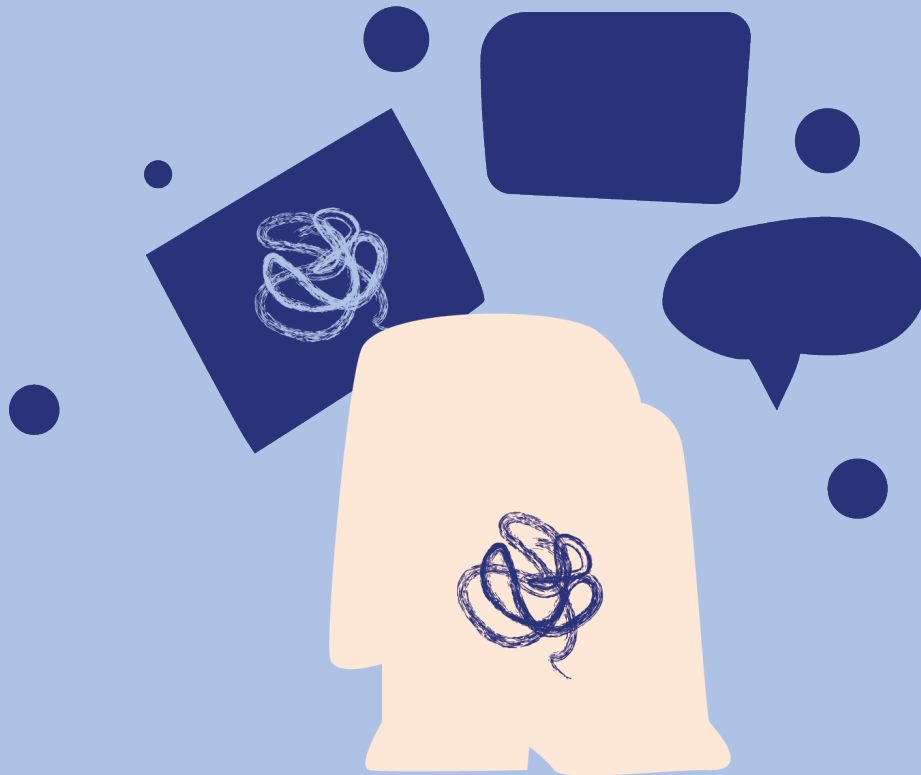


Echoes of Loss



exploring personal grief
through recognition
appendices

Master thesis by Layla de Blok

CONTENT

1/ Design brief	4
2/ Literature review	9
3/ Generative sessions with the target group: procedure, methods, results and limitations	10
4/ Generative sessions: data on miro	14
5/ Interview guide Generative sessions	22
6/ Interview guide: Annelies van Der Ouw	27
7/ Interview guide Rouw chat volunteers and Robin Zuidam	30
8/ Analysis Cruse.org.uk and proposal VLmD Confidential appendix	33
9/ Websites and platforms included in Benchmarking	40
10/ Website and platform inspiration	41

11/ Inspiration boards	45
12/ Validating the themes with VLmd-Results in Miro	48
13/ Pieces of content included in the usertest prototype	51
14/ Guidelines usertest	59

APPENDIX 1/ DESIGN BRIEF

Navigating loss online: connecting bereaved people with fitting support project title

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

start date 13 - 12 - 2022 26 - 06 - 2023 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

In 2021 170.972 people passed away in the Netherlands [1]. On average, each person leaves three next of kin behind. Out of all these bereaved people, 180 thousand wanted some sort of emotional support [1]. There are initiatives that provide support, but they are decentralized and the personal fit is unclear [2]. Undertreating an individual might lead to unnecessarily prolonged suffering and in some cases, it increases the chance of getting prolonged grief disorder [2] [6]. The disorder is defined in the DSM5 [6] as a mental disorder. However, getting treated for this disorder while not having it, can also increase the suffering a bereaved person experiences [2]. Therefore, Vereniging Leven met Doods goal is to make the search for fitting support after bereavement easier and better [3]. To achieve this, the non-profit's ambition is to set up a digital platform about mourning, that provides information and refers people to support and aftercare fitting to their specific needs.

Part of the platform will be the 'Rouw Wegwijzer'. Via a to-be-designed interaction, it will match bereaved people with a source of support that fits their need(s). Most bereaved people indicate they want support, but people often do not know what kind they want or need [2]. It can be argued that talking about and living with death is not something we are accustomed to anymore in western society [2][4]. Most people will avoid engaging with the topic or talking about it if they have the choice [5]. As a result, a lot of people never learned the vocabulary to express their experience when dealing with death and bereavement [5]. This provides the challenge that both the design and research should go beyond text, bringing up the latent needs [7] someone might have (see image 1).

Given that everyone is mortal, anyone, from any demographic within the Netherlands, can become a possible user of the platform. Therefore, inclusivity is important to consider. Next to supporting those who are in grief, the platform should also inform people close to the bereaved person on how to support their loved one [2].

To research the viability, feasibility, desirability, content, and shape of the Rouw Wegwijzer, a research group has been set up. During my graduation, I will be part of this group. Needed resources for building the platform and this feature will be partially estimated based on outcomes from the research group. Therefore, it is not yet known what resources are available for the implementation of the design.

[1] Vereniging Leven met Dood. (n.d.). Webpage. Retrieved December 6, 2022, from <https://vereniginglevenmetdood.nl/>.

[2] Unpublished conversations and literature within research group.

[3] Vereniging Leven met Dood. (n.d.) De rijke historie van Vereniging leven met dood. Online article. Retrieved December 6, 2022, from <https://vereniginglevenmetdood.nl/historie>.

[4] Farberow, N. L. (2013). Taboo topics. AldineTransaction.

[5] Allan, K., & Burridge, K. (2006). Forbidden words: Taboo and the censoring of language. Cambridge University Press.

[6] Appelbaum, P. & Yousif, L. (2022, mei). Prolonged Grief Disorder. <https://www.psychiatry.org/>. Retrieved 14 december 2022, from: <https://www.psychiatry.org/patients-families/prolonged-grief-disorder>

[7] Sanders, E. B. N., & Stappers, P. J. (2012). Convivial toolbox: Generative research for the front end of design. Bis.

[8] Stappers, P. J., & Giaccardi, E. (2017). Research through design. In The encyclopedia of human-computer interaction (pp. 1-94). The Interaction Design Foundation.

[9] Seifu, F., DeDiego, A. C., Rassier, A., & Morgan, M. M. (2022). Death Cafes: An Exploration of the Setting, the Players, and the Conversation. OMEGA - Journal of Death and Dying, 0(0). <https://doi.org/10.1177/00302228221101277>

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Personal Project Brief - IDE Master Graduation

introduction (continued): space for images

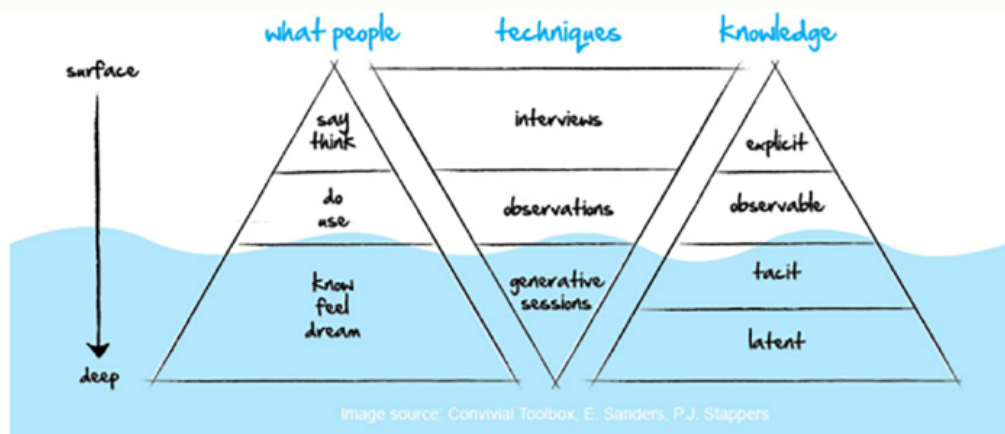


image / figure 1: Latent needs model [7]

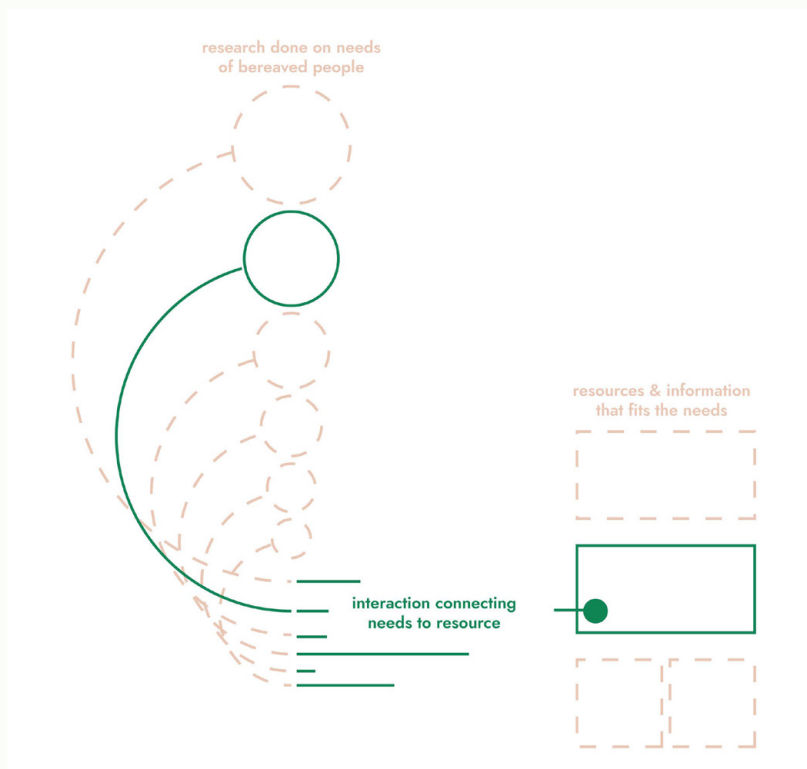


image / figure 2: Research group parts, with my role in green

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

The research group will look at which needs are prevalent among bereaved people and develop fitting information and resources. I will connect the two, by designing an interaction that should assist a bereaved person in finding a fitting (re)source of support (see image 2). This interaction should go beyond making a questionnaire-like flow. On top of that, the interaction should provide a fitting experience, which can differ per person.

Talking about grief can be a deep reflection on life [9]. Yet, this conversation will be facilitated by code and not by an actual human being. This provides some challenges: How to make people feel seen and heard, without someone actually listening? How to prevent someone from feeling tricked or not taken seriously? And how to capture this 'conversation' into a designed interaction, while still respecting that everyone's grief and needs are unique?

To learn how to address and communicate with bereaved people, I formulated the following research question: "What is a current and relevant understanding of what grief is?" I also formulated four design challenges: 1. How to assist the user in finding a resource that fits their need? 2. How to talk and interact about grief and mourning with people who are bereaved? 3. What is the desired experience when using the platform? 3a. What is a fitting interaction vision for the platform? 3b. What kind of flow and interface fits the interaction qualities and desired experience?

For my project, I will focus on bereaved people above 18 that do not experience Prolonged Grief Disorder [2][6]. Involving children will acquire a different approach, both in the interaction and in the research, making the scope too big for this project. Someone experiencing Prolonged Grief Disorder might be a possible visitor on the website. Doing research on how to recognize the disorder and how to refer these people to professional help on the platform is important. However, I am not trained on how to safely involve these people in research. Therefore, they fall outside the scope of this graduation project. The target group will be specified further, based on insights from the literature research and involvement of the Vereniging Leven met Dood.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

For Vereniging Leven met Dood I will design an innovative interaction flow for their platform. This interaction between the user and the platform should help bereaved people find a resource that fits their current needs. The experience this interaction provides should be fitting to the needs of a bereaved person too.

The interaction will connect the research done about the needs a bereaved person has and the sources of support that the Vereniging has or can refer to (image 2). In the end, the three parts together will become one online service. However, all three elements are under construction, which means I will have to work with the information available at this point. Therefore, the way to illustrate how the service work is by 'user cases'. These user cases are made from the information already available and found in literature research (image 2). The shared elements of the different flows for these use cases should be defined and scalable to the other needs and use cases that are still under development/ being researched.

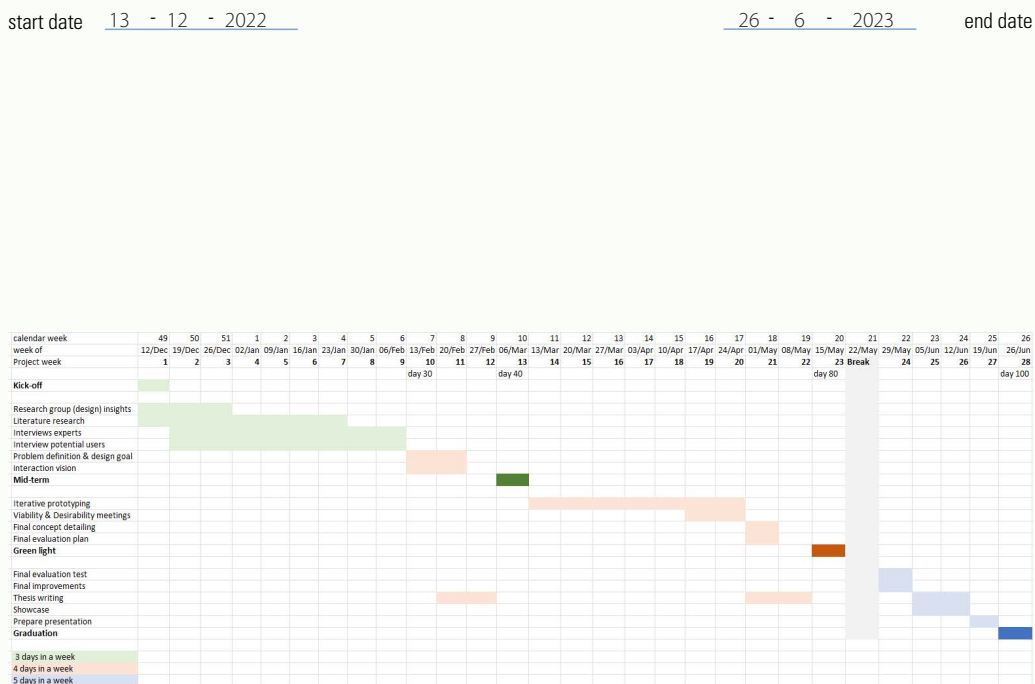
The deliverables for the mid-term will be the insights from desktop research, literature research, and involvement of the target group. This will be written down in a design brief which will state a design goal and an interaction vision. At this point, clear use cases will be formulated. The last deliverable is the first draft of the thesis report.

The green light deliverables will be intermediate prototypes and their insights, a final concept, a validation plan, and 80% of the thesis report.

Deliverables for the graduation are a tested and validated concept, recommendations for further development, a thesis report, a poster, a showcase of the final concept, and a final presentation.

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.



My work starts with desktop research, literature research, interviewing experts, and translating the research available from Vereniging Leven met Dood. I will conduct interviews with the target group, using context mapping methods [7], and with experts. Vereniging Leven met Dood will help me find and select participants. Using all insights, a design goal will be formulated, an interaction vision and define the interaction qualities. The use cases will be created. These results will be presented during the mid-term.

Based on the presented insights, I will start doing iterative design cycles, using a research through design method [8]. In every iterative cycle the fidelity will go up. The user group is involved as much as possible. To make the research less intrusive, all testing will preferably be done with people who have not lost their loved one in the past 6 months [6].

Half April a meeting will be held with Vereniging Leven met Dood specifically to discuss viability and feasibility. A similar session is held with the user group, to discuss the desirability of the concepts. Based on this feedback the final concept is chosen and an evaluation plan is developed.

During the greenlight the final concept and evaluation plan will be discussed. The final evaluation will be conducted after the green light. The last insights will be implemented and /or written down in the thesis. All remaining time will be spent on the report, the showcase, and the final presentation.

During this project, I will reintegrate after burning out during my last graduation project. Therefore, I will not start working full-time right away. I will start by working 24 hours a week (3 study days), then build up to 32 hours a week (4 days) and after my green light, I want to try to work full time (40h/week). Depending on how I am doing, I will update the plan to work more or fewer hours and communicate this with my team.

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, Stick to no more than five ambitions.

During my master's, I realized I enjoy working on socially relevant topics. Especially the ones that are sensitive because I think that, because the topics are neglected, heaps of progress can still be made. I have acquired relevant experience designing for sensitive topics by doing a joint master project for Slachtofferhulp Nederland about people who experienced any kind of non-consensual sexual experience. I noticed that designing for such a topic came with different challenges, considerations, but also opportunities. This piqued my curiosity about how to 'properly' design for sensitive topics. I tackled this question during a research elective with Marieke. The lessons and insights collected from these experiences will serve as inspiration for this graduation project.

This project gives me the opportunity to improve my (digital) prototyping skills, both low and high fidelity. I want to challenge myself to try different mediums and embodiments: cardboard, video, immersive experiences, etc. I want to give myself time to experiment and have fun. I am excited to find out how small or big differences in embodiment and interaction can influence the feel and experience people will have on the platform. I am looking forward to this part because I have not 'really' designed and prototyped in a long time.

This project will be my second graduation project after I decided to discontinue my previous one last May. I do not want to burn out again. Therefore, my decision to work part-time first and gradually increase the work pressure. My personal goal is to stick to the hours written down in my planning and not compensate or overwork, especially not on the weekends. If I notice that I am ready to work more hours, I will update the schedule accordingly. I will also reconsider if I feel I need more time off.

