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## DOCUMENT IDENTIFICATION

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## KEY INFORMATION FROM 'DESCRIPTION OF WORK'

DELIVERABLE DESCRIPTION	Report on the user trials and evaluation. This report describes the results from the two field studies, carried out in T5.2. The first study focused more on a qualitative evaluation including overall 20PwD. The second study, addressed in sum 60 care givers and 60 PwD, who used the system for 6 months. More quantitative measures were applied.
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## ABBREVIATIONS

ABBREVIATIONS	DESCRIPTION
AAL	Active and Assisted Living
AAL CMU	AAL Central Management Unit
PwD	Person with dementia
TP	Test person

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## EXECUTIVE SUMMARY

Based on the outcome of the two user studies in the laboratory, carried out in Austria and Romania (see also D2.3) the identified user experience and usability issues were addressed and the Avatar training was further developed so that users had access to the trainings (Role Play and Lecture) via the app. In order to evaluate the SUCCESS system with potential end users in a real-life context, two field studies were carried out, involving formal as well as informal care givers. The first study had a qualitative focus and aimed at understanding users experience, acceptance and satisfaction when interacting with the SUCCESS system. Moreover, we obtained feedback on the avatar and to what extent the services caused changes in care (for formal as well as informal care givers). Finally, feedback on the business models were obtained and the instruments that have been prepared for the 2<sup>nd</sup> trial (assess burden of care, quality of life for care givers, stage of disease behavioural problems) were tested.

# 1 ABOUT THIS DOCUMENT

## 1.1 ROLE OF THE DELIVERABLE

## 1.2 RELATIONSHIP TO OTHER SUCCESS DELIVERABLES

The deliverable is related to the following SUCCESS deliverables:

DELIVERABLE	RELATION
D5.1	Trial and Training concept: This document describes the overall setup of the two field trials, i.e., implementation plan and research methodology.
D2.3	Low and High Fidelity Prototype Evaluation Report: The results from the evaluations in the laboratory built the basis for the further development of the app.

## 2 FIRST FIELD TRIAL

This section describes the results from the first field trials that took place for a duration of six weeks (21<sup>st</sup>/22<sup>nd</sup> of May until the 29<sup>th</sup>/30<sup>th</sup> of June 2018) in Austria and Romania, involving overall 17 potential end users (formal as well as informal care givers).

The following objectives of the qualitative trial were addressed.

- a) To understand the user experience, acceptance and satisfaction
- b) To obtain feedback on the interaction with the avatar
- c) To obtain feedback on the SUCCESS draft business models
- d) To explore changes in care
- e) To analyse frequency and patterns of use for the SUCCESS App
- f) To test/pilot a set of quantitative instruments which will be used in the quantitative trial to assess the burden of care and quality of life for caregivers and the stage of disease and the behavioural problems of PwD

### 2.1 SAMPLE DESCRIPTION

#### Austria:

The Austrian sample consisted of eight participants, four women and four men, who attended this trial either as formal or informal caregivers.

**Formal caregivers:** Half of the study participants were involved in the professional care of people with dementia, three of the test users themselves have been professionally trained caregivers for several years. One of the participants of the formal care runs a domestic 24 hours care. S/he has not absolved a professional education within the care sector, however has gained experience in caring for persons with dementia, throughout the last years.

**Informal caregivers:** This group of users consisted of relatives or friends involved in the care of PwD. Two participants were main care givers and lived in the same house as the PwD. Even if they did not have any professional training in the field of dementia care, they have already acquired a broad knowledge due to the long-term and continuous nursing task and were well connected with discussion- and self-help groups. The spatial and emotional proximity to the PwD also leads to a high temporal and psychological burden, as well as inescapability of the examination of the topic.

Another two participants of the group of informal caregivers were not main care givers and did not live in the same house as PwD. Due to the technical conditions of the caregiver's smartphones, only one of them was able to transmit and evaluate usage data.

Table 1: Demographic Data Participants Austria

ID (Formal/ Informal)	Gender	Age	Highest completed education	Occupation	Family Status (multiple choice)
TP 1 (Formal)	male	50	Professional School / Apprenticeship	full-time employed	married
TP2 (Formal)	male	47	Professional School / Apprenticeship	full-time employed	widowed

TP 3 (Informal)	female	72	Professional School / Apprenticeship	unemployed	widowed
TP 4 (Formal)	female	24	Other: Certificate for nursing care	full-time employed	living in a partnership
TP 5 (Formal)	female	37	General qualification for university entrance	part-time employed	divorced
TP 6 (Informal)	male	70	General qualification for university entrance	unemployed	married
TP 7 (Informal)	female	64	General qualification for university entrance	unemployed	married
TP 8 (Informal)	male	68	General qualification for university entrance	unemployed	married

### Romania:

For Romania, a total of 10 users were recruited for the study, whereby, the majority of these were informal caregivers (i.e., nine out of ten). One of the participants dropped out of the trial after the initial interview, because s/he travelled to a foreign country). Hence, overall nine users were included in the analysis.

**Formal caregiver:** the formal caregiver included in the qualitative trial provides home care for people with dementia for over ten years. She is 54 years old, trained as a psychologist and provides weekly two-hours cognitive training sessions and occupational therapy for people suffering from dementia.

**Informal caregivers:** The group of users consisted of relatives of PwD (five of them are children, one son-in-law, two are partners and one niece). Seven of the participants live in the same house with the PwD and eight of them are the main caregiver. One of the informal caregivers is medical doctor by background. This participant particularly gave feedback within the evaluation on the novelty of the information.

Table 2: Demographic Data Participants Romania

ID (Formal/ Informal)	Gender	Age	Highest completed Education	Occupation	Family Status (multiple choice)
TP 9 (Formal)	female	54	University degree	full-time employed	divorced
TP10 (Informal)	female	56	Master degree	unemployed	divorced
TP11 (Informal)	male	51	PhD	full-time employed	married
TP 12 (Informal)	female	50	Master Degree	full-time employed	Single

TP 13 (Informal)	female	49	PhD	full-time employed	married
TP 14 (Informal)	female	64	Elementary school	unemployed	married
TP 15 (Informal)	female	32	General qualification for university entrance	full-time employed	single
TP 16 (Informal)	male	75	General qualification for university entrance	unemployed	married
TP 17 (Informal)	female	36	University degree	maternity leave	married

## 2.2 RESULTS

In the following chapter, the main results are described, structured according to our central objectives.

