

# Deliverable 2.4.2

Ethics Manual and Legal Aspects – second iteration: discussing the integration of an US-TTS and SST-service.

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## Abstract

The Ethics Manual in its second iteration discusses ethical aspects which came up during the development process of CARU functions for the field trial. The use of the US service Twilio (speech-to-text service) and the related data transfer required further discussions and consultations of data protection experts. The statement of different partner organisations are presented. Furthermore, the solution approaches as well as a consideration of related, predefined ethical commitments for the project are discussed.

## What is new in this version?

Version	Date	Changes	Name	Organisation
2	9th July 2021	presentation and discussion of data protection issue „Twilio“	Nadine Sturm	JOHA
2	26 July 21	review	Birgit Trukeschitz	WU

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# 1. Executive Summary

The 2nd iteration of the Ethics Manual presents ethical topics that arose during the process of developing functions for CARU to be tested in 2 field trials. The business perspective of testing minimum viable products and using an US-service for speech-to-text and text-to speech transfers has caused issues which needed to be discussed with data protection experts.

Several CARUcares partners have involved legal experts and shared their statements about the issue. The end users of the care sector raised a major concern about data protection even in the testing phases, as real data are planned to be used. For business and development partners, it is necessary to define useful features in the field trials before investing in the development of an internal speech recognition (not using an additional service).

Furthermore, the effects on predefined ethical aspects in the MEESTAR model presented in Del. 2.4.1. are considered in this deliverable.

## 2. Introduction

Humans and technologies operate in a constant and reciprocal interrelation. On the one hand, technologies and innovations are designed by humans for humans and influence social and technological development. On the other hand, technology influences and shapes humans in their living habits, self-perception, judgement and behaviour (Manzeschke et al, 2013). Therefore, it is crucial to keep an eye on ethical aspects when developing innovative technological tools, especially when addressing complex systems as care and social services. Supporting autonomy of and providing services for older people in need of care as well as addressing organisational issues of care service providers is a challenge to be addressed by AAL projects, such as CARUcares.

This deliverable presents actual discussion points in an ethical viewpoint as well as the legal backgrounds.

Ethical issues in CARUcares are mainly related to two domains: the involvement of primary and secondary end users as participants in the co-creation phase (e.g collection of user needs and feedback for the development in a group of vulnerable people) and the field trials (e.g. introducing new technologies in a group of vulnerable people, collection of impressions and personal sensitive data). In line with legal regulations, the project team will protect the security, privacy, and confidentiality of participants and researchers. This statement raised awareness for data protection issues as an US service was planned be used to ensure speech-to-text translation. The results of a constant monitoring process concerning ethical aspects is presented in this deliverable.

## 3. Ethical and legal issues Update - actual status of project development

During the 1st year of the project, an issue arose that required ethical discussions and solutions meeting the requirements of the General Data Protection Regulation (GDPR). Furthermore, in the beginning of 2021 the situation of the consortium changed, which also affects the roadmap concerning ethical issues in CARUcares. In the following chapters, those aspects will be described in further detail.

### 3.1. Integrating a US service (SST and TTS) for the CARUcares field trial

The pilot field trial aims to test new developed functionalities of CARU in real life settings.

The first test phase is the acceptance test. To the current status of the project, it is already finished. It was conducted to test the already integrated feature „emergency call“ of CARU with end users in Switzerland.

For testing the three newly developed features in real-life settings (field trial), it was planned to implement and integrate a so called „minimum viable product“. A minimum viable product (MVP) is a stage of development of a product, where it is possible to test it under real conditions with end users without full integration to an established system. Functions that are crucial are implemented, which enables quick feedback and saves resources. It is the point in product development, where minimal efforts meet qualitative feedback (Wirtschaftslexikon Gabler, online 24.11.2020).

