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Master of Design (Research) Thesis

Breathing life into pursed lip breathing and the implications of designing a product

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Certificate of Original Authorship

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Elizabeth Lewis

Date: 16th December 2016

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Definitions

Chronic Obstructive Pulmonary Disease (COPD): is a long term disease of the lungs which causes shortness of breath.

Comorbid: the presence of one or more additional diseases or disorders simultaneous to a primary disease or disorder.

Entrainment: the patterning of body processes and movement to rhythm.

Feedback: process in which the effect or result of an action is returned or 'fed back' so that the next action can be modified. It is information sent to an entity, be it mechanical, electrical or biological, about its prior behaviour so that the entity can adjust current and future behaviour to achieve a desired result.

Functional capacity: the ability of an individual to perform aerobic activities. The assessment of functional capacity reflects the ability to perform activities of daily living that require sustained aerobic metabolism.

Harmonica Therapy: rehabilitation sessions that are performed in a group and require patients play the harmonica.

Monitoring: to be aware of the state of a system or situation, to observe for changes over a period of time and to report progress.

Motivation: a reason for an individual to behave in a particular way.

Patient interface: the position where interactions between humans and products take place. The goal of the interaction is to allow for effective operation and control by the patient, whilst the product provides information that aids the patient in using the product. The type of interface can range greatly and includes digital, manual, visual, audio and tactile elements.

Pathophysiology: physical and functional changes associated with a disease.

Pharmacology: the properties and reactions of drugs or medication especially with relation to their therapeutic value.

Psychosocial: relates to an individual's psychological development or change within a social environment.

Pulmonary rehabilitation: evidence based, multidisciplinary and comprehensive intervention for patients with chronic respiratory disease who exercise symptoms and often have decreased daily life activities.

Pursed Lip Breathing (PLB): is a breathing technique which focuses on the lengthening of the expiration of breath versus the inspiration of breath

Self-efficacy: an individual's belief in their capacity to perform behaviours that are required to achieve specific performance requirements.

Self-management: an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic illness.

Six-minute walking test: a test that measures the distance that patients are able to walk on a hard flat surface over a six-minute period.

Smartphone: a mobile phone that performs many of the functions of a computer. Typically possesses a touchscreen interface, camera, Internet access and an operating system capable of running downloaded applications and programs.

Spacer: a plastic container with a mouthpiece at one end and a hole for a canister of medication at the other. The plastic container adds space in the form of a chamber between the canister of medication and the patient's mouth, allowing the patient to inhale the medication slowly.

Spirometry: a diagnostic tool that measures the volume of air that can be forcibly exhaled within a specific time period.

Tidal volume: the lung volume representing the normal volume of air displaced between normal inhalation and exhalation when extra effort is not applied.

Abstract

Pursed Lip Breathing (PLB) is one of the many management techniques used by patients suffering from Chronic Obstructive Pulmonary Disease (COPD). Implementation of this technique aims to reduce a patient's feeling of breathlessness and restore a sense of breathing control. Although PLB is widely taught, there is still much unknown about how best to teach the PLB technique and how expert PLB users become skilled. A potential solution is the development of a personal device that guides patients to achieve improved paced breathing whilst simultaneously collecting valuable information for the clinical setting.

This work investigates the characteristics of a product for COPD patients to independently manage their breathlessness by using paced breathing principles. Interviews were conducted with COPD patients to identify rituals, attitudes and learning methods regarding PLB, as well as thoughts on existing respiratory aids and technologies. Findings from these interviews were categorised into 5 themes; monitoring and feedback, adaption, routine, motivation and active learning.

Based on these findings design characteristics were established and a proof-of-concept developed and preliminarily tested to demonstrate that its core features can be realised. These features include breath-by-breath data acquisition, real-time visual feedback during breathing practice and the capacity for remote monitoring by respiratory therapists. The results of this work indicate that paced breathing can be monitored and shared with patients and that incremental targets for improved performance can be set. It is intended that the outcomes of this work will help facilitate future research into COPD management techniques, reveal future product development opportunities and enable sufferers of COPD to improve their quality of life.

Chapter 1: Introduction

1.1. Introduction

> "I had had a bad climbing accident on a mountain in Norway, tearing off the quadriceps tendon of my left leg, as well as doing some nerve damage to it. The leg was useless and I had to find a way to get down the mountain before nightfall. I soon discovered that the best strategy was to 'row' myself down, somewhat as paraplegics do in their wheelchairs. At first I found this difficult and awkward, but soon I fell into a rhythm, accompanied by a sort of marching or rowing song, with a strong heave on each beat, I was musicked along.
>
> Without this synchronization of music and movement, the auditory with the motor, I could never have made my way down the mountain. And somehow, with this internal rhythm and music, it felt much less like a grim, anxious struggle".
> (Oliver Sacks, 2012 pp.254)

When faced with physical and mental challenges, people find interesting and unique ways to adapt. Sometimes the adaption is obvious and at other times it is slow and disguised, but what is interesting is the reasoning and method that underlies the adaption process. In Oliver Sacks' circumstance, his adaption process lay in the power of rhythm. Through his narrative, Sacks describes a phenomenon in which difficult or unnatural movements can be coordinated by rhythm and suggests that in doing so he was able to overcome the physical struggle and gain control.

Another application of the principles of rhythm described by Sacks is in the management of breathing performance. Breathing techniques and breathing training methods place an emphasis on overcoming the challenges of breathlessness through the use of pace. Instead of irregular, inconsistent or strained breathing, people find that by employing a pace, they are able to control their breath and slow their respiratory rate. This is particularly helpful in activities that require exertion or an increase in respiratory rate. The success of this principle is recognised in athletes as they synchronise their breath with movement. Examples include the pacing of breathing between swimming strokes, coordinating breathing with running strides and controlling breathing for precise actions such as archery.

Equally, imposing a rhythm or pace can play an important part in the adaption of dysfunctional or irregular breathing that occurs as a result of respiratory disease. Research has shown that the use of paced breathing techniques does positively influence a patient's sense of control and quality of life (Spahija, De Marchie & Grassino, 2005). The challenge however, is that when a person's breathing function is impaired, their capacity to independently and effectively control, modify and adapt their breathing reduces. To achieve paced breathing, patients should be well-practiced so that it comes almost naturally when breathing becomes strained or difficult.

Although paced breathing is widely taught in the COPD community, research that investigates the teaching methods, monitoring and real-time measurement of paced breathing effectiveness are lacking. As a result, the implications of effective versus non-effective paced breathing practices are not currently known. Based upon these findings, the control of breathing function through a self-directed teaching and learning process becomes an interesting path of exploration for product design.

In placing attention on the learning and monitoring of paced breathing through the use of product interactions and technologies, this research seeks to broadly consider the role of product design in facilitating paced breathing practices. Paced breathing practices extend across a variety of disease states and breathing methods which results in immense possibilities and directions. To determine the day to day needs of patients more specifically, narrowing the scope of research at this time will allow for a more in depth analysis. Moving forward, paced breathing practices will be framed and discussed through the pursed lip breathing (PLB) technique and the specific disease will be limited to chronic obstructive pulmonary disease (COPD). These areas will now be outlined.

1.2. Background

1.2.1. Pursed Lip Breathing (PLB)

Pursed Lip Breathing (PLB) is effective due to its ability to alleviate the physiological symptoms of breathlessness whilst also encouraging patients to focus their attention on controlling their breathing. Defined simply, PLB is a controlled breathing technique that aims to; prolong the total breath cycle duration, slow the breathing frequency, prevent airway collapse and provide an increased ventilatory threshold at both rest and exercise states (Spahija, De Marchie & Grassino, 2005).

Literature suggests that the practice of PLB reduces the immediate feelings of breathlessness whilst enabling patients to self-manage their breathing demands in accordance with their physical needs (National Heart, Lung and Blood Institute, 2010) (Lung Foundation of Australia 2012). As illustrated below (Fig. 1), the PLB principle is a 2:4 ratio, whereby the rate of expiration is double the rate of inspiration. The image at the top demonstrates an inhale through the nose of 2 beats, whilst the image at the bottom demonstrates an exhale through the mouth of 4 beats.

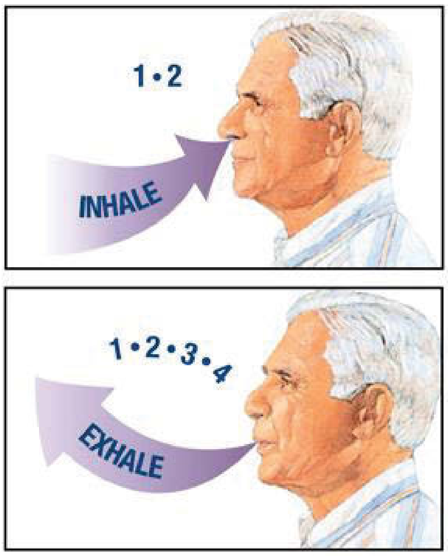


Fig. 1 Pursed lip breathing (PLB) technique
Whole Health Insider, 2012
Image taken from http://www.wholehealthinsider.com/newsletter/2012/put-pulmonary-rehabilitation-into-your-own-hands/

In extending the rate of expiration, the PLB technique encourages patients to slow their breathing through adaption of their personal breathing pace. For example, one patient's beats may be in ½ seconds, thus inhaling for 1 second and exhaling for 2 seconds, whereas another patient may allocate 1 second to their beats, therefore inhaling for 2 seconds and exhaling for 4 seconds. The benefit of this principle is that it is formulated on pace as opposed to metric values.

The 3 key elements of PLB are:

1. To instil a breathing ratio and pace (2:4)
2. To generate a ritual of inhalation through the nose and exhalation through the mouth
3. To adopt a pursed lip formation that aids controlled breathing

Although each of these elements is important in the overall practice of PLB, the first element will become the core focus for research, design conceptualisation and proof of concept development (Chapter 5). This is based upon the underlying role of pace and rhythm in determining a patient's capacity to moderate and control their breathing.

It is recognised that to perform PLB adequately, patients are required to practice and monitor their PLB performance regularly. Current research within the field explores the benefits of integrating PLB principles but there is limited research that investigates products that which may promote and enable patients to learn and practice PLB. While PLB aims to provide patients with a tool to manage their own feelings of breathlessness, particularly at times of exacerbation, patients must be well practiced and familiar with the technique in order to perform this effectively. Research in the area of PLB training and management has highlighted several shortfalls regarding the translation and use of PLB principles demonstrated within literature and bringing this to life within a patient's daily routine.

These shortfalls include ambiguous instructions on patient information sheets and research that is solely focused on the physiological benefits of PLB without consideration of the learning process. Furthermore, uninspiring guidelines may not empower individuals to self-manage their breathlessness and enable the best quality of life possible (Fraser, Kee & Minick, 2006).

To enable further exploration of the PLB principle and the opportunities for product design, it is important to link the benefits of PLB with the physiological principles of breathing. This is best explored through the context of Chronic Obstructive Pulmonary Disease, which will now be introduced.

1.2.2. Chronic Obstructive Pulmonary Disease (COPD)

The primary organ of the respiratory system is the lungs, which breathe in oxygen and breathe out carbon dioxide. When the airways of the lungs are healthy they are elastic which enables them to recoil back to their original shape after they have been filled with air. The elastic quality of the lungs is important as it allows air to move in and out of the lungs quickly (National Heart, Lung & Blood Institute, 2015). For patients diagnosed with Chronic Obstructive Pulmonary Disease (COPD), the airways are no longer able to recoil back to their original shape and may become thicker than normal due to a build-up of mucus (National Heart, Lung & Blood Institute, 2015). When the stretched airways are blocked or obstructed, the lung's capacity to move air in and out is hindered, resulting in a feeling of breathlessness or shortness of breath.

COPD encompasses a number of lung conditions including emphysema, chronic bronchitis and chronic asthma. It can be caused by a variety of factors including genetics, lifestyle choices such as smoking and occupational factors including prolonged exposure to dust and pollutants. Although the experience of breathlessness is unique to each patient, it is considered the most debilitating symptom of COPD. Although breathlessness may initially occur with exercise or strenuous activity, over time this will generally transpire to prolonged feelings of breathlessness with little to no exertion (The Lung Foundation, 2014). Thus, for many patients the impact of breathlessness extends beyond particular activities and triggers to a persistent feeling of not being able to adequately breathe.

The feeling of breathlessness experienced by patients extends beyond physical airflow limitation. In a recent statement by the American Thoracic Society, it was recognised that breathlessness is an accumulation of physiological feelings, interactions, thoughts and emotions (Parshall et al, 2012)]. This was further supported by Mannino & Buist (2007) who found that in managing the complexities of breathlessness, COPD patients often suffer from decreased physical activity and a higher level of reliance on the community for assistance.

Generally, there are pharmaceutical treatments, rehabilitation programs, support networks and educational resources available to assist patients in understanding and managing their breathlessness, however the ownership and implementation of these options within daily life is largely left in the hands of patients. As a result, there is a strong motivation to enable patients to independently recognise, respond to and manage their breathlessness symptoms whilst maintaining the best quality of life possible. Yet, although the motivation and need for self-management is acknowledged, we will learn through the Literature Review that the methods of enabling and supporting patients to learn to self-manage and adapt to breathlessness are lacking.

1.3. Project scope & design opportunity

Dependent upon the research framework and background, literature within the field interchanges and utilises differing terminology when referring to the symptom of breathlessness. Common references include dyspnoea, dyspnea or shortness of breath. To encompass the varying research backgrounds and terminology, this research will use the term breathlessness. This research defines breathlessness as an uncomfortable awareness of breathing which is often described by sufferers as a tightening of the chest, an urge to breathe or a feeling of suffocation.

The scope for this research is determined by two factors. Firstly, improved diagnostic tools, increased education and public awareness surrounding symptoms and management options are driving growth in the number of COPD patients requiring treatment for their breathlessness. Secondly, products currently available on the market lean towards pharmacological solutions as opposed to holistic products that address overall breathing function and management.

Growth in diagnosed COPD

In assessing the global burden of COPD, it has been established by Mannino & Buist (2007) that due to the variation and complexities involved in diagnosing COPD, the scope and economic cost to the community is difficult to both quantify and project. Exploring historical data, The Lung Foundation of Australia (2014) reported that between 2011 and 2012, half a million Australians identified themselves as suffering from COPD, whilst globally, it is estimated that 15.1 million people have been diagnosed with COPD, with an annual cost of US$12 billion [refer to (Falkingbridge & Savapoulos, 2005)]. As indicated by the World Health Organisation, this figure is set to rise with estimates that by 2020 COPD will be the third leading cause of death globally at a cost of US$17.5 billion [refer to (Buist et al, 2007)]. Within Australia, COPD is the second leading cause of avoidable hospitalisations (The Lung Foundation, 2014).

It is apparent that there is a need for thoughtful and holistic approaches for patients suffering the effects of chronic breathlessness. Despite significant investments in the development of innovative options and methods in which to treat the disease, COPD management is generally dominated by pharmacological therapies (PR NewsWire, 2014). Although these therapies are often effective in relieving symptoms, presently there does not appear to be one single therapy or medication that prevents the progression of COPD, but rather patients are offered a blend of multiple therapies including non-pharmacological options. This has resulted in a market whereby trends, product offerings and technological advancements can make the process of navigating treatment options difficult and confusing, particularly as symptoms change or progress.

COPD products, trends & unmet needs

COPD management is recognised as being a complex journey due to the number of influential factors. It must be acknowledged that as the list and combination of potential products and solutions expands so too does a patient's requirement to interpret, understand, maintain and use the prescribed treatment options (Fink, Colice & Hodder, 2013). There is a growing presence of products, systems, digital applications and gadgets that support respiratory performance, health and wellbeing, but these are generally geared towards semi-professional athletes and lifestyle markets. Although various modifications have been made to attract COPD sufferers, few are designed specifically to encourage self-management of breathing patterns and breathlessness symptoms [see (OM, 2015) (Spire, 2014) (Nordmand.P, 2015) (TechSpark, 2014)]. Without specifically designing for COPD patients, there is risk that crucial elements or opportunities are missed such as appropriate user feedback, technology and products that are closely linked to daily routines and lifestyles.

To offer an alternative solution, pulmonary rehabilitation centres may draw upon affordable, easily accessible and simple products that guide patients to be aware and manage their own breathing, particularly during points of exacerbation. An example is Harmonica Therapy, which utilises a simple, familiar and affordable product and adapts its purpose to address a complex respiratory management problem. Equally, literature suggests that the adaption of the harmonica within the self-management context does not address the complexity of the problem but rather offers inspiration as to the possibilities that exist for product design. This will be explored further in Section 2.7.4.

In shifting focus, it is recognised that there is an opportunity to steer product design from a single function response to an outcome that explores the experience of breathing holistically. The following section provides an outline of the research objectives, methods and significance of this research to the field.

1.4. Research outline

Research objectives and methods

This research addresses two objectives regarding the need for a device to aid patients in the management of COPD:

1. Identify and characterise the attributes that have enabled patients to become familiar and confident in PLB practice
2. Develop a design proposal which addresses and explores these characteristics

To address the research objectives, the following processes were conducted. Firstly, a comprehensive literature review (Chapter 2) of COPD research, the physiology of breathing, living with and self-managing breathlessness, and pulmonary rehabilitation was conducted. From here, the methodology for a qualitative study involving COPD patients is presented (Chapter 3). The study's purpose is to understand the particular experiences that form a patient's perspective of PLB and gather patient suggestions and insights regarding technologies and product interactions.

The presentation of results from the qualitative study (Chapter 4) identifies design aspects critical to the development of a device for managing COPD. Using these results, design conceptualisations and proof of concept prototypes investigate possible data collection methods, patient interactions, experience, technologies and applications (Chapter 5). The research will conclude with an outline of the outcomes and future research directions (Chapter 6).

Significance to the field

Effective PLB practice is currently reliant on both a patient's ability to interpret literature and face-to-face guidance that is provided by rehabilitation nurses. Although these approaches raise awareness of PLB principles and potential benefits, there is a gap in the adaption, practice and integration of PLB principles by patients independently within the home (Yancey & Chaffee, 2014).

There is an ever increasing focus to provide individualised and adaptive rehabilitation and self-management programs to patients; however it is recognised that the path is complex and difficult to navigate. Comprising of several treatment options including pharmacological, exercise programs and controlled breathing techniques, a patient's rehabilitation program is often changing with limited tangible products or devices. As a result patients may feel disempowered and unmotivated.

Through a deeper understanding of a patient's experience and understanding, design practice and conceptualisation may expose interactive methods and tools that allow patients to engage in PLB practice more regularly and accurately whilst increasing the physiological benefits. Broadly, this research works towards closing the gap between the notion of PLB and the integration within a patient's lifestyle so as to reduce the impact of chronic breathlessness.

1.5. Conclusion

Without experiencing the overwhelming burden of chronic breathlessness, the challenge of understanding, supporting and guiding patients is enormous. Current PLB approaches can at times be successful, though we do not know how they are successful and when they are not. PLB education in its current form relies heavily on a patient's knowledge of effective breathing practice and their capability to integrate PLB within their lifestyle. Given these factors, there is an opportunity for a review of learning and self-management with a particular focus on the use of pace and rhythm. Requiring a multi-dimensional response, design practice and exploration is best placed to advance breathlessness management approaches through innovative interactions, feedback and experiences.

The following literature review will begin with a comprehensive review of COPD and challenges of living with chronic breathlessness including self-management interventions and aspects of patient motivation. Following on, the physiology of breathing will be discussed which will explain the physiological benefits of PLB. Subsequently, the learning aspects of PLB will be introduced including literature regarding patient behaviour change requirements and the role of rhythm as a pace maker. Lastly, research in the areas of Harmonica Therapy, respiratory feedback and the integration of technologies will be presented.

Chapter 2: Literature Review

2.1. Introduction

Currently, there are millions of people around the world that are experiencing impaired breathing function (Buist et al, 2007). Unable to adequately perform daily tasks, patients with chronic breathlessness suffer from anxiety, depression, social isolation and higher mortality rates (The Lung Foundation, 2014) (Mannino & Buist, 2007). Chronic breathlessness is the primary symptom of Chronic Obstructive Pulmonary Disease (COPD), a disease that cannot be cured but can be treated and managed (National Heart Lung & Blood Institute, 2015).

Pursed Lip Breathing (PLB) is one of many management techniques used by COPD patients to reduce the immediate feelings of breathlessness and restore a sense of breathing control and pace. Defined simply, PLB involves breathing control whereby the expiration of breath is twice the length of the inspiration of breath. PLB aims to prolong the total breath duration, slow a patient's breathing frequency, prevent airway collapse and provide an increased ventilatory threshold at both rest and exercise states (Spahija, De Marchie & Grassino, 2005). Breathing exercises, such as PLB, are commonly used as a part of rehabilitation programs but data supporting their use alone is limited.

A recent Cochrane review carried out by Yancey & Chaffee (2014) assessed the role of breathing exercises in reducing breathlessness, improving exercise capacity and health related quality of life in COPD patients reveals differing directions and methods in the domain of PLB measurement and monitoring. The results from this study indicates that PLB improves six-minute walking test outcomes but when PLB was taught within the home using pulse oximetry for feedback no significant improvement was noted on the University of California-San Diego Shortness of Breath Questionnaire. It was also noted that a study comparing health related quality of life for PLB versus placebo, PLB showed significant improvement in breathlessness symptoms but there was no significant improvement in any other domain including mood, social function and wellbeing.

Although it is acknowledged within the literature that PLB can contribute to the pulmonary rehabilitation process [refer to (National Heart, Lung and Blood Institute, 2010) (Lung Foundation of Australia, 2012)], the evidence for the use of PLB in the rehabilitation and self-management of COPD remains unclear. Furthermore, studies investigating the teaching, monitoring and real-time measurement of PLB effectiveness are lacking. Differing measurement protocols between studies makes it difficult to conclude as to the effectiveness of PLB and ways in which PLB can be further enhanced so as to improve a patient's pulmonary rehabilitation progression. As a result, the implications of effective versus non-effective PLB practice are not currently known.

Based upon these findings, PLB becomes an appropriate design focus as carefully considered product interactions could generate PLB data and patient feedback that is not currently possible. Presently, PLB related studies are reliant on traditional measures such as spirometry, six-minute walking tests and health related questionnaires. These measures are performed before and after the act of PLB practice. Therefore, it is difficult to determine whether the patient is truly practicing PLB during the study and if the results of the study are accurate.

Product design research themes provide an avenue in which to explore the interactions of patients as they perform PLB and to determine if patients receive any benefit. Through examination of engineering principles, integration of technologies, rituals of use, ergonomics and aesthetics, product design can approach PLB teaching and practice in a novel way. Focusing on the interaction between a patient's actual breathing pattern and their desired breathing pattern, product design can incorporate features that guide breathing control. Given that aspects of this research involve a multidisciplinary focus, where appropriate, health related literature will be drawn upon to support the design need, product direction and product use. Referencing literature from the areas of breathing physiology, pulmonary rehabilitation, self-management, patient motivation and product technologies, the following literature review will frame the research study and product design direction.

Beginning with a description of PLB and teaching processes, the literature review will then lead into a detailed account of COPD and the relationship to chronic breathlessness. From there, the physiology of breathing will be explained with particular elements that are relevant to PLB highlighted. Once the physiology of breathing is explained, a patient's experience of living with COPD will be detailed with examples of daily activities and challenges given. At this time, the relationship between PLB, self-management strategies and pulmonary rehabilitation will be explained. This chapter will conclude with a review of the use of products, technology and rhythm within the rehabilitative context and pose research methods which will inform the product design process.

The multidisciplinary response required to answer the research objectives results in complex relationships between literature in the fields of PLB, respiratory physiology, patient experiences and product interventions. The following literature review provides a framework for product design exploration whilst responding to the medical challenges associated with PLB measurement and adherence.

2.2. Pursed Lip Breathing (PLB)

For individuals with diseases that affect the respiratory system, such as COPD, the symptom of chronic breathlessness intrudes upon almost every aspect of their lives. Controlled breathing techniques including diaphragmatic breathing, deep breathing and relaxed breathing are commonly taught to patients to help restore a sense of breathing control. In this work, the specific breathing technique Pursed Lip Breathing (PLB) has been chosen as the research focus. The underlying principle of paced breathing which connects these controlled breathing techniques also be discussed at a later stage.

The PLB principle consists of a lengthening of the expiration of breath versus the inspiration of breath. In extending the rate of expiration, the PLB technique encourages patients to slow their breathing. Illustrated within Fig. 1 (page 5) the PLB principle is best understood as a ratio configuration. This illustration depicts the ratio as a 2:4, whereby the inspiration is 2 counts to every 4 counts of the exhale. It is important to note that the ratio configuration may vary considerably depending on the patient's current respiratory patterns, however this will be explained in further detail within Section 2.4.

Prior to continuing on, it is worthwhile drawing attention to the motion of the breath depicted within Fig. 1 (page 5). Again, the physiological reasoning of PLB will be explained within a later section of this review; however this illustration indicates that practice of PLB requires that the inhalations of breath occur through the nose, whilst exhalations of breath occur through pursed lips. This type of motion aims to place a conscious focus on the control of both respiratory flow and respiratory pace.

Literature supports and promotes PLB as an intervention for reducing the immediate feelings of breathlessness whilst enabling patients to self-manage their breathing demands in accordance with their physical needs (National Heart, Lung and Blood Institute, 2010) (Lung Foundation of Australia, 2012). As highlighted within the introduction, breathing exercises such as PLB are commonly practiced as a part of rehabilitation programs but data supporting their use alone is limited. In particular, the transition from a patient being considered a novice PLB user to an expert PLB user is not well known.

There is considerable literature within the field which frames and discusses the influence of PLB on both the physiological and mental aspects of breathing control [refer to (Ramos et al, 2009) (Spahija, De Marchie & Grassino, 2005) (Bianchi et al, 2004) (Spahija & Grassino, 1996)]. Nevertheless, the impacts of teaching and monitoring processes are not well researched nor are the attitudes of patients towards paced breathing as a management strategy. As a result, it is difficult to determine the required learning processes, the effectiveness of paced breathing principles within daily life experiences, the long-term value of breathing re-training within a pulmonary rehabilitation setting and importantly the appropriate products which may assist.

To tackle these research challenges there is a need for studies that investigate PLB teaching methods, respiratory monitoring and real-time measurement of paced breathing practice. However, commonly used methods, such as spirometry, six-minute walking test and health related questionnaires, are unable to capture the required data. Based upon these findings, PLB becomes an appropriate design focus as carefully considered product interactions can generate PLB data and patient feedback that is not currently possible.

Encouragingly, preliminary investigations indicate that some rehabilitation programs have taken the initial steps to incorporating or experimenting with products within the PLB learning phase. Drawing on simple tools like plastics straws, musical instruments or balloons, these simple items provide a resistance that allows individuals to slow and control their breathing. Such items mimic pursed lips and provide a sensory reference point. Items have also been adapted and invented to provide differing levels of resistance and control depending on the requirements.

Fig. 2 Harmonica
Mother Earth News, n.d.
Image taken from <http://www.motherearthnews.com/nature-and-environment/how-to-fix-a-harmonica-zmaz79zsch>

An alternative response to traditional pulmonary rehabilitation has seen hospitals and pulmonary rehabilitation centres in the United States of America investigating new avenues to teaching breathing control with Harmonica Therapy [see various studies (Mayo Clinic Florida, 2013) (University of Michigan, 2015) (El Camino Hospital, 2014)]. The design and physical characteristics of the harmonica shown in Fig. 2 will be explained in further detail within a later section of this review. Of note at this stage is that the harmonica sessions invite patients to adjust their approach to breathing retraining by learning to play the harmonica in a group setting. The harmonica not only mimics the principles of controlled breathing principles like PLB but also provides musical feedback and interaction not present within other training programs. Thus the product may act as a reference for the establishment of pace and feedback. The link between the harmonica and potential therapeutic benefits for patients with COPD is a continuing area of research with recent theses by Garrett. A (2016) and Hanninen. S (2014) investigating this area more specifically.

Another product that has been introduced within a rehabilitation centre is shown within Fig. 3. Although all the features of the product are not necessarily evident within the image, it is thought that the product is simple to use as the patient breathes through the straw to fill the balloon. These types of products explore various breathing interactions which encourage a patient to consciously control their breathing flow and rate and provide an interesting avenue for exploration.

Fig. 3 Pursed lip breathing aid
Pratibha Prabhakar Pulmonary Rehabilitation Center, 2013
Image taken from
<http://pulmonaryrehabindia.blogspot.com.au/2013/06/pulmonary-rehabilitation.html>

The previous two devices are physically tangible solutions that aid in moderating breathing pace. Despite their simple design and only interfacing with the mouth, they are considered effective tools for teaching paced breathing which is a key element of the PLB technique [refer to (Section 1.2.1)]. Generally, there are various products, systems, digital applications and gadgets on the market that support respiratory performance, health and well-being. Although these may encourage paced breathing they do not capture breathing data, nor are they specific to the needs of COPD patients. Capturing and quantifying breathing data would be useful in monitoring and teaching patients to improve their PLB technique.

To appreciate the subtle yet important differences between existing products on the market and the requirements of PLB specific products, it is advantageous to firstly explain COPD progression, chronic breathlessness and daily living experiences. In doing so, the design process, product concepts and product requirements will be extracted further.

2.3. Chronic Obstructive Pulmonary Disease (COPD)

When climbing a set of stairs, running for a bus or moving heavy boxes, we are performing activities that place a temporary strain on the respiratory system. These tasks often result in feelings of breathlessness. Fortunately, for healthy individuals our bodies are equipped with mechanisms that allow for ease of recovery, to *catch our breath* and continue on. On the other hand, when the respiratory system is hindered by disease, everyday tasks can act as exacerbations to an already strained respiratory system and emotional outlook. Consequently individuals with respiratory disease experience an increase in severity of breathlessness, inconsistent breathing patterns and slower recovery times.

The primary organ of the respiratory system is the lungs, which breathe in oxygen and breathe out carbon dioxide. When the airways of the lungs are healthy they are elastic which enables them to recoil back to their original shape after they have been filled with air. The elastic quality of the lungs is important as it allows air to move in and out of the lungs quickly (National Heart, Lung & Blood Institute, 2015). This is particularly important at times of increased physical activity, as the lungs need to move air through the body at a higher breathing rate. For patients diagnosed with Chronic Obstructive Pulmonary Disease (COPD), the airways are no longer able to recoil back to their original shape and may become thicker than normal due to a build-up of mucus (National Heart, Lung & Blood Institute, 2015). When the stretched airways are blocked or obstructed, the capacity of the lungs to move air in and out is hindered, resulting in a feeling of breathlessness or shortness of breath. PLB becomes a useful technique for patients during these episodes of breathlessness as there is greater awareness placed on expelling the breath prior to taking a new one. Techniques such as PLB become important within the management of COPD long term, as once the airways have been stretched and obstructed, COPD cannot be cured.

The symptom of breathlessness has been hinted at briefly, however patients often suffer from a multitude of symptoms including persistent cough, wheezing, phlegm and chest tightness. Assessment of COPD and recommended treatment options are based upon an individual’s symptoms, risk of exacerbations, the severity of abnormalities and the identification of comorbidities (GOLD COPD, 2015). Forming a treatment and management plan for COPD patients is further complicated by the variability of lung conditions in which it encompasses including emphysema, chronic bronchitis and chronic asthma. For patients faced with a progressive and long-term prognosis, treating the immediate symptoms whilst preparing for and managing the long-term changes requires a multidisciplinary support network of health professionals, family, friends and community members.

Various foundations and institutions have mapped and explained the patient COPD journey [refer to (The Lung Foundation, 2014) (British Lung Foundation, 2013) (COPD Foundation, 2016)]. Among these journey maps there is a consistent COPD management approach of:

1. Identifying symptoms
2. Confirming diagnosis
3. Treating acute symptoms or exacerbations
4. Optimising physical functionality and moving towards management

By combining varying types of interventions and programs, self-management and pulmonary rehabilitation aim to tackle the complex symptoms and experiences facing COPD patients (Australian Institute of Health and Welfare, 2013). Examples include exercise programs, goal setting and promotion of social interaction. It is recognised that the complexity of chronic diseases calls for a dynamic and interdisciplinary approach. However, this research focuses specifically on optimising physical functioning by providing a method of self-management, that being PLB. Surrounding areas of COPD research may be referenced within this thesis to provide context or demonstrate greater associations, but the key discussions will focus on daily living, self-management and pulmonary rehabilitation.

2.3.1. Population

As COPD develops over time, the prevalence and associated age is difficult to determine. Mentioned earlier, the first stage of COPD management is the identification of symptoms and confirmation of diagnosis. This is considered challenging as the symptoms of cough, phlegm, breathlessness and wheezing may develop slowly, be intermittent and present similarly to other disease symptoms. Therefore, the actual prevalence of COPD within the community may not necessarily be affiliated to the rate of diagnosed cases. To ascertain a rudimentary prevalence rate, a recent international Burden of Obstructive Lung Disease study found that in 12 countries there was a formal diagnosis of 10% for people aged 40 and over. Within Australia it was found that there is a prevalence of 4.5% in those aged 55-69, with this increasing to 6.6% within the 70-84 age bracket (Table 1) (Australian Institute of Health & Welfare, 2015).

Age group (years)	Per cent (%)
55 - 69	4.5
70 - 84	6.6
85 +	6.5
55 +	5.87

Table 1 Prevalence of COPD among Australians aged 55 and over, 2011-2012
Australian Institute of Health & Welfare, 2015

The prevalence and economic burden of COPD has been previously introduced (Section 1.4). These figures provide an overview regarding the potential impact and need but provide limited insight regarding the impact of COPD on local communities, hospitals, health services, families and an individual.

2.3.2. Chronic breathlessness

The general symptoms experienced by patients vary depending on the stage of disease, the underlying diagnosis (e.g. chronic bronchitis, asthma, emphysema) and their treatment and management approach. Common symptoms include shortness of breath, cough, phlegm, wheezing, lower muscle weakness and fatigue (National Heart, Lung & Blood Institute, 2015) (British Lung Foundation, 2013). Despite this, breathlessness is considered the most debilitating symptom for the majority of COPD patients (The Lung Foundation, 2014). Breathlessness is described as a subjective experience of breathing discomfort. The sensations of breathlessness derive from interactions among the physiological, psychological, social and environmental factors (Parshall et al, 2012). Diagnosing and treating the cause of breathlessness is difficult as the triggers are diverse, interrelated and disguised. This was further verified in the work of de Peuter et al (2004). As a result, a large responsibility therefore is placed in the hands of patients to recognise their breathing capability, notice when changes occur and act on the changes by seeking help.

For a patient, breathlessness may initially occur with exercises or strenuous activity, similar to when they were healthy individuals. However, over time this will generally transpire to prolonged or persistent feelings of breathlessness when performing what would be considered everyday tasks such as vacuuming, lifting, showering and dressing. (The Lung Foundation, 2014). As described by Yuan, Drost & McIvor (2013), a patient's breathing becomes dysfunctional when their disease has progressed to a point in which they are unable to adapt to increased physical requirements, changing needs and environmental conditions.

As breathlessness is generally experienced during physical activity it would be straightforward to conclude that physical tasks or exercises are the primary triggers. Unfortunately, the triggers of breathlessness are more complex and may be an accumulation of physiological feelings, interactions, thoughts and emotions (Parshall et al, 2012). At this point it is important to note that breathlessness impacts not only a patient's physical functioning but also their quality and outlook on life. In turn, it has been noted by The Lung Foundation of Australia (2014) that COPD patients often suffer from decreased physical activity, anxiety, depression and a have a higher reliance on the community for assistance. This is concept is further supported by the work of Mannino & Buist, (2007).

In summary, the general COPD population is broad and loosely defined in regards to a patient's daily experiences, challenges and goals. At this early stage, framing the design context and the target product user is challenging. Consequently, exploring the physiology of breathing and breathlessness symptomology alongside PLB learning strategies will begin to frame the unique design challenges and facilitate in defining the design problem space more accurately.

2.4. The physiology of breathing

Earlier the respiratory system was defined in terms of lung function. To recapitulate, the function of the lungs was described as the primary organ which enables the body to inhale oxygen and exhale carbon dioxide. The elastic quality of healthy lungs was identified as being important as it allows air to move in and out of the lungs quickly, particularly at times of increased physical activity (National Heart, Lung & Blood Institute, 2015). Detailing the respiratory system further, Fig. 4 (page 26) illustrates the physical characteristics of inhalation and exhalation. The red arrows depict the movement of the chest and diaphragm as a patient inhales and exhales. During inhalation the arrows show that the diaphragm contracts and the chest expands, whilst during exhalation the chest contracts and diaphragm relaxes. These natural movements permit minimal effort by the respiratory system during breathing cycles.

For patients diagnosed with COPD, the airways are no longer able to recoil back to their original shape and may become thicker than normal due to a build-up of mucus (National Heart, Lung & Blood Institute, 2015). When the stretched airways are blocked or obstructed, the lungs capacity to move air in and out is hindered. In these circumstances the natural movement of the respiratory system adapts and the effort required may increase. The abdomen, diaphragm and other respiratory muscles may play a greater role in supporting inhalation and exhalation, thus leading to a higher likelihood of muscle fatigue. When the diaphragm and chest movement is unable to support the increased effort required, feelings of breathlessness or shortness of breath may arise.

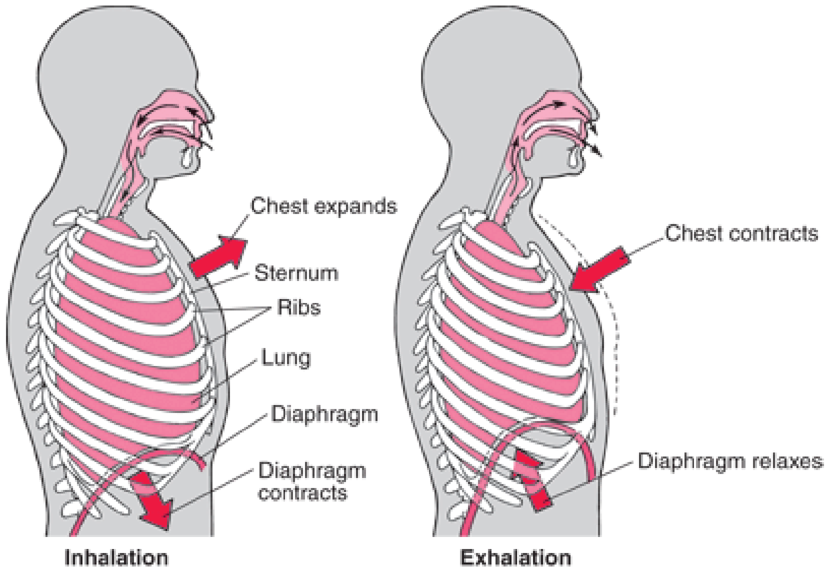


Fig. 4 Physiology of breathing
Biology Corner, n.d.
Image taken from
<http://www.biologycorner.com/anatomy/respiratory/notes_respiratory_system.html>

Although the above description explains the basic premise of respiratory function and helps to explain the immediate challenges facing patients, it was earlier stated that the triggers of breathlessness extend beyond respiratory function and include feelings, interactions, thoughts and emotions (Parshall et al, 2012). This concept is best introduced by referring to Fig. 5 (page 27). Detailing the overall respiratory system interactions, this diagram illustrates the influencing mechanisms present throughout the body.

