TOPIC

The Online Platform for Informal Caregivers
1.1.1.1 Project No. AAL-2012-5-169

Selected End Users

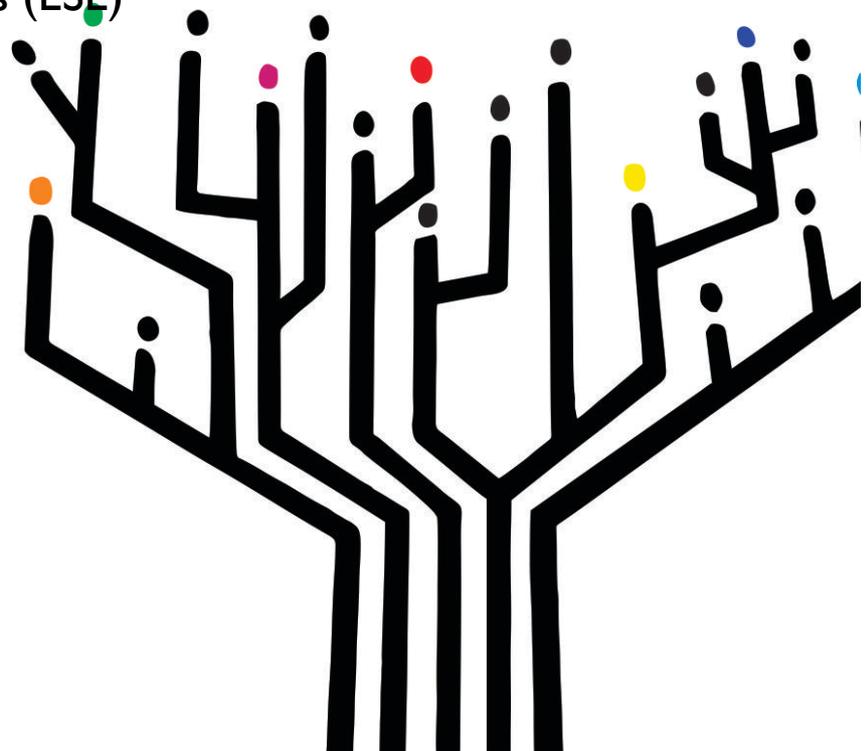|	
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Task	T1.1: Identification of end users
Coordination	Troyes University of Technology (UTT)
Contribution	Vienna University of Technology (TUW)
	University of Siegen (USI)
	SOZIAL GLOBAL Aktiengesellschaft (SOGL)
	SOPHIA Franken GmbH & Co KG (SOPHIA)
	E-Seniors (ESE)

Contents

2 Introduction

Fieldwork and evaluation with caregivers is one of the key dimensions of the user-centred and participatory approach developed in the TOPIC project. Our ambition is to develop innovative solutions from the understanding of informal caregivers' daily life and the problems they may encounter. Our aim is then to follow and work with 90 participants along the different phases of the project, 30 in each participating country (Austria, France and Germany).

The present deliverable reports the work done in task 1.1 "Identification of end users", part of the Work Package 1: "Requirement Analysis and Identification of User Scenarios".

We will first introduce the methodology jointly elaborated by the WP1 partners. It defines how to present the project to potential end-users or "gate keepers", to identify relevant participants and recruit prospective end-users for the different project phases along the development of the *CarePortfolio*. The documents, which have been used to present the project and to support the coordination among the project members, are provided in Appendix.

The T1.1 outcome enables us to begin with confidence the work for the T 1.2 (End-users context and everyday life understanding) as we detail in conclusion.

3 Methodology

This section details the approach developed in T1.1 for recruiting participants, the defined inclusion criteria and the guidelines elaborated to support the WP1 stakeholders to get contact with prospective end users.

3.1 Participant groups

In line with the project objectives, we have defined three groups of end-users, according to the three main phases where strong interactions with end-users are needed:

1. Contribute to the project promotion and to the dissemination of its results;
2. Pre study;
3. Usability tests;
4. Longitudinal study.

