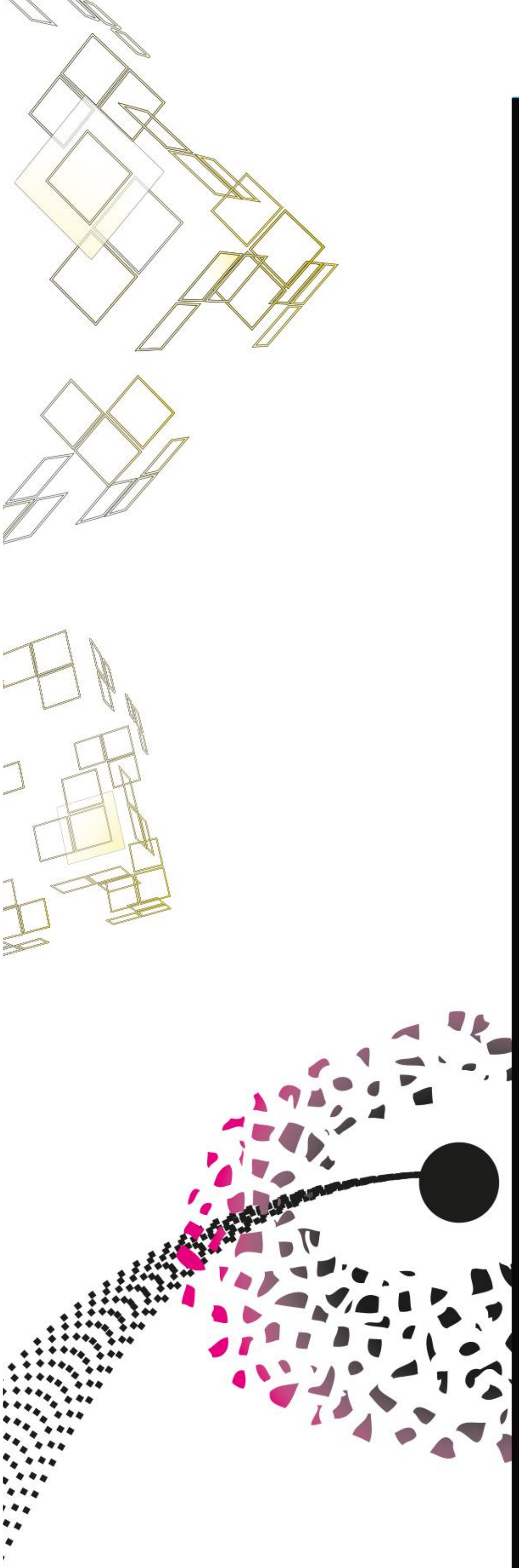
BSc Thesis Creative Technology

Design for COPD Self-Management Support Through a Patient Perspective



Nina Ooms

Supervisor: Eline te Braake

Critical Observer: Prof.dr.ir. Monique Tabak

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Abstract

Introduction: COPD is a burdensome condition affecting many daily life activities. Self-management is applied to reduce this burden by making patients active participants in managing their disease. However, current self-management advice given by healthcare professionals lacks the patient perspective with aspects like emotional and social elements, focusing on the clinical view (medicine adherence and physical exercise). This thesis explores the development of an educational tool for the patient perspective of COPD self-management targeting healthcare professionals.

Methods: With the help of a literature review, interviews and a state-of-the-art analysis, a story map prototype was developed in which users get to experience a patient story following the phases of COPD progression. Decision points are used in which the user gets to interact with the narrative, changing how the patient receives care to gain insights into the consequences of their actions. User evaluations with questionnaires (N=5) and interviews (N=6) were conducted to assess the tool.

Results: The evaluation results showed that the tool is perceived positively for its accessibility, interactivity and realism. It was reported that an increase in empathy and understanding was created towards the patient perspective. However, it was lacking in mechanics indication and support for preferences. The tool was evaluated with an average score of 4.3 out of 5 from SUPR-Q.

Discussion/conclusion: The tool should be implemented in educational settings (professional development and/or studies), since it has potential to increase the patient perspective awareness of healthcare professionals. It contributes to the further development of patient-centered interventions regarding COPD self-management. Future work should focus on the addition of multiple patient stories and improving personalization, including the exploration of different healthcare professional fields.

Acknowledgements

First and foremost, I would like to thank my supervisor, Eline te Braake, for her valuable feedback and encouragement during the graduation project. I am also grateful to Monique Tabak as my critical observer for her valuable insights, refining my progress and ideas. Furthermore, special thanks go to the participants who helped me gain a deeper understanding of the topic from interviews and questionnaires, and were generous with sharing their time and experiences. This input was essential for shaping the tool. Lastly, I want to thank my friends and family for their constant support. Their encouragement was of great help during the difficult times faced throughout the development of this graduation project.

Table of Contents

1. Introduction

1.1 Context

GOLD, a global initiative raising awareness for COPD (chronic obstructive pulmonary disease) describes COPD as “a heterogenous lung condition characterized by chronic respiratory symptoms (dyspnea, cough, sputum production and/or exacerbations) due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive, airflow obstruction” [1, p. 5]. This obstruction can make physical activities challenging, affecting many daily life activities. These symptoms are often regulated with the use of medication. However, by applying ‘self-management’ the patient takes on a more active role in their disease and can adopt a lifestyle based on self-reliance. This concept asks the individual to manage their own symptoms, adapting their behaviour, educating themselves and being independent [2]. As COPD is a heterogeneous disease, the usage of self-management and needs can vary between patients [3]. Healthcare professionals (HCP) generally give self-management advice to patients with COPD when the diagnosis has been given and at yearly check-ups. However, this advice focusses on the clinical view of managing their symptoms. Taking medicine and performing physical exercise is often the outcome from the healthcare professionals; in doing this, they ignore other aspects of self-management which are just as relevant, the patient perspective. Mental health and participating in social activities are examples of elements regarding the patient perspective on self-management. Due to the lack of attention on these fields, patients are expected to research their own ways of managing the symptoms, resulting in a higher burden of their medical diagnoses and/or missing out on useful information [4].

There are already tools present (such as Remote Therapeutic Monitoring [5]) to help with the patient perspective of self-management, but these often require digital literacy as they are generally based on a digital user interaction. Thus, people lacking these digital skills will most likely not be able to reach these facilities. The design of this tool requires research on how to implement knowledge of self-management activities in a tool to produce a feasible product. The design process of Creative Technology will be used to maximize the usability and relevancy of the end product to the users, this process considers previous existing ICT technologies, as well as a user centred design approach [6]. The aim of this research is to design an educational tool for healthcare professionals regarding self-management activities of patients with COPD conditions focusing on the patient perspective, not only paying attention to the clinical view.

1.2 Research Questions

The research and development of the product will be supported by the following research question and sub-questions:

"How can an educational tool be designed for healthcare professionals regarding COPD self-management activities focusing on the patient perspective?"

Sub question 1: What are the key self-management activities for patients from their perspective?

This question aims to identify what key aspects of self-management activities are to the patients themselves, not what healthcare professionals assume is important. Since the main research question focuses on the patient perspective, this sub question ensures that the tool being designed is based on real patient experiences, such as managing mental health, social interactions, or mental health, not just medication and exercise.

Sub question 2: What are the current gaps in healthcare professionals' understanding of patient-centered self-management?

To design an educational tool for healthcare professionals, it needs to be known what they don't already understand or tend to overlook. If this step is skipped, the tool might end up telling healthcare professionals things they already know, or it might miss the actual gap between professionals and patients.

Sub question 3: What are the essential features and content an educational tool should have to enhance healthcare professionals' understanding of patient perspectives?

Once it is known what the patients value and what HCPs are missing, decisions need to be made on how to bridge that gap in the tool itself. This question make sure the tool will include the right methods for information delivery, style/language it contains, and the structure of the tool.

Sub question 4: What design principles and formats are most relevant for educating healthcare professionals and patients on this topic?

Not all tools are equally effective for all users. This question considers how the information is delivered, focusing on accessibility, engagement, and practicality.

2. Background Research

This chapter will outline the background research regarding the ideas presented in the first section. This ensures the required knowledge is stated for a sufficient understanding before exploring the design process. First, the definition of COPD is given, then self-management will be explained. Lastly, a state-of-the-art review focusing on the existing products available on the market.

2.1 Chronic obstructive pulmonary disease (COPD)

COPD is a chronic lung condition which causes respiratory problems. Symptoms can include coughing, wheezing, tiredness and chest tightness. The extend of these symptoms can fluctuate and may end up in an exacerbation (i.e. a worsening of the respiratory issues), which can be triggered in some situations by infections, air pollution and smoking [1]. This is why COPD can be divided into four different stages depending on the amount of air breathed out, forced expiratory volume in one second (FEV1). Stage 1 is classified as having a FEV1 of 80 and above, while stage 4 is the most severe with a FEV1 of 30 and less. Besides FEV1, COPD can also be categorized based on the severity of symptoms with the use of letters: A, B and E. Group A means mild symptoms and unlikely to have exacerbations, B means more acute symptoms and unlikely to have exacerbations, while group E means that exacerbations have a greater possibility to happen. The classifications of FEV1 and symptoms are not necessarily related, as it is possible to have mild symptoms while the FEV1 is at stage 4 [7].

COPD is often a result of lung irregularities such as chronic bronchitis. This disorder is an inflammation of the bronchi which causes a restricted airflow to and from the lungs. Another abnormality commonly present with COPD is damaged alveoli (air sacs in the lungs that regulate the oxygen intake of the blood), also known as emphysema [8]. The main causes of COPD are both genetic, as well as environmental. A possible genetic reason for a higher risk of the development of COPD could be the mutation of a gene regulating a large number of proteins that are managing inflammation and immune responses. However, this is often combined with an interaction between environmental risks. An important risk factor identified is smoking cigarettes, whether it be active or passive, as cigarette smoking has a significant impact on lung irregularities and FEV1 reduction. While COPD is often known as a smoker’s disease, other environmental factors are just as important when looking at key factors, such as the burning of organic waste indoors, air pollution or inhaling chemicals during one’s employment (e.g. pesticides, fumes and chemical agents). The causes of COPD are frequently misunderstood due to the fact that past research was done in countries with a higher-income population [1].

There are several standard prevalent interventions for reducing COPD symptoms and preventing exacerbations. A key factor is the cessation of smoking and other air polluting substances. Another element is avoiding extreme temperatures, whether it be cold or warm, to prevent exacerbations and hospitalisations. Nevertheless, medicinal adherence is additionally a valuable intervention which is often in the form of inhaled therapies using inhaler devices. These require a thorough education and training for the patient to optimize from the benefits [1].

2.2 Self-management

Definition

Due to the nature of chronic diseases, patients will have to deal with their symptoms throughout their life. Many of these patients will apply self-management methods, a lesser-known intervention, to reduce their symptoms and the risk of exacerbations. Self-management has the objective to make the patient an active participant in their health, creating a greater connection and control over their disease. The concept asks the patient to navigate their symptoms, medical care, and the physical, social, and emotional challenges they face while making necessary lifestyle adjustments [9]. Thus, gaining knowledge, building independence, embracing change, accepting their situation, and finding their new position in life. The usage of self-management in the context of COPD has a broad meaning as self-management interventions for COPD can differ from each other. These interventions help promote self-management to patients with COPD to provide information on how to change their behaviour for other (better) health outcomes. COPD is a disease with a wide variety of possible symptoms, which are not always present all times, so this means self-management interventions are often structured, and tailored to individuals in order to facilitate the diverse needs [3].

Importance

Self-management is of great importance when it comes to the quality of life for COPD patients. This concept can lead to significant better health outcomes and lessening hospital admissions [10]. In a study done by Lenferink et al. [11], there has been made a comparison between care including self-management interventions and care excluding these interventions in COPD patients. What they found is that the quality of life from COPD patients was significantly increased when self-management interventions were used with an action plan for the worsening of symptoms. Additionally, a fewer number of patients with at the minimum of one hospital admission for COPD associated reasons where encountered.

Generally, self-management can help facilitate daily struggles encountered by COPD patients, and thus reduce the disease burden, highlighting why self-management is a valuable concept. Problems like feeling downhearted may be helped with social activities and hobbies found with self-management, like visiting a museum. Another element with which COPD patients must cope with is the possible risk of exacerbations. Educating patients to study their own body can create the potential of recognising the early signs of an episode, to hopefully prevent a hospital admission and know when to take medication. General education regarding activities that have to be carried out like medication adherence provided by self-management can decrease the feeling of being overwhelmed by COPD and its consequences. Also, letting patients learn that they should take an active role managing their disease creates realistic expectations for the patient regarding responsibilities and assumptions.

Moreover, self-management can introduce patients with peer-to-peer support. This can battle feelings induced by COPD of loneliness and being alienated in social situations. Patients may be more likely to change their behaviour if a peer illustrates the benefits it can have on them, with feelings of embarrassment being lessened when they are not the only one with COPD-related problems. Finally, education and guidance on certain types of medication like inhalers will be enhanced. Patients can give each other tips on how they tackle difficulties, giving insights healthcare professionals may not have [12].

Reasons for absence

The implementation of self-management by COPD patients is imperfect. Many patients do not make full use of self-management strategies for a number of reasons. The first one being personal patient factors [13]. This can include non-adherence to treatment that is advised by healthcare professionals, personal beliefs, stress, low health literacy and financial burdens. Patients may be calmed by smoking cigarettes which goes against the smoking cessation advice from healthcare professionals, possibly increasing health problems [13]. Another example is patients not making full use of oxygen due to the associated costs that come with it. A large portion of patients are also not educated enough on the usage of certain types of medication, leading to confusion on how e.g. an inhaler is used.

The second reason is environmental factors. Some factors are not capable of being controlled by patients and are usually categorized into two sections: home-related or external factors. Shortness of breath can worsen when certain substances such as cologne or smoke are inhaled indoors. However, outdoor weather can also play a vital role in the condition of patients, where dust and temperature can worsen symptoms. These environmental factors may lead to patients being unable to manage their disease.

Additionally, COPD-related factors like comorbidities and the worsening, chronic character are key elements to the motivation and effectiveness of self-management activities. Patients may lose hope when they only see themselves get worse over time, thinking that the current strategies are not working, resulting in non-adherence to advice. Comorbidities can make self-management more complicated due to a more complex symptom impact, where heart disease can worsen lung health.

Finally, the offering of self-management plans to COPD patients from healthcare professionals can be lacking. Khan et al. [14] reports that in a study they performed, from a population that 62.9% suffered from a severe case of breathlessness, only less than 7% received pulmonary rehabilitation (which includes self-management). They also found that there is a need for an increased publicity for a healthier lifestyle as weight management is barely mentioned to patients, and the fact that only 56% of current smokers were advised to quit smoking. This may be caused by a lack of time, professional skills, low digital literacy and viewing self-management tools as redundant [3].

Current gaps

At present, several healthcare professionals are involved with the implementation of self-management for COPD patients, this includes general practitioners (GPs), physiotherapists, lung physicians, occupational therapists, psychologists, respiratory consultants and dieticians. They will often provide patients with general information regarding the management of the disease during clinic hours. This offers little time to discuss all aspects important for the patient due to a low frequency of appointments with short durations in which patients see their healthcare professional. They may share action plans with patients to take home and fulfil, or a personal diary to keep track of their symptoms. Another option is to refer the patient to pulmonary rehabilitation. According to Meis et al. [15] this concept is an interdisciplinary team consisting of varying healthcare professionals to facilitate COPD patients with a weekly programme. The outcomes of the programme can vary per person as there are several goals possible, but a common objective is to adopt a healthy lifestyle. Reoccurring themes found by them in pulmonary rehabilitation are finding acceptance, setting goals, knowledge increase, transfer to home environment.

Other frequent self-management interventions available to patients currently are eHealth technologies. These technologies often help the patient by monitoring their health conditions, such as the number of steps taken during the day and their heart rate. The main focus of eHealth technologies is the bodily function since they measure the physical aspects of daily life, this generally being in the form of a wearable technology and can be combined with a smart device. Many eHealth technologies fail to take other aspects into consideration besides the physical element. While educating patients is a generally common present aspect being represented in technologies, they fail to recognise other non-physical dimensions like adherence, mental health and quality of life which are just as regular aspects dealt with in day-to-day life for COPD patients [9]. Interventions informing healthcare professionals about self-management are described in the next section, state of the art.

HCP focus

While currently many self-management interventions have been developed for COPD patients directly, this project focuses on healthcare professionals as its target users. A goal of this research is to enhance the way COPD care is delivered by healthcare professionals. This ensures that there is not an additional responsibility for patients to take into account while managing their disease, since patients already have to deal with many other problems like physical, emotional and social burdens from living with a chronic disease. Additionally, this research could change methods of care at the level of the provider by focusing on healthcare professionals. Since healthcare professionals can have a great influence on the health outcomes of patients by communication and recommendations, this will create opportunities for positively affecting many patients' conditions with the rippling effect this project could have. Research shows that making shared decisions will improve the clinical relationship between patients and healthcare providers, which also leads to an increase in COPD treatment adherence from patients [16].