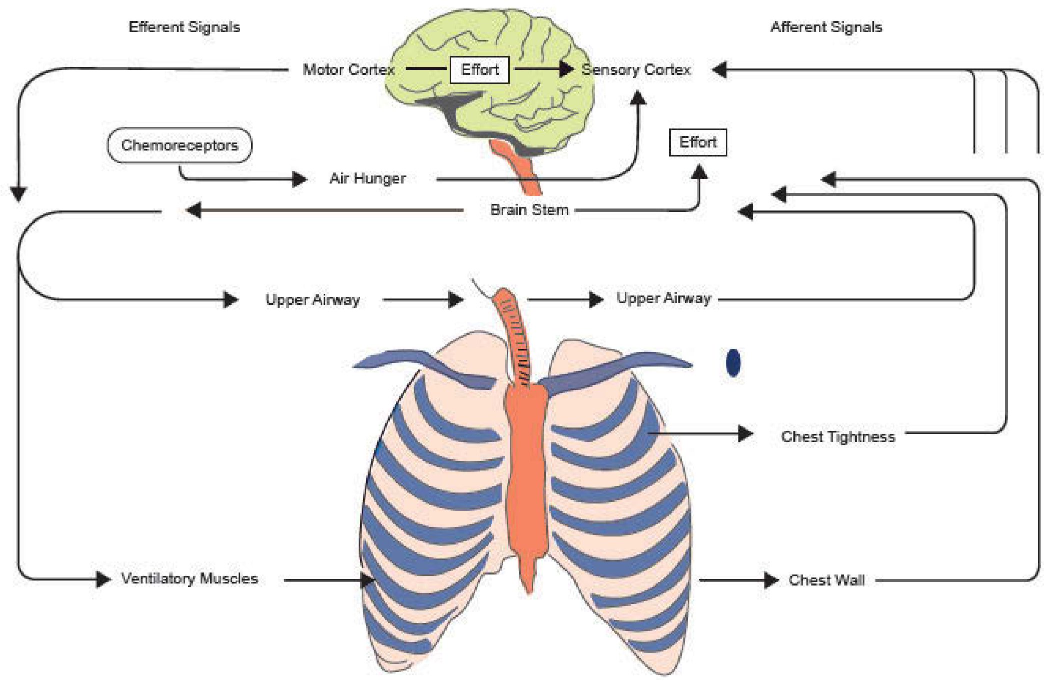


Fig. 5 Respiratory functioning

To explain, consider you are climbing 6 flights of stairs. You begin climbing the first flight of stairs and as you approach the top your breathing becomes heavy and you feel a little *puffed*. This feeling indicates that your lungs are starting to move quicker and your respiratory rate is beginning to increase to meet the increased demand. You continue onto the second flight and as you approach the top you become quite puffed. At this point receptors throughout the body have fed messages to the brain to increase the respiratory requirements. The lungs, diaphragm and abdomen begin to increase their speed to ensure there is enough oxygen supply. You continue on to the third and fourth floor. You may begin to experience chest tightness, audible panting and heavy legs. Again, receptors throughout the body send messages to the brain to increase the respiratory rate. Dependent on how you feel, you may decide to stop at the fourth floor, in which you make a decision to stop and slow your respiratory rate. Alternatively, you may decide to continue on but you may have to mentally tell your body to keep going.

For a patient with COPD, this complex relationship between action and feelings may occur in a similar manner but with far simpler tasks. Also, it may only take you 5 minutes to climb to the top because your body is able to adjust through the stages quite quickly to ensure you have sufficient respiratory function. For a patient the speed in which adjustment occurs may be far slower meaning that they reach the symptoms of floor 4 when they are climbing to floor 1.

The literature describes the breathlessness process as a discrepancy between the current breathing pattern which can be perfectly in line with existing metabolic needs and the breathing pattern associated with the expected metabolic needs (de Peuter et al, 2004). Although the brain continually monitors and adjusts the respiratory system to meet activity demands, where demands increase quickly or beyond the usual demand, feelings of breathlessness will occur.

To explain in further detail, to increase the respiratory rate the sensory cortex communicates with the motor cortex to send a signal to the ventilatory muscles to increase speed and gas exchange, thus increasing the respiratory rate. Once the task has been completed there may still be feelings of breathlessness due to the speed of transition between existing metabolic rates and required metabolic rates but for a healthy individual these would generally subside.

Patients experience a different sensation as the increased respiratory requirements may lead to considerable shortfalls in regards to respiratory performance. Discussed earlier, a patient's lung function is hindered due to reduced or impaired elastic recoil and thickening of the airways. The additional hindrances placed on a patient's respiratory system result in the task of climbing a set of stairs unachievable as the feeling of breathlessness transitions from momentary to persistent. Without detailing the physiological requirements mentioned in too great a depth, it becomes apparent that unravelling each physiological element and solving these independently may not lead to holistic breathing experiences that cater for all potential physical tasks.

The intertwined and complex nature of respiratory function reveals interesting design problems and directions. Design questions associated with optimising a patient's respiratory function begin to manifest. These include; how do you monitor a patient's breathing function or performance? Can you improve task performance by targeting emotions? How do patients comprehend and respond to their breathing performance? Do patients adapt to tasks or does the task adapt to their breathing state?

Reflecting on the earlier introduced concept of PLB, by placing a focus on teaching a patient to slow or control their breathing rate, this may induce a feeling of self-management despite the task. For example, imagine that a patient climbing a set of stairs was able to pace their breathing as they stepped. In doing so they may be able to control their feelings of breathing discomfort more easily. Conversely, there are underlying pathophysiological factors, which also influence this dynamic. These factors include increased load on inspiratory muscles, increased restriction of the chest wall, inspiratory muscle weakness, airway compression and gas exchange abnormalities [see studies (Gosselink. R, 2004) (Manning & Schwartzstein, 2001)]. Whilst it is not immediately evident the role that these factors will play in the design process, there is a direct link between PLB implementation and these factors. The 5 physiological mechanisms, which will now be explained in further detail, are the respiratory rate, air trapping, respiratory muscles, neuro-mechanical dissociation and expiratory flow limitation.

2.4.1. Respiratory rate

The principle of PLB is guided by control of an individual’s respiratory rate. Therefore, understanding the subtle yet important details of respiratory cycles becomes critical to the design process, particularly when exploring breathing pace. To explain, the respiratory system delivers oxygen and removes carbon dioxide effectively in part to the setting of the respiratory rate and tidal volume which in turn are controlled by the receptors placed throughout the body. The respiratory rate is best explained by referencing Fig. 6 (page 30).

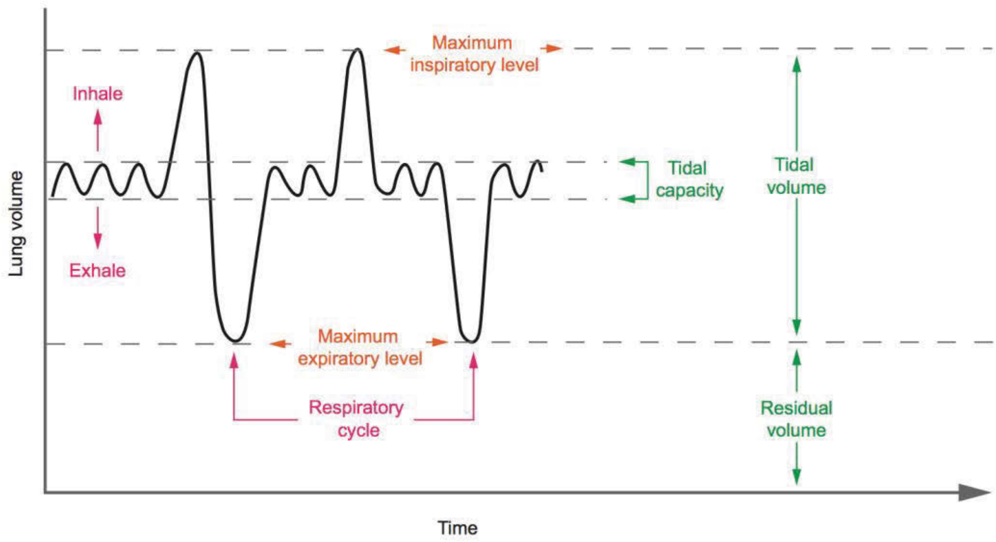


Fig. 6 Respiratory cycles and lung volumes

Respiratory cycle: a cycle consisting of an inhalation of air followed by an exhalation of air; ***Maximum inspiratory levels***: the maximum amount of air that can be inhaled. The volume is determined by lung capacity; ***Maximum expiratory levels***: the maximum amount of gas that can be exhaled; ***Tidal capacity***: the volume that can be inspired/expired after full inspiration or expiration; ***Residual volume***: the amount of gas remaining in the lungs at the maximum exhalation; ***Total lung capacity***: the vital capacity plus the residual volume; ***Forced expiratory volume (FEV)***: measure how much air can be forcibly exhaled in 1 second after a full inhalation.

The following summary is extracted from the work of Yuan, Drost & McIvor (2013). Normal breathing comprises of inspiratory and expiratory phases and occurs with a synchronised movement of the chest and abdomen. The overall tidal volume indicates the volume of air moved in and out of the lungs, with the lung capacity demonstrating the volume of air during inhalation or exhalation. The respiratory rate is measured as the number of breaths or number of inhalation-exhalation cycles in a given period of time. Typically, the respiratory rate is recorded as the number of breathing cycles per minute. The aim of measuring the respiratory rate is to determine where respirations are normal (eupnea), abnormally fast (tachypnea), abnormally slow (bradypnea) or non-existent (apnea).

Importantly, the magnitude of the metabolic demand is reflected in the respiratory rate. Determining a normal resting respiratory range is dependent upon an individual's metabolic demand, lung volume, respiratory muscle control and ventilation. Fig. 6 provides an indicative value, however it is important to note that lung volumes, inspiratory and expiratory levels and respiratory rates differ across the population. As a result the average respiratory rate for adults ranges from 12-20 breaths per minute.

An elevated and fluctuating respiratory rate is due to underlying mechanisms. Illustrated within Fig. 7, a COPD patient's respiratory volumes are often reduced in comparison to a healthy individual due to obstructions. As a result, patients will gravitate to an elevated respiratory rate if their lungs are unable to inhale enough air per respiratory cycle to satisfy metabolic demands. For patients, an elevated resting respiratory rate, typically above 24 breaths per minute, can indicate a progressive disease state and increased respiratory strain. These patients are at a higher risk of experiencing prolonged periods of feeling breathless. The effectiveness of PLB is formed on controlling aspects of the respiratory cycle.

For example, consider that a patient has just finished hanging their clothes out on the clothesline to dry. In completing this task the patient was required to repeatedly lift their arms up for a prolonged period of time thus increasing the metabolic demand and respiratory cycles. In pursing their lips and extending the expiratory cycle, the patient is able to control their breath and regain their normal resting respiratory rate. At the same time the feeling of breathlessness may influence a patient's capacity to practice PLB effectively and regain breathing control in a timely manner. Yet suppose that as the patient completed the task they were able to implement PLB by breathing through the breathing aid shown in Fig. 3, would this reduce the feeling of breathlessness at the conclusion of the task? To explore these ideas fully, an understanding of the underlying mechanisms of air trapping, respiratory muscles, neuro-mechanical dissociation and expiratory flow limitation is required.

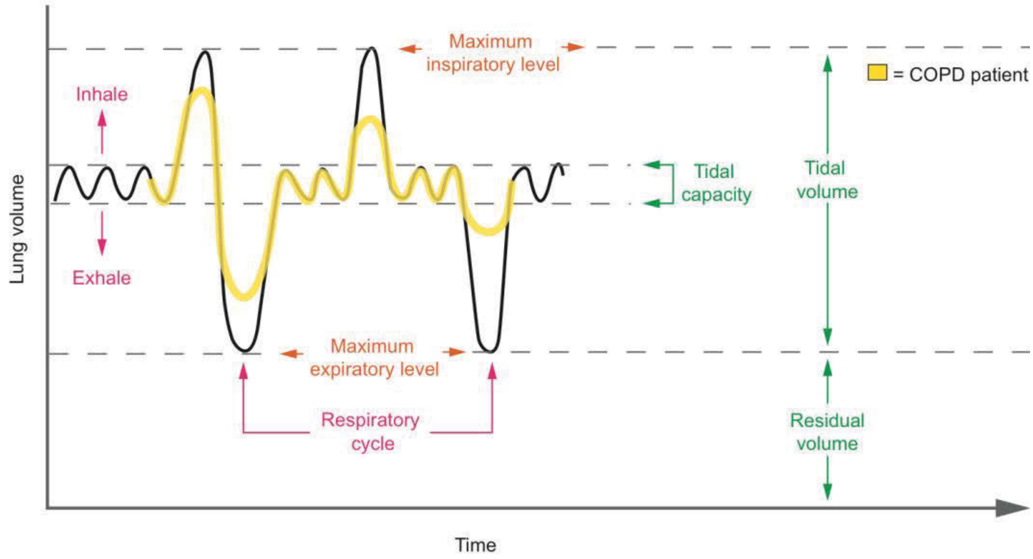


Fig. 7 Example of COPD patient respiratory cycles

Respiratory cycle: a cycle consisting of an inhalation of air followed by an exhalation of air; ***Maximum inspiratory levels***: the maximum amount of air that can be inhaled. The volume is determined by lung capacity; ***Maximum expiratory levels***: the maximum amount of gas that can be exhaled; ***Tidal capacity***: the volume that can be inspired/expired after full inspiration or expiration; ***Residual volume***: the amount of gas remaining in the lungs at the maximum exhalation; ***Total lung capacity***: the vital capacity plus the residual volume; ***Forced expiratory volume (FEV)***: measure how much air can be forcibly exhaled in 1 second after a full inhalation.

2.4.2. Air trapping

Air trapping is an abnormal trapping of air in the lungs and occurs when a patient inhales a volume of air but is unable to exhale it completely, resulting in a feeling of breathlessness and chest tightness. This abnormality occurs as a result of the mechanics of the respiratory cycle. To explain further, consider the process of filling up a balloon. As you inhale air, your diaphragm contracts and pulls down. This makes room for the lungs to expand within the chest cavity. The expansion of the lungs creates a vacuum, allowing air to be drawn in. The sensory receptors within the lungs would then send a signal to the brain to indicate that the lungs were full.

If you were then to exhale that volume of air freely, without the resistance of the balloon, your respiratory system should relax and allow the air to pass out gently. However, when exhaling into the balloon you have to *push* the air against the resistance of the balloon resulting in increased strain on the respiratory muscles to help move the air. In this circumstance, the exhalation phase has moved from a passive movement of air to strenuous motion. Similarly, patients with COPD may have difficulty exhaling due to reduced elasticity of the lungs, build-up of mucus and airway blockages which in turn means that they have to *push* harder and draw on respiratory muscles to force the volume of air out of the lungs. Fig. 7 demonstrates a COPD patient's respiratory cycle, whereby the exhalation phase of the respiratory cycle is shorter in comparison to the inhalation phase. Over a series of respiratory cycles, patients become both tired and breathless and may begin to inhale prior to completely exhaling, resulting in air trapping.

PLB focuses directly on extending the expiratory breath to avoid the physiological occurrences of air trapping but requires focus and commitment by patients to overcome the initial feelings of breathlessness. Encouraging this behaviour through a feedback system, such as lights or music, may enable patients to become aware of this physical occurrence and take action as opposed to the development of undesired habits. Strengthening the respiratory muscles may assist in promoting increased respiratory control as can been seen in the following section.

2.4.3. Respiratory muscles

Respiratory muscle recruitment may affect the sensation of breathlessness. As described above, respiratory muscles such as the rib cage muscles, the diaphragm and the abdomen may play a greater role in respiratory cycles by providing support during both inhalation and exhalation. The respiratory muscles of COPD patients are more likely to fatigue, in turn making it difficult for patients to increase the volume and power required. As a result, patients experience sensations of breathlessness during tasks much earlier than that of healthy individuals and are more likely to withdraw from physical activities such as exercise.

Weakened respiratory muscles caused by reduced or limited respiratory activity cause greater levels of breathlessness as there is limited force and power to interchange between inspiratory and expiratory phases and adjust to metabolic demands. This influences pressures and volumes of airflow throughout the respiratory system [refer to (Gigliotti. F, 2010)].

It is important for patients to participate in rehabilitation programs that exercise the respiratory muscles. Paced breathing strategies such as PLB endeavour to assist patients in adjusting to physical activity and develop respiratory muscle strength whilst continuing to maintain lung volumes. The challenge lies in motivating patients to overcome the initial struggles and continue to exercise their respiratory muscles. The use of the breathing aid and the harmonica (Fig. 2 & Fig. 3) provides a resistance in which patients can be encouraged to develop their respiratory muscles. Conversely, as these products are fixed in their resistance, the required effort may exceed the capability of some patients. Developing a product with varying resistance levels may act as an appropriate rehabilitation tool for developing respiratory muscle strength and it worth consideration during the subsequent design phases.

2.4.4. Neuro-mechanical dissociation

Breathlessness can be the result of a disassociation between motor signals to the respiratory muscles and incoming neural information. The potential sources of neural information include not only the respiratory muscles but also several different receptors throughout the respiratory system. A disassociation occurs when the central ventilatory drive and the magnitude of ventilation produced does not match [refer to (Nishino. T, 2011)]. The underlying complexities of this form of disassociation extends beyond the scope of this research, however in identifying this mechanism as a cause of breathlessness it is acknowledged that there is an association between the neuro-functioning of the respiratory system as governed by the brain and the volume, speed and time of physical ventilation. Thus, the connection between PLB, learning and motivation may be reliant upon the feedback and stimulus throughout the body. Conversely, external feedback and stimulus presented through interaction with products may create a new learning experiences and motivation. This idea was highlighted through the use of the harmonica as a learning and training tool. As a result, tools developed specifically for PLB practice should focus on both the physiological mechanisms as well as the associated mental patterns.

2.4.5. Expiratory flow limitation

Peak expiratory flow is the maximum flow that can be generated during a forced exhale. Tantucci. C (2013) has determined that the peak expiratory flow is closely linked to the total lung capacity. This means that expiratory flow limitation occurs when the flow of air diminishes although there is increasing expiratory effort. To explain, when blowing a balloon with air there is a need for both increased expiratory effort as well as increased control of the flow. The increased expiratory effort generated by the respiratory muscles allows the air to be pushed through the small opening as the rubber expands. Also, in order to blow the balloon up steadily and effectively, the airflow must be controlled thus allowing for the full expiratory volume to be exhaled in one full breath.

Expiratory flow limitation would occur if the volume of air could not be exhaled effectively into the balloon due to a drop in the flow of air prior to the next inhale. To measure the effectiveness of an individual's expiratory volume and flow, spirometry is a diagnostic tool that measures the volume of air that can be forcibly exhaled within a specific time period. Conducting spirometry testing with COPD patients over a period of time provides an indication of their lung capacity and disease progression. Literature suggests that there is a correlation between the forced expiratory volume (FEV) and the symptoms of breathlessness (Spahija, De Marchie & Grassino, 2005) (Fig. 8).

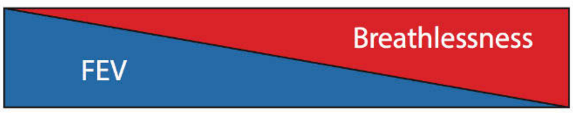


Fig. 8 Disease progression
FEV: forced expiratory volume
Celli et al, 2004

In exploring the link between expiratory flow limitation and PLB, there may be circumstances whereby the patient is trying to adhere to the PLB principle and extend their expiratory time, however their air flow is limited. This may result in a patient attempting a PLB ratio which is beyond their physical capabilities. For example, an attempt at an inhale of 2 seconds and an exhale of 4 seconds, however there are only capable of an exhale of 2.5 seconds. Therefore finding the correct ratio and pace of PLB for each patient is critical in the effectiveness of implementation and longer term use. However, as explained earlier, finding and learning this is currently challenging for patients.

In summary, the physiological challenges facing patients are diverse, evolving and life changing. The characteristics of respiratory physiology produce subtle yet unique variations for each individual and make it difficult for a patient to comprehend the underlying cause of their breathlessness. Approaching the treatment and management of these challenges through the implementation of PLB raises design questions. Primarily, how do we teach a patient to control their breathing? How does a patient implement PLB across a variance of tasks and symptoms? What tools are available to a patient to help them problem solve on a day to day basis? The path for patients in understanding PLB, managing their breathlessness, regaining independence and restoring quality of life is daunting, complex and in need of thoughtful design approaches. However until now it was not clear how this could be achieved. Explanation of respiratory physiology through quantitative studies has begun to set restrictions or design requirements, it is now the time to think of these in the scope of a patients daily life and activity. For design practice, a patient's experiences and perspectives reveal opportunities for novel yet well-considered design solutions. Understanding a patient's behaviours, desires and challenges is particularly important within this context as breathlessness penetrates most facets of their life.

2.5. Living with chronic breathlessness

Previously a patient's feeling of breathlessness was described as being dependent on the physical activity being performed, the severity of the airway restriction and the underlying pathophysical changes (Section 2.4, page 25). Likewise, it was mentioned briefly that a patient's feeling of breathlessness can be influenced by their thoughts and emotions and the way in which they have learnt to self-manage or cope with their symptoms. Referring back to the example of climbing 6 flights of stairs (page 27), in reaching the fourth floor there was a decision phase of continuing on or stopping to catch your breath. For a healthy person, the decision at that point may be quite straightforward as they most likely have a fairly good understanding of their fitness and breathing capacity.

Conversely for a patient with COPD, the signs of breathlessness transpires into fear and anxiety, feelings of choking, chest tightness, not being able to catch their breath and fear of uncontrolled breathlessness. These signs are often fuelled by pathophysical changes within the respiratory system [refer to (Mosenthal & Lee, 2002) (Manning & Schwartzstein, 2001)]. As a result, the patient may physically still have the capacity to perform the task but the initial feelings of shortness of breath are enough to deter them from completing the task. It is at this point that promoting, teaching and implementing self-management strategies within daily life become important for patients.

The principles of self-management will be explained in much greater detail within an upcoming section of this literature review (Section 2.6). At this stage it is important to highlight that the support network for COPD patients aims to both treat and empower patients at all stages of disease progression whilst providing structure and guidance. In doing so, a patient's capacity to live with chronic breathlessness should develop as their exposure to support networks increases.

Initially, patients may begin to notice breathing difficulties when their breathing function converts to a 'front of mind' activity. This transition may result in a patient being consciously aware that their natural breathing rate is not meeting their body's requirements and can act as a prompt to seek diagnosis or treatment. Conversely, a large responsibility is placed in the hands of patients to recognise unique changes in their breathing capability. These changes may best be identified by patients when referenced to daily tasks.

The Lung Foundation (2012) identified key factors that may prompt a patient's feeling of breathlessness. These are:

- The severity of a patient's COPD and the ability for oxygen to pass through the lungs and into the body
- The level of activity involved in a task or activity will affect the amount of oxygen required. For example, the amount of oxygen required between resting and strenuous activity will differ
- A patient's level of fitness will influence the efficiency in moving oxygen around the body
- Stress and anxiety can affect breathing rate. A patient's mood can draw attention to breathlessness and they begin to focus on their breathing

Although these factors outline distinct reasons for breathlessness occurring, patients have a tendency to integrate and merge sensations. As a result, patients may not be able to adequately define, categorise and self-report symptoms (De Peuter et al, 2004). On the other hand, patients may be able to determine or manage changes based on changes to task performance. Noticeable changes such as feeling more breathlessness when climbing their stairs at home may trigger patients to identify that their respiratory capacity is changing. In determining how a patient understands their breathlessness, it is important to recognise that a patient interprets their respiratory restriction within the mind (Staub, 1991). This translates to emotions, adaptions and coping strategies that are unique to each patient and will define their COPD breathlessness story.

To explain further, patients build their understanding of breathlessness upon distinct sensations, activities or interactions but may not be able to define the underpinning physiological, emotional or environmental trigger or cause. Therefore the relationship between the primary symptom of breathlessness and the disease of COPD becomes difficult to quantify, treat and follow as the influential factors extend beyond monitoring physiological changes. For example, a patient may be encouraged to participate in formal exercise programs to improve their lung function. But they may struggle to continue to exercise within their daily routine due to anxiety or fear of breathlessness symptoms. This relationship results in a cyclic disease progression.

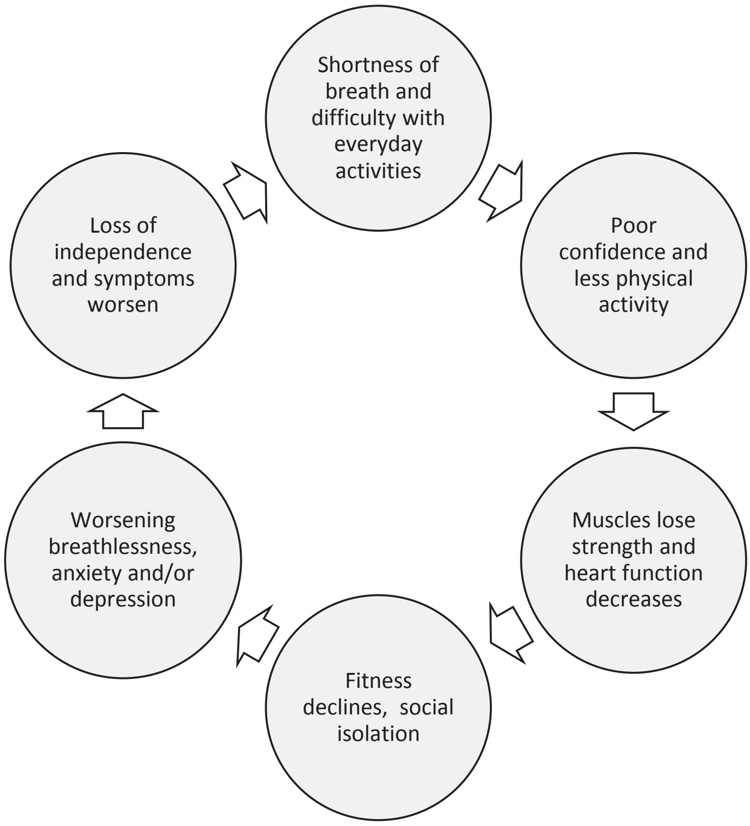


Fig. 9 Cycle of inactivity
The State of Queensland and The Australian Lung Foundation, 2012

The cycle of inactivity and breathlessness is detrimental to a patient's well-being and capacity to manage their breathlessness. The cycle is depicted in Fig. 9 as a continuous progression where the beginning and the end is unclear. If we begin in the top circle, *shortness of breath and difficulty with everyday activities*, and move through the circles in a clockwise direction, it is represented that by limiting and withdrawing, a patient's general fitness deteriorates. In turn, declining fitness levels makes movements and oxygen flow less efficient resulting in a greater effort to complete everyday tasks. As their disease and symptoms progress, a patient will cycle through periods of inactivity, with each revolution reducing their physical capability to participate in activities and perform everyday tasks. Imagine a patient was cycling through each of the circles regularly; it would not take long for their active participation in daily tasks to diminish. Furthermore, reversal of the inactivity cycle is not simple. Presuming that a patient was at circle, *muscles lose strength and heart function decreases*, reversing back to an increase in activity may be quite difficult. When Janssens et al (2011) discuss the aspects associated with a patient's perception of breathlessness, it was found that an increasing awareness of escalating physical limitation and deterioration often leads a patient to feel an escalation in anxiety and depression as well as inability to cope with change.

Currently, studies which capture the unique relationship between physiological occurrences and patient experiences are not explicit in the role that product design plays in shaping these contexts. Although qualitative studies may be rich in patient narratives, emotions and challenges, there may be missed opportunities for design researchers to specifically respond to breathing function and improvement. To further understand the impact of breathlessness on a patient's lifestyle and wellbeing, it is worthwhile describing the impacts by focusing on everyday tasks in which we are familiar. This will assist in extracting the opportunity for design exploration. Although the concept of self-management, pulmonary rehabilitation and PLB are yet to be formerly introduced, defining the relationship between daily activities and breathing performance will indicate and reveal directions in which product design can facilitate breathing control.

2.5.1. Performing everyday tasks

For healthy individuals our knowledge and feelings of breathlessness are often strongly linked to periods of exertion, stress and peak exercise. However, our understanding of breathing discomfort, physiological distress and chest tightness does not equate to that of a COPD sufferer. As described earlier, healthy individuals have moments of *catching their breath* and recovery whereas for patients with COPD the feelings of breathlessness extend into daily life. Exertional breathlessness during activities of daily life (ADL) is the main complaint in patients with moderate to severe COPD. It not only limits a patient's exercise capability but also influences their ability to carry out ADLs such as dressing, bathing and performing household activities. Although management guidelines encourage patients to maintain physical exercise and where possible continue everyday tasks, it has been found within the literature that patients are more likely to accept the impact of breathlessness and move towards the cycle of inactivity mentioned earlier as opposed to continually adapting tasks and management strategies [see studies (Boot, van Exel, van der Gulden, 2009) (Mosenthal & Lee, 2002) (Reticker et al, 2012) (Janssens et al, 2011)].

To confirm and quantify the burden of COPD on ADLs, in 2000 a collaboration of researchers across Europe and the UK conducted the Confronting COPD International Survey [refer to (Rennard et al, 2002)]. Of the 3,265 patients identified, one fifth were breathless when just sitting or lying, one third said they were breathless when doing light housework, and more than two thirds were breathless when walking up a flight of stairs Compared with healthy individuals, patients with COPD had a reduced walking time, standing time and movement intensity during daily life. Additionally, when patients did walk, they walked significantly slower than healthy subjects.

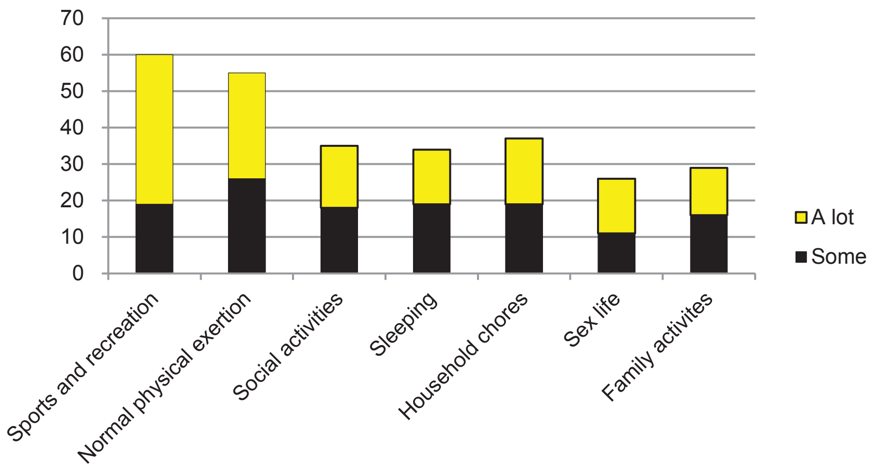


Fig. 10 Impact of COPD on lifestyle and quality of life (%)
Rennard et al, 2002

In a study conducted by Bourbeau. J (2009) it was revealed that there is a considerable burden of disease affecting many aspects of everyday life for COPD patients. Presented within Fig. 10, the results indicate that the impact of COPD is spread across both high intensity activities such as sports and recreation as well as low intensity activities such as sleeping and socialising. This indicates that regardless of the effort required by the task, the impact and influence of disease on a patient's capacity to perform tasks is great. Furthermore, a study conducted by Pitta and colleagues (2005) indicates that there are significant differences in activity levels between healthy elderly individuals and COPD patients. Represented within Fig 11, it was found that COPD patients have a greater sedentary lifestyle with a greater amount of time spent lying or sitting than health individuals. Specifically, the diagram shows that COPD patients spend 64% of their time sitting or lying in comparison to a healthy elderly person who spends 46% of their time sitting or lying. Overlaying this data with the cycle of inactivity, it may be more likely that a sedentary lifestyle will lead to an acceleration of the cycle of inactivity.

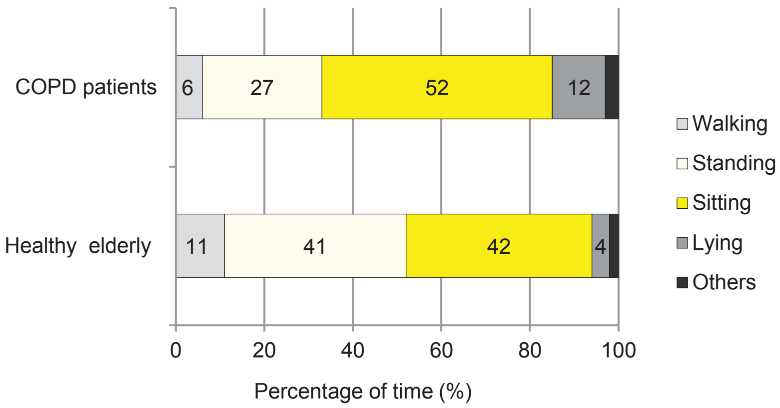


Fig. 11 Percentage of time spent in each of the activities or body positions
Others: cycling or undetermined activity
Pitta et al, 2005

For a COPD patient, the development of comorbid disease such as obesity, diabetes and higher blood pressure continues to challenge their capability to overcome the cycle of inactivity. Thus their breathlessness may become a mixed result of COPD, obesity, injuries, muscle deconditioning and other diseases. This may further exacerbate a patient's experience of breathlessness. However, currently there is limited research or tools that focus on the acceleration or change in activity levels of COPD patients. To assist patients in remaining active and continuing activities that they enjoy, the product design process may consider behavioural change principles or interaction methods, which monitor and feedback a patient's current activity state against their desired activity state. For example the product may provide digital feedback similar to a pedometer whereby the patient tracks their daily steps against a goal step count. The design challenges are to determine what aspects of activity to monitor, how to monitor the activity and how to engage the patient to change.

There is significant quantitative data which confirms that physiological and comorbid disease impacts on COPD disease progression on a patient's capacity to perform tasks. However in framing the intricate needs of a patient it is important to examine a patient's perception of tasks. A complimentary view of patient desires offers beneficial product design clues and insights regarding the novel and changing dynamics of managing a chronic and progressive disease. Importantly, qualitative data and patient extracts establish a design framework, user context and aid in the definition of product opportunities and requirements.

ADL mentioned in patient interviews	
Vacuum cleaning	14
Carrying weight during walking (4-5kgs)	11
Showering	6
Putting on shoes and socks	6
Getting dressed	5
Loading and unloading the dish washer	5
Climbing stairs	5
Dish washing	2
Hanging up laundry	2
Window cleaning	2
Wiping terrace, cleaning the floor	2
Cleaning cupboard	1
Gardening	1
Peeling potatoes	1
The numbers represent the number of times an ADL was mentioned in the 'top 3' of most breathlessness causing activities in patients. Number of patients interviewed: 21	

Table 2 Activities of Daily Living (ADL) mentioned in patient interviews
Lahaije et al, 2009

Specified in Table 2, Lahaije et al (2009) reported a set of patient identified activities that cause breathlessness. Tasks that require large variations in motion such as vacuuming, showering and putting on shoes and socks scored a relatively high ranking. This is noteworthy in defining our understanding of respiratory requirements and management techniques as we often focus on typical tasks such as walking or climbing stairs without necessarily considering the impact of continued upper limb motion on breathing function.

Moreover, it is understood through the work of Boot et al (2009) that there is an underlying pattern and relationship formed by patients between the symptom of breathlessness and activity limitation. Statements such as “if I do this now, I may not be able to do *x* later” and “it will take me *x* amount of time to get over this” begin to illustrate the associations between an individual’s experience of breathing patterns and their behaviour.

In approaching everyday tasks, Jones (2007) suggests that patients evaluate, monitor and adapt to tasks based on the following criteria:

- Activity or tasks is not possible due to breathlessness
- Activity or task is possible but will cause higher levels of breathlessness during or at conclusion
- Activity or task can be completed but at a slower pace or minimal effort

These criteria are the principles in which a patient will begin to define their own self-management framework. It is likely that a patient does not use a single criteria listed above but rather combines the criteria depending on the day, the tasks, their physical capability and their emotions. In other words, for a patient to be able to successfully self-manage their breathlessness they must form adaptive behaviours but also the way in which the task is performed may need to adapt. This unique relationship between the limitation of activity due to breathlessness and performing the activity itself creates a problematic circumstance for design.

Design questions begin to surface such as; can a product reduce the respiratory effort required to perform tasks? Can design processes produce products that enable patients to adapt to tasks more effectively? Should design practice focus on a specific task and design for that unique circumstance? In evaluating the role of product design in reducing the burden of breathlessness, task analysis and design focus towards tasks that are perceived by patients to be the greatest challenge may not be the best avenue for exploration or the correct way to approach the problem. The reason being is that the way in which we naturally perform tasks differs. For example, vacuuming was identified by patients as a task that caused breathlessness. Based on Jones' (2007) methods, a patient could choose to no longer vacuum and source external help, they could choose to vacuum knowing that they would feel breathlessness or they could vacuum slower and try and reduce the effort required. To facilitate a patient's self-management, design could approach the problem by redesigning the characteristics of a vacuum cleaner in order to reduce the effort. Design could reduce the weight, overcome friction when vacuuming carpet and provide unique features that assist in moving the vacuum cleaner around the house but this approach becomes problematic. By segmenting task related problems and solving these independently there is risk that patients will feel restricted rather than feeling enabled to manage all of the tasks that they wish to perform. As a patient's disease progresses their requirements and expectations of products will change. Perhaps the approach should not be to provide an array of specific solutions but rather to provide a tool that can support a patient in adapting and moving across a series of tasks. It has been identified that PLB can move across all tasks and offer immense benefits.

2.6. Self-management of breathlessness

Self-management of breathlessness is recognised as an aspect of the larger disease management approach. Self-management is defined by Barlow et al (2002) as, 'an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic illness'. The primary goal of self-management is to empower patients at all stages of disease progression whilst providing structure and guidance (Effing et al, 2012). The benefits of pharmacological and non-pharmacological treatments in COPD have been established based on measurement of traditional outcomes such as improvements in lung function, exercise capacity, reduction in exacerbations and reduction in mortality rates. Recently there is increasing interest in assessing and confirming aspects of self-management that are important to patients, with a strong focus on increasing patient motivation, understanding social contexts and improving health related quality of life [see studies (Bourbeau.J, 2009) (Von Korff et al, 1997)].

The expansion of self-management principles is informed by cognitive behavioural therapies and social cognitive theory, which emphasises that personal factors interact to influence behaviour [refer to (Gallant. M, 2003) (Newman, Steed & Mulligan, 2004)]. Self-management interventions and strategies have placed a strong emphasis on developing self-efficacy, which is a patient's confidence in their ability to undertake specific self-management behaviours.

On the other hand, COPD self-management is influenced by social and environmental contexts that influence a patient's capacity to manage behaviour. These include interactions with health professionals, relationships with family and friends, access to resources and weather conditions. Given the burden and fatigue that COPD patient's experience, it has been suggested by Disler, Gallagher and Davidson (2012) that it may be difficult for patients to balance the self-management of tasks with activities that give them pleasure. As a result, it becomes difficult to define and assess optimal self-management attitudes and behaviours.

