



# Paving the Way: Trust in Healthcare Systems as a Prerequisite for Technology Usage

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**Abstract.** Health changes in general, but especially in older age, inevitably lead interactions with different people and entities in the health care system. Particularly in the case of severe health decisions, trust in the healthcare system and the people involved is essential. This raises the question of which factors can promote or impede trust and how these can be influenced by individual or circumstantial parameters. Therefore, the current study aims to investigate how trust in healthcare systems is built and maintained in severe health decisions. Understanding trust-relevant factors in severe health decisions provides the basis for further investigations of trust in assistive technologies for people of older age and in need of care. Two semi-structured focus groups with each five participants were carried out and recorded ( $N = 10$ ). The results showed that severe health decisions represent situations in which fundamental aspects of life change so that life is no longer comparable to what it was before. The analyses also identified multiple factors relevant in trust building and maintenance, e.g., competence, empathy, transparency, communication, and financing. By contributing to a greater understanding of the patients' needs, with the results of this study, recommendations for a more targeted and demand-oriented communication between the various stakeholders in health care systems can be derived.

**Keywords:** Trust · Healthcare Systems · Severe Health Decisions

## 1 Introduction

In Germany, roughly  $2/3$  of the population report being in good health. In Germans aged 65 and older,  $1/3$  is affected by chronic diseases [1]. During the span of life, people will come into contact with the healthcare system on multiple occasions. In individuals with chronic diseases however, this number increases substantially and the relationship with their primary care physician and the experiences in the healthcare system become all the more relevant [2]. The relationships between patients and their physicians have the potential to determine and affect the way patients decide [3–5], e.g., with regard to a recommended usage of assisting technologies in older age [6–8]. These relationships and interactions with physicians and other entities within the healthcare systems are based on patients' trust in specific stakeholders but also in the healthcare system itself.

Previous research has examined trust either for very specific phases (e.g., the COVID19 pandemic [9]) or quite generically (e.g., [10, 11]) disregarding underlying trust motives and factors being essential for paving the way to trust medical decisions and recommendations in severe health situations or in older age.

The present study aimed at an explorative identification of relevant parameters for trust in the healthcare system taking changing health conditions, i.e., severe health situations into account. For this purpose, a focus group study was conducted and the results enable to derive recommendations taking into account the requirements and needs of patients. In the following, an overview of previous research in the field of trust within the healthcare system is provided. Following that, the empirical procedure is presented and the results are described. Finally, the insights are discussed including the strengths and weaknesses of the study as well as derived implications.

### **1.1 Relationships of Trust Within the Healthcare System**

There are many ways in which relationships of trust are exercised. One of the most direct and intuitive connection is the one between a patient and their treating physician. This relationship has been focused on in diverse research fields. Bell et al. [2] found that when patient's expectations about their primary care physician, such as medical information, new medications, medical tests, or a specialist referral, were not met, adherence to treatment plans was significantly lower than for patients whose expectation were met in the long run. Specifically in patients with chronic illnesses, patient-physician relationships are predictive of treatment adherence, patient activation, and overall satisfaction with their health plan [3–5].

While the patient-physician relationship is an important predictor for these variables, the construct of trust underlies almost all interactions and not only those with direct physician contact. In the bigger context of healthcare, this includes insurance companies, health care staff, availability of health information, emergency care, and political bodies functioning as sources of information. Studies have shown that trust in the healthcare system is linked to political trust and general trust in the government, as well as subjective health outcomes and the likelihood of seeking medical help [9–13]. In a meta-analysis by Birkhäuser et al. [10], the relationship of trust in healthcare professionals and health outcomes was analysed where they found moderate correlations of trust and health outcomes ( $r = .24$ ). Moreover, they found a high correlation between trust and patient satisfaction ( $r = .57$ ). While the correlation of trust and objective health outcomes was non-significant, it was significant for trust and subjective health outcomes ( $r = .30$ ) and since subjective outcomes are predictive of objective outcomes, trust might have had an indirect effect [14]. The authors conclude that “patients’ trust in the health care professional may best be conceptualized as a contextual factor of treatment effects” [10] which indicates that trust may have both direct and indirect relationships with other factors in the healthcare context.