2.3 State of the Art

The objective of this section is to explore the current existing methods for educating healthcare professionals on self-management with a patient perspective.

2.3.1 eHealth interventions

Digital interventions are designed in many ways. A technology often used by COPD patients is wearable devices that are being combined with mobile apps. With these wearables, health data is collected from the patient, like step count, oxygen saturation and exercise alerts [9]. All these elements together can form a dashboard on a mobile app that shows trends and information about the progression of symptoms and exacerbations. These dashboards are used in consultations with healthcare professionals to gain insights, resulting in a more personalised and evidence-based care.

An example of an eHealth intervention using wearables and a display is Bora care. The user collects data via the smart watch which measures vital signs such as functional oxygen saturation of arterial haemoglobin, heart rate, respiratory rate and skin temperature. The display can make dashboards with the observed data and alert the user if there is an increased risk of an exacerbation.

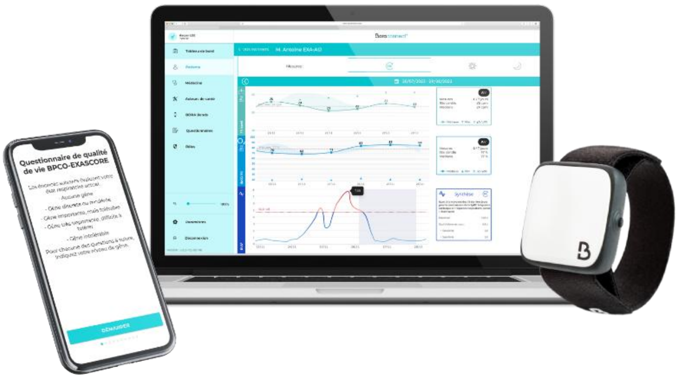


Figure 2.1: Illustration of Bora care technology

Another form of a digital intervention is the use of educational websites. There are quite some resources online that can help healthcare professionals look up information about the patient perspective of self-management. They will often give general advice about the disease itself, but sometimes add more personal and captivating elements like on the website provided by Luchtpunt. This organisation focuses on COPD and pulmonary fibrosis. For COPD, they supply readers with generic information regarding the causes, symptoms and when to see a healthcare professional, but a more personalised aspect is a brochure describing "Life with COPD". It consists of 20 pages containing many topics regarding self-management activities, tips and tricks and patient quotes. Although this website has COPD and pulmonary fibroses patients as its target group, healthcare professionals can also benefit from the information provided.

Leven
met
COPD

luchtpunt.
Het startpunt voor astma, copd en longfibrose

Prettige vakantie

COPD hoeft geen reden te zijn om van vakantie af te zien. Als u wilt, kunt u zelfs voor een aangepaste vakantie kiezen. Stichting MEE heeft daar informatie over.

Maar mocht u zelf op pad willen; geen drukkende zonvakantie aan het Nederlandse strand, maar liever de koele droge bergen in. Of een droog en warm klimaat als Spanje, Portugal of Turkije.

Anita Jutte (49), echtgenote van COPD-patiënt Chris Jutte (62): 'We zijn op vakantie geweest naar Zwitserland. Chris is een dag erg benauwd geweest, maar daarna hadden we een uitstekende vakantie. Misschien gaan we ook nog eens een huisje in de buurt huren. Het is altijd lekker om er een paar dagen tussenuit te gaan.'

Steden met warmte en luchtvervuiling zijn geen verstandige keuze. Net als vakantiehuisjes met huisdieren, roken en stoffigheid. Afhankelijk van de ernst van de COPD is het ook goed om na te denken over de aanwezigheid en kwaliteit van ziekenhuizen en medische voorzieningen in de omgeving.

Houd er met vliegen rekening mee dat het zuurstofniveau in een vliegtuig op grote hoogte wat lager is dan aan de grond. Wellicht wilt u daarom zuurstof meenemen. Dit moet u van te voren regelen met de betreffende maatschappij.

Checklist
- Medisch paspoort (maak ook een kopie)
- Extra medicijnen, in koffer én handbagage
- Medische verklaring van arts over medicijnen. In sommige landen verplicht.
- Telefoonnummer van uw arts
- Vraag uw zuurstofleverancier naar mogelijkheden van bezorging op vakantieadres en naar lichtgewicht tanks.

18

Figure 2.2: Two pages from the Luchtpunt brochure

The information on pulmonary fibrosis is similar to the COPD section. However, it features an additional passage with ‘patient experiences’ showing videos with patients speaking of their journey regarding their diseases.

Patiënt ervaringen

Longfibrose is aan de buitenkant voor familie, vrienden en collega's niet direct te zien, maar de beperkingen zijn er wel. Lees en leer hier meer over de ervaringen van andere longfibrose patienten. Hoe om te gaan met longfibrose en wat is het belang van familie en vrienden?

Longfibrose

behalve op den duur een keer een transplantatie.

Wat is longfibrose

- Ziektebeeld
- Onderliggende auto immuunaandoeningen
- **Patiënt ervaringen**
- Familiaire longfibrose
- Omgeving en medicatie gebruik

Figure 2.3: Screenshot of ‘patient experiences’ passage from Luchtpunt’s website

2.3.2 Physical interventions

Another type of intervention includes tangible/physical tools. Van Harlingen et al. [17] created a printed resource kit for COPD patients, featuring worksheets, folders, contact details, and visual storytelling elements. Asthma and Lung UK, a charity supporting lung health, made a printable COPD self-management plan for COPD patients and their healthcare professionals. It contains many resources for further research, an opportunity for healthcare professionals and patients to discuss important aspects together, and allows them to learn from patient experiences.

14

Eating well

When you're living with COPD, you can help to control your symptoms by maintaining a healthy weight. Your doctor or nurse can help you work out what is a healthy weight for you, give advice and refer you to a dietitian for specialist support if you need it. Read more at blf.org.uk/eating-well

Sex and COPD

Living with a condition that leaves you short of breath can get in the way of sex and relationships, but it doesn't need to. You can read more about managing breathlessness during sex at blf.org.uk/sex

How are you feeling?

When you have a long-term condition, it can be difficult to deal with your emotions. You might feel down, isolated, confused, guilty, angry, or that life is unfair. Living with COPD can make you feel anxious, which in turn can make you feel more breathless and frightened. You might find it helpful to keep a record of your mood, like the one on page 26. Read more at blf.org.uk/mental-health

Top tips to boost your mood

- Being active might be the last thing you feel like doing. But it can lift your mood and help combat depression and anxiety.
- Eating a healthy diet and limiting your intake of alcohol can help you to feel better.
- Talking to your health care professional can really help. Find out if counselling is available in your area. You can also chat to our friendly helpline team, by calling **03000 030 555**.
- Join our web community to chat to other people with lung conditions online, 24 hours a day. Visit blf.org.uk/web-community

call our helpline on 03000 030 555

15

Managing breathlessness

Breathlessness is a common symptom of COPD. Getting out of breath can be frightening, and although living with breathlessness can be difficult, many people find ways to cope with it and still enjoy life.

Breathing techniques can help you reduce your feelings of breathlessness. They can also help if you get out of breath suddenly. Your health care professional can help you find what works best for you.

If you feel breathless, get into a position that helps you to get control of your breathing. You can try one of the positions below:

You can also learn ways to help control your breathing. One way is slow deep breathing:

- Relax your shoulders, arms and hands.
- Breathe in through your nose. Breathe out through your mouth.
- Try to relax and feel calm each time you breathe out.

Read more about breathlessness, including information on living well with breathlessness, at blf.org.uk/breathlessness

visit blf.org.uk/COPD

26

Record of your mood

You might find it useful to keep a record of how you feel to talk about with your health care professional. Download more copies at blf.org.uk/self-help

How I feel today
Not great < 0 1 2 3 4 5 6 7 8 9 10 > *Really good*
Today I'm worried about
Date:
My concerns are: ☐ Practical ☐ Emotional
☐ The future ☐ Spiritual or religious ☐ Lifestyle
☐ Financial ☐ Family or relationships ☐ Other
My plan of action is to...

How I feel today
Not great < 0 1 2 3 4 5 6 7 8 9 10 > *Really good*
Today I'm worried about
Date:
My concerns are: ☐ Practical ☐ Emotional
☐ The future ☐ Spiritual or religious ☐ Lifestyle
☐ Financial ☐ Family or relationships ☐ Other
My plan of action is to...

call our helpline on 03000 030 555

27

How I feel today
Not great < 0 1 2 3 4 5 6 7 8 9 10 > *Really good*
Today I'm worried about
Date:
My concerns are: ☐ Practical ☐ Emotional
☐ The future ☐ Spiritual or religious ☐ Lifestyle
☐ Financial ☐ Family or relationships ☐ Other
My plan of action is to...

How I feel today
Not great < 0 1 2 3 4 5 6 7 8 9 10 > *Really good*
Today I'm worried about
Date:
My concerns are: ☐ Practical ☐ Emotional
☐ The future ☐ Spiritual or religious ☐ Lifestyle
☐ Financial ☐ Family or relationships ☐ Other
My plan of action is to...

visit blf.org.uk/COPD

Figure 2.4: Pages from the self-management plan from Asthma and Lung UK

2.3.3 Group based interventions

Group-based interventions are also a possibility for educating healthcare professionals, before or during their studies. Axelsson et al. [18] implemented a two-day training program for healthcare professionals, incorporating workshops and lectures focused on medication adherence. To encourage discussion, participants were placed in groups of seven to analyse and talk through relevant patient cases. Another collaborative approach involves nurse-led models, as seen in the work of Sturm et al. [19], where nurses take the lead in developing, presenting, and evaluating self-management strategies. They visit the homes of COPD patients to offer help and learn more about the daily activities performed. With this, they make an informed decision on the care they suggest.

Many more extensive resources regarding COPD self-management can be found online on websites offering courses in group settings discussing and analysing relevant topics. The NRS (Netherlands Respiratory Society) is one of these resources. In February 2025, they offered a national lung course for healthcare professionals who are early in their career. On their website, they inform potential people of interest about the topics they will discuss and what the details are of signing up. This offers an accessible way of accessing educational support that is interactive and stimulates discussion within groups of peers.

National Lung Course 2025

National course on lung diseases and lung research for those early in their careers

When: 12 - 14 February 2025
Where: Hotel Heerlickheijd van Ermelo

Maximum class size: 30 people, first come basis.

The primary target audience of the course consists of PhD students (or Master's students likely to begin a PhD in the respiratory field within the next year) and early-stage postdoctoral fellows with backgrounds in clinical, translational, and/or basic sciences. No further restrictions on admission apply. The course aims to enhance understanding of the broader field of pulmonary research and foster networking within the national professional community.

Teaching goals

The course employs a combination of reading literature, lectures, group work, and interactive workshops.

At the end of the course the participant has knowledge about:

1. The structure and function of the lung.
2. The pathogenesis and pathophysiology of pulmonary diseases, including asthma, COPD, interstitial lung disease, lung infections, lung cancer, and vascular lung disease.
3. The impact of these lung diseases on healthcare and patients' quality of life.
4. The use of advanced *in vitro* models in respiratory medicine research.
5. Pharmacological and non-pharmacological treatments for these lung diseases.
6. Career prospects in science in the Netherlands and abroad.

Figure 2.5: Screenshot of NRS website containing details on a course regarding lung disease

2.3.4 Benefits and Drawbacks of Interventions

eHealth Interventions

Digital interventions provide healthcare professionals with easy access to resources and patient health data. These tools often support real-time monitoring, the ability to analyse trends, and remote communication. All this makes it easier to integrate patient self-management into care. Online platforms may also offer multimedia content, such as videos, interactive modules, or patient experiences, helping healthcare professionals emphasize with the emotional and practical aspects of COPD management. Another key advantage is that digital resources can be regularly updated, ensuring alignment with the latest clinical guidelines and research findings [2].

Despite their benefits, digital tools may present challenges related to technological literacy. Some healthcare professionals may find these interventions complex or unintuitive. Managing large amounts of patient data can be time-consuming and may require additional training. Concerns over data privacy and security further complicate the use of digital platforms, particularly in clinical environments where confidentiality is vital [20].

Physical Interventions

Printed or tangible educational materials remain important for many healthcare professionals. These resources provide structured information in a format that is easy to access, refer to and share with patients [21]. Physical tools such as handbooks, worksheets, or reference guides are especially useful in settings with limited internet connectivity or where a preference for non-digital materials exists.

However, physical resources are static and can become outdated as care evolves throughout time. Updating or distributing new versions can be costly and logistically challenging once tailoring care for each patient is necessary [21]. Additionally, they may lack the interactivity or engagement that digital resources can offer. While these tools are helpful in some contexts, especially for older patients or professionals working in traditional care environments, they may not fully capture the complexity of modern chronic disease management.

Group-Based Interventions

Kristjansdottir et al. [22] performed a scoping review on numerous group-based educational interventions, such as workshops, peer discussions and training sessions providing an interactive and reflective learning environment. These formats encourage the exchange of experiences, stimulate peer support, and help healthcare professionals develop practical skills through case-based learning. Engaging with patient scenarios in a group setting allows for more thorough discussion of patient perspectives and challenges, which can result in a higher level of motivation for expanding on the patient perspective, and thus possibly improve COPD care.

However, what they additionally found is that these interventions, while effective, can be resource- and time-intensive. They often require organizers and flexibility in schedules, which may not be feasible in all healthcare settings. Participation levels and learning outcomes can also vary depending on group dynamics and individual engagement. Furthermore, access may be limited for busy professionals in remote areas or for those with limited support for continuing education [22].

In summary, each intervention format (digital, physical, and group-based) offers specific advantages for healthcare professionals seeking to enhance their understanding of patient self-management. However, each also presents limitations that must be considered when designing or selecting design elements. A hybrid approach that integrates the adaptability of digital tools, the clarity of physical materials, and the interactivity of group learning may provide the most suitable opportunities for patient-centred self-management education.

3. Methods and Techniques

This section will report on the design method used for this project. As described by Mader and Eggink [6], the design process used during the bachelor's Creative Technology of the University of Twente is divided into four phases: ideation, specification, realization and evaluation (see Figure 3.1). The method makes use of iterative cycles going through the different phases to ensure adaptability for changes found during the design process. The phases are listed below.

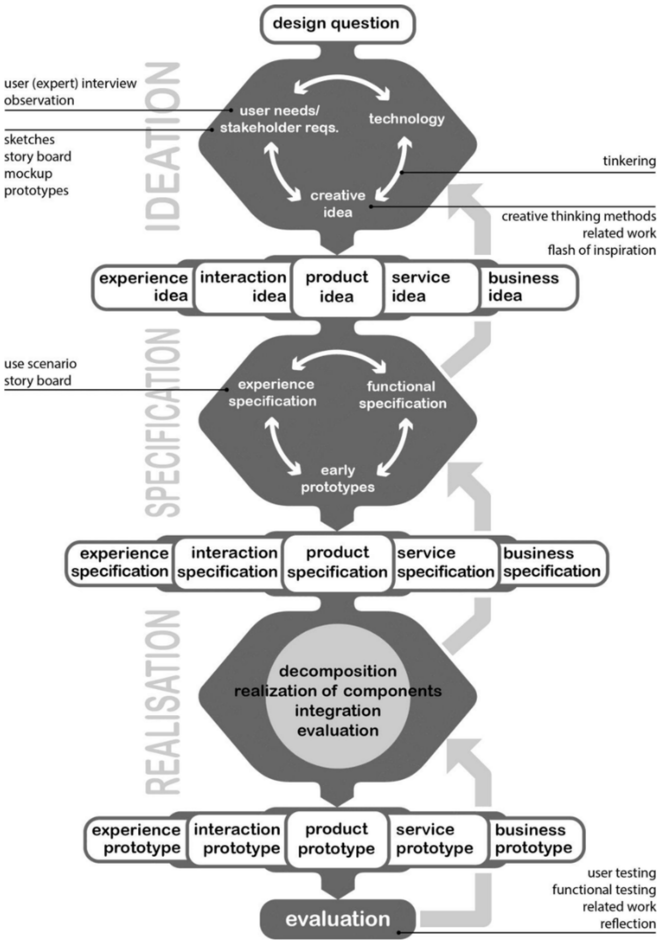


Figure 3.1: Creative Technology design process [6]

3.1 Ideation Phase

The beginning of the ideation phase started with an analysis of relevant stakeholders for the project. This ensures that the interests and needs of these groups are implemented into the product to increase adherence and effectiveness.

The primary stakeholders involved in this project:

- Healthcare professionals working in the field of COPD

- COPD patients

Questionnaires and user interviews are held with the stakeholders to gather vital information for the requirements of the design process. The MoSCoW method will be applied to these requirements for determining the significance of each necessity, sorting them by the categories of Must have, Should have, Could have and Won’t have, as this project has limited resources [23]. After having identified requirements, brainstorming will be done with the Post-it note method which consists of writing individual ideas on a single Post-it note and grouping them by theme. An overview of the different themes with the individual ideas is created and can be used to choose from and combine some elements. This creates a structured way of organising a brainstorming session [23]. Another key element for idea generation is analysing previously developed products which have already been put out on the market (state-of-the-art) and draw conclusions from this [6]. Once several ideas have been worked out, a final main concept will be generated based on the requirements and viability of the product.