### 2.2.1 USAGE TIME AND USER EXPERIENCE

#### 2.2.1.1 USAGE TIME

##### Austria

The exact number of days the participants were using the app ranges from 3 to 21 days. During this period, participants spent between 16 minutes and 5.75 hours in using the app (total time of use). It is noticeable that, on average, informal caregivers spent much more time on using the app than formal caregivers. The two main caregivers used the app most intensively, on 14 / 21 different days at approx. 11 / 16 minutes per day and consulted content from the app 36 / 75 times.

Regarding the usage time, there is no clear difference between the two groups of formal and informal caregivers. The average total usage time of all participants was 01:49 hours, varying from a minimum of 00:16 minutes to a maximum of 05:43 hours (see Table 3).

Table 3: Usage Time

ID (Formal/ Informal)	Usage days	time/usage day	Total usage time	Contents viewed
TP 1 (Formal)	8	00:16:02	02:08:17	49
TP 2 (Formal)	4	00:04:06	00:16:24	12
TP 3 (Informal)	4	00:13:28	00:53:52	11
TP 4 (Formal)	5	00:09:34	00:47:50	19
TP 5 (Formal)	3	00:06:11	00:18:33	5
TP 6 (Informal)	14	00:11:02	02:34:31	36
TP 7 (Informal)	21	00:16:36	05:43:51	75
Average	8,4	00:11:00	1:49:03	29,6

All test users, who are qualified as professional caregivers, generally evaluated the app as positive, although they could hardly gain any new information for themselves and therefore rather recommend it to caregiving relatives or inexperienced caregivers. The experienced caregivers reported

that the usage of the app did not cause any changes in daily care. They pointed out that they have already established fixed routines on the basis of long-term experience.

The article about "hiding and losing objects" has been by far the most read article. Also popular among the participants were articles about physical aggression, false accusations, verbal aggression, repetitive sentence questions and physical sexual advances.

#### Romania:

Self-reported usage patterns ranged from once during the trial period to every few days. Some participants reported that messages sent from the app prompted them to go back to the app, others would go back for the guided meditation or just to re-read some of the articles when more time became available. Due to difficulties with retrieving the usage data, a quantitative analysis of usage times is not available for Romania.

### 2.2.1.2 USER EXPERIENCE, ACCEPTANCE AND SATISFACTION

#### Austria:

Overall, all test users of the first field trial were satisfied with the idea and content of the app, which can be illustrated by the following statement of a participant: *"It is a great app where I could read well prepared contents and concisely presented information. I think it's very good for caregiving relatives. I also like the internet links where you can find some more information."* (TP5)

Linguistic errors, system crashes and the poor design of the avatars were considered critical by all test persons, who indicated that it sometimes affected their motivation to continue using the app. Five participants mention technical problems (e.g., the app was very slow or often crashed) as the most negative experience during the field trial. In addition, all participants identified a need for improvement in the design of the avatars. The strong negative criticism of the participants indicates that the design of the avatars is not yet appropriate. All test users agree that the avatars should be more natural, friendly looking and need to have a more positive appearance.

Apart from that, all eight participants were satisfied with the app and the provided information and would like to be contacted for follow-up studies. Two participants explicitly asked how the study is going to proceed from that point. One participant of the informal caregivers group mentioned several times during the final interview that she would like to keep the app on her private mobile phone to be able to continue supporting the PwD: *"This app is great! It's such a pity I won't have it anymore! I'd like to go into further details, because this is so incredibly great!"* (TP3)

All participants perceived the information provided by the app as useful; four participants stated that the articles are even the most positive experience or favourite function in the entire app. Two other participants were especially positive about the guided meditation.

Three participants mention Quick Help as their favourite function, indicating that they appreciated being quickly directed from a keyword to the corresponding article. Three other participants of the study were not even able to find the Quick Help function and consequently did not use it. Hence, the Quick Help seems to be not good visible for all participants. One participant also stated that s/he was not familiar with the term "Quick Help", hence had difficulties to understand the meaning and purpose behind this function.

Apart from that, six of the eight participants agreed that the videos presented in the app are great, demonstrating concrete care situations. One participant also highlighted the usefulness of internet links, providing additional information if required.

For similar apps developed in the future most of the users would expect the possibility to find all important information in an understandable manner from an app that supports them in everyday care work. Due to big differences in previous knowledge, the provided information needs to be more detailed for professional caregivers and sometimes also for informal caregivers, e.g., for relatives and friends who are only partially involved in care activities. This indicates that there is a need to filter content according to the previous knowledge of the care giver and the severity of dementia.

Results with regard to the technical procedure and the design of the navigation elements indicate that there is a need for improvements in order to ensure an intuitive and problem-free use of all functions.

Users would wish for additional content like a quiz for checking already existing knowledge, instructions for reflecting on aggression, tips for memory training, and contents on the topics "Ageing of people with (mild) dementia" and "Younger people with dementia".

#### Romania:

In Romania, the participants of the first trial also found the SUCCESS app to be useful and the information included valuable. On the "The Usability Metric for User Experience" (UMUX) scale<sup>1</sup>, the users evaluated that the app meets their requirement, the average of 5,13 being reflective of the expressed need of the users for more articles (all items were measured on a 7-point scale, 1=strongly disagree and 7 = strongly agree). Participants evaluated the SUCCESS app to be easy to use and, overall, not a frustrating experience. However, the frequent crash of the app determined users to evaluate the app as slightly time consuming (average 3,13).

