

# **Digitalization from the Patients' Perspective**

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# 1 Introduction

Digitalization in health care is often discussed from the professionals' point of view (e.g. physicians, dentists, nurses), but what about the patients' perspective? Patients face new challenges: They are a cost factor, which has to be monitored. This requires access to all their health care data plus additional information. Patients' behavior may well be measured in the future-mandatory genetic testing could be on the horizon, and in times of coronavirus the question of compulsory vaccinations arises once again. There is more: Should every German citizen automatically become an organ donor by law? Should opting out mean having to make a written declaration? And should the system punish people who opt out, e.g. by putting them last on the waiting list if they need an organ transplant? Is this environment really conducive to creating high acceptance of digitalization from the patients' point of view? We conducted the following three studies, which will help to understand patients' needs and perspectives in the age of digitalization in health care, especially in the hospital environment. Ultimately, patients' acceptance of innovation and digitalization is crucial to the success of implementing new technologies in health care. To achieve higher acceptance, policymakers should promote public campaigns to communicate the advantages of these technologies for all patients in the health care system.

# 2 Three of Our Studies from Recent Years

During the period from 2014 to 2020, we worked on several studies researching different aspects of patients' perspectives in the field of digitalization and innova-

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tion. The research focused on patients' willingness to share and hand over their health care and non-medical data, as well as the acceptance of digital products and services in the hospital environment and in general.

## 2.1 Results from Study No. 1

We turn first to some of the results from a study we presented in July 2014 at the "12th Open and User Innovation Conference" at the Harvard Business School (Boston, USA). This was organized by Prof. Eric von Hippel (Massachusetts Institute of Technology, MIT) and Prof. Karim R. Lakhani (Harvard Business School, HBS). The title was "Users (Patients) willingness to open personal health data for an innovative APP to receive a more efficient health care service." In our abstract, we expounded our research work:

As there is a relationship between periodontal disease and widespread diseases like diabetes or cardiovascular disease, this is an interdisciplinary situation for the user (patient). Personalized health care data management is needed to prevent further threats to the patient's health. The DMD (Doctor of Dental Medicine) can measure relevant parameters in the oral region to define the status of the periodontium on a timeline. The MD (Medical Doctor) has access to all information about the general disease profile of the user (patient).

It would be more efficient for the patient, MD, and DMD to exchange data, combined with information that the patient adds to the app, which is then visible for all three parties (DMD, MD, and patient). This interdisciplinary approach could help users (patients) and reduce costs in health care systems through prevention and by providing early warning indicators. The technology exists, but are patients willing to provide data and information in an app of this kind?

For this paper, from January to December 2013, in a multicenter study (4 dental clinics), we interviewed 528 patients with a periodontal disease history in two groups. In the first group (n = 244), no user had a prior general disease. In the second group (n = 284) they had a minimum of one general disease or more. We found that 93% of the second group would open their individual health care data to such an innovative app, allow the MD and DMD to enter certain medical parameters, and would also input information daily/weekly such as how they feel, what they eat and if they still smoke. In the first group, 32% would open their individual health care data to such an innovative app.

Our empirical results showed significantly that there is a high user (patient) willingness to share personal health data with an innovative app in order to receive a more efficient health care service, among the group of users who have a periodontal disease history *and* one general widespread disease or more. This user willingness should be used to develop appropriate IT solutions, implement them in the health care market, and reduce costs for the health care system. The benefit to users is the prevention of further medical threats to their health.

This study, which we presented in 2014 in the USA, marked the start of the "Dr. Dr. Plugmann APP," which we developed and presented in different international

health care digitalization contests. We used the feedback from participants and organizers to improve our app, and it was used in local private practices to help patients. In 2017 the app was sold.

# 2.2 Results from Study No. 2

The first study, presented in 2014, only considered the flow of health data between the patient, MD, and DMD in interaction with software (an app) and using mobile devices. Having identified in the first study the very high user (patient) willingness (93%) to share personal health data with an innovative app in order to receive a more efficient health care service, the next question was: What if data collection would be expanded to create a holistic approach? The holistic approach to deliver a better health care service to the user (patient) would need medical and nonmedical data about the user. The influence of such a future user community and the potential results from research data based on the future IT service could also help to develop open innovation processes and future research in the open innovation field (Chesbrough and Bogers 2014). These thoughts led us to conduct the following study, which was presented in November 2015 in Santa Clara/Silicon Valley (USA) at the "2nd World Open Innovation Conference (WOIC)." The conference was organized by Prof. Henry Chesbrough, Faculty Director of the Garwood Center for Corporate Innovation, University of California, Berkeley Haas School of Business. The structure of this research study presented in 2015 is described on the following pages.

#### **Research Question**

We prototyped a future IT health care service that would be offered by an open innovation driven health care IT company. That IT product (service) would collect all the personal medical and non-medical data it can get—with the individual's permission—depending on the electronics and sensor system technologies. The research question was whether users would be willing to transfer all their medical and non-medical data to a future IT service provided by an open innovation driven health care IT company. Does such a future IT service prototype meet users' needs? And does it lead to a high level of willingness to transfer all data to an open innovation driven health care company that offers this service? Usually today (in the year 2021) this would be something more like an AI-supported cloud solution with integrated devices.

