

# Leaves

optimizing the mental health and resilience of older Adults that have lost their spouse via blended, online therapy

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## Deliverable 1.1.3 Service Model

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## Abstract

This deliverable focuses on the development of a comprehensive service model design for end-users of LEAVES. In this final version, we report our activities conducted and findings derived from M13 of the project (February 2021) until M24 (January 2022). The activities reported in this current deliverable build upon the basis we described in the first and second installment. As the development of the service model is an iterative process, we have delivered three versions of this document throughout the project in which we have shown the research we have conducted to build the service model.

### *First and second instalment*

A first step in the development of the service model included the identification of the (primary and secondary) end-users. Therefore, we conducted a desk research on the most recent and prominent literature of the process of mourning and we started with the creation of several personas during the kick-off meeting of the project. Around these first persona's, that were refined in an iterative process, the consortium builds the service model. We synthesized and analysed the results to produce four personas, as a representation of our potential users.

We finalized the first deliverable with the four personas representing our potential users. In the second semester of the project (M6-M12) we focused on identifying their needs, but also on mapping their journey with LEAVES as an online service. The activities reported in the second version of the deliverable include a further analysis of the customer journey of the personas defined; the conduction of focus group sessions with most important stakeholders in the three partner countries; as well as a series of creative online workshop sessions with the team to analyse the results of the interviews and focus groups. We gathered valuable insights, for example about the importance of adding offline support to an online tool and the technical challenges that older adults might come across.

### *Final instalment*

The present deliverable serves the following objectives: (1) to report the activities conducted and its outcomes within the context of study 2 and 3 of WP1 (conducted between M12 to M24 in the project lifetime); and (2) to share the final service model. The service model has been developed throughout M1-M24 of the project and in this deliverable we aim to update the service model developed based on the findings obtained in the studies conducted between M6 and M12.

Due to covid-restrictions we needed to postpone the focus group sessions with end users until February 2021. In the end we managed to perform the focus group sessions in two countries and in Portugal we conducted face-to-face interviews. The insights from these sessions were used for the further development of the service model. Through an interactive workshop during the plenary meeting we used these insights to answers important questions to fill in the gaps of the service model.

For instance we learned that end users need help when setting up the online tool. That offline contact is crucial and can't be replaced by an online tool. Furthermore, easy visualisations are crucial and users need to be guided through the program step by step. Finally, national helplines are added to the programm to assist users during difficult moments in their grieving process.

The final step in this WP has been the online survey; the validation of the service model. Through several questions we guided stakeholders and end users through our service model. We have learned that stakeholders are hesitant if older adults can use the tool on their own. Furthermore they think the risk assessment and monitoring is important, but they aren't sure if the latter can estimate a persons wellbeing. This final deliverable and study 3 raise interesting questions we will answer via the results of the real-life evaluation.

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## Symbols, abbreviations and acronyms

AAL	Active Assisted Living
CH	Switzerland
Data Subject	Individual from whom personal data are collected
D	Deliverable
DELA	DELA Natura- en levensverzekering N.V.
GDPR	General Data Protection Regulations
M	Month
NFE	National Foundation for the Elderly
NL	the Netherlands
NTH	Nothing AG
PT	Portugal
RRD	Roessingh Research and Development
SFT	Sensing Future Technologies
SSW	School of Social Work, University of Applied Sciences and Arts, Olten
ULSBA	Psychiatric Department at the Health Unit of Baixo Alentejo
UNL	NOVA University of Lisbon
UoB	University of Bern
UAVG	(Dutch) Uitvoeringswet Algemene Verordening Gegevensbescherming
WBP	(Dutch) Wet Bescherming Persoonsgegevens (Law Protection Personal data)
WP	Work Package

## 1 Introduction

In this document, we report the results with regard to the service model (WP1) gained between M12 and M24 of the project. Within WP1 we specifically focused on a further analysis of the customer journey of the personas defined; the conduction of focus group sessions with most important stakeholders, conducted in the three partner countries; as well as a series of creative online workshop sessions with the team to analyse the results of the interviews and focus groups. In the focus group sessions we further built upon the findings of the individual interviews, discussing the essentials in the support of mourners as well as the lacking elements. In this we distinguished the two stages of the dual-process model, including the loss orientated stage and the restoration orientated stages. Furthermore, we used the focus group sessions to explore the potentials of a service such as LEAVES in the existing services for mourning older adults, both in terms of online and offline support. In the next stage we will conduct focus group sessions with primary end-users and conduct a quantitative study to validate and build upon the results that are presented within this document. The results of these activities will be reported in the final version of this deliverable (M24).

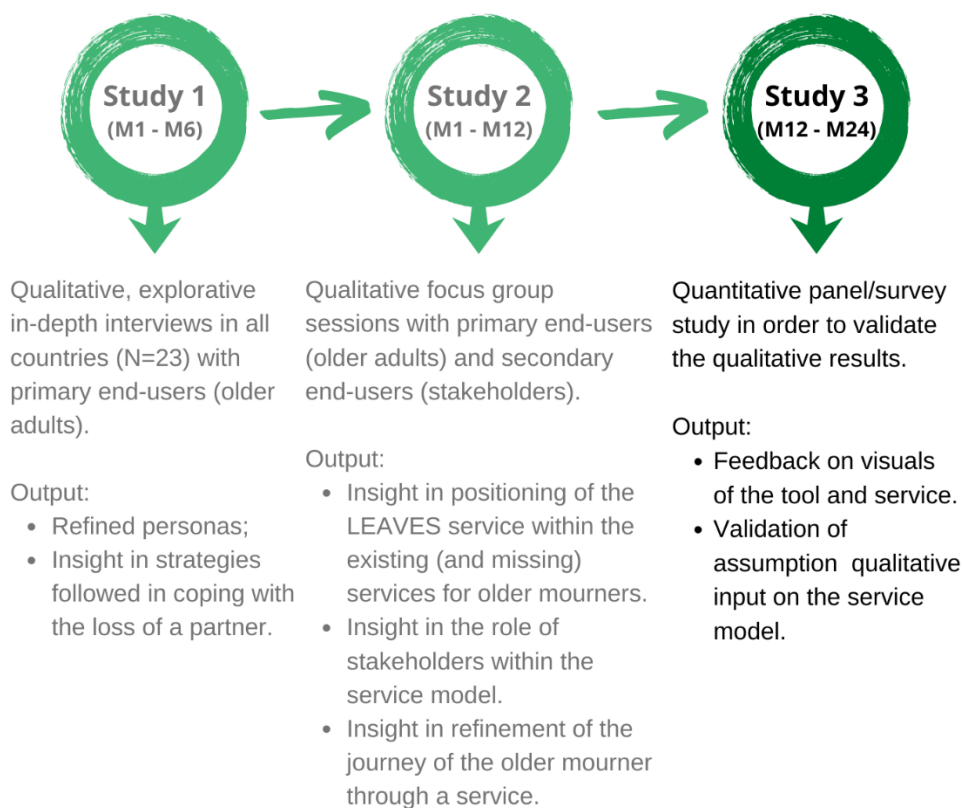
### 1.1 The LEAVES project

The aim of the LEAVES project is to help older adults to process the loss of a spouse in an empathic and caring online environment. Older adults can work through the program at their own time and pace. LEAVES does not offer personal guidance, but the carefully designed online service model is able to detect whether someone might benefit from additional help, and will recommend this to the older adult if that is the case. Moreover, the online service can be used for blended therapy. In this way the LEAVES service will soften the mourning process, prevent depression or social isolation, strengthen mourner's resilience and wellbeing. This might lead to a quicker return of the user to societal participation.

### 1.2 Scope of this deliverable

Based on the desk research as well as the preliminary personas and the internal discussions among the consortium partners, we defined three steps in order to work in this WP1 towards a service model. The defined approach includes both qualitative and quantitative methodologies, starting with explorative activities, followed-up by activities with an increasing validating character.

We divided the activities into three studies, each aimed to be reported in a separate instalment of the deliverable. The different studies and their expected outputs are shown in figure 1. The current deliverable focuses on the final part of WP1 (M12-M24).



**Figure 1: Overview of studies WP1**

In the first version of this deliverable, the activities and results within the context of study 1 were reported: the telephone interviews. The second version of this deliverable reported about the protocol, conduction, results and implacations for study 2, running from M6 (July 2020) until M12 (January 2021) of the project. In version 2, only the focus group sessions with stakeholders were reported, since the sessions with older adults were postponed due to covid-19 restrictions.

Fortunately, we were able to perform focus group sessions in February 2021 in the Netherlands and performed face-to-face sessions in Portugal. Switzerland was able to arrange a focus group session in November 2020 and added three face-to-face interviews in February 2021. Therefore, in this final deliverable we combine the results and findings from the focus group and face-to-face sessions with older adults as well as study 3, the validation of the service model via an online survey.

Throughout the different activities in WP1, we involved several types of end-users and stakeholders. In the (adjusted) DOW the numbers of people we planned to involve are mentioned. Table 1 gives an overview of the involved end-users/stakeholders so far. Whereas in the DOW we combined the numbers for phone interviews and online focus group sessions (15 per country in total), in this update we present them separately.

**Table 1: Overview of participants**

Study	Activity	Type of end-users	Country	Planned	Actual
Study 1	Phone interviews	Older mourners	NL	8	13
			CH	8	6
			PT	8	7
Study 2	Online focus group stakeholders	Stakeholders	NL	8	7
			CH	8	8
			PT	8	8
		Older mourners	NL	3	5
			CH	3	6*
			PT	3	5*
Study 3	Validation	Stakeholders and older mourners	NL	60	50
		Stakeholders and older mourners	CH	60	23
		Stakeholders and older mourners	PT	60	26

\*Switzerland performed a focus group session with 3 older adults in 2020 and added 3 interviews in 2021. Portugal performed 5 face-to-face interviews. Because of the COVID situation it wasn't possible to realize face-to-face focus group sessions in all countries and due to digital illiteracy Portugal decided that an online focus group wasn't possible.

### 1.3 Collaboration and division of tasks

In WP1 all partners that represent end users, as well as the research and technical partners played an important role in the process. End-user and research partners played an important role in the discussions with older adults and stakeholders. The technical partners worked together with end-user partners to conduct and perform the user testing of the different prototypes. Furthermore all consortium partners contributed during the plenary meeting to the service model. NFE hosted a workshop to fill in the gaps in the service model. Through an interactive workshop we constructed the service model. Below you can find a roadmap of all the activities from the beginning of the project up to M18.

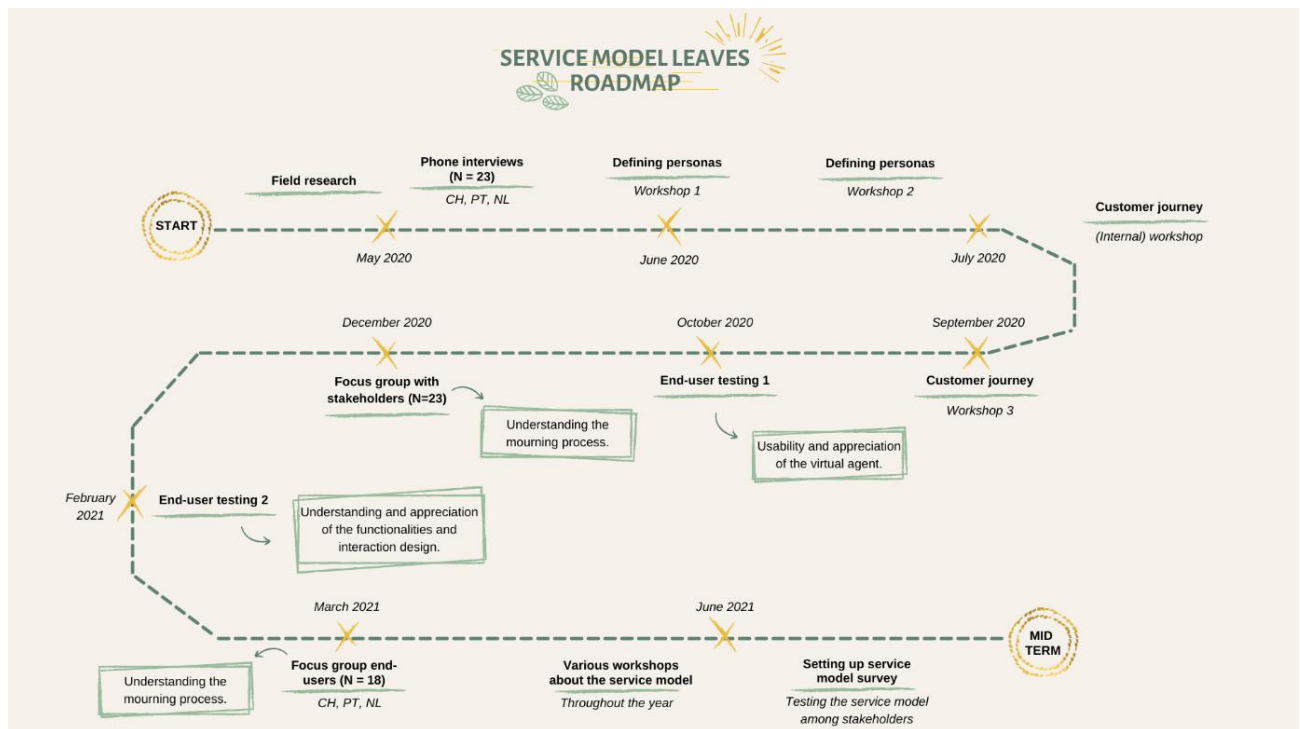


Figure 2: WP1 roadmap

## 1.4 Influence of COVID-19 situation

The restrictions due to the covid-19 outbreak in place almost since the beginning of the project and until the present moment (February 2020 – January 2021) forced us to a certain extent to change our plans. Whereas initially we aimed to start our user-studies with a (face-to-face) focus group session with end-users, we were restricted to start with methodologies that could be conducted remotely. We therefore decided to add individual telephone interviews to the protocol. These were conducted in M1-M6 and reported in the first version of this deliverable.

From M6 until M12 we conducted the focus group sessions that we couldn't organize at an earlier stage. However, despite expectations that the situation would be back to rather normal in this second stage of the project, we were still restricted by the COVID-19 measures. Therefore, the focus group sessions with stakeholders were conducted online. As the group of stakeholders mainly consisted of professionals, who were able and used to work and meet online, this was a suitable approach to achieve the aims of our project, without losing any important data.

In January 2021 the situation was still difficult. We couldn't arrange focus groups but we also didn't want to delay the research. We therefore looked at different possibilities. Switzerland already performed a focus group with end users, but also performed face-to-face interviews. In Portugal we performed face-to-face interviews, but also managed to discuss the answers of other participants during the interviews to enhance the discussion. In the Netherlands we held an online focus group session which worked well. All the participants felt safe to share their experiences and at the end mentioned that they really enjoyed this discussion online.

On the final study we performed, the online survey, the COVID situation had no implications. Therefore, we were able to finish all our studies at the predetermined time.

## 1.5 Reading guide

- In **Chapter 2** we briefly describe the objectives of this deliverable and the relation to other deliverables.
- In **Chapter 3** we give an overview of the state of the art concerning the literature and scientific knowledge in the field of mourning. Although we also described this in the previous versions of this deliverable, we will do this once again, in order to make sure that the currently described activities are theoretically embedded and justified. We therefore explain how we used these insights in our activities.
- In **Chapter 4** and chapter 5 correspond to previous deliverables. In Chapter 4, we again present the preliminary personas, that were defined during the kick-off meeting and served as a basis for the end-user activities in WP1.
- In **Chapter 5** we briefly look back on the activities conducted within the context of study 1 and 2.
- In **Chapter 6** we present the objectives and recruitment strategy of the focus group with end users.
- In **Chapter 7** we describe the results of the focus group sessions and the individual interviews.
- In **Chapter 8** we describe the outcome of the plenary meeting.
- In **Chapter 9** we present the objectives and recruitment strategy of the online survey to validate the service model.
- In **Chapter 10** we describe the results of the online survey.
- In **Chapter 11** we draw a conclusion regarding all three studies conducted from M1 to M24.

## 2 Objectives

The present deliverable serves the following objectives: (1) to report the activities conducted and its outcomes within the context of study 2 and 3 of WP1 (conducted between M12 to M24 in the project lifetime); and (2) to share the final service model. The service model has been developed throughout M1-M24 of the project and in this deliverable we aim to update the service model developed based on the findings obtained in the studies conducted between M6 and M12.

### 2.1 Relation to other deliverables

D1.1.3 is the final deliverable that describes the development of the Service Model Design, which is task 1 of WP1. All activities were conducted within the context of WP1 - Iterative design. In the first deliverable (D1.1.1, completed in M6 – July 2020) we introduced the theory and methodology that served as the basis for the three studies within this WP and, therefore, also in this current deliverable. D1.1.2 gave us more insights into the focus group sessions with stakeholders and shared a first draft of the service model. D1.1.3 is focused on integrating the findings from all the studies and presents the final service model of LEAVES.

Next to task 1, the activities described in this deliverable are also related to task 2 of WP1, namely the visual design. Partner NTH is leading this task and is responsible for deliverable D1.2.1 and D1.2.2. In conducting the activities with regard to the visual design, NTH builds upon the input collected from the different end-users and stakeholders within the context of T1.1 and described in the corresponding deliverables of those tasks.

T1.1. Service model design and T1.2. Visual design, together serve as input for the end-user testing. The end-user testing is conducted as part of T1.3. and the results are reported in D1.3., planned at M24. In the end-user testing, which takes place throughout the project, we have tested several prototypes and the final MVP with primary end-users. The results from the end-user testing were then translated into the work for WP2, the technical design and development.

This deliverable also relates to the tasks and deliverables of WP4, Business Modelling and Exploitation. Within the context of the service model design, we also collected input and insights from potential clients. The way different stakeholders would use LEAVES as a services to their patients/ clients is valuable input for the business modelling activities. Therefore, the deliverable is also relevant for partners working on the business plan. Relevant deliverables mainly include D4.1 and D4.2, (intermediate) business plan.

## 3 Literature and scientific foundations on mourning

### 3.1 Introduction

The results of the workshop on the service model design during the opening conference in Enschede endorsed the insight that the variations in levels of grief of end-users is an important point of focus for the service model. The LEAVES online service might be used in a clinical setting (Portugal and Switzerland) as part of a blended therapy, as well as in a non-clinical setting (the Netherlands). This diffused picture was the starting point for desk research on relevant literature to define the commonalities and differences concerning trajectories of grief that should be attributed within this deliverable.

LEAVES is based on evidence-based scientific theories on grief, such as the model of the four tasks of mourning (Worden, 2009), and the dual-process model of coping with bereavement (Stroebe & Schut, 2001). Within the scope of this project, we combined both models for setting up the trajectory users will follow when using the online service. First, it was important to assess the older adult, the potential end-user, and their level of grief, their patterns, and needs. For the definition of the trajectories, we also



integrated the classifications of Bonanno (2010) for processing the symptoms associated with chronic grief and risk pattern of potentially developing chronic levels of grief into different trajectories within the online service. Integrating the possibility of different grief trajectories, allowed us to develop the program of LEAVES to be sensitive to different grief needs, which resulted in a more inclusive and global intervention.

### 3.2 The dual-process model

The dual-process model was formulated in a response to more 'traditional' theories on grieving. Traditional theories showed shortcomings about effective ways of coping with bereavement, most notably, with respect to the so-called "grief work hypothesis." Criticisms include imprecise definition, failure to represent dynamic processing that is characteristic of grieving, lack of empirical evidence and validation across cultures and historical periods, and a limited focus on intrapersonal processes and on health outcomes. Therefore, a revised model of coping with bereavement, the dual-process model, is proposed. Figure 3 illustrates the two types of coping strategies identified in this model, loss- and restoration-oriented, and a dynamic, regulatory coping process of oscillation, whereby the grieving individual at times confronts, at other times avoids the different tasks of grieving. It also argues the need for a dosage of grieving, that is, the need to take respite from dealing with either of these coping strategies, as an integral part of adaptive coping (Stroebe & Schut, 1999).

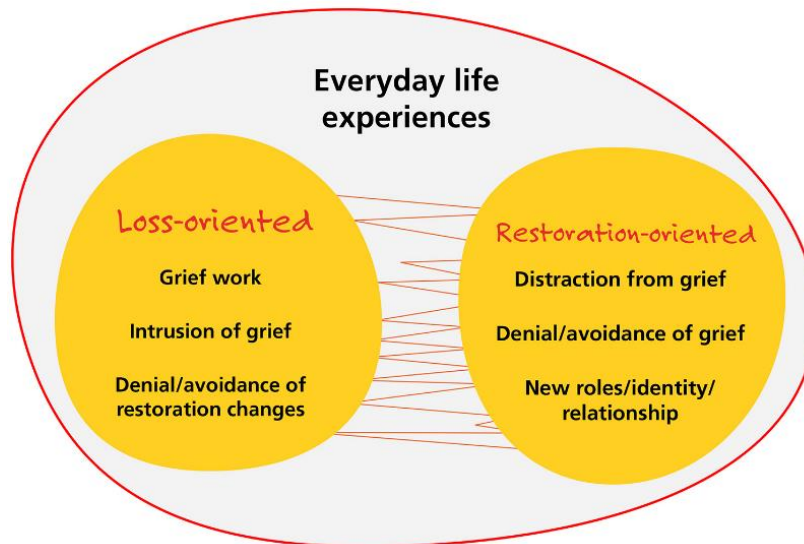


Figure 3: Dual-process model by Stroebe and Schut (1999)

### 3.3 Four tasks of grieving

The second model we base the LEAVES content on, is Worden's four tasks of grieving. These tasks of healthy grief were outlined by psychologist William Worden in his book *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner* (2009). Worden is critical about the Kubler-Ross stages of grief model (5 stages of mourning: denial, anger, depression, bargaining, and acceptance). Many researchers, psychologists, and clinicians are leaving the Kubler-Ross model behind. Worden does not consider grief to be a passive progression of stages that a person is carried through. Rather, Worden empowers mourners to actively engage in four tasks. For this reason, it is interesting to test both the sequential and the self-tailored version of LEAVES. The four tasks described by Worden are:

### **1. Accept the Reality of the loss (grief oriented)**

Some denial can serve a purpose in that it allows one to slowly absorb the full weight of the loss. However, remaining or idling in denial is the antithesis of acceptance. One must confront their own denial and accept that the loss has occurred. Acceptance is the surrendering to reality as it is. Therefore, one has to acknowledge the loss and not pretend that it did not happen. One cannot make loss disappear through denial. Acceptance is the first step towards adapting and moving forward.

On a more complex level, there is accepting the reality of the significance of the loss. For example, one may speak of someone in the past tense and accept their death but may downplay the significance of their relationship with that person, denying the impact the loss will have. On a basic level, they may have accepted the reality of the loss, but on a deeper level, they will not have accomplished this task until they have fully accepted the depth of the relationship and correlating impact.

Another common struggle with this task is around acceptance of the mechanism of the death. A death by suicide, overdose, or other stigmatized death may present challenges to accomplishing this task if family or friends are unable to acknowledge or accept the reality of how the person died.

### **2. Experience the Pain of Grief (grief oriented)**

From sadness, fear, loneliness, despair, hopelessness, and anger to guilt, blame, shame, relief, and countless others, there are many emotions a griever contends with. What is important in this task is acknowledging, talking about, and understanding these complex emotions in order to work through them. The danger, of course, is denying one's feelings and avoiding them. This tendency can be exacerbated by society's discomfort with the feelings that accompany grief, so the griever may feel like they should not feel or acknowledge these difficult emotions. In Western society, it is not always accepted to *feel* nor to share pains with others. One must experience the pain of what was lost. Allow the emotion into the consciousness and take proper steps to process the feelings.

### **3. Adjust to an Environment With the "Deceased" Missing (restoration-oriented)**

Life is not the same now that a loved one has died. One may feel like adjusting to life without the loved one is a betrayal to the loved one. Task three is adjusting to the environment in which the deceased is missing. Worden acknowledges that this task can also mean very different things to people depending on the relationship of the person who has died, as well as the roles that are impacted by the loss. This readjustment happens over an extended period of time and can require internal adjustments, external adjustments, and spiritual adjustments.

It may take a significant period of time just to realize the different roles their loved one performed or internal and spiritual adjustments that are required. This can be especially difficult for bereaved, who may need to learn a wide array of new skills and tasks, ranging from bill paying, parenting, and taking care of the home, to environmental changes, such as living alone, doing daily activities alone, and redefining the self without the other person.

### **4. Find an Enduring Connection with the "Deceased" While Embarking on a New Life (restoration oriented)**

Even though that part of a person is gone and irretrievable as a result of the loss, what was is still part of who someone is. The joy and warmth someone experienced from the deceased loved one will always be with them. The task is about starting out on a new life, but keeping with you those cherished moments and memories as a source of joy and strength. A person is stronger for having known a loved one.

### 3.4 Classification of levels of grief

Next to the models on dealing with grief specifically that are mentioned above, we also want the online service to be sensitive to the different levels of grief that the users are dealing with. This is important, since it makes the program more inclusive and broadens the reach of LEAVES. A task for us was to distinguish the different grief trajectories that exist and to assimilate this into the service, so that the service becomes sensitive to those variations in grief trajectories. The online service should be able to identify and classify these different users and offer a cut to size programme that matches the specific user as well as their specific place in the grief trajectory. As literature shows us, for one person the trajectory can be rather 'resilient', people go through the loss with all emotions involved and with time it naturally gets better. But there are also people who get stuck in the grief process and are dealing with prolonged and chronic levels of grief, perhaps even showing some clinical symptoms like anxiety and depression. In order to make the needed division, we will use the validated classification proposed by Bonanno (2002). Bonanno described the four most common trajectories of grief or potential trauma, later on finetuning them with other subcategories. This research was based on longitudinal data beginning prior to the loss. In subsequent studies, contrary to common assumptions about loss and trauma, Bonanno's research has shown that resilience is the most common pattern (58% of the cases) and that delayed reactions are rare (less than 5%), as shown in figure 4: Trajectories of grief by Bonanno. We used this theory to develop the risk assessment and monitoring questionnaire.

The trajectories and the percentages of people who tend to fall into each category are expanded upon in Bonanno's book of 2010: *The other side of sadness: What the new science of bereavement tells us about life after a loss*. The book also includes graphs of the trajectories. The trajectories are as follows:

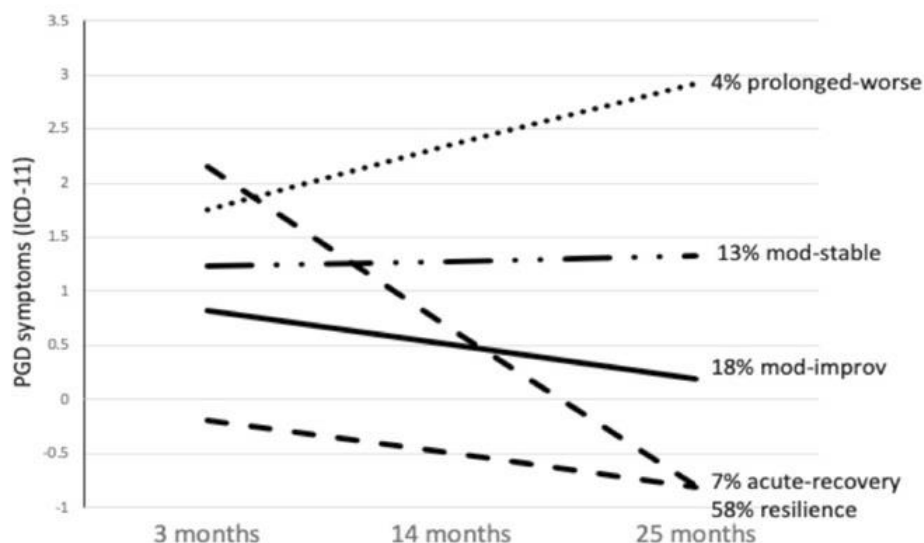


Figure 4: Trajectories of grief by Bonanno

We find it useful to give a more detailed description of the important processes that are at work within this model:

- Resilience:** "The ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event, such as the death of a close relation or a violent or life-threatening situation, to maintain relatively stable, healthy levels of psychological and physical functioning" as well as "the capacity for generative experiences and positive emotions".

