Design and Development of an Interactive Paper-Based Shared Decision-Making Tool for Healthcare Professionals, and Patients with COPD and Comorbidities.

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Abstract

Shared decision-making is a healthcare approach with a focus on the patient making healthcare decisions assisted by their healthcare professional. This process has been shown to improve communication between healthcare professionals and patients as well as patient satisfaction with treatment [1, 38]. Shared decision-making paired with dedicated decision tools further enhances this positive effect on patient healthcare by improving the patient's adherence to treatment plans [8]. The goal of this graduation project was to design and develop an interactive paper-based tool which can be used to facilitate a shared decision-making session between healthcare professionals and their patients with COPD and comorbidities. COPD is a chronic lung disease primarily affecting people aged 40 and older, around 10% of the world population has COPD [15]. Treatment for COPD typically involves lifestyle changes in order to reduce symptoms and improve quality of life [15]. Over the course of this project a prototype for a card-based decision tool which enables conversations between healthcare professionals and patients was developed. The design process was based on criteria that were derived from background research together with design requirements as set by the client of this thesis, RE-SAMPLE. The cards paired with assistance of their healthcare professional help the patient to find a long-term goal they want to achieve within their day-to-day life based on treatment areas, so-called domains. With follow-up cards containing side goals and treatment options, the patient can determine their personalised treatment plan towards this established long-term goal. The final prototype contains 2 domain cards, 4 side goal cards, 3 instruction cards for healthcare professionals, and personal goal cards for the patient. The prototype was evaluated based on a functional analysis, three separate user evaluation sessions, and by using the IPDAS checklist which is an international standard for decision tools. The evaluation phase showed that the developed card-based tool has the potential to facilitate a shared decision-making session. Further development could contribute to the tool's capability to reliably create SDM sessions for healthcare professionals, and patients with COPD and comorbidities.

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Chapter 1 – Introduction

Shared decision-making (SDM) is a healthcare approach in which both the healthcare professional (HCP) and the patient make decisions relevant for the patient's health. These decisions include goal setting, as well as future treatment steps and other healthcare choices [1]. Notably, goal setting in particular is considered to lead to positive health outcomes for the patient [38]. SDM is the opposite of the more "traditional" paternalistic healthcare approach, in which the healthcare professional makes most if not all decisions related to a patient's health [32]. SDM is utilised to enable the patient to make more informed decisions for their health themselves, whilst the healthcare professional can make personalised suggestions for the patient based on the patient's feedback and preferences [34]. A core part of SDM is the variety of options presented to the patient which influences their autonomy to make choices. The amount of options presented is heavily dependent on the healthcare professional and their assessment of the patient as well as their understanding of the options [32]. Wirtz et al. [32] call this the 'framing problem' of patient involved decision-making, and any approach involving shared decision-making should try to address this problem and try to mitigate it. One commonly used approach is the 'Three Decisions' approach by Elwyn et al. [11] which structures the consultation between HCP and patient in three steps which introduce the patient into making health related choices and decisions, while being assisted by the HCP along the way. In addition to shared decision-making frameworks specific tools are utilised to assist and enable SDM. These tools help patients in choosing and following treatment goals and treatment steps, by creating an environment which helps the patient to make choices they are confident in following [8].

In order to do so, decision tools (DTs), also called decision aids, provide the patient with important information, details, steps, and risks about therapeutic and clinical steps they can take [2]. Hsu et al. [3] in their review of randomised controlled trials state that the use of decision tools during SDM have improved the patients knowledge and the patients satisfaction with the decision-making process. Besides offering information to the patient, DTs can also be used to structure SDM consultation sessions and help the HCP organise their conversation with the patient to achieve a shared decision-making setting [11,10]. Decision tools commonly face two correlated problems: The first problem involves the amount of information contained within the tool; the second problem involves the restricted amount of time available for shared decision-making in the setting of a HCP and patient consultation [3,6,7,12]. Due to this lack of time, which is on average around 10 minutes per consultation in Europe [35], decision tools that can be used outside of a consultation session are preferred by healthcare professionals [6,12]. As described by Marrin et al. [7] and Hsu et al. [3] this can decrease the effectiveness of the decision tool and lead to a less successful treatment approach. In addition this removes the shared decision-making conversation and outcome, and its positive effects on patient treatment.

The goal of this Bachelor's thesis is to develop a decision tool which facilitates shared decision-making for use between healthcare professionals and patients, specifically, patients living with COPD and comorbidities.

Chronic Obstructive Pulmonary Disease (COPD) is a chronic lung condition with symptoms involving the feeling of running out of breath (dyspnea), coughing, and sputum production

[15]. COPD is characterised by the exacerbation of its symptoms, which is an acute worsening of COPD respiratory issues. COPD is also characterised by its comorbidities which are other conditions and illnesses which affect patients with COPD. These other illnesses actively affect the progression and treatment of COPD and include heart conditions, diabetes, and depression [15, 17]. Treatment and prevention of this illness and its symptoms primarily relies on the patient actively following lifestyle changes like stopping to smoke, doing workouts or other exercises which help them build up strength and decrease the risk of exacerbations [15, 17]. Here shared decision-making can improve the outcome of treatment due to the positive effects of goal setting [38].

This bachelor's project is part of the RE-SAMPLE [14], an EU-funded research project with the goal of improving the healthcare journey of patients with COPD and comorbidities. RE-SAMPLE does so by creating personalised treatment for patients based on their digital health data gathered through Garmin watches. For this RE-SAMPLE created a digital shared decision-making tool that works in conjunction with the digital health data.

The project for this bachelor thesis will focus on developing an alternative approach to this shared decision-making tool, which instead of being web-based and using digital data, will be paper-based and interactive. Developing and designing this tool will be the focus of this thesis as well as evaluating how successful the approach is in creating a shared decision-making conversation between healthcare professionals and patients.

The following research question guided the design and development of this tool:

R1: What interactive form can a paper-based decision tool take to help guide the shared decision-making process?

The following sub-questions framed the background research as well as the ideation and design process:

a. *In what ways can decision tools help patients and healthcare professionals during shared decision-making?*
b. *What does a shared decision-making session need to look like in order to best fulfil the needs of patients and healthcare professionals?*

After the background research, the development and design was split into four parts:

1. Ideation and brainstorming in order to find a viable idea for the shape of the decision tool.
2. Creating specifications and finding requirements the tool has to fulfil.
3. Realisation of the tool through prototyping within the requirements established in step 2.
4. Evaluation of the tool to determine how successful it is at creating a shared decision-making conversation in the form of user evaluations.

Chapter 2 – Background Research

2.1 COPD

Chronic Obstructive Pulmonary Disease (COPD) is a chronic lung condition with symptoms involving dyspnea, coughing, and sputum production. COPD is characterised by the exacerbation of its symptoms, an acute worsening of COPD respiratory issues [15,17]. These exacerbations decrease quality of life and increase in frequency as COPD progresses. The Global Initiative for Chronic Obstructive Lung Disease (GOLD) [15] states that based on national data around 6% of the world population suffer from COPD, however these numbers are predicted to be higher due to under-diagnosis of the disease and GOLD estimates the global prevalence to be at 10%.

The main causes for COPD development are smoking and inhaling of (toxic) particles and gases from air pollution. Other causes can include abnormal lung development and accelerated lung ageing [15]. An increase in COPD development was found in older people, and while it isn't clear if age itself or the exposure happening during ageing leads to the higher risk, older age increases the risk of developing COPD [15. COPD symptoms are categorised in four stages of severity called GOLD-stages, ranging from mild (GOLD-I), over moderate (GOLD-II), to severe (GOLD-III), and very severe (GOLD-IV) [15].

Comorbidities
COPD is often accommodated by other diseases which impact the treatment and disease development of patients with COPD. These comorbidities can be independent or directly related to COPD, and include cardiovascular diseases and risk factors, psychiatric disorders, as well as anaemia, osteoporosis, reflux, lung cancer, and general pain [15, 16].

Cardiovascular Diseases
Cardiovascular diseases include heart failure, arterial hypertension, and ischemic heart disease. All three of these comorbidities are listed to stand in direct relation and appear in most patients with COPD [15, 16]. Other cardiovascular risk factors include obesity, dyslipidemia, and diabetes [16].

Psychiatric Disorders
Anxiety, insomnia, depression, and cognitive impairment can occur as comorbidities in patients with COPD. Disorders like insomnia and depression increase in prevalence depending on the severity of COPD [15, 16].

Anaemia
Chronic and iron deficiency anaemia is most common in patients with COPD and increases in appearance during exacerbations [15, 16].

Osteoporosis
Osteoporosis is common in patients with COPD and generally underdiagnosed. Osteoporosis was found to decrease exercise tolerance in patients with comorbidity [15, 16].

Gastroesophageal Reflux

Iglesias et al. [16] state that patients with COPD have a higher risk of reflux, and that “the presence of reflux symptoms in COPD patients is related with more frequent and more severe exacerbations” [53].

Lung Cancer

50% to 65% of people with lung cancer show signs of suffering from COPD, and lung cancer has a prevalence of around 4% to 8% in people with COPD. There is evidence showing the association between lung cancer and COPD, smoking and other air pollution being causes for both. Lung cancer does not seem to affect the treatment options for people with COPD [15, 16].

Pain

Iglesias et al. [16] name general chronic pain as another comorbidity as a direct result of COPD. While the pain doesn’t reduce lung function, it influences quality of life and can increase the risk for psychiatric disorders as well as affect eating habits.

COPD Treatment

Current medical research suggests several approaches to the treatment of COPD, ranging from medicine prescription to physical workouts and care. Treatment for COPD can be split into six general types [15, 17, 18]:

- Preventive Therapy
- Pharmacological
- Non-Pharmacological
- Interventional
- Care
- Management of Exacerbations

Preventive Therapy

Preventative therapy’s primary focus is on smoking cessation: Approximately 40% of COPD patients continue to smoke despite their diagnosis of COPD. Quitting smoking has a significant effect on maintaining and increasing lung function [15, 17]. Another form of preventative therapy is vaccination against influenza as COPD patients show an increase in vulnerability and severity of symptoms [15, 17].

Pharmacological

The kind of pharmacological treatment depends on patient exacerbations and comorbidities. The most common types of treatment involve bronchodilators, with patients either being prescribed one mono-dilator or two dilators with different mechanisms [15,18]. Inhaled corticosteroids are prescribed to patients with exacerbations or a history of asthma [18].

Non-Pharmacological

There are two parts to non-pharmacological treatment and both play an important role in treatment of COPD. The first half is self-management education: The goal is to teach the patient how to manage COPD on a day to day basis, as well as to help them adapt their health behaviour [15, 17, 18].

The second part of non-pharmacological treatment is pulmonary rehabilitation (PR). Franssen et al. list exercise training, self-management education, nutritional counselling, psychological support, and occupational therapy as part of PR [18]. The GOLD report states that PR is the most effective therapeutic strategy to improve COPD symptoms and typical PR usually lasts between six to eight weeks [15].

Interventional

Interventional treatment involves surgical operations, namely lung volume reduction surgery, bullectomy, and lung transplantation. [15, 18].

Care

Palliative care, hospice care, and end-of-life care all fall under the category of care. Palliative care aims to prevent and relieve suffering caused by COPD symptoms, and is oftentimes part of end-of-life care [15]. Hospice care usually follows worsening exacerbations and end-of-life care involves support for both patients and families [15].

Management of Exacerbations

The management of exacerbations focuses on preventing subsequent exacerbations and minimising the impact of current exacerbations. Management is done with pharmacological support and respiratory support in the form of oxygen therapy, high-flow nasal therapy, and ventilatory support [15, 17].

Influence of Comorbidities

Medications and treatments for comorbidities can negatively interact with medication and treatment for COPD and need to be adjusted individually per patient [15, 18].

2.2 Shared Decision-Making

Clayman et al. [19] use a coding criteria to categorise the “degree of decision sharing” [54] which refers to the amount a patient is involved in the decision-making process during their consultation. The coding has nine points, four points are doctor-led, four points are patient-led and one point is fully shared. The four points on either side have varying degrees of involvement from the other person, ranging from no involvement, to acknowledgement, to agreement, to incorporating the other side's view into the decision (see Figure 1). Clayman et al. [19] conclude that most decisions tend towards the doctor-led side where most of the decision-making and treatment goals are set by the healthcare professional based on their individual assessment. The decision process largely bypasses the patient; in effect treatment is often in line with the healthcare professional’s pre-existing plan and understanding.

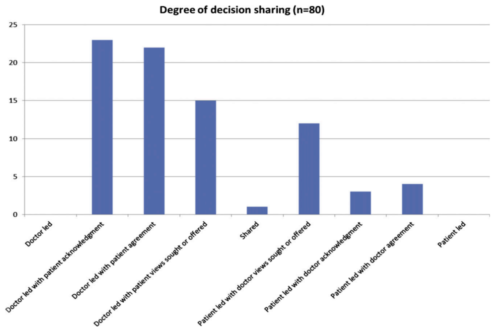


Fig. 1. Degree of decision sharing.

Figure 1: Degree of Decision Sharing Table from Clayman et al. [55]

Shared decision-making (SDM) is a healthcare approach that focuses treatment around patient feedback. During shared decision-making, decisions are made based on personalised information given by the healthcare professional **and** input by the patient, which is based on their informed preferences and concerns [20, 11]. It is important for SDM to ensure that patients are making decisions only after they have been sufficiently informed about key issues as well as leaving room for patients to deliberate and explore their options before making any choices [10,11].

A general approach to shared decision-making is outlined in Elwyn et al. [11], which splits SDM in three parts:

1) **Choice Talk** is about communicating that the patient has the choice between several options. The focus is on encouraging the patient to evaluate and compare the possible options they have.
2) **Option Talk** revolves around discussing the different options that are available for treatment. The healthcare professional needs to make sure that the patient is well informed in terms of what choices exist, what they entail, as well as their potential harms and benefits. Elwyn et al. [11] also suggest utilising decision tools during this process.
3) **Decision Talk** focuses on supporting and encouraging the patient to form their preferences so they can make an informed decision about which option they want to choose as their treatment.

It is emphasised that enough time should be given between and during Option Talk and Decision Talk for the patient to thoroughly deliberate and consider their options, and make a choice regarding what they find most important.

In their comparative research about paternalistic decision-making and shared decision-making, Wirtz et al. [32] highlight how giving options to the patients is often a neglected part of the decision processes which they call the ‘framing problem’. They hereby propose that most models, be it paternalistic or SDM, put a focus on the patient’s opportunity to involve themselves into the final choice of treatment while neglecting that the amount of treatment alternatives influences the autonomy of the patient’s choice. This means that while having the option to make a choice is an important part of the decision-making process, this process is heavily influenced by the amount of alternative options that are available. To highlight this problem Wirtz et al.[32] quote Elwyn et al. [11] whose research showed that HCPs spend the least amount of time on naming alternatives during the consultation sessions. A likely cause for this is that during the decision process, most healthcare professionals filter out options they do not find relevant for the patient’s conditions [33]. The selection of options is further influenced by policies, guidelines, and organisational constraints. Furthermore the healthcare professional’s knowledge about an option can influence whether the option is included into the option-set presented to the patient. Based on this, Wirtz et al.[32] state that patients should have a more active role in the creation of the option-sets, even if that would result in options being included that the HCP lacks knowledge in. In order for that to happen, however, the major ethical dilemma regarding the healthcare professional’s accountability needs to be addressed.

The ‘Three Decision’ approach proposed by Elwyn et al. [11], while promoting and encouraging the patient’s involvement and inclusion, relies heavily on the healthcare professional’s ability to facilitate this process. In their 2011 literature review, Dy et al. [2] investigate and define the main factors which are relevant for successful shared decision-making.They identify seven key concepts which influence shared decision-making; provider competence, provider trustworthiness, cultural competence, communication with patients and families, information quality, patient/surrogate competence, as well as roles and involvement.

Provider Competence

Shared decision-making relies on the healthcare professional’s ability to conduct and support an SDM session; this entails properly identifying issues relevant for the patient as well as being able to apply their own knowledge. In the case of COPD this includes being able to properly identify the most relevant issues a patient has and suggest treatment options while taking into consideration comorbidities and other outside factors [2].

Provider Trustworthiness

A patient’s perception of their healthcare professional plays an important role in following and trusting the healthcare professional's advice. Factors influencing the patient’s perception are related to the other key concepts such as cultural competence and communication with patients and patient families [2].

Cultural Competence

Cultural competence requires the HCP to consider the patient’s religious or cultural beliefs during interaction and communication. These beliefs can influence the patient’s health beliefs as well as their general interaction, and decision-making [2].

Communication with Patients and Families

The focus here isn’t the content of the information, but how the healthcare professional communicates this information and if the information addresses the key information that is relevant for patients and their families [2].

Information Quality

Information given to the patient should communicate “understanding of disease, prognosis, or treatment; quality of life, distress, or needs; caregiver issues; and expectations and perceptions of care” [56]. This information should be individualised for each patient in order to address their personal needs and values [2].

Patient/Surrogate Competence
In order to be effective, shared decision-making relies on both the healthcare professional and patients; therefore, the patient's own competence is equally important for the success of SDM. This also applies to surrogate decision makers for the patients. The surrogate's competence is further complicated by the potential lack of understanding of the patients preferences [2].

Roles and Involvement
The level and process of involvement for a decision should be appropriate for the decision and based on the preference of the patient. In their review, Dy et al. [2] refer to 3 different models for healthcare approaches as suggested by Charles et al. [34] the paternalistic model, the shared model, and the informed model. These three models are related to the 9 "degrees of decision sharing" by Clayman et al. [19]. The paternalistic model only has HCP led decision-making. The shared model uses shared decision-making where all choices are made together by patient and healthcare professional. The informed model only uses patient-led decision options, which are guided by the healthcare professional's input [2].

2.3 Decision Tools

Informed shared decision-making requires the patient to be knowledgeable about their health situation and to understand the options they have. This knowledge should be communicated by the healthcare professional, however this process can or even should be assisted by decision tools, also called decision aids. These tools contain information relevant for the patient in regards to explanations, treatment options, other patient experiences, and suggestions.

Decision tools (DTs) come in various forms and application areas, ranging from printed booklet, to video, to websites and online tools [3, 6, 12, 2]. The core of these decision aids is always the same, they aim to guide the patient along their healthcare decisions, with varying degrees of HCP involvement.

Design Requirements
Decision tools need to consider several aspects in their design and application in order to be effectively used during shared decision-making by healthcare professionals and patients.
First and foremost, decision tools need to help inform the patient about their options regarding their treatment and what they can do going forward [4]. The information should be provided in two different ways; firstly, decision tools themselves should contain and provide knowledge; secondly, they should help the healthcare professional give information to the patient.

Comparing options is named as an important part of decision tools by De Mik et al. [5], as well as Politi et al. [6], and Marrin et al. [7]. De Mik et al. [5] describe how this knowledge can be conveyed by using visual aids as well as questions to guide the patient into finding their preference for treatment options. Bonneux et al. [8] support this, by defining that options need to be clarified if there is more than one valid, alternative option available. This need for clarification is further highlighted by Politi et al. [6] and Marrin et al. [7]: both papers focus on option grids which is a DT format designed to clearly and comprehensively list and compare treatment options.

Another way for decision tools to convey information about options can happen through showing patient experiences. Feldman-Stewart et al. [9] argue that it is easier for people to understand the experience of someone else, instead of an abstract experience of a group. This is provided if a DT describes the narrative of another patient with a treatment choice. Providing another patient’s experience can provide an alternative perspective which can be critical for the patient currently using the decision tool to make an informed choice. However, in the case of using patient experience reports Feldman-Stewart et al. [9] give the advice to use caution with patient narratives, as there is concern regarding how accurately they understand their health situation.

In order to help the healthcare professional give information to the patient, decision tools can guide a shared decision-making session. Elwyn et al. [11] describe a three part approach which ensures that patient and the healthcare professional enter a SDM conversation by utilising decision tools to guide the conversation. The HCP does the majority of informing the patient about their options based on the guidance of the tool. Elwyn et al. [11] further describe how it is important to explore the patient's reaction to information and adapt the conversation and information the HCP gives accordingly. This is further supported by Liu et al. [10] who put a focus on DTs helping healthcare professionals finding treatment options that best align with the patient's wishes. This can be accomplished through the use of digital data analysis as well as DTs providing experience reports of patients in order for the healthcare professional and not the patient to make the informed decision about what options might apply for the patient so the HCP can make suggestions based on that decision.

It is important that the tool does not replace the HCP because each patient has individual concerns and priorities that fall outside the predicted model contained in DTs [9]. Elwyn et al. [11] name informing the patient about their situation as the main requirement a decision tool needs to fulfil. This is necessary in order for the patient to determine what is important to them; thereby, helping the patient deliberate their options is a main requirement for DTs. This means that a decision tool should be designed in a way that lets the patient think and contemplate their current situation and base their decisions on their own individual conclusions about what they value and want.

A commonly named factor which reduces the effectiveness of DTs is time [3,6,7,12]. Based on the survey research conducted by Deveugele et al. [35] across six European countries, the average time spent on a consultation session lies between 7 and 15 minutes, with an overall average of 10 minutes. Internationally the available time can vary from less than a minute to almost 30 minutes [35]. Politi et al. [6] as well as Schultz et al. [12] determined during reviews of existing decision tools that healthcare professionals highlight how time intensive the use of decision tools can be. They point towards DTs that are able to be used outside of consultation hours as an effective alternative to inform the patient about their conditions and treatment options. Notably, only Politi et al. [6] name this as an exclusively positive aspect decision tools can take; Marrin et al. [7] and Hsu et al. [3] highlight the concern of HCPs that tools used without a healthcare professional can decrease the effectiveness of consultations as well as negatively impact future consultations. From this two further aspects a decision tool needs to have can be derived: It needs to be compact enough to be used inside the timeframe of a regular session between healthcare professionals and patients, and also be structured in a way that does not incentivise using the decision tool as an alternative to a session; formats like DVDs, web- or paper-based brochures and booklets seem to most commonly encourage this [3, 6, 12, 13]. In their

‘Ready, willing, and able’ framework, Schultz et al. [12] name training as a factor that influences the effectiveness of decision tools. Training hereby refers to everyone involved in using the tool being aware of their role. It is not enough that the decision tool considers the above requirements, users of this tool also need to know how to use it in order to aid SDM sessions.

During the design of a decision tool it is important to consider that the format that is best for a healthcare professional does not necessarily result in the best outcome for the patient. As stated above, limited time is the most commonly named concern for healthcare professionals, so tools that restrict time the least [7] or even give an option to shift time investment outside of consultation sessions may be preferred [3,6]. However, these tools ignore the other necessary requirements for an effective decision tool. The goal of a decision tool should always be to help the healthcare professional solve the problem of the patient and not for the patient to try and solve the problem themselves.

To summarise, a decision tool needs to give an overview about the condition of the patient and the available options the patient has for treatment. Furthermore, the tool needs to provide information about these options in the form of information texts, statistical data, or patient reports. This information is given in order to help the patient contemplate their options and make a choice regarding what they find important for their treatment. The decision tool should also help the patient to set goals they want to achieve for their treatment, in addition to creating a treatment plan which helps them reach these goals.

While providing information to the patient, the tool also needs to help the healthcare professional communicate information to the patient and help them explain the various available treatment options. In order to be able to be integrated into a consultation session, the tool needs to be designed while keeping in mind the time investment needed to use the tool as consultation sessions are limited in their available time, with an average of 10 minutes per patient. While the tool should inform the patient within, it is not supposed to replace the HCP or the consultation session. Therefore a balance concerning the degree to which the patient has to be informed through the tool needs to be found. Lastly, the tool needs to be easy to use and not require specific training.

The collected requirements for a decision tool are summarised in Table 1.

1	Give an overview of condition and options
2	Inform about options
3	Help set goals
4	Create a treatment plan
5	Support patient contemplation
6	Assist HCP in communicating information
7	Consider time
8	Disencouragement to be used as HCP replacement
9	Easy enough to use without complex training

Table 1: Requirements for Decision Tools

2.4 State of the Art for Decision Tools

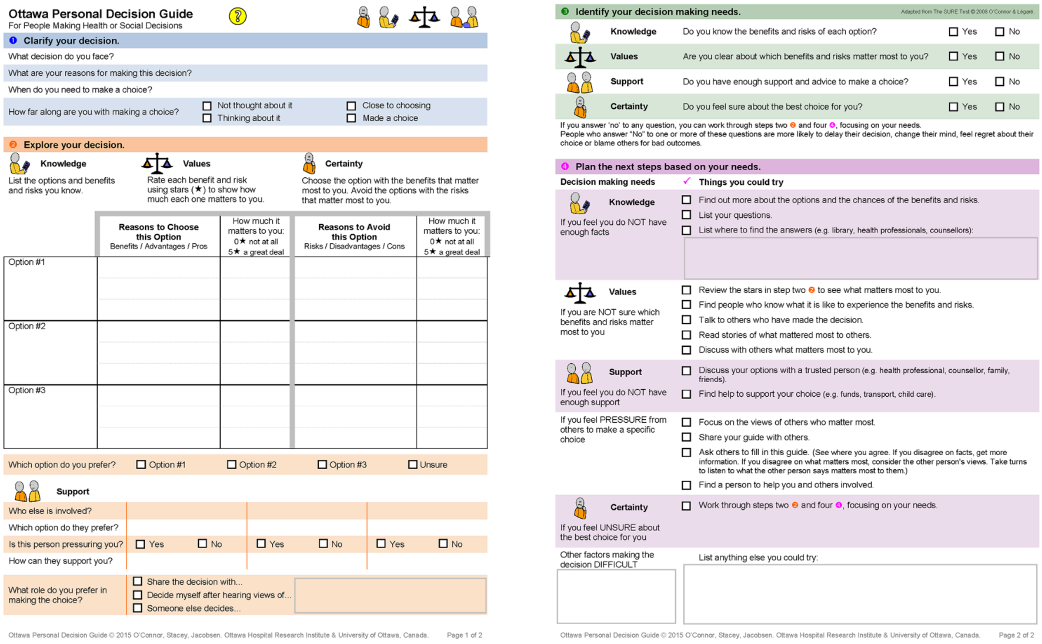
IPDAS

The International Patient Decision Aid Standards (IPDAS) instrument is a tool to measure the quality and reliability of decision tools and decision technology [4]. The instrument consists of a checklist which provides evaluation questions regarding Information, Probabilities, Values, Decision Guidance, Development, Evidence, Disclosure, and Plain Language [4]. While IPDAS is not a decision tool itself, it was made to create an international framework to help develop decision tools.

Questionnaire Decision Tools

Questionnaire Decision Tools usually contain questions about symptoms or situations the patient needs to consider and then answer. Included on the same page can be information about the patient's illness or situation, but that is not always the case. The main goal hereby is to help the patient confront questions they might have with treatment or their illness, in order to bring those questions up to their healthcare professional.

Examples for questionnaires include the Ottawa Personal Decision Guide by the University of Ottawa (Figure 2) [21], ‘Informed Decision Making: Get help from your BRAIN’ by CCMI (Figure 3) [22], and ‘Do I really need antibiotics?’ by the Australian Commission on Safety and Quality in Health Care (Figure 4) [23].



Ottawa Personal Decision Guide
For People Making Health or Social Decisions

❶ Clarify your decision.

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice? ☐ Not thought about it ☐ Thinking about it ☐ Close to choosing ☐ Made a choice

❷ Explore your decision.

Knowledge List the options and benefits and risks you know.

Values Rate each benefit and risk using stars (★) to show how much each one matters to you.

Certainty Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal	**Reasons to Avoid this Option** Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer? ☐ Option #1 ☐ Option #2 ☐ Option #3 ☐ Unsure

Support

Who else is involved?						
Which option do they prefer?						
Is this person pressuring you?	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
How can they support you?						

What role do you prefer in making the choice?
☐ Share the decision with...
☐ Decide myself after hearing views of...
☐ Someone else decides...

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❸ Identify your decision making needs. Adapted from The SURE Test © 2008 O'Connor & Légaré.

Knowledge	Do you know the benefits and risks of each option?	☐ Yes	☐ No
Values	Are you clear about which benefits and risks matter most to you?	☐ Yes	☐ No
Support	Do you have enough support and advice to make a choice?	☐ Yes	☐ No
Certainty	Do you feel sure about the best choice for you?	☐ Yes	☐ No

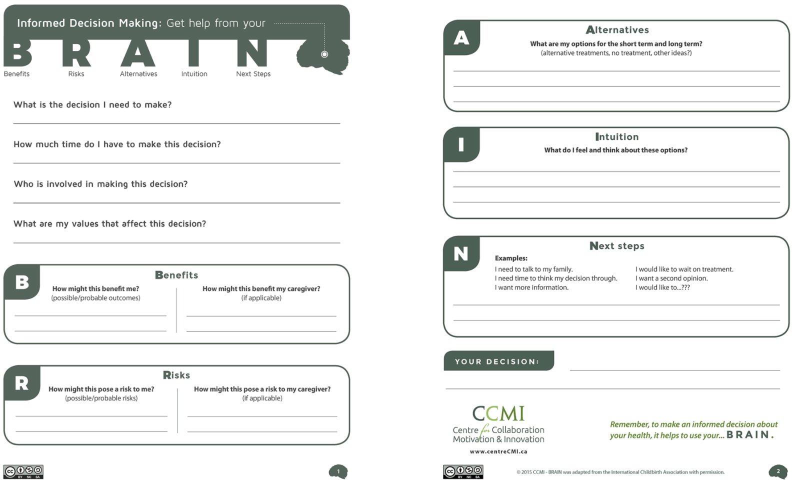
If you answer ‘no’ to any question, you can work through steps two ❷ and four ❹, focusing on your needs.
People who answer “No” to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

❹ Plan the next steps based on your needs.

Decision making needs	✓ **Things you could try**
Knowledge If you feel you do NOT have enough facts	☐ Find out more about the options and the chances of the benefits and risks. ☐ List your questions. ☐ List where to find the answers (e.g. library, health professionals, counsellors):
Values If you are NOT sure which benefits and risks matter most to you	☐ Review the stars in step two ❷ to see what matters most to you. ☐ Find people who know what it is like to experience the benefits and risks. ☐ Talk to others who have made the decision. ☐ Read stories of what mattered most to others. ☐ Discuss with others what matters most to you.
Support If you feel you do NOT have enough support	☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends). ☐ Find help to support your choice (e.g. funds, transport, child care).
If you feel PRESSURE from others to make a specific choice	☐ Focus on the views of others who matter most. ☐ Share your guide with others. ☐ Ask others to fill in this guide. (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person's views. Take turns to listen to what the other person says matters most to them.) ☐ Find a person to help you and others involved.
Certainty If you feel UNSURE about the best choice for you	☐ Work through steps two ❷ and four ❹, focusing on your needs.
Other factors making the decision DIFFICULT	List anything else you could try:

Ottawa Personal Decision Guide © 2015 O'Connor, Stacey, Jacobsen. Ottawa Hospital Research Institute & University of Ottawa, Canada. Page 2 of 2

Figure 2: Ottawa Personal Decision Guide by the University of Ottawa



Informed Decision Making: Get help from your

BRAIN

Benefits Risks Alternatives Intuition Next Steps

What is the decision I need to make?

How much time do I have to make this decision?

Who is involved in making this decision?

What are my values that affect this decision?

B **Benefits**

How might this benefit me? (possible/probable outcomes)	How might this benefit my caregiver? (if applicable)

R **Risks**

How might this pose a risk to me? (possible/probable risks)	How might this pose a risk to my caregiver? (if applicable)

1

A **Alternatives**

What are my options for the short term and long term?
(alternative treatments, no treatment, other ideas?)

