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<p>Abstract:</p> <p>This document gives a description of the privacy protection plan which is going to be used in the CaMeli-project.</p> <p>The plan contains a description about how we deal with the data-collection, data-storage, data-sharing and all the documentation needed for the trials.</p>		

## **Classification and approval**

**Classification:** Public

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## 1 Introduction

### 1.1 Summary

This document will give a description of the privacy issues related to the trials in Switzerland (VIVA) and The Netherlands (Orbis). It discusses issues as which data to collect, where data will be stored, who will be data controller and what National legislation to use if data is shared between countries.

Also described is the development of all the necessary documents for running the two pilots, including quick guide, Informed Consent documents and questionnaires.

### 1.2 Structure of this Document

The document starts with a short description of the trial. The second paragraph handles the privacy documents used for the several parts of the trial. Furthermore a description is given of several aspects related to the collected data, such as data collection, data storage, data control and data and system security.

### 1.3 Relationships with other Deliverables

This deliverable, the Privacy Protection Plan, is closely related to D 1.3 Ethical, Privacy and Legal Considerations. It's important to act according to laws and regulations concerning ethics and privacy. Besides several technical interventions to ensure privacy is being take care of, the information and documents for clients is of great importance as well.

The ethics and privacy committee will be responsible for all ethical issues related to the involvement of both elders and informal and formal caregivers that will be involved in the trials.

Based on the informed consents the data can be collected and analyzed for further improvements and extensions of the CaMeLi system on a legal and secured way.

### 1.4 Contributors

**Table 1: Revision History**

Version	Date	Reason	Revised by
V1	29-1-2014	Initial version	Orbis
V2	14-2-2014	Updated Version	Orbis
V3	27-2-2014	Updated Version	Orbis
V4	30-4-2014	Updated Version	Orbis
V5	15-5-2014	Final Version	Orbis
V6	15-05-2014	Reviewed Version	UniGe

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## 2 Description privacy protection plan

### 2.1 Orbis Hoogstaete (The Netherlands)

#### 2.1.1 *Description of the trial*

The goal of CaMeLi is to provide a system operating on a distributed network of interconnected tablet devices and using as an interface an avatar, able to express emotions, that simulates the way the elder was used to or would like to interact, collaborate, and dialogue, with a human life partner, understanding his emotions and assisting him in carrying out daily life activities at home. The elder will interact intuitively with the system, via voice (optionally supported by screens), emotions expressed and activity conducted, having the illusion of communicating with a real human who understands his behaviour and emotional state and assists him appropriately. The system will provide benefits on a practical, psychological and social level enabling the elderly to feel self confident to remain active longer and independent at home, thus improving their well-being.

By means of group interviews and pre-trials the CaMeLi system will be developed, based on user needs:

- Group interviews with elderly and formal/informal caregivers to get information about their daily activities and the thereby desired support. The analysis of the user needs will be used to develop the technology;
- The first pre-trial in month 8 will consist of a video to be shown to the elderly. This video will show some different options regarding colours, screens (including agenda), moving avatars etc to see how the elderly feel about these first images. We ask both elderly groups of VIVA and Orbis for their feedback, to be able to achieve a greater acceptance from the users.
- Trial: the outcomes of the pre-trial will be used for the final set up.

#### 2.1.2 *Privacy documents used*

CaMeLi includes involvement and observation of elderly, whose privacy is subject to extensive formal regulation. It will be ensured that elderly included in the trial group give a written informed consent to participate.

Participants will be able to withdraw the consent (and consequently withdraw from the project) at any time and without the need to give a reason. An information brochure (attachment Annex 1), written in a simple, understandable local language, documenting the objective of the project will be used to inform the trial group. The project will ensure that all aspects related to possible privacy issues are understood by the participants before the written consent is collected.

Suitable informed consent forms will be used in every phase of the development of the technology, namely group interviews, pre-trial and trial. (Annex 1, 2, 3)

Before the start, the participants will receive detailed information, and the relevant informed consent form.

The consent contains a description of the content of the trial, information about the data collection, data storage and data control. The participants will also be informed about the possibility to withdraw at any moment from the trial. On request the content of the informed consent will orally be explicated. The document will be signed by each participant and stored at the office of the manager and the participant will receive a copy.

