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Master of Arts thesis abstract

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Abstract

This master's thesis explores the use of information design and information visualizations in the context of shared decision making in medicine. More specifically, this thesis focuses on the visualization of risk through its case study, Oravizio. Oravizio is a risk assessment tool for joint replacement surgery that is used prior to surgery when the medical professional and the patient discuss treatment alternatives and how safe a surgical operation would be for that particular patient. The tool has a risk calculating algorithm that takes into account patient-specific data and a graphical user interface that shows the results visualized.

The wider communicative context in which Oravizio is used is called shared decision making. Shared decision making is a practice where the medical professional and the patient discuss options related to a medical decision together. Shared decision making is considered a modern way of communicating at the doctor's office and is used particularly in situations where different treatment options have differing pros and cons.

This thesis assesses how well Oravizio and its information visualizations facilitate shared decision making at the moment and how the tool and its features could be improved in the future. A theoretical background is formed by drawing from various literary sources in information design, risk visualization and shared decision making. To enrich the findings from literature, professionals with experience using Oravizio in a clinical setting are interviewed to gain understanding of how, when and why they use the tool.

This thesis concludes that although the current visualizations of Oravizio already work quite well according to the professionals, improvements can be made. To be able to compare the risk information to the potential gains of the surgery, a possibility of adding other data sources such as patient reported outcome measures to the tool are speculated. Before implementing any changes to the tool and its visualizations, this thesis calls for additional research and insights gathered from the other user group: the patients.

Keywords information design, data visualization, shared decision making, healthcare, elective surgery, visual communication design

Visualizing Risk

How Information Design Can Facilitate Shared Decision Making in Medicine

Heini Kekki
Master's thesis
Aalto University
2021

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Table of Contents

1 Introduction

1.1 Context of the study

The global trend of digitalization of services is affecting industries that have traditionally been heavily regulated. Examples of such industries include insurance services, banking services and gambling. Another example, and one that has been relatively slow to embrace this change, is the healthcare industry (Hansen et al., 2020). As part of this development, software applications intended for medical use have started to emerge alongside more traditional means of healthcare. In addition to electronic patient medical records, hospital information systems and software that determine how different medical gadgets function, software that act as standalone medical devices have also appeared on the market. This master's thesis focuses on one such device: Oravizio, a risk assessment tool for joint replacement surgeries.

Oravizio, a CE-marked medical device developed by Solita Oy and Coxa hospital has been on the market since 2018. The goal of Oravizio is to help orthopaedic surgeons understand patient-level risks related to hip or knee joint replacement surgery and to communicate these risks to the patient. The tool has a risk calculating algorithm that takes into account patient-specific data, and a graphical user interface that shows visualizations of the patient's risks related to the surgery. With the help of Oravizio both parties can make more informed and data-driven decisions concerning the treatment.

Having been employed by Solita Oy, the manufacturer of Oravizio, since 2018 as a visual designer, I was presented the opportunity to build my thesis around improving the tool in early 2021. I had not been part of the Oravizio development team at the earlier stages of the project. As a visual communication design student specializing in information design, quite naturally the tool's risk visualizations came to be my key interest for the thesis. Combining theoretical findings from information design literature and risk visualization literature, this thesis aims to find best practices for visualizing the concept of risk. Bringing these findings together with insight gathered from the users of Oravizio through interviews, the current visualizations in Oravizio are assessed and possible enhancements are suggested.

Watson (2018) has argued that despite its many benefits, digitalization has also brought about negative side effects to medicine. The time the professional spends typing on the computer is time away from the direct doctor-patient interaction and may leave some patients feeling less seen and heard. According to Watson (2018), visualizations could be a way to bridge this gap, if visualizations were used not only as a means for the professional to study data, but for them to communicate their message to the patient.

Consequently, another point of interest of this study is the wider communicative situation in which Oravizio is being used. The tool is meant to be used together by the professional and the patient at the doctor's office when discussing potential treatment alternatives. This practice of the professional and patient discussing options related to a medical decision together is called *shared decision making*.

During the last decades, shared decision making has become an established practice in many branches of medicine, where the role of the professional as a sole authority has traditionally been strong (Kaplan & Frosch, 2005). Within shared decision making, medical professionals are known to have an important role to play as gatekeepers: in order for this more conversational treatment approach to reap benefits, the professionals must adopt and embrace it. Likewise, if applications such as Oravizio and its visualizations are included in the shared decision making process, it is crucial that professionals find the applications useful and understand how to use them. Although as the name suggest, shared decision making puts the emphasis on both the professional and the patient, the main point of view of this thesis is that of the professionals. Through interviews I wanted to discover the orthopaedic surgeons' attitudes towards shared decision making as a whole and the use of visual tools as part of the practice.

Shared decision making relies heavily on a good relationship and open communication between the patient and the professional. Smith (2003) has gone so far as to call communication "the main work of doctors". In this thesis I try to discover what role information visualizations take and could take within the framework of shared decision making. A specific focus is on the role of risk assessment, being the intended use of Oravizio, but study findings explore the possibilites of widening the scope of visualizations beyond the concept of risk.

1.2 Research questions

This master's thesis aims to address the following research questions:

RQ1. What is the potential role of information design and information visualizations in shared decision making and communicating health risk information?

RQ2. How does Oravizio facilitate shared decision making at its current state according to users?

RQ3. How could Oravizio be improved in terms of information visualization and shared decision making?

The first research question will be addressed through a literature review and the second through interviews with orthopaedic surgeons with experience using Oravizio during their practice. Combining insights from both literature and end users, possible improvements to Oravizio will be suggested.

1.3 Structure of the thesis

In the following chapter two, a literature review will go through the different facets of research that are at the crossroads of the thesis topic. Firstly, a ground will be laid by taking a look into information design and its connection to medicine. Secondly, the framework of shared decision making is introduced. Third part of the literature review will bring these two together by focusing on the specific research topic of the master's thesis: visualizing health risk information.

After the theoretical framework in chapter three the case study of Oravizio, a risk assessment tool for joint replacement surgeries, will be introduced: what it is, how it works and what the current state of it is. In this chapter a brief look will also be taken into the world of medical device regulation to understand the boundary conditions regulation sets for design and development of such tools. The following chapter four will cover the methodological choices of the thesis.

The results of the thesis are presented in chapters five and six, followed by a discussion and contemplation of potential future research openings in chapter seven. Finally, in chapter eight, main findings of the thesis are summarized. The annexes containing the interview structure and other materials can be found at the end after the references.

2 Theoretical background

2.1 Information design

2.1.1 INFORMATION DESIGN AS COMMUNICATION, VISUAL LANGUAGE AND VISUAL GRAMMAR

The amount of data in the world has grown to unimaginable levels. In his 2013 book *Functional Art* Alberto Cairo (2013, p. 15) wrote that humans produce the same amount of data in the span of two days, that was produced throughout the entire history up until 2003. Considering it's been eight years since Cairo's book came out, it is safe to assume that the pace has only quickened. What to do with all this data? Spiekerman suggests we turn our eyes to information design:

> Information design can show the way through – and perhaps out of – the jungle that is our modern world. Applied properly, it can turn data into information and information into effective communication and appropriate action.
>
> – Spiekerman, 2017, p. x

Spiekerman's quote reveals the full potential of information design: if used well, information design can not only lead to transmitting information but also ways of making use of that information. Between raw data and information lies a big sea of ambiguity, where it's easy to get lost and anxious. As Wurman has put it:

> Information anxiety takes place between data and knowledge.
>
> – Wurman, 2000

Horn (1999) links information design to a long line of professions with the aim of assisting communication. These kinds of professions have existed for millennia: the works of transcribers of Egyptian hieroglyphs, clerks in charge of the parish registers in Medieval times and data journalists these days all revolve around transmitting information and increasing knowledge. Information design is a modern-day example of the same function.

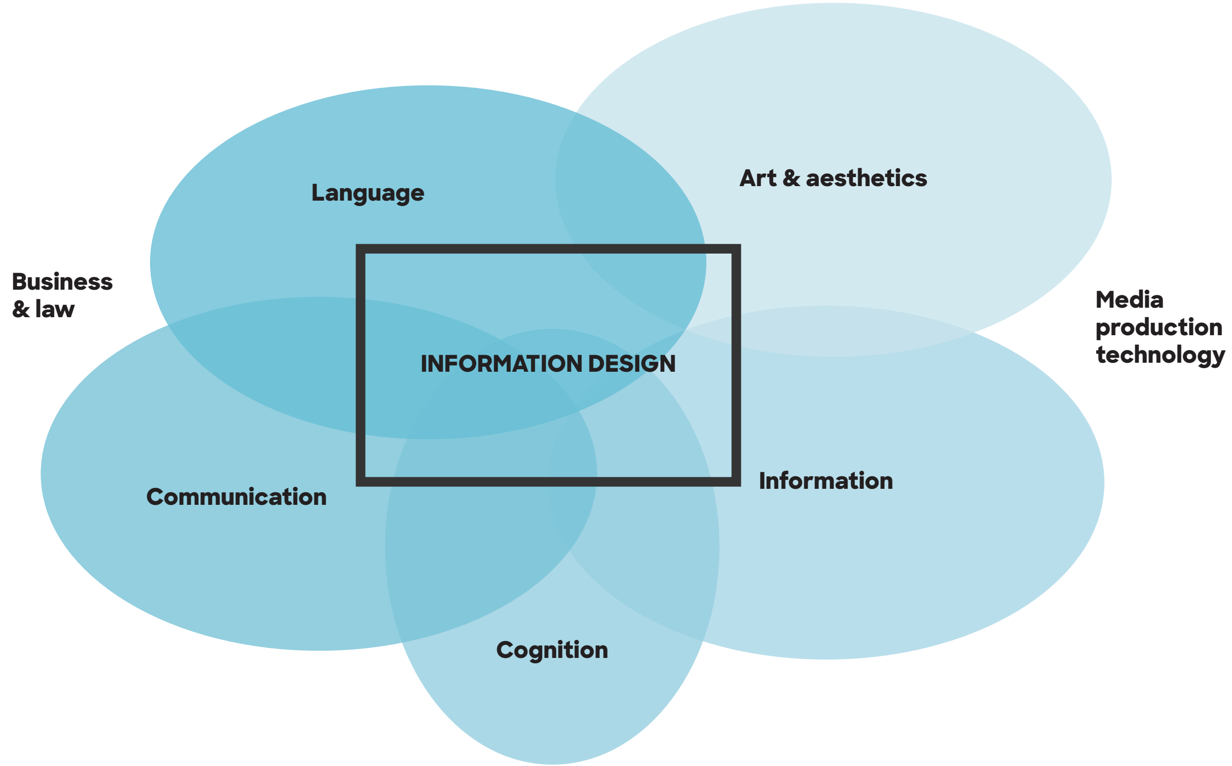

Figure 1: The components of information design, adapted from Pettersson (2002)

There have been many ways to define what information design is, both as an academic discipline and as a practice (Pettersson, 2014). One way of putting it in a nutshell is to say that information design is the process of organizing and presenting information in the best possible way to get to the desired result.Pettersson (2002, p. 4) has situated information design in the crossroads of language, communication, cognition, information and art & aesthetics (see figure 1). Its closer connection to communication than art and aesthetics is also supported by Downs (2012), who has argued that instead of graphic design the profession under which information design would fall should nowadays be called graphic communication. This is in line with how Aalto University has named its study subjects as well: what used to be called graphic design is now called visual communication design.

By its definition of assisting communication, information design doesn't necessarily have to be visual in nature. However, graphic representations of information design – charts, maps, data essays and the like – are probably the first thing that comes to mind when thinking about information design, and they are also the focus of this master's thesis in the context of health risk information.

The different graphic representations of information design can broadly be categorized into two groups: infographics and (data) visualizations (Koponen et al., 2016, p. 20). Cairo (2013) has put these two in a continuum (figure 2), where on the other end are graphics that present information to the reader,

Figure 2: The infographics to visualization continuum as explained by Cairo (2013)

and on the other are graphics to invite the reader to explore for themselves. The goal of an infographic is usually to show information that already exists, whereas a visualization is intended as a playground for new information to be discovered: it doesn't have to have a clear message to deliver.

What makes information design especially relevant in this day and age is the rise of visual language (Horn, 1999, p. 27). Although pictures and images have been used to tell stories and convey information even before writing systems were invented (Koponen et al. 2016, p. 117), the world has become more and more visual in the digital age, and visual culture and visual language have emerged to connect people across other language barriers. This increased exposure to and habit of using visualizations in daily life has created a growing desire to access information in the same format.

Different visuals have different purposes. The difference between an information graphic and a piece of visual art is that the function of an information graphic is to help the user accomplish specific tasks such as giving an answer to a question (Cairo, 2013. p. 25). Where a piece of art can also act as a transmitter of human ideas or emotions, it doesn't necessarily need to have a clear function: it can also just be nice to look at. Comparatively, Cairo (2013, p. 19) argues that "visualization should be seen as a technology". By this he means that an information graphic should be considered a means of getting somewhere: from having a question to having an answer. The goal of an information graphic is not to be beautiful. Instead, its prime goal is to be clear and easy to understand, and the beauty of an infographic should be a result of how well it functions (Cairo, 2013). When evaluating how good an information design is, Stahl-Timmins (2017, p. 451) argues that the key question is how effectively it creates understanding in a specific context.

Different approaches to visualizations are needed to achieve different outcomes. To be able to know which way to go with a visualization, it is also essential to be familiar with the "grammar of information design", as Koponen et al. (2016) have called it. This approach to information design as something having a grammar means approaching it as a visual language of its own. To approach information design as a visual language means acknowledging that information design has its own set of rules, conventions and social constructs, just like any other language. Similarly to other languages, visual language and its conventions are also constantly evolving and being re-created by their users.

The concept of visual rhetoric is strongly linked to visual language (Moys 2017, p. 205). The word rhetoric refers to how well and persuasively a message is delivered. Genre influences the visual rhetoric of different kinds of written and visual materials (Moys, 2017). Certain conventions of presenting information as well as retrieving it are associated with for instance bills, transportation timetables, notifications as well as pharmaceutical leaflets. A different kind of visual rhetoric is required by different types of documents to ensure credibility and that the document functions the way it is intended. Established conventions maintain a degree of order within the world of visual language. This helps designers, because they are aware that certain choices are likely to provoke certain reactions from the public or help them complete certain tasks (Kostelnick, 2017, p. 265).

Cairo (2013) has argued that it has been a long-standing tradition to hold visuals in lower intellectual regard compared to writing, calling for more ambitious and deep visualizations. At the same time, it is vital to take into account the target audience and its graph literacy when thinking about the complexity of the graphic. Cairo (2013, p. 61) notes, however, that there is a difference between aiming for a clear and readable graphic and dumbing it down.

Sometimes no graphic at all is the best solution. Koponen et al. (2016, p. 29) have offered a rule of thumb in their Finnish-language primer *Tieto näkyväksi*: if the same thing can be expressed verbally as clearly or more clearly than a visualization, then there's no need to visualize it. In fact, sometimes visualizing the information can lead to more confusion. In the end, a visualization fulfills its purpose – increasing knowledge and understanding – only if it helps the reader perceive information in a way that text cannot. When the visualization adds just another complex information layer to interpret, it has not performed well.

2.1.2 INFORMATION DESIGN AND MEDICINE

As a tool for assisting communication, transmitting knowledge and facilitating appropriate action, information design has a lot to offer to medicine. Zender et al. (2017) have called medicine and design a good combination. Although they are distinct fields with their own interests and targets, medicine and design often share a common goal: improving the present situation for the better (Zender et al. 2017, p. 656). In the context of medicine this means healing an injury and in the context of design this means making an artifact – material or immaterial – fulfill its function better.

Information design has already contributed to medicine in many ways. Examples of the two fields overlapping include designing health campaign messages, designing medicine package leaflets and other visual or non-visual instructions on how to take a certain medication (Jensen, 2017, Dickinson & Galina, 2017, Spinillo, 2017, van der Waarde, 2017). However, compared to medicine, information design is still a relatively new discipline (Zender et al., 2017) and its use for the benefit of the former still has a lot of unfulfilled potential.

Despite its much longer history, Zender et al. (2017, p. 655) argue that there are still big gaps to be crossed when it comes to how healthcare is organized and how medical practitioners and patients could move towards a more collaborative work in making medical decisions. According to the authors there are three key areas where design can help medicine to be more successful: communication, motivation and engaging the patients.

There are several components that are likely to make medical and design collaboration successful. Firstly, both fields are focused on solving a problem and typically follow an analytical process to achieve the goal. Another one is shared knowledge: designers need to absorb at least a conversational level of knowledge of the medical question at hand. Third component is what Zender et al. (2017, p. 658) call “rigour and tools”. This refers to design’s potential to assist hearing the patients’ side of things complementing the more traditional starting point of medicine, where the practitioner is seen as the sole authority. Understanding the users – or patients – is a key feature of the design process and can assist medicine to become more patients-centered, reflecting the key principle of shared decision making.

As part of the design process, holistic thinking is another benefit that medical and design collaboration can aim for. Designers are used to thinking of the big picture through the creation of context maps, ecology models or customer journeys (Zender et al., 2017, p. 659). This way of handling information can bring new insights into patient care. Compared to medical practitioners, designers are more accustomed to questioning their actions, thoughts and interpretations throughout the process – thinking outside of the box. Designers’ ways of often visualizing their thinking process through sketches and mind maps can also bring something new to the table when collaborating with medical practitioners.

In order for a medical and design collaboration to succeed, both parties need to agree on the content of what the interest is, as well as make use of their potentially differing ways to approach thinking throughout the process. Medical practitioners also need to accept that designing is an iterative process. Data is collected and prototypes and solutions created and discussed over and over again without committing to the first alternative. This is something that might be challenging for the more rigorous and stiffer medical field to adopt.

Decision aids, visual materials to help medical decision making, are an example of a solution where medicine and design come together. According to Zender et al. (2017) decision aids are a great platform for information designers to work on, because they are used at the crossroads of communication: where the inside knowledge of the practitioner meets the information needs of the patient, an outsider. The same can be applied to visualizing risk information, the specific point of interest of this thesis. In their study that focused on designing three different decision support tools in collaboration with designers and medical practitioners, Zender et al. (2017) noted that both parties considered working together to be a fruitful experience. Decision aids are discussed in more detail in chapter 2.2.2.

2.1.3 INFORMATION DESIGN PUT TO PRACTICE

To bring the focus back to the practices of visualizing information, two main principles should be kept in mind when designing any kind of visual presentation of information (Koponen et al., 2016, p. 25): comparison and simplification. When presenting numerical information, a key concern is the ability to compare numbers to each other. One number without a context hardly offers valuable information. The appropriate ways to visualize different variables to enable efficient comparisons are discussed in more detail later in this chapter.

Simplification means that the information visualization should focus on what is important. A map is a typical example (Koponen et al., 2016, p. 28). When comparing a satellite image and a map of the same region, it is easy to recognize that not every single tree or rock seen in the photograph is included in the map, because most likely this information is not relevant to the person using the map to navigate through the roads in the region. Different maps – and other diagrams – have different purposes, which means that the level of simplification also varies. The main point is to show what is relevant for the intended use of the visualization. Simplification in terms of aesthetics is another topic that is discussed later in this chapter, after taking a look at the origins of graphic representations in information design.

Early information design pioneers

The type of visual presentations people nowadays associate with the word information design have gained in popularity in recent decades, but earliest examples date back to the 18th and 19th century, when big advancements in science and technology were made. At that time different societal and other phenomena were starting to be recorded more systematically, and statistics emerged as a field gaining importance (Koponen et al., 2016, p. 123). When the amount of data started to increase, so did the demand for ways to present it. William Playfair (1759–1823) was a key figure in developing and enhancing

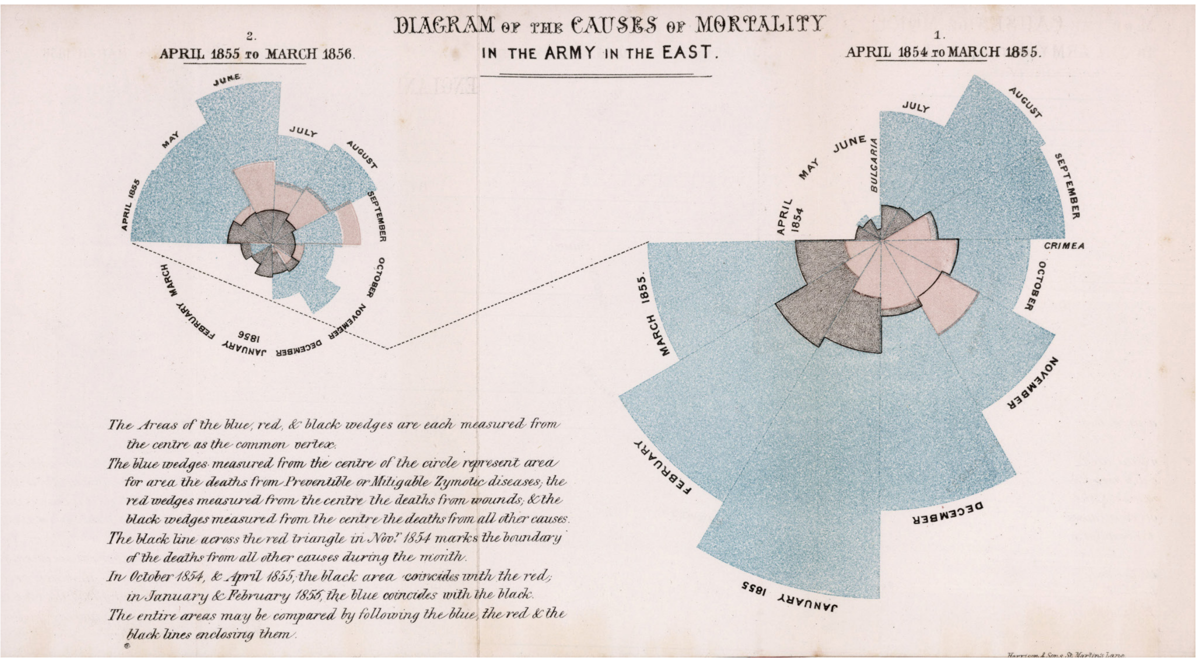

Figure 3: Florence Nightingale was an information design pioneer among her many skills. Her rose chart or polar area diagram depicting the causes of mortality in the army in the East is from 1858. Interestingly, the chart is an early example of medicine and information design coming together.

Figure 4: Römerreich: Städte is an Isotype graph depicting urban populations during the Roman empire. Following the Isotype principle, the symbol standing for 50 000 inhabitants is repeated accordingly as per the size of urban populations. From the 1930 collection Gesellschaft und Wirtschaft: bildstatistisches Elementarwerk.

the designs of many statistical graphics still being used today (Tufte, 2011). The works of Joseph Priestley (1733–1804), Charles Minard (1781–1870) and Florence Nightingale (1820–1910) are examples of early infographics and data visualizations.

Notable advancements in information design were made in the 20th century with the creation of Isotype. Isotype refers to the body of visual work by Otto and Marie Neurath and their team between the 1920s and the 1970s (Kinross, 2017, p. 107). Isotype work focused on visualizing information, statistics and numbers and attempted to create universal rules and practices for the process. Isotype has been described both as a method and a pictorial language (Isotype Revisited, 2021, Kinross, 2017, Koponen et al., 2016).

At the core of Isotype is the pictogram symbol of a fixed size. As a principle in visualizations, when presenting amounts larger than one, the symbol is repeated instead of scaled to be larger. For a value of one an Isotype visualization would have a single symbol, and for the value of ten, ten of those symbols would be presented instead of a symbol that was ten times the size of the first one. Otto Neurath had a belief that presenting data this way makes the information easy for the reader to understand and keeps the presentation honest (Kinross, 2017, p. 109). At the same time Isotype work favored approximations instead of precise numbers. This was to increase the effectiveness of the graph and memorability of the visualization. According to Kinross, Otto Neurath argued that "to remember simplified data-graphics is better than to forget precise numbers".

Contemporary discussions on minimalism versus chartjunk

Although information design has more to do with communication than art, aesthetic choices always come into question when designing a visualization. According to Cairo (2013, p. 61) there has always been a heated debate going on about the decorative level of visualizations between those who side with showing only the bare essentials of the data and those who aim for more dashing visualizations. This debate was especially fierce in the 1980s and the 1990s.

The most prominent figures of the opposing camps of the rivalry are Edward Tufte and Nigel Holmes (both born in 1942). Where Tufte favors minimalism, Holmes is known for his playful data visualizations. Both schools of thought aim for enhancing the graph as a communication tool but have differing viewpoints on how to go about it. As a tool for assessing the efficiency of a graph Edward Tufte coined the term "data-ink-ratio" (Cairo, 2013, p. 64). Data-ink-ratio refers to the surface area of a graph and more specifically, how large a proportion of the ink used for the graph contains elements that represent data and elements that have a more decorative purpose. A graph

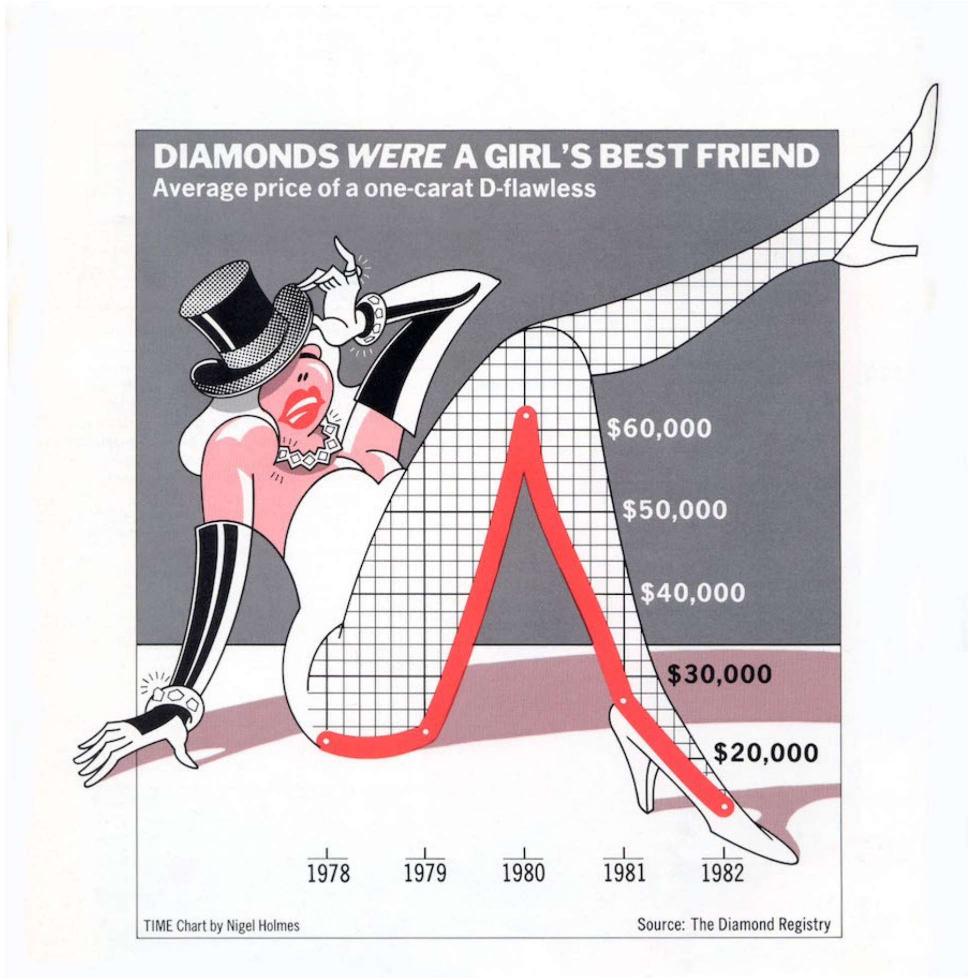

Figure 5: The playful chart by Nigel Holmes (1982) for Time magazine

with a high data-ink ratio is stripped-down and minimalistic, consisting of only the essential elements to communicate the data. A graph with a low data-ink ratio can be colorful and playful, consisting of both elements that encode data and elements that are merely decorations.

