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Artificial Intelligence in Hospitals

The challenges and virtues of AI in contemporary healthcare systems.

Introducing AI to Hospitals

Artificial Intelligence (AI) technologies have developed in recent years and are continuously introduced in new fields. One of those fields is the healthcare system. The range of AI technologies is broad, reaching from simple systems such as decision aids to very complex tools conducting surgery. AI systems already in use are mostly concerned with image-based technologies, meaning that AI might, on the basis of a picture, conduct a diagnosis that otherwise a doctor would do. Naturally, the introduction of AI opens up a wide range of ethical questions that we aim to address in this paper.

This open discussion will focus on a specific case study. Being students at Maastricht University, we had the opportunity to get some hands-on information on an AI tool currently in use in the MAASTRO clinic. We were lucky to conduct two interviews, one with a data scientist currently working on PROSPeCT and a legal advisor who is concerned with legislation on AI in healthcare. Both interviews gave us an in-depth insight into the changes and challenges related to AI in hospitals.

Our project is mainly focusing on decision aids. These are websites or programs provided by healthcare professionals. They give patients the opportunity to find out about different treatment options at home and list the risks and side effects of the different treatments. All of this runs under the concept of shared decision-making. This means that in case of serious diagnoses, doctors should not simply be able to make decisions over the patient's head, but rather make decisions together.

Therefore, a decision-aid is currently in use and further developed at the hospital in Maastricht for cancer patients, more precisely for patients who are diagnosed with prostate cancer. The decision-aid - called PROSPeCT - is an online tool that cancer patients have access to after diagnosis and can thus view the various treatment options for cancer and the associated side effects at home. An AI is built into the decision-aid that collects patient data and the more data is fed in, the more accurate predictions the AI makes about the future and treatment options of the patient. This means that the decision-aid is not just a website that provides information about possible therapies, but rather the patient gives the AI his preferences, his history, his illnesses, and then the AI compares this data with similar cases from the past. Therefore, it gives individualized and personalized treatment options.

Now, a definition of artificial intelligence is in order. The concept of artificial intelligence is a highly contested and uncertain one. This is not only due to Hollywood's imaginative depictions

of sentient robots and malicious computer systems, but also because it is a space that lends itself well for the projection of people's hopes, aspirations, and fears. Even people in the IT industry long for cinematic artificial intelligence to become real (Broussard, 2019). This could partly explain why artificial intelligence is framed in this manner, right next to the intentionally overselling (or deceptive) marketing jargon for tech products. The dream (or nightmare) of the general AI is still far off and perhaps unrealistic altogether; real applications of AI are usually of the narrow kind, mathematical models and datasets created to address a specific task or problem (ibid.). What makes a computer program intelligent? There is no real consensus on where the demarcation between an artificial intelligence and a mere program lies, and many authors skip a definition altogether.

Perhaps it is an untimely matter to decide right now. Indeed, hailing from anthropology, Nick Seaver (2017) observes that critical scholars were seemingly unable to deconstruct and define the concept of the algorithm. Whether algorithms and AI are the same is another can of worms, yet they are closely related and they undoubtedly convey a similar power and significance while remaining both ill-defined and elusive. Instead of deciding on a rigid definition, Seaver (2017) suggests that researchers should do fieldwork to discover what algorithms (and AI in this case) are in practice, in an ethnographic manner. This entails leaving out 'correct' definitions in favor of more sensitive and open inquiry into these systems, treating them as the real socio-technical elements they are - to open the 'black box'. This is what we have done with PROSPeCT; this paper is an attentive and receptive attempt at shedding light on the reality of artificial intelligence in practice.

But don't worry - we do not mean to fast-forward here. Before we dive right into our own research and thoughts, it might be useful to draw a more detailed picture of our 'setting' - the 'stage' where it is all happening, as you will. In the end, who can tell a compelling story or reveal intriguing truths without a plot that keeps it all together? Our story begins, quite sobering I should note, in a Zoom waiting room on 8 February 2021. The white Zoom window read, as it did so often these days, "Please wait for the meeting host to let you in". Had we known our committed and enthusiastic 'meeting hosts' and project supervisors, back then, I imagine that our mood would have been a different one already. But that's quite frankly where our little project took off, in a slightly over-staffed group of three eager students and two enthusiastic supervisors within the digital walls of Maastricht University. And as three European Studies Students, our research journey started quite at the beginning of AI in hospitals, a story that started much earlier than that of our small team, and yet, strangely enough, is still at its very beginning.