Besides this, participants will be asked for permission to use audio recordings, photos and or movies of themselves using the CaMeLi system. Photos will be taken during presentations and instructions.

Agreements for the use of photos and film recordings as well as movie shots are included in annex 4 and 5.

Furthermore participants sign an agreement for the use of the equipment, property of Orbis, during the project. The agreement also covers that the clients may only use the equipment for the purposes and duration of the CaMeLi project. (attachment Annex 6)

### *2.1.3 Data Collection*

Data collection takes place in different ways:

1. Data from questionnaires
2. Data from group interviews
3. Data from oral evaluations during the pre-trial, later written on standard forms
4. Personal data given by the participants
5. Data from observations by care professionals later written on standard forms
6. Data from the CaMeLi system

CaMeLi facilitates technological solutions for gathering and sharing of information from different sources, including sensitive personal information. CaMeLi aims to handle sensitive personal information shared between different stakeholders. The project will address this issue and develop solutions that comply with applicable legislation in the pilot countries. The ethical aspects concern who will have access to what information, and whether it should be access on different levels. The project will therefore initiate discussions with respective data inspectorates while creating detailed definitions of the solution. During the final CaMeLi-trial the collected data will undergo statistical processing where measures will be included to ensure anonymity of users. During the pre-trials some additional anonymized data will be stored and shared by the technology partners to improve and assess the quality of the modules this will be announced in the informed consent.

The technology chosen will be respectful of human dignity.

The CaMeLi system will respect the integrity of its users such that the data collected about its users is not directly used for making a profit by any individual though allowing for commercial services driven by the use of personal data (after users have given their consent for the usage of their data). All elderly information will be maculated after the project's end. To perform trials related to treatment of personal sensitive information there are several directives at European level that will be met (European directives: Directive 95/46/EC on protection of personal data, Directive 97/66EC concerning the processing of personal data, Directive 2002/58/EC directive on privacy and electronic communications). Member states can transpose these into more concrete national implementations.

### *2.1.4 Data Storage*

For some services, data captured by the CaMeLi system must be stored. However, in principle no sound of video streams will be recorded in the final CaMeLi system. During the pre-trials / pilots there might be a need to store video and sound to improve future modules of these analysis tools. The data must be shared with the technology partners in that case. This only holds for the piloting, not for the final system.

The multi-device system will be partially a stand-alone device which is placed in the apartments of the participants in Sittard. Next to that, there will also be a server. Data will be stored temporarily on the server in order to improve the technology during the pre-trials.

In the nursing home the ICT-department can only be entered by authorized persons, by registration of entrance by name. The care apartments are private apartments, authorisation for access should be given by the clients themselves.

Data from questionnaires, the non-digital data is stored on paper and preserved by the manager of Orbis Hoogstaete. These are kept in a locked desk behind a locked door during the absence of the manager.

One of the objectives of the system is “Behavior Analysis”, namely to monitor and learn the daily behaviour of the elderly in order to detect suspicious deviations from what can be considered to be normal. In order to achieve this goal the system will collect large amounts of sensitive data which should not come into the wrong hands or be misused by unauthorized third parties. Therefore, the general rule of CaMeLi is that data collection, storage and processing should be done on a local level (the elderly’s devices), instead of a central location (external device not in the premise of the elderly) to which they will have to be transferred. Even if this demand will possibly increase the equipment costs at the customer’s premises, no raw data shall leave the home.

#### *2.1.5 Data Control*

As an additional measure to control the data, CaMeLi services can only be invoked from the CaMeLi system. Logging information can be sent on request to the server and access will require authentication of an authorized administrator. No debug or test interfaces are exposed externally. Administrative and management interfaces require authentication of an authorized administrator.

As for the part of the system that will have access to internet services, required measures will be taken to guarantee protection of the data. In deliverable 4.1 these safety measures shall be explained in more detail.

#### *2.1.6 Data Protection*

For the trial at Orbis in the Netherlands, data and systems are protected in the following way:

- The software and personal database will run on the stand-alone device in the apartment of the client
- Administrative and management interfaces (for both caregivers and elderly) run on a server in the Orbis data center;
- Predefined logging information will be sent and stored on demand on a server in the Orbis data center;
- Data will be stored temporarily on the server in order to improve the technology;
- the CaMeLi software is maintained by authorized project members;
- administrative and management interfaces require authentication of an authorized administrator.