- **Recovery:** When “normal” functioning temporarily gives way to a threshold or sub-threshold psychopathology (e.g., symptoms of depression or Posttraumatic Stress Disorder (PTSD)), usually for a period of at least several months, and then gradually returns to pre-event levels.
- **Chronic dysfunction:** The prolonged suffering and inability to function, usually lasting several years or longer.
- **Delayed grief or trauma:** When adjustment seems normal but then distress and symptoms increase months later. Researchers have not found evidence of delayed grief, but delayed trauma appears to be a genuine phenomenon.

### 3.5 Models combined for the service design

The combination of the four mourning tasks and the dual-process model (with oscillation between loss oriented and restoration-oriented activities) have also been the foundation of the LIVIA programme. This confirms and endorses that the content of LIVIA is a proper basis for our LEAVES project. LIVIA is one of the programmes that has been co-designed and studied by one of the consortium partners (University of Bern) in order to support people in their mourning process. The content of LIVIA has been validated through the conducted literature study and was serving as a basis for the development of LEAVES.

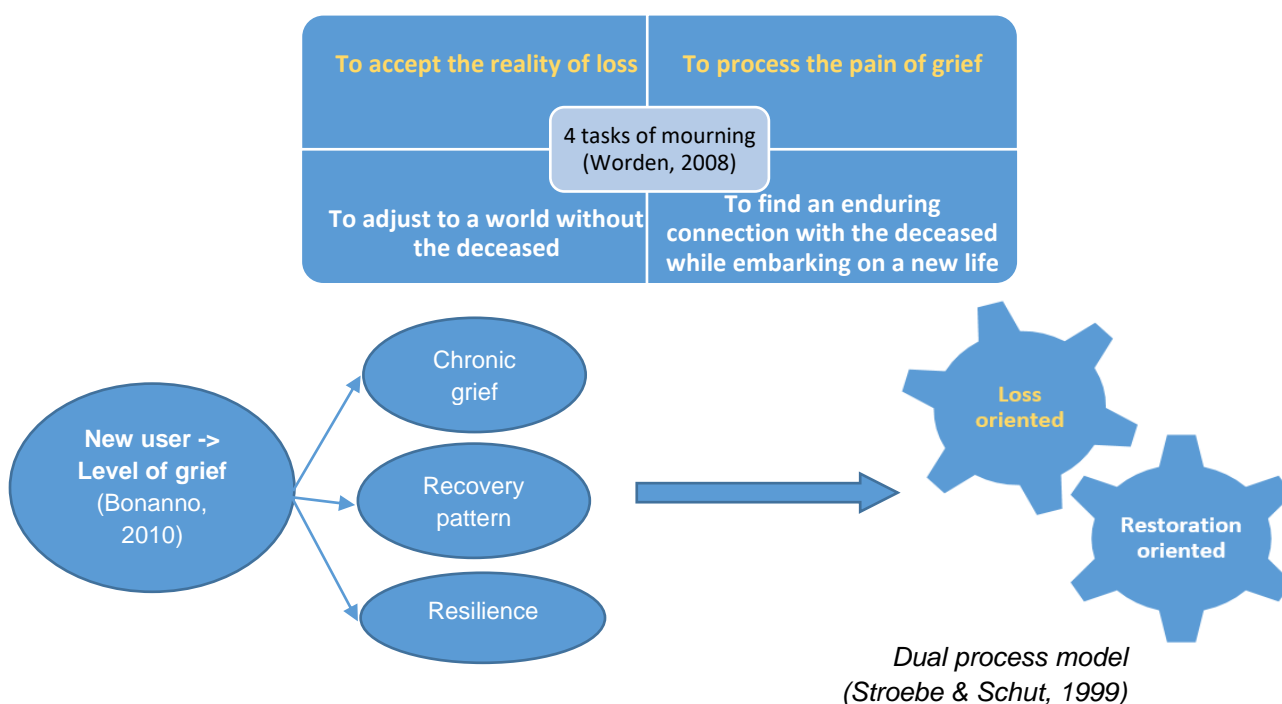


Figure 5: Interactions of the selected scientific models

The three theories and models mentioned above – the dual-process model of Stroebe & Schut (1999), Worden’s four tasks of grieving (2009), and the trajectories of grief by Bonanno (2010) – are our scientific foundation for the development of the service design. Figure 5 shows the dynamic process in which these scientific models interact.

## 4 Preliminary personas

During the LEAVES kick-off meeting in Enschede (February 2020), we organised the first workshop on personas and the service model design. The meeting resulted in a set of roughly designed preliminary personas based on the partners' experiences with the end-users in each country.

As a first step we created personas per country, i.e. the targeted primary end-users we develop our service for. This included older adults who recently lost their partner. Through this set up we aimed to get clearly defined results on cultural differences and the different existing services that are relevant to each cultural context. We created preliminary personas that functioned as a base for designing the research studies on the personas and service model design. Commonalities and differences were deducted from the input from all partners. During the workshop, we stressed that the input is based on the experiences that each partner has with the targeted audience, leading to develop research hypotheses. The rational and initial hypotheses were taken into account for the set-up of the study protocol, they gave us a good foundation to work with. The assumptions and hypotheses were tested and validated within the first study. Based on the preliminary personas we were able to discover some commonalities and differences between the personas created per country.

### 4.1 Description of personas

The workshop at the project kick-off meeting resulted in a first draft of personas. We have formulated these a priori personas with our biases and common knowledge, based on the observations of 'them' as a first assumption.

Monika from Switzerland: Lost her foundation and her rock. She does not know how to move on. Her partner was the one who gave her balance in life and who provided social connections and activities and arranged the practical things in their life.

*'What am I supposed to do now?'*

Ana from Portugal: Ana is a no-nonsense, hard-working woman who takes pride in taking care of her family. Now that she does not have people to take care of anymore since her children moved away, and now also her husband died, she lost her purpose and direction in life. There is no one around to take care of anymore and no big real household to run.

*'I am not doing anything meaningful anymore'*

Jackie from the Netherlands: Jackie is active and stays that way after losing her partner, but she still feels lost. She feels the need to keep on remembering him but fears that she is a burden for her friends because 'she keeps bringing him up all the time' (as she would put it herself). She is looking for a way to remember her husband and share the memories with others. Because she holds on strongly to all the things they did together.

*'You just have to keep on going'*

#### 4.1.1 Commonalities between the personas

- Does not want to be seen as 'sick' or as a person with mental problems (approach not like a 'patient' tone of voice);
- Does not want to be a burden to others (so LEAVES app could be an alternative/addition for the support they do not (dare to) seek in others);
- Looking for a safe place where s/he can freely give room to the loss without being a burden (so also an underlying need to find a way to cope a bit more on their own?);
- Not 100% skilled in the digital world (although through different degrees);

- Needing support to find a way to put the mourning in a healthy position/proportion in their lives. The loss has a big effect on them and they do not really know how to take the rights steps;
- Family and children etc. (closest network) are not directly around.

We also ran into some country-specific details we find relevant to take into account for further studies. They might be of influence on the way we constructed the country-specific personas.

- The Portuguese partners in the project are working from a clinical setting, so they meet the older adults who are struggling with mental and/or psychological challenges. The suicide rate among older adults is rather high in the region of one of the partners. There is also a culture of 'saudade', a 'melancholic' tendency to sit with your problems, a longing to be near something or someone that has been lost. People tend to sit with this feeling instead of trying to fight it or actively trying to work with these emotions and feelings. This attitude towards life is playing a role in how people view their struggle.
- The Dutch partners are mainly in touch with elderly from a non-clinical setting; a wide variety of people with perhaps not a very specific profile. There are a lot of clubs and meeting opportunities for mourners in the Netherlands, like mourning groups. Participants of these groups were also recruited for the first study.
- In Switzerland, the pastor and the church still play a very important role in the grief process and should be taken into consideration as well.

### 4.1.2 Coping strategies

We also noticed different coping strategies within the personas we came up with that at first hand seem to be on polar sides of the continuum.

- **Staying really active:** trying to keep meeting people, doing activities, seeking distraction. The downside of this strategy seems to be that people do not always take enough space to feel their emotions and digest what happened.
- **Withdrawing:** after losing the partner someone loses his or her tie to the outside world, activities disappear out of someone's life. The partner was the connection to the outside world and to other people. A strong loss of purpose is often felt.

**Table 2: Characteristics of preliminary personas**

	Ana	Monika	Jackie
<b>Living conditions</b>	<p><b>Alone</b></p> <p>Remote area/village</p> <p>Family far away</p> <p>Scarce social contact</p>	<p><b>Alone</b></p> <p>City apartment</p> <p>Family around but not very present</p>	<p><b>Alone</b></p> <p>Medium size town (well connected)</p> <p>Family away</p>
<b>Technological/digital skills</b>	<p><b>Limited</b></p> <p>Use of mobile phone</p> <p>Remote control for TV</p>	<p><b>Basic skills</b></p> <p>E-mail, I-pad etc.</p> <p>Smartphone</p> <p>Family helps with setting it up</p>	<p><b>Basic skills</b></p> <p>Kids help with the setup.</p> <p>Also used to stay in touch with kids (skype, games: Word feud etc.)</p>
<b>Media and information</b>	Informed (basic)	Well informed	Well informed

	TV(shows) and radio	Reads books and papers	
<b>Relationships</b>	Family is important but far away	Had a very strong bond with the partner  Partner was social bond to the outer world	Has quite some social circles like sports and hobby clubs. Is also a volunteer  Socially active but family is a bit far away
<b>Perspective on mourning</b>	Discipline mentality, work hard, don't complain too much. You've got to go on and make ends meet	Feels like it will last forever  Mourning is a lonely experience (?)	'Life goes on' mentality (although this mentality does not match her inner world of grief and sadness)
<b>Perspective on asking for help</b>	Does not want to bother others	Does not want to be a burden  Rather withdrawn (but also don't trust others easily for help?)	Does not ask for much. Feels like she should just go and get active and connect so she 'gets over it'
<b>Fears</b>	To be a burden to others  Having no purpose in life  No one to take care for  To have to move to a nursing home/ senior residence	To be a burden  To be stigmatized  Diagnosed as 'sick'	To be stigmatized  That other worry about her  To bring it up 'all of the time' (that's how she self stigmatizes)
<b>Hope</b>	To feel more energetic and useful again	A safe space for her feelings  Finding purpose again	A safe space for her feelings  A place where she can reminisce  Where she can share with (significant ) others the memories

<b>Possible obstacles</b>	<p>Not familiar with applications</p> <p>Not really open towards (professional)help/sup port for mental issues</p> <p>Focus on physical symptoms, not mental (discipline, don't complain).</p> <p>A reserved personality</p> <p>Little insight in own mental/ emotional needs (?)</p>	<p>Very loss orientated, does not look into the future</p> <p>Difficulties integrating technology</p> <p>Does not trust people easily for help</p>	<p>Is not familiar with sources of help. Was always rather independent and active, in control of things</p> <p>Is focused on getting active (go out, do things etc. and by that also avoids to admit to herself the gravity of her loss)</p>
<b>Can be motivated by</b>	<p>Physical benefits like better sleep, more energy</p> <p>To feel useful again, contributing to something</p> <p>Finding purpose again</p>	<p>Perspective on the future</p> <p>Is there a way to live with this feeling? (perspective for it to be easier to endure the feeling)</p>	<p>A place to share and honor what once was. A place to stand still and give room to the loss</p>
<b>Need for LEAVES</b>	<p>To discover purpose</p>	<p>Safe space</p> <p>A place where she can be herself with all her feelings without feeling something is wrong with her (self-stigmatization)</p> <p>Discover new horizons. Does not have her own strong ties to others and activities.</p>	<p>Find a place where there is a way to cope with the loss (also with family and friends) in a beautiful way which honours the lovely times they had together</p> <p>A safe space to stand still and give room to the loss</p>
<b>Clinical aspects</b>	<p>Physical problems (Multimorbidity)</p>	<p>Has a history of anxiety / depression and some trauma (divorce of parents, mother died young)</p> <p>Partner was a pillar in her life, balance is lost now. Lack of own coping skills</p>	<p>It is a proactive person with a hands-on mentality.</p> <p>No clinical needs (yet) but looking for a place to honor, reminisce and toolbox to give shape to this with significant others without being a burden</p>



## 5 Summary Study 1 and 2

### 5.1 Summary M1 – M6 (Study 1)

After defining the preliminary personas, we spent the first six months of the project on studying the strategies of these personas in the three countries (PT, NL and CH). We conducted 23 in-depth telephone interviews with older adults who recently lost their partner, in order to find out their coping strategies. 10 interviews in the Netherlands, 6 interviews in Switzerland and 7 in Portugal. In the first instalment of this deliverable we presented the results of these interviews. The interviews showed e.g. which persons in the social network were important for the persons in grief and which services and types of support they preferred.

#### *Workshop 1*

All partners were invited to the workshops, with special attention to the balance of the attendees from the different countries. Through the means of creative and interactive (online) workshops, the consortium members who conducted the interviews shared their experiences and pinpointed the most important aspects of the interviews that were relevant for the personas and the service model. The videoconferencing tool Zoom (<https://zoom.us>) and the online collaborative whiteboard platform Miro (<https://miro.com>) were used. Through storytelling and iteration methods we were able to refine and validate 4 personas that will serve as a basis to further map the matching service model.

#### *Workshop 2*

In the next steps of study 1, we further focused on one main persona, out of the four initially de- and refined personas. First, in another interactive workshop, we elaborated on the most remarkable characteristics, discussed differences and similarities among the four personas and selected in an iterative process Monica as our main persona to continue the further activities in the study with. In order to fresh-up the reader's mind, (the characteristics of) Monica can be found in figure 6.

#### *Workshop 3*

After selecting Monica as our main persona, we elaborated in a third interactive workshop with consortium members more in-depth on her 'user journey', starting just after she lost her husband. With the interviews in our mind we discussed what steps someone like Monica would follow, or face, in terms of emotions, activities and support by the social network – either requested or provided pro-actively by others.

#### *Procedure*

The final step of this stage of the study included the application of the LEAVES service on the different steps of Monica, the so-called touch points. We discussed how we could help Monica throughout her journey to feel less lost, to feel better, to process her loss and build a new life, and to deal with her emotional stress. After linking several functionalities and features of LEAVES to the important moments throughout the journey of Monica, we got more insight into what moments she could benefit from our service. However, we did not know exactly yet *how* this exactly would look like. For example, we now could see at which moment she would prefer to do the trial session, when she would like to receive support from a therapist or when she might want to use the platform on her own. However, what the service concretely should look like and what content it should provide, was the gap we would focus on in study 2.

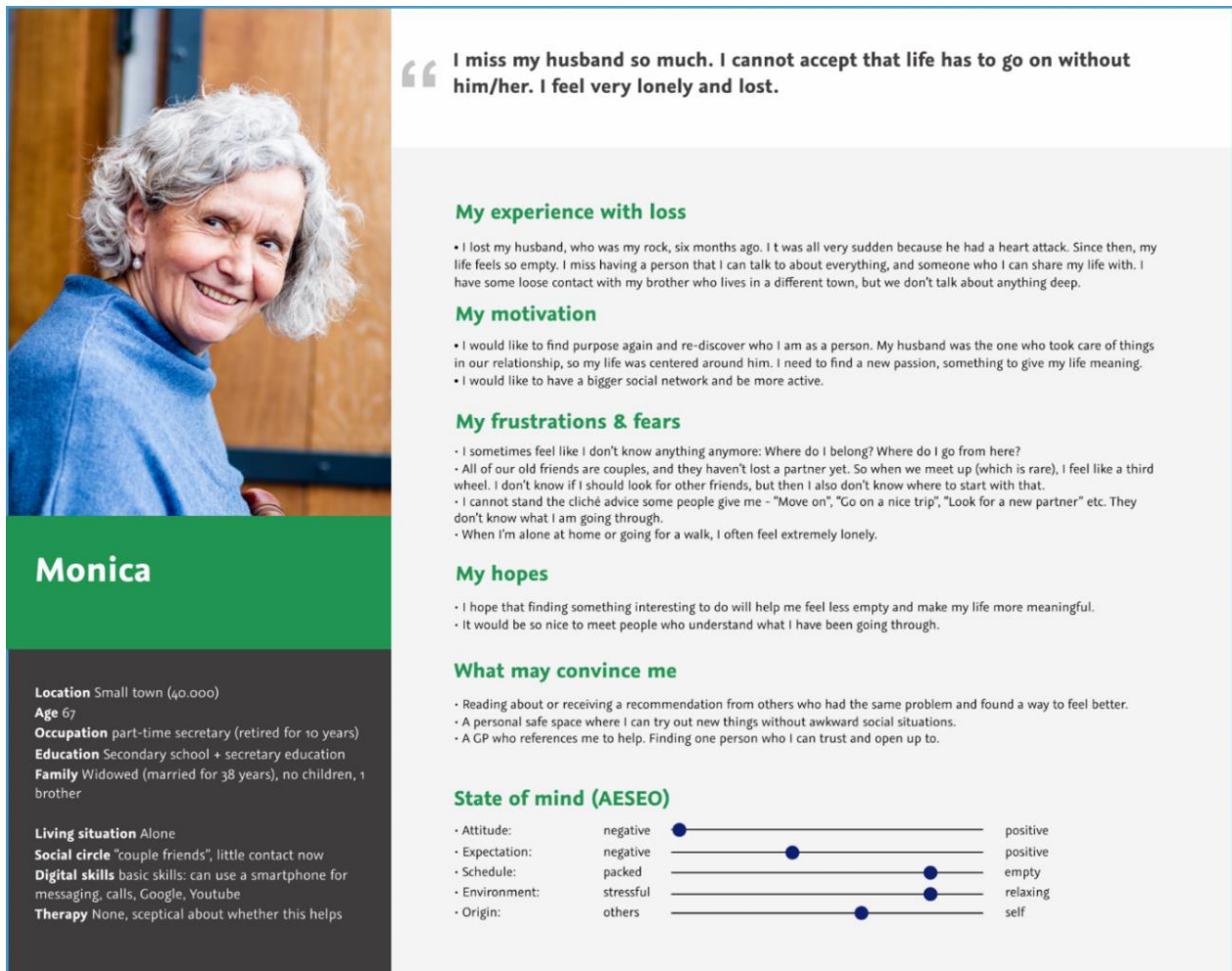


Figure 6: Selected persona Monica

## 5.2 Summary M6 – M12 (Study 2)

In the deliverable presented at M12 we reported about the results of the activities of WP1, as conducted in M6-M12. Whereas initially we planned to conduct focus groups with both primary (older adults) and secondary end-users, we eventually – due to the COVID-19 restrictions – were only able to conduct the sessions with stakeholders. Except for Switzerland; they were able to conduct a focus group with 3 end-users in M10. The sessions with primary end-users for the Netherlands and Portugal were planned in M13 and M14. In Portugal the focus group needed to be adapted to telephone interviews, because an online focus group session was not possible.

There were some pros and cons about having to conduct the focus groups online. All stakeholders have busy calendars and to find a suitable time and date is always a challenge. In this situation people did not have to travel to a location, but were able to call in from home or the office. People felt safe to share information and the online aspect did not hinder this at all. The difficulty with online settings are the technical challenges. It takes a bit longer to explain the online tools and also the discussion runs smoother offline.

In the focus group with stakeholders we focussed on four research goals:

1. Determine what is essential in the existing (online) service for mourners and what is missing in the services that are currently available.
2. Learn in which way LEAVES can contribute to the existing services.

3. Determine in which way stakeholders can use LEAVES in their services to support mourners.
4. Identify which barriers stakeholders can expect for their clients/mourners in regards to the service of LEAVES and how we can overcome these.

Through questions related to these goals we wanted to learn more about the service of stakeholders. For instance which service is provided to older adults who go through the process of grief. As well as which elements are missing. How they would envision the use of an online tool such as LEAVES for their clients and if LEAVES would be a contribution to their service.

As the findings show, we reached all four goals and gathered insightful information through our discussion with stakeholders. Before highlighting a few important similarities and differences between the countries we can conclude that all stakeholders in all three countries were positive about the use of an online tool, such as LEAVES, to enhance and accompany their service. They can foresee that an online tool can for instance contribute by informing their clients beforehand. Let them work on their own, in the privacy of their own home. Even possibly creating an easy and comfortable environment.

### *Similarities between countries*

All stakeholders share a cautious approach to the technical challenges of an online tool. In some cases, clients live in rural areas with no access to a smartphone, tablet or laptop. But not only for these clients the online tool raises a challenge, also for clients who fear new and especially digital tools. The need for offline assistance through family, friends or caregivers is therefore crucial. Furthermore, the interface needs to be easy and intuitive to overcome this barrier. At last, an elaborate tutorial is mentioned to lower the threshold.

Offline assistance is needed for technical support, but also to monitor and give personal contact. Stakeholders mention that human contact, especially in a grieving process is essential and can not be replaced. The online tool can work together with offline services. They can refer to each other and offer their services. LEAVES can also be used to enhance the service of stakeholders. They mention the option of psycho-education, giving information, and letting clients prepare their offline session. It would as well be useful at times when clients can not leave their home because of for instance a pandemic situation we are encountering now with COVID-19.

The final point we want to address that was raised by all stakeholders, is the need for scientific evidence. LEAVES should have a scientific certificate which allows stakeholders and clients to trust the online tool. Scientific ambassadors should give their approval and their recommendation. This would be beneficial to the success and potential of LEAVES from a business perspective.

### *Differences between countries*

An important difference between especially Portugal and The Netherlands is the way people cope with difficult situations such as grief. In Portugal people are more family oriented, they visit for instance the doctor together with their family. In the Netherlands, people do not want to be a burden to others, they want to move on. But it also works the other way around. Family members of a person in grief do not know how to address the situation. They do not mention the name of the deceased. Switzerland is more in line with the Netherlands in this situation.

The lack of literacy and the lack of contact with the technology, as well as the social norms and cultural values of the Portuguese population, makes that this population is more dependent on the family.

Portugal and Switzerland are more focussed on the mental and clinical state of their clients. For Portugal it is essential that prolonged grief is actively prevented. In both countries it is also mentioned that professionals (GP and other care workers) do not have enough time for their clients. In the Netherlands the lack of time is not mentioned, but they do stress the important aspect that clients can get lost between different care takers. The communication between caretakers needs to improve.

The role of the undertaker differs between the countries. In the Netherlands undertakers do not only take care of the logistics, they also contact people months after the loss. In the focus group session it was mentioned that undertakers could connect older adults to care takers with an online tool such as

LEAVES. In Switzerland, undertakers only handle the logistics. In Portugal, they are present during the grieving process towards the funeral and handle the logistics, but this contact ends after the funeral.

When discussing the dissemination of LEAVES, stakeholders in Portugal mention that in some cases stakeholders would need to pay for LEAVES to refer their clients. Private institutions or semi-private institutions do not have to pay for a service like LEAVES and clients can be easily referred. In the Netherlands and Switzerland, this is not mentioned by stakeholders.

### Constructing the service model

With these insights from stakeholders and the research done in M1–M6, we were able to create the first service model (see Appendix D). This model was not yet complete. There were some gaps we needed to fill. Therefore, the plenary meeting in March and the results from the focus group with end users were important for the further development of the service model. With a final research planned for October to validate the service model through an online survey.

## 6 Focus group sessions end-users (study 2)

### 6.1 Introduction

The focus in this second study was to further refine the LEAVES service. We aimed to investigate this by the means of qualitative focus group sessions with both primary end-users (older adults who recently lost a partner) and secondary end-users (stakeholders).

Table 3: Design of study 2

Research type	Topics to be covered	Results	Numbers
Online Focus groups End users	Use of online tools during the loss-oriented and restoration phase. How they value using an online service such as LEAVES	Input for design of the tool and service design	<b>N = 16</b> 3 focus groups, 1 per country (5-8 participants each)

### 6.2 Objectives of the focus group

In study 1 we aimed to investigate the strategies during the process of older adults who recently lost a partner and how we, with the LEAVES service, could help them in their process. We gathered information about what they found important in their grief process and which steps they took. Study 2, including the focus group sessions with stakeholders and primary end-users, aimed to further enrich these findings. By the means of the focus groups, we aimed to add useful information from the perspective of older adults. We formulated the following four goals for the focus group sessions with end users:

1. Clarify what end-users value in using an online service as LEAVES and in which activities offline support adds more value.
2. Determine in both the loss-oriented experiences and the restoration-oriented experiences how end users used or wish to use online support.

3. Determine in the loss- and restoration-oriented experiences how end users wish to receive offline support.
4. Find out how end-users would value LEAVES.

## 6.3 Recruitment

The recruitment of participants for the focus group sessions took place in the three different partner countries. Before contacting older adults, we formulated the following inclusion and exclusion criteria:

Participants must match all criteria:

- 60+ age
- Loss of a partner in the past
- Are actively dealing with a grief process or were dealing with it in the past
- Are able to reflect on the process they went through

Exclusion criteria's:

- Participants unable to participate adequately because of medical, neurological, psychiatric or any other impairing medical conditions
- Extra attention for very traumatic loss, like suicide, murder etc.

### 6.3.1 Recruitment strategy

All partners used their network of expertise to connect with older adults and gather participants for the focus group session.

In the Netherlands, older adults were recruited by NFE. In Portugal, the participants for the face-to-face interviews were recruited by ULSBA. In Switzerland, older adults were recruited by SSW in close collaboration with UoB and NTH.

NFE created an invitation e-mail which was used to invite and inform older adults regarding the focus group sessions and the topics we covered. In the Netherlands we reached out to peer groups, churches and the network of NFE volunteers, and 5 older adults participated. Switzerland managed to include 3 interviews and had already performed a small focus group session in 2020. Portugal performed 5 face-to-face interviews with patients of ULSBA. It wasn't possible to arrange an online focus group session, because digital literacy is very low in Portugal.

After the recruitment and when all participants were confirmed, they received more detailed information about the format of the session and further technical information when the session was held online. Also, participants received the informed consent form which they all signed beforehand, giving us permission to record the session.

## 6.4 Methods

### 6.4.1 Introduction to the focus group

We started the session with a detailed explanation of the online best practices, making sure that the session would run smoothly. To enhance an open and safe environment we created an online energizer (for the online focus group sessions). It was an easy way to introduce everyone and get to know each other before diving into the theory and topics of the session.

