



The Online Platform for Informal Caregivers

TOPIC Meetings 24th – 25th October, 2013 in Paris, France

Minutes

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24th October – TECHNOLOGY MEETING

Participants

TUW – Susi, Ivan, Fabiano
UTT – Myriam, Matthieu
ESE – Daria, Anais
ILOGS – Cornelia, Stefan
AVINOTEC – Michael
WEBINAGE – Thomas, Valerie

Report on the technology meeting in Siegen¹

Michael presented the details of the meeting that took place in Siegen on August 12 and 13, 2013 in Siegen. Participants of this meeting were:

- AVINOTEC: Alexander Weisner, Michael Stepping, Senera Sotke, Anna Jürges
- ILOGS: Steffan Plattner, Walter Liebhart
- USI: Maren Schorch
- WEBINAGE: Thomas van de Velde

The *purpose of the meeting* was for the technical partners to get to know each other and to try to find synergy as well as discuss which company is able to contribute to which part of the TOPIC project.

The meeting was split in two parts for discussing technical and business perspectives of the TOPIC platform, respectively. The following general conclusions were made:

- *Informal and untrained caregivers* were identified as the only target group of the platform. Gender of the users, employment status, and the level of experience with technology are irrelevant.
- The platform will be designed to support the *maximum of 3 personas* (in the meeting referred to as “stereotyped profiles”) that will be defined by the university partners. Personas will facilitate specifications of the platform functions. It was concluded that from the technical perspective it is not feasible to support more than 3 personas.
- A *user handbook* will be developed.
- All products will be developed in *HTML5 and JavaScript* using standard libraries (e.g., jQuery) to support flexibility and multiple platforms. However, when this is not possible and *native applications* must be built (e.g., for video support), they will be developed *for Android* devices. Selection of Android as the target platform is justified by its openness, large market share, and availability on less costly devices.

→ *Decision made*

- The decisions in favour of HTML5 and JavaScript technologies as well as the focus on Android platform in case native programming is required were

¹ The minutes of this meeting are available at http://bscw.media.tuwien.ac.at/bscw/bscw.cgi/d649150/Protocol%20-%20Technical%20Meeting%20-%20Siegen_02.doc



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corroborated by the partners participating in the Technology Meeting on 24th of October and approved in the Consortium Meeting on 25th of October.

As *basic functionalities* of the TOPIC platform, the participants of the Siegen meeting defined the following:

1. “print_it” – underlying service of the device or the operating system
2. “share_it” – exchanging documents, information and links between the users
3. “calendar_it” – helping users keep track of all appointments; connections to Outlook and Facebook are planned and necessary for higher acceptance.

Functionalities of the *Learning Corner* were discussed in detail. The main conclusions were:

- It will be designed as type of a WIKI page;
- The focus will be on reliability, in order to achieve this, it is necessary to decide who will maintain the content;
- It will provide search functions (for the content within the platform and the overall Internet);
- It will provide messaging functions for getting information about the new entries related to the previously searched content;
- It will include an e-learning system, webinars, and remote desktop sessions for learning.

Details of the features of the Learning Corner and other spaces/corners of the platform are available in the minutes of the Siegen meeting¹.

Technology partners had the possibility to present their portfolio and to discuss how their products can be used in the TOPIC project. In this discussion, *responsibilities of each partner* were defined as follows:

- AVINOTEC will build tools and protocols for chat, video, and audio streaming, as well as software infrastructure for webinars.
- ILOGS will provide relevant segments of their knowledge database developed as part of the European Nursing Care Pathways (ENP) project. This knowledge can be used in the Learning Corner for training informal caregivers and providing them with advises for care (e.g., how to bathe care receivers). ENP was presented in detail both in the technology meeting in Siegen and at the TOPIC Consortium Meeting on October 25th, 2013 (see the next section of this document).
- WEBINAGE will provide knowledge platforms for the implementation of the marketplace.

Progress since the last consortium meeting

Representatives of technology partners (AVINOTEC, WEBINAGE, and ILOGS) informed that they have started with the discussion of the features of the TOPIC platform, but have not yet started with the implementation. The partners have reported the following completed tasks:

- AVINOTEC bought 33 smartphones (Samsung Galaxy S3, Samsung Galaxy x Cover 2 and iPhone 5) and 33 tablets (Samsung Galaxy Tab 3 10.1).
- WEBINAGE developed the website for the TOPIC project and investigated the possibilities for the video support.