By focusing on developing problem solving skills and increasing patient goal setting, it has been recognised in the work of Newman, Steed & Mulligan (2004) that management interventions should be focused at sustained behaviour change. In taking a self-management approach that is focused on empowering patients to take control of their breathlessness, the role of product design solutions develops. Referring to the vacuum cleaner, a designer could make design changes to the product to reduce the burden of breathlessness when performing the task, however this would not be aligned to the principles of self-management. As opposed to enabling a patient to monitor and learn about the challenges of breathing, the improved vacuum cleaner would aim to remove the difficulty. In doing so, the product adapts the task as opposed to the patient changing their behaviour of cleaning their carpets. The concern with this approach is that the vacuum cleaner is fixed in its functionality, as a patient's disease and symptoms progress the vacuum cleaner may become redundant in its ability to manage the patient's requirements. From a design perspective, designers should be aligning to the principles of self-management and developing products that promote patient problems solving and adaption skills.

A particular struggle of current interventions and strategies is striking the balance between short-term gains and long-term behaviour change and finding the best way to motivate patients accordingly. To understand these struggles further, we will now turn our attention to self-management interventions and behaviours.

2.6.1. Self-management interventions

Self-management interventions or strategies are designed to target aspects of a patient's management of COPD. Interventions may focus on promoting paced breathing through PLB, managing medication reliance, increasing exercise and lung function or reducing exacerbations and hospital admissions. Historically, interventions focus on an educational approach, with the expectation that greater knowledge leads to appropriate changes in behaviour and improved self-management [refer to (Newman, Steed & Mulligan, 2004) (Effing et al, 2012)]. Investigated by Worth & Dhein (2004), this approach has been found to be effective in certain circumstances, with self-management results occurring in small, specialised COPD learning environments as opposed to educational programs that are generic.

Conversely, Newman, Steed & Mulligan (2004) conducted a systemic review of self-management interventions across chronic illnesses of diabetes, arthritis and asthma and found that adopting a generic approach based on the development of core skills such as problem solving and goal setting may offer similar benefits to those programs that are focused on specific disease management strategies. It was noted within this study that further investigation into the extent in which generic rather than disease specific skills allow for the development of self-management.

In considering the position of product design in guiding and maintaining a self-management approach, a product could be designed specifically for the disease or it could take the generic route, however, each avenue comes with its own set of unique design challenges. Reflecting on the earlier ideas of using pace as an overarching management technique, PLB leans towards the generic problem solving and adaptive approach as described by Newman, Steed & Mulligan (2004). The challenge from here for product design is that in changing a patient's thinking and attitude towards tasks the interactional elements of the design and must be carefully considered. When designing specifically for a predicted physiological state, the interactional elements and outcomes may be more easily predicted. For example, the measuring of lung capacity is determined and restricted by lung volumes and metric outcomes, however when designing a product which focuses on task adaption, problem solving and goals setting, the involvement of patients and response of the product carry a larger range of variances. To determine the effectiveness of teaching more generic and open self-management techniques, a method of constraining and measuring outcomes and success should first be explored.

PLB is an intervention which promotes patient problem solving and adaption. However, the current communication of PLB sits with education and knowledge as opposed to promoting the problem solving aspects. By exploring self-management behaviours, there is an opportunity for designers to bridge the gap between PLB education and PLB skills by designing products with strong behaviour based interactional elements. Focusing specifically on self-management behaviours, Chen et al (2008) found that patients identified with 5 key behaviours (Table 3). Patients chose and combined different approaches depending on the severity of breathlessness, the social and environment context at the time and the specific tasks they wished to perform.

Self-management behaviours	
Symptom management	Management approaches may include: - Withdrawal from tasks - Slowing down or pacing the task - Practicing breathing techniques and PLB - Adhering to medications - Seeking assistance with tasks
Activity and exercise limitation	Adaptions to exercise may include: - Lowering the speed and shortening the distance - Choosing exercise in which they are familiar - Utilising exercise equipment to maintain pace
Environmental control	Management approaches may include: - Avoidance of dust and pollen - Adjusting tasks to the daily temperature and humidity - Rearranging furniture so as to increase air flow
Emotional adaption	Controlling emotions may include: - Positive thinking - Distraction - Acceptance - Adjusting to their symptoms - Knowing their limits
Maintaining a healthy lifestyle	Altering lifestyle by: - Remaining social and independent - Exercising and adhering to medications - Cease smoking

Table 3 Key self-management behaviours
Chen et al, 2008

Although self-management behaviours allow for an adaptive intervention approach, the success is based upon a patient's readiness and motivation to change (Newman, Steed & Mulligan, 2004). Furthermore, in designing an intervention there is the challenge of defining the desired outcome; is the aim to halt symptoms, improve medication adherence, increase physiological functioning, prevent exacerbations or decrease hospitalization rates? This is important, as each patient will possess their own goals and desires which drives their incentive to change and utilise the interventions.

Patients are supported through the transition of managing a chronic illness with literature, online forums, support groups and ongoing education. Interventions currently promoted within a COPD self-management protocol include exercise programs, smoking cessation, medication regimes and PLB. Beginning with the education phase, patient information sheets provide simple tools to patients to practice and integrate within their daily activities. In reviewing a selection of patient information sheet extracts [see Appendix C (Fig. 58 – Fig. 61, pages 196 to 199) there is a common thread in regards to paced breathing and paced activity. Within the examples shown, references to paced breathing have been outlined. These references encourage patients to pace their breathing and monitor their energy expenditure so as to reduce the frequency and impact of breathlessness on daily living. For example Fig. 58, within the red box it is stated 'breathing out should take longer than breathing in'. Although this statement reflects the principles of PLB by promoting controlled respiratory rate (Section 2.3, page 21), the information sheet fails to consider the environment or context in which the patient may attempt to practice. For a patient that is breathless from walking or performing tasks, measuring and adapting the lengths of breaths may be challenging when they are in a panic mode.

A differing example is shown within Fig. 59 (page 197). This information sheet provides an activity context through walking by encouraging patients to 'establish a pattern of breathing that matches your steps and that you can maintain easily'. While patients are guided to adapt or control their breathing by referencing their walking steps, to put this into practice may be challenging, particularly if a patient's rhythm of walking is very different to their rhythm of breathing. This may result in a patient not only having to focus and adapt their breathing but also focus and adapt their walking.

Simultaneously, there are limited tools available that enable COPD patients to find, learn, feel and adapt to their appropriate pace, particularly during physical tasks. Studies have noted that within a prescribed breathlessness management plan, it is suggested that patients 'adapt the rhythm of daytime activity so that there will be sufficient intervals of rest in between' (Bausewein. S, 2013). These types of phrases are often interpreted and communicated to patients as pace your breathing. However, the directive to control and coordinate breathing with daily activities may be difficult to imagine and even more so practice if a patient's overall desire and motivation is to reduce or withdraw from the activity. For example, imagine you are vacuuming. How do you set your breathing pace with the activity? How do you know if the breathing pace is effective? How do you adapt the vacuuming task to fit in with the rest of your day? Does it become a morning activity? Do you split the task? Initially, we begin to formulate our own uneducated but natural self-management strategies. Maybe we should vacuum one room in the morning and then one at night, listen to our favourite tunes to establish a vacuuming pace or set ourselves a time period. But, how are we going to learn generic self-management techniques and apply them specifically to our tasks and requirements?

PLB is an identified self-management technique with literature suggesting that PLB is effective in reducing the immediate feelings of breathlessness whilst enabling patients to self-manage their breathing demands in accordance with their physical needs (National Heart, Lung and Blood Institute, 2010) (Lung Foundation of Australia 2012). As mentioned earlier (Section 2.2, page 17), entrainment of paced breathing principles enables effective breathing control which extends across a range of daily tasks, from vacuuming to walking, to showering and dressing. The key is that patients must be well practiced and familiar with the technique in order to perform this effectively.

Research in the area of PLB training and management has highlighted several shortfalls regarding the translation and use of PLB principles demonstrated within literature and bringing this to life within a patient's daily activities. For example, moving from PLB education to possessing adaptive PLB skills is challenging. Current shortfalls include ambiguous instructions on patient information sheets (Lung Foundation of Australia 2010) (National Heart, Lung & Blood Institute 2010), (Tasmania Department of Health and Human Services 2009) and research that is solely focused on the physiological benefits of PLB without consideration of the learning process and motivation required (Fraser, Kee & Minick, 2006). Thus exposing opportunities to investigate the interaction rituals of PLB, the relationship to patient motivation and how these rituals best fit within daily life.

Patient literature for breathlessness sufferers encourages patients to conserve energy and pace and control their breathing until breathing becomes comfortable. However, the effectiveness of these techniques becomes problematic as the literature is not explicit as to what is required and how an individual can be educated to measure and adjust these techniques appropriately. Additionally, tools and methods that are available to support the change in breathing practice stem from formalised rehabilitation and can appear to be disconnected from daily activities.

Reflecting back to the use of the harmonica as means of teaching and learning paced breathing methods, teaching *Mary Had a Little Lamb* on the harmonica may appear disjointed from the daily tasks such as vacuuming, but imagine if the pace of the tune became the pace of the activity. By first learning paced breathing on the harmonica, the patient is offered the opportunity to learn through musical feedback first before applying the pace to the activity. Thus entrainment of breathing rhythm and pace can then be applied to a variety of tasks.

An understanding of the factors that influence a patient's motivation to adapt tasks and implement self-management interventions such as paced breathing would benefit the product design process. For example, is a patient motivated by positive messages sent via text message? Does a patient adjust their performance based on visual data? Is a patient motivated or uncomfortable when practicing within a group? Exploration of patient motivation will aid in establishing PLB intervention outcomes.

2.6.2. Patient motivation

As identified by Maclean & Pound (2000), there are conflicting definitions within the literature regarding the concept of motivation and what counts as motivated behaviour. The examination and definition of motivation extends beyond the boundaries of this research, however taking cues from earlier mentioned work, it is recognised that patient motivation is informed by a patient's personality, social factors and environment contexts. This results in a somewhat subjective framework whereby a patient can be motivated by their desires, beliefs and values. This becomes problematic for design, as the designer must establish the desired behaviours and interventions and ensure that the patient will be motivated by these.

An alternative approach to understanding patient motivation is to investigate the successful motivational aspects of current self-management interventions. Inopportunely, the literature and data available is limited. Copper and colleagues (2001) performed a meta-analysis to explore the effects of patient education and implications for educational treatment. It was found that of the studies included, details regarding the educational program content, the frequency of educational sessions and the duration of the intervention were not specified. Additionally there was limited information given regarding participation and attrition rates and reasons for non-participation. A limited insight was provided by Cicutto, Brooks & Henderson (2004) who reported that for COPD patients, support from family was identified as an enabler for performing self-care activities and acted as a motivator for living. Based solely on COPD and rehabilitation literature, it is difficult to evaluate the successful elements of traditional interventions and the motivational aspects.

On the other hand, research that focuses on respiratory technologies, Smartphone technology and Internet based rehabilitation approaches the studies from another avenue. Often these studies ask patients to review and provide feedback after the intervention and behaviour has been defined. This provides patients with an opportunity to provide feedback and insight regarding that particular intervention. However, from a design perspective, this approach may lengthen the design process as the design iterations start broadly prior to customisation of COPD products. As a result, the aspects or key features that motivate a patient to practice PLB are not well known. Specific qualitative research that investigate a patient's understanding of PLB and the aspects associated with their motivation to practice may respond to this absence of knowledge. Additionally, documented research regarding a patient's response to similar products within the market may offer clues or direction regarding design requirements, patient preferences and emerging desires.

To summarise, the integration of self-management interventions is effective in allowing patients to continue to perform daily tasks, however a patient must be motivated to repeatedly practice and implement these effectively. This requires patients to not only be motivated to practice but importantly gravitate towards a change in behaviour. The intertwined nature of patient motivation and behaviour change must be approached by the designer in such a way that the ongoing requirements of the patient become explicit.

Pulmonary rehabilitation programs encompass various methods in which to encourage self-motivation in patients. Exploration of pulmonary rehabilitation principles and program structure will facilitate and reveal differing approaches and potential product design characteristics. The following section will focus on rehabilitation setting, program structure and content and the role of technology in assisting the rehabilitation process.

2.7. Pulmonary rehabilitation

Pulmonary rehabilitation is defined as 'evidence based, multidisciplinary and comprehensive intervention for patients with chronic respiratory disease who exercise symptoms and often have decreased daily life activities'. Provided via a patient centered approach, pulmonary rehabilitation is tailored to reduce patient's symptoms, optimise their ability to perform tasks and increase participation (Australian Institute of Health and Welfare, 2013).

To summarize, assessment of COPD and recommended treatment options is based upon an individual's symptoms, risk of exacerbations, the severity of abnormalities and the identification of comorbidities (GOLD COPD, 2015). By combining varying types of interventions and programs, rehabilitation aims to tackle the complex symptoms and experiences facing COPD patients whilst encouraging patients to expand their self-management strategies within daily life (Australian Institute of Health and Welfare, 2013). Consequently PLB acts as one type of intervention within a much larger rehabilitation framework.

Pulmonary rehabilitation is recommended for all patients with COPD to improve physical function and quality of life. This multidisciplinary approach, which includes exercise training, education and psychological support, reduces breathlessness symptoms and functional capacity and lowers rates of hospital admissions and mortality. Although PLB was earlier introduced as a self-management technique, the concept of PLB is often presented and taught to patients within the pulmonary rehabilitation process. As a result, a patient's use of PLB iterates between self-management and rehabilitation. Thus it is important to consider PLB in light of the pulmonary rehabilitation setting and structure.

Prior to continuing, it is an appropriate time to reintroduce concepts outlined within the introduction. Although it is acknowledged within the literature that PLB can contribute to the pulmonary rehabilitation process (National Heart, Lung and Blood Institute, 2010) (Lung Foundation of Australia, 2012), the evidence for the use of PLB in the rehabilitation and self-management of COPD remains unclear. Bearing this in mind, a study conducted by Dechman & Wilson (2004) demonstrates that an improved sense of breathing control and breathing retraining does play a role in the greater management approach.

In approaching the teaching and facilitation of PLB practice, a product or diagnostic tool that measures or provides feedback regarding a patient's PLB practice is non-existent. Therefore there are many unknowns regarding the effectiveness of PLB. By positioning PLB as both a self-management and pulmonary rehabilitation tool, it will become clear that there is a need to design a product that measures breathing frequency and breathing control and allows patients to respond to feedback. To comprehend the design requirements and challenges in further detail, the aspects of pulmonary rehabilitation that will now be discussed are; the setting, the program content and structure and technology assisted rehabilitation.

2.7.1. Setting

Available data suggests that access to pulmonary rehabilitation programs in Australia is limited. In 2007, there were 131 pulmonary rehabilitation programs in Australia. Of those, 80% had a waiting list and in more than half the waiting period was greater than four weeks. Broadly, only 5-10% of patients with moderate to severe COPD were able to access a formal rehabilitation program with 60% of those programs failing to offer long-term engagement [refer to (Australian Institute of Health and Welfare, 2013)]. Studies across Australia, UK, US, Canada and parts of Europe indicate that the demand for services exceeds the resources available [refer to (Liddell & Weber, 2010) (Johnson & Grimmer-Somers, 2010)]. Given the limitations of structured sessions, Gysels & Higginson (2009) highlight that there is uncertainty as to the best methods by which to manage rehabilitation.

Pulmonary rehabilitation can be provided in an inpatient or outpatient setting. Although exercise training in pulmonary rehabilitation is traditionally given under direct supervision of a therapist, newer evidence as presented by Parshall et al (2012) suggests that exercise training in the home environment can be as effective. A pilot study undertaken by Liddell & Weber (2010) suggests that once a week supervised rehabilitation may be capable of producing equivalent improvements in exercise tolerance as a twice a week program. This study indicates that face-to-face guidance and continuing feedback can lead to improved results. However, if adequate feedback mechanisms are provided within the home, for example Smartphone technology or Internet monitoring, the home environment may produce greater improvements as patients could participant more frequently. In transferring aspects of rehabilitation to the home environment, the scope of rehabilitation practices may widen. This is where the relationship between the formal rehabilitation and self-management practices become important. Furthermore, a national study focusing on Australian pulmonary rehabilitation programs reported that most are conducted in an outpatient setting, however it is recognised that home based programs may continue to increases as there is an emphasis on community based rehabilitation and management (Johnston, Maxwell & Alison, 2011).

In considering this direction, it may be prudent to contemplate as to whether the content and structure of the rehabilitation programs adequately considers the home context. Will patients be able to take what they have learnt and implement this effectively? Do they need to use specific equipment? How do they know if they are performing the tasks correctly? For patients who spend a large portion of time managing their breathlessness within their own home, they may find this process isolating as they become unable to perform daily tasks and social interactions which bring them pleasure (Gysels & Higginson, 2009). Therefore understanding the transition between the home and the rehabilitation context is important. Spruit and colleagues (2013) suggest that characteristics of the program, transportation to and from the program, availability of long term programs and cost to the patient or health system are considered when determining the setting for rehabilitation. In light of this, the principles of PLB aim to support the changes between environments and contexts as patients are encouraged to control their breathing and pace as per their daily activity. Further explanation regarding typical program structures and content will help in determining the potential role of PLB.

2.7.2. Program structure & content

Pulmonary rehabilitation does not aim to directly improve functional capacity such as lung mechanics or gas exchange. Rather, it focuses on the function of all body systems so that the effect of respiratory dysfunction is minimised. A typical program includes exercise, education, relaxation training and psychosocial support (Johnston, Maxwell & Alison, 2011) (Yohannes & Connolly, 2004), however the exercise program is often the primary focus. As illustrated by Casaburi & ZuWallack (2009) in Fig. 12 (page 59), exercise focuses on improving overall muscle function so as to lower the ventilatory demand. Additionally, exercise acts as a management technique during periods of anxiety or depression.

There is sufficient evidence within the literature to conclude that the immediate effect of pulmonary rehabilitation results in improved exercise performance for patients with moderate to severe COPD (Cambach et al, 1997) However, a study undertaken by Ries et al (1995) measured the long term benefits of rehabilitation and suggests that the strategies learnt are effective for about 1 year before they begin to diminish. This is further supported by the work of Cockram, Cecins & Jenkins (2006) who found that rehabilitation requires ongoing community based exercise programs.

Moreover, Singh and colleagues (1998) found that the perception of quality of life did not correlate to improvements in physiological performance and outcomes. Therefore, if quality of life outcomes and physiological performance indicators are not necessarily linked there may be capacity for rehabilitation directions that are focused on alleviating the psychological burdens of breathlessness without demonstrating any functional improvement.

Focusing on the barriers to participation, factors may include a perceived lack of support, unwillingness to travel, poor access to transport and lack of perceived benefit. The literature reveals the benefit and results of pulmonary rehabilitation, however completion rates range from 69-77% [refer to (Johnson & Grimmer-Somers, 2010) (Keating, Lee & Holland, 2011)]. In particular, the work of Keating, Lee & Holland (2011) found that current smokers, patients who are depressed and those who live alone are at an increased risk of non-completion.

In addressing the challenges associated with the pulmonary rehabilitation setting, structure and content, the implementation of technology may be able to assist. As the needs of patients develop, technological applications, products and devices may offer a quicker response, provide the benefits of customisation and be able to merge the shifting rehabilitation environments.

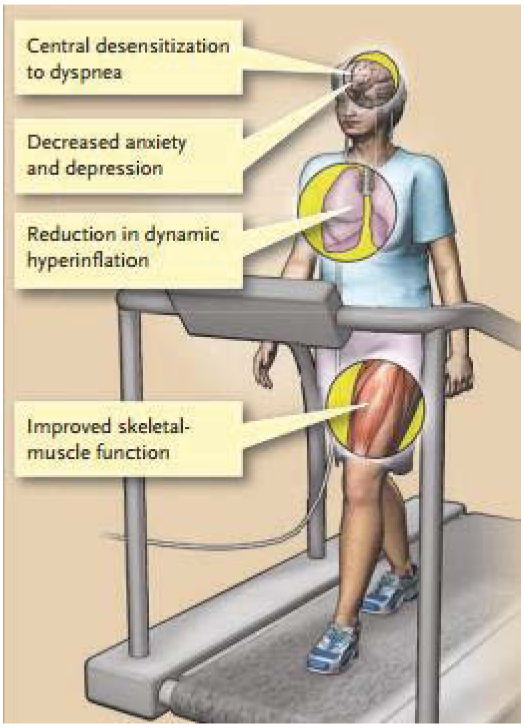


Fig. 12 Targets of exercise training
Targets of exercise training as part of pulmonary rehabilitation program for patients with COPD
Casaburi & ZuWallack (2009, pp. 1330)

2.7.3. Technology assisted rehabilitation

To date, there is limited evidence of the use of technology for pulmonary rehabilitation. Traditional exercise equipment such as treadmills, recumbent bicycles and upper body ergometers are used within inpatient and outpatient programs, however products and devices specifically designed for COPD training are not widely known. On the other hand, studies focusing on mobile technology use in the fields of sports rehabilitation and management of other chronic diseases such as diabetes and asthma have revealed interesting results.

Broadly, mobile technology includes Smartphones, tablets, Smartwatches and wearable devices and has the ability to interface with sensors and other wireless devices. Mobile technology has the capability to overcome barriers to rehabilitation access with the unique advantage of being able to influence health behaviours in real-time (Beatty et al, 2013). A patient can receive information, record and review data, receive feedback and connect with other patients or the greater health community. In responding to the needs of PLB training and feedback, mobile technology would appear to be a valid route of investigation, however as research within the COPD framework is lacking, literature from the broader pulmonary rehabilitation will provide further insight.

A systematic review was carried out by Bort-Roig et al (2014) to verify if Smartphones are a valid means by which to measure and influence physical activity. Firstly, this study found that the rate of publications in this field has been increasing since 2007, indicating that both Smartphone use and research in this area is emerging. Secondly, measurement accuracy is currently based on small sample sizes with the methodology within these studies often placing restraints on the user's range of movement. Furthermore, the variance of in-built and external sensors used across the studies makes it difficult to conclude the accuracy of one over the other. Finally, patients rated monitoring their physical activity profile, receiving real-time feedback, aspects of social networking and goal setting as key features within the Smartphone application.

Investigating the use of motivational cues as a means to changing patient behaviour, Tabak, Akker & Hermens (2014) conducted a study that involved regular communication with patients regarding their exercise performance. The study required patients to use an activity sensor which was paired with their Smartphone. Patients received prompts every 2 hours regarding this performance and encouraged improvement. This study found that patients adapted their activities and behaviour as a result of the ongoing feedback.

Another study conducted by Varnfield and colleagues (2014) trialled the use a Smartphone based home delivery program for cardiac rehabilitation. The program delivered a range of digital interactions to patients including video conferencing with a mentor, text messages, video clips and relaxation audio. The findings from this study indicate that activity monitoring and continuous feedback via the Smartphone not only improves functional outcomes but also increases rehabilitation uptake and completion rates. There were various causes for participant withdrawal from the study, however of note is that some patients withdrew due to the difficulty experienced when using the information technology tools. Now that the principle of remote pulmonary rehabilitation and feedback is understood, a stronger design focus towards user experience and interaction may be able to respond to the technical challenges.

In exploring the relationship of technology and breathing more broadly, Marshall et al (2011) categorised work which considers breath as a direct control and input mechanism. Placed into 2 main categories, assistive technologies or expressive technology, the work of Marshall et al (2011) highlights the varying interactions and experiences that can be embodied within product design. To explain further, assistive technologies are those which require the user to breathe in a particular manner in order to modify a products interface or performance. This form of interaction may be best understood through a game, whereby the user breathes at a particular rate of flow to control the character. Expressive technologies are those that invite a user to become aware of their breathing but do not require direct breathing interaction. Commonly seen in virtual worlds, music and art installations, expressive technologies are open to interpretation and tend to be not as goal orientated as assistive technologies may be.

Assistive technologies currently being explored include the use of breath in virtual games such as EmRoll (Fig.13) (Zangouei et al, 2010), Asthmon (Fig.14) (Panont et al, 2010) and ZenyTime (The Active Times, 2014). As illustrated on pp.63, EmRoll and Asthmon are interactive games that incorporate both digital application and handheld devices to form a virtual breathing learning experience. As a patient encounters differing levels within the game, they are required to learn new breathing techniques or skills to continue. The feedback provided by the game interface guides the patient to consider their technique, performance and seek improvements. These ideas mimic the requirements of self-managing breathlessness as a patient learns to problem solve or adapt when motivated to do so. Although interactive games may be adopted or recommended as part of a rehabilitation approach, the transition of learnt skills from the game into everyday life must be carefully considered through the design process.

Conversely, expressive products and performance monitoring devices such as the OM (Fig. 15) (OM, 2015) and Spire (Fig. 16) (Spire, 2014), along with well-being products Aura (Fig. 17) (Nordmand.P, 2015) and Breathing Stone (Fig. 18) (TechSpark, 2014) demonstrate the increasing number of applications whereby awareness and selfmonitoring of respiratory cycles promotes an increased knowledge of respiratory health. Devices such as OM and Spire provide a representation of current trends in performance monitoring whereby the user wears the device as it captures and records results. Although increased knowledge may empower patients to take action, it may be difficult for a patient to monitor progress if they are unaware of the target breathing behaviour. In other words, these products record and feedback current behaviour but do not offer personalised direction regarding ideal breathing behaviour.

Responsive devices, such as Aura and Breathing Stone, are shaping new rehabilitation experiences as they echo the patient's immediate environment. In these circumstances breathing retraining is determined by the signals and cues detected by the device within the patients surrounding. These may include aspects of stress or mood. Based upon these cues, the patient may be invited to participate in paced breathing exercises by glowing and omitting audio. Although this creates an interesting feedback mechanism, the device is unable to determine if the patient is compliant to the set rhythm or if the patient is struggling. Thus the element of personalised teaching, guiding and monitoring are not present in these types of devices.

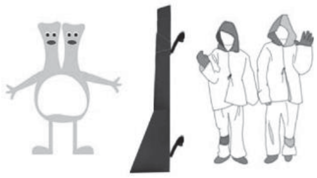


Fig. 13 Emroll
Cameras are positioned in front of the 2 players, picking up on their movements. The character on the left is the Avatar which the players control through breathing.
(Zangouei et al, 2010)

Fig. 14 Asthmon
Asthmon, a portable toy designed as a game and a respiratory flow meter.
(Image: Panont et al, 2010)

Fig. 15 OM
OM is device worn within clothing that measures key performance indicators such as heart and respiratory rate. This device links into an application that provides real time feedback.
(OM, 2015)

Fig. 16 Spire
Worn on the belt, **Spire** monitors real time breathing and provides feedback. Originally designed for the workplace where people are sitting for long periods of time.
(Spire, 2014)

Fig. 17 AURA
AURA is a stress relieving tool designed for desk workers. AURA monitors the environment for signs of stress, when stress is detected AURA guides the users through deep breathing exercises.
(Nordmand.P, 2015)

Fig. 18 Breathing Stone
Breathing Stone takes the user's pulse and generates an audio track to mirror their heartbeat.
(TechSpark, 2014)

In contrast to the earlier described devices, products and technologies that traditionally support COPD self-management are often clinically implemented with limited integration with daily activities and lifestyle. Examples shown below are Resperate (Fig. 19)

(Resperate, 2014), Expand-a-Lung (Fig. 20) (Expand-a-Lung, 2014) and Power Lung (Fig. 21) (Active Forever, 2014). Although these products may have significant benefits to breathless patients, the limited design contribution has resulted in a range of rehabilitation products that are not innovative in their approach or understanding of COPD patient's daily experience. This raises the design question; how can we learn about the user requirements within the initial stages of the design process? It may be possible to learn about the user requirements by utilising a qualitative methodology.

Fig. 19 Resperate
Worn around the chest, **Resperate** assesses breathing pattern and creates a rhythm to guide inhalation and exhalation phases
(Resperate, 2014)

Fig. 20 Expand-a-Lung
Expand-a-Lung is a manual device that requires individuals to breathe against a changing resistance
(Expand-a-Lung, 2014)

Fig. 21 PowerLung
PowerLung is a handheld resistive training device aimed at building respiratory muscle strength
(Active Forever, 2014)

In summary, current self-management strategies and pulmonary rehabilitation programs possess design related challenges. These include difficulties in monitoring patient progress outside of the formal environment, shared technologies and devices amongst groups of patients and a lack of personalised measures and responses.

While PLB aims to provide patients with a tool to manage their own feelings of breathlessness, patients must be well practiced and familiar with the technique in order to perform this effectively. Research in the area of PLB training and management has highlighted several shortfalls regarding the translation and use of PLB principles demonstrated within literature and bringing this to life within a patient's daily activity. Providing a personalised product that helps patients to understand and learn the principles of PLB over a period of time would be beneficial. Harmonica Therapy captures this idea by utilising an existing product to replicate controlled breathing principles.

2.7.4. Harmonica Therapy

Introduced within Section 2.2 (pp 17), an innovative response to pulmonary rehabilitation has seen hospitals and pulmonary rehabilitation centres in the United States of America investigating new avenues to teaching breathing control with Harmonica Therapy [refer to (Mayo Clinic Florida, 2013) (University of Michigan, 2015) (El Camino Hospital, 2014)]. These sessions invite patients to adjust their approach to controlled breathing by learning to play the harmonica in a group setting. The harmonica not only mimics the principles of controlled breathing principles like PLB but also provides a musical feedback and interaction not present within other training programs.

Fig. 22 The Harmonicats
CBS Denver, 2015
Image taken from http://denver.cbslocal.com/2015/03/03/colorado-patients-coping-with-copd-hum-on-the-harmonica-for-help/

The core benefit of practicing controlled breathing by playing the harmonica is the creation of forced conscious breathing, generating a pace and rhythm and the musical feedback. However, for a patient that is suffering from breathlessness, the inability to get a consistent sound out of the instrument, frustration at the time required to invest in the program, a potential delayed feeling of success and at times exacerbation of breathlessness feelings, Harmonica Therapy may be portrayed as unappealing.

To examine this concept more thoroughly, Alexander & Wagner (2012) conducted a study focused on capturing the effect of harmonica playing on both physiological and psychological aspects of both managing and rehabilitating from chronic breathlessness. Generally, this study was unsuccessful in verifying that playing a harmonica provided any of the benefits of paced breathing within COPD rehabilitation, yet glimpses of opportunity and potential were revealed. Overall, the researchers had difficulty recruiting, were unable to sustain substantial adherence to harmonica playing and participants demonstrated low levels of motivation. Due to the limited amount of data, currently there is little scientific consensus that an ongoing rehabilitative benefit can be achieved through current harmonica therapy programs.

Conversely, literature in the area of biofeedback and response indicates that auditory, visual and sensual feedback helps individuals to develop an awareness and voluntary control over their breathing patterns (Siwiak, Berger & Yang, 2009) (Yamamoto, Ikeda & Sasaki, 2008) (Marshall et al, 2011). This aspect was revealed within Alexander and Wagner's study as participants with COPD demonstrated an increase in the health related quality life component in the areas of role physical (+48%), vitality (+21%) and social functioning (+31%). From a physiological perspective, the standardised six-minute walk test was used as a performance measure. This test measures the distance that patients are able to walk on a hard flat surface over a six-minute period. At the conclusion of the study participants with COPD demonstrated an increase in their six-minute walking test results with an average increase of 25.5 meters. Consequently, the harmonica acts as a catalyst for design investigation regarding the adaption of harmonica principles and the alignment to breathing re-training. In particular, the design process may be able to harness the operational foundations of the harmonica but specifically respond to the needs of COPD patients learning to independently pace and control their varying breathing patterns. The harmonica provides glimpses of design opportunity as harmonica therapy uncovers the role of product interaction and experience within a COPD rehabilitation program.

A product which has begun to respond to these challenges is the Pulmonica (2013). The Pulmonica is a specially designed pulmonary harmonica that produces deep, resonant and meditative sounds that can be felt vibrating in the lungs and sinuses (Fig. 23). Designed for patients who want to receive the benefits of playing a wind instrument without any musical training, this product aims to empower patients to obtain the benefits of controlled breathing without the associated anxiety of the traditional harmonica. Promoted as an individual tool, the Pulmonica is currently marketed as a product to use independently at home. It appears within the Pulmonica product pack that there are instructions and online support networks to guide patients as to how to use the Pulmonica effectively. Conversely, the Pulmonica is similar to the harmonica in that it is reliant on the patient being able to create a consistent breath to produce the feedback. Furthermore, monitoring and feedback during practice is limited. Based on the current design, patients may not know how to correct or adapt their breathing during Pulmonica playing so as to improve performance.

A study has been conducted by Weiss, Keller & Casadevall-Keller (2015) for the purpose of validating the effectiveness of the Pulmonica within a COPD support group. The study had a small sample group of nine COPD patients; however it found statistically significant improvements in the six-minute walk test, forced expiratory volume, forced vital capacity and quality of life questionnaires over the eight group sessions. Conversely, it is acknowledged within the study that improvements may be attributed to other clinical programs or treatment, therefore the impact of the Pulmonica is non-conclusive. Equally, participants reported improved breathing through patient statements and feedback after using the Pulmonica.

Fig. 23 The Pulmonica
Pulmonica, 2013
Image taken from http://pulmonica.com/blog/?page_id=31

Although both products possess functional and motivational challenges, both the traditional harmonica and the Pulmonica provide direction regarding the use of products to promote controlled breathing patterns. Furthermore, studies performed in responses to these products continue to highlight the challenges associated with conclusively proving the benefit of pulmonary rehabilitation products. As there is no direct data collection during the use of both products, it is difficult to measure patient accuracy regarding the products intent or longer term breathing goals. Additionally, as the studies approach from a physiological and quality of life protocol, challenges related to rituals of use, patient interaction and continuous feedback are not necessarily captured within the study methods. If the studies were to be approached from a design perspective, factors related to patient interaction, technology, ergonomics and aesthetics could be explored more deeply.

In reviewing each product, there are common threads which warrant further investigation. Importantly, being musical wind instruments, patient interaction by blowing through a device creates a musical feedback. There is literature which suggests that music or rhythm can influence and control bodily movement including breathing patterns. Described as a pace maker, rhythm and rhythmic feedback may aid patients in sustaining controlled breathing patterns over periods of time. The following section will explore the attributes of the rhythmic pace maker and draw linkages with controlled breathing techniques.

2.7.5. Rhythm as a pace maker

This thesis opened with a narrative by Oliver Sacks (2012, pp.254) which described the phenomenon of entrainment whereby bodily actions are synchronised through rhythm. This narrative established the idea that breathing could be synchronised with rhythm and action. This section will introduce research which supports this idea.

Studies that measure coordinating performance have had differing results depending on the physical movement, the length of time that coordination can be held and the overall influence of coordination on respiratory performance [for more detailed review of this work see (Amazeen.P.G, Amazeen.E.L & Beek, 2001) (Elbert et al, 2002) (Decety et al,

1993) (Maclennan et al, 1994) (Babler & Kohl, 1996) (Siegmund et al, 1999) (Paterson et al, 1986) (Jasinskas, Wilson & Hoare, 1980)(Bechbache. R & Duffin.J, 1977)]. Equally, literature in the field suggests that physiological and respiratory coordination may offer measureable performance changes such as lengthening of breathing cycles, ability to alternate cycles depending on task requirements, or alterations to ventilation time [refer to (Hill et al, 1988) (Siegmund et al, 1999)].

In a recent literature review, Panigrahi and colleagues (2014) reviewed studies that use music as a management intervention for COPD. All 7 studies that were reviewed indicate that music can have an impact both on physiological and psychological outcomes. Generally it was found that music is effective in reducing anxiety and breathlessness with some studies demonstrating that music can influence both pulse and respiratory rate for patients suffering from exacerbations. In addition, a study performed by Liu and colleagues (2008) indicates that there may be evidence to support the use of mobile technology paired with music of an appropriate tempo to facilitate correct exercise intensity. This study reported strong results for patients with moderate to severe COPD with improvements in walking distance, inspiratory capacity and quality of life over a 1 year period.

A more direct interpretation of breathing control based on rhythmic outputs is illustrated within the product *Resperate*. Shown in Fig. 24, *Resperate* is a portable product which requires users to listen to rhythmic outputs through headphones and adjust their breathing to match the inhale and exhale patterns. The aim of the product is to enable a patient to synchronise their breathing to the tones and lengthen their exhalation phase. In doing so, the product measures a user’s breathing rate via the relationship to heart rate.

Fig. 24 Resperate
Resperate (2014)
Image taken from http://www.resperate.com

This product exhibits potential for monitoring and influencing breathing control, however the general outcomes and longer term benefits are not currently known. Furthermore, a patient's attraction and motivation to use the device has not been explored.

Introduced earlier, Harmonica Therapy combines many of the principles discussed. The harmonica acts as a point of concentration and reward as patients focus on breathing in a particular pattern and flow in order to make music. By focusing on breathing control and PLB through an object like the harmonica, the body may begin to recognise patterns, behaviours and positions. For example, the harmonica may guide patients on the best way to purse the lips to increase breathing control. Although harmonica therapy does not coordinate directly with physical movement, the principles of controlled and paced breathing that are practiced can be implemented with any task. Similar to Sacks' story, imagine if a patient became so well practiced in playing a tune on the harmonica that when they were vacuuming they were able to breathe this tune without needing the harmonica any longer.

To summarise, current self-management strategies and pulmonary rehabilitation programs are struggling to meet the needs of patients. Research spanning types of interventions, program structures and content and locations for rehabilitation have highlighted the need for products that promote and enable the patients to guide their own breathing control and pace.

2.8. Conclusion

At the beginning of the literature review it was stated that current studies are not explicit in the role of PLB within the pulmonary rehabilitation context. Additionally, surrounding literature which investigates the teaching, monitoring and measurement of PLB effectiveness are lacking. Through a thorough review of literature across the fields of PLB, COPD self-management strategies and pulmonary rehabilitation there were a number of key findings which influence the path for design exploration.

At an overarching level, the literature review exposes both the complexity of the rehabilitation context as well as the limitations of current tools to gather PLB related data. Specifically, the review reveals that there is not one tool or product which enables researchers to measure a patient's adherence to PLB nor investigate a patient's capacity to self-manage or improve their pacing technique. On the other hand, the literature indicates that the facilitation of PLB within the pulmonary rehabilitation context requires thoughtful design approaches.

Specifically, there are particular attributes from the literature review which lend themselves to design exploration. Firstly, the transition from a patient being considered a novice PLB user to an expert PLB is not well known. A variance in study methodologies and an inability to capture inhalation and exhalation phases over a period time makes it difficult to track PLB progression. Study methodologies that incorporate physiological measures alongside patient perception scales demonstrate limited improvement across both breathlessness symptoms, quality of life scores, social function and wellbeing. Product design, through the integration of appropriate technology, may be able to adequately gather this data. This may require a deeper connection between patients and designers during the early product design phases.

Discussed within Section 2.5, it was found that patients who assist in defining the problem space are able to convey product attributes and personal approaches to living with a chronic illness and reveal subtle yet important design cues. Given the current gap in the literature, involving patients in the preliminary stages of the design process is considered an appropriate avenue for design investigation.

