Designing a data-driven Decision Support Tool (DST) for Oncology (Melanoma)

SPECULATING DATA-DRIVEN SHARED DECISION MAKING IN THE FUTURE OF HEALTHCARE

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Speculating Data-Driven Shared Decision Making in The Future of Healthcare

Designing a data-driven Decision Support Tool (DST) for Oncology (Melanoma)

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4D PICTURE

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FOREWORD

From the very outset of my academic journey, the choice to embark on the path of pursuing a Master's degree in Design for Interaction at IDE was not just a decision, but rather a conviction rooted in the program's extraordinary approach to design from a multidisciplinary standpoint. Among the myriad institutions dedicated to design education, what truly distinguished this one for me was the presence of the Medesign track.

In my view, the essence of genuine design reveals itself when it becomes a means to address human needs, enrich lives, and cultivate a sense of desirability. Guided by this foundational belief, the Medesign track resonated profoundly with me as the perfect avenue to explore. My ambition was clear: to leverage design as a force for enhancing human well-being, to explore the intricate tapestry of human interactions, and to harmonize with the burgeoning currents of technology and data-driven systems.

Thus, the moment I encountered Judith and her captivating proposition for a graduation project within the context of 4D picture technology, I was awakened to an immense surge of inspiration. Indifference was simply not an option; an unyielding passion compelled me to actively pursue the opportunity to embark on this project.

Life's trials had not left me untouched; grappling with the challenges posed by cancer and enduring the loss of two beloved uncles during my childhood had imprinted upon me the profound repercussions of adversity on individuals and their families. This personal connection became the wellspring of my resolute determination to contribute, in any conceivable capacity, to easing the burdens cast by this formidable adversary.

As you delve into the pages that follow, I invite you to join me on this expedition—an expedition fuelled by the confluence of academic pursuit, personal conviction, and the relentless pursuit of a better, more compassionate design.

Executive summary

Navigating consequential decisions is a difficult task in and of itself, especially when they have a significant impact on one's life. This is especially true in the complex world of healthcare, where the importance of choices is magnified. The complexities of these issues can make it difficult for patients and their loved ones to effectively address them while dealing with increased stress and uncertainty. Medical professionals are also under immense pressure to ensure the well-being of their patients.

In such scenarios, the indispensable role of decision support tools (DSTs) becomes apparent. These invaluable resources aid both patients and healthcare professionals in selecting the optimal treatment option by carefully considering the risks and benefits involved. DSTs play a vital role in empowering individuals to make well-informed decisions by providing relevant information and facilitating comprehensive analysis. These tools enable the evaluation of various treatment options or potential outcomes. Some DSTs are data-driven, relying on prognostic algorithms. By utilizing analytical methods and algorithms on clinical data, they can offer predictions on survival rates, chances of recurrence, and estimated quality of life, particularly in diseases such as cancer.

Although data scientists have worked consistently to develop algorithms and guarantee the validity of the data used, there has been a noticeable lack of focus on defining the qualities of appropriate interaction with decision support tools. Numerous critical aspects remain unclear, such as identifying the appropriate qualities of interaction with a DST, determining the optimal delivery method for these tools, determining the optimal point in the care path to introduce them, specifying the relevant data to be provided to the DST, and deciding what information should be delivered to empower patients in their decision-making process. Furthermore, the integration and practical implementation of DSTs within the time limitations and complex dynamics of the medical context have been widely disregarded.

In this graduation project, we adopt a speculative design perspective to explore the future of data-driven healthcare. We aim to imagine how DSTs can become meaningful and sustainable components of the care path. Through a process of futurology, we envision an alternative future (or present) to contribute to the doctor and patient (as human actors) seeing the DST (the non-human actor) literally as partners in making decisions.

Project Overview

First Speculation

Speculative Enactment

Second Speculation

Co-speculation

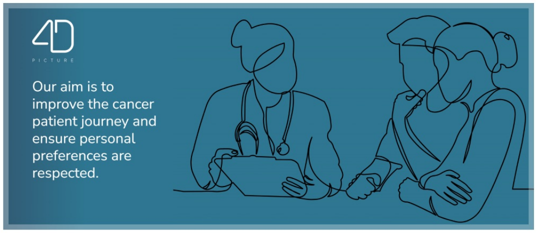
1. Introduction

Cancer presents a wide range of complexities for patients, encompassing various aspects of their lives. Understanding the nature of their diagnosis can be overwhelming, as patients must grapple with unfamiliar medical terminology (Lerner et al., 2000) and intricate details about their specific type and stage of cancer (Costas-Muniz et al., 2013).
Treatment options further add to the complexities (Doak et al., 1998), with patients needing to navigate through a maze of choices, weighing the potential benefits, risks, and side effects associated with each option. Financial concerns also arise, as medical expenses, insurance coverage, and the potential impact on employment and income add additional layers of stress (Park et al., 2013) (Carlsen et al., 2008). Moreover, the emotional and psychological toll of cancer cannot be overlooked, as patients experience a rollercoaster of emotions, ranging from fear and anxiety to hope and resilience (Herschbach et al., 2004).

From the first shock of diagnosis to the struggles suffered during treatments, the psychological repercussions, such as increased stress, anxiety, and dread, are frequently felt. Physical discomfort, exhaustion, and the side effects of therapy all serve to exacerbate the emotional suffering (de Haes et al., 1990). Cancer also has an impact on the mental and emotional well-being of the family members (Lewis, 1986) and caregivers (Johansen et al., 2018) who give unflagging support, in addition to the people who are directly affected by the disease. The complex and varied properties of cancer, combined with its diverse manifestations among individuals, pose a significant challenge for oncologists striving to develop efficient treatment approaches. Likewise, for patients, understanding the most suitable treatment option can be a daunting task. Each patient's cancer journey is unique (Jacobs et al., 2016), requiring personalized approaches that consider factors such as the type and stage of cancer, genetic variations, and individual responses to treatments (American cancer society, 2021).
Simultaneously, patients themselves are confronted with the overwhelming task of comprehending the complex landscape of available treatment options and making informed decisions about their own care. Recognizing the significance of patient preferences in the treatment process, it becomes crucial to involve them as active participants in discussions about their options, allowing their values, goals, and quality of life considerations to shape the treatment plan (Veenstra & Hawley, 2020) (Chewning et al., 2012).
In this ever-evolving field, the collaboration between oncologists and patients becomes vital as they strive to navigate through the intricacies of cancer, considering both medical expertise and patient-centred care to discover the most suitable treatment approach for everyone.

Scope

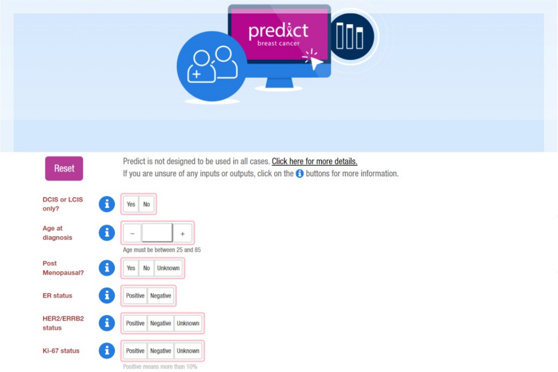
The **4D PICTURE project**, funded by the European Horizon program(Cordis, 2022), aims to improve cancer treatment decisions using prognostic algorithms and personalized care. By redesigning care paths for specific types of cancer like melanoma, prostate cancer, and breast cancer, the project will develop innovative models that predict treatment outcomes based on patient experiences and preferences. These models, driven by data, have the potential to empower patients, improve health outcomes, and promote fairness in healthcare. Ultimately, the goal of the 4D PICTURE project is to revolutionize cancer treatment decision-making and provide personalized and effective care to individuals with cancer (4D Picture, n.d.).



Funded by
the European Union

Figure 1: 4D picture project - https://4dpicture.eu/

During the initial discussions with one of the project's PIs, Dr. Judith Rietjens for the 4D pictures, it was highlighted that there are currently online resources such as PREDICT capable of predicting how various treatments for early invasive breast cancer could enhance survival rates. However, it was the belief that these tools fall short, as they do not encompass patients' preferences and lack a design conducive to seamless integration into the care pathway.



Predict is not designed to be used in all cases. Click here for more details.
If you are unsure of any inputs or outputs, click on the ℹ buttons for more information.

DCIS or LCIS only? ℹ Yes No
Age at diagnosis ℹ – +
Age must be between 25 and 85
Post Menopausal? ℹ Yes No Unknown
ER status ℹ Positive Negative
HER2/ERRB2 status ℹ Positive Negative Unknown
Ki-67 status ℹ Positive Negative Unknown
Positive means more than 10%

Figure2 : PREDICT - (http://breast.predict.nhs.uk)

In this thesis project, it is decided to prioritize **Melanoma** as the primary focus among the three cancers for which the 4D PICTURE project aims to develop data-driven prognostic models. This is because melanoma and skin caner has involves individuals across different ages and genders, making it possible to explore a wider scope of people and interactions. In fact, exploring melanoma, can give us valuable insights that can potentially benefit patients with the other two types of cancer included in the project.

Melanoma is a type of skin cancer that arises from the pigment-producing cells called melanocytes. Unlike other types of skin cancer, melanoma has a propensity to rapidly invade nearby tissues and spread to distant organs, making early detection crucial for favourable outcomes (Melanoma Treatment, 2023). However, recognizing the early signs of melanoma can be challenging, as it can mimic benign moles or exhibit subtle changes that go unnoticed (Jones et al., 2019). This diagnostic difficulty often leads to delayed detection, allowing the disease to advance to more advanced stages, where treatment becomes more complex and less effective.

The risk factors for developing melanoma include: a personal history of melanoma • a family history of melanoma • increased numbers of moles on a total body count (> 100 of more than 2 mm) • solarium use • a fair complexion (including fair skin with poor tanning ability, light or red-coloured hair and blue or green eyes) • a history of blistering sunburn • high levels of intermittent sun exposure (e.g. during outdoor recreation or sunny holidays) • immune suppression and/or transplant recipients • increasing age. In Netherlands, Melanoma cases are rising quickly even though there have been repeated cautions about the risks of sun exposure.

60,267 Dutch patients received cutaneous melanoma diagnoses between 2003 and 2018.For men, the incidence rate rose from 10.9 to 23.9, while for women, it rose from 15.6 to 27.3 (Leeneman et al., 2021).

The care path of Melanoma in the Netherlands is explored in an interview with a general practitioner: A general practitioner should instruct patients who have a higher risk of developing melanoma in the initial step. Where there is a high level of suspicion, the practitioner should refer the patient to a dermatologist for an excisional biopsy. Within Biopsy, to give the pathologist the most tissue possible and enable the study of the tumour architecture, the entire lesion should typically be completely excised (with a 2 mm margin). Within two weeks of the initial consultation with the general practitioner, a biopsy or excision should be performed if melanoma is suspected, and the patient should be informed of the results within a week of the biopsy. After being diagnosed with Melanoma following surgical excision, staging is a crucial component of treatment planning and should be accurately recorded in the patient's medical file. In the **primary care** environment, a dermatologist or general practitioner with the necessary education and experience can do surgery under local anaesthesia with direct primary closure for excision

Figure3 : checking the mole - (https://www.news-medical.net)

biopsy and chosen re-excision for in situ and early-stage melanomas. Surgery should be performed in a primary care setting no later than two weeks after the decision to perform it. After the surgery, there is a need for follow-up care to reduce the chance of reoccurrence. Even the most effective first treatment cannot completely eradicate some tumours. However, depending on the clinical condition, managing disease and disease-related symptoms is frequently doable. Medical oncologists are likely to send individuals with sentinel node-detected metastatic melanoma to discuss the use of **adjuvant systemic treatment**. Within 12 weeks of definitive surgery, adjuvant therapy should be started; and as soon as stage IV disease is clinically relevant, treatment should start, ideally within 4 weeks.

Adjuvant therapy in melanoma refers to additional treatment given after the primary treatment (usually surgery) to help lower the risk of the cancer returning or spreading. In the case of melanoma, adjuvant therapy typically follows the surgical removal of the primary tumour and nearby lymph nodes. The primary goal of adjuvant therapy is to target any cancer cells that might still be present in the body after surgery, but are not detectable by imaging or other methods. These cells could potentially grow and lead to a recurrence of the melanoma. Adjuvant therapy aims to reduce this risk by using treatments such as chemotherapy, targeted therapy, immunotherapy, or a combination of these approaches. This phase usually comes with much more complexities and clinicians struggle a lot on finding the best suitable treatment option.

making a decision about adjuvant therapy for melanoma is a complex process that **should involve a collaborative effort** between the patient and their medical team. Since every individual's situation and preferences are unique, it's crucial for patients to have thorough discussions with their oncologists and healthcare providers before deciding on the best course of action.

The decision-making process for the treatment of life-threatening diseases, such as adjuvant treatment in melanoma care, holds great importance to patients due to the high uncertainty involved and the various treatment options available, making it suitable for the application of Shared Decision Making (SDM) principles (Albrecht et al., 2014).

Shared decision-making (SDM) plays a crucial role in the management of melanoma, recognizing the importance of engaging both patients and clinicians in the treatment decision process. Melanoma treatment decisions are multifaceted, considering various factors such as disease stage, treatment options, potential risks, and individual patient preferences. By actively involving patients in the decision-making process, healthcare professionals can empower them to make informed choices that align with their values, goals, and personal circumstances. Patients gain a deeper understanding of their diagnosis, prognosis, and treatment options, enabling them to actively participate in discussions about their care (Mott et al., 2023). This collaborative approach fosters a sense of ownership and partnership between patients and clinicians, fostering trust and improving patient satisfaction (Krist et al., 2017). Moreover, shared decision-making ensures that treatment plans are tailored to each patient's unique needs and wants considering their preferences, lifestyle, and overall well-being. Embracing shared decision-making in melanoma care not only improves patient satisfaction but also enhances the overall quality of treatment outcomes. By considering patients' preferences, values, and individual circumstances, treatment plans can be tailored to optimize the balance between therapeutic efficacy and minimizing potential adverse effects/ The key characteristics of shared decision-making are suggested to include:

The involvement of **at least two participants**, namely the physician and the patient

The **sharing of information** by both parties;

The steps taken by both parties to build a **consensus about the preferred treatment;**

The **reaching of an agreement** on the treatment to be implemented

(Charles et al., 1997)

However, implementing shared decision-making in the context of melanoma care (and cancer in general) can be challenging. Several barriers can impede the realization of effective shared decision-making processes. One significant challenge is the asymmetry of medical knowledge between clinicians and patients (Buyens et al., 2023). Complex medical information and terminology may be difficult for patients to comprehend fully, hindering their ability to actively engage in decision-making discussions. Time constraints during clinical visits can also limit the opportunity for in-depth conversations and shared decision-making (Légaré et al., 2008 ; Elwyn et al., 2012). Additionally, patients' emotional and psychological states, such as fear, anxiety, or feelings of vulnerability, can impact their capacity to participate fully in the decision-making process (Pel-Littel et al., 2021).

Addressing these challenges necessitates a collective Endeavor involving healthcare providers, patients, and healthcare systems. It requires the cultivation of effective communication channels, the enhancement of patient education, and the provision of decision support tools. Among the various strategies to facilitate communication, the utilization of **Decision Support Tools (DSTs)** holds significant promise. These tools serve as integral components of the shared decision-making process, promoting active engagement from patients in healthcare decisions ("An Introduction to Patient Decision Aids," 2013). They prove particularly valuable in a wide range of common healthcare scenarios. By employing decision support tools, healthcare stakeholders can empower patients, equip them with relevant information, and facilitate their involvement in the decision-making process. Such tools serve as invaluable resources, aiding individuals in understanding their options, weighing the associated benefits and risks, and ultimately making informed choices that align with their preferences and values (National Health Service, n.d.)

Decision support tools can be **data-driven**, and provide evidence-based information, data analysis, and interactive features to support the decision-making process (Capobianco, 2019).

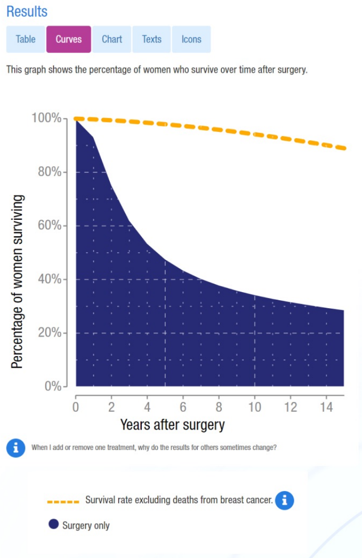
As already talked about, an illustrative instance is the development of **PREDICT**, a tool designed to assess the potential survival advantages of various adjuvant therapies for breast cancer following surgery. This tool generates personalized estimations by considering specific inputs related to the patient and their cancer characteristics (Farmer et al., 2020).

The **Prognosis algorithms** implemented in such tools can enhance SDM by providing objective data-driven insights into the potential risks and benefits associated with different treatment approaches. These models consider factors such as tumour characteristics, stage, biomarker status, and patient demographics to generate individualized predictions (Traeger et al., 2017). Patients can then use this information as a foundation for understanding their prognosis and weighing the potential benefits and drawbacks of various treatment options.

Recent advancements in data collection, analysis, and computational capabilities have revolutionized the development of prognosis models, enabling more accurate and sophisticated predictions in healthcare, including melanoma prognosis. The availability of large-scale datasets, including clinical records, genetic profiles, treatment outcomes, and long-term follow-up data, has provided valuable resources for training and refining prognosis models

The rapid advancements in the field of data are paving the way for a future where we can envision an abundance of decision support tools in the field of oncology.

This transformative shift in healthcare will be driven by data, as patients and clinicians will be equipped with a myriad of data-driven tools. As we embrace this era of data-driven healthcare, it becomes paramount to ensure that the design, implementation, and delivery of these tools are thoughtful and considerate of the human experience.



This graph shows the percentage of women who survive over time after surgery.

When I add or remove one treatment, why do the results for others sometimes change?

Figure4 : outcomes of PREDICT platform - (http://breast.predict.nhs.uk)

Chapter 2

Diving into the project

What are the present dynamics involved in decision-making regarding Melanoma? Who are the key stakeholders, and what are their capabilities, concerns, and practices? How is shared decision-making currently being facilitated? What forms of support are available to aid individuals in their decision-making process? Our objective is to scrutinize the existing interactions comprehensively and utilize that analysis to establish a design goal and create an initial framework for innovative interactions.

Problem Statement

Currently, much attention has been directed towards the technical aspects of decision support technologies (DSTs), such as developing and enhancing prognostic models and algorithms. However, the importance of interaction design and adhering to the principles of Human-Cantered Design has received scant consideration in these endeavours. Existing decision-support tools for care paths have proven largely ineffective in clinical practice due to their failure to incorporate interaction design considerations into their design (Yang et al., 2015). Insufficient attention has been given to developing a platform that successfully delivers desired outcomes while taking into account the interactions that occur within the context of use.

Although ensuring statistical validation is crucial for the algorithms, but it is equally important to prioritize user-friendliness, reliability, and the generation of outputs that are valuable, trustable and comprehensible to users. A decision support tool holds the potential for aiding in treatment decisions by offering accurate predictions. However, it also carries the risk of causing considerable emotional stress for the patient if it presents a low survival chance (Basile et al., 2023). This is especially poignant in the case of diseases such as cancer, where any discouraging signal can have a profound impact on the patient's mental state.

We should explore where and when people on a care path require support from a Decision Support Tool (DST). It should be investigated how such a tool should be offered and who should interact with it. The nature of the interaction should also be examined, including how people can share their data with the DST and receive outcomes from it. It is important to understand what people truly need from this tool and what are the desired interactions. We must explore the appropriate interactive medium to reflect on the outcomes. We need to determine the properties of the behaviours of a an accountable DST.

Focused on Melanoma, our research objective is to think about proper ways of designing and implementing data-driven DSTs that provide both melanoma patients and clinicians (dermatologists, oncologists, nurses...) with comprehensive information they need to act upon. The aim is to:

- enhance patients understanding of melanoma, including its progression and the available treatment options
- enhance the communication flow in a way that clinicians become more aware of patients preferences

To effectively achieve this goal, it is crucial to develop a deep understanding of the current interactions and context. We must find a good understanding of the role of different stakeholders, the context where they interact with and then try to develop and test these interactions iteratively and refine them into a final concept/framework which we can later evaluate in the context.

