

ENGAGEMENT OF TEST PERSONS AND CONSIDERATION LEGAL ASPECTS

Deliverable D.T3.7.2

Version 1
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1. Introduction

This document describes the engagement process of the elderlies, who are to act as test persons for the Monitoring Grid. A total of thirteen people have been acquired for the project and informed about the principles and benefits of the pilot action during an initial meeting. Due to the current situation with Covid-19, only meetings with individuals could be organized. During these meetings, the written consents based on the provisions of the General Data Protection Regulation (GDPR) have been also obtained.

The document is structured as follows: In order to gain enough participants for the project, the definition of the target group had to be adapted first. All changes are described in more detail in “2. Modifications”. “3. Engagement of participants” shows the contact and engagement process. After the participants are described in “4. Description of the participants” a summary of the initial meetings can be found in “5. Description of the initial meetings with participants”. Finally, the legal aspects are discussed in more detail.

2. Modifications

In order to achieve sufficient and measurable results, two major changes were made (according to the requirements of the Application Form).

1. Adaptation of the definition of the target group

In order to be able to contact enough participants, we first adapted the definition of the target group. The target group, as defined in the application form under “D.T3.7.2 Engagement of test persons and consideration of legal aspects” (*engagement of at least 10 residents in Home of assisted living in Mittelburgenland*), was too restrictive. The Samaritan Burgenland Department of Home Care has a total of only ten residents in Homes of assisted living in Mittelburgenland (five in Weppersdorf, five in Lackenbach) and not everybody wanted to take part in the project. For this reason, we have expanded the target group as follows:

Target group	Reason for selection of the target group
Persons,	
1. who are older than 75 years old,	<u>Age</u> : This criteria is based on the Monitoring Grid in Bologna
2. live in Burgenland and	<u>Region</u> : In middle of Burgenland we have too few residents in homes of assisted living and too few home emergency call users. For this reason we have expanded the target group to entire Burgenland.
3. who have a home emergency call, which can be expanded to include the service button. ¹	<u>Use of home emergency call</u> : In the needs analysis, which was carried out in WP T1, it turned out that possible participants also want to have the opportunity to contact the monitoring team. For this reason, this criterion has been added, but it is <u>not mandatory</u> to meet it.

¹ Note: Not all home emergency calls can be expanded to include an additional button. The mobile devices, for example, do not have this option.



2. Contact with home care givers/ family members

The Monitoring Grid focuses in particular on two goals:

- To detect early signs of deterioration of health and social conditions
- To enable elderlies a self-estimated life in their homes as long as possible

Accordingly, the Monitoring Grid primarily appeals to people whose state of health is still so good that they can live alone in their own home. The persons addressed here therefore do not need the support of home care givers or family members. For this reason, no contact could be made with home care givers (as none of the people involved need to seek help from care givers). Furthermore, no contact had to be established with family members, since twelve of the thirteen people involved live alone and all thirteen participants do not have to be looked after by family members.

3. Engagement of participants

As already described under “2. Modifications”, the target group has been expanded to the following:

Persons,

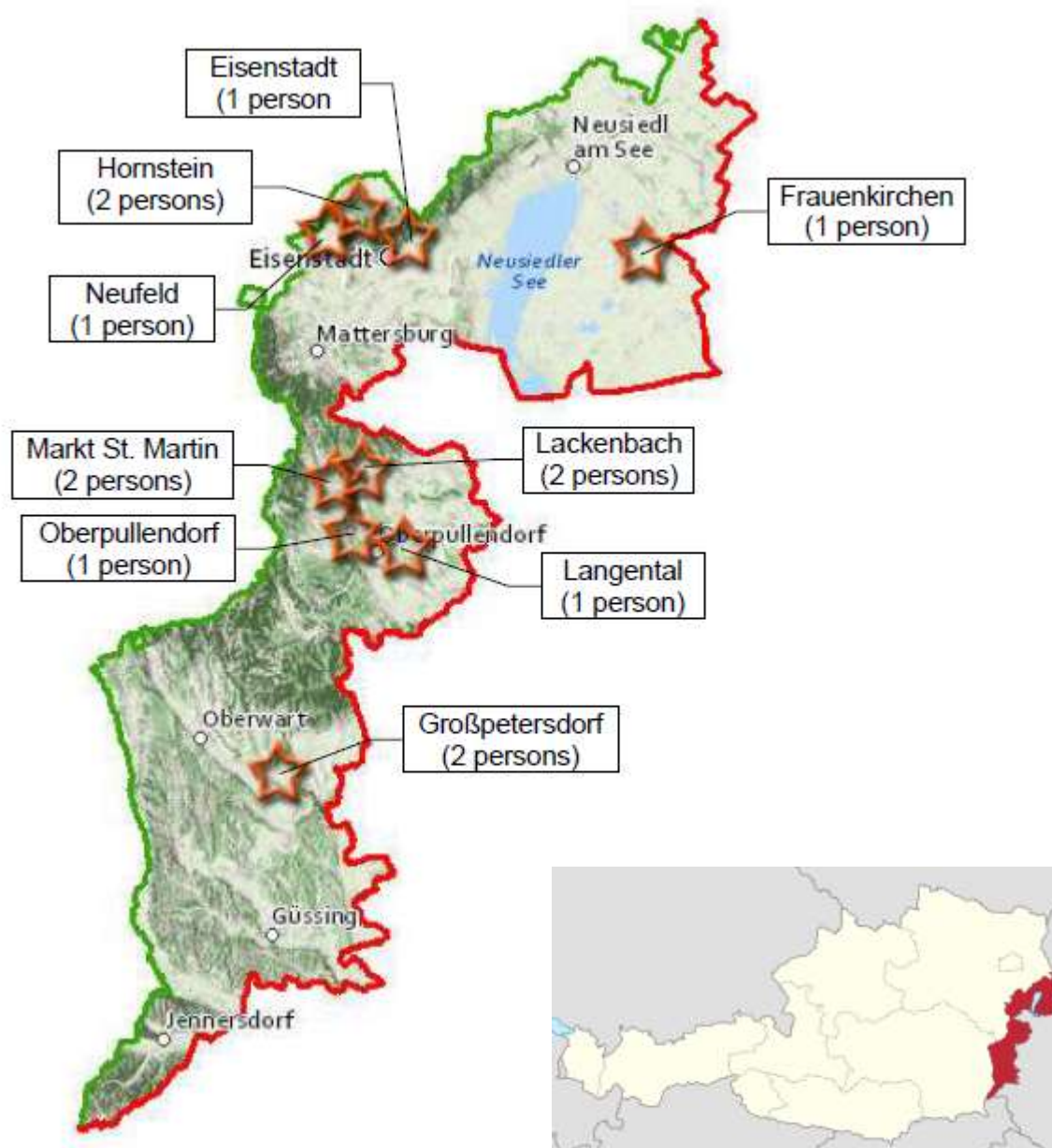
- who are older than 75 years old,
- live in Burgenland and
- who have a home emergency call, which can be expanded to include the service button.

The home emergency call has a total of 200 customers (146 female, 21 male, 33 companies, as of February 2021). Based on the target group listed above, 114 of these 200 customers were contacted in writing in August 2020. (The letter is shown in the appendix). The non-contacted persons were either too young or did not have a suitable home emergency call, which can be expanded to include another function. 103 of the people contacted were female, eleven were male. The youngest person was 75 and the oldest person was 101 years old.

After this letter was sent out, a total of six persons have re-registered by the end of September 2020. Two of them had some questions about the project, but did not want to take part in the pilot action. In order to get more participants, we subsequently actively contacted relevant people by telephone and asked the residential area managers of the nursing and assisted living homes for help in November 2020. As a result, a total of thirteen participants could be engaged by the end of December 2020.

4. Description of the participants

A total of thirteen people between 75 and 87 years old will take part in the project. All participants are female. Unfortunately, male participants could not be acquired for the project. Nine elderlies, who take part in the project, live alone in a house or an apartment, three of them live in the homes of assisted living provided by the Samaritan Burgenland Department of Home Care, and one of them lives with her daughter and son-in-law. Only one person does not have a home emergency call and only two are interested in having their own account in the Monitoring Grid. Three of the participants live in the north (Eisenstadt, Neusiedl am See), eight in the middle (Oberpullendorf), and two live in the south of Burgenland (Oberwart). The exact spatial distribution of the participants is shown in Figure 1. Table 1 summarizes the most important data of the participants. In order to guarantee anonymity and still allow an evaluation of the data, numbers were assigned to the participants.