The distribution of the 30 participants in each country will then be the following:

- 10 participants for the pre-study (T1.2). These participants will participate during the 3 years of the project, from the pre-study to the longitudinal field study (T4.3).
- 10 other participants who will be involved only in the usability tests' sessions (T4.1, T4.2).
- 10 other participants to join the 10 initial participants for the longitudinal field tests (the system will be installed in their homes) (T4.3).

Due to the uncertainties and the potential changes that may occur in the participants' life during the three years of the TOPIC project, the WP1 stakeholders have chosen to develop contact with more participants than the initial 30 and to pursue the recruitment concurrently with the different project phases. In particular, the pre study group has been identified as the most important one, so the recruitment is actually focused on this group, and the WP1 partners plan to recruit more than 10 people in each country.

3.2 Inclusion criteria

The WP1 partners have collectively defined the inclusion criteria for the informal carers participating to the project. These criteria are:

- 50+ years old (extended definition of "elderly").
- Caring for other, ill or handicapped people who need full-time care (friends or family).
- Working (full or part-time) or not working/retired.
- Living or not in the same household with the care recipient.
- Based at rural or urban areas.
- Male or female.

The project members agree to try as much as possible to find a balance between persons living in urban and rural areas, and between genders among the participants.

3.3 Introducing the project and the data collection activities to participants

WP1 partners have collectively defined how to communicate with potential end-users, directly, or via associations or clubs. The result of this collective work is materialized by two flyers, one for informal caregivers (Appendix 1), the other one for associations (Appendix 2), and guidelines on how to present the data collection activity to potential participants (Appendix 3). The flyers were translated in French and German and adopted to the respective countries with the individual partner contracts (appendices provide the shares, English version).

These guidelines were important to define, as the methodology that has been defined in WP1 to collect data (see D1.2) contains several steps, techniques and materials that are essential to entering the highly sensitive field.

The following process has been defined, and is actually carried out in the 3 participating countries (results described below):

1. Contact potential participants (direct end-users or associations or clubs).
2. Present the project using the flyer(s).
3. Inform participants of the data collection activities (following the guidelines).
4. Recruit participants:
    a. Informed Consent Form should be presented and signed at the moment participants agree to take part in the project activities.
5. [Optional] Put participants and researchers in touch (when participants are recruited by non-academic partners):
    a. Informal meeting featuring the participant, the researcher(s) who will be interacting with her/him, and a member from the end-users recruitment organization.
6. Schedule the first observation session.

4 Results

Tables 1and 2 represent the actual state of our recruitment activity:

- Table 1 displays the recruiters, the phase in which the participants will take part and their living area. As already described above, the most important group is the one that will participate to the whole project, we have focused on this target.
- Table 2 displays the values of the inclusion criteria described before, for the care recipient and the informal caregiver.

Table 1: General information on the recruited participants.

Recruiter	Recruitment ID	Phase of recruitment	Country	Town/city	Type of living area
Troyes University of Technology	1	Pre-study and longitudinal study	France	Rigny le Ferron	Rural area
Troyes University of Technology	2	Pre-study and longitudinal study	France	Auxon	Rural area
Troyes University of Technology	3	Controlled lab tests	France	Geraudot	Rural area
Troyes University of Technology	4	Pre-study and longitudinal study	France	La chapelle Saint Luc	Urban area
Troyes University of Technology	5	Pre-study and longitudinal study	France	Buchères	Rural area
Troyes University of Technology	6	Controlled lab tests	France	Troyes	Urban area
Troyes University of Technology	7	Controlled lab tests	France	Saint Lyé	Rural area
Troyes University of Technology	8	Controlled lab tests	France	La chapelle Saint Luc	Urban area
Troyes University of Technology	9		France		
Troyes University of Technology	10		France		
Sozial Global	11	Pre-study and longitudinal study	Austria	Linz	Urban area
Sozial Global	12	Pre-study and longitudinal study	Austria	Wiener Neustadt	Rural area
Sozial Global	13	Pre-study and longitudinal study	Austria	Vienna	Urban area
Sozial Global	14	Pre-study and longitudinal study	Austria	Vienna	Urban area
Sozial Global	15	-	-	-	-
Sozial Global	16	-	-	-	-
Sozial Global	17				
Sophia	18	Pre-study and longitudinal study	Germany	Rattelsdorf	Rural area
Sophia	19	Pre-study and longitudinal study	Germany	Hallstadt	Rural area
Sophia	20	Pre-study and longitudinal study	Germany	Bamberg	Urban area
Sophia	21	Pre-study and longitudinal study	Germany	Bamberg	Urban area
Sophia	22	Pre-study and longitudinal study	Germany	Lichteneiche/Memmelsdorf	Rural area
Sozial Global	23	-	-	-	-
Sozial Global	24	-	-	-	-
Sozial Global	25	Pre-study and longitudinal study	Austria	Vienna	Urban area
E-Seniors	26	Pre-study and longitudinal study	France	Paris	Urban area
E-Seniors	27	Pre-study and longitudinal study	France	Paris	Urban area
E-Seniors	28	Pre-study and longitudinal study	France	Paris	Urban area
University of Siegen	30	Pre-study and longitudinal study	Germany	Kirchen	Rural area