In my 'failed' project, ironically about failure, I learned (once again) that even without desired outcome, in this case, a finished project and master's diploma, you have only failed if you did not learn. During my previous project, I did learn a lot about myself, especially ways of working that make me (un)happy or get lost in a project. Taking this experience with me I want to have regular meetings with my team. Also, I am very eager to have user involvement very early on in the project.

My previous graduation project made me aware of the pitfalls I have when researching. To not repeat mistakes, I have to start formulating clear research questions and goals from the beginning. I should finish up every activity I have done with clear (design) insights, before moving on to the next. Lastly, I want to prevent doing too many things at the same time, losing overview that way. Being unable to make the set deadlines might be a sign that I am struggling or doing too many things at the same time. Instead of changing the deadlines, I might need to take a look at how I am doing and how much I am doing.

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

I have formulated the 'thing/feeling' that makes people decide they desire some support as (latent) needs. I use this, instead of saying a hurdle, something they get stuck on or a wrong feeling. I think that if you peel those moments or feelings down, unmet needs are at the core.

APPENDIX 2/ LITERATURE REVIEW

To create a comprehensive understanding of what grief is and what effects it has on the target group literature has been consulted. Existing literature about grief models and the lived experiences of the target group is consulted, next to creating a better understanding of how and why online resources are currently used.

A2.1/ Research questions

1. What is grief and how do people experience this?
2. What bereavement experiences are specific for bereaved emerging adults?
3. What kind of grief support is considered supportive and currently available (online)?

A2.2/ Procedure and Analysis

Papers were filtered based on search words and publication date (between 2018 and now). If a paper outside of the publication date was mentioned multiple times in other papers, and seemed to be an important source, it was included in the literature list. From the information that seemed to be interesting information cards were made.

To find underlying themes, the information cards were printed out and clustered. These clusters were used to make an outline for the report and also compared to the themes found via other activities.

A2.3/ Search words

The search terms used during the literature research are: "grief process", "grief process theories", "defining normal grief", "dual process model", "loss online", "grief online", "emerging adulthood", "bereaved emerging adults", "grief experience", "grief support", "good grief support", "bereavement support".

APPENDIX 3/ GENERATIVE SESSIONS WITH THE TARGET GROUP: PROCEDURE, METHODS, RESULTS AND LIMITATIONS

To be able to understand the target group and be able to empathize with them, I conducted interviews with 5 people from the target group. All interviews lasted approximately 1.20 hours and were conducted online, three interviews were conducted using Miro and Zoom, one interview at the house of the participant, while still using Miro. One interview was conducted without Miro, due to internet issues. All boards were still shown to the participant. Before the generative session was conducted with the targetgroup, a pilot was conducted, to make sure the generative session would be fruitful and to make sure the right sensitivity was applied, due to the personal topics discussed.

A3.1/ Finding participants

To recruit participants, an informative visual was made which was shared in multiple ways (see visual XX for an example). It was shared with Robin Zuidams personal connections and relevant Facebook groups he was a member of. I also shared it via my personal Facebook and LinkedIn pages. The recruitment resulted in 5 interviews.

A3.2/ Method

In this generative session, I invited the participants to co-create with me using the context mapping method



Figure 01. Recruitment post on Facebook.

(Sanders & Stappers, 2012). According to Sanders and Stappers (2012), generative sessions can help in deepening the conversation and create a greater understanding of the participants' needs, wishes, struggles and

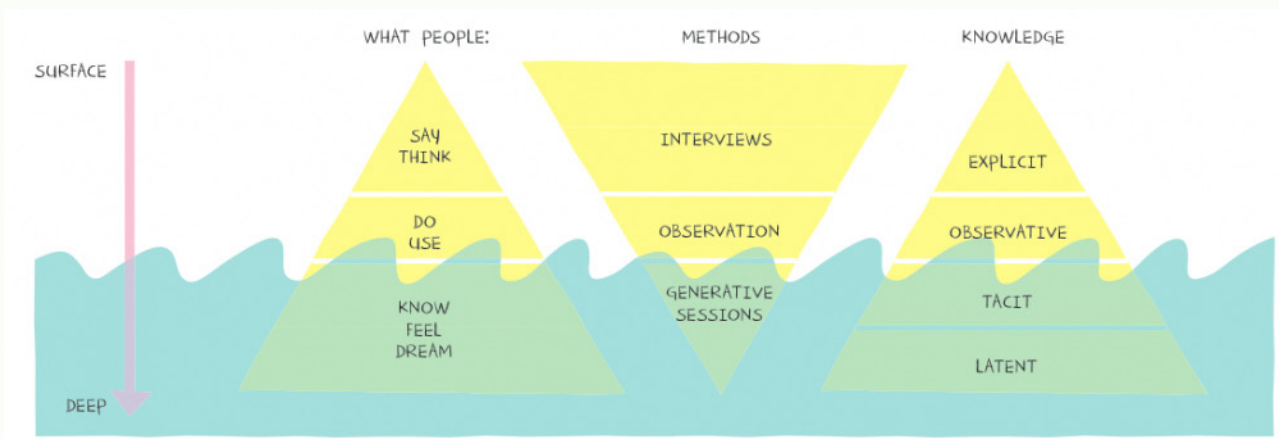


Figure 02. Laten needs as described by Sanders & Stapper (2012).

so forth. It is easy to express what people think and say in the moment, which can be asked during interviews. What people do or use can easily be observed. However, what people know, dream or feel is harder to research. These needs are called latent needs. Asking about needs in the future, without any introduction, will result in shallow answers. Therefore context mapping provides a 'warm-up' for envisioning the future and expressing latent needs. A generative session starts with exploring the current time via a sensitizing activity, then you dive into the past. These steps will be used to reflect on the past and then to envision the future.

A3.3/ Design challenges and research questions

In the generative sessions, I wanted to address the following design challenges :

- How to assist the user in finding a resource that fits their need?
- How to talk and interact about grief and mourning with people who are bereaved?
- What is the desired experience when using the platform?

Following the path of content mapping (see visual FIXME), to address the future envisioned via these design challenges, we first reflect on the current situation and the past. For which I formulated the following

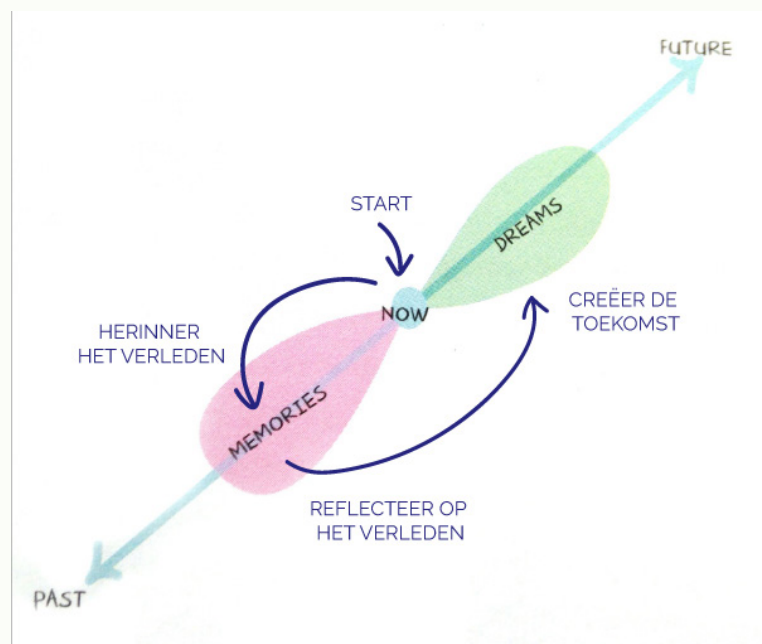


Figure 03. Path to envision the future, as described by Sanders & Stappers (2012)

research questions:

1. What resources did bereaved emerging adults use in the past? What resources do they use now?
2. How did bereaved emerging adults find this resource?
3. How did bereaved emerging adults realize this resource fitted them?
4. How do emerging adults want to be approached when offered support around their grief?
5. How do bereaved emerging adults want to be addressed when talking about grief?
6. How did bereaved emerging adults experience talking about grief with other people?
7. Did bereaved emerging adults use the internet while grieving?
8. How and why did bereaved emerging adults use the internet?

A3.4/ Procedure

To understand and empathize with the target group, 1-on-1 generative sessions with 5 participants were conducted. Using the context mapping method, I invited them to share their grief process and co-design the platform's interactions and experience.

Photo safari: Exploring the now and introducing the parent

Two days before the session a reminder was given and an email was sent with instructions for a sensitizing activity, and the consent form was included (see appendix FIXME & FIXME). The sensitizing activity was the photo safari. During the photo safari, participants were asked to capture images representing sources of solace while experiencing grief. Specifically, sources used during

one or two days. Additionally, they shared a favourite picture of their parent. This picture served as an ice-breaker during the beginning of the session. Its second function was to introduce the 'third person' involved in the interview; the deceased parent, without necessarily focusing on their death yet.

Diving into the past

After that, we discussed the (lack of) pictures sent during the sensitizing assignment. These pictures were then placed on a timeline while discussing both the timeline of how grief developed and how the things in the photo fitted there. See visual FIXME for an example.

Envisioning the future: collecting latent needs

As an invitation to imagine the support that should be provided on the platform, I asked the participants to imagine a physical place for bereavement support. The leading question was: what kind of support and information would they expect to find at a physical place for bereavement support? They could use a white online board to communicate their place, they were able to use a deck of selected photos, which functioned as inspiration material, see visual FIXME. They were also allowed to search for their pictures online.

Afterwards, a discussion followed. We discussed what they made and what they signified. To address the structure of a platform I asked them how they would move through the room and if different services of the space would be separated or not, see visual FIXME for an example.

After creating and envisioning the physical place for grief support, I

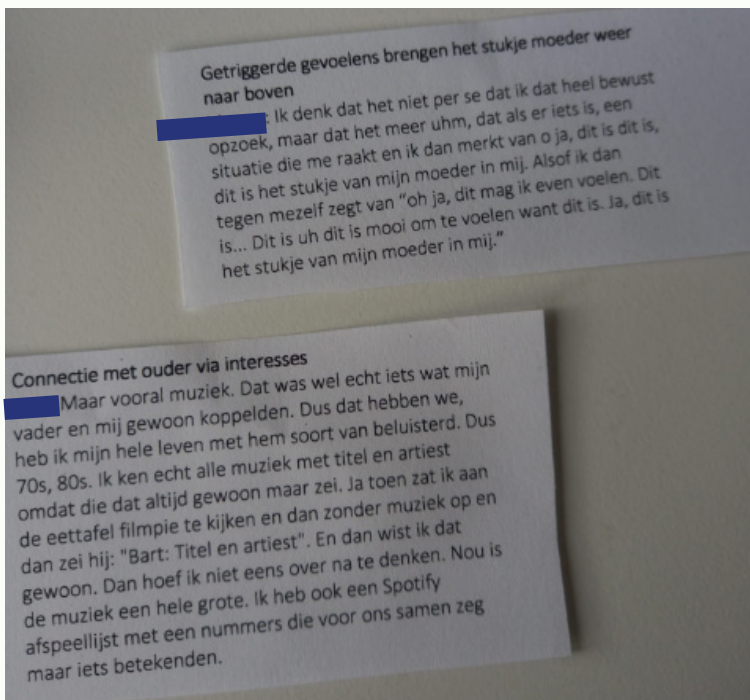


Figure 04. Two quote cards.



Figure 05. Clustering in action

asked the participants what kind of employees/volunteers they would expect. What would be their role? What would be their character? And how did they interact with them? This part was to envision the behaviour of the platform. See visual FIXME for an example of results.

Making the link to an online platform

Next, we had a small discussion

moment. I introduced the idea of VLmD of an online platform that provides personalized content. We discussed this idea and reflected if their answers, expectations and wishes would change if the place and employee would be online. We also discussed if and how they used online resources before.

Finishing the session

To finish the session we 'closed' the physical place they created. What kind of goodbye would they expect? What kind of exit would their physical place for grief support have? And would the employee have a role in?

A3.5/ Analysis

For the analysis, the interviews were transcribed using Trint. Relevant quotes were highlighted and turned into quote cards, see visual FIXME. These cards were then used to cluster, see visual FIXME. Clustering the cards helped in identifying themes.

A3.6/ Limitations

The 5 participants included in the research were homogeneous in multiple aspects. All had lost one parent and the loss was not within the past 3 years. The loss of the parent was between 3 and 12 years ago. This means that all insights collected about the first few years after the loss is all retrospective knowledge.

While analysing data there was a translation from designing a physical space to using this data for designing an online environment. This is prone to biases and interpretations the researcher might have about what this translation would mean.

The same researcher conducted the interviews, documented, and analysed all data, making the results less objective.

APPENDIX 4/ GENERATIVE SESSIONS: DATA ON MIRO

A4.1/ Collected data

The data of the generative sessions were the online boards that were filled in, transcripts made via Trint and quote cards derived from the interviews. The quote cards will not be published in this report, due to the sensitive nature of some quotes. Relevant quotes are used in this report in part 1 and part 2. They function to illustrate a point or to create a deeper feeling of the personal experience someone from the target

group might have.

All interview audio and transcription files are removed, by the time of publishing of this thesis.

A4.2/ Results on Miro

During the generative sessions, data has been collected on Miro. This data is anonymised by hiding identity markers under an orange Post-it. On this post-it, it is described what the data under the post-it looks like. See next pages for results.

Miro results Laura

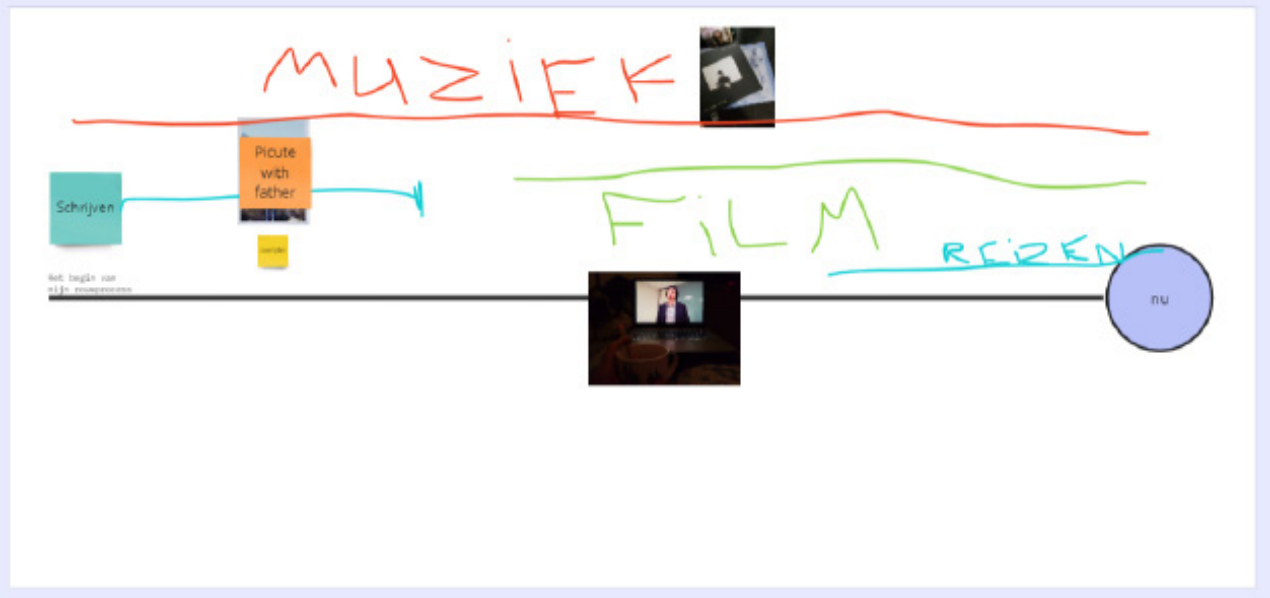
Note: Laura did not make anything for the last two questions, but did answer them verbally.

Timeline containing pictures will not be published

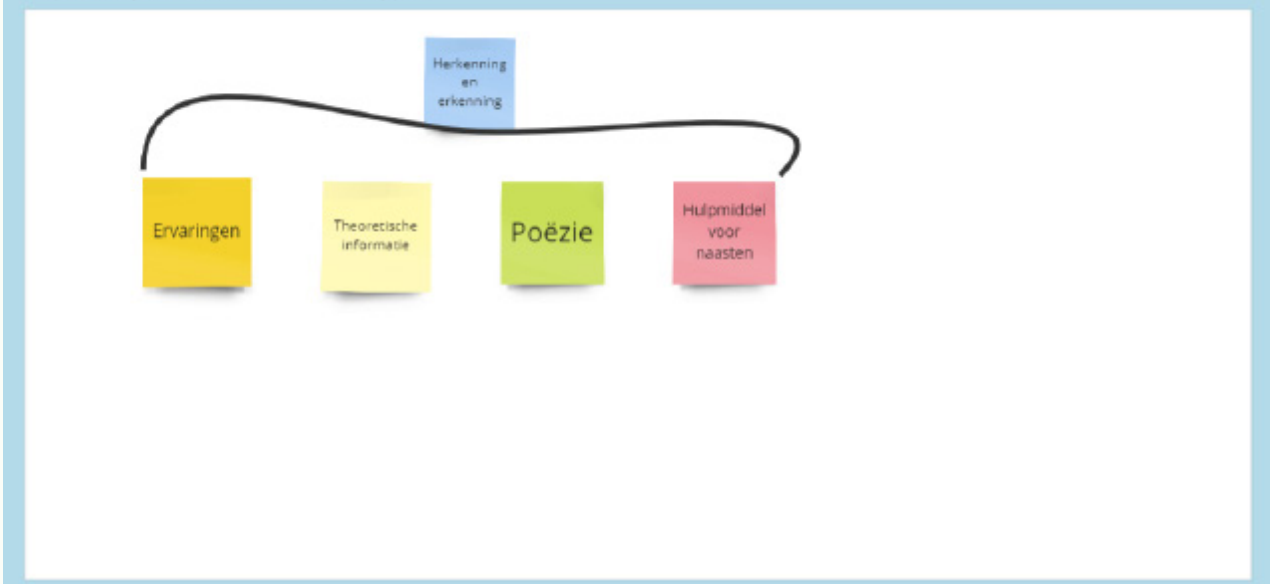


Miro results Stephan

stap 1. Wat ondersteunt jou?



