practitioners: Transparency, involvement, trust and client-therapist relationships.

### 2.4.1 Transparency

A lack of transparency is a recurring problem in therapy, which often negatively impacts collaboration. This section will discuss situations in which transparency is needed and why it needs to be more prominent in therapeutic settings.

Youth and parents emphasized the importance of practitioners being able to discuss sensitive topics with them, without a risk avoidance approach as a response to high-risk behaviour. The study highlights the importance of giving youth control over their treatment decisions, regardless of the concerns it may evoke among parents and practitioners (De Soet, Nooteboom, et al., 2023).

De Soet, Nooteboom, et al. (2023) also state that youth need transparency. Youth are not informed enough about treatment options, obstacles and risks. Also, they are not able to openly discuss suicidality concerns since usually, there are risk avoidant consequences involved. Having clear agreements with caregivers on communication is of high

importance. Youth see a lack of transparency as an obstacle to regain trust in treatment.

This section highlights the importance of transparency for an equitable collaboration between youth, parent and practitioner. Youth need transparency to feel equal and part of the collaboration rather than feeling like the patient that is being treated. Transparency can facilitate open collaboration among all involved parties and the design will include methods to ensure transparency both between and towards all parties.

#### 2.4.2 Involvement

Involvement of youth in treatment decisions influences the way they experience psychiatric treatment. A lack of involvement often means there is a lack of collaboration, as not all parties are equally involved in the treatment or decision making process, leaving some excluded from important matters. This section discusses implications when there is a lack of involvement

In a study done by Simmons et al. (2011) on decision making, youth's experiences of involvement often did not match their preferred level of involvement. The study also made a distinction between being involved in the decision making process and making the final decision. The youth had different preferences in terms of level of involvement but all expressed they would like to be involved at least some of the time.

This goes hand in hand with autonomy and wanting to feel in control. Youth linked knowledge about their treatment to being in control (Bjønness et al., 2020). Autonomy for youth is also a dilemma in therapy: According to practitioners, there should be a balance between directing

and clarifying while recognizing their hopelessness and accepting potential consequences of high-risk behaviour, which means it is best to allow youth to make their own choices. Caregivers disagree on this matter and think that restricting autonomy is necessary for protecting youth from their environment (De Soet, Nooteboom, et al., 2023).

Caregivers experienced a lack of involvement as well; they were often not consulted about decisions in treatment, which resulted in a feeling of confusion and exclusion from the treatment (Bjønness et al., 2020).

Sheikh et al. (2024) state that empowering youth to actively participate in decisions in mental healthcare is important. Youth should have the autonomy to choose the type of support they need, while families and practitioners provide support and guidance.

An important insight from the literature is the need to empower youth by giving them more control over their treatment, allowing them to make decisions on their own or be actively involved.

### 2.4.3 Client-practitioner relationship

The relationship between the youth and practitioner is one of the key factors affecting the course of the treatment and collaboration between all parties, including caregivers. This section discusses some aspects of a client-practitioner relationship.

A research was done proving the importance of epistemic trust –"The degree to which a person trusts the relevance and reliability of the knowledge offered by the other" as defined by Fonagy & Allison (2014). The research concludes the importance of epistemic trust for treatment success. Youth with SEMHP usually exhibit low levels of epistemic trust. With SEMHP, the risk of treatment failure is enhanced,

which may also support the lack of epistemic trust. For practitioners, a lack of trust in the treatment or therapist makes it difficult to treat youth. Solutions are best found in relationships based on trust, where collaboration and ongoing care are central (De Soet, Nooteboom, et al., 2023). De Soet, Vermeiren, et al. (2023) state that in order to regain trust, a genuine therapeutic relationship is crucial.

According to Cunningham et al. (2023), youth feel misunderstood by their caregivers in the theme of mental health problems. The youth also mentioned how being misunderstood makes them feel: Frustrated, defensive, unsupported and not valued. When youth feel misunderstood, it becomes difficult for them to seek support, often leading to avoidance. Feeling understood had positive associations: Relief, confidence, calm, feeling seen and trust. When youth feel understood, the likeliness to approach adults for support in the future increases. When therapists made an effort to understand the youth's unique context, youth were more likely to feel understood.

As the client-practitioner relationship and equitable collaboration are interconnected, both play a big role in the treatment, empowering youth and increasing trust in the treatment. The client-practitioner relationship plays a prominent role in the increase and decrease in epistemic trust whilst overall collaboration focuses on collaboration between youth, parent and practitioner. As epistemic trust is key for preventing stagnation, it can also be helpful to regain epistemic trust to bring stagnated treatment into motion again.

## 2.5 Identity development

This section explores identity development in different ways in the context of mental health care.

### 2.5.1 Illness Identity

When writing a story or a narrative, identity plays a prominent role and comes to surface in stories about people's lives. In this section, a phenomenon called illness identity will be explored, to find out its effect on the story.

De Moor et al. (2024) conducted research on how mental illness and identity can become intertwined: Mental illness identity. This is especially relevant for youth since identity plays an amplified role in this period alongside growing psychological distress. Mental illness identity refers to someone interpreting their illness in relation to themselves, rather than seeing it as an separate factor. Mental illness identity is unhelpful for recovery and damaging for the attitude towards the illness.

Illness can have consequences for someone's sense of self and identity including; uncertainty, shame and being hidden. The meaning that individuals ascribe to their illness is an effort to revive lost order and understanding. It was suggested that narratives could play a role in repairing the damage from their illness. Identity and self can be discovered through narratives (Frank, 1995 cited by Robertson et al. 2019).

Since illness identity can come in different shapes, there is a high chance of it affecting the story in the context of Centering Your Story. This could be affected both positively and negatively, depending on the form. However, knowing this, it could be interesting to use this theory to map the story or rewrite it. It gives insights into how youth

may identify themselves and how they may relate their illness to their identity and perhaps help them find a way to change their perspective.

#### 2.5.2 Narrative identity

Narrative identity is the constantly evolving story of the self that individuals create to give their lives purpose and unity. Theories suggest that starting adolescence, individuals create a story about their experiences in lives that brings together their past, present and future (McAdams, 1996 cited by Adler, 2011). McAdams (2008) argues that narrative identity is not about what really happened, but about individuals' current understanding who they were, are and will be.

Narrative identity is one of the three main domains of personality, including dispositional traits and characteristic adaptations (McAdams, 1995 cited by Adler et al., 2015). The individual differences in personality come to light through stories individuals tell about their life experiences, which is narrative identity. Narratives communicate substantial events in someone's life, but more importantly, they communicate the meaning these events convey for the narrator and how they interpret their experiences (Adler et al., 2011, 2015).

The theme of agency is of importance in narratives since it is linked to individuals' sense of meaning and purpose. Agency also is strongly linked to psychological well-being (Adler, 2011). Interestingly, in qualitative research by Curium was found that youth first need their own vision in order to create these narratives, which can be linked to agency. If youth have agency, their ability to create their narratives may increase. Also, when youth discover their ability to create their own narrative, the feeling of self-efficacy may also increase.

### 2.6 The added value of narratives

Using narratives can add value to youth in mental health care and youth with severe and enduring mental health problems as well. This section explores the value of narratives, narrative identity and the effects of narratives.

#### 2.6.1 Externalization

One of the key strengths of using narratives is the emphasis on externalizing the problem from the person, helping individuals explore coping strategies that promote agency and reduce feelings of self-blame. Some narrative approaches proved to be helpful include: Externalizing the problem, practitioners focusing on strengths and agency, discussing alternative perspectives of the problem story and using a reflecting team (Bennett, 2012).

According to a systemic therapist, the goal of the narrative is externalization of youth's problems, aligning with the found literature. Externalization in this context can be explained as not being the problem but dealing with a problem, making sure it is not part of who the person is (M., personal communication, April 7, 2025).

### 2.6.2 Ascribe meaning

Munson et al. (2014) explained that through narratives, an individual ascribes meaning to their experience and through sharing stories, others contribute to shaping meaning. Narrating can help youth reframe their ascribed meanings to the challenges of severe and enduring mental health problems. For Centering Your Story, this could be relevant since the story will be a combination of personal stories and a shared story.

#### 2.6.3 Reactivation

Each narrated identity has aspects such as significant experiences in life and important memories, of which a lot are emotional experiences, connected to a specific episodic memory. Some episodic memories can affect well-being if parts of it are experienced again when life themes bring them to the surface. The occurrence of reactivation affects well-being at the moment and over time, these effects add up to create lasting impacts on well-being. The way these memories are framed and eventually narrated, lead to a sense of purpose and unity (Adler et al., 2015).

#### 2.6.4 Different narratives

Robertson et al. (2019) wrote that there does not have to be one 'true' narrative but different possible stories, allowing for transformation. A similar conclusion was drawn in the Curium project meeting; more than one story can exist in parallel.

A form of narrative is autoethnography. With autoethnography, a narrative has an extra purpose beyond communicating the story: Reflection and reviewing lived experience are significant elements. Autoethnography frames personal experiences within cultural practices and shared experiences. This could result in better understanding for people reading it, and perhaps increase the possibility of personal and social change (Robertson et al., 2019).

Robertson et al. (2019) also mention using own lived experiences in the research, with the use of quotes and statements that other people have told them. This is inspiring since it is also a way of including different perspectives in the story.

### Story

Another way to include perspectives that was described by Robertson et al. (2019) is peer input, based on shared lived experiences. Peer input was perceived as empowering and reduced individual's negative feelings.

It should also be acknowledged that creating a narrative is not easy and may involve reliving trauma and using other people's perspectives can be complicated. However, it is proven to be helpful to get input from others while creating an individual narrative.

### 2.6.5 Change

Adler (2011) emphasizes the benefits of stories about psychotherapy. They often are spontaneous parts of larger stories, but narrators often refer to psychotherapy experiences as important episodes for the development of their personality. The findings suggest that therapy stories offer a unique opportunity to understand identity changes. When individuals experience change, they first need to understand the transition, connecting their past self to their changed self, which is a difficult process and takes time to reach purpose and unity as the aim of narrative identity. As found in the qualitative study done by Curium, the first narrative may start negatively but can change into a positive story. This is fitting in situations with therapy narrative. Youth can start with a negative narrative and work towards a positive story as they get to understand themselves better.

### 2.6.6 Story insights from Curium

Insights about the story will be highlighted with the information gained from an interview with a systemic therapist and the qualitative

research done by Curium (M., personal communication, April 7; LUMC - Curium, 2024).

Important aspects to focus on when centering the story, based on Curium qualitative research and a systemic therapist , include :

- ♦ Highlighting the positive aspects of the story: In individual therapy, the focus is often on fixing what is wrong rather than emphasizing the positive.
- ♦ A story is a way to uncover values and to understand what is important to people.
- ♦ A story should contain the emotional world of the youth, parent and practitioner.
- ♦ Social discourse: The stories that exist in society about how life should be, should be recognized in the story.
- ♦ A story a child can live in: It does not have to be just one; there can be multiple stories a child can live in, as long as they are not contradictory.
- ♦ The story should serve as a descriptive diagnosis.
- ♦ The story gives the practitioner insights into how the family functions, the youth's system and the causes of the current situation.
- ♦ A story is helpful when families are satisfied with it and feel acknowledged.

## 2.7 The story defined for 'Centering Your Story'

The story was first derived from research done by Curium by examining the open axial codes (LUMC - Curium, 2024). The focus lies on the contents of the story and components that need to be included. The story derived from research consists of two crucial categories: Past and system, where the life story of youth is a big focus. The main goal of the story is: To discover behavioural connections and patterns, uncover the underlying issues, understand why people do what they do and understand each other by creating a shared story. Appendix C offers an overview of the story derived from research.

Subsequently, the final definition of the story for this design thesis was defined. This definition was based on the qualitative research analysis and the scientific literature research and serves as a reference point in the design process. Figure 6 shows the story and its components. The life story is the main body of the story, whilst the other components are additions and important themes to incorporate into the life story. Even though the themes are part of the life story, they should be highlighted and emphasized when creating a story in order to center the personal stories. The aspects of the story in the visual are elaborated in this section.

According to literature, giving youth agency in their narratives can help increase their ability to create narratives and it is linked to psychological well-being. Empowering youth is a key theme in the design statement and the story can help enhance that. Thus, the story is centered around the youth and includes other perspectives as well.

The literature and qualitative research concluded that having several narratives and including other perspectives in the story can have an empowering and positive effect on the story and the youth. For youth especially, including a peer's perspective in the story can be valuable. Thus, the definition of the story includes different perspectives.

Another insight from the literature is that there are benefits of talking about the past and narrating it. This gives the youth the opportunity to connect their past self to their changes self. The past self in this context is related to the self before therapy. Besides that, the past self outside of the context of therapy should also be included.

Some memories can affect well-being when parts are experienced again. This reactivation can create a lasting impact on well-being, which can then lead to a sense of purpose and unity when narrated. Since the past affects well-being a lot and can help youth understand themselves better, this is a crucial part in the defined story.

Related to the past, is also the focus on the inner emotional world, as found from the qualitative research. Relating memories to emotions and understanding yourself through emotions can be helpful when creating a complete story.

Social discourse is a theme that was added to the defined story since it was recurring in different shapes and forms in the qualitative research as well as literature: Youth compare themselves to others, and especially when they are experiencing mental health problems, this can have a negative impact on their self-esteem. This is an issue that requires attention and is important to bring up in order to help uncover patterns.

The qualitative research concluded that putting a focus on positive aspects in the present can make creating a story less dreadful and show what is going well rather than only focusing on the negativity of the current stagnated situation. This aspect is included the story definition, with the main purpose of adding positivity.



Figure 6: The story derived from literature review and Curium qualitative research

### 2.8 Conclusion

This chapter has explored two complementary aspects for the design thesis through literature and qualitative research. Both aspects contribute to a deeper understanding of the context of Centering Your Story.

#### 2.8.1 The field

The literature on the field of psychiatry in the themes of stagnation and youth with SEMHP youth, highlighted the importance of considering the context and challenges youth face.

It was concluded that causes of stagnation, treatment failure and dropout are linked to different layers of interaction. Those layers show interrelatedness and give an overview for designers to understand the complexity as well as find aspects to interfere. For the design thesis, focusing on the design statement could eventually resolve or reduce some causes.

The importance of making sure youth stay engaged is also of relevance to the design thesis. When all treatments have failed or stagnated, they will be even less motivated to engage, which is a factor to take into consideration.

This literature highlights the importance of transparency for an equitable collaboration between youth, parent and practitioner. The final design should put focus on equality, open communication and transparency.

An important insight from the literature is the need to empower youth by giving them more control over their treatment, allowing them to make decisions on their own or be actively involved. The design statement includes empowering youth as an important goal and this is a recurring theme in the design thesis. The literature highlights the importance of epistemic trust for preventing stagnation, which is why it can be helpful to regain epistemic trust to bring stagnated treatment into motion again.

#### 2.8.2 The Story

The literature and qualitative research on the story provided insights into how the story can be defined and specifically helped define the story for the design thesis.

The literature emphasizes the importance of identity and how identity comes to light and can be discovered through narratives. Since identity is an important aspect of the story, it can be helpful for the facilitators of Centering Your Story, or the practitioner, to read the story through the lens of illness identity and narrative identity. Youth, practitioners and parents can understand each other better through the way they narrate their stories.

Secondly, literature stated that narrative identity is for understanding who a person is, rather than a truthful story. Narratives communicate important events in people's lives, its meaning, and how they interpret it.

The research suggested that externalization of the youth's problems should be the goal of creating a narrative, for the youth to not relate their problems to their identity.

Literature also concluded that narrating can help youth reframe their ascribed meanings to the challenges of severe and enduring mental health problems. For Centering Your Story, this could be relevant since the story will be a combination of personal stories and a shared story.

The findings suggest that more than one story can exist at once and that it is most important that the youth can relate and live in the story.

Curium qualitative research specifically highlighted that the story should uncover values and most importantly; The story is helpful when families are satisfied with it and feel acknowledged.

# 3 Analysis of Curium qualitative data

While chapter 2 covered insights specifically related to the story, this chapter provides a broader analysis of the same data set: A selection of the qualitative research done by LUMC-Curium. The research done by Curium is extensive and consists of interviews with youth, parents and practitioners and three focus groups. The approach, analysis and insights will be discussed. The key question is:

What are tensions, wants and needs, and what is considered to be helpful in stagnated treatments, within the themes of hope, motivation, collaboration and empowerment of youth?

## 3.1 Approach

The qualitative research done by LUMC-Curium consists of 33 semi-structured interviews with 11 youth, 10 parents and 12 practitioners who have had experience with Child and Adolescent Mental Health Services between the ages of 12 and 21. The research included three focus groups with the perspectives of youth, parents and practitioners. All data was already analysed by the researchers with a thematic coding and framework analysis method. Since this is a large amount of data and the goal of the design thesis has a different angle, relevant parts of the data were selected to analyse. The decision to conduct another analysis, was driven by the need to be immersed in the data, gain a deeper understanding of its nuances, capture the emotions and extract information that was most relevant for this design thesis. The focus lies on tensions, wants and needs and helpful matters related to stagnated treatments (LUMC - Curium, 2024).

A total of six interviews were listened to and documented in detail: Two from each individual group (youth, parent and practitioner), as well as the three focus groups. The interviews were selected by the company mentor based on the relevance to the topic, to gain a better understanding of the structure and recurring challenges.

The data was analysed using an open, theme-oriented approach inspired by a thematic analysis. The quotes were exported to Miro and sorted by perspective: Youth, parent, practitioner. Then, the quotes were categorized based on six main topics, of which the first three were taken directly from the topics discussed in the interviews: The Story, Equitable collaboration, Experiential expertise, Stagnation, Challenges, Helpful. After the quotes were divided into these categories, they were arranged into smaller titled clusters. The clusters were composed by combining quotes with similar meanings and emerging themes and their titles were based on the key message recurring in the quotes. A range of insights emerged from the analysis

of those clusters, from which the most relevant for the design goal and research findings, were selected as the main findings. The set-up of the Miro can be found in Appendix D.

## 3.2 Clustering

For the clustering of the data, all quotes were first arranged into groups with simple titles. The clusters were subsequently refined to ensure they were both clear and inspiring. The main topics in which the clusters were made will be elaborated. Three were based on scientific literature research and were established by Curium as the three main categories: *The story, Equitable Collaboration* and *Experiential expertise*. The three additional categories are as follows:

- ♦ **Stagnation:** As the main problem that needs to be solved, stagnation was selected as a category. Participants talked about what stagnation is in their experience and why it might occur.
- ♦ Challenges: Since the participants experienced many challenges along the way, also unrelated to the before mentioned categories, challenges were selected as a separate category to really see and take into account the pain points outside of the main topics.
- ♦ Helpful: Participants also had good experiences and ideas on what might have been helpful in their situations. This was selected as a category to make sure helpful interventions will remain and be taken into account when designing.

## 3.3 Insights

To ensure that the results of the analysis did not unfairly reflect a limited segment, the open axial codes were reviewed revealing that the insights closely aligned with the findings from the research conducted by Curium (LUMC - Curium, 2024). This section will discuss key insights found in the analysis for the design thesis, other insights can be found in Appendix E. These insights play a role in the design process and were used as criteria.

#### Key insights include:

- ♦ Some youth lose epistemic trust because their story is not acknowledged or taken into account.
- ♦ Stagnated treatments may lead to fear, demoralization, sadness and loss of energy for all parties.
- ♦ Some youth and parents emphasize the importance of considering background and environmental factors in the story.
- ♦ Some youth found it helpful when practitioners show their emotions and light-heartedness.
- ♦ Youth consider it important to be given a voice and autonomy in their treatment.
- ♦ Parents want to feel heard and be actively involved.

### 3.4 Conclusion

To conclude, this chapter highlighted the insights gained from the qualitative data and helped be immersed in the context of Centering Your Story.

The analysed data illustrated the difficulties youth, parents and practitioners go through when a treatment stagnates. It showed the effect of stagnation, challenges they face and what is needed in order to move forward. Also, youth, parents and practitioners expressed their needs and what they experienced as helpful in the process of stagnation. The insights and context gained from the qualitative data analysis will be built upon in the next design phases.