Secondly, current PLB teaching and learning methods are largely reliant on face-to-face interactions with respiratory therapists. This becomes problematic as the pulmonary rehabilitation setting iterates between formal sessions and implementation within the home. Although studies indicate that face-to-face guidance and continuing feedback can lead to improved results, the expansion of pulmonary rehabilitation and self-management to the home environment requires further design consideration. Preliminary studies investigating the use of Smartphone technology and internet monitoring are beginning to demonstrate that carefully considered product interactions may be able to offer similar benefit to face-to-face interactions (Section 2.7.3, page 59).

In addition to this, the literature indicates that ongoing encouragement and the setting of goals is either facilitated within the pulmonary rehabilitation setting or left in the hands of patients to coordinate. By focusing on the independent practice of PLB within the home, there may be design scope to incorporate guidance modes or goal setting aspects within the product function, thus leading patients towards PLB practice.

In conclusion, the literature indicates that further exploration of PLB within the pulmonary rehabilitation setting requires the involvement of product design processes. In light of the research questions, a qualitative methodology involving patient interviews and discussions will assist in forming the design problem space and the subsequent design approach.

Informed by the literature review, the next chapter outlines a qualitative study methodology. This methodology will be employed to gather data from COPD patients who are currently engaged in pulmonary rehabilitation to provide responses to the research questions posed.

Chapter 3: Methodology

3.1. Introduction

The research objectives, as set out in Chapter 1, were:

1. Identify and characterise the attributes that have enabled patients to become familiar and confident in PLB practice
2. Develop a design proposal which addresses and explores these characteristics

The literature review established that the evidence for the use of PLB in the self-management and rehabilitation of COPD remains unclear. Furthermore, studies investigating respiratory function, breathing control, the experience of living with COPD and technology assisted pulmonary rehabilitation utilise differing measurement protocols. As a result, it is difficult to conclude as to the effectiveness of current strategies, the potential role of product technologies and how best to approach the integration of paced breathing methods. Literature continues to investigate the integration of PLB within COPD rehabilitation but the research questions remain unanswered.

Across COPD and chronic breathlessness research, common physiological measures include measurement of lung capacity through forced expiratory volume tests and improvement in the six-minute walking test protocol. The improvement or change in a patient's breathing reported by studies may be influenced by factors outside of the study protocol which may include medications, additional clinical attention, diet, differences in lifestyle and access to additional resources. As PLB forms one part of a patient program, it is difficult to ascertain and measure PLB associated changes accurately. Current research focusing on the cyclic effect of breathlessness, anxiety, depression, and quality of life captures the language and descriptors used by patients through qualitative means including semi structured interviews [see (Boot, van Exel, van der Gulden, 2009)], quality of life questionnaires, perception scales [see (Ries et al, 1995)] and patient specific case studies [see (Reticker, Nici & ZuWallack, 2012)]. These studies allude to the importance and impact of emotion, environment, rehabilitation programs and support networks but current studies are not explicit in the role of products in teaching or monitoring PLB.

From a design perspective this becomes problematic as the range of physiological values and user perspectives becomes complex, intertwined and difficult to comprehend. In particular, it is challenging to extract the design details of when, where, how and why of PLB implementation. Based upon the surrounding research context, it is not possible to respond to the research questions set for this study based on the literature review alone.

The design of medical products requires stringent care regarding safety and reliability but an equally important measure of their success is their alignment with the clinical needs of patients. Literature focuses on both understanding and addressing the practical issues concerned with the involvement of patients in design practice [refer to (Grocott, Weir & Ram, 2007)]. Specifically, a literature review conducted by Shah & Robinson (2007) focused on the benefits and barriers of involving patients in the product development process. This review found that patients were able to indicate conceptual deficiencies and potential problems in current and future products and were able to suggest appropriate changes and solutions to problems.

At this preliminary stage of research, exploration of the research questions requires a greater connection between the designer and the patient so as to reveal design problems. Drawing upon the work of Vaismoradi, Turunen & Bondas (2013) and Sandelowski & Leeman (2012) for direction, employing a qualitative methodology aims to explore the complex phenomena encountered by patients, resulting in rich contextual narratives. Given these explanations, this research took a qualitative approach, utilising a semi-structured interview methodology. The approach seeks to understand the particular interactions that form a patient's perspective of PLB within their daily lives. Interview questions relate to paced breathing products and technologies, gather patient suggestions and insights and focuses the design process towards patient led solutions.

A study was designed to capture a patient's understanding of their breathlessness as well as their views of products in the market. At the onset, the characteristics and barriers to interviewing patients were carefully considered. Within this chapter the study methodology and due diligence taken in regards to the patient cohort requirements will be detailed. This includes aspects relating to recruitment, location of the study and analysis of data.

The analysis of the interview data was conducted according to a thematic analysis protocol, a commonly used approach in the analysis of qualitative data related to both design and nursing research (Vaismoradi, Turunen & Bondas, 2013). The analysis process arranges patient extracts into categories defined by both the literature review and the emerging themes from the data itself. Performing the thematic analysis process identifies and brings together ideas, comments or insights across the data set which may be meaningless when viewed alone (Leininger. M, 1985).

This chapter will begin with an outline of the study, participant statistics and the data analysis protocol. Following on, the data will be presented within five overarching themes: (1) monitoring and feedback, (2) adaption, (3) routine, (4) motivation, (5) active learning. This chapter will conclude with an outline for the presentation of findings.

3.2. Study outline

The study outline considers the participant cohort, the recruitment processes, and the location of the study, the interview questions and the management of risk. The study design carefully considers the patient needs and the ethical requirements set by both the Illawarra Shoalhaven District Health, the overseeing human research ethics committee at the University of Wollongong and the University of Technology, Sydney.

3.2.1. Participants

Prior to designing the study methodology, it is important to consider the patient cohort. The involvement of COPD patients may pose some challenges and concerns due to patient ages, chronic breathlessness states and the influence of comorbid diseases. Therefore the study methodology and recruitment of participants must be carefully considered.

With these concerns in mind, a controlled design was used for this study. Participants were recruited from a university affiliated outpatient Respiratory Coordinated Care Program at the Shoalhaven District Memorial Hospital. Participants recruited from this program have been exposed to and partaken in the Shoalhaven COPD service model of care (Illawarra Shoalhaven Local Health District, n.d) which includes;

- Pulmonary rehabilitation (a 7 week program of education and exercise to improve functional capacity and development of symptom management strategies)
- Outpatient services including home based exercise programs and weekly maintenance classes
- Regular respiratory support group meetings
- COPD newsletters
- Care planning with specialist physiotherapists, occupational therapist and pharmacist

Generally, patients within the outpatient program have previously completed the 7 week pulmonary rehabilitation program and have been attending the outpatient programs for several weeks. As a result, the recruited patients are familiar with the pulmonary rehabilitation process, resources and tools available. These patients are best placed to evaluate current products and devices as well as anticipating additional requirements or needs.

A limitation of this approach is that these patients may have developed intuitive learning methods, may be familiar and well-practiced in PLB and may be satisfied with current tools or methods due to adaption. Patients may enter the interview sessions in a positive frame of mind without the burden of everyday experiences given that they are in a support environment. However, within the rehabilitation setting patients are encouraged to discuss and problem solve their daily experience and challenges. Patient contributions at this stage of the study indicate where improvements can be made based on informed experiences and perspectives.

The recruitment of suitable patients relied upon the specialist physiotherapist and the site based investigator. Both individuals are trained in respiratory disease and are familiar with each patient's respiratory function and stage within the rehabilitation program. Both the physiotherapist and the site based investigator were consulted during the ethics application process and were familiar of the study purpose and methodology.

The specialist physiotherapist identified appropriate patients attending rehabilitation. The inclusion criteria was based upon,

1. A confirmed diagnosis of COPD with activities of daily living limited by breathlessness
2. Adequate English language skills to be able to contribute to discussion
3. Able to provide written informed consent

12 patients participated in the study. Based on similar studies 10 – 15 participants is an effective number for discussion and analysis (Reticker, Nici & ZuWallack, 2012) (Antypas & Wangberg, 2014) (Chen et al, 2008) (Fraser, Kee & Minick, 2006). Using interview or focus group methodologies, similar studies captured detailed examples of a patient's daily experience, the variability of behaviours amongst the patient population and discussed how these behaviours influence technology design and implementation.
The site investigator collected demographic data from a rehabilitation file and extracted age in years, gender and primary diagnosis. A summary of demographic data for participants is shown in Table 4. The mean (SD) age of the participants was 75 (7.7) years.

	N = 12
Age (mean SD., years)	75 (7.7)
Male (%)	45
Primary diagnosis	
COPD	
Mild	4
Moderate	2
Severe	2
Emphysema	2
Lung cancer lobectomy	1
Obstructive sleep apnea	1

Table 4 Patient demographics

Patients were guided through semi-structured questions related to their perspectives on breathing management products. The discussions were audiotaped and transcribed verbatim for data analysis.

3.2.2. Managing risk

Development of the study methodology considered patient participation and patient requirements via the process of recruitment, the sharing of questionnaires prior to participation and the provision of support and supervision during the study period. The managing and organisation of data will be addressed separately.

Firstly, the Participant Information sheet was provided to patients when they were approached to participate and patients were informed that participation in this study was voluntary. Importantly, patients were advised that if they decided to take part and then change their mind, they were free to withdraw their information from the project at a later stage. If patients choose to withdraw from the study, their routine treatment, relationship with those treating them or their relationship to the Shoalhaven District Memorial Hospital would not be affected.

Secondly, the interviews were conducted by myself with the aid of the student supervisor. The questionnaires had the potential to invoke some emotional or psychological distress and it may have made it difficult for some participants to speak due to their breathlessness. Participants were made aware of the questions prior to the session commencing so that they could decide if these may cause them distress or if they required clarification regarding the study aims and purpose. Thirdly, the site investigator and the student supervisor were appropriately trained about the study protocol. The sessions were monitored carefully by the site investigator and the student supervisor and support was offered when required.

Lastly, the Illawarra Shoalhaven District Health, the overseeing human research ethics committee at the University of Wollongong and the University of Technology Sydney granted human research ethics approval for this study. Patient statements were altered to replace names where required.

3.2.3. Interview questions

Semi-structured interview questions acted as the basis for interviewing. The formal interview template is appended (Appendix 0, page 182). The interview questions were structured into 2 parts. Part 1 consisted of introductory interview questions related to breathing whereas Part 2 consisted of semi-structured interview questions regarding devices on the market.

There is quantitative data which confirms that physiological and comorbid disease impacts COPD disease progression and a patient's capacity to perform tasks [refer to (Rennard et al, 2002) (Bourbeau.J, 2009)]. However in framing the intricate needs of a patient, it is important to gather data regarding their perception of tasks. A complementary view of patient experiences offers beneficial product design clues and insights regarding the novel and changing dynamics of managing a chronic and progressive disease. Beginning with a broad discussion the questions that shaped Part 1 of the interview were:

- Tell me a little about your breathing day to day and what things you do to manage this?
- Are there things you avoid doing because of your breathlessness?

Once patients had reflected upon their daily breathing experience, Part 2 invited patients to focus more specifically on paced breathing and associated products. The initial question asked was,

- What does the term paced breathing mean to you?

For those patients who were unfamiliar with the terminology, pursed lip breathing or controlled breathing principles were explained to provide context. From there, patients were asked to respond to 4 products through the presentation of images.

A search was carried out of commonly used products and a short list of commonly utilised devices compiled. This list was chosen as it contained a cross section of user interactions, features and technologies. Due to the innovative nature of some products referenced within the study, all of the products could not be sourced to act as study examples; instead images of products were used. The use of images as opposed to physical examples of products posed limitations. The images illustrated certain functions or attributes of the product but were unable to represent all their features. In support of this, the interviewer provided verbal descriptions and surrounding context of use. These explanations were drawn from literature referenced in the earlier section (Section 2.7.3). Table 5 provides a summary of the images, descriptions and questions referenced within the interviews.

Image Presented	Description and Questions
 Image taken from <http://www.motherearthnews.com/nature-and-environment/how-to-fix-a-harmonica-zmaz79zsch>	Harmonica The harmonica is used within group therapy sessions to promote breathing control. By playing tunes on the harmonica, patients learn different breathing patterns and tunes. How would you feel about learning this as a part of a group? Do you feel that there would be challenges to doing this? Can you tell me a little about that?
 Image taken from http://www.resperate.com	*Resperate* *Resperate* generates rhythmic tones whilst measuring your heart rate. The tones adjust as your heart rate changes, with the tones guiding you to even, relaxed breathing. *Resperate* is attached to the patient's chest to measure their breathing. The headphones allow the patient to listen to the tones. Have you heard of something like this before? Can you tell me about this? How would you feel about using this kind of device? What concerns might you have? If you were to give it a go, how would you incorporate it into your daily life?
 Image taken from <http://www.zenytime.com/>	*Zenytime* *Zenytime* is a little device that is linked to an app on a phone or tablet. A person breathes into *Zenytime* and the games uses their breath rhythm to play a digital game. By learning to control and adjust their breathing, the person moves through the levels of the game. At the end of each session the game provide feedback about the persons breathing performance. Have you heard of something like this before? Can you tell me a little about this? How would you feel about using this kind of device? What concerns might you have? Can you describe what sorts of apps or online games you use at the moment? What do you like about them? If something like *Zenytime* was made available to you, are there particular times through the day when you might use this? Are there particular locations or places you might use this?

 Image taken from <http://http://vimeo.com/15450046>	*Aura* *Aura* sits on a flat surface and monitors the environment for signs of stress. When stress is detected *Aura* indicates that it wants to be picked up by glowing. *Aura* then guides the user through deep breathing exercises. This device is different to the others as it invites you to use it when it thinks you need a hand. What is your overall feeling towards this kind of device? In thinking about the device, do you think this device will help you with controlling your breathing?

Table 5 Summary of product descriptions and interview questions

The images and questions related to each product were presented consistently to the patients in the order shown above. Whilst it is recognised that the patient responses may be susceptible to the influence of ordering effect, the product imagery, function and features differ sufficiently to prevent confusion and complexity. Moreover, the interviews are semi-structured, which encourages discussion and comparison of product characteristics as they are presented.

3.3. Managing and organisation of the data

The data collected was in the form of dialogue recorded during the interview. Responses were transcribed and then analysed using the thematic analysis procedure. Thematic analysis resulted in 5 overarching themes as well as a series of codes, patterns and relationships between the data sets. The findings are presented within Chapter 4.

3.3.1. Transcription

A transcription service transcribed all interview audio. Due to the semi-structured nature of the interviews, audio was altered prior to transcription to discard personal stories that are not related to the focus of this study. Personal stories that are entwined within the conversation remained so as to capture reflective loops and important quality of life details. The verbatim record of the interviews reported context specific terminology and colloquial language. Strict verbatim sounds, stammers and false starts were not captured.

The interview was structured to guide the patients to reflect on their current breathing state, share their own personal management strategies and provide insight and opinion regarding product function and design. Patients may not consider themselves experts or knowledgeable in the field and therefore may not be able to answer specific questions or find appropriate terminology to describe an idea. By setting the interviews in a semi-structured manner patients and the interviewer had the opportunity to discuss, share and clarify responses. The resulting data set comprised of rich narratives and stories related to patient breathlessness experiences and perspectives.

3.3.2. Thematic analysis

Responses were analysed using the thematic analysis procedure described by Braun & Clarke (2006) and Leininger (1985). The general procedure is summarised in Table 6. Firstly, the data was read carefully to identify any initial ideas, patterns, observations, experiences and research insights. These were noted within a field journal.

Secondly, the data was coded into prominent themes using NVivo software. The initial coding process was informed by the work of Fereday & Muir-Cochrane (2006). The procedure involved recognising an important perspective or idea and encoding it prior to the process of interpretation. This resulted in a variance of codes that were not directed towards the research questions but may offer unexpected direction regarding the design context.

Phase	Description of Process
Becoming familiar with the data	Transcription of all audio data and the noting down of initial ideas, observations and experiences
Generating initial codes	Coding interesting features of the data in a systematic way across the data set, collating data relevant to each code
Search for themes	Collate codes into potential themes and gather all data relevant to each potential theme to obtain a comprehensive view of the data
Reviewing themes	Check if themes work in relation to the coded extracts and the entire data set in order to generate a thematic map of the analysis
Defining and naming themes	Ongoing analysis to refine specifics of each theme and generate clear definitions
Produce report	Select compelling extract: relate back to the research questions and the literature in a scholarly manner

Table 6 Phases of thematic analysis
Braun & Clarke, 2006
Leininger. 1985

Subsequently the codes were grouped and assessed for prominent themes. A theme was defined as an extract, thought or idea that brought meaning and informed the research context. The themes captured and unified the experiences of patients into meaningful relationships (DeSantis & Ugarriza, 2000). It is noted that patterns or recurring topics were not assessed as a theme. Patterns were assessed as recurrent behaviour or perspectives, which contributes to a theme. The coding and thematic analysis phase resulted in 5 key themes, introduced in the next chapter.

Clustered under the key themes, subthemes and micro-patterns were identified and assessed. Although frequency of code may give an indication of importance regarding the overarching patient perspective, frequent use of a word or phrase might reflect a greater willingness or ability to talk about the topic (Vaismoradi, Turunen & Bondas, 2013). To avoid reliance on code frequency, subthemes and micro-patterns were configured and assembled to reflect a novel understanding of PLB. The themes were clustered and assigned phrases to describe the meaning that underpinned the theme (Sandelowski &

Leeman, 2012). The phrases and terms assigned used language that is meaningful and relevant to both the medical and design disciplines.

The thematic analysis process concludes with the presentation of the findings. The identified themes and sub-codes will be presented alongside patient extracts and current literature within Chapter 4. The results of this study establish a basis for product design investigation directly related to PLB.

3.4. Conclusion

The literature review determined that the evidence and support for the use of PLB in the self-management and rehabilitation of COPD remains unclear. Previously conducted research investigates respiratory function, breathing control, the experience of living with COPD and technology assisted pulmonary rehabilitation, however across the studies the measurement and analysis protocols differs. As a result, it is currently difficult to conclude as to the effectiveness of current strategies, the potential role of product technologies and how best to approach the integration of PLB methods

Guided by the research questions, this research takes a qualitative approach to gather interview data describing the complex experiences and perspectives held by patients learning to use PLB within their daily lives. The study methodology carefully considered the particular requirements of the patient cohort and complied with the guidelines set by the relevant human research ethics committees.

The data was transcribed and analysed according to a thematic analysis protocol, resulting in 5 overarching themes. The presentation of the findings corresponding to each theme, the surrounding literature and the research questions will be discussed in Chapter 4.

Chapter 4: Results

4.1. Introduction

The analysis of the data from the interview of 12 COPD patients was conducted according to the analysis process outlined in Section 3.3.2. The initial coding process involved recognising important perspectives or ideas. These were then grouped and assessed for predominant themes. This chapter includes quotes and diagrams from the patients to support the analysis made and concludes with collated results that strongly suggests that patients would benefit from a product which measures, compares and communicates breathing phases and patient adherence to PLB.

Connections between common themes emerging from the data were evident in the responses offered by patients interviewed. This has resulted in 3 layers of thematic analysis. Firstly, PLB associated knowledge and implementation strategies described by patients revealed 3 differing phases of PLB. These are referred to as novice, passive and expert. Based upon the patient statements and discussions, the patient cohort were categorised by a PLB phase. The second layer of analysis involved the identification of the themes as a result of the general patient discussions and descriptions. These were linked to each of the PLB phases. Finally, the third layer of analysis was specific to the product relationships to each theme. From these themes a number of relationships were formed which gave direction for product conceptualisations and development.

4.2. Overview of themes

As stated previously, there are 3 layers of thematic analysis, which has resulted in 5 themes. The data analysis confirms some aspects discussed within the literature review. These will become clear within the following discussion. The literature review indicates that for new product development we can expect that there will be a need for further understanding regarding,

- Monitoring & feedback
- Adaption
- Routine
- Motivation
- Active Learning

By analysing the data at each thematic layer, these 5 themes have emerged which relate directly to both patient experiences of PLB and the features and attributes required for a product that guides effective PLB practice. These themes will now be explained.

Monitoring and feedback

Although PLB literature is not explicit in the use of the term Monitoring and Feedback, this terminology resonates within design and technology literature [refer to Section 2.7.3]. Studies associated with the role of technology in assisting with the rehabilitation process determine that real-time monitoring and feedback of patient behaviours can influence patient performance (Beatty et al, 2013). Digital or technology driven product solutions are not yet utilised within PLB practice, however analysis of current methods such as face-to-face monitoring should suggest where improvements could be made. Furthermore, referencing a range of monitoring and feedback methods displayed in the harmonica, Resperate, Zenytime and Aura will assist in guiding the subsequent design process.

Adaption

The notion of patient adaption to both paced breathing and change in task requirements resonated throughout the literature review. Specifically, the idea of adaption was introduced through the task of vacuuming (Section 2.5.1). It was hypothesised that characteristics of the vacuum cleaner could be designed to reduce the effort required by COPD patients. Alternatively, it was suggested that controlled breathing techniques such as PLB could be adapted to the task. By providing a breathing tool, patients could use PLB across a series of tasks. But until this time, a patient's personal recount of personal adaption or the utilization of tools to adapt has not been captured. The analysis of the interview data should seek to establish the impact of adaption on both a patient's quality of life and their capacity to implement PLB.

Routine

Stemming from adaption, the formation of personal self-management behaviours is rooted in routine (Chen et al, 2008). In particular, the self-efficacy stages defined by Antypas & Wangberg (2014) identifies that maintaining target behaviour despite barriers or challenges enables patients to believe that they can succeed regardless of setbacks. The maintenance of a target behaviour is most likely to occur through formation of routines. Understanding patient routines and management approaches are described within the data and will inform the design process, particularly in the understanding of rituals of use.

Motivation

It was assessed within the literature review (Section 2.6.2) that the aspects or key features that motivate a patient to practice PLB are not well known. However, given that there may be associations between monitoring and feedback and a patient's motivation, there may be occasions or statements presented within the data that informs this theme. Highlighting these occurrences will guide the monitoring and feedback mechanisms implemented within the design process.

Active Learning

Currently the methods by which a patient learns PLB is not well known, however it is suggested that patients learn via either face-to-face sessions with respiratory specialists or through online sources such as patient information sheets. As patients are introduced to alternative products, how they respond to changes in learning methods and if they prefer certain methods or styles may assist in establishing a new design context.

The presentation of the results will begin with the first layer of thematic analysis, the identification of PLB phases.

4.3. Pursed Lip Breathing (PLB) phases

Current literature encourages the use of PLB to reduce the immediate effect of breathlessness whilst enabling patients to self-manage their breathing demands in accordance with their physical needs (National Heart, Lung and Blood Institute, 2010) (Lung Foundation Australia, 2012). However, as noted within the literature review (page 17), there is limited evidence regarding the short and long-term impact of using of PLB for both physiological and quality of life measures.

A complementary view of patient experiences offers beneficial product design clues and insights regarding the novel and changing dynamics of managing a chronic and progressive disease. These views were sought by asking patients, “What does the term paced breathing mean to you?”

Analysis of the transcribed interviews indicates that patients typically fall into one of three groups when describing their PLB practice and implementation. The first group, categorised as experts, comprises of patients that describe, demonstrate and implement PLB techniques within everyday life. The second group, the passive users, includes patients that are aware of PLB but have little interest in practicing or implementing PLB principles. The third group, described as novice users, encompasses patients that are within the early stages of PLB learning and actively describe their PLB implementation strategies. Table 4 (page 80) shows the participant number distribution. Patient statements and examples will be drawn upon to verify each group.

Patient distribution across PLB Phases	
Patient cohort size	12
Novice	3
Passive	7
Expert	2

Table 7 Number of patients in each PLB phase

Given that PLB adherence and performance mechanisms are currently not objectively measured within the literature, little is known as to how a patient may transition between being a novice and an expert, the time and resources required and the underlying reasons as to why PLB is effective for some and not for others. Particular statements within this study provide insight regarding the differing groups and help to shape design direction. Of particular interest are the differences between patients in the expert and the novice group. What are the attributes, learning techniques and training methods that have enabled patients to become familiar and confident in PLB practice? How can product design ease the transitional process between the experts in the first group and the novices in the third? And how can a patient's performance be measured so as to determine their PLB effectiveness?

Those who demonstrated a strong reference to paced breathing and PLB practice were categorised as PLB experts. Through the interview dialogue, these patients suggest that they self-manage their breathlessness by integrating PLB principles within daily activities. One expert PLB patient stated,

> "I go through my breathing exercises in through the nose and I purse out through my lips and wait until it comes good and I can sort of breathe myself asleep I suppose".

Another patient noted,

> “I know how to pace myself breathing wise, you know in through your mouth and out through your pursed lips and just slow down a bit. And it seems ok”.

Focusing specifically on the shape of the lips and mouth, a patient remarked that not pursing the lips during a panicked breathing state effected their capability to control the breath,

> “Yes pursed lips: nice pursed lips because if you go [respondent breathes out, open mouthed] you’re trailing it straight out and you’re not getting the benefit in a panic mode”.

For expert PLB users, these statements indicate that PLB influences their capacity to self-manage and suggests that patients who are familiar with PLB principles may be more confident in using the technique during times of breathing discomfort or stress. Although the interviews were not filmed, the audio transcriptions reveal that these patients were able to both describe and demonstrate PLB principles, indicating that they can not only adhere to PLB guidelines but also understand the reasoning behind the effectiveness of PLB.

The successful understanding demonstrated by patients may be attributed to the face-to-face teaching received within their pulmonary rehabilitation sessions, with patients indicating that a member of staff introduced them to the technique. Additionally, it is suggested by patients that the continued monitoring and feedback provided by staff during exercise enabled patients to maintain focus at times of discomfort or stress. This is verified by a patient stating,

> “Just gradually [therapist name] has shown me to slow the breathing down or [therapist name] has. But at the start of October I’m going on to a two day program with them”.

Monitoring and feedback is a theme that will be analysed in further detail later in this chapter, still it is important to acknowledge the role of face-to-face monitoring and feedback provided by staff during PLB practice. From an interaction product design perspective, this offers an interesting avenue for exploration. How can a product guide patients through the PLB principles and how can the product teach them correctly? Can a product supplement or replace face-to-face teaching of PLB? Can a product teach patients to PLB in different circumstances and adapt to tasks?

Expanding on the interactional aspects of PLB and the relationship to product design, an interesting finding was the reference by patients to pace. Considering this in light of product interaction, it is important that patients are able to control the pace of PLB so that they are receiving adequate airflow and do not feel breathing stress. Although patients indicate that they have inherent sense of breathing pace, a member of staff may have guided this during rehabilitation. Allowing patients to set their own pace but then provide a product which will guide them, much like a teacher, to the correct PLB pace may be an appropriate outcome.

Turning attention to the novice PLB group, it was found that these patients struggled to practice or implement PLB. Based on patient information sheets (Section 2.6.1, page 196), patients should aim to pace or gain breathing control prior to commencing tasks and continue with this breathing pace during the activity. Despite this, patients within the novice group may not be aware of their breathing limitations or the potential consequences of not implementing these strategies. An experience like this was described by a patient as,

> "Simple things; having a shower; I can have a shower and dry myself, I can get dressed and I'm panting like an old billy goat. I think whether that's just because I'm moving my arms all the time, I don't know. I think that's what it is. If I have to bend down to put my shoes on and my socks on, as soon as I get up, you've got no idea. It takes me about 30 seconds before I sort of get able to breathe again you know".

For this novice patient, pacing their showering and dressing movements to controlled PLB may help in reducing their breathing discomfort. Effective PLB may also be able to reduce the recovery time described by the patient.

The findings of this research support the literature within the field. In particular it becomes evident that although we may be able to classify patients into categories of expertise, the requirements which enable effective PLB remain unknown.

4.4. Context specific instances

Now that the patient cohort has been categorised into the PLB phases, the second layer of analysis is presented. This layer of analysis involved the identification of themes as a result of the general patient discussions and descriptions. Patient extracts and statements are referenced to support the identification and description of the theme. Referenced above each patient statement is the PLB phase in which the patient was earlier categorised. The themes will now be discussed in further detail. .

4.4.1. Theme 1: Monitoring and feedback

Patients may engage with multiple products that provide monitoring and feedback. Two patients drew on their experiences of other products to explain their understanding of monitoring and feedback principles and aspects that are helpful to them. The first patient refers to their oxygen cylinder and states,

> Novice
> "I've got an oxygen cylinder and it pulses and you can hear it when you breathe, you can hear that it's pulsing"

For this patient, hearing the pulsing feature during breath provides them with a feedback mechanism related to their breathing performance. The patient does not go on to elaborate on how effective the feedback is, however this statement does suggest that patients are aware when feedback and monitoring aspects are present and active.

Similarly, another patient refers to their Spacer device which provides feedback on their breathing performance. The patient said,

> Passive
>
> "I mean one of my Spacers, the one I carry with me, which makes a sound if you're not breathing the right way"

A simple audio feedback demonstrates to the patient in a short amount of time that they need to adjust or change their breathing. However, this feedback may be limited as it might not then educate the patient as how to make the correct change. As a result, some feedback mechanisms may be helpful in raising awareness to the patient that there is a problem but might not show the patient how to respond effectively.

These statements highlight interesting interaction design problems. In particular, it is important to not only consider the mode in which monitoring and feedback will take place but also the limits, inclusions and exclusions of the monitoring and feedback mechanisms. For example, will the mechanisms highlight all breathing faults, will the feedback occur incrementally or in real-time and how will feedback adjust to personal limits?

4.4.2. Theme 2: Adaption

The theme of adaption responds to patient statements and comments related to changes in daily activities, problem solving and alterations to products or tools. Stemming from literature which describes a patient's experience of living with chronic breathlessness (Section 2.5), this theme provides personal accounts regarding the ways in which patients consciously or unconsciously adapt their experiences and circumstances.

Generally patients used positive language to describe their self-management and rehabilitation experiences, however patients within the novice stages of PLB described complex day to day challenges and feelings of depression and anxiety. In particular, one patient explained their challenges in learning to adapt daily tasks as,

> Novice
>
> "I only have light emphysema evidently but I still have a lot of problems. Simple things; having a shower; I can have a shower and dry myself, I can get dressed and I'm panting like an old billy goat. I think whether that's just because I'm moving my arms all the time, I don't know. I think that's what it is. If I have to bend down to put my shoes on and my socks on, as soon as I get up, you've got no idea. It takes me about 30 seconds before I sort of get able to breathe again you know. Just simple. I can walk; I come here and I can walk a kilometre, no worries. These simple things are driving me nuts, just the very simple things in life. But I don't know how to solve it. They keep telling me if I go to put my shoes on lift my feet up. I can't even lift my bloody feet up.
>
> When I was first diagnosed with it I went into depression mode really bad because my knees were playing up already; they've been playing up for about three or four years now and I was that depressed. I was really depressed. I suffered from anxiety only for the fact that I couldn't accept that I had this problem".

The literature suggests that patients suffer from depression and anxiety throughout various stages of the disease progression (Section 2.5.1) (Boot, van Exel, van der Gulden, 2009) (Mosenthal & Lee, 2002) (Reticker, Nici & ZuWallack, 2012) (Janssens et al, 2012). Given the above statement, there may be a relationship between a patient's capacity to understand their disease state and adapt effectively as their disease progresses. Therefore, those patients who are able to continuously alter their tasks may suffer from fewer occurrences of depression and anxiety. The relationship between adaption of tasks and a patient's feeling of depression and anxiety requires further investigation, however at this preliminary stage of design research there may be scope for product design concepts which aid in adaption of breathing to tasks. This idea is supported by the concept of PLB which encourages patients to perform tasks by adapting and controlling their breathing and tasks requirements (National Heart, Lung, and Blood Institute, 2010). (Lung Foundation of Australia, 2012).

Patients within the expert stages of PLB confirmed that their capacity to learn and adapt to changing requirements appears to be more advanced than those within the novice group. These patients reported new behaviours or routines which allowed them to overcome these complex daily challenges such as showering and dressing. Examples of these statements will be discussed further within the theme titled Routine (Section 4.4.3, page 100).

In addition, these patients tended to have a positive approach to self-management and did not communicate feelings of anxiety or depression. One patient remarked,

> Expert
>
> "And that's why I try not to let this stop me from doing things. I just have to learn to do them a different way".

Another patient commented,

> Expert
>
> "Yeah I try not to let it stop me from living".

This may be strongly associated to feelings of disease acceptance, a patient's capacity to overcome change and the promotion of independence that comes from effective self-management. For recently diagnosed patients, acknowledging the change in moving from an independent, self-sufficient life to a life of relearning and adaption may influence a patient's capacity and speed of learning. In light of these findings, consideration of new PLB teaching tools and methods reveals an opportunity to design a product that promotes independence and self-learning through adequate guidance. A design challenge would be determining what constitutes adequate guidance and in what form this is presented.

4.4.3. Theme 3: Routine

Acknowledged by the literature, living with breathlessness not only limits a patient's ability to exercise but also to carry out daily activities (Jones. P, 2007) (Boot, van Exel, van der Gulden, 2009) (Mosenthal & Lee, 2002) (Reticker, Nici & ZuWallack, 2012) (Janssens et al, 2002). Although self-management strategies and interventions place a strong emphasis on developing self-efficacy, self-management of breathlessness is influenced by social and environment contexts (Gallant. M, 2013). At times patients are placed in challenging circumstances where they must create and adhere to a management routine but also be proficient in adapting their routine should their breathing requirements change.

An example highlighted by 3 patients during the interviews was the influence of weather on their feelings of breathlessness. This becomes problematic for patients, as they may have planned to exercise on that particular day, attend a pulmonary rehabilitation session or participate in a social event. Therefore, routine may play an important role in developing positive self-management and self-efficacy but a patient should be encouraged to learn and adapt their routine.

Following on from the theme of adaption, patients reported that they adapt tasks to meet their breathing requirements. Examples provided include showering, vacuuming and gardening. Overall, patients were able to explain in detail their daily activities but few explained an overall management approach. Still, one patient mentioned a general pacing strategy stating,

> Novice
>
> "I pace myself; I'll do a little bit then I'll have a break, then I'll do a little bit more, have a break".

Although the majority of patients did not describe a daily planning or pacing strategy this does not necessarily indicate that they do not approach their daily routines in this manner. It may be that their self-management behaviour is tacit and intuitive. From a design perspective, exploration of rituals could be investigated further so as to uncover effective adaption techniques being used by patients. In doing so, the differences between a novice and expert patient might be better defined.

An example of a daily ritual as described by a patient is extracted below,

> Novice
>
> "Actually I've worked out now that I take the Spacer to the bathroom and when I get out of the shower I put the bathrobe on because it absorbs some of the water, but I have my spacer then. And then if it's still excessive when I finish I can have it again because I can have it up to 10 times a day".

This particular example demonstrates that patients combine tools and strategies to suit their requirements. For this patient, using a bathrobe and the Spacer (see definitions) together helps in managing the task of showering. This is interesting as products may be designed for a specific task or function but take a new meaning or purpose when integrating within a patient's routine. During the design process, it is important to consider the overarching and specific environments, contexts and rituals so that the product can be adapted to a patient's routine effectively.

A differing example of routine is determined by exercise. In structuring an exercise program within the home, a patient described their routine as, Passive

"My walking at home is around the clothesline. I have to walk down there, through to the garden path, round the clothesline twice, down to the back fence, across there, up that side, around the clothesline again, up to the other side of the house and repeat that".

For this patient, developing a tangible reference to measure and track their performance may not only solidify the exercise routine but may also act as a motivational element. The theme of Motivation will be discussed next, but firstly this example further indicates that integrating a strategy or tool into a daily activity or routine can help patients to bridge the gap between formal rehabilitation sessions and self-management.

A helpful characteristic of routine and planning is that patients are able to compare breathing performance over a series of day-to-day circumstances and specific tasks. Without planning or routine, patients may have otherwise been unaware as to the reasons why their breathing changes are occurring.

Within the literature review it was considered that breathing could be controlled or regulated in line with a task (Section 2.7.5). The example given was that slow, paced vacuuming could be established by listening to a slow, melodic tune (Section 2.5.1). Yet when considering the variation in tasks and the number of routines a patient may perform, could the same melodic tune be applied across a number of tasks? Or could patients have a library of tunes that they access for varying tasks and activities? And how do patients match their breathing to the pace of the music?

Moreover, suppose if a product assisted patients in learning a PLB rhythm or pattern that supported them to adequately perform a variety of tasks. The breathing pace used for vacuuming could also be the breathing pace used for showering and dressing. This may result in the routine being the practice of PLB rather than forming routines based on tasks. This idea could be likened to a pianist practicing melodic scales to improve their performance of a variety of tunes. These design cues and ideas will be discussed further within the next chapter.

4.4.4. Theme 4: Motivation

Within the literature review it was identified that understanding the factors that influence a patient's motivation to adapt tasks and implement self-management interventions such as PLB would benefit the product design process (Section 2.6.2). However, the literature also reveals that the aspects or features which motivate a patient to practice PLB are currently not well known.

Extracts of discussions and statements provided by patients during the study provides insight into some of the aspects of patient motivation. The patient cohort expressed a motivation to self-manage their symptoms based on their personal knowledge of their breathlessness and emotions. Even patients who struggled with aspects of self-care or performing activities expressed a desire to overcome the challenges. Nonetheless, there was little insight provided within the discussions, which indicated how a patient would overcome their challenges. The initial desire and motivation to self-mange may be high but the capacity for a patient to continue to motivate during self-management is not revealed.

Patients tended to describe positive actions through exercise. One patient explained,

> Novice
> "I just feel good in myself doing some exercise".

Another patient combines the guidance of routine with the ongoing motivation to maintain their exercise capacity and states,

> Passive
> "I haven't been for a few weeks and I noticed not coming, not doing the exercises and how you deteriorate and that's why I am back this morning".

As the literature suggests, there may be a strong association between routines, exercise and motivation to self-manage (Cambach et al, 1997). However, the translation of skills learnt within pulmonary rehabilitation must be formed into a daily routine by patients over a longer period of time. As a result, there are discrepancies and uncertainty regarding the length of time that a patient may be motivated to perform exercise activities (Johnson & Grimmer-Somers, 2010). As this particular study was not focused on motivational aspects of patient learning and self-managing, further studies are required to understand the relationships between motivation, routine and pulmonary rehabilitation activities.

Stemming from this, there is an interesting relationship between motivation and product feedback. Earlier, the possible impact of products in forming patient routines was discussed in reference to patient statements. In this circumstance both the oxygen cylinder and the Spacer provided direct feedback cues so that the patient could correct or change their behaviour whilst performing the task. It is anticipated that this form of feedback, through its learning and correction techniques, encourages and motivates patients to continue to stabilise or improve their performance.

However, when presented with the 4 products for review, the patient groups approach to monitoring and feedback features was hesitant. This may have been due to the form of the monitoring and feedback, for example via the Smartphone game, or that a patient's motivation may be founded upon results delivery. Initially patients appeared motivated and interested to learn about the product features and benefits, with 12 instances noted for "give it a go". However it is noted that patients may become unmotivated quickly if results are not immediate. This circumstance was evident in the study conducted by Wagner & Alexander (2012), who recorded significant attrition rates during their harmonica sessions.

At this time, the data does not indicate how long a patient may be motivated to perform a set of tasks or engage with a particular product. Although it would be tempting to conclude that a patient would continue to be motivated as long as results were gained, current research suggests that appropriate product interactions, challenges, goals and feedback should be incorporated within the product to maintain motivation (Beatty, Fukuoke & Whooley 2013) (Bort-Roig et al, 2014).