#### *2.1.7 Data and System security*

For the trial at Orbis in the Netherlands, data and systems are secured in the following way:

- The software and personal database will run on the stand-alone device in the apartment of the client
- Administrative and management interfaces (for both caregivers and elderly) run on a server in the Orbis data center;
- Predefined logging information will be sent and stored on demand on a server in the Orbis data center;
- The server is protected by a firewall which only lets certain authorized network traffic through;
- The server and network are maintained by the Orbis staff and its service providers;
- The CaMeLi software is maintained by authorized project members;
- Administrative and management interfaces require authentication of an authorized administrator.



### 2.1.8 *Data sharing and Transmission*

A subset of the personal data or other sensitive information belonging to the primary user (i.e., elderly) will be shared with various elements of their care community (i.e., family and friends). These people will be previously authorized, having different access rights, ranging from: permission to view data that the user considers private, to add new entries, or manipulate existing data.

The general rule of CaMeLi is that data collection, storage and processing should be done on a local level, instead of a central location to which they will have to be transferred. However, when a critical situation is detected and if the resulting alarm-flag is not cancelled in due time, information shall go to the outside for summoning appropriate help. In this case, the data will have to go through processes of reception and transmission, supported by the system's dispatcher (i.e., GSM, UMTS, WiFi, etc). This implies that a third party, the mobile service provider will also have access to the information in the transaction. The information can be encrypted such that these third party service providers are unable to read the information.

### 2.1.9 *Data after the end of the Trials /Project*

During the running time of the project, data will be stored temporarily in order to improve the technology. After the end of the project the data will be deleted.

## 2.2 VIVA (Switzerland)

### 2.2.1 *Description of the trial*

The goal is globally similar to Orbis', but the challenge here is to also help the participants to remain in their own home as long as possible and as well as possible without significant external aid –which is a crucial point regarding the current political concerns regarding the elderly facing losses in their autonomy.

Just as with Orbis: The goal of CaMeLi is to provide a system operating on a distributed network of interconnected tablet devices and using as an interface avatar, able to express emotions, that simulates the way the elder was used to, or would like to interact, collaborate, and dialogue, with a human life partner, understanding his emotions and assisting him in carrying out daily life activities at home. The elderly will interact intuitively with the system, via voice (optionally supported by screens), emotions expressed and activity conducted, having the illusion of communicating with a real human who understands his/her behaviour and emotional state and assists him/her appropriately. The system will provide benefits on a practical, psychological and social level enabling the elder to feel self-confident to remain longer active and independent at home, thus improving his/her well-being.

The CaMeLi system will be developed based on user needs determined by means of group interviews and pre-trials :

- Group interviews with elderly will be used to get information about their daily activities and the level of support they desired. The analysis of these user needs will be used in the development of the technology;
- Pre-trial (different from Orbis): real-life testing in the use of the avatar. A trial will be arranged at VIVA for simulating daily living activities and teaching the users how to interact with the system with the help of a staff member.
- Trial (different from Orbis): the outcomes of the pre-trial will be used for the final set up. Training sessions will be organized at VIVA, and a VIVA help-line will be available to the elderly when the elderly will have the system installed in their own individual (private) apartments.

### *2.2.2 Privacy Documents used*

Suitable informed consent forms will be used in the individual phases of the development of the technology, namely pre-trial and trial.

Before the start, the participants will receive the relevant informed consent form (annex 7) and an information brochure (attachment Annex 1), written in a simple, understandable local language, documenting the objective of the project and used as information to the trial group. The project will ensure that all aspects related to possible privacy issues are understood by the participants before the written consent is collected.

The consent contains a description of the content of the trial, information about the data collection, data storage and data control. The participants will also be informed about the possibility to freely withdraw at any moment from the trial. On request, the content of the informed consent will be orally explained. The document will be signed by each participant and stored at the office of the manager, while each participant will receive a copy.