# 4 Existing interventions

This chapter serves as an overview of existing interventions and products from the social design field and therapy settings that have elements and similar cases to the design thesis.

In the introduction, existing interventions specific to the case of stagnated treatments were briefly discussed. This chapter goes a step further and explores other areas with potentially helpful interventions for the design thesis. The introduced interventions serve as inspiration and analysis material in the design process. The key question is:

What are existing interventions within therapy settings and what are components that can serve as inspiration for the design process?

## 4.1 Approach

For the analysis of existing products, already known social design studios who have done projects in healthcare were researched, creative interventions in healthcare were looked into and inspiration received from the supervisory team was analysed. Additionally, interventions from literature research were analysed.

In order to analyse existing initiatives, the focus lied on aspects that would be particularly relevant for the design thesis and why it would be of interest for the design thesis.

## 4.2 Open Kaart

Open kaart is a card game designed by Ink (Figure 7), to help children and adolescents develop a positive self-image and get to know themselves better, through the eyes of others (*Open Kaart - Een Sociaal Kaartspel Met Een Twist*, n.d.).



Figure 7: Open Kaart (Open Kaart - Een Sociaal Kaartspel Met Een Twist, n.d.)

**Purpose:** Creating a positive narrative about oneself and learning about own personality. Additionally, it helps with reflecting on oneself and a low-threshold way to learn more about others' personalities.

**Relevance:** This project helps change the narrative youth tell themselves and enables identity development which is a relevant aspect to focus on for youth to create their own story and feel a sense of ownership when creating their own story.

### 4.3 Samen Beslissen

Samen Beslissen is a canvas designed by Ink (Figure 8), for people with enduring mental health problems in psychiatry. This canvas helps addressing life domains to encourage positive lifestyle choices for the clients. This is done together with the practitioner (*Samen Beslissen - Een Canvas Voor Een Betere Levenskwaliteit in De Psychiatrie*, n.d.).



Figure 8: Samen Beslissen (Samen Beslissen - Een Canvas Voor Een Betere Levenskwaliteit in De Psychiatrie, n.d.)

**Purpose:** Helps the person create a plan with concrete steps to improve their life in different domains, communicate this to the practitioner and create more equality between the client and practitioner. The themes of taking control and responsibility for the client are especially important in this intervention.

Relevance: This project is interesting due to its emphasis on the person taking control and their choices being leading. In Centering Your Story, youth and parents feel unheard and whilst completely putting the control in the hands of youth is not the goal, it can be interesting to look into a way of making them feel more as the central figure. Also, the project focuses on improving different life domains, which is a simple way of breaking the big goal into smaller tasks for creating the story.

### 4.4 Netwerk Intake

Netwerk Intake is a conversation tool designed by UMCU (Figure 9) that is used at the start of psychiatric treatment to get an overview of the individual's problems, their community and system and both positive and negative aspects of their life domains (UMCU, n.d.).

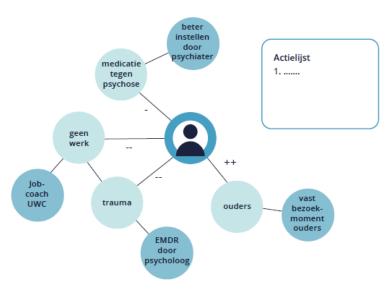


Figure 9: Netwerk Intake (UMCU, n.d.)

**Purpose:** The visual overview helps the person understand where to improve and which aspects to keep in their lives. It helps create a clear plan to work towards in treatment, making it easier to talk about the problems in the Netwerk Intake sketch.

**Relevance:** This intervention creates a detailed overview of different positive and negative areas in the lives of people with mental health challenges. An overview like this can be relevant for mapping the story and seeing all the pain points as well as things that are going well.

For youth, it is very important to keep in mind the positive aspects of life and work towards tangible goals.

## 4.5 Bumpy Road

Bumpy Road is a podcast designed by Redesigning Psychiatry (Figure 10) where young adults can share their stories, difficulties in life and how they deal with them and what might help (Bumpy Road, n.d.).



Figure 10: Bumpy Road podcast (Bumpy Road, n.d.)

**Purpose:** This podcast helps young adults listening to other young adults get out of negative thought patterns and relate to the stories being told. This narrative communication helps them normalise talking about mental health and help others who are struggling.

Relevance: In this podcast, young adults explain what is happening, what they are feeling and also speak about their recovery and how they managed to get out of certain problems. This is similar to peer support workers and the effect they have on youth. When sharing similar experiences, youth do not feel alone and learn how to cope with it. By listening to this podcast, young adults are enabled to ascribe meaning to their own stories as well and since they are peers; it is easier to relate.

## 4.6 Trips

Trips is a booklet designed by Redesigning Psychiatry (Figure 11) to help people struggling with addiction to change their behaviour and implement new behaviours into their lives.



Figure 11: Trips booklet by Redesigning Psychiatry

**Purpose:** This booklet helps people work on themselves in a creative way and map out negative and positive aspects in life and how to improve step by step.

**Relevance:** The approach of using a booklet to map out different behaviours and aspects to improve can give a clear overview. Even though this booklet was specifically designed for people with addictions, it can be helpful for people to have a physical booklet that holds all aspects of the story.

# 4.7 Peer Support Workers

As established by Curium researchers, Peer Support Workers will play a facilitating role in the final intervention as well as the prototype for the design thesis. Literature was reviewed to understand their value and the role they could take on.

**Purpose:** A review done by De Beer et al. 2022 explores the benefits of Youth Peer Support Workers (YPSWs) in mental health services. They established six different roles: Engagement, emotional support, navigating and planning, advocacy and educational. Those roles are based on the needs of youth receiving mental health care and the benefits of integrating YPSWs in recovery practices. The amount of roles suggest that YPSWs could play a big role in different phases of Centering Your Story as a way of supporting youth.

The paper highlights several positive effects of Youth Peer Support Workers on youth in mental health services:

- ♦ Increased hope and empowerment: By sharing their experiences with youth exhibiting recovery, YPSWs provide a sense of hope.
- ♦ Improved self-esteem: Youth feel understood by YPSWs who have experienced similar challenges.
- ♦ Enhanced Treatment Engagement: By building trust with youth, YPSWs help increasing treatment engagement.
- Reduction of stigma: YPSWs assist youth in managing stigma in family related to mental illness, making it easier for them to seek help and be involved in treatment.
- Relatability and trust: YPSWs are viewed as more relatable than non-peer staff by youth since they open up about their experiences, fostering trust and connection.

Overall, Youth Peer Support Workers have a positive impact on how youth experience mental health care.

Other peer support workers include Family Peer Support Workers. The responsibility carers have in youth's recovery process can have substantial effects on their emotional wellbeing and health. A research conducted by Hopkins et al. (2020) examines the impact and effectiveness of a Family Peer Support Work (FPSW) model. A study found that the emotional effects that most carers experience significant levels of anxiety and depression (Leggatt, 2007, cited by Hopkins et al., 2020).

FPSWs provide emotional and practical support to families navigating the complexities of youth mental health services and foster collaboration between the families and clinical teams. The FPSW model evaluated is flexible and includes different shapes of support. Family Peer Support Workers have a unique position where they use their lived experience as caregivers of youth with mental illness in order to empathize and provide insights. Also, since FPSWs provide consistent support, they reduce the carer burden. It is also noted that families trust FPSWs more than the clinical staff due to their shared experiences, lowering the threshold for forming supportive relationships (Hopkins et al., 2020).

Relevance: The literature highlights, as already confirmed, the benefits of including Peer Support Workers in therapy as well as the positive effect they might have when brought in as facilitators for bringing stagnated treatment into motion again. Especially youth peer support workers can play a supporting and comforting role for youth experiencing stagnated treatments.

# 4.8 Holistic approach

Many papers expressed the need for a more holistic approach in therapeutic settings, such as consumer-centered care and personalised interventions, as a crucial step toward making mental healthcare more fitting and accessible for SEMHP youth. This made researching this area essential (De Beer et al., 2022; Vijverberg, 2022).

**Purpose:** Ng and Weisz (2015) state that personalised interventions can provide a future where practitioners can deliver efficient treatment that is adapted and optimised based on youth's needs and preferences. Personalised interventions include among others individually tailored approaches where the practitioner can adapt the method during the treatment, based on the youth's needs and modular therapies where the practitioner combines modules based on the youth's needs in the beginning of the treatment.

Relevance: As holistic approaches provide a lot of space to cater to the needs of youth, current practices and recommended interventions are important to keep in mind to understand if this approach has or could have commonalities with Centering Your Story. The approach has not yet been implemented for resolving stagnated treatments in the context of Centering Your Story, but could be helpful.

#### 4.9 Conclusion

This chapter illustrated various interventions in the theme of therapy and mental health. Some interventions use a playful approach to lighten the mood and strive for more interaction, whilst others put the main focus on completeness and usefulness. A common strategy that reoccurs is putting the user in control and in the center. The need for agency is something that is present in many therapy settings, which

is why it is a recurring theme in interventions. Additionally, redirecting attention to positive aspects of life is a recurring theme. This may be due to the fact that in therapy settings, it is usual to focus on and fix what is going wrong rather than give attention to what is going right. For youth in particular, support is a crucial and recurring theme in all interventions; They need to feel supported and heard. This also links to another theme: Youth having someone to relate to, to not feel alone in their situation.

The interventions provided inspiration for the design thesis, but some gaps were noticed. Firstly, there was no intervention found that is directly focused on resolving stagnation in psychiatry. Secondly, the interventions provided helpful goals, but did not put focus on youth feeling heard and understood, which is a crucial goal for the design thesis. Finally, the found interventions did not explicitly include collaboration with the system or parents of the person, which is for the design thesis a necessary element to include.

Key aspects from these interventions will continue to inspire and shape the designs moving forward.

# 5 Defining design directions

This chapter presents the process of choosing three design directions from the five direction that were established based on the literature and qualitative research. The directions were chosen based on recurring topics in research, pain points and areas where design can make a meaningful contribution. The five directions were presented in the Curium project meeting where a brainstorm was facilitated in order to choose three directions.

# 5.1 Design directions

To define design directions, research insights were reviewed. The design directions emerged from recurring patterns, needs, pain points and tensions related to stagnation in psychiatry across the literature review and qualitative research analysis. Where the literature outlined the bigger picture, the qualitative data gave voice to individual experiences and the feelings behind them. By comparing the two, recurring themes emerged. Initially, five broad directions were defined each exploring different areas around the project Centering Your Story for the design thesis (Appendix F).

It was however decided to choose one of the five broad directions and diverge within. This choice was based on the role and abilities as a designer as well as the vision in this direction. The main design direction is *Centering the Personal Story*.

Within centering the story, five sub-directions were explored, illustrating different steps in the process of centering the personal story. Each sub-direction revealed conditions and requirements. Figure 12 shows the directions for centering the story. The resulting directions aim to bridge theory and practice, offering starting points for meaningful design exploration.

# Design something that *centers the personal story* to bring stagnated treatment into motion



Figure 12: Design sub-directions in the theme of centering the story

# 5.2 Project meeting

Starting with the five defined sub-directions, a presentation and a brainstorm for the Curium project meeting were prepared. The goal of this meeting was to discuss the design goal, find what was missing in the directions and converge to three directions.

The Curium project meeting consists of the project group with healthcare professionals, a parent and an youth peer support worker. For the meeting, a presentation was prepared with the design goal and How-Tos for the sub-directions. Before the brainstorm, the brainstorm rules were explained to the participants to make sure that the results were most valuable (*Design Kit*, n.d.). The participants brainstormed for three minutes in each direction.

# 5.3 Analysis of brainstorm data

After collecting the notes and sticky notes, the analysis started. First, all brainstormed ideas were examined. A selection was made based on interesting and recurring ideas within each direction, as well as ideas that aligned with previous research conducted for the design thesis. Then, the notes on the discussions were reviewed. The design directions *Mapping the story* and *Rewriting the story* had the most reactions and ideas during the brainstorm. These directions were areas that really needed to be explored and improved as a step towards bringing stagnated treatments into motion again. At last, the contents of the selected ideas were examined and it was concluded that *Making the story concrete and useful* had many of opportunities for design and making sure that the process of creating a story is helpful for all.

# 5.4 Chosen design directions

The chosen design directions are as follows: *Mapping the story, Making the story concrete and useful* and *Rewriting the story.* This section will give additional information gathered during the meeting and important focus points within these directions.

#### 5.4.1 Mapping the story

Mapping the story emerged as one of the first steps in centering the story. As a designer, I saw an opportunity to create impact by developing a clear and accessible way to support this process. However, before mapping the story, it is crucial to obtain or access the story in a way and often, people do not yet have a clear version of their own story. This highlights the importance of making space for creating the story.

Mapping the story serves as a bridge towards making the story concrete and useful. In the meeting and in the qualitative research, it became clear that the current practice of mapping the story lacks clarity in terms of format and execution. A few questions emerged that need to be explored:

- ♦ What is the story?
- ♦ How to clarify what the story is exactly and what it entails?
- ♦ Is there one story or can there be several stories?

#### 5.4.2 Making the story concrete and useful

Making the story concrete and useful emerged as the step after mapping the story, towards preparing the story for implementation. As a designer, I saw the opportunity to create impact by finding a way to ensure the story has a purpose. It needs to be clear what actions need to follow after mapping the story. This step will help give the story a supportive role in bringing stagnated treatment into motion. In the project meeting, it was mentioned that the story should be extended into the present and future and not only focus on the past. A few questions emerged to further explore this direction:

- ♦ What are ways to translate the story into actions and movement?
- ♦ When is a story concrete?
- ♦ Is setting goals effective?

#### 5.4.3 Rewriting the story

Rewriting the story is especially important for stories that are negatively framed and emerged as an additional step after mapping the story. From prior research I found that negative narratives can lead to unhelpful stories. As a designer, I saw the opportunity to create impact by developing tools or ways to shift the focus towards positive aspects of the story. The story should not be literally rewritten; the focus should lie on changing the perspective and creating a positive view towards the story and each other. An insight that previously emerged from the qualitative research is that the focus of a story should lie on strengths, qualities and opportunities. A few questions that emerged to explore in this direction are as follows:

- ♦ How can we ensure that negative narratives are reframed in a way that makes the story inspiring and motivating?
- ♦ Does it need to be rewritten or viewed from a different angle?
- ♦ How to rethink and shift the focus towards positive aspects of negative narratives?

### 5.5 Conclusion

This chapter illustrated the process of defining five design directions within the theme of centering the personal story, choosing three directions and giving shape to the chosen design directions for further design phases.

The three chosen design directions are key in the process of centering the personal story. From the project meeting, it was concluded that the three directions feel like three different steps in the process.

Firstly, the story should be mapped and made clear. Since currently, there is a lack of clarity in terms of format and execution of mapping the story, this step is crucial to kick of the process and gather the necessary parties and information.

Secondly, the story should be made concrete and useful since there is a lack of clarity and purpose. It is a step that is needed in order to know which steps to take after mapping the story and defining its purpose.

Finally, rewriting the story is a separate step that can occur after mapping the story, depending on the situation. This step can be beneficial for youth who have a negative view on their lives and on their story and can help direct more attention to positive aspects and a fresh, positive perspective.

Whilst involving everyone in the story and carrying the story together were valuable directions as well, they were left behind in the process of converging where the project group expressed their opinions on the most promising directions. Nevertheless, those directions will be kept in mind and partially absorbed in the chosen directions.

# 6 Conceptual directions

This chapter provides the first conceptualized directions. The chosen directions were made concrete and turned into rough concepts which were used in the co-creation to build upon. The process of conceptualisation will be shown in this chapter.

### 6.1 Approach

The journeys that users would go through in each design direction were examined by writing out the key steps. Subsequently, the insights derived from qualitative research and the Curium project meeting were revisited. Using the *Theory of Change (Design Kit,* n.d.-b) as a framework to transform those insights into positive statements that could serve as criteria. The criteria were added to strengthen the overarching design goal. These criteria were then aligned with the ideas generated in the two monthly meeting. For each statement, new, more elaborate ideas that could contribute to meeting the criteria were added.

Then, a list of core components extracted from existing ideas were formulated and steps in the *Theory of Change* that should be included in each conceptual direction, as well as new design statements. Next, the design directions were visualised and the components were reviewed, creating a detailed overview of the interaction with each concept.

To conclude the process, each concept was evaluated against How-To questions to make sure they aligned with the overarching goal (*Design Kit*, n.d.). The guiding How-To questions were:

How to map the story?

How to make the story concrete and useful?

How to rewrite the story?

The aim of the conceptual phase was to create visual ideas that are concrete but still adjustable. Especially since they are the first visual concepts, they are open for any changes, allowing space for feedback and redesigns from the project group during the co-creation.

### 6.2 Journey and theory of change

This section presents the potential user journeys of the three directions (Figure 13) and shows the theory of change process (Figure 14).

The potential user journeys have overlap and the directions can be seen in the other journeys as well, since the design directions all represent different phases of the Centering Your Story project. Mapping the story is the first step, rewriting the story is the (potential) second step, and making the story concrete and useful is a step later in the process and more focused on practice. The choice between the three directions will inevitably also include aspects of the other directions, but the focus will be different.

In the theory of change process, the statements were based on what was said in the project meeting, information derived from the qualitative data done by Curium and the literature research (LUMC - Curium, 2024). The theory of change statements helped put the main goals in an overview.

This was an insightful process since it sparked creativity for coming up with more elaborate ideas for the concepts. Also, it came to attention that one of the positive statements is unrealistic for this design thesis: regaining epistemic trust. It is too systemic and big for the amount of time. This was recognized when it could not be aligned with any of the previously generated ideas.

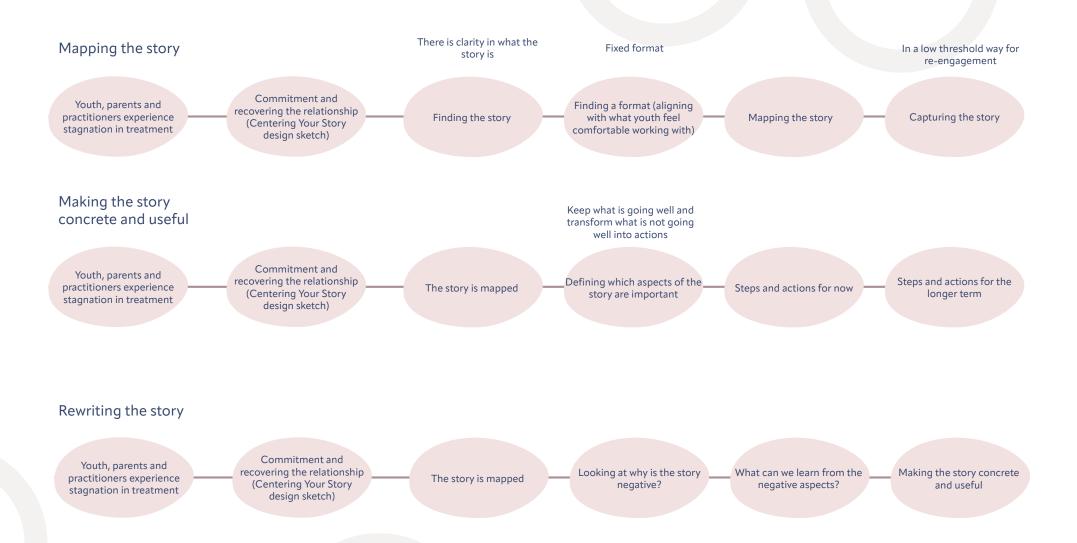
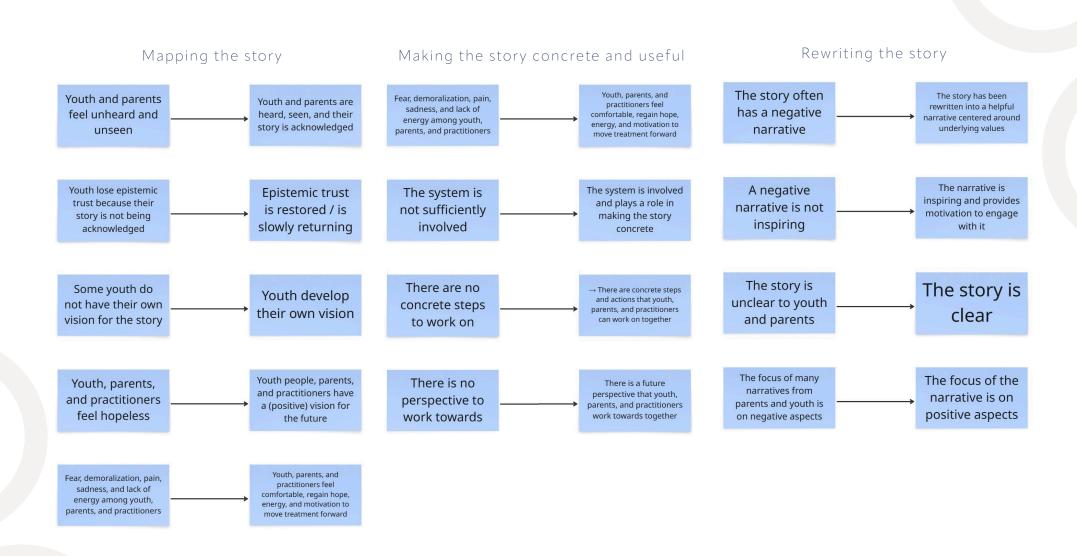


Figure 13: The potential user journeys for the three design directions: Mapping the story, Making the story concrete and useful and Rewriting the story



**Figure 14:** The statements made with the use of the theory of change framework. From left to right: Mapping the story, Making the story concrete and useful and Rewriting the story.