For CARUcares, this means that some of the functionalities, which were selected as potentially useful in the Co-Creation Workshops are at that project stage (Nov 2020) implemented as MVPs. This brings along the issue that there is no full integration of the functionalities to the CARU system. The functionalities have to be tested in a first round with end users to find out if they meet their needs - including the option for further improvements, adaption and implementation for a planned large-scale final field trial.

To test voice-assisted features a system called TWILIO shall be used to transfer speech to text and text to speech between the CARU device and the CARU system for Field Trial 1. This was suggested by the business partner CARU AG. TWILIO is a US company ([www.twilio.com](http://www.twilio.com)). It was decided by the developer team after an evaluation of services that it is the most suitable to use it for testing MVPs. Please see further technical details in Deliverable 2.2. System Architecture.

Major concerns about using this US service arose when the EU-U.S. privacy shield was invalidated in July 2020 by the European Union Court of Justice (CJEU). „As a result of that decision, the EU-U.S. Privacy Shield Framework is no longer a valid mechanism to comply with EU data protection requirements when transferring personal data from the European Union to the United States“ ([www.privacyshield.gov](http://www.privacyshield.gov), 24.11.2020).

The project still relies on handling with personal data. However, several steps to pseudonymize personal data have been taken in the project CARUcares. In a first step, clear names of clients or staff members participating to the study were replaced by a code number - the client ID - by the end user organisation or the service provider of the care management system of the end user organisation. The connection between client ID and sensor ID is done by the end user partner. The sensor ID is used for further transfer of information to the CARU system.

The CARU system calls the service Twilio using a phone number that is registered for a specific sensor ID or client ID at the CARU AG. Therefore, the phone number is not directly registered with Twilio for a specific person. Still, it can be potentially tracked by following the way through sensor ID to client ID to the clear name.

The transfer of data concerns personal data. As also health data will be conveyed, special categories of data according to GDPR Art. 9 will be processed as follows: The project is designed to support mobile care services with speech assistance. On the one hand, the notification function includes information about arrival times of care workers. This data could be used to draw conclusions on the frequency of the use of care services as well as on the presence of other persons in a specific location (e.g. a care worker visits older woman in her flat). On the other hand, the functionality used for care documentation plays back the voice-supported To-Do-List (documentation feature) of a care worker for a certain visit and might contain intimate and detailed information about the health condition of a home care service user (e.g. „change the urinary catheter“). Therefore, it is crucial, especially for the care organisations of the consortium, to protect those data in an appropriate way.

Further concerns arose with regard to understandability of a (technical) process, such as using Twilio for older persons, who have to be informed in detail to give their consent). The informed consent was rewritten to inform participants about the potential access of US authorities. In order to clarify concerns, representatives of the care organisations involved in this project explained the issue orally to participants during the recruitment phase. The handling of the data – the meaning of pseudonymisation - was explained to the trial participants.

These issues have been discussed so far with the data protection officers of JOHA and SLGR. Furthermore, two statements of legal specialists - one lawyer by order of FHWN and the legal department of WUWI - have been gathered. Statements of different partners of the project are presented in the next sections of this deliverable.

### **3.2. Statement of technical partners**

#### 3.2.1 CARU AG

CARU is developing and distributing safety and communication products. These are applied in various settings from public to private spaces. Privacy plays a crucial role in all settings and especially in the use case of care, which is covered by the core product. Since the beginning, CARU has therefore stressed in the development of features that data security is given by design. GDPR compliance is a critical factor in that and absolutely necessary to build trust with our customers.

There is, however, a phase in product development which precedes the actual feature implementation. This is the MVP phase. In this phase, it is crucial to be extremely flexible and fast in order to test various configurations or designs of a feature. In this phase, we cannot afford to implement everything to the end and hence use various external services for the MVPs. A MVP is tested extensively with potential users to check the desirability of the feature. Also, the viability is checked in this phase in order to ensure that a sustainable business model exists for the feature. Lastly, the feasibility is validated by checking the technical implementation. Once all these factors are evaluated positively, a feature is implemented fully and care is taken on all ends to the quality. Be it UX/UI (user experience, user interface), robustness, onboarding - or data security.

