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# Out in the Cold, the Loneliness of Working with Doctors and Patients

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**Abstract**. Working as an HCI researcher in the domain of healthcare can be challenging. The nature of the domain limits our degrees of freedom, which we need to do research of high quality. Doctors never have time, while working with them can be time consuming with little tangible outcomes. Patients from their side might bring the researcher in uncomfortable situations, adding little contribution to the research itself but leading to psychological stress and mental burden on the researcher. And as researcher, it is often difficult to get the research published to the full potential due to the limitations inherent to the domain of healthcare. We found sharing experiences very useful when working out solutions for these issues, so we would like to continue this discussion during the workshop.

**Keywords**: Ethics, Fieldwork, HCI Researcher, Healthcare.

## 1 Introduction

“A hospital is a closed environment, you don’t just walk in here and do whatever suits you” answered the physician in a threatening tone to the question whether I could do a contextual inquiry at ‘his’ hospital department. As the physician argued, the hospital is a place where patients are being treated, and there is little space for experimentation of someone without a white coat. Patients should feel at ease here, and should be able to trust their physicians. For this reason, we submit our protocols to an ethical committee, who can approve our study from an ethical point of view. However, I find these ethical concerns too unidirectional. The subject of the study, e.g. the patient, is well considered before getting approval. But the other side, the researcher, is often left out in the cold.

After two years of working as a HCI researcher in the domain of healthcare, I experienced a number of challenging situations and learned to deal with them as well. This workshop paper discusses some difficulties when working with doctors and patients. As I found sharing experiences with colleagues or reading case studies (e.g. [1], [2]) the most useful way to tackle these challenges, I would like to continue this discussion during the workshop.

# 2 Three sides to the story

Doctors and patients have a strong but delicate relationship. Patients literally put their life in the hands of the doctor. The patient needs to trust the doctor in order to make treatment work. Also in our work as HCI researcher, trust and reciprocity are important in the relationship with the users. So when working in the domain of healthcare, the HCI researcher is dealing with doctors and patients, and thus a triangular relationship arises. While confronting doctors and patients can be interesting, we must be careful not to interfere with the doctor-patient relationship, and thus the medical outcomes. On the other hand, we must try not to be the fifth wheel in our own research project. In the following paragraphs, I discuss some challenges of HCI research in healthcare from the perspective of the doctor, the patient, and the researcher.

## 2.1 Doctors never have time

Doctors, especially specialists, have little time. In Belgium, physicians are paid on performance, which leaves little time for extras. Arranging a meeting can be time consuming, and even during an encounter physicians might need to leave you alone. After all, emergency cases are common in a hospital.

Once, I invited 12 specialists that collaborated in a project for a workshop. Most of them declined the invitation, as their schedule was too busy already. A few did not make it to the workshop because of emergency cases, they said afterwards, and one was late for the same reason. One specialist was on time. Afterwards, the two specialists who did attend our workshop asked us to repeat this exercise with the other specialists because it made them think in a way they were not familiar with. We never did, as we never found a suitable moment.

As their time is limited, working with doctors requires you to be very efficient. On the other hand, it is common for a specialist not to answer my email for weeks and then reply “come and meet me tomorrow”. So in contrast to the requirement of being efficient with their time, I found working with doctors very inefficient from a time management perspective. When working with doctors and specialists, I learned to prepare myself to the maximum and always be flexible with my schedule. I always have a plan B (e.g. some reading material), just in case plans change.

## 2.2 Patients have uncomfortable stories

Patients, for example chronic patients, often have long stories. A disease never comes alone, and the contextual causes and consequences come with it.

Once, I did a diary study with transplant patients. We visited the patients two times in their home environment, first to explain the study and then at the end for a contextual interview. As required, we submitted our protocol to an ethical committee for review. We had to argue why it was necessary to meet patients in their home environment, as we entered the personal sphere of the patient, which could be too obtrusive for some our participants. We got approval after some discussion and could start the study.

Many, if not all, patients warmly welcomed us. At most places, we received coffee and cookies. We received a lot of valuable input for our study and most participants explicitly stated that they were open for future studies. I was surprised how open people were about their health, and their life.

In this openness, we also encountered all kinds of uncomfortable situations. The participants seemed to be glad that they could share their story, as someone was listening. Stories about relationship problems, divorce, alcohol abuse, depression, and loneliness were told, often in tears. As researcher, I felt mental burden and didn't really know what to do with it. But because we were also gaining a lot of insights, I didn't want to change our approach.

In the same study, we had a patient who had acute problems while completing his diary and he was admitted to the hospital. On a Sunday, while I was preparing the home visits for the next day, I received a voicemail from the hospital. The patient, who sounded very weak and had difficulties to find breath, told me he wouldn't be able to finish the diary. He called me to say he gave his diary to a nurse, so they knew where it was. He apologized because he couldn't finish it as planned, and said goodbye. I couldn't get his voice out of my head for several days.

Before the study, I was afraid of confronting patients with uncomfortable thoughts. However, I experienced the exact opposite and maybe came too close to the participants. As researchers, we are interested in the context in which technology is used. But by scratching the surface, patients might bring us in uncomfortable situations. I learned to schedule enough time when visiting patients. If this buffer is not used, it allows me to clear my head before meeting the next patient by writing down my impressions of the visit.

## 2.3 Researchers must publish

Working as HCI researcher in the domain of healthcare is not always straightforward. Of course, some of these challenges are inherent to the work as HCI researcher, or to research in general. Doctors don't have time, and asking too much time of patients can be too exhausting for them. So we do get less time than we would like with less doctors and patients, our users. Often, outsiders are quite surprised that we only worked with 3 hospitals. Others, who are more familiar with the domain acknowledge the difficulties in getting 3 hospitals prepared to open doors to let a stranger in and make time for him. Clinical trials, which can show whether there is an effect take very long, also to get them organized. As we are in a fast-paced domain, these studies can take too long.

Also, in the healthcare domain, we see and hear all kinds of things that we shouldn't. In most situations, taking notes is all we can do. So we also have to be creative on the data gathering and analysis side of our research, which could also be seen as limited by outsiders. While we have the tacit knowledge because we immersed ourselves in the context, we can't back up these insights to the full potential.

## 3 Conclusion

As HCI researcher, we translate domain knowledge, needs, and opportunities from different points of view. These insights might be obvious for some, but eye opening for others. Especially in the domain of healthcare, being disruptive can be very counterproductive. Doctors are sometimes considered as conservative by nature, and reluctant to change. But in our experience, they care about their patients and their treatment. So we had very interesting discussions with them.

Working in the domain of healthcare challenges us to be creative. By sharing stories, we get the inspiration to tackle obstacles along the road when working with doctors and patients. In this workshop, we would like to discuss how we could adapt our methods to fit these specific situations. How can we deal with the contextual factors of working with doctors and patients? How can we do research that matters, balancing empathy and distance between us and patients or topics? And how can we get our results published?

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