Exploring Trust Perceptions in the Medical Context: A Qualitative Approach to Outlining Determinants of Trust in AAL Technology

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Keywords: Trust, Medical Care, AAL, Medical System.

Abstract: Due to a demographic change of the society, health care worker shortage and rising co- and multimorbidity within older adults, constant care at home and at care facilities face a difficult task to combat these challenges. Medical AAL technology offers many opportunities to relieve health care workers and assist older adults with difficulties in managing activities of daily life (ADL). This study has adopted an exploratory interview method to explore the users' perceptions of trust in the medical context and specifically, related to medical AAL technologies. Eleven participants ranging from 20 years to 87 years old (\(M = 52.27; \ SD = 24.2\)) were interviewed and, in line with previous results in the literature, results revealed three categories of influences, namely user factors, technology factors, and context factors. This implies a network of trust dependent on various external and internal influences. These findings have practical implications for clinicians, developers, policy makers and legal professionals.

1 INTRODUCTION

In Europe, the demographic change of the population puts an increasing strain on the health care system. By 2070, it is estimated that 30\% of Europeans are aged 65 years or older which is about 20\% more than today (see European Commission Report on the Impact of Demographic Change). Due to these prognoses, it is necessary to explore the possibilities of relieving the medical system and bringing down the costs of health care. Moreover, there is a shortage of health care personnel which is predicted to increase dramatically in the coming years with an estimated shortage of 4.1 million health care workers in 2030 (Michel & Ecarnot, 2020). At the same time, older people also have a desire to live on their own for as long as possible (Peek et al., 2014). For example, the WHO introduced a model of active ageing in order to promote life satisfaction and quality of life (QoL) in older adults (WHO, 2002). It defines active aging as “[... the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age.]” (WHO, 2002). Given the health barriers and comorbidities older people, especially in Western societies face, it is crucial to connect theories of aging with the demands and challenges of the health care system.

There are several approaches trying to tackle these problems, one of them being active and assisted living technologies (AAL technologies) designed to enhance QoL and independence in older adults. These solutions include wearable or ambient-installed sensors, actuators, and smart interfaces that are integrated into the homes of older adults. In this context, most devices are used for lifelogging which refers to the digital tracking and documentation of behavioural and physiological data in order to extract knowledge about a person’s health status and behaviour (Climent-Perez et al., 2020; Steinke et al., 2012). Given the challenges the health care system faces at the moment and in the future, it is of relevance to introduce and integrate these technologies into the lives of older adults still living at home but also to those living in care facilities. Studies have shown that there are benefits but also barriers of acceptance in the user population (Himmel & Ziefle, 2016; Jaschinski & Allouch, 2015; Wilkowska et al., 2021). The benefits seen by the

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Otten, S. and Ziefle, M.
Exploring Trust Perceptions in the Medical Context: A Qualitative Approach to Outlining Determinants of Trust in AAL Technology.
DOI: 10.5220/0011058300003188
In Proceedings of the 8th International Conference on Information and Communication Technologies for Ageing Well and e-Health (ICT4AWE 2022), pages 244-253
ISBN: 978-989-758-566-1; ISSN: 2184-4984
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users are, among other, e.g., the medical security of instant help, but also the independence of constant care and comfort, the barriers mostly refer to privacy and trust issues and data handling and management, but also usability issues and the fear that technology does not only assist but potentially replaces human care (Ziefle & Calero Valdez, 2017; Schomakers et al., 2021). Users tend to trade-off these benefits and barriers in their overall evaluation of medical technology which is why a user-centric view is important for the implementation of AAL technologies (Offermann-van Heek & Ziefle, 2019). However, it is not only the perception of medical technologies that influences the adoption of such but also the context surrounding the devices, namely the quality and the perceived reliability of the medical system and medical personnel. Trust in the medical system and health care workers is a core component of how people perceive medical technology and thus how open they are to using them in their homes.

There are several conceptualisations of trust in general, the most common throughout literature being trust as a belief and expectancy (McKnight & Chervany, 2001). This study is based on the literature on trust in medical and non-medical contexts and will therefore adapt this construct. Trust is made up of types that each measure a different aspect, i.e., dispositional trust (general trusting stance), institutional or structural trust; and interpersonal trust (trust in specific others) (McKnight et al., 2011; Mayer et al., 1995). The combination of the keywords “TRUST” and “MEDICAL SYSTEM” on the database “Web of Science” results in 10,847 hits up until 2010 whereas up until 2021 there are as many as 53,319 hits on the subject, signalling the growing interest in the role of trust in medical fields. Qiao et al. (2015) found that participants’ trust in medical technology depended on several other context-dependent variables, such as trust in their primary care physician and perception of how the physician uses medical technology. This suggests a complex network of moderating as well as predictive relationships regarding trust in medical technology.