Besides this, participants will be asked for permission to use audio recordings, photos, or movies in which they appear using the CaMeLi system. They will have the opportunity to choose between a use limited to the study, to an academic public, or to a more general public. Agreements for the use of photos and film recordings as well as movie shots are the same as used in Orbis and therefore are included in the attachments.

Furthermore, participants will sign an agreement for the use of the equipment. The equipment is UniGe property during the project.

According to the proposal, the equipment will be kept by VIVA, so the participants may keep the CaMeLi system even after the completion of the project.

### *2.2.3 Data Collection*

I see that it is explained later, maybe there is no need to mention it here.

Data collection takes place in different ways and will be provided from different sources :

1. Data from questionnaires
2. Data from group or individual interviews
3. Data from oral evaluations during the pre-trial, later written on standard forms
4. Data from observations or interviews by the VIVA staff later transcribed on standardized documents
5. Personal data given by the participants
6. Data from the CaMeLi system

### *2.2.4 Data Storage*

Data collected for items 1 to 5 are stored on paper and preserved by the staff of VIVA, in a locked desk, either at the University or within the local of the association.

Digital data from the CaMeLi system is stored on a stand-alone device which is placed in the private apartments of the participants. Authorisation for access should be given by the participants themselves.

Additionally, item 5, “personal data given by the participant” which will most likely include personally identifiable data i.e. contact information, real name, address, etc. should be stored in a

locked location separate from items 1-4 and items 6 and 7. This separates personally identifiable information from research data, as well as data required for the CaMeLi system and the Memory Club (described in D1.2). In order to guarantee the anonymity of the research data, user codes or nicknames will be used instead of the real participants' names in this data and a matching list will be required to identify the participant from the user code or nickname in case it is necessary. Thus, the matching list and the personally identifiable information should be stored separately. This additional layer of protection is required for the VIVA population, as they are not within the security domain of the Orbis site.

The memory club is designed to function by accessing only a limited set of user profile information that can be identified by the system using a nickname, a user id code, or some other methods. Where it is necessary, the user can be identified through the matching list, which is available only to authorized VIVA staff. Where Internet connection is required all data transmitted will be protected by industry strength encryption algorithm. Further specification of the data protection process and mechanisms used in the Memory Club will be detailed in D3.1b.

The data collected are stored on paper and preserved by the staff of VIVA, in a locked desk, or within the local network of the association.

#### *2.2.5 Data Control*

As an additional measure to control the data, CaMeLi services can only be invoked from the CaMeLi system. No debug or test interfaces are exposed externally. Administrative and management interfaces require authentication of an authorized administrator.

As for the components of the system that will have access to internet services, required measures will be taken to guarantee protection of the data. These safety measures shall be explained in more detail in deliverable 4.1.

#### *2.2.6 Data Protection*

For the trial at VIVA members' apartments, data is protected in the following way:

- the software and database run on a stand-alone system
- the CaMeLi software is maintained by authorized project members
- administrative and management interfaces require authentication of an authorized administrator.

For the trial at VIVA, data and systems will be under the supervision of UniGe, and this point still needs to be specified; there is no internal server at the association.

#### *2.2.7 Data and System security*

For the trial at VIVA in Switzerland, data and systems are secured in the following way:

- The software and database run on a stand-alone system.
- The CaMeLi software is maintained by authorized project members.
- Administrative and management interfaces require authentication of an authorized administrator.

### **2.3 Privacy Committee**

A project ethics and privacy committee is set up with representatives from each of the trial sites responsible for developing guidelines and codes of practice for use by the project and to also monitor that the guidelines are being properly addressed throughout the project and beyond it. The ethics and privacy committee is responsible for issues such as confidentiality of personal data related to the involvement of both elders and informal and formal carers that will be involved in the trials. The

project management will collaborate closely with the ethics and privacy committee associated with the two trial sites, and proper authorizations will be collected prior to different studies

### 2.3.1 *Orbis (The Netherlands)*

During the CaMeLi project period, frequent contact with a member of the privacy committee from Orbis will take place to discuss about the privacy issues regarding the project.

This person advises the project-staff about what to do and what not to do concerning privacy, especially related to information for and communication with the elderly, participating in the trials.

The used privacy documents have been made by this member of the privacy committee of Orbis and were assessed with the national legislation in the Netherlands. The privacy committee member gets frequent updates about the project and gives advice, solicited and unsolicited, to the project-staff.