Moreover, trust perceptions in the healthcare system differ across countries, with Germany showing low trust levels in a patient-focused treatment at their health institution [15]. Therefore, it is crucial to investigate how trust in the health care system is conceptualised in order to predict its underlying mechanism in the development and maintenance. Even more than that, it is important to investigate how trust conditions

change across different medical decisions ranging from light to severe. There is an increasing shift from a *paternalistic view* (the healthcare provider being the sole decider of treatment plans, etc.) toward *shared decision making* (patient and provider come to a medical decision jointly) [16]. Research has shown that patient characteristics, such as affective states and previous experience, are influential in how they make decisions about their treatment plan, whether they adhere to medication, etc. [17]. This means that patients are increasingly questioning the information and options provided while they also have more options to choose from. At the same time, individual histories of patients, including their trust perceptions, shape their medical future and can be decisive [18].

## 1.2 Previous Concepts of Trust

Within the literature, trust is most often considered a belief and expectancy and is by definition an interdisciplinary concept, drawing from individual and social psychology, economics, sociology, and other disciplines [19]. Overall, there are three emerging types of trust, namely dispositional, structural, and interpersonal trust. Dispositional trust refers to the general attitude towards trust and decisions requiring some level of trust. It is considered to be a low-level personality trait. Structural (or sometimes called institutional) trust refers to the trust in situations and institutions, implying that there is a level of consistency expected in certain establishments and circumstances. The interpersonal dimension refers to trust between two agents, a trustor and a trustee, and further divides into perceptual, intentional, and behavioural facets of trust. There are many definitions and conceptualisations focussing on different aspects, either from an agent perspective, i.e., the trustor and trustee's attributes, or from a context perspective, i.e., which situations elicit certain trust perceptions. Overall, there is no apparent consensus on the definition nor the approach on how to map trust [19]. It is, however, always assessed with a questionnaire when talking about quantitative approaches to the concept.

Within the context of healthcare, it becomes evident that all three distinctions of trust are highly relevant and need to be considered together. There are two literature reviews which capture the way trust has been operationalized in this field. Ozawa and Sripad [20] found that of  $N = 45$  studies, most used an interpersonal measurement of trust (doctor/patient/nurse), and only some measured systems trust, i.e., institutional trust. Studies that investigated interpersonal trust did not consider institutional trust in their measurements whereas those measuring institutional trust did consider this domain. Moreover, they found that four domains, namely honesty, communication, confidence, and competence were stable across measurements. In their evaluation, the researchers also found that more than half of the studies employed one of more pre-study designs in the form of interviews, focus groups, literature searches, etc. This indicates the importance of pre-testing the hypothesised questionnaire conceptualisation. LoCurto and Berg [21] also reviewed the literature ( $N = 65$ ) on trust and its conceptualisation in the healthcare context. Similarly, the majority of studies investigated interpersonal trust, in this case doctors. Only few others investigated institutional trust relating to systems in healthcare. The researchers found as many as eight determinants of trust in the healthcare system, i.e., honesty, confidentiality, dependability, communication, competency, fiduciary responsibility, fidelity, and agency. On this basis, they recommend a methodological protocol of developing a scale, namely a review of the literature,

interviews or focus groups, a pilot study, and an initial survey of the study, followed by a psychometric evaluation of the effectiveness of the scale. When comparing trust in healthcare with the general operationalisation, there are similarities signalling an underlying construct of trust with context-specific determinants of trust that needs to be outlined and investigated.

### **1.3 Aim of the Present Study**

Taking these approaches together, it becomes evident that more work needs to be done in combining the conceptualisations of trust with regard to interpersonal and institutional trust but also the link to dispositional trust. More studies have focused on the interpersonal domain and as established above; this relationship is highly predictive of health behaviours. It does not however, capture the entirety of the healthcare system. In order to understand how trust in the healthcare system is developed, maintained and predictive of potential adherence to treatment plans, including the use of ambient assistive systems, a patient/user-centric view is needed. Therefore, the present study focuses on an explorative identification of motives and underlying parameters affecting trust in the healthcare system in general. In a second step, the perceptions are deliberately sharpened by defining severe health decisions and using them as an example to eventually adjust previously expressed trust criteria.

## **2 Methods**

In the following, the empirical concept of the present study is described, starting with the procedure of the qualitative interview study. Subsequently, the conducted data analysis and the characteristics of the sample are presented.

### **2.1 Procedure**

Two semi-structured focus groups were conceptualized and conducted in order to exploratively understand, examine and identify relevant factors for the formation and maintenance of trust in severe health decisions.