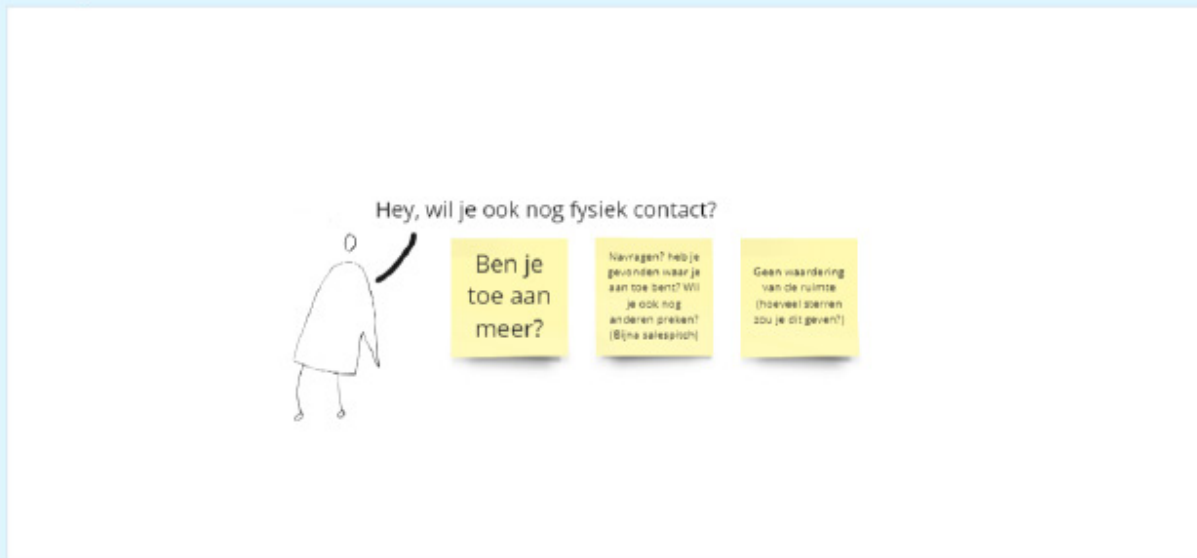
Stap 2. Een plaats voor informatie & support



Stap 3. bouw een medewerker

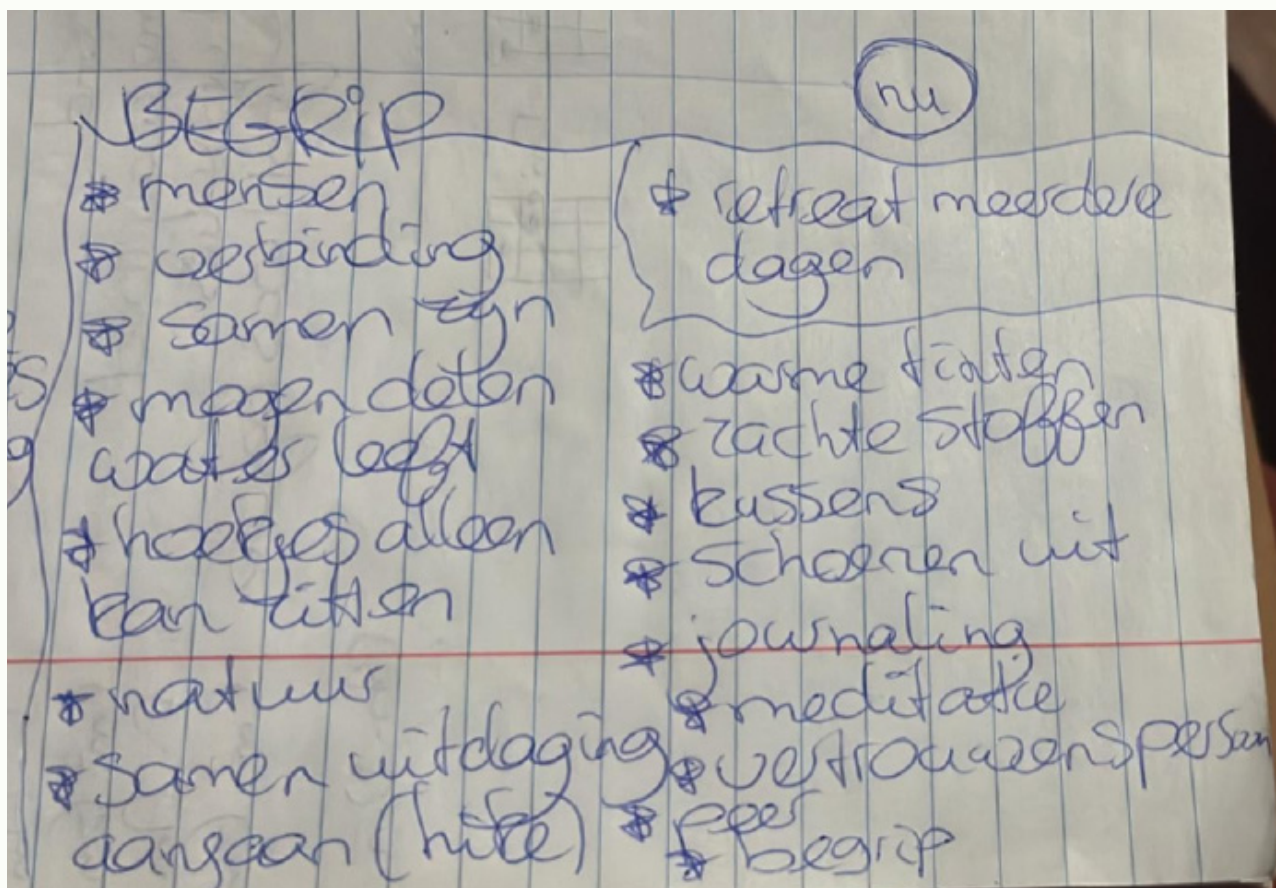
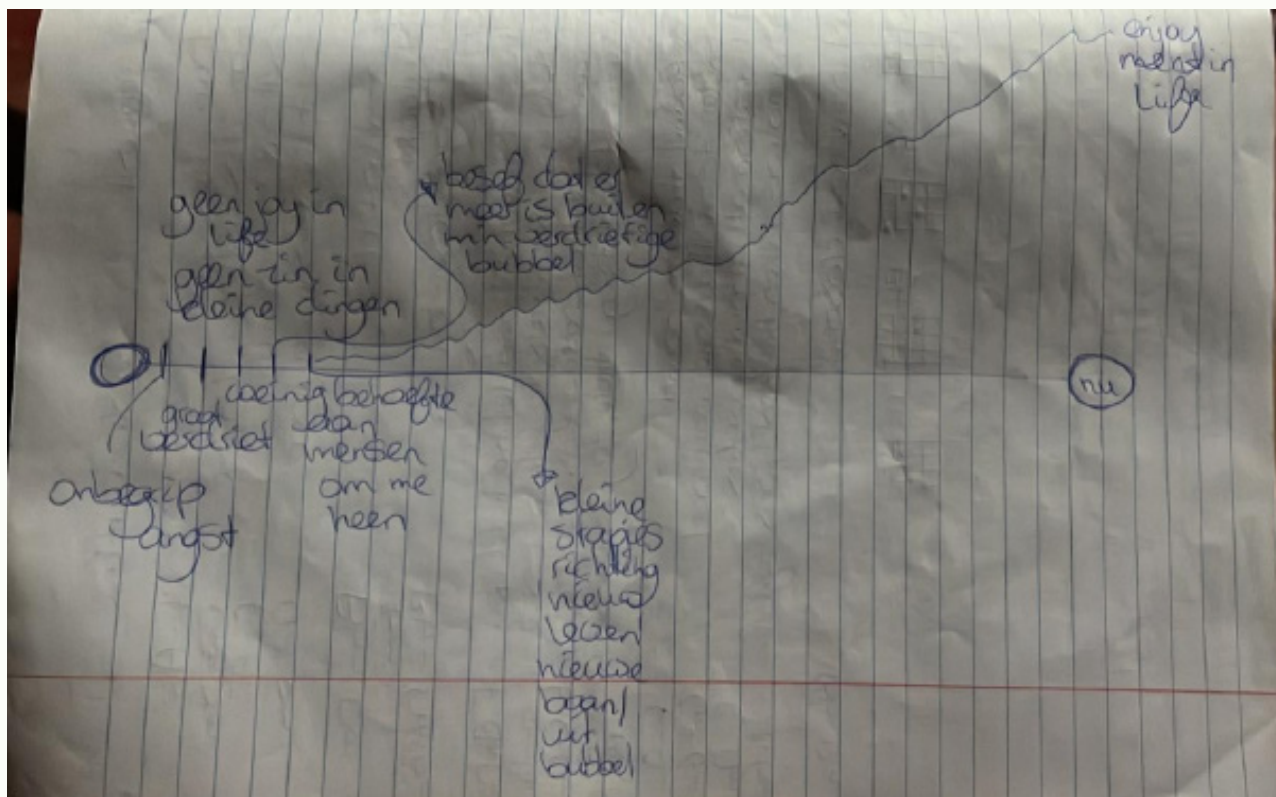


Afsluiting: de welkomsruimte & afscheid



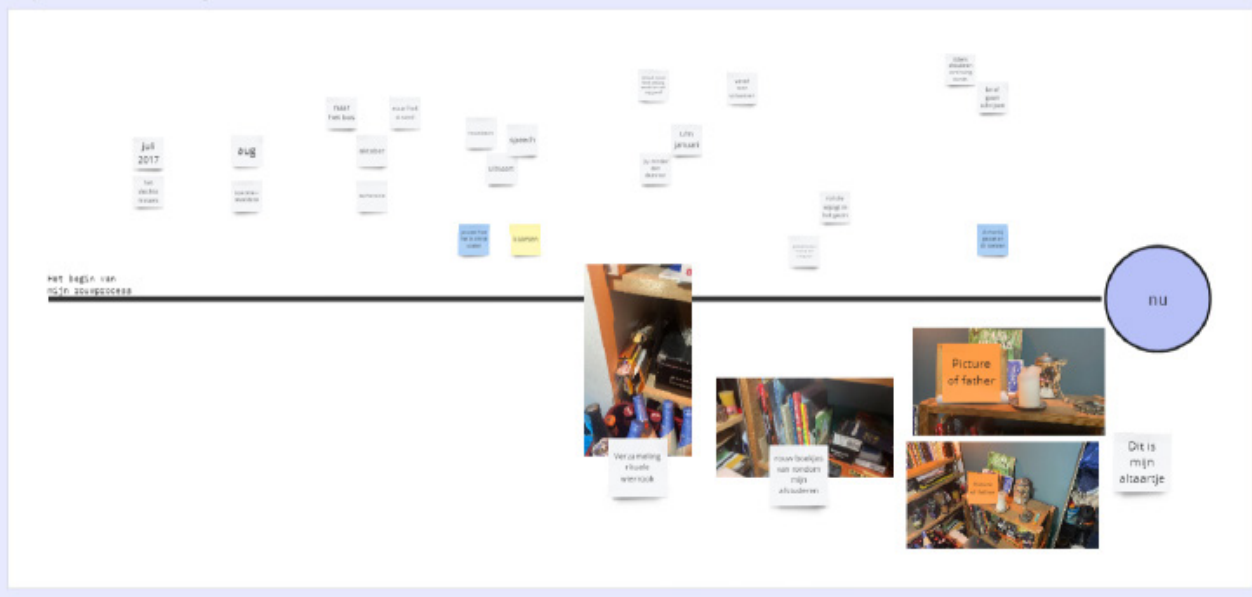
Miro results Elvira

Note: Elvira did not have a strong internet connection therefore the worksheets were send via Whatsapp and answers drawn on a paper.



Miro results David

stap 1. Wat ondersteunt jou?



Stap 2. Een plaats voor informatie & support

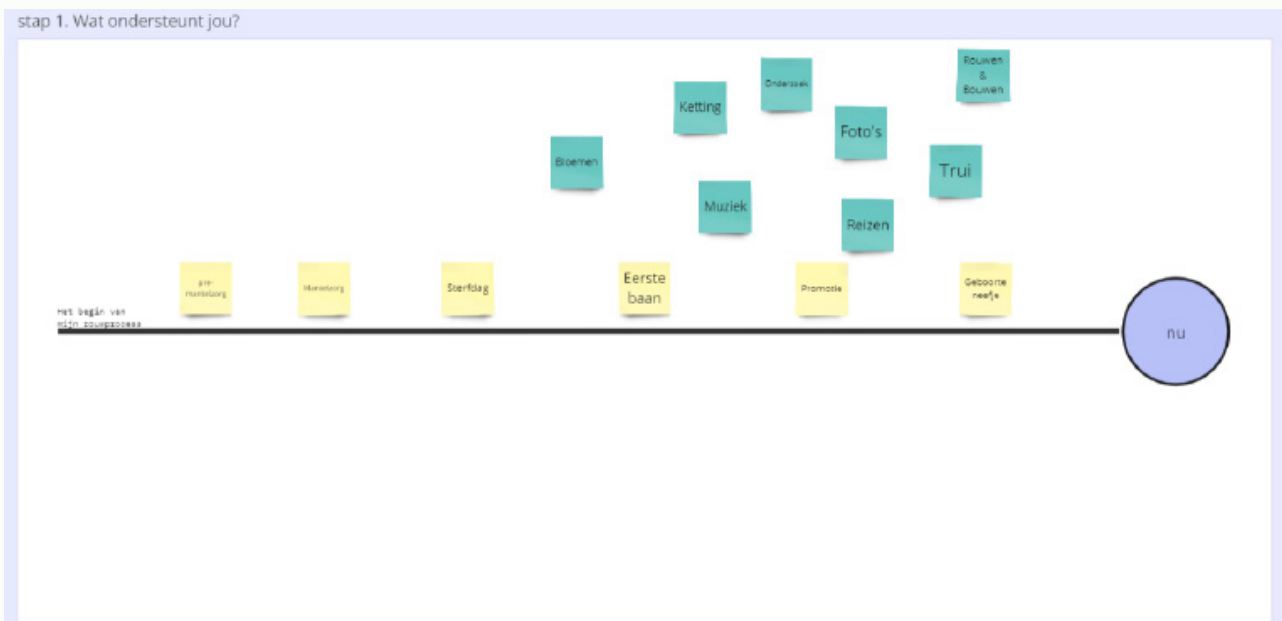


Stap 3. bouw een medewerker



Miro results Iris

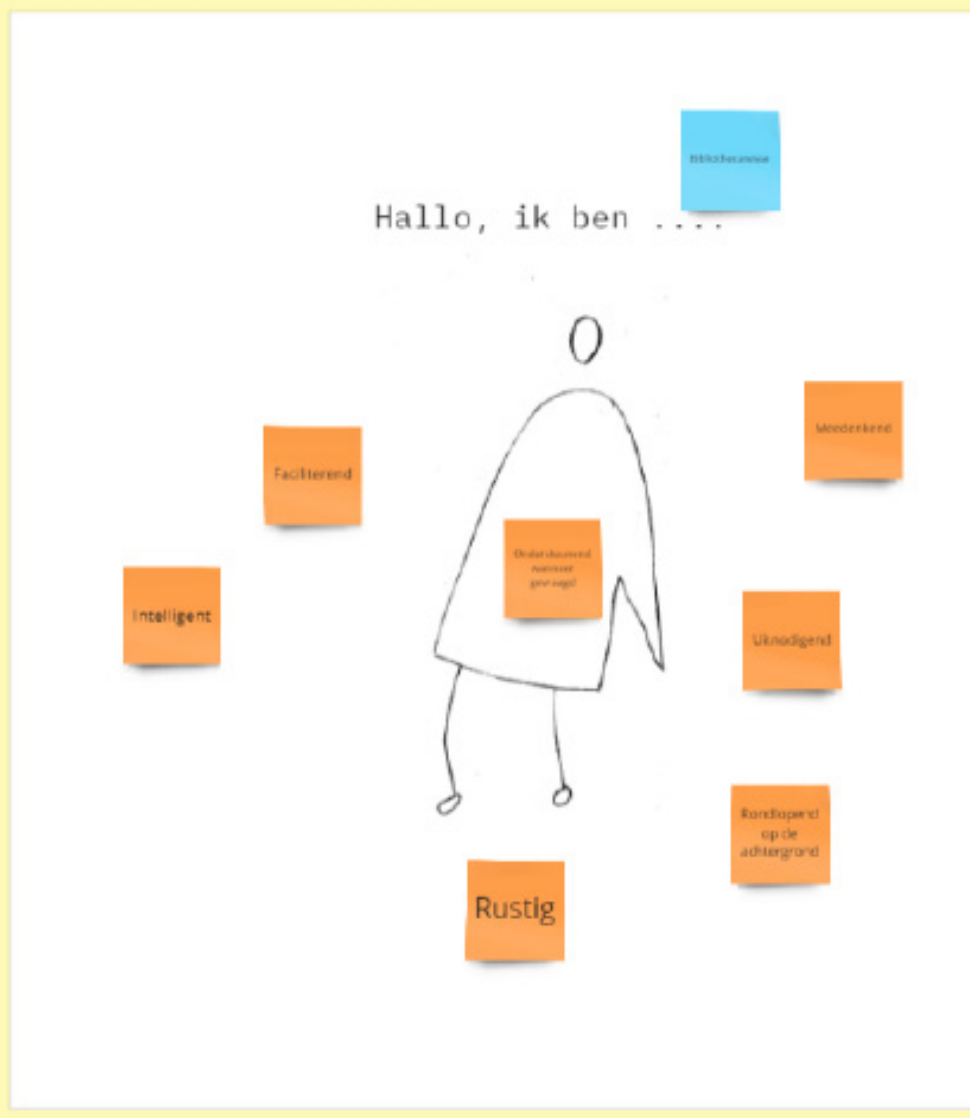
stap 1. Wat ondersteunt jou?



