

AAL Programme

SUCCESS - **SU**ccessful **C**aregiver **C**ommunication and **E**veryday **S**ituation **S**upport in dementia care



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DELIVERABLE DESCRIPTION The deliverable includes the research methodology and the implementation plan

for the two SUCCESS field studies: a) the first study has a qualitative focus (includes 16 carers and 20 PwD they care for in the two trial sites of Austria and Romania); b) the second field study has a quantitative focus (in sum 60 carers and 60

PwD they care for will be invited to use the system for six month).

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ABBREVIATIONS

ABBREVIATIONS	DESCRIPTION
AAL	Active and Assisted Living
AAL CMU	AAL Central Management Unit
PwD	Person with Dementia

TABLE OF CONTENTS

ABBREVIATI	ONS	II
TABLE OF C	ONTENTS	III
EXECUTIVE	SUMMARY	1
1. ABOU	JT THIS DOCUMENT	2
1.1 RO	LE OF THE DELIVERABLE	2
1.2 RE	LATIONSHIP TO OTHER SUCCESS DELIVERABLES	2
1.3 ST	RUCTURE OF THIS DOCUMENT	2
2. AIM	AND STRUCTURE OF THE TRIALS	3
3. CON	CEPT AND METHODOLOGY OF THE QUALITATIVE TRIAL	3
3.1 TH	E GENERAL OBJECTIVE OF THE FIRST FIELD TRIAL	3
3.2 SP	ECIFIC OBJECTIVES	3
3.3 ST	UDY SETUP	4
3.3.1	DURATION	4
3.3.2	PARTICIPANTS	4
3.3.3	DESIGN OF THE TRIAL	4
3.3.4	VARIABLES OF INTEREST AND INSTRUMENTS TO BE USED	4
3.4 ST	UDY PROCEDURE	6
3.4.1	KICK-OFF MEETING	6
3.4.2	TELEPHONE FOLLOW-UP	6
3.4.3	ON-GOING FEEDBACK	6
3.4.4	FACE TO FACE FOLLOW-UP AFTER 6 WEEKS	7
3.4.5	INFORMED CONSENT	7
3.4.6	DATA ANALYSIS	7
3.4.7	DATA MANAGEMENT	8
3.4.8	ACCESS TO DATA	8
3.4.9	REIMBURSEMENT	8
3.4.10	MATERIAL NEEDED	8
4. QUA	NTITATIVE TRIAL CONCEPT AND METHODOLOGY	10
5. APPE	NDIX A	11
5.1 INI	FORMED CONSENT (ENGLISH)	11
5.2 DE	MOGRAPHIC DATA (ENGLISH)	14

D5.1 Trial training concept

5.3	ZARIT CAREGIVER BURDEN SCALE (ENGLISH)	15
5.4	WHOQOL-BREF (ENGLISH)	17
6.	APPENDIX B	21
6.1	USABILITY METRIX FOR USER EXPERIENCE (ENGLISH)	21
6.2	INTERVIEW GUIDELINE INFORMAL CARE GIVERS (ENGLISH)	22
6.3	INTERVIEW GUIDELINE FORMAL CARE GIVERS (GERMAN)	30

EXECUTIVE SUMMARY

This deliverable describes the aim and methodology of both the qualitative and quantitative field trials. Those studies are done in Austria and Romania, conducted by the partners EUR, AIT and RAS.

The aim of the first field trial is to test the first integrated prototype (in terms of acceptance, reliability and performance). The feedback will be subsequently used as input for the further development resulting in the second integrated prototype (during the 2nd integration phase) and finally for the second field trials. After the 3rd integration phase, the final prototype will be developed.

For the qualitative trial altogether 16 carers and 20 Persons with Dementia (PwD) they care for will be included in the two trial sites of Austria and Romania. For the second field study, which has a quantitative focus, in sum 60 carers will be invited to use the system for six months and the outcomes for 60 PwD they care for will also be monitored.

The results of the qualitative and quantitative trial will be described in D5.2 (Report of the User Trials and Evaluation).

1. ABOUT THIS DOCUMENT

1.1 ROLE OF THE DELIVERABLE

This deliverable serves as common document for the methodological conduction and analysis of the qualitative and quantitative trial which will be carried out in Austria and Romania.

1.2 RELATIONSHIP TO OTHER SUCCESS DELIVERABLES

The deliverable is related to the following SUCCESS deliverables:

DELIVERABLE	RELATION
Trials and Evaluation	The data collected automatically by the system and information gathered from the end-users in surveys, diaries, inter-views, questionnaires etc. is evaluated and conclusions are drawn in a final evaluation report.

1.3 STRUCTURE OF THIS DOCUMENT

Chapter 2 describes the aim of the qualitative and quantitative trials.

Chapter 3 describes the concept and methodology of the qualitative trial.

Chapter 4 describes the concept and methodology of the quantitative trial.

Appendix A presents the materials to be used during the Kick-off meeting (qualitative trial). Appendix B presents the materials to be used during the six-week follow-up interview (qualitative trial).

2. AIM AND STRUCTURE OF THE TRIALS

Based on initial plans, initial user needs assessment (through ethnographic studies) as well as feed-back provided on a first prototype (in the framework of two previous lab trials) the SUCCESS team has developed and built up a controlled environment running a special pilot application of the SUCCESS application. This includes mechanisms for monitoring the performance and reliability of the system, deploying updates, and remotely collecting the user feedback.