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Development Environment – TV platform

Thomas gave a short presentation of the following options for developing TV-based solutions as part of the TOPIC project.

1. *Set-top box* – An information appliance device that connects to a TV set over HDMI. It contains an external source of signal, turning the source signal into content in a form that can then be displayed on the TV screen. It has a standalone computing unit that can run certain applications. It uses remote control for operating the device.
2. *Screencast* – Displaying the content from any device (tablet or a smartphone) to the TV set. For example, Chromecast broadcasts from any device with Chrome browser (it is OS independent) and displays it on the larger screen; all interaction goes over the smartphone/tablet. Once when the content is started, the smartphone/tablet may be switched off and the content will still play on the TV. The other example is Miracast. Miracast is a peer-to-peer wireless screencast standard formed via Wi-Fi Direct connections in a manner similar to Bluetooth. It enables wireless or wired delivery of compressed standard or high-definition video to or from desktops, tablets, mobile phones, and other devices. Both the sending and receiving devices must support Miracast for the technology to work. However, to stream audio and video to a device that does not support Miracast, adapters are available that plug into HDMI or USB ports. It allows users to, for example, echo display from a phone or tablet onto a TV, share a laptop screen with the room projector in real-time, and watch live programs from a home cable box on a tablet.
3. *Smart TV* – Integration of the Internet and Web 2.0 features into television sets and set-top boxes, as well as the technological convergence between computers and these television sets/set-top boxes. Allows implementation of certain applications (on modern TVs even implementation of these apps in HTML5).



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Table 1 Pros and cons of different TV-based solutions

| Device type | Pros | Cons |
|--------------------|--|---|
| Set-top box | <ul style="list-style-type: none"> - Price - Possibility to run native applications | <ul style="list-style-type: none"> - No video camera - Requires remote controller (based on Myriam's previous studies, users don't like additional remote controls). - Remote controls are usually complex and contain many small keys (not practical for old people) or use motion sensor (based on gyroscopes), which is particularly problematic for old people (especially the ones with Parkinson's disease). |
| Screencast | <ul style="list-style-type: none"> - Price - Simplicity (does not require development of separate applications) - Control via tablet instead of remote controller (preferred by the users according to Myriam's previous studies) | <ul style="list-style-type: none"> - Turning on the screen sharing may require exiting applications and changes in the settings panel - Limited features (usually only duplication of the screen) – cannot run applications |
| Smart TV | <ul style="list-style-type: none"> - Possibility to develop rich, native applications - Good, native interaction | <ul style="list-style-type: none"> - Price - Usually extremely difficult to program native applications |

→ Decision made

Pros and cons of all solutions were discussed (summarized in Table 1). Based on this discussion, *it was agreed to use a screencast solution*. This will allow caregivers to share certain content with the care receivers by mirroring the image from their device (smartphone or tablet) to the TV set.

Development Environment – Communication of requirements

TUW suggested using Volere for expressing user requirements in a readable form. This document could then be used to translate users' needs into the features of the platform. Fabiano circulated an example of a user requirement described in the Volere template. Based on the discussion with the technology partners, the following was concluded:

- Requirements should be described as part of well-defined use cases. Please note that a use case assembles different requirements that compete to the accomplishment of a task or achievement of a goal. Myriam presented and distributed an example of a use case at the Consortium Meeting.
- Each requirement/use case must be associated to a certain persona.
- Requirements/use cases should be grouped and categorised based on, for example, corners and spaces of the TOPIC platform.



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- Level of details for the description of the requirement must be larger than the one described in the typical Volere example.

→ Decision made

Based on the discussion, it was concluded that Volere should not be used as the artefact for the communication between the technology and university partners. Instead, detailed use cases described in the format of short scenarios should be used.

→ Decision made

It was agreed that the process of communicating and refining the requirements will be as follows:

1. Elaboration of the communication artefact:
 - a. Based on the fieldwork data, use cases should be identified and described as short scenarios (example of the agreed use case format is available at <http://bscw.media.tuwien.ac.at/bscw/bscw.cgi/d654917/Example%20of%20use%20cases.pdf>);
 - b. The scenario should be written using action verbs in a readable text format. Each scenario must include:
 - i. Persona's name
 - ii. Context of the use case (e.g., why the user is doing what he/she is doing),
 - iii. Details of the interaction between the user and the system (in the form of "name + action verb + result", e.g., Simon opens the browser and clicks the "Home" button),
 - iv. Technical analysis/feedback
 - v. Priority
 - c. Requirements should be derived from the use case (possibly use colours to identify characteristics of the actions, e.g., which devices may be used for which actions);
 - d. A sketch should be elaborated to visually represent the interface and interaction requirements.
2. Use cases and sketches will be then discussed with the technical partners who will give suggestions based on the technological nature of the requirements. This may include merging more use cases into one, splitting large use cases into several smaller ones, adding additional use cases, and agreeing whether use cases are worth attention and achievable.