Stap 2. Een fysiek centrum voor informatie & support



Stap 3. bouw een medewerker





APPENDIX 5/ INTERVIEW GUIDE GENERATIVE SESSIONS

QUESTIONS

10 minuten

Intro

Kort babbelen en voorstellen

-Consentform checken-

Bedankt meedoen

Dirisn die te binnen schieten altijd nutting

Geen goede en foute antwoorden

Altijd terugtrekken

Nog vragen aan mij?

-Begin opname-

10 minuten

Ice breaker

Hoe vond je de foto opdracht? (ouder foto)

Is het nog gelukt een foto van je ouder te vinden?

QUESTIONS

- Beschrijft de foto?
- Wat zorgt ervoor dat dit een van jouw favorieten is?
- Kort doorvragen over ouder.

5 minuten

Naar miro
Korte uitleg over hoe je Miro gebruikt

15 minuten

Stap 1
Foto's bespreken

- Wat staat er op een foto?
- Waarom heb je deze foto opgestuurd?
- Is dit iets dat vaker voorkomt?
- Hoe heb je ontdekt dat dit je troost/steun geeft?

Tijdlijn uitleggen

- Heb je een moment wanneer jou rouwproces is begonnen?
- Hoe zou je de fotos erop plaatsen? Wanneer ben je begonnen met dit ritueel?

QUESTIONS

Heb je het gevoel dat er dlrin missen?

Kan je je dlrin herinneren de je vroeger steun gaven, die je nu niet meer doet?

15 minuten

Stap 2

Stel je voor dat er een fysieke plaats is om informatie en steun te vinden in allemaal soorten en maten.

Ik zou graag een impressie te tekenen wat je verwacht te vinden op deze plaats.

Hoe ziet de ruimte/ruimtes eruit en wat vind je er?

Je kan de plaatjes onder het canvas als inspiratie gebruiken

Hoe zou de ruimte er zelf uitzien?

Hoe zou je van een gedeelte naar een ander bewegen?

15 minuten

Stap 3

Nu een beeld hebben van hoe de ruimte(s) eruit zien? Hoe zouden de mensen zijn die er werken?

Welke eigenschappen zou je graag zien bij de medewerkers?

Wat voor rol zou je de medewerkers geven?

Hoe zou je willen dat de medewerkers met je omgaan?

QUESTIONS

Zou je veel medewerkers willen? Of juist heel weinig?

10 minuten

Huidig idee van vereniging uitleggen

Gebruik jij online resources?

Heb jij weleens dlrn over jouw rouw gegoogled?

Weet je nog wat je van de ervaring vond?

Heeft dit jou waardevolle informatie gegeven?

10 minuten

Afsluiting

Ik heb nog een afsluitend opdrachtje

- Hoe ziet de ruimte eruit via waar je naar binnen komt?

- En is dit dezelfde als de uitgang?

- Hoe heet de medewerker je welkom?

3 minuten

Afsluitende vragen

Okay dit waren alle dlrn die ik wilde doorlopen.

Heb je nog het gevoel dat ik iets belangrijks heb overgeslagen?

Heb je nog een vraag aan mij?

Heb je interesse om eventueel feedback te geven op modellen die ik ontwikkel?

QUESTIONS

10 minuten

Geen foto's opgestuurd scenario (vervanging bespreken fotos)

Is het toeval dat je deze dagen niets kon vinden?

- Kan je wel d'risn bedenken van eerder die je troost/ondersteuning gaven?

Heb je ooit gezocht of nagedacht over informatie of d'risn die jou steunen?

Heb je weleens bij anderen of online hiernaar gezocht?

- Hoe was dat?

Zou je hier behoefte aan hebben?

- Wat zorgt er denk je voor dat je deze behoefte niet hebt?

APPENDIX 6/ INTERVIEW GUIDE: ANNELIES VAN DER OUW

QUESTIONS

INTRO

Bedankt meedoen

Dirisn die te binnen schieten altijd nutting

Geen goede en foute antwoorden

VRAGEN

Algemeen

Wat doet de vereniging op dit moment?

Wat is jouw rol binnen de vereniging?

Hoe is de hierarchie opgebouwd? Wie stuurt wie aan?

- Hoeveel mensen werken er? Hoeveel vrijwilligers

- Hebben jullie samenwerktrisin?

QUESTIONS

- Hoe willen jullie dit ontwikkelen dit de komende tijd?

Visie en missie

Wat is jullie reden tot bestaan? (waar is jullie impact?)

Wat is de visie van de vereniging?

Wat is de rol van de vereniging in NL volgende jaar?

- en over 5 jaar?

Wat zijn waardes die jullie hoog houden?

Wat zijn services die totaal niet binnen de vereniging passen?

HET PLATFORM

Wat is de rol van het platform binnen de vereniging?

Wat moet het platform uiteindelijk kunnen doen?

- Wat zou de impact van het platform moeten zijn?

Is het platform informatief, sociaal en/of interactief?

Is de focus op alles wat mensen meemaken? Of alleen op de rouwervaring?

Rouw wegwijzer

QUESTIONS

Wat is de rol van de rouwwegwijzer binnen het platform?

Aanname in persona's:

- Open de word

ONTWIKKELING VAN PLATFORM

Hoe zijn jullie het platform aan het ontwikkelen?

Hoe betrekken jullie de doelgroep bij het project?

Nog d'ris toe te voegen?

APPENDIX 7/ INTERVIEW GUIDE GRIEF CHAT VOLUNTEERS AND ROBIN ZUIDAM

QUESTIONS

Intro

- consent form -

Bedankt meedoen

Dirisn die te binnen schieten altijd nutting

GEEN GOEDE EN FOUTE ANTWOORDEN

Dit interview is gebaseerd op jouw ervaring met als vrijwilliger. Er zijn geen foute of goede antwoorden.

Heb jij nog vragen aan mij?

- Opnemen beginnen -

Vragen

Kennismaking

Vertel me eens kort over jezelf

Wat doe jij binnen de vereniging?

- Hoe ben je hier terecht gekomen?

- Hoe vaak werk je?

Wat motiveert jou om dit werk te doen?

QUESTIONS

Over de chat

Hoe ben je Iriswerkt?

Hoe ziet een werkdag eruit voor jou?

Het gesprek

Zijn er guidelines die je moet volgen?

Hoe wordt het gesprek vaak geopend?

Is er een vast verloop in het gesprek?

Hoe eindig je een gesprek meestal?

Wat is volgens jou het belangrijkste om rekening mee te houden tijdens het gesprek?

Herken je verschillende themas/soorten gesprekken die vaker terugkomen?

Heb je een paar vaste dlrin die je altijd zegt?

- Zijn er bepaalde uitspraken/woorden die je ontwijkt? Waarom?

Hoe herken jij dat een gesprek goed gaat?

- En wanneer escaleert het volgens jou?

Wat is het grootste verschil tussen de gesprekken die je nu hebt en de eerste paar gesprekken?

QUESTIONS

Wat zijn do's en don'ts die je heb geleerd over de tijd?

Invloed leven

Heeft dit werk invloed gehad op jouw leven?

Ervaring/ expertise (als van toepassing)

Helpt jouw ervaring je om het gesprek beter te lijden?

Mijn interviews

Ik ga ook interviews doen. Heb je nog tips voor me?

Wat is iets dat niet werkt? Wat wel?

Afsluiten

Wat was je positiefste en negatiefste ervaring tijdens het werken bij de Rouwchat?

Ben ik iets vergeten te vragen dat belangrijk is binnen jouw werk?

APPENDIX 8/ ANALYSIS CRUSE.ORG.UK AND PROPOSAL VLMD

Currently, there is one online grief support provider that claims to offer personalised grief support: Cruse.org.uk. The screen captures in this appendix show how they do it. VLMD also has an idea about how to provide personalised support. Their proposal is still under development. I am not allowed to share their files,

therefore the screen captures are not shared. The appendix with the visible screen captures will be part of the confidential appendix. Both platforms have been analysed. During the analysis, several issues were identified for the (unintentional) interactions created on the platform. These issues are presented in this appendix.

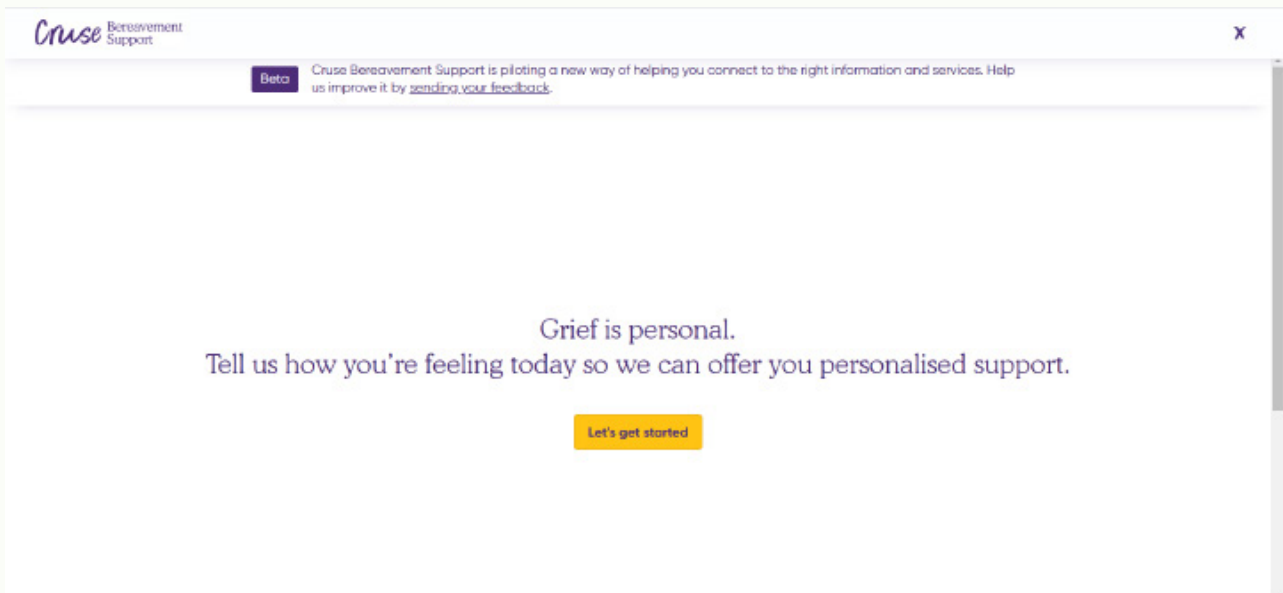


Figure 06. The start page

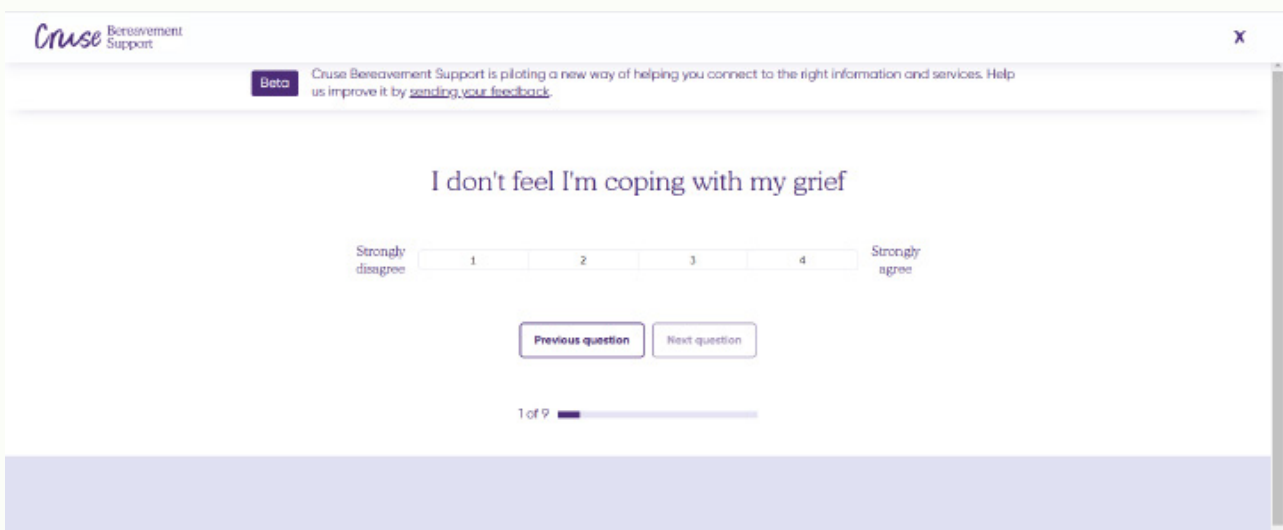


Figure 07. One of the 9 questions of the Likert-scales

Your recommendations

Your Results ⓘ

17/36

Thank you for taking the time to tell us how you're feeling. It sounds like you're having a tough time at the moment.

From your responses, we think the following will be helpful.

Personalised advice for you from Cruse



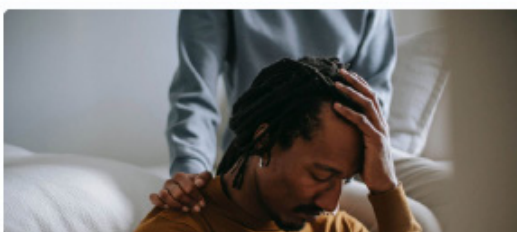
"I don't feel I'm coping with my grief"



"I can't stop thinking about the person who has died"



"It feels like I will be sad forever"



Understanding grief

Our guides to understanding grief, written by bereavement specialists.

[Read more →](#)

Get Support

We're here to help you no matter how long you've been grieving.

[Read more →](#)

The self-assessment is inspired by the themes we use when offering face to face support to bereaved people. Whatever the similarities, it is not and should not be used as an authorised version of the Adult Attitude to Grief scale.

Figure 08. Results of from the 9 questions answered include a score, which is not clarified what the quantities mean to the user, videos that correspond with the questions that were rated high, a link to further general information about grief (understanding grief, and a link a page which shows how to get in touch (Get support), both linked pages are not personalised. The page also features a disclaimer about the diagnosing tool used.

Your recommendations

Thank you for taking the time to tell us how you're feeling. It sounds like you're having a tough time at the moment.

From your responses, we think the following will be helpful.

For urgent help



Call our help line
0808 808 1677



Contact a Samaritan
116 123



Personalised advice for you from Cruse



"I'm struggling to see the point of life at the moment"

Get Support

We're here to help you no matter how long you've been grieving
[Read more →](#)

The self-assessment is inspired by the themes we use when offering face to face support to bereaved people. Whatever the similarities, it is not and should not be used as an authorised version of the Adult Attitude to Grief scale.

Figure 09. Results if the user scored high on most Liker-scales. It shows a number for a (suicide) hotline and only one video, discussing being suicidal due to the experience of grief. This page also links 'get support' link, but does not show the 'understanding grief' link as depicted in figure FIXME.