Table 4: UMUX results

Items UMUX	TP9	TP10	TP11	TP12	TP13	TP14	TP15	TP16	Avr
The capabilities of SUCCESS met my requirement	2	7	5	3	7	7	3	7	5,13
Using SUCCESS is a frustrating experience	1	1	3	3	1	1	2	1	1,63
SUCCESS is easy to use	7	5	4	5	7	7	7	6	6,00
I have to spend too much time correcting the things with SUCCESS	1	2	2	5	6	1	3	5	3,13
Total score (%)	79.1	87.5	70.8	50.0	95.8	100.0	70.8	70.8	78.1

Most of the users' relatives included in the qualitative trial are in the early stages of the disease, which also meant that participants had a limited level of knowledge in the area of behavioural and psychological symptoms and their management, which is illustrated by the following statement:

<sup>1</sup> The UMUX is a short scale, targeted towards the assessment of usability by means of measuring effectiveness, efficiency, and satisfaction.

*“My mother is at the beginning of the disease so first I read the articles about behaviours I could recognise and then read the rest of the article to learn more about situations that might appear in the future”* (TP17). The content included was thus found to be new and relevant by most of the participants (i.e., seven out of ten; an informal caregiver with over five years of experience caring for a PwD, the informal caregiver trained as MD and the formal caregiver were exceptions). For the formal caregiver, the information included in the app was not new but she appreciated that most of the caregivers would find the app very useful if they would be introduced to it soon after the diagnostic of their relative.

The written articles were used and highly appreciated by all participants. However, it was indicated that improvements are required with regard to the structure of the test and small linguistic or punctuation errors, which have been found to be disturbing. In four out of nine cases, malfunctions have been encountered when trying to use the text to speech function for the written articles.

The video for guided meditation was also appreciated by some of the participants (seven participants said they tried it; two reported daily usage).

The Quick help function was unfrequently used or not used at all, reasons for this being either the fact that participants could not identify the button as a different function of the app or they did not understand how it actually works.

The reported usage and satisfaction for the avatar-based sections (i.e., lectures, role-plays and the diary) were less uniform. For some of the participants (almost half of them) these sections have malfunctioned from the beginning (e.g., the avatar was not working at all or was playing very fast) or started to malfunction very soon after installation (rest of the participants). For two participants the role plays included were qualified as not relevant (PwD they cared for do not show the behavioural or psychological problems targeted). All participants reported frequent app crashes when trying to use avatar-based sections or very high response times. In addition to technical issues, aspects related to how the avatar looks and interacts have also been highlighted by the participants (for details see next sections).

Overall, the test users of the first field trial were satisfied with the app. Favorite functions and most positive experiences with the app include the articles, the videos, the quick help and the guided meditation. The most negative experiences of the participants include the frequent crashes of the app and other technical aspects as well as the negative appearance of the avatars. Apart from that, everyone is interested in being contacted for follow-up studies.

#### 2.2.1.2.1 Interaction with the Avatar

##### Austria

**Results from the BIG 5:** Already during the trial, negative feedback regarding the avatar design (for an example of the avatar design see Annex) was reported by the participants during the telephone interviews. The final interviews therefore asked again to what extent the avatar is considered as "appropriate" for the interaction in the role play.

During the final interviews, the participants were asked to think of the PwD they were responsible for and to evaluate the following statements regarding the extent to which they applied to the PwD.

Afterwards they received two versions of the BFI-10<sup>2</sup> for the evaluation of the BIG5 dimensions, assessing personality traits.

In addition to the answer alternatives of the given five-level Likert scale, a further answer option "I cannot estimate" has been added. It is noticeable that especially the avatar could not be evaluated for some items. TP7 could not make an evaluation regarding the imaginative power of the PwD, because according to TP7 the PwD has never been very imaginative but has now hallucinations due to dementia. If no evaluation was made for one item, the value on the dimension was only calculated by the answer to the other item. In one case, no evaluation could be given for both items.

Comparing the assessment of the PwD and that of the avatars, the participants gave varying evaluations for both. Furthermore, there is a trend among the participants that the PwD and the Avatar have similar scores for each dimension (except of TP3 and TP6). However, this could also be the result of the same questionnaire being used twice.

**Experiences when interacting with the avatar:** A picture of the avatar that was used during the role play was presented to the participants. Guided by the request "I would like to ask you to look at this avatar and imagine the life of this person. Please tell me about what you think about this person's life, what does it look like, what does the person like to do...", the participants were asked to talk about their impression.

The avatar did not encourage the participants to imaginative thoughts. They described the appearance of the avatar as worn out, unappealing, scruffy, boyish, with empty gaze and marked by life. All test users described the avatar as inappropriate, very unnatural, unfriendly and in need of improvement. One participant said about the female avatar: "*Strange... the woman looks like the film character Jaws from the movie 007.*" (TP6)

Besides that, users of the app characterized the avatar as aggressive, not tolerating contradictions, having good manual skills, very strict, imperiously, power addicted, not satisfied with the situation and rejecting other people.

The test users described the emotions of the avatar as depressive, strict, frustrated, without any feelings, stressed, sad, radiating negative emotions, suffering, not satisfied with oneself, grumpy and with grumpy facial expression. One participant stated: "*This woman is a disaster! The look, the facial expression - I would prefer not to have anything to do with such a person! Not pedagogically suitable!*" (TP2)

When the participants imagined the life of the avatar, they assumed the avatar had children, smoked (skin of a smoker), used to be sporty (athletic body), had a tough life, or was formerly successful in the profession. One participant said about the female avatar that she knew that she could no longer do everything.

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<sup>2</sup> The BFI-10 (Rammstedt & John, 2007) is an abbreviated version of the well-established BFI (John et al., 1991), consisting of 10 items. It assesses the Big Five by two items per dimension, one coded in the positive and one in the negative direction of the scale.

## Romania

**Results from the BIG 5:** In Romania, eight participants provided answers for the 10 items of the Big Five inventory (BFI-10) for the avatar and six for the PwD they are caring for. Three of the participants have assessed the male version of the avatar and the remaining five have evaluated the female version. In all eight cases, the gender of the PwD the users are caring for is the same as the gender of the avatar they evaluated.

The BFI-10 scale has two items each for the five personality dimensions: Conscientiousness, Neuroticism, Agreeableness, Openness, Extraversion. While the number of participants is rather small for definite conclusions, the results indicate a tendency to evaluate the avatar lower than both the PwD and the normative values provided by Rammstedt (2007) on Agreeableness, Openness and Extraversion. These results are supported by answers to question referring to the experiences users had when interacting with the avatar (see Table 5 and Table 6).