# 6.3 Mapping the Story

Figure 15 shows the concept *Mapping the Story*. This concept is a journal; the journal has three versions: one for youth, one for parents, and one for practitioners. It contains various questions and exercises. The exercises are divided into different phases: Before the first session of Centering Your Story, during the mapping process, and concluding. The completed exercises can be discussed together in the sessions to gain a clear understanding of everyone's story, vision, and expectations. Throughout the process, everyone continues to work on exercises and discuss them, gradually mapping out the story piece by piece. All stories can be combined in a way that creates a complete picture. The questions in the journal are based on interviews about the story and Curium qualitative data (LUMC - Curium, 2024). The non-fixed components in this concept are:

- ♦ Shape/format
- ♦ The amount of versions
- ♦ The method of filling in the journal
- ♦ Shaping the complete picture of the story



Figure 15: Conceptual direction: Mapping the story, journal

# 6.4 Making the Story Concrete and Useful

Figure 16 shows the concept *Making the Story Concrete and Useful*. This concept consists of a card set and canvases. The card set helps participants learn about each others' strengths and qualities and use this as a base to divide roles. It serves as a conversation starter and creates a positive beginning. Together, youth, parents, and practitioners fill in the canvases with overarching goals and smaller actions to achieve those goals, derived from the already mapped-out story. These actions can be assigned to the corresponding roles. The goals and actions are visualised and will be reviewed in each session to track progress, and goals can be adjusted or checked off as needed. The non-fixed components in this concept are:

- ♦ Shape/format
- ♦ The method of combining efforts
- ♦ The method of formulating goals and actions
- ♦ Dividing the roles
- ♦ Assigning actions

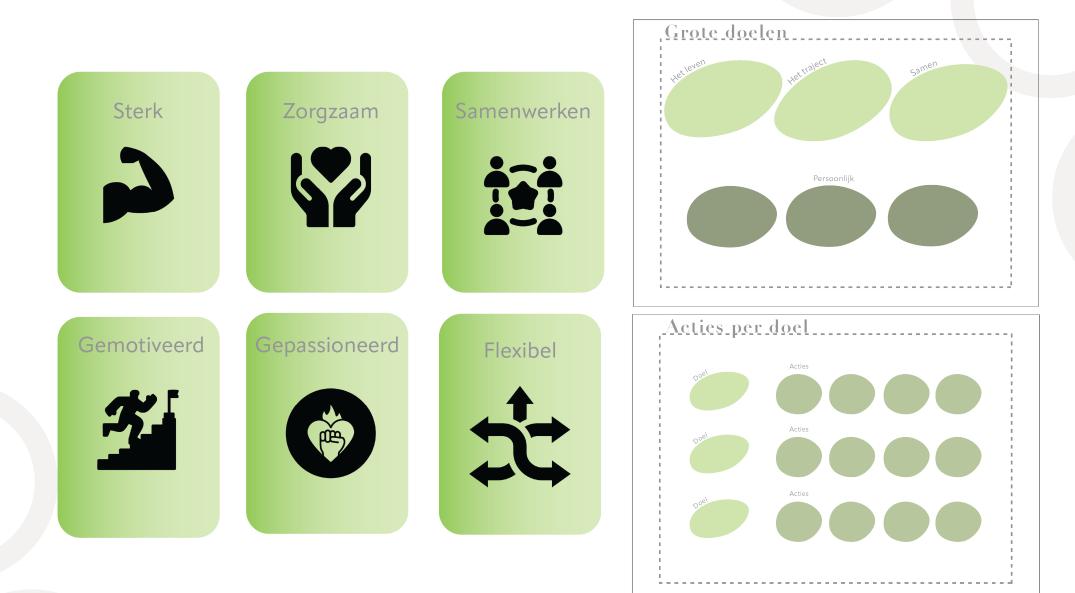


Figure 16: Conceptual direction: Making the story concrete and useful, cards and canvases

# 6.5 Rewriting the Story

Figure 17 shows the concept of *Rewriting the Story*. This concept consists of a card set with various sentence starters. Inspired by 'Open Kaart' (*Open Kaart - Een Sociaal Kaartspel Met Een Twist,* n.d.), the participants fill in the cards for each other rather than for themselves. Whereas Open Kaart focuses on children to understand their identities better, Rewriting the Story focuses on understanding personal stories and values. This approach leads to different types of conversations and new insights about one another, helping them better understand each other's values. It also encourages a more positive perspective of the story and of each another. The cards facilitate meaningful conversations and provide a starting point to collaboratively reshape the story into a helpful narrative. The non-fixed components in this concept are:

- ♦ Shape/format
- ♦ The way of gaining insights about each other
- ♦ Gaining a positive view of the story
- Shaping the next step

Tijdens een gesprek Wat ik nodig heb vind ik belangrijk Een succesvolle behandeling behandeling verlaag betekent voor mij... ik de drempel door...

Figure 17: Conceptual direction: Rewriting the story, cards

# 7 Co-creation I - exploring the conceptual directions

In order to choose one design direction to continue with to the next phase, a co-creation session was conducted with the Curium project group. The three conceptual directions were introduced and participants were asked to redesign different components to create new, more helpful designs. This chapter will discuss the plan, setup, results and conclusions. The key question for the co-creation is:

Which one of the conceptual directions is the most promising to move forward with in the next design phase?

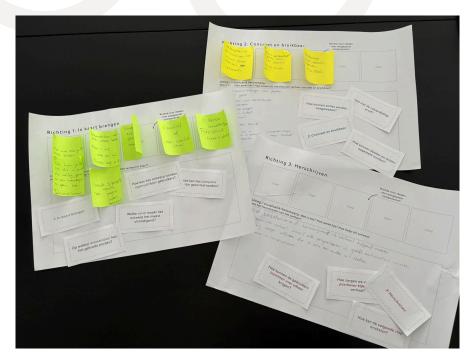
# 7.1 Setup

For the co-creation, the conceptual directions from Chapter 6 were introduced. To make sure the directions did not seem final, a number of adjustable, non-fixed components in each direction were identified. For boosting creativity, the components were transformed into How-Tos (*Design Kit*, n.d.). The audio was recorded for making sure all valuable information could be used.

The setup of the co-creation was as follows:

- ♦ Participants: 8 total 1 youth peer support worker/youth, 1 parent peer support worker/parent, 3 practitioners, 1 researcher, 2 research interns
  - ♦ The participants were divided into two groups of 4, with the research interns as a supporting role and contributing to discussions from a research perspective
- ♦ **Duration:** 1.5 hours
- ♦ **Location:** LUMC-Curium
- ♦ **Materials:** Concepts in a digital presentation, templates for each concept, sticky notes
- **♦** Format:
  - ♦ Presentation of concepts and components
  - ♦ Brainstorm for redesigns with sticky notes
  - ♦ Elaborating on the redesigns using the template
  - ♦ Discussions with the group

Figure 18 shows an impression of the setup of the materials used during the co-creation. All workshop materials can be found in Appendix G.



**Figure 18:** Material setup during the co-creation including the templates, sticky notes and How-To;s for some components

# 7.2 Analysis

After collecting the templates and transcribing the audio, the quotes and results were gathered in Miro and coded into categories: Additions, suggestions, challenges, emotions/dynamics. After labelling, the quotes were divided into titled clusters. The titles were based on themes that emerged from the co-creation session and the specific quotes in the clusters. Insights and suggestions (specific to the presented concepts) were then derived from the clusters. The insights served as the main criteria and the suggestions as helpful criteria in the next ideation phase.

# 7.3 Results and insights

This section covers relevant results and insights gathered.

There was significant enthusiasm about the concept of *Rewriting* the Story. Participants appreciated the opportunity to gain a fresh perspective on the stagnated situation. Also, there was considerable discussion about the distinction between filling in the story for someone else versus asking open-ended questions to elicit their perspective.

All three directions demonstrated potential and sparked reactions and additions. Many participants perceived the directions not as separate pathways, but as sequential steps in the overarching process of *centering the story*.

The conceptual directions were often merged during the co-creation, or components from different directions were combined. The directions became intertwined, with all suggestions being linked back to the process of *Mapping the Story*. This direction was considered the first step and crucial step to take before going to the other directions: *Concrete and Useful* and *Rewriting the Story*.

To conclude, the design directions besides *Mapping the Story* can not be taken separately. *Mapping the Story* should form the foundation of the design; it is the first and crucial step in the process of centering the story. The directions were integrated and reformulated into a coherent design goal (Figure 19).

From the described results and the analysis of the quotes, the following criteria emerged:

- ♦ The story should be adaptable within the design
- ♦ There should be freedom in how the design can be used, in order to accommodate different stories with different components

- ♦ The design offers space for reflection and for piecing things together in preparation for the story
- ♦ The design makes it accessible to reflect together on the stories and work toward a shared story
- ♦ The design breaks the tension between youth, parent, and practitioner and provides an accessible way to do so
- ♦ All perspectives must be heard, with the youth's story taking priority
- ♦ The design serves as a tool for gaining insights into each other
- ♦ Differences and similarities are acknowledged with the design
- ♦ The design empowers the youth

The final list of criteria, including the criteria mentioned before in the process, can be found in Appendix H.

### 7.4 Conclusion

This chapter demonstrated co-creation I and its outcomes. The goal was to choose the most promising conceptual direction, but the conclusion was that the directions should be taken together. Whilst Mapping the Story was chosen as the body, the other directions will not be left behind. They will serve as reference points to design a complete prototype, taking different steps into account.

Finally, a specified design statement was defined for clarity and use for the ideation phase. To support this, and all prior findings from the activities, a final list of criteria was defined, as a reference point for the next design activities.

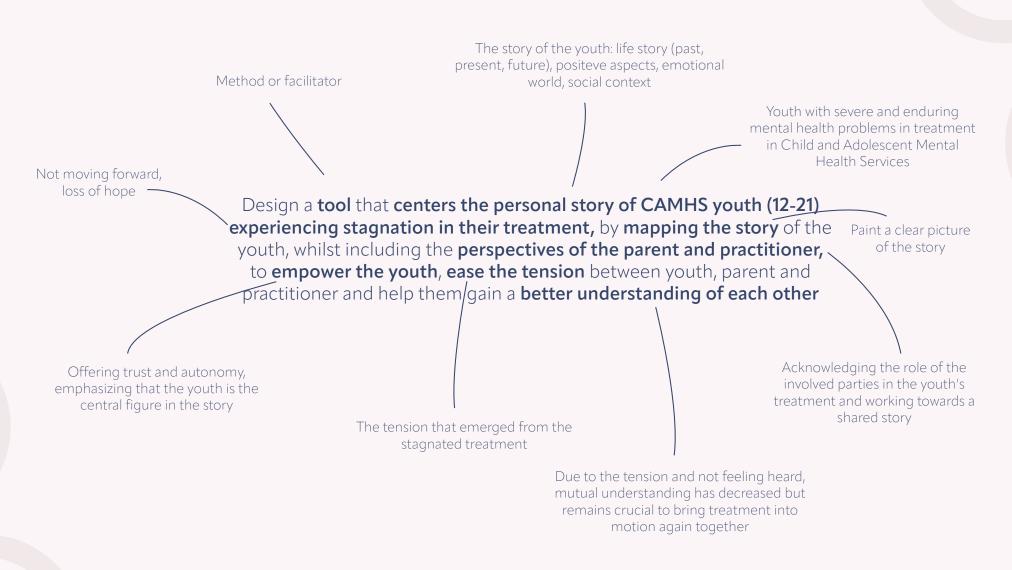


Figure 19: Reformulated design goal combining three design directions with the focus on mapping the story

# 8 Ideation

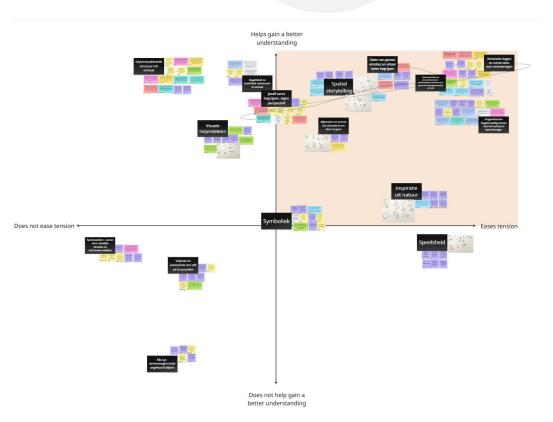
After collecting the insights from the cocreation, they were translated into design criteria. The criteria were used for the ideation phase to diverge within the chosen design direction. Several ideation methods were used in order to generate new, novel and creative ideas. The ideas were clustered and the best clusters were chosen based on design choosing methods to justify the choices made. The ideation phase concluded with elaborate sketches of five directions and finally three chosen directions for designing concepts.

### 8.1 Approach

The ideation process was based on the main criteria defined after co-creation I in Appendix H. Ideas were brainstormed with the use of three ideation methods: Criteria rewritten into How-To questions, negative brainstorming and the Lotus blossom technique. Negative brainstorming is a method where the criteria is rewritten into the opposite, and encourages designers to change their perspective and keep implications in mind. The Lotus Blossom technique is similar to a mind map, but in this context it was used to address dilemmas that occurred in co-creation I with the focus on reaching a middle ground. The choice was made to use several techniques for ideation in order to brainstorm a variety of ideas that could fit the design goal. (*Design Kit*, n.d.; Design Method Toolkit by the Digital Society School, n.d.).

These ideas were categorised and clustered, similarly to the previous clustering processes. The SCAMPER method (Appendix I) was used as the last step of ideation to make sure diversity was reached. Finally, a c-box matrix was used to choose the best fitting clusters. A c-box is a tool to evaluate designs against key goals, supporting clear and informed decisions (Van Boeijen et al., 2020). The criteria in the matrix were: *Eases tension* and *Helps gain a better understanding*. They were extracted from the design goal as they were key criteria that the design should meet. Figure 20 shows c-box set up with the clusters arranged into the boxes.

After choosing the clusters in the c-box, elaborate sketches were made as a step towards concepts. Then, three were chosen by using the weighted objectives method. The weighted objectives method assigns different levels of importance to design goals, reflecting their relative priority. This approach enables designers to evaluate concepts more effectively by focusing on the criteria that matter most.



**Figure 20:** C-box set up: The orange square represents the chosen clusters - meeting both requirements of Eases tension and Helps gain a better understanding

#### 8.2 Outcomes

This section will discuss the choosing process of the three best ideas to develop into detailed concepts.

Five elaborate sketches were drawn and used in the weighted objectives process (Appendix J), which will be explained below:

- ♦ Spatial storytelling: A set of cards with specific questions about important locations in the lives of youth, parents and practitioners. There is a big map where the locations are pinpointed with room for adding photos of the important locations. The users can take these photos or bring them and elaborate with text or by speaking about it.
- Sharing emotions and understanding each other: An adjusted empathy map with materials for collages. The empathy maps can be filled in individually by youth, parent and practitioner and for each other. Finally, in the session, they can be compared and combined into a big empathy map as a shared story.
- Making connections, understanding yourself and acknowledging differences and similarities: A shared mosaic piece. Youth, parent and practitioner all have their own colour mosaic pieces, and there is a fourth colour to use together. The pieces are meant to be written on with the use of prompts, creating a personal story, piece by piece. In the session, youth, parent and practitioner will go through their individual pieces and lay them together, next to connecting or different parts of their personal stories. The fourth colour will be used to write down the shared parts of the story. These pieces will form a visual mosaic showing everyone's colours.
- ♦ Symbolism: A spiralling shell. From the outside towards the inside, there are pieces of the shell that include prompts and questions to talk about to map the story. Towards the core of the shell, the prompts and questions get deeper and more concrete. The story

- can be written on shell-shaped sticky notes in a notebook or album.
- Keeping track, a process that motivates to build the story step by step: A mirror that asks daily questions to the individuals. The youth, parents and practitioners can write the answers on the mirror and the saves the answers and translates them into a digital document. This document contains everyone's answers and together, youth, parent and practitioner can add and make additions to the story to make it a shared story with everyone's individual perspective clearly incorporated.

The weighted objectives used the main criteria previously mentioned. This method helped prioritize which design goals are most important, ensuring that the selected concepts best align with the highest priorities. This approach provides a clear, objective way to compare options by emphasizing the criteria that have the greatest impact on the success of the design. The drawn out ideas and the weighted objectives can be found in Appendix J and K.

The three chosen designs were *Spatial storytelling*, *Sharing emotions and understanding each other* and *Making connections, understanding yourself and acknowledging differences and similarities*. They scored highest in the weighted objectives and therefore have the most potential to be meaningful and have an impact in practice. The other two designs showed potential and certain aspects will be carried forward to help shape improved concepts.

### 8.3 Conclusion

This chapter illustrated the ideation process where many ideas were generated in order to diverge within the chosen design direction. The ideas were divided into titled clusters and mapped on a c-box matrix for choosing which clusters to elaborate on with further ideation. After sketching and elaborating on five clusters, three were chosen with the weighted objectives method.

The three chosen ideas were first improved by making sure they met the criteria from the weighted objectives before they were translated into detailed concepts and mock-ups in the next phase.

# 9 Design concepts

This chapter introduces the three design concepts developed based on the insights and criteria identified in the previous phase and the ideation process discussed in Chapter 8. Each concept explores a different way to reach the goal of mapping and centering the story through mutual understanding and breaking tension.

# 9.1 Concept 1: Where we Stand

This concept is based on the previously mentioned *Spatial Storytelling*. Through sharing memories of meaningful locations throughout their lives, youth, parent and practitioner can understand each other, make connections between their stories and map a shared story together. The shared story is mapped by easing tension between users and help them gain a better understanding of each other.

The concept exists of several steps and has a distinction between an individual and a shared part of the process. The individual part helps everyone reflect on their own story first and prepare for the shared part where stories will be discussed. Figure 21 shows the components of the concept as a whole and Figure 22 presents the intended use of the concept, from the youth perspective. Note that the process is the same for youth, parent and practitioner.

The figures on the cards represent the depth of the questions; the fully coloured figure representing the deepest level and the figure with only the outer layer coloured representing the lighter topics.

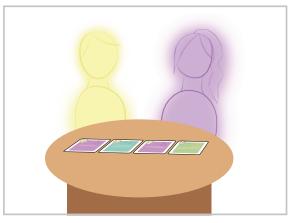
The mock-up for the concept can be found in Appendix L. Note that the mock-up is in Dutch, as this aligns with the target group's language. For this mock-up, a few more questions were added to the cards.