We continued with an introduction to the project and the context for this interview. We provided clarifications about:

- The LEAVES project and the end product we want to develop;

- The purpose of the session, which was to learn from the perspective of older adults and how they perceive online tools.
- Our need to record the session to be able to listen to it again for clarification;
- The confidentiality and anonymization of the data gathered in the interview;
- The right that each participant has to withdraw from their participation at any moment if s/he does not feel comfortable.

### 6.4.2 Focus group design

In the first part of the session, we informed the older adults about the theory behind the Dual Process Model. We refrained from using scientific language and used the phrases 'looking back' and 'looking forward' to clarify the loss-oriented and restoration phases. We asked the participants how they have dealt with these situations and how online tools have helped them or not? Also we informed them about the use of offline tools / services.

After a short break, we continued the discussion. We wanted to zoom in on the online services. The goal was to end this discussion with a full overview of the online and offline tools/services they used during their grief process of which they would have found interesting and helpful. Some questions we covered in this discussion were:

- How would you feel about writing your thoughts down in an online journal?
- Would you want to receive online therapeutic help?
- Would you have wanted to talk with other people who experienced the same? Would you have done this online?
- Would you wish to read the stories of other bereaved spouses?

After we created a complete overview of all the online and offline tools we asked our participants to vote and let them choose the tool/service which helped them the most.

Finally, we made the connection with LEAVES. We gave them a short summary of the service once more, and asked them if they would have used this tool during their grief process. And if they would use this on their own or with a family member or friend. Also what could hinder older adults from using online support and what would encourage them. And also how important offline support is. This section took quite some time, but in all three countries we received a lot of useful information.

The complete protocol of the focus groups with end users is available in Appendix A.

## 6.5 Ethical considerations

### 6.5.1 Proper treatment of participants

We provided the invited participants with information on the project and their potential participation in the invitation for the focus group session. We sent participants a letter with information about the study and asked them to sign an informed consent to permit us to record the session and use their data, under the conditions described below in 6.5.3.

### 6.5.2 Ethical approval

As we addressed sensible topics in the focus group and asked participants permission for recording the session, we found it important to make sure we would act fully according to the standards of ethical committees. As the study conducted in this stage of the project did not include a medical, nor a clinical study, we did aim for a declaration where no medical ethical approval was required.

### 6.5.3 Data storage

All focus group sessions were (video)recorded and saved anonymously on the server of the organization that conducted the session. Contact details of the participants (e-mail, phone number) were also saved to contact the participants for the sessions and were deleted afterwards. Reports/summaries of all sessions were written both in the own language and in English. Both versions have been fully anonymised. The reports in English were stored on the shared drive of the project.

## 7 Findings focus group end-users

### 7.1 Participants

In total 16 older adults participated in the sessions and interviews.

- 5 face-to-face interviews in Portugal
- 3 face-to-face interviews in Switzerland
- 3 participants in the focus group sessions in Switzerland
- 5 participants in the (online) focus group session in the Netherlands.

### 7.2 Results

For the mid-term review we created an overview of the most important findings out of the focus group sessions with end users. We summarized the similarities and differences per country (figure 7). For the full report overview of results see Appendix B.

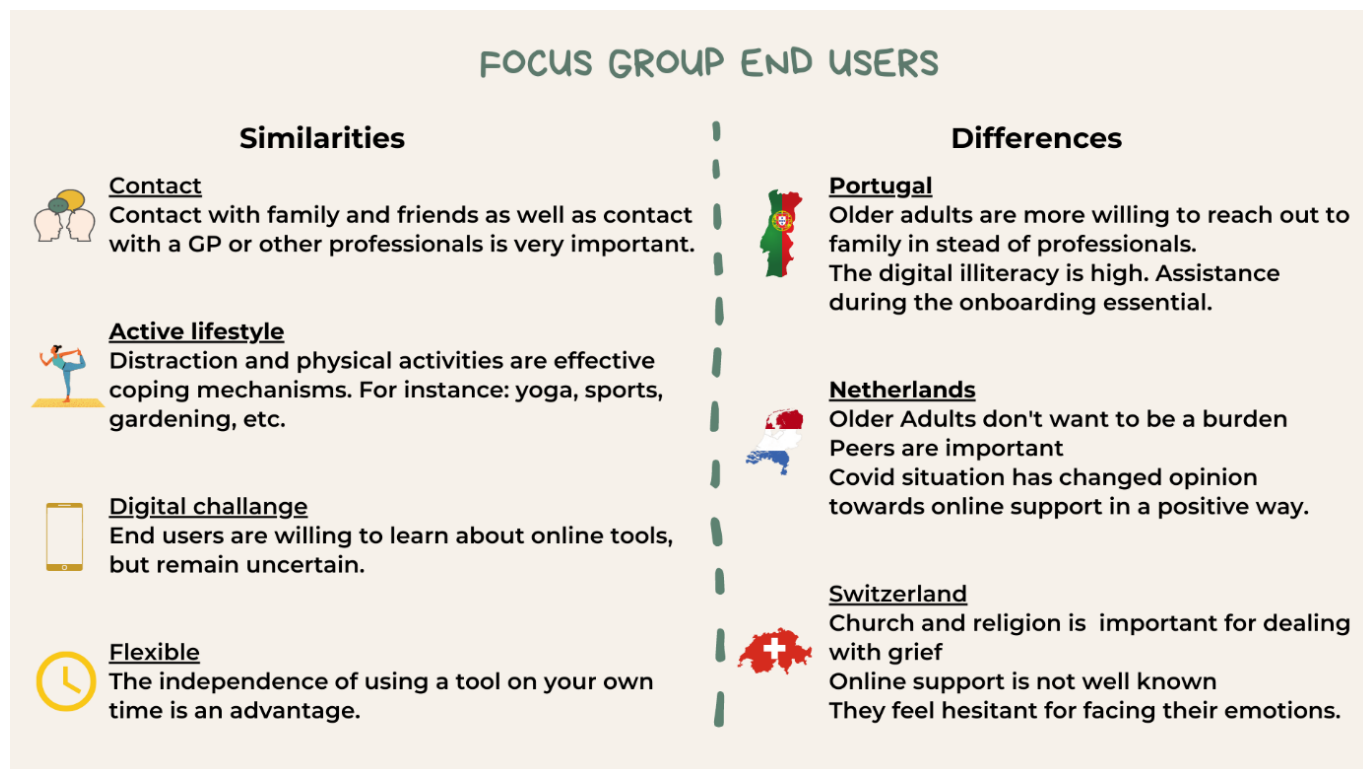


Figure 7: Similarities and differences per country (focus group results)

Besides these findings, we also wanted to fill in the gaps of the service model we created at M12. Therefore, we looked closely at the answers of the participants. We concluded the following findings regarding the onboarding and escalation phase. Two important gaps:

**Onboarding process**

There were some differences between countries. In the Netherlands and Portugal, people mentioned that one would need help during the onboarding process because of low digital literacy; in Switzerland they didn't mention the lack of digital skills. In Portugal, people had privacy concerns. This could be increased because of the lack of digital skills.

**Escalation process**

In every country participants mentioned that contact with professionals is considered important during this phase. Mainly in Portugal, also during escalation, people would appreciate contact with their family. In the Netherlands, it was mentioned that evenings are the most difficult, it would be helpful if there was assistance available at those times, if possible.

The next step in further refining the service model was the plenary meeting with the whole consortium. We needed to discuss all the findings of the studies and answer the important questions.

## 8 Plenary meeting February 2021

At the end of February we had our online two day plenary meeting (M12). All consortium members hosted several workshops. In regards to WP1, NFE constructed the service model workshop to further refine the model and discuss the gaps we still needed to fill. This was important, because WP2 was about to start and needed input and answers from the service model.

Through the means of an interactive workshop with the use of several Mural boards, we created the essential input for the service model (figure 8).

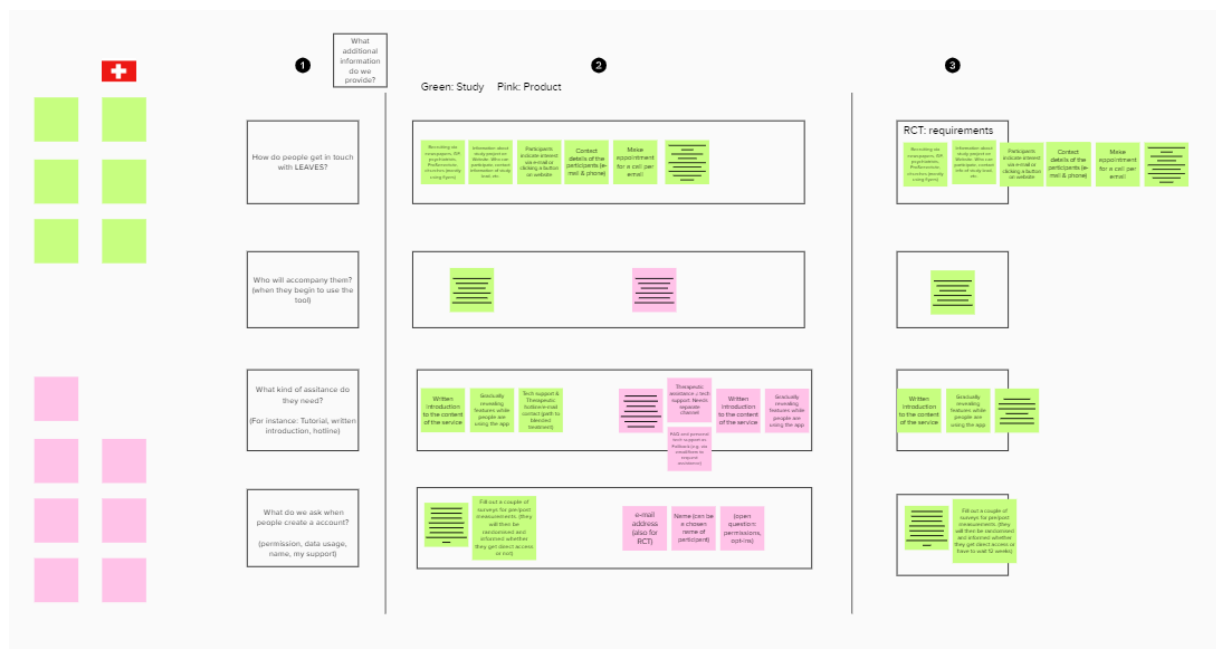


Figure 8: Output of the workshop in Mural



We zoomed in to the two main gaps: the onboarding process and the escalation process. During the workshop we answered the following questions per process together:

#### Onboarding process

- How do people get in touch with LEAVES?
- Who will accompany them (when they begin to use the tool)?
- What kind of assistance do they need? (For instance: Tutorial, written introduction, hotline)
- What do we ask when people create an account? (Permission, data usage, name, my support)

#### Escalation process

- What happens when the escalation route is triggered?
- Who needs to take action and how quickly?
- When can a user return to LEAVES after escalation?

The discussions were very insightful and useful. We made the following decisions:

- During the onboarding the user is guided through the process. Step by step they receive information. Therefore the user is not overloaded with information.
- Furthermore we discussed that a safe environment is very important. *About LEAVES* is a page where we describe the research that has been done and how it is the foundation of LEAVES. We also portray several articles about our research and previous research of LIVIA.
- To further enhance their safe environment, we added the My Support page. Here they can add their own supportlines (family, friends, GP, psychiatrist)
- The user will take action if needed. S/he receives a recommendation message from the system after the risk assessment or monitoring questions when professional help is needed. LEAVES will communicate to the user that they should contact their GP or family members from My Support and provides country specific hotlines for assistance.

We were able to fill in the gaps and further refine our service model. This model was then ready to be validated by several stakeholders and end users. In study 3 we conducted our final research.

## 9 Study 3: Online Survey

### 9.1 Introduction

In study 1 we gathered information about the important steps in the grieving processes of older adults. In study 2, we enriched this information with the opinions of stakeholders about, amongst others, how LEAVES can contribute to existing services and how we can overcome potential barriers for older adults to use LEAVES. With the input of the previous studies and focus groups, we further finalized the service model. The next step was to evaluate this service model. We did this via a survey that walked through the service of LEAVES step by step. The survey mainly targeted stakeholders, since we already gathered insights from older adults (primary end-users) during the usability tests. However, some older adults participated in the survey as well. Participants from all three countries took part in the survey.

### 9.2 Objectives of the survey

In this third study, we focus on the validation of the service model we created, using a quantitative methodology. The research goals of this survey are:

- Validating the service model: the perceived importance of the various steps in the service model, validation of various roles of third parties (e.g. professionals, but also family/friends as contact persons for example);

- Measuring the perceived usefulness;
- Measuring the intention to use;
- Measuring the fit to daily work and existing protocols (stakeholders).

## 9.3 Recruitment

The recruitment of participants for the online survey took place in the three different partner countries. Before contacting several stakeholders we formulated the following **inclusion criteria**:

- The stakeholders need to work with mourners directly or indirectly;
- The older adult has lost their partner.

During study 2, each country created an inventory of stakeholders that could be relevant to this project. These lists consist of various professions, and therefore, they formed a starting point for this study as well.

### 9.3.1 Recruitment strategy

All partners used their network of expertise to connect with stakeholders and gather participants for the online survey. We reached out to stakeholders via both direct contact (telephone, email) as well as via social media like LinkedIn. NFE created the survey links for all three partner countries.

In the Netherlands, participants were recruited by NFE. Stakeholders from various professions were contacted, such as social workers e.g. at municipalities, employees/volunteers at churches, grief counsellors, GPs and their GP-based nurses ('praktijkondersteuner')

ULSBA and UNL recruited participants in Portugal. In Switzerland the recruitment was done by UoB. Both Portugal and Switzerland are more focused on a clinical setting, as explained earlier. Therefore, their stakeholders are also mainly from health care oriented professions, like nurses/health specialists, psychiatrists, psychologists and GPs. But also other professions were addressed.

Portugal and the Netherlands also recruited older adults to take part in the online survey.

All countries encountered difficulties during the recruitment of stakeholders, due to a number of reasons. Firstly, mainly in health care, professionals are very busy due to COVID-19. Secondly, the survey was sent out at the end of November and participants were able to fill in the survey until December 16<sup>th</sup>. This is close to the end of the year, which is also a busy period. Moreover, quite some participants had to be excluded from the analysis, because they did not meet the inclusion criteria. Fortunately, despite the difficulties, almost a 100 participants took part in the online survey.

## 9.4 Methods

### 9.4.1 Introduction to the survey

There were six survey links in total: a version for stakeholders in Dutch, Portuguese, and German, and a version for older adults in Dutch, Portuguese and German. The surveys for both stakeholders and older adults had the same set up, but differed somewhat in wording (e.g. older adults were addressed directly). Also, a few questions were specifically asked to each target group (see description below).

### 9.4.2 Online survey design

The landing page of the survey was an introduction page. It addressed a few topics:

- The aim of LEAVES
- The partners involved in the project
- The rights of the participant (e.g. s/he is able to stop at all times)

- What their answers are used for (e.g. validation of the program, scientific publications)
- Information about data storage

The participant had to agree to these conditions in order to start the survey. Once the participant did, they were asked to fill in some demographics, like gender and age. Older adults were asked whether they had lost their partner. If they did, they were asked how long ago this has happened. If not, they were guided to an exclusion page. The stakeholders were asked what their job was, whether they worked with mourners, what kind of support their clients are looking for and if they use eHealth in their daily work. When the stakeholder indicated that they didn't work with mourners, they were guided to an exclusion page.

After this, the participants were guided through the different steps of LEAVES: the registration process, the risk assessment, the My Support page, the content of LEAVES and the monitoring process. Every step started with a small introduction of that part and a visualisation of a monitor with a screenshot of the program, or a visualisation of an older adult using LEAVES.

The survey ended with several questions that measured the intention to use. The older adults received a question about who they think would benefit the most from LEAVES. The stakeholders received some extra questions about the usefulness of LEAVES in their daily work.

At the end of the survey, participants were able to leave a comment and they were thanked for their participation.

## 9.5 Ethical considerations

### 9.5.1 Ethical approval

As mentioned in 9.4.2. about the online survey design, the survey started with an explanation about LEAVES and the aim of the online program. Next, the partners of the concerned country were introduced. After that, the role of the respective stakeholder or older adult was mentioned and why we value their opinion. Lastly, we explained what would happen with the participant's answers, and in which ways their answers could be used. It was also made clear that the participant had the right to stop at any time. At the end of the page, the participant needed to sign a check box to agree with the conditions before (s)he was able to start the survey.

### 9.5.2 Data storage

The survey links were provided by the NFE. The data is also stored at NFE. When the survey was open for participants, ULSBA and UoB received a link by which they could see main results of their respective country. Hereby, they were able to monitor the amount of participants, etc. Participants were notified by the fact that data will be stored anonymously at least until the end of the project (spring 2023). And that data that will be used for scientific publications will be saved for ten years, because this can be inquired later.

## 10 Findings Online survey

### 10.1 Participants

Stakeholders of all three partner countries contributed; 50 from the Netherlands, 40 from Portugal and 34 from Switzerland. Not all stakeholders finished the survey, and some stakeholders were excluded, because they didn't work with clients that deal with grief (in)directly. In total, results of 84 stakeholders were included in the research report; 39 from the Netherlands, 23 from Switzerland and 22 from Portugal. Besides stakeholders, older adults from the Netherlands and Portugal took part as well; 27 from the Netherlands and 14 from Portugal. Some stakeholders were excluded, because they hadn't lost their partner. In the end, 15 stakeholders completed the survey; 11 from the Netherlands and 4 from Portugal.

This sums up to 99 participants in total. Stakeholders from various professions took part in this survey (table 4).

**Table 4: Professions of stakeholders per country**

Profession	Netherlands	Switzerland	Portugal	Total
Spiritual counselor	14			14
Nurse/health specialist	1	6	6	13
Physiatrist	3		7	10
Psychologist	1	5	3	9
Social worker	7	2		9
Employee/volunteer at a church	3	5		8
Grief counselor/volunteer	3	2		5
General Practitioner/Doctor			5	5
Employee/volunteer at a municipality	2			2
General Practice-based nurse (Praktijkondersteuner) (Only NL)	2			2
Specialist in everyday design and activation		2		2
Volunteer at a non profit	2			2
Technical assistant			1	1
Professional caregiver counselor	1			1
Psycho-social consultant		1		1
Older adults (primary end-users)	11		4	15

### 10.2 Results

The summary of the results can be found in figure 9 below. The summary of results will be explained in this chapter. More information about the demographics and the full research report of results can be found in Appendix E.

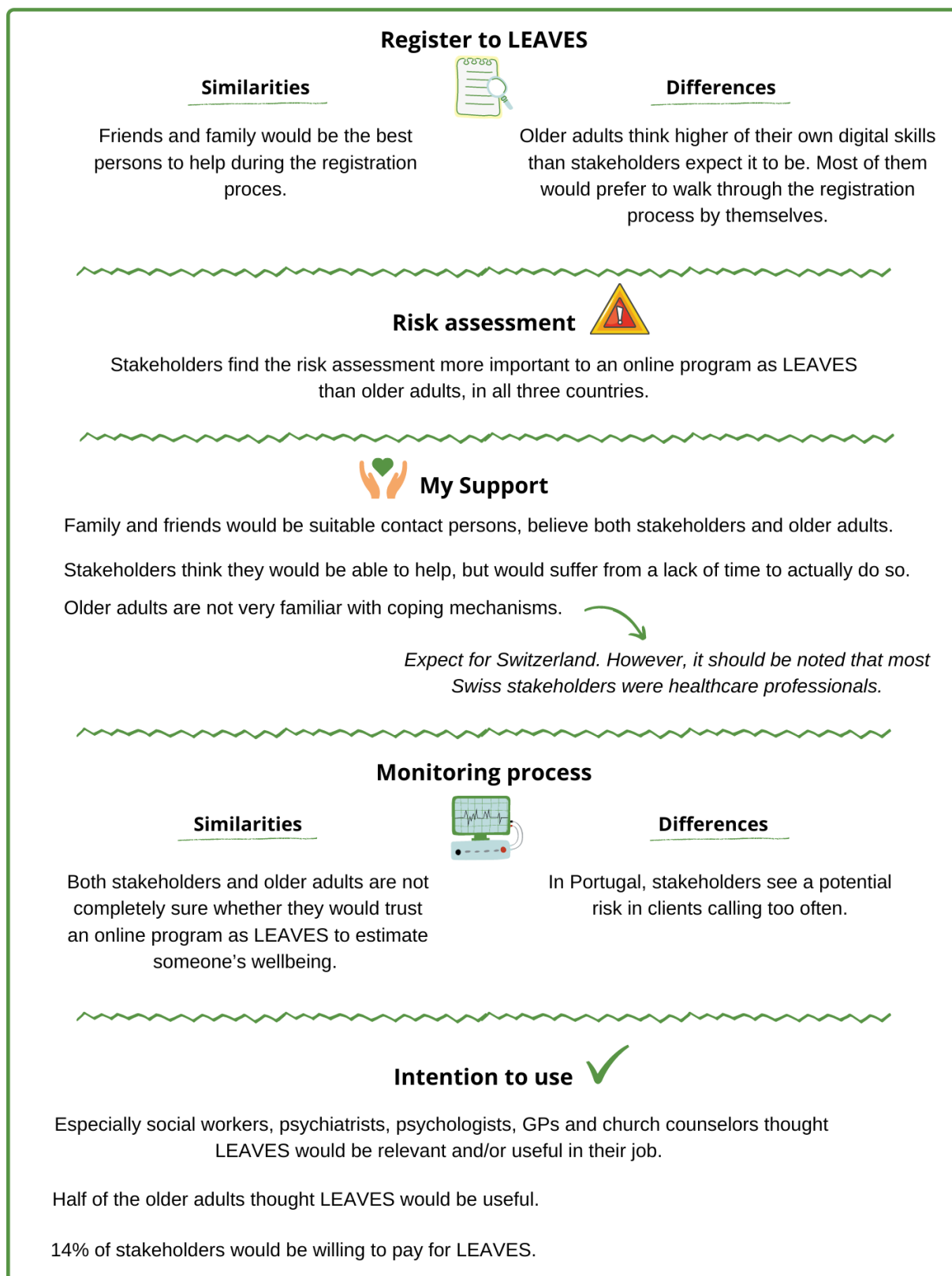


Figure 9: Summary of survey results

### 10.2.1 Register to LEAVES

#### *Similarities between groups*

In all three countries, stakeholders and older adults believe that family members and/or friends would be most sufficient to help older adults during the registration process, if older adults are not able to do this by themselves.

#### *Differences between groups*

However, older adults think higher of their own digital skills than stakeholders; 91.7% of Dutch older adults, and 75% of Portuguese older adults think that they will be able to register to LEAVES by themselves. Furthermore, 73.3% of older adults would prefer to walk through the registration process by themselves. Stakeholders estimate this somewhat different, and it also differs per country. In the Netherlands, 40% of the stakeholders believe that older adults would be able to register themselves, while 22.8% of Portuguese stakeholders and 16% of Swiss stakeholders think that their clients have enough digital skills for this.

### 10.2.2 Risk assessment

#### *Similarities between groups*

In all countries, the majority of stakeholders believe that the risk assessment is very/somewhat important to an online program as LEAVES. Especially in Portugal and the Netherlands (PT: 86.4%, NL: 82.1%, CH: 60.9%).

#### *Differences between groups*

The older adults score a little lower, since 41.7% indicates that the risk assessment is very/somewhat important to an online programs as LEAVES.

### 10.2.3 My Support

#### *Similarities between groups*

Both stakeholders and older adults in all three countries think that older adults are not very familiar with various coping mechanisms. Except for Switzerland; 54.6% of Swiss stakeholders indicate that their clients are familiar with coping mechanisms.

Stakeholders from all three countries think that, again, friends or family members would be suitable contact persons in the My Support page. In Switzerland and the Netherlands, church counselors are more often seen as suitable contact persons. However, it should be noted that in the Netherlands, a lot of the participants were church counselors (36%). In the other-section Dutch stakeholders also name volunteers as potential contact persons.

The older adults consider family or friends (66.7%), psychologists (25%), peers (16.6%) and GPs (8.3%) as most suitable contact persons in the My Support page.

Stakeholders mention that they would be capable to help their clients, but that the lack of time would be a barrier to do so.

#### *Differences between groups*

It should be considered that the differences per country can also be explained by the fact that the majority of Swiss stakeholders worked in the healthcare industry, contrary to Dutch stakeholders for example. They might use coping mechanisms more often with their clients than other professionals. However, this is also the case in Portugal, and their results are quite neutral. When examining the results between professions, it seems that mostly healthcare related professions think that the My Support page is very/somewhat important. For example, GPs/doctors, psychiatrists, psychologists (all 87.5%) and social workers (77.8%) mark the My Support page as (somewhat) important, while only 33.3% of spiritual counselors and 25% of grief counselors say the same.

### 10.2.4 Monitoring process

#### Similarities between groups

Both stakeholders and older adults are not completely sure whether they would trust an online program as LEAVES to estimate someone’s wellbeing. Of all older adults, 25% agree and 50% are neutral. Of all stakeholders, 52.9% of Portuguese agrees, 50% in Switzerland and 39.4% in the Netherlands.

Mainly in the Netherlands, stakeholders feel comfortable with LEAVES referring to them as a professional. This could also be explained by the fact that most stakeholders in the Netherlands were spiritual counselors and they didn’t feel that they won’t have enough time to help as often as other professions had.

#### Differences between groups

A notable difference is that in the Netherlands and Switzerland, stakeholders don’t see a potential risk of clients calling them too often (NL: 27.3%, CH: 18.2%). In Portugal, however, the majority does find this a potential risk (58.8%).

### 10.2.5 Intention to use

#### Older adults

The intention to use amongst older adults varied (figure 10). However, 50% of older adults believe that LEAVES is a useful tool (25% is neutral). Besides that, 37.5% expects LEAVES to be easy to use (37.5% is neutral). Only one older adult would be willing to pay for the usage of LEAVES and two older adults are neutral.

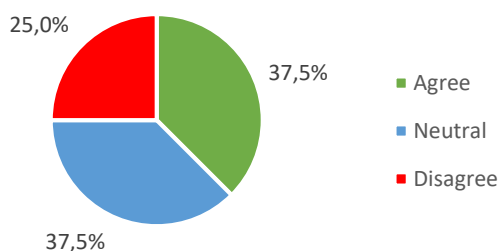


Figure 10: Intention to use LEAVES (end users)

#### Stakeholders

Stakeholders are more positive about the usefulness and relevance of LEAVES to their daily job. Table 5 shows the opinions of the most represented professions in the survey.