A classic example of the latter is the chart Diamonds were a girl's best friend in figure 5 by Nigel Holmes for Time magazine. A large percentage of the surface area of the graph features the print of the woman, her shadow, the gray background and the playful head title of the chart. A much smaller percentage of the surface is printed with the actual numbers, the line chart, the years and the subtitle depicting what the graph is actually about: average price of a one-carat D-flawless diamond. The diamond graph is an example of what Tufte has called "chartjunk": decorating of a graph with features that do not give the reader any new information, leading to low data-ink ratios (Tufte, 2011, p. 107).

Tufte is notoriously sharp and uncompromising with his views on what makes and breaks the design of a graph. Cairo (2013) and Davis (2017) do not

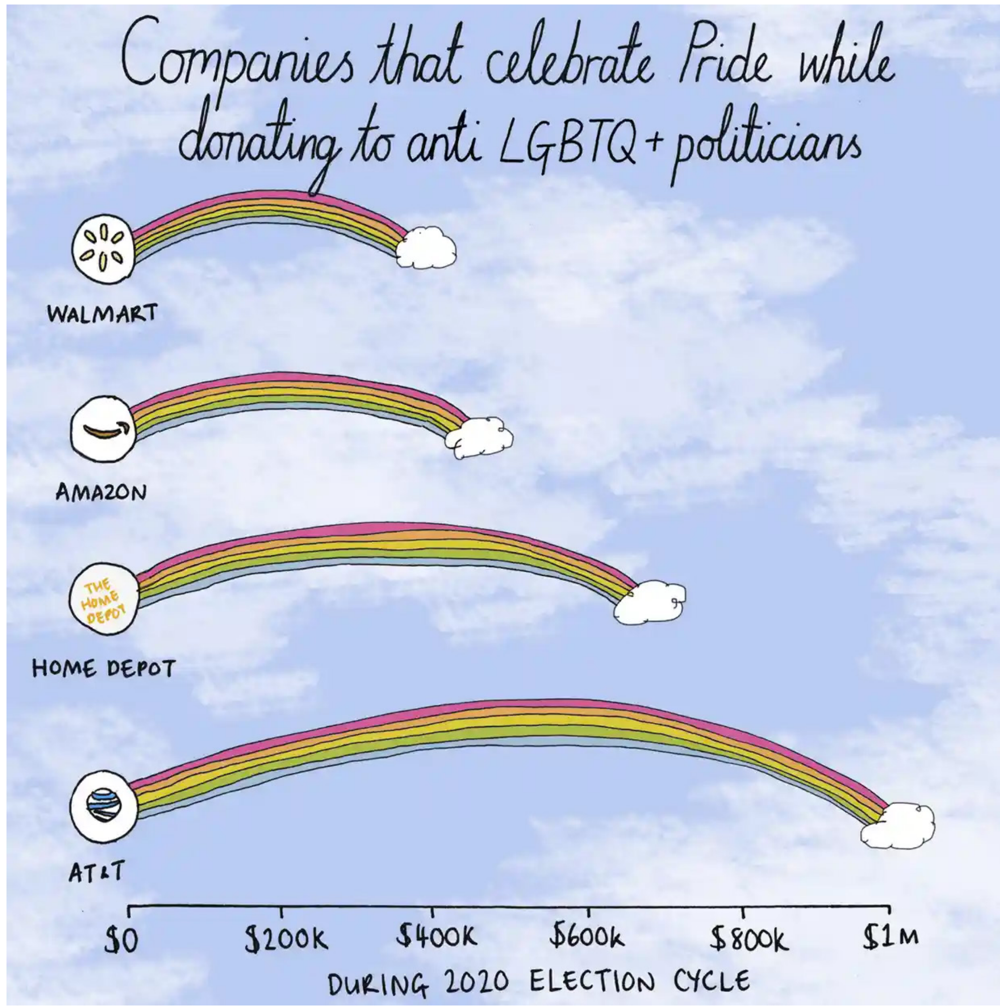

Figure 6: A modern day example of a more playful chart by The Guardian data editor Mona Chalabi, whose work is popular on social media platforms such as Instagram and Twitter

unanimously side with Tufte, however. Davis (2017, p. 4) argues that Tufte's views on minimalist charts as better than more decorative ones is not a factual truth, but an opinion that's still open to debate, despite his matter-of-fact -tone and status as a guru in the field. What the more embellished chart like the diamond graph lacks in minimalism, it possesses in memorability. In fact, studies that have tested Tufte's proposition that minimalist graphs lead to better results have found that both chart types to be equally understandable but that those featuring elements of "chartjunk" were more memorable (Cairo, 2013. p. 67). A conclusion to draw from the discussion is that both decorative and non-decorative charts have their merits, and that both are legitimate if used in the right context aiming for different outcomes (Stahl-Timmins, 2017). For instance the work of Mona Chalabi, a data editor at the Guardian who is known for her hand drawn and colorful data visualizations, aims for social advocacy and her unique and memorable style might be one of the reasons why her work has gained a huge following on social media. An example of the work by Chalabi can be seen in figure 6.

Different ways to visualize information: visual conventions and techniques

To conclude the chapter on information design, a brief look into different conventions and techniques of visualizing data will be taken. The theme will be further discussed in the context of visualizing health risk information in chapter 2.3.

Hierarchy is one of the most important rhetorical approaches designers use to present and organize information (Kostelnick, 2017, p. 257). Hierarchy is a tool to help the public interpret which information has more importance over others. There is a group of visual tools designers can use to constitute hierarchy in images (Kostelnick, 2017, p. 269). These include the use of perspective: more important elements are portrayed at the front of the picture, closer to the reader, on a layer higher to others, for instance. Present-day conventions to establish hierarchy include the use of spot colors, different signs such as arrows and call-outs (Kostelnick, 2017, p. 270).

Figure 7: The hierarchy-flatness continuum adapted from Kostelnick (2017, p. 269)

Not every visual design uses hierarchy, however. Sometimes the opposite – flatness of the image – can be the desired convention (see figure 7). Many icons and signs in public spaces are of this nature: they are minimalistic and straightforward visuals with no or low level of hierarchy between their elements.

Visual conventions also exist for different **colors**, as colors carry with them strong visual codes and meanings (Koponen et al., 2016, p. 101). For example greens and blues are often associated with calmer emotions than red and orange (Kostelnick, 2017, p. 261). According to Waller (2017), page **layout** hasn't been studied as widely as some other elements in visual communication design. Waller argues against overlooking the importance of layout and considers it "an important infrastructure for reading and writing in an age when few make time to engage with long linear texts" (2017, p. 177). In this sense, layout has a similar role in organizing information as hierarchy.

Gestalt principles is a name for a set of rules or principles concerning visual perception originated in German psychology in the 1920s. There is no clear-cut list of all the gestalt principles (Pettersson, 2017, p. 428). The core idea of gestalt principles is that the whole is other than the sum of its parts (Pettersson, 2017). What this means is that when presented with individual visual elements, the human eye has a tendency to see relationships between them and process them as a whole.

Of the different gestalt principles, Pettersson (2017, p. 428) has listed six principles that information designers should especially keep in mind, shown in figure 8. Of these, similarity principle, contrast principle and proximity principle are the most relevant to chart design, as they are related to grouping and categorizing information.

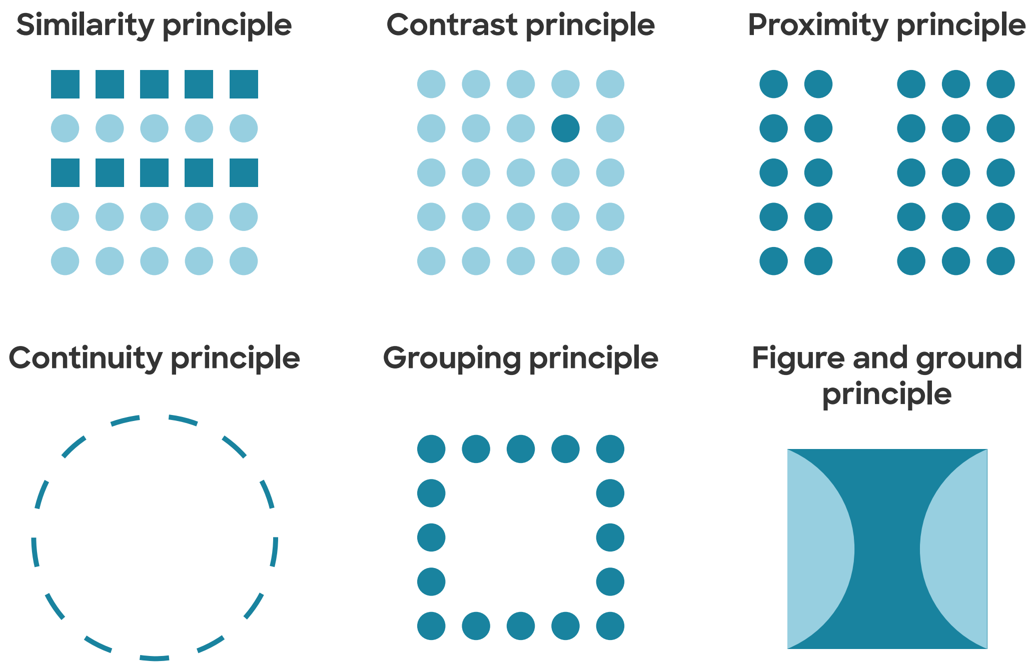

Figure 8: Examples of gestalt principles

Broadly defined, **symbols** are items that represent something else (DeLoache, 2004, p. 66). Visual symbols are images that represent something concrete (for example a car) or something abstract (for example the concept of peace) in the real world. Symbols are used for many different reasons, one of the most important ones being the potential of a visual language to exceed the barriers of verbal languages. Instead of translating a word to many different languages, a symbol can be used instead (Boersema & Adams, 2017).

Even if information is presented in only one language, a symbol can communicate the message more effectively than words. Boersema & Adams (2017, p. 305) list several reasons for this. A symbol may contain the same amount of information as a sentence in a much more condensed form, making it an effective way of communication. Symbols are also easier for the brain and eyes to understand, as symbols of the same size as text can be read from further afar. Additionally, symbols can be recognized faster and more correctly than signs consisting of words alone. Symbols may also be more legible to the parts of a population that are not as familiar with vernacular language. If a country has multiple regions with different dialects, it is likely that the same symbol for a word will translate across the dialects. Lastly, if the reader's vision has been compromised for some reason, studies have shown that symbols retain their legibility better than words, particularly in low-light conditions.

The International Organization for Standardization (ISO, 2021a) defines standardization as an act of describing the best practices of doing something. As the use of symbols is a universal phenomenon, a need has been identified to create international standards for them. For instance, ISO 15223-1 is a standard that is dedicated exclusively to the use of graphical symbols on regulated medical devices. The standard presents symbols for depicting the manufacturer of the medical device, its use-by date, its fragility and its susceptibility to humidity or changes in temperature, among other things.

Koponen et al. (2016) offer an excellent and extensive look at different **visualization techniques** to visualize various kinds of information from scientific illustrations to maps and concept graphics. From here on the focus of this chapter is on diagrams, pictograms and the visualization of numeric information. Often there are multiple ways to present the same statistical information, none necessarily overruling others, but the choice of the graph type should always be carefully deliberated (Holmes, 1984, p. 22).

Diagram is an umbrella term for charts, symbols, signs and other ways of presenting information in a visual form. A map, a chart and a table are all examples of diagrams. Diagrams can be clear or ambiguous depending on the desired outcome: whether the reader is to be informed about something or whether they are invited to explore and discover ideas on their own. A clear diagram points to one desired interpretation whereas an ambiguous diagram is open to many (Tversky, 2017, p. 357). Infographics and data visualizations can thus both be diagrams. The word chart is usually used to refer to data visualization or statistical graphs.

When assembling a diagram, it is good to keep in mind that the vertical axis in a diagram is thought to be the strongest one, as it is associated with gravity. As in the natural world, going up away from gravity's pull requires power and effort, often a data point on a chart higher on the vertical axis is likely to represent a higher, bigger or a better value. A visual convention for diagrams and graphs is the use of different graph elements, of which lines, bars and pies are probably the most used and the ones that Holmes (1984) has defined as the basic types.

Lines are frequently associated with temporal data or trends over time, whereas bars are frequently associated with comparison of exact numbers (Tversky, 2017, p. 352). More precisely, Koponen et al. (2016, p. 186) note that in vertical bar charts both axes are typically used for numeric values whereas in horizontal bar charts the vertical axis is typically used to portray categories or other qualitative information. A histogram is a specific kind of bar chart that is used to portray the distribution of the values in a data set.

	Comparing quantities	Parts of a whole	Trends over time	Correlation of two variables	Reference material	
Bar	■	■	■			
Line			■■			
Pie		■				*Most effective if contains two or three slices*
Histogram	■					*Series of progressive ranges to show distribution of data*
Scatter plot				■■		
Table	■■	■■			■■	

Figure 9: When to use different visualization techniques, adapted from Bigwood & Spore (2017, p. 504)

Pie charts have a bad reputation for transmitting information poorly despite their heavy use and popularity, but Koponen et al. (2016, p. 199) have defended their use in some cases. Pie charts should never be too stuffed with precise information, but rather used to portray approximate parts of a whole. When it comes to other uses of round graphical objects, according to Cairo (2013, p. 40) it is hard for the human mind to calculate areal sizes, in other words, two dimensional surfaces. When presented with a two-dimensional object, the human mind has a tendency to estimate its size by one-dimensional measures: judging by its height or its width. Bubble charts or circles of different sizes when comparing numbers should thus be used cautiously. Although round shapes tend to be attractive to the eye, they don't always transmit information in the best possible way.

An example of a visualization technique that might be thought of as less attractive, is the table. Bigwood & Spore (2017) have argued in their tutorial that although often overlooked, in certain cases numeric tables can be the best way of presenting data. According to Bigwood & Spore (2017, p. 504), as illustrated in the figure 9 tables surpass other forms of visualizations when comparing quantities, presenting parts of a whole or when data is showcased as reference material. They suggest using charts and other alternatives only, when they work better than tables.

Pictograms are stylized, often simplified visual representations of something material. Koponen et al. (2016, p. 132) separate ideograms from pictograms in the sense that they intend to represent a wider idea or a concept than a single item such as a car or a dog. In practice the word pictogram is often used in both cases, as is its synonym pictograph. Pictograms are older than literacy and they form the basis of many early writing systems. Nowadays they are used as part of information graphics as well as in wayfinding and other public signage. Their use in health risk visualization is discussed in more detail in chapter 2.3, after introducing the concept of shared decision making in the following chapter.

2.2 Shared decision making

2.2.1 INTRODUCTION AND DEFINITION

Shared decision making in the context of medicine is a practice where the patient and the health care professional assess together how to go about a medical decision (Kaplan & Frosch, 2005). It has risen as an alternative to the traditional model, where the healthcare professional acts as an authority and makes medical decisions autonomously. According to Elwyn et al. (2012, p. 1361) the core ideal of shared decision making is the patient's self-determination and their capacity to actively participate in decision making. At the heart of shared decision making is a good relationship and open communication between the patient and the professional.

Shared decision making is an applicable approach especially when it comes to conditions that are what Bozic (2013) has called "preference-sensitive conditions". This refers to conditions for which multiple optional treatments exist, none necessarily better than the other, and with differing pros and cons. With these conditions the patient's role in determining the desired outcome of the treatment is of particular importance. Bozic (2013, p. 1412) includes conditions dealing with the body's muscular and skeletal system to be preference-sensitive by default. This includes conditions that might require joint replacement surgery, a medical procedure that Oravizio is developed for.

In 2005, Kaplan & Frosch (2005, p. 550) noted that patients seem to generally have a positive attitude towards shared decision making. Physicians' attitudes towards shared decision making have been researched in a few studies with differing results. Woltz et al. (2018) have noted that Dutch trauma surgeons have a positive overall attitude towards shared decision making, and similar attitude is echoed for instance in the studies by Slover et al. (2012) and Bozic (2013) on orthopaedic surgeon's views on shared decision making, as well as the study by Mathijssen et al. (2020) on physicians and nurses treating rheumatoid conditions. A big motivator for embracing shared decision making for rheumatology professionals was that it was believed it would make the patients more prone to sticking to their treatment plan (Mathijssen et al. 2020). Conversely, it has been argued by some healthcare professionals that patients might not be capable of or willing to participate in making decisions concerning their treatment (Elwyn et al., 2012, Mathijssen et al., 2020).

Elwyn et al. (2012, p. 1362) argue that if shared decision making is to be used, both the professional and the patient should agree on and have a mutual understanding of the underlying principles. This brings us to a pivotal challenge with the practice. Even medical professionals who have a favorable attitude towards shared decision making might have inconsistent understanding of what it really consists of and how to make use of it (Bozic, 2013, De Mik et al., 2018, Woltz et al., 2018, Mathijssen et al., 2020). If the professionals don't know how shared decision making works, it should come as no surprise that patients also tend to have a limited understanding of the concept (De Mik et al., 2018, p. 1727). Bozic (2013, p. 1413) has noted that the practitioner has a key role in furthering the use of shared decision making, as patients have a tendency to have high levels of trust toward their doctors. If the medical practitioners don't embrace the approach, it will not reap benefits.

One model that has been proposed for shared decision making is the three-talk model by Elwyn et al. (2012). According to Elwyn et al. (2012, p. 1362–1363) successful shared decision making includes two things: firstly, the patient is provided enough information that is of high quality, and secondly, the patient feels supported in making the decision. The three talks of the model are called *Choice talk*, *Option talk* and *Decision talk* (Elwyn et al., 2012, p. 1363–1365). As the word talk suggests, communication is emphasized in all steps.

In *Choice talk*, the healthcare professional prepares the patient for the upcoming decision and highlights the possibility of choice as well as factors that might contribute to the choice. In *Option talk*, all possible next steps with their pros and cons are discussed. *Decision talk* is the final step where the healthcare professional helps the patient to choose their preferred option based on information provided. The patient might need time to deliberate their preferred option, possibly discussing options with others. Elwyn et al. (2012) emphasize the role of varying, personal preferences that should be taken into account when making decisions concerning treatment.

Given that medical practitioners have an important role as facilitators in shared decision making, a key concern is raised by Kaplan & Frosch (2005, p. 543) who point to several studies indicating that the practitioners' lack of communication skills might be a hindrance to successful shared decision making. Since shared decision making relies on establishing a good

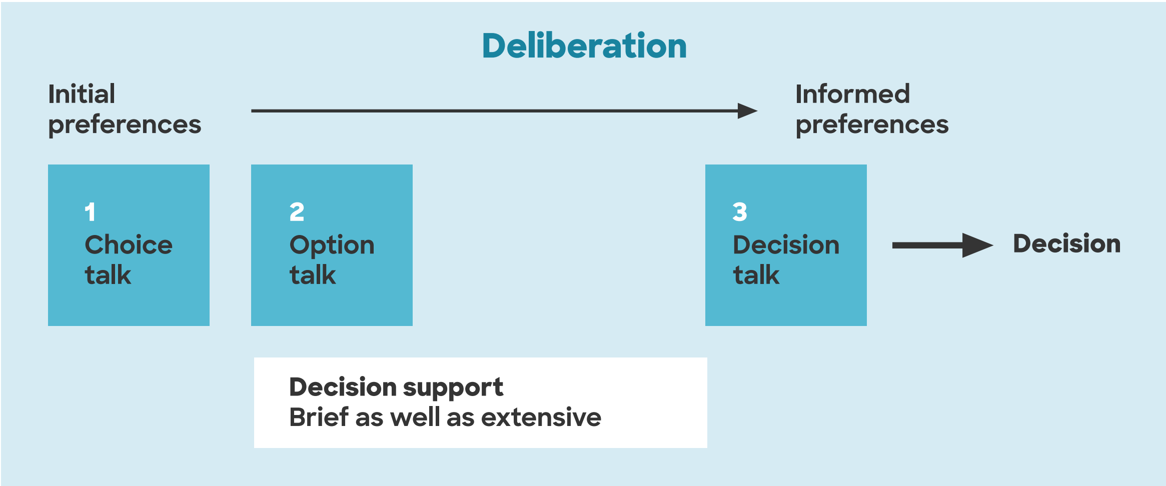

Figure 10: The three-talk model, adapted from Elwyn et al. (2012, p. 1365) According to the authors, "deliberation begins as soon as awareness about options develops. The process is iterative and recursive, and the intensity increases after options have been described and understood."

relationship and contact between the patient and the practitioner, solutions to make up for potential deficiencies in the communication skills are needed.

The medical practitioner's poor communication skills are not the only potential obstacle with shared decision making. Ankuda et al. (2014) have written about shortcomings in successful shared decision making that typically involve the patient's mother tongue being something other than English (in otherwise English-speaking settings) and the patient's lower level of education (Ankuda et al., 2014, p. 332). These two can lead to insufficient understanding of the risks and benefits before the operation. The authors question to what degree informed consent about the operation is realized in these cases.

A possible solution for bridging the gaps in communication between the patients and the medical practitioners is the increased use of decision support tools – a key element also in the three-talk model by Elwyn et al. (2021). This refers to materials – often written and/or visual – that can be used to assist and facilitate shared decision making. The concepts of decision aids and other decision support materials will be discussed in more detail in the following chapter.

2.2.2 DECISION AIDS

Decision aid is an umbrella term for materials, tools and actions taken to help facilitate shared decision making in medicine. Bozic (2013) has listed decision aids and communication aids as the two main types of tools for assisting shared decision making. In terms of terminology, the words decision aid, decision support and communication aid are often used interchangeably, although they refer to slightly different things.

O'Connor & Graham (2005, p. 247) define patient decision aids as "standardized, evidence-based tools intended to facilitate the process of arriving at an informed, values-based choice among two or more health care alternatives". Lowe et al. (2018) also emphasize the patient's values in their definition as well as pointing to their role in supporting the patient to take part in decision making. Decision aids are not meant to be used instead of a consultation with a healthcare professional – rather, they are meant to complement the interaction between the patient and the professional (O'Connor & Graham, 2005, p. 247).

Advocating for the use of such tools, Bozic (2013, p. 1413) has concluded that the tools have potential to guide patients who are more suitable for surgical treatments towards such treatments and likewise patients who might not be ideal surgical candidates away from them. In addition to transmitting information, decision aids might thus have a role in targeting the right treatment to the right cases.

The Ottawa Hospital Research Center (2021) lists almost 300 decision aids that are currently in use. Health concerns of various degrees are included in the topics. There are decision aids for example for bronchitis ("Bronchitis: Should I take antibiotics?") and laser eye surgery ("LASIK surgery: Is it right for you?") as well as end of life issues ("Advance Care Planning: Should I receive CPR and life support?"). Decision aids come in many formats, such as pamphlets, online tools or even videos (Lowe et al., 2018).

In a Cochrane review analyzing the effectiveness of decision aids (Stacey et al. 2017, Lowe et al. 2018) decision aids were found to make the patients feel more knowledgeable, better informed and have a clearer view of their values. The evidence supporting these three findings was of high quality. Moderate-to-low-quality evidence was found for decision aids activating the patients to make decisions, perceive risks more accurately and make decisions that are in line with their informed values.

Decision aids have been used for almost as long as shared decision making has come to be an established medical practice. The first international shared decision making conference was held in Oxford in 2001 (O'Connor & Graham, 2005) and the International Patient Decision Aid Standards IPDAS was established two years after 2003 (International Patient Decision Aids Standards (IPDAS) Collaboration, 2021).

2.2.3 VALUES-BASED OR DATA-DRIVEN SHARED DECISION MAKING?

Decision aids put a lot of emphasis on the patient's personal values and preferences. For example, decision aids developed by Healthwise, a non-profit organization with an interest in health education, have a whole section titled *Your feelings* in the decision aid template used for multiple health issues (e.g., see Healthwise (2020) decision aid Arthritis: Should I Have Knee Replacement Surgery?). Another way of approaching decision support materials in shared decision making is through the use of empirical evidence: data.

Provost & Fawcett (2013, p. 53) define decision making being data-driven, when it is not only based on experience and instincts but relies on numerical evidence – data – that has been analyzed. Medicine is a prime example of a field where decision making has long been based on the practitioner's experience. According to Provost & Fawcett (2013), data-driven decision making doesn't need to be considered a black-and-white alternative to the more traditional approach. Rather, making use of data in decision making alongside experience and craftsmanship could improve treatment outcomes.