I **Intuition**

What do I feel and think about these options?

N **Next steps**

Examples:

I need to talk to my family.
I need time to think my decision through.
I want more information.

I would like to wait on treatment.
I want a second opinion.
I would like to...???

YOUR DECISION:

CCMI
Centre for Collaboration Motivation & Innovation
www.centreCMI.ca

Remember, to make an informed decision about your health, it helps to use your... **BRAIN.**

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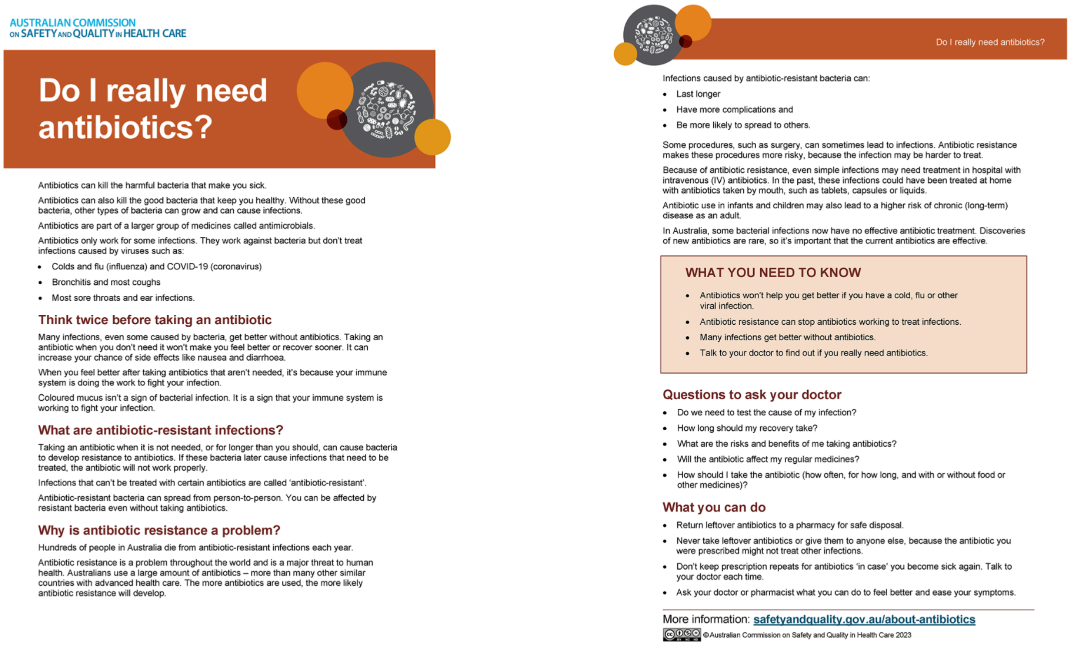
Figure 3: Informed Decision Making: Get help from your BRAIN by CCMI



AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

Do I really need antibiotics?

Antibiotics can kill the harmful bacteria that make you sick.

Antibiotics can also kill the good bacteria that keep you healthy. Without these good bacteria, other types of bacteria can grow and can cause infections.

Antibiotics are part of a larger group of medicines called antimicrobials.

Antibiotics only work for some infections. They work against bacteria but don't treat infections caused by viruses such as:

- Colds and flu (influenza) and COVID-19 (coronavirus)
- Bronchitis and most coughs
- Most sore throats and ear infections.

Think twice before taking an antibiotic

Many infections, even some caused by bacteria, get better without antibiotics. Taking an antibiotic when you don't need it won't make you feel better or recover sooner. It can increase your chance of side effects like nausea and diarrhoea.

When you feel better after taking antibiotics that aren't needed, it's because your immune system is doing the work to fight your infection.

Coloured mucus isn't a sign of bacterial infection. It is a sign that your immune system is working to fight your infection.

What are antibiotic-resistant infections?

Taking an antibiotic when it is not needed, or for longer than you should, can cause bacteria to develop resistance to antibiotics. If these bacteria later cause infections that need to be treated, the antibiotic will not work properly.

Infections that can't be treated with certain antibiotics are called 'antibiotic-resistant'.

Antibiotic-resistant bacteria can spread from person-to-person. You can be affected by resistant bacteria even without taking antibiotics.

Why is antibiotic resistance a problem?

Hundreds of people in Australia die from antibiotic-resistant infections each year.

Antibiotic resistance is a problem throughout the world and is a major threat to human health. Australians use a large amount of antibiotics – more than many other similar countries with advanced health care. The more antibiotics are used, the more likely antibiotic resistance will develop.

Do I really need antibiotics?

Infections caused by antibiotic-resistant bacteria can:

- Last longer
- Have more complications and
- Be more likely to spread to others.

Some procedures, such as surgery, can sometimes lead to infections. Antibiotic resistance makes these procedures more risky, because the infection may be harder to treat.

Because of antibiotic resistance, even simple infections may need treatment in hospital with intravenous (IV) antibiotics. In the past, these infections could have been treated at home with antibiotics taken by mouth, such as tablets, capsules or liquids.

Antibiotic use in infants and children may also lead to a higher risk of chronic (long-term) disease as an adult.

In Australia, some bacterial infections now have no effective antibiotic treatment. Discoveries of new antibiotics are rare, so it's important that the current antibiotics are effective.

WHAT YOU NEED TO KNOW

- Antibiotics won't help you get better if you have a cold, flu or other viral infection.
- Antibiotic resistance can stop antibiotics working to treat infections.
- Many infections get better without antibiotics.
- Talk to your doctor to find out if you really need antibiotics.

Questions to ask your doctor

- Do we need to test the cause of my infection?
- How long should my recovery take?
- What are the risks and benefits of me taking antibiotics?
- Will the antibiotic affect my regular medicines?
- How should I take the antibiotic (how often, for how long, and with or without food or other medicines)?

What you can do

- Return leftover antibiotics to a pharmacy for safe disposal.
- Never take leftover antibiotics or give them to anyone else, because the antibiotic you were prescribed might not treat other infections.
- Don't keep prescription repeats for antibiotics 'in case' you become sick again. Talk to your doctor each time.
- Ask your doctor or pharmacist what you can do to feel better and ease your symptoms.

More information: safetyandquality.gov.au/about-antibiotics

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Figure 4: Do I really need antibiotics? by the Australian Commission on Safety and Quality in Health Care

Decision Cards

Decision Cards focus on informing the patient through comparing the available options with each other. During this comparison they list harms and benefits, or positives and negatives of each option, as well as any other possible factors that might be important for the specific illness or treatment option. The cards also contain some form of information about the treated illness beyond the harms and benefits of the treatment options.

The decision cards by Alliance Health (Figure 5) [24] are representative of this type of decision tool, as well as the decision aid for rheumatoid arthritis developed by Barton et al. [25] (Figure 6) and the 'Medication Choice Diabetes' tables by Care That Fits [26] (Figure 7).

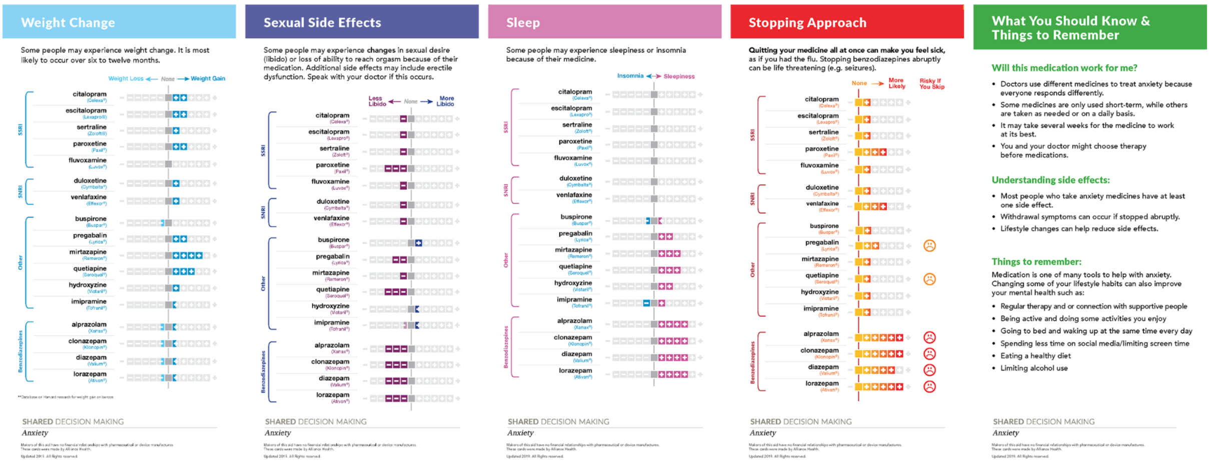


Figure 5: shared decision-making Aid Cards Anxiety by Alliance Health

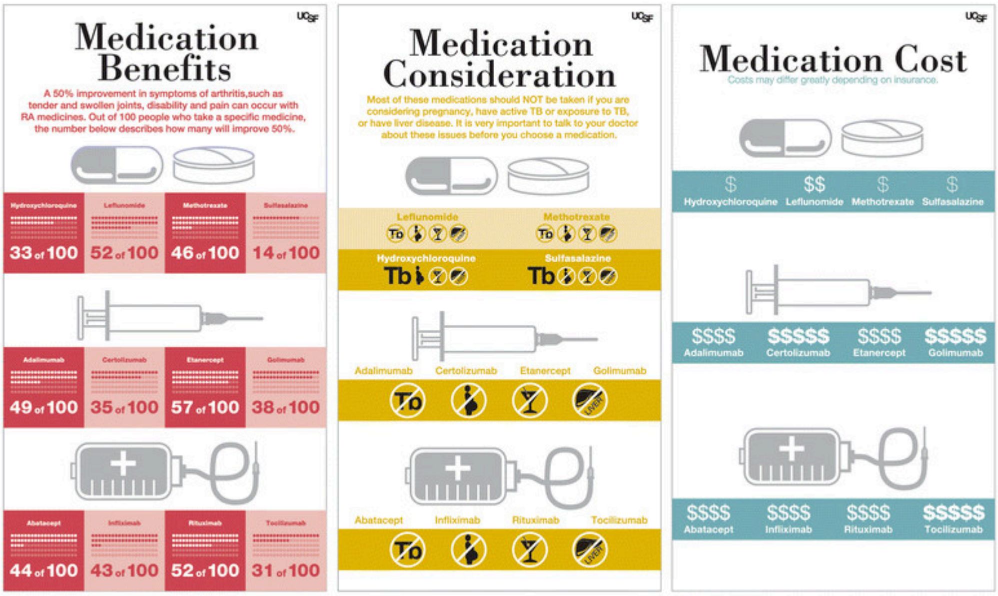
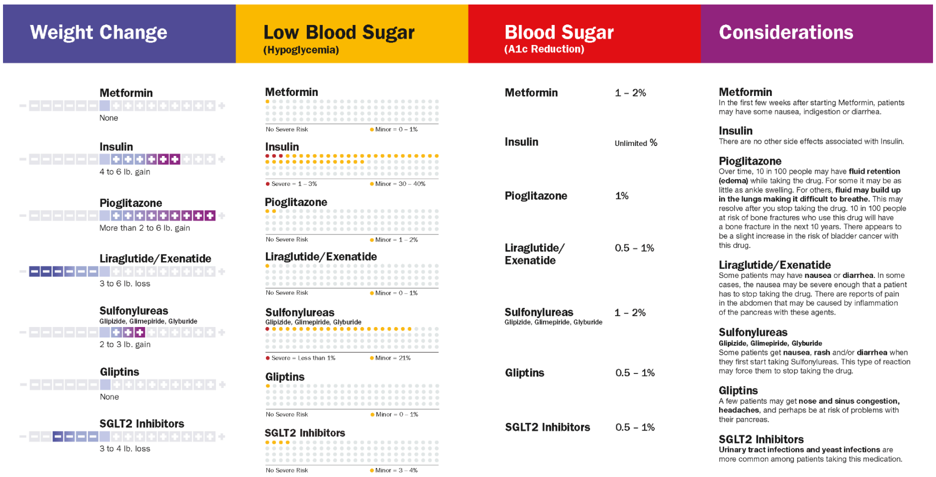


Figure 6: Decision Aid for Rheumatoid Arthritis by Barton et al. [25]



Weight Change	Low Blood Sugar (Hypoglycemia)	Blood Sugar (A1c Reduction)	Considerations
Metformin None	**Metformin** No Severe Risk ● Minor = 0 – 1%	**Metformin** 1 – 2%	**Metformin** In the first few weeks after starting Metformin, patients may have some nausea, indigestion or diarrhea.
Insulin 4 to 6 lb. gain	**Insulin** ● Severe = 1 – 3% ● Minor = 30 – 40%	**Insulin** Unlimited %	**Insulin** There are no other side effects associated with Insulin.
Pioglitazone More than 2 to 6 lb. gain	**Pioglitazone** No Severe Risk ● Minor = 1 – 2%	**Pioglitazone** 1%	**Pioglitazone** Over time, 10 in 100 people may have **fluid retention (edema)** while taking the drug. For some it may be as little as ankle swelling. For others, **fluid may build up in the lungs making it difficult to breathe.** This may resolve after you stop taking the drug. 10 in 100 people at risk of bone fractures who use this drug will have a bone fracture in the next 10 years. There appears to be a slight increase in the risk of bladder cancer with this drug.
Liraglutide/Exenatide 3 to 6 lb. loss	**Liraglutide/Exenatide** No Severe Risk ● Minor = 0 – 1%	**Liraglutide/ Exenatide** 0.5 – 1%	**Liraglutide/Exenatide** Some patients may have **nausea** or **diarrhea**. In some cases, the nausea may be severe enough that a patient has to stop taking the drug. There are reports of pain in the abdomen that may be caused by inflammation of the pancreas with these agents.
Sulfonylureas Glipizide, Glimepiride, Glyburide 2 to 3 lb. gain	**Sulfonylureas** Glipizide, Glimepiride, Glyburide ● Severe = Less than 1% ● Minor = 21%	**Sulfonylureas** 1 – 2% Glipizide, Glimepiride, Glyburide	**Sulfonylureas** **Glipizide, Glimepiride, Glyburide** Some patients get **nausea**, **rash** and/or **diarrhea** when they first start taking Sulfonylureas. This type of reaction may force them to stop taking the drug.
Gliptins None	**Gliptins** No Severe Risk ● Minor = 0 – 1%	**Gliptins** 0.5 – 1%	**Gliptins** A few patients may get **nose and sinus congestion, headaches**, and perhaps be at risk of problems with their pancreas.
SGLT2 Inhibitors 3 to 4 lb. loss	**SGLT2 Inhibitors** No Severe Risk ● Minor = 3 – 4%	**SGLT2 Inhibitors** 0.5 – 1%	**SGLT2 Inhibitors** **Urinary tract infections and yeast infections** are more common among patients taking this medication.

Figure 7: Medication Choice Diabetes Tables by Care That Fits

Chapter 3 – Methods and Techniques

3.1 Methods

The methods used within this project have all been introduced over the past 2.5 years of following the Creative Technology bachelor; they are further elaborated upon in reference to external sources.

Literature Review

Part of the background research was a literature review which focused on decision tools and shared decision-making. The goal was to compare and analyse existing literature about the main topics of this bachelor's thesis and create a list of requirements that are important for decision tools to fulfil. Based on this, a more goal-oriented ideation and design process was derived.

PACA Analysis

The PACA Analysis – People, Activities, Context, Artefacts – is used to summarise and clarify the target group and surrounding circumstances for the to be developed tool in order to guide ideation [57]. The previous background research, as well as expert interviews, and client interviews are used to draw up the four different elements of the PACA analysis. The end goal is to create a better overview of all the circumstances that should be considered during later steps of ideation. People focus on the users of the product, their physical and mental abilities, their social surroundings and status. Each user requires different kinds of aspects in order to engage with the product. Activities are about what the tool is being used for, which in the case of this project is consultation between patient and healthcare professional. Context describes the surroundings of where the product will be used, locations can include at home, in an open space, or inside a clinic. Lastly Artefacts are the ways the users interact with a product, for example by touching it, throwing around, listening to sound, or reading text.

Personas

A persona is a fictional character which incorporates aspects of real life users involved with the product that is being developed [40]. They are used to better outline and understand the needs of the involved target audience and to establish a baseline regarding the requirements for the product. Personas can vary in depth, from just demographic data to fully developed daily routines and background stories.

Mind Mapping

Mind Mapping is a brainstorming method which focuses on generating ideas surrounding one central topic [41]. After the initial brainstorming session which generates ideas directly related to the main topic, further ideas are explored revolving around the ideas of the first step. This way a wide net of related ideas that can branch out into different directions that in turn can be used for further brainstorming and ideation.

Rapid Ideation

During rapid ideation a time limit is set during which as many ideas as possible are being generated and written down. After the time limit runs out, all ideas are brought together, organised, and reviewed in order to find the most viable ideas. All ideas are viable during the brainstorming process no matter how out-there they might be or how viable it would be to realise them. This way the creative process is enhanced due to the lack of limitations and, the time limit and sheer amount of created ideas as well as the reduced risk of getting attached to one specific idea [39]. For this project, rapid ideation was used as the second brainstorming step after the mind mapping brainstorming.

MOScOW Method

To formulate and prioritise requirements for the decision tool, the MOSCoW method was used, which divides requirements into must, should, could and won't requirements [42]. Must requirements need to be part of the tool in order for it to have been successfully realised. Should and could requirements are requirements that are important for the tool's further functionality but not necessarily needed; could requirements take a lower priority than should requirements. Won't requirements are requirements that are not needed for the usability of the tool or viable to be completed within the time frame of the project. These requirements are then further classified into functional and non-functional requirements indicated with (F) or (NF). Functional requirements are requirements that affect how the tool can be used, so requirements which affect its functionality. Non-functional requirements are affected by the functional requirements and describe what should be achieved by using the tool.

Prototyping

As part of the realisation, prototyping was utilised to create a product that could be tested and evaluated. Prototyping was hereby split into two distinct parts, namely, low-fidelity prototyping and high-fidelity prototyping. Low-fidelity prototypes are used to outline and further define the design of a product by creating very low time and money investment versions of the product which can be freely changed and adjusted until a design is found that fits the needed criterias [51]. High-fidelity prototypes are prototypes closely resembling the final product which can then be used during evaluation and then further improved upon afterwards [52]. As part of the rapid prototyping in the specification step, several low-fidelity prototypes were made to test design functionalities without committing to any large cost or time investment. Based on these low-fidelity prototypes design changes were made and a new low-fidelity prototype was created. During the second part as part of Specification, a high-fidelity prototype was developed, which in its design and feel resembles the final product as closely as possible. This high-fidelity prototype then gets used during evaluation.

Prototype Testing

Prototype testing allows for validating and improving the design and functionalities of a product. In the case of this graduation project this means validating whether the design choices made help facilitate shared decision-making, and whether the design of the cards are received positively by the users. The testing allows to determine if the tool was successful and what kind of improvements can be made in order to better fulfil the requirements.

System Usability Scale

The System Usability Scale (SUS) is a likert scale developed by John Brooke [43] to evaluate digital user interfaces. It consists of 10 statements which the user rates on a likert scale from 1 to 5 in terms of Strongly Disagreeing (= 1) to Strongly Agreeing (= 5). The statements iterate between positive and negative statements about the prototype. Afterwards the 10 answers get calculated with a formula by removing 1 from the score of all odd numbered questions, and subtracting the score of all even numbered questions from 5. After adding all 10 numbers together, the sum gets calculated by 2.5 to determine the SUS score. A result between 55 and 75 is a good result and expected of a usable prototype, anything above means it is an excellent prototype performing above expectations and anything below indicates that the prototype is not yet usable and features need to be changed.

For this project the SUS scale was adapted to fit the context of the paper-based tool. In addition, the structure of positive and negative statements was changed to a positive-statements-only structure, to allow for a more focused user interview which was conducted on the basis of the 10 SUS statements.

Figure 8: Example SUS score graph

User Evaluation

To evaluate the functionality of the tool after prototyping, user evaluation was used to get feedback and gain insight into the strength and weaknesses of the tool. Users were invited to take part in a prototype evaluation, with the meeting split into around 15 minutes of test use, and then a 10 minute interview with the test user. To structure the interview a System Usability Scale was used which is a specialised likert scale that allows the feedback to be quantified into numbers so that it can be more closely analysed.

3.2 Techniques

The main design technique that is going to be used is the CreaTe Design Cycle, as defined by Anelika Mader and Wouter Eggink [29]. The process hereby will start with the Ideation Phase which first identifies the user and stakeholder requirements through the use of expert interviews, sketches, storyboarding, and mockups. This is paired with defining the technology that can be used for the solving of these problems. Followed by this are several iterations of design ideas which focus on the product aspects of experience, interaction, service, and business-focused solutions.

- **Experience** describes the way the product is used and the steps that happen while using the product, as well as the overall process of using the product with all its visual, haptical, and interactable components.

- **Interaction** refers to the way the product interacts and communicates with the user, be it through pressing buttons, showing information on a screen, or other kinds of feedback.
- **Service** focuses on the tasks the product needs to fulfil.
- **Business** relates to the sector (education, healthcare, etc.) this product is aimed towards, which defines further specifications that are needed for the product.

The second step of the CreaTe cycle is to find specifications, to further define and outline the product design. At this point, a focus will be placed on how the product should behave. These specifications aim to define the same aspects of the product as in the ideation step, namely: experience, interaction, service, and business.
The third step is the Realisation. Here all separate parts that have been created and iterated in the design phase will be put together and integrated into one unified product.
In the end, the product is evaluated based on the requirements defined in the previous steps and then iterated to create a better product that is based on identified strengths and shortcomings.

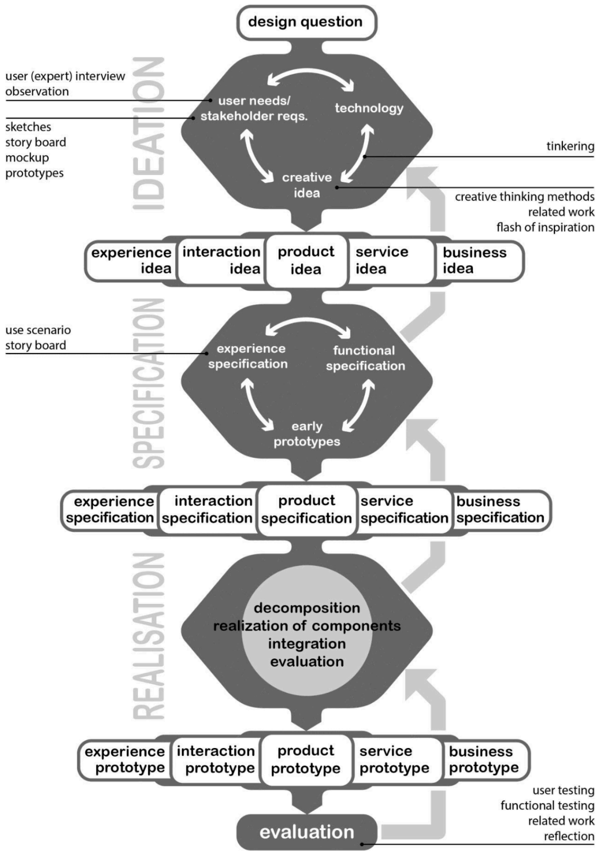


Figure 1. A Creative Technology Design Process

EPDE2014/209

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Figure 9: CreaTe Design Cycle

Chapter 4 – Ideation

The goal of this bachelor's project is to design and develop an interactive paper-based shared decision-making tool for healthcare professionals and patients with COPD and comorbidities. The general context for the decision tool is a shared decision-making session between patient and healthcare professional; it is aimed at assisting both parties in creating a treatment plan for the patient. The tool should also consider digital patient data to be available for healthcare professionals which they can utilise to identify possible treatment options and steps for the patient. To help the ideation process, a PACA analysis has been conducted, furthermore personas were created. These preliminary steps were completed prior to two brainstorming sessions, which then resulted in the development of the final idea.

4.1 PACA Analysis

The aim of this PACA analysis is to further summarise and outline the requirements for the design of the decision tool. The knowledge about the PACA-elements, namely, people, activities, context, and artefacts, is gathered through the analysis of the background research in chapter 2 as well as discussions with the project supervisor Roswita Vaseur.

People

Based on the core of shared decision-making, the people involved are the patients with COPD and comorbidities as well as the healthcare professionals. Both need a different focus in the design.

For patients it is important that they are informed about their treatment options by receiving an overview of the possibilities they have. At the same time, patients also need to contemplate and think about these options during the shared decision-making session. Furthermore, the tool needs to assist patients in goal finding and setting. It should be assumed that most patients are not fully or at all educated about their illness; this should be taken into account when considering which information should be provided.

Healthcare professionals need to be assisted by the tool to convey information during SDM. Here it is important that the tool does not have the ability to replace the HCP in terms of providing enough information to the patient. In addition, the time needed to use the tool is relevant for the HCP, thus time investment should be part of the design considerations. Moreover, the tool should assist the healthcare professional with structuring the shared decision-making process; this should happen through the inherent structure given by the interaction flow of the tool itself.

A need that applies for both patient and HCP is the need to create a treatment plan at the end of the SDM process.

Activities

The main activities of the decision tool is to guide and assist a shared decision-making session by providing information and suggesting a structure for the session. To do so it should visualise and describe options to the patient and through use of colours or numbers communicate to the healthcare professional how to proceed to the next step. The tool should be easy to understand and use, without needing a thorough explanation for healthcare professionals on how to use the tool. The activities should aim at involving at least two people, with the option for additional participants if the patient relies on a third party to make decisions or take actions. In addition the activities should also consider cultural or religious limitations, avoiding any direct conflict or contradictions. One of the activity objectives should be to find a goal for the patient in order to structure their treatment plan around this defined goal.

Context

The environment of the shared decision-making session is the hospital room or practice of the healthcare professional. The space required to use the tool should be no bigger than a table, and if possible the tool should be able to be used without any table or surface to place it on. Another important factor of the surrounding environment is the time restriction of consultation sessions; this means that the tool should not take long to use or get results from, so HCPs are not limited by the tool. Additionally, the tool should communicate comprehensively what is expected of the healthcare professional and the patient with the aid of visuals and comprehensive text. The tool should also be easily distributable in order to facilitate its integration.

Artefacts

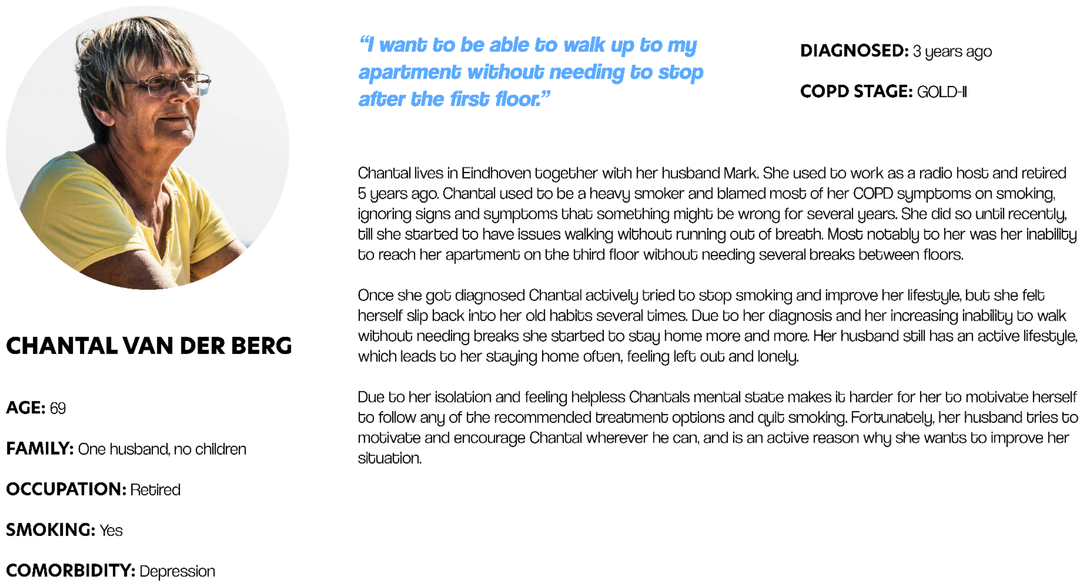
The main interaction with the tool will be physical due to it being made out of paper. This means that the tool can be moved and placed around, passed back and forth between users, and picked up to inspect closer or to view it from close up. The paper-based nature of the tool allows for the freedom of it to be arranged in a visual or understandable formation. Paper-based also means that the tool can be designed to be easily distributed without the need for any effort from healthcare professionals besides a printer to print out the tool, and maybe scissors or something comparable to cut out shapes, or cards, or other forms the tool might have.

Another artefact of the tool will be visuals. Colours, images, and text can be used to communicate different choices and aspects to be considered. One consideration to make is how important colours should be in case the tool can only be printed in black and white.

As part of RE-SAMPLE, the available digital data should be factored into the design consideration, be it by directly integrating data into the tool, or for the tool to refer to the available digital data and make suggestions on how to adjust the tool-use based on the data.

4.2 Personas

Personas help to organise and structure what can be expected from the target group and users. For this purpose, 4 patient personas and 2 healthcare professional personas were developed. These personas encompass the general demographic of the users, as well as their medical history, and general life involving COPD. To get into the mindset of goal setting, each persona also has their own personal goal they want to achieve in the treatment of COPD.



"I want to be able to walk up to my apartment without needing to stop after the first floor."

DIAGNOSED: 3 years ago

COPD STAGE: GOLD-II

Chantal lives in Eindhoven together with her husband Mark. She used to work as a radio host and retired 5 years ago. Chantal used to be a heavy smoker and blamed most of her COPD symptoms on smoking, ignoring signs and symptoms that something might be wrong for several years. She did so until recently, till she started to have issues walking without running out of breath. Most notably to her was her inability to reach her apartment on the third floor without needing several breaks between floors.

Once she got diagnosed Chantal actively tried to stop smoking and improve her lifestyle, but she felt herself slip back into her old habits several times. Due to her diagnosis and her increasing inability to walk without needing breaks she started to stay home more and more. Her husband still has an active lifestyle, which leads to her staying home often, feeling left out and lonely.

Due to her isolation and feeling helpless Chantals mental state makes it harder for her to motivate herself to follow any of the recommended treatment options and quit smoking. Fortunately, her husband tries to motivate and encourage Chantal wherever he can, and is an active reason why she wants to improve her situation.

CHANTAL VAN DER BERG

AGE: 69

FAMILY: One husband, no children

OCCUPATION: Retired

SMOKING: Yes

COMORBIDITY: Depression

Figure 10: Patient Persona 1; Chantal van der Berg

"I want restful sleep, and to enjoy nature again."

DIAGNOSED: 3 years ago

COPD STAGE: GOLD-III

Alfred is a 63 year old former teacher. He worked with children of all ages and found a lot of joy in teaching and school work. After his COPD diagnosis three years ago, on top of his already existing high blood pressure he was forced into early retirement. Alfred tries to balance his two illnesses but struggles to do so.

His COPD leaves him without energy throughout the day, and makes it hard for Alfred to move and be active. His high hypertension requires him to be more active however, so Alfred feels a constant worry and pressure to do something without being able to. This stress on top of his two conditions causes him sleeplessness bordering insomnia and to overeat at times.