3.2 Specification Phase

A key element of the specification phase is the great number of prototypes that will be developed according to the previous ideation phase, which will be combined with an evaluation and feedback loops [6]. The process moves toward refining the requirements by designing and testing prototypes to collect user input, enabling improvements in both functionality and user experience. Early versions of the product are developed, integrating important requirements identified during the ideation phase together with storyboards and use scenarios to encapsulate a realistic usage of the product. These prototypes are evaluated by the stakeholders through questionnaires and/or interviews to assess usability and effectiveness. The feedback gathered will create a feedback loop which is used to create a more functional and user-friendly product by iterating through multiple prototypes.

3.3 Realization Phase

The realization phase consists of developing a high-fidelity prototype after having gone through the specification phase with its associated feedback loops. The final concept will be worked out in detail such as the user interface and the key self-management activities included into the product in order to create a functional product which should match the necessary functional requirements (i.e. what should the system do?) and non-functional requirements (quality, usability, aesthetics [23]).

3.4 Evaluation Phase

The functional product is evaluated during the evaluation phase. This will be executed with the use of interviews and/or questionnaires with the stakeholders while using the final product. The functional and non-functional requirements are being assessed to determine whether the correct elements have been implemented into the product. Based on these tests, the results will be developed and analyzed to gain further insights.

4. Ideation

During the ideation phase the focus lies on the concept generation of the final product. First, a stakeholder analysis is done to identify relevant requirements. These requirements will be analyzed with the use of the MoSCoW method. Then a brainstorming session is held and finally a final concept will be chosen.

4.1 Stakeholder analysis

Stakeholders are relevant individuals who have a role in this project. They may have an interest in the design and/or usage of this product. This could influence certain design choices and the outcomes of the tool.

4.1.1 Direct stakeholders

These stakeholders are considered direct stakeholders as they will interact with the tool directly. Healthcare professionals are the primary end-users of the tool; these consist of physiotherapists, lung physicians, respiratory consultants, dieticians, general practitioners and more. The tool will educate them on where their current gaps are regarding the patient perspective and what information is missing, also highlighting the importance of the implementation of this perspective and what consequences it has when this is missing. The tool will help healthcare professionals stay up to date with information on patient-focused quality of life elements.

Their interests focus on receiving accurate, reliable, and practical insights that can be integrated into their existing workflows without causing disruption. They expect the tool to be efficient, easy to use, and informative. Since they are the primary users, their influence on the design and functionality of the tool is high. However, potential conflicts may occur if the tool is perceived as time-consuming or if it challenges existing routines or clinical authority. Thus, the success of the tool depends significantly on how well it is integrated into their everyday routines without adding a cognitive or time burden.

The most common situations where the usage of such a self-management tool from this project can be used by the direct stakeholders are separated into two options: during studies/training or integrating into regular workdays within their schedule. Firstly, the tool could be integrated during the study of upcoming healthcare professionals before they start working in the field. Then, there are also many training courses that are currently being applied to HCPs who are already in the field working with COPD patients that can implement the self-management tool from this project. Finally, another option is the use of this tool in the regular work schedule from current HCPs. For this project, the most valuable would be the HCPs in training and/or working on their studies. This allows for teamwork with multiple HCPs together with the instructor and a more time-intensive use, leaving more room for the possibility of being informed of the patient perspective. When comparing to the application of this tool in the daily work schedule, HCPs often have little time left for other activities during the day due to their busy schedules. This may lead to the users only briefly interacting with the tool and thus, not having many opportunities for educating themselves.

4.1.2 Indirect stakeholders

Indirect stakeholders are individuals who are affected by the results of the tool, not interacting with it personally. COPD patients are another group consisting of the important end-users, as the tool is intended to improve their care experience. The interests of this group are mainly the inclusion of the patient perspective in self-management tools to increase the quality of life, autonomy, and other aspects that may be overlooked. They will be indirect users, giving vital information about what the patient perspective entails and how it should be implemented in self-management tools. Patients may not use the tool directly, but will experience its benefits throughout their care.

Family and/or acquaintances play an important role in the support of COPD patients in dealing with daily adjustments. They could benefit from this tool by learning the foundations of COPD care and self-management to offer more support with a deeper understanding of the disease. Designers and developers are essential to the creation and execution of this tool. Their interests are that the tool is feasible, accessible and usable, adhering to user-centered design. Also, the production of the tool should be reasonable regarding resources. Organizers regarding COPD trainings and/or studies are another vital stakeholder group since they will be implementing the tool into their programs. They want the tool to fit into their curriculums, easy to use and informative.

4.1.3 User personas

Two personas have been created to create a realistic image of the target end users. This can help guide the ideation phase and make sure the users' needs are prioritized. The following use personas below were based on the user personas made by Grünloh et al. [12] which were made for a study on eHealth self-management tools, relevant to this project.

Jonas Meijer	**Age** 39
Profession Respiratory consultant	**Work experience** 10 years
Attitude Patient-centred care supporter	**Goals** Wants to understand and integrate the patient perspective into his treatment approach to enhance long-term patient outcomes.

“Jonas is a 38-year-old respiratory consultant working in a medical centre. With 10 years of experience, he has seen a wide range of COPD cases and understands the clinical side thoroughly. However, in recent years Jonas has become increasingly aware that clinical elements do not always reflect the daily experiences and quality of life of his patients. He values precision in diagnostics and therapy, but acknowledges that patient motivation and lifestyle play a crucial role.

Jonas often finds that patients feel misunderstood when it comes to their day-to-day challenges, especially with fatigue or emotional distress. He wants to bridge that gap by gaining better insight into what matters to patients and how they perceive their condition. He is motivated to use a self-management tool not only to educate patients but also to improve his own understanding of the patient experience.

He prefers using such tools during multidisciplinary team meetings or scheduled professional development sessions, as his daily schedule with patients is tight. Jonas believes the tool should act as a guide for communication, helping him ask better questions and frame treatment plans in a more collaborative way. However, he is cautious about the tool being too abstract or disconnected from real-world practice, as he needs practical, concise insights that can quickly inform his clinical conversations.”

Nora van Dijk	**Age** 29
Profession Physiotherapist (COPD specialist track)	**Work experience** 5 years
Attitude Open to reflective learning	**Goals** Aims to improve her communication with COPD patients

“Nora is a 29-year-old physiotherapist working in a rehabilitation clinic. For the last five years, she has increasingly focused on pulmonary rehabilitation and is currently completing a specialized course in COPD care. Nora often sees patients referred after exacerbations or hospital discharge, and she works with them to rebuild strength and regain control over their lives.

She has noticed that while she can offer clear physical guidance and structure, some patients do not engage or struggle to adhere to plans. Nora suspects this is due to unspoken concerns, lack of motivation or fear, which often go undetected during assessments. She is interested in tools that help make the invisible elements visible, to discover how patients feel about their disease and what barriers they face in managing it.

Nora appreciates having structured tools during her training and education because it gives her a safe space to explore the patient perspective without the pressure of clinical time limits. She

believes this tool could also be used during group therapy planning or moments with colleagues, where they reflect on patient cases.
She would prefer the self-management tool to include real-world patient scenarios or prompts that help professionals ask better follow-up questions. Nora is mindful that her colleagues may resist if the tool feels theoretical or judgmental about current practices, so it must be designed to support rather than critique the healthcare provider's efforts."

The implementation of a self-management tool that focuses on the patient perspective could create benefits for both direct and indirect stakeholders involved in COPD care. Jonas Meijer, a respiratory consultant with 10 years of experience, is an example of a professional who would benefit from this tool. While he is skilled in clinical diagnostics and treatment, Jonas has identified a gap between clinical views and the experiences of his patients. He would like tools that help him better understand how patients feel about COPD, especially those that support communication and decision-making. Jonas would be most likely to use the tool in learning settings, such as professional development sessions or team-based discussions.

Nora van Dijk, a physiotherapist currently specializing in COPD rehabilitation, represents another user group. Nora is motivated to understand the psychological and emotional elements behind patient behaviours. She found that some patients do not follow self-management due to a lack of confidence or understanding, not due to physical limitations. For Nora, the tool is useful in an educational or training context, where she can focus on patient scenarios in more depth and improve her communication. This allows for more time-intensive engagement and better integration of patient perspectives into her practice. However, potential challenges may arise. Healthcare professionals like Jonas and Nora have limited time during their daily work schedules. If the tool is seen as time-consuming or if it clashes with established routines, the usage could be less likely to occur. Therefore, the tool must be carefully designed to avoid cognitive or time burdens.

Its ability to align with the everyday realities of healthcare professionals like Jonas and Nora is a vital aspect for the success of this self-management tool. If implemented effectively, it can contribute to more personalized and supportive care, improving many health outcomes.

4.2 Pre-liminary design requirements

From the literature, stakeholder analysis and a user interview that was conducted multiple requirements were identified. The user interview explored basic concepts on what COPD patients would prefer as a tool format (e.g. digital or tangible) and where they believe the HCPs' knowledge gaps are. The audio was transcribed into text, and from there analyzed. The requirements discovered are placed in the MoSCoW hierarchy. A MoSCoW hierarchy is a framework used in project management, product design, and development to help decide which requirements or features are most important. The ‘M’ stands for Must have, referring to requirements with which the product cannot function without. If these are not delivered, the project is considered a failure. ‘S’ means Should have, highly desirable features that add significant value, but are not essential. ‘C’ is used for Could have, small or low-effort additions that improve user experience but are not necessary. These can be dropped or added later. Finally, ‘W’ is Won’t have, requirements agreed not to be included in the current project phase.

The user requirements of this project will be placed in a table based on a notation table previously used for eHealth technologies [24]. There are 5 categories involved in this table:

- *Functional and modality requirements*: outline the technical specifications and the platforms (e.g. tablet, smartphone, or desktop).
- *Service requirements*: describe how support services such as marketing and customer assistance should be structured around the technology.
- *Organizational requirements*: detail how the technology should fit into the existing organizational framework and daily workflows.
- *Content requirements*: define what information needs to be delivered through the technology, including language level, tone, persuasive strategies, and any accessibility considerations
- *Usability & User experience*: focus on interface and interaction design, as well as incorporating elements like trust and enjoyment into the user experience.

Together with the MoSCoW hierarchy and the requirement categories the following table is created below.

Pre-liminary requirements:

Requirement #: 1	**Requirement type:** Content
Description: Inclusion of Patient perspective	
Rationale: Educating professionals on this aspect ensures improving quality of life and adherence to treatment.	
Source: COPD patients	**Priority**: Must have
Conflicts: n/a	
Fit Criterion: n/a	

Requirement #: 2	**Requirement type:** Content
Description: The tool is accessible	
Rationale: The demographics for this project differ, resulting in different levels of health/digital literacy.	
Source: Benyon [23]	**Priority**: Must have
Conflicts: n/a	
Fit Criterion: usability testing, a wide variety of HCPs trying the tool to assess whether it is accessible	
Requirement #: 3	**Requirement type**: Content
Description: Information is evidence-based	
Rationale: HCPs rely on accurate, trusted content. Continuous updates ensure that clinical practice remains current and effective.	
Source: Panteli et al. [25]	**Priority**: Must have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 4	**Requirement type:** Usability
Description: the tool is interactive	
Rationale: Interactivity improves knowledge retention, engagement, and the ability to apply clinical reasoning in real-time scenarios	
Source: Benyon [23]	**Priority:** Could have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 5	**Requirement type:** Organizational
Description: The tool will fit in the busy schedules of HCPs	
Rationale: HCPs have little time to spare for other activities. The usage of the tool will not take long	
Source: HCP	**Priority:** Should have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 6	**Requirement type:** service
Description: The tool will ensure data privacy and ethics	
Rationale: Handling sensitive health and behavioural data requires strong privacy protections to build trust and meet legal requirements.	
Source: Mittelstadt [20]	**Priority:** Must have
Conflicts: n/a	

Fit Criterion: n/a	
Requirement #: 7	**Requirement type:** functional
Description: Support interdisciplinary fields	
Rationale: The tool will be applicable to the different kinds of HCPs	
Source: HCPs	**Priority:** Should have
Conflicts: n/a	
Fit Criterion: HCPs	
Requirement #: 8	**Requirement type:** usability
Description: The tool is intuitive to use	
Rationale: Ease of use is critical for adoption. A steep learning curve discourages use in settings like clinics and hospitals	
Source: Benyon [23]	**Priority:** Should have
Conflicts: n/a	
Fit Criterion: usability testing, many HCPs trying the tool to assess whether it is intuitive	

Table 4.1: Pre-liminary requirements

4.3 Concept Generation

With the requirements in mind, ideas were generated and written down. After this process had been done over a course of multiple sessions, categories were found within the brainstorming session idea assortment. Some ideas were fused or deleted because of duplications, and then placed into the theme accordingly. The Post-it note method was used during the concept generation for the tool. This can be seen in the list below.

Empathy and perspective	These tools aim to inform healthcare professionals in the patient's lived experience to create empathy and understanding.
Idea	Explanation
Video game	Day in the life of a patient -> which choices to make in daily activities
Patient logbook	“Handwritten” patient stories, sketches, diary entries about patient perspective
Simulation cards	Each card presents a scenario from a COPD patient’s perspective (e.g., “Today I can’t walk to the store because...”), paired with potential clinician responses and outcomes

Short video series	Each video explains a different topic -> visuals, patient experiences, expert summaries
COPD storybook	Illustrated patient experiences + struggles
Scenario dice	1 with symptom, other with situation -> how to deal with this problem?
Gamified & interactive	These tools use play or structured interaction to encourage learning and reflection.
Idea	Explanation
Board/card game	Promotes discussion and learning through game mechanics.
Scenario dice	1 with symptom, other with situation -> how to deal with this problem?
Simulation cards	Each card presents a scenario from a COPD patient's perspective (e.g., "Today I can't walk to the store because..."), paired with potential clinician responses and outcomes
Flashcards	Info testing
Training & clinical integration aids:	These tools help translate learning into practice, especially within professional development and routines.
Idea	Explanation
Consultation guide	Implementing patient perspective into appointments
Interactive casebook	A collection of short, evidence-based patient cases with patient quotes, symptom timelines, and reflection prompts -> HCPs work through each case in training (could include discussion questions and clinical decision points)
Printable toolkit	Digital or physical -> visual metaphors, patient behaviors tips
Interactive story map	Poster or table-sized printout - > A flowchart showing a COPD patient's journey, with branches representing input from healthcare professionals. Teams trace patient care across roles and discuss how patient perspective shifts in each phase

Visual and conceptual:	Focus on visual storytelling or data interpretation to support insights.
Idea	Explanation
Data visualization	Interpretate data from active visualizations
COPD storybook	Illustrated patient experiences + struggles
Interactive story map	Poster or table-sized printout - > A flowchart showing a COPD patient’s journey, with branches representing input from healthcare professionals. Teams trace patient care across roles and discuss how the patient perspective shifts in each phase
Printable toolkit	Digital or physical -> visual metaphors, patient behaviors tips

Table 4.2: Idea generation

A few criteria were considered whilst selecting the main final concepts:

1. Does it fulfil the aim of the project?
2. Can it follow the requirements?
3. What is feasible?

This was done by placing all ideas in a spreadsheet and analyzing them, resulting in Table 4.3 below:

Idea	Aim	Used With	Time Usage	Patient Perspective	Accessibility	Evidence-Based	Interactivity	How Requirements are Implemented
Board/Card Game	Engage HCPs through a fun, interactive scenario-based game	Small groups, workshops	20–30 minutes	Scenarios involve patient experiences (symptoms, emotions)	Simple, printable, minimal tech required	Scenarios based on real patient journeys	High, HCPs make decisions based on different patient perspectives	Patient perspectives integrated into scenarios; interactivity encourages group discussions; scenarios are research-based and accessible to a wide range of users (low-tech).
Video Game: Day in the Life of a Patient	Allow HCPs to navigate choices based on a COPD patient's daily routine	Solo, training centers	30–45 minutes	Players experience life from a patient's viewpoint, including challenges with symptoms	Requires basic gaming devices; can be played at one's own pace	Based on real patient data, possible use of research-backed events	Interactive decision-making process based on symptom management	Patient perspectives are deeply embedded in gameplay choices and scenarios; the game is accessible via various digital platforms but requires some basic understanding of game mechanics.
Short Video Series	Teach key patient perspective concepts in short clips	Individual HCPs, e-learning platforms	2–5 minutes per video	Features patient stories, struggles, and expert insights about managing COPD	Easy-to-share, subtitled, visually engaging	Expert-reviewed and research-backed information	Optional quizzes or prompts to increase engagement	Videos present real-world patient stories, ensuring the patient perspective is central; videos are brief for accessibility, and interactive components can be added post-video to reinforce learning.
Data Visualization	Represent patient data visually to create a quick understanding	Individual HCPs, classroom sessions	10–15 minutes	Graphs and infographics based on actual patient experiences, data, and outcomes	Simple design, can be viewed on digital platforms or printed	Based on real clinical data, continuously updated	Low, static representation, but prompts for reflection may be included	Uses clear visual data to simplify understanding of patient conditions; designed to help HCPs quickly grasp complex data and its real-world application to patient care.
Flashcards: Info Testing	Help HCPs test their knowledge on patient needs and perspective	Solo, small groups	5–10 minutes	Includes patient symptoms, coping strategies, and the emotional side of the disease	Easy to print and distribute, low-tech solution	Based on clinical guidelines and patient behavior	Flashcards can be used for self-testing or as a team quiz	Flashcards focus on a well-rounded understanding of patient experiences and treatment, bridging the gap between medical knowledge and empathy.
Printable Toolkit	Provide a quick reference and flexible guide for patient care	HCPs individually or in teams	Flexible, on-demand use	Visual metaphors and patient care tips included to highlight the impact of symptoms on daily life	Can be printed, accessible in various settings	Information based on practices and research	Includes prompts for HCPs to consider patient perspective in care decisions	Toolkit offers both physical and visual aids to help HCPs retain patient-centric care practices; simple layout promotes accessibility.
COPD Storybook	Share a patient's journey in a narrative format	Solo, as a personal tool	10–15 minutes	Integrates patient's daily experiences, struggles, and emotional challenges	Accessible in print or digital formats	Includes patient-driven content or patient feedback	Reflective prompts or discussion topics after reading	Illustrations and narratives represent patient experiences. Intended to create empathy among HCPs. Accessible for different HCP groups via easy-to-read format.
Consultation Guide	Help HCPs integrate patient feedback during appointments	Individual HCPs in practice or training	5–10 minutes	Provides consultation strategies focusing on communication from the patient's point of view	Can be printed or accessed digitally	Evidence-backed, based on practices for patient-centered care	Low interactivity unless used in roleplay scenarios	Checklist and prompts make it easy for HCPs to remember key patient-centered behaviors in consultations.
Patient Logbook	Encourage reflection and journaling from a patient's perspective	Solo, group discussions	10–20 minutes	Patient-written or sketch-based entries detailing experiences and symptoms	Printed format, easy to access and personalize	Patient logs offer insights validated by clinical experts	May include reflective prompts to encourage journaling	Designed to create a personal, intimate connection between HCPs and patients, this tool uses real stories to build empathy and understanding.
Scenario Dice	Promote quick, scenario-based decision-making regarding COPD care	Group exercises, training sessions	5–10 minutes per roll	Pairs symptoms with life situations to simulate decision-making	Physical dice are easy to use and portable	Situations based on real patient symptom and lifestyle scenarios	High, users roll the dice and actively solve the problem presented	Combines randomization with patient-centered situations to create varied learning experiences. This tool is low-tech but highly interactive, creating discussion.
Interactive Casebook	Simulate clinical decisions integrating patient needs.	Small teams, academic training	15–20 minutes per case.	Built into patient profiles and branching narrative outcomes	Digital or printed	All cases based on guidelines and validated clinical pathways	Choose-your-path format with feedback per decision	Detailed, patient-driven scenarios guide HCPs through decision-making with interactive choices and evidence-based content learning opportunities
Simulation Cards	Build empathy through story-driven decision prompts	Training groups, team-based learning	5–15 minutes per card	Each card presents a scenario from a patient's viewpoint.	Color-coded for severity, uses icons and minimal text	Validated symptoms and coping behaviors included	Users respond to prompts, justify decisions, and debrief	Integrates patient experiences into decision-making, accessible in low-tech settings.
Interactive Story Map	Create an interactive, visual story of a COPD patient's journey, highlighting symptoms, challenges, and key decisions	Solo, small groups, workshops	30–60 minutes per map	Visualizes patient experiences, showing different stages, emotional struggles, and treatment decisions	Digital, user-friendly	Built on real patient data, reflecting evidence-based practices	High, users make decisions throughout the story, affecting outcomes	User navigates patient's journey, making decisions that impact the patient's condition. Interactive, evidence-based, with multiple HCP roles involved in discussing care options.

Table 4.3: Analysis of generated ideas

In Table 4.3, the generated ideas were analyzed by questioning whether the most vital requirements are met while implementing the tool. This entailed the target users with the corresponding situations, time duration, implementation of the patient perspective, accessibility, interactivity and what data sources will be used. The final column describes how these requirements are applied. Another important element is the aim of the self-management tool, which is also described in the first column.

4.4 Top three concepts

The concepts that were placed in the top three of most fitting for this project are:

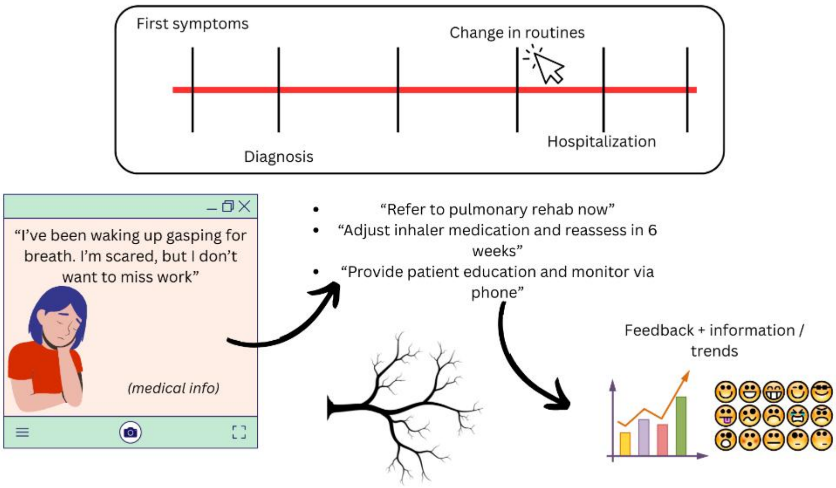
1. Interactive story map
2. Board/card game
3. Short video series

These were deemed as suitable for their adherence to the requirements, with a high level of interactivity, accessibility and the ability to convey the importance of the patient perspective.

Interactive Story Map

An interactive story map guides healthcare professionals through a COPD patient's journey using visual storytelling. It highlights key stages of living with COPD, decisions made, emotional responses, and outcomes. This lays the focus on empathy, patient-centred care, and clinical insight. The structure of the story map is as follows: A visual timeline of a fictional but evidence-informed COPD patient's journey which is divided into chapters or stages (e.g., diagnosis, symptom management, hospitalization, lifestyle changes). Each stage includes background information with a corresponding decision point where the HCP has to make a choice between situations. The story map will then offer the HCP feedback (emotional and clinical) to learn from their decisions from the perspective of the patient they are analysing. It can contain optional data visualizations like scores and trends related to the subject.

So, the decision points are part of a branching framework where HCPs make choices at key points (e.g., “Would you recommend pulmonary rehab now or later?”). Each decision leads to different branches showing patient response. Interactive elements may include sliders for symptom severity, icons for emotional response, quizzes or short feedback from a “patient” persona. The HCP can look back at the other options and see what would be different from the other choice.



"I've been waking up gasping for breath. I'm scared, but I don't want to miss work"

- "Refer to pulmonary rehab now"
- "Adjust inhaler medication and reassess in 6 weeks"
- "Provide patient education and monitor via phone"

Figure 4.1: Interactive story map sketch

User Experience: Step-by-Step

1. Introduction

Firstly, the goal is explained: "Experience a COPD patient's journey. Your decisions will impact their outcomes." Then, optionally a few personalization questions like: Select difficulty level (basic, intermediate) or HCP role (doctor, GP, therapist), which slightly customizes the scenarios.

2. Starting story map

The user sees a story map with branching stages containing icons representing COPD phases (e.g., first symptoms, diagnosis, hospitalization, lifestyle change). Some paths branch based on earlier choices. Users can revisit previous stages or choose to see alternative paths later.

3. Stage begins

Each stage opens with:

- A short story section (text or voiceover) from the patient's point of view.
    - *Example: "I've been waking up gasping for breath. I'm scared, but I don't want to miss work."*
- Clinical context: Objective measurements (e.g. oxygen saturation).

4. Decision point

The HCP is presented with 2–3 decision options, such as:

- *"Refer to pulmonary rehab"*

- *“Adjust inhaler medication and reassess in 6 weeks”*
- *“Provide patient education and monitor”*

5. Immediate feedback & impact

After the choice has been made the map branches depending on the user's choice. The user sees a patient response (e.g., improved mood, worsened symptoms, confusion), possible clinical data updates (e.g., FEV1 % change, hospital readmission risk) and an emotional dashboard (e.g., anxiety 3/10 → 6/10). Then a short reflection prompt appears: *“What else could have helped this patient?”*

6. Optional learning add-ons

The feedback can contain optional pop-ups: “What the guidelines say”, “Here’s how that felt for me…”, “Many HCPs chose option A: here's why.”

7. End of journey / summary

At the end of the story map a recap will be shown containing key decisions and resulting patient outcomes, missed opportunities (alternative branches) and an emotional + clinical outcome scorecard.

Board/Card Game

The game combines character profiles, scenario cards, and action choices. Each team is assigned a fictional patient with unique challenges. Players draw scenario cards that present medical, emotional, or social dilemmas. They then choose response actions and discuss potential outcomes, focusing on both the clinical and patient perspective impacts

User Experience: step-by-step

1. Setup

The number of players would be 3–6 HCPs (workshops or team meetings size) with an average of 15–30 minutes per session. The materials consist of a game board (life journey map or symptom tracker), character cards (COPD patients with different profiles), scenario cards (symptom, social, mental health, clinical), action cards (choices HCPs can make) and challenge tokens (reflect time, stigma, access issues)

2. Gameplay overview

-Each team is assigned a patient character, with a profile card containing details

-Players draw scenario cards, such as: “Your patient reports worsening breathlessness and missed social events”, “They express fear about using oxygen in public”, “A family member pressures them to stop working.”

-Players choose an action card to respond, such as: “Educate on physical activity pacing”. “Refer to a mental health specialist”, “Suggest joining a peer-support group”

-Each decision results in a consequence (printed on the scenario card back or in a guidebook), which impacts several elements (e.g. quality of life or medicine adherence)

-Discussions after each round, possibly asking:

  - Why was this choice made?
  - Was the patient perspective considered?
  - What could have been improved?

3. Optional additions

A point system can be added to the board game to introduce a competitive element for an increased motivation. Another option is to add a contentment slider that indicates the well-being of the patient you are currently playing as, which can go lower or higher depending on the actions played.

Short Video Series

Patient stories or reenactments that focus on the emotional, social, and clinical challenges experienced by patients will be shown with the use of 2-5-minute-long videos. Each video contains a specific theme, such as receiving a diagnosis, managing daily symptoms, dealing with stigma, or navigating care. The videos could be followed by optional elements like reflection prompts or short quizzes to stimulate learning.

Series topics might include:

- The patient gets diagnosed with COPD.
- Struggles with breathlessness while getting ready for work.
- Feeling dismissed in a clinical consultation.
- Mental health and coping strategies.
- The emotional and financial costs of managing treatment.

User Experience: Step-by-Step

1. Accessing the series

The HCPs log into a learning platform or receive a direct link. They will see 2-5 minute-long videos categorized by theme (e.g., diagnosis, daily challenges, stigma, treatment decision-making).

2. Watching the videos

They watch the videos in order which each contains real patients or actors reading scripted or real stories (with consent). This could be in the format of an interview or monologue-style storytelling, sometimes intercut with relevant visuals (e.g., inhaler use, home settings, hospital visits). Information that may be included is being diagnosed with COPD, navigating stigma, frustration, or fear, making daily decisions and interactions (good and bad) with HCPs.

3. Optional interactive layer

After each video reflection prompts can appear: *"What did you notice about the patient's emotions?"*, *"How could the HCP have responded differently?"* or a short quiz to implement interactivity.

4. Learning reinforcement

At the end of a module (e.g. after 3–5 videos) a short summary video or infographic highlights common patterns in patient experiences and clinical takeaways.

5. Replay and reuse

Videos can be replayed anytime, ideal for learning or integration into team discussions.

4.5 Final concept

Method

Currently, the concepts are based on a literature review and a singular user interview. This is not an accurate representation of the current stakeholders; this is why broader research was conducted with a larger number of relevant healthcare professionals. To determine the final concept that will be worked out in detail for the development of the self-management tool, questionnaires and interviews were conducted and analyzed to form a singular final concept. This is an important step in the co-creation of this tool. The questionnaire (found in Appendix B) was sent to several physiotherapist clinics, dieticians, nursery homes and chronic disease organizations to get a variety in healthcare professionals working in different fields of care. The contents of the questions from the questionnaire consisted of general information regarding the use of patient perspective in self-management during workdays and treatment plans. Another topic was the extent of self-management being taught in studies for upcoming healthcare professionals and further education for current providers. Finally, the three potential concepts were explained with corresponding questions about the willingness to adopt them in their field with clarification. Besides a questionnaire, four interviews were held with healthcare professionals, all consisting of physiotherapists. Generally, the same questions from the questionnaire were asked, but phrased differently to support open-ended questions. However, some were removed due to the length of the interview being too long. The results of the interviews were transcribed and rephrased if the information contained any sensitive information.

Results

The questionnaire was filled in by a total of 5 healthcare professionals, including three physiotherapists and two occupational therapists. The results from the questionnaire:

- 80% strongly agree that the patient perspective of self-management is an important aspect in COPD care, with the remaining 20% agreeing normally.
- One out of five reports a disability in applying the patient perspective on self-management in current treatment plans, with four out of five (strongly) agreeing that they do.
- The methods of applying the patient perspective range from fulfilling the patient's personal goals, to following standardized guidelines for asking social-related questions.
- The biggest challenges they face are not getting the full details of their patient's future and/or environment, along with changing the patient's view on their disease (management)
- For the question regarding the amount of focus on patient perspective during studies/training, two out of five got too little, one out of five was neutral and two out of five got sufficient.
- 60% think, out of the three concepts, that the story map is the most viable, while 40% prefer the short video series.
- The board game was seen as inefficient or not fitting for their team, receiving zero votes.
- (More results were found, but these will be presented in the specification section)

It was found from the interviews that all four interviewees were convinced that self-management, including the patient perspective, is a vital aspect within COPD care. They mentioned that there is currently not enough space for the discussion of self-management within their teams. During patient visits, however, the details of their situation outside of physiotherapy is being asked about. Most patients will give an extensive answer which allows for self-management advice, while others do not want to participate in this discussion. These questions are generally asked without an official guideline. Challenges the interviewees face in discussing the patient perspective of self-management is that the patients are not self-aware of the situation they are currently in. They may reflect too little on the problems they are experiencing, or they expect the healthcare professional to fix all their problems while not doing much themselves. Also, some patients take a long time to start this process of self-management, lacking the motivation to participate or unwilling to open up about their struggles. They also found the education for HCPs to be inadequate regarding self-management, some not experiencing any, while others saw some improvement in this field. Lastly, the interviewees were shown the final three concepts with a corresponding explanation. Only one person favored the board game over the other concepts, they thought it was a nice addition to the standard books and literature they have to read, introducing a more exciting and interactive experience. Whereas the remaining three interviewees were convinced that it would be unlikely for them to have the motivation for playing. Then, the other two concepts, videos or a story map, were both perceived as positive during all interviews. With the videos having two votes, due to the concept being familiar from other studies they did, and the story map receiving the final vote.

From the literature, design requirements, questionnaires, and interviews, it was determined that the concept of a story map was chosen. This is because the votes for the short video series and the story map were equal (both having four), however, the short video series has a possibility of making the user think that the patient is only protesting against the present care system, not creating much empathy. The story map digs deeper into the patient experiences and perspective. It contains a phase-based method, with a branched concept showing the user the consequences of their choices on the patient. It creates an environment for the user to create more empathy for patients and provide feedback on the emotional responses to their choices.

5. Specification

This section delves deeper into the design requirements for the tool, together with technical specifications and a more detailed description of the story map.

5.1 Design requirements

The pre-liminary design requirements in section 4.2 described the general requirements that were necessary for the intended tool without knowing the details of the final concept (i.e. accessibility, interactivity, data privacy etc.). In this section, the design requirements will explore the specific demands to accommodate the user, from being based on literature, interviews and the questionnaire.