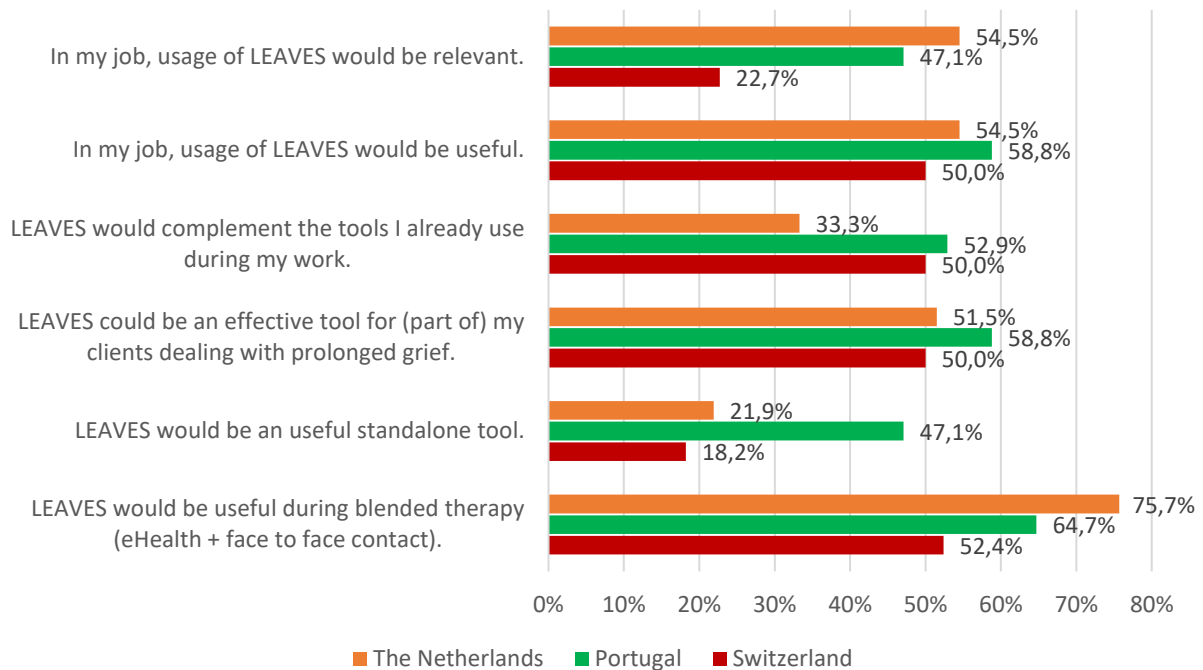
Table 5: Relevance to job per profession

Profession	Relevant in my job	Useful in my job
Social worker	66.7%	77.8%
Psychiatrist	50%	62.5%
Psychologist	57.1%	57.1%
Church counselor	37.5%	62.5%
GP/Doctor	37.5%	50%

Approximately half of the stakeholders think that LEAVES would be an effective tool for (part of) their clients (figure 11) and that it would complement the tools they already use in their work.

Moreover, it stands out that stakeholders find the tool especially suitable as a form of blended therapy (e-Health + face-to-face contact), more than as a standalone tool. Besides that, 83.3% of Portuguese stakeholders would (probably) recommend LEAVES to their clients, and also 59.1% of Swiss stakeholders. Dutch stakeholders are more neutral (41.2%).

Lastly, the willingness to pay differs per country: 29.4% of Portuguese stakeholders are willing to pay, while only 6.1% of Dutch stakeholders and 5.6% of Swiss stakeholders are willing to pay. In the comment part of this question, various stakeholders mentioned that there won't be a budget to pay for the service, hence their answer.



**Figure 11: Relevance to job, answered with (totally) agree (stakeholders)**



## 11 Conclusions

All studies concerning WP1 have been executed and the service model as shown in Appendix F is final. The objective of this work package was to make sure that the service, tools and user interface design is in line with the expectations of all end-user groups of the LEAVES service. Through all the research we have conducted, we can confirm that this is the case. We interviewed, discussed, tested and validated the service, tools and interface design on multiple occasions. Through an iterative process we continuously adjusted the service model, tools and design.

The most important lessons we learned and interegrated in our service model and visual design are:

### LESSONS LEARNED

#### Effects on our service model:



##### Setting up

Older adults might need someone to introduce them to LEAVES. This also differs per country.



##### National helplines

We integrated support helplines in each country that are available 24/7.



##### 'About LEAVES'

The 'About LEAVES' page is important, because users add value to the fact that the service is scientifically based.



##### Notebook

We're considering a notebook, so that people have something tangible.



##### Online vs. face-to-face

An online tool can't replace face-to-face contact.



##### Differences between professions

In general, stakeholders validated the service model. However, there are differences between professions. Mainly healthcare related profession add value to the various steps of the service model.

#### Effects on the visual design:



##### Simple and clear design

No complex visualisations and simple screens with only one action to take at a time.



##### Information load

Don't overload the user with information; guide them through the process by handing out information in pieces.



##### 'My Support' section

We've added the section 'MySupport' for the difficult situations.

Figure 12: Lessons learned about the service model.

In the final year of the research we will conduct a real-life evaluation of the service in all three countries. With this real-life evaluation we will learn if the service model and the way we have constructed the LEAVES tool is sufficient. And more importantly how this service will contribute to preventing prolonged grief. How will primary and secondary end users value the tool?

We already learned about some thresholds and barriers from the research in WP1. The possible lack of digital skills of older adults could be an important threshold in using a tool such as LEAVES. Some stakeholders mentioned that an online tool can't stand on its own, but needs to be part of blended therapy. Furthermore they mention that older adults are not always familiar with coping strategies. On the other hand, in study 3 we found that older adults themselves think they would be able to register by themselves.

The results from the real-life evaluation will further validate the service model or portray changes that are needed to enhance the service and the usability of the tool. In WP4 we will further research the business and exploitation possibilities. These findings can also possibly influence the service model and how primary and secondary end users are approached. Therefore WP3 and WP4 can further refine and shape the service model. It will show how we need to further develop the service and tool to eventually create a mature service which will be market ready.

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## Appendix A: Study Protocol Focus group sessions

### 1 Introduction

In this proposal you can find the protocol and set up for the stakeholder focus group and the end-user focus group that will serve as input for the LEAVES service model design, WP -1 M12. In the previous study for WP1 we have conducted telephone interviews with primary end-users (older adults that have lost their spouse) to understand the process they went/or are going through, and ultimately, to elicit their needs (5 to 10 interviews per country). The next step in the research will be conducting focus groups sessions with stakeholders (e.g., psychologists, municipalities, mourner (representatives), undertakers) as well as with mourners that are capable of participating in an online or offline focus group. In M12 a new version of the service model is ready as input for business modelling and technological development, and the final model is delivered at M24.

Research type	Topics to be covered	Results	Numbers
Online Focus groups Stakeholders <i>(online or group phone call GoToMeeting)</i>  Focus groups stakeholders <i>(online)</i>	What works and what doesn't in the current service? Your role? Where does it end? Is there a gap? What is needed?	Input for design of the tool and service design	<b>N = 15-24</b> 3 focusgroups, 1 per country (5-8 participants each)

Table 1: Overview of content, output and numbers for of the End user studies

### 2 Service Model Design – AAL2019 Outline

The service model will make apparent how the transition from online care to offline care will transpire.

The main service models are foreseen to be:

1. LEAVES services provided by wellbeing organisations such as NFE that use the application as part of their phone service for older people.
2. LEAVES services by undertakers such as DELA that include the application in their support package for mourners.
3. LEAVES services in a Business-2-Business (B2B) setting, where LEAVES licenses are offered to end user organisations.
4. LEAVES services provided by care and clinical organizations such as UoB and ULSB that use the application as part of their support programmes.

The implementation of the LEAVES service model and technology will alter the existing care in several ways:

- 1) it will introduce an intervention to prevent Prolonged Grief (PG);
- 2) it will introduce a self-service approach towards preventing or treating PG;
- 3) it will enable novel means of introducing care to mourning older adults.

Therefore, the most important innovations necessary for implementing the LEAVES service, focus on the current method of identifying older adults with an increased risk of PG, and hence, on altering the existent care path.

## 3 Selection of participants focus groups

### 3.1 Criteria of participants end-user focus group

Participants must match all criteria:

- 60+ age
- Loss of a partner in the past
- Are actively dealing with a grief process or were dealing with it in the past
- Are able to reflect on the process they went through

Exclusion criteria's:

- Participants unable to participate adequately because of medical, neurological, psychiatric or any other impairing medical conditions
- Extra attention for very traumatic loss like suicide, murder etc.
- A maximum of 5 end-users per focus group.

### 3.2 Informed consent end-users

#### LEAVES and the purpose of the study

Many elderly have to deal with the loss of their partner in the last phase of their life. Scientific research shows that 25 percent of the elderly have difficulty coping with this loss, even after an extended period of time. This in turn can lead to loneliness, depression or physical complaints. The [name the partners of your country], together with partners from Switzerland/Portugal and the Netherlands will conduct a study among this target group.

This study will be conducted in the context of LEAVES, a project within the European Active and Assisted Living (AAL) program. Within this project, European researchers, companies and technology developers work together to develop a digital support program to deal with the loss of a spouse. This online service offers grieving seniors the opportunity to share their story and it guides them through the process of their grief. The results of this study help to shape this service. Since that it is no longer to be assumed that we can meet and support each other 'live' because of the corona period - especially for the elderly - digital services offer all kinds of opportunities. The LEAVES project aims to respond to this development in an appropriate manner.

#### Your role in this project

This project takes 3 years and is divided in different stages. We are currently in the first year and the research focuses on the service model design. This means that we investigate how elderly who have lost a spouse deal with the process of grief. How they are experiencing this process and what needs they have. Through these results, we can better shape the LEAVES service and also better understand the process

that someone goes through. Therefore you have a very important role in this study, because your experience is vital for our research.

### **Protection of your data**

When you participate in this study, you can expect the following:

- Your data will be anonymised and processed confidentially;
- Your answers will not be traceable to you as a person afterwards;
- After the interview you are entitled to a summary of the report and you are given the opportunity to respond and let us know any inaccuracies;
- You can ask any question, we will always do our best to answer them;

The [name the partners of your country] consider it very important to handle your personal data with care. The session will be recorded via audio, and we guarantee that we will treat your information anonymously and confidentially. The results are only presented in processed form and will not be traceable to you as a person. The results will initially be used to better shape the LEAVES service. In addition, insights are used for (scientific) publications in the context of this project. We will keep the anonymous data at least until the end of the LEAVES project (spring 2023), because the knowledge provides valuable insights for the development of the service. We keep data that we use for scientific publications for ten years, because this can be inquired about later.

For conducting this study we need to ask for your consent to use the data collected. By signing this form you agree with voluntarily participating in this study and you agree with the collection and use of the data in this study as mentioned.

Place:

Date:

Name:

Signature:

## **4 Performing the Focus groups**

### **4.1 Preliminary checklist end-users (used in all studies)**

Before the start of the focus group we will ask the end-users to sign the informed consent and to fill in the answers on these questions of the checklist.

**1) How do you identify yourself?**

- Man
- Woman
- Transgender
- Other

**2) What is your age?**

**3) How long ago did you lose your partner?**

- 0-6 months
  - 6 months -1year
  - 1-2 years
  - 2 – 5 years
  - 5 – 10 years
  - Longer
- 4) How long were you together with your partner?**
- Shorter than 2 years
  - 2-5 years
  - 5-10 years
  - 10 – 20 years
  - Over 20 years
- 5) Do you have a person in your life whom you trust and can talk to about personal matters?**
- Yes, 1
  - Yes, several
  - None
- 6) Lost partner:**
- Unexpectedly
  - After being ill for a longer period of time
- 7) For how long have you been receiving additional support (if you did) next to support from within your own social network?**
- 0 - 2 months
  - 2 - 6 months
  - 6 – 12 months
  - 1 -2 years
  - More
  - I do not have additional support

## 4.2 Set-up Focus group end-users

### 4.2.1 Introduction

- Explain about the LEAVES project and the end product we want to develop, give a presentation on the product (see 4.4.2.);
- Explain that we want to learn more about the process people go through when they start searching for additional support in their mourning process so we can better understand that process and how to actively tune into it. People can be helped and supported better in that way, we want to learn from their experiences;
- Explain why they are an interesting participant for the focus group;
- Explain that the focus group will be recorded as was stated in the informed consent;
- Explain that the focus group is confidential and answers will be anonymized;

- Are there any further questions? Okay we will start now.

The *informed consent* addresses all the information mentioned above in more detail.

### 4.2.2 Presentation Leaves

LEAVES aims to help older adults to process the loss of a spouse in an empathetic and caring online environment. This online service offers elderly the possibility a program that supports them in processing their loss. It is based upon a text-based online self-help program that psychologists in Switzerland developed, which was scientifically proven to improve grief and depression symptoms and general distress. European researchers, companies and technology developers work together to further develop this intervention and integrate it into a more comprehensive digital support program to deal with the loss of a spouse. The service relies on online treatment if possible but will be blended with telephone or face-to-face counselling when necessary. The LEAVES service aims to soften the mourning process, prevents depression, strengthens mourner’s resilience and wellbeing, and quickens a return to societal participation.

### 4.2.3 Set-up focus group end-users

Workshop focus group END-USERS	
Start / end time	
Meeting location	
Note taker(s)	
Moderator(s)	
Participants	
<p><b>Focus group goals</b></p> <ol style="list-style-type: none"> <li>1) Find out what the end-users value in using an online service as LEAVES and in which activities offline support adds more value.</li> <li>2) Find out in both the loss-oriented experiences and the restoration-oriented experiences how end users used or wish to use online support.</li> <li>3) Find out in the loss- and restoration-oriented experiences how end users wish to receive offline support.</li> <li>4) Find out how end-users would value LEAVES.</li> </ol> <p><b>Important</b> for this focus group session:</p> <ul style="list-style-type: none"> <li>▪ Don't focus too much on personal experiences. Try to ask in context, whether they would use online support or not.</li> <li>▪ Stay away from personal details about the grieving process.</li> <li>▪ During this sessions one person needs to lead the discussion and another person needs to be of the emotions and reactions of the participants. He/she needs to check if everybody is doing ok during the sessions.</li> </ul>	
<p><b>Notes</b></p>	

<b>1) INTRODUCTION (20 min)</b>	
<p><b>Project presentation</b></p> <p>Welcome and thank the participants for joining the session.</p> <ol style="list-style-type: none"> <li>1. Explain LEAVES and mention the practical information (4.4.1 and 4.4.2)</li> <li>2. Mention that we want to learn from them because they know grief. We see them as experts from whom we wish to learn.</li> <li>3. Explain that this is a confidential environment where their views, thoughts and feelings are valued. Nothing that will be said in this focus group will be shared with others (without being anonymized).</li> </ol>	
<b>Notes</b>	
<p><b>Introduction round</b></p> <ul style="list-style-type: none"> <li>▪ Start with a short warming up session. Purpose is to create a safe environment where they feel free so share their views and experiences.</li> <li>▪ Ask the participants to introduce themselves, their first name, when they have lost their partner and what they enjoy doing in their spare time.</li> </ul>	<b>See attachment 1</b>
<b>Notes</b>	
<b>2) CONTENT QUESTIONS (75 min)</b>	
<p><b>Introduction topics</b></p> <p>Everybody handles grief in their own way. Someone will want to talk with others to cope with their grief and another person chooses to deal with their grief privately.</p> <p>Today we will discuss two phases of grief. The first phase is focussed on looking back, on the past. The second phase is about looking forward, to the future.</p> <p>We want to learn from you which support (on- or offline) has helped you. We're not testing you in anyway but we're trying to get your perspective on several topics and ideas.</p>	
<b>Notes</b>	
<p><b>Loss-oriented, looking back (15 min)</b></p> <p>We are wondering how you have dealt with the loss of your spouse and how it was possible to come to terms with this (if at all possible). We are specifically interested in what you helped you as online support.</p>	<p><b>Brainstorm</b></p> <p>They will get a time limit of 5 minutes and need to write everything down on post-its.</p>



<p>We have the following diagram (attachment 5a) for you.</p> <p>Online support – offline support</p> <p>Please think of all the examples of what you did online and offline that helped you to accept your loss and work through the emotions of the loss.</p> <p>Go through 3 questions:</p> <ol style="list-style-type: none"> <li>1. What helped you to accept your loss?</li> <li>2. In what way did online support help you in this? In what way could online support help you in this? (offer examples from attachment 5b if nothing comes up)</li> <li>3. When/In what way was offline support more helpful?</li> </ol>	<p>After the 5 minutes they will place the post-its on the board. Briefly explaining their thoughts when they place it on the board. (every participant had a different colour post-it)</p>
<p><b>Notes</b></p>	
<p><b>Restoration-oriented, looking forward (15 min)</b></p> <p>We are wondering how you have adjusted to your new life without your spouse. We are specifically interested in what you helped you as online support.</p> <p>We have the following diagram (attachment 5a) for you.</p> <p>Online support – offline support</p> <p>Please think of all the examples of what you did online and offline that helped you to accept your loss and work through the emotions of the loss.</p> <p>Go through 3 questions:</p> <ol style="list-style-type: none"> <li>1. What helped you to adjust to your new life without your spouse?</li> <li>2. In what way did online support help you in this? In what way could online support help you in this? (offer examples from attachment 5b if nothing comes up)</li> <li>3. When/In what way was offline support more helpful?</li> </ol>	<p><b>Brainstorm</b></p> <p>They will get a time limit of 5 minutes and need to write everything down on post-its. After the 5 minutes they will place the post-its on the board. Briefly explaining their thoughts when they place it on the board. (every participant had a different colour post-it)</p>
<p><b>Notes</b></p>	
<p><b>BREAK 5 minutes</b></p>	<p>During the break gather all the information in groups that fit each other.</p>
<p><b>Zooming in (10 min)</b></p>	<p><b>Discuss</b></p>

<p>The next step is to zoom in on the possibilities of online services. See if there are aspects they didn't mention which we have covered in our overview. Ask how they would feel about these activities.</p> <ul style="list-style-type: none"> <li>• How would you feel of writing your thoughts down in an online journal?</li> <li>• Would you want to receive online therapeutic help?</li> <li>• Would you have wanted to talk with other people who experienced the same? Would you have done this online?</li> <li>• Would you wish to read the stories of other bereaved spouses?</li> </ul> <p>Select the online activities they wish they had done. Place them also on the board. Do the same for the offline activities.</p>	<p>Going around in the group and focussing on different people. Because you have the overview of the previous assignment you know more about them &amp; their online behaviour.</p>
<p><b>Notes</b></p>	
<p><b>Voting (10 min)</b></p> <p>The board is complete with a lot of on- and offline activities. Let them chose 3 activities per loss- and restoration-oriented experience, which they think would have the most benefit it that situation.</p> <p>When this selection has been made, let them together choose 1 online and offline option which is the most essential for processing their grief.</p>	
<p><b>Notes</b></p>	
<p><b>Make the connection with LEAVES (15 min)</b></p> <p>Now it's time to make the connection with LEAVES. Summarize shortly the LEAVES online service together with offline assistance.</p> <p>Then ask the following questions:</p> <ul style="list-style-type: none"> <li>• Would you have used this tool if someone at the time mentioned it to you? If not, why?</li> <li>• Would you prefer to use such a tool on your own or with the help of a friend or professional caretaker?</li> <li>• It retrospect and with the knowledge you learned today what do you like about online support / activities?</li> <li>• What could hinder elderly from using online support for their grief?</li> <li>• What would encourage elderly to use online support for their grief?</li> <li>• What other benefits are there of having an online tool for grief support? (give examples: sharing my feeling through writing in a journal, having contact with an online assistant, having something to do every day by checking in, etc)</li> <li>• How important is the offline support?</li> <li>• Would you prefer to have professional (offline) support during the process of such a tool? Or would you prefer to have the support of family? Or both?</li> </ul>	

<p><b>Notes</b></p>	
<p><b>3) CLOSING (10 min)</b></p>	
<ul style="list-style-type: none"> <li>▪ Do you have any other suggestions or remarks concerning this focus group?</li> <li>▪ Have we attained our goals?</li> <li>✓ Find out what the end-users value in using an online service as LEAVES and in which activities offline support adds more value.</li> <li>✓ Find out in both the loss-oriented experiences and the restoration-oriented experiences how end users used or wish to use online support.</li> <li>✓ Find out in the loss- and restoration-oriented experiences how end users wish to receive offline support.</li> <li>✓ Find out how end-users would value LEAVES.</li> </ul>	
<p><b>Notes</b></p>	
<p>Thank you for your participation. We can send our notes to you for information.</p> <p>Checking in after session:</p> <ul style="list-style-type: none"> <li>- Share an email with them the following day to check if they are doing ok. If we need to call them if they are upset.</li> <li>- When there has been someone during the session who was not doing ok, make a separate phone call to let them calm down.</li> <li>- When somebody is totally in grief contact friend/relative.</li> </ul>	
<p><b>Notes</b></p>	



## Attachment 1. Introduction warming-up

Start with a short warming up session. Purpose is to create a safe environment where they feel free to share their views and experiences.

Warming up for stakeholders and end-users – First single/album

- 1) Ask the following question: “What’s the first (music) single/album you bought?”
- 2) We have asked the question beforehand, therefore we can show them online to the group
- 3) Let everyone share where they bought the single, why they liked it at the time and what format it was (8track, cassette, CD, vinyl, mp3...)

Facilitator: After the session, surprise the team with a music playlist of all the singles. It will mess up everyone’s Spotify algorithms 😊

## Attachment 2. Dual Process Model

### Loss-oriented experience

Accepting the reality of the loss and processing the pain of this grief.

### Restoration-oriented experience

Adjusting to a world without a deceased and embarking on a new life.



## Attachment 3. Tasks of Grief

### **Accepting the reality of the loss**

In the first task the focus is upon accepting the reality of the loss as it is. It can be understood that we do not wish to see or hear about the loss, because it can be too painful. In this part we wish to learn about what has helped you to deal with the first impact of the loss, and how you were able to accept the impact of the loss of your partner to your life.

### **Processing the pain of the grief**

This task is about acknowledging, talking about, and understanding your emotions, such as sadness, fear, anger, guilt, shame, relief et cetera. It is useful to work through these emotions instead of denying and avoiding them. In our society it is not always accepted to feel and to share pain which accompany the feeling of loss. We wish to hear from you how you have dealt with your emotions concerning your loss and what has helped you in this. We will first look at the things that have helped you which have technical components. Then we will look at the other actions that helped you in dealing with this.

### **Adjusting to a world without the deceased**

The third task is to adjust to the environment in which the deceased is missing. This adjustment happens over a long period of time. It can require different adjustments, internally, externally and spiritually. It may take a significant period of time to realize all the different roles that the loved one performed in one's life. Sometimes it even feels like a betrayal to the loved one when adjusting to a world without him or her. It is however a vital part of dealing with grief. Again we wish to hear what has helped you to come to terms with your life as it is without the loved one.

### **Finding enduring connection with the deceased whilst embarking on a new life**

The last task of grief is about starting on a new life, but keeping the cherished moments and memories with your loved one as a source of joy and strength.

## Attachment 4. Grid for focusgroup stakeholders

Per phase: What is essential/missing in the existing service for mourners?

<p><b>Loss-oriented, looking back, the past</b></p>	<p><b>essential</b></p>	<p><b>missing</b></p>
<p><b>Restoration- oriented, looking forward, the future</b></p>	<p><b>essential</b></p>	<p><b>missing</b></p>



## Attachment 5a. Post-it board end-users

<p><b>Loss-oriented, looking back, the past</b></p> <p><i>Focussing on accepting &amp; processing</i></p>	<p><b>online</b></p>	<p><b>offline</b></p>
<p><b>Restoration- oriented, looking forward, the future</b></p> <p><i>Focussing on adjusting &amp; embarking a new life</i></p>	<p><b>online</b></p>	<p><b>offline</b></p>

## Attachment 5b. On- and offline support examples

**Online support (see explanations task of grief at end document)**

<p><b>Loss-oriented, looking back, the past</b></p>	<p><b>Accepting the reality of the loss</b></p> <ul style="list-style-type: none"> <li>- Regular apps from others about how you are doing</li> <li>- Online therapy services</li> <li>- Reading the stories of other bereaved spouses (e.g. in a forum, a blog, a Facebook group)</li> <li>- Making an online photo album with special memories</li> <li>- LIVIA: Telling the story of the loss and unfinished business and writing a farewell letter (Modules 6, 7, 10)</li> <li>LIVIA M3: Cognitive-behavioural exercises for fostering positive thoughts and emotions</li> <li>- Writing down concrete changes in the context (e.g., in the house, in the routine, make the loss concrete) and ask to briefly describe what used to happen in the specific room/routine</li> <li>- Reading all the cards and statements of support left by friends and family (online)</li> <li>- Making an album with photos and stories, statements from friends and family.</li> <li>- Looking for peers online (like facebook)</li>   <li>- Sharing experiences of other mourners</li> <li>- providing a sort of forum which enabled the user to contact other grievors and talk about how they were grieving)</li> <li>-Write a letter to your deceased one. Include a "Send" button.</li> </ul>	<p><b>Processing the pain of the grief:</b></p> <ul style="list-style-type: none"> <li>- Online peer contact via WhatsApp</li> <li>- Information about help with mourning</li> <li>- Google for help</li> <li>- Online forum for bereaved spouses</li> <li>- Online therapy services</li> <li>- Writing a blog</li> <li>- Writing e-mails to friends</li> <li>- LIVIA: Telling the story of the loss, allowing memories and pain (Module 6)</li> <li>-LIVIA M4: Exercises for finding comfort, walk with all senses, happiness diary</li> <li>- For each identified change in the house/routine, write down the emotions before and after the loss. For example, when you picture your sofa, can you name your feelings at the you lived together? And what are your emotions now?</li> <li>- Do online meditation grief oriented like mindspace</li> <li>- Keeping an online journal</li> <li>- Allowing mourners to mourn for a specific hour per day</li> <li>- Online educating the mourner that this is a normal process</li> <li>- Online peer contact, via social media, such as Facebook, Whatsapp.</li> <li>- Periodic (or on-demand) video calls between the user and a health-care professional, offering guidance and support through the loss</li> <li>- Forward to online yoga, mindfulness an/or relaxation sessions, maybe through videos on youtube or some other platform</li> <li>- Present specific stories on bereavement, asking afterwards to write down what they thought about it.</li> <li>- Give soothing music, meaningful movie suggestions</li> </ul>
<p><b>Restoration-oriented, looking forward, the future</b></p>	<p><b>Adjusting to a world without the deceased</b></p> <ul style="list-style-type: none"> <li>- Online information on how to deal with adjusting to a world without the deceased</li> <li>- Online grief journal which helps structure days to slowly build a new routine and gives motivating feedback</li> </ul>	<p><b>Finding enduring connection with the deceased whilst embarking on a new life</b></p> <ul style="list-style-type: none"> <li>- Use digital tools to increase connectivity with others, family or friends</li> <li>- Think of your loved one in a positive way, receive questions about the loved one, for example in an app</li> </ul>

	<ul style="list-style-type: none"> <li>- looking for new people to meet online to talk about (new) life</li> <li>- Googling for practical things that the lost spouse has done so far</li> <li>- LIVIA: M2: Exercises for assessing current feelings related to the loss, and changes in life due to the loss, analysis of obstacles for positive adaptation</li> <li>LIVIA M3: Cognitive-behavioural exercises for fostering positive thoughts and emotions</li> <li>M4: Exercises for finding comfort, walk with all senses, happiness diary</li> <li>M 5: Exercises for self care (physical, practical and emotional)</li> <li>M 8: Exercises for reviving sources of strength, new tasks and decisions, new strengths and growth</li> <li>- Writing down concrete new areas in the house and new moments in the routines that bring peace and joy.</li> <li>- Writing down what are the triggers of that moments/spaces of peace and joy.</li> <li>- Providing options for recording implementation intentions</li> </ul>	<ul style="list-style-type: none"> <li>- Supporting others online who have lost their spouse</li> <li>- LIVIA Writing a farewell letter (M10), see also adjusting to a world without the deceased</li> <li>- Writing down/Drawing the new ideal house and routine, including the new spaces/moments for peace and joy and the spaces/moments/objects in which the loved is most present in the mourner’s heart and mind (emotion and thought); Make a calendar for a progressive implementation of those new spaces/moments and use the app to register the progress made while it happens; maybe take before/after photos these new spaces/moments/objects.</li> <li>- writing online articles, blogs</li> <li>- Create a repository of cherished memories, photos, music, make it able to be accessible offline somehow</li> <li>- App that asks questions about the partner and their life together, "Where were you last year?", "What was the happiest time you shared?", ...</li> <li>- providing extra activities, offers, suggestions on anniversaries of the deceased, his/hers death, as well as the mourner's anniversary</li> <li>- Ask and warn of friends and relatives' birthdays</li> <li>- Link to local newspapers or radio</li> </ul>
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**Offline support**