#### Secondary Data

From February 2014 to February 2015, in a multicenter study in Cologne and Bonn (4 dental clinics and 6 medical practices) in Germany, we interviewed 821 patients and asked them about the importance of several factors. Out of more than 2439 patients, just 821 met the inclusion criteria. The inclusion criteria for patients were: a past history of dental and medical illness; age 20–75 years; at least one chronic medical disease (e.g. diabetes or coronary heart disease); experienced in using IT;

and a positive attitude to IT services. The definition of data in this study means all data which can be collected in a way that makes sense for a holistic health care IT service approach. For example: food, preparation of food, weight, sports, health data and history, stress profile, genetic risks if testing available, environment, sleep time and quality, regeneration profile, hygiene profile, sun exposure, and protection. The integration of various electronic sensors and devices is required. We emailed 67 directors of small and midsized technology companies in the health care industry in Germany and Belgium to ask for interviews. Just 17 replied and 8 accepted an interview.

#### Primary Data

For this follow-up study, we chose a multicenter study with two steps. First, we used a qualitative research method, where we interviewed eight directors of small and midsize German and Belgian technology companies in the health care sector. We asked about their views on future scenarios of technological products and services for patients based on present or future technologies and concepts. In parallel we interviewed 16 patients, who had a combination of dental and medical illness history, about their expectations of such products in the future, and their willingness to transfer their personal data to an open innovation driven health care company. We then clustered the interviews in three main sectors on the industry and patient side. Next we designed a prototype IT model, and in step two of the study we presented it to patients who met our inclusion criteria. Using a quantitative research method, we asked them questions from a standardized questionnaire, designed based on the experiences of the interviews.

#### Data Analysis

After the interviews (step 1), the main subjects discussed were identified and written down. Later the main subjects of the interviews were coded. The coding helps to identify patterns, and to develop a list of standards from the point of view of the industry and of the user.

The questionnaire that was used to ask questions to users (step 2) was designed based on the results of the interviews. It reflected the most important subjects that came out of the interviews. Finally, the users' answers to the standardized questionnaire were analyzed using statistical analysis software (IBM SPSS 22.0).

#### **Future Health Care IT Service Prototype Model**

This prototype model of a future health care IT service included currently available IT applications in combination with currently available sensor systems technology and electronics, but the combination concept itself is not currently available and represents a future technology approach. This future concept allows users (patients), as the legal owner of their data, to transfer all dental, medical, and other data that they and the company define as relevant, to the health care company (subject to the user's consent), in order to receive an efficient health care service. The open innovation process allows every single user to see anonymous data from other customers, to benefit from research results based on outcomes from the common

data pool of this specific user community, and to interact directly with the company to communicate user wishes. These can then serve to develop an individual evolution model in a very short time to meet user needs.

#### 2.2.1 Findings

On the user side, the results showed that the factor of being able to influence the future IT service in health care through an open innovation process was important to 91.1% (n = 748) of the patients. The security of IT data came in second place with 89.4% (n = 734). In third place was the ability to benefit from scientific research results based on the data pool of the future IT service community, with 86.6% (n = 711). If these three important standards of an open innovation process, IT security, and scientific results from the community data pool would be guaranteed, overall 87.8% (n = 721) of the patients would be willing to transfer their whole medical and non-medical data as mentioned above, in order to receive an efficient health care service.

### 2.2.2 Conclusions

The results of the paper showed that patients who satisfied the inclusion criteria identified three important factors as being a required standard before they would be willing to transfer their medical and non-medical data: an open innovation process which integrates users and their ideas, IT security, and the ability to benefit from the data pool (research results) of the users of this service. Provided these three standards are met, the empirical study showed significantly that there is high user (patient) willingness to transfer personal medical and non-medical data to a future IT service provided by open innovation driven health care companies, in order to receive an efficient health care service.

This paper made a contribution to understanding users' relevance in and their willingness to participate in the open innovation process (Von Hippel et al. 1999), what standards are expected from the users' perspective in the open innovation process (Chesbrough and Bogers 2014) and how far companies have to open themselves up in the open innovation process (West 2003) to succeed in the future health care services market.

## 2.3 Results from Study No. 3

After processing the results of studies no. 1 and no. 2, which were presented in 2014 and 2015, we started to discuss the next research study. Electronic health records (Atasoy et al. 2019), boundary risks, emotion, and consumer willingness to disclose personal health information (Anderson and Agarwal 2011), and the new challenges and opportunities resulting from digitalization in health care (Menvielle et al. 2017) will influence the acceptance of future health care on the patients' side. So the question was: What level of acceptance does digitalization in health care have from the patients' perspective, especially in the hospital environment?