Figure 21: Components of concept 1: Where we Stand



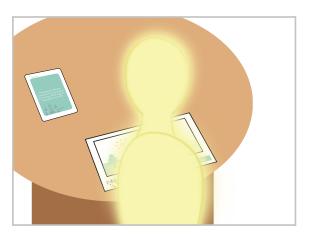
Youth, parent and practitioner all separately receive a box containing the camera, cards and theme stickers.



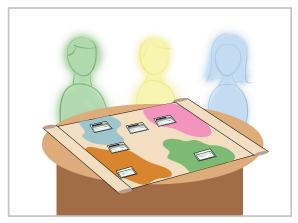
Together with someone from their support system, the youth can choose cards with questions and explore places and objects to photograph that relate to those questions.



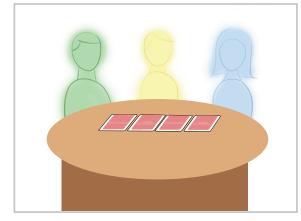
The youth takes photographs for the cards.



The youth can now write down a photo description and answer the question on the card. The theme sticker can be placed on the photo to clarify the theme.



Youth, parent and practitioner can put the photos on the big map and make connections between them. They could focus on differences or similarities such as evoked emotions.



Finally, they can use reflection cards to reflect on the process. This step is meant for bringing their story to the next level, making adjustments if needed, and start thinking about the next steps in the process.

Figure 22: Intended use of concept 1: Where we Stand

# 9.2 Concept 2: The Empathy Page

This concept is based on the previously mentioned *Sharing emotions and understanding each other.* By opening up about themselves and expressing the emotions that arise alongside sensory experiences, and by doing this for each other, youth, parents, and practitioners begin to understand one another through both their own and each other's perspectives. Empathy and emotion become the means to reach mutual understanding and, ultimately, to map their shared story together. The goal of this concept is to gain a better understanding of each other with the focus on inner emotional world, by mapping a shared story.

The concept exists of several steps and has a distinction between an individual and a shared part. The individual part helps the user understand their own feelings and reflect on others' feelings before discussing it together. Figure 23 shows the shared empathy map and Figure 24 presents the intended use of the concept from the youth's perspective. The use is the same for youth, parent and practitioner, with the youth receiving an extra empathy map for someone from the system to fill it in. The other empathy maps, for others and shared, can be found in Appendix M.

After everyone has filled in the empathy maps, youth, parent and practitioner can discuss them together. All parties get the chance to read what the others wrote about them, ask questions and make adjustments to what has been written.

The empathy map includes a question that looks forward to the next step in the process, helping youth, parent and practitioner discuss the purpose of the story and the next steps to be taken.

For the mock-up of *The empathy page*, the pages were printed; A3 size for the individual empathy map and for others and A2 size for the shared story empathy map.

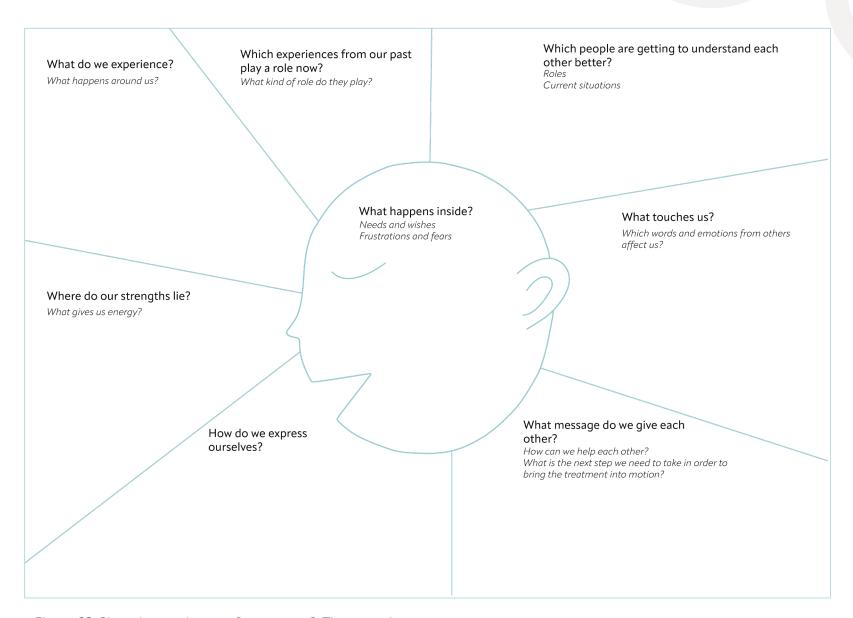
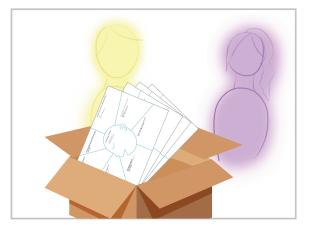
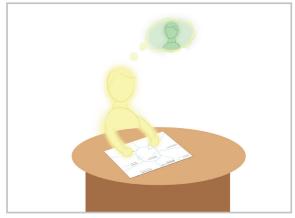


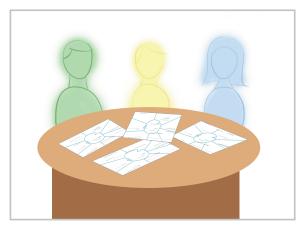
Figure 23: Shared empathy map for concept 2: The empathy page



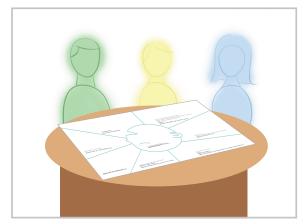
Youth, parent and practitioner receive empathy maps, to fill in for themselves and for the others. The youth gives one extra to someone in their system to fill in for the youth.



The youth fills in the empathy map for their parent, for themselves and for the practitioner.



When everyone has filled in the empathy maps for each other, youth, parent and practitioner will discuss what they wrote about themselves and each other.



When ready, youth, parent and practitioner can use the big empathy map to fill in together and write their shared story this way. The final question will help them reflect and discuss the next steps.

Figure 24: Intended use of concept 2: The empathy page

# 9.3 Concept 3: Mosaic of Us

This concept is based on the previously mentioned *Making connections, understanding yourself and acknowledging differences and similarities.* By focusing on connections, similarities and differences in each of the stories and combining it accordingly, youth, parent and practitioner see all personal stories come together and coexist, and a pathway is created for mapping their shared story. The goal of this concept is to ease tension by mapping the story in a playful and creative way and acknowledge differences and similarities between each other.

The concept exists of several steps and has a distinction between an individual and a shared part. Figure 25 shows the different components and the concept as a whole and Figure 26 presents the intended use of the concept.

Appendix N includes the mock-up of this design. The mock-up includes the booklet and extra questions added.

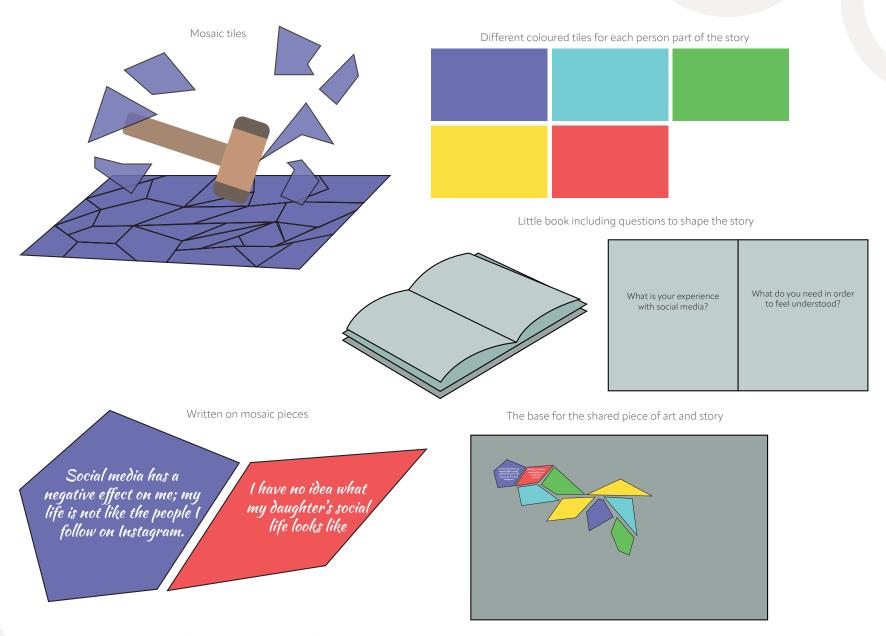
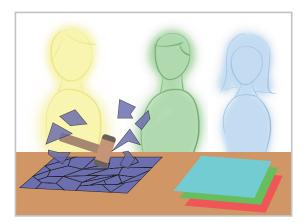
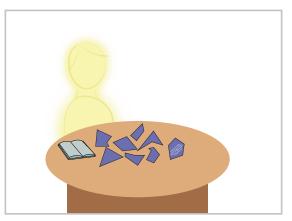


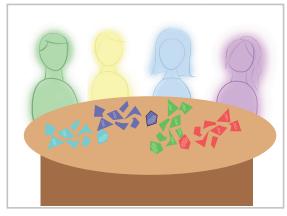
Figure 25: Components of concept 3: Mosaic of Us



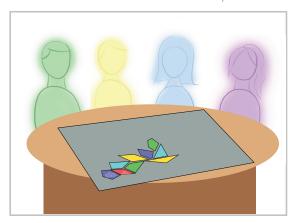
The process is kicked off by breaking the tiles together. Everyone chooses a colour and together they decide who else needs to be part of the story and break a tile for them as well. There is one extra tile for the shared story.



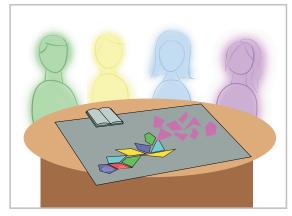
After collecting the mosaic pieces in their own colour, youth, parent and practitioner receive a little book with questions that help them write their personal story on the tiles.



Together, youth, parent, practitioner and others who are part of the story, lay out their mosaic pieces and discuss their stories.



The mosaic pieces can be placed onto a large base. The differences and similarities of the stories can be discussed and the mosaic pieces can be arranged accordingly, creating a shared piece of art.



Lastly, the final colour of mosaic pieces can be filled in together. The book includes questions to complete the art piece with the shared part of the story as well as defining next steps in the process.

Figure 26: Intended use of concept 3: Mosaic of Us

# 10 Co-creation II – evaluating the concepts

The three concepts were presented in the Curium project meeting and their use was refined before the design mock-ups for the co-creation were developed. Co-creation II was conducted to evaluate the concepts presented in Chapter 9. The co-creation was held with people form the target group: youth and a parent who have had experiences with stagnated psychiatric treatment in youth psychiatry. The mock-ups were introduced and the participants were asked to give their feedback and redesign ideas and eventually choose their preferred design. The key question for co-creation II is:

Which design (combination) is the most promising for building on for the final prototype?

## 10.1 Setup

The co-creation was set up in a similar way as co-creation I: Participants were introduced to the designs, and discussions played a key role in gathering opinions and valuable insights.

Before the co-creation, participants were sent a small assignment with a sensitizing purpose. Concept 2: The Empathy Page was sent to them along with a few questions about their first impression.

The three mock-ups were not tested as complete concepts but rather through separate parts and elements of the overall experience. After being presented with the designs, the participants received the mock-ups. The mock-ups had their accompanying scenarios and the participants could interact with the designs and discuss them. After interacting with the mock-ups, the participants could write their opinions on colour-coded sticky notes which were gathered on A3 sized sheets. The sticky notes were divided into four categories: Change/adjust, Keep, Add, Unclear/not fitting/uncomfortable.

The setup of the co-creation session was as follows:

♦ Participants: 3 total – 2 youth, 1 parent

**Duration:** 2 hours

♦ Location: LUMC-Curium

♦ Materials: Designs in a digital presentation, Physical/paper mockups, sticky notes

♦ Format:

◊ Icebreaker

♦ Explanation of the session structure

♦ Presentation of the three designs

♦ Interacting with the mock-ups

- ♦ Writing down feedback on the colour-coded sticky notes
- ♦ Discussions after each mock-up round
- ♦ Final discussion and sharing opinions about their preferred design(s)

# 10.2 Analysis

Audio recordings and sticky notes were gathered as data. For the analysis, the audio was transcribed and the sticky notes were digitalised in Miro. The sticky notes and reactions to each concept were categorised by their colours and divided into pros, cons and improvements. Finally, each participant's preference was taken into account and the pros and cons per concept were weighted against each other. The concept that had the most potential and positive aspects, was chosen as the base for the final prototype. Aspects from the other concepts that were positively experienced and missing in the chosen concept, were added to enhance the final prototype.

## 10.3 Results and insights

This section covers relevant results and insights gained during the cocreation.

### 10.3.1 Concept 1: Where we Stand

Figure 27 shows the setup of the concept during the co-creation.

This concept was experienced as overwhelming. Participants noted that the amount of tasks and steps that need to be taken in order to map the story individually and together, was too much for someone who is experiencing stagnation and feels stuck in their psychiatric treatment. Especially for the youth, the concept would not reach its intended purpose and might even add to the frustrations they are already experiencing.

Some aspects of the questions and statements on the cards were appreciated and participants mentioned the importance of speaking about positive aspects in their past. The questions could however be more simplified and less complex; the complex questions could better be saved for future. This aligns with the intended purpose of the icons showing depth, allowing users to choose how emotionally deep or complex they want to go. Since this remained unnoticed by the participants, it was kept in mind to clarify this element.

Also, using an instant camera and taking pictures was mentioned as a high threshold, since some youth might be undergoing inpatient treatment, and going outside to take pictures might not be possible for them. Besides that, youth who are not undergoing inpatient treatment could still struggle to go outside, even with someone from their system supporting them.

Participants suggested lowering the threshold and making the concept more inclusive by allowing users, especially youth, to print or cut out pictures from magazines.

It was appreciated in the concept that practitioners are full users of the concept, sharing the same role as youth and parent. The encouragement for disclosure of the practitioner was especially valued.



Figure 27: Set-up of design mock-up 1 during co-creation II

### 10.3.2 Concept 2: The empathy page

Figure 28 shows the setup of the concept during the co-creation.

This concept was experienced as very difficult. The questions on The Empathy Pages were difficult to understand and answer for both the individual pages and pages to fill in for others.

The number of questions felt overwhelming and reminiscent of what youth often encounter in treatment; yet another long list of questions to answer, possibly creating a sense of dread.

Something that resonated with all participants was that the explanatory, smaller questions below the big questions, were unclear and made the use more complex. Instead of an extra question, they suggested explanatory answers to the big questions for users to understand what is expected of them.

The questions were also experienced as too deep and personal, making it especially difficult to fill in for others but also for yourself. Participants felt that reflecting on oneself is already difficult, and that in this situation, with the complexity of the questions, it would be more challenging.

One of the participants saw value in the individual part of the concept before discussing answers and filling in the Empathy Page as a shared answer. Individual reflection on such deep questions requires time and should not be rushed.

The future perspective that was a small element of the shared Empathy Page, was appreciated by the participants. However, this could be more emphasized since a future perspective adds a lot of positivity to the story.

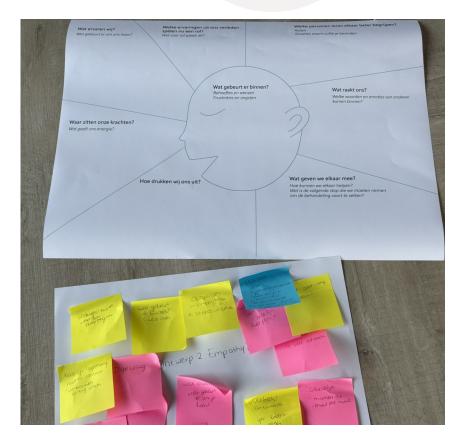


Figure 28: Set-up of design mock-up 2 during co-creation II

### 10.3.3 Concept 3: Mosaic of Us

Figure 29 shows the setup of the concept during the co-creation.

This concept was experienced positively and as the most calm and simple of all. Participants appreciated the creative and collaborative aspects.

A concern that was mentioned, as well as in the Curium project meeting, was that breaking the tiles for the mosaic could be a safety hazard and triggering for youth in psychiatric care. One youth participant mentioned having participated in mosaic making as part of their therapeutic day program and that it might be possible to do it in a safe environment.

The collaborative aspect where users have to work together to create a shared piece of art, was appreciated. Participants mentioned how working together and also focusing on the way the mosaic looks, could lighten the mood.

Giving the youth control over the way the mosaic will be laid out and where each piece goes, was an aspect that participants valued greatly. This is an element that needs more emphasis.

Participants appreciated the flexibility; the freedom to write on the pieces they chose and to arrange them in a visual layout that suited their preferences.

As for the questions, participants found the questions from concept 1 more fitting for this concept.

Again, there was appreciation for the individual reflective part of the concept for users to take their time to answer the questions towards their personal stories.



Figure 29: Set-up of design mock-up 3 during co-creation II

### 10.3.4 All concepts

For all concepts, participants emphasized the importance of restoring the relationship between the three parties before taking part in an activity where users are expected to show vulnerability. Since restoring the relationship is already part of Centering Your Story before my design comes into the picture, there was an assumption that the relationship might already be restored to some extent. However, the parent in the co-creation noted that restoring the relationship takes a long time and is not a fixed step in the trajectory, which is why the final prototype should assume that the relationship between youth, parent and practitioner is not completely restored.

Simplicity was a key theme in all concepts. Creating and conveying a sense of calm is important to help users work together in a low-pressure and meaningful way.

When asked to choose their preferred concept, all participants chose concept 3: Mosaic of Us. This was due to its simplicity, creativity, collaboration and freedom of use. This concept was seen as the most low threshold concept to start using.

### 10.4 Conclusion

A lot of valuable insights were gained during the co-creation. Concept 3: Mosaic of Us was clearly the most successful and calm, which is why it was chosen as a base for the final prototype. Since concepts 1 and 2 had positive aspects as well, elements of them will be incorporated into the prototype.

For the main questions, concept 1 will be used as a reference and combined with valuable questions from concept 2 and 3. The questions from concept 1 were most valued and helped map the story best.

For the questions format, the cards from concept 1 will be used. The cards give the users freedom to choose which questions they want to answer in their preferred order. The cards will be improved through changing and adding themes that align more with the story, such as past and future, and the most valuable parts of the story as mentioned in the co-creation.

As mentioned before, the freedom of use and giving control to the youth should be emphasized in the final prototype. This will be done in the shape of an instruction booklet.

# 11 Prototype: Verbonden

This chapter introduces the final prototype designed for this design thesis: Verbonden. Verbonden, Dutch for connected, is a playful and creative way of mapping personal stories and the shared story of youth, parents and practitioners who are experiencing stagnation in treatment. The goal of Verbonden is to find links between personal stories, revisit memories, envision the future and create a shared story that is helpful for understanding each other and taking the next step towards bringing stagnation into motion. Next to that, the design includes features that help break tension between users and empower youth.

# 11.1 Approach

As explained in the previous chapter, concept 3: Mosaic of Us was chosen as the base for the final prototype. This prototype builds directly on the insights from co-creation II: It combines the preferred concept with key elements from the others. This chapter presents the resulting design, focusing on how the final prototype aims to support mapping the personal story of the youth as well as the shared story of youth, parent and practitioner as a road towards bringing stagnated treatment into motion. Within this aim, easing tension, empowering youth and facilitating a better understanding of each other are key themes to reach the design goal.

## 11.2 Prototype: Verbonden

This section gives an overview of the prototype: Verbonden, by providing the design layout, its components and scenario.

Verbonden exists of several components described below:

- ♦ Story pieces in five colours, 20 pieces per colour
  - ♦ Lightweight wood painted with acrylic paint, in multi-sided geometric shapes with magnetic strips underneath
- ♦ Question and statement cards, 24 pieces
- ♦ Instruction booklet
- ♦ Magnetic board for laying out the pieces, mountable
- ♦ Five felt tips

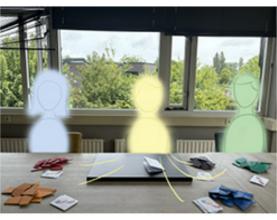
Figure 30 shows a visual overview of the components and Figure 31 shows the user scenario of the design. Appendix O includes all the cards with their questions.