Within the broader context of technology, there are three broad categories of variables that can be outlined, namely technology factors, user factors, and context factors (Xu et al., 2014; Bova et al., 2006). In each category, there are further subgroups that focus on specific aspects of and around the technology and the users. While there are studies investigating all kinds of technology, there is little information about variables that are specific to the medical technology context. In relation to that, there is no unified theory of (the development of) trust across contexts. This makes it crucial to investigate whether there are contemporary influences on trust development and how these fit into the broader concept of trust in the medical field.

2 QUESTIONS ADDRESSED AND STRUCTURE OF THE INTERVIEW PROCEDURE

Based on the existing literature of trust in various contexts, this study investigates the perceptions of trust and trust development in a general and medical context, as well as trust determinants in medical AAL technology. Within the area of Ambient Assisted Living (AAL), yet diverse holistic systems and technical single-case solutions have been developed in both academia and industry to enable staying at home longer and independently (Memon et al., 2014; de Ryter & Pelgrim, 2007, Ziefle, 2021). Still, sustained adoption of these innovative technologies in-home environments have failed (Wichert et al., 2012). Beyond technical and economic reasons as well as legal barriers towards data usage, one major barrier could touch the missing trust of caretakers in the medical technology applied in a very intimate and sensitive usage context. This study therefore focuses specifically on users’ trust in the medical context and medical technology.

It employs a qualitative design with open-ended questions and scenarios visualising AAL lifelogging technology. The structure of the interview moves from general, free association, to specific scenarios. The first part dealt with perception of trust in general, in the medical context, and regarding medical AAL technology. The second part dealt with specific examples of the medical system and from daily life, as well as specific scenarios for the participants to imagine and express their thoughts on trust development in this context. The exact questions and their order can be found in the Procedure section. This was done to gain a first impression of trust perceptions and only then to narrow in on particular concerns of trust perceptions of AAL technologies. Therefore, the first aim is to explore why and under which conditions people trust the medical system. The second aim is to explore how and under which conditions people trust medical AAL technology.

The qualitative approach was chosen to gain insight into ideographic perspectives of potential users. Additionally, the exploratory method serves as a first step into outlining trust perceptions in health care contexts, i.e. the more specific questions were
Participants answers were analysed using a qualitative approach, comparing them to existing factors in the literature. After having evaluated all points, they were categorised according to previously established groupings in the literature (Bova et al., 2006; Xu et al., 2014; Qiao et al., 2015). The analysis was done with MAXQDA 2018 (VERBI Software, 2019)

3.3 Procedure
At the start of the interview, the participants were welcomed, received information about the study and were asked to give informed consent as well as permission to record the conversations which were transcribed verbatim and after all interviews took place. Firstly, they were asked about their perceptions of trust in general, i.e. what they thought influences trust and how they deal with trust and distrust in their daily life. Secondly, they were asked about their perceptions of trust in the medical context, i.e. what made them trust in medical workers and institutions. In the second part, the researcher explained properties of AAL technologies, emphasising that participants could picture the technology themselves, as long as they had some features that are relevant for medical lifelogging, such as recording vital signs and detecting falls. Afterwards, the participants were asked how their perceptions of trust change when thinking about this type of medical technology and how human medical care is different than technological medical care. They were then asked to rate several examples from their daily life and the medical contexts according to their level of trust, e.g. close relatives, medical care personnel, primary care physician, and health insurance provider. Lastly, they were presented with a scenario which employs one form of AAL technology and differs in context-dependant factors (i.e. living situation, type and chronicity of disease, whether the scenario concerned them or a relative, etc.) and asked about their worries and thoughts on the scenario, and technological advancements in the medical field altogether. In an informal last part, they were asked about demographic information, technological affinity, and care experience.

4 RESULTS

4.1 Qualitative Findings
Results from the thematic analysis revealed three major categories of trust predictors, namely user
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factors, technology factors, and context factors. This is close to the three categories outlined by previous research and confirms established patterns of trust development. An overview of the findings can be found in Figure 1.