→ Decision made

- It was agreed that an overall view of the system use cases will be provided to the technology partners, so that they can start thinking of the structure of the platform.
- Overall view of the use cases must be provided in a face to face meeting, whose date was defined in the Friday's session of the Consortium Meeting.
- The use cases from the overall view will be refined with the help of the technology partners.
- Refined version of the use cases should be communicated to the technology partners in modules, so that they have enough information for working on platform functionality.



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24th – 25th October – CONSORTIUM MEETING

Participants

TUW – Susi, Ivan, Fabiano, Hilda
UTT – Myriam, Matthieu
USI – Marén, Bernhard
ILOGS – Cornelia, Stefan
AVINOTEC – Michael
WEBINAGE – Thomas, Valerie
ESE – Daria, Anaïs, Monique (24th and 25th morning)
SOGL – Ursula
SOPHIA – Anton, Sabine
LOKEO – Stéphane (24th)

INTRODUCTION

- Myriam and Fabiano shortly summarise the discussion that took place in the Technology Meeting in the morning and inform the others of the agreements that were elaborated → The agreements were made official on the Friday's session of the Consortium Meeting.
- Fabiano quickly goes through the agenda for the afternoon and explain the purpose of the activities that will be performed.

REPORT ON PRE-STUDY STATUS QUO

TUW's Report

- Susi reports on the status quo of the pre-study in Austria. So far:
 - 6 informed consent already signed out
 - 3 other users to sign the informed consent early in November
 - Participants' profile
 - Gender: 6 women (1 man and 2 women to join in November)
 - Family relationship with care receiver: 3 daughters and 3 spouses
 - Dwelling: except for 1 participant, all the other lives with care receiver
 - Care receivers' condition
 - Among others, Alzheimer's disease, Parkinson's disease, stroke, hearing impairment, vision impairment, and diabetes
 - 11 observations already performed
 - First meeting: no recording, only notes → informal talk to build trust
 - 1st observation already performed with all 6 participants who signed out the informed consent form; 2nd observation performed with 5 of them; 3rd observations already planned.
 - Observations performed by 2 researchers: 1 responsible to take field notes and 1 responsible to video record the session.
 - 6 Cultural Probe kits delivered so far
 - Another user will get the Cultural Probe Kit next time we visit her
 - Feedback while introducing to the elements of the box ranged from „exciting“ and „funny“ to „don't like writing diaries“ and „have no time for that“



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- Social Map: not as easy to understand
- Polaroid instant camera: Everybody liked the handling and the idea of taking photos (most of them took their care receiver as subject for the test-photo – two of the users photographed us)
- Zarit's and Profile Questionnaires to be fetched together with the Cultural Probe kits
- Data gathered: Audio-Files, Video-Files, and Notes → intern on the BSCW-Server
 - Audio Files: informal chats or interviews
 - Video Files: some of the daily routines and also the place where the users and/or the care receivers live
 - Notes: during the whole stay at the users and/or care receivers' home about what participants talked about, what was happening and what the surrounding in the homes looked like
- Fabiano elaborates on some findings coming from the field and explains how these could be used for the definition of the personas that we agreed on in the technical meeting. *Attention* is drawn to the fact that the findings from the field is actually what is driving the elaboration of the personas and the use cases → The platform will not be limited to the corners and functionalities identified in the proposal and a precise description of the target group and the representation of different relevant profiles will only be possible after the conclusion of the pre-study.