Figure 30: Visual overview of the components of Verbonden



Youth, parent and practitioner have a session together where they choose their own colour of story pieces and decide who else should be part of the story.



When everyone has chosen a colour, they bring home the story pieces, a set of cards, an instruction booklet and felt tips.



Individually, everyone chooses the cards and questions they would like to answer and write their answers on the story pieces.



Together, everyone can lay out their pieces and look at connections, similarities and differences between each of their stories. The youth has the lead and decides on a method for how the pieces need to be laid out on the big board.



Then, they write down their shared story with the shared theme of the cards, on a new colour. This story can also be laid out on the board.



Finally, they answer the reflection cards together to think toward a plan for the future and how they can bring the stagnated treatment into motion again.

Figure 31: User scenario of Verbonden

## 11.3 Design decisions

Many of the core design decisions were shaped by the outcomes of the co-creation, but some aspects change or were added throughout the process of designing the final prototype. This section discusses design decisions and the considerations that led to them.

The material for the mosaic, or geometric shapes, was chosen: Lightweight wood. This changes the interaction of the prototype, since the initial idea was that the users start with breaking the pieces themselves. However, after consideration, it was chosen to leave out this part and choose wood as a material. This was due to the fact that with mosaic tiles, there will be a high chance that the pieces might end up too small for writing sentences on them. To still keep the playfulness of the concept, the shapes will differ is size form, and six colours will be available to choose from. Another reason that wood was chosen, is that the design should be adaptable and adjustable, meaning that the tiles need to be able to move easily. With lightweight wood, it is easiest to use magnets and replace pieces. Finally, the final piece of art can be hung more easily on the wall of the room where the sessions take place, as a reference and as a memory of the shared story and art piece – this is especially more convenient with lightweight wood.

Another design decision was the addition of an instruction booklet. Even though the use of the prototype will be facilitated, for the users and facilitators it will be easier to understand how the product can be used. Appendix P shows the contents of the instruction booklet.

Another design decision is the change of the icons for depth of the questions. The icon that was chosen before, did not stand out and remained unnoticed by the participants of the co-creation. Since the icon was so small, the differences were minimal, hence why the icon was changed into a clearer, simplified icon showing depth. Figure 32 shows the before and after. The description of the levels of depth

is based on the pyramid model of knowledge by Sanders (2002) as shown in Convivial Toolbox (Sanders & Stappers, 2013).

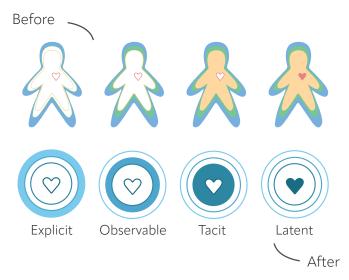


Figure 32: Before and after of emotional depth icons

New themes were added to the cards and existing themes were adjusted. This was done because the first version of themes was not complete and did not align fully with the previously defined story. Also, co-creation II provided insights into the importance of some topics that need more attention. The themes in the concept version were life story, past and social. The final theme was the reflection card, which is not part of the defined story which is why it will not be discussed in detail. The new cards contain the themes Personal, Social, Past, Future and Shared. The themes are illustrated in Figure 33. All cards per theme can be found in Appendix O.



Figure 33: Six themed cards of Verbonden

Life story as a theme was after reflection too broad to be one theme, since it also contains aspects of the past, present and future. That is why the name was changed into Personal, more focused on interests, preferences and the present.

Future was added as a theme, since this was not explicitly present in the other version. Participants in the co-creation mentioned the importance of speaking about desired futures to give a positive twist, which is why the choice was made to add this as its own theme. Also, the future is an important aspect of the defined story.

Shared was added as a theme as inspired by concept 3, highlighting the shared opinions and story. This is a way to link stories and not only show personal stories.

All questions were also reviewed and shortened as the participants thought some questions were long and complicated.

## 11.4 Prototype evaluation

### 11.4.1 Setup

The goal of the prototype evaluation was to evaluate the clarity, emotional experience and to what extent it reaches the design goal and meets the criteria. A set of interview questions were defined for evaluating these aspects.

The prototype was evaluated in two sessions, one with four participants and the other with one.

The first session was conducted with members of the Curium project group: A practitioner, Curium head of research and two parent peer support workers, of which one was outside of Curium. This session lasted 45 minutes.

The participants were presented the prototype and given background information. Then, the prototype was given to the participants and they were asked to interact with it in their assigned roles: Youth, Parent, Practitioner and someone from the youth's system. The participants were guided in the process since in the final use, there will also be facilitators present. After using the prototype, the participants were asked to write their first thoughts on sticky notes. Finally, the evaluation

ended with a discussion about the prototype, with interview questions as quidance.

The second session was conducted with a systemic therapist from Curium who is not connected to Centering Your Story, with experience of stagnated treatments. This session lasted 30 minutes.

The systemic therapist was given more background information. She was asked to read the instructions of the design and explain the use. She asked questions about the prototype and unclarities and expressed her first impression. This session was mainly shaped as an open discussion with interview questions about the prototype as quidance.

### 11.4.2 Results and insights

Both evaluation sessions provided new, valuable insights and suggestions for improvement. The results of the sessions were evaluated against the criteria to conclude to what extent the prototype meets them. This section addresses results and insights.

Figure 34 shows an impression of the results of the prototype evaluation and the setup of the pieces on the magnetic board. The Figure shows the different clusters that the youth role made with the story pieces. When used in real life settings, this setup could be common.



Figure 34: Prototype evaluation results

### Clarity

Firstly, clarity in the steps of the instruction booklet was missing according to participants. This was experienced when participants had to choose cards to answer individually; The themes for together and reflection were not clarified as questions to answer together rather than individually. This suggests a more elaborate instruction booklet as well as an informed facilitator who can help guide the use of the design.

An association was made between the colours of the story pieces and the colours of the themes on the cards, while this was not the intention of the design. This suggests a higher contrast and differentiation between the colours of the pieces and cards.

Participants wondered how they know which question is answered on each story piece. This suggests an addition to the design to clarify this on the pieces could help with discussing everyone's answers.

Additionally, more clarity and context was needed about what the questions were referring to, specifically, which situation participants or users are expected to reflect on. In this situation, it was the goal to reflect on the stagnated treatment as well as personal situations. This suggests that a facilitator could help guide the users to answer the questions accordingly and a clarification in the instructions or questions.

### Emotional experience

A comment was made on the shapes of the story pieces; They are too sharp and might be experienced as triggering by youth. This suggests adjusting the shapes to shapes without sharp edges.

Also, participants suggested that being able to write on the magnetic board could be an addition for making the story their own. The system role suggested that dividing pieces into two drawn sections for the youth, important vs not important, might be helpful.

In the design, users are allowed to choose which questions they want to answer. However, this sparked a discussion between participants since the design should not force users to answer questions but also not give too much freedom for them to dodge all difficult questions. The systemic therapist in the second session suggested choosing a set of questions beforehand as the facilitator in order to have some control over the types of questions that will be answered. The chosen questions will be based on their professional opinion on the situation.

It was mentioned that the themes and questions were too much and random to address in one session and made it feel disorganized. For the youth role, it was mentioned that it felt overwhelming to have so many themes and levels of depth at once, making it difficult to make sense of the storyline. The youth role mentioned to feel a need for more questions on the therapeutic side and perhaps do one theme per session, depending on what the youth would like to discuss. The systemic therapist suggested using the lighter questions as icebreakers at the start of the process, even if they are unrelated to the story. The instruction booklet could include suggestions for different structures of use.

Also, viewed from the youth role, youth need to know what they are working towards. It would be helpful for them to know exactly what they are going to do, how long it is going to take and if there is a way out. This adds safety and a feeling of control.

The youth role felt uncomfortable with being the one in charge of the process of laying the story pieces and choosing the shared questions. It gave them a feeling of being the problem, since everyone was waiting for them to do something. This suggests providing youth more freedom and the facilitators helping them decide the amount of leadership they will take on. The participant suggested that having a peer support worker present might help them feel more comfortable and take control together, which will be implemented in the final design.

From the practitioner's perspective, it was noted that there is no way to hide, since there are many deep, personal questions, though challenging, these were seen as necessary and valuable in the context. However, for some practitioners, this might be a high threshold. This suggests further exploration of questions for practitioners and different types of situations of stagnated treatments.

Participants mentioned the dynamic, creative aspect of writing and laying out the pieces helped ease the tension since the focus is taken away from the heaviness of the situation.

Finally, participants mentioned the importance and the impact of the role of a facilitating systemic therapist. They could guide the conversations and help give everyone a voice in the sessions.

#### Criteria evaluation

The prototype was evaluated against the criteria in order to assess its effectiveness and relevance. This section discusses criteria that were not fully met, as revealed during the evaluations. Appendix Q contains criteria that could not be tested in this phase. The remaining criteria were met, based on the observations and participant responses, and are therefore not discussed further.

The design should give youth a voice and empower the youth

The prototype gives youth control over the session where they can decide how the session goes, where each piece is placed and which shared questions are answered. However, this made the youth role uncomfortable during the evaluation. The design should empower them and make them feel comfortable and safe, suggesting a more nuanced approach that suits every individual.

There should be freedom in how the design can be used, in order to accommodate different stories with different components

The prototype offers freedom, but does not make it clear. This suggests a clarification of different ways to use, provided by the facilitators and instructions.

The design provides guidance for writing a clear story and there are concrete steps and actions that youth, parents and practitioners can work on together

The guidance was experienced as a little unclear and chaotic. This was due to the different themes and levels of depth all at once. The steps created, especially concerning the reflection questions, could be experienced as more concrete and clear if facilitators are involved. Also, users and facilitators may choose to focus on one theme per session.

The design provides space for youth to develop a personal vision for the story

This criterion was not met fully since the design needs to provide space for youth to think about their role in the process as well, in terms of the amount of control they would like to take. This suggest clarification and support during the individual part of use.

# 11.5 Implementation

This section will discuss implementation plans to ensure Verbonden can be successfully put into practice. It includes the setting, the users and stakeholders, how it is introduced, frequency, conditions, potential risks and next steps.

### 11.5.1 Setting

Verbonden is a design that will be part of the trajectory proposed by the Curium project group for Centering Your Story, with the main goal of bringing stagnated treatment into motion. Verbonden will be brought in after the commitment phase and restoring the relationship between youth, parent and practitioner. This trajectory will take place in a therapy setting at LUMC-Curium and when successful, also in other Child and Adolescent Mental Health Care Services in The Netherlands. It is not part of the therapy itself, but rather a separate trajectory when stagnation occurs.

Part of the use of Verbonden will be at a home setting where each user takes cards and story pieces home for individual reflection in preparation for the shared part of Verbonden.

### 11.5.2 Users and stakeholders

Verbonden will be used by youth with severe and enduring mental health problems, their parents and practitioners who are currently experiencing stagnation in treatment as primary users. People from the personal support system of the youth or parent may be involved in the use, based on the preferences of youth and parent.

As facilitators, external youth peer support workers and systemic therapists, will be brought in. They will guide the sessions during the trajectory as well as make sure everyone feels comfortable and equal.

### 11.5.3 Introduction

The trajectory of Centering Your Story, of which Verbonden is part of, will be introduced by the Curium project group to youth peer support workers and systemic therapists. They can sign up as facilitators and will subsequently take part in a facilitator training in order to guide the complete Centering Your Story trajectory. Then, when therapy stagnates and calls for help, they will be brought in to facilitate the trajectory. When Centering Your Story will be fully implemented, there will be a list of trained facilitators who can be brought in whenever needed. Verbonden will be introduced to the users and they will receive a brochure (Appendix R) when the trajectory arrives at the stage of centering the story. During the sessions, an instruction booklet will be handed out to the users and facilitators.

The magnetic board for the story pieces will be kept by the facilitators until the end of the trajectory, giving space for the story to change later in the process. Every case has their own board and when the trajectory is finished, youth and parents may decide to keep the board.

### 11.5.4 Frequency

Verbonden will be used for a flexible amount of time and sessions. Each session may take approximately an hour. The sessions will be structured based to the preferences of the youth and professional opinions of the facilitators. They can decide what order of cards or activities will work best in specific cases.

### 11.5.5 Conditions

For Verbonden to work well in practice, certain conditions are necessary. Firstly, in the starting phases of implementation, Verbonden can only be brought in for stagnated treatments. Secondly, youth, parents and practitioners need to be committed to try bring their stagnated treatment into motion again. All parties need to be emotionally ready and feel comfortable starting the trajectory of Centering Your Story and specifically the stage of Verbonden. Thirdly, the organisation, in this case Curium, should be supportive of the trajectory and provide the necessary space, time and means for Verbonden to be successful.

### 11.5.6 Potential risks

The use of Verbonden comes with potential risks that should be considered before implementation.

Firstly, there might be resistance from users. This refers to all parties, who may feel uncomfortable answering in-depth questions and sharing personal and emotional information about themselves. This might especially be difficult for the practitioners since usually they are the facilitators of the session and disclose little about themselves.

Subsequently, the use of Verbonden may have a deep emotional impact on its users due to its deep questions and highly collaborative nature. It might be draining and a high threshold at first, but later in the process it should be a helpful tool. The emotional impact should be considered and handled with care by the facilitators.

### 11.6 Conclusion

This chapter introduced the final prototype and last iteration for the design thesis: Verbonden. Verbonden is a tool that exists of magnetic story pieces and a magnetic board, where youth, parents and practitioners can map their story together. Cards with different questions help users write their personal and shared stories.

The prototype was evaluated with Curium project group members and an external parent peer support worker, and with a systemic therapist, representing the role of a practitioner and facilitator. The evaluations sparked valuable discussions, insights and suggestions, which can be used in the next stage of Centering Your Story and the development of Verbonden.

Finally, the chapter concluded with implementation plans to help bring Verbonden to the next level and successfully into practice by the Curium project group.

# 12 Conclusion

This report aimed to present an overview of the design thesis based on Centering Your Story, presenting the research and design activities conducted during the course of the design thesis and how it helped shape decisions and final design. A personal goal was to encourage the practical application of design expertise in healthcare settings.

### Literature review

The project st arted with a scientific literature review, diving into the complex world of psychiatric care and youth with severe and enduring mental health problems as well as learning about the meaning, causes and impact of stagnation in treatment.

Firstly, characteristics of youth with Severe and Enduring Mental Health Problems were identified in order to gain insights into challenges they face, their vulnerability and factors that influence them.

Then, causes for stagnation and treatment failure were researched. Some causes for stagnation and treatment failure include: A lack of epistemic trust, loss of hope after prolonged and multiple admissions without improvements, lack of flexibility of therapists, neglection of common factors, poor client-therapist match, lack of transparency and external factors (McCormick, 2021; De Soet, Vermeiren, et al., 2023; De Soet, Nooteboom, et al., 2023).

Additionally, literature on collaboration in therapeutic settings was reviewed to gain insights into why there is a lack of collaboration, what might help facilitate open communication and better collaboration. An important insight from the literature is the need to empower youth by giving them more control over their treatment, allowing them to make decisions on their own or be actively involved.

Epistemic trust was a recurring topic and it was concluded from the literature that: As epistemic trust is key for preventing stagnation, it is also key to regain epistemic trust to bring stagnated treatment into motion again.

Finally, the literature highlighted the benefits of including Peer Support Workers in therapy as well as the potential positive effect when brought in as facilitators for bringing stagnated treatments into motion again.

During the course of the design thesis, a lack of definition of The Story was noted. Since The Story is a crucial part of the thesis and the final design, it was important to reflect on what it should consist of and what the different existing definitions of narratives contain that could contribute to the story in the design thesis. This research was based on scientific literature and referring to the qualitative research done by Curium and helped bring more definition into the design thesis.

### Qualitative data analysis

A selection of the research done by Curium was analysed and insights were gathered to bring to the next phase of the design thesis.

One of the main insights is that youth lose epistemic trust because their story is not acknowledged or taken into account. Secondly, youth and parents emphasize the importance of considering background and environmental factors. Additionally, a personal vision from the youth is needed for creating the story as well as giving youth a voice and autonomy. A further insight is that the story does not have to be perfect, just helpful in order to move forward. Lastly, a significant insight is that parents want to feel heard and actively involved as well.

Due to the complexity of the design thesis, literature research was conducted alongside the design process to continuously incorporate theoretical insights and expert knowledge into the development of the final design.

### Design

After the research, design directions were defined and refined with the help of the project group at Curium during the two monthly project meeting. The design directions were then translated into conceptual directions and presented at co-creation I to the project group at Curium. This co-creation set the tone for the rest of the design thesis and helped redefine the design goal and define a list of criteria for the next phase of diverging in ideation.

Subsequently, the ideation phase started. Many ideas were generated, based on the criteria and inspired by the suggestions from the cocreation. After generating ideas and converging, three elaborate ideas were chosen to conceptualise.

The concepts were presented to the Curium project group, and feedback was used for refining concepts and designing mock-ups. The concepts and mock-ups were then presented and tested with the target group during co-creation II. The feedback given by the target group was finally used to combine and refine concepts and design the final prototype for this design thesis.

Finally, the prototype was designed: Verbonden. Verbonden is a playful and creative way of mapping personal stories and the shared story of youth, parents and practitioners who are experiencing stagnation in treatment. The goal is to break tension, empower youth and help users gain a better understanding of each other by mapping their stories.

Verbonden was evaluated with the Curium project group, an external parent peer support worker and a systemic therapist. Insights will be used in the next phases of the design within Centering Your Story.

The work conducted has provided valuable insights into the context of Centering Your Story, the context of psychiatric care and youth with severe and enduring mental health problems. It helped highlight the key focus points and choose design directions. In addition, cocreations were key moments that helped shape the design thesis and the final design in order to fit the target group as seamlessly as possible.

# 13 Reflection and limitations

Centering Your Story was a complicated project containing different aspects to keep in mind while designing. Working on this design thesis helped me extract information and find a focus in a quick and efficient way. A reflection on the design thesis and limitations will be discussed in this chapter.

# 13.1 Reflection

One of the main complexities of the design thesis was the broadness and the amount of difficulties that need to be addressed. It was difficult to choose a scope and leave other aspects behind that also need to be addressed. However, due to the amount of time, it was unrealistic to try to fix everything and the focus of Centering the Story may contribute to fixing other aspects of the bigger picture as well.

Secondly, another layer of complexity relates to the range of stagnated situations in treatment; designing for various situations at once asks for leaving things open to some extent, while still providing enough guidance for users. This was challenging, as the target group requires concreteness and clear steps to ensure a clear path towards bringing treatment into motion again. To accommodate for this, concreteness and openness were used in a balanced way, only leaving things open when necessary.

Another complexity is the vulnerability of the target groups. The stagnated situation they are experiencing is for most people the last resort of treatment after trying many different treatments, where they have given up and do not see it getting better. When something does come their way to help them out e.g. Centering Your Story, it has to be different and good enough for them to believe they can move forward from the situation. As a designer, some pressure was felt, since it is

important to present something that motivates them and brings back hope rather than contributing to their hopelessness.

Lastly, a notable challenge was catering to the needs of three distinct groups who are not getting along anymore. Designing for more than one target group makes it difficult to shape the language style, visual style and interaction to fit all users. Even with the assumption that the prior commitment phase and working on recovering their relationship has had its contributions, the threshold for all three parties to work together and trust each other remains high. This is why in the design, different levels of topics are introduced to ease the tension first.

### 13.2 Limitations

A limitation that was encountered in the design thesis was that there was only one possibility to do a session with the target group, rather than multiple. Due to the specificity of the target group and with that also the reachability, it was not possible to do more than one session in the span of the design thesis. It would have been helpful to conduct more sessions with more participants for understanding the target group's wants and needs better.

Co-creation II was initially planned with seven participants. However, three participants were present at the end. The remaining three participants were very helpful and made the co-creation valuable, but there was no practitioner present, and more input would have helped gain more insights into the concepts. Also, if more people participated, more perspectives and more improvements for the final prototype could have been gathered. This limitation is one that reoccurs often in healthcare settings with vulnerable groups and topics. More time in the design thesis could have helped gather more participants.