Within CARUcares, we therefore introduced Twilio (before the drop of the privacy shield) as a tool that allows to build MVPs in a lean way. It allowed the project to quickly implement three completely new features without needing to spend resources on implementing services that exist and are commercially available. In our opinion, CARUcares as a research project should focus as much as possible on the research aspect to contribute with novel solutions to the bigger challenge of our society.

In order to prevent the identification of a natural person through the US-service Twilio, several measures have been taken by the development partners to significantly increase the barriers that need to be taken in order to identify respective natural person. Among those, instead of personalized SIM-cards, M2M cards are being used that are registered in the name of CARU AG and hence do not allow to trace back to an individual. Further, the exchange of personal information between the features and the users is not actively stimulated by the UX of the features. For example, closed questions are being asked wherever possible and questions of only a few seconds length are allowed to prevent (lengthy) explanations, which could contain personal information. In the second trial the devices are placed in a lab environment, therefore dramatically reducing the risk of

transferring intimate personal data and being located at a private home. Additionally, an informed consent of the users will be obtained in all tests that involve users.

If the field trials prove that all or any of the tested features fulfill the above stated three aspects, CARU will develop the feature further in order to commercialize them. Data security will then be implemented as required in the respective countries (e.g. GDPR in EU).

Summary of viewpoint:

- Desirability, viability and feasibility of a feature need to be ensured BEFORE the actual implementation can start in order to use the given resources economically responsible.
- MVPs need to be built fast to check these three aspects. They need to be flexible in order to test and iterate quickly.
- Once the proof for all or any of the features is made, the implementation will be carried out considering and carefully implementing data protection regulations.

Summary of risks if viewpoint is not taken seriously:

- Resource usage on feature implementation without validated business case behind.
- Focus on research aspect of the project would be lost as resources are used to copy commercially available tools.

### 3.2.2 University of Applied Sciences Wiener Neustadt (FHWN)

In the CARUcares project, FHWN is responsible for the notification function. This function calculates the arrival time of the care worker based on crew scheduling data and GPS data. The calculation output is a text string. The notification function is provided by FHWN as a service (Figure 1). This service can be triggered by CARU and returns the result string to CARU. The processing of the result string is done by CARU. Currently, they use Twilio for that.