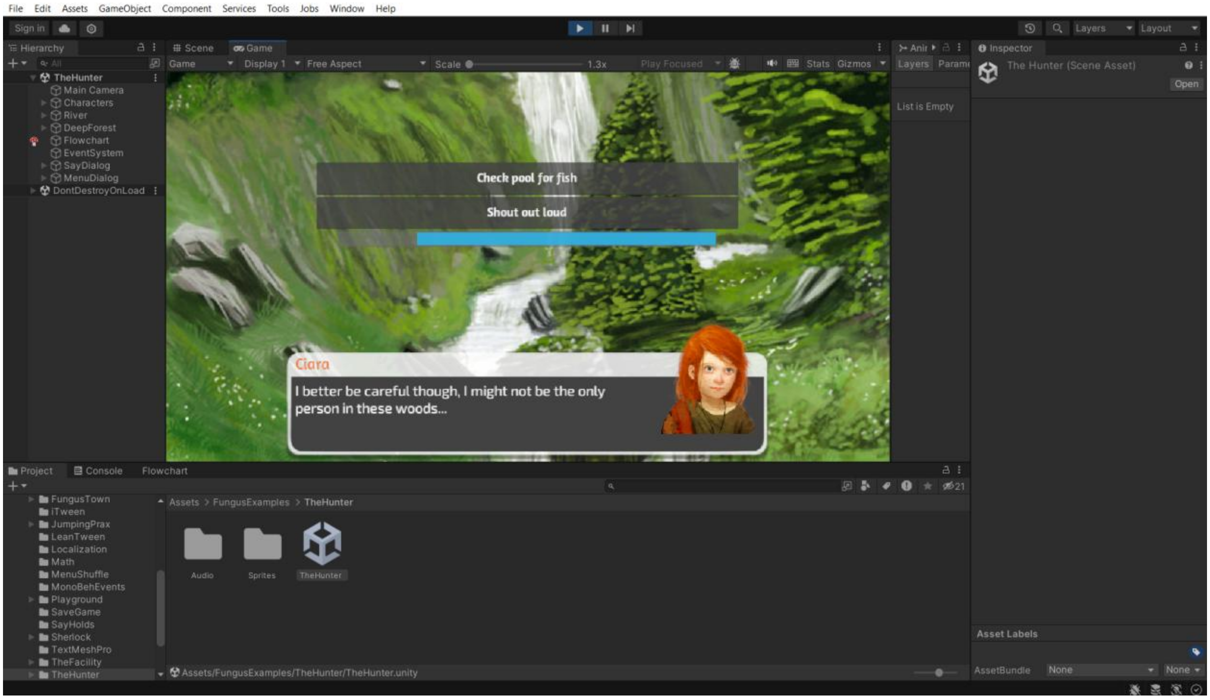
Requirement #: 1 Point and Click game	**Requirement type:** Usability
Description: The game will only use the cursor to navigate.	
Rationale: Point and Click games are less complicated to learn/use than having to use keys on a keyboard to move, thus not needing prior gaming/e-learning experience.	
Source: Healthcare professional	**Priority**: Must have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 2 Cross-platform compatible	**Requirement type:** Functional
Description: The tool will work on modern desktop browsers (Chrome, Firefox, Edge, Safari).	
Rationale: These are the resources often used by healthcare professionals. By utilizing this, the tool will become more accessible for use.	
Source: Healthcare professional	**Priority**: Must have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 3 Adaptability	**Requirement type:** Functional
Description: The software will allow authors/editors to add new branches or decisions without rewriting the core structure.	
Rationale: This ensures the tool will remain up to date with recent health care trends	
Source: Ghaben et al. [2]	**Priority**: Should have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 4 Performance	**Requirement type:** Usability

Description: The tool will load all stages and decision points within a reasonable time to maintain the flow.	
Rationale: The user will be less likely to get frustrated or bored	
Source: Healthcare professional	**Priority**: Should have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 5 Appropriate difficulty level	**Requirement type:** Usability
Description: The decision points and consequences will not be too difficult and not too easy.	
Rationale: Having an appropriate difficulty level puts the user more easily in a state of flow (i.e. optimal experience from balance of difficulty and ability). The theory of flow gets the user in an intense focus, extensively increasing enjoyment and effectiveness.	
Source: Fang et al. [26]	**Priority**: Should have
Conflicts: n/a	
Fit Criterion: n/a	
Requirement #: 6 Realistic situations	**Requirement type:** Content
Description: The story map will follow a situation which is realistic regarding the practices that are being performed during regular workdays.	
Rationale: A realistic situation makes it more likely for the user to participate and learn useful	
Source: Healthcare professional	**Priority**: Must have
Conflicts: n/a	
Fit Criterion: n/a	

Table 5.1: design requirements

5.2 Technical specifications

The software that will be used for the tool is Unity. This is generally used for game development like video games. However, Unity is an extensive software which results in a wide variety of applications, like this project for instance. Unity Fungus, a free asset found in the Unity asset store or GitHub, is downloaded to accommodate the 2D storytelling and branching idea of the story map. It offers a user-friendly experience with visual scripting.



Check pool for fish

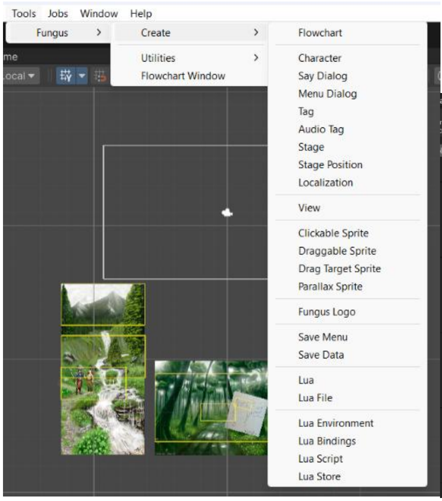
Shout out loud

Ciara

I better be careful though, I might not be the only person in these woods...

Figure 5.1: UI of Unity Fungus with an example

Unity Fungus provides the user with accessible ways to create certain assets like characters, dialogue etc. (which can be seen in Figure 5.2 below).



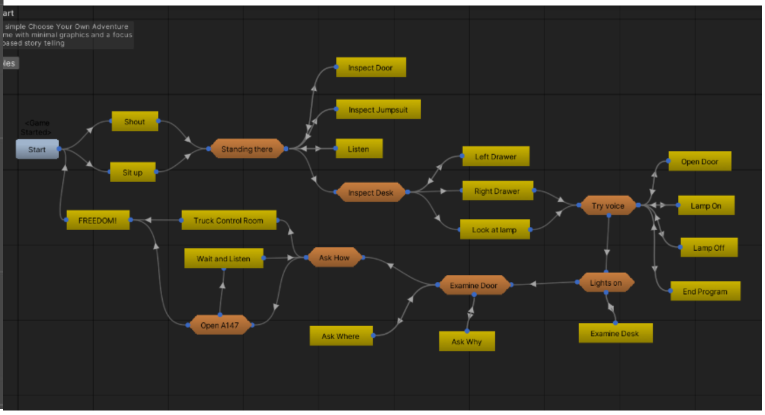


Figure 5.2: Unity Fungus tool set Figure 5.3: Unity Fungus flowchart window

Flowcharts from the game's story can be managed in the flowchart window (Figure 5.3), which is specifically an element added by the Fungus asset. It allows the user to visually see the decision points with their corresponding pathways. Sound effects, like background music or character noises, are sourced from Envato Elements or made by hand with software like FMOD studio. Sprites and/or other illustrations will be drawn in Krita and sourced from Envato Elements.

5.3 Tool overview

The tool will cover a variety of phases from which a COPD patient goes through within their life. In this tool being:

1. First symptoms
2. Diagnosis
3. Initial self-management planning
4. Lifestyle monitoring / adjustments
5. Exacerbation
6. Long-term disease progression
7. End-of-life planning & reflection

The story will begin with an introduction to the user explaining the reason for interacting with this tool and how it works. Then the user will get to know the patient who will be the main character of this tool, along with details of the personality, timeline and environment they live in. After this, the story will start with the branching experience to give the user an impactful experience, which ends in a reflecting phase for the user to look back on the decisions they made and how that impacted the patient. The flowchart below (Figure 5.4) shows the progression of the story with decision points marked in blue, with corresponding answers/actions in red, yellow, or green depending on the quality of the choice.

Figure 5.4: Flowchart of the story progression

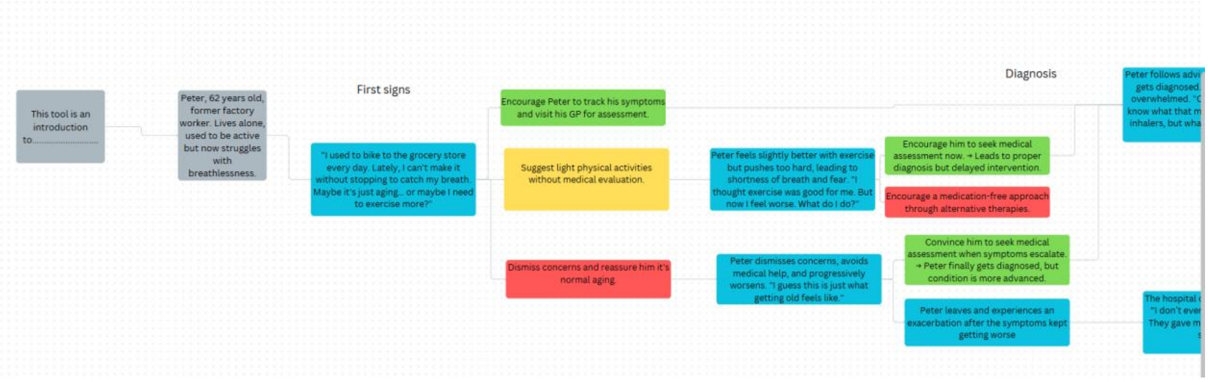


Figure 5.5: Close-up of first two stages of the story

The story map is constructed based on real-life cases that occurred within physiotherapist work with COPD patients. The foundational data was found in literature, educational websites and the interviews held with healthcare professionals, then generalized and assembled into a story.

The story follows a 62-year-old patient called Peter. He is a former smoker and factory worker who lives alone and struggles with breathlessness. He visits the user's office with his concerns regarding the first signs of COPD. The user is then given the opportunity to choose between three pathways: refer him to his GP, suggest physical activities without medical evaluation or dismiss the concerns. These three options each lead to a different outcome in the actions Peter can take, his motivation, health and mental state. The story will go through all seven stages, guaranteed to show the progression of the disease, but the approach will differ depending on the previous actions made by the user during decision points. For example, Peter will feel lost if the user dismisses his concerns often, resulting in certain options not being selectable during future decision points which require a stronger motivation level than Peter currently has. The user will be able to see the state of Peter's health-related variables by looking at a point system on the side of the story, showing the consequences of their decisions: Mental health, physical health, social aspects, and quality of life. Each decision will increase or decrease the number of points in each category. At the end of the story map, the user will see the results of the points together with a reflection on the outcomes based on the choices made during the story.

6. Realization

This section describes the realization of the high-fidelity prototype of the story map in detail.

6.1 Story

As described in the previous section, the goal of this story map is to bridge the gap in healthcare professionals' understanding of the patient perspective in self-management by providing users with feedback on the consequences their actions have while providing patients with advice, to ultimately improve patient-centered COPD care. The story consists of 7 phases (first symptoms, etc.). The information used to create the story map is based on interviews held with healthcare professionals and a COPD patient, combined with background information found within literature [27][28][29]. The story follows the patient Peter throughout his journey with COPD. When starting the story map, the user first gets an introduction to the story map (Appendix F) as follows:

> *"Welcome to this interactive story map in which you follow the disease progression of a patient with COPD. As a physiotherapist, you will have the opportunity to make choices in this story that will directly affect the patient's daily functioning and quality of life.*
>
> *Throughout the different stages of COPD, you will make decisions about treatment goals, guidance and lifestyle interventions. Every choice counts: you will receive points based on how effective your approach is for the patient.*
>
> *This story map has been developed to give you more insight into the patient's perspective and to show how big an impact you can have as a physiotherapist. It helps you to reflect on the importance of appropriate communication, motivation and supporting self-management within your treatment process."*

Once the user has read the introduction, they will then proceed to the next page of the story map by clicking on the text. This is where the user learns about Peter. The information includes that he is a 62-year-old man who is a former factory worker and smoker struggling with shortness of breath, where using stairs and/or light physical activity requires a lot of energy. He lives alone, managing most of his tasks; however, he has noticed an increase in difficulty and loneliness.

From this moment on, the user will begin with the COPD stages, starting with the first symptoms. As seen in Figure 6.1, there are multiple branches the story can follow, where each arrow indicates an option from a decision point. The blocks are moments where the narrator or Peter introduces a problem, question, or reaction. Peter will ask the user what he should do regarding his difficulties traveling to the supermarket. The user can choose between suggesting a medical evaluation from a GP, increasing physical exercise, or convincing him it is an element of aging and thus not needing interventions. If the last option is chosen, Peter will experience a minor exacerbation, leading to a COPD diagnosis at the hospital. The first and second options lead to a COPD diagnosis done by a GP, with the second option containing an extra choice whether to send Peter to his GP or ultimately experience an exacerbation.

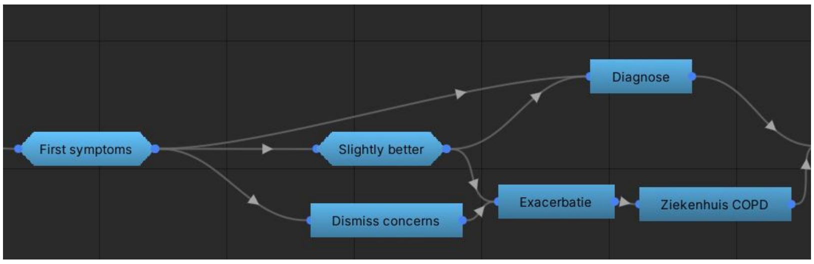


Figure 6.1: Flowchart of ‘First symptoms’ stage in Unity

The second stage contains the first introduction of self-management to Peter (Figure 6.2). Right after the news that Peter received his COPD diagnosis, either from his GP or hospital, the user gets the chance to introduce self-management to him. However, the other options are referring him to the pulmonary rehabilitation or stimulate more physical activity. At the end, all of these options will lead to Peter learning self-management strategies, but in different ways of affecting Peter. For example, one of the options will ask for another step in the process in which Peter goes to pulmonary rehabilitation, where he has to overcome motivation loss that lowers his mental health. Choosing a different option instead, would teach him self-management immediately, avoiding the loss of motivation.

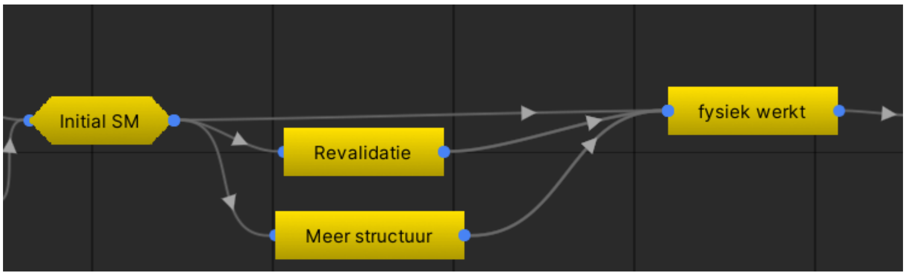


Figure 6.2: Flowchart of ‘Initial self-management’ stage in Unity

After the introduction to self-management, the stage of lifestyle adjustments begins (Figure 6.3). This is where Peter consults the user about his troubles with emotional well-being. He is ashamed of having to rest while out in public with others. The decision point offers Peter three options: Join a local walking group and/or support group for COPD patients, introduce structured training at home with the focus on independence or that he should monitor his symptoms and just take rests when needed without additional adjustments. Then, each outcome will provide the user with a reaction from the narrator and Peter, showing gratitude or motivation loss, which eventually leads to the next stage.

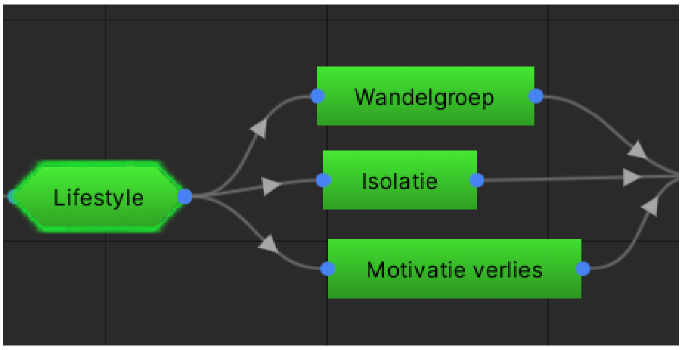


Figure 6.3: Flowchart of 'lifestyle adjustments' stage in Unity

This next stage is an exacerbation (Figure 6.4). Peter will experience an exacerbation regardless of the amount of points the user gained or lost. User interviews indicated that this element should be implemented since exacerbations are a common occurrence, which can affect a patient's mindset greatly. So, letting the user interact with a patient who experienced an exacerbation, can give them more insights into how they should react during such a vulnerable moment. Peter goes through an exacerbation and is admitted to a hospital. When he is released, he returns to the user's practice where he expresses his concerns regarding his progress. He thought that he was doing well, but lost all his confidence due to this exacerbation. The user can comfort Peter by informing him that this is an occurrence commonly seen with COPD patients and evaluating his current strategies to find better-fitting ones. As an alternative, the user can choose to change the medicinal intake of the patient and disregard any behavior changes. Lastly, the user can inform Peter that this is common and does not need any changes to his care.