Another limitation of this design thesis is that the final prototype can not be generalised, since it is highly contextual. The design was based on the limited participants that were encountered and a specific target group experiencing stagnation. Since the design was not tested in other contexts and settings, it can not yet be applied in a broader context.

A final limitation is that the impact of the prototype can not be immediately observed or measured. Mental health care trajectories often unfold over extended periods, making it difficult to evaluate whether the prototype achieves its intended goals within the limited timeframe of the design thesis. Assessing the long-term effects of Verbonden within Centering Your Story, would require a pilot and extended implementation. As a result, this evaluation focuses on immediate impressions and qualitative feedback, offering indications of potential value, although the long-term impact can not yet be measured.

# 14 Recommendations

This section discusses recommendations for further work and exploration concerning the design thesis. Recommendations in different themes and areas will be provided.

### Epistemic trust

Based on literature and qualitative research, epistemic trust plays a big role in treatment failure and stagnation in therapy. Even though this is partly a systemic problem, the fact that youth lose trust in the system remains an issue. The qualitative research concludes that the loss of trust can emerge from youth having to change practitioners frequently. Since youth with severe and enduring mental health problems have had different treatments and practitioners, they have trouble trusting new people. The fact that they change practitioners so often, even in the same care environment, makes it difficult to have to trust again every time. It is therefore recommended that psychiatric practices really look into this issue and find a way for youth to feel safe and trust again.

### Scope

During the design thesis, there was no space for a bigger scope, but it could have brought more richness to the final prototype. It is recommended to conduct more research, with a focus on improving the prototype and broadening the perspective for other areas and phases of Centering Your Story. This way, by enhancing the current design, it can be used in a broader range of contexts and accommodate for other aspects and problem areas in addition to The Story and bringing stagnated treatments into motion.

### Use

Additionally, the final prototype presents one way of use. It is recommended that in the next phases of the design, other ways of use are explored in terms of format and variations to cater to a variety of preferences. A suggestion is creating a booklet of inspiration for facilitators as a way of introducing different ways of use to the users.

### Distinction of users

Furthermore, through the course of the design thesis, the main focus lied on the youth and their experiences. The use of the prototype was also focused on the youth and making sure it fits them as well as parents and practitioners. There is no clear distinction between the use of the prototype for youth versus parents and practitioners. However, in reality this might differ; practitioners might not want to or feel the need to share as much as the youth and parent. Since there was no clear distinction made between the use for the three groups, it is recommended to look further into the dynamics and interactions during the next iteration of the design, to optimise and improve the flow of use if issues arise. It is suggested to evaluate the questions on the cards with all parties and accordingly adjust the cards for each party.

### **Iterations**

Additionally, the final prototype has not been tested with the target group yet, so it is recommended to test the prototype and make another iteration before pilot testing. This is to ensure that the prototype is improved on little aspects that only the target group might notice. One final iteration will make sure the prototype makes the intended impact and reaches its goals.

For the next iterations of Verbonden in the context of Centering Your Story, it is crucial to work closely with systemic therapists before implementation; This assures feasibility and clarity of the design for facilitators.

### Iteration on cards

Also, the design should be evaluated again, with a larger focus on the questions, their intentions and whether it works for mapping a personal and shared story. It is also recommended to test how Verbonden will work when the themes are divided into different sessions, how the youth's emotional experience will be with this adjustment and whether it will help bring calmness and concreteness into the use of Verbonden.

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# Appendix A: Project brief





#### Personal Project Brief - IDE Master Graduation Project

Name student \_ Ece Canimoglu Student number 5,085,500

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT Complete all fields, keep information clear, specific and concise

Project title

"Jouw Verhaal Nu Centraal"

Please state the title of your graduation project (above). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

#### Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

This project proposed by the supervisory team on the TU Delft website, focuses on the medical field of psychiatry, addressing the challenges youths with severe and enduring mental health problems face in treatment. Some of these youths experience stagnation in their treatment. This recurring problem creates significant (psychological) complications, not just for the youth, but also for practitioners and parents. In addition to stagnation, the challenges youths face in treatment significantly impact their quality of life and Bansema et al. (2023) emphasize the need for a more holistic approach- one that focuses on understanding each individual's unique experience and look beyond classifications. The context of this project is LUMC-Curium in Leiden, which is the youth psychiatry department; a specific project this department is working on is with youths aged 12-21. Their goal is to design a solution that helps them resolve stagnated treatments. One of the key challenges is addressing the needs of all involved parties - youths, practitioner and parents - without compromising any of them. An important aspect is the practitioner-patient interaction, which affects the outcome of the treatment greatly in terms of stagnation or even dropout (De Soet et al., 2023). While youths are the main focus, the roles and perspectives of practitioners and parents are crucial in their treatment and recovery process, often leading to different views on issues such as sharing treatment information and involvement.

Personalised intervention in psychiatry is one of the many approaches used to tailor treatment to the patient's needs, smoothening the treatment and combining different types of treatment (Ng & Weisz, 2015). While there is a variety of approaches (in practice and on the rise) centering the patient's needs, indirectly aiming to prevent stagnation in treatment, the problem of stagnation remains despire their higher success than standardized approaches (Li et al., 2024). It is valuable to look into these approaches to determine why stagnation still occurs and what this project can contribute. Figure 1 provides an initial overview of the problems and needs of the stakeholders I will be focusing on. Figure 2 shows some existing initiatives for stagnated treatment in Child and Adolescent Mental Health Services (CAMHS) psychiatry in LUMC-Curium and other CAMHS-institutions.

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#### introduction (continued): space for images

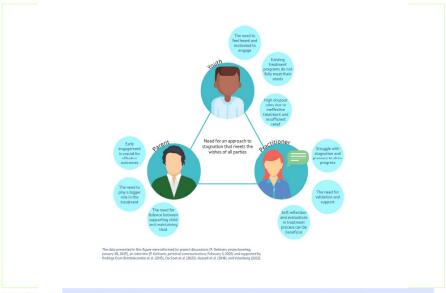


image / figure 1 Initial overview of important problems and needs to take into account per stakeholder

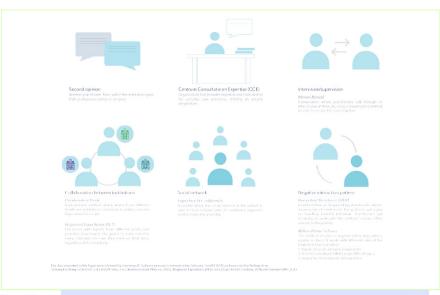


image / figure 2 Some of the existing initiatives used in treatment and for stagnated treatment in youth-psychiatry





#### Personal Project Brief – IDE Master Graduation Project

#### **Problem Definition**

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice. (max 200 words)

The project is focused on youths aged 12-21 who are currently in treatment at Child and Adolescent Mental Health Services (CAMHS) with severe and enduring psychological problems. Some youths in this group, along with their practitioner, experience a lack of progress in their treatment, leaving them feeling stuck. This stagnation can be particularly stressful and demotivating for such a vulnerable group. Patients often do not feel heard at this stage and the focus seems to lie on the problem rather than the patients' wants and needs.

Currently, the trajectory that the stakeholders go into to try continue the treatment, does not engage them enough in the process. There is an opportunity in re-focusing the attention on the personal story, along with the needs and wishes of the youth, offering a new sense of motivation and hope, to eventually contribute my part to resolving the problem of stagnated treatments.

With this project, I would like to put focus on the personal story of youth in their treatment, helping them regain hope and motivation to engage. At the same time, the project includes parents and practitioners in re-evaluating the collaboration between the three parties. The overarching goal is to rebuild trust in the treatment, empower the patient and ease the burden for all involved.

#### Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (I sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

Design a prototype that centers the personal story of CAMHS patients (12-21) experiencing stagnation in their treatment, helping them regain hope and renewed motivation, while including parents' and practitioners' perspectives, with the goal to rebuild trust, empower the patient and ease the burden for all involved

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

Since this is a recurring problem, LUMC and my supervisory team have conducted a lot of research. This research is qualitative: interviews from the perspectives of 11 young people, 10 parents and 12 practitioners who have experiences with stagnated treatments and 3 focus groups (23 participants) with the same perspectives; young people, parents and practitioners. My role in this project will be to organise and analyse collected data relating to my assignment to understand key problems, do more qualitative and scientific desk research to sketch a journey, build on the existing data, and eventually design a final prototype of a new methodology that contributes to continuing stagnated treatment in a more holistic way.

Methods I will use are: \*Qualitative data analysis, \*Scientific research, \*Scenario and journey map sketch, \*Personas, \*Ideation of directions and mock-ups, \*Qualitative research: brainstorming session with stakeholders, co-creations and interviews, \*Conceptualising and lo-fi prototyping, \*Concept choice (Using design methods), \*Final prototype

\*\*Extensive plan attached

#### Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.

(200 words max)

- \*I want to increase my knowledge of healthcare and mental wellbeing to best use my design skills in combination with my empathic skills (such as; journey mapping, empathy mapping, in-depth interviews, pain points and motivations)
- \*I want to conduct in-depth interviews to really understand the stakeholders' emotions, experiences, wants and needs
- \*I want to apply behavioural science insights by understanding key theories and translate them into clear design challenges
- \*I want to build on the co-creation and social design skills I developed during my internship and apply them during my final project with different stakeholders (such as target group and experts) to gather input
- \*I would like to further develop my healthcare design skills by focusing on patient-practitioner interactions and translating these insights into practical design solutions
- \*I would like to develop the skill of establishing my role and contribution in a multifaceted project with experts from different fields

# Appendix B: Designer role

The youths already have it, I can facilitate the process of 'telling' their story (e.g. provide prompts and a format) in a way that aligns with their needs

With the use of knowledge about engagement from scientific papers I can design a method that aligns with the theory and gives that motivation to patients, parents and practitioners

Design a prototype that centers the personal story of CAMHS patients (12-21) experiencing **stagnation** in their treatment, helping them **regain hope** and **renewed** can provide a way to get clear steps and motivation, while including parents' and practitioners' perspectives, with the goal to rebuild trust, empower the patient and ease the burden for all involved

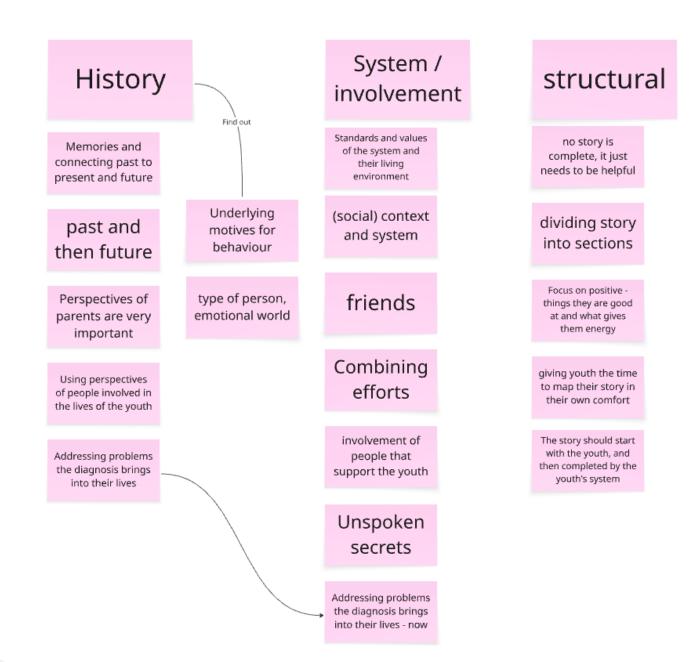
> With the use of Behavioural Science

future perspective, evaluation of collaboration and relationship, clear and realistic changes that need to be made in order to continue treatment effectively

Transparency, clear steps and plan that is communicated to all parties. The plan should include what steps need to be taken when trust is at risk again

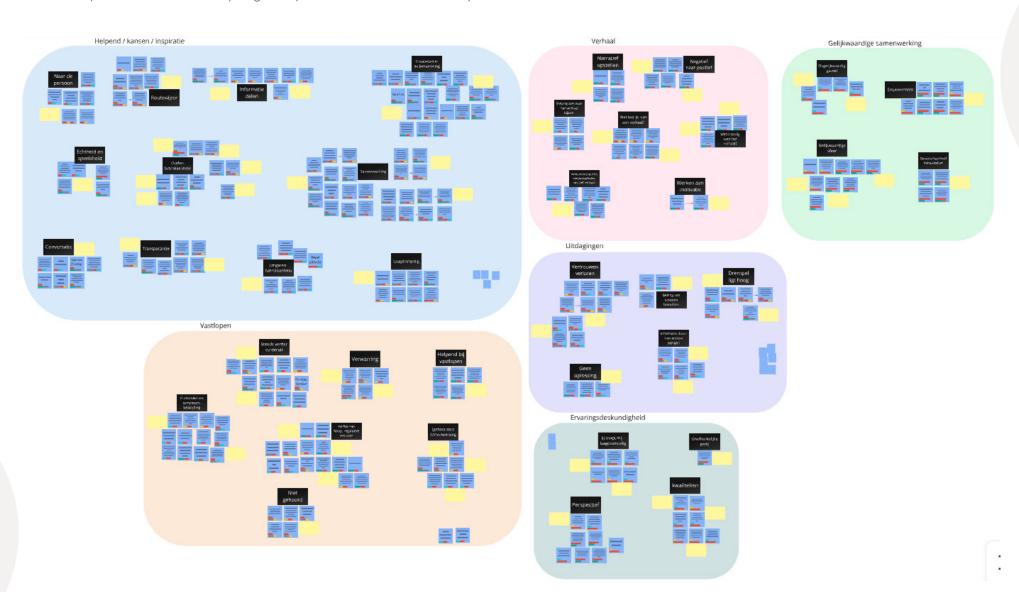
> Main focus on patient perspective including parents and practitioners, prototype will make this clear

# Appendix C: The Story derived from research



# Appendix D: Miro qualitative research

The set-up of the Miro for analysing the qualitative research done by Curium.



# Appendix E: Insights from qualitative research

Space, conversation format, combining different strengths and relaxed context contribute to equal atmosphere

Importance of mentioning that all parties are needed to make progress

Despite hard work and many attempted treatments, there seems to be no progress

Difficult to trust someone again (JVNC) and maintain trust

Can be helpful for youth if experience experts can translate to practitioners Validating parents' feelings is the first step

Feeling heard and actively involving parents - feeling that their opinion counts

Empowering youth through transparency, open communication, taking them seriously and taking action

Using creativity is an approachable way of setting up the narrative

Experts by experience offer youth hope and perspective: it is possible to get better

Reducing behaviour, getting rid of symptoms does not solve the problem - a temporary 'quick fix'

Nothing works anymore, hopelessness for the youth, parent and practitioner

A personal vision from the youth is needed for the story

Lost trust is sometimes not recoverable

There is a lack of clarity in routes and how to raise the alarm as a parent and young person (for JVNC)

Transparency about treatment, how things are going, consequences

Anxiety, demoralisation, pain and sadness, no energy

Initial narrative may start out negative, but this can turn into a positive narrative Showing emotions and lightheartedness from practitioners

Co-creation, deciding together on JVNC's plan

> Giving youth participation and autonomy in treatment

Not comfortable talking to others who do not know the youth well Youth lose epistemic trust because their story is not acknowledged or taken into account

Youth and parents emphasize the importance of considering background and environmental factors.

Narrative does not need to be perfect, just helpful

Carrying the story together

# Appendix F: Broad design directions

Design something to work together to **create trust** and hope in the next step

A new form of hope and confidence

Design something to **empower youth** for the new trajectory

Creates more motivation and the process feels more one's own

Design something to support equal collaboration

Helps motivate all parties to work towards a solution

Design something to support healthcare professionals to show their vulnerability

Showing vulnerability and emotions helps in feeling connected between the parties

Design something that **centers the personal story** to bring stagnated treatment into motion

Centering the story is an important step that is going to help really understand youth and parents

# Appendix G: Co-creation I materials

Welke *vorm* maakt het Hoe kan het complete Hoe kunnen we de krachten ontwerp het meest plaatje gevormd worden? bundelen? uitnodigend? Hoeveel en welke versies Hoe kunnen doelen en acties: 1: In kaart brengen moet het ontwerp hebben? opgesteld worden? Hoe kan het ontwerp worden: Hoe kunnen *acties* worden 2: Concreet en bruikbaar ingevuld door gebruikers? toegewezen? Welke *vorm* maakt het Op welk(e) moment(en) kan Hoe ziet de rolverdeling ontwerp het meest het gebruikt worden? eruit? uitnodigend?

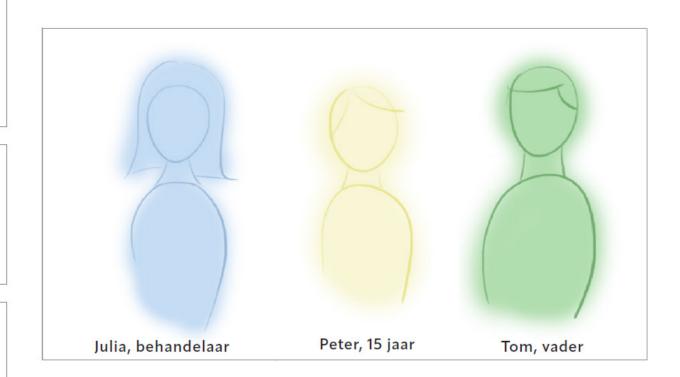
3: Herschrijven

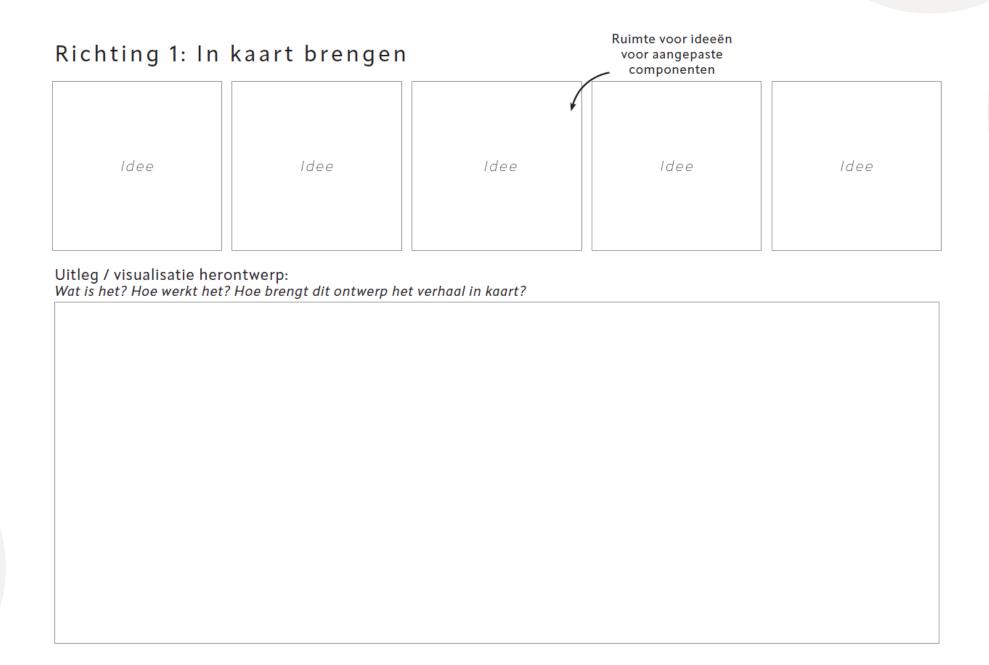
Hoe kan de **volgende stap** eruitzien?

In welke *vorm(en)* is het ontwerp goed te gebruiken?

