Evaluating existing privacy, security and regulation concerns for sensory-based assistive technology

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1.Introduction

The number of seniors in the Dutch society has risen by seven percent in the last thirty years [1]. It is expected that this growth will continue on, which means that more seniors will be in need of care in the coming years. The growth of people working in senior care is not in line with the growth of the seniors [1]. This means it will be challenging to provide care for everyone that needs it. According to research by Prince and Bryce (Source) five to seven percent of seniors suffer from dementia. Alzheimer Nederland calculates that 270.000 people in the Netherlands currently suffer from dementia, mostly people above the age of 65. The amount of people suffering from dementia is expected to grow. To prepare for this growth, innovation in technology that can assist in providing care for seniors is of great importance. The Ambient Assisted Living (AAL) organization focuses on innovation for this purpose. AAL is a joint effort of 23 countries in Europe that invests in ICT-based solutions in the habitat of the seniors that aim to help with issues in our society such as aging, loneliness and healthcare. Technology like this can help in measuring the quality of life of people with dementia. An example of a project they support is an application for devices such as phones or tablets that stimulates people to exercise from home [2].

Another example is a robotic companion named Paro, a stuffed animal made to look like a seal. It includes sensors and a speaker and was made to reduce stress and loneliness in care facilities. Communication between the residents of the care facility and the companion lead to improved psychological health and reduced stress levels [4].

Sensors in the home allow people to control different aspects of their homes. Through the connection to a wireless network, remote control becomes an option. Caretakers can make use of Smart Homes this way to assist or monitor their clients. However, it is expensive and takes infrastructure to install the sensors. Another invention which could be used is a Smart Home, created by Demiris & Hensel [12]. This could be effective

to help seniors live at home longer, by controlling the entire house by either relatives or a caretaker. This way unexpected visitors or unsupervised trips by the patients could be detected and stopped.

Data collection is key with assistive technology, by collecting data it becomes possible to evaluate the quality of life and lifestyle of a person. The Smart Teddy[13] from The Hague University of Applied Science (THUAS) is an example of an assistive technology project which aims to make it possible for seniors with dementia to live independently. By using multiple sensors, a caregiver can remotely assess the quality of life of a senior. Based on the collected data, they can take action if required.

However, the need for human interaction will always be present and cannot be fully replaced by robotic devices. That is why the Smart Teddy intends to serve as additional help at the homes of people with early dementia. Together with the Smart Teddy caregivers can remotely assess the quality of life. Its purpose is not to replace humans, but to assist them.

To be able to measure the quality of life, input from different sensors is required. This is the best way of being able to accurately estimate someone's quality of life remotely. Collecting data from the homes of people is a sensitive topic and can be seen as intrusive. What needs to happen to assure people that collecting data is a safe and necessary tool? Security is essential in any system that handles data, especially when handling personal information. Law and regulation give requirements for safekeeping data but do not give specific guidelines. There are different ways of applying information security and the most optimal way can depend on the goals or methods of the project.

In this project we take a look at the laws and regulations surrounding data collection using sensors in assistive technology and the literature on concerns of people about this technology. We also look into the Smart Teddy device and how it operates. An analysis required by the General Data Protection Regulation (GDPR) [5] will reveal the risks in terms of privacy and security in this project and how to mitigate them.

2. Methodology

Before analyzing the project for privacy and security risks, we take a look at the assistive device and how it operates. Available blueprints and schematics are used to get an overview of the type of sensors used in the device.

Next, we review literature on privacy concerns regarding similar technologies compared to the Smart Teddy (Section 5). These articles have been chosen based on their relevance to this project and how recently they have been published.

The analysis from article 35 of the GDPR has been done by using a template provided by the University of Utrecht [14]. The template consists of statements regarding regulation, privacy and security. They are divided by the following categories; project type, data, involved parties, collection of data, use of data, storage and destruction, and duty to report data leaks. Each statement requires a true or false input and based on that, the template will identify risks and request a measurement to mitigate these risks.

3. The Smart Teddy device

The Smart Teddy is a therapeutic device in the form of a teddy bear. It includes multiple sensors that collect data from the home. Based on the data the algorithms determine what the data means in terms of quality of life, which is then presented in a graphic user interface. The components inside the Smart Teddy device can be seen in Table 1 below.