With the first field trial we aim to evaluate the platform in terms of user experience and its impact on caregiver satisfaction and burden and quality of life with a qualitative focus. After analysing those trials and adapting the prototype, a second field trial with 60 caregivers (and 60 PwD) will be conducted focusing again on the evaluation of user experience and its impact on the caregiver satisfaction and burden and quality of life but with a more quantitative focus. The caregivers will be equipped with the SUCCESS application and will — in addition to a comprehensive evaluation of the system — provide information on selected indicators such as improved caregiver satisfaction, reduced care burden, behavioural problems of the PwD (see section 1.4) in a pre-post design.

Table 1: Overview on study design of the two field trials

Aim	Method	Users	UCD activity
Evaluation of user inter- faces, services, acceptance, user experience, investi- gate effects on users; im- prove the system	Field-based study (qualitative focus).	each 8 (in-)formal carers in AT and RO / each 10 PwD in AT and RO	Evaluate designs against requirements
Evaluation of user inter- faces, services, acceptance, user experience, investi- gate effects on users; im- prove the system	Field-based study; pre–post design (quantitative focus)	each 30 (in-)formal carers in AT and RO / each 30 PwD in AT and RO	Evaluate designs against requirements

3. CONCEPT AND METHODOLOGY OF THE QUALITATIVE TRIAL

3.1 THE GENERAL OBJECTIVE OF THE FIRST FIELD TRIAL

The general objective of the first field trial is to evaluate the first integrated prototype of the SUC-CESS app in terms of user experience (acceptance, reliability, performance) and its impact on caregiver satisfaction and burden and quality of life. As this trial intends to create a use context that is as realistic as possible, i.e. allow the users an experience grounded in their regular everyday life, the methodological interventions were intentionally kept at a minimum level.

3.2 SPECIFIC OBJECTIVES

The specific objectives of the qualitative trial are:

- 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

3.3 STUDY SETUP

3.3.1 DURATION

The qualitative trial is planned to take place between 21st /22nd of May and 29th /30th of June (for a total of six weeks).

3.3.2 PARTICIPANTS

A total number of 16 caregivers and 20 PwD in two countries (i.e. Romania and Austria) will be involved in the trial. The caregiver category will include an opportunistically decided mix of formal and informal caregivers, of all genders and age groups (however, they should be at least 18 years old).

Involved **informal caregivers** are family members or relatives, who aid and supervise for a person living with dementia, as for example the husband, wife, daughter, son, daughter-, son-in-law, mother, father or a friend.

Involved **formal caregivers** are people, who professionally care for a person living with dementia (as an occupation). Thus, they have some kind of medical background but not necessarily are trained to care for a PwD. Formal caregivers involved in the study may work, for example, in a care home, a hospital, day care center, or as professional caregiver in a PwD's home.

3.3.3 DESIGN OF THE TRIAL

The trial will have three different stages, as follows:

- 1. Kick off meeting
- 2. Field phase
 - i. Telephone follow-up after 1 week
 - On-going feedback through dedicated social network channel or diary
- 3. Retrospective face to face follow-up after 6 weeks

3.3.4 VARIABLES OF INTEREST AND INSTRUMENTS TO BE USED

In this trial, we will collect socio-demographic data both for the caregiver and the person with dementia s/he cares for. In addition, for the carer we will also collect data on the usage of the app, both from the carers' perspective through interviews and through the SUCCESS app usage tracking data.

Additionally, the qualitative field trial will be used as a kind of test setting to evaluate some quantitative scales that will be used during the second field trial (e.g., Zarit scale, WHOQOL-BREF scale) (see section 0).

In the following, we provide an overview on data that will be collected during the trial:

- Data about the carer (formal/informal)
 - Socio-demographic data (gender, age, highest completed education, occupation, family status)
 - Background and care situation of formal/informal care giver (e.g., experience in the field of dementia care)
 - User experience data
 - User acceptance and satisfaction
 - User experience: utility, accessibility, ease-of-use and joy-of-use
 - Feedback on interaction design
 - Feedback on service design
 - Feedback on the interaction with the avatar
 - Feedback on business models
 - Changes in care (e.g., in terms of interaction with the PwD)
- System use patterns and frequency automatically collected through the app (usage tracking)
 - Usage frequency and duration for the general app
 - Usage frequency and duration of each content type (articles, video, avatar lecture)
 - Usage frequency of the features (learn and train, emotional support, meaningful activities)
 - Time of day for usage of the features
 - Search history
 - Number of quick info selected in a situation

Qualitative methods to be used:

- Group discussion (kick-off workshop)
- Social media feedback channel (throughout the study)
- Narrative interviews (telephone call after one week)
- Semi-structured interview (individual interviews at the end of the study)

Quantitative instruments to be used

- Burden of care: Zarit scale (pre-test only) (see Appendix A)
- Quality of life: WHOQOL-BREF scale (pre-test only) (see Appendix A)
- Behavioural problems in Dementia: Revised Memory and Behaviour Problems Checklist (pre-test only)
- Stage of dementia: Quick Dementia Rating Scale (QDRS) (pre-test only) (see Appendix B)
- BIG Five Inventory (BFI-10) (Romania, Austria)
- User experience: Usability Metrix for User Experience (UMUX)(Romania only) (see Appendix B)

3.4 STUDY PROCEDURE

3.4.1 KICK-OFF MEETING

The kick-off meeting will gather all caregiver participants (eight per country) and will last max. 2 hours (see Table 2). The objectives of the meeting are:

- To provide information about the trial methods and options to give feedback (i.e., messages, photos, videos, speech messages via social networks if participants wish; could be WhatsApp, Skype, Telegram, Facebook Messenger, etc.),
- To obtain informed consents,
- To provide information to the caregivers in terms of using the app
- To collect socio-demographic data and to fill in the Zarit and WHOQOL-BREF questionnaires,
- To answer the questions of the participants
- Scheduling the telephone call after one week with each participant.