Today's stage of AI in healthcare is shaped by so-called 'push' and 'pull' factors of new technologies, by our need for new solutions versus our desire to create new solutions, searching for problems they might cure. In one way, the 2021 hospital is still marked by the repercussions of the global financial crisis in 2008, which has been used by many more conservative governments around Europe to introduce austerity cuts, extend restrictive measures, expand market space and competition, and reduce state intervention - measures that were borne most heavily by the European public healthcare sectors (Palasca & Jaba, 2015). In our story, we observe a clinic that is understaffed, in the halls of which surgeons and nurses rub their eyes as they start the 15th hour of their workday, a working world in which, regardless of lack of resources and staff, a surgery can last 8 hours or more.

Within the cultural spheres of the Western world, our stage is tainted by our 'great imaginaries' of the 'angels in white', framing doctors and nurses as infallible magicians of medicine. Only that they do fail (as most naturally, all of us do in our jobs, some of us on a daily basis), only that every medical consultation is tied to a budget, a time slot, and ultimately subject to human failure. Within this setting, the notion of medicine as a 'knowledge activity' has increasingly gained traction within the last two decades - due to increasing digitalization and the rise of 'big data' the amount of knowledge available has immensely expanded: if clinicians want to keep up with scientific advances, they can no longer rely on their traditional methods. The increasing amount of variables in healthcare also makes clinical decision-making more complex and choosing the best treatment option is not always clear-cut. This is where Artificial Intelligence and Deep learning technologies step in to take this data off the hand of doctors and make healthcare more precise.

The story of AI begins right where we stand, in a place constrained by the limits of human capacity and economic and temporal frontiers (because as we all know, time is money) and in the midst of the fourth industrial revolution, one that propels technological advances in artificial intelligence (AI), robotics, the Internet of Things (IoT), genetic engineering and more at a whirling pace. We don't know about you, but we have often wondered where the human stands in these fast-paced developments, a creature that is often stubborn, a 'creature of habit' that is slow to adapt, one that distrusts in its very nature. Through this small research project on decision-making tools in hospitals, we aimed to improve our (and ultimately, your) understanding of how Artificial Intelligence is compatible with us and all stakeholders involved in the healthcare system - what are the virtues that relieve our pain points and the challenges we are still facing? How can we make sure to tell a story of AI that makes it safe while allowing open development? How can we make sure that humans and AI get along well? Within the next

chapters, we are taking you on a journey through the experiences and thoughts of different stakeholders in the healthcare system, during which we hope to answer (or at least reflect on) some of these questions.

Dr. Paul Jansen – Urologist

“I am sorry but I must inform you that you have prostate cancer”. Dr. Paul Janssen, urologist, and surgeon at the radiotherapy institute ‘Maastricht clinic’ in Maastricht, watches his client taking a deep breath, holding in the air while staring at the opposite wall, and then slowly burying his face in his hands as he releases the air from his lungs. For Dr Janssen, who goes on to explain the following steps and the different ways to approach the treatment in a calming yet firm tone, this is not a new sight and the diagnosis he just revealed to his only 50-year-old patient is a sad normality of his daily routine. As for his other 10 patients that day, Dr. Janssen had studied the patient's chart thoroughly before entering the sterile examination room, trying to memorize the details of the diagnosis. As an experienced physician, he is aware of the important role of trust between patient and doctor. A misstep on his part, no matter how small, could have a huge impact on the course of his patient's health. It was this pressure, and the many patient files which piled up on his desk, that often exhausted and tired him.

Ultimately, it was this realization that made him a supporter of the new PROSPeCT project, which he now begins to describe to his patient. Even now, he reaches for the greyish folder to double-check his patient's details. Between the many pages he reads each day, his eyes take a while to focus on the words. 50-year-old male, adenocarcinomas, stage 3B. Small business owner, wife, 3 kids. ‘A clear case for surgery, and we must act fast,’ Dr. Janssen thinks to himself. But with the introduction of the new decision-aid tool, his word is no longer fact, which to a degree makes sense to him. He knows how overworked the surgical staff in the hospital is, how difficult it is to manage the daily information overload, and he is well aware of the various mistakes that happen due to human failure, often putting human lives at risk. Good Lord, sometimes he doesn't know himself how much he would trust his own medical assessment after an 8-hour surgery. In a fit of despair, he thinks back to the recent meeting of the chiefs of staff, during which further austerity measures were announced - cost-cutting initiatives that are noticeably trickling down to patient care. One thing is clear: the way patients are treated must become faster, better, and more efficient.