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Figure 1: Burgenland in Austria

Figure 2: Place of residence of the participants in Burgenland

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² <https://de.wikipedia.org/wiki/Burgenland>

³ created in www.geodaten.bgld.gv.at



Data of the participants

Participant number	Sex	Year of Birth	Age (Dec 2020)	District in Burgenland	NUTS Region	Living conditions	Home emergency call	Wants to have a user for Monitoring Grid	Consent to publish photos / videos	Initial meeting
1	female	1934	86	Oberpullendorf	111	alone	Yes	No	Yes	09.02.2021
2	female	1945	75	Oberpullendorf	111	alone	Yes	No	Yes	09.02.2021
3	female	1940	80	Eisenstadt	112	alone	Yes	No	Yes	09.02.2021
4	female	1933	87	Oberpullendorf	111	alone	Yes	No	Yes	10.02.2021
5	female	1938	82	Oberpullendorf	111	alone	Yes	No	Yes	10.02.2021
6	female	1939	81	Neusiedl am See	112	alone	Yes	No	No	11.02.2021
7	female	1936	84	Oberpullendorf	111	with her daughter and son in law	Yes	Yes	Yes	15.02.2021
8	female	1935	85	Oberpullendorf	111	alone	Yes	Yes	No	15.02.2021
9	female	1941	79	Oberpullendorf	111	alone in an assisted living home	No	No	Yes	15.02.2021
10	female	1935	85	Oberpullendorf	111	alone	Yes	No	Yes	15.02.2021
11	female	1937	83	Oberwart	113	alone in an assisted living home	Yes	No	Yes	17.02.2021
12	female	1936	84	Oberwart	113	alone in an assisted living home	Yes	No	Yes	17.02.2021
13	female	1935	85	Eisenstadt	112	alone	Yes	No	No	17.02.2021

Table 1: Data of the participants



After the most important data of the participants have been summarized, the participants and the first perceived impression shall now be briefly introduced:

- 1: lives alone in a house; has a nephew who visits her regularly; do not want to live at home anymore and wants to move in a nursing home; is very skeptical about the project; nephew persuaded her to meet with the project team; after detailed project information and list of the advantages of participating in the project, she has agreed to take part; complains of pain and has difficulties in walking, but has a stick to help her to walk; has no technical knowledge; cannot use a computer.
- 2: lives alone in a house; son and daughter-in-law live next door; has back pain; seems very open to the project; cannot use a computer.
- 3: lives alone in a house; daughter is a doctor and lives in Vienna (about 50 km away); daughter usually visits her regularly, but because of Covid-19, she comes very rarely, but they talk often per phone; is extremely afraid of Covid-19, deals a lot with her hobbies (knitting, crochet, making dolls,...); manages her banking transactions online independently; at the time of initial meeting she is living very isolated due to the current situation with Covid-19; is very open-minded about the project and looks forward to the start of the calls, feels the project is very valuable.
- 4: lives alone in an apartment; feels a lot alone and lonely due to Covid-19; devotes a lot of time to her hobbies (e.g. sewing); has a tablet which she regularly uses for phone calls with her family; family does not live nearby; has hardly any friends anymore, since everyone has passed away; is very open-minded about the project and looks forward to participating in the project.
- 5: lives alone in a house; very open-minded and sociable; likes to talk; very open-minded about the project and looks forward to the beginning.
- 6: lives alone in a house; seems very withdrawn and lonely, has a smartphone that she uses regularly, suffers a lot from Covid-19.
- 7: lives with her daughter and son-in-law in a house; cooks regularly for her grandchildren and great-grandchildren; walks with a walker; is interested in having her own account in the monitoring grid (USER); seems very open-minded about the project.
- 8: lives alone in a house; daughter who takes care of her, lives normally in Vienna and is self-employed, due to Covid-19 she can spend a lot of time with her mother; says of herself that she can still do a lot, but is very slow with the things she does; seems a little bit shy and withdrawn; daughter also says that it is rather difficult to get to her; is interested in having her own account in the monitoring grid (USER), but more as information for daughter; participant has no technical knowledge.
- 9: lives in the homes of assisted living of the Samaritan Burgenland Department of Home Care; has NO home emergency call; has grandchildren and great-grandchildren, who visit her regularly.
- 10: lives alone in a house; is very talkative and sociable; is very involved in her community; has many friends and acquaintances (the phone rang three times during the 1-hour visit); husband had recently died and she is still in mourning, but does not seem lonely or alone.
- 11: lives in the apartments of assisted living of the Samaritan Burgenland Department of Home Care; has 3 sons and daughters-in-law nearby, who also visits her regularly, seems very sociable and open-minded, also has a granddaughter who visits her regularly.
- 12: lives in the apartments of assisted living of the Samaritan Burgenland Department of Home Care; has a dog with whom she regularly goes out; suffers from the consequences of Covid-19, she appears to be very talkative but calm.
- 13: lives alone in an apartment; is very critical and skeptical; does not want anyone to take photos of her; very lonely and isolated; especially Covid-19 hits her very hard; has a son who is, however, only inaccessible; is afraid of data protection abuse and that actions are taken without her consent.