Table 2: Agenda Kick-Off Meeting

Agenda Kick-Off Meeting	Duration
Reception of participants	10.30 – 11.00
Welcome; overview of the meeting agenda; introduction of partici-	11.00 – 11.15
pants	
Information about the project, presentation of the scope, goals and	11.15 – 11.30
methods of 1 st field trial, ethical and data management aspects	
(discussion and informed consent)	
Installation of the app; guided tour and trial of the features	11.30 – 12.00
Q&A session; information about option to give us feedback Data	12.00 – 12.10
collection (socio-demographic data, questionnaires)	12.10 – 12.25
Giving thanks, reimbursement, farewell	12.25 – 12.30
TOTAL	2 h

The materials used for the kick-off meeting are included in Appendix A.

3.4.2 TELEPHONE FOLLOW-UP

The objective of the telephone follow-up is to obtain feedback on possible difficulties encountered while using the app and provide support where needed. Besides the "on the fly" telephone interview, there is no scheduled interaction with the participants during the field phase.

3.4.3 ON-GOING FEEDBACK

The objective of the ongoing feedback is to record difficulties encountered with using the SUCCESS app *in situ*. The participants will be able to use their preferred method (i.e., messages, photos, videos, speech messages) and social networks of choice (e.g., WhatsApp, Skype, Telegram, Facebook Messenger, etc.) to get in contact with the SUCCESS research team. Allowing communication via habitual channels prohibits interference with their everyday life besides the usage of the SUCCESS app and minimizes methodological bias by distorting and interferences of new technology-supported communication channels.

3.4.4 FACE TO FACE FOLLOW-UP AFTER 6 WEEKS

At the end of the six-week trial period, one-hour individual interviews are planned with the 16 caregivers included in the trial. The objective of the semi-structured interviews is to obtain feedback about the use of the SUCCESS app in terms of user acceptance and satisfaction, user experience, interface design, service design, interaction with avatar and business models. In order to do so, we will use the semi-structured interview guide (see Appendix B).

3.4.5 INFORMED CONSENT

Article 17 of the Protocol to the Convention on Human Rights in Biomedicine or Biomedical Research states: "No research on a person may be carried out without the informed, free, express, specific and documented consent of the person".

This places a legal obligation on observers to obtain and record consent from participants or their guardians on the basis of information that should be given to them before their participation begins. In the present project, all participants will be fully informed and asked in advance to state that they are fully aware of the experimental procedure, the potential risks or benefits and that their participation is completely voluntary by signing an informed consent form (see Appendix A).

Participants have the right to withdraw their consent at any time without penalty and without providing reason. Participants can also require that their data is withdrawn from the study and destroyed/deleted. There will be arrangements for safe and straightforward cessation of use by an individual who initially agreed to participate but later decides to withdraw from the study.

Informed consent forms will include all subsets of the following details:

- that the project involves research,
- overall purpose of the project,
- experimental procedure,
- potential risks and benefits,
- inclusion/exclusion criteria,
- the person to contact for further information regarding the project
- the rights of project subjects,
- whom to contact in the event of project related injury,
- planned usage of the data,
- possible commercial exploitation.

3.4.6 DATA ANALYSIS

The qualitative data gathered during the interviews will be analysed by means of a thematic analysis (e.g., using ATLAS.ti) in order to identify main issues and improvement suggestions reported by users as well as aspects of their general satisfaction when using the SUCCESS app.

Questionnaires will be statistically analysed by using SPSS software. However, the main purpose of quantitative data collection in the framework of the qualitative trial is the piloting of instruments.

All issues that come up during the study will be collected and documented in the issue tracking system to inform technical partners and to allow for adapting the prototype for the second field trial.

3.4.7 DATA MANAGEMENT

According to the EU data protection and privacy regulations, people have the right to protection of their privacy and personal data. The right to privacy entitles everyone to respect for his or her private and family life, home and communications. The right to data protection entitles everyone to the protection of personal data concerning him or her.

The users' personal data in SUCCESS is processed fairly for specified purposes and based on the consent of the person concerned or some other legitimate basis laid down by law. SUCCESS also guarantees that every participant has the right to access data, which has been collected concerning him or her, and the right to have it rectified. The right to privacy includes the right to control personal data. That is, the user must be aware of the data, the time period for which they are stored, and people who have access to the information. Further, the user has the right to object to the data processing.

3.4.8 ACCESS TO DATA

Within this study, only employees of the respective organization that conducts the study will have access to the raw data. These are employees of RAS in Romania and employees of AIT in Austria. It is stated explicitly that data will be transferred from one partner to another within the consortium only after it was made pseudonymous. That means AIT (and the rest of the SUCCESS consortium) will only get access to pseudonymized data from the study conducted in Romania and RAS (and the rest of the SUCCESS consortium) will only get access to pseudonymized data from the study conducted in Austria.