A limitation of this study is that the aspects of motivation cannot be unravelled further. Despite this, patient comments reveal attributes for product design development. Self-knowledge and a patient's capacity to internally recognise and monitor their performance indicate that continual feedback and reflection plays an important role in a patient's self-management journey. Specifically, patients may be more conscious of their breathing but may not know how to make the correct adaptions or corrections. Referring to the patient who internally recognised that not exercising for a few weeks was impacting their breathing performance, a product solution which kept the patient on track regardless of face-to-face contact may improve a patient's adherence to the rehabilitation process.

Although the data did not reveal short-term or long-term motivational behaviour patterns, product design has an opportunity to incorporate differing interaction methods to track and engage patients to continue rehabilitation. These types of interactions and designs are increasingly seen in other research areas such as stroke and Parkinson's disease rehabilitation (Azulay et al, 1999) (Morris et al, 1996).

When approaching the motivational aspects of learning PLB, the product design process should consider the strong relationship between routine, adaption and monitoring and feedback. Products create an opportunity to deliver appropriate and well-positioned feedback during PLB, which enables patients to adapt behaviours, learn new techniques and embed routines. In doing so, patients might be motivated to continue to develop PLB techniques during exacerbations, challenging circumstances and disease progression.

4.4.5. Theme 5: Active learning

Formal education, particularly in the management of breathlessness, largely occurs within the pulmonary rehabilitation phase of support (Cambach et al, 1997). Consequently, there is potential for an education gap between patient diagnosis and the patient reaching pulmonary rehabilitation.

This quandary was highlighted through an examination of patient information sheets related to breathing control and PLB strategies (Section 2.6.1, page 47). During the literature review it was highlighted that the information sheets provide knowledge, however patients may face difficulty in interpreting, learning and embedding these strategies. At that point it was signposted that a product or tool which not only facilitates the acquisition of knowledge but also assists in the embedding of that knowledge within the self-management phase may lead to improved breathing control prior to a patient reaching pulmonary rehabilitation. However, prior to proposing this type of solution, it is important to understand the patient's perspective regarding the benefits of face-to-face pulmonary rehabilitation.

The patients interviewed were participating in formal rehabilitation resulting in face-to-face contact with respiratory specialists. Education methods during these sessions as described by the patients included demonstration of products, breathing techniques and guidance within in a face-to-face context. Statements provided by patients include,

> Passive
> "Here they taught me about the Spacer which is marvellous"

> Passive
> "Part of that (rehabilitation) is education. Learning to breathe properly"

Within the discussions it was not explicit as to whether patients received education from resources outside of the pulmonary rehabilitation context, however when questioned about their knowledge of PLB, 8 out of the 12 patients indicated that they had learnt the technique within the formal setting. This finding demonstrates that PLB education is strongly associated with face-to-face instruction.

Despite this, patients generally expressed a desire for tools that would help them self-manage their breathlessness. In particular, patients who were in the early stages of PLB learning appeared to be more likely to seek alternative options and new ways to self-manage. Examples of patient statements surrounding knowledge of market solutions and innovations include, Novice

"There has to be something coming out soon that will be helpful. And getting it out to the public where they are aware of it because a lot of things you are not aware of"

Those patients within the early stages also made reference to monitoring tools and devices such as the Fitbit or Smartwatch. Although it was not necessarily evident within the discussions as to how these patients believed the products would benefit them, there was an inclination that these patients were seeking products which would provide integrated and regular feedback. This idea resonates with the themes of Adaption and Routine and Motivation which associate ongoing monitoring, mentoring and guidance with improved respiratory performance and quality of life.

4.4.6. Summary of findings

To summarise the above analysis, there is a strong association between the novice COPD users and the themes of monitoring and feedback and routine. It is not surprising that monitoring and feedback, particularly regarding the learning of PLB was a prominent theme for the novice group. It was initially anticipated that novice users required ongoing monitoring and feedback in order to perform PLB and the data supports this idea. The forming of routines by the novice group at this stage appears to be intuitive. The data was not explicit in how these routines were formed.

There were subtle suggestions made by the novice group regarding their integration into daily living principles, motivation, education and adaption. These suggestions reveal that there may be underlying need for tools or strategies which help a patient to bridge the gap between the theory of PLB, their current habits and what may motivate them to improve their self-management capacity.

On the contrary, the passive PLB group also subtly suggested ideas towards motivation and education. It may either be that these patients have moved into the unconscious management phase and therefore these ideas are not front of mind. Or, it may be that the passive group feel similarly to the novice group but are unable to articulate their experience or needs.

Lastly, the expert group recorded the fewest number of relevant statements. It may be that their relationship with PLB and COPD self-management has become tacit. There was a relationship between the expert group and adaption, however these statements provide little direction within the product design domain.

Although this second layer of analysis has provided insight regarding related themes and the patient PLB phases, the statements do not lend themselves to product conceptualisations. By presenting 4 products to the patient group, product features and attributes can be examined in reference to the themes. This analysis falls within the final layer, product specific data.

4.5. Product specific data

The use of images as opposed to physical examples of products poses limitations. The images illustrate certain functions or attributes of the product but are unable to represent all their features. In support of this, the interviewer provided verbal descriptions and surrounding context of use. These explanations were drawn from literature referenced in the earlier section (Section 2.7.3, page 59).

The following results and patient extracts are presented in reference to the particular product, with each extract further categorised by theme.

4.5.1. Harmonica

Harmonica therapy was introduced within the literature review (Section 2.7.4, page 65) To recapitulate, the harmonica acts as a method for the introduction of PLB and controlled breathing techniques within either a social pulmonary rehabilitation setting or independently at home. Promoted due to its social interaction, cost effectiveness, recognisable form and feedback mechanism, the harmonica offers inspiration and direction for new modes of breathing practice.

As mentioned, the core benefit of utilising the harmonica for use with COPD patients is the creation of forced conscious breathing, generating a pace and rhythm and the provision of feedback through music. The use of the harmonica as a rehabilitation product promotes social interaction, provides a cost effective alternate to clinical tools and has the added benefit of being recognisable and intuitive for patients. However, as highlighted earlier, the use of the harmonica in its current state may not meet the requirements of patients within the pulmonary rehabilitation phase. In particular, patients within this phase of learning may not be able to produce a consistent sound from the instrument, may shows signs of frustration due to slow results and might fear that the investment of time is not aligned to their daily life goals.

The harmonica was investigated further by Alexander & Wagner (2012) to determine if it was appropriate for the pulmonary rehabilitation setting. This particular study was referenced earlier (pp.65). In summary, it was found that the association between playing the harmonica, improvements in paced breathing, physical functioning and quality of life were unsubstantiated. On the other hand, it was noted that the harmonica reveals opportunities for product design exploration, particularly in relation to guiding, monitoring and measuring of controlled breathing techniques.

Introducing the harmonica to patients during the interviews revealed mixed ideas about the use of the harmonica within their pulmonary rehabilitation program. Below (Fig. 25), lists patient statements and ideas related to the use of the harmonica within both a pulmonary rehabilitation setting and independently.

Mother Earth News, n.d.
Image taken from
<http://www.motherearthnews.com/nature-and-environment/how-to-fix-a-harmonica-zmaz79zsch>

“You can’t carry the harmonica with you all the time”
“Trust me, you wouldn’t want to hear me” –
“I wanted to because there was a harmonica group”
“I would try it but I would have to be in a room by myself. I wouldn’t want anybody to listen to how I go”
“Very tone deaf”
“You would need a lot of air to do that”
“I’d rather physical work”
“Get some notes out of it, was just a dead end”
“It would make your lungs work a lot more”
“I think at home first, maybe later on in a group you know. But I think at home would be the best place to start on it with whoever was starting you off”
“I’d probably be a bit embarrassed but yeah, I’d give it a go. I’d like to be able to play it”
“I think you’d be better doing it as a group. I would probably do it at home but I think probably when you started it would be better as a group to you know, interact with one another and you’ve got a physio there to keep an eye on you to make sure you’re doing it right”

Fig. 25 Patient statements in reference to the Harmonica

Generally, the patient group's attitude towards the harmonica varied from enthusiastic to hesitant and disinterested. Some patients were able to explain their previous experience or understanding of the harmonica and its relationship to improved breathing function whereas others focused on their perception of being unable to play effectively given their current breathing function.

An initial concern raised by a patient was the amount of air required to play the harmonica. This indicates that patient familiarity with the product can act as an encouraging or unhelpful attribute. On one hand, the patient group may able to understand the concept and the direct relationship to their breathing, yet on the other hand it appears that some patients possess a predetermined notion of whether or not they can play the harmonica effectively. This appears to influence some patient's acceptability of the product within the rehabilitation and self-management context.

Design adaptions that might respond to this concern include reduction to the amount of effort required to play the harmonica via changes to the product material, geometry and configuration, modification of the product form so it appears simpler and the introduction technology that teaches the patient how to play the harmonica effectively.

Leading on from this, another concern discussed by patients was practicing the harmonica in a group setting. At this introductory level, some patients prioritised feelings of embarrassment or anxiety above the benefit of practicing in a group where there is guidance and comradery. Conversely, other patients indicated that practicing, as a part of a group was an attractive attribute for learning the harmonica. From a product design perspective, this indicates that a revised or modified harmonica concept may be required to cater for two differing implementation settings, either independent use in the home or within a group. This finding especially influences the interaction design elements for independent use as the product solely guides and teaches the patient to control their breathing.

The idea of social and independent learning overlaps with the sub-theme Motivation. Given that the patients interviewed currently undertake pulmonary rehabilitation in a group setting and are accustomed to face-to-face learning with respiratory specialists and physiotherapists, it may be difficult to conclude as to the significance of social interaction during rehabilitation as this group is experienced within a social setting. When presented with the harmonica two patients felt that they would like to practice within a group similar to their current setting, however a couple of patients indicated that they would like to try independently.

This is interesting as until now very few products are promoted for use independently within the home. As a result, it is worth considering whether the harmonica is best designed for independent learning and what potential attributes or features are required to help patients to learn breathing techniques over a period of time. This theme leads into ideas and concepts related to Motivation.

Although patients suggested that the fear of not being able to produce the musical feedback within the group was demotivating, the patient statements are unclear in specifying the methods in which patients are or could be motivated.

Overall, there were limited mentions or insights regarding how a patient would integrate the harmonica within their daily lives. Patients who mentioned that they would like to try within their own homes provided very few details about how they would achieve this. Although playing an instrument requires regular practice, patients did not focus on this aspect specifically. This suggests that patients may not be aware of the commitment or time required, that they might perceive playing the harmonica as a short-term or fleeting technique or that the harmonica may be used as a supplementary product rather than a dominant or preferred method of learning breathing techniques.

When considering how a newly designed product will fit within a patient's daily life and activities, the product should consider how much time is required, what is expected of the patient and what setting or context is ideal for use. One patient who stated that 'you can't carry the harmonica with you all the time' addressed some of these ideas. If the patient was sure about what was expected, they may have been more willing or likely to integrate a practice routine within their daily tasks. This begins to touch on the theme of Routine, which will be discussed with the theme of Motivation within another section of this chapter.

The final theme raised by the harmonica is Monitoring and Feedback. Patients responded to the musical melody as their performance feedback mechanism, however as mentioned earlier, there were concerns that not being able to reach the required effort levels would affect their capacity to reach musical feedback. Design adaptions or consideration that could be implemented to adjust the feedback mechanism include Smartphone technology, lights and vibration. By widening the feedback potential, the harmonica may be able to substitute or compensate a patient during the learning phase so as to continue to motivate and guide patients. For example, when a patient is struggling to maintain the breathing pace, the harmonica may play *filler* music until the patient can begin to breath at the correct pace.

From this study it becomes clear that further research is required to verify how much effort and time is required to learn controlled breathing via the harmonica and if the harmonica is a suitable product for COPD patients. Additionally, designing a product which is able to measure airflow, breathing cycles and breathing rates may indicate further as to whether or not PLB or controlled breathing is an effective self-management technique. Conversely, the harmonica revealed the complexities of learning environments and highlighted that products designed for this market should consider how patients learn independently, the ways in which patients utilise services and a patient’s willingness to use unfamiliar products within a group context.

4.5.2. Resperate

The intention of Resperate is to reduce stress by leading the user through guided and monitored breathing exercises. The product consists of headphones, a respiratory chest band and a handheld device. The product measures respiratory rate via the respiratory band. The respiratory rate is communicated to the user via tones or melodies heard via the headphones. The user synchronises their breathing to the tones whilst the product slowly guides the user to their ideal breathing ratio. Thus the products possess both a guide mode and teach mode function. To measure the effectiveness of reducing stress, Resperate calculates performance against the user's blood pressure. These results are communicated to the patient via the handheld device.

Although this product does not specifically focus on controlled breathing outcomes, the interactive elements of the product along with the paced breathing characteristic allows for an interesting comparison with the harmonica. Patient statements and sub-themes are shown within Fig. 26.

Image taken from http://www.resperate.com

"Depends how big it is"
"It would be a nuisance when you're doing things"
"I don't want things wrapped around my body"
"Things that go beep in your ear I'm not keen on"
"So while you're doing a strenuous activity it might help you to do the activity"
"Breathe to that instead of breathing to how you want to breathe or how you think you can breathe. That'd be interesting"
"For instance if I start forgetting it and start to go a bit faster, that would make me more aware I should say that I need to slow it back and breathe a bit more"

Fig. 26 Patient statements in reference to Resperate

To begin, Resperate did not elicit any statements regarding social learning or practice. In comparison to the harmonica, patients might view Resperate as a product designed for independent use and to be utilised within a home setting. This may be further supported by the individualised feedback and monitoring. This will be discussed further shortly.

Concerns and potential problems were interlinked with the integration into daily life aspects and the physical attributes of the product. Patients were interested in how the product could be used during activity as opposed to in a sitting, relaxed state. The way in which the product is designed does not indicate that this would be easy. Initial product concerns raised were related to the size of the product, how it is adjusted to fit the body and audio feedback.

From a Monitoring and Feedback perspective, it was anticipated that patients would have been more responsive to the guide mode and teach mode feature of the product but comments and statements related to this feature were limited. Patients who did comment on the guide mode feature were particularly interested in its capability and impact during activity. This may indicate that the guide mode function was either not well understood by patients, required practice and experimentation by patients to provoke further discussion or that the guide mode feature was viewed as relevant to strenuous activity as opposed to resting states.

As mentioned, patients did not indicate that they would use this product within a group setting. The patient feedback is presented in an individualised manner and in doing so may have a greater success in engaging patients to continue to practice and improve. In its current form, the individualised feedback could be appropriate, however further design developments could consider how long the patient is engaged in practice and if sharing results with others would improve their motivation and engagement.

Despite the limited patient feedback, contrasting Resperate results with the harmonica reveals interesting product features and attributes. Resperate offers an innovative pacing mechanism, which has both, teach and guide modes but relies upon the accuracy of the respiratory band. Conversely, the harmonica provides a mouthpiece design for interactive, real-time breathing practice but does not possess guide or teaching modes.

Given this, there is a stronger relationship between the integration into daily life and concerns & potential problems.

At this point in time neither product strikes the right balance between the 2 elements. A product that offers a varying feedback method and incorporates teach and guide modes is Zenytime.

4.5.3. Zenytime

Similar to Resperate, Zenytime is designed to reduce stress by promoting conscious and controlled breathing. Zenytime aims to focus users on their breathing for short periods of time by playing a digital game. To play, users breathe through a puck which is able to measure breathing frequency. In doing so, the puck communicates the respiratory frequency with the Smartphone App and controls elements of the game.

In contrast to Resperate, the game does not set the breathing pace or frequency and there are no predetermined patterns or cues for the user to follow. As a result, patients must learn to control their breathing in response their game performance, however the Smartphone App does store and communicate results over a period of time.

Image taken from <http://www.zenytime.com/>

"They would have to be the games I play"
"I can't see myself breathing through that and playing a game at the same time"
"I think it's more for the Grandkids"
"I'm really past games"
"It's nothing like PlayStation. I don't know"
"There's a time when you're playing a game and you get anxious about it. You start breathing faster"
"I just got rid of my phone because I couldn't understand half the things"

Fig. 27 Patient statements in reference to Zenytime

Largely, the feedback and monitoring aspect of this product received the greatest response amongst the patient group. There was a reluctance to use this product due to the digital game component. On the other hand, the imagery presented to the patients may have influenced their perspectives as the image leans towards child focused graphics and colours. It would be interesting to present a similar concept to patients but present a range of game options.

An interesting statement made by a patient was that playing games may induce a competiveness which is not aligned to relaxed breathing state. Future interaction design elements should carefully consider the competitive nature of games and the way in which this influences breathing rate, short-term learning and the representation of performance.

Additionally, this product requires breathing control and respiratory effort similar to the harmonica however the same concerns were not raised by patients here. This highlights the sensitive manner by which design must approach respiratory requirements, effort and energy. Perhaps the digital attributes of Zenytime versus the manual function of the harmonica influenced this interpretation.

Patients were not specific regarding the integration of the product within their daily life. As this product stems from Smartphone technology, the integration of the product may be more straightforward, however this is dependent on the patient groups comfort with technology and mobile devices. There was one patient statement which indicates a resistance to technology, but a general avoidance or opposition to integration of rehabilitation products with technology was not recorded.

Finally, similar to Resperate, patients did not indicate one way or the other that the practice of Zenytime is for independent or social use. Presentation of the product with a Smartphone may indicate to patients that this is an individualised and personalised product. Interesting design aspects for future consideration are how a patient's performance can be shared on a Smartphone technology platform and if multi-player interaction could lead to improved results. Although the Smartphone may indicate that the product is for sole use, there could be an underlying system of group rehabilitation via an online platform.

4.5.4. Aura

The final product, which was presented to patients for review, was Aura. Aura possesses similar and differing features to the previously explained products, however the interaction method is unique.

Similar to Resperate and Zenytime, Aura focuses on reducing stress by guiding paced and controlled breathing. Aura focuses on signs of stress within the environment. When Aura believes that it is necessary and appropriate, the product glows which invites users to pick the product up and then guide's users through relaxed breathing by pulsating light. The product is passive in its approach as users choose whether or not to engage with the product. Specifically, there is not a direct relationship between the user's breath and the product but rather it is an interpretation by the user.

Image taken from <http://http://vimeo.com/15450046>

"That's a bit weird"
"I'll forget where I left it"
"It would be helpful when I'm walking to start with, housework, anything like that because you do get out of breath sometimes. So I think that would probably remind me to slow down and breathe properly"
"I think because you can concentrate. If you're trying to pulsate like that, you know breathing like that, you're concentrating on it"

Fig. 28 Patient statements in reference to Aura

At an overarching level, patients had difficulty in comprehending the function and context of use and what the product required them to do. It is predicted that this difficulty in comprehension was caused by a number of factors including a vague description provided by the interviewer, limited detail provided in the image and a subtle feedback mechanism. It is recognised that the communication of this product via a photo is a limitation of this study and patients may have responded to the product differently if they were able to hold the product and try it.

As a result, the number and detail of patient statements is limited. Patient insight regarding the integration of Aura within daily life indicates that patients may be interested in passive feedback, which encourages focus and concentration, however there is concern that the product will be ignored or forgotten. The ideal integration and performance of passive technologies would need to be explored more closely to daily activities, tasks and rituals of use.

The monitoring and feedback mechanisms provided by Aura differ to those offered by the harmonica, Resperate and Zenytime. Aura has a guide mode similar to Resperate, however as the product does not measure breathing directly, patients would be unaware if they were performing the task correctly. Although 2 patients indicated that the reminder and concentration aspect of the feedback would be beneficial to them, it is suggested that these patients were drawn to the simple, visual aspect of the immediate feedback rather than the measurement of their long term performance.

The simplicity of the Aura interface and form could be developed specifically for paced breathing. Providing a mechanism for direct breathing measurement and interpretation but continuing to guide the patient via glowing lights may provide a balanced PLB specific product interaction. Incorporating a mouthpiece form that requires the patient to breathe into the product may aid in communicating the product function and application.

Again, this product did not elicit any patient response in regards to social use or context. Some patient responses indicate that patients may visualise this product for use within the home. Similar to design ideas raised within the Zenytime discussion, there could be potential for this product to communicate with other patients, thus creating a dynamic and interconnected feedback process. Further design investigation regarding these features and attributes could lead to differing methods of product interaction and response.

4.6. Conclusion

To summarise, across the spectrum of products there were a number of ideas and responses that help in directing future product design iterations. Each product was discussed in relation to the themes and from a here a number of design challenges, features and attributes were highlighted. However, as the conversations continued patients referenced ideas outside of the 4 products discussed but were related to these 4 themes. It is important to recognise and document these statements as they provide insight into the overall patient experience.

The analysis of the interview data is across 2 concerns; evidence that patients differ in their attitude and approach to PLB and identification of attributes that have enabled patients to become familiar and confident in PLB practice.

i. Evidence that patients differ in their attitude and approach to PLB.

The resulting data from the 12 patient interviews provided satisfactory signs that the patient data could be separated into the 3 PLB phases; novice, passive and expert. The separation into the phases is based upon patient narratives, their description of PLB function and their explanations of circumstances that demonstrate capacity to implement PLB.

Despite the small cohort, there are strong patient statements, which indicate that patients within the novice group approach PLB practice in a methodical manner. Based upon guidance from respiratory therapists, these patients approach PLB with a positive attitude but find the implementation of PLB with tasks challenging. Conversely, patients within the expert group approach PLB in a much more intuitive manner whereby the process is linked to daily practice and routine. For this group, assessing their step-by-step process may be more difficult as explanations from expert users regarding PLB tended to be shorter and succinct. This results in limited knowledge as to how a patient gravitates through the PLB phases.

The nuanced details such as how an expert patient paces their task with their breathing were touched on but require further investigation in subsequent studies. A review of the results suggests that:

- Patients in the early stages of PLB learning require both immediate and ongoing monitoring and feedback
- Expert patients are more proficient in adapting tasks because of learned techniques, accumulated tacit knowledge and personal goal setting.
- Formation of routines assist patients in self-managing their breathlessness
- Face-to-face monitoring and guidance plays a key role in providing ongoing motivation during PLB practice and implementation

ii. Identification of attributes that have enabled patients to become familiar and confident in PLB practice

Presentation of the products to the patient group revealed patient desires, concerns and current product relationships. In particular, the role of monitoring and feedback in measuring, encouraging and guiding a patient through self-management practices should not be underestimated.

Through both the literature review and the patient discussions, it becomes apparent that the lack of breath-by-breath measurement and the monitoring of a patient's breathing ratio limit both the patient and the respiratory therapist's capacity to understand and evaluate PLB performance. Focusing on this unique relationship offers direction for product development. The results suggest that,

- The methods for collection, measurement and feedback of paced breathing practice requires further investigation
- Patients require relevant and specific goal setting to improve their performance
- Active and independent learning is currently reliant on face-to-face guidance

The results of the data analysed in this chapter shows strong evidence between product design processes and developing a patient's understanding of PLB. The following chapter will examine the product design process more deeply and will explore these principles through a proof of concept device for managing breathlessness.

Chapter 5: Product design specification

5.1. Introduction

Until now, the role of product design in the formation of enhanced PLB experiences and interactions has been discussed in a speculative manner. Within the literature review relationships between product interactions, physiology and self-management principles were highlighted. In doing so, these relationships supported ongoing design investigation within this field and the framing of possible design directions.

It was identified in the literature that further data were required regarding a patient's perspective of PLB and product interaction. A qualitative study was carried out which led to an enhanced range of product design enquiries and idea generations. These included the potential role of increased monitoring and feedback during the PLB learning phase and the personalisation of the product interface and translation of data.

At the conclusion of the Results chapter evidence was found that patients differ in their attitudes and responses to PLB and that product design could influence a patient's execution of PLB. However, although the literature and study results indicate that there is a role for product design practice, the design method by which to respond to the contextual problems and challenges is unclear. Thus far the overarching design problem has been presented but there is an underlying multi-dimensional aspect to the design problem which has not yet been explored.

This chapter focuses on the transition from previously identified PLB attributes and characteristics to inform a product design specification. Within this transition there is a complex array of factors that must be understood and addressed through a comprehensive design process. These factors stem from the vast demographic of patients, the varying contexts of PLB use, the myriad of personal rituals of use and the complexity of COPD progression.

The following chapter will begin with an overall review of the design context based upon the findings within the literature and the qualitative interview results. This will be followed by the employment of design methodologies to approach the design objectives presented. The chapter will conclude with a reframing of the design problem and a proof of concept design response.

5.2. The design context

It has been identified that PLB is one of the many paced breathing management techniques used by patients suffering from COPD. Implementation of this technique aims to reduce a patient's feeling of breathlessness and restore a sense of breathing control. However, it was identified within the literature review (Section 2.4.5) that when patients are learning the PLB technique, it is difficult for them to find the correct breathing ratio and pace.
Thus, the central design focus explores the use of a personal device that guides patients to achieve improved paced breathing practice whilst simultaneously obtaining information for the clinical setting.

Establishment of a design process which responds to the breadth and variance of COPD rehabilitation and self-management raises both design challenges and considerations. Exploration of the specific thoughts and requirements vocalised by patients within the literature and the results will aid in guiding the design process.

Specifically, there are 4 primary topics that contribute to the design context. These are; patient demographics, disease progression, variance in daily tasks and self-management. These topics have been discussed previously; however these will now be revisited in light of the design context.

5.2.1. Patient demographics

Throughout the literature a number of statistics were drawn upon to structure the scope and opportunity within the research context. So far, the impact of COPD has largely been defined by the global death statistics and economic cost to the community cited on page 8. These statistics have framed the research context but provide little guidance for the patient specific design context.

Narrowing further, the literature suggests that the age bracket of COPD patients is broad, encompassing ages from 55+ (Table 1). This is consistent with the patient cohort recruited within the study (Table 4), with the mean participant age being 75 years of age. Still, the wide demographic described by age does not reveal interactions or experience of patients or provide the necessary cues for product design.

Due to the variance amongst patients, their access to resources, their home lives, their goals and aspirations and their challenges, it is difficult to profile the user interactions at this time. Based upon the patient interviews, there is a general feeling as to the target user but further design exploration is required. The design process employed to narrow the patient demographics and characteristics will be explained shortly.

5.2.2. Disease progression

It is recognised that the symptoms of COPD are continuously changing and developing through periods of stabilisation and management (refer to Section 2.5). Changes may be slow and incremental or fast and dramatic. Alongside this, patients with COPD are at higher risk of presenting with comorbid diseases such as a high blood pressure, heart disease, chronic infections and obesity (Mannino & Buist, 2007). This may result in patients entering cycles of inactivity as described in Section 2.5.1.

In approaching the design context, it is important within the early design stages that the patient disease journey is considered alongside the lifespan of the product. For example, a patient may be able to perform paced breathing with ease at the early stages of the disease but struggle to maintain paced breathing 6 months later when their disease has progressed. Therefore, attributes or characteristics of the product should consider these types of changes.

By expanding the range of considerations, the design factors begin to encompass nuance interactions and findings based on the patient disease progression and journey. Simultaneously, it was recognised that encompassing all the desired characteristics into a single product outcome is challenging. Therefore careful selection and planning of product outcomes should take place. This can only be accomplished once the interrelationships between characteristics are explored and thoughtfully considered. This process was undertaken through mind mapping that will be demonstrated within the next section (Section 5.3).

5.2.3. Daily task variance

Although management guidelines encourage patients to maintain physical activity and where possible continue everyday tasks, it has been found that patients are more likely to accept the impact of breathlessness and move towards the cycle of inactivity as opposed to continually adapting tasks and management strategies (refer to Section 2.5). This is despite the literature suggesting that the practice of effective PLB may assist patients in overcoming feelings of breathlessness during task performance (refer to Section 2.2).

As stated earlier, the central design focus is formulation of a product that guides patients to achieve improved paced breathing practice, however a decision must be made as to which activities, tasks or experiences take precedence and which ones become secondary. For example if you were to encourage employment of PLB whilst climbing stairs, the product may need to know how many stairs and the pace at which the patient is climbing versus the pace that they would like to climb. The interaction required to perform the task becomes complex and perhaps beyond the measurable means of the product, therefore design boundaries must be determined. Similarly to disease progression, the mind mapping process aids in the differentiation of task requirements and setting of design boundaries.

5.2.4. Self-management

Within the literature review, self-management interventions and pulmonary rehabilitation techniques were discussed in detail (Section 2.6 and 2.7). Patients practice techniques and strategies in a formalised environment, yet there is a requirement to transition these independently within daily life.

In particular, it was found that management of breathlessness by patients within the home can become isolating and restrictive (Section 2.7.1). The principles of PLB aim to enable a transition between environments, however the current learning and implementation structure does not directly correspond with this desire. It was found within both the literature and patient statements within the qualitative study that the learning process is predominately governed by the formal rehabilitation setting. In addressing this concern, the design process focuses on the exploration of technology which provides an equivalent face-to-face learning experience within the home.

However, developing a product that focuses on the independent learning of paced breathing is problematic. The practice of PLB is unique to each patient but there are underlying physiological principles that are common to all patients. Careful consideration of the interaction and feedback mechanisms is critical in the adequate guidance and use of the product.

To begin the design process, an array of problems, proposed solutions, constraints and requirements were explored through the use of mind maps. This tool supports the co-evolution design process as described by Dorst (2003). Employment of these design processes and tools within the following section further defines the central idea and core concept for product design development and prototyping.

5.3. Multi-dimensional design problem

Although the central idea for design exploration has been explained, the complexity of the design problem and the context in which the problem lies requires an evolutionary design process. Dorst (2003) describes this process as a 'matter of developing and refining together the formulation of a problem and ideas for the solution, with a constant iteration of analysis, synthesis and evaluation processes between the two notional design 'spaces' – problem space and solution space'.

Due to the premature nature of the design context, entering into a constrained design brief at this stage of the design process may limit and exclude relationships between problems and ideas. For example, restricting the design brief to the design of a PLB product which uses a particular technology or interface, measures breathing based on chest movement or must meet certain size and weight specifications, limits the design capacity to look for creative and innovative solutions. The problem space at this time has been left deliberately broad.

To facilitate the early evolution process, non-hierarchal mind maps as outlined by Kokotovich (2008) were used to assess patterns, represent understandings and form associations in order to translate underlying themes into larger design ideas. A selection of early mind map investigations has been included in Appendix D [refer to external USB]. The early investigations explored the overarching 'who, what, where, when, how and why' of the design context, with repetitions and clusters of relationships formed amongst the map. This process allowed for a quick and rapid exploration and documented the early design thoughts and approach.

Some of the relationships explored during this time include; learning strategies and the sensorial aspects of the product, structured results versus the undefined experiences of everyday life and a strong focus on movement between home, workplace, transport and clinical spaces and the differences and similarities between these.

These early investigations allowed for the capture of a broad range of design issues. At times this process expanded beyond the central design focus to ensure that unique relationships or associations were considered. Guided by the literature and design practices, from here the associations between ideas were narrowed and a structuring of the problem took place. The narrowing and structuring process was guided by the work of Restrepo & Christianns (2004). The design problem was reduced to 3 key elements: assessment, active learning and personalisation. Yet how these elements coordinate to respond to the challenge of paced breathing teaching and learning requires further attention. A further focus on these 3 clusters will reveal proof of concept directions and iterations.

Assessment

A patient's PLB practice and performance is not well known. As mentioned within the results, given that PLB adherence and performance mechanisms are currently not objectively measured, little is known as to how a patient may transition between the stages of PLB and increase their capacity to pace their breathing. This is attributed to the lack of data collected during the practice phase. As there is no product or device which measures breath by breath ratios, current data collection is limited to observations by both patients and therapists.

A problem cluster which arose during the initial exploratory phase is related to assessment of patients. The results within Chapter 4 lead to a classification of patients as novice, passive or expert PLB users; however this classification is based upon verbal recounts and a perceived understanding of efficient PLB practice. An interesting design problem exists in the acquisition of quantitative data which may confirm or clarify the classification of patients.

This assessment process would assist in verifying the role of paced breathing within self-management and pulmonary rehabilitation programs. The manner in which assessment occurs is to be determined through design practice and investigation.

Early design concepts assess the feasibility of measuring and collecting breath by breath data as a patient practices PLB. A range of concepts were explored including the method of data collection (sensors, mechanical wind turbines, chest movements, pressure ratios), the critical physiological measures required to determine effective PLB (time ratios between inhalation and exhalation, lung volumes, pressure differentiations, arm movements and leg movements) and storage and presentation of data.

As design iterations occurred, it was determined that the assessment of a patient's PLB status is important. If a product could be designed which measures and collects breath by breath related data, this would significantly influence the verification process and evidence for the use of PLB more broadly.

The resulting design objectives for Assessment are;

1. To provide a method for breath by breath data collection
2. Demonstrate accurate monitoring of breathing techniques.
   This includes deciphering between inhalation and exhalations and determining pace based on respiratory cycles

Active learning

This cluster of relationships is driven by the findings within the literature that pulmonary rehabilitation is successful over a short-term basis but limited in its long-term success. Focusing on the study results, it was found that patients predominately learn PLB within the formal setting, particularly through face-to-face guidance.

Looking outwardly at the greater design context, migration of skills from a formal setting to independent practice becomes an interesting design problem. In placing a focus on guiding patients to achieve improved independent paced breathing practice, there is a requirement to generate active learning solutions. Current education tools which are suitable for use within the home, such as online forums and pamphlets, may not generate the active participation and practice required. Within this design framing, independent learning takes the direction of active learning whereby patients must actively engage with and participate in order to improve their breathing control. Thus the product requirement must encourage active engagement and move beyond common monitoring technologies.

Where the previously discussed cluster, Assessment, focused on data collection principles, this cluster is concerned with the communication of data with the patient. The Assessment component gathers the physiological data and the Active Learning component of the product must then communicate this data and encourage appropriate change.

The resulting design objective relating to Active Learning is;

3. Establishment of real-time feedback that demonstrates adherence to paced breathing

Personalisation

The capacity for a patient to learn independently is directly related to the capability of a product to be personalised. To accomplish this, the design process should consider the user at an individual level. For the purposes of this research, personalisation specifically refers to the ways in which a paced breathing product reflects the physiological and emotion needs of the patient.

This cluster is closely related to ideas of adaption, regulating an individual's paced breathing practice and measuring progress. This cluster explores the role of a product in providing continuing guidance and goal setting which is unique and self-directed. Product interactions should be directed by patient inputs and the corresponding physiological data. In doing so, the product interaction aims to guide a patient incrementally to uniquely gain paced breathing improvements.

The resulting design objective relating to Personalisation is;

4. Create targets for improvement

Together, the clusters of assessment, active learning and personalisation direct the design considerations and product characteristics. These considerations will now be discussed.

5.3.1. Design objectives and considerations

The problem clusters discussed earlier has led to 4 design objectives. To recap, these objectives are;

1. To provide a method for breath by breath data collection
2. Demonstrate accurate monitoring of breathing techniques

3. Establishment of real-time feedback that demonstrates adherence to paced breathing
4. Create targets for improvement

To approach the design process, the objectives have been categorised into primary and secondary design considerations (Fig. 29).

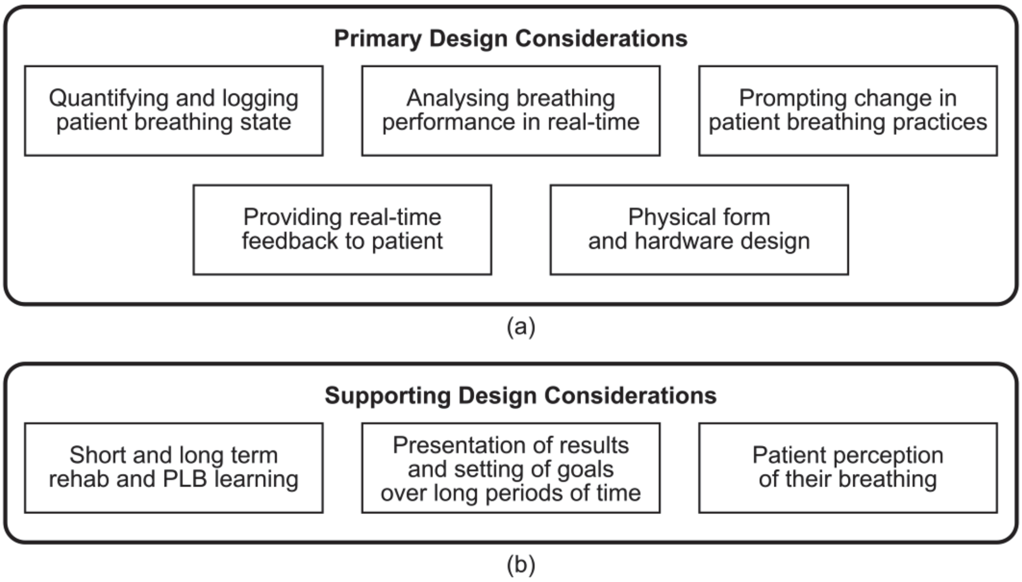


Fig. 29 Identification of primary and supporting design considerations

These considerations address the need to quantify, record, analyse and guide patients in order to achieve effective paced breathing. The primary considerations are interrelated and begin with the development of a feature which allows for the quantifying and logging for current patient breathing states. Of the 4 products reviewed within Chapter 4, none of these captured real-time patient breathing data. To guide a patient to adapt their breathing state, this feature is essential in understanding a patient's current breathing pace.

Once the patient's current breathing pace is accurately quantified and logged, the product must consider how to assess the data and guide the patient towards PLB. This design challenge encompasses the design considerations related to analysing breathing in real-time, promoting change and providing real-time feedback to the patient. The term real-time feedback denotes that the feedback will be communicated with the patient within moments of the occurrence. To explain, it is assumed that the patient will breathe into the product at their current breathing pace. As the breathing rates are quantified and logged, the product will analyse the breathing performance against the principle of paced breathing, which is the expiration to inspiration ratio (2:1). From here, the product will prompt the patient to change their current breathing pace to align more closely to PLB principles. This will occur by providing real-time feedback to the patient. To do this effectively, a primary design consideration is the product form, the interaction aspects and the configuration of hardware which allows for the above recording and analysis.

Although various features and design considerations were discussed throughout the literature review and the qualitative results, those mentioned above form the primary product design considerations which will enable breathing data to be gathered, recorded and communicated to patients. In conjunction with these considerations, supporting design considerations have been listed under (b) (Fig. 29).

These considerations are consistent with a short to long term implementation of the product. Specifically, the product should consider the methods in which the product will adapt with the patient over time, the varying ways in which goals and results could be presented and facilitate a technique for patients to assess their perception of breathing against the physiological data. These supporting considerations may form a secondary design process and focus on enhanced short to long term learning experiences.

The design direction focuses towards the design of a product which captures current breathing data and guides paced breathing practice. The prototype will be introduced.

5.4. Prototype

The prototype demonstrates the way in which the design considerations could be embodied within a product form and illustrates functional components. As discussed in Section 1.2.1 (page 5) a key element of PLB is to instil a breathing ratio and pace. The prototype explores this key element as the primary design focus.

This section will begin with a prototype overview and identification of the components. From here, each component is discussed in detail.