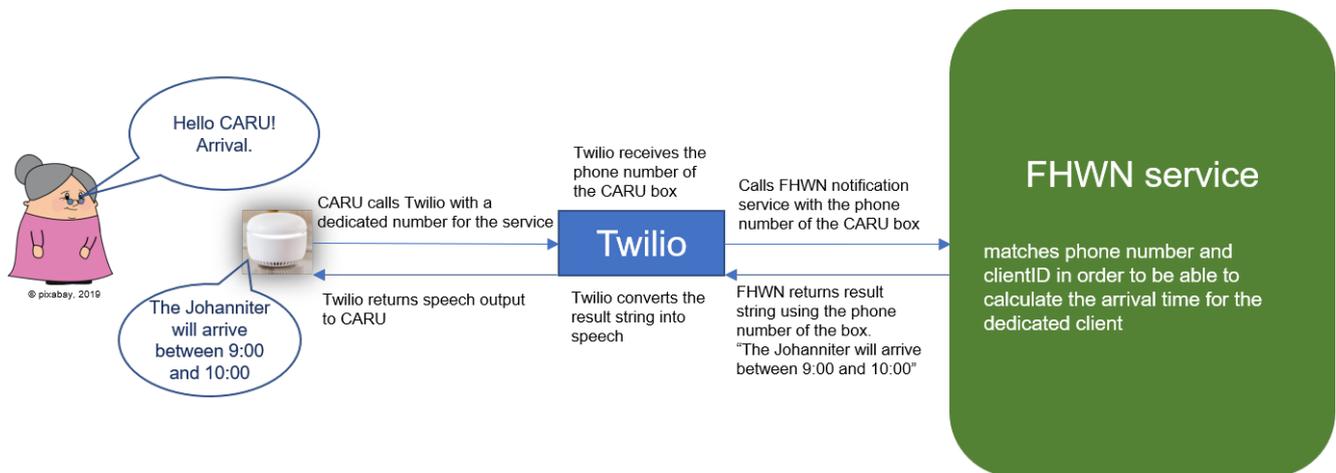


Figure 1: Workflow used by FHWN

The **DPO of FHWN** stated that data transfer to the US is only allowed in compliance with GDPR Art 44ff. This is not the case after 16th July 2020, as the US Privacy Shield has fallen. Therefore, the transfer of personal data to an US service is not allowed unless there is another reason according to GDPR to nevertheless transfer those data. It is recommended to conclude „Standard Contractual Clauses“ which are predefined by the EU. If there are no „Standard Contractual Clauses“ with any US company or service, this must be immediately rectified. Otherwise, the transfer of personal data is not allowed.

### 3.3. Statement of End User Partners and their DPOs

The use of voice assistance in the context of a care setting includes transfer of sensible data - e.g. personal health data or detailed data about the care service and related to does. It was pointed out as one of the major advantages of CARU that data protection is carefully addressed by using GDPR conform methods of data transfer. As it was decided, that the US service „Twilio“ is used, it is necessary to inform older persons about the related data transfer to the US and the fallen privacy shield. Processing is only possible if they voluntarily agree. End user partners raised the issue, if an older person, who is less technically experienced is able to understand this processes and give an informed consent. Still this was the agreement that was made for the first field trial by end user partners, after security measures were taken. For the second field trial, end user partner of the project would not agree to use Twilio or any other service like that anymore.

### 3.3.1. JOHA

The DPO of Johanniter received the excel file listing the required data transfer for the first field trial to decide, if it is pseudonymized or anonymized data that are transferred by using the functionalities of CARUcares.

He gave the following statement:

„All information describe in that sheet is (hopefully) result of pseudonymisation.

Such information may be used in field test 1 (all persons cared for and the carers) have to be informed exact and complete and data may be used only if they sign an appropriate agreement.

### **What does GDPR say?**

#### **Definition**

(5) ‘pseudonymisation’ means the processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person;

#### **Explanation**

(26) The principles of data protection should apply to any information concerning an identified or identifiable natural person. Personal data which have undergone pseudonymisation, which could be attributed to a natural person by the use of additional information should be considered to be information on an identifiable natural person. To determine whether a natural person is identifiable, account should be taken of all the means reasonably likely to be used, such as singling out, either by the controller or by another person to identify the natural person directly or indirectly. To ascertain whether means are reasonably likely to be used to identify the natural person, account should be taken of all objective factors, such as the costs of and the amount of time required for identification, taking into consideration the available technology at the time of the processing and technological developments. The principles of data protection should therefore not apply to anonymous information, namely information which does not relate to an identified or identifiable natural person or to personal data rendered anonymous in such a manner that the data subject is not or no longer identifiable. This Regulation does not therefore concern the processing of such anonymous information, including for statistical or research purposes.

So – using additional information (patient ID – device ID – telephone number stored at ANY project partners place) using “all the means reasonably” **allows to identify the patient.**

### **Article 25 Data protection by design and by default**

1. Taking into account the state of the art, the cost of implementation and the nature, scope, context and purposes of processing as well as the risks of varying likelihood and severity for rights and freedoms of natural persons posed by the processing, the controller shall, both at the time of the determination of the means for processing and at the time of the processing itself, implement appropriate technical and organisational measures, such as pseudonymisation, which are designed to implement data-protection principles, such as data minimisation, in an effective manner and to integrate the necessary safeguards into the processing in order to meet the requirements of this Regulation and protect the rights of data subjects.