3.4.9 REIMBURSEMENT

Participants of the study will be given a reimbursement in the amount of 50 Euro in Austria for their time efforts in participating in the study. The costs for reimbursements are taken over by EUR/AIT in case of Austrian participants.

3.4.10 MATERIAL NEEDED

- Agenda
- Signed agreement of the institution (care home, hospital, etc.)
- Informed Consent

- SUCCESS App installation file
- Interview guide
- Questionnaires
- Voice recorder (for the interview at the end; Smartphone, etc.)
- Reimbursement
- Reimbursement form

4. QUANTITATIVE TRIAL CONCEPT AND METHODOLOGY

The methodology for the 2^{nd} SUCCESS field trial will be reported in the M21 version of this deliverable.

5. APPENDIX A

5.1 INFORMED CONSENT (ENGLISH)

INFORMED CONSENT

1. INTRODUCTION

The study described below is part of the research project SUccessful Caregiver Communication and Everyday Situation Support in dementia care (SUCCESS). This project receives funding as part of the funding programme AAL. You have been invited to participate in this study. Before you agree to participate in this study, please read all information carefully and do not hesitate to ask if you have any questions regarding the study or the potential benefits and risks involved.

2. GOAL OF THE RESEARCH PROJECT

The general objective of the study (a qualitative field trial) is to test the first integrated prototype of the SUCCESS app in terms of user experience (acceptance, reliability, performance) and its impact on caregiver satisfaction and burden and quality of life.

By participating in this study and providing feedback you actively contribute to improvement of the SUCCESS app. Your feedback will be used to improve and optimise the features of the SUCCESS app.

3. CONDITIONS OF PARTICIPATION

Participation in this scientific study is voluntary. You may withdraw or stop your participation at any time without incurring legal or other consequences. Once you have decided to withdraw from the study and have notified the study leader of your decision, your data will not be used in any subsequent phases of the project. It will not, however, be possible to alter any documents containing your data which have already been published or project reports prepared for the funding provider.

4. TARGET GROUP

The persons participating in this study are carers of persons with dementia, who have a caring experience of at least one year and own (and use) an android smart phone that can support the SUCCESS app.

5. PROCEDURE

Place: Bucharest and Vienna

Duration of study: 6 weeks (21/22 May - 29/30 June

Description of study task(s):

The trial will have four different stages, as follows:

- 4. Kick off meeting
- 5. Telephone follow-up after 1 week
- 6. On-going feedback through dedicated social network channel OR diary
- 7. Face to face follow-up after 6 weeks:

You will receive [EUR [...] in compensation for participation after signing Annex./1 and following confirmation by the project manager of the study.] / You will receive no compensation for participation.

6. POTENTIAL RISKS

You do not incur any risk by participating in this study.

7. CONFIDENTIALITY

All personal details and data will be kept strictly confidential and anonymous. The data collected by us will not be able to be used to track your identity at a later date. The information gathered as part of this study will be published in reports on the research project or in scientific papers in the form of statistical evaluations or scenarios without including any personal details. The SUCCESS team will pseudonymise/encrypt/anonymise or otherwise secure any type of personal data used for scientific purposes, as required, so that your name or other personal data cannot be identified by third parties. The personal data provided by you on a voluntary basis will be stored in such a way that only the SUCCESS team has access to them. Personal data will not be disclosed to third parties without your express consent.

8. CONTACT

If you require further information about your rights as a study participant or the study itself, or if you have further questions or wish to abort the study, please contact [...]

9. CONSENT

I have read and understood the Declaration of Consent.

I hereby give AIT permission to use the data (i.e. demographic data, questionnaires and opinions presented in recorded interviews or otherwise) obtained by means of research activities conducted in the framework of SUCCESS first field trial. I furthermore agree that these data are processed for purposes of analysis and used for obtaining results for the SUCCESS study and project.

I will receive [EUR ...] in compensation for participation in the study / I will receive no compensation for participation in the study.

I hereby declare that I have been fully compensated for my activities and for any rights of use granted and warrant that I will not make any further claims against AIT, [....] or third parties.

I, the undersigned, hereby declare that at the time of signing this Declaration of Consent,

☐ I am of full age and legal capacity.

☐ I am not of full age and/or legal capacity [requires additional signature by legal guardian]
Amendments and modifications to this Declaration of Consent shall be made in writing to be valid. This shall also apply to any waiver of the written form requirement.
This agreement is governed by the laws of the to the exclusion of the conflict of laws rules. The exclusive place of jurisdiction shall be Vienna.
Date / Place
Signature
[FULL NAME IN BLOCK LETTERS]
I hereby agree to the participation and use of data as stated above in my capacity as legal guardian Date / Place
Signature
[FULL NAME IN BLOCK LETTERS]

5.2 DEMOGRAPHIC DATA (ENGLISH)

DEMOGRAPHIC DATA

Please answer the following questions about yourself. Once again, we would like to point out that all data collected within the scope of these studies are treated anonymously and confidentially.