His patient, Mr. Bakker, who has now regained his composure, pulls him out of his thoughts: “So how does the ‘AI’ tool work then? How is the medical advice generated?” Although Dr. Janssen had seen this question coming, he has no satisfying answer for his patient. Despite

multiple briefings on this new technology, he himself does not fully understand how the 'machine learning' aspect actually functioned, nor how it generates the information displayed. As always when answering this question, Mr. Janssen sticks to the more general 'recommended' answer which he remembered from his briefing. His patient doesn't look particularly convinced and Dr. Janssen couldn't blame him. How should he rally support for a tool that he himself barely understood? And how should he then, as a medical advisor, transfer control to a technology that he has so little knowledge of? The surgeon suppresses a long sigh. His temple was pulsating painfully again. "And what should I do if - with this tool - if I arrive at a different treatment method than the one you recommend?" Mr. Bakker looks a little helpless and uncertainty resonates in his voice. Dr. Janssen clears his throat, looking at his patient for a little while. He couldn't help but notice that the insecurities caused by the PDA and his own inability to provide useful and clear advice bothered him. And he is worried. Worried about whether Mr. Bakker would be able to fully understand and interpret the information the tool would display to him - all in the absence of an experienced urologist. Once he has answered as many of his patient's questions as the 20-minute time slot allowed, he stands up, shakes hands with Mr. Bakker, sees him out with an encouraging smile, and watches with a mixed feeling as he leaves the room."

Mr. Janssen's experience does not occur in isolation from today's reality within our healthcare sectors. His thoughts and daily concerns demonstrate the increasing challenges posed to the cognitive capabilities of General Practitioners (GPs) with the rise of 'big data' in the healthcare sector (Davis et al., 2003; Walsh et al., 2019). As Davis and colleagues. (2003) have emphasized, health care is a knowledge-based activity, with a massive expansion in the knowledge available in recent years. This does not only increase pressure for clinicians to keep up with scientific advances but at the same time, renders doctor's traditional approaches of relying on memory, reference books, experience, or colleagues insufficient. Especially in the case of Oncology, where the available treatment options for Prostate Cancer (PCa) are increasing in numbers, clinical decision-making is anything but clearcut (Wijk et al., 2019). For each patient, the physicians must make treatment decisions based on the cure rate, median survival, toxicity, comorbidity, quality of life, patient preferences (inform and involve the patient), and (in most healthcare systems) cost-effectiveness, a task that is frankly inhuman seeing that human cognitive capacity is limited to roughly five factors per decision (Lambin et al., 2017; Walsh et al., 2019).

While patient decision aids can relieve this pain point and improve personalized medicine, the integration of such tools fundamentally challenges the power relationship between doctors and

patients, thereby steering healthcare towards a more participative, patient-oriented approach (Walsh et al., 2019; Joseph-Williams et al., 2014; Anderson, 1996). These structural developments in healthcare are not always unproblematic and have met vast resistance from clinicians (and patients!) - a symptom of which is that shared decision-making and the use of decision aids is, in practice, only rarely applied (Knops et al., 2014; Karnieli-Miller & Eisikovits, 2009). In our interview on the development of the PROSPeCT decision-aid tool at Maastricht clinic, data scientist Rianne Fijten, who supervises the project, shared some intriguing insights with us. “Like - all the time? It takes a lot of convincing” she answered our question of whether she ever experienced a backlash from doctors. “I think the main reason is that they are quite confident about their skills, which might be justified or not really. And they don't really feel like the benefits outweigh the costs (...). Most doctors already feel that they're doing shared decision-making, even though they're probably not doing it, but they think they are. They also think ‘what is the benefit of a model, can I really trust this model?’”.

Rianne's concerns are well reflected by our earlier thoughts on our cultural imaginaries of ‘the angle in a white coat’ - a self-imaginary that clinicians wish to hold on to? At the same time, as Mr. Jansen's concerns exemplify, and as multiple studies have demonstrated, many clinicians avoid introducing decision aids, simply because they find them difficult to use or understand (Davis et al., 2003). This becomes especially problematic where so-called ‘BlackBox AIs’ enter the scene - ‘deep learning’ technologies where the decision-making process cannot always be fully comprehended - not even by the data scientist ‘in the loop’ (Smith, 2020). Others might think that the use of decision aids complicates and prolongs the treatment process. While many clinicians hitherto seem to prefer the more traditional paternalistic approach in which the clinician acts as the trusted agent of his/her patient (Davis et al., 2003), multiple studies have identified the immediate benefits of SDM via decision aids for clinicians (Bieber et al., 2006). Accordingly, the use of decision aids reduced their interaction difficulties with their patients, enabling them to explore patient's attitudes and illness beliefs which reduced communication difficulties and distress during the treatment.