Conclusion:

- Field Test 1 may be performed after signing of agreements
- Field Test 2 shall run only with partners in "GDPR-Region"

### **My final comment is:**

- field test 1 may be performed only if all persons cared for and the carers are informed exact and complete and only if they have signed the appropriate agreement
- results of field test 1 have to be evaluated to decide whether the planned processing steps will really be of benefit to the persons cared for and the carers.
- Field test 2 should start only, if evaluation performed in step 2 gives a positive result. To follow article 44 GDPO all data processing steps shall be performed only by organisations / companies which are NOT subject of US American jurisdiction

This is – and will be – my recommendation to the responsible officers at Johanniter International and Johanniter Unfall Hilfe in Österreich" (L.W., DPO of JOHA, received via e-mails on 4th and 5th November 2020).

### 3.3.2. SLGR

The DPO of SLGR was consulted concerning this issue and exchanged her opinion with the DPO of JOHA. The DPOs are in line. As SLGR is only part of the 2nd field trial, the statement of the DPO mainly concerns this part of the project. The conclusion is that the second field trial must not be conducted by using TWILIO.

### 3.3.3 BONA

Bonacasa did not take a position in the discussion.

### ***3.4. Statements of the lead evaluation partner (WUWI)***

In addition to compliance with general data protection regulations, a separate justification is required for transfers of personal data to a third country. Since the invalidation of the EU-US Privacy Shield agreement, data transfers to the US can no longer be based on this framework. The European Commission has not classified the US as a country with adequate levels of data protection (Art. 45 of the GDPR). An additional legal basis is therefore required to transfer data to the US.

Standard data protection clauses should be concluded with Twilio as well as additional safeguards on a case-by-case basis to ensure that an adequate level of data protection is in place. Please note that new standard data protection clauses are currently under review. As an alternative, data subjects can be asked for their consent. This means the data subjects would have to actively consent to the transfer of data to the US after being informed about the risks of a transfer without the existence of adequate data protection or suitable safeguards. We would not recommend this alternative in this case, as it seems unlikely that the target group would understand the full implications of a data transfer to the US.

In addition, please bear in mind that a data processing agreement needs to be concluded with Twilio as an external processor. From a data protection perspective, it would be preferable to switch to a processor where the data is stored in the EU or EEA for any transfers of personal data for your project, so that no data transfer to a third country (including the US) is necessary.

## 4. Legal background for CARUcares

The Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data and repealing Directive 95/46/EWC (GDPR) states in the **General provisions** that (GDPR, 2016):

*(1) The protection of natural persons in relation to the processing of personal data is a fundamental right.*

*(2) The principles of, and rules on the protection of natural persons with regard to the processing of their personal data should, whatever their nationality or residence, respect their fundamental rights and freedoms, in particular their right to the protection of personal data.*

*(4) The right to the protection of personal data is not an absolute right; it must be considered in relation to its function in society and be balanced against other fundamental rights, in accordance with the principle of proportionality."*

*(26) The principles of data protection should apply to any information concerning an identified or identifiable natural person. Personal data which have undergone pseudonymisation, which could be attributed to a natural person by the use of additional information should be considered to be information on an identifiable natural person. To determine whether a natural person is identifiable, account should be taken of all the means reasonably likely to be used, such as singling out, either by the controller or by another person to identify the natural person directly or indirectly. To ascertain whether means are reasonably likely to be used to identify the natural person, account should be taken of all objective factors, such as the costs of and the amount of time required for identification, taking into consideration the available technology at the time of the processing and technological developments. The principles of data protection should therefore not apply to anonymous information, namely information which does not relate to an identified or identifiable natural person or to personal data rendered anonymous in such a manner that the data subject is not or no longer identifiable. This Regulation does not therefore concern the processing of such anonymous information, including for statistical or research purposes.*

**Personal data as well as pseudonymisation is defined in Art (4), Definitions (GDPR, 2016):**

*(1) 'personal data' means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;*

*(5) 'pseudonymisation' means the processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person;*