One thing Alfred is proud of, is quitting smoking almost 5 years ago even before he was diagnosed with COPD. For Alfred getting better starts with restful sleep and going on walks. He wants to be able to enjoy his retirement without worrying about COPD or high blood pressure. To do so he has tried alternative ways to medication and recommended treatment, trying out meditation to calm himself and relax.

ALFRED TUCK

AGE: 63

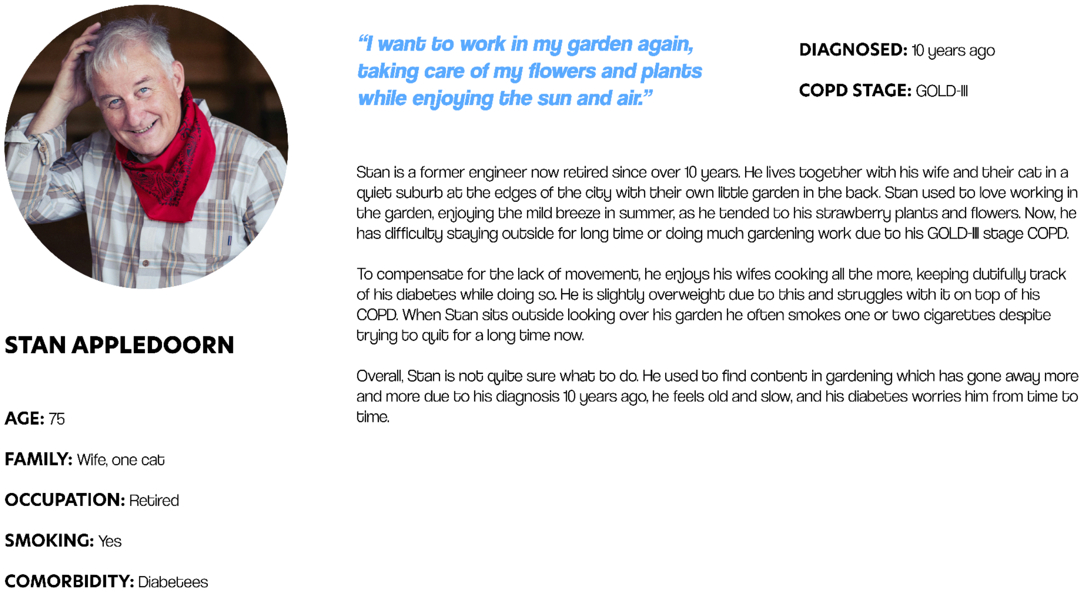
FAMILY: None

OCCUPATION: Retired

SMOKING: Yes

COMORBIDITY: Arterial Hypertension, symptoms of Insomnia

Figure 11: Patient Persona 2; Alfred Tuck



"I want to work in my garden again, taking care of my flowers and plants while enjoying the sun and air."

DIAGNOSED: 10 years ago

COPD STAGE: GOLD-III

Stan is a former engineer now retired since over 10 years. He lives together with his wife and their cat in a quiet suburb at the edges of the city with their own little garden in the back. Stan used to love working in the garden, enjoying the mild breeze in summer, as he tended to his strawberry plants and flowers. Now, he has difficulty staying outside for long time or doing much gardening work due to his GOLD-III stage COPD.

To compensate for the lack of movement, he enjoys his wifes cooking all the more, keeping dutifully track of his diabetes while doing so. He is slightly overweight due to this and struggles with it on top of his COPD. When Stan sits outside looking over his garden he often smokes one or two cigarettes despite trying to quit for a long time now.

Overall, Stan is not quite sure what to do. He used to find content in gardening which has gone away more and more due to his diagnosis 10 years ago, he feels old and slow, and his diabetes worries him from time to time.

STAN APPLEDOORN

AGE: 75

FAMILY: Wife, one cat

OCCUPATION: Retired

SMOKING: Yes

COMORBIDITY: Diabetees

Figure 12: Patient Persona 3; Stan Appledoorn

"I want to be able to freely and without pain walk around and meet my friends."

DIAGNOSED: 12 years ago

COPD STAGE: GOLD-III

Eva lives alone in a nursing home near the centre of Oslo. She has one daughter and one son who visit her semi-regularly. Other than that she has a few friends in the nursing home and gets along well with her caretakers. Eva has COPD stage GOLD-III and she has regular issues with her exacerbations. She has chronic pain and suffers from insomnia due to that.

Eva does not smoke anymore, she was able to quit the habit 2 years into her COPD diagnosis. She struggles with getting any workout or movement done, oftentimes feeling so weak that she needs to be moved around in a wheelchair. She does try to move and build up strength with workout, but she struggles to see the goal of it all and her efforts are less than enthusiastic.

Eva used to put a lot of effort into her treatment but as her age and illness progressed her enthusiasm went down more and more. Her hope is to be able to walk on her own, without the need for assistance from someone else. However, what she needs is motivation.

EVA NAK

AGE: 78

FAMILY: Widow

OCCUPATION: Retired

SMOKING: No

COMORBIDITY: Chronic pain and insomnia

Figure 13: Patient Persona 4; Eva Nak

"I want my patients to be able to live their life the way they wish to and assist them in understanding and managing their illness. "

Pier Vossen is in his final year of becoming a pneumologist, finishing his education at a bigger public hospital in Berlin. He has been working with patients that have COPD for a couple years now, and notices the increased need of understanding and treating such patients.

He wants to help patients with COPD understand their illness and help them approach it in a comfortable way. While he has work experience, he does notice the difference to his colleagues that have been working for 10 years or more, and wants to meet the same standards they do in consulting their patients.

PIER VOSSEN

AGE: 34

FAMILY: Single

OCCUPATION: Pneumologist

WORK EXPERIENCE: 8 years

Figure 14: HCP Persona 1; Pier Vossen

"I want to better help my patients visualise and find their ideal workout and treatment, and make sure they are confident in achieving it."

Natalie has been working with patients for close to 25 years now. Her general approach is to help her patients find a goal they want to reach, and help them get there. She tries to get them motivated with suggestions and examples, but feels like many of her COPD patients struggle with that.

She has a lot of experience with treating patients with COPD, and has a nack for figuring out the best possible treatment for them, but the motivation barrier of her patients makes her wonder if there is an alternative approach to consultation beyond discussing and talking.

NATALIE KEIL

AGE: 52

OCCUPATION: Physiotherapist

WORK EXPERIENCE: 25 years

Figure 15: HCP Persona 2; Natalie Keil

4.3 Brainstorming

The Brainstorming process was split into two parts and took place on paper, in order to collect ideas easier and add small scratches and doodles to the ideas to further flash them out.

4.3.1 Brainstorming Session One: Shapes and Forms of Paper - Mindmapping

The first half was focused on creating an overview of possible forms paper can take, ways of how paper can be used, and alternative forms for physical interaction. The goal hereby was to guide the second half of the brainstorming process through outlining potential options for ideas in the first half. This brainstorming was based on the mind mapping brainstorming approach, limited to the first step of just finding related ideas to the topic of "paper-based", with a side topic of "alternatives to paper".

The ideas were written onto paper with small illustrations next to them, to help the visualisation process during brainstorming. Afterwards these ideas were ordered and arranged into a mind map.

The first brainstorming session resulted in 10 possible shapes for paper, 6 ways of how to use paper, and 4 alternatives to paper.

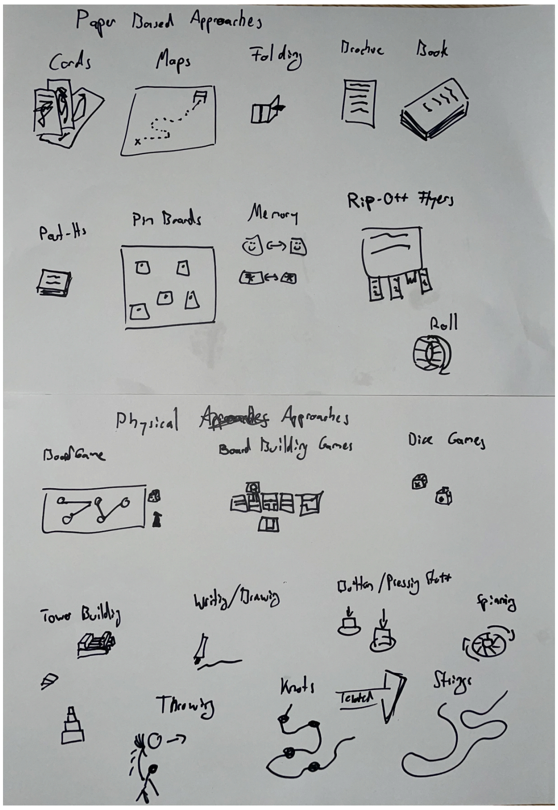


Figure 16: Brainstorming Session One; Ideas and Illustrations

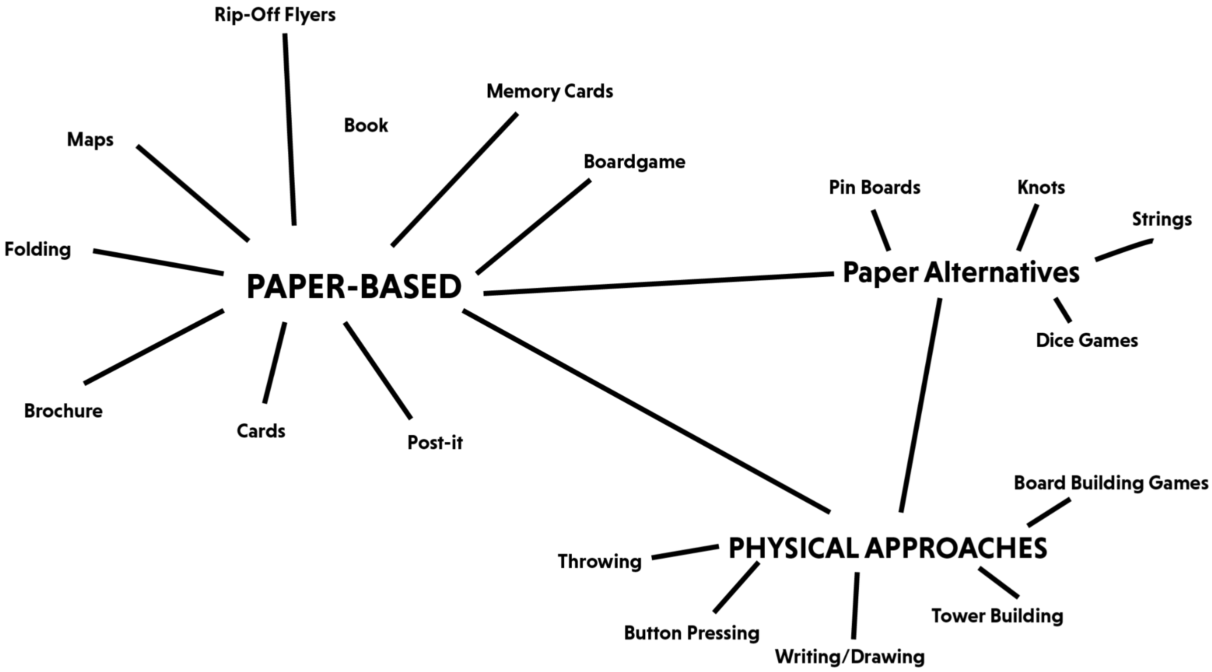


Figure 17: Brainstorming Session One; Mind Mapping

	Shapes	Uses	Alternatives
1	Cards	Tower Building	Pinboard
2	Maps	Writing/Drawing	Dice
3	Brochure	Pressing	Knots
4	Book/Booklet	Folding	Strings
5	Post-Its	Throwing	
6	Memory Cards	Spinning	
7	Rip-Off Flyers		
8	Board Game		
9	Board Building (Card)Game		
10	Paper Roll		

Table 2: Brainstorming Session One; Mind Mapping

4.3.2 Brainstorming Session Two: 50 Ideas - Rapid Ideation

The second brainstorming session focused on actual idea finding with assistance of the mind map created in the previous brainstorming session using the rapid ideation approach. As part of this approach not all of the 50 ideas had to be viable options, and the goal was to just freely come up with possible solutions. The session was split into two 15 minute ideation sessions. In the end, these solutions were compared with each other to find the ideas with the most potential and then combine them into one idea if possible. Another advantage of coming up with so many alternative ideas is that each idea has a potential to contain an important aspect to incorporate later on. Partial inspiration was taken from existing games, past experiences, and methods of how paper is used. All ideas were found by the researcher themselves without joining a brainstorming group consisting of other students. All 50 ideas were written onto paper and accompanied by small sketches to help outline and clarify the idea. All 50 ideas can be found at full size in Appendix B.

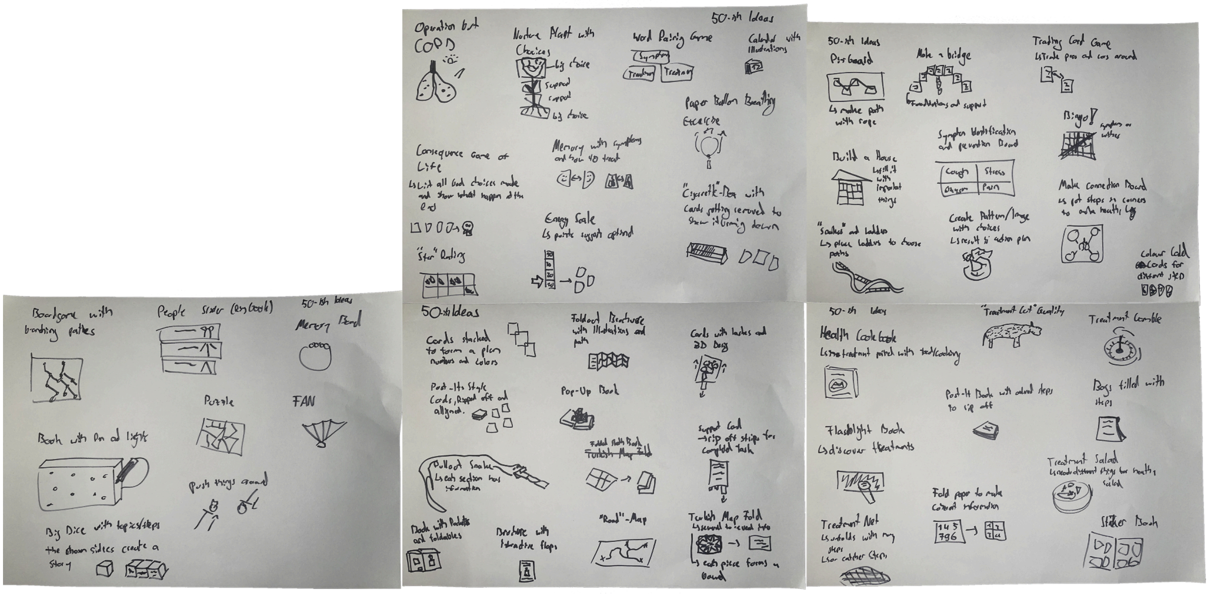


Figure 18: Brainstorming Session 2; 50 Ideas

After the rapid ideation session, the four most viable options were chosen and then compared with each other to find the final idea.

Idea 1: **Cigarette Box with treatment cards**
Each removed card burns down the cigarette highlighting the importance of progressing treatment. The focus hereby would be specifically on people with COPD who are still smoking, which specifically in Europe is the main cause for COPD [15].

Idea 2: **Rip-Off Support Flyers**
This idea is about providing the patient with treatment options and if the option was done, they get to rip off one part from the bottom of the flyer. When all parts are ripped off, the treatment step was successfully completed.

Idea 3: **Cards creating a treatment plan through aligning the cards**
Through the use of cards containing treatment options a step by step treatment plan can be created with interlinking cards, based on the discussion between healthcare professional and patient and the choices for treatment options made by the patient.

Idea 4: **Make a bridge**
Using cards or building blocks, a treatment bridge gets built, with foundations consisting of needed requirements and treatment steps that build the *foundation* of the patient's improved health. Stacked on top are the steps following after the foundation has been successfully established.

Out of the four ideas, idea 1 has the strongest symbolic force attached to it. However, due to the focus on patients who are still smoking a large part of the COPD patients is left out. With the goal of creating a general tool this option was not a viable option for this thesis. In comparison, the rip-off flyers are the most generally applicable idea as they would be able to fulfil the requirements needed for a decision tool, but they would also be the least interesting or new approach to a decision tool. This idea would just result in a stack of flyers with text written on them. Idea 4 and Idea 3 incorporate the idea of creating a treatment plan the best where both are focused on connecting steps in order to build a treatment for the patient. Idea 3 allows for more freedom in doing so, and offers a more versatile medium in the way the cards get combined. This way the patient has a bigger choice in how they want to visualise their treatment plan, and by using standard card layouts the HCP can organise the cards in a visually comprehensive way. The bridge approach works in a similar manner, but has a more boxed-in, predetermined design in the form of foundation cards and follow-up cards. Ultimately, the freedom of aligning cards and choosing options based on patient preference seemed like the more worthwhile approach; therefore,idea 3 was selected.

4.4 Final Concept

The most promising idea is a card-based approach. Cards are inherently interactive, they have the ability to be placed and ordered on any flat surface, they can be easily held in the hand, passed around between users, as well as be stored compactly. If required they can also be quickly printed and cut out making them easily accessible. Cards are also a tool which almost everyone already knows and has some basic understanding on how to interact with. The familiar shape might also help the users to understand the tool more easily.

The cards should not contain too much information and should instead focus on important keywords or inputs and should be mostly visual. The visual design can utilise colours, as well as images to bring a topic closer to the patient, be it goals, or treatment options. This also helps the healthcare professional to control the flow of the meeting as well as not have the focus taken away from them.

The imagined process of this idea is that each potential treatment goal has its own colour assigned to it to associate followup cards with this goal.
A session using these cards would start by the patient and the healthcare professional discussing the possible treatment goals the patient might have, with one being chosen at the end of the first step. In a second step, this coloured treatment goal will have several followup cards which describe treatment options as well as side goals, which also get discussed and concluded with one card being selected. This process can be repeated several times to create a treatment plan which the patient feels confident in following. The general approach hereby follows the natural flow of a shared decision-making process, and helps this process to take shape and be utilised by the healthcare professional and patient.

In addition, the cards being colour coded means that if one of the goals does not fit a patient, the healthcare professional can take the entire stack out beforehand. This can be used in addition to a digital tool, which visualises and highlights relevant patient data.

In summary, the card-based tool helps patients and healthcare professionals to set goals for the patient as well as to create a treatment plan by establishing a shared decision-making environment through its use design.

Other elements that could be incorporated are physical reminders like a pearl bracelet, or reward systems like “Job Well Done” stickers or pins, which get collected by completing one of the tasks or goals set with the card tool.

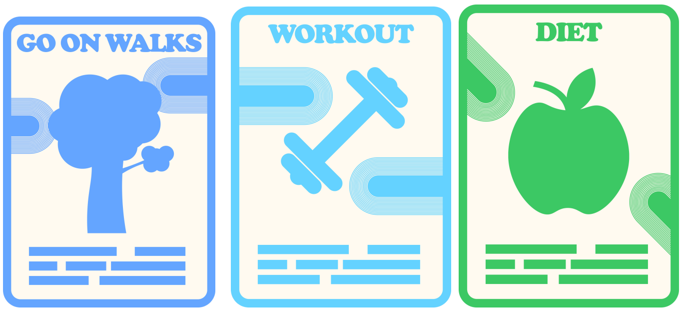


Figure 19: Concept Card Designs

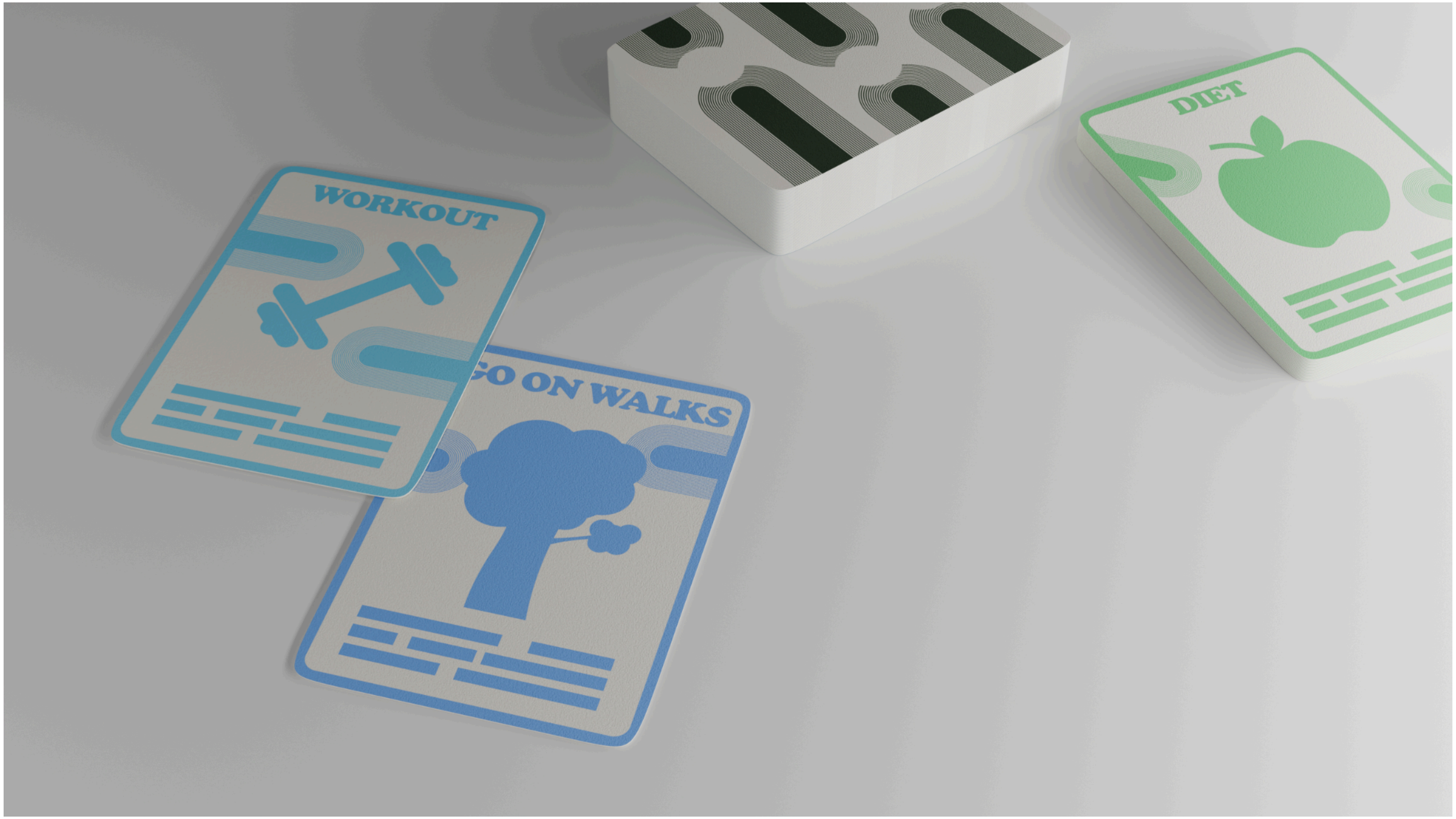


Figure 20: Final Idea Concept 3D-Render

Chapter 5 – Specification

In order to facilitate shared decision-making, the tool needs to fulfil several requirements in order to do so effectively. The tool needs to help the patient find long-term goals for their treatment and help them reach this goal by creating a treatment plan. This treatment plan does not need to be part of the tool itself, but the tool should assist its creation. This means that the decision tool needs to contain information about the different treatment options available to the patient in a structure that also allows the healthcare professional to talk about and explain the treatment options themselves as well as the approach. The tool also needs to allow the patient to compare these options with each other. In this card-based approach this can be realised by placing cards containing different treatments next to each other or arranging several cards with treatment options in a manner that is understandable for the patient. To help the goal setting process, the card-based tool needs to organise the areas in which a patient can find their goal into understandable categories. Furthermore, the tool should allow for the goals that the patient and healthcare professional decide on to be written down. Subsequently, to ensure usability, the decision tool also needs to explain its functions and content to the users, primarily the healthcare professional who will direct the use of this tool. The focus of the instructions should be on the healthcare professional, to avoid the pitfall described in chapter 2 of designing a decision tool to be used without the presence and support of a HCP.

5.1 Requirements

To outline and organise the requirements for the card based decision tool a MOScOW analysis (see chapter 3.1) was conducted, which categorises itself into four parts; requirements that must, should, could, and will not be included. In addition these requirements can be split into functional (F) and non-functional (NF) requirements.Functional requirements are requirements that affect the look and use of the tool. Non-Functional requirements are requirements that the tool should be able to do.

Must requirements describe the required parts and interactions for the cards to work:

- The tool must help establish personal goals for the patient by listing examples to help contemplate their personal goal. (F)
- The tool must help create a treatment plan for the patient by offering a way to set times or patterns for treatment options. (F)
- The tool must include treatment areas like physical health, mental health, or medication adherence. (F)
- The tool must have a variety of different treatment options for each treatment area to allow the patient to choose between them. (F)
- The tool must be able to provide information about treatment options to the patient through the use of information texts or offering patient experience reports. (F)
- The tool must help to compare different treatment options with each other. (F)
- The tool must facilitate a conversation about options and choices between the healthcare professional and the patient. (NF)

- The patient must find a personal goal for their treatment. (NF)
- The patient must understand the contents of the cards and be able to formulate their own choices based on that understanding. (NF)

Should requirements are requirements that should be included in order for the final idea to be fully realised:

- The tool should provide explanation and instructions on how to use it to the HCP by containing instruction texts or checklists. (F)
- The design of the tool should appeal to the users. (NF)
- The tool should organise different areas in a visually comprehensive way. (F)
- The tool should help the HCP to prepare a consultation session with a patient. (NF)
- The illustrations on each card should describe the contents of the card visually and help give an overview. (NF)
- The tool should be usable without extensive prior knowledge or experience with the tool itself. (NF)
- The tool should be usable within a timeframe of a normal consultation session. (NF)

Could requirements are requirements that could be included to further improve the use for the patient and/or the healthcare professional, or to make the cards more appealing to use:

- The tool could include a digital dashboard to note down results of a consultation session. (F)
- The tool could have follow up cards to help the HCP note down results. (F)
- The tool could include a way for the patient to keep track if they followed their treatment plan. (NF)
- The tool could have a box or container for the patient to keep their cards in. (NF)

Won't requirements are requirements that could be implemented, but won't be due to time, technical or budget restrictions:

- The tool won't be developed with a dedicated digital tool.
- The tool won't provide ways to actively track progress or adherence.

Constraints

The design and content of the cards will have a couple of constraints due to the chosen card-based approach. The cards will provide a limited amount of space, so the integration of large explanation texts will rarely be possible or feasible. In comparison to a digital tool, there is a limit on how much external sources can be shown or referenced as the integration of links is restricted to QR codes or writing the links out. It cannot be ensured that the urls will stay active and results in the need for frequent iteration of the tool. This means that as much information as possible needs to stay within the tool itself. Another constraint relates to the content itself: The tool will mostly contain general, research-based treatment options and approaches, it cannot be guaranteed that a healthcare professional will be able to find their usual recommendations and suggested treatment options within the tool.

5.2 System Description

5.2.1 Terminology

Before approaching the details of the system, some new terminology will be introduced and defined in order to create a bridge between the terminology used in the literature and the terminology used by the RE-SAMPLE project.

Domain: A domain describes an area in which the patient can approach their treatment. These areas include but are not limited to physical and mental health, medication adherence, diet, or reducing the risk of hospital admission.

Long-term Goals: Long-term goals describe the goal the patient sets for their treatment within each domain. These goals are not strictly limited to following a certain treatment option, but are more tangible goals set within the day-to-day life of the patient. These goals are something the patient wants to reach to improve their life quality and can be specific to each domain. One example of a long-term goal could be: “Walking up my stairs without running out of breath.”

Side Goals: Side goals are equivalent to treatment options. Treatment options describe options available to the patient in order to improve their health and living conditions with COPD. Within RE-SAMPLE these options are treated as side goals of the patients long-term goal. For example, if their long-term goal is to walk up their stairs without running out of breath, a potential side goal could be: “Going on a 20 minute walk, 2 times a week.” This way, the treatment option is not viewed as a prescription but as something the patient wants to achieve and works towards.

5.2.2 Intended Interaction - How will the cards be used?

Following the three part shared decision-making talk structure as described by Elwyn et al. [11] and combining it with a general preparation step and post-consultation summary step, 3 parts of a consultation session can be described using this card-based decision tool: before, during, and after the consultation session. Using the requirements set in Chapter 5.1, interaction areas with the tool can be defined for each of these parts of the consultation.

Figure 21: Use Flowchart for the Card Based Decision Tool

Before the consultation - Preparation

Before a patient and healthcare professional sit in the same room during a consultation, the tool should enable the HCP to prepare for the coming session. To keep within the constraints of the tool, the tool can provide a checklist of what the healthcare professional might already know regarding the patient. This depends on if the patient has been visiting the HCP for a longer time period or if they are a new patient, this way the HCP can fall back onto previous knowledge if any is available, regarding domains the patient struggles in or should improve in. Another point that can be used to prepare the session and which the decision tool can reference is digital health data that might be available to the healthcare professional. If a dedicated digital tool exists to be used in conjunction with the card based tool, specific data points can be referenced and linked to domains.

For the first step, the decision tool should help organise and pre-arrange the contents of the cards based on the knowledge the HCP has about their patient before the consultation session.

During the consultation - Shared decision-making

Based on the preparation step, the consultation session starts with prepared cards for the patient. These cards are introduced by the healthcare professional: The HCP lets the patient know that they are going to make some decisions during this consultation based on the information provided by the cards and the healthcare professional. Then with the domain card(s) the patient and HCP find a personal goal the patient wants to achieve as the first decision. This is followed by writing the goal(s) down, and followed up by introducing the side goal cards. Here the HCP should introduce these cards by telling the patient that several choices will be made before the options are discussed and compared with each other. The healthcare professional should guide the patient through the cards, and determine the pacing to a degree, but the patient should be given time to read and look at each option at their own pace. Afterwards the patient should decide on the options they would like to pursue, with additional input by the healthcare professional who needs to determine if these choices are able to result in an appropriate treatment, and if needed, suggest additional treatment options to balance the treatment out. Afterwards, the patient takes the cards with the treatment of their choice back home with them in order to be able to re-read the information contained on the cards and remind themselves of the choices that were made and the goals that were set.

If the current consultation session is not the first time the tool is used, part of the consultation should also be about the previously discussed long-term goals and side goals and if the patient was able to achieve them.

The choices within the second step are always accompanied by the structure described by Elwyn et al.[11]. First, the need to make one or several choices is introduced, followed by talking about the different options, and concluded by choosing between the options. These choices are guided by the healthcare professional and assisted by the contents of the cards.

After the consultation - Documentation

Once the consultation session is finished, the healthcare professional should keep track of the shared decisions and choices that were made during the consultation. Which domains were discussed, what long-term goals were chosen, what side goals were chosen? This should ideally happen digitally and not on paper or within the tool itself. There is also a distinction to be made if this was the first session using the decision tool or a repeated use session. For the first session, the previous named points are enough to note down; for a followup session, the HCP should also document if previously set goals were reached and if the patient named any difficulties or successes. The tool can remind the HCP to take these notes, without providing a space on the tool to do so.

The patient's interaction with the tool after the decision revolves around the different cards they chose as their treatment plan. Based on the choices made and the discussion with their HCP, the patient follows the instructions on the cards and tries to achieve the side goals that were set. They then should be able to keep track of their personal progress through noting them down on the cards.