5.4.1. Prototype overview

The prototype comprises of

- Product form
- Mouthpiece design
- Hardware & electronics
- Interaction & feedback

These key components are highlighted within Fig. 30.

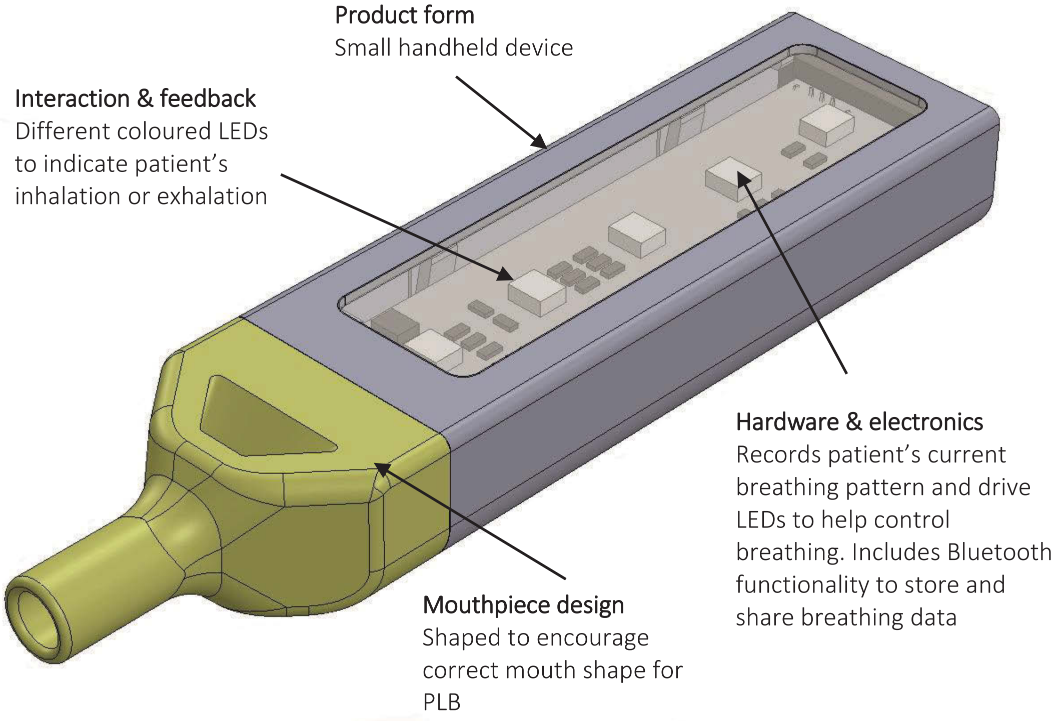


Fig. 30 Product prototype overview

5.4.2. Product form

Based upon the design objectives set and this stage of research, the product form is driven by the technical limitations of incorporating all the electronic components rather than ergonomic and aesthetic considerations. Characteristics of product form which were raised by patients within Chapter 4 included the option for the product to be portable, discreet and hands free. At this time, the product form has not completely resolved these concerns. Future product development and conceptualisation should focus on these concerns more deeply.

The overall dimensions of the prototype is illustrated in Fig. 31.

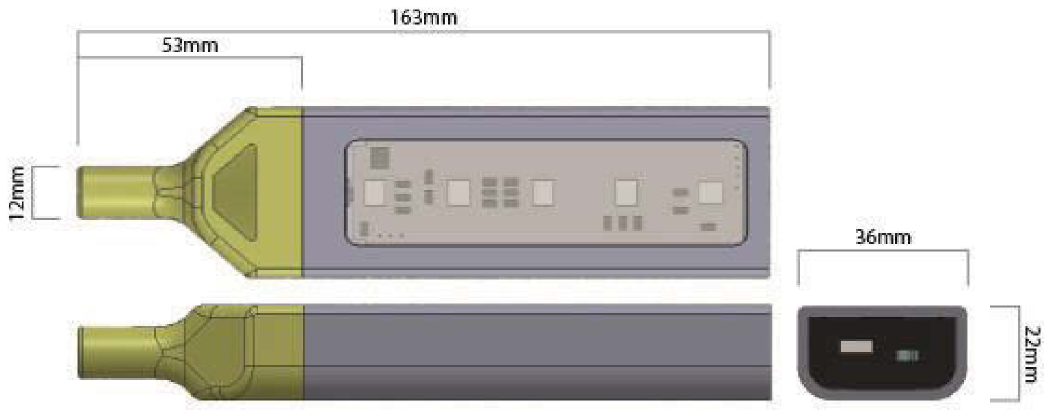


Fig. 31 General product dimensions

The primary feedback, the RGB lights, occurs within the upper surface of the product housing, with Fig. 32 depicting the changing light panel. The light interaction detail will be discussed further within the following section.

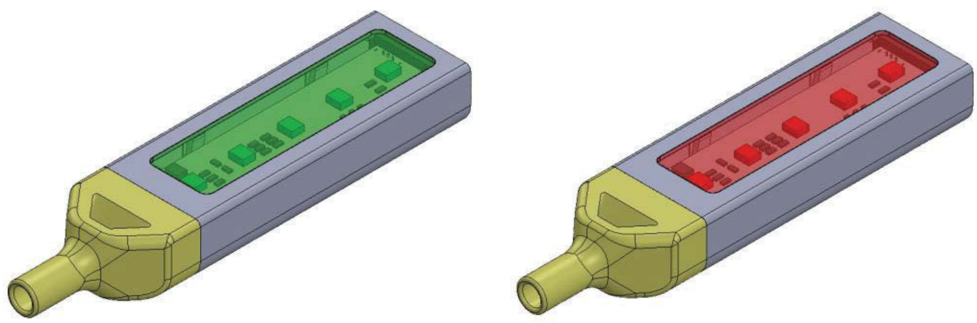


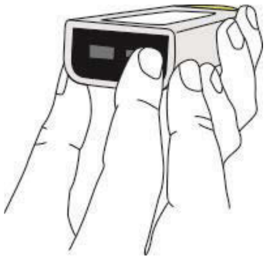
Fig. 32 RGB lights within the top face of the product
The lights change based upon breathing patterns and interactions

Rituals: product functions

The ritual of the product functions are similar to the products shown to patients within the study. In retaining these characteristics, it is anticipated that patients will interact with the product with greater ease and proficiency. The various rituals are shown below.

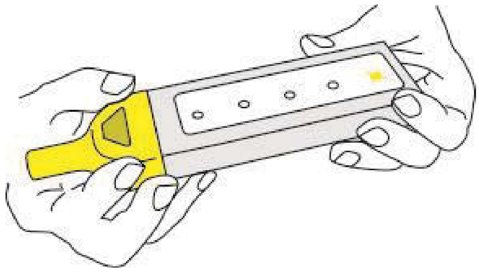
Turning on and off

The on and off button is located at the rear of the product. It is a switch which requires the patient to slide the switch from left to 'on' and right to 'off'. When the product is turned on the lights blink.



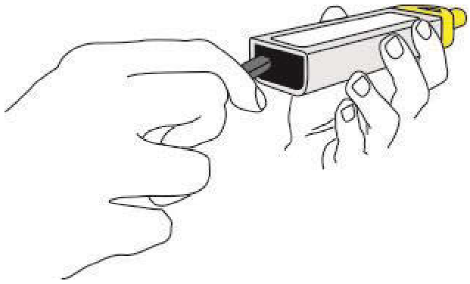
Low Battery

Low battery is communicated to the patient through a flashing light. This is shown on the light furthest from the mouthpiece.



Recharging the battery

The battery is charged via a micro-USB port at the rear of the product.



Syncing

To indicate that the product is syncing with other devices via Bluetooth, the light panel flashes blue for 5 seconds.

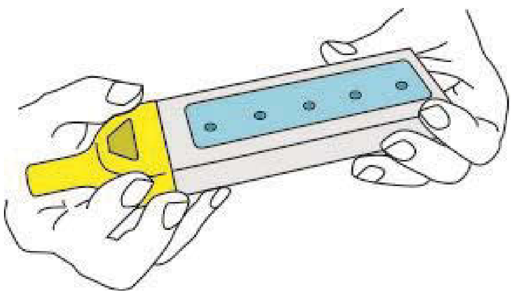


Fig. 33 Product functions

5.4.3. Mouthpiece design

The mouthpiece is influenced by several factors. Firstly, this acts as the primary method of data collection and patient interface. As a patient breaths into the mouthpiece, physiological data regarding their respiratory rate is logged.

At this time, the research focus sits with respiratory rate and therefore design aspects related to respiratory effort were reduced or removed. The concern of respiratory effort, particularly when breathing through a mouthpiece, was highlighted by patients when evaluating the harmonica in Chapter 4. Future development of this concept could look to integrate measurement and feedback of effort.

The mouthpiece design is formed around balancing the respiratory effort required, the reduction of resistance, the integration of the pressure sensor and forming a shape which promotes PLB. The overarching motivation for the mouthpiece design is that the product must measure a patient's breathing rate. PLB is characterised as inhalation through the nose and exhalation through the mouth. However, the motivating aspect of PLB is its relationship to breathing pace and rhythm and as evident in the use of the harmonica as a learning tool. As the first phase of proof of concept, the effects of rhythm and pace will be explored through mouth breathing. Future iterations of the proof of concept would consider the role and implications of nose breathing in establishing the breathing pace. In this circumstance the mouthpiece not only needs to measure a patient's breathing but must be able to differentiate between inhale and exhale.

Following similar principles of musical instrument mouthpieces, for example recorders and flutes, the mouthpiece has been designed with an inlet and outlet. This allows the patient to breathe through the mouthpiece whilst providing a means to measure their breath. The inlet and outlet breathing features have been annotated in Fig. 34.

One of the primary challenges is that the solution requires a means of measuring a patient's breathing phase without imposing too much restriction on the patient's breathing via either an increase in breathing effort or breathing speed. The method that has been proposed in centred on the use of a pitot tube. Shown in Fig. 35, a pitot tube is a pressure measurement method used to measure air flow velocity. It consists of a tube orientated towards the direction of the air flow. As air flows around the tube, the pressure of the stagnant air increases dependent on the air flow rate. Therefore by measuring the pressure at the end of the pitot tube, an estimate of the airflow rate can be calculated. This will be explained in further detail shortly.

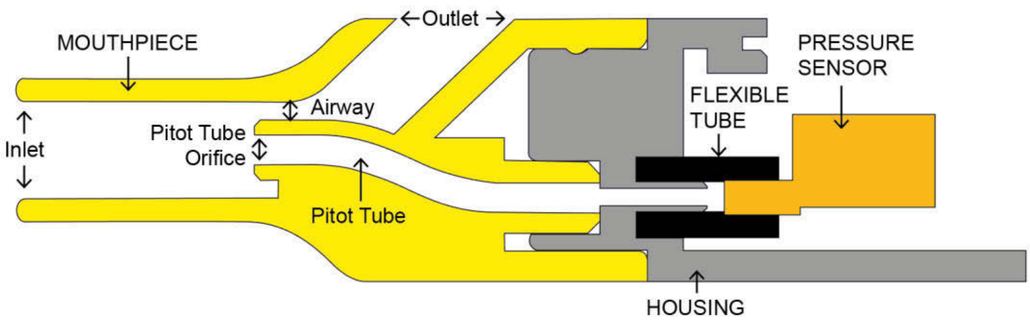


Fig. 34 Mouthpiece connection details and features
Annotated within this diagram are the key features which allow for the passage of air through the product

The implementations of the pitot tubes and sensors which use air pressure measurements to estimate air flow have been used in Spirometry, where the objective is to estimate lung volume capacity. The difference with Spirometry is that the focus is on accurate measurement of patient lung volume capacity. This requires a highly accurate measurement of air flow rate for this to be calculated. However, for this product, the objective is not to estimate volume but to measure breath rate and breathing phase.

As a result, this product direction can use pressure sensing methods without utilising expensive, highly calibrated and complex pressure sensors used within Spirometry. In this product a more economical pressure sensor based on MEMS technology has been proposed. The details regarding the pressure sensor specification and the complimentary electronics will be detailed on pp.146. The pitot tube geometry influences the mouthpiece design and form therefore it is worthwhile explaining this aspect further.

Pitot tube

The pitot tube must be positioned within the mouthpiece so that the airflow can be measured during the patient's breathing cycle. As the patient breathes into the mouthpiece, the air inside of the pitot tube increases in pressure. Conversely, as the patient inhales, the pitot tube air pressure decreases. Hence, measurement of the pitot tube air pressure allows the direction of the patient's airflow as well as the airflow rate to be measured. This allows the product to differentiate between patient inhaling and exhaling phases and provides the data required for breathing rates and ratios to be calculated in real-time.

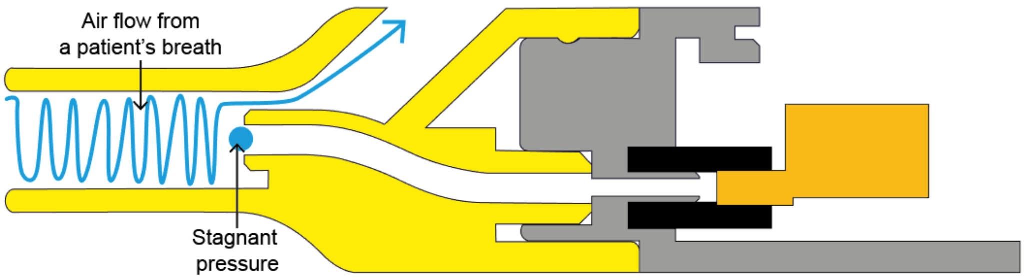


Fig. 35 Measuring a patient's airflow rate

The pitot tube principle relies on the air being stagnant within the tube. The path from the pitot tube orifice to the sensor must be air tight.

A challenge with using a pitot tube for this application is that it requires the speed of the air travelling around the pitot tube to be large enough to produce a measurable change in pressure. To achieve this the airway surrounding the pitot tube should be narrow so as to increase the speed of the air travelling past. However, narrowing of the airway creates an increase in the resistance experienced by the patient. These elements are annotated in Fig. 35. There must be a compromise between the size of the pitot tube aperture and the airway.

The mouthpiece, including the pitot tube, has been designed as a proof of concept utilising 3D printing manufacturing methods. Ideally the pitot tube would be as small as is practically possible so as to minimise restriction to patient breathing. However, the need for the pitot to maintain its mechanical strength and robustness ultimately dictated the final geometry. The airway surrounding the pitot tube was determined experimentally with the objective of making the resistance as low as possible whilst still capable of measuring patient breathing. The proof of concept has an airway gap of 1.5mm and a pitot tube orifice of diameter of 2.5mm. These proportions allow for adequate flow rate and the sensor operates effectively at this rate.

The pitot tube principle relies on the air being stagnant within the tube. Hence the path from pitot tube orifice to the sensor needs to be air tight. As a result, there are 2 important design features. Firstly, the mouthpiece connection to the housing requires careful consideration. The connection detail within the current design has a draft where the pitot tube of the mouthpiece meets the housing. This feature provides a tight fit whilst allowing the mouthpiece to be detachable for cleaning purposes. There is a provision for an O ring to be fitted at this connection, but through testing it was found that this was not necessary. Secondly, connecting the pressure sensor to the housing uses a flexible tube. This method is appropriate as the pressure sensor does not move once fitted.

Earlier it was suggested that developing a product which allows varying resistance levels may help in developing greater respiratory function (Section 2.4.3). The provision of appropriate levels of resistance alongside the desired physiological function is an interesting area for investigation. This may include product attributes such as small orifices to breathe through with the aim of improving respiratory muscles strength or product interactions which require powerful, short bursts of air flow. Although these design specifications would be interesting to explore, they currently sit outside the current scope of paced breathing exploration.

Mouthpiece form

The interaction of the mouthpiece with the patient is an element in the learning of PLB. Forming a PLB shape without jeopardising a patient's comfort or restrict their breathing capability is an important consideration. Lip, cheek and jaw formations influence these aspects. To understand this further, photographs and interactions were used.

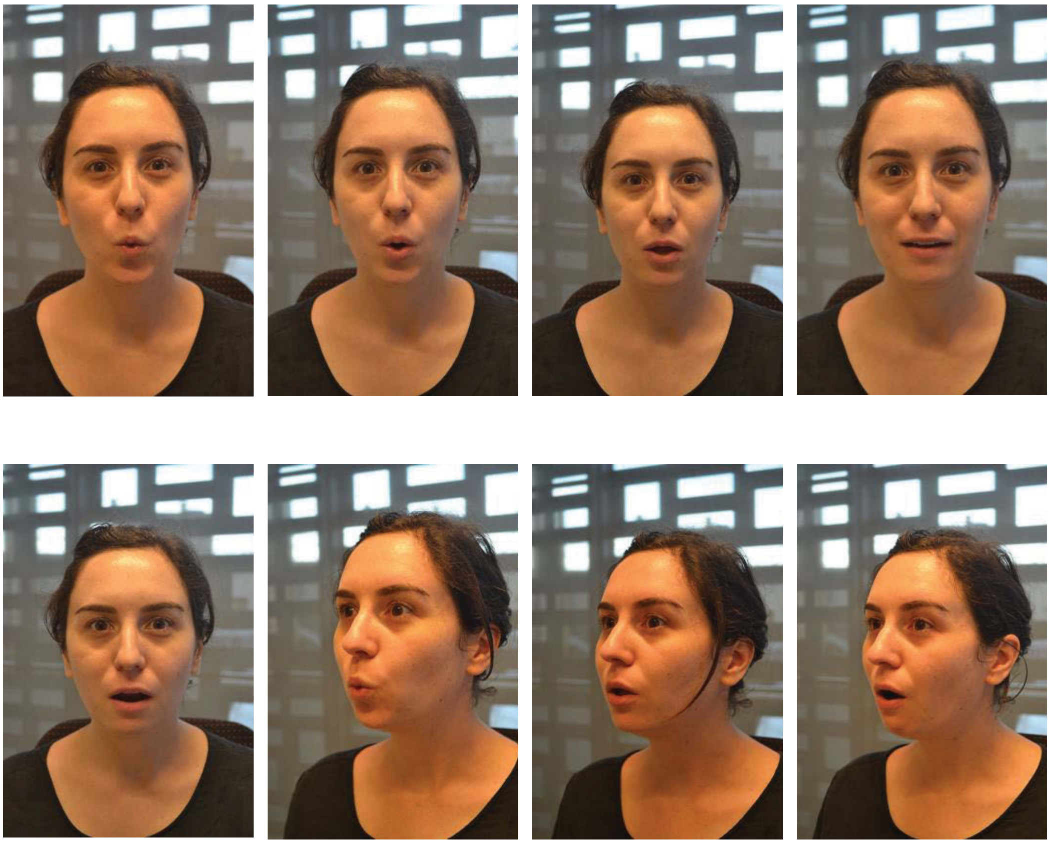


Fig. 36 Mouth formations and positions

The variations in mouth, lip and cheek positions depicted within the photographs (Fig. 36) demonstrate the array of formations which could be described as pursed lipped. For this reason the mouthpiece geometry where the patient places their lips should be generic.

To explore the possibility, 2 differing forms were developed for this prototype. One provides a long, cylindrical shape whereas the other provides a flat top surface and a shorter mouthpiece. These mouthpieces are depicted in Fig. 37. Across both designs, the pitot tube dimensions have remained constant. Future designs may experiment with differing ratios and air pressure flow responses.

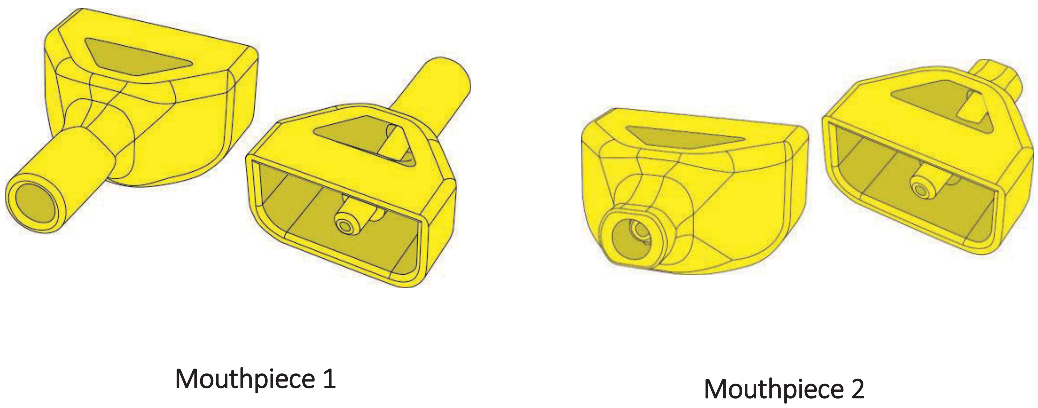


Fig. 37 Mouthpiece designs
Early design concepts explore differing inlet shapes and sizes

Mouthpiece 1 is formed around the simple straw structure. At a diameter of 12mm, the general shape of the inlet allows for differing mouth and lip shapes. Unlike a straw, the mouthpiece is formed in rigid plastic which prevents any moulding to the mouth over time. The rigid material prevents a reduction in the inlet size and subsequent airflow to the sensor, however a softer material may be more desirable.

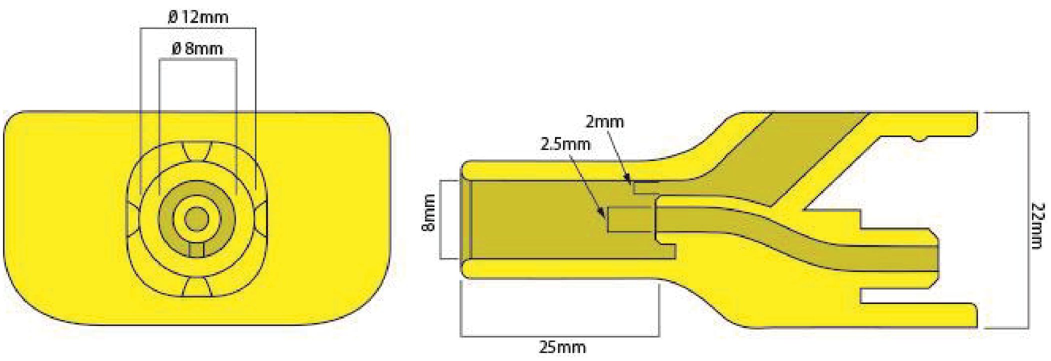


Fig. 38 Mouthpiece 1 dimensions
Dimensions are guided by the plastic drinking straw

Mouthpiece 2 explores the potential for a shorter mouthpiece with a flat surface for lip positioning. When experimenting with this form, it may be more difficult for patients to grip the mouthpiece over a longer period of time, however the flat surface may allow for a more relaxed placement.

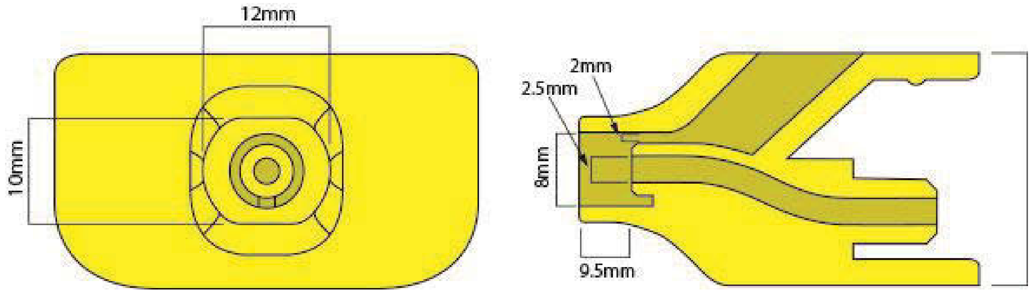


Fig. 39 Mouthpiece 2 dimensions
The length of the mouthpiece has been reduced by 50% in comparison to Mouthpiece 1.

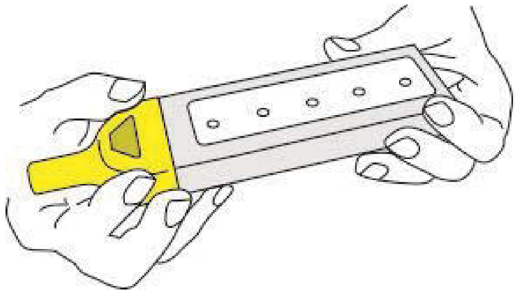
Early investigations regarding mouthpiece form and size indicate that the design may influence a patients comfort and performance over the practice time. Further studies are required to both investigate the range of potential mouthpieces including, size, shape, material types and comfort to conclude as to which may offer the greatest result for patients.

Rituals: mouthpiece

The ritual of removing the mouthpiece for cleaning and replacement is modelled similarly to a musical instrument mouthpiece. As outlined earlier, the internal alignment of the mouthpiece to the product body is critical to the functional operation. The surrounding form of the mouthpiece is designed based on scale, grip and visual cues. Removal requires limited effort which is an important consideration as patients may suffer from arthritis and reduced hand dexterity. In addition, a location pin has been designed to avoid rotation or movement during use. The ritual steps are shown below.

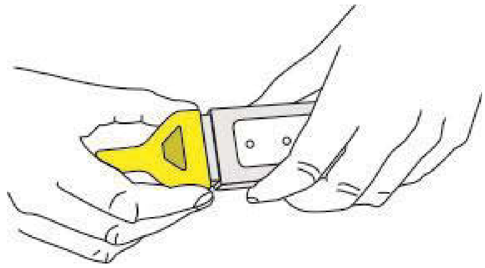
Step 1

Separation of the mouthpiece is defined by a clear parting line and a change in colour. Two hands are required for separation but the size and geometry of each part is designed for an easy grip.



Step 2

Holding each side of the mouthpiece, the user pulls the mouthpiece away from the body of the product.



Step 3

Once separated, the mouthpiece is realigned via the inner lip. The mouthpiece cannot be positioned incorrectly due to the unique geometry.

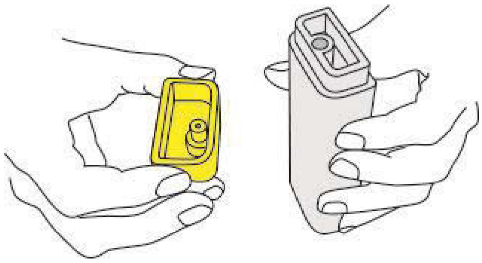


Fig. 40 Removing mouthpiece

Illustrated within the below cross section views, the concentric circle forms within the mouthpiece and body ensure that the parts align effectively. The location pin feature, annotated below, offers added rigidity as the mouthpiece wears over time. Preliminary trials of the product have not required additional sealing; however there is a provision for seals within the housing, if required.

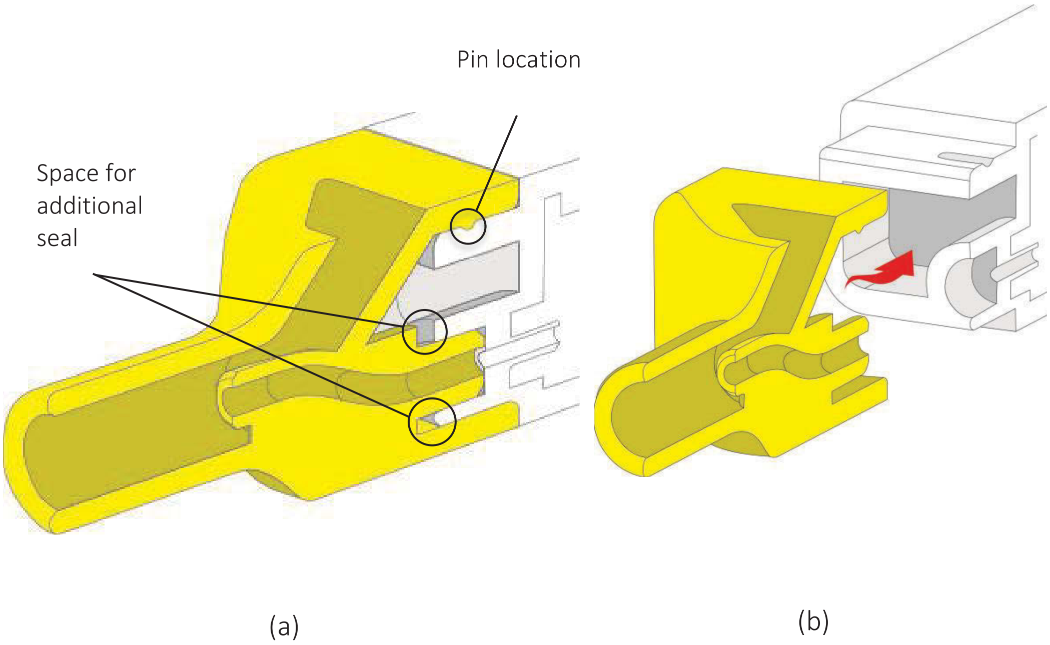


Fig. 41 Mouthpiece connection detail

5.4.4. Hardware and electronics

The development of the hardware and electronics required an iterative and experimental process. By firstly defining the interactive requirements and the data collection mode required, the chosen electronics comprises of technology which enables breath by breath analysis through the mouth. The earlier stages of this research describe PLB as a nose and mouth breathing exercises. At this preliminary stage, the interaction of mouth breathing has become the focus. This reduction in scope stems from the literature surrounding Harmonica Therapy. The harmonica generates breathing pace and auditory feedback as the user inhales and exhales through the holes in the harmonica. The interesting aspects of this interaction are the position of the lips and the user’s skill in controlling their breathing rate to generate musical rhythm. In focusing on this unique interaction and feedback mode further, the prototype development phases concentrate on the interactions of the mouth. Measurement of nose breathing is to be considered at a later stage.

The particular electronics were chosen to enable certain functionality including; breath by breath data analysis, interaction with external devices such as Smartphones and tablets, feedback through light interaction and rechargeable power. There are multiple opportunities to explore interactive elements, however the focus at this stage is to demonstrate that certain principles are viable and accessible at this time.

The early electronic prototypes were laid on breadboard configurations and consisted of a number of iterations, coding developments and testing. One of the early prototypes is shown in Fig. 42. With the pressure sensor as the primary breathing interaction, a singular RGB LED was used to communicate data feedback.

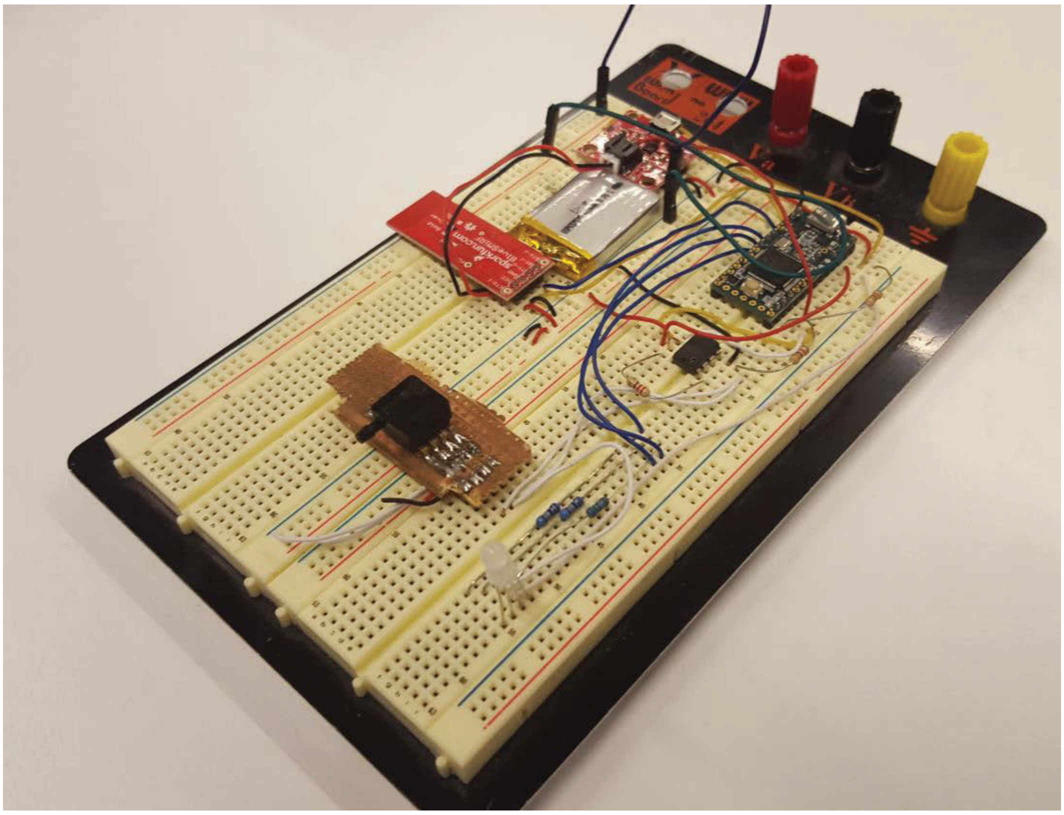


Fig. 42 Early electronic prototype
Experimenting with electronics and the interaction between the elements

Adapting the earlier introduced image by Whole Health Insider (2012) (Section 1.2), Fig. 43 depicts the general layout of the electronics that came about as a result of the various experiments and tests. This figure specifies that 7 components are necessary to meet the design objectives and gather breathing data. These components will be discussed shortly.

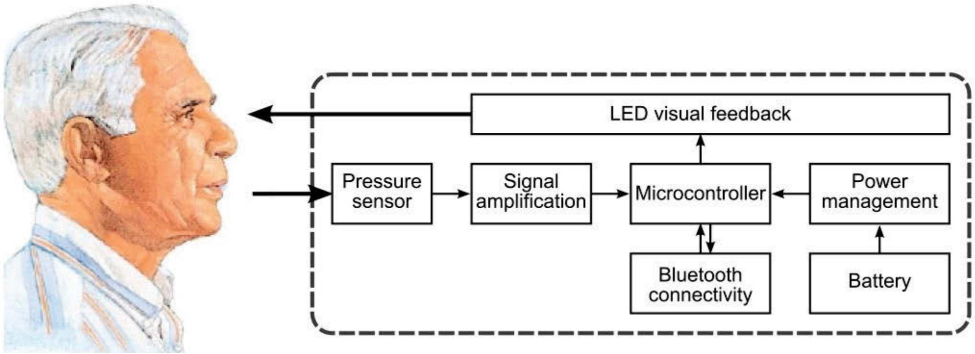


Fig. 43 Overview of the electronic components
(Modified image)
Whole Health Insider, 2012
Original Image taken from http://www.wholehealthinsider.com/newsletter/2012/put-pulmonary-rehabilitation-into-your-own-hands/

Once the suitability and reliability of the hardware and electronics was determined, differing configurations were explored to reduce the size, enable reasonable housing design and interaction. As discussed earlier, a key driver was the specific interaction needs of the sensor. Fig. 44 depicts an early prototype which tests the stacking of the electronics and using a straw to breath into the sensor. Bending the single LED towards the line of sight provided feedback to the user. This early prototype operated successfully, however the mouthpiece configuration with the pressure sensor required further investigation.

Fig. 44 Experimenting with electronic configurations
This configuration is similar to the final prototype

As discussed previously within the mouthpiece design, airflow is required to circle around the sensor to detect changes in pressure. Prior to reaching the current geometry a number of prototypes were fabricated. Examples of these prototypes (Fig. 45 to Fig. 47) signify early design thoughts.

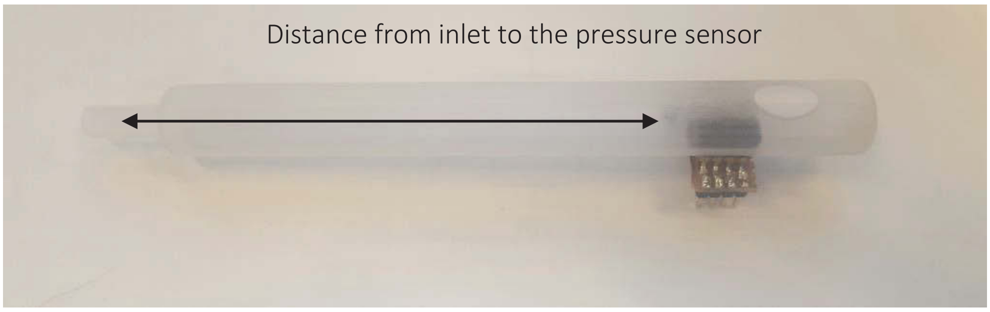


Fig. 45 Extended pitot tube

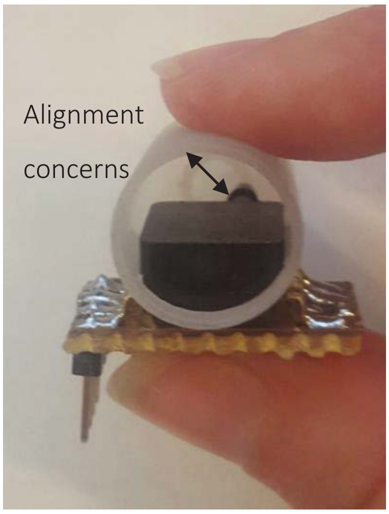


Fig. 46 Alignment of sensor with the pitot tube

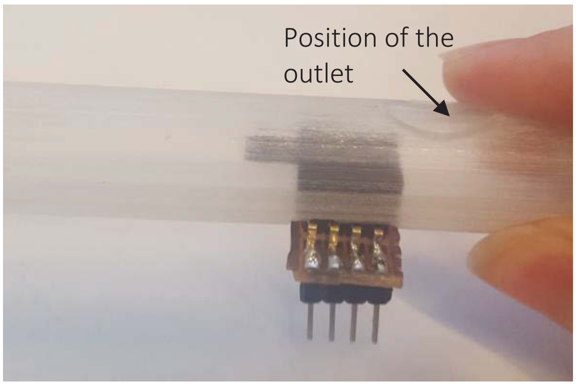


Fig. 47 Position of air outlet behind the pressure sensor

The requirements of the pressure sensor were resolved through the pitot tube and mouthpiece design process. It was determined that the pressure sensor was sufficient in measuring and recording breath by breath analysis through the mouth. At the conclusion of the hardware and electronics testing phase, all components were selected.

The final configuration of the hardware and electronics is shown in Fig. 48 and Fig. 49. Each of the components is annotated in Fig. 50 and will be detailed in the following sections.