USI's Report

- Marén reports on the current status of the pre-study in Germany. She mentions that:
 - They started late, in the middle of the holidays season, and because of that it is being even more difficult to find participants
 - So far
 - 3 families were recruited in the rural area
 - 1 caring for a person with dementia
 - 1 couple caring for their son that is now 48 years old – they care for him since he was a baby, after brain-damage shortly after his birth due to an injection he got
 - 1 family taking care of a person who went through amputation
 - No observation has been carried out so far, but they will be starting the week after the meeting
 - Informal talks has already been carried out – some of them quite long → important for building rapport
 - 1 expert interview has been performed → very good talk and good data material
 - Cultural Probes are ready, but will not be distributed before the second meeting, as they feel it would be important to strength the relationship with participants after introducing the probes → could scare them away.
 - First question they get from participants is how much time they will have to invest on this and what benefits they will have for participating in the project



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- Some people mention that if they visit their house once a month that would already be a benefit
- Their initial observations are that:
 - Diseases have a major impact on the households' everyday life and routines. Some questions that go through the minds of those who will have to care for somebody are:
 - How expensive would it be to care for the person? Can I get financial support? How should we reorganise the finances? How should I reorganise the space? What changes must be made in the house to meet the care receiver's needs?
 - Their first impression is that informal carers are exhausted
 - There are also frustration and struggle involved:
 - Some participants mentioned that when they were working they used to think of how they could enjoy their time after retiring, but then the person they want to share and enjoy this time with develops a condition that force them to give up their plans.
 - There is questioning on how to integrate the care situation in their daily life.
 - Responsibility is a big thing: who will be responsible for what?
- There were other relevant activities in the context of the project:
 - They participated in the:
 - "Dementia week Kirchen"
 - "Humour and Aging" workshop at the "Human and Computer" 2013 conference held in Bremen
 - They have been working in talks and press releases
 - They also have participated in meetings and exchange with members of other AAL-Projects (e.g., FoSIBLE and NeuroCare)

UTT's Report

- Matthiew started with the report on the pre-study situation in France: in Troyes they have recruited 3 participants, all of whom are caring for people with memory disorders
- Daria adds that in Paris they have recruited other 3 participants (one caring for a person with back problems, another one caring for a esquizofrenic daughter)
- Myriam adds that they are reporting only for the ones who signed the informed consent form: they have been in contact with other carers, some of whom will be participating in other stages of the project.
- First meetings are being used for building rapport → in Troyes the first meeting has been performed in a informal care organisation, because some participants would be resistant to open their houses before knowing a bit more about the project
- Profile questionnaire were filled out with the 3 participants in Troyes and 2 participants in Paris.
- ESE has collected 7 Zarit's questionnaire (3 answered by participants who are involved in the pre-stud) → UTT will administer the Zarit's questionnaires later on (after the relationship with the participants is strengthened)



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- 1 shadowing session has been carried out by UTT and 2 by ESE, though for ESE this first session was more about talking with the participant and building rapport
- 1 Cultural Probe have been handed in by UTT and 3 by ESE. ESE mentions that reaction to the Cultural Probes varied. For 2 ladies it was OK, since they were used to it. For the third lady it was a bit complicated because the care receiver (a esquizofrenic daughter) would be very suspicious of all the things in the Probe.
- ESE draws attention to the fact that sometimes carers are willing to participate but care receiver would be a barrier. Other partners share the same experience.
- Myriam shared UTT experience with getting access to the field: following suggestion of people who wanted to participate in the project, they met informal carers and the people they are caring for in an informal get-together in a respite care centre. Participants mentioned that if care receivers see the researchers in such meetings, it is easier for them to accept the researcher in their homes.
- Preliminary findings suggest that:
 - Coping with cognitive overload are related to time management
 - Carers seek triggers for starting out activities with care receivers
 - Carers have difficulties in finding products and services tailored for their needs

Discussion

- Hilda draws attention that all this difficulties and struggles to get access to the field is part of the project and tell us a lot about struggles that informal carers undertake.
- Fabiano adds to the point mentioning that this shows us how sometimes informal carers are overruled by care receivers and how this could lead to an added layer of stress.
- Hilda also mentions that shadowing sometimes may be difficult, because it might happen that we are there and nothing happens: they don't talk, don't do anything, just eat, etc. etc. However, being there and seeing that nothing is happening, that some type of interaction is missing also tells a lot.
- Bernhard adds that nothing happening could be interesting, but this would mean that we will need to interpret things, what could be problematic.
- Fabiano points out that, although we will have to interpret a lot of things, the fact that we are using different data collection instruments helps to get closer to the real situation (e.g., we could explore with the carers unclear situations observed during the shadowing).
- Fabiano questions whether anyone has observed any interaction between informal carers.
 - Myriam mentions that attending the meeting at the respite care centre were insightful and useful for observing this type of interaction. They also could observe interaction between informal carers and professional carers who visited their homes whilst the observation was going on.
 - Thomas shares his experience with the elderly and mentions that it is a requirement to know each other for interaction to happen.