5.2.3 Exemplary Use Case

Using the personas from chapter 4.2, the healthcare professional Natalie Keil has a follow-up meeting with her patient Alfred Tuck. Based on their previous consultation, Natalie and Alfred decided that he should first focus on his medication adherence in order to try and regulate his pain. As a follow-up for this session, Natalie is now preparing the physical activity domain and side goal cards, to talk with Alfred about steps he can take towards improving his physical strength. In addition, she prepares a new personal goal card for Alfred to write his new goal onto. Once Alfred arrives, the two discuss his success with taking his medication at the prescribed amounts to which Alfred says he managed to take it diligently.

Afterwards, Natalie transitions into the introduction to the new domain she would like to focus on with Alfred, presenting the Physical Activity domain by talking about the benefits and reasons why they should approach this domain. Afterwards, she and Alfred go through the example goals of the domain and talk about them until Alfred gets a clear picture of what he would like to use as his personal goal. Alfred misses walks through the forest and going on hikes, so they make this part of his goal: “I want to enjoy nature again.” and write it onto the personal goal card.

Once the goal is found, Natalie places several physical activity side goal cards in front of Alfred which best correlate to his goal, keeping potential motivation and effectiveness in mind while choosing these side goals. Once placed down, each card gets introduced and Alfred is asked which side goal he thinks he is most interested in. This choice is used to start the discussion about the goals, but all placed down cards will be discussed during the consultation. Alfred points out the side goal for “Going For A Walk”. The card gets flipped around, and the back contains several suggestions of where to take a walk as well as for how long these walks should last and how often they should happen. Natalie asks Alfred what he thinks seems most accomplishable to him, and after talking about Alfred’s suggestion and Natalie’s encouragement to go for a bit more intensity, they decide on “20 minute walks to the park, 2 times per week”. They write these choices onto the side goal card and then talk about the other side goals Natalie placed on the table.

Alfred and Natalie decide on two more side goals before the consultation ends. Alfred leaves the consultation with 1 domain card, 3 side goal cards, and a new personal goal card. The previous goal card from the session before Alfred keeps and is told to continue following, in addition to the new physical activities that were set. Natalie notes the choices down into the digital tool she uses in her practice for patient management, and then the consultation with Alfred ends.

5.3 Content - What will the tool look like?

5.3.1 Card Types

Domain Card

Domain cards focus on starting the conversation between healthcare professional and patient about a specific area in which the patient needs to approach treatment in order to improve their health. These cards contain example long-term goals relevant to each domain, as well as motivation texts for the patient to highlight the benefits of approaching this domain. The colour of the domain card also determines the colour of the correlating side goal cards. Possible domains are: Physical Activity, Medication Adherence, Exacerbation Management, Diet, and Mental Health.

Side Goal Card

As follow-up cards to the domain cards, the side goal cards introduce the different treatment options available to the patient. Each domain should have at least four to five side goal cards, with potential for more if applicable. The side goal cards contain different more specific options for each treatment option. For example, a side goal card like ‘Workout’ includes workout suggestions like ‘Upper and Lower Strength Training’, ‘Chair Yoga’, or ‘Joining a sports group’. Due to the limited space on the cards not all options will be listed; therefore the healthcare professional should suggest additional options that are either contained within the tool already as follow up cards, or, by providing options they possess outside of the tool. Another part of the side goal cards is going to be to set time and frequency of the chosen options, in order to create a treatment plan. To allow this, each side goal card will have suggestions concerning the time and frequency for the listed options which the patient and HCP decide together.

Explanation Cards

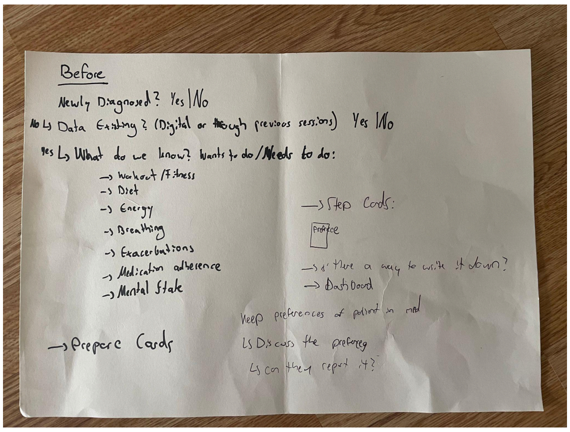
While the domain and side goal cards set the goals and facilitate the setting of the treatment plan for the patient, the explanation cards are purely informative and serve as a recourse to explain options and activities listed on the side goal cards. The explanation cards exist to ensure that the patient can obtain more information about the options they chose, as well as remember the details of these options without the healthcare professional in the same room. In addition for instruction reliant cards like certain workouts, or ways of taking medication, these explanation cards can contain these instructions.

Personal Goal Card

Personal goal cards provide the space for the patient to write down their decided long-term goal. This way there is a written version of it to remind the patient of what they want to achieve. The personal goal card can also contain space to keep track of the patient following along with their side goals. This can happen through stickers, checkmarks, or a calendar in which the patient writes what they did that day.

Instruction Card

The instruction cards are aimed at the healthcare professional and not the patient. While all other cards are used by both, the instruction cards are exclusive to the professional. These cards provide instructions and suggestions on how to approach a shared decision-making session, following the three choice structure[11] as well as instructions on how to use the tool. They provide a checklist and steps for the three steps of before, during, and after the consultation named in chapter 5.2.2.



Before

Newly Diagnosed? Yes | No
No ↳ Data Existing? (Digital or through previous sessions) Yes | No
Yes ↳ What do we know? Wants to do / Needs to do:
→ Workout / Fitness
→ Diet
→ Energy
→ Breathing
→ Exacerbations
→ Medication adherence
→ Mental State

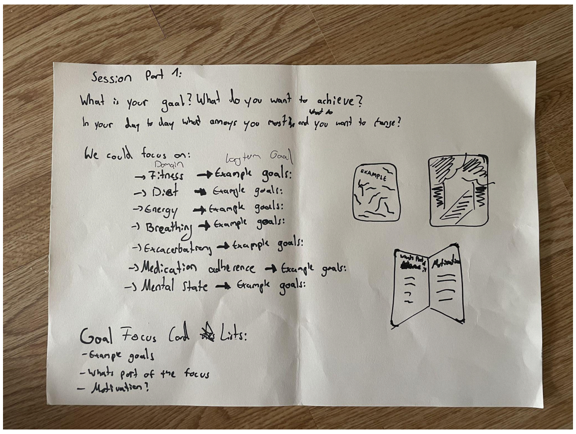
→ Step Cards:

→ is there a way to write it down?
→ Dashboard

Keep preferences of patient in mind
↳ Discuss the preference
↳ can they report it?

→ Prepare Cards

Figure 22: Initial Use Flow and Card Type Ideation; Before

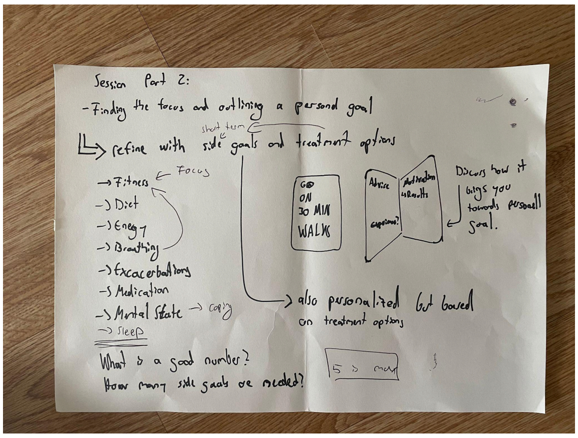


Session Part 1:

What is your goal? What do you want to achieve?
In your day to day what annoys you most and what do you want to change?

We could focus on: long term Goal
Domain
→ Fitness → Example goals:
→ Diet → Example goals:
→ Energy → Example goals:
→ Breathing → Example goals:
→ Exacerbations → Example goals:
→ Medication adherence → Example goals:
→ Mental State → Example goals:

Goal Focus Card ~~&~~ Lists:
- Example goals
- Whats part of the focus
- Motivation?



Session Part 2:
- Finding the focus and outlining a personal goal

↳ refine with short term side goals and treatment options
→ Fitness ← Focus
→ Diet
→ Energy
→ Breathing
→ Exacerbations
→ Medication
→ Mental State → coping
→ Sleep

→ also personalized but based on treatment options

Discuss how it brings you towards personal goal.

What is a good number?
How many side goals are needed?

Figure 23: Initial Use Flow and Card Type Ideation; During Part 1
Figure 24: Initial Use Flow and Card Type Ideation; During Part 2

5.3.2 Appearance

Dimension

To find a suitable size for the cards, commercial card types were compared with each other and evaluated based on the overall size and space for information and instructions. The largest commonly available cards that came to mind were tarot cards with a dimension of 7 cm by 12cm [30]. Based on this size, a couple cutouts were made as very low-fidelity prototypes. Tarot cards felt too thin for the height they had, so the dimensions were increased to 10cm by 15cm which was the size that was ultimately decided on for the cards of the decision tool. This card size was small enough to comfortably be held in one hand, while also providing a lot of space for text and illustrations.

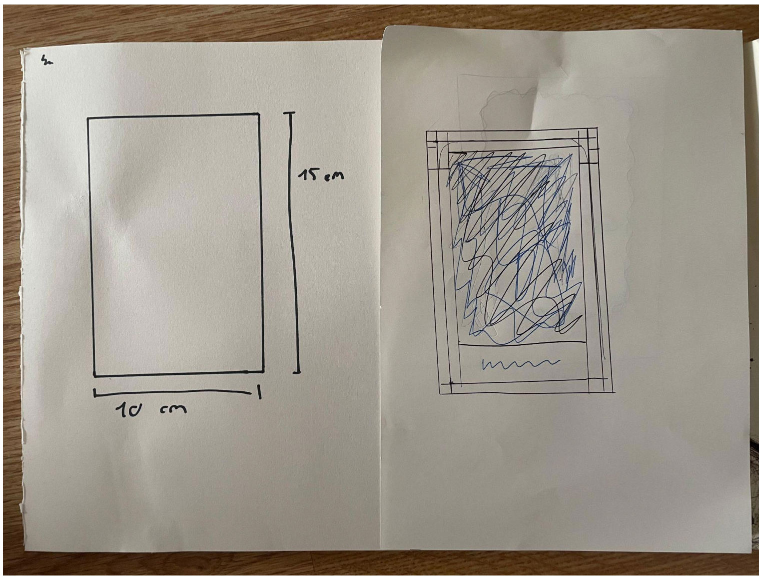


Figure 25: Size and Layout Lo-Fi Prototyping

Font Size

In order to ensure legibility for the patients who are on average aged 40 years and older [15], the font size needs to be large enough to be easily readable. The suggested font size for text is 12pt [31], so no text found on the cards will be smaller than this.

Colours

In order to avoid aggressive colours, the colour scheme of the cards will be kept more muted, with high black and white saturation in the colours.

Visuals

Illustrations were chosen as visuals to allow the users to interpret their own understanding into the images, rather than choosing photographs which would create a too concrete visualisation. The illustrations on the front of the cards incorporate the specific colour assigned to each domain, and represent the core aspect of the content of the card. For example, ‘Workout’ would have an illustration related to workout out, be it dumbbells, a workout mat or a workout machine, and something like ‘Medication Adherence’ would have illustrations of medication on it.

5.4 High Fidelity Prototype Planning

For the high fidelity prototype and in turn the realisation of this project, certain limitations were set to focus the work put into the design of the cards while still ensuring a prototype that is viable for the testing of its ability to create a shared decision-making session. During discussions with this project's supervisor, it was decided to create a core card set of **2** Domain cards, and **4** side goal cards, accompanied by however many cards were needed for instruction and personal goal cards, which ended up being **3** instruction cards, and **1** personal goal card design (see Figure 26).

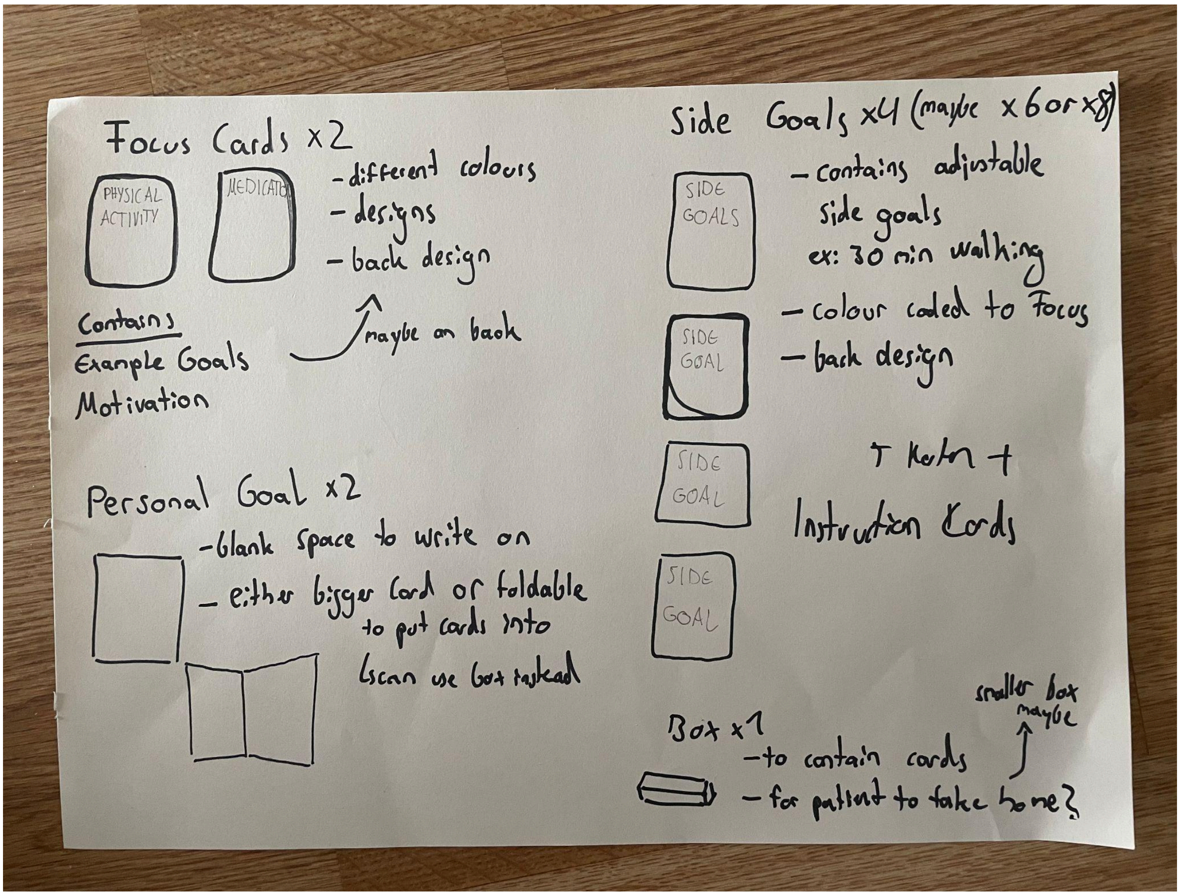


Figure 26: Card Type Planning for the Hi-Fi Prototype Infographic

2 x Domain Cards
The two domains chosen for the hifi prototype are ‘Medication Adherence’ and ‘Physical Activity’. Reasoning behind these two domains is the availability of RE-SAMPLE’s version of their webbades decision tool which has these two areas fully flashed out. This way, the already existing tool could be referenced for content and structure.

4 x Side Goal Cards
The side goal cards all relate to the ‘Physical Activity’ Domain, in order to have a variety of choices for one of the two domains. The focus on physical activity is also based on the suggestion of this project's supervisor, with content taken from both the RE-SAMPLE tool as well as individual research. The four side goal cards will contain information and options about ‘Going for a walk’, ‘Riding your bike’, ‘Workout’, and ‘Gardening’. The suggested treatments on these side goal cards will only include parts of all the possible options

available, in order to start the conversation about the side goal with the HCP having the option to suggest additional options to the patient directly.

3 x Instruction Cards
Three instruction cards were chosen to cover the three-step process of before, during, and after. The contents of these cards are designed as a checklist for the healthcare professional to go through and check based on which step they are discussing and deciding.

1 x Personal Goal Cards
To allow for enough space for the patient to write their goal, the personal goal card will be primarily blank. At the bottom, the personal goal card has space to allow for a side goal tracker in the form of stars; the patient can fill this section out once a side goal was completed. Two versions of personal goal cards were considered, the first version is in line with the rest of the card designs which consist of being a double-sided card; the second form is a foldable card which could also function as storage for the other cards at the end of the consultation session. In the end, the choice fell on the double-sided card, and to replace the storage functionality with a box to store the cards in.

Chapter 6 – Realisation

Figure 27: Printed Hi-Fi Prototype Cards

The current final realisation of the paper-based decision tool is in the form of a high fidelity prototype consisting of 10 cards in total. **2** Domain Cards, **4** Side Goal Cards, **3** Instruction Cards, and **5** Personal Goal Cards. The amount of five personal goal cards was set to allow for five user evaluations. All card designs can be found in full-size in Appendix B on page 87.

Figure 28: Card Type Infographic of the Hi-Fi Prototype

6.1 Card Design Aspects

6.1.1 Fonts

Two fonts are used within the cards. Niveau Grotesk is used for the headlines and titles. This font was chosen due to its symmetric design, while still containing a bit of character with its small edges and curves. It is a big, easily readable sans-serif font. On the card front Niveau Grotesk is used in size 24pt with font-weight Black, while at the back the headlines are kept at 16pt also with font-weight Black.

The body text is written in Zeitung Micro Pro at font-weight Extralight. Zeitung Micro Pro was chosen as the body text font as it is a notably open font with clean and readable character design. The cards use it at size 12pt with a leading of 14pt.

6.1.2 Colours

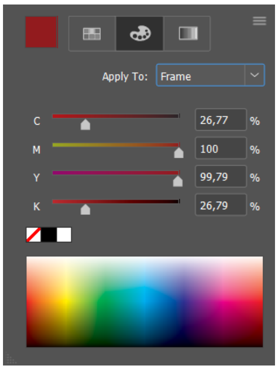
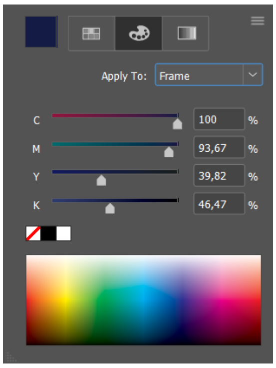
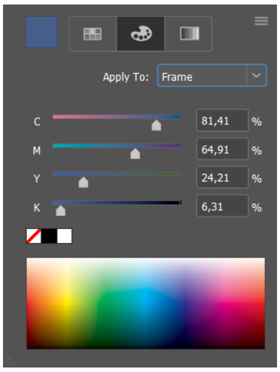
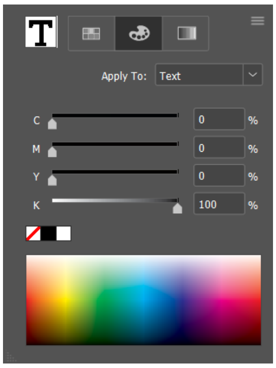
The Physical Activity domain and its side goal cards use a dark red with the colour code #921a1c.	 Apply To: Frame C 26,77 % M 100 % Y 99,79 % K 26,79 %	The Medication Adherence domain uses a dark blue with the colour code #121b45.	 Apply To: Frame C 100 % M 93,67 % Y 39,82 % K 46,47 %
The Personal Goal cards use a light blue with the colour code #465d89.	 Apply To: Frame C 81,41 % M 64,91 % Y 24,21 % K 6,31 %	The Instruction cards use full black with colour code #000000.	 Apply To: Text C 0 % M 0 % Y 0 % K 100 %

Table 3: CMYK Setting for the card colour codes in Adobe InDesign

6.1.2 Domain Cards

The front of the domain cards is fully taken up by the illustration and the title of the domain, with the text, illustration, and card border all kept in the domain specific colour choice. The background of the illustrations is kept white in order to highlight the items that define the domain. The backside is split into 2 parts, the example long-term goals that would fit into the domain, and the motivation text which describes and highlights the benefits of improving and following a long-term goal within this domain.

6.1.3 Side Goal Cards

Side goal cards differentiate themselves visually from their domain cards by having distinct borders between illustration and card title. For the side goal cards, all card names are in black writing at the bottom of the front, with a framed illustration above it. In addition, there is a distinct space between the card border and the rest of the content. The back of the cards are split into three parts. The first part is about the possible options available to the patient, and lists suggestions what could be done within this side goal card. The second part is for setting the treatment plan, how often should the chosen option be done and for how long. The duration and frequency are designed so that the patient or healthcare professional can highlight the chosen times. This second part is also the only part that uses icons to help communicate the contents of it. The third part adds additional information and motivation about the side goal card, highlighting the specific benefits of focusing on this side goal.

6.1.4 Instruction Cards

Currently the instruction cards only contain content on the front of the card, containing checklists and suggestions for the healthcare professional. The backside only has a visual design. The colour black was specifically chosen for the instruction cards to be in contrast to the rest of the cards in this tool and be quickly distinguishable as cards that only the healthcare professional should use.

6.1.5 Personal Goal Cards

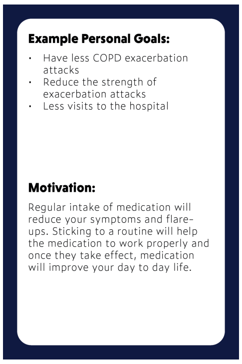
Personal Goal Cards were designed with lots of space for writing in mind and kept very simple and open. In addition they contain a space for the patient to keep track of their achieved side goals.

6.1.6 Print

The cards were printed with a digital print with offset printing quality on an HP Indigo printer on 200mm paper. After printing, the cards were covered in a wrap foil to protect them from wear down and water. During production, green electricity was used to keep the cards as climate friendly as possible.

6.2 High Fidelity Prototype

6.2.1 Domain Cards

	**Example Personal Goals:** • Have less COPD exacerbation attacks • Reduce the strength of exacerbation attacks • Less visits to the hospital **Motivation:** Regular intake of medication will reduce your symptoms and flare-ups. Sticking to a routine will help the medication to work properly and once they take effect, medication will improve your day to day life.	**Purpose and Content** Medication Adherence focuses on goals that are related to exacerbation management. Follow-up cards for side goals would introduce ways on how to keep track of when medication was taken, as well as suggestions for specific kinds of medication depending on the stage and symptoms the patient struggles with. **Colour** Blue was chosen as the domain colour due to its typical association with medicine and doctors,

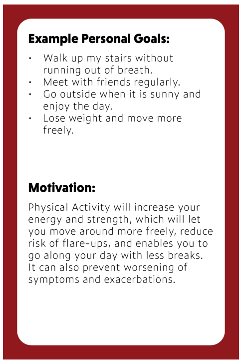
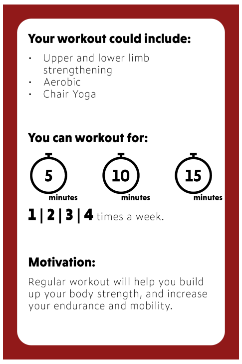
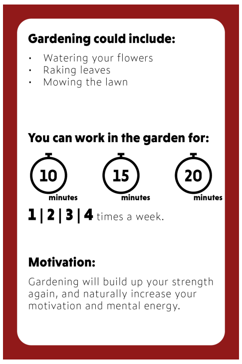
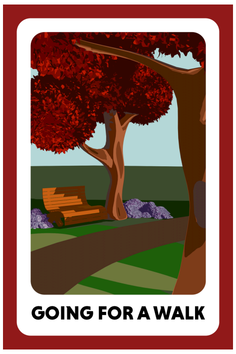
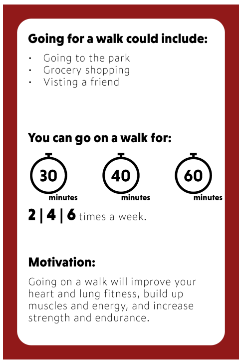
		and the colour being calming [44]. **Illustration** The illustration at the front was kept simple, and includes two possible forms of medication for COPD patients can take, oral medication (left) and inhaled medication (right).
	**Example Personal Goals:** • Walk up my stairs without running out of breath. • Meet with friends regularly. • Go outside when it is sunny and enjoy the day. • Lose weight and move more freely. **Motivation:** Physical Activity will increase your energy and strength, which will let you move around more freely, reduce risk of flare-ups, and enables you to go along your day with less breaks. It can also prevent worsening of symptoms and exacerbations.	**Purpose and Content** Physical Activity revolves around strength building, as a lot of COPD patients struggle with keeping active due to their illness [15]. Due to its day-to-day relevance, the suggested long-term goals focus on everyday situations the patient might experience. Based on these goals the patient is encouraged to think about their daily struggles and which one they would like to remove. The motivation text focuses on highlighting the benefits of increasing one's physical activity. The information for this domain was partly taken from the RE-SAMPLE prototype website with additional information gathered from the American Lung Association website [31] as well as the GOLD 2023 [15] report. **Colour** Red was chosen as this domain's colour due to red being an energetic and active colour. In order to be too aggressive the red chosen is more muted and close to burgundy. **Illustration** The illustration includes design elements of the 'Going For A Walk' and the 'Riding Your Bike' side goal.

Table 4: Domain Cards; Images and Descriptions

6.2.2 Side Goal Cards

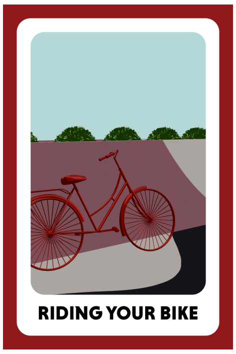
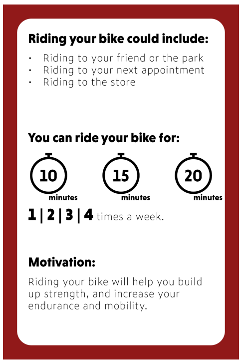
 	 **Your workout could include:** · Upper and lower limb strengthening · Aerobic · Chair Yoga **You can workout for:** 5 minutes 10 minutes 15 minutes **1 | 2 | 3 | 4** times a week. **Motivation:** Regular workout will help you build up your body strength, and increase your endurance and mobility.	**Purpose and Content** 'Workout' focuses on a more traditional physical activity approach, focusing on strength training or other guided workout activities. The suggested workouts try to offer a range of intensity. Upper and lower limb strengthening is the most "workout"-focused activity. Aerobic tries to offer an alternative that is less focused on weights and more on music and movement while still improving body strength [48]. Chair yoga offers an option which gets the patient started with working out through a lower intensity approach while still improving body strength and balance [49]. Aerobic and Chair Yoga both are activities that suggest a group setting to further help motivate the patient during the workout. **Illustration** The illustration for 'Workout' depicts a room with a red training mat on the floor with two dumbbells placed on top of the mat. These two items were chosen to visualise workout without directly potingint to any machinery or heavy weights. Next to the mat is a water bottle to fill out the scenery. The windows on the right side of the room serve the same purpose.
 	 **Gardening could include:** · Watering your flowers · Raking leaves · Mowing the lawn **You can work in the garden for:** 10 minutes 15 minutes 20 minutes **1 | 2 | 3 | 4** times a week. **Motivation:** Gardening will build up your strength again, and naturally increase your motivation and mental energy.	**Purpose and Content** 'Gardening' is the lowest intensity option available; it is not focused on getting the patient to actively build up strength, but to offer a low intensity start into routinely working on strengthening their body [45]. Due to its involved activities gardening helps build up strength, while in addition helping with motivation and mental health [47]. The only drawback to this goal is that the patient needs to have access to a garden or at the very least flowers so it is more situational than the other options. **Illustration** The illustration for 'Gardening' depicts a small flower bed with rose bushes inside. Roses were chosen as they are a typically red flower to fit the colour scheme of the domain. In front of the rose bushes is a green shovel and more dirt to fill out the scenery and suggest that there is gardening work in progress.

<table>
<tr>
<td> </td>
<td>
Going for a walk could include:
· Going to the park
· Grocery shopping
· Visting a friend

You can go on a walk for:
30 minutes 40 minutes 60 minutes
2 | 4 | 6 times a week.

Motivation:
Going on a walk will improve your heart and lung fitness, build up muscles and energy, and increase strength and endurance.</td>
<td>Purpose and Content
Going for a walk focuses on getting the patient to go outside and walk around in order to build up their strength [46]. The suggestions focus on providing alternative spaces in which the patient could take a walk in order to integrate this activity into their day-to-day activities.

The suggested durations are rather high for someone who is starting to actively try to work on improving their physical activity. This was done on purpose in order to make them a side goal. The patient is not supposed to achieve these times the first time they try them, but to slowly work towards them as part of reaching their main long-term goal.

Illustration
The illustration for ‘Going For A Walk’ shows a park dirt path with trees to either side of it. At the end of the visible path is a bench next to a tree surrounded by a couple of rocks. The leafs of the trees are shaded in red to make the connection to the domain colour.</td>
</tr>
<tr>
<td> </td>
<td>
Riding your bike could include:
· Riding to your friend or the park
· Riding to your next appointment
· Riding to the store

You can ride your bike for:
10 minutes 15 minutes 20 minutes
1 | 2 | 3 | 4 times a week.

Motivation:
Riding your bike will help you build up strength, and increase your endurance and mobility.</td>
<td>Purpose and Content
Riding Your Bike follows the same design as ‘Going For A Walk’, by suggesting times and situations during which the patient could ride their bike instead of driving by car or going on foot. Riding a bicycle is more intense than going for a walk, so the duration and frequency is kept lower than in ‘Going For A Walk’ [50].

Illustration
The illustration for ‘Riding Your Bike’ depicts a bike leaning against a wall with small bushes on top. The bike is in the domain colour red, and to give the wall more texture it is coloured in both pastel red and beige using the same colour scheme as the ‘Workout’ card. The initial idea behind the card design was to depict the wall of a café, to visualise a potential destination for the bike ride.</td>
</tr>
</table>

Table 5: Side Goal Cards; Images and Descriptions

6.2.3 Instruction Cards

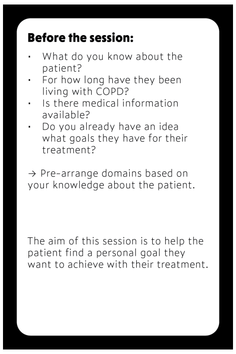
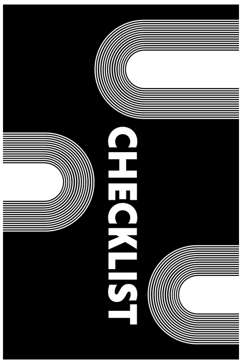
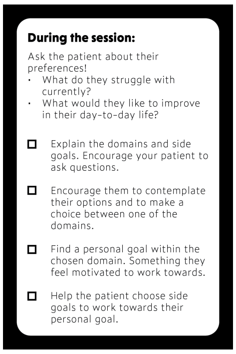
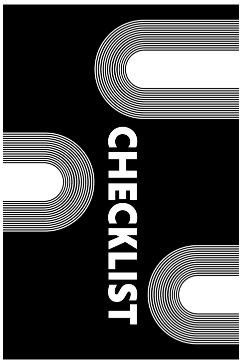
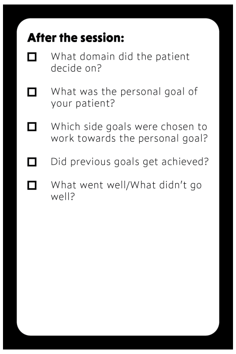
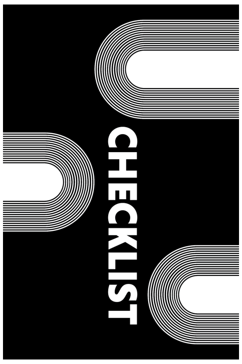
 **Before the session:** • What do you know about the patient? • For how long have they been living with COPD? • Is there medical information available? • Do you already have an idea what goals they have for their treatment? → Pre-arrange domains based on your knowledge about the patient. The aim of this session is to help the patient find a personal goal they want to achieve with their treatment.		The preparation questions for the 'Before the session' card focus on asking the healthcare professional what they already know about their patient in order to guide them into preparing the best fitting domains. The card also describes in one sentence the purpose of this consultation session in combination with using this tool is to find a goal for the patient.
 **During the session:** Ask the patient about their preferences! • What do they struggle with currently? • What would they like to improve in their day-to-day life? ☐ Explain the domains and side goals. Encourage your patient to ask questions. ☐ Encourage them to contemplate their options and to make a choice between one of the domains. ☐ Find a personal goal within the chosen domain. Something they feel motivated to work towards. ☐ Help the patient choose side goals to work towards their personal goal.		The 'During the session' card gives instructions to the healthcare professional as well as providing a checklist on what to do during the session. The focus of this card is to provide a structure that facilitates shared decision-making, having the HCP ask the patient questions which encourage them to think about their current situation and what they want to achieve.
 **After the session:** ☐ What domain did the patient decide on? ☐ What was the personal goal of your patient? ☐ Which side goals were chosen to work towards the personal goal? ☐ Did previous goals get achieved? ☐ What went well/What didn't go well?		'After the session' provides a checklist about the choices and decisions that were made during the consultation session, in order to help the healthcare professional to note these down.