Age	Month of birth / year of birth:/						
Gender	female	0	male O	no ans	wer O		
Highest completed E	ducation						
0	Elementa	Elementary school					
0	Profession	onal Sch	nool / Apprentic	eship			
0	General	qualifica	ation for univers	ity entrance			
0	Universit	У					
0	Others:						
Family Status (multip	le choice)					
	single						
	married						
	living in a	a partne	ership				
	widowed						
	divorced						
Occupation							
0	full-time	employe	ed				
0	part-time employed						
0	on mater	nity lea	ve / leave of ab	sence			
0	in-service	e trainin	g				
0	unemplo retired or			s, who are not work	ing, people, who are		
Relationship with PwD							
Main carer of the PwD	Yes O	١	No O				
Live in the same house as the PwD	Yes O	N	No O				
Age PwD	Month of	birth / y	ear of birth:	/			
Gender PwD	female C)	male O	no ans	wer O		
Year of diagnostic							
MMSE score							

5.3 ZARIT CAREGIVER BURDEN SCALE (ENGLISH)

ZARIT CAREGIVER BURDEN SCALE

The next set of questions asks about how often certain situations arise as a result of any emotonal support or physical assistance that you provide to the person you are caring for.

	Never	Rarely	Some- times	Quite Frequently	Nearly Al- ways
1. How often do you feel that [he/she] asks for more help than [he/she] needs?	0 🗌	1	2 🗌	3 🗌	4 🗌
2. How often do you feel that because of the time you spend with [him/her] that you don't have enough time for yourself?	0 🗌	1	2 🗌	3 🗌	4 🗌
3. How often do you feel stressed between caring for [him/her] and trying to meet other responsibilities for your family or work?	0 🗌	1 🗌	2 🗌	3 🗍	4 🗌
4. How often do you feel embarrassed over [his/her] behavior?	0 🗌	1	2 🗌	3 🗌	4
5. How often do you feel angry when you are around [him/her]?	0 🗌	1	2 🗌	3 🗌	4 🗌
6. How often do you feel that [he/she] currently affects your relationships with other family members or friends in a negative way?	0 🗌	1	2 🗌	3 🗌	4 🗌
7. How often are you afraid of what the future holds for [him/ her]?	0 🗌	1	2 🗌	3 🗌	4 🗌
8. How often do you feel [he/she] is dependent on you?	0 🗌	1	2 🗌	3 🗌	4 🗌
9. How often do you feel strained when you are around [him/her]?	0 🗌	1	2 🗌	3 🗌	4 🗌
10. How often do you feel your health has suffered because of your involvement with [him/her]?	0 🗌	1	2 🗌	3 🗌	4 🔲

0 🗌	1	2 🗌	3 🗌	4 🗌
0 🗌	1	2 🗌	3 🗌	4 🔲
0 🗌	1	2 🗌	3 🗌	4 🔲
0 🗌	1 🗌	2 🗌	3 🗌	4 🗌
0 🗌	1 🗌	2 🗌	3 🗌	4
0 🗌	1	2 🗌	3 🗌	4 🔲
0	1	2 🗌	3 🗌	
0 🗌	1	2 🗌	3 🗌	4 🗌
0 🗌	1	2 🗌	3 🗌	4 🗌
0 🗌	1	2 🗌	3	4 🗌
0 🗌	1	2 🗌	3 🗌	4 🗌
0 🗌	1	2 🗌	3 🗌	4 🗌
		0	0	0

5.4 WHOQOL-BREF (ENGLISH)

WHOQOL-BREF

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

(Please circle the number)						
Very poor	Poor	Neither poor nor good	Good	Very Good		
1	2	3	4	5		

1. How would you rate your quality of life?

	(Please circle the number)								
	Very dissa- tisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satis- fied				
h	1	2	3	4	5				

2. How satisfied are you with your health?

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		(Please circle the number)					
		Not at all	A little	A moderate amount	Very much	An extreme amount	
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5	
4.	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5	
5.	How much do you enjoy life?	1	2	3	4	5	
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5	

		(Please circle the number)					
		Not at all	Slightly	A Moderate amount	Very much	Extremely	
7.	How well are you able to concentrate?	1	2	3	4	5	
8.	How safe do you feel in your daily life?	1	2	3	4	5	
9.	How healthy is your physical environment?	1	2	3	4	5	

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		(Please circle the number)						
		Not at all	A little	Moderately	Mostly	Completely		
10.	Do you have enough energy for everyday life?	1	2	3	4	5		
11.	Are you able to accept your bodily appearance?	1	2	3	4	5		
12.	Have you enough money to meet your needs?	1	2	3	4	5		
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5		
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5		

(Please circle the number)						
Very poor	Poor	Neither poor nor well	Well	Very well		
1	2	3	4	5		

15. How well are you able to get around?

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

		(Please circle the number)					
		Very dissa- tisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	
16.	How satisfied are you with your sleep?	1	2	3	4	5	
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5	
18.	How satisfied are you with your capacity for work?	1	2	3	4	5	
19.	How satisfied are you with your abilities?	1	2	3	4	5	
20.	How satisfied are you with your personal relationships?	1	2	3	4	5	
21.	How satisfied are you with your sex life?	1	2	3	4	5	
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5	
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5	
24.	How satisfied are you with your access to health services?	1	2	3	4	5	
25.	How satisfied are you with your mode of transportation?	1	2	3	4	5	

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

			•		•	
		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings, such as blue mood, despair, anxi- ety, depression?	1	2	3	4	5

(Please circle the number)

(Please circle Yes or No)

6. APPENDIX B

6.1 USABILITY METRIX FOR USER EXPERIENCE (ENGLISH)

THE USABILITY METRIX FOR USER EXPERIENCE

English:

Instruction: "How strongly do you agree with the following statements about SUCCESS? Please rate each statement on the scale from 1="Strongly Disagree" to 7="Strongly Agree"."