<b>Loss-oriented, looking back, the past</b>	<p><b>Accepting the reality of the loss</b></p> <ul style="list-style-type: none"> <li>- The contact with the undertaker</li> <li>- Planning the funeral</li> <li>- Going through the rituals of the funeral ceremonies</li> <li>- Informing others of the loss</li> <li>- Writing a goodbye letter</li> <li>- Reorganising the home, putting spouse’s things away or in a special space</li> <li>- Making a photo album with special memories</li> <li>- LIVIA: all exercises which should be implemented in daily life</li> <li>- Writing down concrete changes in the context (e.g., in the house, in</li> </ul>	<p><b>Processing the pain of the grief:</b></p> <ul style="list-style-type: none"> <li>- Contact with family or other loved ones to share stories about the deceased</li> <li>- Keeping a grief diary</li> <li>- Writing down the story of the loss</li> <li>- Talking to a therapist or grief counselor</li> <li>- Talking to a priest or religious grief counselor</li> <li>- Meditation</li> <li>- LIVIA: all exercises which should be implemented in daily life</li> <li>-Visiting places that are connected with (emotional) memories of the deceased and than allow feelings</li> </ul>
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	<p>the routine, make the loss concrete) and write in a book an episode (a memory) of that space/routine.</p> <ul style="list-style-type: none"> <li>- Collecting the ashes and choosing an urn</li> <li>- Decorating the gravesite</li> <li>- Sending out thank you notes after the funeral( family effort)</li> <li>- Reading all the cards and statements of support left by friends and family (offline)</li> </ul>	<ul style="list-style-type: none"> <li>- Call family/friends to talk about the emotions and thoughts associated to each identified change in the house/routine, before and after the loss.</li> <li>- Do yoga or other exercise</li> <li>- Join a talking group of peers</li> <li>- Visiting peer groups</li> <li>- read a book about grief</li> <li>- contact list of family and friends to call</li> <li>- include maybe a few audios or videos to relax, such as white noise, sounds of nature, breathing exercises or on muscle relaxation</li> <li>- Advising daily readings with positive messages</li> </ul>
<p><b>Restoration-oriented, looking forward, the future</b></p>	<p><b>Adjusting to a world without the deceased</b></p> <ul style="list-style-type: none"> <li>- Finding purpose</li> <li>- Take charge of practical arrangements</li> <li>- See other people on a single basis</li> <li>- Grief journal which helps structure days to slowly build a new routine</li> <li>- Self-care (taking a bath, watching a movie, getting a massage)</li> <li>- Learning to do the spouse’s chores (e.g. repairing)</li> <li>- LIVIA: all exercises which should be implemented in daily life</li> <li>- Identify new routines that bring peace and joy and put marks on the spaces/routines that can trigger/be reminders of those new peaceful moments</li> <li>- re-organising house with a new place for the loved-ones clothing, fav chair etc. Maybe even clearing some stuff.</li> <li>- reading books about grief</li> <li>- Start new activities/hobbies</li> <li>- Redecorate the house</li> <li>- Make a diary of useful contacts for every day life, such as pharmacy, shops, supermarkets, hospital, residence, restaurants, police, firemen, emergency services</li> <li>- calendar to introduce daily tasks</li> <li>- clock to introduce alarms</li> </ul>	<p><b>Finding enduring connection with the deceased whilst embarking on a new life</b></p> <ul style="list-style-type: none"> <li>- Meeting new people and establishing new relationships</li> <li>- Find new activities (walking, yoga, knitting, sports)</li> <li>- Get a new pet</li> <li>- Finding an activity or a new object (decoration / jewellery / ...) which can “honor” the spouse while not being the center of the bereaved person’s lives</li> <li>- LIVIA: all exercises which should be implemented in daily life</li> <li>- Makes changes in the house/routines that incorporate the new spaces/moments for the new life and invite family/friends to show those changes. The mourners would also identify the spaces/objects in which they feel close to their loved ones but would keep it private or would tell only to the closest family/friends.</li> <li>- Celebrating with others the important moments like birthday’s or date of losing loved-one.</li> <li>- Finding a regular time each week/month to stand still about the deceased</li> <li>- Meet new people and establish new relationships</li> </ul>

	<ul style="list-style-type: none"><li>- Excel sheet for writing accounting</li><li>- calculator, cognitive exercises</li><li>- food diary</li><li>- provide a built-in ebook</li></ul>	<ul style="list-style-type: none"><li>- Write down notes, thoughts, emotions or write a letter to the partner</li><li>- Task suggestions, such as "Feel like going to pay him/her a visit at the graveyard?"</li></ul>
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## Appendix B: Focus group end-users report

End users																	
	Portugal					Switzerland						The Netherlands					
Person	1A	1B	1C	1D	1E	2A	2B	2C	2D phone intervi ew	2E phone interview	2F	3A	3B	3C	3D	3 E	3 F
Gender/identific ation <i>m/w/t/o</i>	w	w	w	w	w	M	W	W	W	W	M	W	M	W	M	W	
Age	71y	78y	67y	85y	83y	75	66	73	85	76	74	60	74	76		6 5	
How long ago did you lose your partner? <i>0-6m/6m-1y/1- 2y/2-5y/5- 10y/&gt;10y</i>	>10y	4-10y	5-10y	0-6m	>10y	2-5y	2-5y	>10y	5-10y	Longer (>10y)	5-10y	14 y	3,5 y	14 y	16 y	3 y	
How long were you together with your partner?	>20y	>20y	>20y	>20y	>20y	10-20y	>20y	>20y	>20y	10-20y	>20y						



>2y/2-5y/5-10y/10-20y/>20y																	
Do you have a person in your life whom you trust and can talk to about personal matters?  Yes 1/Yes more/None	Yes	Yes	Yes	Yes	Yes	None	Yes more	Yes, more	Yes, more	Yes, more	Yes, more						
Lost partner  Unexpected/III longer period	III longer period	III longer period	III longer period	III longer period	III longer period	Unexpected	Unexpected	III longer period	III longer period	Unexpected	III longer period						
For how long have you been receiving additional support (if you did) next to support from within your own social network?  0-2m/2-6m/6-12m1-2y/More/No other support	No other support	No other support	No other support	No other support	No other support	More	No other support	No other support	No other support	No other support	No other support						



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Focus Group End users			
Important findings per country	Switzerland	Portugal	Netherlands
Introduction round	<p>The test persons agree that there is a so-called "year of mourning". You have to go through this year of mourning "by yourself" and support from outside can contribute very little.</p> <hr/> <p>2D emphasizes in the beginning that she did not have a grieving phase. She did not have any problems with grieving and being alone. This shapes the entire interview process. We focused on the questions: What things did she do/experience and what could have helped her if she had more problems after the loss?</p> <p>2E emphasizes that everyone copes in their own way and that her way cannot be compared to how others experience it.</p>	End user show interest by project and like to know more about it.	
<p><b>Loss-oriented, looking back</b></p> <p><b>Task 1 – Accept the reality of the loss</b></p>		<i>We ask you to split loss-oriented results of the focusgroup in the 2 different tasks of grief. Please write down what is relevant for</i>	





		<b>task 1. (see attachment 3, tasks of grief)</b>	
<p>What has helped the end-users in this?</p>	<p>The participants agree that the conversations with family and friends have helped them most. One also wrote poems, looked for information about death on the internet and read stories about illnesses similar to their deceased partner's. They have also distracted themselves in other ways, such as through daily activities, physical exercise or work. One of them sought support from the family doctor and was then taken to a psychiatric day clinic, which helped him a lot.</p> <hr/> <p>Phone interviews:</p> <p>2D:</p> <ul style="list-style-type: none"> <li>- preparatory talks with partner in which they could tell each other everything they needed to know or wanted the other to know</li> <li>- Vision before loss and beautiful moment together with partner where she could say goodbye</li> <li>- perceiving death as salvation</li> <li>- belief that there is something after death</li> </ul>	<ul style="list-style-type: none"> <li>-Keep working</li> <li>-Take care of the granddaughters</li> <li>-Help the sons</li> <li>-Go living with my daughter.</li> <li>-I made up myself that life is like this and that my husband would not live much more time with the disease he dad.</li> <li>-The nursing home professionals were who more helped me just after the dead of my spouse.</li> </ul>	<ul style="list-style-type: none"> <li>• 113 online, suicide helpline. Followed the 1 one 1 course with homework. Created a safety plan.</li> <li>• Stayed in contact via whatsapp with family and friends, but preferred face-to-face contact.</li> <li>• Taking walks in nature</li> <li>• Hosting diners with friends and keep talking about my partners</li> <li>• Therapist</li> <li>• Diner with friends</li> <li>• Peer groups</li> </ul>

	<ul style="list-style-type: none"><li>- good talks with woman from church</li><li>- talks with people who have experienced something similar</li></ul> <p>2E:</p> <ul style="list-style-type: none"><li>- her 3 children</li><li>- a lot of friends who listened to her: she needed to talk a lot about it.</li><li>- working in her garden</li><li>- Book about grief</li><li>- singing</li><li>- walking in nature</li><li>- thinking and reflecting</li></ul> <p>2F:</p> <ul style="list-style-type: none"><li>- his children</li><li>- relatives, acquaintances, friends (invitations)</li><li>- being part of a choir</li><li>- support of his daughter in the household for the first few days after the loss</li><li>- responding to condolence cards</li><li>- pastor (private talks)</li></ul>		
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<p>In what way did online support help them in this or could have helped them in this?</p>	<p>Online support was hardly used by the end-users. Only one respondent searched on the internet for information on death/illness and came across a similar story in which she found confirmation and what helped her.</p> <hr/> <p>2D: - Looking up things on the internet; especially philosophical videos, TV shows and texts</p> <p>- In a phase before the loss in which she was especially sad for some reason she had kept an online diary</p> <p>2E: Nothing online could have helped her.</p> <p>2F: Nothing online. But recently he watched a video on YouTube about losing a close one and can imagine that this could have helped him.</p>	<p>-I never had support online.</p>	<ul style="list-style-type: none"> <li>• Whatsapp with family and friends</li> <li>• I didn't use online that much. Looked somethings up, but that was it.</li> <li>• Tried yoga online but didn't like it.</li> <li>• Didn't use online during this period, prefer face-to-face</li> </ul>
<p>When/In what way was offline support more helpful?</p>	<p>Discussions with others were the most helpful. Support from professionals was seen by one</p>	<p>-My main support has always been my family and my children.</p>	<ul style="list-style-type: none"> <li>• Peer group, learned what is means to grief. Nothing is to crazy. Everyone will have doubts and it was really</li> </ul>



	<p>respondent as important and very helpful.</p> <hr/> <p>2D: Talking with others (needs an opposite &amp; eye contact)</p> <p>2E: Visits from friends, they actually “being there” was extremely important. Body contact, hugs etc. Working in the garden was also important.</p> <p>2F: Online is too anonymous, one is still alone and can't discuss things with someone else; he needs personal contacts</p>	<p>-The family doctor followed me in consultations.</p> <p>-When I needed it, the doctor prescribed sleeping pills, painkillers, antidepressants.</p> <p>-Have my sons with me since the beginning was the best help. And to feel they needed me and I could be useful in their lives helped me to go on.</p>	<p>nice to share. We also stayed in contact besides the group</p> <ul style="list-style-type: none"> <li>• Followed a grief course, but this was not helpful.</li> <li>• Support through books and reading. Especially about grieving, gives more insights.</li> <li>• Therapist was essential, crucial.</li> <li>• Didn't experience prolonged grief.</li> <li>• Process before the death of the partner was very important. Good talks with partner and doctors. Also with family, friends and colleagues.</li> <li>• It helped to create the coffin. Created an monument for partner and installed it at the cemetery.</li> <li>• Created a path, towards a life without my partner.</li> <li>• Walked a lot and kept in contact with family and friends.</li> <li>• Read a lot about grief</li> <li>• It was difficult that people stayed away.</li> </ul>
<p><b>Loss-oriented, looking back</b> <b>Task 2 - To work through the pain of grief</b></p>	<p><b>(Here again the same answers)</b></p>	<p><b>And write down what was relevant in task 2</b></p>	



<p>What has helped the end-users in this task?</p>	<p>The participants agree that the conversations with family and friends have helped them most. They also wrote poems, looked for information about death on the internet and read stories about illnesses similar to their deceased partner's. They have also distracted themselves in other ways, such as through daily activities, physical exercise or work. One of them sought support from the family doctor and was then taken to a psychiatric day clinic, which helped him a lot.</p> <hr/> <p>Phone interviews:</p> <p>2D:</p> <ul style="list-style-type: none"> <li>- preparatory talks with partner in which they could tell each other everything they needed to know or wanted the other to know</li> <li>- Vision before loss and beautiful moment together with partner where she could say goodbye</li> <li>- perceiving death as salvation</li> <li>- belief that there is something after death</li> <li>- good talks with woman from church</li> <li>- talks with people who have experienced something similar</li> </ul>	<p>-Be with my daughter and granddaughters.</p>	<ul style="list-style-type: none"> <li>• Keep active through work, diner with friends and family and hobbies.</li> </ul>
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	<p>2E:</p> <ul style="list-style-type: none"><li>- her 3 children</li><li>- a lot of friends who listened to her: she needed to talk a lot about it.</li><li>- working in her garden</li><li>- Book about grief</li><li>- singing</li><li>- walking in nature</li><li>- thinking and reflecting</li></ul> <p>2F:</p> <ul style="list-style-type: none"><li>- his children (talking to them and knowing he is not alone)</li><li>- relatives, acquaintances, friends (invitations)</li><li>- being part of a choir</li><li>- support of his daughter in the household for the first few days after the loss</li><li>- responding to condolence cards</li><li>- pastor (private talks)</li></ul>		
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<p>In what way did online support help them in this or could have helped them in this?</p>	<p>Online support was hardly used by the end-users. Only one respondent searched on the internet for information on death/illness and came across a similar story in which she found confirmation and what helped her.</p> <hr/> <p>2D:</p> <ul style="list-style-type: none"> <li>- Looking up things on the internet; especially philosophical videos, TV shows and texts</li> <li>- In a phase before the loss in which she was especially sad for some reason she had kept an online diary</li> <li>- Looking up hotels she went to in the past with her partner to see how they look now</li> </ul> <p>2E:</p> <p>Nothing online could have helped her.</p> <p>2F:</p> <p>Nothing online. But recently he watched a video on YouTube about losing a close one and can imagine that this could have helped him.</p>	<p>-I never had support online.</p>	<ul style="list-style-type: none"> <li>• Sport, yoga</li> <li>• Meditation (youtube), my sister gave me the tip</li> </ul>
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<p>When/In what way was offline support more helpful?</p>	<p>Discussions with others were the most helpful. Support from professionals was seen by one respondent as important and very helpful.</p> <hr/> <p>2D: Talking with others, because she needs an opposite &amp; eye contact → She is very computer savvy, does a lot online and can spend a lot of time online, but when it comes to grief work she would need offline contact with people</p> <p>2E: Visits from friends, they actually “being there” was extremely important. Body contact, hugs etc. Working in the garden was also important.</p> <p>2F: Online is too anonymous, one is still alone and can’t discuss things with someone else; he needs personal contacts</p>	<p>-To talk with my family doctor about the loss. -To talk with my daughter about accept the loss. -To talk with friends who have experienced the loss of a loved one.</p>	<ul style="list-style-type: none"> <li>• Signed up as volunteer to help people who have lost their partner.</li> <li>• Didn’t have the right age for certain grieving groups.</li> <li>• Started working very quickly</li> <li>• Picked up dancing</li> <li>• Started a meditation class (drawing mandala’s)</li> <li>• Peergroup, talked a lot with other people who lost their partner to cancer.</li> <li>• Work with a lot of older adults and they don’t like online. They prefer house visits or calls. Coming together is very important.</li> <li>• After the funeral I arranged several dinners with family and friends. Talked about my partner and their life together. Wasn’t afraid to mention her name.</li> </ul>
<p><b>Restoration-oriented, looking forward</b></p>		<p><i>We ask you to split the restoration-oriented results of the focusgroup in the 2 different tasks</i></p>	



<b>Task 3 - To adjust to an environment in which the deceased is missing</b>		<b>of grief. Please write down what is relevant for task 3.</b>	
<p>What has helped the end-users in this task?</p>	<p>The participants distracted themselves mainly by talking to family members, friends or even professionals (e.g. GP/psychotherapist) as well as through physical activity, such as doing sports, working or cleaning the house.</p> <hr/> <p>2D:</p> <ul style="list-style-type: none"> <li>- helping others</li> <li>- starting to think for herself instead of asking her partner (in daily life or concerning philosophical questions)</li> <li>- liking to be alone and being good at it</li> <li>- preparatory talks with her partner in which he told her everything she needed to know (e.g. about the bank)</li> <li>- not wanting a new partner</li> <li>- having a nice apartment where she could stay alone (and not a house where she would have to move out, because she couldn't stay there alone)</li> <li>- going on holidays with a friend</li> </ul>	<ul style="list-style-type: none"> <li>-Having to work at the time.</li> <li>-Having to take care of my granddaughters.</li> <li>-Having to help my daughter kept me busy.</li> <li>-Go live with my daughter.</li> <li>-Talk with other people living the same.</li> <li>-I still can't think about the future (she lost her husband 3 months ago).</li> </ul>	<ul style="list-style-type: none"> <li>• Keep working and stay in contact with family and friends</li> <li>• Meditation, dancing and following classes</li> <li>• Keep active and busy</li> </ul>

	<p>2E:</p> <ul style="list-style-type: none"> <li>- Seek out places she's been with him, alone, to reoccupy them so she doesn't always associate those places with him.</li> <li>- Move to another village to get away from her role as "wife of..." and find her new role.</li> <li>- Go back to work in an old job of hers to get her own identity back.</li> <li>- work itself helped her to focus on something</li> <li>- Teaching seminars about grief recovery.</li> <li>- Making a radio show about grief</li> </ul> <p>2F:</p> <ul style="list-style-type: none"> <li>- finding his new role alone in society</li> <li>- becoming more independent (doing the household alone)</li> <li>- Having meals in restaurants where he can be among people</li> <li>- being integrated in his social circle</li> <li>- doing things together with others and talking</li> </ul>		
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	<ul style="list-style-type: none"> <li>- journal/diary</li> <li>- new relationship with a woman</li> </ul>		
<p>In what way did online support help them in this or could have helped them in this?</p>	<p>None of them have sought online support in this regard. However, they see the most potential in getting online information on how to deal with adapting to a world without the deceased. They also see the use of digital means (e.g. email or Skype) to maintain or improve their connection with others, family or friends as a valuable option. The option of an online mourning diary, which helps to structure days in order to slowly build a new routine, was also seen as interesting and possibly helpful. In addition, the respondents could also consider online therapeutic help (but only if they already knew the person personally).</p> <hr/> <p>2D:</p> <ul style="list-style-type: none"> <li>- subscribing to a youtube channel with cooking recipes</li> <li>- subscribing to a youtube channel with gymnastic exercises and doing these regularly</li> <li>- looking things up on the internet</li> </ul>	<p>-I never had support online.</p>	<ul style="list-style-type: none"> <li>• Followed a class Philosophy</li> <li>• Birdclass online</li> <li>• Doesn't imagine how activities can be done online, prefers offline contact and activities.</li> </ul>



	<p>2E: Nothing online could have helped her.</p> <p>2F: Nothing online could have helped him.</p> <p>He thought about doing his journal online, because then he could search for key words, but he wants to be able to take it along with him and doesn't want to carry a heavy computer/laptop with him.</p>		
<p>When/In what way was offline support more helpful?</p>	<p>Distraction/occupation of any kind (e.g. sports, tidying up, working etc.) as well as support by qualified personnel.</p> <hr/> <p>2D: When something is broken in the house or she needs help with her computer.</p> <p>2E: Nothing can replace physical contact and nothing is as important as that.</p> <p>2F:</p>	<p>-I did not need additional support. I faced the situation alone because I had responsibilities and I knew that my husband would not survive, so I prepared myself.</p> <p>-After a period living with my daughter, I went back to my house, and then I had help from my friend to talk and with homemade.</p> <p>- When my spouse dead at hospital, I have asked if I wanted to have psychological support, but at the beginning, the best help for me was the presence of my sons. Then I had a consultation with a psychiatry but then I kept follow up with my family doctor.</p>	<ul style="list-style-type: none"> <li>• Picked up my life very quickly, with dancing classes.</li> <li>• Meditation which was focussed on creating a new life</li> <li>• Seek for new people, talking about their loss. You need to proceed.</li> <li>• Seeking help is really important.</li> <li>• Work was the only thing normal</li> <li>• A lot of people from work helped</li> <li>• Singing group</li> <li>• Lot of dinners with friends</li> <li>• Being active in the garden</li> <li>• Keep going with own activities and hobbies</li> </ul>

	Because he didn't know about any online resources or how they work.		<ul style="list-style-type: none"> <li>Woodcarversclass, keeps me going for hours. Also in the evening when the loneliness is difficult.</li> </ul>
<p><b>Restoration-oriented, looking forward</b></p> <p><b>Task 4 - To find an enduring connection with the deceased while embarking on a new life</b></p>		<b>And write down what is relevant for task 4</b>	
<p>What has helped the end-users in this task?</p>	<p>Conversations with others about the deceased and memorabilia (e.g. photos, letters, objects, etc.) and places.</p> <hr/> <p>2D:</p> <p>- keeping the urn with her partner's ashes on her terrace close to her and with that fulfilling his wish</p> <p>2E:</p> <p>- Reflect on what is the good about what happened (not asking why did this happen to me but what for? Where are the opportunities?)</p> <p>2F:</p>	<p>-My head was busy and I didn't have time to think about anything else.</p> <p>-Since my husband was diagnosed for a chronic disease I was working myself about the loss, to accept the sense of life.</p> <p>-My daughter helped me to accept the loss and understand that if he had continued living longer he would have suffered.</p> <p>-For me, phone contact is a good contact, especially if it is free.</p>	<ul style="list-style-type: none"> <li>Keep working and stay in contact with family and friends</li> <li>Meditation, dancing and following classes</li> <li>Keep active and busy</li> <li>Create a path, a new path for your new life.</li> </ul>

	<p>- faith, religion (believing he is not alone)</p>		
<p>In what way did online support help them in this or could have helped them in this?</p>	<p>A test person might imagine that an online diary could be helpful to write down his or her memories, thoughts and feelings. They could also imagine a digital folder with photos, files, etc. - but the majority of them still belong to the generation that keeps such things in albums, on paper, etc.</p> <hr/> <p>2D: - Looking up hotels she went to in the past with her partner to see how they look now</p> <p>2E: Nothing online could have helped her.</p> <p>2F: Nothing online could have helped him.</p> <p>He does have digital folders for his photos and likes to look for information online sometimes, but</p>	<p>-I never had support online.</p>	<ul style="list-style-type: none"> <li>• Meditation and yoga classes</li> <li>• Starting new hobbies and classes online</li> </ul>

	<p>not related to his loss/grief and that didn't help him with his grief. He wouldn't want to look at photos, because that would increase his grief and it's important to look forward and not back.</p>		
<p>When/In what way was offline support more helpful?</p>	<p>Personal conversations and exchanges with other people who knew the deceased or went through a similar experience.</p> <hr/> <p>2D: - Emphasizes that it is important to be able to be alone. People need to learn that.</p>	<p>-Being busy thinking and helping my family. -To go prepare my thoughts and feelings since I knew the diagnosis of my spouse and the prognosis of it. -To talk to accept the loss.</p>	<ul style="list-style-type: none"> <li>• People are afraid to talk about the partner who past away. The result is that you also don't want to talk about it. Want to keep everything cosy and fun.</li> <li>• Need to do all the administration, but this also gave me a good feeling. That I could do this on my own.</li> </ul>
<p><b>Zooming in on possibilities online services</b></p>			
<p>How would you feel of writing your thoughts down in an online journal?</p>	<p>The group is of mixed opinion: two out of three would not write an online diary. One person thought the idea was good. The others would not use an online diary because they do not write a diary or prefer to write it down by hand in a calendar and find it impersonal online.</p> <hr/> <p>2D: She would like that and has already done that.</p>	<p>-I think it would feel good because the thoughts would go out of my head and I would unload that weight. -I don't know to write, but I think I would like to share thoughts with other widowers. -I don't know to read or write, but I would like to receive training on the use of technology and would accept online support.</p>	<ul style="list-style-type: none"> <li>• Have written a lot, this could also be done online.</li> <li>• Would be nice to receive advice on how to write and structure your thoughts</li> <li>• I would prefer to write down in a psychical journal, because I would also love to draw.</li> </ul>



	<p>2E: She's not good online and with computers and considers it a waste of time. Writing things down is a good things, but by hand, because that's way more intensive and helpful.</p> <p>2F: No, he wants to be able to carry it with him.</p>	<p>-I think I would feel sad to remember some things of the process.</p>	
<p>Would you want to receive online therapeutic help?</p>	<p>Again, mixed opinion: Someone can imagine it well, someone only if they already know the person and someone could not imagine it at all because they find it too abstract and appreciate a face-to-face conversation.</p> <hr/> <p>2D: No, that's not for her, she needs a person opposite her.</p> <p>2E: Nothing for her. She is a person that likes people and likes to see and "feel" them. She even prefers going to a counter and talking to people face-to-face instead of making a phone call. Personal contact is</p>	<p>-I don't know how to use that (technology), but I think having that support would be better than having nothing.</p> <p>-I think that when more time I talk to this, I feel worse and I tend to forget all of this.</p> <p>-I don't know use computers, but with help from my family I would want receive online therapeutic help because I think it would be good to live together and for feel better.</p>	<ul style="list-style-type: none"> <li>• Not online, maybe for a younger generation.</li> <li>• But everything is better than nothing. Especially now in the corona period it's always better than being on your own.</li> <li>• Offline is always preferred, but it's mentioned that online could also be a possibility. It's always better then nothing.</li> <li>• For the company family and friends are needed, but for difficult situations professional help is crucial.</li> </ul>





	<p>extremely important for human beings and that gets lost in the times we are in now. That worries her.</p> <p>2F:</p> <p>Reading things, yes, but not dialogues, then he needs to be able to look into his opposite's eyes. In his grief he wouldn't want video calls, as well.</p> <p>E-Mails he doesn't want, as well, because it takes so long.</p>		
<p>Would you have wanted to talk with other people who experienced the same? Would you have done this online?</p>	<p>The majority of the group would not want to take up this option, but still find it a good one. Online, however, the test persons could hardly imagine it. The majority of them also explained that they already have a good and supportive social environment.</p> <hr/> <p>2D:</p> <p>She has done that offline and has helped others through that, but wouldn't want to do it online. She would be too anxious. For example, she knows people who look for a partner online, but she would be too fearful to do that.</p>	<p>-I like to talk and I usually talk with other people who are widows too. I don't like talk about other people's lives, but I don't mind talking about of mine; it helps me to vent.</p> <p>-Yes, I like live together and talk with other people who experienced the same.</p>	<ul style="list-style-type: none"> <li>• It's really nice to do activities together. It's easy to talk about memories during an activity. Don't know if this will work online.</li> <li>• Peer groups are now online due to COVID. It helps that people already know eachother offline and then continue online.</li> <li>• Mixed feelings about therapeutic help online. Sometimes it works, but not all the time. Personal contact can't be replaced.</li> <li>• It's not possible to build relationships online</li> </ul>