Table 5: Scores BFI-10 for the Avatar (N=8)

Dimension	Mean	SD	Mean (B. Rammstedt, 2007 N=2567)	SD (B. Rammstedt, 2007 N=2567)
Conscientiousness	4,06	1,32	4.10	.69
Neuroticism	3,56	1,49	3.49	.85
Agreeableness	2,81	1,3	3.20	.83
Openness	2,5	1,62	3.41	.88
Extraversion	2,43	1,15	3.24	.88
Mean	3,07	0,71	3.49	.83

Table 6: Scores BFI-10 for the PwD (N=6)

Dimension	Mean	SD	Mean (B. Rammstedt, 2007 N=2567)	SD (B. Rammstedt, 2007 N=2567)
Neuroticism	3,7	1,16	3.49	.85
Conscientiousness	3,5	1,94	4.10	.69
Extraversion	3	1,26	3.24	.88
Agreeableness	3	1,37	3.20	.83
Openness	2,1	1,2	3.41	.88
Mean	3,06	0,61	3.49	.83

These results are supported by answers referring to the experiences users had when interacting with the avatar.

**Experiences when interacting with the avatar:** Overall the avatar was perceived as strange (“creepy”) by some participants and the voice of the avatar was perceived as being metallic (digital): *“The way he speaks is not very friendly”*. The avatars were also perceived as *“not very intelligent, perhaps due to the harsh features”*(TP10).

Some participants indicated that the clothes, the hair, and the face of the avatar do not fit the age, i.e., are experienced inappropriate: *“Few of the elderly people dress in active wear; the hair of the avatar is not white and there are no wrinkles on the faces of the avatars”*(TP10). One participant even commented that the female avatar *“looks like a corner street beggar lady who could use a shower”*(TP17).

The body of the avatar is perceived as being rather rigid and creates the impression that it is difficult to communicate with; one user mentioned that *“it is disturbing that the avatar is holding his hands on the hips”*(TP12) and some users would prefer to see only the upper part of the avatar. Otherwise, the female avatar was described as an active person, without physical problems but possible inadequate for portraying a person with dementia: *“she has a good posture but not necessary adequate for the situation of the PwD”*(TP13) (i.e. persons, who suffer from dementia might be a bit more frail).

In terms of personality, the avatar was described as *“not very friendly, a though person who dosen’t look like he suffers from Dementia. The eyes of the avatar are different from the eyes of a PwD, who seem a bit lost”*(TP10). Another participant indicated that the avatar *“looks like a clown with a rather hostile attitude (it makes me feel alerted)”*(TP12). Users also pointed out that the avatar seems to be *“upset all the time”*. For the female avatar, some users also indicated that she seems like a violent person, who is upset and can inspire fear.

Possible jobs the avatar might hold, indicated by the users were: a) for the female avatar: *“She works in a factory, on a production line”*(TP12); *“She is a tough manager or a very tough teacher”* (TP14); b) for the male avatar: *“He works in IT or in a corporation; he dosen’t look like needing medical care”*(TP16); *“He is a lonely person who works in an office, perhaps even a management job”*; *“a person who like to work with his hands, perhaps a a handyman, farmer or carpenter”*(TP10).

For hobbies, the female avatar was perceived as loving sports and walking; also users said that she is *“not very good at cooking or knitting”*(TP17). For the male avatar, hobbies mentioned by users were reading or watching TV.

In general, test users described the avatars as unappealing, aggressive and stressed. All participants agreed, that the avatars are not appropriate for the interaction in the role play. Improvements are required with regard to the appearance and also the behavior (postures, gestures).

## 2.2.2 BUSINESS MODELS

### Austria

None of the participants had ever downloaded an app on their mobile phones to support them in their daily care routine. Only one user could not imagine paying for an app that supports him/her in maintenance, because s/he already had a lot of previous knowledge. S/he also noted that despite of his/her active search for information and good networking, s/he does not know any app that could be helpful in everyday care. Another participant from professional care could only imagine paying for an app that supports him/her in everyday care if it would provide a wide range of tips on how to behave in different care situations for people with various diseases.

All other participants could imagine paying for an app like SUCCESS. In addition to improved technical usability (e.g., appropriate time required and compatibility with various operating systems), such an app would then have to offer quick and concrete tips to help in specific situations. One participant would like the app to be easier to understand and be offered in different languages.

Most participants do not have a reference point regarding the costs of an app in general but said that they would be willing to pay 2 Euro per month (one participant) or between 5 Euro and 15 Euro per month.

### Romania

None of the Romanian participants has previously used a mobile app to support them in their daily care routine, but they indicate they would buy SUCCESS if proved to be useful. For the price, the participants offered that they would be willing to pay what should be comparable to a similar app or a book (between 1 and 5 Euros a month).

Most of the participants could imagine paying between 2 and 15 Euro per month in Austria and between 1 and 5 Euros per month in Romania for an app like SUCCESS, expecting that the technical problems are resolved, usability is improved and more quick and concrete tips for specific situations are provided.

## 2.2.3 CHANGES IN CARE

### Austria

The use of the SUCCESS app had different effects for formal and informal caregivers. Statements of the participants regarding changes in the care situation, care behaviour, care activities, and routines were extracted, thematically structured, and are summarized below.

#### 2.2.3.1 CHANGES IN CARE FOR FORMAL CAREGIVERS

Three out of four formal caregivers stated that they did not experience any changes, as they had already established a firm and successful routine and were consolidated in their nursing activities. However, one participant stated, that the app helped him/her to break out of his/her daily routines.

Accordingly, only a few changes in care for formal care givers have been reported. The topics that were discussed in this context are described below.

**Aggression:** Two participants explained that the app allows to train preventing aggressive behavior in a “safe environment”. One participant reported that the app helped him/her to stay calm while the person s/he was caring for, became aggressive.