4.1.1 User Factors

Within this category, participants mentioned things related to dispositions about trust and remarks about general trusting stance. They mentioned phrases like “basic trust” [P11] and “benefit of the doubt” [P6] when referring to interactions with other people. Moreover, they mentioned that a certain advance in trust is needed in daily life, without which interactions of any kind would not be possible. One participant said that trust is the foundation for a relationship because it creates intimacy between two people.

“[without trust] there is a certain distance. I think trust creates a huge amount of closeness to a person or a group” [P1]

Overall, they each said that trust is crucial in day-to-day interactions and depends on the person that the interactions is with but most importantly, they also said that trust develops over time and needs to be fostered to be strengthened.

“trusting someone completely right at the start, I’d be cautious with that. It develops over time” [P7]
“a certain basic trust is there but evidently it grows by doing things together” [P11]
“it depends on how long you’ve known a person or generally if you know the person” [P1]

When asked about what generally makes people trust the first time, participants often talked about “intuition” [P5], “chemistry” [P8], and a “gut feeling” [P8] which, when asked to elaborate, turned out to be an emotional component that people either felt they had or did not have. In addition to that, behavioural components were also important to participants’ trust feelings. This included experience, caution, and observation on the trustor’s part but also a congruency of saying and doing on the trustee’s side. The participants felt like they needed to be able to depend on what is being said and to know that the other side was being honest and sincere with them which is shown with their actions.

“that the person opposite of me is honest with me and shares their thoughts and feelings with me, or at least does not lie about them” [P3]

“that something I am expecting to happen also comes true in that way” [P5]
“that I feel 100% safe and [...] that things are not happening behind my back” [P6]

Lastly, the participants were asked about how they deal with distrust and how they would act if someone betrayed their trust. Seven participants said that they would try to trust again but also mentioned that if there was any doubt about the honesty of the other person, they would withdraw from the relationship. Moreover, they said that the other person had to show their remorse and willingness to be trusted again. Generally, they all mentioned that it would take time and was not easy to rebuild and also depended on the importance and secrecy of the topic. The other four participants said that no matter how much time passed and how the other person acted after the betrayal, they would not fully trust that person again and would keep their distance about sharing information and spending time with them.

4.1.2 Technology Factors

In the interview, the participants were asked how their trust in the medical context differed when thinking about medical AAL technology. They mentioned general opinions on medical AAL technology as well as detailed requirements they would expect from such devices.

General Aspects. Participants were generally accepting and enthusiastic about the technology. They mentioned mostly positive aspects about it and could picture themselves using it. When questioned about how trust in medical AAL technology differed from general trust in the medical context, they said that there was not much of a difference. More precisely, they looked for the same qualities that they also looked for in their physician or care personnel. In relation to the technology, this included the topic being researched (their physician being experienced, having sound medical knowledge), having been informed about what it does and where the data goes (honesty and integrity of the physician), and an improvement of their health situation (benevolence of care personnel carrying out the medical care). Next to the positive aspects, some participants also mentioned concerns which are almost all related to the camera based AAL technology and included the handling of data, invasion of privacy, and whether the technology is merely a way of companies trying to sell things that are not absolutely necessary. Specifically, one participant felt strongly that this type of technology could not provide the kind of warmth, empathy, and
company that human care could provide and when given the chance, she would not want it in her home.

“there is something missing and I just wouldn’t want to use it […] Right now, I see it with my mother because it’s the most beautiful thing for her when someone stops by, talks to her, holds her hand […]. I just think that it is very important for people, even if it’s just little things. It’s something the machine can never give, this kind of warmth.” [P7]

All in all though, they saw AAL technologies as a possibility of enhancing medical care carried out by humans and agreed about its benefits to relieve healthcare workers, but none of them expect for one participant could picture this solution as a replacement of human care. In addition to that, almost everyone said that they would prefer human care over technological care, and would only use it if it was medically indicated.

Specific Requirements. While some people mentioned that they expected the technology to be more precise than human medical care, they also said that they wouldn’t want to rely on it completely. They argued that because it does not have situational factors like humans do, i.e. fatigue, traffic, human error, the technology should work around the clock. Moreover, one participant expected it to have a 100% success rate because it should be tested to the point where it does not make any errors anymore.