Both focus groups were held in German, lasted about an hour and were transcribed afterwards. Before beginning with the focus group process, the participants were welcomed and introduced to the intent of the focus group. Their rights were explained to them and informed consent as well as permission to record was obtained. Participants were firstly asked about demographic variables including age, gender, acute and chronic illnesses, profession, level of education, technical affinity, and experience with medical technology.

The focus group process consisted of two main parts: The first part focused on an exploration of relevant conditions and prerequisites for trust in the healthcare system. In more detail, the participants were asked to discuss several questions and form opinions about the relevance of various trust-building factors in the healthcare system, e.g., “What is important for you to trust in the healthcare system?” and “What defines a good functional/bad dysfunctional health care system for you?”.

In the second part, the participants were asked to define what severe health decisions mean to them: i.e., “What do you describe as a severe health decision for you personally?”. This was meant to explore the boundaries of severe as opposed to “regular” or less severe health decisions. Further, the participants were asked to outline and discuss specific scenarios in which trust could be put to the test, i.e. “If you had to imagine a specific situation in which a severe health decision had to be made and you had to trust the health care system, what would that look like for you?”.

Lastly, and to combine the topics trust and severe health decisions, it was explored how and whether considerations for decision making would differ if the severity of their decisions differed: e.g., “When you think about these types of decisions, do you think differently about the health care system and relevant factors for trust?”.

Finally, the participants were thanked for their participation, they were asked to provide feedback on the focus group and on an optional basis there was time to discuss about the topic and open questions in general.

## 2.2 Data Analysis

The focus groups were transcribed verbatim and in German language. The results were analysed according to the guidelines of qualitative content analysis by Mayring [22] with the software MAXQDA 2018 and compared to existing factors in the literature combining inductive and deductive analyses. The answers were also checked for group differences and groupings that are similar in answer patterns. Within the results section, the findings are structured following the main categories identified during data analysis.

## 2.3 Sample

Each focus group had five participants. Totally, five male and five female participants with a mean age of 30.2 ( $SD = 12.39$ ) and a range of 22 to 55 years took part. Based on information about the sample, their evaluated technical affinity was rather good ( $M = 4.6$ ,  $SD = 1.48$ ). The average level of education was vocational training, whereas two participants were currently enrolled as students. The majority had experience with medical technology. Some respondents stated to have chronic diseases, among others ulcerative colitis, Hashimoto disease, and chronic pain.

## 3 Results

In this section, the results of the qualitative focus group study are presented, starting with insights regarding relevant factors and conditions for trust in healthcare systems. An overview can be found in Fig. 1. Further, it is showed how the participants defined and discussed severe health decisions. In a last step, it is described if and how the relevance of trust conditions changed in the context of severe health decisions.

### 3.1 Trust Conditions in the Healthcare System

When discussing which aspects and factors are necessary for trusting the healthcare system in their interaction with it, participants agreed on three categories, namely **Competence & Efficiency**, **Cost Allocation & Fairness**, and **Communication & Empathy**. The respective results are now presented depending on these three categories.

**Competence & Efficiency.** This factor entailed both a correct diagnosis and treatment plan but also a good education of medical professionals in the first place.

*“I would have no confidence in the system at all if I went to the doctor five times and five times I was given the wrong diagnosis and five times I was given the wrong treatment.”* [male, 26 years]

Moreover, participants agreed on the importance of sticking to appointment schedules, not being sent away as a patient, and also the guarantee the security of supply, i.e., that in an emergency, medical help was accessible. This point was heavily influenced by perceptions of the healthcare system during the Covid-19 pandemic. In both groups, it was unanimously agreed that this was the most important aspect for trust.

*“Keeping promises, scheduling appointments, that when I say I need a referral that I get it and don’t have to run after all the bureaucratic stuff in my already bad shape.”* [female, 24 years]

**Cost Allocation & Fairness.** This category was specific to the German healthcare insurance which distinguishes between public and private insurance. While everyone is provided with public insurance, some people can decide to switch to private insurance which typically covers more treatment options and offers other (time-efficient) benefits. Only relating to the aspect of cost allocation, participants agreed that nobody should have to worry about covering medical costs. They compared the German system to other countries, e.g., the US, and agreed that they would not trust or positively evaluate a system in which everyone is responsible for their own coverage.