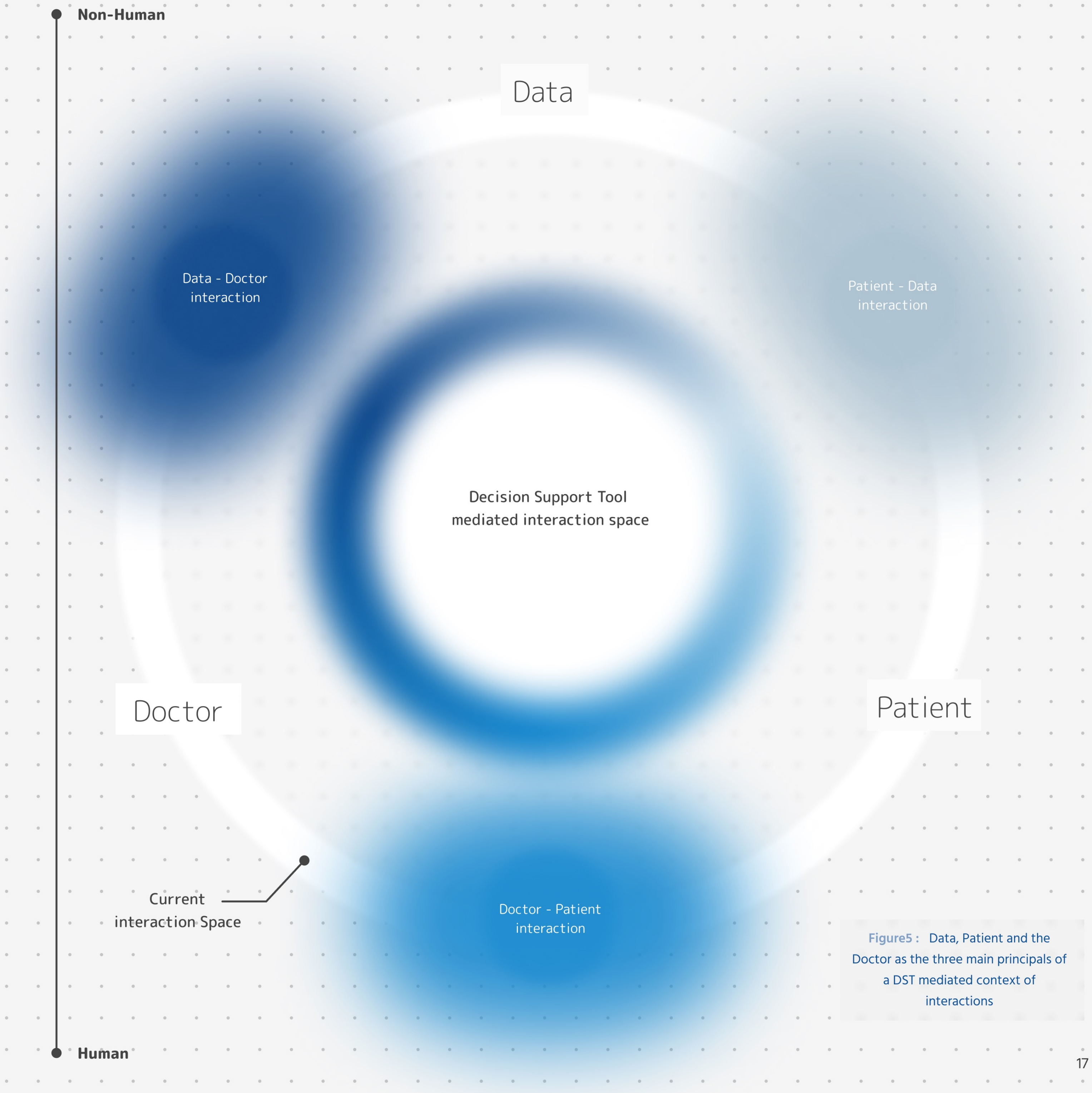


Figure5 : Data, Patient and the Doctor as the three main principals of a DST mediated context of interactions

Patient Doctor interaction Space

Patient–physician interaction space in the context of cancer care has received significant attention because of its fundamental connection to respecting patient autonomy (Adamson et al., 2018). A cancer diagnosis can be a life-altering event that brings about fear, uncertainty, and emotional turmoil for both patients and their significant others. In this context, effective communication and empathy between patients and their healthcare providers become paramount. There are some major aspects to be considered when exploring this interaction space:

- **Trust and Confidentiality:**
  Trust is at the heart of the doctor-patient interaction. Patient trust in physicians is a complex concept with numerous interpretations across disciplines. It can be defined as a set of beliefs or expectations about a care provider's performance, while it can also refer to an emotional characteristic in which patients have a reassuring sense of faith or reliance on their care provider's intentions (Krot & Rudawska, 2016). When patients trust their doctors, they are more likely to share important information, allowing doctors to gain a comprehensive understanding of their medical history, lifestyle, and concerns (Asan et al., 2021).

- **Empathy and Emotional Support:**
  It is believed that the development of a therapeutic bond depends on a doctor's capacity to build an empathic understanding of their patient's circumstances (Eby, 2018). Medical conditions, such as melanoma, can evoke strong emotional responses in patients. Doctors who show genuine empathy and understanding create a safe space for patients to express their fears, and concerns openly (Moudatsou et al., 2020). This emotional support is essential in addressing the psychological impact of the diagnosis, allowing patients to navigate the challenges with a sense of reassurance.

- **Knowledge Exchange:**
  The interaction space acts as a bridge for the exchange of knowledge and information. Doctors impart medical expertise, explaining complex medical concepts in a way that patients can comprehend. Patients, in turn, share their symptoms, concerns and preferences, providing critical insights that aid in the diagnostic process. This exchange empowers patients to be informed of the treatment options, and doctors being aware of patient’s preferences , & in result a sense of collaboration between the doctor and the patient will be made (Parker, 2006).

But what preferences mean in decision making?

Preferences

Every individual has some preferences. Preferences are formed by personal experiences, cultural background, values, and a variety of other factors. Food, music, hobbies, movies, books, fashion, and other interests are examples of preferences.

Recognizing that different individuals have varying preferences allows for a more inclusive decision-making process. It enables us to consider multiple perspectives, find common ground, and reach decisions that accommodate the preferences of all involved parties. Moreover, being aware of the influence of preferences on decision-making can help us navigate conflicts and disagreements. Understanding and respecting these differences can lead to improved communication, empathy, and appreciation for different points of view.

Preferences In medical context

In the medical context as well, Patients bring their distinct set of preferences and values to their medical experiences. The field of medicine is deeply intertwined with human preferences and choices. Patients often have personal preferences when it comes to their healthcare decisions, and these preferences can vary greatly from person to person.

However, there is a lack of consistent definition for the term "patient preferences," as it is used with both implied and explicit meanings. Despite the varying definitions, there is a growing consensus that patient preferences encompass statements made by them regarding their relative desirability for a range of health experiences, treatment options, or health conditions (Brennan & Strombom, 1998). In a more simple statement, preferences are what patients want from their healthcare (Street et al., 2012). Understanding the various dimensions and attributes of patient preferences is more crucial than merely focusing on their definition.

Patients facing complicated cases like cancer often find themselves in unfamiliar and emotionally challenging situations. As Street, Elwyn, and Epstein state, their desires regarding their care can become conflicted, making it difficult to express clear preferences. For instance, patients may struggle between wanting "to do everything possible" to fight the disease or prioritizing a more comfortable life with reduced treatment intensity. Moreover, preferences may involve a trade-off between maximizing treatment effectiveness and minimizing side effects.

Doctor-Data interaction Space

Data plays a fundamental role in informing medical decisions and ensuring evidence-based care. The interaction between doctors and data is essential in the following ways:

- **Medical Records and test result of the patient:** The interaction between doctors and patient data, particularly medical records and test results, forms a pivotal foundation for informed decision-making in healthcare. Test classic results further enhance this process by offering quantitative measurements that guide medical decisions. Whether it's blood tests, imaging studies, or genetic analyses, these results provide objective information about a patient's physiological state.

- **The Electronic health records (EHRs)** have transformed the traditional paper-based documentation system, providing doctors with a centralized repository of patients' health information. These digital records encompass vital details such as medical history, diagnoses, treatments, medications, and test results (Ash, 2004). By having this wealth of data readily available, doctors can make informed decisions more efficiently, leading to improved patient outcomes. Maintaining accurate and up-to-date medical records also enables seamless care coordination among healthcare providers. Whether patients seek medical attention from different specialists or visit various healthcare facilities, the shared access to EHRs ensures that relevant information is readily available to all authorized practitioners (Hsiao et al., 2011). This collaboration streamlines patient care, reduces redundancies, and enhances the overall efficiency of the healthcare system.

- **Evidence based medical & clinical data:** The ability of doctors to analyze and interpret data is pivotal in providing evidence-based care. Medical professionals continuously rely on research studies, clinical trials, and medical literature to stay informed about advancements in medicine. By critically evaluating and synthesizing this vast pool of knowledge, doctors can integrate the latest evidence into their clinical decision-making process (Glasziou et al., 2008). Evidence-based practices have revolutionized healthcare delivery by shifting the focus from tradition and intuition to objective data-driven approaches (Sackett et al., 1996).

Through rigorous data analysis, doctors can identify the most effective treatment modalities, avoid unnecessary procedures, and minimize potential risks. This data-centric approach not only enhances patient outcomes but also contributes to cost-effective healthcare practices.

Doctors can directly go through these type of data on their own and make decisions counting on their own experience. However, for complex cases like cancers, Decision support tools, Clinical prediction models, or other types of prognostic tools have been developed to address more complex cases. These systems analyze patient data in real-time and offer valuable insights, suggestions, and alerts to aid in diagnosis and treatment decisions (Sittig & Singh, 2010). Decision support systems are built upon algorithms that consider patient-specific data, medical history, and current clinical guidelines to provide personalized recommendations. The integration of decision support systems in clinical workflows has shown promising results in reducing medical errors and improving diagnostic accuracy (Bright et al., 2012). By assisting doctors in identifying potential issues and providing evidence-based guidance, these systems act as valuable tools to enhance the overall quality of care.

Patient-Data interaction Space

Empowering patients with access to their health data and encouraging active engagement in their own healthcare journey has emerged as a transformative approach in modern healthcare. The interaction between patients and data encompasses various aspects, providing patients with the tools to actively manage their health, participate in shared decision-making, and foster collaborative relationships with healthcare professionals.

- **Personal Health Records (PHRs):**
  Personal Health Records (PHRs) have become instrumental in placing patients at the center of their care. Patients maintain and manage their PHRs, which include essential information such as medical history, allergies, medications, immunization records, and test results (Tang et al., 2006). The accessibility of PHRs empowers patients to monitor their health status, track changes over time, and take proactive measures to improve their well-being. PHRs facilitate informed discussions with healthcare professionals, as patients can share accurate and up-to-date health information during medical appointments (Prashad, 2017). This collaborative

exchange enables doctors to gain a comprehensive understanding of the patient's health status, preferences, and goals, leading to more personalized and patient-centered care plans.

- **Health app and devices:**
  The advent of health apps and wearable devices has revolutionized how patients interact with their health data on a daily basis. Patients can now monitor various health metrics, such as heart rate, physical activity, sleep patterns, and blood glucose levels, using their smartphones and wearable devices (Jembai et al., 2022). These data points offer patients real-time insights into their health status, promoting self-awareness and motivation for healthier lifestyle choices. Health apps and devices also promote patient engagement by encouraging individuals to take an active role in managing chronic conditions and preventive care (Higgins, 2016). Many apps offer personalized health recommendations and educational resources, empowering patients to make informed decisions about their health.

- **Patient portals**
  Patient portals provided by healthcare providers serve as secure gateways for patients to access their medical records and interact with their healthcare team. These portals offer a wide range of functionalities, including:
  - Access to Medical Records: Patients can view their laboratory test results, imaging reports, and treatment summaries, promoting transparency and patient involvement in their care.
  - Communication with Healthcare Team: Patient portals facilitate secure messaging between patients and healthcare professionals, enabling patients to seek clarifications, ask questions, and discuss health concerns remotely (Ricciardi et al., 2013).
  - Appointment Management: Patients can schedule and manage appointments, leading to greater convenience and reducing wait times.

Patient portals foster patient-provider communication, enhancing care coordination, and ultimately leading to improved patient satisfaction (Irizarry et al., 2015).

Another aspect of the problem

In the examination of the existing literature, and upon a in-depth investigation of current usage of data-driven decision support tools in the field of oncology, it becomes apparent that the primary utilization of these tools is by medical practitioners rather than the patients themselves. Patients usually interact only with online platforms where possible outcomes of treatments are displayed.

From curious observation, it is rather peculiar that when one conducts an online search for "data-driven decision support tools" in the context of oncology, a large proportion of the results returned direct the searcher to software or resources that predominantly facilitate enhanced diagnosis and treatment planning by clinicians. Interestingly, the involvement of the patient in this process conspicuously lacks adequate representation. There appears to be a distinct neglect of patient input in the operation of these tools.

However, if one modifies the search parameters and instead investigates "decision support tools" or "**decision aids**", a noticeable shift occurs. These searches produce more patient-focused results, usually presenting a variety of resources such as booklets (Ilic et al., 2015), videos (Volandes et al., 2012),(Pignone, 2000) and webpages (Ruffin et al., 2007) aimed at informing patients about their health status and possible treatment options. This is not indeed in line with what that is intended to be explored in this research as DST.

However, even with this alteration of the spectrum, there is still a scarcity of decision support tools designed to thoroughly encompass all the fundamental factors and interactions of shared decision-making.

Sum up and define research scope

In principle, informed medicinal decisions are forged when patients are adequately apprised of their treatment choices, doctors are informed of patient preferences, and both parties actively engage in the decision-making process. Yet, the reality about current state of DSTs is that they manifest as a series of complex algorithms that solicit input from doctors and process this information through prognosis models to yield potential outcomes for each medical intervention. One significant limitation here, as observed, is the lack of involvement of patients and their preferences.

This, however, can be perceived not as a barrier, but rather as an opportunity; an invitation to employ design and interaction tools to conceive and establish a decision-making support tool that does not exclusively cater to one user demographic, but instead encourages substantial and meaningful dialogue between patients and physicians. Indeed, the aspiration of this research is to shift the focus from a solely technical standpoint to one that is more human-centered. The predominant challenge lies in the relative lack of experience both patients and clinicians have in using such a Decision Support Tool (DST). Consequently, uncertainty prevails regarding how this tool should be designed, where it should be integrated into the care path, and how users should engage with it. In response to this quandary, it becomes essential to adopt certain design practices that allow us to project into a future where such tools are already in existence and use. To do this, I personally think we must consider this tool as an entity, an object of the present. By doing so, we can begin to envision how, if people possessed this tool today, they would interact with it and potentially benefit from it. This 'thing', as it is called, should not be seen as a distant concept; rather, its existence should be considered an immediate possibility.

Chapter 3

Project Approach

The problem and the context we are dealing with in this project, have numerous aspects and layers. There are various stages involved in caring for someone with melanoma or any other type of cancer, from diagnosis and pre-treatment phase to assisting the person in recovering after the treatment. There are numerous actions that the medical team and patient must perform. There are so many emotional ups and downs, physical changes, and attitudes in patients and their companions that may shift through the journey. Other factors such as age, gender, literacy, and comorbidity also play a role, which is why each person's experience of care is so unique. That is why a systematic protocol for the research is required to study how the research questions could be explored and to find ways to address the issue.

Developing a robust and comprehensive research framework is crucial for this study. To achieve this, a diverse range of methods should be incorporated to approach the project effectively. These methods need to address certain key aspects that will enable a thorough investigation into the envisioned future and its design solutions.

Based on my current understanding of the context, it appears evident that focusing solely on the "present" when seeking answers to our questions might not be the optimal strategy. This is due to three primary reasons. Firstly, there is a scarcity of data-driven Decision Support Tools (DSTs) developed with a patient-centric perspective. Consequently, it becomes imperative for us to equip ourselves with the means to envision a future or even a present where the sought-after patient-centric DST is already in active use and embraced by the public.

Another crucial factor to consider is that when delving into interactions within medical settings, the inherent context introduces numerous limitations and constraints. If we confine our study of interactions within the current framework, we inevitably bind ourselves to these constraints, impeding the exploration of interactions with the desired freedom, and potentially compromising the richness of available data.

Moreover, our subject of interest revolves around an innovative technology that hasn't achieved widespread availability yet. Developers are still in the process of refining algorithms and models to enhance their accuracy.
Considering these aforementioned points, the project team, after thorough discussions, has concluded that adopting a speculative design approach forms the nucleus of this project. This approach can be complemented by various other methods that facilitate participant engagement in the subject matter and facilitate uncovering latent knowledge regarding user needs.

Figure 6 : The tools needed for the research

Speculative Design

Speculative design is a discursive technique based on critical thinking and dialogue that questions the practice of design (and its modernist definition) and extends this critical practice into imagination and visions of alternative possibilities. It liberates designers from some of the present's cognitive, normative, and behavioral constraints and creates a creative space for designers to contemplate and communicate the consequences of contemporary and future ways of being (Van Boeijen et al., 2020). The term "speculative design" was introduced by Anthony Dunne and Fiona Raby as part of a critical design practice that looks ahead and imagines future design proposals. Rather than prioritising commercial objectives, its goal is to create design proposals that address and spark debate on crucial problems that may arise in the future (Dunne & Raby, 2013). One of the primary motivations for this discursive and critical practice is to broaden the popular audience by moving discussions about technology beyond the domains of experts. Indeed objects are seen as instigators of debate or philosophical analysis (Auger, 2013). Speculative design, according to James Auger, has three essential aspects. It first liberates itself from the limitations imposed by commercial practices that are driven by the market. Second, it enters the fiction world and engages in speculative thinking about potential future systems, services, products, and even whole worlds. This makes it possible to critically assess how emerging technologies affect and have implications for our daily lives. Finally, speculative design serves as a catalyst, encouraging communication between experts like scientists, engineers, and designers and the audience, who will ultimately use these new technologies.

Participatory Speculative Design (PSD), a more inclusive and participatory form of speculation that allows for the participation of a wider range of stakeholders, has emerged from the confines of design-art showrooms. As a result, this method has grown significantly in popularity and is now being used in a variety of industries, including healthcare, demonstrating its applicability (Farias et al., 2022). Since healthcare issues tend to be complicated and multifaceted, dealing with access, affordability, quality of care, technology, and social dynamics, speculative design can be suggested as a perspective for confronting this area. Indeed, by developing practical and thought-provoking prototypes or scenarios, speculative design may help stakeholders see and comprehend the possible effects of new technology, regulations, or societal shifts in healthcare. The core value of speculative design can be regarded as the ability to create speculative worlds where people can suspend disbelief of change and imagine alternatives (Hoang et al., 2018).

The future of healthcare can be discussed in depth by the public, legislators, and healthcare professionals when designers submit speculative concepts. These discussions can lead to greater awareness, informed decision-making, and the identification of potential risks and opportunities. Speculative design also allows for the exploration of ethical, social, and cultural implications of healthcare interventions, fostering a more holistic and responsible approach to innovation in the field. Dunne emphasizes that speculative design can not only offer new speculative products and services, but also new social and political systems (worlds) (Mitrovic, 2015). It can promote a proactive and anticipatory approach, assisting in the development of a future health care systems and interactions that are more responsive to the wants and needs of clinicians, patients and their significant others (Tsekleves et al., 2019).

This approach to design necessitates the production of hypothetical artefacts or potential future alternatives for data-driven healthcare that can spark debates. It involves engaging design researchers, clinicians, healthcare providers, patients, and even individuals without health issues to challenge prevailing healthcare norms and elicit insights into latent needs. The optimum situation would be to test this artefact through clinical trials and formal participant studies. However, due to the time constraints of the graduation project and the restrictions imposed by strict patient research policies, our focus lies on speculations that can be investigated outside of the clinical setting.

More Than Human Design

Imagine a Decision Support Tool (DST) equipped with its own voice, enabling direct communication without the need for a mediating interface. This concept raises intriguing possibilities for studying and designing AI systems, particularly data-driven decision support tools. By adopting a more-than-human approach, we can gain valuable insights and enhance our understanding of these tools' potential.

The more-than-human approach views intelligent entities, such as AI systems, as experts with their unique perspectives. In the design process, they are treated as active participants. This approach is commonly employed during the initial stages of design, but it can also be applied to evaluate existing products to uncover hidden biases and speculate on unintended consequences in the future (Reddy et al., 2021; Nicenboim et al., 2020).

In our research, I (Kamran) conducted Thing Interviews, employing the more-than-human design approach to delve into the DST's perspectives, and its interactions with both humans and nonhumans. During the enactment sessions, I assumed the voice of the DST, facilitating interactions with individuals as though I were the AI itself. Through these speculative conversations, we identified several themes that shed light on the emergent qualities of people's relationships with the DST within a futuristic data-driven care path.

Research Through Design

We will employ the method of research through design (RtD) to evaluate the outcome of the speculative design from a research perspective. RtD, as described by Zimmerman and Forlizzi (2014), is a forward-looking approach, contrasting with traditional research that centers on historical and current aspects. It complements speculative design perfectly as both methodologies envision potential futures. However, their emphasis differs: speculative design envisions the imaginary outcome, while RtD concentrates on extracting valuable insights from these design speculations.

Due to traditional scientific research's limitations in capturing and addressing the projective, imaginary, and uncertain aspects that design practice and research confront (Prochner & Godin, 2022), design activities and artefacts are progressively gaining recognition as effective means of generating and communicating knowledge (Stappers & Giaccardi, 2017).

Starting from the artifact and from notions of making is an alternative to reading through design from the perspective of practice (Redström, 2021). In the context of Research through Design (RtD), artifacts assume a significant role, as many researchers consider the creations of designers to be fundamental to the process. This designerly contribution can range from providing basic stimulus materials for others' research to more common instances where designers develop prototypes (or artifacts) that closely resemble 'products' and hold a central position in the knowledge-generating process (Stappers & Giaccardi, 2017).

Context Mapping

To gain insights into the data-driven Melanoma care path and the potential needs and desires of future users, the study utilizes various methods outlined in the Convivial Toolbox book (Sanders & Stappers, 2012). To conduct a more in-depth analysis of the interviews, specific generative research elements from the Convivial Toolbox are applied:

Sensitize Booklet: Sensitize Booklet: Before the enactment session, a sensitizing booklet is provided to the DST (Data-Driven Care Path) users, encouraging them to contemplate the use of DST in the context of data-driven care. These booklets are presented to the patients as "scenario books" and are sent to them a week before the interview. As real patients couldn't be recruited, these booklets are used to sensitize participants to the scenario and immerse them in their imaginary roles.

Generative Session: During the interviews with medical experts, visual materials and physical items are created to support the discussion. These tools serve as generative aids to foster expression and creativity. Various materials, such as empty textboxes and physical puppets of doctors and patients, are utilized in different interviews (see Chapter 8).

Statement Cards: This thesis makes use of statement cards, which comprise quotes, paraphrases, and raw transcription data obtained from the enactment sessions.Each card is color-coded to correspond to a specific enactment session. These cards play a crucial role in the initial data analysis, as they are used for clustering similar interview cards into specific topics. This clustering process allows for the extraction of valuable knowledge and insights from the data.

Chapter 4

Crafting a speculation

How we crafted a speculation ...

To craft a speculation:

To craft a speculation, we primarily adopted the framework presented by Augur in his paper titled **"Speculative design: crafting the speculation".** Augur introduced speculative design as a methodology and emphasized the importance of striking a balance so that the speculation remains relatable to participants, without venturing too far into the distant future where it becomes implausible and disengaging. By employing this approach, he believed that speculative design could liberate itself from constraints, allowing goals to be driven by questions and discourse rather than market-driven agendas.

Although speculative design is widely used in various design projects, there is no clear-cut and standardized approach for designers to follow. Augur attributes this lack of structure to the uniqueness of each speculative design project, characterized by diverse subjects, contexts, technologies, perspectives, and audiences. The continuous development of new techniques and the growing sophistication of old methods as the practice evolves further contribute to the absence of a definitive "how-to" guide.