Data-driven artificial intelligence (AI) (Montani & Striani, 2019, p. 120) is one of the two methodological approaches to artificial intelligence (the other being knowledge-based AI). Oravizio is an example of a tool that makes use of data-driven AI: the starting point is a large volume of data, that is then treated with machine learning methods to gain insight (a more detailed description of Oravizio can be found in chapter 3). According to Montani & Striani (2019), data-driven methods are gaining popularity as more and more data are generated in the world and as machine learning techniques are improving. A concern about data-driven methodologies is their complexity and potential lack of clarity to the users (Montani & Striani, 2019, p. 121).

One key variable related to medical decision making that can be calculated in numeric terms is the risk of some undesired event or outcome. In the context of surgery this can mean the risk of failure, risk of revision or risk of infection, for example. Communicating risk information has been called an important part of shared decision making (Mercer et al., 2018, p. 167) and more generically, a core element in healthcare (Dolan & Iadarola, 2008). Risk calculators are defined as tools that usually communicate risk information via numeric information. Oravizio is an example of such a tool. Mercer et al. (2018, p. 168) note that although statistical prediction models offer more accurate predictions of risk than for instance clinical evaluation by a professional, they are still rarely used in clinical practice.

Possible reasons for this include inadequate skills for understanding and presenting numerical risk information with both patients and practitioners. Fagerlin et al. (2011) have also noted patients' poor numeracy skills as a cognitive hindrance to making informed health-related decisions. Many patients have a hard time comprehending numeric information such as percentages: for instance, what the risk of a revision being 4% really means. The same applies for written language as well: in the context of the United States for example, there is a clear mismatch between the literacy level of the average patient and how difficult health education materials they are provided (Fagerlin et al., 2011, p. 1436).

Fagerlin et al. (2011) present three strategies for communicating risk to patients, that are backed by strong evidence for improving patient understanding and decision making. Number one is using plain, understandable language. Number two is communicating risks using absolute rather than relative risks. The third recommended strategy is using visualizations to communicate risk information.

Compared to values-based decision aids, visualizations can be even more important when it comes to communicating hard-to-grasp numeric information to the patients. The following chapter 2.3 will take a closer look at the best practices of visualizing health risk information.

2.3 Visualizing health risk information: a design problem where shared decision making and information design meet

2.3.1 WHY VISUALIZE RISK

Based on the literature review, two motivating arguments for this thesis can be drawn: communicating risk efficiently is key to making informed health-related decisions, and visual aids are known to be beneficial tools for facilitating risk communication (Dolan & Iadarola, 2008, Fagerlin et al., 2011, Garcia-Retamero & Cokely, 2017, Mercer et al., 2018.). Adding visualizations to plain numbers to communicate risk helps both patients and medical professionals to understand and interpret the numbers more accurately (Bell et al. 2018). It is therefore important to study in more detail, what the best practices in visualizing health risk information are.

In general, it has been argued that graphics possess three key attributes by which their use could make it easier for the reader to understand numerical risk information (Lipkus & Hollands, 1999, p. 149, Lipkus, 2007, p. 702). The first one is that graphics make any possible patterns in the data visible. Another benefit is that certain graph types may automatically be associated with certain mathematical operations: for instance, pie charts are associated with depicting parts of a whole. This means that good visualizations require less brainpower to communicate the same message compared to numbers that require more extensive mental calculation (Ancker et al., 2006). The third benefit is that as visual elements, graphs are more likely to capture the eye of the reader and keep them engaged.

Despite visualizations' advantages over plain numbers, there is a lot of variance in how well different types of visualizations work. These variations are discussed in the following chapter.

2.3.2 DIFFERENT WAYS TO VISUALIZE RISK

Drawing from the studies by Lipkus & Hollands (1999) and Ancker et al. (2006), the best practices in designing a risk graph depend on two things: the purpose of the graph and the characteristics of the risk in question. Risk characteristics refer to features such as the size of the risk, whether the risk is relative or absolute in nature and whether the risk is cumulative or set in one specific point in time (Lipkus & Hollands, 1999). The variance in risk and the interconnections of different risk factors are also characteristics that have been studied. Two key purposes that a risk graph might have are transmitting information and influencing the patients' behavior (Ancker et al., 2006, Zipkin et al., 2014), although audience's preferences and satisfaction with graphs have also been included as purposes.

In their article Lipkus & Hollands (1999) evaluate seven different types of visualizations used to communicate risk information. Examples of the types are shown in figure 11 and include the risk ladder, pictographs, line graph, a field of dots, marbles, pie chart and a histogram. Out of these, pictographs, line graph, pie chart and histogram have been widely discussed in more recent studies as well.

According to Lipkus & Hollands (1999, p. 153) pictographs or other icons depicting a face have been shown to affect how risk, especially low-probability risk, is perceived. Compared to plain numbers the use of stick figures or face pictographs is also more likely to lead to changes in behavior and encourage the reader to avoid risks when possible. In their article Helping Patients Decide: Ten Steps to Better Risk Communication Fagerlin et al. (2011, p. 1438) recommend using pictographs for communicating risk at a fixed point in time: for example, how big the risk is after two years. According to

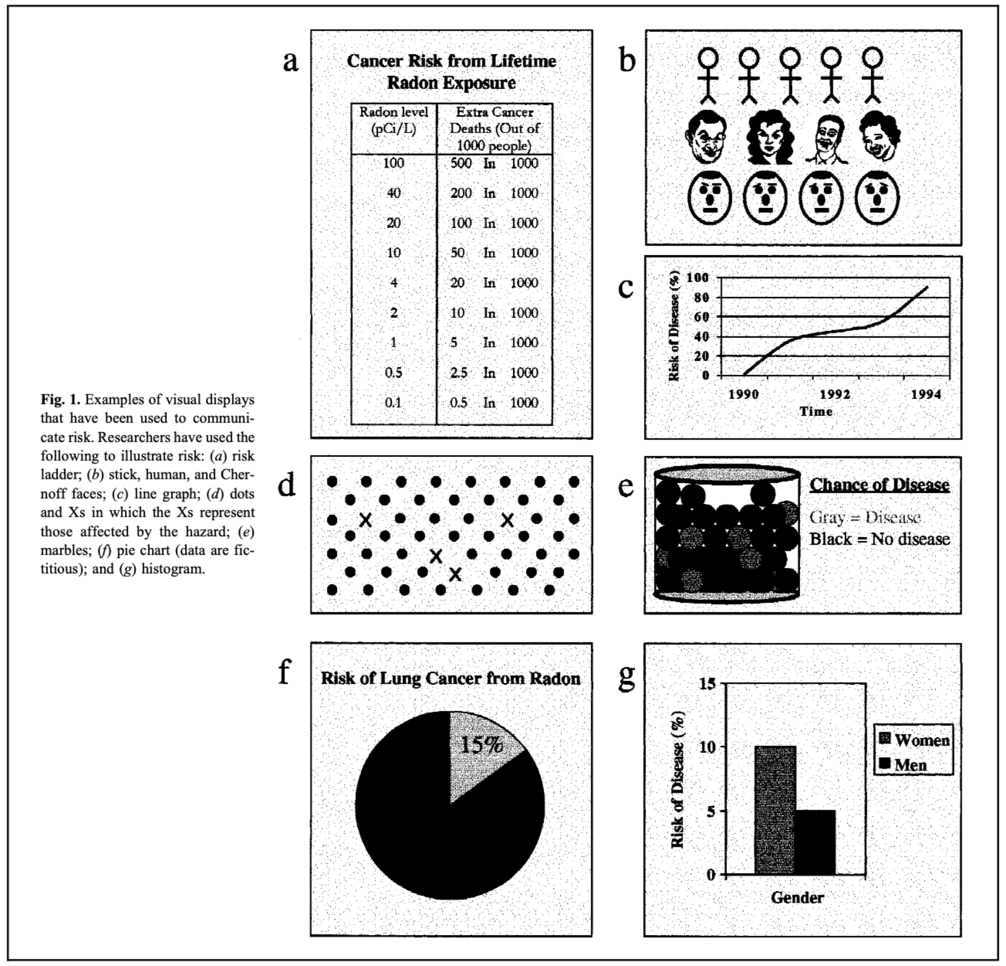

Figure 11: Risk visualization examples from an article by Lipkus & Hollands (1999, p. 150)

Fagerlin et al. (2011) pictographs are easy to understand as they translate probabilities into frequencies, for example five out of a hundred instead of five percent. For natural frequencies visualized in icon arrays, Garcia-Retamero & Cokely (2017) recommend using equal denominators when comparing risks.

When the complexity of icons or pictographs has been studied, it has been found that it makes no difference how detailed the icons are in terms of how beneficial an icon array is considered (Garcia-Retamero & Cokely, 2017, p. 595). A visualization will be comprehended differently from plain numbers, but it doesn't matter as much what type of a visualization it is. Concerning the structure of the graphs, with icon arrays the arrays should be arranged in sequences (Ancker et al., 2006). Randomly arranged icon arrays make comprehension difficult and have been found to be visually disapproved of by the public, although there have been some studies suggesting that the random arrangement might be a good choice for communicating chance and uncertainty in data.

According to Zipkin et al. (2014, p. 276) both icon arrays and bar charts work well in communicating risk. In a study on how well patients understand different types of graphs, van Weert et al. (2021) found bar charts to be the best understood. In the same study, concerning which graphs patients preferred, the bar chart placed second after a clock chart. However, the clock chart was not as nearly well understood. This finding is in line with the previous studies such as Ancker et al. (2006) concluding that liking a visual representation doesn't necessarily mean it works well. According to van Weert et al. (2021) this leads to a puzzling question: should visual aids be designed in ways that improve their function, or in ways that please the eye of the patients, possibly leading to improved engagement with them? To combine both understanding and visual preferences, the authors recommend using the bar chart (van Weert et al., 2021, p. 114).

The chart Lipkus & Hollands (1999) call the risk ladder is essentially a table that displays risk information on a scale from high to low. Typically, higher risks are placed higher on the ladder as well. Lipkus & Hollands (1999, p. 151) conclude that the risk ladder can be beneficial in putting the risk in perspective as both the high and low end of the ladder act as reference points. In the study by van Weert et al. (2021) tables were found to be a way to visualize risk information that may not be visually preferred, but one that leads to improved understanding especially with older adults (van Weert et al., 2021, p. 115). This is in line with the findings of Bigwood & Spore (2017).

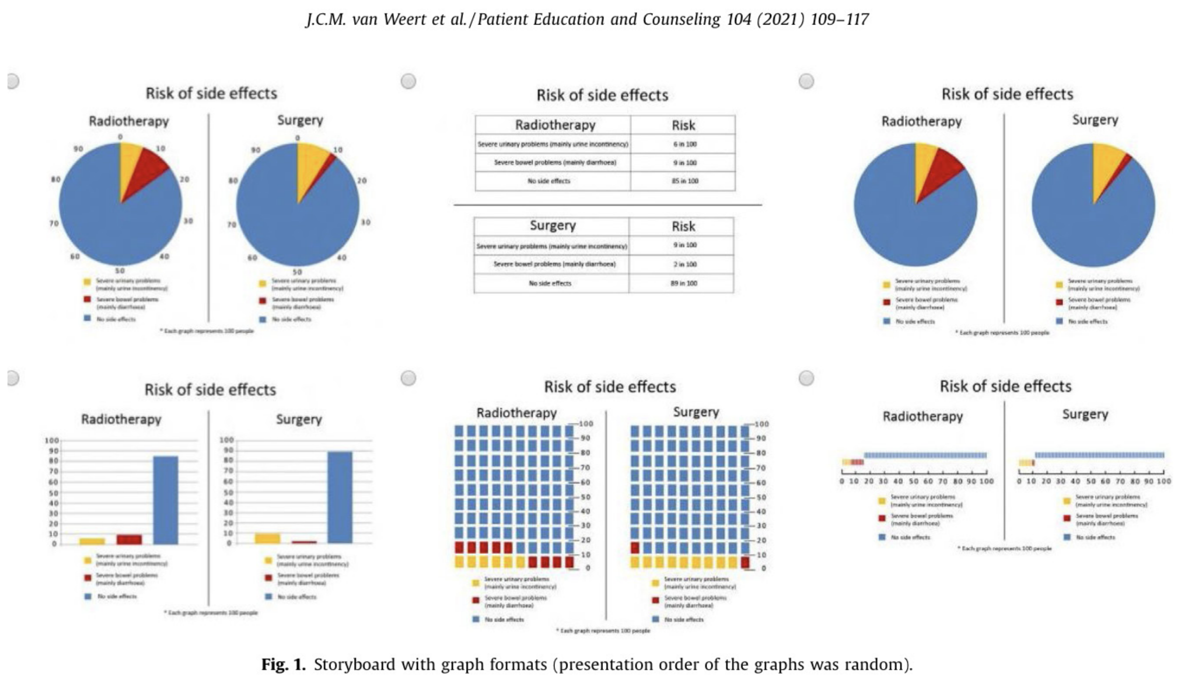

Figure 12: Compared types of visualizations in the study by van Weert et al. (2021).

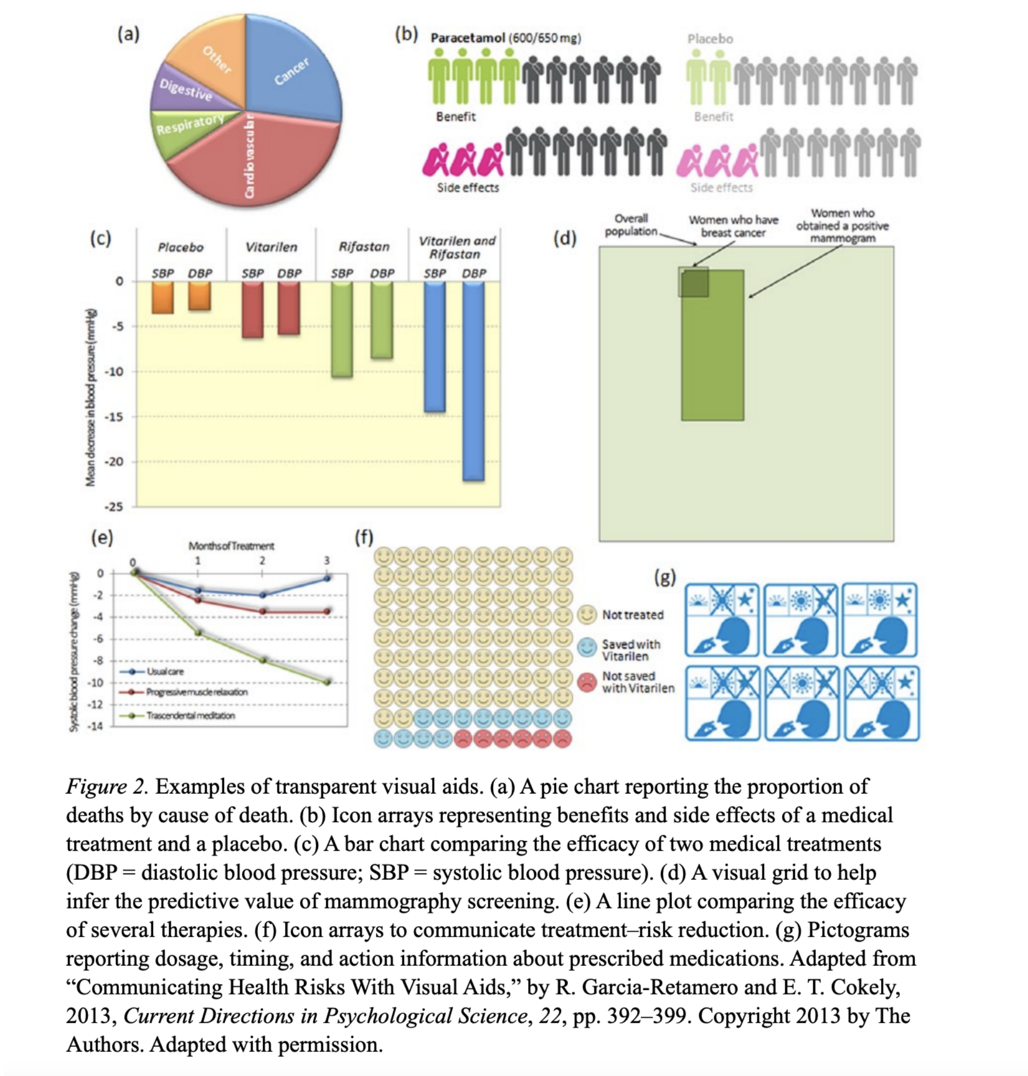

Figure 13: Transparent visual aids as in Garcia-Retamero & Cokely, 2017, p. 587.

Of the other chart types the findings of the risk visualization literature are similar to the findings of the more general information design literature. Zipkin et al. (2014) refuse to claim that one way of visualizing risk would clearly be better than others. Instead, the authors recommend a multitude of approaches for different uses and situations. One thing that most authors agree on is that line graphs are best suited for communicating temporal variations in risk data (Lipkus & Hollands, 1999, Fagerlin et al., 2011).

As a general rule, for visual aids to yield best possible outcomes, Garcia-Retamero & Cokely (2017, p. 587) argue that they need to be transparent: essentially, as clear and accurate as possible, focusing only the essential information presented with absolute risk numbers that can be visually viewed and compared with one another. Lipkus & Hollands (1999, p. 154) write that even simple visuals such as pie charts can be easily misunderstood when they are used to communicate risk. Hence the writers suggest that alongside the visualization the main message should be written out as well.

According to Dolan & Iadarola (2008) the problem with most studies concerning risk communication is the fact that they focus on events that are quite probable – one in five or more. What is lacking is research on how to best communicate low probability events, for which Dolan & Iadarola (2008) have defined a threshold of less than five percent. Lipkus & Hollands (1999) have argued that understanding low-probability risk is difficult with or without visualization of the numbers, making visualizing it a particularly challenging task.

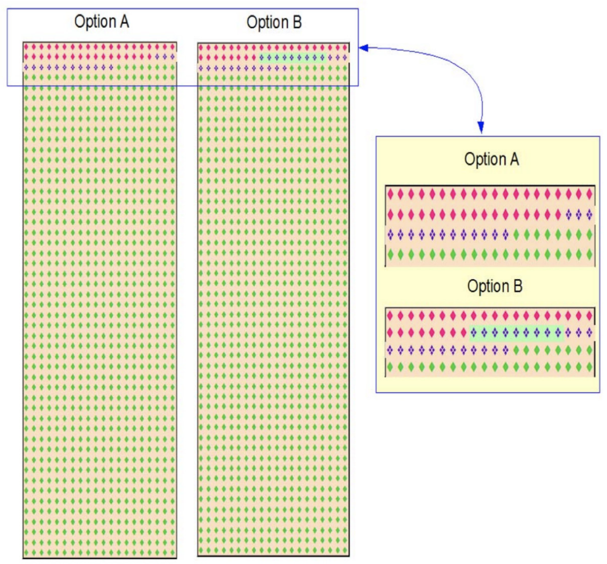

Figure 14: The augmented icon display that was tested with users by Dolan & Iadarola (2008) to find best practices to present small probabilities visually

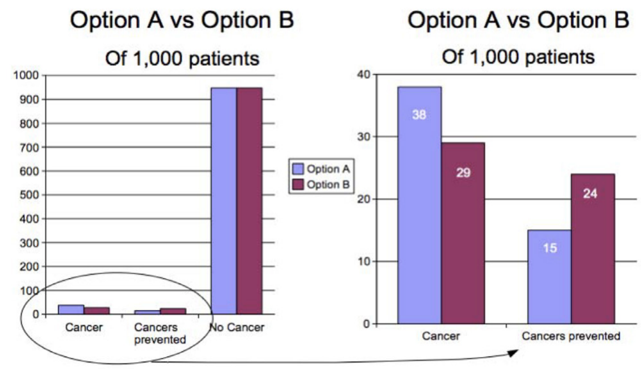

Figure 15: The augmented bar chart that was tested with users by Dolan & Iadarola (2008) to find best practices to present small probabilities visually

Joint replacement surgeries are an example of a medical operation, where the risk of an adverse outcome might be small, but still something that needs to be communicated. Dolan & Iadarola (2008) have suggested the use of augmented charts as an alternative to communicate low probability events. (See figures 14 and 15 for their examples). Lipkus & Hollands (1999) on the other hand suggest that visualizing a cumulative risk over a certain period of time could be a better substitute.

As noted earlier, visualizations may vary with their intended outcome. If the main goal is to transfer numerical information, the size of the graph features should be in line with the numbers they represent (Ancker et al., 2006, p. 616). If they are not, the readers are more likely to look at the graphic representation. To depict relative numbers, portions to a whole, bar charts as well as icon arrays are likely to spur an automatic reaction to process visual areas and judge proportions.

When it comes to influencing behavior, visualizations of the numerator, the absolute risk magnitude, instead of a proportionate risk, is more likely to lead to behavioral changes (Ancker et al., 2006, p. 616). Especially when comparing risks, risk aversion is more likely with these types of visualization compared to plain numbers. When a visual focused on the numerator compares risks as three against six, instead of three out of a hundred against six out of a hundred, the difference in the risks is highlighted more. The authors claim that "providing relative risks without absolute risks has long been known to inflate the apparent magnitude of the risk difference, even with educated audiences" (Ancker et al., 2006, p. 616). Since reporting relative risk and risk reduction is more likely to persuade the patient towards specific action Zipkin et al. (2014) have advised to be cautious when using them.

A more recent review by van de Water et al. (2020, p. 1764) on risk visualization for cancer patients noticed that how positively or negatively the visualization topic is framed (whether it depicts number of patients survived or number or patients deceased, for instance) makes a difference in how patients view potential treatments. A more positive framing may lead to better engagement with treatments, but again, due to heterogeneous studies and experimental setups, a definite conclusion on the matter cannot be made.

2.3.3 CHALLENGES WITH RISK VISUALIZATION

As noted earlier, communicating numerical risk information to the public is a challenging task (Ancker et al., 2006, p. 608). Not everyone works well with probabilities, and especially events that have a low probability can be difficult for everyone to grasp. According to Ancker et al. (2006), people often have a tendency to either overestimate low probabilities or brush them off as nonexistent. Poor numeracy skills play a role in many cases. Age, stress and other factors can also weaken the people's capacity to understand numerical risk information.

There is a link between numeracy and patient health outcomes, according to Garcia-Retamero & Cokely (2017, p. 584). Numeracy can be defined as a person's capacity to use mathematics in everyday problem solving.

Especially statistical numeracy has been linked to a person's capacity to make decisions. Low numeracy has been shown to be linked to delays in seeking medical help, following the prescribed medical regimen and inclination to comorbid conditions. Patients with low numeracy are also more prone to making mistakes when estimating benefits and risks of possible treatment. Improving patients' risk understanding is essential to improved health outcomes. There is a substantial part of the population who struggle to understand probabilities and numerical information related to health (Garcia-Retamero & Cokely, 2017, p. 586).

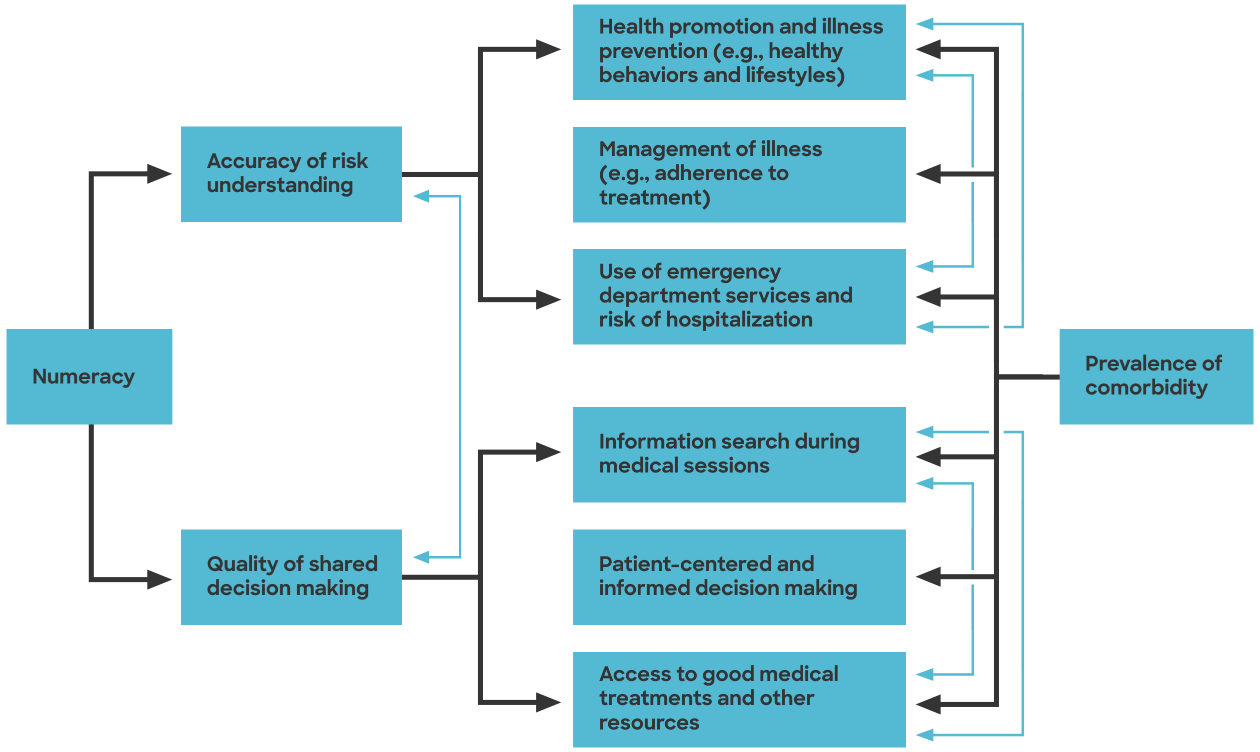

Figure 16: Conceptual framework of the effect of numeracy on prevalence of comorbidity and the mediating effect of accuracy of risk understanding and quality of shared decision making. Adapted from the original by Garcia-Retamero & Cokely (2017, p. 585).

