Health Informatics Meets eHealth G. Schreier and D. Hayn (Eds.) © 2018 The authors and IOS Press. This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/978-1-61499-858-7-278

# Using MEESTAR to Identify Ethical and Social Issues Implementing a Digital Patient-Centered Care Platform

Johannes WUTZKOWSKY<sup>a,1</sup>, BRITTA BÖCKMANN<sup>a,b</sup>

 <sup>a</sup> Department of Computer Science, University of Applied Sciences and Arts, Dortmund, NRW, Germany
 <sup>b</sup> Institute of Medical Informatics, Biometry und Epidemiology (IMIBE), University Hospital Essen, Germany

Abstract. The PIQ research project ("Pflege im Quartier") aims for optimizing communication and patient-centered care for elderly people by implementing a digital, patient-centered care platform, with particular attention is paid to the consideration of ethical, legal and social issues. In this work, an instrument for the ethical evaluation of social-technical arrangement was used to map features of the platform with ethical concerns. The results include precise ethical questions based on scenarios identified and possible solutions to address them, regarding the ethical and privacy issues. These insights will be continuously integrated in the future system design and implementation as well as research.

Keywords. elderly; independent living; home nursing; ethics

# 1. Introduction

The demographic change in the Federal Republic of Germany which is accompanied by social challenges (e.g. the predicted shortage of professional nurses and the increasing need for care) which are to be encountered by innovative technology in the area of health and long-term care. For this purpose, research projects are funded by the Federal Ministry of Education and Research (Bundesministerium für Bildung und Forschung, BMBF), which contribute to the development and research of innovative approaches to support people in need of care and people involved in the medical and nurse health care. One goal of these new technological innovations and systems is to enable elderly people in need of care and assistance, to live a self-determined and independent life in their homes and in a familiar environment [1]. This leads to reduce costs, relieve caregivers (professional, informal) and contribute towards efficient networking.

In particular, technology that is designed and developed for elderly, who are or will be in need of care and are therefore more vulnerable, must be ethically evaluated to guarantee a harmless use, as well as it can contribute to the user-acceptance, and reduce the market entry barriers [2]. It is important that the ethical evaluation accompanies the development process from the beginning to ensure potential advantages and reduction of risks.

<sup>&</sup>lt;sup>1</sup> Corresponding Author: Johannes Wutzkowsky, University of Applied Sciences and Arts, Department of Computer Science, Emil-Figge-Straße 42, 44227 Dortmund, E-Mail: <u>johannes.wutzkowsky@fh-dortmund.de</u>

In this contribution, we present recent work-in-progress from the BMBF-funded project PIQ (2016-2019) where scientists are accompanied by ethical experts that contribute to identifying and assessing ethical conflicts and their relevance. The purpose is to establish a systematic approach using a model for the ethical evaluation of socio-technical arrangement (MEESTAR) [3]. We identified a collection of ethical/ moral conflicts and principles that take a significant role in the development of a technical assistance system. Next to the identification of conflicts, we develop potential solutions.

# 1.1. The Project PIQ (Pflege im Quartier): general information

The main approach of the project deals with the information, communication and networking around nursing for people in need of care, their relatives, certified nurses and informal caregivers. The development and use of technical assistance systems in the everyday life of elderly people who may be in need of care and because of their cognitive abilities or other restrictions are no longer able to reflect the scope of their decisions or do not understand the full functionality of the system, comprehensible explanations and an intuitive use of the system are essential to avoid excessive demands.

The aim of the project is to optimize and build up real and digital structures that exist in four heterogenic quarters in the city of Gelsenkirchen in North Rhine-Westphalia, Germany. The optimization includes the improvement of the medical and nursing health care by supporting the home care of people in need to live an independent and selfdetermined life in their own preferred environment [1]. Furthermore the professionals are supported by expanding the integrative supply through a demand-meeting information exchange that contains structured data and is based on established medical standards, such as HL7 CDA based electronic nursing record [4]. This supports the comprehensive networking between all those people and institutions involved especially as part of the care transition and hospital discharge [5].