In crafting my speculation for a futuristic data-driven healthcare system, I began by contemplating the temporal context of my design. Instead of specifying a specific time in future, my aim was to envision an era when the notion of healthcare systems had undergone significant semantic transformations.

I envisioned a future where AI agents had already established themselves within the healthcare industry, regarded as distinct entities that assist individuals. Within this speculative framework, I imagined that data-driven care was continuously evolving and gaining prominence, and people were increasingly embracing its potential.

In my future scenario, sub-systems integrated in the healthcare, will gather extensive patient data from diverse sources such as electronic health records (EHRs), wearable devices, genetic profiles, social determinants, and environmental factors. These data collection modules can be executed by clinicians, patients themselves, or autonomously. A notable change in this health system is the increased involvement of patients in their care journey, aligning with a shift towards palliative care. Patients are empowered to take on some of the treatments independently, having a more active role in their own healthcare. The process of collecting and analysing data has become more undrestandable and transparent to people.

Moreover, in my speculation, advancements in medical science are progressing rapidly due to the utilization of machine learning-based tools. Consequently, people have access to a wider range of treatment options. The continuous development in medical science, facilitated by data-driven approaches, ensures that individuals receive more personalized options for their treatments.

What if healthcare became fully data-driven, with datasets as the foundation of the healthcare system, and AI agents were seen as commonplace entities?

Imagine a future where decision support tools (DSTs) have surpassed their current capabilities. In this speculative world, DSTs have evolved into intelligent and personalized companions for cancer patients and their loved ones, transforming the decision-making process into a collaborative and empowering journey. They proactively gather medical data from evidence-based clinical trials and multidisciplinary sessions conducted in medical centres. Utilizing wearable devices, they continuously monitor patients' physical well-being, keeping DSTs informed with real-time information about the patient. Additionally, small widgets and flash memories not only capture textual information but also document the concerns, emotions, and values expressed by the patients.

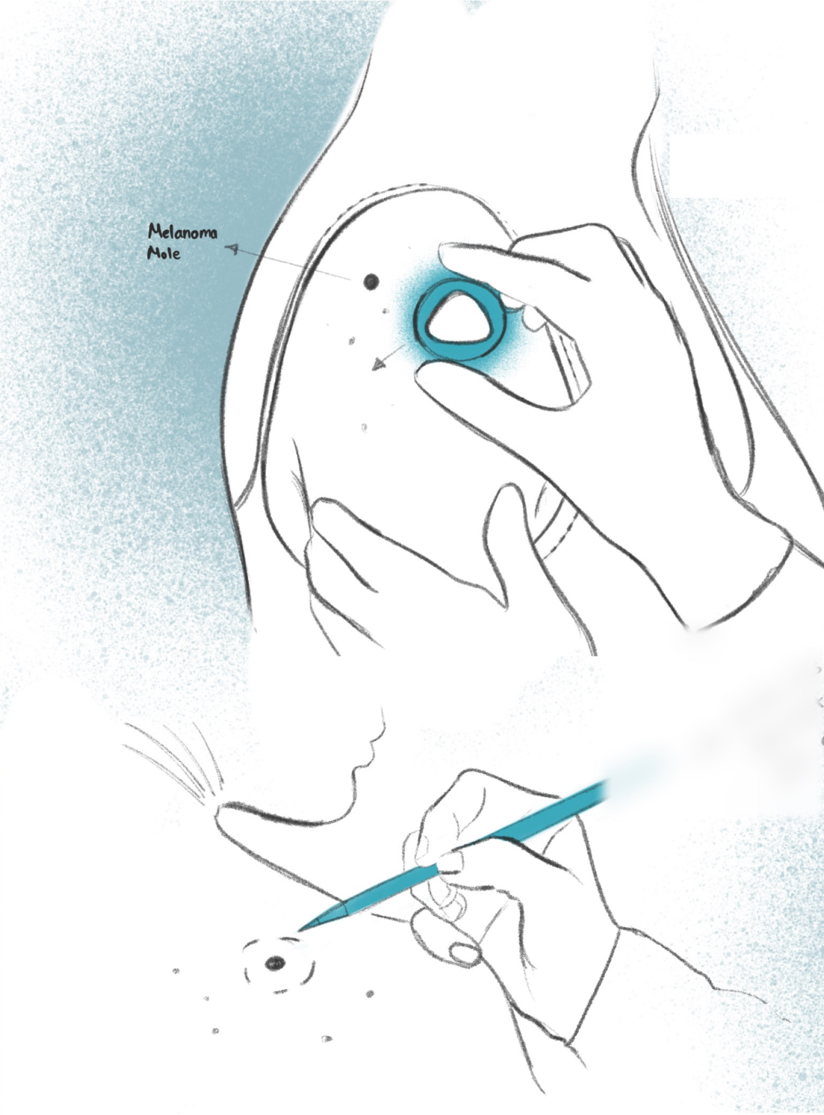
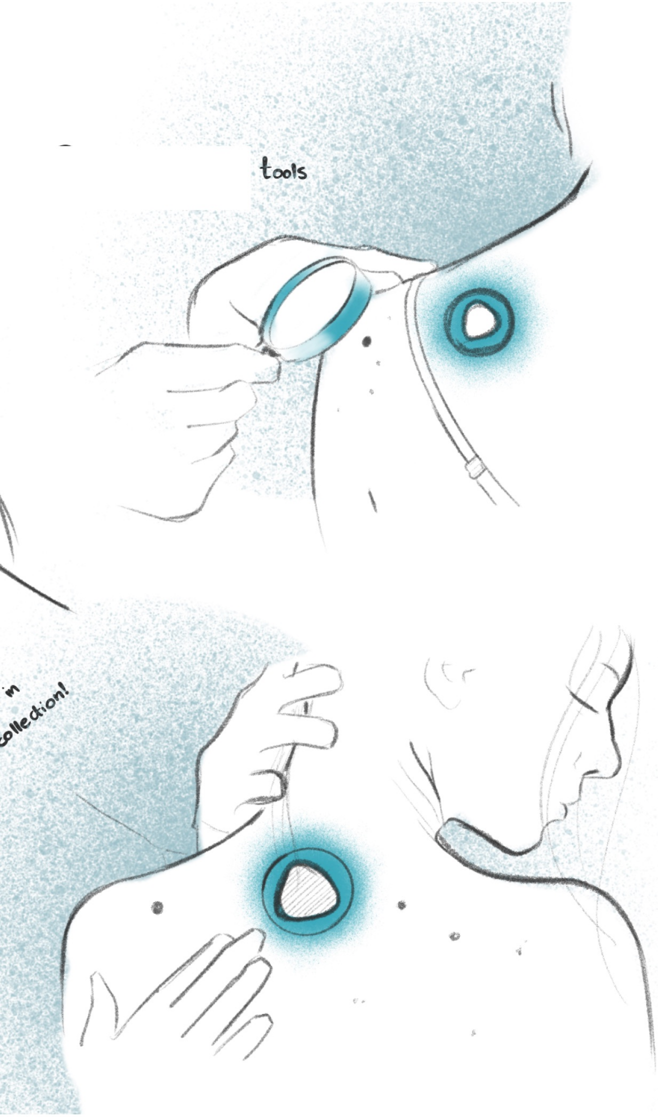


Figure 7 : crafting the speculation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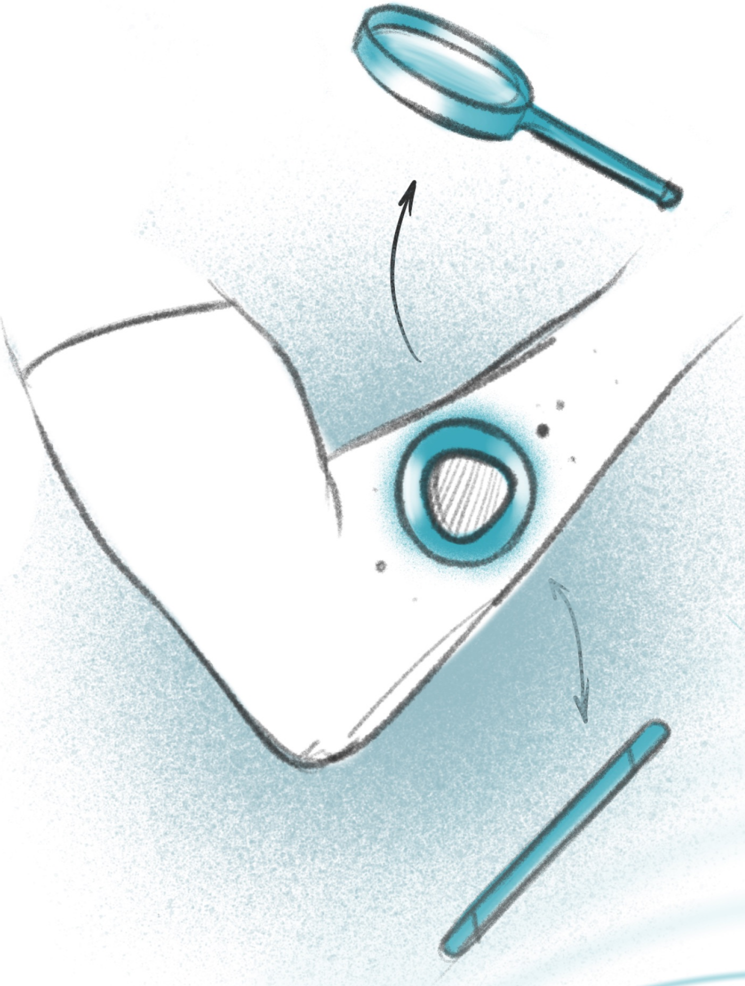


Figure 8 : Data collectors and data reflectors, entities of the speculated future

To crystallise my speculation, I began by outlining initial concepts. My primary focus was on the core function of a Decision Support Tool: providing visual representations of prognostic algorithms, projecting outcomes related to mortality, recurrence, and expected quality of life after treatments. To make it easier to grasp, I imagined a relatable metaphor—a magical crystal ball in the shape of a DST that predicts treatment outcomes.

Another crucial aspect shaping my vision of the future was data collection. I speculated a future where data-collecting devices are everywhere, forming a vast and interconnected network. In this vision, any medical device has the capability to participate in data collection. This includes clinical tools, wearables, and various other types of devices. The goal is to create a seamless and comprehensive data collection system that gathers information from a diverse range of sources, ultimately contributing to enhanced healthcare practices.

To make the concept of "data" more tangible for those involved in my speculation, I devised widgets known as DCs (Data Collectors). These DCs resemble small flash memories that actively collect data within a futuristic healthcare system, contributing to data-driven systems. People will be empowered to adjust services they receive based on their own specific data.

Initiate to speculative enactment

Speculative design is increasingly integrating participatory methods and co-design techniques to broaden its impact. This trend is being driven by the increasing diversity of domains in which speculative design is conducted. While involving others in the design process may minimize the designer's authority over the final outcome, the emergence of participatory speculative design (PSD) allows people to imagine freely and emancipate from constraints by actively including various stakeholders in the design process, thereby broadening participation and ownership of speculative ideas (Farias et al., 2022).

In order to present our crafted speculation and conduct research from a participatory speculative design perspective, we decided to use a new approach called speculative enactment. Speculative enactments involve inviting participants to act within speculative but consequential circumstances, enabling empirical analysis of their actions (Elsden et al., 2017). The aim is to explore in an experiential level, how participants can engage with a data-driven futuristic decision support tool if it was already present in the context. What users want from it, and how might it be beneficial to them?

In our project, one potential speculative enactment could entail the creation of a simulation or role-playing practice. There, participants would represent different stakeholders within the data-driven health system, and would be tasked with navigating scenarios that require data-driven decision-making based on prognostic algorithms. Using this methodology allows us to observe possible outcomes, evaluate alternatives, and decide on the most favourable course of action.

With speculative design, we can gain a more integrated understanding of the system we are designing and uncover implicit assumptions about its interactions. Therefore, this approach can become a potent tool to determine what questions participants might ask about a future where they can make decisions based on a data-driven decision support tool present in the clinic. We can observe what works well and challenges that may arise when people feed their specific data into prognostic models and become aware of the predicted outcomes. We can examine what aspects people like or dislike. We aim to understand the discourses that occur after role-playing the scenario, and how people compare it with the current healthcare system. Indeed, speculative design offers a proactive way to identify and potentially tackle issues or challenges that may emerge in the system's actual application.

Chapter 5

Enactment Session

This part provides a detailed overview of the research setting and context for the study conducted at the Faculty of Industrial Design Engineering (IDE) - TU Delft. The primary objective of this research was to delve into the intricate dynamics inherent in a futuristic data-driven healthcare scenario, with a specific focus on what different stakeholders may expect from a decision support tool and how these (DSTs) that can prognosticate the treatment outcomes become meaningful agents in healthcare who can literally support users in making critical decisions.

Participants

The speculative enactment session was advertised through social medial channels like WhatsApp and LinkedIn associated with faculty of industrial design engineering ad TU-Delft. They were asked to be improvisational actors of the future stakeholders of a future data-driven health care. The research study assembled a total of 12 participants, each carefully selected to bring diverse perspectives and expertise to the exploration of DSTs in data-driven healthcare. These participants were collaboratively grouped into four distinct teams, with each team comprising three individuals. The intentional heterogeneity in academic backgrounds (engineers, strategists, designers, researchers and computer scientist) allowed for a comprehensive understanding of data-driven healthcare from various viewpoints.

The participant demographics showcased a rich mix of academic disciplines, fostering a holistic approach to the study:

- 3 students from Integrated Product Design (IPD)
- 3 students from Strategic Product Design (SPD)
- 4 students from Design for Interaction (DFI)
- 1 student from Computer Science
- 1 Ph.D. candidate from Industrial Design Engineering (IO)

Notably, one of the teams included a real-life romantic couple, introducing an intriguing dimension that could potentially reveal unique perspectives on healthcare interactions within a personal relationship context.

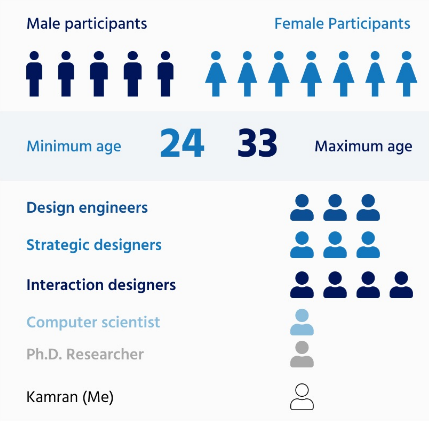
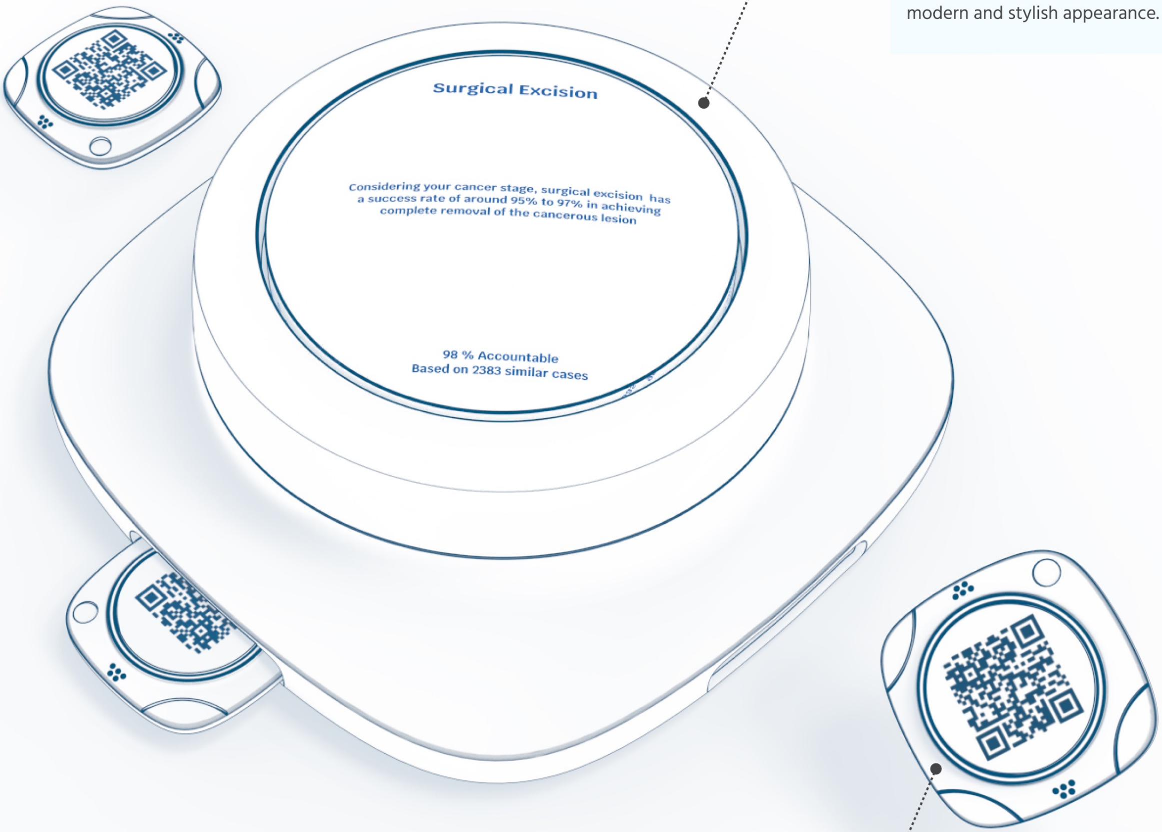


Figure 9 : Demography of the enactment session

The artefact - “Dixon” [1]



A) This artifact which reflects on data, serves as a contemporary embodiment of a crystal fortune-telling device. It’s purpose is to strongly evoke the same functionality (forecast and prognosis the treatment outcome), while maintaining a modern and stylish appearance.

B) This object functions as an artifact that gathers data and acts as a tangible tool for integrating data into prognosis algorithms.

Figure 10 : Dixon, the provocative

The concept was named Dixon after Jeane Dixon (January 5, 1904 – January 25, 1997), a renowned American psychic and astrologer owing to her prediction of the assassination of President John F.

The artefact and interface for the futuristic DST is named "Dixon." Inspired by the metaphor of a magical crystal ball often used in fiction to foresee the future, Dixon serves as a visual tool to depict potential futures, much like DSTs. To make the concept more tangible, we embraced the idea of material speculation, which involves using tangible design artifacts to generate potential scenarios for critical reasoning and exploration (Wakkary et al., 2015).

With Dixon, we translated the magical ball into a physical gadget that people can easily believe in and relate to (see A on figure 10). This gadget sits on the table and provides a visual representation of available treatment plans, along with the corresponding success percentages for each option. Users can insert another artifact that is in charge of data collection into the gadget, after which they see their data being loaded and combined with data from other stakeholders. Subsequently, Dixon suggests tailored treatment plans, with the interface visualizing the benefits and risks associated with each option.

Sensitization:

To sensitize the participants and help them immerse into their roles, we provided scenario booklets for each role. Each character had a scenario booklet to help him/her become more familiar with the features and nuances of the character they wanted to portray. These three booklets guided the participants through a four-day activity in a future data-driven care path, from diagnosis to an imaginary medical appointment session for choosing a treatment option.

In these booklets, the patient, significant other, and doctor went through a common journey, individually. Additionally, they received an interactive widget, as an artefact that acts as a data collector (see B on figure 10). The widget helped the participants take part in the process of data collection in a tangible way. The widget featured a distinct QR code etched onto it. By scanning this QR code, users could access a link that allowed them to upload specific information they wished to share with the DST (Department of Science and Technology). This information might include pictures of moles or their test results. In the four days leading up to the enactment session, they worked with the widget based on the activities assigned to them according to the character they were portraying.

The scenario booklets are available in the appendix (See Appendix 1).

Structure & Roles

To create a realistic and immersive research environment, the participants were divided into 4 groups. each group consisted of 4 characters:

- **The Doctor:** Responsible for delivering care and making data-driven decisions based on the hypothetical healthcare scenario presented, the doctor's role was crucial in evaluating how DSTs can assist medical professionals in decision-making processes.
- **The Patient:** Representing the individual receiving healthcare, the patient's role provided valuable insights into how data-driven approaches might impact patient experiences, outcomes, and the empowerment of patients in their own care decisions.
- **The Significant Other:** Portraying a support role, this participant represented a close companion or family member involved in the patient's healthcare journey. The significant other's role offered perspectives on the effects of data-driven decision-making on patient-relationship dynamics and how DSTs could augment support systems.
- **The AI:** I (Kamran) took on the role of AI, embodying a prognosis model or the Decision Support Tool (DST). Indeed I was the voice of DST. My objective was to engage with the participants as if I were an intelligent system capable of providing insights and predictions.

The arrangement was carefully designed to simulate critical roles commonly encountered in real-life healthcare settings, allowing the research to delve deeply into the complexities and ethical considerations associated with data-driven decision-making, particularly with the potential involvement of DSTs in the future healthcare landscape.

Figure 11 : Session arrangement

Speculated Context

The context of enactment was an in-person clinical appointment, where these four people came together around a table, in a consultancy session to discuss the treatment options, utilize the DST, and decide on a care path. In this session, they were supposed to interact with Dixon, which could assist them in understanding the predicted outcomes of each treatment. One of the key areas of interest in this study was to explore how DSTs, powered by artificial intelligence, data-driven algorithms, and prognosis models, could potentially support healthcare stakeholders, including doctors, patients, and their companions. The goal was to enable them to compare the risks and benefits associated with each treatment option and empower them to make informed decisions based on data-driven insights.

The arrangement was carefully designed to simulate critical roles commonly encountered in real-life healthcare settings, allowing the research to delve deeply into the complexities and considerations associated with data-driven decision-making, particularly with the potential involvement of DSTs and the significant role of data in decision making within the future healthcare landscape.