Numeracy and graph literacy (how skillful a person is to obtain information and meaning from data visualizations) of the user also play a role in how well visual aids work (Garcia-Retamero & Cokely, 2017, p. 588). After reviewing studies on risk and graph literacy between years 1995 and 2016, Garcia-Retamero & Cokely (2017, p. 591) concluded that a clear majority (88%) of the studies reviewed showed that visual aids improve the users' risk literacy. The visual aids in question were static graphs and other visualizations. The studies on graph literacy revealed that visual aids benefited people with at least some level of graph illiteracy.

Graph literacy is also tied to the patient's background and different visualizations work for different audiences: even though it has been argued that visualizations are not tied to language barriers, according to Ancker et al. (2006) along with how skillful the audience is, graph literacy varies based on how familiar they are with the visualization type in question. Even the more common graph types, such as bar charts, could come with a verbal instruction attached to them to promote their comprehension.

When designing future research on shared decision making, van de Water et al. (2020) call for taking the participants' numeracy and graph literacy as well as their social and cultural background into account. Garcia-Retamero & Cokely (2017, p. 586) have noted that for the less numerate patients the so-called "paternalistic model of medical decision making", where the practitioner makes the decisions for the patients, may be easier to accept. However, as the shift towards shared decision making continues to take place, the needs of less numerate and graphically literate patients should be considered when designing decision aids and other decision support materials.

3 Case study Oravizio

3.1 Description of the Oravizio tool

As a case study this thesis focuses on Oravizio, a risk assessment tool for joint replacement surgeries developed by Solita Oy and Coxa hospital, where the tool was introduced into clinical use in 2018. Oravizio is a software tool that helps orthopaedic surgeons understand patient-level risks and expected outcomes related to hip or knee joint replacement surgery together with the patient. The tool has a risk calculating algorithm that takes into account patient-specific data as well as the patient's history data. This data is then visualized in an understandable manner that makes it easier to communicate treatment risks to the patient.

The goal of Oravizio is to facilitate shared decision making between the patient and the surgeon. The surgeon is responsible for manually inserting data into the tool but the user interface showcasing the results is meant to be viewed by the surgeon and the patient together. With the help of Oravizio both parties can make more informed and data-driven decisions concerning the treatment. Despite being a tool that aids shared decision making between the surgeon and the patient, the final treatment decision as well as evaluation of the contraindications must always be done by a healthcare professional.

Oravizio is meant to be used prior to surgery. To use the tool, two requirements must be met:

1. The surgeon has assessed that the joint replacement surgery would benefit the patient by resulting in pain relief, improved functionality and better quality of life.
2. No absolute contraindications for the surgery exist, meaning the patient is fit enough for major joint replacement surgery.

3.1.1 WHAT INFORMATION ORAVIZIO GIVES

Oravizio provides the user with three types of risk information: risk of infection, revision and mortality. Infection risk means the risk of infection within a year of operation, revision risk means the risk of revision within two years of operation and mortality risk means the risk of mortality within two years. Individual risk of the patient and the relative risk compared to the reference group are both presented to the user.

3.1.2 WHAT DATA ORAVIZIO'S ANALYSIS IS BASED ON

Oravizio features individual risk models for infection, revision and mortality. The models are based on data collected at Coxa hospital between 2008–2018 of over 30 000 patients. The data contains approximately 750 variables including patient general information, medication, pre-existing diagnoses, laboratory values, information provided by the patients and variables derived from these. Part of the dataset was used for training the models and part for testing them.

All three risk models make use of a selection of these variables. The variables for each model were chosen based on scientific literature, medical understanding and computational methods. The variables used in the models are detailed in figure 17.

Variable	Explanation	A variable used in a specific risk model			
		Infection (1y)	Revision (2y)	Long term revision	Mortality (2y)
Birth year	Patient's age	■	■	■	■
BMI	Body mass index	■	■	■	■
Sex	Male or female	■	■	■	■
Operated joint	Knee or hip	■	■	■	
ASA	ASA Physical status classification system (Classification 1, 2, 3, 4+) ASA summarises large set diagnoses and indicators of the state of patient's health	■	■	■	■
Drugs	Diuretics (the only drug group at the moment)				■
Diagnoses	Preoperative infection	■	■		
	Mental and/or neurological disorders		■	■	
	Cancer				■
	Peripheral vascular diseases	■	■		■
Primary cause	Primary cause of operation: Select one of these: Osteoarthritis, Rheumatoid arthritis, Fracture, Necrosis, Other	■	■	■	
Laboratory results	P-AFOS				■
	e-GFR	■	■		■
	B-Hb	■	■		
	B-HbA1c	■	■		

Figure 17: The chosen variables used in the Oravizio models

3.2 Current state of Oravizio's user interface design

After logging in to Oravizio, the user (the orthopaedic surgeon) is asked to manually insert the patient's information to the tool. Information required includes the patient's birth year, height, weight, sex, joint to be operated, primary cause and ASA classification value. Additional information that can be also included to get better results include the possible use of diuretic drugs, pre-existing diagnoses and laboratory results of three different variables P-AFOS (alkaline phosphatase), e-GFR (estimated glomerular filtration rate of the kidneys) and B-Hb (hemoglobin). If the latter ones are not filled with patient-specific values, the models will use reference values for patients over 18 years old. The user interface for inserting the patient information is shown in figure 18.

After the surgeon has filled in the information, the patient-level risks based on the data model are showcased. The visualizations of the risks appear on the right side while the input fields for the patient's information remain visible on the left and can be modified later. The user interface with the visualizations can be seen in figures 19 and 20. In the user interface, the risks of infection, revision and mortality are all shown on their own separate tabs. For each risk category similar visualizations are shown: at the top, the individual risk of the patient both as a numeric value in percentages and visualized with an icon array as frequencies, and below it, the relative risk compared to a reference group both as a numeric value in percentages and visualized with a bar chart containing both the individual risk and the risk of the reference group with a confidence interval. If the individual risk is over twofold compared to the reference group, a slightly pulsating exclamation point will appear on the tab of the corresponding risk category.

The icon array features a simple pictograph depicting a human face. The denominator of the icon array portraying individual risk changes so that the numerator is always one. For example, the risks for the same patient could be 1 in 20 persons for infection, 1 in 9 persons for revision and 1 in 48 persons for mortality.

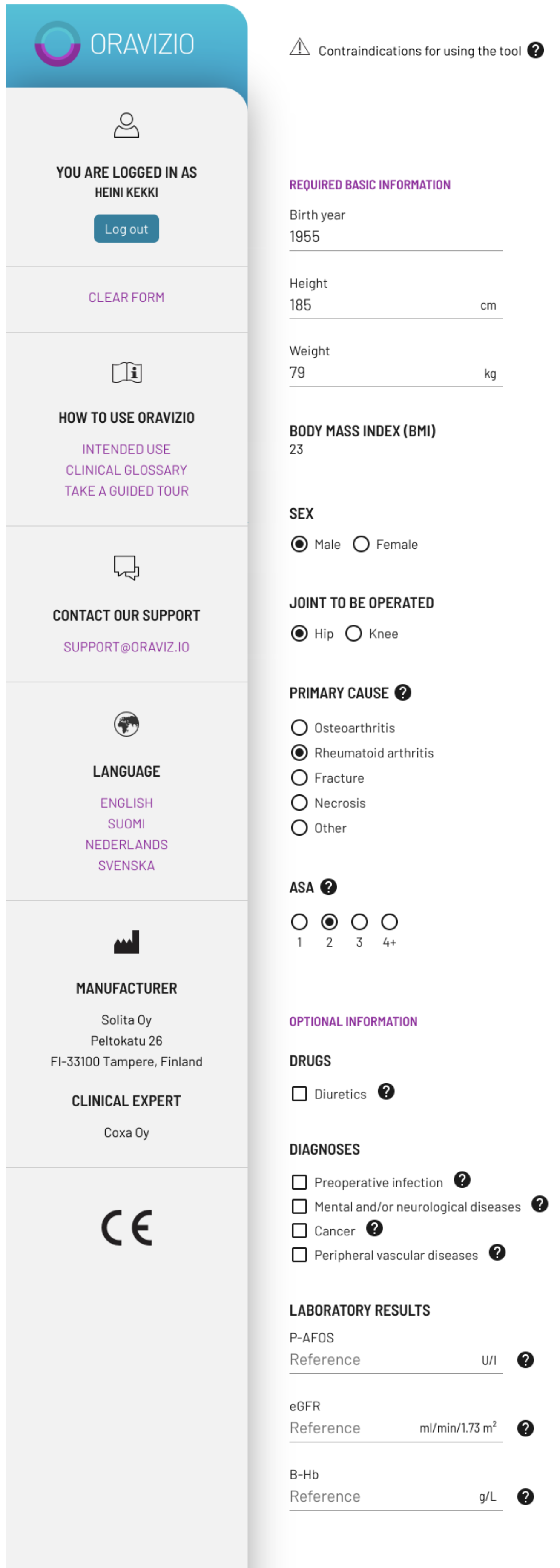

Figure 18: Input fields for patient information in the current version of the Oravizio tool

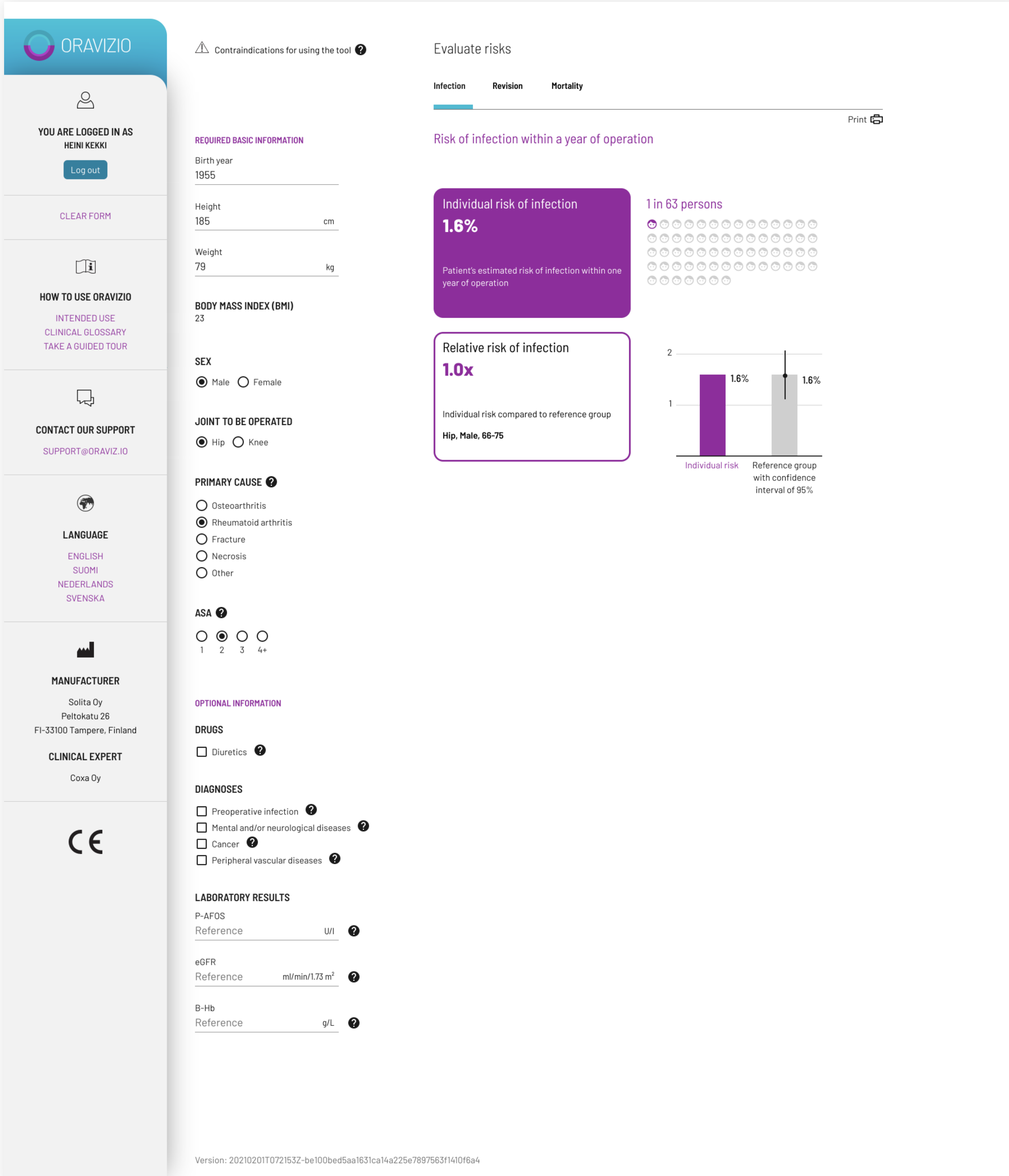

Figure 19: Input fields for patient information and results as shown in the current version of the Oravizio tool. Risk of infection risk, revision and mortality are shown on their own separate tabs with same visualizations. Risk of infection is shown here as an example.

Figure 20: If the relative risk of the patient is over twofold compared to the reference group, a pulsating exclamation mark will show up both in the results page and on the tabs

3.3 Regulatory framework: from MDD to MDR

Although not the focal point of this thesis, a brief look is taken at the regulatory framework Oravizio is tied to as a CE-marked medical device, as regulation poses challenges for the tool development.

Oravizio is a CE-marked medical device, meaning that the manufacturer guarantees that the product has been assessed and conforms to specific legal requirements for the European market. The cavalcade of CE-marked medical devices is vast: other examples include pregnancy tests, blood pressure monitors, adhesive bandages and various prostheses (Fimea, 2021). From a regulatory standpoint, it makes no difference what form a medical device takes: the same legal requirements apply for physical devices, devices that include a software element and software that act as medical devices on their own (Granlund et al., 2020).

Companies wishing to enter the market with a software-as-medical-device (SaMD) product must take regulations, quality management, and standards into account along with software development already when designing the product. Major changes for medical device regulation on the European market are currently taking place, as the new Medical devices regulation MDR (EU/2017/745) replaces the old Medical devices directive MDD (MDD 93/42/ETY). The new MDR came into effect on May 26, 2021, but certain devices are still allowed to remain on the market under the existing declaration of conformity or certification issued in accordance with MDD until the end of the so-called grace period in May 2024 (The European Parliament and the Council of the European Union, 2017). Oravizio is an example of such a medical device.

During the grace period, no significant changes to the design or the intended use of the medical device can be made (Medical device coordination group, 2020). Significant changes to the design and intended use include extension or change of the intended purpose of the device, the inclusion of a new user or patient population, new or modified architecture or database structure, change of an algorithm, and new user interface or presentation of data, for example (see Medical device coordination group, 2020, for a more comprehensive list). Changes to the appearance of the user interface, including a new language, new layout, or new graphics, could be considered minor changes.

To make any significant changes to Oravizio during the grace period, the manufacturer needs to certify the software to conform to the new MDR requirements. This certification process needs to take place before launching an updated version of the tool. Under both MDD and MDR certifications, medical devices have been assigned a certain classification. Under MDD, Oravizio has been classified as a class I/MDD device and a class IIa/MDR device under MDR. In practice, as a result of reclassification into a higher class, European notified body involvement is required in the assessment of the conformity of the device and the manufacturer's Quality Management System. Under MDD, no third-party assessment for Oravizio was required. However, even without any significant changes, an MDR certification process is required to keep Oravizio on the market after the end of the grace period.

From the visual design point of view, manufacturers are guided by several ISO- and IEC standards when developing and designing medical devices. For instance, manufacturers are obliged to use specific symbols to convey essential information as instructed in the ISO 15223-1 standard (ISO 2021b). This includes the symbol for the manufacturer featured at the bottom of the leftmost panel in the Oravizio user interface. In essence, standardization aims at making it easier for the user to find essential information related to the medical device. Standardization does not set boundary conditions for non-essential UI elements and components.

At this point, any changes proposed in this thesis to the design or information content of Oravizio are to be treated as theoretical. Due to the complex nature of the regulatory framework, implementation of such changes is out of the scope of this thesis and something to consider at a later developmental stage.

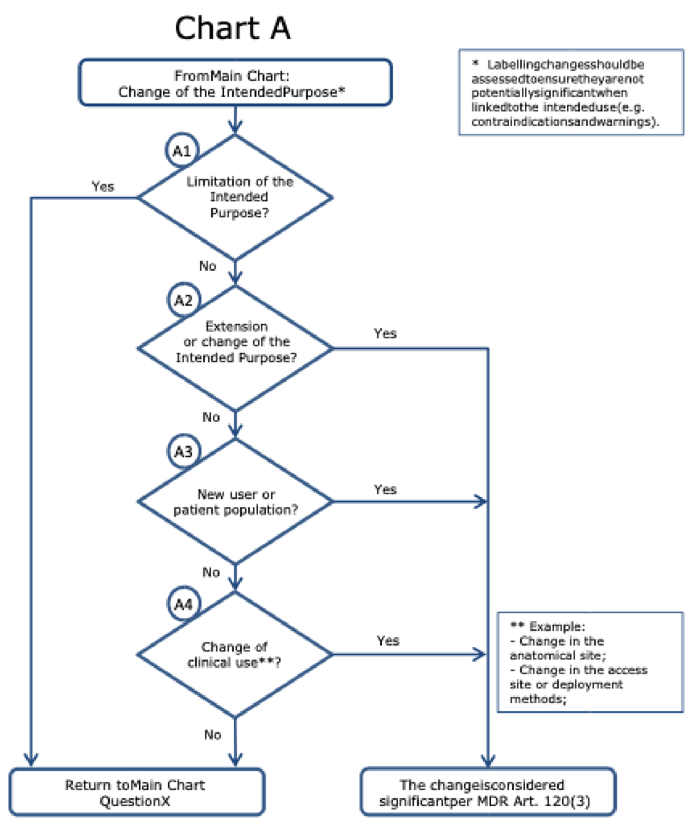

Figure 21: A flow chart from the MDCG 2020-3 document to help interpret significant changes to a medical device (Medical device coordination group, 2020)

4 Methodology

4.1 Premises

In the second chapter, the theoretical framework of risk visualization and its role within shared decision making was reviewed. The goal of the following chapters is to enrich the theoretical findings with insights gathered from medical professionals who have used Oravizio in real life. Against this backdrop the current design and information content of the user interface can be assessed and improvements or modifications can be proposed. In this chapter four the approach and methods used for gathering user insight are explained.

To start off with, there was some pre-existing information on the current user interface of Oravizio, a usability test conducted in 2018 before the initial launch of the tool. The usability test revealed problems with the following tasks related to the visual design of the product: "Identify what relative risk is based on", "Identify what is patient's reference group", "Identify patient has an elevated risk calculation", "Identify what inputs factored most to high risk". Three users (medical practitioners) took part in the usability test, and with these aforementioned tasks two out of three of them failed to succeed. These four tasks can be viewed as critical in terms of transmitting medical information to the patient. In addition, two out of three participants failed to succeed with the tasks "Identify which inputs are used in 1-year infection risk" and "Identify which inputs are used in 2-year revision risk model", which are also indirectly related to transmitting information to the patient.

The aim of the thesis is not to reiterate a similar usability test concerned with specific tasks. Rather, the key interest is how the users view the tool and the use of information visualization from the point of view of shared decision making as a whole. This connects the upcoming part of the thesis with the second facet of the research problem: How does Oravizio facilitate shared decision making at its current state according to users? The earlier challenges professionals faced in the usability test are something to keep in mind, however, when considering how information content and visualization in Oravizio could be improved.

4.2 Study approach and method

According to Dyson (2017, p. 448), being a multidisciplinary field, information design is not tied to a single research method or an approach. Choosing the right method for a study depends on the case and the context at hand. Deciding what research methods to use on an information design evaluation project depends on the information content, who will be the target audience, how will it be used and how much time and resources are available for the design (Stahl-Timmins, 2017, p. 452).

The research approach used in this thesis falls into the category Blandford (2014) has coined semi-structured qualitative studies. Instead of testing a hypothesis, semi-structured qualitative studies approach the study subject with curiosity, trying to gain knowledge of the matter (Blandford, 2014). Semi-structured qualitative studies stand somewhere between a quantifiable survey and pure ethnography: less structured than the first, as surveys typically have already limited the potential answers a participant can give, but more structured than the second, as ethnography can be merely observational. The possible methods semi-structured qualitative studies encompass are endless, which provides an opportunity and a challenge at the same time.

This thesis makes use of one of the most widespread qualitative methods: the interview, or more specifically, the semi-structured interview. According to Blandford (2014) an interview is a valuable method to use when the interviewer wants to gain understanding of the attitudes and feelings of the user. In the context of this thesis, the goal is to understand how the orthopaedic surgeons experience the use of Oravizio as a facilitator for shared decision making. The literature review has provided viewpoints on how decision aids should and could work in theory, and the second part of the thesis – the interviews – aims to provide viewpoints on how this particular tool works in assisting the decision making process in a real-life context.

Interviews can vary from the conversational and free flowing unstructured interview to the structured interview that resembles a survey. Semi-structured interviews fall somewhere between these two categories (Blandford, 2014). This means that the topic of conversation is planned in advance, key questions may be drafted but the conversation between the interviewer and the interviewee is not tied to those questions alone. This leaves room for the interviewer to follow interesting leads that might turn out in the conversation. When interviewing multiple people, the interviews may also have slightly different emphases based on how the conversation flows. The semi-structured interview wireframe used in the interviews for this thesis can be found in the annexes in chapter 11.

Requirements for the interviewees were to be a professional in the field, an orthopaedic surgeon, and to have at least some experience using Oravizio in clinical settings. Interviewees were found and suggested by Kimmo Kivirauma from Solita, based on his previous work with Oravizio and knowledge on which professionals were in the habit of using the tool. Some other ortohopaedic surgeons at Coxa were also contacted by taking a random selection of names from the hospital website. The intent was to potentially get differing viewpoints from professionals who use the tool less. However, this form of contacting did not lead to any interviews, as all the professionals who wrote back claimed they hadn't used Oravizio enough to be interviewed.

In the end, altogether four professionals were interviewed. Three of the interviewees were orthopaedic surgeons at Coxa hospital and one was a Welsh orthopaedic consultant in Cardiff, UK, who is taking part in an Oravizio pilot. The interviews were conducted in Finnish or English. The interviews were conducted remotely over Zoom and Teams and a permission to record all the sessions was granted. The recording audio lengths range from approximately 40 minutes to a bit over an hour. The recordings were transcribed to text in the same language that they were conducted in.

4.3 Analysis

To go through the transcribed data gathered from the interviews a very traditional approach to analyzing qualitative data was used: thematic analysis. The goal of a thematic analysis is to reveal and establish thematic patterns in the interview data (Braun & Clarke, 2012, Mortensen, 2020). Although thematic analysis is a broad term that includes various techniques, they all follow the same steps: getting to know the data, coding the data based on content, looking for thematic patterns in the codes, reviewing the themes, defining the themes further and naming them, and finally, producing a report (Mortensen, 2020). Benefits of a thematic analysis include its flexibility and usability (Braun & Clarke, 2012, p. 58). It can be both inductive or deductive in nature, meaning that it can be used in an exploratory way or to find possible evidence for pre-existing ideas. In practice this means that the codes either rise from the data or the codes already exist, and the researcher analyzes how well the data supports findings, ideas and concepts gathered from theory, for instance. Despite which direction the researcher takes with thematic analysis, it is important to be aware and explain to the reader why these particular choices were made.

In the case of this thesis the approach leans more towards the deductive approach. After having read extensively on the study subject I entered the interviews with certain presumptions in mind. Likewise, these presumptions have been present when analyzing the data. At the same time, choosing to do a semi-structured interview also allowed for some unexpected findings. An accurate description of my approach would be that I had some themes and concerns in mind before the interview, but the interviews helped me clarify the relative importance of the different themes and topics.

To start with, I read through and familiarized myself with the transcribed interviews. After getting to know the data, I started drafting the initial codes. First round of coding resulted in 27 codes. In the second round these codes were reviewed and expanded resulting in 13 codes including two completely new codes. An example of how this part of analysis looked like in practice can be seen in the mockup example of transcribed data in figure 22. Finally, these codes were further reviewed and categorized into six final themes. All the codes and final themes are visible in figure 23.

Mockup example of level two coding of a transcribed interview (6/13 codes present)

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Communication | Professional usage | Risk and benefits

Freedom of choice | Patient's expectations | Responsibility

Figure 22: A mockup example of coding transcribed interviews

FIRST ROUND CODES

Patient's responsibility
Professional's responsibility
Patient's negative experience
Communication
Talking differently to different patients
Argumentation support
How the professional uses Oravizio
Professional's interests
Benefits of Oravizio
Previous knowledge and craftmanship
Decision making
Freedom of choice
Patient's perception
Size of the risk
Risk-benefit ratio
Realistic expectations
Patient preferences
Quality of life
Function
Hospital resources and treatment times
Varying treatment practices
Established treatment practices
Smoking
Obesity
Sugars
Data model or IT related
Development ideas
Interventions and patient motivation
Shared decision making vs. paternalistic approach

SECOND ROUND CODES

Responsibility for the outcome
Patient's responsibility, Professional's responsibility, Patient's negative experience

Communication
Communication, Talking differently to different patients, Argumentation support

Oravizio and the professional
How the professional uses Oravizio, Professional's interests, Benefits of Oravizio, Previous knowledge and craftmanship

Freedom of choice
Decision making, Freedom of choice

Patient's perception

Size of the risk
Size of the risk, Risk-benefit ratio

Patient's expectations
Realistic expectations, Patient preferences, Quality of life, Function

Hospital practices
Hospital resources and treatment times, Varying treatment practices, Established treatment practices

Risk factors
Smoking, Obesity, Sugars

Data model or IT related
Datamalliin liittyvä tai tietojärjestelmiin

Development ideas

Interventions

Shared decision making vs. paternalistic approach

FINAL THEMES

Responsibility and choice
Responsibility for the outcome, Freedom of choice

Understanding
Patient's perception, Size of the risk, Patient's expectations

Communication
Communication, Shared decision making vs. paternalistic approach

Professional use
Oravizio and the professinal, Hospital practices

Interventions
Interventions, Risk factors

Further development

Figure 23: All the codes and final themes resulted from the thematic analysis

The final themes – responsibility and choice, understanding, communication, professional use, interventions and development ideas – were present in all four interviews although the emphasis put on each varied from professional to professional. Some talked more about the broader concepts and principles of listening and including the patient in the decision making process, whereas some others focused more on interventions and individual risk factors. Key findings of each theme are described in the following chapter five. There is considerable overlap and interconnectedness with some of the themes, especially responsibility, understanding and communication. They are nonetheless covered separately to highlight the different sides of this multifaceted topic. Visualized offerings of the interviews are presented in chapter six.