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Table 2: Inclusion criteria values for the recruited participants.

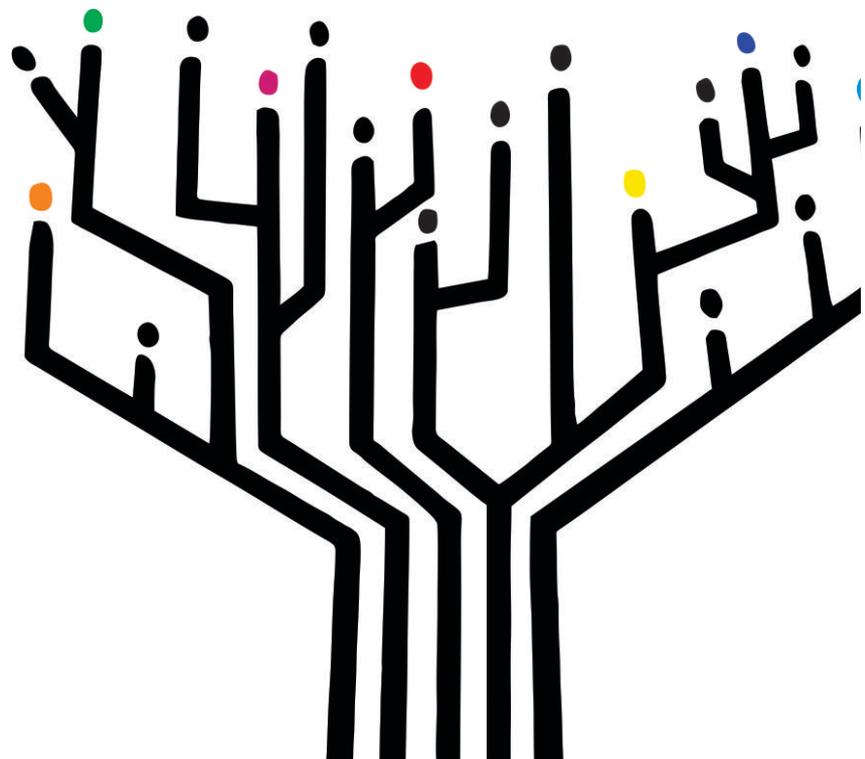| Carers' information								Care receivers' information					Recruitment ID
Age Group OR Year of birth	Gender	Employment status	Relation to the care receiver	Familiarity with technology	Mobility	Vision	Hearing	Age group OR Year of birth	Gender	Medical condition	Type of condition	Mobility	
60+	female	Retired	spouse	Yes	Fully mobile	Slightly impaired	Not impaired	60+	male	Alzheimer's disease or related	Chronic	Fully mobile	1
60+	female		daughter		Fully mobile	Slightly impaired			female	Alzheimer's disease or related	Chronic		2
60+	female	Retired	spouse		Fully mobile	Slightly impaired	Not impaired		male	Alzheimer's disease or related	Chronic	Fully mobile	3
60+	female	Retired	spouse	Yes	Fully mobile	Slightly impaired	Not impaired	60+	male	Alzheimer's disease or related	Chronic	Fully mobile	4
60+	female	Retired	spouse		Fully mobile	Slightly impaired	Not impaired		male	Alzheimer's disease or related	Chronic	Fully mobile	5
	male		spouse		Fully mobile	Slightly impaired			female				6
	female		spouse		Fully mobile	Slightly impaired			male				7
	male		spouse		Fully mobile	Slightly impaired			female				8
	male		spouse						female				9
	female		spouse						male				10
	female	Retired	spouse	Partly	Fully mobile	Slightly impaired	Slightly impaired		male	Alzheimer's disease or related	Chronic	Partly mobile	11
	female	Retired	daughter						female				12
	female	Part time employment	daughter						female				13