On the other hand, research in this arena has challenged the assumption that decision aids empower patient's medical decisions versus that of their clinicians. A study by Joseph-Williams et al. (2014) reveals that patients need both knowledge and power, to participate in shared decision-making with their doctors. In this way, knowledge does not, as often anticipated, automatically translate into increased power, but instead, knowledge provision, acquisition, and expectation to contribute personal preferences are done in the context of a power imbalance between clinicians and patients. It is this power imbalance that must be addressed in the first

place in order for patients to feel confident in using their newly acquired knowledge and to prepare for the essential first step of the SDM encounter. In contrast, Karnieli-Miller and Eisikovits (2009) have found that ‘shared decisions’ are often the result of persuasive tactics by clinicians, based on power and hierarchical relationships. Their findings show that GPs often use persuasion strategies, only providing partial information about the diagnosis, being mostly focused on enhancing the chances of accepting the treatment option preferred by the physician. While choices were often presented in a way that required immediate decision-making, thereby limiting time and opportunity for reflection and deliberation, patients usually ended up making decisions according to the ways in which time and circumstances were presented by the physician (much rather than basing their decisions off their own knowledge or that provided by the decision-aid).

The insights from this literature raise some important questions for us - among which is: Is it always so negative if clinicians provide stronger guidance in the decision-making process? Indeed, Cohen & Britten’s (2013) study has found that patients welcomed the directive role assumed by their clinician, while the convincing strategies of the latter helped some patients to build trust in their doctor and feel safe with the suggested treatments. While demands for a more egalitarian structure of healthcare in the last decades (Anderson, 1996), and the elevation of marginalized groups and unheard voices is beyond doubt legitimate, this perspective is certainly also valid - seeing the technical power and expertise of the physicians in contrast to the lack of medical competence of the patient. Thereby, many patients expressed anxieties about taking responsibility for the treatment outcomes after using a decision-aid (Cohen & Britten, 2003). In the end, several studies confirm that it is the process of involvement that appears to deliver benefits for patients, not the act of making the decision (Edwards & Elwyn, 2006). According to the authors, the clinician then takes on the important role of a ‘facilitator’ and ‘manager’ of the decision-making process, making sure that the patient’s preferences and actual decisional responsibility are aligned.

In the end, such a role involves many difficult questions for the clinician - some of which there are simply no answers yet, according to our interviewee Rianne. “So I actually my father in law was also diagnosed with prostate cancer a couple of weeks ago, and I was with him at the consultation where he got the news.”, she told us at some point in the interview. “And I remember ... the doctor who was very nice, but still he just flipped the screen and said ‘oh, look, you have a five percent chance of being OK’ and it just had a percentage there (...) and then we moved on to something else.” She would continue by talking to us about the many uncertainties that are involved in the use of AIs and the many important features of the dataset it is all based

on, that need to be taken into consideration. Nevertheless, she explained to us, many clinicians simply do not have the time to explain these uncertainties to someone who just got diagnosed with prostate cancer: “But we need to inform patients somehow. The question is how much do we need to inform them and how? And I don't know how we can best do that, but I remember being a bit shocked that he was just like going ‘here's your data. OK, let's move on.’” She shook her head and laughed a bit. “That was a bit weird.”

Thijs - Patient, Assistant Manager, Husband

“Thijs De Jong is a 59-years old assistant manager in a medium-sized business that manufactures domestic plumbing sealant. His health insurance and GP recommended that he would get himself tested for Prostate Cancer because of his age and less-than-ideal diet during lunch breaks at work. In the end, it was his wife that convinced him to finally make an appointment. Thijs was reluctant to get tested because he did not know of any cases in his family and somehow it is always the others that get sick. But this time it was him.

At the Urologist's office

Naturally, Thijs was in shock. To him, cancer is a spectre that haunts media, health magazines, and hushed conversations at large family gatherings or weddings. He had an immediate feeling of regret about making this appointment and getting tested, as if the test had given him the cancer or that it would not exist if he had not known about it. In some ways, the latter is almost true. His urologist informed me that the cancer in his prostate is rather benign and had not spread to other places. Considering the typically slow growth of prostate cancer and his age, there is a good chance that he will never experience significant health problems. Yet, his urologist recommended removing it anyway because, while low but not insignificant, the risk of leaving an active cancer in his body was unnecessary. He briefly went over the alternative forms of treatment, two of them involving radiotherapy which immediately invoked images of very sickly-looking husks-of-men in my mind. There was also one where they would just let the cancer be, but his urologist seemed to disprove of this and did not explore it any further. Instead, he argued that it would be easiest, and also best for his peace of mind, to surgically remove the cancer from his body. He said that he had done this with numerous patients and has had great experiences with it, yet he admitted that there were some possible side effects. There was a chance that there would be complications with peeing and that his ‘sexual functions might be impaired’. This was of course a sensitive issue to him, to say the least. However, as his urologist argued, alternative treatments or leaving the cancer as it would have similar

effects. He felt the professional spoke with good authority and his casual attitude while recommending the treatment made him less anxious and more trusting.