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INTRODUCTION OF IDEAS EMERGING FROM THE FIELDWORK

UTT's Ideas

- Matthew introduces the idea of implementing something to help manage respite care services – *something like an electronic pen*, which allows informal carers to keep their paper-based diary at the same time that they create an electronic version that could be shared with other informal carers and service supplier that they are in contact with. From the observations and interviews they can confirm that there is a need for such a support.
- The second idea is about elaborating a comprehensive *catalogue of products and services* that informal carers might need. This catalogue would be made available through the platform and the platform users could rate products on it. Idea emerged from an express interview and fieldwork observations so far collected.

TUW's Ideas

- Ivan reports on the TUW's ideas, starting with the one named "*Lunch for 4*". This would consist of two couples having lunch at different locations are connected via a video communication tool so that they can talk to each other as they have their meal. The idea came out from observations of different couples that have communication difficulties due to the condition of the care receiver. WEBINAGE informs that they have already developed a similar support in the past deployed on touch screen PCs to make interaction easier (this solution was presented in the Friday's session of the Consortium Meeting).
- Second idea was "*Howdy? for social awareness*", an RFID-based input and output device to support social awareness at homes. It enables entering data created by friends who are thinking of other friends and want to make them aware of that. The idea emerged from a master's project at TUW.
- Third idea was to do with *bridging communication between informal carers and care receivers* who are not living in the same household. The idea was originated from comments made by an informal carer who does not live with the person she cares for and cannot communicate with this person because she is hearing impaired.
- Fourth idea was related to a support for *communication between linguistic impaired and a hearing impaired informal carer and care receiver* via a tablet-application showing words, phrases, the alphabet, or maybe pictograms. The source of the idea was the observation of a couple in which the husband (in this case the care receiver) could hardly speak – only in a very unclear way – because he suffers of Parkinson's disease and dementia and the wife (the informal carer) is hearing impaired.

USI's Ideas

- Marén informs that since the fieldwork has just started, no actual ideas have been discussed yet. However, the ideas presented by UTT and TUW resonate with the observations that they carried out so far.

Discussion and Deliberations

- Thomas raises the question whether we should keep talking about the ideas previously presented → Are they top priority in the feature list? What about the Learning Corner? What should be integrated in it?



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- Fabiano and Hilda draw attention to the fact that we don't know how each corner will exactly look like in the end. They will be shaped with findings from the fieldwork: this is what a user-centred and participatory design means.
- Cornelia raises some questions about the preliminary findings previously presented:
 - In case of the observation in Germany, what is meant by “conflicts with experts”?
 - Marén replies to that explaining the one of the couple shown concerns about wrong treatments, wrong medications, etc. and the responsibility of the outcomes from these wrong procedures/approaches.
 - In terms of recruitment, what was the selection process? How were these people found? She is concerned that it seems that the cases reported so far are not representative of those that the consortium proposed to explore in the project.
 - Hilda explains that the participants who have been recruited so far are in fact representative of the target group that the consortium committed itself to explore. This was discussed within WP1 and approved in one of the Consortium Telco. The only real criteria from the proposal are that we will explore solutions for elderly/aging caregivers (recruitment criteria was revisited during the Friday's session of the Consortium Meeting).
 - In regards to profiling, the participants are asked about their experience with informal care (e.g., how long they have been caring for someone, whether they have done this before, whether they have attended courses?)
 - Profile questionnaire elaborated by SOPHIA and refined in WP1 are being administered and all of the participants will have answered it by the end of the pre-study.
- A discussion on how the session should proceed is carried out.
 - Hilda highlights the fact that the agenda was designed in order to foster collaboration between all partners, to get everybody working in common things whilst they are together, and to generate action points so that everyone knows clearly what they have to do in the next months.
 - A discussion is performed on how the session on discussing ideas for the platform should progress. Two approaches are discussed:
 - Splitting the partners in 3 different groups and having each group to choose one of the corners described in the proposal, think of things that should be there, try to connect them to the data coming out of the field, report it back to the other groups and discuss how use cases could be generated from the issues stemming from the discussion.
 - Splitting the partners in 3 different groups and having each group to choose 3 of the 6 ideas previously presented, identify to which of the corners described in the proposal they would fit, discuss the feasibility of their development, think of a use case scenario for the idea, and report back and discuss it with the other groups.