**Interaction with the PwD:** Since the professional caregivers were already experienced in interacting with people with dementia, the use of the app primarily encouraged them to reflect upon their own behavior and established routines in order to remedy possible carelessness or errors. Apart from that, none of the formal caregivers' interaction with the PwD was affected by the app.

**Caregiver's life:** Three of the formal caregivers stated that they did not notice any changes in their own life when using the SUCCESS app. However, the person, who runs the 24-hour care indicated that s/he can imagine that the app might have an impact on the caregiver's working life in terms of care relationship, methods, and day-to-day organization. Another participant indicated that there

certainly might be changes for employees, who do not work professionally. Only one test user noticed during the trial that s/he remains calmer in specific situations and could better deal with aggressive behavior. In addition, the app helped him/her to break out of the usual routine.

**Selfcare:** Half of the formal caregivers had a very good impression of the self-reflection function and perceived the presented information as sufficient: *“I really like the fact that the caregiver can just lean back and check what is good for me, what is important for me? Can I now use the family's resources? Recognizing these things is very important to the caregiver, simply to look at oneself and not to get lost in the daily stress.” (TP1)*

It is interesting that the other half of the formal caregivers had the opinion that they do not personally need self-reflection or the self-reflection-function, but believe that it can be very helpful for other people: *“I think it's good, I think it's fine, I can imagine it for caregiving relatives. But I personally don't need it.” (TP4)*

One participant stated that the app made her more aware of when she needed a moment to shut down and when she was over- or underchallenged in her current work situation.

Most of the professional care givers reported that the use of the app did not lead to any changes in self-reflection, satisfaction in care, emotional state, care relationship with the PwD or the possibility of maintaining care over a longer period of time. Due to many years of working experience, training and further education, the caregivers have already gained the necessary skills and knowledge, which they considered similar to what is provided via the app. They indicated that they have already successfully built up routines and set up a stress limit that is acceptable to them.

However, three of four formal caregivers agreed, that the SUCCESS app could be especially helpful for informal caregivers, who do not work as professional caregivers.

#### 2.2.3.2 POSSIBLE CHANGES IN CARE FOR FORMAL CAREGIVERS IN HOME CARE

According to the expert from the field of 24-hour home care, the SUCCESS app can have quite positive effects on the working life of formal caregivers who have no specialist training as (health) caregivers. A positive influence on the relationship between caregiver, relatives, and the PwD is conceivable, for example, through suggestions for a meaningful design of everyday life that can be created together.

It was indicated that learning appropriate communication strategies can also have a positive effect on the care relationship, for example, in dealing with aggression and by improving the PwD's response to the caregiver's actions. If the app supports the handling of changes regarding the level of dementia, so that a caregiver can still maintain the care activity, this can positively influence the relationship and trust between all persons involved. Self-reflection was considered critically, because although it is necessary for caregivers of 24-hour care, it cannot be guaranteed that they always have the time and motivation to do so.

#### 2.2.3.3 CHANGES IN CARE FOR INFORMAL CAREGIVERS

Relatives and friends of people with dementia, who tested the SUCCESS app continuously reported about changes that they observed during or after the period of use. The topics describing these changes in care are presented below.

**Aggression:** An important issue is how to deal with aggression and aggressive behavior on behalf of the PwD. Generally, informal caregivers reported that the app enabled them to find appropriate

action alternatives in critical situations and that the app supported them in dealing with aggressive feelings and emotions. One test user stated, that the learn & train function of the app helped him/her to deal with his/her own aggression as well as with the partner's aggression. In the context of preventing verbal aggression, two participants found the self-reflection function very helpful.

**Interaction with the PwD:** Improvements reported by the participants can be seen in the relationship to the PwD, which is based on an interplay of improved communication and interaction with the PwD, a more balanced emotional state of the caregiver through self-reflection and self-care and an increased trust and positive reaction of the PwD, as a result of the more intensive occupation with the subject.

All informal caregivers reported that they became more sensitive to the needs and signals of the PwD. They also realized to be more sympathetic and calm. One test user stated that the app is also very helpful for reminding oneself not to patronize the PwD too much, but to accept wishes and self-determination more understandingly and patiently. Moreover, this test person pointed out that the support in terms of communication and the information about validation could help to avoid that a situation escalates into a dispute or provoked anger (for example when refusing to drink or take medication or repeatedly asking questions after a change of location). The app was considered to be helpful in resolving disputes calmly, communicating one's own needs and limits more sensitively, and helping to cope with changes in the level of dementia.

**Caregiver's life:** All informal caregivers agreed, that the SUCCESS app had a big impact on their daily life regarding various aspects. One participant stated that s/he pays much more attention to the words and phrases that are used during the communication with the PwD. Another test user said it was now easier for him/her to understand specific situations. By using SUCCESS s/he has reached a different level of knowledge and reflection: *"I know that everything is not always as I want it to be. But it is also necessary not to exaggerate and to take some time off. It will then be possible to work under pressure again."* (TP8) Two test users said that the app can serve as a good reminder to take time for oneself.

It was furthermore reported by two participants, that SUCCESS could provide help and problem-solving strategies in critical situations: *"It helps me to find my way when I don't know what to do - when I actually know it theoretically, but don't know what to do at that specific moment and then I will check."* (TP6)

**Self-Care:** The use of the app also reminded the participants to take care of themselves, to set personal limits and to take time for themselves, e.g., by using self-reflection and meditation techniques. Accepting the care activity as a learning process, as well as reflecting and confirming of already existing or learned abilities to act, also increased confidence in care and in the PwD's own competence.

All informal caregivers perceived the self-reflection function as very positive and were very satisfied with the contents provided by the app. Two test users even named the guided meditation as their favourite function or as the most positive experience when interacting with the app.

Only one participant stated that it is now everyone's own responsibility to implement this useful content. S/he himself/herself did read the content of self-reflection in the app but did not make use of it, because s/he had already strategies how to deal with difficult situations, which is illustrated in the following statement: *"If I have problems, I go to the forest"*. (TP6)

**Resources:** Most of the users reported that they were encouraged by the app to ensure their own resilience and to reflect on their crisis management strategies as well as on available or required resources. They were encouraged to think about if there are other people who could relieve them, although this does not mean that someone is already there to help. The use of SUCCESS made participants aware of the need to pay attention to whether further resources need to be activated.