Towards the end of the appointment, he suggested that they would meet again in one week to start the treatment and that he should think about it. When This was already fiddling with his jacket and standing up, the urologist mentioned almost in passing that they had a new app-thingy with more information and that might help Thijs make a decision regarding the treatments. He was still rather shaken by the whole situation and had kind of already made up his mind according to the urologist's personal recommendation – he seemed rather dismissive of the app he had just suggested so he did not heed it much attention. Thijs was handed a flyer with an internet address and one of those checkered code squares which his daughter told him one could scan with your smartphone camera. He took the flyer, stuffed it into his pocket, and went home to break the news to his wife.

At home with the system

Thijs never really made the jump to the 'smart' world. Sure, he has an iPhone which he uses for work and messaging with his friends and family but he does not know my way around them as his daughters do. Luckily, his wife spends more time than he does with her phone so she was able to help me. It took a few minutes to install the app but thanks to the flyer they managed just fine.

Thijs was greeted by a colorful screen that asked him to create a profile by indicating his risk group (low) and then presented him with information about the different treatment types. It was reasonably easy to use. He was surprised to find out that the other options were considerably less invasive than his urologist had made them out to be compared to the radical prostatectomy he recommended. Furthermore, he learned about the Active Surveillance the clinician had been so dismissive about. It made more sense to him now: surgery and radiotherapy had significant risks, yet his cancer was currently harmless. Why then should he treat it now? Would not checking on it in regular intervals be more desirable? Suddenly, he realized that he no longer felt as ill and injured as he had since my diagnosis yesterday. He did not have any pain or symptoms, indeed, without the test, he would have never known about it. Undergoing invasive surgery felt no longer urgent or even sensical to him. Thijs concluded that he would bring it up at his next meeting with my clinician. Next, the system asked him a series of questions about the information it had just given, like a school test. Thijs felt rather irritated and it made him take the app slightly less seriously again. Then it asked him about his priorities and preferences regarding his health and functioning of his body. It followed up by asking him to identify his

least favorite treatment. Lastly, it printed a results sheet which he could reference and use for his next meeting with the urologist. Now Thijs feels more informed and less cornered than when he left the urologist's office the day before, yet also more unsure. He feels uncertain about his next meeting with him – how will he react when Thijs contradicts his recommendation?”

The story of Thijs De Jong could be considered a realistic depiction of the experience an individual patient might have. In this case, the system works successfully in tandem with its user. Naturally, different people will have very different reactions and stories, in fact, each of them is unique. Nevertheless, the vignette can be used to unpack a number of problems and challenges that patients can face in the interaction with doctors and AI-assisted decision aids. In the section of the doctor, we already discussed the concept of shared decision-making which the PROSPeCT decision-aid tool is supposed to complement and facilitate. It was considered how uncertainty should be communicated to patients and how understanding could be improved. In this section, the focus lies on patient-side issues.

As mentioned above, people are highly diverse and will have highly differing interactions with the doctor and the system, even if the latter two remained constant. Setting character traits and attitudes aside for a moment, patients bring a wide range of external factors into the decision-making process. According to Berry et al (2012), education, race/ethnicity (especially minorities), income, and marital status were significant influences on the preparedness for and satisfaction with the decision-making in prostate cancer cases. Socio-economic disadvantages also seem to translate to disadvantages in preparing and understanding a medical decision. The archetype least likely to be well-informed before the treatment is the “anxious, single man with less than college education and no Internet access” (Berry et al, 2012, p.266). They recommend that clinicians should attempt to categorize their patients to establish which patients are likely to need more or less assistance. How realistic this in lieu of the high pressure and short consultation times is a matter for a different discussion, yet it underlines how important it is to consider the diversity of patients. This also aligns well with Prainsack's (2018) criticism of the personalized medicine turn in healthcare, pointing out that people are rarely as ideally bounded, independent, and strategically rational as health care providers and innovators presume them to be. She suggests taking a more differentiated, sensitive, and relational approach to personhood in health care. As of now, it is highly improbable that decision-making aids can be so personalized to take patients with all their needs into account. Indeed, they do not ask for socioeconomic status or personality types, thus remaining entirely focussed on the medical status of the patient. Accepting more (voluntary) data about the patient's circumstances to not

only offer better-suited treatment suggestions but also adapt the system for better intelligibility for the patient might be a worthwhile avenue for improving decision aids.