5 Thematic findings from the interviews

5.1 Responsibility and choice

Responsibility and choice are themes that could be described as the moral backbone of the entire discussion on shared decision making. At first it seemed like these two should be divided into separate categories of their own, but according to the professionals' views the two seem to be interlinked. Elwyn et al. (2012, p. 1361) have called self-determination the core ideal of shared decision making. In the context of joint replacement surgery, this means that the patient always gets to have the final word whether they are willing to have the operation done. Surgeries that Oravizio is used for are elective in nature: they are not life-saving operations, but voluntary. The orthopaedic surgeon is responsible for assessing the patient's situation, but when the surgeon thinks it's safe and reasonable to operate, the patient still gets to choose not to get surgery. The surgeon won't operate without the patient's consent.

However, with the freedom to choose comes responsibility. Most of the orthopaedic surgeons interviewed claimed that the operation is the easy part of the treatment process. The more difficult and strenuous part comes after the surgery, with exercise and rehabilitation making up at least half of the end result: an improved knee or hip. This part is the patient's responsibility. If the patient chooses to have the operation, in order to get the benefits, they also must put in the work afterwards. Likewise, the patient's responsibility and choice are also present in the possible interventions that are needed before the surgery to lower the risk of the operation. Although the professionals deliver the message on what the patient could do to lower surgical risks, more often than not it is down to the individual to make the improvements: to quit smoking, for instance.

It is the professional's responsibility to assess the patient's situation, consider all their health concerns and come to a decision on what is the best treatment plan. If an operation is considered, it is the professional's responsibility to inform the patient of the risks involved. This was heavily emphasized in all the interviews, with some professionals making the statement more than once: the patient must know the risks, they must know what they are signing up for. According to the interviewees, sometimes the patients are reluctant to hear the risks, considering them too intimidating. Even then, the professionals need to go through them. If the misfortune of an infection or a revision should happen, it's a much more difficult situation if the patient feels they were not informed of the risks beforehand. In such cases, in addition to the trouble caused by the infection or revision, the patient may have to deal with feelings of resentment and bitterness.

All in all, the professional is responsible for the operation as well as informing the patient beforehand. In addition to informing the patient of the risks, the surgeon needs to familiarize the patient with other practicalities concerning the treatment, such as prognosis and recovery time. The responsibility of the decision to go into surgery is shared as both the professional and the patient need to be in favor of it. After the operation the responsibility for the rehabilitation moves over to the patient. In this way, shared decision making in the context of an elective surgery such as a knee or hip replacement means shared responsibility for the outcomes as well.

5.2 Understanding

The second theme, understanding, refers to the ideas and notions the patient and the professional have of the joint replacement surgery before, during and after the decision making process. This includes the patients' (potentially variable) expectations as well as their perception of the risks and benefits related to the operation.

An expression that kept repeating across the interviews when discussing this theme was realistic expectations. The surgeons expressed that an important aspect of the decision making process and an important goal of informing the patient was to leave the patient with realistic expectations for the operation. This means not only informing the patient of the risks but also other outcomes: what the patient can expect to do after the surgery. It was noted that sometimes patients' expectations before consulting the professional tend to be unrealistic: for instance, that they want to be able to run a marathon with a knee replacement three months after the surgery. In situations like this it is the professional's job to bring the expectations down to a realistic level.

Keeping the expectations realistic is not synonymous with pessimism. Rather, according to some of the interviewed professionals, having a realistic goal to work towards helps the patients to commit to post-operative rehabilitation.

This realistic goal can sometimes be the result of the discussion the professional and the patient have together concerning the risks, benefits and outcomes of the operation. Sometimes the patients can cope with the symptoms, but they just want to understand what is happening to them.

It was highlighted in multiple interviews that getting to know what motivates the patient to get the surgery is an important part of the discussion. What the patients want out of the joint replacement surgery varies depending on the patients' life situation and lifestyle. For some, a motive for the operation is to be able to keep living in their own home independently. For others, a motive could be to be able to continue with a recreational pursuit such as hiking.

Creating realistic expectations is important because in order to consider the risks of the operation, the risks need to be weighed against potential gains: what can be achieved with a successful operation. If the surgeon recommends an operation, it means that they estimate the potential gains to be bigger than the potential risks and that the quality of life of the patient would significantly improve with a successful operation. In order to come to this conclusion, the professional needs to understand the patient's situation and what drives them.

Many of the interviewees mentioned that often the patient's discomfort with the joint is not severe enough that it would make sense for them to get the operation. In fact, it was pointed out that often the best outcomes are achieved with the worst X-rays. This slightly counterintuitive idea means that sometimes the joint replacement simply wouldn't improve the patient's condition enough: the risks of the operation would be too big weighed against what could be achieved and performing the operation would be a disservice to the patient. In a situation like this, if the patient had their mind set on surgery with hopes of feeling better, the professional refusing the operation needs to be able to communicate the why of the decision in a way that the patient will understand.

On the other hand, if the patient's condition is severe, it's possible that they are willing to take bigger risks because they feel they have more to win than to lose. Likewise, the surgeon will be more likely to back that decision. It is understood that surgery is often the last resort in treating knee and hip malfunctions, one to turn to when other measures such as physiotherapy have not been effective enough.

If the conclusion of the professional is that a surgery would make sense to the patient, they need to present the risk information to the patient. What the literature already pointed out was heavily echoed in the views of the professionals: that small risk percentages are notoriously difficult for the patients to grasp. This, as the professionals pointed out, is where Oravizio comes in handy. Unanimously the interviewees agreed that the icon array with face pictographs depicting the different risks was the most useful way of presenting information. It was deemed as offering a concrete and visual way of putting it: if this and this many people go under the knife, one will get an infection. The professionals agreed that offering the information visually rather than verbally seems to lead to improved understanding.

Another way of expressing risk information in Oravizio that the professionals estimated the patients understand better was the reference figure: how manyfold the patient's risk is compared to a reference group. Plain percentages were considered valuable information for the professional, however, with some of them writing them down on patient records. Offering the same information in multiple ways was thought to be an effective way of delivering the message. At the same time, it was praised that Oravizio is not overly filled with statistics. One interviewee said that there is enough information to make it relevant, but not too much to make it complicated or overwhelming.

The need for simple and understandable information became apparent in the discussions with professionals. It was noted that when the patient and the professional meet up for consultation, the patient is likely to get so much varying kinds of information that digesting it all is difficult. In addition to learning about the risks, prognosis and outcome, the patient might have to give all sorts of details about their medical past, think about schedules for the next appointment or the operation and possibly be referred to another specialist for some other kind of consultation. The patient might feel scared, anxious and stressed. In the midst of all this, the information that needs to be given, needs to be delivered effectively and understandably.

It is understandable that for the average patient risk values are difficult to understand, as in the case of elective surgeries such as joint replacement surgeries the absolute risk values are not – or do not seem – very big. One professional mentioned that the largest infection risk rate he had gotten out of the Oravizio tool was 7%. 7% doesn't sound like much but expressing that the risk is sevenfold compared to the average person, it suddenly does sound bigger. Another said that 1/30 risk – 3,3% – is already high. Again, without the help of someone or something putting these values into perspective, a value such as 3,3% could easily be brushed off as next to nothing. The professionals also said that although the probabilities of an infection on a population level are low, when that infection happens, it happens to that patient one hundred percent. This means antibiotics, associated complications, possible redos of the surgery, more time spent in hospital and longer recovery periods. The discomfort of an infection without prior experience of it is hard for the patient to grasp.

At the same time, it was agreed that oftentimes the infection, revision and mortality risk rates are not insurmountable if the surgery is truly required. For a patient who is overly scared of the operation, the professional might need to create understanding in the other direction - that most likely the end result of the surgery will be good. It is a delicate balance communicating small risk percentages without either downplaying or exaggerating the values. The patient needs to understand that a joint replacement surgery is not a small procedure like a mole removal, but a big operation with possible serious side effects. At the same time, in order to get the full understanding for the decision making, the patients also need to take into account the positive consequences. Having their eyes set on the positive goal is also vital for full recovery.

Generally speaking, patients tend to be more interested in understanding what they can do with the joint replacement after the surgery than the risks involved in the operation. Pain and function and how they will improve are key interests for the patient. Regarding function, all the interviewees mentioned the Oxford Knee Score and Oxford Hip Score, patient reported outcome measures that are collected from all the patients before and after the surgery. The Oxford Scores feature questions such as “For how long have you been able to walk before the pain from your knee becomes severe (with or without a stick)” and “Have you been able to climb a flight of stairs?”. The data from these reports help the professionals create understanding for what can be expected from a successful operation.

5.3 Communication

The third theme, communication, along with understanding is a key theme considering the research topic of this thesis. A prerequisite for understanding, communication was understood to be an essential part of the shared decision making process, and shared decision making itself was described as a modern way of communicating at the doctor’s office. Many professionals considered it to be the most important aspect of their work and something that is present daily. One interviewee argued that the operation is the easy part of the job and interacting with the patient the harder part. It is obvious that the themes or responsibility, understanding and communication are connected to one another, as simply put it is the responsibility of the professional to create understanding for the patient, gain understanding from the patient and these are achieved through various means of communication. These means of communication are discussed in more detail in this chapter.

In some of the interviews typical uses for Oravizio were discussed. In essence I wanted to know in what kind of a communication situation the professionals think Oravizio supports their work the best. Typical situations mentioned included argumentation either in favor of the surgery or against it. Oravizio was used to justify the claims of the professional, to show the patient that it’s not just their word that the patient needs to count on. One interviewee said that they use Oravizio so that the patients would believe them. Another mentioned that especially when explaining the procedure to someone who was really scared, Oravizio was a useful tool to communicate to the patient that risks are relatively small and that their fear may be exaggerated. Using Oravizio as part of the discussion was considered easy and natural.

An interesting divide came up in the interviews regarding what information content in Oravizio the professionals share with the patient. Everyone showed the patients the infection risk but with revision and mortality there was more variance. Especially with mortality some professionals considered the theme too delicate and complicated to be communicated using the Oravizio tool. One interviewee mentioned that if a higher chance of mortality needs to be discussed with the patient, it is a conversation they want to have looking into the eyes of the patient, not looking back and forth from a computer screen. One professional did say that sometimes they use the high mortality rate as justification not to operate, if the patient has a hard time believing that the surgery would be too risky.

More generally speaking regarding communication, it was recognized by the professionals that they might need to use slightly different communication methods and tones with different kinds of patients. For instance, if the patient is clearly fearful of the risks, maybe the professional will discuss them in a more reassuring way and not emphasize them more than is necessary. For someone else, a briskier tone of voice might work better. One mentioned that they have found a conversational take on the discussion to often be the most fruitful when dealing with difficult topics. When discussing potential interventions that the patient needs to make, such as reduce their weight, they emphasized that the patient should not be blamed. Instead, the topic should be framed into discussing what measures could be taken to make sure the patient has the best possible outcomes. By taking an uncompromising, paternalistic approach the conversation is much more likely to end up on a collision course leaving both the patient and the professional dissatisfied. Communication is a two-way street and hearing the patient’s needs and thoughts is just as important as informing them. One interviewee mentioned that when a mutual understanding is reached with someone who initially disagrees with them, it is very rewarding professionally. Being able to communicate a complex topic to a patient was recognized as an important part of their expertise.

An example of a conversational take on the discussion on the patient’s expectations for the surgery was one professional’s way of asking the patient: “what would you do with this knee/hip if it worked well?”. This was the professional’s way of directing the conversation towards a positive goal, that would help the patient commit to the entire process, including the bits they are in charge of such as rehabilitation. Communication seen in this light is not just about informing the patient of facts: it is also a tool for guiding their attention and mindset to a helpful direction. This way of communicating highlights that interventions aiming for an improved surgical outcome can also be psychological in nature.

All the interviewees mentioned an age divide when discussing whether some patients favored a more paternalistic take on the decision making and conversation on the treatment. Despite older generations perhaps being more used to respecting professional authority and counting on them for making the decisions, it was mentioned that people of all ages do want to feel involved. With older people, maybe the discussion revolves more around other concerns and worries they may have rather than the operation itself. It was mentioned that patients also communicate more with each other than they used to, thanks to social media and the multitude of messaging platforms available these days. That means they also come better prepared and more informed to the consultation, leading the conversation on different tracks that would be in the case with someone who just expects the professional to tell them what's going on and what to do next.

Regarding what should be communicated verbally and what visually, the professionals still seemed to think the patients' values and expectations are something to discuss verbally. As of right now, Oravizio is used only to communicate the risks – the cons – and the expected outcomes – the pros – are talked about without any assisting visual material. When proposing to the professionals if Oravizio or a similar tool could be used to communicate the benefits of the operation as well, many were open to the idea, if suitable data existed.

5.4 Professional use

Continuing with the more practical theme of how Oravizio is used by the professionals, all of the interviewees said that they use Oravizio routinely or regularly for elective and primary joint replacement surgeries. In addition to using it as a communication tool, all the interviewees seemed to have their own professional interest with its results as well. For instance, those who did not share all the different risk variables with the patients would nonetheless study the numbers themselves and take them into consideration. It was noted that at its current state, Oravizio seems like a tool more intended for the professional to use rather than as a decision aid for the patient.

Nonetheless, the most important function of Oravizio according to professionals was undoubtedly informing the patients of the risks associated with surgery. That means Oravizio would be used and shown to the patient at some point during the conversation on possible treatment plans. Most of the interviewees couldn't think of other similar tools they would have used before and said that explaining the risks to the patient to be at least somewhat easier with Oravizio. Many considered the fact that Oravizio gives patient-specific tailored risk information instead of population wide averages to be the tool's most significant feature.

At Coxa hospital the patient's basic information comes to Oravizio from other hospital IT systems automatically. In other cases, the surgeon has to type in the information manually as of now. If the surgeons want to make a point by showing how much a risk would change if for instance BMI changes, they make the adjustments to the variables manually. Some of the interviewees said they would print out the Oravizio material for the patient if they requested it, but that they rarely do. The professionals share the user interface with the patient in the part of conversation when risks are discussed but that is the only moment the patient sees the visualizations.

The professionals claimed that their understanding of the risks is formed by creating a holistic picture and understanding of the patient's condition and possible other diseases. It was positively noted that Oravizio often seems to give risk values that are in line with what the professionals would have estimated by gut feeling and previous experience as well. The professionals seemed to agree that although it's nice if their intuition is correct, it's valuable to get a data-based verification for it.

Not all professionals are interested in using a risk assessment tool like Oravizio. This became evident both in the interviews and with my search for interviewees from the Coxa orthopaedic surgeons. All in all, regarding practices of shared decision making it was noted that all professionals have their own way of doing this. There is no mandate from hospital management on using Oravizio or how professionals should communicate with the patients, other than the mandatory information content that needs to be shared in order to gain informed consent. It was assessed by some interviewees that it is possible that professionals with stronger inclinations towards research might be more interested in using the tool. Similarly, those who are more comfortable with digital tools in general are more likely to be interested in it. One interviewee estimated that in all likelihood tools such as Oravizio would become more and more common in the next decade.

As far as hospital-wide practices go, some development ideas arose from the interviews. One was implementing the use of Oravizio already at an earlier stage in the treatment process. It was suggested that the general practitioner who makes the referral for a surgical consultation would already use Oravizio with the patient. As the waiting times for a consultation can be long, if some interventions to bring down the risks were in order, they could already be made before meeting with the orthopaedic surgeon. Another idea was widening the information content of Oravizio to include an estimate for how long the patient will have to stay in hospital post-operation due to their increased risk for infection, for instance. This would help in planning for hospital capacity and would probably be of interest to the patient as well.

5.5 Interventions

According to the risk visualization literature, two possible things are typically intended as a goal for the visualizations: transmitting information or motivating the reader to alter their behavior. At its current state, Oravizio can only be seen to have and fulfill the first goal: its sole purpose is presenting the risk information in an understandable manner to the user. The interface itself doesn't propose the user to make any changes in order to bring down the risk levels. If the surgeon wants to demonstrate to the patient that for instance by losing weight their infection risk would become smaller, the surgeon needs to come up with the idea on their own and to manually alter the values. Despite the Oravizio interface not actively making suggestions for interventions, the professionals use it to back up their own arguments for them.

In the interviews I tried to gain understanding of the different factors associated with surgical risks, what factors can be altered and what interventions can be made. The patients can't change their age or the reason they come to the consultation and might not be able to change their other diagnoses, medications or ASA classification. What they can change is their weight and some of their laboratory results. Obesity, overweight and BMI were probably the most popular intervention-related words mentioned in all interviews. It was a universally accepted fact that a higher BMI means a higher surgical risk. One interviewee mentioned that differences in risk become clearly visible especially in morbid obesity such as BMI being 50 or above. Another modifiable factor that is currently featured in the Oravizio algorithm and was mentioned in all the interviews was hemoglobin.

Some other modifiable factors that the professionals associated with elevated risk values were smoking and blood sugar levels or diabetes. Neither of these are featured as risk factors in the Oravizio algorithm, which caused some confusion with the professionals. One interviewee mentioned that based on literature pre-diabetes or diabetes that is not under control would strongly correlate with a high infection risk. Especially smoking was thought to be such an evident factor that would negatively impact surgical outcomes, and one interviewee suggested that perhaps factors such as these could be added to Oravizio as more generic risk factors: even if they didn't show up in the individually tailored data model, they could still be included and flagged as potential risk factors.

Interventions do not mean actions that the patient is responsible for alone. In the case of obesity, the patients might get help from a dietician or even a referral for consultation for a weight loss surgery. In the case of low hemoglobin, the reason should be investigated, and proper measures taken. The patient could be referred to a completely different operation if they have severe other health problems. In the case of smoking, they could be referred to a stop smoking clinic. Although not everyone is able to make the changes to bring the risks down, the best possible outcome could be a positive domino effect where for instance a weight loss leads to improved sugar levels and blood pressure, better mobility and better overall health.

Interventions to bring down the surgical risks are needed both for the sake of the patient and the society as a whole. As stated earlier, the consequences of an infection can be disastrous to the individual, meaning antibiotics, associated complications, possible redos of the surgery, more time spent in hospital and longer recovery periods. For society, an infection means additional expenses in the range of tens of thousands of euros. Despite the appalling nature of these worst-case scenarios, it became evident that motivating the patients for interventions through positive rather than negative made sense to the professionals. Not blaming the patients, but instead, focusing on the improved outcomes and lower risks, was thought to be more effective. It was agreed that going into the surgery with lowest possible risk makes the operation much more pleasant for all parties involved.

5.6 Further development

I ended all the interviews with a question "how could Oravizio help you help the patients even better?". Although the professionals clearly thought Oravizio helps them in their work as it is, all of them had some ideas for further development. Contrary to what I had predicted, the ideas had more to do with the information content of Oravizio, and less with the visualizations themselves. Some of the development ideas have already been referred to in the earlier chapters but are all still summarized here. The development ideas can be broadly divided into two categories: those that intend to improve and enhance the current information in Oravizio and those that propose adding completely new content to the tool.

Starting with potential improvements to the existing content, it was mentioned that it could be stated more clearly in the interface what variables are connected to the risk results. This reflects the earlier findings of the 2018 usability study. At the moment there is a small turquoise triangle pointing to the input variables that affect risk, but the connection could be highlighted more. In a similar vein, it was proposed that input variables or risk factors could be grouped as modifiable and non-modifiable, making it easier for the patient to get a clear picture of what they can act on to improve the situation. At the moment, the professional needs to point it out and explain and heavily act as an interpreter for the causalities. An alternative to grouping the variables into modifiable and non-modifiable could be some sort of flagging system that would underline what factors can be changed and what interventions could be taken. Of factors that are known to be connected to infection risk, such as blood sugar level or smoking, it was suggested that maybe they could be mentioned as general risk factors, instead of patient-tailored.

Concerning the visualization of the current version of Oravizio, most interviewees praised the way it looks and commented that it is something that is nice to show to the patient. It was mentioned in one interview that a proposed addition to the user interface for some time has been a traffic light visualization that would give a combined result on whether it's safe to operate (green), if some measures need to be taken (yellow) or if it's not safe to operate (red). The professional interviewed was a bit wary of the idea. It was discussed if such a visualization would overly simplify a complex topic: most likely a large part of the cases would end up in the middle yellow category, which means that more investigation would be needed anyway. In some cases, the light might be red, but the only possible treatment would still be to operate. This might leave the patient confused. All in all it was argued that maybe for a sophisticated and scientific data algorithm a traffic light is too simple of a visual. Although keeping it simple often works best, credibility issues also need to be taken into consideration, especially when dealing with medical software.

A more profound developmental outlook was to add completely new information to the tool. All of the interviewees mentioned pre-operative and post-operative Oxford scores as potential data that could be used. Possible solutions would be presenting information in probabilities based on the data: for instance, patients with a similar background that were able to walk this many kilometers before the surgery, can walk this many kilometers after the surgery on average. Or patients with a similar background rated their pain to have decreased by this much after surgery. Another idea was something similar to an NPS-score: how many percent of patients with a similar background would make the same decision on going into surgery, or how many percent would recommend the procedure to their best friend.

Adding function-related data, such as outcome scores, to Oravizio would mean showing “both sides of the coin”, as one interviewee put it. As the concept of risk is closely linked to probabilities, and both can be expressed numerically, it wouldn't drastically change the nature of the data-driven tool. However, it would make Oravizio a more balanced aid for decision making. At the moment, it is showing the potential negative outcomes of an operation, but nothing of the positive outcomes. Those are still discussed verbally. One interviewee was at first cautious of adding more outcome-related data to Oravizio in fear of it becoming too complicated. Later it was added, however, that most surgery delays result not from the risks being too high, but from the patient not benefiting from the operation enough. Including and visualizing that dimension of reasoning to the tool as well, was deemed potentially useful. It was also noted that for the patient such information might be more useful than for instance mortality.

Other development ideas off the scope of this thesis included developing a completely different app or a programme for the patient to use. This could include both risk assessment elements as well as an interface through which to send needed documents or additional information to the treatment facility between visits. That would essentially mean a broader treatment path application. Another idea was adding treatment time related information to Oravizio and broadening both its use to the entire treatment process and its users to include nurses, general practitioners and other related staff.

6 New prospects for Oravizio visualized

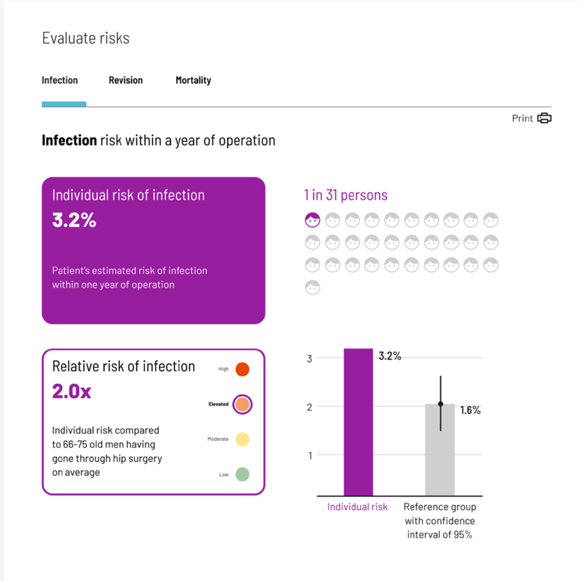
Based on the literature and interview findings some possible improvements and adjustments to the user interface and information content of Oravizio are speculated in this chapter. It is worth noting again that due to time constraints and the complex nature of the regulatory framework concerning medical devices, these visualizations are to be treated as theoretical prototypes only. Should they be taken further as part of an actual design process, they would need to be tested and re-evaluated with users. At minimum this would mean sharing the designs with the interviewed professionals, and as a better alternative, more users, both professionals and patients would be included. In order to guarantee a successful redesign, implementing changes to the actual product should only be considered after this phase. As explained in chapter 3.3, for implementing any changes to a CE-marked medical device, the changes would need to be assessed within the manufacturer's change assessment process.