Table 6: Instruction Cards; Images and Descriptions

6.2.4 Personal Goal Cards

 **I want to,** **I achieved my side goals**		The design of the 'Personal Goal' card is kept fairly simple. The upper half of the card simply has the words "I want to, " written at the top to introduce the sentence of the personal goal. This way, the patient and healthcare professional can formulate a goal that focuses on something the patient wants to achieve without binding the personal goal card to any specific domain. Goals can look like, "I want to sleep through the night.", "I want to go outside without struggle.", and "I want to meet with friends more often." At the bottom, are 4x7 stars, which the patient

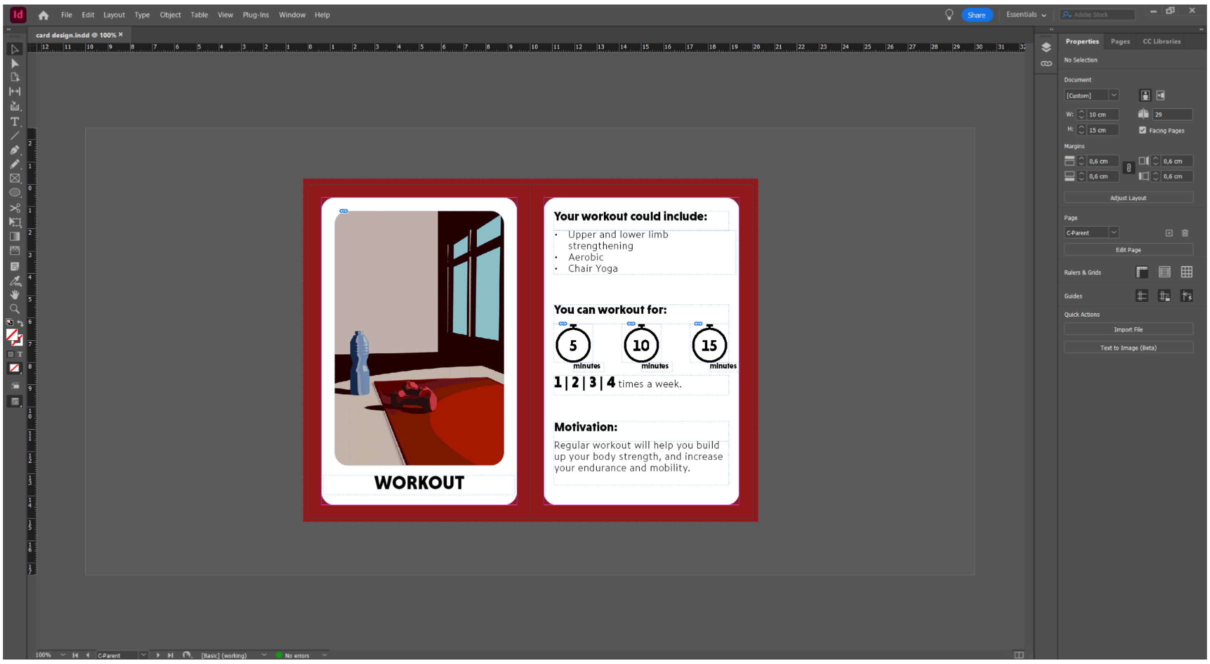
		can fill out if they manage to achieve their side goals for the day. These stars are intended to help the patient keep track if they fulfilled their side goals for the week and they can also provide information to the healthcare professional about how reliably the treatment plan was followed.

Table 7: Personal Goal Cards; Images and Descriptions

6.3 Tools

6.3.1 Adobe Creative Cloud

Adobe InDesign was used to create the layout of the cards and arrange the illustrations and the texts. The pages in InDesign are set to 100 mm by 150 mm, with a margin of 6mm on each side. The 6mm margin was used as the guide for the card borders, with all illustrations and written content organised within the left over space. In addition to Adobe InDesign, Adobe Illustrator and Adobe Photoshop were used to edit the illustrations and create the stopwatch icons on the cards.



Your workout could include:

- Upper and lower limb strengthening
- Aerobic
- Chair Yoga

You can workout for:

5 minutes 10 minutes 15 minutes

1 | 2 | 3 | 4 times a week.

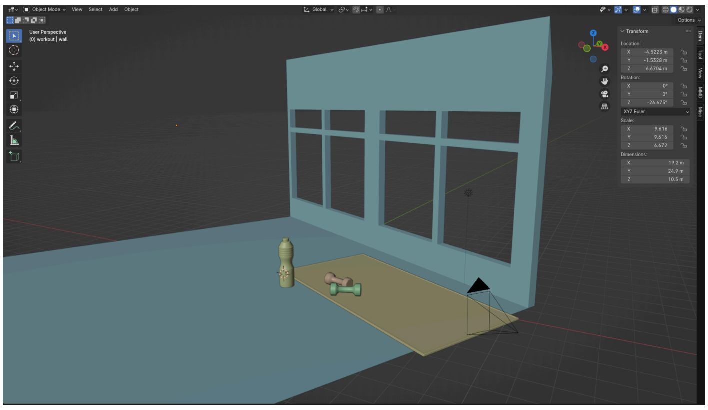
Motivation:

Regular workout will help you build up your body strength, and increase your endurance and mobility.

Figure 29: Example Card Layout in Adobe InDesign

6.3.2. Blender

Blender was used to create the illustrations on the front of the cards. To create the images, the first approach was to create the scene in 3D. Rough starting sketches were made beforehand, what each card should kind-of look like, which was then realised by sculpting the 3D-models in Blender and arranging them.



User Perspective
(0) workout | wall

Transform

Location:
X -4.5223 m
Y -1.5328 m
Z 6.6704 m

Rotation:
X 0°
Y 0°
Z -26.675°
XYZ Euler

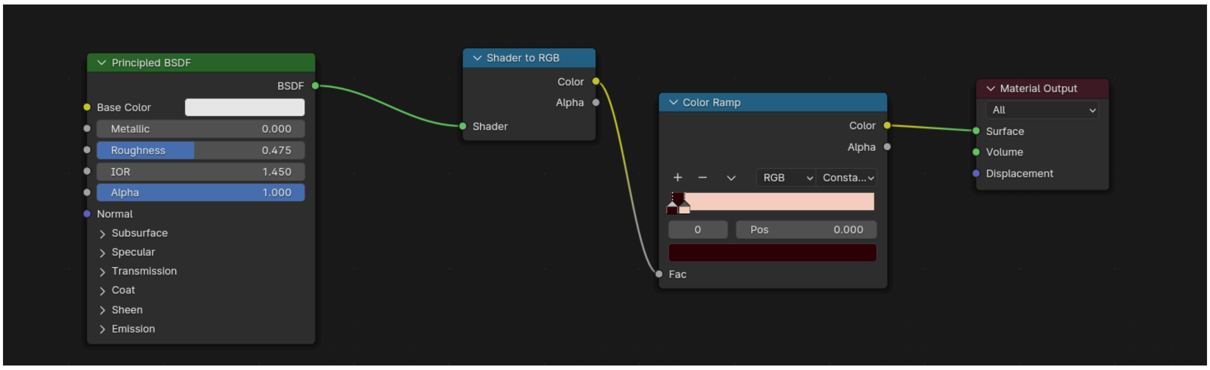
Scale:
X 9.616
Y 9.616
Z 6.672

Dimensions:
X 19.2 m
Y 24.9 m
Z 10.5 m

Figure 30: Blender Model Viewer of the ‘Workout’ Card Illustration

Afterwards, cel shading was utilised to create the illustrated look of the images. To enhance the illustrated look, colours for objects were kept mostly monochromatic for each object, except for the card defining items within the image which used a more elaborate colour range. The shader set-up follows a very simple design with the Principle BSDF shader node going into a converter node for Shader to RGB, which then is connected to a Color Ramp before the final rendering node. The different colour tones in the Color Ramp node define how many shades the object has based on the distance and angle to the light source. Figure 31 only has two colours, so anything that gets illuminated will be beige and any part of the object that is in the shadows will be dark red.

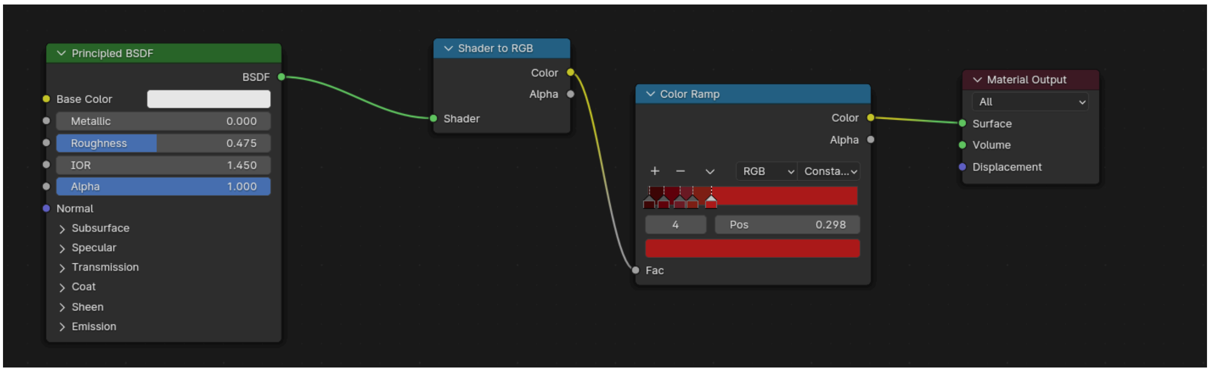
For the key object of the image a Color Ramp node was used, with 5 different shades of red which can be seen in Figure 32. This way the distance to the light source had a bigger effect on the colour of the object within the image. This makes it a more prominent part of the image and draws the attention of the viewer to it.



Metallic 0.000
Roughness 0.475
IOR 1.450
Alpha 1.000

0 Pos 0.000

Figure 31: Background Shader Setting in Blender



Principled BSDF

BSDF

Base Color

Metallic 0.000

Roughness 0.475

IOR 1.450

Alpha 1.000

Normal

Shader to RGB

Color

Alpha

Shader

Color Ramp

Color

Alpha

RGB Consta...

4 Pos 0.298

Fac

Material Output

All

Surface

Volume

Displacement

Figure 32: Key Object Shader Settings in Blender

During rendering, the background of the 3D-world was kept transparent in order to add more colours with Adobe Photoshop before the images were used as illustrations within InDesign.

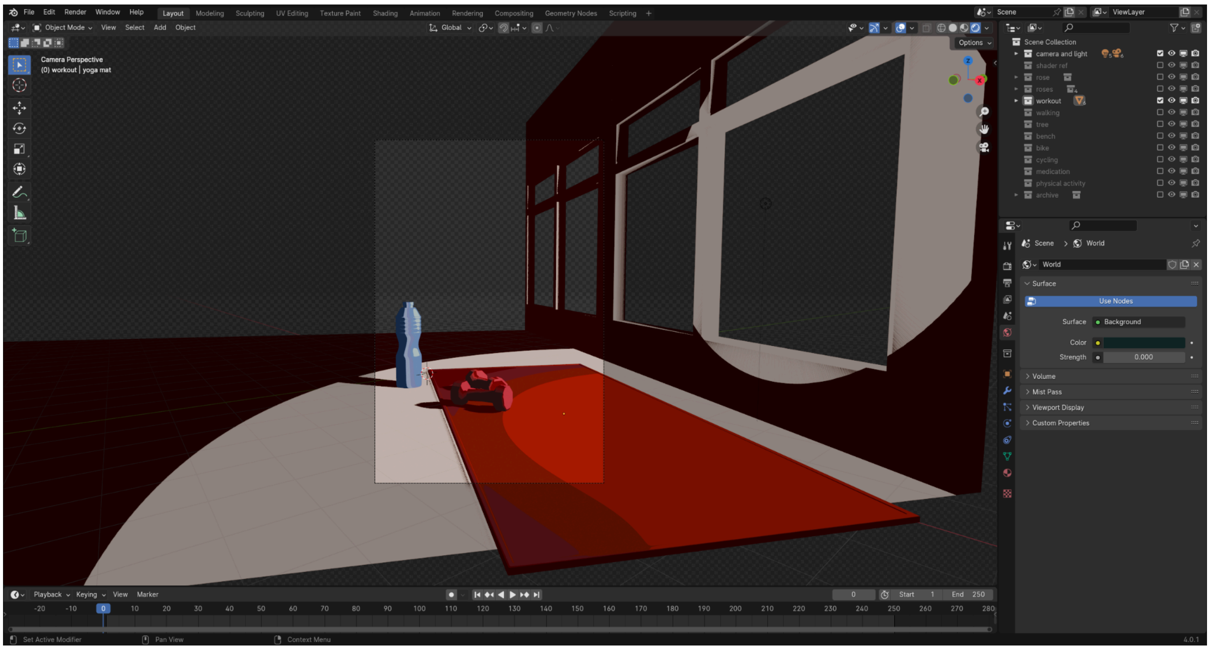


Figure 33: Render View of the ‘Workout’ Card Illustration in Blender

As Blender is a 3D-program, it does not necessarily come to mind to create illustrations, however, this tool was chosen due the experience of the researcher in using it, and their simple art style when drawing illustrations by hand. In addition, a big effort was made to avoid using AI tools to create content for the decision tool, so using Blender seemed the best option.

Chapter 7 – Evaluation

To determine if the functional requirements set in chapter 5.1 were met, an evaluation checklist was created which will test if the requirements are included in the high fidelity prototype, and thus are part of the decision tool. Next the non-functional requirements will be evaluated by conducting a user evaluation with test users, who will be using the tool under supervision of the researcher and later on during an interview will be asked to rate their use and understanding of the tool using a System Usability Scale (see chapter 3.1).

7.1 Functional Requirements Evaluation

Nr	Requirements	Test	Satisfied
	Must Requirements		
1	The tool must help establish personal goals for the patient by listing examples to help contemplate the personal goal.	The backside of the domain cards contain example personal goals. The instruction cards also list that a personal goal should be found.	Yes
2	The tool must help create a treatment plan for the patient by offering a way to set times or patterns for treatment options.	The backside of the side goal cards contain suggestions for time and durations for the options within each side goal. These times and duration in combination with the conversation between HCP and patient build the basis of a treatment plan.	Yes
3	The tool must include treatment areas like physical health, mental health, or medication adherence.	The tool currently contains physical activity and medication adherence as treatment areas.	Yes
4	The tool must have a variety of different treatment options for each treatment area to allow the patient to choose between them.	The treatment options are found in the form of side goals. Physical Activity has 4 side goal cards, while Medication Adherence has no followup cards.	Mostly
5	The tool must be able to provide information about treatment options to the patient through the use of	The cards contain information in the form of motivation texts about	Mostly

	information texts or offering patient experience reports.	each option, highlighting the benefit of following treatment. The tool does not contain experience reports.	
6	The tool must help to compare different treatment options with each other.	The tool being designed as cards allows due to its form to directly compare options by placing the cards next to each other and allowing the user to compare them this way.	Yes
	Should Requirements		
1	The tool should provide explanation and instructions on how to use it to the HCP by containing instruction texts or checklists.	The instruction cards provide checklists and example questions and approaches to the HCP.	Yes
2	The tool should organise different areas in a visually comprehensive way.	Each card type has its own colour, with each domain having its own unique colour that the side goal cards follow.	Yes
	Could Requirements		
1	The tool could include a digital dashboard to note down results of a consultation session.	The tool does not include a digital dashboard. The ‘Before the session’ instruction card references a digital tool if available but it is not part of the tool itself.	No
2	The tool could have follow up cards to help the HCP note down results.	The final instruction card for the HCP has a short checklist of what was part of the session and asks questions about these parts. The tool does not include space or a way to note these information down directly.	Mostly

Table 8: Function Requirements Analysis Table

Based on this functional requirement evaluation we can see that 4 of the 6 must requirements were fully fulfilled and 2 of the 6 must requirements were mostly fulfilled. Both of the 2 should requirements were fully fulfilled, and of the 2 could requirements, 1 was mostly fulfilled and the other was not fulfilled.

9 out of 10 of the functional requirements have been at least mostly met, with only the could requirement regarding a digital assistance tool having not been met. A step for further development can be to create a digital tool to be used in tandem with the paper-based decision tool.

7.2 Non-Functional Requirements Evaluation through a User Evaluation

The focus of this project is to create a shared decision-making environment with the help of the decision tool. In the context of a consultation session between healthcare professional and patient; this means that by using this interactive paper-based decision tool, the healthcare professional and the patient with COPD and comorbidities naturally fall into a conversation that resembles a shared-decision making session. Thus, the conversation manages to help set goals, creates a treatment plan, supports the patient in contemplating their options, and assists the healthcare professional in communicating the relevant information to the patient. In addition, the tool is easy enough to use without training, and is able to be used in a suitably quick timeframe.

Based on the requirements set in chapter 5.1 the non-functional requirements that need to be evaluated are the following:

Nr.	Non-Functional Requirement (NF)
1	The tool must facilitate a conversation about options and choices between the healthcare professional and the patient.
2	The patient must find a personal goal for their treatment.
3	The patient must understand the contents of the cards and be able to formulate their own choices based on that understanding.
4	The design of the tool should appeal to the users.
5	The tool should help the HCP to prepare a consultation session with a patient.
6	The illustrations on each card should describe the contents of the card visually and help give an overview.
7	The tool should be usable without extensive prior knowledge or experience with the tool itself.
8	The tool should be usable within a timeframe of a normal consultation session.

Table 9: Non-Functional Requirements Table

This user evaluation focuses on evaluating if the tool is able to create a conversation with patients, help set treatment goals, as well as create a treatment plan for the patients. A secondary aspect of the evaluation also looks at the ability for healthcare professionals to use and understand this tool, as well as if the test users like the design of the tool. The only requirement this evaluation will not test is whether the tool is usable within a suitable time frame for a consultation session.

Based on the above requirements a hypothesis has been formulated which will form the basis of the non-functional requirements evaluation.

“This card based approach to consultation appeals to the users and using this decision tool creates an environment that facilitates shared decision-making, and helps set goals the patients want to achieve.”

This evaluation hypothesis focuses on the following dependent variables:

- Users engage with the cards
- Users enter a conversation about the cards
- The users feel satisfied with the set goals
- The cards appeal to the users

The independent variables for this evaluation were the users, as well as the way the test was conducted. The evaluation was split into **three** parts.

The **first session** was testing the prototype with students taking the role of patients with COPD and comorbidities and the researcher taking the role of the healthcare professional without a script. The evaluation focused on the 5 non-functional requirements 1,2,3,4, and 6.

The **second session** was students taking the role of healthcare professional following the instructions on the cards, with the researcher taking the role of the patient. The evaluation focus for the second session consists of 1,4,5,6, and 7.

The **third session** tested the prototype with real life patients that have COPD and comorbidities as test users, and the role of the healthcare professional being played by a student with a script they had to follow. The evaluation focus is the same as for session 1, focusing on the non-functional requirements numbered 1,2,3,4, and 6.

7.2.1 Evaluation Method and Type of Assessment

The evaluation was split into three separate evaluation sessions. The first and third session focused on evaluating the functionality of the prototype from the perspective of the patient with COPD. The second session focused on evaluating the prototype from the perspective of the healthcare professional.

An observation protocol was held for each evaluation session, observations were written down and related to how the user interacted with the cards. The goal hereby was to not only assess the users opinion of the tool after using the prototype, but to also document any behaviour or use cases that fell in and out of the expected interaction with the tool.

	Observations To Be Made
1	Did the user enter a conversation about options on the cards?

2	Did the user find a personal goal?
3	Did the user need help to understand the purpose of using the cards?
4	Did the user have difficulty reading or understanding the contents of the cards?
5	How did the user behave in the conversation?

Table 10: User Evaluation Observation List

To document the users opinion of the tool after the user testing session, an interview was conducted by using a System Usability Scale (SUS) [43] as the basis. The System Usability Scale consists of 10 statements about the tool and the session, and the user is asked to rate their agreement with these statements on a scale from 1 to 5, which correlate to Strongly Disagree (1) and Strongly Agree (5). Based on their answers, the interviewer asked for explanations why they gave a specific rating with follow-up questions for further elaboration asked if needed. The SUS result was then used to calculate a score for the user evaluation which can be used for analysing the results and gives an overview of how well the prototype was received.

Two different System Usability Scales were used during the evaluation sessions. Session 1 and Session 3 share the same scale which has statements related to the perspective of the patient; session 2 has a scale adapted to the perspective of the healthcare professional.

	Statements	Strongly Disagree Strongly Agree
1	I feel confident in the future progress of my treatment.	○1 ○2 ○3 ○4 ○5
2	The conversation helped me realise what I find important for approaching my condition.	○1 ○2 ○3 ○4 ○5
3	I was able to find a personal goal.	○1 ○2 ○3 ○4 ○5
4	I feel like I had a say in the conversation and how it progressed.	○1 ○2 ○3 ○4 ○5
5	I feel like continuing this kind of approach to conversations will positively impact my treatment.	○1 ○2 ○3 ○4 ○5
6	The conversation felt natural.	○1 ○2 ○3 ○4 ○5
7	The information on the cards helped me understand them better.	○1 ○2 ○3 ○4 ○5
8	The information on the cards had a good balance between information and setting treatment goals.	○1 ○2 ○3 ○4 ○5
9	The colours and images fit the contents and conversation.	○1 ○2 ○3 ○4 ○5
10	I liked the design of the cards.	○1 ○2 ○3 ○4 ○5

Table 11: System Usability Scale for Session 1 and Session 3

	Statements	Strongly Disagree Strongly Agree
1	I was able to follow the instructions.	○1 ○2 ○3 ○4 ○5
2	I understood the purpose of the tool.	○1 ○2 ○3 ○4 ○5
3	I would be able to set a treatment plan with the side goal cards.	○1 ○2 ○3 ○4 ○5
4	The information on the goal cards helped me explain the cards to the patient.	○1 ○2 ○3 ○4 ○5
5	I feel like continuing this kind of approach to conversations will positively impact treatment.	○1 ○2 ○3 ○4 ○5
6	The cards felt natural to use.	○1 ○2 ○3 ○4 ○5
7	It was clear to me what cards to choose for the specific domain.	○1 ○2 ○3 ○4 ○5
8	The information on the cards had a good balance between information and setting goals.	○1 ○2 ○3 ○4 ○5
9	The colours and images fit the contents and conversation.	○1 ○2 ○3 ○4 ○5
10	I liked the design of the cards.	○1 ○2 ○3 ○4 ○5

Table 12: System Usability Scale for Session 2

7.2.2 Procedure and planning

Session 1: User Testing with Students acting as Patients

The first evaluation session was conducted with 5 students who were asked to participate individually. Each evaluation was planned for a timeslot of 30 minutes, with introduction, testing, and post test interview being conducted in that time frame. This number of testers was chosen in order to have a one-to-one ratio between students and real life patients with COPD and comorbidities which would conduct the evaluation in session 3. The goal was to compare the results obtained during Session 1 with the results of Session 3 in order to get a more general evaluation of the prototype and also compare differences in results.

During the testing of the prototype and during the interview the researcher took notes based on the observation points set in 7.2.

Before	Students get a short prompt sent to them 1 day before their scheduled interview.
2 Minute	Consent form reading and signing. (See Appendix C)
5	Setting the scene and introducing the students to the table, cards on a pile and

Minutes	getting them started with the use of the cards.
10-15 Minutes	Using the cards in a consultation session, with the students taking the role of a patient and the researcher taking the role of a healthcare professional.
10 Minutes	Post use interview and SUS statement discussions.

Table 13: Time Schedule for Session 1 of the User Evaluation

During testing the researcher followed a general script to ensure a comparable setting for each evaluation which can be found in Appendix D.

Session 1: The prompt for students

For this prototype evaluation you are asked to roleplay as an older adult between the age of 50-75 who suffers from the illness COPD. Symptoms of COPD include trouble breathing, loss of strength and mobility, and oftentimes lack of motivation and energy. Treatment for COPD heavily involves changing your day-to-day activities, often including some form of workout in order to help your body build up strength again.

The setting of this prototype testing is a consultation between you and your doctor, to find ways for you to start regular activities to help you with progressing your treatment.

Session 2: User Testing with Students acting as Healthcare Professionals

The second session was conducted with 3 students. These students were approached in public university spaces and asked if they had time to participate in the evaluation. After introducing the students to the graduation project, they were given a prompt and the task to follow the instructions on the black instruction cards. During the user testing, the role of the patient was taken by the researcher. In order to help the students complete their role of healthcare professional any gaps in knowledge regarding treatment and COPD were filled out by the researcher. The evaluation was planned for 30 minutes, which included the introduction, testing, and interview.

2 Minute	Consent form reading and signing.
1 Minute	Reading and explaining the prompt for the students. (See Appendix C)
5 Minutes	Setting the scene and introducing the students to the cards, and letting them read and familiarise themselves with them.
10-15 Minutes	Using the cards in a consultation session, with the students taking the role of a healthcare professional and the researcher taking the role of a patient with COPD.
10 Minutes	Post use interview and SUS statement discussions.

Table 14: Time Schedule for Session 2 of the User Evaluation

Session 2: The prompt for students

For this prototype evaluation you are asked to roleplay as a healthcare professional for patients with COPD which is a chronic lung illness. Symptoms of COPD include trouble breathing, loss of strength and mobility, and oftentimes lack of motivation and energy. Treatment for COPD heavily involves the patient changing their day-to-day activities, often including some form of workout in order to help them build up strength again.

The setting of this prototype testing is a consultation between you and your patient, to find ways for them to start regular activities to help with the progress of their treatment. The **focus** for today will be on physical activity and helping the patient find ways to approach this.

Session 3: User Testing with Patients Living with COPD and Comorbidities

A request was sent out to past participants of RE-SAMPLE studies and evaluations, asking for general interest in participating in the user evaluation. Based on this request, 3 users were found. The planning for the third session was similar to the planning for the first session, with an almost identical time plan and the exact same SUS statements.

Before	Test users receive a consent form and information brochure sent to them 1 week before the user testing, informing them about the research they are participating in and the graduation project.
5 Minute	Consent form reading and signing. (See Appendix D)
3 Minutes	Setting the scene and introducing the test users to the table, cards on a pile and getting them started with the use of the cards.
10-15 Minutes	Using the cards in a consultation session, with the users taking the role of a patient and the researcher taking the role of a healthcare professional. The researcher follows a script.
10 Minutes	Post use interview and SUS statement discussions.

Table 15: Time Schedule for Session 3 of the User Evaluation

However, because neither of the three participants were fluent in English, the evaluation had to take place in Dutch. For this, a third party had to be asked to conduct the user testing and interview, on account of the researcher not being fluent in Dutch. For this a more detailed script was written for the tester, as well as all cards translated into Dutch. The script both in English and in Dutch translation can be found in Appendix E.

On the day of the evaluation only one of the three users arrived for the prototype test. One participant did not appear, and the other participant did not manage to find the location and drove back home. Due to this, only one instead of three users were part of the user evaluation for session 3.

7.2.3 Experimental Design and Test Conditions

Session 1 and session 3 were conducted in one of the Horst Tower rooms of the University of Twente. The tower rooms were chosen due to their availability and easy access for students to book and use for projects. The rooms can be reached by stairs and elevators, which for session 3 was important in order to ensure easy access for all users. The only disadvantage of these rooms is the distance to the nearest parking space, which requires 3-4 minutes of walking to reach. All users of the two sessions were informed of the location a couple days before the evaluation. Each evaluation had a timeslot of 30 minutes allocated to it, with a buffer of 10 minutes in between test users in case more time was required.

The scripts for both sessions were designed in a similar way, with the script for session 3 being more structured with tasks and test variables. This was done in order to ensure a more controlled test to reduce the reliance on the researcher to answer questions the tester did not know the answer to. This way, the conversation was able to stay more between the user and the tester.

Session 2 was conducted at the Design Lab of the University of Twente, which is an open learning space for students. Part of this space are woodworking and electronic workshops. The Design Lab was chosen for session 2 due to many students of different studies and years usually spending time there or working on their own projects. Students were randomly asked if they were available for a 30 minute user evaluation with 3 students finding time to conduct the user evaluation. The test users got time to read the information brochure and prompt, before being asked to follow the instructions on the card and conduct a shared decision-making session with the researcher as the patient. The users did not get a script for following the tool with the tool being utilised as its own test script.

7.2.4 Evaluation Results

After concluding the interview with the user filling out the System Usability Scale and scoring each statement on a scale from 1 to 5 a result can be calculated which indicates the usability of the prototype. The System Usability Scale was designed to evaluate web-based user interfaces, so most of the statements were adapted to fit the prototype. In addition, instead of a statement being first positive then negative, all statements were changed to positive statements in order to create a more positive back and forth conversation between the interviewer and the user. The statements were paired with follow-up questions asking for elaborations for the score given to each statement.

Evaluation Results of Session 1

For session 1 the evaluation focus was on determining if the tool met the non-functional requirements from the perspective of the patient. For this, a System Usability Scale was used to get feedback regarding the requirements 1,2,3,4, and 6 listed in 7.2 and to determine if they were fulfilled. As seen in Figure 35, with an average score of 4 and above for all statements except statement 2 which had an average score of 3.8, it can be concluded that the non-functional requirements were fulfilled. The average SUS score of 79.5 highlights this even further.