	<p>2E: She has done that in the seminars she taught and in the radio show. But she wouldn't want to do that online.</p> <p>2F: He has talked to other offline, but mostly not about their loss. He wouldn't want to do this online.</p>		
<p>Would you wish to read the stories of other bereaved spouses?</p>	<p>The test persons are divided. Someone has been helped a lot by reading about a similar (disease) story (because she has found confirmation in it), someone cannot imagine it (because every story is different and therefore only individual elements from their story could help themselves), and a respondent seems indecisive.</p> <hr/> <p>2D: Yes, but only if she can help them in some way.</p> <p>2E: Heard in a personal exchange: yes – read: no.</p>	<p>-Yes, in general like to read and I would like to know other people's stories; each one has its problems.</p> <p>-I don't know read, I have vision problems, but I would like to know the stories of the other widowers.</p>	<p>It could help if you can hear about how other people coped with the loss and which activities they did and what has helped them.</p>

	<p>2F: Yes, if he can learn something. But afterwards he needs to be able to talk to them.</p>		
<b>Voting</b>			
<p>Loss-oriented: What were the 3 most helpful online options?</p>	<ul style="list-style-type: none"> <li>• Online information about death, mourning and more (e.g.: course of illness, history of other people who have gone through the same) was chosen as the only option.</li> </ul> <p>There were no other options, as the subjects were very inexperienced with online options.</p> <hr/> <p>2D:</p> <ul style="list-style-type: none"> <li>- Looking up things on the internet; especially philosophical videos, TV shows and texts</li> <li>- In a phase before the loss in which she was especially sad for some reason she had kept an online diary</li> <li>- Looking up hotels she went to in the past with her partner to see how they look now</li> </ul> <p>2E:</p>	<p>-They never had support online.</p>	<ul style="list-style-type: none"> <li>• WhatsApp contact</li> <li>• Meditation / yoga classes</li> <li>• Search for information about grief (books)</li> <li>• Peer group could also be online (especially now during COVID)</li> </ul>



	<p>Everything had the same importance and belonged together.</p> <p>2F: -</p>		
<p>Loss-oriented: What were the 3 most helpful offline options?</p>	<ul style="list-style-type: none"> <li>• Conversations with family and friends.</li> <li>• Distractions/occupation (e.g. through exercise, work, writing, etc.).</li> <li>• Contact with professionals.</li> </ul> <hr/> <p>2D:</p> <ul style="list-style-type: none"> <li>- Vision before loss and beautiful moment together with partner where she could say goodbye</li> <li>- preparatory talks with partner in which they could tell each other everything they needed to know or wanted the other to know</li> <li>- good talks with woman from church</li> </ul> <p>2E:</p> <p>Everything had the same importance and belonged together.</p> <p>2F:</p>	<ul style="list-style-type: none"> <li>-Be with family.</li> <li>-Treatment with family doctor.</li> <li>-Keeping working.</li> </ul>	<ul style="list-style-type: none"> <li>• Peer groups</li> <li>• Reading / books / magazines</li> <li>• Contact with social worker / GP / psychologist</li> <li>• Contact with friends</li> <li>• Determine the new route</li> </ul>



	<p>- His children (talking to them and knowing he is not alone)</p>		
<p>Restoration-oriented: What were the 3 most helpful online options?</p>	<p>The test persons did not use these online options, but could imagine that they would be helpful:</p> <ul style="list-style-type: none"> <li>• Using digital means to keep in touch with others, family or friends.</li> <li>• Online information on how to deal with adapting to a world without the deceased.</li> <li>• Online diary.</li> </ul> <hr/> <p>2D:</p> <ul style="list-style-type: none"> <li>- Looking up hotels she went to in the past with her partner to see how they look now</li> <li>- subscribing to a youtube channel with cooking recipes</li> <li>- subscribing to a youtube channel with gymnastic exercises and doing these regularly</li> </ul> <p>2E:</p> <p>Everything had the same importance and belonged together.</p> <p>2F: -</p>	<p>-They never had support online.</p>	<ul style="list-style-type: none"> <li>• Several online classes</li> </ul>



<p>Restoration-oriented: What were the 3 most helpful offline options?</p>	<ul style="list-style-type: none"> <li>• Conversations with family and friends.</li> <li>• Distractions/occupation (e.g. through exercise, work, writing, etc.).</li> <li>• Contact with professionals.</li> </ul> <hr/> <p>2D:</p> <ul style="list-style-type: none"> <li>- helping others</li> <li>- liking to be alone and being good at it</li> <li>- having a nice apartment where she could stay alone (and not a house where she would have to move out, because she couldn't stay there alone)</li> </ul> <p>2E:</p> <p>Everything had the same importance and belonged together.</p> <p>2F:</p> <ul style="list-style-type: none"> <li>- doing things together with others and talking</li> </ul>	<ul style="list-style-type: none"> <li>-Help family.</li> <li>-Follow-up with family doctor.</li> <li>-Keeping mind distracted.</li> </ul>	<ul style="list-style-type: none"> <li>• Hobbies and activities</li> <li>• Peer groups</li> <li>• New classes</li> <li>• Being outside / walking and gardening</li> </ul>
<p>One online option which was most essential to dealing with their grief</p>	<p>Online information (of any kind).</p> <hr/> <p>2D:</p>		



	<p>- Looking up things on the internet; especially philosophical videos, TV shows and texts</p> <p>2E: -</p> <p>2F: -</p>		
<p>One offline option which was most essential to dealing with their grief</p>	<p>Conversations with family members, friends and professionals.</p> <hr/> <p>2D:</p> <p>- Vision before loss and beautiful moment together with partner where she could say goodbye</p> <p>2E:</p> <p>Everything had the same importance and belonged together.</p> <p>2F:</p> <p>- his children (talking to them and knowing he is not alone)</p>	<p>-The family support.</p>	
<b>Connection with LEAVES</b>			
<p>Would the end-users have used this tool if someone at the time mentioned it to them? If not, why?</p>	<p>The test persons would have used it and taken a look inside out of curiosity. One participant, however,</p>	<p>-If it had been offered to me at that time, I would have accepted the help, because it would keep me distracted.</p>	<ul style="list-style-type: none"> <li>• Yes, together with help and assistance. It needs to click</li> </ul>

	<p>is very sceptical that such a programme could help just by reading (especially in crisis situations it is seen as problematic).</p> <p>2D: She wouldn't have needed it. But for people who need it she sees it positively.</p> <p>2E: She wouldn't. "You can't hug someone online." She would rather attend some spiritual rituals (e.g. burning the clothes of the deceased).</p> <p>2F: Yes, but he would have to know about it. He wouldn't have looked for it, because it is too impersonal. He likes to use the internet for all kinds of things, but is not sure about using it for grief-related things.</p>		<p>with what you need at that point.</p> <ul style="list-style-type: none"> <li>• Contact with therapist can't be replaced by online</li> <li>• little mimic and jokes can only be done face-to-face. A screen can be discomfoting.</li> <li>• Online is not always ideal, but times are changing. Especially now due to COVID. It's always better nothing.</li> <li>• It would be really nice if someone from societal perspective helps you with starting up.</li> </ul>
<p>What do they like about online support / activities?</p>	<ul style="list-style-type: none"> <li>• The possibility to obtain a wide range of information.</li> <li>• The lower inhibition threshold and because it is more anonymous.</li> <li>• The independence of time and place is seen as an advantage. (Although one likes the chance</li> </ul>	<ul style="list-style-type: none"> <li>-Music (because I sing when I am upset because music helps me calm down).</li> <li>-News.</li> <li>-Tips to carry the day.</li> <li>-Chat to talk to and contact other people.</li> </ul>	<ul style="list-style-type: none"> <li>• Online platform where you can find the right information which are scientific based.</li> <li>• Platform with books and articles.</li> <li>• A national platform about grief, where you can meet people or hear about their stories.</li> </ul>




	<p>to leave the house in order to go to the clinic/his psychiatrist)</p> <hr/> <p>2D: - That she can look it up whenever she wants and is ready without having to call somewhere and make an appointment. - She has a lot of possibilities: When she doesn't like one she can try another.</p> <p>2E: For example, when there is a lock down and people can't go anywhere, then it's a support.</p> <p>2F: That he can do it whenever he wants.</p>	<p>-To live together with other people.</p>	
<p>What other benefits are there of having an online tool for grief support? (give examples: sharing my feeling through writing in a journal, having contact with an online assistant, having something to do every day by checking in, etc)</p>	<p>However, one of the test persons seems to have doubts about her self-discipline for using such a programme. (BM: Motivation promotion could still be an important topic for the self-help platform LEAVES).</p> <hr/> <p>2D:</p>	<p>-To having contact with an online assistant. -To having something to do every day by checking in.</p>	<ul style="list-style-type: none"> <li>• Writing in a journal, but doesn't prefers online</li> <li>• Hear about other stories from peers</li> <li>• Learn about new books</li> </ul>

	<p>Sometimes she doesn't want to go out and meet people.</p> <p>2E:</p> <ul style="list-style-type: none"> <li>- To find and contact people who have experienced something similar or a psychologist or someone else who understands them.</li> <li>- People might want to join a gymnastics or singing programme online.</li> </ul> <p>2F:</p> <p>He doesn't need to give answers. When being in grief one does not always want to talk, but can get information so that one is able to talk again afterwards.</p> <p>He can chose what he wants to look at, what interests him.</p> <p>There would be a phone number he can call when he doesn't get something or wants to know more. Or he can tell something about himself that can help others.</p>		
<p>How important is the offline support?</p>	<p>Is perceived by all test persons as very important, helpful and valuable. One person notices that not everyone has this offline support.</p>	<p>-I am afraid of internet contact and of what I hear in the news about theft money or information by internet;</p>	<p>- really important and sometimes more peers or professionals, because you don't want to bother</p>



	<p>2D: Very important. She likes to talk face-to-face, because she needs to see the people's facial expressions to know what they think etc.</p> <p>2E: The most important!!!</p> <p>2F: Very important.</p>	<p>because of this I prefer face-to-face contact.</p> <p>-I don't know use computers and for this reason for me it is better offline support.</p> <p>-Between offline or online support I think I prefer offline support and be lonely to keep my privacy.</p>	<p>people and they know what you're going through.</p>
<b>Closing</b>			
Closing topics / remarks	<p>According to the respondents, it might have been advantageous to ask these questions using a questionnaire - the focus group was felt to be laborious. It might also have been an option to ask non-affected people, because they could bring in other interesting ideas if they were hypothetically involved.</p> <hr/> <p>2E: For her it's important that people do their things (e.g. online gymnastics class or Leaves) at the same time every day even if it's online to have a structure in their days and not sink to deeply into their grief.</p>	<p>-They never had support online.</p> <p>-The main support have been family and family doctor.</p> <p>-It exists low literacy and poor conditions for technologies as a main barriers to use online support.</p> <p>-They show interest to learn and use this application.</p>	<p>- only a flyer about Leaves is not enough. The threshold is high, energy is low and you need a bit of a push.</p> <p>- The threshold is where can I find my help.</p> <p>- A newspaper is also a good media channel</p>



**Alberto**

**Location** rural area  
**Age** 78  
**Occupation** car manufacturing worker (retired)  
**Education** primary school, no further education  
**Family** Widowed (married for 42 years) with 2 sons

**Living situation** Alone  
**Social circle** Neighbors, phone contact with children  
**Digital skills** Avoids technology beyond TV & phone  
**Therapy** psychiatrics visits in the hospital every 6 months. Likes it, but it's too infrequent.

**“ My wife’s death has made my life difficult and since then, I have some issues. I would like to overcome the issues and become fully functional in life again. ”**

**My experience with loss**

- I lost my wife 15 months ago after 33 years of marriage. During the last years of his life, she was very sick and I cared for her. Noone from our family helped us during this time, which was very hard. Since my wife died, I live alone, and my sons visit me rarely.

**My motivation**

- I would like to understand what is happening to me and figure out what to do to feel better.
- I would like to restructure my life and find meaningful activities to fill my days.

**My frustrations & fears**

- I feel abandoned and isolated. I don't want to ask for help, but it would have been nice if more people were interested in how I am doing.
- I have some financial issues - the funeral arrangements were expensive and now I have less income.
- My arthritis is bothering me on a daily basis, and I often have trouble sleeping, but I don't really know how to change that. I don't really like my GP, but at least he forwarded me to a nice psychiatrist for the sleeping issue.
- I am not a talker, so I don't want to talk to everyone about my feelings. I have learned to trust and talk to my psychiatrist - this helps, but every six months is not enough to make me feel better.

**My hopes**

- I would like to have more contact with my sons and to spend time with them and their families.
- I started seeing a psychiatrist 4 months ago, and my next appointment is in 2 months. After two meetings, I have a good feeling and I hope that he can help me in the long term to feel better and to function well.

**What may convince me**


- A service that is easy to use and where I can receive help for how to use it.
- I would like to regularly receive advice from my family and medical professionals on how to deal with difficult things in my life.
- Someone who can help me to achieve my daily tasks better, incl. practical advice and help for my physical issues.

**State of mind (AESEO)**

• Attitude:	negative	●	positive
• Expectation:	negative	●	positive
• Schedule:	packed	●	empty
• Environment:	stressful	●	relaxing
• Origin:	others	●	self

## Appendix C: Defined Persona's

Through the means of the creative and interactive workshops, the consortium members who conducted the interviews shared their experiences and pinpointed the most important aspects of the interviews that were relevant for the personas and the service model. Through storytelling and iteration methods we were able to refine and validate 4 personas that will serve as a basis to further map the matching service model.



**Joanna**

**Location** Medium-sized town (150.000)  
**Age** 75  
**Occupation** Elementary school teacher (retired)  
**Education** university degree (teaching)  
**Family** Widowed (married 45 years), 2 daughters and 1 son, 2 sisters

**Living situation** Alone  
**Social circle** Part of community in her town, especially 55+ club and senior gymnastics club  
**Digital skills** Comfortable: once the technology has been set up.  
**Therapy** none, "good but I don't think I need it"

**“ I pride myself on being strong, with a good social network. I have a tendency to ignore difficult situations and concentrate on other things instead. Losing my husband is harder to ignore, though... ”**

**My experience with loss**

- I lost my husband of 45 years eight months ago to cancer. We were always quite active together so it was hard to see him go through this (luckily short) battle and lose in the end. Since then, I have tried to embark on a new life, but I still miss having him as my "partner in crime".

**My motivation**

- I would like to talk to other people with similar experiences.
- Seeing that my actions have an impact and help others makes me happy. If I can help others by sharing my experience, I would be happy to do that. (I also have a hard time motivating myself for things that are just for myself.)

**My frustrations & fears**

- I have always been the "positive" person in my group of friends. I feel like my friends don't want to talk about my loss, and I lost contact to some people because of my husband's illness and death.
- I am proud to be independent, but this was easier when I had husband to talk to about things that were going on in my life. Now I feel like I would be a burden to others if I brought up that I am still sad sometimes.
- Everyone (including me sometimes) thinks I am fine because I am so active, but sometimes I get very sad and lonely, especially when I am at home alone at night.

**My hopes**

- Finding and talking to people who understand what I am going through, I think that would help me.
- I have a tendency not to talk about negative feelings because I don't want to be seen as weak. I hope to find a space outside my normal social circle where I can be open without fear of being judged.

**What may convince me**

- Being able to process my grief through social interaction with others in a similar situation.
- It is easier for me to consider help more when it is presented indirectly and from a reputable source, for example a report or advertisement in a newspaper, or official information from an organisation for the elderly.
- I am a curious person and like to read about life and death, grief etc. - an offer that includes in-depth information about these topics is interesting for me.

**State of mind (AESEO)**

• Attitude:	negative	●	positive
• Expectation:	negative	●	positive
• Schedule:	busy	●	empty
• Environment:	stressful	●	relaxing
• Origin:	others	●	self



**Monica**

**Location** Small town (40.000)  
**Age** 67  
**Occupation** part-time secretary (retired for 10 years)  
**Education** Secondary school + secretary education  
**Family** Widowed (married for 38 years), no children, 1 brother  
**Living situation** Alone  
**Social circle** "couple friends", little contact now  
**Digital skills** basic skills can use a smartphone for messaging, calls, Google, Youtube  
**Therapy** None, sceptical about whether this helps

“ I miss my husband so much. I cannot accept that life has to go on without him/her. I feel very lonely and lost.

**My experience with loss**

- I lost my husband, who was my rock, six months ago. It was all very sudden because he had a heart attack. Since then, my life feels so empty. I miss having a person that I can talk to about everything, and someone who I can share my life with. I have some loose contact with my brother who lives in a different town, but we don't talk about anything deep.

**My motivation**

- I would like to find purpose again and re-discover who I am as a person. My husband was the one who took care of things in our relationship, so my life was centered around him. I need to find a new passion, something to give my life meaning.
- I would like to have a bigger social network and be more active.

**My frustrations & fears**

- I sometimes feel like I don't know anything anymore: Where do I belong? Where do I go from here?
- All of our old friends are couples, and they haven't lost a partner yet. So when we meet up (which is rare), I feel like a third wheel. I don't know if I should look for other friends, but then I also don't know where to start with that.
- I cannot stand the cliché advice some people give me – "Move on", "Go on a nice trip", "Look for a new partner" etc. They don't know what I am going through.
- When I'm alone at home or going for a walk, I often feel extremely lonely.

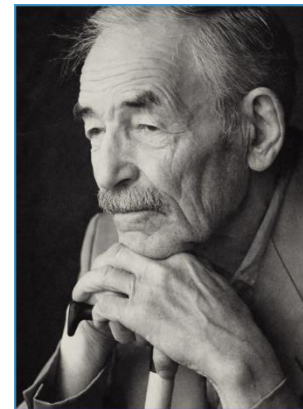
**My hopes**

- I hope that finding something interesting to do will help me feel less empty and make my life more meaningful.
- It would be so nice to meet people who understand what I have been going through.

**What may convince me**

- Reading about or receiving a recommendation from others who had the same problem and found a way to feel better.
- A personal safe space where I can try out new things without awkward social situations.
- A GP who references me to help. Finding one person who I can trust and open up to.

**State of mind (AESEO)**



**Peter**

**Location** small town (40.000)  
**Age** 80  
**Occupation** salesman (retired)  
**Education** primary and secondary school (10th grade)  
**Family** Widowed (married 55 years), 3 sons and 1 daughter, no living siblings  
**Living situation** Alone  
**Social circle** neighbors, nursing home residents  
**Digital skills** Mostly smartphone for staying in touch with kids and their families (Whatsapp)  
**Therapy** none, is not familiar but not against it

“ I have been sad since my wife passed away but it wasn't unexpected. Now, I struggle with a way to stay connected with her and remember her in a positive way, but this is important to me.

**My experience with loss**

- My wife developed dementia a few years ago. She died one year ago. I am still sad, but it was also hard in the end because she was a different person. Now, I still visit the nursing home where she lived during the last year because I built contacts there and it reminds me of the time we had together.

**My motivation**

- I want to find a way to be less lonely and find a positive way to deal with my wife's death without being a burden to others. I love my children and we have a great relationship, but I want them to be able to live their lives.
- I would like to find something that gives me stability - going to the nursing home of my wife is nice, but one of my friends there has also died recently.

**My frustrations & fears**

- We had been living in the same apartment for a long time but it was too expensive for me alone, so I had to move to a smaller apartment. This was a lot of work (my children helped me), and I don't feel at home in this new place. It also makes it a little harder to remember my wife.
- My hip and my legs are bothering me. Sometimes I can't sleep because it is uncomfortable or painful.
- Other people have already forgotten about my wife when she moved to the nursing home. This makes me angry because I feel like people just want me to move on.

**My hopes**

- I would like to have contact about things other than grief, but with people who have experienced the same thing. Talking to other men, for example about sports.
- That I can stay relatively independent during the last years of my life. My children are still working, so I don't want them to worry about me, and I don't want to go to a nursing home.

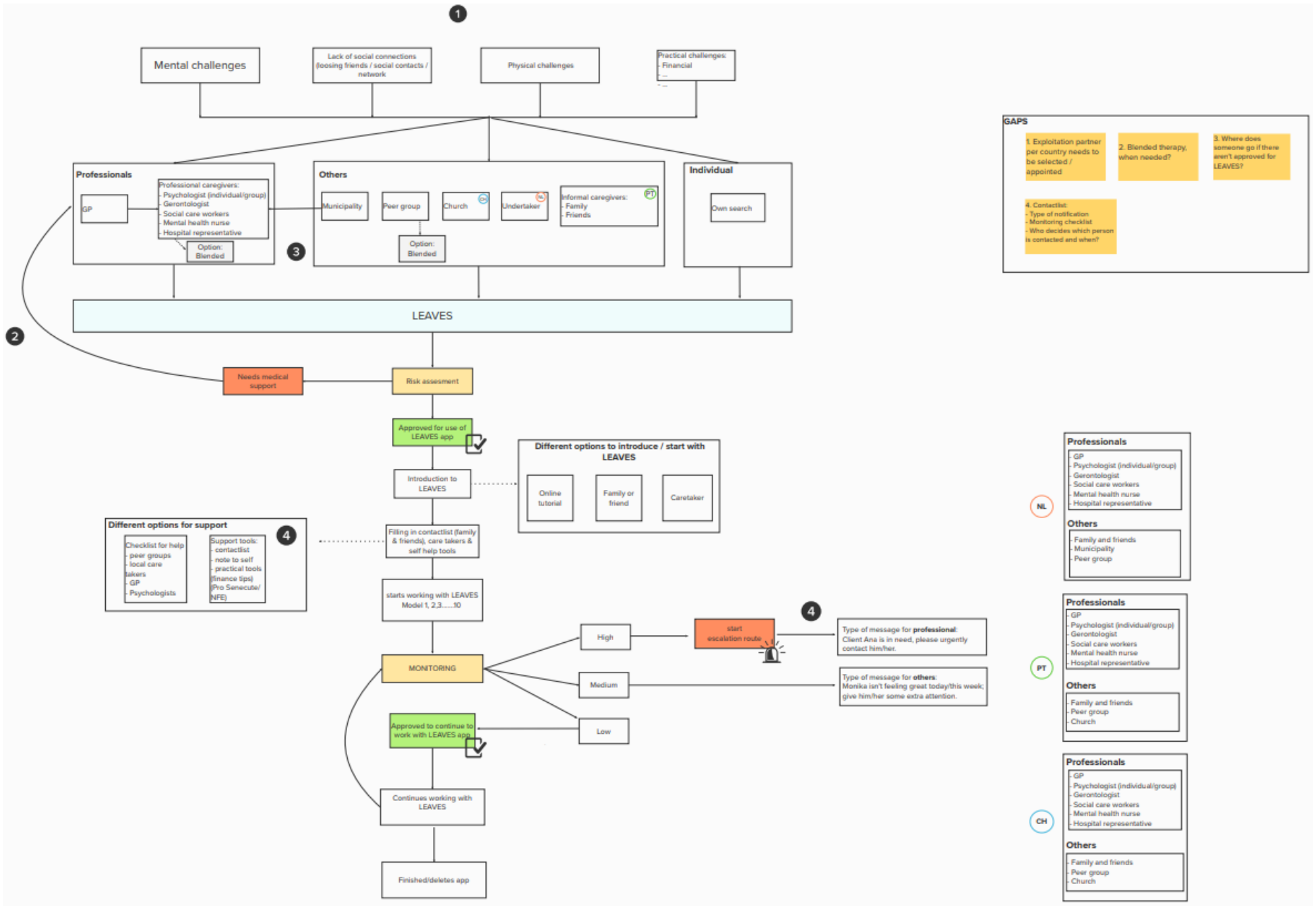
**What may convince me**

- An offer that takes my belief into consideration (I am catholic). The offer could also come directly from the church.
- A safe space where I can be open about my feelings without consuming too much time from others.
- Something that helps me keep a diary and memories of my wife. Something that I can keep for myself and share with my family as a positive way to remember her.

**State of mind (AESEO)**



## Appendix D: Service Model – V01



# Appendix E. Survey results (validation of the service model)

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# 1. Participants

## 1.1. Demographics

This survey mainly targeted stakeholders to test the service model of LEAVES. Stakeholders from all three countries participated; 50 from the Netherlands, 40 from Portugal and 34 from Switzerland. Not all stakeholders finished the survey, and some stakeholders were excluded, because they don't work with clients that deal with grief (in)directly. In total, results of 84 stakeholders were included in this research report; 39 from the Netherlands, 23 from Switzerland and 22 from Portugal.

The service model was partly tested amongst end users during an usability test. To get their opinion about the structure of the service model, some end users were included in this survey as well; 27 from the Netherlands and 14 Portugal. Some stakeholders were excluded, because they haven't lost their partner. In the end, 15 stakeholders completed the survey; 11 from the Netherlands and 4 from Portugal.

This sums up to 99 participants in total.

## 1.2. End users

From all end users, 60% was female and 40% was male. The average age was 75. The youngest participant was 56 years old, the oldest one was 90 years old. Table 1 shows how long ago the end users lost their partner.

Partner lost	Percentage
Less than 1 year ago	6.7%
0 – 1 years ago	20%
1 – 3 years ago	13.3%
3 – 5 years ago	13.3%
5 – 10 years ago	13.3%
More than 10 years ago	33.3%

*Table 1. Time since the loss of the partner.*

## 1.3. Stakeholders

77.4% of all stakeholders was female and 22.6% was male. The average age was 54 years old, the youngest being 27 years old and the oldest 73 years old.

Table 2 shows the various professions of the stakeholders. 86.9% of the stakeholders work with clients that deal with (prolonged) grief directly, and 13.1% indirectly. On average, stakeholders see 6.9 clients that deal with (prolonged) grief per month. This amount differs a lot however; the lowest amount was 1, the highest 80.

A minority of stakeholders uses e-Health during their daily work. This also differs per country: 27% of stakeholders in Portugal uses e-Health, 15% in the Netherlands and 11% in Switzerland. This could, however, also be explained by the division of professions, since the stakeholders of Portugal were mainly psychiatrists and psychologists, who might use e-Health on a more regular basis than church counselors, for example.



Profession	Netherlands	Switzerland	Portugal	Total
Spiritual counselor	14			14
Nurse/health specialist	1	6	6	13
Physiatrist	3		7	10
Psychologist	1	5	3	9
Social worker	7	2		9
Employee/volunteer at a church	3	5		8
Grief counselor/volunteer	3	2		5
General Practitioner/Doctor			5	5
Employee/volunteer at a municipality	2			2
General Practice-based nurse (Praktijkondersteuner) (Only NL)	2			2
Specialist in everyday design and activation		2		2
Volunteer at a non profit	2			2
Technical assistant			1	1
Professional caregiver counselor	1			1
Psycho-social consultant		1		1

Table 2. Professions of the stakeholders.