Table 2 (ctnd.): Inclusion criteria values for the recruited participants.

		Carers' information								Care receivers' information				
Age Group OR Year of birth	Gender	Employment status	Relation to the care receiver	Familiarity with technology	Mobility	Vision	Hearing	Age group OR Year of birth	Gender	Medical condition	Type of condition	Mobility	Recruitment ID
	female		daughter						female				14
-	-	-	-	-	-	-	-	-	-	-	-	-	15
-	-	-	-	-	-	-	-	-	-	-	-	-	16
													17
	male		son						female				18
1956	female	Part time employment	daughter	Unknown	Fully mobile	Slightly impaired	Not impaired	1927	female		Chronic	Partly mobile	19
	female		spouse						male				20
	male		cohabitee						female				21
	female		spouse						male				22
-	-	-	-	-	-	-	-	-	-	-	-	-	23
-	-	-	-	-	-	-	-	-	-	-	-	-	24
	female	Part time employment	spouse		Fully mobile				male				25
	female		mother	Yes					female				26
	male		son						male				27
	female		mother						female				28
	male	Retired	father	No	Fully mobile	Slightly impaired	Not impaired	1966	male	Irreparable brain damage	Chronic	Not mobile	30

5 Further work

The relationship that has started with the recruited participants will have to be strengthened in order to build a durable link with them and to ensure trustfulness.

The recruitment activity will go on to ensure new recruitments for the next steps of the project, so new versions of this deliverable will be provided.

6 Appendices

6.1 1. Flyer – Introducing TOPIC to prospective participant users

THE ONLINE PLATFORM FOR INFORMAL CAREGIVERS

People, like you, whose beloved ones are in need of help and support, care about their quality of life and work to improve it.

Sometimes this work can be very demanding and you may feel overwhelmed. Indeed, you may need help to properly give them the care they require.

Providing the effort that you put into caring, you may possibly not have enough time for yourself.

Our aim is to increase the quality of life of informal caregivers, like you, within your familiar home environment with the help of an online platform.
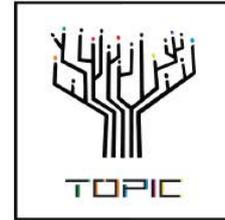
This way you will be able to meet people who are in the same situation as yours and exchange experiences, thus helping each other.

You may contribute to this project by…

Participating in interviews, workshops, talks, and observations.

Testing the first prototypes of the online platform at your own home, and giving feedback about problems you find, doubts you have and also giving inputs through new ideas and suggestions.
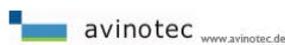
Using the online platform at your home over a longer period and cooperating for its improvement by means of feedback during the workshops.

Preconditions

For participating you need no technical knowledge or prior experiences in dealing with computers.

The only requirements for participation are to be open for new technical developments and willing to contribute with time and curiosity.

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TOPIC is a European research project under the Ambient Assisted Living Joint Programme. If you are interested in participating in the project and/or have some questions about it, please contact:
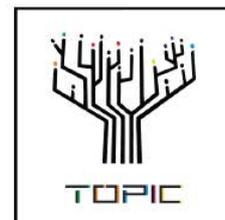
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6.2 2. Flyer – Introducing TOPIC to associations

THE ONLINE PLATFORM FOR INFORMAL CAREGIVERS

OUR AIMS

We strive to support informal carers in their daily needs by providing an integrated set of online shared spaces and services by enabling learning and orientation about care.