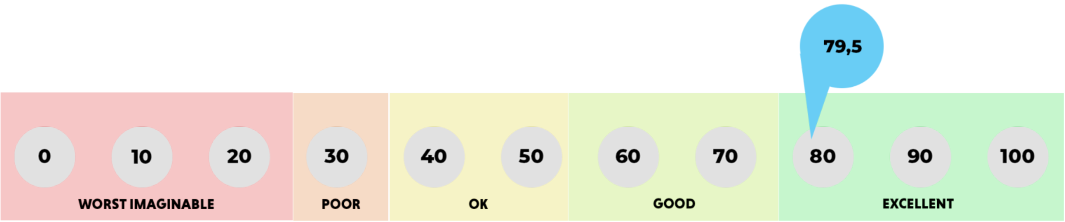


Figure 34: SUS result for User Evaluation Session 1

The users gave the feedback that the cards overall gave the conversation a good flow, and a general structure which helped them organise their thoughts about the treatment approach. In addition, all 5 users felt that the personal goal they had to find at the start of the consultation was a great motivator and beginning of the conversation. One user said that by splitting the options up into cards it helped them approach the topic at a less overwhelming pace. Another user highlighted the fact that the suggested duration and frequencies started relatively small, which gave them the impression that they could start with small steps and improve over time.

In Statement 4, three of the five users gave their involvement in the conversation a rating of 4 on account of feeling that the healthcare professional had a strong role in the progression of the conversation. However, overall all users agreed that they felt like they had a say in the conversation and that the conversation felt natural, which for the decision tool means a shared decision-making session was achieved.

All patients strongly agreed that they liked the design of the cards, regarding the colour choices, the illustrations, and the contents at the back of the cards. In terms of specific content and card designs, the feedback was less uniform. Two users felt that the motivation texts on the side goal cards were redundant due to the context being almost identical to the motivation text on the Physical Activity Domain card. Instead they would have preferred some more information about the side goal itself. Another user did not like the design of the Physical Domain card, and would have liked a different image. They were unable to describe what a different image should look like, but felt it had to be different than the tree and bike. A third user was not sure if the illustration for the Workout side goal card was fitting enough, feeling that the weights and training mat suggested a too intense workout.

All users were able to find a personal goal as their long-term goal within the Physical Activity domain. All users felt that the example goals on the domain card helped them contemplate and think about their own long-term goal.

Four of the five users made the statement that the cards contained in the prototype felt like a first step into treatment and that follow-up sessions should probably have different cards with more activity intense options or follow-up treatment steps. By doing so, they feel that it would give them the impression that they were progressing together with the tool. One user also highlighted that they feel that this kind of treatment approach would be appropriate for a physiotherapist, but not for a more traditional medical consultation.

For session 1, the evaluation hypothesis holds true, and the card based decision tool was able to create a shared decision-making conversation with students acting as patients, and the researcher taking the role of the healthcare professional.

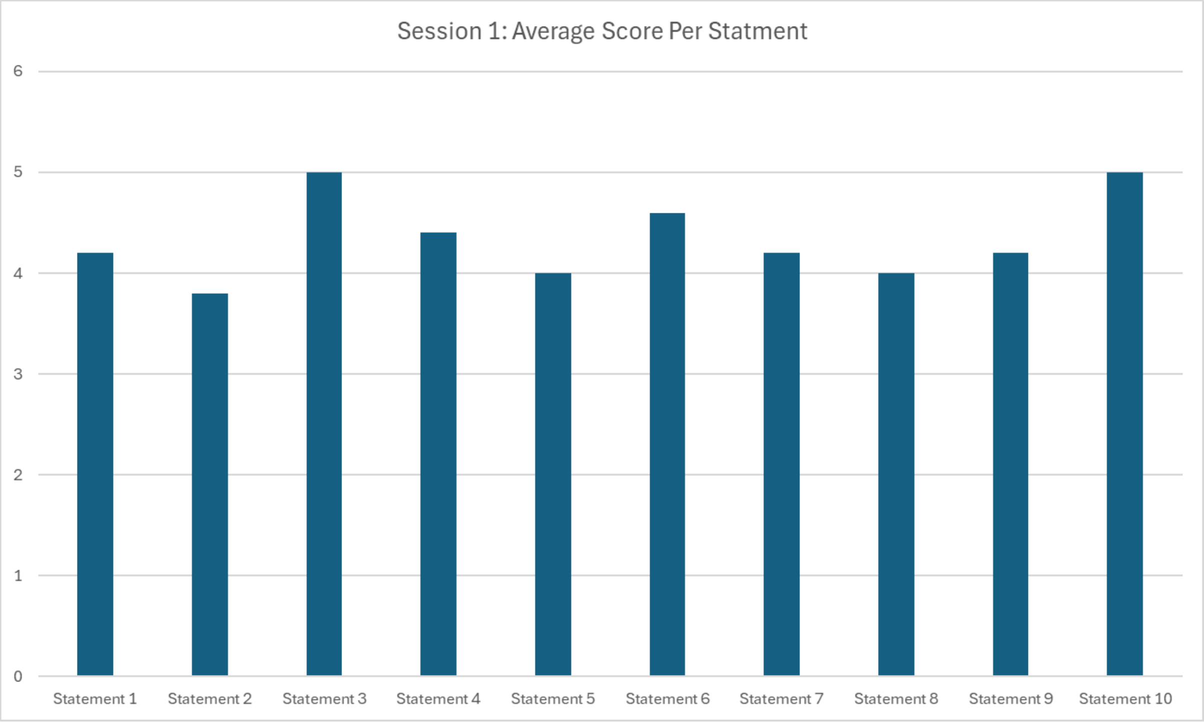


Figure 35: Average score per statement for session 1, with n= 5

Evaluation Results of Session 2

For session 2 the evaluation focus was on determining if the tool met the non-functional requirements from the perspective of the healthcare professional. For this, a System Usability Scale was used to get feedback regarding the requirements 1,4,5,6, and 7 listed in 7.2 and to determine if they were fulfilled. While most statements have an average score of 4 and above, statements 1, 7, and 10 fall below the rating of 4 (see Figure 37). For statement 1 and 10, the result stem from only one user disagreeing with the statements, for statement 7 however, all three users did not agree with the statement, with one user disagreeing with a rating at 2, and the other two rating their agreement at 3 which correlates to neutral. The overall SUS score for session 2 is a 77.5, which still falls into the good to excellent results. Overall, the tool was received well, and a conversation resembling a shared decision-making session was achieved, however not all non-functional requirements were fully achieved.

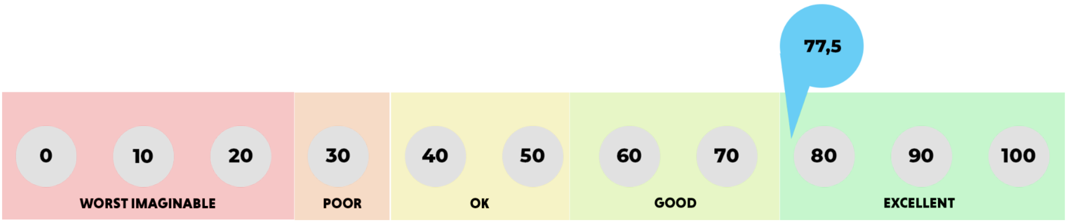


Figure 36: SUS result for User Evaluation Session 2

The first non-functional requirement was hardest to reliably test, due to the users not being familiar with the topic and medical approaches to COPD. The assumption that was made to allow for the evaluation was that if the user can follow the instructions on the card, they would be able to create a conversation with full knowledge about the treatment.

Two of the three users fully agreed that they were capable of following the instructions, while one user disagreed. The information amount on the cards prevented them from quickly understanding the cards and following the instructions reliably. Another user felt that while they were able to follow the instructions the instruction cards should highlight more directly that the patient needs to make decisions and choices, including the personal goal finding.

While all users agreed that they liked the design of the cards in terms of colour choices and image design, all three users had issues with parts of the card design which resulted in an average rating of 3,6 for statement 10 which relates to the 2.6 rating of statement 7. Looking at statement 7 which makes the statement that the user had no issue identifying the domain and follow-up side goal cards, all users did not agree with that statement. They had issues identifying the domain card, as they felt that the layout change of the front was not enough to highlight the difference between domain card and side goal card. A change to the border of the side goal card would have helped them identify them as a denominator of the domain card. The illustration at the front of the Physical Activity card also contributed to the users having issues properly identifying it, and they would have preferred a different illustration. Another aspect two of the three users took issue with, was the content on the side goal cards. The motivation text felt redundant to them, and for their choices as healthcare professionals they would have preferred some form of statistics or other more tangible information rather than a motivation text. One user also suggested a change of hierarchy on the side goal cards, to answer the question ‘Why?’, ‘What?’. and ‘How Long?’ by first providing information and motivation, then the different options within the side goal, followed by the time and duration. Lastly, all three users had issues with the terminology. The terms domain and side goal did not feel intuitive to them, and only upon the explanation that domains refer to treatment areas, and side goals refer to treatment options, the purpose of the cards became more clear.

Despite the above design and understanding issues all users felt that through the use of the cards, they would be able to help a patient find a treatment plan and personal goal. In parts due to all users feeling that the use of the cards to create and guide the conversation felt natural to them.

The evaluation hypothesis holds mostly true for session 2, with improvements needing to be made in order to fully uphold it. The users were only partly able to create a shared decision-making conversation with the contents of the cards being the biggest cause for them to not fully understand the instructions and steps. In regards to the instructions on the cards, they were mostly understandable to the users with the exception of one.

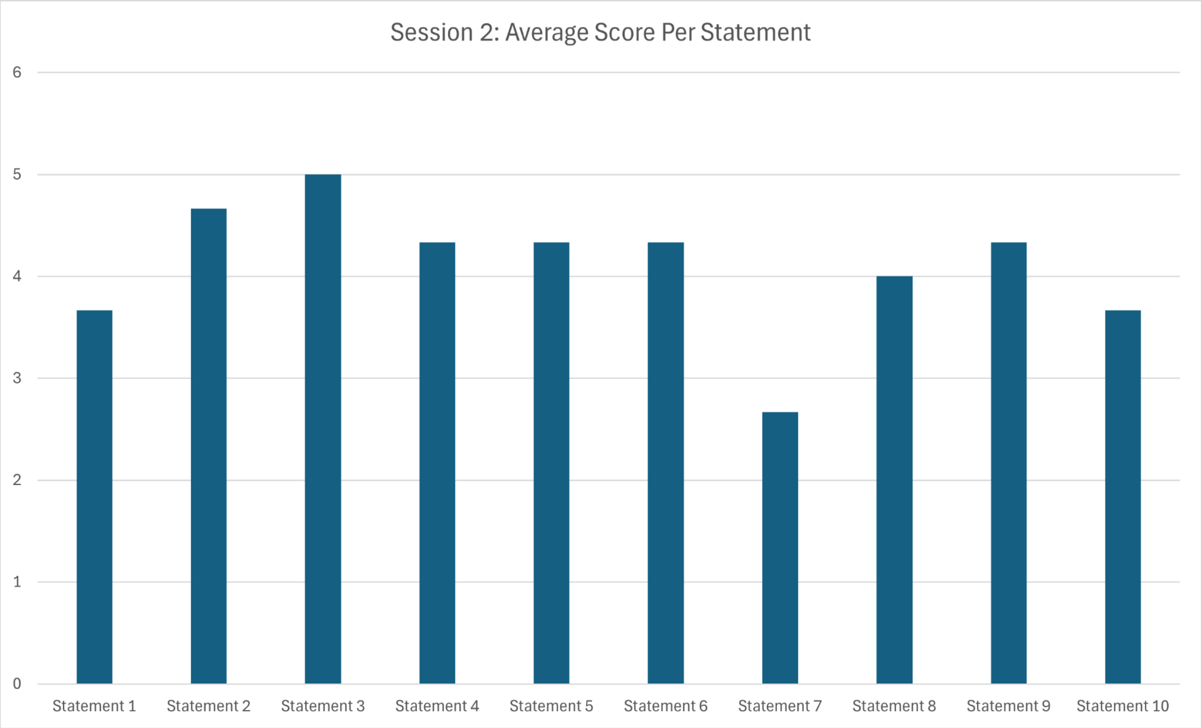


Figure 37: Average score per statement for Session 2, with n= 3

Evaluation Results of Session 3

For session 3 the evaluation focus was on determining if the tool met the non-functional requirements from the perspective of the patient. For this, a System Usability Scale was used to get feedback regarding the requirements 1,2,3,4, and 6 listed in 7.2 and to determine if they were fulfilled. The user fully agreed with all statements except for statement 4, 8, and 9. They disagreed fully with statement 4 giving it a score of 1, and disagreed with statement 8 and 9, giving each a rating of 2 (see Figure 39). The final SUS score was 75, which puts it between good and excellent on the scale. Overall, the user was satisfied with the approach the tool took, but the user did not feel like they had a say in the conversation. They also disliked the colour choices of the cards, and would have preferred less text on the side goal cards. The SUS score shows that the decision tool was usable as a prototype, it resulted in a personal goal and the user felt that continuing this kind of approach would help them with approaching their treatment. However, with statement 4 being rated at 1, a shared decision-making conversation did not take place for the user.

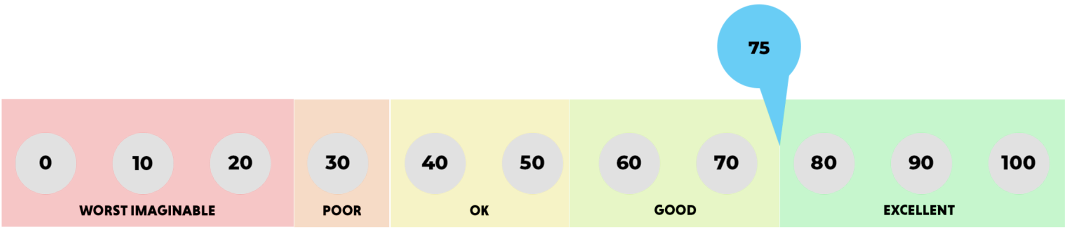


Figure 38: SUS result for User Evaluation Session 3

The user did not feel like they had a say in the conversation which for our evaluation means they did not have a shared decision-making conversation. The user gave the feedback that they require a lot more information than what was given by the cards and the evaluator in order to make a choice they would be comfortable with. They also stated that using the decision tool would feel better if an actual healthcare professional would use it with them and was able to explain the details to each treatment option. Another improvement they suggested was to replace the motivation text on the side goal cards with more visual information in order to make the information simpler to understand.

One big concern for the user was a question of price for the listed options. Choosing ‘Riding your bike’ as one side goal option was only considered after making sure that they could use a biking machine at their physiotherapist as opposed to getting a bike for themselves.

Another point the user brought up was that this kind of approach to a consultation would feel inappropriate for a general practitioner or pulmonologist, but would fit well into a session with their physiotherapist. Part of the reasoning for this was that the approach does not feel clinical which the user associates with their physiotherapist.

Regarding the design of the cards, the user liked the overall look and feel of them including the illustrations and hue of the colours. However, they did not like the colour choice of red for the physical activity cards, because red felt too aggressive to them and would have preferred the colour green. Due to this they gave statement 9 a rating of 2.

The evaluation hypothesis only holds partially true. The session was able to establish a long-term goal for the user, and the user understood the purpose of the cards and how they could help them in their treatment. The cards were also able to create a natural feeling and progressing conversation for the user. However, the user did not feel like they had a say in the conversation, and also did not feel comfortable to make the choices. While the overall design of the cards appealed to the user, they had issues with design details.

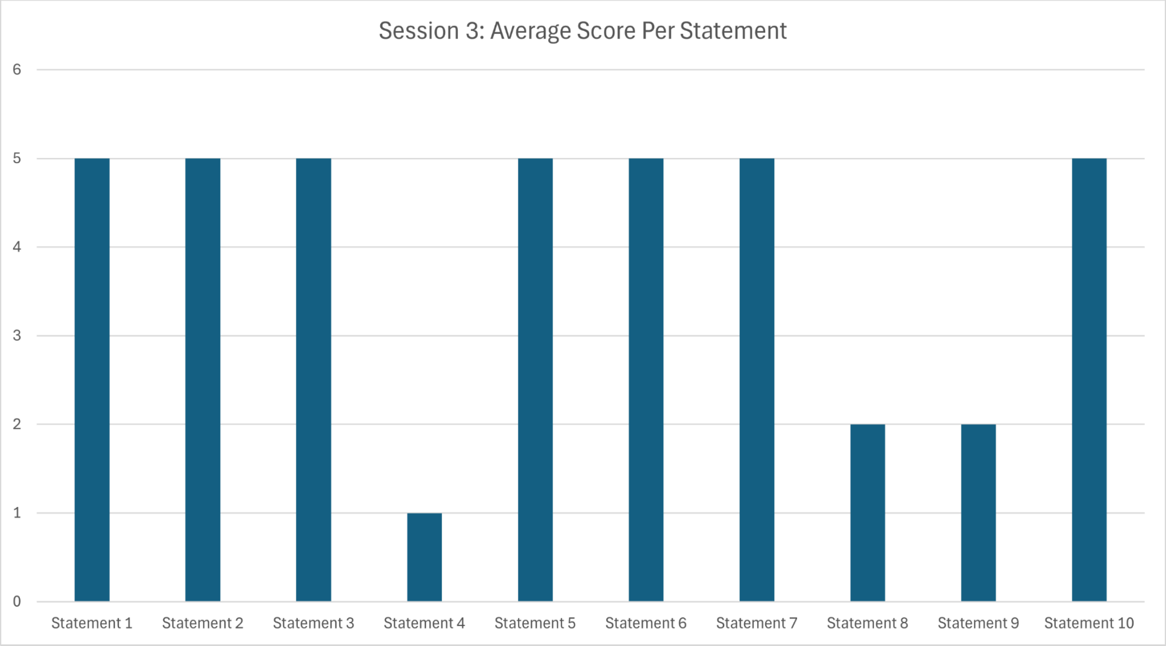


Figure 39: Average score per statement for session 3, with n= 1

7.2.5 Non-Functional Requirements Evaluation Summary

The goal of the non-functional requirements evaluation was to determine if the card based decision tool manages to create a shared decision-making conversation between patient and healthcare professional. In addition, the second goal of the evaluation was to determine if the design and function of the tool appeals to the user.

For the evaluation of the decision tool being able to create a shared decision-making session, only the first session resulted in a successful SDM conversation. The users in session 2, who evaluated the prototype from the perspective of the healthcare professional, were only partially able to create a shared decision-making conversation. The most commonly named cause for this was the users having trouble with the contents of the cards, while the instructions themselves were mostly understood. Session 3 did not succeed at creating a shared decision-making conversation. The user agreed that the consultation conversation itself felt good with the assistance of the cards, but they did not feel like they had a say in that conversation which means no SDM was achieved. The user named two reasons for that, one being that they would need a lot more information, and another was that they would have preferred someone with actual healthcare background during the evaluation.

For the second goal of the evaluation the users of session 1 and 3 fully agreed that they liked the design of the cards, while also naming improvements they would like to see in the future. Due to the difficulties the users of session 2 faced in fulfilling their role of a healthcare professional their rating for the design of the cards fell below 4, even though 2 of the 3 users said that they liked the design of the cards.

The hypothesis established for the non-functional requirements evaluation only holds partially true, however with improvements made to the contents of the cards and the evaluation conditions, the following hypothesis should hold fully true:

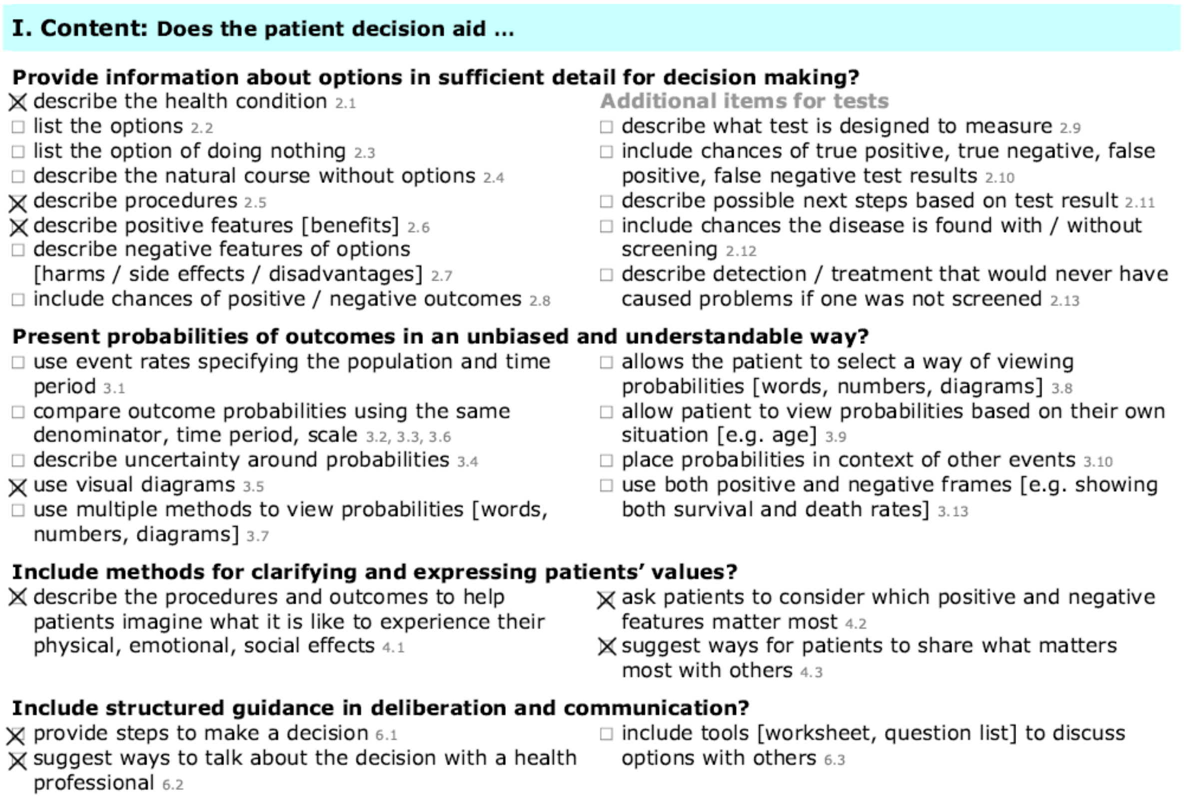
“This card based approach to consultation appeals to the users and using this decision tool creates an environment that facilitates shared decision-making, and helps set goals the patients want to achieve.”

One non-functional requirement that was not able to be evaluated during these three sessions was the 8th requirement from Table 9 on page 59. Further evaluation focusing on this aspect should be conducted in the future.

2.3 IPDAS Evaluation

In addition to the functional and non-functional prototype evaluation a third evaluation was concluded using the IPDAS ‘Patient Decision Aid Checklist for Users’ provided by the IPDAS Collaboration [37]. IPDAS was created with the goal of having a unified international standard for decision tools, so evaluating the paper-based tool created for this graduation project seemed appropriate. Based on the IPDAS evaluation areas were found in which future development should focus on, and aspects with which current content can be improved. This evaluation was conducted by the researcher themselves, so a certain level of bias has to be expected even though attempts were made to stay as unbiased and neutral as possible. In addition, this evaluation is not going to be used to derive a definite result or input on how successful the decision tool is; instead, this evaluation can show areas that could be addressed in order to improve the tool.

In the first part of the checklist about the content of the tool, two areas were found in which the current version of the tool is lacking. The first area regards information about COPD itself, which the tool does not provide at all. Information is given about the options for approaching treatment of COPD, but not regarding COPD and what it entails. The second area is about providing statistical information for the various treatment options and approaches. This outcome was to be expected, on account of the prototype focusing on creating a shared decision-making conversation by using a card-based approach. Future versions of this tool should definitely include cards focusing on these two areas.



I. Content: Does the patient decision aid ...

Provide information about options in sufficient detail for decision making?

☒ describe the health condition 2.1
☐ list the options 2.2
☐ list the option of doing nothing 2.3
☐ describe the natural course without options 2.4
☒ describe procedures 2.5
☒ describe positive features [benefits] 2.6
☐ describe negative features of options [harms / side effects / disadvantages] 2.7
☐ include chances of positive / negative outcomes 2.8

Additional items for tests

☐ describe what test is designed to measure 2.9
☐ include chances of true positive, true negative, false positive, false negative test results 2.10
☐ describe possible next steps based on test result 2.11
☐ include chances the disease is found with / without screening 2.12
☐ describe detection / treatment that would never have caused problems if one was not screened 2.13

Present probabilities of outcomes in an unbiased and understandable way?

☐ use event rates specifying the population and time period 3.1
☐ compare outcome probabilities using the same denominator, time period, scale 3.2, 3.3, 3.6
☐ describe uncertainty around probabilities 3.4
☒ use visual diagrams 3.5
☐ use multiple methods to view probabilities [words, numbers, diagrams] 3.7
☐ allows the patient to select a way of viewing probabilities [words, numbers, diagrams] 3.8
☐ allow patient to view probabilities based on their own situation [e.g. age] 3.9
☐ place probabilities in context of other events 3.10
☐ use both positive and negative frames [e.g. showing both survival and death rates] 3.13

Include methods for clarifying and expressing patients’ values?

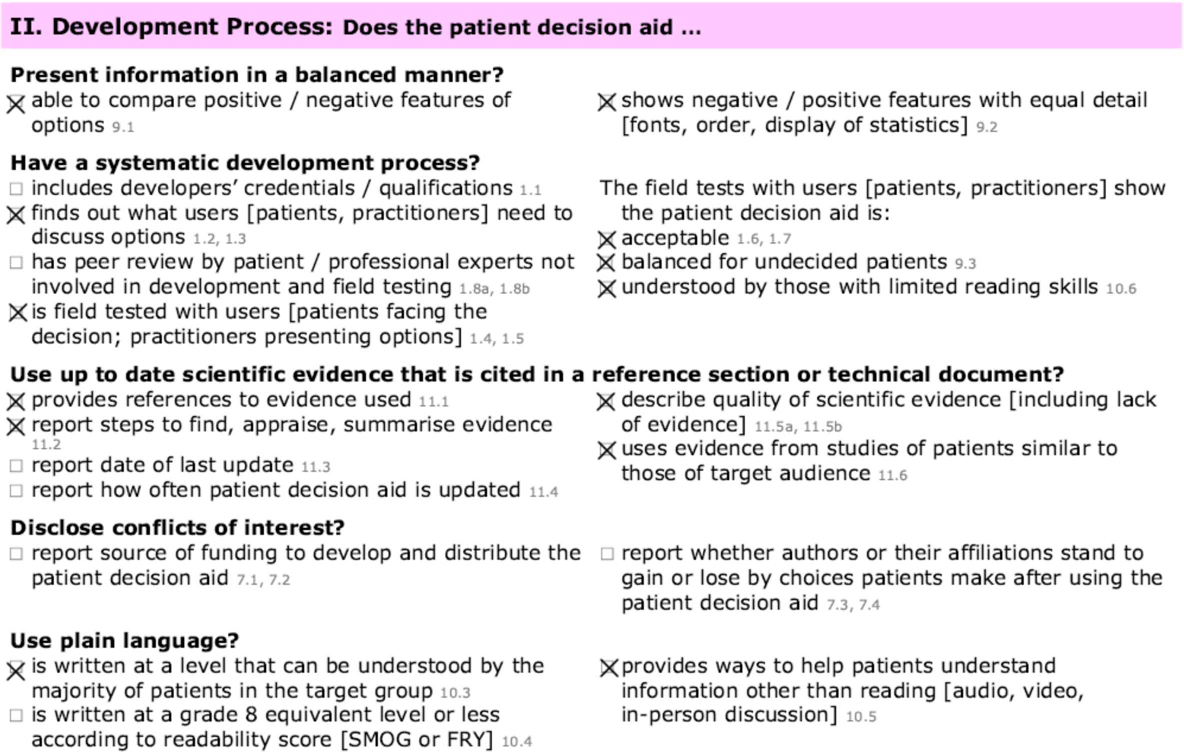
☒ describe the procedures and outcomes to help patients imagine what it is like to experience their physical, emotional, social effects 4.1
☒ ask patients to consider which positive and negative features matter most 4.2
☒ suggest ways for patients to share what matters most with others 4.3

Include structured guidance in deliberation and communication?

☒ provide steps to make a decision 6.1
☒ suggest ways to talk about the decision with a health professional 6.2
☐ include tools [worksheet, question list] to discuss options with others 6.3

Figure 40: Filled Out Part 1 of the IPDAS Questionnaire

The second part of the IPDAS checklist focuses on the research involved behind the decision tool. In this area most items of the checklist are fulfilled, except for the tool being peer reviewed. For this, an additional evaluation with healthcare professionals and patients as user groups should be conducted.



II. Development Process: Does the patient decision aid …

Present information in a balanced manner?

☒ able to compare positive / negative features of options 9.1

☒ shows negative / positive features with equal detail [fonts, order, display of statistics] 9.2

Have a systematic development process?

☐ includes developers' credentials / qualifications 1.1

☒ finds out what users [patients, practitioners] need to discuss options 1.2, 1.3

☐ has peer review by patient / professional experts not involved in development and field testing 1.8a, 1.8b

☒ is field tested with users [patients facing the decision; practitioners presenting options] 1.4, 1.5

The field tests with users [patients, practitioners] show the patient decision aid is:

☒ acceptable 1.6, 1.7

☒ balanced for undecided patients 9.3

☒ understood by those with limited reading skills 10.6

Use up to date scientific evidence that is cited in a reference section or technical document?

☒ provides references to evidence used 11.1

☒ report steps to find, appraise, summarise evidence 11.2

☐ report date of last update 11.3

☐ report how often patient decision aid is updated 11.4

☒ describe quality of scientific evidence [including lack of evidence] 11.5a, 11.5b

☒ uses evidence from studies of patients similar to those of target audience 11.6

Disclose conflicts of interest?

☐ report source of funding to develop and distribute the patient decision aid 7.1, 7.2

☐ report whether authors or their affiliations stand to gain or lose by choices patients make after using the patient decision aid 7.3, 7.4

Use plain language?

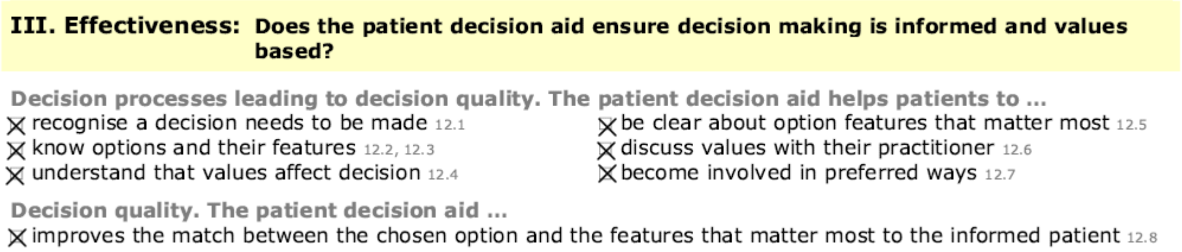
☒ is written at a level that can be understood by the majority of patients in the target group 10.3

☐ is written at a grade 8 equivalent level or less according to readability score [SMOG or FRY] 10.4

☒ provides ways to help patients understand information other than reading [audio, video, in-person discussion] 10.5

Figure 41: Filled Out Part 2 of the IPDAS Questionnaire

For the third and last part of the checklist regarding the tool ensuring an informed decision-making all criterias were fulfilled. The cards put a focus on the 'Three Decision' approach by Elwyn et al. [11], which outlines the importance of encouraging the patient to make decisions about their treatment approach. Based on this, the instructions for the HCP highlight this as an important part for the use of the decision tool. In addition, by setting a goal as the first task the patient gets a chance to formulate what they find important for their treatment.