5. Description of the initial meetings with the participants

The first meetings with the engaged participants fell in a risky phase of Covid-19. All measures prescribed by the government were complied with:

- Organization of meetings with only one person
- Continuous wearing of a FFP2-mask
- Keep distance
- Compliance with all hygiene measures

The breakfast briefing (D.C.6.1 Breakfast briefings with elderly and caregivers) was not allowed to take place at all.

The following activities were carried out during these first meetings:

1. The participants were informed about
 - a. the most important benefits and principles of the project. In order not to overwhelm the elderly, they were also given written project information with the most important project data and contact details. This enabled them to read through everything important again after the visit and, if questions arise, to call the responsible person.
 - b. the functionality of the Monitoring Grid and the time span of the testing as well as the further procedure of the pilot.
 - c. that this phase is a pilot and that the Samaritan Burgenland Department of Home Care cannot give any guarantee for all measures taken. This is also anchored in the written consent.
 - d. the possibility that the data or the analysis of the data can also be viewed from the elderly themselves. However, only two of the thirteen participants visited wanted to make use of this opportunity.
2. The home emergency call service button was installed and activated. This gives the participants the opportunity to contact the monitoring team by themselves. The activation of the service button could be done for twelve of the thirteen participants. One participant does not use the home emergency call. More information about the installation process can be found in the deliverable “D.T3.7.4 Installation and testing of technical devices and application.”
3. The written consents, which were worked out together with the legal department of the Samaritan Vienna Department of Home Care and an external expert, was explained to the elderlies and the signature obtained.
4. Some questionnaires, which are supposed to show whether the Monitoring Grid improves the quality of life or the social isolation, for example, over time, were carried out with the participants. It was up to them to decide whether we should go through the questionnaires together or whether the participants want to fill them out alone. This should allow the elderly as much discretion as possible.

These visits took place from 09.02.2021 to 17.02.2021 and lasted an average of one hour.

6. Consideration of legal aspects

Since the project mainly collects and analyzes personal and health-related data, the legal provisions of the EU's General Data Protection Regulation (GDPR) must be addressed in particular. For this reason, the following documents were developed together with the legal department of the Samaritan Vienna Department of Home Care and external experts who are specialized in these matters as part of the project:

1. Data protection information

This document serves as the basis for the declaration of consent under data protection law and informs the participants about important articles of the General Data Protection Regulation in connection with the project, such as the rights of the participants (Articles 15-20 of the GDPR) as well as the use, processing, storage duration, and transmission of the data collected.

2. Declaration of consent under data protection law

This document obtains the written consent of the participants for the storage and further use of the health-related and other data obtained. In addition, it provides information about the revocation that is possible at any time. The signature was obtained during the initial meeting.

3. Declaration of consent for the transmission of data

This document obtains the consent of the participants for a possible transfer of the data to other institutions and organizations, such as funding agencies. The signature was obtained during the initial meeting.

4. Declaration of consent for use of images from videos and photos

This declaration obtains the consent of the participants in the event that the Samaritan Burgenland Department of Home Care takes photos of the participants as part of the project and uses them for marketing measures or as evidence for external test centers and for project documentation. In addition, it provides information about the revocation that is possible at any time. The signature was obtained during the initial meeting.

5. Data protection impact assessment

The “Data protection impact assessment” is a structured risk analysis in order to be able to evaluate possible consequences of the processing of the collected data in advance.

In addition to these documents, the three interviewers have completed **special training courses** offered by the Samaritan Burgenland Department of Home Care, namely “data protection training” and “digital security at work”. The training of the interviewers in this direction is intended to additionally ensure the protection of the participants' data.

7. Conclusion

A total of thirteen people between 75 and 87 years old have been acquired for the project. All participants are female. Unfortunately, male participants could not be gained for the project. During an initial meeting, the participants have been informed about the principles and benefits of the project and the written consents have been obtained. Furthermore the home emergency call service button was activated during this initial meeting and some questionnaires, which are supposed to show whether the Monitoring Grid improves the quality of life or the social isolation, for example, over time, were carried out with the participants. The initial meetings took place from 09.02.2021 to 17.02.2021 and lasted an average of one hour.

In order to ensure the protection of the collected data in accordance with General Data Protection Regulation (GDPR), various documents were drawn up together with the legal department of Samaritan Vienna Department of Home Care and external experts who are specialized in these matters, including diverse declarations of consent. Furthermore, the three interviewers have completed special training courses offered by the Samaritan Burgenland Department of Home Care, namely “data protection training” and “digital security at work”.



8. Appendix

1. First cover letter to possible test subjects
2. Data protection information + Declaration of consent under data protection law + Declaration of consent for the transmission of data
3. Declaration of consent for use of images from videos and photos
4. Data protection impact assessment
5. Signed consents forms from the participants