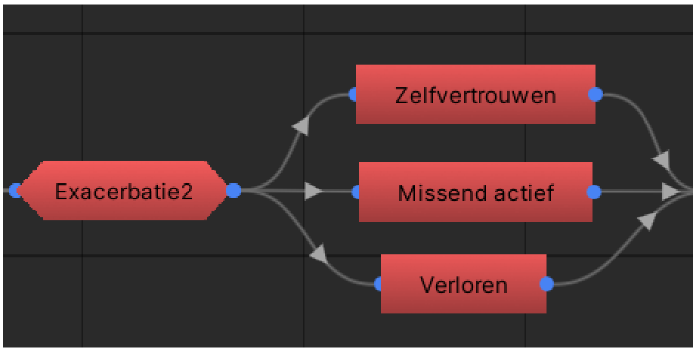


Figure 6.4: Flowchart of 'exacerbation' stage in Unity

The stage following exacerbation is the 'long-term progression' stage (Figure 6.5). At this point, Peter has growing concerns about the progression of his disease since the exacerbation. He is afraid he will lose all his independence. As the user, you can choose between encouraging participation in nurse care and focusing on comfort, help Peter establish energy conservation techniques or shift to medical interventions (without the focus on lifestyle). Depending on the choice made, Peter will increase either his physical or mental health, or both.

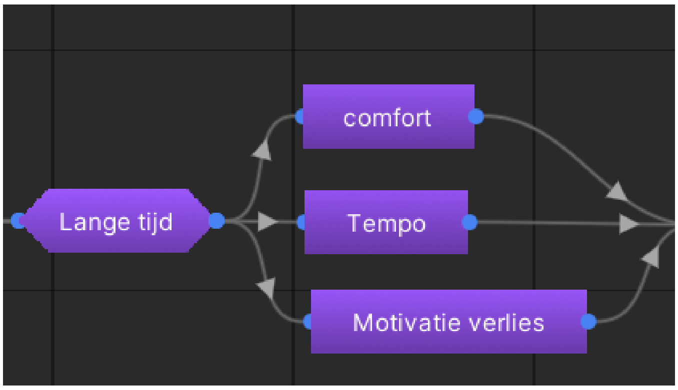


Figure 6.5: Flowchart of ‘long term progression' stage in Unity

The final phase of the story is end-of-life planning (Figure 6.6). Peter feels he is getting weaker and is lost on what he can do at this stage. The healthcare professional may decide on facilitating conversations about advance healthcare planning and emotional wellbeing, introducing symptom-focused comfort care strategies, or avoiding discussion regarding future planning and focusing on immediate symptoms. Peter will accept the changes, but his mental health can fluctuate greatly based on the decision made.

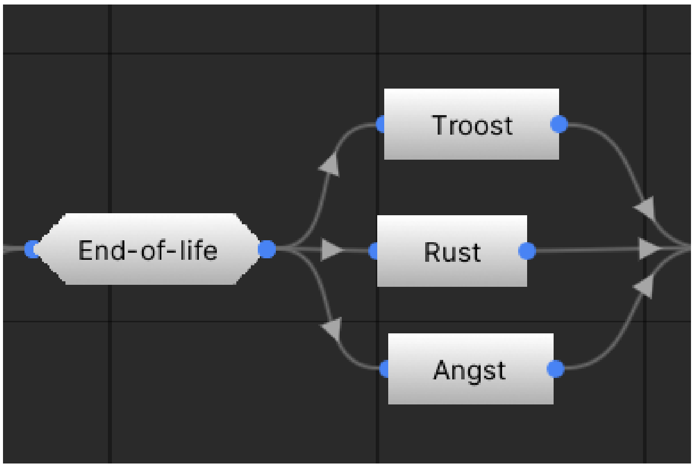


Figure: 6.6 Flowchart of ‘End-of-life' stage in Unity

When all of the stages have been encountered, the user is taken to a final reflection of the story map, which contains questions they can answer and look at their score:

“You have now gone through the story of a COPD patient and experienced how your choices as a physiotherapist can influence the course of the disease and the patient's experience. Take a moment to look back at the decisions you have made:

- Have there been moments when you would act differently now?

- How does your approach connect with the patient's life and needs?

This story map shows that every choice, big or small, matters

What will you take from this story to your own practice?”

The story map comes to an end after this reflection and the user can close the software. The visuals of the story map can be seen in Appendix C.

6.2 Mechanics

Decision points

Decision points are the main function within the story map flowchart. These are blocks within the flowchart that branch off to different texts and reactions. A decision point consists of three elements: the narrator, Peter, and options. Firstly, the narrator will explain the consequences of the previous choice. Peter will give his opinion and response to this consequence with an additional problem. The tool then presents the user with two or three options to choose from, which will guide the user further into the story.


Moedig Peter aan om zijn symptomen bij te houden en voor een beoordeling naar zijn huisarts te gaan.

Stel lichte fysieke activiteiten voor zonder medische beoordeling.

Zet de zorgen opzij en stel hem gerust dat het normaal is om ouder te worden.

Welk advies geef jij?

Figure 6.7: Decision point

Point system

Within the decision points there is a point system. This system gives users immediate feedback to the choices made within decision points. There are four categories within the point system: physical health, mental health, social elements and quality of life. All these categories start with zero points at the beginning of the story. Each option chosen by the user can decrease or increase this amount depending on the consequences it has on Peter, with a corresponding sound effect. A decrease in points will play a distressed tone, while an increase will play a joyful tone This change in points was determined by referring to literature and clinical guidelines about self-management [2][30][31][32]. For example, pulmonary rehabilitation often improves quality of life and reduces hospital admissions [27], thus leading to an increase in the metrics of quality of life and physical health. While most responses were determined with a clinical viewpoint, some asked for a patient-centred lens of imagining what the patient would feel in those situations with ethics in mind.

The points are managed by a ‘set variable’ command in each decision point, changing the number of points collected. The code managing this can be found in Appendix D. A list on the left side of the screen shows the score during the story. At the initial brainstorming sessions, it was planned to have the point system regulate which choices were selectable during decision points. This meant that users could only access some multiple-choice options if points exceeded a certain quantity. It was removed since the player could not always visit the alternative paths of the story due to a low number of points, eliminating the key element of seeing the consequences of the other options.

Return button

The story map features a button on the right side of the screen at all times, the ‘return’ button. This button brings the user to the previous block of the story in the flowchart. The user can utilize this button to go back and read text they missed or have forgotten, to answer the next question. Another application of this button is visiting other options during decision points. The user can choose an option they want to see initially and see the results. However, if they want to see the consequences of the other option, they can click the return button, read the other options and choose a different one. The return button is managed with a ‘PreviousBlock’ string variable. Anytime the user is about to go to the next block, the current block is saved into the PreviousBlock variable and executed when the return button is pressed. The code can be found in Appendix E.

Sprites

Lastly, sprites (i.e., small 2D images of characters or effects) of Peter were added to the dialogue box on the right side. There are four alternative sprites that can show up depending on the reaction of Peter: confused, confident, disappointed, and content. They will only be displayed when Peter is talking, according to the dialogue box. So, if the user chooses an option for Peter with negative consequences, the disappointed sprite will be visible.

These four emotions were chosen to symbolize a patient’s state of mind. Confusion expresses the lack of clarity patients can feel when given unclear advice and/or instructions which could be overwhelming. Confidence shows that the patient is well-informed and supported by the action, it empowers them and increases their motivation. Disappointment can occur when the patient feels neglected or dismissed, believing that they did not receive sufficient support. Contentment means that the patient sees the advice as fitting, being in line with their expectations and/or goals.

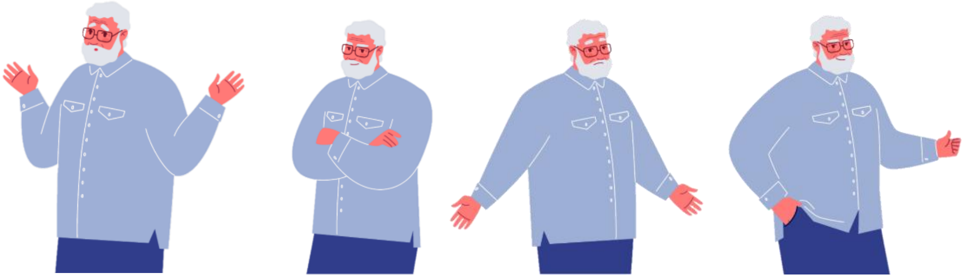
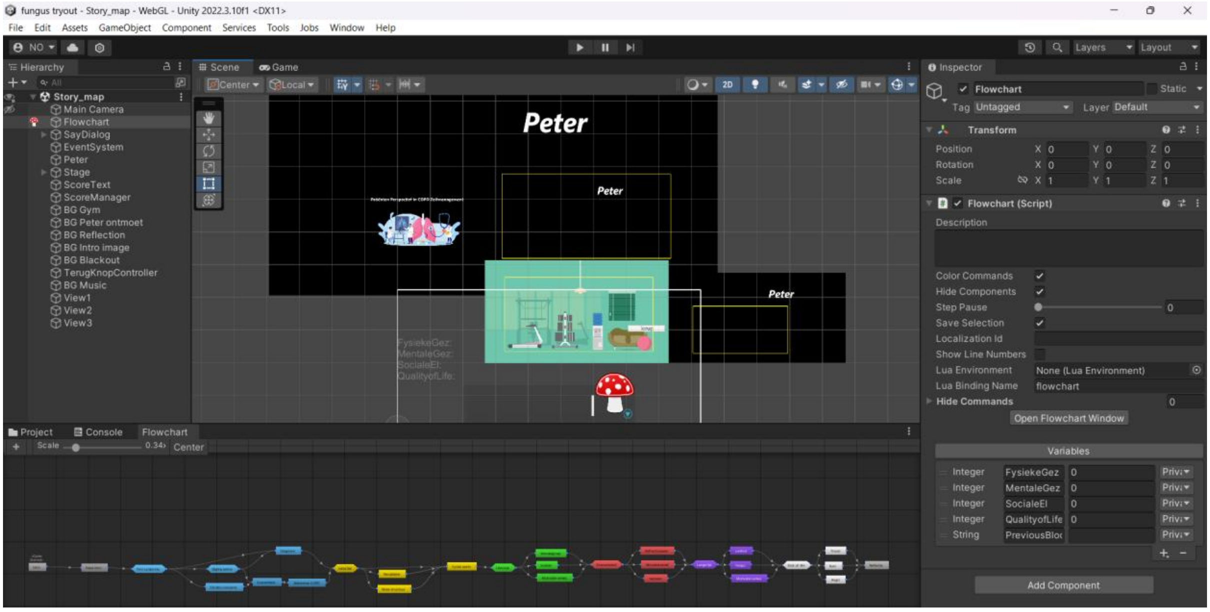


Figure 6.8: Peter character sprites (in order: confused, confident, disappointed and content)

6.3 Audio

Audio is an important element of enhancing the user experience. This is why it has been approached carefully for this aspect of the story map, ensuring auditory feedback and ambient sounds. Firstly, the story map has background music containing a peaceful soundtrack with piano music, creating a higher opportunity for the formation of empathy towards Peter. This background music can be heard throughout the entirety of the experience. Then, when Peter shows up on the screen, vocalizing his concerns or questions, a mumbling can be heard. It is not understandable to ensure that the requirement of adaptability of the content remains. It would cost a lot of resources and time to redo voice acting when the content of the story map is changed. Thus, using mumbling audio instead of voice acting makes the process less demanding. Lasty, the point system within the decision points contains feedback on the type of choice the user made. A negative sound can be heard when any of the variables are lowered, while a positive sound is played when any of the variables is increased. This makes the user more aware of the variable changes, as well as its impact.

6.4 Unity workings



Flowchart
Static
Tag Untagged
Layer Default

Transform

Position	X 0	Y 0	Z 0
Rotation	X 0	Y 0	Z 0
Scale	X 1	Y 1	Z 1

Flowchart (Script)

Description
Color Commands ☑
Hide Components ☑
Step Pause 0
Save Selection ☑
Localization Id
Show Line Numbers ☐
Lua Environment None (Lua Environment)
Lua Binding Name flowchart
Hide Commands 0

Variables

Integer	FysiekeGez	0	Priv
Integer	MentaleGez	0	Priv
Integer	SocialeEl	0	Priv
Integer	QualityofLife	0	Priv
String	PreviousBloc		Priv

Figure 6.9: Unity workspace

The Figure above (Figure 6.9) shows an overview of the workspace within Unity. The middle viewport is the location where all elements are placed in their corresponding locations. The backgrounds which are formed during various scenes, together with the views where the camera will move towards are set as the central aspects. Then, the white wireframed box shows the display of the tool. The elements placed in this box are always visible on screen and will move along with the main camera, like the score list containing several patient perspective related topics, the return button, scrollbar, 'continue' button, and the dialogue box. The dialogue box contains several elements that can be changed around with dynamic settings throughout the progression of the tool. In the top left corner, a name will be shown when a specific character is reading out text, grouped together with a sprite. These will disappear once the patient is finished, and the narrator continues. The mushroom is a temporary replacement image, which will automatically be substituted for the correct sprite.

The hierarchy is displayed on the left side of the workspace. It contains all objects and empties required for the working of the tool. Various objects will influence each other, like the 'ScoreManager' makes sure that the score is up to date. An overview of the flowchart integrated into the story map can be seen on the bottom of the screen. Here, all (decision) blocks are visible, each with different workings and commands. An example can be seen in Figure 6.10. Several commands are displayed in a list which are executed in order from top to bottom. Firstly, a set variable for the scores is used to lower the social metric score by one point. Then, the narrator and Peter himself will give a response with text and corresponding visuals. The multiple-choice question is then displayed showing the options with a menu command. The block will then change the variable ‘PreviousBlock’ to the block it is currently on, after the user has made a decision that made them move on to the next block in line. This example from the ‘Lifestyle’ block only shows a fraction of the commands available and/or used for this tool.

Execute On Event <None>

Commands

Set Variable	*SocialeEl -= 1*
Say	*"Peter is fysiek gewend, maar heeft het e*
Say	*Peter: ""Ik voel me niet meer mezelf. Ik ve*
Menu	*Stimuleer deelname aan een lokale COPD*
Menu	*Introduceer gestructureerde oefeningen*
Menu	*Zeg hem dat hij de symptomen in de gate*
Set Variable	*PreviousBlock = Lifestyle*

Figure 6.10: Unity commands

7. Evaluation

This section describes the method of the evaluation performed on the story map with its corresponding results. The goals of the evaluation are to gain insight into the effectiveness of creating awareness of the patient perspective for healthcare professionals in self-management regarding COPD patients through the story map. Additionally, the story map will be tested for usability, content, visuals, and willingness to implement into professional development and/or studies.

7.1 Method

Five interviewees were found who were willing to participate in the evaluation. They were all physiotherapists who had some experience with COPD patients, either through direct clinical care or rehabilitation programs. Their years of practice varied, ranging from a few years to a more experienced practitioner who has been working for 20+ years. Some of the participants had followed COPD-related courses, while others did not, resulting in diverse levels of background information related to self-management. However, all of them had worked with COPD patients before. Their familiarity with COPD gave them the ability to assess whether the content was realistically and effectively integrated in the tool.

Procedure

The interviewees were invited to a Teams meeting individually via an email they received. Multiple interviewees were present during previous interviews regarding this research, thus only needing a reminder of the project, while others were newly introduced.

The story map was then presented to the users via a link which was sent in the chat during the meeting. This would lead to a ‘game’ uploaded on Itch.io for a simple way of accessing the story map without requiring the download of any files. However, before starting the story map, the interviewees were asked to use the Think aloud protocol where users are asked to say their internal monologue out loud. This provides the interviewer with useful insights into the thought processes of the user without having to make assumptions about the reasonings of their actions while using the tool. Once they were informed about this protocol, the interviewees started the story map. One of the requirements of the tool is that it should fit in the current schedules of situations where it will be implemented; this is why the tool’s time duration was measured during each evaluation. It started when the user pressed the ‘play’ button, and ended once the user finished the reflection. The users experienced the story map from the beginning until the end, where they stopped the tool.

After the story map had been completed, participants were requested to participate in a semi-structured interview focusing on the general impressions of the tool. Questions were asked related to topics like the strengths and weaknesses of the tool, accuracy of the content, their opinion on the visuals, and the application of the tool in certain situations (the original questions can be found in Appendix G). Finally, they were sent a link to an online questionnaire, SUPR-Q [33], which they could then fill in.

Data analysis

The recordings of the evaluations were analyzed for body language of the interviewees during the usage of the tool to gain further insights, as well as to transcribe the recorded audio to text with censoring and paraphrasing where sensitive information was given to maintain anonymity.

A standardized format of eight questions was used, SUPR-Q (Standardized User Experience Percentile Rank Questionnaire). It makes use of five-point Likert scales (1=strongly disagree, to 5=strongly agree) with an additional ten-point Likert scale for the final question. The points gathered from the SUPR-Q questionnaire can be converted to scores for a final review of the tool.