Another concern regarding usability and intelligibility is that prostate cancer patients on average are of advanced age - thus they might face difficulties making full use of decision-aid systems (Ankolekar et al, 2019). This seems to be a generational problem and one that might no longer be a concern in the near future with rising levels of IT usage across all ages (see for example Pew Research Center, 2021). Yet, it must be taken into account that the target demographic for the system might not feel at home using it and might have difficulty interpreting or understanding beyond the assumed issue of making the data intelligible to patients. In reviewing their ProDeCa system, Ankolekar et al (2019) admitted that this issue was left unaddressed in their system, blaming a lack of literature and guidance on how to make PDA systems appropriate for elders. Fortunately for Thijs de Jong, he is not of advanced age yet, and though not fully accustomed to 'smart' devices, he was able to use the system in tandem with his wife.

Patients also interact very differently with technology, particularly if their participation is desired. Patients will employ different tactics of material participation to pursue their aims or expectations. While Nielsen and Langstrup's (2018) study explores the tactics of patients involved in a study, their findings could also be applied to the usage of a decision-aid tool. For instance, patients can assume an *activist* role in which they will actively use and engage with the tool and might take their experiences outwards to assist a larger community. Another (probably more frequent) tactic is that of *compliance*, where patients will use the tool solely because their clinician had 'commanded' them to do so. These individuals are unlikely to benefit much from a decision-aid tool, are more dependent on the attitude of their clinician toward the system, and probably not long-term users. Some patients are very active in shaping their own treatment or even demand it, whereas others (perhaps rightfully) reject being shouldered with this responsibility with their limited understanding, preferring instead to trust the professional. A theorized role that surprisingly did not appear among Nielsen and Langstrup's (2018) participants was the tactic of independent self-management which partly characterizes the experience of Thijs de Jong. Using this tactic, the patient will make use of the system to create and furnish their own treatment, or at least their expectations thereof. While the fictional Mr. De Jong is emotionally stressed from his diagnosis, initially influenced by his clinician's attitudes towards treatment and the system and not well-versed in technology, he finds himself changing his opinion through the decision-aid. His new-found expectations of his treatment might clash with the preferences of the clinician, yet it is precisely this that shared

decision-making and decision aids produce - and will hopefully convert into better healthcare outcomes.

Maud - The Data Scientist, Daughter

“Hey, Maud, I got bad news today”. While she was rushing through the hospital, this call forced her to break out of her daily routine. It was her father, and what he told her did not come as a surprise after all: “I got the results today. And I have prostate cancer. I mean... the doctor said it’s still early stage, and I shouldn’t worry too much, but I still just couldn’t wait until you’re home. Hope... hope I’m not disturbing you.” This felt weird. Ms. Vanderhoek, a data scientist at MAASTRO, is confronted day to day with these diagnoses. As the main driving force behind the development of the PROSPeCT tool, she is well aware of prostate cancer and its implications, but the datasets she works with, those are... strangers, really. Harsh to say, but this immense data just doesn't feel like much.

When she got home later, she had a strange feeling, which at first she could not clearly identify. Then, when warming up the leftover food from yesterday in her microwave, it suddenly struck her – it was determination. Dedication to the work she is doing. Maud felt the strong urge in herself to continue developing this decision-aid, this surprising technology that might revolutionize healthcare. AI models offer a rich potential for the future, and data scientists like her are convinced of its possibilities in healthcare. Like for her father, who recently got diagnosed with prostate cancer, PROSPeCT offers a reliable and trustworthy opportunity to get individualized recommendations on treatment options. She is very sure that decision aids can give patients more freedom in their treatment choices, more independence from doctor’s recommendations, and higher satisfaction with the process and outcome of treatment.

This feeling should, however, change throughout the upcoming days. First, it was replaced by fear. She took her car, drove a couple of hours to see her dad in Groningen, and she was afraid of him. He lived by himself, her mother already passed away. How was he going to handle the upcoming months and the treatment?