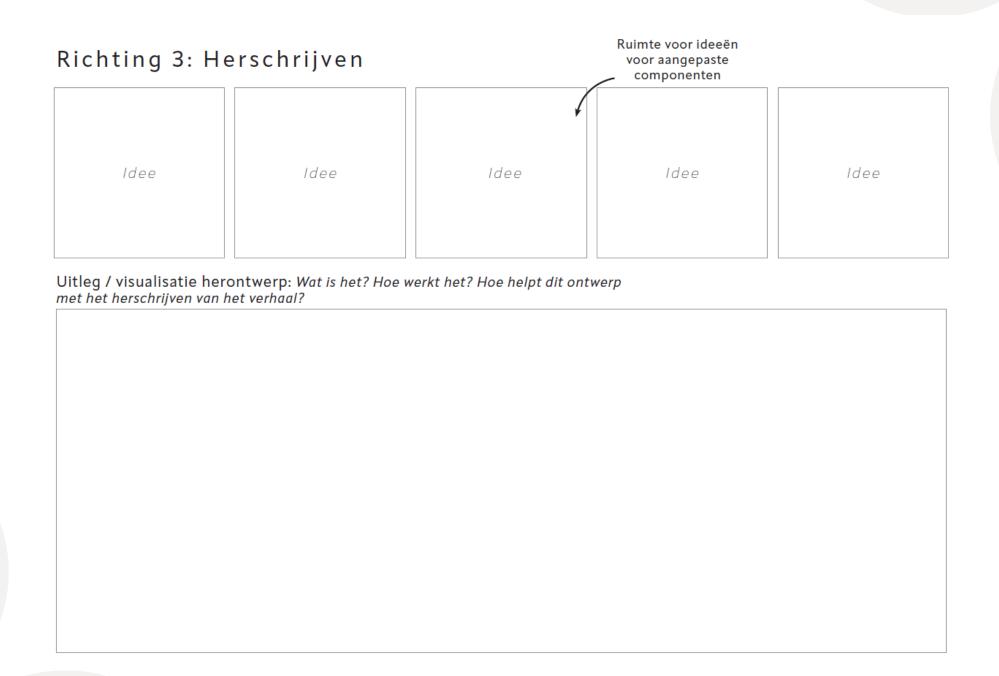
Hoe kunnen de gebruikers inzichten over elkaar krijgen?

Hoe zorgen we voor een positiever kijk op het verhaal?





Richting 2: Concreet en bruikbaar			Ruimte voor ideeën voor aangepaste componenten					
Idee	Idee	Idee	Idee	Idee				
Uitleg / visualisatie hero Wat is het? Hoe werkt het?	Uitleg / visualisatie herontwerp: Wat is het? Hoe werkt het? Hoe maakt dit ontwerp het verhaal concreet en bruikbaar?							



## Appendix H: Final list of criteria

## Based on desk research

The design makes youth and parents feel heard, seen, and acknowledges their story

The design involves the system in making the story concrete

The design provides guidance for writing a clear story → There are concrete steps and actions that youth, parents, and practitioners can work on together in the design

The design provides youth, parents, and practitioners with a (positive) vision for the future The design provides the means to envisioning a future perspective that youth, parents, and practitioners work towards together

The design should make youth, parents, and practitioners feel comfortable, regain hope, energy, and motivation to move treatment forward The story written with the design is inspiring and provides motivation to engage with it

The design makes the parents feel heard and actively involves them

The design provides the means to write a helpful story for youth, parents and practitoners

The design provides space for youth to develop a personal vision for the story The design should give the youth a voice

## Based on The Story research

A story should contain the emotional world of the youth, parent and practitioner.

Social discourse: The stories that exist in society about how life should be, should be recognized in the story.

The story should be considered helpful when families are satisfied with it and feel acknowledged. A story should uncover values and help understand what is important to people.

A story a child can live in: It does not have to be just one; there can be multiple stories a child can live in, as long as they are not contradictory.

The story should include reflecting on the past

## Co-creation 1 / Main

#### The story should be adaptable within the design

The design offers space for reflection and for piecing things together in preparation for the story

The design makes it accessible to reflect together on the stories and work toward a shared story

All the perspectives must be heard, with the youth's story taking priority

The design empowers the youth

There should be freedom in how the design can be used, in order to accommodate different stories with different components

The design serves as a tool for gaining insights into each other

The design breaks the tension between youth, parent, and practitioner and provides an accessible way to do so

Differences and similarities are acknowledged with the design

# Co-creation 1/ Sub

# The story is mapped individually and becomes a shared story afterwards

The design should offer space for practitioners to reflect on themselves and the provided help

Needs (and unfulfilled needs) and wishes should be included in the design

The design should have several means of communication

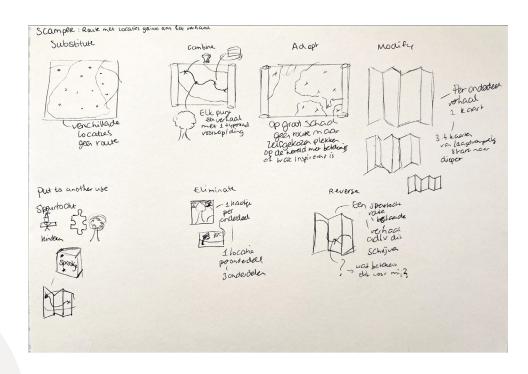
The story is mapped out first before the story is rewritten or made concrete and useful

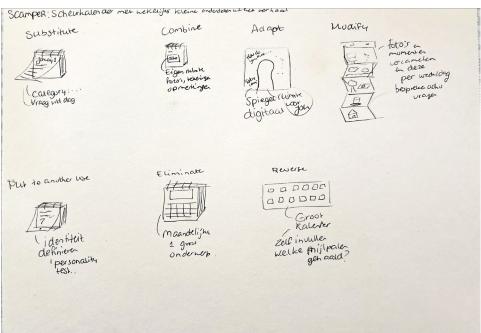
The design gives the users the space to talk about their values

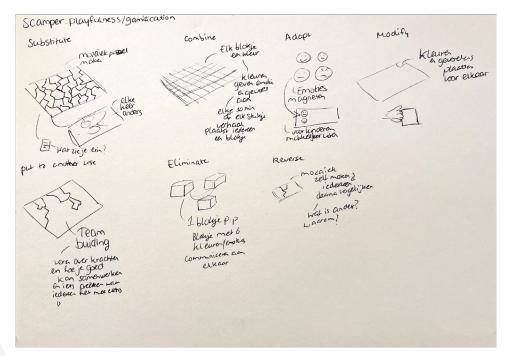
The design offers space for interpretation, so it can resonate with different users

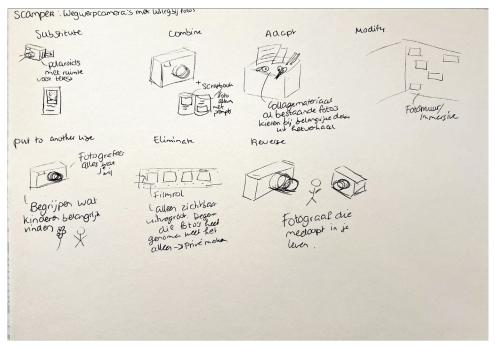
## Appendix I: SCAMPER ideation

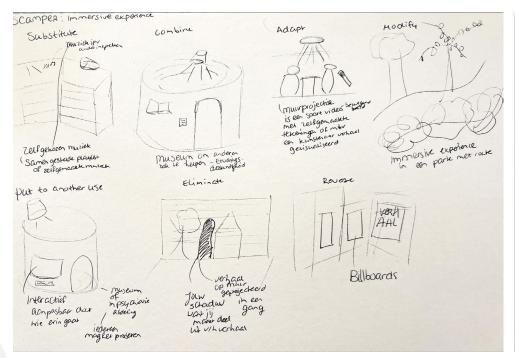
SCAMPER = Substitute, Combine, Adapt, Modify, Put to another use, Eliminate and Reverse

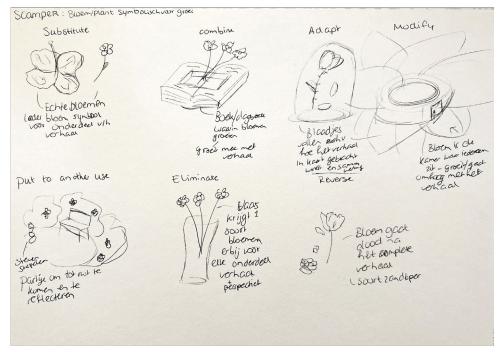




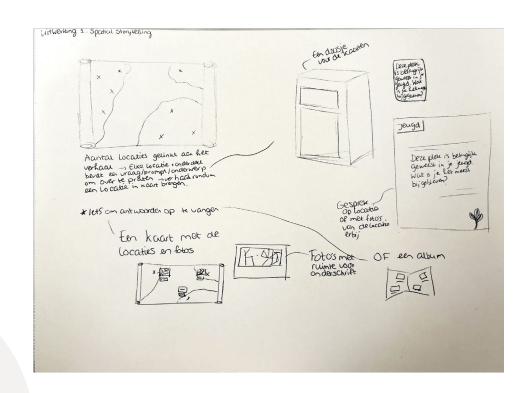


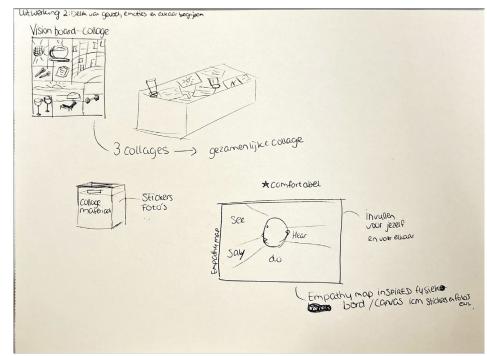


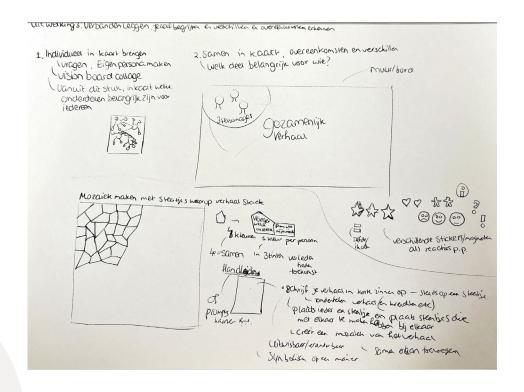


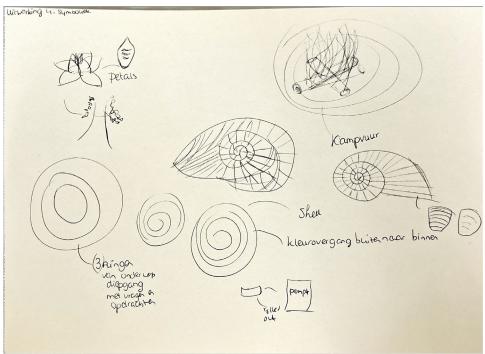


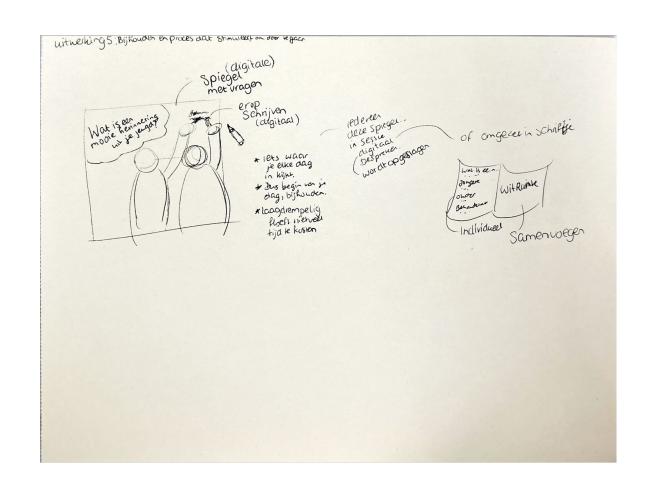
## Appendix J: Five elaborate sketches











## Appendix K: Weighted objectives

Criteria	Weight	Grade	W x G	
The design breaks the tension between youth, parent and practitioner in a gentle way	10	6	60	-Toevoegen: in kleine stappen - kaarten beginnen met locaties die niet veel diepgang hebben
The design is a tool for writing a shared story and for getting insights about each other - gain a better understanding	10	9	90	Door verhalen te delen op een concrete manier leer je elkaar beter begrijpen
The design empowers the youth	9	7	63	Iedereen krijgt zijn eigen moment om zijn verhaal te doen over de specifieke locaties
The design makes it possible to reflect on the stories together and from here work towards a shared story	8	8	64	De kaart wordt samen gevuld en ingericht
Differences and similarities need to be acknowledged in the design	8	6,5	52	Toevoegen: iets dat de verhalen beter aan elkaar linkt
The design provides space for involving perspectives of the system of the youth and parent	7	7	49	Personen gelinkt, aan de locaties kunnen aan het woord komen of van tevoren iets delen over de locaties
The design provides space for reflection and figuring things out in preparation for the story	7	8	56	Locaties worden vooraf gekozen
Total:			434	

Criteria	Weight	Grade	W×G		
The design breaks the tension between youth, parent and practitioner in a gentle way	10	5	50	Je duikt meteen in het diepe	toevoegen/veran deren: een laagdrempelige start, oppervlakkige onderwerpen
The design is a tool for writing a shared story and for getting insights about each other - gain a better understanding	10	9	90	Je leert elkaar beter begrijpen als je elkaars empathy maps ziet en ook als je ziet wat lemand over Jou heeft ingevuld	
The design empowers the youth	9	6	54	Toevoegen> iets dat duidt dat de jongere de hoofdpersoon is in het verhaal	
The design makes it possible to reflect on the stories together and from here work towards a shared story	8	8,5	68	Er wordt concreet gereflecteerd samen om aan een gedeeld verhaal te werken	
Differences and similarities need to be acknowledged in the design	8	8	64	Door er Serien naar te lejken en de om te adhrijven mar oon gezonen ijk warme i overlijken de vorftijken ook ondigeleken on de tonsklich vank er georbert hon overrendermaas en verschilden in het vertoof te trij klinden komen.	
The design provides space for involving perspectives of the system of the youth and parent	7	4	28	Dit wordt individueel gedaan en alleen met jongere, ouder en behandelaar	Toescegen system kan helpen met het twallen von de empalty maps, lemand de jou goet kent en ook een eigen perspectief kan bretlan.
The design provides space for reflection and figuring things out in preparation for the story	7	9	63	Door het eerst individuael In te vullen, heb je ruimte om be ralbetzeran op je eigen serhaal voordat het In groepswertand in kaart wordt gebracht	
Total:			417		

Criteria	Weight	Grade	WxG		
The design breaks the tension between youth, parent and practitioner in a gentle way	10	6	60	Hecis gedeeltelijk visueel maar bijficaleen voorden - heck on helpen om zelf vormen te kleendmaken en hienaan een onderdeel van je eligen verhaal te kooppelei	of zelf kiezen welke stukjes je eerst wil delen - bv groot naar klein (wat jij op de voorgrond wil)
The design is a tool for writing a shared story and for getting insights about each other - gain a better understanding	10	8	80	Je leert over elkaar door de stukjes te lezen en met elkaar te delen	
The design empowers the youth	9	6,5	58,5	De jongere heeft een eigen kleur en dit komt voornamelijk terug in de mozaiek	Toevoegen: de jongere breekt zelf de stukjes
The design makes it possible to reflect on the stories together and from here work towards a shared story	8	8	64	ledereen zijn stukjes worden samen bekeken en samen wordt de laatste kleur ingevuld	
Differences and similarities need to be acknowledged in the design	8	7	56	Door stukjes bij elkaar te leggen die bij elkaar passen of gelinkt zijn, worden similarities aangepakt	Er wordt nu niet veel gedaan met verschillen maar het kan dat juist stukjes die heel verschillend zijn bij elkoar worden gezet
The design provides space for involving perspectives of the system of the youth and parent	7	6	42	Het kan dat iemand uit het systeem helpt met het invullen van de stukjles maar dit is niet concreet in de uitwerking	
The design provides space for reflection and figuring things out in preparation for the story	7	8	56	Door van te voren individueel eraan te werken is er ruimte voor reflectie	
Total:			416,5		

Criteria					
The design breaks the tension between youth, parent and practitioner in a gentle way	10	9	90	De vorm van het ontwerp maakt het laagdrempelig en de eerste vragervlonderwerpen beginnen over lichtere onderwerpen	
The design is a tool for writing a shared story and for getting insights about each other - gain a better understanding	10	8	80	Je leert elkaar beter begrijpen in gespreksvorm met de prompts	
The design empowers the youth	9	5	45	lets toevoegen dat de jongeren helpt empowered te voelen	
The design makes it possible to reflect on the stories together and from here work towards a shared story	8	7	56	De verhalen worden opgevangen in een soort album met schelpvormige post-its die samen worden ingevuld	Er moet een tussenstap komen die helpt met het reflecteren voordat het concreet wordt gemaakt
Differences and similarities need to be acknowledged in the design	8	7	56	Door naast elkaar de verhalen te plaatsen en samen het verhaal te schrijven in een alkauri, kon je de verschillen en overeenkonsten goed den	Dit is nog niet expliciet genoeg
The design provides space for involving perspectives of the system of the youth and parent	7	4	28	Omdat dit alleen tijdens de sessie wordt gedaan, worden de perspectieven van het systeem niet meegenomen	Jemand/meerdere personen uit het systeem meenemen bij de eerste sessie met dit ontwerp, en vervolgens met z'n drieën doorgaan
The design provides space for reflection and figuring things out in preparation for the story	7	5	35	Het wordt allemaal tijdens het traject gedaan, en niets ter voorbereiding	een opdracht ter voorbereiding
Total:			390		

Criteria				
The design breaks the tension between youth, parent and practitioner in a gentle way	10	4	40	Omdat de voorbereiding individure is en allen somenbrengen semen, is et geen menier dat het ontwerp biedt om de spønning te door breken
The design is a tool for writing a shared story and for getting insights about each other - gain a better understanding	10	6	60	Het ontwerp helpt woord het individu on is net de bool om samen een verhad is ook hyen - hel helpt vel maar de main sooi moet juist de samenererding bevorderen
The design empowers the youth	9	7	63	Door elke dag voor de spiegel te staan en wagen over jezelf te beantwoorden kunnen jongeren zich meer empowered voelen
The design makes it possible to reflect on the stories together and from here work towards a shared story	8	7	56	Samen kan er gereflecteerd worden mbv de indvidueel en samengevoegde antwoorden
Differences and similarities need to be acknowledged in the design	8	8	64	Dopr antwoorden bij elkaar te plaatsen zullen verschillen en overeenkomsten aan het licht komen
The design provides space for involving perspectives of the system of the youth and parent	7	6	42	Dit zou kunnen door op eigen initlatief dit te doen. maar is nog niet expliciet in het ontwerp
The design provides space for reflection and figuring things out in preparation for the story	7	8	56	Vooraf aan het verhaal is er veel ruimte om individueel te reflecteren op het verhaal
Total:			381	