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- Anton suggests that we think of the use cases that we want to tackle in the platform development, associate them with the different types of users that could be interested in the system and group them in the corners.
 - Hilda points out that the relationship between use cases and types of users is an important issue and asks the user organisations to raise the relevant concerns about this in the group work, specially when they see that something described in a use case would not work with a particular user group.
 - It is also highlighted that clustering use cases would not be possible now because we don't know enough of them → The pre-study still going on.
 - There are some disagreements on this. → Some partners think that we should already know enough from each use case, because we wrote about them in the proposal and some of the partners also have large experience with informal carers.
 - It is emphasised that ***this is a research project that adopts a user-centred and participatory design approach; therefore, the development of the system should be driven by what is observed in the field and identified as the user needs and not on our own experience.***
 - Hilda reassures the technical partners that we will have an online platform in the end – this is something that cannot be changed, as it is the purpose of the project – but that it might be that some of the corners are not in the platform because the users did not consider them useful or relevant. E.g., so far in Austria no informal carer manifested interest for something like the Learning Corner. From the preliminary findings they seem to know the procedures and what they have to do. However, the need for social support and coordination tools is constantly observed. *Notice:* These are preliminary results and can be changed as the pre-study evolves.
 - Some technical partners raise the issue that sometimes the users do not know what could be offered to them and, therefore, “we should be clever” with them. Myriam brings to the attention that during the interviews after the observations of the pre-study, it will be possible to explore with the user innovative ideas that they may not have thought about before.
 - After clarification on the project approach to the identification and elaboration of the features for the platform, the partners opted for the second approach.

ELABORATION ON 3 IDEAS

After the discussion on the project approach and how the meeting should proceed, partners were split into 3 groups:

- Group 1: Marén, Valerie, Cornelia, Myriam, Matthiew, Susi, Anaïs
Group 1 chose to work on UTT's idea on the development of developing a *peer-recommended catalogue of needed products and services*.
- Group 2: Fabiano, Thomas, Bernhard, Sabine, Michael, Hilda
Group 2 chose to work on TUW's idea named “*Lunch for 4*”.



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- Group 3: Stéphane, Stephan, Anton, Ursula, Ivan, Daria
Group 3 chose to work on the idea of *bridging the communication between informal carers and care receivers who do not live in the same household.*

Report on Idea 1 “peer-recommended catalogue of needed products and services”

- Group 1 has written an actual scenario.
- The persona in the scenario is Maria, who is caring for her husband, who lost a leg, and she has difficulties to find trousers for him or to adapt the trousers she finds in the shopping. In the scenario, she uses the platform to find an appropriate solution for her case. Different interaction aspects are described in the scenario, e.g., how she navigates through the platform and so forth.
- Issues regarding browsing and asking information to other people on the platform are discussed (e.g., when one doesn’t find the product, one may ask the others whether they know how to adjust the trousers).
 - Stéphane questions the probability of getting an answer to something asked in the platform.
 - The group shares positive experience with peer recommendation systems, especially in cases when people on the platform experience the same challenges and difficulties.
 - Myriam shares the thought that maybe that platform could start with some recommendations from the end-users who participated in the project so that the other users could build upon them.

Report on Idea 2 “Lunch for 4”

- Group 2 reports on “Lunch for 4”.
- Other names that were thought of during the discussion: “Lunch over wire” or “e-Lunch”.
- It was discussed whether we should keep it only between two places or try to have it connecting several different places. Having several places would make it difficult from the technical point of view.
- Open question about what we should do before somebody can invite somebody else for lunch:
 - Shall we think in a matchmaker system – e.g., the platform would recommend people who share the same interest as the one who wants to have a lunch session over “Lf4”?
 - Should the system allow this type of invitation only between people who know each other?
 - If so, how to represent this in the platform?
 - Wouldn’t we get too close to a social network system? What makes then our system special?
- Lf4 can potentially be used to connect people who know each other (e.g., friends and family members).
- It can also be used for other scenarios. → Not only for lunch, but, for instance, have a Yoga session together with other people. Can we use for this the same platform?
- Anton raises a concern about security of the platform users. → Inviting people who you don’t know to have lunch together over the Internet could give bad-intentioned people a pic of the place.