### Romania

#### 2.2.3.4 CHANGES FOR FORMAL CAREGIVERS

For Romania, there was only one formal caregiver included in the qualitative trial. As s/he had over ten years of experience of providing care for PwD, s/he did not report any changes following the use of the app in any of the following dimensions: self-reflection, satisfaction in care, emotional state, care relationship with the PwD or the possibility of maintaining care over a longer period of time. However, she evaluated the app as potentially being very useful for informal carers, who find it difficult to adjust their behaviour in the beginning stages when they are slowly learning more about Dementia (*"It will be useful for family members because their job becomes easier once they understand how to manage the behavioural and psychological problems of PwD."*(TP9)).

#### 2.2.3.5 CHANGES FOR INFORMAL CAREGIVERS

**Aggression:** A better understanding of the aggressive behaviours of PwD was one of the main benefits highlighted by informal caregivers. One participant mentioned that the most positive experience with SUCCESS was to learn more about aggression after her mother had a violent reaction. The information provided via the app helped her to understand that his/her mother's behaviour might be due to the disease and helped him/her to better react.

**Interaction with the PwD:** In terms of interaction with PwDs, the main impact of using the SUCCESS app was at the level of better understanding the behavioural and psychological problems of PwD. Two categories of changes in understanding were prevalent: a) following the diagnosis, some carers limited the tasks and involvement of PwD in most types of activities in order to protect them *"I thought she would feel better if I don't involve her in daily activities"*(TP13). For them, the app provided a good basis for understanding that keeping PwD active is very important for slowing down the cognitive and functional decline of the PwD, while maintaining a good quality of life for the PwD; b) the second category of users continued to treat the PwD as a normal person after the diagnosis, which also meant that they would easily get upset and/or criticize the PwD for any "mistake" they would make. For them, the use of the SUCCESS app provided more information about the behavioural and psychological problems experienced by PwD and the appropriate behaviours to have in response to these (*"My mother is functional but by using the app I have realised that my mother has a serious problem and that I need to learn how to interact. I had the tendency to treat her as a normal person and I was criticizing her when she was doing something wrong. Now I don't do that anymore. I don't have to get mad when she does something wrong. I have to stay calm. The information about activities that can be planned for the PwD was also very helpful."* - TP13).

Another user mentioned that the suggestions for activities helped her better plan for joint activities with her mother (*"During the trial period we better worked together and she was more willing to cooperate, I reserved more time for planning activities together; My mother is not the person I knew; she is a different person. The app helped me see her with different eyes and to avoid taking everything she says personally. I tried to use the suggestions for interaction included in the app for anger and mistrust and it worked"*TP10).

Another user was initially enthusiastic about the SUCCESS app, when contacted after the first week of the trial. S/he reported having successfully tried out several of the strategies included in the app. However, at the final interview s/he was rather pessimistic about the changes in the interaction with her husband (*“What I have now understood is that there is not much I can do. He refuses to go out and is lethargic most of the day” TP14*).

#### **Caregiver’s life and self-care:**

Two of the nine participants reported that they used the guided meditation frequently as a way to relax at the end of the day. Both of them reported having tried beforehand several relaxation techniques but preferred to use the video included in the app because it was in Romanian and easy to find in the app.

One participant was particularly enthusiastic about the diary function which s/he reported being the favourite feature of the app. S/he indicated that she frequently used it during the trial.

Secondary benefits of using the app were also reported by one participant, who mentioned that, due to the app, s/he could provide advice to a friend, who was recently accused of stealing something from an elderly person (*“I could help a friend which was accused that she stole something; I showed her the app, she understood that it might be a symptom and she didn’t take it personally anymore” TP10*).

Due to many years of working experience, training and further education, the formal caregivers had already gained the necessary skills and knowledge, so the app didn’t lead to major changes in self-reflection, satisfaction in care, emotional state or care relationship with the PwD.

In contrast, all informal caregivers agreed that the app in fact did lead to positive changes in the interaction with the PwD, in their own lives and in their self-reflection. In addition, the content of the app influenced important everyday challenges such as aggression and the correct use of resources in a positive way.

## 2.3 IMPLICATIONS

The following list includes a summary of all issues regarding the functionalities and the content of the SUCCESS app, that were found during the first SUCCESS field trial in Austria and Romania.

Issues found in both countries are **colored black**, issues only found in Austria are **colored blue**, issues only found in Romania are **colored green**.

Table 7: Most urgent Issues (Prio 1)

Category	Description	Suggestions for improvement
App crashes	<p>App crashes quite often, especially</p> <ul style="list-style-type: none"> <li>• when using the “back” arrow</li> <li>• when trying to leave the avatar role-play</li> <li>• during avatar-lectures</li> <li>• during “Selbstreflexion” (self-reflection) function (e.g. after tapping “5-Minuten-Meditation”)</li> <li>• when quickly moving through the app</li> </ul>	<ul style="list-style-type: none"> <li>• reasons for bugs needs to be checked</li> </ul>
Role-play	<ul style="list-style-type: none"> <li>• Users could not easily navigate through the role-play / could not easily make use of the role play</li> <li>• Reasons include:</li> <li>• Avatar did not speak in some cases (hence, users were not sure what to do next)</li> <li>• Unclear what user is supposed to do (e.g. how to start the conversation)</li> <li>• Unclear (partially no) function (or functioning) of the arrow or answer buttons at the bottom</li> <li>• “back” arrow did not work</li> <li>• Loads very slowly /does not work properly when used too fast</li> </ul>	<ul style="list-style-type: none"> <li>• Make sure Avatar always speaks during his part of the conversation (bug?)</li> <li>• Only show buttons if they have a function; change the appearance of the button if it changes its function or add a transition animation, e.g., hide and show buttons, when new commands appear</li> <li>• Make sure navigational buttons work properly</li> </ul>
Avatar	<p>Appearance of the avatars was strongly criticized.</p> <p>Especially the female lecture-avatar “looks and sounds unnatural” (e.g. claw-like hand, hair, teeth and outfit). Expressions and movements do not look appealing and realistic but rather threatening. Role-play avatar (especially female) looks neglected, mean/angry/unnatural</p> <p><b>The old female avatar also looks scary</b></p> <p><b>The avatar cannot be personalized (hair, clothes, etc.)</b></p> <p><b>The movements of the avatar are rigid</b></p>	<ul style="list-style-type: none"> <li>• Needs to be discussed with Emanuel</li> <li>• Improve appearance (especially of female avatars)</li> <li>• Give more avatar options or the possibility to personalize the avatar</li> </ul>