**Article 25 regulates Data protection by design and by default (GDPR, 2016):**

*1. Taking into account the state of the art, the cost of implementation and the nature, scope, context and purposes of processing as well as the risks of varying likelihood and severity for rights and freedoms of natural persons posed by the processing, the controller shall, both at the time of the determination of the means for processing and at the time of the processing itself, implement appropriate technical and organisational measures, such as pseudonymisation, which are designed to implement data-protection principles, such as data minimisation, in an effective manner and to integrate the necessary safeguards into the processing in order to meet the requirements of this Regulation and protect the rights of data subjects.*

**Article 28 addresses processing of data from someone on behalf of a controller (GDPR, 2016):**

*1. Where processing is to be carried out on behalf of a controller, the controller shall use only processors providing sufficient guarantees to implement appropriate technical and organisational measures in such a manner that processing will meet the requirements of this Regulation and ensure the protection of the rights of the data subject.*

*(...)*

*4. Where a processor engages another processor for carrying out specific processing activities on behalf of the controller, the same data protection obligations as set out in the contract or other legal act between the controller and the processor as referred to in paragraph 3 shall be imposed on that other processor by way of a contract or other legal act under Union or Member State law, in particular providing sufficient guarantees to implement appropriate technical and organisational measures in such a manner that the processing will meet the requirements of this Regulation. Where that other processor fails to fulfil its data protection obligations, the initial processor shall remain fully liable to the controller for the performance of that other processor's obligations.*

The processing of special categories of personal data such as health data is prohibited in general but is possible under specific circumstances explained in Art (9, 2.), if:

*(a) the data subject has given explicit consent to the processing of those personal data for one or more specified purposes, except where Union or Member State law provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject;*

**Therefore, it is absolute crucial to ensure information about data processing has reached any testperson taking part in Field Trial 1 and informed consent was given.**

## 5. MEESTAR outcomes for CARUcares

For the project CARUcares, a MEESTAR-analysis was conducted in a first iteration in the first project phase (first 6 months). It will be repeated in accordance with the next iterations of the ethic manual deliverable. Upcoming issues often can be named as cross-topic but have been allocated to one of the given dimensions. Main guidelines for the project work can be derived from the outcomes of the analysis. The findings were already allocated to specific work packages and, if possible and applicable, even to single tasks according to the description of work of the CARUcares proposal.

To analyze the relevant dimension further and dedicate it to the process of the project the description is always divided in:

1. Dimension of MEESTAR (e.g. care) and short description according to the project
2. Factor: headline description of issue
3. Description and relation to CARUcares: detailed description of the ethical issue
4. Measures: how will this be considered in the project content, how can the targeted outcome be intended. Measures are to be understood as concrete practical guidelines for the further progress of the project.
5. Ethical sensitivity assessment: rating the issue from 1-4
6. Level of impact: social, organisational or individual
7. Status: actual status of the issue in the project
8. Reference to workpackage and task

In the following sub chapters, the discussion and outcomes of the MEESTAR analysis will be described in detail. Measures taken to address the ethical issues are written in bold and blue font as they can be understood as guidelines for the further progress of the

project. The full table which was used to conduct the analysis can be found in the appendix.

To provide a short overview, the following table concludes factors that have been assigned to a specific ethical dimension.