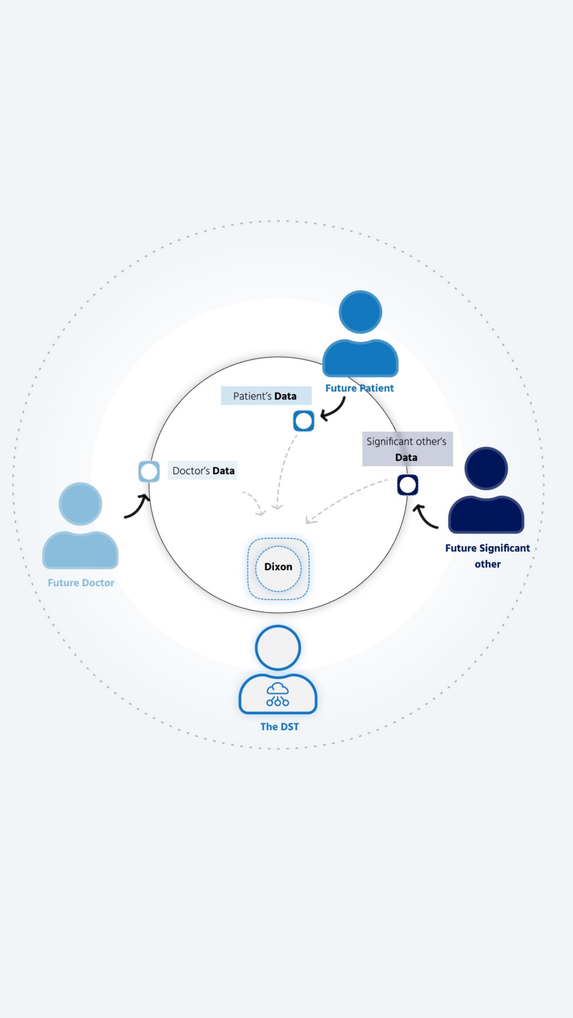


Figure 12 : Diagram of interaction within the session

Research Procedure

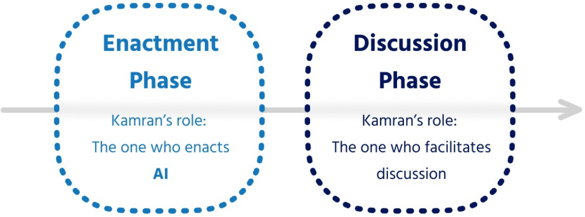
The research session took place after a four day sensitizing process where actors could go through a prior experience from diagnosis to the decision making appointment using the booklets and the artefacts. The session was divided into two distinct yet interconnected phases:

1. Enactment Phase (20-30 minutes): During the initial half-hour, participants were fully immersed in their assigned roles (doctor, patient, or significant other). With a carefully constructed and detailed healthcare scenario, participants engaged in authentic role-play, simulating real-life interactions between healthcare professionals, patients, and their companions. This phase aimed to create a rich and realistic experience, facilitating a deeper understanding of the potential implications of data-driven decision-making, particularly with DST support, on patient care, relationships, and overall healthcare experiences.

2. Discussion (30-40 minutes): Following the enactment phase, the remaining 30 minutes were dedicated to an open and introspective reflection session. Participants were encouraged to candidly discuss their experiences, share personal perspectives, and delve into their emotional responses to the hypothetical data-driven healthcare scenario. This reflective segment provided a unique opportunity to gather profound insights into the intricate thoughts, feelings, and reactions of the participants when considering DSTs' potential role in decision-making processes.

Rationale and Importance

By combining the enactment and reflection phases, we aimed to achieve a comprehensive and multi-layered understanding of the potential challenges and opportunities within a data-driven healthcare scenario, particularly concerning DSTs' support for stakeholders' decision-making. The active role-playing aspect allowed participants to intimately experience the complex decision-making processes, while the subsequent reflection provided valuable context for interpreting the underlying motivations and considerations behind their actions.
This blend of experiential learning and introspection enhanced the reliability and relevance of the study's results, providing crucial insights into how DSTs could be developed and integrated effectively to benefit both patients and healthcare professionals.



Analysis

With participants' consent, the sessions were audio recorded, and these recordings were meticulously transcribed to capture the entire research session, including each participant's dialogue and interactions during the enactment phase.

Subsequently, a comprehensive analysis of the transcribed statements was conducted. To facilitate the analysis, statement cards were created out of the transcription, enabling a detailed examination of each conversation to identify recurring themes, patterns, and significant moments. The most unique and distinctive statement cards, which provided an in-depth understanding of stakeholders' needs and preferences when interacting with the Decision Support Tool (DST) and data-driven algorithms during the healthcare scenario, were highlighted and clustered. Selected quotes from the transcriptions were used as illustrative examples, showcasing key insights and participants' perspectives. This rigorous process of transcribing and analysing the data contributed to the exploration on how DSTs could potentially support stakeholders in making critical decisions within a futuristic data-driven healthcare setting.

Figure 13 : Participants enacting the future in the speculation sessions

Chapter 6

Back to the future

My initial impression during the speculative sessions on the future of data-driven healthcare cantered around the realization that shared decision-making cannot be adequately facilitated solely by introducing predictions regarding potential treatment pathways. This approach seemed lacking and ineffective. Participants displayed disinterest in engaging with the extensive charts and numerical data outlining various treatment options. The individuals role-playing as patients and their significant others found themselves inundated, struggling to comprehend the array of treatment choices presented. Additionally, there was ambiguity surrounding the responsibility of both the Decision Support Tool (Me) and the doctor in terms of presenting, recommending, and conveying treatment information to the patient.

Interaction with a Decision Support Tool (DST) is associated with many complexities. The experience of cancer is a multidimensional problem in which interactions between clinicians, patients, and their companions may be influenced by various factors. There was significant diversity among the ways participants approached this speculated Melanoma care path and the envisioned DST. Personal characteristics, values, and preferences can vary greatly from one patient to another. Based on the discussions between participants after enactments, it seems quite challenging to devise a general solution that would equally inform all these persona groups. The key insights extracted from the analysis are as follows:

1

In the context of data-driven decision making, **accuracy doesn't always equate to effectiveness**. Patients and their loved ones were not easily persuaded by mere statistics and percentages provided by prognostic models. Instead, they require stories and narratives about the future, providing insights into what they might expect during and after specific treatment choices, including how a day of their life may look like after treatments.

2

Most of the participants agreed that interaction with a Decision Support Tool (DST) and the process of educating patients about treatment options **shouldn't be limited to doctor's appointments, as almost all of the actors became overwhelmed** with the information they received in the session.

The ones who enacted patients preferred to be better-informed about treatment options and their potential risks before meeting with the doctor. This can empower them to make better decisions when evaluating the treatment options in the clinic and also experience more productive communication with the doctor.

The actors who enacted the character of doctors also stated that it could be beneficial for them to have access to tailored strategies offered by a DST before meeting with the patient, rather than during the session, as it allows them to facilitate the DST-patient interaction more effectively.

3

In this future scenario, patients are far from being passive spectators of the Decision Support Tool (DST) outcomes. On the contrary, they take an active part in sharing their patient-specific data with the DST at various stages of their healthcare journey. **Consequently, in a context where patient-specific data is collected rapidly, issues such as data ownership and privacy will become increasingly significant.** Patients need clarity on who has access to their information and wish to have control over which parties receive it. For instance, they want to be reassured that their data is not shared with insurance companies. Transparency plays a vital role in ensuring that patients fully understand the data being shared, its intended purpose, the recipients involved, and the duration for which the data will be accessible.

4

It is possible that the DST's recommendations may contradict the medical team's professional judgment. If the functions designated for a DST do not align with the work culture at a specific medical centre or the available resources and facilities, healthcare providers may find it challenging to base their decisions on the outcomes provided by the DST. Consequently, doctors may choose to disregard or neglect prognostic algorithms, and such incidents could erode patients' trust in the DST.

5

Making a decision is not an instantaneous process; doing so suddenly can be overwhelming. This is why many patients tend to be passive in decision-making, as they may feel uninformed or unsure. Expecting people to make informed choices and play an active role solely by providing them with information on treatment outcomes may not be enough, especially when they are under emotional pressure. **Decision-making is indeed a journey,** patients need moments of solitude to contemplate their situation and the options, discuss them with others, seek advice from friends, understand their emotions, and share their feelings with others. They need to feel the challenge and become self-aware of their preferences. This necessitates multiple interactions with the DST, both for patients and doctors, allowing them the time and space to process the information, consider different aspects, and engage in a more comprehensive decision-making process.

6

Patients do not like it to see the doctors they have trusted are relying excessively on a DST to make treatment decisions. Seeing a doctor being guided by a DST in determining treatment outcomes may lead patients to believe that the doctor does not have a thorough understanding of their individual needs and circumstances. This perception can lead to a loss of trust in both the doctor's expertise and the DST's dependability. Healthcare providers must find a balance between using decision support tools and maintaining a strong patient-doctor relationship based on trust, empathy, and personalized care. It should also be explored which aspects of a doctor-DST interaction should be exposed to the patient.

7

Patients and significant others could not come up with clear preferences on their own. They could only reveal them when they are asked curation question. Furthermore, The influence of personal preferences, values, and expected quality of life on treatment options remains unclear, especially **when most decisions prioritize safety**. The decision doesn't always appear to be a dilemma between a better quality of life and a higher chance of survival. For the three main prognostic tool outcomes -chance of survival, chance of recurrence, and expected quality of life- it is not evident how patients' individual inputs can be incorporated. Participants who represented patients and their significant others expressed a **desire for greater transparency regarding how their preferences might impact the outcomes**.

8

As expected based on the literature, some patients prefer to actively participate and engage in the process of shared decision making, whereas some prefer to accept whatever the doctor comes up with since they have complete faith in the medical team and prefer to rely entirely on them

9

Asking participants about how they think of proper interaction with DST, several interaction spaces were suggested:

One potential application is in the home, where the DST can inform both patients and their significant others about the various treatment options available. Here, the DST evolves into more of an **educational product for patients**.

Another possible context is the appointment setting, where the DST can help the patient and the care team engage more in building trusted connections and sharing preferences. Here, the Decision Support Tool evolves into more of an **communication facilitator**.

A DST can also be used by the medical team during multidisciplinary sessions when the patient is not present. Here, the we can expect the DST **as a clinical tool for better planning the treatment based on evidence based outcomes.**

Conclusion

We set out on a journey to understand our project context to design appropriate interactions. We gradually delved into the realm of future data-driven care through initial speculations, employing speculative design techniques to explore possibilities and envision potential futures. This process allowed us to make assumptions about the users' needs, wants, wishes, and concerns. We have explored and provided some explanations for the qualities of appropriate interactions.

A significant insight drawn from all the enactment sessions is that all stakeholders strive to establish a shared mindset about the problem, even though they are under immense work and emotional pressure.

Doctors seek to inform patients about available medical options, while patients try to communicate their treatment preferences to the doctors. In the process, significant others may act as mediators to facilitate communication or reflect on ways to support the patient. Each character endeavours to comprehend the others' approaches to the problem, and **decisions become more assured when they perceive alignment in their mindsets.** This moment of agreement marks the point where decisions are reached.

One limitation of the research is that ethical approval complexities prevented conducting the experiment with real patients. As a result, the insights gained from the study may not fully capture real-world patient interactions. However, considering the current phase of the project, these insights seem to hold valuable implications for further development and understanding.

Having achieved a comprehensive understanding of the potential interaction opportunities with a Decision Support Tool (DST) and partially mapped the context, as well as the needs, wishes, wants, and concerns of the stakeholders to empower their decision-making, I want to further reinforce my findings with relevant theories. By enacting clinical appointment, I experienced some challenges and opportunities. Now I want to explore theories that will aid in constructing an enhanced experience of shared decision making for a visionary DST in the context of melanoma healthcare. In this phase I want to explore how we can facilitate evolving a shared mindset between stakeholders for making informed decisions using interactive tools.

Shared Mind

The context of cancer treatment includes multiple dimensions of interactions throughout the care path. We know that the key players in this journey are clinicians, patients, and their significant others but what we disregard is that they do not operate as separate entities, but rather collaborate, share ideas, and provide support to one another throughout the process.

It is critical to recognize that they cannot navigate this journey alone, as numerous challenges and obstacles will arise that will necessitate the participation of others. Consider a patient who wants to schedule surgery with their clinician at an outpatient Melanoma clinic. In such a case, it is critical to ensure that the patient's significant other can provide care and support after the surgery for removing the lesion is completed and the patient is discharged from the clinic. Similarly, a doctor may need to explain how to properly be prepared for a biopsy session to an elderly patient.

These interactions go beyond the practical aspects of care to include information exchange and dealing with complexities. Cancer patients usually have difficulty processing complicated information and ambiguity (Kohli et al., 2007) and they may dismiss information and make hasty decisions not taking into account their own preferences and the scientific evidence, which results in decisions that are not completely informed or autonomous. They experience cognitive overload when confronted with this complex, ambiguous, and emotionally laden context of cancer and to address this, people frequently rely on (trusted) individuals to assist them in thinking and feeling their way through important decisions as they may not be very conscious of their own cognitive biases when left alone (Epstein & Street, 2011).

Our findings from the speculative enactment sessions align significantly with this concept of **shared mind**, introduced by Epstein and Street (Epstein & Street, 2011).

Epstein introduces the concept of a "shared mind" in the context of healthcare decision-making. This shared mind emerges through collective thinking and shared emotions between patients and clinicians during their interactions. While not all decisions require a shared mind, in cases of serious and chronic illnesses like Melanoma, decisions typically arise from deliberations among individuals. To facilitate the shared mind, three important aspects are highlighted:

Collaborative cognition involves patients seeking help from family members to navigate complex choices.

Attunement refers to a feeling of connection and trust that emerges during discussions and promotes commitment to treatment decisions.

Sensemaking, facilitated by attunement and collaborative cognition, allows participants to appreciate new perspectives, discuss values and preferences, and avoid oversimplification of complex situations.

According to Epstein's concept, the promotion of a shared mind occurs when the following practices are in place:

- **Sharing Information**: The information shared should be relevant to the patient's situation and meaningful to them. This includes objective details about the disease, treatment options, and prognosis, as well as understanding the patient's values, beliefs, and fears.
- **Sharing Deliberation:** Deliberation involves exploring the patient's preferences, whether they are clear or vague, stable or changing, informed or uninformed, and influenced by others. Shared deliberation avoids premature simplification and encourages considering multiple perspectives before making decisions.
- **Sharing Decisions:** Patient-cantered decision-making should not merely involve negotiation and consent but also curiosity, consensus, awareness, and empathy. Interactional care emphasizes understanding and empathy over distance and concreteness, fostering a collaborative approach to decision-making between patients and physicians

Recognizing the limitations of the initial speculative construct and observing how interactions within the enacted scenario could devolve into unproductive and unhelpful exchanges for collective decision-making, along with discerning which facets of the process hold potential for further exploration and which should be revaluated or eliminated, in the pursuit of more favourable interaction dynamics, a decision was made to undergo an iterative refinement of the speculation.

One particularly enlightening phenomenon was the realization that despite being mired in uncertainty, all participants endeavoured to collaborate in understanding each other's viewpoints regarding treatment options and their preferences. Nevertheless, this collaboration proved insufficient, as many participants concluded the session without complete certainty about their ultimate choices, expressing a preference for additional time. This prompted my search for theories that could underpin this procedural aspect.

Going through Epstein's elucidation of the elements crucial to developing a shared mindset seems to offer robust qualities for a subsequent round of speculation—perhaps a more potent one!

Chapter 7

“Doctor in the box”

With the first design experiment with our participants enacting the future, it became evident that even by providing patient with prognostics about accurate outcomes of treatment options, arriving at a decision involves embarking on a learning and collaborative journey. This process cannot occur instantaneously within the constraints of time and location typical of a medical appointment. Patients require a more substantial amount of time to grasp the facets of cancer relevant to their situation, as well as to gain an understanding of their medical condition and the treatment choices at their disposal.

Through this initiative, our aim was to have our speculation fine-tuned and to create a more robust position in the future. This speculation encompasses a context where the key challenges of dealing with data, particularly those related to difficulty, complexity, and ambiguity, were effectively overcome by providing both clinicians and patients with more time to communicate.

The aim was indeed to achieve a more productive shared decision-making process by extending the duration of communication between clinicians and patients.

Co-speculation session

Doctors and medical experts frequently express grievances about time pressure and an overwhelming workload. Undoubtedly, time consistently poses an obstacle in the implementation of innovations within the medical field. The limitations of time can present hurdles for conducting empathetic conversations between doctors and patients. Emotional and psychological support holds paramount importance for numerous patients during discussions about their health conditions or treatment alternatives. Empathy and active listening from doctors assume a pivotal role in offering reassurance and solace.
However, establishing a robust doctor-patient relationship and addressing emotional concerns within a confined timeframe can be arduous. Doctors often find themselves with restricted time for each patient due to factors such as a high patient volume, administrative obligations, and scheduling restrictions. Consequently, doctors may experience a sense of haste and encounter difficulties in engaging in extensive and empathetic dialogues.

Some patient cases are inherently complex and necessitate more time for thorough comprehension and discussion. Patients may have multiple concerns, questions, or emotional needs that require the doctor's empathy and compassion. It can be challenging to address these complexities within the allotted appointment time. Effective communication is required for an accurate diagnosis, shared decision-making, and treatment planning. Patients must have enough time to express their symptoms, concerns, and medical history, while doctors must gather relevant information and explain medical concepts. Time constraints can impede information exchange, resulting in a lack of understanding and potential miscommunication for an accurate diagnosis, shared decision-making, and treatment planning.

Building trust is another significant aspect of doctor-patient interactions. Empathy and rapport are built over time through consistent communication and understanding. However, when time is limited, it becomes difficult to establish and nurture this trust. Patients may feel rushed, unheard, or that their concerns are not adequately addressed, which can negatively impact the doctor-patient relationship.

Imagine a future where doctors can create clones of themselves and offer them using an interactive medium like Google Alexa. In our speculative scenario, we envision a future where patients are provided with a physical device that houses a novel data-driven NLP (Natural Language Processing) model. This device simulates the narrative and speech of the doctor to help the patient feel like they are really talking with their doctor. The models serve as a virtual counterpart to their (real) doctor, offering patients valuable insights about their treatment plans within the comforts of their own homes and with their doctor's specific narrative. The emphasis lies in ensuring that the interaction with the device is personalized and tailored to replicate the authentic presence of a trusted healthcare professional. Just imagine a world where doctors can create exact replicas of themselves, incorporating their extensive knowledge, mindset, and years of experience. These replicas would be made available to patients, empowering them with the information they need to make well-informed decisions and gather their preferences. While this concept is purely speculative, it holds significant relevance, particularly in addressing the time constraints and challenges associated with providing empathetic consultations to patients.

In our envisioned scenario, it's important to highlight that this interactive device, referred to as a "clone," stands apart from conventional voice recognition products available in the market. Unlike generic AI characters with artificial voices, the clone device aims to create a genuine experience where patients feel as if they are in a voice call with their own doctor, thanks to the utilization of a natural AI-generated voice. It means, if you have a scheduled appointment with Dr. Epstein in two weeks, the whole experience with the device, the voice you hear, the mindset you confront, and the mentality you communicate with are all based on Dr. Epstein's attributes. The AI-generated voice simulates a realistic voice call with Dr. Epstein, creating an immersive interaction every time you engage in a conversation with the device. It aims to replicate the familiarity and sense of connection you would typically feel when interacting directly with Dr. Epstein. A similar example that can represent the same quality of interaction/communication can be seen in the robot that starred in the movie "Interstellar" (TARS), which could truly deliver human-like communication with other astronauts using an NLP model loaded with datasets.

Figure 14 : TARS robot in Interstellar

Moreover, the device serves as a valuable tool for patients to gather knowledge and data about their health. By discussing their current state of health with the AI-generated version of their doctor, patients can receive personalized recommendations, educational resources, and guidance on self-care practices. This continuous flow of information (in a setting where there is no time constraint) fosters a proactive approach to healthcare, as patients become better equipped to manage their conditions and promote overall well-being.

In addition to providing information, the device allows patients to share their preferences and concerns. During conversations, patients can openly reflect on the subjects they want their doctor to be aware of, such as specific symptoms, lifestyle factors, or treatment preferences. This personalized approach ensures that doctors have a comprehensive understanding of each patient's unique circumstances, facilitating more effective and tailored treatment plans.

Furthermore, the device can serve as a valuable communication channel between patients and healthcare providers. The conversations initiated by patients provide a wealth of information that can be relayed to human doctors for further analysis and consideration. This collaborative approach between AI-generated doctors and healthcare professionals promotes a more holistic and comprehensive understanding of patients' needs, resulting in improved diagnosis and treatment outcomes.

The interaction with the device consists of 5 different layers:

Replication

This layer encompasses the procedure in which doctors generate an AI clone or duplicate of themselves. Replicating ourselves in devices, often referred to as digital or virtual replication, involves creating a digital representation of oneself that can interact and communicate with others through technology. It may involve instructing an artificial intelligence system to imitate their expertise, decision-making capabilities, and medical knowledge, thereby creating a replica or doppelganger. Through the utilization of sophisticated algorithms and machine learning techniques, doctors strive to replicate their skills and expertise within an AI system. Compared to the other layers of interaction, this particular process may appear more futuristic, abstract, and vague. The reason for this is that, until now, the general public, especially those who are not extensively involved in machine learning and computer science, have primarily encountered NLP-based systems and chatbots that offer responses in a neutral or generic manner. We rarely have experienced the concept of replicating a digital version of ourselves that interacts with others while embodying our unique personality and characteristics since we don't currently have the technology to replicate our entire consciousness or being in a device.