	<p><b>Not clear why the avatar places the hands on the hips</b></p>	<ul style="list-style-type: none"> <li>• Make movements more natural and flexible</li> <li>• Show only the upper part of the avatar</li> </ul>
<p>“Selbstreflexion” (self-reflection)</p>	<p>Users could not easily navigate through self-reflection. Reasons include:</p> <ul style="list-style-type: none"> <li>• Too much happening on the intro screen</li> <li>• unclear what users are supposed to do, (e.g. “next” button has no function)</li> <li>• Users did not understand that the “intro” button in the end led back to the beginning because the module was completed</li> </ul>	<ul style="list-style-type: none"> <li>• Allow user to pause, mute and continue avatar monolog</li> <li>• make sure avatar speaks within all parts of the module</li> <li>• Rename navigational buttons so that their function is clear → suggestions could be directly added to translation list (AIT)</li> <li>• <i>To be discussed with AIT designer Michael</i></li> </ul>
<p>Quick-help</p>	<p>Not all participants realized that the Quick-Info is a function in itself. It was not clear how to use the function App crashes when searching for keywords with no results</p>	<ul style="list-style-type: none"> <li>• There seems to be still a problem to understand the overall function “quick help” – we need to look into this in detail ...</li> <li>• <i>To be discussed with AIT designer Michael</i></li> <li>• Add explanatory text above /in search bar; e.g. “What kind of tip are you searching for?” or grey out suggestion in search bar</li> <li>• more keywords/synonyms so that results are displayed – avoid that the app crashes due to the lack of key words</li> <li>• Provide a solution if there are no keywords for a search (e.g. show keywords for which tips are available)</li> </ul>

Avatar Lecture  
„ein sinnvolles Leben schaffen“

Avatar only speaks during the intro and when choosing “Work”, but not during the other options. Then again the avatar starts speaking every time the user returns to the intro

*(See also suggestions/comments for “self-reflection” above)*

- incorporate Avatar throughout the entire lecture
- option to pause, mute and continue the avatar lecture
- Rename navigational buttons so that their function is clear

Table 8: Issues Prio 2-4

Category	Description	Suggestions for improvement
OTHER ISSUES (Prio 2)		
Language	<p>Many parts are in English even when using the German/Romanian version e.g.:</p> <ul style="list-style-type: none"> <li>• Diary prompt</li> <li>• Content category names</li> <li>• Tools menu</li> <li>• Description text role-play “verbal aggression”</li> <li>• Buttons in “Selbstreflexion” (self reflection function)</li> </ul>	<ul style="list-style-type: none"> <li>• Translate parts that are in the wrong language</li> </ul>
Performance of app	<p><b>App is very slow, especially in the sections with the avatar</b></p> <p><b>Users reported the temptation to press repeatedly on the arrows or on the avatar; they also tried to drag the text on the avatar to get a reaction from the avatar</b></p>	<ul style="list-style-type: none"> <li>• Improve performance of app/avatar content elements</li> <li>• Drag text on top of the avatar? (TBD)</li> </ul>
Text/Avatar text	<p>There are many grammar and language mistakes and even nonsense (Selbstreflexion -&gt; Regenerierung sometimes it just mentions Doktor Kristin Neff out of nowhere. Roleplay „Aggression/persönliche Wut“ is missing a word in line 8...) throughout the app. Have a look at the avatar monolog text, as it appears while the avatar is speaking capital letters and punctuation are neglected but when tapping on the avatar the full text appears in an improved version.</p>	<ul style="list-style-type: none"> <li>• Improve text, especially grammar and sentence structure</li> </ul>
Voice of the avatar (Romanian version of App)	<p><b>The voice of the young male avatar is the voice of a woman in the diary;</b></p> <p><b>In the lecture part of the app the male avatar does not speak at all</b></p> <p><b>The young woman does not speak at all neither in the diary section nor in the lecture</b></p> <p><b>The voice is unpleasant (metallic/digital)</b></p>	<ul style="list-style-type: none"> <li>• Change the voice of the young avatar with a male voice in the diary section</li> <li>• Check the text to speech</li> <li>• Improve the voice of the avatar</li> </ul>
Text to speech (Romanian version of App)	<p><b>For text to speech, sometimes the pronunciation is completely wrong. It might be due to diacritics or punctuation</b></p>	<ul style="list-style-type: none"> <li>• Check whether the pronunciation can be improved by correcting punctuation and/or diacritics</li> </ul>
Readability	<p>Participants found articles difficult to read.</p> <ul style="list-style-type: none"> <li>• Grammar and spelling mistakes, incomplete and wrong sentence interfere with pleasant reading experience</li> </ul>	<ul style="list-style-type: none"> <li>• Add paragraphs, highlights, improve grammar etc. to make text structure more appealing</li> </ul>