*“I believe that you shouldn’t get into a process where you have to arrange something yourself, that all costs are covered [by the insurance company].”* [male, 24 years]

In one focus group, they came to the conclusion that medical institutions, such as hospitals should not be allowed to be privatised, as is the case in both Germany and other countries. On that same note, they also would evaluate a hospital as less trustworthy if they knew that they administered unnecessary procedures to patients to earn more money.

*“We also have many patients who stay much longer than they should. The treatment alone, if they get something intravenously, we get much more money than if we give it as tablets. I also have to wonder if I have to pump a 20-year-old full of it all the time. Or for a 90-year-old granny who can manage without pain and is always fiddling around with it, no. But it pays more money...”* [female, 22 years]

With respect to the aspect of fairness, both groups agreed that they would define the healthcare system as being fair if everyone received the medical help they required,

regardless of any other characteristics like socio-economic status, gender, race or else. Here, it was also relevant that where the funds go is transparently communicated to the patients by both the institutions themselves but also the insurance companies.

*“For me, fairness is relatively easy to define, and that is that everyone should have access to the treatment options or the doctor they need for their condition.” [male, 26 years]*

However, both fairness and cost allocations as factors were put together because participant almost always referred to them in relation to one another. For them, being treated fairly is mostly decided by the cost allocation of the healthcare insurance companies and policies.

*“It may be transparent what they are allowed to charge, but where a large part of the money disappears is not transparent at all.” [male, 55 years]*

**Communication & Empathy.** Participants described this category almost exclusively in relation to patient-physician communications. They mentioned that above all, a physician should have respect for the patient and a genuine interest to listen to them.

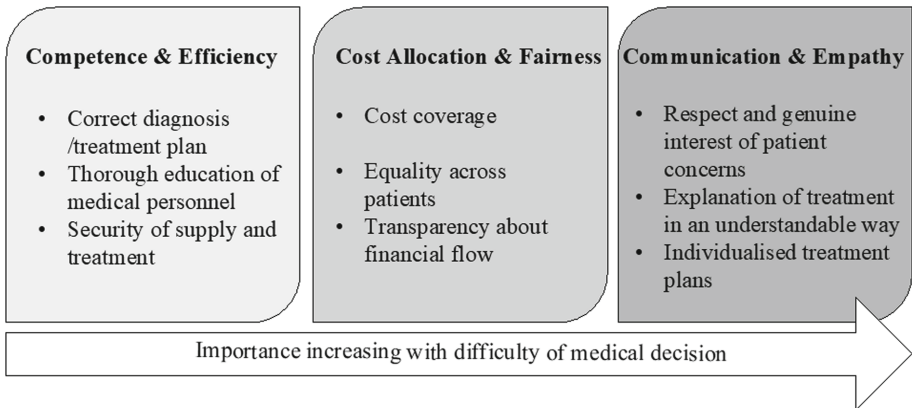
*“Empathy [...] and that I am also taken seriously, so, also during the initial anamnesis, that the doctors do not dismiss me and take time to consider my concerns.” [female, 24 years]*

They also expected physician to consider the individual care plan of the patient and adapt it according to their needs. All participants also agreed that doctors should be taught how to deliver medical information in a way that is understandable and accessible patients who are non-experts.

*“For me, it’s the clarification, and sometimes you don’t feel properly informed by the doctor and don’t know what to do now, or you’re sent to another doctor and referred, who suggests a completely different treatment. But both doctors can’t explain exactly why this treatment and another doctor says something else, so you have to accept that, which I think is a shame because I want to know exactly why something is being done. And I would like to have that for the trust.” [male, 26 years]*

Above all, whether they perceived a physician to be transparent about why they chose a particular treatment was also indicative of whether or not they would trust them. These aspects were the second most important aspect for trust in the healthcare system and both groups quickly agreed on their qualities.

*“Yes, the doctor should definitely communicate with his patient in a way that they understand. It’s no use for him to beat you over the head with something and say everything will be fine, and then you don’t know what’s wrong with you.” [male, 55 years]*



**Fig. 1.** Overview of Categories

### 3.2 Definitions of Severe Health Decisions

The strongest criterion of whether participants judged a medical decision to be severe or not was whether it would alter the course of their life. They agreed that when they had the choice to decide between contradicting treatments whereby one would alter the course of their life irreversibly, such as an amputation or a high-risk surgery to remove cancerous tissue, they would classify it as a severe health decision.