ethical dimension	FACTOR
<b>CARE</b>	Factor 1: Support optimization in care processes
	Factor 2: Enhance quality time in care processes
<b>AUTONOMY</b>	Factor 1: Support autonomous living via communication and security features
	Factor 2: Using the device at the end-users' own discretion
	Factor 3: Can be used without help – intuitive design
	Factor 4: Consider the preconditions of the end users
	Factor 5: Mode of control
	Factor 6: Create benefits and added value for users
	Factor 7: Employ services / technical options after consent
	Factor 8: Consider physical and mental integrity of the end users
<b>SAFETY</b>	Factor 1: Avoid Health impairments due to system failures
	Factor 2: Additional physical or psychological burden
	Factor 3: Liability definition in case of malfunction
<b>JUSTICE</b>	Factor 1: Discrimination based on income
	Factor 2: Discrimination based on social status
	Factor 3: Discrimination based on age
	Factor 4: Discrimination based on gender
	Factor 5: Discrimination based on education level
	Factor 6: Discrimination based on technical affinity
<b>PRIVACY</b>	Factor 1: Data processing
	Factor 2: Notifications using GPS
	Factor 3: Limits of care documentation via speech recognition
	Factor 4: Sensitive user data
	Factor 5: Unauthorized access and processing
	Factor 6: Privacy statement
	Factor 7: Consent follows transparent information
<b>PARTICIPATION</b>	Factor 1: Facilitates easy and new ways of communication
	Factor 2: Systemic steering of preferred mode of participation
	Factor 3: Withdrawal from contract
<b>SELF-CONCEPTION</b>	Factor 1: Transport manifold pictures of age
	Factor 2: Avoid discrimination/stigmatisation and standardization

Table 1: MEESTAR, CARUcares, ethical dimension and factors overview (Del. 2.4.1)

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These factors are further described, rated according to ethical sensitivity and dedicated to the project in the 1st iteration of this deliverable (Del. 2.4.1).

**For the category of “privacy”, factors defined are presented here again (Del. 2.4.1):**

**PRIVACY:**

Factor 1: **Data processing**

Description and relation to CARUcares:

Collection and further processing of data, which are passed on from the private environment of users of age-appropriate assistance systems to third parties, must be processed in such a way that no further information (e.g. linking of the data) can be derived. This is especially relevant for CARU during the field tests and the pilot (phase 2+3) but also after the project runtime.

Measures:

- **Ensure pseudonymous data collection, secure data storage and implement limited access rights for different actors and stakeholders.**
- **Conduct close monitoring of data quality and integrity.**

Ethical sensitivity assessment: 3

Level of impact: individual, organisational

Status: in progress

Reference to: WP3, all tasks

Factor 4: **Sensitive user data**

Description and relation to CARUcares:

The collection and transmission of data from the core area of user privacy through age-appropriate assistance systems must be safeguarded by special protective measures, as is the case with all data processing systems.

Measures:

- **Sensitive data will only be collected according to already existing processes of care organisations in reference to actual (national) legislative.**

Ethical sensitivity assessment: 3

Level of impact: organisational, individual, societal

Status: in progress

Reference to: WP2, Task 2.2 and WP3, all tasks, WP4, Task 4.1

Factor 5: ***Unauthorized access and processing***

Description and relation to CARUcares:

Third parties may not unauthorized access or process personal information from users. This also includes access to data of the care, medical or nursing staff (employee data protection).

Measures:

- **Systems are protected and users have different access rights.**

Ethical sensitivity assessment: 3

Level of impact: organisational, individual, societal

Status: in progress

Reference to: WP2, Task 2.2 and WP3, all tasks, WP4, Task 4.1 and Task 4.2

Factor 6: ***Privacy statement***

Description and relation to CARUcares:

Privacy statements should be written in a simple and clear way and should be communicated transparently.

Measures:

- **Design clear and transparent informed consents.**

Ethical sensitivity assessment: 3

Level of impact: organisational, individual

Status: finished

Reference to: WP2, WP5, all tasks

Factor 7: ***Consent follows transparent information***

Description and relation to CARUcares:

The users should be informed about the scope, depth, functionality and data usage of the respective age-appropriate assistance systems in a comprehensive, comprehensible and appropriate manner. Only on the basis of this information users should decide on the use of assistance techniques.