When Maud arrived at his place, she was not aware that her fear would soon be overflowed by frustration. She sat down with her father, after making a coffee, and he started explaining what the doctor told him. While listening, she saw a scrunched-up piece of paper on the table, and when unfolding, she realized it was a QR-code to scan. An odd feeling of pride rushed through her when she realized the code would lead to the former model of PROSPeCT, which would make it easier for her dad to inform himself. She looked up, and her father, who had until then

stopped talking, opened his mouth again: “Yeah, so this is what Mr. Jansen gave me when I left. He said if I have a phone I could log in there and read about the cancer if I want. But really, why do we need phones even in the hospital now? I just want to ask Mr. Jansen next time what he thinks, he looks reliable to me, a good guy.”

Maud was stunned by his bluntness, and a wave of anger rushed through her. All the benefits she saw in PROSPeCT, all the trust she put into her work, were wiped away with just a few words. But she was not surprised: hesitation is something she has to face every day. Doctors in MAASTRO and elsewhere are still hesitant towards the use of the decision aid. They have so little time for their patients already and needing to explain how PROSPeCT works takes away these precious minutes needed to discuss the diagnosis in detail. And they are convinced by what they’re doing – why use an additional tool if doctors could also themselves explain the available options against prostate cancer? And her father, sipping his coffee, provided the perfect counterpart. He doesn’t really know his way around the phone, rarely uses it. He has always been ignorant about technology, while Maud was from a young age so sure that developing innovative solutions for the future is what she wants to do in her career. Trust is a big issue, still. Patients are hesitant to take up responsibility and inform themselves. She understands this – it’s scary. Having cancer is scary, and having to know enough to make a treatment decision without a white angel sitting next to you is a lot of pressure. One that most patients like to roll off their shoulders – even if it’s their bodies being the ones needing the treatment. Maud sighs, and her brain rushes through all the possibilities of how to react to her father’s statement. Should she accept his hesitation? She doesn’t want to force him to do something he does not feel comfortable about. Should she start arguing, as she did so many times with other doctors in the hospital? Should she explain the benefits of the AI model?”

Introducing AI in hospitals opens up several ethical questions. Especially Black Box AI has multiple layers of input-output connections which even data scientists do not always fully understand. This makes it even more difficult for doctors to understand how the AI arrives at its decisions and where errors might occur. The big ethical question is now whether this knowledge deficit can have an impact on the quality of medical care? As an example, I would like to pinpoint one possible mistake that is already identified in AI models being in use in the healthcare sector, the one of bias (Anderson & Anderson, 2019). Having talked to data scientist Rianne Fijten, it is clear that AI developers are and should be careful to avoid biases in the datasets. Rianne told us that many datasets are developed on a white, Caucasian population, which might lead to a situation where AI models are less applicable to other demographic groups like women or people of color.

The problematic ethical situation is also displayed by the hesitance of many doctors regarding the use of AI. Luxton (2019) writes that AI models in hospitals are there to give doctors greater confidence in their diagnoses and the decisions they have to take for their patients. However, the opposite seems to happen: Rianne Fijten clearly admits that, according to her personal experience, the majority of physicians are skeptical about AI. According to her, they often doubt the added value of AI and would prefer to continue their way of working.

The presented vignette also touches upon the question of responsibility that needs to be further elaborated upon. This debate revolves around concerns of decision-making and the resulting responsibility. Patients might be hesitant to make decisions by themselves, afraid that even having used a decision-aid, doctors are more trustworthy and knowledgeable. Informed consent is a relevant issue in making treatment decisions, meaning that patients generally need to be informed about the purpose, potential benefits, and risks as well as alternatives to the treatment (Schiff & Borenstein, 2019). Including AI complicates this process. As the vignette shows, the use of external decision aids leads to confusion of the patients who are often already overwhelmed by a heavy diagnosis such as prostate cancer. The use of a decision-aid forces them to read up on even more documents that are not directly related to their treatment. As has already been said, also doctors are required to have sufficient knowledge about the AI in use. They are responsible to educate themselves on the AI technologies, which poses a major challenge to already understaffed hospitals and doctors that have to handle a large number of patients.

But responsibility also refers to a second issue, being the big question of who is responsible for mistakes the AI might and will undergo (Luxton, 2019). Since there is only little regulation on AI technology, some sort of “blame-shifting” starts, where no one feels responsible for errors occurring in the use of AI. This gets increasingly difficult when a Black Box AI is concerned, where it is impossible for both data scientists and doctors to clearly understand how the AI arrives at its decisions (Anderson & Anderson, 2019).