# 1.2. The Project PIQ: platform and mobile application

The digital components that are developed within the project include a mobile application and a patient-centered platform for people in need of care, their relatives and people that are involved in the medical and healthcare process.

One aspect of the platform includes the possibility to locate people in certain situations through the tracked location by their phone if the mobile application is installed. Possible situations are e.g. if they are far away from their supposed location over a longer period or got lost. On one hand, a set of rules can be defined by the caretakers and confidants that are authorized to keep track of the current whereabouts of their relatives or people in need of care and on the other hand an emergency call/ alarm can be triggered manually by a "Help through the touch of a button"- function.

The mobile application offers features to import a printed medication plan (bundeseinheitlicher Medikationsplan) and to organize the medication within. The information given by the medication plan is automatically transformed into a structured format, so that it can be stored on the mobile device. The structure of the medication plan relies on the technical specification that is part of the pharmacotherapy safety to provide a consistent and structured format for the electronic management, storage and crosssystem exchange of the currently prescribed medication. The goal of integrating and exchanging the medication plan is to prevent adverse effects by recognizing and reviewing drug interactions and contraindications and to contribute to the pharmacotherapy safety [6,7]. The medication plan contains information about the prescribed medication that a specific person is currently taking. This functionality enables the people in need of care and their relatives to organize and their medication management and support their safety.

Another feature is the integrated marketplace in the system. It allows people to get in touch with volunteers and neighbours in their quarter to increase participation in social life. It is possible to offer and search for abilities and help as well as for support of activities in their everyday life that can then be arranged. The use of this feature is optional, which guarantees the right not to participate. There will be new digital advisory services that include new formats to involve people with voluntary commitment as well as training content related to caretaking for the relatives based on the care-level and the current situation of the people in need of care.

The paper is organized as follows: First, in section 2, we will describe the selection of the evaluation model and how it can be integrated into the software development and workflow process. Section 3 describes the intermediate results consisting of selected scenarios and developed solutions. In section 4 a summary of the work will be presented and demonstrates which future work will have to be done.

# 2. Methods

When deciding which framework for the ethical evaluation should be used, it is important to consider the appropriateness for the particular context, the scope and purpose of the ethical analysis as well as the way in which the instrument addresses issues within the considered domain. The provided theoretical, ethical principles and conflicts have possible limitations by their generalization and transferability or applicability.

The system that is developed includes features that are intended to support people in need of care in their everyday life through localization and orientation functions, medication management, care-related information and communication and networking options to participate in social life. An instrument for the ethical evaluation should be practically (normatively) usable and integrable into the process of designing and developing an information and communications system.

In contrast to other guidelines and ethical evaluation instruments such as "a model for the ethical evaluation of socio-technical arrangement" (MEESTAR), the "Model of Assessment of Telemedicine" (MAST) or the VDI Guideline 3780. MAST was developed for telemedicine applications, while the VDI guideline is for the evaluation of technology in a more general sense that enables a normative assessment but provides no clear methodology how it could be performed [8]. In contrast, MEESTAR provides a clear methodology and enables a normative assessment. For these reasons, the MEESTAR model has been selected as a suitable tool to conduct the ethical reflection.

# 2.1. The MEESTAR-Model

MEESTAR offers an approach to identify and describe ethical issues and dilemmas that can be assigned to given ethical dimensions. In addition, it provides questions for each dimension that can be used as a basis for a discussion and evaluation. The analytical model is divided into three different axes that need to be considered (Figure 1). One axis shows the three different points of view from which the socio-technical system is examined by: the individual level, the organizational level and the social level. For each of these levels an evaluation takes place which includes seven ethical dimensions: care, autonomy, safety, justice, privacy, participation and self-conception. The third axis contains four stages with a different ethical sensitivity that the functionality or the ethical topic is categorized to. These stages comprise the completely harmless use (stage I), the ethical sensitivity that can be compensated in practice (stage II), the ethical extreme sensitivity that requires either permanent monitoring or the introduction should be questioned (stage III) and the rejection of use (stage IV).