Measures:

- **Design clear and transparent information and informed consents.**

- **Provide additional information if needed and in an appropriate way.**

Ethical sensitivity assessment: 3

Level of impact: organisational, individual

Status: in progress

Reference to: WP2, WP5, all tasks

## 6. Commitment to ethical guidelines for CARUcares

The following guidelines were formulated in Del. 4.2.1 as an essence of the issues presented in the deliverable. They are the main ethical guidelines for the project CARUcares. Highlighted are now those issues related to the discussed data protection aspects discussed above:

### General commitment:

- Laws and legal standards, on national and international level are the basis for all ethical aspects that must be taken into account by the CARUcares consortium members
- The ethical discussion will be conducted continuously and ethical aspects will be monitored. The partner JOHA will be responsible for updates.
- The conducted MEESTAR analysis and especially its measures have to be taken into account for the assigned work packages and tasks by responsible project members.
- All project members commit to respect and consider those ethical aspects. If any kind of ethical aspect changes or new ethical aspects come up this has to be reported to the partner JOHA, who will integrate this to the further process of discussion.
- All project members commit to respect and integrate the formulated ethical guidelines to the project CARUcares.

### Commitment about the development process and end user integration:

- Support autonomous living by integration of communication and security features as well as respecting the free decision of the end user to not use the system.
- Create a clear benefit and added value for the end-user. Avoid discrimination and stigmatization.
- Only persons who read, understood and signed the informed consent must be included to the study.
- Integrate practitioners as much as possible in the development process and recognize also ethical critical issues. Analyze them and integrate findings in the next project steps.
- Support and share a manifold and diverse picture of older persons.

- Ensure efficient data collection, pseudonymous data processing, secure data storage and implement limited access rights for different actors and stakeholders. Conduct close monitoring of data quality and integrity. Sensitive data must only be collected according to already existing processes of care organisations in reference to actual (national) legislative.
- The users should be informed about the scope, depth, functionality and data usage of the respective age-appropriate assistance systems in a comprehensive, comprehensible and appropriate manner. Only on the basis of this information, users should decide on the use of assistance techniques.
- The informed consent should contain:
  - Information about data processing and storage
    - consequences, liabilities and responsibilities in case of a shut down or malfunction
    - responsible person/call center and further contact for emergency function
    - information about notification function and GPS tracking for care workers and service employees
    - modes and (no) consequences of withdrawal
- To be considered for the developing functions:
  - Address communication and security features
  - Avoid dead ends and labyrinths
  - Contain an explanation or back to start function
  - Consider preconditions of the end users physical and cognitive status well
  - Ensure that emergency calls reach a responsible person/call center in time and help will be provided
- To be considered for further process:
  - Provide transparent information and a clearly written manual (ideally approved by persons of the target group) to use the system.
  - Provide first and second level support

## 7. Actual Solution Approaches

In a first step, the use of other speech-to-text translation services was considered by the technical partners of the project. The following possibilities have been elaborated:

- MessageBird (messagebird.com) uses a SMS approach like Twilio.
- Mozilla Voice (voice.mozilla.org) offers with Voice STT and Voice TTS two open source services.
- Mycroft (mycroft.ai) an open voice assistant.

Still, the commitment in the consortium was to use Twilio for the first field test and inform the participating older persons in detail about the US service respectively the related data transfer.

During the preparation for field test one the overall project plan changed due to the change of coordination and the change of the situation of CARU AG. The care organisations demanded to use a TTS and STT service with GDPR-conform data procession. At the time of decision, this was not evaluated as being successfully met. Furthermore, no appropriate different solution was provided. Thus, the design of the final trial had to be changed from a large field trial to a small-scope lab trial. Only a lab trial, using artificial data, ensures that no personal data were processed. In the meantime, CARU AG has signed standard contractual clauses with TWILIO. No further measures, however, were arranged. Taken together, the process has shown the importance of well-considered data management especially concerning data protection and legal standards for end user organisations. This is a very important issue to be considered carefully for the business strategy of the product.

This is also emphasised in the general ethical principles of CARUcares. GDPR-conformity was pointed out as a fundamental precondition for the future product, even more as a sector which needs to deal with high sensitive personal data for the providing service every day (see Del. 2.4.1).

## 8. References

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## 9. Definitions, Acronyms and Abbreviations

AAL	Ambient Assisted Living
CC-WS	Co-creation stakeholder workshop