	1 (Strongly Disag- ree)	2	3	4	5	6	7 (Strongly Agree)
The capabilities of SUC-CESS meet my requirements.							
2) Using SUCCESS is a frustrating experience.							
3) SUCCESS is easy to use.							
4) I have to spend too much time correcting things with SUCCESS.							

(We will discuss the ratings after wards with the participants. E.g. "You rated the first question with a x. Could you please describe why?")

6.2 INTERVIEW GUIDELINE INFORMAL CARE GIVERS (ENGLISH)

Interview Guideline informal care giver

•	May the conversation be recorded? Yes / No
•	Apart from the SUCCESS app, have you ever downloaded an app to your SmartPhone that could support you in everyday caregiver activities? (e.g. an advisory) Yes / No
	If so, did you pay for it? Yes / No
	If so, how much?€
•	Can you imagine paying for an app that supports you in your daily care routine? Yes / No
	If so, what would such an app have to offer?
•	How much would you be willing to pay?€

1. General issues

As you know, the SUCCESS application is not yet a fully finished and perfectly working technology. Therefore, we would be very interested in hearing things that did not work or did not work properly. Can you tell us about anything that happened over the weeks?

2. Changes in care

Please think about the last weeks using the SUCCESS application: Did you experience any changes in your daily care routines or activities? Which ones?

3. General experiences with SUCCESS

- b. Please tell me about your most positive experiences with SUCCESS
- c. Please tell me about your most negative experiences with SUCCESS.
- d. What are your most favourite features of SUCCESS? Why?
- e. Can you tell us whether the SUCCESS App had any impact on aspects on your life?

If not mentioned by the participants, please ask for the following aspects:

- (Care) relationship between carer and PwD
- Potential of retaining care activities for longer time
- Satisfaction with care activities
- Self-confidence in care activities
- Compliance of PwD in care
- Caregiver burden
- Taking more care for oneself

4. Use of Features

- a. Did you use the Learn & Train feature? Yes / No
 - If yes: What was your impression?
 - If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
 - If yes: What did you think about the presented information?
 - If yes: What could be done to improve the Learn & Train feature?
 - If no: why?
 - If no: What could be done to improve the Learn & Train feature?
- b. Did you do role plays with the avatar? Yes/No
 - If yes: What was your impression?
 - If yes: What did you think about the presented information?
 - If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
 - If yes: To what extent do you consider the avatar to be "suitable" for the interaction in role play?
 - How was the comprehensibility
 - How was the naturalness (facial expressions, gestures, movement, charisma)?
 - What was the appearance like?
 - How did you feel about the emotions shown by the avatar?
 - If yes: What could be done to improve the role plays with the avatar?
 - If no: why?
 - If no: What could be done to improve the avatar role plays?
- c. Did you use the Quick info feature to get fast support in special situations? Yes / No
 - If yes: What was your impression?
 - If yes: What did you think about the presented information?
 - If yes: When did you use the Quick info feature?
 - If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
 - If yes: What could be done to improve the Quick info feature?
 - If no: whv?
 - If no: What could be done to improve the Quick Info feature?
- d. Did you use the Meaningful activities feature? Yes / No
 - If yes: What was your impression?
 - If yes: What did you think about the presented information?

- If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
- If yes: What could be done to improve the Meaningful activities feature?
- If no: why?
- If no: What could be done to improve the Meaningful activities feature?
- e. Did you use the Emotional support feature? Yes / No
 - If yes: What was your impression?
 - If yes: What did you think about the presented information?
 - If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
 - If yes: Did you experience any changes of your emotional state during the last weeks?
 - If yes: What could be done to improve the Emotional support feature?
 - If no: why?
 - If no: What could be done to improve the Emotional support feature?

5. Avatar in Roleplay (the order of block 6 and 7 is interchanged amongst participants)

a. Which avatar did you use in the roleplay? F / M
If you haven't tried the role play, which of the two avatars would you rather use?





b. I would like to ask you to look at this avatar and imagine the life of this person. Please tell me how you think this person is like, what their life looks like, what they like to do in their free time and so on.

How well do the following statements describe the personality of the avatar?

	1 = "E agre strong	e gree	- "Nei- ther	"Agree	5 = "Agree strongly"	6 = "I can't make an asses- ment"
(1) He/she is reserved.						
(2) He/she is generally trusting.						
(3) He/she tends to be lazy.						
(4) He/she is relaxed, handles stress well.						
(5) He/she has few artistic interests.						
(6) He/she is outgoing, sociable.						
(7) He/she tends to find fault with others.						
(8) He/she does a thorough job.						
(9) He/she gets nervous easily.						
(10) He/she has an active imagination.						

The following descriptions characterize changes in the cognitive and functional abilities of the person with dementia. You will now be asked to compare the person as he or she is now with what the person was like before - the main feature is the change. Choose one answer for each category that fits best to the person with dementia

- NOTE, not all descriptions must be available to select an answer.

1.	1. MEMORY AND REMEMBRANCE					
	No obvious memory loss or fluctuating forgetfulness that does not interfere with daily activities.					
	Constant slight forgetfulness or only partial remembrance of events that can disrupt everyday activities; repeated questions/statements, misplaced objects, forgets appointments.					
	Mild to moderate memory loss; more noticeable in recent events; impairs everyday activities.					
	Moderate to severe memory loss; only very well learned information is stored; new information quickly forgotten.					