Personalization	The tool function at the top right includes a huge amount of options but users have trouble finding (all of) them	<ul style="list-style-type: none"> <li>• Allow users to create their profile when tapping on the circle in the middle (e.g. add name and use this name in the diary prompt and Avatar conversations), allow for avatar personalization here. Make progress visible in profile, allow filtering for content, etc.</li> <li>• Move diary to "Selbstreflexion", make diary entries visible</li> <li>• So that the tool function only includes technical-settings</li> </ul>
Change Avatar	Users have difficulties changing the avatar from female to male.	<ul style="list-style-type: none"> <li>• Make avatar change option more salient, e.g. in profile option (when tapping on the circle in the center)</li> <li>• Make Avatar personalization possible (e.g. By allowing to change name and using this name in role-play)</li> </ul>
Summary under videos	Most videos (except for „Geführte Meditation“) do not have an introduction, description or summary	<ul style="list-style-type: none"> <li>• Add summary text like for video „Geführte Meditation“</li> </ul>
Home screen	Sometimes it is difficult to return to the home screen	<ul style="list-style-type: none"> <li>• Provide a uniform way to return to the home screen from all parts of the app</li> </ul>
Amount of content (Learn and train)	<p>Users missed information on certain topics/situations:</p> <ul style="list-style-type: none"> <li>• Roleplay on the topic „I want to leave!“/ Running away</li> <li>• Aggression against PwD (domestic violence)</li> <li>• Content related to situations that affect the freedom and autonomy of individuals with less advanced dementia, e.g.</li> <li>• The person is still driving, to what extent is it safe and what to do if the person gets lost?</li> <li>• The person does not want to be placed in a care home, how can the transition be arranged?</li> </ul>	<ul style="list-style-type: none"> <li>• Additional content to be provided</li> </ul>

	<ul style="list-style-type: none"> <li>• content for dealing with younger people who become demented</li> <li>• first steps after diagnostic</li> </ul>	
Amount of content (Activities)	<p>At the moment, there is almost no content available in the category “Activities”; users proposed:</p> <ul style="list-style-type: none"> <li>• Memory training</li> <li>• Creative activities with music, coloring etc.</li> <li>• Train patience with PwD</li> <li>• Quizzes</li> </ul>	<ul style="list-style-type: none"> <li>• Additional content to be provided</li> </ul>
Content (Quick-help)	<p>Due to missing keywords (synonyms), certain content elements are hard to find</p>	<ul style="list-style-type: none"> <li>• Provide additional keywords for content elements</li> </ul>
Content (Formal caregivers)	<p>Formal caregivers with proper training would need much more detailed information in order to gain extra advantages from using the app</p>	<ul style="list-style-type: none"> <li>• TBD</li> </ul>
OTHER ISSUES (Prio 3)		
Diary prompt	<ul style="list-style-type: none"> <li>• User reports that sometimes diary prompt leads to the diary even when “cancel” is selected</li> <li>• Users were bothered by the prompt</li> <li>• Users thought that the self-reflection was important but did not do it because they didn’t have the time</li> </ul>	<ul style="list-style-type: none"> <li>• If this is a bug it may be fixed</li> <li>• rename the buttons to make clear which button will lead to the diary and which one wont (e.g. “I’ll do it later” and “Write diary”)</li> <li>• Allow to set reminder for diary/self-reflection to a self-chosen time</li> </ul>
Content box	<p>The last box for each content (e.g. the last box with a preview of the article) is not completely visible</p>	<ul style="list-style-type: none"> <li>• Adjust spacing so that the entire content-box is visible</li> </ul>
Filter content	<p>Not all content in the learn &amp; train function is relevant for informal vs. formal caregivers or caregivers of people with different levels of dementia</p> <p>Info for the post-diagnostic period (e.g. general info, local resources, etc.)</p> <p>The suggestions for reactions/activities are also not particularized for different stages of dementia</p>	<ul style="list-style-type: none"> <li>• Add option to filter content</li> <li>• Add option to sort for favorites</li> <li>• Add new articles</li> <li>• Recommend activities/reactions based on the level of dementia</li> </ul>
Links in Articles	<ul style="list-style-type: none"> <li>• Links are read out loud with all special characters</li> <li>• Links are not clickable</li> </ul>	<ul style="list-style-type: none"> <li>• Turn links into hyperlinks</li> </ul>

Role-play	Introductory text too long	<ul style="list-style-type: none"> <li>• Make text structure of introduction more appealing by dividing text into paragraphs (e.g. one paragraph description of the situation at hand, second paragraph theoretical background info) and adding highlights, while leaving out irrelevant sentences</li> </ul>
Avatar lectures	Structuring of visual text output	<ul style="list-style-type: none"> <li>• add paragraphs, highlights etc.</li> </ul>
OTHER ISSUES (Prio 4)		
Title for content	Article with the title “Bewegungsstörungen” is actually an article on “Verstecken und verlieren ”	<ul style="list-style-type: none"> <li>• Change Article</li> </ul>
	Video with title „Medikamentenverweigerung“ is actually the same video as „Kommunikation mit Menschen mit schwerer Demenz“	<ul style="list-style-type: none"> <li>• Change Video</li> </ul>
Enlarge video	User did not find option to make video larger or the video stopped when screen was tilted	<ul style="list-style-type: none"> <li>• TBD</li> </ul>
Video subtitles	Video subtitles are incorrect/nonsense	<ul style="list-style-type: none"> <li>• Change subtitles</li> </ul>
Link from quick-help to learn & train	Quick help contains simple tips but no in-depth information.	<ul style="list-style-type: none"> <li>• Add a link from the quick-tip to the relevant Article, Video, Lecture or Roleplay in the Learn &amp; Train Function</li> </ul>
Content images	<p>The image next to the content is not descriptive (e.g. image of the “Lernen &amp; trainieren” function is the image from the “Aktivitäten” function; every image is the same)</p> <p>Images to choose an avatar do not show the right avatars</p>	<ul style="list-style-type: none"> <li>• Use different and more representative images for different content</li> </ul>
Use of multiple languages	Missing subtitles/translations for videos / Bugs related to multi-language support	<ul style="list-style-type: none"> <li>• Provide translations/subtitles to the videos</li> <li>• Fix bug within progress counter, progress ring (counter goes above 100% when reading articles in multiple languages)</li> </ul>

Self reflection	Nice-to-have features for self-reflection part	<ul style="list-style-type: none"><li>• Give opportunity to see past entries (e.g. action list)</li><li>• Integrate diary in this function (TBD)</li></ul>
Calendar	No possibility to plan for an action	<ul style="list-style-type: none"><li>• Link the app to a calendar where actions could be planned OR have a planning section</li></ul>

### 3 SECOND FIELD TRIAL

The results of the second field trial will be reported in the M31 version of this deliverable.

## REFERENCES

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## ANNEX