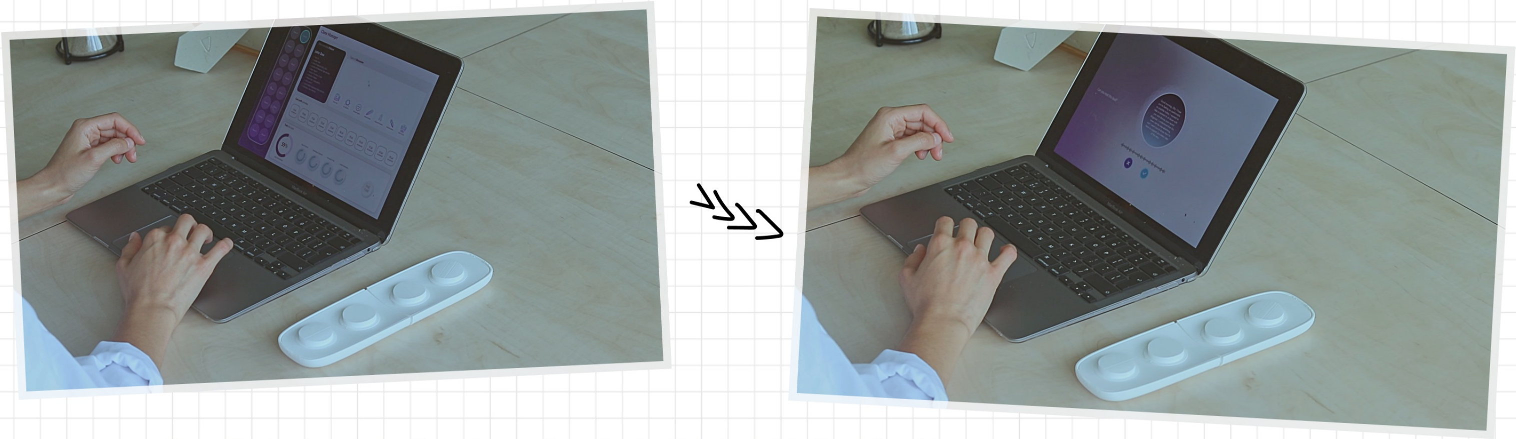


Figure 15 - Doctors cloning themselves and transferring their traits into the mini modules...

Probably the only tech-based phenomenon that can have similar qualities of interaction would be making avatars in the metaverse. Therefore, this aspect of the interaction process may seem less familiar and more forward-looking.

The act of creating digital replicas possesses a remarkable attribute within our speculative endeavours, surpassing the limitations imposed by technology. It is crucial for us to consider how we wish to convey this alternative future scenario to individuals. As previously mentioned by Auger, careful speculation management is a vital aspect of a successful speculative design project. If the speculation veers too far into the future, showcasing implausible concepts or unfamiliar technological environments, the audience will struggle to relate to the proposal, leading to a lack of engagement or connection. Consequently, this layer of interaction within our speculation necessitates the establishment of a bridge between the audience's perception of their own world and the fictional element of making digital replications. To establish this connection, we need to consider some probable chaoses:

- Personal Identity: Virtual replication challenges our understanding of personal identity. If a doctor has a digital replica of him/herself, is it still "him/her"? Does it possess the same qualities, knowledge, and experiences the doctors who they are? Or how should doctors train a model to act the same and mimic their approach toward patient. How should they explore to integrate an identity which was always tied to their physical bodies into digital or non-physical realms.

- Consciousness and Self-Awareness: Consciousness of the digital replica can be an ambiguous aspect for doctors replicating themselves in a device. Does a digital replica possess consciousness or self-awareness in the same way as the character which it is originated from? Can it have subjective experiences and emotions? Can it react to the actions of patient the same way they do in the real setting? The nature of consciousness is a complex and whether it can be replicated or simulated in a digital environment is a topic of much speculation and debate.

Representat

In this layer, the doctor's virtual replica is manifested to the user (patient and their significant other) in a tangible manner. This embodiment could involve the creation of an avatar or a virtual representation of the doctor, facilitating a more interactive and immersive experience. However, since this approach toward embodiment lies so much within the context of the metaverse and virtual reality (VR), which could make people (who will confront the speculation) biased by the qualities of such interactions, we aim to present this virtual replica in a physical form. This physical form interacts with individuals through voice and light, in an effort to materialize the presence of the doctor and foster enhanced engagement with patients or other users. One may wonder why we choose to represent this virtual replica in a tangible form instead of utilizing a mobile application, software, or an online platform. To address this query, let's reflect on one of the key findings from the initial speculation:

When it comes to sensitive data, such as personally identifiable information (PII) or health records, people generally prefer to have a clear understanding of how this information is handled. They want reassurance that appropriate measures are in place to protect their data from unauthorized access, breaches, or misuse. **Transparency** and **comprehensibility** seem to be the key factors in addressing these concerns. Individuals desire clear explanations regarding the collection, storage, and sharing of their data. They want to know who has access to their information, the purpose for which it is being used, and how it is protected. When these details are communicated effectively and in a manner that is easy to comprehend, people feel more confident about sharing their data. One aspect that participants found valuable about the initial concept proposal was the inclusion of personal data collectors (DCs) for storing medical records. These DCs ensured that individuals had control over sharing their data with online systems, as they could decide when to share the information. However, participants were uncertain about whether, after inserting the DC into the gadget on the table, the shared data would be stored within the prognosis models or if it would only serve as input for generating treatment outcome predictions.

Figure 16 - Digital clone of the doctor being manifested to the Melanoma patient....

Relation

This layer focuses on establishing communication and interaction between the device and the sources of data, such as patients or wearable devices. The device collects relevant data, such as medical records, real-time health monitoring data, or user input, to enhance the understanding of prognostic models of the situation. This connection enables the device to gather the necessary information to provide personalized care and make informed recommendations. It is crucial for it to establish strong relationships with both the patients and their significant others. To achieve this, the device is designed to host a local NLP model and an interactive voice chatbot. During these interactions, the device assumes the role of a doctor, providing comprehensive and authoritative information. Therefore, the product's affordances should adhere to the following principles:

A- It ensures that they are well informed about their health conditions, treatment plans, medication instructions, and any other essential medical knowledge they should be aware of. at this level, the device serves as a comprehensive educational tool for patients and their loved ones, offering valuable knowledge about Melanoma, including its causes, risk factors, symptoms, and stages. It highlights the significance of early detection and regular skin screenings, urging users to monitor suspicious moles or changes in skin appearance. In addition, the device provides in-depth information on treatment options like surgery, radiation therapy, immunotherapy, targeted therapy, and chemotherapy, explaining the potential benefits and side effects of each. It also keeps users updated on emerging advancements and clinical trials.

B- The device also offers empathetic support to patients and their loved ones. The interactive voice chatbot should be there to understand and respond empathetically to the emotional needs and concerns of the patients. Through an interactive voice chatbot, it strives to understand and respond empathetically to their emotional needs and concerns. It serves as a compassionate listener, offering comfort, encouragement, and reassurance during challenging moments. This is where the significance of the "virtual replica" concept becomes even more evident. The device is supposed to exhibit empathy, akin to a specific doctor being physically present with the patient and unrestricted by time constraints. In fact, this is the core value of our speculation: **What if doctors are liberated from time constraints not having to deal with all the patients?** By proposing the idea of clinicians creating clones of themselves, aided by AI/ML technology to mimic their own empathetic pre-treatment process, we want to aim to investigate the possibility of incorporating additional valuable preferences into prognosis models.

C- The device motivates patients to reflect on their personal preferences, values, and individual circumstances. By engaging in interactive conversations, the device helps patients explore their own desires and goals related to their healthcare. It encourages them to consider their personal preferences when making decisions about their treatment options or lifestyle choices. The device should prompt patients to reflect on their personal goals, aspirations, and values beyond their melanoma diagnosis. It encourages reflection on what is most important to them and how they can integrate those aspects into their lives during treatment. This may involve discussing strategies for managing daily activities, maintaining social connections, addressing emotional needs, and pursuing hobbies or interests. By recognizing and supporting patients' personal goals, the device promotes a holistic approach to their well-being. Indeed, at this stage, we want to explore if the "packed-in-box doctor" can facilitate patient reflection on personal preferences, treatment options, lifestyle choices, emotional well-being, and personal goals, aiming to consider the data as an input for prognostic models.

D- It is important for the product to actively demonstrate that it is collecting data when it is actually doing it. This can be achieved by showcasing the loading of patient information and displaying a progress indicator. It is crucial to provide clear indications to the user regarding when the device is actively collecting data and when it is not. It is understandable that people do not want a device in their room that records all of their conversations, so privacy and transparency are vital considerations.

E- The device can gather data from various sources, including the patient's wearable devices, digital records, and other advanced technologies. This allows for a comprehensive collection of information about the patient's health and well-being. By integrating data from wearable devices, such as health trackers or smartwatches or futuristic mole trackers (which can be used as an alternative to biopsy for scanning the properties of the mole), alongside digital records and emerging futuristic technologies, healthcare providers can access a wealth of real-time and historical data to gain insights into the patient's condition. This holistic approach to data collection enables the audience of our speculation to experience a setting where a more accurate and comprehensive understanding of the patient's health status is followed, facilitating personalized and effective care.

Figure 17- The interaction between the patient and the digital clone of the doctor is being established...

Reflection

When the device reflects on what it collected from the patient

Reflecting the AI-generated profile to the patient:

The device actively gathers patient-reported data, including symptoms, daily activities, and overall well-being, and encourages regular sharing of this information. Simultaneously, the device analyzes the collected data and provides meaningful outcomes of the data by converting the conversations to patient attributes. A digital interface can be offered to showcase how the NLP model creates a profile of the patient, encompassing their physical/health attributes as well as their preferences and values. This interface, which reflects the patient's profile resulting from conversations with the virtual doctor, can either be embodied in the device itself or accessed through other patients' devices such as phones or laptops. To ensure local data transfer between the digital interface displaying the AI-generated patient profile, and the tangible device, methods like Bluetooth can be employed without requiring an internet connection to follow the previously stated qualities of interaction. It is important to note that the reflection presented may or may not align exactly with what the patient intended to convey to the clinician. Thus, patients should have a degree of autonomy to remove the AI-generated attributes. This feature can be effective in mitigating potential mistakes made by the AI and NLP models.

Reflecting the agreed profile to the doctor

Certainly, the utilization of AI-generated patient profiles is expected. One concern commonly faced by clinicians is the challenge of managing a multitude of patients, making it difficult to remember each patient's specific circumstances, conditions, and preferences. As a result, clinicians often rely on written patient profiles to review patient histories. In the context of data-driven healthcare, it is crucial to incorporate this profile review process. Therefore, we believe clinicians should have access to the AI-generated patient profile, allowing them to familiarize themselves with the patient's data. A proper option could be for patients to share their profile with the doctor while waiting at the clinic before their appointment. This would provide doctors with an opportunity to acquaint themselves with the patient's information, enabling a more informed interaction.

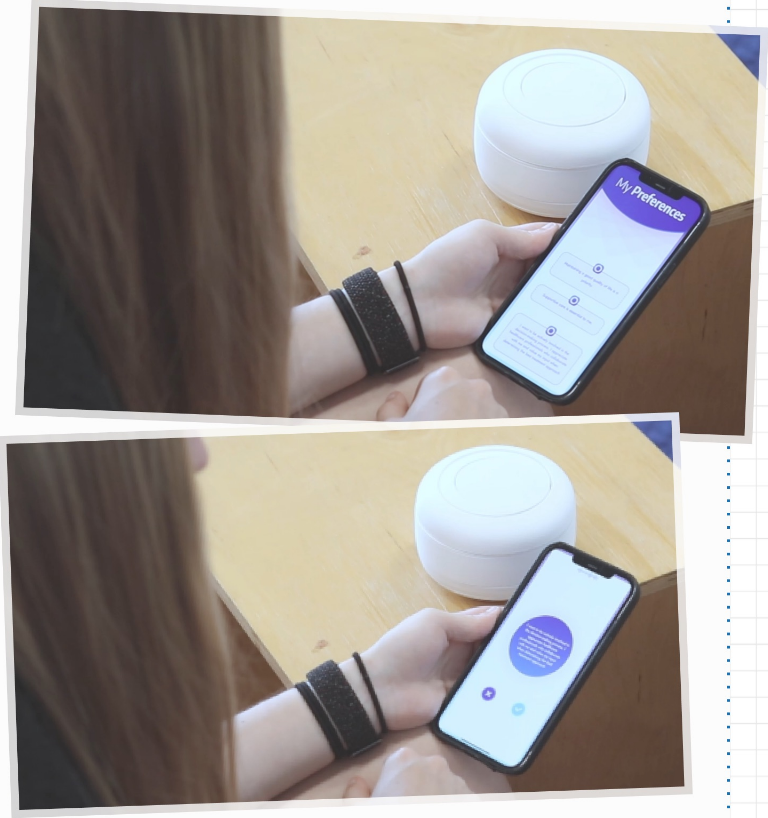


Figure 18 - The DST reflects on the collected preferences and patient can approve or reject them...

5

Revelation

When the device comes up with the suggested care path

In the final layer, the device presents the suggested care path to the user. Based on the AI's analysis of the collected data and the doctor's replicated expertise, the device generates recommendations for treatment plans, diagnostic pathways, or preventive measures. It delivers this information to the user in a clear and understandable manner, facilitating informed decision-making and enhancing the overall quality of care.

One of the challenges that arose in the fictional appointments, where participants took on the roles of patient, doctor, and significant other, was the inability to effectively relate and interact with a decision support tool (DST) that only provided numerical information about the outcomes associated with different treatment plans. While the participants could grasp the initial and subsequent predictions regarding the future, they struggled to compare and evaluate the various treatment options based solely on numbers. Remembering the numerical associations for each treatment strategy proved to be difficult.

To address this issue, we propose that a DST designed to empower patients should go beyond presenting mere numbers and instead provide suggestions for care plans. A truly effective data-driven decision support tool would become more user-friendly if it explained and described the future using narratives rather than relying solely on numerical data. This way, patients could maintain their autonomy while receiving valuable guidance and recommendations from the DST. By transforming the information into narratives that explain and describe potential future scenarios, an optimized, data-driven decision support tool can be more user-friendly and effective for individuals.

During a co-design session with designers at IDE, It was suggested that there is a remarkable potential for an immersive interaction to showcase personalized treatment plans. One of the innovative ideas that emerged from the session was to create an engaging and tangible experience for patients. The envisioned process involved patients carrying a portable device with them when they visit the clinic. This device would store their relevant data and preferences, enabling seamless integration between their personal information and the decision support tool. Once at the clinic, patients would have the opportunity to share their devices with a large interface, such as a magnificent table or a similar immersive platform. This interface would provide a visually captivating and interactive experience where patients could witness the unveiling of a meaningful and understandable treatment plan based on the data they provided.

Figure 19 - The DST presents the suggested care path....

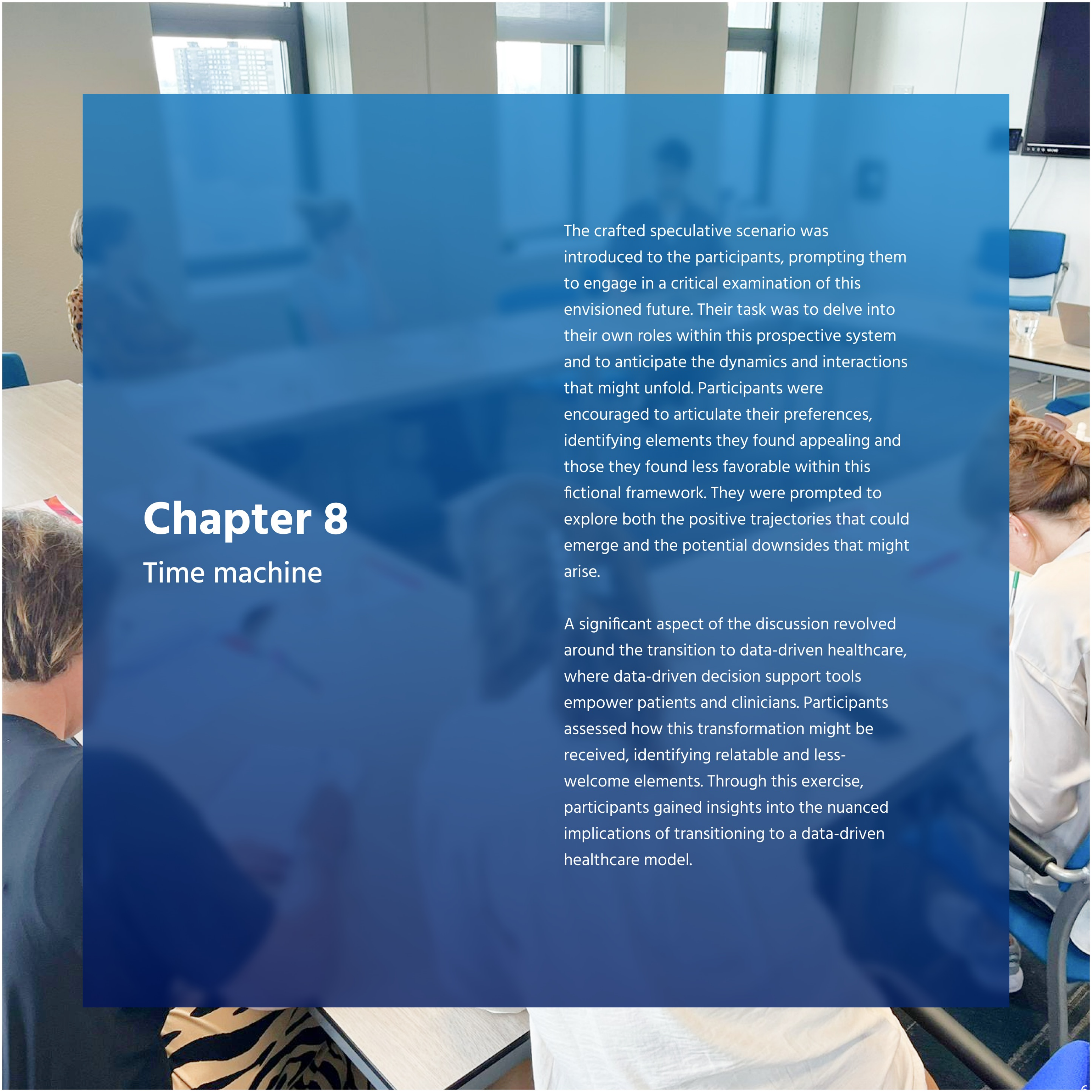
As the patient's information is integrated with the interface (by sharing the module that stores data within itself with the interactive interface), they would observe dynamic visualizations showing that the data is being used by the prognosis models to picture a proper future for them. They will go through graphics, and narratives that present the potential treatment plans and associated risks and benefits. This immersive interaction aims to enhance comprehension and empower patients by enabling them to see how their personal data is translated into a tailored and comprehensible treatment plan. Indeed, instead of giving the DST a passive role to only estimate the outcomes based on the input, it brings them insights and facts that they can act upon.

The large interface acts as a collaborative space, allowing healthcare professionals to engage in shared decision-making with patients. Now that they saved a lot of time by giving some of their responsibility to their clone, they can explore different treatment scenarios together, discussing the benefits, risks, and implications of each option. Also, they can discuss patients' feelings and emotions about each treatment option. The use of immersive technology gives users a space for merging personal data,

visualizations, and narratives, offering patients a deeper understanding of their healthcare journey and the confidence to make informed decisions.

Figure 20 - And together, they make a decision!

Fin!



Chapter 8

Time machine

The crafted speculative scenario was introduced to the participants, prompting them to engage in a critical examination of this envisioned future. Their task was to delve into their own roles within this prospective system and to anticipate the dynamics and interactions that might unfold. Participants were encouraged to articulate their preferences, identifying elements they found appealing and those they found less favorable within this fictional framework. They were prompted to explore both the positive trajectories that could emerge and the potential downsides that might arise.

A significant aspect of the discussion revolved around the transition to data-driven healthcare, where data-driven decision support tools empower patients and clinicians. Participants assessed how this transformation might be received, identifying relatable and less-welcome elements. Through this exercise, participants gained insights into the nuanced implications of transitioning to a data-driven healthcare model.

Co-speculation session

A session was organized at Erasmus Medical Center in Rotterdam, gathering a diverse group of experts specializing in the different fields of medical health. The attendees comprised a wide range of professionals, including master students, Ph.D. students, medical researchers, a nurse, a medical doctor and one university professor*.

Figure 21 : Demography of the enactment session

The session commenced with an introduction to speculative design, highlighting its distinctive features and capabilities when compared to traditional design approaches. The attendees were provided with an overview of how speculative design encourages thinking beyond current constraints and envisioning future possibilities. Following the introduction, a video was shown, showcasing a vision of the future. Presenting an alternative future in speculative design involves envisioning and communicating a potential future scenario that challenges existing norms and assumptions.

That's why a video was made to picture the future where CLONE is part of it. We pictured how different target users of future can interact with this scenario of the future of data-driven health care. The central theme of the video focused on the concept of doctors being able to clone themselves and the potential implications for decision-making. The scenario portrayed an extended timeframe allowing for close interactions and empathic communication between patients and clones of doctors who possess identical qualities, expertise, communication style, tone of speech, and other attributes. The objective was to investigate the potential impact of this technological advancement on the decision-making process within healthcare settings.

Goal: Our primary objective was to delve into the following question:

What if we could create clones of doctors, replicating all their attributes, and utilize these clones to empathize with patients?

What if we can utilize the clones to:

- **educate patients** about necessary medical information, treatment options, and the associated risks and benefits?
- **gather patients' preferences** throughout their interaction with this device and provide the collected data to clinicians for further analysis and decision-making?

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* One of the participants noted that she practices as a medical nurse and is also pursuing her Ph.D.

Our objective was to investigate the capacity for patients to connect with the cloned doctors within the device on an empathetic level. Within our alternative vision of the future, we endeavoured to forge a link between patients and these empathetic clones, envisioning a healthcare experience where patients can get much more support for making decisions and the support is more individualised and compassionate. Within this scenario, to comprehend patients' emotional requirements, empowering them to make well-informed choices, and cultivating a feeling of confidence in the results provided by data-driven interventions, patients are not constrained by the brief duration of clinic visits when expressing their concerns.

To strike a balance between reality and fiction in our vision of the future, an important consideration was that we made the deliberate choice to allow the clones to fully emulate the behaviour of their associated doctors and accurately portray the distinctive character of the doctor, while being limited to voice-based communication and lack certain qualities of human interaction such as eye contact and facial expressions.

Making the speculation, tangible!

To fully immerse participants in the speculative scenario, effective communication of the concept was essential. Different mediums were employed to bridge the gap between the envisioned future and the participants' present reality. The decision was made to create a prototype of the "Doctor in the Box" concept.

To illustrate the dynamics of interactions with the device, a compelling video was produced. Two skilled actors were chosen: one portraying a dermatologist and the other taking on the role of a melanoma patient. The scenario's storyline cantered around a doctor's efforts to assist her patient in making decisions about cancer treatment options. The patient grappled with the challenge of selecting the most suitable treatment approach.