*“Exactly, life-changing. An amputation or something. Of course, this builds up to a decision where it’s really a matter of life and death. ‘Do I do the surgery and live another 5 years or do I not do it and die in 2 weeks?’. So a severe medical decision for me starts when it really affects your life, where it will never be the same again [...]. If from a medical point of view it will be like before, I will be as healthy as before the illness or before the accident, whatever, it is not a difficult decision for me, because then the doctors will do what is right for me, [...] everything will be fine. But as soon as it has an impact on my life, it becomes a difficult decision for me.” [male, 24 years].*

*“I would rather say when it comes to an operation or treatment where the consequences, depending on the outcome, are irreversible.” [male, 26 years].*

Meanwhile, if they were in a situation where medical help was necessary but the course of treatment would ensure them getting back to “normal”, such as a broken leg that needed to be set straight in a cast, they agreed that this decision was hardly severe as there were no consequences that would inevitably change their life. One participant also mentioned that the simple decision of seeking medical help alone would be a severe one, as this meant admitting that they needed help in the first place. This concern however, was not shared by the majority of the group. For the most part, seeking help was not much of an issue but dealing with the consequences of deciding on and undergoing therapy was hard for them.



### 3.3 Changes in Relevance of Trust Conditions in Severe Health Decisions

Participants were asked to reflect on their definitions of severe health decisions and their previously discussed factors for trust in interaction with the healthcare system. Subsequently, they were asked to combine their factors and outline any changes in the importance of factors or even completely different trust conditions. To that end, no one mentioned any novel conditions or factors needed for their trust in the healthcare system. However, there was consensus among members of both focus groups that with increasing severity and medical necessity, the importance of all facets of trust would rise exponentially.

*“...the importance of the criteria increases with the severity of the disease.”*  
[female, 24 years]

They also argued that this was because they were forced to trust the system in a state of medical emergency as they only had limited resources to help themselves. Collectively, they agreed that if their health situation was not of critical status, they could spend more time evaluating and considering their needs and wants. In turn, this would give them more autonomy on the choice of medical help.

*“If I had something serious, I think my trust would be greater, because I would want everything to work smoothly. Then my trust would necessarily have to grow because I would then voluntarily or involuntarily place myself in the care of other people and from then on I would no longer have any control over myself.”* [male, 26 years]

In both groups, there were two participants each that argued about the relevance of empathy (of the treating physician) in relation to competence (of medical advice). One of them would argue that in a medical emergency, competence would have to take precedence over empathy, and they would renounce it if it added to the condition of competence.

*“Empathy then is no longer an issue for me. I wouldn’t care if he was empathic or not, I would just like to know how I would be treated best.”* [female, 26 years]

The other participants would then argue the especially in times of a medical emergency, they would expect all the more empathy from their physician since they would want to be educated, taken seriously, and have their worries considered. To them, that was equally important when compared to the condition of competence.

*“If I were to get a serious diagnosis and the doctor told me, but I don’t have time now, I have to go to lunch, I think I would slap him in the face, that would make my worries even worse, so empathy for me would be just as important.”* [female, 24 years]

### 3.4 Group Differences in Answers

When comparing participants demographic characteristics, the most recognisable difference was that between participants working in the medical field and those not working in

the medical field. In both groups, there was one nurse and one health insurance employee, respectively. Overall, they had a bleaker perception of the healthcare system, focusing more on unfair insurance policies (specifically in relation to public and private insurance), inefficient processes, monetary interest over patient interest, and an overworked but under-appreciated system in general.

*“I think that the healthcare system is not fundamentally bad, but it is simply far too overloaded, so people are simply broken, whether it’s patients, doctors, or nurses. I just think they can’t cope anymore and it’s too much for everyone.”* [female, 22 years – nurse]

*“It’s really shocking to hear that from you [to the nurse], because as an outsider I would say that everything is working quite well so far, because I don’t notice anything bad about it.”* [male, 26 years - engineer]

Participants that did not work in the medical field however, painted more optimistic pictures, e.g., that the German healthcare system is generally satisfactory, the medical treatment is very good, and the basis of it is fair and just towards every member of the community. Another aspect that emerged was that male participants stated that, when asked about what a severe medical decision meant to them, they had more issues with seeking medical help in the first place. Female participants on the other hand, did not share this concern but rather focused on the factual decision making outlined above.