The clients of the stakeholders are often looking for someone to talk to, or professional help. Figure 1 shows the differences per country. In the Netherlands and Switzerland, ‘someone to talk to’ is the most frequent help question. In Portugal, professional help is most searched for.

The most asked help question also differs per profession (Figure 2). Not surprisingly, professional help is most often asked for to psychologists and psychiatrists. However, it is notable that doctors and health specialists mention that most clients look for someone to talk to, and not professional help.

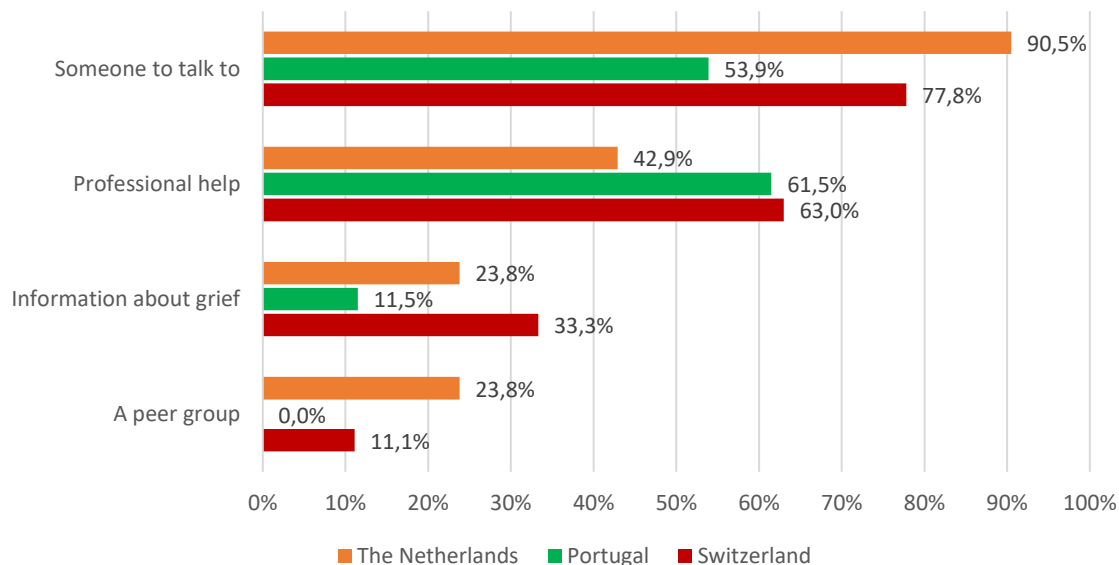


Figure 1. Help question per country.

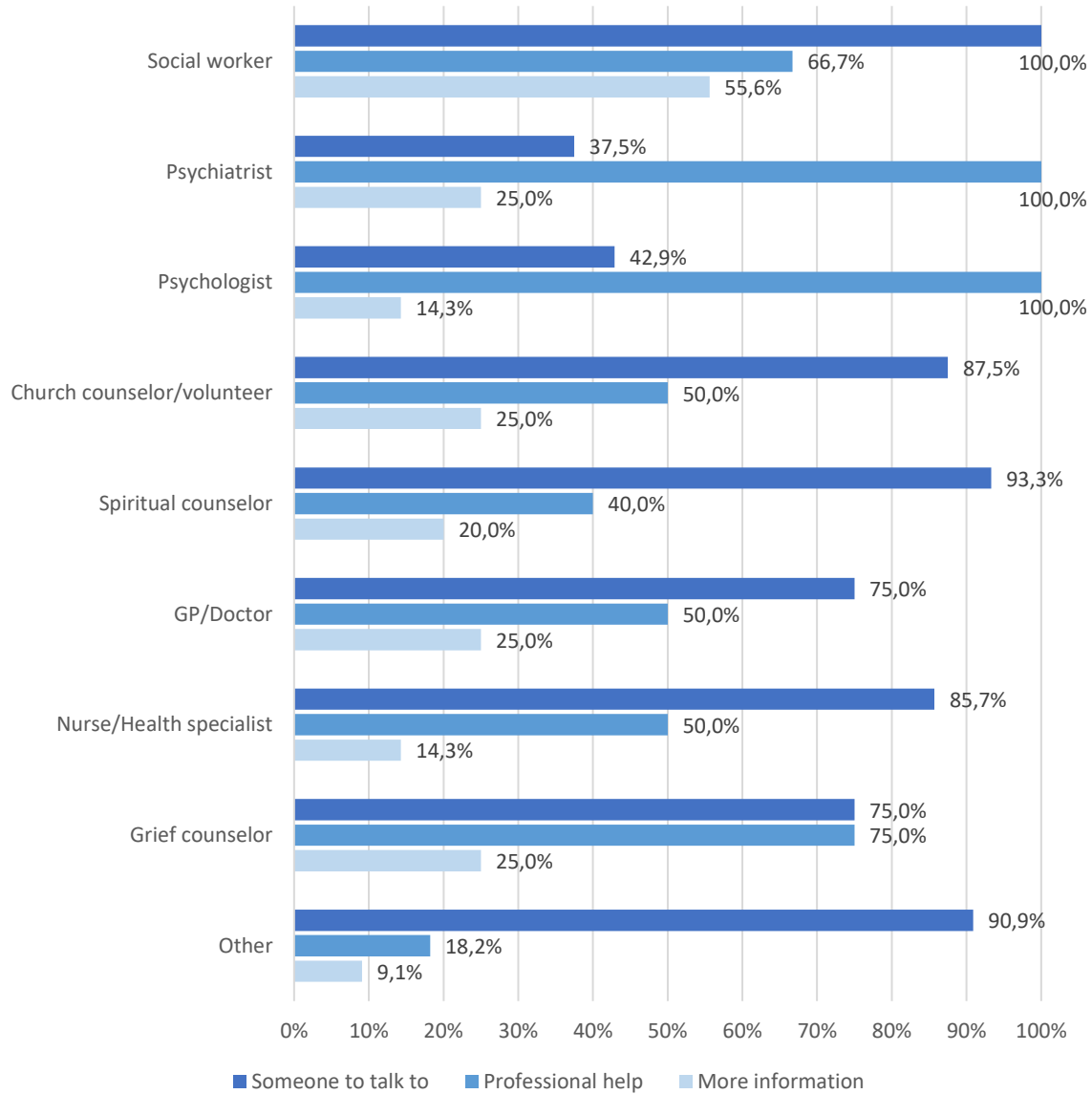


Figure 2. Help question per profession.

## 2. Register to LEAVES

### 2.1. Introduction

Once the demographics and background questions were asked, the survey walked through the service model, using visuals of the online program of LEAVES.

The first step is that the older adult registers themselves to LEAVES. The survey showed a visual about this process and participants were explained that the older adult is asked for their name, the name of their deceased partner, and an email address.

### 2.2. Results

After the instruction above, the stakeholders were asked whether they think that their clients are able to fill in this information by themselves (e.g. whether their clients have enough digital skills). It is notable that Dutch stakeholders more often estimate that their clients are able to register themselves without help, than Portuguese and Swiss stakeholders (Figure 3).

Remarkably, the older adults think higher of their digital skills than the stakeholders: 91.7% of Dutch older adults, and 75% of Portuguese older adults think that they will be able to register to LEAVES by themselves. Furthermore, 73.3% of end users would prefer to walk through the registering process by themselves.

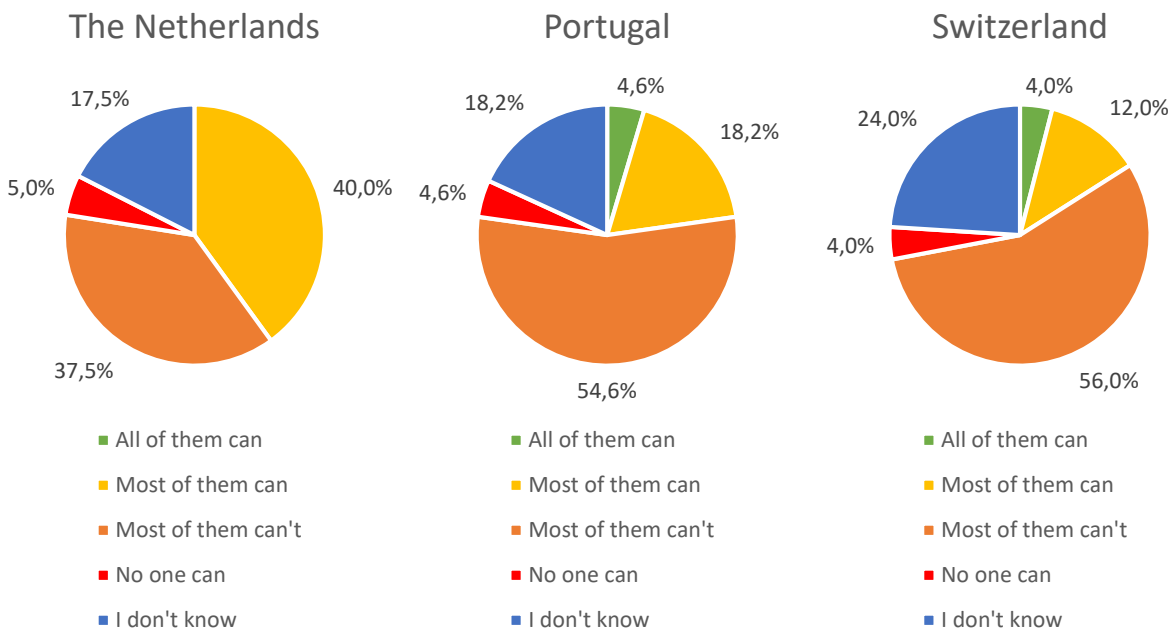


Figure 3. Estimation of clients that can register themselves without help.

According to stakeholders in all countries, family members and friends would be most sufficient to help the older adult when they are not able to register by themselves (Figure 4). In Portugal, they specifically mention caregivers. Also nurses/health specialists, church employees/volunteers and social workers are considered to be able to help older adults.

In ‘other’, the most mentioned comment is that it doesn’t matter what the capacity of the person is, as long as it is someone the older adult trusts. In the Netherlands, also ‘volunteers’ are considered an option.

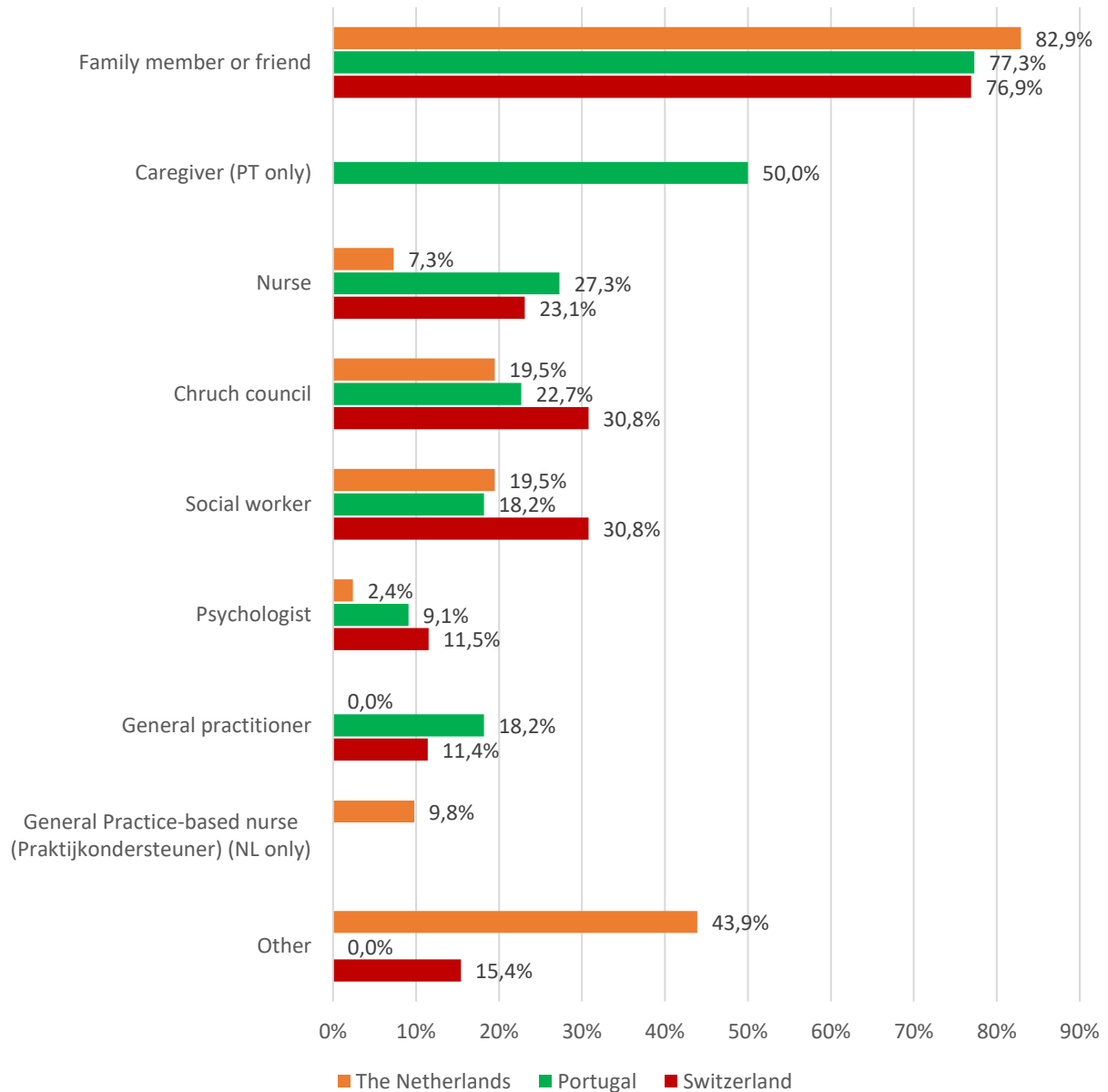


Figure 4. Person who would be most sufficient to help the older adult.

### 3. Risk assessment

#### 3.1. Introduction

Part of the registering process, is the risk assessment. This assessments consists of a couple of questions to estimate whether an older adult could benefit from LEAVES, or whether they might need other/more/professional help. The survey explained that an older adult will get a notification that either the program could be useful, or that it is advised to search for more help. This explanation was supported by a visual of the notifications.

#### 3.2. Results

In all countries, the majority of stakeholders believe that the risk assessment is very/somewhat important to an online program as LEAVES. Especially in Portugal and the Netherlands

The older adults scored somewhere in between; 41.7% believes that the risk assessment is important for an online program as LEAVES.

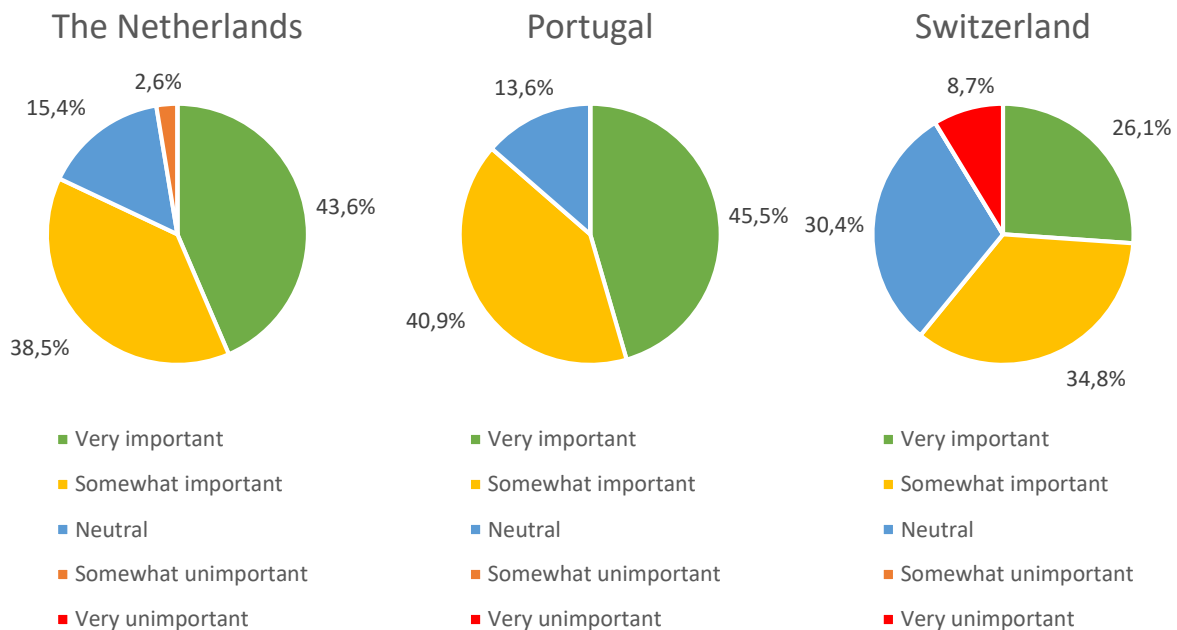


Figure 5. The importance of the risk assessment according to stakeholders.

## 4. ‘My Support’-page

### 4.1. Introduction

Next in the survey, participants could read that users of LEAVES are asked to fill in a ‘My Support’- page. On this page, users can save numbers of contact persons, write down activities they like to do when they experience difficult moments, etc.

### 4.2. Filling in the ‘My Support’-page

Only 1 of the older adults is familiar with setting up a coping strategy. All the others were somewhat- or totally unfamiliar. Older adults were also quite neutral about the importance of a ‘My Support’-page for an online program like LEAVES.

The stakeholders from the Netherlands and Portugal also believe that not a lot of their clients are familiar with setting up a coping strategy. In Switzerland however, stakeholders reckon that more than half of their clients are very- or somewhat familiar with setting up a coping strategy (Figure 6). This image could be slightly skewed, since approximately half of the Swiss stakeholders worked in the healthcare industry and might use coping strategies more often with their clients than other professions. However, this is also the case in Portugal, and their results are quite neutral.

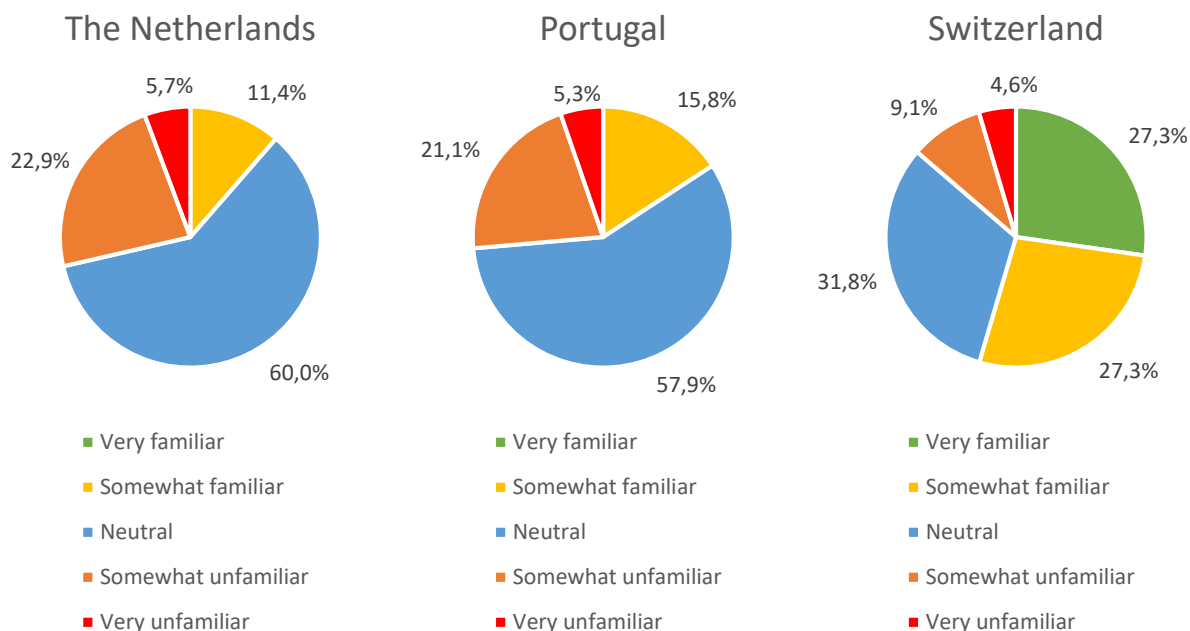


Figure 6. Estimation of clients that are familiar with a coping strategy.

Figure 7 shows the variation between professions in how important the 'My Support'-page is according to stakeholders. Results show that GPs/doctors, psychiatrists, psychologists, social workers and church counselors most often think that the 'My Support'-page is important to LEAVES.

Besides that, stakeholders in Portugal more often think that the 'My Support'-page is important; 89.5% answered with 'somewhat important' or 'very important'. (Versus 64.7% in the Netherlands and 63.6% in Switzerland). It should be kept in mind, however, that Portugal's stakeholders mainly consisted of psychiatrists and psychologists, what might influence these numbers.

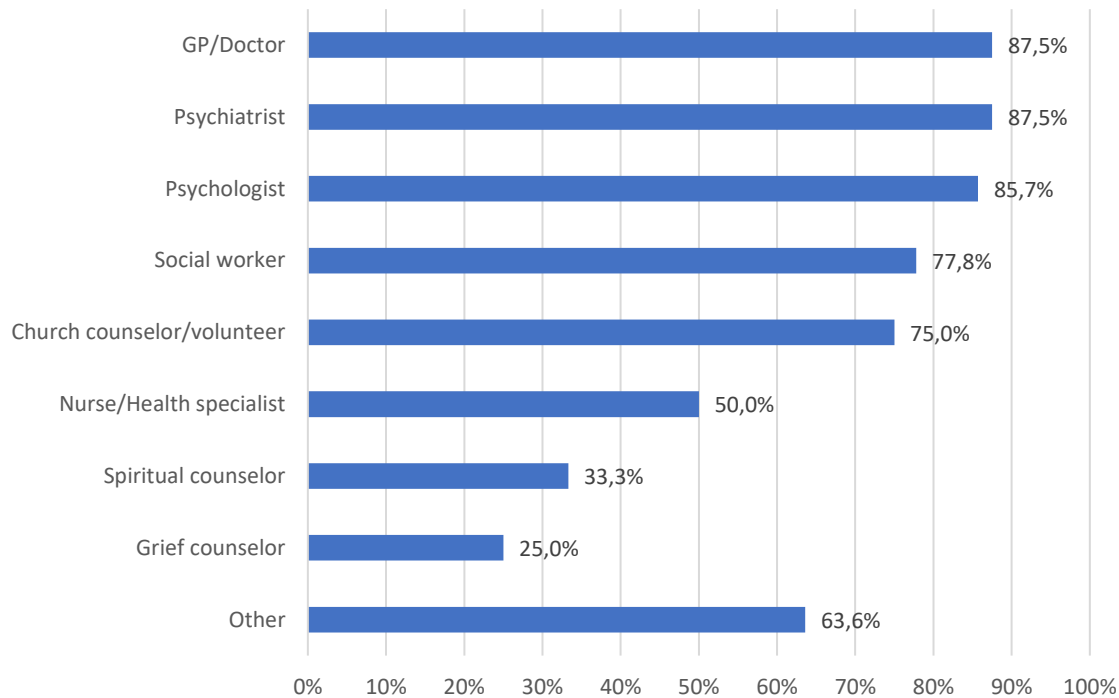


Figure 7. Importance of 'My Support' (somewhat- or very important) by profession.

Stakeholders from all three countries think that friends or family members would be suitable contact persons in the 'My Support'-page (Figure 8). In Portugal, psychologists/psychiatrists and peers are more frequently mentioned than in other countries. In Switzerland and the Netherlands, church counselors are more often seen as suitable contact persons. It should be noted that in the Netherlands, a lot of the participants were church counselors however. In 'other', Dutch stakeholders also name volunteers as potential contact persons.

The older adults consider family or friends (66.7%), psychologists (25%), peers (16.6%) and GPs (8.3%) as most suitable contact persons in the 'My Support'-page.

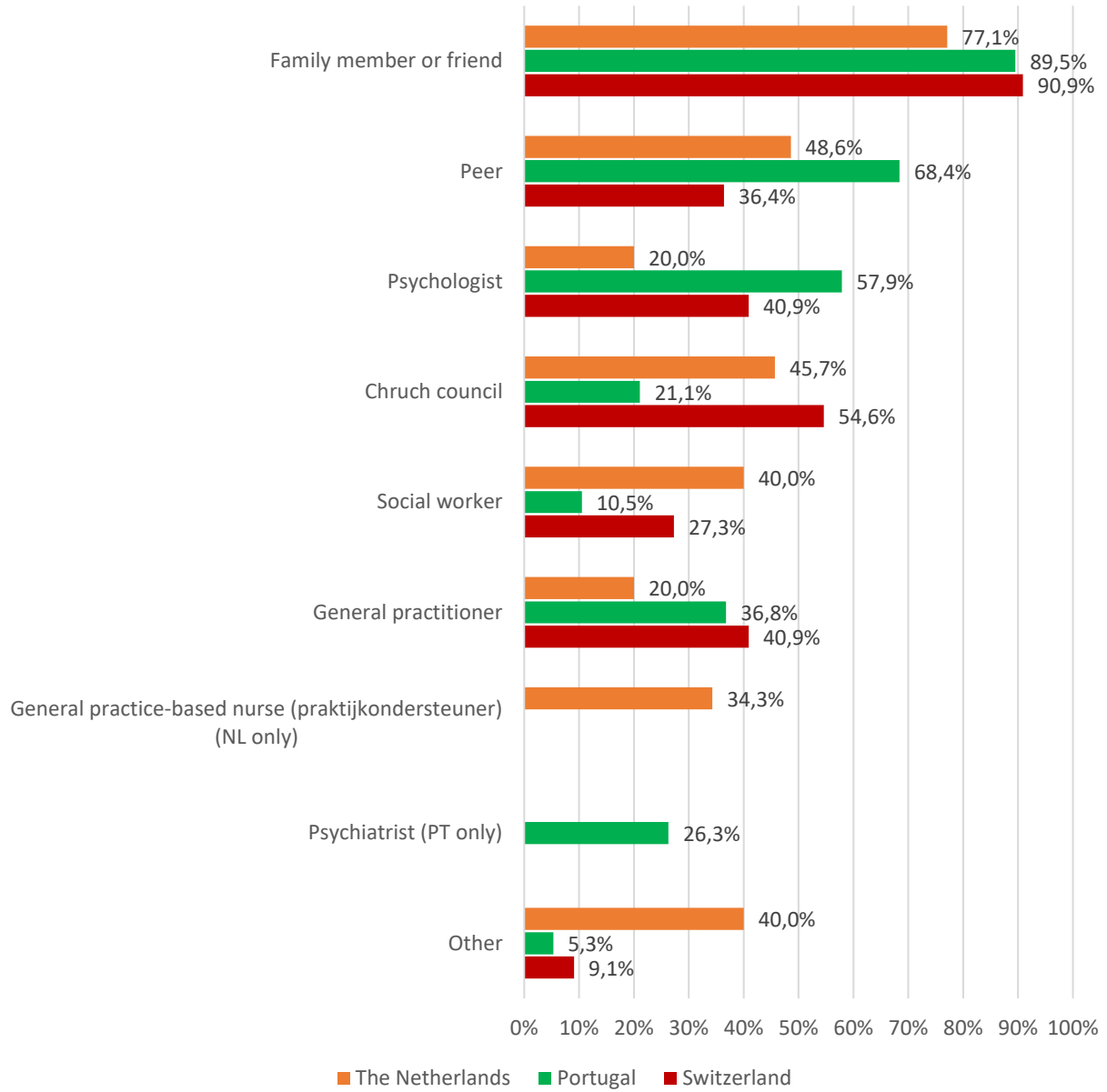


Figure 8. Suitable contact persons according to stakeholders.