	Severe memory loss, almost impossible to retain new information; long-term memory may be impaired.
2.	Orientation
	Completely oriented in terms of person, place and time, almost at any time.
	Slight difficulties with time recording; forgets the day or date more often than in the past.
	Slight to moderate difficulties in tracking the time and sequence of events; forgets month or year; orients to familiar places but gets confused outside familiar areas; gets lost or wanders around.
	Medium to severe difficulties, mostly disorientated in terms of time and place (familiar and unknown); often dwells in the past
	Only orientated towards the own name, however, can possibly recognize family members.
3.	DECISION-MAKING AND PROBLEM-SOLVING SKILLS
	Solves everyday problems without difficulty; manages personal business and financial matters well; decision-making ability equal to previous performance.
	Slight impairment or longer time needed to solve problem; problems with abstract concepts; decisions still well-founded.
	Moderate difficulty in dealing with problems and making decisions; postpones many decisions to others; social judgment and behavior can be easily impaired; loss of insight
	Seriously impaired in dealing with problems, only makes simple personal decisions; social judgment and behaviour often impaired; lack of insight.
	Unable to make decisions or solve problems; others make almost all decisions for the patient.
4.	ACTIVITIES OUTSIDE THE HOUSE
	Independently in their activity at the usual level of performance in work, shopping, community and religious activities, voluntary work or social groups
	Slight impairment of these activities compared to previous performances; slight change in driving ability; still able to cope with emergency situations.
	Unable to work independently, but still present and engaged; appears to others as "normal"; noticeable changes in driving skills; concerned about ability to cope with emergency situations

	No appearance of independent action outside the home; seems fit enough to be taken to activities outside the home, but generally needs to be accompanied						
	No independent activities; appears too sick to be taken to outside activities.						
5.	5. FUNCTION AT HOME AND HOBBY-ACTIVITIES						
	Tasks at home, hobbies and personal interests are well cared for in comparison to the previous performance.						
	Minor impairment of or interest in these activities; difficulties in operating equipment (in particular new purchases).						
	Slight but definite impairment of the home and hobby activity; more difficult activities or tasks neglected; more complicated hobbies and interests abandoned.						
	Only simple activities remain, very limited interest in hobbies that are poorly maintained.						
	No meaningful activity in the household or previous hobbies.						
6.	6. GOING TO THE TOILET AND PERSONAL HYGEINE						
	Full self-care ability (dressing, hairdressing, washing, bathing, going to the toilet).						
	Slight changes in skills and attention to these activities.						
	Requires the request to perform these activities, but can still perform them independently.						
	Requires help with dressing, hygiene, storage of personal belongings; occasionally incontinent.						
	Requires considerable help with body care and hygiene; frequent incontinence.						
7.	7. BEHAVIOURAL AND PERSONALITY CHANGES						
	Socially appropriate behaviour in the public and private spheres; no personality changes.						
	Questionable or very mild changes in behaviour, personality, emotional control, adequacy of decisions.						
	Slight changes in behavior or personality.						
	Moderate behavioural or personality changes, affects interactions with others; can be avoided by friends, neighbours or distant relatives.						
	Severe behavioural or personality changes; often makes interactions with others unpleasant or avoidable.						
8.	LANGUAGE AND COMMUNICATION SKILLS						

	No language difficulties or occasional word searching; reads and writes as well as in the past.					
	Persistent minor difficulty in finding words, uses descriptive terms or takes longer to communicate a topic, minor communication problems, fewer conversations; may interfere with reading and writing.					
	Moderate difficulties in finding words in the language, cannot name objects, significant reduction in word production; reduced understanding, conversation, writing and/or reading.					
	Moderate to severe impairments in speech production or comprehension; has difficulty communicating thoughts to others; limited ability to read or write.					
	Severe deficits in language and communication; little or no understandable language is produced.					
9.	MOOD					
	No change in mood, interest or motivation.					
	Occasional sadness, depression, anxiety, nervousness, or loss of interest / motivation.					
	Daily slight problems with sadness, depression, anxiety, nervousness or loss of interest / motivation.					
	Moderate problems with sadness, depression, anxiety, nervousness, or loss of interest / motivation.					
	Severe problems with sadness, depression, anxiety, nervousness, or loss of interest / motivation.					
10	. ATTENTION AND CONCENTRATION					
	Normal attention, concentration and interaction with the environment and surroundings.					
	Slight problems with attention, concentration and interaction with the environment and surroundings, may appear sleepy during the day.					
	Moderate problems with attention and concentration, may have gaze rigidity or spend time with closed eyes, increased drowsiness during the day.					
	A considerable part of the day is spent sleeping, without paying attention to the environment, can say things in conversation that are illogical or do not agree with the subject.					
	Limited to no ability to pay attention to external environment or surroundings.					

How well do the following statements describe the personality of the PwD?

	1 = "L agre strong	ee gree	- "Nei- ther	"Agree	6 = "I can't make an asses- ment"
(1) He/she is reserved.					
(2) He/she is generally trusting.					
(3) He/she tends to be lazy.					
(4) He/she is relaxed, handles stress well.					
(5) He/she has few artistic interests.					
(6) He/she is outgoing, sociable.					
(7) He/she tends to find fault with others.					
(8) He/she does a thorough job.					
(9) He/she gets nervous easily.					
(10) He/she has an active imagination.					