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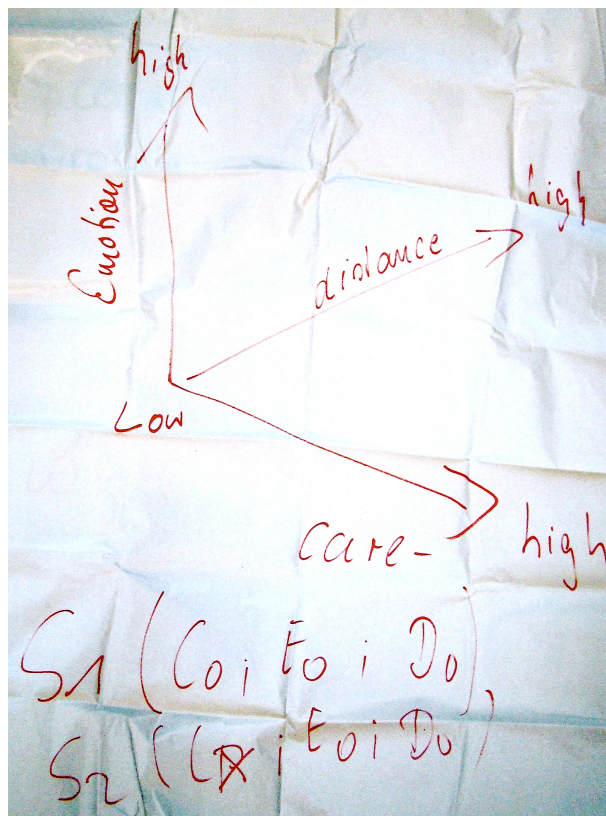
- Michael points out that this is something related to the business model. → The ones deploying the platform should put in place a policy regulating who would be accepted in the platform, so that a trust environment is provided.
- A challenge is identified: how to foster collaboration between informal carers who do not know each other personally? Open question: should we?

Report on Idea 3 “bridging the communication between informal carers and care receivers who do not live in the same household” → “online calendar/timetable”

- Group 3 informs that the discussion within the group led them to elaborate on an idea different from the one they previously selected. They report on issues of an online calendar/timetable which is relevant when more than one informal carer share the responsibility for taking care of someone.
- What roles should be represented in the timetable?
- Ethical issues: who should be allowed to see what in the timetable?
- Possibility of adding picture to it: interesting for cases where people are caring for people with dementia, who could forget something, but be reminded through the pictures in the timetable.
- Myriam observes that some carers might want to keep the paper based version the timetable → she suggests exploring solutions like having a digital pen, which can write in any type of paper at the same time that it creates an electronic copy of the note being made on the diary.
- Hilda draws attention that an electronic timetable is good as long as there is power/battery available. So we should take into consideration what happens if the energy is down → the paper copy is of special relevance in this case.

INPUT FROM SOPHIA: STRUCTURED SCENARIOS

Anton presented an idea for structuring the scenarios with a 3-dimension-scale:





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Anton wrote a “paper to work” for this idea and uploaded it to the BSCW-Server: <http://bscw.media.tuwien.ac.at/bscw/bscw.cgi/d655307/TOPIC%20use%20case%20development.docx>

The idea of Anton will be considered in further analysis work. It is very useful to systemize and structure our analysis if it is completed with the findings from the case studies.

PERSONAS AND USE-CASES

It was suggested that we would create exactly 3 Personas, which are matching 70-80% of all informal caregivers. We would also create Non Personas (care receiver, professionals, etc.). Myriam presented an example of use cases and how it is written.

→ *Decision made*

We will use the type of use cases Myriam presented and use them in this way within the TOPIC-Project. To discuss the first use cases between academic and technical partner, we will meet in Vienna at TUW from 15th to 16th of January 2014.

PRESENTATIONS OF COMPANY PORTFOLIOS

ILOGS

Cornelia presented the MOCCA platform developed at ILOGS. It is a large e-health platform focusing on nursing care. Its target group are professional carers and not medical doctors. As part of their planning of services and interventions module, they provide a European Nursing Care Pathways (ENP) system, which Cornelia presented in detail. ENP is a nursing language that originated from the need for a practical and appropriate inter-sectoral communication instrument to describe nursing situations. ENP is not only designed for specific nursing institutions, but it can be used in all areas in which nursing takes place. At the same time ENP is a classification system that consists of the elements of nursing diagnoses with characteristics, ethology, resources, objectives, interventions as well as detailed guiding interventions.

A possible benefit for the TOPIC project is that ENP provides concrete and specific descriptions for nursing situations. The structure of ENP supports the nursing process because all necessary elements for the description of the nursing situation are provided. ENP is a multilingual tool as it is translated into English, German, French, and Italian. Carers using ENP system can use the large knowledge base to learn about the care, express their tasks and care recipient’s state and diagnosis, and manage their care tasks. ENP contains a large set of functionalities out of which only a small subset could be used for the TOPIC project. These functionalities are related to the set of know-hows and practical advices about the care (e.g., how to bath a person with Parkinson’s disease, how to identify certain medical problems, etc.).