### 4.3. Helping with the usage of LEAVES

Stakeholders were asked whether they would be able to help older adults with the usage of LEAVES if necessary (Figure 9). Mainly church counselors and psychologists think they would be able to. Psychiatrists and nurses/health specialists most often think they won't be able to help the older adult with the usage of LEAVES. When stakeholders indicate that they won't be able to help an older adult, it is mainly because of the lack of time (Figure 10). This is the most frequently mentioned reason of almost all professions, except for nurses/health specialists. They indicate that they need more information when someone calls.

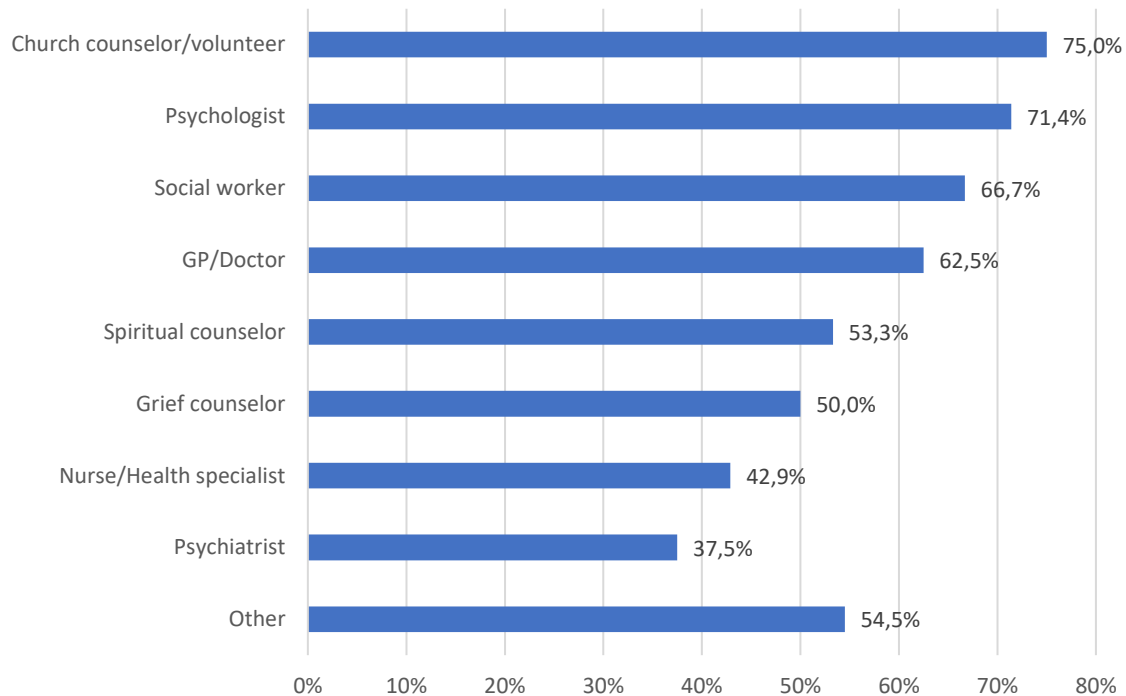


Figure 9. “Would you be able to help an older adult using the online tool of LEAVES?”, answered with ‘yes’.

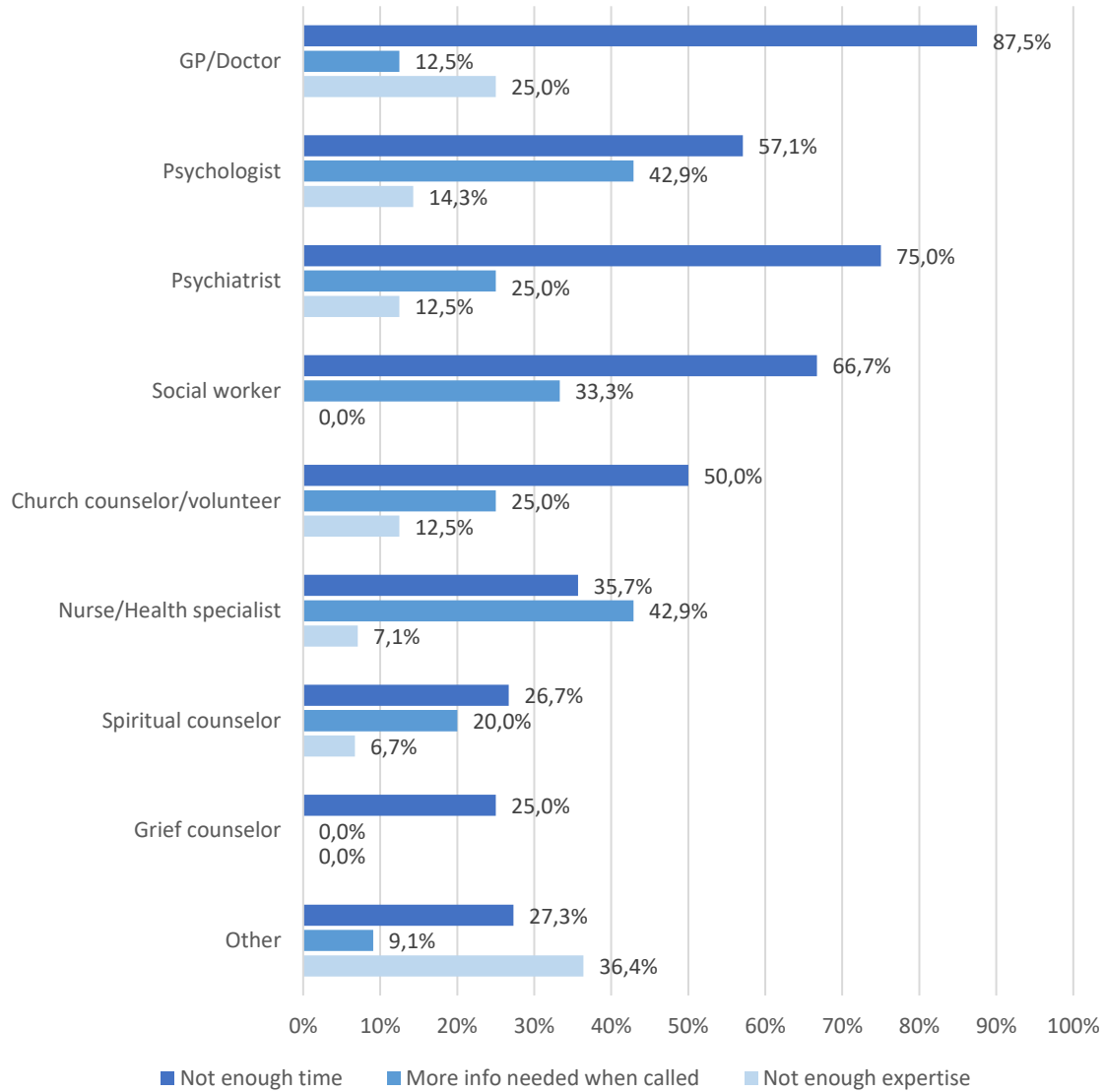


Figure 10. Challenging aspects about helping clients using LEAVES.

## 5. Content of LEAVES

### 5.1. Introduction

When an user of LEAVES finishes the registering process, they are able to use the content of LEAVES. Participants of the survey were shown which topics are addressed in LEAVES and that users are able to work through the content at their own time and pace, in an empathic and caring environment.

### 5.2. Results

Participants were asked whether they believe that the topics addressed in LEAVES are important for someone who is dealing with grief.

From all stakeholders, mainly GPs/Doctors, psychologists, psychiatrists and social workers somewhat/totally agreed with this (Figure 11). Spiritual counselors least agreed that the topics in LEAVES could be helpful for older adults that are dealing with (prolonged) grief.

Besides the stakeholders, 50% of the end users think the topics of LEAVES could be helpful, and 40% thinks neutral about this question.

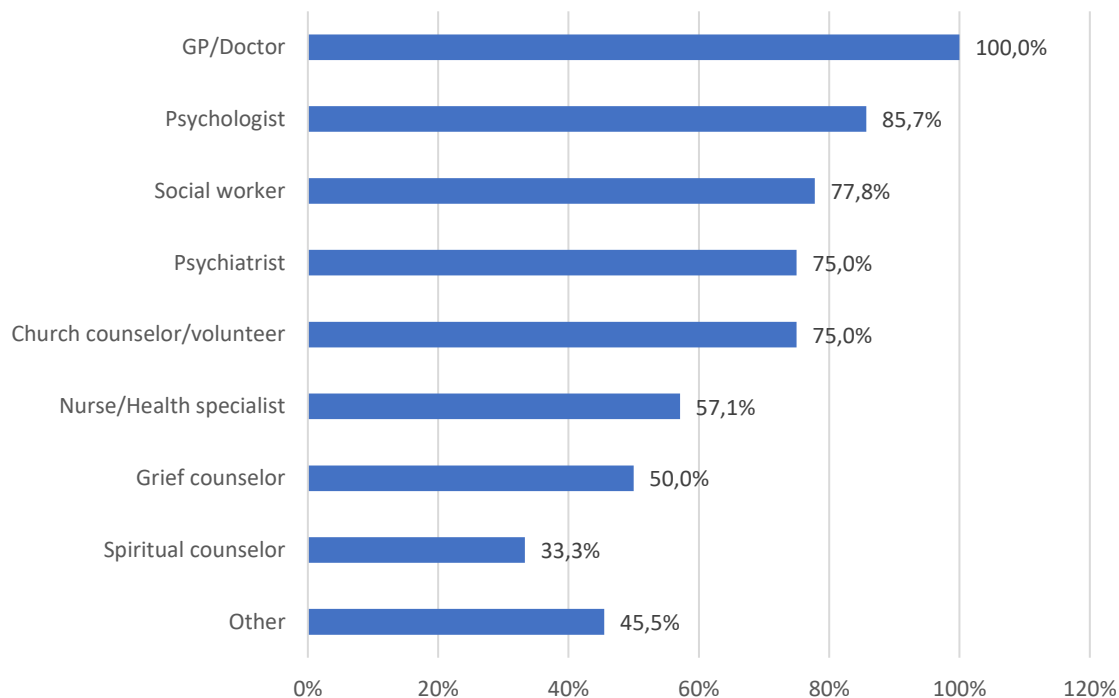


Figure 11. “Could the topics be helpful for an older adult that is dealing whit (prolonged) grief?”, answered with somewhat- and very important.

Mainly stakeholders in Portugal think that LEAVES could be combined with face-to-face therapy (Figure 12). This result could also be explained by the division of professions. 85.75% of psychologists (totally) agrees and 62.5% of psychiatrists.

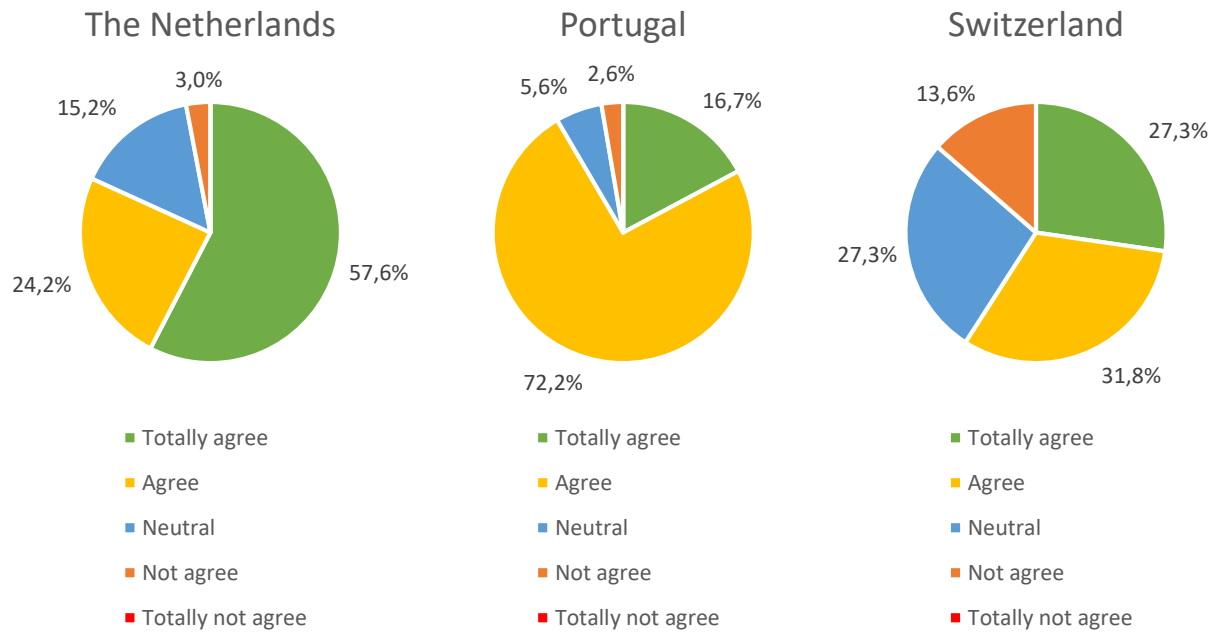


Figure 12. Extend to what LEAVES could be combined with face-to-face therapy.

## 6. Monitoring process

### 6.1. Introduction

The last important part of LEAVES is the monitoring process. During the usage of LEAVES, the older adult will be asked to fill in a monitoring questionnaire to check how (s)he is doing. If it turns out the older adult is not doing well, (s)he will be advised to call someone from their 'My Support'- page and will also see some national helplines they can call. This explanation was guided by a visual of the questionnaire.

### 6.2. Results

End users are a little doubtful whether they would trust an online program as LEAVES to estimate someone's wellbeing; 25% agrees and 50% is neutral. Moreover, they believe that the monitoring part is not that important; 37.5% says monitoring is a little of very important. End users feel like older adults that have difficulties with dealing with their emotions of grief, and older adults that feel lonely, would mostly benefit from LEAVES.

Stakeholders are also not completely sure whether they trust an online program as LEAVES to estimate someone's wellbeing, mostly in the Netherlands (Figure 13). However, stakeholders do believe that monitoring is important in an online program as LEAVES.

Mainly in the Netherlands stakeholders feel comfortable with LEAVES referring to them as a professional. This could also be explained by the fact that most stakeholders in the Netherlands were spiritual counselors and they didn't feel they won't have enough time to help as often as other professions had.

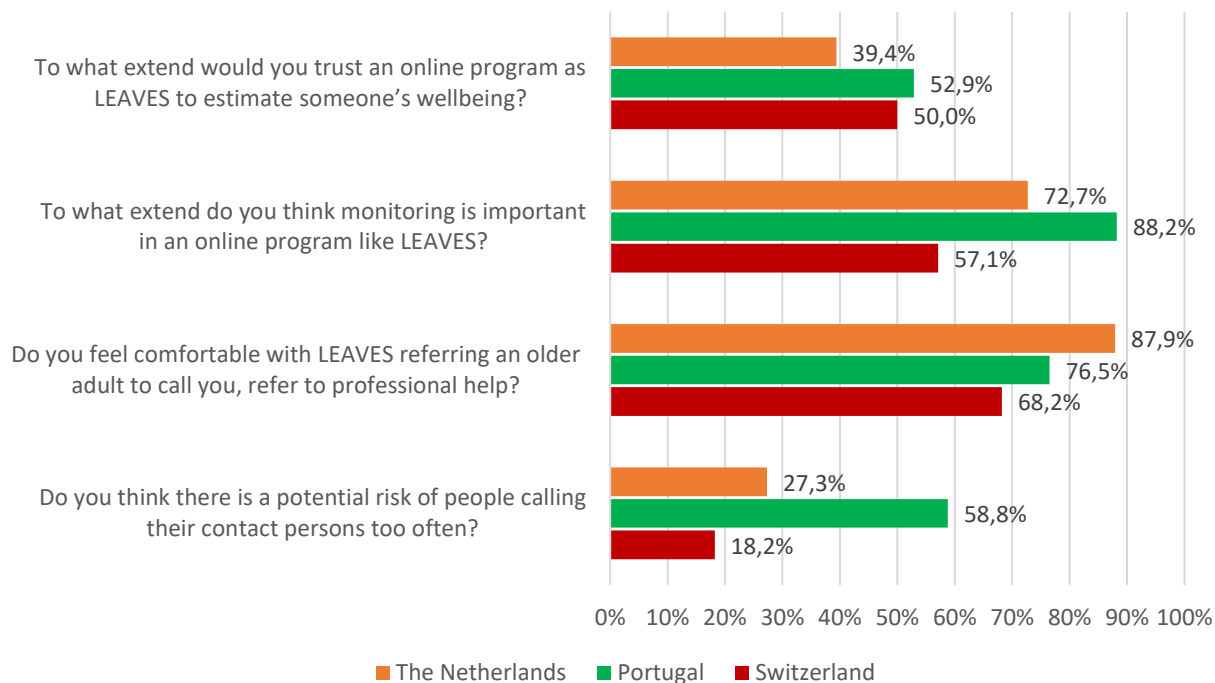


Figure 13. Questions of the monitoring part per country, answered by stakeholders with 'a little' or 'a lot'.

## 7. Intention to use

### 7.1. Introduction

After the walk through the service model was finished, the survey ended with several questions that give an indication about the intention to use LEAVES.

### 7.2. Usefulness of LEAVES

50% of end users believe that LEAVES is a useful tool (25% is neutral). Besides that, 37.5% expects LEAVES to be easy to use (37.5% is neutral). The answers to the question whether they intend to use LEAVES, were somewhat similar: some will, some won't and some are neutral (Figure 14).

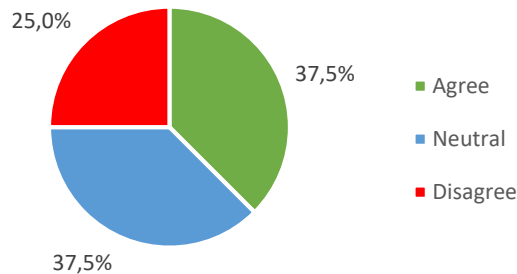


Figure 14. "Assuming I have access to LEAVES, I intend to use it", according to older adults.

Stakeholders were even more positive, around 65% (Figure 15). Expect in Switzerland; less than half of the Swiss stakeholders are of the opinion that LEAVES is a useful tool for older adults that deal with (prolonged) grief.

Stakeholders seem a little unsure about whether LEAVES would be easy to use and whether they would use it if they had access to it.

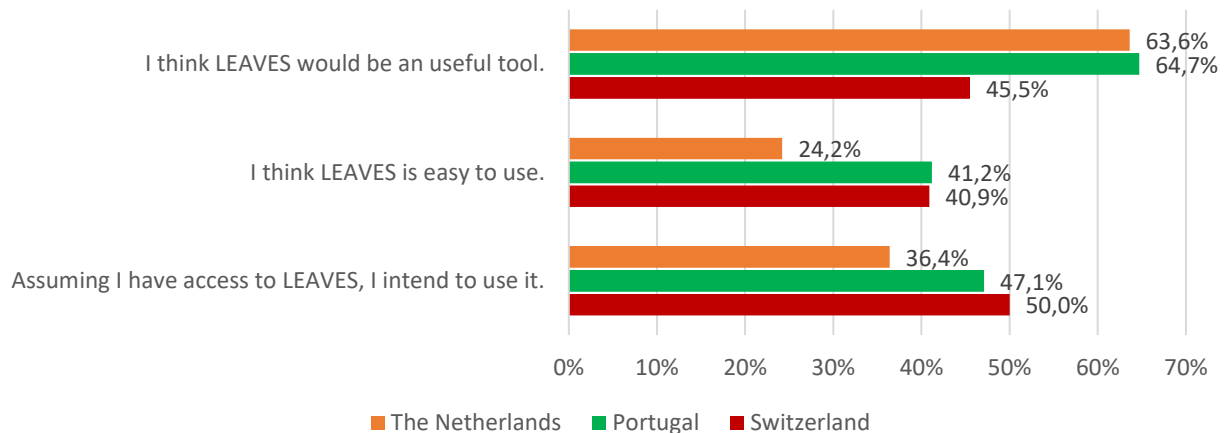


Figure 15. Usefulness of LEAVES according to stakeholders, answered with (totally) agree.

### 7.3. Relevance to job

To look into this answers a little further, stakeholders were asked how LEAVES would fit into their daily work (Figure 15). Even though stakeholders are not sure whether they would use LEAVES if they had access to it, they do often think that LEAVES would be useful and relevant in their job, mainly in Portugal and the Netherlands. Table 3 shows that especially social workers, psychiatrists and psychologists share this opinion. Church counselors and GPs/Doctors are not sure whether LEAVES would be relevant, but do think it could be useful in their daily work.

Profession	Relevant in my job	Useful in my job
Social worker	66.7%	77.8%
Psychiatrist	50%	62.5%
Psychologist	57.1%	57.1%
Church counselor	37.5%	62.5%
GP/Doctor	37.5%	50%

Table 3. Relevance to job per profession.

Approximately half of the stakeholders think that LEAVES would be an effective tool for (part of) their clients (Figure 16) and that it would complement the tools they already use in their work.

Moreover, it stands out that stakeholders find the tool especially suitable as a form of blended therapy (e-Health + face-to-face contact), more than as a standalone tool. Lastly, 83.3% of Portuguese stakeholders would (probably) recommend LEAVES to their clients (Figure 17), and also 59.1% of Swiss stakeholders. Dutch stakeholders are more neutral (41.2%).

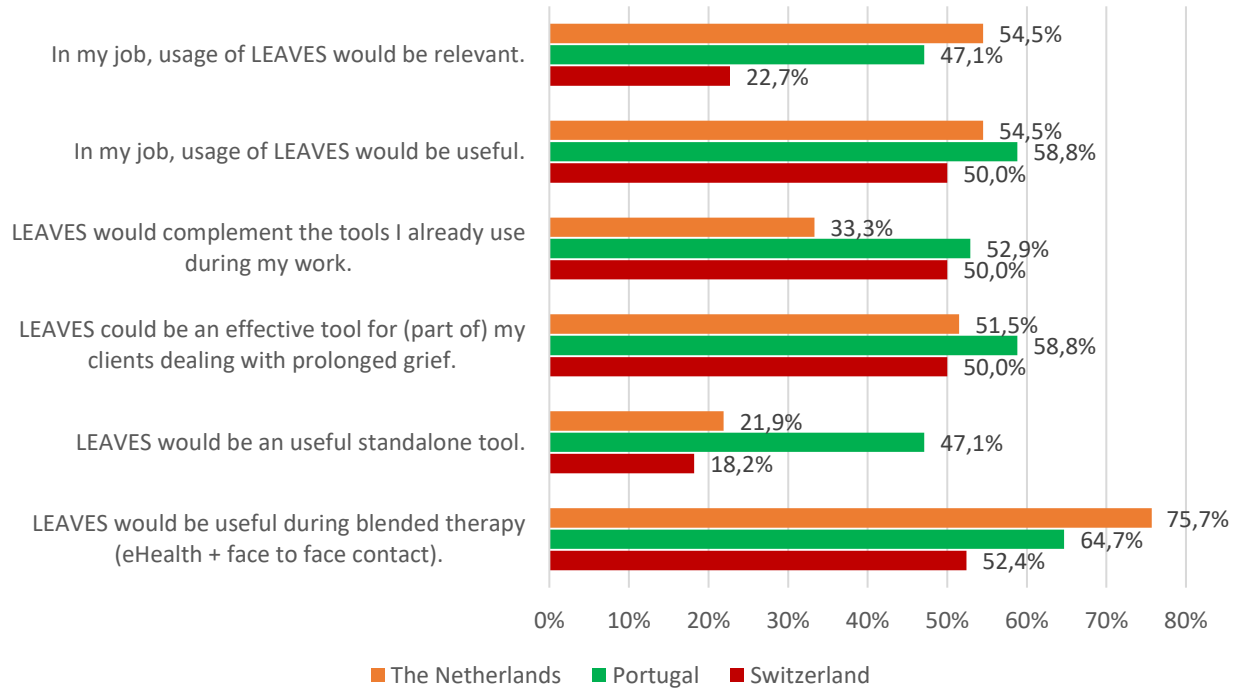


Figure 16. Relevance to job according to stakeholders, answered with (totally) agree.

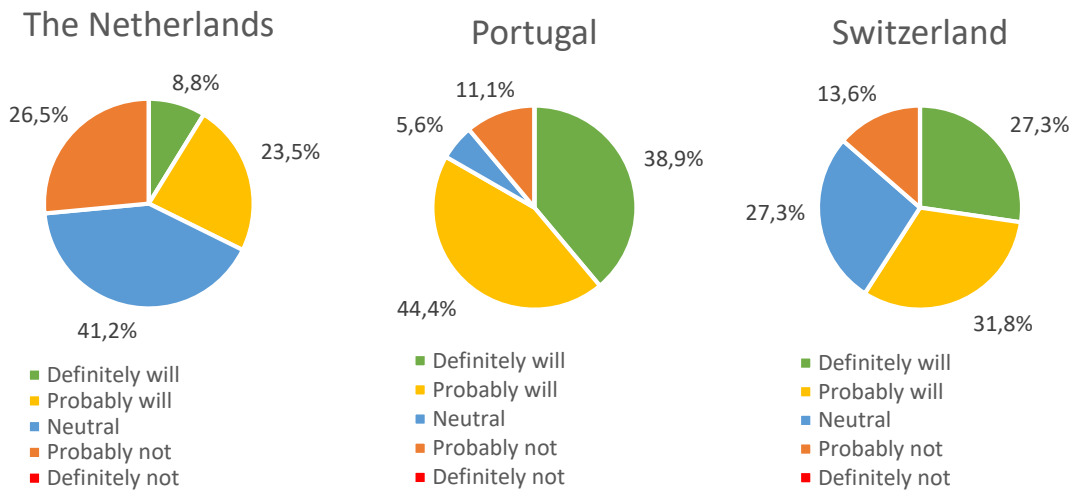


Figure 17. “To what extend would you refer you client to LEAVES?”



## 7.4. Willingness to pay

The final question of the survey to both stakeholder and end users was whether they would be a onetime fee to use LEAVES.

Of the end users, only one says that they would and 2 persons are neutral. Amongst stakeholders, 11.4% is willing to pay. This differs per country: 29.4% of Portuguese stakeholders is willing to pay, while only 6.1% of Dutch stakeholders and 5.6% of Swiss stakeholders are willing to pay. In the comment part of this question, various stakeholders mention that there won't be a budget to pay for the service, hence their answer.

When asked how much stakeholders would be willing to pay, by far most of them answer that they don't know and find it hard to estimate this while they haven't been able to preview the tool first. Two stakeholders of each country mentioned a number:

- The Netherlands: €70 and €500 (73 CHf and 522 CHf)
- Portugal: €20 and €30 (21 Chf and 31 CHF)
- Switzerland: 100 CHf and 200 CHF (€95 and €191,50)

# Appendix F. Final Service Model