The SUPR-Q was used for determining the user experience of websites and other digital tools. It provides insight into several elements regarding the product: usability, credibility, appearance and loyalty. Hence, the reason it was chosen for this research is as many other standardized questionnaires only take general user usability into account and SUPR-Q has a broader approach. Each category contains two questions each:

- The website is easy to use. (Usability, 1-5)
- It is easy to navigate within the website. (Usability, 1-5)
- The information on the website is credible. (Trust, 1-5)
- The information on the website is trustworthy. (Trust, 1-5)
- I find the website to be attractive. (Appearance, 1-5)
- The website has a clean and simple presentation. (Appearance, 1-5)
- I will likely return to the website in the future. (Loyalty, 1-5)
- How likely are you to recommend this website to a friend or colleague? (Loyalty, 0-10)

SUPR-Q can be scored in two ways: raw or a percentile score rank. The raw score contains the foundational answers from the users on a scale from one to five, with the final question ranging from zero to ten to determine the average score of all categories combined or the individual categories. The percentile score rank is calculated and can be compared to many other digital tools from the SUPR-Q database for the determination of its rank. However, this database only contains websites located in the United States and requires a license, not fitting the extend of this research. Thus, why only the raw score will be considered.

$$Raw\ SUPRQ\ score = \frac{Q1 + Q2 + Q3 + Q4 + Q5 + Q6 + Q7 + (0.5 * Q8)}{8}$$

7.2 Results

Usage duration and general impressions

The duration found during the evaluation extended between five minutes to ten minutes, with three out of five interviewees finishing around 5.5 minutes and the remaining two taking approximately nine or ten minutes.

The overall impression of the story map was received as positive among all participants. Although one participant reported that the story map experience felt like a test. There were also a few elements that could be improved. The music and sound effects were generally perceived as a fun addition to the tool, with one interviewee being too distracted by these and thus preferring no audio. Another participant indicated that they were missing a more detailed report on the severity of the disease which could change possible choices made during the tool. Two out of five also mentioned being somewhat confused at the first decision point when being asked what their decision would be. They did not know that clicking the screen would give the user multiple-choice options, and thought they had to come up with their own answers. Both cases continued rather quickly instead of being stuck.

Many elements were also found to be well-executed. Especially the seven-phase game walkthrough of the tool was seen as beneficial. It made a clear pathway of the journey a COPD patient goes through in life, showing that this disease is not to be cured with its corresponding barriers. They mentioned that the format of multiple choice is preferred over open questions and thought the process is appropriately clear, not facing any major difficulties while using the tool. Three out of five participants explained that this tool helped them see the importance of the decisions made by healthcare professionals and how they could facilitate independence for patients. Two out of five participants mentioned they were compelled by Peter’s story, creating empathy for him and understanding his concerns.

Content evaluation

Another aspect tested during this evaluation is the content within this tool. All users experienced the content of the situation as realistic. The problems indicated by Peter are often seen during their workdays, such as fear of worsening symptoms and being ashamed of the progression of their disease.

The ‘exacerbation’ phase was often seen as a vital element of the story, as this is a moment in many patients’ lives which has a big impact on their health, mentally and physically, so to pay extra attention to this could lead to a smaller burden. Currently, the content of the story was not found to be seen as new. Most of the data and scenarios were known by the users, however, they did mention it was pleasant to have a reminder. Five out of five users stated that the format in which the content is being presented within the story map is a new concept for them. They noted that current courses and studies regarding self-management for COPD are largely provided by lectures or plain texts they must read, so having an interactive way of studying this topic was refreshing for them.

Potential for implementation

All interviewees reported a motivation for the usage of the story map during courses or studies. The moment of use differed between the users as they were asked if they would use this tool for creating awareness or specific questions that occurred during cases. Most of the users mentioned the tool being suitable for creating awareness as the information is generalized with an open-minded patient, however, they could also see the story map being applicable to real life cases with minor modifications to details and the addition of multiple patient stories to choose from. Many saw potential in the usage of the story map in group settings where the decision points can be discussed within classrooms and small groups.

Observations

Some observations found within the evaluation are that all participants went through the story in one take without using the ‘return’ button once. It was used a few times to reread the previous text if it was accidentally continued by the user without having the time to read, but never to try other options from the decision points. Another mechanic the users missed was the score system. When asked about the score during the interview, none of the participants mentioned having paid much attention to it. Lastly, the body language from the users was neutral and did not provide much opportunity for observation, only showing emotional signs when they were confused or surprised by an answer.

SUPR-Q

Category	Mean
Usability	(4.60 + 4.40) / 2 = 4.5
Trust	(4.40 + 3.80) / 2 = 4.1
Appearance	(4.40 + 4.20) / 2 = 4.3
Loyalty	(4.40 + (8.40*0.5)) / 2 = 4.3
Average	4.3

Table 7.1: Average raw SUPR-Q scores of each category

The SUPR-Q questionnaire provides a quantitative overview of the user experience in four categories: usability, trust, appearance, and loyalty. The scores are as follows: usability=4.5, trust=4.1, appearance=4.3, and loyalty=4.3. This results in an average score of 4.3 out of 5. Usability, the highest score from the four categories, suggests that the users found the tool intuitive and easy to use, experiencing minor barriers. The lowest score, trust, is still relatively high. It indicates a generally positive attitude towards credibility and reliability regarding the content of the tool. Appearance and loyalty both score a 4.3 out of 5, implying a favorable impression for the visuals and motivation for future use, including recommendations to others. Altogether, these results indicate a positive user experience on different aspects while interacting with the story map.

8. Discussion

This section describes the results of the user evaluations done with the tool and summarizes the key findings. The research questions from chapter one will also be answered with the information gathered from the project. Lastly, the limitations of the research together with recommendations for future work are presented.

8.1 Key findings

The results of the user evaluation are a vital part of the analysis of the tool. Several findings have been established. Firstly, the story map is seen as engaging as all the users were intrigued while interacting with the tool. They liked the tool's narrative design. However, it was not always seen as intuitive. Some moments caused confusion for the users (e.g., continuation of the text), which could result in a decrease in the frequency of when the user is in a state of flow, as described by Fang et al. [26]. This indicates that the user interface should be improved to enhance the effectiveness of the tool. This observation aligns with the findings from Benyon [23], in which it is pointed out that a clear user interface will lead to higher acceptability, thus increasing the effectiveness. Furthermore, more personalization options could be implemented to accommodate the different preferences of the users, like having the opportunity to mute certain audio applications, as some found it distracting, while others stated it to be enjoyable. This is reflected in a previous study performed by Ghaben et al. [2], in which they found that personalization increases adherence and effectiveness in tools.

As stated before, the content of the story map is mostly not new to the users. This may be due to the fact that the physiotherapists interviewed during the evaluation have had many years of experience with COPD patients and have followed specialization courses regarding this topic. Thus, it serves more as a reflection tool for experienced healthcare professionals to increase empathy than it being educational. If the tool were to be implemented in the target locations, this would be less of a problem as healthcare professionals attending courses and/or studies will be less likely to be familiar with these concepts.

Additionally, some mechanics of the tool were underused. The point system being ignored or not seen by the user implies that an important part of the feedback given to the user is not being perceived, which leads to a decrease in learning impacts. Also, since users did not make full use of the return button, the exposure to different perspectives and outcomes was limited. This can indicate that the user interface and/or information given was not clear enough on the different options of the return button (going back for other perspectives or rereading text), and should inform users more clearly on its capabilities. This makes it more likely for the user to utilize the safe environment of testing other types of advice and perspectives. The same thing can be mentioned regarding the point system, where an increase in size, different placement, or color changes may help the user notice the points.

Participants found the narrative, story-based format of the tool more stimulating than the classic textbook or lecture style way of accessing education. This highlights the importance of unique formats in educational settings for professional development, creating more motivation for learning and a higher level of empathy. Comparable results were found by Kononowicz et al. [34], where it was highlighted that virtual patients could improve motivation. Similarly, the appeal of applying the story map in group settings found by the participants indicates that there are even more opportunities for amplifying the reflection regarding this tool. This is where the social learning theory comes into view; it states that people will adopt and learn from others in social situations [35]. So, when someone observes another peer interacting with the story map tool, they may increase their understanding and reflection on how healthcare professionals differ in their perspectives and approaches. This is also highlighted in the work of Kristjansdottir et al. [22] regarding group-based patient education for HCPs.

Finally, the SUPR-Q scores indicate that usability, appearance and loyalty were satisfying to the participants, scoring an average of 4.3 or 4.5 out of 5. Yet, trust was scored the lowest of all categories with a 4.1 out of 5. This indicates that the users were slightly questioning the sources of the content. Other iterations can include the references and guidelines used for the content to stimulate more trust, particularly if this tool were to be used in official medical and/or physiotherapy programs. While being based on evident-based content, the fictional nature of the patient story may have raised questions about clinical accuracy. The average SUPR-Q score was calculated to be 4.3 out of 5, indicating a positive and high level of user satisfaction with some room for improvement.

Relation to previous work

Previous educational interventions regarding COPD self-management mainly focused on the clinical view of COPD care, objective measurements and eHealth technologies (often implementing dashboards combined with smart wearable measuring devices) [2][9]. These tools are still valuable for tracking physical symptoms, but often overlook the patient perspective. In contrast, the story map was developed with the patient perspective as its main focus, offering a structured method to connect with it. Physical interventions are providing users with accessible methods of interacting with care [17]. However, these lack adaptability, and will become outdated. The story map accounted for this by ensuring that the tool is easily updated with the use of variables and preventing many manual changes. Group-based interventions have great potential to affect healthcare professionals positively through collaboration [22]. The story map is also promising for either solo use or collaboration in group settings (with minor modifications). So, prior work has provided valuable insights into important aspects that had to be integrated in the tool.

8.2 Answering research questions

The design process of this research was built on several research questions that were stated at the beginning of the study. The sub-questions and main research question will be answered below.

Sub-question 1: *What are the key self-management activities for patients from their perspective?*

From the literature and interview conducted with a COPD patient, it was found that key self-management activities according to patients are present in a wide variety, ranging further than only medication and physical exercise. Patients highlighted the importance of managing mental health (e.g. shame, fear, or anxiety) as the progression of the disease can take a great toll [4][36]. Maintaining social interactions was also seen as a vital element to reduce isolation. This was often seen hand-in-hand with seeking support and learning from peers who are likewise dealing with COPD [30]. Moreover, monitoring symptoms and knowing when to act on them is another aspect that can offer important insights into COPD care since it can prevent exacerbations [2]. Lastly, adapting lifestyles and routines, like accepting limitations or pacing daily activities, is acknowledged as valuable [31]. All these activities can help patients significantly with their ability to manage their condition.

Sub-question 2: *What are the current gaps in healthcare professionals' understanding of patient-centered self-management?*

An analysis of interviews and survey data suggested several gaps. Healthcare professionals often rely on objective measurements collected from the patient (e.g. FEV1 or medication) and lack the focus on mental, social and emotional aspects and challenges. This may be caused by different reasons. A lack of time or tools for taking the patient’s perspective of self-management into account since appointments are brief. Also, the education on this topic has been lacking according to healthcare professionals. There was little time invested in the patient perspective of self-management during the education of upcoming physiotherapists, and carrying out professional development requires resources which are not always available due to time and/or budget restraints. The gap is then created since healthcare professionals are lacking structured methods for approaching patients about their daily struggles, which is also suggested by King et al. [29].

Sub-question 3: *What are the essential features and content an educational tool should have to enhance healthcare professionals’ understanding of patient perspectives?*

Fundamental features and content were revealed by the analysis of tool concepts and feedback. Realistic and evidence-based patient stories should ensure that the user is reflecting on reasonable patient journeys as implied by Kononowicz et al. [34]. The ability to show users the consequences of their choices by showing them the impact they have on patients they are taking care of, by making interactive decision points, can give the user an impression of future cases. Additionally, when an educational tool has a feedback system integrated into the product, it will encourage learning experiences and awareness of their actions. Finally, making the tool simple and accessible will lead to a more straightforward use for users with different levels of experience.

Sub-question 4: *What design principles and formats are most relevant for educating healthcare professionals and patients on this topic?*

This research concludes that effective principles and formats should promote active participation. This may be in the form of interactive branching narratives or other methods in which users must be greater involved in the progress. Patient storytelling may help with this concept; it can create more empathy and understanding that can stimulate the learning process. As healthcare professionals are rather busy with occupied schedules, the tool should be quick to use with a low barrier when interacting with it. Making it complicated to set up or use will lessen the motivation of healthcare professionals to engage with the product, thus less likely to educate themselves. Lastly, avoid formats that are overly theoretical. Most of the education on this topic is given in text with little ways of interacting with it, making it less enjoyable for users, according to Kononowicz et al. [34] and the interviews with healthcare professionals who followed self-management courses. Giving them other ways of content delivery creates a refreshing look towards the tool, and makes it more likely to give motivation for usage.

There can now be focus on the main research question as all four sub-research questions have been answered.

Research question: *"How can an educational tool be designed for healthcare professionals regarding COPD self-management activities focusing on the patient perspective?"*

From this project, it can be seen that an educational tool for COPD self-management with a patient perspective targeting health professionals has been created with many steps. First, a literature review is performed to gain certain background information on the topic, together with insights from interviews and questionnaires, requirements (such as adaptability and usability), and ideas are generated that are suitable for the target group. After having constructed a prototype, evaluations are held with users to gain insights into feedback and improvements. This will be featured in the following prototypes, resulting in an iterative process. This research indicated that an interactive story map is an effective tool for conveying the patient perspective of COPD self-management, with considerations for accessibility, being intuitive, and realistic.

8.2 Limitations & future work

Limitations

Even though valuable insights were found within the research done, some limitations should also be mentioned. The interviews and questionnaires were answered by a small number of individuals. While many companies and individuals were reached out to, only a few responded with interest in participating. Such a limited sample size makes evaluating more complicated since there will always be differences in preferences, but there is no possibility for generalization. This means that there is a risk of bias among the participants during this research, not having the chance of receiving opinions from the bigger, overall target group. However, by integrating findings from existing background literature and aligning them with the results, interpretations could still be made within a broader context. Also, most participants were physiotherapists within the limited sample size, only having two occupational therapists. Although physiotherapists have an important role in the care for COPD patients, COPD requires a broad range of healthcare professionals like GPs, dieticians, lung physicians, and psychologists. This means that there is a missed opportunity to apply this tool in other fields to also educate these healthcare professionals on the patient perspective, just like physiotherapists. Also, perspectives from other healthcare professionals in different fields could not have been implemented in the research. Time constraints was also a general problem found within this project. More time could have been invested in gathering a larger number and variety of participants and improving the tool if the project duration would have been longer. Nevertheless, with prioritizing core functions, usability, and content, meaningful insights were still gathered within the time frame with the use of detailed interviews.

Future work

Several developments and improvements are recommended for future work related to these findings. Future evaluations should seek a more diverse population regarding the target group to fully encapsulate the patient perspective in COPD self-management care into the story map. This could lead to interdisciplinary input and communication among healthcare professionals for improving the patient perspective. Additionally, increasing the scale of the user tests with more participants would validate the findings further and lead to more improvements. Finally, future iterations of the story map should accommodate a wider variety of patient stories. This would capture the heterogeneous characteristics of COPD by showing the users the different patient cases found within regular workdays. For example, changing patient personalities to having closed-minded individuals not willing to share their experiences or not open to advice given by the healthcare professional could give insights into different approaches and clinical scenarios. The COPD stages can also be modified. Currently, the user sees a patient's story of someone before they officially receive their COPD diagnosis, but other stories could include patients who are further into the progression of COPD, containing different struggles and goals.

9. Conclusion

This research delved into the exploration of how an educational tool can be designed for educating healthcare professionals on the patient perspective of COPD self-management. The study investigated an important problem occurring in COPD care: patient perspectives are often overlooked in the work of healthcare professionals. This entails that elements like social constraints, mental health and quality of life are not considered in current educational resources and practices, while aspects of the clinical side (i.e. medication adherence and physical exercise) have a greater focus. Accordingly, this leads to a lack of knowledge of what COPD self-management entails from the perspective of patients resulting in gaps of communication and quality of care. The research identified several findings: patients are finding self-management activities outside of the clinical view vital, healthcare professionals often lack the time and/or resources for an application of the patient perspective and that current interventions fall short of accessibility and interactivity.

A prototype was developed for an interactive story map with the use of a structured, iterative process following the Creative Technology design process combined with literature reviews and stakeholder input, focusing on realistic, intuitive and accessible usage. The tool made it possible for healthcare professionals to follow a patient story of someone going through the phases of COPD, from the beginning to the end, in a narrative representation with decision points where the user can influence the story. The story map will let users experience what the consequences are of their choices through the eyes of a patient, creating empathy and understanding.