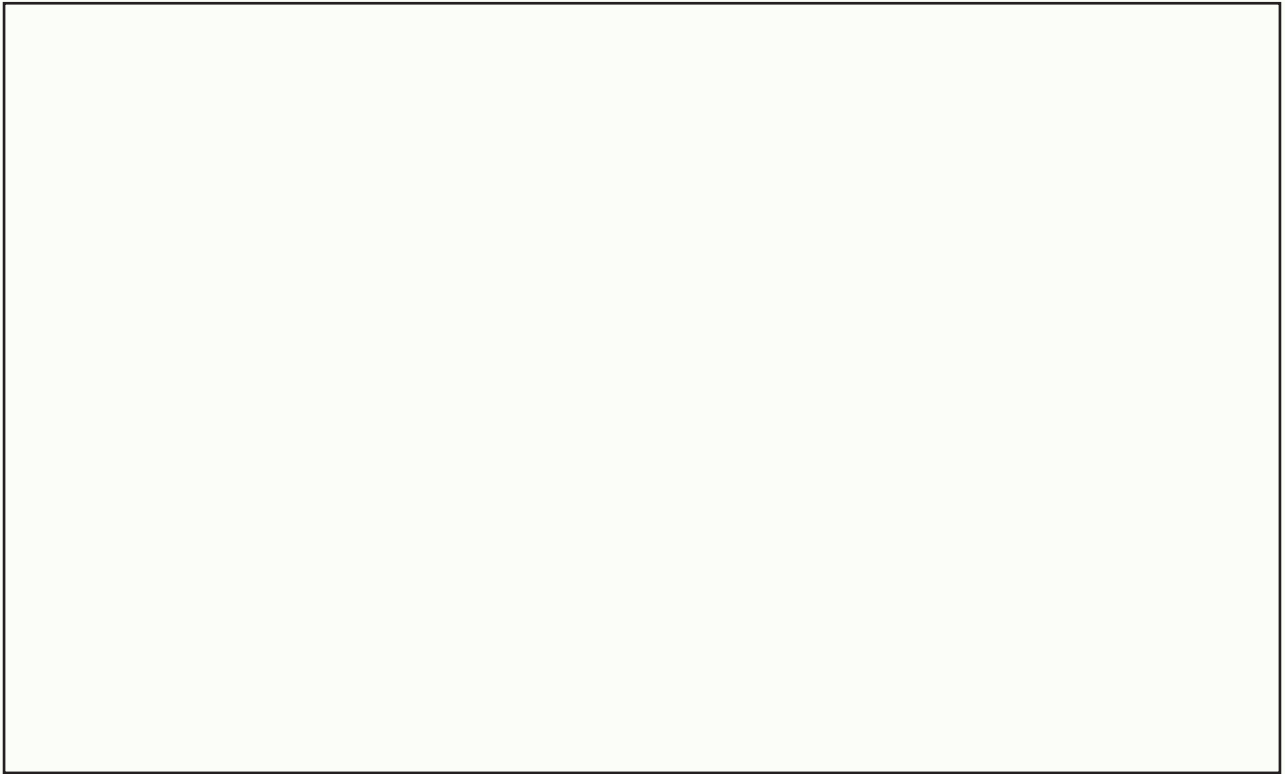


Figure 10. The first question on the Rouw Wegwijzer asks the user what they want to know.

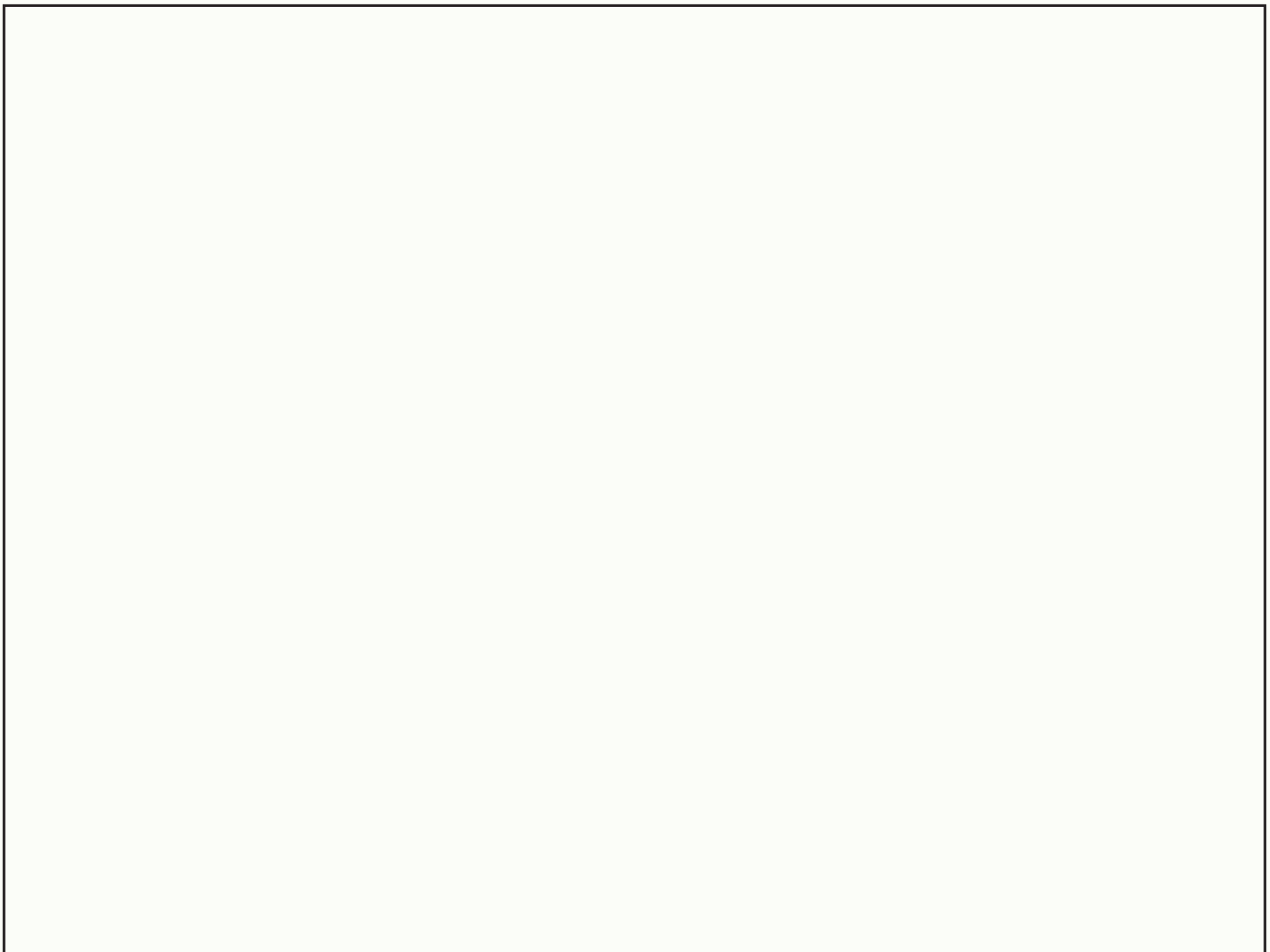


Figure 11. After that data is collected about demographics and the context of the loss.

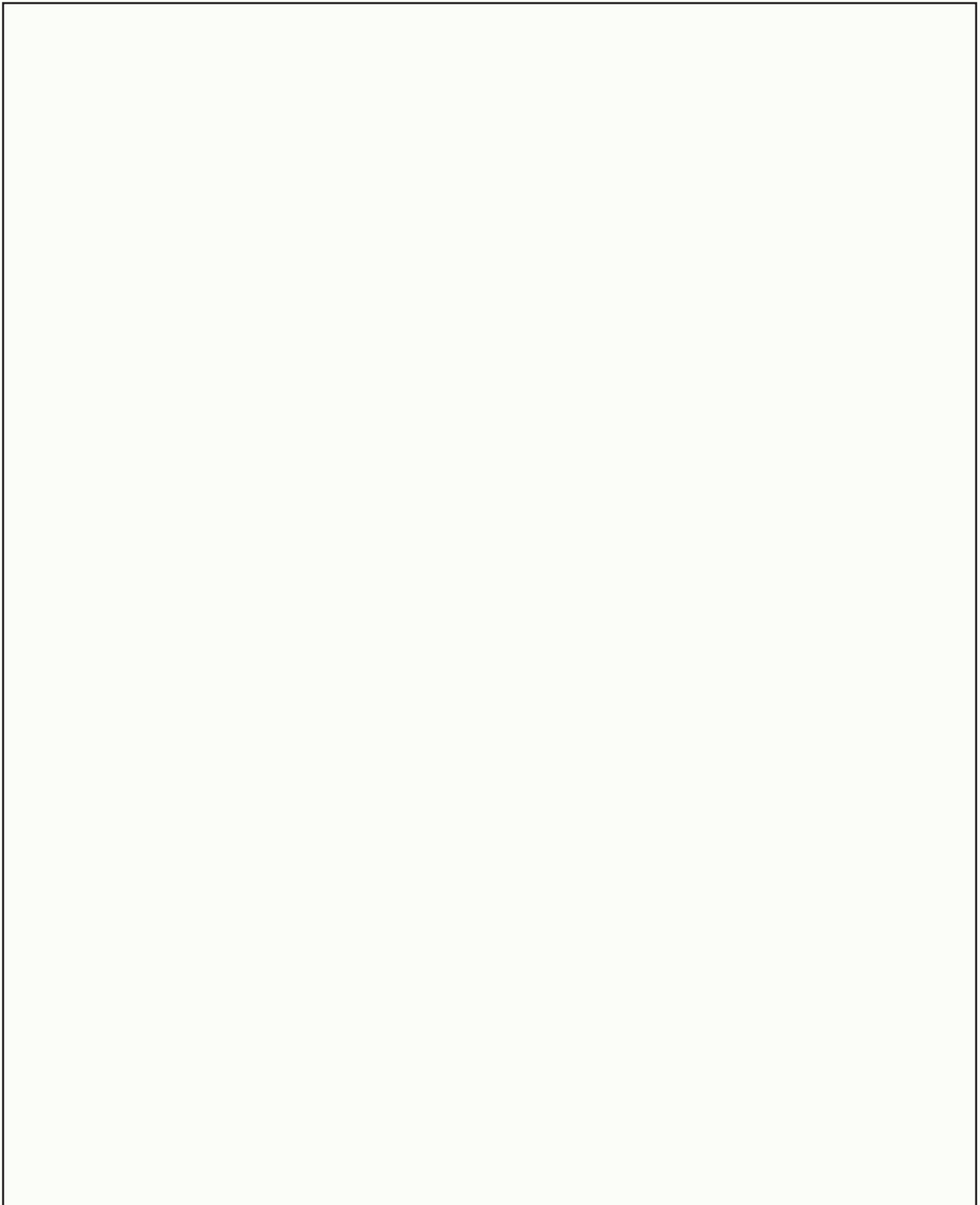


Figure 12. The platform then asks if there are any additional questions from the bereaved. Based on the input given by the user, more questionnaires are provided, in the concept proposal about the experience of the bereaved user. Based on this input more specified informational support is provided.

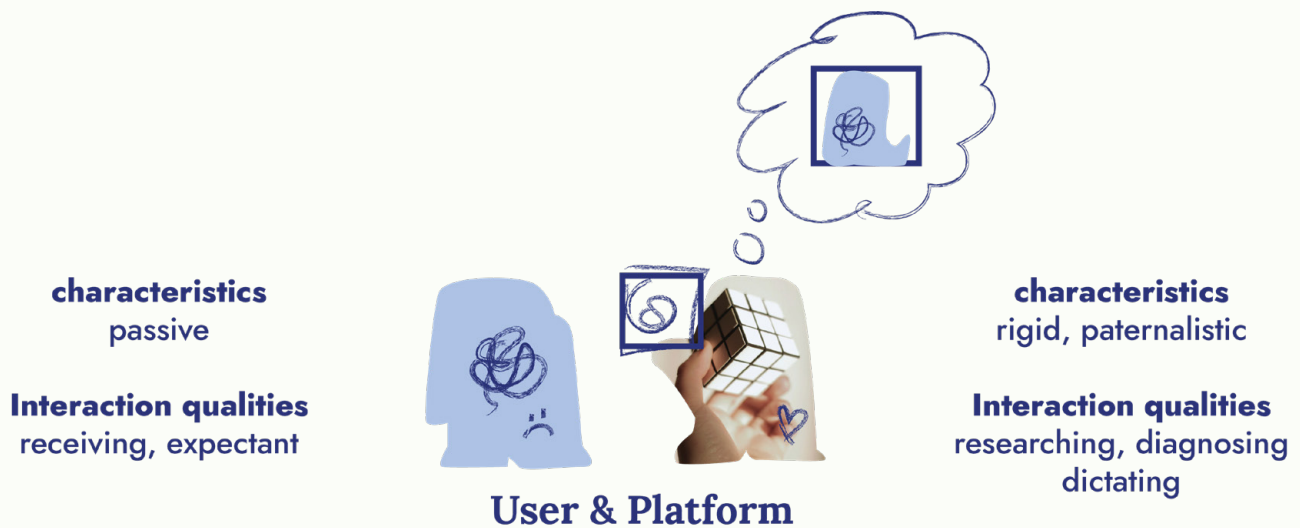


Figure 13. Interactions between the user and the proposal of the Rouw Wegwijzer bij VLmD.

A8.1/ Paternalistic roles

The personalised support Cruse.org.uk and VLmD provide resembles a doctor's visit. As discovered before, dictating support is considered unhelpful, as are characteristics that feel medical. The platforms are designed in such a way, that they are researching and diagnosing the user. In both designs, the user is not provided with the opportunity to correct the platform. They have to answer questions and receive (and adhere to) the results provided by the platform, giving them a passive, receiving role, see visual FIXME. The result is a paternalistic relationship between the platform and the user.

A8.2/ Data-centric point of view

Another example illustrating the challenges when creating a digital transformation for grief support is VLmD. This example shows how the method and point of view taken when designing, influence the interactions on the platform. The current proposal of VLmD provides their support based on context factors and demographics. Knowing these factors can help understand and anticipate the grieving experience an individual might

have, as they might influence and predict some aspects of a bereaved person's grief experience (Skrozcic & Kijamet, 2022). For example, the bereaved person's personality, attachment style, age, health status and the circumstances around the death statistically have an impact on how grief is experienced (Skrozcic & Kijamet, 2022). However, only asking for contextual factors decided on priorly, without input from the target group, creates an unequal power dynamic between the bereaved and the provider of support. After all, someone else than the bereaved is deciding what is good and relevant for them, based on parameters or biases that might be arbitrary (for the bereaved). The 'needs' for the system are put as a priority: what does the system need to know to give an output. The bereaved is diminished to a statistic. This top-down, paternalistic approach creates gatekeeping from relevant information and support sources, which is not desirable from a user-centred design perspective (Gulliksen, 2003).

This data-centric approach might influence the experience of the bereaved. As providing all the input

deemed necessary for the system can be experienced as a tedious task, with no clear relevance for the bereaved. It is also at risk of being seen as unhelpful grief support, due to potentially stereotyping or stigmatizing the bereaved. On top of that, gatekeeping could be considered systematic hindrance, also considered unhelpful according to Aoun et al. (2018).

A8.2/ Promise of personalised support

Cruse.org.uk bases their output on 9 statements about the (negative) experiences of grief, the user has to score high if they agree with the statement. If a statement is scored high, a corresponding video is shown. Resulting in one to nine corresponding videos of circa 2 minutes as personalised content and one separate video for users who score high on every question. The content of the videos can be described as a mix of emotional and informational support. The people in the videos seem genuine and the information provided is valuable, however, due to the promise made that it is personalised, which it is arguably not, it does not feel genuine or relevant.

The promised personalised support is lacking. The advice provided is based solely on 9 questions. It seems that a blanket approach is taken, where everyone is provided with the same treatment despite their unique differences. Which is the opposite of personalised support. Arguably, personal variety is missing. This type of grief support is often viewed as generic, not personal, or just standard practice by those who receive it (Aoun et al., 2017).

A8.3/ Unintentional interactions due to digitization

When talking about digital transformation, it is important to understand the difference between digitization and digitalization. Digitalization considers how the whole service, system or even company should be updated to fit the digital world (Accenture, n.d.). Digitization makes a one-on-one translation from offline to online, for example, by digitizing a database. If a service is digitized, not digitalized, the offline experience most likely is not automatically copied. Cruse.org.uk serves as a good example. Their digitization of a service created an undesirable experience for the user. In physical contact, providing the same advice and support to multiple people sequentially might not be experienced as generic, because it is delivered by a person directly to you. Making the message and intention feel personally targeted to you. However, in the online design made by Cruse.org.uk, it is clear that everyone receives the same message in the same way, with very little variety. The message does not feel personal or targeted anymore. This creates the experience of a blanket approach, which is the opposite of the promised personalised support. As a result, the support appears insincere and generic, therefore unsupportive.

A8.4/ Input from the user

VLmD asks a lot of input from the user, making filling in the Rouw Wegwijzer a time consuming and challenging exercise. Arguably, this creates high expectations from the user for the results as reward for their effort.

APPENDIX 9/ WEBSITES AND PLATFORMS INCLUDED IN BENCHMARKING

shapesofgrief.com

Offers: text & articles, some visuals and videos, which are content, podcast, which is content

childbereavementuk.org

Offers: Articles, videos, a chat, store with resources offering informational support.

hospicefoundation.ie

Offers: Articles, chat and call function

griefchat.co.uk

Offers: Articles, a chat, lifeledger and an online memorial place.

goodgrief.co

Offers: Downloadable PDF articles, video, all providing informational support. Peer to peer interactions in their app.

whatsyourgrief.com

Offers: Articles and other text based resources

Rouwnetwerkjong.nl

Offers: Text (articles and poetry), podcasts, videos and social media. Grief support groups. All specifically focused on your bereaved people.

Grief refuge (app + website)

Offers: blog, podcasts, peer groups and retreats. In the app: mood tracking, daily reflections.