Within this scenario, both the doctor and patient were guided through the shared decision-making process by a data-driven decision support tool. The video introduced a novel concept: doctors creating clones of themselves to engage with patients, gather their preferences, and then leverage this information as input for the data-driven decision support tool. This tool then generated a customized care pathway, elegantly showcasing the seamless integration of technology to elevate the healthcare experience.

The aim was to provoke critical thinking and stimulate discussion among the participants. That's why the actors were asked to portray various stages of interaction with the products of our visionary data-driven healthcare system in different locations, representing different settings such as the clinic, home, and office. Although the interactions with the products were shown in the video, specific dialogue or statements from the doctor, cloner, clone, patient, and complementary software and apps were intentionally omitted. This was done to eliminate any potential bias and ensure that the participants approached the scenario with an open mindset.

Speculative design can sometimes seem too distant from the present reality, which can make the proposed design concepts feel unrealistic or too far-fetched. The challenge lies in finding the right balance between impossible fiction and something that feels closer to reality. While the speculative label is relevant within the design research community, it may not resonate well with the people from healthcare domain and medical audiences. Instead, it's preferable for the design concepts to appear more real, creating a sense of verisimilitude where the boundaries between truth and fiction are blurred, and the audience can suspend disbelief (Auger, 2013). This approach, often referred to as design fictions, allows for more effective engagement and acceptance of the proposed ideas.

Hence, in our engagement with medical experts, we went beyond simply presenting the speculative future through a video. Alongside the video, physical mockups of the products used in the video's interactions were positioned on the table for all to see. This deliberate choice aimed to offer a concrete and relatable portrayal of our vision for the future.

These physical mockups enabled participants to closely examine the tangible elements, fostering enhanced comprehension and driving more substantive conversations. By engaging with these mockups directly, participants were empowered to grasp the concept more effectively and engage in discussions that were more substantial and insightful.

Facilitating the session

Throughout the session, my role was to create and foster an open-minded environment that encouraged the attendees to transcend their mental limitations when it comes to technology. Whenever someone mentioned a perceived limitation related to technology, it was my responsibility to remind them that in the future we envisioned, such limitations would no longer be an issue.

To facilitate creativity, we introduced puppets to make the characters of doctors and patients more tangible. We recognized that medical experts may be less accustomed to co-creation settings that encourage expressing their thoughts. To address this, we placed two sizes of puppets in front of each participant or group: larger one representing the doctors who can be cloned and smaller ones representing the patients. The session was designed as an open discussion where participants could critically engage with our vision of the future. The ideal scenario was to let the discussion naturally take shape, without me (as the session facilitator) constantly asking them questions like in an interview setting. To achieve this, right after the video was ended, we as four main questions were posed to prompt critical reflection and spark insightful conversations. These questions aimed to challenge the participants' preconceived notions, encourage imaginative thinking, and explore potential ethical and practical implications:

- How do you fill about decisions made using a hybrid doctor/doctor's clone system. Do you think this switch is essential for making informed decisions?
- Imagine you are a doctor in this future, and you want to create a virtual version of yourself for certain tasks. How do you feel about cloning yourself? What should/should not the clone do in this context.
- Imagine you are a patient in this future. You are likely much more informed when you want to meet your doctor for the first time compared to the past. Do you think this state of being more informed helps you make better decisions?
- How do you feel about patients sharing data with a clone of a doctor? Do you think that helps the doctor to be more informed about the patients' preferences?
- How do you think the interactions between the doctor and patients should look like in this future. How do you design this future? You can use puppets to depict the future. The big puppets are the doctors and the small ones are the patients.

The physical mock-up of the DST and the video of interactions within the speculated space was showcased...

Some materials where provided to increase the engagement of the participants in the subject...

Figure 22 : The co-speculation session at Erasmus M.C.

Time Machine!

Perhaps this section can be regarded as the pivotal and most valuable core of this research. We meticulously crafted a scenario depicting the data-driven future of healthcare and facilitated the immersion of participants from medical backgrounds into this envisioned future. In this prospective landscape, data-driven tools assume more active roles, substantially reducing the barriers within the clinical team.

Our strategy involved placing participants in a metaphorical "Time Machine," allowing them to explore this journey through a critical lens. This approach was a fundamental aspect of our initial plan, aimed at ensuring participants could establish a relatable connection with this future setting. We strived for their comprehension of ongoing developments, the alignment of their own roles within this narrated future, and the recognition of how their interactions with various components of this speculated scenario (such as stakeholders, AI, prognostic tools, colleagues, and the overall system) could take shape and become meaningful.

To encapsulate the essence of speculation, which entailed delving into moments, qualities, and interactions that deviated from the immediate concrete reality—striking a balance between avoiding the constraints of the present and venturing too far into an unfathomable future—our endeavor focused on providing a range of speculative and thought-provoking materials. These materials acted as tools, drawing individuals into this future by offering a tangible connection.

The tangible components of the "doctor in the box" concept, along with the accompanying video demonstrating interactions between a doctor, patient, and a representative prognostic tool capable of responding in the doctor's voice, served as effective facilitators. These elements expedited the seamless transition from the current state to the context of speculation.

Having enabled participants to traverse this future with a discerning perspective, the subsequent phase involved reflecting on the diverse approaches adopted by participants during the speculative session. We delved into the major themes that emerged from discussions, traced the flow of conversations, and examined the array of questions stemming from the core "what if" inquiries assigned for the session.

Contrasting perspectives

in approaching the future

Rather than immediately delving into assumptions derived from future discourse, introducing this futurism with a focus on the intriguing array of dualities that surfaced as participants grappled with the challenges presented by the envisioned future scenario could be an engaging approach.

A: Futurists vs Present-Centric:
While some individuals naturally grasp future possibilities and trends, others find it imperative to anchor these possibilities within the present context.

On one side of the spectrum, there were those who eagerly embraced the notion of immersing themselves in the future, swiftly transporting themselves to the realm of speculation. These participants contributed valuable insights, meticulously dissecting the intricacies of interactions within the speculative scenario. This group showcased an impressive comprehension of potential challenges and pitfalls linked to the implementation of data-driven systems, particularly in the form of a data-analyzed decision support tool. On the other side of the spectrum, some participants approached the speculation with a more cautious stance, seeking to bridge the gap between the speculative and the practical. They appreciated the concept's futuristic aspects but also emphasized the need to assess its viability in the current medical landscape. These participants critically examined the potential disruptions that data-driven systems might introduce and the potential discrepancies between the speculative scenario and the present healthcare context.

Interestingly, despite these differing approaches, both groups shared a common thread of curiosity and engagement. The first group skilfully navigated around the constraints that data-driven decision support tools might impose, envisioning a future where these tools become integral to the caregiving journey. The second group, while being mindful of present realities, also recognized the value of exploring future possibilities, indicating a willingness to adapt and integrate innovative tools within the healthcare domain.

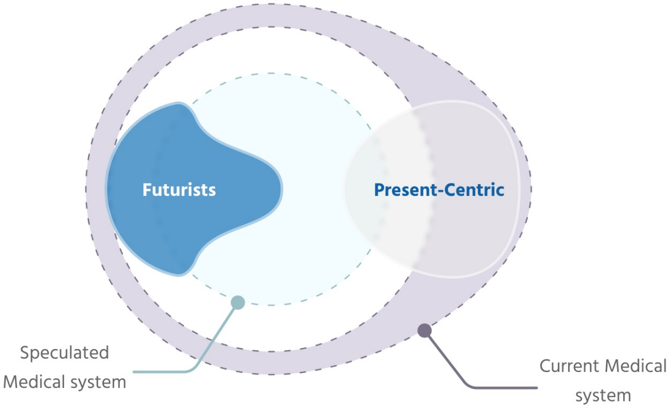


Figure 23 : The capability of futurists to navigate the realm of speculation compared to Present-Centrics, who remain anchored in the present.

B: Technology Adherents vs. Nature Philosophers: There are those who are immersed in emerging technologies and their potential impact on the future, and those who value current, less manipulated by technology care practices when imagining future possibilities.

The idea was to provide a doctor-patient interaction that extended beyond the clinical appointment and into daily life, home and work settings, and even private life. Indeed, we hoped to open up doors to a future vision by offering some tool as a doctor clone that could interact with patients outside of the clinic and contribute to the process of informed decision making by continuously teaching the patients the options that they have and the associated risks and benefits, as well as collecting the patients' specific preferences. This vision of a data-driven decision support tool was adhered to by one group but not by another.

Some people saw this as an opportunity to provide patients and significant others with continuous interaction with the digital doctor in order to make them better informed about the care path and decision options. They argued that having a doctor clone would not only enhance patients' understanding of their medical conditions and treatment options but also foster a sense of companionship and reassurance.

On the other side of the spectrum, those who were cautious about the extended interaction model emphasized the importance of privacy and the potential for information overload. They believed that patients might feel overwhelmed or even anxious with a constant stream of medical information and reminders. These sceptics argued that the traditional doctor-patient relationship should not be diluted, as the emotional and psychological support provided by in-person consultations could not be replicated by a virtual clone. They also raised concerns about the accuracy of medical advice given by a non-human entity, highlighting the potential risks associated with relying solely on machine-generated recommendations.

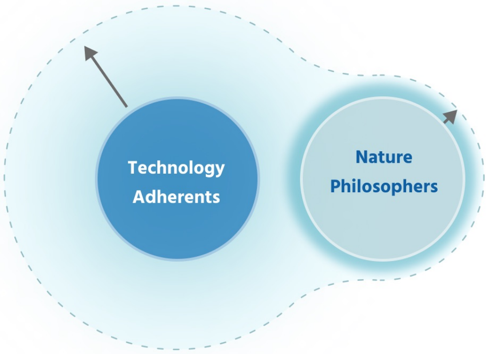


Figure 24 : Technology Adherents vs. Nature Philosophers: Arrows denote the reach of interaction diffusion, while colour saturation signifies the degree to which interactions retain a humanlike quality.

C: Holistic System Thinkers vs Individualistic Isolators:

Some people view the future as a complex web of interconnected systems and roles, considering multiple factors, while others see it as a linear progression from one specific subject.

In the context of speculative foresight, a subset of medical experts exhibited a distinctive tendency: they seemed unable to venture into the future without placing themselves and their designated roles at the centre of their contemplations. These individuals, firmly anchored within their own professional identities, shaped their vision of what lay ahead primarily through the lens of their immediate interactions with various stakeholders. Their perspective on the future was so closely intertwined with their own positions that it appeared as though they had constructed a personal echo chamber, where the ripples of change barely extended beyond their individual purview.

What sets this particular group apart, however, is their capacity to unravel the intricate complexities of data-driven systems within their domain. They possess an acumen for delving deeply into the implications of technology and data integration, meticulously scrutinizing how these innovations could potentially reshape their roles within the broader healthcare framework.

On the other hand, the other cluster takes a broader perspective when envisioning the future of healthcare. These individuals understand that medical healthcare is intricately interconnected, with various systems, elements, and variables influencing one another in intricate ways. They analyse potential outcomes by considering a multitude of factors, ranging from environmental impacts and technological advancements to social dynamics and economic trends. Holistic thinkers believe that predicting the future requires a deep understanding of these complex interactions between patients, clinicians, data-driven systems, and strategists, and the ability to anticipate how changes in one area might reverberate throughout the entire medical system.

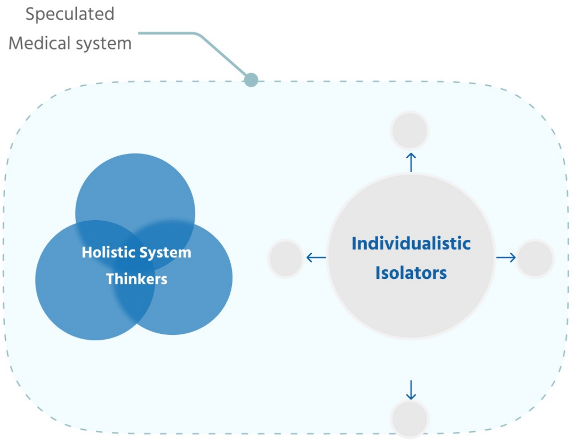


Figure 25 : Holistic System Thinkers vs Individualistic Isolators in relation with the speculated world

Having delved into the contrasting perspectives of individuals with a medical background regarding this crafted speculation, the moment has arrived to systematically gather essential inquiries, apprehensions, and declarations about the visioned future.

This will involve a thorough examination of each **major quotation**, followed by an attempt to categorize, group, and distil them into a coherent and meaningful synthesis. Our objective is to brainstorm potential functionalities that the concept we're envisioning for the future could offer.

Simultaneously, we will delve into the necessary **considerations** that developers, designers, managers, and decision-makers should bear in mind while working on the development of data-driven systems.

Potentials of the speculated device to help patients manage data overload

"My initial observation is that having the opportunity to engage in conversation, even if it's not with a human, is quite valuable. I am of the opinion, and my understanding supports this, that **after a patient departs from the clinic, much of the information shared tends to be forgotten.** Hence, having dedicated time to absorb the information privately and being able to consult the AI when questions arise is a beneficial aspect"

This quote highlights the importance of enabling individuals to communicate, even with an artificial entity rather than a real doctor. The participant contends that information conveyed during a clinic visit tends to be forgotten once the patient departs, potentially due to various reasons. Therefore, having a solitary period to absorb the information, along with the option to clarify doubts through an AI, Prognostic tool, or another non-human agent as questions arise, is suggested as a valuable approach. This perspective underscores technology's potential to address the issue of retaining and accessing post-clinic information.

"During medical appointments, patients may have difficulty **recalling all of their preferences and concerns from memory when asked questions.** This makes it challenging to have a thorough discussion with the doctor. Patients often wish they had a device to quickly get answers to questions that come up during the appointment"

The quote emphasizes that the real-time access to information of the doctor can be beneficial, since patients often struggle to recall their concerns and preferences, impacting clinical interactions. The idea of an data-driven decision support tool that provides immediate and accurate responses aligns with the need for effective patient-clinician communication is appreciated. The data-drivens tool's ability to quickly retrieve relevant information is valuable beyond routine check-ups, assisting patients with specific health knowledge can be definitely helpful.

Potentials of the speculated device to help patients manage data overload

“I believe that when patients visit a physician, **they tend to underestimate their symptoms, complaints, and adverse events.** However, in real-time situations where patients interact with nurses or other healthcare professionals, or **when they are asked daily questions through a web application, they are more open about expressing their genuine complaints and symptoms.** It’s because they know that their responses on that online platform are being directly communicated to a healthcare professional, even though they may not always be aware of the specific person behind the communication.”

The quote emphasizes the importance of real-time access to information of the doctor, since patients often struggle to recall medical details during consultations, impacting clinical interactions. The idea of an data-driven decision support tool that provides immediate and accurate responses aligns with the need for effective patient-clinician communication. The data-driven tool's ability to quickly retrieve relevant information is valuable beyond routine check-ups, assisting patients with specific health knowledge.

"I am aware of my own tendency to become a bit impatient in the clinic, and I would readily embrace a clone of myself devoid of this particular trait.”

This perspective aligns with the evolving notion of AI as a versatile tool that adapts to the preferences and needs of healthcare professionals. By incorporating traits that might be different from a doctor's, such as patience or a consistent demeanour, AI can serve as a valuable partner in ensuring consistent and empathetic interactions with patients. Developers have a unique opportunity to design DSTs that strike a balance between efficiency and human connection. Customizable AI characteristics can be tailored to align with individual healthcare professionals' strengths and areas for improvement. For instance, an AI with infinite patience can help address instances where a doctor might feel rushed or stressed, thereby contributing to a more positive patient experience.

Potentials of the speculated device to help patients manage data overload

> “When patients are left in a state of uncertainty, they often resort to searching their questions on Google, resulting in an influx of information. It becomes challenging to determine what exactly to search for and what constitutes reliable information. In my daily interactions, I frequently encounter individuals who jump to conclusions, associating minor symptoms like headaches with serious conditions like cancer. This prevalent fear of mortality leads them to turn to Google for answers. This device, however, can tailor the information for the patient based on their needs.”

The quote points to the role of data-driven DST in addressing the "Dr. Google" phenomenon, where individuals turn to search engines for medical advice. By offering a trusted source of information within a Decision Support Tool, developers have an opportunity to foster a healthier and more constructive way for patients to seek answers to their health-related questions.

This statement highlights the need for data-driven healthcare tools to serve as curated, reliable, and empathetic sources of information, and that's why this speculation can be appreciated for.

It also emphasizes the overwhelming abundance of information available on the internet, particularly when it comes to health-related concerns. It emphasizes the importance of a reliable and curated data source, suggesting that a Decision Support Tool should provide accurate, context-aware information to alleviate patients' fears and ensure informed decision-making.

> “ It seems, we don't need nurses anymore in this future. I wonder if patients will ask physicians questions instead of relying on this system (clones) in the future. **When it comes to emotions, they'd rather talk to the nurse.** In the palliative phase, a specialized physician, usually an oncology nurse, is more appropriate for these discussions. ”

> “When you have a perfect device, it's like you have a second opinion, but then in a perfect way. So, as a doctor, I would feel disturbed or I would find it difficult to deal with a colleague, a perfect colleague in this device that acts like me, but makes better decisions”

The passage delves into a conservative perspective on the evolving role of technology, particularly AI and data-driven systems, in healthcare, prompting reflections on the potential impacts of this transformation. It challenges the idea of a future where data-driven tools may replace traditional healthcare roles and their interactions, emphasizing the irreplaceable aspects of human involvement, such as emotional support and nuanced expertise, especially in sensitive phases like palliative care. It highlights the need for trust and effective communication between patients and healthcare providers amidst increasing technological influence. While recognizing the benefits of data-driven tools, the quote underscores the enduring value of human empathy, understanding, and specialized medical knowledge in patient care, ultimately asserting that technology can assist but not fully replicate the complex nature of human interactions and emotions in healthcare.

“On the other hand, if the device offers too much support or performs too well, there's a possibility that the patient might neglect or disregard the actual human interaction with the real doctor. This person, who is imperfect, might be overlooked because the device appears to be flawless. The device can accommodate every idea and answer every question, providing unwavering patience. It's unlikely to find such a remarkable doctor in one's life. **Consequently, there is a risk of becoming overly reliant on this device.** I'm unsure about the best approach to navigate this situation.”

One of the most significant impressions from the quote is the acknowledgment of human imperfection. Healthcare providers, while not flawless, bring an element of empathy, understanding, and personalized care that is challenging for data-driven tools to replicate fully. The warmth of a reassuring smile, the compassion in a tone of voice, and the ability to read subtle non-verbal cues are all hallmarks of human interaction that contribute to patient well-being.

Developers must embrace this insight by designing data-driven tools that amplify the strengths of both technology and human interaction. The tool should not aim to replace healthcare professionals but to empower them and patients alike. This could involve creating an ecosystem where data-driven tools enhances patient education, facilitates efficient information sharing, and supports decision-making, all while encouraging patients to actively engage with their healthcare providers.

In navigating this landscape, ethical considerations take center stage. Developers have a responsibility to ensure that the data-driven tool's capabilities do not overshadow the importance of human-centric care. The tool should align with the principles of patient autonomy, well-being, and shared decision-making, rather than steering patients away from meaningful human interactions.

DSTs can be designed with a level of emotional intelligence, recognizing indicators of emotional states and tailoring responses accordingly. This can create a semblance of empathy in AI interactions, even though it doesn't replicate genuine human emotion.

In essence, while AI can undoubtedly enhance healthcare decision support, developers should remain mindful of the irreplaceable value of human communication. Developers should consider the concept of "augmented intelligence" rather than "artificial intelligence" in healthcare. This entails designing AI tools that amplify human expertise not by focusing on emphatical communication, but by providing relevant data and insights, thereby enabling healthcare professionals to make more informed decisions.

“I'm doubting that if it can fully act as a replacement. Because, um, the non verbal part of communication, you totally miss it. And it's very important, in the doctor patient relationship.”

"Doctor in the box" not being seen as a threat, but rather as an opportunity that simplifies the role of doctors

"So, I wouldn't say doctors are becoming obsolete, but rather the more monotonous, tedious aspects of their job are becoming easier to replicate, freeing up their time. As a result, doctors can focus more on the indispensable parts of their profession and dedicate additional time to them."

"Since the device operates using the doctor's voice, in my own perspective, I believe that can facilitating the establishment of **trust** and fostering a connection between patients and physicians."

The evolution of data-driven tools in healthcare represents a transformative opportunity, one that doesn't render doctors obsolete, but rather empowers them to elevate their roles. AI's ability to handle data analysis, information retrieval, and other routine tasks can significantly enhance doctors' efficiency and accuracy. This, in turn, grants doctors the precious gift of time – a resource often in short supply – enabling them to immerse themselves in the art and science of medicine.

Doctors can now devote their energy to the deeply human aspects of their practice. Patient interactions become more meaningful, as doctors have the bandwidth to truly listen, understand, and connect with patients on a personal level. The holistic care that doctors provide can be enriched, as they delve into complex cases, collaborate with interdisciplinary teams, and make nuanced decisions that require years of medical expertise.

"Doctor in the box" not being seen as a threat, but rather as an opportunity that simplifies the role of doctors

> “I think that the difference between making it a clone of a doctor and making it to be a perfect doctor on its own is really important to explore and to be well defined, because as a doctor, I prefer to think that I don't actually have a perfect colleague, this is actually me, a copy of myself which takes Google and years of medical school researches and everything else to help me make decisions.”

This quote delves into the field of perception and identity in the context of AI in healthcare. It prompts a reflection on how we perceive and relate to technology that simulates human expertise. The idea of a data-driven DST as a "perfect doctor" with an identical voice might initially sound appealing, yet it also underscores the complexity of this dynamic.

In a world where AI can process vast amounts of medical data, simulate complex scenarios, and generate informed recommendations, the idea of presenting it as a "version of oneself" but magnified by advanced capabilities is thought-provoking. It poses questions about how we reconcile the natural human inclination to trust and relate to human-like entities with the reality that AI operates on an entirely different level.

In the end, the quote encourages a nuanced view of data-driven tools role in healthcare. It's not about replicating human doctors, but rather about fostering a harmonious coexistence between human wisdom and technological prowess. It highlights the need for clear communication and education so that patients, doctors, and society at large can appreciate the transformative potential of data-driven tools without losing sight of the unique qualities that define our human experience in the realm of healthcare.