III. Effectiveness: Does the patient decision aid ensure decision making is informed and values based?

Decision processes leading to decision quality. The patient decision aid helps patients to …

☒ recognise a decision needs to be made 12.1

☒ know options and their features 12.2, 12.3

☒ understand that values affect decision 12.4

☒ be clear about option features that matter most 12.5

☒ discuss values with their practitioner 12.6

☒ become involved in preferred ways 12.7

Decision quality. The patient decision aid …

☒ improves the match between the chosen option and the features that matter most to the informed patient 12.8

Figure 42: Filled Out Part 3 of the IPDAS Questionnaire

Chapter 8 – Discussion & Future Work

8.1 Discussion of the Functional Requirements Evaluation

The requirements which were evaluated as being ‘mostly fulfilled’ during the functional evaluation were number 4 and 5 of the must requirements, and number 2 of the could requirement. The fourth requirement is about the need to include a variety of different treatment options in order for the decision tool to be fully usable. The reason the prototype only mostly fulfils the fourth requirement is because while it contains two domain cards, there are no followup cards for the ‘Medication Adherence’ domain which is why it was rated as only mostly fulfilled. In order to fully fulfil this requirement side goal cards for this domain should be developed at the very least. Additionally, more domain cards should be developed with their own side goal cards. Domains could include ‘Mental Health’, ‘Diet’, and ‘Exacerbation Management’. Including several options is also important to avoid the ‘framing problem’ drawn up by Wirtz et al.[32]. Wirtz et al. also point out that options get excluded due to outside factors like policies and guidelines, but also due to HCPs not being familiar with an option. In order to avoid this the domains and the areas they cover should be based on peer review to make sure they are understandable and achievable by healthcare professionals.

The fifth requirement’s focus is on the availability of information to the patient. The decision tool prototype contains motivation texts regarding each option and what the benefit is of choosing this option, however no further information is included. Other forms of information that the tool could utilise are patient experience reports, statistical information, drawbacks, and general explanatory information. As Elwyn et al. [11] describe, having these forms of information is important in order for the patient to make informed decisions which then lead to higher patient satisfaction with the SDM process [3]. Including this kind of variety in the cards quickly runs into one of the main constraints of this design approach to decision tools: The cards only have a limited amount of physical space and having several cards for one domain or side goal can likely lead to confusion. As can be seen in the second non-functional requirement evaluation session, users who were using the tool for the first time had issues with identifying the correct side goal cards with a choice of 5 cards in the same colour, this problem is only bound to increase with more cards for each individual side goal. A design that clearly distinguishes between main card and add-on cards is needed in order for this to be a viable option.

If we compare these forms of providing information with the IPDAS check-list [37] another way this tool should offer information is by giving general information about COPD. In order to best fit into the structure of this card based tool, as well as into the time limitation of a consultation, this kind of information should be included on cards that are not used during the session but given to the patient to take back home with them as part of their treatment plan. If done this way, the information cards should also include instructions and information about the use of the tool and how the side goal and long goal cards are to be used outside the consultation session with the healthcare professional.

The requirement which was not fulfilled by the prototype was the first could-requirement, regarding a digital dashboard for the HCP to note down the results of consultation sessions. A dedicated digital dashboard or sister tool could not only assist the decision tool but is also relevant for this project as it directly connects to the RE-SAMPLE project [14] which this bachelor thesis is part of. Using a digital tool could allow for extra information streams to be used for consideration before and during the SDM consultation. Digital health data could be used and analysed to help the healthcare professional prepare domains for a consultation depending on the areas that are identified as troubling. A dedicated tool for the card-based decision tool would also allow for easier entry of the choices made during a consultation, by having checklists or options directly related to what is available in the paper-based tool. Another aspect that could improve the SDM process is for the digital tool to include explanations and further information about options exclusively for the healthcare professional. This way, the HCP can look up any option they might run into for which they lack information and then convey this information to the patient.

8.2 Discussion of the Non-Functional Requirements Evaluation

Looking at the three non-functional evaluation sessions, several differences can be found, especially between session 1 and session 3. The evaluation process and focus was the same, however outcomes were very different in the area of achieving a shared decision-making session, as well as liking the design of the cards. The main factor contributing to the discrepancy in feeling like the user had a say in the conversation most likely stems from the person conducting the user evaluation. For session 1, the researcher of this project conducted all parts of the evaluation, and thus was able to easily answer questions and help the user understand the cards, as well as have a more practised approach to the evaluation.

For session 3 another student was asked to help conduct the evaluation due to the need for the evaluation to take place in Dutch as all users who were invited only spoke Dutch and no English, with the researcher not speaking any Dutch. The student who was asked to conduct the evaluation in the researcher's place had only limited time to become familiar with the script and the contents of the cards themselves, without the possibility of familiarising themselves with the more in depth part of the project. In result, the evaluation session was not able to go too in depth into the side goal discussion and the tester had to rely more on the provided evaluation script than a more free flowing conversation which contributed to the test user feeling less involved in the consultation. Another factor for the low score regarding shared decision-making in session 3 was the user needing a lot more information about the available options in order to feel comfortable in making a choice stating they would have preferred either a more in depth explanation or a lot more information within the tool. This correlates with the IPDAS checklist, which showed the tool lacking in the areas of providing information. This lack was partly by design in order to allow the HCP to provide the needed information via conversation with the patient, aiming at creating a better basis for a shared decision-making conversation. However, this does not work if the person embodying the healthcare professional lacks this crucial information, which was the case in session 3. A future step should be to conduct an evaluation with people living with COPD and actual healthcare professionals. This also correlates with the third factor named by the test user, in which they stated that they would have felt more comfortable talking about treatment approaches with someone with a medical background such as a physiotherapist.

For session 3, this lack of feeling of having a say in the conversation also relates to their rating of the contents of the cards: Session 3 had a very different rating than session 1 and 2. They had the impression that the cards lacked information, while the motivation text on the cards was too much text. They would have preferred an approach that used illustrations and icons with informative text, rather than motivational text. This is comparable to the feedback from session 2 and session 1, where the users felt that the motivation texts were redundant, despite liking the overall information provided during the session. For session 2 especially, the feedback was that the users playing healthcare professionals would have liked more statistical information in order to better advise and understand the different options. Feldmann-Stewart et al. [12] recommend patient experience reports as a possible way for decision tools to communicate information, which for the cards seems a viable option. This way the medical information can still be conveyed by the healthcare professional while the more personal side of the treatment option is contained on the cards, letting the patient make a more informed decision. This approach also aligns with the design goal of this paper-based decision tool which is to ensure that the tool contains only enough information to allow the patient to get alternative viewpoints while still keeping a focus on the healthcare professional being vital to acquire the full information about options. This way the concern voiced by Marrin et al. [7] and Hsu et al. [3] of the tool being used without the assistance of a HCP is reduced.

In session 3 the user did not like the colours of the cards, mainly due to the red colour choice for the ‘Physical Domain’ card and side goal cards. This rating should be compared to both session 1 and session 2 which gave the colour choice an average rating of 4.2. Notably, the user feedback for session 3 was limited to only one person, which means that the colour preference might just be a personal preference; it is therefore advisable to conduct a user survey about colour preferences with the age group most likely to use the decision tool which for COPD are adults aged 40 and older [15]. This way a generational difference can be excluded and the tool is more likely to ensure that options are not disregarded or badly received due to colour choice.

In addition to changing the colours of the cards, a general re-design for the cards should happen in order to include a more direct design difference between domain cards and side goal cards. During session 2, the feedback was that all users who had to use the tool from the perspective of a healthcare professional had issues identifying followup cards for the ‘Physical Domain’ card. Suggestions that were given were to change the border style of cards to allow for a more immediate distinction besides text and illustration layout. This could be achieved by giving the side goal cards striped borders in the colour of their domain or by making the domain cards one uniform colour without a border while the side goal cards retain their borders. The main takeaway from this feedback is that the distinction between card types should be made easier. Based on the feedback received in session 2, this design change would also improve the ability to follow the instruction cards contained with the decision tool.

Another point that was brought up by the users of session 2 was that they as healthcare professionals would have liked more medical and statistical information for the options. This way they could have better analysed the possible options and determine how applicable they are to the user, which would have allowed them to give better advice. In order to avoid the issue of the tool being used by the patient outside a consultation as described by Marrin et al. [7] and Hsu et al. [3] this information should be available in a separate part of the decision tool. One possible option could be the digital dashboard mentioned in the functional requirements. This way HCP specific information about the cards can be provided without running into the space restrictions of the cards or the danger of providing too much information within the cards.

One statement which all user groups of the non-functional evaluation agreed on, was that the conversation resulting from using the cards felt natural. This is important as it shows the viability of using the card-based decision tool as part of a consultation conversation as they do not interfere with the conversation itself and instead enhance it. Taking the cards out and giving the users the time to read them in order to then base the conversation around the options of the cards resulted in a conversation the users enjoyed. Especially during session 1 and 2 observations were made of the users enjoying holding and looking at the cards, getting them more involved in the evaluation session itself. Also in session 3, the user studied the cards though no increase of engagement could be observed. This correlates with the rating of the design of the cards with 7 out of 9 users fully agreeing that they liked the design, 1 user agreeing that they liked the design though they did not find the illustrations particularly appealing, and only one user from session 2 disagreeing with the statement and giving the cards a rating of 2.

8.3 General Discussion

The conducted evaluations were able to highlight the strength of the paper-based decision tool and to show the areas which can be improved. Overall, the evaluations show that the tool is capable of creating a shared decision-conversation, and the overall design as well as the feel of the cards was positively received; furthermore, the cards were able to engage the users into a more involved consultation. One aspect that was not able to be evaluated was a peer-based evaluation from the perspective of actual healthcare professionals. Ideally, at least one additional evaluation session should have been conducted with a healthcare professional. Throughout the project, several attempts were made to reach out to healthcare professionals, which all resulted in either no reply or a ceased communication from the side of the healthcare professional after initial responses. A future step should be to work more closely with HCPs and get direct feedback from them in order to ensure equal input from both intended user groups.

Another future point for evaluation should be focusing on the time needed to conduct a consultation using the cards. Time is a commonly named factor which prevents HCPs from utilising decision tools [3,6,7,12]. This need is highlighted by the information provided by Politi et al. [6] as well as Schultz et al. [12], who point towards healthcare professionals preferring tools that can be used outside a consultation session in order to reduce the time investment needed. This is not possible with the card-based decision tool of this project as tool is specifically designed to avoid this preference: It is intended to only be fully usable by involving both parties. The three conducted evaluation sessions did limit the use of the tool to 10 to 15 minutes which falls into the rough average for the time spent on consultation sessions [35], however, this was with a scripted and planned use of the tool and does not fully represent a real-life consultation session. Evaluating the time needed to use this tool and successfully achieve a SDM consultation with a patient, should be paired with the evaluation involving actual healthcare professionals. This way insights can be gained concerning the HCPs compression of the tool as well as the way the tool would be used in the field.

One issue that was encountered during the non-functional requirement evaluation session 3, was that 2 out of the 3 confirmed users did not show up for the evaluation. The first user who did not appear simply forgot about the appointment, so making sure that reminder emails are sent out at least a day before the evaluation session is advised. The other test user did make it to the campus of the University of Twente, however, after not finding the building as well as being frustrated with the location of the parking area, this user left before contacting the researchers. Something to consider for future evaluation with patients who live with COPD is to conduct the evaluation in a space that is more easily accessible by car. This way it is less of a burden for people struggling with walking long distances to reach the evaluation location.

8.4 Future Work

The current version of the paper-based tool is on the basis of a prototype. This means that the basis for the tool is finished, with layout of the cards, visual design, and functionality, but the content needs to be expanded upon in order to be fully usable as a decision tool for shared decision-making with healthcare professionals and patients with COPD. The tool needs more domains, with their own side goal cards and treatment options. In addition, design improvements based on the evaluation feedback should be implemented.

Future domains could include ‘Mental Health’, ‘Diet’, and ‘Exacerbation Management’. For the domains that have already been worked on, ‘Medication Adherence’ needs to receive side goals. For ‘Physical Activity’, additional side goals could be developed in order to offer a wider range of options. This also ties into the feedback received during session 1, where the users would like to see the tool progress together with them. This could be achieved by having side goal cards that increase in “difficulty” or that are only available once a certain step is reached in the treatment progress. One aspect to keep in mind however is that more cards will result in more time investment needed to fully use the tool, so there needs to be a balance between card amount and available time. In addition, creating explanation cards for the different options listed on the side goal cards would help the tool communicate information better. For options like ‘Chair Yoga’ which can be found on the ‘Workout’ side goal card, this explanation card could have different exercises listed with illustrations and instructions on how to do them. With that, the patient can re-read and make sure they follow the exercise properly even without a HCP in the same room.

One aspect that could be improved for a future version of this tool is to create a design that makes it easier to distinguish between domain cards and side goal cards. This way the confusion encountered in session 2 can be reduced and the tool can more easily ensure that the cards are used properly. This includes potential colour changes based on a user survey. In addition to that, the instruction cards should be revised and expanded upon to allow a better understanding of the tool. To help with that a companion dashboard could be implemented that allows the HCP to get medical information about card options as well as assist them to document the consultation.

Then, in order to more closely follow the IPDAS requirements for a decision tool, information cards should be included that focus more on talking about COPD and what it entails rather than just the goal finding aspect of SDM.

Improving the tool in these areas should result in a more rounded and well-defined decision tool that during all applications results in a shared decision-making session.

Chapter 9 – Conclusion

Shared decision-making in combination with decision tools has been shown to improve the communication between patients and healthcare professionals, improve the patients satisfaction with the treatment [1, 38], as well as improve the patients adherence to treatment plans [8]. This adherence is especially helpful for treatment of COPD, where lifestyle changes are a typical a big part of the treatment [15].

The goal of this graduation project was to design and develop an interactive paper-based tool which can be used to facilitate a shared decision-making session between healthcare professionals and their patients with COPD and comorbidities. Over the course of this project, a prototype for a card-based decision tool which enables conversations between healthcare professionals and patients was developed, consisting of 2 domain cards, 4 side goal cards, 3 instruction cards for the HCP, and personal goal cards for the patient.

The prototype was evaluated based on a functional analysis, three separate user evaluation sessions, and by using the IPDAS checklist which is an international standard for decision tools. The evaluation phase showed that the developed card-based tool has the potential to facilitate a shared decision-making session. Further development could contribute to the tool’s capability to reliably create SDM sessions for healthcare professionals, and patients with COPD and comorbidities.

In addition, using a digital dashboard could increase the versatility of this paper-based tool, allowing it to tie into the RE-SAMPLE project which uses digital data to enhance patient and healthcare professional communication. This data paired with the card-based tool has the potential to create a successful shared decision-making conversation between patients and their healthcare professionals, and allows the patients to make more informed choices regarding their health.

Appendix A - Sources

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Appendix B - Card Designs

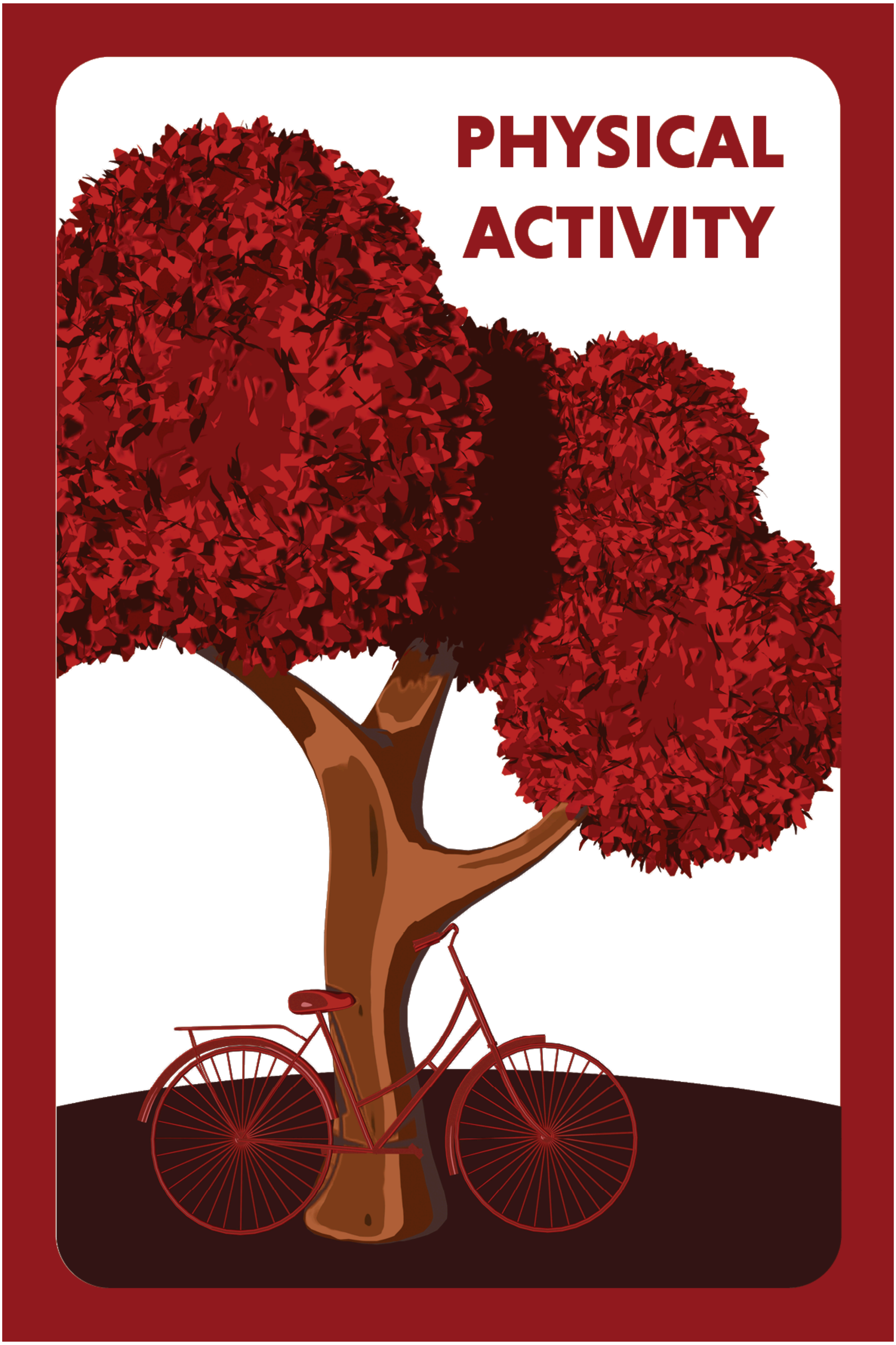
Example Personal Goals:

- Have less COPD exacerbation attacks
- Reduce the strength of exacerbation attacks
- Less visits to the hospital

Motivation:

Regular intake of medication will reduce your symptoms and flare-ups. Sticking to a routine will help the medication to work properly and once they take effect, medication will improve your day to day life.

PHYSICAL ACTIVITY



Example Personal Goals:

- Walk up my stairs without running out of breath.
- Meet with friends regularly.
- Go outside when it is sunny and enjoy the day.
- Lose weight and move more freely.

Motivation:

Physical Activity will increase your energy and strength, which will let you move around more freely, reduce risk of flare-ups, and enables you to go along your day with less breaks. It can also prevent worsening of symptoms and exacerbations.

WORKOUT

Your workout could include:

- Upper and lower limb strengthening
- Aerobic
- Chair Yoga

You can workout for:

5 minutes **10** minutes **15** minutes

1 | 2 | 3 | 4 times a week.

Motivation:

Regular workout will help you build up your body strength, and increase your endurance and mobility.

GARDENING

Gardening could include:

- Watering your flowers
- Raking leaves
- Mowing the lawn

You can work in the garden for:

10 **minutes** **15** **minutes** **20** **minutes**

1 | 2 | 3 | 4 times a week.

Motivation:

Gardening will build up your strength again, and naturally increase your motivation and mental energy.

GOING FOR A WALK

Going for a walk could include:

- Going to the park
- Grocery shopping
- Visting a friend

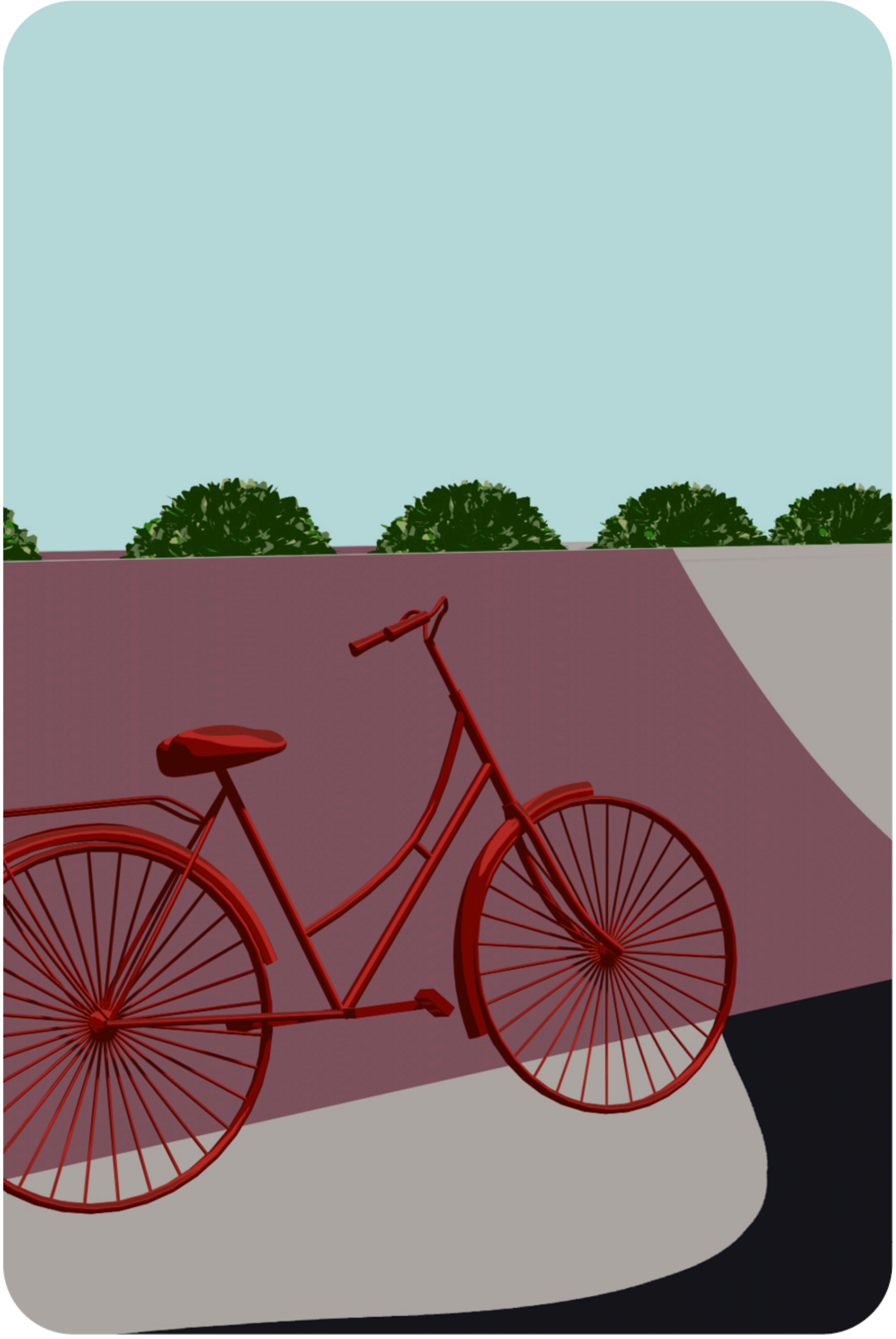
You can go on a walk for:

30 minutes **40** minutes **60** minutes

2 | 4 | 6 times a week.

Motivation:

Going on a walk will improve your heart and lung fitness, build up muscles and energy, and increase strength and endurance.



RIDING YOUR BIKE

Riding your bike could include:

- Riding to your friend or the park
- Riding to your next appointment
- Riding to the store

You can ride your bike for:

10 minutes **15** minutes **20** minutes

1 | 2 | 3 | 4 times a week.

Motivation:

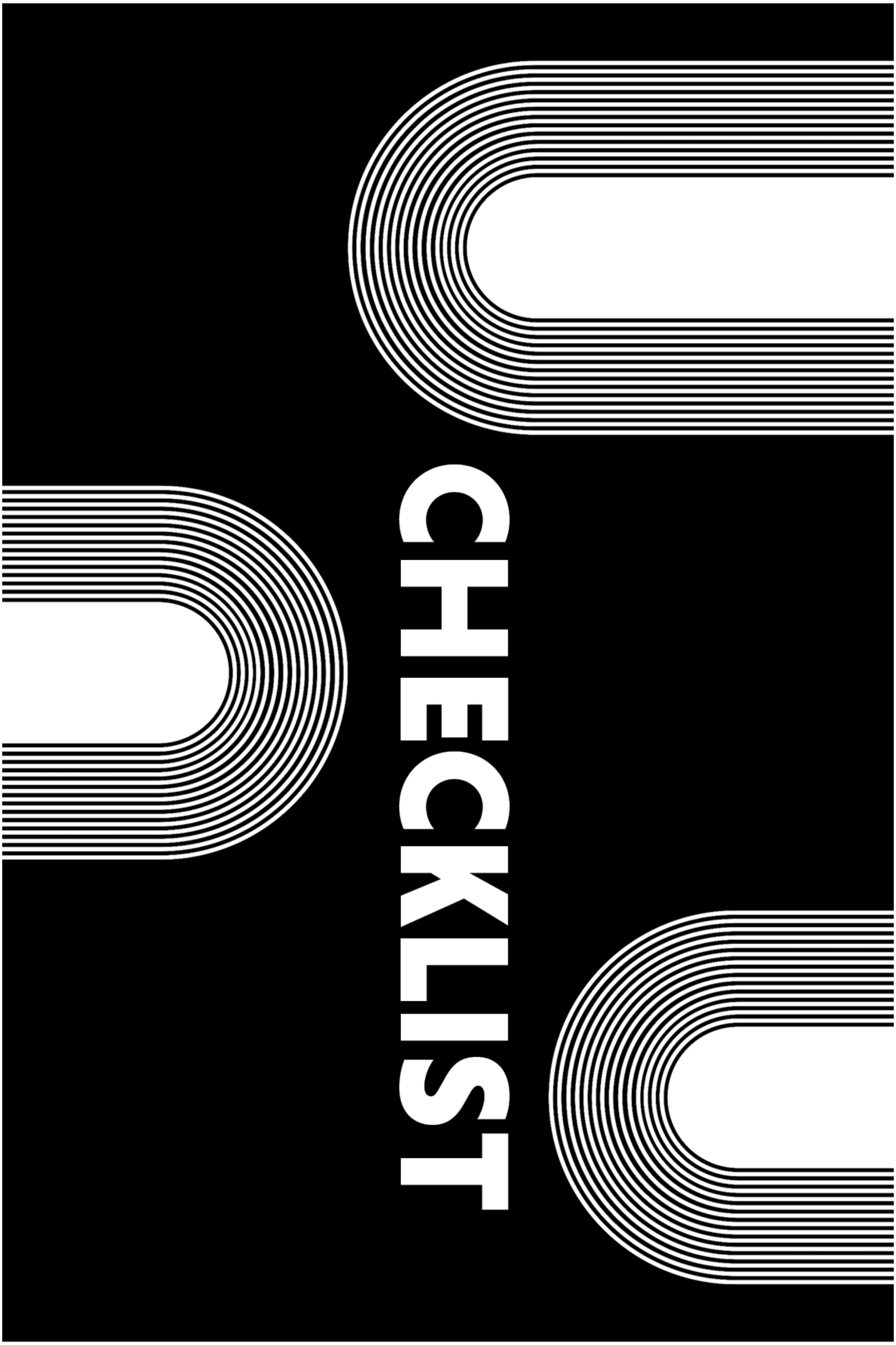
Riding your bike will help you build up strength, and increase your endurance and mobility.

Before the session:

- What do you know about the patient?
- For how long have they been living with COPD?
- Is there medical information available?
- Do you already have an idea what goals they have for their treatment?

→ Pre-arrange domains based on your knowledge about the patient.

The aim of this session is to help the patient find a personal goal they want to achieve with their treatment.



CHECKLIST

During the session:

Ask the patient about their preferences!

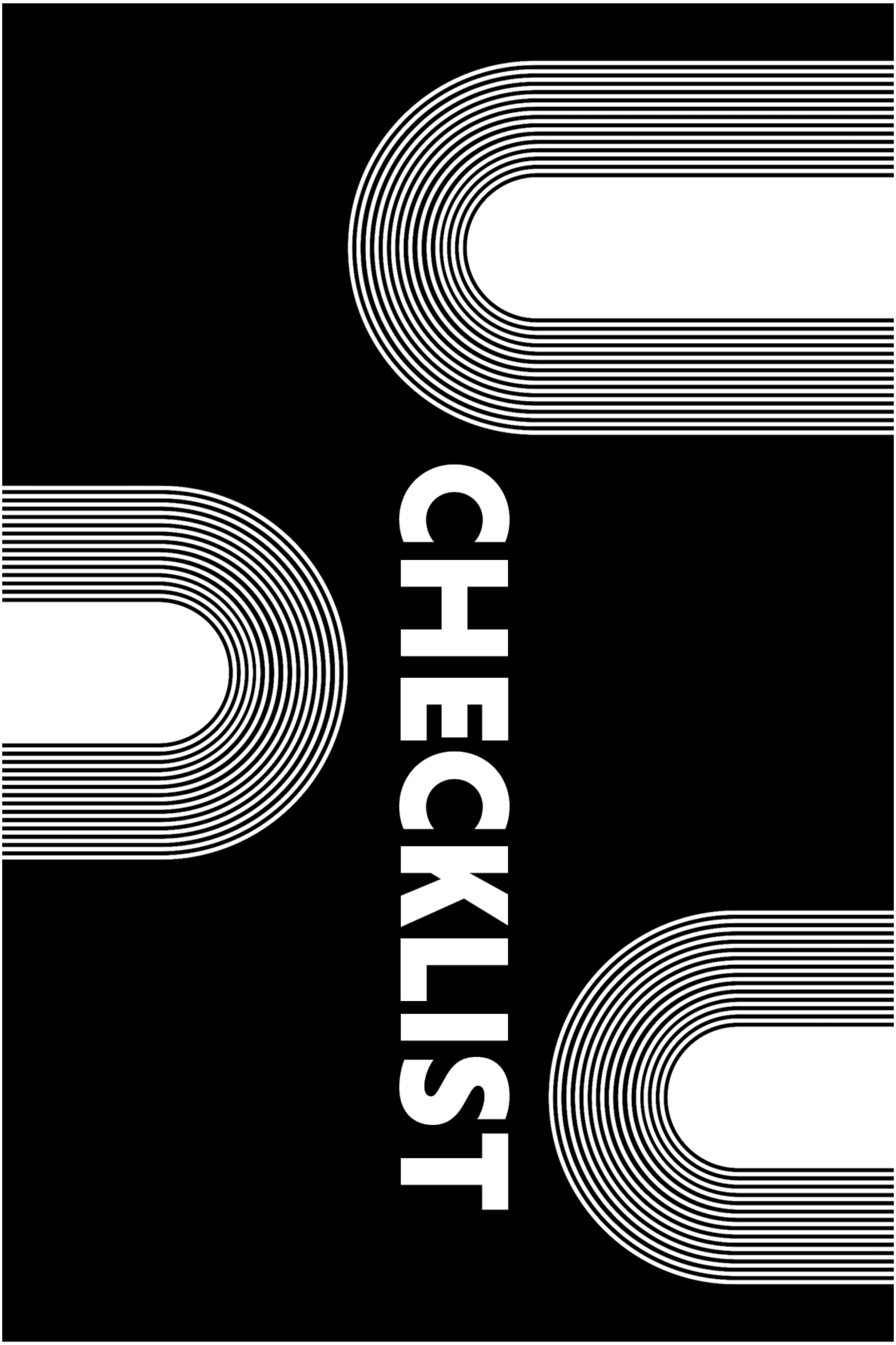
- What do they struggle with currently?
- What would they like to improve in their day-to-day life?