APPENDIX 10/ WEBSITE AND PLATFORM INSPIRATION

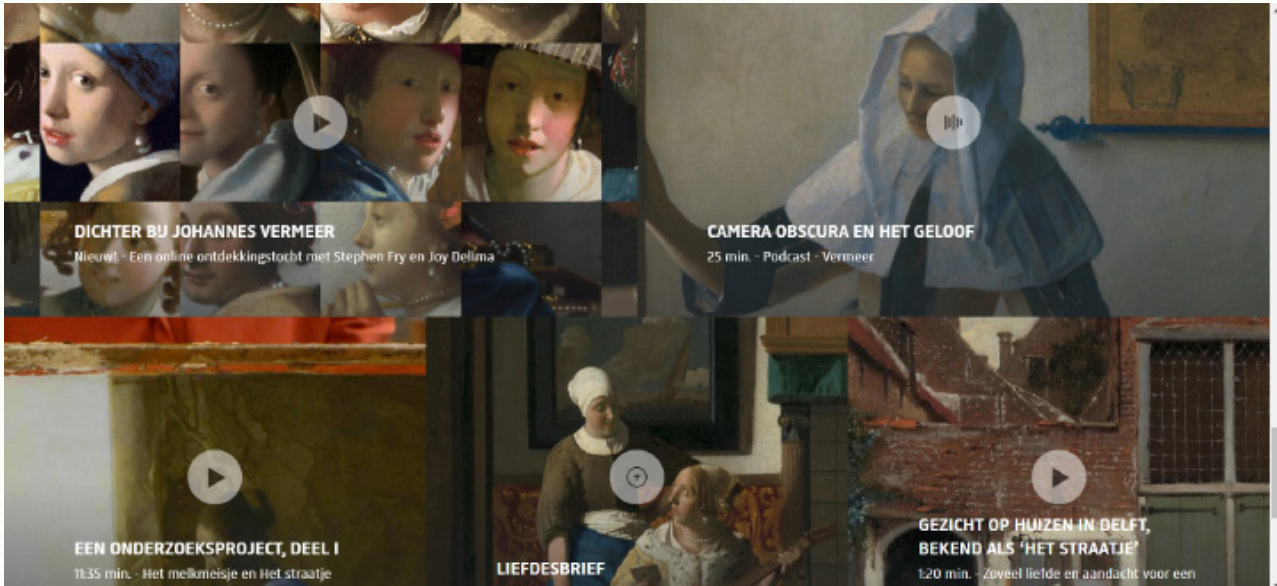


Figure 14. <https://www.rijksmuseum.nl/nl/stories>

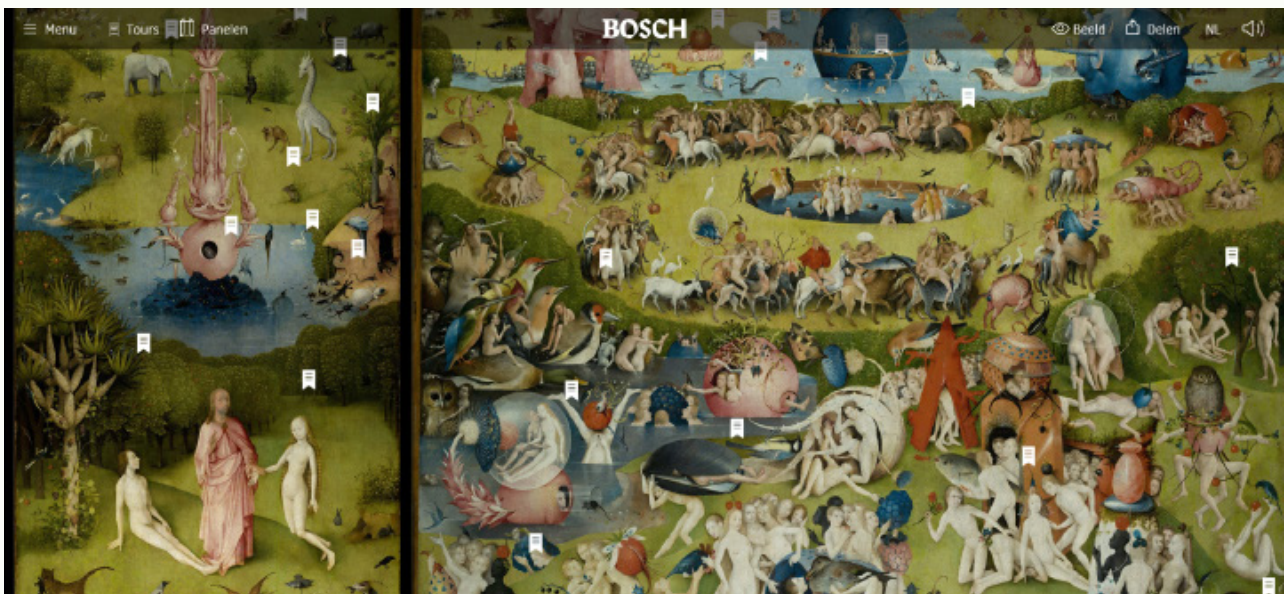


Figure 15. <https://archieff.ntr.nl/tuinderlusten/index.html>



Figure 17. <https://indischmonument.nl/>

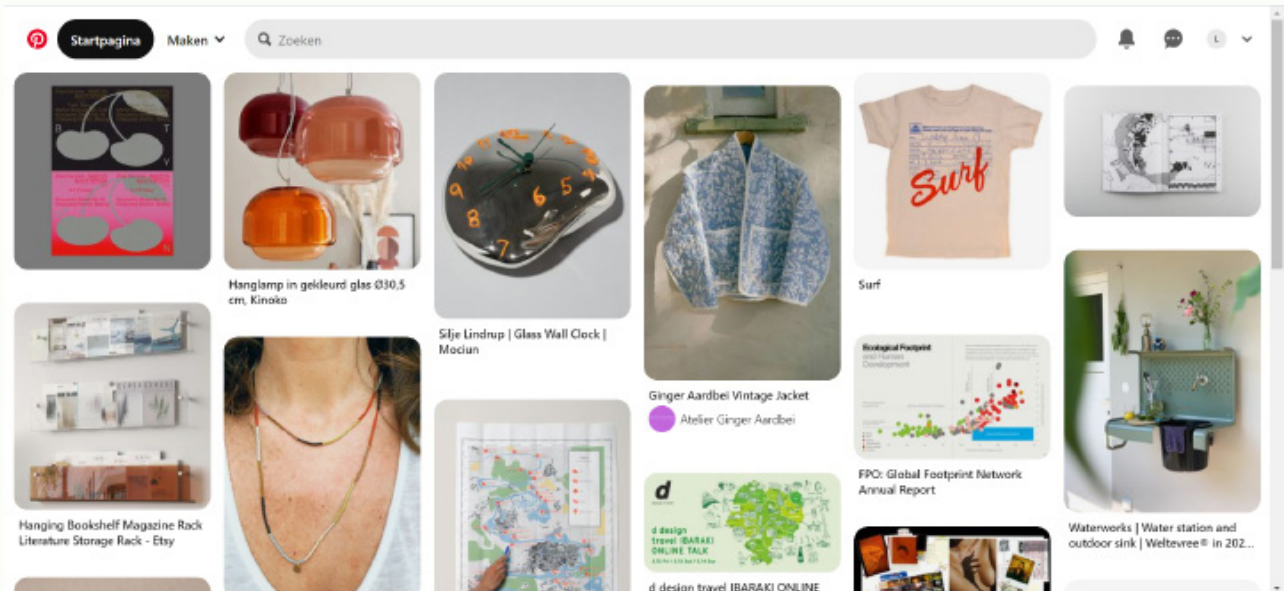


Figure 16. <https://nl.pinterest.com/>

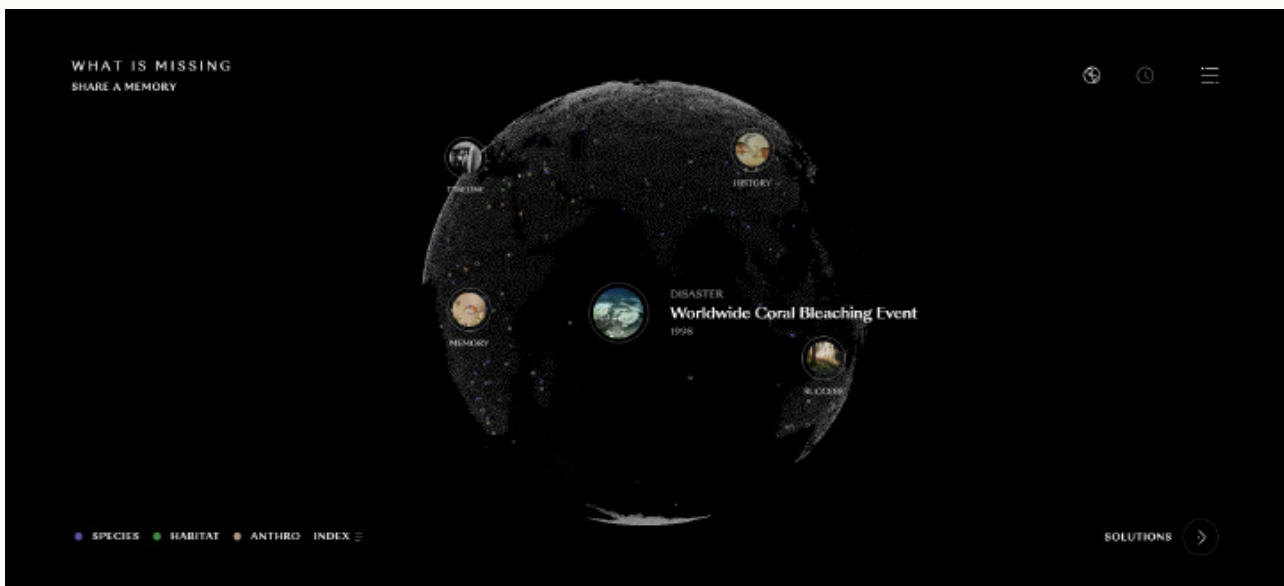


Figure 18. <https://www.whatissinging.org/>



Figure 21. <https://wtf.nl/>

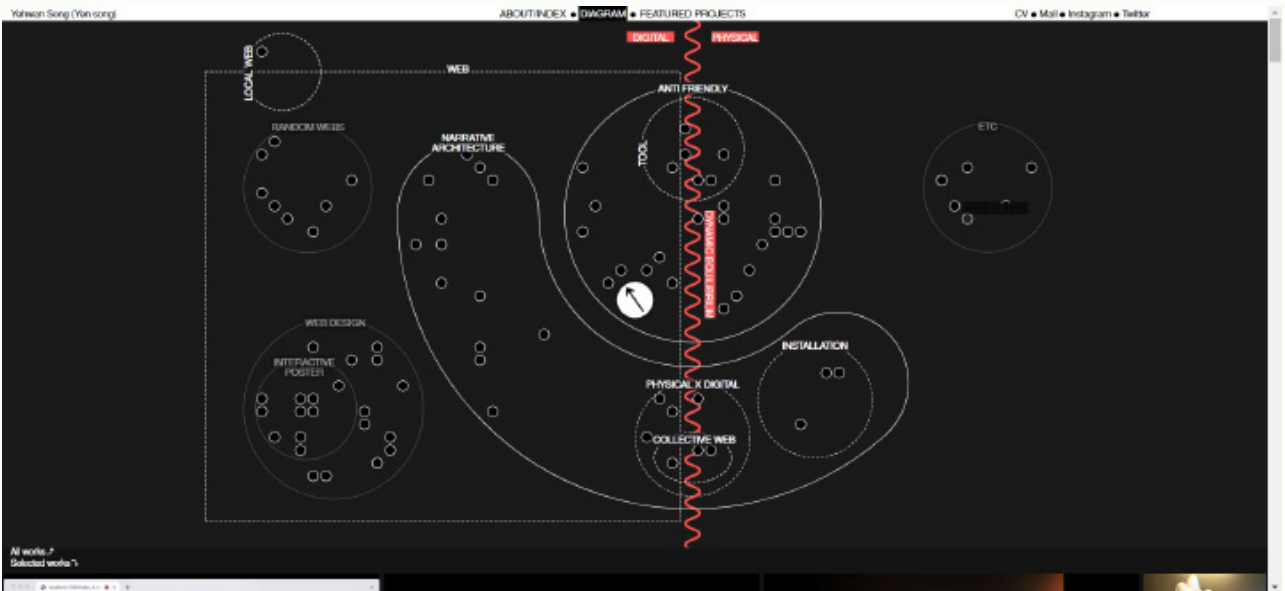


Figure 20. <https://www.yhsong.com/>

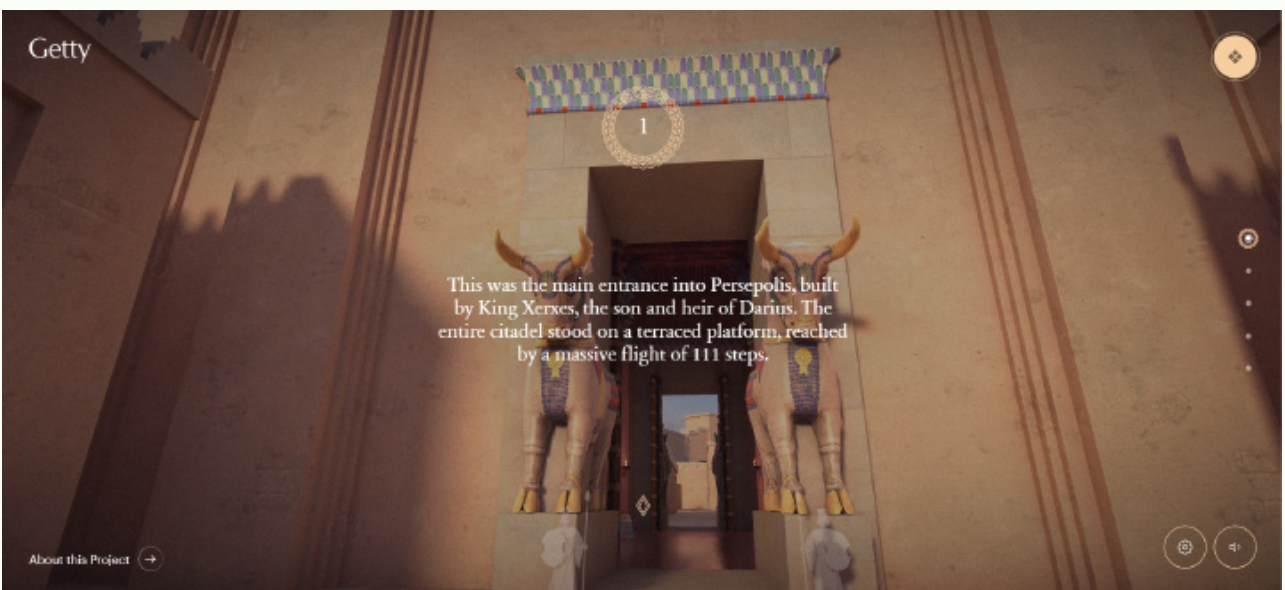


Figure 19. <https://persepolis.getty.edu/>



Figure 22. Not live anymore, but depicted on these websites:
<https://ilovecreatives.com/internet-gem-websites/by-the-books>
<https://land-book.com/websites/18683-mailchimp-presents-by-the-books>

APPENDIX 11/ INSPIRATION BOARDS

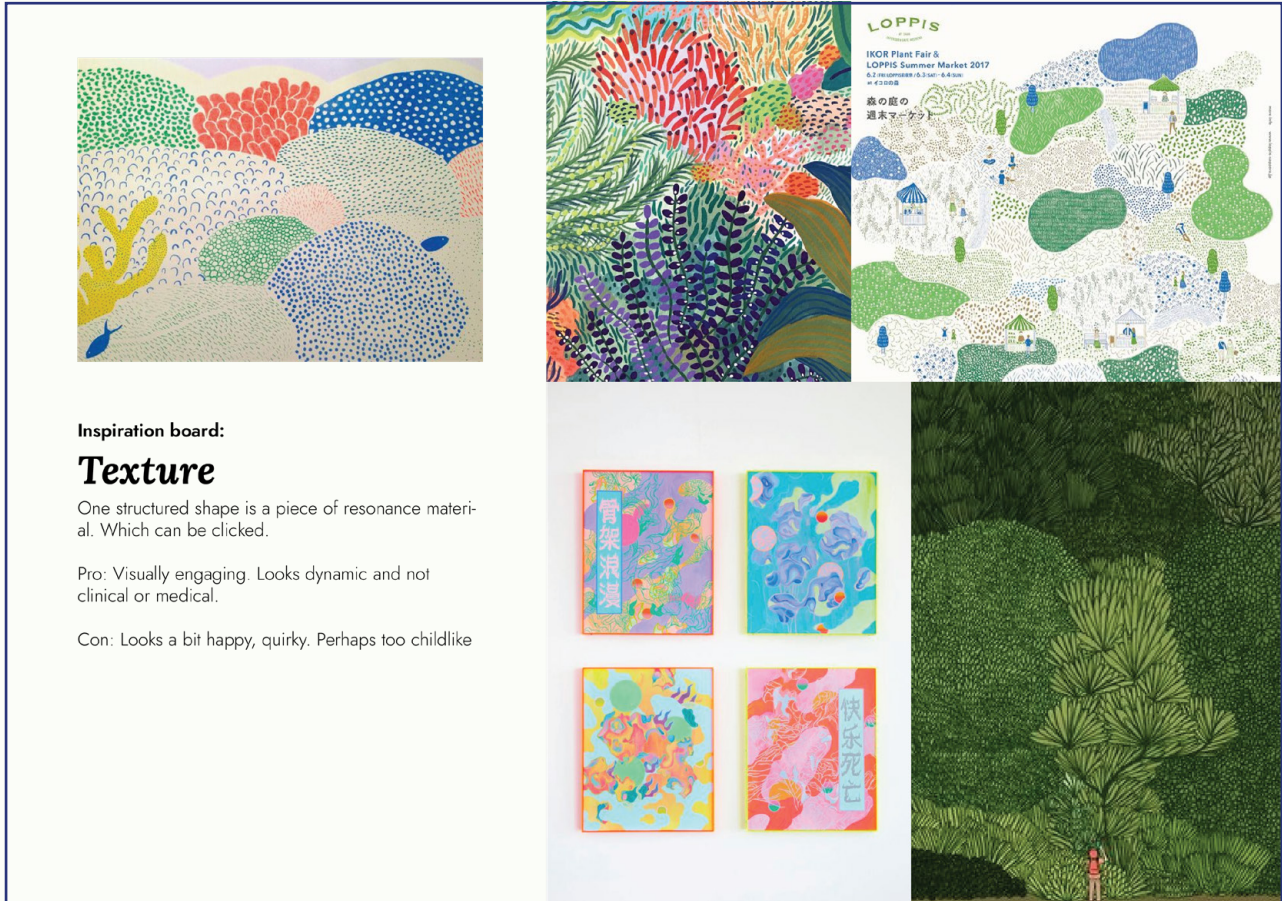


Figure 23. Image sources:

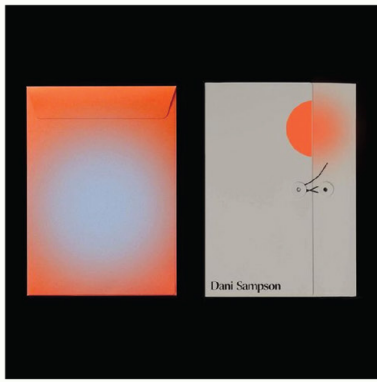
<https://nl.pinterest.com/pin/554787247859143187/>

<https://nl.pinterest.com/pin/33003009762232772/>

<https://nl.pinterest.com/pin/127508233191309061/>

<https://nl.pinterest.com/pin/663999538832463171/>

Figure 24. <https://nl.pinterest.com/pin/495958977720200375/>



Inspiration board:
Gradients 1.0

The resonance material is a 'blob' of gradients. The gradients can merge and are dynamic.