"That's the question. Whether they prognostic tools will be like, less biased. Yeah, you never know. Because in the end, they are man made, I guess. And we are biased, so we have to be very aware that we don't put our biases also onto the systems."

This quote poses a thought-provoking question about biases in data-driven tools and technology. It acknowledges that even in a perfect future, data-driven systems can still be influenced by the biases inherent in human decision-making since they are being created by humans. This recognition underscores the need for a vigilant and proactive approach among developers to ensure that their own biases do not inadvertently find their way into the data-driven systems they design.
Developers stand at a crossroads where they have the power to either perpetuate biases or mitigate them through careful and intentional design.

"But, what if this device is not perfect? Let's say the doctors or the developers could have biases when programming it. And if there's no human or medical knowledge involved, those biases could affect the device's decisions. What if the device wrongly identifies something as cancerous when it's not? I was wondering about the potential mistakes and ethical limitations of relying solely on this device in a medical context. What are the boundaries of this device?"

Developers and clinicians should recognize that even the most sophisticated AI algorithms can make mistakes, especially in complex medical diagnoses. This underscores the importance of maintaining a collaborative framework that includes healthcare professionals who can provide critical oversight and judgment over prognostic models outcome.

Concerns about potential bias in the data-driven systems

“As healthcare professionals, we sometimes make assumptions about people based on their background or appearance and anticipate their treatment preferences accordingly. We, we never do it on purpose, I think. But we also are aware that we do it a lot.”

This quote touches upon a critical issue that pervades healthcare decision-making – the presence of unconscious biases. It candidly acknowledges that healthcare professionals, despite their best intentions, can unintentionally make assumptions based on factors such as a patient's background or appearance. This recognition highlights the need for data-driven decision support tools to not only provide accurate medical information but also actively contribute to addressing these biases.

Developers of data-driven tools have a unique opportunity to be catalysts for change in this regard. They can create technology that acts as a counterbalance to these biases and empowers healthcare professionals to deliver more equitable and patient-cantered care.

“I was wondering, to what extent is a patient able to manipulate the data, and what are the consequences? I mean in a perfect world, I hope everyone is honest, but I don't think that will be the case. What if the patient doesn't state preferences honestly. I don't know to what extent there's control over it. What are the consequences, when they make the decisions?”

Developers should implement mechanisms to verify the accuracy of patient-provided data, cross-referencing it with existing medical records or external sources to detect inconsistencies or discrepancies.

DST and data-driven systems could educate patients about the importance of accurate data and how manipulations can affect their care. Patients need to understand that the quality of recommendations relies on the accuracy of information shared. Doctors should also be able to discuss the importance of honesty and how accurate data contributes to optimal care.

Apprehensions about the influence of intuition and the necessity to take it into account.

"However, there are also situations in which patients might disagree with the doctor's best interpretation, based on their own reasons and preferences. This relates to the discussion we had earlier about the importance of individual preferences. Sometimes, patients may trust their own intuition and have a gut feeling that the doctor's judgment is incorrect."

"However, I believe, and there is scientific evidence to support this, that a significant part of decision-making is influenced by various factors beyond just reliable information. These factors can vary from person to person and may play a significant role in shaping their decisions."

"But your gut feeling is not always based on evidence or scientific knowledge any other piece of data, but it still has value. And I would find it difficult than convince the patient that their gut feelings can not be valid**"**

These quotes highlight a critical aspect of decision-making that goes beyond the straightforward provision of information. It underscores the reality that healthcare choices are influenced by a complex interplay of individual factors, cognitive processes, emotions, and cultural context. While data-driven decision support tools excel at delivering accurate and relevant data, they must also acknowledge and address the intricate web of influences that guide patients' decisions about their health. What can be suggested here is that prognostic models can also be implemented in a way to learn from human intuition by actively recognizing, analysing, and integrating instances where human intuition has led to successful medical decisions. This process allows data-driven tools to enhance their decision-making abilities by considering not only data but also the valuable insights that arise from the experienced and intuitive judgment of healthcare professionals.

Extent of boundaries and functionality limitations.

> “In a scenario where a device provides advice on the best treatment for a patient, do you believe that is the ideal situation? Personally, I have reservations about it and feel that it might not be the optimal choice to let the device advice them a care path without presence of doctor .”

Absolutely, this quote touches upon a critical aspect of the Role of data-driven tools in healthcare. – the extent to which they should influence treatment decisions. It raises valid concerns about the potential pitfalls of relying solely on technology for such crucial matters. This quote highlights the delicate balance that developers need to strike between leveraging prognostic model's capabilities and preserving the essence of human judgment and personalized care in medical decision-making. The key lies in harnessing AI as a powerful tool that enriches, amplifies, and informs medical decision-making. Developers must design prognostic algorithms that provide comprehensive insights, offer a spectrum of treatment options, and consider relevant data points. However, the final decision – one that takes into account the patient's unique circumstances, preferences, and the doctor's clinical expertise – should remain a collaborative effort. AI should be positioned as a valuable aid, especially in scenarios where its analytical capabilities shine, such as data analysis, pattern recognition, and treatment outcome predictions. It's an opportunity to free up healthcare professionals' time from routine tasks, allowing them to focus on the human-centered aspects of medicine – empathy, communication, and individualized care. Lastly, it's crucial to foster open dialogue and collaboration between developers, healthcare professionals, patients, and ethicists. This multidisciplinary approach ensures that AI tools are designed with a deep understanding of the medical field's intricacies and ethical considerations.

Extent of boundaries and functionality limitations.

"The tool should not be viewed or framed as the one who's going to make the decision, but supports them for decision making providing data for both parties(patients and clinicians). the tool should have curtain boundaries in making interactions"

The quote reflects a thoughtful understanding of the delicate balance that AI developers must strike when designing Decision Support Tools. It underscores the importance of maintaining the human touch in medical decision-making, while leveraging prognostic models capabilities to provide data-driven insights and analysis. This approach aligns with the idea that medical decisions are influenced by a multitude of factors, including clinical expertise, patient preferences, and ethical considerations.

Moreover, the notion of setting clear boundaries for data-driven systems interactions speaks to the ethical and psychological dimensions of integrating them in healthcare. By establishing well-defined limits, developers can ensure that patients, clinicians, and the DST itself understand the extent of its role and avoid potential misconceptions.

> “as a doctor, sometimes you are very empathetic in your communication and with some other people you try to communicate more direct. When you're so empathetic, It may be the case that they hardly follow whatever you would advise them. I wonder whether this kind of systems could also make this differentiation based on the person just in front of you. So I think that's most important. I think it's even more important than the content you are telling. And I don't know whether this kind of system could do that.”

This perspective underscores the diversity of patient reactions to different communication strategies and their potential influence on compliance with medical advice. Data-Driven Systems (DST) offer the opportunity to adapt communication approaches according to individual patient preferences and receptiveness. This approach aims to strike a balance between empathy and directness, addressing the challenge posed by varying communication needs among patients. Developers have the chance to craft data-driven systems that excel both in interpersonal interactions and medical expertise. By analyzing patient interactions and learning from effective communication strategies, Artificial Intelligence can personalize its approach for each patient, thereby increasing the likelihood of fostering patient engagement and adherence to medical recommendations.

"What can a Decision Support Tool do when preferences are no longer feasible? One idea is that the tool could interact with the patient in a way that while it is aware of the preferences and wants to respect them, they can't be followed because of the limits., We need to also explore whether the doctor should take this initiative or if the tool should communicate it with the patient."

The quote prompts debatable issues regarding the function of a decision support tool in comprehending and navigating patients' concealed preferences and restrictions, especially when those preferences cannot be practically accommodated. In order to communicate with patients about preferences that cannot be met, developers should investigate how DSTs and clinicians should interact with them.

"The concern is that implementing a device with medical functionality, even in a home setting, could remind people of their illnesses and create a barrier to acceptance. Past experiences with medical apps have shown that individuals prefer not to be reminded of their medical conditions when they're at home. This introduces the question of whether people will truly embrace such a device, as it essentially brings the hospital environment and its associations into their homes. This potential obstacle is a key consideration."

As we embrace technological advancements, it's crucial to recognize that healthcare extends beyond hospital walls. The integration of technology into patients' homes should be a thoughtful and deliberate process that takes into account their emotional needs and preferences. It necessitates a design approach that empowers patients, allowing them to control their engagement and ensure that their homes remain spaces of solace.

This quote reinforces the importance of fostering a human-cantered approach to healthcare technology. It prompts us to envision solutions that seamlessly blend the benefits of technology with the human touch, preserving the dignity, autonomy, and emotional well-being of patients.

Navigating the fluctuations in preferences

> "We possess numerous undisclosed preferences, much like the abundance of unspoken limitations, specifically when we are ill. The device can be helpful in revealing them since it spends more time with the patient."

> "I continue to believe that the device is monitoring me in order to gather data, which can then be utilized for improving decisions. In my opinion, tracking over an extended period would be more advantageous, as preferences tend to change over time. This would allow for a comprehensive coverage of these evolving preferences."

These quotes highlight the benefits of data-driven tools continuously tracking patient data to enhance decision-making by accommodating evolving preferences over time. This concept suggests that extended data monitoring can yield more comprehensive insights and ultimately lead to better healthcare outcomes.

Patient preferences can change due to various factors, including health status, lifestyle shifts, and personal experiences. Data-driven tools can analyze these changes to provide accurate and current recommendations. Continuous data collection enables personalized suggestions that consider the patient's current state, recent experiences, and changing preferences.

This aligns with the idea that medical decisions should adjust to changing circumstances rather than relying on static information. However, ethical responsibilities come with this potential. The concept of continuous data tracking raises concerns about patient consent, data security, and transparency. Striking a balance between gaining insights from ongoing data tracking and respecting patient privacy is crucial.

Chapter 9

“The Journey, the transition”

We embarked on this research with the initiative to explore the qualities of proper interaction with a data-driven decision-support tool. This tool should empower participants to play an active role in the shared decision-making process and enable them to make informed decisions. We aim to investigate how such a tool should be presented to its users.

In this section, our goal is to translate the insights gained from the co-speculation session with healthcare providers into meaningful considerations for designers, developers, data scientists, strategists, healthcare providers, and any consortium members involved in the transition from traditional decision-making to data-driven decision-making

From ambiguity to an evolved shared mind

a model for Exploring the Patient-Doctor Interactions Supported by Data-Driven Decision Support Tools for Shared Decision-Making in Oncology

The Transition:

Our research so far reveals that the interactions between patients and doctors often involves an Endeavor to transition from a state of initial ambiguity to a point of shared understanding regarding the medical situation and individual preferences. This process underscores the importance of effective communication and mutual collaboration in healthcare. Patients and doctors alike seek to bridge the gap of uncertainty by engaging in open dialogue, exchanging information, and aligning their perspectives. This journey from uncertainty to clarity not only enhances the doctor-patient relationship but also contributes to informed decision-making and patient-cantered care.

This state of clarity represents a scenario in which all individuals engaged in the decision-making process have progressed, as articulated by Epstein, toward the concept of a "shared mind." This notion underscores the collaborative nature of effective decision-making, wherein all relevant stakeholders have converged their perspectives, preferences, and information. Epstein's characterization of a "shared mind" highlights the significance of comprehensive communication and the synthesis of diverse viewpoints. In this cohesive state, the collective understanding serves as a foundation for well-informed decisions, fostering a harmonious and informed decision-making environment.

What sets this project apart is its distinctive approach, wherein Decision Support Tools (DST) function as companions for both patients and doctors, working collaboratively as facilitators of enhanced decision-making for patients and doctors alike. These tools play a pivotal role in condensing the vast, dispersed pool of data into a concentrated, pertinent reservoir of information that encapsulates individual preferences, current status, and the stage of cancer, as well as prospective directions.

The primary function of Decision Support Tools (DST) indeed is to streamline information, guiding both cancer patients and doctors (Dermatologist, Oncological surgeon and other relevant care providers) through a transformative journey from a state of ambiguity to an evolved shared mind. These tools serve as navigational aids within the complex landscape of medical data, offering a structured path towards clarity and understanding.

By harnessing advanced prognostic algorithms and data processing capabilities, DST distill the wealth of available information into meaningful insights and action points. This refinement process entails organizing, categorizing, and prioritizing data relevant to a specific medical situation. This curated information equips patients and doctors with a comprehensive grasp of pertinent details, enabling them to make well-informed decisions.

In the context of this project and based on insights obtained from speculative sessions, the pivotal functionalities of a Decision Support Tool (DST) are inherently observed to align with this transitional process. Patients traverse a trajectory that encompasses two key phases, and the DST plays a crucial role in facilitating this transition.

Initially, patients embark on a stage characterized by limited knowledge about their cancer diagnosis and the array of treatment choices available. During this phase, there exists a notable lack of self-awareness regarding their preferences and the factors that hold significance in their decision-making process. The DST (in collaboration with the medical team) can step in as an illuminating guide, gradually unraveling the complexities of the medical landscape. It can provide patients with comprehensive information about their condition, demystify treatment options, and introduce them to the array of available treatment options. Through this educational journey, the DST can be seen as a tool that empowers patients to elevate their understanding, fostering a sense of empowerment and engagement in their own healthcare decisions. As patients progress, the DST continues to play a transformative role. Patients transition into a phase where they are not only acquainted with their available treatment alternatives but are also attuned to their personal priorities and values. This evolution of self-awareness is a direct result of the DST's support, which prompts patients to reflect on their preferences and weigh the implications of different treatment paths. Armed with a deeper understanding of their own aspirations and concerns, patients are poised to make decisions that align with their unique circumstances.

Absolutely, the transformational journey facilitated by Decision Support Tools (DST) extends to doctors as well. Just as patients evolve through stages of understanding and self-awareness, doctors undergo a parallel transformation in their approach to treatment selection.

Initially, doctors often operate from a position where they possess limited knowledge about their patient's specific circumstances. They may rely heavily on their past experiences and general medical knowledge to devise treatment plans. This reliance on established practices and past encounters can lead to treatments that may not be optimally aligned with the individual patient's needs and preferences. Additionally, factors such as treatment feasibility and availability can significantly influence the options presented to patients.

Enter the DST, which serves as a catalyst for change in the doctor's decision-making process. As doctors engage with the tool, we speculate a transition to an evidence-based approach that is deeply rooted in the latest medical research and evidence-based data. The DST can be seen as a tool that presents doctors with a comprehensive overview of treatment options, showcasing the outcomes, potential benefits, and drawbacks associated with each choice. This evidence-driven perspective empowers doctors to make more informed decisions that are backed by the most current and relevant information available from clinical trials.

More importantly, the DST encourages doctors to adopt a patient-centered approach. By emphasizing patient preferences and values, the tool nudges doctors to consider treatments that resonate with the patient's unique circumstances and aspirations. This shift from a one-size-fits-all mindset to a personalized, patient-aligned approach is instrumental in fostering trust and collaboration between doctors and patients.

Three stages of interactions within the transition:
The progression from a state of ambiguity to the shared mindset state unfolds in a structured manner through three distinct stages: the foundation stage, the exchange stage, and the empowerment stage.

A- The foundation stage:
The foundation stage marks the initial step in this transformative journey. During this phase, the emphasis is on instigating interactions that lay the groundwork for mutual trust and emotional connection among the doctor, patient, and the Decision Support Tool (DST). These interactions serve as the building blocks for a robust doctor-patient-DST relationship, fostering an environment where open communication and collaboration can thrive.

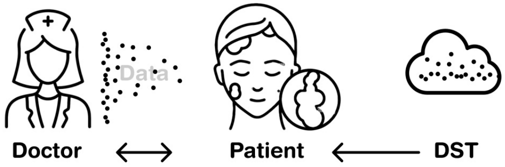


Figure 26 : DST-Patient-Data interaction in the foundation stage

B- The exchange stage:

Advancing to the exchange stage, the role of DST becomes pivotal in facilitating the exchange of vital information between the patient and doctor. Here, the DST acts as a conduit for patient-doctor information sharing. Patients share their preferences and personal inclinations with the doctor, allowing for a comprehensive understanding of their individual values and priorities. In turn, doctors reciprocate by sharing their medical expertise and insights, enhancing patient literacy about their condition and available options. This stage reinforces the collaborative nature of healthcare decision-making, where the DST acts as a facilitator of information flow, enriching the doctor-patient relationship.

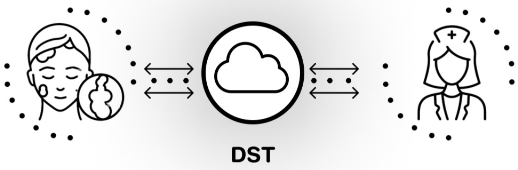


Figure 27 : DST-Patient-Data interaction in the exchange stage

C- The empowerment stage:

Culminating in the empowerment stage, the DST takes on the role of an active participant in the decision-making process. At this juncture, the DST steps forward to provide tailored suggestions to both the patient and doctor. These suggestions are aimed at crafting a personalized care path that aligns with the patient's preferences, medical needs, and the doctor's expertise. This stage underscores the transformative power of technology in augmenting the decision-making landscape, ensuring that choices are well-informed, patient-centered, and in harmony with medical best practices.

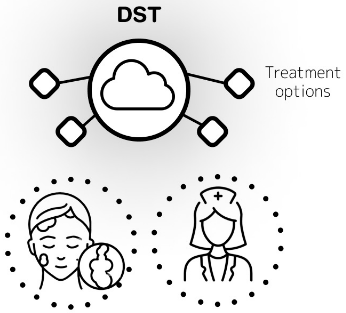


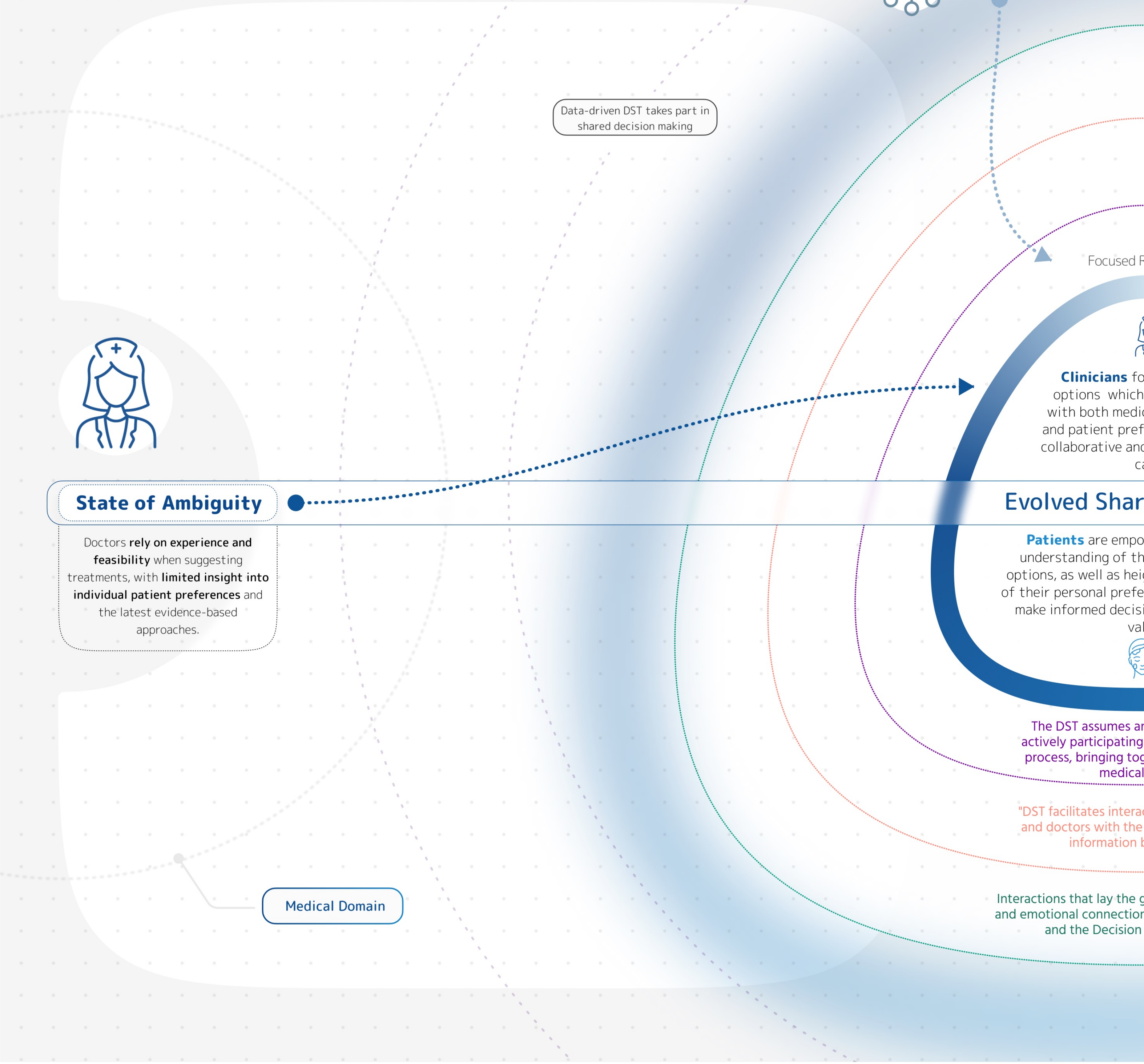
Figure 28 : DST-Patient-Data interaction in the empowerment stage

The transition from unawareness to clarity, which is the implication of our proposed speculations, accompanied by the different stages of interaction facilitated by data-driven DST, is depicted in the model "**From Ambiguity to an Evolved Shared Mind**." This model embodies the progression through foundational trust-building, information exchange, and eventual empowerment. Each stage underscores the role of DST in guiding patients and doctors from uncertainty to understanding, as tuned data fuels a collaborative journey towards shared decision-making (See next page).

Figure 29 :

From ambiguity to an evolved shared mind

A Model for Exploring Human-DST Interactions for Shared Decision-Making in Oncology



Scattered-
Outspread Data

Data-driven DST takes part in
shared decision making

Focused F

Clinicians fo
options which
with both medic
and patient pref
collaborative and
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State of Ambiguity

Doctors **rely on experience and feasibility** when suggesting treatments, with **limited insight into individual patient preferences** and the latest evidence-based approaches.