Feedback from the evaluation phase with healthcare professionals revealed that the tool has potential in being implemented in professional development and education. Participants stated that the tool's content is realistic and relatable, with an appreciation for the different format than they were used to. This prototype is a foundation for further development since it is in an early stage. More patient stories and perspectives can be added for an increase in diversity and insights, the user interface can also be modified to adhere to the many varying preferences, and stories could be altered to fit healthcare professionals from different fields.

In summary, this thesis is contributing to the shift of patient-centered healthcare by providing insights into interventions including the patient perspective, with the use of a prototype incorporating usability and accessibility.

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Appendix

A Generative AI usage

During the preparation of this work the author(s) used ChatGPT in order to help solve coding problems and modify user personas. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the work.

B Concept questionnaire

Algemene gegevens

-Wat is uw functie in de zorg? (bv. arts, verpleegkundige, longfysiotherapeut, etc.)

-Hoeveel ervaring heeft u met COPD-patiënten?

- ○ 0–2 jaar
- ○ 3–5 jaar
- ○ 6–10 jaar
- ○ Meer dan 10 jaar

Vragen over omgaan met het patiëntperspectief in de praktijk

-Hoe belangrijk vindt u het patiëntperspectief in de behandeling van COPD?

(1 = helemaal niet belangrijk, 5 = zeer belangrijk)

-In hoeverre lukt het u om het perspectief van de patiënt actief mee te nemen in uw behandelplan?

(1 = zelden, 5 = altijd)

-Hoe verwerkt u het perspectief van de patiënt in uw behandelplan?

-Op welke manieren verzamelt u informatie over de beleving van COPD-patiënten? *(meerdere keuzes mogelijk)*

- ○ Directe gesprekken tijdens consulten
- ○ Vragenlijsten
- ○ Informatie van mantelzorgers

- ○ Besprekingen
- ○ Ik doe dit momenteel niet actief
- ○ Anders, namelijk:

-Wat zijn volgens u de grootste uitdagingen om het patiëntperspectief echt te begrijpen?

- In hoeverre bespreekt u gevoelens/gedachten (zoals angst, stigma of eenzaamheid) actief met COPD-patiënten?

(1 = vrijwel nooit, 5 = bij vrijwel iedere patiënt)

-Krijgt u tijdens scholingen of bijscholing voldoende aandacht voor het perspectief van de patiënt?

(1 = helemaal niet, 5 = zeer voldoende)

-Welke van de onderstaande onderwerpen rondom patiëntperspectief zouden volgens u meer aandacht mogen krijgen in scholing?

- ○ Angst en onzekerheid bij ademnood
- ○ Impact van diagnose op het dagelijks leven
- ○ Stigma en schaamte bij gebruik van hulpmiddelen (zoals zuurstof)
- ○ Communicatie tussen zorgverlener en patiënt
- ○ Behoefte aan eigen regie en autonomie
- ○ Patiënt-doelstellingen in plaats van medische doelen
- ○ Andere suggesties:

-Hoe vaak reflecteert u met collega's op de manier waarop patiënten hun zorg ervaren?

- Wekelijks
- Maandelijks
- Af en toe
- Nooit

-Wat zou u helpen om het patiëntperspectief vaker of beter te integreren in uw zorgverlening?

Algemene vraag over educatieve voorkeuren

-Hoe leert u het liefst over patiëntgerichte zorg?

- ○ Praktijksituaties
- ○ Video's
- ○ Spelvormen
- ○ Interactieve simulaties
- ○ Lezingen/artikelen
- ○ Anders, namelijk:

-Hoeveel tijd bent u bereidt om hiervoor aan te besteden?

- ○ <1 uur
- ○ 1-2 uur
- ○ 3-5 uur
- ○ >5 uur

Feedback per concept

1. **Interactieve story map**

-----(Uitleg Concept)-----------

-In hoeverre vindt u dit concept nuttig voor het verbeteren van inzicht in het patiëntperspectief bij COPD?

(1 = helemaal niet nuttig, 5 = zeer nuttig)

-Hoe gebruiksvriendelijk verwacht u dat dit concept is?

(1 = zeer lastig, 5 = zeer gebruiksvriendelijk)

-Wat spreekt u het meest aan in dit concept?

-Wat zou u verbeteren aan dit concept?

-Zou u dit concept gebruiken (in teamverband of scholing?)

(Ja/Nee + toelichting)

2. Bord-/Kaartspel

-----(Uitleg Concept)-----------

-In hoeverre vindt u dit concept nuttig voor het verbeteren van inzicht in het patiëntperspectief bij COPD?

(1 = helemaal niet nuttig, 5 = zeer nuttig)

-Hoe gebruiksvriendelijk verwacht u dat dit concept is?

(1 = zeer lastig, 5 = zeer gebruiksvriendelijk)

-Wat spreekt u het meest aan in dit concept?

-Wat zou u verbeteren aan dit concept?

-Zou u dit concept gebruiken (in teamverband of scholing?)

(Ja/Nee + toelichting)

3. Korte Videoserie

-----(Uitleg Concept)-----------

-In hoeverre vindt u dit concept nuttig voor het verbeteren van inzicht in het patiëntperspectief bij COPD?

(1 = helemaal niet nuttig, 5 = zeer nuttig)

-Hoe gebruiksvriendelijk verwacht u dat dit concept is?

(1 = zeer lastig, 5 = zeer gebruiksvriendelijk)

-Wat spreekt u het meest aan in dit concept?

-Wat zou u verbeteren aan dit concept?

-Zou u dit concept gebruiken (in teamverband of scholing?)

(Ja/Nee + toelichting)

Totale voorkeur

-Welk van de drie concepten spreekt u het meest aan als leermiddel?

- Interactieve story map
- Bord-/kaartspel
- Korte videoserie
- Anders, namelijk:

-Waarom heeft u voor dit concept gekozen?

C Tool visuals

Moedig Peter aan om zijn symptomen bij te houden en voor een beoordeling naar zijn huisarts te gaan.

Stel lichte fysieke activiteiten voor zonder medische beoordeling.

Zet de zorgen opzij en stel hem gerust dat het normaal is om ouder te worden.

Welk advies geef jij?

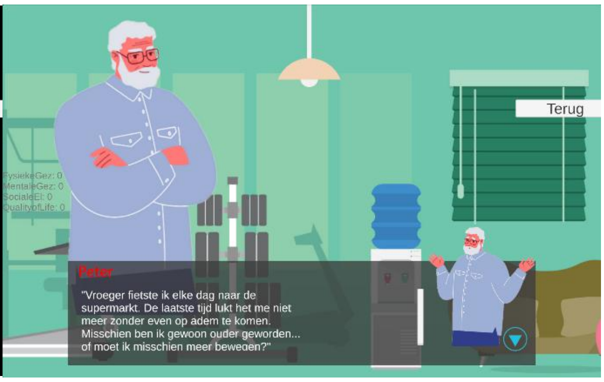
Patiënten Perspectief in COPD Zelfmanagement

Welkom bij deze interactieve story map waarin je het ziekteverloop volgt van een patiënt met COPD. Als fysiotherapeut krijg je in dit verhaal de kans om keuzes te maken die direct invloed hebben op het dagelijks functioneren en de kwaliteit van leven van de patiënt.

Peter

Peter

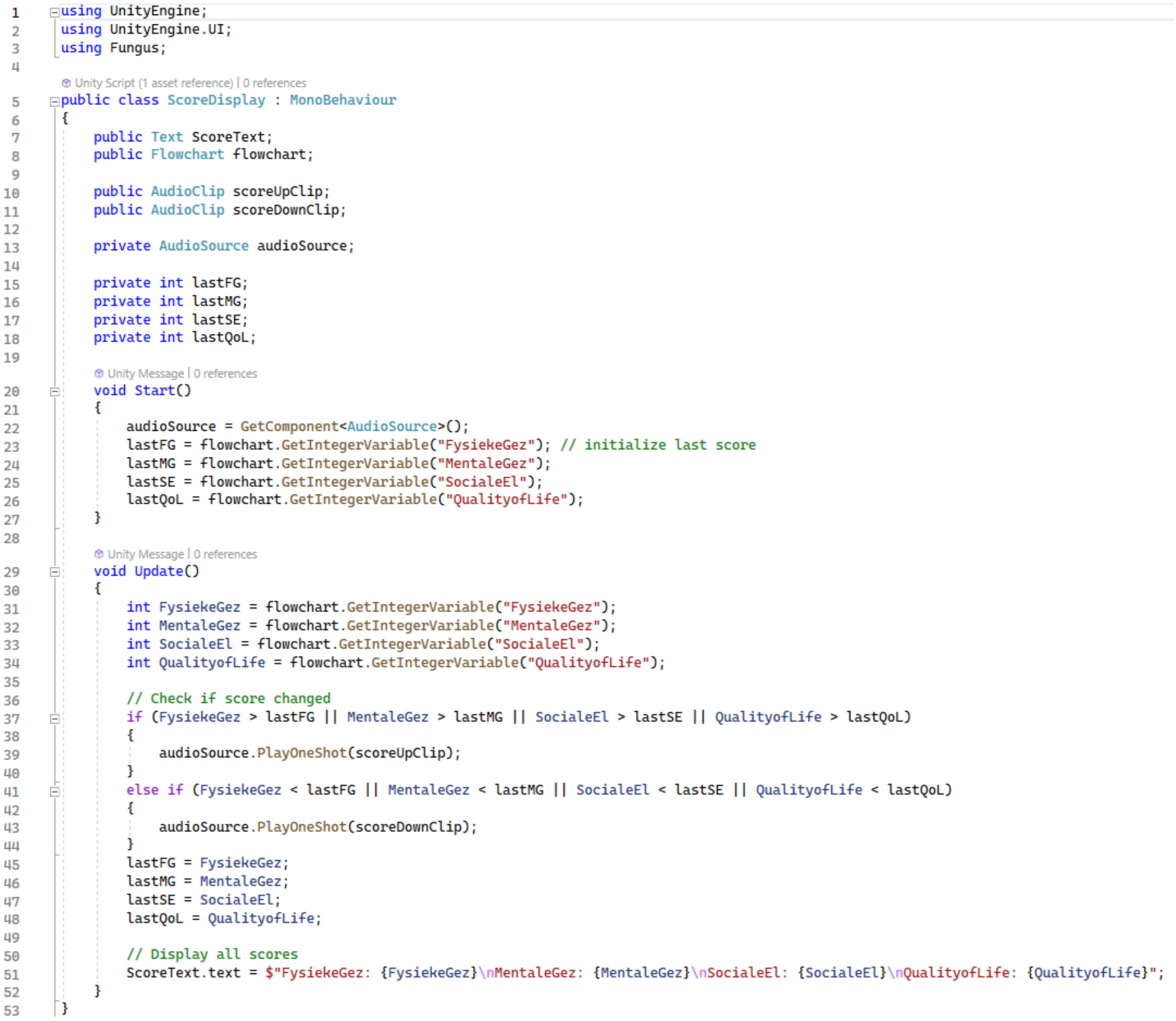
Peter is een 62-jarige man, voormalig fabrieksarbeider en ex-roker. Vroeger was hij fysiek actief, maar door aanhoudende kortademigheid is zijn uithoudingsvermogen sterk afgenomen. Traplopen of zelfs lichte inspanning kost hem nu veel moeite. Peter woont alleen en redt zich grotendeels zelfstandig, maar



Peter

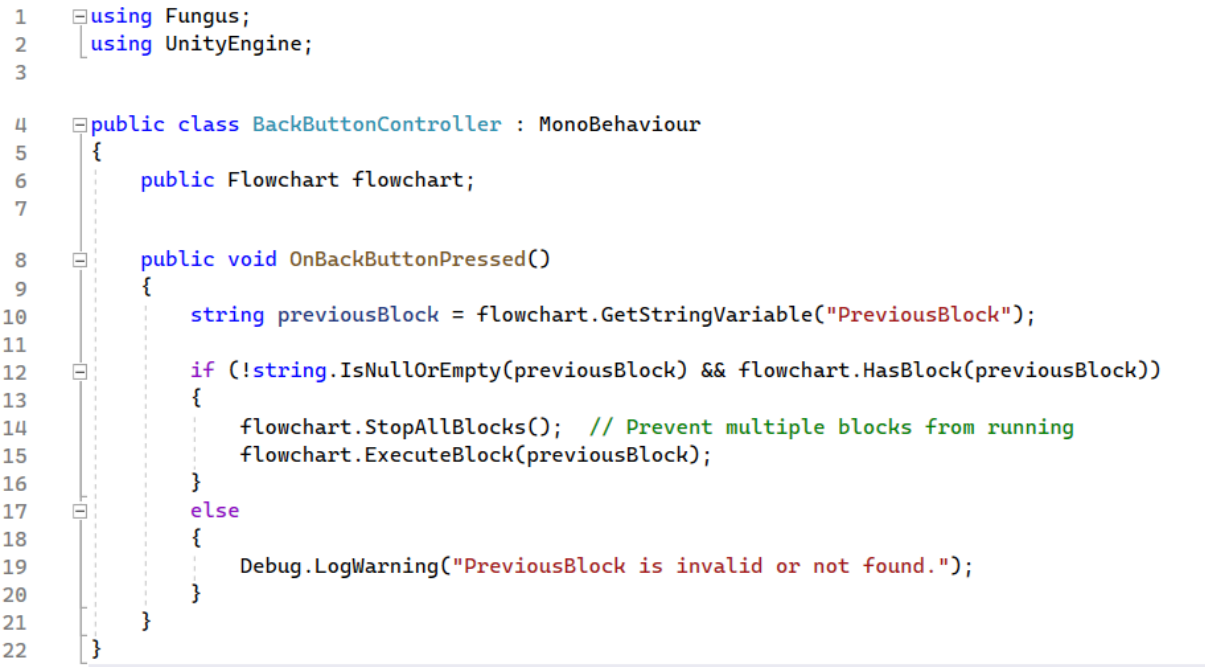
"Vroeger fietste ik elke dag naar de supermarkt. De laatste tijd lukt het me niet meer zonder even op adem te komen. Misschien ben ik gewoon ouder geworden... of moet ik misschien meer bewegen?"

D Code for point system



```
using UnityEngine;
using UnityEngine.UI;
using Fungus;

public class ScoreDisplay : MonoBehaviour
{
    public Text ScoreText;
    public Flowchart flowchart;

    public AudioClip scoreUpClip;
    public AudioClip scoreDownClip;

    private AudioSource audioSource;

    private int lastFG;
    private int lastMG;
    private int lastSE;
    private int lastQoL;

    void Start()
    {
        audioSource = GetComponent<AudioSource>();
        lastFG = flowchart.GetIntegerVariable("FysiekeGez"); // initialize last score
        lastMG = flowchart.GetIntegerVariable("MentaleGez");
        lastSE = flowchart.GetIntegerVariable("SocialeEl");
        lastQoL = flowchart.GetIntegerVariable("QualityofLife");
    }

    void Update()
    {
        int FysiekeGez = flowchart.GetIntegerVariable("FysiekeGez");
        int MentaleGez = flowchart.GetIntegerVariable("MentaleGez");
        int SocialeEl = flowchart.GetIntegerVariable("SocialeEl");
        int QualityofLife = flowchart.GetIntegerVariable("QualityofLife");

        // Check if score changed
        if (FysiekeGez > lastFG || MentaleGez > lastMG || SocialeEl > lastSE || QualityofLife > lastQoL)
        {
            audioSource.PlayOneShot(scoreUpClip);
        }
        else if (FysiekeGez < lastFG || MentaleGez < lastMG || SocialeEl < lastSE || QualityofLife < lastQoL)
        {
            audioSource.PlayOneShot(scoreDownClip);
        }
        lastFG = FysiekeGez;
        lastMG = MentaleGez;
        lastSE = SocialeEl;
        lastQoL = QualityofLife;

        // Display all scores
        ScoreText.text = $"FysiekeGez: {FysiekeGez}\nMentaleGez: {MentaleGez}\nSocialeEl: {SocialeEl}\nQualityofLife: {QualityofLife}";
    }
}
```

E Code for return button



```
using Fungus;
using UnityEngine;

public class BackButtonController : MonoBehaviour
{
    public Flowchart flowchart;

    public void OnBackButtonPressed()
    {
        string previousBlock = flowchart.GetStringVariable("PreviousBlock");

        if (!string.IsNullOrEmpty(previousBlock) && flowchart.HasBlock(previousBlock))
        {
            flowchart.StopAllBlocks();  // Prevent multiple blocks from running
            flowchart.ExecuteBlock(previousBlock);
        }
        else
        {
            Debug.LogWarning("PreviousBlock is invalid or not found.");
        }
    }
}
```

F Link to tool

https://ninaoo.itch.io/zelfmanagement-bij-copd

G Evaluation questions

- What is the overall impressing you got from the story map?
- What aspects did you not like? What improvements would you suggest?
- What aspects did you find well-executed?
- Is the content of the story map accurate and/or realistic? Were some important elements forgotten?
- How appealing were the visuals?
- (How) would you consider using this material? Specific questions or creating awareness?
- Is the information new to you? Is it valuable?
- How would you see this tool work in professional development?