“if this technology failed and didn’t notice its error, if it functioned 90% of the time but everyone relied on it to work 100% of the time, it would quickly become dangerous to the person in need of care […]. Right, that’s why it needs to work 100% 24/7 for me to trust it.” [P1]

“Well, if humans made an error I wouldn’t be as pissed as if a machine made an error” [P5]

On the other hand, one participant said that as long as it added to her overall medical care, she would accept a certain error rate. This participant, however, also said that she would check the accuracy of the system beforehand as she herself works as an ICU nurse.

“The more ‘false alarms’, the less people react to it but someone will still come. Well, I can still be sure that if I’m lying on the ground and can’t call for help myself, that even if it’s not in five minutes, somebody will come to check on me in half an hour.” [P10]

Other participants felt like they could never expect as much from a piece of technology than they could from a health care worker. They felt like the technology could be an addition but would always have to be checked by a human. Across those interviews, there was a discrepancy when these participants were asked about the technology itself and when asked to picture themselves in a scenario where they would use it. In the scenario, they referred to the human care as superior but when only asked about the technology, they referred to it as being more objective and accurate that human judgement.

4.1.3 Context Factors

After exploring general trust perceptions, participants were asked about how trust manifested in the medical context. Strikingly, all participants first spoke of physicians when talking about medical trust. They mentioned that, similar to general trust perceptions, chemistry was a major component. Specifically, most participants needed to feel that the physician had the suited expertise and knowledge to treat them. In relation to that, the outcome of previous patients was also of importance. This was summarised as the “word of mouth” [P1] in their social groups and in media reports. On an emotional level, about half of the participants wanted to “feel heard and listened to” [P9] and that the physician paid attention to their problems. This was summarised as empathy towards the patient. The other half did not mention this as a particularly important aspect, and one participant thought it was not necessary for successful medical treatment altogether.

Mostly participants that did not work in the medical context felt that trust in the medical context was more important than in other context as it concerned their personal well-being and health. Moreover, they said that there was no way for them to verify the information given by the physician other than seeing another medical professional.

“especially in the medical context [trust] needs to be bigger because it is about your own body and not about whether your kitchen is even or your house is built well” [P1]

“It’s the same thing when the nurse says that the medication is correctly prescribed and given out but in reality someone messed it up, then that’s something that influences trust, in particular when it’s about body and soul” [P3]

“without trust you wouldn’t want to place your body in the hands of that person [physician]” [P4]
Conversely, one participant who is a trained physician mentioned that experience of the treating physician was not only unimportant but was even a negative aspect for her, as she felt that having treated many patients was not predictive of competence and most often associated with unjustified confidence.

“[Experience] is more of a negative factor, actually, because I have experienced that physicians who insist on having experience usually don’t pay attention to details anymore” [P5]

Taking these concerns together, it becomes evident that most of the subsequent behaviour of patients is related to how they perceive their treating physician and care personnel. “Medical context” is a term that all participants related to people, in particular physicians. When asked about medical technology, almost all of them connected it to the conditions under which it would be introduced to them, i.e. whether their physician appeared to understand it themselves, whether it was covered by their insurance, and whether they would receive assistance in using it. Overall, it was clear that if they trusted the medical personnel they were closest to, they were more willing to try the technology as well. However, if they felt disregarded and suspicious of the intentions of health care workers, they would not want to use the technology or risk having their data be stored in medical files.

“as with the technology I’d say that that the human is part of it, if the person explains to me why this technology is useful and what it can do, then I’d trust it for now” [P2]

“my first thought is that I wouldn’t trust the care personnel that gets these alarms in the end. [...] I’d trust the technology, yes, but I’d question the people behind the system” [P4]

“the entire clinical staff should have knowledge about this technology for me to trust it” [P2]

These points suggest that the way of introducing AAL technology is highly relevant for the acceptance and willingness of potential users in this context. However, there are other context factors that were mentioned to be important as well. Participants felt good about AAL technology, if it relieved the burden on family members. They felt that they would most likely try out the technology if they otherwise had to rely on their family members to care for them. On the other hand, they also felt more comfortable using the technology if they lived alone and without social support. The reasoning for this was that since they had no one to help them with any of the tasks that are provided in AAL technology, the technology would be the assistance commonly expected of relatives.

“Especially when I imagine living alone, I would probably perceive this as an extreme relief” [P6]

Lastly, one participant also said that it depended on his health status. He perceived it less of a choice but more of a medical necessity, i.e. if he is healthy, he wouldn’t try it as there is no need for it. However, if he was sick and had to be cared for and there was no medical personnel or family members to help, it would be irrelevant as to whether he trusted the technology because there would not be another option.