OUR CHALLENGES

We especially tackle two challenges:
1. The lack of an integrated social support platform serving all relevant aspects of carers' needs.
2. The lack of accessible ICT applications for elderly that might automate many tasks of general care giving.

OUR APPROACH

Our consortium uses a user-centered and participatory design approach combined with an evolutionary development. This means that end-users will be involved during the whole development process.
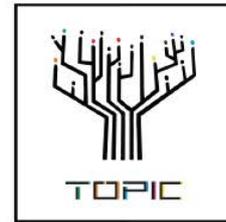
THE PLATFORM

The solution we offer to develop, the *CarePortfolio*, will provide multimodal social support to informal carers. It will integrate six dedicated shared spaces:

Learning Corner...
... is a space where informal carers can ask questions to professional caregivers and follow online training for particular tasks.

Fun Corner...
... is a "way out" space, where informal carers can engage in activities to relax and have fun with others.

Chat Room...
... is the meeting point where caregivers can talk about anything with anybody they want who is using *CarePortfolio*.

Support Group Corner...
... supports group sessions to talk about care giving and to share personal experience.
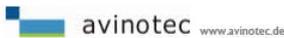
Market Place...
... is a place to exchange or share objects and/or services between peers.

Surveillance Corner...
... will allow informal caregivers to access data coming from the surveillance devices, which may be installed in the home of the person they are taking care of.

PARTNERS

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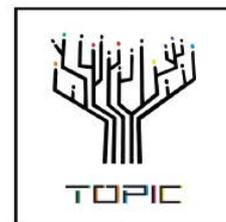Project duration: May 2013 – May 2016

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Federal Ministry for Transport, Innovation and Technology

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6.3   3. Guidelines to introduce the data collection activity to participants

General
- Show the adequate modified time plan for the data collection activities, which is available in a separate document
- Use simple language → **avoid** the word **researcher**
    - Use "I" or the "name of the person" you are making reference to

On the pre-study
- Mention to the participant that:
    - In the first phase of their participation, we want to **spend time** with them to learn about the activities they engage in as an informal carer
    - The fist time that we will be with them, we will ask them to fill in a short questionnaire to collect some **general** information
        - *This refers to the Zarit's questionnaire*
    - We will give them some artefacts (e.g. any paper-based probes, disposable cameras, etc.) so that they can register some events that happened when we were not with them and that they think it would help us understand a little better their responsibilities, difficulties, etc.
        - *This refers to the Cultural Probes*
    - We will be with them once every 2 weeks for around 3 hours so that they can show us how they usually deal with different care situation; also mention that we would appreciate if we could audio and video record this sessions
        - *This refers to observations*
        - *Don't approach them saying that we will observe them for 4 times in the next 2 months. ;)*
    - After 2 months we want to sit down to ask about different thinks we saw during the time we stayed with them, so they help us to better understand some situations
        - *This refers to the semi-structured interview*
    - After the interview, we will not see them for a while (about 12 weeks)
    - After these 12 weeks, they will participate in a group discussion to give their opinion about some sketches of the system that we plan to design
        - *This refers to the focus groups*
        - **Notice:** each participant will be required to participate in only one focus group session that will be schedule some time in March 2014. Please, refer to the simplified timeline that accompany this document.

On the longitudinal study
- Mention to the participant that:
    - The longitudinal study will last 12 months
        - *Avoid saying that it will take one year*
    - During this phase we meet them once a month and stay a day with them, so they can show us how they are using TOPIC
        - *This refers to the observations*
    - We would like them to write down any information or take pictures of things they want to show us when we meet them the next time
        - *This refers to the media diaries*
    - By the end of the phase we would like to talk with them so that they can share their experiences with the system and give us suggestion of how to improve it
        - *This refers to the last interview*

On the usability test
- There is no modified timeline for this phase available now
- Mention to participant that:
  - We would need them to participate in 1 or 2 test sessions
  - We will evaluate the system performance not their performance
  - In these sessions they will
    - Use the system we are developing
    - Tell us what they like and do not like in the system
    - Tell us if there was something not working with the system
    - Give us suggestions to improve the system

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