The use of the model for evaluating an information and communication system can contribute to highlight potential ethical conflicts that arise from the use of technology in nursing and medical health care that should be considered. A situation is assigned to a dimension and viewed from the specific levels (e.g. the individual level). After careful assessment of the existing conflicts an ethical stage is assigned. In addition, it provides ethical guidelines that should be considered to create the system. The model does not offer a definitive assessment of the system, it rather contributes to the considerations of ethical and moral conflicts.

# 2.2. Integrating MEESTAR into the software development and workflow process

The system is developed according to a development process model, which consists of six different steps (Figure 2). MEESTAR was integrated and applied after the system requirements were defined to identify ethical aspects and develop appropriate measures as soon as possible and to include them in the conception and implementation process of the system. MEESTAR provides a procedure for the ethical evaluation that is often used as a basis for discussions in workshops. We deviated from that process and we slightly modified the proceeding. For this reason, we applied MEESTAR in the development process as follows. The model was used to identify the ethical and moral conflicts and extended to reveal more specific questions that can be met by possible solutions.

**Step 1:** Together with involved people in the medical health care system or in the caring process (e.g. nursing service, nursing bases, public health care personal, people in need of care, relatives etc.) from the selected areas demands and requests are determined.

To achieve this, semi-structured interviews and the attendance of the mobile care process were performed. The requirement analysis is done by an interdisciplinary team.

**Step 2:** The gathered information and results can be used to define problems and scenarios to develop requirements for the system. In addition to the legal and technical



Figure 1: MEESTAR-Model Source: Own representation based on ([3], p.14)



Figure 2: Integrating MEESTAR in the development

specifications and possibilities, it is important to identify ethical and moral conflicts/ dilemmas.

**Step 3:** To frame the ethical/ moral conflicts and dilemmas, some scenarios are analyzed by taking a particular perspective (individual, social, organizational), the affected dimensions, and related questions provided by MEESTAR into account.

**Step 4:** The affected dimensions and the identified moral/ ethical conflicts offer a possibility to focus on a specific aspect and to concretize risks and benefits. These can be compared to each other to make fundamental decision to define possible solutions.

**Step 5:** In this case, a critical/ objective position to the system must be taken and all possible points of view and different interests must be considered to ensure that the use of the system guarantees greatest possible safety and security. The developed solutions can be technical and non-technical as well as new requirements for the system.

**Decision:** Because of the different complexity of the identified problems the process can be repeated several times. This is done until it has been ensured that the risks have been reduced to a minimum or are eliminated, no further risks or conflicts have been identified and all affected dimensions, perspectives and interests have been considered.

**Step 6:** In the final step, the established solutions and measures are realized and continuously monitored and evaluated.

# 3. Results

Currently the project PIQ has reached mid-term. Hence, the system is in development and preliminary results are presented in this section, including the identified scenarios,

Dimension	Ethical question/ Ethical conflict	Developed solution	Assigned stage
Autonomy	How can a comprehensible provision of access rules and permissions be provided?	Simplified list of questions that binds control- and security settings to pre-configurated profiles.	I
	How to acquire the ability to consent?	Gain the user consent on basis of an informed consent discussion. If necessary relatives/ authorized representatives can be present.	Ι
	How to handle and grant access to nurse-related medical information?	In depth and simplified configuration of profiles for access-control and access-policies.	Ι
Safety	Could displaying the drug safety assessment lead to uncertainty?	Autonomy has to retain within the responsibility of the doctor/ pharmacist. The functionality is not implemented.	IV
	Could the marketplace as a possibility for networking and participation be abused to harm people in need?	The networking feature is supervised and controlled by an involved organization. Participation is optional.	III
	Could the localization function that is meant to support safety and mobility also restrict freedom and independence?	Functionality can be (de)activated. Transparency through logging. Reason for localization must be stated and is recorded.	Π
Self- Conception	Can users develop a dependency on the functionality of the system?	e Must be further evaluated.	
	Can the functionality cause possible behavioral adjustments?	Must be further evaluated.	