The member of the privacy committee from Orbis involved is Mrs. Drs. M. Mohrmann, [m.mohrmann@orbisconcern.nl](mailto:m.mohrmann@orbisconcern.nl).

### 2.3.2 *VIVA (Switzerland)*

During the CaMeLi project period, frequent contact with a member of the privacy committee from UniGe, in the name of VIVA, will take place to discuss about the privacy issues regarding the project.

This person advises the project-staff of VIVA about what to do and what not to do concerning privacy, especially related to information for and communication with the elderly, participating in the trials.

VIVA will use the privacy documents that have been made by the member of the privacy committee of Orbis and will be assessed with the national legislation in Switzerland by the member of the privacy committee from UniGe.

The privacy committee member gives frequent updates about the project and gives advice, solicited and unsolicited, to the project-staff.

The member of the privacy committee from UNiGE involved is Prof. Dimitri Konstantas, [dimitri.konstantas@unige.ch](mailto:dimitri.konstantas@unige.ch).

### **3 Conclusion**

This deliverable defined the Privacy Protection Plan that will be considered during the development of the CaMeLi system in this project. A short description of the important aspects during the trials has been provided and a description is also given for several aspects related to the collected data such as data collection, data storage, data control as well as data and system security. Also in this deliverable the necessary documents for running the two pilots, including Informed consent documents, quick guide and questionnaires have been developed and presented.

## 4 Glossary

**Table 3: List of terms, abbreviations and acronyms**

ICT	Information and Communication Technology
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## 5 References

- [1] [www.wetten.overheid.nl](http://www.wetten.overheid.nl) (Dutch laws)
- [2] <http://eur-lex.europa.eu/> (European Laws)

**Annex A: Informed consent forms**

1. Consent for group or individual interviews project Care Me for Life (CaMeLi)
2. Consent for pre-trial project Care Me for Life (CaMeLi)
3. Consent for trial project Care Me for Life (CaMeLi) (under construction)
4. Consent for photo and film recordings
5. Consent movie shots project Care Me for Life (CaMeLi)
6. Agreement on the use of the equipment project Care Me for Life (under construction)



## 1. CONSENT FOR GROUP INTERVIEWS PROJECT Care Me for Life (CaMeLi)

The project CaMeLi has as a goal to support elderly, helped by technology, with their daily activities.

We interview elderly to get information about their daily activities and the thereby desired support. With this information, we make an analysis of the user needs. This analysis will be used to develop the technology for this project. The data from the group interviews will be analyzed anonymously. We will also make audio recording, which will only be used for analysing the data from the interviews.

You already gave us your consent to participate in these group interviews.  
To be careful and thorough we ask your written consent in this form.

*To be filled in by the participant*

I declare that I have been properly informed about the project CaMeLi. I also received an information brochure.

I hereby declare voluntarily to take part in a group interview. I know that the data from this interview will be analysed anonymously and that audio recordings of these interviews are being made.

I hereby keep the right to end my participation at any time, without having to give a reason.

Name participant:

.....

Date: .....

Signature participant: .....



Formulaire de consentement	
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Responsable du projet : Association VIVA (Valoriser et Intégrer pour Vieillir Autrement), via sa présidente, Dre A.-C. Juillerat Van der Linden

Membre référente de VIVA : Emilie Joly, Psychologue Junior à VIVA, Chercheuse à la Faculté de Psychologie et des Sciences de l'Education, Université de Genève.

Je soussigné(e) ..... confirme que :

1. On m'a informé(e) de la nature et des buts de ce projet de recherche, ainsi que de son déroulement.
2. Ma participation à cet entretien est volontaire et je peux me retirer à tout moment.
3. Les données de cette étude seront traitées en toute confidentialité et anonymement, mais elles pourront être utilisées à des fins commerciales et scientifiques.
4. J'ai pu poser toutes les questions voulues concernant ce projet et j'ai obtenu des réponses satisfaisantes.
5. J'ai pris connaissance du formulaire d'information et du présent formulaire de consentement éclairé
6. J'ai lu le présent formulaire et je consens volontairement à participer à cet entretien.