*“So for me, because I wouldn’t like to go to hospital, I wouldn’t like to admit to myself that I have to go there, it’s the pride that makes it difficult for the decision. So putting myself in the care of other people to get better, I would say that’s a bit of a threshold.”* [male, 26 years]

*“If it’s a serious illness, then I’d be more concerned with the “what therapies can you do”. I’d find that more stressful than going to hospital or to a doctor at all.”* [female, 52 years]

## 4 Discussion

In this section, the findings of the focus group are discussed, starting with the key insights of the study. Afterwards, the strength and weaknesses of the approach are described and implications are derived.

### 4.1 Key Findings

This study employed a qualitative focus group design with the purpose of defining severe health decisions and establishing relevant trust conditions in such interactions with the healthcare system. In that respect, participants agreed on severe health decisions as life-altering, often irreversible choices of treatment. There were individual differences about the perceptions of when a severe decision begins, ranging from the decision to seek out medical help to actively making a decision to get a particular treatment which were mediated by gender. Moreover, participants working in the medical field had an overall worse impression of the current state of the healthcare system and met the trust

conditions with more suspicion that participant that did not work in the medical field. This suggests that (previous) experience with the medical system severely impacts.

Based on the answers and discussions in the focus groups, relevant trust criteria included competence & efficiency, cost allocation & fairness, and communication & empathy. These factors increased in significance when participants imagined having to make a severe decision in the context of the healthcare system. While most participants agreed that all factors remained equally relevant but only increased in necessity, some argued about trading of empathy & communication for competence & efficiency. These findings corroborate previous research on trust conditions in the healthcare system [20, 21]. While some studies may have come to different groupings of dimensions, there are several common conditions, e.g., competence, empathy, communication, and transparency. In essence, these criteria are in line with the theoretical basis of trust with respect to structural and interpersonal trust [19]. What this means is that participants construe their trust heavily around the institutional and situational expectations and their interpersonal contact with medical personnel and most prominently, their treating physician. Connecting this back to the use of assistive technology, it becomes clear that trust is embedded in all of these situations and whether patients trust their healthcare provider, both on a macro- and micro-level, is essential for the integration of any such technology. The results also show that there are individual differences and trade-offs when it comes to the relevance of these factors.

## 4.2 Strengths and Weaknesses

As with any study, there are several strengths and weaknesses. First of all, the broad identification of relevant trust parameters in healthcare focusing not on specific entities or specific contexts (e.g., pandemic) can be considered helpful. It builds a basis for deepening and elaborating on the trust parameters needed in decision situations in the healthcare system. The results also show changes in the identified trust criteria: it relates and compares criteria within different situations of (severe) health decisions. These things serve as a first step that enables consecutive quantifications and experimental analyses.

However, subsequent (quantitative) studies are necessary to validate the findings while the influence of specific contexts and individual situations could be investigated in more detail. With regard to the sample, it is worth noting that it was relatively balanced with regard to gender and diverse professional backgrounds but still comparatively small and young. Therefore, perceptions of older people (aged 65 years and above) should be considered in future studies as they represent. Lastly, the sample was conducted in Germany on German participants which limits the generalisability of the definition of what the healthcare system constitutes. While some aspects can be interpreted as universal (e.g., communication & empathy), there are grave (inter)national differences in how the healthcare system is conceptualised. Adding to cultural implications, this needs to be taken into account and compared with other healthcare systems in other countries to derive robust results and trust criteria.

### 4.3 Implications and Conclusion

Although these findings are in line with existing literature on trust in general, they provide new insights into trust-relevant and trust-building factors related to severe health decisions. Moreover, looking at this topic from different perspectives, such as professional experience, has strong implications of the various requirements needed for different groups of people. The qualitative identification of relevant factors for trust in healthcare systems in severe health decisions opens up the possibility of validating the findings in subsequent quantitative studies. Furthermore, these results broaden the understanding of people's requirements for trust in healthcare within severe health decisions, paving the way for investigations of trust-relevant factors of using assisting technology in such severe health situations. In future studies, this interplay of variables should be broadened and other influences, such as health literacy and knowledge and expectations about the working of the medical system, could be taken into account as well. Globally, this study enables the identification of crucial requirements for patients to trust their respective healthcare provider. Moreover and by contributing to a greater understanding of the patients' needs, with the results of this study, recommendations for a more targeted and demand-oriented communication between the various stakeholders in health care systems can be derived.

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