The development of the Smart Teddy occurs in two phases, namely the Research-Phase and the Production-Phase. During the Research-Phase the device is being designed and tested in collaboration with a care-home facility during which all personal information is anonymized. In fact, during the Research-Phase all personal data will be anonymized since the data will only be used to configure the algorithms and to be certain the data collected by the sensors give an accurate representation of the quality of life.

During the Production-Phase the Smart Teddy will be actively used in the homes of the patients and will serve as an addition for caregivers to get more information about the quality of life of their clients. Therefore it is no longer possible to anonymize the data in order to use it to later provide targeted support to the seniors who require it.

Table 1. Components of Smart Teddy device.

Hardware	Purpose	Type of data
mmWave sensor	radar to track people's movement in the room	Biometric / Personal
Touch sensor	when someone touches the teddy	Biometric
Microphone	to pick up sounds	Personal
Light sensor		
GPS		Personal
Gyroscope	movement of the teddy itself	
Smoke sensor		
Speaker		
Servo	to move the tail	
Wireless charger		
Microphone (base)		Personal
Mini PC	processing data	Personal
Smoke sensor		

Speaker (base)		

4. Laws and regulations regarding personal data

The Smart Teddy project makes use of personal information and therefore must follow the General Data Protection Regulation (GDPR). Personal information is defined as information that is about a person or that can be used to trace back to a person [6].

According to the GDPR some of the data being collected falls under the category of special personal information. In order to be allowed to collect this information the project must comply to one of the following five exceptions:

- If consent has been given explicitly

- If biometric information is necessary for carrying out obligations of the controller or the data subject in the field of employment, social security, and social protection law

- If it's essential to protect the individual's vital interests and he/she is incapable of giving consent.

- If it's critical for any legal claims

- If it's necessary for reasons of public interest in the area of public health.

The GDPR states that a processing agreement needs to be made between the responsible entity and the processor of the personal data. Because the Smart Teddy project collects data about people's health and lifestyle there will have to be additional restrictions and measurements to guarantee data security [7] The results from Data Protection Impact Analysis (DPIA) tell us how this will be achieved (see Section 6).

5.Concerns about privacy

Assistive technology can play a meaningful role in future healthcare, however it can also cause privacy concerns due to the collection of data that is necessary for the technology to function. Privacy does not have a set definition, the concept of privacy can have different definitions depending on who you ask. Some examples of the meaning of privacy are: Freedom of thought, control over your own body, being alone in your residence, control over personal data, freedom from monitoring. People can have different opinions on the meaning of privacy [8].

Because privacy does not have a set definition or numeric value, it can only be measured in a qualitative way. The importance of privacy is different for each person. Some are willing to share more than others. The result of sharing information can also have an impact on the willingness of sharing data. When sharing information leads to access to certain products or services people are more inclined to make that decision [9].

Examples of ways to measure concerns about privacy are asking open questions or giving statements to participants and asking them whether they agree with that statement or not.

The literature says the acceptance of smart technology in homes or assistive technology is generally low. The way data is collected and the location of the device inside of the home have an impact on the acceptance. Audio is preferred over video [10].

Age plays a role in the level of acceptance of assistive technology (AT). Seniors and people who suffer from health problems are more accepting towards AT in comparison to young people. However, privacy is still one of their main concerns. This concern could be reduced by implementing certain standards in the technology. Data security is one of the most important factors in deciding whether to bring assistive technology inside their home [10]. Seniors believe it is important to be aware of who is responsible for monitoring their health and behavior and to be in control of the devices. According to studies, informing the seniors of who collects and processes the data is of great importance. Seniors value information about technology but are concerned they will become too dependent on it and lose human contact. [11]

The Smart Teddy collects data by using multiple sensors from within the home. This means some people might see this as privacy sensitive information and have concerns about the collection of their data. To combat these concerns security measurements will be taken, such as encryption of data, limited access and local secure hosting.

6. Data Protection Impact Analysis of Smart Teddy Project

A Data Protection Impact Analysis (DPIA) was conducted for the Smart Teddy Project to identify several risks in regards to data security and privacy. Two analyses have been made, one for the Research-Phase of the project and one for the Production-Phase.