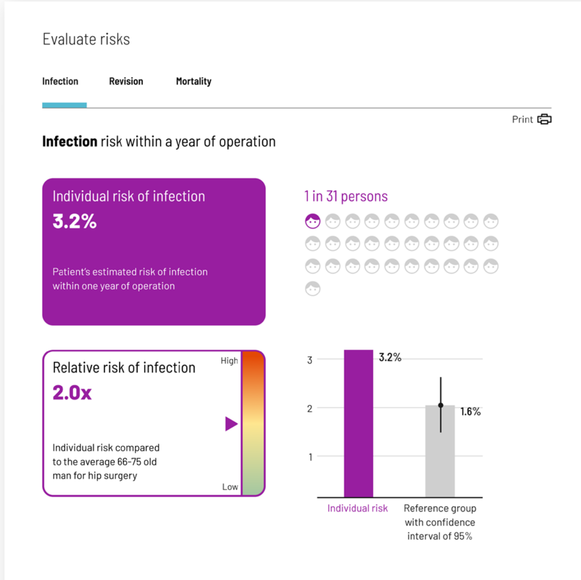
6.1 Improvements for risk visualization

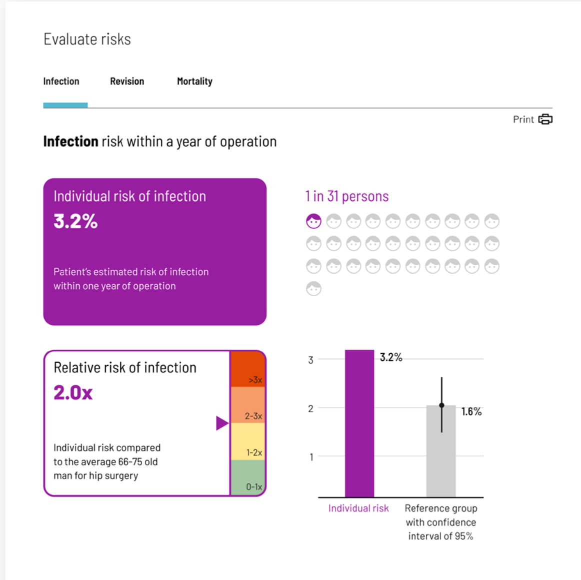
6.1.1 INFORMATION TRANSMISSION

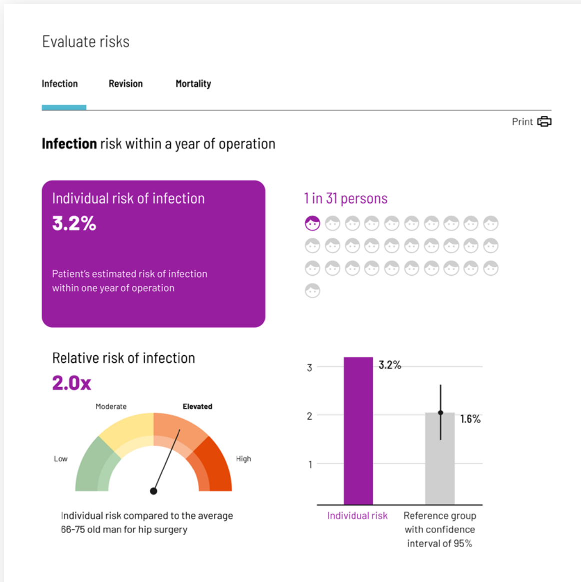
The first possible improvements concern the function of transmitting risk information visually. Based on risk visualization literature the current Oravizio risk visualizations were already relatively good. The two chart types most favored in literature, icon array and bar chart, were already featured in the visualizations. The interviewed professionals also seemed happy with the current user interface. However, as the earlier usability study revealed that participants had some issues with detecting several connections within

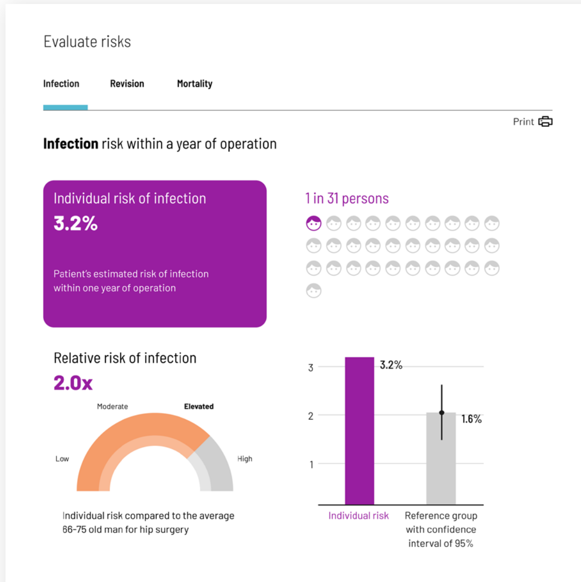
Figures 24–29 on the facing page on the right: Potential alternative visualizations for depicting relative risk











the information and the user interface, some improvements are suggested in this chapter. Based on the usability study, problematic areas included identifying the reference group, what relative risk is based on and identifying that patient has an elevated risk.

Figures 24–29 on the previous page feature zoomed views on the results panel of the Oravizio interface that depicts the values for three different risks. The versions in the figures play with different ideas on how to enhance the visibility of relative risk. In the current version of Oravizio, if the patient's relative risk compared to the reference group is twofold or more, a pulsating exclamation point will appear to warn the user. Instead of – or in addition to – the exclamation point, some of these versions include an element of color to draw in the eye of the reader. The colors are attached to a four-tiered classification system for evaluating risk magnitude.

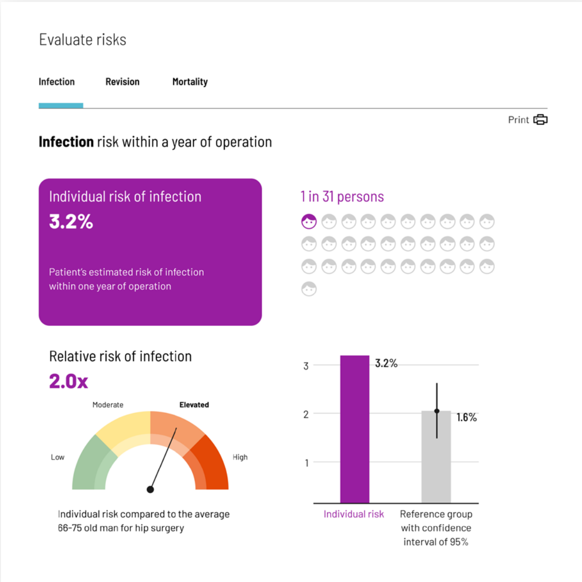


Figure 30: a new multicolored gauge chart for depicting relative risk next to the old vertical bar chart

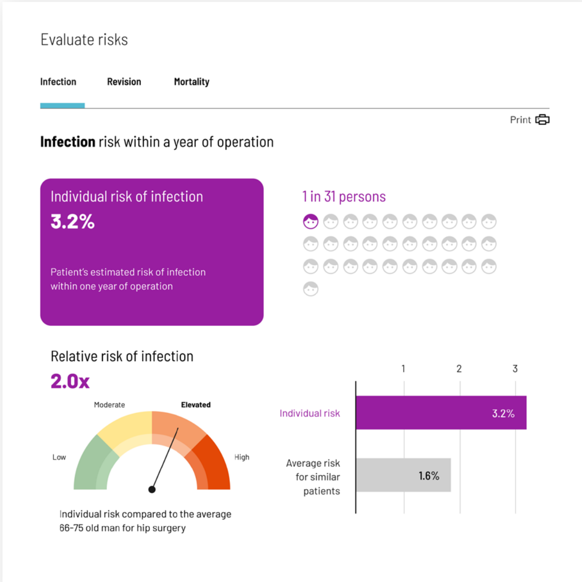


Figure 31: a new gauge chart for depicting relative risk next to a new horizontal bar chart

The gauge chart presented in the bottom-most figures on the previous page as well as on figures 30 and 31 draws its shape from the Oravizio logo. In figures 30 and 31 all the other elements stay the same, but the bar chart is flipped from vertical to horizontal. Though the geometry of the bar charts remains the same, a horizontal presentation could improve understanding, highlighting the fact that the two values are comparable categorical values. To make visual comparisons of the bars easier, one solution would be to leave out the distracting visual element for the confidence interval. An example of this in the form of vertical bar charts is visible in figures 32 and 33.

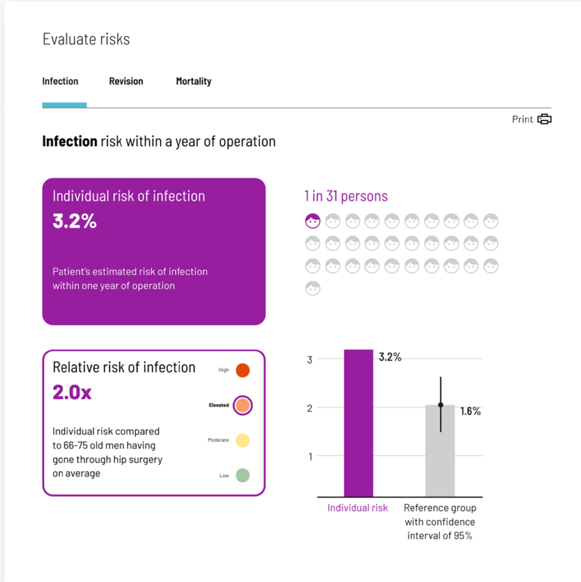


Figure 32: The bar chart in the bottom right as it is in the current version of Oravizio

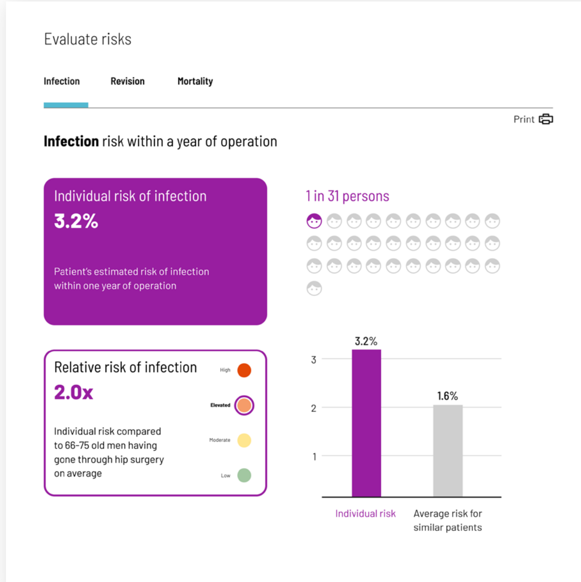


Figure 33: A possible, simplified version of the bar chart to help visually distinguish the bar sizes

Identifying the reference group has caused problems in the current Oravizio user interface. As the relative risk of infection is a key value in the results panel, understanding what or whom the relation is to is crucial. Figure 34 below compiles some possible alternatives for making the reference group stand out better visually.

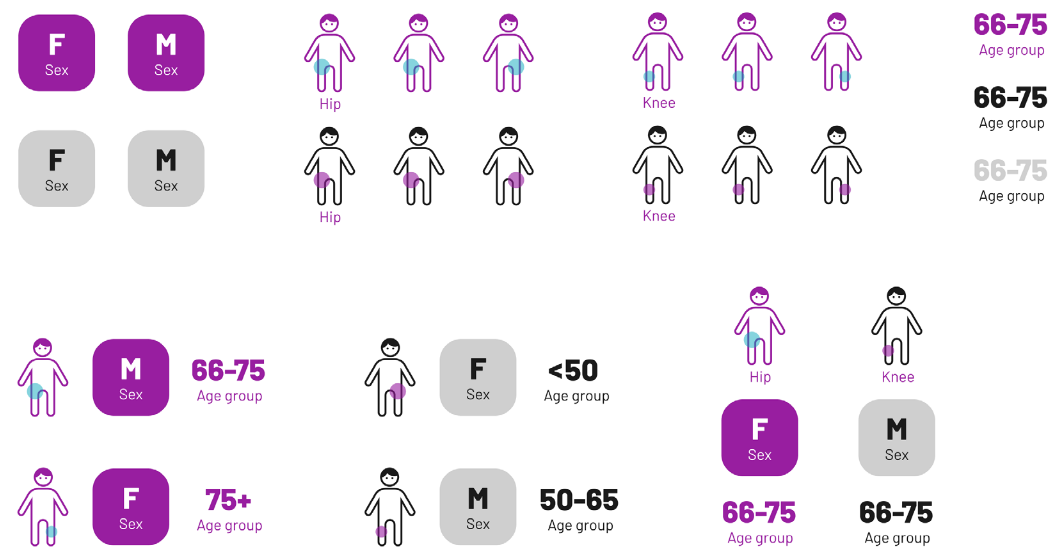


Figure 34: Drafts for presenting the reference group visually. The reference group consists of three categories: the joint to be operated (hip or knee), sex and age group. Individual risk of the patient is compared to the average patient who belongs to the same categories to get the relative risk.

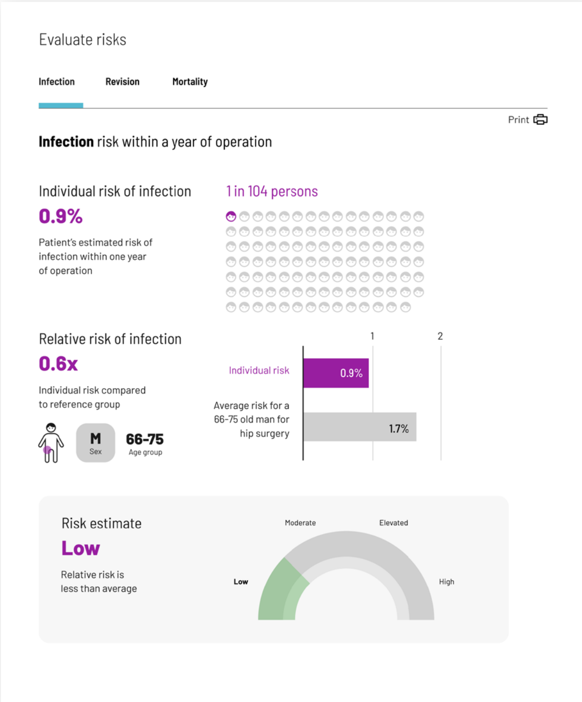


Figure 35: A possible solution for the results panel showing results for someone with a low infection risk

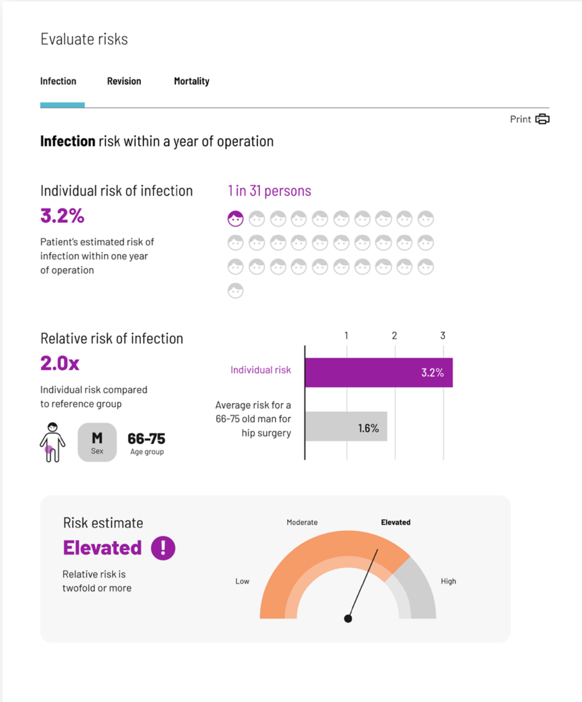
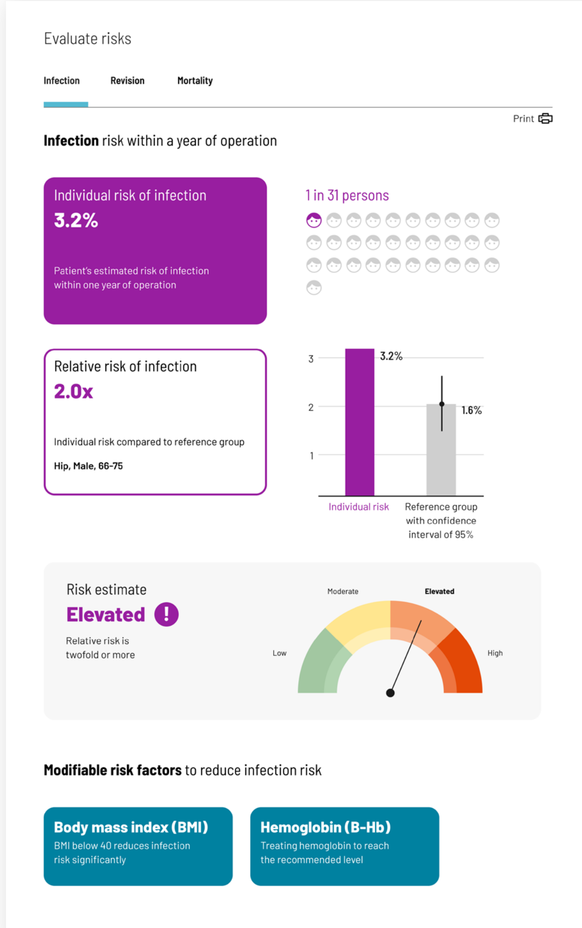


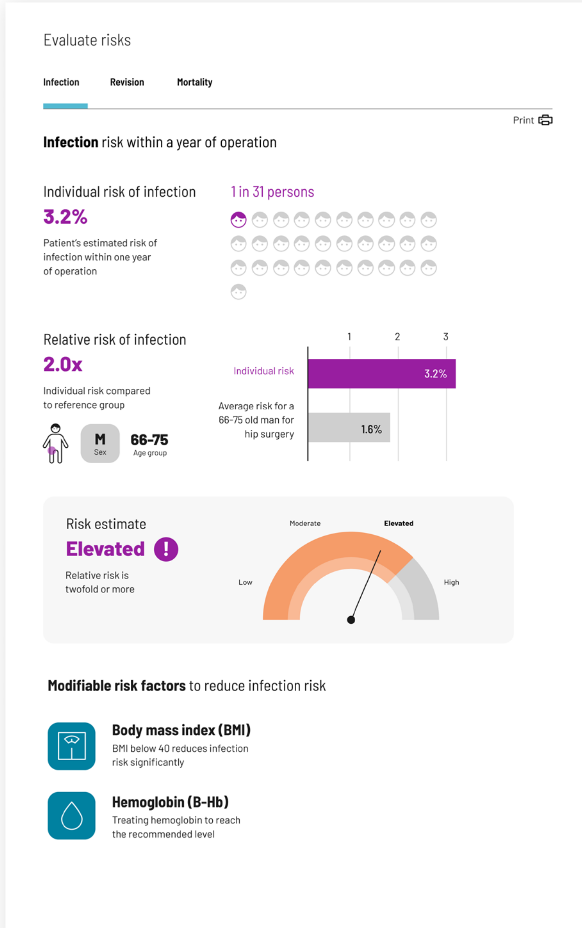
Figure 36: A possible solution for the results panel showing results for someone with an elevated infection risk

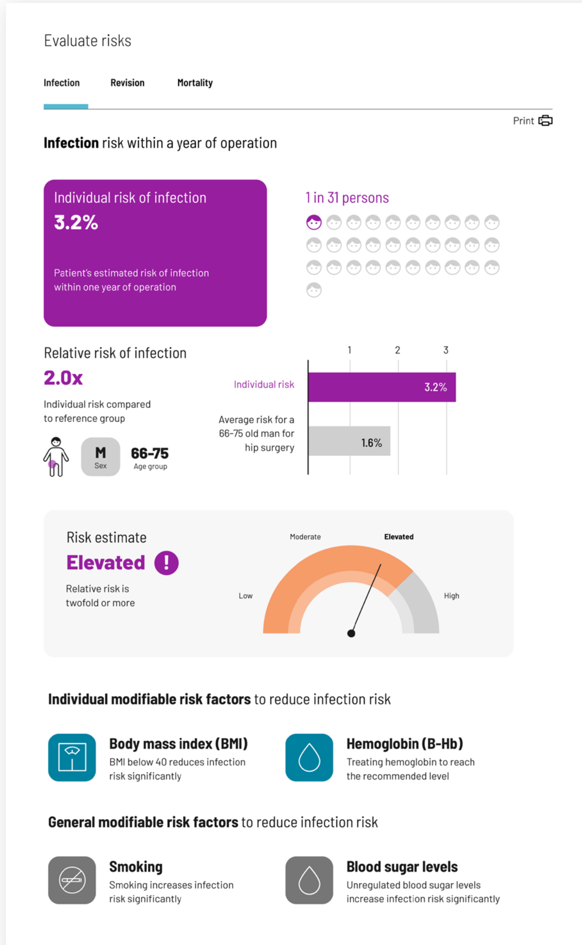
Figures 35 and 36 show possible new information visualizations assembled together. Fearing that the addition of a gauge chart and visualizations for the reference group would make the ensemble too busy, boxy frames for the risk values have been removed. The shown examples are for a patient with a low risk estimate and for a patient with an elevated risk estimate. The data in the figures, the gauge chart categories (low, moderate, elevated and high) and their cut-off points are hypothetical and invented just for the purpose of these visualizations.

6.2.1 MOTIVATING CHANGE

One possible alteration to the Oravizio interface discussed in the interviews was emphasizing corrective action the patient (or the patient and the professional together) could take to bring down the surgical risks. This could be implemented in several ways. On the other hand, the factors that increase the patient's risk and that can be modified could simply be highlighted or flagged up, and on the other hand the tool could be modified so that it would suggest potential interventions to the user. Figures 37-40 on the next page speculate possible solutions for directing the user's attention to what can be changed. Assuming that Oravizio risk algorithms stay as they are, modifiable risk factors that were brought up in the interviews included body mass index and hemoglobin.







Figures 37-40: Some possible solutions for highlighting factors that contribute to high risk and can be modified with interventions. The version on the bottom right corner features general known risk factors that affect infection risk but are not included in the Oravizio risk algorithm.

In the risk visualization literature, it was pointed out that some ways of presenting risk information are more likely to lead to behavioral change. In terms of numeric risk information, one way was to emphasize the numerators only. In Oravizio, this is essentially done by presenting relative risk information with the bar chart and expressing relative risk in multitudes. Bringing even more focus to the relative risk value with visualizations similar to the ones presented in the previous pages has theoretical potential in affecting behavioral outcomes of the patients. If motivating behavioral change was to be included as an intended use of Oravizio or some similar tool, it would make sense to test how different visualizations affect the patients' attitudes towards interventions.

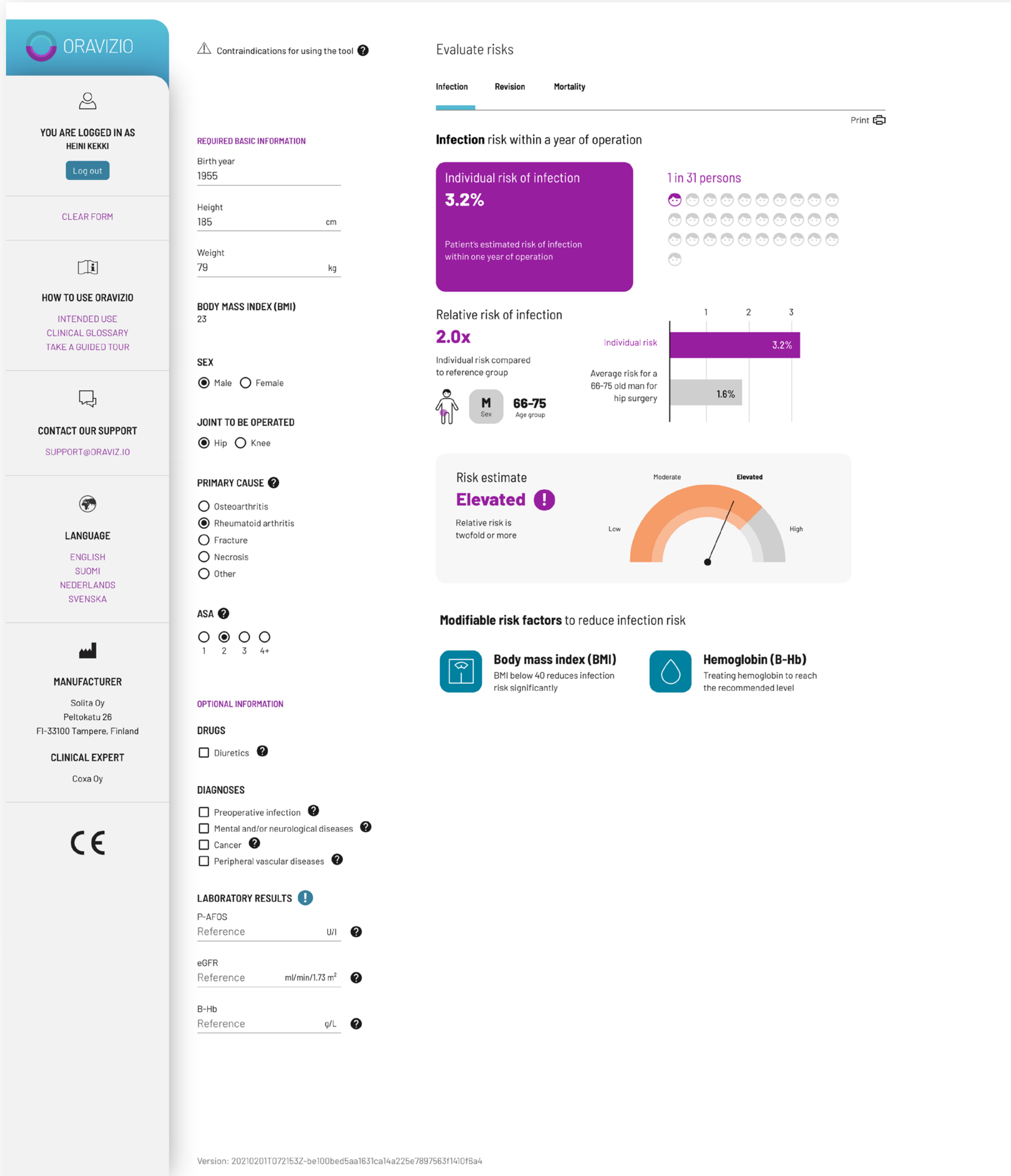


Figure 41: The Oravizio desktop user interface with some of the possible new visualizations

6.2 From a risk assessment tool to a data-driven decision aid?

One of the more profound ideas that surfaced in the interviews when considering future prospects for Oravizio was widening its scope to a more balanced tool to assist in the decision making process. This could mean that patients were presented other, more positive information along with the risks. Traditional decision aids tend to focus on the patient's values and aim at finding a solution that feels right for them. They help the patient to be introspective instead of presenting them with new information.