Evolved Shar

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understanding of th
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Interactions that lay the g
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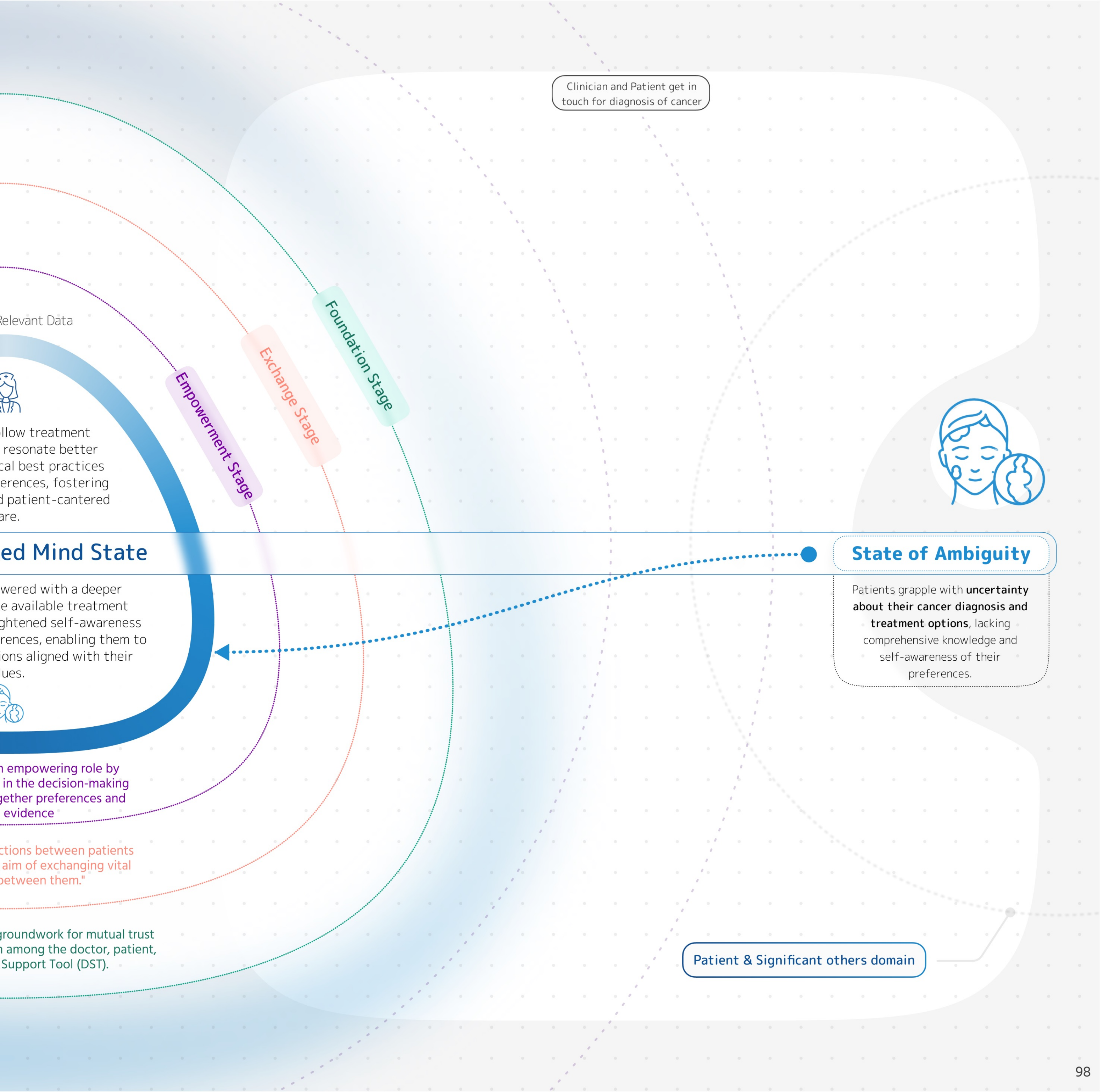
Medical Domain



Clinician and Patient get in touch for diagnosis of cancer

Foundation Stage

Exchange Stage

Empowerment Stage

Relevant Data

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resonate better
cal best practices
erences, fostering
d patient-cantered
are.

ed Mind State

wered with a deeper
e available treatment
ghtened self-awareness
rences, enabling them to
ions aligned with their
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State of Ambiguity

Patients grapple with **uncertainty about their cancer diagnosis and treatment options**, lacking comprehensive knowledge and self-awareness of their preferences.

n empowering role by
in the decision-making
gether preferences and
evidence

ctions between patients
aim of exchanging vital
between them."

groundwork for mutual trust
n among the doctor, patient,
Support Tool (DST).

Patient & Significant others domain

Foundation Stage

DST should stay present, in the absence of the doctor

Clinical patient-doctor interactions can be emotionally intense. Patients often grapple with a multitude of diverse physical and emotional challenges, experiencing pain, stressful thoughts, and uncertainties about how cancer might impact their lives. An ideal data-driven Decision Support Tool should step in to provide support for patients after their clinical appointments, especially when faced with an overwhelming amount of information. The reduction in the duration of hospital stays and the shift towards outpatient care amplify the requirement for patients and their families to access targeted information (Kessels, 2003). Leveraging prognostic tools and comprehensive datasets, this tool should facilitate a comprehensive review of available information on treatment options and their associated benefits and potential outcomes. By doing so, it can help patients engage more effectively with their healthcare journey and fill in any gaps that might have arisen from their in-person discussions with their doctors.

Empathy and the Role of Data-Driven Doctor-Patient Communication

While there's speculation about Data-Driven Systems (DST) mirroring doctors through voice communication, fueled by integrated NLP models, it's important to recognize that such systems can't replicate all the facets of empathetic doctor-patient interactions. This limitation isn't exclusive to this specific type of interface; it extends to any similar approach. Regardless of the delivery method (a website, a mobile application, or a physical device), the absence of human communication might result in the loss of certain empathetic qualities. However, in the pursuit of efficient doctor-patient engagement, there is an appreciation for delegating certain responsibilities to a more accessible (to the patient) version of doctors, considering the constraints of time pressure. This delegated version should be adept at addressing patient concerns, answering questions, and alleviating reservations about the proposed care trajectory. While this approach may sacrifice certain elements that contribute to genuine doctor-patient dynamics, it gains ground by transcending time limitations and medical center boundaries, a feat that real doctors struggle with. Indeed, while not all dimensions of real doctor-patient interactions can be replicated, the cloned persona of a doctor (or any analogous data-driven system) possesses the potential to provide a level of empathy that aligns with or even surpasses, that of actual doctors. This potential stems from the ability of virtual replicas to extend empathy beyond the confines of a medical facility and into the patient's everyday life, thereby offering a unique avenue for holistic support and guidance.

Considerations for Vulnerable Cancer Patients in Data-Driven Healthcare

It is possible that vulnerable cancer patients may be more inclined to share their data with a data-driven system if it contributes to their overall well-being. However, the type of information they are expected to share with these systems is often of a deeply personal nature. It is crucial to emphasize that if prognostic models and algorithms require patient-specific data for effective operation, stringent measures must be in place to prevent irrelevant parties from accessing this data (for instance, certain participants expressed concerns about their data being shared with insurance companies). It is important to emphasize that patient-specific data, necessary for the operation of prognostic models and algorithms, should be received by the systems solely to provide users with the relevant feedback and information they require. The data should not be stored; instead, it should be exclusively applied to algorithms for processing. This principle should be communicated clearly and thoroughly to the patient to ensure transparency and understanding.

Underscoring Informed Usage for Data-Driven Decision Support Tools in Medicine

Prior to implementing any data-driven system and a decision-support tool that utilizes prognostic models within the medical field, it is of utmost importance to provide a clear understanding of their intended purpose. These systems are designed to enhance patient care by offering data-driven insights for informed decision-making. Users need to grasp how prognostic algorithms can guide patients in the medical realm. To ensure safe and effective utilization, it is essential to establish well-defined boundaries. Users should be made aware of the specific powers and limitations of data-driven systems within a medical context. This education empowers patients to discern when to rely on data-driven tools and when to consult a healthcare professional. It's imperative to underscore that using these tools beyond their intended scope can jeopardize patient safety. Throughout the development process of decision support tools, it is highly advisable to integrate clear expectations and boundaries. By doing so, users gain a realistic understanding of what to anticipate from these tools and what areas require medical expertise. This approach not only promotes informed decision-making but also safeguards patients by discouraging the misuse of data-driven tools for purposes they were not designed to address.

Exchange Stage

Balancing Engagement:

Individual patients can exhibit varying degrees of engagement with data-driven decision-support tools. While certain patients may have a preference for actively receiving regular updates regarding relevant evidence and the corresponding treatment outcomes akin to their situation, others might find solace in remaining uninformed. Consequently, the frequency and duration of interventions of a data-driven decision support tool within individuals' daily routines hold significance. These interventions serve the dual purpose of imparting necessary information and gathering preferences, underscoring the importance of striking an appropriate balance

Navigating Evolving Preferences in Cancer Care

Preferences are inherently unstable, particularly within the intricate care path of cancer, displaying the potential for significant fluctuations over time. Patients who express a positive outlook towards advance care planning demonstrate a heightened inclination towards prioritizing their quality of life compared to other patients. In the initial stages following a cancer diagnosis, patients typically lean towards treatments that extend life, but as the prospect of death becomes more imminent, the emphasis shifts towards enhancing the quality of life (Voogt et al., 2005). Sustained engagement of a decision support tool with the patient is imperative, as it facilitates a comprehensive understanding of the core preferences, motivations, and underlying values. In many clinical settings, patients may struggle to accurately articulate their preferences and effectively communicate their needs and desires. Therefore, for a data-driven decision support tool to effectively leverage patient preferences in forecasting the most suitable individualized care path, it must base its predictions on a solid foundation of well-reasoned and extensively researched preferences.

Valuing Active Participation

Patients should be made cognizant of the value placed on their engagement with a data-driven decision support tool for improving their experience of the care path. They should realize that their active participation leads to advancements as they interact with prognostic models, and the DST should communicate this message to patients that they are accomplishing something by communicating with the DST. Their confidence in utilizing a DST should stem from the understanding that their engagement empowers them to partake in decision-making. A clear awareness of their ongoing learning journey and their progress therein is crucial. While comprehending every medical term in test results isn't necessary, patients should at least retain a degree of agency and not relinquish complete control to the medical team. By attaining a balanced comprehension of the requisite information for making informed decisions, patients can avoid becoming overwhelmed by extraneous data. Importantly, the DST should establish communication with the patient, indicating their progress toward becoming more capable of making decisions regarding their care path.

Empowerment Stage

Addressing Bias in Data-Driven Systems:

In an ideal future scenario, it remains possible that even in highly advanced data-driven systems, certain errors and biases could persist due to their human origins. Consequently, when it comes to supplying predictive tools to patients, a prudent strategy would involve limiting their utilization mainly to the purpose of providing information about feasible choices and potential personalized care routes, rather than furnishing them with explicit action plans. On the contrary, medical practitioners would desire a deeper understanding of the statistical basis underpinning each treatment alternative. As a result, when developers delineate the attributes of prognostic model outcomes, they should factor in the specific recipients of this data and acknowledge this differentiation. For oncologists, surgeons, and dermatologists, information should be grounded in evidence-based facts that align with each patient's medical condition and action plans should be provided. Simultaneously, patients should gain an understanding of the potential experiences associated with various treatment options. To achieve this, a prudent strategy during the development of data-driven systems and prognostic models is to clearly identify the specific audiences for each outcome criterion. This approach can help ensure that the right information reaches the appropriate stakeholders.

Beyond Numbers:

A truly effective data-driven Decision Support Tool cannot immediately empower both patients and clinicians to make decisions solely based on evidence-driven data and numerical figures. Formulating a simple numerical assessment of why a particular treatment option might work better than the other one is an oversimplification. Patients often don't adhere to statistics alone; they also rely on their instincts, personal feelings, or the reassuring assurance from a doctor regarding the potential success of a specific treatment. Thus, relying solely on numerical values and percentages for decision-making is inadequate for being empowered in decision-making. Patients require a more comprehensive explanatory rationale, detailed outcomes, and substantiated facts that assist them in envisioning the potential outcomes associated with their choices.

Delivering Secure and Tailored Information for Informed Decision-Making

The need for reliable information is undeniably conspicuous within the current landscape. When faced with a cancer diagnosis, patients instinctively seek out information. It's a common behaviours for individuals to Google their specific symptoms and gauge the gravity of their situation. Therefore, there exists a clear imperative to furnish patients and their significant others with a secure and tailored database that aligns with their distinct characteristics. It's imperative to shield patients from unnecessary stress stemming from exposure to inaccurate information that holds no relevance to their case. As previously underscored, the provision of reliable and pertinent information, directly linked to the patient's condition, serves as a valuable catalyst for informed decision-making.

DSTs not as decision makers, but literally decision aids

Data-driven decision support tools should not assume the role of decision-makers, but rather function as collaborative agents aimed at aiding the decision-making process. This entails their ability to streamline communication between the patient's circle (including the patient and their close associates) and the healthcare team (comprising dermatologists, oncological surgeons, caregivers, and nurses). These tools should serve the purpose of conveying essential medical information to the patient while also alerting clinicians to the patient's unique preferences, thus fostering a seamless exchange of insights and preferences among all parties involved.

Fostering Transparency and Community

Transparency is a pivotal aspect when considering Decision Support Tools (DST), ensuring outcomes are not only understandable but also accountable. However, this doesn't necessarily entail displaying the intricate mechanisms of information provision and availability to users. In reality, demanding that patients invest their already limited time and energy, especially during stressful situations, to comprehend the inner workings of treatment suggestions might be impractical. What truly resonates with patients is the need to access the experiences of individuals who have faced similar circumstances. Understanding the care journey of patients with comparable conditions, the treatment decisions they opted for, and the desirable outcomes they encountered with a DST holds more significance. Insights from those who shared the same stage of cancer and similar characteristics provide valuable guidance. This includes what aspects they appreciated about their decisions and the positive experiences they had, as well as any unfavourable encounters they underwent. Ultimately, the emphasis shifts from intricate technicalities to fostering a community of shared experiences. This user-focused approach ensures that DST doesn't just deliver data but also offers meaningful insights that can empower patients to make informed decisions about their own care.

Chapter 10

Recommendations

In the preceding chapter, we introduced a model that delineates the path undertaken by patients, their caregivers, and clinicians, facilitated by a data-driven Decision Support Tool (DST). The primary goal is to navigate them towards an elevated state of shared understanding. This entails acquiring a comprehensive grasp of the medical intricacies inherent in the situation they are facing, in conjunction with an awareness of the individual preferences of each stakeholder. This transformation signifies a shift from initial ambiguity to a state characterized by active participation of stakeholders in the shared decision-making process.

The model we presented illuminates three domains of interaction through which the data-driven DST engages with its users. These interactions are designed to redirect them from the overwhelming deluge of information often encountered at the commencement of their care journey. Instead, users are steered towards more manageable and actionable data points.

However, we want to first zoom out a bit and think about the process that has been followed thus far. Finally, the aim is to provide some hints so that the audience of this report can be prompted by this exploration and begin their journey into the future.

Personal Reflection on the speculation

The journey that was experienced could help us to explore the future of healthcare, taking into account the opinions of healthcare insiders and outsiders people. Through the lens of speculative design, we came up with a practice where we could explore the future without being anchored to the limitations. However, in the end, It seemed to be needed to validate our outcome so far and come up with a list of recommendations less focused on the future, but on the implementation of the mindset we achieved so far. Indeed we do not want to state how the proposed concept "Doctor in the Box” should be implemented since we used it as a provocative for exploration, but we want to refine the speculation we came up with so far and explore the the next steps.

In this chapter, I intend to delve into my personal perspective on this project. From the moment I committed to delving into this subject, up to now, my priorities have undergone significant transformations. Initially, I envisioned my role as that of a designer focused on enhancing the digital interface, perhaps an upgraded version of the existing one on the **PREDICT** website. My focus was cantered on optimizing layout and graphics for maximum user usability.

However, as I delved deeper into the project, I became acutely aware of numerous unresolved issues and uncertainties. Extensive literature substantiated that data-driven Decision Support Tools are typically sophisticated statistical software primarily accessible to expert clinicians. Even for them, implementing these tools within healthcare pathways and medical centers is constrained by time pressures and compatibility concerns. This realization led me to reconsider the core of the project, which was Shared Decision Making. It dawned on me that such tools might not effectively facilitate this process. Questions arose: How could patient preferences be integrated? Could the DST aid communication between patients and doctors? In what ways could such tools enhance engagement in decision-making? How could a tool solely based on predicting outcomes foster collaboration among clinicians, patients, and stakeholders? And what about patients receiving unfavorable predictions from the DST? How could a DST truly be meaningful?

These doubts shifted my perspective. It was clear that a solid foundation for design was missing. Consequently, I zoomed out, freeing myself from the constraints imposed by the healthcare realm. This is where the speculative approach emerged as my best tool to confront this intricate context. What

I take pride in is the complete overhaul of how DSTs and prognostic models were perceived by those focused on their development. I began to shape my distinct definition of data-driven DSTs.

My perspective transformed into viewing DSTs as empathetic tools, fostering meaningful interactions with patients through the data they house. This interaction space serves as a platform for educating patients about their condition, and treatment options and collecting their preferences. This approach alleviates the burden on doctors with limited time and energy. From now on, I don't want to call this, “doctor in the box” anymore. I've dubbed this concept "Amine" acting as a technology-based bridge for interactions between patients and doctors. Amine, portrayed in Figure 30, isn't a clone of a doctor but a knowledgeable companion who shares awareness, addresses queries, and mitigates concerns.

This tool offers information tailored to what patients need to know, eliminating overwhelming irrelevant data. It adjusts its involvement to the patient's preferences, fostering a symbiotic learning process. Amine, whether realized as a tangible device housing a robust NLP model, a mobile app, a cloud-connected website, or other forms, maintains these core functionalities. It enables crucial interactions between patients and doctors when needed most. I've also employed Amine to chart the journey of patients and clinicians, guiding them from uncertainty to informed decisions.

My approach, rooted in speculation and future-oriented thinking, didn't culminate in a mere to-do list. Instead, I presented a model that serves as a guide for exploring potential DST scenarios and desired interaction qualities. I've created a forward-looking context where interactions evolve, weaving connections between data, patients, doctors, and stakeholders. Now, the onus lies on developers, stakeholders, managers, engineers, and healthcare strategists to ground this vision and devise a plan to transition this speculation into reality.

Amine is a Persian phrase which means "trustworthy" or "faithful."

Amine

A speculation pertains to a Decision Support Tool device with the ability to host prognostic models and NLP systems. This device would serve as a technological bridge, facilitating interactions between oncologists and cancer patients. Its purpose is to engage patients and oncologists in shared decision-making by informing patients about their treatment choices and updating doctors about patient preferences.

Figure 30 : Amine

A rotary key that enables patient adjust how much active/passive Amine should be in informing patient of medical information

A gauge that reflects the extent to which a patient has progressed in becoming informed and developing a shared mind

Mole Tracker module

Figure31 : The functionalities of Amine

Patients can receive Amine in a pack after being diagnosed with melanoma

Figure32 : Amine

I want to be actively involved in the decision-making process. I appreciate healthcare professionals who collaborate with me and value my input when determining the best treatment approach

"Amine" can collect patients' preferences by interacting with the patient. Patients can see what is being collected from their discussions and remove the preferences that he/she might think are not valid. This way, the patient can always maintain control of the data being collected.

Figure33 : Adjusting preferences with Amine

Limitations

While I'm not a data scientist and I could not act as a person who could develope prognostic models and iterate on their functionality, I've managed to identify aspects that warrant consideration during the development of such tools. Nevertheless, I'm of the belief that my model can provide data scientists with a glimpse into the envisioned future. It's possible that they already possess an innate understanding of the desired interactions, being human beings themselves :))

That's essentially the essence of design: unearthing ideas that inherently exist but gaining an element of awe-inspiring innovation through creative illumination. It's plausible that numerous feasibility challenges may exist with the proposed interaction qualities, yet this shouldn't be a deterrent. My limited grasp of data constraints has paradoxically granted me greater freedom to explore this future. This exploration has been rooted in a human-centric approach, addressing emotions, needs, and desires that demand fulfilment.

Perhaps years could elapse before data-driven tools can fully realize the speculative realm I've envisaged. Alternatively, this realization might arrive sooner than expected—it's a question mark. However, within the confined time frame of a graduation project, I've managed to translate my futuristic insights into tangible manifestations. These manifestations allow individuals to harbour aspirations, hoping for them to one day become attainable through the capabilities of DSTs.

Acknowledgements

I would like to sincerely extend my gratitude to Judith for her steadfast trust in me. The project has not only brought me immense satisfaction but has also allowed me to grow. I am truly grateful for the faith you have shown in me by entrusting me with this opportunity. Your wholehearted support of your role and the responsibilities you have bestowed upon me have significantly bolstered my self-confidence in ways beyond my expectations.

Big shoutout to Marco – the guy who not only rolled with my crazy ideas and our design convos, but also pushed me to ditch the same-typical design solutions. His move wasn't just about adding cool direction to the project, but it seriously stamped some unique vibes into how we went about things. Teaming up with the Expressive Intelligence Lab and Studio Lab through his intro wasn't just about cool spots to work, but also brought in a bunch of fresh design perspectives that totally hit the spot.

I want to express my gratitude to the 4D Picture Project team - Elfi, Claudia, Ida, and Hester. Their patience in explaining things to me, given my non-medical background, was invaluable and made a significant impact on how our project evolved. I truly appreciate their role in bringing everything together the way they did. Furthermore, I'd like to extend my gratitude to the team at StudioLab for providing me with the space and facilities I needed for prototyping and testing them.

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Sending a massive dose of love to my awesome "Hey, Hello!" buddies out in the Netherlands! You might not have always been on board with my late-night cosy plans and ambitious workout ideas, but the unforgettable memories we made in Delft, Andijk, and Renesse are etched in my mind. I'm looking forward the amazing adventures that still lie ahead!

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برای زن، زندگی، آزادی

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