 Table 1. Ethical conflicts and developed solutions (Assigned stage refers to Figure 1)

the development of precise solutions and countermeasures that will be included and realized. This was achieved using the software development process introduced in section 2.2. Additionally, an interdisciplinary workshop, which consisted of representatives from the fields of ethics, medical informatics and social science was performed to validate findings.

## 3.1. Identified scenarios

A collection of eight scenarios was identified and evaluated with the approach presented in section 2.2 (Table 1). Each of the scenarios and related ethical conflicts result in a different set of benefits and risks that needs to be encountered with appropriate measures. Solutions were created for each of these conflicts and each will be monitored during the ongoing research, e.g. through focus groups, expert discussions and field test.

## 3.2. Example Scenario: Localization

As an example, the process of evaluating the localization function is shown (Table 2). The system provides the feature to locate and determine the whereabouts of an affected person. Along with increased safety by localization in emergency situations, the function could be abused for controlling and surveillance. These consequences can be traced back to conflicts that concern the dimensions autonomy, self-conception, privacy, safety and care. The MEESTAR-Model provides different questions that help to identify the ethical conflict related to these dimensions. These questions were substantiated and derived to receive more concrete questions that can be encountered by possible solutions. This process leads to support of the user with comprehensive security and control features to remain in control of his personal information. Solutions were developed to prevent and minimize the improper use and to counter the negative risks of the offered functionality.

Demand/ request	"When I'm on the road. I want to be sure that someone knows where I am "	
Requirement	Current location is tracked by smartphone and transmitted to the platform where it can be accessed by authorized people only.	
Dimension(s)	Autonomy, Self-conception, Privacy, Safety, Care	
Ethical conflict	<ul> <li>"[] at which point does a well-intended caregiving attitude become a patronizing or negatively paternalistic approach []?" ([3], p.15)</li> <li>"How do we resolve conflicts between safety and privacy and between safety and autonomy (freedom)?" ([3], p.16)</li> <li>"How can people be assisted in their autonomy on the basis of practices consistently throughout the individual's right to autonomy?" ([3], p.15)</li> </ul>	
Substantiated/	Who profits from the surveillance system?	
derived ethical	How does the safety/ surveillance affect the behaviour of the people involved? Does	
questions	the localization serve the safety of the affected person or the certainty of the relative/ localizer?	
Risks	Excessive use by the user; Inappropriate use (surveillance) by authorized people; limitation of personality development through the surveillance system	
Benefits	increase mobility, security; support participation in social life; enhance independence	
Solution	The functionality can be (de-) activated. Transparency is established by complete and accessible log entries. A reason for a performed localization must be given. Freedom to choose and use technology. Authorization can be configured for a specific time range and for specific persons.	
Ethical stage	II ("its use is ethically sensitive but this can in practice be compensated for")	

**Table 2**. Evaluating the localization function (Assigned stage refers to Figure 1)

# 3.3. Further aspects

To increase the self-determination and autonomy of the user an informed consent discussion will take place. This procedure will be designed to achieve transparency and clarify that the system does not patronize, but rather promotes the digital competence and autonomy of the user before they give their consent. In this context, the individual circumstances, physical abilities, the ability to consent/ anticipate the consequences and the conception on the safety of the person can be determined. This ensures that solutions and achievements by the system and other alternatives can be explained, proposed and discussed. The user is supported to deal with the provision and use of his personal data depending on his competence and values. Based on the provided information they have the option to configure settings and access authorization and are free to choose and use the provided system functionality. The transparency is an important aspect when dealing with personal data, so the users will be able to inquire their saved personal data at any time using the system.

To provide the user with adequate comprehension about the system functionality, data acquisition, collection and processing, explanations and information are presented appropriate regarding the target audience of elderly people. Depending on the user's preference more detailed information, system settings and permissions can be accessed. In combination with pre-defined profiles to grant access authorization and access permissions for involved persons a comprehensible system knowledge can be established and a demand-oriented configuration and usage can be provided.