# **Study Design**

We conducted a multicenter study in three dental clinics and one clinic of general medicine. The clinics were in the cities of Bonn, Leverkusen, Cologne, and Düsseldorf (Northern Westphalia, Germany). The age of the patients (n = 142) was between 20 and 85. Between January 2019 and June 2020, a questionnaire was put to patients, who were chosen at random. 36 patients were asked in each practice. The patients could answer "YES" or "NO." The inclusion and exclusion criteria for the persons surveyed in this research study were as follows:

Inclusion criteria:

- Individuals who had been treated in hospital at least once.
- Age: 20–85 years.

Exclusion criteria:

- Individuals who had never been treated in hospital before.
- Age: younger than 20, older than 85 years.

We also asked the patients about why certain processes should be provided in person. The responses from this qualitative part of the study will be published at a conference in 2022. We took 14 processes that occurred frequently for us in the hospital environment, and asked patients about their acceptance if this process would be led by artificial intelligence (AI), robotics, or an automated voice. We also asked if communication with the hospital staff and physicians could be delivered through an iPad, augmented reality (AR)/virtual reality (VR), or an avatar.

### **Pre-results**

We are still in the process of analyzing the demographic parameters with SPSS and performing the qualitative part of the evaluation, but as pre-results we can give readers the following information. Here are the current initial statistical findings on patients' acceptance (as percentages):

- 1. Check-in: (AI driven, automatic voice) 92%
- 2. Waiting room and call to go to the treatment room: (AI driven, automated voice) 84%
- 3. Providing data about personal medical, dental and mental history: (AI driven, automated voice) 56%
- Going to the X-ray room and getting an X-ray: (AI driven, robotics, automated voice) 31%
- 5. Taking blood: (AI driven, robotics, automated voice) 6%
- 6. Receiving diagnosis information from the staff or physicians: (via iPad, AR/VR, avatar) 14%
- 7. Educational information about the treatment: (via iPad, AR/VR, avatar) 23%
- 8. Educational information about drugs: (via iPad, AR/VR, avatar) 21%
- 9. Receiving information about a bad prognosis: (via iPad, AR/VR, avatar) 1%

- 10. Receiving information that a family member has died: (via iPad, AR/VR, avatar) 2%
- 11. Receiving information about, e.g. a non-operable cancer diagnosis: (via iPad, AR/VR, Avatar) 0%
- 12. Being transported in self-driving hospital beds: (AI driven, robotics) 64%
- 13. Condition monitoring by apps: (AI driven, automated voice) 81%
- 14. Post-treatment feedback services, customer satisfaction questions: (AI driven, automated voice) 76%

The pre-results show that standardized processes like check-in, being called from the waiting room, entering an X-ray room, condition monitoring by apps, and selfdriving hospital beds have a certain high acceptance, but if it is a serious talk about non-operable cancer or a terminal diagnosis, the patients want to have a personal talk. This face-to-face interaction has still an extremely high value for the patient. Unfortunately, from the global perspective of all international health care systems, it is often the case that nothing like enough time or resources are available for this kind of personal interaction. This scarcity will only increase in the future.

# 3 Conclusions

Today, with regard to digitalization in health care, it may seem that from the patients' perspective "face-to-face interaction" is the dominant requirement for the acceptance of communication in health care systems, especially in the hospital environment. But the future will change everything. Health care systems do not have much time for feelings. This time for personal contact will be a luxury in the future, for those who can afford "face-to-face interaction." If an AI system can analyze an X-ray, the AI can also transfer the patient and their data to the next doctor or department. Robots can take blood, information can be transmitted digitally and communicated by automated voices, avatars, or fantasy characters, and no face-to-face interaction is needed. If the pre-surgical or pre-treatment discussion is standardized, a virtual talk (telemedicine) or a video is acceptable. Notifying the death of a family member by tablets, avatars or AI is out of step with today's ethical standards, but in times of social distancing (coronavirus), with time constraints caused by economic pressure in the health care system and fewer people willing to work in health care, these kinds of automatization, digitalization, and costoptimization strategies will open the doors to the increasing dominance of AI, telemedicine, and AR/VR in health care with less and less face-to-face interaction. This process is unstoppable. And by the way, as unethical as this "no face-toface communication" or long-distance telemedicine combined with AI and robotics seems to be, for space travel and the colonization of new planets, this kind of health care system will be the standard of the far future.

Summarizing these three research studies, it seems that the issue is not so much digitalization and automatization as such—even the transfer of health care and nonmedical data seems acceptable to patients—but rather the strong desire for face-toface interaction in one room. Further research over the years ahead will deliver more results in this field and give a better understanding of digitalization in health care from the patients' perspective. AR/VR technologies, new AI applications, and new haptic innovations could one day perhaps give patients the feeling of "face-to-face interaction" even if the physician or staff is not present. This could emotionally help individuals and families to deal with very sad news. We need innovative products and services for the new mode of "face-to-face interaction" to solve the problems of the future in health care from the patients' perspective.

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