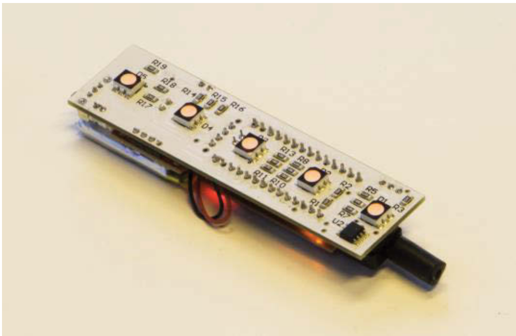


Fig. 48 Electronics top view

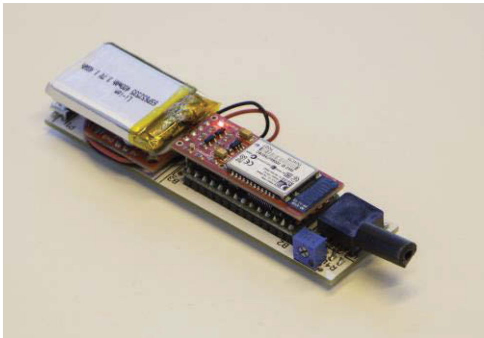


Fig. 49 Electronics bottom view

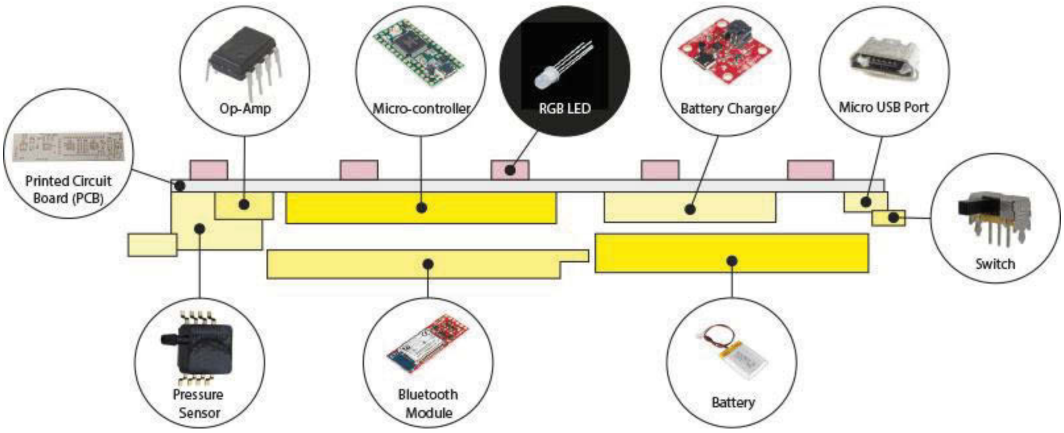


Fig. 50 Overall position of each component

Pressure Sensor

Breathing flow rate and direction is measured using a MEMS pressure sensor. A pressure sensor is chosen as other methods such as using a small wind-driven propeller may produce too much resistance to the patients breathing. A pressure sensor used to measure the flow rate in a “pitot-tube” arrangement can allow flow rate of the breath to be measured with minimal resistance. More on this is detailed in the earlier Section 5.4.3 on mouthpiece design.

The MEMS sensor is also suitably accurate and hence useful for obtaining quantitative measurements of the user's breath. It is also cheap, and has no moving parts which will benefit the longevity of the device and reduce maintenance. The specific sensor MPXV2010GP-ND was chosen as its pressure sensing range is able to detect breath movements accurately.

Printed circuit board (PCB)

A printed circuit board was fabricated to fit the overall sizing requirements. The PCB is a standard 1.6mm double sided board. The board was fabricated in white to reflect the LEDs and was designed to be as small as possible whilst accommodating all of the additional components.

Signal amplification and the microcontroller

The pressure sensor outputs a voltage differential proportional to the pressure experienced at the inlet. The voltage output has a maximum of 25mV at full scale. To aid the microcontroller in digitizing the sensor's output, an amplifier is used to increase the amplitude of the signal. Output from the pressure sensor is amplified using an instrumentation amplifier Op-Amp INA126PA.

The amplified analogue output is digitised and processed by a microcontroller to identify breath information (inhale, exhale, no breath) and breath intensity. The specific microcontroller chosen is the Teensy 3.2. From the data, measures of the patient's breath performance (ratio, frequency) can be calculated and compared to healthy values. More details on the breath data processing and how it is used to provide breath cues to the user are detailed in Section 5.4.5.

LED visual feedback

Various feedback mechanisms were considered during the design development process. As this is the preliminary proof of concept stage, LED lights offer the most appropriate level of feedback given that their behaviour can be easily controlled by the microcontroller.

RGB (red-green-blue) lights are positioned to illuminate across the top of the device. The lights are capable of displaying various colours and intensities, which will be used to give more dimensions to the feedback. Additionally the LEDs are diffused to provide a better view from an angle.

The lights are distributed along the length of the device, allowing various patterns to be produced which may be used to providing additional feedback. The lights also can be used to provide status about the device, e.g. low battery, Bluetooth sync, etc.

Connectivity

The supporting design considerations may require connectivity to external devices or systems for the sharing of data. The electronic set up has allowed for Bluetooth hardware, should this be a consideration for future work. The prototype is set up using a BlueSMiRF Bluetooth module connected to the microcontroller. The potential transmission distance is 18 metres.

Power

The electronics requires power. To satisfy the design requirement of being portable, a small lithium-ion battery will be incorporated in the device, so no external power supply needs to be carried. Also, the battery is rechargeable, making it more convenient.

A Polymer Lithium Ion Battery was chosen. It has an energy capacity of 400mAH.

A small lithium-ion battery charging circuit is incorporated for charging the battery and providing a regulated power source to the rest of the electronics. Charging occurs via a micro USB port at the end of the device.

5.4.5. Interaction and feedback

Varying interaction methods and feedback modes have been previously discussed. Earlier, concepts related to the harmonica (Section 2.7.4, page 65) establishing a breathing pace through entrainment (Section 2.7.5, page 68) has been introduced. Referring back to the project scope outlined in Section 5.3.1 (page 131), the overarching product design specifications and subsequent prototypes must address the following interactional elements,

- Measure a patient's current breathing rate
- Communicates the current breathing rate to the patient
- Guide patients to extend their expiratory breath over a period of time
- Considers continuous paced breathing feedback and performance status communication

Based upon the product form, mouthpiece design and hardware selected, the prototype possesses a mirror and guide mode functionality. Based upon the physiological reasoning described Section 2.4, PLB focuses directly on extending the expiratory breath but requires focus and commitment by patients to overcome the initial feelings of breathlessness. Earlier it was suggested that feedback through lights may enable patients to become aware of this physical occurrence and take action. The development of mirror and guides feedback modes explores this product attribute more thoroughly and provides a mechanism for further testing and investigation. The following description of these modes addresses the objectives outlines within the design brief. We will first establish the principles of mirror mode.

Mirror mode

Initially when the product is used, the product does not have enough information regarding the patient’s breathing to guide them. In this case the device simply provides feedback to the patient representing their actual breathing behaviour. This mode of operation is referred to as “mirror” mode.

The mirror mode function provides feedback to the patient regarding their current breathing phase. Illustrated in Fig. 51, as the patient breathes into the product, the LED lights mirror their breathing as inhale or exhale. As they inhale through the device, the lights show red and as they exhale through the device the lights will turn green.

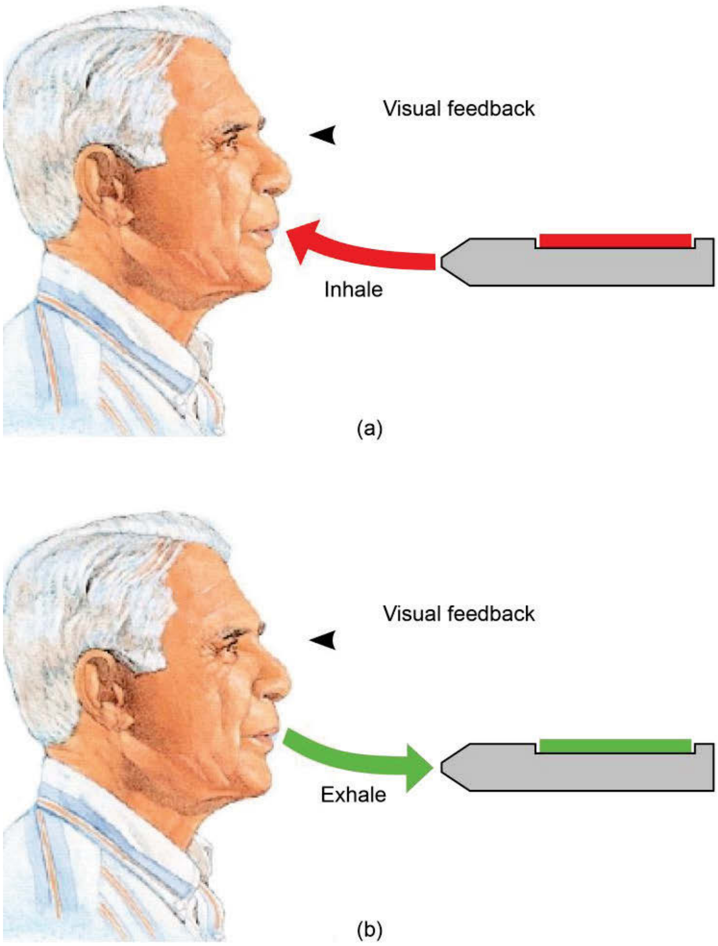


Fig. 51 Interaction and feedback in mirror mode
(Modified image)
Whole Health Insider, 2012
Original Image taken from http://www.wholehealthinsider.com/newsletter/2012/put-pulmonary-rehabilitation-into-your-own-hands/

The mirror mode function addresses 2 interactive requirements. Firstly, this function provides an intuitive means for learning how the cues correspond to the breathing phase. It is anticipated that within a few breathing cycles the patient will be able to follow the way in which their breathing phases are controlling the colour of the lights. The operation of the device to facilitate this mirror mode is shown below in Fig. 52, represented as a Finite State Machine [for definition of Finite State Machine see (Black. P, 2016)].

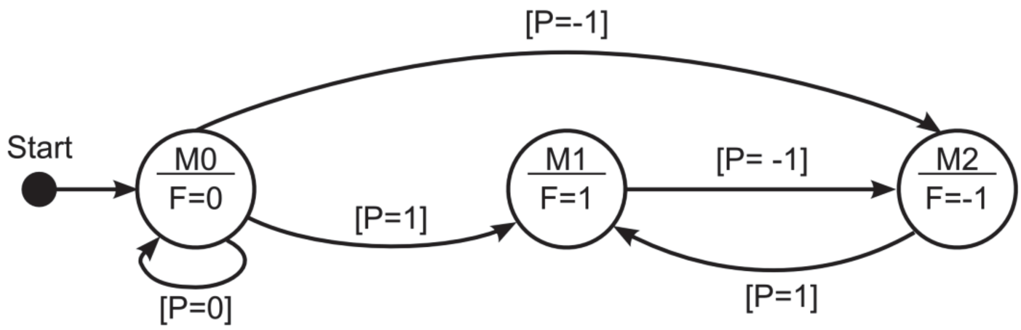


Fig. 52 Finite State Machine of Mirror mode
P= Patient (breath as measured), M = State name (mirror), F = Feedback

The device in mirror mode has 3 states (M0, M1, M2). The breath of the patient is represented by the variable P which is set to either $P = 1$ (inhale), $P = -1$ (exhale) or $P = 0$ (no breath) as measured by the pressure sensor. The LED feedback to the patient is represented by the variable F which is set to either $F = 1$ (green), $F = -1$ (red), or $F = 0$ (no lights). Initially when first turned on, the device enters state M0 which sets the feedback to $F = 0$ (no lights). The device remains in state M0 while $P = 0$. When the patient's breath is observed, the change in variable P causes the mirror mode state to change to either M1 or M2 depending if the breath was inhale or exhale. As the device enters the new state, it sets the feedback to the patient accordingly. The result is a feedback to the patient that mirrors or follows the breaths of the patient.

Secondly, during the mirror mode the product is quantifying and logging the patient's breathing performance. By gathering a series of breathing phases, the product begins to *know* the patient breathing pace as well as inspiration and expiration times. The processing of these phases is possible through simple software programming. The way in which this occurs will now be explained in further detail.

Capturing up to current time

The first stages of capturing the breathing data and determining breathing phases requires the conversion of pressure sensor voltage and classification as either an inhale or an exhale. Fig. 53 depicts 2 stages of the classification process.

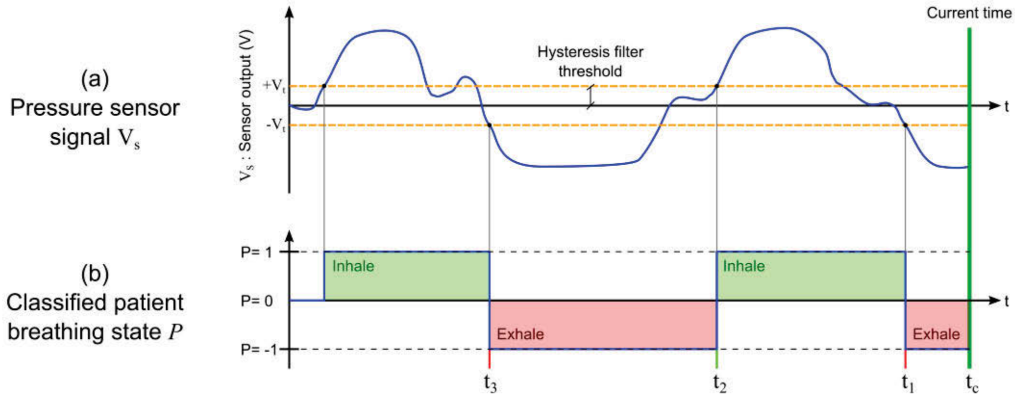


Fig. 53 Classifying current breathing phases up to current time
V = Voltage, P = Patient (breath as measured), t = Time

(a) As the patient breathes into the device, the pressure sensor produces an analog voltage, which varies in response to the flow of air in and out of the mouthpiece. The microcontroller measures and records this voltage so that the patient's breathing volume can be analysed. A hysteresis filter with predefined thresholds is applied to the sensor signal. This is shown in orange.

(b) The pressure sensor voltage is processed to identify if and when the patient is inhaling and exhaling. The current breathing state of the patient is represented using a variable *P*, with P=1 representing inhaling, P=-1 representing exhaling, and P=0 representing no breath. A transition of *P* from 1 to -1 represents the patient transitioning from inhale to exhale, and vice versa.

The time at which transitions of *P* are observed are recorded by the device, and are used to calculate the breath frequency and inhale-exhale ratio. Every time the patient's breath transitions, i.e. *P* changes from 1 to -1 or vice versa, the time at which this happens is logged. The time at which the current breath state began (either inhale or exhale) is represented as t_1. The time when the breath state before it began is represented as t_2. The breath state before that as t_3, and so on. When a new time is recorded, the values for t_1 becomes the new time, t_2 becomes the old t_1. Fig. 54 depicts the process of updating the breathing state variable *P* and the corresponding times when the transitions occur.

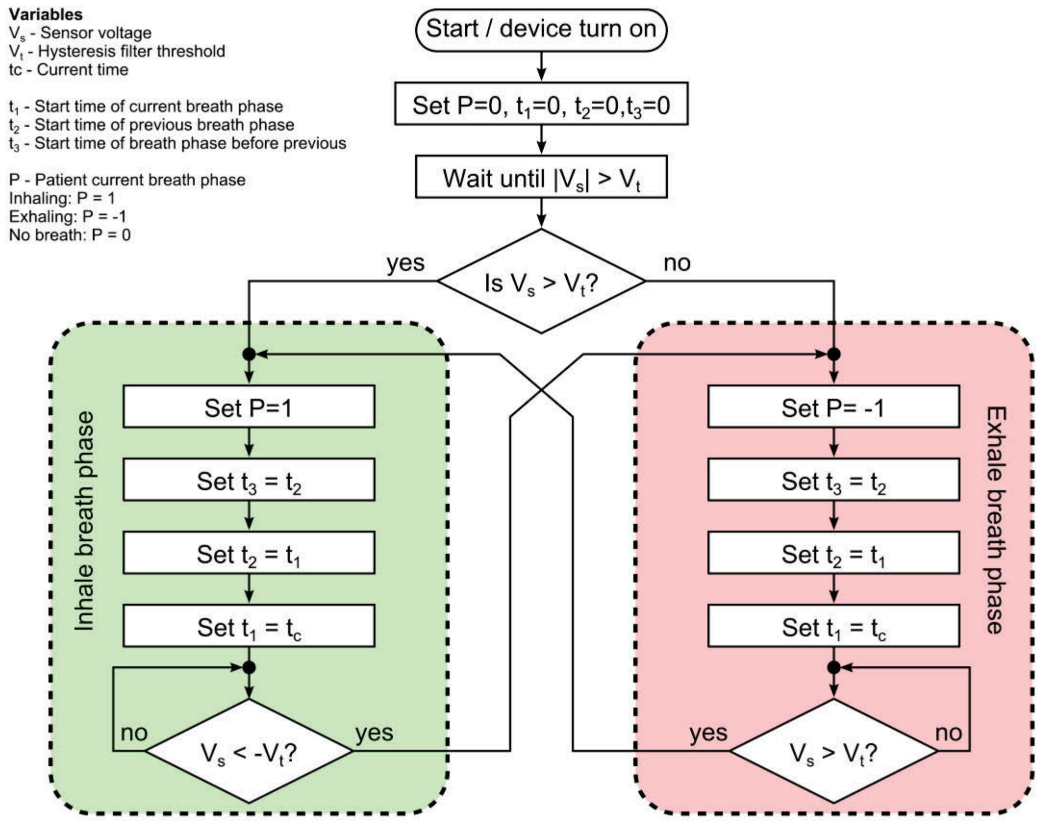


Fig. 54 Representation of Flow Chart
Representation of Flow Chart as breath transitions between inhale and exhale

Following the diagram above, when the device is turned on, all values are set at 0. As the patient breathes into the mouthpiece a voltage is registered within the sensor. If the voltage registered is greater than *Vt*, the breath phase is registered as an inhale and the time is logged. To move from the inhale phase on the left to the exhale phase on the right, the patient must reduce the sensor voltage to –*Vt*. Until this occurs the time continues to be clocked against the inhale breath. As soon as the patient moves from an inhale to an exhale, we move across to the right side of the diagram. At that point the *P* values are updated and time is clocked against the exhale breath phase.

This loop between inhale and exhale continues until such time that sufficient real-time calculation of patient breathing frequency and ratio has been assessed. Calculating the frequency and the ratio directly relates to the products capacity to determine if a patient is performing PLB. The process for assessing this calculation will now be explained.

Real-time calculation of patient breathing frequency and ratio

An estimate of the patient's current breathing frequency f_B (Hz) can be calculated from the time between the current breathing state and the matching state before it:

$$f_B = \frac{1}{t_1 - t_3}$$

The ratio of breathing is defined as the duration of inhale divided by the duration of exhale. A healthy PLB ratio is approximately 2 seconds of inhalation to 4 seconds of exhalation, or 1:2. The current ratio of patient breathing r_B is calculated as:

$$r_B = \begin{cases} \dfrac{t_1 - t_2}{t_2 - t_3} & if\ P = 1 \\ \dfrac{t_1 - t_2}{t_2 - t_3} & if\ P = -1 \end{cases}$$

After mirror mode has operated for sufficient period of time as to gather the required breathing phases, the product automatically switches into *guide* mode. Guide mode provides a modified feedback to the patient in an attempt to guide their breathing towards the PLB principles.

At this preliminary stage, a minimum of 3 breaths is used to predict future state. However, with further studies, the number of previous breaths required to make accurate calculations and predictions may be higher. This is due to inter-breath variability, individual patient breathing patterns and adherence to predicted values.

Guide Mode

Once enough information is available, the device can alter its feedback in an attempt to guide patient's breathing towards what is considered good PLB practice. As shown in the figures below, guide mode results in a differing light feedback. Rather than the light directly mirroring or corresponding to the patient breathing phase, the light will indicate to the patient the breathing phase that they should be in.

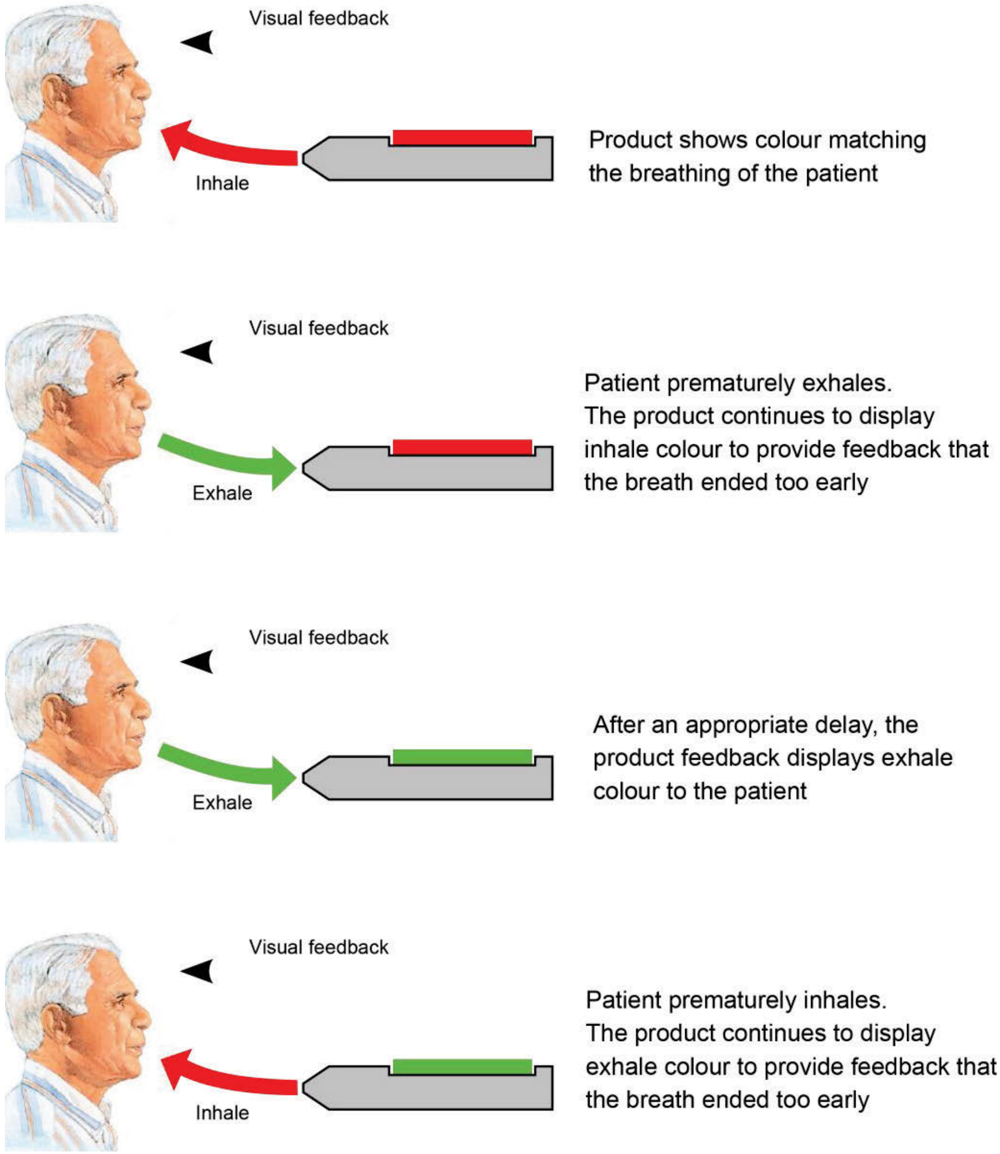


Fig. 55 Interaction and feedback in guide mode
Modified image
Whole Health Insider, 2012
Original Image taken from http://www.wholehealthinsider.com/newsletter/2012/put-pulmonary-rehabilitation-into-your-own-hands/

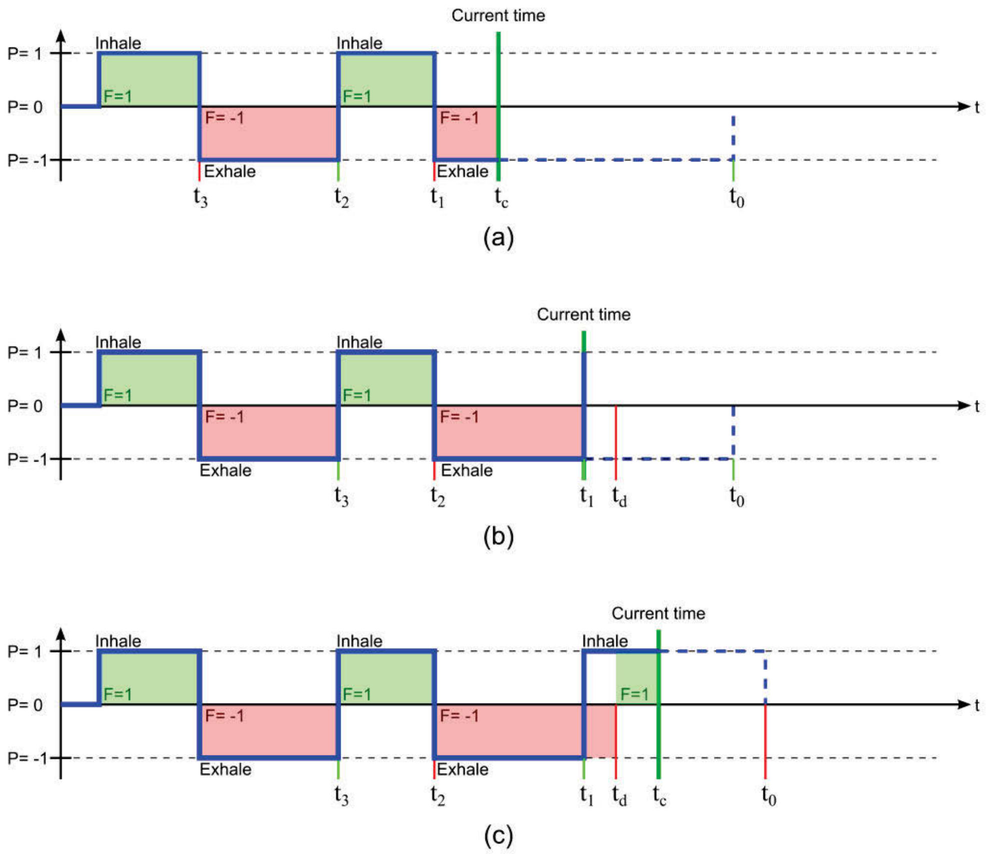


Fig. 56 Classifying current breathing phases within guide mode
P = Patient (breath as measured), t = Time

Following the figure above, the guide mode will now be explained. The patient breath as measured by the sensor, P, is shown versus time t as the solid blue line.

(a) As a patient begins a breath phase, the time that this breath will ideally end is calculated as t_0. This ideal breath is shown in the figure as the dotted blue line and is calculated from the time the breath began (t_1) based on a goal breath frequency and ratio. The device continues to monitor the patient's current breath, providing the same feedback until one of two cases happen.

If the patient ends their breath phase before the ideal time ($t_c < t_0$) the device provides feedback to the patient instructing them that their breath should have continued for longer. This is shown with Fig. 56(c) as t_d, the delay phase.

To explain further, the patient began to exhale and the LEDs were shown as red. During the exhale, a time for exhale completion was predicted as t_0. The patient was unable to exhale all the way to the t_0 value and thus a delay was shown. This means that the patient began to inhale but the lights on the LED remained red to indicate that they should have continued to exhale.

As shown within Fig. 56(c), the delay phase does extend to the full $t_0$value but rather acts as a 'nudge' to guide the patient to extend further on the next exhale breath phase. Currently the feedback switching is delayed to time t_d which is calculated as: $t_d = t_c + \max\{\, K(t_0 - t_c), 0.2\}$, with K being an appropriate constant which can be tuned.

If the patient continued their breath for longer than the ideal time, the feedback switches when the time is up ($t_c > t_0$).

The switching of the feedback state F is show in the Fig. 59, below.

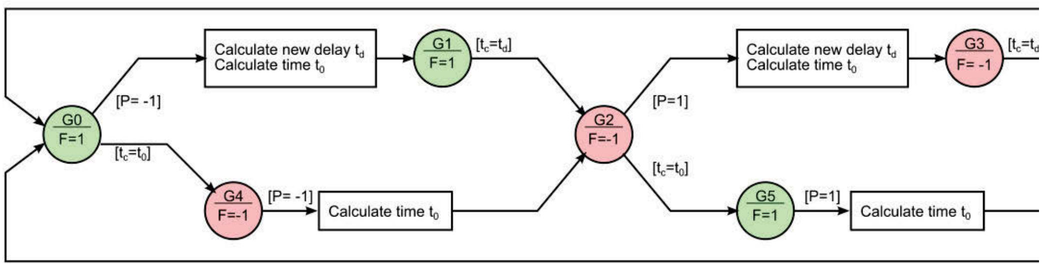


Fig. 57 Finite State Machine of Guide mode
P= Patient (breath as measured), G = State name (Guide), F = Feedback

To explain, starting on the left (state G0), the patient is currently within an inhale breathing phase and the lights shown to them would be green. If the patient inhales to the point where $t_c = t_0$, the lights change to red indicating to the patient to exhale (F=-1)

However, if the patient begins to exhale before reaching t_0, a new delay is calculated and set as t_d and the lights remain green for the delay period. Once the delay period has been reached, the lights change to red to correspond with the current exhale breathing phase. This process continues on until the patient concludes their practice.

The principles of the *Mirror* and *Guide* mode as illustrated in the Videos appended (Appendix D). Video 1 illustrates Mirror mode whereby the breath blown by the user is depicted in the light panel. Video 2 illustrates a guide mode whereby the user is encouraged to extend their breath and follow the light direction. These video clips illustrate that the principles can be implemented with current technology.

The speed in which the guide and mirror mode feedback is delivered to the patient may be critical in the learning experience and breathing retraining process. As suggested within Section 2.4.4, there is an association between the neuro functioning of the respiratory system and the physical mechanisms of breathing. Product interactions, particularly through real-time feedback, offer an opportunity to embed new behaviour and breathing patterns through repetition and guidance. In addressing this issue, the feedback modes developed within this prototype operate within milli seconds of breathing occurrence. Further testing is required to determine the short and long term effects of this type of practice and feedback methods.

5.5. Conclusion

The research development process led to the learning and acquisition of new skills by the researcher. These include three-dimensional modelling, programming and electrical design. Replication of the product concepts by others in the field may require further skill development or collaboration.

The prototype responds to aspects of the project scope and design requirements outlined within the design brief (Section 5.3).Largely, the prototype explores two prominent factors, the design requirements associated with breathing function and those focused towards product design. The prototype will be discussed in reference to these aspects.

5.5.1. Breathing rate

The prototype addresses 4 aspects related to breathing rate. Firstly, the prototype employs a combination of technologies to measure breathing rate and direction (inhale or exhale) in real-time. Secondly, the prototype collects continuous streams of breathing rate data as the patient breathes into the device. From here, the prototype is able to communicate the breathing rate data to the patient. Lastly, the programming and coding technology considers how a patient can be encouraged to adjust their breathing rate. These aspects will be discussed under the headings of measure, collecting, communicate and adjust.

It is important to reiterate that although the PLB principle depicts an inhale through the nose and an exhale through the mouth, the prototype development has been focused on gathering data solely via mouth breathing. Algorithms and code for collecting breath data using this method were developed, implemented and tested. Although it is not directly measured by the device, it may be possible to infer nose breathing via the absence of breathing through the mouth. The feasibility and benefit of this is a potential area for future development of the prototype.

Measure

Utilising a combination of technologies, the prototype is able to differentiate between an inhale and an exhale breath as well as determine the length of time that the breath is held. An important attribute of the chosen pressure sensor is that the force required by humans to register a breath is considered close to that of normal breathing force. Further testing, particularly in the accuracy of the pressure sensor when used by COPD patients, is required to validate the chosen technology. Additionally, adjustments may be needed to the filtering of data collected to ensure that those patients with weak or inconsistent breathing patterns are registered accurately.

Collecting

Once the measurement of the breath is logged by the prototype, breathing cycles are collected and stored. This process was described earlier as the Mirror mode. The continuous method of collecting the breathing cycles has been determined and preliminarily tested. Based on the algorithms provided earlier (page 157), at this stage the methodology appears sound. However, as the collection of the Mirror mode data is critical in determining the Guide mode response, further testing with a wider variety of scenarios is required. Potential scenarios include fluctuating breathing flow, inconsistent breathing pressure and stop/start breathing by the patient.

At this time the prototype only collects and stores data from the time turned on until the time turned off. There is an opportunity to increase this functionality to collect and store data over a series of sessions, days, weeks or months. The benefit of this functionality will be discussed shortly.

Communicate/feedback

As the patient breathes into the product, the LED lights mirror their breathing as inhale or exhale in real-time. As they inhale through the device the lights show red, and as they exhale through the device the lights will turn green. As described earlier, the Mirror mode function addresses 2 interactive requirements. Firstly, this function provides an intuitive means for learning how the cues correspond to the breathing phase and secondly, during the Mirror mode the product is quantifying and logging the patient's breathing performance. By gathering a series of breathing phases, it is anticipated that the prototype begins to *know* the patient breathing pace as well as inspiration and expiration times.

At this preliminary phase, the feedback method is presented to patients as a single band of colour, either red or green. This simplicity was required to aid in programming, trouble-shooting and testing. Patient, carer and respiratory therapist contributions would be drawn upon for the next stages of interaction design with the aim of developing more engaging and informative interfaces.

Adjustment

Once data has been gathered within the mirror mode function, a patient can be guided towards what is considered good PLB practice. As suggested earlier, a change in the light sequence indicates to the patient the breathing phase that they should be in at that given time. This function responds to aspects of the Adaption and Motivation theme by providing real time feedback and direction to patients. This widens the scope for independent PLB practice within the home as patients are directed and encouraged through a product interface as opposed to reliance on intermittent face-to-face guidance within formal rehabilitation.

Further investigation regarding the learning experience, particularly in the forming of new behaviours, would offer further product design direction. Further testing of this function is required to determine the short and long term learning opportunities.

5.5.2. Product

This section details the aspects related to the design of the product. There are elements which cross over between breathing function and the product design. These will be discussed accordingly.

Mouthpiece

Detailed within Section 5.4.3 (page 138), the mouthpiece design has been developed for 2 functions. Firstly, the mouthpiece promotes a PLB mouth formation and secondly, the mouthpiece directs air pressure towards the pressure sensor whilst enabling the release of pressure so as to reduce resistance. Various mouthpiece forms have been conceptualised, however further development and testing is required. It may be that further iterations of the design allow for personalised mouthpieces to be used by patients rather than a standard fitting. This idea requires further testing and analysis.

The complexity of the mouthpiece form, particularly within the pitot tube, poses manufacturing challenges. The current mouthpiece geometry is possible through 3D printing technology, however further investigation regarding materials and geometry should aim to simplify this arrangement for cost reductions during manufacture.

Aesthetics

Given the challenges and physical requirements of the mouthpiece and the hardware, little attention has been made to the aesthetic detail during the prototype development. Further design iterations are required to create a more resolved and sophisticated product form. Additionally there is scope for advanced features such as wearable components, flexible details and improved controls.

Portable

Rehabilitation equipment is becoming increasingly portable. This was further evident within the interview stages as the products presented were hand held and wireless. As a result, it was important that the prototype achieved this goal. The portable nature of the prototype is possible due to a rechargeable battery and Bluetooth. As mentioned above, further design features may improve the hand held nature of the device. Developing a comprehensive range of patient user scenarios may contribute to this process.

Modes of interaction

Within the design objective it was stated that the product interface should utilise multiple senses when providing feedback. These methods could range from lights to sound to vibration. It is acknowledged that within the prototype only light has been used, however it is anticipated that further research and development with patients, carers and respiratory therapists will lead to an array of possible interaction methods.

Through the provision of Bluetooth connectivity within the current prototype, this process could be readily explored in the next phase of research. Smartphone connectivity as well as the sharing of data on a common platform offers scope for interactive and unique interactions and experiences. This could include participation in group rehabilitation programs via an online network and recording and sharing of data over time.

Cleaning and hygiene

As this is a product which patients will breathe through, there is concern regarding the build-up of moisture, particularly saliva. The mouthpiece can be removed from the housing for cleaning, however the transition of moisture into the pitot tube within the housing is possible. Revisions to the product form may see the inclusion of a membrane or similar mechanism which prevent moisture accessing the electronics. This type of solution may become a consumable or replacement part within the product operation. Further investigation and design consideration is required, particularly if it is proposed that the product is shared.

This research will now conclude with an overall response to the research objectives and an outline for future work in this field.

Chapter 6: Conclusion

6.1 Introduction

A large component of this research was the examination of the design attributes of a prototype that enables patients to become confident in PLB practice, and the development of a proof of concept prototype that responds to these attributes. The broad conclusions are that patients require ongoing monitoring, feedback and motivation during the PLB learning and implementation phase. Once patients become expert in PLB implementation, they demonstrate a capacity to adapt PLB to tasks and develop routines. An underlying attribute that facilitates the movement from learning to implementation is the active learning process.

The interview data suggests that patients move through levels of PLB practice, from novice to expert and that the guiding attributes of Monitoring and Feedback, Adaption, Routine, Motivation and Active Learning enable this transition. This is outlined within Chapter 4. Based on the information obtained through the qualitative study, the scope and opportunities for design investigations were explored and a product solution that responds to the identified attributes was developed. This opportunity was investigated with Chapter 5 through a proof of concept prototype.

6.2 Summary of findings

The literature indicated that PLB may be effective in enabling patients to control their feelings of breathlessness, however it was identified early in the research phase that how a patient becomes skilled is not well known or documented. To identify the attributes that facilitate effective PLB, the qualitative study outlined within Chapter 3 was carried out. Twelve COPD patients were interviewed with questions relating to paced breathing and existing products on the market. The interview data was collected, transcribed and analysed according to the thematic analysis protocol outlined in Table 6 (page 86). From the results of this study the patients were categorised as either novice, passive or expert PLB users (Table 7, page 93), and 5 key themes identified: (1) Monitoring and Feedback, (2) Adaption, (3) Routine, (4) Motivation and (5) Active Learning. Each theme was explored and characteristics relevant to the design of a product for facilitating PLB learning and monitoring were found. Each of these along with their findings will now be summarised.

Monitoring and feedback

Within the introduction to this thesis it was proposed that PLB practice is currently reliant on a patient's ability to interpret literature and face-to-face guidance that is provided within formal rehabilitation. Through a review of the literature it was found that studies investigating the teaching, monitoring and real-time measurement of PLB effectiveness are lacking. Therefore, the best methods for PLB teaching and learning could not be assessed.

Analysis of the qualitative data suggests that independent PLB practice and implementation is presently reliant on subjective feelings and memory of face-to-face teachings and that there is not any process available for a patient to judge their PLB performance based on metric data. In other words, patients are unaware if they are meeting the requirements of extended exhale to inhale ratios. As a result, monitoring of a patient's respiratory rate and sharing this information with them is important in guiding correct PLB behaviour. This is particularly significant for patients practicing within the home.

The findings of this study suggest that a product for aiding COPD should not just raise awareness of patient breathing performance but should also provide the patient with feedback that guides them to an improved performance state. The theme of Monitoring and Feedback explores methods in which breath by breath data could be collected and the manner in which this could be relayed to patients.

There are a range of feedback approaches which could be employed (e.g. digital game, lighting feedback, musical interaction). It became evident within the patient statements that the form or method of feedback may influence a patient's perception of whether they would enjoy that activity. The extent to which the interaction and feedback influences the patient engagement and motivation over both short and long term practice of PLB could not be determined within the current study protocol. A limiting factor in exploring the monitoring and feedback methods for PLB practice is that there is a lack of products and systems which focus on the PLB interface requirements. Although a range of monitoring mechanisms were presented to patients within the study, the responses provided can only be assessed to provide a broad design direction as they do not specifically respond to the product requirements outlined above. In developing a prototype which addresses the product requirements, a secondary study could be performed to further explore these attributes.