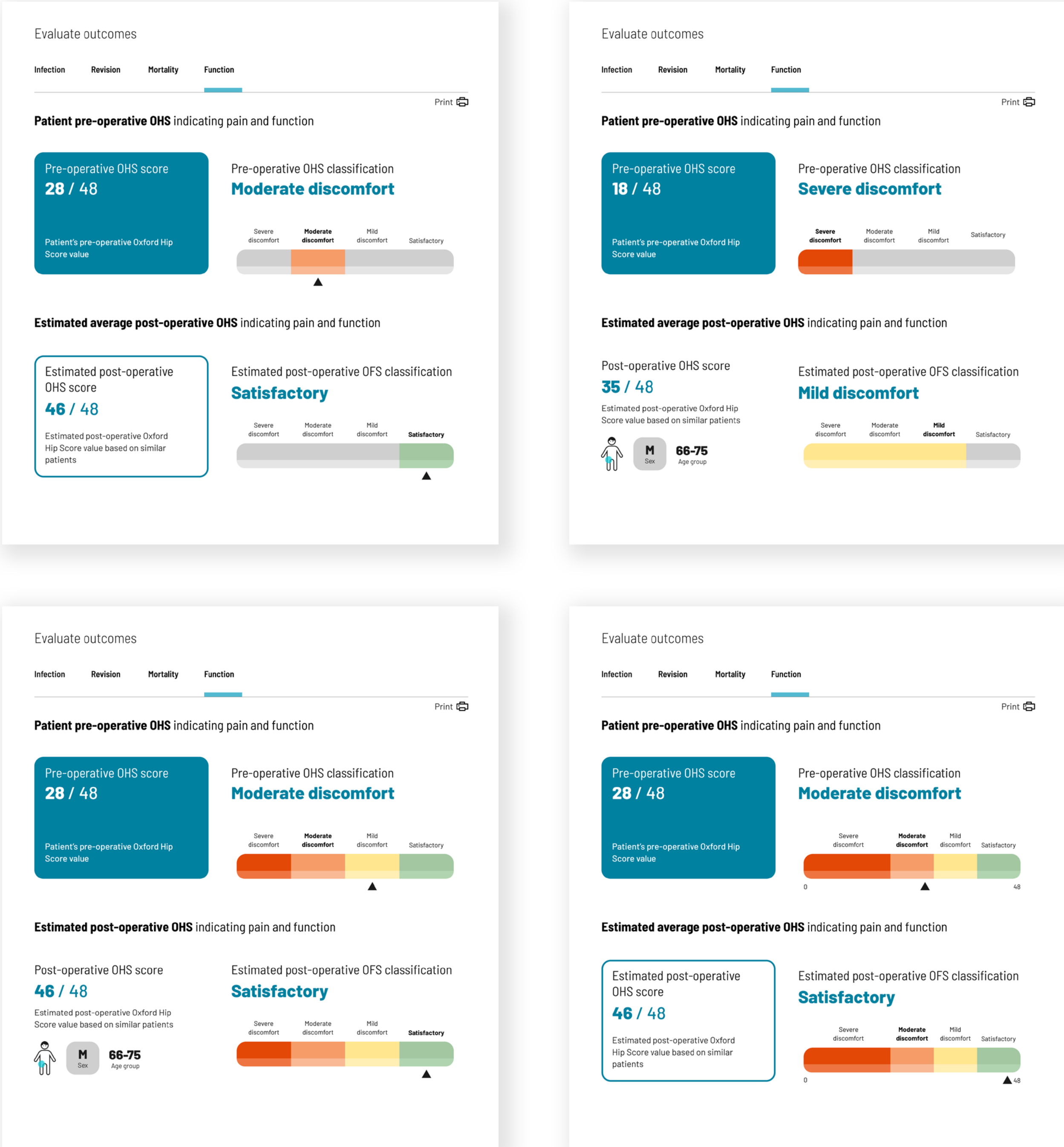
Finding a solution that feels right for the patient could also be achieved by taking into account the facts and figures that surround the decision. Oravizio is at its heart a data-driven tool. One way to widen its usefulness while still remaining data-driven would be to include expected outcomes of the surgery in the results. A potential data source for this is patient reported outcome measures.

In order to come to a conclusion whether or not surgery is a valid option for the patient, the risks of the operation need to be weighed against potential gains. As one interviewee put it, sometimes it makes sense to refrain from an operation not because the risks are too high, but because the benefits would not be good enough. A data-driven decision aid taking into account both the risks and the benefits and offering an overview based on both could make the risk information easier for the patients to understand.

6.2.1 INTRODUCING PATIENT REPORTED OUTCOME MEASURES

The Oxford knee and hip scores (OKS and OHS from here on) have become established and widely utilized patient reported outcomes in orthopaedics internationally since their formulation in the late 1990s (Murray et al., 2007, p. 1010). OKS and OHS scores were also mentioned by all the interviewees as being routinely collected from patients having gone through a hip or a knee replacement surgery.

Both the OKS and OHS feature twelve similar questions related to pain and function. All the questions have five options to choose from for an answer that are graded with points from 0 to 4. The maximum points are thus 48 indicating satisfactory functioning of the joint in question. The OKS and OHS patient reported outcome measure forms of Coxa hospital can be found in the annexes of the thesis. The Coxa version of the questionnaire also includes additional questions at the end. Out of the additional questions, question E “How do you personally evaluate the outcome of the surgery?” (options excellent, good, satisfactory, poor; original wording in Finnish “Minkälaisen arvion itse annatte leikkauksen tulokselle?”) is particularly interesting from the point of view of this thesis.



Figures 42-45: Possible ways to visualize and add patient reported outcome measure data to Oravizio. One solution would be replacing the title of the results panel to Evaluate outcomes and adding a fourth tab at the top, named Function here as an example.

No actual data based on the OKS or OHS scores was available for the purpose of this thesis. However, possible ways of visualizing the data can be drafted based on the questions. Murray et al. (2007, p. 1011) have noted that as the results of patient reported outcome scores such as OHS and OKS tend to decrease with older patients, it would make sense to compare one patient's score to the average of those in the same age group. Murray et al. (2007) have also noted that due to the same reason, limit values between the different result classes should be adjusted based on the population in question. For the purpose of this thesis the chosen values are used by way of example. Likewise, this thesis does not take a stand on where the cut-off points between classes should be.

Several example visualizations of OHS and OKS data can be seen in figures 42 onwards on the previous and following pages. In these mockup visualizations the OHS and OKS data range of 0-48 has been divided to four classes. Total points up to 19 would land the patient in the class of severe discomfort, total points of 20-29 in the class of moderate discomfort, total points of 30-39 in the class of mild discomfort and total points of 40-48 in the class of satisfactory. In figures 42-45 the score and classification at the top indicate the patient's own pre-operative score. The score and classification below indicate the estimated average post-operative score for patients with similar starting points: same joint to be operated, same sex, same age group. Using the same reference group for both relative risk and the estimated average post-operative outcome scores allows for an easier comparison between the two variables.

In figures 42-45 the OHS or OKS score is presented in two points of time: before and after the surgery. In one of the interviews the orthopaedic surgeon explained the whole treatment process regarding joint replacement surgery

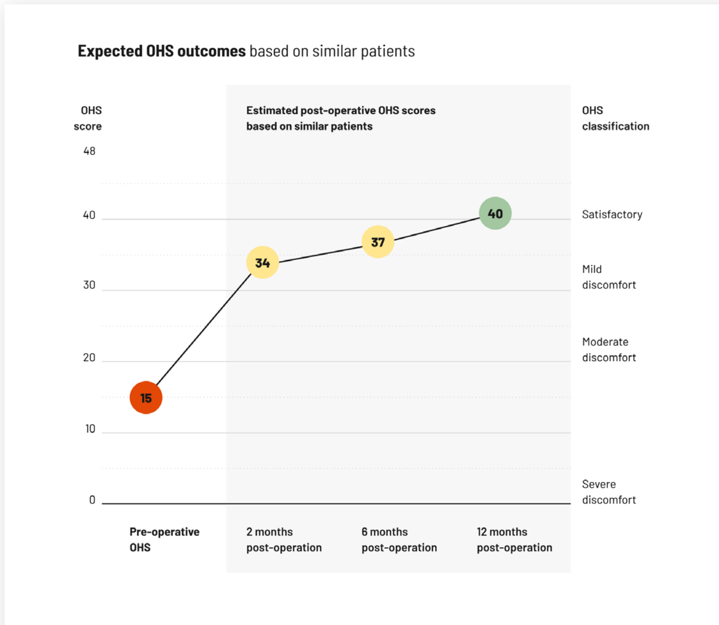


Figure 46: If temporal data of the progress of OHS and OKS scores was collected, one way of visualizing it would be with a line chart with colour-coded symbols for the different values

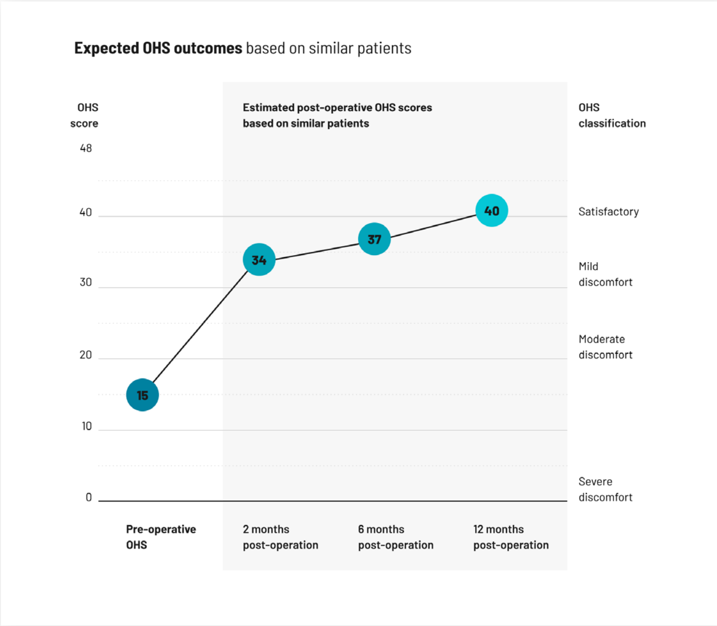


Figure 47: The line chart depicting the progress of OHS or OKS scores in shades of the signature Oravizio turquoise

and mentioned that post-operative OHS or OKS patient reported outcome measures are collected from patients 2-3 months after surgery. Murray et al. (2007, p. 1011) have argued that functional improvements following a joint replacement surgery are most likely to present themselves within the first year of surgery. The progress of OHS and OKS scores could thus be evaluated up to one year post operation.

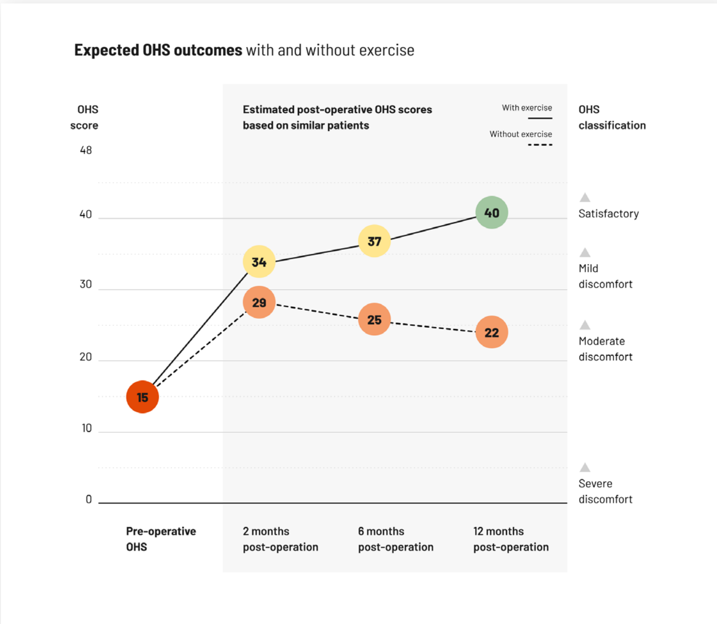
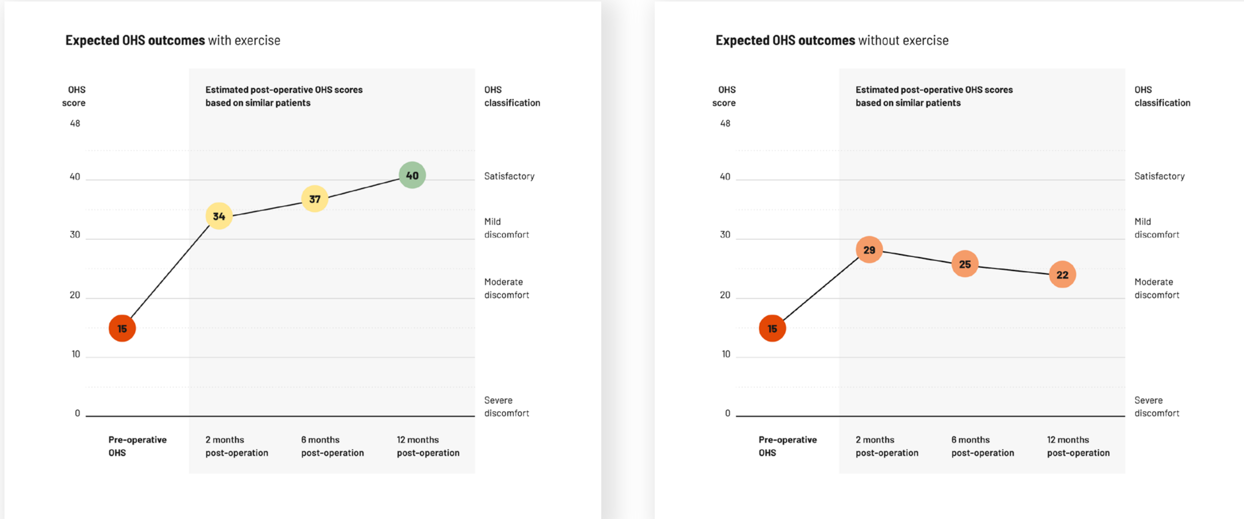


Figure 48: The line chart depicting the progress of OHS or OKS scores with expected outcomes with or without exercise combined in the same chart



Figures 49 and 50: Alternatively, the expected outcomes with or without exercise could also be presented next to each other in separate graphs

Figures 46-50 feature speculated visualizations of how the progress of OHS or OKS scores could be presented, if data was available for more than one point in time post operation. By way of example these visualizations imagine OHS and OKS scores being collected from patients 2 months after surgery, 6 months after surgery and 12 months after surgery.

Several interviewees emphasized how the work the patient puts in in terms of exercise and other rehabilitation post operation is key to achieving the desired outcomes. The surgery can only do so much, and the patient shares the responsibility for improved function in the hip or the knee. Figures 48-50 depict similar line charts as above, but with the added element of comparison of scores of patients who have followed an instructed exercise plan and patients who haven't. At the moment, it is the professional's job to verbally instruct the patient and describe the expected outcomes to them. A visual prompt might be helpful for the patient to clarify their role in the treatment process and motivate them to actually commit to it.

6.2.2 FOCUSING ON DIFFERENT FUNCTIONALITIES

In addition to a general OHS or OKS scores, some specific questions in the patient reported outcome measures might be interesting to visualize and look at as well. Based on the interviews, patients understand risks and other numeric information best when presented with a concrete example. The OHS and OKS questionnaires offer many possible solutions for this. This thesis doesn't take a stand on whether or not it would be advisable to single out specific questions when the OHS and OKS results are presumably meant to be interpreted as a whole. From a speculative point of view, some interesting potential subject matters are visualized in the following figures 51 onwards. Figure 51 depicts the visualization of the additional question E in the OHS and OKS forms by Coxa hospital (How do you personally evaluate the outcome of the surgery?). Figure 52 is a mockup version of a fictional NPS score for

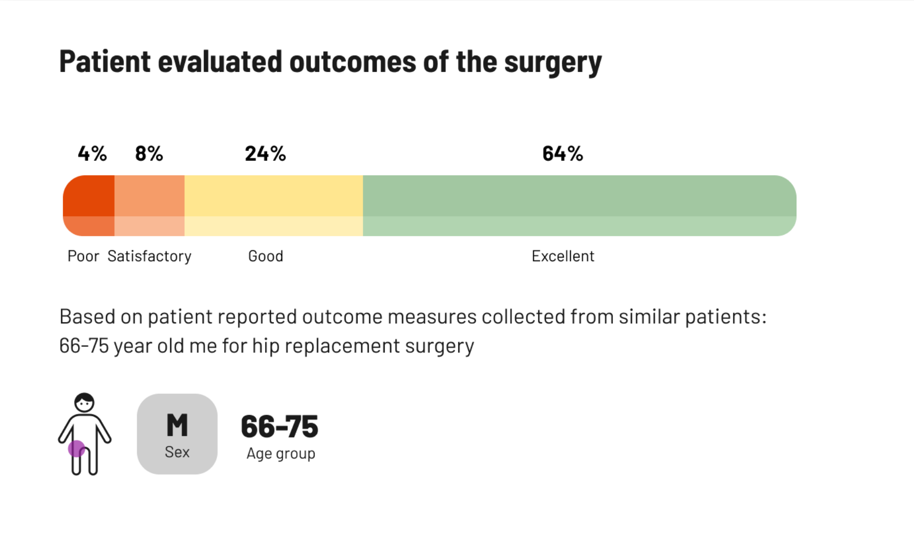


Figure 51: A stacked horizontal bar chart visualization of patients' own evaluation of surgical outcomes

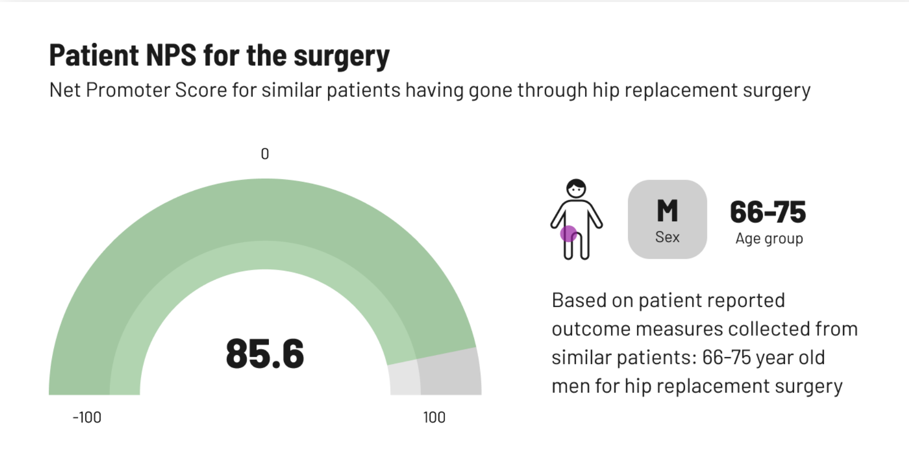


Figure 52: A visualization of a fictional NPS score collected from the patients

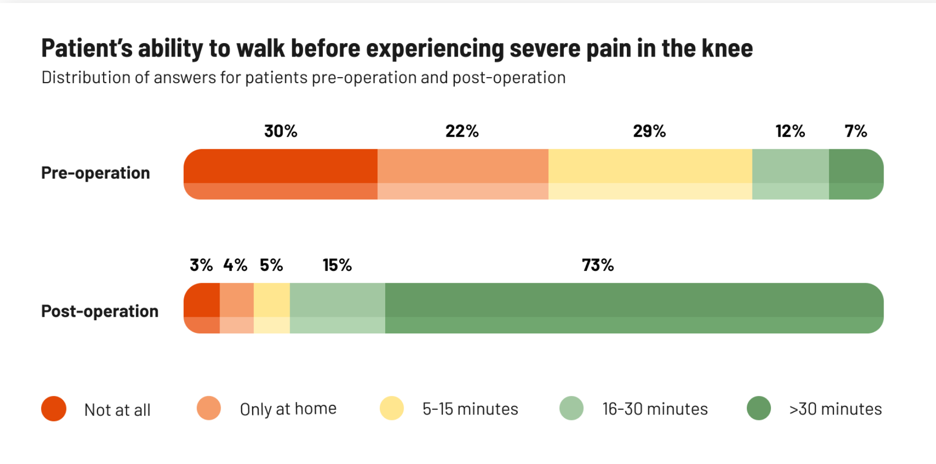


Figure 53: Two bar charts depicting for how long the patients can walk before experiencing pain before and after surgery, allowing for an easy visual comparison

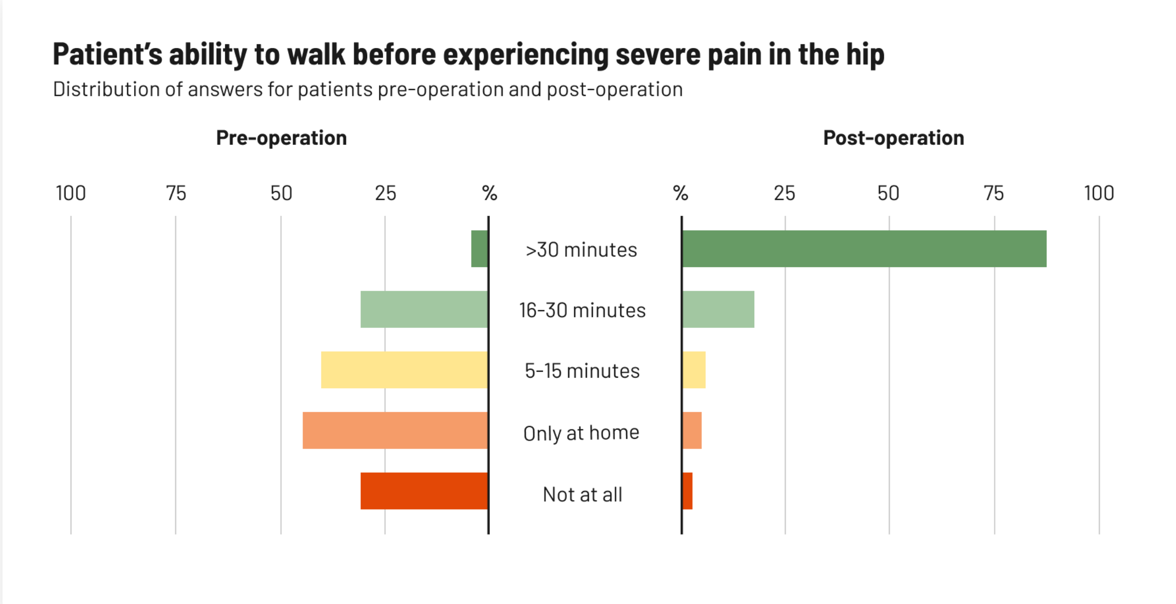


Figure 54: A butterfly chart for another way of comparing two datasets at the same time

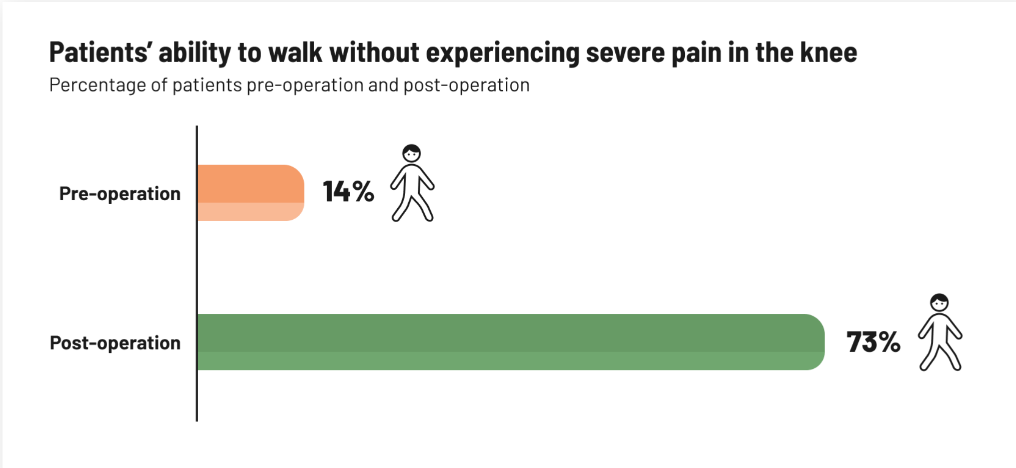


Figure 55: A comparative visualization focusing on the share of patients who can walk without pain before and after the surgery

the operation as suggested by one interviewee. Figures 53-55 focus on one of the more concrete measurable aspects of suffering from hip or joint pain: the ability to walk. The figures play with different ways to explain the same information or focusing on just one part of it (figure 55). In essence, the basic shape in all these three figures is the simple bar yet visualized differently in each version.

7 Discussion

7.1 Discussion

Starting with this master's thesis I was immediately intrigued by the topic's broader connection to the world of healthcare. For a visual communication design student, the world of healthcare and medicine offer endless possible research topics as issues concerning sickness and health are often shadowed by worry, fear and uncertainty and require clear communication methods to navigate through them. Another thing that makes the topic interesting is the fact that dealing with the healthcare system and being in contact with healthcare professionals is something that (almost) everyone has first-hand experience of.

Poor communication skills of medical professionals is a stereotype often repeated in stories depicting awkward or downright awful visits to the doctor's office. When thinking of my personal unfortunate encounters with doctors, several examples immediately come to mind. The character of a brilliant doctor with poor social skills has been featured in numerous television shows and movies, perhaps most famously in the series *House, M.D.* in which Hugh Laurie portrays the protagonist, Dr. Gregory House, a medical genius who sadly also happens to be a misanthrope. In one episode where House sees walk-in clinic patients, he tells one patient who offers to get him a gift for the good news he delivered, that "sometimes the best gift is the gift of never seeing you again". The medical world in *House, M.D.* is highly paternalistic: the patients are typically portrayed as either being ignorant or liars and the show's doctors are the ones who resolve the situations in the end.

Luckily, in the real-life case of Oravizio and joint replacement surgeries this stereotype of medical practitioners detesting encounters with patients seemed faraway. Based on the interviews, the orthopaedic surgeons had very favorable attitudes towards communication with the patients. In the shared decision making literature some authors raised concerns for professionals' mixed feelings toward the practice. In this case study – albeit small with only four interviewees – all the professionals seemed to have no doubts about the usefulness of shared decision making. Shared decision making was described as a modern way of communicating at the doctor's office, pretty much the default mode of working. Interviewees also seemed to be aware of how to implement shared decision making in practice, although it was mentioned that customs vary from professional to professional. It is worth noting, however, that as participating in the interviews was voluntary, the selection of professionals might be biased in addition to being small. Most likely I got to talk to professionals with particularly favorable attitudes towards shared decision making, the use of decision aids, risk assessment tools and other shared decision making applications. The findings of this thesis cannot therefore be generalized to apply to all orthopaedic surgeons.

The fact that the interviewees were a selected group of people who already were in the habit of using Oravizio might also contribute to their positive attitude towards the visualizations. It would have been interesting to talk to professionals with differing views on the usability, content and design of the visualizations, but unfortunately such professionals were not willing to be interviewed. At the same time, it makes sense to develop the visualizations, decision aids and tools with professionals who will actually use them. As noted earlier, in order for shared decision making to reap benefits, the professional as a gatekeeper and somewhat of an authority in the doctor's office needs to embrace the approach. The same goes for all applications assisting and facilitating shared decision making, such as Oravizio.

A very interesting finding from the interviews was how the professionals deemed visualizations more appropriate with certain kinds of information versus others. This was reflected in the professionals' reluctance to show the mortality risk and visualizations to the patients. It was interesting and heartwarming to hear how humanely some of the interviewees treated delicate matters discussed during appointments. Some interviewees clearly valued the interpersonal communication aspect of their job and wanted to take sole responsibility for delivering the message concerning sensitive topics, such as mortality. Following this, it can be questioned if the mortality risk should be included in the user interface at all? The professionals were clearly interested in the value, but future development of Oravizio user interface should pay close attention to whose eyes its visualizations are directed to the most: the patient or the professional.