Would you like to add anything else?

Have you used your own mobile phone or an AIT mobile phone?

- If own mobile phone: Send tracking
- If AIT mobile phone: return

May we contact you again in the future for follow-up studies etc.? Yes / No

6.3 INTERVIEW GUIDELINE FORMAL CARE GIVERS (GERMAN)

Interview Guideline formal care giver

•	May the conversation be recorded? Yes / No
•	Apart from the SUCCESS app, have you ever downloaded an app to your SmartPhone that could support you in everyday caregiver activities? (e.g. an advisory) Yes / No
	If so, did you pay for it? Yes / No
	If so, how much?€
•	Can you imagine paying for an app that supports you in your daily care routine? Yes / No
	If so, what would such an app have to offer?
•	How much would you be willing to pay?€

1. General issues

As you know, the SUCCESS application is not yet a fully finished and perfectly working technology. Therefore, we would be very interested in hearing things that did not work or did not work properly. Can you tell us about anything that happened over the weeks?

2. Changes in care

Please think about the last weeks using the SUCCESS application: Did you experience any changes in your daily care routines or activities? Which ones?

3. General experiences with SUCCESS

- b. Please tell me about your most positive experiences with SUCCESS
- c. Please tell me about your most negative experiences with SUCCESS.
- d. What are your most favourite features of SUCCESS? Why?
- e. Can you tell us whether the SUCCESS App had any impact on aspects on your life?

If not mentioned by the participants, please ask for the following aspects:

- (Care) relationship between carer and PwD
- Potential of retaining care activities for longer time
- Satisfaction with care activities
- Self-confidence in care activities
- Compliance of PwD in care
- Caregiver burden

Taking more care for oneself

4. Use of Features

- a. Did you use the Learn & Train feature? Yes / No
- If yes: What was your impression?
- If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
- If yes: What did you think about the presented information?
- If yes: What could be done to improve the Learn & Train feature?
- If no: why?
- If no: What could be done to improve the Learn & Train feature?
- b. Did you do role plays with the avatar? Yes/No
- If yes: What was your impression?
- If yes: What did you think about the presented information?
- If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
- If yes: To what extent do you consider the avatar to be "suitable" for the interaction in role play?
 - How was the comprehensibility
 - How was the naturalness (facial expressions, gestures, movement, charisma)?
 - What was the appearance like?
 - How did you feel about the emotions shown by the avatar?
- If yes: What could be done to improve the role plays with the avatar?
- If no: why?
- If no: What could be done to improve the avatar role plays?
- c. Did you use the Quick info feature to get fast support in special situations? Yes / No
- If yes: What was your impression?
- If yes: What did you think about the presented information?
- If yes: When did you use the Quick info feature?
- If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
- If yes: What could be done to improve the Quick info feature?
- If no: why?
- If no: What could be done to improve the Quick Info feature?

- d. Did you use the Meaningful activities feature? Yes / No
- If yes: What was your impression?
- If yes: What did you think about the presented information?
- If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
- If yes: What could be done to improve the Meaningful activities feature?
- If no: why?
- If no: What could be done to improve the Meaningful activities feature?
- e. Did you use the Emotional support feature? Yes / No
- If yes: What was your impression?
- If yes: What did you think about the presented information?
- If yes: How useful was this feature to you? Could you please describe a typical situation when you used it?
- If yes: Did you experience any changes of your emotional state during the last weeks?
- If yes: What could be done to improve the Emotional support feature?
- If no: why?
- If no: What could be done to improve the Emotional support feature?

•

- **5. Avatar in Roleplay** (the order of block 6 and 7 is interchanged amongst participants)
- a. Which avatar did you use in the roleplay? F / M

If you haven't tried the role play, which of the two avatars would you rather use?





I would like to ask you to look at this avatar and imagine the life of this person. Please tell me how you think this person is like, what their life looks like, what they like to do in their free time and so on.

b. How well do the following statements describe the personality of the avatar?

	1 = "E agre strong	ee gree	- "Nei- ther	"Agree	6 = "I can't make an asses- ment"
(1) He/she is reserved.					
(2) He/she is generally trusting.					
(3) He/she tends to be lazy.					
(4) He/she is relaxed, handles stress well.					
(5) He/she has few artistic interests.					
(6) He/she is outgoing, sociable.					
(7) He/she tends to find fault with others.					
(8) He/she does a thorough job.					
(9) He/she gets nervous easily.					
(10) He/she has an active imagination.					

How well do the following statements describe the personality of the PwD?

	1 = "D agre strong	e gree	ther	"Agree	6 = "I can't make an asses- ment"
(1) He/she is reserved.					
(2) He/she is generally trusting.					
(3) He/she tends to be lazy.					
(4) He/she is relaxed, handles stress well.					
(5) He/she has few artistic interests.					
(6) He/she is outgoing, sociable.					
(7) He/she tends to find fault with others.					
(8) He/she does a thorough job.					
(9) He/she gets nervous easily.					
(10) He/she has an active imagination.					

Would you like to add anything else?

Have you used your own mobile phone or an AIT mobile phone?

- If own mobile phone: Send tracking

- If AIT mobile phone: return

May we contact you again in the future for follow-up studies etc.? Yes / No