Pro: Fits the desired descriptors for visual design

Con: hard to create understandable UI with gradients. As a result the clickable parts are often 'hard'. Also, the example pieces have a lot less information on the page, than the Rouw Wegwijzer will have.

Colours are very bright and vibrant. Might become too 'happy'.



Figure 25. Image sources:

<https://nl.pinterest.com/pin/699887598364398033/>, <https://nl.pinterest.com/pin/83949980547845561/>, <https://nl.pinterest.com/pin/359936195231219224/>, <https://nl.pinterest.com/pin/56224695340067079/>, <https://nl.pinterest.com/pin/734368283001421236/>



Inspiration board:
Scribbles

The resonance material is little shapes with scribbles.

Pro: Represents the overwhelmedness of grief well.

Con: I can see this becoming very busy and overwhelming. Does not really fit the desired experience description.

Potentially very happy.



Figure 26. Image sources: <https://nl.pinterest.com/pin/672936369345597848/>, <https://nl.pinterest.com/pin/118712140166939653/> <https://nl.pinterest.com/pin/301881981286991486/> <https://nl.pinterest.com/pin/301881981286991479/>
 46



Inspiration board:

Illustrations hinting the content

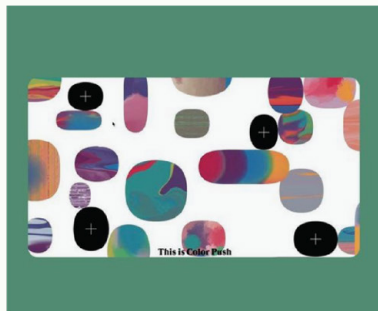
The resonance material can be found when the user clicks on little drawings. The drawings depict something that is discussed or part of the resonance material. This inspiration board is not so much about the visuals style, but more about the idea of having these visuals 'hint' the content.

Pro: If done less 'happy' than the inspiration visuals, it can become visually interesting for collecting. The preview step is already part of the first visual

Con: For every piece of content a fitting illustration needs to be made. Can become a bit overwhelming.



Figure 27. Image sources: <https://nl.pinterest.com/pin/320740804725085031/> <https://nl.pinterest.com/pin/635781672410419508/> <https://www.behance.net/gallery/5725767/Augustine-Claret-website> <https://nl.pinterest.com/pin/545639311084874396/> <https://in.pinterest.com/pin/176484879137075485/>



Inspiration board:

Gradients 2.0

The design created based on inspirationboard 'gradients 1.0'. While designing I encountered the following issues with the visual style:

- The gradients are difficult to use for clear UI design.
- The blur is difficult to use for clear UI design. On top of that, my computer cannot handle that much calculation power, making the process of designing extremely slow.
- The colours have the tendency look joyfull when combined.
- The background looks very empty

In this proposition the colours are more subdued. It also gived more tools for background colours and UI-elements

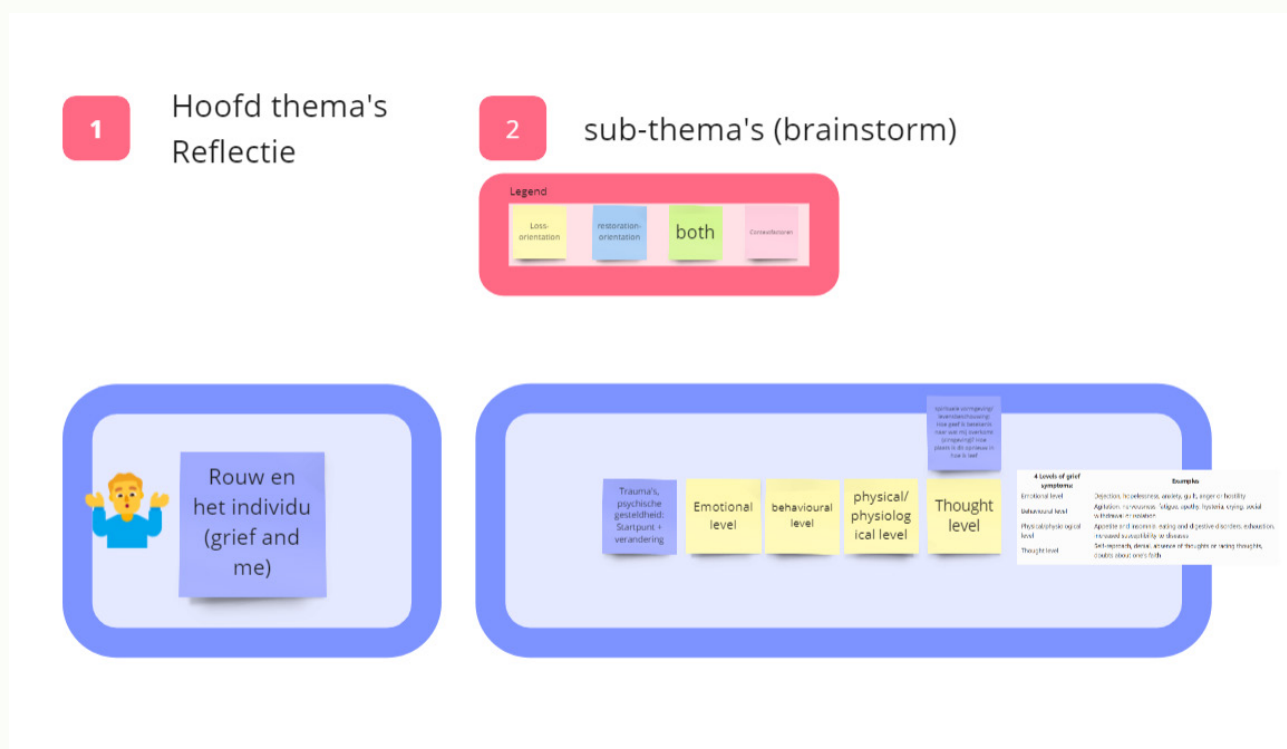
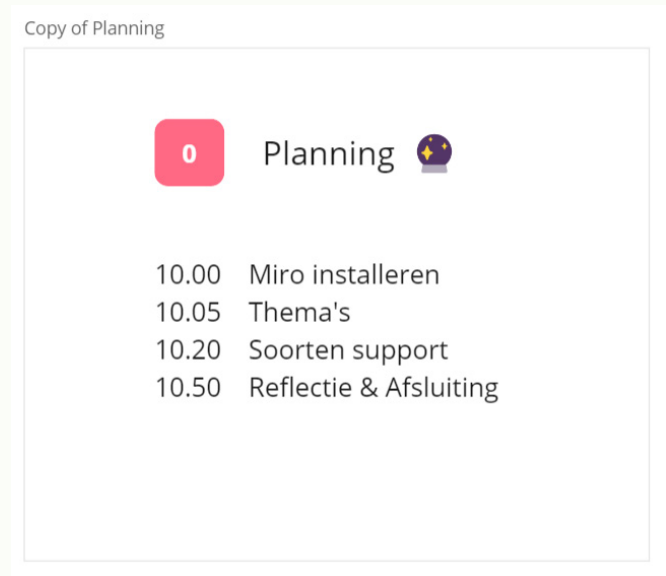


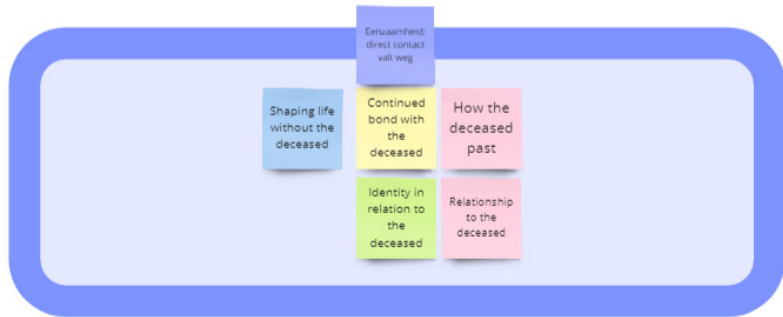
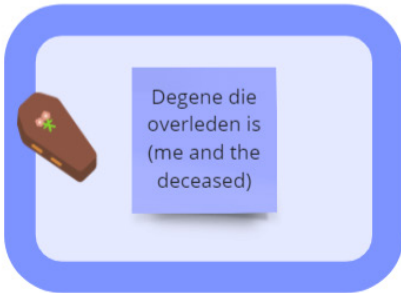
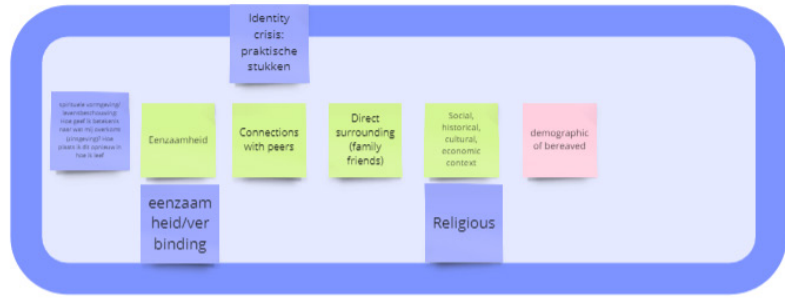
Figure 28. Image sources: <https://nl.pinterest.com/pin/429249408249345780/> <https://nl.pinterest.com/pin/49863299008740964/> <https://nl.pinterest.com/pin/1047298088322329829/> <https://nl.pinterest.com/pin/71846556546698589/> <https://nl.pinterest.com/pin/9288742974866438/> <https://nl.pinterest.com/pin/563018695300067/> <https://nl.pinterest.com/pin/367958232063375065/> https://media.pitch47fork.com/photos/5e7e733069dca000873f125/1:1/w_600,h_600,c_limit/dragon.jpg

APPENDIX 12/ VALIDATING THE THEMES WITH VLMD- RESULTS IN MIRO

The validation for the themes identified in the research phase was done with Annelies van der Ouw and Robin Zuidam. All dark blue post-its are add-ons from them.

Not all post-its with identified themes are legible, but they are all themes included in the visual in the main body, so if you want an overview you are referred to that visual.





After creating an overview of grief themes, we mapped out the different kinds of support that are available.

Welke soorten support kan een nabestaande krijgen?

fysiek, sociaal,
psychologisch,
spiritueel: 4
dimensies
(palliatieve zorg)

emotional,
informatie
support,
practisch

Peergroups

maatschappelijk
werk

informatie

maatjes

informele
support

Professionele
hulp dmv
gesprekken 1-
op-1 (psycholoog,
rouwbegeleider)

Door VLmD

Online
spreken met
iemand
(Rouwchat,
RouwMail etc)

Functie: samen
kijken naar wat de
volgende stap is.
Deze mensen
hebben de sociale
kaarten.

Je
resultaten/data
uitlezen samen

De connectie

Overzichtskaart
van kwalitatieve
1-op-gesprek
hulpverleners

Overzichtskaart
van kwalitatieve
peergroups

Directe
doorverwijzing
naar de dokter
(CG)

3e partijen

Professionele hulp
dmv gesprekken 1-
op-1
(maatschappelijke
werker,
rouwbegeleider)

Psycholoog
etc buiten
scope

Peergroups

dokter:
doorverwijzen

eventueel
tweedelijnszorg

APPENDIX 13/ PIECES OF CONTENT INCLUDED IN THE USERTEST PROTOTYPE

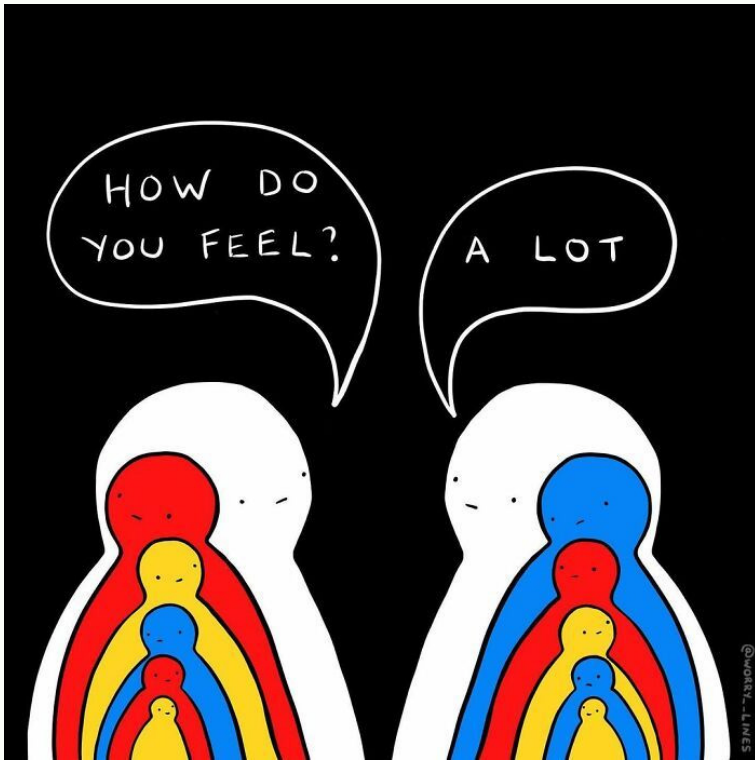
Note, all music was complimented with the lyrics of the songs, so users can get a better impression of what the song is about.

This list of pieces of content was created by asking friends and family if they could send me videos, audio, texts or images about grief that they found inspiring, interesting or touched them. I have added pieces of content that I found interesting, or because they represented a tone of voice that was not yet included in the selection.

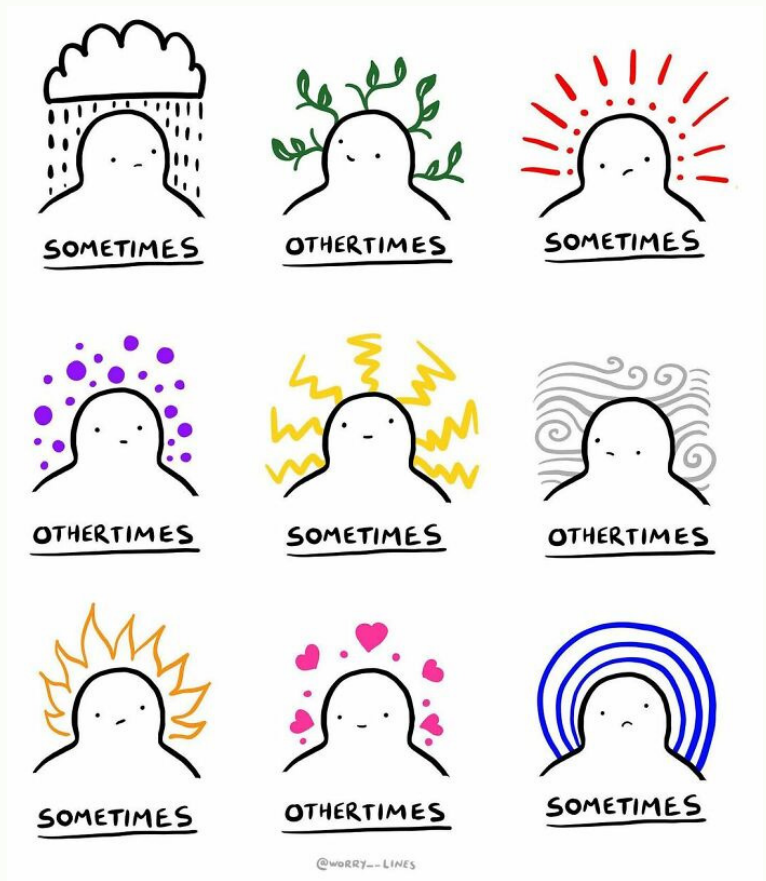
Images



Source: https://www.google.com/url?sa=i&url=https%3A%2F%2Fen.wikipedia.org%2Fwiki%2FPieta%25C3%25A0_%2528Michelangelo%2529&psig=AOvWaw0oZjTLYQiMFkaqr1Fz-SiyJ&ust=1700253011085000&source=images&cd=vfe&opi=89978449&ved=0CBEQjRxqFwoTCLCK-v5euyYIDFQAAAAAdAAAAABAE



Source: https://www.instagram.com/worry_lines/



Source: https://www.instagram.com/worry_lines/

ME AND MY SADNESS



Source: https://www.instagram.com/worry_lines/



<https://www.theartnewspaper.com/2017/04/04/death-destruction-and-deity-painting-guernica>



<https://artuk.org/discover/artworks/the-touch-of-comfort-55804>



<https://nl.pinterest.com/pin/303641199892029958/>



<https://nl.pinterest.com/pin/317714948730642493/>

Videos

De fysieke symptomen van verdriet (youtube video)

Source: <https://www.youtube.com/watch?v=Gcp-1G0eIUYk>

Wat je NIET moet zeggen tegen jonge mensen in ROUW | CRUX #6 (youtube talkshow)

Source: <https://www.youtube.com/watch?v=46R4oN40-MQ&t=2112s>

Are You Still There? (short film)

Source: https://www.youtube.com/watch?v=87C_A2Apz58

Overgave (documentary)

Source: <https://www.2doc.nl/documentaires/2022/10/overgave.html>

If Anything Happens I Love You TRAILER (animated video)

Source: <https://www.youtube.com/watch?v=3kH75xhTpaM&t=2s>

This is what grief looks like... (Tiktok video)

Source: <https://www.tiktok.com/@travelingthroughgrief/>

My interpretation of this model (Tiktok video)

Source: <https://www.tiktok.com/@amagiovany>

Audio

Maaïke Ouboter - Dat ik je mis (music)

Rob De Nijs - Vanaf Vandaag (music)

Arlo Park – Hurt (music)

James Morrison - in my dreams (music)

The Science & Process of Healing from Grief | Huberman Lab Podcast #74 (podcast)

Dag voor Dag (podcast)

Liesbeth Raasker raakte op tienjarige leeftijd haar moeder kwijt en later verloor ze de persoon die een oogje in het zeil zou houden na haar moeders dood. Deze twee ervaringen met verlies bewogen haar tot het maken van deze podcast. In de afleveringen bespreekt zij de onderwerpen die impact hebben op het rouwproces. Dit doet zij op een intieme manier, aan de keukentafel met een drankje, voor houvast en begrip.