“Even at the risk of this thing making mistakes, because I myself couldn’t do it at all, I would make mistakes in any case. [...] So, it would always be worse without that machine.” [P3]

In line with part of this argument, more participants mentioned that if they did have the ability to manage without these systems, they would always try to avoid having to use them. This suggests that AAL technology is associated with a decline in health status as they most often used examples of advanced scenarios in disease management, e.g., having severe dementia or being physically bed-bound.

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<tr>
<th>Technology Factors</th>
<th>User Factors</th>
<th>Context Factors</th>
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<tr>
<td>Similar expectations than for human care workers</td>
<td>General trusting stance</td>
<td>Expertise &amp; knowledge of health care worker</td>
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<tr>
<td>Researched</td>
<td>Benefit of the doubt</td>
<td>Empathy &amp; warmth</td>
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<tr>
<td>Information</td>
<td>Basic trust</td>
<td>Experiences from social group &amp; media reports</td>
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<td>Improvement of health situation</td>
<td>Gut feeling</td>
<td>Importance of own health status</td>
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<td>Data handling</td>
<td>Experience &amp; time</td>
<td>Social support</td>
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<td>Invasion of privacy (surveillance)</td>
<td>Congruency of expectations &amp; consequences</td>
<td>Living situation</td>
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<td>Medical necessity of machine</td>
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<td>Accuracy &amp; error rate</td>
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Figure 1: Illustration of Categories.
DISCUSSION

This paper set out to investigate perceptions of trust in a general and medical context, narrowing in on trust in medical AAL technology. The first aim was to explore why and under which conditions people trust the medical system. The second aim was to explore how and under which conditions people trust medical AAL technology. As the nature of this study was exploratory, there were no expectations about the outcomes. Based on previous literature searches, three categories of trust influences could be outlined, namely technology factors, user factors, and context factors (Xu et al., 2014; Bova et al., 2006). The results of this study suggest that these categories also fit the answers given by the participants.

5.1 Trust Issues for the User Factors

In the category User Factors, participants mentioned that trust is generally associated with time and experience, meaning that that while there is a basic level of trust, only time and experience will strengthen this feeling sustainably. Moreover, participants also felt that honesty and credibility were important for trusting someone. This is shown by words, but also with actions that signal integrity and commitment to the relationship. Lastly, most of the participants agreed that a serious betrayal of trust would either result in the termination of the relationship or could not be fully restored. On the other hand, others mentioned that, while it is a long process, trust could be regained over time and with continuous action that both parties want to reconnect. Ultimately, this category revealed the importance of consistent behaviour in the formation of trust and in the maintenance of it. This suggests a predisposition of trust but also shows that for the majority of people, time and trusting behaviour is a key component. Relating these results back to existing literature, there is congruency between past studies and this one, namely that there are specific influences of user characteristics which alter the overall acceptance of these technologies (Wilkowska & Zielfe, 2018; Xu et al., 2014).

5.2 Trust Issues for the Technology Factors

In the category Technology Factors, answers closely overlapped with the aspects mentioned for general trust. Participants felt that AAL technologies should have the same qualities as humans, i.e. knowledge or correct results, honesty and integrity, and benevolence. While the reactions were mostly enthusiastic, some participants were also concerned about their data being stored, although this was strongly related to who had access to it. Moreover, other concerns were with regard to the lack of empathy and warmth provided by the technology and the error rate, i.e. to which extent the technology gives incorrect data and alarms. Overall, participants agreed that the technology should not be a replacement of health care workers but an enhancement for them. The aspects that were mentioned in this category are in line with literature on medical technology, but also with other contexts, such as autonomous driving, E-commerce, and internet application, e.g., Facebook & Excel (McKnight, 2011; McKnight & Chervany, 2014; McKnight and Chervany, 2001; Montague et al., 2009, Hengstler et al., 2016).