Date :  
Date :

Signature :  
Signature du référent :

## 2. CONSENT FOR PRE-TRIAL PROJECT Care Me for Life (CaMeLi)

The CaMeLi-project aims to support elderly, helped by technology, with their daily activities.

By means of group interviews, in which you participated, we already gathered information about the daily activities of elderly and the thereby desired support.

With this information, we made an analysis of the user needs which is used to develop the technology for this project.

In this phase of the project, we will show you videotapes of the tablet screen and the avatar (moving fictive person) in different colors and designs. We will ask you for your opinion about that and what kind of adjustments you would prefer. That information will be used to improve items before the definite trial will start.

You already gave us your consent to participate in the pre-trial.

To be careful and thorough, we ask your written consent in this form.

You can withdraw from the pre-trial at any time, without having to give a reason for ending your participation. This will not have any consequences.

*To be filled in by the participant*

I declare that I have been properly informed about the project CaMeLi. I also received an information brochure.

I hereby declare voluntarily to take part in the pre-trial. I know that the data from this pre-trial will be analysed anonymously.

I hereby keep the right to end my participation at any time, without having to give a reason.

Name participant:

.....

Date: .....

Signature participant: .....

### 3. CONSENT FOR TRIAL PROJECT Care Me for Life (CaMeLi) (under construction)

The CaMeLi-project aims to support elderly, helped by technology, with their daily activities.

By means of group interviews, in which you participated, we already gathered information about the daily activities of elderly and the thereby desired support.

With this information, we made an analysis of the user needs which is used to develop the technology for this project.

During the pre-trial phase of the project, in which you also participated, we gathered information about the desirable lay-out of the tablet screen and the avatar.

In this phase of the project the definite trial will start. In your apartment a tablet with avatar will be placed. The avatar will assist you in your daily activities by giving helpful instructions, like remind to take your medicines or go to an activity.

In order to be able to give instructions you will be monitored. This will happen in a way that you are unidentifiable. The registered information is therefore anonymous.

When there are, besides you, other people in your apartment, the tablet with avatar will automatically switch to sleep mode. Furthermore you can switch off the avatar any time you wish.

You already gave us your consent to participate in the trial.

To be careful and thorough, we ask your written consent in this form.

You can withdraw from the trial at any time, without having to give a reason for ending your participation. This will not have any consequences.

*To be filled in by the participant*

I declare that I have been properly informed about the project CaMeLi. I also received an information brochure.

I hereby declare voluntarily to take part in the trial. I know that the data from this trial will be stored and analysed anonymously.

I hereby keep the right to end my participation at any time, without having to give a reason.

Name participant:

.....

Date: .....

Signature participant: .....

#### 4. CONSENT FOR PHOTO AND FILM RECORDINGS

Undersigned hereby declares, as client or as legal representative of client,

Name client: .....

Birth date: .....

Address: .....

Permission to make photos and movies for communication purposes of Orbis Medisch en Zorgconcern (for example flyers, website and other informative material)

You can withdraw your permission at any time.

In case you or your family does not wish to use the images after a possible decease, you can mention this to the manager of your living department. From that moment on, the images will not be used anymore when developing informative materials. In case of a reprint of existing informative materials, the concerning images will be removed.

Client / Representative\*:

Name.....

Date.....

Signature .....

\* Delete what is not applicable

## 5. CONSENT MOVIE SHOTS PROJECT Care Me for Life (CaMeLi)

The project CaMeLi has as a goal to support elderly, helped by technology, with their daily activities. To develop the technology for this project as good as possible, the firm Noldus Information Technology will make movie shots of a few elderly persons. This firm will use these images only for internal analysis.

You already gave us your consent to participate in these movie shots by Noldus Information Technology.

To be careful and thorough we ask your written consent in this form.

*To be filled in by the participant*

I hereby declare voluntarily that I give permission to Noldus Information Technology to make movie shots of me. I know these images will only be used internally to develop the technology for the project CaMeLi as good as possible. I hereby keep the right to end my participation at any time, without having to give a reason.

Name participant:

.....

Date: .....

Signature participant: .....

**6. AGREEMENT ON THE USE OF THE EQUIPMENT  
PROJECT Care Me for Life (CaMeLi)**

**Under construction**