There is a clear need to open up an ethical debate about responsibility (Luxton, 2019). There is a whole set of stakeholders involved and responsibility is spread over all levels that Schiff & Borenstein (2019) layout in detail: First and foremost, we need to mention data scientists as presented in the vignette. Coders and designers need to document what they create and be able to explain how the technology works. With the introduction of Black Box AI, this naturally is more difficult. Secondly, with the commercialization of AI, we need to hand over responsibilities to medical device companies. They need to research and keep track of the types

of errors that can happen. They need to stay in touch with hospitals using a specific AI and update the tool if necessary. Medical device companies shall track side effects and typical errors, their likelihood, and severity and how they are spread across demographic subgroups and patient histories. When selling AI tools, they need to create and hand out clear instructions on the use and possibly give additional training to doctors.

Related to this is also the responsibility of hospitals themselves. They need to monitor the proper functioning of the AI protocol use and practices and communicate that to the medical device companies. Certainly, physicians and other healthcare professionals need to be taken into consideration since they are responsible for the treatment recommendations they give to their patients (Schiff & Borenstein, 2019). In the long run, there will be a need to include AI education already to medical students at the university level. This poses a major challenge since medical students are already going through a long and extensive training process. There is also a need for politics to step up on the issue, design proper legislation, and allocate responsibilities. Health insurers as well need to cover AI use for their patients in the future.

Ways Forward for Artificial Intelligence

Hitherto, experimental writing has been a rather uncommon approach to academic research, yet we chose the form of vignettes to voice our concerns related to AI in hospitals. Vignettes are a piece of writing that enables the researcher to convey experiences of reality or the research process to the reader. They help illustrate the complexity and reality of the lived experience of the actual people that deal with the research subject – the thing that actually matters. Based on our experiences, we would like to make a case for vignettes. Vignettes are very useful in bringing the reader closer to the object of research. They commonly have a double function: that of the ‘evidence’ for a claim, and being a container of complex meanings that must be mined and interpreted.

Vignettes are marked text integrated into another text and only in the vignette, we allow ourselves to be vivid. We think that vignettes are being treated unjustly. Vignettes are often essential to the point made in papers, but they are treated as if they were an optional ornament. They are often followed by a section that insists on the primacy of theory. It seems the papers and their authors are insecure about including stories with less theory – vignettes are stories that feel guilty about being a story. This already shows in the word ‘vignette’ – which is a diminutive word – conveying petiteness.

Yet, we think story-telling has its place in academic research. The development of AI technologies opens up a whole set of ethical questions. These are difficult to address with traditional research methods since there is a need to focus not only on the technologies but also on who is standing behind - in this case, doctors, patients, data scientists. Vignettes are a valid and in our view necessary tool in order to understand and unpack the emotions, thoughts, and ideas of both users and creators. Cancer, and especially prostate cancer, is a sensitive issue that heavily impacts the health and life satisfaction of those diagnosed. Survival chances are usually high for prostate cancer, but side effects may harm the daily lives of many patients. Understanding their perspective and their emotions related to diagnosis and treatment is important in order to develop better decision aids that are useful to patients. Vignettes are a way to “unpack the client”, as Berry et al. (2010) formulate it. Patients are often a black box to researchers, it is difficult to understand their thoughts and their stance towards innovations in healthcare. There is a clear need to take into account the thoughts of patients about the development of AI.

Additionally, it is not only complex to understand the patient’s perspective, but also the AI technology itself. There is no clear definition of AI, thus also here an exploratory approach is needed in order to better grasp the concept of AI. Our vignettes help to understand the interactions happening between AI and patients, which actually define the AI in itself. There is no stringent definition, but rather a need to remain open to what AI means for different stakeholders and actors in the whole process.

With this case in point, our small research team ends its journey through the world of AI. However, we are certain that AI has a long and exciting road ahead of it. Whether such new technologies will ‘make it’ in the healthcare sector, adding true added value to medical care and treatment in the future remains an open question for which simply not many answers yet exist. Despite these open questions, we have learned that the future application of AI requires that we acknowledge and further explore some of the challenges that we have outlined above. Who is responsible for the decisions made by BlackBox AI? How much legal regulation is needed to make AIs safe for their use in healthcare? How can we make sure that clinicians and patients accept AI in their treatment routines? Certainly, much more research is needed in the future to address these issues and provide a better understanding of the field, forwarding a regulatory and a political framework that provides enough room for experimentation and new directions while keeping them in check (and users safe).

Until then, we have learned that, where we want to better understand the interaction between humans and new technologies, we simply need better and more experimental research tools to address how humans feel, think and interact with new technologies. This also means to let our research culture evolve ‘as we go’ and as new research topics open up to us. We believe that, in the end, this could be an important next step in improving the integration of new technologies in society: acknowledging that it’s not the patient, the doctor, and the data scientist who interact with the decision-aid, but Thijs, Dr. Janssen and Maud.

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