5.3 Trust Issues for the Context Factors

In the category Context Factors, the results outline the dependent relationships of trust within the medical system and the participant’s social context. Most participants mentioned an emotional component related to the treating physician, i.e., that they felt taken seriously and that the physician paid attention to their concerns. Moreover, they looked for expertise and knowledge when confiding in health care workers. The most common line of reasoning was that they did not have the training themselves and were obliged to believe a professional. In line with this, the results suggest that if they trusted their primary care worker, they would be more open to trying new technology. This was under the condition that the person introducing it to them was also skilled at using and explaining it, and the participants were informed about data handling. With regard to living arrangements, it became clear that there was a higher acceptance and more enthusiasm about AAL technology if they either lived alone or if it relieved the burden of care on their family members and by extension, health care workers. Conversely, most of them did not believe AAL technology could provide the same quality of medical care than human medical care. Within the literature, there are studies validating some of the aspects, i.e. experience of the physician, information about the technology and perception of how health care worker use the technology (Bova et al., 2006; Qiao et al., 2015). In this study however, there was a proportionally bigger association of human care and AAL technology than in other existing studies that could be found. This implies a strong moderation of context factors on trust in
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5.4 Strengths and Limitations

This study was exploratory in nature which can considered a strength since it set out to capture unbiased opinions and concerns of trust in the medical context. It was structured from very general questions to specific scenarios, enabling the participants to freely associate. Moreover, the sample was relatively balanced, with four people of younger age, four people of middle age, and three people of advanced age. Six of the eleven participants were female, and there were six people with care experience, either personally or due to their profession. Lastly, the results were in line with previous research, suggesting that the approach was appropriate for this research question. As with every study, there are also limitations to consider. Firstly, the sample was entirely German, limiting the generalisability with regard to cultural implications. Secondly, while the exploratory approach has its advantages, there are downsides to it as well. Because of the generic approach, many important feelings and thoughts might not have been captured and could be explored more precisely in future studies. Moreover, the features of AAL technologies were described superficially which might have made it difficult for participants to imagine a specific, tangible camera or sensor. Some of the participants also mentioned that they could not imagine a specific technology performing these actions and mostly referred to devices that they have had contact with, e.g., fitness tracker and emergency wrist bands. Ideally, participants can physically try out AAL technology for them to have a more realistic and less scenario-based experience.

6 IMPLICATIONS: RESEARCH AND APPLICATION

Given the results of this study, the next step is to operationalise the aspects and concerns into a scale with the goal of quantifying them. While the qualitative approach is useful for an idiographic view on perceptions of trust, it is necessary to strengthen the validity of the results and expand their generalisability with a systematic, quantitative approach. On the basis of these results, future studies might focus on specific variables and their individual influence on trust development in the context of AAL technologies. As the results revealed three major categories, future studies can direct their focus on each of these individually and in due time, address them in a network of all relevant factors. With the ultimate goal of mapping trust in the health care context, this study served as a first step for outlining idiographic factors and concerns by potential users. Consequentially, these have to be considered in a quantitative context with clearly defined parameters. This will build the foundation to investigate trust from a psychometric perspective and ultimately, each influence could be integrated into a model of trust in health care contexts and AAL technology, for other researchers to disseminate and corroborate. Finally, future research could benefit from experimental studies that look at trust not only from a correlational or even scenario-based perspective but can investigate causal mechanisms of important variables in the health care and AAL context. Moreover, as the concept of trust in the medical system and medical technology is of relevance in all cultural settings, the socio-cultural influences could be explored by investigating the research aims in different countries.

7 CONCLUSIONS

In line with previous research, this study has shown that trust is a multi-factor concept embedded in a network of variables that interact with each other. This has implications for professionals in various areas of expertise. However, more research, specifically with a larger sample, is needed to validate and corroborate these preliminary findings. This study has implications for not only researchers in the field, but also clinicians, policy makers and developers of medical technology. Trust is not one variable influencing another but is embedded in a network of mediators and moderators, most prominently physicians and care personnel but also independent institutes and health insurance companies. In addition, developers can make use of specific user requirements, such as data handling and specifically error rates and accuracy measures, when conceptualising AAL technology and specifically training of clinicians and health care workers that are the first to introduce medical AAL technology to (future) users. Developers could also incorporate the technological requirements of the users in the design of AAL technology, such as perfecting the error rate...
and optimising the user interface. On a higher level, policy makers and legal professionals might benefit from incorporating general protocols that respect the users’ need of feeling heard and being informed. This could be implemented in specific training for health care workers which in turn, might increase trust of the users in their treating care personnel.

ACKNOWLEDGEMENTS

The authors thank all participants for their participation and willingness to share their experiences. This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 861091. The researchers also thank Alexander Hick, Caterina Maitdof, and Julia Offermann for research support.

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