A DPIA is required by the GDPR under article 35 every time one begins a project that may involve a high risk to other people's personal information [5]. The DPIA helps one identify privacy risks that were previously not brought to light, so that measurements can be taken to mitigate these risks. Performing a DPIA is not a one time action, it is a continuous process. Changes in the data processing of the project or organization means adjustments to the DPIA have to be made. New methods or technology for data processing means the DPIA will have to be carried out again [7].

6.1. DPIA criteria

The DPIA looks at different aspects, namely the type of project, data and involved parties. The DPIA may identify risks in these areas depending on the use of data. More on this below.

6.1.1. Data

The data being collected during the Research-Phase of the project is exclusively used to train algorithms that are meant to recognize certain patterns in someone's lifestyle. The data types have been reviewed to make sure that only data which serves a purpose for the algorithms is being collected. Audio data can give caretakers clues to someone's eating pattern or social contact. Other data such as gas levels within the home can indicate gas leaks. This data can be anonymized during the Research-Phase since it will only be used to train the algorithms. In the Production-Phase, no data is needed for training the algorithms as it will already be implemented inside the Smart Teddy itself. The Teddy's estimation of the quality of life indicators based on this data will need to be traced back to the senior in order to provide care advice. In the final product this information serves only as advice for caretakers, actions will not be based purely on conclusions drawn from the algorithms. In order to give the most optimal advice for seniors the data has to be as accurate as possible.

In the final product, information classified as "special" according to the GDPR, is being collected to assist seniors living at home. The project meets one of the exceptions required to collect this data, as seen in Sections 4. In order to convince people of the legitimacy of the Smart Teddy device as much information has been publicly revealed. The goals of collecting data are in line with the goals presented. Given consent from the seniors who may make use of this product is always required before the product can be used. Once they feel they no longer wish to use the Smart Teddy they may withdraw their consent.

6.1.2. Involved parties

During the Research-Phase no third parties other than the care-home facility are involved in the development of the Smart Teddy. The care-home facility is the most important partner for the Smart Teddy project. In collaboration with them, the Smart Teddy is being tested and adjusted according to feedback from caregivers and seniors.

When the project goes into the Production-Phase outside parties will be involved. In compliance with article 9 of the GDPR, personal data will not be shared with production parties and access to personal data is limited to the caretakers and the responsible organization, such as care homes, who will be applying the Smart Teddy as an addition to their work.

In terms of law and regulations, the Research-Phase is noticeably less complicated than the Production-Phase. Due to anonymizing personal data and data collected from sensors, there is no way to trace it back to an individual. Because of this the data is no longer seen as personal data according to the GDPR (GDPR, Recital 26). In order to be fully anonymized it is advised to review the data for ways that could possibly trace back to an individual indirectly. The collected sensor data that does not fall within the scope of the GPDR (e.g. anonymized data) is easier to use as restrictions from the European laws no longer apply.

During the Production-Phase, data cannot be anonymized as the product will be in use and the data must be traced back to an individual in order to assist them in their lives. Because of this, The Hague University of Applied Sciences must comply with the GDPR and other regulations regarding use of personal data.

6.2 Impact of DPIA on the project

The DPIA has shown that by anonymizing personal data during the Research-Phase, law and regulation no longer form restrictions on how to use the data. This also means privacy is being protected as it is no longer possible to trace it back to a person. During the Production-Phase measurements will have to be taken in order to comply with the GDPR, such as secure data hosting and policies regarding data storage.

7. Conclusion

Developers are working hard to create new ways to stimulate patients, decrease their stress and increase their Quality of Life. The use of home companions seems the most effective, for now.

However, the developing technological solutions also come with a price. The privacy seniors might have to give up to be able to live at home longer. Privacy among seniors is a sensitive issue. Though not all patients care for it, it should still be performed correctly and legally. During the development of the Smart Teddy, it has been shown that by anonymizing data during research, complying with law and regulation is made much simpler and privacy concerns are also taken away. Once the technology goes into production, more barriers will be overcome to comply with law.

With increasing numbers of demented seniors world-wide, the coming inventions will help control the overflow of patients and help relieve stress from the patients and care facilities.

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