☐ Explain the domains and side goals. Encourage your patient to ask questions.

☐ Encourage them to contemplate their options and to make a choice between one of the domains.

☐ Find a personal goal within the chosen domain. Something they feel motivated to work towards.

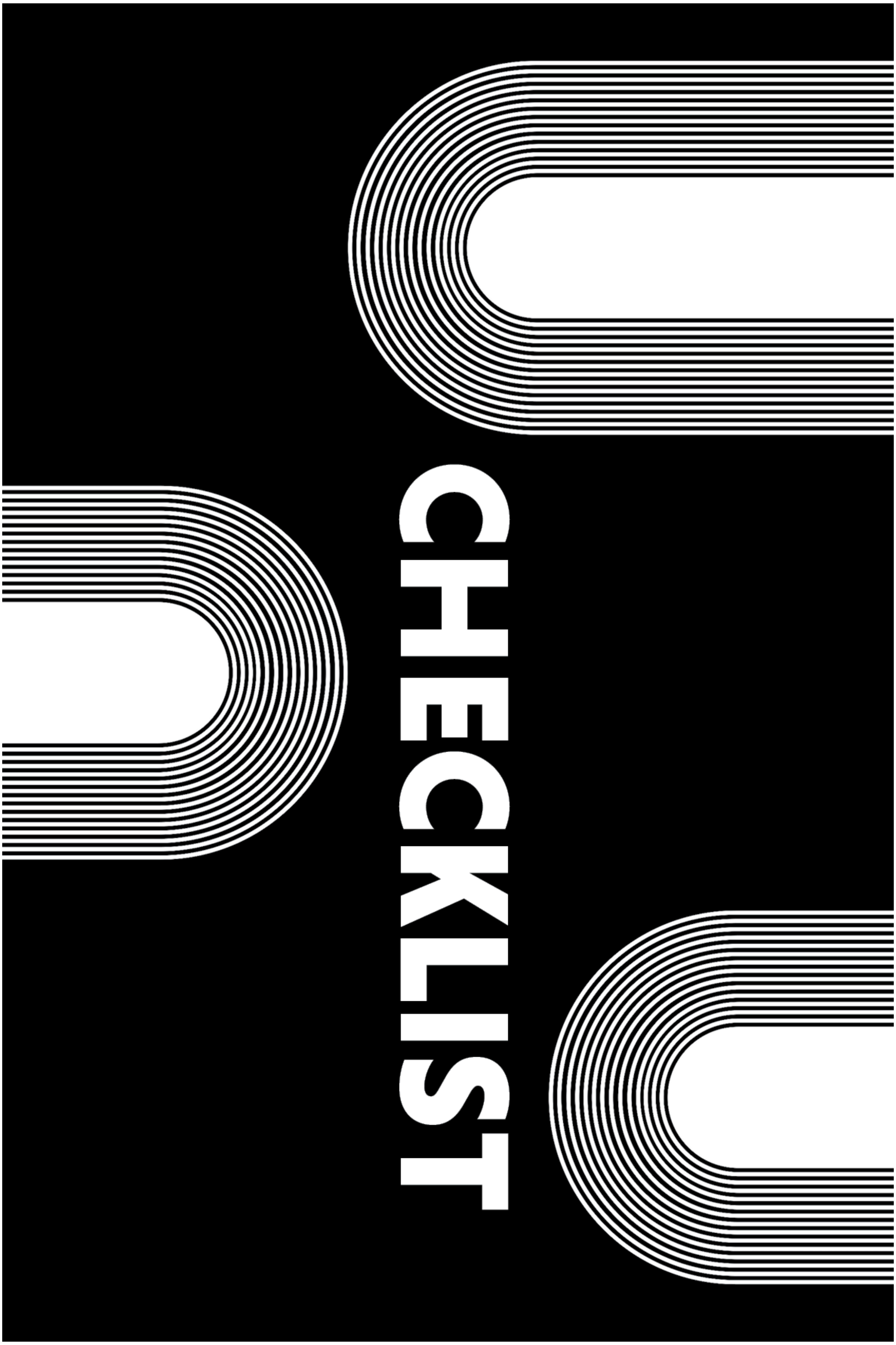
☐ Help the patient choose side goals to work towards their personal goal.



CHECKLIST

After the session:

- ☐ What domain did the patient decide on?
- ☐ What was the personal goal of your patient?
- ☐ Which side goals were chosen to work towards the personal goal?
- ☐ Did previous goals get achieved?
- ☐ What went well/What didn’t go well?



CHECKLIST

I want to,

I achieved my side goals

☆ ☆ ☆ ☆ ☆ ☆ ☆

☆ ☆ ☆ ☆ ☆ ☆ ☆

☆ ☆ ☆ ☆ ☆ ☆ ☆

☆ ☆ ☆ ☆ ☆ ☆ ☆

MY GOAL

Appendix C - Information Brochure and Consent Form for Session 1 and 2

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Information Brochure

You are asked to participate in research activities concerning the design of a shared decision-making tool for COPD patients and healthcare providers as part of the bachelor's thesis of **Byron Wider**. You will be informed both in writing by this brochure and orally before the start of the prototype evaluation. This information brochure is meant to inform you more generally and more detailed information will be given orally. Your participation in this research is voluntary, and you are free to withdraw from participation at any time.

What is the purpose of this research?

This research, led by the University of Twente with the faculty of Biomedical Signals & Systems (BSS), is conducted in the context of the bachelor thesis: "Design of a paper-based shared decision-making tool for patients with COPD and comorbidities.". The objective of the thesis is to research the design for an interactive paper-based shared decision-making tool which incorporates a decision aid for the process of shared-decision making.

You are asked to participate in a prototype testing session, which will have you interact with the prototype tool guided and assisted by a researcher. The tool consists of several cards with visuals and information text about potential approaches on how to improve existing conditions of COPD. The focus hereby is going to be on 'Physical Activity'. During this test you are asked to interact and use the tool together with the researcher with the goal of finding a 'personal goal' for you to approach therapy of COPD. This is followed by a short interview afterwards asking about your impressions as well as a short questionnaire. This questionnaire will ask you to rate several statements about the tool. At no point during or after the test will you as user be evaluated, the purpose of the prototype testing is to evaluate only the tool itself.

What is shared-decision making and decision aids?

Shared decision-making (SOM) is a collaborative approach to healthcare that involves patients, clinicians, and other stakeholders working together to make informed decisions about patient care. In Chronic Obstructive Pulmonary Disease (COPD), SOM can be crucial in managing the disease and improving patient outcomes. Some critical aspects of shared decision-making for COPD include: Patient Engagement, Communication, Evidence-Based Decisions, Personalized Care and Empowerment (Moleman, 2021).

Decision aids are tools designed to assist patients and healthcare providers in making informed decisions. They can include Clinical Guidelines, Patient Education Materials, Health Information Technology Systems, and Simulation Models (Bonneux, 2021).

In summary, shared decision-making and decision aids work together to support COPD patients in making informed decisions about their care. By engaging patients in decision-making and providing evidence-based information, healthcare providers can help patients manage their COPD effectively and achieve better health outcomes.

What research techniques will be employed, and how will my data be used?

You are asked to participate in a prototype evaluation for a decision tool made for shared decision-making with healthcare professionals, and patients with COPD and comorbidities.The evaluation will take around 30 minutes. The researcher will explicitly discuss which topics you are comfortable discussing, and you have the right not to answer questions or to refuse doing any task without needing to provide a reason. The researcher will take notes during the evaluation and during the follow-up interview. Your data will be anonymised, which will only be accessible to the researchers involved in this project. These are the supervisors of this bachelor thesis and possibly other students working on a similar topic involving COPD patients and shared decision-making. None of the data will be made public, and none will be used for promotional purposes. Your anonymized data may be utilised for further research by the supervisors of this work.

Additional Information:

If you wish to seek independent advice or file a complaint, you can contact the secretary of the ethics committee of the University of Twente (ethicscommittee-cis@utwente.nl). For any additional questions regarding this research, please get in touch with Roswita Vaseur (r.m.e.vaseur@utwente.nl) or the researcher themselves, Byron Wider (b.c.wider@student.utwente.nl) or Anica Kruger (a.kruger@student.utwente.nl).

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Consent Form for Design and Development of an Interactive Paper-Based Shared Decision-Making Tool for Healthcare Professionals and Patients with COPD and Comorbidities.

YOU WILL BE GIVEN A COPY OF THIS INFORMED CONSENT FORM

Please tick the appropriate boxes	**Yes**	**No**
Taking part in the study		
I have read and understood the study information in the form of the Information Brochure dated ___|___|____ or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	○	○
I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions or perform any tasks and I can withdraw from the study at any time, without having to give a reason.	○	○
I understand that taking part in the study involves interacting with the prototype to perform certain tasks, while the researcher will take notes. There will be a follow-up interview about the prototype and my opinion, where all my data and notes on my session are anonymized.	○	○
Use of the information in the study		
I understand that information I provide will be used for the report of the Bachelor Thesis, which can be published later on. As well as used by the supervisor of the project and the client of the project: RE-SAMPLE	○	○
I understand that personal information collected about me that can identify me, such as [e.g. my name or where I live], will not be shared beyond the study team.	○	○
Future use and reuse of the information by others		
I agree that my information may be shared with other researchers for future research studies that are similar to this study. The information shared with other researchers will not include any information that can directly identify me. Researchers will not contact me for additional permission to use this information.	○	○
I give the researchers permission to keep my contact information and to contact me for future research projects.	○	○
I give the researchers permission to keep my contact information and to contact me for future research projects.	○	○

Signatures

_____________________ Name of participant

_____________________ Signature

________ Date

UNIVERSITY OF TWENTE.

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

________________ ____________________ _________

Researcher name Signature Date

Study contact details for further information:

Byron Wider

b.c.wider@student.utwente.nl

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee Information & Computer Science: ethicscommittee-CIS@utwente.nl

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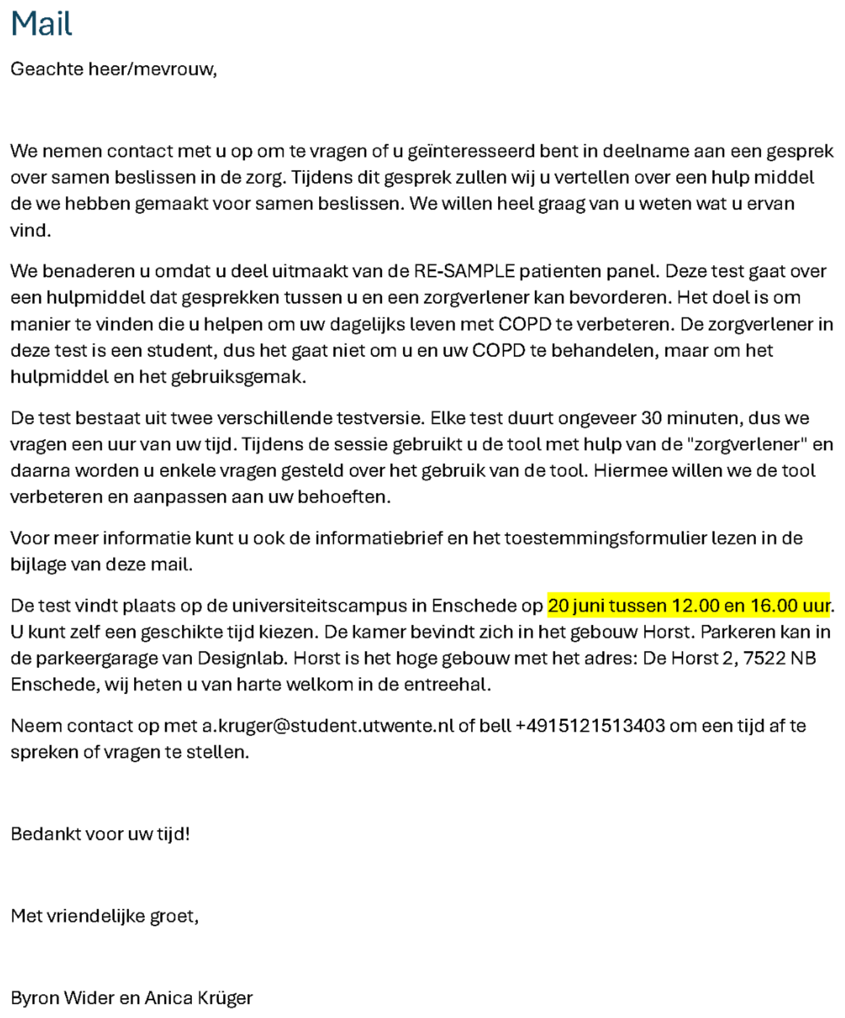
Appendix D - Information Brochure and Consent Form for Session 3



Mail

Geachte heer/mevrouw,

We nemen contact met u op om te vragen of u geïnteresseerd bent in deelname aan een gesprek over samen beslissen in de zorg. Tijdens dit gesprek zullen wij u vertellen over een hulp middel de we hebben gemaakt voor samen beslissen. We willen heel graag van u weten wat u ervan vind.

We benaderen u omdat u deel uitmaakt van de RE-SAMPLE patienten panel. Deze test gaat over een hulpmiddel dat gesprekken tussen u en een zorgverlener kan bevorderen. Het doel is om manier te vinden die u helpen om uw dagelijks leven met COPD te verbeteren. De zorgverlener in deze test is een student, dus het gaat niet om u en uw COPD te behandelen, maar om het hulpmiddel en het gebruiksgemak.

De test bestaat uit twee verschillende testversie. Elke test duurt ongeveer 30 minuten, dus we vragen een uur van uw tijd. Tijdens de sessie gebruikt u de tool met hulp van de "zorgverlener" en daarna worden u enkele vragen gesteld over het gebruik van de tool. Hiermee willen we de tool verbeteren en aanpassen aan uw behoeften.

Voor meer informatie kunt u ook de informatiebrief en het toestemmingsformulier lezen in de bijlage van deze mail.

De test vindt plaats op de universiteitscampus in Enschede op 20 juni tussen 12.00 en 16.00 uur. U kunt zelf een geschikte tijd kiezen. De kamer bevindt zich in het gebouw Horst. Parkeren kan in de parkeergarage van Designlab. Horst is het hoge gebouw met het adres: De Horst 2, 7522 NB Enschede, wij heten u van harte welkom in de entreehal.

Neem contact op met a.kruger@student.utwente.nl of bell +4915121513403 om een tijd af te spreken of vragen te stellen.

Bedankt voor uw tijd!

Met vriendelijke groet,

Byron Wider en Anica Krüger

Informationbrief

Beste lezer,

Met deze brief willen wij u informatie geven over het groepsgesprek waaraan u mee gaat doen. Dit groepsgesprek zal plaatsvinden op donderdag 20 juni 2024 van 12:00 tot 16:00, op de universiteit van Twente (UT). Via dit gesprek, dat samen beslissen heet, willen we graag meer te weten komen over uw ervaring met samen beslissen in de zorg en uw voorkeuren wanneer informatie met u gedeeld wordt tijdens een afspraak met uw arts. Deze informatie geeft ons meer inzicht hoe we samen beslissen tussen u en uw arts kunnen vergemakkelijken. Dit zullen we doen in het RE-SAMPLE project dat wordt gecoördineerd door de Universiteit van Twente. In RE-SAMPLE doen we onderzoek naar mogelijke voorspellers van ziekte achteruitgang van Chronic Obstructive Pulmonary Disease (COPD) en andere chronische ziekten. Wij hopen dat de RE-SAMPLE aanpak zal helpen bij het voorkomen van achteruitgang en patiënten zal ondersteunen in zelfmanagement en beslisvorming

Wat moet ik doen als ik meedoe?

In de gesprekke zullen we door de volgende stappen heen gaan:

1. Eerst zullen de onderzoekers kort vertellen wie zij zijn en wat ze gaan doen.
2. Daarna geven we een introductie van onze testversies
3. Daarna ga je aan de slag met de versies
4. Daarna willen we van u meer weten over samen beslissen en uw voorkeuren daarvoor.
5. Als laatste sluiten we nog even samen af en het is tijd voor vragen.

Zijn er nadelen als ik meedoe aan de studie?

Er zijn geen risico's bij dit onderzoek. Deelname aan het onderzoek is vrijwillig; u kunt op elk moment besluiten te stoppen zonder daarvoor een reden te geven en zonder dat het gevolgen heeft.

Wat doen jullie met mijn data?

Tijdens het onderzoek zullen we de volgende data verzamelen:

- Uw toestemmingsformulier
- Uw demografische data
- Uw antwoorden tijdens het interview

We zullen daar voorzichtig mee omgaan. Nadat wij alle gesprekken gevoerd hebben zullen we op de volgende manier alle data verwerken:

- Uw toestemmingsformulier zullen wij inscannen. De papieren versie wordt na het scannen vernietigd en de digitale versie wordt na 10 jaar verwijderd.
- We gebruiken in plaats van uw naam een code, waarmee we uw geslacht en leeftijd aan uw uitspraken kunnen koppelen.
- Aantekeningen tijdens de gesprekken zullen anoniem gemaakt worden. Ook deze anonieme aantekeningen worden 10 jaar bewaard en daarna verwijderd.
- De anoniem gemaakte teksten, anoniem gemaakte aantekeningen en de achtergrondinformatie kunnen wel gedeeld worden met andere onderzoekers binnen ons project en quotes hieruit kunnen gebruikt worden in onze artikelen en presentaties. Ook combineren we deze data mogelijk met data uit andere studies binnen ons project.

Toestemmingsformulier

Beste lezer,

U bent gevraagd mee te doen aan een groepsgesprek over samen beslissen in de zorg. Leest u alstublieft de zinnen hieronder goed door en vink het vakje aan als u het er mee eens bent.

	Ja	Nee
1. Ik heb de informatiebrief met datum 12-06-2024 gelezen, of deze is mij voorgelezen.	☐	☐
2. Ik kon vragen stellen over het onderzoek en die zijn goed beantwoord.	☐	☐
3. Ik neem vrijwillig deel aan dit onderzoek.	☐	☐
4. Ik snap dat deelname aan het onderzoek betekent dat ik meedoe in een gesprek.	☐	☐
5. Ik weet dat ik op elk moment kan weigeren vragen te beantwoorden en kan stoppen met mijn deelname zonder dat dat gevolgen heeft.	☐	☐
6. Ik behoud het recht om deze toestemming af te zeggen zonder daarvoor een reden te geven en ben me ervan bewust dat dit op elk moment kan.	☐	☐
7. Ik begrijp dat alleen de geanonimiseerde data gedeeld worden binnen het project.	☐	☐
8. Ik begrijp dat de geanonimiseerde data gebruikt kan worden in (wetenschappelijke) publicaties en presentaties. Mogelijk worden hierbij ook anonieme quotes gebruikt.	☐	☐
9. Mij is duidelijk dat mijn persoonlijke gegevens (inclusief de audio opnames) niet zonder mijn uitdrukkelijke toestemming met derden gedeeld zullen worden.	☐	☐

Ondertekend in tweevoud:

________________	________________	________________
Naam deelnemer	*Handtekening deelnemer*	*Datum*

Ik heb toelichting gegeven over het onderzoek. Ik verklaar mij bereid om nu en in de toekomst eventuele vragen over het onderzoek te beantwoorden.

________________	________________	________________
Naam onderzoeker	*Handtekening onderzoeker*	*Datum*

Vragen
Als u nog vragen heeft over deelname aan het onderzoek kunt u die stellen aan Anica Krüger (zie contactinformatie onderaan de brief). De plannen voor dit onderzoek zijn gecontroleerd door de Ethische Commissie Geesteswetenschappen van de Universiteit Twente.

Met vriendelijke groet,
Anica Krüger en Byron Wider

Uitvoerder:

Anica Krüger
Universiteit Twente, EEMCS, Creative Technology
Email: a.kruger@student.utwente.nl
Tel: +4915121513403

Demografische data

Datum:

Tijd:

Interviewee:

1. Wat is uw geslacht?
    - ☐ Man
    - ☐ Vrouw
    - ☐ Anders

2. Wat is uw geboortejaar? (JJJJ) _______________

3. In welke COPD GOLD fase zit u?
    - ☐ GOLD-I
    - ☐ GOLD-II
    - ☐ GOLD-III
    - ☐ GOLD-IV
    - ☐ Ik weet het niet

4. Welke comorbiditeiten heeft u?
    - ☐ Geen
    - ☐ Angst/depressie
    - ☐ Diabetes
    - ☐ Chronisch hartfalen
    - ☐ Ischemische hartaandoeningen
    - ☐ Anders, namelijk _______________

5. Wat is uw onderwijsniveau?
    - ☐ MBO
    - ☐ HBO
    - ☐ WO
    - ☐ Anders, namelijk _______________

6. Wat is uw beroep?
    - ☐ _______________
    - ☐ Ik werk niet

7. Heeft u enige ervaring met hulpmiddelen die samen beslissen kunnen ondersteunen?
    - ☐ Nee
    - ☐ Misschien, namelijk: _______________________________
    - ☐ Ja, namelijk: _______________________________

8. Wat is uw houding tegenover hulpmiddelen die samen beslissen kunnen ondersteunen?
    - ☐ Helemaal niet nuttig
    - ☐ Kan soms nuttig zijn
    - ☐ Nuttig
    - ☐ Heel nuttig

    ☐ Anders: _________________________

Appendix E - User Evaluation Scripts

General script for Session 1 and Session 3

Introduction
Good afternoon, I'm glad you could make it today.
How are we feeling today?

As you are aware, we are here today to test a prototype made to help conversations between patients with COPD and doctors. To do so we will play-out a short consultation between you and a doctor played by me. This is not an actual consultation, but a simulation to test the tool.

Let me give you a quick outline of what we will be doing today. I would like to start by asking you some questions about you and your experience with COPD. Afterwards us two will interact and talk about the decision tool while we complete some tasks together. Once those are completed, I would love to hear your opinion and impression regarding the tool and your interaction with it, and any suggestions for improvements you might have.

Afterwards, I would like to ask you to fill out a short 10 statement list and rate your agreement on a scale from 1 to 5. I will explain this in more detail once we get there.

I will start with the background questions. If you would rather not answer some of these questions, that is perfectly fine and we will skip those.

Questions
So, if I may ask, for how long have you been living with COPD?
What is your favourite thing to do in your free time?

Testing
Thank you very much. Let us start with the tool and the first task.

Before we start I just want to highlight a few things. We are not testing you, we are testing the tool. So if something is not clear to you, or you are having some issues following along that is not something you have done wrong, but an issue with the tool. This means that we have to improve something, not you. There are no wrong answers, interactions, or outcomes.

While we use the tool, please think aloud regarding anything you see or feel.

And finally, we would like to ask you to be as honest as possible. If something does not feel right please tell us about it, it will not hurt our feelings.

- We will first start by finding a personal goal. To do so, we will be using the physical activity card. There are some examples, but those are just for inspiration, is there anything that comes to mind that you would like to reach?
  → talk about options and help think about ideas

- Okay, now that we have a goal, please write it down onto your personal goal card.
- To help you reach this goal, there are a couple activities we could do. (Place down the treatment option cards) Please look at these cards and tell me if any of them speak to you. We want to decide on **one** option today which will help you with your personal goal.
  → talk about the cards and have them choose one
- This option can vary in intensity and type, so let us find the one you feel best with. What kind of intensity do you think would work best for you? (Talk and discuss their preference and make a choice on option, how long, and how often)

With this chosen, let us summarise and see if this sounds good to you.
(Name their personal goal, the side goal card they chose and the final choice of activity, duration, and frequency)

Post-Interview
Thank you so much. With the tasks done, let us start the interview and statements.
Do you have any immediate feedback? Anything you liked or disliked or were unsure about.
(talk, discuss, note down)

Then I have here a list of 10 statements. I will read them one by one and then you can say whether you completely agree, somewhat agree, unsure, disagree or totally disagree. Based on your answers, I may ask your reasoning.

	Question To Be Asked	Strongly Disagree Strongly Agree
1	I feel confident in the future progress of my treatment.	○1 ○2 ○3 ○4 ○5
2	The conversation helped me realise what I find important for approaching my condition.	○1 ○2 ○3 ○4 ○5
3	I was able to find a personal goal.	○1 ○2 ○3 ○4 ○5
4	I feel like I had a say in the conversation and how it progressed.	○1 ○2 ○3 ○4 ○5
5	I feel like continuing this kind of approach to conversations will positively impact my treatment.	○1 ○2 ○3 ○4 ○5
6	The conversation felt natural.	○1 ○2 ○3 ○4 ○5
7	The information on the cards helped me understand them better.	○1 ○2 ○3 ○4 ○5
8	The information on the cards had a good balance between information and setting treatment goals.	○1 ○2 ○3 ○4 ○5
9	The colours and images fit the contents and conversation.	○1 ○2 ○3 ○4 ○5
10	I liked the design of the cards.	○1 ○2 ○3 ○4 ○5

Wrap-Up

With this, we are done. Thank you so much for participating and coming in today. We appreciate it a lot, and value your feedback immensely. Thank you!

Session 3 Script Dutch Translation: User Testing with Users living with COPD and comorbidities

Introductie
Goedemiddag, ik ben blij dat jullie vandaag konden komen.
Hoe voelen we ons vandaag? Ik ben Sven en ik doe vandaag het interview en de test. Dit is Byrons project, maar hij spreekt jammer genoeg niet genoeg nederlands om de test zelf te doen.

Zoals u weet, zijn we hier vandaag om een prototype te testen dat is gemaakt om gesprekken tussen COPD-patiënten en artsen te vergemakkelijken. Hiervoor zullen we een kort consult uitspelen tussen u en een arts, gespeeld door mij. Dit is geen echt consult, want ik heb zelf geen geneeskunde gestudeerd, maar een simulatie om het hulpmiddel te testen.

Ik zal u een kort overzicht geven over wat we vandaag gaan doen. Ik wil beginnen met u een aantal vragen te stellen over uzelf en uw ervaring met COPD. Daarna zullen we samen praten over de beslissingstool terwijl we een aantal taken uitvoeren. Als die zijn voltooid, zou ik graag uw mening en indruk willen horen over de tool en uw interactie ermee, en eventuele suggesties voor verbeteringen die u heeft.

Daarna willen we je vragen om een korte lijst met 10 stellingen in te vullen en je akkoord te geven op een schaal van 1 tot 5. We zullen dit in meer detail uitleggen zodra we daar zijn.

Ik begin met de achtergrondvragen. Als u sommige van deze vragen niet wil beandwoorden, dan is dat prima en slaan we die over.

Vragen
Dus, naam, als ik vragen mag, hoe lang leef je al met COPD?
Wat is uw favoriete bezigheid in uw vrije tijd?

Test
Hartelijk dank. Laten we beginnen met de tool en de eerste taak.

Voordat we beginnen wil ik een paar dingen benadrukken. We testen jou niet, we testen de tool. Dus als iets je niet duidelijk is of als je problemen hebt om het te volgen, dan is dat niet iets wat je verkeerd hebt gedaan, maar een probleem met de tool. Dat betekent dus dat wij iets moeten verbeteren, niet U. Er zijn geen foute antwoorden, interacties of uitkomsten.

Het zou prettig zijn als u hardop na kon denken over alles wat u ziet of voelt terwijl we het hulpmiddel gebruiken. Dat geeft ons een beter beeld op het gebruik van de tool.

Tot slot willen we je vragen om zo eerlijk mogelijk te zijn. Als iets niet helemaal prettig is, vertel het ons dan alsjeblieft, dat helpt ons meer dan dat u ons tevreden probeert te stellen.

- We beginnen met het vinden van een persoonlijk doel. Hiervoor gebruiken we de fysieke activiteitenkaart. Er staan enkele voorbeelden op, maar die zijn alleen ter inspiratie. Is er iets dat je te binnen schiet dat je zou willen bereiken?
  → opties bespreken en helpen nadenken over ideeën

- Oké, nu we een doel hebben, schrijf dat dan op je persoonlijke doelkaart.
- Om je te helpen dit doel te bereiken, zijn er een paar activiteiten die we kunnen doen. (Leg de kaarten met behandelopties neer) Kijk alsjeblieft naar deze kaarten en vertel me of een ervan je aanspreekt. We willen vandaag een beslissing nemen over één optie die je zal helpen bij je persoonlijke doel.
  → Bespreek de kaarten en laat ze er een kiezen.
- Deze optie kan variëren in intensiteit en type, dus laat ons de optie vinden waar jij je het beste bij voelt. Wat voor soort intensiteit zou voor jou het beste zijn? (Praat en bespreek hun voorkeur en maak een keuze voor de optie, hoe lang en hoe vaak)

Met deze keuze laten we samenvatten en kijken of dit goed klinkt voor jou.
(Noem hun persoonlijke doel, de kaart met nevendoelen die ze hebben gekozen en de uiteindelijke keuze van activiteit, duur en frequentie)

Post-interview
Hartelijk dank. Nu het speelgedeelte klaar is, kunnen we beginnen met het interview en de vragenlijst.
Hebt u nu al feedback? Iets wat je goed of minder goed vond of waar je onzeker over was. (praten, bespreken, noteren)

Dan heb ik hier een lijstje met 10 uitspraken. Ik zal ze een voor een voorlezen en dan kan u zeggen of u het er helemaal mee eens bent, een beetje eens, onzeker, niet mee eens of helemaal niet mee eens. Op basis van uw antwoorden kan het zijn dat ik uw redenatie zal vragen.

	Statement	Zeer mee oneens Zeer mee eens
1	Ik heb vertrouwen in het verdere verloop van mijn behandeling.	○1 ○2 ○3 ○4 ○5
2	Het gesprek heeft me geholpen me te realiseren wat ik belangrijk vind om mijn aandoening aan te pakken.	○1 ○2 ○3 ○4 ○5
3	Ik heb een persoonlijk doel kunnen vinden.	○1 ○2 ○3 ○4 ○5
4	Ik heb het gevoel dat ik inspraak had in het gesprek en in het verloop ervan.	○1 ○2 ○3 ○4 ○5
5	Ik heb het gevoel dat het voortzetten van dit soort gesprekken mijn behandeling positief zal beïnvloeden.	○1 ○2 ○3 ○4 ○5
6	Het gesprek voelde natuurlijk aan.	○1 ○2 ○3 ○4 ○5
7	De informatie op de kaarten hielp me om ze beter te begrijpen.	○1 ○2 ○3 ○4 ○5
8	De informatie op de kaarten had een goede balans tussen informatie en het stellen van behandeldoelen.	○1 ○2 ○3 ○4 ○5

9	De kleuren en afbeeldingen passen bij de inhoud en het gesprek.	○1 ○2 ○3 ○4 ○5
10	Ik vond het ontwerp van de kaarten er goed uit zien.	○1 ○2 ○3 ○4 ○5

Samenvatting
Hiermee zijn we klaar. Heel erg bedankt voor uw deelname en uw komst vandaag. We stellen het zeer op prijs en waarderen jullie feedback enorm. Als bedankje willen we jullie dit kleine chocolaatje geven als teken van dankbaarheid. Hartelijk dank!