Concerning the visualizations from a more technical point of view, further study and development of the chosen chart types would also be justified. At this point, it would be most fruitful to get some comments directly from the patients. It was evident that for clinical use of the professionals the current visualizations already work well enough, but that might be because the professionals are thoroughly familiar with their own area of expertise. For them, a risk of 3% is easy to understand even in plain numbers. One of the biggest downfalls of this thesis is the fact that due to time constraints and organizational challenges I didn't get to talk to patients and hear how they view the visualizations. This is also the main reason why the visualizations in chapter six are to be treated as initial prototypes only. Design processes are all about iteration and it would not make sense to refine the visualizations any further without testing them with end users – both professionals and patients.

If further testing of the visualizations with end users was to happen, it would be interesting to see how patients react to different kinds of charts and graphs. Would they be more drawn to a minimalist style or a more colorful one? How would they feel about showing the same information both visually and verbally? Would they prefer a horizontal bar chart to a vertical bar chart, or just the opposite? It has been argued in the risk visualization literature that it makes a difference whether or not the risk is visualized, but less of a difference in what way they are visualized. Even if the details or the style of the visualizations are less relevant, it is still essential to test that the visualizations function the way they are intended to: by increasing comprehension.

Judging by the literature review, the current Oravizio information visualizations are likely to perform already quite well. Some broader questions raised by theory can still be pondered, however. Koponen et al. (2016) have argued that comparison and simplification are the two key principles to keep in mind when designing information visualization. At its current state, comparison in the risk information is realized through the presentation of relative risk: the individual risk can be compared to the average risk of a reference group. However, what could be further developed is the possibility to compare the individual risk in scenario A and in scenario B. This idea is presented in the potential visualizations of the OKS and OHS scores, where one version of the line graph features expected outcomes when the patient follows an exercise routine and another when they don't.

The question of simplification is more complex and relates to the information content, volume as well as aesthetic choices. At the moment, the look and feel of Oravizio is quite sleek and minimalistic. The icon array with the faces is the tool's most playful and symbolic feature - which might be the reason why the users gravitate towards it the most. Would the addition of a gauge chart or some other visual element with color make the information more captivating or more confusing to the user? The current information volume of Oravizio was praised by one interviewee, who said that there is enough information to make it relevant but not too much to make it complicated. Views on the matter of information volume and complexity should definitely be also collected from the patients in the next stages of tool development.

The words of Otto Neurath, "to remember simplified data-graphics is better than to forget precise numbers", would seem to suggest that the use of a simplified, perhaps color-coded visualization like the gauge chart might be a welcome addition or an alternative to the current user interface. When thinking about the design of the visualizations, it is important to take into consideration the situation and the context in which they are used. As noted in the interviews, the time patients have to look at the Oravizio results is a brief and passing moment during a possibly hectic and information-packed visit to the doctor's office. The professionals can spend all the time they want with the results, but what the patients often just get is just a glimpse. Will they remember what number stood in the purple box at the top or in the other box below it? Most likely the one thing they will remember is the faces in the icon array but in the end, even they present numerical values, albeit frequencies as suggested by the literature. A traffic light might be too charged of a visualization, but it is worth considering if some other color-coded and categorized piece of risk information might make the information more useful and memorable.

Going back to the reasoning behind the chosen chart types in Oravizio, the literature-recommended icon array and bar chart were already being used, which is a good thing. The bar chart is also heavily present in the new speculated visualizations of patient reported outcomes. As an alternative, some of the simpler charts such as the share of patients who can walk without pain before and after surgery as depicted in figure 55 could be substituted with a pie chart. In the current Oravizio interface, the visually attractive element of roundness is present in the rounded corners of chart boxes. Round shapes are also present in the icon array, which was the most preferred out of the current visualizations based on interviews. Due to this, changing its appearance seemed less of a priority than coming up with potential solutions to other design challenges with the tool. In literature, the table was celebrated as an underused yet highly functional visualization format, but again, considering the situation in which Oravizio visualizations are used, I would recommend against using this text-heavy chart type and to go for something easier on the eye.

Concerning the possibility of widening the use of Oravizio from a mere risk assessment tool to something resembling a more well-rounded decision aid, the actual implementation of such changes is out of scope of this thesis. However, from a theoretical point of view, this possibility is highly interesting and worth considering, although in practice, regulatory and financial restraints might pose some obstacles. Many changes proposed in this thesis would most definitely fall in the category of significant changes as defined in the medical device regulation related documents. Making any changes to Oravizio would require its manufacturer, Solita, to evaluate the changes according to the manufacturer's change assessment process. Making any significant changes to Oravizio would require Solita to have the tool go through an MDR certification process. Even if the findings of this thesis were not to be directly applied to Oravizio, hopefully they will offer something valuable for the future development of other data-driven decision aids or other applications facilitating shared decision making.

As pointed out by the literature, a great advantage of decision aids is that they can help connect the right people to the right treatment. This benefits all parties involved as unnecessary surgeries can bring with them costs – financial, physical and psychological – that would best be avoided. As suggested by the interviews, a key thing to remember when considering risks as part of the decision making process is to weigh the risks against the potential gains. In this light, it would be interesting and well-founded to bring the two together in the same decision aid. As patients tend to be more interested in the gains and benefits of the surgery than the risks involved, perhaps the risks would also seem more interesting or at least more understandable, if paired with the other side of the coin. Although the concept of risk has been central to this thesis, the concept of probability of some desired outcome, such as the reduction of pain, is essentially a similar numeric value that might be just as hard for the patient to grasp. There is no reason to doubt information visualizations might be beneficial in communicating this kind of more positive numeric information as well.

If risks and benefits were paired together in the same presentation, there is a chance that the more interesting information would outweigh the other. In that sense, the presentation of risks on their own without any distracting elements is justified as this is information that is required for the patient to know in order to gain informed consent for a surgery. At the same time, the interviewed professionals said that they often use Oravizio as a visual argument to back up their opinions. Sometimes, the professional's opinion is that the benefits of the surgery are not big enough and that is why they are not willing to operate. In situations like these, information visualizations could also come in handy in explaining the risk and benefit ratio to the patient.

Through the interviews this thesis has aimed to get a holistic view on the entire communication situation in which Oravizio and its visualizations are being used. Understanding the context, not just one piece of the puzzle, is key to designing better products. Within the framework of shared decision making, risk assessment tools and other visual aids make up for one part, along with the broader themes covered in chapter five. These broader themes need to be taken into account when considering future directions of the more practical applications. At this point, the interviewees' experience with tools similar to Oravizio was still limited. Most likely, with more and more data being collected every year, the next decade will see many more data-driven tools similar to Oravizio surfacing. In the age of big data, it would only make sense to harness that data for the benefit of healthcare.

7.2 Limitations of the study

Although some of the limitations of this study have already been covered in the previous chapter, the key points with some additions are still summarized here.

Methodologically speaking, it goes without saying that although qualitative in nature, the data from four interviews is not sufficient enough to draw major academic conclusions from. Ideally, the number of interviewees would have been higher, five to eight or even ten, but unfortunately this was the number of professionals with experience using Oravizio I was able to gather. Considering that the starting point of this study was a pre-existing product with earlier documentations, usability tests and other material available, the number of interviewees seemed sufficient enough for the purpose of this thesis.

However, to get a better look on the orthopaedic surgeons' experiences and attitudes towards using the tool, it would have been vital to talk to not only more professionals, but a more varied group of professionals. Many of the professionals I interviewed knew Oravizio very well and some had even been part of the development process at Coxa hospital. Although the kind of tacit knowledge I was able to get from professionals who are deeply involved with the tool was highly useful and interesting, the insight gained from these professionals cannot be generalized to apply to orthopaedic surgeons as a whole. As one interviewee mentioned, at Coxa hospital there is no one way of practicing shared decision making, but all the professionals have their own way of doing things. It would have been valuable to talk to professionals who had different, perhaps more sporadic habits of using the tool.

A major shortcoming of this thesis is the fact that through the interviews I only heard one side of the users' story. In order to get the full picture of how Oravizio and its visualizations are used as part of the shared decision making process, all parties involved should have been included. Only through understanding the whole user base - both professionals and patients - is it possible to design products that will succeed.

Related to this, despite being a study interested in visual design, a deficiency in this thesis is that I wasn't able to follow a thorough design process from start to finish. This refers to user-centered portion of the study being limited to only medical professionals and not continuing further on from there. Essentially, my work up to this point can be considered the beginning of a bigger design process, that will hopefully continue with engagement of the patients as well. Similarly, the visualizations drafted in chapter six would also need to be iterated multiple times before even considered to be used clinically.

8 Conclusion

This master's thesis has studied Oravizio, a risk assessment tool for joint replacement surgeries and a CE-marked medical device, from the point of view of how the tool and its information visualizations can help facilitate shared decision making. The current design and content of the visualizations in Oravizio's graphical user interface have been assessed by comparing them to key findings from the literature review. Additionally, professionals with experience using Oravizio in a clinical setting have been interviewed to gain understanding of how, when and why they use the tool and how its use links to the wider communicative situation of shared decision making.

Going through the three research questions laid out in the introductory chapter, the following remarks can be made to conclude this thesis:

RQ1. What is the potential role of information design and information visualizations in shared decision making and communicating health risk information?

Concerning the first research question, it was discovered that information design and information visualizations have a lot to offer for shared decision making. A prerequisite for successful shared decision making is that the patient is provided enough information concerning the decision at hand. Visits to the doctor's office can be brief and hectic and the patients may be overloaded with all kinds of information during that short amount of time. In this context, it is vital that essential information needed to gain informed consent from the patients is communicated as efficiently and understandably as possible.

Visualizations pose several advantages that make them stand out as optimal tools for communicating information, especially numeric information: they are easier for the brain to process than verbal information, they are more likely to capture the eye and keep the person looking at them engaged, and they make it easier to understand patterns and relations within the information.

All sorts of verbal and visual material have been used in medicine to assist the patient in the process of shared decision making. Collectively, this material is referred to as decision aids. While the more traditional decision aids have focused on the patient's values and feelings, data-driven decision aids have also started to emerge. The kind of risk assessment tool that Oravizio is can be considered a type of data-driven decision aid: it helps the user to consider their treatment options in terms of numbers. In the case of Oravizio, these numbers depict the different risks (infection risk, revision risk and mortality risk) regarding a joint replacement surgery. In order to come to an informed decision about the operation, the patient's values and what they are looking to gain from the operation need to be weighed against the different potential risks.

Numeric risk values are notoriously difficult for the general public to comprehend, especially when talking about low probability risks such as the ones related to an elective surgery like joint replacement surgery. Adding visualizations to plain numbers to communicate risk helps both patients and medical professionals to understand and interpret the numbers more accurately.

RQ2. How does Oravizio facilitate shared decision making at its current state according to users?

Concerning the second research question, the interviews revealed that the professionals in this study (N=4) find Oravizio to be a useful tool in their work and use it regularly with patients. The professionals use Oravizio to back up their arguments both when they recommend the patient to have surgery or when they recommend against it. They also use it with patients who are overly scared of the operation to put the risk numbers in perspective. Oravizio is also used to motivate the patients to make some changes in their lifestyle to bring down surgical risks, by demonstrating with the tool how much the risk would decrease if the patient lost some weight, for instance. Most importantly, Oravizio is used to communicate essential risk information to the patients, as the professionals are required to do before an operation. The use of Oravizio was in line with what the literature suggested risk visualization is typically used for, although the focus was heavily on information transmission over other possible functions.

RQ3. How could Oravizio be improved in terms of information visualization and shared decision making?

Concerning the third research question, the current information visualizations in Oravizio were found to be working quite well as they are. However, some changes and additions to how the information is presented were suggested, most notably by adding some kind of a color-coded risk classification visualization to the graphical user interface. It was also speculated whether Oravizio's intended use could be widened from a mere risk assessment tool to a more holistic data-driven decision aid with the inclusion of data from patient reported outcome measures. The interviews pointed out that the surgical risks must always be weighed against potential gains and visualizing both in the same decision aid could lead to even more informed and balanced decision making. Actual implementation of such changes needs to be carefully considered, however, due to Oravizio's status as a regulated medical device.

9 Literature

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10 Image sources

Figures not referenced here are either made by the author or connected to a literary source cited in the caption next to the figure. These literary sources can be found in chapter 9, Literature.

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11 Annexes

Annex A. Interview structure

INTRODUCTION

Brief introduction of myself and my work, the goal of this interview, mention that the session is recorded but the data is handled anonymously

GETTING STARTED

What do you do?
What do you like about it and what do you dislike?
Generally speaking, what is your relationship with communicating with the patient as part of your work?

THEME 1. SHARED DECISION MAKING

Shared decision making - what comes to mind when you think about your experience with it?
Do you make use of shared decision making in your everyday work?
What do you think is good about shared decision making?
Are there any downsides to it?
Is shared decision making more appropriate in some cases versus others?
Are there established practices of shared decision making at your workplace?
Are the concept and the practices of shared decision making clear to the patients?
How do patients feel about actively taking part in decision making based on your experience?

THEME 2. ORAVIZIO / VISUAL AIDS FOR SHARED DECISION MAKING

Oravizio - what comes to mind when you think about your experience with it?
How often do you use Oravizio with or without patients?
Do you have experience using other visual aids besides Oravizio in shared decision making?
What do you use Oravizio's visualizations for?
How does Oravizio facilitate shared decision making at its current state?
In terms of shared decision making, how could the information shown in Oravizio be improved in terms of its content?
In terms of shared decision making, how could the information shown in Oravizio be improved in terms of how it is presented?

THEME 3. FURTHER QUESTIONS

Is there some other information Oravizio should show? Is the information shown relevant to the patient's participation and understanding of risks?

Based on literature, there are two key goals risk visualizations aim for: firstly, to transmit information and secondly, to motivate the patient's behavior. How do you see Oravizio's potential concerning the latter?

What role do the patient's own actions have on either lowering or increasing the risk of infection/revision/mortality with joint replacement surgeries?

Summing up: how could Oravizio better help you help the patients?

Annex B. Oxford Knee Score patient reported outcome measure by Coxa hospital

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J

Viimeksi kuluneiden neljän viikon aikana...

☒ Valitse kunkin kysymyksen kohdalla yksi vaihtoehdoista

1 **Viimeksi kuluneiden neljän viikon aikana...**
Miten kuvailisitte polvessanne tavallisesti esiintyvää kipua?

Ei kipua	Hyvin lievää	Lievää	Kohtalaista	Kovaa
☐	☐	☐	☐	☐

2 **Viimeksi kuluneiden neljän viikon aikana...**
Onko teillä ollut vaikeuksia peseytymisessä ja itsenne kuivaamisessa (kauttaaltaan) polvenne takia?

Ei vaikeuksia	Hyvin lieviä vaikeuksia	Kohtalaisia vaikeuksia	Hyvin suuria vaikeuksia	Se on ollut mahdotonta
☐	☐	☐	☐	☐

3 **Viimeksi kuluneiden neljän viikon aikana...**
Onko teillä ollut vaikeuksia istua autoon ja nousta sieltä ulos, tai käyttää julkisia kulkuneuvoja polvenne takia? (sen mukaan kumpaa yleensä käytätte)

Ei vaikeuksia	Hyvin lieviä vaikeuksia	Kohtalaisia vaikeuksia	Hyvin suuria vaikeuksia	Se on ollut mahdotonta
☐	☐	☐	☐	☐

4 **Viimeksi kuluneiden neljän viikon aikana...**
Kuinka kauan olette pystynyt kävelemään, ennen kuin kipu polvessa on muuttunut kovaksi? (kepin kanssa tai ilman)

Ei kipua / yli 30 minuuttia	16-30 minuuttia	5-15 minuuttia	Vain kotona	En lainkaan - kävely aiheuttaa kovaa kipua
☐	☐	☐	☐	☐

5 **Viimeksi kuluneiden neljän viikon aikana...**
Kun olette aterioineet (ruokapöydässä), kuinka kovaa kipua olette tuntenut tuolista ylös noustessa polvenne takia?

Ei lainkaan kipua	Lievää kipua	Kohtalaista kipua	Kovaa kipua	Sietämätöntä kipua
☐	☐	☐	☐	☐

6 **Viimeksi kuluneiden neljän viikon aikana...**
Oletteko ontunut kävellessä polvenne takia?

Harvoin / en koskaan	Joskus tai vain liikkeelle lähtiessä	Usein, en pelkästään liikkeelle lähtiessä	Lähes koko ajan	Koko ajan
☐	☐	☐	☐	☐

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Viimeksi kuluneiden neljän viikon aikana...

☒ Valitse kunkin kysymyksen kohdalla yksi vaihtoehdoista

7 **Viimeksi kuluneiden neljän viikon aikana...**
Oletteko pystynyt menemään polvillenne ja nousemaan taas ylös?

Kyllä, helposti	Pienin vaikeuksin	Kohtalaisin vaikeuksin	Hyvin suurin vaikeuksin	En, se on ollut mahdotonta
☐	☐	☐	☐	☐

8 **Viimeksi kuluneiden neljän viikon aikana...**
Onko polvikipu vaivannut teitä öisin sängyssä?

Ei kertaakaan	Vain yhtenä tai kahtena yönä	Muutamina öinä	Useampina öinä	Joka yö
☐	☐	☐	☐	☐

9 **Viimeksi kuluneiden neljän viikon aikana...**
Kuinka paljon polvikipu on häirinnyt tavanomaisia töitänne (kotityöt mukaan lukien)?

Ei lainkaan	Hieman	Kohtalaisesti	Paljon	Estynyt täysin
☐	☐	☐	☐	☐

10 **Viimeksi kuluneiden neljän viikon aikana...**
Onko teistä tuntunut, että polvenne voisi yhtäkkiä "pettää" tai "mennä alta"?

Harvoin / ei koskaan	Joskus tai vain liikkeelle lähtiessä	Usein, ei pelkästään liikkeelle lähtiessä	Lähes koko ajan	Koko ajan
☐	☐	☐	☐	☐

11 **Viimeksi kuluneiden neljän viikon aikana...**
Oletteko pystynyt käymään itse ruokakaupassa?

Kyllä, helposti	Pienin vaikeuksin	Kohtalaisin vaikeuksin	Hyvin suurin vaikeuksin	En, se on ollut mahdotonta
☐	☐	☐	☐	☐

12 **Viimeksi kuluneiden neljän viikon aikana...**
Oletteko pystynyt laskeutumaan portaita yhden kerrosvälin?

Kyllä, helposti	Pienin vaikeuksin	Kohtalaisin vaikeuksin	Hyvin suurin vaikeuksin	En, se on ollut mahdotonta
☐	☐	☐	☐	☐

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LISÄKYSYMYKSET

A Onko teillä sellaisia nivelvaivoja, jotka rajoittavat arkisia askareitanne?

Kyllä	Ei
☐	☐

B Onko teillä muita sairauksia tai vaivoja, jotka rajoittavat arkisia askareitanne?

Kyllä	Ei
☐	☐

C Jos käytätte apuvälinettä liikkuessa, mitä apuvälineitä käytätte sisätiloissa?

En käytä apuvälinettä sisätiloissa	Keppiä	Kahta keppiä tai kyynärsauvoja	Rollaattoria	Pyörätuolia
☐	☐	☐	☐	☐

D Entä ulkona?

En liiku ulkona	En käytä apuvälinettä ulkona	Kävelysauvoja, keppiä, kahta keppiä tai kyynärsauvoja	Rollaattoria	Pyörätuolia	Potkupyörää tai potkukelkkaa
☐	☐	☐	☐	☐	☐

E Minkälaisen arvion itse annatte leikkauksen tulokselle?

Erinomainen	Hyvä	Tyydyttävä	Huono
☐	☐	☐	☐

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Annex C. Oxford Hip Score patient reported outcome measure by Coxa hospital

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Viimeksi kuluneiden neljän viikon aikana...

☒ Valitse kunkin kysymyksen kohdalla yksi vaihtoehdoista

1	**Viimeksi kuluneiden neljän viikon aikana……** Miten kuvailisitte lonkassanne tavallisesti esiintyvää kipua?				
	Ei kipua ☐	Hyvin lievää ☐	Lievää ☐	Kohtalaista ☐	Kovaa ☐
2	**Viimeksi kuluneiden neljän viikon aikana……** Onko teillä ollut vaikeuksia peseytymisessä ja itsenne kuivaamisessa(kauttaaltaan) lonkkanne takia?				
	Ei vaikeuksia ☐	Hyvin lieviä vaikeuksia ☐	Kohtalaisia vaikeuksia ☐	Hyvin suuria vaikeuksia ☐	Se on ollut mahdotonta ☐
3	**Viimeksi kuluneiden neljän viikon aikana……** Onko teillä ollut vaikeuksia istua autoon ja nousta sieltä ulos, tai käyttää julkisia kulkuneuvoja lonkkanne takia? (sen mukaan kumpaa yleensä käytätte)				
	Ei vaikeuksia ☐	Hyvin lieviä vaikeuksia ☐	Kohtalaisia vaikeuksia ☐	Hyvin suuria vaikeuksia ☐	Se on ollut mahdotonta ☐
4	**Viimeksi kuluneiden neljän viikon aikana……** Oletteko pystynyt vetämään itse sukat tai sukkahousut jalkaan?				
	Kyllä, helposti ☐	Pienin vaikeuksin ☐	Kohtalaisin vaikeuksin ☐	Hyvin suurin vaikeuksin ☐	En, se on ollut mahdotonta ☐
5	**Viimeksi kuluneiden neljän viikon aikana……** **Oletteko pystynyt** käymään itse ruokakaupassa?				
	Kyllä, helposti ☐	Pienin vaikeuksin ☐	Kohtalaisin vaikeuksin ☐	Hyvin suurin vaikeuksin ☐	En, se on ollut mahdotonta ☐
6	**Viimeksi kuluneiden neljän viikon aikana……** Kuinka kauan olette pystynyt kävelemään, ennen kuin kipu lonkassa on muuttunut **kovaksi**? (kepin kanssa tai ilman)				
	Ei kipua / yli 30 minuuttia ☐	16-30 minuuttia ☐	5-15 minuuttia ☐	Vain kotona ☐	En lainkaan – kävely aiheuttaa kovaa kipua ☐

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Viimeksi kuluneiden neljän viikon aikana...

☒ Valitse kunkin kysymyksen kohdalla yksi vaihtoehdoista

7	**Viimeksi kuluneiden neljän viikon aikana……** **Oletteko pystynyt** kiipeämään portaita yhden kerrosvälin?				
	Kyllä, helposti ☐	Pienin vaikeuksin ☐	Kohtalaisin vaikeuksin ☐	Hyvin suurin vaikeuksin ☐	En, se on ollut mahdotonta ☐
8	**Viimeksi kuluneiden neljän viikon aikana……** Kun olette aterioineet (ruokapöydässä), kuinka kovaa kipua olette tuntenut tuolista ylös noustessa lonkkanne takia?				
	Ei lainkaan kipua ☐	Lievää kipua ☐	Kohtalaista kipua ☐	Kovaa kipua ☐	Sietämätöntä kipua ☐
9	**Viimeksi kuluneiden neljän viikon aikana……** Oletteko ontunut kävellessä lonkkanne takia?				
	Harvoin / en koskaan ☐	Joskus tai vain liikkeelle lähtiessä ☐	Usein, en pelkästään liikkeelle lähtiessä ☐	Lähes koko ajan ☐	Koko ajan ☐
10	**Viimeksi kuluneiden neljän viikon aikana……** Oletteko tuntenut äkillistä kovaa kipua – "vihlontaa", "pistosta" tai "kramppeja" – lonkassanne?				
	Ei kertaakaan ☐	Vain yhtenä tai kahtena päivänä ☐	Muutamina päivinä ☐	Useimpina päivinä ☐	Joka päivä ☐
11	**Viimeksi kuluneiden neljän viikon aikana……** Kuinka paljon lonkkakipu on häirinnyt tavanomaisia töitänne (kotityöt mukaan lukien)?				
	Ei lainkaan ☐	Hieman ☐	Kohtalaisesti ☐	Paljon ☐	Estänyt täysin ☐
12	**Viimeksi kuluneiden neljän viikon aikana……** Onko lonkkakipu vaivannut teitä öisin sängyssä?				
	Ei kertaakaan ☐	Vain yhtenä tai kahtena yönä ☐	Muutamina öinä ☐	Useimpina öinä ☐	Joka yö ☐

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LISÄKYSYMYKSET

A Onko teillä sellaisia nivelvaivoja, jotka rajoittavat arkisia askareitanne?

Kyllä ☐ Ei ☐

B Onko teillä muita sairauksia tai vaivoja, jotka rajoittavat arkisia askareitanne?

Kyllä ☐ Ei ☐

C Jos käytätte apuvälinettä liikkuessa, mitä apuvälineitä käytätte sisätiloissa?

En käytä apuvälinettä sisätiloissa ☐ Keppiä ☐ Kahta keppiä tai kyynärsauvoja ☐ Rollaattoria ☐ Pyörätuolia ☐

D Entä ulkona?

En liiku ulkona ☐ En käytä apuvälinettä ulkona ☐ Kävelysauvoja, keppiä, kahta keppiä tai kyynärsauvoja ☐ Rollaattoria ☐ Pyörätuolia ☐ Potkupyörää tai potkukelkkaa ☐

E Minkälaisen arvion itse annatte leikkauksen tulokselle?

Erinomainen ☐ Hyvä ☐ Tyydyttävä ☐ Huono ☐

F Onko leikatussa lonkassa ollut poikkeavaa ääntelyä? (vinkuminen, narina, rutina tms.)?

Kyllä ☐ Ei ☐

G Onko leikatussa lonkassa ollut muljahtelua tai sijoiltaanmenon tunnetta?

Kyllä ☐ Ei ☐

H Onko leikatussa lonkassa ollut jatkuvaa paineen tunnetta tai näkyvää turvotusta?

Kyllä ☐ Ei ☐

I Onko leikatun lonkan seudussa (pakarassa tai reidessä) ollut puutumista?

Kyllä ☐ Ei ☐

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