### Appendix L: Concept 1 Mock-up











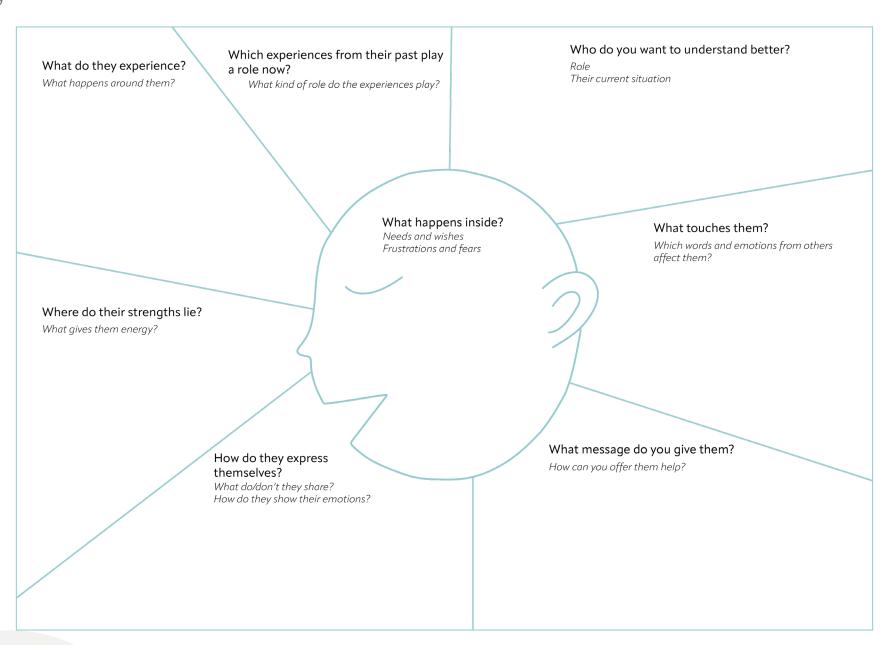


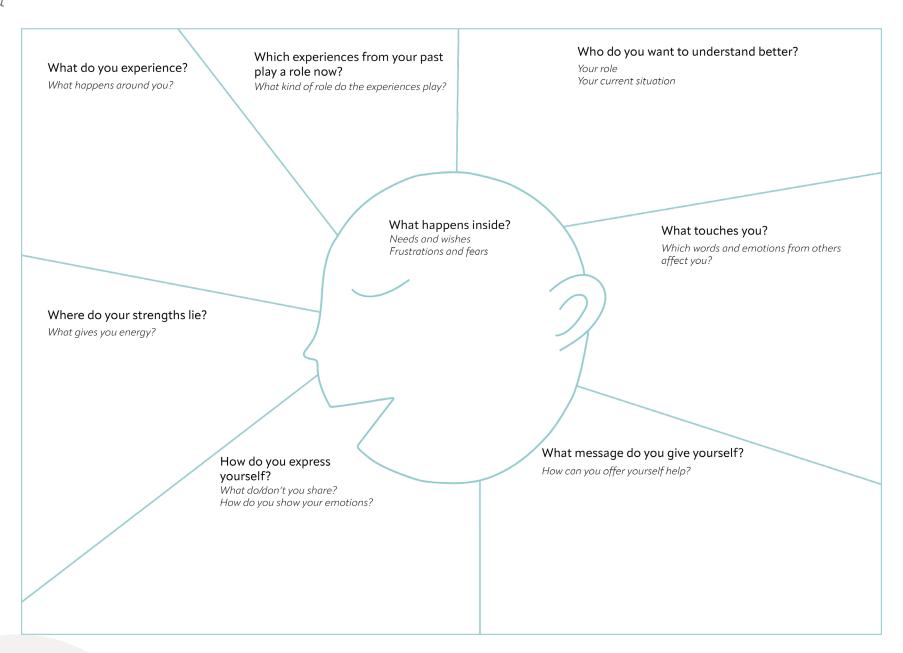


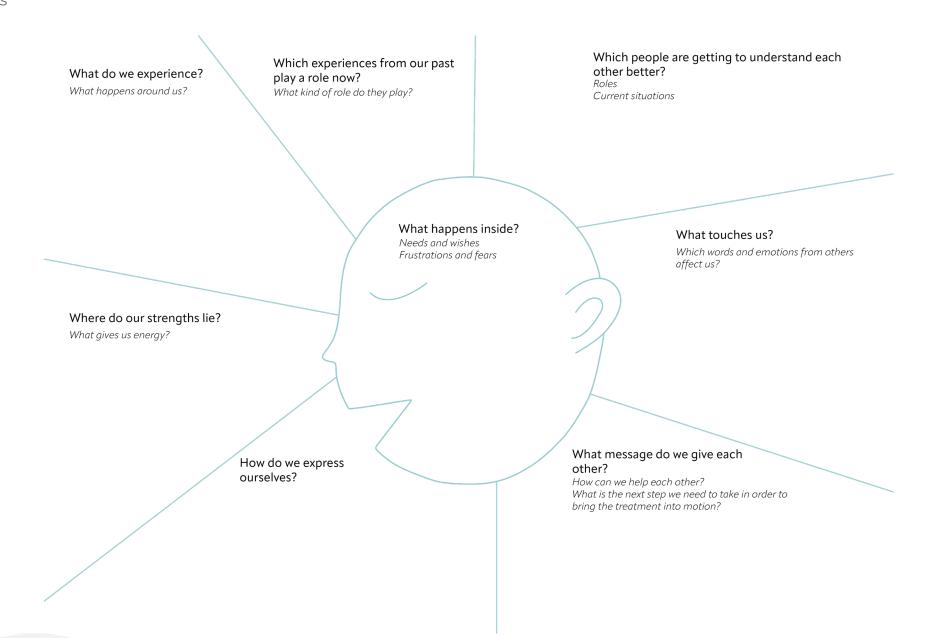


## Appendix M: Concept 2 Empathy pages

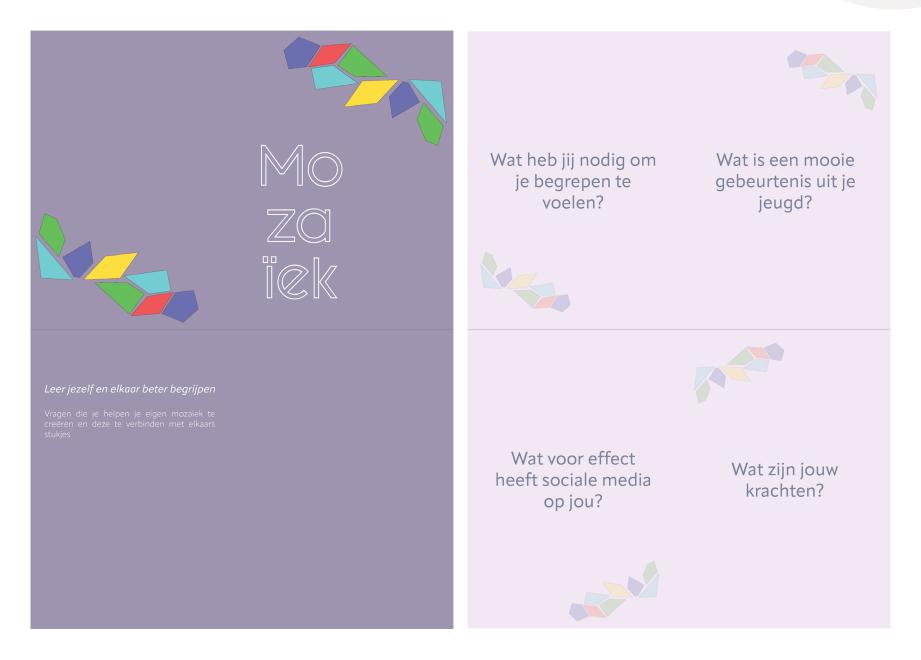
#### They







## Appendix N: Concept 3 Mock-up



## Appendix O: Cards with questions





## Appendix P: Instruction booklet



### Leer jezelf en elkaar beter begrijpen

Vragen die je helpen je eigen verhaal te schrijven en deze te verbinden met elkaars verhalen



Voor jongeren, ouders en behandelaren die een vastgelopen behandeling ervaren in de GGZ-jeugdpsychiatrie

## Instructies

1 Beslis met z'n drieën wie, naast jullie, onderdeel mag zijn van het verhaal.

Kies ieder een kleur houten stukjes die bij jou past, om jouw verhaal op vast te leggen. Kies ook een kleur voor andere personen die bij het verhaal horen.

Neem jouw stukjes, een stapel kaarten en een stift mee om je eigen verhaal te schrijven.

Lees de kaarten door en kies zelf welke vragen je wilt beantwoorden. De thema's *gezamenlijk* en *reflectie* zijn voor later!

4

Schrijf je antwoorden op de stukjes, en neem deze mee naar de sessie van 'Jouw Verhaal Nu Centraal'.

Bespreek samen jullie antwoorden en leg stukjes bij elkaar op het magneetbord. Kijk naar verschillen, verbanden en overeenkomsten. De jongere heeft de leiding en beslist de uitendelijke opstelling van de stukjes!

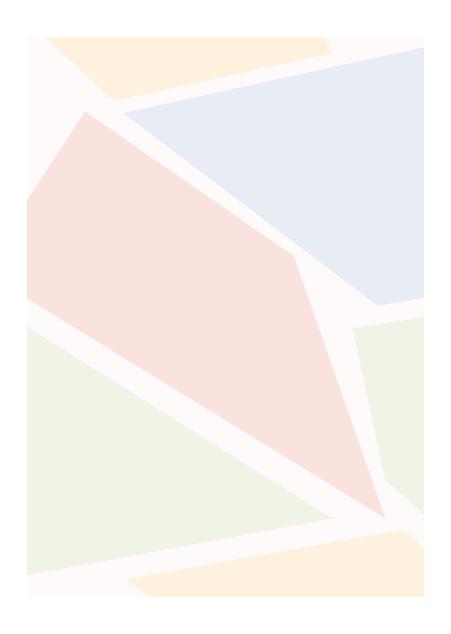
Als de stukjes zijn gelegd, kunnen jullie het *gezamenlijke* onderdeel van het verhaal schrijven op een nieuwe kleur houten stukjes. Gebruik de bijbehorende kaarten.

Sluit af met de *reflectiekaarten* en denk samen na over de vervolgstappen voor de behandeling.

Dit hoeft niet allemaal in één sessie, en stukjes mogen aangevuld worden of van plek veranderen. Neem de tijd om een helpend verhaal te schrijven.







## Appendix Q: Criteria that was not tested

The criteria can be tested after the design is complete and has been used by several groups for a period of time.

## could not test

The story written with the design is inspiring and provides motivation to engage with it

Needs (and unfulfilled needs) and wishes should be included in the design

The design should offer space for practitioners to reflect on themselves and the provided help

The design should have several means of communication

The design gives the users the space to talk about their values

## **Appendix R: Brochure**

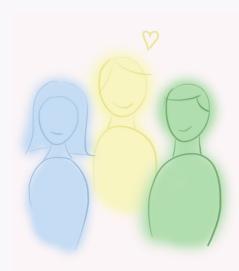
#### Dutch 1/2

#### Volgende stappen

Samen met de andere onderdelen van Jouw Verhaal Nu Centraal, zal Verbonden in de praktijk worden ingezet als proefproject. Er zal gekeken worden naar de effectiviteit en Verbonden zal vervolgens, na een verbetering, uitgevoerd worden bij vastgelopen hulpverlening.

Er zal steeds worden gekeken naar hoe jongeren, ouders en behandelaren het ervaren en aanpassingen zullen worden gemaakt om het hulpmiddel te optimaliseren. Het is belangrijk dat Verbonden een goede bijdrage levert zodat jongeren, ouders en behandelaren een beter zicht krijgen op het verhaal en weer een stapje vooruit kunnen.

#### Verbonden blijven?



Scriptie en materialen: http://bit.ly/4lmHj6Y 17 juli, 2025



Ontworpen door: Ece Canimoglu MSc Design for Interaction TU Delft in opdracht van LUMC-Curium

Onder leiding van: Chair: Prof. Dr. Judith Rietjens, Professor Design for Public Health Mentor: Deanne Spek, PhD Kandidaat aan TU Delft Bedrijfsmentor: Paul Gelissen, PhD kandidaat aan LUMC

#### Jouw Verhaal Nu Centraal

#### Verbonden

Een hulpmiddel voor het in kaart brengen van het verhaal van jongeren, ouders en behandelaren om vastgelopen behandelingen weer in beweging te brengen





#### Jouw verhaal Nu Centraal

Dit project is opgezet door het Leids Universitair Medisch Centrum, afdeling Kinder- en Jeugdpsychiatrie en bestaat uit meerdere modules om vastgelopen behandelingen weer in beweging te brengen.

Vastgelopen behandelingen kunnen veel negatieve gevolgen hebben voor de betrokkenen, waaronder het verlies van hoop en vertrouwen. Jongeren en ouders voelen zich niet gehoord en het begrip voor elkaar neemt langzaam af.

De bestaande methodes voor het oplossen van deze situaties, zijn niet optimaal en een nieuwe aanpak waarin alle partijen gehoord worden, gelijkwaardig zijn en weer door één deur kunnen, is nodig.

Jouw Verhaal Nu Centraal neemt de tijd en ruimte om naar jongeren, ouders en behandelaren te luisteren en gezamenlijk een plan te maken om de behandeling weer in beweging te brengen.Hetwordtuitgevoerd dooreenexternesysteemtherapeut en een jongere ervaringsdeskundige.

Na de commitmentfase en het herstellen van de relatie, komt een nieuw onderdeel: Het verhaal in kaart brengen en uitwisselen. Voor dit onderdeel is Verbonden ontworpen. Hierbij was ik, Masterstudent ontwerper, betrokken om een ontwerpersblik erop te werpen en te doen waar ontwerpers goed in zijn: Verdiepen in het onderwerp, onderzoeken en van daaruit inzichten vertalen naar een passend hulpmiddel. Voor mijn afstudeerscriptie heb ik een half jaar gewerkt aan Verbonden, om een bijdrage te leveren aan louw Verhaal Nu Centraal.

In dit half jaar hebben verschillende activiteiten en bijeenkomsten plaatsgevonden met jongeren, ouders en behandelaren, waaronder het projectgroep van Jouw Verhaal Nu Centraal. Deze activiteiten hebben ervoor gezorgd dat veel experts en betrokkenen hun mening hebben gedeeld. Naar alle partijen is er geluisterd en Verbonden is ontworpen voor en door jongeren, ouders en behandelaren

#### Ontwerpdoel

Ontwerp een hulpmiddel dat het persoonlijk verhaal centraal stelt van GGZ-jeugd jongeren (12-21) die een vastgelopen behandeling ervaren, door het verhaal van de jongere in kaart te brengen, terwijl het perspectief van de ouder en behandelaar wordt meegenomen, om de jongere in zijn kracht te zetten, de spanning te verbreken tussen jongere, ouder en behandelaar en bij te dragen aan meer begrip voor elkaar

#### Verbonden

Verbonden bestaat uit een set kaarten met vragen in verschillende thema's en houten verhaalstukjes waar de antwoorden op komen.

De jongere, ouder en behandelaar kiezen ieder een kleur verhaalstukjes.

Individueel, voorafgaand aan de gezamenlijke sessie, gaan alle deelnemers hun verhaal schrijven op de verhaalstukjes. Dit kan met behulp van de kaarten.

Gezamenlijk kunnen de antwoorden worden besproken en de stukjes worden gelegd op het magneetbord, gebaseerd op verschillen, overeenkomsten en verbanden. De jongere mag de leiding nemen en bepalen hoe de stukjes worden gelegd.

Nadat de stukjes zijn gelegd, kunnen de gezamenlijke en reflectiekaarten samen worden beantwoord op een nieuwe kleur verhaalstukjes. Ook deze stukjes komen op het magneetbord.

Uiteindelijk is er een gezamenlijk verhaal en kunstwerk gecreëerd. Het verhaal mag aangepast worden gedurende Jouw Verhaal Nu Centraal

#### Kaarten



De kaarten hebben vier niveaus van diepgang en deze worden aangegeven met de volgende icoontjes:









Onderlasa

Verbonden zorgt ervoor dat iedereen op een gelijkwaardige manier samenwerkt. Ook de behandelaar zal uit de uitvoerende rol stappen: Verbonden zal worden geleid door een systeemtherapeut en een jongere ervaringsdeskundige. Ze zorgen er samen voor dat iedereen aan het woord komt en gehoord wordt. Ook zorgen ze er voor dat de sessies goed verlopen en houden ze de voortgang bij.

Het verhaal van de jongeren heeft prioriteit en daarom mogen jongeren, samen met de jongere ervaringsdeskundige de leiding nemen. Het gaat hierbij om hoe de sessies worden ingedeeld, welke thema's worden besproken en hoe de stukjes worden gelegd. Hoe dit eruit gaat zien kunnen ze samen vooraf bespreken.

Hoeveel sessies en hoe lang het gebruik van Verbonden zal duren, zal verschillen per situatie. Er zal worden gezorgd voor een comfortabele sfeer waar de tijd wordt genomen zodat jongeren, ouders en behandelaren elkaar beter begrijpen.



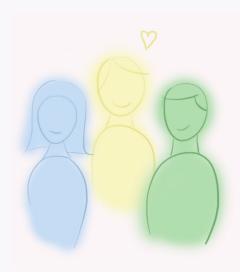
#### English 1/2

#### **Next steps**

Together with the other parts of Centering Your Story, Verbonden will be used in practice as a pilot project. Its effectiveness will be evaluated, and after improvements, Verbonden will be used in situations where psychiatric care has stagnated.

The experiences of youth, parents, and practitioners will be regularly checked, and changes will be made to improve the tool. It is important that Verbonden makes a good contribution so that youth, parents, and practitioners get a better view of the story and find a way forward.

#### Stay connected?



Design thesis and materials: http://bit.ly/4lmHj6Y 17 July, 2025



Designed By: Ece Canimoglu MSc Design for Interaction TU Delft commissioned by LUMC-Curium

Coached by: Chair: Prof. Dr. Judith Rietjens, Professor Design for Public Health Mentor: Deanne Spek, PhD cadidate at TU Delft Company mentor: Paul Gelissen, PhD candidate at LUMC

#### Centering Your Story

#### Verbonden

A tool that helps youth, parents and practitioners map their shared story to bring stagnated psychiatric treatment back into motion





#### Centering Your Story

This project was set up by the Leiden University Medical Center, Department of Child and Adolescent Psychiatry, and consists of several modules aimed at getting stagnated treatments moving again.

Stagnated treatments can have many negative consequences for those involved, including the loss of hope and trust. Youth and parents often feel unheard, and mutual understanding slowly fades.

The existing methods for resolving these situations are not ideal. A new approach is needed—one in which all parties are heard, treated equally, and able to reconnect.

Centering Your Story creates time and space to listen to youth, parents, and practitioners and to make a shared plan to restart the treatment process. It is carried out by an external systemic therapist and a youth peer support worker.

After the commitment phase and restoring the relationship, a new part follows: mapping and exchanging the story. Verbonden was designed for this part. I was involved in this as a Master's student in design, to bring in a designer's perspective and do what designers do best: dive into the topic, explore it thoroughly, and translate insights into a fitting design. As part of my graduation thesis, I worked on Verbonden for six months to contribute to Centering Your Story.

During these six months, various activities and meetings took place with youth, parents, and practitioners, including the Centering Your Story project group. These activities ensured that many experts and stakeholders shared their perspectives. All voices were heard, and Verbonden was designed with and for youth, parents, and practitioners.

#### Design goal

Design a tool that centers the personal story of youth (12-21) in Child and Adolescent Mental Health Services experiencing stagnation in their treatment, by mapping the story of the youth, whilst including the perspectives of the parent and practitioner, to empower the youth, ease the tension between youth, parent and practitioner and help them gain a better understanding of each other

#### Verbonden

Verbonden consists of a set of cards with questions on different themes and wooden story pieces to capture the answers.

The youth, parent, and practitioner each choose their own color of story pieces.

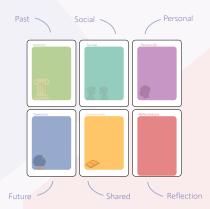
Individually, before the joint session, each participant writes their story on the story pieces. The cards can be used as a quide.

Together, the answers can be discussed, and the pieces are placed on the magnetic board based on differences, similarities, and connections. The youth is invited to take the lead and decide how the pieces are arranged.

After placing the pieces, the shared and reflection cards can be answered together using a new color of story pieces. These pieces are also placed on the magnetic board.

In the end, a shared story and artwork are created. The story can be adjusted throughout Centering Your Story.

#### Cards



The cards have four levels of depth, which are indicated by the following icons:









Late

Verbonden ensures that everyone works together in an equal way. The practitioner will also step out of the directing role: Verbonden will be led by a systemic therapist and a youth peer expert. Together, they make sure that everyone has a chance to speak and be heard. They also ensure that the sessions run smoothly and keep track of progress.

The story of the youth has priority, which is why youth, together with the youth peer support worker, are allowed to take the lead. This includes how the sessions are organized, which themes are discussed, and how the pieces are placed. How this will look, can be discussed together beforehand.

The number of sessions and how long Verbonden is used will vary depending on the situation. A comfortable atmosphere will be created where enough time is taken so that youth, parents, and practitioners can better understand each other.