Mignonnus de podcast (podcast)

In het eerste seizoen van de podcast van Mignon Nusteling leest zij voor uit haar nooit uitgegeven manuscript 'Wat niemand je vertelt wanneer je vader doodgaat'. Hierbij bespreekt ze de ongemakkelijkheden van rouw en verlies. Deze autobiografische verhalen roepen al snel herkenning op en brengen op een lichte manier zware onderwerpen naar boven.

Een Doodnormale Podcast (podcast)

Twintigers Benthe en Sabien onderzoeken wat het betekent om jong te rouwen. Ze spreken jonge schrijvers, muzikanten en acteurs, die een dierbare hebben verloren en vragen experts vele vragen over rouw en alles wat daarbij komt kijken. Waar omgaan met de dood in Nederland vooral wordt gekleurd door ongemak en het wegstoppen van gevoelens, halen Sabien en Benthe voor hun podcast hun kop uit het zand en kijken de dood recht in de ogen.

Tekst

Hereindigen

Dat herinneringen 'herdacht' moeten worden vanuit het bewustzijn dat iemand dood is. Er moet aan elke herinnering een einde worden toegevoegd. De mogelijkheid op 'nog een keer' is weg en dat geeft de herinnering een andere kleur.

Zo is een van mijn lievelingsherinneringen het beeld van mijn moeder met een kop thee in de boomgaard als ik thuis kom. Ineens moet ik aan de herinnering toevoegen dat ik haar nooit meer in die stoel ga zie zitten en dat er geen kop thee meer op tafel komt te staan.

Source: <https://www.verlieskunst.nl/nieuwe-taal-voor-rouw/>

Dodemoederclub

Het speciale gevoel dat uitgaat van mensen die ook hun moeder zijn verloren.

Een geheim genootschap waar je liever geen lid van bent, maar als je dan toch je moeder kwijt bent, je blij bent dat we er zijn. Hoewel de feitelijke omstandigheden van ieder lid anders zijn, resoneert op een diepe laag een verlies dat het persoonlijke overstijgt.

Source: <https://www.verlieskunst.nl/nieuwe-taal-voor-rouw/>

Aanwezig In Afwezigheid

Hoe iemand er nog is, in de lege plekken die die achter liet.

Eén stoel aan tafel blijft al maanden leeg. Altijd dezelfde. We hebben er niks over gezegd. Ondanks dat het een fijne zitplek is, beter dan de stoel in die gekke hoek, gaan we toch op die gekke stoel zitten als we als laatste aan tafel komen. De lege plek blijft leeg.

Soms komt er bezoek. Die gaat dan op de stoel zitten. Dan halen we allemaal opgelucht adem als het bezoek weer weg en de stoel weer leeg is. Het bezoek vraagt of we al plannen hebben voor kerst. Of we langs komen? Maar het kerstdiner dit jaar kunnen we niet verplaatsen. Een nieuwe tafel heeft geen lege stoel voor haar.

Hoe de leegte een monument voor haar kan zijn. Een lege plek om te bewaren.

Source: <https://www.verlieskunst.nl/nieuwe-taal-voor-rouw/>

Anders Leren Vasthouden

Een fysieke, lichamelijke relatie stopt. Maar de liefde stopt niet, die zoekt een andere vorm.

De liefde die ik door mijn lijf voel stromen voelt onwennig door het ontbreken van de aanwezigheid van mijn moeder in lichamelijke vorm. Het is een zoektocht naar hoe ik de liefde naar buiten kan laten stromen. Een zoektocht naar hoe ik onze relatie na haar dood vorm geef.

Soms manifesteert de liefde zich in de vorm van rituelen, zoals op zaterdag haar lievelingsbloemen halen en haar notentaart op onze verjaardagen, een grafbezoek of in dierbare spullen die mini monumenten zijn geworden. Soms zijn het minder fysieke manifestaties. Bijvoorbeeld in de vorm van het ophalen van herinneringen, doorgaande, ingebeeld gesprekken met haar of een fantasie dat ze er nog is. In zo'n fantasie stel ik me voor dat ze nog één keertje achter me staat en mijn haar streelt terwijl ik op de bank een boek lees. De tv staat aan, vast het journaal. Zij heeft net koffie gezet, ik drink een kopje mee ook al weet ik dat ik daar later vast spijt van krijg. Haar ogen zijn op de tv gericht, ze keuvelt een beetje. Ik weet dat zij ook meer bij haar handen en bij mij is dan bij het journaal. Ze vlecht, ook al weet ik dat ik geen elastiekje heb om de vlecht te laten zitten.

Source: <https://www.verlieskunst.nl/nieuwe-taal-voor-rouw/>

De Nieuwe Worden

Je kunt niet terug naar wie je ooit was, er kan enkel een nieuwe jij ontstaan waarin het verlies geïntegreerd is.

Mensen vragen of ik weer de oude ben. Maar ik weet dat ik nooit meer de oude kan worden. Mijn moeder is dood en daarmee een deel van mij. De Oude Ik bestaat niet meer.

Langzaam laat ik het idee los dat ik weer de oude kan worden. Ook het idee dat ik de oude wil worden begint te slijten. Het begint me te dagen dat dit Lessen In Nederigheid zijn. Dat ik het leven niet in de hand heb. Dat ik, hoe hard ik ook wens, ik niet krijg wat ik het liefste wil. En pas nadat ik dit zo hard mogelijk gewenst heb (ik moet het toch tenminste proberen) en wanneer het

moment daar is, kan ik ophouden met wensen. Pas dan, niet eerder, zal ik de Nieuwe worden.

Source: <https://www.verlieskunst.nl/nieuwe-taal-voor-rouw/>

Op Instagram krijgt rouwen een nieuwe dimensie (Fragment)

Nadat een vriend van Jo was overleden, bleef ze hem nog steeds dm'en. Ze hoopte half dat er een 'gezien'-vermelding zou komen, al wist ze ook wel dat dat onmogelijk was. "Ik vind het wel prettig om nog steeds berichtjes te kunnen sturen en foto's te bekijken, maar ik kan me voorstellen dat andere mensen het een beetje too much vinden. En misschien is het ook wel helemaal niet zo gezond," zegt ze. "Ik heb het denk ik ook alleen gedaan toen ik wat gedronken had, en als je dan de volgende ochtend wakker wordt en je realiseert dat je dat gedaan hebt is dat best gek. Voordat social media bestond kon dit niet echt, tenzij je naar een seance zou gaan."

Source: <https://www.vice.com/nl/article/d3a57m/op-instagram-krijgt-rouwen-een-nieuwe-dimensie>

Anoniem

Nadat je wegging,
klopte er helemaal
niets meer: het voelde alsof
de wereld verging,
maar toch bleef de zon opkomen
dag na dag.

Source: <https://rouwnetwerkjong.nl/>

Rouwen

Hoe verloopt een rouwproces?
Rouw is zo oud als de mens en zo oud als de mens zijn ook de visies op en theorieën over rouw. Deze visies en theorieën worden constant bijgesteld en kunnen dienen als handvatten om meer zicht te krijgen op het eigen rouwproces of dat van

een ander. Met de nadruk op handvatten en géén absolute waarheid; rouw, net zoals een mens, is nu eenmaal niet te vatten in een kant-en-klaar 'modelletje'. Een van de meest recente ontwikkelingen op het vlak van rouw is dat er niet meer wordt gesproken van rouwverwerking. Verwerken impliceert dat er een einde komt aan rouw; dat er een einde komt aan het verdriet en de pijn, want het is 'verwerkt'. Maar pijn en verdriet kunnen terugkeren op (onverwachte) momenten in het leven die je herinneren aan het verlies. De huidige visie op rouw is dat je leert leven met de pijn en het verdriet van een verlies; dat je werkt aan de integratie ervan in je leven. Daarom wordt er in plaats van rouwverwerking ook wel gesproken van rouwarbeid.

Verschillende theorieën over rouw

Om meer zicht te krijgen op hoe een rouwproces kan verlopen, volgen hieronder vier rouwtheorieën van de afgelopen decennia.

De rouwfasen van Elisabeth Kübler-Ross

De meeste mensen zijn wel bekend met de vijf rouwfasen van Elisabeth Kübler-Ross: ontkenning, woede, marchanderen (onderhandelen), depressie en aanvaarding. De opvatting over deze theorie was lange tijd dat deze fasen in een vaste volgorde verlopen; als een soort 'rouwroute'. Dit is niet hoe Elisabeth Kübler-Ross het bedoelde toen zij de fasen omschreef; het zijn reacties op een verlies, maar het zijn zeker niet de enige reacties. En niet iedereen doorloopt alle stadia, laat staan in een vaste volgorde. Heen en weer gaan tussen de verschillende stadia en verschillende reacties is niet ongewoon voor iemand die rouwt.

De rouwtaken van William Worden

William Worden spreekt over rouw als unieke 'rouwarbeid'. Hiermee wil hij duidelijk maken dat rouwen geen passief proces is, maar een actief mentaal, emotioneel en fysiek proces. In het rouwproces maakt hij een onderscheid tussen vier taken: de werkelijkheid van het verlies onder ogen zien, de pijn van het verlies ervaren (doorleven), je aanpassen aan het leven na het verlies en het leven weer oppakken (door er weer van te genieten en de herinneringen te bewaren). Net zoals de rouwfasen van Elisabeth Kübler-Ross, hoeven de rouwtaken niet in een vaste volgorde opgepakt te worden. Taken kunnen zelfs opnieuw worden doorlopen in een later stadium wanneer nieuwe/andere facetten van het verlies naar boven komen. Riet Fiddelaers-Jaspers omschrijft de rouwtaken van William Worden ook wel als: erkennen, herkennen, verkennen en verbinden.

Het duale procesmodel van Maggie Stroebe en Henk Schut

Het duale procesmodel gaat uit van het principe dat het niet heilzaam is om constant bezig te zijn met rouwen, maar ook niet om de rouw constant af te houden. Er wordt uitgegaan van een slingerbeweging waarin je je tussen twee 'eilanden' heen en weer beweegt: de één gericht op het verlies (rouwen) en de ander gericht op het leven (waarin je bijvoorbeeld afleiding zoekt en nieuwe dingen oppakt). Hoe, hoelang en hoe vaak je je tussen de twee eilanden beweegt is persoonlijk. Waar het om gaat is dat je de tijd neemt voor je pijn, voor je rouw, en anderzijds dat je het jezelf ook gunt om afleiding te zoeken. Iedereen doet dit op zijn of haar eigen manier.

De verliescirkel van Riet Fiddelaers-Jaspers

De verliescirkel wordt vaak gebruikt tijdens de rouwbegeleiding van kinderen en jongeren. De verliescirkel beeldt rouw uit als een cyclus. Hoe je deze cyclus doorloopt is afhankelijk van de basisvoorwaarde of je als kind veilig gehecht of onveilig gehecht was. Voor een veilig gehecht persoon bestaat de verliescirkel uit de volgende stappen: welkom voelen, kunnen hechten, intimiteit ervaren, afscheid nemen, rouwen en betekenis geven. Voor iemand met een onveilige hechting zie je de stappen in de cirkel verschuiven naar: terugtrekken, onthechten, intimiteit vermijden, vastklampen, gestolde rouw en zinloosheid ervaren. Bezien vanuit de verliescirkel is het niet ongewoon om heen en weer te gaan tussen het gevoel een stap vooruit te hebben gezet en het volgende moment weer twee stappen terug te hebben gedaan.

Source: Vereniging Leven met Dood

APPENDIX 14/ GUIDELINES USERTEST

QUESTIONS

Intro

Kort babbelen en eventueel voorstellen

- Power point open, vorige miro resultaten terug geplaatst

-Consentform samen invullen

https://docs.google.com/forms/d/e/1FAIpQLSfWADSFPT2_9MPxi_6hd_FzEI4vR7xo1gLgMXBixiPYHWD9w/viewform?usp=sf_link

Bedankt meedoen

Dingen die te binnen schieten altijd nutting

Geen goede en foute antwoorden

Er is geen foute manier van iets gebruiken: dan is het dus niet goed ontworpen

Geef het vooral ook aan als je feedback hebt die niet positief is, dit helpt mij ook verder

Altijd terugtrekken

Nog vragen aan mij?

Denk hardop na

platform is altijd verkeerd, niet jij

-Begin video opname-

QUESTIONS

Introductie verhaal

Stel je voor je hebt via een vriend die ook rouw heeft meegemaakt van een online platform gehoord.

Diegene vertelde dat dit platform helpt met woorden vinden voor rouw.

Het platform biedt content waar je jezelf potentieel in kan herkennen

Op basis van stukjes content die je bewaard raadt het platform support aan die zou kunnen passen.

Beetje blind erin gooien

FLOW 1

Powerpoint

- Wat zie je?

- Wat denk je dat er gebeurde?

Slide 1: begin pagina & entrance

Slide 2: Navigeren

Slide 3: Flow tot opslaan

Slide 4: Flow tot thema's laten zien

Slide 5: Gehele flow

QUESTIONS

Miro

https://miro.com/welcomeonboard/YXBkU1I2REpVeW5NSHpiYng4V-Fo2RFNlcmMxOTMzZkjhQUcyYW5WSGV4bEhFQVZjVkdqbkpEMUw-4MUw3QlFSRHwzMDc0NDU3MzQ3MzU4NjQwMDg5fDI=?share_link_id=37381662381

We gaan nu een werkend prototype doen

Hier heb je een miroboard met allemaal stukken content

Content is niet door mij uitgekozen

3 minuten

Opdracht: bekijk een stuk of 5 en als je iets hebt dat je raakt, dan mag je die hierheen slepen

Denk hardop na.

Interview:

- Wat vond je van deze ervaring? 3-5 woorden
- Hoe zou je de interactie/ rol van het platform beschrijven?
- Wat vind je van deze manier herkenning zoeken?
- Wat vond je van de stukken content die je hebt gezien?
- Is er bepaalde content die jij zou verwachten?
- Is er bepaalde content die jij zou willen kunnen vinden hier?

QUESTIONS

Flow 2

<https://xd.adobe.com/view/560cd165-9eae-4fe1-b3a7-d128aa219a14-035f/?fullscreen&hints=off>

1. Enter het platform

2. Je wil je verzamelde content bekijken.

- Wat zie je?

3. Je wilt passende resources vinden.

- Wat zie je?

Interview

- Wat vond je van deze ervaring? 3-5 woorden

- Wat vindt van op deze manier resources aangeboden te krijgen?

Interaction qualities valideren

Klopt de experience? (supportive, facilitating, explorative)

-Wanneer vond jij het platform (niet) supportive? Soft & Warm

- Op wat voor manier vond jij dat (niet) supportive?

-Wanneer vond jij het platform (niet) faciliterend? Humble & Unassuming

- Op wat voor manier vond jij dat (niet) faciliterend?

QUESTIONS

"-Wanneer vond jij het platform (niet) explorative? Nuanced, dynamic & researching

"

- Op wat voor manier vond jij dat (niet) explorative?

Afsluiting

Zou je dit aanraden aan een vriend? Zie je hen dit gebruiken?

Denk je dat je zoiets als dit in het verleden gebruikt zou willen hebben? Of in de toekomst?

Wat zou je nog veranderen?

Wat mis je nog op het platform?

Dit was alles wat ik wilde voorleggen

Heb jij nog iets dat je wil toevoegen, of wil vermelden?

Uitnodigen afstudeerpresentatie