The prototype that was developed and tested was successful in being able to collect breath by breath data through the use of electronics, hardware and the mouthpiece design. Utilising a pitot tube configuration and an inlet and outlet design within the mouthpiece, the data collection process was able to occur with little resistance to breathing. This was important as it was intended that patients breathe freely through the mouthpiece at a similar respiratory effort as free breathing.

The mouthpiece is used in conjunction with a MEMS pressure sensor which determines the direction of the airflow (i.e. inhale or exhale) based on the change in stagnant pressure within the pitot tube. This configuration was successful in collecting breath by breath data as well as the time in which the breath transition occurs, thus a breathing ratio of inhale and exhale can be determined.

Future research should focus on testing of the algorithms to ensure accuracy and reliability. Further development of the mouthpiece geometry should concentrate on developing the form to suit a broader spectrum of potential users whilst considering any technical implications.

Adaption

Within both the literature and the qualitative data a resonating theme was the transition of patients between rehabilitation and self-management contexts. This requires patients to interpret strategies and effectively implement these independently. Therefore understanding the transition between the home and the rehabilitation context became important. These investigations were grouped under the theme of adaption.

Within the patient statements it was found that as patients became more skilled and capable of controlled breathing, their capacity to adapt to daily tasks and independent self-management tended to increase. Whether a patient's capacity to adapt was influenced by their stabilised disease progression, engagement with rehabilitation over time or external support such as family and friends remains to be established.

It was found that those patients confident in their PLB practice adapted their pace to perform tasks. Within this group there was a strong correlation between tasks, routines and management of symptoms which indicates that PLB can be encompassed and embedded within daily life. In establishing the processes which promoted or enabled adaption to occur, the progression appears to be somewhat intuitive, unregulated and largely untaught.

The patient statements are vague when it comes to descriptions specific to the adaption process which indicates that designing for the process of adaption may be more closely aligned to psychological elements of breathing and disease management as opposed to specific actions or metric outcomes. This means that although the product requirements may have a metric focus, exploration as to the way in which the product motivates or changes a patient's behaviour is as important.

It was noted within the literature that patients who spend a large portion of time managing their breathlessness within their own home may find the process isolating (Section 2.7.1). PLB practice aims to support the changes between environments. However a reoccurring challenge is that patients must be proficient in utilising PLB. Therefore, rather than focusing on PLB and its relationship to tasks, PLB was approached as an evolving strategy which requires continued practice and reflection.

Stemming from the earlier work outlined within Monitoring and Feedback, the prototype explores ideas of adaption by providing a mechanism for independent use within the home. In providing a personal learning tool, the prototype becomes a mechanism for self-learning and eventually self-management. This was realised by the selection of technologies, hardware and the design of the mouthpiece interaction, resulting in a portable prototype capable of remembering patterns of breathing behaviour and encouraging improved performance.

Future work could explore the impact of the prototype in stabilising irregular breathing pace, the expected timeframe before stabilisation is realised and the relationship between disease progression and ongoing PLB adaption.

Routine

The link between routine and management only became apparent when patients were able to provide tangible references where a product or system enabled self-management. Examples included the use of the Spacer during a shower routine and the clothesline as an exercise marker. This indicates that products provide a direct link between self-management and daily routines or activities.

At this time, overarching routines or pacing strategies were not evident within the statements. This suggests that although general management strategies, such as PLB, may be promoted as transitional and adaptive, patients may interpret, understand and implement the strategy when linked to an activity or task. Consideration as to the way in which a product encourages task based PLB learning and implementation is significant.

The initial stages of prototype development focused on the delivery of a product which would enable self-regulation of irregular breathing. For example, if a patient was vacuuming their house and their breathing became irregular and strained, drawing on a product to stabilise their breathing function may assist. The mirror and guide mode functions within the prototype are currently set up to guide the patient towards a more controlled and relaxed breathing state based on the principles of PLB. Within this framework, the product is approached as a reactive tool to regulate irregular breathing.

Conversely, the patient may be able to begin a task such as hanging clothes on the line. Knowing that this task causes strained breathing, the patent may first engage with the product to generate a pace and feeling of breathing control. Once the pace is embedded, it is expected that the patient would then implement this pace whilst completing the task. Therefore the product is proactive in establishing pace prior to the commencement of tasks.

Regardless of the order in which the product is used, there is opportunity and scope for the product is be integrated within daily routines. Further testing of these ideas is required to confirm that the prototype functions are suitable for a range of rituals and activities and that the product function is intuitive.

Motivation

It was stated within the literature that a patient's motivation is informed by their personality, social factors and environmental contexts, which results in a subjective framework whereby a patient is motivated by their desires, beliefs and values (Section 2.6.2). Within the patient statements obtained from the qualitative data, it was found that patients generally appear motivated to engage with new products related to improving their self-management of breathlessness. However, the underlying nuanced details of motivation could not be uncovered from the data set. It was noted that patients may become unmotivated if feedback was not immediate or if the task was deemed too challenging to perform. This suggests that real-time feedback is critical for a patient to remain motivated and engaged in PLB practice

Within the initial stages of research it was identified that there is currently no method to set measureable PLB goals and to evaluate if patients were reaching these goals. Within this finding there is a design opportunity. Developing a product which enables incremental goal setting may offer longer term motivation and engagement in PLB practice.

In response to these challenges, the prototype explores both the establishment of real-time feedback (referred to as mirror mode) and guidance towards improved breathing pace (referred to as guide mode). When the prototype is in mirror mode, the changes between inhale and exhale are communicated to the patient in real-time via a LED panel across the top of the prototype. This process is made possible through coding of the data which is best explained within Section 5.4.5.

Once adequate breathing data has been collected, the prototype is able to determine an improved breathing state. The LED panel which provides real-time feedback is also used to guide the patient's breathing. Unlike mirror mode which changes the LED panel to reflect the patient's actual breathing, this guide mode skews the visual feedback, either switching before the breath has ended or persisting after the breath. As the patient alters their breathing to follow the skewed feedback the device guides their breathing towards a goal considered an improved breathing pace based upon the principles of PLB.

Now that the mirror and guide functions are operational within the prototype, the next stage of investigation is to test the response of these functions with patients. As the aspects which influence patient behaviour change over a short and long term period are not well known, it would be interesting to test the incremental and guide mode prompts more thoroughly.

As mentioned with Monitoring and Feedback, the feedback mode of LED lights was strongly linked to current technical requirements. Investigation of varying feedback modes and interaction details such as audio, video and interactive light systems and the relationship between these modes and a patient's ongoing motivation to self-regulate their breathing pace would be an interesting next stage of research.

Active Learning

Patients may utilise PLB in times of respiratory distress. Finding their own breathing ratio and pace is critical in effective implementation and longer term use. As previously mentioned, there are currently limitations in the learning process, however within the literature an association between neuro functioning of the respiratory system and the physiological responses was found (Section 2.4.4). The theme of active learning explored the role of product design in forming continuing learning processes which require concentration and focus within the mind, and active engagement in physiological responses.

Within the literature, the harmonica was identified as a respiratory learning and training tool. This product requires active participation by patients as they focus on learning rhythm and melodies through practice. It was found that the harmonica is lacking in PLB specific direction, however the introduction of this product within the rehabilitation setting demonstrates scope for novel PLB learning practices.

Based upon the patient statements alone, it is difficult to determine how a patient learns the principles of PLB and how they are guided to improve. It was concluded that it is likely the majority of patients were introduced to PLB through the rehabilitation sessions in which they are all enrolled and that the learning process predominately occurs in a face-to-face manner. Although alternative approaches such as Harmonica Therapy are emerging, these are not widely practiced.

Those patients that were in the early stages of learning appeared more eager to seek products and systems which help them to learn independently at home. This may be a result of a desire to increase their practice beyond the formal setting or move towards a more intuitive and adaptive approach as described by the experts. The development of an interactive prototype enabled these ideas to be investigated further.

The prototype has been specifically designed to require patients to breathe through the device to create feedback. In doing so, it is anticipated that an increased awareness of breathing pace occurs. However, raising awareness is only the first step in active learning. Once the patient enters guide mode it is expected that patients respond to the feedback by making adjustments to their breathing pace. The prototype fosters an active learning cycle which involves concentration, reflection and action by raising awareness and offering appropriate triggers for change. In creating a cycle of learning through product interactions, it is proposed that patients may move towards embodiment of paced breathing similar. The active learning process supports the earlier discussed themes of Adaption and Routine.

Now that the initial principles of active learning are reflected within a prototype, future stages of testing should explore the principles of active learning more specifically. This could include investigation into the number of repetitions required to induce short term breathing pace changes, personalisation of active learning tools to reflect an individual's learning style and testing of any potential long term behaviour changes.

6.3 Conclusion & future work

This work sought to broadly consider the role of product design in facilitating paced breathing practices, namely PLB, for sufferers of COPD. Effective PLB practice is currently reliant on both the patient's ability to interpret literature and face-to-face guidance provided within the formal rehabilitation setting. Although these approaches raise awareness of PLB, there is a gap in the practice and integration of PLB principals independently. A qualitative study found that patients differ in their attitude and approach to PLB. Attributes were identified that enabled patients to become familiar and confident in PLB practice. These attributes were then explored within a design framework to develop and test a prototype device for aiding breathlessness.

The results of this work indicate that paced breathing can be monitored and shared with patients and that incremental targets for improved performance can be set. Now that this has been established, future studies could be developed to further test the prototype functionality and use within the rehabilitation setting. Studies may include further analysis of current PLB use amongst COPD patients, development of prototypes for testing with patients and further exploration of the motivational aspects of learning and behaviour change. Proposed next stages of research are briefly explained below.

The prototype was designed to address one of the key elements of PLB, namely to instil a breathing ratio and pace [refer to (Section 1.2.1)]. Future work could explore the device with respect to the other elements. For example designing of different mouthpiece for differing lip configurations and users, and the ability of the device to quantify breathing ratio and pace and discriminate between mouth and nose breathing. Further technical investigations are required to determine if the current technology and interaction can be modified to increase the scope to all 3 elements or if differing directions are required.

In this preliminary work, 12 COPD patients were interviewed. Within this cohort only 5 were active users of PLB and were capable of providing insight regarding PLB learning and practice methods. Future studies would benefit from a cohort consisting of a larger number of active PLB users.

Data was available regarding the cohort's diagnosis and severity of COPD. An interesting study would be to investigate the relationship between diagnosis and the habits of PLB practice. Due to the small sample size in this study it is not practical to draw conclusions, however studies with a larger number of participants could investigate this relationship further.

The next phase of work would be to revisit the cohort with the prototype to gather general impressions and feedback. A study of this type would require additional ethical approval as it involves preliminary testing of the functionality of the prototype by a patient cohort. This would investigate the efficacy of the device to measure, monitor and assess PLB breathing and the mode in which feedback is communicated. This is particularly important in verifying that the Guide mode can have a positive effect for the patient.

Appendices

A Participant information sheet and consent form

Questionnaire Group Setting

B Ethics approval - University of Technology, Sydney

Ethics approval - University of Wollongong, local health district

Ethics Approval – honorary research appointment/site specific approval

C Patient Information Sheets

D Exploratory mind maps (external USB device)

E Video Files (external USB device)

A

Participant information sheet and consent form

Participant Information Sheet and Consent Form

Non-interventional Research

Title	Dyspnoea: Designing for the coxswain in the mind
Principal investigator	Elizabeth Lewis
Department	Respiratory Coordinated Care Program
Organisation	Shoalhaven District Memorial Hospital

Part 1 – What does my participation in this study involve?

Introduction

You are invited to take part in this study, as you are able to provide valuable insight regarding devices that might be helpful to you in managing the sensation of your breathlessness. Your insights will help to guide the design of a paced rehabilitation product that aims to improve a person's ability to manage the sensation of breathlessness.

This Participant Information Sheet and Consent Form explains what is involved in this study and will help you decide if you would like to take part. Please read the information carefully. Please ask any questions or ask for further details about any aspect of this study. Before deciding if you would like to take part in this study, you may wish to talk to a family member, friend or health worker.

What is the purpose of this research?

The purpose of this research is to gain patient's perspectives on using devices to manage the sensation of breathlessness.

Why have I been chosen?

You have been invited to participate in this study because you are able to provide us with the information we need to find out about the experience and sensation of breathlessness.

Do I have to take part in the research?

It is up to you to decide if you would like to take part. If you do decide to take part you will be given this Participant Information Sheet and Consent form to sign and you will be given a copy to keep. If you decide to take part you can change your mind and withdraw from the study at any stage without giving a reason.

Other relevant information

This research is being conducted by Elizabeth Lewis, Masters by Research candidate from the University of Technology, Sydney in collaboration with the staff at the Respiratory Coordinated Care Program, at Shoalhaven Memorial District Hospital, Elizabeth is supervised by Rebecca Disler, Tim Luckett and Vasilije Kokotovich from the University of Technology, Sydney.

What will happen to me if I take part?

If you agree to participate in this study, you will be asked to sign the Participant Consent form.

You will be asked to participate in a one hour discussion about your perspectives on using devices to manage the sensation of breathlessness.
The session will take place at the pulmonary rehabilitation clinic at Shoalhaven District Memorial Hospital. The session will be facilitated by two study investigator and audio will be recorded. A part of this study you will also be asked to give us permission to collect details from your pulmonary rehabilitation file on you gender, age in years, your primary diagnosis and length of time since diagnosis.

Your confidentiality will be maintained at all times and to do this we will assign you a unique number which is the only identifying information that will appear on study documents and databases.

There are no costs associated with this study.

What do I have to do?

If you would like to participate, you will need to sign the consent form and a time will then be negotiated for you to attend the group discussion.

What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research. Possible benefits may be the design rehabilitation tool that will improve pulmonary patients' ability to live with breathlessness, however it may not directly benefit you.

What are the risks of taking part?

You may feel that some of the questions are upsetting or stressful or it may become difficult to speak due to your breathlessness. If you do not wish to answer a question you may skip it and go onto the next one, take a break or stop immediately. If you become upset or distressed as a result of your participation in the study, the study coordinator is able to arrange for counselling or other appropriate support. Any counselling or support will be provided by staff who are not a member of the study team.

What do I do if I wish to withdraw from the research?

Participation is voluntary. If you do not wish to take part you do not have to. If you decide to take part and change your mind, you are free to withdraw your information from the project at a later stage. If you wish to withdraw from this study please advise the study team by contacting Rebecca Disler on 02 9514 5746.

What happens when the study ends?

It is anticipated that the information collected during this study will be presented in a variety of forums. Your identity will not be disclosed.

In accordance with relevant Australian and New South Wales privacy and other relevant laws, you have the right to request access to the information collected and stored by the study team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the study team coordinator if you would like to access your information.

Part 2 – How is this study being conducted?

What will happen to the information about me?

By signing the consent form you consent to the study coordinator collecting and using the responses provided in this study. Any information collected during this study that can identify you will be kept confidential. To ensure your confidentiality the study investigators will assign you a unique number which is the only identifying information that will appear on study documents and databases. The list that links this number and you will be stored separately from the data. Your information will only be used for the purpose of this study and it will not be disclosed without your permission, unless required by law.

As part of this study you will be asked to give us permission to collect details from your pulmonary rehabilitation file on your gender, age in years, your primary diagnosis and length of time sine diagnosis.

Study data will be accessible by the investigators. Data will be stored for the mandatory period of 5 years. Upon completion of the 5 year period the data will be permanently deleted and paper copies shredded.

It is anticipated that data collected from this study will be published and/or presented in a variety of forums. Information provided in these forums will not allow for you to be identified.

In accordance with relevant Australian and New South Wales privacy and other relevant laws, you have the right to request access to the information collected and stored by the study team about you. You also have the right to request that any information with which you disagree be corrected.

What if something goes wrong?

If you suffer any injuries or complications as a result of this study, you should contact the study team as soon as possible. The team will assist you in arranging appropriate medical treatment.

Who is organizing and funding the research?

The University of Technology, Sydney is conducting this study in collaboration with the Respiratory Coordinated Care Program, at Shoalhaven District Memorial Hospital. No researcher will receive a personal financial benefit from your involvement in this study.

Who has reviewed this study?

The Illawarra Shoalhaven Local Health District and the University of Technology Sydney Human Research Ethics Committees (HREC) have reviewed this study granted approval.

Further information and who to contact

If you would like further information regarding this study you may contact Elizabeth Lewis on [redacted] or Rebecca Disler on 02 9514 5746.

If you would like to talk to someone not directly involved in this study for further information, you may contact the Illawarra Shoalhaven Local Health District research office on (02) 4221 5014 and quote the HREC reference number He15/305.

Participant Consent Form
Non-interventional Research

Title	Dyspnoea: Designing for the coxswain in the mind
Principal investigator	Elizabeth Lewis
Department	Respiratory Coordinated Care Program
Organisation	Shoalhaven District Memorial Hospital

1. I have read the attached Participant Information Sheet outlining the purpose of this study and I understand what I am being asked to do.
2. I have discussed my participation with a member of the study team named below. I have had the opportunity to ask any questions and I have received all my answers.
3. I have been informed of the possible risks of taking part in this study
4. I freely consent to participate in the study as described in the attached participant sheet.
5. I understand that my participation is voluntary and that I am free to withdraw at any time during the study.
6. I understand that I have been invited to participate in a one hour discussion about my perspective on using devices to moderate the sensation of breathlessness
7. I understand that focus group discussion will be recorded and transcribed verbatim
8. I consent to collection of my gender, age in years, primary diagnosis and length of time since diagnosis to be collected from my pulmonary rehabilitation file

Name of participant	Signature of participant	Date
Name of witness	Signature of witness	Date
Principal Investigator (Nick Spiliopolous)	Signature of investigator	Date

Withdrawal of Participation

Non-interventional Research

Title	Dyspnoea: Designing for the coxswain in the mind
Principal investigator	Elizabeth Lewis
Department	Respiratory Coordinated Care Program
Organisation	Shoalhaven District Memorial Hospital

I hereby wish to WITHDRAW my intent to participate further in the above research project. I understand that such withdrawal will not jeopardize my future health care.

Participants Name (printed) : ______________________________________

Signature: ______________________________________

Date: ______________________________________

In the event that the participant decided to withdraw verbally, please give a description of the circumstances. Coordinating investigator to provide information here:

Coordinating investigator to sign the withdrawal of consent form on behalf of a participant if verbal withdrawal has been given.

Participants Name (printed) : ______________________________________

Signature of investigator: ______________________________________

Date: ______________________________________

A

Questionnraire Group Setting

Questionnaire Group Setting Non-interventional Research

Title	Dyspnoea: Designing for the coxswain in the mind
Principal investigator	Elizabeth Lewis
Department	Respiratory Coordinated Care Program
Organisation	Shoalhaven District Memorial Hospital

Part 1 – Semi-structured interview questions

Broad opening discussion question:

1. Tell me a little about your breathing day to day and what things you do to manage this?
2. Are there things that you avoid doing because of your breathlessness?

Part 2 –Semi-structured interview questions regarding devices on the market

I'd now like to talk to you a little about pacing of breathing.

1. What does the term paced breathing mean to you? You may have talked about this in your pulmonary rehabilitation sessions.

I have some images of current devices that are designed for use by patients like you to help with pacing of breathing and managing breathing sensation. I am going to show you these products, explain briefly how they work and then I will ask you some questions.

Image	Description
Harmonica 	The Harmonica is used within group therapy sessions to promote breathing control. By playing tunes on the harmonica, patients learn different breathing patterns and tunes.
The device is used in a group therapy session. How would you feel about learning to play the harmonica to help you with your breathing? How would you feel about learning this as part of a group? Do you feel that there would be challenges to doing this? Can you tell me a little about that?	
Resperate 	Resperate generates rhythmic tones whilst measuring your individual breathing pattern. The tones adjust as your breathing patterns changes, with the tones guiding you to even, relaxed breathing. Resperate is used by attaching a non-constricting band around your chest to measure your breathing, with headphones so that you can listen to the tones.
Have you heard of something like this before? Can you tell me a little about this? How would you feel about using this kind of device? What concerns might you have? If you were to give it a go, how do you think you would incorporate it into your daily life?	

<table>
<tr><td>Zenytime
</td><td>Zenytime is a little device that is linked to an app on your phone or tablet. You breathe into Zenytime and the game uses your breath rhythm to play a digital game. By learning to control and adjust your breathing, you move through the levels of the game. At the end of each session the game gives you feedback about your breathing performance.</td></tr>
<tr><td colspan="2">Have you heard of something like this before? Can you tell me a little about this?

How would you feel about using this kind of device? What concerns might you have?

Can you describe what sorts of apps or online games you use at the moment? What do you like about them?

If something like the Zenytime was available to you, are there particular times through the day when you might use this? Are there particular locations or places you might use this?</td></tr>
<tr><td>Aura
</td><td>Aura sits on a flat surface and monitors the environment for signs of stress. When stress is detected, Aura indicates that it wants to be picked up and then guides the user through deep breathing exercises.</td></tr>
<tr><td colspan="2">This device is different to the others as it invites you to use it when it thinks you need a hand. What is your overall feeling towards this kind of device?

In thinking about the device, do you think this device will help you with your controlling your breathing?</td></tr>
</table>

Close the discussion thanking the participants and asking if they have any further comments they would like to make.

General prompts: How does that make you feel? Would you be able to tell me more about that? Can you explain that to me? Use paraphrasing of participants' responses back to the group to check meaning.

B
Ethics Approval

UTS
UNIVERSITY OF TECHNOLOGY, SYDNEY

Prof Marion Haas
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
PO Box 123 Broadway
NSW 2007 Australia
T: +61 2 9514 9681
F: +61 2 9514 0000
Research.Ethics@uts.edu.au
www.uts.edu.au

UTS CRICOS PROVIDER CODE 00099F

8 August 2014

Dr Vasilije Kokotovich
School of Design
CB06.06.58
University of Technology

Dear Applicant,

UTS HREC 2013000758 – KOKOTOVICH, Dr Vasilije, (Ms LEWIS, Elizabeth, Master Student) – "Dyspnoea: Design for the coxswain in the mind"

Thank you for your response to the Committee's comments for your project titled, "Dyspnoea: Design for the coxswain in the mind". Your response satisfactorily addresses the concerns and questions raised by the Committee who agreed that the application now meets the requirements of the NHMRC National Statement on Ethical Conduct in Human Research (2007). I am pleased to inform you that ethics approval is now granted.

Your approval number is UTS HREC REF NO. 2013000758 Your approval is valid five years from the date of this email.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

Yours sincerely,

Professor Marion Haas
Chairperson
UTS Human Research Ethics Committee

B

Local health district ethics approval

APPROVAL
In reply please quote:HE15/305
Further Enquiries Phone: 4221 3386

4 August 2015

Ms Elizabeth Lewis
University of Technology
1 Buckland Street
Alexandria NSW 2015

Dear Ms Lewis

I am pleased to advise that the Human Research Ethics application referred to below has been **approved. Before you can proceed with the project you must first have authorisation from the relevant Local Health District. Please forward a copy of this advice to them.**

Ethics Number:	HE15/305
AuRED Number:	LNR/15/WGONG/36
Project Title:	Dyspnoea: Design for the coxswain in the mind
Name of Researchers:	Ms Elizabeth Lewis, Mr Nicolaos Spiliopoulos, Dr Vasilije Kokotovich, Ms Rebecca Disler, Dr Tim Luckett
Sites Approved:	Shoalhaven District Memorial Hospital
Documents Approved/Reviewed:	Initial LNR Application (submission code: AU/6/4BCE13) Participant Information Sheet and Consent Form Version 1, 7 April 2015 Questionnaire Group Setting Non-interventional Research Version 1, 7 April 2015 UTS HREC Approval Letter noted
Approval Date:	4 August 2015
Expiry Date:	7 August 2016

The University of Wollongong/ISLHD Health and Medical HREC is constituted and functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research. The HREC has reviewed the research proposal for compliance with the National Statement and approval of this project is conditional upon your continuing compliance with this document.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at http://www.uow.edu.au/research/rso/ethics/UOW009385.html. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

Ethics Unit, Research Services Office
University of Wollongong NSW 2522 Australia
Telephone (02) 4221 3386 Facsimile (02) 4221 4338
Email: rso-ethics@uow.edu.au Web: www.uow.edu.au

As evidence of continuing compliance, the Human Research Ethics Committee also requires that researchers immediately report:

- proposed changes to the protocol including changes to investigators involved
- serious or unexpected adverse effects on participants
- unforseen events that might affect continued ethical acceptability of the project.

Please note that approvals are granted for a twelve month period. Further extension will be considered on receipt of a progress report prior to expiry date.

Please note that Governance approval is required for research within NSW Ministry of Health. Before you can proceed with this research project you must complete a Site Specific Assessment (SSA) for each Local Health District included in your project. Refer to: https://ethicsform.org/Au/SignIn.aspx

For further information regarding the SSA in the ISLHD, contact:

Research Governance Officer
Illawarra Shoalhaven Local Health District
Research Directorate
Wollongong Hospital
Block C, Level 8
P: 02 4253 4876
E: Kristy.Pierce@SESIAHS.HEALTH.NSW.GOV.AU

A copy of this letter has been forwarded to the ISLHD Research Governance Officer.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rso-ethics@uow.edu.au.

Yours sincerely

Professor Colin Thomson
Chair, UOW & ISLHD Health and Medical
Human Research Ethics Committee

cc: Governance Officer, Research Directorate, ISLHD

Ethics Unit, Research Services Office
University of Wollongong NSW 2522 Australia
Telephone (02) 4221 3386 Facsimile (02) 4221 4338
Email: rso-ethics@uow.edu.au Web: www.uow.edu.au

B

Honorary Research Appointment/Site specific approval

Health
Illawarra Shoalhaven
Local Health District

Research Directorate
Telephone: 02 4253 4800
Facsimile: 02 4253 4803

TRIM NO: DT15/62282
Ref: HE15/305
APPROVAL

Mr Nicolaos Spiliopoulos
Clinical Nurse Consultant
Respiratory Coordinated Care Program
Shoalhaven District Memorial Hospital
P O Box 246
NOWRA NSW 2541

Dear Mr Spiliopoulos

HREC project number: HE15/305
Project title: Dyspnoea: Design for the coxswain in the mind

Thank you for submitting a Site-Specific Assessment Form for Low and Negligible Risk Research application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

- Respiratory Coordinated Care Program – Shoalhaven District Memorial Hospital

This approval is valid with a current Human Research Ethics Committee approval.

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

KRISTY PIERCE
Research Governance Officer

11 August 2015

c.c. Bradley Scotcher, Acting Director of Nursing
Ian Power, Acting General Manager, Shoalhaven Hub - FYI

Research Directorate
Level 8, Block C, Wollongong Hospital
(LMB 8808, SCMC NSW 2521)

C

Patient Information Sheets

Better Living with Chronic Obstructive Pulmonary Disease *A Patient Guide*

and out of the lungs. Airway clearance techniques can help to keep the breathing tubes or airways clearer and assist in making breathing easier (see chapter 13).

5. When you are living with COPD, you may be unable to continue your normal level of activity, which can result in a cycle of inactivity (see the previous diagram). Frequently, this will lead you to reduce your physical activities, causing you to become unfit or poorly conditioned. Being **unfit or poorly conditioned** makes your movements less efficient and requires greater effort to complete everyday activities.
6. People who have COPD often experience **increased anxiety** about becoming breathless or short of breath. This anxiety can lead to a fear of undertaking activities.

In summary, people with COPD need to work harder than others to breathe.

How do you better control or reduce your breathlessness?

There are many treatment options and management strategies that can help you control or reduce your breathlessness.

1. Medication

Using your reliever, maintenance and preventer medication can assist in controlling breathlessness. It is important that medications are used correctly to ensure their effectiveness.

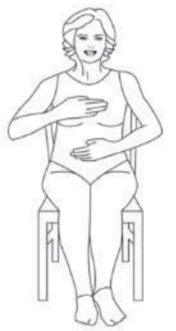
For more details on medications and inhalation devices, refer to chapter 7 'Knowing your medication' and chapter 8 'Using your inhalation devices'.

2. Relaxed breathing

People who have COPD have more difficulty breathing out fully. The body's normal reaction when breathlessness occurs is to breathe faster and shallower. However, faster and shallow breathing is not an effective way to regain control of your breathing.

You could practice relaxed breathing any time you are trying to catch your breath. For example, relaxed breathing may be useful after coughing or exercising.

Aim to breathe out slowly and without force. As you breathe out, let your shoulders and neck muscles relax. Most of your breathing should occur by the lower ribcage expanding and relaxing, rather than in the upper chest.



Relaxed breathing technique

By breathing out fully, you will be able to breathe in better. You may find it useful to practice relaxed breathing when you are at rest so that you are familiar with the technique.

To practice relaxed breathing, place one hand on your chest and one hand on your stomach at the level of your navel while sitting. When you take a deep breath in, the hand on your stomach, rather than the hand on your chest, should move first. Practice breathing so that the hand on your stomach moves first.

3. Prolonged expiration breathing

The purpose of prolonged expiration breathing is to try to reduce the amount of air trapped in the lungs and reduce airway collapse by prolonged breathing out (unforced expiration). Breathing out should take longer than breathing in.

Breathing out through pursed lips is an example of this technique. Pursed lips (lips that are closer together than usual, as if you were whistling or kissing somebody) create a smaller opening for the air to flow through.

4. Recovery positions

Good posture is very important. The more you slump, the more you squash your lungs and stomach, and the harder it is to breathe.

Try taking a deep breath while slumped. Now try again while standing or sitting fully upright with a tall spine. Can you notice a difference?

A comfortable recovery position is important. Typically, recovery positions are upright with your arms supported. Common examples of recovery positions are shown in the images on the following page.

 54

Fig. 58 Better Living with Chronic Obstructive Pulmonary Disease: a patient guide
The State of Queensland and The Australian Lung Foundation, 2012

Resting against a sign

Resting against a tree

5. Pace yourself

This is a very important skill and is often overlooked. If you have breathing problems and are noticing that you are more short of breath than previously, you will need to slow down to get your tasks done.

If you rush and try to beat the shortness of breath, you will spend longer trying to catch your breath. If you go slowly and pace yourself, you will go a lot further before needing a rest. For example:

- While walking, try to establish a pattern of breathing that matches your steps and that you can maintain easily. For example, you may breathe with every step or over a number of steps depending on your level of breathlessness and fitness.
- If you change your pace of walking, you will need to adjust your breathing pattern.
- Before you begin climbing stairs or walking up hills, it is important to gain breathing control.
- Do not hold your breath and rush through the task to 'get it over with' as this will only make you more short of breath.
- Aim to find a rate of breathing that matches your effort. If you find an activity too hard to do, simply stop and recover before restarting the activity at a slower pace.

6. Improve your fitness

Better fitness levels or improved tolerance to exercise will enable a decrease in the effort required to perform everyday activities.

7. Manage your anxiety

Learning how to manage or control your anxiety, or situations that cause your anxiety, can assist your breathing control (see chapter 18 'Managing stress, anxiety and depression', page 76).

Why do you need energy conservation?

With lung disease, the body is no longer as efficient in meeting the body's demand for oxygen.

When the body receives less oxygen, energy supplies become limited. This can cause fatigue, shortness of breath and possible anxiety or panic with everyday activities.

By learning to conserve energy with everyday tasks, you will be able to perform many activities with less effort and less shortness of breath.

Along with exercise, keeping active in normal daily activities is an important part of maintaining your fitness.

Before stopping an activity, consider whether you could make it easier by using the following energy saving techniques.

> By learning to conserve energy with everyday tasks, you will be able to perform many activities with less effort and less shortness of breath.

Fig. 59 Better Living with Chronic Obstructive Pulmonary Disease: a patient guide
The State of Queensland and The Australian Lung Foundation, 2012

Management

Goals of management

- Define the goals of care, dependent upon: the wishes of the patient, the prognosis, the likely benefit of treatment and the risks and inconvenience of treatment and investigation.
- Identify whether chronic onset or rapid onset and whether death is imminent (i.e. the terminal phase, the last hours or days of life) (National Library for Health - UK 2004).
- Use non-pharmacological and pharmacological measures to reduce breathlessness and its perception.

Non Pharmacological Management

- **Positioning -** sit the patient up, avoid abdominal or chest compression and restrictive clothing.
- **Airflow -** encourage cool airflow over the face - open window, electric fan, ceiling fan, hand held fan.
- **Distraction -** reading, relaxation, company, music, TV or radio.
- **Energy conservation**
    - Functional pacing: encourage pacing and planning of exertion to tolerance.
    - Consider Physiotherapy /Occupational therapy referral.
- **Controlled Breathing**
    - Aim to reduce the rate of breathing (breath in, blow out).
    - Encourage diaphragmatic ("use lower chest muscles") breathing and pursed lip breathing.
    - Encourage relaxation of shoulders (e.g. take weight off the shoulders by resting arms on support) and upper chest muscles on breathing.
    - Massage of shoulders may further assist relaxation and encourage diaphragmatic breathing.
- **Assess psychological factors**
    - Listen to, understand, and address the patient's fears.
    - Relaxation techniques used regularly can reduce long-term levels of anxiety and can be taught.
    - Written management plan for patient /carers.

Pharmacological Management

Reduce the perception of dyspnoea

- Opioids are the drug of choice and should be considered where there is dyspnoea at rest or on minimal exertion. RCT level 4 evidence (Abernethy, Currow et al. 2003). Take care in patients with renal impairment.
- Oral Morphine:
    - If opioid naïve, start with morphine mixture 2.5mg 4hrly PRN +/- background long-acting morphine 10 - 20mg daily;
    - If established on a regular opioid: increase the dose by 30 – 50% every 2 – 3 days (titrate benefit versus side effects);

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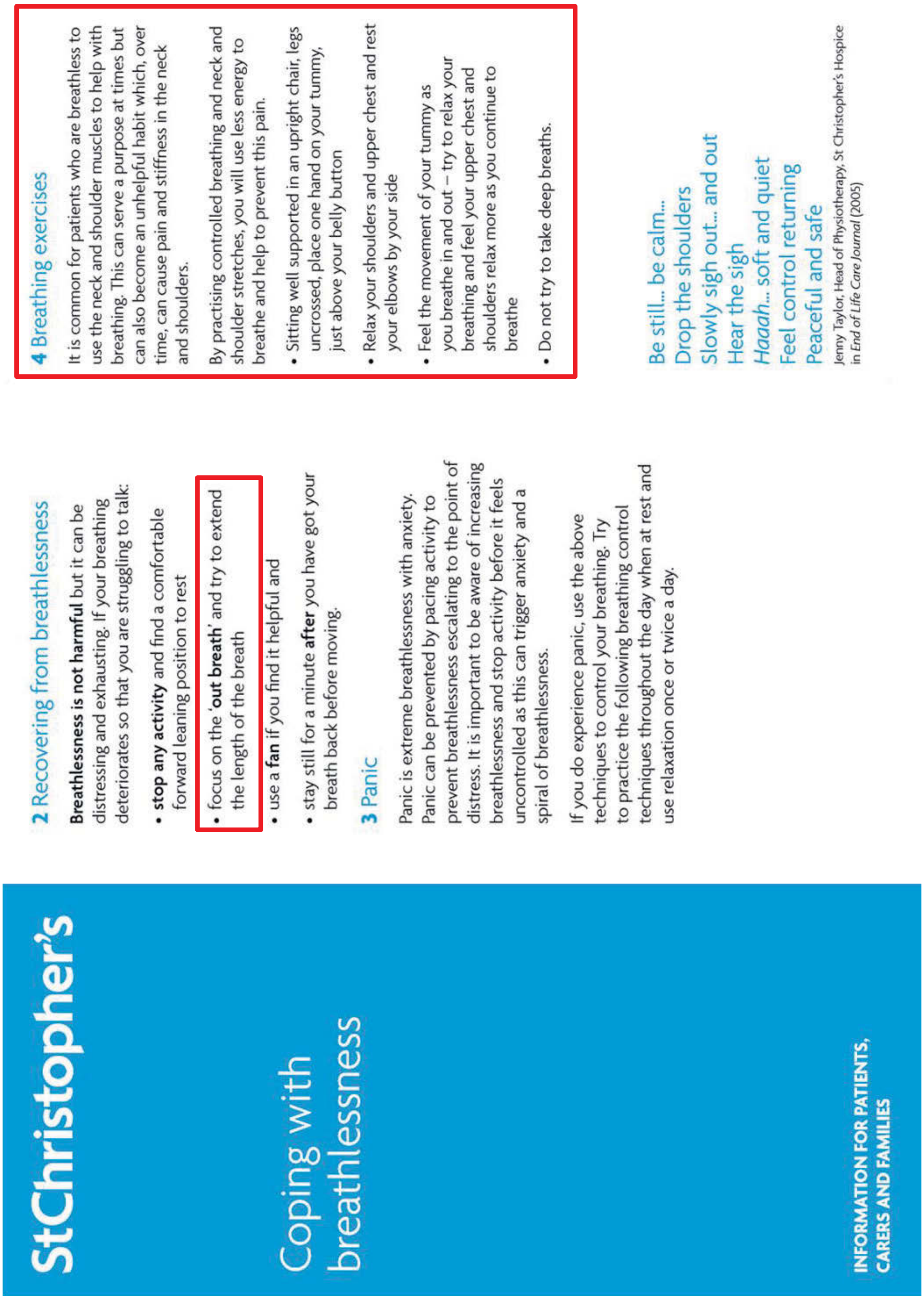
Fig. 60 Care Management Guidelines: breathlessness
Tasmanian Department of Health & Human Services, 2009



StChristopher's

Coping with breathlessness

INFORMATION FOR PATIENTS, CARERS AND FAMILIES

2 Recovering from breathlessness

Breathlessness is not harmful but it can be distressing and exhausting. If your breathing deteriorates so that you are struggling to talk:

- **stop any activity** and find a comfortable forward leaning position to rest
- focus on the '**out breath**' and try to extend the length of the breath
- use a **fan** if you find it helpful and
- stay still for a minute **after** you have got your breath back before moving.

3 Panic

Panic is extreme breathlessness with anxiety. Panic can be prevented by pacing activity to prevent breathlessness escalating to the point of distress. It is important to be aware of increasing breathlessness and stop activity before it feels uncontrolled as this can trigger anxiety and a spiral of breathlessness.

If you do experience panic, use the above techniques to control your breathing. Try to practice the following breathing control techniques throughout the day when at rest and use relaxation once or twice a day.

4 Breathing exercises

It is common for patients who are breathless to use the neck and shoulder muscles to help with breathing. This can serve a purpose at times but can also become an unhelpful habit which, over time, can cause pain and stiffness in the neck and shoulders.

By practising controlled breathing and neck and shoulder stretches, you will use less energy to breathe and help to prevent this pain.

- Sitting well supported in an upright chair, legs uncrossed, place one hand on your tummy, just above your belly button
- Relax your shoulders and upper chest and rest your elbows by your side
- Feel the movement of your tummy as you breathe in and out – try to relax your breathing and feel your upper chest and shoulders relax more as you continue to breathe
- Do not try to take deep breaths.

Be still... be calm...
Drop the shoulders
Slowly sigh out... and out
Hear the sigh
Haaah... soft and quiet
Feel control returning
Peaceful and safe

Jenny Taylor, Head of Physiotherapy, St Christopher's Hospice in *End of Life Care Journal* (2005)

Fig. 61 Coping with breathlessness
Harris Hospice with St Christopher's, 2015

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