Because the system contains an electronic medication plan, it was discussed whether there should be a review of the interactions and contraindications when importing a new medication plan, and a warning should be displayed if the result is positive. As it is possible that this functionality could cause further non-targeted actions by the user, e.g. stop taking the drug without seeking medical advice. As this could be contrary to the actual benefit of the medication plan. The function is not implemented until there is found an acceptable solution that does ensure harmless use.

# 4. Discussion

In this work we included the model MEESTAR in a structured and systematic methodology to identify ethical and moral conflicts successfully in the process of concepting and implementing a patient-centered system within the PIQ project. The given dimension, different points of view, fundamental ethical and moral conflicts and associated questions were used to critically reflect the functionality and possible impacts on those who use and integrate the system in their daily life. The inclusion and discussion of ethical aspects led to encourage awareness and consideration of ethical assessment in the ongoing designing and implementing of the system.

By extending and specifying ethical questions specific measures and solutions could be developed that are further enhanced and monitored in an iterative process. We derived concrete solutions for specific scenarios and their related ethical conflicts based on the presented proceeding (sec 2.2). The specification is necessary because the pre-defined ethical conflicts and guidelines provided by MEESTAR are partially to general and had to be extended to provide a complete consideration of the functionality of the system.

However, results presented in this work are based on expert knowledge and the developed process only. In future work, we will evaluate consequences and effects that arise from the developed solutions with appropriate quantitative and qualitative methods: we will make use of focus groups to include the potential system users and measure their accordance with the identified scenarios, and ethical conflicts presented in this work using the developed process and expert knowledge.

## References

- VIEHWEGER, Axel ; KARMANN, Alexander ; UHLMANN, Michael: Selbstständiges Wohnen bis ins hohe Alter : Eine volkswirtschaftliche Analyse. Dresden : VSWG, 2015
- [2] MARING, Matthias [Hrsg.: Vom Praktisch-Werden der Ethik in interdisziplinärer Sicht : Ansätze und Beispiele der Institutionalisierung, Konkretisierung und Implementierung der Ethik. s.l. : KIT Scientific Publishing, 2015, pp. 299-341.
- [3] MANZESCHKE, Arne ; WEBER, Karsten ; ROTHER, Elisabeth ; FANGERAU, Heiner: Ethical Questions in the Area of Age Appropriate Assisting Systems. Ludwigsfelde : Druckerei Thiel Gruppe, 2015
- [4] FLEMMING, Daniel ; GIEHOFF, Carsten ; HÜBNER, Ursula: Entwicklung eines Standards für den elektronischen Pflegebericht auf Basis der HL7 CDA Release 2. In: Pflegewissenschaft (2008), Nr. 12, pp. 676–682.
- MÜLLER-MIELITZ, Stefan ; LUX, Thomas: E-Health-Ökonomie. Wiesbaden : Springer Fachmedien Wiesbaden, 2017, pp. 821-847.
- [6] MÖLLER, Horst ; ALY, Amin-Farid: Definitionen zu Pharmakovigilanz und Arzneimitteltherapiesicherheit (AMTS). In: Zeitschrift für Evidenz, Fortbildung und Qualitat im Gesundheitswesen 106 (2012), Nr. 10, pp. 709–711.
- [7] KUSKE, S. ; LESSING, C. ; LUX, R. ; SCHMITZ, A. ; SCHRAPPE, M.: Patientensicherheitsindikatoren zur Arzneimitteltherapiesicherheit (AMTS-PSI) : Internationaler Status, Übertragbarkeit und Validierung\*. In: Gesundheitswesen (Bundesverband der Arzte des Offentlichen Gesundheitsdienstes (Germany)) 74 (2012), Nr. 2, pp. 79–86.
- [8] PFANNSTIEL, Mario Alexander (Hrsg.); KRAMMER, Sandra (Hrsg.); SWOBODA, Walter (Hrsg.): Digitale Transformation von Dienstleistungen im Gesundheitswesen III : Impulse f
  ür die Pflegepraxis. Wiesbaden : Springer Fachmedien Wiesbaden, 2017, pp. 71-87.