→ *Decision made*

The consortium agreed with ILOGS that ENP can be useful to the TOPIC project, but also expressed the concern about several issues:

- Inexperienced and untrained carers could use the system to make self-diagnosis and perform medical actions, which could be of a great danger;
- The language and details available in the system can be too complicated for informal care givers;



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- The selection criteria and configurations need to be adapted for informal care givers;
- The information made available for the informal care givers need to be selected carefully in order to avoid any complications and problems in care processes ...

WEBINAGE

WEBINAGE presented their software product designed for elderly who are alone at home that provides communication, entertainment, and security features to its end users. The product was brought to the market 18 months ago. It is a tool developed in HTML5 that can run as an application on multiple devices (tablets, smartphones, desktop computers, and touch screen PCs). Younger people use the software product with tablets, whereas elderly people prefer using a touch screen computer. Its features include the following:

- Maintaining list of contacts (with photo, name, and online status);
- Communication with contacts over audio and video connection;
- Sharing files (e.g., photos) with contacts during the video connection (both the photos and the video of the contacts are visible at the same time);
- Games (single and multiple players: “Connect Four”, “Pairs” and “Whiteboard”);
- Sending messages (with history of send and received messages);
- Directory of companies and people responsible for household issues (e.g., plumber, electrician, etc.);
- Local information and news;
- Emergency calls.

You can't connect more than 2 persons with a video call because WEBINAGE made the experience that for elderly it is too difficult to manage more participants. WEBINAGE also learned that elderly only accept video communication with people they already know very good – but it is okay for them to connect through audio communication with a person they do not know very well yet.

→ *Decision made*

The consortium agreed with WEBINAGE that this system is useful to the TOPIC project, especially its simple user interface, compatibility, and scalability are very important for TOPIC to build upon. We will use this platform for several use cases we have already discussed.

WP1

- Thomas suggested introducing more structure for the development of scenarios and collecting use cases. He suggested classifying scenarios in three dimensions:
 - Emotional impact of the carer, i.e., the emotional connection between the carer and the care receiver,
 - Presence of the carer, i.e., physical distance between the carer and the care receiver, and
 - Intensity of care required, i.e., the scale of care.

Each scenario has a level assigned for each of the dimensions. Level space of the dimensions is defined on a three-rank scale (“low”, “medium”, or “high”). This structure should be helpful for all partners responsible for the technical aspects of the project, as it would facilitate understanding the situation of informal carers.



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- TUW presented their methodology for performing observations. Namely, TUW uses several methods for data collection: field notes, as well as audio and video recording. Audio and video files are stored on the BSCW server and are indexed. Indexing audio and video files means marking and classifying topics of discussions, settings of the environment, and other important observations, and relating them to certain time stamps of the audio/video file to facilitate later analysis.

Maren and Myriam expressed their concerns about video recording of the observations and interviews. They were worried about ethical issues (e.g., to which limits we should go with recording, what if care receivers are so ill that they are not aware that they are being recorded, etc.). It was concluded that only non-sensitive situations will be recorded (e.g., situations such as bathing will not be recorded). Furthermore, they were not convinced whether users would accept being openly recorded.

→ *Decision made*

Agreements on how to describe use cases and scenarios: We will use the example presented by Myriam for this. See the example of the agreed use case format at <http://bscw.media.tuwien.ac.at/bscw/bscw.cgi/d654917/Example%20of%20use%20cases.pdf>.

WP5

- WEBINAGE developed the website for the TOPIC project, which was demonstrated to the consortium.
- Website is currently available only in English, but important parts (about the project, about the partners, and contacts) should be translated into German and French. Deadlines for these tasks are not defined.
- It was agreed that AVINOTEC will create and maintain Facebook page for the project.

→ *Decision made*

The consortium accepted the website and agreed to make it public until the end of October. Consortium partners are obliged to proofread the data on the website until October 31st.

WP6

→ *Decision made*

- University and technology partners agreed to meet in Vienna on January 15th and 16th, 2014 in Vienna to discuss communication of use cases and scenarios. Until that meeting, university partners are obliged to define several important use cases, describe them using the agreed templates, and discuss them with SOGL, SOPHIA, and ESE.
- It was decided that the next consortium meeting will take place in Bamberg, Germany on March 20th and 21st, 2014.